

THE EFFECTS OF A LUNG CANCER AWARENESS INTERVENTION IN KWAZULU-NATAL (KZN): A STRATIFIED CLUSTER BASED STUDY IN FIVE REPRESENTATIVE COMMUNITIES

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November 2022

DECLARATION

I, Siyabonga B. Dlamini declare that:

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As the supervisors, we approve this thesis for submission.

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		i

DECLARATION 2: PUBLICATIONS AND MANUSCRIPTS

Journal Articles

Article 1

Dlamini SB, Sartorius B, Ginindza TG. Knowledge, attitudes and practices towards lung cancer among adults in KwaZulu-Natal, South Africa: A cross-sectional survey. Accepted and published by the *Journal of Public Health in Africa* (Accepted in April 2022).

Contributions: DSB conceptualised the study, collected data, analysed the data, interpreted the results, compiled, and wrote the manuscript. DSB, SB and GTG developed the analysis strategy. Moreover, DSB and SB contributed to the statistical analyses and to the interpretation of the results. GTG and SB assisted and supervised the development of the study, including the study pilot and data collection. All authors critically reviewed the draft versions of the manuscript.

Article 2

Dlamini SB, Hlongwana K, Ginindza TG. Community health worker experiences of the training on lung cancer community awareness intervention in KwaZulu-Natal, South Africa. Under review by the *African Journal of Primary Health Care & Family Medicine* (Submitted in December 2021).

Contributions: DSB conceptualised the study, collected data, analysed the data, interpreted the results, compiled and wrote the manuscript. DSB and HK contributed to the statistical analysis and to the interpretation of the results. GTG and HK assisted and supervised the development of the study, including the study pilot and data collection. All authors critically reviewed the draft versions of the manuscript.

Article 3

Dlamini SB, Sartorius B, Ginindza TG. Pre-and post-intervention survey on lung cancer awareness among adults in selected communities in KwaZulu-Natal, South Africa: A Quasi-Experimental study. Accepted and published by the *Journal of Public Health in Africa* (Accepted in June 2022).

Contributions: DSB conceptualised the study, collected data, analysed the data, interpreted the results, compiled, and wrote the manuscript. DSB, SB and GTG developed the analysis strategy. Moreover, DSB and SB contributed to the statistical analysis and to the interpretation of the results. GTG and SB assisted and supervised the development of the study, including the study pilot and data collection. All authors critically reviewed the draft versions of the manuscript.

Conference proceedings

Article 1

Dlamini SB, Sartorius B, Ginindza TG. Knowledge, attitudes and practices towards lung cancer among adults in KwaZulu-Natal, South Africa: A cross-sectional survey. *Oral presentation,* presented at the Public Health Association of South Africa (PHASA) 2021 Conference themed, "Keeping the promise: Closing the gap" in Gauteng, South Africa from 15 to 17 February 2021.

Article 2

Dlamini SB, Hlongwana K, Ginindza TG. Community Health Worker experiences of the training on lung cancer community awareness intervention in KwaZulu-Natal, South Africa. ePoster, presented at the Annual Comprehensive Hematology and Oncology Education Review (AnCHOR) Conference themed, "Towards Innovation & Advancements in Sub-Saharan Africa" in Eldoret, Kenya from 20 to 23 April 2022.

Article 3

Dlamini SB, Sartorius B, Ginindza TG. Pre- and Post-intervention survey on lung cancer awareness among adults in selected communities in KwaZulu-Natal, South Africa: A Quasi-experimental study. *ePoster*, presented at the Annual Comprehensive Hematology and Oncology Education Review (AnCHOR) Conference themed, "Towards Innovation & Advancements in Sub-Saharan Africa" in Eldoret, Kenya from 20 to 23 April 2022.

THE EFFECTS OF A LUNG CANCER AWARENESS INTERVENTION IN KWAZULU-NATAL (KZN): A STRATIFIED CLUSTER BASED STUDY IN FIVE REPRESENTATIVE COMMUNITIES

SIYABONGA B. DLAMINI 203517606

A thesis by Manuscript submitted to the Department of Public Health Medicine, College of Health Science, University of KwaZulu-Natal in fulfilment of the academic requirements for the degree of Doctor of Philosophy in Medicine (PhD) (Public Health Medicine).

This is to attest that the contents outlined in this thesis are the original research work done and reported by the author (Siyabonga B. Dlamini). The research work detailed in this thesis has not been previously submitted to any tertiary institution for the award of a degree or diploma. The use of other researchers/scientists' work in the text has been acknowledged accordingly.

As the candidate's supervisors, we have approved this thesis for submission

Supervisor		
Signed:	Name: Prof. Themba G. Ginindza	Date: 2022/11/28
Co-supervisor		
Signed:	Name: Prof. Benn Sartorius	Date:

FORMAT OF THESIS DISSERTATION

This thesis was presented in manuscript format, which included submitted and prepared journal articles emanating from the research project in this field.

Research Approval

Name of Ethics Committee	Date	Reference number
Biomedical Research Ethics Committee	18/01/ 2019	BF 585/18 (Phase 1& 2)
(BREC)		
Biomedical Research Ethics Committee	15/10/2020	BF 585/18 (Phase 3)
(BREC)		

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DEDICATION

This work is dedicated to my wife, Nthabiseng, my son Yada and my daughters Zamar and Lerato, and my mother, Zamekile B.A. Dlamini.

ABSTRACT

Background

Lung cancer is the leading cause of cancer mortality worldwide, accounting for approximately 1.8 million cancer deaths in 2020. In South Africa, lung cancer is among the top four ranking cancers in terms of morbidity and mortality after breast, prostate, and cervical cancers. There is limited research on community awareness of lung cancer in resource-limited settings such as South Africa. The objective of the study was, therefore, to investigate the level of awareness about lung cancer and its screening among communities in KZN, in an attempt to increase awareness of this disease across the province.

Methodology

A quasi-experiment study was conducted among the selected communities in KZN, a baseline study assessing the level of lung cancer awareness. In total, forty out of 879 clusters were selected, using the probability proportional to population size (PPS) sampling for pre- and post-intervention surveys, where a comparison between two cross-sectional surveys was done. Twenty households were selected from each cluster via maps of the selected wards. A minimum of twenty participants were randomly sampled within each cluster to allow a precision of \pm 5% assuming a design effect of 2 with 95% confidence and assuming maximum variability (i.e., p=0.5 or 50%). Therefore, a total sample size of n = 800 was required. An intervention aimed at raising awareness of lung cancer, including its causes, screening, early diagnosis and treatment was developed, implemented and evaluated in these communities. A stratified random cluster sampling method was employed across these communities. A binary logistic regression model was used to measure the effects of the intervention. Community health workers were trained to implement the intervention in the selected communities. A focus group discussion was conducted with the community health workers to explore their training experiences.

Results

At baseline, the mean knowledge score was 41.8% (95% CI 35.7 - 47.9%). Approximately 59.9% (95% CI 52.0 - 67.3) of the participants reported having heard of lung cancer. About 5.7% (95% CI 3.9 - 8.1) of the participants were screened for lung cancer at the time. Coughing up blood was the most recognised symptom (61.0%, 95% CI 52.1 - 69.1). Post-intervention, the mean knowledge score increased to 59.9 (95% CI 53.8 – 66.0) (p<0.001). There was a reduction in the number of cigarettes smoked per day (p<0.001) and the number of packs smoked per week (p=0.026). However, the prevalence of smoking remained relatively the same before and after the intervention, at approximately 18% (p=0.958). The proportion of participants willing to screen for lung cancer remained high, post-intervention (97.5%; 95% CI 95.5 – 98.6). The intervention had a statistically significant effect (aOR 4.370, 95% CI 1.477-12.928) on the level of lung cancer knowledge in the selected communities (p<0.001). Regarding the community health workers' experiences of training, they felt empowered through the newly acquired knowledge and were keen to help their communities. However, some expressed a desire to have other forms of learning incorporated in future training. They also recognised existing gaps in their knowledge that could be elaborated on in preparation for potential questions by the community. Some confirmed their role as agents of change.

Conclusion

The level of awareness of lung cancer among the communities included in this study was low. The intervention in this study demonstrated the ability to raise awareness of lung cancer at a community level. It also reduced the number of cigarettes smoked among smokers. Therefore, integration into smoking cessation programmes should be explored. A national lung cancer screening programme should be introduced to encourage health-seeking behaviour. The integration of a lung cancer awareness intervention into the already existing community health worker programmes, such as the tuberculosis response strategy, is recommended.

DEFINITION OF TERMS

Term	Definition
Awareness	: Possessing knowledge and understanding of a particular subject, in this case, lung cancer. ¹
Cluster	: An area with defined boundaries and population within a ward in the community.
Dyspnoea	: Shortness of breath or having difficulty in breathing.
Early Diagnosis	: The detection of the disease at an early stage that increases the chances of survival when treated appropriately.
Health-seeking Behaviour	: Any activity undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy.
Primary Lung Cancer	: Cancer that originates in the lungs.
Quasi-experimental Design	: A design where an intervention is tested for how well it achieves its objectives, without the random assignment of targeted study participants into either treatment or control groups.
Probability Proportional to Size	: A method of sampling from a known population in which a size measure is available for each population unit before sampling, and where the probability of selecting a unit is proportional to its size.

¹ Cambridge Business English Dictionary. Definition of awareness. Cambridge University Press. https://dictionary.cambridge.org/dictionary/english/awareness

ABBREVIATIONS AND ACRONYMS

aOR	Adjusted Odds Ratios
BREC	Biomedical Research Ethics Committee
CHWs	Community Health Workers
CALD	Culturally and Linguistically Diverse
CAM	Cancer Awareness Measure
CCG	Community Caregiver
CI	Confidence Interval
COPD	Chronic Obstructive Pulmonary Disease
Co-PIs	Co-Principal Investigators
DOH	Department of Health
FGDs	Focus Group Discussions
GLMs	Generalised Linear Models
GP	General Practice
GPS	Global Positioning System
HICs	High-Income Countries
KAPs	Knowledge, Attitudes and Practices
KZN	KwaZulu-Natal
Lung CAM	Lung Cancer Awareness Measure
LHWs	Lay Health Workers
LIMCs	Low- and Middle-Income Countries
MRC	Medical Research Council
NHI	National Health Insurance
SCLC	Small Cell Lung Cancer
OR	Odds Ratios
OTLs	Outreach Team Leaders
РНС	Primary Health Care
PI	Principal Investigator
PMB	Pietermaritzburg
PLWHIV	People living with HIV
PPS	Probability Proportional to Population Size

Research Assistants
Randomised Controlled Trial
Research Electronic Data Capture
South Africa
Small Cell Lung Cancer
Standard Deviation
Socio-economic Status
Sub-Saharan Africa
Syllabic Abbreviation of Words "Statistics" and "Data"
Unadjusted Odds Ratio
United Kingdom
University of KwaZulu-Natal
United States
United States of America
Ward-Based Primary Healthcare Outreach Teams

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TURNITIN REPORT

The Effects of a lung cancer awareness intervention in KwaZulu-Natal

ORIGINALITY REPORT						
1 SIMILA	1% ARITY INDEX	11% INTERNET SOURCES	% PUBLICATIONS	0% STUDENT PAPERS		
PRIMAR	Y SOURCES					
1	research	nspace.ukzn.ac.	za	3%		
2	WWW.PU	blichealthinafrio	ca.org	2%		
3	cideru.u	<mark>kzn.ac.za</mark>		1 %		
4	Systema Internet Source	aticreviewsjourn	al.biomedcent	ral.com 1%		
5	WWW.NC	bi.nlm.nih.gov		1 %		
6	research	nonline.lshtm.ad	c.uk	1 %		
7	uir.unisa			<1%		
8	www.bn			<1%		
9	WWW.res	searchsquare.co	om	<1%		

CHAPTER 1

MOTIVATION AND OVERVIEW OF THE STUDY

INTRODUCTION

This chapter provides the background information, problem statement, study justification and purpose of the study. It presents the study's aim, objectives, hypotheses, list of manuscripts and summary of the chapters.

BACKGROUND

Cancer morbidity and mortality continue to be a major public health challenge and a leading cause of death worldwide (1). Globally, there was an estimated 19.3 million cases of new cancer cases in 2020 and 10 million related deaths (1). These cases included 1.2 million nonmelanoma skin cancer and approximately 100 000 nonmelanoma skin cancer deaths. Worldwide, over 20 million new cancer cases have been projected for 2025, compared to about 14.1 million and 17.5 million new cases in 2012 and 2015, respectively (2-5). Lung cancer accounted for almost 1.8 million of all cancer cases diagnosed in 2012 (5). Global cancer cases increased by 33% between 2005 and 2015 (4). The top ten globally ranked cancers by incidence from the most to the least are: (a) female breast, (b) lung, (c) prostate, (d) nonmelanoma skin, (e) colon, (f) stomach, (g) liver, (h) cancer of the rectum, (i) cervical and (j) oesophageal (1). Although female breast cancer leads in cancer incidence, lung cancer is the leading cause of cancer deaths worldwide (1), with approximately 1 796 144 (18%) deaths in 2020, increasing from 1 590 000 in 2012 (6), most of whom were males (2, 5-8). Tobacco, indoor air pollution, outdoor air pollution and occupational exposures to lung toxins are the main drivers of lung cancer (6, 7). In South Africa, lung cancer ranks among the top four cancers in terms of morbidity and mortality after breast, prostate, and cervical cancers (4). However, the trends in lung cancer mortality in Africa are based on scant epidemiological evidence (6), and the burden of disease is perhaps wholly underestimated (9). Smoking has been associated with lung cancer in the country, where a study demonstrated that about 70% of deaths between 1999 and 2007 among males were smokers (10). About 55.4% of those were attributable to smoking. Among females, the proportion of smokers was lower at 49.6%, and smoking was attributable to 38% of those deaths. In 2016, the deaths attributable to

smoking were 14.2% among males and 5.4% among females (11). A study published in 2022 indicated a downward trend in smoking among adults, from 25.0% in 1998 to 19.4% in 2012 (12). Among males, the decline was from 40.5% to 31.9%, whereas among females, from 10.8% to 7.9%. The smoking attributable risk of lung cancer among males was 22.5 and 14.1 among females in the same period. However, when comparing the attributable burden of smoking in 2000, 2006, and 2012 in the South African population was 77.4%, 76.4% and 75.8%, respectively.

The lung cancer survival rates have been reported in high-income countries (HICs), such as the United States of America (USA), European, and Eastern European countries (13-15). There is limited reporting in other contexts, including South Africa (16). In the United States (US), the 1year survival rate of lung cancer was 47% between 2011 and 2014 (13). The majority of lung cancer cases (61%) were diagnosed at stage IV, and their 5-year survival rate was 4% compared to those diagnosed with stage I (57%). The 5-year survival rates for small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC) were 6% and 23%, respectively. A 2014 study in the US demonstrated a 5-year survival rate of 17% (17). The study did not report on the staging. In the United Kingdom (UK), males' age-standardised 1-year and 5-year survival rates from 2012 to 2017 were 36.3% and 12.9%, respectively (14). For females, these rates were 43.2% and 17.7%, respectively, in the same period. The European mean age-standardised 5-year survival rate of lung cancer patients for the period 2000 to 2007 increased from 11.6% in 1999-2001 to 13.4% in 2005-2007 (15). In Northern Europe, the rate was 12.2%, compared to the UK and Ireland (9.0%), Central Europe (14.8%), Southern Europe (13.2%), and Eastern Europe (10.6%). Lung cancer was among the poorest survival rates compared to other cancers in these regions. In Thailand, the 2013-2017 Khon Kean Cancer Registry data on lung cancer (n=2 149) indicated that the majority of cases (53.5%) were diagnosed as stage IV and the minority were stage I (1.6%) (18). The 1-, 3-, and 5-year survival rates were 31.2 %, 12.9 %, and 10.2%, respectively. The rates in these studies suggest the need to intervene at an earlier stage of disease development where the chances of survival are greater. Therefore, there is a need to raise awareness about the disease and encourage health-seeking behaviour at the community level. The table below summarises the recently reported survival rates by stage, type of lung cancer and country (Table 1). The data suggest that the patients that are diagnosed early tend to survive longer. Therefore, encouraging patients to seek medical help early through awareness campaigns could assist in this regard.

Country /	Stage of	1-year	3-year	5-year
Region	lung cancer	survival rate	survival rate	survival rate
USA (13,	No staging	47%	NR	17%
17)	done			
	Stage IV	NR	NR	4%
	Stage I	NR	NR	57%
	SCLC	NR	NR	6%
	NSCLC	NR	NR	23%
UK (14)	No staging	36.3%	NR	12.9%
	done ^a			
	No staging	43.2%	NR	17.7%,
	done ^b			
Thailand	No staging	31.2%	12.9%	10.2%
(18)	done			

Table 1: Lung cancer survival rates by stage, type of lung cancer and country.

NR - Not Reported

^a Age standardised survival rate for men

^b Age standardised survival rate for women

Literature suggests that greater awareness and recognising the signs and symptoms, in addition to early diagnosis and access to appropriate treatment, could ensure improved lung cancer outcomes (6, 19, 20). Prevention is considered the best approach to reducing the burden of lung cancer (6, 7). A study conducted in Malaysia among smokers and non-smokers, demonstrated that participants were willing to be screened if they were informed as being at high risk of lung cancer, especially smokers (20). While prevention is undeniably the optimal early intervention to address cancer, lifestyle choices remain a challenge. It is accepted that socio-economic developments and technologically complex human and constructed environments have profound effects on the scale and profile of cancer, hence low- and middle-income countries (LMICs) are now experiencing the greatest increase in cancer incidence (3). In Sub-Saharan Africa (SSA), cancer is predicted to have more than 85% increase by 2030, hence Morhason-Bello et al. (21) and Williams et al. (22) propose multiple interventions, including cancer awareness, advocacy, research, workforce care training and funding to avert these circumstances. Furthermore, there is poor access to quality of care for cancer patients in SSA, and South Africa is less than optimal (23). Hence, there is a dire need for improved awareness, earlier detection and appropriate intervention.

Community health workers (CHWs) have been part of the health system in many countries for many decades (24-43). They perform various duties, which have led them to be classified either as generalists or disease-specific CHWs (44). In South Africa, they have been an invaluable component of healthcare teams since the early 1930s (45). Their roles and duties have been variously defined as that of treatment defaulter and contact tracing, screening, condom distribution, and participating in community campaigns, especially in the prevention and control of human immune-deficiency virus (HIV) and tuberculosis (TB) (37, 46). This study utilised the CHWs in promoting lung cancer awareness in selected communities in KwaZulu-Natal.

PROBLEM STATEMENT

Lung cancer is among the leading causes of death among non-communicable diseases internationally (1). In South Africa, there is no national lung cancer screening programme. Lubuzo and colleagues demonstrated the resultant uncoordinated nature of lung cancer screening services in the public health sector (47). Thus, an overwhelming majority of lung cancer patients are not diagnosed early, and treatment is initiated late. This reduces the effectiveness of treatment, which results in most lung cancer patients dying whilst on treatment (48-51). Most patients with advanced cancer will die prematurely, and the length of survival (five and ten years) may vary considerably, affecting the quality of life if they enter remission. Some of the contributing factors include:

- i) structural systems: The patient pathways of care that hinder early diagnosis,
- ii) lack of appropriate health-seeking behaviour: where the patients do not access health facilities early to be screened and initiate treatment early, and
- iii) cultural beliefs: may serve as barriers for individuals to seek medical assistance timeously
 (52) as cultural beliefs may influence individuals to attribute their ill-health to
 spiritual/supernatural causes.

They may consult traditional healers as their first health-seeking contact, thereby delaying their presentation to formal health facilities. Clearly, there are cultural respect and agency for those who access their traditional healers, however, there is a need for communities to understand that healthcare and traditional systems are, in fact, complementary (53, 54). Little is known about knowledge, attitudes, and practices among populations regarding cancer, particularly lung cancer among communities in South Africa, including KZN. This study, therefore, presents an effective

awareness intervention and evaluates the resultant effects in selected communities in KwaZulu-Natal.

PURPOSE OF THE STUDY

Research has emphasised varying factors that affect the health-seeking behaviour of patients with lung cancer (55). This study revealed that these factors comprise three categories, namely i) delays in help-seeking: the patients' failure to act on suspicious symptoms was the main reason for the delay. ii) patients' understanding of symptoms: patients with lung cancer were inclined to attribute their symptoms to other, less serious causes. This was further complicated by the presence of a pre-existing lung health-related condition (such as chronic obstructive pulmonary disease (COPD) and asthma), or other medical conditions presenting with similar symptoms, and iii) social factors: patients believed that they were stigmatised by society, as smoking is generally associated with lung cancer. Moreover, the study revealed that appropriately, four in every five cases of lung cancer are attributable to smoking (56). Furthermore, smoking seemed to increase other cancers, such as cancer of the mouth, pharynx (upper throat), nose and sinuses, larynx (voice box), oesophagus (gullet or food pipe), liver, pancreas, stomach, kidney, bowel, ovary, bladder, and cervix (56).

It has been demonstrated in England that large-scale interventions to raise public awareness of lung cancer symptoms can be effective in changing the knowledge of lung cancer and health-seeking behaviour in communities, thereby increasing early diagnosis (57). In this study, it was found that, following the intervention, there was an increase in public awareness of a persistent cough being a precursor of lung cancer. There were increased General Practice (GP) referrals for suspected lung cancer and a general increase in the diagnosis of lung cancer. An increase of approximately 3.1% in the diagnosis of Stage 1 small cell lung cancer was observed, following the intervention. A systematic review was conducted to assess the effects of cancer awareness interventions on early presentation (58). This study found that the interventions (either at individual level or community level) were able to increase levels of cancer awareness, but limited to no evidence was found to suggest that these interventions were effective in promoting early presentation, as these interventions were tested in developed countries. There appears to be a lack of or limited studies testing such interventions in resource-limited countries like South Africa.

AIM AND OBJECTIVES

Overall Aim

The aim of the study was to investigate the level of awareness about lung cancer and its screening among communities in KZN and increase awareness of the disease, in terms of risk factors, routine screening, early diagnosis and treatment.

Specific Objectives

- To assess the level of awareness (including knowledge, attitudes and practices) about lung cancer and its screening among selected communities in KZN.
- To develop and implement an awareness intervention on lung cancer in terms of its causes, screening, and the importance of early diagnosis and treatment.
- To evaluate the effects of a lung cancer awareness intervention in the selected communities in KZN.

THESIS OVERVIEW

This thesis consists of ten chapters:

Chapter 1: This introductory chapter of the thesis provides the background on the research topic, the problem statement, the purpose of the study, its aims and objectives.

Chapter 2: This chapter covers the literature review, which discusses the current literature on lung cancer awareness. It examines the knowledge lung cancer in various contexts, the attitudes towards lung cancer, the related help-seeking behaviour, the interventions to raise lung cancer awareness, and the role of community health workers as implementing agents.

Chapter 3: This chapter presents the methods employed in the execution of the study. It provides details about the study setting, the population of interest, and ethical considerations. The different phases of study implementation are highlighted in this chapter.

Chapter 4: This chapter discusses the lung cancer awareness intervention development and its implementation in the selected communities by the community health workers.

Chapters 5, 6 and 7: These chapters present manuscripts (two published and one submitted for publication). Each manuscript addresses a corresponding objective of the study.

Chapter 5: This chapter reflects on the results of a baseline survey, in terms of the level of knowledge about lung cancer, attitudes towards lung cancer, help-seeking behaviour, willingness to screen for lung cancer, and the prevalence of smoking in the selected communities. This manuscript was submitted to the Journal of Public Health in Africa in December 2021. It is entitled: "Knowledge, attitudes and practices towards lung cancer among adults in KwaZulu-Natal, South Africa: A cross-sectional survey." It was accepted for publication in April 2022.

Chapter 6: This chapter discourses on the experiences of community health workers regarding training as implementers of the lung cancer awareness intervention at the community level. This manuscript was submitted to the African Journal of Primary Health Care and Family Medicine in December 2021. The title of the manuscript is: "Community health worker experiences of the training on lung cancer community awareness intervention in KwaZulu-Natal, South Africa." It is currently under review.

Chapter 7: This chapter presents the effects of a lung cancer awareness intervention. The manuscript was submitted to the Journal of Public Health in Africa in December 2021. The title of the manuscript is: "Pre- and Post-intervention survey on lung cancer awareness among adults in selected communities in KwaZulu-Natal, South Africa: A Quasi-Experimental study." It was accepted for publication in June 2022.

Chapter 8: This chapter contains additional results that were not discussed in the manuscripts in the previous chapters.

Chapter 9: This chapter synthesises the above chapters, presenting a summary of the research findings, its strengths and limitations.

Chapter 10: This chapter presents the conclusions based on the results of this study. It also addresses key recommendations about public health policy awareness, interventions on lung cancer, including the monitoring and evaluation strategies to track progress.

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CHAPTER 2 LITERATURE REVIEW

2.1. Overview

This chapter presents an overview of the literature pertaining to lung cancer awareness. It will focus on the existing body of knowledge, critique of the literature, and identifying existing gaps. The following sections will be discussed: i) determinants of lung cancer awareness in various contexts, including South Africa, ii) interventions on lung cancer awareness at community level, and iii) community Health Workers as collaborative team members within the healthcare system.

Various databases, including World Catalogue and Google Scholar, were included in the search for the associated literature. EBSCOhost also hosts the following databases, Academic Search Complete, AHFS Consumer Medication Information, eBook Collection, Health Source (both Consumer and Nursing/Academic Editions), and Medline. The following search terms were used: lung cancer awareness [644], lung cancer community awareness [11], lung cancer awareness interventions [10], predictors of lung cancer awareness [1], Community Health Workers programmes [57 400], Community Health Workers in South Africa [17 800], and CHW and TB programmes [5 390]. The literature review was a mini review (1). Therefore, the literature search was limited to literature published in the last ten years.

2.2. Determinants of Lung Cancer Awareness

Thirteen studies have been conducted to assess the level of lung cancer awareness among different communities worldwide in the last ten years (2-14). These comprised qualitative and quantitative studies inclusive of a wide range of ages and target groups.

2.2.1. Knowledge and Awareness of Lung Cancer

A qualitative study conducted in Dublin, Ireland, investigated participants' awareness of early signs and symptoms of lung cancer and help-seeking behaviour (2). It included both males and females with ages ranging from fifty-one to ninety years. It revealed that most participants

possessed fragmented information about lung cancer. Some participants in particular associated smoking with developing lung cancer (2). In some instances, social smoking, vaping, and ecigarettes were considered more dangerous than cigarettes. Working in occupations, which were perceived to have higher exposures to environmental risk factors (such as the construction industry) and other environmental exposures, were considered to pose a risk of developing lung cancer. Some participants had a fatalistic perception about being diagnosed with lung cancer. This qualitative study provided a comprehensive understanding of the level of knowledge of lung cancer in a more affluent community.

Another qualitative study was conducted in Glasgow, Scotland among patients (forty years and older, both males and females, n = 40) with COPD to determine how they appraised the daily symptoms they experienced (15). Their recognition of experienced symptoms was not associated with any other medical condition other than COPD. They did not anticipate the potential of COPD developing into lung cancer, as COPD is one of the risk factors. This emphasised the similarity of symptoms patients with other lung diseases experienced. In South Africa, the proportion of the population diagnosed with TB is about 737 per 100 000 population (16). Therefore, there might be TB patients who fail to identify lung cancer symptoms. In addition, as demonstrated in the Glasgow study, the possibility of health care providers also failing to identify these symptoms exhibited in patients, was also noted.

An Australian mixed methods study was conducted among residents (both males and females, and over forty years of age) of New South Wales (7). The qualitative component of the study comprised sixteen focus group discussions (FGDs), each with between seven to eight participants of mixed gender (n = 126). The quantitative aspect of study enrolled approximately 1000 participants. The qualitative study grouped the participants based on their location, socio-economic status (SES = low or medium-high), age (40 to 64 years, 65+ years) and smoking status (never smoked, former smoker, and current smoker). Although most groups were able to identify some symptoms of lung cancer, they were not necessarily confident that these would increase their suspicion of lung cancer should they experience them. Participants agreed across groups that this hesitancy could lead to delays in seeking assistance, unless they assumed the symptoms were severe enough. Coughing up blood and chest pains were the two symptoms identified to fit that category. For the quantitative

results of the study, smoking was identified, by most of the participants (90.6%) as a lung cancer risk factor, followed by second-hand smoke (25.6%). Shortness of breath was the most recognised lung cancer symptom (55.5%), followed by coughing up blood (39.1%). It is noteworthy that chest pain was not cited by most participants as a lung cancer symptom, even though they identified it as one of the symptoms that would prompt seeking medical assistance. Furthermore, this misperception confirms the complex nature of lung cancer and the limitations that communities experience where there is a lack of knowledge and awareness.

A study conducted among UK male and female university students (n = 120) investigated their awareness of breast, lung and cervical cancers, revealing smoking as the most recognised risk factor of lung cancer by females (100%) and males (97%) (9). This was followed by old age (females = 60%, males = 55%), and relatives with cancer (females = 57%, males = 37%). The overall awareness score for lung cancer was 0.78 (SD 0.25), and females had a higher score (0.80) than males (0.76). However, this small sample size may not be representative of the entire student population in the UK. Furthermore, the context of students in an HIC may be vastly different to that of students in a LMIC and as such, a replication of this study will require inclusion of contextual factors.

A qualitative study was conducted in New South Wales, Australia, among men and women from a culturally and linguistically diverse (CALD) population (11). The study included Chinese, Vietnamese, and Arabic-speaking participants (n = 51) who were either smokers or non-smokers. Similar to the Glasgow study, there were mixed responses regarding the symptoms of lung cancer. However, coughing up blood and weight loss were generally accepted as symptoms that would prompt seeking medical assistance. Generally, there was recognition of their limited knowledge of lung cancer. The participants agreed that a person over forty years, male, and a regular long-term smoker or heavy smoker, was more likely to develop lung cancer. Nonetheless, the Arab-speaking smoker group was less inclined to agree with this statement. Perhaps, denial justifies the continuation of smoking without entertaining feelings of guilt.

In the UK, a study conducted among households from England (n = 2360), Wales (n = 2298) and Northern Ireland (n = 2307) with both males and females using the Cancer Awareness Measure (CAM) established that the symptom mostly recognised for lung cancer was persistent coughing or hoarseness (69.5%) (14). However, this study did not explore risk factors; it investigated lung, breast and rectal cancer awareness. Due to this scope of the study, other constructs of lung cancer were not investigated.

A qualitative study was conducted in East and North East England among patients (n=35) referred to selected hospitals for secondary and tertiary care, including lung cancer (13). Most of these patients experienced difficulty in recognising the symptoms of lung cancer. In most cases, the symptom was declared to be caused by ageing or smoking, or an illness they could manage themselves. All these patients had comorbidities and did not have awareness of lung cancer symptoms. Some of them had comorbidities that were lung-related, which contributed to the complexities of their health.

A Malaysian descriptive study was conducted among the general population of eighteen years and older (n = 394) in Klang Valley in 2015 (4). This study indicated that the commonly known risk factors were air pollution and some form of exposure to tobacco products. The participants recognised approximately ten of the fourteen lung cancer symptoms. The most identified symptom was the worsening of, or change in, an existing cough (88.8%, n = 340), followed by persistent chest infections (85.9%, n = 325), and coughing up blood (85.3%, n = 332). Over 40% of participants were unaware that having a history of cancer was a risk factor, while about a third agreed. Current and ex-smokers considered themselves at higher risk of lung cancer than non-smokers. Although this study was conducted in an LMIC, there are contextual, cultural and health system differences between Malaysia and South Africa. Similarly, these differences could be noted in the context of HICs.

A study in Estonia, among males and females with ages ranging from thirteen to seventy-four years (n = 403), demonstrated that smoking was the commonly stated risk factor (95.8%), followed by previous lung cancer or family history of lung cancer (31.3%) (5). However, there was a difference between the risk factors that the participants were able to recall and those that were able to recognise. The most recognised risk factor remained smoking (99%), followed by second-hand smoking (95%), and previous lung cancer or family history of lung cancer (86.6%). Prolonged

coughing was the most recalled symptom (59.1%), followed by dyspnoea (shortness of breath) (45.4%). On the contrary, the most recognised symptoms were a prolonged cough (85.6%), fatigue (85.4%), and chest pains (82.1%). More participants (63.0%) assumed that lung cancer occurred more often among males, which appears to be similar in South Africa (17). None of the participants maintained that only males have lung cancer.

A study conducted in India among female college teachers with age ranging from twenty-six to fifty-nine years, (n = 872) in Delhi, Mumbai, and Jaipur indicated that about 80.2% of the teachers were able to correctly identify smoking as a risk factor for lung cancer (8). Second-hand (passive) smoking (68.2%) was also evident. A persistent cough was the most lung cancer symptom known to the teachers (67.5%), followed by shortness of breath (56.5%), and blood in the sputum (42.8%). Magazines, newspapers and television were the main sources of information regarding lung cancer. This study was conducted with a small sample of the population and confined to female college teachers that could be considered affluent and not a representative sample of the entire population of the cities included in the study.

An Iraqi study conducted by Dawood and colleagues investigated the knowledge and perceptions of smokers versus their intention to quit. The study indicated that 80.6% of the participants were aware that smoking cigarettes caused lung cancer (18). However, this study did not question the participants about their knowledge of the symptoms of lung cancer. Fewer participants (30.1%) agreed that passive smoking was an important risk factor for lung cancer among non-smokers. This poses a significant public health challenge in terms of preventative measures towards lung cancer. If individuals are unaware of the risk posed by passive smoking, they are more likely to smoke in the presence of children, other family members, and colleagues (19, 20). Thus, passive smoking place them at risk of developing lung health complications, including lung cancer.

In Nigeria, a study among adults (18 years and older) (n = 1125) Ilorin West and East Local Government Area of Kwara State revealed that the participants' Lung Cancer Awareness Measure (Lung CAM) score was low regarding the warning signs and lung cancer risk factors (8). Coughing up blood was the most recognised symptom (41.1%), followed by a persistent cough (39.3%) and persistent chest infections (38.8%). In terms of recognition of lung cancer risk factors, tobacco

smoking was mentioned the most (69.0%), followed by air pollution (56.4%) and second-hand smoke (51.4%). Less than half of the participants recognised the top three symptoms of lung cancer. In addition, more than two-thirds recognised smoking as a risk factor.

This is one of the few studies conducted in Africa regarding lung cancer awareness, which provides significant insight into the current levels of awareness on the continent and should be replicated in other African countries to increase the knowledge base.

2.2.2. Attitudes towards Lung Cancer

Attitudes, perceptions, and beliefs towards lung cancer could influence how individuals respond to the disease. Although, in the Irish study, some participants expressed the belief that lung cancer can be detected and treated promptly, because of the available modern technologies, whilst others perceived it as a death sentence (2). Most of the participants who held the latter belief were either heavy smokers or older. Nonetheless, these beliefs did not seem to contribute to modifying their behaviour or ensure that they adopt healthier behaviours, such as quitting smoking. It appears as if there was a tacit acceptance that they were going to die irrespectively, either because of old age or smoking. Most participants had experienced the loss of a loved one to lung cancer, and this experience contributed to their perceptions of the disease.

This fatalistic attitude towards lung cancer was also observed in the Glasgow study (3). This study focused on COPD patients' awareness and understanding. Perhaps, this view of the world was informed by their experiences of living with COPD and being diagnosed with lung cancer would compound the situation further. Some participants expressed the need to seek medical assistance if coughing or experiencing a persistent chest infection for three weeks or more. Others maintained that deteriorating health was expected during the aging process. The smoking participants' perceptions of the health care providers was also identified as a factor in their reluctance to seek medical attention.

The Malaysian study demonstrated that participants assumed that early detection of lung cancer could, more often than not, lead to more effective treatment, and this could increase the chances of survival (4). Interestingly, more males (72.1%, n = 124) agreed with this statement than females

(60%, n = 127). This was a statistically significant difference. In the study, a willingness to screen for lung cancer was expressed (91.4%, n = 352) if they were informed that they were at increased risk of lung cancer. This seems contrary to the Dublin, Glasgow, and Australian study findings of the fatalistic worldview (2, 3, 11). Quaife and colleagues also observed a similar trend among smokers in economically deprived communities of South-East London, where lung cancer was perceived as an uncontrollable disease (21). They also believed that the lungs were an untreatable organ of the body, which demonstrates a lack of knowledge and understanding. This perception demonstrates the inter-relatedness of knowledge and attitudes towards lung cancer.

2.3. Help-seeking Behaviour

From literature, it became evident that specific aspects exist, that influence help-seeking behaviour, which is elaborated on in this section.

Health care professionals, especially general practitioners (GPs), are pivotal in seeking help, particularly in HICs (2, 12). They have been acknowledged as the first point of contact when experiencing symptoms. The difficulty in accessing a GP was perceived as a barrier in the Australian qualitative study (11). In the CALD study, some groups (Chinese and Vietnamese) expressed confidence in the GPs and acceptance of their recommendations (11). However, among the Arabic-speaking participants, low levels were observed. This suggested cultural differences and influences towards how these groups perceive health care professionals such as GPs, and whether they proceed to seek medical assistance from them. This phenomenon may be different in contexts such as South Africa, since the majority of patients use primary healthcare services in public health sector facilities for health services (22, 23). These lower level primary health care facilities are often staffed by nurses and referrals made to higher level facilities for specialised services (24, 25). This model often introduces systematic delays to patients when investigating lung cancer. Early diagnosis (i.e., Stage I/II) and treatment initiation, in this context, would then be a challenge.

Recognition of symptoms suggestive of lung cancer could also prompt patients to seek help (2, 7, 8, 11-13). Coughing up blood and chest pains were regarded as severe symptoms that necessitated urgent medical attention (2). The recognition of the symptoms as a sign of an acute illness often

prompted early help-seeking behaviour (13). Occasionally, this recognition was furthered by family members and friends, who insisted on seeking assistance. In Australia, the Cantonese-speaking smokers indicated that they would seek assistance if they coughed persistently for more than three months (11). Additionally, both smokers and non-smokers from Vietnamese-speaking and Arab-speaking groups specified that they would consult their GPs about lung cancer-related symptoms.

It has been revealed that the stigmatisation of smoking limits help-seeking behaviour (21). The current smokers maintained that the health professionals blamed them for their ill-health. Therefore, they maintained that the health care practitioner was humiliating them. However, more ex-smokers were positive about being screened for lung cancer, in the hope of the availability of modern treatments and probabilities of survival. This study highlights the importance of supporting lung cancer awareness with healthcare interventions.

In the UK study, females (51.2%, n = 2145) were willing to wait for more than two weeks before seeking help if they coughed persistently (12). In the same study, the 50 to 59-year-olds (56.5%, n = 1291), those who were married/cohabiting (51.9, n = 1914), white (50.1%, n = 3298), had a degree or above (60.3%, n = 921), residing in England (50.7%, n = 1153), had access to healthcare (49.0%, n = 2739) and were prepared to wait for more than two weeks before seeking help if they coughed persistently. The predictors of waiting for more than two weeks were being female (OR 1.24), 70+ years old (OR 0.52), non-white (OR 0.44), having an education below a degree (OR 0.61), ease of consulting with a doctor (OR 1.20) and lack of recognition of symptoms (OR 1.30). A Nigerian study demonstrated that being male (aOR 1.50), having a level of education below tertiary (aOR 1.90), low monthly income (aOR 1.86), and lack of recognition of symptoms (aOR 3.09) predicted waiting more than two weeks to seek medical help (8).

An Australian study among newly diagnosed lung cancer patients investigated their help-seeking behaviour from a variety of sources or places: (i.e., i. support services, such as support groups, brochures, cancer care coordinators and financial support, and ii. people, including a partner, friend, oncologist, or other health care professionals) (26). This study revealed that these patients were aware of 7.8 (SD = 4.9) out of thirteen services, but only used 2.5 (SD = 2.4) of these services.

About 91% of the participants agreed that they would seek help from their local GP if they experienced problems related to their lung cancer diagnosis. The study also demonstrated a statistically significant relationship between perceived lung cancer stigma and perceived legitimacy of discrimination against patients with lung cancer. This perceived discrimination may negatively influence help-seeking. Similarly, this study was conducted in a HIC where the majority of the population had access to private GPs, unlike the South African context where patients' first line of contact is with clinics (27). Therefore, the patients' experiences of the health system in the Australian context may vastly differ from that of the patients in the South African context, which often has challenges of long waiting times before patients are afforded a consultation by health care professionals (28, 29). Moreover, this study was confined to patients already diagnosed and not those who were undiagnosed.

2.4. Intervention on Lung Cancer Awareness

There is a demonstrable lack of literature on community interventions of lung cancer awareness in LMICs, such as South Africa. Most of the published literature to date is on HICs (30-36). Prevention is paramount in addressing lung cancer (37, 38). It has been demonstrated in England that large scale interventions to raise public awareness of lung cancer symptoms can be effective in changing the knowledge and health-seeking behaviour among communities, thereby increasing early diagnosis (30). In this study, it was demonstrated that following the intervention, there was an increase in public awareness about persistent coughing as a lung cancer symptom. There were increased GP referrals for suspected lung cancer and a general increase in the diagnosis of lung cancer. About a 3,1% increase in the diagnosis of Stage I small cell lung cancer (SCLC) was observed following the intervention. Unlike England, in South Africa, many patients must be referred up to three levels from the primary health centres before being diagnosed by a specialist. As reiterated previously, lengthy waiting periods contribute to the delay in an appropriate health care response to patients (28, 29).

An Australian randomised controlled trial (RCT) study among long-term smokers demonstrated no noticeable difference in knowledge of lung cancer symptoms between baseline and postintervention tests (31). However, there was a 40% increase in the respiratory consultations with a GP, following the intervention in the trial group. A study among Chinese Americans in San Francisco, USA, to evaluate the effects of a cancer prevention education demonstrated increases in some aspects of knowledge, risk factors, and both the intention to screen and actually screening for lung cancer post-intervention (32). However, the level of knowledge on lung cancer was already high at baseline, in both the control and intervention groups.

Some interventions focused on the level of knowledge on screening for lung cancer (33, 34). These interventions were able to increase the desired outcomes of these studies. However, the limitations of the Texas study should be noted, as the sample size was low (33). No meaningful conclusions beyond that context could be reached. However, it does suggest a trend towards responsiveness to change when people are knowledgeable to make informed decisions about their health. The study by Jessup and colleagues demonstrated that when both the public and health care providers possess increased awareness about the importance of lung cancer screening, there is likely to be a corresponding increase in the service utilisation (34). This study was conducted in a HIC (USA) and utilised online resources (Facebook, Twitter, and LinkedIn) that may not be as accessible in the South African context, where internet accessibility in impoverished communities remain a challenge (39-41).

A systematic review of the studies promoting lung cancer awareness, help-seeking and early detection was conducted by Saab and colleagues recently (42). These studies reported varying degrees of success and post-test timeframes. They were able to demonstrate the desired outcomes, some immediately after the intervention, and others a month or more after the intervention. In addition, these studies determined increases in the knowledge of lung cancer symptoms and risk factors, benefits and risks of screening, and help-seeking (i.e., uptake of screening and consulting with a GP). Most of these studies, however, have been conducted in HICs which reaffirms the lack of research in LMICs regarding lung cancer awareness.

2.5. Community Health Workers as Implementing Agents

CHWs have been an integral component of the healthcare system, providing services at the community level in Africa and elsewhere for decades (43-63). It has been contended that, perhaps, too much responsibility has been placed on them, with little to no remuneration for their services (64, 65). Furthermore, their responsibilities seem to be increasing, rather than remaining constant

or even decreasing (66). In South Africa, the CHWs have been providing health services in tandem with the public health sector since the 1930s (67). Since then, they have been performing duties such as treatment defaulter and contact tracing, screening, condom distribution, and participating in community campaigns, especially in the prevention and control of HIV and TB (56, 68). However, their scope of work has been expanding over time (47, 69). Seutloali and colleagues indicated that the CHWs have been overburdened with competing priorities that tend to divert their focus from their routine functions (47). In Lesotho, for example, a shift of CHW functions was observed, where resources were moved from health promotion to home-based care due to higher HIV and AIDS and TB burden in the country (47).

A Kenyan study demonstrated that some lung cancer patients were first investigated for TB before being referred appropriately for lung cancer investigation, diagnosis and treatment (70, 71), thus delaying their diagnosis and treatment initiation. This could contribute to the lung cancer patients being diagnosed at late stages of the disease (Stage III/IV). The implications of these findings in the African context, where there is a lack of studies conducted to explore the actual and realistic burden of lung cancer, potentially creates an underestimation of the prevalence of this disease and under-service of the patients with the disease. This also suggests inadequate data accuracy, which often influences decision-making and the allocation of the necessary resources.

Lubuzo and colleagues indicated that, in the South African context, the health professionals lack knowledge of lung cancer and have a low lung cancer suspicion index at primary health care (PHC) level. Some patients with lung cancer could be suspected of TB and referred for TB investigation. Consequently, there is a delay in seeking proper care and the lack of early intervention with appropriate treatment and care. The health system may need to be agile enough to refer patients for lung cancer investigation, diagnosis and treatment, should TB be excluded as a possible. CHWs can play a vital role in community lung cancer education and conducting risk assessments at that level. This strategy could assist in accelerating the patients' agency and seeking medical help early should they suspect symptoms associated with lung cancer, as demonstrated in the Malaysian study (4).

A study by Murphy and colleagues on the CHW policy implementation in South Africa revealed that although the implementation was, for the most part, in accordance with policy, there were vital challenges (72). These challenges posed threats to the stability of the CHW programme and full integration into the PHC strategy. For example, in some of the districts where the study was conducted, the outreach team leaders (OTLs) were inexperienced, which would negatively affect the supervision and support of CHWs. In some cases, there were debates about the qualification level of the OTLs (i.e., professional nurse vs enrolled nurse) and their competencies. However, the dilemma is that professional nurses are often inundated with other responsibilities, thus spending less time on responsibilities deemed of lesser priority. In terms of the CHW programme, the study revealed that in some cases, there was less supervision and integration of CHWs into the PHC strategy and a lack of respect towards CHWs. Nonetheless, this was not a common occurance, since there are examples where the CHWs seemed to be appropriately integrated and even allocated space within their work facilities. At times, they were assigned cubicles from which they could access their allocated patient lists. This alludes to their integration into the PHC system. The main areas of contention were lack of uniforms and name tags, low remuneration, concerns about career development, and safety and security whilst working in the community. The latter has become an increasing national focus with other health care professionals being attacked when attempting to respond to medical emergencies. Tseng and colleagues compared the performance of CHW programmes in South Africa, where the CHW teams reported to a clinic-based nurse were compared with those the reported to a community-based nurse (73). They disclosed that the clinicbased teams led by senior supervisors were better integrated and were able to guarantee continuity of care. In contrast, the other teams were unable to sustain high levels of trust in the community and were not well-integrated with the clinic staff.

The essential role of CHWs in the South African health system cannot be re-emphasised, as they are central to improving health care. The key functions of the CHWs were primarily to be generalist, including health promotion, health education, behaviour change/modification, and social change. In addition, they were to provide first aid and referrals to healthcare providers (47, 74, 75). However, due to the high burden of disease, of HIV and AIDS, TB and other diseases, these functions have evolved to include home-based, specialist and/or single disease focus (47, 74, 75). Supervision and support are key to its success, and proper orientation and training of OTLs,

whether a professional nurse or an enrolled nurse, it is non-negotiable. Respect for the CHWs and recognition of the work they do would contribute towards fostering a sound working environment, boosting their confidence, and require no monetary commitments. Some of the interventions to address the issues mentioned above do require financial investments, which poses a challenge within a financially constrained health budget. Nonetheless, the Constitution of South Africa refers to the progressive realisation of the right to health, and therefore commitments towards improving the working conditions of CHWs. Thus, improving the services they offer to the communities they serve is vital, as they form a liaison between the communities and the healthcare facilities. They are the cornerstone of the national Ward-Based Primary Healthcare Outreach Teams (WBPHCOT) (76). Some districts attempted to solve the safety and security concerns by pairing the CHWs so as to act as a deterrent and any potential harm to personal safety (72). However, the threat of safety was not mentioned as a concern in all the districts, as CHWs reside in the same communities they serve and are known in the community. Hence, the value of the work they do is appreciated. However, it remains important to monitor the safety and security of the CHWs and pair them as far as possible.

The current study engaged with CHWs in the delivery of lung cancer awareness interventions at the community level, which appeared to be an under-utilised strategy in expanding the health care team in the South African context, compared to other contexts (77-80).

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CHAPTER 3

METHODOLOGY

Overview

This section describes the methods that the study employed to achieve the research objectives as outlined previously.

Study design

A quasi-experiment study was conducted in the selected communities in KZN. The closest example of a similar study in the literature to the current study is the WHO global hand hygiene study that utilised a quasi-experimental design with the before (baseline) and after (Post-intervention) measurements of the desired outcome(s) (1). White and Sabarwal suggest that a quasi-experiment study should identify a control group that is as similar as possible to the treatment group in terms of characteristics (2). The current study utilised the same communities and clusters as the control group, where the baseline measures were used to compare with the post-intervention measures. The study was conducted in three phases.

Phase 1: To establish a baseline to assess the level of awareness about lung cancer in the selected communities.

Phase 2: To develop and implement an intervention to raise awareness about the causes of lung cancer, screening, early diagnosis and treatment.

Phase 3: To evaluate the intervention in the selected communities.

Population and Study Sample

The study population as described in Table 2 below was sub-divided according to the different phases of the study.

Table 2: Description of Study Participants by Phase.

