Language differences as an access barrier for Xhosa speaking patients at a children's hospital in Cape Town.

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Thesis submitted for the degree
of Master of Medicine
University of Cape Town

August 2004

DECLARATION

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Abstract

The research documented in this thesis was conducted between November 2002 and March 2003.

Rationale for the study.

A problem faces many health professionals – that of communication between ourselves and patients who may differ from us in terms of the language spoken, educational level, medical knowledge, models of illness, socio-economic status, race and power.

Aim / research question.

The objective was to identify barriers to optimum care for Xhosa speaking parents of patients at Red Cross War Memorial Children's Hospital. The relative contributions of these barriers were assessed. The contribution of language difficulties was assessed as a possible barrier to health care for this group.

Design.

Qualitative and semi-quantitative research was performed. This took the form of in-depth interviews and a semi-structured questionnaire. Attention is given to qualitative and sociological research methodology and the "EMIC" or culture-neutral approach to the research which necessitated the use of unstructured and open-ended questions.

Setting.

Red Cross War Memorial Children's Hospital is a tertiary paediatric hospital situated in Cape Town, in the Western Cape Province of South Africa. Research was conducted in the short stay (S11) ward and in the asthma and allergy clinic.

Methodology.

Two methodologies were used to evaluate parents' barriers to optimum medical care.

Pilot qualitative interviews were performed with subsequent consultation of experts in the fields of qualitative research methodology, linguistics and medical anthropology. This enabled changes to be made to the research procedures to ensure that the data collection methods adhered to high standards. The qualitative interviews explored the patients' and doctors' perceptions of the nature of the communication between them. This gave an overview of the scope and nature of the problem, and provides examples which richly describe the barriers experienced by patients and doctors.

In concert with "action learning" theory, data from these qualitative interviews was used to devise a semi-quantitative "access barrier questionnaire", enabling quantitative analysis of the parents' concerns about access to hospital, service within the hospital and communication.

Subjects.

Subjects recruited for the study comprised English (or Afrikaans) speaking doctors and parents who were first language Xhosa speaking and did not have tertiary education. Qualitative interviews were conducted on 39 parents whose children had chest illnesses and were being seen at the short stay ward (S11) or the allergy and asthma clinic, as well as 8 doctors. An "access barrier questionnaire" was administered to 53 Xhosa speaking parents in the short stay ward whose children had any illness.

Results.

Results showed that in addition to significant structural and socio-economic factors, communication problems were perceived as a major barrier to access to health care for their children. Parents did not have access to same-language practitioners or interpreters, and experienced difficulties with understanding the doctors, making themselves understood, and asking questions. Overall, parents were dissatisfied with communication between themselves and their doctors. Doctors were also dissatisfied with communication between themselves and their patients and conceded that language barriers are a significant problem, affecting their work performance and impacting negatively on the quality of the care they provide to the patient.

Doctors seldom used interpreters for routine history taking, but most doctors utilized interpreters when more in-depth history or parental counselling was required. Doctors raised concerns about the possibility of interpreter errors in certain cases.

Conclusions and recommendations.

Communication between doctors and Xhosa-speaking patients is a significant problem at Red Cross War Memorial Children's Hospital. Recommendations are provided for improving communication between parents and health care professionals. These include the avoidance of jargon, the appropriate use of medical terminology as well as selection and training of health care professionals . Guidelines are given for the doctor-patient relationship, for monolingual providers in a multilingual environment and for the effective use of interpreters. Recommendations are made for further research in this area.

Acknowledgements

I acknowledge with thanks the contributions of the following to the successful completion of this project.

I am grateful for the support and encouragement received from Professor Eugene Weinberg. Without his advice and kind words, this project would never have been completed. My thanks are also due to Professor Cas Motala for supervision, guidance and advice. I am indebted to him for reviewing draft after draft and for his invaluable help with the final manuscript.

Nolubabalo Tyam and Jackie Nxasana conducted pilot interviews. I am grateful for the hard work that the Xhosa-speaking researchers put into the study. Nonkululeko Mabandla and Thami Makubalo conducted the bulk of the interviews, transcribed and translated the interviews and administered the access barrier questionnaires. I am indebted to them for their advice and guidance in language issues.

The Department of African languages (University of Cape Town), the Department of Sociological Research Methodology (University of Cape Town), the Ilwimi sentrum (University of the Western Cape) and African Voices for reviewing the progress of the research, advice and criticism.

Dr Glenn Flores kindly allowed me to base my "access barrier questionnaire" on a similar questionnaire from his study[13].

The project was funded in part by an ALLSA / Glaxo-Smith Kline research grant and a grant from the Institute of Child Health.

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Research Problem

Communication between doctors and patients is generally difficult, and is compounded by differences in language, education, knowledge and power. In many instances, translators are not available, and monolingual English speaking doctors who may have limited language proficiency in an African language are forced to communicate with monolingual Xhosa speaking parents, using a medical lingua franca. Communication is especially difficult with those parents who are primarily Xhosa speaking, have limited education, and are originally from rural areas.

At Red Cross War Memorial Children's Hospital (RCWMCH), 1100 staff members treat approximately 18 500 inpatients and 155 000 outpatients per annum[1]. Only two full time interpreters are employed, and are available from 8am to 5pm. There are no specific posts for interpreters, thus they occupy two nursing posts. There are delays in access to the interpreters if they are busy when they are requested to interpret. There are interpreters available for selected individual clinics such as the developmental clinic and the infectious disease clinic. A non-governmental organisation, Wola Nani, has an office at the hospital where Xhosa speaking lay counsellors provide education and emotional support for HIV-related counselling. There is no after hours or weekend interpreter service.

English is the home language of only 9 % of South Africans[2], and at RCWMCH there are significant differences between the languages spoken by patients, nurses and doctors[3]. Only 5.5 % of doctors and 15 % of nurses currently employed at RCWMCH are Black African. Although both racial and language statistics are kept by the hospital, significant gaps exist due to large numbers of patients details being unrecorded. Of a total of 19 537 patients admitted in the year up to June 2004, 7 338 were classified as Black African, (38 %). Yet 3 684 patients' race details were not recorded (19 %). Extrapolating these data makes for an estimate of 46 % of admitted patients being Black Africans, yet the true figure may be higher as it seems from the language breakdown of these unrecorded patients that the large majority may well be Black. The statistics for languages spoken by these patients are slightly better. Of the same 19 537 patients, the first language was not recorded in 1 950 patients (10 %). Xhosa was spoken by 7 847 patients (40 % of total, 44.6 % of those recorded), Afrikaans by 5 040 (25.8 % of total, 28.7 % of those recorded) and English by 4 606 (23.6 % of total, 26.2 % of those recorded). Only 46 patients are recorded as speaking another of the official South African languages.

The objective was to identify barriers to optimum care for Xhosa speaking parents of patients at Red Cross War Memorial Children's Hospital. The relative contributions of these barriers were assessed. The contribution of language difficulties was assessed as a possible barrier to health care for this group.

Chapter 1: Literature review.

Interest in the relationship between communication and medical care can be traced as far back as Hippocrates. It was only in the 1960's that *miscommunication* in medical settings became the study of empirical research. Concern for the topic was fuelled by the growing realisation that problems in communication were implicated in two of the most pressing problems in medicine: patient dissatisfaction and patient failure to follow medical advice. [4]

1.1 Factors effecting the prevalence and severity of illness

Health and disease are not simply biologically determined, nor are disease patterns randomly distributed. Rather disease is closely linked to the social context in which we live.[5] Language, ethnicity, race and socio-economic factors are all interlinked and all have effects on one's risk for certain illnesses and chances of receiving adequate care. Studies examining these issues, and aiming to explain them in order to formulate solutions, often have difficulty in teasing apart which factor is responsible for which effect. Social scientists define social stratification as structured inequalities between different groupings of people. In South Africa, the apartheid system classified people in terms of race and through its policies entrenched a superposition of race, social class (and poverty) and language. Giddens[6] argues that social structured explanations for racial patterning in health highlight the social conditions in which for example Africans or Asians live which may be harmful to their health. These include overcrowding and unemployment. The effects of racism, which can be experienced directly or in institutionalised forms, compound these material factors. In this regard, Giddens suggests that language barriers provide difficulties, as do culturally specific understandings of health and illness which are not taken seriously by orthodox health professionals.

In South Africa, history has further clouded these issues. According to the population registration act (1950), all South Africans were assigned to a population group at birth. Until 1991, when the act was repealed, "the whole pattern of every individual's life – from cradle to the grave – was circumscribed by his race" [7]. Statistics based on racial group are thus often actually surrogate markers for socio-economic factors which may affect access to health care. Black people in South Africa have higher poverty rates, poorer living environments, and poorer health than their White counterparts. Although language may co-incide with race and thus also be a confounder for socio-economic status, it also has an independent role in the interplay between patients and the health services.

This problem is not confined to South Africa –it is experienced worldwide. In 1982 the Black report provided extensive evidence of inequality in health status and the use, availability and provision of health services between

different social groups in the U.K. [8] "The health divide: inequalities in the 1980's", published in 1987, showed that social inequalities remained entrenched in most areas of health. [9] In the USA an extensive review conducted in 1993, of studies looking at ethnocultural variations in the prevalence of childhood chronic diseases, revealed higher prevalence among White children overall rather than Black children. This difference was found mostly in the milder range of allergy-related chronic conditions such as hayfever, respiratory allergies, food allergies and eczema. The authors attribute the difference in prevalence to better reporting rather than higher incidence. They note that non-white children have more severe illnesses and less access to physicians and preventative services. [10] Non-white children in 1995 had a 25 % higher prevalence of asthma, and when admitted for asthma exacerbations were less likely to have received maximally effective preventative therapy and had poorer quality of care planned after discharge[11]. Poorer children were 40 % less likely to have seen a physician, yet were 40 % more likely to be hospitalised. [12] Multivariate analysis of selected health outcomes showed low family income among North American Latino children was significantly associated with a greater likelihood of the child having suboptimal health status, and an increased number of doctors visits in the past year, but a reduced odds of being bought for routine care.[13]

1.2 Which factors prevent good care for parents

Why there are such marked ethnocultural variations in the prevalence and severity of disease remains unclear. Genetic factors may be relevant in some instances, but other factors may also be of importance. Some of the factors cited include socio-economic factors and structural and institutional problems such as waiting times and transport difficulties serving as barriers to the access of medical care. Cultural differences are afforded great priority in the American literature, and recent research has focussed on language discordance as an important barrier. The problem of illiteracy has also received some attention.

In the USA, lower utilisation rates for curative and preventative services on the part of minority children can be ascribed to economic barriers, such as lack of health insurance or inadequate income. [10] Non-financial barriers relate to physician supply (especially availability of culturally competent providers), transportation difficulties and child care needs. [14]

Flores et al[13] conducted one of the best studies to determine patients' perceptions of barriers to their care in 1998. When asked to name the single greatest barrier to health care for their children, Spanish speaking Latino parents cited language problems (26%), financial issues (20 %) and long waiting times at the doctor's office (15%). When parents were asked if a particular barrier had ever caused them not to bring their child in, financial issues were cited by 34 %, transportation by 21 %, excessive waiting time by 17 % and lack of cultural understanding by staff by 11 %.

