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AN ETHNOGRAPHY OF ADULTS LIVING WITH APHASIA IN KHAYELITSHA

Carol Frances Legg

A dissertation submitted to the Faculty of Humanities, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Doctor of Philosophy

Johannesburg, 2010

ABSTRACT

This thesis is concerned with the experience of aphasia in Khayelitsha, a township on the outskirts of Cape Town characterised by poverty, violence, limited resources and a culture and language that differs from the setting of most speech and language services in South Africa. It is based on three years of intermittent fieldwork that entailed participant observation of the everyday life of five adults living with aphasia and interviews with participants, kin and healthcare workers in various settings. Grounded in sociocultural theory, this thesis has aimed to provide an ethnographic account of cultural frameworks of interpretation of communication impairment following stroke and of the daily reality of life for adults living with aphasia in this setting.

An exploration of causal notions in this setting provided interesting commentary on social and cultural processes and how people, caught up in these processes, search for meaning and for cure. Participants entertained plural notions of causation of aphasia and explored numerous therapeutic avenues. The wide variation in causal notions included biomedical causes, social and behavioural determinants, and the influences of supernatural powers, such as witches and ancestors. Similarly participants experienced aphasia through multiple healing systems, including traditional, biomedical and religious therapy options. All however seemed to be ambiguous sources of help. Whilst encounters with the health system presented serious challenges to participants, traditional and religious avenues for help were obscured by a burgeoning and not always ethical open market offering miracle cures.

An articulation of the circumstances of this group of adults provided further commentary on the influence of the social context on aphasia. In a context where sociopolitical processes have had a disintegrating effect on social cohesion, questions of support, care and security were of primary concern. Prejudices towards the elderly and women were more acutely felt and vulnerability, isolation,

insecurity and fluidity of circumstance emerged as overarching themes. The central argument in this thesis is that the genesis of these experiences can be found in contextual factors in Khayelitsha, such as poverty, inequality, urbanisation and changing cultural paradigms.

These emerging themes highlight the disjunctions between the medical alignment of the discipline of speech language therapy in South Africa and the capacity for socially-engaged practice. They also highlight the socio-cultural complexity of the experience of aphasia, specifically the influences of culture and poverty. There is thus theoretical and clinical relevance in using anthropological objectives to explore the world of the adult living with aphasia and the interface between context and service provision. Interventions and healthcare communications that will make a meaningful difference to adults with aphasia in a setting such as Khayelitsha are proposed.

Key words: aphasia, ethnography, Khayelitsha, speech and language therapy, rehabilitation, participant observation, fieldwork, anthropology, communication impairment, culture

DECLARATION

I declare that this dissertation is my own unaided work. It is submitted for the degree of Doctor of Philosophy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination in any other university.

Carol Frances Legg
February 2010

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NOTES ON TERMINOLOGY AND PRESENTATION

There are a number of terms which are used throughout this thesis that require clarification. Firstly, I have not classified or described participants according to classifications of aphasia. Nor have I distinguished between speech and language as is done so in the field of aphasiology and speech and language therapy, where speech is defined a motor act, and language, a cognitive system of referents and representation. In the everyday reality of people with aphasia, although they might not have motoric difficulties of speech, they have difficulties speaking, difficulties understanding what others say to them, and difficulties in social interaction. I use these terms when describing their difficulties. I also use the term communication. Here I refer more generally to speaking, listening, understanding and verbal expression.

Secondly, I refer to aphasia as a disabling condition and a disability. I describe communication difficulties as both impairments and afflictions. I acknowledge that these are loaded terms. In Khayelitsha, stroke is regarded as an illness. People who have long term limitations due to stroke, including language impairments, are not necessarily regarded as disabled. These seem to include elderly people and those with only moderate communicative and physical impairment. The use of the term 'disability' in Khayelitsha appeared to reflect an identity. In addition, the term was used specifically in reference to the disability grant. I use the term affliction to convey the associated misfortunes, social burdens and concerns arising from particular impairments.

There are times when crude racial classifications of black, white, Indian and coloured are employed, reflecting only popular terminology in Khayelitsha. Throughout modern-day South Africa these terms, rooted in Apartheid classifications of ethnic segregation, continue to be used to identify and categorise people. Here coloured refers to a group of people of mixed-race.

I have referred to the adults living with aphasia who participated in this study as participants. I also use this term for primary caregivers who participated in the research, and point out to readers that in relation to the Mdubeki case (see 6.1), the point of view is that of Mavis, George's wife and primary caregiver. George was present at most of our interviews and was incorporated as far as possible but one cannot ignore that his voice is missing. I have made some assumptions regarding his feelings. These were based on his body language, general well-being and responsiveness and to direct questioning using communicative supports. Other participants were all able to express themselves verbally, although only in a limited way. When referring to health care experiences, I use the term patients, less laborious than health service users and reflective too of popular terminology.

In this thesis, direct quotes as jotted down in my fieldnotes are italicised. Verbatim transcriptions from nurses are from recorded interviews that were directly translated from isiXhosa to English. I use numerous Xhosa terms throughout this thesis, reflected in brackets after their English equivalents. A glossary of frequently used isiXhosa terms is included at the end of this report.

I have used general referents to refer to institutions and have changed the names of participants (including clan names) to uphold confidentially.

As this thesis is about context, places are of importance. In order to orient the reader to both the setting of the study and the settings of studies cited in this thesis, I have included maps in the pages to follow. The national map shows neighbouring countries in southern Africa, provincial boundaries, sites of the former homelands of Ciskei and Transkei and reference points to towns that are mentioned in this study. The map of the Cape Town Metropole shows the position of Khayelitsha within the city. I have labelled neighbouring townships that are mentioned in the accounts of participants and in the cited literature for the reader's reference. The map of Khayelitsha shows the divisions of the township and the positions of the Community Health Centres. Although the areas of Khayelitsha are officially labelled as numbered towns and villages (eg. Town Two – Village One,

or T1 – V1), I have opted instead to use the popular names of areas, as this is how they are referred to in Khayelitsha.

GLOSSARY OF ISIXHOSA WORDS

Abathandazeli – faith healer

Amagqirha – traditional healer

Amaprofeti- prophets of the churches, faith healers

Amasiko – cultural traditions

Amathonga – dreams

Amaxhwele – herbalists

Amayeza- chemist store (unregulated)

Ibeleko-poison sent by witch

Idliso – poison sent by witch which when ingest turns into a snake that feeds on the body and soul

Inkenkqe – illness as a sign of calling to be a healer

Inyanga – herbalist

Isidenge – stupid or mad (derogatory term)

Isithunzela – zombie

Istroke/ isistroke – stroke(s)

Izinyana – ancestors

Makwerekwere - foreginer

Manyano – women's prayer union

Mbeleko – naming ceremony

Sangoma – traditional healer

Spaza – local convenience store, usually operating from a home

Stokvel – savings club

Storum –stcik used to stir healer's substances/ the resaide on the stick

Thikoloshe – a dwarf-like creature that bewitches people

Ticket - tithe

Ubugqirha – witchcraft

Ubuthakatha - sorcery

Ukhutwasa – training tobecome a healer

Umkhapo – mortuary rites

LIST OF ACRONYMS

ANC – African National Congress

AIC – African Independent Church

CHC – Community Health Centre

ICF – International Classification of Functioning

LPAA – Life Participation Approach for Aphasia

SHAWCO – Student Health and Welfare Centres Organisation (affiliated to University of Cape Town)

WHO – World Health Organization

TABLE OF CONTENTS

ABSTRACT	i
DECLARATION	Iii
ACKNOWLEDGEMENTS	Iv
NOTES ON TERMINOLOGY AND PRESENTATION	Vi
GLOSSARY OF ISIXHOSA WORDS	Ix
LIST OF ACRONYMS	X
TABLE OF CONTENTS	Xi
LIST OF TABLES	Xvi
LIST OF FIGURES	Xvii
AREA MAPS	Xviii
CHAPTER ONE: INTRODUCTION	1
1.1. Introductory Perspective	1
1.2. The Themes of the Thesis	5
1.3. The Theoretical Context of the Thesis	8
1.4. Addressing the Impact of Stroke and Aphasia in South Africa	9
1.5. The Context of Speech and Language Services in South Africa	10
1.6. A Description of Chapters	11
PART ONE: CONVERGING ROADS TO ANTHROPOLOGICAL RESEARCH IN APHASIA	**15**
CHAPTER TWO: CONCEPTUALISING AND CONTEXTUALISING APHASIA	16
2.1. Introduction	16
2.2. Qualitative Research in Aphasia	19
2.2.1. Phenomenological studies in aphasia	21
2.2.2. Narrative enquiry in aphasia	22
2.2.3. Ethnographic methodologies in aphasia	24
2.2.4. Applied conversation analysis in aphasia	26
2.3. The Contribution of Qualitative Research to the Conceptualisation of Aphasia	27
2.3.1. Aphasia and the psychological realm	28

2.3.2. Aphasia and the realm of interpersonal relationships 29
2.3.3. Aphasia and the family 30
2.3.4. Aphasia and the broader society 31
2.3.5. Theoretical frameworks 32
2.4. The Contribution of Qualitative Research to Practice 35
2.5. Unexplored Issues: Relational Dynamics and the Cultural Context of Aphasia 37
2.6. South African Research into the Cultural Context of Communication Disorders 40
2.7. The Cultural Context of Aphasia 43
2.8. Conclusion 45

CHAPTER THREE: A CULTURAL FRAMEWORK OF INTERPRETATION 46
3.1. Introduction 46
3.2. The Cultural Context 46
3.3. Medical Anthropology in Brief 48
3.3.1. Ethnomedicine 49
3.3.2. Applied clinical anthropology 52
3.3.3. Critical medical anthropology 56
3.4. Understanding Aphasia with an Anthropological Toolkit 57
3.5. Anthropology and Disability 61
3.6. Conclusion 63

PART TWO: SETTING THE SCENE OF THE STUDY 64

CHAPTER FOUR: THE METHODS OF THE STUDY 65
4.1. Guiding Questions 65
4.2. Data Collection 66
4.2.1. My journey as participant observer 67
4.3. Working in a Mediated Language Context 73
4.4. Data Capturing and Analysis 74
4.5. Validity 75
4.6. Ethical Considerations 76

CHAPTER FIVE: THE SETTING OF THE STUDY: KHAYELITSHA 79

CHAPTER SIX: CASE ACCOUNTS 93
6.1. Case One: The Mdubekis' Help-seeking Journey and an Account of their Circumstances 93
6.2. Case Two: Linah's Difficult Circumstances 100
6.3. Case Three: Tata Liliso's Quest for a Cure 103
6.4. Case Four: Vuyokazi's Life History and Ongoing Illnesses 106
6.5. Case Five: Nyathi's Recovery Following his Stroke 111

PART THREE: THE CULTURAL CONSTRUCTION OF APHASIA 116

CHAPTER SEVEN: FRAMEWORKS OF INTERPRETATION OF APHASIA 118
7.1. Illness Causation in Southern Africa 118
7.2. Descriptions of Stroke and Aphasia in Khayelitsha 118
7.3. Ideas of Causation of Stroke and Aphasia in Khayelitsha 119
7.3.1. Ancestors and communication loss 122
7.3.2. Witchcraft in communication loss 126
7.3.3. Mechanistic explanations for stroke 131
7.3.4. Contribution of hardship to stroke 132
7.3.5. A prevalent 'not-knowing ' 133
7.4. Discussion of Causal Notions of Aphasia 133
7.5. Conclusion 140

CHAPTER EIGHT: THE QUEST FOR CURE: HELP-SEEKING JOURNEYS OF PEOPLE WITH APHASIA IN KHAYELITSHA 142
8.1. Introduction 142
8.2. Therapeutic Options in Khayelitsha 143
8.3. The Magic of Medicine 143
8.4. Faith Healing 146
8.4.1. The rise of African Independent Churches 146
8.4.2. Ritualised healing in Khayelitsha 148
8.4.3. 'The miracle of prayer' 150
8.4.4. A reconfiguring of AICs: The gospel of prosperity 151
8.4.5. Faith healing community as a gendered domain 152

8.4.6. The two sides of faith healing: Use and abuse 154
8.5. Traditional Healing 155
8.5.1. South African healers 156
8.5.2. Traditional healers in Khayelitsha 158
8.6. Experiences of Healing Practices 160
8.6.1. The costs of healing 162
8.6.2. Mistrust of healers in urban settings 165
8.6.3. Changing paradigms of healing 167
8.7. Rituals and Representatives: Traditional Healing in aphasia 169
8.8. The Help-seeking Journey in Aphasia 171
8.9. Discussion of Help-seeking in Khayelitsha 174
8.10. Conclusion 178

PART FOUR: THE SOCIAL CONTEXT OF APHASIA 179

CHAPTER NINE: THE SOCIAL EXPERIENCE OF APHASIA 180
9.1. Introduction 180
9.2. The Nature of Community in Khayelitsha 181
9.3. The Vulnerability of Life Post-stroke 184
9.4. The Isolation of Life Post-stroke 187
9.4.1. The limits of neighbourly support 188
9.4.2. The limits of kin 189
9.5. Support Networks Outside the Home 191
9.5.1. Church groups 191
9.5.2. Non-governmental agencies: The adult day care club 194
9.6. Concluding Comments: Community Experiences in Aphasia 195
9.7. Experiencing Family 196
9.7.1. A review of the literature 196
9.7.2. Particular family circumstances for participants of the study 197
9.7.2.1. Fluidity of living circumstances 197
9.7.2.2. Intergenerational tensions 202
9.7.2.3. The experience of aphasia across gender lines 206
9.8. Aphasia in the Context of Socio-economic Strain 209
9.9. Discussion of the Social Context of Aphasia 211
9.10. Conclusion 214

CHAPTER TEN: ACCESSING CARE: THE HOSPITAL AND COMMUNITY HEALTH CENTRE 215
10.1. Introduction 215
10.2. Negotiating Levels of Care: The Tiered Structure of Health Services 215
10.3. Experiences of State-run Health Facilities in Khayelitsha 218
10.3. Experiences of Outpatient Rehabilitation at Local Day Hospitals 221
10.4. Trust and Mistrust of Health Workers 225
10.5. Communication Barriers and Moral Discourses 227
10.6. Discussion and Conclusion 229

CHAPTER ELEVEN: CONCLUSION 231
11.1. Glancing Back on Emerging Themes of the Thesis 231
11.2. Recommendations for Service Provision 232
11.2.1. Taking cue from global initiatives: Structural reform in service delivery 233
11.2.2. Taking cue from local initiatives: Site-specific methodologies for communicative accessibility in the health care system 236
11.2.3. Culturally-relevant health communication in aphasia 238
11.3. Anthropological Perspectives in Clinical Aphasiology 240
11.4. Further Study 241
11.5. Concluding Reflections 243

REFERENCES 245
APPENDICES 281
Appendix 1: Participant Information Sheets and Consent Form (English) 282

LIST OF TABLES

Table 1: Interviews Conducted with Healthcare Workers and Other Relevant Personnel 78

Table 2: Summary of Key Case Accounts 114

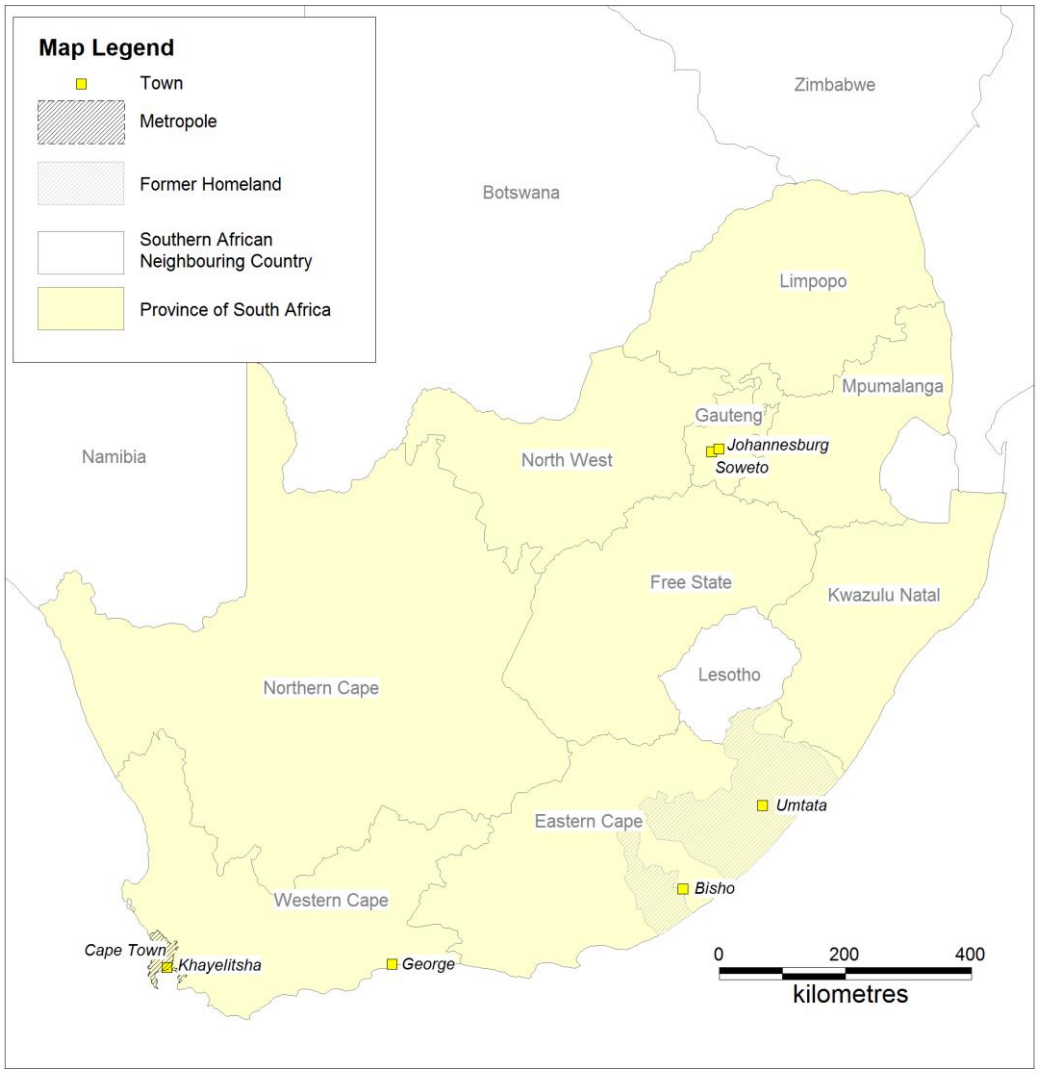
Table 3: Causal Attributions of Aphasia Derived from Various Informants During the Course of this Study 121

LIST OF FIGURES

Figure 1: The layers of experience of aphasia 28
Figure 2: The cultural layer of aphasia 44
Figure 3: Fieldwork Timeline 72
Figure 4: Map of Khayelitsha and surrounding townships 79
Figure 5: Map showing location of photographs 81
Figure 6: A typical street scene in Khayelitsha 82
Figure 7: New housing development 82
Figure 8: Recently developed commercial zone 83
Figure 9: Entrance to the Site B Day Hospital 83
Figure 10: State-run health care services for people with stroke 217

AREA MAPS

NATIONAL MAP



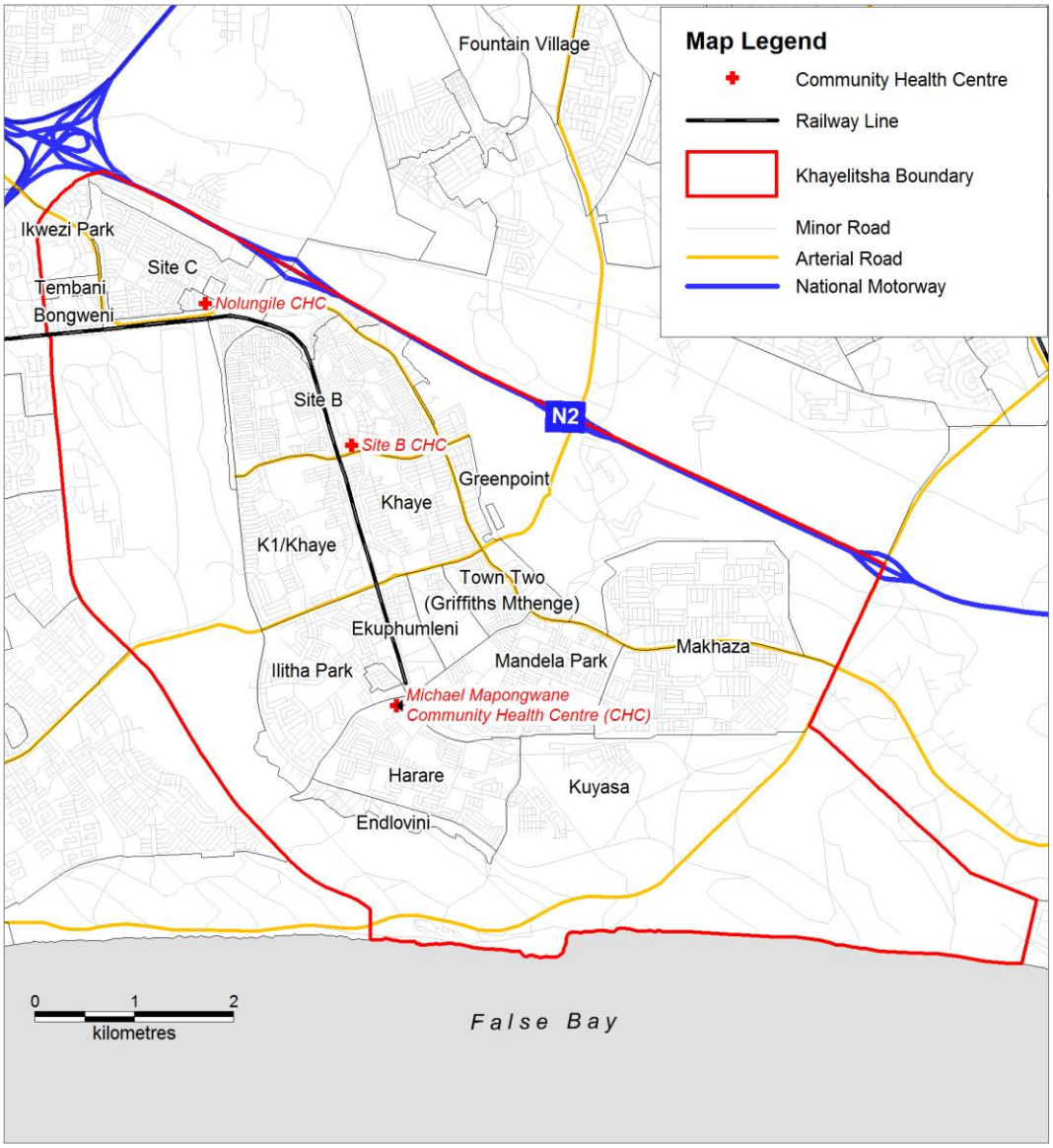
(Source: Chief Directorate Surveys and Mapping, Department of Land Affairs and Statistics South Africa). The former homeland states of Ciskei and the more northerly and larger Transkei are shaded.

THE CAPE TOWN METROPOLE



(Source: Chief Directorate Surveys and Mapping, Department of Land Affairs and Statistics South Africa)

KHAYELITSHA



(Source: Chief Directorate Surveys and Mapping, Department of Land Affairs and Statistics South Africa)

CHAPTER ONE
INTRODUCTION

1.1. Introductory Perspective

This thesis is an ethnographic study of the experience of aphasia for adults living in Khayelitsha, a community characterised by poverty, violence and a culture and language that differs markedly from the setting of most speech language services in South Africa. Following detailed observation of a small group of participants, I describe the experience of aphasia for adults in this community as it relates to their position within community and household; networks of support; frameworks of interpretation of communication loss; and experiences of health services. In doing so, I have aimed to shed light on explanatory models of aphasia and to approach questions regarding the influence of context on the course of this disabling condition.

At a theoretical level, this thesis seeks to contribute to an understanding of the sociology of communication loss. The field of aphasia rehabilitation and more generally that of speech language therapy has in recent years espoused a social approach to rehabilitation. With input from qualitative research and other disciplines, particularly the social sciences, the understanding of communication loss and language disruption is evolving towards a holistic understanding of the lived experience. It is now well recognised that by embracing this approach, aphasia therapists position themselves for a more potent impact on patients, on the health system and on the promotion of the profession. Social approaches to aphasia have attempted in some way to break down ignorant social practices and reorientate healthcare. Related literature in the form of insider, autobiographical, ethnographic and conversational accounts of aphasia has taught us that aphasia is a pervasive disorder of person and of society. However much of what has been written about aphasia as a psychosocial construct is anchored to individual perceptions, and variables of culture, religion, gender, family, health belief

systems and socioeconomic status have been left largely unexamined. Yet, how are communication loss, stroke and disability interpreted by the cultures and societies in which we practice? What is the situation for adults with aphasia in a setting where there is a pronounced difference in understanding, in language and in experience between health professional and patient? How do adults with aphasia experience their communication difficulties in communities, characterised by poverty, where resources are sparse and specialists are few? It is these questions with which this thesis is concerned.

I have approached these questions through anthropological enquiry, a research paradigm that I contend will facilitate understanding of the multiple layers of the aphasic experience. The decision to make the focus of enquiry an anthropological one is framed by global movements in disability and clinical aphasiology, in which interventionists have recognised the need to understand and co-construct life systems in order to impact the lives of the disabled (Coleridge, 1993; Imrie, 1997) and by local needs to construct a dialogue between clinical and sociocultural understanding of disability and communication loss.

Ethnography, as a flexible and naturalistic research paradigm of the discipline of anthropology, is well suited to understanding cultural perspectives and social actions. It can be described as a general strategy of qualitative research through which 'the ethnographer participates, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions, in fact collecting whatever data available to throw light on the issues with which he or she is concerned' (Hammersley & Atkinson, 1983: 2). There is much support for the application of ethnographic methodology in the social and health sciences (Flick, 2002; Lincoln, 1992; Scheper-Hughes, 1990), and in aphasiology, where ethnographic methods have been used to study naturally occurring communicative behaviours (Davidson, Worrall & Hickson, 2003; Lyon, 1992; Simmons-Mackie & Damico, 1995); clinical encounters (Simmons-Mackie, Damico & Damico, 1999) and perspectives of clients living with a communication disorder (Parr, Byng, Gilpin & Ireland, 1997).

In South Africa, where there are vast cultural and social differences between the setting of the clinic and the daily reality of aphasic individuals, ethnographic research as a methodology may be better suited than other qualitative methodologies such as the open interview. Traditional paradigms for investigating aphasia, especially those within the discipline of speech language pathology, seem insufficient to explain the impact of aphasia in a South African context. In addition, Khayelitsha's changing political and cultural climate influenced by deepening impoverishment and the brutality of AIDS encapsulates Geertz's description of the 'world in pieces' where neat and structured research approaches have limited application (Geertz, 2000: 218)

The impetus behind this study is a personal one. It stems from the challenges I faced as a speech and language clinician working in this environment in weekly clinics for five years prior to the study. My specific role here was to establish student-led clinics for speech and language services. During these years I was excited by the opportunities presented to me as a clinician in our transforming society but also increasingly concerned that the imported ideas, systems and approaches of my professional training simply did not work in this context and my efforts were largely impotent.

At this time, the field of aphasiology was embracing a social approach to intervention. Qualitative research into the psychosocial experience of aphasia began to dominate academic discourse. This research was set in the context of the social approach to aphasia, an alternate service delivery system to traditional language therapy. Whilst this approach held promise for addressing aphasia and other communication disabilities in South Africa, much of what was written about aphasia as a psycho-social construct did not address key practice issues I was facing as a clinician working in Khayelitsha. This research had as its point of departure sociological constructs such lifestyle and coping that bore limited relevance to the daily experiences of the adults with aphasia that I had come to know. In addition, focus was on perceptions of the individual and there was scant

reference to the structural conditions that produce exclusion from social and economic life.

In parallel to this reconfiguration of therapeutic approaches in aphasiology, new policies for health rehabilitation and integration promoted the role of community in service and resource provision in South Africa. The imperatives of community based rehabilitation were incorporated into rehabilitation training programmes and research into cultural issues was promoted. But the conceptual bias towards quantitative research in the rehabilitation fields meant that researcher-clinicians had limited theoretical insights and tools to interpret culture and community. Much of the resulting work was survey-type projects that framed findings against schemata of knowledge, beliefs and attitudes. These seemed to offer parochial insights to a clinician trying to understand a community in the context of economic hardship and social change.

I embarked on a study of this nature in order to develop an adequate conceptual framework for thinking about the nature of aphasia and the social processes that mitigate or problematise the experience within a South African setting. I wanted to grasp the social and cultural planes of this community in order to establish services that bore relevance to the daily lives of the adults with aphasia.

Clinically, therefore, this thesis aims to document a diverse reality and cultural context in order to inform rehabilitation practice. My proposition is that anthropological understanding of a community can help clinicians to work with communities in a constructive and enabling manner and address domestic and community matters with cultural sensitivity and proficiency. Moreover, it can offer a window to understanding the position of the voiceless in this country. Health policy priorities have shifted towards childcare and mobilisation around HIV/AIDS, marginalising the elderly and victims of stroke and neurological injury[1]. In describing their current situation, the foundation can be laid for a more

[1] A number of important changes have been made to the South African National Health System since 1994 which impact on the rehabilitation services for individuals with stroke and aphasia. These changes include the implementation of Primary Health Care principles delivered through

involved role of the speech language therapist in the broader socio-political processes of advocacy and activism for communication disability.

1.2. The Themes of the Thesis

This ethnography has been guided by three broad concerns. Of primary concern, is the social context of the adult with aphasia in this setting. Such enquiry can approach questions regarding the influence of social circumstances on the experience of aphasia. Such enquiry could also aid the dialogue of service transformation in South Africa where healthcare policy is shifting towards community-based care (African National Congress, 1994); a move that has been promoted by health professions and policy makers and justified by the notion of community. Community as a concept, however, is paradoxical (Thornton and Ramphele, 1988, 29). The idealised notion of '*ubuntu*'[2] that encapsulates the moral obligation of community members to care for its disabled and the networks of support that hold its members together is contrasted with a community under strain; where mechanisms of support are altered due to poverty, violence and domestic fluidity. Moreover, due to past decades of Apartheid segregation, professions such as speech language pathology have limited knowledge as to what 'community' truly represents. One can also argue that the medicalisation of chronic disease and disablement (and in this case communication loss) and the conceptual bias towards quantitative research has left the profession with limited

District Health Systems. As a result, limited funds have been channeled from tertiary level rehabilitative services and subacute care to establish basic health services at a primary level. Further difficulties arise with the allocation of funds within health services. Certain illnesses or individuals are considered to be priority such as HIV/AIDS, pregnant woman and children under 6. Dedicated geriatric services have fallen away. Even more discrepancies exist between services provided for disabled individuals where wheelchair provision and cataract operations have been considered priority treatments (ANC, 1994a).

[2] The notion of 'Ubuntu' is derived from the Xhosa saying *Umntu ngumntu ngabanye abantu* meaning a person is a person through other people. This cultural value is realised through the building of social support networks and shared resources. 'Ubuntu' is conceptualised as an ideal that can underpin community development and empowerment and has been used to rationalise health policy shifts to 'community-based care'. See Lorenzo (2003).

theoretical insights and tools to interpret community and the cultural, social and environmental factors that modify this reality.

There is a large body of literature in the social sciences that explains historical and modern concepts of relatedness that extend beyond kinship and respond to social, political and environmental conditions (Carsten, 2000). In addition, there are sociological debates around the notion of 'community' based on rural, pre-industrial and ideal conceptualisations of small organic societies (Mayo, 1994: 52), especially in South Africa where community is not a politically neutral term. It is relevant therefore that policy makers and health professionals advocating community care understand to what extent 'community' persists and what resources can be employed to carry the burden of care within communities, particularly in the context of social upheaval, mass urbanisation and economic hardship.

This study is also concerned with cultural accounts of aphasia. In both local and global contexts, there is a call for widespread social and attitudinal change that embraces diversity and culture. In the realm of health service provision, this has been a call for patient-centred care within a biopsychosocial framework (Brody, 1999; Engel, 1997). Central to this is the notion of culturally competent care.

These calls speak directly to South African concerns where therapists must respond to multicultural and multilingual caseloads. The last two decades of research within the discipline of speech language pathology in South Africa have been concerned with examining communication disorders in cultural and linguistic contexts and investigating alternate avenues for assessment and treatment. Whilst local research into alternate assessment and treatment paradigms has resulted in promising new frameworks for therapeutic projects[3], research into cultural understanding of communication difficulties has been cursory. This is

[33] For example, local research into interpreting practices in speech and hearing services and more generally health care (Penn, 2007), the application of narrative-based medicine to clinical practice (Penn, 2002; Evans, 2001); the establishing of therapy groups (Penn & Jones, 2006) and interventions for multilingual language impaired clients (Jordaan, 2001; Penn, 1993).

because this research has been based on a health beliefs model of research wherein cultural variables are treated as constant and thus unexamined (for example Bham & Ross, 2005; Dagher & Ross, 2004; De Andrade & Ross, 2005). In addition, the trend has been to frame findings against the scheme of knowledge, beliefs and attitudes, despite current debates in cross-cultural literature that models emanating from this research are 'straw men' and hold little social or clinical reality[4].

The outcome is that a South African epistemology of communication disorders remains under construction. Penn (2002) has therefore called for a critical approach to speech language pathology, one that will reflect sensitivity to cultural, linguistic and organisational influences and their interface with communication disorders. My ethnographic study of adults with aphasia in a South African community is a response to this call. Enhancing cultural knowledge can illuminate disparity between health services and the responses of individuals, families and community to this disabling condition and increased sensitivity to cultural variables can be applied to intercultural clinical encounters[5]. In addition, South Africa, as a dynamic mix of cultural and social influences, undoubtedly holds significant theoretical insights for scholarship into the psychosocial aspects of aphasia in general.

A third concern of this study is the reality of services for individuals with aphasia in Khayelitsha. In this setting, there are likely unique experiences of health care and other services due to barriers of language and education, in addition to limited accessibility and increasing marginalisation of the communicatively disordered adult due to poverty and the AIDS pandemic. Anthropological enquiry into the accessibility of support services will help us to understand the real experiences of the client with aphasia and their families within healthcare and social systems. This objective is based on the need for advocacy and activism for a group of

[4] See Pelto and Pelto (1997) for an examination of the knowledge and beliefs schemata widely employed in cross-cultural studies. See also Swartz (2006).

[5] According to Chick (1995: 238), people in South Africa are particularly susceptible to miscommunication across cultures due to the political, geographic, economic and social distances between cultural groups established by Apartheid.

individuals living with an under-researched and increasingly marginalised disabling condition. This objective is also linked to the objectives of exploring the social and cultural context. Explanatory models are linked inextricably to treatment options and help seeking is shaped by accessibility and availability of services.

1.3. The Theoretical Context of the Thesis

This thesis both draws on and extends across a number of disciplines including aphasiology, disability studies, sociology and anthropology. I am a practising speech and language therapist in South Africa and my clinical and research background is within aphasiology. The various disciplines represented in this study reflect my own journey as a researcher to find the interpretive framework that could help me explain the nature of living with aphasia in Khayelitsha and a methodology that could cross enormous language and cultural divides, including those created by aphasia itself. I spent the first year of study reading sociology, in particular the sociology of health and illness, and delving into disability studies and the policy development models that underpin dominant frameworks of understanding in aphasia today. These disciplines offered valuable theoretical concepts and tools of thinking about the nature of adult language impairment. However even after this lengthy period of study, I couldn't ignore that the theoretical and methodological tools of these disciplines, whilst helpful, did not really allow me to engage fully with the life worlds of adults living with aphasia in Khayelitsha. In my search for a different approach, I had a chance encounter with Dr Hayley MacGregor whose anthropological insights into the lives of adults living with mental illness in Khayelitsha resonated strongly with my early thoughts about the nature of language loss in this setting. And so began my foray into ethnography. My research and writings have been inspired and enriched by the writings of MacGregor (2002), Scheper-Hughes (1993), Farmer (1999), Poole (1994), Fadiman (1997), Livingston (2005), Ashforth (2005) and Comaroff (1985). These anthropologists, among others, showed me the potential of long-

term fieldwork in developing relationships across any social divide and offered me a rich interpretive framework in which to understand and not only to document the experience of stroke and aphasia in the community in which I worked. I have also been strongly influenced by writings of Penn (1993, 2002, 2005) in my own field and of Swartz in cross-cultural psychology. In his preface to Swartz's (1998) book about culture and mental health in southern Africa, Kleinman asserts that Swartz's writings demonstrate that difference is not beyond understanding. My aim in this thesis has been to achieve such understanding.

1.4. Addressing the Impact of Stroke and Aphasia in South Africa

This study is an attempt to foster understanding of aphasia in a unique context in order to reform language intervention services and build upon the theoretical understanding of aphasia as a desocialising condition. A study of this nature can also shed light on how communities deal with the impact of stroke[6] in a general sense. Although there are no conclusive figures stating the incidence of aphasia in South Africa, what is known is that incidence of stroke in this country is reaching crisis proportions. In 2004, the South African Stroke Prevention Initiation (SAPSI) documented that the prevalence of stroke in rural South Africa is higher than previously thought and the prevalence of stroke survivors requiring help with daily living is at high-income country levels. Based on this report, SAPSI has raised the alarm that South Africa suffers from a huge burden of HIV/AIDS and diseases of poverty and violence, as well as an imminent epidemic of vascular disease (SAPSI project team, 2004). These emerging prevalence statistics have been confirmed by Connor (2008) in his doctoral thesis concerned with the burden of stroke in both urban and rural South Africa. These findings are also reflected in morbidity rates for Khayelitsha where stroke is one of the leading causes of death next to HIV/AIDS, violence and injury (Groenewald et al, 2003). There are also a number of recent reports associating AIDS with increased risk of stroke (Cole,

[6] No evidence-based information could be found regarding the etiology of aphasia in this community or in the Western Cape. Thus I acknowledge that regarding stroke as the primary etiology of aphasia in this community is an assumption based on global statistics.

Pinto, Hebel, Buchholz, Earley et al., 2004; Connor, 2007; Hoffmann, Berger, Nath & Rayens, 2000; Mochan, Modi & Modi, 2003). Although there is as yet little conclusive evidence that HIV independently causes stroke, HIV is associated with neurological and vascular disease (such as meningitis, toxoplasmosis, vasculopathy and vasculitis) and certainly there is anecdotal evidence for increased risk of stroke in young people who are HIV positive (Connor, 2007).

Despite these figures, little is known about social constructions of stroke and the resources within marginalised communities to carry this burden. In describing the situation of the adult with aphasia, this thesis can contribute towards an understanding of the recognition and management of stroke within this sociocultural context.

1.5. The Context of Speech and Language Services in South Africa

The nature of healthcare and local speech and language services is the backdrop to this study. A brief overview is necessary. The vast majority of speech and language therapists in this country work as independent practitioners in the private health care sector. Private speech and language therapy is an exercise in cost and a resource available only to those on comprehensive medical aid schemes or to those who can afford it. Within the public health sector, there are dedicated speech and language services for adults with communication disorders. These are confined to tertiary level care. Here therapists provide acute management and outpatient care at large provincial hospitals and inpatient sub-acute care at rehabilitation facilities. Recently community service posts for newly graduated speech and language therapists have been established at district hospitals outside of the larger metropolitan areas. Here therapists work for a period of a year in a team of rehabilitation therapists providing a broad range of services to their respective communities. Across the board however one-on-one hospital based speech and language therapy is the mainstay approach and as the profession is dominated by white, English or Afrikaans-speaking females, therapists in this

country continue to struggle to extend speech and language services across cultural lines, language divides and into poorer communities. There are limited speech and language posts at the primary level and speech and language therapists are not well represented in social service organisations, in non-governmental agencies or in disability advocacy groups.

In Khayelitsha itself, there are as yet no locally-based speech and language therapy services. There are sporadic student clinics associated with the University of Cape Town and the University of Stellenbosch linked to service organisations in this community. These however are project-based and most often directed at empowering caregivers of disabled children. Adults with aphasia from Khayelitsha may receive hospital-based therapy in the acute and sub-acute stages following stroke and may be offered outpatient services. This situation is complicated by a number of factors. Capacity is limited and as a result sessions are short and spread out. Tertiary hospitals remain geographically inaccessible and although there is a sliding scale of fees, these are still out of reach for many families in Khayelitsha, especially once transport costs are included. Lastly therapy is likely to be in English and Afrikaans, or mediated by ad-hoc interpreters. The challenges facing therapists are enormous; the majority of people receive no therapy at all.

1.6. A Description of Chapters

This thesis is divided into five parts. The first part of the thesis, incorporating Chapters Two and Three, positions this study within its theoretical and methodological context. The focus of Chapter Two is the lived experience of aphasia. I describe recent studies in clinical aphasiology that have engendered understanding of the impact and meaning of aphasia for those who live with it. I frame these studies within theoretical and methodological movements in aphasiology, that being the social approach to aphasia and qualitative research, and consider their value in generating accurate descriptions of aphasia and

providing direction for worthwhile interventions. I argue that although recent movements in aphasia rehabilitation have recognised the importance of the individual, emotional and psychological dimensions to profound language impairment, there is a mutual influencing of these dimensions and the external world that has been largely overlooked in contemporary research.

In Chapter Three, I consider a methodology and interpretive framework that can be appropriately applied to understanding aphasia in context, and in the diverse and changing environment of South Africa. I begin this chapter by describing the basic domains and applications of medical anthropology. I then consider the theoretical perspectives emerging from medical anthropology and suggest that these perspectives can be used to deepen our understanding of communication loss and the role of context in approaches to rehabilitation and living with language impairment, particularly in the context of South Africa. My proposition is that anthropology offers valuable methodological frameworks and theoretical insights to understand the lived experienced of language loss.

Part Two sets the scene of the study. In Chapters Four, Five and Six of Part Two I detail the methods of the study, the setting of the study and the case accounts of key people who participated in this research.

Parts Three and Four of this thesis incorporate the central findings. Each of the four chapters within Parts Three and Four present background theory, the ethnographic material and a discussion of issues. Part Three, incorporating Chapters Seven and Eight, is concerned with cultural constructions of aphasia. Here I consider explanatory models and beliefs around stroke and aphasia within a 'traditional' framework of interpretation. Chapter Seven begins with a broad description of the understanding of stroke and aphasia in Khayelitsha. I then describe ideas of illness causation and apply these to causal notions in aphasia. The ethnographic data reflects wide ranging interpretations. I show how notions of ancestral interventions and evil agents are considered alongside those of biomedical, behavioural and social causes of ill health and that these notions

emphasise the immediate material and social concerns of everyday life in Khayelitsha.

In Chapter Eight I document the help-seeking journeys of the participants. I examine the nature of local healing practices in the urban context of Khayelitsha and consider help-seeking activities in particular relation to aphasia, to resources and to interpretive frameworks. I show how help-seeking efforts were not necessarily pragmatic or consistent with ideas of causation. They were ultimately efforts based on hope and people were susceptible to promises of a cure from those who profit from misfortune and uncertainty. I conclude with a discussion of applied issues.

Part Four, incorporating Chapters Nine and Ten, is concerned with the experiences of community, family and formal health care for adults living with aphasia in Khayelitsha. Here my primary concern is the contextual factors shaping these experiences. Chapter Nine, using anthropological theory in contemporary South Africa and in poor urban settings as the backdrop, describes the social experiences of the adult with aphasia and their primary caregivers. The post-stroke trajectory for adults who participated in this study seemed to be characterised by vulnerability, isolation, fluidity of circumstance and insecurity - experiences that spoke strongly to the context. I have attempted to show how prevailing socioeconomic, gender and generational burdens in Khayelitsha influence community and family responses to aphasia.

I turn to the context of the health system in Chapter Ten. Here I describe services for stroke patients and the specific experiences for adults with aphasia within these. I consider the difficulties that participants had in moving between levels of care, and in describing aspects of primary care, including chronic disease clinics and outpatient rehabilitation, I highlight possible deficits. Although I have attempted to foreground the influence of aphasia on these experiences, it is not always easy to tease apart variables of age, gender, staff attitudes, and the

structure of health services themselves that may equally limit opportunities for care within the health care system.

The final chapter forms the conclusion. I conclude this thesis by discussing the overarching themes. Here I attempt to draw clinical recommendations and present emerging methodological and theoretical insights.

PART ONE

CONVERGING ROADS TO ANTHROPOLOGICAL RESEARCH IN APHASIA

CHAPTER TWO
CONCEPTUALISING AND CONTEXTUALISING APHASIA

2.1. Introduction

While the field of clinical aphasiology is predominantly oriented to clinical activity, it is founded upon nearly a century of careful research initiatives that have aimed to delineate the disorder, capture its essence and generate interventions. Although both quantitative and qualitative methodologies have been employed in this pursuit, quantitative research paradigms have held a dominant place in the literature. This may be because clinical aphasiology is closely allied with medical disciplines, and has adopted the philosophy of objective investigation and used related research methods (Enderby & Emerson, 1996).

The conceptual bias towards quantitative enquiry in clinical aphasiology has had a limiting effect on the understanding of aphasia as a sociological construct. Three primary reasons for this have been proposed. Firstly, in the pursuit of scientific credibility, research in aphasia has focused on tangible and quantifiable variables to the exclusion of the psychosocial aspects of aphasia (Parr, 2001; Sarno, 1993). Secondly, research pursuits attempted to quantify observable handicap, leading to the belief that psychosocial handicap is an associated and secondary consequence of aphasia that may or may not be present (Lyon, 1992). Thirdly, owing to this 'quantitative' bias, methodological tools that can sufficiently explore the impact of aphasia are poorly understood and underdeveloped (Gainotti, 1997, Lyon, 1992).

However, recently developed social perspectives in disability and in clinical aphasiology have recognised the need to redress this conceptual bias in order to understand and co-construct life systems (Kovarsky, Culatta, Franklin and Theadore, 2001), to uncover meaning and explanatory models (Parr, 2001) and to

identify infrastructural factors that affect the lives of disabled people (Pound, Parr, Lindsay and Woolf, 2000). These perspectives, developed in response to the long-term psychosocial problems of aphasia and to global movements in disability that view handicap as a societal problem, rather than as residing in the individual, underpin the social approach in aphasia.

Although it has long been recognised that aphasia is experienced as more than only a disorder of language (Sarno, 1981), the social approach, predominant in clinical aphasiology in the last decade, has brought psychosocial dimensions of aphasia to the fore of theoretical and clinical practice. There is a growing number of publications advocating the theoretical acknowledgement and practical implementation of qualitative research (See for example *Aphasiology*, 1999, volume 13 (9 - 11); *Clinical Forum of Aphasiology*, 1998, volume 12 (6), *Seminars in Speech and Language*, 1999, volume 20 (1), *American Journal of Speech-Language Pathology*, May 2003 as well as Parr, 2001; Skeat & Perry, 2008; Sorin-Peters, 2004). There has also been a plethora of recent research efforts that have employed qualitative methodologies to define aphasia and understand its associated psychological and social dimensions. Themes that thread through these studies include the impact of aphasia on social and psychological functioning, disabling barriers experienced by people living with aphasia, methods of coping and accommodation and the systemic nature of communication impairment. Whereas once these experiences were considered associated and secondary consequences of aphasia (Lyon, 1992) they are now regarded as the very core of the condition: Aphasia exists beyond the realm of language loss and is conceptualised as a pervasive and multilayered disorder of the internal and external self.

Consideration of the context of aphasia is not new to the social approach. Rather, the social approach is a logical step on the road to understanding the real-life consequences of communication loss, consequences that permeate the realms of social and psychological functioning. The functional approach in aphasia, led by Sarno's work in the 1950s and then Holland's pioneering work in the 1980s,

viewed aphasia in the context of human activity and the limitations imposed upon activity by language impairment. Emerging parallel to functionalism was the pragmatic approach. The pragmatic approach, based on speech act theory, considered aphasia in the context of interpersonal interaction and the cognitive, linguistic and social frameworks that shape this interaction (Penn, 1999). These approaches were a move away from impairment-based acontextual perspectives in aphasia and brought aphasiology closer to understanding both the complexity and variation of language loss. In the 1990s, the understanding of the psychosocial consequences of aphasia was largely influenced by the World Health Organization's framework of impairments, limitations and participation restrictions, now referred to as the International Classification of Functioning (ICF) (Worrall, 2000). The social approach to aphasia emerged from this paradigm. It is a way of thinking about aphasia and a model of intervention that focuses on social communication and barriers to participation in social life. This approach underpins an emerging conceptual and empirical understanding of the condition and aphasia is increasingly described in sociological terms.

This thesis is set in the context of the social approach to aphasia. It approaches questions regarding the situation for adults with aphasia living in an urban South African community. A central concern of this thesis is the local situation and its related and particular challenges. This is a departure from previous research studies of the lived experience of aphasia, where metatheories and grand narratives are driving concerns. Nevertheless it is on the back of these studies that this thesis has emerged. In the following chapter, therefore, I review recent qualitative studies that explore the psychosocial dimensions of aphasia. This review does not include the entire scope of such publications but rather aims to highlight how the methodologies of phenomenology, narrative enquiry, ethnography and applied conversation analysis have been employed in aphasiology and in what ways this has broadened the understanding of aphasia. In reviewing the contributions of these studies, I argue for a cultural conceptualisation of aphasia and a related framework of interpretation

2.2. Qualitative Research in Aphasia

A relevant point of departure is to review the concept of qualitative research and how it is defined in the aphasiology literature. Qualitative research is essentially an analytic paradigm underpinned by a postmodern philosophy that appreciates multiple realities and recognises that research is value bound and affected by time and context. Qualitative methodologies are concerned with the detailed description and analysis of social phenomena as they occur in natural contexts. With roots in the social sciences, anthropology and sociology in particular, qualitative methodologies include phenomenology, grounded theory, conversation analysis, ethnography, narrative enquiry and case study, among others. Within these modes of enquiry, naturalistic data is collected in authentic settings through direct observation and informant-driven interviews. Data is then described in detail and interpreted in terms of sociological theory and human meaning.

Qualitative research has been increasingly applied in psychology and the health sciences. This is because the qualitative paradigm can better accommodate an increasingly plural and diverse world, one that requires understanding of variables within their local and relative context. In the introduction to her text on qualitative research, Flick (2002: 2 - 10) considers the historical context of this shift to qualitative methods. Philosophers and social researchers in the 1960s began to question deductive quantitative approaches in the context of rapid social change and the diversification of life worlds. Without any a priori understanding of their fields or subjects under study, it was no longer possible for them to generate hypotheses from theoretical models of human behaviour and then test them in a traditionally empirical way. Scholars began to argue for inductive methodologies to sensitise them to the social context. Parallel to this, postmodernism led to a ‘shattering’ of objectivity (ibid: 3) as researchers recognised that findings spoke more to subjects, situations and settings than to grand narratives and discourses.

Only recently has there been evidence in the aphasia literature of an appreciation for the sophisticated critical theory driving qualitative enquiry in the social

sciences. Most qualitative studies previously published in the field are qualitative in so far as that they are descriptive, using words to describe attributes of events as opposed to numbers. These methods have a place in clinical aphasiology: descriptive case studies provided the appropriate means to describe individual differences and patterns of commonality in subjects for a sophisticated understanding of language processing impairments, neurological conditions and the manifestation of aphasia in certain linguistic or neurogenic populations. These case studies drew on a long tradition in neurology where case studies of individuals with proposed disruptions in identified regions of the brain provide valuable information regarding the contribution of the cerebral structures to aspects of human functioning. Case reports on specific treatment approaches have also laid the groundwork for more extensive efficacy research.