Phase 1	Phase 2	Phase 3
Adult males and females (18 years and over) residing in the selected communities in KZN.	Implementers of the awareness intervention.	Adult males and females (18 years and over) residing in the five selected communities in KZN.
Inclusion Criteria		
<i>Males and females:</i> 1. Residents of Umlazi, Chatsworth, South Durban, iMbali and Sobantu. 2. Eighteen years and older.	1. Community Health Workers	<i>Males and females:</i> 1. Residents of Umlazi, Chatsworth, South Durban, iMbali and Sobantu. 2. Eighteen years and older.
Exclusion Criteria		
 Males and females: 1. Younger than 18 years. 2. Not residents of Umlazi, Chatsworth, South Durban, iMbali and Sobantu. 3. Visiting individuals (non-residents). 		<i>Males and females:</i> 1. Younger than 18 years. 2. Non - residents of Umlazi, Chatsworth, South Durban, iMbali and Sobantu. 3. Visiting individuals (non- residents).

Sample Size and Selection of Sample

Sample Size

The sample size was calculated for Phases 1 and 3 in consultation with a statistician. A stratified random cluster sampling method was applied, with clusters randomly stratified across five representative communities. For the continuous outcome, in order to demonstrate a minimum 2.5-unit average increase in knowledge overall (and in particular knowledge components) post-intervention compared to pre-intervention, with a power of 80% and a statistical significance level of 5%, we estimated a need for a sample of around 40 communities (primary sampling unit), with 40 pre-intervention and 40 post-intervention clusters from the same communities. We assumed that the combined standard deviation of the knowledge score to be 10 and that the average number of subjects to be sample per community would be at least 20. The sample size also takes into account the need to adjust for intracluster correlation, which is a consequence of randomising at one level (communities) and analysing at another (subjects). The adjusting factor was conservatively assumed to be 0.1.

Sample size calculator (Cluster trial - continuous outcome)

This spreadsheet is designed to calculate the number of clusters required for a two-arm CLUSTER randomised controlled trial comparing two MEANS The user must enter:

the mean difference between intervention and control the standard deviation of the control group measure the average cluster size an estimate of the intracluster correlation

The total number of clusters required in each group is calculated with 80% power and 5% significance

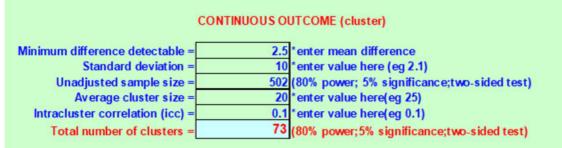


Figure 1: Sample size calculation for both Phase 1 and 3 for a continuous outcome

For the binary outcome, increase in order to demonstrate a minimum 12% increase in knowledge score overall exceeding 50 points (and in particular knowledge components) post-intervention compared to

pre-intervention, with a power of 80% and a statistical significance level of 5%, we estimated a need for a sample of around 40 communities (primary sampling unit), with 40 pre-intervention and 40 post-intervention clusters from the same communities. We assumed that the baseline knowledge score proportion in excess of 50 points to be 0.5 or 50% and that the average number of subjects to be sample per community would be at least 20. The sample size also takes into account the need to adjust for intracluster correlation, which is a consequence of randomising at one level (communities) and analysing at another (subjects). The adjusting factor was conservatively assumed to be 0.1."

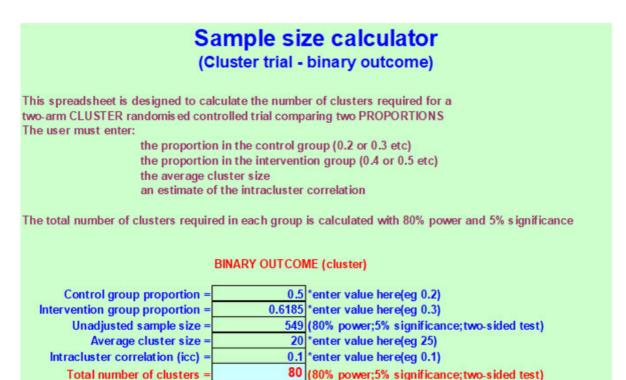


Figure 2: Sample size calculation for the binary outcome for both Phase 1 and 3.

In total, forty out of 879 clusters were selected using probability proportional to population size (PPS) sampling for phases 1 and 3 (see Table 3 below). Twenty households were selected from each cluster using maps of the selected wards. A minimum of twenty participants were randomly sampled within each cluster to allow a precision of \pm 5% assuming a design effect of 2 with 95% confidence and assuming maximum variability (i.e., p=0.5 or 50%). A total sample size of n = 800 was therefore estimated.

Phase 2: Ten community health workers.

CLUSTER	SAL_CODE	POPULATION	COMMUNITY
1	5620074	559	iMbali
2	5620106	660	iMbali
3	5660451	545	iMbali
4	5660657	673	iMbali
5	5660672	684	iMbali
6	5660694	701	Sobantu
7	5660697	704	iMbali
8	5660710	715	iMbali
9	5660749	750	Sobantu
10	5660775	782	Sobantu
11	5660799	808	iMbali
12	5660850	916	iMbali
13	5990812	467	Umlazi
14	5991130	413	Umlazi
15	5991141	453	Chatsworth
16	5991657	521	Chatsworth
17	5991927	482	Umlazi
18	5992267	588	South Durban - Wentworth
19	5992368	585	Umlazi
20	5992389	577	South Durban - Wentworth
21	5992699	583	Umlazi
22	5992712	584	Umlazi
23	5993091	686	South Durban - Wentworth
24	5993575	696	Umlazi
25	5993796	784	South Durban - Wentworth
26	5993904	819	Chatsworth
27	5994070	854	Chatsworth

Table 3: Selection of clusters in the five communities in Durban and Pietermaritzburg

28	5994257	909	South Durban - Wentworth
29	5994320	929	Umlazi
30	5994543	997	South Durban - Wentworth
31	5994624	1012	Chatsworth
32	5994774	1463	Chatsworth
33	5994775	1482	Chatsworth
34	5994785	1636	Chatsworth
35	5991984	543	Umlazi
36	5994107	784	Umlazi
37	5660768	770	Sobantu
38	5994153	847	South Durban - Wentworth
39	5992836	653	Chatsworth
40	5660752	754	iMbali

Selection of Sample

The study sample selection was per study site and according to the study phases. Both Phases 1 and 3 used the same sampling technique. A comparison between two cross-sectional surveys was done. These were two different random samples of subjects from the same clusters and communities. Phase 1 served as the baseline for Phase 3.

Phase 1 and 3:

Maps were used to identify the selected clusters together with their boundaries. In each selected cluster, a starting point was selected, i.e., a landmark, which could be a community hall or a church or a local shop. From the selected starting point, the first house to the left was selected, and thereafter households were selected randomly until the required sample size was reached. In each selected household, one adult was randomly selected by assigning numbers to the adults that met the inclusion criteria and were present during data collection. These numbers were written on pieces of paper, shuffled, and one piece of paper was selected. The adult represented by the number on the selected piece of paper was invited to participate in the study.

Inclusion / Exclusion Criteria

Table 2 above (Page 33) provided a detailed description of the inclusion and exclusion criteria for each phase.

Sources of Data

Table 4 below illustrates the different instruments that will be used to collect data:

Research Instrument	Variables	
Phase 1 and 3		
Questionnaire	 Sociodemographic data (Age, sex, education, socio-economic status, setting, race, GPS coordinates of the dwelling/household). Knowledge of lung cancer (risk factors). Knowledge about screening for lung cancer. Importance of early diagnosis. Knowledge about the availability of lung cancer treatment. History of exposures (smoking, working in chemical factories or mines, residing with family members who smoke). Family history of lung cancer. Prevention of lung cancer (eating healthy, exercise). Health-seeking behaviour about lung health. Role of traditional health practitioners Local radio stations exposed to and level of exposure. Sources of information about lung cancer and lung health. 	
Phase 2		
Documenting the training of community health workers	1. Questionnaire Knowledge, attitudes, beliefs about lung cancer, and perceptions of readiness to implement the intervention– before and after training.	2. Focus Group Discussions (FGDs) In-depth exploration of the attitudes and beliefs about the intervention training.

Table 4: Sources of data and variables by phase

Data Collection

Phase 1 and 3:

Trained community health workers (CHWs) collected data using an electronic structured questionnaire. This questionnaire was on a Research electronic data capture (REDCap) platform and accessed using a tablet. REDCap is a secure online platform that facilitates the creation of databases that can be used to collect data electronically (3). The questionnaire was translated from English into isiZulu for consistency and standardisation purposes. Thereafter, it was translated back into English by a different person to ensure the accuracy of the translation.

Phase 2:

An interview guide was used to guide the discussion points with the CHWs. A trained CHW who was part of the training conducted the FGD, which took about an hour. More information is provided on the article (see Chapter 6: Community health worker experiences of the training on lung cancer community awareness intervention in KwaZulu-Natal, South Africa). The FGD was audio-recorded and transcribed. The CHWs completed a questionnaire before and after the training on the lung cancer awareness intervention. This questionnaire intended to measure if there had been an improvement in the knowledge scores of the CHWs on lung cancer, and to identify knowledge gaps that might exist. Similarly, this questionnaire was on REDCap and accessed using a tablet. Typically, behavioural studies have three measurements (i.e., baseline, post-intervention, and end-line) (4-6). The baseline survey would be before the intervention. The post-intervention survey would be between a month and six months after the intervention, and the end-line six months or more after that. Because lung cancer is usually diagnosed at late stages, as discussed before, and the need for people to take action as soon as they notice related symptoms together with the CHWs working in the community, a postintervention survey one after the intervention survey appropriate.

Data Management

Phase 1 and 3

For the first phase, the questionnaires were printed in both English and isiZulu because of technological challenges. The researcher collected the completed questionnaires which were stored in a locked cabinet. They were then captured on REDCap by a trained research assistant. For the third phase, the questionnaires were accessed through an electronic device (tablet) connected to a server with redundancy protocols. Access to the server was password protected. The devices were stored securely as specified by the University's protocol. The datasets were downloaded and prepared for analysis. The downloaded datasets were also stored in a password-protected folder. Only the PI and Co-PIs have access to the dataset. The identity of the participants was protected in the datasets to ensure confidentiality.

Phase 2

The audio recording and transcript from the FGD were also password-protected in a secure folder. Only the PI and Co-PIs had access. Similarly, storage protocols as stipulated by the University were adhered to for Phase 2.

Data Analysis Strategies

The quantitative data were analysed using STATA, and the qualitative data with QSR NVivo 12. The qualitative data and its analysis informed how successful the training on the awareness intervention was and whether the implementers of the intervention were confident about implementing the intervention. This had implications for the successful implementation and sustainability of the knowledge gained from the training, in terms of whether this knowledge and training will be used beyond the period of the study. As such, the qualitative component of the study was vital, albeit a small component of the overall study. Therefore, no theoretical framework was necessary for the qualitative component. However, the data from the transcripts were coded, where the researcher attached labels to lines of text in order to group chunks of data and later compared similar or related information (i.e., Thematic analysis, Table 5)(7, 8). The codes were thereafter organised in terms of parent codes and sub-codes to make meaning of the data. This process of organising data into code and sub-codes generated themes and sub-themes. Transcendental phenomenology study design was used in the qualitative study, because the work done by the CHWs would involve experience that could potentially evoke emotional responses. More information regarding the methods of this section is elaborated on in Chapter 6 (from Page 67).

For pre- and post-intervention surveys, 95% Confidence Intervals (CI) for key study outcomes were estimated using survey weights based on the complex multistage sampling design. The bivariate comparisons were made using survey-weighted t-tests and Chi-square tests. The post-intervention quantitative data analysis included the two approaches used to assess the outcome of the intervention: i) change in knowledge score (Multilevel mixed-effects ordered logistic regression), and ii) improvement in categorized knowledge (\leq 50% and 50+% - Multilevel mixed-effects binary logistic regression). Both approaches used a multi-level mixed-effect regression approach model to account for nested cluster correlation. Also, add the various interactions you tested (e.g., change in score by age group, time, etc.) The binary logistic regression model was ultimately chosen as the final model, because of fewer resoponses per category in the ordered logistic regression model. Thus, rendering the analysis ineffective.

Table 5 below captures the different analyses as per phase of the study:

Phase 1	Phase 2	Phase 3
Quantitative Analysis: Descriptive	Quantitative Analysis: Descriptive	Quantitative Analysis: Descriptive
 Frequency tables (sex, race, marital status, SES). Summary stats (Age, income, education). 	 Frequency tables (sex, race, area). Summary Stats (Age, education). Knowledge scores (before and after training). 	 Frequency tables (sex, race, marital status, SES) Summary stats (Age, income, education)
Analytic	Qualitative Analysis: Analytic	Analytic
 Predictors: health-seeking behaviour. Knowledge of and attitudes towards lung cancer. 	- Transcendental phenomenology study design: Experiences of the CHWs on awareness interventions and training. Thematic analysis – inductive approach (themes emerge from the data).	- Effects of the intervention on knowledge, attitudes, and health-seeking behaviour about lung cancer and lung health, using a binary logistic regression model.

Table 5: Methods of data analysis by project phase

Ethics and Human Subjects Issues

Ethics approval for this study was provided by the University of KwaZulu-Natal (UKZN) Biomedical Research Ethics Committee (BREC) with reference number BF585/18. The entire engagement with the participants was guided by beneficence, nonmaleficence, autonomy and justice. The CHWs were trained on the informed consent process, and would not proceed administering the questionnaire, nor the intervention, without valid consent given by the potential participants. Only after the participants' valid consent could the research team continue to work with the participants.

During the recruitment process, the potential participants were provided with an information page in their preferred language. This information page contained all the aspects pertinent to the study, (see Appendix 1 to 120. It also detailed voluntary participation i.e., they could withdraw from the study at any time without any adverse effects. The information page also explained the benefits of participating in this study and the associated risks.

In addition, the contact details of BREC, the supervisors and the PhD student were included. Once the information page was explained by the research team, the potential participants were required to provide written consent by signing a consent form. A witness was also expected to sign. This was thereafter considered valid consent. If the potential participants were not able to sign for reasons of illiteracy, they were requested to mark an "X" in the space provided for the participant's signature.

It was envisaged that the study would not present with any biological, social, legal, or financial risks. However, should a psychological risk present itself with any trauma associated with death and any association with lung cancer, referral to psychological services in either a public or private health facility was available to the participants.

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CHAPTER 4

LUNG CANCER AWARENESS INTERVENTION

INTRODUCTION

This chapter addresses the development and implementation of the lung cancer awareness intervention in the selected communities that were selected to participate in the study. Various interventions on lung cancer awareness and prevention have been discussed in the literature review chapter (1-8). All these interventions, but one, were developed and conducted in high-income settings that are not comparable to resource-limited settings such as South Africa. In Africa, the only intervention implemented in Kenya focused on screening, not on awareness. Therefore, a need to develop an awareness intervention for Lowand Middle- income countries (LMCs) setting like South Africa was identified. Most of these interventions were at the facility level rather than at the community level (1-7). As discussed in the literature review, most lung cancer patients generally do not survive treatment because of late diagnosis, where they are diagnosed at either stage III or IV. The 5-year survival rate for patients with stage I was reported at 57% in 2019, whilst for those with stage IV, at 4% (9). When differentiated by the type of lung cancer, the survival rate of small cell lung cancer (SCLC) was 6%, and that of NSCLC was 23% for all stages. When compared to rates reported in 2014 in the US, SCLC survival rates remained similar at 6.1%, compared to NSCLC's rate of 17.1% (10). These rates remain low compared to that of all adult cancers at 66%.

Lung cancer deaths in South Africa are ranked among the top five cancers among males and the top ten among females (11). Part of the reason is the late presentation to the health facilities due to, among other reasons, a lack of knowledge about lung cancer, fear of a lung cancer diagnosis, and fear of stigma from smoking (12-19). These factors necessitate intervening before patients present to the health facilities, especially in LMICs such as South Africa, as patients must enter the public health system at the PHC level. Once in the health system, they must follow the referral pathways before the final diagnosis (20), which may result in significant delays before they are diagnosed with lung cancer. Therefore, raising awareness about this cancer at the community level, together with mobilisation efforts, could assist patients with starting the process of seeking help earlier than they would otherwise have done and thereby improve patient outcomes and survival rates. Thus, working with the CHWs in this study was deemed an important strategy.

THE INTERVENTION DEVELOPMENT AND IMPLEMENTATION

This intervention utilised the CHWs as they form a bridge between communities and healthcare service provision within health facilities and act as the cornerstone of South Africa's WBPHOTs (21). The intervention focused specifically on raising awareness on lung cancer and smoking as the leading risk factor for lung cancer. The awareness intervention was subsequently developed based on the baseline survey results. The intervention addressed, among other aspects, i) knowledge gaps, ii) attitudes towards lung cancer screening and treatment, and iii) health-seeking behaviour. This intervention was adapted from the lung cancer training manual developed by the pulmonologists in the Lung Laboratory -Research and Intervention Centre and CANSA. The information about the benefits of quitting smoking (22) and tips on how to quit (23) were sourced from The American Lung Association and CANSA, respectively. The CHWs were not trained on the smoking cessation aspect, as literature has demonstrated that smoking cessation is often offered during patient-doctor consultations for lung cancer screening (24-26). In this study, the CHWs' optimal role was deemed to be before this step. However, they were to sensitise the community members about the benefits of quitting smoking and tips on how to quit. Nonetheless, recent literature advocates for the training of CHWs on smoking cessation (27). The CHWs employed in the current study were trained in each aspect of the intervention, namely, the content of the intervention (as discussed above), the duration of the intervention, how the intervention will be administered and the target population. The information, education and communication (IEC) materials were piloted to test for clarity and acceptability to the local context and whether the material was at the correct level. The pilot was conducted in community clusters not selected for the study. One cluster was an isiZulu-speaking community (five households), and another cluster was an English-speaking community (five households). The isiZulu materials on the causes of lung cancer were revised after the pilot, specifically the key facts about lung cancer and managing the risk for lung cancer. The CHWs then implemented the intervention in the forty selected clusters over the study period, where they would visit the households within these clusters.

The implementation of the intervention was based on the Medical Research Council's (MRC) framework for developing and evaluating complex interventions (28, 29). This framework acknowledges that a randomised controlled trial may not always be possible, hence the use of quasi-experimental and observational study designs. The current study utilised the quasi-experimental design because of the twotiered nature of the intervention, the inclusion of large community clusters (large scale) and the strong possibility of cross-contamination across community clusters. The intervention included radio campaigns on community radio stations in the targeted communities. These campaigns were meant to supplement the door-to-door campaign at the community level. The researchers appeared on the local stations to raise awareness about lung cancer, particularly the warning signs and symptoms, risk factors, the importance of quitting smoking, and seeking help soon after recognising the symptoms. In addition, the team conducted community campaigns, especially at public events using a PA system. Pamphlets with relevant information were distributed to the households visited by the CHWs.

The main delivery of the intervention was the door-to-door campaign in the 40 clusters that were selected for the study. The CHWs spent time with the household members and administered the intervention. They introduced themselves, explained the purpose of the visit, and assessed whether they had time for them at that time or would prefer a different time. When the households were unable to receive the CHWs, they made appointments to come back at a convenient time. They explained how long the process was likely going to take. The CHWs were encouraged to build rapport with the household members before they started the session and display a non-judgemental attitude as they engaged with the households. The CHWs established that the discussions would be kept private and confidential, and the records of their participation would not be publicly available. They would ascertain what the household members about lung cancer, address their questions about the disease, and distribute pamphlets on various topics about lung cancer. They explained the diagnosis process. The CHWs encouraged the household members who exhibited lung cancer symptoms to seek professional medical help. The CHWs would spend about 30 minutes in each household.

The CHWs kept records of the households they visited. They recorded the address of the households, the contact numbers of at least one person present during the visit, the number of people they spoke to in the household, the topics they discussed, and the number of people they encouraged to visit the health facilities because of the symptoms they exhibited. These data points were recorded using REDCap, which was installed on tablets. The researcher visited the CHWs in their clusters every Friday to collect the data from the tablets and address potential challenges in the field. One of the data points they were supposed to collect was the GPS coordinates. However, this feature did not prove useful as the REDCap software did not keep the original coordinates during the download of the data to the servers. The CHWs visited about 2328 households and reached 10 434 individuals. About 4 236 individuals in the study communities were identified with the discussed signs and symptoms and encouraged to go to their local

health facilities for further investigation and care. More information about the intervention is included in Appendices 17 and 18 (Pages 177 to 202).

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CHAPTER 5

KNOWLEDGE, ATTITUDES AND PRACTICES TOWARDS LUNG CANCER AMONG ADULTS IN KWAZULU-NATAL, SOUTH AFRICA: A CROSS-SECTIONAL SURVEY

The earlier three chapters provided the background, the rationale for this study (**Chapter 1**) and current scientific evidence or existing knowledge and identified gaps that needed addressing (**Chapter 2**). The third chapter described the methodology employed to conduct the study.

This chapter addresses the first objective of this study, which is, to assess the level of awareness (including knowledge, attitudes and practices) about lung cancer and its screening among the selected communities in KZN. Additionally, it provided invaluable data on the level of awareness about lung cancer in resource-limited settings such as South Africa. The findings of this study can assist the Department of Health (DOH) in creating lung cancer awareness and screening interventions throughout the country.

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ORIGINAL ARTICLE



Knowledge, attitudes and practices towards lung cancer among adults in KwaZulu-Natal, South Africa: a cross-sectional survey

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Abstract

Background. Lung cancer remains the number one cause of cancer mortality estimated at 1.8 million deaths. There are limited studies in resource poor countries regarding knowledge, attitudes and practices towards lung cancer.

Objective. This study aimed to describe the knowledge, attitudes and practices regarding lung cancer in selected communities in KwaZulu-Natal, South Africa.

Methods. An observational, analytic cross-sectional study design was conducted using a standardized questionnaire. A stratified random cluster sampling method was applied across five communities. A regression model was developed to identify the predictors of the level of knowledge.

Results. About 59.9% (95% CI 52.0 - 67.3) of the participants reported to have heard of lung cancer. The mean knowledge score was 41.8% (95% CI 35.7 - 47.9%). Coughing blood was the most recognized symptom (61.0%, 95% CI 52.1 - 69.1). About 17% (95% CI 14.7 - 21.5) of participants reported to be smokers. Many respondents reported that they would go to a health centre or clinic in case they were coughing blood (72.4%, 95% CI 93.9 - 79.5). Less than 10% (95% CI 3.9 - 8.1) of participants was screened for lung cancer at the time. Gender, history of working in the chemicals industry, screening for lung cancer, and time taken to seek health care when sick were significant predictors of lung cancer knowledge.

Conclusions. Public health interventions should be explored to increase the levels of community awareness regarding lung cancer, particularly focusing on the importance of screening, early diagnosis and treatment. Keywords: Lung cancer, community awareness, screening, prevention.

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INTRODUCTION

ancer morbidity and mortality is increasingly becoming a major public health problem and it is the second leading cause of death worldwide¹. Globally, over 20 million new cancer cases are projected for 2025 compared to about 17.5 million new cases in 20151-4. Globally, new cancer cases estimates have been trending upwards between 2008 (12.7 million) and 2021 (19.3 million)5-8. About 19.3 million new cases of cancer were estimated globally in 2020, with lung cancer being the second most commonly diagnosed cancer (2.2 million, 11.4%) after female breast cancer (2.3 million, 11.7%)8. Lung cancer remained the number one cause of cancer mortality estimated at 1.8 million deaths (18%). In South Africa, lung cancer is among the top four ranking cancers in terms of morbidity and mortality after breast, prostate, and cervical cancers1. However, the trends of lung cancer mortality in Africa are based on scanty epidemiological evidence9, and the burden of disease is underestimated⁶.

Greater lung cancer awareness, symptom recognition, early diagnosis, and access to appropriate treatment may improve outcomes.^{9–11} Lung cancer prevention is best.⁹ A Malaysian study found that smokers and nonsmokers were willing to go for lung cancer screening if they knew their risk.¹¹ In contrast, 92.8% of USA veterans were willing to screen for lung cancer regardless of smoking.^{12,13} A study on smoking cessation among USA veterans found that most saw lung cancer screening as stimulating and self-reflective.¹⁴They also liked lung cancer screening. During screening, some were anxious.

Low- and middle-income countries (LMICs) have done few studies on lung cancer knowledge, attitudes, and practices (KAPs). Morhason-Bello et al. and Williams et al. propose cancer awareness, advocacy, research, workforce care training, and funding to avert this situation.^{15,16}Cancer care is poor in SSA, including South Africa.¹⁷Better awareness and detection are needed.

The purpose of this observational cross-sectional study was to describe the knowledge, attitudes and practices regarding lung cancer in selected communities in KwaZulu-Natal, South Africa.

MATERIALS AND METHODS

Study setting and design

This study was conducted in selected communities (townships: Umlazi, Chatsworth, Lamontville, Imbali and Sobantu), and suburb: Bluff) in KwaZulu-Natal (KZN), South Africa. A township is an area where the previously disadvantaged communities (predominantly Black African people) were forced to live in during the apartheid era in South Africa¹⁸. Households were visited between March and May 2019. An observational, analytic cross-sectional study design was conducted using a standardized questionnaire. The questionnaire was piloted in each of the five study communities. Ten participants were recruited in the pilot study. These participants were not included in the study sample, and they were not from the study sites.

Study population, inclusion, and exclusion criteria

Adults from the legal age of 18 years and above residing in the one of the selected communities were targeted to participate in this study. Both genders were invited to participate in the study. People younger than 18 years were excluded from participation.

Sample size and sampling method

A stratified random cluster sampling method was applied, with clusters randomly stratified across five representative communities. A total of 40 out of 879 clusters were selected using probability proportional to population size (PPS) sampling. Twenty households were selected from each cluster based on maps of the selected communities. A minimum of

Supplementary information The online version of this article (Tables/Figures) contains supplementary material, which is available to authorized users.

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20 participants were randomly sampled within each cluster to allow a precision of \pm 5% assuming a design effect of two (2) with 95% confidence and assuming maximum variability (i.e. p=0.5 or 50%). A total sample size of 800 was estimated.

Data collection tool

A standardised questionnaire was used in this study as a measurement instrument that consisted of different sessions including participants' sociodemographic data, knowledge, attitudes and practices (and health-seeking behaviour) regarding lung cancer. The socio-demographic variables were from the National Income Dynamics Study, Wave 3 questionnaire¹⁹, and the variables about lung cancer were taken the Cancer Research UK. Lung Cancer Awareness Measure Toolkit. Version 2.1. 2011²⁰. The variables that were collected were: Gender, Age, Race/ethnicity, Socioeconomic status, Type of settlement, Level of education, Smoking behaviour, Knowledge (e.g., sign and symptoms, risk factors, and treatment of lung cancer), Attitudes (what to do if coughing blood, persistently, or suspecting lung cancer), and Health-seeking behaviour towards lung cancer. The questionnaire was in English and translated into isiZulu for the participants to choose their preferred language. A team of field workers administered the questionnaires. The data was captured using REDCap²¹ which is connected to a server that has redundancy protocols, only accessible to users with granted access through login credentials.

Data analysis

The data was analyzed using STATA 15 and summarized and presented using tables. Cronbach's Alpha was calculated for the knowledge (0.94) and attitude (0.08) domains of the questionnaire to test for internal consistency. The knowledge score was calculated by summing all the knowledge variables, dividing the outcome by the number of the variables (34), and then multiplying them by hundred to get the percentage. Each correct response was assigned a value of one (1) and zero (0) for an incorrect one. The participants' knowledge scores were grouped either as poor knowledge (<50%) or good knowledge (\geq 50%). The two groups were then compared in terms of the socio-demographic factors. Because of the sampling design, it was possible to have sample weighted 95% Confidence Intervals (CI) around the point estimate. A regression model was developed to identify the predictors of the level of knowledge.

Ethics approval and consent to participate

The study was granted ethics approval from the University of KwaZulu-Natal Biomedical Research Ethics Committee (BREC). The study approval number is BF585/18. The participants gave a written informed consent after the field workers explained the study aim, objectives and methods to potential participants before participating in the study. The participants' confidentiality was protected through administering the questionnaires in an environment comfortable and in the privacy of the participants' homes. The completed questionnaires were kept under lock and key, and the captured data in a password protected computer.

RESULTS

Description of the sample

A total of 793 respondents participated in this study. About 12.8% refused to participate in the study. The majority (51.5%, 95% CI 47.8 - 55.2) of the participants were males (Table 1). The participants' mean age (± standard deviation [SD]) was 52.5 (SD±14.8) years. Most of the participants were Africans (70.3%, 95% CI 53.9 - 82.7), followed by Asians/Indians (20.6%, 95% CI 10.8 - 35.6) and Coloureds (mixed race) (7.8%, 95% CI 3.0 - 18.6). Many participants (67.4%, 95% CI 51.4 - 80.2) reported isiZulu as their preferred language, followed by English (30.8%, 95% CI 18.1 - 47.4). Fewer participants (44.5%, 95% CI 38.5 - 50.6) reported reaching grade 12 level of education. Less participants (18.9%, 95% CI 14.1 - 24.7) reported reaching tertiary education. About 30.4% (95% CI 24.7 - 36.9) reported a monthly household income of \$100 (where USD 1=ZAR15). Less than three percent reported an income of \$1800 or more. Just over 17% (95% CI 14.7 - 21.5) of participants were smokers, with the average number of cigarettes smoked per day of seven (7) and the average packs of 5.5 per week.

Most participants (78.2%; 95% CI 70.2 - 84.6) did not paying for health services. The average paid per health visit was \$17 (95% CI \$8.57 - \$25.75). Less participants 12% (95% C I8.7 - 16.3) had worked in a chemicals industry. An average of seven years was reported by those that had worked in the industry (95% CI 4.9 - 8.5). A lower proportion (1.9%; 95% CI 1.2 - 3.0) had worked in the mines, with an average of 4.5 years (95% CI 0.5 - 8.5) working there.

Knowledge of lung cancer

Of the sample, about 59.9% (95% CI 52.0 - 67.3) of the participants reported having heard of lung cancer (Table 2). Fewer participants (34.8%, 95% CI 28.9 - 41.2) had heard of lung cancer through radio, followed by television (28%, 95% CI 22.2 - 33.6), newspaper (~25%, 95% CI 18.8 - 32.2) and health professional (~16%, 95% CI 11.9 - 21.3). Coughing blood was the most recognised lung cancer symptom (61.0%, 95% CI 52.1 - 69.1), followed by Persistent chest pain (50.1%, 95% CI 41.2 - 59.0), persistent shortness of breath (49.1%, 95% CI 39.5 - 58.7), and a cough that does not go away for two to three weeks (40.8%, 95% CI 32.3 - 49.9). The mean knowledge score was 41.8% (95% CI 35.7 - 47.9%).

Smoking was the most recognised risk factor (81.2%, 95% CI 72.2 - 87.4), followed by exposure to harmful mineral dust in the mines (56.2%, 95% CI 45.4 - 66.4), and inhaling harmful chemicals (54.6%, 95% CI 44.9 - 64.0). Less participants (10%, 95% CI 6.8 - 12.0) knew someone that was diagnosed with lung cancer. Chemotherapy was cited by most participants (52.2%, 95% CI 42.6 - 61.7) as a treatment option for lung cancer, followed quitting smoking (40%, 95% CI 31.3 - 49.7).

Most participants (77.4%, 95% CI 69.4 - 83.9) agreed that avoiding smoking reduces the risk of lung cancer. This was followed by avoiding second-hand smoke (56.6%, 95% CI 47.6 - 65.1), using protective equipment when working in the mines or chemicals industry (52.8%, 95% CI 43.0 - 62.3), exercising (30.8%, 95% CI 23.2 - 39.6), and lastly eating fruit and vegetables and reducing sugar and starch (30.5%, 95% CI 23.1 - 39.1). Less participants (18.7%, 95% CI 14.2 - 24.3) had heard about lung cancer screening. Fewer participants (48.9%, 95% CI

41.0 - 56.8) knew that lung cancer can be detected early.

Attitudes towards lung cancer prevention

Many participants (72.4%, 95% CI 93.9 - 79.5) reported that they would go to a health centre or clinic in case they were coughing blood. Fewer (24.9%, 95% CI 17.9 - 33.6) said that they would consult a medical doctor (private GP). Just over a percent said they would not do anything in that situation (1.5%, 95% CI 0.9 - 2.5). Similarly, more participants (75.4%, 95% CI 67.2 - 82.1) said they would go to the health centre of clinic, if they were coughing persistently. Many participants (71.0%, 95% CI 62.5 - 78.3) reported that they would take between one and three days to consult a medical doctor, if they thought they has symptoms of lung cancer. Most participants (71.4%, 95% CI 63.2 - 78.4) would not consult a traditional, if they thought they had symptoms of lungs cancer. Most participants (93.7%, 95% CI 89.7 - 96.2) expressed willingness to screen for lung cancer. Most participants (97.7%, 95% CI 95.4 - 98.2) wanted a national screening program in the future, however, they were unwilling to pay for service (64.7%, 95% CI 57.4 - 71.3) (Table 3).

Health-seeking behaviour

Less participants (10%, 95% CI 3.9-8.1) were lung cancer-screened. More participants (57.6%, 95% CI 49 - 65.8) said fever prompted them to seek medical care, followed by diarrhoea (17%, 95% CI 11.3 -24.7) and cough/pneumonia (11.3%, 95% CI 7.6 -16.5) Fewer respondents (42.1%) said they waited two to three days after getting sick to seek care. They were followed by those who reported within 24 hours (42%) and more than three days (13.6%). Many participants (76.9%, 95% CI 69.8-82.7) agreed that distance did not affect their attendance at the health facility. Transport to the hospital averaged \$2.50 (95% CI \$1.60-3.11) per trip. More participants (59.6%, 95% CI 51.6 - 67.1) didn't get the health services they needed (Table 4).

Community knowledge predictors

Sample knowledge ranged from 4.1% to 97.1%. In the lung cancer knowledge predictive model, only statistically significant variables were included. Unadjusted and adjusted odds ratios are presented (Table 5). Gender, chemical industry experience, lung

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cancer screening, and time to seek care when sick predict lung cancer knowledge. Although gender wasn't a statistically significant predictor of lung cancer knowledge in the unadjusted model, it was included for its importance. Females were 1.86 times more likely to have good lung cancer knowledge in the adjusted model (p=0.016). Imbali residents were 0.093 times less likely to have good lung cancer knowledge (p=0.040). The adjusted model lost significance (aOR 0.401, 95% CI 0.026-6.132, p=0.512).

Working in the chemicals industry predicted good lung cancer knowledge (uOR 2.328, 95% CI 1.259-4.305) (p=0.007), and this was maintained in the adjusted model (aOR 2.361, 95% CI 1.142-4.884) (p=0.021). Screened participants were 5.455 times (95% CI 2.149-13.847) more likely to have good lung cancer knowledge (p0.001), and this was maintained in the adjusted model (aOR 4.887, 95% CI 1.684-14.188, p=0.004). Participants who sought care within two to three days of being sick were less likely to know about lung cancer. The adjusted model maintained this effect (aOR 0.411, 95% CI 0.238-0.711, p=0.001).

Age, race, preferred language at home, level of education, smoking cigarettes, household income, paying for health services, history of mine work, knowing someone with lung cancer, participants' behavior when coughing blood, and participants' behavior when coughing persistently were also included in the univariate model but were not significant. The adjusted model omitted these variables.

DISCUSSION

Studies investigating lung cancer awareness in LMICs are limited. The current study contributes to a greater understanding of lung cancer knowledge and awareness in such contexts. Such understanding could contribute to how countries in these contexts respond with prevention strategies, early diagnosis treatment and care.

Knowledge of lung cancer

The sample knowledge mean score was 41.8% (95% CI 35.7% - 47.9%) in the current study. A study

conducted among students at a tertiary institution in Malaysia found that over 50% of those students had good knowledge regarding lung cancer.22 In the current study, coughing blood was the most recognised warning sign at 60.9%, followed by persistent chest pain (50.1%) and persistent shortness of breath (49.1%). Conversely, a Malaysian study found that a worsening of, or a change in an existing cough was the most recognised (88.8%) warning sign of lung cancer.¹¹ This sign was followed by a persistent chest infection (85.9%), and coughing up blood (85.3%). In an Indian study of college teachers, the persistent cough was the most recognised warning sign (67.5%) of lung cancer.23 The second and third most recognised signs were shortness of breath (56.5%) and sputum streaked with blood (haemoptysis) (42.8%), respectively. A study among secondary school male teachers in Malaysia, chest pain (87.3%), coughing up blood (86.0%) and shortness of breath (84.7%) were the three most recognised signs of lung cancer.24 More participants in the Malaysian studies were able to recognise the top three warning signs of lung cancer in relation to their study samples compared to the current study.

A few studies reported on the knowledge of risk factors associated with lung cancer. In the current study, over 81% of the sample agreed that smoking increased lung cancer risk. Similarly, cigarette smoking was acknowledged as a risk factor of lung cancer by a few studies. 11,23-25 In this study, fewer participants (49.2%) recognised second-hand smoking as a risk factor. Similarly, quitting smoking, as part of the mitigating factors for lung cancer, was acknowledged by fewer participants. A similar trend was observed in an Australian study that investigated the knowledge of signs and symptoms and risk factors associated with lung cancer among individuals 40 years and above.²⁶The study found that although most participants (90.6%) could recognise smoking as a risk factor, less (25.6%) could also recognise second-hand smoking as a risk factor.

In the current study, history of working in the mines, screening for lung cancer, and time taken to seek health care when sick were predictors of lung cancer knowledge. Most studies on this topic in recent years have focused on the level of knowledge of lung

cancer. Not enough attention has been given to the predictors of lung cancer knowledge.

Smoking behaviour

In this study, the proportion of smokers seemed to be low (17.8%). This result should be interpreted with caution as this is a self-reported measure²⁷. Possible assumption could be that some participants may have not reported their smoking status correctly for fear of stigma and/or discrimination. A United Kingdom (UK) study explored the perceptions and experiences of lung cancer patients regarding stigma, where the patients felt stigmatised as the disease was associated with smoking²⁸. Nonetheless, an American Cancer Society report on tobacco use in Africa reported an upward trend in tobacco use from 1990 to 2010²⁹. However, the reported trend for South Africa seemed to be the opposite in the same period. A study by van Welbeek also reported a similar trend from year 1993 to 2000, where the smoking prevalence dropped by 16.9% in that same period. However, there seemed to be an increase in smoking in the 15+ years segment of the population during this period.

Health-seeking behaviour

Most of the participants reported to have never screened for lung cancer, even though they were open to the idea of screening. Most of them were for the idea of the authorities providing the services, but fewer were willing to pay for the service. This may explain the low uptake of the screening low uptake of the service among the participants. A London study among smokers, former smokers and never smokers from a lower socioeconomic background found that former (14.5%) and never smokers (13%) believed that there was no point in screening for lung cancer if a person was still smoking³⁰. A study done in England found that patients tended to delay going for consultation, despite having symptoms, such as, coughing, breathing changes and pain in the chest³¹. A study conducted in the UK found that about 48% of participants waited more than two (2) weeks to seek medical advice, when they experienced persistent cough32. A qualitative study in England among 41 to 88 year olds found that participants delayed seeking medical help, because they thought that a symptom they were experiencing was due to either ageing or smoking and could be self-managed33.

In some cases, having a lung comorbidity such as Chronic Obstructive Pulmonary Disease (COPD) complicated the situation. The prompt to go seek medical help was the worsening of the symptoms.

The key strength of the current study was that primary data were used to ascertain the study outcomes. This study is the first of its kind in the context of South Africa to the best knowledge of the authors and is added to the body of knowledge on the subject. Limitation of the study is that the study cannot be generalized beyond the study's target population, because of the limited sampling frame. However, it may have implications for populations with similar group characteristics. The participants' responses may be biased because of social desirability bias, particularly when answering questions regarding smoking.

CONCLUSIONS

Public health interventions should be explored to increase the levels of community awareness regarding lung cancer, particularly focusing on the importance of screening, early diagnosis and treatment. Interventions to sensitise health personnel (including doctors and nurses) with a view to increase the level of alertness regarding lung cancer as a public health concern (suspicion index) should be investigated, as this could contribute towards early detection and diagnosis. Health policy on lung cancer prevention, screening and early detection should be strengthened to address the issues raised in this study. Very few individuals reported to have screened for lung cancer before. Nonetheless, there was a general willingness to screen for lung cancer, provided the service fee was not for their account. Public health policy makers need to develop policy on screening and early detection, as this could play a critical role in the early diagnosis of lung cancer patients (i.e., diagnosis at stage I/II) when treatment is more likely to be effective.

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Characteristic	n	% (95% CI)		
Age (yr), mean		52.5 (50.6 - 54.5)		
Age group				
≤29 years	41	5.8 (3.6 - 9.3)		
30-39 years	97	13.8 (11.0 - 17.3)		
40-49 years	160	22.8 (19.5 - 26.5)		
50-59 years	190	27.1 (23.4 - 31.1)		
60-69 years	116	16.5 (13.1 - 20.7)		
≥70 years	98	14.0 (11.2 - 17.3)		
Gender				
Female	357	48.4 (42.4 - 54.3)		
Race				
African	524	70.3 (53.9 - 82.7)		
Coloured	58	7.8 (3.0 - 18.6)		
Asian/Indian	153	20.5 (10.8 - 35.6)		
White	8	1.1 (0.2 - 6.2)		
Other	2	0.3 (0.1 - 1.1)		
Preferred Language				
isiZulu	500	67.5 (51.4 - 80.2)		
English	228	30.8 (18.1 - 47.4)		
isiXhosa	8	1.1 (0.5 - 2.5)		
Sesotho	5	0.7 (0.2 - 2.2)		
Highest level of education				
Lower Primary	22	3.8 (2.1 - 6.8)		
Higher Primary	84	14.5 (11.1 - 18.8)		
Up to Grade 10	106	18.3 (14.2 - 23.3)		
Up to Grade 12	257	44.5 (38.5 - 50.6)		
Tertiary	109	18.9 (14.1 - 24.7)		
Currently smoke cigarettes				
Yes	125	17.8 (14.7 - 21.5)		
No	635	83.6 (80.1 - 86.5)		
Cigarettes smoked per day, mean		7.0 (5.9 - 8.2)		
Packs smoked per week, mean		5.5 (2.6 - 8.4)		
Household income				
None	103	14.0 (9.5 - 20.1)		
More or less than R750	67	9.1 (5.8 - 13.9)		
More or less than R1500	224	30.4 (24.6 - 36.8)		

Table 1: Sample socio-demographic characteristics in the selected communities in Durban and Pietermaritzburg, KwaZulu-Natal, 2019 (N=793)

More or less than R3000	188	25.5 (20.8 - 30.9)
More or less than R6000	98	13.3 (9.9 - 17.6)
More or less than R11000	37	5.0 (2.6 - 9.5)
More or less than R27000	20	2.7 (1.5 - 4.9)
Paying for services at the health facility		
Yes	145	20.7 (14.3 - 28.8)
No	557	79.3 (71.2 - 85.7)
Average paid for health services/visit in USD, mean Participant distribution by		17.0 (8.57 - 25.75)
chatsworth	176	22 2 (12 0 20 0)
Charlotterin	176	23.2 (12.0 - 39.9)
South Durban	141	18.6 (8.8 - 35.0)
Umlazi	196	25.8 (14.0 - 42.6)
Imbali	168	22.1 (11.1 - 39.2)
Sobantu	79	10.4 (3.8 - 25.6)
Ever worked in the mines		
Yes	13	1.9 (1.2 - 3.0)
No	661	95.4 (93.2 - 96.9)
Years worked in the mines, mean Ever worked in the chemicals		4.5 (0.5 - 8.5)
industry		
Yes	82	12.0 (8.7 - 16.3)
No	586	85.6 (81.1 - 89.1)
Years worked in the chemicals industry, mean		6.7 (4.9 - 8.5)

Characteristic (knowledge)	n	% (95% CI)
Ever heard of lung cancer		
Yes	440	59.9 (52.0 - 67.3
No	292	39.6 (32.1 - 47.5
How did you hear about lung cancer?		
Oral communication	112	14.8 (11.3 - 19.0
Newspaper	189	24.9 (18.8 - 32.2
Radio	264	34.8 (28.9 - 41.2
Television	209	27.5 (22.2 - 33.6
Conference	16	2.1 (1.3 - 3.5
Medical doctor or hospital	122	16.1 (11.9 - 21.3)
Church	22	2.9 (1.5 - 5.6
School	39	5.1 (3.5 - 7.6
Non-Governmental Organisation	45	5.9 (2.7 - 12.6
Knowledge Score, mean		41.8 (35.7 - 47.9
Symptoms of lung cancer		
Coughing up blood	463	60.9 (52.1 - 69.1
Recurring chest infections	256	33.7 (24.9 - 43.7
Shortness of breath (persistent)	373	49.1 (39.5 - 58.7
Loss of appetite	293	38.6 (29.6 - 48.4
Chest pain (persistent)	381	50.1 (41.2 - 59.0
Fatigue or feeling weak	231	30.4 (22.3 - 39.9
Hoarseness of the voice	196	25.8 (17.9 - 35.7
Unexplained weight loss	207	27.2 (19.3 - 37.0
Cough that does not go away for 2 to 3 weeks	310	40.8 (32.3 - 49.9
Persistent shoulder pain	113	14.9 (8.9 - 23.8
Ache or pain when breathing	184	24.2 (17.0 - 33.2
Painful cough	253	33.3 (26.2 - 41.2
Changes in the shape of the fingers or nails	101	13.3 (8.4 - 20.4
Unexplained loud, high-pitched sound when breathing	91	12.0 (7.7 - 18.3
Worsening or change in existing cough	95	12.5 (7.7 - 19.6
Situations that would increase chances of developing lung of	ancer	
None	757	99.6 (98.8 - 99.9
Smoking	617	81.2 (72.8 - 87.4
Exposure to harmful mineral dust in the mines	427	56.2 (45.4 - 66.4
Exposure to inhaling harmful chemicals	415	54.6 (44.9 - 64.0
History of lung cancer in the family	298	39.2 (30.0 - 49.2
Second-hand cigarette/tobacco smoke	374	49.2 (40.1 - 58.3
Exposure to asbestos	356	46.8 (37.0 - 57.0

Table 2: Level of knowledge about lung cancer in the selected communities in Durban and Pietermaritzburg, KwaZulu-Natal, 2019 (N=793)

Know someone diagnosed with lung cancer		
Yes	66	9.1 (6.8 - 12.0)
No	609	83.9 (80.3 - 87.0)
Treatment options for lung cancer		
Surgery	247	32.5 (25.3 - 40.6)
Radiation	224	29.5 (22.4 - 37.7)
Chemotherapy	397	52.2 (42.6 - 61.7)
Supportive care (e.g., palliative care)	145	19.1 (13.2 - 26.8)
Quitting smoking (if smoker)	305	40.1 (31.3 - 49.7)
Reducing the risk of lung cancer		
Avoiding smoking	588	77.4 (69.2 - 83.9)
Avoid second-hand smoke	430	56.6 (47.6 - 65.1)
Using protective equipment when working in the mines & chemicals industry	401	52.8 (43.0 - 62.3)
Eating fruit and vegetables, and reducing sugar and starch	232	30.5 (23.1 - 39.1)
Exercising	234	30.8 (23.2 - 39.6)
Ever heard about lung cancer screening?	135	17.8 (13.5 - 23.0)
Did you know that lung cancer can be detected early?	353	46.5 (39.1 - 53.9)
In the next year, who is most likely to develop lung		
cancer?		
A 30- year- old	107	14.9 (9.9 - 22.0)
A 50- year- old	117	16.3 (11.8 - 22.2)
A 70- year- old	103	14.4 (10.0 - 20.4)
Lung cancer is unrelated to age	389	54.3 (43.9 - 64.4)
The following may put you at risk of lung cancer: mean		
Exposure to another person's cigarette smoke [†]		3.9 (3.8 - 4.0)
Having had treatment of any cancer in the past [†]		3.2 (3.0 - 3.4)
Having a close relative with lung cancer [†]		3.2 (3.1 - 3.3)
Exposure to chemicals (i.e. asbestos) [†]		3.8 (3.7 - 3.9)
Having a previous history of cancer, such as head and neck cancer [†]		3.3 (3.2 - 3.5)
Air pollution [†]		3.9 (3.8 - 4.0)
Being a smoker [†]		4.0 (3.9 - 4.2)
Having a previous history of lung disease, such as chronic obstructive pulmonary disease (COPD) [†]		3.4 (3.3 - 3.5)
How confident are you that you would notice a symptom of lung cancer? ¹ Coding (1= Strongly disagree, 2= Disagree, 3= Not sure, 4= Agree, 5= Strongly agree)		1.5 (1.3 - 1.8)

[†]Coding (1= Strongly disagree, 2= Disagree, 3= Not sure, 4= Agree, 5= Strongly agree) [‡]Coding (0= Not at all confident, 1= Not yet confident, 2= Fairly confident, 3= Very confident)