In South Africa, an interesting recent study on client satisfaction was performed in 1999 and 2000 in the East Griqualand and Usher Memorial hospital in Kokstad.[15] The study regarded satisfaction as depending on the expected service and the perceived service. The expected service is seen as being influenced by past experience, external influences, personal needs and word of mouth. The perceived service is seen as being influenced by the various dimensions of service quality. These are divided into the following categories:

- Tangibles
- Reliability
- Responsiveness
- Competence
- Courtesy
- Credibility
- Security
- Access
- Communication
- Understanding the client

It is interesting to note that the highest number of these variables refer in some way to the communication or interaction between the health professionals and their clients. Although the recommendations of this study are somewhat cumbersome, they focus on increasing awareness of the problem, reducing institutional barriers to patient care and improving access to the hospital.

A separate list of factors that staff feel would make them satisfied about service at the hospital contains repeated references to interpersonal issues such as politeness, good signage, respect and privacy. Staff's recommendations include references to feedback, clear explanation and provision of information, with specific regard to patients being:

- Informed about their condition.
- Informed about treatment and when treatment changes.
- Treated as an individual.
- Being made aware of their rights and responsibilities.
- Confidentiality being maintained.
- Being prepared for discharge well in advance to allow for patients to arrange transport home.
- Being informed about and receiving a letter about his/her condition, further treatment required and activities.
- Having arrangements for follow-up visits being made and communicated.

Every single one of these recommendations requires effective communication. It is difficult to imagine how these goals can be achieved without the use of same-language practitioners, unless the burden of all this must fall upon same – language nursing staff!

1.3 The effects of language barriers in medicine

Language barriers are an important part of the difficulties parents experience in accessing health care for themselves or their children. The doctor-patient relationship is built through effective communication. Skills critical to being an effective doctor are clinical reasoning, eliciting clinical signs, history taking and observing non-verbal cues. A cliché taught to doctors early on is that 50 % of the diagnosis is in the history.[16] Skilful use of language endows the history with its clinical power and establishes the medical interview as the clinician's most powerful tool. Language is the medium through which the doctor aims to understand the patient's belief about health and illness, creating an opportunity to address and reconcile two potentially different belief systems.[17] It is through language that the doctor must counsel the patients about their illness and promote continued care at home (including adherence to treatment), describe danger signs for the patient to return and arrange appropriate follow up. In addition it is through language that doctors and patients achieve an empathic connection that may be therapeutic in itself. [18]

Thus if language barriers exist, it is likely to impact on the patient-doctor relationship as well as on patient care. Kleinman[17] states that "medical officers have become accustomed to getting by with sub-standard communication, where frequently only rudimentary and inadequate medical histories are obtained, on which diagnosis and treatment plans are made. This acceptance of sub-standard level of communication with patients who speak indigenous languages has been referred to as 'veterinary care'."

Many studies have consistently shown where language barriers exist there is patient dissatisfaction.[23 25] In Flores' study it was the most commonly cited variable, by 26 % of parents, as a single barrier preventing health care for their children. Specifically, 15 % cited that it was a barrier that nurses and doctors did not speak Spanish, and 11 % cited a lack of interpreters.[13] Research in the U.K. and the United States has shown that many patients rate this as the least satisfactory aspect of their care.[4] Where language barriers exist, parents' perceptions are that adverse health consequences for their children occur, including the prescription of inappropriate medication.[13] Rosen[19] reported that 12 % of Spanish speaking patients were not satisfied with their emergency room visit vs. 0 % of English speaking controls. Doctors from the emergency room were taught Spanish as an intervention measure. A subsequent survey involving 143 exclusively Spanish-speaking patients revealed significant improvement in client satisfaction with the

service. In the second survey, families were more likely to agree that the doctor was concerned about their child, made them feel comfortable, was respectful and listened to what they said. [20]

The negative impact of language barriers on patient understanding of diagnoses, medication and follow up is well documented. Rosen's survey[19] showed that a telephonic survey of Spanish speaking patients, 28 % did not understand, at least in part, their diagnosis or instructions. These problems with communication have been linked to patients' non-adherence to medical advice[4] in adult[21] and paediatric settings.[22] In addition, the language barriers are directly associated with reduced quality of care. A review of 21 studies from 1983 to 1993 by Stewart et al[23], showed the quality of communication both in the history-taking component of the consultation and discussion of the management plan influenced several important patient health outcomes. These include, in descending order of frequency, emotional health, symptom resolution, function, physiologic measures and pain control. A recent study in the USA showed that interpreter errors were a common occurrence in a paediatric outpatient department and also impacted negatively on health outcomes.[24]

Language barriers impair the exchange of information from patient to doctor, resulting in less information being available to the doctor for their assessment and possibly resulting in misdiagnosis. [13] [23] Woloshin et al[25] postulate that in some instances, a doctor who does not obtain a full history may miss important clues, making it less likely they will order needed tests. Most studies, however, have shown that language discordance may lead to increased resource utilisation and longer visit times. This is because physicians may be less certain of their diagnosis after the history and more dependent on performing diagnostic tests. Hampers et al[26] found that where a language barrier existed between doctors and patients, there were longer paediatric emergency department visits, more laboratory tests and higher costs. Waxman et al[27] documented increased tests in non English speaking adults with abdominal pain including blood tests, urine analysis, ECG's and abdominal CT scans, suggesting the doctors even had difficulty in determining in which system the problem was.

Language discordance may be associated with inappropriate assessment of severity (cautious medicine) and higher admission rates. Hampers et al[26] found that children with diarrhoea were more likely to be admitted and to get a bolus of intravenous fluid where language barriers existed, even though the two groups were no different with respect to the severity of disease. Lee et al[28] found a 70 % relative difference (35 % vs. 21 %) in admission rates between non-English speaking and English speaking adults.

1.4 South African studies of communication in hospitals

Despite the perception that communication problems may be more prevalent and severe in South Africa than in other parts of the world, there is very little published on this subject in South African hospitals. In recent years, this has been somewhat ameliorated by a number of unpublished masters and doctoral theses that have been conducted under the auspices of the department of speech pathology and audiology at the University of the Witwatersrand and funded by SANPAD, the South Africa Netherlands Research Programme on Alternatives in Development.

In South Africa, where we have 11 different official languages, discrepancy between the language spoken between patients and doctors is extremely common. The overwhelming majority of health professionals, with the exception of nurses, cannot speak any of the indigenous African languages.[2] Leslie Swartz[29] published an overview of the problem of language differences in health care in 1992. His article deals with the issues of power discrepancies and differences in explanatory models, and recommends language requirements for health and social service workers and increased selection of native speakers of African languages.

Crawford[30] documented problems at all levels of contact with the health service and formulated it in terms of the system of power-relations operating within the health system (and country) as a whole. Crawford[31] cites problems with structural barriers to health care, the attitudes of nurses to act as interpreters, incompatible constructions of illness and differing or overlapping lexical relations between Xhosa and English words. Incorrect pronunciation of Xhosa names in the waiting room led to delays and patient anxiety, nurses were unwilling to interpret and lay translators were mostly used with subsequent errors in translation. She questioned how well a poor, monolingual black woman could possibly be helped by an ethnocentric and largely monolingual health service.

At Chris Hani Baragwanath hospital[32], language problems are common due to lack of interpreters and inability of most doctors to speak an African language. In this 1998 survey, 22 of 1118 patients reported English or Afrikaans as their first language. Of the 80 doctors polled, 4 were Black doctors who spoke 2 or more African languages, and 8 English-speaking doctors indicated they conversed in basic Zulu. Nurses and ad-hoc interpreters were most often used for translation and poor quality care resulted including inappropriate discharge leading to medical consequences and patient non-compliance with medication. Substantial patient distress, frustration from doctors and resentment from nurses has been documented. A follow up study in 1999[33] documented lack of communication leading to misdiagnosis. 40 % of nurses said they were not willing to help doctors with interpreting. 35 % of patients said nurses did not want to speak African languages other than their own. Doctors indicated they were willing to learn an African language, and it was

suggested that courses be given, focussing on common problems and providing a phrasebook of key questions and responses.

Professor Claire Penn[34], head of the department of Speech Pathology and Audiology at the University of the Witwatersrand, has pioneered the use of conversation analysis as a technique for analysing the nature or dynamics of medical interviews in South Africa. She has been most interested in the triad of interpreter, client and doctor, and the development of techniques that serve as facilitators of good communication, and those factors that deter communication in the context of a mediated interview. Results from her work show that the power relations between participants are a primary factor in the success or failure of communication. Techniques that facilitate communication include code switching (the insertion of words from the second language into the client's first language) and the use of repetition. Inhibitors of good communication include interruption and complicated "repair trajectories". Cultural brokerage could not be identified as either a facilitator or an inhibitor. A workshop conducted by Professor Penn in November 2003 at Groote Schuur Hospital with interpreters, doctors, language practitioners and nurses identified the following themes:

- Power / Control: Interpreters' acceptance of responsibility vs. power of clinicians
- Relationships: Relationship between patient and interpreter vs. the interaction between clinician and interpreter
- Institution: Quantum of resources available for interpreting vs. quality of resources available for interpreting
- Resources: Overall level of resources for task vs. use of resources
- Expertise: Expertise of clinician to engage in mediated interview vs. medical field knowledge of the interpreter

Prof Penn has drafted the curriculum for the first lectures on health communication given to 3rd year medical students at the University of Cape Town as part of semester 6, which commenced on 13th July 2004.

In 2004, Taryn Schwartz[35], under the supervision of Professor Penn, submitted research towards a masters thesis at the University of Cape Town. Her study investigated policies, practices and perceptions of institutions, doctors, nurses and interpreters on the issue of interpreting. The study compared three different levels of the health services in the Western Cape, using Red Cross War Memorial Children's Hospital (tertiary), Jooste Hospital (secondary) and the Khayelitsha Site C Clinic (primary). She found that there was no formal policy regarding interpreters at national, provincial or institutional level. The results show significant disparity between the languages spoken by patients and caregivers at all three levels. This was more marked between doctors and patients than between nurses and patients, and more marked at tertiary rather than primary level.

At tertiary level, the study used race statistics (table 1) as a surrogate for language. In addition, the study estimated the proportion of Black patients from the perceptions of the staff polled, rather than from gathering data. This data differs from the statistics documented by Red Cross War Memorial Children's Hospital's (RCWMCH) statistics department.

The 31 staff sampled rated their proficiency in Xhosa. 3.1 % of doctors and 27.2 % of nurses rated themselves as "very good" in Xhosa, while 90.4 % of doctors and 72.8% of nurses rated themselves as "poor" or "very poor". At the Khayelitsha clinic, 5 % of doctors and 100 % of nurses speak Xhosa as a first language.

The most striking feature finding of the study was the difference in perceptions between doctors, nurses and interpreters of the roles of interpreters within a mediated interview. This is displayed in table 2. This may reflect the different roles that are "allowed" in the interview where a more equal power relationship exists between doctor, interpreter and patient. The possible roles for interpreters are as passive, "word-for-word" translating machines (power held exclusively by the doctor) or as active team members (equal role) involved in the communication with (and care of) the patient.