Descriptive study alone, however, does not exploit the qualitative paradigm to its full potential and qualitative research methods in clinical aphasiology remain 'largely untapped' (Sorvin-Peters, 2004: 937). Looking back, it appears that the most valuable contributions of qualitative research to our field have come from the fields of sociology and sociolinguistics and much of what we understand about communication, discourse, social interaction and conversation is derived from social science research (Simmons-Mackie & Damico, 2003). Nonetheless, qualitative paradigms have, over the last decade, received increasing attention from researchers and clinicians interested in aphasia and other communication disorders. This is because they offer tools to approach complex questions regarding individual manifestations of aphasia that elude quantitative enquiry and because they permit insight impossible to obtain from the confines of the clinic. Qualitative research has engendered important insights about the psychosocial consequences of aphasia and I turn to a consideration of such studies in the following sections.

2.2.1. Phenomenological studies in aphasia

Phenomenology is essentially the study of the ways in which people experience the world they live in. Uncovering new perspectives and points of view is the impetus behind this approach. Interview is the principal means of data collection and data is usually analysed thematically in order to delineate categories and interpret the uncovered perspectives (Flick, 2002: 188). There have been a number of studies that have adopted phenomenological approaches to further understanding of the psychosocial consequences of aphasia. Parr (1994) interviewed 20 individuals with aphasia regarding their everyday coping practices; Le Dorze & Brassard (1995) investigated the disability and handicap of aphasia through the reported concerns of nine individuals with aphasia and their family and friends; Ireland and Wotton (1996) drew on personal experiences of counselling; Garcia, Barrette and Laroche (2000) explored the perceptions of individuals with aphasia regarding the obstacles for returning to work; Alberts (2002) examined the handicapping consequences of aphasia along the continuum of recovery and, Michallet, Tetreault and Le Dorze (2003) interviewed the spouses of five people with aphasia in order to delineate their unique stresses and adaptation processes.

These studies have shown how researchers can transcribe, analyse and interpret in-depth interviews to reveal themes, such as coping strategies, social support and participation not revealed by questionnaires and attitude scales. They have prompted reflection on the impact of aphasia, proposed models of the relationships between dynamic variables of disability, and provided valuable insight into needs for service delivery. They have also been used to advocate the development of socially valid assessment measures and treatment paradigms. Phenomenology in this way has offered aphasiology a powerful tool to begin to understand the complex relationships between aphasia and social and personal identity.

Limited interpretation, however, tempers the contribution of these studies. Data analysis, while oriented to illuminating common themes (often perceived as mutually exclusive) does not extend to sociocultural processes and their meanings, or develop emerging concepts in relation to established sociological theory. For example, although Le Dorze & Brassard (1995) highlight the handicapping consequences of aphasia over impairments associated with the condition, catch-all categories such as relationship and employment difficulties provide little insight into how these difficulties come about and play out in the lived experience of aphasia. In a related way, Alberts' (2002) analysis of the impact of aphasia against the International Classification of Functioning (ICF) framework showed declining participation along the continuum of recovery but with little specificity of the nature of reported problems. There is arguably a simplification of the complex issues relating to living with aphasia and these studies may be perceived to be anecdotal or reductionistic (Parr, 2001). Of concern too, is the limited acknowledgement of the role of the researcher in the data, especially considering that much of this research is driven by an advocacy-agenda and that the interview method incorporates researcher objectivity rather than the reality created by the subjects' personal experience. The reality of the personal and subjective experience is powerful. Categories and themes perhaps are no substitute for the power of the narrative.

2.2.2. Narrative enquiry in aphasia

Narrative enquiry is concerned with the sociological and anthropological aspects of illness understood and expressed in the framework of one's life story. Kleinman's (1988) recognition that stories people told about their illnesses are significant not only in diagnostic terms but also in terms of uncovering the meaning, both social and cultural, that people ascribe to illness was precedent to a large body of future work in the intersecting disciplines of anthropology, sociology and medicine. Here illness narratives are used as analytic and literary tools to offer unique insider perspectives about the experience of chronic illness

and the ‘existential qualities such as inner hurt, despair, hope, grief, and moral pain which frequently accompany, and may even constitute, people's illnesses’ (Greenhalgh & Hurwitz, 1999: 48). Illness narratives have also been used to study cultural accounts and narrative research has made a central contribution to the understanding of sociocultural concepts of illness and the needs for service delivery reform. McKevitt’s (2000; 2003) work in narratives of stroke provides a relevant example.

In aphasiology, narrative enquiry has been used to explore the experiences of people living with aphasia. Parr (1994) used narrative enquiry to this end with a group of twenty adults with aphasia. These narratives captured the experience of aphasia on an external and internal level. Externally, people with aphasia face barriers to participation in society, such as structural, attitudinal and informational barriers. Narratives were able to delineate these barriers and their impact. Internally, aphasia is a dynamic and systemic disorder of identity and the narratives, importantly, illustrated this complexity. Parr et al’s (1997) study highlighted the inadequacy of outsider-driven concepts and models that propose stages of adaptation to aphasia. Narratives here were a powerful reminder that aphasia has no time line: ‘Clinical and research procedures that exclusively and inflexibly apply professionally driven constructs may not always match with the inside, individual experience’ (Parr, 2001: 286).

Narrative enquiry has significantly furthered the pursuit to understand aphasia in all its dimensions. Its value as a research tool can also be extended to understanding cultural accounts and to inform and reflect on therapy. Pound, Parr and Duchan (2001) used narratives of spouses of people with aphasia to uncover the impact of aphasia and subsequently develop, deliver and evaluate intervention programmes. And, excitingly, narrative enquiry not only provides ‘fascinating and complementary perspectives on the condition as well as on diagnostic and therapeutic regimes’ (Penn, 2000: 72), but valuable assessment and therapeutic options particularly in a cross-cultural context.

Narratives however have been criticised as journalistic endeavours and as poor alternatives to social analysis that document day-to-day behaviour and experience (Littlewood, 2003). Ethnography may offer a more appropriate tool in this regard.

2.2.3. Ethnographic methodologies in aphasia

Ethnography[7], a further method of qualitative enquiry, is well established in fields such as anthropology, sociology, education, and linguistics. Essentially, ethnography is an interpretive science, where through 'thick description'[8] of events and experiences, meaning is held paramount to determinants of behaviour. In aphasiology, ethnographic methods have been used to study naturally occurring communicative behaviour. Holland's (1982) naturalistic observation of the functional communication of 40 people living with aphasia remains a benchmark in the field. Recently Lyon (1992) and Davidson, Worrall & Hickson (2003) also employed naturalistic observation to observe the social communication of adults living with aphasia. In addition, these methods have been applied to the study of clinical encounters (Simmons-Mackie, Damico & Damico, 1999) and insider perspectives of clients living with a communication disorder (Parr, Byng, Gilpin & Ireland, 1997). Although these studies were not ethnographies, they showed how rigorous ethnographic methods of naturalistic observation and ethnographic interviewing can be successfully employed in both the research and clinical domains. For example, Davidson et al (2003) used naturalistic observation to gather data on the everyday communication behaviour of elderly people with and without aphasia in urban Australia. This study corroborated functional assessment measures but also highlighted the predominance of social (as opposed to functional) communication acts in the lives of their elderly participants that

[7] See Introduction, p. 2

[8] Geertz (1973: 6) used the term 'thick description' to describe the work of ethnography as an intellectual effort; thick description thus referred to the rich and detailed description of the context of interpretation. Denzin (1989: 83) elaborated on Geertz's term. He suggested that 'thick description' is not only the act of recording observed events in detail. It is essentially an interpretive act, whereby the historical and situational context of events and the emotions, intentions and social connections of the actors are interwoven in the accounts of the day to day actions of those under study.

functional measures fail to capture. Parr et al's (1997) longitudinal and in-depth description of the barriers facing fifty adults with aphasia in England continues to be applied to advocacy projects and Simmons-Mackie et al's (1999) macro-analysis of aphasia therapy has furthered our understanding of compensatory strategies in aphasia, of feedback and of good communication practices.

In addition, although social approaches to aphasia are based largely on an advocacy agenda and much of our understanding of the psychosocial impact of aphasia has been derived from interviews or surveys in the clinical context (for example, National Aphasia Association, 1988), recent studies using ethnographic methods have empirically tested the underlying assumptions of reduced participation and desocialisation as a consequence of aphasia (Ashton, et al 2008; Davidson, Worrall & Hickson, 2003; Cruice, Worrall & Hickson, 2006; Howe, Worrall & Hickson, 2008b; Parr, 2007; Worrall, Rose, Howe, McKenna & Hickson, 2007).

Although ethnographic methods offer the appropriate tools to understand the broader cultural context in which people with aphasia are embedded, the interactional space (that is verbal interactions or conversation) remains the primary focus of the studies that I have reviewed. Parr's (2007) naturalistic observation of social inclusion and exclusion for people with severe aphasia appears to be the first published study of community practices in clinical aphasiology. In other studies I find little evidence of the social and cultural context of the issues under review. Whilst these studies have answered *what* happens to people with aphasia, they don't truly approach questions of *why*. For example, it is possible that socio-political and legal rights have shaped inclusion and exclusion practices for people living with aphasia in Parr's United Kingdom and that social participation parameters of the elderly is influenced by the aging and middle class environment of Davidson's Australia.

2.2.4. Applied conversation analysis in aphasia

Conversation analysis is a powerful and empirically rigorous qualitative methodology that involves inductively uncovering patterns within conversations that highlight the processes and problems encountered by participants in their construction of conversations (Damico, Oelschlaeger & Simmons-Mackie, 1999; Perkins, 1995). This is done through the detailed transcription and analysis of the step-by-step details of a conversation, such as pausing, overlap, eye gaze, intonation or non-verbal cues. This method, developed in the 1960's, partly in reaction to the more formal schools of linguistics of the time, which considered language structures out of their interactional context, focuses on spoken dialogues that actually occur. Conversation analysis integrates the study of language, context, meaning and action. This makes it a transdisciplinary field, drawing from linguistics, sociology and especially a branch of sociology called ethnomethodology[9].

Recent work in aphasiology has highlighted the value of conversation analysis in understanding the psychosocial dimensions of aphasia. For example, Laakso and Klippi (1999), Ferguson (1998) and Lindsay and Wilkinson (1994) examined repair strategies in aphasic conversation, highlighting collaborative processes. Wilkinson (1995) illustrated the value of context in shared understanding and Simmons-Mackie and Damico (1997) documented the role of conversational principles in communication success. Simmons-Mackie and Kagan (1999) revealed, through conversation analysis, the behaviour of good versus poor interlocutors and Hoffman (2004) documented the tendency of nursing staff to avoid and gloss over trouble in conversational attempts with patients with aphasia. In this way, aphasiologists have shown some adaptations from the fundamental principles of conversation analysis (Hesketh & Sage, 1999), yet these deviations have been insightful and significant and can be applied to training interlocutors and implicitly or explicitly improving the communicative behaviour of therapists (Perkins, 1995; Wilkinson, 1999). For example, Booth and Perkins (1999) have

[9] Ethnomethodology is the study of the codes and conventions that underlie social activities and interactions (The American Heritage Dictionary of the English Language, 2009, 4th edition).

used conversation analysis to guide carers and Horton and Byng (2000) and Simmons-Mackie and Damico (1999) have used this approach to shed light on effective and emancipatory therapy practices. Moreover all of these studies provide empirical evidence for the participation limitations brought on by aphasia and go further to provide valuable advice for dealing with conversation.

2.3. The Contribution of Qualitative Research to the Conceptualisation of Aphasia

Qualitative studies into the psychosocial consequences of aphasia have engendered a deeper and more sophisticated understanding of aphasia as a desocialising and pervasive condition. In Figure 1 presented below, I have conceptualised the domains of aphasia as layers. Sharing language disruption as the common core, these layers represent the psychological, interpersonal, familial and social[10] contexts that are both affected by aphasia and affect how aphasia is experienced. Particular themes and research foci can be discerned within each context.

What follows is a more detailed description of the consequences of aphasia within each of these realms of experience. I draw on key qualitative studies into the lived experience of aphasia and some of the theoretical orientations that underpin this research.

[10] Here I use the term social to refer to human interactions within society.

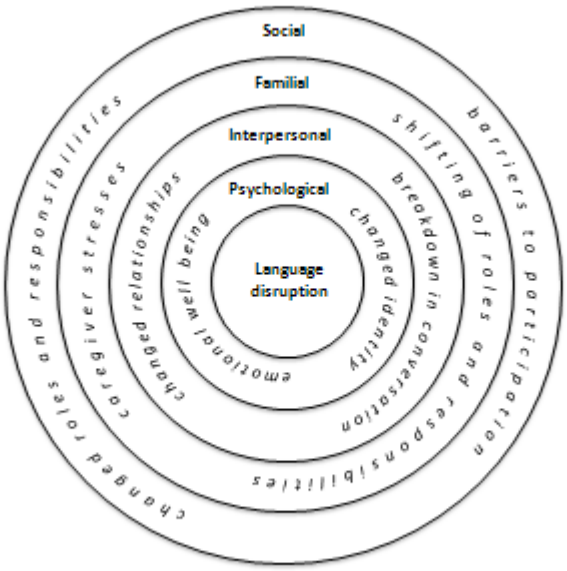


Figure 1: The layers of the experience of aphasia

2.3.1. Aphasia and the psychological realm

It is well recognised that aphasia is associated with depression, frustration, irritability, mood disorders and loss of emotional control. These are rooted in both the neurological effects of stroke and the impact of language loss on social functioning. Recent narrative and phenomenological studies of aphasia have shown these effects of aphasia to be some of the most complex, impenetrable and distressing consequences of the disorder (Brumfitt, 1993; Byng et al, 2000; Code, Hemsley & Herrmann, 1999; Le Dorze & Brassard, 1995; La Pointe, 1999; Parr, 1994; Sarno, 1997). Aphasia can affect psychological well-being in a profound way, shaking up notions of personhood and identity. Shadden (2005) goes as far as to describe aphasia as identity theft. This is consistent with various sociolinguistic theories and constructs that recognise the centrality of language in sense of self (Goffman, 1967). When interaction is disrupted or unnaturally difficult, people with aphasia experience a disconnection between their previous sense of self as they bump up against the reality of painful and failed interactions with others.

Correspondingly, the experience of aphasia is shaped by the pre-morbid self and psychological resources. The relationship however is complex as words are psychological tools in learning how to cope with disablement and conversation is the forum for narrating and building a new personhood (Gee, 1999). Questions exist as to how adults with aphasia make sense of aphasia. Aphasiologists have looked to sociological theories of grief responses and the illness experience to map the journey to acceptance. Although the grief response model suggested by Kubler-Ross (1969) is largely acknowledged, narrative enquiry into the aphasic experience shows that aphasia is a dynamic and systemic disorder of identity with no timeline (Parr et al, 1997). In addition, outsider-driven models do not capture the positive actions or new behaviour that people adopt in order to cope with aphasia (La Pointe, 1997). Both La Pointe (1997) and Parr (1994) document the importance of leisure pursuits, sport and hobbies in adapting to aphasia. These actions together with spiritual support appear to be dominant forms of coping with aphasia for those who live with the disorder. Jordan (1998) however highlights the considerable variability in coping and emphasises that people adopt multifaceted coping strategies which change over time.

2.3.2. Aphasia and the realm of interpersonal relationships

Gee (1999) considers the function of language to be dual. It scaffolds performance of social activities and it scaffolds human affiliations to others and to social groups. Aphasia as a disorder of language is therefore a desocialising one, disrupting both the vehicle for social activity and the links that connect individuals. Kagan (1995) proposes that loss of conversation is at the heart of this social breakdown. Drawing on the sociolinguistic theories of Schiffrin (1988), Kagan considers conversation as a process of both transaction - of novel messages between conversation partners - and interaction - as the medium for establishing and maintaining relationships, developing thoughts, exerting influence and sharing the self with others. It is not surprising therefore that psychosocial research in aphasia considers social isolation central to the experience of aphasia

(Bethoux, Calmels, Gautheron & Minaire, 1996, Davidson et al., 2008; Le Dorze & Brassard, 1995; National Aphasia Association, 1988; Parr, 2007). In addition to this, people with aphasia report changed relations, where a loss of words within the interactional context translates into a loss of power and loss of freedom in a social context.

Proponents of the social approach to aphasia contend that just as aphasia disrupts interpersonal relationships; interpersonal relationships, specifically, dialogical interactions, shape the experience of aphasia. In this respect, Kagan (1995) has argued for a new definition of aphasia, one that considers the role of the interactional context and the conversation partner in either creating or minimizing difficulties in communication. From this perspective, aphasia exists at the site of an interpersonal exchange and both the clinical and theoretical gaze has to a certain extent shifted from the person with aphasia, to the site of interaction.

2.3.3. Aphasia and the family

Psychological and sociological enquiry into the experience of aphasia has engendered understanding of the systemic nature of aphasia. The condition affects spouses, families and carers, often in profound ways. Servaes et al (1999), in a literature review of studies investigating the impact of aphasia on carers and families, suggest that difficulties in interaction between partners appear to contribute most to the burden of disease. In the studies reviewed, communication difficulties were the most frequently cited problem for carers of stroke patients; the degree of severity of communication problems was significantly correlated with strain on the carer and, in comparison, to carers of stroke patients without aphasia, carers of adults with aphasia experienced more strain, poorer overall adjustment and more negative attitudes in their caring role.

Norlin (1986) describes how families also experience identity crises following aphasia. These are often associated with emotional upheaval. Identity is closely

bound to the roles played within the marital and familial context and to the interactional styles that individuals traditionally adopt with family members. Aphasia, which alters roles, responsibilities and interactional patterns, can throw off the homeostatic balance of the family unit. Furthermore, altered social participation permeates throughout the family and family members too are vulnerable to social isolation and depression (Bernath, 2005).

There are a number of recent studies that consider the impact of aphasia on families and management of aphasia has extended into the family realm (Bauer & Kulke, 2004; Hinckley & Packard, 2001, Le Dorze, Tremblay & Croteau, 2009). The relationship between the experience of aphasia and the family however is a bi-directional one and both clinicians and researchers recognise that the family, and the emotional and material resources therein, can to a large extent shape the experience of aphasia.

2.3.4. Aphasia and the broader society

Aphasia creates a situation of social disruption, shifting 'one's place in society' (Lafond, Giovanni, Joanette, Ponzio and Sarno, 1993, 216) and changing the nature of social roles and responsibilities (Code et al, 1999; Parr et al, 1997). Further, as social evaluation and validation occurs through the medium of language, adults with aphasia are often perceived to be incompetent (Duchan, Maxwell & Kovarsky, 1999; Kagan, 1995). As a result, aphasia impacts upon how one is able to relate to and operate within the social structures of the world. Employment opportunities are restricted and consequently aphasia can mean financial ruin or the interruption of a career path. There is loss of leisure pursuits, loss of opportunities to participate in social and community activities and loss of autonomy – where the verbal world is mediated for adults with aphasia by supportive others and decisions are by necessity made on behalf of the person with aphasia (Davidson, Worrall & Hickson, 2003; Hinckley, 2002; Parr, 2001; Simmons-Mackie & Damico, 2007).

In the social approach the loss of opportunities to participate in the social structures of society as the result of language loss is considered to be a function of societal limitations. Parr et al (1997) highlighted the numerous disabling barriers faced by people living with aphasia, conceptualising these barriers as environmental, structural, attitudinal and informational in nature. Environmental barriers are those barriers that sideline people with aphasia from the language environment. They primarily include the rapidity, complexity and abstraction of everyday spoken language. Structural barriers exist in the media of language. These barriers are compounded by attitudes towards disablement, differences and aging. Societal notions of communication as a reflection of cognitive and personal competency may also form the building blocks of these attitudinal barriers. Additionally adults living with aphasia experience informational barriers. Accessing both written and spoken information limits opportunities for learning and opportunities for negotiating services and support. Pound and Hewitt (2004: 163) further suggest time as a significant barrier to both social transactions and interactions. According to Parr et al., (1997) these barriers do not only create the situation of social disruption described above, they also engender a sense of vulnerability and powerlessness for adults living with aphasia.

The identification of barriers and facilitators to social participation and inclusion has underpinned much work in clinical aphasiology in the Australian context (for example, Ashton et al, 2008; Brown et al, 2006, Howe, Worrall & Hickson, 2008a + b). Recently these barriers have been explained in terms of interactional principles that drive theoretical models of social action (Simmons-Mackie & Damico, 2007).

2.3.5. Theoretical frameworks

In the preceding section, I have described in brief the psychosocial consequences of aphasia against realms of experience. I have conceptualised these realms as layers of the lived experience of aphasia. Each layer represents both the context of

aphasia and the moderating influences on the course of this condition. Aphasia, as Shadden (2007) states, produces an unsettled life and qualitative research has afforded clinical aphasiologists the tools to understand this experience. The personal, familial and social losses associated with aphasia are now well documented.

These studies have emerged from a new tradition in clinical aphasiology that reflects an alliance with disability studies and its political agenda for improving the lives of people living with aphasia. Two broad approaches appear to distinguish this body of research. The first approach is interactional and is framed in sociolinguistic theories of the processes of human interaction. Studies are concerned with the changing nature of conversation in the face of language impairment and the implications of this for the lived experience of aphasia. The second, and predominant approach is that of the insider perspective. This approach shifted the analysis of aphasia from an interactional experience to a subjective and personal one. Framed within the larger sociological study of the illness experience, these studies explore the meanings patients ascribe to their illness, their subjective reports and cognitive representations. The conceptualisations of biographical disruption (Bury, 1982) and loss of self (Charmaz, 1983) underpin these explorations into the devastating consequences of aphasia, but studies have also noted the positive actions of those affected by illness and recognised that patients and their family are not passive victims, but their own agents in dealing with chronic illness.

A dominant theoretical framework in the interpretation of these studies is that of the International Classification of Functioning (ICF), a World Health Organization manual that classifies disease and its consequences. The ICF has been defined as a multipurpose classification tool designed to serve various disciplines with the aim of providing a scientific basis for understanding and studying health and health-related stages, outcomes and determinants (WHO, 2001). It provides a description of impairments (abnormalities in the structure or function of the body), activity limitations, participation restrictions and the

environmental and personal factors that contribute to a health condition (WHO, 2001). Disease is described in a linear model, wherein disease causes impairment which in turn limits activity (disability) and restricts social and economic participation (handicap). Although widely applied in recent aphasia research, I believe that this framework, far from enriching our understanding of the psychosocial aspects of aphasia, has deflected attention from the context of aphasia, specifically the inner psychological world and the outer cultural world of the illness experience. I draw from Alberts' (2002) research to exemplify. Alberts used semi-structured interviews to investigate the consequences of aphasia for fifteen adults at different stages of post-stroke recovery through documenting their life needs and coding these needs according to the ICF[11]. Recurring themes in her data included empathy, tolerance, awareness, acceptance, and overprotection (all arguably cultural variables), which were collapsed and coded under the category of 'support and relationships' within the ICF, leaving little if any room for capturing both the personal dimensions of language disability and the cultural processes intrinsic to these social values, acts and experiences. Penn's (2005) commentary of the use of the WHO framework in the appraisal of aphasia similarly questions the displacement of the personal meaning of aphasia onto abstracted codes and the neglect of cultural processes in explaining both the genesis and significance of participatory restrictions.

As a result, many of these studies are contextually thin and, although Sarno (1993) has long cautioned that the experience of aphasia cannot be viewed as separate from the context of the lives of those who live with the condition, the profound ways in which sociocultural processes shape the experience of aphasia are yet to shape the understanding of aphasia as a psychosocial disorder. This is a discussion I return to in section 2.5.

[11] The 2001 version of this framework, then called the International Classification of Functioning, Disability and Health or the ICIDH-2 was employed.

2.4. The Contribution of Qualitative Research to Practice

From a philosophical standpoint, qualitative studies have prompted clinician-researchers to deconstruct the notion of aphasia as a personal tragedy and highlighted the limits of the medical model in capturing the complexity of aphasia. This has helped us to move beyond medical ideology and recognise the downfalls of a rehabilitation culture oriented to individual limitations and functional inabilities. Insights from qualitative research have broadened our definitions of aphasia both horizontally and vertically and interspersed throughout recent psychosocial literature are descriptions of aphasia as a co-constructed, systemic, dynamic, deeply subjective illness. In addition, the literature is no longer dominated by documentation of the problems facing aphasics and their families, but attention has also been directed to the processes of adaptation to and accommodation of the aphasic experience (La Pointe, 1997).

Importantly too, I believe that qualitative enquiry has initiated a process of introspection and personal growth in therapists and there is burgeoning interest in the processes of the therapeutic relationship. Here, ethnographic investigation has highlighted that the clinic is indeed a unique social context and the relationship between clinician and client is influenced by power and reciprocity (Horton, 2007; Parr, 1996; Pound, 2004; Simmons-Mackie & Damico, 1999). These are important insights for the aphasia therapist concerned with collaborative and democratic models of intervention.

Similarly, qualitative research has empowered people with aphasia in various ways. Collaboration in research and in the establishment of intervention programmes is favourable practice and the 'voice of aphasia' has entered our academic journals where 'their fragmented, condensed, non-standard language (is) often used to powerful and poetic effect' (Parr, 2001).

Qualitative research has also informed clinical practice. Not only in terms of therapy initiatives such as training conversation partners (Kagan, 1995, 1998;

Lyon, et al., 1997, McVicker, Parr, Pound & Duchan 2009); addressing the needs of carers (Servaes, Draper, Conroy and Bowring, 1999); facilitating group work (Elman, 1999); establishing support networks (Kagan & LeBlanc, 2002; Lyon et al., 1997); promoting advocacy (Elman, Ogar & Elman, 2000); and addressing participation barriers, particularly in the health care context (Hersh, 2008; Parr et al., 1997; Pound et al., 2007; Simmons-Mackie et al, 2007) but also in terms of providing us with tools, such as narrative enquiry, ethnography and conversation analysis, to approach questions regarding the experience and management of aphasia in various social and cultural contexts (Le Dorze, Croteau, Brassard & Michallet, 1999) and to address the complicated byproducts of aphasia such as identity change and disrupted biography (Hagstrom, 2004; Shadden and Agan, 2004). As Lyon (1999) emphatically states, 'these methods mean the possibility of eliminating nongeneralisable clinical notions by first looking for and incorporating reasonable ways that people confronting aphasia are already coping with everyday life' (ibid: 698).

Similarly with regard to assessment, qualitative research has not only prompted the refinement of socially valid assessment measures[12], but also cultivated scepticism around the objective assessment of social-emotional issues. Outsider-driven frameworks for assessment and interpretation have been criticised for their inadequacy of predicting everyday social reality for aphasic individuals (Oxenham, Sheard and Adams, 1995) and there is growing recognition that the field needs to draw on theoretical bases in the development of assessment approaches (Chapey, 1992; Parr, 2001, Penn, 1999) and use powerful ethnomethodological tools, such as conversation analysis and ethnography, in individualised assessment (Parr, 1996; Tetnowski and Franklin, 2003).

Pound (1998) proposed that, until recently, clinical researchers have not addressed long-term social consequences of aphasia because of an absence of appropriate theoretical frameworks to guide thinking about disability and handicap level therapies; an absence of acceptable and meaningful outcome measures, which

[12] For example see Doyle, McNeil, Le, Hula and Venture (2008) and Rautakoski, Korpijaakko-Huuhka & Klippi (2008).

relate to both the explicit aims of therapy and to the complexity and diversity of change in the individual with aphasia's emotional and psychological well-being; and a profound difficulty on the part of the clinician to step outside the predominant culturally determined attitudes and beliefs about disability. There is much recent evidence to suggest that qualitative research has provided a more appropriate framework of interpretation than what has been previously proposed (for example, the WHO's International Classification of Functioning remains anchored to medical categorisation); has offered a number of evaluation methods (Cunningham and Ward, 2003; Pound et al., 2001; Simmons-Mackie and Damico, 2001) and has further sensitised clinician researchers to both context and conversation (Penn, 2004), thereby moving us beyond the clinical domain.

2.5. Unexplored Issues: Relational Dynamics and the Cultural Context of Aphasia

Some issues however remain unexplored. Firstly, as the focus of many of the studies is cognitive, I believe that the mutual influencing of the internal and external realms of aphasia has been largely underplayed. A key concept in psychosocial theory is that the internal psychological world is influenced by family and society - thoughts, responses and perspectives are to a large extent shaped by societal attitudes and norms and there are psychological impressions of class, race and gender closely linked to identity (Hoggett, 2006). Equally, the internal world contributes to both social sentiment and group behaviour, making relational dynamics relevant to understand. Hoen, Yoelander and Woseley (1997) and Lyon (1992) have shown how family is only the first level of a broader series of interactions that define norms and values and people draw on their cultural background in order to understand their experience.

Secondly, although this body of research has directed attention to notions of coping and accommodation, there has been limited acknowledgement that material and social conditions impact heavily upon how individuals are able to grasp and manage problems. Put another way, recent studies in aphasia have

overlooked the relationship between environmental constraints and social demands upon an individual's space in which to make choices and act. Although there is an emerging understanding that long term outcomes in aphasia are influenced by age (Dalemans, De Witte, Wade & Van den Heuvel, 2008) marital status (Croteau & Le Dorze, 1999) and social networks (Hilari & Northcott, 2006), there remains little empirical evidence that aphasia outcome is influenced by quality or quantity of support.

Similarly, there has been limited acknowledgement that strain on carers and family members is bound to both the interaction stresses associated with aphasia and, as Tomkins, Spencer and Schulz (1999) note in their response to Servaes et al's (1999) article, to variables existing outside of aphasia. Studies that have taken into account broader variables affecting strain and psychosocial responses of carers of people with aphasia have considered coping style, an essentially medical concept. Cant (1999), himself a social scientist living with dysarthria following a stroke, suggests that such studies cannot capture the complexity of the carer's experiences and how this experience is influenced by the geographic and socioeconomic context. Ethnographies of care have shown that care of disabled individuals is less a function of attitudes than of financial resources within the family (Ingstad and Whyte, 1995: 18) and that conditions of poverty confound the implementation of sociopolitical rights and supportive infrastructure for disabled people (K.S. & Duncan, 2006: 303).

There are strong arguments in the disability literature and in sociology for researchers to take cognisance of socioeconomic conditions and material resources when trying to understand the real-life dimensions of illness and disablement. In sociology, research has highlighted economic resources as the most important variables affecting illness behaviour (Young, 2004). Increasingly, sociological studies into the illness experience have taken socio-economic variables into account. For example, Pound, Gompertz and Ebrahim (1998) looked at the impact of stroke in an elderly, working class community in the East End of London and showed how accumulated life experiences, particularly

hardships and suffering, mediated response to illness. Although the participants of this study endured devastating functional consequences on everyday life as a result of their stroke, they did not view the experience as particularly disruptive, but rather as normal within the contexts of their hard lives. Watson (2004), whose research among disabled adults in both urban and rural African communities in South Africa, considers occupation[13] and chronic illness in the context of poverty, describes the juxtapositions between disability, poverty and occupation. Poverty creates a monotonous life over which people have little control, choice and variety in activity, and this affects in a profound way the extent to which people are able to be resourceful in the face of disabling illness.

Thirdly, although there is reference to the relevance of cultural processes in psychosocial literature (for example, Lafond, Giovanni, Joanette, Ponzio & Sarno, 1993), recent qualitative studies do not explore cultural variables on the course of this disabling condition. For me, as a clinician-researcher working in a diverse African society, this has been a critical oversight. Culture is both the context of our lives and the lens through which we interpret our experiences and create meaning. Helman defines culture as

> … a set of guidelines (both explicit and implicit) that individuals inherit as members of a particular society, and that tell them how to view the world, how to experience it emotionally, and how to behave in it in relation to other people, to supernatural forces or gods, and to the natural environment (2000: 2) …,

Culture is therefore integrally linked to the experience of communication and communication loss; shaping interpersonal spaces and relationships between language skills, identity, social roles and responsibilities. It is also integrally linked to the experience of illness and disability, shaping the nature of both formal and lay care. In a related way, the concept of disability in itself is a cultural construct. Ingstad and Whyte (1995: 10) argue that biomedical and legal

[13] Occupation in this regard is defined as 'what people do, how they spend their time and energy, and what captures their attention'. (Watson, 2008: 8)

institutions in Europe and North America have largely shaped the construct of disability as it understood in sociological literature and this is likely to be the same for aphasia, where much of the psychosocial literature explores the lived experience of aphasia for people who experience their condition in a biomedical and rehabilitative environment. In addition, the collective context, such as prevailing historical, cultural and socio- political influences, affects how individuals experience illness and ascribe meaning to their conditions. For example, disability activism has engendered a more positive image and experience for people with disabling conditions (Lawton, 2003).

Despite this, I believe that the cultural context has been poorly conceptualised and inadequately addressed in the social approach in aphasia: cross-cultural perspectives remain limited and related research has not fully exploited the relevant theoretical bases of sociology and anthropology to explore culture and the corresponding variables of social networks, attitude, religion, gender, socioeconomic status and health beliefs. In this way, these qualitative pursuits have produced what Kleinman (1988: 28) describes as `thinned out images' of the person with aphasia.

2.6. South African Research into the Cultural Context of Communication Disorders

There have been a number of recent studies in South Africa that have considered the cultural context of aphasia and other communication disorders. These have been on the back of transformation in South Africa's socio-political landscape and in the profession of speech and language pathology, where cultural competence has assumed an increasingly important role in the delivery of therapy services. Pioneering this research in aphasia in South Africa is Claire Penn, who has long argued that cultural variables may be key to long term outcome in aphasia. Penn has turned her attention to the culturally-bound linguistic features of aphasia such as code-switching and compensatory behaviours in bilingual aphasia, and to

culturally-bound communication practices, such as the narrative. Her premise is that a diverse cultural and multilingual context needs to be harnessed for opportunities and facilitators in the clinical realm (Penn, 2007). Most other studies however have been concerned with the documentation of causative beliefs and traditional healing practices (for example Baboo, 2001; Bham & Ross, 2005; Dagher & Ross, 2004; De Andrade & Ross, 2005; Mosese, 2001; Penn, Jones & Milner, 1992; Platsky & Girson, 1993). Framed in health beliefs theory, these studies have considered culture from a utilitarian perspective. This, according to Good (1994: 42) is a perspective that culture is a single and constant variable about which people can be selective. We know from these studies that the diverse South African population holds equally diverse beliefs about the causes of language disorders; that some of these causative beliefs draw on cosmological understandings and that as a result people seek various forms of healing for aphasia and other communication disorders. But these studies only scratch the surface of cultural factors in the lived experience of aphasia and many important questions remain unexamined in the local literature. These include questions about the nature of frameworks of interpretation and care, about mechanisms of support and about the challenges for adults living with aphasia in their particular setting. None of these studies acknowledged the many interfaces between cultural practice and time, space, circumstance, choice, resources and methodology. All presented healing practices as fixed, as traditional and as largely psychologically beneficial to clients.

Swartz' (2006) critique of local mental health research is relevant. According to Swartz (2006), survey-type studies that document beliefs and attitudes tend to neglect the fact that health beliefs and indigenous knowledge have already been documented. He questions continuing literature that draws on abstracted and romanticised ideas of 'culture' in South African mental health studies and the lack of sufficient engagement with questions of evidence. In addition, Swartz (2006) contends that the abstracted study of indigenous beliefs and culture needs to be counterbalanced against the daily reality for most South Africans. He raises the fundamental paradox in that the very people to whom we ascribe a particular

'indigenous' or 'traditional' position, and assume that their frameworks are associated with something that has a long history and are immutable, are commonly those who lead the most disrupted and fragmented lives—people who, because of poverty and oppression, are most at risk of having their lives thrown into instability and turmoil for a range of reasons.

What seems needed is research that critically explores the relational and contextual (specifically cultural and socioeconomic) dimensions of aphasia, a way of thinking about the psychosocial impact of aphasia that will balance individual and psychological dimensions of language loss with an understanding of economic and sociocultural conditions.

This is particularly pressing in the South African context where the majority of adults living with aphasia live in conditions of poverty. The individualistic and cognitive focus in clinical aphasiology may be more logical in highly individualised cultures and in societies where people are free agents. In poor urban black South African communities, experience is closely linked to environmental, sociopolitical and cultural phenomena. Moreover, in South Africa, the majority of adults living with aphasia live in a linguistic and cultural reality far removed from the clinic. Illness may be understood within a spiritual framework and the use of traditional healing practices is commonplace. Preliminary data shows that supernatural beliefs extend to the beliefs surrounding communication disorders (Baboo, 2001; De Andrade & Ross, 2005; Mosese, 2001; Penn, Jones & Milner, 1992; Platsky & Girson, 1993).

In today's changing health care environment, where community-based rehabilitation is promoted, a cultural and relational understanding of aphasia is of more than academic interest. Unless interventions are designed in a culturally appropriate way with consideration of the material demands of care, the opportunity to bring about effective change may be lost (Groce, 1999: 38). In addition, a sensitive understanding of the culture of others reduces communication barriers in a cross-cultural interaction (Chick, 1995: 238) and examination of the

cultural context of aphasia will put the South African speech language therapist in a more potent position to practise relevant and empathic care.

The question that arises now is what will enable this broadened understanding?

2.7. The Cultural Context of Aphasia

At the outset of thinking about this chapter, I was convinced that I would argue for a methodology, one that stood out from other qualitative methods, in its relevance to understanding the lived experience of aphasia in a black urban South African situation. However, reflecting on the contribution of recent qualitative studies to the psychosocial dimensions of aphasia and how they fall short for me as a clinician-researcher in my particular setting, I am not convinced it is a particular methodology that is needed. These studies have demonstrated that all qualitative methods hold value in furthering our understanding of aphasia and their application in a cross-cultural context seems appropriate. Moreover, social scientists now advocate a melding of methodologies (Flick, 2002: 226) and there is increasing evidence of such a melding of methods in aphasiology (for example Howe, Worrall & Hickson, 2008a + b).

What is needed however is a new way of thinking about the nature of the lived experience of aphasia and a new sensitivity to qualitative research. Aphasiology literature depicts aphasia as a multilayered disorder, one that affects psychological well-being and social interactions. Earlier I represented these layers of aphasia within a concentric circle model, where the ever-widening circles represent the various realms of both experience and influence of aphasia. The cultural context, I believe, needs to be conceptualised as an important part of this layering. Indeed research that extends to this context may well demonstrate that culture is the context in which all other realms are integrally embedded, highlighting that thinking about the cultural context of aphasia means thinking in a relational way. I propose a model of the lived experience of aphasia, presented in Figure 2 below,

that includes culture as the outer layer that envelopes the psychological and social domains and recognises that these layers mutually influence each other. For example, the cultural context will relate to the value placed on speech and social communication within families and societies. The cultural context of the lived experience of aphasia may also include how people understand their condition and make meaning of language loss, the strategies that people employ in order to seek help and the responses of families and communities to people living with communicative disability.

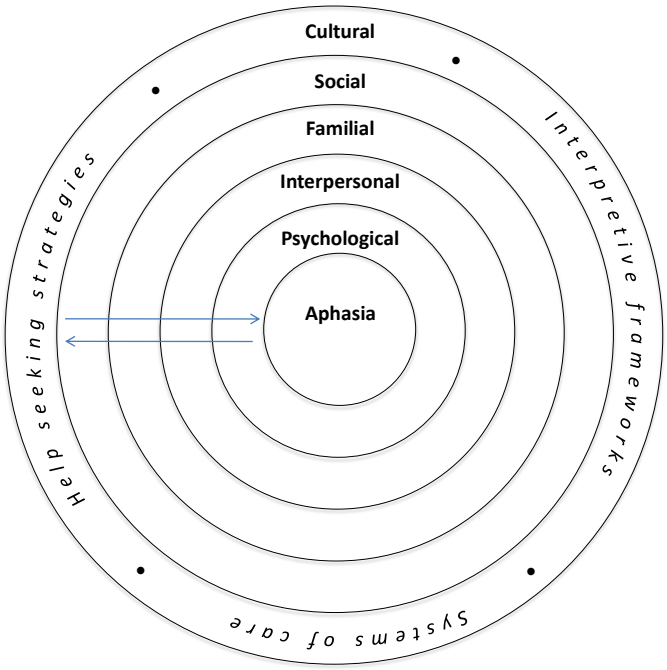


Figure 2: The cultural layer of aphasia

Thinking about aphasia in this way however demands a shift in the approach to research and a way of thinking about research findings that is different to what has come before. Previous research has implicitly regarded the psychosocial aspects of the disorder as universal and there appears to be a preoccupation with the development of 'objective' measures and metatheories. Previous research has also largely drawn on the discipline of sociology as an interpretive paradigm,

highlighting microsociological processes as important variables in the lived experience of aphasia. Thinking culturally about aphasia, on the other hand, is about thinking contextually (in terms of place) (Swartz, 1997: 261) and relatively (in terms of time) (Comaroff & Comaroff, 1993: xxxi). With a cultural lens, the lived experience of aphasia is not easily separated from the sociopolitical and cultural circumstances of people's lives. Universal perspectives need to shift to local understandings. Subjectivity needs to be valued over objectivity. The broader context of circumstance needs to be articulated. These are not new arguments in qualitative research (Flick, 2002: 2) but their application to the study of aphasia in context is timely.

2.8. Conclusion

The title of this chapter, 'Conceptualising and contextualising aphasia', reflects the ever broadening field of clinical aphasiology, which has drawn on multiple theoretical perspectives and employed a range of methodologies in order to understand this condition in all its dimensions. Two broad approaches in recent literature are discerned, that being the interactional approach and insider perspective research. I propose a third approach, a cultural approach, also driven by the social needs of the adult with aphasia and by service delivery transformation, but distinct in that it is grounded in sociocultural theory. At the centre of this approach is the broadened perspective that people exist in the context of cultural phenomena, social conditions and structural constraints. How does one study aphasia from such a perspective? In the following chapter I explore context-relevant frameworks of interpretations and approaches to research.

CHAPTER THREE
A CULTURAL FRAMEWORK OF INTERPRETATION

3.1. Introduction

In Chapter Two I argue for a broadened perspective of aphasia, one that considers the cultural context in research aligned with the mission of the social approach. I also argue against the study of purportedly cultural aspects of communication disorders from a reified and bounded notion of culture, and the documentation of traditional management of communication disorders without critical engagement. It is with these precepts that I turn to the discipline of anthropology, specifically medical anthropology, and in my study I have drawn on its theoretical and analytic tools. In this chapter, I consider in more detail anthropological notions of culture. I also review the domains of medical anthropology and some of their associated tools of analysis. In doing so, I hope to establish for the reader some of the perspectives that framed this study.

3.2. The Cultural Context

As a point of departure I feel it is important to clarify what I mean when I distinguish the social context of aphasia from the cultural context (see figure 2 in the previous chapter). Following essentialised theories of social interaction implicit in the social approach to aphasia, I present the social context as the context of human interaction, the medium of which is primarily conversation and the organisation of which is the family and broader society, whereby society interchangeably refers to the locus of interaction, to public spaces and to people in general. Although the field of speech and language therapy and clinical aphasiology gives primacy to the social context and regards culture as one aspect of this context, this is not the perspective of culture that I describe. Following a basic premise of the discipline of anthropology, I present culture, not as an aspect

of interaction, but rather as the overriding system that structures all of society and all of the interactions that occur within it.

What therefore are some of the notions of culture that underpin anthropological understanding? I draw here on Helman's (2000) explanations in his textbook introduction to the scope of medical anthropology. Helman at the outset of this discussion acknowledges the many definitions of culture in operation in anthropology. In my own broad stroke reading of the larger discipline it would seem that defining culture is a contentious issue, but nevertheless Helman's basic description of culture as a set of guidelines and as a lens through which we perceive and understand the world seems to embrace the anthropological perspective. Importantly however this lens is understood to be variable across time, person and place. Cultural precepts are neither 'homogenous' nor 'static' nor entirely correlated with the actions of people (2000: 3). In addition, Helman describes how culture interfaces with economics, politics and pragmatism and it cannot be considered in a vacuum. This is what Helman refers to as the cultural context.

I also draw on Geertz (1973: 5) notion of culture as a web of significance, partly because it is foregrounded in many contemporary anthropological writings, and partly because like Helman's description it provides a blueprint for interpretation of data. Geertz' in a series of essays of culture, peels away the layers of language, dress, ritual, objects and social behaviour, to describe culture, not as a set of patterns or requisite behaviours, but rather as a control mechanism that governs this behaviour. Geertz writes that the function of this control mechanism is to orient man to his existence and to create meaning (ibid: 44). According to Geertz, therefore, the interpretation of culture is, at its essence, a search for meaning.

I have attempted to apply these definitions to the study of the cultural context of aphasia for adults living with aphasia in Khayelitsha. In doing so, I have drawn on a body of anthropological research to guide both method and interpretation. Much of this research is positioned within the particular domain of critical medical

anthropology. In the following section therefore I broadly describe the basic domains and applications of medical anthropology, a branch of anthropology concerned with the cultural context of disease, illness, sickness and medicine. In keeping with a central precept of the discipline that experience is situated in both time and place, I have structured this review in a more or less chronological fashion. I acknowledge that there is a wide range of theoretical perspectives in medical anthropology and the broader discipline of anthropology itself. Domains certainly overlap[14] and the frameworks that I present are only one way of categorising studies and historical movements. I have looked to these frameworks as they appear to have relevance for my study.

3.3. Medical Anthropology in Brief

Helman (2000: 4) describes medical anthropology as a broad spectrum of enquiry, ranging from the study of cultural and social groups, of which health and healthcare is an aspect, to the study of sociocultural influences on biological processes. Medical anthropology is a bridge between the social and biomedical sciences. It has moorings to biomedicine in terms of disease classification and it draws on conceptual systems developed for understanding broader phenomenological domains. It also draws on conceptualisations in medical sociology in order to understand health beliefs, health practices and the lived experience of illness. Medical anthropology is described as a theoretical, applied or critical science. These broad distinctions reflect in some ways historical periods in medical anthropology, with each period reflecting characteristic methods of research and interpretive frameworks. I turn now to a description of each respective approach.

[14] There is overlap too between sociological of health and illness and medical anthropology.

3.3.1. Ethnomedicine

Fabrega (1971) defines ethnomedicine as the theoretical enquiry into interpretive frameworks, healing practices, rituals and the management of misfortune in particular cultures. This approach in medical anthropology[15] includes ethnographic accounts of how people (particularly non-western communities) explain their distress and illness, often blaming social circumstances, relationship problems, witchcraft or sorcery, or a broken taboo. Ethnomedicine also explores the social organisation of groups to better understand the position of the ill in broader social networks and their treatment in society using ethnographic frameworks of research and interpretation.

Fabrega (1971) in a review of medical anthropological research between 1963 and 1971 describes the five broad, but overlapping emphases of this branch of medical anthropology. Firstly, according to Fabrega, there are ethnomedical studies that are broad in character and that give principal attention to general beliefs and definitions of illness. The premise of this branch of research is that medical beliefs are constituents of the general philosophy of a culture. These studies include descriptions of how illness is defined and managed within cultural groups and documentation of the cultural symbols of illness and causal beliefs. These broad ethnomedical studies once focused on health beliefs in rural villages, untouched by global trends and the processes of acculturalisation. More recent ethnomedical studies of this character however emphasise traditional healing practices in the face of social and cultural change and the sociocultural implications of competing medical systems (for example Teuton, Dorwick & Bentall, 2007 and Wreford, 2008). Nichter (1992: x) writes that ethnomedical studies that have focused on illness beliefs, illness classifications and health care seeking are frequently concerned with cross-cultural and comparative analyses.

According to Fabrega (1971) the second category of ethnomedical enquiry includes descriptions of culture-specific syndromes. These studies describe the

[15] Nichter (1992: ix) however argues for the recognition of ethnomedicine as a field in its own right. Medical anthropology he writes is the applied study of medicine and anthropology.

manifestations of these particular disorders and the process of diagnosis and treatment. Some studies attempt to relate these syndromes to cultural patterns and the social context. In these descriptions, emphasis is placed on social and interpersonal dimensions of syndromes as opposed to biological processes, and behaviour is interpreted within psychiatric frameworks. Examples include *nervios* or *ataques de nervios* in Latin and South America. Lund and Swartz' (1998) description of psychosis and *amafufunyana* provides a local example.

The third emphasis of ethnomedicine involves the study of the context of healing practices, such as the traditional health practices within urban settings or the pluralism practised by the emerging middle class in non-western societies. The fourth category of ethnomedicine incorporates rich descriptions of actual practices. These include traditional healing, religious conversion, curing ceremonies and rituals. These studies are descriptive in nature and may emphasise the emotional factors involved in healing practices, such as hope or faith. Linked to this category is the fifth broad area of study, and that is the personal characteristics of healers. In these studies 'shamanistic' practitioners are described against their roles, methods, intentions, knowledge, recruitment practices and personalities. These studies attempt to explain the basis of the healing powers of these individuals.

Ethnomedicine has been criticised on a number of levels. Firstly according to Fabrega (1971), discourse and special examination of the vocabulary of illness, symptoms and healing is neglected and few studies incorporate structural linguistic approaches to understand a culture's semantics of pain, symptoms, biological change, illness and health. Secondly, ethnomedicine has been criticized for operating from the vantage point of what is conceptualised as 'western'. Worsley (1982) however questions the reality of the distinction between western and non-western approaches and the very conceptualisation of non-western medical systems. According to Worsley (1982) non-western may be a dubious assumption, which firstly implies that the systems under study share a common approach and secondly fails to consider that there has been a bi-directional flow of

knowledge between east and west for centuries. Worsley is also critical about the assumption that the systems under study are medical, highlighting that ethnomedicine does not deal with illness per say but misfortune in a broader sense. Comaroff (1981) writes that studies in ethnomedicine that consider illness beliefs or stock responses to illness as a discrete domain of enquiry are a form of theoretical closure. She describes such descriptions of illness and healing as disembodied, offering little in the way of meaning and cultural significance.

Nevertheless, ethnomedicine has provided a rich understanding of cultural health beliefs and responses and provided new perspectives – that of the cosmic framework, the interdependence of nature, the supernatural, person and society, and the critical value of the social network in healing (Worsley, 1982). Ethnomedicine cannot provide a model of traditional health systems that is universally valid, but research into the cultures of sub-Saharan Africa, pre-Columbian America, jungle tribes in the Amazon and Australian aboriginal societies, provides evidence enough that in these societies illness is not explained as a biomechanistic breakdown but as a disequilibrium in the delicate relationship between man, his social matrix, nature and the supernatural. Therapies include faith healing, divination, herbalism and shamanism. Magic, witchcraft and sorcery also have their place. Ethnomedicine has certainly enhanced appreciation of the great diversity of medical systems in existence worldwide and has built the capacity to examine critically and compare different systems of thought and behaviour.

However Nichter (1992: ix) writes that these subjects are but points of departure in ethnomedicine. What is really at stake in the documentation of illness and healing in everyday life is the evolution of theories of normality, of ideologies, of the production of knowledge and of the embodiment of suffering and power. In this way, ethnomedicine continues to have an important place in medical anthropology. Non-industrial cultures are in the throes of massive social upheaval and processes of urbanisation have changed structural operations. Nevertheless traditional healing practices remain commonplace, and not only in rural areas. In

fact some contend that there is an upsurge in the use of traditional healing practitioners as urbanisation brings its own particular afflictions (Pfeiffer, 2002). In peri-urban areas characterised by poverty, violence and a breakdown of family structures, faith healing practices have proliferated and fears of witchcraft and sorcery are heightened (Ciekawy & Geschiere, 1998; Comaroff & Comaroff, 1999). Although beliefs appear resilient, some practices are new, particularly healing practices of evangelistic churches, and many are idiosyncratic. Methods shift and mould in response to current sociocultural processes, transculturation and larger political imperatives as Linda Thomas (1999) demonstrated so powerfully in her ethnography of ritual healing of St John's Apostolic Faith Mission Church in Gugulethu. In addition, medical pluralism is, albeit mostly informally, the standard approach to health care and composite accounts of the social and cultural meaning of illness have become the focus of study (Singer & Baer, 2007: 121).

