

https://dspace.org/

Perspectives on healthcare, chronic noncommunicable disease and healthworlds in an urban and rural setting

Ibanez-Gonzalez, Daniel Lopes

2014-08-25
http://hdl.handle.net/10539/15245

Downloaded from a DSpace repository. https://dspace.org/

PERSPECTIVES ON HEALTHCARE, CHRONIC NONCOMMUNICABLE DISEASE AND HEALTHWORLDS IN AN URBAN AND RURAL SETTING

by

DANIEL LOPES IBANEZ-GONZALEZ

Supervisors

PROFESSOR SHANE A NORRIS

PROFESSOR STEPHEN M TOLLMAN

PROFESSOR RAN GREENSTEIN

A THESIS

Submitted to the School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, in fulfilment of the requirements for the degree

of

Doctor of Philosophy

JOHANNESBURG, SOUTH AFRICA

2014

Declaration

I, Daniel Lopes Ibanez-Gonzalez, declare that this thesis is my original work. Where there has been contribution from other people, this has been duly acknowledged. It is being submitted for the degree of Doctor of Philosophy in Public Health in the University of the Witwatersrand, Johannesburg, South Africa. It has not been submitted before for any degree or examination at this or any other University.

Name: Daniel Lopes Ibanez-Gonzalez

Signature: Date: 13 May 2014 (Nrishma Catudasi)

Dedication

To

His Holiness Bhakti Caitanya Swami

Whose order made it possible

One should try to understand the distress of accepting birth, death, old age and disease….No one wants to be diseased, and no one wants to become old, but there is no avoiding these. Unless we have a pessimistic view of this material life, considering the distresses of birth, death, old age and disease, there is no impetus for our making advancement in spiritual life.

His Divine Grace A.C. Bhaktivedanta Swami Srila Prabhupada

Bhagavad Gita As It Is, Purport (13.9) pp.691-692, 2011

Original Papers

I. Lopes Ibanez-Gonzalez, D. and Norris, S. A., 2013. Chronic noncommunicable disease and healthcare access in middle-aged and older women living in Soweto, South Africa. *PlosOne*, 8(10): e78800.

Student's contribution to the paper:

Study design, project implementation and management, data management and analysis, and writing of manuscript.

II. Lopes Ibanez-Gonzalez, D., Mendenhall, E. and Norris, S. A. A mixed methods exploration of patterns of healthcare utilization of urban women with non-communicable disease in South Africa (Submitted BMC Health Services Research, 2014)

Student's contribution to the paper:

Study design, project implementation and management, data management and analysis, and writing of manuscript.

III. Lopes Ibanez-Gonzalez, D. and Greenstein, R., 2014. Chronic illness and the urban healthworld: A sowetan case study. *South African Review of Sociology*, 45(2), pp.97-116.

Student's contribution to the paper:

Study design, project implementation and management, data management and analysis, and writing of manuscript.

IV. Lopes Ibanez-Gonzalez, D., and Tollman, S. M. Clinics, Churches and Healers: Health Seeking of Older Women with Chronic Noncommunicable Disease in Rural South Africa (Submitted, Journal of Religion & Health, 2013)

Student's contribution to the paper:

Study design, project implementation and management, data management and analysis, and writing of manuscript.

Conference Proceedings

Lopes Ibanez-Gonzalez, D., and Tollman, S. M. Clinics, Churches and Healers: Health Seeking of Older Women with Chronic Noncommunicable Disease in Rural South Africa. Poster presentation at the annual Wits Health Sciences Research Day, 19 September 2012, Wits University, Johannesburg, South Africa.

Awards

Fellowships

1. Post-graduate Merit Award 2011: University of the Witwatersrand

2. Qualitative Research Workshops: Qualitative Research Methods Network Africa: Network of Excellence for Qualitative Research in the Social Sciences: Sub-Saharan Africa, 29 August 2009 to 6 January 2010, hosted by the University of the Witwatersrand, South Africa

Abstract

Background: This study is located within a complex network of paradigmatical methodological, and institutional relationships, and draws concepts from a range of scholastic traditions. The hermeneutical tradition within Sociology, particularly as exemplified in the work of Jurgen Habermas, provides a starting point for exploring and interpreting the experiences of chronic illness and healthcare access. The concept of the lifeworld/ healthworld as a description of the complex of health beliefs and behaviours of individuals in relation to the ailing body is used to describe chronic illness and healthcare access, both as lived experience and as fields for public health intervention.

Aim: To understand how women living with chronic illness experience their illness and access healthcare in an urban and rural context.

Methods: This study is a mixed-methods comparative case study of the healthcare access experiences of women with chronic illness in an urban and rural area in South Africa. The core of the study methodology is a comparative qualitative case study, with quantitative methods serving to contextualise the findings. The urban component of the study was conducted in Birth to Twenty (Bt20), a birth cohort study located in Johannesburg-Soweto. The rural component of the study was conducted in Agincourt, a sub-district of the Bushbuckridge district in Mpumalanga Province. The quantitative context for the Soweto case study uses secondary data collected by Bt20 to construct a historical overview of the use of formal and informal healthcare services in Soweto. It also uses the findings of a large scale cross sectional survey of the primary caregivers of the Bt20 cohort, conducted between November 2008 and June 2010. The rural case study

is contextualised by a detailed review of research conducted in the Agincourt sub-district. For the qualitative case studies I employed a qualitative methodology incorporating serial narrative interviews to present an experience-based overview of concepts of disease causation, self treatment and coping.

Results: The cross-sectional survey describes a low resource population with a high prevalence of chronic noncommunicable disease (NCDs). Over one third (37.3%) of the population in Soweto could be categorised as having a low socio-economic status, defined as access to only one or less of 5 socio-economic items. Slightly over half the respondents in Soweto (50.7%) reported having at least one chronic illness. Only around a third (33.3%) of the survey participants with chronic illnesses reported accessing formal healthcare services in the last 6 months. Similar trends were found in the review of research carried out in Agincourt. The qualitative case study in Soweto is characterised by a preoccupation with how the medicine from the clinic interacts with the body. The search for alternative remedies took place not as an attempt to cure disease, but to reach a deeper understanding of the diseased state of the body. The Agincourt qualitative case study highlights the importance of church membership, particularly of African Christian Churches, as the strongest factor motivating against the open use of traditional medicine. In both study sites there is evidence that traditional healers were consulted for social purposes rather than health-related purposes.

Discussion: Soweto and Agincourt share similar patterns of healthcare utilisation and healthcare belief. Both study sites were characterised by increasing trends in formalisation. At the same time, only a small portion of individuals in both study sites with chronic illness utilised formal healthcare services. A consideration of the findings

suggests five broad themes for further research: (1) Processes of constructing body narratives; (2) Encounters with purposive-rational systems; (3) Encounters with traditional medicine; (4) Encounters with contemporary informal medicine; and (5) Religion and healthcare. These five themes constitute the beginning of a comprehensive map of the lifeworld/ healthworld schema. Such a schema has implications for healthcare policy and practice, particularly with regard to the development of integrative paradigms in South Africa as exemplified by Community Oriented Primary Care (COPC).

Conclusion: The aims and objectives of the study were met through the development of an initial lifeworld/ healthworld schema, which suggests that the coexistence of diverse public healthcare concerns of high NCD prevalence and low formal healthcare utilisation is best addressed through the adoption of integrated healthcare approaches based on lifeworld/ healthworld rationalistion.

Keywords: Hermeneutics; Sociology; Habermas; chronic noncommunicable disease; healthcare access; healthworld; mixed-methods; comparative case study; body narratives; public health discourse; South Africa

Acknowledgements

This work owes much of its integrity to the efforts of my supervisors, Professor Shane A Norris, Professor Stephen M Tollman, and Professor Ran Greenstein, each of whom made a unique contribution in shaping the final product. Professor Shane A Norris contributed to the practicality of the overall findings. He motivated me to think about the public health implications of the work. Professor Stephen M Tollman contributed in small, but crucial ways to refining the arguments and the overall presentation of the thesis for a public health audience. Professor Ran Greenstein ensured by his critical reviewing and comments that the sociological foundation of the thesis was sound. In these, and many more ways, my supervisors encouraged me in the completion of this thesis. A word of thanks is owed to Annette Gerritsen, who patiently read through the thesis, and made useful comments. I am also grateful to Elizabeth Kimani-Murage, whose own PhD thesis for the School of Public Health informed me on numerous points of layout and design for the present thesis.

I owe a debt of thanks to the fieldwork staff who assisted me in data collection. In Soweto, Norman Vundla, Joyce Moiloa, Sipho Dlamini, Corlett Ndlovu, Andries Phake, Meikie Hlalele and Palesa Tsoaedi assisted in quantitative data collection, and Palesa Tsoaedi assisted in the interpretation and transcription of the indepth interviews. In Agincourt, Zodwa Khoza conducted, translated and transcribed the indepth interviews.

I am grateful for the financial assistance provided by the Wellcome Trust, the University of the Witwatersrand, SANPAD, MRC (SA) and MRC/DfID (UK; Africa Research Leader Award).

I am thankful for the loving support of my wife, Radhika Prasad devi dasi, my parents Mimo Ibanez Gonzalez and Fernanda Lopes Gonzalez, and my sister, Sandra Ibanez Lopes.

Finally, I would like to thank all of the study participants who selflessly gave of their time and energy in participating in this study.

Table of Contents

Declaration ii
Dedication iii
Original Papers v
Conference Proceedings vi
Awards vi
Abstract viii
Acknowledgements xi
Table of Contents xiii
List of Figures xv
List of Tables xv
List of Abbreviations/ Acronyms xvi
Preface xviii
1 Study Background 3
1.1 Introduction 3
1.2 Definitions of chronic noncommunicable disease 5
1.3 NCDs in South Africa 6
1.4 Problem Statement 9
1.5 Definitions of healthcare access 9
1.5.1 The A-frame definition of healthcare access 10
1.5.2 The Health Belief Model 12
1.5.3 The dynamic response framework 14
1.5.4 A consolidated conceptual model of healthcare access 16
1.6 Sociological perspectives: Social constructionism and development 18
1.6.1 Introducing the lifeworld/ healthworld 19
1.7 Applying the lifeworld/ healthworld concept to public health research 23
1.8 Study aim and objectives 24
1.9 Study themes and structure 24
2 Methodology 29
2.1 Defining the case study 29
2.2 The study sites 30
2.3 Describing the context of the case studies 31
2.3.1 Urban context (part 1): secondary data analysis 31
2.3.2 Urban context (part 2): Soweto quantitative survey 31
2.3.3 Urban context (part 3): The analysis of primary and secondary data 33
2.4 Conducting the case studies 34
2.4.1 Narrative Enquiry 34
2.4.2 The qualitative study instrument 35
2.4.3 Sampling in an urban and rural study setting 35
2.4.4 Qualitative data analysis: Soweto and Agincourt 37
2.4.5 Reflexivity in urban and rural contexts 39
2.5 Ethics 41
3 Results 43

3.1 The urban context 43
3.1.1 Historical trends in the use of formal and informal healthcare in Soweto 43
3.1.2 Healthcare access and belief in Soweto: The 2008-2010 survey 46
3.2 The Rural context 55
3.2.1 Population trends in the Agincourt subdistrict 55
3.2.2 Health status in Agincourt 57
3.3 The qualitative case studies 59
3.3.1 A brief description of the study participants 59
3.3.2 The urban case study (Soweto) 62
3.3.3 The Rural Case Study (Agincourt) 75
4 Discussion 86
4.1 Historical-comparative community description 86
4.1.1 High prevalence of NCDs and low utilisation of formal healthcare services 86
4.2 Implications of case study findings for social theory 87
4.2.1 Processes of constructing body narratives 88
4.2.2 Encounters with purposive-rational systems 89
4.2.3 Encounters with traditional medicine 90
4.2.4 Encounters with contemporary informal medicine 91
4.2.5 Religion and healthcare 92
4.2.6 Mapping the lifeworld/ healthworld schema 92
4.3 Implications for healthcare policy and practice 94
4.4 Study Limitations 96
4.5 Future work 98
5 Conclusion 100
References 104
Original Papers 121
Paper I 121
Paper II 128
Paper III 158
Paper IV 179
Appendices 203
Appendix 1: Ethics forms and clearance certificates 203
Appendix 2: Qualitative study instruments and fieldnotes 207
Appendix 3: Quantitative study instrument and coding sheet 233

List of Figures

Figure 1: Multiple health and healthcare polarities in South Africa 9
Figure 2: The A-Frame definition of healthcare access 10
Figure 3: Dynamic responses framework 15
Figure 4: Consolidated conceptual model of healthcare access 18
Figure 5: Applying the lifeworld/ healthworld concept to public health research 23
Figure 6: Overall use of Formal and Informal Healthcare from 6 months to 16 years 45
Figure 7: Conceptual map of the lifeworld/ healthworld schema 93
Figure 8: Process for addressing problem statement and study aim and objectives 101

List of Tables

Table 1: Study components and research themes 25
Table 2: Mean comparison of healthcare utilisation in different phases of healthcare use reported in the Bt20 cohort 46
Table 3: Population characteristics of Bt20 caregivers between 2008 and 2010 (N=1102) 48
Table 4: Access to healthcare services in Soweto as reported by Bt20 caregivers between 2008 and 2010) (N=1102) 50
Table 5: Correlating healthcare utilisation of persons with NCDs with individual, societal and healthcare system determinants in the Bt20 cohort 2008-2010 (N=1089) 54
Table 6: Quantitative comparison of case study participants in Soweto (N=12) and Agincourt (N=13) 2009-2010 59

List of Abbreviations/ Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ANC	African National Congress
Bt20	Birth to Twenty
COPC	Community Oriented Primary Care
DPHRU	Developmental Pathways for Health Research Unit
FBO	Faith Based Organisation
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
LMIC	Low and middle income countries
MRC	Medical Research Council
The Agincourt research unit	MRC/Wits Rural Health and Health Transition Unit in Agincourt
NCD	Chronic Noncommunicable Disease
PHC	Primary Health Care
PhD	Doctor of Philosophy
Prof	Professor
SAMRC	South African Medical Research Council
TB	Tuberculosis
UK	United Kingdom
WHO	World Health Organisation
Wits	University of the Witwatersrand

Preface

This research began as an exploration of healthcare access in Soweto and Agincourt. I was working as a researcher in Birth to Twenty (Bt20), now the Developmental Pathways for Health Research Unit (DPHRU), of the University of the Witwatersrand, and was requested to begin work on healthcare access in fulfilment of the unit's Wellcome Trust grant application. At the same time, there were ongoing discussions about linking the research conducted by Bt20 in Soweto with the work done by the MRC/Wits Rural Health and Health Transition Unit in Agincourt (the Agincourt research unit). Such collaboration was intended to shed light on rural-urban differences and similarities in the development of lifestyle disease.

My input into the research topic came in the preference for an exploratory, qualitative methodology in the tradition of interpretive sociology. This was chosen mainly as a starting point in understanding the concept of "healthcare access", which I knew little about. Finally, I chose to focus the study on the experiences of women in using healthcare and living with chronic noncommunicable disease (NCD). Again, this was taken as a starting point: the exploration of the concept of healthcare access is best begun by focusing on the experience of a particular group of people who, by virtue of their practical experience in utilising different forms of healthcare on behalf of themselves and their families, could be considered experts in healthcare access.

My personal aims in conducting this research were to achieve the following:

1. To conduct interdisciplinary research which presents sociological and public health perspectives on NCDs and healthcare access;
2. To conduct meaningful comparative research which makes use of comparative methodologies to illuminate something unique about the topic; and
3. To conduct mixed methods research which combines quantitative and qualitative methods and premises in a coherent way to produce original research.

I approached this study by thesis with publications, which enabled me to focus on the different and complex components of the study individually, and to integrate the findings in an integrative narrative. Because this was a definitional study, making use of comparative methodology, I chose to make each study site, one in an urban area and one in a rural area, the focus of one or more papers. In the following pages I attempt to distill the lessons learnt in each site in relation to the other. The result is a reflection on contemporary beliefs and practices regarding NCDs and healthcare access and their implications for healthcare policy in South Africa.

Study Background

1 Study Background

1.1 Introduction

> The age of heroic medicine has been replaced by the mundane medical management of chronic as opposed to acute illness. (Turner and Samson, 1995, p.8)

Within the practice and theory of public health, a clear shift in emphasis has occurred as health practitioners are coming to terms with the increasing "chronic" or long-term nature of disease. From disease and cure, increasing attention is paid to health and prevention of disease; from the treatment of acute disease in hospitals, health practitioners are exploring the management and monitoring of disease in communities; from treating the patient, we are increasingly called upon to treat "the person" (Nettleton, 2006).

This change, however, is seldom conveyed in mundane or unheroic terms. On the contrary the challenges posed by chronic disease often evoke urgent, even emotive responses from public health practitioners. For example, in 2005, the World Health Organisation (WHO) released a report entitled "Preventing Chronic Diseases: A Vital Investment", in which Lee Jong-Wook, the director-general of WHO, in a forward subtitled "The cost of inaction is clear and unacceptable" stated:

> "This ground-breaking report presents the most recent data, making clear the actual scale and severity of the problem and the urgent need for action." (Lee, 2005, p.vii)

Elsewhere, it is stated that NCDs are reaching "epidemic proportions worldwide" and that "concerted action" could prevent "36 million premature deaths by 2015" (Daar et al., 2007).

The solution to the problem of NCDs is generally presented as a "double-pronged" approach focusing on population-based and clinical services (Adeyi et al., 2007; Steyn, 2006), or in other words the prevention and management of NCDs. Other domains of action include a wide range of policy interventions and research activities, and the related mobilization of a wide variety of national and international organisations and funding agencies (Daar et al., 2007). While emphasis is usually placed on population-wide prevention measures, we are urged to acknowledge the "burden" of chronic disease, and deal with the pressures that this will place on public health systems (Adeyi, et al., 2007).

We can conclude that there is a certain way of talking about NCDs, particularly found in WHO publications and scientific journals. The fact that there is a certain way of discussing NCDs raises a number of questions such as: (1) what are the main features of this discourse? (2) How was it formed? and (3) For what purposes is it enacted? We should also be interested in other ways of articulating NCDs and the effects these may have on the the lives of people with these conditions.

1.2 Definitions of chronic noncommunicable disease

There is a distinction between types of literature dealing with illness and disease in general, and NCDs in particular. Broadly speaking, the literature on these phenomena may be of two types: The preceding paragraphs have presented views associated with the "objectivist" or "positivist" approach. This approach is characterised by a heavy reliance on quantitative measures of biomedical definitions of disease which conceive disease as deviations from biomedical norms (Martin and Peterson, 2008). The alternative approach is referred to as the hermeneutic approach, or the "social constructionist approach", and is characterised by an interest in the experience of illness, the interpretive work performed by people with illness and their social relations in defining and managing the experience of illness (Martin and Peterson, 2008). A social constructionist approach is rooted in the conceptual distinction between illness, understood as the lived experience of disease, and disease, understood as the biological condition, or rather, the reinterpretation of the illness experience by specialists in terms of technical classifications (Kleinman, 1988; Conrad and Barker, 2010).

In the objectivist tradition, the South African Medical Research Council (SAMRC) has defined NCDs (also termed "chronic diseases of lifestyle") as a group of diseases sharing similar risk factors, resulting in long term disease processes and culminating in high mortality rates (SAMRC, 2013). The spread of NCDs in low- and middle income countries is generally attributed to the adoption in those countries of the unhealthy lifestyle habits of high-income countries, particularly over-nutrition, low physical activity and tobacco use (Nugent, 2008; Steyn, 2006). These three factors, termed "modifiable

lifestyle behaviours" are generally held to be the direct cause of the whole spectrum of NCDs, including heart disease, stroke, diabetes, obesity, metabolic syndrome, chronic obstructive pulmonary disease, and some types of cancer (Al-Maskari, 2010).

A social constructionist definition of NCDs, or "chronic illness", focuses on the interpretation and lived experience of the illness. McGuire (1990), for example, has observed that chronic illness often leads to a radical reassessment of one's self in relationship to past and future. Chronic illness poses basic problems for the sufferer's sense of self. The body is no longer able to sustain a presentation of the self as a normal, reliable participant in social action, and basic relationships and social interactions may be severely disrupted (McGuire, 1990). The diseased body becomes the product of a new social process, in which the embodied self and others make sense of "being-in-the-world". Irony, parody, narratives and memory become the processes by which the individual maintains and negotiates his or her identity as a vital means of coping with illness (Von Wolputte, 2004).

In this thesis I refer to both definitions in relation to healthcare access, and use the term NCD interchangeably with chronic illness. Generally, I focus on the biomedical definition to understand the scope of a condition which is understood primarily in social constructionist terms as a bodily and social experience.

1.3 NCDs in South Africa

NCDs are considered to be the leading causes of death globally, contributing to two-thirds (63%) of global mortality. Around 80 percent of these deaths occur in low- and

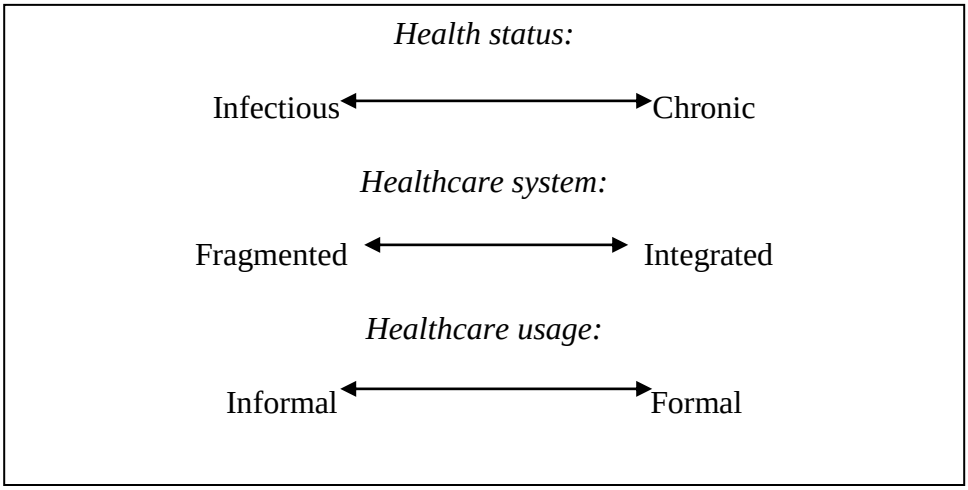
middle-income countries (LMICs) (WHO, 2011). South Africa's share of chronic disease has not been as high as the global estimate, with NCDs accounting for 28% of the total burden of disease measured by disability-adjusted lifeyears in 2004 (WHO, 2004).

South Africa has been described as a country undergoing a health transition characterised by the simultaneous occurrence of epidemic and infectious diseases (Mayosi et al., 2009). The rise of NCDs is associated with an increase in risk factors in both urban and rural areas. For example, a 2007 study conducted in Free State, South Africa indicated a prevalence of 62.6% and 48.3% for self-reported hypertension in rural and urban communities respectively. Around 40% of rural women had a cumulative risk for 3 or more factors for NCDs (Van Zyl et al., 2012).

Evidence from South Africa suggests that the increasing trend in NCD prevalence coexists with low healthcare utilisation (Goudge et al., 2009). This has been attributed to the poor affordability and availability of healthcare services in South Africa (Department of Health et al., 2007), and a healthcare system still marked by apartheid-era inefficiencies (Coovadia et al., 2009). Although a great deal of progress has been made with regard to South Africa's health system reforms (Mayosi et al., 2009; Coovadia et al., 2009), the full achievement of equitable distribution of healthcare through a Primary Health Care (PHC) approach has been hampered by a number of obstacles, including health worker shortages, inequities in resource distribution, shortcomings in health leadership and the health transition noted earlier (Kautzky and Tollman, 2008).

In addition to supply-side reforms, increasing attention has been paid to the demand-side of healthcare access in South Africa. Research in South Africa has shown relatively large prevalence rates for the combined use of healthcare modalities, particularly for NCDs (Peltzer et al., 2008; Singh et al., 2004). This study is therefore situated in a context marked by multiple transitions: the transition from high prevalences of infectious to chronic diseases, the transition of a racially fragmented and inefficient healthcare system to an integrated healthcare system, and the transition of individual healthcare practices from informal to formal healthcare treatment. While this formulation implies direction, at this stage, all that can be safely assumed is a bi-directional continuum representing the coexistence of different states of health and healthcare in South Africa.

Figure 1: Multiple health and healthcare polarities in South Africa



1.4 Problem Statement

Given the high prevalence of NCDs as well as the dynamic nature of healthcare systems in South Africa, the key question for this study is how the diverse concepts within objectivist and social constructionist public healthcare approaches can be utilised to contribute to our understanding of NCDs and healthcare access.

1.5 Definitions of healthcare access

As with NCDs, definitions of healthcare access may be located within broader paradigms. The stated or unstated goal of increasing utilisation of formal healthcare services, even when there is no illness experience, forms the basis of most positivist definitions of healthcare access (Gilson, 2007, Andersen, 1995, Thiede et al., 2007, Rosenstock, 2005). This is commensurate with approaches to disease which endorse the extension of formal

rational systems as a response to NCDs described as a state of emergency. We shall now examine some of these definitions of healthcare access in closer detail.

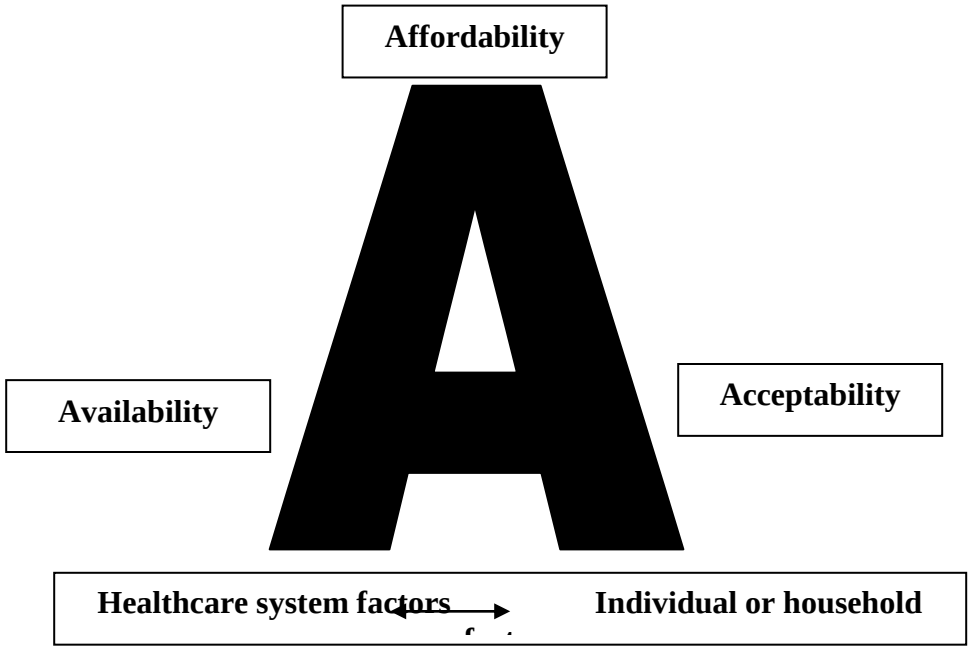
1.5.1 The A-frame definition of healthcare access

The A-Frame definition of healthcare access (Thiede et al., 2007) identifies the following 3 dimensions:

1. Availability or physical access of healthcare services in space and time;
2. Affordability or financial access; and
3. Acceptability or cultural access.

Underlying these 3 dimensions is the "degree of fit" between the healthcare system and its users, which is conceived as a dynamic process of interaction (Gilson and Schneider, 2007).

Figure 2: The A-Frame definition of healthcare access



The "A-Frame" definition of healthcare access, by emphasizing the role of freedom, acknowledges the possibility that individuals may choose alternatives to formal healthcare services, not due to barriers of affordability, availability, and acceptability, but because they knowledgeably accept alternative healthcare practices as more appropriate for the treatment of their condition (Thiede et al., 2007). However, the acceptability dimension of the A-frame definition, by focusing our attention on the internal reasoning of participants as to why they might not access formal healthcare services, poses the danger of clouding this distinction. Where does concern over cultural barriers end, and cultural hegemony begin? In other words, how concerned should we be about people's usage of formal healthcare services, and is such concern helpful for people with chronic illness? Hitherto, it appears that research has not examined these questions in sufficient detail.

The conceptualisation of acceptability has been traditionally marked by concerns with patient compliance with formal healthcare systems. Acceptability is linked to patient unwillingness to reveal past medical history, limited patient adherence to treatment, and lower self-reported health status (Gilson and Schneider, 2007). While these concerns may be framed in terms of healthcare reforms, without attempting to understand the perspectives of healthcare users, public health researchers will always be confronted with the issue of patient compliance with formal medical procedures. This approach does not take into account the integral nature of acceptability barriers in formally rationalised healthcare systems. Formal healthcare systems are universally characterized by the presence of bureaucratic organisational features, and interaction with bureacracy often

entails a "process of degradation" or the stripping of civil identity through a series of public rituals (Turner and Samson, 1995); this almost always begins with waiting in a queue.

1.5.2 The Health Belief Model

The "A-Frame" can be described as a definition of healthcare, rather than a model, because, while it identifies a number of components of healthcare access it has little to say about the process of accessing healthcare: why people choose to utilise healthcare systems, and why they choose not to. Rosenstock (2005) has suggested that "superior studies" of healthcare access focus on the linking mechanisms between personal characteristics and behaviour, or explicating the health decision-making process in which the individual moves through a series of stages, with events at each stage shaping subsequent decision-making (Rosenstock, 2005).

Rosenstock is identified with the Health Belief Model (HBM) of healthcare. This model focuses more on health behaviour than illness behaviour, that is, behaviour undertaken to prevent a disease, or detect disease at the early, asymptomatic stages (Rosenstock, 2005). The HBM is focused on the subjective state of the healthcare user, and how this relates to his or her subsequent healthcare seeking behaviour. In particular, the model focuses on two classes of variables:

1. the psychological state of readiness to take a specific action; and
2. the extent to which a particular course of action is believed to reduce the threat.

In addition to these factors, Rosenstock (2005) mentions the necessity for an instigating event, either internal or external, to trigger the healthcare seeking behaviour. The purpose of the model is always to influence behaviour. Rosenstock (2005) writes:

> ...its [the HBM] ultimate usefulness would depend upon the extent to which the health beliefs can be modified in a planned way. (Rosenstock, 2005, p.17)

While there is an interest in understanding the causal processes of health behaviour, even if only for the aim of modifying it, it is surprising that the aim of the model should be to alter beliefs when little is known about their origin (Rosenstock, 2005). Notwithstanding this, the model is so strongly oriented to inducing the "voluntary" use of formal healthcare services that at one point, after mentioning the role of law enforcement and job requirements, Rosenstock argues for the use of fear-inducing measures to ensure the use of these services. He writes:

> …to conclude that fear is uniformly to be eschewed in educational programs is premature…the attempts to induce fear might, for certain subgroups of the population be much more effective than a more neutral or, as sometimes called, a more 'positive' approach. (Rosenstock, 2005, pp.23-24)

A key element in the model is the extent to which the potential healthcare user feels threatened, or vulnerable to a dangerous condition, with a particular emphasis on emotional as opposed to cognitive aspects of their health beliefs, as being more powerful in influencing behaviour (Rosenstock, 2005).

While the "certain subgroups" referred to in the above quotation are not explicitly defined, it is clear that they refer to lower or marginalized socioeconomic groups, the "poorly educated", "lower income" and "non-white" groups being regarded as not readily willing to respond to cues to seek healthcare. Conversely, "middle class" groups are regarded as more likely to engage in deliberate planning and the deferment of immediate gratification for long-term goals (Rosenstock, 2005, p.27 and p.18). It is to be remembered that such efforts are directed at people who have, as yet, no tangible reason to present at a formal healthcare provider.

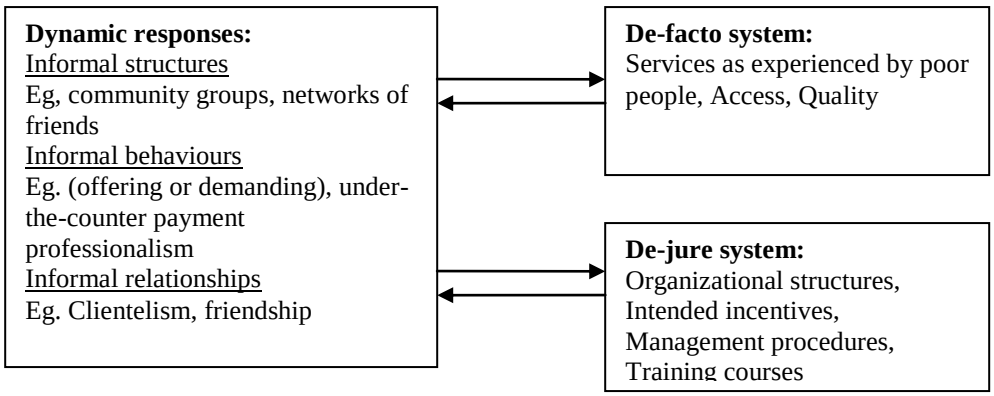
1.5.3 The dynamic response framework

Balabanova and colleagues (2006) has argued for an approach to healthcare systems – an approach termed "the dynamic response framework" - which takes account of their complexity, and which seeks to understand emergent patterns, rather than cause-and-effect sequences. Rather than creating simple (or complex) models of access, the dynamic response framework identifies "mechanisms" which sit between *de jure* and *de facto* healthcare services (Balabanova et al, 2006). Central to this approach is:

1. Seeing healthcare systems as dynamic interactions of different elements, where change in one element can alter the context for all the other elements; and

2. Giving emphasis to the informal behaviours and relationships which mediate the various processes within a healthcare system, leading to intended and unintended consequences for accessibility.

Figure 3: Dynamic responses framework



The strength of the dynamic response framework lies in its identification of features of healthcare access which cannot be encompassed in a simple model. These features include:

1. The long-term engagement with healthcare services, marked by interlinked contacts with a wide variety of caregivers over a lengthy period;
2. The social embeddedness of decision-making, where individuals are encountered with multiple choices; and
3. The dynamic, long-term interaction between provider and patient behaviour which shapes future interactions.

(Balabanova et al, 2006)

In the face of these complexities, healthcare users develop multifaceted coping strategies, informed by their own experiences and the experiences of others in their acquaintance. What predominant healthcare models see as acceptability, or cultural, barriers become intentional and context-specific strategies for maximizing functional utility for the fulfillment of personal goals, as opposed to "good health", as defined by others.

1.5.4 A consolidated conceptual model of healthcare access

In consideration of the preceding discussion of models of healthcare access it is important to distinguish between the healthcare systems to which these models refer. These may be grouped into two categories: Orthodox medicine, or formal healthcare; and complementary and alternative medicine, or informal healthcare. It has been seen that when definitions of healthcare access focus only on formal healthcare services the intention is generally prescriptive. Conversely, the recognition of the coexistence of multiple systems of healthcare compels a deeper understanding of the interpersonal relationships which mediate healthcare access.

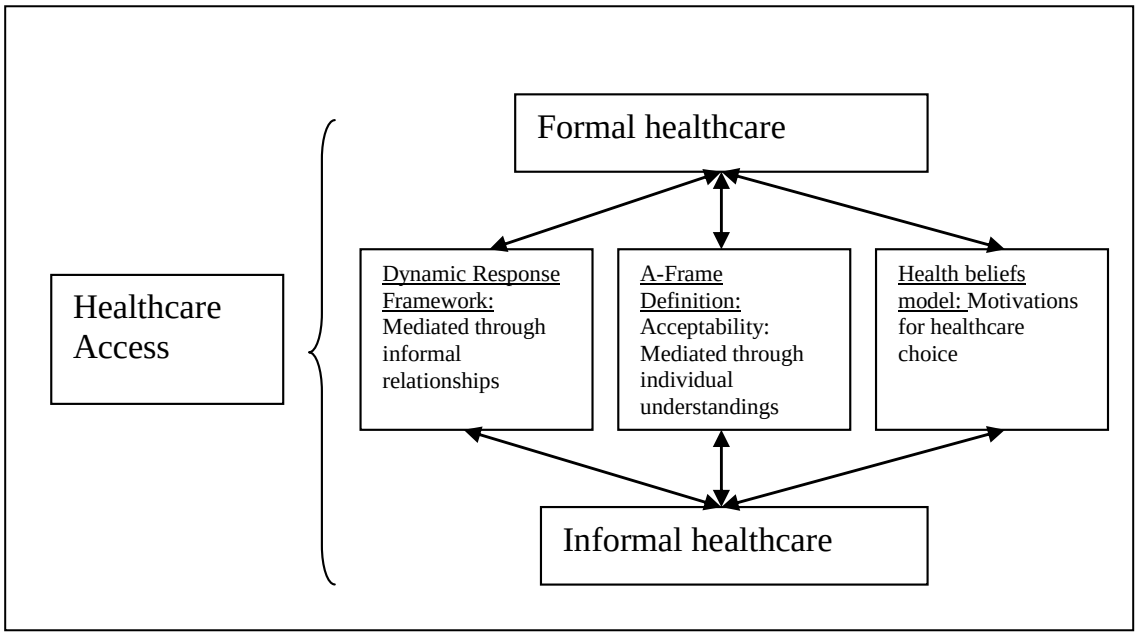
Informal healthcare systems may be defined as groupings of healthcare practices based on the principle of "vitalism", or the notion that living organisms are sustained by a vital force beyond physical and chemical forces. In instances when informal healthcare does not explicitly make such claims, weaker versions of vitalism focusing on the healing power of nature, and consequently the limited role of the physician is assumed (Coulter and Willis, 2004).

Motivations for the increasing use of complementary and alternative medicine may be grouped into two categories: bad experiences with orthodox medicine and a general belief in the alternative paradigm (Baarts and Pedersen, 2009). Baarts and Pedersen (2009) have found that individuals become convinced of the benefits of complementary and alternative medicine even in cases where it failed to relieve them of the symptoms of chronic illness. They argue that complementary and alternative medicine practices increase bodily awareness, enabling practitioners to enact changes in their personal lives. This is based on the formation of coherent "body narratives" covering a range of bodily transformations spanning the life-course. The treatment is viewed more positively than conventional treatments because it encourages patients to begin exploring their own bodies (Baarts and Pedersen, 2009).

Narrative formation in relation to the body and healthcare systems, because it relates primarily to the self, provides the integral feature of a comprehensive model of healthcare access. Such a model should incorporate both formal and informal healthcare systems, the multiple use of which is mediated through narratives in relation to the following key features of the previously discussed models:

1) Interpersonal relationships highlighted by the dynamic response framework;
2) Individualised interpretations of healthcare encounters, highlighted by the acceptability feature of the A-frame definition; and
3) Individual motivations for the use of different healthcare systems, highlighted by the HBM.

Figure 4: Consolidated conceptual model of healthcare access



This initial model of healthcare access will guide the discussion which follows. There is, however, a need to consider further how the key role of narrative explicates this model. For this, we turn to sociological and social constructionist literature.

1.6 Sociological perspectives: Social constructionism and development

Increasingly, social constructionist perspectives have approached biomedical interventions in the arena of NCDs and healthcare access as a discourse of development. The discourse of development consists of pre-established rules for determining the relationships between experts, forms of knowledge, theory and objects of study, and the implementation of plans and policy (Gow, 1996). Development as a discourse is "anchored" in the Western economy (Escobar, 1992: 22), and shares key features with colonising discourses which situate the "other" - the object of development - as dependent on, and subordinate to the giver of development (Naz, 2006).

In its language or ugency, its call for progress, and its focus on the under-developed, most of the public health literature shares features with the discourse of development. The limitation of research conducted within this paradigm lies in its lack of reflexive engagement with the knowledge systems and reasoning practices of social actors in shaping experiences of chronic illness and healthcare access. As a result research findings and the practices they endorse remain substantively disconnected from the people they refer to. In the words of Majid Rahnema (1997):

> The issue is, therefore, not that development strategies or projects could or should have been better planned or implemented. It is that development, as it imposed itself on its 'target populations', was basically the wrong answer to their true needs and aspirations. (Rahnema, 1997, p.379)

Addressing this problem requires that we give serious attention to the experiences, or rather the narratives of chronic illness and healthcare access.

1.6.1 Introducing the lifeworld/ healthworld

The hermeneutic tradition within sociology, particularly as exemplified in the work of Jurgen Habermas, provides a starting point for exploring and interpreting narratives of chronic illness and healthcare access. It is within this tradition that researchers of chronic illness and healthcare workers have been called upon to reflexively pursue the enhanced rationalization of the lifeworld (Scambler, 2000). The lifeworld may be understood as the

culturally transmitted and linguistically organised stock of background knowledge which a person brings to their daily communicative encounters with others and with institutions (Habermas, 1987). The concept of the "healthworld" draws on the same hermeneutic tradition. It is a description of the complex of health beliefs and behaviours of individuals in relation to the ailing body (Germond and Cochrane, 2010).

The primary interest in Habermas's work was how participants in social situations reach common understandings. This ideal of free communication or communication without coercion is called communicative action (McCarthy, 1984), and is described by Habermas as a situation in which:

> …participants are not primarily oriented to their own individual successes; [but rather] they pursue their individual goals under the condition that they can harmonize their plans of action on the basis of common situation definitions. (Habermas, 1984: 285-6)

The concept of communicative action resonates closely with that of body narratives in the sense that the goal of action is not merely the attainment of health but the attainment of personal and interpersonal meaning. It has elsewhere been observed in relation to healthcare provider choice that individuals do not merely aim to maximize their health, but rather their overall utility, or their ability to fulfill personal goals (Grobler and Stuart, 2007). This becomes particularly relevant in the case of chronic illness, where even biomedicine, or formal healthcare, can offer no hope for a final cure. In this scenario the

search for meaning becomes just as important as the search for mesurable health outcomes.

The relationship between the search for meaning in chronic illness and the need for substantial improvements in physical functionality is conceptualised in the theory of communicative action in terms of the relationship between communicative action and 'purposive-rational' or ego-centric action. Rather than being governed by consensual norms and reciprocal behaviour, purposive-rational action is governed by technical rules based on empirical knowledge (Habermas, 1972). As it relates to healthcare, purposive-rational action is related to measurable health outcomes, and is expressed in terms of medical technical conceptions of disease, disease causation and treatment. These concepts focus on the control of isolated natural processes via the scientific method, and while they may lead to increasing technical knowledge, to the extent that they exclude communicative action, they remain "unpractical", that is, they fail to enhance the character or the quality of social interaction (Habermas, 1972: p55).

The theory of communicative action posits communicative action against purposive-rational action, in terms of goals, functional characteristics, and loci of social action. But the question remains to what extent this conceptual dualism reflects the reality of lived experience. Within the theory of communicative action, the dualism implies the harrowing consequence of lifeworld colonisation. The colonisation of the lifeworld refers to the constriction of communicative action by system-based modes of rationality, and manifests in healthcare practice as the infusion of the practices and perceptions of biomedical science into everyday life (Bury, 1998). This extension of technically exploitable knowledge within the lifeworld/

healthworld stifles the redemptive process of reflection (Habermas, 1972), through which individual experiences are related with social and spiritual communities of understanding (Cochrane, 2007). The practical consequences of this process may be seen in the institutional transformation of medical practice from the guild to the bureaucracy, from the application of the practical art of healthcare, to the administration of scientific methods to whole categories of medical cases (Illich, 1976).

The solution to the problem of disconnected technical power lies in re-establishing lifeworld/ healthworld and system in a mutually-enriching relationship, which may also be referred to as the rationalisation of the lifeworld (Habermas, 1987; Scambler, 2000). Lifeworld/ healthworld rationalization may be thought of as a process of individual empowerment, but more specfically refers to:

i) A commitment to increasing the scope of communicative action (action free from external and artificial constraints);
ii) Promoting the formation of institutional procedures reflecting rational intersubjective will-formation (or which systematically supports, acknowledges and engages with individuals' conceptions of their own illnesses); and
iii) Publicising and addressing issues of concern in the lifeworld/ healthworld of people with chronic illness (Scambler, 2000).