This illustrates how doctors at RCWMCH tend to regard translators as a vehicle or "translating machine" rather than as an integral member of a team. Because the doctors hold this opinion, they impose this role on the nurses who thus feel they are being used as a vehicle when engaged in translating. This is in agreement with the findings of Crawford[30], documenting the negative perceptions of nurses when used as translators. At the Khayelitsha clinic, where doctors perceive interpreters as part of the team, the roles adopted in the interview are different. When nurses are used as interpreters here, they feel they are allocated as mediators that are part of a team, and thus they expressed trust, satisfaction and job enjoyment with regard to this additional role!

Another masters thesis under the supervision of Professor Penn, was submitted by Leila Prince[36] in 2004. She looked at "turn-taking" behaviour in the conversation between doctor, patient and translator. Turn taking behaviour is the study of how people order their speaking to each other to share knowledge. In general, turn taking studies the response of B to A's utterance and A's re-response which often takes the form of re-inforcing, agreeing or disagreeing. In this way it can be seen that at least 3 turns are required to reach the certainty of shared meaning. Questions and answers form part of a limited form of turn-taking called an "adjacency pair", where B responds to A's utterance and only comprises 2 turns. Furthermore in mediated interviews these utterances are staggered in time with an "inserted sequence" of "pair parts".

Table 1:

Demographics of subjects studied at Red Cross War Memorial Children's Hospital (RCWMCH) for study "Communication in health within the South African context"[35].

	Nurses	Doctors
Black	15 %	5.5 %
Coloured	74.8 %	11.8 %
Indian	9.7 %	8.1 %
White	0.5 %	74.5 %

Table 2: Perceptions of doctors, nurses and interpreters of the roles of interpreters within a mediated interview in the study "Communication in health within the South African context"[35]

	RCWMCH doctors	RCWMCH Nurses (when used as interpreters)	RCWMCH interpreters	Jooste doctors	Khayelitsha doctors
Team member	54.5 %	5 %	100 %	35.3 %	100 %
Patient voice	-	-	-	17.6 %	-
Vehicle	45.5 %	80 %	-	20.4 %	-
Other / depends	-	15 %	-	17.8 %	-

1) Doctor: 1st pair part

2) Interpreter: 1st pair part

3) Patient: 2nd pair part

4) Interpreter: 2nd pair part

The form above was found by Prince to be the overwhelming majority of forms used by clinicians (who conduct the interview) chaining additional questions together without responding or allowing the interpreter the opportunity to respond to the patient with more than 2 turns. This, in her opinion, reflects the inequality of power between patients, doctors and interpreters and resulted in very few questions from the patients. In her opinion, an alternative form of interviewing which allows interpreter initiated expansion and responses, can enhance communication efficiency. In this form, the inserted sequence is allowed feedback and reflection beyond the minimal 2 turns.

1) Doctor: 1st pair part

2) Interpreter: 1st pair part

3) Patient: response

4) Interpreter: re-response

5) Patient: response

6) Interpreter: response

Although Prince claims this will enhance communication efficiency, I believe this needs to be reconciled with the findings of Penn[34] and Schwartz[35], who claim that there are additional, perhaps more powerful determinants of the success or failure of communication. The form of conversation she advocates can only be employed when two preconditions are present. Firstly, the interpreter needs to have a strong and thorough grasp of the material that needs to be covered, and secondly, the relationship between the interpreter and doctor must allow the freedom to pursue this strategy. It is only in this situation that these more personal and thorough methods of questioning can be employed. If these preconditions are fulfilled, such a strategy may enhance communication efficacy and may also allow the interpreter to assume the additional role of cultural brokerage.

Despite the advances that have been made in recent years, there is still a dearth of information regarding communication in South African Hospitals. In 1999, the editor of the South African Medical Journal, Prof. Daniel Ncayiyana, summed up the problem and made a plea in his editorial that all non-African language speaking health care

providers obtain a copy of a local African language phrasebook and carry it with them at all times to "establish that special bond with their patients that only comes through language."[37]

1.5 Literacy

A large proportion of Xhosa-speaking parents who attend the Red Cross War Memorial Children's Hospital are undereducated and illiterate. Lack of adequate literacy skills is a further barrier to receiving proper health care and adults with limited literacy face formidable problems using the health care system. They are less likely to use screening procedures, follow medical regimens, keep appointments or seek help early in the course of a disease.[38] Studies have validated instruments to assess the ability of patients to understand medical instructions and health care information presented in prose form and passages containing numerical information (medication labels and appointment slips)[39 40] These people have difficulty understanding discharge instructions, consent forms, oral instructions, educational materials [41] and labels on medication containers. [42]. A large majority of people (in studies elsewhere in the world) with limited literacy describe themselves as reading and writing English well and do not disclose their problems to spouses or children, making the task of responding to their problem more difficult. [38]

The definitions of "literacy" and "illiteracy" have been changing in the international literature, with recent definitions tending to be broader than earlier definitions. A previous UNESCO definition of literacy: "*reading and writing a short, simple statement on his everyday life*" has been substantially broadened to "*acquiring the essential knowledge and skills which enable him to engage in all those activities in which literacy is required for effective functioning in his group and community...*" This functional definition is mirrored in the Persepolis declaration:

> (*Literacy is) not just the process of learning the skills of reading, writing and arithmetic, but a contribution to the liberation of man and his full development. Thus conceived, literacy creates the conditions for the acquisition of a critical consciousness of the contradictions of society in which man lives and of its aims; it also stimulates initiative and his participation in the creation of projects capable of acting on the world, of transforming it, and of defining the aims of an authentic human development. It should open the way to a mastery of techniques and human relations. Literacy is not an end in itself. It is a fundamental human right.*

In line with these trends, literacy in English and/or Afrikaans has for many years been considered necessary to be defined as literate in South Africa. This is because it is hardly possible to operate effectively and independently without

being literate in a dominant language. The departments of Arts and Culture Subcommittee, however, recently promoted a broad definition requiring literacy to be defined in multilingual terms, and thus adopted the position that anybody, to be fully effective as a literate citizen in South Africa, should be literate in more than one language.[43]

In broad summary, there are nearly seven and a half million adults (aged 15 and over) who are illiterate or severely under-educated. Nearly three million are totally unschooled and over four and a half million more have so little primary education (itself of poor quality) that they are barely literate. This gives an adult illiteracy rate of 29 %. In 1991 only 37,4% of the total South Africa population was in possession of a standard six (grade 8) or higher qualification, and 7,3 million Black African people of all ages had no formal educational training and a large proportion of pupils from this group who obtained their matriculation certificates in 1993 were not fully literate.

Table 3 indicates the number of people categorised as functionally illiterate (less than Std 7 / Grade 9) in 1994[44].

According to the old population classification, Whites and Asians have high literacy rates (99% and 88% respectively) and Coloureds less so (74%). From this it can probably be deduced that native English speakers are nearly all literate and most Afrikaans speakers are too (allowing for some level of illiteracy among Afrikaans-speaking Coloureds). African language speakers have the lowest literacy rate (67%). As a surrogate for literacy, I included data on the highest educational level that parents attained, as formal assessment of literacy skills was not included in this study.

Table 3:

Number of people categorised as functionally illiterate

(less than Std 7 / Grade 9) in South Africa in 1994[44].

Adults (15+) with less than Standard 7 (Grade 9) education			
No education	Grades 1 to 6 (Std 4)	Grades 7 to 8 (Std 6)	Total
2 803 437	4 653 592	4 972 809	12 429 838

1.6 Communication

1.6.1 Model of communication

The most simplistic model of communication is viewing it as the process of transferring meaning through speech. Speech act theorist, John Searle[45] specified, " On the speaker's side, saying something and meaning it are closely connected with intending to produce certain effects on the hearer. On the hearer's side, understanding the speaker's utterance is closely connected with recognising his intentions. In the case of literal utterances the bridge between the speaker's side and the hearer's side is provided by their common language."

This simplistic model presupposes the presence of a common language and a shared lexicon. Where these are not present, the process of communication may not be that simple. Even between native speakers, "there arises from a bad and inept formation of words a wonderful obstruction to the mind".[46]

1.6.2 Miscommunication

Interaction between native and non-native speakers readily displays how the lack of shared linguistic systems can result in miscommunication. Most researchers assume that interactants must share basic lexical meanings and explore more subtle linguistic codes that are culturally determined.[47] In these settings, differences in lexical meanings, modes or styles of communication and cultural systems may all adversely effect communication. In the medical setting, even in the situation where patients and doctors may not differ in language, socio-economic status or culture, differences in education, status, power and knowledge may effect their interactions.

1.6.3 Miscommunication in medicine

Research on communication problems in medical settings has a rich tradition in both clinical and social sciences. Among the recurring themes in the literature are the limiting consequences of using specialised technical vocabulary (jargon), cultural differences between providers and patients, and institutional constraints on the forms of interaction that occur in medical milieu.[4] These constraints include time pressure and the effect of power differentials between doctors and patients.

Factors linked to dissatisfaction with communication in this setting have identified the amount of information patients receive, with most studies showing patients were dissatisfied with how little they were told about virtually every aspect of their care. Wallen's[48] analysis of interactions between patients and doctors revealed that less than 1 % of total talking time is spent in doctors explaining to patients, most doctor time being questions aimed at eliciting a history or

diagnosis. In doctor patient exchanges, the overwhelming majority of doctor-initiated utterances are questions to patients whereas patient-initiated utterances are seldom questions. In addition doctors often interrupt patients whereas it is rare for a patient to interrupt the doctor. Lastly in doctor-patient interchanges patients overwhelmingly believe that too little time has been spent in the encounter.[49] Analyses of the content of medical dialogues revealed that doctors often use specialised jargon that is not well understood by their patients. Studies showed that in medical situations it was not just highly technical terms that were misinterpreted, but that even the names of common illnesses (such as arthritis, diabetes and stomach ulcer) often meant something different to the patients than to the provider. [50]
This has been borne out in other studies where "tuberculosis", for example, was not understood but "TB" could be translated and technical terms were mistranslated with "breathlessness" used for "asthma" and "being mad" for "epileptic fits". Words such as "gynaecological", "waterworks" and "gallstones" were not translated at all.[51]

1.7 The use of Interpreters in medicine

Language issues are afforded great importance in the constitution of South Africa. The bill of rights prohibits discrimination on the basis of language and proclaims that everyone has the right to use the language of his or her choice. The official languages of the republic are Sepedi, Sesotho, Setswana, siSwati, Tshivenda, Xitsonga, Afrikaans, English, isiNdebele, isiXhosa and isiZulu. The constitution states "recognising the historically diminished use and status of the indigenous languages...the state must take practical and positive measures to elevate the status and advance the use of these languages," and provided the legal basis for the establishment of the Pan South African Language Board (PANSALB) and the commission for the promotion and protection of the rights of cultural, religious and linguistic communities.

Professional interpretation is a commonly used service in business and international diplomacy. The bill of rights states that "accused persons have the right to a fair trial, which includes the right to be tried in a language that the accused person understands or, if that is not practicable, to have the proceedings interpreted in that language." Recently, in this country, this has come into full practise and professional interpreters are available to enable defendants with limited English to participate meaningfully in the legal process, as required by law.