Characteristic (attitudes)	n	% (95% CI)
What would you do in case of coughing up blood?		
Nothing	11	1.5 (0.9 - 2.5)
Consult a medical doctor	181	24.9 (17.9 - 33.6)
Go to a health centre/clinic	526	72.4 (63.9 - 79.5)
Go to a traditional healer	1	0.1 (0.0 - 1.0)
What would you do in case of coughing persistently?		
Nothing	14	1.9 (1.1 - 3.4)
Consult a medical doctor	158	21.7 (15.4 - 29.8)
Go to a health centre/clinic	548	75.4 (67.2 - 82.1)
Go to a traditional healer	3	0.4 (0.1 - 1.3)
If you had a symptom that you thought might be a sign your doctor?	n of lung cancer, how	soon would you contact
None	12	1.7 (0.9 - 3.1)
1-3 days	517	71.7 (63.3 - 78.8)
4-6 days	67	9.3 (6.6 - 13.0
1 week	72	10.0 (7.1 - 13.9
2 weeks	40	5.5 (2.6 - 11.5
1 month	10	1.4 (0.6 - 2.9
3 months	1	0.1 (0.0 - 1.1
6 months	1	0.1 (0.0 - 1.1
≥12 months	1	0.1 (0.0 - 1.1)
If you had a symptom that you thought might be a sign help from a traditional healer?	n of lung cancer, how	soon would you seek
None	502	76.2 (68.0 - 82.1)
1-3 days	103	15.6 (11.3 - 21.3)
4-6 days	16	2.4 (1.2 - 4.7
1 week	12	1.8 (0.8 - 4.1)
2 weeks	21	3.2 (1.3 - 7.7
1 month	3	0.5 (0.2 - 1.4
≥12 months	2	0.3 (0.1 - 1.2)
Are you willing to get a lung cancer screening test?		
Yes	680	97.3 (95.2 - 98.5
No	19	2.7 (1.5 - 4.8)
Would you want a national screening programme mad	le available in the futu	re?
Yes	706	98.7 (97.6 - 99.4
No	9	1.3 (0.6 - 2.5
Are you willing to pay for a lung cancer screening test	t?	
Yes	213	32.1 (25.7 - 39.3)
No	450	67.9 (60.7 - 74.3)

Table 3: Attitudes regarding lung cancer in selected communities in Durban and Pietermaritzburg, KwaZulu-Natal, 2019 (N=793)

Characteristic (practices)	n	% (95% CI)
Have you ever been screened for lung cancer before?		-
Yes	38	5.7 (4.0 - 8.1)
No	630	94.3 (91.9 - 96.1)
What sickness prompts you to seek health care?		
Fever	417	59.1 (50.1 - 67.5)
Diarrhoea	123	17.4 (11.7 - 25.2)
Cough/pneumonia	82	11.6 (7.8 - 16.9)
Other	24	11.9 (8.0 - 17.3)
How long after the sickness do you seek health care?		
Within 24 hours	307	43.1 (36.0 - 50.4
Within 2 to 3 days	307	43.1 (37.9 - 48.4
More than 3 days	99	13.9 (10.4 - 18.3
Does distance affect your attendance?		
Yes	159	22.2 (16.4 - 29.4
No	556	77.8 (70.6 - 83.6
Money spent on transport/single trip (USD), mean [†] Time spent waiting for services in the health facility		2.50 (1.60 - 3.11)
Less than 30 minutes	78	11.4 (7.4 - 17.1)
Between 30 min & 1 hour	141	20.6 (16.0 - 26.0)
More than 1 hour	467	68.1 (59.1 - 75.9)
Do you usually get the services you need at the health t	facility?	
Yes	432	60.4 (52.3 - 68.0)
No	283	39.6 (32.0 - 47.7

Table 4: Practices regarding health-seeking behaviour in the selected communities in Durban and Pietermaritzburg, KwaZulu-Natal, 2019 (N=793)

	Knowledge Score S	ummary	ά.		с э	ć.
Characteristic	Poor % (95% CI)	Good % (95% CI)	Unadjusted OR (95% CI)	p-value	Multivariable adjusted OR (95% CI)	p-value
Age (yr), mean	52.18 (50.81-	53.22 (51.33-	0.997 (0.983-1.012)	0.724		
Gender	53.55)	55.11)				
Male	52.3 (47.2-57.3)	49.6 (37.9-61.4)	Ref		Ref	
Female	47.7 (42.6-52.8)	50.4 (38.6-62.1)	1.367 (0.904-2.068)	0.138	1.863 (1.121-3.094)	0.016
Race						
African	43.9 (31.4-57.3)	25.7 (16.1-38.6)	Ref		Ref	
Other races	19.1 (11.1-30.9)	11.2 (6.2-19.3)	1.710 (0.613 -4.770)	0.305	7.982 (0.469-135.001)	0.151
Preferred language		10.52 50				
isiZulu	68.0 (50.7-81.5)	66.5 (46.7-81.8)	Ref		Ref	
English	30.5 (17.2-48.2)	31.3 (16.0-52.1)	4.132 (1.018-16.777)	0.047	2.092 (0.128-34.057)	0.684
Other	1.5 (0.4-5.1)	2.2 (0.9-5.6)	0.821 (0.156-4.305)	0.815	1.178 (0.106-13.102)	0.894
Education						
Lower Primary	2.3 (0.9-5.6)	6.0 (3.1-11.0)	Ref			
Higher Primary	13.3 (9.4-18.5)	15.6 (10.5-22.5)	1.272 (0.349-4.634)	0.715		
Up to Grade 10	21.0 (16.1-26.9)	14.7 (8.9-23.2)	0.841 (0.231-3.062)	0.793		
Up to Grade 12	49.6 (41.7-57.5)	36.7 (29.3-44.8)	0.980 (0.291-3.300)	0.974		
Tertiary	13.9 (9.6-19.6)	27.1 (18.9-37.1)	2.402 (0.673-8.576)	0.177		
Currently smoke						
cigarettes						
No	17.5 (14.3-21.3)		Ref			
Yes	82.5 (78.7-85.7)	84.7 (77.6-90.0)	1.042 (0.614-1.767)	0.879		
Household income						
None	14.1 (9.3-20.9)	13.9 (7.1-25.3)	Ref			

Table 5: Knowledge predictors of lung cancer in five selected communities in Durban and Pietermaritzburg, KwaZulu-Natal, 2019 (N=793)

More/less R1500	37.4 (20.7-45.8)	42.7 (30.7-55.6)	1.143 (0.583-2.242)	0.696		
More/less R3000	26.7 (20.9-33.6)	23.4 (16.7-31.7)	1.308 (0.655-2.609)	0.447		
More/less R6000	21.7 (14.8-30.7)	20.1 (11.9-31.7)	1.652 (0.827-3.302)	0.155		
Paying for services at						
the health facility						
No	78.3 (68.9-85.5)	81.0 (69.5-88.8)	Ref			
Yes	21.7 (14.5-31.1)	19.0 (11.2-30.5)	0.992 (0.586-1.680)	0.976		
Participant distribution						
by area						
Chatsworth	19.2 (8.8-37.0)	31.0 (14.3-54.8)	Ref		Ref	
South Durban	20.9 (9.7-39.6)	14.2 (5.4-32.4)	0.268 (0.028-2.552)	0.252	0.082 (0.057-1.174)	0.065
Umlazi	20.1 (9.6-37.3)	34.7 (17.4-57.3)	1.423 (0.185-10.951)	0.735	7.645 (0.529-110.523)	0.136
Imbali	25.6 (12.3-45.8)	16.1 (4.9-41.6)	0.093 (0.010-0.895)	0.040	0.401 (0.026-6.132)	0.512
Sobantu	14.1 (5.2-33.1)	4.0 (11.5-13.1)	0.122 (0.008-1.838)	0.128	0.809 (0.313-20.901)	0.898
Ever worked in the						
mines						
No	98.4 (96.9-99.2)	97.6 (95.6-98.7)	Ref			
Yes	1.6 (0.8-3.1)	2.4 (1.3-4.4)	1.465 (0.320-6.708)	0.623		
Ever worked in the						
chemicals industry						
No	90.8 (86.7-93.7)	83.1 (75.2-88.9)	Ref		Ref	
Yes	9.1 (6.3-13.3)	16.9 (11.1-24.8)	2.328 (1.259-4.305)	0.007	2.361 (1.142-4.884)	0.021
Know someone						
diagnosed with lung						
cancer						
No	91.6 (87.8-94.3)	89.6 (84.5-93.2)	Ref			
Yes	8.4 (5.7-12.2)	10.4 (6.8-15.5)	1.218 (0.713-2.080)	0.470		
What would you do in						
case of coughing up						
blood?						

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Nothing	1.3 (0.6-2.9)	1.9 (0.8-4.3)	Ref			
Consult a medical	28.3 (20.0-38.5)	19.8 (11.9-31.1)	0.470 (0.110-1.997)	0.306		
doctor			n an			
Go to a health centre	70.3 (60.2-78.9)	78.0 (66.6-86.3)	0.963 (0.233-3.983)	0.959		
Go to a traditional	0 (0-0)	0.4 (0.1-2.7)	5.220 (0-~)	1.000		
healer						
What would you do in						
case of persistent						
coughing?						
Nothing	2.0 (1.0-4.0)	1.9 (0.1-5.1)	Ref			
Consult a medical	24.2 (16.7-33.7)	17.7 (10.3-28.6)	0.790 (0.215-2.910)	0.723		
doctor						
Go to a health centre	73.4 (63.8-81.2)	80.1 (69.1-87.8)	1.530 (0.215-2.910)	0.514		
Go to a traditional	0.4 (0.1-1.7)	0.3 (0.05-2.8)	5.427 (0.833-	0.427		
healer			353.563)			
Have you ever been						
screened for lung						
cancer before?						
No	97.4 (95.4-98.6)	88.7 (83.0-92.6)	Ref		Ref	
Yes	2.6 (1.4-4.6)	11.3 (7.4-17.0)	5.455 (2.149-13.847)	< 0.001	4.887 (1.684-14.188)	0.004
How long after the						
sickness do you seek						
health care?						
Within 24 hours	39.1 (33.0-45.5)	49.8 (36.3-63.3)	Ref		Ref	
Within 2 to 3 days	48.3 (42.5-54.2)	34.0 (25.6-43.8)	0.554 (0.351-0.872)	0.011	0.411 (0.238-0.711)	0.001
More than 3 days	12.6 (8.9-17.6)	16.1 (10.3-24.3)	0.684 (0.357-1.310)	0.964	0.531 (0.254-1.108)	0.092

CHAPTER 6

COMMUNITY HEALTH WORKERS EXPERIENCES OF THE TRAINING ON LUNG CANCER COMMUNITY AWARENESS INTERVENTION IN KWAZULU-NATAL, SOUTH AFRICA

Based on the results of the baseline survey, an awareness intervention and training manual on lung cancer was adapted from The Lung Laboratory - Research and Intervention Centre's lung cancer training manual, developed by pulmonologists in the field. This manual was used to train community health workers (CHWs) that would implement the intervention in the communities from which they were selected.

This chapter presents the CHWs' experiences of the training they received in preparation for the implementation of the intervention. This is part of the second study objective. Appendices 16 and 17 present the intervention and training manual (Pages 194 - 219) that were adapted and implemented for this study.

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Lung cancer awareness training experiences of community health workers in KwaZulu-Natal, South Africa

Original Research

Page 1 of 9



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Read online:

Scan this QR code with your smart phone or mobile device to read online. Background: Lung cancer is the leading cause of cancer mortality worldwide. Awareness interventions in the developing world remain scarce. Community health workers (CHWs) are a critical component towards ensuring efficient delivery of healthcare services in low- and middle-income countries.

Aim: This study explored the experiences of CHWs of their training as lung cancer awareness intervention implementers.

Setting: The study was conducted in a resource-poor setting, with CHWs from previously disadvantaged communities.

Methods: On the last day of training, 10 CHWs were requested to voluntarily participate in a focus group discussion regarding their experiences of the training, utilising a discussion guide.

Results: The participants expressed positive experiences with the training. They cited the amenable and conducive learning environment established by the facilitator. The participants felt empowered through the newly acquired knowledge and wanted to help their communities. However, some participants expressed a desire to have other forms of learning incorporated in future training. The participants were also cognisant of existing gaps in their own knowledge that could be elaborated upon in preparation for potential questions by the community. Some participants confirmed their role as agents of change.

Conclusion: The authors propose large-scale intervention studies of lung cancer awareness utilising the CHW programme to gather conclusive evidence regarding their effectiveness at a community level.

Contribution: This article provides insight into the training of community health workers on lung cancer awareness and future research on the integration of the intervention into already existing programmes.

Keywords: lung cancer; community awareness; community health workers; prevention; training experiences.

Introduction

Community health workers (CHWs) remain a critical component towards ensuring efficient delivery of healthcare services in low- and middle-income countries (LMICs). They are integral in the prevention, treatment and care of individuals living with various disease conditions, such as human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS), childhood illnesses and tuberculosis (TB), as well as provision of palliative care services through home-based care.¹²³ The provision of these services by CHWs has been especially vital in remote areas, where inaccessibility to health facilities is a challenge.

In South Africa, the services offered by CHWs are included within a primary health care (PHC) ward-based outreach team. This team consists of a professional nurse, environmental health practitioner, health promotion practitioner and four to five CHWs⁴ These teams have since been experiencing varying degrees of success throughout the country.^{567,89,30,10,12,13,34} It could be argued that potentially there could be a risk of overwhelming the CHWs with health interventions at community level. However, the CHWs have been instrumental in combating TB infection in South Africa and other countries of similar contexts through the directly observed treatment and therapy programme,^{315,36,17,18,19} apart from their other responsibilities. Evidently, TB shares similarities in terms

of signs and symptoms with lung cancer, hence poor treatment response by their patients misclassified as TB patients.^{20,21}

The authors' project, as part of a larger study of lung cancer in sub-Saharan Africa, introduced the training of CHWs on lung cancer community awareness intervention, as a contribution to promoting early lung cancer screening, detection and care. In South Africa, lung cancer is among the top four ranking cancers in terms of morbidity and mortality after breast, prostate and cervical cancers.22 Among men, lung cancer is the leading cause of cancer deaths in the country, while it ranked third among women.23 However, the trends of lung cancer mortality in Africa are based on scanty epidemiological evidence,24 and the burden of disease may be underestimated.25,26 Poor health outcomes have been documented for lung cancer patients, including death while undergoing treatment.²⁷ More than 80% of lung cancer cases are linked to cigarette smoking and other tobacco products,28 therefore making a case for expanded prevention efforts at the community level. Community health workers are better placed to carry out this function at this level. To the authors' knowledge, there are limited published studies on lung cancer health interventions by CHWs at the community level. In addition, it has been established that currently, the CHW curriculum does not include lung cancer awareness.^{29,30} Hence, the opportunity to work with CHWs in raising awareness on lung cancer at community level was considered an important contribution to potentially ensuring early disease detection, diagnosis and treatment, as CHWs often serve as linkages between health facilities and patients. Therefore, the integration of lung cancer awareness interventions on the training of CHWs should be explored. This article explored the CHW experiences of the lung cancer awareness intervention training in a South African province.

Research methods and design

Study design

This was a qualitative study conducted among CHWs who attended the training on lung cancer. This study used phenomenology to explore the training experiences of CHWs about lung cancer.³¹ The aim of phenomenology is to understand the meanings that people make of the world in their everyday lives. This is normally done through discovering meanings in people's conversations or text. In this case, the conversation was in the form of a focus group discussion (FGD).

Study setting

Community health workers were recruited from the selected communities in the two metropolitan cities in a South African province. These communities consisted of townships where previously disadvantaged populations dwell and a suburb. Initial meetings to introduce the project were held with the local ward councillors. The ward councillors offered their cooperation and assisted with identifying the CHWs who could potentially work in the project as data collectors (a baseline paper on lung cancer knowledge, attitudes and practices is currently under review) and project implementers. They were in possession of lists of CHWs who were awaiting placement on community projects. Given the political nature of ward councillors, the received names of CHWs were subjected to stringent selection criteria and the successful CHWs attended training on lung cancer awareness.

Logistics

The period of the training was weeklong. The CHWs travelled to a central location and resided at a training venue for the duration of the training. All subsistence expenses were supported through the project funds. Prior to the commencement of training, the CHWs completed a questionnaire to assess their level of knowledge of lung cancer and pitch the training at an appropriate level but also to incorporate additional concepts into the training materials. The questionnaire contained sociodemographic details, questions on their knowledge of lung cancer signs and symptoms, their attitudes towards lung cancer and their health-seeking behaviour when suspecting lung cancer. Upon completion of the training, they completed the same questionnaire to observe any change in their level of knowledge. The results of these assessments will be presented elsewhere. Tablets were used to administer the questionnaire. The questionnaire took approximately 20 min to complete. The REDCap software (Vanderbilt University, Nashville, Tennessee, United States) was most appropriate because of the accessibility of the platform even in areas with no Internet access and password protection of the data.

Training of community health workers on the intervention

The researcher conducted the training during the 5 days using a printed training manual which was provided to each CHW on the first day. This manual was adapted from the Lung Laboratory – Research and Intervention Centre's lung cancer training manual, developed by pulmonologists in the field. The following content was included: (1) background and lung cancer in the South African context; (2) types of lung cancer; (3) how lung cancer affects the body; (4) stages of lung cancer; (5) signs and symptoms of lung cancer; (6) causes and risk factors of lung cancer; (7) diagnosis, management and treatment of lung cancer; and (8) referral pathways of lung cancer patients. The training also addressed vital steps for consideration by CHWs during the implementation of the intervention in their respective communities.

Smoking, as the major risk factor for lung cancer documented by the literature,^{22,33} was discussed during the training, including the benefits and processes of quitting smoking. The information, education and communication (IEC) materials included for the training were in English. During training, these contents were translated into the predominant local language by the facilitator, who is also the researcher, with the assistance of CHWs to ensure clarity and understanding. These translations were included in the information package provided to the CHWs for implementation purposes. Role plays on the delivery of the content at the household level were included on the fourth and fifth days of training, which afforded reinforcing learning content.

Study population and sampling strategy

During the selection process of the CHWs, approximately 50 names were provided by ward councillors as potential participants. They had to have attained at least a Grade 12 qualification to be selected in the project, and a total of 25 CHWs were selected to participate in the training.

The researcher met with all the identified CHWs to introduce the project. Of the 25 selected CHWs, the majority (n = 21) were female. Two young men eventually retracted from the project. They were introduced to the processes of training on a series of topics (including data collection for baseline survey on lung cancer awareness, lung cancer community awareness intervention and data collection for the postintervention survey) during the project. This article focuses on their experiences during the community lung cancer awareness intervention training. These experiences were explored through a FGD.

Data collection

On the last day of training, 10 CHWs were identified to voluntarily participate in a FGD regarding their experiences of the training. These participants had a wide range of work experience, and the group was mixed in age, including both male and female participants to allow for sufficient depth and multiple perspectives to emerge. They were considered information-rich to adequately address the topic of interest. This FGD took place in the same room used for training in the absence of other CHWs for privacy. Although the FGD was facilitated by a novice CHW, who also participated in the training to ensure inclusivity and openness during the discussion, she was trained on FGD and other necessary research processes pertinent to qualitative research. Furthermore, the lead researcher had worked with this group of CHWs in prior training, which provided an opportunity of building and consolidating rapport with the group. The CHW worked under close supervision of the experienced research team. The lead author had prior training and experience in qualitative methodologies, with one co-author involved in the teaching and supervision of master's- and PhD-level students using qualitative research methods. The CHW FGD facilitator was apprised of the study aim and the discussion guide as a data collection tool. A debriefing session was conducted after she completed the facilitation and the FGD had ended. She utilised the discussion guide to engage with the group. The group discussion was conducted in both English and a local language for one hour. The researcher was not present during the discussion. The group discussion with permission from the participants was recorded, transcribed and thereafter translated into English. The transcription and translation were done by an experienced research assistant. The researcher checked the transcript and translation against the original recording for quality.

Data analysis

The English transcript was analysed by the researcher using NVivo version 12 (QSR International, Burlington, Massachusetts, United States). The researcher used thematic analysis for emergent themes. Thematic analysis is a method often used for identifying, analysing and understanding patterns of meaning emerging from qualitative data.^{34,35} Although this method has been deemed devoid of theoretical commitments, its application has been demonstrated across a variety of theoretical frameworks and research paradigms.³⁵ In this study, thematic analysis was used to identify patterns in relation to the CHWs' lived experiences regarding the lung cancer awareness training they participated in, following an inductive approach.³⁶ Chunks of data were coded as themes that emerged from the data.

Ethical considerations

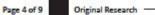
This study obtained ethics approval from the University of KwaZulu-Natal Biomedical Research Ethics Committee (BREC) (reference number BF585/18) and gatekeeper permission from the local ward councillors. The informed consent process was explained, emphasising the voluntariness of their participation and that if they chose not to participate, they would not face any penalties. Thereafter, they signed the informed consent form. Confidentiality was ensured through anonymising the participants' responses in the transcript and assigning numbers to them.

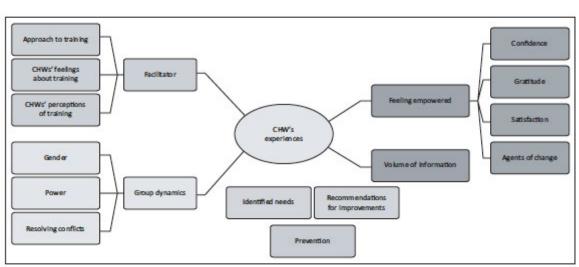
Results

A final total of 23 CHWs participated in the training, after two potential CHWs retracted from the 25 initial selected. Ten participants (six women and four men) volunteered to participate in the FGD. Their ages ranged from 20 to 52 years. The majority were women who resided in the communities identified by the project (Table 1). The majority of the CHWs did not have postmatric qualifications. A few possessed postmatric training (e.g. a certificate-level training).

TABLE 1: Demographic profile of the community health workers participating in the focus group discussion regarding their experiences of lung cancer training.

Variable	Number	Percentage
Gender		
Female	6	60
Male	4	40
Age (in years)		
< 25	2	20
25-30	2	20
31-35	з	30
> 35	3	30
Marital status		
Single	6	60
Married or living with a partner	2	20
Widowed, divorced or separated	2	20
Educational status		
Matric (Grade 12)	10	100
Postmatric (certificate, diploma, degree)	5	50
Race or ethnicity		
Black people	8	80
Mixed-race people	2	20





CHW, community health worker.

FIGURE 1: The matic representation of community health workers' experiences of lung cancer awareness training in KwaZulu-Natal.

Figure 1 provides a descriptive summary of the emergent themes that emanated from the FGD data of the CHWs' experiences of the lung cancer awareness training.

Facilitator-related factors

The approach of the researcher, who was also the training facilitator, to the training was deemed engaging and acceptable in promoting understanding of all participants, particularly in being cognisant of the various levels of CHWs' knowledge. There was consensus on his accessibility and effort to ensure understanding of contents:

The facilitator was very understanding in explaining to everybody and making sure that everyone understood what he was trying to portray, and also his style was very easy to understand ... He even made some drawings on the board to explain more what he was doing and what he was trying to say.' (Participant 6, male, 23 years)

'The way the teacher taught us was good, and when you asked a question, he didn't have a correct and wrong answer. It was equal, so even when you came with an idea, he would listen. Even when you came with a question that was not based on the training, he would answer, so everything was good.' (Participant 5, female, 32 years)

The CHWs were trained by professionals who were also proficient in the local languages, which facilitated understanding of the various concepts included in the training. Despite the CHWs' overall appreciation of the style of facilitation, some offered alternatives for inclusion to enhance the modality of teaching and learning:

'I think what would help is that as much as we are learning the book, it would help also if whilst learning we could be doing some practicals at the same time so that when we teach other people, we teach them something we know and understand. So that by the time we go to the community, we already know it and understand it better.' (Participant 4, female, 34 years) These experiences emphasise the various CHW needs for consideration during training. Individuals effectively learn through various approaches and media, as supported by our results. While the majority communicated the extensive knowledge acquired, others suggested more attention to reinforce learning as essential. Participants communicated their positive experience by citing the amenable and conducive learning environment established by the facilitator:

'I felt that he was extremely approachable; you could ask him anything you want, basically just feel at home and feel very welcome.' (Participant 2, male, 23 years)

The way he taught us, he made us all able to ask questions without fear, when you were not clear ... ' (Participant 1, female, 43 years)

Such a learning environment established the CHWs as valued partners in the learning experience. They suggested no inferiority was evident and they were viewed as active participants in their own learning process.

Group dynamics

Participants alluded to the gender dynamic since the majority of the CHWs were female and the training facilitator was a man in his early 40s. One participant valued the difference and appreciated the professionalism in coping with discord or disagreement within the group.

'[...W]hat I saw, considering he is a male teaching a class full of women where sometimes there are conflicts as women, but he was able to handle all that because he was the head ...' (Participant 4, female, 34 years)

Culture seems to have played a role on how the participants viewed and interpreted their relationship with the training facilitator. Culturally, a man is accepted as the head of the household and therefore is expected to lead. This expectation was not communicated explicitly. However, this role of headship was naturally afforded to the training facilitator, which was positively experienced.

The inherent power dynamics were captured by a CHW whose observation of the training facilitator's leadership skills was valued. It is evident that the dichotomy of the teacher-learner was appreciated rather than an egalitarian relationship within the context of engagement. The amenable approach to conflict resolution was acknowledged:

'[...E]veryone reported to him; if there was something he heard, he wouldn't come harshly to talk to you and tell you not to do something, and he was able to handle situations well.' (Participant 4, female, 34 years)

'[...T]he way he treated his learners and the way he conducted himself as a teacher. So the friendship he built trying to bond with his learners. I thought it was very good, which makes one see their way forward.' (Participant 9, male, 30 years)

Acquisition of empowering knowledge

The value of expanding their own knowledge to further engage purposefully with the community was supported by the data:

'[...T]he community didn't know much about the lung cancer; they know there are cancers, but they are not able to differentiate them, and the lung cancer is the one they don't understand much. They just ask you questions even you don't know how you will answer. But now I think with everything I have learnt, I will be able to give answers.' (Participant 4, female, 34 years)

'The training was very informative and really taught us a lot about lung cancer; it taught us a lot of things we didn't know and a lot of things that now we can teach other people...' (Participant 6, male, 23 years)

The confidence of their acquired knowledge incrementally capacitated them towards advocacy:

'My biggest wish is that we could go to the companies, especially the ones that are using these things that cause cancer, to do awareness and double-check whether they really do get all the uniform, how their safety measures are for the people working there. Even in construction companies, we sometimes see people working without safety gear...' (Participant 9, male, 30 years)

Their self-assurance through their expanded knowledge was expressed and justified:

'I feel very confident right now. I feel like I could be a doctor [they laugh], because that's how much information we learnt about lung cancer. Everything was so good...' (Participant 6, male, 23 years)

In addition to the self-assurance, they conveyed their gratitude of being an inextricable part of the solution in their communities:

'I am grateful, and I am 100% that I can do what I have to do for my community.' (Participant 4, female, 34 years)

Community health workers as agents of change

Some CHWs confirmed their role as agents of change:

'[...T]he importance of knowing that cancer can be cured. It's not like you have a death disease, you have a death sentence; you can get back up and survive, there are a lot of people who have survived ... If we could bring back hope that they can still live and be all right.' (Participant 10, female, 38 years)

'I am very proud of what I am about to do, and I'm very proud that I will go out to the community to help people with this information that I got.' (Participant 3, female, 34 years)

Volume of information

The volume of information covered during the training and its comprehensiveness was observed and could potentially be overwhelming:

'I think there was definitely not a shortage of information, maybe at times a bit too much ...' (Participant 2, male, 23 years)

Others were satisfied with the volume of content:

'I think the information we got was good and even though we still need to know more about lung cancer ... we are satisfied with what we got for now, the information we have available.' (Participant 7, female, 36 years)

Community health workers' identified needs

The participants were also cognisant of existing gaps in their own knowledge that could be elaborated upon in preparation for potential questions by the community:

'I think what we have learnt is all good, but we wish for the next session we will have to incorporate other cancers because in the community we get a lot of questions about a lot of things we don't know.' (Participant 5, female, 32 years)

One participant reflected on a specific and pervasive aspect of cravings for cigarettes and how they can help:

'I wish to know more so that we can be able to help our brothers who are in trouble with cigarettes, who are in trouble with cravings, what can we do to end the cravings, so we need to know more of what I can do for them. Maybe with them too it's not easy when we come and say cigarette this and that, we also need to have a plan that we can come up with, "OK, maybe if you can use this when maybe the cravings start."" (Participant 8, male, 28 years)

Recommendations for improvements based on the training

There were definitive areas of improvement identified by the CHWs. Based on the training, the CHWs felt strongly that the targeted areas could be expanded to maximise the effect of the awareness campaign:

'I wish we could go out to rural areas, because now what tends to happen is that only Durban gets taught, but in other areas they know nothing. Like in prisons, you see, in prisons there are sick people, but there are no people advising them on how to handle this. They smoke cannabis, cigarettes and all that.' (Participant 8, male, 28 years)

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'[...W]ill echo Number 1, who mentioned that we need to go to the schools, to the kids in school. I think that even in primary schools, we can go whilst the kids are still young so that when they grow up, they would already have knowledge about what actually happens with cancer. What actually happens with a person who smokes. In high schools we can go. The children there are looking at their brothers who smoke and they also want to do that, but if as they grow, they know that cigarettes are dangerous ...' (Participant 8, male, 28 years)

'[...M]aybe to places like the clubs, although we might not be able to go in, because in there, there is a lot of smoking happening and different kinds of substances – because what we are fighting is lung cancer. Warning them about cigarettes, it would be great to continue more with our outreaches and reach the small kids so that in the end we don't end up with a nation that has a huge lung cancer problem ...' (Participant 3, female, 34 years)

Another participant recommended specific aspects of the training sessions on including assessments:

'I suppose what I would have done differently is maybe the time frame, the length of the training and also, perhaps, added in some more written tests on certain subjects regarding lung cancer.' (Participant 2, male, 23 years)

Clearly, the above participant preferred continued engagement on the contents to gauge his knowledge acquisition.

Discussion

This study showed that CHWs had, on the whole, positive experiences of training, and this seemed to have encouraged CHWs to be a positive change in their communities. The training facilitator's approach to the training was embraced positively. This fostered positive interactions and a positive learning environment. Consequently, this environment could increase the likelihood of the CHWs performing their tasks more competently in their communities. A study conducted in Bangladesh, Mexico, Guatemala and South Africa assessing the CHWs' ability to screen for cardiovascular disease revealed the CHWs were able to conduct their tasks at levels comparable to the formally trained health professionals.³⁷

Although most of the CHWs highly appreciated the knowledge gained during training, some of the CHWs suggested using alternate modes of learning as reinforcement. A study mapping the evidence from various CHW trainings demonstrated an increasing trend on the use of mobile technologies to support training in LMIC contexts.³⁸ However, this trend was not widely adopted for broad training, service delivery interventions and supervision at the community level involving CHWs. In settings where Internet connectivity and mobile data availability are not a challenge, these mobile technologies could be a viable platform for providing training and support to the CHWs. However, South Africa may not be able to provide such platforms and service, especially in the rural areas where CHWs services are most valuable.^{39,40,41} For these technologies to be implemented in South Africa, the

Internet infrastructure needs to be made widely accessible and be stable for use in the rural areas of the country.

The CHWs were encouraged to be active participants in their own learning, thus enforcing a positive learning environment. A study conducted on the training of CHWs regarding oral health intervention indicated that the CHWs performed well on their knowledge scores after training.⁴² When questioned about the presenters leading the training, the CHWs also communicated a positive opinion. Similarly, they felt that the level of the training together with its duration were ideal. These results seem to align with the findings of the present study. However, a study conducted among CHWs in Cape Town on noncommunicable diseases and training concluded that the knowledge on the subject matter was poor while their training was unstandardised and haphazard.⁶

Although culture seems to have played a role in the group dynamics, it is not clear whether a male training facilitator would be preferred in the future trainings among this group of individuals. Future studies could explore this phenomenon and inform the successful training of CHWs. Studies have investigated how culturally adapted interventions implemented by CHWs affect service provision.^{44,6,44,7,88}

The dynamics of power between the group and the researcher were perceived positively, which seem to have contributed to the learning environment. These findings affirm that if there is a relationship of trust and collegiality, it fosters a good learning and working environment. VeneKlasen and Miller⁴⁹ offer that power relationships do not have to be onedimensional; they are viewed as toxic and unchanging. These relationships can also be collaborative and transformative (i.e. power with). The efforts of sharing of power were noted by participants. A study conducted in South Africa regarding interpersonal trust among CHWs and their supervisors indicated the importance of this concept.50,51 Because the CHWs' supervisors were perceived negatively in terms of their relationship with the CHWs, this seemed to affect the CHWs' performance at work. By extension, this performance could even spill over to their training and learning environment. Nonetheless, the acknowledgement of the brokenness of these by those in power usually leads to the willingness to work together in resolving them and moving forward.50

The feeling of empowerment through the knowledge gained from the training was seen as a confidence booster to engage with the community regarding lung cancer. A study conducted in rural Cape Town on self-management training among CHWs indicated that the CHWs expressed confidence about what they learnt and motivated them to change or modify certain behaviours detrimental to their own health.⁵² Although CHWs participating in the present study hardly viewed the newly acquired knowledge in relation to their own health, they still considered that information would help them better perform their tasks as CHWs. Some suggested that their motivation to engage in training was their desire to assist others. Similar sentiments were also conveyed in a study that evaluated CHW training outcomes in two districts of KwaZulu-Natal, which revealed that the CHWs had marked improvements on their knowledge scores.⁵³ They also reported high levels of contentment with their training and discernible increases in their confidence in advising clients. However, increases in the level of knowledge after training does not always translate to confidence providing services that they are trained for. A Brazilian study on the training of CHWs regarding cervical cancer screening alluded to this phenomenon.⁵⁴ It has also been demonstrated that poor training and supervision often results in poor knowledge retention and job performance.⁴⁵ Invariably, this could also affect feelings of being empowered and motivated to perform on the job.

The CHWs' roles of being advocates and agents of change were not necessarily motivated by politics or progressivism, as has been reported in other studies,^{55,54} although it could be suggested that visiting companies where employees are deemed to be at risk of lung cancer, doing uniform inspections and assessing whether the safety protocols are observed is a form of activism. In this case, it seems to be the desire to assist their community members and those deemed at risk of lung cancer in avoiding the dire consequences of not attending to the disease early, suggesting an altruistic motivation.^{55,57,58} Being the agent of change in this case means effecting behaviour change or being part of the process of achieving desired outcomes at the community level.⁵⁹

Some of the CHWs had strong feelings about going to the places of entertainment to raise awareness about risk factors of lung cancer. The South African government has put restrictions and prohibitions in the advertisement of tobacco products in public spaces, including clubs.⁴⁰ Therefore, these actions would be responding to the government's prerogative of reinforcing the regulations. It is not clear, however, how this could be accomplished in the clubs, as the club owners have a right to restrict what happens in their places of business. This kind of awareness could possibly be done outside the club as the patrons are waiting to go inside the club.

L.M. English and colleagues investigated the trends of cigarette use among the youth in South Africa and Botswana using the Global Youth Tobacco Survey (GYTS) data.^{dl} They demonstrated a significant decreasing trend of tobacco use over time in South Africa. However, this trend was no longer significant when factoring the parental use of cigarettes. In Botswana, the trend was the opposite of the South Africans', where there was an observed upward trend over time. This highlights the importance of intervening early, as mentioned by the participant above.

Studies conducted in LMICs regarding assessments of training outcomes of CHWs have varying success of knowledge retention among CHWs.⁶² Half of the studies used pre- and post-training assessments and the other half added a follow-up test 6–8 months after training. In our study, pre-

and post-training assessments were done. These assessments were used as a measure to gauge the CHWs' knowledge increase because of the training, not in the traditional sense where students write a test and are graded. However, the results are not part of the scope of this article. The current study gives important insights on the approach and content of a lung cancer awareness training programme for CHWs and the integration of such training to existing training curricula. Nonetheless, the results are from the experiences of a limited number of CHWs. Finally, researchers' experiences in qualitative research, establishment of rapport between the lead researcher and the research participants, training of the FGD facilitator, use of debriefing sessions between the FGD facilitator and lead researcher, use of verbatim quotes in the presentation of the results, as well as clear audit trail of the research process all contributed to the trustworthiness of the study findings.

Conclusion

Overall, the CHWs' training experiences seemed to be positive. The group session afforded acknowledgment of the gains in knowledge and closing of the existing gaps among CHWs. They offered definitive thoughts on improvements and identified strategies that could be utilised in the process. The training seemed to have succeeded in empowering CHWs to perceive themselves as agents of change in the communities. The advocacy role was pivotal in sustaining learning. Although gender and age differences were acknowledged between the training facilitator and the participants, it positively influenced the interactional nature of learning. This component warrants further investigation.

Some studies have reported on the importance of follow-up training to reinforce learning.^{41,61,64,65} Future trainings of this group of health workers should consider other modes of training and reinforcing learning, such as the use of technology.

The CHWs recognise the significance of their training in facilitating their engagement and knowledge awareness of lung cancer in the communities. Evidently, they affirmed that early detection through awareness was a vital component of training in reducing the number of lung cancer cases. Their expressed commitment to such awareness was notable. The various sections of their 1-week training proved extensive and adequate in preparing them for further engagement with their communities of service. Hence, it would be prudent to consider integrating this modality of training and learning in the CHW TB training curriculum, because of the overlap in symptomatology between the two diseases and the misdiagnosis of lung cancer for TB. However, large-scale intervention studies are required to arrive at conclusive evidence on the effectiveness of such interventions and wide-scale adoption of such.

This article provides insight into the training of community health workers on lung cancer awareness and future research on the integration of the intervention into already existing programmes

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Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

Authors' contributions

S.B.D. made a substantial contribution to conception and design, acquisition of data, and analysis and interpretation of data. S.B.D., K.W.H and T.G.G drafted the manuscript or critically revised it for important intellectual content. All authors approved the final version to be published.

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Data availability

Data sharing is not applicable to this article, as no new data were created or analysed in this study.

Disclaimer

A statement that the views expressed in the submitted article are his or her own and not an official position of the institution or funder.

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CHAPTER 7

PRE- AND POST-INTERVENTION SURVEY ON LUNG CANCER AWARENESS AMONG ADULTS IN SELECTED COMMUNITIES IN KWAZULU-NATAL, SOUTH AFRICA: A QUASI-EXPERIMENTAL STUDY

This chapter presents the final phase of the study, which was to evaluate the effects of the lung cancer awareness intervention in the selected communities. The manuscript highlights the main results of the intervention one month after the intervention was administered in the selected communities of KwaZulu-Natal.

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Pre- and post-intervention survey on lung cancer awareness among adults in selected communities in KwaZulu-Natal, South Africa: A quasi-experimental study

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Availability of data and materials: All data generated or analyzed during this study are included in this published article.

Ethics approval and consent to participate: Ethics approval from the University of KwaZulu-Natal Biomedical Research Ethics Committee was obtained (BREC) (BF585/18). A team of trained field workers were employed to administer the questionnaires after the informed consent process. The participants gave a written informed consent after the field workers explained the study aim, objectives and methods to potential participants before participating in the study. The participants' confidentiality was protected through administering the survey in an environment comfortable and in the privacy of the participants' homes using tablets.

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Abstract

Background: Lung cancer remains the number one cause of cancer mortality estimated at 1.8 million deaths. There are limited studies in resource poor countries regarding knowledge, attitudes and practices towards lung cancer.

Objective: This study aimed to assess the effects of a lung cancer awareness intervention in selected communities in KwaZulu-Natal, South Africa.

Materials and Methods: A quasi-experimental study design was conducted in the selected communities in KwaZulu-Natal. A community intervention was administered in the communities after a baseline survey. The intervention effects were assessed a month after implementation.

Results: There were statistical differences in the mean age (p<0.001) and proportion of males and females (p<0.001) at baseline and post-intervention. There were no differences in terms of smoking status (p=0.958), however, there was a reduction in the number of cigarettes smoked per day (p<0.001) and the number of packs smoked per week (p=0.026). The mean knowledge score increased from 41.8% (95% CI 35.7 - 47.9) at baseline to 59.9 (95% CI 53.8 - 66.0) post-intervention (p<0.001). The proportion of participants who were aware that lung cancer can be detected early increased from 46.5% (95% CI 39.1 - 53.9) at baseline to 81.1% (95% CI 71.7 - 87.9) post-intervention (p<0.001). The intervention had a statistically significant effect (aOR 4.370, 95% CI 1.477-12.928) on the level of lung cancer knowledge in the selected communities (p<0.001).

Conclusions: Interventions increasing the recognition of signs and symptoms, focusing on the importance of early detection and health seeking behaviour (including screening), smoking cessation, and addressing the perceived health system barriers are required.

Introduction

Lung cancer continues to be the leading cause of mortality among cancer deaths worldwide.1 In Low- and Middle-Income Countries (LMICs), it is uncommon to diagnose lung cancer early.24 This late diagnosis is similar to other cancers', maybe due to numerous factors, such as lack of knowledge of its signs and symptoms, and poor health services.3,5-7 The LMICs, currently, could be experiencing the greatest increase in cancer incidence, including lung cancer.8 Therefore, interventions at different systemic levels are required to address this pertinent challenge. These

include prevention, screening and early detection, treatment and care, and health policy framework. Currently, South Africa does not have policy and guidelines on lung cancer prevention and screening, although a final draft has been submitted for approval. Thus, leading to late presentation and diagnosis for most lung cancer patients. Studies have indicated that greater awareness, recognition of the signs and symptoms, together with early diagnosis and access to appropriate treatment could lead to improved lung cancer outcomes.⁹⁻¹¹ Prevention strategies are pivotal towards reducing the burden of lung cancer.^{9,12}

Studies on lung cancer awareness intervention have been conducted, largely, in High Income Countries (HICs) with varying degrees of success.¹³⁻¹⁹ These studies focused on differing components of awareness including signs and symptoms, risk factors, prevention (smoking cessation), screening and early detection. However, to the best of the authors' knowledge, there is minimal to no studies conducted in LMICs pertaining to lung cancer awareness. The South African Ministry of Health has been addressing the prevention and health promotion interventions outlined in the national cancer strategic framework.20 The prevention efforts include tobacco control legislation.²¹ This legislation is applicable to many cancers, not specific to lung cancer.20 The health promotion interventions include vaccination against hepatitis B virus and prevention and control of Human Papilloma Virus (HPV).20 Nonetheless, the framework does not address specifics on lung cancer in terms of prevention and control. Also, there exists a lack of available literature on effectively increasing lung cancer awareness in South Africa. The research question for this study was, "What are the effects of a lung cancer awareness intervention in the selected communities of KwaZulu-Natal, South Africa? The intervention addressed knowledge about lung cancer, including its signs and symptoms, the importance of early detection and treatment, the effects of smoking and tips for quitting smoking. The intervention was administered from the month of October to mid-December 2020.

Materials and Methods

Study setting and design

This study was conducted in the selected communities in KwaZulu-Natal (KZN), South Africa. They included townships (Umlazi, Chatsworth, Lamontville, Imbali and Sobantu), and a suburb (Bluff). A township is a residential area where the previously disadvantaged communities were forced to reside during the apartheid era in South Africa. They are predominantly inhabited by Black South African people from varying socio-economic statuses²². The selected communities were visited at baseline (March and April 2019) and a month after the intervention (mid-January and February 2021) was concluded.

Study population, inclusion, and exclusion criteria

Adults of both genders from the age of 18 years and above, residing in one of the five selected communities were invited to participate. People with mental incapacity to understand the questions and those that do not meet the inclusion criteria.

Sample size and sampling method

A stratified random cluster sampling method was applied, across the selected representative communities. A total of 40 out of 879 clusters were selected using probability Proportional to Population Size (PPS) sampling. Twenty households were selected from each cluster based on maps of the selected communities. A minimum of 20 participants were randomly sampled within each cluster to allow a precision of \pm 5% assuming a design effect of two (2) with 95% confidence and assuming maximum variability (*i.e.*, p=0.5 or 50%). A total sample size of n=800 was estimated. The same clusters were visited before and after the intervention, not necessarily the same households.

Data collection tool

A standardised questionnaire was used that consisted of different sessions including participants' socio-demographic data, knowledge, attitudes, and practices (and health-seeking behaviour) about lung cancer. The socio-demographic variables were from the National Income Dynamics Study, Wave 3 questionnaire, 23 and the variables about lung cancer were included from the Cancer Research UK, Lung Cancer Awareness Measure Toolkit, Version 2.1. 2011.24 The analysis of their responses determined whether the data collected met the objectives of the study. The variables that were collected included: gender, age, race/ethnicity, socioeconomic status, type of settlement, level of education, smoking behaviour, knowledge (e.g., sign and symptoms, risk factors, and treatment of lung cancer), attitudes (what to do if coughing blood, persistently, or suspecting lung cancer), and health-seeking behaviour towards lung cancer. The questionnaire was in English and translated into isiZulu upon determining preference of the participants. The data was captured using REDCap25 and stored in a password protected computer.

Data analysis

The data was analysed using STATA 15 and summarized and presented using tables and figures (where applicable). Cronbach's Alpha was calculated for the knowledge (0.94) and attitude (0.08) domains of the questionnaire to test for internal consistency. The knowledge score was calculated by summing all the knowledge variables, dividing the outcome by the number of the variables (34), and then multiplying the by hundred to get the percentage. Each correct response was assigned a value of one (1) and an incorrect one the value of zero (0). The participants' knowledge scores were grouped either as poor knowledge (<50%) or good knowledge (>50%). The differences between various constructs at baseline and post-intervention were measured. The effect of the intervention on knowledge was measured accounting for the differences.

Ethics approval and consent to participate

Ethics approval from the University of KwaZulu-Natal Biomedical Research Ethics Committee was obtained (BREC) (BF585/18). A team of trained field workers were employed to administer the questionnaires after the informed consent process. The participants gave a written informed consent after the field workers explained the study aim, objectives and methods to potential participants before participating in the study. The participants' confidentiality was protected through administering the survey in an environment comfortable and in the privacy of the participants' homes using tablets. The tablets were password protected, and the survey was only accessible through login credentials only made accessible to the study team. The downloaded data was kept in a password protected computer.

Results

Socio-demographic differences

A total of 1516 participants (baseline = 760, and post-intervention = 756) were included in the analysis. There were statistical

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Article

Table 1. Comparison of sociodemographic	factors of study	participants	regarding lung	cancer	awareness	at
baseline and post-intervention in the selected	d KZN communit	ies.				

Characteristics	Baseline (% (95% Cl))	Posi-intervention (% (95% CI))	p-value
Age (yr), mean	52.53 (50.57 - 54.49)	42.39 (40.64 - 44.13)	< 0.001
Gender			
Male	51.6 (45.6 - 57.5)	38.1 (33.4 - 43.1)	
Female	48.4 (42.5 - 54.4)	61.9 (56.9 - 66.6)	< 0.001
Race			
African	70.3 (54.0 - 82.8)	69.3 (52.5 - 82.2)	
Coloured	7.8 (3.0 - 18.5)	7.7 (3.0 - 18.3)	0.105
Asian/Indian	20.5 (10.8 - 35.6)	21.2 (10.7 - 37.7)	0.437
White	1.1 (0.2 - 6.2)	1.9(0.5-7.0)	
Preferred language			
IsiZulu	67.5 (51.4 - 80.3)	66.2 (50.3 - 79.1)	
English	30.8 (18.0 - 47.3)	30,6 (17.7 - 47.4)	
Afrikaans	0 (0 - 0)	0.2(0.0-1.1)	0.259
isiXhosa	1.1 (0.5 - 2.5)	2.2 (1.1 - 4.1)	
Sesotho	0.7 (0.2 - 2.2)	0.9 (0.3 - 2.7)	
Highest level of education			
Lower Primary	3.6 (2.2 - 5.6)	1.5 (0.6 - 3.5)	
Higher Primary	11.1 (8.3 - 14.8)	3.4 (1.4 - 7.8)	
Up to grade 10	15.3 (11.6 - 19.9)	7.4 (4.8 – 11.1)	< 0.001
Up to grade 12	50.3 (44.5 - 56.1)	38.4 (31.4 - 45.9)	
Tertiary	19.8 (14.7 - 26.0)	49.4 (40.5 - 58.3)	
Currently smoke cigarettes		3	
Yes	18.2 (15.0 - 21.9)	18.3 (14.3 – 23.2)	0.958
No	81.8 (78.1 - 85.0)	81.7 (76.8 - 85.7)	0.958
Cigarettes smoked per day, mean	7.0 (5.9 - 8.2)	6.3 (3.7 - 9.0)	< 0.001
Packs smoked per week, mean	5.5 (2.6 - 8.4)	2.0 (1.2 - 2.8)	0.026
Household income*	20		
More or less than \$50	9.1 (5.8 - 13.9)	6.7 (3.9 – 11.1)	
More or less than \$100	30.4 (24.6 - 36.8)	19.7 (14.5 – 26.3)	
More or less than \$200	25.5 (20.8 - 30.9)	22.9 (17.1 - 30.1)	< 0.001
More or less than \$400	13.3 (9.9 – 17.6)	11.3 (7.8 – 16.2)	~0.001
More or less than \$733	5.0 (2.6 - 9.5)	5.2 (3.0 - 8.8)	
More or less than \$1800	2.7 (1.5 – 4.9)	2.9 (1.6 – 5.2)	
Paying for services at the health facility			
Yes	20.4 (14.1 - 28,5)	18.0 (13.4 – 23.6)	0.757
No	78.2 (70.2 - 84.6)	79.9 (73.8 – 84.8)	0.757
Average paid for health services/visit in \$	17.2 (8.7 – 25.6)	13.1 (6.9 – 19.3)	0.384
Participant distribution by area			
Chatsworth	23.2 (12.0 - 40.0)	23.8 (12.5 - 40.7)	
South Durban	18.6 (8.8 - 35.0)	18.0 (8.5 - 34.2)	
Umlazi	25.8 (14.0 - 42.6)	26.5 (14.4 - 43.5)	0.835
Imbali	22.1 (11.1 - 39.2)	21.2 (10.3 - 38.6)	
Sobantu	10.4 (3.8 – 25.6)	10.6 (3.8 - 26.3)	
Ever worked in the mines			
Yes	1.9 (1.2 – 2.9)	0.8 (0.3 – 1.9)	0.277
No	95.4 (93.2 - 96.9)	97.7 (94.5 - 99.0)	0.277
Years worked in the mines, mean	3.6 (0.9 - 6.3)	1.3 (0.1 – 2.4)	0.112
Ever worked in the chemicals industry			
Yes	12.0 (8.7 - 16.3)	7.8 (4.5 – 13.1)	0.202
No	85.6 (81.1 - 89.1)	91.0 (85.6 - 94.5)	0.202
Years worked in the chemicals industry, mean	6.7 (4.9 - 8.5)	4.1 (1.5 - 6.7)	0.084

*Dollar to Rand conversion is \$1=R15



differences in the mean age (p<0.001) and proportion of males and females (p<0.001) at baseline and post-intervention (Table 1). The participants at post-intervention tended to be younger (42.39 years; 95% CI 40.64 - 44.13) than those at baseline (52.53 years; 95% CI 50.57 - 54.49). More males (51.6%; 95% CI 45.6 - 57.5) participated in the baseline survey than at post-intervention (38.1%; 95% CI 33.4 - 43.1). There were no statistically significant differences in terms of race (p=0.437) and language spoken at home (p=0.259) at baseline and post-intervention. However, there were observed differences in the level of education between the two time points (p<0.001). At post-intervention, more participants (49.4; 95% CI 40.5 - 58.3) reported acquiring tertiary level education than at baseline (19.8; 95% CI 14.7 - 26.0). There were no differences in terms of smoking status (p=0.958), however there was a reduction in the number of cigarettes smoked per day (p<0.001) and the number of packs smoked per week (p=0.026). In terms of reported household income, there seemed to be a reduction in the proportion of participants earning \$400 and less at baseline and post-intervention (p<0.001). There were no other statistically significant differences regarding geographic distribution of participants (p=0.835), paying for health services (p=0.757), history of working in the mines (p=0.277) and chemicals industry (p=0.202) at baseline and post-intervention.

