

## **An ethnography of adults living with aphasia in Khayelitsha, South Africa.**

Carol Legg and Claire Penn

Department of Speech Pathology and Audiology, University of the Witwatersrand, South Africa

*1200 word abstract*

*Aim and background to the study:* This paper presents emerging findings of an ethnographic study presently underway that examines the situation of adults with aphasia in Khayelitsha, a South African township characterised by poverty, violence, limited resources and a language and culture different to the standard setting of healthcare in South Africa. We describe five case accounts that highlight the experience of aphasia for adults in this community as it relates to status and position within the community and household; networks of support and strategies for coping; frameworks of interpretation of communication loss; ideas about causation and recovery; and experiences of health and social services.

Examination of the social context may shed light on explanatory models of aphasia where illness is understood within a spiritual framework and the use of traditional healing practices is commonplace. In addition, this study hopes to approach questions regarding the experience and management of aphasia in poverty and for people living on the social fringes.

*Methodology:* This study is employing ethnographic methods, embedded in sociological theory and narrative tradition, to explore the setting and challenge of living for the adult with aphasia in Khayelitsha. The principal researcher, aided by a trained Xhosa speaking interpreter, has conducted fieldwork in this community for a period of 18 months. Fieldwork has entailed the detailed observation and documentation of the everyday life of a small group of aphasic adults living in this community and ethnographic interviews with participants, kin, community leaders and health care workers in relation to their insights around the experiences of communication loss and help-seeking strategies. This data is oriented to understanding sociocultural processes in the context of Khayelitsha and what this ultimately means for the adult with aphasia. Our guiding questions include what are the social experiences of the adult with aphasia in Khayelitsha and what cultural, social and environmental factors influence or modify this reality?

*Setting:* Khayelitsha is situated 32 kilometres from Cape Town's city centre in the Western Cape of South Africa. Home to over a million, mostly Xhosa speaking and recently urbanised people, Khayelitsha has become one of South Africa's largest, but poorest townships. Conditions of life in this area would appal most. Khayelitsha is a sprawling maze of formal and informal settlements, where simple one and two room brick houses and shacks built of corrugated iron, plastic and timber stand within meters of each other. These crowded dwellings house an average number of 5.6 people and although water and electricity supply is slowly reaching all, many still only have access to a communal tap and a shared toilet bucket (City of Tygerberg, 2000). High

unemployment levels are glaringly evident and the low level of average household income is alarming. These conditions are reflected in the health statistics where Khayelitsha presents with the highest incidence of communicable diseases in Cape Town (Scott et al, 2001). Tuberculosis is endemic and HIV and AIDS have, at a conservative estimate, affected more than 30% of the area's population. Infant mortality rates are among the highest in the world and Khayelitsha has a significantly higher burden of disease and morbidity for non-communicable illnesses (Scott et al, 2001). 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 and the seven primary care clinics are over-run and ill-equipped. Similarly, educational, social and recreational facilities are lacking. Khayelitsha is known as the murder capital of South Africa and assault, rape and theft are pervasive experiences. However, within this, there exist strong networks of support in the form of alliance households, kin ties, people originating from the same rural areas, neighbours and members of religious or political organisations. This fabled sense of community is culturally explained and used to promote policy changes that relegate care for the chronically ill and disabled to the community, where prevalent assumptions of illness are those conceived as traditional Xhosa explanations. Disease and sickness is interpreted within a spiritual framework and healing practices include the use of diviners, herbalists and faith healers.

*Emerging findings:* We describe the help-seeking journeys of five isiXhosa speaking adults living with aphasia in Khayelitsha. In their unique cultural and social setting, these adults explore numerous avenues in search for help and entertain plural notions of causation and cure. Voicelessness has rendered them vulnerable to crime and exploitation. Their effort to secure resources, such as the disability grant and healthcare, is hankered by poverty of access. Their living circumstances are necessarily fluid and their position in their family and household is tenuous. Notwithstanding, when these adults talk about their aphasia, they do not only refer to the loss of expression but to their whole life that has been disrupted. Discourses of the illness are woven into wider narratives about individual, gender, family, community and existential struggles.

*Conclusion and Implications:*

Emerging findings suggest that communicatively disordered people in this community are vulnerable to deepening impoverishment, social abuse and marginalization and their challenge in accessing health services, legal representation, constitutional rights and equality is great.

Anthropological enquiry helps us to understand the real experiences of adults with aphasia and their families within healthcare, legal and social systems and the influence of social circumstances on coping with aphasia. Thus, ethnographic study of adults living with aphasia in this community is not only relevant to the application of intervention services in South Africa. South Africa, a diverse and developing society, provides an ideal platform for researching sociocultural processes and contextual variables

influencing the course of this disabling condition. Knowledge and skills, coping strategies, community and familial support, professional intervention and material assistance are frequently cited as necessary resources to deal with chronic disablement within a social model, yet ironically, it is these resources that are often unavailable to low socio-economic groups, where overwork, poverty, tension and sheer exhaustion limit the extent to which the community can act as a safety net.

This study has shown that when thinking about social approaches to aphasia, we should not take the social fabric for granted. South Africa's legacy of oppression and segregation of racial groups has played a large role in eroding the social fabric in the community of this study. Yet, prejudice, medical systems, issues of modernity and globalization, and difficulty in establishing and maintaining social relationships are not unique to South Africa. Few social resources may endure the chronicity of aphasia. The South African experience is also relevant to understanding the pluralism of healing approaches in today's postmodern world.

*References:*

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