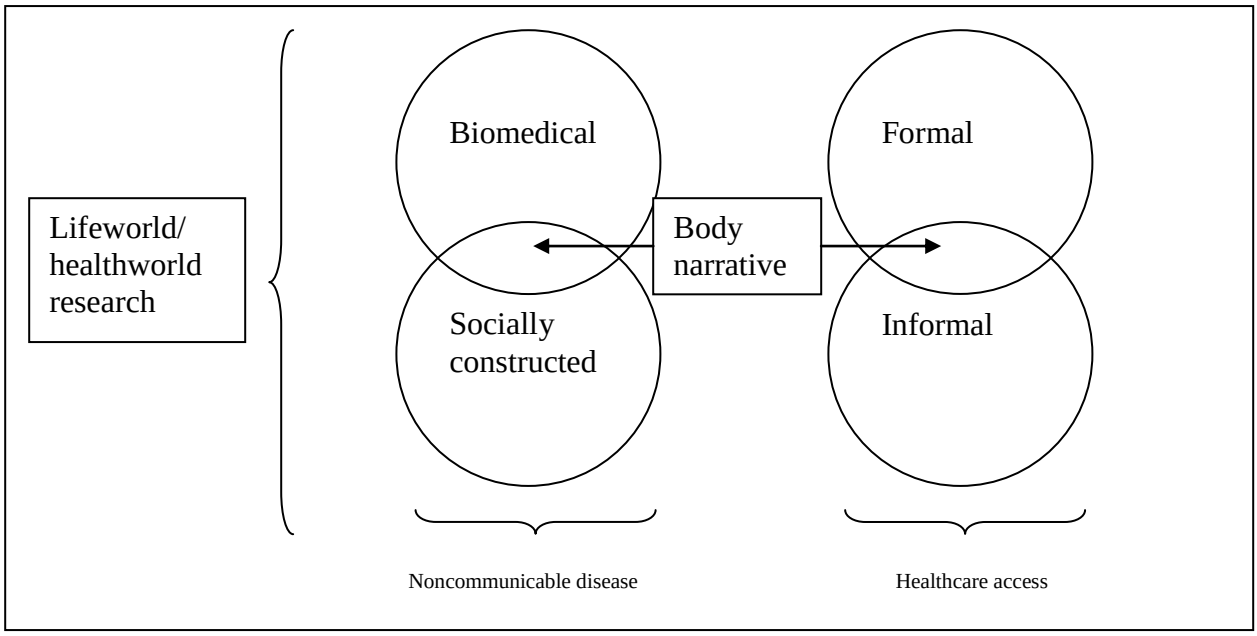
The narrative is an important feature both of communicative practice and of lifeworld rationalisation. Narratives enable mutual understanding between the participants of social situations, as well as the self-understandings of persons. Both these functions are carried

out by the successful connection between social events and the lifeworld (Habermas, 1987).

1.7 Applying the lifeworld/ healthworld concept to public health research

The lifeworld/ healthworld forms the background of social action around healthcare. It is the substrate of all social interactions, personal understandings, and personal motivations mediating different kinds of healthcare access. By understanding the lifeworld/ healthworld, we can gain a better understanding of how chronic illness and healthcare access are manifested in daily interaction.

Figure 5: Applying the lifeworld/ healthworld concept to public health research



The integral place of narratives in lifeworld/ healthworld research informs the techniques of data collection and analysis, and focuses our attention on the the interaction between different realms of social action, allowing us to integrate the diverse healthcare

approaches discussed in this chapter. The lifeworld/ healthworld provides a viable approach to the problem statement in 1.4.

1.8 Study aim and objectives

The broader vision directing the research leads towards a schematic framework of the lifeworld/ healthworld and its application in public health research and policy around NCDs. Given this goal, the aim of the study was to understand how women with chronic illness experience their illness and access healthcare in an urban and rural context. Specific objectives included:

1. Formulating a historical-comparative community description of the study sites using primary and secondary quantitative data; and
2. Analysing the experiences of chronic illness and healthcare access in an urban and a rural area.

1.9 Study themes and structure

This is a thesis with publications. The body of the thesis (the integrative narrative) describes the entire research process, and presents the findings, as well as a discussion and conclusion. Each of the publications emerging from the study addressed key components of the study aim and objectives. The key themes of the study (Table 1) included establishing the urban and rural contexts of the study, describing the lifeworld/ healthworld within each context, and relating these findings to the broader vision of the study. Each of these themes are addressed by different study components..

Table 1: Study components and research themes

Component	Context	Urban lifeworld/ healthworld	Rural lifeworld/ healthworld
An urban contextual survey **P1**: **Chronic noncommunicable disease and healthcare access in middle-aged and older women living in Soweto, South Africa** **P2: A mixed methods exploration of patterns of healthcare utilization of urban women with non-communicable disease in South Africa**	X	X	
An urban qualitative study **P3: Chronic illness and the urban healthworld: A Sowetan case study**	X	X	
A rural qualitative study **P4: Clinics, churches and healers: Health seeking of older women with chronic noncommunicable disease in rural South Africa**	X		X

In summary the thesis consists of five chapters. Chapter 1 - Study Background - locates the research question within current theoretical developments in public health practice and sociology. Various models and definitions of healthcare are presented, and key concepts are introduced. The chapter defines the problem statement and the study aim and objectives.

Chapter 2 – Methodology - describes the methodology of the study as a mixed-methods comparative case study. The chapter describes the study population, and identifies as the case study the narratives of chronic illness and accessing healthcare in each of the study sites. The study settings (Agincourt and Soweto) are described in detail, as well as the qualitative and quantitative study components.

Chapter 3 - Results - presents the results of both site studies, beginning with a presentation of the urban case study. Both case studies begin with discussions on the study context, and the key themes emerging from primary and secondary quantitative data analysis. The findings go on to discuss the key patterns emerging from the qualitative site studies.

Chapter 4 – Discussion - revisits the problem statement and study aim and objectives in light of the findings. We discuss the implications of the findings for healthcare policy in South Africa, as well as the theoretical implications of the study approach and findings. We also discuss the study limitations, and areas for future research.

Chapter 5 – Conclusion – summarises the key arguments of the thesis.

The second part of the integrative narrative includes the four papers emerging from the study. The first paper, **Chronic noncommunicable disease and healthcare access in middle-aged and older women living in Soweto, South Africa**, presents the descriptive results of a health-seeking behaviour survey conducted in Soweto. The second paper, A mixed methods exploration of patterns of healthcare utilization **of urban women with non-communicable disease in Soweto, South Africa**, is a follow-up paper which investigates the reasons behind some of the key findings of the first paper. The third paper, **Chronic illness and the urban healthworld: A Sowetan case study,** describes the qualitative study conducted in Soweto. The fourth paper, **Clinics, churches and healers: Health seeking of older women with chronic noncommunicable disease in rural South Africa,** describes the qualitative study conducted in Agincourt. The appendices include the ethics clearance certificates, consent form templates, the site summary notes for the qualitative case studies, quantitative and qualitative study instruments, the code sheet for the qualitative studies, and the code sheet used for secondary data analysis.

Methodology

2 Methodology

This study is a mixed-methods comparative case study of the healthcare access experiences of women with NCDs in an urban and rural area in South Africa. The core of the study methodology is a comparative qualitative case study, with quantitative methods serving to contextualise the findings.

2.1 Defining the case study

A case study is defined as an intensive study of a single case for the purpose of understanding a larger class of similar units (Gerring, 2007). In the present study, the case study focuses on descriptions of the experiences of illness and healthcare access of women with chronic illness in a rural and urban area. With reference to Thomas's definition of the case study (Thomas, 2011), such descriptions constitute the subject of the case study, whereas the object of the case study, that is, the theoretical frame which such descriptions elucidate, is the lifeworld/ healthworld of South African women with chronic illness. The case study is interpretive, focussing on how experiences of chronic illness and healthcare access are articulated in an urban and rural area, and exploring how these modes of articulation relate to the lifeworld/ healthworld.

The case study design resembles a "most similar" system of comparative case studies, which has been described as an exploratory investigation of an outcome of theoretical interest where both cases share similar factors, but intensive study of such cases reveal crucial differences contributing to different outcomes (Gerring, 2007). The study sites for this study are different, in that one may be described as "rural" and the other as "urban",

but in order to trace out the origin of any differences in the articulation of our study participants' illness and healthcare access experiences, I have tried to ensure that the study sites where the research was conducted was as similar as possible, at least in terms of the availability and affordability of healthcare facilities as well as access to basic resources such as water and electricity.

The choice of study participant, namely women with chronic illness was guided by two considerations. Firstly, the study was institutionally located within research and surveillance units for which there was ample demographic data for female caregivers residing in Soweto and Agincourt. Secondly, there is sufficient reason to accept such participants as well experienced in negotiating healthcare access, both on their own behalf and on behalf of their dependents (Nteta et al., 2010; Zwane 2005), making their views worthwhile soliciting and understanding.

2.2 The study sites

The urban component of the study was conducted in Bt20, a birth cohort study located in Johannesburg-Soweto, which enrolled all singleton children born to women resident in the area from April to June 1990. From its inception Bt20 has conducted multidisciplinary research in tracking the growth, health, wellbeing and educational progress of urban children throughout their lives in Soweto-Johannesburg (Richter et al., 2007).

The rural component of the study was conducted in Agincourt, a sub-district of the Bushbuckridge district in Mpumalanga Province, situated in rural north-east of South

Africa near the Mozambican border. Agincourt was established as a district health demonstration site in 1992 by the University of Witwatersrand's Health Systems Development Unit and the then "homeland" health service (Kahn et al., 2007; Robbins, 1997).

2.3 Describing the context of the case studies

2.3.1 Urban context (part 1): secondary data analysis

The context of the case studies were described using primary and secondary data. In Soweto, I used secondary data collected by Bt20 to construct a historical overview of the use of formal and informal healthcare services. These were indicated by composite variables based on measures and types of healthcare utilisation asked of the Bt20 caregivers in various successive waves of data collection. In particular, the variables are based on annual data collection from 1990 to 1995, and from 2002 to 2006. Diverse data on place of healthcare utilisation were recoded into a uniform categorical variable called "healthcare utilisation" which indicated 3 options:

1. Exclusive use of formal healthcare services;
2. Exclusive use of informal healthcare services; and
3. Mixed use of formal and informal healthcare services.

This data was used to present an overview of healthcare utilisation trends in Soweto.

2.3.2 Urban context (part 2): Soweto quantitative survey

Primary contextual data on healthcare access and beliefs were collected in Soweto by a large-scale survey. The survey was a cross sectional study of the primary caregivers (female heads of households) of the Bt20 cohort. A semi-structured questionnaire was

administered at home by a team of research assistants in the home language of the study participants (mainly seSotho and isiZulu) between November 2008 and June 2010.

- *Sampling*

The survey included all the Bt20 caregivers in the cohort residing in Soweto. I focused on Soweto for two reasons:

1) To conform to the principle of "most similar" comparative case studies, the urban case study was intended to be as homogeneous as possible, and to approximate as closely as possible the socio-economic features of the rural case study; and
2) The survey was intended to provide contextual information for Soweto, where the qualitative case study would be held.

- *The survey instrument*

The questionnaire included a number of domains. The demographic section included demographic measures, asset based socio-economic status, employment status, and religious affiliation and adherence. The general healthcare access section included measures of availability and affordability of healthcare services, medical aid and perceived obstacles to accessing public healthcare. The specific healthcare access section included measures of recent illness and healthcare services accessed, as well as experiences of the healthcare visit. The healthcare seeking behaviour section included measures of reliance on family and community networks for accessing healthcare and measures of patient strategy when interacting with formal healthcare systems. This section also included measures of use of traditional healers and self-rated assessments of

the efficacy of traditional healers. The final section included measures of NCD prevalence and the use of lifelong medication.

The measures in the final section of the questionnaire, as well the measures on general and specific healthcare access were adapted from the Adult Questionnaire of the South African Demographic and Health Survey (Department of Health et al., 2007). The questionnaire was piloted in October of 2008, and the final questionnaire administered from November 2008 to June 2010. The questionnaire took less than an hour to complete.

2.3.3 Urban context (part 3): The analysis of primary and secondary data

The primary data (data collected by the 2008-2010 survey) were descriptively analysed using STATA/ IC 10.0. A series of Pearson's chi-squared analyses described the basic relationships between demographic and disease state characteristics and healthcare seeking behaviour. The analysis included multiple logistic regressions to show the adjusted effects of individual, societal and healthcare system factors on healthcare utilization.

The secondary data were also analysed using STATA/IC 10.0, but in this instance, the data were applied to the question: Is there an increase in the exclusive use of formal healthcare services by caregivers in the Bt20 cohort over time? The hypothesis was that there had been an increase in the exclusive use of formal healthcare services by caregivers in the Bt20 cohort over time. Selecting a significance level of $p=0.05$ at the 95% confidence interval, I employed a Wilcoxon rank sum test for non-parametric data to test the hypothesis.

2.4 Conducting the case studies

For the qualitative case studies I employed a qualitative methodology incorporating serial narrative interviews to present an experience-based overview of concepts of disease causation, self treatment and coping. I collected the data in Soweto between October 2009 and February 2010; and in Agincourt between July and September 2010. Where possible, two interviews were conducted with each respondent in both study sites. Each interview was conducted in the home of the research participant. The primary questions were:

1. How do women experience chronic illness? And
2. How do women experience healthcare systems (formal and informal) in relation to their chronic illness?

2.4.1 Narrative Enquiry

Narrative enquiry is defined as revolving around an interest in the biographical particulars of the interview respondents as narrated by them (Chase, 2005). In the narrative interview, a conceptual shift is made from the question-answer format of traditional interviews, towards an interview which encourages respondents to tell their own story of living with chronic illness and accessing healthcare.

The interviews were open-ended to encourage respondents to tell their own stories of chronic illness and healthcare access using their own idioms. The interviews were also serial, or conducted twice with each respondent to encourage the telling of private (actual), as well as public (normative) accounts of chronic illness and healthcare access (Nettleton, 2006).

2.4.2 The qualitative study instrument

The choice of narrative enquiry as the primary methodology required me to view the interviewee as a narrator with a unique life history (Chase, 2005). As a result, I designed the interview guide to invite life histories around specific encounters, focusing on descriptions of chronic illness, initial reactions to disease, experiences and observations of allopathic and informal healthcare services, and the impact of chronic illness on social life.

2.4.3 Sampling in an urban and rural study setting

The sampling for the Soweto qualitative case study was based on the initial findings of the survey. I selected 12 women from a larger group of women who self-reported NCDs and the use of support systems in the healthcare access survey. At the midway point of data collection a group of women were randomly selected within a stratified population of women who had one or more NCDs and who were willing to participate in a follow-up study. This population was dually stratified by intensity of disease (determined by number of NCDs and the use of life long medication), and use of support systems (home based care or other support systems). Participants were selected within each stratum to ensure a broad range of experience, including mild and severe cases of chronic illness. All participants had lived with their condition for at least a year.

In Agincourt I employed a different sampling strategy. I conducted the research in 3 villages within the subdistrict, which were selected based on key informant discussions with resident researchers within the Agincourt research unit. In keeping with the “most similar” design of case studies, I selected three villages in the Agincourt sub-district

which, like much of Soweto, had local clinics and access to basic infrastructure. In this way both Agincourt and Soweto would have affordable formal healthcare services which were readily available, and so any differences in the findings of the qualitative studies would most likely emerge from acceptability factors. The research analysis would then focus on describing how these factors are shaped, as they in turn shape, the body narratives of the research participants, and what this process reveals about the lifeworld/ healthworld in these settings.

The villages selected for the rural case study were Agincourt, Cunningmoor A, and Kildare A. Agincourt village had one clinic, the Agincourt Health Centre, and one home based care organisation operating out of the clinic (Swa Koteka and LINC, 2010). Cunningmoor A was comparable to Agincourt in terms of facilities such as schools, churches, small businesses and communal water taps. The local clinic in Cunningmoor A, the Cunningmoor Clinic, was easily accessible to the villagers and rarely out of stock of medication (Swa Koteka and LINC, 2010). Cunningmoor A had a large proportion of former Mozambizan refugees residing in the village. In contrast with the other villages, many of the houses in Cunningmoor A had outdoor kitchens in the yard.

Kildare A was much the same as Agincourt and Cunningmoor A in terms of access to schools, churches, small businesses and communal taps, although unique in its atmosphere. More remote than the other two villages but less traditional, it had the feel of a desolate suburb. Most of the houses were newly built and surrounded by high brick walls, which was in stark contrast to Cunningmoor A and Agincourt, where the houses

were surrounded mainly by low wire fencing. Many of the houses in Kildare A were not completely built, and those that were seemed to be empty and locked, most of the occupants apparently at work. The nearest clinic was a little difficult to reach and often out of stock due to being visited by people from other villages (Swa Koteka and LINC, 2010).

We selected the rural study participants from a list of respondents within the three villages who had participated in the 2006 INDEPTH-World Health Organisation Study on Global Ageing and Adult Health. The original sample size for the WHO-INDEPTH study was 575, and consisted of men and women aged 50 and older (Gomez-Olive, et al., 2013). For the current study we selected participants from a list of 28 women in the three villages who had participated in the WHO-INDEPTH study, and who had indicated the presence of one or more long term illnesses, including arthritis, stroke, angina, diabetes, chronic lung disease, asthma, depression, hypertension, cataracts, and loss of teeth. We employed a purposive sampling technique to ensure sufficient variation in terms of village of residence and number of reported NCDs, and concluded our selection of participants once it became clear that the initial coding categories were exhausted. We completed a total of 25 interviews with 13 respondents.

2.4.4 Qualitative data analysis: Soweto and Agincourt

In each study site, data collection resembled a "grounded theory" approach, in that data collection and analysis occur concurrently, with each process informing each other, and data collection generally proceeding until a "saturation point" had been reached (referring to the exhaustion of conceptual categories for identifying key observations) (Kortraba et

al., 2003). In this initial phase of data analysis initial coding categories were derived through the analysis of detailed fieldnotes, and were generally applicable to each interview as a whole. These fieldnotes were based on debriefing sessions held immediately after the first interview.

The serial methodology enabled us to develop initial coding schemes during the process of data collection and present them to the research participants during the second interview. This method had been successfully used by Kotarba and colleagues (2003) in their qualitative study of inner strength of people with HIV/ AIDS, in which the study participants were encouraged to discuss their experiences chronologically and biographically.

After data collection was concluded we employed a content-analytic approach for the additional analysis of textual data. While the interview schedule provided a broad guide for formulating the analysis plan, additional layers of subthemes were inductively derived through the raw data (Zhang and Wildemuth, 2009). During this phase, the transcripts were hand coded (coded without recourse to software) using an open coding technique to sort through the data and develop additional coding categories. A dual process of data analysis was followed to sort through the interview transcripts:

1. Listening to voices within interviews: including the compilation of fieldnotes, inductive identification of themes and the compilation of interview summaries; and

2. Locating themes across interviews: including comparative analyses across all the interview transcripts conducted in the study site and the further development of the coding scheme and the collation of interview sections by theme.

An independent scientist not connected with the study followed the same inductive coding process with a sample of the transcripts and we found a high level of agreement in our coding. At this point, the data analyses were presented in separate research papers based on the qualitative site study conducted in each site.

For the presentation of the entire study in this thesis, a further stage of data analysis was conducted, involving the comparative analysis of the qualitative site studies, and the identification of key themes for further comparative research.

2.4.5 Reflexivity in urban and rural contexts

The concept of reflexivity refers to a recognition of the knowledgeable character of social participants, and entails a commitment by the social researcher to continually monitor his or her own motivation in conducting the research as well as the nature of the social interaction with the research participants (Giddens, 1997). This concept reminds us of the value of communicative action in the research process as an important resource in the production of research findings.

The process of data collection in the urban and rural setting contained a number of similarities and differences which begin to explain the findings. In both study sites I found myself in the position of an outsider. In both contexts I was dependent on the

assistance of a research assistant competent in the languages of the research participants, and who, in most cases, conducted the interviews.

At the same time there were some features of the "outsider" status which enhanced the (reflexive) quality of the interviews. The presence of an outsider often creates the social space in which topics of life with chronic illness and experiences of accessing healthcare can be formally discussed. It allowed the research participants to systematically reflect on this particular aspect of their lives. In addition, my experience as an outsider meant that every aspect of the study participants' lives took on the quality of a new experience, allowing me to be surprised and to take interest in those features of social life which might ordinarily have been taken for granted. For example, it appeared to me significant that all the interviews in Agincourt were conducted in the garden beneath a tree, whereas in Soweto they were conducted indoors. This was not due to seasonality, but rather indicated that the garden or field is more central in rural social life, and that there is a greater degree of communality with close neighbours in the rural setting.

The disparities in our social world gave rise to a number of research processes to ensure the reliability and validity of our data. In this respect, we followed a similar process in both study sites. In each study site I worked with a different research assistant, but in both cases we compiled detailed fieldnotes which identified key themes and concepts as an initial coding schema. In both study sites the recorded interviews were transcribed and translated by the research assistant, a sample of which was checked for accuracy. In Agincourt, the interviews were conducted in Shangaan, whereas in Soweto, eleven of the

interviews were conducted in English (in all cases the second language of the research participants), eight in Sotho, and four in Zulu.

Finally, it is worth noting some of the striking similarities in the research experience conducted in both sites. In particular the study participants in both sites were highly familiar with the research process, all of them having participated in previous research studies. Consequently the research participants were able to recognise and participate in the study in expected ways, although it must be said that the process of qualitative narrative research was new to them, and in many instances, it proved difficult to break out of the question-answer format and to induce autobiographical reflections.

2.5 Ethics

Each participant understood the purpose of the study: namely to investigate the experience of chronic illness and accessing healthcare in a rural and urban area. All personal information is kept confidential, and study participants are referred to by pseudonyms. Each participant gave her informed consent by signature to participate in the study and to have the interviews recorded and the recordings kept by the researcher for a period of 6 years. The research was approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (M090235).

Results

3 Results

This section begins with the presentation of the secondary quantitative data from Soweto, and the analysis of the primary data from Soweto. This is followed by a discussion of health and demography in Agincourt. Together, these subsections provide the context of the qualitative findings which follow. The qualitative findings from both site studies are presented separately. A comparative discussion of the case studies is presented in the next chapter.

3.1 The urban context

3.1.1 Historical trends in the use of formal and informal healthcare in Soweto

The following data on healthcare utilisation refers to utilisation of healthcare services by Bt20 caregivers on behalf of their children for various medical and developmental problems. While we should therefore be cautious in inferring from this data trends of healthcare utilisation for chronic illness, the data may be taken as broadly indicative of general healthcare utilisation trends in Soweto-Johannesburg from the early 1990s to around 2006.

From 1990 to 1992 caregivers reported on place of treatment for a range of childhood illnesses including sneezing, runny nose, eye problems, dry coughs, wet coughs, hoarseness, difficulty breathing, noisy breathing, rapid breathing, wheezing, runny ears, colic, diarrhoea, vomiting, poor fever, poor appetite, rash, irritability, worms and allergy.

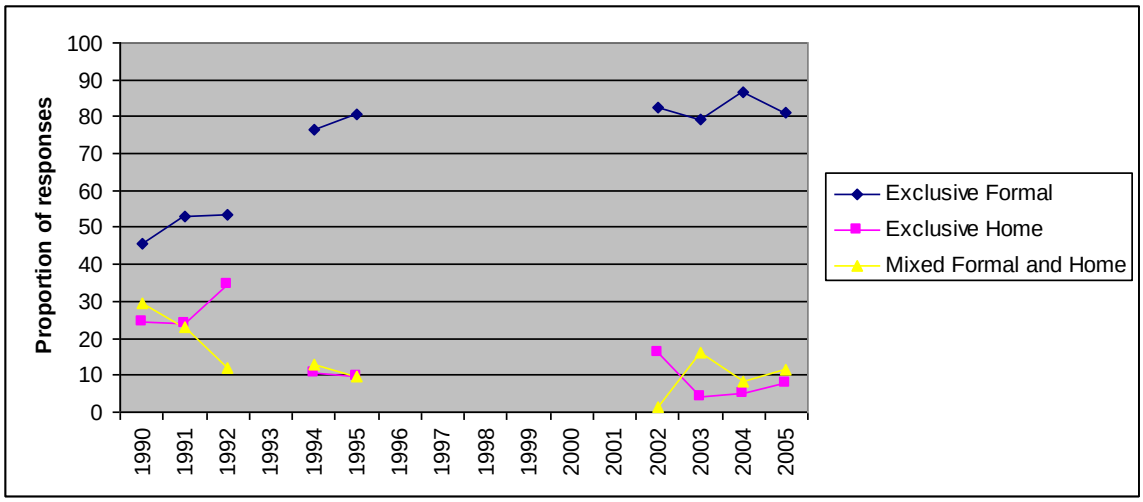
During the following years, namely, 1994, 1995, 2002, 2003, 2005 and 2006 these questions were left open-ended. In other words, caregivers were asked to specify any medical or developmental problems occurring with the child and where the child was treated.

The data from these years were recoded into three types of response:

1. Responses indicating exclusive use of formal healthcare services (including doctors, clinics, hospitals, therapists and dieticians);
2. Responses indicating the exclusive use of home-based treatment and informal healthcare services (including priests, ministers, churches, homeopaths, pharmacies and traditional healers); and
3. Responses indicating the mixed use of formal and informal healthcare services.

Below we include a diagrammatic representation of these reported utilisation patterns (Figure 6). The figure represents the proportion of responses to the place of treatment question by three categories, namely exculsive use of formal healthcare services, exclusive use of informal healthcare services, and mixed use of formal and informal healthcare services.

Figure 6: Overall use of Formal and Informal Healthcare from 6 months to 16 years



The data available for the analysis occurs in two phases: from 1990 to 1995, and from 2002 to 2006, with a large gap in the data from 1996 to 2001. Despite the gap in the data, a trend of increasing exclusive use of formal healthcare services and a decreasing trend of exclusively informal and mixed formal and informal healthcare utilisation is suggested by the cross-sectional analysis.

In order to confirm this trend, a mean healthcare utilisation score was created for both phases. This score was created by aggregating the instances of formal healthcare utilisation in both phases, and dividing it by the number of times the question was asked. The score represents a probability of exclusive use of formal healthcare utilisation in each of the phases. The same procedure was followed for exclusive use of informal healthcare services and the mixed use of formal and informal healthcare services. This process provides us with one score which is roughly representative of healthcare utilisation for

the entire phase; first from 1990 to 1995, and then from 2002 to 2006. The mean scores were compared by an unpaired means comparison test:

Table 2: Mean comparison of healthcare utilisation in different phases of healthcare use reported in the Bt20 cohort

	Mean 1990 to 1995	Mean 2002 to 2006 years	P value at 95% CI
Average Formal Healthcare Utilisation	0.611968	0.818473	0
Average Informal Healthcare Utilisation	0.209674	0.065325	0
Average Mixed Healthcare Utilisation	0.178358	0.116202	0

The unpaired means comparison test shows increasing exclusive use of formal healthcare services for childhood medical and developmental problems, and decreasing exclusive use of informal healthcare services and mixed use of formal and informal healthcare services. Although such findings should be interpreted with caution, the picture which emerges regarding broad healthcare utilisation trends in Soweto is one of increasing reliance on formal healthcare systems, represented by clinics, hospitals and private doctors, and the decreasing use of informal healthcare systems, represented by home remedies and traditional medicine.

3.1.2 Healthcare access and belief in Soweto: The 2008-2010 survey

The aim of this component of the study was to describe the current healthcare access, beliefs, and practices of middle-aged and old women residing in Soweto.

- *Study Demographics*

A total of 1102 women participated in the survey. The demographic profile of the survey sample describes a low resource population with a high prevalence of chronic illness.

Table 3: Population characteristics of Bt20 caregivers between 2008 and 2010 (N=1102)

Variable	Category	N	%
Age	30 to 39	266	24.1%
	40 to 49	589	53.5%
	50 to 65	245	22.2%
	Missing	2	0.2%
	Total	**1102**	**100%**
Socio-economic indicators (Ownership)	Indoor hot and cold water (n=1102)	405	36.8%
	Flush toilet inside (n=1102)	538	48.8%
	Live in house (n=1101)	980	88.9%
	Own house (n=1101)	885	80.3%
	Own motor vehicle (n=1099)	348	31.6%
	High SES (4-5 items)	190	17.2
	Medium SES (2-3 items)	496	45.0
	Low SES (0-1 items)	411	37.3
	Missing	5	0.5
	Total	**1102**	**100%**
Employment	Formal or informal paid labour	582	52.8%
	Housewife/ pensioner/ unemployed	519	47.1%
	Missing	1	0.1%
	Total	**1102**	**100%**
Self-reported chronic noncommunicable disease	No chronic disease	543	49.3%
	One chronic disease	339	30.8%
	More than one chronic disease	219	19.9%
	Missing	1	0.1%
	Total	**1102**	**100%**

The large majority of participants lived in and owned houses, which, however, were without sole access to indoor hot and cold water or indoor flush toilets (Table 3). Over one third (37.3%) of the population could be categorised as having a low socio-economic status, defined as access to only one or less of 5 socio-economic items, including indoor running hot and cold water, indoor flush toilets, living in a house, owning a house, and owning a motor vehicle.

Slightly over half the respondents (50.7%) reported having at least one NCD. Of this group, 32.5% had high blood pressure, 12.8% had arthritis, 8.7% had high blood cholesterol, and 6.5% had diabetes. The remaining 17.4% of responses were distributed over a variety of NCDs, which individually included less than 5% of the total responses. Of those reporting some form of chronic illness, over two-thirds (69%) used prescribed lifelong medication on a daily or regular basis. Respondents reported an average duration of chronic illness of 8 and a half years, with an average self-reported delay of treatment of about 9 and a half months.

- *Access to Healthcare Services*

Access to healthcare services was determined by measures of availability and affordability. The availability of healthcare services was determined by whether a healthcare service provider was available within a 2 km radius or 20 minute walking distance from the respondent. Those who reported availability of healthcare service providers in their neighbourhood were asked whether they felt the services were affordable for them.

Table 4: Access to healthcare services in Soweto as reported by Bt20 caregivers between 2008 and 2010) (N=1102)

	Proportion of respondents reporting availability within 2km radius	Proportion of respondents reporting affordability (if available)
Private medical practice (n=1102)	75.1%	59.1%
Private hospital or clinic (n=1102)	7.4%	52.4%
Government or community clinic (n=1102)	61.5%	83.6%
Government hospital (n=1102)	3.9%	88.4%
Community organisation (n=1102)	30%	63.8%
Pharmacist (n=1101)	37%	72.9%
Sangoma or traditional healer (n=1101)	32.1%	28.2%
Herbalist (n=1101)	15%	63.9%
Faith Healer or priest (n=1102)	18.2%	57.5%

Private medical practices were more easily available than government clinics (75.1% and 61.5% respectively), although not as affordable (59.1% and 83.6% respectively) (Table 4). While sangomas were easily available for almost a third of the respondents (32.1%), they were reported as the least affordable (28.2%) of the formal and informal healthcare services.

An additive index of formal healthcare services, including private doctors, hospitals and clinics and public hospitals and clinics, shows that around 85.8% of the respondents had

at least one type of healthcare service available within a 2 km radius of their homes. Of this group 18% felt that these services were unaffordable. Around 17.4% of respondents had medical aid.

- *Experiences of Healthcare Services*

In the context of a high prevalence of NCDs in the study population, it is surprising that slightly less than a quarter of the respondents (24.3%) reported an illness within the last 6 months which obliged them to access a healthcare service. The precise phrasing of the question was: 'Have you had any illness or condition in the last 6 months so that you have had to seek treatment or healthcare?' Those with chronic illness were significantly more likely to report such illnesses ($p<0.05$), with around a third (33.3%) actually doing so.

All participants reporting an illness in the last 6 months (n=268) were grouped into the following categories:

1) Trauma, including accidents, burns, and operations;
2) General ailments, including problems with ears, teeth, sinuses etc.,
3) Infectious diseases, such as bronchitis, TB, HIV, and infections; and
4) NCDs, including osteoporosis, hypertension, diabetes, and arthritis.

Most of those respondents reporting an illness in the last 6 months had general ailments (35.8%), followed by NCDs (34.3%). Around 22% reported infectious diseases in the last 6 months, while 7.8% reported trauma.

Over half the respondents (60.5%) who reported a disease or condition treated their illnesses at a public healthcare facility (defined as a government clinic or hospital), with the remainder utilising some form of private healthcare service (private medical practice, private hospital or clinic, self-treatment and pharmacist). None of the respondents reported visiting sangomas or herbalists. Respondents with chronic illness were significantly more likely to utilise public healthcare services, particularly public clinics, and less likely to utilise private healthcare services ($p<0.05$), reflecting repeat visits for the collection of medication. Other than this, the type of illness reported appeared to have no further effect on choice of healthcare provider.

A series of questions focused on the experiences of respondents who had accessed healthcare services in the last 6 months. Users of public clinics were more likely to report waiting times of over half an hour ($p<0.01$), consultation times of less than 10 minutes ($p<0.01$), more likely to access the services by walking ($p<0.001$), and less likely to incur expenses ($p<0.001$). Only about a third (32%) of those accessing private hospitals or clinics incurred expenses. The possession of medical aid was significantly likely ($p<0.001$) to influence the choice of a private healthcare provider, particularly private doctors and clinics.

We asked all respondents (n=1 102) what were the main problems they experienced in accessing healthcare from government clinics and hospitals. The top five problems (mentioned by over 75% of respondents) were long waiting times (24.5%), unfriendly staff or poor service (17.8%), lack of medication (17.3%), overcrowding (13.9%), and

short consultation times (5%). Around 12% of respondents felt that there were no problems in accessing public healthcare services.

We asked the research participants a separate question about whether there were some diseases which could only be treated by traditional healers, and not by doctors. Slightly less than a third (31.8%) of respondents felt that there were some diseases which could only be treated by traditional healers. We grouped these responses into different categories, the top three being ‘witchcraft/ curses/ poisoning/ evil spirits’ (23%), ‘fits/ headache/ mental illness’ (17.7%) and ‘HIV/ AIDS’ (12.8%). Around 10% (9.9%) felt that various forms of chronic illness (mostly ‘stroke’, or ‘high blood’ and to a lesser extent diabetes) could be treated properly only by traditional healers.

- *Social characteristics and healthcare access*

In order to explain the apparently low healthcare utilisation of participants with NCDs, we examined the relationships existing between social characteristics and disease status (Table 5), focusing particularly on those respondents with NCDs (excluding from the analysis respondents with TB).

Table 5: Correlating healthcare utilisation of persons with NCDs with individual, societal and healthcare system determinants in the Bt20 cohort 2008-2010 (N=1089)

		Utilization	**No utilization**	**Total**	**P-value**
Individual Determinants	Age (mean ± SD) (N=545)	46 ± 6.7	45.1 ± 6.5	45.7 ± 6.6	p=0.07
	Socioeconomic Status (N=542)				
	Low	34 (18.9%)	51 (14.1%)	85 (15.7%)	p=0.15
	Medium to High	146 (81.1%)	311 (85.9%)	457 (84.3%)	
	Employment (N=545)				
	Formal or informal paid labor	81 (44.8%)	144 (39.6%)	225 (41.3%)	p=0.25
	Housewife/ pensioner/ unemployed	100 (55.3%)	220 (60.4%)	320 (58.7%)	
	Medical aid (N=545)	41 (22.7%)	52 (14.3%)	93 (17.1%)	p=0.01
	Regular medication (N=545)	126 (69.6%)	253 (69.5%)	379 (69.5%)	p=0.98
Societal Determinants	Social support for participants with chronic disease				
	Shared hlth beliefs family (N=545)	179 (98.9%)	361 (99.2%)	540 (99.1%)	p=0.75
	Shared hlth beliefs comm (N=545)	142 (78.5%)	302 (83%)	444 (81.5%)	p=0.2
	Specific belief in traditional healers (N=542)	66 (36.9%)	108 (29.8%)	174 (32.1%)	p=0.09
	Use of patient strategies (N=545)	61 (33.7%)	89 (24.5%)	150 (27.5%)	p=0.02
Healthcare System	Availability of formal healthcare services (N=545)	165 (91.2%)	306 (84.1%)	471 (86.4%)	p=0.02
	Affordability of formal healthcare services (N=545)	136 (75.1%)	244 (67%)	380 (69.7%)	p=0.05

A means comparison test suggests that the age of women with an NCD, was closely, although not significantly, related to healthcare utilization (p=0.07) (Table 5). Pearson's chi-square tests indicate that the possession of medical aid was the strongest individual level factor influencing the utilization of healthcare (p=0.01). Amongst societal level factors, the self-reported use of patient strategies was significantly related to the utilization of healthcare services. The use of patient strategies was determined by the combination of two statistically associated Likert-scale measures regarding the selective

disclosure of the symptoms of illness, and the private rehearsal of what symptoms to present to formal healthcare workers. Those respondents with NCDs who admitted to using patient strategies when consulting healthcare workers were significantly more likely to utilize healthcare services (p=0.02). Specific belief in traditional healers, or the belief that there were some conditions which could only be treated by traditional healers, and not by doctors, was closely, although not significantly related to healthcare utilization (p=0.09), the results showing that such beliefs were positively associated with healthcare utilization. Both availability and affordability of healthcare services were significantly positively related to reported healthcare utilization (p=0.02 and p=0.05).

Logistic regression of individual, societal and healthcare system factors influencing the utilization of healthcare services in the last six months by persons with NCDs confirms the importance of the possession of medical aid for utilizing healthcare services (OR=1.7, CI=1.01-2.84). It also confirms the close relationship between healthcare utilization and the use of patient strategies for negotiating healthcare access (OR=1.6, CI=1.04-2.34).

3.2 The Rural context

3.2.1 Population trends in the Agincourt subdistrict

The settlement patterns in Agincourt are typical of rural communities across South Africa, particularly within areas ("homelands") previously demarcated for black inhabitants of South Africa under the Apartheid regime. Being itself located in a former homeland in north eastern South Africa, the study setting consists of a number of densely populated villages surrounded by fields used for grazing and harvesting of natural

resources (Hunter et al., 2007). Plots of land are generally too small to support subsistence farming (Kahn et al., 2007). Reliance on foraging in the surrounding countryside to supplement diets remains a common feature of household life in Agincourt (Hunter et al., 2007).

At the time of data collection, infrastructure within the Agincourt sub-district was limited, although undergoing rapid development. The area was marked by an absence of formal sanitation, erratic supply of piped water to communal standpipes, gravel roads and limited electricity supply. Local employment and farming was limited, with most adults seeking work elsewhere. There was one health centre and five satellite clinics within the site, and three public hospitals within 60 kilometers of the site (Kahn et al., 2007).

The historical pattern of circular migration to and from a densely populated rural reserve has persisted in the period since the demise of apartheid. Agincourt is still characterised by large numbers of separated families, with about 60% of men and 20% of women aged 20 to 60 years regularly migrating to and from the countryside (Clark et al., 2007). Return migration back to rural homes with the progression of illness and death is a significant feature of the Agincourt countryside, although the cause of death and illness has shifted in recent years with increasing prevalence of HIV/ AIDS. This has created a household situation characterised by loss of household income coupled with the burden of caring for ill and dying family members (Clark et al., 2007).

3.2.2 Health status in Agincourt

The extensive research work in Agincourt has revealed an increasing mortality rate in children and young adults during the mid 1990s. Up until 2005, there has been an 87% increase in all cause mortality resulting largely from an increase in infectious disease, as well as an increase in NCDs in adults (Kahn et al., 2007b; Tollman et al., 2008).

The INDEPTH-WHO study conducted in Agincourt suggests that the prevalence of NCDs in Agincourt is comparable to that in Soweto, with 42% of the study participants reporting muscularskeletal pain and 31% reporting hypertension. Around 43% of participants who did not report hypertension had high blood pressure levels compatible with hypertension (Gomez-Olive et al., 2013). Elsewhere, hypertension has been reported as the commonest risk factor in Agincourt, with 43% of the population having some degree of hypertension (Thorogood, 2007).

The INDEPTH-WHO study reports that around 80% of participants who had hypertension reported taking medication for their condition in the last 12 months, but also shows similar trends with the Soweto data in that 43% of the sample, a third of whom had been diagnosed with a NCD, reported not needing any healthcare in the last 12 months (Gomez-Olive et al., 2013). This may be due to the presence of multiple disease narratives. For example, Thorogood and colleagues (2007) have found that hypertension is understood both naturalistically and socially in Agincourt, resulting in a variety of treatments commensurate with the differing causes. High levels of sugar and fats in modern diets, heredity and "thinking too much" about personal difficulties were

commonly sited causes for hypertension in Agincourt. The use of prayer and treatment by a prophet or healer in conjunction with herbal mixtures and tablets obtained from the clinic is not unusual (Thorogood, 2007). However, Thorogood and colleagues (2007) point out that the majority of people with high blood pressure (around 76%) were not taking any treatment, due, they explain, to obstacles originating at the clinic.

Notions of health and disease in Agincourt consist of both western scientific orthodoxy and traditional understandings of disease causation (Posel et al., 2007). Adoption of scientific orthodoxies merely supplement natural explanations for illness, such as eating too much sugar as a cause of diabetes or exposure to dust causing TB in mine workers. In addition to these explanations are explanations which focus on the (mis)application of human agency, either through the violation of cultural taboos or through witchcraft (Golloba-Mutebi and Tollman, 2007).

Posel and colleagues (2007) found in a series of focus groups that traditional discourses underlie popular understandings of HIV/ AIDS, even those which, on the surface, resemble the western scientific orthodoxy. Deaths brought about by HIV/ AIDS are seen as "bad deaths' having social and cultural causes typical of traditional medicine (Posel et al., 1997). Death and illness are accepted as the inevitable result of the erosion of traditional social relations, especially during the post-apartheid democratic period in South Africa. The close association of western formal institutions with the erosion of traditional values manifests in the suspicion that public healthcare services are directly responsible for the sick and dying society (Posel et al., 2007).

3.3 The qualitative case studies

3.3.1 A brief description of the study participants

For the qualitative site studies a total of 22 interviews were conducted with 12 participants in Soweto, and a total of 25 interviews were conducted with 13 participants in Agincourt.

Table 6: Quantitative comparison of case study participants in Soweto (N=12) and Agincourt (N=13) 2009-2010

	Soweto (N=12)	**Agincourt (N=13)**
Age (mean)	54.9	70.9
Age (range)	45-91	55-90
Hypertension	7 (58.3%)	11 (84.6%)
Muscularskeletal pain	7 (58.3%)	6 (46.2%)
Diabetes	4 (33.3%)	4 (30.8%)
Other	7 (58.3%)	4 (30.8%)
Comorbiity	9 (75%)	10 (76.9%)
Allopathic treatment	12 (100%)	12 (92.3%)
Alternative treatment	6 (50%)	8 (61.5%)

There was a difference in the age ranges in both study sites (Table 6). The participants in Soweto were younger, with an age range of 45 to 91. Ten of the 12 respondents were under 60 years of age. In Agincourt the age of participants ranged from 55 to 90 years, with only one of the participants being under the age of 60. The discrepancy in age across

both study sites was due to the different nature of the sampling frames. In Soweto, the sampling frame consisted of the Bt20 caregivers, the biological mothers of children born in 1990. In Agincourt, the sampling frame was specifically fixed at inividuals over the age of 50.

There was no great difference in the range of chronic illnesses of the research participants in both sites. Most of the respondents in Agincourt (11 out of 13) described symptoms of hypertension ("high blood"), whereas in Soweto seven of the twelve participants described these symptoms. Six of the 13 in Agincourt, and seven of the twelve in Soweto described symptoms of arthritis, while diabetes was mentioned by four participants in each site. In both sites all but three participants mentioned a combination of these and other symptoms.

The severest cases of chronic illness were found in the Soweto site study, a fact which may be partially attributed to the sampling, as the sampling frame in Agincourt did not include women with cancer, or communicable chronic disease. In Soweto one participant had cancer and one participant had HIV/ AIDS and TB. There were also severe cases of the other chronic illnesses in Soweto. One participant with arthritis had also developed a hump in her spine due to childhood TB. Another participant had visible symptoms of stroke, while a third described very severe symptoms of arthritis. By contrast, only one participant in the Agincourt sample was visibly affected by her chronic illness, in this case a crippled leg.

Quantitatively, the two groups were similar in terms of their acceptance of formal healthcare services. All of the participants in Soweto, and all but one of the participants in Agincourt primarily used formal healthcare services to cope with their condition. In Agincourt 8 participants, and 6 participants in Soweto, reported using some form of complementary medicine.

These initial differences in the sample, particularly those related to severity of illness, may lead us to expect a more stark description of the implications of chronic illness in every day life in Soweto. The fact that most of the women in Agincourt were older suggests that many of them were receiving pensions, ensuring a greater degree of flexibility in the management of their day-today lives.

Bearing these key similarities and differences in mind, we may now proceed to the identification of the key themes and patterns of the respective experiences of chronic illness and healthcare access in both study sites. We first present each case study in its own right, before proceeding to a comparative discussion. In both case studies and the comparative discussion, key patterns of understanding chronic illness and healthcare access are presented within each of the three themes discussed in the interviews, namely initial experiences of chronic illness, experiences of healthcare systems, and living with chronic illness.

3.3.2 The urban case study (Soweto)

- *The Experience of Chronic Illness*

In Soweto, due to the presence of study participants with severe cases of chronic illness, the implications of chronic illness were more dwelt upon, as in the case of Thandi, aged 49, who had arthritis. During the interview she stated that at one time she underestimated her disease: "When you are young you don't see it's a problem" (Thandi, 49, Soweto). However this view changed with the development and experience of arthritis. She went on to say:

> When you are locked in your bones, in your knees, you can't walk. When your spine is shifted, you can't move. You can't do anything. So the pain in your body is so painful, the pain in your body. It is so painful that you can't sleep, you can't do anything, and there are no tablets which can help you. (Thandi, 49, Soweto)

In this particular case, Thandi reported using a combination of healthcare approaches to manage her illness. She initially consulted a doctor, and was advised that she had arthritis of the spine. She was advised to go for an operation, but refused, and subsequently treated her condition by wearing a special corset recommended by the doctor. She said of the tablets recommended to her by the doctor, "it works just to minimize the pain. It's not something that is healing" (Thandi, 49, Soweto). Rather, she concentrated her treatment plan on the taking of a cinnamon and honey mixture, which was recommended to her by a friend. She said of this mixture, contrasting it with the tablets prescribed by her doctor:

"It heals. It is not going to harm me" (Thandi, 49, Soweto). She attributed to this mixture her remarkable recovery from the initial symptoms of arthritis: "Now I am walking, I am doing everything" (Thandi, 49, Soweto).