Knowledge differences at baseline and post-intervention

Table 2 presents the differences regarding the knowledge constructs measured among the participants at baseline and post-intervention. Significantly more participants (90.0%; 95% CI 85.2 -93.3) reported hearing about lung cancer post-intervention than at baseline (59.8%; 95% CI 51.9 - 67.2) (p<0.001). Oral communication (p<0.001), newspaper (p=0.010), NGOs (p<0.001), and home visits (p<0.001) had increases in the proportions of participants reporting these as their sources of information about lung cancer. There was an overall increase in the recognition of lung cancer related signs and symptoms. Similarly, the mean knowledge score increased from 41.8% (95% CI 35.7 - 47.9) at baseline to 59.9 (95% CI 53.8 - 66.0) post-intervention (p<0.001). Regarding the situations that would increase risk of developing lung cancer, only second-hand smoking indicated statistically significant differences at baseline (49.2%; 95% CI 40.1 - 58.3) and post-intervention (62.4%; 95% CI 51.4 - 72.3) (p=0.022). However, the recognition of smoking as a risk lung cancer remained high (76.4%; 95% CI 67.8 - 83.2) even post-intervention (p=0.326).

Although there were increases in the recognition of other risk factors (i.e., exposure to harmful mineral dust in the mines, exposure to inhaling harmful chemicals, history of lung cancer in the family, and exposure to asbestos), they were not statistically significant (p=0.503, p=0.299, p=0.208, and p=0.329, respectively). Statistically significant differences were observed about treatment options for lung cancer. There were statistically significant increases on the recognition on what to do to reduce the risk of lung cancer. The largest increase was on chemotherapy, which had about a 15% difference between baseline (52.2%; 95% CI 42.6-61.7) and post-intervention (67.5%; 95% CI 58.4 - 75.4) (p<0.001). Participants who had heard of lung cancer screening increased from 17.8% (95% CI 13.5 - 23.0) at baseline to 57.3% (95% CI 47.4 - 66.6) post-intervention (p<0.001). Similarly, there was an increase in the proportion of participants who were aware that lung cancer can be detected early from 46.5% (95% CI 39.1 - 53.9) at baseline to 81.1% (95% CI 71.7 - 87.9) post-intervention (p<0.001).

Attitudes towards lung cancer at baseline and postintervention

There were no observed statistically significant differences at baseline and post-intervention regarding what the participants would do should they cough blood (p=0.2831) (Table 3). Likewise, no significant differences were observed regarding what they would do if they coughed persistently for two weeks or more (p=0.2204). Concerning how soon they would contact their doctor if they had a symptom that they thought might be a sign of lung cancer, there were statistically significant differences between baseline and post-intervention responses (p=0.035). Post-intervention, most participants (98.1%) indicated that they would consult their doctor within a week of recognising lung cancer symptoms. None of the participants suggested that they would wait for three months or more to consult with their doctor, compared to 0.42% at baseline.

When questioned about how soon they would contact their traditional healer if they presented with a symptom they thought might be a sign of lung cancer, 76.2% (95% CI 68.0 - 82.8) at baseline it was noted that they did not consult a traditional healer compared to 80.1% (95% CI 63.1 - 90.5) post-intervention (p<0.001). There were no baseline and post-intervention statistical differences in terms of their willingness to screen for lung cancer (p=0.846). However, the proportion of participants willing to screen for lung cancer remained high post-intervention (97.5; 95% CI 95.5 - 98.6). The desire for a national screening programme was high both at baseline (98.7%; 95% CI 97.6 - 99.4) and postintervention (98.8%; 95% CI 97.1 - 99.5) (p=0.909). Approximately 13% increase in the proportion of participants that were willing to pay for the screening test post-intervention was noted (45.7%; 95% CI 36.8 - 54.9) than at baseline (32.1%; 95% CI 25.7 - 39.3) (p=0.005).

Effects of the intervention on lung cancer awareness

Unadjusted and adjusted model

The effects of the intervention on the level of knowledge about lung cancer (Table 5) were statistically significant in the unadjusted regression model (uOR 5.123, 95% CI 4.217-6.222) (p<0.001). The statistical significance was sustained in the adjusted model (aOR 4.370, 95% CI 1.477-12.928) (p=0.008). Similarly, the effects at post-intervention among the different age groups, genders, education levels, smoking status, household income, area of residence, history of working in the chemicals industry, having heard of lung cancer, health-seeking behaviour, and willingness to pay for a lung cancer screening test trended favourably and were statistically significant. In the adjusted model, age groups (30-39 years (aOR 6.753, 95% CI 2.122-21.493), 40-49 years (aOR 4.711, 95% CI 1.542-14.393), 50-59 years (aOR 3.704, 95% CI 1.173-11.697), 60-69 years (aOR 6.707, 95% CI 1.576-28.554) and 70+ years (aOR 19.647, 95% CI 1.586-243.355)) had a statistically significant effect on knowledge (p=0.001, p=0.007, p=0.026, p=0.010, p=0.020, respectively).

Gender's effect was no longer significant in the adjusted model (p=0.325). Participants that reached higher primary or up to grade 10 seemed to have lower level of lung cancer knowledge in the adjusted model (aOR 0.078, 95% CI 0.008-0.781 (p=0.030), and aOR 0.071, 95% CI 0.009-0.556 (p=0.012), respectively). The rest of the educational levels did not have a significant effect in the adjusted model. Similarly, the smoking behaviour did not have a significant effect, neither did household income. Residing in South

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Table 2. Comparison of knowledge constructs regarding lung cancer among adults in five selected KZN communities at baseline and post-intervention.

Characteristic (knowledge)	Baseline (% (95% CI))	Post-Intervention (% (95% CI))	p-value
Ever heard of lung cancer?			
Yes	59.8 (51.9 - 67.2)	90.0 (85,2 - 93.3)	<0.001
No	39.7 (32.2 - 47.7)	9.6 (6,3 - 14.3)	
How did you hear about lung cancer?			
Oral communication	14.7 (11.3 – 19.0)	57.8 (47.3 – 67.5)	<0.001
Newspaper	24.9 (18.8 - 32.2)	38.8 (29.8 - 48.7)	0.010
Radio	34.7 (28.9 - 41.1)	38.2 (28.2 - 49.1)	0.537
Television	27.5 (22.2 - 33.5)	24.8 (16.8 - 35.0)	0.526
Conference	2.1 (1.3 - 3.5)	4.9 (2.8 - 8.4)	0.004
Medical doctor or hospital	16.1 (11.9 – 21.3)	14.4 (9.0 – 22.4)	0.650
Church	2.9 (1.5 - 5.6)	5.0 (3.2 - 7.8)	0.137
School	5.1 (3.5 - 7.6)	5.3 (2.8 - 10.0)	0.921
Non-Governmental Organisation	6.0 (2.7 – 12.6)	19.8 (11.7 – 31.5)	<0.001
Home Visit	0 (0 - 0)	12.2 (5.4 - 25.1)	0.001*
Knowledge Score, mean	41.8 (35.7 – 47.9)	59.9 (53.8 - 66.0)	<0.001
Symptoms of lung cancer	102		
Coughing blood	60.9 (52.1 - 69.1)	82.5 (76.6 - 87.4)	<0.001
Recurring chest infections	33.7 (24.9 - 43.7)	52.4 (42.3 - 62.3)	<0.001
Shortness of breath (persistent)	49.1 (39.5 - 58.7)	64.1 (54.0 - 73.1)	0.005
Loss of appetite	38.6 (29.6 - 48.4)	55.3 (44.9 - 65.3)	<0.001
Chest pain (persistent)	50.1 (41.2 - 59.0)	65.1 (55.4 - 73.6)	0.005
Fatigue or feeling weak	30.4 (22.3 - 40.0)	43.2 (34.2 - 52.6)	0.003
Hoarseness of the voice	25.8 (17.9 - 35.7)	47.3 (37.4 – 57.4)	0.001
Unexplained weight loss	27.2 (19.3 - 37.0)	49.5 (39.0 - 60.1)	<0.001
Cough that does not go away for 2 to 3 weeks	40.8 (32.3 - 50.0)	60.4 (51.0 - 69.2)	<0.001
Persistent shoulder pain	14.9 (8.9 - 23.8)	35.7 (26.8 - 45.8)	<0.001
Ache or pain when breathing	24.2 (17.0 - 33.2)	47.3 (37.4 - 57.4)	<0.001
Painful cough	33.3 (26.2 - 41.2)	59.9 (50.0 - 69.1)	<0.001
Changes in the shape of the fingers or nails	13.3 (8.4 - 20.4)	35.6 (26.5 - 45.8)	<0.001
Unexplained loud, high-pitched sound when breathing	12.0 (7.7 – 18.3)	41.8 (31.5 - 52.9)	<0.001
Worsening or change in existing cough	12.5 (7.7 – 19.6)	44.9 (34.6 - 55.6)	<0.001

To be continued

Article

developing lung cancer			
None	0.4 (0.1 – 1.2)	0,1 (0-1.0)	0.335
Smoking	81.2 (72.8 - 87.4)	76.4 (67.8 - 83.2)	0.326
Exposure to harmful mineral dust in the mines	56.2 (45.4 - 66.4)	59.9 (48.6 - 70.2)	0.503
Exposure to inhaling harmful chemicals	54.6 (44.9 - 64.0)	60.4 (50.4 - 69.6)	0.299
History of lung cancer in the family	39.2 (30.0 - 49.2)	46,5 (36,7 - 56.6)	0.208
Second-hand cigarette/tobacco smoke	49.2 (40.1 - 58.3)	62,4 (51,4 - 72.3)	0.022
Exposure to asbestos	46.8 (37.0 - 57.0)	52,5 (41,3 - 63.4)	0.329
Know someone diagnosed with lung cancer			
Yes	9.1 (6.8 - 12.0)	9.2 (6.1 - 13.6)	0.994
No	83.9 (80.3 - 87.0)	83.5 (77.8 - 87.9)	
Treatment options for lung cancer			
Surgery	32.5 (25.3 - 40.6)	44.0 (33.5 - 55.0)	0.041
Radiation	29.5 (22.4 - 37.7)	37.7 (27.5 - 49.2)	0.185
Chemotherapy	52.2 (42.6 - 61.7)	67.5 (58.4 - 75.4)	0.001
Supportive care (e.g., palliative care)	19.1 (13.2 - 26.8)	31.3 (23.6 - 40.3)	0.028
Quitting smoking (if smoker)	40.1 (31.3 - 49.7)	50.2 (39.1 - 61.3)	0.030
Reducing the risk of lung cancer	. 95	R	
Avoiding smoking	77.4 (69.2 - 83.9)	85.1 (79.8 - 89.3)	0.009
Avoid second-hand smoke	56.6 (47.6 - 65.1)	75.3 (66.0 - 82.7)	<0.001
Using protective equipment when working in the mines & chemicals industry	52.8 (43.0 - 62.3)	66.3 (55.9 - 75.3)	0.002
Eating fruit and vegetables, and reducing sugar and starch	30.5 (23.1 - 39.1)	45.2 (34.8 - 56.0)	0.004
Exercising	30.8 (23.2 - 39.6)	47.5 (36.6 - 58.7)	< 0.001
Ever heard about lung cancer screening?	17.8 (13.5 - 23.0)	57.3 (47.4 - 66.6)	<0.001
Did you know that lung cancer can be detected early?	46.5 (39.1 - 53.9)	81.1 (71.7 - 87.9)	<0.001
In the next year, who is most likely to develop lung cancer?			
A 30-year-old	14.9 (9.9 - 22.0)	11.6 (7.1 – 18.4)	0.031
A 50-year-old	16.3 (11.8 - 22.2)	13.5 (8.4 – 21.2)	
A 70-year-old	14.4 (10.0 - 20.4)	26.5 (18.3 - 36.6)	
Lung cancer is unrelated to age	54.3 (44.0 - 64.4)	48.4 (36.5 - 60.5)	
The following may put you at risk of lung cancer: mean			
Exposure to another person's cigarette smoke [†]	3.9 (3.8 - 4.0)	4.4 (4.3 - 4.6)	<0.001

To be continued

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Article

Having had treatment of any cancer in the past [†]	3.2 (3.0 - 3.4)	3.9 (3.7 – 4.0)	<0.00
Having a close relative with lung cancer [†]	3.2 (3.1 – 3.3)	3.9 (3.7 – 4.1)	<0.00
Exposure to chemicals (i.e., asbestos) [†]	3.8 (3.7 - 3.9)	4.5 (4.3 - 4.6)	<0.00
Having previous history of cancer, such as head and neck cancer ^{\dagger}	3.3 (3.2 – 3.5)	3.8 (3.6 - 4.0)	<0.00
Air pollution [†]	3.9 (3.8 - 4.0)	4.6 (4.4 – 4.7)	<0.00
Being a smoker [†]	4.0 (3.9 - 4.2)	4.6 (4.5 – 4.7)	<0.00
Having previous history of lung disease, such as chronic obstructive pulmonary disease (COPD) [†]	3.4 (3.3 – 3.5)	3.8 (3.6 - 4.0)	<0.00
How confident are you that you would notice a symptom of lung cancer? [‡]	1.5 (1.3 - 1.8)	2.4 (2.3 – 2.6)	<0.00

*Fisher's exact test

[†]Coding for 1-10 (1 Strongly disagree, 2 Disagree, 3 Not sure, 4 Agree, 5 Strongly agree)

[‡]Coding for 11 (0 Not at all confident, 1 Not yet confident, 2 Fairly confident, 3 Very confident)

Durban (aOR 0.067, 95% CI 0.014-0.312 (p=0.001)) and Imbali (aOR 0.178, 95% CI 0.036-0.890 (p=0.036) had an opposite effect on the level of lung cancer knowledge. Having a history of working in the chemicals industry had a negative effect on the level of knowledge post-intervention. Those who had heard of lung cancer were at least seven times more likely to have good knowledge on lung cancer post-intervention (aOR 7.806, 95% CI 2.393-25.467) (p=0.001). Consulting a doctor (aOR 14.184, 95% CI 1.368-147.105 (p=0.026)) and going to a health facility (aOR 10.961, 95% CI 1.098-109.462 (p=0.041)) when coughing persistently had a positive effect on lung cancer knowledge. However, the confidence intervals were wide, and the results should, therefore, be interpreted with caution.

The desire to pay for a lung cancer screening test did not have a statistically significant effect on the knowledge of lung cancer (aOR 1.111, 95% CI 0.468-2.637 (p=0.812)). Likewise, contacting a doctor and seeking help from a traditional healer in case of experiencing lung cancer-like symptoms did not influence lung cancer knowledge.

Discussion

This study demonstrated gains in awareness on lung cancer at community level. On average, an overall improvement of the mean knowledge score of 18% (p<0.001) was observed among the communities participating in the study. Studies on lung cancer awareness intervention at community level seem to be limited, particularly in LMICs. This study contributes to this body of knowledge especially within a resource-limited health environment. Since this study was conducted at community level rather than at an individual level, there were observed statistically significant socio-demographic differences in the samples at baseline and post-intervention. However, the effects of the intervention studies reported in the literature were conducted an individual level.^{13,26-31}

In the current study, more males participated in the baseline than post-intervention. The mean age of the participants post-intervention was younger than at baseline. In addition, here were differ-

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ences in the level of education. More participants reported higher levels of education post-intervention than baseline. Although there was no difference in the proportion of smokers in the sample at baseline compared to post-intervention (p=0.958), there was a decrease in the average number of cigarettes smoked per day (p<0.001) and packs smoked per week (p=0.026). The proportion of smokers in this study (18.3%) was comparable to the findings of other local and international studies (17.6% and 15.5%),^{32,33} although lower than those published by the World Bank (23.8%).³⁴ These results allude to the difficulty of quitting smoking. The intervention in the current study addressed quitting smoking, yet no change was observed. Other studies have documented smoking cessation efforts by smokers utilising various models.^{35,40}

Significantly, more people heard of lung cancer post-intervention than at baseline. Similarly, there were significant increases in the recognition of symptoms of lung cancer post-intervention than at baseline. The most recognised symptom was coughing blood (82.5%, 95% CI 76.2-87.4), followed by persistent chest pain (65.1%, 95% CI 55.4-73.6) and shortness of breath (64.1%, 95% CI 53.9-73.1). An increase in the recognition of worsening or change in existing cough, as a lung cancer symptom, was observed from 12.5% (95% CI 7.7-19.6) to 44.9% (95% CI 34.6-55.6). Comparably, an England study demonstrated increases in the public's recognition of persistent cough as a symptom of lung cancer. together with prompt referrals of suspected lung cancer patients by General Practitioners (GPs), and lung cancer diagnoses.¹³ The referral pathways in the South African public health system do not allow for direct referral from the primary health care (PHC) facilities to tertiary health facilities. This context highlights the inherent differences between the South African public health system and that of England's National Health System (NHS),41 which could have implications in the delays in lung cancer diagnosis.

The current study was conducted during the oncology crisis in KwaZulu-Natal, especially in Durban where most of the targeted communities are located.⁴² Participants were encouraged to visit their nearest health facilities if they experienced lung cancer related symptoms. Nevertheless, the intervention increased the proportion of community members that were knowledgeable of early detection of lung cancer (from 46.5%, 95% CI 39.1 – 53.9 to

Table 3. Baseline and post-intervention comparisons of attitudes towards lung cancer among adults in the selected KZN communities.

Characteristic (attitudes)	Baseline (% (95% CI))	Post-Intervention (% (95% CI))	p-value
What would you do in case of coughing blood?			
Nothing	1.5 (0.9 – 2.5)	0.7 (0.3 – 1.7)	0.110*
Consult a medical doctor	25.2 (18.1 - 33.9)	21.8 (15.6 - 29.7)	
Go to a health centre/clinic	73.2 (64.4 - 80.4)	77.4 (69.4 - 83.9)	
Go to a traditional healer	0.1 (0.0 – 1.1)	0 (0 - 0)	
What would you do in case of coughing persistently?			
Nothing	1.9 (1.1 – 3.4)	0.7 (0.3 - 1.8)	0.072
Consult a medical doctor	21.9 (15.5 - 29.9)	21.4 (15.2 - 29.2)	
Go to a health centre/clinic	75.8 (67.4 - 82.6)	77.9 (69.8 - 84.3)	
Go to a traditional healer	0.4 (0.1 - 1.3)	0 (0 - 0)	
If you had a symptom that you thought might be a sign of lung cancer, how soon would you contact your doctor?		~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~	
None	1.7 (0.9 – 3.1)	0 (0 - 0)	<0,001
1-3 days	71.7 (63.3 - 78.8)	76.6 (66.2 - 84.6)	
4-6 days	9.3 (6.6 - 13.0)	11.7 (7.3 – 18.2)	
1 week	10.0 (7.1 – 13.9)	9.8 (6.2 - 15.2)	
2 weeks	5.6 (2.6 - 11.5)	1.8 (0.7 - 4.7)	
1 month	1.4 (0.7 – 3.0)	0.2 (0.0 - 1.1)	
3 months	0.1 (0.0 - 1.1)	0 (0 - 0)	
6 months	0.1 (0.0 – 1.1)	0 (0 - 0)	
>=12 months	0.1 (0.0 – 1.1)	0 (0 - 0)	
If you had a symptom that you thought might be a sign of lung cancer, how soon would you seek help from a traditional healer?			
None	76.2 (68.0 - 82.8)	80.1 (63.1 - 90.5)	<0.001
1-3 days	15.6 (11.3 – 21.3)	1.3 (0.3 – 4.7)	
4-6 days	2.4 (1.2 - 4.7)	9.0 (3.8 - 19.8)	
1 week	1.8 (0.8 - 4.1)	3.9 (1.2 - 12.0)	
2 weeks	3.2 (1.3 - 7.7)	3.9 (1.3 - 10.6)	
1 month	0.5 (0.2 - 1.4)	1.3 (0.3 – 5.7)	
3 months	0 (0 - 0)	0.6 (0.1 - 5.2)	
6 months	0 (0 - 0)	0 (0 - 0)	

To be continued

>=12 months	0.3 (0.1 – 1.2)	0 (0 - 0)	
Are you willing to get a lung cancer screening test?			
Yes	97.3 (95.2 - 98.5)	97.5 (95.5 – 98.6)	0.846
No	2.7 (1.5 - 4.8)	2.5 (1.4 - 4.5)	
Would you want a national screening program made available in the future?			
Yes	98.7 (97.6 - 99.4)	98.8 (97.1 – 99.5)	0.909
No	1.3 (0.6 – 2.5)	1.2 (0.5 – 2.9)	
Are you willing to pay for a lung cancer screening test?			
Yes	32.1 (25.7 - 39.3)	45.7 (36.8 - 54.9)	0.005
No	67.9 (60.7 - 74.3)	54.3 (45.1 - 63.2)	

*Fisher's exact test

81.1%, 95% CI 71.7 – 87.9), and those that had heard of lung cancer screening (from 17.8%, 95% CI 13.5-23.0 to 57.3%, 95% CI 47.4-66.6). Similarly, a study promoting awareness of lung cancer screening among disparate populations demonstrated an increase in screening test knowledge from 25.3% to 79.8%.³⁰ There was also an increase in the proportion of individuals that were willing to pay for a lung cancer screening test (from 32.1%, 95% CI 25.7 – 39.3 to 45.7%, 95% CI 36.8 – 54.9). This is confirmed by a Malaysian study conducted among smokers and non-smokers that demonstrated their willingness to be screened, if they were knowledgeable about their susceptibility to lung cancer.¹¹

There were no statistical differences between baseline and post-intervention in terms of seeking medical attention when coughing blood and coughing persistently. Perhaps, the cause was because of the already high proportion of participants already reporting to seek medical attention at baseline. Nonetheless, there was statistically significant increase (76.6%, 95% CI 66.2-84.6 vs 71.7%, 95% CI 63.3-82.6) in the proportion of participants that would consult with the doctor within three days, if they thought they had a lung cancer symptom (p=0.035). There was a reduction in the proportion of participants that would consult traditional healers, if they thought they had a lung cancer symptom. These changes indicate the participants' understanding of early presentation to the health facilities and early detection. The findings of this current study concur with a study conducted in the United Kingdom (UK), which reported that those that did not recognise the persistent cough as a warning sign for lung cancer were likely to wait for over two weeks to seek medical help (OR=1.30, 95% CI 1.17 - 1.46).43 However, an Australian study demonstrated mixed responses on whether participants would seek medical assistance from a (GP) if they had a persistent cough.²⁷ Some of these mixed responses explained whether the participants trusted their doctor or not. Those that reported high levels of trust expressed more willingness to consult their doctors. Another pertinent study in the UK revealed that the decision to consult a health

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care professional and seek medical help was prompted, largely, by patient and disease factors, and the healthcare factors had a lesser role to play.²⁹ This study also demonstrated the simplicity of being appropriately diagnosed in the region. On the contrary, in South Africa a patient might wait for a protracted period before receiving a diagnosis because of health system related factors.⁴⁴⁻⁴⁶ These factors may influence patients negatively in terms of seeking medical health early.

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Close to half of the participants were willing to pay for a lung cancer screening test post-intervention (45.7%, 95% CI 36.8-54.9) compared to baseline (32.1, 95% CI 25.7-39.3) (p=0.005). Nevertheless, there were no differences at baseline and post-intervention regarding the willingness to screen for lung cancer and the desire for a national lung cancer screening programme being available in the country. These were already highly subscribed at baseline. This concept has not been explored in other studies and lung cancer screening in LMICs is uncommon.⁴⁷

Conclusions

The public health implication from these results suggests the importance addressing the following issues in the community response strategy on lung cancer prevention: i) increase the recognition of signs and symptoms, ii) focus on the importance of early detection and health seeking behaviour (including screening), iii) smoking cessation, and iv) addressing the perceived health system barriers. This study also demonstrated the participants' willingness to be screened and even paying for the services. The introduction of a lung cancer screening programme and streamlining the referral pathway for lung cancer patients by health policy makers is recommended. This has a potential to encourage patients to utilise the health services as observed in the England and UK studies.^{13,29} However, increasing awareness and lung cancer suspicion index among healthcare workers at Primary Health Care level should be deliberately addressed for optimum results.⁴⁴⁴⁷

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Table 4. Knowledge outcomes of a lung cancer awareness intervention among adults in the selected KZN communities.

			dian Score (IQR)	
Characteristic	Baseline	Post- Intervention	Median change in score	
Time	42.4 (22.7,59.2)	63.5 (40.1,80.5)	+21.1 (17.4,21.3)	<0.001
Age group				
20-29 years	36.1 (18.5,65.3)	60.5 (40.1,76.1)	+24.4 (10.8,21.6)	<0.001
30-39 years	42.5 (25.0,56.5)	65.9 (43.0,83.3)	+23.5 (18.0,26.8)	0.825
40-49 years	42.2 (16.3,56.9)	63.1 (38.0,80.5)	+20.9 (21.7,23.6)	0.005
50-59 years	39.9 (19.5,59.5)	68.8 (40.1,85.7)	+28.9 (20.6,26.2)	0.001
60-69 years	45.2 (25.6,59.4)	66.1 (33.1,80.5)	+20.9 (7.5,21.1)	<0.001
70+ years	45.4 (24.9,62.4)	66.2 (60.0,83.1)	+20.8 (20.7,35.1)	<0.001
Gender				
Male	42.5 (27.9,59.5)	65.9 (40.1,80.5)	+23.4 (12.2,21.0)	
Female	42.4 (18.3,59.3)	63.4 (40.2,83.1)	+21.0(21.9,23.8)	0.188
Highest level of education				
Lower Primary	48.3 (31.3,64.9)	66.2 (57.6,88.7)	+17.9 (26.3,23.8)	
Higher Primary	48.3 (36.9,62.4)	80.3 (34.4,88.7)	+32.0 (-2.5,26.3)	0.527
Up to grade 10	36.8 (16.2,56.5)	62.9 (17.6,80.5)	+26.1 (1.4,24.0)	0.659
Up to grade 12	36.9 (19.4,53.9)	63.4 (37.5,80.4)	+26.5 (18.1,26.5)	0.626
Tertiary	51.1 (36.6,65.1)	65.8 (43.1,80.5)	+14.7 (6.5,15.4)	<0.001
Household income				
None	37.1 (25.3,76.5)	43.3 (31.6,71.6)	+6.2 (6.3,-4.9)	
More/less R1500	44.5 (25.4,59.2)	70.4 (57.6,86.1)	+25.9 (26.9,32.2)	0.623
More/less R3000	38.4 (16.9,59.8)	68.8 (54.7,82.9)	+30.4 (23.1,37.8)	0.663
More/less R6000	45.1 (28.1,54.3)	66.1 (40.1,80.5)	+21.0 (12.0,26.2)	0.013
Participant distribution by area				01010
Chatsworth	47.5 (19.4,66.6)	63.3 (20.1,74.8)	+15.8 (0.7,8.2)	
South Durban	39.9 (31.0,54.0)	38.9 (29.0,57.3)	-1.0 (-2.0,3.3)	0.804
Umlazi	49.8 (34.0,59.7)	77.6 (54.8,86.2)	+27.8 (20.8,26.5)	0.067
Imbali	14.2 (5.7,53.5)	77.3 (40.1,94.4)	+63.1(34.4,40.9)	0.373
Sobantu	39.8 (31.4,45.4)	66.2 (60.3,74.5)	+26.4(28.9,29.1)	0.634
Ever worked in the chemicals industry	0,00 (01.11,10.11)	00.2 (00.0,71.0)	.20.1 (20.7,27.1)	0.051
No	41.7 (21.8,56.8)	65.9 (40.2,82.9)	+24.2 (18.4,26.1)	
Yes	51.0 (35.8,62.4)	45.9 (34.8,70.5)	-5.1 (-1.0,8.1)	0.662
Ever heard of lung cancer			0.1 (1.10,0.1.)	01002
No	35.6 (8.5,62.4)	43.1 (6.3,77.6)	+7.5 (-2.2,15.2)	
Yes	42.8 (32.2,56.8)	65.9 (43.1,82.9)	+23.1(10.9,26.1)	<0.001
What would you do in case of coughing persistently?	1210 (0212,0010)	0000 (1011,0200)		01001
Nothing	45.3 (36.0,56.5)	40.0 (37.4,51.6)	-5.3 (1.4 -4.9)	
Consult a medical doctor	39.9 (29.5,53.9)	46.1 (34.4,66.2)	+6.2 (4.9,12.3)	0.817
Go to a health centre/clinic	42.6 (21.9,59.8)	68.8 (48.7,83.3)	+26.2 (26.8,23.5)	0.401
Go to a traditional healer	13.5 (8.5,59.6)	0 (0)	-13.5 (-8.5 -59.6)	0.756
Are you willing to pay for a lung cancer screening test?				
No	41.4 (19.7,56.9)	66.2 (43.3,80.5)	+24.8 (23.6,23.6)	
Yes	45.7 (28.5,62.7)	63.4 (43.0,83.2)	+17.7 (14.5,20.5)	<0.001
If you had a symptom that you thought might be a sign of lung cancer, how soon would you contact your doctor?				

To be continued



None	48.1 (41.8,76.9)	0(0)	-48.1 (-41.8 -76.9)	
1-3 days	42.8 (27.6,59.5)	66.2 (43.6,83.0)	+23.4 (16.0,23.5)	0.509
4-6 days	26.9 (8.4,45.3)	68.8 (40.2,86.2)	+41.9 (31.8,40.9)	0.538
1 week	42.3 (27.9,63.9)	54.7 (34.7,66.2)	+12.4 (6.8,2.3)	0.668
2 weeks	48.3 (19.3,69.5)	27.7 (13.3,47.2)	-20.6 (-6.0-22.3)	0.582
1 month or more	42.2 (16.2,62.4)	46.3 (46.3,46.3)	+4.1 (30.1-16.1)	0.666
If you had a symptom that you thought might be a sign of lung cancer, how soon would you seek help from a traditional healer?			0	
None	42.4 (25.0,56.9)	66.2 (43.4,83.3)	+23.8 (18.4,26.40	
1-3 days	42.6 (24.3,62.8)	57.3 (30.2,80.1)	+14.7 (5.9,17.3)	0.155
4-6 days	38.2 (14.2,36.8)	45.7 (14.3,77.2)	+7.5 (0.1,40.4)	0.023
1 week	46.7 (16.3,76.9)	18.9 (14.5,40.2)	-27.8 (-1.8-36.7)	0.229
2 weeks	53.8 (18.2,73.7)	28.8 (14.5,68.8)	-25.0 (-3.7-4.9)	0.402
1 month or more	53.6 (48.4,59.6)	43.0 (28.7,54.3)	-10.6 (-19.7-5.3)	0.802

Table 5. Knowledge outcomes of a lung cancer awareness intervention among adults in the selected KZN communities.

		Unadjuste	Multivariable Model			
Characteristic	Baseline	p-value	Post-Intervention	p-value	Adjusted OR (95% CI)	p-value
Time	Ref		5.123 (4.217-6.222)	< 0.001	4.370 (1.477-12.928)	0.008
Age group			25			
20-29 years	Ref		3.338 (1.719-6.484)	<0.001	Ref	
30-39 years	0.832 (0.422-1.640)	0.596	4.638 (2.419-8.893)	< 0.001	6.753 (2.122-21.493)	0.001
40-49 years	0.662 (0.347-1.263)	0.211	3.812 (1.990-7.301)	<0.001	4.711 (1.542-14.393)	0.007
50-59 years	0.935 (0.494-1.770)	0.836	3.281 (1.650-6.525)	0.001	3.704 (1.173-11.697)	0.026
60-69 years	0.878 (0.448-1.722)	0.705	3.098 (1.407-6.825)	0.005	6.707 (1.576-28.554)	0.010
70+ years	0.777 (0.390-1.549)	0.473	3.735 (1.493-9.342)	0.005	19.647 (1.586-243.355)	0.020
Gender	0					
Male	Ref		4.235 (3.152-5.690)	<0.001	Ref	
Female	0.900 (0.693-1.693)	0.431	4.361 (3.347-5.683)	< 0.001	1.429 (0.720-2.906)	0.325
Highest level of education						
Lower Primary	Ref		2.380 (0.620-9.135)	0.207	Ref	
Higher Primary	0.959 (0.423-2.171)	0.919	1.273 (0.434-3.731)	0.661	0.078 (0.008-0.781)	0.030
Up to grade 10	0.731 (0.330-1.621)	0.441	2.654 (1.126-6.250)	0.026	0.071 (0.009-0.556)	0.012
Up to grade 12	0.791 (0.377-1.661)	0.536	3.579 (1.681-7.617)	0.001	0.162 (0.021-1.239)	0.079
Tertiary	1.266 (0.577-2.781)	0.556	7.305 (3.429-15.564)	<0.001	0.349 (0.046-2.626)	0.307
Cigarettes smoked per day, mean	Ref		0.924 (0.880-0.970)	0.001	0.956 (0.873-1.046)	0.325

To be continued

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Packs smoked per week, mean	Ref		0.916 (0.855-0.981)	0.012	0.938 (0.829-1.061)	0.312
Household income						
None	Ref		1.482 (0.938-2.342)	0.092	Ref	
More/less R1500	0.603 (0.383-0.948)	0.028	8.580 (5.149-14.295)	< 0.001	0.624 (0.196-1.985)	0.424
More/less R3000	0.722 (0.449-1.160)	0.178	5.205 (3.136-8.638)	< 0.001	0.387 (0.117-1.284)	0.121
More/less R6000	1.228 (0.766-1.969)	0.394	4.599 (2.803-7.544)	< 0.001	0.555 (0.217-1.419)	0.219
Participant distribution by area						
Chatsworth	Ref		2.087 (1.463-2.977)	<0.001	Ref	
South Durban	0.996 (0.243-4.087)	0.996	1.436 (0.348-5.933)	0.667	0.067 (0.014-0.3120	0.001
Umlazi	1.852 (0.510-6.719)	0.349	12.305 (3.357-45.110)	<0.001	1.974 (0.431-9.043)	0.381
Imbali	0.159 (0.041-0.623)	<0.001	10.782 (2.683-43.333)	0.001	0.178 (0.036-0.890)	0.036
Sobantu	0.740 (0.138-3.965)	0.725	5.315 (0.996-28.367)	0.051	0.761 (0.106-5.465)	0.786
Ever worked in the chemicals industry						
No	Ref		5.469 (4.386-6.819)	<0.001	Ref	
Yes	1.562 (1.053-2.317)	0.027	3.396 (2.022-5.704)	<0.001	0.212 (0.011-0.733)	0.014
Ever heard of lung cancer						
No	Ref		1.254 (0.702-2.240)	0.444	Ref	
Yes	2.056 (1.545-2.734)	<0.001	9.084 (6.832-12.078)	< 0.001	7.806 (2.393-25.467)	0.001
What would you do in case of coughing persistently?					0.0	
Nothing	Ref		5.327 (0.803-35.326)	0.083	Ref	
Consult a medical doctor	1.009 (0.407-2.501)	0.985	2.530 (1.012-6.325)	0.047	14.184 (1.368-147.105)	0.026
Go to a health centre/clinic	0.918 (0.381-2.215)	0.850	5.640 (2.326-13.674)	<0.001	10.961 (1.098-109.462)	0.041
			250		To be	e continue
Ge to a traditional healer	0.884 (0.107-7.301)	0.000	1		20 326 (0 257-1609 006)	0.177

Ge to a traditional healer	0.884 (0.107-7.301)	0.909			20.326 (0.257-1609.006)	0.177
Are you willing to pay for a lung cancer screening test?		<	0.			
No	Ref		5.459 (4.168-7.150)	< 0.001	Ref	
Yes	1.907 (1.416-2.568)	<0.001	7.758 (5.806-10.366)	<0.001	1.111 (0.468-2.637)	0.812
If you had a symptom that you thought might be a sign of lung cancer, how soon would you contact your doctor?	6					
None	Ref		1		Ref	
1-3 days	0.603(0.200-1.822)	0.370	3.180 (1.055-9.591)	0.040	0.175 (0.004-7.963)	0.371
4-6 days	0.278 (0.084-0.914)	0.035	4.518 (1.379-14.805)	0.013	0.114 (0.002-7.285)	0.306
1 week	0.777 (0.239-2.523)	0.675	1.554 (0.479-5.039)	0.463	0.039 (0.001-2.329)	0.120
2 weeks	0.529 (0.154-1.811)	0.310	1.375 (0.300-6.298)	0.682	0.084 (0.001-12.096)	0.329
1 month or more	0.607 (0.145-2.547)	0.495	3.467 (0.157-76.372)	0.431	0.097 (0.000-19.100)	0.386
If you had a symptom that you thought might be a sign of lung cancer, how soon would you seek help from a traditional healer?						
None	Ref		5.824 (4.670-7.264)	< 0.001	Ref	
1-3 days	0.826 (0.570-1.197)	0.312	3.521 (2.402-5.160)	<0.001	0.416 (0.127-1.368)	0.149
4-6 days	0.580 (0.230-1.465)	0.249	4.538 (0.498-41.383)	0.180	0.809 (0.017-38.833)	0.914
1 week	1.191 (0.410-3.458)	0.748	1.652 (0.684-3.990)	0.265	1	
2 weeks	1.424 (0.643-3.156)	0.384	2.822 (0.750-10.616)	0.125	1	
1 month or more	1.156 (0.263-5.078)	0.848	2.226 (0.675-7.338)	0.189	0.208 (0.008-5.736)	0.354



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CHAPTER 8

ADDITIONAL RESULTS

This chapter presents additional results of the baseline survey, implementation of the intervention and post-intervention.

Baseline

In response to questions regarding the barriers to seeking medical assistance from public health facilities (Figure 4). 'Long queues' was the most cited barrier to the utilisation of public health facilities (25%), followed by poor staff attitudes (21%), and lack of medication (15%). Increased and /or long distance travelling to the nearest clinic was the least cited barrier (4%).

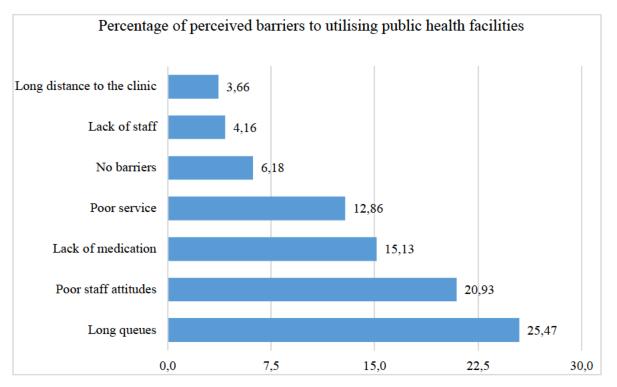


Figure 3: Percentage of perceived barriers to utilising public health facilities.

Although most participants (n=558, 73.4%) did not agree that long queues were a barrier to public health facilities, among those who agreed, approximately 35.6% (n=72) of the participants were

from Umlazi (Table 6). This was followed by 27.7% (n=56) from Chatsworth, 15.8% (n=32) from South Durban, and 12.4% (n=25) from Imbali.

Variable	Long Queues							
Community	No (n (%))	Yes (n (%))	Total (n (%))	P-value				
Chatsworth	120 (21.5)	56 (27.7)	176 (23.2)	< 0.001				
South Durban	109 (19.5)	32 (15.8)	141 (18.6)					
Umlazi	124 (22.2)	72 (35.6)	196 (25.8)					
Imbali	143 (25.6)	25 (12.4)	168 (22.1)					
Sobantu	62 (11.1)	17 (8.4)	79 (10.4)					
Total	558 (73.4)	202 (26.6)	760 (100)					

Table 6: Long queues as a barrier to seeking health care in selected communities in KwaZulu-Natal

Regarding poor staff attitudes as a barrier to public health facilities (Table 7), among those that agreed (n=166, 21.8%), the participants from Umlazi were the highest at 30.1% (n=50) followed by Imbali (n=45, 27.1%), Chatsworth (n=39, 23.5%), and South Durban (n=21, 12.7%).

Table 7: Staff attitudes as a barrier to seeking health care in selected communities in KwaZulu-Natal

Variable	Poor staff attitudes						
Community	No (n (%))	Yes (n (%))	Total (n (%))	P-value			
Chatsworth	137 (23.1)	39 (23.5)	176 (23.2)	0.026			
South Durban	120 (20.2)	21 (12.7)	141 (18.6)				
Umlazi	146 (24.6)	50 (30.1)	196 (25.8)				
Imbali	123 (20.7)	45 (27.1)	168 (22.1)				
Sobantu	68 (11.5)	11 (6.6)	79 (10.4)				
Total	594 (78.2)	166 (21.8)	760 (100)				

Table 8 presents a comparison by area of residence of those who thought lack of medication was a barrier (n=120, 15.8%) versus those that did not (n=640, 84.2%). Among those that did, more

were from Umlazi (n=35, 29.2%) than from Chatsworth (n= 24, 24.2%), Imbali (n=23, 19.2%), and Sobantu (n=17, 14.2%).

Variable	Lack of medication						
Community	No (n (%))	Yes (n (%))	Total (n (%))	P-value			
Chatsworth	147 (23.0)	29 (24.2)	176 (23.2)	0.253			
South Durban	125 (19.5)	16 (13.3)	141 (18.6)				
Umlazi	161 (25.2)	35 (29.2)	196 (25.8)				
Imbali	145 (22.7)	23 (19.2)	168 (22.1)				
Sobantu	62 (9.7)	17 (14.2)	79 (10.4)				
Total	640 (84.2)	120 (15.8)	760 (100)				

Table 8: Lack of medication as a barrier to seeking health care in selected communities in KwaZulu-Natal

An overwhelming majority of participants (n=658, 86.6%) did not think that poor service was a barrier to seeking health care from public health facilities (Table 9). However, among those that did, many were from Umlazi (n=62, 60.8%), followed by South Durban (n=21, 20.6%), Chatsworth (n=11, 10.8%) and Sobantu (n=8, 7.8%).

Variable		Poor se	rvice	
Community	No (n (%))	Yes (n (%))	Total (n (%))	P-value
Chatsworth	165 (25.1)	11 (10.8)	176 (23.2)	< 0.001
South Durban	120 (18.2)	21 (20.6)	141 (18.6)	
Umlazi	134 (20.4)	62 (60.8)	196 (25.8)	
Imbali	168 (25.5)	0 (0.0)	168 (22.1)	
Sobantu	71 (10.8)	8 (7.8)	79 (10.4)	
Total	658 (86.6)	102 (13.4)	760 (100)	

Table 9: Poor service as a barrier to seeking health care in selected communities in KwaZulu-Natal

Only a small percentage (n=49, 6.5%) of participants agreed that there were no barriers to seeking health care in public health facilities (Table 10). Most of these participants were from Chatsworth (n=15, 30.6%), South Durban (n=13, 26.5%), and Imbali (12, 24.5%).

Variable	No barriers			
Community	No (n (%))	Yes (n (%))	Total (n (%))	P-value
Chatsworth	161 (22.6)	15 (30.6)	176 (23.2)	0.053
South Durban	128 (18.0)	13 (26.5)	141 (18.6)	
Umlazi	191 (26.9)	5 (10.2)	196 (25.8)	
Imbali	156 (21.9)	12 (24.5)	168 (22.1)	
Sobantu	75 (10.6)	4 (8.2)	79 (10.4)	
Total	711 (93.6)	49 (6.5)	760 (100)	

Table 10: Participants who reported no barriers to utilising public health facilities in the selected communities in KwaZulu-Natal

Even fewer participants (n=33, 4.3%) regarded the lack of professional staff as a barrier (Table 11). These participants were predominantly from Chatsworth (n=20, 60.6), Umlazi (n=6, 18.2%) and South Durban (n=3, 9.1%).

Table 11: Lack of staff as a barrier to seeking health care in selected communities in KwaZulu-Natal

Variable	Lack of professional staff			
Community	No (n (%))	Yes (n (%))	Total (n (%))	P-value
Chatsworth	156 (21.5)	20 (60.6)	176 (23.2)	< 0.001
South Durban	138 (19.0)	3 (9.1)	141 (18.6)	
Umlazi	190 (26.1)	6 (18.2)	196 (25.8)	
Imbali	166 (22.8)	2 (6.1)	168 (22.1)	
Sobantu	77 (10.6)	2 (6.1)	79 (10.4)	
Total	727 (95.7)	33 (4.3)	760 (100)	

When comparing males and females regarding long queues as a barrier (Table 12), among those who agreed (n=198, 26.9%), more males (n=117, 59.1%) believed that queueing was a challenge.

Variable	Long queues			
Gender	No (n (%))	Yes (n (%))	Total (n (%))	P-value
Male	263 (48.8)	117 (59.1)	380 (51.6)	0.016
Female	276 (51.2)	81 (40.9)	357 (48.4)	
Total	539 (73.1)	198 (26.9)	737 (100)	
Race group				
African/Black	390 (66.0)	134 (66.3)	524 (66.1)	1.000
Other races	201 (34.0)	68 (33.7)	269 (33.9)	
Total	591 (74.5)	202 (25.5)	793 (100)	
Age group				
<50 years	210 (35.5)	88 (43.6)	298 (37.6)	0.044
50+ years	381 (64.5)	114 (56.4)	495 (62.4)	
Total	591 (74.5)	202 (25.5)	793 (100)	
Preferred home language				
isiZulu	376 (63.6)	124 (61.4)	500 (63.1)	0.613
Other languages	215 (36.4)	78 (38.6)	293 (37.0)	
Total	591 (74.5)	202 (25.5)	793 (100)	
Educational level				
Up to Secondary	147 (30.8)	47 (27.7)	194 (29.9)	0.768
Matric	238 (49.8)	88 (51.8)	326 (50.3)	
Tertiary (post matric)	93 (19.5)	35 (20.6)	128 (19.8)	
Total	478 (73.8)	170 (26.2)	648 (100)	
Household income				
None	78 (14.5)	25 (12.5)	103 (14.0)	0.760
More/less R1500	206 (38.4)	85 (42.5)	291 (39.5)	
More/less R3000	138 (25.7)	50 (25.0)	188 (25.5)	
More than R6000	115 (21.4)	40 (20.0)	155 (21.0)	
Total	537 (72.9)	200 (27.1)	737 (100)	
History of working on the mines				

Table 12: Long queues as a barrier to seeking health care by gender in selected communities in KwaZulu-Natal

No	503 (98.4)	177 (97.3)	680 (98.1)	0.342
Yes	8 (1.6)	5 (2.8)	13 (1.88)	
Total	511 (73.7)	182 (26.3)	693 (100)	
History of working in the chemicals industry				
No	449 (88.7)	154 (86.0)	603 (88.0)	0.350
Yes	57 (11.3)	25 (14.0)	82 (12.0)	
Total	506 (73.9)	179 (26.1)	685 (100)	
Knowing someone who had lung cancer				
No	489 (92.8)	171 (85.9)	660 (90.9)	0.006
Yes	38 (7.2)	28 (14.1)	66 (9.1)	
Total	527 (72.6)	199 (27.4)	726 (100)	

Black Africans (n=524, 66.1%) were compared with other race groups (n=269, 33.9%) regarding long queues as a barrier. More black South Africans (n=134, 66.3%) agreed that long queues were a barrier. Among the participants that were fifty years and older (n=495, 62.4%), over half (56.4%) agreed that long queues were a barrier.

More participants with isiZulu as their home language (n=124, 61.4%) believed that long queues were a barrier. However, more participants (n=591, 74.5% vs n=202, 25.5%) did not agree with this statement. The matriculated participants (n=326, 50.3%) had a higher percentage (n=88, 51.8%) of those who believed long queues were a barrier. Those with tertiary education (n=35, 20.6%) mentioned this barrier the least.

Regarding the monthly household income, more participants (n=537, 72.9%) did not mention long queues as a barrier. Nonetheless, more of those that earned more or less R1500 per month (n=85, 42.5%) alluded to this barrier. They were followed by those who earned more or less R3000 per month (n=50, 25.0%) and more than R6000 monthly (n=40, 20.0%).

There was a similar split between those who thought long queues were a barrier and those who did not regarding having a history of working on the mines. Among those who had never worked on the mines (n=680, 98.1%), most participants (n=177, 97.3% vs n=503, 98.4%) mentioned long queues as a barrier.