3.3.2. Applied clinical anthropology

Clinically applied anthropology emerged in post-World War II America as an auxiliary to biomedicine. Following the 'trails blazed by sociologists' (Hahn & Kleinman, 1983: 305), medical anthropologists used sociological conceptualisations to explore biomedical practice – its domains, divisions of labour, social organisation and discourse – to provide new perspectives and discern links between the practice of biomedicine and political, religious and social currents. Clinically applied medical anthropology is concerned with health service delivery and aspects of health and illness in the clinical setting, including patient's responses to medical procedures and forms of treatment. Linked to this domain of study, medical anthropologists also borrowed methodologies and conceptualisations from medical sociology to explore health related beliefs and practices within their own industrial societies - sociological concepts of lifestyle, coping mechanisms and stress were possibly more suitable to apply to western (American and European) societies than the ethnographic framework developed

for understanding sickness in structurally simple, kinship based societies. Although this approach has been criticised for relying on American middle class concepts such as 'coping mechanisms', 'socioeconomic status', 'lifestyles' and 'stress' and for displacing political and economic determinants of sickness (Young, 1982), it engendered conceptual systems that remain central to the discipline of medical anthropology. These are centred on the 'social and experiential peculiarities of sickness and healing' (ibid: 261) and include the distinctions between disease and illness, and curing and healing.

Young has called this body of research the anthropologies of illness and sickness. Underlying this domain of the broader field of medical anthropology is the understanding that human illness is essentially semantic, highly personal and meaningful and that as a consequence clinical practice highly interpretive. Arthur Kleinman is possibly the most influential researcher in this domain of medical anthropology and his writings certainly the most prolific. For this reason. I look to Kleinman's writings and his conceptualisation of the explanatory model to define the anthropologies of illness and sickness as studies within their own right.

Kleinman, a psychiatrist and medical anthropologist, has studied social roots of disease, the doctor-patient relationship, culture and health care, and the moral basis of medical practice for more than three decades. Kleinman's predominant interest in medical beliefs and practices is clinical. He concentrates on core clinical functions, that is, how systems of knowledge and practice enable people to construct illness as a psychosocial experience, to manage illness through semantic networks, to provide therapy and to cope with outcomes (Kleinman 1981; 1988). Kleinman's premise therefore is that illness is an adaptation process guided by a set of culturally bound beliefs, which relate to etiology, onset, pathophysiology, course and treatment (1988: 18). Kleinman calls this set of beliefs the explanatory model, a highly personal, dynamic and culturally moulded model that creates order and meaning and provides a plan of action for sufferers of illness. Kleinman's scheme of disease and illness has become a standard framework for understanding the lived experience of disease and his concept of

the explanatory model has launched a research tradition[16]. This research is also termed interpretative anthropology and is concerned with the individual level of the patient experience.

More specifically, Kleinman's (1988: 121 - 122) explanatory model is the meaning that illness holds for a person. Meaning is vested in symptoms and illnesses have particular cultural, personal and social significances. Both patients and clinicians hold explanatory models, which provide explanations for the etiology or cause of the condition, the timing and onset of symptoms, the pathophysiological processes involved, the natural history and severity of the illness and the appropriate treatments for the condition. Patients' explanatory models are regarded as being idiosyncratic and dynamic and are influenced by both personality and cultural factors. Explanatory models are contextually bound to the social and economic organisation and the dominant ideology of the society in which the patient experiences illness, including the power relations in the doctor-patient relationship.

Kleinman's recognition of explanatory models allows for more creative approaches to study health, to discover patterns of illness and to identify influential variables in the patient's reality. These models have challenged the hegemony of the materialistic, bioscientific medical model as being the only exclusive perspective in health and healing. As Kleinman states, explanatory models held by clinicians tend to be based on a single causal train of scientific logic (Kleinman, 1981: 122 - 136). Kleinman's work has not only sensitised practitioners to the lived realities of illness, particularly chronic illness, but has also provided practical frameworks for use in the clinical setting. Kleinman's method of interview is widely employed.

Related to Kleinman's explanatory model is the illness narrative. A feature of subjective explanations of ill health is that they often take the form of a narrative. Illness narratives draw on both personal story and a repertoire of culturally bound

[16] For example see Bhui, and Bhugra (2002), Lund and Swartz (1998) and Patel (1995).

metaphors and significances - they are the verbal representation of the explanatory model and are becoming increasingly theoretically established in sociology and anthropology. Earlier I have written that the study of narratives provides a method for documenting the existential qualities such as inner hurt, despair, hope, grief, and moral pain which frequently accompany, and may even constitute, people's illnesses (Greenhalgh & Hurwitz, 1999) and for gaining new perspectives on diagnostic and therapeutic regimens (Penn, 2002). In addition, links are made between personal and social suffering and contain reference to changes in social and economic life (Charon, 2004). Illness is often a metaphor for current social problems and past suffering (McKevitt, 2000: 87). This is larger however to a clinical endpoint (Monks, 2000).

The study of narrative in medicine has progressed the understanding of various medical conditions and their sequelae, including social suffering, and is a vital point of intersection among many disciplines (Hyden, 1997; Penn, 2002). Nevertheless Littlewood (2003) contends that the attempt to retell a story of loss or neglect cannot substitute as a form of social analysis and that the narrative tradition in anthropology is a move away from the metanarratives of theory. Littlewood (2003) questions the political imperatives of this method of anthropological enquiry that casts patient as victim and doctor as perpetrator and that celebrates subjectivity and individualism.

The primary critique of Kleinman's anthropologies of illness is that he looks from the clinical setting outwards and he only alludes to the social determinants of sickness (Pappas, 1990). Kleinman's focus on the doctor-patient relationship largely overlooks power relations that reside between social groups and classes. Frankenberg (1980) and Young (1982) contend that anthropologists need also concern themselves with the 'making social of disease' (Frankenberg, 1980: 197) and propose that Kleinman's scheme of disease and illness is expanded to incorporate sickness as a concept that captures the process whereby behavioural and biological signs are given socially recognisable meaning. Sickness therefore is a process for socialising disease and illness (Young, 1982: 270) and it is

sickness that determines the choice and form of medical interventions, and not illness. According to Young (1982) the lived experience of disease is influenced by socially determined knowledge prototypes, it is made real or unreal by social and cultural currents in society.

A relevant framework in this body of research is that developed by Scheper-Hughes and Lock (1987). They contend that anthropological research needs to engage with 'three bodies' to facilitate understanding of the multiple layers of illness. The individual body constitutes the layer of lived experience. The social body encompasses the way in which the individual body becomes a kind of canvas upon which nature, society, and culture is represented. The body politic refers to the regulation, surveillance, and control of bodies in reproduction and sexuality, work, leisure, and sickness.

3.3.3. Critical medical anthropology

Applied medical anthropology has been criticised for remaining auxiliary to the political and economic imperatives of biomedicine. Nancy Scheper-Hughes (1990) contends that it is impossible to separate theoretical debate in cultural anthropology and applied commitment to the health and survival of communities. She instead advocates for critical engagement. This approach, termed critical medical anthropology, refuses the theory/applied divide and moors loose from biomedicine. Critical medical anthropology parallels the emergence in the broader discipline of anthropology of what is termed the new ethnographies. New ethnographies are critical interpretive in their orientation and exhibit awareness of the stories they construct and sensitivity to the relation with the local people who provide information. In contrast to applied medical anthropology, critical medical anthropology is cautious of the systems of authority and domination and exhibits awareness of the changing global environment, which brings all cultures into contact with all others and reveals all societies as always undergoing transformation (Singer, 1990).

The new ethnographies in medical anthropology capture the themes of hunger and poverty, crime and violence, war and affliction and the nature of social suffering through rich and powerful descriptions of everyday lives in the broader context of globalisation, urbanisation, chronic underemployment, social disarray and decreasing standards of living [for example Das et al. (2001), Dettwyler (1994), Farmer (1992; 2004), Scheper-Hughes (1993)]. In this way, critically applied anthropology responds to Mischler's call for social scientists to take up the struggle for social justice (Mischler & Steinitz, 2001) and the new medical ethnographers have been outspoken critics of the dominant system. Critical medical anthropology raises important questions about the impact of global political and economic structures on health and disease. Farmer (2004) for example illustrates through case studies stretching across a number of different lower-income contexts that the real causes of social suffering related in this case to HIV/AIDS, may not be in the illness or disability itself, but in the roots of disabling conditions such as poverty and failed policies. In this way, this approach has expanded the context within which medical anthropology operates by focusing on health care systems in the context of class, race, gender and politics and how they function at multiple levels, being those of patient experience, physician-patient relationships, local health care systems, particularly hospitals and clinics, and the level of global political-economic systems.

3.4. Understanding Aphasia with an Anthropological Toolkit

My study of the everyday reality for adults living with aphasia in Khayelitsha is first and foremost a study in clinical aphasiology. This is its vantage point; it is concerned with acquired language impairment, an essentially scientific and medical classification of altered language ability with the aim of improved understanding and clinical care, based on medical notions of rehabilitation. Anthropologists may baulk; aphasia is a fascinating human condition whereby the vehicle of thought and human interaction is fundamentally altered. I believe it offers a unique window, as a disorder that is neither physical nor intellectual but

manifests as both, into notions of personhood. It was to my surprise that I was unable to find an anthropological study, ethnomedical, social, linguistic or otherwise, that explored the experience of aphasia. But this is not what I have set out to do. I am after all a speech and language therapist, and do not at any point try to situate this study within the discipline of anthropology. What I have attempted to do however is to understand the domains of anthropology, specifically medical anthropology, in order to find the tools therein that may be helpful in my pursuit. In the following section I highlight useful tools and frameworks, situated within the broad domains of medical anthropology that I have described above.

Earlier I suggest that an anthropological definition of culture offers a tool within itself. These definitions are linked to cultural constructivism, the understanding that knowledge and reality are inextricably linked to culture. This notion underpins medical anthropology, particularly pursuits in ethnomedicine. This understanding is frequently juxtaposed against another notion that underpins the discipline, and that is of structuralism, a point of view that regards 'hard-nose ecological relations' (Dressler, 2001: 456) such as sociopolitical and environmental realities as the important things to understand in disease and illness. Structuralism appears to be given primacy in the critical approach in medical anthropology. However, a closer reading of all three domains of medical anthropology (or at least those domains that I make distinct and describe) suggests that most researchers occupy the middle ground between these two general theoretical orientations. For example, the explanatory model, proposed by Kleinman (1981) and Good (1986) among others, is a methodological tradition that is concerned with the cultural views of illness and human social life as well as the structural constraints that shape the illness experience. According to Good (1986: 161) explanatory model research aims to:

> Understand how members of a society bring meaning to those disorders that appear as fundamental and unwelcome realities, how they construe the relationships of those realities to previous and

> concurrent difficulties in their lives, how illness idioms articulate the experiences of the disorders and how individuals seek and engage therapies in an effort to transforms those illness realities.

Such a framework provides a blueprint for enquiry that straddles cultural constructivism and structuralism. This form of straddling is widely cited as having evolved from the philosophies of Bourdieu (1990: 123), which not only advocate for both constructivism and structuralism but also fill the theoretical gap of the intersection between these two stances and how this intersection leaves it mark. Bourdieu views individuals as having agency, that is the capacity to reflect and respond, but recognises that this agency is bounded to structural constraints that reflect larger structures of social, political and economic conditions (Dressler, 2001). In contemporary anthropological studies that take their cue from Bourdieu's views, both agency and structure are regarded as equal forces in shaping how people go about their everyday lives. This is essentially Bourdieu's concept of practice and it has been applied to the understanding of how cultural constructions collide with structural constraints in medical anthropological studies in urban, developing contexts (Dressler, 2001; Obrist, 2003, Obrist, Van Eeuwijk & Weiss, 2003). In these studies, consideration of both human agency and structural constraints in health-seeking behaviours and attention to health practice among poor inhabitants of developing cities proved a valuable means of highlighting the particular health-related challenges of the urban environment and the unique responses of inhabitants, particularly to a pervasive uncertainty.

Lock and Scheper-Hughes's (1987) proposition for anthropologists in pursuit of an understanding of illness to engage with the individual and social body as well as the body politic offers a related understanding to Bourdieu's middle ground. This broad and bi-focal (or tri-focal) theoretical orientation has influenced how medical anthropologists now define and analyse experience, as the 'intersubjective medium of microcultural and infrapolitical processes in which something is at stake for participants in local worlds' (Kleinman & Kleinman, 1990: 275); as something therefore that 'mediates the relationship between

context and person, meaning and psychobiology in health and illness and in healing' (ibid). This orientation also serves to sharpen researchers' awareness of the sociopolitical sphere, which is almost always based on power and resource imbalances, and prompts them to gaze in both directions, from microlevel to macrolevel and back again (Singer, 1989).

Why do I argue that these theoretical orientations seem particularly suitable to the study of aphasia in the context of Khayelitsha, or at least more suitable than those already widely employed in clinical aphasiology, where theoretical frameworks in sociology and psychology have exerted a strong influence? In the introductory chapter to this thesis, I outline my fundamental argument, that being the ever present and powerfully dominating influences of culture and poverty on the lives of adults living with aphasia in this community. Here I offer two additional perspectives.

The first comes from urban health studies. In a review of urban health studies within developing countries between the years 1992 and 2001, Harpham and Molyneux (2001) chart a progression from an earlier biomedical emphasis on prevalent infectious disease caused by substandard water, sanitation and ventilation to an understanding that, although these diseases persist, chronic illness and debility, particularly among the elderly, have become epidemic in these settings and that vulnerability, declining social support and plural help-seeking strategies seem to characterise this illness experience. Harpham and Molyneux conclude that the changing epidemiology of disease in poor, urban contexts demands not only attention from health care providers and policy makers but also a re-assessment of community from social sciences researchers.

The second perspective comes from a conceptual framework offered by Parker and Aggleton (2003) for understanding AIDS-related stigma and discrimination. These authors criticise the widespread application of Goffman's (1963) theories of stigma as an *attribute* and as a *value* in health-related discourses. They argue that the conceptualisation that stigma is a relatively static attitude that can be reduced

by promoting tolerance or empathy fails to recognise the social processes and power relations at play when ill or disabled people experience discrimination in various forms from others. Instead, researchers need to direct attention to social processes and prevalent prejudices in particular localities in order to understand and respond to marginalising and discriminatory practices against people with illness or disability.

These perspectives seem to support the application of an anthropological lens to understand aphasia in the setting of Khayelitsha, and indeed to understand other chronic illnesses within particular societies and particular disciplines (for example nursing or occupational therapy). It is becoming more and more common that other disciplines within the social and health sciences engage with anthropology. One such engagement has been between anthropology and disability studies. I describe this engagement in brief in the following section by drawing largely on the writings of Benedict Ingstad and Susan Reynolds Whyte who have spearheaded this research in Africa. Here I also consider helpful frameworks for my research.

3.5. Anthropology and Disability

While disability seems to be underrepresented in anthropology, the last two decades have seen a growing number of disability theorists and anthropologists using anthropological objectives to explore the world of the disabled person in both developed (for example Ablon, 1996; Atkinson & Walmsley, 1999; Kasnitz & Shuttleworth, 1999; Murphy, 1990; Rapp & Ginsburg, 2001) and developing contexts (Ingstad & Whyte, 1995, 2007; Livingston, 2005). These studies differ from the mainstay approaches in medical anthropology and disability studies in three important ways. Firstly, they have rejected the disembodied view of disability so prominent in disability studies that, whilst successful in politicising disability, has created fragile distinctions between mind and body and between structure and culture. An anthropological account of disability on the other hand

sees impairment as social and disability as embodied. Secondly, they have adopted relativist perspectives about human perceptions of normality, difference, competence and value. This perspective reflects an anthropological one. In contrast, disability studies, with human rights as their conceptual foundation, adopt a structuralist and universalist perspective that gives primacy to activity limitations in the experience of disability. Thirdly, these studies have moved beyond a focus on therapeutics as is apparent in ethnomedicine, to capture how social and community organisation, zeitgeists (including the disability rights movement) and cultural and moral conceptions of personhood and body filter into the everyday experience of disability in a range of contexts and across a range of disabling conditions.

Cross-cultural disability research in developing contexts is largely represented by two collections of works edited by Ingstad and Whyte. The first collection published in 1995 (Ingstad & Whyte, 1995) contains studies which, from the theoretical lens of personhood, consider notions of value, meaning, responsibility, dependence and identity. Emerging from this collection of works is not only the variation in interpretation of disability across cultures, but also the finding that these interpretations and the systems of care for people with disability within particular localities speak more to financial constraints than to moral precepts and cultural practices. For example, Ingstad (1997) debunks the myth that people of Botswana hide their disabled by showing that poverty, lack of support and lack of knowledge is what makes people struggle to cope with the care of a disabled family member and not stigmatising superstitions about the origin of disability or the impairment itself. In their introduction to this collection, Whyte and Ingstad (1997: 3 – 34) outline the anthropological perspective in disability. They write that this perspective includes analysis of social organisation (such as occupational structure, household composition), social position (such as social or economic status or age and gender), egocentric and sociocentric notions of personhood (including the individualistic versus relational notions of personal purpose and value) and historical transformations. In a later volume Ingstad & Whyte (2007) present a series of projects which, from the theoretical lens of embodiment,

describe how disability is shaped by globalising forces. They highlight the role of the disability movement in shaping community-based rehabilitation practices in developing contexts and in establishing rights-based discourses within all corners of the world. This has in turn shaped individual experiences of disability. The studies in this volume, as with the former volume, offer a methodological path for the psychosocial study of aphasia. None of the studies within these collections however offer perspectives on speech and language disability in developing contexts. These missing voices cannot be ignored.

3.6. Conclusion

In this chapter I have attempted to describe some of the broad domains of medical anthropology, domains that I believe offer helpful frameworks for this study and in a more general sense, historical lessons for clinical aphasiologists concerned with the psychosocial dimensions of aphasia. Whilst there are many important insights that the social model of aphasia has brought to our understanding of what it means to live with aphasia, and while the field has thankfully not ignored the personal as a significant part of the experience of aphasia, there is a limitation to the social model. The experience of aphasia is almost certainly entangled in a complex web of social and cultural constructs and structures which require examination beyond what general theoretical orientations in the social model can offer. In a setting such as Khayelitsha, this complex web may exert a particularly strong influence on living with aphasia. Penn (2000) has long argued that the study of communication sciences cannot be easily separated from the study of culture and it may be within anthropology, where cultural and sociopolitical processes are held as central to experience, that we find the tools and theoretical context to deepen our understanding of circumstance and humanity in a cross-cultural, ever-changing and complex environment.

PART TWO

SETTING THE SCENE OF THE STUDY

CHAPTER FOUR
THE METHODS OF THE STUDY

4.1. Guiding Questions

This study aimed to explore the setting and challenge of living for the adult with aphasia in Khayelitsha utilising ethnographic methods. Data was oriented to understanding sociocultural processes and what this ultimately meant for adults with aphasia. As I was committed to constructing an ethnography of adults living with aphasia in Khayelitsha, there was no explicit research question or hypothesis, but a flexible design, underpinned by participant observation, that enabled an understanding of the experiences of the participants. I was guided however by overarching questions around the experience of aphasia and the cultural, social and environmental factors that influence or modify this reality.

In aphasiology, research into the experience of aphasia has frequently included questions around barriers to participation in various life domains such as communication, family life, friendships, work activities, economic pursuits and health care. In Chapters Two and Three I have described the methodological and interpretive frameworks underpinning such studies and have argued that these questions cannot fully approach understanding of aphasia in a different cultural context. Whyte and Ingstad (1995: 3) in the preface to their volume of essays in cross-cultural disability write that in order to understand the experience of disability within a particular context, questions should include those that consider how disability is understood and dealt with within particular societies. Questions that examine the social organisation relevant to disability are also critical. According to Whyte and Ingstad (ibid: 14) such questions include; what is the ability of the family to care for an infirm member? How does the structure of the society incorporate people with impairments? What special programmes, institutions, and organisations exist for people with such disabilities? And, how does impairment interact with factors like sex, age, and economic standing to

create different situations for different people? I felt that these questions were aligned to the three broad concerns of this study (being the social position of the adult with aphasia, the cultural conceptualisation of aphasia and the experience of health care) that I detail in the introductory chapter. These questions therefore aided my decisions around methodology, case and material selection and conceptualisation of interview schedules.

In addition, my central concern was to acquire an understanding of processes of cultural change and the socio-political context that shape the experience of aphasia in Khayelitsha. I sought to uncover the explanatory models that people drew on in order to make sense of their experiences by including the following questions: What are local discourses around aphasia and stroke, what characterises a person's help-seeking journey and how do people interlink their experiences with other aspects of their circumstances? The interest in local explanations of illness, often referred to as the meaning-centred approach, stems back to Good (1977, 1994) and Kleinman (1980) who showed how local interpretations of illness reflect people's experiences, hopes and fears, cultural conceptions of health and the ways in which they make sense of their suffering, frequently by linking it to larger socio-political issues.

Lastly, the question that guided me in the interpretation of my data was what implications derive for the health care professional? In alignment with the new ethnographies, these implications serve as the 'moral of the story' (Goodall, 2000: 122).

4.2. Data Collection

This thesis is based on periods of fieldwork in Khayelitsha. As the violence and targeted crime in Khayelitsha constrained possibilities for continuous participant observation, fieldwork entailed intermittent daily trips in and out of the area over a three year interval. In the following section I describe the various stages of

fieldwork, sampling procedures and ethnographic interviews.

4.2.1. My journey as participant observer

Stage one: Entry into the community

I began my fieldwork by establishing links (and strengthening established links[17]) with healthcare and social services within Khayelitsha. These structures included chronic disease clinics and outpatient rehabilitation services at two community health centres, a number of primary level health facilities, an old age home, a church group, a community-based organisation supporting elderly people and a day care centre for disabled adults. I spent three mornings at the old age home, five mornings with the community-based organisation for the elderly and one day with the church group. I visited five primary level health facilities, spending a morning at each one and spent a period of a month observing the rehabilitation services and chronic disease clinics at the three community health centres in Khayelitsha. Observation and interviewing in all these contexts provided valuable information about the social and cultural setting of Khayelitsha, including constructions of disease and help-seeking strategies, as well as the local factors that shape the nature of health or social service provision. I also observed nurses and rehabilitation workers in the general routine of the day hospital and their respective clinics; joining them on home visits and attending meetings in the hospital setting.

Stage two: Selecting fieldwork companions and informants

The aim of fieldwork in this study was to provide an account of aphasia beyond the context of the clinic. As I have already mentioned, fieldwork in this

[17] As I have already mentioned in the introductory chapter, the rationale for doing this study stems from five years of experience in Khayelitsha in the capacity as supervisor of clinical services for speech language pathology students working at community clinics. Some relationships were thus already established with gatekeepers in the community and my experiences with health and non-governmental services provided me with a broad awareness of issues of relevance to this specific community.

community is however complicated due to both targeted crime and language barriers. My strategy, therefore, was to link with local people involved in social and health services in order to facilitate access to people with aphasia. I accompanied these key individuals to clinics, support groups and home visits. These individuals helped me to identify and recruit adults living with aphasia in Khayelitsha for the study. They were also able to provide me with valuable information regarding the cultural and linguistic context.

Stage three: Selecting participants for the study

Adults experiencing speech and language difficulties following stroke were identified by my fieldwork companions, by rehabilitation workers at one of the larger provincial hospitals and by community members themselves whom I had met over the course of my fieldwork. These adults and their families were, where possible, approached for participation in the study[18]. Not all these people had aphasia. Some had dysarthria, a motor speech impairment with no associated difficulties understanding language or with the formulation of their thoughts. Some presented with intellectual impairments. People with aphasia were largely identified by me on the basis that they presented with difficulties in speaking, in understanding and that this was due to left hemisphere stroke. Of the people that I met that did present with aphasia, there were only a few that I was able to follow up. Further contact with potential participants was prevented by illness, Tuberculosis in particular, and by fluid living arrangements[19]. Following stroke, people moved among kin both within Cape Town township areas and rural Eastern Cape villages.

Longitudinal contact was maintained with five adults living with aphasia in Khayelitsha. Although I have also incorporated observations from others that I met and interviewed over the course of my fieldwork, including people living with aphasia, their caregivers, nurses and therapists, in this ethnography I reflect

[18] Many of the contacts passed on to me proved unavailable due to transient addresses and telephone contact numbers and to administrative errors within the health care referral system.
[19] Refer to 9.3.1.

in particular on these five cases[20]. It is difficult in a small study such as this to suggest that these cases were typical but they were critical, providing insights into the ways in which the social, economic and cultural characteristics of Khayelitsha intersected with age, gender and aphasia in explicit ways. Glaser and Strauss (1967: 37), in recognition of the limits of abstract sampling in qualitative research, define this as theoretical sampling. Theoretical sampling is the process whereby cases are incorporated into the data, not on the basis of predefined criteria, but on what they offer to the researcher and areas of enquiry and I selected cases against the variables of age, gender, confounding disabilities and socio-economic status. This decision afforded me the opportunity to consider the experience of aphasia against the theoretical backdrop of what is known about the elderly, the disabled, the poor and women in this particular society. In addition, critical cases that could provide cultural accounts of aphasia and accounts of traditional healing encounters were integrated into the study. The critical case is linked to Morse's (1994: 226) description of the good informant as someone who can provide unique insights and accounts of particular experiences.

Stage four: Longitudinal observation of cases

I followed each key participant for a period of six months or more and attempted as far as possible to maintain weekly contact with these participants and their families within this time. Whilst my fieldwork contact with each participant varied depending on their circumstances, I spent approximately 90 hours visiting the five key participants in their homes on multiple occasions, observing them in their daily settings and accompanying them on clinic visits. My role within these settings was that of participant observer. Denzin (2009: 186) defines participant observation as 'a field strategy that simultaneously combines document analysis, interviewing of respondents and informants, direct participation and observation and introspection'. However there were limits to the extent to which I was able to fulfil this role. As a white female English speaking health professional, my influence in this community was always that of an 'outsider'. I chose participant

[20] See Chapter Six for a detailed account of these cases.

observation over detachment or inaction as my observational stance. I made referrals where necessary, answered questions around aphasia and provided counselling to families around mitigating communication barriers. This approach I felt was ethically more viable over detachment or inaction in a context where speech and language services are nominal. It also helped me to establish sustained relations with the individuals and institutions that hosted me.

These observations were augmented by interviews, carried out in participant's homes and yards, at bus stations, whilst offering rides, whilst walking in their neighbourhoods, on benches at local clinics and at centres of support and care. I conducted interviews with participants and their close relations for their viewpoints and accounts of experiences relating to life with aphasia. These interviews, largely informal and dialogic, provided commentary of the daily reality that unfolded in observation periods. Interviews were also used for the purpose of obtaining biographical information and shedding light on events or practices (particularly cultural rites) that I could not observe during the time of the study. My concern here was the experiences of participants and their families in valued social and cultural domains including communication, ritual and spiritual life, household and family and health and social services. I was also interested in local discourses around stroke and aphasia and the range of healing practices in this community.

Stage five: Experiencing broader contexts

Finally, after my period of fieldwork in Khayelitsha, I spent a week with disabled adults in a district in the former Transkei where aspects of traditional culture are still part of everyday life. This visit was in the context of a larger study into the daily occupation of disabled adults in a rural district of the Eastern Cape. Together with the research team of this project, I visited fifteen disabled adults in their households. I also visited and interviewed two adults with aphasia and their caregivers. I spent time with the chief of the district who provided me with valuable information about village life, about the history of the people of the area

and about pressing social and health problems in rural Eastern Cape. This visit allowed me to make exploratory comparisons between rural and urban life, to deepen my insight into cultural practice and changing interpretive frameworks in the context of urbanisation and to gain a better understanding of the rural Eastern Cape social setting. One of the predominant experiences for the adult with aphasia in Khayelitsha is circular migration between urban township areas in the Western Cape and rural Eastern Cape villages from which they originate. This circular migration is a strategy to share the burden of care when resources are limited but many people also return to their rural villages for the execution of particular cultural rites.

I have attempted to formalise my journey as a participant observer in Khayelitsha by describing my fieldwork against stages of data collection. Importantly however these stages were not always linear and there were intervals in the course of the study marked by my absence in the field. These were due to a period of maternity leave and other work commitments. I have plotted these stages of fieldwork, at times interlinked, at other times separated, against a time line (see Figure 3) stretching from my entry into the field to the point at which I decided to end my journey as participant observer. I cannot however state that theoretical saturation (Glaser and Strauss, 1967: 61) marked the end point of my journey. Khayelitsha is both a complicated and dynamic landscape and aphasia by its nature is similarly diversely experienced. My end point was instead marked by what I felt was my ability to present a sensitive articulation of circumstance.

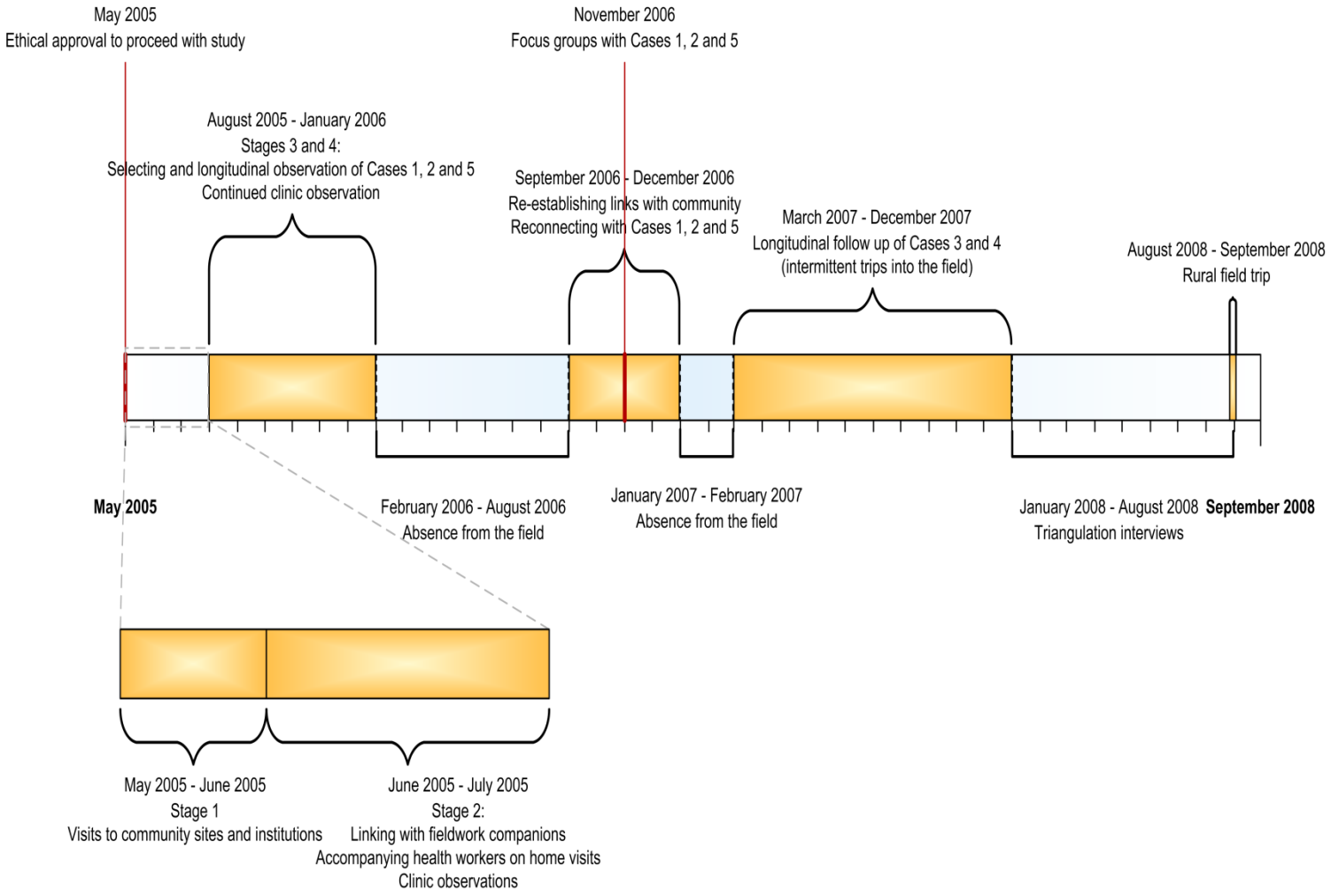


Figure 3: Fieldwork Timeline

4.3. Working in a Mediated Language Context

Although Evans-Pritchard ([1951] 2004: 79) asserts that 'any anthropologist worth his salt will make the learning of [language] his first task and will altogether, even at the beginning of his study, dispense with interpreters', the notion of gaining linguistic competence in order to proceed with a study of this nature was an unrealistic one. To negotiate the language divide, I made use of two interpreters. Both held some field-specific knowledge of disability and healthcare at the outset of the study, although they were not affiliated to any organisations within Khayelitsha. I further employed people to transcribe and translate recorded data from the interviews that were recorded. Prior to any research activities, I trained these individuals in specific interpreting and interviewing techniques. Here I drew on principles that have emerged from current work being conducted in the South African health care sector on interpreting (Penn, 2008). I also drew on these principles during mediated conversations by adopting a hermeneutic approach to translation and allowing my interpreters to conduct open-end and informal interviews with participants. The content and nature each conversation was then shared with me both during and after conversational exchanges. My interpreters proved to be valuable sources of information and I have included their insights in my data.

In this study, communication barriers did not only exist because of the language difference between me and the community under study. Aphasia presented a further barrier in communication. Although I believe that longitudinal observation of participants in their everyday life reduced these barriers, I adapted my verbal input in order to ensure that participants with aphasia understood me and had a means of responding. I did this by talking slowly and in short sentences and I supported my speech with key gestures, written key words and pictures, including maps, timelines and scales. I trained my interpreters to do the same. Where appropriate, participants with aphasia were encouraged to use gestures and yes/no pointing system in order to clarify their own verbal attempts.

These communication adaptions facilitate participation in medical interviews and in informed consent (Kagan, 1995; 1998) and were used in some of my interactions with some of the participants. Whilst this approach aided communication exchange, it did not preclude understanding difficulties for all involved in the interviews and there were times when it was necessary for me to go back and forth between participants, participant's family members, my interpreters in order to clarify the details and points of view that were being expressed. There were also times when the concern of the fieldwork contact was not one of interviewing and here I noted only the physically observable events of an interaction or discussion. My interpreter and I spent time together at the end of each day in the field to talk about what had unfolded.

4.4. Data Capturing and Analysis

My observations and interview data were documented in fieldnotes both during and immediately after each fieldwork contact. These notes contained descriptive accounts of both observed and reported events, as well as my own impressions and interpretations and notes for future lines of questioning. As far as possible I noted specific words, phrases and summaries of conversations. Fifteen interviews with health care workers in Khayelitsha were conducted in isiXhosa and audio recorded. Data were transcribed verbatim in isiXhosa and translated into English by a Xhosa-first language health care professional.

Both my fieldnotes and interview data remained unstructured and not coded throughout the period of my data collection. This was an overt attempt to avoid imposing a system of coding across a limited set of predetermined categories. Savin-Baden (2004) writes that the danger in the analysis stage of the research process is that data is deconstructed, over simplified and placed into 'catch all' categories as opposed to letting the true complexity of the situation emerge. Instead, my method of analysis fieldnotes was one of interpretive reflection on the meanings of my findings. Following Goodall (2000: 129) I looked for overarching

themes shared by the participants and organised my data to support them. Thereafter, I aimed to illuminate the relationships between findings and the larger socio-political and cultural context within which my observations were made. I used theoretical coding described by Strauss and Corbin (1990) to analyse the transcribed interview data. This data was primarily concerned with ideas of causation of stroke and aphasia. Theoretical coding allowed me to identify concepts within the data and develop these concepts in relation to both theory and to my own observations of the research setting.

4.5. Validity

There are arguments in the social science literature as to the degree of validity in ethnographic research (Hammersley, 1992: 124 – 127). There is however validity in the process of participant observation in natural settings and in the non-linear process of data collection and analysis that affords the refinement of developing theory. Nevertheless, according to Flick (2002: 151) there remains a risk of 'arbitrariness'. I therefore incorporated the strategies of verification and disciplined subjectivity into the research process to ensure authenticity. Simmons-Mackie and Damico (1999) discuss verification as a critical procedure in this respect. Verification is the process whereby the researcher makes an observation and interpretation and then reviews the data and collects additional data to confirm or refute this hypothesis. Verification is accomplished through triangulation where multiple data sources, multiple instances of phenomena and multiple levels of analysis form the basis of an emerging hypothesis. Simmons-Mackie and Damico (1999) also discuss disciplined subjectivity as an additional means of ensuring validity. Approaches to achieve such subjectivity included triangulation, researcher journals and participant feedback. In this respect I conducted three informal focus groups with three of the five key participants. During these groups, these participants and I discussed some of my emerging findings and I documented their responses to these findings in field notes. I also conducted numerous interviews with health care workers and other relevant

individuals encountered during field contacts. These individuals are listed in Table 1. Although there was no imposed schedule on the interviews that I conducted with these residents of Khayelitsha and health and social service workers, they were guided by descriptive, structural and contrast questions that helped me to attach meaning to my observations.

4.6. Ethical Considerations

A full ethics clearance process was obtained from the University of the Witwatersrand Human Research Ethnics Committee and from the relevant bodies governing clinics in Khayelitsha before this study was initiated. During the study, informed consent was sought on the basis of verbal and written information in both English and isiXhosa and was obtained from all institutions and participants for access, recruitment, observation and interviews. All consenting bodies or individuals were informed of the aims and nature of the study and the roles of the participants and the researcher in the study at initial contact and on subsequent fieldwork contact. English information sheets and consent forms are included in appendix 1. These were translated into isiXhosa where appropriate. There were many times when the process of obtaining written informed consent was inappropriate. Some participants were illiterate. In these situations, verbal informed consent was sought. For adults with aphasia who participated in this study, Supported Conversation techniques (Kagan, 1998) were employed to verify input from both sides (that is, the researcher and the subject).

In this context of scare resources and limited service provision, it was also necessary to engage with participants in ongoing discussion regarding my role within the research process and my withdrawal from the field. Some participants were hopeful that I could provide clinical services or monetary help. Whilst I did a provide referrals for health care services that were requested or deemed appropriate and assist some families with education about stroke, aphasia and communication, my primary role of observer and interviewer was one that I

needed to negotiate throughout my fieldwork contact to prevent therapeutic misconception. Cognisant of the unequal balance of power between myself as a clinician and researcher and participants who presented with communication difficulties, I continued to stress the voluntary nature of participation in this project and nurtured growing relationships of mutuality through longitudinal contact.

Biographical data and interviews were treated with confidentiality. All names of participants have been changed and I have not made specific reference to institutions or health care workers.

Table 1: Interviews Conducted with Healthcare Workers and Other Relevant Personnel

Interviewee	Focus of interview	Context/ Setting
Physiotherapist and resident	Availability of assistive devices	Special needs school, Khayelitsha
Physiotherapist and resident	Nature of outpatient physical rehabilitation services	Community Health Centre, Khayelitsha
Physiotherapist and resident	Nature of health care services; Burden of care on women Referral system	Community Health Centre, Khayelitsha
Community service physiotherapist	Accessibility issues in service provision	Community Health Centre, Khayelitsha
Community service physiotherapist	Accessibility issues in service provision	Community Health Centre, Khayelitsha
Occupational therapist	Nature of outpatient physical rehabilitation services Cultural constructs of stroke and aphasia	Community Health Centre, Khayelitsha
Occupational therapist, disability grants panel	Communication difficulties and the grant process	Telephonic interview
Occupational therapy assistant	Support groups in Khayelitsha	Old age home, Khayelitsha
Manager of adult day care centre	Position of disabled adult; Availability of social services	Adult Day Care Centre, Khayelitsha
Co-ordinator of women's association	Needs of elderly	Church hall, Khayelitsha
Manager of old age home in Khayelitsha	Institutional facilities and services for the elderly	Old age home, Khayelitsha
Co-ordinator - community-based rehabilitation	Home visits and care of elderly stroke patients	Research meeting
Co-ordinator of satellite clinics to Khayelitsha	Health care needs of elderly	Old age home, Cape Town
Manager of old age home	Social and welfare services for elderly	Old age home, Cape Town
Co-ordinator of rehabilitation services	Rehabilitation services in Cape Town Referrals between tertiary and primary levels of health care	Provincial hospital
Speech and language therapist	Nature of acute hospital-based aphasia therapy	Provincial hospital
Speech and language therapist	Discharge issues for adults with aphasia living in Khayelitsha	Sub-acute rehabilitation facility
Registered nurses and nursing auxiliaries (13) (mediated through a trained interpreter)	Cultural constructs of stroke and aphasia Traditional and faith healing practices	Sub-acute rehabilitation facility
Nursing sister and resident	Cultural constructs of stroke and aphasia; traditional healing practices	Community Health Centre, Khayelitsha
Nursing sisters (5)	Cultural constructs of stroke and aphasia; traditional healing practices	Chronic illness clinics, Community Health Centre, Khayelitsha
Khayelitsha resident	Terminology around health, illness, disability and stroke	Resident's home
Pastor and resident	Faith healing and church groups	Resident's home
Disability activist	Cultural constructs of disability; Issues of stigma and prejudice	Research meeting

CHAPTER FIVE
THE SETTING OF THE STUDY: KHAYELITSHA

Khayelitsha provides a setting of huge problems. It is an intriguing mixture of both vibrant and desolate urban spaces. It captivates and appals.

MacGregor, 2002: 3



Figure 4: Map of Khayelitsha and surrounding townships (Source: Chief Directorate Surveys and Mapping, Department of Land Affairs)

Khayelitsha is situated 30 kms from Cape Town's city centre, between the N2 motorway and False Bay. Its terrain is sand dunes, where weather extremes contribute to the harshness of life. Hot winds in summer threaten the outbreak of runaway fires and in winter, the vast basin is prone to flooding. Inhospitable as the weather may seem, Khayelitsha is home to around half a million people[21]. The

[21] Although the 2001 census reports a population figure of 329 000 (Statistics South Africa, 2001), this is widely disputed and both municipalities and service organisations report that Khayelitsha's

township, meaning new home in isiXhosa, was established in 1983 as a dormitory town for the expanding African population of the Western Cape. According to Dewar and Watson (1984), those who relocated to Khayelitsha did so to obtain housing and escape the state-fuelled violence omnipresent in other Cape Town townships. The township grew rapidly with voluntary migrants from the Eastern Cape to become one of South Africa's largest townships. According to Statistics South Africa, 97% of Khayelitsha's residents originate from the former Transkei and Ciskei and accordingly, isiXhosa[22] is the predominant language of the area.

Today in the post-apartheid milieu, Khayelitsha has emerged as a sprawling maze covering approximately 50 km^2 of densely situated formal and informal settlements atop sand dunes and within sand basins. Formal settlements are comprised of small brick houses built by residents better off than most, and rows upon rows of what are popularly known as RDP[23] housing. Informal settlements, which house the vast majority of Khayelitsha population (62%), comprise shacks built of corrugated iron, plastic and timber erected on municipally serviced land (that is land allocations providing some form of water, sewerage and electricity supply and refuse collection service) and on unserviced land areas, where people only have access to a communal tap and a shared toilet bucket (Residential Growth Monitoring System for the City of Cape Town, 2008). Close to 86 000 households can be found here and the average number of people living in each home is 5.6. The vast majority of this population are young, with two-thirds younger than 30 years of age, and 52% being female (Khayelitsha Population Register Update, 2005).

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burgeoning population has exceeded 1 million. In June 2008, the Strategic Development and Information and Geographic Information Systems Department of the City of Cape Town published a figure of 429 185 for Khayelitsha's population. This figure is a population estimate extracted from the 2001 national census and corroborated with aerial photography.

[22] IsiXhosa or Xhosa, is a branch of the Nguni languages and is thus mutually intelligible with other Nguni languages including Zulu, siSwati and Ndebele. isiXhosa is an official language of South Africa and is the second most common home language in the country. Like other Bantu languages spoken across Africa, isiXhosa is a morphologically based language, characterised by clicks.

[23] The Reconstruction and Development Programme initiated in 1994 was an action-oriented policy document to rebuild the nation following nearly 46 years of Apartheid rule. It provided impetus for the widespread erection of housing within township areas such as Khayelitsha. These houses are commonly known as matchbox houses and provide basic shelter for disadvantaged families. They are depicted in figure 7.

Khayelitsha, a peri-urban township in the old dispensation, has now been subsumed into the municipality of the City of Cape Town and there are attempts to integrate the community into the larger metropolitan area of the city. However in many ways, the community remains economically, linguistically and socially isolated from the city at large. Many residents of Cape Town's wealthier suburbs have never visited this community and within Khayelitsha, educational, recreational and commercial facilities are lacking. People rely on roadside fruit, vegetable and meat stalls and the *spaza* shops (small convenience stores usually operating from a home) that exist within every neighbourhood for food and other provisions. The area is divided into three towns, comprising villages and smaller suburbs. Site B lies south of Site C and is considered the commercial centre of the community, where the main railway station and one of the day hospitals can be found.

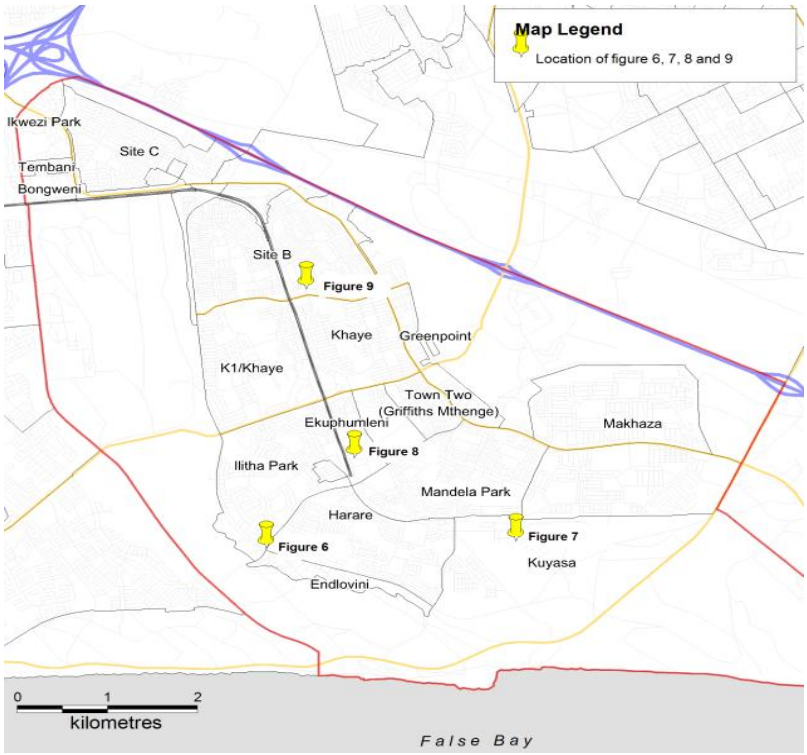


Figure 5: Location of photographs



Figure 6: A typical street scene in Khayelitsha



Figure 7: New housing development (Source: City of Cape Town Urban Renewal Programme)



Figure 8: Recently developed commercial zone (Source: City of Cape Town Urban Renewal Programme)



Figure 9: Entrance to the Site B day hospital

When one enters Khayelitsha, the high rate of unemployment is glaringly evident. Men line the offramp from the N2, ever waiting for the offer of piece jobs. Further into the township, groups of people congregate on sidewalks in front of their shacks. Seated on paint cans, they spend their days talking, smoking and watching passers-bys, without funds for transport to head into town to seek work. According to the 2001 census, only 35% of the population have secured permanent employment. Others rely on an unsteady income from micro-enterprises (such as hawking, side walk hair salons, fruit and vegetable stalls, and telephone services), survival activities and casual labour although unemployment stands at 52%. The low level of average household income is alarming: 72% of households within this community survive below the household subsistence level and 19% of the population are in receipt of social income grants (Statistics South Africa, 2001).

Khayelitsha is therefore a setting of hardship. Most residents of the community are socio-economically insecure. The poverty here has been described as structural in nature, which means that is it the result of underlying conditions in the economy, both during and after Apartheid (Desai, 2005). Wilson and Ramphele (1989), who conducted the first comprehensive study of poverty in black communities in South Africa, show through both statistics and case studies that this kind of poverty is foremost the end product of apartheid's social engineering policies which not only established wage earning as the only viable means of livelihood but also simultaneously denied black Africans the means with which to do so. Legislation jointly worked to force young men into migrant labour in South Africa's mining and industrial sector. This included the imposition of land tax, the state control of agricultural resources, the restriction of movement and trade on black Africans and the deliberate neglect of education. This meant that for decades, young men had to relocate to urban areas where they were accommodated in mono-functional dormitory townships on the outskirts of the cities and paid meagre wages. Influx control measures prevented many wives and children from following men to the city and the subsequent effects of this on black

South African families continue to be felt[24]. A small percentage of women moved to the cities for employment in domestic work in the 'white' suburbs of South Africa, but this industry was unregulated and underpaid and movement was strictly controlled.

Despite influx control measures, rurally-based people continued to move to South Africa's urban townships due to declining agricultural resources in the former homelands. The townships grew rapidly but, built only for the purpose of temporary accommodation of the labour force, had little in the way of infrastructure and social services. Living standards were poor. In addition, these areas had no economic base from which to develop. Coupled with the costs of circular migration and remittance to rural areas, this meant that most people in the townships remained poor. In the Western Cape, this was exacerbated by job reservation, the intention behind the Coloured Labour Preference Policy which prevented both the formal and informal sectors from legally employing African migrants (Ndegwa, Horner & Esau, 2007).

This situation has persisted since the advent of democracy and poverty in Khayelitsha continues to be marked despite massive uptake of social income support grants, in the form of old age pensions[25], disability grants, child support grants and grants in aid. This is partly due to the widespread urbanisation that has taken place in South Africa, and in particular in the Western Cape, since the lifting of influx control measures in the 1990s. Khayelitsha continues to experiences massive influx of people and approximately 60% of the present population are new migrants to the area (Khayelitsha Population Register Update, 2005). As people have flocked to the city in search of employment and a better life, Khayelitsha has burgeoned in the absence of any economic or infrastructural development and core housing areas established by the state in the 1980s were

[24] See Ramphele (2002) for an ethnography of domestic life in Cape Town's townships in the Apartheid years.

[25] South African citizens over the age of 60 who do not draw income from other sources are eligible for a non-contributory state pension in the form of a monthly cash payment. Similarly adults with a disability that precludes their employment in the open labour market and who live below a predetermined asset and income threshold qualify for a monthly grant of the same amount. Amounts for both the old age and disability grant at time research was initiated were R820.00 per month. For current monthly cash grant amounts go to www.sassa.org.za.

quickly surrounded by sprawling squatter communities (Ndegwa et al., 2007). This has undermined ongoing development efforts in the housing, health and educational sectors. In addition, unemployment has continued to escalate in South Africa: the shrinking demand for labour in the industrial, agricultural and mining sectors, the increasingly skill-based technical workplace, and apartheid's discriminatory educational practices have converged to create a situation of increased inequality. The HIV/AIDS epidemic is an added burden (Desai, 2005).

Conditions of life in Khayelitsha would appal most. Shack dwellings are small but densely[26] situated makeshift structures that are ill-equipped to withstand the weather conditions of the area. Formal houses, frequently self-built, are also small and include basic accommodation facilities. For example none of the homes that I visited were carpeted and few had inside plumbing and toilets. Whilst many have running water and electricity, there are frequent service delivery disruptions in the area making these services sporadic. Gardens are scarce and streets are largely unpaved and littered with uncollected refuse. The narrow spaces between the shacks and houses are often used for clothes washing and drying, for ablutions and waste disposal. Many public spaces are in disrepair and newly built facilities such as schools, clinics and centres are basic and often ill-equipped.

These conditions of life are reflected in the health statistics where Khayelitsha presents with the highest incidence of communicable diseases in Cape Town (Scott et al, 2001). For example, Tuberculosis is endemic with an incidence of 1612 per 100 000; HIV and AIDS has affected approximately 30% of the area's population and infant mortality rates are among the highest in the world (31.66 / 1000)[27]. Premature mortality is disproportionately higher than any other Western Cape district[28]. In addition, Khayelitsha has a significantly higher burden of disease and morbidity for non-communicable illnesses, such as stroke and

[26] Population density is estimated to be 7 748 inhabitants per km^2 (Khayelitsha Population Register Update, 2005)

[27] For 2006. From the City of Cape Town Health Statistics. Available on www.web1.capetown.gov.za.