In the Soweto interviews we found that the experience of severe impairment of bodily functioning and its social consequences were decisive factors in finally impelling individuals to seek formally organised or purposive-rational healthcare, as is evident in the following excerpts:

> I was at church, I couldn't see….I could see somebody, but I couldn't realise who was that. You know, at the congregation we know each other, but I couldn't recognise who was sitting over there. (Rosaline, 49, Soweto)

> …lately talking to people with this problem I realised that it was serious. Then I started taking it serious. Then I went to the clinic. (Shirley, 53, Soweto)

Complex Aetiologies

Problems within the family, such as disease, death, and unemployment were spoken of as causes of Chronic illness. Chronic illness was related to crises brought about by the accumulated strains of life. Two respondents ascribed their diseased condition to the strains of looking after their grandchildren, in one instance due to the death of the parent.

Sarafina traced her arthritis to the time just after she married, when she was living with her husband's family, and, to relieve the stress, she would do the washing:

> I used to wash a lot with my hands. I was taking out the stress. I was living with my in-laws by then, so I was taking out the stress with my washing. (Sarafina, 45, Soweto)

Sarafina was a married and self-employed business woman who baked and sold confectionary. Although she initially said that her arthritis was not very severe, during the course of the interview it became clear that her condition was at one time fairly severe, and still had an impact on her life. On the advice of her husband, she consulted a private doctor in the neighbourhood who prescribed some tablets which she shortly afterwards discontinued. Her greatest help in coping with arthritis she felt were the black rubber rings and bracelets which she wore on her hands. She explained:

> I was in the [minibus] taxi and there was an elder guy at my left side. I was taking money from the back. Yabona, every time, when I lift my hand it will 'Qa', it will make a sound 'Qa! Qa! Qa!', and that gentleman said to me … 'You know this bracelet from the paraffin drums?' I said 'Yes', 'You must use them. Wear those bracelets, I am telling you, your arthritis will be fine.' …. He told me that my bones are fragile and what. And since then they helped me a lot (Sarafina, 45, Soweto).

In this narrative it is clear that Sarafina's knowledge of her condition and how to treat it was based on a background stock of knowledge which included diverse explanations and technologies of healthcare. She spoke further of living with arthritis:

> And arthritis, it doesn't want you just to stay holding hands. You must use your hands, you must walk. You must stretch your bones, otherwise….My mum's older sister, but she has passed on now, her hands were like this...crooked. You see, like this. It is arthritis, and she was so lazy, you know, and I used to tell her, 'Use your hands!' and she will say 'No, they are so painful', and I will tell her 'Use them! Use your hands. Wash the dishes with warm water.' You know? 'Do the dusting….' You see? (Sarafina, 45, Soweto)

This narrative shows how the experience of chronic illness was communicatively rationalised, enabling Sarafina to connect her experiences of chronic illness with life stories and with culturally transmitted stocks of knowledge. In this instance, the body narrative is presented as an ongoing test of endurance which serves the purpose of character development.

In Soweto there were also instances of potential ruptures in the healthworld by system encounters. Two respondents spoke at length about medical causes for their condition: Linda, aged 49, suffering from high blood pressure and symptoms of stroke, and Monica,

aged 50, who, together with arthritis, had a disability resulting from poorly treated childhood tuberculosis.

Linda had experienced two strokes. She initially underestimated her illness, saying "I didn't think what I was having, it was so serious. I was feeling better then. I never thought anything would happen" (Linda, 49, Soweto). Her encounters with formal healthcare systems disrupted her initial estimation of her illness, creating conditions of increased anxiety, as is evident in the following excerpt:

> I just went to the doctor. I didn't think there was anything happening with the heart. I did go there for the flu. Then even the doctor he didn't say anything, he just opened the heart, (unclear), but I didn't say anything to do with the heart. I didn't say anything to do with heart. (Linda, 49, Soweto)

Linda went on to describe with great emotion her history of multiple heart operations, which she connected with her strokes:

> Yes, after I just had the op, I had a stroke, and then I had another op, and then another stroke. So first operation, then stroke, then another op, then a stroke again. (Linda, 49, Soweto)

Linda also spoke of high levels of stress due to the strains in her relationship with her husband, which became particularly severe when she ran out of prescribed medication. At the same time, Linda was able to integrate her experiences in a redeeming body narrative. Despite the trauma of the heart operations she felt that they were beneficial saying "I think the doctor did help me for my health, and it has changed my life a lot" (Linda, 49, Soweto). She suffered from severe speech impairment as a result of the stroke, but found positive value in the experience, largely through her ability to relate the experience to a religious narrative:

> I think with my heart, I talk a lot with my heart. I talk with my heart. A lot of people told me, I always talk with my heart, since the operation I always talk with my heart and then the pain starts in my heart. (Linda, 49, Soweto)

She described the constant solace she derived from her religious beliefs, saying "God loves me. Even now, he gives me health" (Linda, 49, Soweto). This enabled her to connect the traumatic events in her life to the development of her character. Talking with the heart, although painful, is expressed as an accomplishment of withstanding severe sufferings.

- *The Experience of Healthcare*

The clinic is the first point of entry in the overall healthcare system, offering a range of free basic services at the community level. In Soweto the visit had become a familiar routine, taking place about once a month. Respondents described a dual procedure at the

clinic: one for dispensing prescribed medication, and the other for diagnosis and treatment:

> The way they treat patients doesn't change, it's the same way. Each and every nurse turns the clinic card and checks what the last one gave and then follows the same route in giving you the same medication without checking you, unless you say that you are not feeling well. Then and only then will they check you. (Joyce, 70, Soweto)

The process for dispensing medicine is, on the surface, a quick and efficient one: the visit to the clinic is entered into a personal file and a prescription is issued. The process is called "repeats":

> Now at the clinic they have got, they call it "repeats". When you go there they just view your card, they put the stamp, and they sign for which room to go. You don't queue, you just go to fetch your medication, and they don't help you, they don't take your blood pressure and your sugar (Rosaline, 49, Soweto).

The uniformity and repetitiveness of the clinic bureaucracy is encountered both as an accomplishment of purposive-rational action and as a barrier to communicative action. It is an accomplishment of purposive-rational action in that it shortens the amount of time required to obtain the medication, and a barrier to communicative action in that there is

no personal attention, or attempt to connect the unique diseased condition to larger frameworks of meaning. The dissatisfaction is apparent in the following statement:

> Hayi, at the clinic it is the same. Even when you explain they will just give you those tablets the "bruffens", the pain block. (Monica, 50, Soweto)

Narratives of conflict at the clinic are expressed largely as frustration, as in the cases above. The narratives speak of the depersonalising influence of the formalised social interactions at the clinic. The resulting frustration is further expressed by one respondent:

> …when you get into that room, you are sick and tired of them [the nurses], you don't even want to talk to them, because you wait there for a long time, you just want to get your pills and go, you are not even friends when you get there. (Shirley, 53, Soweto)

The descriptions of the visit to the clinic are remarkably similar in their identification of the bureaucratic features of the healthcare encounter. The visit to the clinic is described as a consequence of disease, but one which does not directly assist the participant in the construction of body narratives.

Medicine-taking

Respondents in Soweto identified three limitations of medicine from the clinic: 1) Its effects are temporary; 2) They treat the symptoms of disease (mainly by blocking the

pain) rather than the causes; and 3) They have potentially harmful side-effects. However, more important than these limitations was the conception of medicine from the clinic as extending purposive rationality within the body (colonising the lifeworld).

The primary purpose for visiting the clinic was to collect medication. In Soweto we found a preoccupation with how the medicine from the clinic interacts with the body. This potentially creates conditions for dissonance in the ongoing attempt to construct communicatively rational body narratives. This is illustrated in the following narratives:

> I don't feel good about it. It's just that I don't have a choice. Sometimes it does irritate to have to take tablets. It's not a nice thing. (Joyce, 70, Soweto)

Shirley articulated her ambivalence as concern about what the pills were doing to her body:

> But when I'm alone I ask myself "I take these tablets everyday, and then, what are they doing to my body?" and then you know what I do? I drink a lot of water. I think I'm washing them out. (Shirley, 53, Soweto)

Rosaline related her experience as follows:

> Once I was washing dishes, so one tablet…fell on the floor. So I said "OK, I'll take another one". So I take that pill and throw it in the sink. I close the tap, and wash the dishes. I finish, take out the water and, I thought, you know it would melt, and it didn't, and from there I get worried. "What is happening? What is going on when I drink these tablets everyday in my system? Where does it….?" I don't know where it is going. What is going on in my system? You know? You drink that pill everyday, and you know? And I sit down, and take that pill, and take two spoons and I try to press it, to squeeze it, to squeeze it. It never squeezes. You know? [starts to laugh]. (Rosaline, 49, Soweto)

Rosaline relied mainly on Chinese teas to regulate her high blood pressure, although she intermittently took the tablets from the clinic. Her goal was to wean herself off the clinic medication. Her narrative shows how medication which is identified with purposive-rational systems comes to be seen as a foreign element within the body, something which interferes with "my system" (Rosaline, 49, Soweto). The reflexive features of this narrative, such as self-deprecating humour and observation, incorporate the distressing encounter with purposive-rational systems into an overarching body narrative enabling diverse healthcare action.

- *Living with chronic illness: the search for alternatives*

In the Soweto case study, we found that the search for alternative remedies took place not as an attempt to treat chronic illness, but to reach a deeper understanding of the diseased

state of the body, or to construct a coherent body narrative. This is illustrated in the following case study:

Anna, aged 54, developed diabetes in 2000 and high blood pressure in 2002. She was then diagnosed with arthritis in 2007, and experienced heart failure in 2009. She regularly attended the local clinic once a month. She identified a number of problems at the clinic: long queues, shortages of medication, and being turned away when she arrived later than usual. She took her medication everyday, seven tablets in the morning and one at night, and was ambivalent about its efficacy, saying: "You find that today I'm OK, tomorrow I'm not, that's the only thing" (Interview, 10 November 2009).

In addition to her clinical regimen, she also reported taking a variety of alternative medicines, including a home remedy prepared by a neighbour, intermittent visits to a Chinese clinic, and, most importantly for her, the soqi gym. Soqi refers to an alternative therapy incorporating natural healing therapies and various machines intended to balance the body's thermal, nutritional, electromagnetic and motion energies (Chi Machine International, 2012).

Anna first found out about Soqi when she received a pamphlet advertising free treatment in central Johannesburg. Since that time she attended the free Soqi sessions, given by people in uniform, on almost a daily basis, saying "I live there, at the machines". She felt that soqi gym had been her biggest help in coping with her chronic illness:

> I had chubabas [black spots] on my face and on my nose before I went there. Soqi gym cleans your blood. You see, when you get there you lie down and let them move the machine all over your body. Even those who look like they are dying or found on the street get well. As long as they get to the machines, their illnesses are nothing. People get there very early, like at 2 in the morning, because its long queues. I once slept there myself on card boxes just so I can get in when they open. They even sell the machines now around 6000. If I had means I will buy it and make some money. (Anna, 54, Soweto)

Her attendance at the soqi gym complemented her attendance at the clinic:

> …since I have been going to soqi gym I even gets repeats at the clinic, so when I go to the clinic I only get tablets and they will check me maybe in January, after 2 months. (Anna, 54, Soweto).

The narrative presents a stark contrast between ideologically contrasting systems of healthcare, both of which demonstrate features of formal rationality, namely formal systems of dispensation (queues) and representation (uniforms). Both make use of technologies whose precise operations are beyond the immediate cogency of participants (tablets in the case of clinics, and 'machines' in the case of the soqi gym), and which instantiate broader realms of technology, or systematised knowledge claims on the ontological nature of the body and the emergence and treatment of disease. This narrative

gives no indication of greater knowledge of the alternative treatment, nor does it show how such treatment connects immediate diseased conditions to broader narratives. It only shows high levels of enthusiasm for an alternative remedy based either on the belief of its efficacy in the treatment of chronic illness or on its unconventional nature.

This may be contrasted with another case study. Prudence, also aged 54 did not use alternative medicine, nor did she fear or question the clinical regimen. She did not construct lengthy narratives during her interview, but answered the various probing questions concisely and briefly. She was diagnosed with arthritis and high blood pressure, as well as with heart failure. She was referred to a hospital outside of Soweto for treatment, and then to another hospital inside Soweto, before finally requesting and obtaining regular treatment at her local clinic. She did occasional work to support her grandchildren, whom she had cared for since the death of her son. Her narrative is notable for its complete absence of references to alternative healing paradigms. She summarised her experiences as follows:

> I have arthritis and high blood. So at the clinic they discovered that I have heart failure and they sent me to Helen Joseph. So I don't have money to go there anymore since I have to pay for transport. So when I went to start at Tladi clinic they gave me a card and told me to go back to Helen Joseph so that they can write down the medication they used to give me, but now, because I do not have money, and I'm a bit tied up by the grandchildren, I'm waiting for month-end so that I can go there

> and they will do that, and then I will be able to take treatment here at Tladi because I can walk there. (Prudence, 54, Soweto)

This narrative was unique in our data collection because of its absence not only of references to alternative healing paradigms, but also of expressions of fear or regret with having to attend the clinic. This respondent chose to focus only on the clinic for the treatment of her chronic illness. She was able to construct a coherent body narrative without recourse to alternative medication, but neither does her account indicate a passive reception of formal healthcare paradigms. Her treatment of the formal healthcare system as a bureaucracy displayed features of resistance through a relentless engagement with the healthcare system. Her understanding of well-being was predominated by her concern for the well-being of her family, who were in difficult circumstances due to a lack of income, prompting her to say at the end of the interview: "I wish I could get grant money" (Prudence, 54, Soweto).

3.3.3 The Rural Case Study (Agincourt)

- *The experience of chronic illness*

In Agincourt respondents described a variety of symptoms of chronic illness ("high blood", "dizziness", "headaches", "not having power", "sugar diabetes", and "stress"), but in many cases they tended to understate the severity of their illness. For example, respondents answered the question "What is your condition?" in various ways:

> I am fine, it's just that I was not feeling well. (Linah, 60, Agincourt)

> I can say that I am not that much ill exactly. (Katherine, 63, Agincourt)
>
> I consulted the doctor, but I was taking it easy. (Thabiso, 61, Agincourt)

None of the participants appeared particularly uncomfortable during the interviews. The chronic illnesses imposed some inconvenience, but they were not in themselves major causes of distress. They were described as "just the illnesses of nowadays" (Katherine, 63, Agincourt) Most respondents had resorted to using their pension money to employ people to help them farm and perform domestic duties, particularly washing.

Complex Aetiologies

Three broad explanations for the causes of chronic illness emerged from the interviews in Agincourt: 1) Occupational causes: resulting from strenuous work; 2) Dietary causes: related to increase of meats, oil, sugar and processed food in diets; and 3) Social causes: related to "thinking too much" about family difficulties, such as the loss of children.

Thabiso, aged 61, attributed her high blood pressure solely to her diet, and later went on to describe how she treated her chronic illness by avoiding junkfood. Marta, aged 82, said:

> I don't know, but I think it is because of the food that we are eating every day, for example too much meat and food with too much oil. We don't eat vegetables and other food that we were getting from the farm. Nowadays we're used to buying food. (Marta, 82, Agincourt)

Social causes, however, were most prominent in the interviews, particularly as they related to stressful social circumstances, such as the stress of losing a family member or the stress of motherhood, as described by 63 year old Katherine:

> If you are a mother everything that is painful it will pass by you. (Katherine, 63, Agincourt)

The death of a relative may also bring about different types of stress, depending on the social environment of the surviving relations. It might bring about extreme anxiety related to isolation and vulnerability, as expressed below:

> I'm staying alone, no one to talk to and no one to share anything. So I'm thinking that maybe they will attack me and kill me. Besides as I'm having sugar diabetes what if it drops? Who will assist me? (Hunadi, 67, Agincourt)

In this excerpt, the chronic illness (diabetes) is only a secondary cause of anxiety. Her real anxiety emerged from the fact that she was living a relatively isolated and solitary life.

Whereas all the participants could refer to some form of care they were receiving from family members, a few spoke at greater length about their own caregiving roles within their families. In Agincourt two respondents were caring for their grandchildren due to

the death of their children. These respondents, who both had high blood pressure, attributed their disease to the stress of looking after their grandchildren:

> I'm thinking too much because of my grandchildren. You find that I don't have anything to help them. I do get the pension, but I can't get by with that only, so I'm always thinking. That is why I know that the cause of the high blood is because I'm thinking too much. (Marta, 82, Agincourt)

The death of their children brought added pain to the stresses of life, which can be felt in the reflection: "if you have lost your children things are difficult. I have some, but I am not satisfied" (Phipas, 63,Agincourt).

- *The Experience of Healthcare*

In Agincourt, where all three study villages had clinics, the clinic or hospital was generally described as the first and main access point. Diagnosis and treatment for either high blood pressure or "sugar diabetes" was straight-forward, with little variety in experience:

> I first consulted the clinic. I was given the pills and instructed to take them on time and the right dose. So I'm doing like that even now. (Linah, 60, Agincourt)

A unique feature of formal healthcare access in Agincourt was the purposeful use of clinics or doctors further away. The theme of "better services elsewhere" emerged in the interviews, such as with Katherine, aged 63, who never used the local health centre in Agincourt, preferring to use Xanthia clinic further away. In this instance, the preference was guided by a low opinion of the confidentiality and caring-nature of the nurses at the Health Centre. Hunadi avoided using her local clinic for counseling services because of low staffing, and saved money for transport to clinics further away. Nomses, aged 70, could afford private doctors, and therefore she avoided clinics and the long queues found there. But even for private doctors, she preferred travelling to Hazyview, some 60 kilometres away.

Respondents described a uniform experience at the clinic, characterised by minimal interaction with the clinic staff and patients, and centred around collecting medication. One respondent described the process as follows:

> What they are doing at the clinic, they check the BP [blood pressure]. So they will tell you if it is high or low. If they find that it is high they will give you the small pill. After a few minutes they will recheck, and if they find that it is still high they will give you the same pill. Then you go home. (Idah, 63, Agincourt)

The respondents in Agincourt tended to express sympathy with the clinic staff and to excuse any shortcomings which they might have observed at the clinic. Hunadi, for example, said:

> At the clinic they are taking good care of us. What I have seen is the shortage of the nurses: one person must do a lot of work. (Hunadi, 67, Agincourt)

Another respondent elaborated further on how she dealt with any interpersonal difficulties which emerged at the clinic:

> The problem is that if some one has a problem with a nurse or something at the clinic they just write their concerns and put it in the suggestion box until the inspectors come and take that box. We are not doing like telling each other what happened, no we just write if we want. (Idah, 63, Agincourt)

The sympathy for the nurses is expressed as a type of etiquette which prohibits gossip at the clinic. The view is that if there are any problems, one should make use of the suggestion box, rather than talk openly about it:

> They even told us to write our concerns if we have. There is a suggestion box there, so if you have something to say you just write.

> We are not talking because it will be like we want them to be fired. (Phipas, 63, Agincourt)

Medicine-taking

In Agincourt a common and powerful response to the question: "What helps you most to cope with your illness?" is simply to go to the hospital or clinic to collect pills. For Linah, the clinic was where she had "gotten life" because of the clear diagnosis and treatment (Linah, 60, Agincourt). Marta, who relied on the clinic treatment, contrasted it with home and traditional remedies in terms of the relative simplicity of the clinic treatment:

> I don't use any home remedy. I don't even know how to mix it. Even if you can explain to me how they mix I will forget, because I'm not used to it. What I know is the medicine from the clinic…. I'm not educated but I know how to take the pills and how they are working. (Marta, 82, Agincourt)

Marta was very clear about relying only on the clinical medication, saying "if you concentrate on the pills you will live" (Marta, 82, Agincourt). However, Marta's preference for clinically-based medicines was closely connected with religiously-based concepts of maintaining good health, as is evident in the following statement:

> Even if you just drink medicine, if you don't believe you won't get well. So the only thing is to believe in what you are doing. (Marta, 82, Agincourt)

While Marta only took medicine from the clinic, her core belief with regard to coping with chronic illness was living an active life. She went on to say:

> Even if I can show you my card you will see that my high blood is not too bad because I can control it every time. I laugh with people to avoid thinking, or take a hoe to clean the farm. I can't sit still because I know that I will start thinking, so I always do some jobs to avoid stress. (Marta, 82, Agincourt)

- *Living with chronic illness: the search for alternatives*

Home remedies refer to herbal supplements based on folk knowledge of local herbs and their properties, and which may or may not be prescribed by a traditional healer. Traditional medicine, on the other hand, refers to medicine, including home remedies, which is specifically prescribed by a traditional healer, who bases her therapies on powers of divination (Ngubane, 1992). In their eagerness to dissociate themselves from traditional healers, some respondents in Agincourt would also deny the use of home remedies, although they would later mention taking some form of complementary or alternative medicine.

Church membership, particularly of African Christian Churches, was the strongest factor motivating against the open use of traditional medicine, although the cost of traditional healers was also mentioned as a reason for not using them. When we asked Anah whether she used home or traditional remedies, her answer was emphatic: "No I'm a Zion" (Anah,

90, Agincourt). At the same time, the church itself was a source of home remedies, in Anah's case holy water.

Cabiya, aged 89, while consulting a number of doctors for her sore stomach, also tried a traditional healer. She tried the medicine, but it did not work, and so she discontinued the treatment. She then started attending a Pentecostal church, and said that she could not therefore go to the traditional healer (Cabiya, 89, Agincourt). As a member of the congregation, she is expected to abstain from consulting traditional healers. The church advises her to consult only the clinic, and to take only the medicines prescribed by the clinic. However, like Anah, Cabiya's church encourages the use of a particular alternative remedy, in this case, Vaseline, which "removes white sputum" (Cabiya, 89, Agincourt).

Traditional healers were consulted for social purposes rather than health-related purposes. For example, Khisoze, aged 80, who was a member of the Zion Christian Church, said that in her youth she consulted a traditional healer for the purposes of conceiving a child. Linah made a clear distinction between home remedies and traditional medicine. There was an undertone in her response which indicated that she knew when to consult a traditional healer and when to consult the clinic, and that she was not willing to discuss her private reasons for visiting the traditional healer:

> I'm not taking home remedy, but I do consult the traditional healer, but not because of high blood. It is because of something else. (Linah, 60)

In Agincourt only Thabiso and Phipas were confident in discussing home remedies. Phipas, aged 63, suffered from high blood pressure, and supplemented her clinical treatment with a home remedy: a local herb called *nkanka*. The herb is sometimes used as a dietary supplement with porridge, but, when boiled, can be drunk as a tea for high blood pressure. Phipas sometimes voluntarily abstained from the pharmaceutical medication, which made her feel dizzy, relying solely on *nkanka* when she felt her heart beating fast.

Thabiso described a life-change: from what she described as a depressing reliance on daily medication, to a proactive approach including physical activity, drinking one litre of water per day, abstaining from soft drinks, sugar and condensed milk, and regularly drinking aloe tea. This life event led her to stop taking pills for her high blood pressure and diabetes, which she felt she was able to control by her new life-style:

> I was always listening to the programme on television. Sometimes they interview the doctors about the illness of nowadays. You find that sometimes we are creating the illness on our own, like eating Rama [margarine], meat….So you find that all these foods are not good for you. Sometimes they will say you must avoid cooldrinks, sweet things…and if you are following you will be better. (Thabiso, 61, Agincourt)

Discussion

4 Discussion

4.1 Historical-comparative community description

4.1.1 High prevalence of NCDs and low utilisation of formal healthcare services

Soweto and Agincourt share similar patterns of healthcare utilisation and healthcare beliefs. Only a small portion of individuals in both study sites with NCDs utilised formal healthcare services. In Soweto, where over half (50.7%) of the participants of the quanitative survey reported having some form of chronic illness, only a third (33.3%) of these participants reported accessing healthcare in the last 6 months. In Agincourt, studies show that not only may hypertension be under-reported (Gomez-Olive et al., 2013), but at least a third of people with NCDs do not access healthcare for ongoing treatment (Thoroughgood et al., 2007; Gomez-Olive et al., 2013). These low healthcare utilisation rates are comparable to that reported in the South African Demographic and Health survey, which reported a public healthcare utilisation rate of 24% for adult women (Department of Health et al., 2007). These contextual findings are mirrored more broadly in the regional context, with one systematic review suggesting that in sub-Saharan Africa up to 60% of people with hypertension have not been diagnosed, and up to 70% of those who have been diagnosed are not regularly taking treatment (Addo et al., 2013).

These findings, as well as the findings of the current study clearly begin to establish a foundation for objectivist recommendations relating to public education, early

identification and treatment of NCDs, and the removal of barriers to treatment, as has been done elsewhere (Addo et al., 2013; Hendriks et al., 2012). The unique contribution of this study lies in its ability to go beyond calls for well-established public health interventions, and to focus attention on the equally important goal of communicatively rationalising the experience of chronic illness, both as a means of interpersonal growth and of institutional reform.

4.2 Implications of case study findings for social theory

The theory of communicative action and the development of a lifeworld/ healthworld schema integrates and accounts for the presence of different paradigms relating to chronic illness and healthcare access. The development of a lifeworld/ healthworld schema proves central to the project of lifeworld/ healthworld rationalisation, a process in which public health researchers and social scientists prioritise body narratives within formal healthcare institutions (Scambler, 2000). In such a research enterprise, the motivation is not to improve healthcare access, or to promote a particular public health paradigm, but simply to explore and publicise the lifeworld/ healthworld of participants within healthcare settings.

A close consideration of the qualitative case studies suggests at least five themes within the lifeworld/ healthworld which should feature in any comprehensive schema:

1. Processes of constructing body narratives;
2. Encounters with purposive-rational systems;
3. Encounters with traditional medicine;
4. Encounters with contemporary informal medicine; and

5. Religion and healthcare.

We now turn to the discussion of the qualitative case study findings in relation to these five themes.

4.2.1 Processes of constructing body narratives

The body narrative was defined as a narrative describing a range of bodily transformations over the life-course (Baarts and Pedersen, 2009). Narratives may be broadly of two types: narratives which identify resources for coping with illness, and narratives which problematise resources. In any one narrative we may find both tendencies, although generally one or the other will predominate. For example, the narrative of Sarafina in Soweto tended to identify resources for coping with arthritis, and also positioned arthritis itself as a resource for character development. Joyce from Soweto expressed frustration at her lack of choice in having to take tablets for her high blood pressure, but also exerted some agency in regulating her intake of pills by sometimes relying on herbal teas. Joyce did not see her own self-regulation of her formal medical regimen as an acceptability barrier. Rather, from her point of view, the obligation to regularly take the pharmaceutical medication was itself a barrier to the construction of a redeeming body narrative. In this instance, the use of alternative medications facilitated a body narrative in which a lifelong dependency on pharmaceutical medication is one day overcome. The need of individuals with chronic illness to seek healthcare experiences which enhance the construction of body narratives has been observed elsewhere (Stratton and McGivern-Snofsky, 2008).

4.2.2 Encounters with purposive-rational systems

Within this aspect of the lifeworld/ healthworld, we may expect to find varying degrees of sociological observation regarding the experience of the formal healthcare system. In Soweto we found a phenomenon not paralleled in the Agincourt site study, namely, the potential of the formal healthcare experience to disrupt communicative action, or to colonise the lifeworld. The process of lifeworld colonisation is not an intentional one. Rather, it is often experienced as the unintended consequence of a depersonalised bureaucratic process built upon the technical knowledge of disease. In the Soweto case study, this was starkly manifested in the recurring theme of the unknown effects of pharmaceutical medication within the body, or as the profoundly intrusive experience of the medical encounter.

In Agincourt we were confronted with the unexpected finding, at least in terms of previous research conducted in Agincourt (Goudge et al., 2007; Thorogood et al., 2007) and other African contexts (Hjelm and Mufunda, 2010), that, for older women with chronic illness, clinical treatment and pharmaceutical medication was a prominent feature of treatment, reinforced by church-based healthcare practices. Not only were no substantial concerns raised regarding the side effects of pharmaceutical medication, we found such medication to be favourably compared with home-based remedies in terms of simplicity and reliability. There was a high level of acceptability of purposively-rational healthcare systems and medication. Most of the respondents used either the clinic or the doctor as the first option in treating their chronic illness. Switching of healers occurred largely within the paradigm of western healthcare, manifested as looking for better

clinical services elsewhere. Sympathy with the nursing staff featured more prominently than criticism.

This discussion suggests that encounters with purposive-rational systems are marked not only by the absence or presence of critical reflections on the treatment process, but are accompanied by varying degrees of confidence or anxiety, and appear to be largely determined by the quality of the relationships between the users and the staff of formal healthcare services.

4.2.3 Encounters with traditional medicine

Traditional medicine did not feature very strongly in either of the study sites. However, while traditional medicine appeared irrelevant in the Soweto case study, it appeared more taboo in Agincourt. The quantitative survey in Soweto suggests that, like in Agincourt, traditional healers may be regularly consulted for non-biomedical purposes. None of the respondents in the quantitative survey reported using traditional healers or herbalists to treat diseases, a finding reported elsewhere in South Africa (Nxumalo et al, 2011; Department of Health et al, 2007). However, almost a third of respondents in Soweto (31.8%) felt that there were some diseases which could only be treated by traditional healers.

In the lifeworld/ healthworld, there is no clear distinction between relational aspects of wellbeing and physical expressions of the body in pain. For example, in the Basotho concept of bophelo (wellbeing) the condition of an individual's social relations with family, community, people and ancestors are integral to physical health (Germond and

Molapo, 2006). But this is not to suggest that such features of the lifeworld/ healthworld are specific to any given population, or that they constitute an acceptability barrier. Rather, a paradigmatically reflexive research process suggests that the relational aspect of health and disease has a real foundation in social life, and constitutes an important resource in living with chronic illness.

4.2.4 Encounters with contemporary informal medicine

Most striking in our findings is the fact that none of the alternative medicines and treatments mentioned in the Soweto case study seemed to have indigenous foundations. In Soweto contemporary forms of complementary medicine, with strong emphases on self-management, featured very strongly in narratives of living with chronic illness, whereas traditional medicine hardly featured at all.

The use of contemporary forms of informal medicine, which featured particularly strongly in the Soweto case study, but which was also not entirely absent from the Agincourt case study (as with the case of Thabiso) is indicative of a transforming social environment marked by a modernised view of healthcare in terms of multiple market-related commodities. At the same time the scope such views provide for individualised approaches to coping with chronic illness are also related to the need for establishing a communicatively rationalised experience of chronic illness. In Soweto, where almost all participants expressed frustration with waiting in queues at the clinic, Anna was enthusiastic about spending the whole night waiting in a queue to access Soqi sessions. Such cases confirm the relational function of the lifeworld/ healthworld, that is the function of connecting life experiences with broader realms of meaning. Indeed, such

observations are possible even in highly modernised contexts, where similar trends in the use of holistic and individualised treatments for chronic illness have been found (Brien et al., 2010).

4.2.5 Religion and healthcare

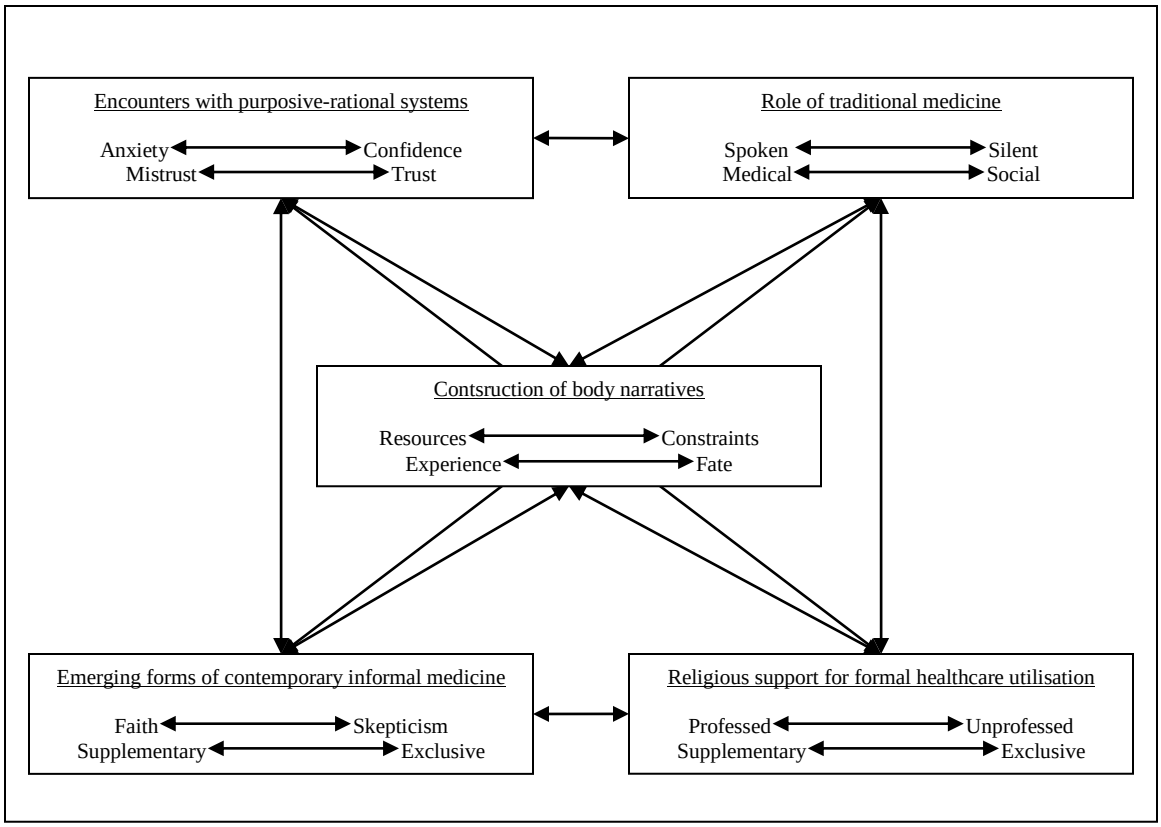
Qualitative studies conducted in Agincourt confirm that traditional understandings of disease causation, including witchcraft and the violation of cultural taboos, coexist with formal understandings of disease (Posel et al., 2007; Golloba-Mutebi and Tollman, 2007). Indeed the presence of cultural taboos and the role that they play in the formation of different types of disease has a long history in the Bushbuckridge district (Niehaus, 2002), reminding us of the social character of illness in the lifeworld/ healthworld. But our findings highlight the important role played by religious profession in modifying people's relationships with traditional norms and taboos. In Agincourt we found that religious discourse forced traditional medicine and its emphasis on social relations into regions of the lifeworld/ healthworld where to speak of them in itself was taboo. Religious belief thus plays an important role in delineating the proper uses of traditional medicine, and generally seemed to exclude such usage from the domain of healthcare practice. This undoubtedly must create tension, however, as we have seen that well-being encompasses social as well as biophysical dimensions within the lifeworld/ healthworld.

4.2.6 Mapping the lifeworld/ healthworld schema

Each component of the lifeworld may be conceived as consisting of a series of polarities that describe communicative practice between the individual and social institutions related to healthcare. For example, narratives describing encounters with purposive-

rational systems may tend either towards constructing the self as a passive recipient subjected to anxiety or towards the construction of the self as an active and confident participant in purposive rational systems. Similarly the role of traditional medicine is described by narratives which tend to make hidden the role of traditional healers, and those which make it explicit, and by narratives which describe a medical or social role for traditional healers (Figure 7).

Figure 7: Conceptual map of the lifeworld/ healthworld schema



Several of the dual items within each component may exist within other components, and the items presently described are not exhaustive. However, this serves as an outline for the development of a more extensive lifeworld/ healthworld schema.

The use of body narratives to describe the lifeworld/ healthworld may be described as a reciprocal process: the narratives clarified conceptual definitions, which in turn enabled a meaningful discussion of a large quantity of textual data. This suggests that lifeworld/ healthworld rationalisation, or the removal of barriers to effective communication, is a meaningful goal in healthcare settings, requiring concern not with how individuals with chronic illness can better adopt clinical regimens, but with how they can practically access and use the scientific knowledge of disease to manage their illness within a redemptive healthworld narrative.

4.3 Implications for healthcare policy and practice

The development of a broader interest in the use of body narratives to illustrate the lifeworld/ healthworld of persons with chronic illness has the potential to inform emergent healthcare approches which aim to bridge hermeneutic and objectivest public healthcare. This "third way" has been described as the domain of healthcare practitioners who integrate evidence-based medicine with narrative approaches (Martin and Peterson, 2009).

With regard to healthcare practice, body narratives serve to recast the role of clinicians as facilitators or supporters of individualised treatment plans (Bodenheimer et al., 2002). In such a role, the causes of disease attributed by the person with chronic illness, such as stress, arguments with spouses and the death of family members, become the basis of a treatment plan formed together with the clinician.

Indeed, a narrative approach to the formation of treatment plans has long been a *de facto* practice in a number of institutional settings. In Africa community-based organisations, particularly faith based organisations (FBOs) have used these approaches in providing healthcare services (Green et al., 2002). Often competing with FBOs in this regard in many African countries are traditional healers, who generally embody accepted world views and who rely on narrative technique for diagnosis and treatment (Madamombe, 2006).

In the South African contexts, body narratives and lifeworld/ healthworld rationalisation have a potentially revolutionary role to play in current attempts to revitalise PHC. For example, the use of body narratives and lifeworld/ healthworld rationalisation are particularly enhanced by the participation of community healthworkers and community-based organisations, both of which play a key role in the development of Community Oriented Primary Care (COPC). In this regard, a coherent lifeworld/ healthworld schema will prove integral in the primary aims of COPC not only in ensuring the congruence of formal healthcare services with community needs, but also in designing and implementing community-based interventions based on indepth assessments of community healthcare needs (De Maeseneer and Flinkenflogel, 2010).

The successful implementation of the COPC approach marks the beginning of healthcare access studies which do not focus primarily on the utilisation of clinical services, but rather on the participation of individuals with chronic illness in community-based healthcare structures. Ensuring the relevance of the PHC approach for South African

communities will require innovative research and leadership that is responsive to community social dynamics with regard to the perception and experience of illness. The theory of communicative action, the body narrative and the lifeworld/ healthworld schema orients public health intervention towards an integrated healthcare approach which takes into account community and cultural resources in the management of chronic illness.

4.4 Study Limitations

We have discussed how our sampling strategies in both Agincourt and Soweto were determined by the available data in both study sites. This resulted in an older group of participants in Agincourt, who generally had milder forms of chronic illness than the Soweto group. This may partly explain the predominance of themes of anxiety and mistrust of formalised healthcare in Soweto, yet our thematic analysis also made it clear that social mores, etiquette and custom exert a greater influence over the healthcare encounter in Agincourt. In otherwords, obstacles presented in the sampling may guide our interpretation of the findings, but they did not prevent thematic analysis of body narratives.

The very fact of the greater influence of social mores in Agincourt suggests the possibility of social desireability bias in the findings, particularly in relation to expressed approval of the clinic and disavowal of traditional medicine. This in itself is a valuable finding: the role of the church in shaping healthcare beliefs and practices is prominent in Agincourt. At the same time, we note the consistency of the narratives which explain

different reasons for the preference of clinical medication, including the simplicity of the treatment.

The qualitative site studies were not intended to be generaliseable, but were rather intended to identify the key thematic features of the lifeworld/ healthworld in urban and rural areas. But the question may be raised to what extent our study sites were indeed representative of urban and rural areas? It should be noted that the distinction between urban and rural in this instance is not clear cut. Both study sites display differing levels of urbanisation, or the extension of purposive-rational systems of social life. While it cannot be said that the study sites are completely divergent, they do appear to exist within a continuum of urbanisation, a fact which makes comparative analysis possible.

We were limited in the use we could make of contextual data for both qualitative site studies. Whereas in Soweto we had access to a wealth of primary and secondary data for contextualising the urban case study, in Agincourt we had to make due with a review of previous studies carried out in that sub-district. This limitation is partly addressed by the fact that the study is exploratory, and greater emphasis is placed on the qualitative site studies than on the contextual findings. Even given this limitation it is clear that Agincourt and Soweto display similar broad trends of healthcare utilisation and health beliefs. This initial finding prompts further comparative investigation of urban and rural healthcare practices and beliefs.

Finally, the limitations involved in adopting any particular approach to chronic illness should be mentioned. Although I have attempted to use two approaches in researching chronic illness and healthcare access in South Africa, namely the positivist and social constructionist approaches, there are other approaches which shed their own unique light on the study phenomena, including a health economics approach, a political economy approach, a gender approach, a social identity approach, and so on. While I have chosen a primarily hermeneutic approach to the present study, the presence of a wide diversity of research paradigms constitutes a valuable resource in generating further work in communicatively rationalising the lifeworld/ healthworld of persons with chronic illness.

4.5 Future work

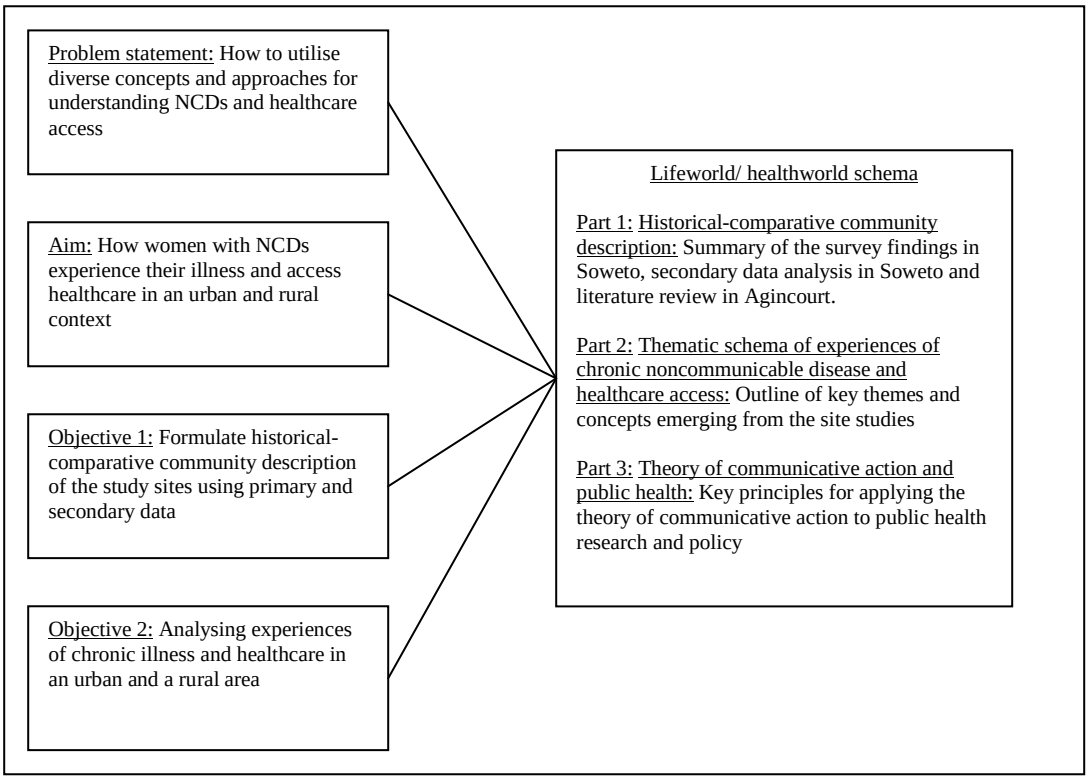
This study began as an exploration of healthcare access and chronic illness. The research soon lead to a vast array of literature spanning divergent healthcare paradigms. In an attempt to formulate an integrated concept of healthcare access and chronic illness, we made use of the lifeworld/ healthworld concept within the tradition of hermeneutic sociology. A broad vision of the study crystallized, in which the final outcome would be a comprehensive schema of the lifeworld/ healthworld as it relates to chronic illness and healthcare access in South African urban and rural contexts. Such a schema would form the basis of ongoing lifeworld/ healthworld rationalisation in individuals' participation in formal and informal healthcare institutions. At the conclusion of the research, it must be said that such a comprehensive schema has not been formed. Indeed, the realisation of this vision will require far more work, both in terms of comparative, mixed methods research and practical application in the revitalisation of PHC in South Africa.

Conclusion

5 Conclusion

The problem statement for this study focused on how to construct meaningful research findings within the context of several contrasting dichotomies, both in terms of discourses of chronic illness and approaches to healthcare access. We sought to integrate these dichotomies through exploring the lifeworld/ healthworld of women with chronic illness in an urban and rural area. Our aim was to explore how women with chronic illness experience their illness and access healthcare in an urban and rural area, and our objectives were to formulate historical-comparative community descritptions of the study sites and analyse the experiences of chronic illness and healthcare in both study sites. The problem statement and the study aims and objectives were addressed through the development of a lifeworld/ healthworld schema. This process is represented in Figure 8 below:

Figure 8: Process for addressing problem statement and study aim and objectives



Our first objective of formulating a historical-compartive community study of both study sites was addressed by an analysis of primary and secondary data for Soweto, and a review of previous research conducted in Agincourt for that sub-district. We found that both sites show similar trends of low utilisation of formal healthcare services, a high prevalence of NCDs, as well as the presence of multiple healthcare beliefs. This immediately raised the question of why formal healthcare services appear to be under utilised?