Similarly, having a history of working in the chemicals industry did not seem to be associated with long queues as a barrier. Among those who had a history of working in the chemicals industry (n=82, 12.0%), more participants (n=25, 14.0% vs n=57, 11.3%) mentioned long queues as a barrier.

Most participants (n=660, 90.9%) did not know someone who has or had lung cancer. Among the participants who had knowledge of someone with lung cancer (n=66, 9.1%), about 14.1% (n=28) mentioned long queues as a barrier.

Regarding poor staff attitudes as a barrier to seeking health care from public health care facilities, more participants (n=572, 77.6%) did not regard this as a barrier (Table 13). However, among those that did (n=165, 22.4%), more males (n=81, 50.9%) than females recognised this as a barrier.

Variable		Poor staff a	ttitudes	
Gender	No (n (%))	Yes (n (%))	Total (n (%))	P-value
Male	296 (51.8)	84 (50.9)	380 (51.6)	0.860
Female	276 (48.3)	81 (49.1)	357 (48.4)	
Total	572 (77.6)	165 (22.4)	737 (100)	
Race group				
African/Black	394 (62.8)	130 (78.3)	524 (66.1)	< 0.001
Other races	233 (37.2)	36 (21.7)	269 (33.9)	
Total	627(79.1)	166 (20.9)	793 (100)	
Age group				
<50 years	222 (35.4)	76 (45.8)	298 (37.6)	0.015
50+ years	405 (64.6)	90 (54.2)	495 (62.4)	
Total	627 (79.1)	166 (20.9)	793 (100)	

Table 13: Poor staff attitudes as a barrier to seeking health care by gender in selected communities in KwaZulu-Natal

Preferred home language				
isiZulu	378 (60.3)	122 (73.5)	500 (63.1)	0.002
Other languages	249 (39.7)	44 (26.5)	293 (37.0)	
Total	627 (79.1)	166 (20.9)	793 (100)	
Educational level				
Up to Secondary	152 (29.8)	42 (30.7)	194 (29.9)	0.896
Matric	256 (50.1)	70 (51.1)	326 (50.3)	
Tertiary (post matric)	103 (20.2)	25 (18.3)	128 (19.8)	
Total	511 (78.9)	137 (21.1)	648 (100)	
Household income				
None	78 (13.6)	25 (15.2)	103 (14.0)	0.545
More/less R1500	230 (40.2)	61 (37.0)	291 (39.5)	
More/less R3000	140 (24.5)	48 (29.1)	188 (25.5)	
More than R6000	124 (21.7)	31 (18.8)	155 (21.0)	
Total	572 (77.6)	165 (22.4)	737 (100)	
History of working on the mines				
No	534 (98.3)	146 (97.3)	680 (98.1)	0.494
Yes	9 (1.7)	4 (2.7)	13 (1.9)	
Total	543 (78.4)	150 (21.7)	693 (100)	
History of working in the chemicals industry				
No	473 (87.8)	130 (89.0)	603 (88.0)	0.774
Yes	66 (12.2)	16 (11.0)	82 (12.0)	
Total	539 (78.7)	146 (21.3)	685 (100)	
Knowing someone who had lung cancer				
No	510 (90.6)	150 (92.0)	660 (90.9)	0.645
Yes	53 (9.4)	13 (8.0)	66 (9.1)	
Total	563 (77.6)	163 (22.5)	726 (100)	

More black African participants (n=130, 78.3%) mentioned poor staff attitudes as a barrier, compared to 21.7% 9 (n=36) from other race groups. The majority of the participants (n=627, 102

79.1%) did not share the same views. Among those who considered poor staff attitudes as a barrier to seeking health care from public health facilities (n=166, 20.9%), approximately 54.2% (n=90) were fifty years or older. In terms of preferred home language, among those who spoke isiZulu at home (n=500, 63.1%), 73.5% (n=122) mentioned poor staff attitudes as a barrier. Nonetheless, more participants (n=627, 79.1%) did not share a similar viewpoint.

Those with a grade 12 level of education (n=70, 51.1%) were the highest percentage of those who perceived poor staff attitudes as a barrier. They were followed by those who had reached secondary level (n=42, 30.7%), and tertiary education (n=25, 18.3%). A similar trend was observed among those who did not identify it as a barrier. Household income did not appear to have any association with poor staff attitudes as a barrier. Similar proportions were observed among the different categories of household income. The history of working on the mines was not associated with poor staff attitudes. Most participants (n=543, 78.4%) were not concerned about this barrier.

Having a history of working in the chemicals industry was not associated with poor staff attitudes. Most participants (n=539, 78.7%) did not identify it as a barrier. Similarly, knowing someone with lung cancer was not associated with poor staff attitudes as a barrier. Similar trends were observed among all the groups.

Regarding the lack of medication as a barrier to seeking health care from public health facilities and gender (Table 14), there were no differences between males and females in their perceptions of this barrier. This table also presents the lack of medication as a barrier to seeking health care from public health facilities by race group. Of the participants that mentioned lack of medication as a barrier (n=120, 15.1%), 75.8% (n=91) were black Africans. About 84.9% (n=673) did not recognise this barrier.

Variable		Lack of me	dication	
Gender	No (n (%))	Yes (n (%))	Total (n (%))	P-value
Male	320 (51.9)	60 (50.0)	380 (51.6)	0.765
Female	297 (48.1)	60 (50.0)	357 (48.4)	
Total	617 (83.7)	120 (16.3)	737 (100)	
Race group				
African/Black	433 (64.3)	91 (75.8)	524 (66.1)	0.016
Other races	240 (35.7)	29 (24.2)	269 (33.9)	
Total	673 (84.9)	120 (15.1)	793 (100)	
Age group				
<50 years	249 (37.0)	49 (40.8)	298 (37.6)	0.474
50+ years	424 (63.0)	71 (59.2)	495 (62.4)	
Total	673 (84.9)	120 (15.1)	793 (100)	
Preferred home language				
isiZulu	412 (61.2)	88 (73.3)	500 (63.1)	0.013
Other languages	261 (38.8)	32 (26.7)	293 (37.0)	
Total	673 (84.9)	120 (15.1)	793 (100)	
Educational level				
Up to Secondary	162 (29.4)	32 (33.3)	194 (29.9)	0.010
Matric	290 (52.5)	36 (37.5)	326 (50.3)	
Tertiary (post Matric)	100 (18.1)	28 (29.2)	128 (19.8)	
Total	552 (85.2)	96 (14.8)	648 (100)	
Household income				
None	84 (13.6)	19 (16.0)	103 (14.0)	0.488
More/less R1500	242 (39.2)	49 (41.2)	291 (39.5)	
More/less R3000	156 (25.2)	32 (26.9)	188 (25.5)	
More than R6000	136 (22.0)	19 (16.0)	155 (21.0)	
Total	618 (83.9)	119 (16.2)	737 (100)	
History of working on the mines				

Table 14: Lack of medication as a barrier to seeking health care by gender in selected communities in KwaZulu-Natal

No	569 (97.9)	111 (99.1)	680 (98.1)	0.704
Yes	12 (2.1)	1 (0.9)	13 (1.9)	
Total	581 (83.8)	112 (16.2)	693 (100)	
History of working in the chemicals industry				
No	507 (87.7)	96 (89.7)	603 (88.0)	0.630
Yes	71 (12.3)	11 (10.3)	82 (12.0)	
Total	578 (84.4)	107 (15.6)	685 (100)	
Knowing someone who had lung cancer				
No	552 (90.6)	108 (92.3)	660 (90.9)	0.725
Yes	57 (9.4)	9 (7.7)	66 (9.1)	
Total	609 (83.9)	117 (16.1)	726 (100)	

There were no differences between the age categories regarding their perception of lack of medication as a barrier. Similar proportions were observed among the different age categories. Of all the participants who mentioned the lack of medication as a barrier (n=120, 15.1%), 73.3% (n=88) isiZulu was their preferred home language.

Among the different categories of educational level (secondary education, Matric, and tertiary or post-matric), those with a Matric level of education (n=36, 37.5%) were the highest proportion that mentioned this barrier. Secondary education was the second highest category (n=32, 33.3%) and lastly, tertiary qualification (n=28, 29.2%). Household income did not have any association with lack of medication as a barrier. Similar proportions were observed among the different categories of household income.

The history of working on the mines was not associated with the lack of medication. Most participants (n=581, 83.8%) did not cite this as a barrier. Having a history of working in the chemicals industry was not associated with the lack of medication. Most participants (n=578, 84.4%) were not concerned about this barrier. Likewise, knowing someone with lung cancer was not associated with a lack of medication as a barrier. Similar trends were observed among all the groups.

There were no differences between males and females regarding their perception of poor service as a barrier (Table 15). Race was not associated with poor service as a barrier. Likewise, age was not associated with poor service as a barrier.

Fewer participants (n=102, 12.9%) regarded poor service as a barrier. However, there was no association between the preferred language spoken at home and poor service as a barrier. The educational level was not associated with poor service as a barrier.

Variable		Poor se	ervice	
Gender	No (n (%))	Yes (n (%))	Total (n (%))	P-value
Male	323 (50.7)	57 (57.0)	380 (51.6)	0.282
Female	314 (49.3)	43 (43.0)	357 (48.4)	
Total	637 (86.4)	100 (13.6)	737 (100)	
Race group				
African/Black	453 (65.6)	71 (69.6)	524 (66.1)	0.436
Other races	238 (34.4)	31 (30.4)	269 (33.9)	
Total	691 (87.1)	102 (12.9)	793 (100)	
Age group				
<50 years	258 (37.3)	40 (39.2)	298 (37.6)	0.743
50+ years	433 (62.7)	62 (60.8)	495 (62.4)	
Total	691 (87.1)	102 (12.9)	793 (100)	
Preferred home language				
isiZulu	432 (62.5)	68 (66.7)	500 (63.1)	0.444
Other languages	259 (37.5)	34 (33.3)	293 (37.0)	
Total	691 (87.1)	102 (12.9)	793 (100)	
Educational level				
Up to Secondary	166 (29.6)	28 (31.8)	194 (29.9)	0.567
Matric	286 (51.1)	40 (45.5)	326 (50.3)	
Tertiary (post-matric)	108 (19.3)	20 (22.7)	128 (19.8)	

Table 15: Poor service as a barrier to seeking health care by gender in selected communities in KwaZulu-Natal

Total	560 (86.4)	88 (13.6)	648 (100)	
Household income				
None	88 (13.9)	15 (14.7)	103 (14.0)	< 0.001
More/less R1500	262 (41.3)	29 (28.4)	291 (39.5)	
More/less R3000	168 (26.5)	20 (19.6)	188 (25.5)	
More than R6000	117 (18.4)	38 (37.3)	155 (21.0)	
Total	635 (86.2)	102 (13.8)	737 (100)	
History of working on the mines				
No	599 (98.4)	81 (96.4)	680 (98.1)	0.201
Yes	10 (1.6)	3 (3.6)	13 (1.9)	
Total	609 (87.89)	84 (12.1)	693 (100)	
History of working in the chemicals industry				
No	529 (88.6)	74 (84.1)	603 (88.0)	0.220
Yes	68 (11.4)	14 (15.9)	82 (12.0)	
Total	597 (87.2)	88 (12.9)	685 (100)	
Knowing someone who had lung cancer				
No	572 (91.4)	88 (88.0)	660 (90.9)	0.264
Yes	54 (8.6)	12 (12.0)	66 (9.1)	
Total	626 (86.2)	100 (13.8)	726 (100)	

Monthly household income appeared to be associated with poor service as a barrier to seeking health care. The participants from households that earned more than R6000 a month (n=38, 37.3%) had the highest proportion among those that mentioned poor service as a barrier. They were followed by those who earned approximately R1500 per month (n=29, 28.4%), and R3000 per month (n=20, 19.6%), respectively.

Having a history of working on the mines was not associated with poor service as a barrier. Equally, having a history of working in the chemicals industry was not associated with poor services as a barrier. Having knowledge of someone who had lung cancer was not associated with poor service as a barrier. There were varying levels of knowledge by area regarding lung cancer (Figure 5). Most areas demonstrated limited knowledge of lung cancer at baseline.

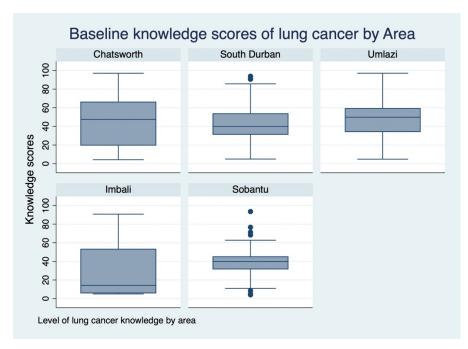


Figure 4: Baseline lung cancer knowledge scores of participants from selected communities in KZN

CHW Before and After Training results

The results below present the characteristics of the CHWs who participated in the lung cancer awareness intervention training before it was administered in the selected communities (Table 15). The second table compares the differences in the knowledge levels of CHWs before and after the training was conducted (Table 16).

Most of the CHWs trained were females (n=19, 82.6%) and of Black African race (n=20, 87.0%). Most CHWs had a secondary/high school education (n=15, 65.2%), followed by a post-matric qualification (n=6, 26.1%) and a primary school education (n=2, 8.7%). Although grade 12 was a requirement for the CHWs, the two CHWs with less than grade 12 education were chosen because of their experience working in the community, chosen by the community leader and their maturity. More than 69% (n=16) of the CHWs were single, followed by those that were married or living

with a partner (n=4, 17.4%) and widowed (n=2, 8.7%). However, one of the CHWs preferred not to indicate their marital status. The median (IQR) number of dependents the CHWs were responsible for at home was 2 (0, 3). Their median age (IQR) was 33 (25, 43).

Characteristic	Number (%)
Sex	• •
Male	4 (17.4)
Female	19 (82.6)
Race	
Black African	20 (87.0)
Mixed race	3 (13.0)
Educational level	
Primary Education	2 (8.7)
Secondary/High School	15 (65.2)
Post-matric (certificate, diploma, etc.)	6 (26.1)
Marital Status	
Single/never married	16 (69.6)
Married/living with a partner	4 (17.4)
Widow	2 (8.7)
Prefer not to say	1 (4.4)
Median no. of dependents (IQR)	2 (0, 3)
Median age (IQR)	33 (25, 43)

Table 16: Sociodemographic characteristics of the CHWs who participated in the lung cancer awareness training (N=23).

There were noticeable increases in recognition of both warning signs and symptoms of lung cancer, and the recognition of the risk factors for lung cancer. There was about a 40-point difference between their initial median knowledge score (IQR) before the training (59.1, 36.4, 86.4) and after the training (100, 95.5, 100). Before the training, persistent chest pain (n=22, 95.7%) was the most recognised warning sign and symptom, followed by a tie between coughing up blood and pain when coughing at 82.6% (n=19). The worsening of the existing cough was the third most recognised warning sign and symptom (n=17, 73.9%), followed by shortness of breath (n=15, 65.2%). The least recognised warning sign and symptom was losing weight (n=9, 39.1%). After the training, the recognision of all of the signs and symptoms increased. The least recognised symptom was a tie between persistent shoulder pain and lack of energy at 82.6% (n=19).

The least recognised risk factor for lung cancer before training was a tie between having a close relative with a history of lung cancer and being exposed to harmful chemicals at 39.1% (n=9). Having a history of lung disease, such as COPD, a history of previous cancer, and having had treatment for cancer in the past were equally recognised as risk factors (n=10, 43.5%). Interestingly, there was a difference between exposure to cigarette smoking (n=21, 91.3%) and being a smoker (n=23, 100%). A few CHWs (n=2, 8.7%) initially did not recognise second-hand smoke as a risk factor. After the training, all the CHWs were able to recognise the risk factors for lung cancer. The majority of the CHWs (n=17, 52.2%) were not very confident about noticing the lung cancer warning signs and symptoms before training. Only 13% (n=3) were very confident about that. However, most CHWs (n=17, 73.9%) were very confident about noticing lung cancer warning signs and symptoms after training, followed by being fairly confident (n=6, 26.1%).

Table 17: Before and after comparison of lung cancer symptoms among CHWs during the	
awareness training (N=23).	

Characteristic	Number (%)		
	Before	After	
Recognition of lung cancer symptoms			
Weight loss	9 (39.1)	22 (95.7)	
Persistent chest infection	11 (47.8)	23 (100)	
Coughing for weeks	12 (52.2)	23 (100)	
Shortness of breath	15 (65.2)	23 (100)	
Lack of energy	11 (47.8)	19 (82.6)	
Persistent chest pain	22 (95.7)	23 (100)	
Persistent shoulder pain	11 (47.8)	19 (82.6)	
Coughing up blood	19 (82.6)	23 (100)	
Pain when breathing	13 (56.5)	23 (100)	
Loss of appetite	11 (47.8)	23 (100)	
Pain when coughing	19 (82.6)	23 (100)	
Changes in the finger nails	10 (43.5)	20 (87.0)	
Unexplained high pitch sound	10 (43.5)	23 (100)	
Worsening of existing cough	17 (73.9)	23 (100)	
Recognition of lung cancer risk factors			
Exposure to cigarette smoke	21 (91.3)	23 (100)	
Had treatment for any cancer in the past	10 (43.5)	23 (100)	
Have a close relative that with a history	9 (39.1)	23 (100)	
of lung cancer			
Exposure to chemicals	9 (39.1)	23 (100)	
Previous history of cancer	10 (43.5)	23 (100)	
Air pollution	23 (100)	23 (100)	

Being a smoker	23 (100)	23 (100)
History of lung disease (i.e., COPD)	10 (43.5)	23 (100)
Median knowledge score (IQR)	59.1 (36.4, 86.4)	100 (95.5, 100)
Confidence about noticing lung cancer		
warning signs		
Not very confident	17 (52.2)	0 (0)
Fairly confident	8 (34.8)	6 (26.1)
Very confident	3 (13.0)	17 (73.9)

Implementation of the intervention

More than two thousand households (n=2 328) participated in the intervention and approximately 10 388 people were reached. In total 4 236 were identified with symptoms signifying lung health problems (i.e., coughing for more than two to three weeks, chest pains, and shortness of breath). They were duly encouraged to seek medical assistance at their closest health facilities. However, the study was not able to follow up on them and verify whether they had been able to seek help at a health facility due to limited resources.

Pre- and Post-Intervention

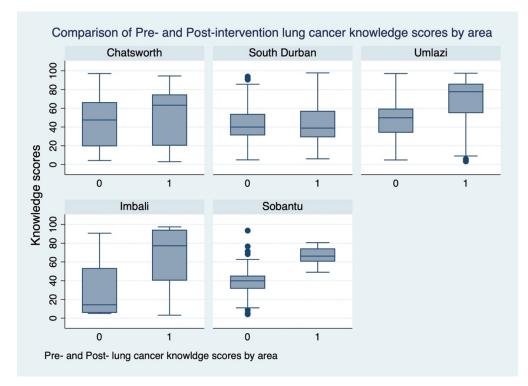
There were differences between baseline and post-intervention regarding the barriers to seeking medical assistance. More participants reported long queues at post-intervention (45.4%) than at baseline (32.8%) (p<0.001). Fewer participants reported distance to the clinic as a barrier at post-intervention (1.2%) than at baseline (4.7%) (p<0.001). The proportion of participants reporting poor service at public health facilities was reduced by almost half at post-intervention (11.6%) compared to baseline (22.4%) (p=0.004).

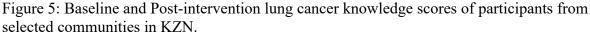
Variable		Time				
	Pre (N (%))	Post (N (%))	Total (N (%))	P-value		
Poor staff attitudes						
No	691 (90.9)	695 (91.9)	1386 (91.4)	0.687		
Yes	69 (9.1)	61 (8.1)	130 (8.6)			
Total	760 (50.1)	756 (49.9)	1516 (100.0)			
Long queues						
No	511 (67.2)	413 (54.6)	924 (61.0)	< 0.001		
Yes	249 (32.8)	343 (45.4)	592 (39.1)			
Total	760 (50.1)	756 (49.9)	1516 (100.0)			
Long distance to the clin	nic					
No	724 (95.3)	747 (98.8)	1471 (97.0)	< 0.001		
Yes	36 (4.7)	9 (1.2)	45 (3.0)			
Total	760 (50.1)	756 (49.9)	1516 (100.0)			
Poor service						
No	590 (77.6)	668 (88.4)	1258 (83.0)	0.004		
Yes	170 (22.4)	88 (11.6)	258 (17.0)			
Total	760 (50.1)	756 (49.9)	1516 (100.0)			
Lack of medication						
No	637 (83.8)	670 (88.6)	1307 (86.2)	0.095		
Yes	123 (16.2)	86 (11.4)	209 (13.8)			
Total	760 (50.1)	756 (49.9)	1516 (100.0)			
Lack of staff						
No	729 (95.9)	737 (97.5)	1466 (96.7)	0.315		
Yes	31 (4.1)	19 (2.5)	50 (3.3)			
Total	760 (50.1)	756 (49.9)	1516 (100.0)			
No barriers						

Table 18: Comparison of perceived barriers to seeking medical help at a public health facility by participants from selected KZN communities at Pre- and Post-Intervention

No	711 (93.6)	728 (96.3)	1439 (94.9)	0.056
Yes	49 (6.5)	28 (3.7)	77 (5.1)	
Total	760 (50.1)	756 (49.9)	1516 (100.0)	

Four out of the five areas demonstrated an increase in the median knowledge scores postintervention compared to baseline (Figure 6).





Cigarette smoking pre- and post-intervention

The table (Table 19) below presents the summary of the number of cigarettes smoked per day at baseline and post-intervention. The mean number of cigarettes smoked pre-intervention was reported at 7.21 (SD 5.202), whereas post-intervention was 6.33 (SD 6.81). One cigarette was the lowest number of cigarettes smoked per day, and the highest number was 20. The number of cigarettes that were below or above the 25th or 75th percentile, respectively, was regarded as outliers.

Number of cigarettes smoked per day								
		Base	eline	Post-intervention				
	Percentiles	Smallest			Percentiles	Smallest		
1%	0	0			0	0		
5%	2	1			0	0		
10%	2	1	Obs	97	0	0	Obs	157
25%	4	1	Sum of wgt.	97	0	0	Sum of wgt.	157
50%	5		Mean	7.206186	4		Mean	6.33121
		Largest	Std. dev.	5.202039		Largest	Std. dev.	6.81005
75%	10	20			10	20		
90%	15	20	Variance	27.06121	20	20	Variance	46.37678
95%	20	20	Skewness	1.326069	20	20	Skewness	1.058185
99%	20	20	Kurtosis	3.935493	20	20	Kurtosis	2.832793

Table 19: Summary of the number of cigarettes smoked per day before and after the intervention.

The mean number of cigarette packs smoked per week at baseline was 4.55 (SD 5.14) compared to 2.03 (SD 2.13) post-intervention (Table 20). Similarly, the number of packs smoked per week that was below or above the 25th or 75th percentile, respectively, was considered an outlier.

	Number of cigarette packs smoked per week								
		Base	eline	Post-intervention					
	Percentiles	Smallest			Percentiles	Smallest			
1%	0	0			0	0			
5%	1	1			0	0			
10%	1	1	Obs	89	0	0	Obs	152	
25%	1	1	Sum of wgt.	89	0	0	Sum of wgt.	152	
50%	3		Mean	4.550562	1		Mean	2.032895	
		Largest	Std. dev.	5.136791		Largest	Std. dev.	2.126521	
75%	5	20			4	7			
90%	12	20	Variance	26.38662	5	7	Variance	4.52209	
95%	20	20	Skewness	2.183112	5	7	Skewness	0.831636	
99%	20	20	Kurtosis	6.86032	7	8	Kurtosis	2.458069	

Table 20: Summary of the number of cigarette packs smoked per week pre- and post-intervention

The figure (Figure 7) below presents the median differences between the reported number of cigarettes smoked per day at baseline and post-intervention, and the number of packs smoked per week at baseline and post-intervention. The median number of cigarettes smoked per day at baseline was five cigarettes compared to four post-intervention. The same pattern was observed with the median number of packs smoked per week, where the baseline packs were three [3] compared to one [1] post-intervention.

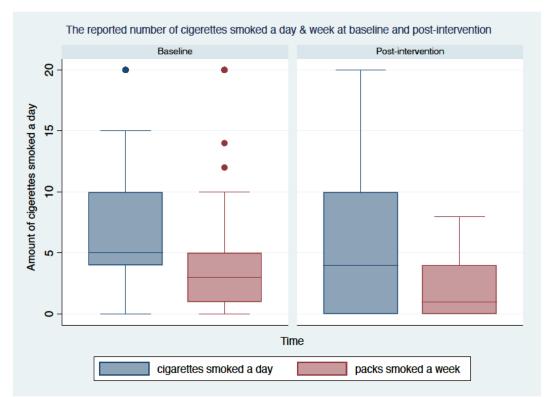


Figure 6: A comparison of the reported number of cigarettes smoked daily and the number of packs smoked per week pre- and post-intervention

CHAPTER 9

SYNTHESIS

Overview

This chapter reviews and synthesises the various outcomes in relation to the objectives of the entire study. The Table below presents the research objectives as the associated papers from the study.

Table 21: List of the stud	v objectives	s against the	publications	from this study
	/]	0	1	

Objective	Paper	Journal
i) To assess the level of awareness (including knowledge, attitudes and practices) about lung cancer and its screening among the selected communities in KZN.	towards lung cancer among adults in KwaZulu-Natal, South Africa: A	
ii) To develop and implement an awareness intervention on lung cancer focusing on causes, screening, and the importance of early diagnosis and treatment.	experiences of the training on lung	•
iii) To evaluate the effect of a lung cancer awareness intervention in the selected communities in KZN.		

Baseline Results

The results of the baseline study demonstrated the consistent necessity to raise community awareness on lung cancer. A small proportion of the participants were exposed to or were acquainted with someone who was diagnosed with lung cancer. Similarly, a small percentage had been screened for lung cancer. The score for average knowledge was poor (41.8%), reiterating the significance of interventions to be inclusive of awareness, and to mobilise communities to consider screening to ensure early detection and diagnosis for the disease. Although the majority of participants articulated the desire for a national lung cancer screening programme, only a few were receptive to the option of paying for such a service. Essentially, the participants had a positive attitude towards seeking medical assistance, should they experience symptoms such as persistent coughing, and more specifically if they coughed up blood. Most participants reported using health facilities in the public health sector. However, they noted barriers regarding the use of public health facilities, which included long queues, and lengthy waiting periods, poor staff attitudes towards patients, lack of medication and health staff shortages and incompetent service. In addition, they affirmed travelling long distances to the health facility.

The predictors of knowledge of lung cancer at baseline were gender, history of working in the chemicals industry, screening for lung cancer, and the time taken to seek health care when ill. This emphasises the significance of addressing these factors to increase community awareness. Currently, in South Africa, there are no community awareness strategies on lung cancer. However, addressing the lack of knowledge in isolation is inadequate. Chapter 10 will discourse on the associated recommendations for lung cancer awareness. A study by Lubuzo and colleagues on health providers' perceptions about pathways of lung cancer care declared other critical factors for consideration when responding to this challenge (1). These interrelated factors include patients, health providers, and the persistent health system challenges. In their study, they interrogate these relational factors more broadly.

In relation to patient factors, inadequate access to healthcare was identified as a barrier, which included illness representations and beliefs, the patient's place of residence and socioeconomic status, the latter affecting the affordability of the costs of treatment and care. Furthermore, the health care providers factors include uncoordinated screening services, ineffective teams (i.e., lack

of practitioner knowledge and expertise), lack of equipment and infrastructure, and mismanagement and ineffective supervision. Similarly, Lubuzo and colleagues also observed the organisational interconnectedness of the system. These include inadequate resources (lack of human and financial resources, and mismanagement of these resources), the inaccessibility of services, both at patient and system levels due to cost, and poor screening services (1).

Barriers in communication were acknowledged as crucial. In addition, low suspicion index towards lung cancer among healthcare providers due to competing priorities, existing comorbidities among patients, and a lack of knowledge at the lower levels of healthcare (i.e., Primary Health Care level) was evident. This is confirmed by Cunningham and colleagues, whose study established the difficulty of recognising lung cancer symptoms among patients with COPD (2).

The Pivotal Role of Community Health Workers in Raising Awareness on Lung Cancer

This study included CHWs in the implementation of a lung cancer awareness intervention among the selected communities in KwaZulu-Natal. This intervention sought to increase community awareness of lung cancer. It was expected that the attitudes and health-seeking behaviour, which included the screening of these communities for lung cancer, would influence the community positively after the intervention. The intervention was adapted from The Lung Laboratory Research and Intervention Centre's Lung Cancer training manual, developed by pulmonologists in the field.

The following content was included: i) Background and Lung Cancer in the South African Context, ii) Types of Lung Cancer, iii) How Lung Cancer affects the Body, iv) Stages of Lung Cancer, v) Signs and Symptoms of Lung Cancer, vi) Causes and Risk Factors of Lung Cancer, vii) Diagnosis, Management and Treatment of Lung Cancer, and viii) Referral pathways of Lung Cancer Patients. The training addressed vital steps for consideration by CHWs during the implementation of the intervention in their respective communities. Although 25 CHWs, including four males, were recruited in the first phase of the study, two males retracted before the commencement of the second phase, which included intervention development and training of CHWs. They were replaced before the commencement of the intervention training.

The experience of including CHWs in delivering healthcare programmes at community level has been widely documented, with varying degrees of success (3-22). These documented experiences are reflected in both service delivery and research contexts. It can be conceded that their responsibilities and scope of practice have expanded Field due to the multiple numbers of interventions CHWs are involved in (23). Thus, posing a challenge to the quality of services and the outcomes of their engagement with clients. Hence, the increase in allocating duties requires scrutiny, to ensure maximum benefits to their client communities. In South Africa, the CHWs have been deemed to be highly valuable assets to the health care teams since the early 1930s. Recently, their roles have included performing duties such as treatment defaulter and contact tracing, screening, condom distribution, and participating in community campaigns, particularly in the prevention and control of HIV and TB (16, 24). Tseng and colleagues documented the challenges confronting CHWs in recent years (25). The CHWs who did not receive proper training, supervision or were supervised by inexperienced managers, and shared less resources in their working environment, tended to perform less efficiently. They have also been included in multiple health interventions such as HIV and TB. In the context of the current study, some similarities exit between TB and lung cancer, in terms of signs and symptoms, and risk factors. Therefore, extending the scope of practice to include lung cancer through appropriate training, consistent support, and comprehensive supervision, as demonstrated in the current study, is deemed logical.

It is generally accepted that within the African context, where there is a lack of studies conducted to explore the accurate burden of lung cancer, it is thought that potentially, the prevalence of this disease may be woefully underestimated. Consequently, gaps in the existing data may exist. This conclusion is also congruent with the results of Lubuzo and colleagues, which includes the health professionals' lack of knowledge and a low lung cancer suspicion index at PHC level. Thus, some patients with lung cancer could be suspected of TB and referred for TB investigation, resulting in a diagnosis with advanced stage (IIIb-IVb) of lung cancer (26, 27) due to the lack of early intervention in terms of appropriate treatment and care.

The current study revealed inadequate community knowledge of lung cancer. Consequently, they may be unable to discuss alternatives with the health professionals if the prognosis does not improve. This study suggests that CHWs can play a vital role in community lung cancer education and conducting risk assessments. This has not been the focus of the CHW programme in the past, as TB and HIV were the then focal priorities. Therefore, integration and inclusion of lung cancer awareness with the existing CHW-TB training programmes could be explored and expanded. In addition, the existing similarities between the two conditions, in terms of presentation, is evident.

The present CHW-TB training programme typically addresses the following topics: i) knowledge about TB (including treatment, multi-drug resistance, and side effects), ii) TB/directly observed treatment (DOT) support, and iii) Attitudes towards people with TB (28, 29). Therefore, the following topics are recommended for inclusion: i) similarities between the TB and lung symptoms, ii) the importance of timeous interventions and verifying diagnosis of TB or lung cancer (screening and early diagnosis), iii) the advantages of early treatment for both lung cancer or TB and survival, iv) importance of treatment completion, v) the risk factors of both TB and lung cancer (including smoking) and vi) referral to relevant facilities for further investigation and diagnosis.

These inclusions would expand on present knowledge and ensure early intervention to consult professionals. In addition, should further investigations be required, the necessary processes would be expedited, especially if the patients fit the risk profile for lung cancer. In terms of the approach, training should include and consider, among others, i) a conducive learning environment inclusive of validating their presence in the team; ii) inclusion of alternate modalities of teaching and learning to cater for different styles of learning abilities; iii) cultural sensitivity and responsiveness to group needs; and iv) being cognisant of the volume of content shared with the CHWs.

A review study on the ongoing training of CHWs in LMICs revealed that not all training occurs in a face-to-face setting (in-person training) (30). Some have adopted the use of mobile technologies (31-33). Although this approach has potential advantages, specifically in the current COVID-19 context, there exist contextual challenges such as the educational level of the CHWs, resources required for such training, network connectivity, and the human element, discipline, to engage

with training. The COVID-19 pandemic compelled most of the training institutions to utilise online platforms for their ongoing training needs (34-36). The lessons learnt from these experiences have applicability in the context of training CHWs during pandemics such as COVID-19, and to be particularly aware of the South African context and availability of data and internet connectivity.

The South African Government is moving towards adopting the National Health Insurance (NHI) plan as the funding model for health services in the country (37). At the core of this strategy, Reengineering Primary Health Care is among the key pillars. CHWs are presented as an integral part of the Re-engineering PHC programme. Some of the criticisms against the implementation of NHI is the lack of clarity of the roles of the CHWs and lack of resource allocation within the PHC Reengineering programme (38, 39). These challenges, together with those emphasised earlier, require close attention for the desired outcomes to be achieved. CHWs' successes have been demonstrated globally, provided that critical components of their role are clarified, to ensure maximising on their presence in the health care team (40).

The CHWs perceived their role, among others, as one of advocacy, where they suggested the necessity to work with industry (e.g., construction) to ensure that the employees have adequate uniforms and safety/protection gear. Their increased confidence in executing on the lung cancer awareness intervention was observed post-training. A study in Malawi among lay health workers (LHWs) also revealed an increase in disease specific knowledge, after TB training over a three-month period, and confidence in their abilities to perform duties (41). Dageid and colleagues revealed in their study that one of the motivating factors to work in the communities among CHWs was the need to share information with the long-suffering PLWHIV(42). Although CHWs are expected to implement multiple healthcare interventions in the community, a further coordinated integration on health priorities will ensure that the inclusion of training in lung cancer awareness is necessary, as suggested previously.

Lung Cancer Awareness Interventions

Studies on lung cancer awareness intervention at the community level are limited, particularly in LMICs. The present study contributes to this body of knowledge, especially within a resource-limited health environment.

Post-intervention, the level of knowledge increased significantly (mean score 59.9%, 95% CI 53.8 - 66.0) compared to baseline (mean score 41.8%, 95% CI 35.7 - 47.9). An England study demonstrated increases in the public's recognition of persistent coughing as a symptom of lung cancer, together with prompt referrals of suspected lung cancer patients by GPs, and lung cancer diagnoses (43). As demonstrated by recent systematic and scoping reviews, no intervention studies have been conducted in the African region recently (44, 45). The South African referral pathways and use of public health sector facilities trends introduce delays in the diagnosis of lung cancer (1, 46). It is unclear how the NHI will specifically solve this challenge as the country moves to adopt this funding model for the healthcare system (37). This study, however, was conducted during the oncology crisis in KwaZulu-Natal, particularly in Durban, where most of the targeted communities were located (47). This holds direct implications for lung cancer screening, unclear referral pathways, delays in diagnosis, treatment, and care, results in poor patient outcomes.

Nevertheless, the intervention increased the proportion of community members who were knowledgeable on the early detection of lung cancer (from 46.5%, 95% CI 39.1 - 53.9 to 81.1%, 95% CI 71.7 - 87.9), and the number of people that were willing to pay for a lung cancer screening test (from 32.1%, 95% CI 25.7 - 39.3 to 45.7%, 95% CI 36.8 - 54.9). The attitude towards lung cancer and intentions to seek medical help for warning signs and symptoms like coughing up blood did not increase significantly post-intervention, although there was a significant increase in knowledge and awareness of lung cancer. There was already a large number of participants (combined 98.4%) that reported that they would consult a doctor (25.2%) or visit a health facility (73.2%) if they were coughing blood pre-intervention. Consequently, it would be harder to detect a small statistical difference (1.3%) post-intervention due to the sample size.

The proportion of smokers remained the same before and after the intervention. The intervention included messages on quitting smoking, including tips for quitting and the benefits of quitting smoking. However, the intervention was intended to raise awareness about lung cancer and encourage health-seeking behaviour among community members that experience lung cancer-related symptoms. Tan and colleagues (48) suggest that CHWs also be trained on smoking

cessation, a role that has been traditionally played by doctors during screening. This prospect should be explored in future studies in settings like South Africa.

Currently, in South Africa, there is no national lung cancer screening programme. A study investigating cancer screening programmes in LMICs concluded that there was a lack of evidence to support the implementation of a lung cancer screening programme, among others (49). From the Kenyan experience, it is evident that low numbers are observed for lung cancer, because the lung cancer patients are referred for TB, as these diseases share similar symptoms. The few who are eventually diagnosed with lung cancer, tend to be diagnosed with late stages (i.e., Stage III/IV), where treatment success is greatly reduced. South Africa is yet to address this challenge (1, 46).

The CHWs were able to identify and refer approximately 4 236 community members with lung health challenges out of 10 434 individuals visited. However, they were unable to follow up on those referred to the health facilities, due to resource limitations. This relates to the lack of continuation and the poor quality of services offered to the local communities. During the awareness intervention phase of the study, some community members expressed their reluctance to visit the health facilities and complained about the long queues and poor quality of service at the public health facilities. The PHC re-engineering strategy was supposed to address these challenges and bring healthcare services closer to the people (29), however, these problems persist (50). These complaints were consistent with the survey results on barriers to seeking health care from public health facilities, which emphasised how strongly the communities felt about these challenges. Interventions aiming to increase the utilisation of services at public health facilities should also address these perceived barriers to increase the likelihood of public utilisation of these facilities. In addressing these identified barriers at healthcare provider level, the staff could be retrained on the Batho Pele principles (Placing People First), especially the manner in which the patients are treated (51).

The issue of available medication and human resources may be beyond the control of the health staff at the facility level, however, how they treat their clients is within their control. James and Miza reported how the inadequacy of human and material resources, and the lack of proper implementation of the Batho Pele principles contributed to the negative attitudes of the professional staff towards these principles (52). Therefore, proper planning and allocation of adequate financial and material resources by DOH should include new initiatives, such as staff reorientation, training and performance incentives, to avoid resistance against the same.

In the South African context, the referral pathways tend to be complex, which presents delays for lung cancer patients in particular (1, 46). Simplification of the continuum of care for lung cancer patients could mean the difference between early diagnosis, where treatment is still effective, and late diagnosis, when treatment is no longer effective. This affects the patients' chances of survival. Therefore, in addition to raising awareness, the DOH should address the referral pathways for lung cancer, commencing with screening, which is non-existent currently, and should continue up to treatment initiation. Reviewing and revising these pathways would assist in addressing the scepticism of these communities about seeking medical help for lung cancer-related challenges.

Future Plans

I am planning to expand this work in my postdoctoral programme and publish the additional results section. This section provides further context that could be helpful in planning and designing integrated interventions in the public health sector. Understanding the perceived barriers that could prohibit patients from utilising the services is important so that they can be addressed. This strategy can be useful in increasing the likelihood of service utilisation. Publishing these results and disseminating these results to policymakers could assist in advocating for service delivery improvements for patients. Thus, increasing the possibility of the patients' health-seeking behaviour.

Study limitations

The study design chosen for this study has implications on the strength of evidence produced thereof. The gold standard would be a randomised controlled trial (RCT), where study participants are randomly assigned to either an experimental/intervention group or a control group of the study. Only the experimental group would receive the intervention. The two groups would be administered a survey questionnaire at baseline and after the intervention or experiment and compared to observe the effects of the intervention. Only the experimental group would be expected to show the desired effect. The assumption in such a study design is that there is no

contamination in the control group (i.e., the control group would not receive the intervention being tested or would receive what is being offered currently). Given the choice of intervention in the study (community intervention), it would not be possible to apply randomisation and achieve a controlled environment in this study.

A quasi-experimental design was therefore chosen as the best design for this study. This study was designed to measure the knowledge, attitudes and practices regarding lung cancer at the community level rather than the individual level. The limitations of conducting assessments at this level are: i) it is not possible to measure changes at an individual level since it is not necessarily the same individuals being measured before and after the intervention. By design, this study is not meant to measure these changes at the individual level. ii) The observed changes or differences may have occurred as a result of another intervention than the one under study. However, that can be accounted for in the analysis, where participants are asked about their exposures to other similar interventions in the same period of study. iii) There may be differences in sample variances between the pre-intervention and post-intervention samples due to chance. Nonetheless, the sampling strategy and selection of participants are such that these differences cancel out each other. The community health workers that worked in the study were employed by the project. They were engaging in activities exclusive to the project. Therefore, their employment conditions might not represent the conditions in which community health workers generally work.

Measures to reduce selection bias and information bias

Selection Bias

A selection bias might have been introduced in the sample at baseline and post-intervention. Since some households might not be accounted for on the list from the municipal town planning offices, especially in the peri-urban clusters, maps were used to identify the houses within the boundaries of the clusters. The selection of households was done using a random pattern from the chosen starting point, as mentioned earlier. This strategy is deemed adequate to limit the effect of selection bias.

Information Bias

Participants in the study may not have been able to recall certain events in the past accurately. Measures were taken to try and limit this bias by limiting the questions to recent events. Due to the fear of the stigma associated with smoking and lung cancer, the study participants may have underreported their smoking habits. The smoking results should be interpreted with caution.

The attitudes' reliability scale (Cronbach's alpha)

The Cronbach's alpha for attitudes' reliability scale was very low, which suggests the poor development of the questions for this measure. This is an area of the survey questionnaire that needs further development.

Post-Intervention Survey

The effects of the intervention were measured a month after the intervention. Although this is a short time after the intervention was administered, in real life, the CHWs would help reinforce the messages to sustain the effects as they work in these communities on a regular basis. Their base of operation is in the community.

Conclusion

The above discussion emphasises the importance of lung cancer awareness interventions focusing on several critical yet practical implementation issues. These are recognition of signs and symptoms of lung cancer, the importance of early detection and health-seeking behaviour (including screening), smoking cessation, and addressing the perceived health system barriers. However, the persistent health system challenges should be deliberately addressed for optimum results.

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CHAPTER 10

CONCLUSIONS AND RECOMMENDATIONS

Conclusions

This study revealed that CHWs can play a pivotal role in raising awareness of lung cancer in the communities of South Africa. When suitably trained and supported, they can be a motivational human resource to help their communities understand the risks associated with lung cancer, recognise its signs and symptoms, the importance of screening, and mobilise community members to seek medical help when they experience lung health challenges like lung cancer.

These systemic challenges include:

i) The level of awareness of lung cancer among the communities included in this study was low. This challenge can be extrapolated to communities that share similar contexts in the country and the African continent. The intervention in this study demonstrated the ability to raise awareness of lung cancer at community level. Furthermore, there is a low level of suspicion of lung cancer among health care workers, particularly at primary health care level. This leads to delays in the healthcare pathway for these patients.

ii) Although there is a willingness to screen for lung cancer, South Africa lacks a national lung cancer screening programme.

iii) Although the prevalence of smoking cigarettes was less than 20% in this study, smoking tobacco products and second-hand smoking remains the main risk factor in more than 80% of lung cancer cases, both locally and internationally. This study demonstrated a reduction in the number of cigarettes smoked among the smokers after the intervention.

iv) At least a third of those included in the study identified a number of barriers to seeking medical assistance from public health facilities. These barriers (e.g., long queues, poor staff attitudes, lack of medication, and poor service) provide opportunity for improved service delivery in the public health system, where the overwhelming majority of South Africans access health services.

Recommendations

It is vital that the challenge of lung cancer is addressed via a multi-pronged approach. Increasing its awareness at community level alone is not an effective strategy. However, awareness campaigns provide a solid starting point in the efforts to curb the effects of this disease. The CHWs indicated that, with proper training and support, they were eager to implement lung cancer awareness campaigns in the communities they serve. Therefore, awareness should be implemented both at the community level through the CHWs and facility level among those at risk. Smoking cessation and/or risk reduction interventions should be integrated into these interventions. The synergising of lung cancer awareness interventions into the already existing CHW programmes, such as the tuberculosis response strategy, is recommended. The lung cancer suspicion index among healthcare workers at the PHC level should be increased. Therefore, healthcare professionals, particularly primary healthcare professionals in the public health sector, should be capacitated with tools to identify those patients at risk for lung cancer in order to make appropriate referrals for those at risk.

The Government, through DOH, should deploy a national lung cancer screening programme. However, a phased approach is preferred, where a pilot is conducted among the at-risk groups (i.e., smokers with at least twenty years of exposure, a history of working in the mines or chemicals industry, and over the age of fifty years) in order to preempt unforeseen challenges before extending it to the rest of the country. These interventions should be underpinned by clear guidelines and policy that commit both human and financial resources towards prevention, (including awareness), and early detection programmes. These interventions would play a role in encouraging health-seeking behaviour among communities.

Barriers to seeking medical help from public health facilities were identified. Eliminating such barriers would contribute towards reinforcing positive health-seeking behaviour among communities. The Batho Pele principles were instituted in an attempt to address such challenges. However, due to the fragmented implementation of these principles, the health care workers were reluctant to adopt these principles in providing much needed care in their daily duties to their clients (patients). Health care providers at all levels of care should be trained on how to provide client-oriented services and client satisfaction to combat some of these identified barriers.

Furthermore, streamlining the referral pathway for lung cancer patients would reduce long queues and lengthy waiting times, and could be done through appointment systems and improved diagnostic algorithms and protocols.

Future Research

It is important for the DOH to adopt evidence-based interventions, because of their limited available resources to distribute towards service provision in the public health sector. This section identifies areas of potential research to strengthen the evidence needed to make informed decisions regarding services provision in lung cancer prevention, care and support. The following areas have been identified for further research:

i) The feasibility integrating lung cancer awareness intervention into the CHW-TB response strategy. The HCSI could be instrumental in evaluating this integration and this should be investigated.

ii) A study investigating the feasibility of integrating a smoking cessation intervention into a CHW programme is recommended.

iii) A pilot and costing of a lung cancer screening programme should be conducted before national implementation is considered.

iv) A study exploring how to increase the level of lung cancer suspicion among healthcare workers at the PHC level, and whether that would produce the desired effects on patient outcomes.

v) Streamlining the pathways of care for lung cancer patients is crucial, as most of these patients do not survive treatment and are often diagnosed at late stages of the disease. This area requires further research in a context such as South Africa.

vi) The Chronbach's alpha for the attitudes measures in the questionnaire was low. More work must be done to further develop this area.

APPENDICES

Appendix 1: Regression Model with the knowledge score as a continuous

outcome

Knowledge	e Score
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Mixed-effects ML	Number of obs	=	1,431
regression Group variable: time	Number of groups	=	2
	Obs per group:		
	min	=	689
	avg	=	715.5
	max	=	742
	Wald chi2(1)	=	16.70
Log likelihood = -6219.6237	Prob > chi2	=	0.0000

knowledge score	Coefficient	Std. err.	Z	P>z	[95% conf.	interval]
time	17.26585	4.225318	4.09	0.000	8.98438	25.54732
_cons	41.64774	2.98323	13.96	0.000	35.80072	47.49476

Random-effects	effects Estimate Std. err.		[95% conf.	interval]
parameters				
time: Identity				
var(R.Cluster)	322.8303	55.16957	230.9456	451.2727
var(Residual)	296.7086	11.40083	275.184	319.9167

Number of obs	=	1,431
F(2, 1428)	=	94.74
Prob > F	=	0.0000
R-squared	=	0.1189
Root MSE	=	24.715
	F(2, 1428) Prob > F R-squared	F(2, 1428) = Prob > F = R-squared =

knowledge score	Coefficient	Robust std.	t	P>t	[95% conf.	interval]
		err.				
time	18.02993	1.311129	13.75	0.000	15.45798	20.60187
Cluster	0.081931	0.060978	1.34	0.179	-0.037685	0.201546
_cons	40.08257	1.628765	24.61	0.000	36.88754	43.2776

Appendix 2: Baseline Information Leaflet in English

INFORMATION SHEET FOR THE MULTINATIONAL LUNG CANCER CONTROL PROGRAM (BASELINE SURVEY)

Project Title: Raising awareness of lung cancer in the communities of KwaZulu-Natal.

What is this study about?

Siyabonga Dlamini, a PhD student at the University of KwaZulu-Natal, would like to understand factors influencing community awareness regarding lung cancer in KwaZulu-Natal. He would especially like to know, among other things, what the communities know about lung cancer, its treatment, community members' health seeking- behaviour, and the history of lung cancer, together with its risk factors.

Why is the study being done?

Lung cancer is among the most common cancers in the world. It is estimated that globally, about 1.8 million new cases of lung cancer occur every year. Over 58% of lung cancer cases occur in the developing countries. The overwhelming majority of cancer deaths are due to lung cancer. Many African countries lack understanding of the epidemiology of this disease, thus making it difficult to develop tailored prevention strategies. Therefore, the burden of lung cancer is arguably hugely under-estimated. Many sufferers of lung cancer present to the health facilities very late, making treatment and care less effective. The majority of lung cancer cases result in preventable deaths due to late presentation. The researcher wants to understand, therefore, how the communities of KwaZulu-Natal can be assisted in raising awareness of lung cancer with the aim to help prevent as much death as possible from this disease through behaviour change.