[28] The Medical Research Council cautions that provincial statistics mask inter-provincial variation where mortality rates in Khayelitsha are approximately 1.5 times higher than overall figures for Cape Town (Scott et al, 2001).

diabetes mellitus, as well as injury (Scott et al, 2001) suggesting that chronic illness and disablement is prevalent. These health conditions are fuelled by poverty, undernourishment, inadequate housing and the notorious violence integral to Western Cape township life.

Despite this, health services are limited. There are no secondary health facilities in Khayelitsha, but nine primary care clinics, three community health centres and one Maternity and Obstetrics Unit linked to one of the Western Cape's academic hospitals. The largest of these health facilities offers a day unit and the second larger a 24-hour trauma service. These services are run by nurses and rely on referral to tertiary units but this system is complicated by inadequate ambulance services. Clinics are over-run and ill-equipped and due to the ever-expanding density of the area, accessibility has become more and more limited. There is a growing acknowledgement too of the less tangible influences on accessibility to health care in an environment such as Khayelitsha. These include policy reform, language, attitudinal and financial barriers (Drennan & Swartz, 2002; Gibson, 2001; Gilson, 2003; Jewkes, Abrahams & Mvo, 1998).

Deepening impoverishment, social upheaval and the absence of supportive community institutions in Khayelitsha has in many ways lead to a breakdown in community relations. Khayelitsha is termed the murder capital of South Africa in local papers and murder, rape, theft and assault are pervasive experiences. Substance and alcohol abuse is also prevalent (Havenaar et al, 2008) and the high number of shebeens and taverns, whilst providing public space for recreation and leisure, present a concern to many residents of the community.

Strong networks of support, rooted in African culture and shaped by apartheid practices, exist within this setting of community disruption. The social geography of Khayelitsha is shaped by historical and political influences. The vast majority of residents of this township originate from the former homelands of Transkei and Ciskei and claim ancestral ties to the Nguni tribe who occupied the south western areas of what today is the Eastern Cape Province. As described by Hunter (1961:

379), the Nguni tribe was a partilineal society comprised of local lineage groups whose homesteads were scattered across hillsides. Each homestead consisted of extended kin who lived in circular huts in close proximity to one another and shared resources (such as livestock and land) and responsibilities (strictly defined by gender, age and rank). Homesteads within the same area would form a grouping and, led by a headman, come together for protection in times of fighting and shared celebration and religious rites. The society was a patriarchal one where power was vested in male elders and women and children obeyed a strict set of rules to ensure respect for patrilineage.

Although the historical notion of the resilient African extended family and sense of community has been criticised and considered an idealisation of pre-colonial times (Thornton & Ramphele, 1988: 29), resilient alliances continue to exist between individuals connected by origin and marriage in Khayelitsha and many residents maintain strong ties to the rural villages from which they come; sending money and assistance when needed and returning there in times of distress or cultural celebration. In my fieldwork, I observed how people in Khayelitsha introduced themselves to others by sharing not only their first names and surnames, but also their clan names and their places of origin. People shared with me their sense of trust of those belonging to their broader clans and of those who originated from the districts of their own birth. Similarly, notions of right behaviour governing roles and responsibilities within a kinship or social network are still perceived as important ones. McGregor (2002) brings this notion of 'right behaviour' to life, providing anthropological evidence for both the strains of obligation for caring for kinsmen on community members and the strains of those suffering from mental distress to maintain behavioural norms to ensure their eligibility for support.

The political influences on networks of support in Khayelitsha are also profound. Migration and resettlement as some of the 'most distinctive characteristics of apartheid' (Gordon & Speigel, 1993: 92) have had social, cultural and religious impact. For example, Ramphele (1993) has shown how migrant labour and

impoverishment have given rise to a new domestic unit in Western Cape townships. Ramphele describes the single bed, rather than the household, as the primary unit of domesticity, which has had pernicious effects on child-rearing, gender equality and care of the aged. The revival of cultural rites and practices is largely seen as a symbol of resistance to apartheid ideology and the gaining popularity of charismatic churches and faith-healing practices in Khayelitsha is thought to stem from economic hardship (Kiernan, 1995b: 126). In addition, in response to deepening impoverishment and the spatial, cultural, social and economic separation of the township from the rest of the city, residents have created strong networks of support where neighbours, street committees, financial mutuals such as '*stokvels*[29]' and church groups provide material and emotional support to others. Culturally explained by '*ubuntu*', a virtue of African culture that leaves no one destitute or alone[30], these associations emerged in townships across South Africa between the 1950s and 1970s in the attempt to replace traditional networks broken down by both the spatial reconstructions effected under Apartheid rule (including segregation, migrant labour and forced relocation) and processes of urbanisation. Scanlon (2007) describes how the absence of social and welfare provision under apartheid made many of these organisations critical to women's survival – they functioned therefore not only for social purposes but also as economic safety nets, in a time where formal financial support structures were denied to black South Africans. Scanlon (2007) also describes how these associations continue to flourish today. They function to establish and maintain social and mutual financial support particularly among women in the townships. Alliance with these networks is secured by ongoing reciprocity of cash, food and childcare and their role in ensuring survival in a new and abject environment and in creating community cohesion is an important one (Spiegel, Watson & Wilkinson, 1996).

[29] The 'stokvel' (from the English stockfair) is a popular form of association in Khayelitsha and includes burial societies, mutual benefit clubs and saving clubs. These associations are usually short-term schemes that help families mange their limited income. Small groups of people contribute weekly or monthly to a central fund, that is then used by a respective member to meet a particular expense, such as school fees or new shoes.

[30] See Coertze (2001) for a full discussion on the historical and cultural roots of the term '*ubuntu*' and its contemporary referents of human rights and nation building.

The literature, however, describes these social and familial networks as tenuous. The loss of resources could prompt a household to drop out of such networks (Spiegel, 1997). Even within the family unit, domestic flux is a way of life and relatedness is often short term and remittance-dependent. Although the moral and social ideal of '*ubuntu*' is extolled, the strain of poverty creates a different reality. Similarly, in this community disabled people struggle to negotiate status and avoid stigma despite Constitutional reform and rights-based discourses (K.S. & Duncan, 2006; Lorenzo, 2003; MacGregor, 2002). In addition, broad statistics reveal that disabled Africans remain trapped in a cycle of deepening impoverishment and social isolation. Disabled people are disproportionately among the poorest of the poor and generally accessibility to health services remains problematic (McClain, 2002).

This may also be the case for elderly people. In the previous dispensation, where migrant labourers were the only black individuals eligible for urban relocation, the black elderly were predominantly rurally based and those who resided in urban settlements such as Khayelitsha returned to their rural origins in old age or with the onset of illness. However, this practice appears to be declining and now elderly persons make up an increasingly larger part of the population structure in Khayelitsha (Sagner, 1997). Charlton (2000) provides a detailed review of the position of the elderly in the urban township areas surrounding Cape Town. Citing data from the 1995 Western Cape Community Housing Trust (WCCHT) study of these settlements, Charlton describes elderly households (those households where one or more members are over the age of 60) as larger and poorer compared to young households, with a higher dependency ratio. In about half of the 113 elderly households in the WCCHT study, the elderly appeared to be the sole source of income and attracted kinfolk, children and grandchildren who relied on their state pension as the primary resource. Sagner and Mtati (1999) found that pensioners in Khayelitsha 'act as magnets for economically weaker persons' (399). The elderly, therefore, play an important economic and social role in Khayelitsha, contributing substantial proportions of their pensions to households and assuming responsibilities for childcare and daily household management. In addition the

elderly form the link between urbanised generations and their rural roots - making frequent visits to the former Transkei and upholding age old cultural customs.

Studies in the Western Cape since the large-scale urbanisation in the early 1990s have however highlighted that as a grouping, these individuals face particular stresses relating to crime, health, economic difficulties and gender inequalities (Charlton, 2000). Although the elderly, and in particular grandmothers, are central figures in households, they are made vulnerable by targeted crime and in some instances, remain housebound and isolated for fear of violent attacks and robberies. The impact of social dislocation and economic hardship on the elderly is also profound and Gillis, Welman, Koch and Joyi (1991) report a prevalence of depression in older women in the township. Dedicated geriatric services are limited. There is one old age home in Khayelitsha. This is a non-governmental, church-based organisation that has a live-in facility and runs a number of out-reach projects for primary health care of the elderly. There is also a day care centre, run by a University charity and numerous smaller non-governmental organisations that provide social services, such as food gardens, health services, such as HIV/AIDS awareness and recreational facilities, such as groups and crafts, for elderly people.

In Khayelitsha, there are various ways in which people account for their troubles, explain their misfortunes and explore meanings. Prevalent assumptions are those conceived as traditional Xhosa explanations of illness. Although these cultural accounts are interesting and provide insights into the African worldview, they should not deflect attention from economic influences on the status of disabled persons. In addition, residents of Khayelitsha are in a state of transition and acculturation, resulting in changing frameworks of interpretation and social actions for healers and consumers alike and in changing patterns of care and responsibility.

The setting of Khayelitsha is one of poverty and environmental and social hardship, making it a fascinating place to explore accounts of the social and

cultural meaning of aphasia and communication disability as well as human experiences of suffering in the face of disability and poverty. Khayelitsha also exemplifies the urban black township, offering a window to life in communities that have been described as perversions of urbanisation and illustrations of apartheid segregation.

This study is not only concerned with the challenges of life for the adults with aphasia in an urban township settlement. Networks of support and strategies for coping are also of interest. In this respect, Khayelitsha may offer another window. This seemingly abject community has also been described as a 'hope zone', an area where health programmes (particularly those directed at HIV/AIDS treatment) are reporting successful outcomes[31] and dedicated non-governmental and religious organisations provide support to the ill (Morgan, 2002). There are an abundance of non-governmental organisations involved in delivering health care, education, poverty alleviation and social support to the area. Although these programmes are mostly mobilised around AIDS, general development, ambitious dreaming and a working together for change are still apparent. For those living in Khayelitsha, life is difficult, but there is a spirit here; palpable on the bustling pavements of this area and manifesting in the colour and song that constantly surrounds one. Many homes are vibrantly painted, township music is played from street stalls and local shebeens and taverns (unlicensed drinking establishments) and day tourists abound. There is visible evidence of micro-enterprise, including hair salons, telephony services and furniture repair companies that are housed in disused shipping containers on the side of arterial roads. There is also ongoing structural development and constant progress despite massive influx of people, deepening poverty and worsening service delivery and this, according to Morgan (2002), stands Khayelitsha apart from other poverty and disease-stricken areas across the country.

[31] See Azevedo (2007)

CHAPTER SIX
CASE ACCOUNTS

In this chapter I present case accounts for the five key participants of this study. These case accounts describe the living arrangements, social support and help-seeking journeys of each participant. Throughout the rest of this thesis, I draw on these case accounts in presenting the findings of this study.

6.1. Case One: The Mdubekis' Help-seeking Journey and an Account of their Circumstances

George Mdubeki suffered his stroke at the age of 53. He had recently returned from a visit to his rural village over the Christmas of 2004 when he collapsed at his home and was taken by ambulance to a large provincial hospital. He spent a week here and then a further 3 months at a sub-acute rehabilitation facility before being sent back home to be cared for by his wife Mavis. George was dependent on Mavis for almost all his physical needs, from bathing to dressing and to moving between his bed and a chair in front of the television in the front room of their home. He was able to walk and stand with the help of his wife and a crutch, but he is a heavy man and this was with great difficulty. George was also unable to talk. He nodded and waved to greet people and his attempts to communicate were limited to saying '*ewe*' (isiXhosa for yes). He used 'ewe' repeatedly in various tones to indicate consent or disagreement, to indicate his wants and needs and at times to join conversations. His understanding of language was also impaired, although with supportive gestures and simplified input George was able to follow the gist of discussions and answer questions through a yes/no system of communication.

Mavis and George Mdubeki had been married for 30 years. They both came from the same rural village in the former Ciskei near Bisho and were married there before they moved together as a couple to Cape Town to seek work and establish their lives here. They moved first to Langa, an older more established township

closer to Cape Town's city centre, until they lost their house and all their belongings to fire in the early 1990s. They re-established themselves in Town Two in Khayelitsha in 1994 and had been living there for 12 years. Prior to his stroke George was a relatively successful businessman and operated a small taxi venture. Mavis worked once a week as a domestic worker for a family in the city centre.

Their home in Town Two hinted of a past prosperity, lost now since the stroke that left George unable to work. It was a self-built double storey brick construction of about $20m^2$ with electricity and inside plumbing. This house stood in stark contrast to the surrounding single room brick constructions and shack houses that characterise Town Two. But it was in disrepair: bright orange paint peeled from the walls, a number of the windows in the upstairs storey were shattered and the outside toilet was broken. A Volkswagen Polo was parked in the yard in front of the house. George and Mavis shared the house with their five children (4 girls and a son, their youngest), George's brother's child and their two grandchildren. The downstairs area comprised a kitchen, bathroom and living area, sparsely but neatly furnished with a plastic covered lounge suite and a TV unit. As George was no longer able to move upstairs, he now slept downstairs with Mavis in a bed against the back wall of the house. Two bedrooms comprised the top storey of the house and this is where the 8 children slept. The Mdubeki's youngest two children were both in Grade 11 at a local secondary school. Their three eldest daughters had finished schooling although only one was employed. She held a job in telesales at a large newspaper publisher and her child stayed at home in Mavis's care. With her salary, she had secured vehicle finance and the car that stood in the driveway was there should there be an emergency with George. Not being able to rely on ambulance services into their area, they hoped that someone in the neighbourhood could drive in the event of George needing urgent medical care.

Although seemingly surrounded by people, the journeys for George and for Mavis since George was debilitated by the stroke appeared to be lonely ones. During the

first year and a half following his stroke, George spent most of his days housebound, seated in front of the television. His neighbour visited him during the televised soccer matches of the local Premier League. United by their ardent support for Kaiser Chiefs, a popular South African soccer team, he and George sat together for a few hours each week. But social interaction was limited to these visits and sporadic outings to church groups and prayer sessions.

When we first met, George seemed both down and angry. His taxi operating business was folding. Although Mavis tried to continue managing the drivers since George's stroke, theft, corruption, disloyal employees and embezzlement slowly sunk the venture. George watched helplessly as drivers he had previously employed stole taxis and car parts from outside his home and even his possessions inside his home. Mavis had no control over the drivers who refused to hand over earnings and lied about their whereabouts. With time, there was nothing left of the operation and their remaining financial resources did not stretch to procuring legal assistance or help for the business.

Mavis's troubles were not only financial. Friends and members of their extended family, once dependant on George and Mavis for financial assistance when needed, no longer visited or offered any form of support. Her only respite from her role as carer was when she left the house for her weekly job as a domestic worker in the city. Mavis often spoke quite nostalgically of a lost sense of community in Khayelitsha.

As Mavis tried to direct the business and watched as it slipped out of her reins, so she tried to hold together their children and watches helplessly as the respect and traditional values that George upheld in the home slip away in the absence of his voice. Their eldest daughter turned to drinking over the time of my knowing the family and lost her job. Their son, in whom they had vested much hope, failed his matric exams, and took to partying. On a number of my visits, Bongani left the house, laughing as Mavis hankered after him with questions about studying and completing chores.

Despite these woes, Mavis remained hopeful of a cure for George's afflictions. On numerous occasions she asked me what pills could make George talk again and over the time of our relationship she explored numerous different therapeutic avenues at a fair amount of cost to the family. Mavis placed a great deal of trust in pills. In addition, she turned to prayer and became very actively involved in weekly prayer meetings. Although these meetings involved mostly singing as a form of worship and supplication, Mavis used them as a chance to meet other women in her situation. She joined a Methodist Women's Association and every so often hosted prayer meetings in her home. After a time, however, the visits dwindled and Mavis became sceptical of the support proffered by the group.

Mavis and George also visited other church establishments in the hope of a miracle cure. They went to the faith healing assemblies that operate in the large newly built arena in Khayelitsha over the weekends. Here after a period of singing, dancing and praying, the pastors calls forward the sick and asks the congregation to pray for them. People are asked to put their prayers down on paper and send remittance to the front. Mavis felt these exercises lifted her spirits and she valued seeing others with afflictions like George's. Mavis took George to a faith healer associated with the local apostolic church. The healer blessed him with water and cleansed him of the impurities that were sent to cause his stroke. Over the time of my research, they often spoke of their plans to visit a miracle worker from iXolo in the Eastern Cape, who ran the Church of Hope in Khayelitsha. Her work was well recognised and people came from all other the city with their requests for aid and rescue.

Prayer and faith healing formed only a partial part of the family's help-seeking journey. George attended clinics at the local primary level hospital for blood pressure monitoring and dispensing of his medication. Occasionally he attended an exercise group run by the physiotherapy department. However, short visits to the nearby hospital took the better part of the day. Mavis needed to help George walk to the main road in order to take a taxi – a few hundred metres on a gravel, pot-holed pavement would take them over an hour to cover – and once at the

hospital, they spent many hours waiting in queues for their folder to be drawn, for pharmacy to dispense the medication, for a consultation with a nurse or for the exercise group to run. On the three occasions that I arranged to accompany George to the exercise group and to his checkups at the high blood pressure clinic, staff were in meetings or absent from work or on tea or otherwise busy and we returned home after waiting a few hours. Mavis and George continued however to seek out the services of the nurses and physiotherapist at the hospital, each time hoping that the exhausting walk and long queues would be a fruitful exercise.

When Mavis turned to traditional healing in her quest for help for George's affliction, she angered her daughters and risked a fairly serious family fall out. Nevertheless they pursued this avenue and consulted with ten various herbalists and diviners in the first year and a half following George's stroke. A costly exercise, one herbalist required a R1000.00 deposit and a further R9000.00 over the course of treatment. R10 000 was the metaphorical cow that could open the chest containing herbal ministrations to cure George's paralysis and mutism and protect him from further misfortune. When the herbal remedies did not alleviate George's suffering, Mavis turned to a diviner who advised them to place R18 000 under George's pillow as an appeasement to their ancestors. This diviner however disappeared after a robbery at the Mdubeki home family[32].

Our discussions of traditional healing practices were often whispered. Mavis did not want her children overhearing that she continued to entertain notions of magical cures contained in dreams and in the execution of traditional rites, despite the robbery. Her scepticism of divining practices was directed at diviners who did not originate from the Eastern Cape and there was open distrust of healers who came from other countries, specifically Zimbabwe.

Mavis's search for cures extended into the realm of homeopathic medicine. When she had the resources she used Arnica oil to alleviate the building pain in George's limbs. She bought nutritional shakes, herbal supplements and vitamin

[32] I recount this incident in full in 8.5.3.2.

pills, all the while hoping that they would not only bring improved health but provide the miracle cure - George could walk and talk again. Her endeavours never faded and her questions continued but in all the while of our relationship, she never appeared to reach acceptance. More than once, Mavis said that George's recovery would return good fortune to the family.

The family frequently asked me had caused George's stroke. At different times, the family looked to different causal agents to explain why George was so suddenly struck by his debilitating illness. The family spoke of possible links to stress, bad diet, lack of exercise, being overweight and suggestions of diabetes. They also suspected the hand of George's family, as George had suffered the attack so soon after returning from his annual visit from his rural homeland. George was relatively well-off, and his children showed prospects for achieving well in life. Although George was the financial fallback for many members of his extended family, jealously was not disregarded as a motive. Mavis believed that her husband was poisoned by evil agents acting for jealous family or possibly even neighbours. Mavis spoke of George's aphasia as relative proof that he had suffered at the hands of evil people, claiming that he had seen who had afflicted him and that is why he needed to be silenced.

George's brother and nephew looked to their family history to explain the misfortune. According to them, George's father was a migrant labourer who died after a short illness on the mines. News of the death did not reach the family for a number of months and so the father received a state burial far from his home. The first the family heard of the death was when a returning labourer approached their home to ask why they had abandoned their father. George was an eight year old boy at the time, but as the senior male in the family, the onus fell on him to slaughter a cow to accompany his father to the afterlife. George's brother believes that because due course was not followed, displeased ancestors wrought misfortune on the family. The Mdubekis frequently spoke of returning to the former Ciskei to slaughter a cow in the absence of a proper burial service for the

father. As time passed the likelihood of them securing the resources to do so became less and less.

The family's financial difficulties became increasingly more pronounced over the time that they were involved in my study and particularly for Mavis life became a struggle. She felt that her community and family had abandoned her and in particular, she felt unsupported by the healthcare facilities that had treated George at the time of his stroke. Little was reported to me about George's period of time at the state rehabilitation facility. Mavis was certain that he was discharged home without referrals for support services or outpatient care. She had been told by nurses that George had been a difficult patient and had little prospects for improvement. Mavis spoke to me of her feelings about George's untimely discharge from the hospital and felt he had been unfairly labelled as lazy and uncooperative because he was unable to speak. As did a number of other families in Khayelitsha, she ascribed this to racist discrimination (from coloured nursing staff) and shared stories of abuse by nurses.

Mavis met with a doctor at the time of George's stroke to initiate a disability grant application. She was given a form that she had to submit to the primary level hospital but she was mugged whilst waiting for a train to return to Khayelitsha later that day. Her handbag and with it the form was lost. Mavis returned to the hospital on a number of occasions for a year and a half following the stroke in order to re-obtain the relevant form, without which the local hospital would not process the grant. She returned home each time empty handed. It took the intervention of the physiotherapist at the primary level hospital to secure the much needed grant. The first payout was at 16 months post-stroke. After this, Mavis accompanied George to the payout facility in Harare each month to collect the grant.

Over the time period of my study, George showed much improvement in both his affect and his mobility. This made him more independent. Eighteen months after his stroke, George found refuge in an adult day care centre run by a University

funded community project. On our last meeting together I accompanied George to the facility that he had begun to attend daily. A bus arrived early each morning to collect him. Here George met other people with aphasia. After a long and largely unfruitful help-seeking journey, George had found a place where he could both socialise and exercise, finally offering Mavis some respite. The family placed great trust in this institution, hoping that the facility could offer long term help. Their financial security remained a pressing concern and they continued to feel the weight of George's unmet responsibilities of being the eldest son. Mavis continued to shoulder the burden of care for George, for her children and her now two young grandchildren. She seemed tired and alone and it did not appear as if her immediate kin and children would be of future support.

6.2. Case Two: Linah's Difficult Circumstances

Linah heard of my research from neighbours and she walked to see me one afternoon when I was visiting another participant who lived several blocks away. Linah is barely mobile and the walk took her over an hour. Nevertheless she embraced me when we met and said she had come to talk about her stroke.

Linah is a frail, elderly woman in her early 70s who has suffered two previous strokes, the second of which in 2002 left her with an expressive aphasia. She has an accompanying right hemiplegia and ongoing respiratory ailments. When I met Linah she was living with her son and his girlfriend in a small (approximately $10m^2$) cement brick house with a zinc roof in Town Two. Although their house is a brick house with basic plumbing and electricity, they are surrounded by shack dwellings in an area where there is little in the way of infrastructure. Roads have long since collapsed and pavements have been usurped by shacks. Poverty is marked and due to heightened gang activity the area is generally regarded as unsafe.

Relations in Linah's household were strained but Linah's pension was the household's sole source of income and this afforded her some security. She however did not feel that she could raise issues of discontent about her living circumstances and in a small focus group one afternoon Linah opened up to the group about difficulties at home. Despite her ailments, she did the housework and food preparation, relying on neighbours to bring groceries. Linah's son and girlfriend drink alcohol using up scarce cash resources. They become aggressive when they drink and there were times when Linah needed to stay out of their way. Linah believed these circumstances brought on her second stroke.

Linah is a widow. She has five children, 14 grandchildren and by her own account, has lost track of how many great grandchildren she has. Her family is dispersed, having all left their rural home in the Eastern Cape to seek work in Gauteng or Cape Town. In the mid 1990s Linah migrated from rural Eastern Cape to live with her daughter and her daughter's husband in Mitchell's Plain. Soon after settling there, she suffered her first stroke after she was robbed of her monthly social grant on her return from the mobile pension pay unit in Mitchell's Plain. After her stroke, Linah went to live in Johannesburg with one of her sons. He abused her pension grant and when she tried to raise this issue with her son and his girlfriend, they kicked her out, accusing her of witchcraft. She returned to Cape Town without her belongings, seeking a new place to stay with her youngest son in Town Two. This is where I met her.

Owing to her present living circumstances, Linah preferred to meet with me at Nothemba's house[33]. One afternoon however I drove her back to her son's house in Town Two. The yard around the house was scattered with litter, discarded plastic objects and rusted car parts. The house looked out onto a similarly derelict street. The house was dark inside and sparsely furnished. A large front room combined a small kitchen and living area and contained a melamine table and chairs. Two bedrooms led off this room. Both were filled with a double bed. Linah's belonging were all kept in a suitcase at the foot of her bed and on her wall

[33] See 9.2.1.

hung a prayer that had been etched on to small mirror. There were a people at home when I accompanied Linah inside, one of these her son. They did not greet me and Linah appeared to be very uncomfortable. She did not talk to them at all.

Linah was able to express herself verbally, although not without difficulty. She took a long time to formulate her sentences and was only able to speak in short bursts. She relied heavily on gesture and tone to portray her emotions and contributed to our discussions by furiously nodding or shaking her head and waving her hands. Linah's central concern was for a *lost youth*. She frequently spoke about tensions between young and old, about alcohol and substance abuse in the area, about crime and about a revival of witchcraft beliefs among the younger generation. Linah rooted her health concerns in these broader social troubles and intergenerational tensions. Similarly she rooted her communication difficulties in these tensions. She did not attend the clinic. Nor did she seek remedies or healing for her physical and speech difficulties. She wanted to attend a support group of sorts but this never worked out. I was struck by the constraints of Linah's environment. She was unable to walk to the nearest taxi route. The roads in her area were badly potholed and shacks sprawled over the pavement. She also had no phone and was dependent on concerned neighbours to deliver messages. Nothemba's granddaughter encouraged her to maintain contact with them, but in harsh weather, many weeks passed without them seeing her. When I tried to contact Linah after not seeing her for a period of time, I was told she was not living there anymore. I did not see her again.

However this was not the last I heard of Linah. During an interview with the manager of an old age home in Khayelitsha in 2007, I learnt that Linah was now living in the home. Earlier that year, Linah spoke to members of her church about her home circumstances. Linah was being verbally and physically abused by her son and his girlfriend. Concerned for her safety, they arranged for her to be transferred to the home.

6.3. Case Three: Tata Liliso's Quest for a Cure

Tata[34] Liliso is a quiet gentle man of 69 years. I met him and his wife, Nondwe, one wet and misty winter morning at a taxi station near the day hospital where Tata Liliso collects his medication. This is a far journey each month, considering they live in close proximity to another community health centre that dispenses chronic medications, but this is preferable to Tata Liliso. The staff at the day hospital is known to be more sympathetic than those at the centre close to their home and he is willing to endure long waits and very early mornings over unbearable interactions with clinic nurses. *I would rather die on my bed than go to the clinic*, he tells me.

Tata Liliso lives with his wife, youngest daughter and one of their grandchildren in a small two bedroomed home in K1 (Khaye) in Khayelitsha. Born in 1937 in the small village of Molteno, 80 km north of Queenstown in the Eastern Cape, Tata Liliso migrated to Cape Town in 1973 in the hope of better prospects for his wife and then three young children. They first settled in the Old Crossroads area and moved to Khayelitsha in the early 1980s when the township was first established. They had two more children here and have been living in their present home for 26 years. Their home was well-built and surrounded by a cemented yard and small wall. Inside it was well furnished and tidy. The walls of the living areas were decorated by framed school photograph portraits of the Liliso children and of the reverend of the Liliso's church. Iconic Christian posters and blessings were also hung above the dining table and in the kitchen of the home.

When I met Tata Liliso he had been living with aphasia and a right hemiparesis for nearly a year. He walked with the help of a crutch. He seldom spoke and could only communicate in short phrases and gestures. He understood language if Nondwe repeated information to him in what appeared to be a well-devised communication system between the couple. A year before then, on a cold August morning, Nondwe had found Tata Liliso in their bedroom conscious but mute and

[34] Tata is the isiXhosa word for father and is a term of respect for elder men. Tata Liliso was referred to as such by both his wife Nondwe and his neighbourhood.

disoriented. Their neighbours transported him to the local clinic where they waited until evening for an ambulance transfer to the district hospital. Once at the hospital Tata Liliso was left to lie on a stretcher until admitted to the ward in the afternoon of the following day. Nondwe recalls how she waited on a bench alongside Tata Liliso, fearful that, like two other persons awaiting admission that day, he would not survive the wait.

After a brief stay at the district hospital, Tata Liliso was transferred to a subacute rehabilitation facility in Cape Town's southern suburbs. He stayed here for a month and was very unhappy. He tells me of a traumatic stay at the unit, relating particularly to his early feeding difficulties. Food was taken from him, and no help was offered over mealtimes. Nondwe looked after Tata Liliso once he was discharged home. She returned to work when he was able to walk independently. Tata Liliso's ability to communicate has gradually improved over time. He began to use single words about two month following his stroke. He can understand most verbal exchanges and when matters are pressing, he can express his needs using words, short sentences and gestures. For the most part however, Nondwe speaks on his behalf. When he is alone at home during the day, his neighbours look in on him from time to time.

Nondwe was often asked by the Liliso family why Tata Liliso fell ill. She believed they suspected her agency in the stroke. On one occasion, Nondwe was called to Tata Liliso's brother's home and asked to explain the chronology and circumstances of the stroke. His brother said that Tata Liliso's illness bore him semblance to the *isithunzela*, a disinterred corpse who cannot speak but moves with programmed actions of a witch, most frequently the wife. The family seemed satisfied with Nondwe's defence but the ordeal left her anxious about dealing with family matters and feeling unsupported by kin.

Tata Liliso is supported by a monthly state pension. Nondwe worked as a cleaner for a corporate cleaning company until the beginning of 2008 when she too qualified for a state pension. Supported by their pensions are two unemployed

children, and two grandchildren, one of whom lives with them. She passed her Grade Twelve a few years ago but has since not managed to secure employment. Nondwe talks frequently about their woes for this grandchild who does not contribute to household responsibilities and parties frequently. She wonders to me if this worry is not the cause of Tata Liliso's stroke or the ongoing stomach ulcers that have plagued him for many years.

Tata Liliso attends daily services at the United Church of Africa. Nondwe joins him on the weekend services. These frequently last for most of Saturday and Sunday. When not at church, Tata Liliso spends a lot of time at home listening to his reverend on the community radio stations. He is surprised that I haven't heard of this charismatic man. Tata Liliso refers to the tithes at his church as tickets. He regards his contributions against these tickets, such as the *amaticket*, the *umama ticket*, the *amadaughter ticket* and the *Christmas ticket* as a means of procuring of divine protection for himself and his family. Although members are not cast from the congregation for not paying their tithes, most do. '*Without your tickets the church won't bury you.'* Nondwe explains.

Since his discharge home, Tata Liliso has sought help for his communication difficulties from a number of various sources including spiritual healing, herbal remedies and individual speech therapy at the provincial hospital. At first he attended monthly speech therapy sessions, when possible, and then later biannual speech therapy appointments. These sessions, conducted by an Afrikaans-speaking therapist without the assistance of an interpreter, focused on oral motor exercises. Tata Liliso felt he had benefitted from speech therapy in the first few months following his stroke. More importantly though he knows these appointments allow him to remain an outpatient at the provincial hospital. Tata Liliso considers his outpatient status at the provincial hospital as a visa to better medical care should he require it. The reality however was that he only attended every second or third appointment, when he could afford to. As a pensioner he is not charged for hospital visits, but transport costs to the provincial hospital 25

kilometres away are significant and Nondwe is not able to work on the 'speech therapy' days.

Nondwe and Tata Liliso travelled to a spiritual healer in the Eastern Cape three times. Here they attended mass assemblies, under temporary tarpaulin constructions in a veld. Tata Liliso waited with other afflicted individuals at the front of the large congregation for the laying of hands of the healer and the simultaneous prayers of the congregation. Tata Liliso also consulted with herbalists to cure his speech difficulties. First he visited a local herbalist who charged R800.00 for the consultation and provided a herbal infusion. Tata Liliso found this medicine to be unpalatable and so sought a herbalist in Delft, a settlement north of Khayelitsha, who claimed success in treating stroke. His R50 consultation fees were considered more reasonable. Tata Liliso speaks about herbal remedies with ambivalence but accepts that they have helped others. For this reason he continues to drink herbal remedies daily.

In April 2008, Tata Liliso travelled to a private general practitioner in Molteno in the Eastern Cape who claimed success with treating stroke. Later that year, he travelled to a similar doctor in Queenstown. On both these occasions, he was given medical drugs but again by his assessment these were ineffective in helping either his physical complaints or communicative difficulties. On return from the second trip, Tata Liliso said to me, '*Now I give up'*.

6.4. Case Four: Vuyokazi's Life History and Ongoing Illnesses

Vuyokazi was 35 years old and living in a shack house in Site C in Khayelitsha when I met her. She had been brought up in a rural village in the former Transkei, near Mthatha, and was one of 10 siblings. Her mother died when she was 9 and as her father worked on the mines in Johannesburg, she was then sent to live with her uncle's family in a nearby homestead. In 1987, when she was 18 years old she came to live with an older sister in Khayelitsha in order to complete her schooling.

She finished her matric in 1989 and thereafter found a job in a city restaurant. Soon after that Vuyokazi fell pregnant and married the father of her first child in the traditional way. As her job entailed late night shifts, her daughter was cared for by her sister. When her sister's husband died however, Vuyokazi sent her child to live with her husband's mother near George, a Western Cape town 475 km from Cape Town. Vuyokazi stayed with her husband for only a short number of years. He worked as a seasonal farm worker in the surrounding farm areas of Paarl and Worcester. Vuyokazi left her job in town to follow him but he drank heavily and physically assaulted her. So she fled back to Khayelitsha and stayed with her sister. She did not see her husband again.

After this, Vuyokazi lived with her sister for a number of years. During this time, she had a second daughter and found work as a domestic worker for a family in town. Vuyokazi's sister married again and moved from Khayelitsha to another township area. Vuyokazi remained living in Khayelitsha with her young daughter. She maintained contact with the father of her second daughter but they did not get married.

In 2006, a year before I met her, Vuyokazi collapsed at the taxi rank waiting to board a taxi home after work. She had suffered a stroke. People at the taxi rank used her cell phone to call her sister who came with her husband and took her to a private doctor. The doctor referred them to the secondary hospital in Mitchell's Plain, a district to the west of Khayelitsha, and from there Vuyokazi was transported to Groote Schuur, the large provincial and academic hospital complex in Cape Town. She was told that she had a heart condition and suffered from hypertension. She was discharged to the care of her sister the following day. Vuyokazi's stroke was not categorised as severe but she was left with a mild right hemiplegia and following her discharge she remained confused. She also realised that she did not recall things clearly, that she was extremely sensitive to noise and that she battled to express herself and to understand complex matters. In addition, there was a large emotional component to the effects of the stroke. Vuyokazi needed to send her daughter to live with her paternal grandmother in Nyanga, a

neighbouring township and to move in with her sister and her sister's husband. Her former boyfriend and father of her younger daughter no longer maintained contact with her. She struggled to come to terms with all this and with her diagnosed heart condition.

Following her stroke, Vuyokazi continued to suffer from a mild hemiplegia and associated pain and discomfort in her right shoulder. She also continued to present with communication difficulties. She would describe how she battles to remember what is said to her, how jokes allude her, how she finds it difficult putting her ideas into words, how she confuses words, such as 'tomorrow' when she means 'today' and how she needs practical help in completing forms and in reading correspondence. She also frequently stated that she comes across as *not right* to other people.

It is the latter complaint that concerns Vuyokazi most about her language difficulties. She feels that this renders her vulnerable to crime and to exploitation from men. As a result Vuyokazi chooses not to be involved in any new relationships. She also continues to live without her daughters, seeing them only over the weekends or school holidays. As she put it, *"The community here know that I am not right. They take their chances with me. I don't want them to take their chances with my daughters too."* She continued further that she feels unable to protect her daughters from the dangerous elements in her community as the result of her own physical and cognitive difficulties.

When I met her, Vuyokazi lived on her own in a shack in Khayelitsha. This shack, a wooden frame covered in metal sheets, was approximately two by three metres in size and contained a steel single-sized bed, a small table and a two kitchen chairs and a cabinet containing her provisions and groceries. Vuyokazi made use of a shared toilet and tap located in a nearby street and washed in a bowl. She cooked and heated her small abode using a paraffin cooker. Although Vuyokazi stayed with her sister and brother-in-law in another township in the months following her stroke, she was forced to move when their marriage was under

strain and her brother in-law blamed her for their difficulties. Her sister continues to help her both practically (in terms of housework, shopping and managing day-to-day affairs) and financially. Vuyokazi is now also reliant on her neighbour, Thandeka, for practical and emotional support. Thandeka will loan money and provisions when needed and Vuyokazi feels that she keeps a watch out for her. She also helps her negotiate doctor's appointments and her medication regimes.

Vuyokazi is on a number of chronic medications. At the hospital following her stroke she was placed on medication for hypertension and for cholesterol. Since then, she had been prescribed with medicine to control suspected seizures, insomnia, anxiety and inflammation (due to ongoing pain in her right shoulder). Over and above this, Vuyokazi was diagnosed with an ulcer and takes medication for this too. On a monthly basis, Vuyokazi collects her medicine for hypertension and cholesterol from the day hospital near to her. Every six months she attends an outpatient orthopaedic clinic at the provincial hospital in the city due to her ongoing difficulties with her shoulder. She attends an outpatient neurology clinic for the purpose of monitoring her suspected seizures. Vuyokazi also however seeks the services of private doctors in Khayelitsha in between these visits. She has other ongoing physical ailments. It seemed to me that with each new consultation, more medicine is incorporated into her regime. On one interview, I enquired about this and Vuyokazi produced the bottles and packets of medicine that she was currently taking – some regularly, some only symptomatically. These included:

Tegretol (carbamazepine) and Epilum (sodium valproate) for suspected seizures (packets empty, no longer on this medication)
Simvastatin for elevated cholesterol levels
Ridaq (hydrochlorothiazide) for hypertension
Ten bloka (atenolol) for her heart condition
Dormicum (midazolam) for sleeping
Nexiam (esomeprazole magnesium) for her ulcer
Cataflam (diclofenac) for her shoulder pain
Adco-dol (codeine) for headaches
Mucospect (carbocysteine) for ongoing upper respiratory tract infections and allergy

Mouth ulcer gel
Berocca (combination of group B vitamins and vitamin C) for her general well-being
Vitamins for premenstrual syndrome
Rescue remedy (Bach flowers) for anxiety
Ginkgoforce (Ginkgo Biloba extract) for memory
Generic eye drops and ear drops

Not surprisingly, I felt Vuyokazi was confused about her medication. She was also confused about her health care in general. She had difficulty understanding information given to her by the various health workers treating her numerous health concerns. At the provincial hospital, this was exacerbated by Vuyokazi's difficulty in English but she experienced similar problems at the day hospital.

In the time that I knew Vuyokazi, the concerns she took to both state-run clinics and private doctors in Khayelitsha and in Cape Town were treated by medication. She received no referrals for other kinds of support or help, although I felt that her visits were part of her search for both understanding of these symptoms and for relief from a difficult life. Her problems seemed to get worse too. She no longer attended the church group to which she once belonged. She became estranged from some of her siblings and seemed overcome with the demands of the world. She did however manage to maintain part-time employment. Vuyokazi worked as domestic worker with a sympathetic family who accommodated her physical weakness. Although Vuyokazi felt that her communication difficulties did not interfere with her work, her employer was concerned about her memory problems and Vuyokazi really battled with the physical nature of her work. But she pressed on. She did not qualify for a disability grant - her physical, cognitive and communicative difficulties were not considered severe enough to preclude her employment.

6.5. Case Five: Nyathi's Recovery Following his Stroke

Nyathi was a cheerful and kind man in his forties who lived with a mild to moderate expressive aphasia following a severe stroke four years previously. He was also a very proud father of two young daughters and a husband to Nomangesi who taught at a local primary school. Despite evident word finding difficulties and effortful sentence formulation, Nyathi could communicate verbally. This was not always the case. Following his stroke, he was unable to communicate at all and remained non-verbal for three months, before he slowly regained most of his language skills. Nyathi considered himself a lucky man to be walking and talking and, being deeply religious, a blessed man too. Nevertheless his life was irrevocably changed by his stroke. He could no longer work as a sales agent at a car hire company, due to the high literacy demands of his previous work, and stayed home to look after his daughters. The family was now financially dependent on Nomangesi's salary, although Nyathi operated a small school lift club in his *bakkie*[35] for extra income.

Nyathi not only lost his job as the result of his aphasia, he also lost his ability to preach. Nyathi was formally a pastor of a small Anglican church in Khayelitsha. He continued however to play an important role in his church and his neighbourhood. He visited the sick and provided lifts to neighbours and church members. He also supported those in his neighbourhood who had suffered strokes. Here he was forthcoming with practical advice, particularly about diet and exercise, which he proclaimed to be the '*new medicine'*. I met him on one of his morning visits to the Mdubeki household. He was excited to learn about my study and asked immediately to be involved my research. Nyathi felt that people in his community understood little about stroke in general and nothing at all about aphasia. This, he felt, translated into people not being able to make lifestyle changes, such as eliminating red meat from their diet or exercising their impaired limbs in order to regain their health and functioning. Nyathi practised what he preached in this regard. He went to a private gym in Site B most mornings of the

[35] The common South African term for a light body pick-up truck.

week and for a time took George with him too, showing George how to begin to use his right hand and arm.

It was evident that Nyathi had adopted a medical framework of interpretation of his stroke and subsequent aphasia although as I came to know him better, it seemed that he straddled the divides between traditional, religious and medical life worlds. He believed his stroke was due to high blood pressure, a condition he was not aware of until he stroked whilst driving home from work one day and woke up in hospital. His recovery he ascribed to both divine intervention and his own efforts in rehabilitation and lifestyles changes. Others that he knew however had had strokes because of actions or events in their past that either displeased the ancestors or made them vulnerable to sorcery. Nyathi wasn't averse to talking about these notions, like others that I met in my fieldwork, but he repeatedly made it clear to me that, as a pastor, he was not really allowed to entertain such notions.

Nyathi was one of the few people I encountered in Khayelitsha who received aphasia therapy by a language therapist in the acute stages of their stroke. Although it was so long ago, he could remember few details. What he did recall however were the difficulties of going home three months after having suffered his stroke with no referral for follow up therapy. His wife was not involved in his rehabilitation in any way. He was placed in a facility in the city centre and she was only able to visit him on weekends. When Nyathi was discharged home, Nomangesi was told about blood pressure medication and how to help Nyathi to move from his bed to a chair. She did not learn anything about the nature of his communication difficulties post-stroke but they did find a way to communicate around pressing functional needs. Nyathi often reflected on this time immediately following discharge, recalling how he was excluded from most discussions about plans for how his family would now function without him as its head.

Nyathi was referred to the physiotherapy outpatient department at a Community Health Centre and attended exercise groups for the first year following his discharge home. Here Nyathi learnt about healthy living and eating. In addition,

acting on advice from family, friends and neighbours, he also tried numerous medicinal remedies, vitamins, oils and supplements for his physical ailments.

Nyathi received a disability grant for the first three months following his stroke. The grant application process had been handled by a social development worker at the rehabilitation centre. Nomangesi collected the grant but did know that it was temporary until she was turned away at the payout facility in Khayelitsha. Soon after Nyathi returned home, his grant was suspended on the basis that the physical and communicative sequelae of his stroke were temporary. He was expected to make a full recovery. At this stage Nomangesi attempted to apply for a permanent grant on Nyathi's behalf but this application was rejected on medical grounds - Nyathi had apparently made a full recovery. Despite this however he was never able to return to his former employment.

Nyathi and his wife Nomangesi hoped that one day he could work again in the same capacity prior to his stroke. They had hoped to be able to send their daughters to school in the city where English is the medium of instruction and where education standards are higher. They had hoped to make renovations to their house or even one day move to a more suburban area, where they could have a lawn, a telephone line and better security. For now however they lived within their small means.

As a point of reference for the reader I have summarised information relating to the key participants in Table 2 presented below. The results of this ethnographic study, based largely on these case accounts, are presented in the chapters that follow.

Table 2: Summary of Key Case Accounts

Participant	Age	Gender	Details of Stroke	Communication abilities	Living circumstances	Causal beliefs	Help-seeking strategies	Health care	Social support
George Mdubeki	55	Male	Massive left hemisphere stroke in January 2005, dense hemiplegia and severe aphasia, requiring assistance for all aspects of daily functioning	Verbal abilities limited to *yes* and *no* and to gestures showing strong emotions. Only able to understand simple language	Lives with wife, 4 daughters, 1 son, 1 grandchild, 1 nephew in self-built brick home	Sorcery sent by jealous kin Eating too much meat 'Sugar' Neglecting mortuary rites of father	Herbalists Traditional healers Faith healers	Rehabilitation centre Outpatient physiotherapy Local clinic for medication and monitoring of hypertension	Monthly state disability grant Neighbourhood friends Woman's prayer group (George's wife) Adult day care centre
Linah	76	Female	First stroke – right hemisphere Second stroke – left hemisphere in 2002	Communicates in short sentences and makes use of a lot of gesture, can understand verbal language	Lived with son and girlfriend in brick home, later placed in old age home	Mugging Alcohol abuse of child	None	None	Monthly state pension Church Neighbour
Tata Liliso	69	Male	Left hemisphere stroke in 2006	Usually quiet and withdrawn; expresses himself in short sentences but his speech is slurred, can understand verbal language but experiences confusion	Lives with wife, daughter and grandson in brick home	Behaviour of daughter and grandson Family accused his wife of witchcraft	Herbalists Faith healers Speech therapist	Rehabilitation centre Outpatient speech therapy Local clinic for medication and monitoring of hypertension	Monthly state pension Church Neighbour Brother
Vuyokazi	35	Female	Left hemisphere stroke in 2006	Communicates verbally, has difficulty	Lives alone in shack dwelling, two	Heart disease	Medications and remedies	Private doctors	Part-time employment as a

				understanding written language and complex verbal language, particularly in English.	daughters sent to live with their respective grandmothers after stroke			Local clinic and tertiary hospital-based clinics for medical management of chronic ailments	domestic worker Neighbor Sister Church group
Nyathi	43	Male	Left hemisphere stroke in 2001	Gradually regained ability to speak following stroke but has difficulty finding words. Struggles to read and write.	Lives with wife and 2 daughters in brick home	High blood pressure	Local gym Commercially available remedies	Rehabilitation centre Inpatient speech and language therapy Outpatient physiotherapy at primary care	Church

PART THREE

THE CULTURAL CONSTRUCTION OF APHASIA

In Part Three of this thesis I look to cultural interpretations of aphasia and indigenous therapeutic choices in Khayelitsha. How is impaired speech and language loss interpreted in a community where spiritual frameworks of illness and misfortune co-exist with processes of modernity and with biting poverty? How do these interpretive frameworks, and the cultural and social context in which they operate, influence treatment seeking and ultimately the experience of aphasia?

In approaching these questions, I first explore understandings of stroke and communication loss in Khayelitsha. I describe how this affliction is presented and understood by residents and I detail how people account for the sudden and long term consequences of stroke. Much of my understanding in this regard comes from discussions with nurses at the local clinics and hospitals. Regarding me as somewhat of a specialist in stroke, they frequently engaged me in dialogue around causal explanations. In addition, the discussion of cause by adults with aphasia and their families was one they returned to again and again. These discussions came to assume a wider significance than stroke and were essentially about the individual, gender and community struggles that beset their lives.

Secondly I describe the range of indigenous healing practices explored by the participants of my study. Their journeys reflect the plural nature of healing in South Africa. Whyte's (1982) critique of the operational definition of medical pluralism however seems relevant here. Whyte argues that in African contexts, different therapeutic systems represent various cultural heritages within one society as opposed to a definition of pluralism that refers to alternative health societies within one dominant culture. In this section I draw specifically on two of the key case studies of this thesis in an attempt to illustrate the socio-cultural

complexities of healing in Khayelitsha. Their help-seeking journeys were so much a part of their experience of aphasia, particularly so in the first year following their strokes. In my discussion, I have attempted to apply these anthropological understandings to rehabilitation practice. My objective is to consider appropriate clinical recommendations.

CHAPTER SEVEN
FRAMEWORKS OF INTERPRETATION OF APHASIA

7.1. Illness Causation in Southern Africa

Anthropological accounts of ideas of disease or illness causation in southern Africa describe a vast set of assumptions. Attempts have been made to systematise these assumptions [for example, Wessels' (1985) classification of the five bound syndromes] however as Green (1997: 93) emphasises, these aetiological categories are 'permeable'. Generally though, broad classifications can be drawn. Ngubane (1977: 23) describes two categories of illness amongst the Zulu people. Illnesses of natural causes, including illnesses caused by biological disruption or by harmful substances in the environment and pollution, are referred to as *umkhuhlane*. Green (1999) contends that the idea of pollution, essentially a theory of contagion, is central to these causal notions of disease. Then there is the category of illness referred to as *ukufa kwabantu*, the diseases of the African people. According to Ngubane these diseases are so classified because of ideas of their causation. Hammond-Tooke (1989: 46) proposes four basic etiological agents in African illness. These he suggests are witchcraft, ancestors, pollution and God. Here the idea of an ultimate cause is common, particularly in the case of a chronic or incurable disease, where questions of cause centre around '*why me*', '*why now*' and '*who sent this'*. Westerlund (1989: 205) however reminds us that these categories of illness are ideal types; in practice they are usually combined.

7.2. Descriptions of Stroke and Aphasia in Khayelitsha

Stroke is a well recognised phenomenon in Khayelitsha and is referred to as *istroke* or *isistroke* in the plural. The understanding is that stroke is an affliction that happens – '*(s)he got a stroke*' being a familiar descriptor. The metaphor of attack seems common too. Although the affliction is frequently described as one

that involves the '*hand and foot not working'*, stroke is considered alongside epilepsy, head injury and other neurological diseases. My data suggests that stroke, and the cognitive and communicative sequelae arising from stroke, is differentiated from mental disturbance and forms of dementia. It is generally regarded as an affliction of the elderly that is in more recent times affecting the youth. People seek explanations for this perceived rising incidence in current social problems.

Following stroke, speech was described as absent, slurred or normal. There appeared to be no category of description for effortful speech attempts or non-communicative speech or impaired comprehension. In this way, people did not seem to make apparent differentiations between speech and language problems following stroke. Notions of blame and agency were evident in descriptions of speech impairment. These include speech being '*cut*', '*taken away'* and '*removed*'. In addition, total loss of speech was often associated with shock. In these instances the locus of problems was considered to be the throat. Those who were unable to speak at all were also sometimes labelled as insane or stupid and nonsense or jumbled speech was associated with a loss of intellect or with mental illness. A common descriptor for someone who cannot talk was '*isidenge'* described to me as a term for '*someone who doesn't know anything*'. It is a derogatory term. Many people spoke about others with aphasia as being children and requiring the same protection and care as children require.

7.3. Ideas of Causation of Stroke and Aphasia in Khayelitsha

In Khayelitsha, I encountered numerous different explanations as to the cause of stroke and aphasia. These are presented in Table Three. Prevalent were traditional Xhosa explanations that gave credence to ancestors, and agencies of sorcery and witchcraft. Within these were interesting metaphors around loss of voice. Mechanistic explanations were also offered, in particular '*high blood*' and '*sugar*'. The understanding of these was often obscure and sometimes concrete.