Our second objective of analysing the experiences of chronic illness and healthcare in an urban and rural area was addressed by the thematic content analysis of a number of serial in-depth interviews conducted in both study sites. The results of this analysis highlighted

a concern not with the availability, affordability or acceptability of formal healthcare services, or even an under utilisation of those services, but an overwhelming concern with the development of body narratives – of deeply meaningful and personal ways of talking about and coping with chronic illness.

In our discussion of the findings, we argued that the diverse concerns raised by the findings can be met by the adoption of an integrated healthcare approach focused on lifeworld/ healthworld rationalisation and the ongoing development of body narratives. It is to be hoped that the current thesis marks one step in realising this vision.

References

References

Addo, J., Smeeth, L. and Leon, D.A., 2007. Hypertension in sub-saharan Africa: A systematic review. *Hypertension*, 50, pp.1012-1018.

Adeyi, O., Smith, O., and Robles, S., 2007. *Public Policy and the Challenge of Chronic Noncommunicable Diseases*. [pdf] Washinton DC: The World Bank.

Al-Maskari, F., 2010. Lifestyle Diseases: An Economic Burden of the Health Services. *UN Chronicle*, [online] Available at: <http://www.un.org/wcm/content/site/chronicle/home/archive/issues2010/achieving_global_health/economicburdenonhealthservices> [Accessed 28 January 2013].

African National Congress (with the technical support of WHO and UNICEF), 1994. *A National Health Plan for South Africa*. Johannesburg: African National Congress (ANC).

Andersen, R.M., 1995. Revisiting the Behavioral Model and Access to Medical Care: Does it Matter? *Journal of Health and Social Behvior*, 36, pp.1-10.

Baarts, C. and Pedersen, I.K., 2009. Derivative benefits: exploring the body through complementary and alternative medicine. *Sociology of Health & Illness*, 31(5), pp.719-733.

Balabanova D., Parkhurst J., McKee M. and McPake B., 2006. Access to health care: taking into account health systems complexity. *HSD working paper*, [online] Available at <http://www.hsd.lshtm.ac.uk/publications/hsd_working_papers/Access_to_health_care_web_version.pdf> [Accessed 5 March 2009].

Bam, N., Marcus, T., Hugo, J., Kinkel, H-F., 2013. Conceptualizing Community Oriented Primary Care (COPC) – the Tshwane, South Africa, health post model. *African Journal for Primary Health Care and Family Medicine*, 5(1), 423.

Bodenheimer, T., Lorig, K., Holman, H. and Grumbach, K., 2002. Patient Self-management of Chronic Disease in Primary Care. *Journal of the American Medical Association*, 288(19), pp.2469-2475.

Bradshaw, D. and Steyn, K., 2001. *Poverty and Chronic Diseases in South Africa Technical Report 2001.* Cape Town: MRC South Africa and World Health Organisation.

Brien, S., Bishop, F.L., Riggs, K., Stevenson, D., Freire, V. and Lewith, G. T., 2011. Integrated medicine and the management of chronic illness: A qualitative study. *British Journal of General Practice*, 6(583), pp.e89-96. doi:10.3399/bjgp11x556254.

Bury, M., 1998. Post-modernity and health. In: G. Scambler and P. Higgs, eds. 1998. *Modernity, Medicine and Health: Medical Sociology Towards 2000*. London: Routledge, pp. 1-28.

Chase, S.E., 2005. Narrative Inquiry: Multiple Lenses, Approaches, Voices. In: N.K. Denzin, and Y.S. Lincoln, eds. 2005. *The Sage Handbook of Qualitative Research 3rd Edition*. Thousand Oaks: SAGE Publications, pp. 651-679.

Clark, S.J., Collinson, M.A., Kahn, K., Drullinger, K., and Tollman, S., 2007. Returning hone to die: Circular labour migration and mortality in South Africa. *Scandinavian Journal of Public Health*, 35 (69), pp.35-44.

Chi Machine international, 2012. *SOQI – Natural Healing*. [online] Available at: <http://www.chimachine4u.com/SOQI.html> [Accessed 01 October 2012].

Cochrane, J.R., 2006. Conceptualising Religious Health Assets Redemptively. *Religion and Theology*, 13(1), pp.107-120.

Cochrane, J.R., 2007. On Healthworlds. *CCIH-News.* [online] 28 February 2007. Available at: <http://www.ccih.org/pipermail/news_ccih.org/2007-February/000093.html> [Accessed 04 December 2012].

Conrad, P. and Barker, K., 2010. The Social Construction of Illness: Key Insights and Policy Implications. *Journal of Health and Social Behavior*, 51, pp.67–79.

Coovadia, H., Jewkes, R., Barron, P., Sanders, D., McIntyre, D., 2009. The health and health system of South Africa: historical roots of current public health challenges. *The Lancet*, 374(9692), pp.817-834.

Coulter, I.D. and Willis, E.M., 2004. The rise and rise of complementary and alternative medicine: a sociological perspective. *Medical Journal of Australia*, 180, pp.587–589.

Daar, A.S., Singer, P.A., Persad, D.L., Pramming, S.K., Matthews, D.R., Beaglehole, R. Bernstein, A., Borysiewicz, L.K., Colagiuri, S., Ganguly, N., Glass, R.I., Finegood, D.T., Koplan, J., Nabel, E.G., Sarna, G., Sarrafzadegan, N., Smith, R., Yach, D. and Bell, J., 2007. Grand challenges in chronic non-communicable diseases. *Nature*, 450, pp.494-496.

De-Graft Aikins, A., Unwin, N., Agyemang, C., Allotey, P., Campbell, C. and Arhinful, D., 2010. Tackling Africa's chronic disease burden: from the local to the global. *Globalization and Health*, [e-journal] 6(5). Available at <http://www.globalizationandhealth.com/content/6/1/5> [Accessed 05 July 2013].

De Maeseneer, J., and Flinkenflogel, M., 2010. Primary health care in Africa: do family physicians fit in? *British Journal of General Practice* 60(573): 286-292.

Department of Health, Medical Research Council, OrcMacro, 2007. *South Africa Demographic and Health Survey 2003*. Pretoria: Department of Health.

Department of Health, 2007. *A Policy on Quality in Healthcare for South Africa – Abbreviated Version*. Pretoria: Department of Health.

Epping-Jordan, J.E., Pruitt, S.D. Bengoa, R., Wagner, E.H., 2004. Improving the quality of healthcare for chronic conditions.Quality & Safety in Health Care, 13, pp.299–305.

Escobar, A., 1992. Imagining a post-development era? Critical thought, development and social movements. Third World and Post-colonial Issues, 33, pp.20-56.

Feierman, S. and Janzen, J.M., 1992. Introduction. In: S. Feierman and J.M. Janzen, eds. 1992. *The Social Basis of Health and Healing in Africa*. Los Angeles: University of California Press, pp.1-23.

Germond, P. and Cochrane, J.R., 2010. Healthworlds: Conceptualizing Landscapes of Health and Healing. *Sociology*, 44(2), pp.307-324.

Germond, P. and Molapo, S., 2006. In Search of Bophelo in a Time of AIDS: Seeking a Coherence of Economies of Health and Economies of Salvation. *Journal of Theology for Southern Africa*, 126, pp.27-47.

Gerring, J., 2007. *Case Study Research: Principles and Practices*. Cambridge: Cambridge University Press.

Giddens, A., 1997. *The Constitution of Society: Outline of the Theory of Structuration*. Cambridge: Polity Press.

Gilson, L., 2007. Acceptability, trust and equity. In: D. McIntyre and G. Mooney, eds. 2007. *The Economics of Health Equity.* Cambridge: Cambridge University Press.

Gilson, L. and Schneider, H., 2007. Understanding Health Service Access: Concepts and Experience. *Global Forum Update on Research for Health*, 4, pp.28-32.

Golooba-Mutebi, F. and Tollman, S.M., 2007. Confronting HIV/AIDS in a South African village: The impact of health-seeking behaviour. *Scandinavia Journal of Public Health*, 35(69), pp.175-180.

Gomez-Olive, F., Thorogood, M., Clark, B., Khan, K. and Tollman, S., 2013. Self-reported health and health care use in an ageing population in the Agincourt sub-district of rural South Africa. *Global Health Action*, [e-journal] 6. Available at < http://www.globalhealthaction.net/index.php/gha/article/view/19305> [Accessed 05 July 2013].

Goudge, J., Gilson, L., Russel, S., Gumede, T., and Mills, A., 2007. Affordability, availability and acceptability barriers to healthcare for the chronically ill: Longitudinal case studies from South Africa. *BMC Health Service Research*, [e-journal] 9(75). Available at <http://www.biomedcentral.com/1472-6963/9/75> [Accessed 05 July 2013].

Goudge, J., Gumede, T., Gilson, L., Russel, S., Tollman, S.M., and Mills, A., 2007. Short Communication: Coping with the Cost Burdens of Illness: Combining Qualitative and Quantitative Methods in Longitudinal, Household Research. *Scandinavian Journal of Public Health*, 35(69), pp.181-185.

Gow, D., 1996. The anthropology of development: Discourse, agency and culture. *Anthropological Quarterly*, 69(3), pp.165-173.

Green, A., Shaw, J., Dimmock, F., and Conn, C., 2002. A shared mission? Changing relationships between government and church health services in Africa. *International Journal for Health Planning and Managemen,t* 17:333-353, doi:10.1002/hpm.685.

Grobler, C. and Stuart, I.C., 2007. Healthcare Provider Choice. *South African Journal of Economics*, 75, pp.327-350.

Habermas, J., 1972. Technical Progress and the Social Life-world. In: J. Habermas, ed. 1972. *Toward a Rational Society: Student Protest, Science and Politics*. Boston: Beacon Press, pp.50-61.

Habermas, J., 1987. *The Theory of Communicative Action. Volume 2. Lifeworld and System: A Critique of Functionalist Reason*. Boston: Beacon Press.

Hendriks, M.E., Wit, F.W.N.M., Roos, M.T.L., Brewster, L.M., Akande, T.M., de Beer, I.H., Mfinanga, S.G., Kahwa, A.M., Gatongi, P., Van Rooy, G., Janssens, W., Lammers, J., Kramer, B., Bonfrer, I., Gaeb, E., van der Gaag, J., Rinke de Wit, T.F., Lange, J.M.A. and Schultsz, C., 2013. Hypertension in sub-saharan Africa: Cross-sectional surveys in four rural and urban communities. *PLoS ONE*, [e-journal] 7(3). Available at <http://www.plosone.org/article/info:doi/10.1371/journal.pone.0032638> [Accessed 05 July 2013].

Hjelm, K., and Mufunda, E., 2010. Zimbabwean diabetics' beliefs about health and illness: an interview study. *BMC International Health and Human Rights*, [e-journal] 10(7). Available at <http://www.biomedcentral.com/1472-698X/10/7> [Accessed 05 July 2013].

Hunter, L.M., Twine, W., and Patterson, L., 2007. Locusts are now our beef: Adult mortality and household dietary use of local environmental resources in rural South Africa. *Scandinavian Journal of Public Health Supplement*, 35(69), pp.165-174.

Illich, I., 1976. *Limits to Medicine, Medical Nemesis: The Expropriation of Health*. London: Marion Boyars.

Kahn, K., Tollman, S.M., Collinson, M.A., Clark, S.J., Twine, R., Clark, B.D., Shabangu, M., Gomez-Olive, F.X., Mokoena, O., and Garenne, M.L., 2007. Research into health, population and social transitions in rural South Africa: Data and methods of the

Agincourt Health and Demographic Surveillance System. *Scandinavian Journal of Public Health Supplement*, 35(69), pp.8-20.

Kahn, K., Garenne, M.L., Collinson, M.A., and Tollman, S.M., 2007. Mortality trends in a new South Africa: Hard to make a fresh start. *Scandinavian Journal of Public Health*, 35(69), pp.26-34.

Kautzky, K. and Tollman S.M., 2008. A Perspective on Primary Health Care in South Africa. In: P. Barron and J. Roma-Reardon, eds. 2008. *South African Health Review 2008*. Durban: Health Systems Trust, pp.17-30.

Kleinman, A., 1988. Response: On Reading Schweder's Reading of Social Origins of Distress and Disease. *Culture, Medicine and Psychiatry*, 12, pp.499-502.

Kotarba, J.A., Haile, B., Landrum, P., and Trimble, D., 2003. Inner Strength and the Existential Self: Improving Managed Care for HIV+ Women Through the Integration of Nursing and Sociological Concepts. In: J.J. Kronenfeld, ed. 2003. *Research in the Sociology of Healthcare Volume 21: Reorganizing Healthcare Delivery Systems: Problems of Managed Care and Other Models of Healthcare Delivery*, Oxford: Elsevier Jai, pp.87-106.

Lee, J., 2005. Foreword: the cost of inaction is clear and unacceptable. *Preventing chronic diseases: a vital investment: WHO global report*. [pdf]. Geneva: WHO Press.

Available at: <http://www.who.int/chp/chronic_disease_report/contents/foreword.pdf> [Accessed on 28 January 2013].

Madamombe, I., 2006. Traditional healers boost primary health care: Reaching patients missed by modern medicine. *Africa Renewal, January 2006*. [e-magazine]. Available at <http://www.un.org/africarenewal/magazine/january-2006/traditional-healers-boost-primary-health-care> [Accessed 20 March 2013].

Martin, C.M. and Peterson, C., 2008. The social construction of chronicity--a key to understanding chronic care transformations. *Journal of Evaluation in Clinical Practice*, 15(3), pp.578-85.

Mayosi, B.M., Flisher A.J., Lalloo, U.G., Sitas, F., Tollman, S.M., Bradshaw, D., 2009. The burden of non-communicable diseases in South Africa. *The Lancet.* 374(9693), pp.934-947.

McCarthy, T., 1984. Translator's Introduction. In: J. Habermas, ed. 1984. *The Theory of Communicative Action. Volume 1. Reason and the Rationalization of Society*. Boston: Beacon Press, ppv-xxxvii.

McGuire, M.B., 1990. Religion and the Body: Rematerializing the Human Body in the Social Sciences of Religion. *Journal for the Scientific Study of Religion*, 29(3), pp.283-296.

Naz, F., 2006. Arturo Escobar and the development discourse: An overview. *Asian Affairs*, 28(3), pp.64-84.

Nettleton, S., 2006. *The Sociology of Health and Illness*. 3rd ed. Cambridge: Polity Press.

Ngubane, H., 1992. Clinical Practice and Organization of Indigenous Healers in South Africa. In: S. Feierman and J.M. Janzen, eds. 1992. *The Social Basis of Health and Healing in Africa*. Los Angeles: University of California Press, pp.366-375.

Niehaus, I., 2002. Bodies, Heat, and Tabboos: Conceptualizing modern personhood in the South African Lowveld. *Ethnology*, 42 (3), pp.189-207.

Nteta, T.P., Mokgatle-Nthabu, M. and Oguntibeju, O.O., 2010. Utilization of the Primary Healthcare Services in the Tshwane Region of Gauteng Province, South Africa. *PLoS One*, [e-journal] 5(11). Available at <http://www.plosone.org/article/info:doi/10.1371/journal.pone.0013909> [Accessed 05 July 2013].

Nugent, R., 2008. Chronic diseases in developing countries: Health and economic burdens. *Annals of the New York Academy of Sciences*, 1136(1), pp.70-79.

Nxumalo, N., Alaba, O., Harris, B., Chersich, M., and Goudge, J., 2011. Utilization of traditional healers in South Africa and costs to patients: Findings from a national household survey. *Journal of Public Health Policy*, [e-journal] 32. Available at: <http://www.palgrave-journals.com/jphp/journal/v32/n1s/full/jphp201126a.html> [Accessed 05 July 2013].

Peltzer, K., Friend-du Preez, N., Ramlagan, S., and Fomundam, H., 2008. Use of traditional complementary and alternative medicine for HIV patients in KwaZulu-Natal, South Africa. *BMC Public Health*, [e-journal] 8. Available at <http://www.biomedcentral.com/1471-2458/8/255> [Accessed 05 July 2013].

Posel, D., Kahn, K. and Walker, L., 2007. Living with death in a time of AIDS: A rural South African case study. *Scandinavian Journal of Public Health*. 35 (69), pp.138-146.

Rahnema, M., 1997. Towards post-development: Searching for signposts, a new language and new paradigms. In: M. Rahnema and V. Bawtree, eds. 1997. *The Post-Development Reader*. Claremont: David Philip Publishers, pp. 377-403.

Richter, L.M., Norris, S.A., and De Wet, T., 2004. Transition from Birth to Ten to Birth to Twenty: the South African cohort reaches 13 years of age. *Paediatric Perinatal Epidemiology*, 18, pp.290-301.

Richter, L., Norris, S.A., Pettifor, J., Yach, D., and Cameron, N., 2007. Cohort Profile: Mandela's Children: The 1990 Birth to Twenty Study in South Africa. *International Journal of Epidemiology*, 36(3), pp.504-11.

Robbins, D., 1997. *Agincourt: A District Health Demonstration Site*. Durban: Health Systems Trust.

Rosenstock, I.M., 2005. Why People Use Health Services. *The Milbank Quarterly*, 83(4), pp.1-32.

Scambler, G., 2000. Medical Sociology and Modernity: Reflections on the Public Sphere and the Roles of Intellectuals and Social Critics. In: G. Scambler and P. Higgs, eds. 2000. *Modernity, Medicine and Health: Medical Sociology Towards 2000*, London: Routledge, pp.46-65.

Schneider, H., Barron, P. and Fonn, S., 2007. The Promise and the Practice of Transformation in South Africa's Health System. *The State of The Nation Report*. Pretoria: HSRC Press.

Singh, V., Raidoo, D.M. and Harries, C.S., 2004. The prevalence, patterns of usage and people's attitude towards complementary and alternative medicine (CAM) among the Indian community in Chatsworth, South Africa. *BMC Complementary and Alternative*

Medicine, [e-journal] 4(3). Available at: <http://www.biomedcentral.com/1472-6882/4/3> [Accessed 05 July 2013].

South African Medical Research Council, 2013. *An overview of chronic diseases of lifestyle, The South African Medical Research Council*. [pdf] Cape Town: South African Medical Research Council. Available at: < http://www.mrc.ac.za/chronic/overview.htm> [Accessed 1 July 2013].

Steyn, K., Fourie, J. and Temple, N., 2006. *Chronic Diseases of Lifestyle in South Africa: 1995 - 2005. Technical Report.* Cape Town: South African Medical Research Council.

Stratton, T.D., and McGivern-Snofsky, J.L., 2008. Toward a sociological understanding of complementary and alternative medicine use. *Journal of Alternative and Complementary Medicine*, 14(6), pp.777-783.

Swa Koteka and LINC, 2010. *Community mapping project: Agincourt, Mpumalanga, South Africa*. Agincourt: University of the Witwatersrand.

Swa Koteka and LINC, 2010. *Community mapping project: Cunningmoor A, Mpumalanga, South Africa*. Agincourt: University of the Witwatersrand.

Swa Koteka and LINC, 2010. *Community mapping project: Kildaire A, Mpumalanga, South Africa*. Agincourt: University of the Witwatersrand.

Thiede, M., Akweongo, P., and McIntyre, D., 2007. Exploring the Dimensions of Access. In: D. McIntyre and G. Mooney, eds. 2007. *The Economics of Health Equity.* Cambridge: Cambridge University Press, pp.103-123.

Thomas, G., A typology for the case study in social science following a review of definition, discourse, and structure. *Qualitative Inquiry,* 17(6), pp.511-521.

Thorogood, M., Connor, M.D., Lewando Hundt, G., and Tollman, S.M., 2007. Understanding and managing hypertension in an African sub-district: A multidisciplinary approach. *Scandinavian Journal of Public Health Supplement,* 35(69), pp.52-59.

Tollman, S.M., Kahn, K., Sartorius, B., Collinson, M.A., Clark, S.J., and Garenne, M.L., 2008. Implications of mortality transition for primary health care in rural South Africa: a population-based surveillance study. *The Lancet,* 372, pp.893-901.

Turner, B.S. and Samson, C., 1995. *Medical Power and Social Knowledge*. London: Sage Publications.

Van Zyl, S., Van der Merwe, L.J., Walsh, C.M., Groenewald, A.J., Van Rooyen, F.C., 2012. Risk-factor profiles for chronic diseases of lifestyle and metabolic syndrome in an urban and rural setting in South Africa. *African Journal of Primary Health Care and*

Family Medicine, [e-journal] 4(1). Available at: <http://dx.doi.org/10.4102/phcfm.v4i1.346> [Accessed 02 August 2013].

World Health Organization, 2005. *Preventing chronic diseases: a vital investment: WHO global report*. [pdf]. Geneva: WHO Press. Available at: <http://www.who.int/chp/chronic_disease_report/contents/foreword.pdf> [Accessed on 28 January 2013].

World Health Organization, 2008. *The global burden of disease: 2004 update*. [pdf]. Geneva: WHO Press. Available at: <http://www.who.int/healthinfo/global_burden_disease/2004_report_update/en/index.html > [Accessed on 28 January 2013]

World Health Organization, 2011. *Global status report on noncommunicable diseases 2010*. [pdf]. Geneva: WHO Press. Available at: <http://www.who.int/nmh/publications/ncd_report_full_en.pdf> [Accessed 28 January 2013].

Zhang, Y. and Wildemuth, B.M., 2009. Qualitative analysis of content. In: B. Wildemuth, ed. 2009. *Applications of Social Research Methods to Questions in Information and Library Science.* Westport: Libraries Unlimited, pp.308-319.

Zwane, I.T., 2005. *Assessing Quality of Care and Responsiveness of Health Services for Women in Crises Settings: Swaziland Case Study*. Geneva: World Health Organisation.

Original Papers

Paper I

Lopes Ibanez-Gonzalez, D. and Norris, S. A., 2013. Chronic noncommunicable disease and healthcare access in middle-aged and older women living in Soweto, South Africa. *PlosOne*, 8(10): e78800.

OPEN ACCESS Freely available online

PLOS ONE

Chronic Non-Communicable Disease and Healthcare Access in Middle-Aged and Older Women Living in Soweto, South Africa

Daniel Lopes Ibanez-Gonzalez*, Shane A. Norris

Developmental Pathways for Health Research Unit, University of the Witwatersrand, Johannesburg, South Africa

Abstract

The aim of the current study was to describe the healthcare access, beliefs, and practices of middle-aged and older women residing in Soweto. This is a cross-sectional study of the primary (female) caregivers of the Birth to Twenty Cohort, based in Soweto, South Africa. The study instrument was administered to 1 102 caregivers as part of routine annual data collection. Over half the respondents (50.7%) reported having at least one chronic non-communicable disease (CND), only a small portion (33.3%) of whom reported accessing a healthcare service in the last 6 months. Reported availability of private medical practice and government clinics was high (75.1% and 61.5% respectively). The low utilisation of healthcare services by women with CND is a concern in terms of healthcare management. There is a need to further investigate how healthcare beliefs are formed, as well as the feasibility of programmes to support the ongoing management of CND in Soweto.

Citation: Lopes Ibanez-Gonzalez D, Norris SA (2013) Chronic Non-Communicable Disease and Healthcare Access in Middle-Aged and Older Women Living in Soweto, South Africa. PLoS ONE 8(10): e78800. doi:10.1371/journal.pone.0078800

Editor: Willem Daniel Francois Venter, Wits Reproductive Health and HIV Institute, South Africa

Received May 2, 2013; **Accepted** September 23, 2013; **Published** October 29, 2013

Copyright: © 2013 Lopes Ibanez-Gonzalez, Norris. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Funding: This research was funded by the Wellcome Trust, the University of the Witwatersrand, SANPAD (South Africa Netherlands research Programme on Alternatives in Development), MRC (SA) and MRC/DfID (UK; Africa Research Leader Award). The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing Interests: The authors have declared that no competing interests exist.

* E-mail: Daniel.Lopeslbanez-Gonzalez@wits.ac.za

Introduction

Since the dis-establishment of racially segregated public healthcare services in South Africa, substantial progress has been made in the formulation of healthcare policy and the integration of the healthcare system [1]. These efforts have been based on a commitment to a primary health care (PHC) approach in South Africa with an emphasis on full community participation in the planning, provision, control and monitoring of healthcare services within an integrated national health system (NHS) [2]. At the same time, the full achievement of a PHC oriented national health system has been hampered by a number of obstacles, including health worker shortages, inequities in resource distribution, shortcomings in health leadership and a protracted health transition [3]. The rise of chronic non-communicable disease (CND) in this context is projected to increase the demand for healthcare services, accounting for 28% of the total burden of disease measured by disability adjusted life years in 2004 [4].

In the context of a changing healthcare system and an increasing burden of CND, public health researchers and policy makers have increasingly recognised the need to focus on the "demand-side" of healthcare access, including the study of the preferences of healthcare users [5]. The need to focus on user preferences extends beyond the private-public domain, into the domain of healthcare beliefs regarding the efficacies of different healthcare modalities. The aim of our study was to describe the healthcare access, beliefs, and practices of middle-aged and old women residing in Soweto, South Africa.

Methods

Study population

This is a cross-sectional study of the female caregivers of the Birth to Twenty (Bt20) cohort. The Bt20 cohort started in 1989 with pilot studies to test the feasibility of a long-term follow-up study of children's health and wellbeing [6]. Women were enrolled in their second and third trimester of pregnancy through public health facilities. Singleton children (n = 3 273) born between April and June 1990 and resident for at least 6 months in the municipal area of Soweto-Johannesburg were enrolled into the birth cohort [7,8]. The study is currently in contact with 70% of the cohort.

Between October 2008 and June 2010 the research team administered a semi-structured questionnaire to the primary caregivers of the Bt20 cohort in their home language (mainly Sotho and Zulu), after obtaining written consent. The study protocol was approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (M090235).

Study protocol

The questionnaire included a number of domains. The demographic section included demographic measures; asset-based socio-economic status; employment status; and religious affiliation and adherence. The general healthcare access section included measures of availability and affordability of healthcare services; medical aid; and perceived obstacles to accessing public healthcare. The specific healthcare access section included measures of recent illness and healthcare services accessed, as well as experiences of the healthcare visit. The health-seeking

behaviour section included measures of reliance on family and community networks for accessing healthcare and measures of patient strategy when interacting with formal healthcare systems. This section also included measures of use of traditional healers and self-rated assessments of the efficacy of traditional healers. The final section on CND included measures of disease prevalence and the use of lifelong medication. These measures, as well as some of the measures on general and specific healthcare access were adapted from the Adult Questionnaire of the South African Demographic and Health Survey [9].

The research team piloted the questionnaire in October of 2008, and administered the final questionnaire from November 2008 to June 2010. The questionnaire took less than an hour to complete. The interviews were conducted in the homes of the study participants in their preferred language by trained and experienced fieldworkers. The home setting coupled with the long-standing rapport and trust with experienced fieldworkers over the 18 years of the study facilitated more frank responses.

Statistical analyses

The principal investigators descriptively analysed the data using STATA/IC 10.0. A series of Pearson's Chi-squared analyses described the basic relationships between demographic and disease-state characteristics and health-seeking behaviour.

Results

Study Demographics

A total of 1 102 women participated in the study. The demographic profile of the study sample describes a low resource population with a high prevalence of CND (Table 1).

The large majority of participants lived in and owned houses, which, however, were without sole access to indoor hot and cold water or indoor flush toilets (Table 1). Over one third (37.3%) of the population could be categorised as having a low socio-economic status, defined as access to only one or less of 5 socio-economic items, including indoor running hot and cold water, indoor flush toilets, living in a house, owning a house, and owning a motor vehicle. Over half (52.8%) of the population were engaged in some form of paid employment, with a significant positive correlation between employment and socio-economic status ($p<0.05$).

Slightly over half the respondents (50.7%) reported having at least one CND. Of those that reported a CND 32.5% had high blood pressure, 12.8% had arthritis, 8.7% had high blood cholesterol, and 6.5% had diabetes. The remaining proportion of responses was distributed over a variety of CNDs, which individually constituted less than 5% of the total responses. Of those reporting CND, over two-thirds (69%) used prescribed lifelong medication on a regular basis. Respondents reported an average duration of CND of 8 and a half years, with an average self-reported delay of treatment of about 9 and a half months.

Access to Healthcare Services

Access to healthcare services was determined by measures of availability and affordability. The availability of healthcare services was determined by whether a healthcare service provider was available within a 2 km radius or 20 minute walking distance from the respondent. Those who reported availability of healthcare services were asked whether they felt the services were affordable for them.

Private medical practices were more easily available than government clinics (75.1% and 61.5% respectively), although not as affordable (59.1% and 83.6% respectively) (Table 2). While sangomas were easily available for almost a third of the respondents (32.1%), they were reported as the least affordable (28.2%) of the formal and informal healthcare services.

An additive index of formal healthcare services, including private doctors, hospitals and clinics and public hospitals and clinics, shows that around 85.8% of the respondents had at least one type of healthcare service available within a 2 km radius of their homes. Of this group 18% felt that these services were unaffordable. Around 17.4% of respondents had medical aid.

Experiences of Healthcare Services

In the context of a high rate of CND in the study population, it is surprising that slightly less than a quarter of the respondents (24.3%) reported an illness within the last 6 months which obliged them to access healthcare services. The precise phrasing of the question was: 'Have you had any illness or condition in the last 6 months so that you have had to seek treatment or healthcare?' Those with CND were significantly more likely to report such illnesses ($p<0.05$), with around a third (33.3%) actually doing so.

All participants reporting an illness in the last 6 months ($n = 268$) were grouped into the following categories:

1) Trauma, including accidents, burns, and operations;
2) General ailments, including problems with ears, teeth, sinuses etc.,
3) Infectious diseases, such as bronchitis, TB, HIV, and infections; and
4) Chronic diseases, including osteoporosis, hypertension, diabetes, and arthritis.

Most of those respondents reporting an illness in the last 6 months had general ailments (35.8%), followed by chronic diseases (34.3%). Around 22% reported infectious diseases in the last 6 months, while 7.8% reported trauma.

Over half the respondents (60.5%) who reported a disease or condition treated their illnesses at a public healthcare facility (defined as a government clinic or hospital), with the remainder utilising some form of private healthcare service (private medical practice, private hospital or clinic, self-treatment and pharmacist). None of the respondents reported visiting sangomas or herbalists. Respondents with CND were significantly more likely to utilise public healthcare services, particularly public clinics, and less likely to utilise private healthcare services ($p<0.05$), reflecting repeat visits for the collection of medication. Other than this, the type of illness reported appeared to have no further effect on choice of healthcare provider.

A series of questions focused on the experiences of respondents who had accessed healthcare services in the last 6 months. Users of public clinics were more likely to report waiting times of over half an hour ($p<0.01$), consultation times of less than 10 minutes ($p<0.01$), more likely to access the services by walking ($p<0.001$), and less likely to incur expenses ($p<0.001$). Only about a third (32%) of those accessing private hospitals or clinics incurred expenses. The possession of medical aid was significantly likely ($p<0.001$) to influence the choice of a private healthcare provider, particularly private doctors and clinics.

The satisfaction ratings with receiving attention at the healthcare service provider, the helpfulness of the healthcare service provider, the waiting time, the willingness of staff to listen to concerns, and the healthcare service provider's understanding of needs and concerns were all significantly influenced by the type of healthcare service accessed ($p<0.001$) (Table 3). Satisfaction ratings were consistently lower for public hospitals, and

Table 1. Population Characteristics.

Variable	Category	N	%
Age	30 to 39	266	24.1%
	40 to 49	589	53.5%
	50 to 65	245	22.2%
	Missing	2	0.2%
	Total	**1 102**	**100%**
Socio-economic indicators (Ownership)	Indoor hot and cold water (n = 1102)	405	36.8%
	Flush toilet inside (n = 1102)	538	48.8%
	Live in house (n = 1101)	980	88.9%
	Own house (n = 1101)	885	80.3%
	Own motor vehicle (n = 1099)	348	31.6%
	High SES (4–5 items)	190	17.2
	Medium SES (2–3 items)	496	45.0
	Low SES (0–1 items)	411	37.3
	Missing	5	0.5
	Total	**1 102**	**100%**
Employment	Formal or informal paid labour	582	52.8%
	Housewife/pensioner/unemployed	519	47.1%
	Missing	1	0.1%
	Total	**1 102**	**100%**
Self-reported chronic disease	No chronic disease	543	49.3%
	One chronic disease	339	30.8%
	More than one chronic disease	219	19.9%
	Missing	1	0.1%
	Total	**1 102**	**100%**

doi:10.1371/journal.pone.0078800.t001

particularly public clinics. Satisfaction ratings were generally lower for waiting times across all types of healthcare service providers.

We asked all respondents (n = 1 102) what were the main problems they experienced in accessing healthcare from government clinics and hospitals. The top five problems (mentioned by over 75% of respondents) were long waiting times (24.5%), unfriendly staff or poor service (17.8%), lack of medication (17.3%), overcrowding (13.9%), and short consultation times (5%). Around 12% of respondents felt that there were no problems in accessing public healthcare services.

Health-Seeking Behaviour

We asked the respondents a series of questions focused on three broad areas of health-seeking behaviour, namely reliance on family or friends for initial diagnosis and referral, utilisation of patient strategies when consulting doctors, and beliefs regarding the efficacy of traditional healers.

Table 2. Access to Healthcare Services in Soweto.

	Proportion of respondents reporting availability within 2 km radius	Proportion of respondents reporting affordability (if available)
Private medical practice (n = 1 102)	75.1%	59.1%
Private hospital or clinic (n = 1 102)	7.4%	52.4%
Government or community clinic (n = 1 102)	61.5%	83.6%
Government hospital (n = 1 102)	3.9%	88.4%
Community organisation (n = 1 102)	30%	63.8%
Pharmacist (n = 1 101)	37%	72.9%
Sangoma or traditional healer (n = 1 101)	32.1%	28.2%
Herbalist (n = 1 101)	15%	63.9%
Faith Healer or priest (n = 1 102)	18.2%	57.5%

doi:10.1371/journal.pone.0078800.t002

Table 3. Comparison of satisfaction ratings by type of healthcare service provider (spell out).

	Private doctor or clinic	Public hospital	Public clinic	
Satisfaction with getting someone to attend to me (N = 243)	94.7%	86.1%	66.7%	p<0.001
Satisfaction with the helpfulness of the staff (N = 242)	94.7%	88.4%	63.5%	p<0.001
Satisfaction with the waiting time (N = 242)	86.3%	73.8%	45.7%	p<0.001
Satisfaction with willingness of staff to listen to concerns (N = 241)	92.6%	86.1%	72.8%	p<0.001
Satisfaction with staff's understanding of needs and concerns (N = 242)	92.6%	83.7%	71.4%	p<0.001

doi:10.1371/journal.pone.0078800.t003

Reliance on family and friends for initial diagnosis and referral was high (76.7% and 81.8% respectively) although only around 10% (10.4%) reported exclusive reliance on the advice of family and friends for accessing healthcare services (Table 4). Respondents reported a low use of patient strategies; including partial disclosure of symptoms (16.3%) and rehearsal (15.9%), although almost a quarter (24.9%) indicated partial compliance with medical regimens.

Belief in the efficacy of traditional healers was low, with the large majority of respondents (80.6%) feeling that formal medical institutions were more effective than traditional healers in treating illness. Less than half the respondents (44.8%) felt that traditional healers were well respected within their communities.

We asked the research participants a separate question about whether there were some diseases which could only be treated by traditional healers, and not by doctors. Slightly less than a third (31.8%) of respondents felt that there were some diseases which could only be treated by traditional healers. We grouped these responses into different categories, the top three being 'witchcraft/curses/poisoning/evil spirits' (23%), 'fits/headache/mental illness' (17.7%) and 'HIV/AIDS' (12.8%). Around 10% (9.9%) felt that various forms of CND (mostly 'stroke', or 'high blood' and to a lesser extent diabetes) could be treated properly only by traditional healers.

Discussion

The prevalence of CND in this study population is double (32.5%) that reported in the South African Demographic and Health Survey (1998), which reported a 15.9% prevalence rate for hypertension in females [10]. The most noticeable feature of the findings is that over half the respondents (50.7%) in the current study reported having at least one CND, but only a third (33.3%) of these respondents accessed healthcare services in the last 6 months. The fact that 69% of respondents were using chronic treatment may suggest that respondents who actually accessed healthcare via the pharmacy to collect medication did not view this as healthcare access. However, this is unlikely as the pharmacy is located within the clinic, and thus a visit to the pharmacy would be seen as a visit to the clinic for those respondents who used a public clinic for this purpose. Rather, this finding suggests that most respondents with CND did not regularly comply with treatment regimens. This conclusion is supported by the fact that the overall healthcare utilisation rate for this study (24.3%) was the same as compared to the utilisation rate reported in the South African Demographic and Health survey [10].

Table 4. Health-seeking behaviour.

	N	%	Total
Family and friends help interpret symptoms	841	76.7%	**1 096**
Family and friends advise where to seek healthcare	899	81.8%	**1 099**
Only seek healthcare when family and friends say so	114	10.4%	**1 097**
Do not always tell doctor all symptoms	179	16.3%	**1 098**
Rehearse before consulting doctors	175	15.9%	**1 098**
Do not always do what doctor says	273	24.9%	**1 098**
Doctors are more effective than traditional healers	883	80.6%	**1 096**
Traditional healers are respected in community	490	44.8%	**1 095**

doi:10.1371/journal.pone.0078800.t004

It is unlikely that the low healthcare utilisation rate reported in the current study is due to poor availability or affordability of healthcare services in Soweto, as we found these to be high (86% and 82% respectively). The fact that around 16% of respondents felt that government clinics, which are free of charge in South Africa, are unaffordable suggests that indirect costs such as transportation and time-off work may prevent regular access to the clinics; a finding which has been reported elsewhere in South Africa [11]. This alone, however, cannot account for the low utilisation found in our study.

We can neither attribute the utilisation rate to dissatisfaction with healthcare services, since our satisfaction ratings, although significantly lower for public than private healthcare facilities, were still above 80% (with the exception of waiting times). The fact that almost a quarter of respondents (24.9%) reported partial compliance with medical regimens suggests that a large portion of respondents strategically select their intake of medication and their subsequent visits to the clinic to collect medication.

The coincidence of the self reported non-utilisation of traditional healers with high proportions of responses indicating knowledge of the location and cost of traditional healers within the neighbourhood (32.1%) warrants further consideration. Furthermore, a sizeable proportion of respondents (19.4%) disagreed with the statement that doctors were more effective than traditional healers in treating illness, and, in a separate question, almost a third of respondents (31.8%) felt that there were some diseases which could only be treated by traditional healers. In this instance it is difficult to attribute the low reported utilisation of traditional healers to social desirability bias, given its apparent absence in the other questions. The low utilisation of traditional healers is similar to other findings in South Africa [12,13,14].

These findings suggest a demarcation between the utilisation of traditional healers for treating conditions identified as chronic disease, and the use of traditional healers for other purposes. The

findings from our study indicate that only 10% of those respondents who stated that traditional healers were more effective than doctors specified that traditional healers could more effectively treat CNDs. The disparity in figures relating to utilisation of traditional healers for the treatment of conditions conceived as disease on one hand and general knowledge on the other, may indicate that traditional healers are often consulted for non-biomedical conditions, such as protection from witchcraft and poisoning. Given the specific Sowetan cultural background, fits and headaches may also be interpreted as primarily spiritual or social in nature [15].

Conclusion

Our study highlights the potentially poor management of CND due to infrequent access of health care despite it being accessible and affordable. The low utilisation of healthcare services indicates that the full realisation of PHC in South Africa has not been attained. In particular, our findings illustrate that a large proportion of those with CND do not access regular treatment most probably out of choice, as availability, affordability, and even acceptability (via high satisfaction ratings) of formal health services were generally high. More research as to the barriers to regular health care attendance and adherence to chronic medication is urgently warranted.

For African countries undergoing transition, the South African scenario highlights the need to develop innovative strategies for the implementation of PHC. African countries which have previously demonstrated the political will to develop and implement PHC have often been hampered by weak economies and limited budgets [16]. In this context, community based organisations, particularly faith based organisations (FBOs) have played an important role in providing health care services, often drawing from long histories of intervention [17]. Often competing with FBOs, but also functioning as *de facto* health care provider in many African countries are traditional healers, who in many African populations embody generally accepted world views [18].

For South Africa, community participation in community health centres is a key principle of the PHC approach, but developing community commitment to PHC remains a challenge [19]. It appears from our findings that both demand-side and supply-side features of PHC in South Africa must be addressed to ensure full and satisfying utilisation of formal healthcare facilities. In this regard, the recognition of the potential role played by community partnerships in the implementation of PHC has been a key factor informing new approaches to revitalise PHC in South Africa and Gauteng. In particular, regions of Gauteng have recently been identified as sites for the implementation of Community Oriented Primary Care (COPC), entailing the development of service units within communities largely resourced by Community Health Workers (CHWs) and community based organisations [20]. Primary healthcare workers and general practitioners have an important role to play within COPC not only in ensuring the congruence of formal healthcare services with community needs, but also in designing and implementing community-based interventions based on in depth assessments of community healthcare needs [21]. Such an approach heralds the return of the optimism marking the birth of PHC on South African soil [3]. In the ongoing management of CND, it should be remembered that community and group self-management programmes have proved effective in maintaining social connectedness and community support in the management of CND, especially in the context of low formal healthcare utilisation [22].

The successful implementation of the COPC approach marks the beginning of healthcare access studies which do not focus primarily on the utilisation of clinical services, but rather on the participation of individuals with CND in community based healthcare structures. Such studies should further investigate how healthcare beliefs are formed and how they interact with formalised knowledge of CND in the management practices of women with CND. Ensuring the relevance of the PHC approach for South African communities will require innovative research and leadership that is responsive to community social dynamics with regard to the perception and experience of CND.

Acknowledgments

The research for this paper was conducted by the field staff of the Developmental Pathways for Health Research Unit (Birth to Twenty).

Author Contributions

Conceived and designed the experiments: DL SN. Performed the experiments: DL. Analyzed the data: DL. Contributed reagents/materials/analysis tools: DL. Wrote the paper: DL SN.

References

1. Coovadia H, Jewkes R, Barron P, Sanders D, McIntyre D (2009) The health and health system of South Africa: historical roots of current public health challenges. Lancet 374(9692):817–834, doi:10.1016/S0140-6736(09)60951-X.
2. African National Congress (1994) A national health plan for South Africa. Johannesburg: African National Congress.
3. Kautzky K, Tollman SM (2008) A Perspective on Primary Health Care in South Africa. In: Barron P, Roma-Reardon J, editors. South African Health Review 2008. Durban: Health Systems Trust. pp. 17–30.
4. Mayosi BM, Flisher AJ, Lalloo GU, Sitas F, Tollman S, et al. (2009) The burden of non-communicable diseases in South Africa. Lancet 374(9693): 934–947, doi:10.1016/S0140-6736(09)61087-4.
5. Grobler C, Stuart IC (2007) Health Care Provider Choice. S Afr J Econ 75(2): 327–350.
6. Yach D, Cameron N, Padayachee N, Wagstaff L, Richter LM, et al. (1991) Birth to ten: child health in South Africa in the 1990s. Rationale and methods of a birth cohort study. Paediatr Perinat Epidemiol 5:211–233, doi:10.1111/j.1365-3016.1991.tb00702.x.
7. Richter LM, Norris SA, De Wet T (2004) Transition from Birth to Ten to Birth to Twenty: the South African cohort reaches 13 years of age. Paediatr Perinat Epidemiol 18:290–301, doi:10.1111/j.1365-3016.2004.00572.x.
8. Richter LS, Norris SA, Pettifor J, Yach D, Cameron N (2007) Cohort Profile: Mandela's children: the 1990 Birth to Twenty study in South Africa. Int J Epidemiol 36:504–511, doi:10.1093/ije/dym016.
9. Department of Health, Medical Research Council, OrcMacro (2007) South Africa Demographic and Health Survey 2003. Pretoria: Department of Health.
10. Norman R, Bradshaw D, Steyn K (2001) Chronic Diseases, Risk Factors and Lifestyles Based on the South African Adult Demographic and Health Survey. In: Bradshaw D, Steyn K, editors. Poverty and Chronic Diseases in South Africa: Technical Report. Medical Research Council and World Health Organisation. pp. 53–103.
11. Goudge J, Gilson L, Russel S, Gumede T, Mills A (2009) The household costs of illness in rural South Africa with free public primary care and hospital exemptions for the poor. Journal of Tropical Medicine and International Health 14: 458–467.
12. Nxumalo N, Alaba O, Harris B, Chersich M, Goudge J (2011) Utilization of traditional healers in South Africa and costs to patients: Findings from a national household survey. Journal of Public Health Policy 32:S124–136, doi:10.1057/jphp.2011.26.
13. Department of Health, Medical Research Council, OrcMacro (2007) South Africa Demographic and Health Survey 2003. Pretoria: Department of Health.
14. Statistics South Africa (2012) General household survey 2011. Pretoria: Statistics South Africa.
15. Truter I (2007) African traditional healers: Cultural and religious beliefs intertwined in a holistic way. South African Pharmaceutical Journal 74(8): 56–60.
16. Magawa R (2012) Primary health care implementation: A brief review. Public Health Discussion Paper. Consultancy Africa Intelligence. 16 Aug. Available: http://www.consultancyafrica.com/index.php?option = com_content&view = article&id = 1096:primary-health-care-implementation-a-brief-review-&catid = 61:hiv-aids-discussion-papers&Itemid = 268. Accessed 2013 Mar 20.