Description of the study

Teams of trained research assistants and community health workers will visit five communities, including Umlazi, South Durban, Chatsworth, Mbali and Sobantu. These teams will approach various households in the said communities and talk to household members about lung cancer. The questions that will be asked will include knowledge of lung cancer and its treatment, where people can go for medical/health problems, and how long people wait to seek medical help when they are ill. This will take about forty-five to sixty minutes to answer.

Potential risks of the research

There are no risks associated with this study. However, you may feel uncomfortable with some of the questions that will be asked, including enquiring about family members suffering from lung related diseases such as lung cancer. A list of organisations offering psychological services will be made available to you should you require this.

Potential benefits of the research

The data from this study will assist the researcher in understanding the communities' knowledge of lung cancer, symptoms, treatment and care, and their health-seeking behaviour. This understanding will be used to develop an awareness intervention to help communities better understand how lung cancer affects their lives and how they can access care and treatment. This awareness intervention will then be implemented in these same communities, which may have positive consequences in terms of increased early diagnosis and treatment of lung related health problems.

Do I have to participate in this research, and can I withdraw at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study, or if you withdraw at any time, you will not be penalised or lose any benefits to which you may otherwise qualify for.

Confidentiality

Every effort will be made to keep personal information confidential. The information collected will be protected, and only the study team members will have access to it. All the information will be stored on the servers, which require a username and password to access. Absolute confidentiality cannot be guaranteed, but personal information may have to be disclosed if required by law. However, such an occurrence is highly unlikely.

Organisations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the Research Ethics Committee of the University of Kwa-Zulu Natal. When the results are published, no individuals or cohorts will be identified.

What if I have questions?

If you have any questions about the research study itself, please contact the researcher: Siyabonga Dlamini. Contact details: Cell: 071 905 9171, Email: dlaminis24@ukzn.ac.za Postal Address: Discipline of Public Health Medicine 2nd floor George Campbell Building, Howard College Campus Research Unit Room 219 Rick Turner road, Gate 3. Science Drive 4001

Should you have any questions regarding this study and your rights as a research participant, or if you wish to report any problems you have experienced related to the study, please contact the research supervisors or the Biomedical Research Committee: Research Supervisors: Prof Benn Sartorius / Dr Themba Ginindza: 031 260 4459/4214 BIOMEDICAL RESEARCH ETHICS ADMINISTRATION Research Office, Westville Campus Govan Mbeki Building Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 260 2486; Fax: 27 31 260 4609; Email: BREC@ukzn.ac.za

Appendix 3: Baseline Information Leaflet in Zulu

INFORMATION SHEET: THE MULTINATIONAL LUNG CANCER CONTROL PROGRAM (BASELINE SURVEY)

Isihloko Socwaningo: Ukwenyusa izinga lokuqwasha mayelana nesifo somdlavuza wamaphaphu emiphakathini yaKwaZulu-Natal (Raising awareness of lung cancer in the communities of KwaZulu-Natal).

Lolucwaningo lumayelana nani?

u-Siyabonga Dlamini, ungumfundi weziqu zobudokotela eNyuvesi yaKwaZulu-Natali, ufisa ukuqonda kabanzi ngezinto ezinomthalela ekuqwasheni komphakathi mayelana nesifo somdlavuza wamaphaphu KwaZulu-Natali. Ufuna ukwazi ikakhulukazi, phakathi kwezinyo izinto, ukuthi ikuphi imiphakathi ekwaziyo mayelana nomdlavuza wamaphaphu, ukwelashwa kwawo, izindlela zomphakathi zokufuna usizo lwezempilo, kanye nomlando womdlavuza wamaphaphu emndenini kanye nezinto ezibeka abantu engozini yokuthola lesisifo.

Yini imbangela yokuthi kwenziwe lolucwaningo

Umdlavuza wamaphaphu uyinto ejwayeleke kakhulu emhlabeni. Kubalwa inani labantu abangaphezu kuka 1.8 million abatholwa benomdlavuza emhlabeni wonke njalo ngonyaka. Kungaphezu kwamaphesenti awu-58 wabantu abanomdlavuza wamaphaphu abasemazweni asafufusa. Iningi labantu abanomdlavuza abafayo basuke benomdlavuza wamaphaphu. Maningi amazwe ase-Afrika angenakho ukuqonda okunzulu mayelana nokubhebhetheka kwalesisifo emiphakathini yabo, okwenza kube nzima ukwakha izinhlelo ezifanele zokuvikela lesisifo. Ngakho-ke, akwazeki kahlehle ukuthi ungakanani umthwalo nokukhinyabezeka okudalwa wumdlavuza wamaphaphu. Abaningi abanalomdlavuza bayaphuza ukuza ezikhungweni zezempilo, okwenza ukuthi kube nzima ukuyilapha nokunakekela abanayo. Iningi labantu abanomdlavuza bagcina beshona yize noma bekungavinjwa lokho, ngoba beza ukuzothola usizo sekuhambe isikhathi. Ngakho-ke umcwaningi ufuna ukuqonda ukuthi imiphakathi yaKwaZuluNatali ingasizwa kanjani ukwenyusa izinga lokuqwasha mayelana nomdlavuza wamaphaphu ngenhloso yokuvimbela ukufa kwabantu ngenxa yalesisifo ngokushintsha indlela abantu abenza ngayo.

Ukubamba kwakho iqhaza

Amaqembu abasizi babacwaningi kanye nonompilo bazovakashela imiphakathi, okubalwa Umlazi, i-South Durban, i-Chatsworth, iMbali kanye neSobantu. Lamaqembu azovakashela amakhaya ahlukene kulemiphakathi ebaluliwe bese exoxisana namalungu omndeni mayelana nomdlavuza wamaphaphu. Imibuzo ezobuzwa lapho izobandakanya ulwazi ngomdlavuza wamaphaphu kanye nokwelashwa kwawo, izindawo lapho abantu beya khona mayelana nosizo lwezempilo, kanye nokuthi abantu balinda isikhathi esingakanani ngaphambi kokuthi baye kofuna usizo uma begula. Lokhu kuzothatha isikhathi esingaba imizuzu ewu-45 kuya kwewu-60 ukuphendula.

Ingcuphe ongaba kuyo kanye nenzuzo ngalolucwaningo

Abukho ubungozi obukhona mayelana nalolucwaningo. Kodwa-ke, kungenzeka uzizwe ungaphathekile kahle ngokuphendula eminye yemibuzo, emayelana namalungu omndeni ake

aphathwa izifo zamaphaphu njengomdlavuza wamaphaphu. Uzonikezwa uhla lwezinhlangano ezisebenza ukusiza abantu ngezimo zomqondo uma kwenzeka uludinga.

Okuzohlonyulwa kulolucwaningo

Ulwazi oluzotholakala kulolucwaningo luzosiza umcwaningi aqonde ukuthi yini imiphakathi eyaziyo ngomdlavuza wamaphaphu, izinkomba zawo, ukwelashwa kwawo nokunakekelwa, kanye nendlela abenza ngayo ukuthola usizo lwezempilo. Lokhukuqonda kuzobe sekusetshenziswa ekwakheni uhlelo lokuqwashisa imiphakathi ukuze yazi ukuthi umdlavuza unomthelela kanjani ezimpilweni zabo nokuthi bangathola kanjani ukunakekelwa nokwelashwa. Loluhlelo luzofakwa kuyona futhi lemiphakathi, okungadala imiphumela emihle mayelana nokunyuka kwenani labantu abasheshe batholakale ukuthi banenkinga emaphashini, futhi bathole ukwelashwa izinkinga zamaphaphu ngokushesha.

Ngabe ngiphoqelekile ukuba kulolucwaningo futhi ngingayeka yini nganoma isiphi isikhathi?

Ukubamba kwakho iqhaza kulolucwaningo kungokuzikhethela kwakho. Ungakukhetha ukungabi yingxenye nhlobo yalolucwaningo. Uma unquma ukubamba iqhaza kulolucwaningo, ungayeka nganoma isiphi isikhathi. Uma ukhetha ukungabi kulolucwaningo noma uyeka nganoma isiphi isikhathi, angeke ujeziswe noma ulahlekelwe inzuzo obekufanele engabe uyayithola.

Ukugcinwa kwemfihlo

Kuzokwenziwa ngokusemandleni ukugcina imininingwane yakho iyimfihlo. Ulwazi lwakho oluzoqoqwa luzovikelwa, lapho kuzoba iqembu labacwaningi kuphela abazoba nemvume kulo. Lonke ulwazi luzogcinwa emshinini, lapho kuzodingakala ukuthi umuntu abe nendlela eqashiwe yokungena kulo. Ngeke sakwazi ukuqinisekisa ngokupheleleyo ukuba yimfihlo kwemininingwane yakho uma siphushwa abomthetho ukuthi siyidalule. Kodwa-ke, amathuba alokho ukuthi kwenzeke ayingcosana. Izinhlangano okungenzeka ukuthi zihlole noma zikopishe imininingwane yakho kulolucwaningo ukuqinisekisa iqophelo eliphezulu locwaningo kanye nokuhlaziya ulwazi olutholakalayo kubandakanywa Ikomiti elengamele ucwaningo lweNyuvesi yaKwaZulu-Natali. Uma imiphumela yalolucwaningo isishicilelwa, akekho umuntu noma amaqembu abantu abazodalulwa.

Kwanzakalani uma nginemibuzo?

Uma unemibuzo ngalolucwaningo uqobo, sicela uthintane nomcwaningi oluphethe lolucwaningo: u-Siyabonga Dlamini. Imininingwane yakhe: Tel: 031 260 4499 / Cell: 071 905 9171; Email: dlaminis24@ukzn.ac.za Postal Address: Discipline of Public Health Medicine 2nd floor George Campbell Building, Howard College Campus Rick Turner road Gate 3. Science Drive, 4001 Uma unanoma iyiphi imibuzo ngalolucwaningo kanye namalungelo akho ngokubamba kwakho

iqhaza kulolucwaningo, noma ufisa ukubika izinkinga ohlangabezane nazo mayelana nalolucwaningo, sicela uthintane nababhekelela ukuthi luhamba kahle lolucwaningo noma Ikomiti elengamele Ucwaningo Lwezempilo:

Ababhekelele ucwaningo (Research Supervisors): Prof Benn Sartorius / Dr Themba Ginindza: 031 260 4452/4214

IKOMITI ELENGAMELE UCWANINGO LWEZEMPILO Research Office, Westville Campus Govan Mbeki Building Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 2602486 - Fax: 27 31 2604609 Email: BREC@ukzn.ac.za

Appendix 4: Baseline Informed Consent Form in English CONSENT FORM FOR THE MULTINATIONAL LUNG CANCER CONTROL PROGRAM (BASELINE SURVEY)

Title of Research Project: *Raising awareness of lung cancer in the communities of KwaZulu-Natal.*

The study has been described to me in the language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I have not been coerced in any way to participate in this study. I also understand that I have a right to withdraw from the study at any time. I have been given an opportunity to ask questions that I might have about my participation in the study.

I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Signature of Participant

Date

Signature of Witness (Where applicable)

Date

Signature of Translator (Where applicable)

Date

Appendix 5: Baseline Informed Consent Form in Zulu

CONSENT FORM FOR THE MULTINATIONAL LUNG CANCER CONTROL PROGRAM (BASELINE SURVEY)

Isihloko Socwaningo: Ukwenyusa izinga lokuqwasha mayelana nesifo somdlavuza wamaphaphu emiphakathini yaKwaZulu-Natal (Raising awareness of lung cancer in the communities of KwaZulu-Natal).

Ngichazelwe ngalolucwaningo ngolimi engiluqondayo futhi ngizikhethele ngokukhuleka ukuthi ngibambe iqhaza kulolucwaningo. Imibuzo yami ngalolucwaningo iphenduliwe. Angizange ngiphoqwe nganoma iyiphi indlela ukubamba iqhaza kulolucwaningo. Ngiyaqonda futhi ukuthi nginelungelo lokuyeka kulolucwaningo nganoma isiphi isikhathi. Nginikeziwe ithuba lokubuza imibuzo ekungenzeka ukuthi benginayo mayelana nokubamba iqhaza kulolucwaningo.

Ngiyaqonda ukuthi imininingwane ngami ngeke idalulwe futhi ngingayeka kulolucwaningo ngaphandle kokunikeza isizathu noma inini futhi ngeke ngikhinyabezeke nganoma iyiphi indlela.

Ukusayina kobamba iqhaza

Usuku

Ukusayina kukafakazi (Uma kudingeka) Usuku

Ukusayina kotolikayo (Uma kudingeka) Usuku

Appendix 6: Awareness Information Leaflet in English

INFORMATION SHEET FOR THE MULTINATIONAL LUNG CANCER CONTROL PROGRAM (AWARENESS INTERVENTION)

Project Title: Raising awareness of lung cancer in the communities of KwaZulu-Natal.

What is this study about?

Siyabonga Dlamini, a PhD student at the University of KwaZulu-Natal, would like to understand factors influencing community awareness regarding lung cancer in KwaZulu-Natal. He would especially like to know, among other things, what the communities know about lung cancer, its treatment, community members' health seeking behaviour, and history of lung cancer together with its risk factors.

Why is the study being done?

Lung cancer is among the most common cancers in the world. It is estimated that about 1.8 million new cases of lung cancer occur every year, globally. Over 58% of lung cancer cases occur in the developing countries. The overwhelming majority of cancer deaths are due to lung cancer. Many African countries lack understanding of the disease's epidemiology, thus making it difficult to have tailored prevention strategies. Therefore, the burden of lung cancer is arguably hugely underestimated. Many sufferers of lung cancer present to the health facilities very late, making treatment and care less effective. The majority of lung cancer cases result in preventable death due to late presentation. The researcher wants to understand, therefore how the communities of KwaZulu-Natal can be assisted in raising awareness of lung cancer with an aim to help prevent as much death as possible from this disease through behaviour change.

Description of the study

Teams of trained research assistants and community health workers will visit five communities, including Umlazi, South Durban, Chatsworth, Mbali and Sobantu. These teams will go to different households in the mentioned communities and talk to household members about lung cancer. They will be raising awareness about lung cancer including lung cancer signs and symptoms, its treatment, causes of lung cancer, and where people can go for lung health problems when they are sick. This will take five sessions each lasting about 60 minutes.

Potential risks of the research

There are no risks associated with this study. However, you may feel uncomfortable with some of the questions that will be asked, including asking about family members suffering from lung related diseases like lung cancer. A list of organisations that offer psychological services will be made available to you should you need it.

Potential benefits of the research

The information distributed by this study will help communities understand more about lung cancer, its symptoms, treatment and care, and how they can seek help early if they suspect lung related health problems. This understanding will help increase the number of people with lung health problems that go to seek help early in the communities and therefore reduce the number of people that present to the health facilities late for treatment and care.

Do I have to be in this research, and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you may otherwise qualify.

Confidentiality

Every effort will be made to keep personal information confidential. The information that will be collected will be protected, where only the study team members will have access to it. All the information will be stored on the servers, which require username and password to access. Absolute confidentiality cannot be guaranteed as personal information may have to be disclosed if required by law. However, such an occurrence is highly unlikely.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the Research Ethics Committee of the University of KwaZulu-Natal. When the results are published, no individuals or cohorts will be identified.

What if I have questions?

If you have any questions about the research study itself, please contact the researcher: **Siyabonga Dlamini. Contact details:** Tel: 031 260 4499 / Cell: 071 905 9171 Email: dlaminis24@ukzn.ac.za Postal Address: Discipline of Public Health Medicine 2nd floor George Campbell Building Rick Turner road Gate 3. Science Drive Howard College Campus 4001

Should you have any questions regarding this study and your rights as a research participant, or if you wish to report any problems you have experienced related to the study, please contact the research supervisors or the Biomedical Research Committee:

Research Supervisors: **Prof Benn Sartorius / Dr Themba Ginindza: 031 260 4459/4214. BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus Govan Mbeki Building Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 260 2486- Fax: 27 31 260 4609 Email: <u>BREC@ukzn.ac.za</u>

Appendix 7: Awareness Information Leaflet in Zulu

INFORMATION SHEET: THE MULTINATIONAL LUNG CANCER CONTROL PROGRAM (AWARENESS INTERVENTION)

Isihloko Socwaningo: Ukwenyusa izinga lokuqwasha mayelana nesifo somdlavuza wamaphaphu emiphakathini yaKwaZulu-Natal (Raising awareness of lung cancer in the communities of KwaZulu-Natal).

Lolucwaningo lumayelana nani?

u-Siyabonga Dlamini, ungumfundi weziqu zobudokotela eNyuvesi yaKwaZulu-Natali, ufisa ukuqonda kabanzi ngezinto ezinomthalela ekuqwasheni komphakathi mayelana nesifo somdlavuza wamaphaphu KwaZulu-Natali. Ufuna ukwazi ikakhulukazi, phakathi kwezinyo izinto, ukuthi ikuphi imiphakathi ekwaziyo mayelana nomdlavuza wamaphaphu, ukwelashwa kwawo, izindlela zomphakathi zokufuna usizo lwezempilo, kanye nomlando womdlavuza wamaphaphu emndenini kanye nezinto ezibeka abantu engozini yokuthola lesifo.

Yini imbangela yokuthi kwenziwe lolucwaningo

Umdlavuza wamaphaphu uyinto ejwayeleke kakhulu emhlabeni. Kubalwa inani labantu abangaphezu kuka 1.8 million abatholwa benomdlavuza emhlabeni wonke njalo ngonyaka. Kungaphezu kwamaphesenti awu-58 wabantu abanomdlavuza wamaphaphu abasemazweni asafufusa. Iningi labantu abanomdlavuza abafayo basuke benomdlavuza wamaphaphu. Maningi amazwe ase-Afrika angenokho ukuqonda okunzulu mayelana nokubhetheka kwalesisifo emiphakathini yabo, okwenza kube nzima ukwakha izinhlelo ezifanele zokuvikela lesisifo. Ngakho-ke, akwazeki kahlehle ukuthi ungakanani umthwalo nokukhinyabezeka okudalwa wumdlavuza wamaphaphu. Abaningi abanalomdlavuza bayaphuza ukuza ezikhungweni zezempilo, okwenza ukuthi kube nzima ukuyilapha nokunakekela abanayo. Iningi labantu abanomdlavuza bagcina beshona yize noma bekungavinjwa lokho, ngoba beza ukuzothola usizo sekuhambe isikhathi. Ngakho-ke umcwaningi ufuna ukuqonda ukuthi imiphakathi yaKwaZulu-Natali ingasizwa kanjani ukwenyusa izinga lokuqwasha mayelana nomdlavuza wamaphaphu ngenhloso yokuvimbela ukufa kwabantu ngenxa yalesisifo ngokushintsha indlela abantu abenza ngayo.

Ukubamba kwakho iqhaza

Amaqembu abasizi babacwaningi kanye nonompilo bazovakashela imiphakathi, okubalwa Umlazi, i-South Durban, i-Chatsworth, iMbali kanye neSobantu. Lamaqembu azovakashela amakhaya ahlukene kulemiphakathi ebaluliwe bese exoxisana namalungu omndeni mayelana nomdlavuza wamaphaphu. Lamaqembu azoqwashisa ngomdlavuza wamaphaphu okubandakanya izimpawu nezinkomba zawo lomdlavuza, ukulashwa kwawo, ukuthi udalwa yini umdlavuza wamaphaphu, kanye nokuthi abantu bangaya kuphi ngezinkinga zezempilo eziphathelene namaphaphu futhi begula. Loluhlelo luzothatha amaseshini amahlanu, bese iyodwa ithathe imizuzu engangamashumi ayisithupha (60 minutes).

Ingcuphe ongaba kuyo kanye nenzuzo ngalolucwaningo

Abukho ubungozi obukhona mayelana nalolucwaningo. Kodwa-ke, kungenzeka uzizwe ungaphathekile kahle ngokuphendula eminye yemibuzo, okungaba mayelana namalungu omndeni

ake aphathwa izifo zamaphaphu njengomdlavuza wamaphaphu. Uzonikezwa uhla lwezinhlangano ezisebenza ukusiza abantu ngezimo zomqondo uma kwenzeka uludinga.

Okuzohlonyulwa kulolucwaningo

Ulwazi oluzotholakala kulolucwaningo luzosiza imiphakathi iqonde kabanzi ngomdlavuza wamaphaphu okubalwa izimpawu zayo, ukwelashwa nokunakekelwa kwayo, nokuthi bangasheshe bathole kanjani usizo masinyane uma besola ukuthi banezinkinga zezempilo eziphathelene namaphaphu. Lokhukuqonda kuzosiza ekunyuseni isibalo sabantu emphakathini abanezinkinga zezempilo emaphashini abasheshe bahambe ukuyofuna usizo okwenza kunciphe isibalo sabantu abaphuzayo ukuya ezikhungweni zezempilo ukuze belashwe futhi banakekelwe.

Ngabe ngiphoqelekile ukuba kulolucwaningo futhi ngingayeka yini nganoma isiphi isikhathi?

Ukubamba kwakho iqhaza kulolucwaningo kungokuzikhethela kwakho. Ungakukhetha ukungabi yingxenye nhlobo yalolucwaningo. Uma unquma ukubamba iqhaza kulolucwaningo, ungayeka nganoma isiphi isikhathi. Uma ukhetha ukungabi kulolucwaningo noma uyeka nganoma isiphi isikhathi, angeke ujeziswe noma ulahlekelwe inzuzo obekufanele engabe uyayithola.

Ukugcinwa kwemfihlo

Kuzokwenziwa ngokusemandleni ukugcina imininingwane yakho iyimfihlo. Ulwazi lwakho oluzoqoqwa luzovikelwa, lapho kuzoba iqembu labacwaningi kuphela abazoba nemvume kulo. Lonke ulwazi luzogcinwa emshinini, lapho kuzodingakala ukuthi umuntu abe nendlela eqashiwe yokungena kulo. Ngeke sakwazi ukuqinisekisa ngokupheleleyo ukuba yimfihlo kwemininingwane yakho uma siphushwa abomthetho ukuthi siyidalule. Kodwa-ke, amathuba alokho ukuthi kwenzeke ayingcosana.

Izinhlangano okungenzeka ukuthi zihlole noma zikopishe imininingwane yakho kulolucwaningo ukuqinisekisa iqophelo eliphezulu locwaningo kanye nokuhlaziya ulwazi olutholakalayo kubandakanywa Ikomiti elengamele ucwaningo lweNyuvesi yaKwaZulu-Natali. Uma imiphumela yalolucwaningo isishicilelwa, akekho umuntu noma amaqembu abantu abazodalulwa.

Kwanzakalani uma nginemibuzo?

Uma unemibuzo ngalolucwaningo uqobo, sicela uthintane nomcwaningi oluphethe lolucwaningo: **u-Siyabonga Dlamini.**

Imininingwane yakhe:

Tel: 031 260 4499 / Cell: 071 905 9171 Email: dlaminis24@ukzn.ac.za Postal Address: Discipline of Public Health Medicine 2nd floor George Campbell Building Rick Turner road Gate 3. Science Drive Howard College Campus 4001

Uma unanoma iyiphi imibuzo ngalolucwaningo kanye namalungelo akho ngokubamba kwakho iqhaza kulolucwaningo, noma ufisa ukubika izinkinga ohlangabezane nazo mayelana

nalolucwaningo, sicela uthintane nababhekelela ukuthi luhamba kahle lolucwaningo noma Ikomiti elengamele Ucwaningo Lwezempilo: Ababhekelele ucwaningo (Research Supervisors): **Prof Benn Sartorius / Dr Themba Ginindza: 031 260 4452/4214 IKOMITI ELENGAMELE UCWANINGO LWEZEMPILO** Research Office, Westville Campus Govan Mbeki Building Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 2602486 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

Appendix 8: Awareness Informed Consent Form in English

CONSENT FORM FOR THE MULTINATIONAL LUNG CANCER CONTROL PROGRAM (AWARENESS INTERVENTION)

Title of Research Project: Raising awareness of lung cancer in the communities of KwaZulu-Natal.

The study has been described to me in the language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I have not been coerced in any way to participate in this study. I also understand that I have a right to withdraw from the study at any time. I have been given an opportunity to ask questions that I might have about my participation in the study.

I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Signature of Participant

Date

Signature of Witness (Where applicable) Date

Signature of Translator (Where applicable)

Date

Appendix 9: Awareness Informed Consent Form in isiZulu

CONSENT FORM FOR THE MULTINATIONAL LUNG CANCER CONTROL PROGRAM (AWARENESS INTERVENTION)

Isihloko Socwaningo: Ukwenyusa izinga lokuqwasha mayelana nesifo somdlavuza wamaphaphu emiphakathini yaKwaZulu-Natal (Raising awareness of lung cancer in the communities of KwaZulu-Natal).

Ngichazelwe ngalolucwaningo ngolimi engiluqondayo futhi ngizikhethele ngokukhuleka ukuthi ngibambe iqhaza kulolucwaningo. Imibuzo yami ngalolucwaningo iphenduliwe. Angizange ngiphoqwe nganoma iyiphi indlela ukubamba iqhaza kulolucwaningo. Ngiyaqonda futhi ukuthi nginelungelo lokuyeka kulolucwaningo nganoma isiphi isikhathi. Nginikeziwe ithuba lokubuza imibuzo ekungenzeka ukuthi benginayo mayelana nokubamba iqhaza kulolucwaningo.

Ngiyaqonda ukuthi imininingwane ngami ngeke idalulwe futhi ngingayeka kulolucwaningo ngaphandle kokunikeza isizathu noma inini futhi ngeke ngikhinyabezeke nganoma iyiphi indlela.

Ukusayina kobamba iqhaza

Usuku

Ukusayina kukafakazi (Uma kudingeka) Usuku

Ukusayina kotolikayo (Uma kudingeka) Usuku

Appendix 10: Community Health Worker Information Leaflet in English INFORMATION SHEET FOR THE MULTINATIONAL LUNG CANCER CONTROL PROGRAM (CHW TRAINING EXPERIENCES)

Project Title: Raising awareness of lung cancer in the communities of KwaZulu-Natal.

What is this study about?

Siyabonga Dlamini, a PhD student at the University of KwaZulu-Natal, would like to understand factors influencing community awareness regarding lung cancer in KwaZulu-Natal. He would especially like to know, among other things, what the communities know about lung cancer, its treatment, community members' health seeking behaviour, and history of lung cancer together with its risk factors.

Why is the study being done?

Lung cancer is among the most common cancers in the world. It is estimated that about 1.8 million new cases of lung cancer occur every year, globally. Over 58% of lung cancer cases occur in the developing countries. The overwhelming majority of cancer deaths are due to lung cancer. Many African countries lack understanding of the disease's epidemiology, thus making it difficult to have tailored prevention strategies. Therefore, the burden of lung cancer is arguably hugely underestimated. Many sufferers of lung cancer present to the health facilities very late, making treatment and care less effective. The majority of lung cancer cases result in preventable death due to late presentation. The researcher wants to understand, therefore how the communities of KwaZulu-Natal can be assisted in raising awareness of lung cancer with an aim to help prevent as much death as possible from this disease through behaviour change.

Description of the study

I want to ask you, together with a group of your peers a few questions about your experiences of training on lung cancer awareness. A trained community health worker will conduct the group discussion so that you are comfortable and are free to answer honestly without feeling pressured to answer one way or the other. This discussion will be recorded to make sure that nothing is lost from the discussion. This discussion will take about 60 minutes.

Potential risks of the research

There are no risks associated with this study. However, you may feel uncomfortable with some of the questions that will be asked, including asking about family members suffering from lung related diseases like lung cancer. A list of organisations that offer psychological services will be made available to you should you need it.

Potential benefits of the research

The information obtained from this discussion will help me understand about your experiences of lung cancer awareness training and how we can help communities understand more about lung cancer, its symptoms, treatment and care, and how they can seek help early if they suspect lung related health problems. This understanding will help increase the number of people with lung health problems that go to seek help early in the communities and therefore reduce the number of people that present to the health facilities late for treatment and care.

Do I have to be in this research, and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you may otherwise qualify.

Confidentiality

Every effort will be made to keep personal information confidential. The information that will be collected will be protected, where only the study team members will have access to it. All the information will be stored on the servers, which require username and password to access. Absolute confidentiality cannot be guaranteed as personal information may have to be disclosed if required by law. However, such an occurrence is highly unlikely.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the Research Ethics Committee of the University of KwaZulu-Natal. When the results are published, no individuals or cohorts will be identified.

What if I have questions?

If you have any questions about the research study itself, please contact the researcher: **Siyabonga Dlamini. Contact details:** Tel: 031 260 4499 / Cell: 071 905 9171 Email: dlaminis24@ukzn.ac.za Postal Address: Discipline of Public Health Medicine 2nd floor George Campbell Building Rick Turner road Gate 3. Science Drive Howard College Campus 4001

Should you have any questions regarding this study and your rights as a research participant, or if you wish to report any problems you have experienced related to the study, please contact the research supervisors or the Biomedical Research Committee:

Research Supervisors: **Prof Benn Sartorius / Dr Themba Ginindza: 031 260 4459/4214. BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus Govan Mbeki Building Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 260 2486- Fax: 27 31 260 4609 Email: <u>BREC@ukzn.ac.za</u>

Appendix 11: Community Health Worker Information

Leaflet in isiZulu

INFORMATION SHEET: THE MULTINATIONAL LUNG CANCER CONTROL PROGRAM (CHW TRAINING EXPERIENCES)

Isihloko Socwaningo: Ukwenyusa izinga lokuqwasha mayelana nesifo somdlavuza wamaphaphu emiphakathini yaKwaZulu-Natal (Raising awareness of lung cancer in the communities of KwaZulu-Natal).

Lolucwaningo lumayelana nani?

u-Siyabonga Dlamini, ungumfundi weziqu zobudokotela eNyuvesi yaKwaZulu-Natali, ufisa ukuqonda kabanzi ngezinto ezinomthalela ekuqwasheni komphakathi mayelana nesifo somdlavuza wamaphaphu KwaZulu-Natali. Ufuna ukwazi ikakhulukazi, phakathi kwezinyo izinto, ukuthi ikuphi imiphakathi ekwaziyo mayelana nomdlavuza wamaphaphu, ukwelashwa kwawo, izindlela zomphakathi zokufuna usizo lwezempilo, kanye nomlando womdlavuza wamaphaphu emndenini kanye nezinto ezibeka abantu engozini yokuthola lesifo.

Yini imbangela yokuthi kwenziwe lolucwaningo

Umdlavuza wamaphaphu uyinto ejwayeleke kakhulu emhlabeni. Kubalwa inani labantu abangaphezu kuka 1.8 million abatholwa benomdlavuza emhlabeni wonke njalo ngonyaka. Kungaphezu kwamaphesenti awu-58 wabantu abanomdlavuza wamaphaphu abasemazweni asafufusa. Iningi labantu abanomdlavuza abafayo basuke benomdlavuza wamaphaphu. Maningi amazwe ase-Afrika angenokho ukuqonda okunzulu mayelana nokubhetheka kwalesisifo emiphakathini yabo, okwenza kube nzima ukwakha izinhlelo ezifanele zokuvikela lesisifo. Ngakho-ke, akwazeki kahlehle ukuthi ungakanani umthwalo nokukhinyabezeka okudalwa wumdlavuza wamaphaphu. Abaningi abanalomdlavuza bayaphuza ukuza ezikhungweni zezempilo, okwenza ukuthi kube nzima ukuyilapha nokunakekela abanayo. Iningi labantu abanomdlavuza bagcina beshona yize noma bekungavinjwa lokho, ngoba beza ukuzothola usizo sekuhambe isikhathi. Ngakho-ke umcwaningi ufuna ukuqonda ukuthi imiphakathi yaKwaZulu-Natali ingasizwa kanjani ukwenyusa izinga lokuqwasha mayelana nomdlavuza wamaphaphu ngenhloso yokuvimbela ukufa kwabantu ngenxa yalesisifo ngokushintsha indlela abantu abenza ngayo.

Ukubamba kwakho iqhaza

Ngifuna ukukubuza imibuzo, uhlangene nozakwenu njengonompilo, mayelana nokuqeqeshelwa kwenu uhlelo lokuqwashisa ngesifo somdlavuza wamaphaphu. Unompilo oqeqeshiwe uyena ozoqhuba izingxoxo ukuze ninethezeke futhi nikhululeke ukuphendula imibuzo ngokuthembeka nangaphandle kokuzizwa niphoqelekile ukuphendula ngendlela ethile. Lezizingxoxo zizoqoshwa ukuze kuqinisekiswe ukuthi akukho okulahlekayo ezingxoxweni. Lengxoxo izothatha imizuzu engaba amashumi ayisithupha (60 minutes).

Ingcuphe ongaba kuyo kanye nenzuzo ngalolucwaningo

Abukho ubungozi obukhona mayelana nalolucwaningo. Kodwa-ke, kungenzeka uzizwe ungaphathekile kahle ngokuphendula eminye yemibuzo, okungaba mayelana namalungu omndeni

ake aphathwa izifo zamaphaphu njengomdlavuza wamaphaphu. Uzonikezwa uhla lwezinhlangano ezisebenza ukusiza abantu ngezimo zomqondo uma kwenzeka uludinga.

Okuzohlonyulwa kulolucwaningo

Ulwazi oluzotholakala kulengxoxo luzongisiza ukuthi ngiqonde kabanzi ngokuqeqeshwa kwenu ngesifo somdlavuza wamaphaphu nokuthi singawusiza kanjani umphakathi ukuthi uqonde kabanzi ngesifo somdlavuza wamaphaphu, okubalwa izimpawu zayo, ukwelashwa nokunakekelwa kwayo, nokuthi bangasheshe bathole kanjani usizo masinyane uma besola ukuthi banezinkinga zezempilo eziphathelene namaphaphu. Lokhukuqonda kuzosiza ekunyuseni isibalo sabantu emphakathini abanezinkinga zezempilo emaphashini abasheshe bahambe ukuyofuna usizo okwenza kunciphe isibalo sabantu abaphuzayo ukuya ezikhungweni zezempilo ukuze belashwe futhi banakekelwe.

Ngabe ngiphoqelekile ukuba kulolucwaningo futhi ngingayeka yini nganoma isiphi isikhathi?

Ukubamba kwakho iqhaza kulolucwaningo kungokuzikhethela kwakho. Ungakukhetha ukungabi yingxenye nhlobo yalolucwaningo. Uma unquma ukubamba iqhaza kulolucwaningo, ungayeka nganoma isiphi isikhathi. Uma ukhetha ukungabi kulolucwaningo noma uyeka nganoma isiphi isikhathi, angeke ujeziswe noma ulahlekelwe inzuzo obekufanele engabe uyayithola.

Ukugcinwa kwemfihlo

Kuzokwenziwa ngokusemandleni ukugcina imininingwane yakho iyimfihlo. Ulwazi lwakho oluzoqoqwa luzovikelwa, lapho kuzoba iqembu labacwaningi kuphela abazoba nemvume kulo. Lonke ulwazi luzogcinwa emshinini, lapho kuzodingakala ukuthi umuntu abe nendlela eqashiwe yokungena kulo. Ngeke sakwazi ukuqinisekisa ngokupheleleyo ukuba yimfihlo kwemininingwane yakho uma siphushwa abomthetho ukuthi siyidalule. Kodwa-ke, amathuba alokho ukuthi kwenzeke ayingcosana.

Izinhlangano okungenzeka ukuthi zihlole noma zikopishe imininingwane yakho kulolucwaningo ukuqinisekisa iqophelo eliphezulu locwaningo kanye nokuhlaziya ulwazi olutholakalayo kubandakanywa Ikomiti elengamele ucwaningo lweNyuvesi yaKwaZulu-Natali. Uma imiphumela yalolucwaningo isishicilelwa, akekho umuntu noma amaqembu abantu abazodalulwa.

Kwanzakalani uma nginemibuzo?

Uma unemibuzo ngalolucwaningo uqobo, sicela uthintane nomcwaningi oluphethe lolucwaningo: **u-Siyabonga Dlamini.**

Imininingwane vakhe:

Tel: 031 260 4499 / Cell: 071 905 9171 Email: dlaminis24@ukzn.ac.za Postal Address: Discipline of Public Health Medicine 2nd floor George Campbell Building Rick Turner road Gate 3. Science Drive Howard College Campus 4001 Uma unanoma iyiphi imibuzo ngalolucwaningo kanye namalungelo akho ngokubamba kwakho iqhaza kulolucwaningo, noma ufisa ukubika izinkinga ohlangabezane nazo mayelana nalolucwaningo, sicela uthintane nababhekelela ukuthi luhamba kahle lolucwaningo noma Ikomiti elengamele Ucwaningo Lwezempilo:

Ababhekelele ucwaningo (Research Supervisors): Prof Benn Sartorius / Dr Themba Ginindza: 031 260 4452/4214

IKOMITI ELENGAMELE UCWANINGO LWEZEMPILO

Research Office, Westville Campus Govan Mbeki Building Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 2602486 - Fax: 27 31 2604609 Email: BREC@ukzn.ac.za

Appendix 12: Community Health Worker Informed Consent in English CONSENT FORM FOR THE MULTINATIONAL LUNG CANCER CONTROL PROGRAM (CHW TRAINING EXPERIENCES)

Title of Research Project: Raising awareness of lung cancer in the communities of KwaZulu-Natal.

The study has been described to me in the language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I have not been coerced in any way to participate in this study. I also understand that I have a right to withdraw from the study at any time. I have been given an opportunity to ask questions that I might have about my participation in the study.

I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Signature of Participant

Date

Signature of Witness (Where applicable)

Date

Signature of Translator (Where applicable)

Date

Appendix 13: Community Health Worker Informed Consent in isiZulu

CONSENT FORM FOR THE MULTINATIONAL LUNG CANCER CONTROL PROGRAM (CHW TRAINING EXPERIENCES)

Isihloko Socwaningo: Ukwenyusa izinga lokuqwasha mayelana nesifo somdlavuza wamaphaphu emiphakathini yaKwaZulu-Natal (Raising awareness of lung cancer in the communities of KwaZulu-Natal).

Ngichazelwe ngalolucwaningo ngolimi engiluqondayo futhi ngizikhethele ngokukhuleka ukuthi ngibambe iqhaza kulolucwaningo. Imibuzo yami ngalolucwaningo iphenduliwe. Angizange ngiphoqwe nganoma iyiphi indlela ukubamba iqhaza kulolucwaningo. Ngiyaqonda futhi ukuthi nginelungelo lokuyeka kulolucwaningo nganoma isiphi isikhathi. Nginikeziwe ithuba lokubuza imibuzo ekungenzeka ukuthi benginayo mayelana nokubamba iqhaza kulolucwaningo.

Ngiyaqonda ukuthi imininingwane ngami ngeke idalulwe futhi ngingayeka kulolucwaningo ngaphandle kokunikeza isizathu noma inini futhi ngeke ngikhinyabezeke nganoma iyiphi indlela.

Ukusayina kobamba iqhaza

Usuku

Ukusayina kukafakazi (Uma kudingeka) Usuku

Ukusayina kotolikayo (Uma kudingeka) Usuku

Appendix 14: BREC Approval



18 January 2019

Mr SB Dlamini (203517606) School of Nursing and Public Health College of Health Sciences Dlaminis24@ukzn.ac.za

Dear Mr Dlamini

Protocol: Effectiveness of a lung cancer awareness intervention in five communities in KwaZulu-Natal (KZN): A Stratified cluster based study in five representative communities. Degree: PhD BREC Ref No: BF585/18

BREC FULL APPROVAL LETTER (Phase 1 and 2)

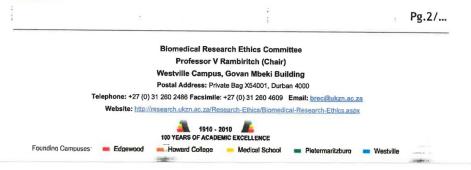
The Biomedical Research Ethics Committee (BREC) has considered the abovementioned application at a meeting held on 13 November 2018.

I wish to advise you that your responses dated 16 January 2019 and 10 December 2018 to BREC letters dated 24 November 2018 and 16 January 2019 were noted and approved by a sub-committee of the Biomedical Research Ethics Committee. Please ensure that site permissions are obtained and forwarded to BREC for approval before commencing research at a site. Please note that only Phase 1 and 2 of the above study has been approved by BREC. Phase 3 intervention details must be provided to BREC for reviewing and approval.

This approval is valid for one year from **18 January 2019.** To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research



BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The following Committee members were present at the meeting that took place on 13 November 2018:

Prof V Rambiritch	Pharmacology (Chair)
Dr N Abbai	Microbiology and Molecular Biology
Prof C Aldous	Genetics
Prof R Bhimma	Paediatrics & Child Health
Rev SD Chili	External – Community member
Dr S Ganesh	Research Clinician
Dr R Harrichandparsad	Neurosurgery
Dr K Hlongwana	Public Health
Mr H Humphries	Research Psychology and Public Health
Dr B Hira	HIV Clinician
Dr M Khan	HIV Clinician
Dr R Lessells	Infectious Diseases Specialist
Prof TE Madiba	General Surgery
Dr K Naidoo	Family Medicine
Dr S Paruk	Psychiatry
Prof C Rout	Anaesthetics
Prof D Singh	Critical Care
Prof S Singh	Dentistry
Dr T Sookan	Biokineticist

This approval will be noted at the full BREC meeting to be held on 12 February 2019.

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

PROFESSOR V RAMBIRITCH Chair: Biomedical Research Ethics Committee

Linder at

Supervisor: Co Supervisor: Co-investigator: Postgrad admin:

Sartious@ukzn.ac.za Ginidza@ukzn.ac.za HlongwanaK@ukzn.ac.za ramlalm@ukzn.ac.za



15 October 2020

Mr SB Dlamini (203517606) School of Nursing and Public Health College of Health Sciences <u>Dlaminis24@ukzn.ac.za</u>

Dear Mr Dlamini

Protocol: Effectiveness of a lung cancer awareness intervention in five communities in KwaZulu-Natal (KZN): A Stratified cluster based study in five representative communities. Degree: PhD BREC Ref No: BF585/18

FULL COMMITTEE APPROVAL LETTER (Phase 3)

I wish to advise you that your response dated 24 February 2020 to BREC letter dated 12 December 2019 was noted and approved by the Biomedical Research Ethics Committee at a meeting held on 13 October 2020.

Please note that Phase 3 (Interventional component) of the study has now been given full approval by the Biomedical Research Ethics Committee.

Please ensure that site permissions are obtained and forwarded to BREC for approval before commencing research at a new site.

This approval is valid for one year from 15 October 2020. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

This approval is subject to national and UKZN lockdown regulations dated 26th August 2020, see (<u>http://research.ukzn.ac.za/Libraries/BREC/BREC_Lockdown_Level_2_Guidelines.sflb.ashx</u>). Based on feedback from some sites, we urge PIs to show sensitivity and exercise appropriate consideration at sites where personnel and service users appear stressed or overloaded.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678). Pg. 1/....

Biomedical Research Ethics Committee Chair: Professor D R Wassenaar UKZN Research Ethics Office Westville Campus, Govan Mbeki Building Postal Address: Private Bag X54001, Durban 4000 Email: <u>BREC@ukzn.ac.za</u> Website: <u>http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx</u> Website: <u>http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx</u> Founding Campuses: Edgewood Meword Colege Medical School Pletermariltzburg Westville INSPIRING GREATNESS The following Committee members were present at the meeting that took place on 13 October 2020:

Prof D Wassenaar	Clinical Psychology (Chair)
Prof R Bhimma	Paediatrics & Child Health (Deputy Chair)
Prof S Singh	Dentistry (Deputy Chair)
Prof N Abbai	Microbiology and Molecular Biology
Prof C Aldous	Genetics
Prof T Hardcastle	Surgery
Dr K Hlongwana	Public Health
Dr A Harrichandparsad	Public Health
Dr H Humphries	Research Psychology and Public Health
Dr Z Khumalo	KZN Health (External) General Medicine
Dr R Lessells	Infectious Diseases Specialist
Dr K Naidoo	Family Medicine
Prof V Rambiritch	Pharmacology
Dr T Sookan	Biokinetics
Dr D Singh	Critical Care

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely,

In Imuna

PROFESSOR D WASSENAAR **Chair: Biomedical Research Ethics Committee**

 Supervisor:
 Sartious@ukzn.ac.za

 Co Supervisor:
 Ginidza@ukzn.ac.za

 Co-investigator:
 HlongwanaK@ukzn.ac.za

 Postgrad admin:
 ramlalm@ukzn.ac.za

Appendix 15: Pre- and Post-Intervention Survey Questionnaire

Multinational Lung Cancer Control Programme (KZN Awareness Programme)

A1	House/apartment n	umber (<i>If any</i>)			
A2	Street Address (If a	ny)			
A3	GPS Coordinates	Lati:,	·	Long:,	
A4	Local area type	1 <u>—</u>	Suburb		1
			Townshi	ip	2
			Rural		3
			Farm		4
			Informa	l Settlement	5
			Other (S	pecify)	6
			Do not k	now	8
			Refused		9
A5	Suburb / local area				
	Umlazi, Chatsworth,	Mbali, Sobantu, South			
	DBN				
A6	Cellular number (if	any)			

A. How to find the dwelling:

Interviewer Details

A7	Interviewer Name				
A8	Date of Interview (dd/mm/yyyy)	//	A9	Interview start time	:

Appointments Log

	Date (dd/mm/yyyy)	Time	Outcome	Any new phone number discovered
A10.1	//	:		
A10.2	//	:		

A11	What is the main reason for refusa	? Too busy	1
		Not interested/waste of time	2
		Questionnaire too personal/too intrusive	3
		Do not trust surveys	4
		Never do surveys	5
		Too old	6
		Other (Specify)	7
		Illness / Recent Death/ Recent child	8
		It took too long last time	9
A12	Degree of interaction with person	None – Refused calling card	1
	refusing	Very little – they cut me short, said no	2
		thanks	
		Some – Got to say I was doing an	3
		important survey	
		Serve men me ereenne,	4
		and spend a bit of time trying to talk them	
		around	
A13	Gender of person refusing	Male 1 Female 0)
A14	Age of person refusing		
A15	Comments regarding the		
	refusal		

B. Demographic Data:

Interviewer instruction: Listed below are people who lived in this household for at least 4 days in a week or people who have been part of the household in the last 12 months for at least 15 days a year.

- Use first names only
- Do not exclude babies
- Live-in domestic workers and lodgers are separate households: a separate household questionnaire should be completed for them.

Interviewer to read out: Please list all the people who have lived under this 'roof' or within the same compound/homestead/stand at least 15 days during the last 12 months as part of the family. Please do not forget to include the babies. We will deal with people who do not live here any longer at a later stage. **Interviewer instruction:** For each of the people listed on the roster ask the following questions. (Move across, not down and complete each person before moving on to the next person).

B1	B2	B3	B4	B5	B6	B 7	B8
name	тет	pres	alive	absm	absexp	absprov	absacc
Names of	Has []	Does []	Is [] still	How many	What was	If still	If still
people living	lived under	usually	alive?	months did	the main	absent, in	absent, in
in the	this 'roof' or	reside here at		[] spend	reason for	which	what kind of
household	within the	least 4 nights	Yes = 1	away from	his/her	province	accommodati
	same	a week?	No = 2	the	absence?	does [] stay	on is []
	compound/h			household in		now?	staying?
	omestead/	Yes = 1	If No , then	the last 12			

	stand at least 15 days during the	No = 2 Died = 3	skip to B9	months? Interv'r: If less than 1		If No Longer Absent, write 11	
	last 12	Skips:		of none,		and skip to	
	months as part of the	If Yes , then go		write 0.		<u>B9</u>	
	family?	to B5		If 0 skip to			
	Yes = 1	If Died , then		<i>B9</i> .			
	No = 2	skip to B9					
	Died = 3						
	If No , then skip to B4						
	If Died, B9						
	Use Box B2	Use Box B3	Use Box B4	Months	Use Box B6	Use Box B7	Use Box B8
1							
2							
3							
4							
5							
6							
7							
8							
9							
10							

			_
Yes	No	No, They	
		Died	
1	2	3	
1	2	3	
1	2		
	Yes 1 1 1 1	Yes No 1 2 1 2 1 2 1 2	Yes No No, They Died 1 2 3 1 2 3 1 2 3

Codes for Q	uestion B6	Codes for Question B7	Codes for Question B8
1= Employment	9= Living elsewhere	1= Western Cape	1= Boarding school
2= Seeking employment	10= Prison	2= Eastern Cape	2= Hall of residence
3= Schooling	11=Vacation	3= Northern Cape	3= Old age home
4= Student	12= In hospital/clinic	4= Free State	4= Retirement village
5= Personal reasons	13= Away on business	5= KwaZulu-Natal	5= Prison
6= Escape violence /Political	14= Other (specify):	6= North West	6= Hospital or clinic
problems			
7= Visiting spouse/family	-8= Refused	7= Gauteng	7= Private house
8= Visiting friends	-9= Do not know	8= Mpumalanga	8= Other (specify)
		9= Limpopo	-8= Refused
		10= Outside of South Africa	-9= Do not know
		11= No longer absent]
		-8= Refused	
		-9= Do not know	

Must complete above questions for everyone on the list, before moving on to the next question. The next question is not asked of every individual but is a separate question, before leading back into the questions t asked of each person.