1.7.1 Lack of interpreters

While common in other environments such as law and business, professional interpreters are rarely available in health care. Studies done on language barriers that document the frequency of interpreter use in their surveys consistently

show that even where language barriers are thought to exist and interpreters are present in the hospital, a large proportion of doctors do not get professional interpreters to help in the consultation.[26 27]

The problem of lack of interpreters is not limited to South Africa. New York City, which has one of the largest limited English speaking populations in the USA, does not employ professional medical interpreters in its public hospitals.[25] A survey of 258 American emergency departments showed that in departments with 40 % to 60 % Spanish speaking patients, only 41 % always have and 14 % rarely have a translator within the department.[19]

Where there are no trained interpreters, one of three suboptimal mechanisms is used to facilitate doctor-patient communication. Doctors may rely on their own language skills and those of the patients, the skills of family or friends of the patient, or ad hoc interpreters of two types – staff at the hospital or bilingual strangers from the waiting room.

1.7.2 Doctors language skills.

Most English-speaking doctors in South Africa are not sufficiently proficient in any African language to conduct a medical interview or counsel the patient[2]. In a busy clinic, when time is short or interpreters are unavailable, doctors and patients do try to communicate with inadequate language skills, detracting from the care the patient receives and leading to frustration on both sides[30]. The doctors polled in this study pointed out that although they are able, in some cases, to take rudimentary histories and guide an examination, they are unable to counsel a patient or transmit meaningful information to them regarding their illness. This lends strong impetus to recommendations that more interpreters be available at public hospitals.

1.7.3 Ad hoc interpreters

Although doctors are aware of some of the pitfalls, specifically citing confidentiality issues, bilingual strangers are often used as ad hoc interpreters. Untrained interpreters may lack sufficient language skills and frequently commit errors that may result in serious distortions of meaning and adversely affect care.[25 24] Untrained interpreters commonly commit errors. Five basic "interpreter errors" were classified by Vasquez[55], viz. omission, addition, condensation, substitution and role exchange. Omission is when the interpreter completely or partially deletes a message sent by the speaker. Addition is the tendency to include information not expressed by the speaker. The tendency to simplify or explain is referred to as condensation and the tendency to replace concepts as substitution. Role exchange occurs when the interpreter takes over the interaction and replaces the interviewers questions with the interpreters own, thus assuming the role of interviewer. Ebden and Bhatt[51] referred to "mistranslation" in an observational study that documented between 23 % and 82 % of words and phrases interpreted by Gujarati speaking relatives were incorrectly translated. Even the best lay interpreter mistranslated or did not translate almost a quarter of questions. In the field of

psychiatry, Marcos[52] referred to interpreters error accounting for "distortions" and Price[53] referred to "alterations in meaning" leading to misevaluation of the patient's mental status in psychiatric interviews.

Besides for the errors untrained interpreters make, the use of strangers for interpretation raises the question of ensuring patient confidentiality and may undermine patient's confidence in the doctor and the system. Use of family members or strangers from the waiting room may make patients feel inhibited, embarrassed or angry.[25] A problem experienced by many non-English adult patients is the use of their English-speaking children as an interpreter for the doctor. This may expose them to sensitive information and change family dynamics. Children may find it difficult to translate questions about their parent's bodily functions,[51] and young children may suffer serious psychological problems as a result of being put in such a position.[54]

Medical staff (in our situation, usually nursing staff) are most often called upon to help interpret. Although it is likely that their language skills and medical knowledge will be better than lay relatives, they are still not trained in interpretation and are not as proficient as trained interpreters. An additional problem may be a lack of interest in providing quality translation, regarding it as an unwelcome imposition, a distraction from their other duties or an unpaid burden. [33 55 25]

1.7.4 Training, qualifications and accreditation of interpreters

Professional interpreters are formally trained at tertiary institutions in South Africa[43], yet only one institution trains interpreters at a comprehensive level. Translation and interpreting courses at South African tertiary institutions are shown in table 4. Most tertiary courses in translation do however offer an introduction to interpreting. Furthermore, language choices are limited, especially with reference to the African languages and Sign Language.

In addition to this, on the basis of establishing experience, it takes at least three years of in-service and on-the-job training for a person to function as a professional translator or interpreter whose work is of a high enough quality so that it does not require supervision. This is regardless of the level of formal training.

A three-week course in translation/interpreting[43] has been supported in government circles, but reservations about this course caution that it will not equip an untrained or inexperienced person to translate or interpret satisfactorily. People who undergo this three-week intensive course in translation have better awareness of translation issues, but unless they have a bachelor's degree and considerable experience in translation, this training does not on its own produce good translators. People who have undergone these courses are used as apprentice translators under the supervision of an experienced and qualified translator and only deal with very straightforward translation work. [43]

Table 4: Translation and interpreting courses in South African tertiary institutions.[43]

	Translation courses					Interpreting courses				
	Certificate	**Diploma**	**Degree**	**Honours**	**Masters**	**Certificate**	**Diploma**	**Degree**	**Honours**	**Masters**
US		X								
UNISA		X		X						
UOFS	X	X			X	X	X			X
WITS		X			X					
RAU				X						
PUCHO			X							
RU	X					X				
Tech. Pta		X								
Cape Tech.		X								
Tech. OFS		X								

The value of trained interpreters is however indisputable. Not only are they proficient in mediating between people who speak different languages, they often also serve a vital role in cultural brokerage at times when these issues can obscure good communication.

1.7.5 The effective use of interpreters.

The provision of adequate numbers of well-trained interpreters is necessary to improve communication in medical institutions. Also, doctors should be encouraged to use interpreters more regularly and become skilled in their use. In my study, most doctors noted difficulty in the use of interpreters, but tended to ascribe blame to the interpreter, rather than looking for sources of miscommunication in the triad of doctor, patient and interpreter. Professor Penn's study[34], looking at factors affecting the success of translator-mediated medical interviews showed factors attributable to both interpreter and doctor's skills. Factors facilitating success were an equal and active role for the interpreter, the use of code switching (varying between source and target language), familiarity and co-operation between the interpreter and doctor, and the use of techniques for good communication such as the elimination of jargon, repetition, paraphrasing and tolerating silence. Recommendations for improving the quality of the interaction between interpreters, practitioners and clients are contained in the section on recommendations.

1.8 Jargon

"Jargon" refers to technical vocabulary used by members of a specific group, which are appropriate to the activity concerned but not part of everyday language. In many cases, technical words are necessary as a means of talking precisely about aspects of that particular subject, and distinctions need to be made that non-specialists have no need to make. Doctors are very concerned with accuracy. They may feel that it is their obligation to set a comprehensive, highly accurate context for any information that they are going to stand behind, and that such concise definitions may be essential to the conception and practice of their work.

In some cases a technical word may have a common-language synonym and use of the jargon serves as a mark or badge of membership of a group and perhaps as a means of mystification for non-specialists. The medical profession is noted for its proliferation of technical vocabulary based on Latin and to a lesser degree Greek. Latin was for a long time the language of communication for medical scientists and biological classifications were originally undertaken in that language. It also serves as a suitable source of mystification in the doctor-patient relationship, though a health and fitness obsessed generation has taken many of these terms into the common vocabulary.[56] When it comes to communicating with a non-technical audience, jargon can result in some serious miscommunication because the details often confuse the listener, rather than help.

Chapter 2: Methodology

2.1 Qualitative and Quantitative issues

Most scientists and medical practitioners are familiar to a greater or lesser degree with quantitative research. In the biomedical literature, quantitative studies such as epidemiological investigations and clinical trials are used to test well-specified hypotheses concerning some predetermined variables. These studies are designed to answer questions such as whether (did an intervention do more good than harm), or how much (how strongly does a risk factor predispose to a disease, or how much does an intervention affect a prespecified outcome).[57]

Qualitative[58] research may be used to answer different kinds of questions from those studied using quantitative methods, and may also be used for examining phenomena whose investigation lies beyond the scope of the latter. Qualitative research typically seeks to answer "what", "why" and "how" questions rather than "who", "when" or "how many". The prime goal is not to simplify, categorise and enumerate, but to preserve complexity of a complex phenomenon so that the nature can be explored and better understood. It may well be the case that once qualitative methods have yielded a better understanding of a social phenomenon that quantitative methods can be developed in order to measure the magnitude or effects of these phenomena, often using a questionnaire derived from a previous qualitative study.

Qualitative studies in the medical literature often look at social, emotional and experiential phenomena such as patients' or doctors' perceptions, experiences, behaviour and beliefs. Insights are gained which are helpful in understanding illness behaviour, health seeking behaviour and models of patient adherence and satisfaction.

Commonly used methods include semi-structured or in-depth interviews, focus group sessions and observation, and outputs are not typically answers but narrative accounts, explanations, typologies of phenomena and conceptual frameworks.

2.1.1 What is good qualitative research?

Different criteria are required to evaluate qualitative research from those used for quantitative work. A good quantitative study needs to measure a phenomenon accurately, must be capable of replication, and controls for "extraneous" variables so that results can be generalised beyond the particular context in which the research has been conducted. In contrast, the aim of a good qualitative study is to access a phenomenon of interest as completely as

possible from the perspective of the subjects, to describe what is going on, and to emphasise the importance of the process followed and the context of the research. Quantitative studies are usually judged in terms of validity, representativeness and reliability, qualitative studies are judged in terms of creditability, transferability, confirmability and dependability.[57]

2.1.1.1 Generalising or transferring from qualitative research.[57]

Some qualitative research may aim to be capable of generalisation beyond the sample studied and may use sampling methods that are similar to quantitative research. Other studies will purposefully seek out examples where people disagree or extremes of opinion in order to explore the broadest range of responses and reach a fuller understanding of a phenomenon. Such "purposive" sampling is foreign to quantitative research. In order to allow the reader to judge for him/herself whether findings are generalisable to other contexts, full descriptions of the context, the subjects and the findings must be provided.

2.1.1.2 Validity or creditability.[57]

Clinical readers assess quantitative studies in terms of research validity – the truthful correspondence of results with an objective reality. They assume an unchanging universe that has a static objective reality, whereas quantitative researchers hold that the social context is always changing, and that the concept of both validity and replication is inherently flawed when applied to qualitative questions. Qualitative researchers use the term credibility to refer to the overall rigor of qualitative research in which insights must emerge from systematic observation and competent interpretation, corresponding well to the social reality experienced by the participants and having meaning and relevance for those who will read the report.

2.1.1.3 Dependability and reliability.[57]

Methodological rigor needs to be applied to qualitative research using appropriate study design. Was the study designed to address its research question and objectives appropriately and was it conducted rigorously enough to achieve its aims? Methodologies should describe how study participants were selected, how data was generated, the comprehensiveness of data collection and procedures for analysing, interpreting and confirming the data. Dependability involves researchers keeping clear records of the research process and of its products so that, in principle at least, the study can be replicated. Such a research audit enables readers to decide if procedures have been carried out carefully.

2.1.1.4 Selecting participants[57]

The units of analysis in a qualitative study may include broad social groups, social situations, dyads of interaction, individuals, dialogues or settings. Units of enquiry may cut across these categories looking at an issue from different levels simultaneously. The scope of the study therefore needs to be limited by specific questions or areas of interest with the rationale clearly presented to the reader. Consecutive or random sampling is replaced by purposive sampling in qualitative research, aiming to cover the target group thoroughly to examine the phenomenon from many perspectives. Selection criteria may evolve over time with specific respondents or situations being sought out to cast light on a specific question.