17. Green A, Shaw J, Dimmock F, Conn C (2002). A shared mission? Changing relationships between government and church health services in Africa. Int J Health Plann Mgmt 17:333–353, doi:10.1002/hpm.685.
18. Madamombe I (2006) Traditional healers boost primary health care: Reaching patients missed by modern medicine. Africa Renewal, January 2006. Available: http://www.un.org/africarenewal/magazine/january-2006/traditional-healers-boost-primary-health-care. Accessed 2013 Mar 20.
19. Bhatia M, Rifkin S (2010) A renewed focus on primary health care: revitalize or reframe? Globalization and Health 6:13, doi:10.1186/1744-8603-6-13.
20. Bam N, Marcus T, Hugo J, Kinkel H-F (2013) Conceptualizing Community Oriented Primary Care (COPC) – the Tshwane, South Africa, health post model. Afr J Prm Health Care Fam Med 5(1), 423.
21. De Maeseneer J, Flinkenflogel M (2010) Primary health care in Africa: do family physicians fit in? Br J Gen Prac 60(573): 286–292.
22. Johnston S, Irving H, Mill K, Rowan MS, Liddy C (2012) The patient's voice: an exploratory study of the impact of a group self-management support program. BMC Family Practice 13:65.

Paper II

Lopes Ibanez-Gonzalez, D., Mendenhall, E. and Norris, S. A. A mixed methods exploration of patterns of healthcare utilization of urban women with non-communicable disease in South Africa (Submitted BMC Health Services Research, 2014)

Running Title: HEALTH SEEKING OF CHRONICALLY ILL IN SOUTH AFRICA

A mixed methods exploration of patterns of healthcare utilization of urban women with non-communicable disease in South Africa

Daniel Lopes Ibanez-Gonzalez[1] (Daniel.IbanezLopes@gmail.com), Emily Mendenhall[2] (Emily.Mendenhall@gmail.com), Shane A Norris[1] (san@global.co.za).

Affiliation:

[1]MRC/Wits Developmental Pathways for Health Research Unit, University of the Witwatersrand, Johannesburg, South Africa

[2]Walsh School of Foreign Service, Georgetown University, Washington DC

Corresponding Author:

Daniel Lopes Ibanez-Gonzalez

Developmental Pathways for Health Research Unit

University of the Witwatersrand Medical School

7 York Road

Parktown 2193

South Africa

Abstract

Background: Non-communicable diseases (NCDs) are the leading causes of mortality globally, and are increasingly afflicting populations in low- and middle-income countries. Despite the growing burden of NCDs in South Africa, very little is known about how people living in urban townships manage these illnesses. In this article we expound upon the findings of a study showing that only one-third of women with an NCD participating in the Birth to Twenty (Bt20) cohort study of Soweto-Johannesburg, South Africa, had sought biomedical services in the previous six months.

Methods: We evaluated quantitative data from a cross sectional health access survey conducted with adult women (mean age= 44.8) and examined 25 in-depth narrative interviews with twelve women who self-reported at least one NCD from the larger study.

Results: The qualitative findings highlight the potential role of negative experiences of healthcare services and biomedicine in delaying the seeking of healthcare. Multivariate analysis of the quantitative findings found that the possession of medical aid (OR=1.7, CI=1.01-2.84) and the self-reported use of patient strategies in negotiating healthcare access (OR=1.6, CI=1.04-2.34) were positively associated with the utilization of healthcare services. Belief in the superior efficacy of traditional healers over doctors was associated with delay of NCD treatment (OR=2.4, CI=1.14-4.18).

Conclusion: Our data suggest that low healthcare utilization is due in part to low rates of expectation for consistent and high-quality care and a common mistrust of the medical

system. We conclude that both demand-side and supply-side measures focusing on high trust management practices will prove essential in ensuring access to healthcare services.

Keywords

Healthcare utilization; non-communicable disease; mixed methods; trust

Background

Non-communicable diseases (NCDs), such as hypertension and type-2 diabetes, are the leading causes of death globally, contributing to two-thirds of global mortality [1]. Around 80 percent of these deaths occur in low- and middle-income countries (LMICs) (WHO, 2011). Although historically NCDs afflicted affluent populations, increases in NCD prevalence, morbidity, and mortality have been measured among lower income groups [2, 3]. This is largely due to increases in obesity that have corresponded with the increased availability and consumption of higher caloric diets, lower physical activity due to mechanization, and tobacco use [2, 3]. As these lifestyle trends move from the affluent to the middle class and working poor, increasing NCD incidence and prevalence confront inadequate healthcare services for these populations in many LMICs [4].

Evidence from South Africa suggests that increasing NCDs coexist with low healthcare utilization [5]. For example, the South Africa Health and Demographic Survey found affordability and availability of healthcare services prevented 39% and 31% of women, respectively, from accessing healthcare in 2003 [6]. Some of the healthcare access issues may result from a large burden of disease upon a healthcare system historically rendered inequitable and inefficient by a racially-fragmented public healthcare approach [7]. One of the greatest challenges for NCD care involves universal coverage of healthcare services, which integrate community-based preventive services with hospital-based curative care [8].

Despite the growing burden of NCDs in South Africa, very little is known about how people living in urban townships manage these illnesses and engage with biomedical

healthcare systems. We found in a health access survey conducted with late-adult women in Soweto that around 50% had been diagnosed with an NCD, from hypertension to diabetes and epilepsy. However, only one-third (33.3%) of these women had sought biomedical services for an illness episode in the past six months [9]. In our initial analysis, we could not attribute the low utilisation of healthcare service either to problems with the availability or affordability of healthcare services, which was relatively high, nor the professed belief in traditional healers, since this appeared to be related primarily to problems not associated with NCDs or conditions understood as biomedical in nature. Rather, we explained these findings with reference to the fact that they indicate partial compliance with medical regimens in accordance with largely self-defined treatment plans [9].

Whereas we have briefly described patterns of healthcare utilization in Soweto, the aim of the present article is to further explore the reasons for these findings by the consideration of additional data collected in the health access survey, in a supplementary qualitative sub-study, and with reference to Andersen and Newman's framework of healthcare utilization.

Andersen and Newman's framework views healthcare utilization as an individual behaviour which is influenced by societal determinants both directly, and through the healthcare system [10]. As applied to the current study, we are interested in exploring the factors facilitating or inhibiting tertiary healthcare utilization defined as the multiple use of formal healthcare services over a period of time for the treatment of NCDs. Andersen an Newman speculate that in this type of scenario, societal level determinants, consisting primarily of technology and norms, may prove decisive [10].

Methods

This study was conducted with the female caregivers (mothers) of the Birth to Twenty (Bt20) cohort, based in Soweto-Johannesburg, South Africa. The Bt20 cohort started in 1989 with pilot studies to test the feasibility of a long-term follow-up study of children's health and wellbeing [11]. Women were enrolled in their second and third trimester of pregnancy through public health facilities. Singleton children (n=3 273) born between April and June 1990 and resident for at least 6 months in the municipal area of Soweto-Johannesburg were enrolled into the birth cohort [12, 13]. The study is currently in its 24th year, and has completed 20 data collection waves. The study is in contact with 70% of the initial cohort enrolled in 1990.

Data Source

The quantitative data comes from a cross sectional health access survey conducted with the primary Bt20 caregivers residing in Soweto. The study instrument combined adapted elements from the Adult Questionnaire of the South African Demographic and Health Survey [6] with standard community and demographic measures employed in Bt20. The questionnaire included demographic measures and measures of availability and affordability of healthcare services. In this regard, we asked participants whether specific healthcare services (including private and public doctors, clinics and hospitals, as well as traditional healers, herbalists and social services) were available within a two kilometre radius of their homes, and, if so, whether they considered theses services affordable for them. The questionnaire was piloted before being administered from November 2008 to

June 2010. The survey instrument was administered in the homes of the study participant in their home language by a team of research assistants.

In addition to the survey, we conducted 25 in-depth narrative interviews with 12 caregivers who self-reported at least one NCD and the use of at least one support system in the health access survey. The interview guide was designed to generate insight into healthcare access and beliefs. It included 3 themes, along with subsidiary questions regarding: (i) the first signs of NCD and initial feelings and responses; (ii) experiences with formal healthcare services; and (iii) the impact of NCD on daily life and coping with NCD.

In each interview, the NCD was identified and referred to as the illness that they had identified in the screening process (interview questions addressed, for example, "your diabetes" instead of "your NCD"). The qualitative study participants were randomly selected and had one or more NCDs. Each research participant was interviewed twice during the period of October 2009 to February 2010. The interviews were transcribed and translated in the same document, and the accuracy of the translations was checked by a research assistant not involved with data collection. The study protocol was approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (M090235).

Quantitative Data Analysis

In the present analysis, we developed a series of tables describing sample characteristics, including sociodemographics and NCD characteristics including type of NCD, duration of illness and comorbidity. In contrast to our previous analysis, in this analysis we excluded

respondents who reported only tuberculosis, keeping the focus of our present study on participants with NCDs.

Drawing upon the behavioral model of Andersen and Newman, we conducted a series of Pearson's Chi-squared analyses to determine potential relationships between NCD status and individual, societal, and healthcare system characteristics as well as healthcare utilization. We conducted an additional series of Pearson's Chi-squared analyses to determine potential relationships between healthcare utilization and individual, societal and healthcare system determinants.

The analysis included multiple logistic regressions to show the adjusted effects of individual, societal and healthcare system factors on healthcare utilization, type of healthcare utilization, and delay in formal treatment for NCDs.

The individual determinants in these analyses included the possession of medical aid, age, employment status, socioeconomic status and the use of lifelong medication for the treatment of NCDs. Societal level determinants focused on norms such as specific belief in the efficacy of traditional healers as opposed to formal healthcare services, shared healthcare beliefs with community and family, and the use of patient strategies. The use of patient strategies was determined by the combination of two statistically associated Likert-scale measures regarding the selective disclosure of the symptoms of illness, and the private rehearsal of what symptoms to present to formal healthcare workers. Healthcare system level determinants included the availability and affordability of formal healthcare services.

Qualitative Data Analysis

Data analysis proceeded in a multi-staged process. We used content analysis to evaluate the three overarching themes in the interview guide: first signs of NCD and initial feelings and responses; experiences with formal healthcare services; and the impact of NCD on daily life and coping with NCD. In follow-up interviews, we focused on two themes that were identified in the first interview: Impact of NCD on daily life, and experience of formal healthcare services. The questions within these two themes focused on elaborating the personal narrative of the interview respondents. We also reviewed detailed field notes, which were compiled immediately following the initial interview. At this stage we could begin compiling interview summary notes, and identify key themes. Exemplar case studies of the general themes are presented in this paper to describe "common" experiences reported by the women in this study and identified in the quantitative findings.

Results

Descriptions of the demographic and NCD characteristics of the sample are provided in Tables 1, 2 and 3. Half (50.2%, *n*=547) of the survey participants reported having been previously diagnosed with one or more of the following NCDs (Table 2): heart attack or angina, stroke, high blood cholesterol, diabetes, emphysema, asthma, arthritis, osteoporosis, epilepsy, or cancer. High blood pressure was the most prevalent form of NCD, affecting 32.8% of the study participants, followed by arthritis, which affected 12.9% of the population and high blood cholesterol, which affected 8.8% of the population (Table 3). The average duration of any NCD was 8.5 years (Table 2), and older participants were more likely to report one or more NCDs than younger study participants (Table 4). We

found no relationship between socio-economic status and being diagnosed with an NCD, but those who were unemployed were more likely to report a NCD than those who were employed (Table 4).

Qualitative Findings

The first stage of analysis, within-interview analysis, resulted in the identification of key themes for subsequent analysis. These are summarized by interview respondent in Table 6.

[Table 6]

Across all interviews, themes emerged that indicated an ambivalent relationship between the research participants and formal healthcare systems and pharmaceutical medication. In some cases this manifested in multiple modes of treatment for NCD. In other cases the ambivalent relationship with formal healthcare systems was expressed as frustration with the ways in which clinics operate, and in other cases as fear, both of taking and ignoring pharmaceutical medicine. The illness narratives demonstrate unique challenges faced by women with NCDs, both in terms of managing the disease and seeking treatment for it.

A number of themes emerged from the narratives which explain the low utilization of healthcare services by persons with NCD in Soweto. The first theme emerged in interview B, relating to frustration with government clinics for only treating the symptoms, as opposed to the causes of NCDs. In this case study, the participant, Monica aged 50 described suffering from tuberculosis (TB) since she was a young girl and this has had a

significant impact on her spine. She noticed symptoms of arthritis in the wrists and fingers and reported chronic suffering from the disease, although she had never been diagnosed. She rarely went to the clinic because of mistrust and said: "When I go to the clinic what happens is that I sometimes feel pain in my bones, especially my hands and I cannot even hold things properly. But then the sisters at the clinic will normally give me pain killers." Mistrust of the clinic emerges due to the fact that, despite her care-seeking, Monica has yet to receive a diagnosis or formal treatment for her physical suffering. Notably, with this case study, the role of earlier medical neglect emerged as a contributing factor to mistrust of formal healthcare services.

Additional themes suggesting reasons for avoiding formal healthcare services include the stress of visiting formal healthcare facilities (interviews C and E) and uneasiness with regularly taking medication for NCDs. This last theme is particularly prevalent in Rosaline's case study, highlighted below (Figure 1).

Evidence from the qualitative interviews suggests that women with NCD also delay attending the clinic upon first noticing symptoms of NCD (interviews A, E and H). This delay in utilizing formal healthcare services appears to be largely motivated by fear of the consequences and implications of living with NCDs. Ignoring the potential NCD status enables the person with an NCD to live in a state of false security and comfort. This is expressed in Shirley's narrative (Figure 2).

Quantitative Findings

Table 4 relates individual, societal and healthcare system characteristics with NCD status. Overall, one-third (33.2%) reported accessing healthcare services in the last six months

compared to only 15.2% of those without an NCD, indicating that those with an NCD were significantly more likely to utilize healthcare services ($p<0.05$). Of those who reported accessing some form of healthcare service in the last six months (n=263), almost two-thirds (61.3%) of respondents with an NCD made use of public healthcare services compared to around 56% of respondents without any NCDs who also made use of these services, although the difference was not statistically significant. Over two-thirds (69.7%) of those with an NCD used prescribed lifelong medication on a daily or regular basis. Respondents reported an average delay of treatment of about 9.6 months (Table 2).

A means comparison test suggests that the age of women with an NCD, was closely, although not significantly, related to healthcare utilization ($p=0.07$) (Table 5). Pearson's chi-square tests indicate that the possession of medical aid was the strongest individual level factor influencing the utilization of healthcare ($p=0.01$). Amongst societal level factors, the self-reported use of patient strategies was significantly related to the utilization of healthcare services. Those respondents with NCDs who admitted to using patient strategies when consulting healthcare workers were significantly more likely to utilize healthcare services ($p=0.02$). Specific belief in traditional healers, or the belief that there were some conditions which could only be treated by traditional healers, and not by doctors, was closely, although not significantly related to healthcare utilization ($p=0.09$), the results showing that such beliefs were positively associated with healthcare utilization. Both availability and affordability of healthcare services were significantly positively related to reported healthcare utilization ($p=0.02$ and $p=0.05$).

Logistic regression of individual, societal and healthcare system factors influencing the utilization of healthcare services in the last six months by persons with NCDs confirms

the importance of the possession of medical aid for utilizing healthcare services (OR=1.7, CI=1.01-2.84). It also confirms the close relationship between healthcare utilization and the use of patient strategies for negotiating healthcare access (OR=1.6, CI=1.04-2.34).

Additional logistic regression analyses of the influence of individual, societal and healthcare system factors on type of healthcare service accessed and the likelihood of delaying treatment for persons with NCDs were conducted. The possession of medical aid strongly influenced the use of private as opposed to public healthcare services (OR=9.6, CI=3.52-26.11), while the taking of lifelong medication was significantly related to the use of public as opposed to private healthcare services (OR=0.25, CI=0.11-0.56). The possession of regular employment was also closely, though not significantly related to the use of private healthcare services (OR=1.9, CI=0.89-4.49), most likely due to the fact that medical aid is generally provided through formal employment.

Logistic regression analysis of the likelihood of delaying treatment for an NCD suggests that the belief in the superior efficacy of traditional healers over doctors for certain types of diseases is significantly related to the delay of NCD treatment (OR=2.4, CI=1.14-4.18). On the other hand, shared healthcare beliefs with the community was significantly related to the absence of delays in treatment for NCDs (OR=0.32, CI=0.16-0.64). Closely, although not significantly related to the delay of treatment for NCDs was the professed use of patient strategies when consulting healthcare workers (OR=1.8, CI=0.94-3.65).

None of the respondents reported using traditional healers, but the belief in the superior efficacy of traditional healers compared to formal healthcare services was relatively high (31.8%). Most of these responses (19.1%) related to various types of curses, poisonings, or possession, which may be said to lie within the realm of magic or witchcraft

(Table 7). Fits, headaches and mental illness were also considered suitable for treatment by traditional healers (17.3%). Around 13.5% and 11.8% believed that traditional healers could treat NCDs and HIV/AIDS, respectively.

Discussion

To our knowledge, this is the first study to examine perceptions and behaviors for health-seeking and NCD-care in urban South Africa. Combining qualitative with quantitative data, we found that the relatively low levels of healthcare utilization amongst women with NCDs in Soweto is due in part to low rates of expectation for consistent and high-quality care and a common mistrust of the medical system (as demonstrated in Rosaline and Shirley's stories).

Although low utilization of healthcare services has been documented [6] [12], our quantitative data underscore the potential severity of low healthcare utilization in Soweto, as only one-third (32.5%) of women with an NCD reported utilizing formal healthcare services. This is alarming as it may indicate poor medical management of the NCD, which may not only exacerbate the condition but also lead to premature mortality.

The case studies suggest that mistrust of formal healthcare services may be based on negative past experiences, as with Monica (who felt that clinics provided only pain killers rather than diagnosis and treatment) and Shirley (who described a frustrating encounter with bureaucracy at the clinic), or on uncertainty, as with Rosaline (who was apprehensive about the effect of pharmaceutical medication on the body). Other studies in the African context suggest that negative experiences of public healthcare services are frequently due to the fact that they are overburdened, resulting in shortage of medication and long waiting

times to access care [14]. Our data suggest that reasons for low healthcare utilization may not only be structural but also interpersonal ones, as mistrust seems to be a central barrier to healthcare utilization in this context.

The possession of medical aid was the strongest individual-level factor influencing the use of formal healthcare service suggested by our quantitative analysis. This suggests that low levels of healthcare utilization may be explained in part by economic insecurity, a notion confirmed by our finding that the perceived affordability of formal healthcare services was significantly associated with healthcare utilization.

It is easy to see why the possession of medical aid would be positively related to healthcare utilization, but it is less easy to see why the perceived affordability of healthcare services should prove a factor, especially given the fact that basic healthcare services are free of charge in South Africa. It has been suggested elsewhere that cost-related barriers to healthcare utilization may be associated with costs of transport, and medication and healthcare services typical of complex treatment patterns [5] [9]. Our quantitative findings underscore the importance of further exploring how economic insecurity functions as a barrier to healthcare seeking in the urban South African context.

The self-reported use of patient strategies was the strongest societal-level factor associated with healthcare utilization by women with NCDs. Respondents who reported utilizing formal healthcare services were more likely to admit to the use of patient strategies. We classify the use of patient strategies as a societal-level determinant of healthcare utilization with the understanding that they functions as norms of social interaction and that they indicate the development of tacit knowledge guiding interpersonal interactions in the healthcare setting. Werner and Malterud have found in the qualitative

study that women with chronic illness have to "work" to ensure that they are perceived as credible patients [15]. But the fact that such behavior is related to increased healthcare utilization suggests that experience of accessing healthcare at public healthcare facilities, combined with resilience, accounts for continuing healthcare use.

The lack of trust of formal healthcare services appears to be a key factor, spanning societal and healthcare system factors. Elsewhere it has been suggested that race or ethnicity may contribute to increased mistrust of healthcare services [16], but in the South African context it has been found that poor experiences of public healthcare facilities related to the lack of prompt attention and communication may be of greater concern [17]. Our case studies reveal that many women depend upon alternative and complementary medicine and therapy to complement the ongoing interaction with formal healthcare services. This suggests that self-diagnosis and reliance on traditional medicine emerge as responses to mistrust in biomedicine which simultaneously allow for the exercise of control over the intake of biomedicine.

The quantitative findings indicate that few people trust traditional healers for NCD treatment; only one in ten people interviewed believed a traditional healer could heal their NCD. Those diseases that people believed were treatable by traditional healers, as opposed to doctors, were illnesses of the social, spiritual, and emotional world. At the same time, the general belief in the efficacy of traditional healers over that of formal healthcare workers was associated with a delay in accepting formal long term treatment for NCDs. Other studies in the South African context have shown that the use of traditional healers and other alternative therapies is generally associated with poor adherence to formal treatment regimens [18] [19]. Our findings suggest that the belief in the efficacy of traditional healers

may delay the onset of treatment at a formal healthcare facility, but that once such contact is initiated, the enduring belief in traditional healers does not affect the ongoing utilization of formal healthcare services, suggesting that such experiences may modify the belief in traditional healers, confining their utility to a more social role.

The availability and affordability of healthcare services emerged in our Pearson's Chi squared analysis as significant healthcare system factors influencing the utilization of healthcare services, although they did not emerge as significant factors in our multi-factorial model. Nor did these emerge as themes in our qualitative analysis. Our results therefore indicate that while initial gains made in improving healthcare access in Soweto have been significant, further work is needed particularly in enhancing the experience of the healthcare visit.

The cross-sectional study design did not allow us to investigate healthcare utilization trends over time in relation to independent variables, such as socio-economic status and education. Future studies should also include surveys of healthcare providers within different areas of Soweto, and relating these findings with healthcare users' beliefs and practices. There is a need to include role-players from government and community sectors in the research process, and to ensure that the findings of future research feed into healthcare strengthening programs. Nevertheless, this research underscores the need for more research in urban South Africa on people's beliefs about and access to healthcare for NCDs.

Conclusion

Our study has highlighted the role played by poor experiences of formal healthcare services and low levels of trust in explaining low healthcare utilization in Soweto. Demand-side reforms, such as increasing the number of healthcare workers and medical supplies will certainly prove important in changing the general perception of healthcare services and increasing healthcare utilization. At the same time, our findings underscore the importance of previous healthcare experiences and community perceptions of healthcare in shaping individuals' choice to utilize formal healthcare services. Our findings suggest that low healthcare utilization in Soweto has as much to do with poor trust of formal healthcare services, based on past negative experiences, as it does with lack of information and misconceptions about NCDs.

Trust, understood as the relational commitment between individuals in social settings, is developed along with the development of the institutional frameworks for communication and decision-making as well as the personal characteristics of the individuals involved in the trusting relationship, such as competence, empathy, congeniality and fairness [20] [21]. As such, it proves the linking concept between demand-side and supply-side healthcare reforms required to improve the quality of the healthcare interaction, and consequently the utilization of health care services for the management of NCDs. Responding to the evident lack of trust in formal, particularly public healthcare systems in Soweto, and in South Africa, should be based on high trust management practices by healthcare service providers.

Competing interests:

The authors declare that they have no competing interests.

Authors' contributions:

DLIG and SN contributed to the study conception and design. DLIG participated in data collection. DLIG and EM analysed the data. DLIG drafted the manuscript. All authors read and approved of the manuscript.

Acknowledgements:

The fieldwork staff at Developmental Pathways for Health Research Unit (DPHRU) who collected the date included Norman Vundla, Joyce Moiloa, Sipho Dlamini, Corlett Ndlovu, Andries Phake, Meikie Hlalele and Palesa Tsoaedi. Palesa Tsoaedi assisted in the interpretation and transcription of the indepth interviews. The study was funded by the South African Medical Research Council and the UK Wellcome Trust.

References

1. World Health Organization: *Global status report on noncommunicable diseases 2010.* Geneva: WHO Press; 2011.
2. Popkin BM, Adair LS, Ng SW: **Global nutrition transition and the pandemic of obesity in developing countries.** *Nutr Rev* 2012, **70**(1): 3-21.
3. Nugent R: **Chronic diseases in developing countries: Health and economic burdens.** *Ann N Y Acad Sci* 2008, **1136**(1): 70-79.
4. Mendenhall E, Shivashankar R, Tandon N, Ali MK, Narayan KMV, Prabhakaran D: **Stress and diabetes in socioeconomic context: A qualitative study of urban Indians.** *Soc Sci Med* 2012, **75**:2522-2529.
5. Goudge J, Gilson L, Russell S, Gumede T, Mills A: **The household costs of health care in rural South Africa with free public primary care and hospital exemptions for the poor.** *Trop Med Int Health* 2009, **14**(4): 458-467.
6. Department of Health, Medical Research Council, and OrcMacro: *South Africa Demographic and Health Survey 2003.* Pretoria: Department of Health; 2007.
7. Coovadia H, Jewkes R, Barron P, Sanders D, McIntyre D: **The health and health system of South Africa: historical roots of current public health challenges.** *The Lancet* 2009, **374**: 817-834.
8. Mayosi BM, Lawn JE, van Niekerk A, Bradshaw D, Abdool Karim SS, Coovadia HM, for The Lancet South Africa team: **Health in South Africa: changes and challenges since 2009.** *The Lancet* 2012, **380**(9858): 2029-2043.

9. Lopes Ibanez-Gonzalez D, Norris SA: **Chronic Non-Communicable Disease and Healthcare Access in Middle-Aged and Older Women Living in Soweto, South Africa.** *PLoS ONE* 2013, **8**(10): e78800. doi:10.1371/journal.pone.0078800.
10. Andersen R, Newman JF: **Societal and individual determinants of medical care utilization in the United States.** *The Milbank Quarterly* 2005, **83**(4):1-28.
11. Yach D, Cameron N, Padayachee N, Wagstaff L, Richter LM, Fonn S: **Birth to ten: child health in South Africa in the 1990s. Rationale and methods of a birth cohort study.** *Paediatr Perinat Epidemiol* 1991, **5**: 211-233.
12. Richter LM, Norris SA, De Wet T: **Transition from Birth to Ten to Birth to Twenty: the South African cohort reaches 13 years of age.** *Paediatr Perinat Epidemiol* 2004, **18**:290-301.
13. Richter LS, Norris SA, Pettifor J, Yach D, Cameron N: **Cohort Profile: Mandela's children: the 1990 Birth to Twenty study in South Africa.** *Int J Epidemiol* 2007, 36:504-511.
14. Kayombo EJ, Uiso FC, Mahunnah RLA: **Experience on healthcare utilisation in seven administrative regions of Tanzania.** *J Ethnobio Ethnomed* 2012, **8**(5). DOI: 10.1186/1746-4269-8-5
15. Werner A, Malterud K: **It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors.** *Soc Sci & Med* 2003, **57**: 1409-1419.
16. Jacobs EA, Mendenhall E, McAlearney AS, Rolle I, Whitaker E, Warnecke R, Ferrans CE: **An exploratory study of how trust in health care institutions varies**

across African American, Hispanic and white populations. *Communication and Medicine* 2011, **8**(1):89-98.

17. Peltzer K, Phaswana-Mafuya N: **Patient experiences and health system responsiveness among older adults in South Africa.** *Glob Health Action* 2012, **5**:18545 – http://dx.doi.org/10.3402/gha.v5i0.18545.
18. Peltzer K, Friend-du Preez N, Ramlagan S, Fomundam H: **Use of traditional complementary and alternative medicine for HIV patients in KwaZulu-Natal, South Africa.** *BMC Public Health* 2008, **8**: 255.
19. Peltzer K, Friend-du Preez N, Ramlagan S, Fomundam H, Anderson J: **Traditional complementary and alternative medicine and antiretroviral treatment adherence among HIV patients in KwaZulu-Natal, South Africa.** *Afr. J. Trad. CAM* 2009, **7**(2): 125-137.
20. Gilson L: **Trust in health care: theoretical perspectives and research needs.** *J Health Organ Manag* 2006, **20**(5): 359-375.
21. Gilson L: **Trust and the development of health care as a social institution.** *Soc Sci & Med* 2003, **56**: 1453-1468.

Figures

Figure 1: Where does the medicine go in my body?

Figure 2: Taking NCDs seriously?

Table 1: Sample Characteristics

	N (%)
Age (N=1089)	
30-39 yrs	263 (24.2%)
40-49 yrs	582 (53.4%)
50-65 yrs	244 (22.4%)
Socioeconomic Status (N=1086)	
Low	187 (17.2%)
Middle	490 (45.1%)
High	409 (37.7%)
Employment (N=1090)	
Formal or informal paid labor	513 (47.1%)
Housewife/ pensioner/ unemployed	577 (52.9%)

Table 2: NCD Characteristics

Chronic Disease (N=1090)	N (%)	N (%)
None reported	543 (49.8%)	
One NCD reported	328 (30.1%)	547 (50.2%)
More than one NCD reported	219 (20.1%)	
Lifelong Medication (N=547)	381 (69.7%)	
NCD Duration (years) (N=452)	8.5 ± 9.2	
Treatment Duration (years) (N=405)	8.1 ± 9.2	
Delay in treatment (years) (N=405)	0.8 ± 3.1	

Table 3: NCD Prevalences

NCD	N	% responses	% cases
High Blood pressure	358	43%	32.8%
Arthritis	141	16.9%	12.9%
High blood cholesterol	96	11.5%	8.8%
Diabetes	71	8.5%	6.5%
Asthma	54	6.5%	5%
Emphysema/Bronchitis	33	4%	3%
Heart attack or angina	30	3.6%	2.8%
Osteoporosis	20	2.4%	1.8%
Stroke	18	2.2%	1.7%
Epilepsy	7	0.8%	0.6%
Cancer	4	0.5%	0.4%
Total	832	100%	76.3%

Table 4: Correlating NCD status with individual, societal and healthcare system determinants and healthcare utilization

Domain	Determinants	No NCD	NCD	Total	P-value
Individual	Age (mean ± SD) (N=1089)	43.7 ± 5.8	45.7 ± 6.6	44.7 ± 6.3	p=0.00
	Socioeconomic Status (N=1085)				
	Low	102 (18.9%)	85 (15.6%)	187 (17.2%)	p=0.16
	Medium to High	439 (81.2%)	459 (84.4%)	898 (82.8%)	
	Employment (N=1089)				
	Formal or informal paid labor	287 (52.9%)	225 (41.1%)	512 (47%)	p=0.00
	Housewife/ pensioner/ unemployed	255 (47.1%)	322 (58.8%)	577 (53%)	
	Medical aid (N=1086)	98 (18.2%)	94 (17.2%)	894 (82.3%)	p=0.67
Societal	Social support for participants with chronic disease				
	Shared hlth beliefs family (N=1090)	540 (99.5%)	542 (99.1%)	1082 (99.3%)	p=0.48
	Shared hlth beliefs comm (N=1090)	435 (80.1%)	446 (81.5%)	881 (80.8%)	p=0.5
	Specific belief in traditional healers (N=1085)	170 (31.4%)	175 (32.2%)	345 (31.8%)	p=0.79
	Use of patient strategies (N=1090)	119 (21.9%)	150 (27.4%)	269 (24.7%)	p=0.03
Healthcare System	Availability of formal healthcare services (N=1090)	462 (85.1%)	473 (86.5%)	935 (85.8%)	p=0.5
	Affordability of formal healthcare services (N=1090)	387 (71.3%)	380 (69.5%)	767 (70.4%)	p=0.5
Healthcare utilization	Place of Treatment* (N=263)				
	Private healthcare services	36 (43.9%)	70 (38.7%)	106 (40.3%)	p=0.42
	Public healthcare services	46 (56.1%)	111 (61.3%)	157 (59.7%)	
	Health Care Utilization (N=1086)				
	Utilization in last 6 months	82 (15.2%)	181 (33.2%)	263 (24.2%)	p=0.00
	No Utilization in last 6 months	459 (84.8%)	364 (66.8%)	823 (75.8%)	

* Respondents could provide more than one answer. First answer taken

Table 5: Correlating healthcare utilization of persons with NCDs with individual, societal and healthcare system determinants

		Utilization	No utilization	Total	P-value
Individual Determinants	Age (mean ± SD) (N=545)	46 ± 6.7	45.1 ± 6.5	45.7 ± 6.6	p=0.07
	Socioeconomic Status (N=542)				
	Low	34 (18.9%)	51 (14.1%)	85 (15.7%)	p=0.15
	Medium to High	146 (81.1%)	311 (85.9%)	457 (84.3%)	
	Employment (N=545)				
	Formal or informal paid labor	81 (44.8%)	144 (39.6%)	225 (41.3%)	p=0.25
	Housewife/ pensioner/ unemployed	100 (55.3%)	220 (60.4%)	320 (58.7%)	
	Medical aid (N=545)	41 (22.7%)	52 (14.3%)	93 (17.1%)	p=0.01
	Regular medication (N=545)	126 (69.6%)	253 (69.5%)	379 (69.5%)	p=0.98
Societal Determinants	Social support for participants with chronic disease				
	Shared hlth beliefs family (N=545)	179 (98.9%)	361 (99.2%)	540 (99.1%)	p=0.75
	Shared hlth beliefs comm (N=545)	142 (78.5%)	302 (83%)	444 (81.5%)	p=0.2
	Specific belief in traditional healers (N=542)	66 (36.9%)	108 (29.8%)	174 (32.1%)	p=0.09
	Use of patient strategies (N=545)	61 (33.7%)	89 (24.5%)	150 (27.5%)	p=0.02
Healthcare System	Availability of formal healthcare services (N=545)	165 (91.2%)	306 (84.1%)	471 (86.4%)	p=0.02
	Affordability of formal healthcare services (N=545)	136 (75.1%)	244 (67%)	380 (69.7%)	p=0.05

Table 6: Key Themes by interview respondent

A	i) Predictions of future illness
	ii) Resourcefulness in use of treatment, linked to distinguishing oneself from the condition of the body, and utilizing health care from an "unauthorized" source
B	i) Frustration with clinics treating the symptom and not the cause
	ii) Belief that earlier medical neglect caused present condition; Coping with the help of her family
C	i) Medical and treatment related stress aggravating chronic condition
	ii) Coping with the help of friends and community based organizations
D	i) Determination required in dealing with formal health care
E	ii) Fear of consequences of leaving condition untreated
	iii) Ambivalence towards clinic and lifelong medication
F	1. Acceptance of a flawed health service
G	i) Pragmatic approach to treating chronic illness, using a wide variety of approaches
	ii) Adapting and living with chronic illness
H	i) Where does the medicine go in the body?
I	i) Regular use of clinic, but improved health attributed to alternative remedies
J	i) Encouraged by family members with same disease
	ii) Arguments with nurses at the clinic
K	i) View of condition in a non-specific way, as a part of life:
L	i) Invasive encounters with medical system

Table 7: Belief among people with NCD that diseases can be treated only by traditional healers

Diseases	**N**	**%**
Witchcraft/curses/poisoning/evil spirit	33	19.1%
Fits/headache/mental illness	30	17.3%
NCD	23	13.3%
HIV/AIDS	20	11.6%
Unclear	16	9.3%
STI/ sex-related problems	13	7.5%
Ancestral/Calling	10	5.8%
Other	10	5.8%
Swollen feet/legs	9	5.2%
Rash/ skin disease	5	2.9%
Cleansing/ Protection/ Ritual	3	1.7%
TB	1	0.6%
Total	**173**	**100%**

Paper III

Lopes Ibanez-Gonzalez, D. and Greenstein, R., 2014. Chronic illness and the urban healthworld: A sowetan case study. *South African Review of Sociology*, 45(2), pp.97-116.

CHRONIC ILLNESS AND THE URBAN HEALTHWORLD: A SOWETAN CASE STUDY

Daniel Lopes Ibanez-Gonzalez
MRC/Wits Developmental Pathways for Health Research Unit
Faculty of Health Sciences
University of the Witwatersrand
Daniel.LopesIbanez-Gonzalez@wits.ac.za

Ran Greenstein
Department of Sociology
University of the Witwatersrand
ran.greenstein@wits.ac.za

ABSTRACT

The sociology of health and illness recognises that illness is both a biological and a social phenomenon, requiring both technically competent healthcare as well as social and interpersonal meaning. The dual nature of illness is thought to underlie the observed phenomena of the combined use of different healthcare practices that develop illness narratives as well as treat the illness. In this article we describe the social nature of chronic illness and healthcare access by narrative enquiry and healthworld explication. We explore the narratives of 12 women with chronic illness residing in Soweto, South Africa, employing a qualitative methodology with serial interviews. The interviews focus on concepts of disease causation, treatment and coping. The findings describe a complex pattern of encountering chronic illness and accessing healthcare. Individual, familial, and social relations, including relations with Western biomedical healthcare, were intertwined in narrations regarding the development of chronic illness. The examination of diseased conditions by means of the healthworld locates the experience of disease within a social and autobiographical context, and focuses on the interaction between participants and healthcare systems. Narratives preserve biographical continuity in the face of biographical disruptions such as chronic illness, suggesting that a complete definition of healthcare access must address the concomitant search for meaning by individuals with chronic illness.

Keywords: healthworld, chronic illness, narrative enquiry, healthcare access, Soweto, South Africa.

South African Review of Sociology VOL 45 • NO 2 • 2014
ISSN 2152-8586/Online 2072-1978
© South African Sociological Association pp 97–116
DOI:10.1080/21528586.2014.917891

SARS 45(2)2014_layout.indd 97 4/24/2014 15:57:34

INTRODUCTION

The interest of sociologists of health and illness has traditionally focused on the motivational factors involved in disease aetiology, coping and cure, and is arguably rooted in the observation by Parsons that illness is both a biological and social phenomenon, and that the institutionalised treatment of illness fulfils social as well as biological functions (Williams 2005). The close connection between the biological and social dimensions of illness highlights the need of ensuring the accessibility of technically competent healthcare systems as well as a fulfilling social experience of such systems. Indeed, the question has been raised regarding the contribution of sociology to such healthcare access, given the perceived separation of the technical knowledge of biology and disease from most sociological analyses (Timmermans and Haas 2008).

The strength of sociological analyses of health and illness, however, has traditionally lay in describing social interaction around healthcare systems and highlighting the risk and uncertainty inherent in such interactions. The complex nature of illness and healthcare access has been thought to underlie the increased usage of combined healthcare practices encompassing Western biomedical healthcare as well as complementary and alternative healthcare (Williams 2005). Indeed, research in South Africa has shown relatively high rates for the combined use of healthcare practices, particularly for chronic illnesses (Peltzer et al. 2008; Singh et al. 2004).

While the use of different types of healthcare practices is not mutually exclusive, motivations for the increased use of complementary and alternative healthcare has elsewhere been grouped into two categories: bad experiences with Western biomedical healthcare and a general belief in the alternative paradigm (Baarts and Pedersen 2009). Baarts and Pedersen (2009) have found that individuals become convinced of the benefits of complementary and alternative healthcare even in cases where it failed to relieve them of the symptoms of chronic illness. They argue that complementary and alternative healthcare practices increase bodily awareness, enabling practitioners to enact changes in their personal lives. This is based on the formation of coherent 'body narratives' covering a range of bodily transformations spanning the life-course. Alternative treatment is viewed more positively than conventional treatments because it encourages patients to begin exploring their own bodies (Baarts and Pedersen 2009).

The narrative turn in sociology was marked by the recognition that social encounters and the way in which they are described consist of narratives. In the sociologies of medicine and of health and illness, the central problem came to be articulated in terms of dissonance between modern technical accounts of disease and the lay experience of illness. The study of narratives of illness promised to shed light on its disrupted experience, its implications for the apprehension of meaning in everyday life, and the steps taken to cope with it (Bury 2001). The narrative turn heralded a renewed interest in the quality of the healthcare encounter, and became central to 'third way' approaches to healthcare marked by the integration of evidence-based medicine with narrative approaches (Martin and Peterson 2009). Such approaches recast the role of clinicians

SARS 45(2)2014_layout.indd 98 4/24/2014 15:57:34

as facilitators or supporters of individualised treatment plans based on eliciting and engaging with patient narratives (Bodenheimer et al. 2002).

The emergence of narrative enquiry in the study of chronic illness has raised a number of questions regarding its central methodological assumptions. Firstly, there is the question regarding those things that narrative enquiry cannot account for, such as tacit understandings within social encounters, although these may at least partially be reflected in retrospective narratives. More worrying for the researcher using narrative enquiry is the treatment of the narrative itself. Such work has been described as fragmenting respondents' narratives with the purpose of sustaining the researcher's discursive project, along with its underlying ruling/knowledge relations between the privileged writer/reader and the respondent (Frank 2001).

Such concerns demand constant attention to the aim of the research project. In the present case, this has not been to amplify stories of suffering. Rather, the aim of this study was to make a beginning in defining healthcare access. The respondents in the present study were consulted primarily as experts, whose views could assist us in arriving at a definition of healthcare access. The focus on chronic illness provided an entry point into the study of healthcare access, but also increasingly made us aware that in this context, healthcare access is not focused upon cure, but upon managing illness in the context of daily life (Bury 2001).

The focus upon the healthworld suggests the use of narrative technique, largely due to the origins of the concept of the healthworld in the lifeworld research of Jurgen Habermas and the hermeneutical social sciences. Germond and Cochrane (2010) have defined the healthworld in relation to the Habermasian notion of the lifeworld and the theory of communicative action. The healthworld was developed as a means of understanding the complex of health beliefs and behaviours of individuals in a southern African context, although there is no reason why the concept may not be equally employed in other contexts (Germond and Cochrane 2010). In this article we focus on the interpretive tradition of this concept, and its implications for the analysis of the healthcare practices of women with chronic illness residing in Soweto.

The healthworld and the theory of communicative action

The lifeworld was conceived by Habermas as the 'culturally transmitted and linguistically organised stock of interpretive patterns' (Habermas 1987: 124) that guide the individual's interactions with others and with social institutions. In the case of the healthworld, these interactions are understood as relating to the pursuit of health and wellbeing. As a consequence of their close interrelation, the concepts of the healthworld and the lifeworld share much in common. Both concepts are understood in terms of a stock of knowledge forming the background of social encounters, items of which enter into individual consciousness in particular action situations (Germond and Cochrane 2010, Habermas 1987).

Within the Habermasian tradition, the objective of social science is to explicate

SARS 45(2)2014_layout.indd 99 4/24/2014 15:57:34

the key features of the lifeworld and to pursue reflexively its enhanced intersubjective rationalisation in relation to encounters between individuals and formalised systems of healthcare (Scambler 2000). The primary concern of lifeworld research is to arrive at a point where participants in social encounters can reach common understandings regarding the purpose and the functional features of those social encounters. This ideal of free communication, or communication without coercion is called communicative action (McCarthy 1984), and is described by Habermas as a situation in which:

> participants are not primarily oriented to their own individual successes; [but rather] they pursue their individual goals under the condition that they can harmonize their plans of action on the basis of common situation definitions (Habermas 1984: 285–256).

In terms of healthcare research, the concept of communicative action suggests that the goal of healthcare access is not merely the attainment of health but the attainment of personal and interpersonal meaning. It has elsewhere been observed in relation to healthcare provider choice that individuals do not merely aim to maximize their health, but rather their overall utility, or their ability to fulfill personal goals (Grobler and Stuart 2007). This becomes particularly relevant in the case of chronic illness, where even Western biomedical healthcare can offer no hope for a final cure. In this scenario the search for meaning becomes just as important as the search for measurable health outcomes.

The relationship between the search for meaning in chronic illness and the need for substantial improvements in physical functionality is conceptualised in the theory of communicative action in terms of the relationship between communicative action and 'purposive-rational' or ego-centric action. Rather than being governed by consensual norms and reciprocal behaviour, purposive-rational action is governed by technical rules based on empirical knowledge (Habermas 1972). As it relates to healthcare, purposive-rational action may be related to measurable health outcomes, expressed in terms of medical technical conceptions of disease, disease causation and treatment. These concepts focus on the control of isolated natural processes via the scientific method, and while they may lead to increasing technical knowledge, to the extent that they exclude communicative action, they remain 'impractical', that is, they fail to enhance the character or the quality of social interaction (Habermas 1972).

The theory of communicative action posits communicative action against purposive-rational action, in terms of goals, functional characteristics, and loci of social action. But the question remains to what extent this conceptual dualism reflects the reality of lived experience. Within the theory of communicative action, the dualism implies the harrowing consequence of lifeworld colonisation. The colonisation of the lifeworld refers to the constriction of communicative action by system-based modes of rationality, and manifests in healthcare practice as the infusion of the practices and perceptions of biomedical healthcare, as institutionalised in the clinic, the hospital and the laboratory into everyday life (Bury 1998). This extension of technically exploitable

SARS 45(2)2014_layout.indd 100 4/24/2014 15:57:34

knowledge within the lifeworld or healthworld stifles the redemptive process of reflection (Habermas 1972), through which individual experiences are related with broader communities of understanding (Cochrane 2007). The practical consequences of this process may be seen in the institutional transformation of medical practice from the guild to the bureaucracy, from the application of the practical art of healthcare, to the administration of scientific methods to whole categories of medical cases (Illich 1976).