	Question	Answer options	Validation rules	Skips
B 9	Who is the head of the household?	Select from the list in B1	B1 not empty, new or B2 equal to yes	If person not on the list, then go back and add them to the list or they are not the head
	Is [] deceased? i.e does B2 =3 or	Yes		Next Person
	B3 = 3 or B4 = 2	No		

The next set of questions should be asked of every person on the roster

	B10	B11	B12	B13	B14	B15	B16.1	B16.2	B16.3
	What is []'s relationship to [Name from B9]? [] is [Name for B9]'s	What race group does [] belong to? African = 1 Coloured = 2 Asian/Indian = 3 White = 4 Other (Specify) = 5 Refused = -8 Do not know = -9	What is []'s gender? Male = 1 Female = 2 Refused = -8 Do not know = -9	What is []'s date of birth? (dd/mm/yyyy)	What is []'s age in YEARS? If younger than 14 years, Skip B17. If older than 14 years, Skip B19.	What is []'s preferred language?	What is the highest grade in school that [] successfully completed (passed)?	Has [] successfully completed any diplomas, certificates or degrees outside of school? This includes NTC courses. Yes = 1 No = 2 (Skips: B17)	What is the highest level of education [] successfully completed?
Person	Relationship Code	Race	Gender	DOB	Age in Years	Language	Education Code	DII)	Education Code
1									
2									
3									
4									
5									
6									
7									
8									
9									
10									

	B17.1	B17.2	B18	B19	B20
	Is []'s spouse or partner	Are they formally married	Is [] widowed, divorced	Is []'s biological father	Is []'s biological mother
	listed on this roster? If yes,	or living together?	or have they never been	listed on this roster?	listed on this roster?
	please list them.	(Including customary or	married?		
		traditional marriages)		No, Deceased $=$ 44	No, deceased $= 44$
	No Spouse or partner $= 0$		Widow/Widower = 3	No, not part of this	No, not part of this
	No, deceased = 44	Formally married $= 1$	Divorced or separated $= 4$	household $= 77$	household = 77
	No, Spouse not part of	Living together= 2	Never Married = 5	Do not know $= -9$	Do not know $= -9$
	this household $= 77$	Not living together $= 3$	Refused $= -8$	Refused $= -8$	Refused = -8
	No, partner not part of	Refused = -8	Do not know $= -9$		
	this household = 66	Do not know = -9			
	Do not know = -9 Refused = -8	(Skip to B19)			
	(If no spouse listed skip to B18, if spouse				
	deceased or don't				
	know, skip to B19)				
Validation	Name list of over 14s	Name list of over 14s		Name list of males more	Name list of females more
Rules	from B1	from B1		than 12 years of age	than 12 years of age
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					

C. Mortality History:

Interviewer to read out: Now I would like to ask you about the recent deaths in your household in the last 24 months

				Skip
C1	Has any member of this household, who usually lived here for at least four	Yes	1	
	nights a week, died in the last 24 months?	No	2	D1
		Do not know	-8	D1
		Refused	-9	D1

	C2 Starting with the death that occurred most recently, what was the name of the deceased?	W	(/hat was [2 3]'s gend	er?	C4 What was []'s relationship to [Name from B9]? [] was [Name for B9]'s	C5 What was []'s date of death? Interviewer: If do not know the month, write 99. If do not know the year, write 9999	C6 How old was [] when he/she died? Interviewer: If less than 1 year write 0. If do not know, write '- 9'.	C7 Was [] living here when he/she died?			C8 Was []'s death a result of an accident or violence?				
#	Name	Male	Female	Refuse	Don't know	Select from list	mm/yyyy	Years	Yes	No	Refuse	Don't know	Yes	No	Refuse	Don't know
1		1	2	-8	-9		/		1	2	-8	-9	1	2	-8	-9
2		1	2	-8	-9		/		1	2	-8	-9	1	2	-8	-9
3		1	2	-8	-9		/		1	2	-8	-9	1	2	-8	-9
4		1	2	-8	-9		/		1	2	-8	-9	1	2	-8	-9
5		1	2	-8	-9		/		1	2	-8	-9	1	2	-8	-9

C9 Name of respondent

D. Household Living Standards:

<u> </u>	Household Living Stand				
D1	What is the total number of rooms that the household				
	occupies in all structures in this dwelling? Please				
	note this excludes bathrooms	and toilets.			
	Number of rooms:				
	Refuse		-8		
	Do no know		-9		
D2	What is the main material used		alls of the main		
	dwelling? Interviewer: Select f				
	Type of material	D4.1 Roof	D4.2 Walls		
	Bricks	1	1		
	Cement block/concrete	2	2		
	Corrugated iron/zinc	3	3		
	Wood	4	4		
	Plastic	5	5		
	Cardboard	6	6		
	Mixture of mud and	7	7		
	cement				
	Wattle and daub	8	8		
	Tile	9	9		
	Mud bricks	10	10		
	Thatching	11	11		
	Asbestos/cement roof sheeting	12	12		
	Stone and rock	13	13		
	Refuse	-8	-8		
	Do not know	-9	-9		
D3	What is the main material us	ed for the floor of t	he main		
	dwelling? Interviewer: Sele	ct from the list			
	Type of material		Floor		
	Mud/Earth		1		
	Concrete		2		
	Carpet		3		
	Tiles		4		
	Wood		5		

Linoleum/Vinyl	6
Refuse	-8
Do not know	-9

				Skips
D4	Does the household pay rent?			
	Yes		1	
	No		2	D6
	Refuse		-8	D6
	Do not know		-9	D6
D5	What is the amount paid for rent ea	ch month?		
	Amount	R		
	Refuse	-8		
	Do not know	-9		
D6	Does a household member own this	s dwelling?		
	Yes		1	
	No	2	D9	
	Refuse	-8	D9	
	Do not know		-9	D9
D 7	Is this property fully paid off?			
	Yes		1	D9
	No		2	
	Refuse	-8		
	Do not know	-9		
D8	Did the household receive any gove	ernment assist	ance (e	e.g. RDP
	housing) to obtain this dwelling or	another dwelli	ng?	
	Yes		1	
	No	2		
	Refuse		-8	
	Do not know		-9	
D9	What is this household's main sour	ce of water?		
	Piped (tap) water in dwelling		1	D12
	Piped (tap) water on site or in yard		2	D12
	Public tap		3	
	Water-Carrier/tanker		4	
	Borehole on site		5	D12

	Borehole off site/communal	6				
	Rain-water tank on site	7	D12			
	Flowing water/stream	8				
	Dam/pool/stagnant water	9				
	Well	10				
	Spring	11				
	Other (specify)	12				
	Refuse	-8	D12			
	Do not know	-9	D12			
D10	How far is the water source from the dwelling?					
	Interviewer: Read out options.					
	Less than 100 m	1				
	More than 100 m - less than 200 m	2				
	More than 200 m - less than 500 m	3				
	More than 500 m - less than 1 km	4				
	1 km or more	5				
	Refuse	-8				
	Do not know	-9				
D12	What type of toilet facility is available for this household?					
	Interviewer: Read out options.					
	Flush toilet with on-site disposal (septic tank /	1				
	soak-away)					
	Flush toilet with offsite disposal	2				
	Chemical toilet	3				
	Pit latrine with ventilation pipe (VIP)	4				
	Pit latrine without ventilation pipe	5				
	Bucket toilet	6				
	None	7	D14			
	Other (specify) toi_o	9				
	Refuse	-8	D14			
	Do not know	-9	D14			
D13	Is the toilet facility shared with other households	s?				
	Yes	1				
	No	2				
	Refuse	-8				
	Don't know	-9				

D14	Does this household have electricity even if currently						
1014	disconnected?	e electricity e	ven n current	ly			
	Yes			1			
	No			2			
	Refuse			8			
	Do not know			.9			
	Do not know			-			
				Skips			
D15	What is the main source						
	Energy/fuel course	D15.1	D15.2	D15.3			
	Energy/fuel source	Cooking	Heating	Lighting			
	Electricity from mains	1	1	1			
	Electricity from	2	2	2			
	generator						
	Gas	3	3	3			
	Paraffin	4	4	4			
	Wood	5	5				
	Coal	6	6				
	Candles			7			
	Animal Dung	8	8				
	Solar Energy	9	9	9			
	Other (specify)	10	10	10			
	None	11	11	11			
	Refuse	-8	-8	-8			
	Do not know	-9	-9	-9			
D16	Does this household have		elephone in the	e dwelling?			
	Yes - Currently in work			1			
	Yes - Currently not in w	orking conditi	ion	2			
	No			3			
	Refuse			-8			
	Do not know			-9			
D1 7	Is there a cellular teleph	one available	to this househ	old for			
	regular use?						
	Yes			1			
	No			2			
	Refuse			-8			
	Do not know			-9			

	•	
D18	Has anyone in this household received income from go	vernment
	grants last month? Please note that this includes old age	
	child support grant, disability grant, care dependency g	grant or
	any other kind of grant.	
	Yes	1
	No	2
	Refuse	-8
	Do not know	-9
D19	Did anyone in this household receive income from priv	vate
	pensions, dividends or interest on investments last mon	ith?
	Yes	1
	No	2
	Refuse	-8
	Do not know	-9
INTE	RVIEWER READ OUT: We understand that income is	a difficult
and set	nsitive question. However, due to its importance, we wou	ld like to
ask yo	u for the range into which your last month's household in	come
(after t	ax) falls.	
D20	Would you say the last month's household income was	:
	More than or less than R750?	1
	More than or less than R1500?	2
	More than or less than R3000?	3
	More than or less than R6000?	4
	More than or less than R11000?	5
	More than or less than R27000?	6
	Refuse	-8
	Do not know	-9

E. Health-seeking Behaviour:

E1	Where do you or your household members usually go first for			
	health problems?			
	Stay at home	0		
	Public clinic	1		
	Public hospital	2		
	Other Public Health facility	3		
	Private clinic	4		
	Private hospital	5		
	Private doctor / Specialist	6		
	Pharmacy	7		
	Traditional healer	8		
	Spiritual healer / Church	9		
	Health facility provided by the employer	10		
	Alternative medicine (e.g., homoeopathist)	11		
	Refuse	-8		
	Do not know	-9		
E2	What means of transport is usually used by most household	•		
	members to get to the health facility the household normally	uses?		
	Walking	1		
	Minibus taxi/sedan taxi/bakkie taxi	2		
	Bus	3		
	Train	4		
	Own transport	5		
	Bicycle/motorcycle	6		
	Other (Specify)	7		
	Refuse	-8		
	Do not know	-9		
E3	How long does it take you to get the health centre?			
	Less than 15 minutes	1		
	Between 15minutes and 30minutes	2		
	Between 31 and 1 hour	3		
	More than 1 hour			
	Refuse	-8		
	Do not know	-9		
E4	Are there any diseases that can only be treated in a health fac	cility?		
	Yes	1		
	No	2		

	Refuse	-8
	Do not know	-9
E5	Are there any diseases that can only be treated by a tradition	al
	healer?	
	Yes	1
	No	2
	Refuse	-8
	Do not know	-9
E6	Are there any diseases that can only be treated by a spiritual	healer
	or church?	
	Yes	1
	No	2
	Refuse	-8
	Do not know	-9
E7	Are there any diseases that can only be treated by an alternat	ive
	medicine practitioner (e.g., Homoeopathist)?	
	Yes	1
	No	2
	Refuse	-8
	Do not know	-9
E8	What are the main barriers that prevent community member	rs from
	seeking medical care from the health facility?	
E8a		
БО	What do you think can be done by Health Workers in this fa	. 11.4
E9	make services in the health centre attractive?	cinty to
EQ.	make services in the health centre attractive?	
E9a		
E10	Do you usually pay money for treatment at the Health Facili	tv?
1210	Yes	1
	No	2
	Refuse	-8
	Do not know	_9
	DO NOT KHOW)

E11	How much do you usually pay for he	alth services?	How much do you usually pay for health services?					
	Amount	R						
	Refuse	-8						
	Don't know	-9						
E12	Does this influence where you seek h	ealth care from?						
	Yes		1					
	No							
	Refuse							
	Do not know		-9					
E13	What sickness usually prompts you to	o seek health care?						
210	Fever		1					
	Diarrhea		2					
	Cough / pneumonia		3					
	Other (Specify)							
	Refuse							
	Do not know							
E14	How long after the sickness, do you usually seek health ca							
	Within 24 hours							
	Within 2 to 3 days							
	More than 3 days							
	Refuse							
	Do not know		-9					
E15	Does the distance affect your attendance at a health facility?							
	Yes		1					
	No							
	Refuse							
	Do not know		-9					
E16	How much do you spend on transport to the health facility? Only							
	Ask if they answered (2-7) in E2							
	Amount	R						
	Refuse	-8						
	Do not know	-9						
E17	How much time do you usually spend	d at the health facility w	aiting					
	to be attended to?		U					
	Less than 30 minutes		1					
	Between 30 minutes and 1 hour		2					
	More than 1 hour		3					
	Refuse		-8					

			0		
	Do not know	1 1	-9		
E18	Do you usually get all the services you may need at the	he healt	h		
	facility?		4		
	Yes		1		
	No		2		
	Refuse		-8		
	Do not know		-9		
E19	In the past 12 months, did any adult (18 years and about the past 12 months) and a solution of the past 12 months are solution of the past 12 months and a solution of the past 12 months are solution of the past 12 months and a solution of the past 12 months are solution of the past 12 mo		this		
	household go hungry because there was not enough for	ood?			
	Never		1		
	Seldom		2		
	Sometimes		3		
	Often		4		
	Always		5		
	Not Applicable (No adults in the household)		6		
	Refuse		-8		
	Do not know		-9		
E20	In the past 12 months, did any child (17 years or younger)				
	household go hungry because there was not enough for				
	Never		1		
	Seldom		2		
	Sometimes		3		
	Often		4		
	Always		5		
	Not Applicable (No children in the household)		6		
	Refuse		-8		
	Do not know		-9		
E21	Please tick all appropriate events that have happened	to vou	within		
	the past 6 months. Answer with Yes=1 or No=0	5			
E21.1	Has any household member (including yourself)	1	0		
	been injured because of violence in the areas where				
	you live or work?				
E21.2	Has any household member (including yourself)	1	0		
	been a victim of a violent crime (e.g., murder,				
	robbery, mugging, assault, rape)?				
E21.3	Did you witness a violent crime (e.g., murder,	1	0		
	robbery, mugging, assault, rape)?				
E21.4	Have you or anyone in your close family been	1	0		
	seriously ill?		_		
			170		

Did any member of your close family pass away?	1	0
Is there anyone in your close family (including	1	0
youself) with a serious disability (for example,		
epilepsy, mental retardation, deafness, blindness,		
mental illness)?		
Have you had any serious fights or been alienation	1	0
from members of your family or your close		
neighbours?		
Have you or any member of your close family been	1	0
on a non-routine matter?		
Is there anyone in your close family (including	1	0
youself) that has a problem with drugs or alcohol?		
Have you or other household members ever been tested for HIV?		HV?
Yes		1
No		2
Refuse		-8
Do not know		-9
	Is there anyone in your close family (including youself) with a serious disability (for example, epilepsy, mental retardation, deafness, blindness, mental illness)? Have you had any serious fights or been alienation from members of your family or your close neighbours? Have you or any member of your close family been arrested, had to go to court, or consulted a lawyer on a non-routine matter? Is there anyone in your close family (including youself) that has a problem with drugs or alcohol? Have you or other household members ever been test Yes No Refuse	Is there anyone in your close family (including youself) with a serious disability (for example, epilepsy, mental retardation, deafness, blindness, mental illness)?1Have you had any serious fights or been alienation from members of your family or your close neighbours?1Have you or any member of your close family been arrested, had to go to court, or consulted a lawyer on a non-routine matter?1Is there anyone in your close family (including youself) that has a problem with drugs or alcohol?1Have you or other household members ever been tested for H Yes1NoRefuse1

F. Lung Health:

F1	Over the past 4 weeks, I or a household member have coughed		
	Not at all	1	
	Only with lung / respiratory infections	2	
	A few days a month	3	
	Several days a week	4	
	Almost everyday	5	
	Refuse	-8	
	Do not know	-9	
F2	Over the last 4 weeks, I or a household member have broug phlegm (sputum)	ght up	
	Not at all	1	
	Only with lung / respiratory infections	2	
	A few days a month	3	
	Several days a week	4	
	Almost everyday	5	

	Refuse		-8
	Do not know		-9
F3	Over the last 4 weeks, I or a household member have had shortness		
	of breath		
	Not at all		1
	Only with lung / respiratory infections		2
	A few days a month		3
	Several days a week		4
	Almost everyday		5
	Refuse		-8
	Do not know		-9
F4	Over the last 4 weeks, I or a household member have had episo		
	of wheezing		
	Not at all		1
	Only with lung / respiratory infections		2
	A few days a month		3
	Several days a week		4
	Almost everyday		5
	Refuse		-8
	Do not know		-9
			Skips
F5	What are the symptoms of lung cancer? Choose as r	nany	
	answers.		
	Coughing up blood	1	
	Recurring chest infections	2	
	Shortness of breath	3	
	Loss of appetite	4	
	Chest pain	5	
	Fatigue or feeling weak	6	
	Hoarseness of the voice	7	
	Unexplained weight loss	8	
	Cough that does not go away for 2 to 3 weeks	9	
	Persistent shoulder pain	10	
	Ache or pain when breathing	11	
	Painful cough	12	
	Changes in the shape of your fingers or nails	13	

	Developing an unexplained loud, high_pitched sound when breathing	14		
	Worsening or change in an existing cough	15		
	Refuse	-8		
	Do not know	-9		
F6	Have you ever heard about lung cancer?			
	Yes	1		
	No	2	F8	
	Refuse	-8	F8	
	Do not know	-9		
F7	How did you hear about lung cancer? Choose as n	nany ans	wers.	
	Oral communication	1		
	Newspaper	2		
	Radio	3		
	Television	4		
	Conference	5		
	Medical doctor or at the hospital	6		
	Church	7		
	School	8		
	Non-governmental Organisation (NGO)	9		
	Traditional healer	10		
	Refuse	-8		
	Do not know	-9		
F8	Which situations increase the chances of developing lung cancer? Choose as many answers.			
	None	0		
	Smoking	1		
	Exposure to harmful mineral dust in the mines	2		
	Exposure to/inhaling harmful chemicals	3		
	History of lung cancer in the family	4		
	Second-hand cigarette/tobacco smoke	5		
	Exposure to asbestos	6		
	Refuse	-8		
	Do not know	-9		

Skips

TO		1	
F9	In your close circle of acquaintances, do you know someone who		
	has had lung cancer? Mark one answer only.	1	
	Yes	1	
	No	2	
	Refuse	-8	
	Do not know	-9	
F10	How can lung cancer be treated? Choose as many a	nswers.	
	Surgery	1	
	Radiation	2	
	Chemotherapy	3	
	Supportive care (i.e., Palliative care)	4	
	Quitting smoking (if smoker)	5	
	Refuse	-8	
	Do not know	-9	
F11	How can the risk of lung cancer be reduced?		
	Avoiding smoking	1	
	Avoiding second-hand smoke	2	
	Using protective equipment when working in the	3	
	mines and chemicals industry		
	Eating fruit and vegetables and reducing sugar and	4	
	starch		
	Exercising	5	
	Refuse	-8	
	Do not know	-9	
F12	Have you ever heard about lung cancer screening?	· · · · · · · · · · · · · · · · · · ·	
	Yes	1	
	No	2	
	Refuse	-8	
	Do not know	-9	
F13	Did you know that lung cancer can be detected early	/?	
1 10	Yes	1	
	No	2	
	Refuse	-8	
	Do not know	-9	
	20 NOT RHOW		
F14	What would you do in case of coughing up blood?	· · ·	
	Nothing	0	
	Consult a medical doctor	1	
	Go to a health centre/clinic	2	

	Go to a traditional healer	3
	Refuse	-8
	Do not know	-9
F15	What would you do in case of coughing persistently?	
	Nothing	0
	Consult a medical doctor	1
	Go to a health centre/clinic	2
	Go to a traditional healer	3
	Refuse	-8
	Do not know	-9
F15B	If you had a symptom that you thought might be a sig	n of lung
	cancer, how soon would you contact your doctor to m	ake an
	appointment or visit a health worker at your local clin it?	ic to discuss
	1-3 days	1
	4-6 days	2
	1 weeks	3
	2 weeks	4
	1 month	5
	3 months	6
	6 months	7
	≥ 12 months	8
	Never	9
	Do not know	-9
F15C	What is the main reason for the time taken?	
F15D	If you had a symptom that you thought might be a sig cancer how soon would you seek help from a tradition	
	1-3 days	1
	4-6 days	2
	1 weeks	3
	2 weeks	4
	1 month	5
	3 months	6
	6 months	7
	≥12 months	8
	Never	9
	Do not know	_9

F15E	What is the main reason for the time taken?		
1102			
F16	Are you willing to regularly consult a me	dical doctor/health	
	centre/clinic for screening of lung cancer	?	
	Yes	1	
	No	2	
	Refuse	-8	
	Do not know	-9	
F17	Are you willing to undergo a screening te	est?	
	Yes	1	
	No	2	
	Refuse	-8	
	Do not know	-9	
F18	Would you want a lung cancer national so	creening program to be	
	made available in the future?		
	Yes	1	
	No	2	
	Refuse	-8	
	Do not know	-9	
F19	Are you willing to pay for a lung cancer s	screening test?	
	Yes	1	
	No	2	
	Refuse	-8	
	Do not know	-9	
F20	Have you ever been screened for lung car	ncer before?	
	Yes	1	
	No	2 F22	
	Refuse	-8 F22	
	Do not know	-9 F22	
F21	When was your last screening for lung ca	ncer?	
	Date		
	/		
	Refuse	-8	
	Do not know	-9	
F22	Do you use chemicals of plants to care fo	r your lung problems?	
	Yes	1	
	No	2	

	D C	0	
	Refuse	-8	
	Do not know	-9	
F23	Do you smoke?		
	Yes	1	
	No	2	F26
	Refuse	-8	F26
	Do not know	-9	F26
F24	How many cigarettes do/did you smoke a day?		
	Number of cigarettes	1	
	Refuse	-8	
	Do not know	-9	
F25	How many packs do/did you smoke a week?		
	Number of packs		
	Refuse	-8	
	Don't know	-9	
F26	Have you ever worked in a mine?		
	Yes	1	
	No	2	F28
	Refuse	-8	F28
	Do not know	-9	F28
F27	How many years have you worked on the mines?		
	Number of years		
	Refuse	-8	
	Do not know	-9	
F28	Have you ever worked in a chemicals industry?		
	Yes	1	
	No	2	
	Refuse	-8	
	Do not know	-9	
F29	How many years have you worked in the c	hemica	als
-	industry?		
	Number of years		
	Refuse	-8	
	Do not know	-0	
F30	In the next year, who is likely to develop lun	/	.9
гз0		g cancer	1
	A 30 year old A 50 year old		1
	A 70 year old		2
	A /U year old		3

	Lung cancer in unrelated to age	4	
The fol	lowing may or may not increase a person's chance of dev	1	
	ncer. How do you agree that each of these increases a per-		
	of developing lung cancer?	5011 5	
F31A	Exposure to radon gas (a naturally occurring radioad	tive gas)	
10111	Strongly disagree		
	Disagree	2	
	Not sure	3	
	Agree	4	
	Strongly Agree	5	
F31B	Exposure to another person's cigarette smoke	J	
TUID	Strongly disagree	1	
	Disagree	2	
	Not sure	3	
	Agree	4	
	Strongly Agree	5	
F31C	Having had treatment for any cancer in the past	0	
1010	Strongly disagree	1	
	Disagree	2	
	Not sure	3	
	Agree	4	
	Strongly Agree	5	
F31D	Having a close relative with lung cancer		
	Strongly disagree	1	
	Disagree	2	
	Not sure	3	
	Agree	4	
	Strongly Agree	5	
F31E	Exposure to chemicals (such as asbestos)		
	Strongly disagree	1	
	Disagree	2	
	Not sure	3	
	Agree	4	
	Strongly Agree	5	
F31F			
	Strongly disagree	1	
	Disagree	2	
	Not sure	3	

	1	
	Agree	4
	Strongly Agree	5
F31G	Air pollution	
	Strongly disagree	1
	Disagree	2
	Not sure	3
	Agree	4
	Strongly Agree	5
F31H	Being a smoker	
	Strongly disagree	1
	Disagree	2
	Not sure	3
	Agree	4
	Strongly Agree	5
F31I	Having previous history of lung disease, such as chronic	
	obstructive pulmonary disease (COPD)	
	Strongly disagree	1
	Disagree	2
	Not sure	3
	Agree	4
	Strongly Agree	5
F32	How confident are you that you would notice a symptom of	f lung
	cancer	-
	Not at all confident	1
	Not yet confident	2
	Fairly confident	3
	Very confident	4

Appendix 16: A List of Psychological Services

Name of Organisation/Specialist	Address	Contact
Umlazi and Lamontville (Part of So	uth Durban)	
Psychologist N.W. Mbhele	Suite 6, Pardy Rd, Isipingo, Durban, 4110	031 902 8635
Miss Arthurine Thelma Thandeka Ntuli (Psychologist)	Eyethu Career & Information Centre, Ithala Centre V1317	031 906 8467
Phumelele J Zungu (Clinical Psychologist)	L04 Umlazi Mega City, 50 Mangosuthu Highway	072 677 7157
Prince Mshiyeni Memorial Hospital	Griffiths Mxenge Hwy, Umlazi V, Umlazi, 4060	031 907 8111
Miss Zamaphemba Ntuli	Montclair Medical and Dental Centre,70 Wood Road, Montclair, 4004	031 462 4404
Chatsworth		
Dr Narainsami Chetty (Psychologist)	Room 220 Chatsmed Medical Centre, 80 Woodhurst Drive	031 409 4065
Dr Guru Kistnasamy	80 Woodhurst Dr, Woodhurst, Durban, 4092	031 459 8067
South Durban		
Dr Dale Davidson (Clinical and Sport Psychologist)	41 Olsen Rd, Brighton Beach, Bluff, 4052	073 963 6913
Dr Y Gramani	Meremed M Cntr, Krishna Rabilal Rd, Merewent, Durban	031 468 8584
Carol Lamprecht	14 Chislehurst Close, Brighton Beach, Durban	031 467 8142
Wentworth Hospital	Boston Rd, Jacobs, Durban, 4026	031 460 5000
Pietermaritzburg		
Imbalenhle Community Health Centre	Unit 3, Thwala Road, Imbali	033 398 9100
Impilwenhle Clinic	Unit 14, Imbali, Pietermaritzburg, 3201	033 322 2790
Thokozani Sithole (Counselling Psychologist)	Famcare Therapy Centre, 190 Retief Street, Pietermaritzburg, 3201	073 889 2375
Help Centre	420 Jabu Ndlovu St, Town, Pietermaritzburg, 3201	033 342 7002

A list of Psychological Services Available by Area:

Appendix 17: Lung Cancer Awareness Intervention

This section describes the intervention that will be implemented by the CCGs in the community. The CCGs will be working in the five selected communities (i.e., Umlazi, Chatsworth, South Durban, Imbali and Sobantu) going door-to-door educating household members on lung cancer. In each cluster selected to be part of the study, the CCGs will visit all the households. They will only work in households that allow them to work with the household. They will cover the following topics:

- 1. Signs and symptoms of lung cancer
- 2. Causes of lung cancer
- 3. Benefits of quitting smoking
- 4. How cancer is treated
- 5. The importance of early diagnosis

The CCGs will work with the members of the household to help them understand the importance of going to the health facilities, should they exhibit the signs and symptoms discussed during their meeting. The households will be handed pamphlets with information on lung cancer (including signs and symptoms, benefits of quitting smoking, causes of lung cancer, and who is more likely to get lung cancer). These pamphlets will be written in both Zulu and English. The translations were done by the researcher together with the CCGs. The samples of the pamphlets are given below in Figures 1, 2, 3, and 4.

The researcher, together with the CCGs will also seek opportunities to address the community members at community meetings to raise awareness on lung cancer. The five topics mentioned above will be discussed . The community members will have the opportunity to ask questions.

Opportunities to work with community radio stations in the five communities will be sought in order to reach a wider audience. The same five topics will be addressed.

What you need to know about

5 Key Facts

- · Lung cancer is a leading cause of cancer deaths in men and women worldwide
- · Smoking counts for the majority of preventable lung cancers
- Lung cancer is more common in men. (As more women have started smoking, the number of women developing lung cancer has increased)
- People who don't smoke can also develop lung cancer
- Survival rates for people diagnosed with lung cancer are low. People diagnosed at earliest stages have the greatest chances for recovery

Signs and symptoms of **Lung Cancer**

- A new cough that doesn't go away
 - Changes in a chronic cough or 'smoker's cough'
 - A cough that gets worse or does not do away
 - Coughing up blood, even a small amount
 - Shortness of breath or wheezing
 - Constant chest pain especially when coughing
 - Frequent chest infections
 - Wheezing/hoarseness
 - Swelling of the neck and face Fatigue (feeling very tired all the time)
 - · Loss of appetitite/losing weight without trying
 - Bone pain
- Headache

Manage your risk for Cancer

- Quitting smoking at any time can lower risk
- Exposure to second hand smoke increases the risk in non-smokers two to three fold
- Healthy diet and moderate physical activity play a role in lowering risk
- Exposure to asbestos increases risk, and combined with smoking the risk is greatly increased



Toll-free 0800 22 66 22 www.cansa.org.za

- Chemicals used in industry and around homes may increase risk. Labels on home products such as wood stripper, and Material Safety Data Sheets provide information on
- safe exposure and proper masks to use Exposure to radon in the house is the second leading cause of lung cancer overall, and the number one cause in non-smokers. (Radon is an invisible radioactive gas that results from the normal decay of radium in the soil)

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Need help quitting

Visit the CANSA website for info on our e-Kick Butt programme or call us toll-free

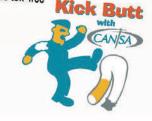




Figure 7: Signs and symptoms of lung cancer pamphlet in English (From CANSA website)

Izinto ezinhlanu ezisemqoka

Umdlavuza wamaphaphu uwona ohamba phambili ekubulaleni abantu besilisa nabesifazane emhlabeni wonke

Ukubhema ugwayi ikona okuhamba phambili ekudaleni umdlavuza wamaphaphu okungavimbeka

Umdlavuza wamaphaphu ujwayeleke kakhulu kwabesilisa. (Njengoba sebe baningi abesifazane ababhemayo, isibalo sabantu besifazane abathola lomdlavuza siyanda).

Abantu abangabhemi bangawuthola umdlavuza wamaphaphu

Isibalo sabantu abasinda kulomdlavuza sincane. Abantu abasheshe batholakale ukuthi banomdlavuza wamaphaphu basemathubeni angcono okusinda

Izinkomba nezimpawu zomdlavuza wamaphaphu

Ukuqala kokukhwehlela okuyimbelesela (okungapheli)

lzinguquko ekukhwehleleni okungapheli noma ukukhwehlela komuntu obhemayo

Ukukhwehlela okuqhubekayo noma okungapheli

Ukukhwehlela igazi, noma ngabe lincane

Ukuphelelwa (ukunqanyukelwa) umoya noma ukunswininiza kwesifuba

Ubuhlungu obungapheli esifubeni – ikakhulukazi uma ukhwehlela

Izifo zesifuba ezithelelanayo ezibuya njalo

Ukuhoshozela kwezwi

Ukuvuvukala kwentamo nobuso

Ukuzizwa ukhathele ngasosonke isikhathi

Yehlisa amathuba akho okuthola umdlavuza wamaphaphu

Ukuyeka ukubhema nganoma isiphi isikhathi kunciphisa amathuba okuba sengcupheni yomdlavuza wamaphaphu

Ukuhogela intuthu kagwayi komuntu ongabhemi kwenyusa ubungozi bomdlavuza wamaphaphu ngokuphindwe kabili noma kathathu

Ukudla ukudla okunempilo nokuzivocavoca kunendima okuyidlalayo ekunciphiseni amathuba okuba sengcupheni yomdlavuza wamaphaphu

Ubhestazi (itshe-boya) wenyusa amathuba okuthola lomdlavuza, kanti uma kuhlanganiswa nokubhema ubungozi balomdlavuza buphindaphindiwe

Amakhemikhali asetshenziswa ezinkompolo nasemakhaya angalinyusa ithuba lokuba sengcupheni. Amalebuli abekwa emkhiqizweni yasekhaya

Figure 8: Signs and symptoms of lung cancer pamphlets in Zulu (REAR of the English version)

Imbangela yomdlavuza wamaphaphu:

- Ukubhema kusahamba phambili ekudaleni umdlavuza wamaphaphu.
- Bangaphezu kwamaphesenti awu-66.7% abantu abanomdlavuza wamaphaphu abafayo ngenxa yokubhema emhlabeni wonke.
- Noma iluphi uhlobo lokubhema lubukeka lwenyusa amathuba okuthola umdlavuza wamaphaphu. Ukubhema usikilidi, isigazu, kanye nenqawe nehookah, konke kuyabandakanywa nomdlavuza wamaphaphu.
- Ukubhema insangu kungawanyusa amathuba okuthola umdlavuza wamaphaphu, ikakhulukazi kubantu abasha.
- Ukuhogela intuthu kagwayi kuyawanyusa amathuba okuthola umdlavuza wamaphaphu. Kubalelwa kubantu abangaphezu kwezinkulungwane ezintathu ngonyaka abathola umdlavuza wamaphaphu ngonyaka ngenxa yokuhogela intuthu kagwayi.
- Ukuba nesandulela ngculaza (HIV) kungaholela
 ekutholeni umdlavuza wamaphaphu.
- Sekuyabonakala ukuthi uma uke waba nesifo sofuba (TB) ngaphambilini ungaba sengozini yomdlavuza wamaphaphu.
- Kunganzeka lomdlavuza ube wofuzo emndenini.

Vakashela isikhungo sezempilo esiseduze nawe!

Ungaphezu kweminyaka ewu-50 years Wake wabhema / usubhema ngaphezu kuka-10 years Usebenza / usebenze ezimayini isikhathi eside Usebenza / usebenze embonini yamakhemikhali Usukhwehlele ngaphezu kwamasonto amabili



Causes of Lung Cancer:

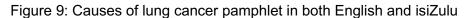
- Smoking is still the number one cause of lung cancer.
- Over two-thirds (66.7%) of lung cancer deaths worldwide are because of smoking.
- Any kind of smoking seems to increase the risk of lung cancer. Smoking cigarettes, cigars, and pipes, hookah, have all been linked to lung cancer.
- Smoking marijuana may also increase the risk of lung cancer, especially in young people.
- Second-hand smoke also increases the risk of lung cancer. It is estimated that more than 3,000 non-smoking adults die of lung cancer each year as a result of breathing second-hand smoke.
- HIV positive status is a risk factor for lung cancer.
- A previous history of tuberculosis is emerging as a risk factor for lung cancer.
- Lung cancer can run in families.

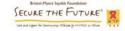
Visit a health facility near you!

Older than 50 years

Ex-smoker / Smoking for more than 10 years Working / worked in the mines for a long time Working / worked in the chemical industry for a long time

Coughing for more than 2 weeks





Ongakuzuza ngokuyeka ukubhema:

UNGAWUNQOBA UMDLAVUZA WAMAPHAPHU!

Emva kwemizuzu ewu-20 uyekile.	Inhliziyo iyehla ukushaya ngamandla.	20 minutes after quitt
Emva kwamahora awu-12.	Izinga lomoya ongcolile nentuthu emzimbeni liyehla.	After 12 hours.
2 wamaviki kuya 3 izinyanga.	Ukuphampa kwegazi nokusebenza kwamaphaphu kuyenyuka.	In 2 weeks to 3 month
1 kuya 9 wezinyanga.	Ukukhwehlela, nokun <mark>gamukelana</mark> komoya kuyehla. Iziboya ezincane emaphashini zigala zisebenza kahle, zisuse udoti emaphas <mark>hini.</mark>	In 1 to 9 months.
Emva konyaka uyekile.	Amathuba esifo senhliziyo ayahhafuleka kunalowo osabhemayo.	
Emva kweminyaka emihlanu.	Amathuba okuthola umdlavuza womlomo, umphimbo, kanye nesinye ahhafuleka phakathi. Amathuba womdlavuza wesibeletho ayafana nomuntu ongabhemi.	In 1 year after quitting
Emva kweminyaka eyishumi.	Amathuba okubulawa umdlavuza wamaphaphu awuhhafu womuntu osabhemayo,	CER CONTROL
Emva kweminyaka ewu-15	Amathuba esifo ayafana nawomuntu ongabhemi.	After 10 years
		After 15 years
KWAZULU-NATAL INYUVESI YAKWAZULU-NATAL	1	

The benefits of quitting smoking:

YOU CAN BEAT LUNG CANCER!

	Inhliziyo iyehla ukushaya ngamandla.	20 minutes after quitting.	Your heart rate and blood pressure drop.
	Izinga lomoya ongcolile nentuthu emzimbeni liyehla.	After 12 hours.	The carbon monoxide level in your blood drops to normal.
ga.	Ukuphampa kwegazi nokusebenza kwamaphaphu kuyenyuka.	In 2 weeks to 3 months.	Your circulation improves and your lung function increases.
	Ukukhwehlela, nokungamukelana komoya kuyehla. Iziboya ezincane emaphashini zigala zisebenza kahle, zisuse udoti emaphashini. Amathuba esifo senhliziyo ayahhafuleka kunalowo osabhemayo,	In 1 to 9 months.	Coughing and shortness of breath decrease. Tiny hair-like structures that move mucus out of the lungs (called cilia) start to regain normal function in your lungs, increasing their ability to handle mucus, clean the lungs, and reduce the risk of infection.
nu.	Amathuba okuthola umdlavuza womlomo, umphimbo, kanye nesinye ahhafuleka phakathi. Amathuba womdlavuza wesibeletho ayafana	In 1 year after quitting.	The excess risk of coronary heart disease is half that of someone who still smokes. Your heart attack risk drops dramatically.
ni.	nomuntu ongabhemi. Amathuba okubulawa umalavuza wamaphaphu awuhhafu womuntu	5 years after quitting.	Your risk of cancers of the mouth, throat, esophagus, and bladder is cut in half. Cervical cancer risk falls to that of
	osabhemayo.		a non-smoker. Your stroke risk can fall to that of a non-smoker after 2 to 5 years.
5	Amathuba esifo ayafana nawomuntu ongabhemi.	After 10 years	Your risk of dying from lung cancer is about half that of a person who is still smoking.
		After 15 years	Your risk of coronary heart disease is that of a non-smoker's.
NATALI			Bristich-Hyers Squide Poundation SECURE THE FUTURE*

Figure 10: Benefits of quitting smoking pamphlet in both English and isiZulu

Appendix 18: Training Manual of the Lung Cancer Awareness Intervention







Training Manual: Lung cancer

Manual for fieldworkers (including CCGs and support team)

Training Manual on Lung Cancer Awareness

This training manual is designed to assist Community Caregivers and support teams to help people who may have lung cancer. The aim is to support EARLY recognition of signs and symptoms of lung cancer, thus EARLY presentation at health facilities for further management and care.

Table of Contents				
	1.	Introduction		
	2.	Lung Cancer in South Africa		
	3.	Learn about LC		
	4.	LC Types		
	5.	How LC Affects the Body		
	6.	Lung Cancer Stages		
	7.	Symptoms of LC		
	8.	Causes of LC		
	9.	Risk Factors		
	10.	Complications		
	11.	Diagnosis		
	12.	Management and Treatment		
	13.	Suspected Lung Cancer: Recognition		
		Referral		
		Investigations		
	14.	Holistic Needs Assessment		
	15.	Treatment Options		
	16.	Patient Information and Support		
-	17.	Additional Resources		

PATIENT EDUCATION POINT:

Being referred to a specialist does not mean you have cancer. Few people who are referred to a specialist actually have cancer. However, it is important that you are checked soonest to find out. If you do have cancer, an early diagnosis can mean treatment is easier and more likely to be successful.

1. Introduction

Lung cancer is devastating: it takes more lives than breast, colon and prostate cancers COMBINED.

Lung cancer is unrelenting: In the US, 1 in every 14 people will be diagnosed with lung cancer; just 17.8% will live five years past their diagnosis.

Lung cancer takes the lives of almost twice as many American women as breast cancer and three times as many men as prostate cancer each year. Noone knows the South African figures – lung cancer is under-diagnosed and under-reported. It is predicted that lung cancer in South Africa is a much more serious problem than previously thought.

However, there is hope; more new treatments have been approved in the last decade than in the previous thirty years.

Lung cancer patients have high levels of anxiety due to the 'blame game' and the statistics they must cope with.

ANYONE can get lung cancer - and no one deserves it.

Simple awareness can lead to earlier diagnoses and lives saved.

Research funding for lung cancer per cancer death pales in comparison to private and public funding for other major cancers, which claim fewer lives each year. This lack of research funding has dramatically slowed the progress for developing effective screening and new treatments. • Research, awareness and advocacy have brought about improvements in screening, diagnostics and treatments for other cancers that have led to longer and better lives for patients. Together, we must do the same for lung cancer. Research investment saves lives and lung cancer is not fairly funded. • There are many promising areas of research that could lead to drastic improvements for lung cancer patients, but more funding is needed to support these efforts.

2. Lung Cancer in South Africa

Poor data exists about the true incidence of lung cancer in this country. There is a major gap in the understanding of risk factors, HIV, TB, smoking and occupational exposures. South Africa as a developing country has a population at high risk for developing lung cancer. Unfortunately, lung cancer is seldom looked for or diagnosed in our communities. Awareness of the disease in many communities is very low. The high prevalence of TB means other chronic lung diseases are often overlooked. Incidence and mortality rates for

lung cancer are rising, particularly among women. One of the main reasons is the acceleration in tobacco consumption and the spread of smoking among women. The main occupational risk in South Africa is exposure to mineral dust, silica, or asbestos (related mostly to the mining industry). There remains a high tobacco exposure burden in both males and females, with a forecast of a further increase in rates of lung cancer incidence and deaths. Control of respiratory carcinogens at work continues to be a problem, particularly in the present scenario of economic and political pressures in South Africa.

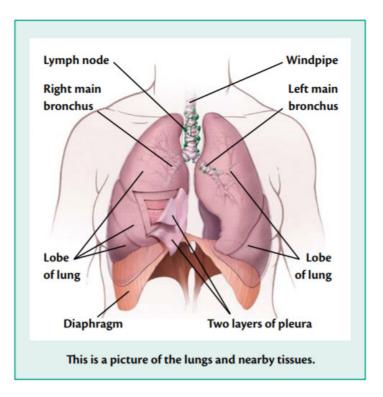
3. Learn about Lung Cancer

- The 5-year survival rate for people with stage IA NSCLC is 49%.
- For people with stage IB NSCLC, the 5-year survival rate is 45%.
- For stage IIA cancer, the 5-year survival rate is about 30%
- For stage IIB cancer, the survival rate is 31%
- The 5-year survival rate for stage IIIA NSCLC is 14%
- For stage IIIB survival rate is 5%
- Stage IV NSCLC, has a 5-year survival rate of 1% or less

4. LC Types

a. Primary lung Cancer:

Lung cancer typically starts in the lining of the bronchi (the main airways of the lungs), but can also begin in other areas of the respiratory system, including the trachea, bronchioles, or alveoli.



There are two main types of primary lung cancer:

• 1. Non-small Cell Lung Cancer (NSCLC)

Represents 80% to 90% of all lung cancer cases each year. These lung cancers include *adenocarcinoma*, the most common form of lung cancer; *squamous cell carcinoma*, which accounts for about 25% of non-small cell lung cancers; and *large cell carcinoma*, which accounts for the remaining 10% of non-small cell lung cancers.

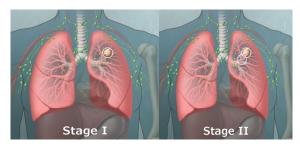
• 2. Small Cell Lung Cancer (SCLC)

Represents 10% to 20% of all lung cancer cases each year. Generally, small cell lung cancer tumours tend to grow more quickly than non-small cell lung cancer tumours, but they also tend to be more responsive to chemotherapy than NSCLC.

5. How LC Affects the Body

Lung cancer often has no symptoms until it has spread (metastasized). This is because there are few specialised nerves (pain receptors) in the lungs. When lung cancer symptoms do occur, they may vary, depending on the type of lung cancer and the location and size of the tumor. Some lung cancer symptoms are similar to those of other common illnesses. Treatment decisions are based on the *types* of cancer and *stage* of cancer. Staging lung cancer is critically important because the treatment chosen can be very different, depending on the stage. The patient's prognosis is impacted on by the stage type, and the stage of LC dictates the kind of treatment plan.

6. Lung Cancer Stages





The cancer is in one lung and the lymph nodes between the two lungs in the middle of the chest.

The term **Stage IIIA** usually describes lung cancer that has spread to lymph nodes on the same side of the chest as the cancer, or that may have spread to adjacent structures like the chest wall, esophagus, or heart.

Stage IIIB means that the cancer has spread from the lungs to the lymph nodes on the opposite side of the chest or above the collarbone.



Small Cell Lung Cancer has two stages:



Limited or Extensive **7. Symptoms of Lung Cancer**

- Early lung cancer usually does not cause noticeable symptoms. Unfortunately, many times it is discovered late, though even in these situations, there are often good options for treatment
- Sometimes lung cancer is discovered incidentally: on a chest x-ray, CT or CAT scan that is being performed for another reason, such as a respiratory infection.

Symptoms of lung cancer can affect the entire body:

Local disease

- Coughing (most common, 50% of cases)
- Blood in sputum (hemoptysis)
- Shortness of breath (dyspnea)
- Wheezing
- Pain in the chest
- Fatigue
- Pneumonia (especially if no response to antibiotics)

Locally advanced disease (cancer has spread from where it started to nearby tissue or lymph nodes)

- Hoarseness
- Difficulty or pain in swallowing (dysphagia)

- High-pitched sound, usually heard while taking a breath, similar to wheezing (stridor)
- Excess fluid in the lining of the lung (pleural effusion)
- Excess fluid in the lining of the heart (pericardial effusion)

Distant:

Brain

- Headaches
- Seizures
- Nausea
- Vomiting
- Weakness
- Confusion
- Visual disturbances

Bone

• Bone pain

Liver

- Stomach pain (right side)
- Yellowing of the skin and eyes (jaundice)
- Fatigue
- Weight loss
- Nausea

Cancer can also cause symptoms far from the tumour that may not be related to the cancer or spread. These include:

- lack of appetite, weight loss, weakness (cancer cachexia or wasting syndrome)
- clubbing of fingers
- too much calcium in the blood (hypercalcemia)
- low red blood cells (anaemia)



PATIENT EDUCATION POINT

Everyone coughs sometimes, but a cough that continues for more than 2 weeks – especially if it occurs with other symptoms, such as blood-tinged sputum and overall weakness – should raise a red flag.

Tuberculosis **always** needs to be looked for. Patients can have TB and lung cancer TOGETHER.

Anyone with a cough for more than two weeks needs first to be checked for TB (sputum GENE Xpert and TB culture).

If the patient has PTB, ensure that the patient is followed up six weeks later to ensure he/she is improving.

Ensure patients keep all their X-rays safely.

Comparisons of previous X-Rays are important for follow-up appointment.

Everybody coughs sometimes, but a cough that persists – especially if it accompanied by other signs, such as blood in the mucus or unexplained pain – should always be evaluated

LEARNING POINT

Red Alert Signs and Symptoms in these patients:

Once tuberculosis has been ruled out (sputum Genexpert and culture negative) OR PTB treated for at least six weeks without clinical or radiological improvement, then referral is considered if the patienhas any of the following

Patient has at least a 20-pack year smoking history (or other high-risk factors*); is between the age of

40 and 75 years AND:

- 1. Coughing up blood
 - a. Clubbing of the fingers (new)
- 2. Suspicious lymph nodes (head, neck, armpits)
- 3. Difficulty in swallowing
- 4. Unexplained changes in existing symptoms in patients with underlying chronic respiratory diseases

Any of the following unexplained signs or symptoms lasting more than two weeks:

- 5. Cough
- 6. Change in voice (hoarseness)
- 7. Weight loss or loss of appetite
- 8. Persistent shortness of breath
- 9. Chest or shoulder pain
- 10. Abnormal chest signs

Send these patients for an XRAY and review the XRAY within two weeks of having the XRAY



8. Causes of Lung Cancer

- Smoking is still the leading cause of lung cancer
- The American Cancer Society estimates that 80% to 85% of all lung cancer cases in the United States are related to smoking, which includes people who have quit smoking
- Any kind of smoking seems to increase the risk of lung cancer. Smoking cigarettes, cigars, pipes and hookah, have all been linked to lung cancer
- Smoking marijuana may also increase the risk of lung cancer, especially in young people
- Second-hand smoke also increases the risk of lung cancer. It is estimated that more than 3,000 non-smoking adults die of lung cancer each year as a result of breathing second-hand smoke.
- An HIV positive status is a risk factor for lung cancer
- A previous history of tuberculosis is emerging as a risk factor for lung cancer
- E-Cigarettes/Vaping E-cigarettes contain nicotine, and, like tobacco cigarettes lead to nicotine addiction. Some claim that inhaling e-cigarettes may be safer than tobacco smoking and that it may help smokers quit. Others believe that e-cigarettes may lead more young people to start smoking tobacco. No safety data exists,
- **Familial Cancers** lung cancer can run in families. Certain genetic mutations genes that work differently than their 'normal' versions are linked to lung cancer. People with those mutations may be more likely to get lung cancer than people who have the normal genes. Having one of these genes may be a reason why some non-smokers develop lung cancer.

Environmental and Occupational Exposures

- Exposure to **asbestos**, a mineral-based substance that was once used in insulation and building construction, may cause lung cancer, especially in smokers.
- **Silica** Silica is a mineral found in materials such as sand, stone, rock, concrete, and brick that is used in numerous industries, including construction, mining and manufacturing. There is a strong correlation between silica exposure and lung cancer
- Air pollution has also been linked to lung cancer.

9. Risk Factors

It is important to understand that the risk of developing lung cancer seems to be dosedependent: the more and the longer you smoke (more cigarettes, more years), the greater your risk. At least eight out of ten people who develop lung cancer are smokers. Research shows that quitting smoking at any time of your life decreases your risk of lung cancer.