2.1.1.5 Data collection methods[57]

Common methods are field observations, interviews and document analysis. Field observations are most appropriate to record social phenomena directly and prospectively. Participant or non-participant observation is used to look at social situations or interactions between people. Interviews are more useful for gaining insight into people's beliefs and perceptions of their experiences. Individual interviews are more useful for evoking personal experiences, and group interviews for capturing interpersonal dynamics, cultural and language issues. Group interviews can be used to confirm or refute the general acceptance of issues or theories generated through individual interviews. Structured standardised questionnaires are usually inappropriate because they presuppose too much of what the respondent might say and do not allow respondents to answer in their own terms, so semi-structured, in depth interviews are often used. These interviews are often used as a basis for the development of structured questionnaires.

2.1.1.6 Data comprehensiveness[57]

Quantitative studies rely on achieving a large enough sample size to preclude random variation being responsible for a statistical result. Rather than aiming for a specific number of participants (or other units of analysis be they people, interactions, situations or words), qualitative researchers should strive for adequately in depth observation of the phenomenon. Data collection needs to be adequate both in term of breadth (number and types of observations) and depth (extent of observation of each type) to generate creditable findings. Whether data is adequate depends on the nature of the results – if they are consistent and well understood, thus a predetermined number or time of data collection is usually not of application to quantitative research. However, this necessitates iterative data collection followed by analysis, in turn influencing further data gathering and analysis. The extensiveness of the data gathering needs to pay attention to the number of observations, interviews or documents, the duration of the observations, the duration of the study period, the number of investigators involved in analysing and interpreting data and the degree of involvement of

investigators in the data collection and analysis. Attention needs to be paid to detail in the collection and recording of information, emphasising thoroughness appropriate to the type of investigation.

2.1.1.7 Data analysis and corroboration

The grounded theory approach of Strauss and Corbin[59] is probably the most widely used strategy for analysis of qualitative data. It is fundamental to this approach that concepts and theory emerge from the data itself. Qualitative research does not start with a clearly defined hypothesis – it starts with an area of study and an unanswered question. Theory and concepts are grounded in the data collected, and it is up to the researcher to extract these, uncovering the research subjects' own understandings and explanations. Relevant data is collected, allowing patterns to develop and organisation of these into a framework to develop a theory. This cycle is repeated many times, with analysis guiding further data collection. The iteration between data collection, analysis and theory generation continues until a conceptual framework is well developed and further observations yield minimal or no new information to further challenge or elaborate the framework. This point is referred to as "theoretical saturation"[60] or "informational redundancy" and is the criteria by which it is judged appropriate to stop further qualitative analysis. In the course of this analysis, key findings must be corroborated using multiple sources of information; a process referred to as triangulation. The researcher should actively seek out exceptions or contradictions to their theory, and test other explanations before reaching final conclusions. Different types of triangulation are investigator triangulation (using more than one investigator to independently collect, analyse and interpret the raw data) and theory triangulation (comparing emergent theory to existing social science theories). Data triangulation is the strategy of using different methods of collecting data to corroborate findings. For example in one study, one may use non-participant observation, open ended interviews and questionnaires with both open and closed ended questions.

2.1.2 EMIC vs. ETIC approaches

The neologisms "emic" and "etic" were derived from an analogy with the terms "phonemic" and "phonetic" by the linguist Kenneth Pike[61], who introduced the terms into linguistics and anthropology in 1954. The anthropologist Marvin Harris[62] modified the concept in the 1960's to develop his own theory in anthropology, called Cultural Materialism. In Harris' use of the terms, they refer to an "inner" understanding of knowledge, from the perspectives of those who are in possession of it to start with (emic), as opposed to an "outer" viewpoint looking at it from the outside and comparing it with previously known or internalised personal beliefs (etic). The original problem was of understanding the degree of correspondence between kinship terms in different societies. The distinction between the "emic" and "etic" approaches in this instance is that kinship terms convey more than simply genetically created biological relationships between individuals, but also culturally constructed meanings of inter-relationships between

people. A researcher asking, "What is the name of your uncle?" is imposing his or her own definitions of the use of that term on his or her subject. In most Western society, "uncle" refers to father's brother, mother's brother, father's sister's husband and mother's sister's husband. These discriminately different biological relationships have different connotations in different communities, and many have separate words to refer to some or all of these relationships. The "emic" approach requires asking informants for the terms designating each of these biological categories and attempting to understand the social and cultural relations that may link these terms in order to understand the biological and cultural relations in the informant's community from their own perspective. To ask "who is your uncle?" is to risk being a prisoner of one's own cultural constructs.

2.2 Selection of subjects

2.2.1 Parents' inclusion criteria

Xhosa speaking parents were interviewed from November 2002 to March 2003. For the interviews only parents of children admitted to the short-stay ward for respiratory illnesses or attending the allergy and asthma clinic were selected. For the access barrier questionnaires, parents of children who were admitted to the short stay ward for any illness were included. Only parents who spoke Xhosa as their home language were included. The rationale for restricting parents to this "vulnerable" group is because that is the group who is most likely to have difficulty in communicating to non-Xhosa speaking staff, and therefore the group in which the results will be the most useful. In addition, this group comprises the great majority of patients in the public health sector in the Western Cape. The parents attending the short-stay ward and allergy clinic on each study day were asked about the presence of exclusion factors and then invited to participate in the study. No strict randomisation process was applied to the selection of respondents.

Demographic data was gathered on the group in order to describe the group fully for the readers of the results so they know the characteristics of the group concerned and can decide whether to generalise the results to other groups or not. The issues of education and home language are clearly central variables on language use as a possible barrier to medical care and therefore form the variables by which the group is defined. Variables such as age, gender, degree of contact with health services etc are secondary, less important variables. These were collected, not for the purpose of formal subanalysis, but as a description of the group, so that the reader can judge for him/herself the applicability of these findings to any other group of patients. The same information was collected on the parents of children attending the allergy and asthma clinic, and analysis was done to see if this group differed significantly in terms of these variables.

2.2.2 Doctors' inclusion and exclusion criteria

Doctors were recruited from Red Cross War Memorial Children's Hospital's paediatric medicine department. All the doctors attending a departmental clinical meeting were asked to respond to a short questionnaire rating their competence in speaking Xhosa on a linear scale of 0 – 10, and whether they speak to their Xhosa speaking parents never, infrequently, frequently or always. In addition they gave their name, home language, contact telephone number and indicated their willingness to be interviewed about language issues. Doctors were excluded if they indicated they never speak Xhosa or speak it infrequently, if they were extremely proficient in Xhosa (9 – 10 on the questionnaire) or spoke a Nguni language as their first language, and if they indicated they were not available. From the remaining pool of respondents a broadly representative convenience sample of doctors, with widely varying degrees of experience, was invited to participate.

Doctors who couldn't or didn't speak Xhosa to their patients or who were extremely proficient in speaking Xhosa were excluded from this research. A major focus of the doctor's interviews was to gain an impression of whether doctors perceived difficulties in communication between themselves and their patients. Fluent Xhosa speaking doctors (in the minority at Red Cross War Memorial Children's Hospital) would clearly have little or no problems communicating with Xhosa speaking patients, and doctors with no Xhosa language skills would clearly have the greatest difficulty communicating. This research thus focused on the problem of communication between Xhosa parents and the non-Xhosa doctor grappling with multilingualism, to assess whether in this situation, language was still seen as a significant barrier by the doctors. Within the doctor group expertise in any language apart from Xhosa or another Nguni language was not an exclusion factor. Different factors (the doctor's level in the medical hierarchy, experience and level of clinical interaction) were perceived as possibly affecting the doctors' communication with their parents than was postulated for the parents. Thus as a means of describing the group, data was collected on their age, training in speaking Xhosa, and duration of working as a doctor, rather than duration of urbanisation, educational level, gender, proficiency in other languages etc.

2.3 Sample size

2.3.1 Language interviews

39 parents and 8 doctors were included for language interviews. No attempt was made in this study to correlate language or illness features with age, class, occupation or any other sociological factor. Rather, the goal was to achieve a rich description of the barriers to care that are experienced by parents so as to elicit examples, and guide the formation

of the access barrier questionnaire. However, it is acknowledged that no qualitative data acquired from a small group can be assumed to represent any other group fully.

A pilot study of the first five interviews was performed with subsequent consultation of experts in the fields of qualitative research methodology, linguistics and medical anthropology. This enabled changes to be made to the research procedures to ensure that the data collection methods adhered to high standards.

Attention was paid to qualitative research methodologies and issues, rather than to stipulating a sample size prior to the commencement of the study. The sample size was dictated by grounded theory methods, in which repeated cycles of data gathering and analysis dictated whether further data gathering was necessary. This iterative process of data gathering continued well beyond the point of "saturation".

This explains why the numbers differ markedly between doctors and parents. 8 doctors was found to be a sufficient sample to get a full representation of their perceptions of communication between themselves and their patients. Doctors are as a group confident people who are familiar with giving descriptions, definitions and explaining concepts. In contrast to this, I found far more variability in the responses from the Xhosa speaking laypeople, thus data collection proceeded with a far greater number of parents.

2.3.2 Access barrier questionnaires

53 parents completed the access barrier questionnaires, enabling a sufficiently representative sample of the major problems which these parents face in their quest to get medical care for their children. The sample size is not sufficient to enable subgroups to be elucidated within the group to look at which factors may make it more difficult or easier for a subgroup to get good medical care. In concert with "action learning" theory, issues that were raised in the interviews were incorporated into the questionnaire, enabling quantitative analysis of the issues that had emerged from qualitative research.

2.4 Data gathering

2.4.1 Qualitative Interviews

Parents who agree to participate were interviewed by a fluent Xhosa speaker. Although the study was done with two research assistants at all times, four research assistants took part in this project. After the pilot study, which comprised the first five interviews, was completed, one of the researchers was asked to leave the project as her English language skills were found to be sub-optimal. The second researcher resigned shortly thereafter for personal reasons. The subsequent research assistants conducted the remainder of the interviews, transcription and translation, and administered all the access barrier questionnaires. The demographics of the research assistants are shown in table 5.

Table 5: Demographics of research assistants.

Name code	Gender	Age	Qualifications	Additional skills	Mother tongue	Home languages
NT	Female	26	BA	Translation	Xhosa	Xhosa
JN	Female	25	BA	Sociological research methodology	Xhosa	English Xhosa
TM	Female	26	ATLS	Speech & Drama, advertising	Xhosa	English Xhosa
NM	Male	36	BA	Drama	Xhosa	English Xhosa

After briefly describing the goals of the study and taking full informed consent the parent was taken to a private room in the allergy and asthma clinic. The interviewer then re-introduced herself and immediately outlined the scope of the study and the types of responses required by the subject. It was stressed as part of this introduction that the interviewer wanted the subject to explain exactly what he/she believed from his/her own perspective, not to try and gives answers that would be seen as "correct" or "pleasing" to the interviewer. It was explained that this was not a "test", it was a "quest" for their own knowledge, and interest was expressed in the subject's unique perspective. Then the demographic details, including age, gender, level of formal schooling, number of admissions for similar problems, amount of time a doctor or nurse has spent explaining their child's problem, degree of proficiency in other languages, place of residence and place of birth was recorded.