At another level, I encountered widely held notions that stress, relating to present living circumstances, crime, unemployment, intergenerational tension and lack of cash resources, played a part in the onset of stroke and long term affliction. Here '*pressure*' (used interchangeably with high blood pressure) and '*thinking too much'* (used interchangeably with depression) were idioms of distress, seemingly derived from biomedical notions. Using anthropological evidence from my time in Khayelitsha, these different perspectives will now be considered. Of interest are the influence of context and the role of causal beliefs in help-seeking and social experiences.

Table 3: Causal Attributions of Aphasia Derived from Various Informants During the Course of this Study

Causal Attributions of Aphasia
Ancestor reprisal
Not performing rituals or rites to appease ancestral shades (*amasiko*)
Not performing ritual slaughter to accompany the dead to the afterlife
Not returning to graves of dead kin
Not having gone through traditional rites of passages such as: naming ceremonies (*mbeleko*), circumcision (*ukwaluka*), and female fertility rites (i*ntonjane*)
Adoption of mother's clan name
Ingestion of meat considered taboo, not slaughtering according to customary ways
Calling to a healing vocation (*ukhutwasa)*
Not heeding call to healing vocation
Bearing witness to the activities of the water spirits
Killing ancestral manifestations or messengers, such as the frog
Adopting the ways of the church
Adopting white ways
Hitting another's child
Abandoning familial obligations
Witchcraft and sorcery
Attacks by jealous neighbours and kin
Ingesting of poison (*ibeleko)*; stepping on poisons that had been placed in path
Being hit by the *storum*
Coming into contact with witches' familiars, kicked by *mpundulu*
Seeing perpetrators of witchcraft; bearing witness with the *naked eye*
Seeing that which you should not see; seeing *ukwelama*
Other cultural conceptions
Too much heat in the blood / body
Mechanistic explanations
'High blood'
Pressure
Sugar
Thinking too much
'Confusion on the brain'
The *Plague (*reference to HIV and AIDS*)*
Cut vein in the head
Obesity
Unbalanced diet; consuming excessive red meat; eating white man's food
Social causes
Stress and anxiety
Progress
Burden of care on women
Stressful living conditions
Separation from family
Divorce
Lack of access to cash resources
Single parenting; difficulties of raising children
Misunderstanding between family members, an argument
Intergenerational tension
Prevalent crime; vulnerability of elderly to crime
Not knowing

7.3.1. Ancestors and communication loss

Veneration of ancestors is a common practice in African culture. Among the amaXhosa the ancestral spirits (*izinyana*) are usually the deceased senior males of the clan who oversee that cultural obligations are fulfilled and morality is upheld. Failure to perform ritual duties, ignoring cultural traditions (*amasiko*) and neglecting family obligations may displease ancestors who send punishment for these wrongdoings (Kiernan, 1995a: 22 - 23). In addition, failure to heed the call of a healing vocation is met with reprisal from the ancestors. Ancestors are also thought to remove their protection from individuals for breaking taboo or custom, exposing them to the polluting agents in the environment and the malevolent agents sent through witchcraft.

In Khayelitsha, a failure to perform some or other ritual duty is a common explanation for misfortune in general, including stroke. Stroke is believed to be sent by ancestors and was described to me as a '*harsh reminder*' from ancestors that a ritual needed to be performed. Ritual included the slaughter of a cow or goat to accompany the dead to the afterlife (*umkhapho* and *umbuyiso*), a return to the graves of dead kin, naming ceremonies (*imbeleko*) and rites of passage such as circumcision (*ukwaluka*) and female fertility rites (*intonjane*). Stroke is also seen as a warning sent by angry ancestors to people who had abandoned traditional ways. In particular, adults who had adopted their mother's clan name and who had not been formally initiated (*imbeleko*) into their father's clan are regarded as vulnerable to stroke. Although most explanations I encountered were extended to general misfortune and ill health, there was a sense that the latter explanation was more particularly focused on stroke.

Sudden loss of speech was considered by some as analogous to choking. In ritual slaughter, the cow or goat must bellow before it is killed. If this does not happen, the act cannot be considered customary and eating this meat is considered taboo. People who were unable to communicate were sometimes described as having choked because of eating this meat.

For some, aphasia following stroke was associated with ancestral intervention because of failure to heed the calling to be a healer. Episodes of emotional upheaval or illness, termed *inkenkqe*, are interpreted as a calling to be a healer and to embark on training in this regard (*ukuthwasa*). This calling can also come in dreams (*amathonga*) and can be repeated at various intervals over the course of an individual's adult life. Repeated failure to heed such callings could result in eventual mutism and loss of voice, or even loss of mind. Those who ignored the vocation of being the voice of their ancestral shades risked having their voice taken away in later years. Funeka, a nurse at the rehabilitation hospital, described this process:

> Ancestors may want to use a person in their own way. If you are a Xhosa, maybe you are supposed to be an *igqirha*[36] or be called according to our belief. Sometimes they say it's a slight stroke, then they [ancestors] bring you to the *igqirha* and they can talk about you and things you should follow. Then you are told several times that you should do certain things and you don't follow the dreams that you've been told by your ancestors claiming some things to you. Sometimes you dream of yourself wearing white clothes and white chains[37]. Then you reject those dreams and that's the place where you're supposed to be. Then you dream of yourself digging the herbs, then you reject again. Now what they are going to do is remind you by force to know that you understand. They don't stop. They cut your speech.

Ancestors also reportedly send stroke as reprisal for errant behaviour. I encountered explanations for stroke that included smacking another's child, abandoning family and ignoring family obligations. In this regard too, stroke was punishment. Stroke however was not only regarded as a reprisal for wrongdoing.

[36] Meaning a diviner. See 8.5.1.

[37] According to Hirst (2005) the colour of white is of significance in dreams and represents the diviner or novice. The diviner wears white beads. White in dreams may be interpreted as a signal to the dreamer they are being called by ancestors to a healing vocation. *Inkenkqe* is referred to as the white sickness.

Stroke, particularly in younger people, was also considered a sign of *inkenkqe*. My informant's sister suffered a stroke as a young adult and lost her speech. She embarked on *ukuthwasa* and is now a practicing healer in Beaufort West. The recovery of her speech was a sign that the ancestors were appeased[38].

I came upon a number of references to river myths and water spirits in regard to stroke and aphasia. Ancestral shades live in the rivers, forests, sea and grasslands. Those who live in the river manifest as mermaids or snakes and play a particular role in the calling of healers. If someone suffers a stroke after going down to the river, the stroke is attributed to the water spirits and interpreted, at times[39], as *inkenkqe*. I learnt that 'going down to the river' was also a metaphorical description of the dream associated with ancestral calling.

The water spirits also caused stroke and loss of voice in individuals who saw but who weren't supposed to. This latter explanation was more related to communication loss following stroke; aphasia was considered the result of shock or fear from seeing what one is not supposed to see. Some mentioned that the water spirits may purposefully remove a person's capacity for speech so that they will be unable to bear witness. Water spirits are believed to come out of the water at night and it is for this reason that it is considered dangerous to go to the river at night. Certain water creatures, the frog, otter and hippopotamus among others, are believed to be messengers for the water spirits. These messengers may summon people to the water. Also considered ancestral manifestations, many believe these creatures shouldn't be harmed. I encountered two explanations for stroke that had incorporated this aspect of the water myths. One, from a nurse at the local hospital, was interestingly metaphorical:

[38] For a full description of *ukuthwasa* see Ensink and Robertson (1996).
[39] Hirst (2005) explains that when an episode of illness or emotional or mental disturbance is interpreted as *ukuthwasa*, there are almost always associated personal characteristics of perceptiveness and hints of psychic abilities.

> A patient that we just had hit the frog then she lost the speech. She tried to talk but there was nothing coming out except kokoko-kokoko. Then I knew she had just killed the frog.

These wide-ranging explanations of ancestor reprisal for stroke were predominant over other causes. The central concern was thus: signs of affliction, including stroke, are the result of customs not being upheld. In Khayelitsha, it would seem that aphasia attributed to ancestral intervention is interpreted in four ways. Firstly ancestors may remove a person's capacity for speech as a punishment. Secondly ancestors may remove their protection from people exposing them to harmful agents. Loss of ability to communicate is also thought to be related to shock at bearing sight of the ancestral shades. Lastly disruption to speech can be interpreted as a sign of *inkenkqe* – the particular illness sent by ancestors to individuals as a calling.

In Khayelitsha, ancestor reverence roots people in both customs and moral ways. It also assists in maintaining membership to clans and connections to rural homes. The accompanying rituals of ancestor reverence involve slaughtering and cattle fines. Fulfilling these obligations is however difficult in an urban setting. Firstly substantial cost is involved. Cattle fines and bridal wealth are now in reality cash transactions and people may need to travel far distances back to their rural homes. Secondly, it is necessary for all elder family members and those within the clan to be present at many of the rituals, yet families in this context are almost always fractured. Thirdly, a cow or a goat needs to be purchased. This is both costly and in the urban environment, ritual slaughter has become a controversial issue[40]. Lastly, many people cannot afford to take up *ukuthwasa*. This means periods of unemployment and training fees. As a result most people in Khayelitsha have unfulfilled obligations and a wide range of illness and misfortune is attributed to this. Here, there is a sense of entrapment. The urban environment has brought constraints in performing wishes of the ancestors, making these people vulnerable

[40] M. Williams, 'Pink house owner slaughters sheep at home, Cape Argus, M.Louw, SPCA after Yengeni for 'ritual', *Die Burger*, 08/08/2005, 22/01/2007, World Cup stadium 'cow sacrifice' plan sparks row, *BBC News*, 01/12/2009, retrieved from http://news.bbc.co.uk.

to illness and fearful of reprisal. These constraints similarly impose on this community's ability to remedy situations and seek ancestral intervention in the healing process. Equally, social difficulties, such as female headed households and the disintegration of the family unit, limit the extent to which this community can adhere to cultural custom.

Possibly because reprisal for unmet obligations was common cause in Khayelitsha, I never sensed that these beliefs played a role in a disabled individual's acceptance by society. People spoke about stroke due to ancestral displeasure in a matter of fact manner. Many regarded stroke as a new phenomenon, both increasing in incidence and afflicting young and old alike. Regarding stroke and other misfortunes as ancestral punishment gave voice to their present struggles to maintain cultural custom in an urban environment. Stroke was not only attributed to ancestor reprisal but also to the forces that make it difficult for this community to maintain links with their ancestors. In particular, people found themselves divided between carrying out the actions of ancestor reverence and following the ways of their church. As one Khayelitsha resident explained to me, '*people get saved and forget about his roots'*

7.3.2. Witchcraft in communication loss

Although there was a general reluctance to talk about witchcraft[41], it certainly held a central place in causal beliefs among resident of Khayelitsha. Witchcraft and sorcery in Africa have always been a source of study for anthropologists. Evans-Pritchard's classic analysis of Azande witchcraft (1937) is now considered against a revival of witchcraft ethnographies in sub-Saharan Africa. This is because beliefs in the occult forces are predominant, possibly even heightened. Witches are thought to bring afflictions to people through visitations from fantastical and

[41] The distinction between witchcraft (*ubugqirha*) and sorcery (*ubuthakatha*) is blurred in Xhosa culture (Hirst, 2005).

certainly evil creatures such as the *thikoloshe*[42], a malicious dwarf-like creature with a large penis, the lightning bird (*impundulu*) and the snake (*mamlambo*) or by poisoning through the ingestion of poison (*idliso*)[43], sent to people through dreams or by jealous others. The work of the witch causes misfortune, social death, infertility and loss of material resources, a disruption in the life path of the sufferer of chronic ailments or mental disturbance. In Khayelitsha, jealousy was regarded as the primary motive for witchcraft.

There are a number of recent anthropological works that explain the centrality of witchcraft in the narratives of suffering and ill health among African communities in post-Apartheid South Africa. In the following discussion, I summarise these works as I believe the explanations are important for a sensitive and realistic understanding of what may seem at the surface to be irrational contentions or retreats into tradition.

Witchcraft is a universal phenomenon, particularly in times of social instability and accusations arise out of the social realities that people have to contend with such as poverty, unemployment, disease, insecurity (Comaroff & Comaroff, 1999; Ciekawy & Geschiere, 1998). The sources of witchcraft therefore are not to be found in the supernatural realm, they are an expression of the structural social problems in South Africa today. Kiernan (1995b: 124) contends that recently urbanised migrant labourers, unable to grasp the political forces and market operations of the city, applied pre-existing thought patterns to make meaning of their misfortune. The social strain and competitiveness, the limited resources and the rising levels of disease and malnutrition in the cities led to the conviction that sorcery had become rampant. Bahre (2002) in his ethnography of intimate relations among migrant Xhosa workers in Cape Town shows how the pressing concerns in everyday township life, being violence, economic insecurity and

[42] See Bahre (2002) for a detailed description of the *thikoloshe*, a creature frequently featuring in historical Xhosa myth and in contemporary beliefs of witchcraft practices.
[43] Ashforth (2005a: 9) describes *idliso* as much more than the usual English translation of poison. *Idliso* is a poisonous substance created by the witch, which when ingested takes the form of a creature such as the snake and devours the victim from within 'causing all manner of misfortune to befall the person in the process'.

difficulty maintaining relations, bear close resemblance to the horrifying practices of witches and witch familiars. Comaroff and Comaroff (1999), describing the increase in witch hunts, ritual murders, and beliefs in magic in the Limpopo Province, explain witchcraft as a new form of consciousness that expresses the disintegrating effects of globalisation on value, social networks and generational order. The Comaroffs contend that political liberation did not bring liberation from the grind of daily life for most rural Africans in this region. Explanations of witchcraft are invoked to explain material inequalities, particularly between the youth, with few prospects for employment and the elder generation who were relatively more well off. Accumulation of wealth is an elusive phenomenon in economic hardship. Those who seem to have accessed the new found prosperity are accused as having used evil means. Ironically, the more well off are in fear of jealousy by kin and neighbours and frequently ascribed misfortune is this. Ashforth (1998) links the perceived increase in witchcraft in Soweto, a large township south of Johannesburg, to spiritual insecurity from rapid social transformation and to material differentiation in the context of impoverishment. Segar (1997) in examining explanations for illness used by Ciskeian villagers relates the prevalence of ideas of witchcraft to the powerlessness that permeates all aspects of the lives of a community living in poverty and isolation. Ciekawy and Geshiere (1997) describe the increase in discourses of witchcraft in parts of Africa as a metaphor of the uncertainty of this global age. Witches use technological forms of communication and transport to bring affliction to communities that were once relatively sheltered from the outside world.

If one considers witchcraft as a social gauge and an indicator of social instability, its centrality to the discourse of illness and affliction in Khayelitsha is not surprising. Suffering at the hands of both tangible and intangible forces was a pervasive experience for the participants of my study. For them, acquisition of health and wealth is as intangible as the occult forces. This was captured for me in a striking way by a comment from Thandeka, a young nurse from Khayelitsha. *We accuse each other because no one knows*, she told me. In addition, stroke may be the archetypal affliction of witchcraft in its suddenness, its invisibility, its

disabling sequelae and its chronicity. Adults living with aphasia post-stroke may bear close resemblance to the *izithunzela*[44](zombie), agents of the witch who are 'bereft of tongue[s] to give voice to their affliction[s]' (Comaroff & Comaroff, 1999: 289). Nondwe was accused by kin of bewitching her husband in this way.

Jealousy as the primary motive for witchcraft is a well documented social phenomenon in contexts where material differentiation exists in the context of poverty. People in Khayelitsha believed that stroke could be the result of poisoning (*ibeleko*) by jealous kin or neighbours who sought the agency of a witch to send *ibeleko* to the intended victim in a dream. *Ibeleko* could also be purchased from witches (or errant healers) and placed where it could come into contact with the intended victim, such as in their path.

When jealousy was not presented as the motive behind witchcraft, people considered attacks arbitrary or accidental. Some strokes were attributed to having seen or overheard malicious intent or activity. In these instances it was thought that people were struck dumb with terror or targeted by evil agents who did not wish to be exposed. Here the loss of voice was considered significant.

People could also be harmed by coming into contact with the tools used by the witch or with the poisonous substances concocted for others. I encountered explanations for stroke that involved being hit by the *storum*. Some residents explained to me that the *storum* is the stick used to stir herbal concoctions by both healers and evil agents. Other residents suggested that *storum* is the mixture of substances and if hit on the head with the stick used to stir these substances,

[44] The occult phenomenon of *izithunzela* explains the practice whereby a witch enslaves the dead, forcing them to work for her at night. This was described by Hunter in 1961 (289). Comaroff and Comaroff (2002) however argue that there is a resurgence of the zombie phenomenon linked to the neoliberal economy in post-apartheid South Africa. The attainment of wealth is no longer a tangible and logical process and those excluded from this process thus draw on both old and new and local and global explanatory theories to make sense of their exclusion. The practice of the zombie is a way of explaining their joblessness and their inability to secure a material and social family life.

residual *storum* could bring on a stroke[45]. Either way, being hit with the *storum* could bring on stroke immediately or later in life. Coming into contact with the familiars of witches, such as the lightning bird *(impundulu*) was also presented as a causal notion.

Evidence for these causal attributions was sought in the physical manifestations of stroke. Mavis considered whether her husband's speech difficulties after a stroke were because he had bore witness to his perpetrators. They in turn took away his voice so that he could not seek reprisal. A local diviner corroborated Mavis's theory. Some participants spoke of the physical disablement of stroke as evidence for *ibeleko* in the path of the victim. Victims would experience paralysis in the foot and leg that stood on the poisonous substance and this substance may travel to the mouth and brain. Walking in the early hours of the morning was considered dangerous. The suggestion here was that animals should tread the path before them in order to crush possible poisonous substances that could have been placed in their way (*umkhondo*), highlighting, again, that the changes brought about in an urban environment constrain the extent to which people can protect themselves from harmful intent.

Fear of jealousy by kin and neighbours was a common theme in conversation in this community. People were conscious about concealing material accumulation. There was scepticism and mistrust that either underscored potential resources that people could turn to in times of need or that gave expression to the limited value of social security in this community. I found this gave yet another expression to the iniquity of poverty; inequality between people who depend on one other erodes relations and networks of support, a discussion I present in Chapter Nine of this thesis.

[45] I was unable to find published clarification on the exact meaning of '*storum*'.

7.3.3. Mechanistic explanations for stroke

The terms '*high blood*' and '*sugar*' frequently punctuated the discussions about health. These terms also repeatedly came up at stroke groups in the primary care clinic, in discussions with primary care nurses and in care centres for the elderly, suggestive of the wide held notion that high blood and sugar were diseases that predisposed someone to stroke. While at first glance such attribution implies an understanding of biomedical notions of blood pressure and diabetes, it became clear, however, that these terms were understood in a more concrete way. Sugar referred to sugar in the blood and high blood to excessive amounts of blood in the body. Even in the primary care clinics, these terms did not necessarily refer to hypertension or diabetes. Similarly, I encountered varied interpretations of '*pressure*' where high blood pressure bore reference to the pressure of everyday life. This has also been described in a community in Dar es Salaam, Tanzania (Strahl, 2003) and reflects what Nichter (1981) describes as an idiom as distress.

I don't believe these causal attributions reflect a breakdown in communication between health professionals and patients in this community as much as failure on the part of health care practitioners who don't have the time or skills to help patients reach an understanding of biomedical explanations. '*Sugar*' or '*high blood*' sufficed. Yet, health care workers and families alike spoke of sugar and high blood as if they were diagnostic entities. These terms may therefore be adopted terms, with their own local meaning, arising from the interactions between health professionals and patients of diverse educational, language and cultural background. The biomedical references in the terms '*sugar*' and '*high blood*' are evident, however they also resonate another 'interpretive authority' (Ashforth, 1998: 65). In theories of ancestor reprisal, disturbed relations with the ancestors are thought to cause disturbances in the blood leading to illness. There are also numerous references to blood in discourse of witchcraft (Bahre, 2002). Similarly, the term sugar is often linked to balance and imbalance, a central concept of illness beliefs in traditional African medicine.

There are inherent dangers to the adoption of local terms. In the healthcare context, it may obscure superficial understanding of mechanistic explanations. In my experience in Khayelitsha, staff at the clinic did not necessarily consider the variable meanings of the terms sugar, high blood and pressure. However, the participants of the study were determined to make the necessary lifestyle changes to reduce high blood and sugar, presumably responding to prevention programmes at the clinic, even if their understanding of the relationship between the two was obscure.

Another expression that came up frequently in allusions to causes of stroke was '*thinking too much*'. In Khayelitsha, '*thinking too much*' refers to high levels of anxiety and worry or to depression. Among residents and health care workers, this term was frequently used to explain emotional disturbance, absence from work, unusual behaviour and mental or neurological illness. In relation to stroke, there was the suggestion that thinking too much can cause the mind to stop, or alternately to explode. Thinking too much was also thought to trigger high blood pressure and nurses at the high blood pressure clinic frequently advised patients to stop thinking so much. For the participants of this study, understanding of the behavioural contributors to health highlighted both their constraints to do anything about this. Meals were a pragmatic choice, stress was inescapable.

7.3.4. Contribution of hardship to stroke

In their interpretations of stroke, the participants emphasised the immediate material and social concerns of their everyday life. Crime, stressful living conditions, separation from family, divorce and lack of access to cash resources were presented as triggers for stroke. In Linah's case account her first stroke was attributed to the theft of her pension outside the pension pay out facility in Mitchell's Plain. Her second stroke was attributed to the stress she experienced whilst living with her son, who abused her grant and consumed alcohol. Nondwe attributed Tata Liliso's ongoing health concerns to their wayward grandchild. When talking about stroke, residents highlighted the particular struggles of the

elderly as well as the burden on women in this community. The burden of childcare, full domestic responsibility and errant husbands underlay ill health and stroke, again, giving voice to present hardships.

7.3.5. A prevalent 'not-knowing[46]'

It was not uncommon for people not to know what caused stroke. I initially considered this as a 'not knowing' of the biomedical process or a reflection of power differentials at play in my relationship with the participants. Yet, I learnt that many individuals in this community, including health workers, did not hold any explanation for stroke, traditional or otherwise. Most did not hold an explanation for aphasia and I did not encounter consistent theories about stroke and impaired communication. These findings hold meaning within themselves. Last (1981), based on his ethnographic work on the Islamic health system in Malumfashi, Nigeria, contends that a prevalent 'not knowing' reflects a breakdown of the traditional medical system which (although flourishing in practice) becomes desystematised and shrouded in secrecy. 'Not knowing' is also a manifestation of the failure of the biomedical health system. Last (1981) regards this as a denial of biomedicine's claim to universality. Language and attitudinal barriers and resource limitations in the state-run health facilities may play a role here too. In addition, the breakdown of health knowledge in Khayelitsha can be seen as manifest of the disintegration of the extended family and the diminishing respect directed toward the older generation (Mji, 2002).

7.4. Discussion of Causal Notions of Aphasia

The data reflects that causal attributions for stroke and aphasia in Khayelitsha acknowledge wide ranging interpretations. Notions of ancestral interventions and evil agents are considered alongside those of biomedical, behavioural and social

[46] After Last (1981)

causes of ill health. Data also reflects the fluidity of interpretation and the tendency for people to retain beliefs that offer security and to adapt biomedical terms to ones which hold meaning in their everyday lives. It is not possible to answer what interpretations are specific to aphasia and what are applicable to chronic illness in general. This would entail further research and a different methodology. There are hints in my data that stroke and aphasia elicit particular explanations (such as the loss of speech as a cruel curse and stroke as a reminder of the dangers of neglecting cultural custom) but it is not my intention to provide a complete list of these theories. Rather I look to the ethnographic evidence to consider the meaning and value of variation in causal notions in this community.

Causal notions of ancestor reprisal and witchcraft hold a central place in interpretation of stroke and aphasia in this community. These explanations relate to a wide range of illness and to misfortune in general. The causes of stroke are also regarded as the causes of unemployment, marital discord, poor fortune and difficult relationships. In addition, causal notions that encompassed traditional Xhosa constructs were highly variable and offered as possibilities or questions. Like MacGregor (2002: 114), who documented discussion around causal notions of mental health problems within a mental health support group in Khayelitsha, I observed the ongoing and open discussion of possible causes amongst participants, families and groups of nurses. They considered options, presented their own circumstances and discussed the case of others they knew.

Participants offered mechanistic and physical interpretations of the stroke alongside those of supernatural and occult forces, such as ancestor reprisal and witchcraft. A particular chronology of causal attributions was not evident, and the wide variation of causal notions was not presented as inconsistent. Participants seemed to embrace numerous interpretive accounts in their search for assistance and family members actively sought out options. The Mdubekis explanatory efforts provide an example. Ancestral displeasure, bewitchment and jealousy of kin, the adoption of white ways, weight gain and a diet high in red meat were all thought about as causal factors in George's stroke and these conversations were

almost always woven into wider narratives of a ‘difficult life’. It seemed that diverse explanations could answer a range of causal questions; questions regarding the mechanism, selection and timing of stroke.

Regardless of the interpretations of stroke that participants offered, they all ask me about the site, process and prognosis of stroke. It seemed that beliefs about the origin of loss of voice were open interpretations suggesting that, in Khayelitsha where plural understanding is commonplace, causal considerations are closely related to the search for therapy and hope. This was highlighted for me when my biomedical explanations to participants were followed with the questions as to what medicine could cure the problem. It was difficult for the participants to retain the beliefs about stroke and aphasia that I offered. The perspective that they were permanent conditions gave no hope and no direction for treatment.

Such variation of causal attributions caution against the classification of illness beliefs, shed light on the sociocultural processes that characterise the everyday life of adults living with aphasia and their families in Khayelitsha and highlight the process and meaning of causal attribution. What follows is a discussion of each of these issues.

There have been numerous attempts to systematise causal notions and etiological categories of illness in African communities. For example, Wessels’ (1985) classification of the five culture-bound syndromes suggests that particular illnesses are thought to arise from spirit possession, sorcery, poisoning, pollution and ancestral displeasure. There have been some attempts to correlate various communication pathologies with traditional aetiological categories (Platsky & Girson, 1993, Mosese, 2001, De Andrade & Ross, 2005) However, although we know from this limited body of research that causes for both developmental and acquired speech and language problems are sought in the supernatural realm, I raise caution about interpreting data that attempt to classify beliefs within this realm. Ethnographic examination shows little evidence for bound categories or consistent theory. Interpretations were almost always varied and etiological

categories were permeable. In addition to this there was a sense of uncertainty when people presented cultural interpretations and an expressed mistrust for diviners, the ostensible authorities on cultural matters.

This can be understood from a number of different perspectives: Firstly, as Last (1981) contends, colonisation in Africa led to a breakdown in traditional healing systems. Although practice still flourishes at a grass roots level, it has been necessarily shrouded in secrecy and fragmented. This is nowhere more evident than in South Africa where political forces in the Apartheid era forced the operation to, so to speak, go underground.

Secondly, cultural constructs are dynamic. Even though it is long recognised that there is always room for development and for change in cultural paradigms, cross-cultural research continues to attempt to document 'indigenous' practices and propose systems of belief without regard for the moderating influence of sociopolitical processes. Swartz (2005) emphasises the irony of this approach in his critique of mental health studies in South Africa – we look to the very communities characterised by uncertainty and social upheaval to document traditional beliefs systems. Certainly, most recent anthropologies into health and illness practices have shown that it is political and social realities that shape beliefs. In post-Apartheid South Africa an increase in beliefs in the occult and a strong alignment to what is presented as cultural custom has been related to economic hardship, and the continued echoes of the apartheid era.

Lastly, adults living with aphasia and their families sought highly individual explanations that were almost always closely linked to their past and present circumstances. The Mdubekis brandished theories about jealous kin being behind the affliction sent to them in the form of George's stroke as he had suffered a stroke so soon after returning from a visit to his rural home. Nyathi told me about an Anglican priest in his parish who was living with aphasia as he had been hit by the *storum* in his youth. Although the boy's parents had sought herbal

interventions after the incident, Nyathi regarded this stroke as evidence that the intervention had not been strong enough to last the years of adult life.

Whilst classification systems of disease causation imply either/or formulations of cause, participants did not regard the various religious, cultural and medical causal notions that they held as dichotomous or inconsistent. This may indicate that either/or frameworks of causal attributions ignore the complexity of attaching causal meaning to illness and the reality of those afflicted with chronic illness. The semantic overlap between causal attributions, such as the reference to blood or imbalance, reflecting both cultural and biomedical causal notions and the term 'pressure' referring to social and biomedical terms highlights that divisions between healing systems may not necessarily be recognised by the participants of this study or their community at large. The presentation of causal notions to me over my years of fieldwork is resonant of Last's contention that 'what may seem to the outsider a Babel of different medical ideas is to the insider an adequately homogenous means of coping with illness in all its forms' (1981: 391).

Although many recognised the contribution of chronic disease and lifestyle whilst acknowledging supernatural forces that bring affliction such as stroke, not all participants presented this wide range of causal notions as consistent. Some were quite verbal about their rejection of traditional ideas of illness causation and I encountered a conscious alignment to biomedicine. Linah's position was thus: '*A lot of people talk about witchcraft, but I don't take that seriously*'. When talking about stroke Nyathi presented himself as a pastor of the Anglican Church who eschews traditional beliefs, as a sort of conscious disclaimer. The Mdubeki's children were bemused and frustrated by their mother's talk of witchcraft and ancestral shades. In addition, many people presented causal notions as those held by them and then those held by others who continue to follow traditional ways. Of course this needs to be considered against my position as a researcher and health professional.

This division between the biomedical causal notions and those with their roots in traditional Xhosa explanatory models was emphasised by some of the nurses in the clinic. They positioned themselves strongly with biomedicine and scolded patients who proposed other notions. But I did not observe this to be a general trend. Most nurses whom I interviewed straddled both positions. Families relied on them to administer herbal remedies to their afflicted kin in the rehabilitation units. Many encouraged patients to investigate causes extending beyond the sphere of biomedicine.

Exploring ideas of causation was a window on the everyday life of adults living with aphasia and their families in Khayelitsha. I have already discussed the centrality of witchcraft discourses in the post-Apartheid milieu, reflecting a certain social instability[47]. The widely held notions of stress, crime, poverty and intergenerational tension reflect the everyday hardship, possibly accentuated for the elderly and those chronically ill. Pertinent here too are the findings that many did not know about the causes of stroke. Ashforth (1998) looks to competing authorities as the source of this insecurity and not knowing. The church, the clinic, traditional healers, the media, the young and the old in this community offer their own perspectives. Vuyokazi, a young nurse in Khayelitsha, tells me the story of a beautiful young girl who believes her stroke was bewitchment and will not entertain Vuyokazi's explanation that she was 'studying too much'. She explains:

> She is blaming the witches because her aunt came to her house before her exams and took her book and read it when she was trying to read it. Then she had a terrible headache. The following day she woke up and found out her whole arm and leg were not working at all. She could not talk. I was talking with her but she didn't want to hear from me. I told the girl, 'Man, don't you think it is caused by too much studying because you want to pass standard 10'[48]. She said, 'No it's not like that'. She

[47] Comaroff and Comaroff (1993: xxviii) caution against the purely metaphorical interpretation of witchcraft, making the point that in South Africa witchcraft is '*chillingly concrete'*.
[48] Standard 10, or Matric, is the final year of secondary schooling in South Africa.

> understood that it's her aunt. And if one has already had that on her mind you can't change her mind at all.

In addition, not knowing may reflect the limited resources and limited treatment options in this community. Choices are necessarily pragmatic ones (Heap & Ramphele, 1991). Mechanistic beliefs highlight possible miscommunication in the medical arena. Adoption of terms highlights the lack of a common language between the clinic and the community.

Lastly, causal attributions are relevant to understand as they reflect a process in coping and provide meaning for those who live with the chronic and disabling sequelae of stroke, in particular aphasia. Certainly, discussions about causal attributions included discussion about the mechanism of stroke and the selection – what has been termed by Evans-Pritchard (1937) as process and agency. This would seem to be central to the African conception of illness. Illnesses that are persistent, severe or unusual are more likely to provoke enquiries of agency. In this study, however, agency was important in that it approached questions regarding the ultimate cause. Many times it was beliefs of the ultimate cause that directed help seeking and made the experience of stroke meaningful to everyday life. When Funeka spoke about her father's stroke and the subsequent search for cause, she did so in terms of the meaning for her and family.

> My father got stroke. This is how we only found out that my father doesn't belong to the clan that he associated us with, he belongs to another clan. The clan we grew up associated with is called *Mashiya* and all along I'm not *Mashiya* I am *Mqocwa*. My father got punished, attacked by the stroke but he knew why and it was hard to deal with because he used to associate himself with *Mashiya* for a long period of time. They went to the *iqhirwa* and all over the place to get help. They all stated that he knows the reason why he got stroke and he didn't deny. It was clear that he must go back to where he belongs. He was from

> Didimana. He left his cows there. He slaughtered a cow in order to announce that he is going back to where he belongs and he gave up using his mother's clan name. He was supposed to take the skin of the cow in order to make a necklace to follow the *BuQocweni* way. It was a very difficult situation but I thank him now because he died after letting us know that we belong to which clan name.

Importantly causal explanations of agency (including those involving witchcraft) did not exclude other knowledge about cause and effect. These distinctions at an analytical level have been noted by Whyte (1982).

The very fact that participants held varied and fluid interpretations of the cause of stroke and aphasia illustrates that beliefs are sought out as part of the coping process. Whyte (1997) discusses this notion in her ethnographic accounts of the search for meaning of illness in Eastern Uganda. She suggests that people are not looking for certainty in causal notions. Rather they look to causal notions that provide security and hope. Ancestor reprisal can, not without effort, be remedied. Invisible forces not only bring affliction but also offer miracle cures and relief from illness and everyday hardship. Medical notions almost always have the offer of a cure in the form of pills or injection, even if this promise is seldom fulfilled. Uncertainty drives the search for meaning.

7.5. Conclusion

There has been much ethnographic interest in causal ideas of illness in Africa and documentations of the Xhosa belief system abound. In addition, the few studies into cultural accounts of communication disorders frequently consider causal attribution, possibly because causal beliefs are core to theoretical models of illness behaviour and are thought to direct help seeking strategies[49].

[49] See 2.6.

In this study, ethnographic accounts of the search for meaning highlight the complexity of causal attributions. Distinctions between disease classifications in traditional African medicine are blurred. Explanations of illnesses are at once fluid, open-ended and multifactorial and there is acknowledgement of the adaptation of notions of causation to modernity and changing discourses within even small localities (Comaroff & Comaroff 1993, MacGregor, 2002: 112 – 122). I encountered constructs of stroke and aphasia in Khayelitsha that were shaped not by a fixed system of disease classification, but by meaning, hope and sociocultural processes, in particular prominent discourses and prevalent social problems. In this study, it is the range and variation of causal notions that is relevant, and not reductionist categories. Even if not epidemiologically precise, causal attributions within themselves are emotionally and behaviourally adapative processes (Becker & Kaufman, 1995; French et al, 2005). In this way varied discourses do not compete, as is often the supposition in primary health care literature, but co-exist.

Similarly in Khayelitsha various therapeutic approaches co-exist. Although these approaches reflect interpretative frameworks where efforts to tackle illness involve offerings to ancestors and eliminating pollution, they also reflect a complicated reality where distinctions between interpretive frameworks and help seeking strategies are common. This discussion is developed in Chapter Eight.

CHAPTER EIGHT
THE QUEST FOR CURE: HELP-SEEKING JOURNEYS OF PEOPLE WITH APHASIA IN KHAYELITSHA

8.1. Introduction

After Tata Liliso returned from a second trip to the Eastern Cape to visit a medical doctor who proclaimed miracle treatment for stroke and its sequelae, he said to me '*Now I give up'*. Tata Liliso's words reflected a year long quest for relief from aphasia and paralysis that had involved clinic visits, speech therapy appointments, faith healing, herbal remedies and promises of a miracle cure. For now, the quest for cure that had dominated his life (and that of his wife's) for a year was over. The options known and available to them were exhausted. But, like other families dealing with stroke in Khayelitsha, the Liliso's held out hope for new options, for a miracle. Talk of miracles is part of the everyday discourse of Khayelitsha and new possibilities for relief from affliction are embraced.

In the following section I describe the prevalent healing practices in Khayelitsha and the experiences of participants. In doing so, I hope to gain understanding of the contextual influences of healing resources and practices in this community and the impact of these on the experience of aphasia for people living within it. The participants in this study experienced aphasia through multiple healing systems. Yet the experience was generally unsatisfactory. Belief in miracle buffered the effect of these experiences while at the same time making participants susceptible to promises of a cure from those profiting from misfortune and uncertainty.

The information I present is based on case accounts and I relate the experiences of the participants in the study as told to me. I did not directly observe the healing practices I describe. Aspects of care relating to the clinic and to biomedical practices of state-run health services are explored in the Chapter Ten.

8.2. Therapeutic Options in Khayelitsha

In Khayelitsha, as in many parts of Africa, people use biomedicine, traditional medicine and faith healing in response to illness. At times, particular approaches are used to address particular concerns or symptoms. At other times, all approaches are used, either sequentially, as in a 'hierarchy of resort' described by Romanucci-Ross (1969, cited by Good, 1994: 44) or simultaneously. Generally strategies to seek help are thought to follow logically on from causal notions; from the foundational distinction between natural illness and man-made illness (Ngubane, 1977: 24). People will look to biomedicine for natural illness and to various kinds of traditional healers to treat afflictions that have been caused by man or spiritual intrusion. Different approaches are also used to treat the different analytical levels of illness, where biomedicine is sought to treat immediate symptoms of an illness and other healing forms are called on to treat the underlying social issues, such as those of responsibility or blame (Whyte, 1997). Good (1994: 44) however suggests that it is limiting to consider help-seeking as only a cultural process. Social factors and macro-level structures constrain and direct health care decisions to a large extent. These include available options, resources, access, cost and perception of efficacy. Help-seeking is also a quest spurred by hope and the need for meaning (Whyte, 1997: 18).

8.3. The Magic of Medicine

Regardless of their causal beliefs, all the participants of my study sought conventional medicine for cure from stroke and aphasia. Their expectations of medicine, although often unfulfilled, seemed to be resilient and they placed trust, and their hope for miracle, in modern pharmaceuticals. Although doctors and health professionals working in Khayelitsha were respected for their knowledge (considered blessings even by many), medicine was the most frequent reason that people visited the local clinic[50]. Participants made monthly trips to local clinics

[50] This desire for medicine has been described by Segar (1997).

and the hospital to collect chronic medication, usually for high blood pressure, but visits for social support groups, exercises groups and checkups dwindled after the first few appointments. The effort to return again and again to the clinic was motivated by medicine and participants were generally satisfied with their clinic visits if medication was supplied.

Many private general practitioners operating in Khayelitsha supply tablets to their outpatients as a matter of course. Often it would be a short supply of vitamins or analgesics handed out in small plastic packets for an array of health concerns. Private doctors who provided tablets as part of their consultation fee were regarded as both effective and caring. Medicines were not only sourced from clinics and private practitioners. Over the course of my field work, the Mdubeki family, Nyathi and Vuyokazi purchased a wide range of remedies for their general well-being from local stores and healers. Traditional healing practitioners both in Khayelitsha and in rural settings have incorporated over-the-counter pharmaceuticals into the gamut of their usually herbal ministrations; as have the *amayeza* stores, Xhosa chemists that trade in herbal medicines, often as roadside stalls or from booths behind shops. On a number of my visits to the Mdubeki household, Mavis turned out a stock of ministrations (over and above blood pressure medication) that she purchased. These tablets, milkshakes and oils were sold to her for the general well-being of her husband. However Mavis continued to hold out hope that these medications would effect change in her husband's speech and walking. Similarly, Vuyokazi believed that the daily analgesics and anti-inflammatory medications that she took would help her to achieve improved physical and communicative functioning. Vuyokazi carried four to five different bags of tablets with her at any point in time. However she was not always able to relate what medicine was needed for which physical complaint and her neighbour tried to help oversee her medicine regime. Vuyokazi attended a number of outpatient clinics, both at her local hospital and at the larger provincial hospital, to secure her medicines.

Van der Geest and Whyte (1982) describe the charm of medicine in various African settings as being related to their concreteness, their associations of sophistication and to their ability to give illness experiences tangible forms and illness sufferers a modicum of control over their illness. Medicine, they explain, is both a metaphor and a metonym and its availability underpins the utilisation of primary health services in many parts of Africa. They suggest that the foreignness of medicines in Africa has also contributed to their popularity. Within the particular South African context, this response to medicine may also in part be due to the doctor's role in the mediation of the social and disability grant within South Africa where ongoing compliance to chronic medication is often an unstated requisite for grant eligibility (Segar, 1994; MacGregor, 2006). Participants often enquired if I had pills to help them or their family members talk again.

Cocks and Moller (2002) describe the flourishing trade of the *amayeza* stores in the Eastern Cape and suggest that these stores play a significant role in the help-seeking behaviour of the Xhosa people. These stores stock traditional herbal medicines as well as manufactured herbal medicines, animal and synthetic fats used in traditional medicine and remedies derived from Dutch, Indian and Chinese cultures. According to Cocks and Moller (2002) these self-ministrations are used for a broad range of maladies and afflictions. For the most part though they are used to protect people from evil spirits, to remove pollution and poison, to clean the blood and to bring luck in love, in finances, in court and in studies. Like Van der Geest and Whyte (1982), Cocks and Moller (2002) argue that the range of products available in the amayeza stores reflects the extent to which people in difficult life circumstances try to gain control over their lives. Customers are African people from all walks of life; rural farm workers and urban professionals, pensioners, mothers and scholars, traditional healers and those strongly affiliated to Christian churches. Products purportedly have limitless potential to enhance well-being and ensure safety from misfortune. Although these products are affordable and accessible to people wanting to treat themselves for both physical

ailments and culturally-bound syndromes, they are commercial products and unregulated.

8.4. Faith Healing

Although informants frequently rooted stroke and ill health in the increasing authority of the church and subsequent renouncing of cultural practices, faith healing practices are commonplace in Khayelitsha. In fact, ritualised faith healing was the most common and most ongoing treatment sought by the participants of the study.

8.4.1. The rise of African Independent Churches

There are a wide variety of independent churches in Khayelitsha. Collectively referred to as African Independent Churches (AICs), these churches are made up of relatively small congregations, led by charismatic pastors or prophets who profess healing powers and practise a range of healing methods. AICs constitute the largest faith in southern Africa and are rooted in Zionist and Apostolic movements. Referred to as the 'African expression of the worldwide Pentecostal boom' (Meyer, 2004: 447), AICs' key tenets include belief in the healing power of the holy spirit, authority of New Testament scripture, ritualised speaking in tongues and ceremonies of baptism, combined with acceptance of African frameworks of illness causation and spiritual agents in misfortune. Practices invoke the Holy Spirit as the source of power to protect and heal the congregation and ward off evil spirits.

There has been much anthropological interest in AICs[51] and studies have rooted the rapid growth of the church in South Africa in a wide range of sociopolitical processes. Kiernan (1995b: 124) describes the rise of AICs as a response to forced urbanisation. The church, in its syncretic approach to Christianity, functions as a

[51] Here I refer the reader to Prozesky and de Gruchy (1995) for a historical background to settler Christianity in South Africa.

bridge between the rural and urban experience. AICs as central establishments in impoverished communities throughout South Africa also function as a buffer against the harsh realities of poverty, offering either 'ephemeral distraction' (Pfeiffer, 2002: 194) or a form of resistance and socio-political transformation (Comaroff, 1985; Thomas, 1994). Comaroff, in describing ritual practices of a Zionist church in Mafikeng under extreme Apartheid rule in 1980s South Africa, reveals how syncretic churches attempt to create a new moral order to replace that which has been lost within the shifting social and economic landscape (Comaroff, 1985). As Ashforth (2005a: 204) explains in his ethnographic study of the pervasive experience of witchcraft in Soweto, ancestors have lost most of their purchase in Soweto, but mushrooming from the community are churches, preoccupied with rules and norms of right behaviour, to take their place. In addition to these converging processes which have promulgated the church as an organisational and social institution in response to the needs of poor and displaced Africans, Comaroff and Comaroff (1999) ascribe its increasing popularity to its credence in occult phenomena. AICs provide a public space for communities to deal with fears of witchcraft and spiritual threats in the context of growing social inequalities.

Possibly however it is the church's emphasis on healing and management of misfortune that has ensured its centrality in urban African communities. Medicine and health services were both costly and scarce under Apartheid rule, despite all too prevalent experiences of disease. In response, healing and protective functions of the church were brought from the periphery to occupy a central place in the movement and its practices (Kiernan, 1995b: 125). Most people enter AICs for healing, which through invoking the power of the Holy Spirit, offers protection against illness and misfortune and deliverance from troubles. There is active recruitment of people who are acutely ill. Vuyokazi and George, in the acute stages following their strokes, received visits from church members[52].

[52] See 9.5.1.

Prophets of the various independent churches profess healing powers and, like diviners and herbalists, have come to be regarded as traditional healers. These prophets or faith healers, termed *abathandazeli* in isiXhosa or *amaprofeti* colloquially, operate from the same frameworks of disease interpretation as diviners and herbalists in that they recognise African aetiology of disease but they claim that their healing powers come from the Holy Spirit and emphasise the teachings and healing activities of Jesus Christ. Faith healers practise a range of healing methods such as prayer, baptism and biblical prophesising. Thomas (1999: 65) describes how prophets also engage in forms of divination, referred to as telling (*ukuhlahluba*) by randomly opening the Bible and drawing prophecies thereof. Their diagnoses of illness are usually located in sin, aberrant behaviour, sorcery and the work of jealous neighbours and are based on prophecies, divination and interpretation of dreams.

8.4.2. Ritualised healing in Khayelitsha

In Khayelitsha, the spectrum of faith healing practices included prayer and the use of blessed water, also referred to as prayed water, for douching, enemas and imbibing, as well as for sprinkling on the congregation and in homes and in baths to ward off evil spirits, cleanse away disease and polluting agents and restore health. This water is thought to contain the healing power of the Holy Spirit. Ash, salts and green Sunlight soap[53] (as an agent of purity) may be added to the water to increase its healing potency and cleansing properties. Laying of hands, lighting candles, applying anointed bandages and oils, wearing white cloth, drinking purges including tea from Moria[54], and forms of divination included the range of faith healing practices described to me by participants. These practices however are performed as adjuncts to prayer ceremonies and it is prayer, not whispered

[53] Sunlight soap, a green laundry detergent bar, is a South African icon and is the brand of choice for hand washing laundry. It is widely available in spaza shops throughout Khayelitsha.
[54] Zion City Moria, in the Limpopo Province is the seat of Zionist Church. Zionists from all over South Africa congregate in Moria over Easter for three days of open air worship and healing rituals.

supplication, but active, vibrant and collective prayer, that is the primary healing ritual in AICs in Khayelitsha.

These services were described by participants during our discussions on help-seeking. During services, the congregation prays enthusiastically with song and movement to engage the power of the Holy Spirit. The sick or afflicted are either placed in the front of the congregation or are encircled by the congregation and it is the collective concern for the ill that is thought to bring the Holy Spirit into their midst (Kiernan, 1995b: 125). The prophet then lays his hands on the sick to (to extend the metaphor) sharpen the focus of the Holy Spirit. He later reinforces the healing ritual through sermon and scripture. These healing rituals are not exclusively directed at those afflicted. The entire congregation is thought to be touched by the healing powers in their presence and people move into trance-like states, dancing, singing and speaking in tongues.

Prayer ceremonies operate throughout the week in Khayelitsha, although Sunday is reserved for most as the day of prayer. Services on a Sunday begin early in the morning and continue throughout the day. On occasion, these prayer rituals become vigils and prayer that is started on a Friday night is continued until late on a Sunday afternoon.

Prayer for people in Khayelitsha seems to be a powerful way of coping with adversity. Residents described the trance-like state and altered periods of consciousness as a means of both mental and physical escape from their daily reality and troubles. Thomas (1999) describes such a scenario in a neighbouring township Gugulethu, where ritualised healing at the St John's Apostolic Church addresses the strains of poverty and social stress. In the absence of other recreational diversions and funds to support the pursuit of leisure, much value was placed in prayer as a coping strategy for carers and adults with aphasia alike. However the extent to which adults with aphasia could participate in collective prayer ceremonies was limited. Prayer in this community is a decidedly verbal

and physical ritual and by Tata Liliso's account, others would now pray on his behalf.

8.4.3. 'The miracle of prayer'

Prophets and faith healers (*abathandazeli*) are also referred to by residents of Khayelitsha as miracle workers and, as with other traditional healers, particular trust is placed in those who hail from the Eastern Cape. When George was discharged from the rehabilitation unit the family's first step in their own active quest for healing was a faith healer who used water to cleanse him and who engaged spirit power to restore his speech and ability to walk. Later, when George was able to walk with the aid of a crutch, Mavis took him one Sunday to the Mew Way Assembly Hall. This construction, built in the mid 1990s as an indoor sports arena for part of South Africa's Olympic Bid, transforms itself into a modern day church each Sunday where people amass for collective supplication and faith healing. At the end of the service, George, together with other ill and disabled people, was sent to the front with a slip of paper on which Mavis had noted both his affliction and their prayers for him to talk again. Attached to this note was a remittance. Mavis explained that the more the remittance, the more potent the energy directed towards those seeking healing.

After a while Mavis began to question the efficacy of faith healing rituals. George's physical health was returning slowly, but no gains were made in his efforts to talk again. Prayer however remained a mainstay in their quest for healing and they continued to attend various ceremonies and services if '*only for the miracle of prayer'*. By her account, prayer uplifted their spirits and healing services were regarded as valuable opportunities to see others with afflictions like George's. Later, with growing disillusionment in the supportive role of people, including kin, neighbours and health workers, Mavis spoke of prayer as the one resource available to her and her husband that did not depend on others. As she put it: '*People are scarce but God is here.*'

Mavis's account highlights the value of prayer as a healing resource in a community where support networks are tenuous and in an experience of chronic affliction where help is short term. The question (statement?) '*What else can we do but pray*?' is cited more than once in my fieldnotes. Prayer strengthens, reconstitutes and helps people endure difficult circumstances, particularly so for those without financial resources to alleviate ill health and affliction in other ways.

8.4.4. A reconfiguring of AICs: The gospel of prosperity

When residents of Khayelitsha discuss the value of prayer as a healing choice, they do not exclude the fact that prayer and faith healing is far more affordable to them than are private medical services and traditional healing. Prophets of Zionist and Apostolic churches do not directly charge members of their congregations for healing rituals and members of the congregation who are unable to pay tithes are not excluded from the church's community. Nevertheless tithes are spoken of as a means of procuring divine protection for both self and loved ones. In the more charismatic churches, such as the Universal Church of the Kingdom of God and the Church of Hope, voluntary remittances are forwarded for healing rituals and prophets who are thought to overcharge for their services are regarded suspiciously.

But affordability is not the only fiscal attraction of the faith healing churches. Prayer and rituals are not only pleas for physical healing, but for general social and emotional well being, including above all economic betterment - a panacea for ill health and misfortune, and realistically so considering the close links between difficult circumstances and a lack of cash resources.

The Universal Church of the Kingdom of God, referred to in Khayelitsha as the Universal Church, is becoming increasingly popular in South Africa. The focus is on prosperity; miracles are requested in exchange for cash. Entire services are devoted to requests for employment or financial betterment and those who tithe

are promised material gain (Comaroff & Comaroff, 1999). Meyer (2004) in her review of anthropological research into Christianity in Africa suggests that the Universal Church and similar institutions represent a reconfiguration of AICs and collectively refers to these churches as Pentecostal Charismatic Churches (PCCs). Certainly the small congregations, pastoral robes and modest buildings associated with the AICs in Khayelitsha contrast starkly with the images depicted by Meyer of flamboyant leaders in sunglasses and fashionable attire, leading large congregations and televising or broadcasting prosperity gospel and demonising traditional healing practices (ibid: 447). In a setting such as Khayelitsha, it is not only the modern and global character of the Universal Church and its promise of material gain that has contributed to the rise of the church. People feel that the church offers them a level of protection from witchcraft. The blessed water used during ceremonies can counteract witchcraft. As one resident explained, '*my neighbours will not curse me if they see that I attend the Universal Church*'.