Conceptually, the solution to the problem of disconnected technical power lies in re-establishing lifeworld and system in a mutually enriching relationship, which may also be referred to as the rationalisation of the lifeworld (Habermas 1987; Scambler 2000). Lifeworld rationalisation may be thought of as a process of individual empowerment, but more specifically refers to a commitment to increasing the scope of communicative action and publicising issues of concern within the lifeworld (Scambler 2000). The narrative is an important feature both of communicative practice and of lifeworld rationalisation. Narratives enable mutual understanding between the participants of social situations, as well as self-understanding. Both these functions are carried out by the successful connection between social events and the lifeworld (Habermas 1987).

This study is concerned with exploring the implications of narrative enquiry and healthworld rationalisation for understanding healthcare access for the chronically ill in an urban context. Narratives prove central to this investigation, because they constitute features both of communicative practice, and of explication of the healthworld. Our current exploration of the healthworld focuses on the narratives of women with chronic illness residing in Soweto, South Africa.

METHODOLOGY

We provide a summary of a series of interviews conducted between October 2009 and February 2010. The choice of study participant, namely women with chronic illness residing in Soweto, was guided by two considerations. Firstly, the study was institutionally located within a birth cohort for which there was ample demographic data for female caregivers residing in Soweto. Secondly, there is sufficient reason to accept such participants as accomplished participants in healthcare practices, both on their own behalf and on behalf of their dependents (Nteta et al. 2010), making their views worthwhile soliciting and understanding. We employed a qualitative methodology incorporating serial narrative interviews to present an experience-based overview of their concepts of disease causation, self treatment and coping. The primary questions of the study were:

1. How do women experience chronic illness? and
2. How do women experience healthcare systems (formal and informal) in relation to their chronic illness?

SARS 45(2)2014_layout.indd 101 4/24/2014 15:57:34

We paid close attention to those features of healthcare narratives that could assist us in the analytical development of the healthworld within this urban setting.

Study Sample

We describe the experiences of 12 women selected from the female caregivers (mothers or foster mothers) of the Birth to Twenty cohort. The cohort started in 1989 as a long-term follow-up study of children's health and wellbeing (Yach et al. 1991). Singleton children (n=3 273) born between April and June 1990 and resident for at least 6 months in the municipal area of Soweto-Johannesburg were enrolled into the birth cohort (Richter et al. 2004).

The study participants were selected from a larger group of women who self-reported chronic illness and the use of support systems in a health access survey administered to the Birth to Twenty caregivers residing in Soweto between October 2008 and March 2010. At the midway point of data collection, a group of women were randomly selected within a stratified population of women who had one or more chronic illnesses and who were willing to participate in a follow-up study. The population was dually stratified by intensity of chronic illness (determined by number of chronic illnesses and use of life-long medication), and use of support systems (home-based care or other support systems). Participants were selected within each stratum to ensure a broad range of experience, including mild and severe cases of chronic illness. All potential participants had lived with their condition for at least a year.

Ethics

Each participant was informed of the purpose of the study: namely to investigate the experience of chronic illness and accessing healthcare in Soweto. As long-term participants in a well established cohort study, the respondents were already quite familiar with the research process, including the process of informed consent. No specific concerns were raised by respondents at the time of obtaining informed consent. The association of this specific study with Birth to Twenty meant that our visit to their homes was seen as a routine visit for data collection. In this paper, all personal information is kept confidential, and study participants are referred to by pseudonyms. Each participant gave her informed consent by signature to participate in the study and to have the interviews recorded and the recordings kept by the researcher for a period of six years. The research was approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (M090235).

Data collection

We employed narrative enquiry for the interviews, defined as revolving around an interest in the biographical particulars of the interview respondent as narrated by her (Chase 2005). In the narrative interview, a conceptual shift is made from the question-answer

SARS 45(2)2014_layout.indd 102 4/24/2014 15:57:34

format of traditional interviews, towards an interview that encourages the respondent to tell her own story of living with chronic illness and accessing healthcare. Each of the research participants was interviewed twice in the period of October 2009 to February 2010. Each of the interviews was conducted in the home of the research participant.

The interviews were conducted by two researchers, the principal investigator, who could speak only English, and a fieldwork assistant, competent in English, Sesotho and isiZulu. Six of the interviews were conducted in English (in all cases the second language of the research participants), four in Sesotho, and two in Zulu. The limitations presented by the different linguistic communities of the research participants were addressed in detailed debriefing sessions during the course of data collection, and in follow-up interviews, which were conducted to further elaborate and confirm themes identified in the first interview. These measures ensured a high level of coherency in the final interview transcripts and analyses.

Data analysis

We employed grounded theory for data collection and analysis employing an inductive process, in which data collection and data analysis occurred concurrently, with each process informing the other (Kortraba et al. 2003). After data collection was concluded we employed a content-analytic approach for the analysis of textual data, in which key themes and patterns in participants' accounts of chronic illness and healthcare access were examined. We derived the coding categories directly and inductively through the raw data (Zhang and Wildemuth 2009), and coded the data in two phases: coding during data collection and coding post data collection.

The coding was based a dual process of data analysis: Listening to voices within interviews and locating themes across interviews. In the first process of data analysis, the stages included compilation of field notes, inductive identification of themes, and compiling interview summaries. In the second process, comparative analyses across 23 interview transcripts were conducted, including the further development of the coding scheme and the collation of interview sections by theme. An independent scientist not connected with the study coded a sample of the transcripts and we found a high level of agreement in our coding.

FINDINGS

Key patterns of understanding chronic illness and healthcare access are presented within each of the three themes discussed in the interviews, namely initial experiences of chronic illness, experiences of healthcare systems, and living with chronic illness. The themes and analysis follow a narrative sequence, identifying emerging patterns within each of the three themes.

SARS 45(2)2014_layout.indd 103 4/24/2014 15:57:34

The initial experience of chronic illness

The descriptions of the experience of chronic illness we encountered in Soweto were marked by expressions of anxiety, particularly in relation to the future implications of the disease if left untreated. This is evident in the case of Thandi. During the interview she stated that at one time she underestimated her disease: 'When you are young you don't see it's a problem' (Thandi (49) 15 October 2009). However, this view changed with the development and experience of arthritis. She went on to say:

> When you are locked in your bones, in your knees, you can't walk. When your spine is shifted, you can't move. You can't do anything. So the pain in your body is so painful, the pain in your body. It is so painful that you can't sleep, you can't do anything, and there are no tablets which can help you (Thandi 15 October 2009).

Chronic illness is here described in stark experiential terms, as a sudden and severe disrupture of the bodily experience. In the excerpt above, the foregrounding of extreme pain and its consequences for an implicitly understood notion of normal bodily functioning is contrasted with the ineffectualness of purposive-rational healthcare, summed up in the phrase: 'there are no tablets which can help you' (Thandi 15 October 2009). At the same time, this respondent, and in fact all the 12 respondents in our study, regularly used Western biomedical healthcare, both for managing the symptoms of chronic illness and for other symptomatic bodily ailments. In this particular case, Thandi reported using a combination of healthcare approaches to manage her illness. She initially consulted a doctor, and was advised that she had arthritis of the spine. She was advised to go for an operation, but refused, and subsequently treated her condition by wearing a special corset recommended by the doctor. She said of the tablets recommended to her by the doctor, 'it works just to minimize the pain. It's not something that is healing' (Thandi 15 October 2009). Rather, she concentrated her treatment plan on the taking of a cinnamon and honey mixture, which was recommended to her by a friend. She said of this mixture, contrasting it with the tablets prescribed by her doctor: 'It heals. It is not going to harm me' (Thandi 15 October 2009). She attributed to this mixture her remarkable recovery from the initial symptoms of arthritis: 'Now I am walking, I am doing everything' (Thandi 15 October 2009).

Other narratives suggest that the healthworld is indeed characterized by background knowledge about interactions with Western biomedical healthcare systems that come to the foreground of consciousness in the acute situation of bodily pain and social impairment. Another respondent related to us how she changed her view of her chronic illness simply by talking with others who had the disease. She said:

> lately talking to people with this problem I realised that it was serious. Then I started taking it serious. Then I went to the clinic. (Shirley (53) 12 January 2010).

SARS 45(2)2014_layout.indd 104 4/24/2014 15:57:34

Shirley described how she had known for a long time that she had high blood pressure, but only became sufficiently concerned about it to take up a regular course of treatment from the clinic after she had heard from her friends about the potentially serious consequences of leaving the condition untreated. She went on to describe how she treated her chronic illnesses (including high blood sugar, high blood cholesterol and arthritis) by regularly taking a range of medicines issued to her by the clinic, which she visited once per month.

Rosaline, aged 49, related how she first encountered her chronic illness:

> I was at church, I couldn't see …. I could see somebody, but I couldn't realise who was that. You know, at the congregation we know each other, but I couldn't recognise who was sitting over there (Rosaline 10 November 2009).

Rosaline continued to say that it was at that time that she decided to seek treatment, although in this case, the clinic, or doctor was not her first point of call. Rather, she first approached what she called a 'Chinese health shop'. She was already aware at that time that she may have been suffering the symptoms of diabetes or hypertension, saying:

> I didn't know why did I think it's blood pressure and sugar, and I said to them they must give me something for high blood pressure and sugar, and they said to me "No, did you test it?" and I said "No", they said no, they couldn't give me anything. I must go to the clinic first thing and go and check it (Rosaline 10 November 2009).

In this excerpt it is particularly relevant that the respondent had some awareness of her condition and the means of treating it before consulting either the clinic or a doctor. She subsequently went on to describe a mixed regimen of Western biomedical medication and Chinese herbal remedies for managing her chronic illness.

Social aetiologies

Problems within the family, such as illness, death and unemployment were spoken of as causes of chronic illness. In the narratives of chronic illness, the condition was usually related to crises brought about by the accumulated strains of life. For example, Shirley, mentioned above, described how she at first felt that the symptoms she was experiencing were due to the excessive worry of caring for her teenage daughter's child. Subsequent to the diagnosis, she still felt that social anxiety played a role in aggravating her symptoms of hypertension, saying that her pharmaceutical medication worked only 'when I don't have anything that is worrying me, but all the time there are problems' (Shirley 30 October 2009).

Sarafina, age 45, traced her arthritis to the time just after she married, when she was living with her husband's family, and, to relieve the stress, she would do the washing:

SARS 45(2)2014_layout.indd 105 4/24/2014 15:57:34

> I used to wash a lot with my hands. I was taking out the stress. I was living with my in-laws by then, so I was taking out the stress with my washing (Sarafina 7 December 2009).

Sarafina was a married and self-employed business woman who baked and sold confectionery. Although she initially said that her arthritis was not very severe, during the course of the interview it became clear that her condition was at one time severe, and still had an impact on her life. On the advice of her husband, she consulted a private doctor in the neighbourhood who prescribed some tablets, which she shortly afterwards discontinued. She felt that the greatest help in coping with arthritis was the black rubber rings and bracelets (*mosomi*), which she wore on her hands. She explained:

> I was in the [minibus] taxi and there was an elder guy at my left side. I was taking money from the back. Yabona, every time, when I lift my hand it will "Qa!", it will make a sound "Qa! Qa! Qa!", and that gentleman said to me … "You know this bracelet from the paraffin drums?" I said "Yes", "You must use them. Wear those bracelets, I am telling you, your arthritis will be fine" He told me that my bones are fragile and what. And since then they helped me a lot (Sarafina 4 November 2009).

In Sarafina's narrative, knowledge of how to treat arthritis came initially from an outside source, a stranger in the taxi. Sarafina had no background knowledge regarding the properties of the black rubber bracelets she saw other people wearing. She said: 'I used to see people wearing them but I didn't know what for. I thought maybe it was just for glamour, you see?' (Sarafina 4 November 2009). But at the same time, it is notable that she had seen them before, and obtained them very easily: 'I got them from, there was a gentleman who was painting my house, he was wearing them. There were so many, I asked two of them' (Sarafina 4 November 2009). This episode marks an induction into new knowledge regarding cultural artifacts, which were at least partially familiar to her.

Sarafina felt that the amelioration of the symptoms of her arthritis was entirely due to the black rubber bracelets that she wore. But at the same time, she continued to recognize a social dimension to arthritis. It was a condition whose severity was related to individual moral characteristics and social interactions. She said:

> And arthritis, it doesn't want you just to stay holding hands. You must use your hands, you must walk. You must stretch your bones, otherwise …. My mum's older sister, but she has passed on now, her hands were like this ... crooked. You see, like this. It is arthritis, and she was so lazy, you know, and I used to tell her, 'Use your hands!' and she will say 'No, they are so painful', and I will tell her 'Use them! Use your hands. Wash the dishes with warm water.' You know? 'Do the dusting….' You see? (Sarafina 7 December 2009).

In this narrative, the chronic illness becomes the ground against which personal moral character is tested and developed.

We also encountered narratives in which a long history of regular encounters with Western biomedical healthcare was intertwined with stories regarding the development of chronic illness. One such narrative was related by Linda, aged 49, who had experienced

SARS 45(2)2014_layout.indd 106 4/24/2014 15:57:34

two strokes. Her narrative was marked by a severe speech impairment resulting from her strokes. In the narrative, her troubled relationship with her husband and the anxiety of running out of her prescribed medication for hypertension precipitated the onset of her strokes. She said of her first stroke:

> I was living in Pimville with my husband, so I was having some problems with my husband, and another thing, I was taking [medication] back then. So I was upstairs, so I had a heart problem, I didn't have [my medication] I think for a week, I didn't take [my medication] so I had a stroke [starts to cry] (Linda 26 October 2010).

The narrative of her second stroke was remarkably similar:

> It was January it was after New Year, I was at home, I was with my husband here …. I was taking my tablets but, I think it was … because I ran out of my tablets, but I took them, three days I was fine, so like "How, what day this is?" … then I told my husband, "You know what, I don't have my [medication] just go to the clinic." But he doesn't so he doesn't go so … they took me to [the] clinic, so I had, even, stress, low energy … that was in 2007 (Linda 26 October 2010).

Linda also described a long history of interactions with doctors and clinics, much of which was experienced as strange and unfamiliar. She said:

> I just went to the doctor. I didn't think there was anything happening with the heart. I did go there for the flu. Then even the doctor he didn't say anything, he just opened the heart, [unclear], but I didn't say anything to do with the heart. I didn't say anything to do with heart (Linda 10 December 2010).

Linda went on to describe with great emotion her history of multiple heart operations, which she connected with her strokes:

> Yes, after I just had the op, I had a stroke, and then I had another op, and then another stroke. So first operation, then stroke, then another op, then a stroke again (Linda, 10 December 2010).

Despite the trauma of the heart operations, she felt that they were beneficial, saying 'I think the doctor did help me for my health, and it has changed my life a lot' (Linda 10 December 2010). She suffered from severe speech impairment as a result of the stroke, but found positive value in the experience, largely through her ability to relate the experience to a religious narrative. She described the constant solace she derived from her religious beliefs, saying 'God loves me. Even now, he gives me health' (Linda 10 December 2010). This enabled her to connect the traumatic events in her life to the development of her character. In particular, since the operation she began 'talking with her heart' as described below:

SARS 45(2)2014_layout.indd 107 4/24/2014 15:57:34

> I think with my heart, I talk a lot with my heart. I talk with my heart. A lot of people told me, I always talk with my heart, since the operation I always talk with my heart and then the pain starts in my heart (Linda 10 December 2010).

Talking with the heart is described as a painful experience, contributing to increased anxiety, but she added that she found some relief in talking with friends and thereby forgetting her worries.

The experience of health care

The clinic is the first point of entry in the overall healthcare system, offering a range of free basic services at the community level. For those who accessed the community clinic, the visit had become a familiar routine, taking place about once a month. Respondents described a dual procedure at the clinic: one for dispensing prescribed medication, and the other for diagnosis and treatment:

> The way they treat patients doesn't change, it's the same way. Each and every nurse turns the clinic card and checks what the last one gave and then follows the same route in giving you the same medication without checking you, unless you say that you are not feeling well. Then and only then will they check you (Joyce (aged 70) 4 November 2009).

The process for dispensing medicine is, on the surface, a quick and efficient one: the visit to the clinic is entered into a personal file, and a prescription is issued. The process is called 'repeats':

> Now at the clinic they have got, they call it 'repeats'. When you go there they just view your card, they put the stamp, and they sign for which room to go. You don't queue, you just go to fetch your medication, and they don't help you, they don't take your blood pressure and your sugar (Rosaline 10 November 2009).

The bureaucratic features of Western biomedical healthcare, particularly the clinic is described both as an accomplishment of purposive-rational action and as a barrier to communicative action. While the system of repeats shortens the amount of time required to obtain the medication, it also circumvents opportunities for personal interaction with the clinic staff regarding the experience of chronic illness, unless, as stated above, the patient initiates a conversation with a clinic staff member. But it appears that interactions that elicit and shape experiences and meanings of chronic illness are not sought in the clinical setting. Rather, the clinic tended to be described simply as a place for collecting medication. The frustrated attempt to construct meaningful diagnosis and treatment is expressed by one respondent, Monica, aged 50, in the following statement:

> Hayi, at the clinic it is the same. Even when you explain they will just give you those tablets the "bruffens", the pain block (Monica21 October 2009)

SARS 45(2)2014_layout.indd 108 4/24/2014 15:57:34

Viewing the clinic primarily as a place for collecting medication also has implications for the possibilities of pursuing a communicatively rational experience at the clinic. If one visits the clinic solely for the purpose of obtaining medication, then the possibility of engaging in meaningful interpersonal discussions regarding chronic illness, or any other topic, is encountered as an obstacle. Shirley said of her experience at the clinic:

> … when you get into that room, you are sick and tired of them [the nurses], you don't even want to talk to them, because you wait there for a long time, you just want to get your pills and go, you are not even friends when you get there (Shirley (53) 21 January 2010).

The socialisation of medicine

Respondents identified three limitations of pharmaceutical medicine obtained from the clinic: 1) their effects are temporary; 2) they treat the symptoms of disease (mainly by blocking the pain) rather than the causes; and 3) they have potentially harmful side-effects. Narratives regarding the harmful side-effects of pharmaceutical medication positioned the tablet as a foreign element within the body, compelling respondents to flush them out, or to stop taking them altogether. Shirley articulated her ambivalence as concern about what the pills were doing to her body:

> But when I'm alone I ask myself "I take these tablets everyday, and then, what are they doing to my body?" and then you know what I do? I drink a lot of water. I think I'm washing them out (Shirley 21 January 2010).

Rosaline relates her experience as follows:

> Once I was washing dishes, so one tablet … fell on the floor. So I said "OK, I'll take another one". So I take that pill and throw it in the sink. I close the tap, and wash the dishes. I finish, take out the water and, I thought, you know it would melt, and it didn't, and from there I get worried. "What is happening? What is going on when I drink these tablets everyday in my system? Where does it …?" I don't know where it is going. What is going on in my system? You know? You drink that pill everyday, and you know? And I sit down, and take that pill, and take two spoons and I try to press it, to squeeze it, to squeeze it. It never squeezes. You know? [starts to laugh] (Rosaline 10 November 2009).

Rosaline relied mainly on Chinese teas to regulate her high blood pressure, although she intermittently took the tablets from the clinic. Her goal was to wean herself off the clinic medication. The remarkable feature of her illness narrative is its ability to evoke humour about her encounters at the clinic. Both the visit to the clinic and her ambivalence towards the medication she obtains there are clearly causes of anxiety, but her narrative reveals the absurd nature of her engagement with Western biomedical care through the medium of pharmaceutical medication.

SARS 45(2)2014_layout.indd 109 4/24/2014 15:57:34

Living with chronic illness

We have already seen how the process of living with chronic illness entails communicative action, or the search for a meaningful diagnosis of chronic illness, its underlying causes (often conceived as more than merely biological in nature) and a treatment plan that incorporates a variety of approaches to healthcare. The search for a meaningful treatment plan is a strategic one. It focuses upon the resources available to individuals to manage the symptoms of chronic illness. These resources reflect the social milieu in which the individual finds herself. Thus while we have seen some complementary and alternative treatment plans that were distinctly South African (such as Sarafina's black rubber bracelets, the *mosomi*), there were also many more global in nature, and their usage attests to the modern cosmopolitan nature of Soweto as an urban environment. This is highlighted in the following case study.

Anna, aged 54, developed diabetes in 2000 and high blood pressure in 2002. She was then diagnosed with arthritis in 2007, and experienced heart failure in 2009. She regularly attended the local clinic once a month. She identified a number of problems at the clinic: long queues, shortages of medication, and being turned away when she arrived later than usual. She took her medication everyday, seven tablets in the morning and one at night, and was ambivalent about its efficacy, saying: 'You find that today I'm OK, tomorrow I'm not, that's the only thing' (Anna 10 November 2009).

In addition to her clinical regimen, Anna reported taking a variety of alternative medicines, including a home remedy prepared by a neighbour, intermittent visits to a Chinese clinic, and, most importantly for her, the Soqi gym. Soqi refers to an alternative therapy incorporating natural healing therapies and various machines intended to balance the body's thermal, nutritional, electromagnetic and motion energies (Chi Machine International 2012). She first found out about Soqi when she received a pamphlet advertising free treatment in central Johannesburg. Since then, she attended the free Soqi sessions, given by people in uniform, almost on a daily basis, saying 'I live there, at the machines' (Anna 10 November 2009). She feels that the Soqi gym has been her biggest help in treating her chronic illnesses (hypertension, diabetes and arthritis), as well as other ailments:

> I had chubabas [black spots] on my face and on my nose before I went there. Soqi gym cleans your blood. You see, when you get there you lie down and let them move the machine all over your body. Even those who look like they are dying or found on the street get well. As long as they get to the machines, their illnesses are nothing. People get there very early, like at 2 in the morning, because it is long queues. I once slept there myself on card boxes just so I can get in when they open. They even sell the machines now around 6 000 [rand]. If I had means I will buy it and make some money (Anna 10 November 2009).

Her attendance at the Soqi gym complemented her attendance at the clinic:

SARS 45(2)2014_layout.indd 110 4/24/2014 15:57:34

> … since I have been going to soqi gym I even gets repeats at the clinic, so when I go to the clinic I only get tablets and they will check me maybe in January, after 2 months (Anna 10 November 2009).

The narrative presents a stark contrast between ideologically contrasting systems of healthcare, both of which demonstrate features of formal rationality, namely formal systems of dispensation (queues) and representation (uniforms). Both make use of technologies whose precise operations are beyond the immediate cogency of participants (tablets in the case of clinics, and 'machines' in the case of the Soqi gym), and which instantiate broader realms of technology.

This narrative may be contrasted with another case study, in which no alternative or complementary treatment was sought for chronic illness. Prudence, aged 54, did not use alternative medicine, nor did she fear or question the clinical regimen. She did not construct lengthy narratives during her interview, but answered the various probing questions concisely and briefly. She was diagnosed with arthritis and high blood pressure, as well as with heart failure. She was referred to a hospital outside Soweto for treatment, and then to another hospital inside Soweto, before finally requesting and obtaining regular treatment at her local clinic. She did occasional work to support her grandchildren, whom she had cared for since the death of her son. Her narrative is notable for its complete absence of references to alternative healing paradigms. She summarised her experiences as follows:

> I have arthritis and high blood. So at the clinic they discovered that I have heart failure and they sent me to Helen Joseph. So I don't have money to go there anymore since I have to pay for transport. So when I went to start at Tladi clinic they gave me a card and told me to go back to Helen Joseph so that they can write down the medication they used to give me. But now, because I do not have money, and I'm a bit tied up by the grandchildren, I'm waiting for month-end so that I can go there and they will do that, and then I will be able to take treatment here at Tladi because I can walk there (Prudence 26 October 2009).

This narrative indicates that the strategic use of resources in managing chronic illness does not necessarily imply the usage of complementary and alternative medicine. The resources identified in patient narratives may lie well within the realm of Western biomedical healthcare. But the engagement of such resources is shaped by the social circumstances of women with chronic illness, and is thus not necessarily predictable, or in full accord with the systemic imperatives of Western biomedical healthcare models, which, as in the case above, do not recognise such circumstances. Prudence's understanding of well-being was predominated by her concern for the well-being of her family, who were in difficult circumstances due to a lack of income, prompting her to say at the end of the interview: 'I wish I could get grant money' (Prudence 26 October 2009).

SARS 45(2)2014_layout.indd 111 4/24/2014 15:57:34

DISCUSSION

We examined narratives of chronic illness in an attempt to explore the concept of the healthworld and to arrive at a working definition of healthcare access. But we found that our approach revealed to us much about chronic illness. The examination of diseased conditions by means of the healthworld located the experience of chronic illness within a societal and autobiographical context at the same time that it focused our attention on the interactions of participants with Western biomedical and alternative healthcare systems.

This study of the healthworld by means of narrative enquiry may be positioned within the sociology of health and illness, which focuses the research agenda on lay narratives of illness, disease causation, healthcare encounters, and the use of diverse healthcare practices. As such, our findings resonate with several themes already identified in the sociological literature of health and illness.

The initial experiences of chronic illness were described as biographical disruptions. The concept of biographical disruption entails a disruption to the lifeworld caused by inescapable pain and suffering occasioned by chronic illness. This concept proves to be consistent with a healthworld approach to the study of chronic illness, in that it entails the foregrounding of previously taken-for-granted assumptions regarding bodily functioning, and social relationships (Williams 2000). The biographical disruptions described in the findings are marked by accounts of the foregrounding of knowledge of chronic illness and its treatment that was previously unacknowledged by the respondents.

At the same time, biographical disruption was closely related to the causes of chronic illness. These biographical disruptions are presented as dramatic life events, occurring often in childhood and youth, which precipitate the onset of chronic illness later on in life as a different type of biographical disruption. We may recall Monica's physical disability, which she attributed to poorly treated tuberculosis as a child. Sarafina attributed her arthritis to the stressful period following her marriage, while Linda's narrative of heart disease and stroke began from recurring illnesses and encounters with Western biomedical healthcare systems from the beginning of her life. Such narratives reveal how biographical disruption is often integrated in narratives that preserve biographical continuity, and suggest ways in which chronic illness may be meaningfully encountered.

Within our narrative approach, healthcare access is not positioned as a goal or outcome, but tended to be described in terms extending beyond the availability, affordability or acceptability of Western biomedical healthcare services posited by current understandings of healthcare access (Thiede et al. 2007). Rather, the narrative approach suggests that the accessing of Western biomedical healthcare services forms only a part of a larger quest for health, a quest in which questions of meaning play an important role.

The treatment of chronic illness emerged as a process that potentially incorporates a wide range of cultural and personal resources. Sarafina, for example, not only made

SARS 45(2)2014_layout.indd 112 4/24/2014 15:57:34

use of a cultural resource in the form of *mosomi,* but also positioned arthritis itself as a resource for character development. Rosaline expressed frustration at her lack of choice in having to take tablets for her high blood pressure, but also exerted some agency in regulating her intake of pills by sometimes relying on herbal teas. The use of alternative medications facilitated a narrative in which a lifelong dependency on pharmaceutical medication is one day overcome.

Our findings indicate that any concept of healthcare access should take into account the complexity of healthcare systems, including both Western biomedical healthcare and complementary and alternative healthcare systems, and of health seeking behaviour. Indeed, formative work on the complex nature of healthcare access has begun to conceptualise access primarily as a series of dynamic interactions between different elements of different healthcare systems, mediated through informal behaviours and processes (Balabanova et al. 2006). It appears, however, that such work has yet to develop into a robust literature that can influence healthcare policy.

Our present study may contribute in a small way to the development of healthcare access frameworks, which take account of complexity by suggesting the importance of narrative enquiry and lifeworld exploration in such an endeavour. Our study has been confronted with a number of limitations. As indicated earlier, our generic approach to chronic illness, or the limited number of our participants, means that the findings may be of limited clinical or public health relevance. However, we always conceived of this study as a first step in the exploration of healthcare access via a sociological method. At the conclusion, our study suggests that lifeworld research will prove highly resourceful in understanding specific chronic illnesses and healthcare access in clinical as well as policy-related contexts.

ACKNOWLEDGEMENTS

The research for this paper was conducted by the field staff of the Developmental Pathways for Health Research Unit (Birth to Twenty), and was funded by the Wellcome Trust, the University of the Witwatersrand, SANPAD, MRC(SA) and MRC/DfID (UK; Africa Research Leader Award).

REFERENCES

Baarts, C. & Pedersen, I.K. 2009. Derivative benefits: Exploring the body through complementary and alternative medicine. *Sociology of Health & Illness* 31(5): 719–733.

Balabanova D., Parkhurst J., McKee M. & McPake B. 2006. Access to health care: taking into account health systems complexity. HSD working paper, [online] Available at <http://www.hsd.lshtm.ac.uk/publications/hsd_working_papers/Access_to_health_care_web_version.pdf> (accessed 5 March 2009).

Bodenheimer, T., Lorig, K., Holman, H. & Grumbach, K. 2002. Patient self-management of chronic disease in primary care. *Journal of the American Medical Association* 288(19): 2469–2475.

Bury, M. 1998. Post-modernity and health. In G. Scambler and P. Higgs (eds.), *Modernity, Medicine*

SARS 45(2)2014_layout.indd 113 4/24/2014 15:57:34

and Health: Medical Sociology Towards 2000, 1–28. London: Routledge.

Bury, M. 2001. Illness narratives: Fact or fiction? *Sociology of Health & Illness* 23(3): 263–285.

Chase, S.E. 2005. Narrative inquiry: Multiple lenses, approaches, voices. In N.K. Denzin, and Y.S. Lincoln (eds.), *The Sage handbook of qualitative research 3rd Edition*, 651–679. Thousand Oaks: SAGE Publications.

Chi Machine International. 2012 SOQI – Natural healing. Retrieved from http://www.chimachine4u.com/SOQI.html (accessed 01 October 2012).

Cochrane, J.R. 2007. On healthworlds. CCIH-News, February 28 2007. Retrieved from http://www.ccih.org/pipermail/news_ccih.org/2007-February/000093.html (accessed 04 December 2012).

Frank, A.W. 2001. Can we research suffering? *Qualitative Health Research* 11(3): 353–362.

Germond, P. & Cochrane, J.R. 2010. Healthworlds: Conceptualizing landscapes of health and healing. *Sociology* 44(2): 307–324.

Grobler, C. & Stuart, I.C. 2007. Healthcare provider choice. *South African Journal of Economics* 75: 327–350.

Habermas, J. 1972. Technical progress and the social life-world. In J. Habermas, *Toward a rational society: Student protest, science and politics*, 50–51. Boston: Beacon Press.

Habermas, J. 1987. *The theory of communicative action. Volume 2. Lifeworld and system: A critique of functionalist reason.* Boston: Beacon Press.

Illich, I. 1976. *Limits to medicine, medical nemesis: The expropriation of health*. London: Marion Boyars.

Kotarba, J.A., Haile, B., Landrum, P. & Trimble, D. 2003. Inner strength and the existential self: improving managed care for HIV+ women through the integration of nursing and sociological concepts. In J.J. Kronenfeld (ed.), *Research in the sociology of healthcare Volume 21: Reorganizing healthcare delivery systems: Problems of managed care and other models of healthcare delivery*, 87–106. Oxford: Elsevier Jai.

Martin, C.M. & Peterson, C. 2008. The social construction of chronicity – a key to understanding chronic care transformations. *Journal of Evaluation in Clinical Practice* 15(3): 578–585.

McCarthy, T. 1984. Translator's Introduction. In J. Habermas, *The theory of communicative action. Volume 1. Reason and the rationalization of society*, v–xxxvii. Boston: Beacon Press.

Nteta, T.P., Mokgatle-Nthabu, M. & Oguntibeju, O.O. 2010. Utilization of the primary health care services in the Tshwane Region of Gauteng Province, South Africa. *PLoS One* 5(11): e13909, online publication 9 November 2010, doi: 10.1371/journal.pone.0013909.

Peltzer, K., Friend-du Preez, N., Ramlagan, S. & Fomundam, H. 2008. Use of traditional complementary and alternative medicine for HIV patients in KwaZulu-Natal, South Africa. *BMC Public Health* 8: 255, online publication 24 July 2008, doi:10.1186/1471-2458-8-255.

Richter, L.M., Norris, S.A. & De Wet, T. 2004. Transition from birth to ten to birth to twenty: The South African cohort reaches 13 years of age. *Paediatric Perinatal Epidemiology* 18: 290–301.

Scambler, G. 2000. Medical sociology and modernity: Reflections on the public sphere and the roles of intellectuals and social critics. In G. Scambler and P. Higgs (eds.), *Modernity, medicine and health: Medical sociology towards 2000*, 46–65. London: Routledge.

Singh, V., Raidoo, D.M. & Harries, C.S. 2004. The prevalence, patterns of usage and people's attitude towards complementary and alternative medicine (CAM) among the Indian community

SARS 45(2)2014_layout.indd 114 4/24/2014 15:57:34

in Chatsworth, South Africa. *BMC Complementary and Alternative Medicine*. 4: 3, online publication 4 February 2004, doi:10.1186/1472-6882-4-3.

Thiede, M., Akweongo, P. & McIntyre, D. 2007. Exploring the dimensions of access. In D. McIntyre and G. Mooney (eds.), *The economics of health equity*, 103–123. Cambridge: Cambridge University Press.

Timmermans, S. & Haas, S. 2008. Towards a sociology of disease. *Sociology of Health & Illness* 30(5): 659–676.

Williams, S.J. 2000. Chronic illness as biological disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness* 22(1): 40–67.

Williams, S.J. 2005. Parsons revisited: From the sick role to …? *Health* 9(2): 123–144.

Yach, D., Cameron, N., Padayachee, G.N., Wagstaff, L., Richter, L.M. & Fonn, S. 1991. Birth to ten: Child health in South Africa in the nineties: Rationale and methods of a birth cohort study. *Paediatric and Perinatal Epidemiology* 5: 211–233.

Zhang, Y. & Wildemuth, B.M. 2009. Qualitative analysis of content. In B. Wildemuth (ed.), *Applications of social research methods to questions in information and library science*, 308–319. Westport: Libraries Unlimited.

INTERVIEWS

Anna (pseudonym). Her residence, Tladi, Soweto, Johannesburg, 10 November 2009. Translated from Sotho by P. Tsoaedi.

Dora (pseudonym). Her residence, Central Western Jabavu, Soweto, Johannesburg, 11 November 2009. Translated from Sotho by P. Tsoaedi.

Dora (pseudonym). Her residence, Central Western Jabavu, Soweto, Johannesburg, 21 January 2010. Translated from Sotho by P. Tsoaedi.

Hyacinth (pseudonym). Her residence, Meadowlands, Soweto, Johannesburg, 19 November 2009. Interview conducted in English.

Hyacinth (pseudonym). Her residence, Meadowlands, Soweto, Johannesburg, 22 January 2010. Translated from Sotho by P. Tsoaedi.

Joyce (pseudonym). Her residence, Diepkloof, Soweto, Johannesburg, 4 November 2009. Translated from Sotho by P. Tsoaedi.

Linda (pseudonym). Her residence, Tshiawelo, Soweto, Johannesburg, 26 October 2009. Interview conducted in English.

Linda (pseudonym). Her residence, Tshiawelo, Soweto, Johannesburg, 10 December 2009. Interview conducted in English.

Monica (pseudonym). Her residence, Emdeni South, Soweto, Johannesburg, 21 October 2009. Translated from Zulu by P. Tsoaedi.

Monica (pseudonym). Her residence, Emdeni South, Soweto, Johannesburg, 07 December 2009. Translated from Zulu by P. Tsoaedi.

Prudence (pseudonym). Her residence, Naledi, Soweto, Johannesburg, 28 October 2009. Translated from Sotho by P. Tsoaedi.

Prudence (pseudonym). Her residence, Naledi, Soweto, Johannesburg, 9 December 2009. Translated

SARS 45(2)2014_layout.indd 115 4/24/2014 15:57:35

from Sotho by P. Tsoaedi.

Rosaline (pseudonym). Her residence, Molapo, Soweto, Johannesburg, 10 November 2009. Interview conducted in English

Rosaline (pseudonym). Her residence, Molapo, Soweto, Johannesburg, 21 January 2010. Interview conducted in English.

Ruth (pseudonym). Her residence, Klipspruit, Soweto, Johannesburg, 19 November 2009. Translated from Zulu by P. Tsoaedi.

Ruth (pseudonym). Her residence, Klipspruit, Soweto, Johannesburg, 22 January 2010. Translated from Zulu by P. Tsoaedi.

Sarafina (pseudonym). Her residence, Protea Glen, Soweto, Johannesburg, 04 November 2009. Interview conducted in English.

Sarafina (pseudonym). Her residence, Protea Glen, Soweto, Johannesburg, 07 December 2009. Interview conducted in English.

Shirley (pseudonym). Her residence, Jabulani, Soweto, Johannesburg, 30 October 2009. Interview conducted in English.

Shirley (pseudonym). Her residence, Jabulani, Soweto, Johannesburg, 12 January 2010. Interview conducted in English.

Thandi (pseudonym). Her residence, Klipspruit, Soweto, Johannesburg, 15 October 2009. Interview conducted in English.

Thandi (pseudonym). Her residence, Klipspruit, Soweto, Johannesburg, 10 December 2009. Interview conducted in English.

BIOGRAPHICAL NOTE

Daniel Lopes Ibanez-Gonzalez completed his Master's in Sociology at the University of the Witwatersrand, and subsequently worked for several years at the Community Agency for Social Enquiry, focusing on healthcare research. He now works at the Developmental Pathways for Health Research Unit, where he is completing his Ph.D. on perspectives on healthcare access in urban and rural study settings.

Ran Greenstein is an Associate Professor in the Department of Sociology at the University of the Witwatersrand. He obtained his Ph.D. at the University of Wisconsin-Madison focusing on settlement, resistance and conflict in South Africa and Palestine/Israel. From 1998 to 2001 he was Deputy Director of the Community Agency for Social Enquiry. He has published chapters in books and has contributed numerous articles to local and international publications.

SARS 45(2)2014_layout.indd 116 4/24/2014 15:57:35

Paper IV

Lopes Ibanez-Gonzalez, D., and Tollman, S. M. Clinics, Churches and Healers: Health Seeking of Older Women with Chronic Noncommunicable Disease in Rural South Africa (Submitted, Journal of Religion & Health, 2013)

Conference Proceedings

Lopes Ibanez-Gonzalez, D., and Tollman, S. M. Clinics, Churches and Healers: Health Seeking of Older Women with Chronic Noncommunicable Disease in Rural South Africa. Poster presentation at the annual Wits Health Sciences Research Day, 19 September 2012, Wits University, Johannesburg, South Africa.

Clinics, Churches and Healers: Health Seeking of Older Women with Chronic Noncommunicable Disease in Rural South Africa

Daniel Lopes Ibanez-Gonzalez[1] and Stephen M. Tollman[2]

[1]University of the Witwatersrand, Johannesburg, South Africa

[2]University of the Witwatersrand, Johannesburg, South Africa

Corresponding Author

Daniel Lopes Ibanez-Gonzalez, Developmental Pathways for Health Research Unit, Department of Paediatrics and Child Health, University of the Witwatersrand Medical School, 7 York Road, Parktown, 2193, Johannesburg, South Africa

Email: Daniel.LopesIbanez-Gonzalez@students.wits.ac.za

Acknowledgements

This research was funded by the National Research Foundation. Zodwa Khoza conducted, translated and transcribed the interviews. The MRC/Wits Rural Public Health and Health Transitions Research Unit facilitated the fieldwork. Nina Lewin validated the coding. Nicole Agliotti and Fred Golooba-Mutembi reviewed the article.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

Bios

Daniel Lopes Ibanez-Gonzalez, MA, is a doctoral research fellow at the Developmental Pathways for Health Research Unit of the School of Clinical Medicine, University of the Witwatersrand.

Stephen M. Tollman, PhD, is the director of the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt) and is an associate professor and head of the Health and Population Division at the School of Public Health, University of the Witwatersrand.

Abstract
We describe a qualitative study of 13 women with chronic noncommunicable disease in a rural area in South Africa. The purpose of the study was to generate key concepts of health care access and the management of chronic noncommunicable disease in a rural African context. We used a content analytical approach to examine key themes and patterns in participants' accounts of disease and health care. "Healer-shopping" tended to occur within the allopathic paradigm, as opposed to across paradigms. The preference for clinically-based medicines was contextualized by religious concepts of maintaining good health. Church membership was the strongest factor motivating against the open use of traditional medicine, although traditional medicine might still be used privately for social, rather than medical purposes. The results highlight the importance of recognizing the role of church communities in reinforcing formal health care access for women with chronic disease.

Keywords
Africa, South; health behavior; health care, access to; health care, remote / rural; health care, users' experiences; health seeking; illness and disease, chronic; interviews, semistructured; narrative inquiry; older people

The use of a variety of health care service providers, and the delayed use of modern allopathic health care services are prevalent themes in much of the health access literature in low and middle income and rural settings in Africa. For example, half the respondents in a quantitative study with psychiatric patients in Jimma, Ethiopia sought traditional treatment from either religious leaders or herbalists before coming to a hospital (Girma and Tesfaye, 2011). A qualitative study in north western Tanzania found thematic linkages between social or traditional explanantions for tuberculosis as curses or divine punishments and delayed care seeking at the hospital level (Verhagen, Kapinga and van Rosmalen-Nooijens, 2010). Another qualitative study in Uganda, however, suggested that health care was mainly sought among doctors and nurses in the professional sector because of the severe symptoms of chronic disease, with traditional healers being the last resort (Hjelm and Atwine, 2011).

Mixed findings regarding the conception of disease and health seeking is similarly reported in South African rural areas. Goudge et al. (2007) report that villagers in north eastern South Africa switch numerous times between healers, and have little knowledge of allopathic diagnosis, using allopathic health care facilities only as a last resort after traditional therapies are judged to have failed. Golooba-Mutebi and Tollman (2007) argue that the strong reliance on traditional therapy and folk beliefs in the same area has facilitated the transmission of disease, particularly HIV/AIDS. Thorogood et al. (2004), however, report in the same area in north eastern South Africa that most survivors of stroke (79%) sought treatment from an allopathic doctor, hospital or clinic, although around 41% also sought treatment from traditional healers. Lewando-Hundt et al. (2004)

also find in the same area a complex distinction of allopathic and traditional conceptions of disease and plural healing methods which include visits to doctors, healers, prophets and churches.

Traditional medicine is thought to be more prevalent in rural areas than in urban areas in terms of numbers of practitioners, organization of traditional healers and acceptance of the traditional paradigm (Ngubane, 1992). African healers are divided into two main groups: *inyangas*, who are usually men and who specialise in herbal remedies, and *sangomas*, who are usually women and who specialise in divination and communication with spirits. Both have in common a holistic approach to diagnosis and treatment, which can include a number of alternative therapies, western and traditional (Ngubane, 1992).

This article describes a qualitative study conducted with 13 women with chronic noncommunicable chronic disease in rural north eastern South Africa. We conducted the study with the purpose of generating insights into health seeking and the treatment of chronic diseases in a rural African context.

Methodology

The article addresses the question: "How do women with chronic noncommunicable disease access health care in a rural South African setting?" We sought to answer this question with a qualitative methodology, using serial semistructured narrative interviews with women with chronic noncommunicable disease.

Study Setting

The settlement patterns of the study setting are typical of rural communities across South Africa, particularly within areas ("homelands") previously demarcated for black inhabitants of South Africa under the Apartheid regime. Being itself located in a former homeland in north eastern South Africa, the study setting consists of a number of densely populated villages surrounded by fields used for grazing and harvesting of natural resources (Hunter, Twine, and Patterson, 2007). At the time of data collection, infrastructure within the subdistrict was limited, although undergoing rapid development. The area was marked by an absence of formal sanitation, erratic supply of piped water to communal standpipes, gravel roads and limited electricity supply. Local employment and farming was limited, with most adults seeking work elsewhere. There was one health centre and five satellite clinics within the site, and three public hospitals within 60 kilometers of the site (Kahn et al., 2007).

Study Sample

We conducted the research in 3 villages within the subdistrict, basing our selection on key informant discussions with resident researchers within a local demographic surveillance unit. The selection of villages was designed to focus on acceptability factors of health care access, and as a result we selected villages which resembled urban areas in terms of availability and affordability of health care services (Thiede, Akweongo and McIntyre, 2007). We selected the study participants from a list of 28 respondents who had participated in the 2006 INDEPTH-World Health Organisation Study on Global Ageing and Adult Health, and who had indicated the presence of one or more long term illnesses, including arthritis, stroke, angina, diabetes, chronic lung disease, asthma, depression, hypertension, cataracts, and loss of teeth. We employed a purposive sampling

technique to ensure sufficient variation in terms of village of residence and number of reported chronic diseases, and concluded our selection of participants once it became clear that the initial coding categories were exhausted. We completed a total of 25 interviews with 13 respondents.

Ethics

Each participant understood the purpose of the study: namely to investigate the experience of chronic disease and accessing health care in a rural area. All personal information is kept confidential. Each participant gave her informed consent by signature to participate in the study and to have the interviews recorded and the recordings kept by the researcher for a period of 6 years. The research was approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (M090235).