The interview was conducted in a private room, which was comfortable and contained a table, two chairs and some pictures on the wall. Refreshments were provided for the participants during the interview session. Proceedings were discreetly recorded (with the consent of the parents) using a tape recorder and video camera concealed in two pot plants. The tape in the tape recorder needed to be turned over during the session, but the videotape ran without any interruption during the interview. The tape machine was used on conference setting to enable the study participants to talk in their normal voices. The interviewer avoided interrupting the respondent or talking at the same time as them. It was not deemed necessary to ask any respondent to talk more clearly, slowly or louder to enable adequate audio recording.

2.4.1.1 Design of research tool

The interview was based on a semi-structured questionnaire. The schedule for this semi-structured interview is appended as annexure A. After informed consent was taken, an introduction was done and demographic data was collected. The parent was then asked what problems they had experienced, and what day-to-day obstacles had prevented their child from getting good medical care. They were subsequently asked whether they had had problems with communication with the doctor. The nature of the problems, perceived causes of the problems, possible effects of these on them or their child, and possible solutions were sought. The interview continued with ascertaining parents' perceptions or understanding of the meanings of medical terminology. (The linguistic analysis of word meanings is not included in this dissertation but will be submitted towards a doctoral thesis in Applied Language Studies in 2005.)

2.4.1.2 Pilot study and internal review

A pilot phase was built into the study to assess the organisational aspects, the performance of the interviews and the adequacy of the research tool. After five interviews were performed (2 doctors and 3 parents), and the data had been transcribed and translated, a meeting was held to discuss these issues and assess the adequacy of the outputs. This meeting agreed that there were no problems with the organisational aspects or performance of the interviews, but noted problems with the transcription and translation process. Of the two research assistants, one had been doing all the work of transcribing and translating, as the other researcher's language skills were found to be inadequate for the task. As only one researcher had done all the work, the adequacy of the transcription and translation process of the 3 Xhosa interviews had not been checked by a second person. It was decided to submit the 5 interviews done so far to an external person to check the transcription against the original audiotapes, and assess the quality of the translation. It was also resolved to replace the second researcher with someone with excellent language skills. An advertisement was placed at the University of Cape Town's postgraduate computer laboratory, and in various departments and an excellent replacement was found.

2.4.1.3 External audits

The tapes of the first 3 Xhosa interviews were reviewed by a Xhosa first language speaker and compared with the transcriptions. Subsequently the quality of the translation was checked. Comments from the external audit showed that the quality of the translation and transcription was excellent with almost word for word transcription and translation that had lost none of the subtleties of meaning in the source text. Thus these interviews were included in the final analysis.

2.4.1.4 Phase 1 review with consultation of experts

After 11 interviews had been done (5 doctors and 6 parents) another internal review was done, but this time I consulted various experts in their fields. Issues raised in this discussion were the replacement of the previous researcher, concerns about the responses of the Xhosa respondents and technical issues.

Problems with the Xhosa interviews focused around the problem of Xhosa respondents not wanting to "criticise" the hospital. It was also found that Xhosa respondents were getting bored and irritable with the length of the interviews and were concerned about issues like missing the doctors' ward round or long waiting times for medications at the pharmacy. To address these issues the researchers stressed as part of the introduction that they were not connected with the hospital in any way, and that parents responses would help hospital personnel, even if negative, to improve service delivery. Interviews were scheduled not to clash with ward rounds and parents were offered help with obtaining their children's medications directly after the interview was concluded (obviating the necessity for a long wait at the pharmacy.) It was also found that interviewers were not always covering the full range of questions about communication viz. adequacy, problems, effects, causes and solutions, and were asked to pay more attention to these details.

Technical issues concerning the audio recording focused on eliminating background noise, avoiding simultaneous speech and trying to speak clearly and slowly. Although soft or inaudible speech was a factor preventing transcription of speech in a few interviews, it was only for a few seconds at a time and the second data source of the audio track from the video recordings was sufficient to allow full transcription in the majority of those cases. It was thus decided not to draw undue attention to the taping process and respondents were not asked to speak louder, clearer, slower or in any other unnatural fashion. It was suggested that paraphrasing the respondent's last sentence would allow the parent to repeat and clarify what they had already said and enable consistent and accurate transfer of meaning.

With regard to the transcription and translation process, the two researchers were doing very well, checking each other's work and reported no problems. It was decided that a first language English speaker should do the English

transcriptions, and an experienced paediatric secretary was hired to perform this job. The researcher checked English interviews.

External experts in the fields of linguistics, sociological research methodology, clinical quantitative research and paediatrics agreed that the organizational and methodological issues were well managed.

2.4.1.5 Changes to research tool for phase 2

No major changes were made to the research tool after the review. The introductions on commencing the interviews were changed for parents as described above to allay concerns that parents had about the process, as well as to focus the type of responses required to obtain the best data for the research.

2.4.1.6 Recording of information

Information was recorded on mini cassettes (1 hour long tapes requiring a turn after 30 minutes) using an Olympus H350 Dictaphone recorder set on conference mode. The Dictaphone machine was placed on the table between the researcher and respondent concealed by a pot-plant. The video recording was done uninterrupted. The video recorder was concealed above a cupboard behind a pot-plant.

2.4.1.7 Transcribing and translation

Transcription was done using a transcribing machine with variable speed, volume and tone control and pedals for reverse, forward and play function. The transcriptions were done using MS Word and were checked by the second researcher using either the audio recording or the video soundtrack in the few cases where some of the audio recording was unclear. The Xhosa transcriptions were translated into English to allow further analysis.

2.4.2 Access barrier questionnaires.

The emerging themes from this data were compared with the themes raised from data in previous studies in South Africa and in the rest of the world. Issues of access barriers prior to entering the hospital, service within the hospital and communication issues were compiled into a quantitative coded questionnaire, forming the basis of a questionnaire looking at access barriers to health care for this group of parents. The format of this questionnaire was based, with kind permission from the authors, on the questionnaire used by Flores[13] in his article "Access barriers to health care for Latino children". The questionnaire used multiple methodologies to ask the same questions viz. open ended questions, selection from lists and yes/no questions. This is in concert with qualitative research methodologies emphasis on triangulation of data collection methods. Aspects of parents' difficulties that were not covered by questionnaire used in

Flores' study were added to our questionnaire, and the wording was changed to reflect the realities of our health care system rather than the American system (I.e. deleting references to Medicare and Medicaid, and American systems of hospital payment). In addition, I added questions regarding the socio-economic status of our communities, regarding access to telephones and electricity, the type of dwelling and duration of urbanisation.

The four page "access barrier questionnaire" is attached as annexure B. In short, demographic details were first collected on the respondents, including age, gender, relationship to patient and marital status. The place of birth and place of residence were noted as well as the duration that the respondent had lived in Cape Town. The type of housing, number of occupants and presence of a telephone were recorded. The highest level of education attained, occupation, self-rated ability to speak English, home language and additional languages spoken were recorded. The respondents use of traditional healers and prior use of medical services was assessed. Caregivers were asked about communication in the last interview with a doctor. They were asked about their concerns about access to hospital, service within the hospital to identify access barriers to health care for their children. These questions were repeated using a variety of methodologies (triangulation of methodologies) to ensure that results were consistent. Thus caregivers were asked open questions requiring them to cite the single greatest obstacle they had faced in getting medical care for their child, as well to select the single greatest obstacle from a list. They were further asked to select the three greatest obstacles from a list. They were asked "yes / no" questions about specific barriers that may have prevented them from bringing their child in to health care as well as adverse effects on their child because of communication problems. Finally the caregiver was asked the total family income and the researcher rated their assessment of the caregivers ability to speak English.

Interviews were conducted in private, by Xhosa speaking researchers . The questionnaire was completed within 30 minutes and interviews were not recorded. Informed consent was taken and arrangements were in place to ensure the parent was available if the doctor wanted to counsel the mother or examine the child.

2.5 Interpretation

2.5.1 Analysing the access barrier questionnaires.

The access barrier questionnaires were entered into a database using STATISTICA 6 and where applicable subjected to descriptive analysis. Simple frequency tables, pie charts or histograms were generated of categorized variables. Non-categorised variables were grouped into categories and represented in the form of histograms. Different methods of questioning parents on their access barriers (open questions or selecting from lists) resulted in slightly different results and all results were analysed and are reflected here.

Chapter 3: Socioeconomic and demographic data

3.1 Caregivers interviewed

In order to ascertain whether parents differed from each other in terms of the variables I had deemed important (age, educational level, duration of urbanization and socio-economic status), descriptive characteristics of the parents who conducted the language interviews was compared with the same variables of the group of parents that had completed the access barrier questionnaires. Language interviews were conducted on parents from the short stay ward (S11) and allergy and asthma clinic. The descriptive data of these two groups is shown separately in figures 1 to 12.

The two groups of caregivers undergoing language interviews were similar in all respects except for the duration of stay in the city, with those from allergy clinic having spent a significantly longer period in Cape Town ($p < 0.05$). Caregivers from short stay ward had spent a mean of 12.1 years in Cape Town (standard deviation 10.6, range 5 months to 43 years) compared to 20.2 years for caregivers from the allergy and asthma clinic. (standard deviation 14.8, range 4 to 47 years)

Figure 1: Age distribution of respondents from short-stay ward.

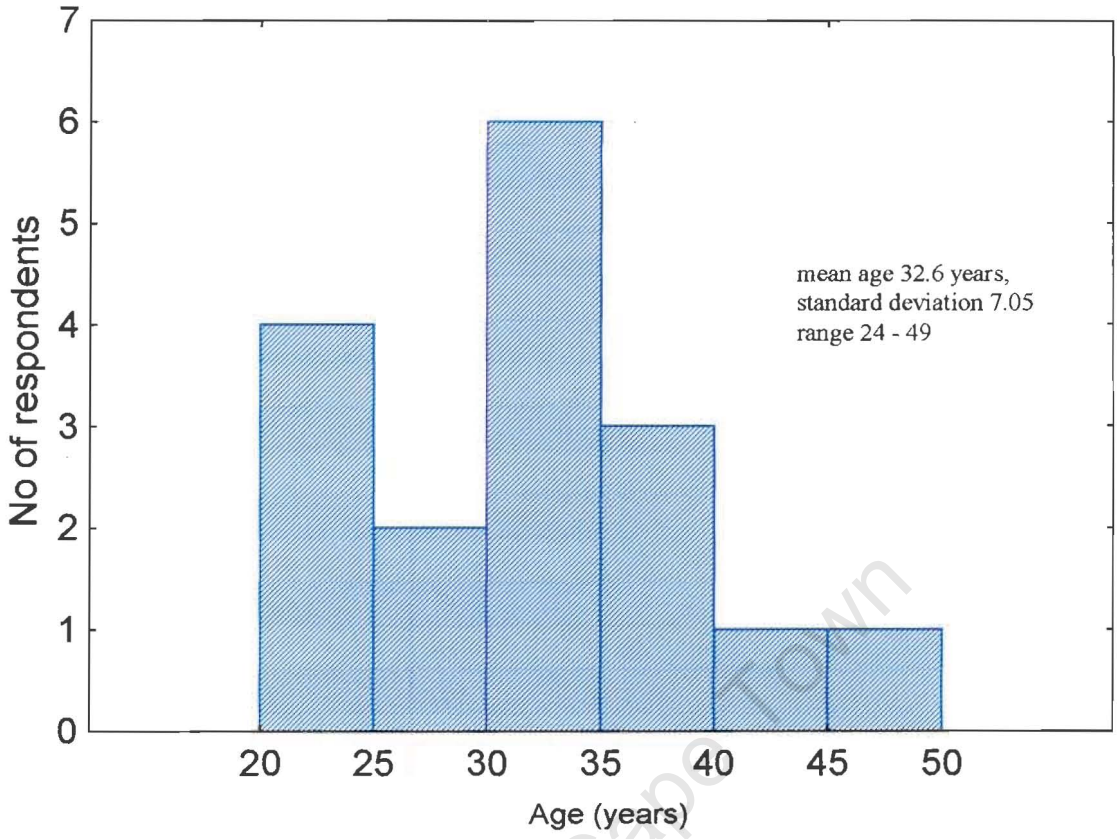


Figure 2: Age distribution of respondents from allergy / asthma clinic.