The older participants of my study remained strongly aligned to AICs. People told me that they were concerned about the rise of churches that preach against the following of cultural ways and encourage followers to turn their back on their ancestors. Younger people whom I spoke with however were well versed in prosperity gospel and among a group of young mothers of cerebral palsy children at a care centre that I visited, healing services of the Universal Church were favoured over other treatment options. One only has to listen to radio broadcasts and watch popular television in Khayelitsha (as I often did whilst waiting for scheduled appointments during my fieldwork) to realise that this form of Christianity, both modern and global in character (Meyer, 2004), has mass appeal.

8.4.5. Faith healing community as a gendered domain

In Part Four, Chapter Nine of this thesis I describe how the church functions as a valuable system of support for women in Khayelitsha. Although I encountered both men and women in Khayelitsha who had and do engage in faith healing

practices, many women openly expressed their suspicions of traditional healing practices and in the same breath declared their beliefs in God, Jesus, miracle and prayer. Talk of illness was balanced with talk of miracle and religious purpose and I encountered this discourse among women in clinics and in other health establishments such as old age homes and community organisations. I observed nurses advising patients on prayer as a health strategy and initiating prayer within health consultations. Focus groups, meetings, workshops and even some informal get-togethers of women in the community were opened with collective prayer and song. This was most evident in the health care arenas. Following is an extract from my fieldnotes:

At 8.15 am, the mood in the hospital changes. The nurses leave their stations and move to the front of each designated waiting area. A nurse tells me to find a place at the back of a waiting area. I stand next to a male health care worker against a wall at the back. The whole hospital, already brimming with patients (I attempt a head count but stop after a thousand), starts to sing in prayer. The nurses are leading the praise and patients join in. The singing is loud and people are moving and clapping in unison. Then there is a pause, silence, until a nurse begins to speak a prayer, each nurse then follows on, some patients shout out in agreement, others offer up their verbal prayers too. Again there is a pause, this time people look down, in silent prayer it seemed. It is a very moving and beautiful thing to observe. Then the singing, clapping and hand waving begin again and continue for about ten minutes. At the end, patients turn to each other and shake hands. I can't be sure what they are saying to each other, it could be 'peace be with you'? A number of people approach me and shake my hand too and share their blessings. Two people embrace me. I look again at the sea of people and it is women that I see.

Pfeiffer (2002, 2005) describes a shift in treatment-seeking among women in urban Mozambique. Local healers were traditionally consulted to treat persistent or severe illness thought to overlie spiritual causes but in recent times more and more people, in particular women, are renouncing traditional healing and seeking

the healing services of the church. Pfeiffer's work holds valuable insights for Khayelitsha, where women in my study expressed growing distrust in traditional healers and were turning to the church with their afflictions and those of their spouses and children. It is Pfeiffer's contention that this shift has been driven by social conflict and intensified inequality in the region as the result of the collapse of social systems of support and increasing commoditisation. His argument is two-pronged. Women are no longer able to afford the services of traditional healers. Secondly Pfeiffer locates this shift in escalating gender and household conflict in a community where fears of witchcraft and sorcery are heightened. Women have retreated from healing practices that may further erode their already tenuous social relations.

8.4.6. The two sides of faith healing: Use and abuse

The healing function of AICs and their centrality within Khayelitsha however cannot be regarded apart from the communities of mutual support and aid that are established and maintained by these institutions, a discussion I present in the following chapter. For the participants of my study, faith healing was not necessarily only about cure. In this way, therapeutic practices of the healing churches paralleled the holistic frameworks of interpretation of aphasia held by the participants of the study. The associated rituals held emotional and psychological value. In addition, the church seemed to offer membership in a sympathetic community and practical support.

Churches in Khayelitsha hold a prominent place in informal health care networks and the Holy Spirit, the power of prayer, the miracle and in converse evil hold central places in the discourse of health and illness in the community in general and within its clinics and support organisations. Pfeiffer (2002) holds that AICs throughout southern Africa are crucial sites for provision of health care among the poor and influence formal health service utilisation. This is relevant to health professionals as these institutions may support health initiatives. More importantly

however Pfeiffer situates the relevance of his findings in what they reveal about health care itself. In Mozambique, privatisation and development of health care has marginalised the poor, and in particular women, who when ill and in need of treatment, have sought refuge in church structures.

In Khayelitsha, the church provides healing for those unable to afford the direct or indirect costs of health care and therapy and its rituals offer psychological and emotional support that I did not observe in clinic structures.

However, there is another side to this coin. Although I suggest that faith healing was not only about cure, this reflects the position held by the participants towards the end of their quests for therapy. Cure was the motive behind their participation in ritualised healing and the reason for their families investing hard earned savings and travelling long distances to seek out the miracle workers they had heard about. Churches and faith healers did not advertise heightened consciousness or spiritual upliftment, they advertised cure - cure from paralysis, from voicelessness and from financial despair. The purported benefits of faith healing should not deter from the likely possibility that faith healing can be a commercial enterprise that exploits those who hold out hope for miracles.

8.5. Traditional Healing

In the following section I describe the various forms of traditional healing in operation in Khayelitsha, beginning with an overview of the ideology of African medicine and the general practice of healers. I then present the views regarding traditional healing held by participants and their families and I document the experiences of the two participants of the study who consulted traditional healers.

At the outset however I need to clarify what is meant when I refer to traditional healers and traditional medicine. Traditional is a term that has been used to describe processes or peoples objectified as ahistorical and unchanging (Feierman,

1985). Traditional has also been used to imply non-western and or non-rational processes and peoples, often regarded as the antithesis of modern (Comaroff, 1981). The anthropological literature however shows traditional medicine to be a dynamic system that adapts to sociopolitical and economic trends and that readily absorbs medical practices from other medical systems (Feierman & Janzen, 1992: xvii, Whyte, 1982). I therefore use the term traditional healing to refer to the range of current Xhosa therapeutic practices that have drawn on African ideology and that exist outside of the state-run and state-regulated health care services in Khayelitsha.

8.5.1. South African healers

Healers remain central to the African health system, despite growing eclectism in treatment choices and urbanisation. They can be consulted for a wide variety of afflictions including physical and mental concerns and general misfortunes of life, such as marital conflict and unemployment. All these afflictions are considered under the rubric of ill health, which is considered to be the result of disequilibrium in a person's web of relations between their family, society, ancestors and god. Traditional healing practices follow on from beliefs of causation and incorporate a spiritual dimension, where help-seeking activities are aimed at restoring ancestral relations. They may also include rituals for protection from witchcraft, acts to counteract witchcraft and the ingestion of substances which purge the body of pollutants and strengthen the body against harmful agents (Ngubane, 1981). The several types of traditional healers can be broadly categorised as diviners, herbalists and faith healers (described above).

Diviners (*amagqirha* or *sangoma*[55]) are those healers that are called by the ancestors to train in indigenous knowledge and healing practices to become custodians of traditional matters. In a long process of initiation and training,

[55] Ashforth describing use of traditional healers in Soweto states that 'discussions of traditional healers generalise the Zulu usage of sangoma and inyanga to cover all traditional healers serving Africans in the region, regardless of ethnicity' (2005a: 52). Similarly people in Khayelitsha used the terms sangoma and inyanga. This was not the case in rural Eastern Cape where isiXhosa terminology for healers was used.

diviners learn the skills of communication with ancestral shades and it is from the ancestors that their special powers and prophecies are thought to come. Diviners act as intermediaries between humans and ancestors, channelling the diagnostic and healing powers of the ancestors by interpreting messages from the ancestral spirits (Ngubane, 1981). They may use divination objects, interviews with relatives or their divinatory powers together or alone to gain insights from the spirits to interpret dreams, diagnose causes of problems and illness and identify a course of action. As problems are often located in social conflict and relationships, diviners prescribe actions to resolve social conflict, but they may also prescribe herbal remedy, usually a purgative. In addition, diviners carry out rituals to protect against witchcraft and misfortune (Kiernan, 1995a: 24).

Practice and the nature of explanation varies considerably between healers even of the same type. As with ideas about illness causation, documentations of healing practices reveal local idiosyncrasies and fluid approaches (Feierman & Janzen, 1992). Kiernan (1995a: 24) however describes the general divination practices in Nguni culture. These include throwing of bones or dice from which diagnoses and prophecies are drawn, interpretation of dreams, interrogation of the patient's party and by means of their responses narrowing down possible causes for the problem at hand and acting as spirit mediums for ancestral shades. These practices are accompanied by drumming and often supported by psychotropic substances. Whyte (1982), based on her ethnographic work of health practices among the Nyole people in Uganda in the 1970s and 80s, cautions that although explanations of social situations of patients and accompanying rituals, such as those presented above, bear the greatest ideological weight, healing practices of African healers are dynamic. Diviners readily incorporate biomedical elements of treatment and develop new methods of divination in response to new situations. This is now nowhere more evident than in today's global context, where healers effect divination via telecommunications and the internet[56].

[56] For example see www.nativehealer.co.za and www.internationalhealer.co.za.

Herbalists (*amaxhwele* or *inyanga*) on the other hand are healers who have acquired extensive knowledge of magical technique but who do not typically possess occult powers (Kiernan, 1995a: 24). They diagnose, and prescribe medicine for everyday ailments and illness, prevent and alleviate misfortune or evil and provide protection against witchcraft and misfortune. Herbal medicine that is used may consist of bark, root or leaves, or a complicated concoction, of sometimes toxic chemical substances, pharmaceutical drugs, commercially manufactured herbal remedies and synthetic animal fats (Cocks & Moller, 2002). Herbalists trade in medicine developed for harmony, fertility, prosperity, protection of property, health, well being, sexual attraction and potency. Some claim to specialise in remedies for stroke (Hewson, 1998). These remedies are brewed and imbibed, ingested, applied externally via small incisions in the skin or worn as charms. Anthropologists have documented a trend towards herbalism, compared to divination. Herbalism, as Whyte (1989: 294) suggests, frees people from social and religions entanglements and fits well into the pharmaceutical emphasis of Western medicine.

8.5.2. Traditional healers in Khayelitsha

Ashforth (2005b) notes that the literature on traditional healing in South Africa has historically been concerned with describing healing systems and practices within particular African groups. This literature also included general accounts, textbook versions of traditional healing, directed at medical personnel. More recently literature on traditional healing in South Africa has been concerned with how traditional healers can collaborate with biomedicine, particularly in the context of HIV and AIDS (Wreford 2005)[57]. According to Pfeiffer (2002) the literature has conceptualised traditional healers as religious and political leaders, as agents of social cohesion, as psychologists and as preservers of indigenous and endangered knowledge. There is suggestion that traditional practitioners are a valuable resource for health provision and community upliftment in the post-

[57] Also see Wreford (2008: 21 - 29) for a detailed description of various clinical and research collaborative projects in Southern Africa.

Apartheid milieu. However they are also closely associated with stigma and harmful or ignorant practices, and this is particularly so in the urban environment, where training practices are not closely regulated by networks of healers (Ngubane, 1981). Nearly 30 years ago, Ngubane called for research into urban traditional healers. Despite this however there is very little in the way of research that documents the ambit, innovations and organisation of traditional healers in an urban township such as Khayelitsha, despite indications that not all of these practices are safe (Ashforth, 2005b).

Nattrass (2006) analysed survey data of 570 Khayelitsha residents to determine who consults diviners in this community. Although methodologically problematic, as Nattrass herself highlights, findings show that the vast majority of residents of Khayelitsha seek the services of a biomedical practitioner at the onset of illness. Six percent of residents reported that they consulted with a diviner the last time that they were ill. These residents were more likely to be women in receipt of a disability grant, thus marginalised citizens, who operated from a paradigm of good and bad fortune. Nattrass reported that in most cases residents consulted with a diviner because they believed that they had been poisoned or bewitched by their mother or a close family member.

Nattrass' (2006) findings are in line with another larger South African study that has attempted to answer the questions of who consults traditional healers and for what ailments or afflictions (Case, Menendez & Ardington, 2005). Case et al (2005), by examining verbal autopsy reports in KwaZulu Natal, showed that an approximate six percent of people consult healers but that the nature of illness is a strong determinant of health-seeking behaviour. People may consult more readily with a traditional healer for mental health problems or infertility for example, diseases that are considered to have social and spiritual etiologies. In addition, people suffering from chronic illnesses were more likely to seek out traditional healing over the protracted course of their illness. Considering this data and the onset, course and nature of aphasia, it is possible that African adults with aphasia and their families consult traditional healers to help them cope with the affliction

of communication loss. The cursory South African research into traditional healing for communication disorders has attested to this assumption although this research offers little in the way of critical analysis (Dagher & Ross, 2004; De Andrade & Ross, 2005; Platsky & Girson, 1993, Penn et al, 1992). Although the window I offer is small, information on the views and anecdotal experiences of traditional healing of people living with communication disorders, can approach questions regarding the role of traditional healing for Africans in living with communication disability.

8.6. Experiences of Healing Practices

I met Mma Gubevu on my trip to a rural village in the Eastern Cape during which time I was interested in exploring the rural experience of traditional healing for adults who had suffered strokes. Many residents of Khayelitsha return to their rural homes in the Eastern Cape following stroke for healing. The market place for healing in the small town in the area was immediately evident. There were signs to *amayeza* stores, and to both diviners and herbalists in the main roads and throughout the small residential area surrounding the town. Herbalists plied their trade from roadside stalls and pavements, supplying products to the people from the surrounding villages. Mma Gubevu lived with her husband in one of the further flung villages from the town. They lived in a brick homestead atop a hill overlooking the rest of the village and rolling mountains. They had a small piece of agricultural land and harvested corn and reared chickens. Their children had a long since grown up and moved to major cities in South Africa.

The skin of a genet cat hung over the door to Mma Gubevu's two roomed, protecting her from the elements of witchcraft that had shortened her nerves to close her throat, cut her speech and minimise the movement in her right arm and leg. Other, less recognisable animal skins hung near her bed to ward off evil spirits. Mma Gubevu's face and arms were marked with scars of incisions made by a diviner who rubbed his protective substances into these incisions. In the

corner of Mma Gubevu's room were a number of old two litre plastic Coco-Cola bottles filled with a brown murky substance. She drinks this infusion three times a day. It is a purgative that will remove any internal traces of the pollution that was sent to her by villagers jealous of her productive life. She smokes local plant substances that will open her throat to allow her voice through once again. These medicines are from Dr Mbosa, a herbalist in the district well known for his ability to cure the symptoms of stroke. Mma Gubevu had visited a healer within their own locality immediately following the stroke, but he told them that there was nothing he was able to do for her. She was then told of Dr Mbosa by a man whose wife had suffered a stroke.

Mr Gubevu arranged for them to travel to Dr Mbosa, but when they arrived Mma Gubevu was not able to walk down the steep path to Dr Mbosa's hut. Dr Mbosa heard that she was waiting there for him and so sent them to his homestead where he asked that Mma Gubevu live with him for the period of a week. Later that day, Dr Mbosa arrived with a pipe and herbs for Mma Gubevu to smoke. After the first day, Mma Gubevu began to utter the first words since her stroke. When she returned home a week later, she was once again able to speak. Her voice remains soft, strained and hypernasal and her sentences effortful and largely telegrammatic. Importantly though she is not reliant on others to interpret her needs and contends that her improvement is ongoing. She continues to drink the infusion supplied by Dr Mbosa and he will continue to supply it as long as she feels that she requires it. His charge of R800.00 is for the entire course of his treatment, he does not demand any more money from the Gubevus, only continued reassurance that his medicine will cure. Women from the local Methodist church visit her at her homestead from time to time and offer a communal prayer for her release from the evil spirits that have removed her speech.

Both Tata Liliso and George are also received purgatives to drink from herbalists based in Khayelitsha. These were dried plant substances. Nondwe and Mavis brewed an infusion of these substances each day for their husbands to drink. This

was for the specific purpose of speech recovery by removing the pollutants that were thought to cause the strokes. Mavis also felt that some of the plant substances provided strength to George and helped protect him from future illness.

George had further consulted with seven diviners, all based in Khayelitsha. They were generally once-off consultations at the diviner's home wherein the diviner spent time with George and then questioned Mavis regarding their family circumstances. Four of these diviners told Mavis that the recourse to George's recovery was for George to fulfil his familial and cultural obligations to his late father. One purported healer promised cure in return for a monetary offering to the ancestors, an incident that I describe in further detail in 8.6.2. Two diviners told Mavis that George's stroke and subsequent loss of speech was the result of poisoning sent to them by jealous relatives. This confirmed Mavis' fears regarding the cause of her husband's stroke and her response was to purchase herbal ministrations for George's further protection.

Despite their repeated visits to traditional healing practitioners in Khayelitsha, the Lilisos and the Mdubekis presented traditional healers as an unclear source of help and this sentiment resonated with many of the other residents in Khayelitsha who shared with me aspects of traditional healing practices. In the next section, I consider some of the reasons for this.

8.6.1. The costs of healing

The costs of traditional healing to the Liliso and Mdubeki families were substantial and ongoing. These included expenses for consultation fees, travel fees and the meat and beer required for associated rituals. Consultations ranged from R50.00 to R10 000.00[58]. Participants were quick to accuse healers who charged

[58] At the time of my fieldwork, the cost of consulting a private general practitioner in Khayelitsha was around R80.00.

sizeable sums as charlatans but at the same time they seemed to equate expense with effectiveness and both the Mdubekis and the Lilisos first consulted expensive healers.

Tata Liliso consulted with two herbalists in the first year following his stroke. The first healer charged R800.00 for his treatment, an amount equitable to Tata Liliso's entire monthly pension. This included the herbalist's assessment and a two litre plastic bottle of herb-based remedy that Tata Liliso drank each day which could be replaced indefinitely until Tata Liliso was healed. Tata Liliso however could not drink the infusion and said that it made him feel sick. The Lilisos spoke with others in their neighbourhood to find another herbalist, one perhaps with a reputation for curing stroke. They heard of a man who had been cured of stroke by a herbalist in Delft, a historically coloured township north of Khayelitsha. This herbalist's fees were R50.00 per consultation and included the dispensing of dried plants substances to be drunk as a tea on a daily basis. Tata Liliso consulted with this herbalist every few weeks in order to purchase the tea. He reported to me that he did not believe that the tea had effected any change in his speech or physical abilities or in his general health but he continued to use it in the hope that he would recover as well as another of the herbalist's clients – a Khayelitsha resident who had been cured of speech problems and hemiplegia following treatment.

The Mdubekis consulted ten Khayelitsha-based healers, either herbalists or diviners or both, in the 18 months following George's stroke. Although costs varied, some were substantial to the family. One herbalist charged R1000.00 deposit and then a further R9000.00 over the course of his treatment. The Mdubeki's used their savings in order to cover some of the initial costs of this treatment (in an amount of R4000.00) but they could not afford to complete the treatment and did not believe that it was effective in any way.

The number of healers that Mavis and George visited contributed in a significant way to the costs of their help-seeking. Mavis insisted on these consultations in her

attempt to pursue all possible recourses for George's cure and to follow up word-of-mouth referrals and advertised promises for a cure. It was common practice that healers demanded an upfront payment. Some herbalists required a deposit before they opened the chest (termed *tas,* an Afrikaans word for chest) containing their remedies. Some diviners required payment before they engaged in any communication with clients or spirits. This payment was sometimes metaphorically referred to as the *cow*[59] or as '*vula umlomo'*, literally translated as '*open my mouth'*.

Costs did not only include consultation fees and the direct costs of herbal ministrations. There were also costs involved in travelling and associated rituals. The Lilisos travelled by bus to the Eastern Cape on three occasions to consult with a herbalist, a faith healer and a medical doctor who claimed to cure stroke. At the time of the study, return bus tickets were in the region of R300.00. The Mdubekis could not afford to travel and this made it *'hard to do what [they] were told by traditional healers'*. In addition, the family could not afford to oversee the mortuary passage of George's father which involved slaughtering a cow.

Commonly in policy documents and in the current rehabilitation discourses, traditional healing is described as affordable and accessible to patients throughout South Africa. Over the course of my fieldwork however the Liliso and the Mdubeki families incurred great expense in their pursuits of cure. The greatest of these expenses was for traditional healing.

Ashforth (2005b: 233) cautions against underestimating the cost of traditional healing to ill clients. Although based on his experiences in Soweto, his argument seems to mirror the experiences of the Liliso and Mdubeki families and I quote him at length:

[59] In Xhosa society, as in other Southern African societies, cattle have long since been the primary object of wealth. Cattle is thus used as a commodity in the exchange of wives and healing services and in offering to ancestral spirits. In urban contexts cash has, for the most part, replaced cattle as a commodity.

> Consultations with traditional healers are almost always an ongoing process, more like prolonged psychotherapy in their general structure than a visit to the general practitioner. Cure is never final. There is always some other detail needing attention, resulting in further expense. Moreover, as the practice of healing usually involves mending relations with family, both living and dead, while overcoming forces of evil dispatched by others, the costs of healing include things such as feasts for ancestors and their hungry descendants and reinforcing protections against witches. Such procedures can easily run into the thousands of rand. In fact, without spending thousands, it is impossible to be assured that everything that could be done to deal with a particular case of misfortune has been done. At the end of the day, if misfortunes persist, a whole new regime of treatment, even a new healer, and more expense might be required.

8.6.2. Mistrust of healers in urban settings

Residents of Khayelitsha often spoke to me about their concerns regarding the authenticity of healers in their urban context. They questioned their mercenary intentions, especially as healing practices appeared to be mushrooming in both Khayelitsha and in their rural villages. Some residents raised concerns that people became healers in order to improve their status within their rural communities and to ensure access to beer and meat at traditional ceremonies; but some related far more malevolent stories. The story of the Mdubekis related below is a case in point:

Six months after George had suffered his stroke, Mavis approached a diviner in their search for relief from his severe aphasia and dense hemiplegia. Their initial course of action had been herbal treatment but they felt that this was both expensive and ineffective. The diviner's fees were substantially less than the

previous healers they had consulted and Mavis was hopeful. At the first consultation attended by both Mavis and George the diviner told them that in eight days time, George should place R18 000 in cash under his pillow where he slept at night. This would appease his ancestors and he in turn would regain his speech. The Mdubeki children were angry that their parents had consulted a diviner, but eventually helped them to secure a loan for the money. Eight days following the consultation, George slept with the cash under his pillow, but armed robbers broke into the house, went directly to George and took the money.

Following this Mavis and George were sceptical of healers who did not come from their rural home and became increasingly mistrustful of foreign healers who had recently settled in Khayelitsha. Healers from other Southern African countries, in particular Zimbabwe, were mistrusted due to reasons I situate within the current wave of xenophobia that has swept across South African townships in the last few years[60]. Generally people were wary of healers in urban settings as, unlike healers who hailed from their rural villages in the Eastern Cape, people had no background knowledge of the healer's training and it was easier for swindlers to remain in operation. In addition mistrust of local healers was also based in a generalised sense of mistrust of neighbours[61]. Could local healers have been hired by neighbours to curse them? Could neighbours in turn accuse them of cursing them after it was known that they had consulted a healer? People in Khayelitsha reported that they preferred to consult healers in the Eastern Cape. Here healers

[60] In Khayelitsha, as in townships in the rest of South Africa, black people from the rest of Africa are called *'makwerekwere'.* This Sesotho word is a derogatory term implying limited competence in speech and language. In May 2008, the looming xenophobia towards black immigrants to South Africa exploded into violence that spread from Alexandra, Johannesburg to the Western Cape in a matter of days. In Khayelitsha, Somali owned shops were looted. Non-Xhosa speaking black people were forced to flee the township and sought refuge in camps established by the city. 65 people across the country lost their lives. A year later the process of reintegration continues to be slow. See Comaroff and Comaroff (2002) for an earlier discussion of xenophobia in the post-Apartheid economic context. See also J. Wilmot, 'Sitting on a Timebomb', Cape Argus supplement, Never Again! 17/06/08 and Misago, Monson, Polzer and Landau (2010) for a description of the violent May 2008 attacks on foreign nationals.

[61] Pfeiffer (2002, 2005) describes growing mistrust of traditional healers in urban Mozambique. He considers this in the context of economic disparity and declining social security. Traditional practitioners who may locate blame within already strained relationships are eschewed.

were more powerful and more trustworthy and people travelled great distances to consult with them following stroke[62].

Similarly people in Khayelitsha were ambivalent about locally available herbal medicines. Although some people regarded herbal ministrations as safe and effective, others raised concerns about substances contained within the medicines and related stories of harm.

8.6.3. Changing paradigms of healing

Many residents expressed scepticism in the actual practices of divination and in the power attributed to traditional medicines. Explanations for this expressed mistrust were predominantly rooted in religious beliefs and those of their churches that recognise Christian doctrine and ancestral spirits but challenge the use of traditional healing. As inextricably bound to discourses of witchcraft, a few participants expressed concerns about the moral ambiguity, *'the danger'*, of traditional healing practices. This was the case for Linah and Nondwe following their clashes with witchcraft; Linah was accused of being a witch by her own children and Nondwe was accused by the Liliso family of bewitching her husband. Explanations were also rooted in people's attempts to embrace modern ways; in their education and in their professionalisation[63].

In the Mdubeki household, discussions of traditional healing practices were whispered. Mavis's children felt that she entertained notions of magical cures and shared with me their feelings of either frustration or bemusement around traditional healing and the execution of rituals for health. For them it was a cost issue more than anything else. Mavis, on the other hand, felt that her children

[62] Interestingly, people in the rural villages that I visited also consulted healers outside of their localities. The explanation given to me was the developing tension between community health workers in each village and residents who consulted traditional practitioners.

[63] Some people would express their mistrust of traditional healing in non-personal ways. For example, Nyathi said '*As a minister I am not allowed to believe in these things*'.

lacked an understanding of Xhosa ways, and, not wanting to risk upsetting them, consulted healers without their knowledge.

In Khayelitsha, I participated in discussions with young people who were dismissive of the traditional healing practices followed by their parents and grandparents. They described traditional healing as '*backward*', '*old*' and *'rubbish*'. In their bemusement and criticism these children seemed to hold perceptions of Xhosa culture that South African novelist Zakes Mda describes as '*the red coat of unenlightenment*'[64]. Older participants and health workers expressed concern that the youth had abandoned cultural ways. These participants also ascribed some of the current social and health problems in Khayelitsha to the younger generation. In section 9.7.2. of this thesis I argue that generational tensions loom in Khayelitsha. These are brought to the fore when children need to care for their parents following stroke or disability. Livingston (2005: 236) roots these tensions in the context of migrant labour, commodification and individualisation[65]. Comaroff and Comaroff (1999) argue that inequality lies at the heart of these tensions[66]. In addition, I observed how disparate frameworks of interpretation bump up against each other in the context of aphasia, stroke and disability as decisions about help-seeking and expenses come to be argued and negotiated.

Disparate frameworks of illness interpretation did not only foster tensions between older and younger residents of Khayelitsha. Tensions within and between health workers and patients, were evident too[67]. Local nurses discouraged people from consulting with traditional healers and many people chose not to tell nurses and therapists about other help-seeking activities. However, this situation is not clear cut. I interviewed nurses at a rehabilitation facility regarding their own perspectives of traditional healing and biomedicine. Many considered stroke to be a reminder of the dangers of losing cultural ways.

[64] Mda (2003) uses red as a metaphor of traditional Xhosa who would paint their bodies in red ochre and wear red blankets.
[65] See 9.7.2.
[66] See 9.7.2.
[67] See 7.4, p. 17.

Early on in my fieldwork I noted the 'crowded marketplace' (Ashforth, 2005b: 232) of healing in Khayelitsha. Roadside stalls sell medicinal plants. Healers advertise their services on the walls of their homes and on wooden plagues nailed onto fences. They also distribute pamphlets that list their services and advertise in the local newspaper. These services range from increasing sexual potency to exorcising ghosts. However I also quickly encountered local discourses of mistrust and disillusionment with traditional healers, particularly those within the township. Above I have outlined some of the factors that may contribute to this. Tales abound of corrupt healers, of aberrant practices, and of exploitation of those desperate for relief from affliction. Despite this however people of Khayelitsha continue to use traditional healers. For the Mdubekis and the Lilisos the tendency was to consult various healers, diviners and herbalists, though preference for rural healers was expressed. Further, each consulted traditional healers together with faith healers, doctors and rehabilitation therapists. These help-seeking journeys were not necessarily pragmatic. Nor were they consistent with ideas of causation or religious frameworks. Their help-seeking activities were ultimately efforts based on hope. They went to inordinate efforts to seek out a cure and poured savings into these objectives.

Are these experiences unique to those living with aphasia? In the following section I consider this question. Firstly I consider the complexities of traditional healing in aphasia. Next I consider how aphasia may influence the course of the help-seeking journey in a setting such as Khayelitsha.

8.7. Rituals and Representatives: Traditional Healing in Aphasia

It is not my intention to document traditional healing practices in aphasia as indication of a systematic 'pathway to care' in this domain of healing. Considering the philosophical underpinnings of traditional healing, practices are likely to be more related to the spiritual well-being of the adult with aphasia than

to the severity and nature of the communication problem[68]. A meaningful question to ask however is: how is aphasia accommodated in the diagnostic and therapeutic activities of traditional healing, where speech is central to investigation and interpretation of misfortune and to the associated rituals of confession and healing?
The case account of George sheds some light on these questions.

It worried Mavis that George was unable to relate his dreams to both her and to the healers that they had visited. She felt that one of the reasons for his treatment failure was that she had engaged the various healers and not her husband. She maintained that George should dream of the healer who could cure his aphasia. This was how his ancestors would direct him to a chosen person. Mavis also felt that their ancestors would have sent other signs to George and that these remained uncommunicated. The fact that George's brother, who also suffered a stroke, died without being able to communicate made this matter all the more pressing for Mavis. Mavis and I had many discussions about dreaming and the nature of aphasia; she questioned whether George's '*dreams had been removed too*'. The spirits of the ancestors revealed in dreams are significant in the interpretation of illness causality in Xhosa culture; they aid a diviner's diagnosis and treatment and guide those with illness in their help-seeking quests (Hirst, 2005).

It was not however a concern to Mavis that George was unable to communicate with the healers with whom they had consulted. By virtue of their healing powers, healers should be able to intuit George's social and spiritual relations. But the Mdubeki family held that in order to restore his health, George needed both to confess to his ancestors and to execute the mortuary rites of his father, to return him home so that he may be united with the ancestral shades. It was this issue that remained unresolved. In Xhosa culture, '*to invoke the ancestors and to confess one's faults in a loud voice before the tethering-post is the first step to obtaining redress for any infraction of tradition*' (Hirst, 2005: 3). The family knew that without his voice George would be unable to confess and thereafter unable to

[68] Residents however informed me that there are traditional healers (herbalists in particular) that specialise in treatment for stroke.

participate in *intlwayelelo* (meaning to sow seeds by broadcasting), a propitiatory ritual to the ancestors, often in the case of illness or misfortune (ibid: 3). Mavis did not have any answers, nor did George's younger brother. The family were considering engaging a representative to confess on George's behalf but recognised that as the oldest living son, the responsibility was on George to play the leading role in the duties of ancestor worship[69].

The Mdubeki family engaged me in a number of discussions about aphasia, dreams and confession. Although these discussions were all based on cultural premises, they were by and large existential discussions, centred on man's spiritual connections. In the previous section I note that many of the causal notions of impaired speech and language in this community are rooted in spiritual distress. This was not unexpected considering the holistic explanations of illness in African thought. Most chronic, severe or unusual illnesses are explained as such. But for the Mdubeki family, and possibly for many African families, the spiritual dimensions of aphasia were not constrained to causal explanations. The family had questions around George's ability to connect with his ancestors and the nature of his communication in the afterlife. Aphasia, as Mazwai (1998) philosophises, '*needs to be seen in the light of both horizontal and vertical human relationships'*.

8.8. The Help-seeking Journey in Aphasia

Below I consider how aphasia may influence the course of the help-seeking journey in a setting such as Khayelitsha. I have already described experiences of faith healing and traditional healing for the participants of the study and for the Khayelitsha community at large. Accounts of help-seeking in Khayelitsha emphasise the range of healing options available to people but also expose the limits of these healing options and call into question the nature of the healing

[69] It proved difficult in my study to obtain further information about aphasia and confession for Xhosa adults living with aphasia. Berglund (1989) describes confession as central to Zulu rituals and essential to the restoration of health.

market in this setting. The participants of the study, despite their expressed mistrust in healers, were vulnerable to promises for cure and to a growing disillusionment and uncertainty. The concern is the sociocultural processes that shape these experiences.

Ashforth (2005b) links the prevalence of unauthentic practices in urban South African townships to the unregulated healing market. This he links partly to cultural frameworks. The broad etiological framework and expansive treatment possibilities associated with African illness conceptions underlie much of the difficulty in regulating healers and in scientifically investigating herbal remedies, despite policy rhetoric. Traditional medicine has subsequently become '*a Trojan horse for all purveyors of unproven substances*' (Nattrass, 2005: 10). Comaroff and Comaroff (1999) link the prevalence of unauthentic healers to globalisation in post-apartheid South Africa, where, profiting from heightened beliefs in witchcraft, charlatans and cult healing movements have mushroomed[70]. Certainly the help-seeking journeys for many in Khayelitsha are characterised by encounters with the occult. The search for help was also characterised by the pursuit of promises of cure and this led to disillusioned help-seekers. On one of my afternoon visits to the Mdubeki household, Mavis appeared particularly down. She usually bore the pressures of her daily existence with a robust faith. After a glass of water and some small talk, she spoke at length to my interpreter who then turned to me and said '*None of their promises are forthcoming'*. By '*their*', my interpreter meant the numerous health practitioners and healers that Mavis and George had encountered along their journey of help-seeking.

People in Khayelitsha may adopt multi-pronged approaches in their search for help from illness and not necessarily in a sequential fashion. Generally people used conventional medicine for relief from pain, for control of high blood pressure and for diabetes. Traditional healers, if consulted, were, on the other hand, consulted for cure, for relief from misfortune and to approach questions of why and possibly who was responsible. The Mdubeki family in particular took the

[70] Comaroff and Comaroff (1999) consider the rise of the Universal Church in black townships as one such healing institution.

'*unfinished business*' (Wreford, 2006: 74) of George's stroke to traditional practitioners. By this, Wreford refers to the social, moral and psychological underpinnings of the illness. People sought faith healers for cure and relief from misfortune, including the financial misfortune that comes hand in hand with illness and disability. Faith healing was also used for spiritual rejuvenation and as a source of inner strength. In addition both traditional healing and faith healing rituals offered people protection from harmful agents and polluting substances.

Plural approaches are integral to health care within African contexts, reflecting various cultural heritages (Whyte, 1982) and the open nature of African health systems (Comaroff, 1981). People use all possible means available to them, particularly in the context of chronic illness[71]. A patient whose illness lasts over a period of time moves through the broadest possible range of therapeutic alternatives (Feierman, 1981) and healers of all kinds are consulted. Whyte (1997: 3) describes a quest, where people deal hopefully and actively with illness. Ashforth (1998) however argues that this hope is short-lived. He describes the situation in Soweto where disagreement between specialists leaves help-seekers with a sense of fruitlessness and an uncertainty, unable to make sense of their misfortune in the context of competing knowledge systems and multiple authorities.

The help-seeking journey for adults with aphasia in Khayelitsha may well be marked by experimentation across various therapeutic options. This is led by the search for cure. In the absence of effective language rehabilitation and social services for people living with aphasia, people rely on word of mouth advertising of treatment possibilities. And, especially in the context of financial and social hardship that cannot endure the strains of ongoing support, people hold out for the possibility of a cure. Segar (1997) suggests that the significance of medicines and the search for the quick-fix cure can also be viewed as the kinds of health-seeking behaviour that take place in a context where more personalised types of healing are not commonplace. This may be why both George and Tata Liliso and their

[71] This is not unique to African contexts. Kleinman (1988: 48) describes the 'rough seas' of chronic illness where people try to negotiate the various forms of help and advice.

wives had been vulnerable to purported healers of all kinds – the Lilisos travelled far to visit a medical doctor who proclaimed he could cure stroke and the Mdubeki's fell into the trap of a thief posing as a diviner. In Khayelitsha, due to the lack of a supportive infrastructure and massive social and cultural change, these purported healers may be many.

In addition, what was largely consistent about the adults living with aphasia that I met in Khayelitsha was that their help-seeking strategies included affiliation with a church group and occasional faith healing rituals. As aphasia is a relatively obscure disorder, it is likely to invoke enquiry into cause and to be interpreted as spiritual intrusion. Resolution of the social and psychological consequences of aphasia to the individual and the family are most frequently sought within the spiritual realm. Anthropological theory suggests the success of the church in healing is that it draws on African inceptions and places ill health in the context of difficult living circumstances (Comaroff, 1985, Kiernan, 1995b, Meyer, 2004). In addition, therapeutic rituals seem to be workable in a setting where many other therapeutic options prove impossible to implement.

Management of aphasia consistent with cultural frameworks of causal understanding is constrained or unworkable in this environment. As I previously discussed, upholding cultural rites and performing rituals is both expensive and difficult in the context of fractured families. And even if people connect aphasia with bewitchment, there is very little evidence that they may openly accuse kin and neighbour and engage in efforts to counteract the curse. Thus, in Khayelitsha, despite the fact that cultural notions of causation may dominate, surveys[72] highlight low use of traditional healers and the utilisation of biomedicine as a first resort. Heap and Ramphele (1991) contend that this is a pragmatic decision, frequently a financial one. Similarly, Segar (1997) shows that although culture and beliefs are relevant, it is the lack of disposable income that predominantly shapes help-seeking for poor isiXhosa people living in the former Ciskei. In Khayelitsha, people often spoke about therapy options but seldom carried through.

[72] See Hoffman et al (1997), Heap and Ramphele (1991) and Cooper et al (1991) for an analysis utilisation of health services in Khayelitsha and surrounding townships.

George and Mavis, Nyathi and Tata Liliso and Nondwe all imagined moral, social and behavioural recourses to aphasia but they had pressing practical concerns, such as a need for cash, living arrangements, child care, transport, physical pain and ill health that first had to be addressed.

8.9. Discussion of Help-seeking in Khayelitsha

I do not contend that these descriptions of help-seeking represent a typical trajectory of dealing with aphasia for people in Khayelitsha. The descriptions are drawn from a small group of nurses and adults living with aphasia and their families. However it is the application of anthropological understanding to these perspectives and experiences that has implications for rehabilitation[73], where the study of cultural parameters is supported by funding and underpinned by rehabilitation policies that foster community interventions.

One of the primary objectives of this study was to gain a deeper understanding of the cultural context of aphasia. A description of causal attributions and help-seeking journeys in aphasia shows that the experience of aphasia, although always personal and social, is indeed also shaped by the larger cultural context. People draw on cultural premises to make sense of the misfortune of stroke and aphasia and these to some extent influence the strategies that people adopt to seek help. However exploring cultural conceptions of stroke and aphasia helped me to approach questions regarding the moderating influence of broader social and political factors, possibly more so than coming to a sensitive understanding of the Xhosa belief system and how it relates to aphasia. When I analyse the reams of varied explanations gathered in my fieldwork that were so often presented with uncertainty, with disclaimers and with a romanticised past of what used to exist and what should exist for a better life, like Swartz (2005) I question the value of

[73] The conceptualisation of rehabilitation in this section is broad; I refer to interventions within the healthcare and social sectors that are aimed at restructuring the lives of people living with chronic illness or disability following stroke.

documenting 'cultural' interpretations without giving voice to uncertainty (about cultural conceptions), to fluidity (in interpretation in extraordinarily difficult circumstances) and to vulnerability (and the interconnectedness of this experience to the occult beliefs). Uncertainty and vulnerability appear to be central to the experience of aphasia in the setting of Khayelitsha. In this thesis, they have emerged as overarching themes[74]. They find expression in illness interpretations. Similarly, they resonate in the strategies that people may or may not adopt to seek help. Help-seeking journeys illuminate cultural factors, such as belief systems and sectors of health care. But they also illuminate cultural change, adaptations to poverty, generational dynamics and structural constraints. These issues may contribute to the uncertainty and vulnerability in the experience of aphasia. Further, we hit up against them when we work with people. Below I discuss some of these complexities in the context of rehabilitation services in this setting.

The prevalence of misfortune in a community stimulates interpretive and help-seeking activities (Ashforth, 1998). This in turn creates a situation where multiple interpretive authorities, such as traditional healers, herbalists, faith healers and preachers, claim to speak the truth about the forces that bring misfortune to people. This manifests in what Ashforth describes as 'spiritual insecurity' (ibid: 65). The wide range of causal attributions and local therapeutic endeavours in Khayelitsha may attest to this. Mavis's story is illustrative. So is the Liliso's belief in faith healers and medical practitioners that promised total cure. It is also important however to consider that the range of causal attributions and therapy endeavours may emerge from hope for change in difficult circumstances.

I have suggested that people in Khayelitsha are inclined to believe in the existence of a miracle cure that can reverse the consequences of stroke. In Khayelitsha where social support is strained and where both financial and effective rehabilitative resources are limited, belief in a miracle cure is what sustains the hope of both patients and families that things will improve one day. This response may also have a cultural basis. The broad etiological framework in African illness

[74] These themes are developed in Part Four of this thesis.

interpretation leads to the possibility of an equally broad array of possible cures (Ashforth, 2005b). People believe that if the right treatment is sought, or the appropriate ritual is carried out or sophisticated medication is procured, then illness and its associated disability and misfortune will be cured (Mokhosi and Grieve 2004). Although this paradigm of thought sustains hope and opens avenues to help-seeking and possibilities of care, it also fuels counterfeit therapies and influences the individual and family response to rehabilitation where rapid and total cure is rare. This raises an important ethical issue for rehabilitation practitioners working in this community, who may want to deconstruct notions of a cure in the effort to convince families of rehabilitation. Mokhosi and Grieve (2004) who explored rural African families' perceptions of brain-injury suggest that paradigms that hold out for a possibility of cure help families to accept the brain-injured person. Berg (2003) describes the psychological depth in ancestral reverence. My data support the theory that culturally-constructed illness beliefs are a frame to interpret real life concerns and social problems (Good, 1986: 166). However, should rehabilitation therapists authorise people's notions of various miracle cures, particularly when these notions have made people vulnerable to expedient healers? Swartz (1997: 15 - 16) recommends that therapists need to adopt a fluid process of therapy which allows patients and families to view illness from their own individual and spiritual perspectives. In the context of an unregulated market, therapists need to do this whilst helping people learn about facilitating infrastructure within their community and helping people to foster perspectives about the chronicity of the condition.

Furthermore, it is not enough just to know that patients and families will consult various practitioners (such as traditional healers). We need to understand the complexity of their decisions to do so or not to do so. These decisions are largely financial ones. My data show that people who lack a disposable income are constrained in their help-seeking choices. The role of the church in coping with chronic illness in this community is central not least because it offers affordable membership in a community of hope. And people continue to remain part of the church beyond the acute stages of their illness as it is here where they can bring

their domestic, financial and emotional troubles to be healed. In addition, Feierman (1985) makes the point that although healers, including spiritual healers, diviners, herbalists and medical doctors are all authorities in most African communities, they are less important in the context of healing activities than the factors that shape domestic and community organisation. I spoke with a number of women who used the healing approaches followed by their affines regardless of their own perspectives.

Help-seeking decisions also reflect changing paradigms and beliefs. Many people living in Khayelitsha do not necessarily hold the view of traditional healing systems nor do they necessarily consider Christianity and traditional religion to be related systems of thought and practice. Ensink and Robertson (1997) reported a similar finding within Xhosa-speaking patients at a psychiatric health service in Cape Town. This is not a theoretically new insight, but, in the context of the proliferation of Pentecostal church movements in township communities where traditional healing and ancestral reverence are demonised, it is becoming an increasingly important consideration for culturally-competent practice.

8.10. Conclusion

In this chapter I have attempted to describe and explain the complex nature of help-seeking in Khayelitsha. Although activities may have a cultural basis, the data shows that it is just as relevant to understand them along political and social lines. One such example of this is the scenario where availability of treatment shapes interpretation systems and creates the need or desire for the treatment in itself (Whyte, 1997: 3). I turn to this consideration in Part Four, where I examine the social context of the lived experience of aphasia.

PART FOUR

THE SOCIAL CONTEXT OF APHASIA

In Part Four of this thesis I explore the social experiences of adults living with aphasia and their primary caregivers in Khayelitsha. I do this by considering how family and community life in this setting shape the experience of aphasia and how aphasia is interpreted in the context of prevailing social processes. I also describe experiences of health care and social services. My data are drawn from the narratives of participants and observations of family and community life and health care services. I also draw on interview data from relevant health care workers. In both cases, I have attempted to extract overarching themes in the lived experience of aphasia for adults who participated in this study. I consider these themes from two perspectives: firstly, in terms of sociocultural theory; and secondly, in terms of what they might suggest about the lived experience of aphasia in this particular setting. How does what we know about the psychosocial consequences of aphasia transfer across social and cultural lines? How, if at all, is aphasia set apart from life's struggles in general? How is accessing care complicated for those with aphasia? And, how does this speak to the nature of health care services? These are the questions I deal with in Part Four. I deal with the applied issues arising from them in the overall conclusion to this thesis.

CHAPTER NINE
THE SOCIAL EXPERIENCE OF APHASIA

9.1. Introduction

In this chapter, I describe how adults with aphasia experience family and community in Khayelitsha. I have focused on social and domestic relations and networks of support for the participants of my study. Changing relationships subsequent to aphasia are well recognised in the literature. My objective however is to understand these changes in the cultural and social context of Khayelitsha. The purpose of such understanding is both theoretical and clinical. Theoretically, there is a need to understand the relationship between long term adjustment issues in aphasia and the cultural and social context. Clinically, relationships between the environment and aphasia need to be better responded to by health professionals, particularly as social and community-based models of rehabilitation resonate in policy rhetoric and in local discourses in speech language therapy. Livingston (2005) and Ingstad (1997) in their ethnographic explorations of care for disabled and chronically ill people in Botswana have shown that, although most cross-cultural studies in disability and in medical anthropology have a 'therapeutic theme' (Whyte & Ingstad, 1997: 3) and focus on local healing beliefs and practices, it is familial care that predominates – and that this familial care operates within the shifting politics of gender, age, family and community.

This chapter is an attempt to understand these shifting politics of care as they relate to the adult with aphasia in Khayelitsha. In order to approach such understanding I consider how historical and contemporary processes have shaped the social geography and the nature of care in Khayelitsha. I draw on recent anthropological research into living circumstances in urban and poor settlements in Africa and against this backdrop, I examine the position of the adult with aphasia living here. I describe the social experiences of my participants and incorporate my observations from home visits and visits to places of care. I also

reflect on interviews with health and social development practitioners working in this community.

9.2. The Nature of Community in Khayelitsha

MacGregor (2002: 12 - 13), in her ethnography of adults living with mental illness in Khayelitsha, describes the contrasting images of 'community' in the discourse of local residents. It is a term, she notes, that on the one hand conjures an image of an urban area characterised by economic hardship and prevalent violence. This use of the word is frequently noted in the discourse of rehabilitation services where '*working in the community'* is akin to working in townships areas such as Khayelitsha. On the other hand however, 'community' is also presented as a figurative notion, pertaining to the cultural directive to care for each other. In this regard, MacGregor describes how 'community' is used synonymously with 'culture' and presented as a thriving social network that incorporates the dictum of '*ubuntu*', and the notion of the traditional extended African family.

Even early on in my fieldwork I noted these numerous referents for 'community' in my discussions with residents of Khayelitsha and with health care workers. The contrasting notions of community as a demoralised urban space and as a positive web of supportive social relations were explained in terms of an idealised past and a more recent breakdown in community functioning. Suggestions that the community has lost its ethos of care were common and it was a widely held perception that crime, distrust and immorality were escalating. This was a common theme of discussion among elderly residents but young adults also presented 'community' as an ideal, as something that used to exist but no longer does.

Livingston (2005: 228 - 236), in her anthropological writings about the historical and contemporary processes shaping the nature of disability in Botswana, notes a rhetoric of progress among elderly villagers. She explains the presentation of an

idealised past as reflective of the changing economies of care and the changing epidemiologies of disability. According to Livingston, increasing incidences of chronic illness and disability in the impoverished African setting of her research converged with massive shifts in traditional social roles of women and of the elderly to create a situation wherein long term care within the family is no longer guaranteed. Livingston writes that as people struggle to accommodate growing illness, disability and human suffering within their community, they imagine these dilemmas as moral ones and 'a past where suffering was hardly possible' (ibid: 1 – 2).

In a different way, Thornton and Ramphele (1988: 38) suggest that an idealised past is a notion that people use to provide hope. Thornton and Ramphele discuss how a pre-colonial idealised image of community was drawn in South Africa's liberation struggle to present an image of a future free of oppression (ibid: 29). Although the reality of this notion is questioned, it continues to maintain a place in current discourses of community in Africa and in social and health policy. It seems that the contrasting images of community presented by residents of Khayelitsha reflect a gap between the idealisation of community, rooted in struggle discourse, in political rhetoric and in cultural conceptions, and a reality fraught with problems.

What has created such a reality? Residents attribute a breakdown in community functioning to modernisation, poverty, illness and generational tension. This is confirmed in the socio-anthropological and epidemiological literature, where poverty and modernisation have been shown to have a disintegrating effect on community functioning (Cattell, 2001; Guyer, 1981; Kawachi, Kennedy & Wilkinson, 1999; Pilisuk & Frolund, 1978) and where in Southern Africa, these processes have converged with widespread urbanisation and with gender and generational divides. Burgeoning illness is an added variable (Frolich, 2005). A central tenet of this literature is that old ties of kin and clan have been disrupted and new ties are tested in the context of deepening impoverishment (Guyer, 1981; Seekings, 2008). These newly evolving ties are described as short-lived and

contingent upon mutual reciprocity as people struggle both physically and emotionally with economic uncertainty and inequality. As a result recent socioanthropological studies caution against the widely held assumption that African social networks are well established (Bossart, 2003; Higson-Smith, 2002). Certainly for the adults with aphasia who participated in this study, the historical notion of the resilient African extended family and sense of community is contrasted with a practice that is uncomfortably different.

In addition to shrinking social networks, research has also shown that poor urban communities experience increasing competition among community members, decreasing levels of trust, declining mutual aid and mushrooming social problems including alcoholism, substance abuse and violent crime (Kawachi, et al, 1999). These are all aspects of life in Khayelitsha. The resulting situation is likely to be one of social isolation for vulnerable members of society and immense strain on the household as the broader safety nets fall away. A breakdown in community functioning can also significantly affect the experience of illness or disability if it penetrates the domestic realm, as Pfeiffer (2002) has shown in his ethnography of growing gender conflict in the context of increasing inequality in post-war Mozambique.

Contrasting discourses of community in Khayelitsha are however not only explained by a romanticised past and a present society in trouble. These discourses were rooted in the very real experiences for adults living with aphasia here. What came with their sudden progression into a life of changed functioning was exposure to the contrasts of this setting. Participants at once experienced support from a limited range of community structures and a new vulnerability to crime, exploitation and social isolation. In the following section I discuss the vulnerability and isolation of life post-stroke for the adults who participated in this study. My concern is the contextual factors that have created this situation.

9.3. The Vulnerability of Life Post-stroke

Khayelitsha is a violent society. Fear of crime is a constant undercurrent and experiences of crime are common. During the course of my fieldwork, a social worker from one of the day hospitals was hijacked and killed on her way to a home visit, my interpreter's son was murdered in a revenge gang attack and a security guard manning the door to the Site B day hospital was shot and killed whilst on a weekend shift. These were my direct experiences, but stories about others abound. Few people risked moving about after dark. Some even confined themselves to their dwellings by day.

Although the participants of this study had all been victims of crime prior to their strokes, after their strokes they and their families felt a heightened sense of vulnerability. Whilst I could find no available police statistics to substantiate this, residents told me that physical and communication impairments rendered people helpless against the criminal gangs that operate in Khayelitsha and participants regarded themselves as easy targets.