Data Collection

We collected the data between July and September of 2010, during which time 2 interviews were conducted with each respondent, with the exception of the last respondent who was unavailable for the second interview. The serial methodology allowed us to refine the initial coding categories during the second interview. We interviewed each respondent in her home, usually in a quiet spot in the garden and beneath a tree. The interviews were conducted in Shangaan by a local research assistant, who was accompanied by the principal investigator (first author). Together we compiled detailed field notes on the mood and content of the interviews, and identified key themes for further investigation. We recorded each interview, which was later transcribed and

translated by the research assistant. An independent fieldworker fluent in Shangaan checked a sample of the translated transcripts and found a high level of accuracy.

Our choice of narrative enquiry as the primary methodology required us to view the interviewee as a narrator with a unique life history (Chase, 2005). As a result, we designed the interview guide to invite life histories around specific encounters, focusing on descriptions of chronic disease, initial reactions to disease, experiences and observations of allopathic and traditional health care services, and the impact of the chronic disease on social life.

Data Analysis

We employed a grounded theory, content analytical approach to data collection and analysis, and examined key themes and patterns in participants' accounts of disease and health care. We derived the coding categories directly and inductively through the raw data (Zhang and Wildemuth, 2009). We coded the data in two phases: coding during data collection and coding post data collection. We derived the initial coding categories during data collection via the analysis of detailed fieldnotes. Post data collection, we hand coded the transcripts using an open coding technique to sort through the data and develop additional coding categories. An independent scientist not connected with the study coded a sample of the transcripts and we found a high level of agreement in our coding. The process of coding during data collection and open coding post data collection resulted in the following broad coding scheme:

1) Family environment
2) Experience of chronic disease

3) Understandings of the causes of chronic disease
4) Accessability of the clinic
5) Clinic experience
6) Treating chronic disease
7) Home remedies and traditional medicine

We compiled and integrated all of the coded text from 13 respondents and 25 interviews into a single document including all coding categories. The document went through several iterations during which we refined all the coding categories into a concise summary of the findings.

Findings

We present the findings according to the primary coding categories listed above to approximate the narrative flow of the interview. The results begin with contextual findings related to family support, and continue to describe experiences and explanations of chronic disease, access to and experiences of allopathic health care service, self-managed treatment of chronic disease and the use of alternative and complementary medicine. The 13 participants were between 55 and 90 years of age, and described a combination of chronic diseases, with hypertension being a common complaint. Only 1 participant reported not taking any form of allopathic medicine, whereas 8 participants reported using some form of complementary medicine in conjunction with allopathic medicine.

Family Environment

With one exception, all respondents stayed either with their children, their grandchildren, their husbands, or their relatives. Living with the family ensured that they had someone to talk to about their illness, to promote their interests in interacting with the clinic, and to help them with household duties. Only one respondent, whose husband had recently passed away, lived alone, although she continued to receive financial support and regular visits from her son. She also regularly visited with one of her sisters, who advised her about which foods to eat and which to avoid. She expressed anxiety and fearfulness about living alone and was advised by the nurses at the clinic to seek counseling. Generally, the family was the first to be informed of the first signs of chronic disease. In all of these cases, the family recommended either the clinic or the doctor.

Whereas all the participants could refer to some form of care they were receiving from family members, a few spoke at greater length about their own caregiving roles within their families. One respondent spoke about her responsibility for monitoring her granchilren, who she had cared for since her children passed away:

> When they are ill I always take them to the clinic and make sure that they take the pills accordingly. And if I see that my grandchild is taking the pill and alcohol at the same time I will shout at him because it is not good.

Experience of Chronic Disease

Respondents described their condition as “high blood,” “dizziness,” “headaches,” “not having power,” “sugar diabetes,” and “stress.” The respondents tended to understate the severity of their disease. For example, a respondent might answer the question “What is

your condition?" with the words "I am fine, it's just that I was not feeling well," or "I can say that I am not that much ill exactly." Their reaction is mildly expressed, such as "I consulted the doctor, but I was taking it easy." None of the participants appeared particularly uncomfortable during the interviews. The chronic conditions imposed some inconvenience, but they were not in themselves major causes of distress. They were described as "just the illnesses of nowadays." Most respondents had resorted to using their pension money to employ people to help them farm and perform domestic duties, particularly washing.

Understandings of the Causes of Chronic Disease

Three broad explanations for the causes of chronic disease emerged from the interviews:

1. Occupational causes: resulting from strenuous work;
2. Dietary Causes: related to increase of meats, oil, sugar and processed food in diets; and
3. Social Causes: related to "thinking too much" about family difficulties, such as the loss of children

Social causes were most prominent in the interviews, particularly as they related to stressful social circumstances, such as the stress of caregiving. In the words of one participant, "if you are a mother everything that is painful, it will pass by you." The death of a relative may also bring about different types of stress, depending on the social environment of the surviving relations. It might bring about extreme anxiety related to isolation and vulnerability, as expressed below:

> I'm staying alone, no one to talk to and no one to share anything. So I'm thinking that maybe they will attack me and kill me. Besides as I'm having sugar diabetes what if it drops? Who will assist me?

The stress brought about by the death of children is quite different from the death of older family members. This brings the added responsibility on elderly caregivers of caring for and regulating the behaviour of grandchildren. One respondent, for example, attributed her high blood pressure to "thinking too much" about her grandchildren:

> I'm thinking too much because of my grandchildren. You find that I don't have anything to help them. I do get the pension, but I can't get by with that only, so I'm always thinking. That is why I know that the cause of the high blood is because I'm thinking too much.

Four respondents had lived through the death of children. The death of their children brought added pain to the stresses of life, which can be felt in the reflection: "if you have lost your children things are difficult. I have some, but I am not satisfied."

Access to the Clinic

Keeping in mind that all three villages had clinics, it is not surprising that no concerns were raised during the interviews regarding the general accessibility of the clinic. The clinic or hospital was generally the first point of call. Diagnosis and treatment for either high blood pressure or "sugar diabetes" was described as a straight-forward affair, with little variety in experience. One respondent summarised the general experience: "I first

consulted the clinic. I was given the pills and instructed to take them on time and the right dose. So I'm doing like that even now."

Although the clinic is often the first point of call, this is not always the closest clinic to the respondent. The theme of "better services elsewhere" emerges in the interviews, such as with one respondent, who never used the local clinic in her village, preferring to use a clinic in a neighbouring village. This particular choice was informed by a low opinion of the confidentiality and caregiving of the nurses at her local clinic. Another respondent avoided using her local clinic for counseling services because of low staffing, and so saved money for transport to clinics further away. Another respondent, who could afford private doctors, avoided clinics as a rule because of the long waiting times. However even for private doctors, she preferred travelling to the closest town, some 60 kilometres away.

Another common feature emerging from narrations of the first access of the clinic is the cross-referral. From the first presentation at the clinic with a physical ailment, the patient is referred to the local hospital for diagnosis, a process which might require a stay of some days at the hospital. Following the diagnosis is the course of treatment, which is described as a standard process of collecting medication. Because this is a standard process, it can be carried out more easily for the patient at the local clinic. It is left to the patient to request a referral back to the local clinic.

Clinic Experience

We asked the respondents a series of questions designed to elicit narratives about their experiences at the clinics. The questions included: "what is a typical visit to the clinic like?" "What are the problems you experience?", and "How are patients treated at the clinic?" Respondents described going to the clinic, collecting the pills and going home, without much interaction with the clinic staff or other patients. Respondents were sympathetic of the nurses at the clinic, and tended to excuse any shortcomings which might have been observed. One respondent, for example, said: "At the clinic they are taking good care of us. What I have seen is the shortage of the nurses: one person must do a lot of work."

The sympathy for the nurses is expressed as a type of etiquette which prohibits "telling each other what happened," or perpetuating gossip at the clinic. The view is that if there are any problems, one should make use of the suggestion box, rather than talk openly about it, because "it will be like we want them to be fired." The reticence of interview participants regarding their clinical experience can also be explained by the uniformity of the experience itself. One respondent describes the process:

> What they are doing at the clinic, they check the BP [blood pressure]. So they will tell you if it is high or low. If they find that it is high they will give you the small pill. After a few minutes they will recheck, and if they find that it is still high they will give you the same pill. Then you go home.

This view is indicative of acceptance of the chronic disease, and the established treatment procedures for it. Her complacence has reduced the impact of the chronic disease in her everyday life and consciousness.

Treating Chronic Disease

A common and powerful response to the question: "What helps you most to cope with your illness?" is simply to go to the hospital or clinic to collect pills. For one respondent, the clinic is where she has "gotten life" because of the clear diagnosis and treatment. Another respondent who relied on the clinic treatment contrasted it with home and traditional remedies in terms of the relative simplicity of the clinic treatment:

> I don't use any home remedy. I don't even know how to mix it. Even if you can explain to me how they mix I will forget, because I'm not used to it. What I know is the medicine from the clinic. . . . I'm not educated but I know how to take the pills and how they are working.

This respondent was very clear about relying only on the clinical medication, saying "if you concentrate on the pills you will live." However, her preference for allopathic medicines was closely connected with religious concepts of maintaining good health, as is evident in her statement: "Even if you just drink medicine, if you don't believe you won't get well. So the only thing is to believe in what you are doing." Although this respondent only took medicine from the clinic, her core belief with regard to coping with chronic illness lay in living an active life. She had earlier said:

> Even if I can show you my card you will see that my high blood is not too bad because I can control it every time. I laugh with people to avoid thinking, or take

a hoe to clean the farm. I can't sit still because I know that I will start thinking, so I always do some jobs to avoid stress.

Home Remedies and Traditional Medicine

Home remedies refer to herbal supplements based on folk knowledge of local herbs and their properties, and which might or might not be prescribed by a traditional healer. Traditional medicine refers to medicine, including home remedies, which is specifically prescribed by traditional healers who base their therapies on powers of divination (Ngubane, 1992). In their eagerness to dissociate themselves from traditional healers, some respondents would also deny the use of home remedies, although they would later mention taking some form of complementary or alternative medicine.

Church membership, particularly of African Christian Churches, is the strongest factor motivating against the open use of traditional medicine, although the cost of traditional healers was also mentioned as a reason for not using them. When we asked one respondent whether she used home or traditional remedies, her answer was emphatic: "No I'm a Zion." At the same time, the church itself is a source of home remedies, in this case holy water.

Another respondent explained that while consulting a number of doctors for her sore stomach she also tried a traditional healer. She tried the medicine, but it did not work, and so she discontinued the treatment. She then started attending a Pentecostal church, and therefore she now "cannot go" to the traditional healer. As a member of the congregation, she is expected to abstain from consulting traditional healers. The church

advises her to consult only the clinic, and to take only the medicines prescribed by the clinic. At the same time, her church encourages the use of a particular alternative remedy, in this case, Vaseline, which "removes white sputum."

It appeared that traditional healers were consulted for social purposes rather than for treating disease. For example, one respondent, who was a member of the Zion Christian Church, said that in her youth she had consulted a traditional healer for the purposes of conceving a child. Another respondent made a clear distinction between traditional and allopathic medicine. There was an undertone in her response which indicated that she knew when to consult a traditional healer and when to consult the clinic, and that she was not willing to discuss her private reasons for visiting the traditional healer: "I'm not taking home remedy, but I do consult the traditional healer, but not because of high blood. It is because of something else."

Generally, the respondents adopted the clinical regimen as the authoritative treatment for chronic disease. The exceptions to the rule were two respondents. The first respondent described a life change from what she described as a depressing reliance on daily medication, to a proactive approach including physical activity; drinking one litre of water per day; abstaining from soft drinks, sugar and condensed milk; and regularly drinking aloe tea. This life event led her to stop taking pills to control high blood pressure and diabetes, which she subsequently felt able to control by her new lifestyle. She described the life change as follows:

> I was always listening to the program on television. Sometimes they interview the doctors about the illness of nowadays. You find that sometimes we are creating the illness on our own, like eating Rama [margarine], meat. . . . So you find that all these foods are not good for you. Sometimes they will say you must avoid cooldrinks, sweet things . . . and if you are following you will be better.

The second respondent also suffered from high blood pressure, though she supplemented, rather than replaced, her clinical treatment with a home remedy: a local herb called *nkanka*, which is drunk like a tea. The herb is sometimes used as a dietary supplement with porridge, but, when boiled, can be drunk as a tea for high blood pressure. She sometimes voluntarily abstained from the pharmaceutical medication, which made her feel dizzy, relying solely on nkanka when she felt her heart beating fast.

Discussion

Our findings indicate a familiarity with chronic disease and the construction of coherent explanations of the causes of chronic disease which are mostly stress related, but also include occupational and dietary causes. The formal health care facility has a high level of acceptability from respondents, who generally used either the clinic or doctor as the first option in treating their diseases. Switching of healers occurred largely within the paradigm of western health care, manifested as looking for better clinical services elsewhere. Sympathy with the nursing staff featured more prominently than criticism. Either because of their advanced age or their rural lifestyle, respondents were slow in forming and harbouring complaints about the clinic.

We are able to confirm previous findings reporting the use of multiple treatments commensurate with personally defined illness aetiologies (Thorogood, Connor, Lewando-Hundt, and Tollman, 2007; Hjelm and Mufunda, 2010), but also affirm that clinical treatment is a prominent feature of treatment, reinforced by church-based health care practices. We can also confirm the finding of a general, church-based social approval of clinical treatments, and social disapproval of traditional healers (Golooba-Mutebi, Tollman, 2007). At the same time, treatment preferences are for pills and clinics because of the simplicity and authority of the treatment. This treatment is generally supplemented with socially approved (church or folk-based) home remedies and practices for ameliorating the effects of the disease and controlling dependence on clinical regimens. Traditional healers might still be privately used at some considerable expense for social purposes, such as warding off jealousy or attaining conception.

Conclusion

Our research enables us to question the notion that older rural women are "disempowered" in relation to formal public and private health care institutions (Goudge et al., 2007). We can also question the notion that for older rural women, formal health care is a last resort in a hierarchy of health care choices (Golooba-Mutebi and Tollman, 2007). Rather, we have made a start in uncovering the social networks which guide and reinforce health-seeking behaviour in rural areas.

Our interpretation of the findings is limited by the narrow selection of research participants. However, the findings are not intended to be generaliseable, but rather to identify key themes for research in rural health care. There is the possibility of social

desireability biases in the findings, particularly in relation to expressed approval of the clinic and disavowal of traditional medicine, especially since use of the latter is discouraged both by the church and the clinic. We address this suspicion is by noting the consistency of the narratives which explain different reasons for the preference of clinical medication and which make clear connections between disease and the clinic, and social problems and traditional healers. Our findings did not show multiple understandings of chronic noncommunicable disease. These were understood as physical in nature with natural causes, such as occupation, diet and stress.

Church-based practices are prominent in reinforcing allopathic treatment for chronic disease, at the same time providing acceptable cultural practices supplementing the taking of medicine. The role of church communities and church-related social interaction in guiding self-treatment for chronic disease requires greater attention. Endeavours to reinforce health care access in rural areas should take account of the role played by churches and religious beliefs in encouraging and supporting the health care practices of women with chronic disease.

References

1. Chase, S. E. (2005). Narrative Inquiry: Multiple Lenses, Approaches, Voices. In N. K. Denzin & Y. S. Lincoln (Eds.), The Sage Handbook of Qualitative Research 3rd Edition (pp.651-679). Thousand Oaks: SAGE Publications.
2. Hjelm, K., & Atwine, F. (2011). Health-care seeking behaviour among persons with diabetes in Uganda: an interview study. BMC International Health and Human Rights, 11, 11. Retreived from http://www.biomedcentral.com/1472-698X/11/11
3. Hjelm, K., & Mufunda, E. (2010). Zimbabwean diabetics' beliefs about health and illness: an interview study. BMC International Health and Human Rights, 10, 7. Retreived from http://www.biomedcentral.com/1472-698X/10/7
4. Hunter, L. M., Twine, W., & Patterson, L. (2007). "Locusts are now our beef": Adult mortality and household dietary use of local environmental resources in rural South Africa. Scandinavian Journal of Public Health Supplement, 69, 165-74. Retreived from http://www.ncbi.nlm.nih.gov/pubmed/17676519
5. Girma, E., & Tesfaye, M. (2011). Patterns of treatment seeking behavior for mental illnesses in Southwest Ethiopia: a hospital based study. BMC Psychiatry, 11, 138. Retreived from http://www.biomedcentral.com/1471-244X/11/138
6. Golooba-Mutebi, F., & Tollman, S. M. (2007). Confronting HIV/AIDS in a South African village: The impact of health-seeking behaviour. Scandinavia Journal of Public Health Supplement, 69, 175-180. Retreived from http://www.ncbi.nlm.nih.gov/pubmed/17676520

7. Goudge, J., Gilson, L., Russel, S., Gumede, T., & Mills, A. (2007). Affordability, availability and acceptability barriers to health care for the chronically ill: Longitudinal case studies from South Africa. BMC Health Service Research, 9, 75. Retreived from http://www.ncbi.nlm.nih.gov/pubmed/19426533
8. Kahn, K., Tollman, S. M., Collinson, M. A., Clark, S. J., Twine, R., Clark, B. D., Shabangu, M., Gomez-Olive, F. X., Mokoena, O., & Garenne, M. L. (2007). Research into health, population and social transitions in rural South Africa: Data and methods of the Agincourt Health and Demographic Surveillance System. Scandinavian Journal of Public Health Supplement, 69, 8-20. Retreived from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2826136/
9. Lewando-Hundt, G., Stuttaford, M., & Ngoma, B. (2004). The Social diagnostics of stroke-like symptoms: Healers, doctors and prophets in Agincourt, Limpopo Province, South Africa. Journal of Biosocial Science, 36(4), 433-443. Retreived from http://wrap.warwick.ac.uk/749/
10. Ngubane, H. (1992). Clinical Practice and Organization of Indigenous Healers in South Africa. In S. Feierman & J. M. Janzen (Eds.), The Social Basis of Health and Healing in Africa (pp. 366-375). Los Angeles: University of California Press.
11. Thiede, M., Akweongo, P., & McIntyre, D. (2007). Exploring the Dimensions of Access. In D. McIntyre & G. Mooney (Eds.), The Economics of Health Equity (pp: 103-123). Cambridge: Cambridge University Press.

12. Thorogood, M., Connor, M. D., Lewando-Hundt, G., Tollman, S. M. & Ngoma, B. (2004). Secondary prevention of stroke – results from the Southern Africa Stroke Prevention Initiative (SASPI) study. Bulletin of the World Health Organisation, 82, 503-508.
13. Thorogood, M., Connor, M. D., Lewando Hundt, G., & Tollman, S. M. (2007). Understanding and managing hypertension in an African sub-district: A multidisciplinary approach. Scandinavian Journal of Public Health Supplement, 69, 52-59. Retreived from http://sjp.sagepub.com/content/35/69_suppl/52.refs
14. Verhagen, L. M., Kapinga, R., & van Rosmalen-Nooijens, K. A. W. L. (2010). Factors underlying diagnostic delay in tuberculosis patients in a rural area in Tanzania: a qualitative approach. Infection, 38, 433-446. doi: 10.1007/s15010-010-0051-y
15. Zhang, Y. & Wildemuth, B. M. (2009). Qualitative analysis of content. In B. Wildemuth (Ed.), Applications of Social Research Methods to Questions in Information and Library Science (pp: 308-319). Westport: Libraries Unlimited.

Appendices

Appendix 1: Ethics forms and clearance certificates

Ethical clearance for Soweto Survey

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ibanez-Gonzalez

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M081007**
PROJECT	An Exploration of Perceptions of Health and Halth Care Access in Soweto
INVESTIGATORS	Mr DL Ibanez-Gonzalez
DEPARTMENT	Department of Paediatrics
DATE CONSIDERED	08.10.31
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 09.03.23 **CHAIRPERSON** .....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Dr S Norris

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

Ethical clearance for overall study protocol

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Dr Daniel L Ibanez-Gonzales

CLEARANCE CERTIFICATE	M090235
PROJECT	Perceptions of Health and Care Access in Urban and Rural Communities: A Comparative Study of Women with Chronic Disease in the....
INVESTIGATORS	Dr Daniel L Ibanez-Gonzales.
DEPARTMENT	School of Public Health
DATE CONSIDERED	09.02.27
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 09.03.20 CHAIRPERSON .....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Dr S Norris

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

.....

Template of study consent form

University of the Witwatersrand
Medical School
7 York Road
Room 4L17
Parktown
2193
Tel: 011717-2701 or 2198

INFORMED CONSENT for SURVEY

I agree to myself being a participant in the Birth to Twenty/ Agincourt study.
The goals and methods of the study are clear to me. I understand that the study will involve interviews. All the details and purposes of this study have been explained to me. I understand that I have the right to refuse to participate in the study.

I agree to participation in the study on the condition that:

1. I can withdraw from the study at any time voluntarily and that no adverse consequences will follow on withdrawal from the study.

2. I have the right not to answer any or all questions posed in the interviews and not to participate in any or all of the procedures / assessments.

3. The University of the Witwatersrand Human Ethics committee has approved the study protocol and procedures.

4. All results will be treated with the strictest confidentiality.

5. The study team are committed to treating participants with respect and privacy through interviews conducted in private and follow-up counselling available on request.

6. I will receive a referral note to a health service if any result is out of the normal range or a problem is detected in the course of the study.

PARTICIPANT (Caregiver)

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

RESEARCH ASSISTANT:

Printed Name	Signature	Date and Time

Template of consent to tape interview form

University of the Witwatersrand
Medical School
7 York Road
Room 4L17
Parktown
2193
Tel: 011717-2701 or 2198

I have read or understood the project information sheet, and I understand that it is up to me whether or not the interview is tape-recorded. It will not affect in any way how the interviewer treats me if I do not want the interview to be tape recorded.

I understand that if the interview is tape-recoded that the tape will be destroyed six years after the interview.

I understand that I can ask the person interviewing me to stop tape recording, and to stop the interview altogether, at anytime.

I understand that the information that I give will be treated in the strictest confidence and that my name will not be used when the interviews are typed up.

Yes, I give my permission for the interview to be tape recorded

No, I do not give my permission for the interview to be tape recorded

PARTICIPANT (Caregiver)

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

RESEARCH ASSISTANT:

Printed Name	Signature	Date and Time

Appendix 2: Qualitative study instruments and fieldnotes

Template of in-depth interview schedule

Phase 1: Introduction, Chronic Illness and Accessing Health Care

1. First of all, please can you describe your medical condition/s?
    - When did you first develop the illness/es?
    - What were the symptoms?

    If there are more than 1 chronic illness, describe each one separately

2. Now let us talk about when did you first start to treat the illness
    - What was first reaction when you started to notice symptoms?
    - Who did you first speak to about the symptoms? *(What did they say? Did you agree with them?)*
    - When did you first decide to go to the clinic? What may you decide to go to the clinic?
    - What other advice did you seek for your condition? What was experience with other service providers?

3. Now let us talk about your experiences at the clinic
    - How regularly do you visit the clinic for your illness? Which clinic do you visit?
    - Please take me through a typical visit to the clinic (*Do you make preparations on the day for going to the clinic? How do you get to the clinic? What is the first thing you see when you get to the clinic?*)
    - What are the problems that you experience?
    - Please tell me about your relationship with the nurse (*Are you able to discuss your illness/ ask questions with the provider?*)
    - Please tell me about your relationship with the Doctor (*Are you able to discuss your illness/ ask questions with the provider?*)
    - What advice do you get with the clinic? Is it practical? *(e.g. Diet, exercise etc.)*
    - How are patients treated by this provider/ at this facility? Are different people treated differently? Please explain.
    - Please tell me about your medicine taking (*How often do you take medicines? Are there any side effects? Please explain. Do you take traditional medicines/ Home remedies? Please explain*)
    - Did you consult a traditional healer? If yes, please describe the consultation.

4. Now let us talk about how your illness impacted your family life

- Can you please tell us about your family life at the time that you first developed the chronic illness? *(Who were you living with? Were you working or a housewife? How old were the children?)*
- Did anyone else in the household have illness or disability?
- How did your family respond to your illness? *(Did they give you any advice about symptoms or treatment?)*
- Has the illness at anytime interfered with your household duties/ work/ family relationships? How?
- What do you think caused the illness?
- Did any you parents have this or similar illness? How did they deal with the illness? What did they think was the best way to treat it? Do you agree with it?
- What has been the biggest help for you in coping with your illness?
- Do you expect more from health services? Please explain.

5. Is there anything else you would like to add?

Thank you very much for your time.

Revised coding scheme for qualitative interviews

Causes
Medical Causes
Occupational Causes
Dietary Causes
Social Causes

Access to the Clinic
Walking distance
Do not use – confidentiality
Better services elsewhere
Clinic/ hospital first point of call

Impact interview
Interview as interacting with the clinic
Relieving anxiety
Active listening\ Courtesy
Clinical orthodoxy
Reflexivity

Clinic experience
Research and Clinical acceptance
Clinic as Pill Dispensary
Cross-referrals
A place to go
Bureaucratic Procedure, Social Setting
Personal Care
Nutritional and lifestyle advice

Pills
Efficacy of pills
Daily Schedule
Irregular adherence
Side effects
Pill-weariness

Family Support
Accommodation
Cooking and food
Transport and referral
Counseling
Caring for others
Family atmosphere

Medical experience
The limits of medicine
Persistence
Knowledge gaps

Traditional medicine
Knowledge of orthodoxy, pragmatic practice
Religious taboos on traditional medicine
(confounded with home remedy)
Home remedies/ folk knowledge
Private reasons for use
Expense of traditional healers

Experience of illness
Type of illness
Mild views of illness
Illness impact
Recent onset
Disclosure
Family response

Stress of life
Motherhood caregiving
Death of near and dear/ thinking too much
Isolation

Coping with illness
Reliance on clinic/ hospital
Spirituality
Activity
Family and diet
Occupation impact
Community views
Knowledge of illness

Site study summary (Soweto)

Note: the summaries below make use of psuedonyms

Respondent summary (Soweto)

Name	Dates	Area	Age	Language	Condition	Treatment
Thandi	15-Oct-09 10-Dec-09	Klipspruit	49	English	Arthritis and asthma	Private doctor; CAM (Cinnamon and honey)
Monica	21-Oct-09 07-Dec-09	Emdeni South	50	Zulu	TB and arthritis	Clinic; Pharmaceutical medication
Linda	26-Oct-09 10-Dec-09	Tshiawelo	49	English	Stroke, heart attack and hypertension	Clinic; Private Doctor; Pharmaceutical medication; Home Based Care
Prudence	28-Oct-09 09-Dec-09	Naledi	54	Sotho	High blood and arthritis	Clinic; Pharmaceutical medication
Shirley	30-Oct-09 12-Jan-10	Jabulani	53	English	High blood, diabetes and cholesterol	Clinic; Pharmaceutical medication; CAM (Diet)
Joyce	04-Nov-09 Deceased	Diepkloof	70	Sotho	High blood and arthritis	Clinic; Pharmaceutical medication; CAM (Rubbing ointment)
Sarafina	04-Nov-09 07-Dec-09	Protea Glen	45	English	Arthritis	Private doctor; CAM (Gym, *Mosomi* bracelets, calcium tablets, Faith)
Rosaline	10-Nov-09 21-Jan-10	Molapo	49	English	High blood and diabetes	Clinic Pharmaceutical medication; CAM (Broad leaf Holly and Jiaogulan teas)
Anna	10-Nov-09	Tladi	54	Sotho	High blood,	Clinic; Pharmaceutical

	Not Available				diabetes, arthritis, heart failure	medication; CAM (Gym, herbal tea)
Dora	11-Nov-09 21-Jan-10	Central Western Jabavu	48	Sotho	HIV and TB	Clinic; Pharmaceutical medication
Ruth	19-Nov-09 22-Jan-10	Klipspruit	91	Zulu	High blood, diabetes, arthritis and asthma	Clinic; Pharmaceutical medication; CAM (Holy water)
Hyacinth	19-Nov-09 22-Jan-10	Meadowlands	47	English/Sotho	Cancer	Clinic; Pharmaceutical medication (pain killers)

Key themes by respondent (Soweto)

A	**Prediction of future illness:** *…when he checked he told me, the doctor said that I will have arthritis and when I get to 50, I will never walk again, because my bones are not quite strong.* *(Interview A, Round 1, 15 Oct 2009* **Resourcefulness in use of treatment, linked to distinguishing oneself from the condition of the body, and utilising health care from an "unauthorised source** *I believe I will not be overcome by something that does not speak. That is why I believe that if somebody comes with something that will help me then I will do it because I don't want something that does not speak to overcome me* *(Interview A, Round 1, 15 Oct 2009)*
B	**Frustration with clinics treating the symptom and not the cause** *It's mostly TB, and when I go to the clinic what happens is that I sometimes feel pain in my bones, especially my hands and I cannot even hold things properly, but then the sisters at the clinic will normally give me pain blocks and bruffen.* *(Interview B, Round 1, 21 Oct 2010)* **Belief that earlier medical neglect caused present condition; Coping with the help of her family (her youngest son)** *The little one is very inquisitive, shed ask me stuff like- ma what's happening here? And then, I tell her that I wasn't born like this, I got sick when I was in std 3 and had to go to hospital where they told me I have TB of the spine, I tell her about the pain that I went through and still at times when I'm in pain I ask her to punch my back, it feels like a wound and at times like something is digging in, so when I have pains I ask her to punch me, you see when you punch it feels better* *(Interview B, Round 2, 07 Dec 2009)*
C	**Medical and treatment related stress aggravating chronic condition** *I was having some problems with my husband, and another thing, I was taking Worfarin back then so I was upstairs, so I had a heart problem, I didn't have Worfarin, I think for a week, I didn't take Worfarin, so I had a stroke (starts to cry),* *(Interview C, Round 1, 26 Oct 2010)* **Coping with the help of friends and community based organisations** *Yes I just joined them. They are funny (Laughter) we do a lot of things like exercises. I have fun with them. They keep me busy. We do exercises, the old grannies they jump, at the hall.* *(Interview C, Round 1, 26 Oct 2010)*
D	**Resigned determination in dealing with formal health care**

	But regarding that, I went to Zola Clinic and they referred me to Bara. I was admitted at Bara but wasn't given any treatment and that is how this ended. *(Interview D, Round 1, 28 Oct 2009)*
E	**Fear of consequences of leaving condition untreated** *It is because, you know I just decided to take it serious because each time I go to the doctor, and even different doctors they will tell me, you know, "your blood pressure is so high" and then sometimes they will say "you must come maybe after a week or two to check it", but I used to ignore that, but, now lately talking to people with this problem I realized that it was serious, then I started taking it serious, then I went to the clinic, after I took my grandson to the clinic, then I started taking my medication regularly now.* *(Interview E, Round 2, 12 Jan 2010)* **Ambivalence towards clinic and lifelong medication** *One day I wish something can happen that I can stop taking my medication. I don't like taking it, but I don't have a choice* *Ya. Sometimes you know, I ask myself "Where these tablets are going in my body?" Can you tell me?* *(Interview E, Round 1, 30 Oct 2009)*
F	**Resigned acceptance of a flawed health service** *No they just check your card and give you tablets and tell you that you will be fine and if you don't get well they tell that you are not taking care of your self* *(Interview F, Round 1, 04 Nov 2009)*
G	**Pragmatic approach to treating chronic illness, using a wide variety of approaches** *Ya, like tablets, and exercising. Hay, I have tried so many things, because the doctor, my neighbouring doctor, he just sent a statement. He told me to go to the gym. I went there. Ja, I think everything helped me.* *(Interview G, Round 1, 04 Nov 2009)* **Adapting and living with chronic illness** *And arthritis, it doesn't want you just to stay holding hands. You must use your hands, you must walk. You must stretch your bones, otherwise….My mum's older sister, but she has passed on now, her hands were like this (Showing with her hands) crooked. You see, like this. It is arthritis, and she was so lazy, you know, and I use to tell her, "Use your hands!" and she will say "No, they are so painful", and I will tell her "Use them! Use your hands. Wash the dishes with warm water, you know, do the dusting…" you see.* *(Interview G, Round 2, 07 Dec 2009)*
H	**Where does the medicine go in the body?** *Once I was washing dishes, so one tablet, eh Nedforin, fell on the floor, so I said "OK, I'll take another one", so I take that pill and throw it in the sink. I close the tap, and wash the dishes. I finish, take out the water and, I thought you know it would melt, and it didn't, and from there I get worried. "What is happening? What is going on when I drink these tablets everyday in my system? Where does it….?" I don't know where it is going. What is going on in my system? You know you drink that pill everyday, and you know, and I sit down, and take that pill, and take two spoons and I try to press it, to squeeze it, to squeeze it. It never squeezes. You know…(starts to laugh)* *(Interview G, Round 2, 07 Dec 2009)*
I	**Regular use of clinic, but improved health attributed to alternative remedies** *No,, it's just that since I have been going to Sarah gym I even get repeats at the clinic, so when I go to the clinic I only get tablets and they will check me in January after 2 months)* *(Interview I, Round 1, 10 Nov 2009)*
J	**Encouraged by family members with same disease** *My child encouraged me so much and I thought I'm certainly going to be encouraged* *(Interview J, Round 1, 11 Nov 2009)* **Arguments with nurses at the clinic** *No she is cheeky. She said that the last time I was at the Clinic she gave me enough tablets and claims that I must have written on my Clinic card. She doesn't treat us well and I get impatient and wonder why should I be wasting my time by going to the Clinic when I have pills as she claims?* *(Interview J, Round 2, 21 Jan 2010)*
K	**She began to view her condition in a non-specific way, as a part of life:**

	You see my child, I don't know anymore because I'm now breathing well, the only problem now is my sight and the fact that I don't hear well any more *(Interview K, Round 2, 22 Jan 2010)*
L	**Unhappy surrender to the medical process** *My second Doctor was better than the first one who kept injecting me without telling me what the problem was. My second Doctor even indicated that first doctor would kill me by not telling me what the problem with me was.)* *(Interview L, Round 2, 22 Jan 2010)*

Interview summaries (Soweto)

Respondent A (Thandi): Predictions of future illness

Thandi is 51 years old. She is somber and soft spoken. Thandi suffers from arthritis and asthma.

She copes with her asthma without recourse to medical treatment. It has become an accepted and integral part of her life. Her mother also had asthma, and treated it in the same way. Her mother advised her from an early age to exercise as a way of controlling her asthma.

With regard to arthritis, Thandi noticed a pain in her hip 2 years ago. Her spine had moved, and was pinching a nerve, and she was experiencing pain in her knees. She was told by her mother that she had arthritis when she was 17 years old, but, because she was young, she did not pay much attention to her. Then, about 15 years ago she fell down while she was trying to change a light bulb in her house. When she went to Lesedi clinic she was again told by the doctor that she had arthritis. At that time, the symptoms were so severe that someone had to hold her whenever she got up. She almost gave up her job because her joints were locked up and she could not move.

She was advised to go to the hospital to correct her spine with surgery, but she did not go, as she does not believe in hospitals or operations. Thandi subsequently went to a bone specialist where she was prescribed some tablets and given a corset to wear to correct the movement of her spine. She used the corset with some success.

Her only contact with the formal health care establishment is with her doctor, whom she sees about once every three months for check-ups and for **ailments other than arthritis**. Her main treatment for arthritis is the corset and a home remedy recommended by her friend who did an internet search and discovered a home remedy, consisting of 2 tablespoons of honey and cinnamon mixed with boiling water. Thandi felt that the honey and cinnamon mixture actually built up her body, in particular, the fluid around her knees, to be able to live with arthritis. It is not only that an inactive or voiceless condition, a label, should have no power over the active, those with a voice, but implicit in the victory of the active principle is the preparedness to accept help from an "unauthorised" source.

Respondent B (Monica): Clinics treat symptom, not cause

Monica lives in a shack in Emdeni South near Zola clinic. She wore brown slippers with pink roses embroidered upon them. The shack is located in the yard of a built up house.

She has suffered from TB of the spine from a very young age (she was in standard 3, or grade 5), and has recently noticed symptoms of arthritis in the wrists and fingers, but she has not been officially diagnosed with the disease.

At one point during the interview she stood up, turned around, and, lifting her shirt, showed us a hump on her back which developed as a result of the TB in the spine. She later indicated that if she had been adequately treated in childhood, this condition would not have emerged.

She attends the clinic at irregular intervals, depending upon how she is feeling, however, she was disappointed at what she sees as the typical response of the clinic staff to her health concerns:

Monica related how she had always to tell her youngest son, who was very inquisitive about it, and how she would ask him to lightly hit the spine whenever it was causing her pain.

She stopped going to school because of the difficulty of carrying heavy bags, and would cover her spine so as to avoid people asking her questions. She has never worked at anytime of her life due to her condition.

Respondent C (Linda): Coping with the help of friends

Linda lives in Chiawela and has suffered stroke and cardiac disease. Her main problems are with speech and weakness, resulting from her stroke. She spoke very quickly, and with a noticeable speech defect as a result of the stroke.

Linda suffered from 2 strokes, both of which occurred under remarkably similar circumstances. In both strokes, occurring in 1993 and 2007 respectively, she reported high levels of stress due to strains in the relationship with her husband and running out of medication. In addition, both strokes occurred after heart surgery.

Linda brought out all her medical papers as well as her medicines during the interview. The letters described the need for surgery on 2 heart valves. The surgery was also a source of considerable distress to Linda, who cried during the interview. However, she felt that the operations had been worthwhile, that they had been for her benefit. She was also positive about her experiences in the various clinics she had been to.

Her main source of strength is her relationships with friends, with whom she is able to talk, laugh and relax. Linda said that she is prone to stress and to becoming emotional, and that this counted heavily in bringing about her stroke. She said “I think too much” and “my heart is strained” and that she “keeps things inside”.

She also mentioned that she has just joined the local Home Based Care organisation. Even though the group consists mostly of older women, she visits them 3 times a weak

and they do exercise, talk and laugh. She said that God had blessed her, and she was very grateful that in spite of so many ailments, she was able to receive top quality care.

Respondent D (Prudence): Resigned determination
Prudence was interviewed her home in Naledi, Soweto. She has a strong and tough appearance, a large upper lip which betokens grimness, or strength of character. She sat comfortably and at ease during the interview, answering the questions concisely and briefly.

Prudence has arthritis and high blood pressure. She went to the clinic, where she was diagnosed with heart failure. She was then referred to Helen Joseph Hospital outside of Soweto for treatment. Her story was one of an unrelenting encounter with a medical bureaucracy, though one which left her undaunted.

Her main reason for attending the clinic was to collect her medication. Prudence had very little to say regarding the accessibility of the clinics she has attended, although it was apparent that she had been to quite a few in the course of her illness. Prudence has worked on and off over the years with "piece-work". She receives no help or support, but, on the contrary, appears to be the main financial provider for the household. She said that the clinic has been her biggest help.

Respondent E (Shirley): Ambivalence toward lifelong medication
Shirley is a large-set and robust woman in her mid forties, recently divorced, self employed, and resident in Krugersdorp as well as Jabulani, Soweto.

In 2005 she was diagnosed with high blood pressure, and in 2008 she was diagnosed with sugar diabetes, cholesterol, and arthritis. She was diagnosed with these illnesses when she took her son to the clinic, and decided to also have a check-up. She always knew that she had high blood pressure, and finally decided to "take it seriously" when she was told by friends and neighbours of some of the possible consequences of leaving it untreated, such as getting a stroke.

Since her diagnosis, Shirley has been taking a wide range of tablets. Her experience with chronic illness revolves largely around her medication. She visits the Krugersdorp hospital once a month to pick up her medication, and consults with a doctor once every 3 months. At first, she portrayed the procedure as quick and efficient. It was only in the second interview that she revealed some misgivings about the nurses, as well as the medical experience as a whole.

Shirley had an ambivalent attitude towards her medication. On the one hand, she said that it had been her biggest help in coping with her illness, and she had even bought a little bag in which she keeps all of tablets. On the other hand, she also felt some reservation about taking her medication. However, she felt that her regimen was better than herbal remedies, because there were too many of them.

Respondent F (Joyce): Resigned acceptance of flawed health service
Joyce was interviewed in her home in Diepkloof, Soweto. Her home is a "grannies" home, filled with old wooden furniture and the smell of cakes. She has statuettes of horses and ducks upon the cupboard. The interview is conducted at the table, with an embroidered table cloth and colourful artificial flowers. During the interview Joyce fetched her baby great granddaughter from the room next door and propped her up before her. During the interview she would occasionally kiss and fondle the baby, while the baby would occasionally return these affectionate dealings.

Joyce has high blood pressure and rheumatism. She has had high blood pressure since the early 1960s, and rheumatism since the 1980s. She regularly attends the clinic, and the clinic was her first port of call upon noticing the symptoms. She did not seek any other advice. She attends the clinic on a monthly basis for checkups (for high blood pressure) and she visits the clinic for her arthritis when needed. Her description of the clinic visits was one of a routine procedure, with little personal attention or consultation unless there is a pressing need, and that the queues are long,

Her only home remedy appears to be the cream she rubs on her joints for arthritis. The illnesses appeared to have very little impact on her daily life. Both her parents had high blood pressure, and her mother, like her, went regularly to the clinic for her check-ups. She said that her biggest help has been her visits to the clinic.

Respondent G (Sarafina): Adapting and living with chronic illness
Sarafina is a self-employed business woman, who bakes and sells confectionary. She did not look very old, and was youthful and lively in her mannerisms. Sarafina has arthritis, and while she said that her case was not very severe, during the course of the interview it became clear that the condition is fairly severe, and has an impact on her life.

Sarafina said that she developed arthritis since moving to her current home in Protea Glen in 1994. After about a year, she consulted a private doctor in the neighbourhood, following the guidance of her husband, who had heard about the doctor from friends. The assistant doctor informed her that she has arthritis, and prescribed some tablets for her to take, which she shortly afterward discontinued

When asked what has helped her the most with her arthritis, Sarafina drew attention to the black rings and bracelets which she wore on both hands and wrists. Sarafina had become accomplished in living with her arthritis and coping with its limitations. She stopped taking the prescribed pills because of the drawn out process, but continued with calcium supplements which are easier to get. She said that it makes no difference.

Respondent H (Rosaline): Where does the medicine go in the body?
Rosaline lives in Molapo Soweto. She appears to be in her 40s, and is short, dark, and lively. She developed diabetes and high blood pressure about 3 years ago. She noticed that she could not see clearly and that she felt dizzy. She finally decided to go to the

clinic when she noticed that she could not even recognise fellow congregation members at the church. She now attends the clinic at least once a month.

Rosaline takes 2 kinds of medication, one for diabetic and 2 for blood pressure (once in the morning and once at night). She admitted that she does not take her medication every day. She traced her reluctance to take medication to a particular event. She heard about Chinese tea from a lady at the clinic. The tea she takes is from a company called South African Chinese Medicine (SACM) and is called Natural Health Tea, made of Broadleaf Holly leaf, and said to help with blood circulation and high blood pressure, amongst other things. She also takes Jiaogulan Tea, which delays aging and regulates the blood fat.

She continues to take Chinese herbs, as well as her diabetes tablets, although she sometimes skips days with regard to her diabetes tablets. She is still not happy about taking these tablets everyday, and looks forward to the day when she will no longer have to take them.

Respondent I (Anna): Uses the clinic, but is healed by alternative healthcare
Anna, is an elderly lady and was interviewed in her home in Tladi, Soweto. She has high blood pressure, diabetes and arthritis, and suffered from a heart failure in 2000. She has had diabetes since around that time, and about 2 years later developed high blood pressure and arthritis. She was treated for heart failure in Baragwanath, and has not had any more heart problems since then. She regularly attends the Tladi clinic, once a month.

Anna was taking a home made remedy from a lady who was selling diabetes medication in the clinic, but her son took away all the medicine and instructed her to continue taking the prescribed medication from the clinic. Despite this, Anna continued to seek alternative remedies, and went on to describe the virtues of “Sarah-Gym” (So-Chi), a therapy focused on massage and exercise. The therapy was for free in Bree Street, but Anna later on said that sometimes people are charged to use it. She uses this therapy everyday, travelling to locations in Johannesburg and Soweto where the device is on trial and available for public use, sometimes at a cost and sometimes for free.

Respondent J (Dora): Arguments with nurses at the clinic
The tenth interview was conducted in Central Western Jabavu with Dora. Dora is small, soft spoken, and of gentle appearance. She first noticed the symptoms of TB last year, when she felt tired. She consulted a neighbourhood doctor before going to the clinic, and followed a 6 month course of treatment for her TB before she recovered. She affirmed that the treatment had cured her of TB. However, she was more recently diagnosed with HIV/AIDS.

In terms of family response to her illness, at the end of the interview Dora said that only she and her children know about her status. She also said that her oldest child also has HIV/AIDS.

During the second interview, Dora was more forthcoming about some of the problems she encountered in the clinic, partly motivated by the fact that she had been unsuccessful in getting the head nurse at the clinic to support her application for the disability grant. She said she was tested for HIV on the recommendation of the nurses, who noticed that she had a low CD4 count. She also said that she recommends that people go for an HIV test. She said that her brother was recently tested positive, and, while he has reacted strongly against the medication, she has advised him to continue taking it.

Respondent K (Ruth): Non-specific condition, a way of life
The 11th interview was conducted in Klipspruit with Ruth, a 91 year old widow who reported having arthritis, asthma, cramped legs, high blood pressure and diabetes. All these conditions developed at around the same time, about 2 to 3 years ago, following an operation to remove gall stones.