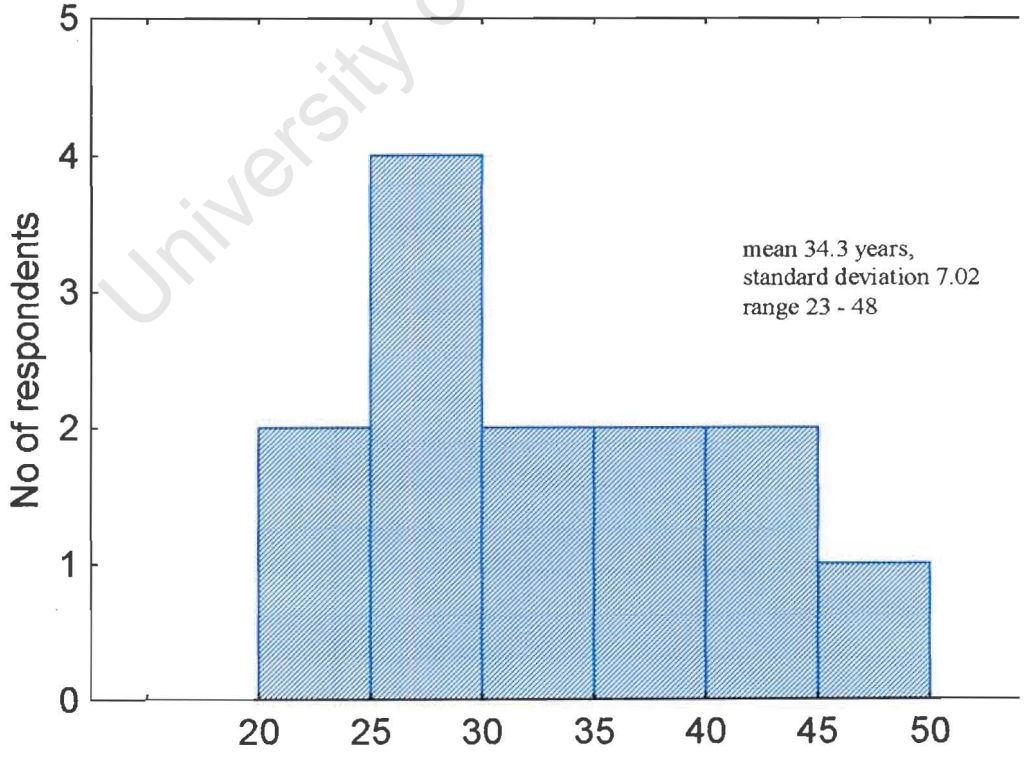


Figure 3: Duration of urbanisation of respondents from short stay ward.

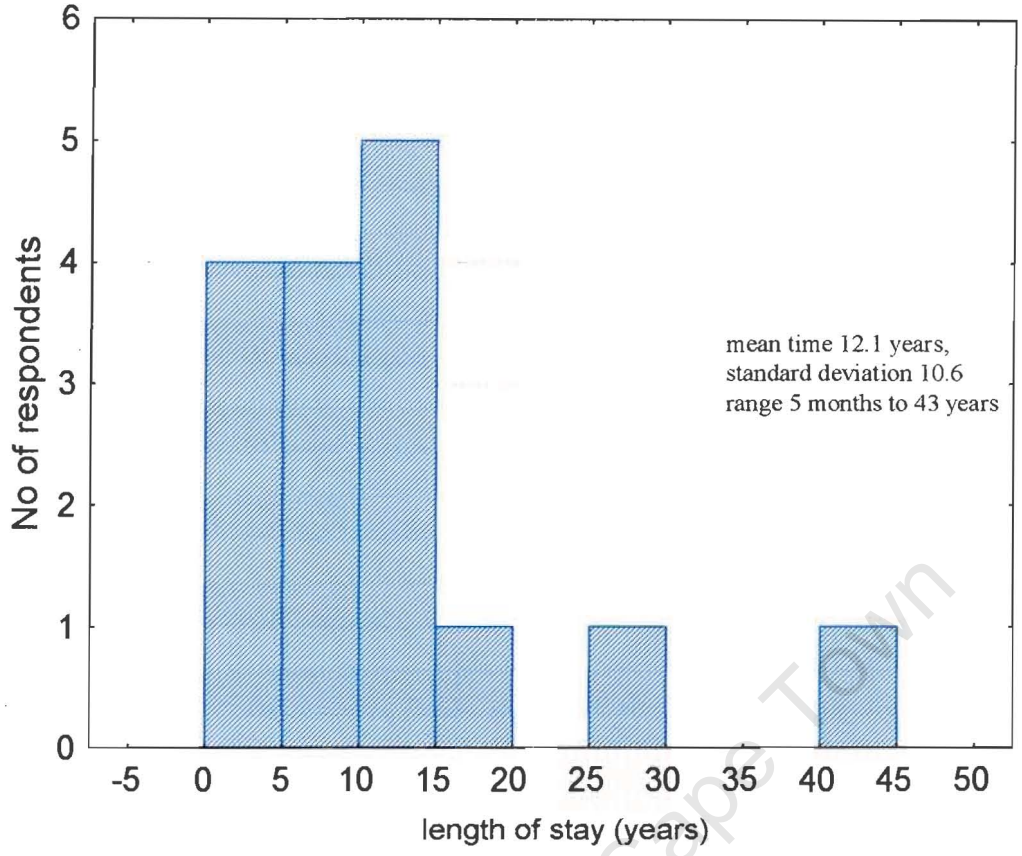


Figure 4: Duration of urbanisation of respondents from allergy / asthma clinic.

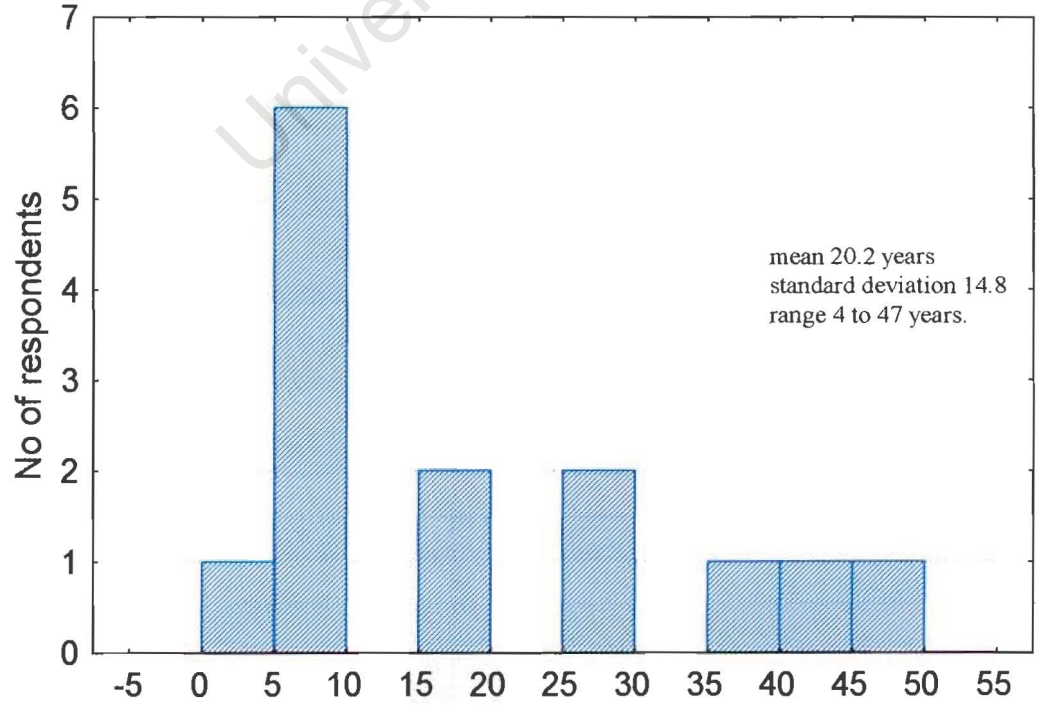


Figure 5: Number of occupants in the home of respondents from short stay ward.

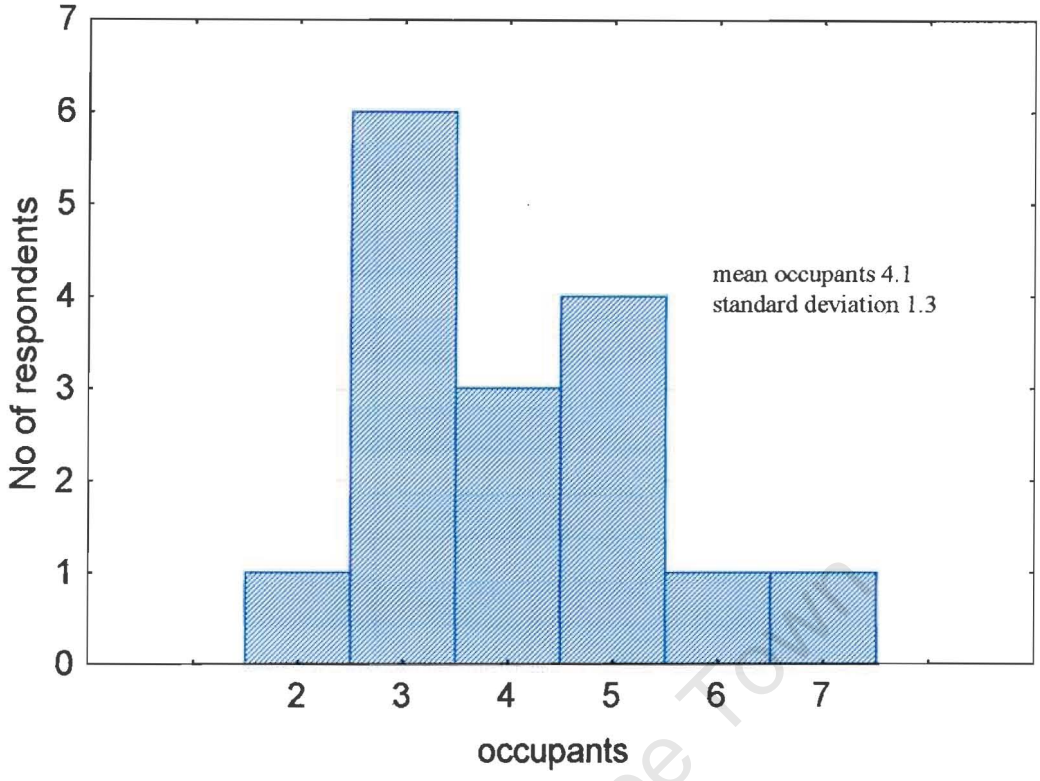


Figure 6: Number of occupants in the home of respondents from allergy / asthma clinic.