A history of cancer in another part of the body. People with a history of head and neck cancer or esophageal cancer, both of which are also associated with tobacco use, are at higher risk for lung cancer.

People who have had cancer in a different part of the body, such as breast, colon, or prostate cancer, are at increased risk of having lung cancer.

Age. The risk of lung cancer increases with age. Only about 10% of lung cancer cases occur in people younger than fifty years of age.

Prior radiation therapy. Radiation is an important cancer treatment, but radiation to the chest area, especially for treatment of another cancer, seems to increase the risk of developing lung cancer.

Other lung diseases. Diseases such as chronic obstructive pulmonary disease (COPD), interstitial lung disease, and tuberculosis (TB) and HIV itself may increase lung cancer risk. In addition, scarring of the lungs, which emanated from other diseases, may set the stage for developing lung cancer.

LEARNING POINT is better

Having more than one risk factor increases your chances of developing lung cancer.

For instance, a smoker exposed to asbestos has about four times the risk of developing lung cancer than a smoker who has been exposed to asbestos, and eighty times the risk compared to someone who neither smoked nor was exposed to asbestos.

10. Complications

Most patients will experience one or more of these complications related to lung cancer.

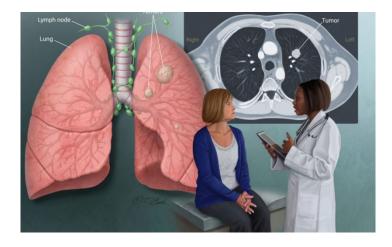
- a. Coughing up blood
- b. Pain
- c. Shortness of breath
- d. Change in voice

All of these complications can be relieved by appropriate medical care.

Certain complications are irreversible:

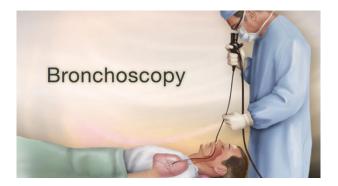
a. Stroke

11. Diagnosis



Specialised healthcare personnel conduct/perform tests to confirm the lung cancer diagnosis. In KwaZulu-Natal, these tests are done at Inkosi Albert Luthuli Central Hospital (IALCH) in Durban and Grey's Hospital in Pietermaritzburg. It is important that these tests are done as early as possible to increase the chances of diagnosing the disease early, whilst treatment is still effective. It is therefore recommended, that if a person exhibits the signs and symptoms together with the risk factors discussed above, they should go to the health facilities for help as soon as possible. If they are suspected to have lung cancer, they will be referred accordingly for further management and care.

NB: It is important for CCGs to encourage people that have the signs and symptoms together with the risk factors discussed earlier, to approach the health facilities for help. The CCGs will record the number of people encouraged to visit the health facilities and make follow- up appointments with them if they did go to the health facilities thereafter. They will also follow up on the outcome of the visit to the health facilities.



12. Management and Treatment

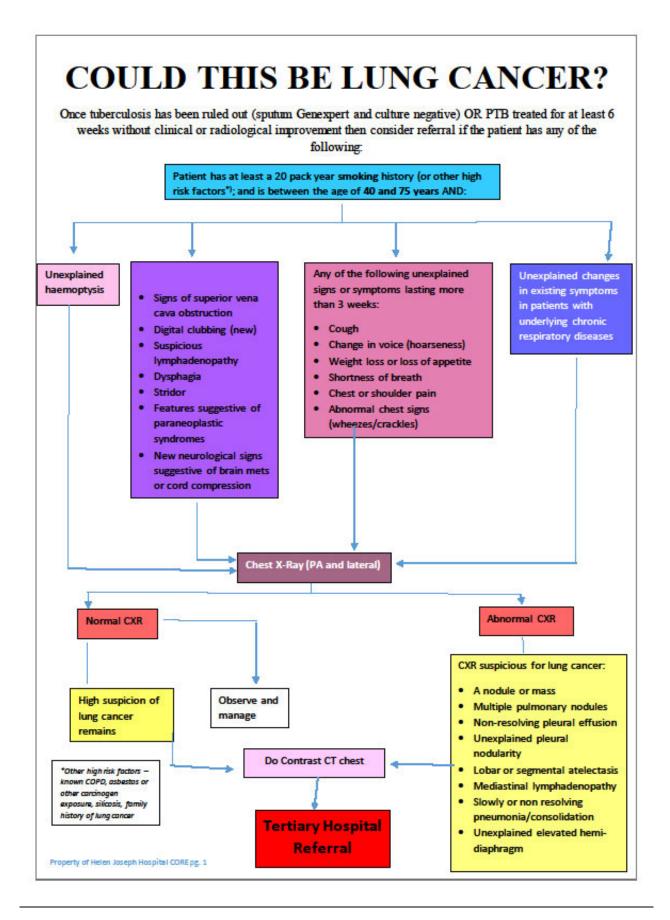
Lung cancer treatment depends on the type of lung cancer, the stage, and whether the cancer contains any biomarkers that indicate which treatment might work best. The patient's overall health and wishes need to be taken into account when planning treatment.

It is important to treat the patient holistically – ARV's if HIV positive, inhalers for COPD, etc. As CCG's, you are going to discuss with the community members if they need any of the above-mentioned items. Encourage them to visit the health facilities for help, should they need it. Be sure to make follow-up appointments.

Remind the community members that living with cancer is challenging, but they can overcome it if they work closely with the health care workers and follow the plan designed for them. Be kind to themselves, accept offers of help, and remain positive.

13. Suspected Lung Cancer:

Use the tool below to help the community members understand the process of diagnosing lung cancer.



Recognition (see above signs)

Patient needs a CXR either at a CHC or secondary level clinic and have it reviewed (can send tertiary doctor the CXR images) within two weeks of seeing the patient.

Referral

Explain to the community members how referrals are done in a timely manner and provide relevant and detailed information to the tertiary respiratory clinic (within two weeks of seeing the patient if possible).

- Provide the patient with the following information:
- 1) How the referrals work and where the patient will be referred to
- 2) <u>Who the patient will see</u>
- 3) What the patient can expect from the resp clinic
- 4) <u>The expected timeframes</u>
- Advise the patient to be in possession of all the current and previous X-rays (and CAT scan if done).
- Explain what happens to the sputum results, HIV results and any other tests when the patient goes for the next appointment.
- Advise the patient to stop smoking (See additional information).
- Ensure the patient's need for continuing support is addressed while awaiting the referral appointment.

Obtain the contact details and home address for follow-up visit.

Telephone or SMS the patient a reminder the day before the appointment.

The Tertiary Centres:

- Grey's Hospital Pietermaritzburg (PMB)
- Inkosi Albert Luthuli Central Hospital Durban
- Addington Hospital Durban

14. Holistic Needs Assessment

Explain to the patient that whatever the diagnosis turns out to be, the doctor will offer care and management for their problem and refer appropriately if need be. Doctors, social workers, dieticians, physiotherapists, spiritual counsellors, professional cancer nurses, palliative care nurses and their support team will provide a holistic needs assessment for the lung cancer patient.

15. Treatment Options

Depending on the type and stage of the cancer, different treatment options are available. These include curative surgery, chemotherapy and radiation.

Many different health care professionals play a role in lung cancer treatment. Some of them include:

- **Medical oncologists** are physicians who specialise in treating cancer. Often the medical oncologist is the key person who refers the patient to additional specialists, such as radiation oncologists (cancer doctors who administer radiation therapy) and surgical oncologists (cancer doctors who perform surgery). Lung cancer patients are encouraged to be seen by a thoracic oncologist, a cancer doctor with expertise in lung cancer.
- **Oncology nurses** are specially trained to administer cancer treatments such as chemotherapy, monitor side effects during treatment, and educate patients and families about the treatment and its side effects.
- **Oncology social workers** are trained to provide counselling and practical assistance to cancer patients. They can provide emotional support, assist in coping with the treatment and treatment side effects, help patients to communicate with their treatment team, and refer patients for disability grants for financial assistance.
- Palliative care specialist/Pain management specialists are physicians who have special training in managing side effects from the cancer and also in pain management.
- **Pathologists** are physicians who examine the lung cell tissue samples collected during a biopsy to determine if the patient has lung cancer, including the type and stage of the disease.
- **Physical therapists** help patients regain their strength and movement during and after treatment.

- **Psychologists** are mental health professionals who provide psychotherapy for people experiencing anxiety, depression, and other psychological illnesses
- Pulmonologists specialise in the diagnosis and treatment of lung disease. He or she can
 perform tests and biopsies, and treat patients who have respiratory issues related to lung
 cancer.
- Radiation oncologists are specialists who use radiation to treat cancer.
- Radiologists are physicians who utilise imaging and interpret follow-up CT, PET and MRI scans during and after treatment to monitor disease progression and response to treatment.
- **Registered dietitians** counsell patients to assist them in managing weight loss or gain or other nutritional issues.
- Thoracic surgeons perform chest surgery and may also have specialised training in surgical oncology—the use of surgery to remove cancerous tumours and tissues in and around the lung.

16. Patient Information and Support

Provide the person with information on the possible diagnosis (both benign and malignant) in accordance with their wishes for information and their understanding. Other information to provide patients and their support systems: where the person can be referred to

how long they will have to wait for the appointment

how to obtain further information about the cancer suspected (see patient handout)

what to expect from the service the person will be attending

what type of tests may be carried out, and what to expect during the diagnostic

procedures.

A social grant can be applied for (through the referring doctor) when the diagnosis is confirmed.

Smoking Cessation – Quit Smoking Help Line: 011-720 3145



Quit Smoking – 10 Tips:

- Decide on a date to quit smoking and do it.
- Throw away all reminders of smoking: cigarette packets, ashtrays, lighters. Drink lots of water it will help flush the nicotine from your body.
- Become more active exercise (i.e., walk, jog, gym).
- Change your routine. Avoid smokers and things that make you want to smoke for the first couple of days.
- Tell your family and friends that you are trying to quit so that they can offer you support.
- You may experience some dizziness, headaches or coughing once you have stopped smoking. This is normal and should improve after a day or two and disappear within fourteen days.
- The first two to three days are the most difficult, after that it becomes easier. Your cravings will reduce and eventually disappear.
- If you are worried about gaining weight, eat at regular times during the day. Snack on fruit between meals. Take time to exercise. Not all ex-smokers gain weight.
- Do not use a crisis or special occasion as an excuse for 'just one' cigarette. One cigarette leads to another and another.

CANSA Support lines:

6 0800 22 6622

© 072 197 9305 English and Afrikaans O71 867 3530

info@cansa.org.za

Xhosa, Zulu, Sotho and Siswati

What you need to know about

5 Key Facts

- · Lung cancer is a leading cause of cancer deaths in men and women worldwide
- · Smoking counts for the majority of preventable lung cancers
- Lung cancer is more common in men. (As more women have started smoking, the number of women developing lung cancer has increased)
- People who don't smoke can also develop lung cancer
- Survival rates for people diagnosed with lung cancer are low. People diagnosed at earliest stages have the greatest chances for recovery

Signs and symptoms of Lung Cancer

- · A new cough that doesn't go away
 - · Changes in a chronic cough or 'smoker's cough'
 - A cough that gets worse or does not go away
 - Coughing up blood, even a small amount
 - Shortness of breath or wheezing
 - Constant chest pain especially . when coughing
 - Frequent chest infections
 - Wheezing/hoarseness
 - Swelling of the neck and face Fatigue (feeling very tired all the
 - time) Loss of appetitite/losing weight without
 - trying

Need help quitting Visit the CANSA website for info

on our e-Kick Butt programme or

lick Butt

with

CANSA

call us toll-free

- Bone pain
- Headache

Manage your risk IOF Cancer

- Quitting smoking at any time can lower risk
- Exposure to second hand smoke increases the risk in non-smokers two to three fold
- Healthy diet and moderate physical activity play a role in lowering risk
- Exposure to asbestos increases risk, and combined with smoking the risk is greatly increased



- Chemicals used in industry and around homes may increase risk. Labels on home products such as wood stripper, and Material Safety Data Sheets provide information on safe exposure and proper masks to use Exposure to radon in the house is the second leading cause of lung cancer
- overall, and the number one cause in non-smokers. (Radon is an invisible radioactive gas that results from the normal decay of radium in the soil)

f 🕒 👂 📖 🖸



Toll-free 0800 22 66 22 www.cansa.org.za

Research • Educate • Support

Izinto ezinhlanu ezisemqoka

- Umdlavuza wamaphaphu uwona ohamba phambili ekubulaleni abantu besilisa nabesifazane emhlabeni wonke
- Ukubhema ugwayi ikona okuhamba phambili ekudaleni umdlavuza wamaphaphu okungavimbeka
- Umdlavuza wamaphaphu ujwayeleke kakhulu kwabesilisa. (Njengoba sebe baningi abesifazane ababhemayo, isibalo sabantu besifazane abathola lomdlavuza siyanda).
- Abantu abangabhemi bangawuthola umdlavuza wamaphaphu
- Isibalo sabantu abasinda kulomdlavuza sincane. Abantu abasheshe batholakale ukuthi banomdlavuza wamaphaphu basemathubeni angcono okusinda

Izinkomba nezimpawu zomdlavuza wamaphaphu

- Ukuqala kokukhwehlela okuyimbelesela (okungapheli)
- Izinguquko ekukhwehleleni okungapheli noma ukukhwehlela komuntu obhemayo
- Ukukhwehlela okuqhubekayo noma okungapheli
- Ukukhwehlela igazi, noma ngabe lincane
- Ukuphelelwa (ukunqanyukelwa) umoya noma ukunswininiza kwesifuba
- Ubuhlungu obungapheli esifubeni ikakhulukazi uma ukhwehlela
- Izifo zesifuba ezithelelanayo ezibuya njalo
- Ukuhoshozela kwezwi
- Ukuvuvukala kwentamo nobuso
- Ukuzizwa ukhathele ngasosonke isikhathi
- Ukungakuthandi ukudla / ukuncipha emzimbeni ngaphandle kokuzama
- Ubuhlungu bamathambo
- Ukuphathwa ikhanda

Yehlisa amathuba akho okuthola umdlavuza wamaphaphu

- Ukuyeka ukubhema nganoma isiphi isikhathi kunciphisa amathuba okuba sengcupheni yomdlavuza wamaphaphu
- Ukuhogela intuthu kagwayi komuntu ongabhemi kwenyusa ubungozi bomdlavuza wamaphaphu ngokuphindwe kabili noma kathathu
- Ukudla ukudla okunempilo nokuzivocavoca kunendima okuyidlalayo ekunciphiseni amathuba okuba sengcupheni yomdlavuza wamaphaphu
- Ubhestazi (itshe-boya) wenyusa amathuba okuthola lomdlavuza, kanti uma kuhlanganiswa nokubhema ubungozi balomdlavuza buphindaphindiwe
- Amakhemikhali asetshenziswa ezinkompolo nasemakhaya angalinyusa ithuba lokuba sengcupheni. Amalebuli abekwa emkhiqizweni yasekhaya anikeza ulwazi ngokuthi kumele lemikhiqizo isetshenziswe kanjani ngendlela ephephile.

UNGAWUNQOBA UMDLAVUZA WAMAPHAPHU!

17. Additional Resources:

Steps to follow in the Awareness programme

Your dress code should be that of a professional. Wear your branded T-shirt and name tag appropriately and visibly.

Be prepared and have your materials (pamphlets) ready.

STEP 1 – IDENTIFY THE HOUSEHOLD

- Introduce yourselves
- Introduce the purpose of your visit
- Ask if you could be invited in

STEP 2 – ESTABLISH WHETHER PEOPLE IN THE HOUSEHOLD HAVE TIME

- It is important not to rush through. You must have enough time with the household.
- If they do not have time at the moment, make an APPOINTMENT to return later.
- Give them an estimation of how long the awareness discussion is going to take (~ 30 min).

STEP 3 – ESTABLISH WHAT THEY KNOW ABOUT LUNG CANCER

- Ask if they have heard of lung cancer before.
- Ask if they have questions about lung cancer.
- You want to be responsive to their needs (fill the gaps in their knowledge/understanding).

STEP 4 – HAVE A CONVERSATION WITH THE MEMBERS OF THE HOUSEHOLD

- You are building a relationship with the household members (RAPPORT and trust).
- Your conversation must be factual (Refer to your notes).
- Hand out pamphlets.
- DO NOT be afraid to admit that you are not sure of something, and that you will confirm and get back to them. Make a note of it.
- The conversation about smoking is important at this point (**pamphlets on tips on quitting smoking and the benefits of quitting smoking should be given**).

STEP 5 – IDENTIFY POTENTIAL PATIENTS (PEOPLE AT RISK)

- This is based on the signs and symptoms (Record on the Outreach tool Tablets).
- Emphasise to the household members that this discussion will be kept **confidential** and what you have discussed with them will not leave the household. However, you will record some details for follow-up purposes.
- Encourage those who are at risk to visit a health facility near them for screening and diagnosis.

STEP 6 – DIAGNOSIS PROCESS

- Explain to the household the steps that are involved in reaching a diagnosis (Sputum/GeneXpert, X-ray, CT scan, Biopsy (Confirmation and Staging).
- They may have reservations/anxiety about health facilities. Helping them to understand the process may relieve that stress.

STEP 7 – SET UP A FOLLOW-UP APPOINTMENT

- Make sure to set up a follow-up visit with those who have been encouraged/advised to go to the health facility.
- You want to find out whether they actually did go to the health facility and whether they were cleared of lung health problems (**outcome**).
- This also brings closure.

Appendix 19: Interview Guide for Post-Training Focus Group Discussions

- 1. What are your impressions of the level of detail the training presented?
 - a. How did you find the language used?
 - b. What about the terminology? used?
 - c. How simple was it to understand?
- 2. How were your interactions with the facilitator(s)?
 - a. How approachable were they?
 - b. Can you comment on their facilitating style(s)?
- 3. Please comment on the areas that you felt satisfied with.
- 4. Please comment on the areas that you felt you needed more information.
- 5. What could be improved on regarding the training?
 - a. What would you do better?
 - b. How would you do things differently? a and b will elicit similar responses
- 6. Tell me about your confidence in using this information to raise awareness in the community.

Appendix 20: Guidelines for Authors | Journal of Public Health in Africa

Guidelines for Authors

Manuscript will be carefully scrutinized for evidence of plagiarism, duplication and data manipulation; in particular, images will be carefully examined for any indication of intentional improper modification.

Any suspected misconduct ends up with a quick rejection and is then reported to the US Office of Research Integrity.

Ensure that your work is written in **correct English before submission. Professional copyediting** can help authors improve the presentation of their work and increase its chances of being taken on by a publisher. In

case you feel that your manuscript would benefit from a professional a professional English language

copyediting checking language grammar and style, you can find a reliable revision service at:



The Corresponding Author must submit the manuscript online-only through our Manuscript Submission

System.

Authors are kindly invited to suggest potential reviewers (names, affiliations and email addresses) for their manuscript, if they wish.

Manuscript preparation

Title Page (first and second pages of manuscript file). REQUIRED for all submissions.

The first page must contain:

- I. title (lowercase), without acronyms;
- II. first name and family name of each author, separated by commas;
- III. affiliation(s) of each author (in English);
- IV. acknowledgments;
- V. full name and full postal address of the corresponding author. Phone, fax number and email addressfor the correspondence should also be included;
- VI. three to five key words.

The second page should contain:

- I. authors' contributions, e.g., information about the contributions of each person named as havingparticipated in the study (http://www.icmje.org/#author);
- II. disclosures about potential conflict of interests;
- III. further information (e.g., funding, conference presentation ...).

Tables and Figures

If *tables* are used, they should be presented each on a separate page at the end of the manuscript after the references. They must be numbered in the order they are cited in the text of the manuscript; each must be cited in the main text.

If *figures* are used, they must be submitted as **.tiff** or **.jpg** files, with the following digital resolution:

- I. color (saved as CMYK): minimum 300 dpi;
- II. black and white/grays: minimum 600 dpi;
- III. one column width (8.5 cm) or 2 column widths (17.5 cm).

A different caption for each figure must be provided at the end of the manuscript, not included in the figure file.

Authors must obtain **written permission** for the reproduction and adaptation of material which has already been published. A copy of the written permission has to be provided before publication (otherwise the paper cannot be published) and appropriately cited in the figure caption. The procedure for requesting the permission is the responsibility of the Authors;

PAGEPress will not refund any costs incurred in obtaining permission. Alternatively, it is advisable to use materials from other (free) sources.

Other

If abbreviations are used in the text, authors are required to write full name+abbreviation in brackets [e.g. Multiple Myeloma (MM)] the first time they are used, then only abbreviations can be written (apart from titles; in this case authors have to write always the full name).

If *names of equipment or substances* are mentioned in the text, brand, company names and locations (city and state) for equipment and substances should be included in parentheses within the text.

Ethical considerations

JPHIA requires the following two components related to ethical conduct of research:

1. Ethical Considerations section in main text. An Ethical Considerations sub-section is **REQUIRED in the methods section** for all studies involving human or animal subjects. Authors must include the following:

1) name of Institutional Review Board or ethics committee or institution that reviewed the study,

- 2) study approval number (or statement that a waiver was granted),
- 3) manner (oral, written) in which consent was obtained from participants, and

4) methods used to protect data and confidentiality of participants.

For Original articles and Brief Reports that did not require ethical review or approval, authors must provide a justification or statement in the Ethical Considerations section.

2. Clearance documentation. For studies that involve human or animal subjects, authors must upload a copy of the approval letter, certificate or waiver from their IRB or ethics committee as a supplementary file.

Journal Sections

The **manuscript file for all article types must contain the following required elements:** a title page, abstract, main text, references, acknowledgements, tables and figures, in that order. Manuscript files must be 1.5 or 2.0 spaced.

DO NOT format the text of the abstract, main text and references in multiple columns.

DO NOT submit required elements as separate files.

Formatting

Manuscripts must be formatted according to the instructions below.

Original Articles

Original articles are full reports of results from original research. They provide an overview of innovative research in a particular field with or related to the focus and scope of the journal.

<u>Abstract</u>: Maximum 250 words. Must be structured using the headings: *Background, Objective, Methods, Results, Conclusion.*

<u>Main text</u>: Maximum 3500 words. Must be stuctured using the headings below.

First-level headings: Introduction, Materials and Methods, Results, Discussion, Conclusion.

NOTE: The *Results* and *Discussion* sections <u>must</u> be presented as <u>separate sections</u>; do not submit manuscripts with the Results and Discussion combined into a single section.

Second-level headings:

The *Materials and Methods* section must contain an *Ethical Considerations* section presented as its first sub-section. See **Ethical Considerations** section above for detailed requirements.

The *Discussion* must include a *Limitations* section presented as its last section <u>References</u>: Approximately 30.

Tables/Figures: Maximum 5 total.

Reviews

Review articles provide an in-depth exploration of recent developments in any field related to public health. All funding, writing assistance, and/or other relationships to possibly conflicted sources must be fully disclosed at the time of submission.

Systematic reviews:

<u>Abstract</u>: Maximum 250 words. Must be structured using the headings *Introduction, Objective, Methods, Results, Conclusion.*

<u>Main text</u>: Maximum 4000 words. Must be structured using the headings: *Introduction, Methods, Results, Discussion, Conclusion.* The Methods section must clearly describe the search strategy (keywords, inclusion/exclusion criteria, search engines used, etc.)

Narrative reviews:

<u>Abstract</u>: Maximum 250 words. May be unstructured.

Main text: Maximum 4000 words. Required headings:

Introduction. Provide background to put the report in context and define the aim of the study.

Methods. Briefly (about 1 paragraph) discuss the search terms and documents used for the review.

Topical headings. Other headings as determined by the authors should be used to designate major topics and serve as a guide for readers.

References: Minimum 40.

Tables/Figures: Maximum 5 total.

Public Health Pictures

Public Health Picture articles showcase experience and perspectives (rather than research) on knowledge, practices, technological concepts and/or developments related to public health in Africa and other limited-resource settings.

<u>Abstract</u>: Maximum 250 words. May be structured using topic-appropriate headings or unstructured.

Main text: Maximum 3500 words. Required headings:

Introduction. Provide history, background, and/or context for readers to understand the context

Topical headings. Other headings as determined by the authors should be used to designate major topics and serve as a guide for readers.

Conclusion. Summarize the main 'take home messages' from the experience or perspective being reported.

<u>References</u>: Approximately 20. <u>Tables/Figures</u>: Maximum 5 total.

Brief Reports

Brief Reports must provide conclusive findings: preliminary observations or incomplete findings cannot be considered for publication.

<u>Abstract</u>: Maximum 150 words. Must be unstructured and focus on the objective or aim of the study, most important results and conclusion.

<u>Main text</u>: Maximum 2000 words. Must be structured using the headings below First-level headings: *Background, Methods, Results, Discussion, Conclusion*. Second-level headings:

The Methods section must contain an *Ethical Considerations* section presented as its first sub-section. See **Ethical Considerations** section above for detailed requirements.

The *Discussion* must include a *Limitations* section presented as its last section

<u>References</u>: Approximately 20.

Tables/Figures: Maximum 2 total.

Case Reports

Case Reports describe observations on clinical cases that can be educational, including adverse effects of drugs or outcomes of a specific treatment.

<u>Abstract</u>: Maximum 150 words. Must be structured using the headings: *Introduction, Case Presentation, Management and Outcomes, Conclusion.*

<u>Main text</u>: Maximum 2000 words. Must be structured using the headings below First-level headings: *Introduction, Case Presentation, Management and Outcomes, Conclusion.*

Second-level headings: The *Case Presentation* section must contain an *Ethical Considerations* section presented as its first sub-section. See 'Permission to

publish' below and **Ethical Considerations** section above for detailed requirements.

<u>References</u>: approximately 20.

Tables/Figures: Maximum 3 total.

<u>Permission to publish</u>: Must have been obtained from patients, parents or guardians (for children), and/or next of kin (for deceased patients). This must be stated in the Ethical Considerations section. Authors must upload a copy of the signed permission form as a supplementary file.

Letters to the Editor

Letters to the Editor are short essays that express the authors' viewpoint, may respond to published manuscripts in our journals, or deliver information or news regarding an issue related to the Journal scope. If the letter relates to a published manuscript, the authors of the original manuscript will be given the opportunity to provide a response. Authors of Letters to the Editor should provide a short title.

<u>Abstract</u>: None. Letters do not have abstracts <u>Main text</u>: Maximum 1500 words. Topical headings are not generally expected, but may be included if helpful for readers. <u>References</u>: Approximately 20. <u>Tables/Figures</u>: Maximum 1 total

Opinion

Opinion articles off er short pieces or personal perspectives (not research) on knowledge, practices, technological concepts and/or developments that highlight recent, exciting research or policy developments related to any aspect of public health.

Abstract: None. Opinion articles do not have abstracts.

<u>Main text</u>: Maximum 2000 words. Topical headings should be used to help guide readers. <u>References</u>: Approximately 15.

Tables/Figures: Maximum 2 total.

For further details on the specific layout to follow for the different types of papers published by the Journal, please refer to the **Section Policies**.

References

References should be prepared strictly according to the Vancouver style. References must be numbered consecutively in the order in which they are first cited in the text (not alphabetical order), and they must be identified in the text by Arabic numerals in superscript. References in the main text must always be cited after dots and commas. References to personal communications and unpublished data should be incorporated in the text and not placed under the numbered references [Example: (Wright 2011, unpublished data) or (Wright2011, personal communication)]. Where available, URLs for the references should be provided directly within the MS-Word document. References in the References section must be prepared as follows:

- I. more than three authors, cite 3 authors, et al. If the paper has only 4 authors, cite all authors;
- II. title style: sentence case; please use a capital letter only for the first word of the title;
- III. journal titles mentioned in the References list should be abbreviated according to the following websites:
 - a. ISI Journal Abbreviations Index (http://library.caltech.edu/reference/abbreviations);
 - b. Biological Journals and Abbreviations (http://home.ncifcrf.gov/research/bja);
 - c. Medline List of Journal Titles (ftp://ft p.ncbi.nih.gov/pubmed/J_Medline.txt);
- IV. put year aft er the journal name;
- V. never put month and day in the last part of the references;
- VI. cite only the volume (not the issue in brackets);

VII.pages have to be abbreviated, e.g., 351-8.

To ensure the correct citation format, please check your references in the PubMed database (http://www.ncbi.nlm.nih.gov/pubmed).

Examples:

Standard journal article

Halpern SD, Ubel PA, Caplan AL. Solid-organ transplantation in HIV-infected patients. N Engl J Med 2002;347:284-7.

<u>Proceedings</u>

Christensen S, Oppacher F. An analysis of Koza's computational effort statistic for genetic programming. In: Foster JA, Lutton E, Miller J, Ryan C, Tettamanzi AG, eds. Genetic programming. EuroGP 2002: Proceedings of the 5th European Conference on Genetic Programming, 2002 Apr 3-5, Kinsdale, Ireland. Berlin: Springer;2002. pp 182-91.

Article with organization as author

Diabetes Prevention Program Research Group. Hypertension, insulin, and proinsulin in participants with impaired glucose tolerance. Hypertension 2002;40:679-86.

<u>Books</u>

Murray PR, Rosenthal KS, Kobayashi GS, Pfaller MA. Medical microbiology. 4th ed. St. Louis, MO: Mosby; 2002.

Bjørn Lomborg, ed. RethinkHIV - Smarter ways to invest in ending HIV in Sub-Saharan Africa. Cambridge: Cambridge University Press; 2012. Meltzer PS, Kallioniemi A, Trent JM. Chromosome alterations in human solid tumors. In: Vogelstein B, KinzlerKW, eds. The genetic basis of human cancer. New York, NY: McGraw-Hill; 2002. pp 93-113.

Peer-review policy

All manuscripts submitted to our journal are critically assessed by external and/or in-house experts in accordance with the principles of peer review (http://www.icmje.org/#peer), which is fundamental to the scientific publication process and the dissemination of sound science. Each paper is first assigned by the editors to an appropriate Associate Editor who has knowledge of the field discussed in the manuscript. The first step of manuscript selection takes place entirely in-house and has two major objectives: i) to establish the article appropriateness for our journals readership; ii) to define the manuscript priority ranking relative to other manuscripts under consideration, since the number of papers that the journal receives is much greater than it can publish. If a manuscript does not receive a sufficiently high priority score to warrant publication, the editors will proceed to a quick rejection. The remaining articles are reviewed by at least two different external referees (second step or classical peer review). Manuscripts should be prepared according to the Uniform Requirements established by the International Committee of Medical Journal Editors (ICMJE)(http://www.icmje.org/#prepare).

Authorship

All persons designated as authors should qualify for authorship according to the ICMJE criteria. Each author should have participated sufficiently in the work to take public responsibility for the content. Authorship credit should only be based on substantial contributions to i) conception and design, or analysis and interpretation of data; and to ii) drafting the article or revising it critically for important intellectual content; and on iii) final approval of the version to be published. These three conditions must all be met. **Participation solely in the acquisition of funding or the collection of data does not justify authorship. General supervision of the research group is not sufficient for authorship.** Any part of an article critical to its main conclusions must be the responsibility of at least one author. Authors should provide a brief description of their individual contributions.

Obligation to Register Clinical Trials (http://www.icmje.org/#clin_trials)

The ICMJE believes that it is important to foster a comprehensive, publicly available database of clinical trials. The ICMJE defines a clinical trial as any research project that prospectively assigns human subjects to intervention or concurrent comparison or control groups to study the cause-and-effect relationship between a medical intervention and a health outcome. Medical interventions include drugs, surgical procedures, devices, behavioral treatments, process-of-care changes, etc. Our journals require, as a condition of consideration for publication, registration in a public trials registry. The journal considers a trial for publication only if it has been registered before the enrollment of the first patient. The journal does not advocate one particular registry,

but requires authors to register their trial in a registry that meets several criteria. The registry must be accessible to the public at no charge. It must be open to all prospective registrants and managed by a non-profit organization. There must be a mechanism to ensure the validity of the registration data, and the registry should be electronically searchable. An acceptable registry must include a minimum of data elements (http://www.icmje.org/#clin_trials). For example, ClinicalTrials.gov (http://www.clinicaltrials.gov), sponsored by the United States National Library of Medicine, meets these requirements.

Protection of Human Subjects and Animals in Research

When reporting experiments on human subjects, authors should indicate whether the procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2013 (https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects). If doubt exists whether the research was conducted in accordance with the Helsinki Declaration, the authors must explain the rationale for their approach and demonstrate that the institutional review body explicitly approved the doubtful aspects of the study. When reporting experiments on animals, authors should indicate whether institutional and national standards for the care and use of laboratory animals were followed. Further guidance on animal research ethics is available from the World Medical Association (2016 revision, https://www.wma.net/policies-post/wma-statement-on-animal-use-in-biomedical-research) and from the International Association of Veterinary Editors' Consensus Author Guidelines on Animal Ethics and Welfare

(http://www.veteditors.org/consensus-author-guidelines-on-animal-ethics-and-welfare-foreditors). When reporting experiments on ecosystems involving non-native species, Authors are bound to ensure compliance with the institutional and national guide for the preservation of native biodiversity.

Journal of Public Health in Africa

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eISSN 2038-9930

Appendix 21: Instructions to Authors – African Journal of Primary Health Care and

Family Medicine

Overview

The author guidelines include information about the types of articles received for publication and preparing a manuscript for submission. Other relevant information about the journal's policies and the reviewing process can be found under the about section. The **compulsory cover letter** forms part of a submission and must be submitted together with all the required **forms**. All forms need to be completed in English.

Editorials

Editorials are by invitation only and are intended to provide expert comment on relevant topics within the focus and scope of the journal.

Word limit	800 words
References	10 or less

Country Profiles

Country Profiles are by invitation only and are intended to provide expert insight on the state of family medicine and primary health care training in selected African countries.

Word limit	800 words
References	10 or less

Book Reviews

Book reviews are brief articles providing insights or opinions on new books within the research field of the journal. Please contact the editor if you would like to suggest a book for review.

Word limit 1000 words

Scientific Letters

A presentation of original research where the scope of the work does not justify a full research article, but the findings have a social and scientific value. The letter should follow the usual format for a research article – introduction, aim, methods, results, discussion and conclusion. Scientific letters will be subject to peer review and will require ethical clearance. The editor may on occasion suggest that an original research article be presented as a scientific latter.

Word limit	800-1500 words (excluding the structured abstract and references)
Structured abstract	250 words
References	20 or less
Tables/Figures	no more than 2 Tables/Figure

Conference Reports

The publication of conference reports are arranged with the Editor-in-Chief.

Word limit	1500 words
References	6 or less
Tables/Figures	no more than 1 Table/Figure

Opinion Papers

Short opinion pieces or personal perspectives (not research papers) personal viewpoint on family medicine and primary health care research that provides a contextual and holistic view of family medicine as practiced across the continent. With rare exceptions, these essays are meant to express a personal viewpoint and should have no more than two authors.

Word limit	2000 words (excluding the structured abstract and references)
Structured abstract	250 words
References	15 or less
Tables/Figures	no more than 2 Tables/Figure
Ethical statement	should be included in the manuscript, if applicable

Short Reports

A discussion on a particular topic, whereby the authors share innovations and best practices in terms of a particular aspect of family medicine and primary health care studies in their region.

Word limit	800-1000 words (including the structured abstract and references)
Unstructured abstract	250 words to cover a Background, Experience/Innovation, Learning/Reflection and Conclusion
References	20 or less
Tables/Figures	no more than 1 Table/Figure

Original Research Articles

An original research article presents innovative research within the focus and scope of the journal, according to a clear and well-structured format. Detailed instructions are given below on the structure and contents required. The introduction should argue for the social and scientific value of the research and end with the aim and objectives of the study. Any conceptual or theoretical framework can also be included in the introduction. The methods section should be structured according to the following sub-headings: study design, setting, study population and sampling strategy, intervention (if appropriate), data collection, and data analysis. Occasionally a different structure may be required, for example, in quality improvement or participatory action research. The methods should be followed by a section on ethical considerations. After this, the results are presented. The article should end with a discussion section that summarises the key findings, and then discusses these findings, the strengths and limitations of the study, and any implications or recommendations. This should be followed by a conclusion, acknowledgements and references sections.

Word limit	3500-7000 words (excluding the structured abstract and references)
Structured abstract	250 words to cover a Background, Aim, Setting, Methods, Results and Conclusion
References	60 or less
Tables/Figures	no more than 7 Tables/Figure
Ethical statement	should be included in the manuscript
Compulsory supplementary file	ethical clearance letter/certificate
Language	only manuscripts presented in English or French will be considered

Obituaries

Is a news article that reports the recent passing of a person, typically along with an account of the person's work achievement and life.

Word limit	400 words
Photo	a photograph of the deceased

Review Articles

These must be critical reviews of the literature on topics that have social and scientific value and must be within the focus and scope of the journal. Reviews should follow a structured approach as for a systematic or scoping review and outline a clear review question(s), search strategy, selection of articles, extraction and analysis of data. Reviews should not be personal and selective reviews of the literature. They are equivalent to original research articles, but usually without a need for ethical clearance, and will be subject to peer review.

Word limit	3500-7000 words (excluding the structured abstract and references)
Structured abstract	250 words to cover a Background, Aim, Method, Results and Conclusion
References	60 or less (more can be considered by the editor if necessary for the review)
Tables/Figures	no more than 7 Tables/Figure
Ethical statement	should be included in the manuscript, if applicable
Language	only manuscripts presented in English or French will be considered

Correspondence

They may be subjected to the peer-review process and their eventual placement is at the discretion of the editorial team. Kindly include a correspondence address.

Word limit	400 words (excluding the references)
Abstract	n/a
References	10 or less
Tables/Figures	no more than 1 Table/Figure

Patient studies

A detailed account of a specific patient as a case study. The patient study should highlight a critical issue that is relevant to the field of family medicine and primary care.

Word limit	800 words (excluding the unstructured abstract and references)
Unstructured abstract	250 words to cover a Background, Aim, Method, Results and Conclusion
References	20 or less
Tables/Figures	no more than 1 Table/Figure
Ethical statement	should be included in the manuscript
Compulsory supplementary file	proof of written informed consent from the patient

Corrections

A correction provides the platform to communicate important, scientifically relevant errors or missing information in a published article. Any changes after publication that affect the scientific interpretation (e.g., changes to a misleading portion of an otherwise reliable publication, an error in a figure, error in data that does not affect conclusions or addition of missing details about a method) are announced using a Correction. Read our submission procedure for <u>corrections</u> and <u>publishing policies</u>.

Compulsory title	The title of the submission should have the following format: 'Corrigendum: Title of original article'.
Submission File	completed Correction Submission Form (required)
Compulsory supplementary file	any supporting documents or emails, <u>Author Change Request</u> Form (if applicable), <u>Corresponding Author Change Request</u> Form (if applicable)

Cover Letter

The authorship, disclosure statements, copyright, and license agreement form is our compulsory cover letter which needs to form part of your submission. Kindly download and complete, in English, the provided <u>form</u>.

Anyone that has made a significant contribution to the research and the paper must be listed as an author in your cover letter. Contributions that fall short of meeting the criteria as stipulated in our policy should rather be mentioned in the 'Acknowledgements' section of the manuscript. Read our **authorship** guidelines and **author contribution** statement policies. Original Research Article full structure

Title: The article's full title should contain a maximum of 95 characters (including spaces).

Abstract: The abstract, written in English, should be no longer than 250 words and must be written in the past tense. The abstract should give a succinct account of the objectives, methods, results and significance of the matter. The structured abstract for an Original Research article should consist of six paragraphs labelled Background, Aim, Setting, Methods, Results and Conclusion.

- Background: Summarise the social value (importance, relevance) and scientific value (knowledge gap) that your study addresses.
- Aim: State the overall aim of the study.
- Setting: State the setting for the study.
- Methods: Clearly express the basic design of the study, and name or briefly describe the methods used without going into excessive detail.
- Results: State the main findings.
- Conclusion: State your conclusion and any key implications or recommendations.

Do not cite references and do not use abbreviations excessively in the abstract.

Introduction: The introduction must contain your argument for the social and scientific value of the study, as well as the aim and objectives:

- Social value: The first part of the introduction should make a clear and logical argument for the importance or relevance of the study. Your argument should be supported by the use of evidence from the literature.
- Scientific value: The second part of the introduction should make a clear and logical argument for the originality of the study. This should include a summary of what is already known about the research question or specific topic and should clarify the knowledge gap that this study will address. Your argument should be supported by the use of evidence from the literature.
- Conceptual framework: In some research articles it will also be important to describe the underlying theoretical basis for the research and how these theories are linked together in a conceptual framework. The theoretical evidence used to construct the conceptual framework should be referenced from the literature.
- Aim and objectives: The introduction should conclude with a clear summary of the aim and objectives of this study.

Research methods and design: This must address the following:

- Study design: An outline of the type of study design.
- Setting: A description of the setting for the study; for example, the type of community from which the participants came or the nature of the health system and services in which the study is conducted.

- Study population and sampling strategy: Describe the study population and any inclusion or exclusion criteria. Describe the intended sample size and your sample size calculation or justification. Describe the sampling strategy used. Describe in practical terms how this was implemented.
- Intervention (if appropriate): If there were intervention and comparison groups, describe the intervention in detail and what happened to the comparison groups.
- Data collection: Define the data collection tools that were used and their validity. Describe in practical terms how data were collected and any key issues involved, e.g. language barriers.
- Data analysis: Describe how data were captured, checked and cleaned. Describe the analysis process, for example, the statistical tests used or steps followed in qualitative data analysis.
 Ethical considerations: Approval must have been obtained for all studies from the author's institution or other relevant ethics committee and the institution's name and permit numbers should be stated here.

Results: Present the results of your study in a logical sequence that addresses the aim and objectives of your study. Use tables and figures as required to present your findings. Use quotations as required to establish your interpretation of qualitative data. All units should conform to the <u>SI convention</u> and be abbreviated accordingly. Metric units and their international symbols are used throughout, as is the decimal point (not the decimal comma).

Discussion: The discussion section should address the following four elements:

- Key findings: Summarise the key findings without reiterating details of the results.
- Discussion of key findings: Explain how the key findings relate to previous research or to existing knowledge, practice or policy.
- Strengths and limitations: Describe the strengths and limitations of your methods and what the reader should take into account when interpreting your results.
- Implications or recommendations: State the implications of your study or recommendations for future research (questions that remain unanswered), policy or practice. Make sure that the recommendations flow directly from your findings.

Conclusion: Provide a brief conclusion that summarises the results and their meaning or significance in relation to each objective of the study.

Acknowledgements: Those who contributed to the work but do not meet our authorship criteria should be listed in the Acknowledgments with a description of the contribution. Authors are responsible for ensuring that anyone named in the Acknowledgments agrees to be named. Refer to the acknowledgement structure guide on our *Formatting Requirements* page.

Also provide the following, each under their own heading:

- Competing interests: This section should list specific competing interests associated with any of the authors. If authors declare that no competing interests exist, the article will include a statement to this effect: The authors declare that they have no financial or personal relationship(s) that may have inappropriately influenced them in writing this article. Read our **policy on competing interests**.
- Author contributions: All authors must meet the criteria for authorship as outlined in the **authorship** policy and **author contribution** statement policies.
- Funding: Provide information on funding if relevant
- Data availability: All research articles are encouraged to have a data availability statement.
- Disclaimer: A statement that the views expressed in the submitted article are his or her own and not an official position of the institution or funder.

References: Authors should provide direct references to original research sources whenever possible. References should not be used by authors, editors, or peer reviewers to promote self-interests. Refer to the journal referencing style downloadable on our *Formatting Requirements* page.

Review Article full structure

Title: The article's full title should contain a maximum of 95 characters (including spaces).

Abstract: The abstract should be no longer than 250 words and must be written in the past tense. The abstract should give a concise account of the objectives, methods, results and significance of the matter. The abstract can be structured and should consist of five paragraphs labelled Background, Aim, Method, Results and Conclusion.

- Background: Why is the topic important to us? State the context of the review
- Aim: What is the purpose of your review ? Describe the aim or purpose of your review.
- Method: How did you go about performing the review? Describe the methods used for searching, selecting and appraising your evidence.
- Results: What are the findings? What are the main findings of your literature review.

• Conclusion: What are the implications of your answer? Briefly summarise any potential implications. **Introduction**: Present an argument for the social and scientific value of your review that is itself supported by the literature. Present the aim and objectives of your literature review.

Methods: Although this is not a systematic review (see instructions on original research for this type of article) it is still necessary to outline how you searched for, selected and appraised the literature that you used. Discuss any methodological limitations.

Review findings: Present your review of the literature and make use of appropriate sub-headings. Your review should be a critical synthesis of the literature.

Implications and recommendations: Discuss the findings of your review in terms of the implications for policy makers and clinicians or recommendations for future research.

Conclusion: This should clearly state the main conclusions of the review in terms of addressing the original aim and objectives.

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Also provide the following, each under their own heading:

- Competing interests: This section should list specific competing interests associated with any of the authors. If authors declare that no competing interests exist, the article will include a statement to this effect: The authors declare that they have no financial or personal relationship(s) that may have inappropriately influenced them in writing this article. Read our **policy on competing interests**.
- Author contributions: All authors must meet the criteria for authorship as outlined in the **authorship** policy and **author contribution** statement policies.
- Funding: Provide information on funding if relevant
- Data availability: All research articles are encouraged to have a data availability statement.
- Disclaimer: a statement that the views expressed in the submitted article are his or her own and not an official position of the institution or funder.

References: Authors should provide direct references to original research sources whenever possible. References should not be used by authors, editors, or peer reviewers to promote self-interests. Refer to the journal referencing style downloadable on our *Formatting Requirements* page.

Book Review full structure

Title: The article's full title should contain a maximum of 95 characters (including spaces).

Book details: This should give the full reference to the book you are reviewing (including, year, ISBN, publisher, number of pages, price).

Main text: This should contain the body of the article, and may also be broken into subsections with short, informative headings. Here are some questions you might want to consider:

- Who is the book intended for and does it meet the intended audience's needs?
- What new information does it present and how might it affect readers' practice?
- What evidence does it present and how convincing is it?
- Are the style, organisation and size of the book appropriate for its purpose?
- Are there any studies, facts, or ideas the authors have neglected to consider?
- Would you like to make any further reading suggestions?
- And last, but not least: why should anybody read this book or why not? Is it regarded as an important book?

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- Competing interests: This section should list specific competing interests associated with any of the authors. If authors declare that no competing interests exist, the article will include a statement to this effect: The authors declare that they have no financial or personal relationship(s) that may have inappropriately influenced them in writing this article. Read our **policy on competing interests**.
- Author contributions: All authors must meet the criteria for authorship as outlined in the **authorship** policy and **author contribution** statement policies.
- Funding: Provide information on funding if relevant
- Data availability: All research articles are encouraged to have a data availability statement.
- Disclaimer: a statement that the views expressed in the submitted article are his or her own and not an official position of the institution or funder.

References: Authors should provide direct references to original research sources whenever possible. References should not be used by authors, editors, or peer reviewers to promote self-interests. Refer to the journal referencing style downloadable on our *Formatting Requirements* page.

Patient Study full structure

Title: The article's full title should contain a maximum of 95 characters (including spaces).

Abstract: The abstract should be no longer than 250 words and must be written in the past tense. The abstract should give a concise account of the Introduction, Patient presentation, Management and outcome and significance of the matter. The abstract can be structured and should consist of four paragraphs labelled Introduction, Patient presentation, Management and outcome, and Conclusion.

- Introduction: Describe the context and the reason for publishing this patient study.
- Patient presentation: Describe your 3-stage assessment of the patient.
- Management and outcome: Describe the management plan, progress and final outcome.
- Conclusion: Summarise the lessons learnt and key implications or recommendations.

Introduction: Convey clearly what is particularly interesting about the patient that you want to describe to the reader. It is useful to begin by placing the study in a historical or social context. If similar cases have been reported previously, please describe them briefly. Clarify your aim or objectives in publishing this patient study.

Ethical considerations: Papers based on a case study that involves the treatment of humans must adhere to the Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects. Specify the recognised ethics committee from which approval for the case study was obtained; also state the serial number of the ethical clearance. Case studies must have the consent of the patient(s) or waiver of consent approved by an ethics committee.

Patient presentation: Describe your patient in detail with consideration of the following aspects:

- Describe the information that was gathered on the patient's medical problem(s) from the consultation, physical examination and results of any investigations.
- Describe the information that was gathered on the patient's perspective of their illness (loss of function, ideas, beliefs, concerns, expectations, or feelings)
- Describe the information that was gathered on the patient's context (family structure and function, occupational issues, environment)
- Provide a 3-stage assessment of the patient's clinical, individual and contextual issues.

Management and outcome: In this section, you should clearly describe the plan for care, as well as the care that was actually provided, how the patient's condition progressed over time and the final outcome.

Discussion: Summarise the key points, lessons learnt and discuss these in relation to the literature. Clarify the implications or recommendations that arise from this patient study.

Acknowledgements: Those who contributed to the work but do not meet our authorship criteria should be listed in the Acknowledgments with a description of the contribution. Authors are responsible for ensuring that anyone named in the Acknowledgments agrees to be named. Refer to the acknowledgement structure guide on our *Formatting Requirements* page.

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- Author contributions: All authors must meet the criteria for authorship as outlined in the **authorship** policy and **author contribution** statement policies.
- Funding: Provide information on funding if relevant
- Data availability: All research articles are encouraged to have a data availability statement.

• Disclaimer: a statement that the views expressed in the submitted article are his or her own and not an official position of the institution or funder.

References: Authors should provide direct references to original research sources whenever possible. References should not be used by authors, editors, or peer reviewers to promote self-interests. Refer to the journal referencing style downloadable on our *Formatting Requirements* page.