She has consulted a doctor in Kliptown, and makes regular visits to the clinic for medication, where she says that they treat the patient well, only they sometimes run out of medicine.

The nurse and doctors at the clinic have given her advice on which foods to take, mentioning cabbage and spinach. She take her pills every day. They include 2 types of vitamin supplement (vitamin B3 and Vitamin B complex), cetapon, and lennon theamine hydrochloride, as well as eye drops and an asthma inhaler. She also takes church water, which she held onto during the interview. Ruth was emphatic in stating that she did not consult with traditional healers. She spoke a little about her Home Based Care organisation, Sizanani Home based care, and the fact that they will no longer provide her with food support since her grandchildren have reached 17 years of age.

Respondent L (Hyacinth): Unhappy surrender to the medical process
The first interview with Hyacinth was conducted in English by the principal investigator. As a result of the difference in background between the discussants, as well as to the nature of her chronic illness (cancer of the womb) Hyacinth was very reticent during the interview, answering questions with one-word answers, or sometimes a nod of the head.

She occasionally looked at the tape recorder, suggesting that she was not at ease during the interview.

The follow-up interview was conducted in Sotho, by a female research assistant, and as a result, Hyacinth was more forthcoming regarding her medical experiences. This first indication of the experience is related with regard to the machines used to “clean” the cancer in her womb. The medical experience was itself a traumatic one, explaining why Hyacinth was so reluctant to talk about it during the first interview. She stayed at Bara for 6 months, following a daily schedule which saw her transported with other patients to Hillbrow, and from then on to Johannesburg hospital, where she would be treated by machines. At first she felt uncomfortable, but soon got used to it. She said that the nurses and doctors at Bara were very supportive of her.

Site study summary (Agincourt)

Note: the summaries below make use of psuedonyms

Respondent summary (Agincourt)

Name	Dates	Area	Age	Condition	Treatment
Saliah	23-Jul-2010 16-Aug-2010	Agincourt	79	Crippled and Painful leg.	Pills
Kathrine	26-Jul-2010 24-Aug-2010	Agincourt	63	Hip leg pain/ Sores on face/ Ulcers	Pills
Anah	27-Jul-2010 16-Aug-2010	Agincourt	90	Dizzy spells/ Lacking power	Pills and Holy Water
Lettie	27-Jul-2010 16-Aug-2010	Agincourt	55	High blood pressure/ Ulcers/ Hot body/ Swelling	Avoiding junk food/ Pills/ ZCC tea
Khisoze	29-Jul-2010 18-Aug-2010	Cunningmoor A	80	High blood pressure/ Diabetes/ Body not well	Pills/ ZCC tea/ Avoiding sugar and salt
Hunadi	29-Jul-2010 18-Aug-2010	Cunningmoor A	67	High blood pressure/ Diabetes/ Arthritis or gout on hips, arms and legs/ Dizziness and stress	Pills/ Avoiding sweets and fatty foods
Cabiya	29-Jul-2010 18-Aug-2010	Cunningmoor A	89	High blood pressure/ Diabetes Stomach problem/ Constipation	Traditional healer/ Pills/ Avoiding sugar and salt/ Prayer/ Vaseline from the church
Marta	02-Aug-2010 23-Aug-2010	Cunningmoor A	82	High blood pressure/ Diabetes	Pills/ ZCC tea/ Prayer/ Activity
Linah	02-Aug-2010 23-Aug-2010	Cunningmoor A	60	High blood pressure	Pills/ Avoiding salt and sugar

Idah	02-Aug-2010 23-Aug-2010	Cunningmoor A	63	High blood pressure/ Sore legs/ Headaches	Pills/ Avoiding salt, sugar and tea
Phipas	06-Aug-2010 24-Aug-2020	Kildare A	63	Headaches/ Dizziness/ Knees	Pills/ Home remedy (*nkanka*)/ Bandages for knees
Thabiso	06-Aug-2010 24-Aug-2020	Kildare A	61	High blood pressure/ Headaches/ Sore legs	Pills/ Avoiding stress/ Activity/ Drinking water/ Avoiding junk food/ Aloe tea
Nomses	10-Aug-2010	Kildare A	70	High blood pressure/ Dry cough/ Poor eyesight	Traditional healer / Pills/ Home remedy

Key themes by respondent (Agincourt)

A	**Regular Clinical experience:** *Interviewer: What are the problems that you are facing?* *Respondent: When I reach the clinic they just welcome* *Interviewer: Are you able to talk about your problems at the clinic or anything?* *Respondent: They know what I'm suffering of because every time I'm going there* *Interviewer: Is there any advice you are getting from them concerning your illness?* *Respondent: No advice. They just give us the pills only.* *(Interview A, Round 1, 23 July 2010)* **Traditional Medicine for Socially caused illness** *Respondent: I have consulted the traditional healer because I have eaten something like poison* *Interviewer: What have you eaten?* *Respondent" It's like when someone gives you food you won't know if she is giving you with pleasure or with bad* *(Interview A, Round 2, 16 Aug 2010)*
B	**Mild Views of Illness** *Interviewer: Is the illness disturbing you in your daily work?* *Respondent: No. That is why I'm telling myself that it will end even if I don't go to the clinic because I'm not feeling the pain every time* *(Interview B, Round 1, 26 Jul 2010)*
C	**Impact of interview** *Respondent: "My daughter! Come and answer. Their questions are too many" She is my daughter. She must take care of me because she is my biological daughter.* *(Interview C, Round 1, 27 Jul 2010)*
D	*(Interview D, Round 1, 27 Jul 2010)*
E	**Traditional Medicine and Social Relationships** *Respondent: I'm not taking home remedy or consulting the traditional healer, but last time I have consulted the traditional healer but it was not because of the illness, it was because we didn't have a child, so we were trying if we can get a child. So if people say that "go there" you will go to try. Even my husband was not consulting the traditional healer. I found him going to the Apostolic church, but*

	he was the one who took me to the traditional healer for the child *(Interview E, Round 1, 29 Jul 2010)*
F	**Impact of interviews** *Respondent: I have once asked my son to look for one child, so he said that their parents refused because some people take their children to abuse them….I think that here she was going to stay nice. No one would abuse her, so I will try again. But I can say thanks very much for coming. As I have spoken with you, something is released in my mind. I'm feeling better now because of your visit.* *(Interview F, Round 1, 29 Jul 2010)*
G	**Religion and Medicine** *Respondent: I have to withdraw from the traditional healer. I can't go there.* *Interviewer: What advices are you getting from your friends in the church concerning your illness?* *Respondent: They said that we must concentrate on the pills only* *(Interview G, Round 1, 29 July 2010)*
H	**Cause of Illness and coping** *Respondent: My illness is High Blood and Sugar. I think that it started because I am thinking too much…I have lost my children and even the one that I am staying with is ill….So what I am doing to reduce my high blood is to work most of the time. As you can see here it is clean. I am doing it on my own. No one is doing it for me, so you find that even if I go to the clinic they find that my high blood is not very high.* *(Interview H, Round 1, 02 Aug 2010)*
I	**Joy of life or Illness and Everyday Life** *Interviewer: I heard you saying that at the clinic they told you to avoid salt, sugar and sour food. What did they say about alcohol?* *Respondent: They are talking about it, so they even ask if I have taken the beer and I am telling them the truth because it is not good to lie. You must say the truth because it will happen one day that you become ill and they can't help you if you lie to them* *(Interview I, Round 1, 02 Aug 2010)*
J	**Benign Clinic Experience** *Respondent: What they are doing at the clinic they check the blood pressure. So they will tell if is high or low. If they find that it is high they will give you the small pill. After a few minutes they will re-check, and if they find that it is still high, they will give you the same pill. Then you go home.* *(Interview J, Round 1, 02 Aug 2010)*
K	**Traditional Medicines** *Respondent: They were saying that I must drink because I am having high blood, but now I'm not taking the pill. I just drink nkanka when my heart is beating fast.* *(Interview K, Round 1, 06 Aug 2010)*
L	**Knowledge of Illness** *My question is: I want to know if you be able to help others about what I have said, because you find that most of the people are creating the illness on their own, like the way I was doing. I mean that if you visit others, please tell them about this: They must avoid meats, sweet tea, and cooldrinks. Maybe they can mix when they eat, like taking some vegetable, not the meat only. A person can say that I am rich but one day you will regret about what you are eating, telling yourself that you are rich.* *(Interview L, Round 1, 06 Aug 2010)*
M	**Traditional Medicines** *Respondent: There was no sign. I was just coughing and the cough was not stopping, and the people were saying that it was mafularha, because we have lost many people here. I then consulted the traditional healer.* *Interviewer: What did the traditional healer do?* *Respondent: I can't explain that* *(Interview M, Round 1, 06 Aug 2010)*

Interview summaries (Soweto)

Interview A: Saliah

The sun was shining and the leaves danced in the wind.

We arrived at the house to find Saliah sitting outside underneath a tree. She was frail and seemed a bit hard of hearing. The people she was previously staying with died. She now stays with her daughter in law. Although her daughter in law provides her with one cooked meal per day, she does not help her with her medication.

Saliah said that she had a broken leg. She treated her broken leg at Pretoria many years ago. They performed an operation, gave her some pills, and referred her to Acornhoek to continue with the medication. Saliah said that they did not do the operation properly because she was still feeling pain.

Saliah now visits the Health Centre once a month. She does not get any advice, but she goes there to collect her medication. Sometimes they refer her to the hospital. She takes the medication once a day after bathing and eating.

During the interview she showed us a crutch and an umbrella, which are her walking aids. She also showed us her medication, and held her medication during the interview.

When asked about what the family did when she became ill, she replied that "they died", and she said that after they died they took her from where she was staying and put her in her current house.

Saliah once consulted a traditional healer because someone gave her food with poison. She did not know who that person was. She consulted a traditional healer, who told her that she had eaten poison. They gave her some medicine. She started with diarrhoea and vomiting. Afterwards she did not feel that thing in her stomach which she was feeling before.

Interview B: Katherine

We found Katherine for the first interview in the house of another study participant, Lettie. Katherine was with a group of women cooking a feast for a funeral.

The women said in a joking but testing mood that we at Wits always visited them to ask them questions, that we derived a salary from doing so, but they did not get any benefit. They asked me why I did not give them a pension.

Katherine said that she does not know about the clinic because she does not go to the clinic. What she knows is that people don't like the clinic, that the clinic is not good, and that there is no confidentiality at the clinic. She said that most people with HIV complain about the clinic (The Health Centre), saying that the nurses gossip about them, so that when they walk in the street, people point at them and say "she has HIV". People in the community were talking about the nurses at the Health Centre, as there were recently feedback meetings conducted by Wits.

Katherine said that she has a bone problem, which pains her from the hips to the legs, most especially at night. She also had sores on her face, which had left scars on her face. There were no preliminary signs of the bone problem. It started fairly suddenly this year.

Katherine is not going to the clinic, nor did she consult a traditional healer. She said that she is telling herself that she will be fine. She is not feeling very ill, and her husband reassured her that it was temporary. Her daughter also has and she also has not been to the clinic because it is intermittent.

She once consulted with a doctor, who had found ulcers in her stomach. The doctor told her that she was stressed, and that she should not be angry, because it causes a pain in her stomach. The doctor gave her medicine, which removed the pain. The things that give her stress are painful things, like the death of a relative. She will think about that most of the time until her heart is painful. She thinks that that way she is getting ill.

She said that if the pain gets worse, she will go to the clinic - but not now. If she goes to the clinic, she will go to the Zanthia, because they are good at Zanthia, and many people prefer the Zanthia clinic to the Health Centre.

Interview C: Anah

We found Anah just preparing to lie down on her straw mat in the shade of some papaya trees. A wooden grinding mortar lay flat next to a nearby papaya tree.

At first Anah was unwilling to sign the consent forms without the presence of her daughter. They had once signed some forms before, only to find that the persons presenting her with the forms started deducting moneys from her pension.

Anah soon began to feel tired from the questions. She said that she suffers from dizzy spells whenever she stands or sits. It started after the death of her daughter. When the spells started she went to the clinic with her son in their own car (the Health Centre). This was the first time that she went to the clinic.

The illness is disturbing her, because since the illness started, she can't make mats any more. She also used to go to the farm, but now she is no longer doing those things, because when she stands up, she feels as if she is going to fall down. It was the first time that she felt ill, and she thought that it was due to the death of her daughter.

The clinic referred Masana Hospital at Bushbuckridge. She stayed at the hospital for three weeks. At the hospital they diagnosed high blood pressure and they were given pills every day to drink. She is taking the pills from the clinic every month. She does not take herbal medicine or consult a traditional healer. She is a Zionist Christian.

When they were young, they took home remedies, but she cannot remember. She did not use home remedies for her children, because she started with the Zion church. The Zionists treat illness with prayer and holy water. The pastor will place hands on the patient and pray, and they are getting well by that treatment.

Interview D: Lettie
Lettie was not surprised to see us, because the Wits people used to come to her house, and she is not afraid to answer questions. During the interview she asked if she could cancel the interview, but she continued.

She has high blood pressure and an ulcer, which both started in 2000. The symptoms of high blood pressure were a hot body, feeling at night that her body was burning, and that her face was swollen. The ulcer caused a burning chest. After having these symptoms, she told her daughters. She has two daughters and two sons. She is now staying with one daughter, the others have their own homes.

She decided to go to the clinic. At the clinic they found that the BP was too high, and they referred her to Masana hospital in Bushbuckridge. At Masana, she had a "special doctor" who always consulted with her whenever she went to Masana. She got advice to avoid salt and sugar, and fatty foods, such as fish oil.

She thought that the high blood was caused by the death of her husband, but at the clinic, they asked her if anyone else in the family had high blood. She responded that her two sisters had high blood pressure, and that one of her sisters had died of high blood pressure, after having a stroke. At the clinic they explained that her high blood was not due to her husband's death, but that she had inherited it from her mother, because her sister also had high blood.

She said that at the clinic (the Health Centre) they take a long time. The nurses ignore people, and they don't have confidentiality. Most people prefer Xanthia to the Health Centre.

She is getting a lot of support from the daughter that she is staying with. She is following the rules of the clinic, and is encouraged by her son and daughter. She continues with her household chores. She does not use traditional healers, and her sisters advised her not to use traditional healers, but just to use the medicine from the clinic. She also takes a ZCC tea prepared by the pastors of the church. They advise her to always take her pills together with the tea.

Interview E: Khisoze
We arrived, parking the car at the Zionist church, a low open structure underneath some trees. We saw a woman seated on one of the low walls.

Khisoze is a jovial and friendly person, blind in one eye, and a pleasant talker. She was willing and happy to be interviewed, explained her condition in some detail, gesticulating often with her hands and employing a wide range of tonal colours and emphases of voice in her narration. We interviewed her outside the kitchen, in a spacious yard adorned with various kinds of fruit trees, such as banana, mango, and lemon. As with most interviews, chickens ran about the yard, pecking at the ground.

Khisoze has sugar diabetes, high blood, as well as an eye problem in her right eye. It was previously a normal eye. She does not know when the high blood and sugar diabetes started, but it was a long time ago. She said that she is always ill. She is unable to fully do the cleaning and washing, so she has hired someone to do those things for her. If she wants to cook porridge, she will cook for herself.

There was a time when her brother took her to Baragwanath hospital in Soweto for her eye problem. They tried to clean her eye. She always revisited, until the eye eventually closed.

Her high blood pressure and diabetes started before Cunningmoor Clinic was established. She regularly attended Masana Hospital to collecte medication, and now continues to go to Cunningmoor Clinic for her medication. She said that clinic was very good, and that they advise her every time. If she has a problem, she is able to tell them, and they advise her to avoid sugar and salt, and to eat before taking the pills.

The first person she spoke to about her illness was her husband, who gave her tea from ZCC. She said that the tea helped her. After her husband passed away, she stopped taking the tea, although she continues to go to church. At the church they say that she should take her pills, and she is supposed to take a tea preparation everyday. The pastor always prepares the tea for her

She went to the traditional healer before her husband died, but it was not due to chronic disease, but in order for her to bear children. She did not get a child after taking the medicine. She never bore children.

Interview F: Hunadi
She was lying on a couch watching Knight Rider

Hunadi has high blood pressure and sugar diabetes, as well as stress, dizziness, headaches and sore legs, which started at the same time. At first the staff at Cunningmoor clinic couldn't tell what she was suffering from. She was then diagnosed by researchers from Wits with high blood pressure and sugar diabetes. From then, she went to the clinic with a referral letter. At that time, in 2003, they started giving her medication.

She is worried by stress resulting from the loss of her husband in October of last year. She always remembers her husband. She had 3 sons, but 2 died, and the one that is alive is staying at Thulamahashe with his wife. He always comes to check on her, and when she is ill, he takes her to the hospital.

She is taking the pills at the Cunningmore clinic every month, and they always give her advice, because they know her story. They sometimes ask if she is still staying alone, and when she replies yes, they say that she should find someone to stay with her, because if diabetes or high blood pressure start, there will be no one to assist her. They advise her to go to the neighbours and spend more time her.

She does not visit the neighbours, but she goes to church on Sundays. Most of the time she stays alone, watching TV. She has hired someone to help her with cooking, and cleaning 3 days a week. She pays her with her pension money. She can buy food with the remaining money, but it is not enough. Sometimes her son gives her money to buy more, but not all the time, because as the husband has a wife, it is difficult to take money to his mother.

She is worried staying alone, especially at night, and is thinkinh of getting someone to stay there. Alternatively, she was thinking of getting an orphan child. She needs someone to talk to, to relieve everything that she has in her heart.

After our visit she was feeling better, and less stressed.

Interview G: Cabiya

The garden was spacious, but neglected, rank with dried weeds, although there were a few clumps of banana trees. A chicken occasionally wandered within view.

Cabiya has a stomach problem - constipation. She also experiences pain starting from her legs, and rising up to her waist. She consulted a private doctor at Mkhuhlu village about the pain in her legs. He said she had cancer. Although she was given pills, she did not get better. She then consulted another doctor at Hazyview. He said that her stomach is "black inside". She does not know what that "black" is about. She then consulted a third doctor who said that if she was young, he would have done an operation on her stomach.

She then started to have high blood and sugar diabetes. For high blood she was admitted at Matakwana Hospital for 3 days. They told her not to eat salt, sugar, and fatty things.

Cabiya believes that the high blood is caused by her grandchild. She had 4 children: one boy and one girl died, and she is left with one boy and one girl. The daughter that died left a son and daughter. The grandson is giving her problems because he is smoking and drinking and he has left school. He is now living at Witbank. The granddaughter is now finishing school. She is staying alone. Her other son is at Witbank, and her daughter is married, and is staying nearby. She always helps to take her to the clinic and looks after her.

She walks to the clinic. She does not take medicine from the traditional healer. She does not consult the traditional healer because at first she consulted the traditional healer but she was not helped. She felt better when she went to the IPCC church, and so she has not been to the traditional healer. She is using the pills from the clinic. The problem is that she is taking the pills, but she is not getting better.

She believes that God one day will help her about her grandson. When we visited some weeks later she informed us that her grandson was back and attending the church. She still prays for him that he will be better than how he is.

Interview H: Marta

As we entered the yard, Marta was already carrying a bench for us to sit upon.

Marta has "high blood". She thinks it is caused by her thinking too much, because she lost her children. There were 10 children, but now she is left with only one daughter, and even she is sick, although now her health has improved ever since she started taking medicine from the doctor, where she consulted with R300.

She said that when she starts thinking, she does not feel like eating, and she sweats. She thinks about her children, and she worries about the daughter that is left. Some of her children passed away due to illness, others due to 'natural causes'. She said that if she wants to avoid thinking, she cleans the yard. She keeps busy all the time, and she always talks with people. She doesn't like to be angry, that is why she makes sure that she is busy, but not when it is hot. She always works in the morning before it gets too hot.

She started to treat the illness in the last 2 years. She always takes the pills from the clinic. There was the time when her BP was high, and then they referred her to Matakwane Hospital. She stayed there for 3 days.

Marta mentioned that one of her grandchilden was admitted to Matakwana and then to Pretoria for burn wounds when boiling water was spilt on her. She has since passed away. One nurse was fired, because Marta found the nurse beating her grandchild. She went to the doctor, and the doctor fired the nurse.

Her daughter and grandchildren always remind her about taking her pills and going to the clinic. And the nurses are also very good to her, because they remind her about taking pills at the right time and at the right dose.

Marta does not have the money to consult a traditional healer. Besides, her mother was going to the Church of England, and so even when she was young, they did not consult traditional healers, but went instead to the chemist to buy medicine when someone was ill. Marta's mother died a long time ago, but not high blood. High blood is just for nowadays. People suffer from high blood pressure nowadays because they eat too much meats, salts and vegetables. Previously people grew their own vegetables, like Morogo.

Marta gets tea from the ZCC church and cooks it herself because she is old, and the tea cannot be prepared by someone who is sexually active. She believes in prayer, because if you don't pray, you cannot be well. If you pray to God, He will answer your prayers.

Marta gave Zodwa a lot of practical advice. She always ignores gossiping people. Even if she hears people gossiping about her, she does not mind. She advised Zodwa to avoid having "too many friends".

Interview I: Linah
In the centre she sat, with a small group of women, around a pot of boiling brew.

We found Linah at home, cooking home brewed beer in her yard. She runs a shebeen out of her back yard. At first Linah was soft spoken and laconic, but, as the interview proceeded she laughed and started talking more freely. An affectionate granddaughter, still a toddler, came and cuddled up to her as she conducted the interview.

Katrina has high blood pressure, and her body is always in pain. It started in 2000. She said that the first symptom was a fast-beating heart. She consulted the clinic, and was given the pills. She takes the pills from the clinic every month. She takes the pills 3 times a day, according to the way they told her.

She has 8 children. Some are working, and some are married. At her house, she is staying with 4 of her children. Her husband passed away last year. The children are always supportive. When she told them that she had a heart-beat problem, they advised her to go to the clinic.

At the clinic they advised her not to take too much salt and sugar. They even said that she must not take the home brew, because at the clinic they know that she is always cooking it. They asked her at the clinic if she was still taking it, and she said "I am still taking it. I won't lie to you".

Linah admitted to Zodwa that it was not good for her to take the home brewed beer, but when they are drinking, she feels a need to drink it also. She only takes it at night, but not during the day. She said it is difficult to leave the home brew, but it is not easy. She always worries about what the family will eat for that day. That is why she cannot stop selling African beer.

Interview J: Idah

The pieces of straw are woven together with nylon strings, suspended at either end of the rack by old batteries.

We found Idah sitting in the yard at a low rack for making straw mats. She said that she had a leg problem, pains in her knees, and high blood pressure. The leg problem started a long time ago, she cannot even remember the year. Even with high blood, she cannot remember when it started, but she remembers that her heart was beating fast and that she was feeling pain in the body.

Linah started to consult Cunningmoor clinic in 2007. At the clinic they told her to avoid sugar and salts. They wrote her a referral letter to Matakwane Hospital. She used to take a taxi to Matakwane Hospital to collect her medication, but it was too expensive. She told the doctors at the hospital and they wrote a letter referring her again to Cunningmoor Clinic.

She stays with 3 children, 2 are working, and one is doing matric. Her husband died last year, but she does not "think too much" about him. She is coping with the loss. Her children always remind her to take pills from the clinic.

She said that at the clinic, they are very good. Even if there are some people that have complaints, there is a suggestion box. She did not see anything bad. She knows that she always gets. She takes pills three times a day after eating. She does not take home remedies or go to the traditional healer.

She makes mats and does other duties, but when the pain starts, she cannot do anything. If she takes pills, she feels better. They give her pain-blocking pills for the legs, and a leg rub ointment. She avoids food with too much salt, juice, and tea. She cannot say that she misses anything, because it is for the sake of her life and health. She is always following the rules and instructions from the clinic.

Interview K: Phipas

Cowbells were ringing from the cows grazing nearby, and the sun peeked through grey windy clouds. Three pigeons sit on a line.

Phipas's husband sat close by during the interview, occasionally offering a few words. Phipas is suffering from high blood pressure and arthritis in the knees, especially when she wants to stand up. Her legs are painful and she is unable to walk properly. Before all of this started she had frequent headaches.

Phipas was taking pills from Kildare Clinic and Matakwane Hospital, but she did not get better. After taking the pills, she always felt dizzy, but if she leaves the pills, the dizziness stops. Now she is not taking the pills, because she feels dizzy. What helps her is *nhlanhlana.* Her parents used to care for her with *nhlanhlana*. They cooked it for her to drink as she was having a problem with headache and dizziness, and after taking it she was feeling better. (*Nhlanhlana* is a small tree or shrub. Zodwa also takes this with porridge, like spinach. People generally take it with peanuts, but some people do take it like a tea for high blood pressure. To drink it you must crush the leaves and boil it with water until it becomes strong, taking a little each day). Phipas only uses *nhlanhlana* when she doesn't have pills, when there is a strike or if her legs are hurting her too much to go to the clinic.

Phipas thinks that the cause of the high blood has been the loss of her 3 children. A boy died in 2003, a girl in 2006, and the last born in 2009. The first two passed away due to illness, and the third was hit by a car. Her legs always pains when she stands up, so she can't do farming. She hires women to clean the yard. Her grandchild helps her to cook, clean and wash.

When she talks to friends about her illness, they say that she must consult a traditional healer. She refuses, because she does not have money to give to traditional healers, and she does not trust them.

Interview L: Thabiso

Thabiso had headaches and high blood pressure, as well as sore legs, but she said that now she is fine, and she does not have any problem - her illness stopped when she was visited by Wits in 2005. They were doing some research related to illness, and the Wits

people told her to avoid sweet things, to exercise, to avoid anger and stress, and to drink one litre of water per day.

Thabiso wanted to try the advice given to her by Wits. She started doing housework, drinking lots of water and abstaining from sweets. She then realised that she was feeling better and so stopped taking the pills, and even at the time of the interview she was not taking pills.

Before the illness, she was feeling tired all the time and had constant headaches. This started in 1982, and she started to seek treatment at the clinic in 1990. Thabiso said that the cause of the high blood may have been the loss of her 3 children. The first was born in 1966 and died in 1968. In 1968 she gave birth to the second born, who died in 1970. In 1970, she gave birth to twins, and one died in 2006. She now has 2 children.

Thabiso experienced some side effects from the pills she was taking from the clinic. Her body and stomach were bigger and she suffered from incontinence. She was collecting pills once a month, and taking them 3 times per day. They always advised her at the clinic to keep busy with housework to avoid stroke. She said that she is taking aloe now. The aloe is washing her blood, because she was black before, but now she is lighter in complexion. Thabiso learnt about the benefits of taking aloe from another woman who had since passed away.

Thabiso said that it would be good if we advised others to abstain from sweet things. She used to take 2 litres of colddrink and tea with condensed milk everyday. She did not know that that was causing her illness.

Interview M: Nomses

Nomses had a dry cough and aching bones, as well an eye problem. She said that sometimes darkness covers her eyes. She does not know exactly when it started, but it was a long time ago. There were no signs before the sickness.

Nomses consulted the traditional healer before the doctor. The traditional healer told her that it was *tindzaka*. *Tindzaka* has the same symptoms of TB. When someone dies in the family, one is supposed to follow certain rules and rituals. Failing to follow those rituals will cause *tindzaka,* or *mafulara.* They suspected *tindzaka* because she had lost her child. The traditional healer gave her a medicine to inhale, but the medicine didn't work. Sometime they were cooking medicine, and she was to remove her clothes and go over the steaming medicine with a blanket. It didn't help. She then consulted different doctors at Hazyview. They diagnosed her with high blood pressure.

Nomses then started taking pills from the doctors, and she became better. She did not visit the clinic, but she sometimes goes there. She is bored staying there a long time in the qeueu, that is why she prefers going to the doctor.

Nomses also uses Home remedies, but not every time, only when people come to visit her with medicine. She said that it is a "mixed" remedy. She thinks that the cause of the high

blood was the loss of her daughter, but she can't remember the year. Her daughter left 3 children: 2 girls and 1 boy. The boy died in a car accident. So she is always thinking about that. She thinks that that is maybe why she has high blood pressure.

Appendix 3: Quantitative study instrument and coding sheet

Annotated survey instrument for Soweto survey



University of the Witwatersrand
Department of Paediatrics and Adolescent Health

BIRTH TO TWENTY BARA SITE: 18TH YEAR
CAREGIVER HEALTH ACCESS QUESTIONNAIRE

DATE: Day ☐☐ **Month** ☐☐ **Year** ☐☐☐☐

BTT ID NUMBER: ☐☐☐☐☐☐☐

BONE STUDY ID NUMBER: ☐☐☐

Demographic Information

Before asking about your experiences with health care, I would like to ask you for some information regarding your living conditions and education.

1. What is the main language that you speak at home? [DO NOT READ OUT. ONE OPTION ONLY][1]

English		Xhosa	
Zulu		Tswana	
Sotho		Ndebele	
Venda		Shangaan	
Afrikaans		Portuguese	
Other (specify)			

2. Do you have no access, shared access or sole use of the following facilities? [READ OUT EACH ITEM][2]

[1] This question is used as a proxy for ethnicity. Ethnicity may influence the use of lay referral networks and alternative healers in accessing health care.

Facility	No access [0]	Shared access [1]	Sole use [2]
a) Indoor running hot and cold water			
b) Indoor running cold water only			
c) Outside tap only on property			
d) Water from other sources (please **specify**) _____			
e) Flush toilet inside the home			
f) Flush toilet outside the home			
g) Pit latrine			
h) Bucket system			
i) Other type of toilet (please **specify**) _____			

3. Do you have any of the following items in your household and in working condition at the present time? [READ OUT EACH ITEM]

Item	No	Yes	Item	No	Yes
Electricity			Television		
Motor vehicle			Radio		
Fridge			Video machine/DVD		
Microwave			DSTV/Satellite		
Washing machine			Computer		
Landline telephone			Internet access		
Cell phone					

4. How would you describe where you live – as a: [ONE OPTION ONLY]

Shack/Zozo		Hostel	
Flat/cottage		Back room/ garage	
House		Shared house with another family	
Other (specify)			

5. Is your home: [ONE OPTION ONLY]

Owned	
Rented from another person	
Renter from local authority	
Provided by employer	
Other (specify)	

6. How would you describe your employment status: [ONE OPTION ONLY]

[2] *Antenatal Questionnaire* (Birth to Twenty 1989). The following 4 standard questions on socio-economic status will constitute a socio-economic measure for the participants. Socio-economic status may influence use of health care and health care behaviours of the study participants.

A Housewife		***Go to Q8***
Formally employed		***Go to Q7***
Casually employed		***Go to Q7***
A Student		***Go to Q8***
Unemployed		***Go to Q8***

7. What is your current occupation?

8. Do you belong to any religious group?[3]

Yes		***Go to Q9***
No		***Go to Q11***
Don't Know		

9. If YES, which group? [DO NOT READ OUT. ONE OPTION ONLY]

AIC (ZCC)		Jehova's Witness	
Catholic		12 Apostolic Church	
Protestant		Muslim	
Anglican		African traditional	
Other (Specify)			

10. Can you please state the name of your church?

11. How important would you say religion is in your life?

Not at all	
Somewhat	
Very important	

12. Please explain[4]

[3] Relious affiliation and intensity of commitment to religious practices may influence health-seeking behaviour. Germond and Molapo (2006) note that "for some religions, and most notably in Southern Africa, forms of African traditional religion, some African Initiated Churches, and some forms of Pentecostalism, healing, in the richest sense of the word, is the preoccupying quest of both individual and community. In these religious worlds the ability to restore wellbeing to social and physical dis-ease constitutes a foundational moment in the discursive practice of the religious community." (Germond and Molapo, 2006: 27-8)

[4] While religious affiliation may provide some resources to cope with illness, the type of information regarding the internal resources such practices provide is not readibly accessible through a structured survey instrument. This particular question was added in after the piloting phase. It was found in initial interviews that respondents often voluntarily expand upon why religion is important in their lives,

13. How often do you attend religious/spiritual services? [ONE OPTION ONLY]

Not at all	
Less than once a year	
Once or twice a year	
Not every month, but at least once every 2 or 3 months	
Not every week, but at least once a month	
Once a week	
More than once a week	

General Accessing of Health Services

14. Who is the **FIRST** person you would normally speak to when **YOU** are **NOT** well? [DO NOT READ OUT. ONE OPTION ONLY]

Family Member/Member of household		Private Hospital Worker	
Neighbour		Home/Community Based Care Worker	
Private Doctor (General Practitioner)		Chemist/Pharmacist	
Gov Clinic/ Comm. Health Centre Worker		Homeopath/Herbalist	
Mobile Clinic Worker		Faith Healer	
Government Hospital Worker		Sangoma/Traditional Healer/Inyanga	
Private Clinic Worker		Social Worker/Counsellor	
Other (Specify)			

15. Are the following health care service providers in your community (within 2 kilometers or 20 minutes walking distance of your home)? If **YES**, please specify the number of service providers and whether you think they are affordable to you? [READ OUT EACH ITEM]

	2km/ 20 minutes walking		Number of service providers	Affordable for you		
Private Doctor (General Practitioner)	Y	N		Y	N	DK
Gov. Clinic/ Comm. Health Centre	Y	N		Y	N	DK

suggesting that this may as well be formally asked in the questionnaire. Cochrane (2006) has observed that the "internal" dimension to religion – that which explains the motivations, commitments, attitudes, actions, self-understandings and world-views of practitioners – is largely missing from studies on religious health assets. More detailed information in this regard will be solicited from the qualitative site study.

Mobile Clinic	Y	N		Y	N	DK
Government Hospital	Y	N		Y	N	DK
Private Clinic	Y	N		Y	N	DK
Private Hospital	Y	N		Y	N	DK
Home/Community Based Care	Y	N		Y	N	DK
Chemist/Pharmacist	Y	N		Y	N	DK
Homeopath/Herbalist	Y	N		Y	N	DK
Faith Healer	Y	N		Y	N	DK
Sangoma/Traditional Healer/Inyanga	Y	N		Y	N	DK
Social Worker/Counsellor	Y	N		Y	N	DK

16. Are you covered by a medical aid?[5]

Yes	
No	
Don't Know	

17. What in your experience are the main problems with getting Health Care from public (government) clinics and hospitals in your community? [DO NOT READ OUT. TICK AS MANY AS APPLY]

There are no clinics or hospitals in the community	
Health care services are overcrowded	
There are no medicines available	
Clinic or hospital staff are rude or unfriendly	
The waiting times are too long	
Consultations are too short	
There is not enough time to access health care	
The clinic or hospital is too far away	
There are no problems getting health care	
Other (specify)	

18. Have you had any illness or condition in the last 6 months so that you have had to seek treatment or health care?

Yes		***Go to Q19***
No		***Go to Q22***
Don't Know		

19. Please state your illness or condition

[5] *South Africa Demographic and Health Survey: Adult Questionnaire* (15 August 2003). The Survey reports a decrease in access to Medical Aid since 1998 (from 18% to 14%) (Department of Health, Medical Research Council, OrcMacro. 2007. *South Africa Demographic and Health Survey 2003. Pretoria: Department of Health.)*

1)	
2)	
3)	
4)	

20. Which health services did you use to treat your condition? [DO NOT READ OUT. TICK AS MANY AS APPLY][6]

a) Self treatment	
b) Private Doctor (General Practitioner)	
c) Government Clinic/ Community Health Centre	
d) Mobile Clinic	
e) Government Hospital	
f) Private Clinic	
g) Private Hospital	
h) Home/ Community Based Care	
i) Chemist/Pharmacist	
j) Homeopath/ Herbalist	
k) Faith Healer	
l) Sangoma/Traditional Healer/ Inyanga	
m) Social worker/ Counsellor	
n) Dentist/Oral therapist/Hygienist	
o) Optometrist	
p) Rehabilitation Therapist (Occupational, physio-, speech, hearing, language, prosthetist)	
q) Other (specify)	

Please NOTE**: option **a) Self treatment is NOT APPLICABLE to Q21

[6] The following options were included in the *South Africa Demographic and Health Survey: Adult Questionnaire* (15 August 2003). The question in the current questionnaire was amended to extend to a 6 month recollection period, rather than the 1 month period specified in the South Africa Demographic and Health Survey. This is in keeping with past practice within the Birth to Twenty data collection waves, which generally use a 6 month recollection period. The option "Health Services in the Workplace" was not included in the list of options for the sake of brevity. The piloting phase with field workers at Birth to Twenty highlighted the fact that "Community Health Centre" and "Government Clinic" are synonymous terms within the community. Consequently, these were grouped together in the current questionnaire.The option of "Mobile Clinic" was introduced after piloting the questionnaire in the field.

21. If you have answered YES to any of the above, please specify for each service accessed...

a) SHEET 1

Health Service 1	

How did you find out about the service?

Family member		Family doctor	
Friend/ Neighbour		Social Worker	
Government clinic/ Community health centre		Signboard/ Advert	
Mobile Clinic		Employer	
Pharmacist/ chemist		Other (Specify)	
Other			

What was the reason for your visit?			
In the last 6 months, how many times did you access this service?	*times*	**What was the average waiting time?**	*___hrs____min*
What was the average duration of each consultation?	*___hrs____min*	**In general, what was your mode of transport (eg. Car, taxi, bus, train, walking)?**	
What was your average transport time?	*___hrs____min*	**What was the average cost of consultation (round off to rands)**	*R*

Were you satisfied…	Satisfied	Don't know/ Neutral	Unsatisfied
…with getting someone to attend to you?			
…with the helpfulness of staff?			
…with the waiting time?			
…that the health care staff was willing to listen to your concerns?			
...with the staff's understanding of your needs and concerns[7]			

Please state how you think the service could have been improved
1)
2)

[7] Turner, B. S., and Samson C. (1995) Medical Power and Social Knowledge, Sage Publications, London. It is observed that there is potential conflict, in terms of power, knowledge and status between doctor and patient leading to situations of low trust and minimal confidence.

3)

Health Seeking Behaviour

Now we are going to speak about your general attitude towards health care providers and how you go about dealing with health problems.

22. Please listen to the following statements and specify whether you strongly agree, agree, disagree, or strongly disagree with them: [READ OUT EACH OPTION]

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Family and friends will usually help me to interpret my symptoms when I am ill[8]					
Family and friends will usually advise me about where to seek health care[9]					
If I am ill, I only seek out health care when my family or friends tell me to[10]					
I do not always tell the doctor all of my symptoms if they are too embarrassing[11]					
I practice what I am going to say to the doctor before visiting him/her[12]					
I do not always do everything that the doctors say I should do[13][14]					

[8] *Using Health Services* (a presentation) J. Irvine (23 October 2000) http://www.psych.yorku.ca/jirvine/3440/lectures/lecture_6_using_health_services/sld013.htm

[9] *Ibid*

[10] Medical Anthropology and African American Health – EJ Bailey Bergin & Garvey, Westport, Connecticut (2002). Bailey (2002) observes that social networks can alleviate stress by helping the person instrumentally and psychologically to cope with the situation (p.21) and there is an opportunity for everyone to be involved in the healing process. This question tests the extent to which reliance on family support may exclude the respondent seeking support from other sources.

[11] Nettleton, S (2006) *The Sociology of Health and Illness* (*2nd edition)*, Polity Press, Cambridge. Nettleton points out that the outcome of a consultation depends not only on the nature of the patient's medical complaint but also upon the nature of the negotiation. Patient strategies include rehearsing, presenting symptoms only partially, excluding information and ignoring the doctor's advice. This and the following two questions will provide a preliminary measure of the use of strategies by patients as an alternative source of power in accessing health care. This aspect will be more fully explored in the qualitative site study.

[12] *ibid*

[13] *ibid*

[14] *A Policy on Quality in Health Care for South Africa* (Pretoria: National Department of Health 2007), Abbreviated version. The policy states that a common problem is patient refusal to participate in recommended interventions, such as in the treatment of TB. The current questionnaire does not focus on patient adherence to prescribed medication. This is the focus of the qualitative site studies, which focuses on the experience of coping with illness and accessing health care.

Doctors and clinic staff are more effective than traditional healers and herbalists in treating illness					
Traditional healers and herbalists are respected for their healing abilities within my community					
I am able to easily access information about symptoms and treatment for any illnesses I may experience					
I am able to easily access information about health care services that are available in my community					

23. Sometimes, one misses appointments with a health service provider. What were the most common reasons that you missed an appointment with a health service provider the last time this happened? [DO NOT READ OUT. TICK AS MANY AS APPLY][15]

Do not usually miss appointments		Cannot take time from work	
Lack of money		No transport available	
Lack of time		Too ill to travel	
I forgot		Other responsibilities	
I felt better		Do not want to go back to the service provider	
Other (specify)			

24. Do you think that there are some things which can only be treated by traditional healers, and not by doctors?

Yes		***Go to Q25***
No		***Go to Q26***
Don't Know		

25. If yes, please specify in which circumstances a traditional healer would be more effective than a doctor

[15] *South Africa Demographic and Health Survey: Adult Questionnaire* (15 August 2003)

Social Support and Community Integration

26. Please listen to the following statements about your relationship with your family and community and say whether you strongly agree, agree, disagree, or strongly disagree with them: [READ OUT EACH OPTION]

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
There are people who can help me if I have a really big problem and need help, with money, the children, accommodation and so on					
I can talk to my parents, other family members or friends about any problems that I may have					
I can talk to my husband or partner about any problems I may have					
Sisters at the clinic are **not** very helpful					
My family and I share similar beliefs about health and health care					
My community and I share similar beliefs about health and health care					
My family express concern about my health and well being					
My neighbours express concern about my health and well being					

Chronic Illness and Accessing Health[16]

27. Has a doctor or nurse or health worker at a clinic or hospital told you that you have or have had any of the following conditions: [READ OUT EACH OPTION][17]

[16] This section of the questionnaire has the 2-fold purpose of outlining the prevalence and intensity of chronic disease amongst the sample, and selecting participants for the in-depth qualitative site study.

[17] The following chronic diseases are covered in the *South Africa Demographic and Health Survey.* (Department of Health, Medical Research Council, OrcMacro. 2007*. South Africa Demographic and Health Survey 2003. Pretoria: Department of Health.)*

	Yes	No	DK
High blood pressure			
Heart attack or angina (chest pains)			
Stroke			
High blood cholesterol (fats in blood)			
Diabetes (blood sugar)			
Emphysema/ Bronchitis			
Asthma			
Arthritis (sore joints)			
Osteoperosis (bone disease)			
Epilepsy/ Fits			
TB			
Cancer			

If the respondent answered YES to any of the above, please proceed to Q28. Otherwise, please conclude the questionnaire.

28. Do you use any lifelong medicine regularly or daily that a doctor or nurse has prescribed for your condition?[18]

Yes		***Go to Q29***
No		***Go to Q30***
Don't Know		

29. What medication do you use?

1)
2)
3)
4)

30. Do you receive Home Based Care for your condition (that is care at home from a community organisation)?

Yes		***Go to Q31***
No		***Go to Q32***
Don't Know		

31. Please identify the Home Based Care organisation

[18] The following 2 questions are adapted from the *South Africa Demographic and Health Survey*.

32. Do you have any other support to help you cope with your condition? (e.g. taking medicine, taking you to the doctor, bathing, going to the toilet etc.)

Yes		***Go to Q33***
No		***Go to Q34***
Don't Know		

33. If Yes, who supports you and what type of support do they offer?

Name	Relationship	Support offered

34. Would you be interested in participating in further in-depth study regarding your experiences in coping with your illness and accessing health care?

Yes	
No	
Don't Know	

Thank you!

Secondary Data Codesheet

The health utilisation variables reported on are composite scores based on measures and types of healthcare utilisation asked of the Birth to Twenty Cohort in various successive waves of data collection. In particular, the variables are based on data collected at the following time points: 6 month; 1 year; 2 year; 4 year; 5 year; 12 year; 13 year; 15 year; 16 year.

Year 3 was excluded due to insufficient numbers, while in Year 7 and Year 10, data capturing problems excluded the data for analysis. In Year 7, place of treatment was not captured, while in year 10, only the suburbs were captured, not the type of treatment sought, which was the case in earlier data collection waves.

In the recoding process, different data were recoded into uniform variables for the sake of comparison across different time points. Diverse data on place of healthcare utilisation were recoded into a uniform categorical variable called "Healthcare Utilisation" which indicates 3 options:

1. Exclusive use of Formal Healthcare Services
2. Exclusive use of Informal Healthcare Services
3. Mixed use of Formal and Informal Healthcare Services.

The following coding scheme was used throughout the coding process:

Initial Category	Recoded Category	Initial Category	Recoded Category	Initial Category	Recoded Category
None	Informal	Faith healer	Informal	Doctor, Clinic, Hospital	Formal
home remedy	Informal	Homeopath	Informal	Social worker, Counsellor	-
Chemist	Informal	Nyanga	Informal	Lawyer, Legal Aid	-
traditional healer	Informal	Sangoma	Informal	Therapist (Occupational, Speech, Physio)	Formal
private doctor	Formal	General practitioner	Formal	Dietician	Formal
public clinic	Formal	Clinic	Formal	Police	-
Well baby clinic	Formal	Hospital	Formal	Priest, Minister, Church	Informal
hospital	Formal	Pharmacist	Informal	Traditional healers	Informal