George's repeated experiences of robbery exemplify this. Although George lived with his wife, five children, young nephew and two young grandchildren, there were times during the day when he was alone at home. Mavis (his wife) worked as a domestic worker for a family in the city once a week and every Thursday she attended her women's prayer group (*manyano)*[75]. The children were all either employed or at school and the young grandchildren stayed with a neighbour when Mavis went to work. On these days, Mavis seated George on a large plastic-covered armchair in front of their television, with a view onto the yard. It was on a day like this, three months after George's stroke, that a group of young men known to him came into the yard and stole the wheels of his two minibus taxis parked outside – apparently in his full sight. A few weeks later, the group of men returned again, this time taking the taxis. As Mavis often said, *'They know that no one will come out when the dogs bark*'. Later still, another group of teenage boys

[75] See 9.5.1.

kicked open their front door and ransacked their home in front of George who was unable to deter them or to raise alarm. Mavis suspected a neighbour's son and his friends but George was unable to provide any information that could assist in a criminal investigation. The family continued to be targeted by robbers throughout the time of my association with them. Some incidents were minor theft of goods from the yard, one was an armed robbery within their home[76].

It was not only impairment and disability that rendered people vulnerable to crime post stroke. Tata Liliso and Linah, the elderly participants of this study, received a monthly state pension and George qualified for a disability grant. This made them at risk for muggings and robberies on 'pension days'. A few years prior, Linah was mugged at a payout facility and believed that this incident precipitated her first stroke. Although pension and disability grants can be directly deposited into recipient's bank accounts, many people in Khayelitsha do not have bank accounts (due to illiteracy, high costs of banking and limited access to banking facilities) and so collect their monthly grants in cash from mobile collection points. This was the case for Tata Liliso, Linah and George. Their trips to the payout points were stressful events. This vulnerability contributed considerably to both the isolation and the psychosocial stresses of those living with aphasia. It was also at the fore of the concerns of the carers in this study. Despite this, however, Mavis and Nondwe had little choice but to leave their husbands alone at home and go to work.

People with aphasia were also vulnerable to other forms of exploitation. Their help-seeking journeys were marked by some experiences of expedient healers, experiences I described in Chapter Eight. In my fieldwork I learnt of an abundance of scams in operation to defraud people of their pensions and disability grants and people were distrustful of friends and health workers who offered help in securing and managing financial assistance. After Vuyokazi suffered a stroke, she sent her daughter to live with the child's paternal grandmother in a more established area in a neighbouring township. When I asked her why she had done

[76] I have described this incident in 8.6.2.

this, she replied: '*The community know I am not right, they take their chances with me. I don't want them to take their chances with her too'*. Vuyokazi's sources of anxiety were the prevalent crime in her area, rape in particular. But she also expressed ongoing concerns about her relationships with her immediate neighbourhood. There were times when she was ridiculed by people in the street and endured teasing about her facial palsy and reluctance to converse. She felt that if people could treat her so differently, they could accuse her of wrongdoing for their own purposes. She would be unable to defend herself should any accusations be cast and she was mistrustful of the street committee[77] who oversaw land allocation and dealt with disputes between residents.

People often spoke about the unsympathetic nature of their broader community. Like Vuyokazi, others also endured public ridicule. Nothemba, an elderly woman who lived near Linah, had severe aphasia. She had limited understanding of speech and language and her own attempts at speech were either repetitive or nonsensical. Nothemba no longer went out into the road beyond her home as children in the neighbourhood threw stones at her, despite that she was well known to the community prior to her stroke. Nothemba's adult granddaughter felt that the community had labelled her grandmother as *phambene* (mad) and her incoherent babbling drew strong reactions from others who understood little about her condition. The young adults I met at a weekly stroke group at the physiotherapy outpatient department at one of the day hospitals reported that they were teased about their facial palsy and that people in the community regarded them strangely. The label '*isidenge*' was applied to them, a term loosely translated to mean 'stupid' or 'mad'.

[77] Street committees were established in townships like Khayelitsha in the Apartheid regime. They consist of a group of elder and respected community members who preside over land allocation and neighbourly conflicts and who act against criminal threats within their particular neighborhoods. Their authority within shack communities is often described by residents as ambiguous however and some are especially corrupt and oppressive.

9.4. The Isolation of Life Post-stroke

Fear of crime was a significant contributor to the isolated existences led by Tata Liliso, George and Linah, who spent most of their time alone at home. Other contextual factors included the structural constraints of the environment, the nature of public spaces and an unaccommodating public transport system. Most people in Khayelitsha rely on public transport to move both within and beyond the area. Nyathi, with his own car, was a rare exception. Private minibus taxis are the most popular form of transport but there is also a bus and rail transport system that commutes people between Khayelitsha and the city. Despite this, difficulties with public transport were recurring concerns raised by Vuyokazi, Linah, Mavis, Tata Liliso and Nondwe. They generally avoided the train. The train is physically inaccessible due to stairs and gaps between the platform and carriages. It is also dangerous as commuters desperate to begin their journey may shove elderly or disabled people aside to board the crowded carriages. Once Vuyokazi was trampled on the platform. She hurt her wrist and lost her shoes. Travelling by bus was somewhat safer, but participants only risked empty buses in the later part of the morning or waited, sometimes for many hours, for an empty bus to arrive. They chose to use private minibus taxis instead, despite the higher costs. Yet even here, taxi operators afforded them little tolerance. Few stopped for them as they took considerable time to get in and out of the vehicles and needed room for their crutches, space which could otherwise accommodate additional passengers. Participants reported that they had to wait much longer than others to be picked up by the mini bus taxis and were frequently charged more than other commuters. In addition, the buses and mini bus taxis generally only operated on the main arterial roads in Khayelitsha, and participants had to walk to these routes. For Linah this was not possible. She was largely confined to her house. For Tata Liliso and George, this was only possible with assistance from their wives and when the weather was mild. Their journeys were always arduous and long. Pavements in Khayelitsha have been appropriated by sprawling shack houses and roadside stalls and the roads are potholed and uneven.

9.4.1. The limits of neighbourly support

As a result of these difficulties, neighbours, known as *ummelwane,* a term that refers to someone living in the immediate vicinity, were a valued source of support for participants. This was in terms of providing reciprocal child care, daily commodities, loans and relaying and delivering messages, particularly as all the participants of this study were unable to communicate effectively over the telephone, if at all. Neighbours also provided protection against criminal threats and checked in on participants from time to time. For example, Nondwe had arranged with her neighbour to be watchful over their home whilst she was at work, knowing that Tata Liliso may be a particular target to criminals. Vuyokazi relied heavily on her neighbour for basic provisions, such as sugar or milk, when she had no money. In addition her neighbour helped with correspondence and transactions that required complex language understanding as well as with the management of her health affairs, including her drug regime and follow up appointments. Linah's neighbour bought provisions for her. Cynthia, whose case I describe in greater depth in section 9.8, relied on her neighbour to run the *spaza*[78] shop that she operated out her kitchen door in the first few months following her stroke.

In this study, neighbourly support was particularly noted by other stroke survivors living close to participants. All participants could point out to me others in their neighbourhoods who had previously suffered strokes and valued their referrals to healers or their advice about services. Two men in the Mdubeki neighbourhood visited George on a frequent basis. Both had previously suffered strokes and recovered well. One visited to soccer matches with George. In turn, Mavis was supportive of neighbours in their vicinity who were also stroke survivors and regularly checked in on them. Mavis frequently spoke about establishing a weekly support group in the neighbourhood and arranged a number of group meetings in their home. I was invited to attend these groups and here, together with George and Mavis, a few other residents of Town Two who had also previously suffered

[78] *Spaza* shops exist throughout Khayelitsha and South Africa's townships. They are small retail outlets based in residential homes that supply basic provisions to their neighbourhoods.

strokes, came together and spoke about the struggles that beset their lives. At the first meeting there were four people and two spouses, including George and Mavis. At the second and third meetings, due to others being hospitalised for TB, only two others attended. These people however relied on Mavis to walk with them to and from home and this took Mavis two hours. The wet winter weather, ill health, mobility constraints and an irregular telephone service precluded most of the proposed meetings and after a while Mavis gave up trying to co-ordinate such support.

Although the dense housing in Khayelitsha facilitates neighbourly support, the environment also limits support offered to and by those recovering from stroke, particularly those with mobility restrictions. Wheelchairs are not viable in many parts of Khayelitsha, including the areas in which the five key participants of this study resided and walking with aids is hard. Most of the people that I met with hemiplegia were therefore housebound, particularly when the weather was bad. In addition the extent to which a support group, such as the one envisioned by Mavis, could be anymore than short term was also restricted by the changing nature of people's living circumstances, a discussion I return to in 9.7.1.

9.4.2. The limits of kin

The narratives of the adults who participated in this study resounded with feelings of loneliness. Although I have argued that the structural environment of Khayelitsha is an obstacle to social interaction, it was clear from my discussions with participants that the isolation they experienced post-stroke was also a function of socioeconomic decline and strained kin relations. For example for the Mdubekis, kin ties were a source of anxiety and an unstable support network. Since relocating to Cape Town, the couple had maintained strong ties to their rural village; they had sent money and assistance and had almost annually returned there in times of distress or cultural celebration. As the senior male in his extended family with a relatively plentiful income, George attracted kinfolk,

children and grandchildren who relied on him and his family as a financial resource and as a link to their cultural customs. They had helped with childcare, and over the period of my fieldwork, two young children had lived with them for a time. They provided assistance to the families of their brothers and sisters who were struggling financially. However, since the stroke, they could not rely on any recipriocity. Mavis felt that her husband's kin had abandoned their obligations to him. She hoped for their visits but received none and was unable to rely on them for loans or respite care. It was a concern for them that they had not returned home to their rural village since the stroke. This was for a number of reasons. The reality of travelling with George in his present condition posed a major obstacle and they lacked the financial resources to do so. However, there was also the sense that kinships ties were slowly eroding – Mavis not only bemoaned the fact that her relatives offered her little help in their time of need, she also suggested that kin may have had a causal hand in the stroke itself[79]. The family's betterment had led to resentment by others. Sharp and Spiegel (1985) describe these tenuous and remittance-dependent familial networks in the context of economic hardship. With ill health and the subsequent loss of resources, support from kin, who themselves are struggling, is not necessarily assured.

For the other participants of this study, the day to day influence of kinship was more readily observable in their narratives about their own biographies and identities than in their experiences of support and care[80]. Vuyokazi and Linah were estranged from most members of their families and extended families. Their changing living circumstances and the strains of the poverty that they had experienced for so much of their lives played a role here. Tata Liliso and Nyathi, who like George, had once played a pivotal role in the connectivity of their broader families, now only maintained regular contact with kin who lived nearby. This was due to their inability to communicate over the telephone and they both described how difficult it was for them to remain in contact with relations who lived scattered around the country. Participants drew on the rhetoric of the

[79] See 6.1.
[80] As I have already mentioned in Chapter Five, it was common practice for people in Khayelitsha to share their clan names and their villages of origin on first introductions.

changed nature of the African community to make sense of their isolation from relatives.

9.5. Support Networks Outside the Home

Within these broader experiences however, there are thriving positive communities that exist in Khayelitsha. I have already mentioned the existence of support structures including '*home boys'* (people originating from the same rural area) and a diverse array of clubs and associations including burial societies, civic associations and saving clubs (*stokvels*). There are also an abundance of church groups and non-governmental agencies. These latter systems of support were of particular importance in offering practical and emotional support to the adults who participated in this study.

9.5.1. Church groups

Many women in Khayelitsha are heavily involved in the religious associations[81], referred to as *manyanos*. *Manyano* is a Xhosa term for a Methodist African women's prayer union but this term is often used generally and across African denominations to refer to an organisation of church women. Most of the women that I met in Khayelitsha belonged to a *manyano*. These associations are predominantly made up of women in the middle to upper socioeconomic groups in Khayelitsha (that is those who occupy formal houses) and are built around values of religion, education, prudence, reciprocal obligation and African solidarity (Scanlon, 2007). Meetings are traditionally held each Thursday and women who attend don distinct uniforms, such as navy or maroon skirts, white blouses and berets. Although religious in nature, these meetings have come to

[81] Scanlon (2007) writes that up to 70 percent of African women belong to some type of *manyano*. According to a report on the needs and experiences of elderly people in Mpumalanga presented to provincial government in 2004, 82.9% of elderly black urban dwellers belong to a church organisation (Makiwane, Schneider & Gopane, 2004).

assume a wider meaning than worship for the women of Khayelitsha. *Manyanos* provide opportunities for sharing personal problems and members look to others for practical or material help. They function as both safety nets - financial and material assistance is given to those in need – and as thriving communities of hope in a place where life in general is difficult.

In Khayelitsha, I noted how the *manyanos* played a valuable role in supporting stroke sufferers and their families, in addition to the charitable and welfare work in which many of these organisations were involved. In the first instance, the *manyanos* offered intense practical and emotional support in the acute stages of recovery from stroke. Members took turns holding evening prayers sessions at people's houses following their return home from hospital. Over and above collective prayer, they offered meals. The people visited by the *manyanos* were not necessarily members of the prayer union or associated church, but kin, neighbours and acquaintances in some cases. *Manyanos* used these times of need in acute illness to recruit other women or families into their church. Yet the care and support they offered to other residents of Khayelitsha in the acute stages following stroke could not endure through the chronic stages of stroke and aphasia. Visits to the Mdubeki household dwindled once George moved beyond the acute phase of his recovery. Mavis became sceptical of the support proffered by the group; she felt that they no longer supported her when her need was most pressing. Similarly Vuyokazi withdrew from her *manyano* when her situation ameliorated and she could not fulfil the expectation of mutual support

In the second instance, the *manyanos* seemed to be a valuable source of health information to women in Khayelitsha. They offered advice regarding nutrition, exercise and care. Mavis for example professed to obtaining support and help from other members of her *manyano* who found themselves in a similar caregiving situation.

Thirdly, the *manyanos* provided a safety net for vulnerable women and men not necessarily assured by health and social services within this community. For

example, women from Linah's church helped to secure accommodation for her in Khayelitsha's old age home after becoming aware of her home circumstances. One group provided a weekly meal to the destitute elderly, always on the alert for signs of neglect and abuse. At one stage this group secured transport for these people and would collect them for a social gathering in Khayelitsha's newly built stadium one morning a week, arranging not only a meal and seating arrangements for card games, but also health education talks.

Although associations such as *manyanos* developed in response to Apartheid processes that both fractured and impoverished families, contemporary social and structural problems within Khayelitsha, including poverty, the erosion of marital, familial and kin support networks and the poor delivery of health and social services ensure that these informal associations continue to be a necessary social and survival strategy, particularly so for women in this community (Scanlon, 2007). In addition, their role in the acute stages of recovery from stroke underscores the importance of reinforcing healing with social and material support and the need for re-establishing new forms of community, a kind of '*reweaving of the social fabric*' (Pilisuk and Frolund, 1978: 279), in order to address effectively illness and disablement in this context. It was interesting that when I enquired about people's perspectives on disability, many responses were couched in Christian values of compassion[82]. In this regard, Ashforth (2005: 204) suggests that church associations in urban black areas in South Africa are more than just the functional equivalent of kin - with their uniforms and systems of rules and structures, they have in many ways replaced cultural custom. Certainly, church groups, church services, choir groups and prayer unions were an integral part of the social lives of the participants of this study. This was not only for the women of this study. Nyathi and Tata Liliso remained heavily involved in their churches after their strokes even though they did not resume the responsibilities they held prior to their aphasia.

[82] Some were couched in the teachings of Mandela. Mandela's reconciliatory and rights-based oratory has certainly become part of a discourse of behaviour in Khayelitsha. In fact, to '*Mandela*' someone means to give them a lecture about their behaviour.

9.5.2. Non-governmental agencies: The adult day care club

There are many non-governmental agencies in Khayelitsha providing health, educational and social services to people in need. Most are oriented to children and mothers. Whilst there is one old age home and a number of smaller NGOs supporting the elderly, there is only one day care centre for elderly people and disabled adults in this community. The Mdubekis were told about the centre by a pastor and later by a physiotherapist at the community health centre. Once George began attending the adult day care club, two years following his stroke, the family frequently emphasised the benefits of the group for him and for their own needs for respite. In addition, it was evident to me that the Mdubekis' active, ongoing help-seeking came to an end at this time. Mavis' urgency to pursue a cure lessened as they found some security here.

The group was housed in a small building in central Khayelitsha, an area known as K1 to its residents. The care centre is run by SHAWCO, a student led community development and health care initiative of the University of Cape Town. Here elderly citizens and adults with disabilities, particularly stroke survivors, came each day for exercise, conversation, occupational activities and a simple meal. The centre was run by some full time staff and training health professional students. Most of the adults who regularly attended the group were elderly and it was here they received health information and medical checkups a few times a year. The centre seemed to offer a social environment for its members who were otherwise isolated. It also offered a safety net for the members and staff informally monitored the living situation and well being of the members outside of the group. Transport to and from the centre was part of the service offered by SHAWCO. The daily bustle of the centre stood in contrast to the often empty rooms set aside for hypertension clinics or exercise groups for stroke survivors at the two local hospitals. People that I spoke with at the centre felt that above anything else the centre offered them security during the day, a place where they could feel safe from the community at large.

9.6. Concluding Comments: Community Experiences in Aphasia

I began this section by describing how the discourse of community among residents of Khayelitsha marks the township as a place of both spirit and despair. When people talk about social breakdown in Khayelitsha they frequently refer to crime, to isolation and to the apparent lack of care for others. When however they talk about the spirit of the community, it is frequently the church and charitable NGO's to which they refer. These were aspects common to the experience of aphasia in Khayelitsha too. I have described the post-stroke trajectory for adults in Khayelitsha as one that appears to be characterised by vulnerability and isolation. Common to the adults with aphasia and the primary caregivers that participated in this study were experiences of crime and shared feelings around a lack of community support. There is much anthropological literature describing how historical processes of migrant labour and contemporary processes of urbanisation and inequality have led to drastic implications on society's ability to care for vulnerable members. In Khayelitsha, the effect was a growing distrust for people and a deep sense of insecurity. Neighbours appeared to be an important means of social support but participants' own attempts to establish social networks within their neighbourhoods were restricted by domestic flux and difficulties with access. Although church groups and the day care centre provided important examples of interventions that mitigated the vulnerability and isolation, ultimately people were troubled by their communities, despite prevalent discourses that suggest otherwise. It seemed that care and support and compassion fell largely to the immediate family. Although in this setting, family was not something that was assured. Many times George's friends expressed his good fortune in having a wife and children to look out for him. There was the sense that they offered protection from abandonment and isolation in a community where the possibility of this lingers close.

In the following section I consider more closely aspects of family life for the participants of this study.

9.7. Experiencing Family

9.7.1. A review of the literature

In Khayelitsha state resources and institutions for care and rehabilitation are thin on the ground. The care of the person with aphasia and other sequelae of stroke falls largely on the household. Most of the families that I met in the course of my fieldwork showed an overriding concern to 'do the right thing' in helping their spouse or parent or sibling to recover and cope as well as possible[83]. This brought increased economic and social strain on households. For some people with aphasia, this meant fluidity in their living circumstances; for others, intergenerational and gender tensions surfaced. In the following section I describe fluidity of living circumstances, intergenerational tensions and gender conflict in the context of aphasia. Although these are features of domestic life in Khayelitsha in general, as a review of the literature in the subsequent sections will show, certain aspects of living arrangements and certain psychosocial stresses became evident as participants tried to cope with the debilitating and chronic nature of the condition of aphasia, shaping how it was people experienced their condition.

In Khayelitsha, as in the rest of South Africa, domestic life is shaped by cultural ideals, urbanisation patterns and domestic reconstitution practices in response to poverty. As such, the structure and functioning of households[84] in this community is varied. Although some research has documented the persistence of the extended and multigenerational household[85] in both ideology and practice (Russell, 1998), there is also evidence of a trend toward the nuclear-family household in urban settings. This is explained in terms of 'convergence' theory, where urban black families are influenced by Western-like domestic relations. Smaller households also reflect the breakup of the clan and the constraints of a smaller and more

[83] In chapter seven, I describe how families also showed overriding concern to cure aphasia and stroke, and this shaped their help-seeking strategies and significantly added to the costs of care.
[84] Due to the dynamic and complex range of households in contemporary South Africa, family and household are regarded as distinct social, and thus analytic, units (Seekings, 2008).
[85] In historical anthropological literature, the African family is portrayed as dynamic, extended and multigenerational. See Guyer (1981) for a historical review of household and community in African studies.

regulated living environment (Amoateng & Heaton, 2007: 12). Yet, although some households are stable over time, many households in poor urban settings are both complex and fluid, constantly shifting in response to an unsteady cash income and needs for care (Ross, 2003). There is no one answer to the question as to what constitutes the typical household in Khayelitsha. What is known however is that migrant labour, urbanisation, poverty and its subsequent social ills and HIV/AIDS have had drastic implications on household structure (Seekings, 2008). In Khayelitsha, shared living arrangements among family and other dependents are common. Mobility within the area and between surrounding townships is high as households are reconstituted in response to material needs, needs for care and for personal security, making many household units in Khayelitsha unstable ones. In addition, the proportion of female-headed households is high (Cooper et al, 1991).

Ethnographers have also documented the impact of migrant labour, urbanisation and poverty upon family functioning in urban African contexts. In essence, these researchers have described how situations of prolonged insecurity have constrained the ability of the family to act as a social safety net and wrought changes in social norms about family ties, intergenerational support and gender relations (Bossart, 2003; Pfeiffer, 2002; Ramphele, 1993; Sharp & Spiegel, 1985).

9.7.2. Particular family circumstances for the participants of this study

9.7.2.1. Fluidity of living circumstances

The social lives of many people living in Khayelitsha are shaped by movement between the township and rural villages in the Eastern Cape. This form of oscillating migration is rooted in apartheid migrant labour and influx control policies that denied any form of legal tenure for African labourers and their families in urban areas. Although these policies have long been abolished and there has been widespread and rapid urbanisation, particularly in the Western

Cape, urban-rural movement continues to be a feature of life in Khayelitsha (Ndegwa, Horner & Esau, 2007). People maintain strong connections to the rural communities from whence they come and many refer to their rural homesteads as home (*ikhaya*) and to their dwellings in Khayelitsha as a place of residence (*indlu* meaning house). A large number of the residents of Khayelitsha return to their rural villages each December if they can afford to do so, and throughout the year send remittance to rural kin. There is also ongoing movement as people travel for cultural and religious ceremonies.

Migration between Khayelitsha and rural Eastern Cape was a particular feature of life for people who had suffered a stroke or other forms of disablement. This took two forms. Firstly adults would return to the Eastern Cape following their initial hospitalisation period to seek healing practitioners, to attend to cultural directives as part of their quest for cure and/or for a period of convalescence. These trips were considered an important part of recovery although they were often delayed owing to lack of finances and concerns about fitness to travel by mini bus taxis and buses.

Secondly, many disabled adults and chronically ill elderly people were sent back to their rural villages to be cared for by (usually elderly) kin on a more permanent basis. I encountered a widely held perception that adults with debilitating illness were better off among rural kin than living in Khayelitsha but many reported that this practice is dwindling. In this regard, urban-rural movement as a strategy for care was bi-directional and people from the Eastern Cape moved to Cape Town in times of illness or needing care. As more and more people have settled in Khayelitsha on a long-term basis, adults with disabilities who had been in the care of an elderly relative in the Eastern Cape have moved to the city following the death of their elderly, rural-based carer. Disabled or chronically ill adults also move to Khayelitsha from the Eastern Cape in order to access health services in the city, to obtain a disability grant and/or to obtain a wheelchair or other assistive devices.

In this study, people with aphasia and chronically ill or disabled adults seemed to experience higher levels of mobility not only between Khayelitsha and the Eastern Cape, but also within Khayelitsha and the surrounding townships as the burden of their care was shared across urban households connected by family. This kind of movement was either oscillating, where people moved between two households (such as was the case with Vuyokazi who moved between her own home and that of her sister's) or ongoing where accommodation in households was short-lived and resource-dependent. For example Tata Sobukwe, who had lived independently in Khayelitsha for about two decades in a shack dwelling, suffered a stroke at the age of 73 and was subsequently taken in by his eldest daughter who lived in Khayelitsha in a brick home with her three children. He lived with this daughter for five months but when she gained full-time employment as a childminder in the city, he was sent to live with another daughter in a nearby township. His demands for care were high due to his dense hemiplegia and severe aphasia. Soon after this move however Tata Sobukwe returned to the Eastern Cape where the family still maintained their rural residence. His eldest daughter told me that this move was prompted by the constraints of space and accessibility in his younger daughter's shack home. Although she was unemployed and therefore able to be with Tata Sobukwe, she lived in a densely crowded area of informal housing and activities of daily living such as washing and toileting were almost impossible for Tata Sobukwe. The plan was that Tata Sobukwe would return to Khayelitsha after a period of time.

Domestic flux is a well known feature of township life, particularly for children. In the anthropological literature this is seen as a strategy against deepening impoverishment (Ross, 2003; Spiegel, Watson & Wilkinson, 1996) and as a form of kinship practice (Russell, 1998). Although this practice can be regarded as one that may well mitigate the effects of disability and illness, contemporary ethnographies have illustrated that household reconstitution for the care and welfare of both children and dependent adults also comes at a cost. Adults struggle for domestic consolidation (MacGregor, 2003) and children are vulnerable to the resentment of caregivers, whose own support networks are short-

lived (Ramphele, 2002). In addition, Seekings (2008) suggests that accommodation of children and adults in extended households appears to be increasingly contingent upon reciprocity and perceptions of 'just desert'. By this, Seekings (ibid) refers to the notion that some are regarded as more deserving of help than others. In this study, movement of people across households was in response to needs for care, but Linah and Vuyokazi were acutely aware that they could be turned out of their households for not assisting with household chores or for consuming precious resources such as sugar. Moreover, although for a time their respective pensions and wage earnings afforded them some level of security within their reconstituted households, their financial contributions offered no insurance in the face of marital or generational conflicts. Conflict within households and families was another reason for temporary and changing living arrangements.

Fluidity of circumstance brought added complexities to the experience of aphasia. Firstly, it limited people's ability to access formal structures of health care, rehabilitation and social support. Primary level rehabilitation services in Khayelitsha and tertiary level outpatient care largely demanded regular attendance at scheduled appointments, even though regular attendance was rare. 'No shows' and sporadic attendance were equated with a level of non-compliance and in most situations the offer of services was withdrawn after people failed to arrive. Changing living arrangements also thwarted the efforts of health care and social development workers to make home visits, to follow up patients in their care and/or to establish therapeutic projects such as support and exercise groups. In a similar way, this complicated my own research efforts. Nine other potential participants over the course of this study moved away from Khayelitsha after initial contact, leaving me with the sense of how easily people are 'lost to the system' in necessarily unstable circumstances.

Problematic access to services in this setting of unstable domestic arrangements brought additional strain to carers. As access to rehabilitation services is largely initiated by the attending doctor at the acute presentation of stroke, families who

took on added responsibilities of caring for a chronically ill or disabled family member most often did so without any formal assistance from social and/or health agencies. Mma Dlamini's story provides an example:

Mma Dlamini is a retired school teacher and lives in a neat three bedroomed brick house along a busy road in Harare. Mma Dlamini's adult son stays there infrequently when he is on bad terms with his girlfriend. Her niece's 8 year old daughter lives there too. Vuselwa also stays in Mma Dlamini's home. Vuselwa is an orphaned teenage girl who attends a school for children with special needs as she has a form of uncontrolled epilepsy. Vuselwa was brought to Mma Dlamini's home by a teacher at her school. She had lived with various relatives and foster parents before coming to live with Mma Dlamini but time after time had been sent away. Mma Dlamini believes this is because Vuselwa doesn't help with domestic chores and is a hungry child who likes jam and a lot of sugar in her tea. In addition, '*People also don't like her fits*', she tells me. Mma Dlamini also looks after her husband. Her husband cannot walk or talk as the result of a recent massive stroke. He also cannot feed or swallow well and requires care for all his daily needs. When Mma Dlamini's husband arrived to stay with her however she had not seen him for 15 years prior to that. He had been living with a girlfriend in an adjacent township who would not take on the demands of his care after his stroke. This now fell to Mma Dlamini, but she knew very little about the healthcare needs of either Vuselwa or her estranged husband. She struggled for a long time to secure paperwork to apply for necessary support grants for both. The local hospital was not helpful in locating previous medical records. In addition, she hoped for a home visit by someone from the local hospital who could help her with her husband but received none. Instead she relied on advice from other elderly women that she knew and did her best to ensure that her husband was clean and fed.

Secondly, such circumstances made it hard for people to establish their own support networks outside of the household and cement their relationships with their community. Linah's story is illustrative. Although she lived in a densely

populated area of Town Two, where living spaces are cramped, her existence was isolated and social relations were few. Certainly her limitations of both communication and mobility, confounded by the structural constraints of her environment, contributed to her social isolation but it was the ongoing dislocations in Linah's life that had created a situation wherein she was solely dependent on her immediate family for accommodation, support and companionship. Linah's only ongoing engagement with people outside of her immediate family was with her neighbour who purchased needed commodities in return for a small fee, with Nothemba, and in as more indirect way, with members of the congregation of the church where she occasionally attended services. Linah did not have any knowledge of enabling infrastructure in Khayelitsha, nor did she have any significant relationships with peers or with other women in her community.

9.7.2.2. Intergenerational tensions

Just as domestic flux is described as an important strategy for both survival and care among poor communities in South Africa, so is the multigenerational household (Seekings, 2008). Save for Vuyokazi who lived on her own in the time of me knowing her and Nyathi who lived with his wife and two daughters, the other key participants and elderly residents that I met in my fieldwork all lived in multigenerational households. Here grandparents played important roles in child care and in financial support of their households. The monthly pension was the primary means of support in Linah's household. In some households children played important roles in reciprocally supporting their elderly parents and attending to their needs for care following stroke. But this wasn't always the case as the accounts of Linah and Tata Liliso exemplify. For them, living with their children brought added complexities to their experience of stroke and aphasia.

Intergenerational tensions have been described as a feature of society in post-Apartheid South Africa. In Khayelitsha, this finds expression in the narratives of

the elderly, in their status in their households, and in the reported marginalisation and ill treatment of elderly people at social welfare and health care facilities[86]. This also finds expression in the care of the elderly and at its zenith in accusations of witchcraft against older women.

There are various anthropological writings on the genesis of this antagonism. Comaroff and Comaroff suggest that anxiety about issues of employment and production have translated into generational oppositions. Using ethnographic material from Limpopo Province of South Africa before the turn of the millennium, the Comaroffs (1999) contend that a breakdown in intergenerational support is a new social phenomenon in response to growing inequality, manifesting in its most malevolent form as witch hunts. They present accounts of disillusioned and angry youth who, without apartheid as the enemy, have turned on the older generation who are seen to have accumulated wealth. They also present accounts of the reciprocal demonisation of youth by elderly people. In a related way, Jean Comaroff (2007) argues that generational antagonism is the outcome of disrupted life paths. Impoverished (often male and often black) youth occupy a position of liminality, of being 'betwixt and between', in the social structures of contemporary South Africa. No longer children, but without employment or prospects to enable their entry into adulthood, they escape the obligations of care and exist in their own peer-defined and ethically ambiguous society.

Livingston (2005) describes a number of other processes working simultaneously to create the rifts between young and old in a Batswana village. At the fore is a changing economy of care. In this increasingly commodified society, Livingston describes how daughters and sons leave their rural homesteads to seek employment in urban areas in both Botswana and South Africa, leaving the elderly to shoulder the burden of care for children. Although many migrant labourers continue to meet familial obligations through remittance and contribute to their rural homesteads by bringing material gifts and commodities, many don't

[86] See 10.3.

or are constrained in their ability to do so and generational rifts begin to surface. These are further entrenched by processes of modernisation. As younger wage earning adults are exposed to modern ways, the elderly lose their authority in matters of religion, leadership and healthcare. In addition, Livingston describes how in a society where care and familial obligation have to a significant extent transformed into money, government pensions have had the unintended consequence of alienating the elderly from the care chain (ibid : 57).

Although these are ethnographic interpretations from societies that differ in both geography and culture to Khayelitsha, they offer a relevant framework of understanding for some of the concerns and experiences of older people living with aphasia and their spouses[87]. As Tata Liliso and Nondwe, George and Mavis and Linah shared their worries about life with me, it was clear that they carried huge uncertainties about their safety and their welfare. These uncertainties were ascribed in part to their children and generational tensions were pronounced. The ways in which they surfaced are discussed below.

Firstly, the older participants of this study spoke harshly about younger generations, whom they associated with crime, alcohol and drug abuse and with a changing framework of values about frugality, education and family obligations. Both Linah and Tata Liliso believed that their worries about disrespectful children and grandchildren contributed to their strokes and ongoing ill health; a notion that I described in Chapter Seven.

Secondly, participants believed that they commanded little respect from the younger generation despite the purported value that is attributed to the elderly in African culture and despite their care of grandchildren and their financial contributions to their households. This failing respect played out in how little they were helped in their homes and in their neighbourhoods. Older participants

[87] Comaroff's theory gives substance to other features of life in Khayelitsha as well, including high level levels of crime and widespread misogyny.

reported receiving minimal practical and social support from their children and grandchildren and then only through incentives and bribery. In the Liliso household, for example, Nondwe alone took care of all Tata Liliso's needs and cooked and cleaned, despite working long shifts as a cleaner. Her unemployed granddaughter, in her early twenties, sometimes helped with household chores in return for cash, but would not help care for Tata Liliso in any way. Similarly, Linah received help from her younger neighbour when she could afford to pay her neighbour, but none from her son and his girlfriend.

Thirdly, older people were at risk for targeted crime and ill treatment. Linah endured both, in the community at large and at the hands of her children. People involved in social services for the elderly in Khayelitsha confirmed this situation.

There were occasions when these tensions led to conflict. Linah's experience provides an extreme example but relations were difficult between parents and children in the Liliso and Mdubeki's households too. Despite the fact that George's children helped out when and where they could, Mavis was troubled by her children since George's aphasia. They went out more, drank alcohol, neglected their studies and became increasingly disrespectful to her wishes.

The elderly people in this study invoked popular theories of modernisation as an explanatory model for these experiences. These included individualism and the culture of rights. They were also cognisant of the complexities brought by the grants they or their husbands received – younger people saw no reason to offer either material or practical help to those who received monthly cash payments. In this respect, it appeared that stroke and subsequent physical and communicative disablement exacerbated the generational tensions in the homes of the participants and that the basis of this was financial. Changing belief systems also played a part[88].

[88] See 8.6.3.

Such tensions contributed to the feelings of uncertainty that characterised the journey following stroke for Linah and for George and Tata Liliso and their wives. They had little assurance as to who would look after them in the future. This was despite the claims on their pensions by children.

9.7.2.3. The experience of aphasia across gender lines

One afternoon on a visit to a primary health care clinic in Khayelitsha, I sat with a group of female nurses in the sun outside the clinic who were debating whether life was harder for single or for married women. The nurses all recognised the difficulties of both rearing children and earning a living without the support of a male partner, but together they drew the conclusion that life with a boyfriend or husband was harder. Having a male partner, they felt, meant the added burden of cooking, cleaning and caring for the man and the likelihood of both anxiety and conflict within the home. This conversation progressed, like many other others that I listened to in my fieldwork, to complaints about the behaviour of men in this community. They bemoaned a man's lack of responsibility for children, lack of financial support, binge drinking and numerous girlfriends. Men were described as reluctant to assist with domestic chores and expectant on women for meals and laundry and childcare.

Such conversations just hint at the extent of the gender divides in Khayelitsha, a community marked by widespread gender conflict, where women suffer from the consequences of alcohol and drug abuse by their husbands and where domestic violence is rife[89]. Bahre (2002) ascribes this to the backlash against what is referred to as a crisis of masculinity in present day South Africa: Male unemployment is high and men have lost much of their cultural and political authority in the urban environment. In addition, many women in Khayelitsha shoulder the responsibilities of child-rearing and household maintenance over and

[89] Between March 2008 and February 2009, 2119 protection orders were lodged by women against their male partners at the Domestic Violence Support Desk in the Khayelitsha Magistrate Court. (Mosaic Fact Sheet 1: Domestic Violence in Khayelitsha, retrieved from www.mosaic.org.za).

above needing to generate income through either formal employment or micro-enterprises. They also shoulder the burden of care for sick or disabled members of society.

The situation for many women in Khayelitsha is insecure. Vuyokazi's case indicated a number of aspects common to many women in this community. She lived alone and had a long history of difficult relationships with men. She suffered both physical and emotional abuse by her partners and the fathers of her two daughters abandoned their obligations to them. This situation intensified following her stroke. Her partner left her for another woman almost immediately after her stroke and she had no choice but to send her daughters to live with their respective grandmothers. She lived with her sister for a while but her sister's husband turned her out. Although she had employment, her financial situation was precarious. As a result of these experiences, Vuyokazi made a conscious decision to pursue a single life as she learnt how to cope with her aphasia and her heart condition. This was regarded strangely by her neighbourhood. Her primary concern relating to her aphasia was being exploited by men. She lived in fear of being raped.

Linah's case was also one of insecure living circumstances. She was almost entirely reliant on external community structures for support and care. Her son's accusations of witchcraft her deeply cynical about human nature and she described the life of women in her situation as a difficult one.

The situation for many women in Khayelitsha is also an onerous one. The burden on wives and daughters to care for those chronically ill or disabled is great. I spent a good deal of time with Nondwe and Mavis, who shouldered responsibilities for housework, income, childcare and for the support of their husbands, whose needs for care were at times very demanding. They lived with physical and emotional exhaustion. Physiotherapists and nurses at the community health centres stated that married men were less responsive to physical rehabilitation efforts as they had wives to meet all their needs for care. Yet, ironically, they felt that it was

more likely men that presented at their clinics for rehabilitation, as they had the assistance and support of their wives or partners to carry this through. The stroke groups were for the most part made up of disabled men and their wives or partners. It was telling that neither Linah nor Vuyokazi had pursued rehabilitation following their strokes. I regarded the consequences of their aphasia as devastating and they both battled with ongoing physical weakness and co-ordination difficulties, but without the support of close others, attendance at weekly appointments was impossible for them[90].

Above I have shown that the associated vulnerabilities of living with aphasia in Khayelitsha may be greater for women and that care in this community is a gendered activity. I have mentioned how this situation is frequently brought up in discussion among health and rehabilitation workers. In this regard, I encountered a prevalent discourse in Khayelitsha that men do not involve themselves in both formal and informal support structures. Women certainly hold the moral high ground in discussions about who cares for whom. However, men like Nyathi and Tata Liliso and George's friends played important roles in volunteerism and support, particularly to other men. They played important roles in their families too. Just as both stroke and aphasia heightened the pre-existing insecurity in the lives of Linah and Vuyokazi, so it heightened the pre-existing uncertainty for Nyathi, Tata Liliso and George in the roles that they played in rituals, cultural authority and sustaining kinship. Neither George nor Tata Liliso had the verbal capacity to express this, but Nyathi did and his empathy towards men living in his community with aphasia as a result was both expressed and acted upon.

How then is aphasia experienced in a setting such as Khayelitsha? I have described experiences of increased fluidity of living circumstances, increased insecurity (as guarantees about who will care for whom fall away) and increased vulnerability (to crime and to a prejudicial environment). As the literature has

[90] Gender however appeared to be only one of the multiple variables as to why neither Linah nor Vuyokazi had never received any formal support or rehabilitation directly aimed at treating the communicative and physical sequelae of their strokes. The nature of services, and the prevailing socio-economic burdens in this community also contributed.

shown, poverty is central to these experiences of domestic flux, vulnerability and insecurity. It also compounds the isolation evident in the lives of adults living with aphasia in this community. Financial constraints shaped the experience of aphasia in other important ways too. I consider this in the following section.

9.8. Aphasia in the Context of Socio-economic Strain

I have described how financial resources played a role in help-seeking. It also seemed to play a role in the recognition of aphasia. For example, both Linah and Vuyokazi downplayed their communicative difficulties and rooted their social isolation in the broader context of their difficult lives. They were hard pressed to manage their daily existence and mobility and independence were deemed more important to them than good speech and language skills. In another example, aphasia was not regarded as a psychological or social obstacle because it did not disturb daily household and economic activities. This was in the case of Cynthia:

Cynthia ran a *spaza* shop from the kitchen of her newly built RDP home in the area of Green Point alongside the N2 motorway. Cynthia lived with a younger niece who came from the Eastern Cape to finish her schooling in Khayelitsha. She did not have a husband and her children were grown up. Cynthia's kitchen was divided by a cage-like structure through which she sold snacks and daily commodities to her neighbours. Her shop operated from early morning to late at night throughout the week. When she was not in her house, she sat with neighbours in their doorways or yards. I met Cynthia a few weeks after she suffered a left-hemisphere stroke when I accompanied a local rehabilitation therapist on a home visit. Cynthia could walk, although she had a fairly dense right hemiplegia and no functional use of her arm. Cynthia could talk, but her verbal repertoire was limited to '*ewe*' (yes), clicks for signalling 'no' and the occasional word or slurred phrase. Importantly she appeared to understand everything that others said to her and had a firm sense of what she needed to do in order to maintain her livelihood. First she wanted to learn how to get in and out of

bed independently. Once this was achieved, she wanted the rehabilitation therapist to show her how to get in and out of her small bath on her own. Whenever her therapist, who acted as my interpreter during our visits to Cynthia, probed about her speech difficulties, she laughed and slapped her thigh and right forearm, signalling to us what it was that she wanted to us to talk about. Three months after her stroke, Cynthia was managing her shop independently with occasional help from her niece. As local customers shouted their orders, she handed crisps, detergent, paraffin or body lotion through the wire cage with generally broad gestures and a smile. She continued to spend her free time with other women in her street.

For others however, the primary impact of aphasia was financial. For example, although Nyathi was able to resume his roles within the home as a husband and a father and continued to play an active role in social and community life, he was unable to work in the high level capacity of his former job. Yet the nature of Nyathi's aphasia meant that he didn't qualify for a disability grant. Having no other contingency funds, such as a sufficient contributory pension or disability insurance, the family was propelled into a socioeconomic crisis soon after Nyathi's stroke. Similarly, the Mdubekis experienced George's stroke and aphasia as a financial loss. George had been the primary breadwinner but his severe aphasia precluded him from having any further involvement in his minibus taxi operation. Like Nyathi, George had no contingency funds and the unregulated and informal nature of the minibus taxi industry meant that there was no legal safety net to secure his business following his stroke. Although Mavis tried, she did not have the cultural authority to take over the management of George's drivers. The family became reliant on the income of their eldest daughter, fuelling household and familial tensions. The costs of George's health care were an added burden.

Uncertainty about the application and eligibility process for disability grant was an important part of the experience of aphasia for Nyathi and George and their wives. The process of securing the grant was administratively and linguistically problematic for them and precluded their own involvement. Sympathetic health

care workers in the acute stages following stroke often process initial applications on the patient's behalf, but later, as the cases of both Nyathi and George showed, when dockets are misplaced, follow up procedures are misunderstood and grants are suspended further down the line, adults with aphasia and their families have little recourse and virtually no knowledge of how the application system operates. In the time of my fieldwork there was also uncertainty around the disability grant among health workers in this community, reflecting the point that Gibson (2005) makes that state-run health services in South Africa cannot be analysed without consideration of the prolonged and systemic transformation of the health system since 1994. In the years prior to my fieldwork, the disability grant system was under review. Attempts to align the process to social models of disability were actualised by the creation of assessment panels and community involvement. However, this review process was abandoned and former systems were re-initiated, which positioned the medical officer as solely responsible for decisions around granting eligibility status, and entrenched medical perspectives of the temporary nature of stroke.

9.9. Discussion of the Social Context of Aphasia

Central to this chapter are issues of social support. These issues are of particular importance in a setting such as Khayelitsha where both historical and structural processes continue to have a disintegrating effect on social support. The role of social support networks in aphasia rehabilitation has begun to receive attention in the literature and supportive relationships are known to have important implications for adjustment following stroke and aphasia. Sociological theory suggests that in illness and disability, the more dense the network, the better the outcome (Young, 1982). At present there is no empirical evidence that aphasia outcome is influenced by ethnic or cultural group affiliation, or by quality or quantity of support. I cannot address any such questions or comparisons in a study of this nature. What I have attempted to show is that there are additional problems associated with aphasia in this setting. Anthropological literature suggests that the

genesis of these processes lies in the broader political and economic context where urbanisation and poverty limit the extent to which the community can act as a safety net. These influences similarly find their expression in the household and in the experience of aphasia, gender, generational and money tensions are brought to the fore.

I argue that these problems cannot be divorced from the experience of aphasia. An important question to ask however is, is the experience of aphasia altogether different from the general experience of life in Khayelitsha or from other forms of chronic illness and disability? Fluidity of circumstance, insecurity and vulnerability are arguably key features of life for most residents in Khayelitsha. It is difficult to unravel the complexities of the social costs of poverty and disability, but the narratives of adults living with aphasia and those of their family members suggested that stroke and aphasia heightened the vulnerability, isolation, insecurity associated with both community and family functioning in this setting. Questions of support, care and security were plain. Prejudices towards the elderly and women were more acutely felt.

These findings were not surprising. Emmett (2006) in a volume on disability and social change in South Africa presents data to show that the oppression associated with disability in South Africa and globally is an extension of prevailing systems of power (or conflict) in society, including race, gender and class. In conditions of poverty, these divisions are exacerbated and people who live with chronic illness or forms of disability are likely to experience vulnerability, isolation, insecurity and increased domestic flux.

What therefore may relate specifically to the problem of aphasia for adults in this setting? Considering that aphasia is above all an interactional disorder, one would expect that a difficulty in establishing and maintaining relationships would set it apart from other disabling illness. This wasn't always clear. People described physical disabilities as far more of a burden to them than their aphasia. Tata Liliso, Linah, Nyathi and Vuyokazi felt that the practical realities of their lives

clouded concerns about their communication difficulties. Mavis was always more worried about George's immobility than his inability to communicate. This was the same for Mma Dlamini. Similarly, in contrast to the psychologically and cognitively oriented literature into the psychosocial dimensions of aphasia, participants described loneliness as a function of their living circumstances and not as a consequence of the communicative disability. Loneliness was most often attributed to changing social norms about care and to gender and generational oppositions. '*This kind of no support is happenings these days*' Mavis tells me and often wonders aloud if there will be someone to look after her '*when her turn comes*'.

Thus, in the broader context of a struggling society, it may be that aphasia, particularly when some verbal abilities are maintained, is overshadowed by people's more basic needs to get by and by the associated troubles of a prejudicial and sometimes violent environment. Yet it was my observation that disturbed speech did appear to be a stigmatising condition, as the public experiences of Nothemba and Vuyokazi showed. Here aphasia was considered under the rubric of mental illness and people responded with teasing, name calling and social rebuffs. Facial palsy was mentioned as a feature that draws public reaction. George's vulnerability to crime was linked to his inability to communicate and there were also clear links between the uncertainties facing spouses and their questions regarding the nature of aphasia. The fact was they had no idea how to support the communication attempts of their husbands and both George and Tata Liliso were excluded from dialogue within their homes.

It is also likely that people downplayed their communication difficulties as these were largely unrecognised by attending health care workers, including doctors and rehabilitation therapists, and because there were no local speech and language support services beyond the acute stages of their strokes. Ingstad and Whyte (2007: 38) note that the availability of solutions or programmes directed at a particular disability plays an important role in shaping people's understandings of their problems and in identifying people with particular disabilities. My

developing relationships with Linah, Vuyokazi, Nyathi and Tata Liliso gave substance to this argument. They became more interested in discussing their communication difficulties as I came to know them. It seemed that my presence in the community gave credibility to their afflictions. But this ultimately led to questions about possible solutions and, as I have already mentioned in Chapter Eight, to questions about a cure.

Beyond all else though, exploring the social context of aphasia in this setting highlighted that community functioning was the most troubling aspect of aphasia for adults in Khayelitsha, reflecting Cattell's (2001) contention it is as much 'poor places' as 'poor people' that affect quality of life in illness. Although vulnerability, changing living circumstances, insecurity and isolation may well be a general feature of life in this setting, these were the major themes of the lived experience of aphasia and people drew on these themes, and their political and moral underpinnings, in order to make sense of their experiences.

9.10. Conclusion

This chapter is about aphasia in context, not from an interactional perspective, nor from a psychological perspective – ways in which context has previously been studied in this field. Rather it is a consideration of the social context, of prevailing social processes and how aphasia is interpreted and experienced within these. This chapter is essentially therefore an articulation of circumstance that highlights the insecurity, isolation and vulnerability associated with living with aphasia in Khayelitsha. These experiences, and that of uncertainty that I describe in Part Three, are part of the 'grand narrative' (after Hyden, 1997) of stroke and of aphasia. It is my contention however that the social, economic and cultural context of Khayelitsha is the genesis of these experiences and thus the experiences of aphasia, although always individual, have anthropological dimensions that are critical to understand.

CHAPTER TEN
ACCESSING CARE: THE HOSPITAL AND COMMUNITY HEALTH CENTRE

10.1. Introduction

In this chapter, I use material gathered through observations at the local hospitals, as well as through interviews with participants, therapists and nurses to explore the reality of health and rehabilitation services for adults living with aphasia[91]. This material, oriented to how participants negotiated the local and hospital structures of healthcare, presents a picture of a strained system where practices negate health care reform. Reports of abuse by nurses are commonplace and the experience of local hospitals and rehabilitation facilities is physically uncomfortable. I argue that there may be moral discourses operating in health and rehabilitation services that are brought to light in the reported experiences of adults with aphasia. My findings are not a definitive examination of health services. Rather I aim to begin a process of discussion about rehabilitation and speech and language therapy services in South Africa with the intention of encouraging further research and developing interventions.

10.2. Negotiating Levels of Care: The Tiered Structure of Health Services

In the post-apartheid structuring of the national health system, the primary level became the level of entry into the health system. Patients in Khayelitsha are expected to enter health services at community health centres (known as day hospitals). If their condition is severe or expertise is needed to treat them, they are

[91] Although I am familiar with the context of the tertiary-based medical and speech and language services and the rehabilitation facilities where Nyathi, Tata Liliso and George were admitted (having worked as a clinician in these environments prior to this study), I did not carry out ethnographic observation in these settings. I refer only to interview data when describing experiences at these institutions.

referred to the secondary and tertiary levels. The secondary (district) hospital linked to Khayelitsha is in Mitchell's Plain. There are two tertiary (provincial) hospitals in the Western Cape and as Khayelitsha lies geographically between these hospitals, people are referred to either. Following a stroke, the proposed chain of events for patients in Khayelitsha is that they are taken to the day hospital by family or ambulance and from here transferred to either the district or provincial hospital. Thereafter patients discharged to rehabilitation units for a period of subacute nursing care and rehabilitation or discharged home. The five subacute rehabilitation facilities in the Cape Metropole were amalgamanted into one in the first year of my fieldwork. From here, patients are referred back to the tertiary level for specialist services, including speech and language therapy, and to the primary level for physiotherapy, occupational therapy, chronic medication, blood pressure and glucose monitoring and disability grant processing. This pathway of care is represented in figure 10.

Although the purpose of such a process is to preclude overburdening at the tertiary level and improve long term follow up of patients and care within the community, movement between these levels of care for patients in Khayelitsha is complicated and often unsuccessful. For participants, this seemed to limit their opportunities to access services that may have improved their care. At a most basic level this was due to transport. Only two ambulances are in operation in Khayelitsha and participants' recounts of acute stroke management indicated concerning delays in receiving care. In addition, movement between levels of care was almost always characterised by long periods of waiting on what Gibson (2005: 520) describes as the 'threshold of care'.

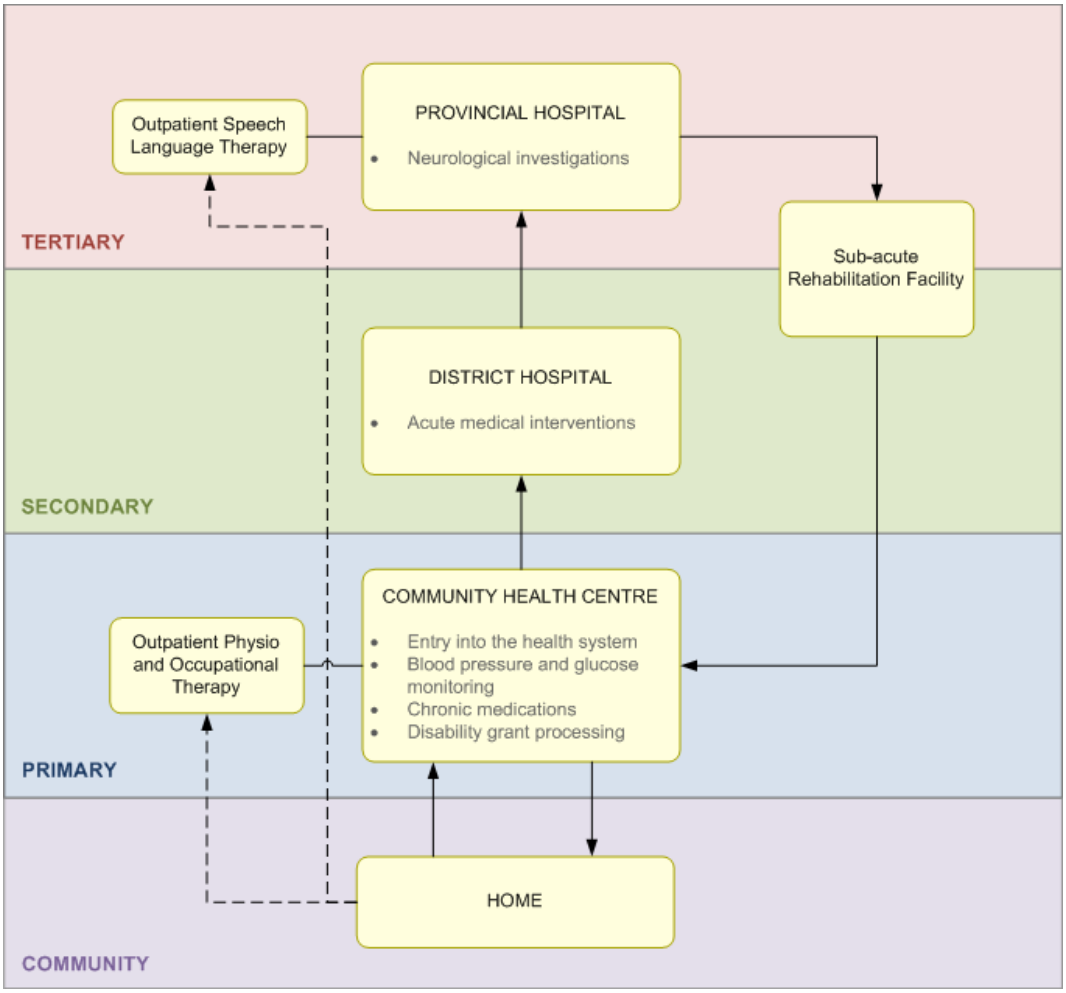


Figure 10: State-run health care services for people with stroke

Complicated movements between levels of care also appeared to be due to a lack of co-ordination between services and clinics both between and within various levels. Vuyokazi for instance attended clinics at a tertiary hospital for her heart condition and for her shoulder pain, but reported to a primary care institution for her hypertension and for her ulcer, both of which were treated at different vertically structured primary care programmes. She had also been prescribed numerous chronic medications[92] quite independently of others. Tata Liliso who also suffered from hypertension and chronic ulcers attended two different clinics on two different mornings each month. This resulted in a considerable number of clinic appointments for participants but, paradoxically, gaps in their care. For

[92] See 6.4.

example although Mavis regularly accompanied George to the hypertension clinic since his stroke, he was only diagnosed with diabetes 18 months after his stroke when his eyesight began to fail, and it was a physiotherapist who recognised his symptoms and made the necessary arrangements for medical investigations. As an examination of primary care services will show, referral of patients between levels of care is not assured. There was also a notable lack of co-ordination between the primary level rehabilitation services of physiotherapy, and occupational therapy, tertiary-based speech and language therapy and rehabilitation units, translating into a lack of follow up care. None of the participants of my study were linked to community-based rehabilitation workers in Khayelitsha. Tata Liliso was the only adult with aphasia that I met over the course of my fieldwork that attended speech and language therapy sessions at the outpatient department at a tertiary hospital. He attended half hour individual therapy sessions twice a year.

10.3. Experiences of State-run Health Facilities in Khayelitsha

In Khayelitsha, state-run health services are heavily used. These include nine primary health care clinics and three larger community health centres (CHCs) referred to as day hospitals by residents of Khayelitsha. The clinics are staffed by nurses who deal with a range of minor ailments, run family planning clinics, baby and child nutrition clinics, ante-natal clinics and immunisation programmes. Participants went day hospital for monthly monitoring of blood pressure and blood glucose levels and for physiotherapy. Participants also visited the day hospitals for treatment of other medical conditions such as ulcers and tuberculosis and for access to chronic medication from the attached dispensaries.

The day hospitals in Khayelitsha are nurse driven institutions. Here doctors practise in a limited capacity. They oversee weekly clinics, such as the psychiatry and HIVclinics, process disability grants and run the trauma centre. Two of the hospitals are 24-hour facilities although there are no beds and patients requiring hospital admission are transferred to a secondary level facility.

Although residents of Khayelitsha used state-run biomedical services, visits to the day hospitals were fraught with long waits and difficult interactions with nursing staff. Typically, in order to ensure that they were attended to at monthly clinics for blood pressure monitoring and the dispensing of chronic medication, people needed to be at the clinic by seven o'clock on the relevant morning[93] and it was not unusual that patients waited four to five hours on crowded wooden benches before receiving treatment. At times even after having waited for many hours, people were turned away and told to return the following day or week.

Nurses acknowledged the long waiting periods; frequently blaming overwhelming case loads, abuse of the free system of health care and understaffing. It was evident that the day hospitals in Khayelitsha were brimming with patients waiting to be seen. However it was also evident that health workers in this setting by and large contributed to the problem. They took tea breaks and lunch breaks with almost technocratic regularity yet were slow to resume clinics after such breaks. Although mornings were frenetic, the afternoons were quiet and usually only the hospital dispensary functioned after lunch time; although by half past two in the afternoon patients were turned away from the dispensary. On the days that George or Vuyokazi or Tata Liliso and I left the hospital after a fruitless morning, there was disappointment but not surprise. Patients had come to expect to wait and thus although uncomfortable and dissatisfied with the circumstances, none ever took issue with the hospital. Coupled with these expectations however, was the fact that they were not prepared to risk confrontation with the nursing staff.

The participants of the study generally expected that the nurses at their local clinics and the day hospitals treated them discourteously. Older patients in particular expressed distress at their (mis)handling by the nurses. They felt that consultations were rushed and that their communicative and mobility impairments were not accommodated by the nurses. In discussions outside of the day hospitals and in participants' homes, varying forms of abuse at the hands of nurses emerged

[93] Queues outside the day hospitals would start to form from as early as 3.30 am. The participants of my study however chose not to travel at night for safety reasons and this meant joining the back of an already lengthy queue by morning.

as an important theme in people's experiences of stroke and aphasia. This was not confined to the local state-run services. Participants' accounts suggest widespread mistreatment at secondary and provincial hospitals and rehabilitation units as well. Jewkes, Abrahams and Mvo (1998), who uncovered prevalent clinical neglect and verbal and physical abuse at the hands of nursing staff when investigating obstetric services in the Western Cape, contend that an ethos lacking in care has become established within nursing practice in state-run clinics. They suggest that nurses abuse patients in order to assert power and maintain distance in a context where they are traditionally subordinate to other healthcare professionals and identified with patients (due to common cultural backgrounds). Jewkes et al argue that difficult working conditions are only partly to blame. Certainly I witnessed unethical care and abusive treatment by nurses towards patients during my fieldwork. The effect is a mistrust for state-run health care and for local services in particular[94]. That the participants in this study used state-run health care facilities should not belie the fact that their expectations for service were very low.

It is also important to emphasise that the nurses at the day hospitals in Khayelitsha were expected to play a predominant role in long term management of stroke patients but few were skilled beyond blood pressure and glucose monitoring and repeat prescriptions for chronic medication. The clinics were not oriented to the kind of personalised care that is required in long term management of stroke and nursing staff were ill equipped to make appropriate referrals or recommendations. Nurses showed a generally poor understanding of the nature of stroke, aphasia and of other disabling sequelae yet, contributing to their uncertainty, there were no doctors overseeing the clinics or supporting them. The provision of their services was also made difficult by administrative failures. Patients' files and referral letters were frequently mislaid and the supply of drugs was irregular.

[94] Despite the fact that the services were accessible and freely available, all participants used private doctors that charged fees of around R80 per consultation when they could afford to do so. The specific reason for this was dissatisfaction with state-run services.

It was impossible for adults with aphasia who participated in this study to negotiate these services independently. Although clinics were run with routine, people with aphasia had difficulty discerning names called out over the loudspeakers that signalled their turn to move to the various stations of patient management. There wasn't a sense from participants that this was a concern to them, in fact they were glad that they were accompanied. But, this did mean that they were largely excluded from interaction within consultations. Nurses did not address participants directly and interaction was with spouses or daughters or the accompanying carer. This interaction however was limited – time constraints were often evident and there was a strong biomedical focus. Nurses checked blood pressure and made decisions regarding the need for referral to a doctor. Nurses spoke to carers about adherence to medication, diet, exercise and the importance of blood pressure monitoring. Questions raised about possible co-morbid illness were largely around diabetes. Concerns around other co-morbid conditions such as aphasia or hemiplegia or dysphagia (swallowing or feeding difficulties) were neither expressed nor addressed.

One of my obvious conclusions from observations at this level and participant interviews therefore, was that people with aphasia were disempowered in their interactions in this health care context. How much this differed from other non-communicatively disordered people is not clear though. Many patients were illiterate and had limited knowledge of biomedicine, including physiological processes and pharmaceuticals.

10.3. Experiences of Outpatient Rehabilitation at Local Day Hospitals

Over the time of my study, there were two physiotherapists working at the three day hospitals in Khayelitsha, providing outpatient rehabilitative care. One was permanently based at the one day hospital, the other moved between the two other day hospitals. These physiotherapists were supported by an occupational therapist at one of the day hospitals and one occupational therapy assistant who ran self

help and support groups for people with mental illness and for elderly people at the old age home in the area. The physiotherapists generally provided individual therapy for issues around mobility. Adults with stroke formed the largest part of their case loads. A physiotherapist at one of the day hospitals ran a weekly exercise group for people with stroke. Adults with stroke also formed the largest part of the case load for the occupational therapist who conducted home visits in certain areas of Khayelitsha, if transport was available and if the area was considered safe. Here the occupational therapist conducted needs and safety assessments. Both physio- and occupational therapists in Khayelitsha assisted with the securing of assistive devices, such as walking sticks and wheelchairs, for people with stroke and helped families to process disability grants.

I interviewed a number of therapists over the course of my fieldwork at two of the day hospitals. These interviews were not formal. Some were conducted in vehicles on our way to home visits or to auxiliary support structures in the community. Many took place whilst waiting for patients to arrive at scheduled appointments within the departments themselves. Common to these discussions was the feeling from therapists that rehabilitation services in Khayelitsha were underutilised. In exploring some of the common themes that emerged in my interviews with participants and therapists, I hope to shed some light on the contextual variables that created this situation.

Firstly it appeared that the referral system between the community health centres, subacute rehabilitation centres and acute care hospitals is in collapse. George was the only participant referred from a rehabilitation facility to physiotherapy at his local day hospital. He was not referred for occupational therapy as these services were not based at the community health centre closest to him and he was not referred back to speech therapy at either of the two larger tertiary care hospitals in Cape Town. Tata Liliso was referred for outpatient speech and language therapy at a tertiary hospital but not for other rehabilitation services. Nyathi was discharged from his rehabilitation facility without follow up care and both Linah and Vuyokazi never received any referrals for paramedical care. I never asked any

of the participants or their family members whether they were told about follow up care outside of biomedical services. I could not presuppose that there were no other reasons as to why the health workers who attended to participants in their acute stages of stroke did not make referrals, other than a generally limited awareness of available services, of patients needs and of a low referral rate. However, therapists trying hard to establish rehabilitation services on the other side of the service provision fence reported a similar situation. They felt referrals were generally limited, their diaries largely open.

Secondly, and in a related way, it seemed that primary level rehabilitation services are underutilised as the result of pervasive administrative failure within the health care system. Confusion with regards to dates, times, clinics, names and telephonic contact details contributed to people not arriving at scheduled appointments and therapists were constrained in their ability to follow up patients, or to make home visits. I shared their evident frustration. Over the course of my study, I was given permission to contact adults living in Khayelitsha who had presented with stroke at the neuro-ward of one of the tertiary hospitals in order to approach them for participation in my study. In a period of two years, one of the 18 telephonic contact details was correct.

Thirdly services were not continuous. A number of factors contributed to this. In the context of a lack of disposable cash and transport difficulties, patients were not always able to adhere to scheduled appointments. Urban-rural movement and movement between townships in the early stages following recovery from stroke made it difficult for rehabilitation workers in Khayelitsha to maintain contact with patients, particularly so in the context of failing administrations where contact details were frequently absent or erroneous. And importantly, services themselves were not continuous. Over the course of my fieldwork, two of the permanent rehabilitation posts were replaced with community service posts[95] where

[95] Community Service for speech-language therapists and audiologists, physiotherapists and occupational therapists among other health professionals, was introduced by the Department of Health in 2003, with the aim of improving health service delivery, especially in under-served and rural areas throughout South Africa.

graduating physiotherapists and occupational therapists worked for a year. With the yearly change of staff, stroke groups became sporadic and long term relationships and follow up became impossible. The structuring of community service posts appeared poorly suited to the needs of patients with chronic illness or disablement in the context of Khayelitsha. In a similar way, health sciences student placements were erratic and two of the Xhosa-speaking therapists left their jobs after being approached by private corporate and academic institutions.

Health services were suspended during times of public unrest or mass strike action and people largely avoided the clinic when there were outbreaks of taxi violence, or violent disputes between transport operators. This was not infrequent. Over the course of my fieldwork, health services were disrupted or suspended by public service protests in July 2005, the South Africa Transport and Allied Workers Union security guard strike from March to May 2006 and public servants strike in June 2007 during which 30 health workers from one of the day hospitals in Khayelitsha were dismissed. In addition, residents of Khayelitsha protested following a spate of runaway fires between November 2005 and January 2006, blocking roads and stoning motorists.

Fourthly, patients and therapists were sometimes at odds about the function of primary level rehabilitation services. Some therapists felt that many residents of Khayelitsha viewed their services as part of the disability grant process and once their grant was secured, most often with the help of the therapist, they no longer attended individual therapy or group support. In the focus groups that I conducted with Nyathi, George and Mavis and Linah, the notion that physio and occupational therapists could help secure a disability grant was foregrounded, but Nyathi and Mavis also shared the complicated picture that this was the only observable outcome for them. The difficulties of getting to therapy were not balanced with the benefits of an irregular exercise group, which usually ran late, if at all.

Lastly, therapists felt constrained by bureaucracy. Meetings were frequent and lengthy. Changes to policy and process were often. To exemplify I reflect on an interview with a physiotherapist at a special needs school in Khayelitsha who took me to a locked room to show me a wall of folded wheelchairs that were donated by an external agency. She couldn't issue these until the handover had been officially sanctioned by personnel from the ministry of health.

Despite these challenges however, participants seemed to value rehabilitation facilities and hold high regard for therapists. Therapists however were not always able to discern aphasia, particularly across language and cultural divides. Quite early in my fieldwork, I met a young man with right hemiplegia at one of the stroke exercise groups. He was unable to communicate verbally. According to his friend who accompanied him, this young man had been left voiceless by his stroke. Later however, the therapist told me that *'he is a quiet man; it's just in his personality to be like that'*. It was telling that over the time of my fieldwork there were no referrals between local outpatient rehabilitation services and tertiary-based speech and language services.

Above I have described local health care and rehabilitation services based on fieldwork observations and interview data for the participants of this study. Following I consider some pervasive themes in participants' reflections of their experiences at all levels of care, including the tertiary level and at rehabilitation units and social services. The first of these themes is that of trust or mistrust of health workers. Language barriers and non-compliance were other issues. These all contributed to the uncertainty that seemed to pervade experiences of health care for participants and their family members.

10.4. Trust and Mistrust of Health Workers

Seldom did race classifications come up in my interactions with residents of Khayelitsha, until topics of discussion turned to health care. Here the race labels

of '*black nurses'*, '*white doctors'*, *'coloured Sisters'*, '*Indian doctors*' and '*foreigners*' punctuated the sentences of participants, families, friends and residents. Largely, people expressed distrust of '*black'* nurses, ascribing to them actions of abuse and inferior training. Similarly, widespread distrust of foreigners, especially people from other African countries, was extended to foreign doctors. These people were begrudged for filling jobs that should be reserved for South Africans and residents derided African health workers who were unable to communicate in isiXhosa. I observed interactions wherein patients spoke only in isiXhosa to other African health workers despite knowing that they could not converse at all in this language. Attitudes towards '*coloured*' health workers were ambiguous. Some told me how the '*coloured'* sisters at the secondary hospital and rehabilitation facilities gave preferential care to *'coloured'* patients, bumping them up on waiting lists and providing meals to them. Others expressed feelings that '*coloured*' sisters were better trained and more empathic. '*I only go to the coloured nurses*' was a striking statement from one of the participants. Indian doctors were regarded as highly skilled, white health care workers were considered '*blessings*'.

An integrated analysis of these sentiments is beyond the scope of this thesis; deep rooted prejudices, legacies of educational discrimination and processes of power and social structuring are at play. It is the pervasive distrust however that I want to highlight, particularly as people spoke mistrustfully of traditional healers and their broader community too[96]. Mistrust was central to the uncertainty that characterised the experience of stroke and aphasia for adults in Khayelitsha and it seemed that this was compounded by the encounters that people had with the medical establishment. Gilson (2003) has linked prevalent mistrust of health workers among South African health services users to both denigrating treatment of patients by health workers and the associated occupational challenges facing health workers in a transforming society. She offers a conceptual model of these two interrelated conditions that is relevant to Khayelitsha. Certainly, the concerns participants had about their treatment at the hands of health workers were real

[96] See sections 8.6.2 and 9.3.

ones, but I believe that this mistrust is also linked to the uncertainty that both patients and health care workers faced, as they attempted to manage the full spectrum of stroke, including aphasia, without the knowledge and resources in order to do so.

10.5. Communication Barriers and Moral Discourses

Segar (1994: 283) describes communication between patients with epilepsy and their doctors at a day hospital in Grahamstown in the Eastern Cape as a 'fog of confusion' due to the lack of a common language between patients and their care providers. In this study, participants' accounts of their experiences of health care at all levels of care reflected a certain haziness too. Biomedical terms were understood in a concrete way as I describe in section 7.3.3. In addition, participants frequently requested clarification from me regarding their follow up care, their specific diagnoses and the processes of a disability grant application. Many times in my fieldwork people approached me with clinic cards and asked for clarification. This was not always due to aphasia, both Nondwe and Mavis struggled to relate details about the care their husbands received at the tertiary hospitals and rehabilitation units, but the case of Vuyokazi indicated how aphasia might exacerbate this situation:

Vuyokazi relied on her neighbour to translate information about the time and place of various scheduled appointments using her clinic card as the only reference guide. Vuyokazi could not tell what medication treated what condition and did not understand the intricate details of her prognosis or management. This was evident one morning when Vuyokazi was noticeably distressed. When I enquired what was wrong, she handed me her clinic card and told me that she was due to arrive at the hospital for a scheduled shoulder operation that same morning. Although she had agreed to meet with me on that specific date, she later noticed on her hospital card that she had a scheduled appointment on the same day, but she did not want to let me down. We phoned the orthopaedic ward at the hospital

in order to explain why Vuyokazi had not arrived for her scheduled operation. I was fortunate to get hold of her attending doctor. According to him though, Vuyokazi's appointment was only a check up. He had suggested to her that she may require a shoulder operation sometime in the future but this was not immediately indicated. Vuyokazi had clearly misinterpreted her doctor's explanation. This incident was an example of the difficulties that Vuyokazi had in negotiating her health care. Although she tried her best to adhere to medication and to arrive for appointments, she remained unsure of what was required of her. As a result, Vuyokazi had little control over her medical care. She frequently raised concern about the amount of medication she was on. Yet according to her doctor at the orthopaedic clinic, Vuyokazi was unreliable in her reporting of her medical complaints and a difficult patient to work with.

Participant reports suggested a relationship between their difficult interactions with health workers and their feelings of mistrust and uncertainty. This was not unexpected. A rich and expanding research base of health communication practices in South Africa has documented the centrality of communication practices in either bridging or widening language, culture and power divisions between health workers and patients (Evans, submitted; Penn, 2008; Watermeyer, 2008) These studies have considered health communication practices from both a micro and a macro perspective, taking into account interactional dynamics and institutional and broader socio-political variables. Although researchers have looked carefully for evidence of practices that positively impact health care, the situation portrayed in their findings is largely bleak. In addition to this, there is also research coming out of the United Kingdom focused specifically on health care interactions with adults with aphasia (Law, Bunning, Byng, et al., 2004; Pound et al., 2007; Simmons-Mackie et al., 2007). This research has exposed communication practices within health care that marginalise the patient with aphasia and adults with aphasia are described as 'lost in the undertow' of the operations of the health system (Parr, et al., 1997: 63).

My data also hints at moral discourses in the health system that may equate communicative limitations with non-compliance. In a related way, George and Tata Liliso were described as unsuitable candidates for rehabilitation. Nurses told Nondwe that Tata Liliso did not want to get better. Rehabilitation workers told Mavis that George was disinterested in his care and did not try to assist nurses and therapists. Both families disagreed with perceptions and were disappointed. They believed their husbands received little, if any, therapy over the time and that they were discharged home prematurely because of these perceptions.

10.6. Discussion and Conclusion

In this chapter I have explored participant's experiences of health care and have attempted to foreground those experiences that may relate to their aphasia. In doing so I have suggested that opportunities for comprehensive stroke management, including consideration of and responses to aphasia, may be limited by the following: apparent strong biomedical focus (despite possibly limited knowledge of stroke and aphasia and irregular supplies of medicine); vertically structured programmes to address prevalent chronic illness in this society; possible ageist prejudices and moral discourses operating in medicine and rehabilitation regarding patient compliance and 'suitability' for intervention.

These suggestions raise more questions than answers about the particular challenges for adults with aphasia. Although there is the constant reality that aphasia, in this health care context, is a largely unrecognised and poorly understood condition, I question how important variables of age, language, culture, staff attitudes and technical operations interface with aphasia to create the situation wherein people were largely disappointed with their health care? Why was it that some participants were not referred for rehabilitation services at all, and why were those who received subacute rehabilitation, including language therapy, not followed up; why was is that acute stage rehabilitation for George and Nyathi appeared largely impotent in helping their families both understand

and cope? Can I assume that if Vuyokazi did not have aphasia she would be empowered to negotiate and manage her health care? And again I raise the question, is aphasia overshadowed by other pressing problems that influence health care and limit its processes?

Local research has demonstrated that training medical students how to communicate with adults with aphasia improves the structure and the content of the case history interview (Legg, Young & Bryer, 2005). However, in the everyday world of health care clear links between the above mentioned variables need to be forged before we can assume that interventions for improving communicative access will work. Raising two more important questions, how can these links be forged, and how can language practitioners interested in improving health care access for adults with aphasia respond to them? I attempt to answer these questions in the following and final chapter of this thesis.

CHAPTER ELEVEN
CONCLUSION

11.1. Glancing Back on Emerging Themes of the Thesis

This study is about aphasia in context. Specifically, it is about how aphasia is interpreted and managed in an African township outside of Cape Town. Here a newly urbanised community straddles two geographic and cultural contexts, that of the rural village and the city, and their related ways of life. The township is characterised by other contrasts too. In Khayelitsha one finds hope and promise for development amidst a more general disillusionment that poverty has continued into democracy. One sees new clinics and housing developments amidst widespread deficits in service delivery. One glimpses a deep sense of humanity in community and family life whilst being simultaneously overwhelmed by an evident breakdown in social functioning.

In a setting of such contrasts, questions about causal notions and frameworks of interpretation of stroke and aphasia provide interesting commentary on social processes and how people, caught up in these processes, search for meaning and for cure from affliction. Some of the adults with aphasia in this study explored numerous avenues in their search for help and entertained plural notions of causation. The ethnographic data showed no evidence of a discrete cultural construct of aphasia but rather a wide variation in causal notions that included biomedical causes, social and behavioural determinants, transgression of social rules, and the influences of supernatural powers, such as witches and ancestors. People sometimes sought treatment on the basis of these causal notions. Here biomedical categories were equated with medicine and medicine was sought for a palpable cure. Some people traversed the range of traditional, biomedical and religious cures for aphasia. All therapeutic options however were complicated. Whilst encounters with the health system presented serious challenges to participants and their families, traditional and religious avenues for help were

obscured by a burgeoning and not always ethical open market offering miracle cures. Uncertainty prevailed. Dialogue around such treatment paths and causal notions with healthcare workers from this community was revealing of their own struggle to negotiate the divides between the biomedical world of their work and the cultural context of their lives.

In this setting, an articulation of the circumstances of a small group of adults living with aphasia aimed to provide further commentary on the influence of the social context on aphasia. Voicelessness rendered people vulnerable to crime and exploitation. Some attracted stigma. Some struggled with social isolation and a declining support network of kin. It was instead the church, neighbours and the adult day care centre that were regarded as valuable sources of social support. Efforts to secure other resources, such as the disability grant and healthcare, were hampered by poverty of access and institutional disarray. Some of living circumstances of participants were fluid as they moved between households for care. Some lived with the uncertainty of holding a tenuous position in their family and households. Notwithstanding, when these adults or their primary caregivers spoke of stroke and aphasia, they did not separate communicative difficulties from the struggles that beset their lives. Discourses of aphasia were woven into wider narratives about individual, gender, generational, family and community. Some seemed to show small concerns for language disruption when material and social support was lacking. For them, the physical demands of life seemed all consuming.

11.2. Recommendations for Service Provision

In this thesis, I have argued that there are contextual factors in Khayelitsha that create uncertainty, vulnerability and social isolation for the adult living with aphasia. This is based on the stories of George, Linah, Tata Liliso, Vuyokazi and Nyathi and other participants. Whilst I do not wish to suggest that their stories are emblematic, it is likely that contextual influences will find expression in the

experiences of aphasia for people in similar circumstances. It is important that these contextual influences are understood not only in terms of how they may affect people's responses to rehabilitation, but also in terms of how aphasia therapists might respond to them. In the following discussion therefore I consider ways in which the emerging themes of this thesis can be applied to the local context to improve the post-stroke trajectory for adults with aphasia and their caregivers and to facilitate clinical exchange.

I begin with a broad perspective. Whilst an understanding of the life worlds of people living with aphasia can indeed facilitate clinical interactions between the speech and language therapist and patients, I believe that the priority message of this thesis is the need for a contextually-relevant interpretation of the social approach and of primary health care philosophy. This requires a critical awareness of the dominating influences of culture and poverty on aphasia and responses to rehabilitation and an understanding of the everyday realities of the communities and the systems in which we practice. This also requires reflexive engagement. It is evident from the material in this thesis that local service delivery structures in rehabilitation and the discipline of speech and language therapy do not seem to fare well as support systems for aphasia in this urban context of chronic poverty.

11.2.1. Taking cue from global initiatives: Structural reform in service delivery

The themes emerging from this study speak strongly to the need for speech and language therapists in South Africa to create support systems for adults living with aphasia that exist outside the realm of biomedicine and beyond the acute stages of stroke. This implication, whilst derived from local realities, is no different from those emerging from research into the psychosocial aspects of aphasia in North America, Australia and the United Kingdom. Here aphasia therapists have responded by establishing communities for adults living with aphasia (called aphasia centres). More than group therapy, the aphasia centre is a systemic, community-based organisation that provides a physical context in which

people with aphasia can interact with others and a platform upon which people with aphasia can access other aspects of social participation. These therapeutic projects and advocacy initiatives fall under the rubric of the Life Participation Approach to Aphasia (Chapey et al., 2000), essentially a professional position statement, prescribing therapy that is tailored to real-life social and psychological needs of adults living with aphasia.

The aphasia centre seems to be a good fit for an approach that will address local needs for social interaction, mutual support and a safe space in the community (after MacGregor, 2002: 47). What some of the anthropological literature and the material from this study suggests is that urbanisation, poverty and the reality of health services limit the extent to which this community can act as a safety net for disabled adults. Participants did not always experience the directive to support others (encapsulated in the cultural conception of 'community' and 'kin'). Whilst church groups rallied around people in the acute stages following stroke, this support was short term. Vulnerability to crime was a constant fear. In addition, mobility difficulties (exacerbated by the terrain and poor infrastructure of the area) and fluid living arrangements limited the extent to which people with aphasia could seek out and maintain their own networks. In this way, the aphasia centre as a permanent and open resource seems more suitably structured to providing long term and accessible support than the current model of scheduled appointments.

The aphasia centre also seems to be a good fit for an approach that will foster a broader awareness of the condition and provide a gateway to healthcare, social and possibly legal services for those who struggle to access such services due to communicative difficulties.

With such a possible goodness of fit, one needs to question why speech and language therapists in South Africa have not yet attempted to model their practice on LPAA initiatives. The answer may lie in geography, resource-bases and professional alignments. In the Cape Town Metropole, for example, state-run

speech and language therapy services for adults with communication impairments are based solely in tertiary care institutions or rehabilitation facilities. Here the focus of engagement is bedside evaluation of impairments, educational counselling and subsequent inpatient therapy. Outpatient services are similarly structured and remain geographically and financially inaccessible for people who live in the further flung, low-income areas surrounding the city. Although these departments recognise the gaps in service delivery, their material and personnel resources do not stretch beyond present services and they are forced to prioritise services for adult patients in need of tracheotomy care and dysphagia (swallowing disorder) management. Community service posts have not been established outside of tertiary-based centres within the Cape Town Metropole, although I question whether short term placement of speech and language therapists in settings such as Khayelitsha would provide a suitable solution. As the material in this thesis has shown, there are constraints in implementing facility-based traditional rehabilitation services. In addition, it is plain that establishing support systems and building gateways to other services for those living with aphasia in a setting that presents multiple challenges to the clinician requires more than short term engagement.

The seeming unlikelihood of a thinly stretched hospital-based service being able to accommodate the everyday realities of people who live with aphasia in underserviced urban communities raises a critical issue for the profession of speech and language therapy in South Africa. Whilst committed to the political imperatives of the social model of disability and to community-based rehabilitation, the profession's moorings to medical institutions, particularly for adult speech and language services, arguably limit practice to acute management and push clinicians to prioritise acute services, such as safe feeding practices. The result may be an undesirable marginalisation of people who live with chronic language-based impairments.

The development of practical and on the ground interventions for adults with aphasia, that can accommodate people's needs for social interaction, daily security

and help with language or literacy-based transactions, therefore demands a break away from the clinical domain. Forging links with established non-governmental agencies that provide community-level dedicated services for elderly and disabled adults in settings such as Khayelitsha is one potential solution. Forging links with statutory social services is another. Ultimately however the discipline of speech and language therapy in South Africa needs to respond to the growing awareness here and in the international arena that acute and chronic caseloads require different, separate even, models of service delivery and advocate for related structures. There is also a need for professional debate around the possible disjunctions between the medical alignment of the discipline and the capacity for socially-engaged practice. These disjunctions were particularly apparent in my interviews with rehabilitation workers who indicated that age, co-morbid illnesses, emotional difficulties, low socio-economic status, inability to speak English and aphasia made for poor candidates for rehabilitation. Without such debate, the recommendation for the establishment of systemic and sustainable support structures in urban localities such as Khayelitsha is an unrealistic one.

11.2.2. Taking cue from local initiatives: Site-specific methodologies for communicative accessibility in the health care system

Outside of developing long term support systems for adults living with aphasia, the themes emerging from this study also speak strongly to the need for both education and training within the health care system to improve communicative accessibility in the clinic and hospital, and to ensure that aphasia is recognised and appropriate referrals are made. This may reduce problematic interactions between adults with aphasia and healthcare providers and facilitate attitudinal reform.

Again, this theme is similar to those emerging from aphasia research in the global context where therapists have responded by implementing communication training programmes in the health care arena. These programmes, developed in the spirit of LPAA, train health care workers in appropriate use of verbal and non-

verbal communication strategies to enable the adult with aphasia to participate in aspects of their own care (Bindman et al., 1995; Kagan, 1995; Law et al., 2005; Parr, Pound & Hewitt, 2006). Whilst an exploration of the encounters with the health care system for the adults who participated in this study highlights the need for LPAA-modelled interventions, it also contests the notion implicit in these approaches that verbal impairment singularly precludes participation in health care. There are seemingly multiple variables influencing the activities of health workers and limiting care in our local context. This raises an important question about the applicability of focused interventions for improving access to health care for adults with aphasia.

To work towards communicative accessibility for adults with aphasia, I therefore propose that researcher-clinicians of aphasia take their cue from local site-specific health communication projects in the HIV/AIDS management arena that have considered actual communication practices, the cultural context, larger social movements and the exercise of power to forge links between variables affecting communication and care (Evans, submitted; Penn, 2008; Watermeyer, 2008). These projects have also shown that site-specific practice, grounded in the structural and functional operations of the institution, is effective in making change in a context where improving accessibility is an enormous task.

Reflecting on the particular findings of my study, I believe that a site-specific methodology for improving communicative access to health care for adults with aphasia is especially important to address the particular gaps in the knowledge base of health care workers, to identify the communication pitfalls of adopted terms, such as *high blood* and *sugar*, and local idioms of distress (after Nichter, 1981) and, to develop appropriate responses. I do not wish to suggest that appropriate responses are *educating* the patient about *correct* biomedical diagnoses. The anthropological perspective that I adopted in this study showed that this is not necessarily assimilated by patients or helpful to them, particularly when not tied into a cure. Rather I wish to suggest that terms need to be understood for their local referents and how they are used in the health care arena,

as opposed to their proposed cultural translations. Site-specific practice is also needed to strengthen institutional ties and referral pathways to enable easier movement between levels of care for people with aphasia. Administrative structures that will facilitate access to people's biographical data and networks of support may be a crucial aspect to this. Despite high levels of domestic flux of people within this community, it was my impression that healthcare workers did not pay sufficient attention to the need to capture correct contact details of patients and those of their families in order to maintain long term relationships in the context of fluid living arrangements.

11.2.3. Culturally-relevant health communication in aphasia

Above I have suggested that the aphasia centre and interventions to ensure access to healthcare might make a real difference to the lives of adults living with aphasia in our South African context. Emerging from this thesis is also the understanding that therapists need to respond to the themes of uncertainty and insecurity. Perspectives from medical anthropology suggest that this can be achieved by enhancing attention to the clinician-patient interface (Kleinman, 1988: 230). This is the context of healthcare communication, where interaction between therapist and patient, or practitioner and patient, is regarded as the site of healthcare. On the back of a now well-established body of research in medical anthropology and sociology, there is growing recognition that this interaction is crucial to the management of chronic conditions in both developed (Gerhardt, 1990; Thorne, 2006) and developing contexts (Swartz, 2002; WHO, 2002). There is also growing recognition that this interaction needs to attend to individual realities and cultural phenomena.

Ethnographic research into the lives of adults living with aphasia provides the clinician with an informed understanding of what ought to be discussed with patients and their families in order to make a meaningful difference. This is especially important in a setting where therapists and patients are likely to come

from vastly different backgrounds. For example, in this ethnography I describe the purpose and meaning behind causal attributions of aphasia for the adults who participated in the study. I also describe the wide variation in causal notions as reflective of a pervasive uncertainty about illness and about avenues for help. People were uncertain about the trajectory of stroke and aphasia, about the possibility of treatment and, about the integrity of healers and healthcare workers. People were also uncertain about their own alignments in this setting where Christianity, indigenous culture, biomedicine and western thought wrestle for hegemony. There seems to be a very real need for therapists to create the space in which causal attributions can be discussed and processed. There is also a need for clear communication about the nature of aphasia and realistic gains in rehabilitation. This may well reduce the uncertainty associated with the onset of aphasia and associated susceptibility to exploitation. In Chapter Eight I suggest that people in Khayelitsha are inclined to believe in the notion of a miracle cure and that this renders them more susceptible to counterfeit healing operations in the medical, traditional and faith healing approaches. Clinicians therefore need to engage with such perceptions in clinical interactions as a means of empowering the patient and their families within the context of a 'miracle' market. Clinicians also need to engage with such beliefs because they are imbued with significance. Whilst belief in the miracle may be a response to powerlessness and the lack of any tangible opportunities to improve the situation, it may also be a means of creating and sustaining hope.

Reflecting on other findings of this study, the foregrounding of gender, generational and cultural conflicts in many of the conversations that I had with residents of Khayelitsha, indicate that there may be benefit in discussing these issues in the clinical space, even in the context of aphasia. And, possibly particularly in the context of aphasia as it is these issues that are brought to the fore as individuals and families attempt to cope with communication loss and its associated disablement. My experience as participant observer in this setting is that engaging people in discussion around the broader issues that influence their lives gives credibility to their struggles.

Thus far I have focused on local concerns. I now consider how this ethnography can be applied to the global context.

11.3. Anthropological Perspectives in Clinical Aphasiology

In the first instance, the results of this study may provide insight into the situation for adults with aphasia living on the social fringes of developed societies; in societies where social interventions for language disability are not well established; and, in the context of plural healing approaches.

At a theoretical level, this study can also contribute to the growing understanding of the sociological meaning of aphasia. In the global context of clinical aphasiology, there is emphasis on the shift to socially-engaged practice. This emphasis has promoted a generation of insider research and aphasia therapists now have a grounded understanding of what it is like to live with aphasia. Such research has portrayed the adult living with aphasia as a reflexive being who, disrupted by the sudden inability to speak or to understand language, employs individual coping strategies to reconstruct their lives.

My interpretation of the stories of George, Linah, Tata Liliso, Vuyokazi and Nyathi offers a different perspective. Broader historical processes have undoubtedly shaped their immediate circumstances and the support systems and therapeutic options available to them. These in turn defined how they experienced language loss. Equally, their responses to aphasia were shaped by cultural practices and the world views through which they interpreted their lives.

This perspective is an anthropological one. Although limited by the small number of participants, it has highlighted the socio-cultural complexity of aphasia, thereby lending support to the integrated analysis of individual subjects, cultural phenomena, social conditions and structural constraints in understanding the

experience of aphasia. Whilst of particular relevance to the local context, there are arguably key social and cultural dimensions in all societies that will find expression in the experience of aphasia and in the feelings and thoughts of individuals and families, in responses to treatment and in systems of care. In addition, the material in this study has shown the relevance of examining the social fabric and how it might endure the chronicity of aphasia. Although South Africa's legacy of oppression and segregation of racial groups played a large role in eroding the social fabric in the community of this study, the challenges to establishing and maintaining social relationships in the context of social prejudice, urbanisation, modernity and globalisation are not only local ones.

Anthropological enquiry, as an approach that balances the psychological dimensions of aphasia with recognition of the economic, cultural and social factors that can confound the experience, seemed to provide a suitable tool for such integrated analysis. It also provided a rich interpretive framework that offered conceptual clarity on local understandings of aphasia, on traditional healing practices and on people's daily experiences of living with aphasia.

11.4. Further Study

My aim in this study has been to document the setting and challenges of life for the adult with aphasia living in a poor urban South African context. My orientation has been largely structural and my gaze has been toward socio-political processes. In this regard, anthropological tools and theory provided unique insights that would have been impossible to glean in the context of the clinic. They also enabled a nuanced view of interpretive paradigms and social processes that a survey approach or health beliefs model may not have been able to capture.

This thesis is based on a few case studies and observational material from a limited number of contexts. This thesis has also focused on causal beliefs, help-

seeking strategies and social and familial circumstances. These are both limitations of the study and further qualitative exploration is needed for full understanding of aphasia within this context. Specifically the effect of communication disability on social roles and relationships within this cultural and social setting could be explored through illness narratives and further ethnographic enquiry. This could hopefully also draw attention to stigma and marginalisation for people with communication disorders. Research into the relationships (if any) between causal beliefs and help-seeking and social circumstance would be of both theoretical and clinical interest. The findings relating to health care services and disability grant eligibility warrant further investigation and ethnographic exploration of rehabilitation services for isiXhosa speaking people with stroke through the tiers of the health and social support systems is needed to strengthen some of the findings of this study.

In thinking about the cultural context of aphasia, many important questions also remain unexamined. These are largely questions about how cultural notions of personhood interface with social responses and inclusionary or exclusionary practices in aphasia. Consideration needs to be given to the African notion of personhood, described as more interactional than material (Whyte & Ingstad, 1995: 10), and the associated value ascribed to those with language skills (or by corollary the devalue of those with language impairment). Yet at the same time the occupational structures of many African societies make modest demands on sophisticated language or literacy skills and whether this mitigates the consequences of aphasia is an important question to pose.

There are also unexamined questions about the value placed on clearly formed speech in African societies and how such values might evolve through the stages of life. A further consideration is the how aphasia interrupts culturally-defined communicative styles and how it manifests in the interactional characteristics of African languages and in social communication. In isiXhosa the word *ukonkola* meaning to chat, joke, to speak familiarly among friends or to gossip (Kropf's Dictionary, 1915) describes communicative exchanges among residents of

Khayelitsha to the foreign ear. Communication here is a vibrant, open, and often loud exchange, combined with gesture and both facial and prosodic emphasis. The isiXhosa spoken in this setting is also hybridised and dynamic – conversations are punctuated with English and Afrikaans referents and often humourous terms of slang (*isicamtho*) shaped by township life and current affairs. More philosophical exchanges are filled with metaphors and proverbs and creative descriptions abound.

Lastly a home grown response to the needs of adults with aphasia requires exploration of cultural constructions of self-representation and how these influence responses to group work, alternative communication systems and supported communication. While these initiatives are aligned with rights-based discourses in South Africa, their cultural relevance cannot simply be assumed.

Such an anthropological understanding of aphasia could help to build the epistemology of communication disorders in South African. It could also contribute to the broader theoretical understanding of the sociological nature of aphasia, in a field where political agendas have entrenched essentialised notions of participation and disembodied constructions of society in frameworks of understanding. But a cautionary word: As this ethnography has shown, cultural parameters are complex and changing and inextricably linked to social processes and individual circumstances.

11.5. Concluding Reflections

This studied has examined the current situation of adults living with aphasia in Khayelitsha using anthropological methods. Through careful ethnographic study of five adults, I have described the challenge of living with aphasia as it relates to their position within communities and households; their networks of support; their frameworks of interpretation of communication loss; their encounters with traditional and faith healing activities; and, their unique experiences of health

services. Such examination has shed light on explanatory models of aphasia in this cultural context as well as the influence of poverty on the course of aphasia. It has also provided a powerful motivation for meaningful reform of speech and language services for adults with aphasia in local contexts.

It is my hope that this ethnography is a thoughtful response to the needs of adults living with aphasia in Khayelitsha. The anthropological lens has enabled me to think deeply about the issues uncovered in the articulation of the circumstances of the participants and about the social, political and cultural convergences on the experience of aphasia. Importantly it also presented an attitude of respect, gave priority to understanding and reflected back critical insights for professional practice. In the search for approaches that will make a difference to both understanding and practice, I believe that anthropology offers a valuable alternative.

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APPENDICES

APPENDIX I: PROTOTYPICAL INFORMATION SHEETS AND CONSENT FORMS

1. Health care workers at Community Health Centres and carers at organisations working with stroke patients
2. People with aphasia and family members
3. Consent form
4. Consent statement for audio recoding of interviews

INFORMATION SHEET – HEALTH CARE WORKERS AND CARERS

A STUDY OF ADULTS LIVING WITH APHASIA IN KHAYELITSHA

My name is Carol. I am a speech therapist and I would like to conduct research into the lives of adults living with aphasia in Khayelitsha. This research is for my doctoral studies through the University of the Witwatersrand.

THE RESEARCH PROJECT

Stroke is one of the biggest causes of disability in adults in South Africa. A stroke occurs when blood to the brain is blocked or when there is bleeding within the brain and so blood cannot reach some parts of the brain. These areas of the brain then become damaged. This damage may cause a number of problems including weakness of the body, problems with memory, problems with eyesight, as well as problems in speaking.

Aphasia is the loss of language following stroke or other times of brain injury. Adults who suffer from aphasia are either unable to communicate or have severe difficulties in speaking, understanding, reading and writing. Very little is known about the understanding of this condition in your community as well as the problems facing people who have aphasia. In this study I hope to gather information about aphasia in your community and well as look at the difficulties facing this group of people in terms of everyday living and health and social services. I also hope to look at how this group of people copes with their difficulties and the community's support structures that aid them.

This study may help to understand the needs of stroke patients in your community, specifically those who have lost their ability to speak or understand language as the result of their stroke or injury.

FIELDWORK AND INTERVIEWS

In order to do my study, I plan to make daily trips in and out of Khayelitsha for about a year. During these visits, I plan to visit people with aphasia in their homes and to visit clinics and centres for people who have had strokes. At these visits, I will watch what goes on and I will interview people, such as health workers and the partners and families of people with aphasia. We will talk about the problems facing people with aphasia in your community.

PARTICIPATION (CARERS)

As you are involved with elderly and disabled adults in your community, you would be a suitable person to assist me in this project. Participating in this project would involve being interviewed by myself. Interviews will be about the difficulties facing people with aphasia in your community and about your experiences as a person involved in caring for stroke patients. I will also ask you to help identify people with aphasia in your community who could participate in this study.

My study will take place from June 2005. I would like to visit you and your centre many times during my study. I would like to visit your centre at the start of my study and then return to your centre many times later in the year. At your centre, I would like to observe support groups and accompany you on home visits to stroke patients. Each time I visit, I will contact you before hand and make these arrangements and only accompany you at times suitable for you.

PARTICIPATION (HEALTH WORKERS)

One of the parts of life for people with aphasia that I want to look at is health care. I would like to study how people who cannot speak, manage in clinics and in consultations with doctors and nurses. If you and your clinic participate in the study, I would like to sit in on some appointments with you and people with

aphasia (for example at your stroke or high blood pressure clinics) and interview you. The interviews will be about your experiences of working with people who are unable to speak or understand because of aphasia. As I will be accompanied by an interpreter, interviews will be in English or isiXhosa depending on your choice.

I would like to visit your clinic many times during my study. I would like to watch the high blood pressure and stroke clinics for a period of a month at the start of my study and then return to your clinic later in the year. I would also like to observe any support groups for stroke patients or elderly patients. Each time I visit your clinic, I will request permission from the Sister-in-Charge as well as from yourself and other staff members.

Participation in this study is completely voluntary. That means that you can choose not to participate. If you choose to participate, you can change your decision and decide not to participate at any time during the study.

INTERPRETING

As I am first language English, I will be assisted by a trained Xhosa speaking interpreter. This interpreter will accompany me on visits and interviews will be conducted in English or in isiXhosa. Any information given to the interpreter will be kept confidential by myself and by the interpreter.

RECORDING

I will take notes when I watch consultations and I will take notes during interviews. These notes will only be read by me and will help me to remember information.

There will be times when I would also like to audiotape interviews. I will always ask your permission to do this. I will not tape any interview without first asking

you. These tapes will only be listened to by my interpreter and myself. They will be kept in a safe place in my workplace so that no one else will be able to listen to them during and after the study. I will keep the tapes after the study but they will only be used for the purposes of this study.

CONFIDENTIALITY

Your full name and identity will not be used in this study. I will make every effort not to reveal information that can identify you. Actions or things said to me during interviews will be recorded or noted down by me but I will not make specific reference to you. If at any time, you would not like our conversations to be noted or recorded, you have this right.

RISKS AND BENEFITS

Participation in this project should not involve risks to you. The information that I gather from will not be given to structures of authority in your community.
You will not be paid for your participation in this research project.
The study itself may be helpful in increasing understanding for health workers and therapists. At the end of the study, I will be able to give feedback to you and to health services in your community about the needs of stroke patients and people with aphasia. This will hopefully improve the situation for adults with aphasia.

INFORMATION SHEET – GUIDELINES FOR VERBAL INFORMED CONSENT FROM ADULTS WITH APHASIA AND FAMILY MEMBERS

A STUDY OF ADULTS LIVING WITH APHASIA IN KHAYELITSHA

My name is Carol. I am a speech therapist and I would like to conduct research into the lives of adults living with aphasia in Khayelitsha. This research is for my doctoral studies through the University of the Witwatersrand.

THE RESEARCH PROJECT

Stroke is one of the biggest causes of disability in adults in South Africa. A stroke occurs when blood to the brain is blocked so blood cannot reach some parts of the brain or when there is bleeding on the brain. These areas of the brain then become damaged. This damage may cause a number of problems including weakness of the body, problems with memory, problems with eyesight, as well as problems in speaking.

Aphasia is the loss of language following stroke or other times of brain injury. Aphasia means that you have difficulties in speaking, understanding, reading and writing. These problems also affect work, relationships and daily life. Very little is known about aphasia in your community as well as the problems facing people who have aphasia. In this study I hope to look at the difficulties facing you and your family and other people with aphasia. I also want to look at the health care that you get and how you cope with the communication difficulty.

FIELDWORK AND INTERVIEWS

In order to do my study, I plan to make daily trips in and out of Khayelitsha for about a year. During these visits, I plan to visit you and other people with aphasia in your homes and to visit clinics and centres for people who have had strokes. At these visits, I will watch what goes on and I will interview you and your family.

We will talk about the problems facing you and other people with aphasia in your community.

PARTICIPATION

If you choose to participate in my study, this will mean that I will observe you in your home and at clinics for a number of weeks. I will ask you to share stories about your life since your stroke and I will ask family members about their experiences too. I will only speak to other people about you and your needs if you will allow me to do so.

I would also like to accompany you to your clinic appointments. I will ask for your permission to do this.

Participation in this study is completely voluntary. That means that you can choose not to participate. If you choose to participate, you can change your decision and decide not to participate at any time during the study.

INTERPRETING

As I am first language English, I will be helped by a trained Xhosa speaking interpreter. This interpreter will come with me on visits and interviews will be in English or in isiXhosa. Any information given to the interpreter will be kept confidential by myself and by the interpreter.

RECORDING

I will take notes when I watch you and I will take notes during interviews. These notes will only be read by me and will help me to remember information.

CONFIDENTIALITY

Your full name and identity will not be used in this study. Actions or things said to me during interviews will be recorded or noted down by me but I will not use your name. If at any time, you would not like our conversations to be noted or recorded, you have this right.

RISKS AND BENEFITS

Participation in this project should not involve risks to you, but our conversations may deal with sensitive issues such as financial issues, beliefs and health.
You will not be paid for your participation in this research project but if you need to travel to meet with me, I will pay for the costs of your transport.
If you are involved in the study, I cannot assist you with health or social difficulties that you may be concerned about. But the information that you share with me will help health workers better understand the needs of people who have had strokes and the needs of people with aphasia. At the end of the study, I will be able to give feedback to health services in your community about the needs of stroke patients and people with aphasia. This will hopefully improve the situation for adults with aphasia.

CONSENT STATEMENT

I have read and understand the description of this research project, including information about the risks and benefits of my voluntary participation.

_____ _____

Signature Date

_____

Print Name

Your help in this study is appreciated.

CONSENT STATEMENT FOR AUDIO RECORDING

I consent to audio recording of today's conversation. I have read and understand the description of this research project, including information about the risks and benefits of my voluntary participation and that information will be treated confidentially. I understand that this recording will be used by the interpreter and the researcher. I understand that the tapes will be kept in a safe place during and after the study and will only be used for this study.

_____ _____

Signature Date

_____

Print Name

Your help in this study is appreciated.