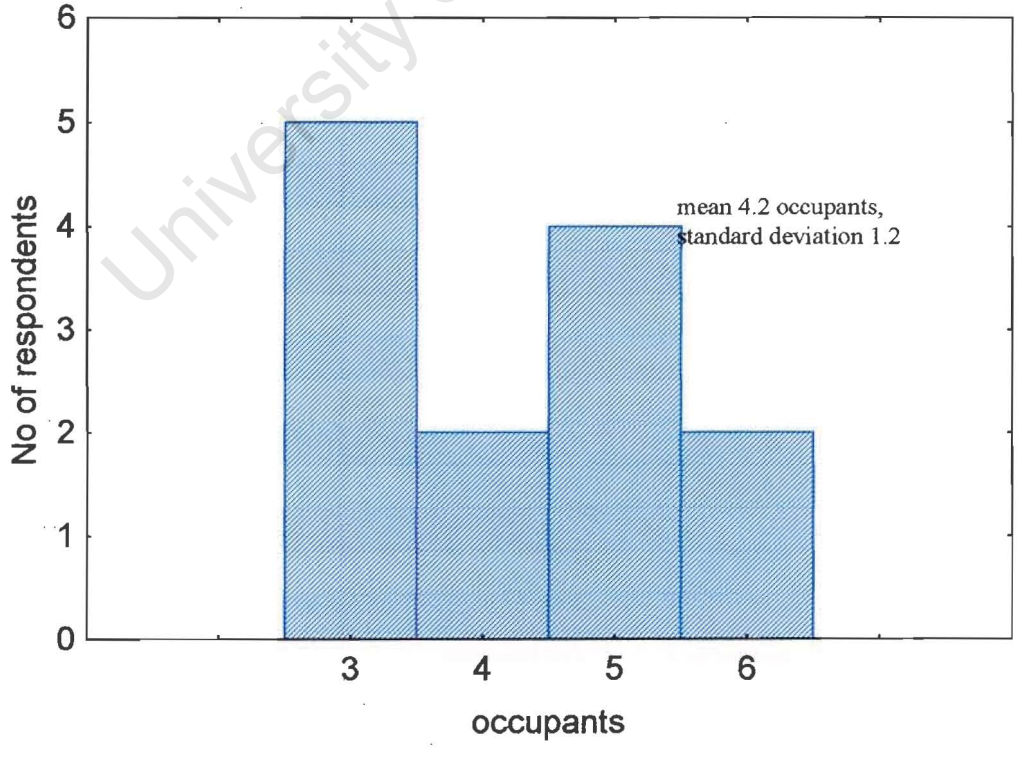


Figure 7: Educational level of respondents from short stay ward.

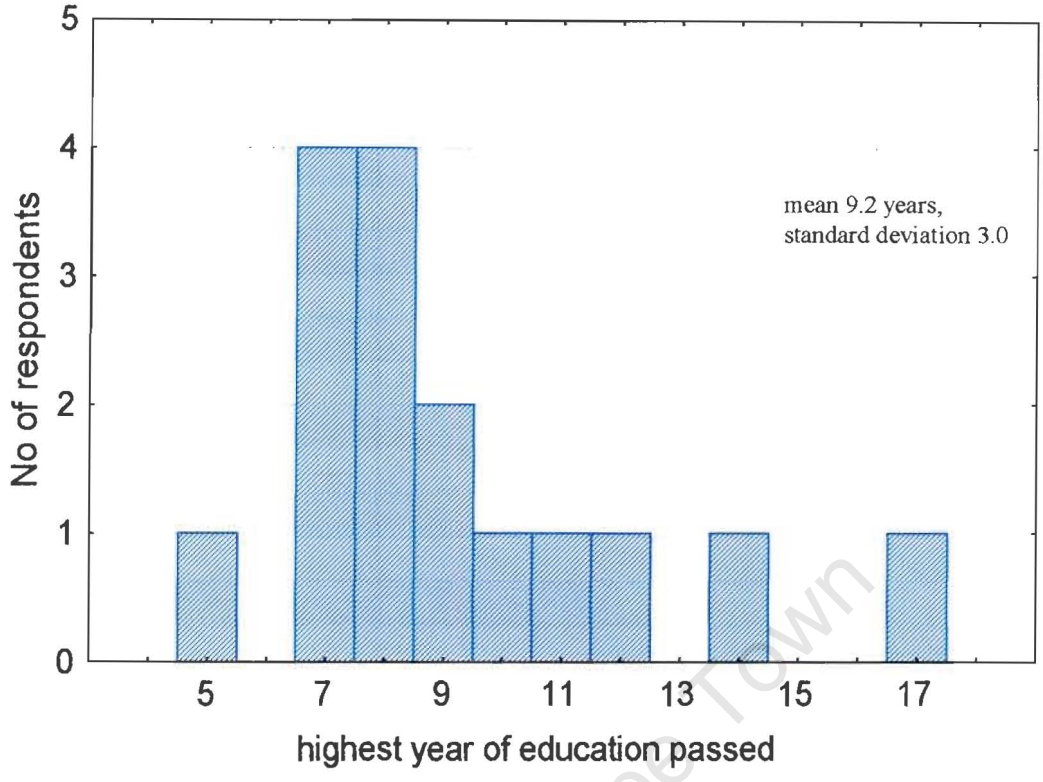


Figure 8: Educational level of respondents from short stay ward.

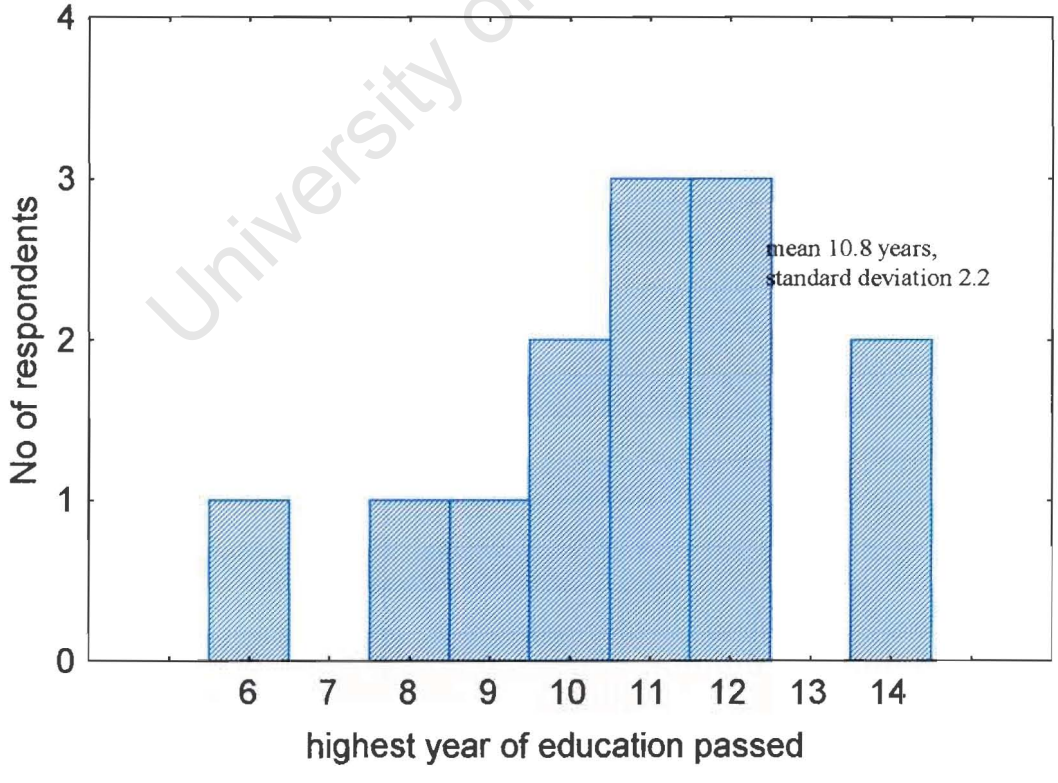


Figure 9: Duration of previous interview with doctor in short stay ward.

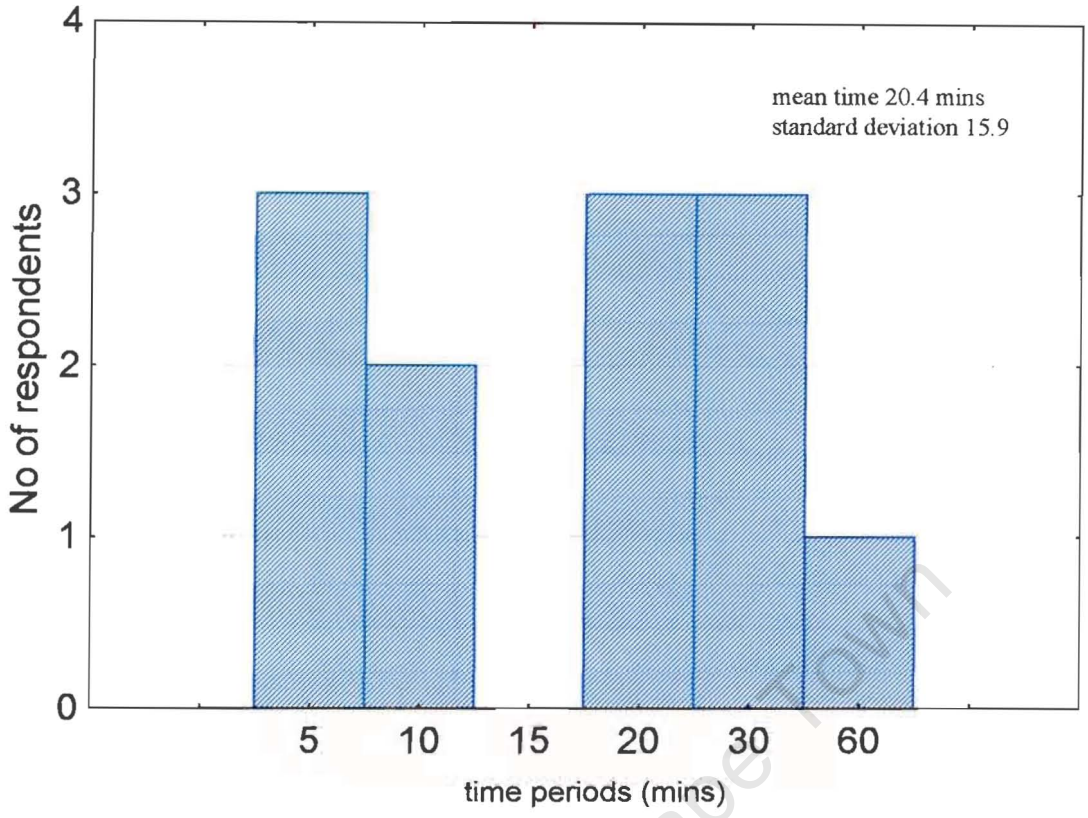


Figure 10: Duration of previous interview with doctor in allergy / asthma clinic.

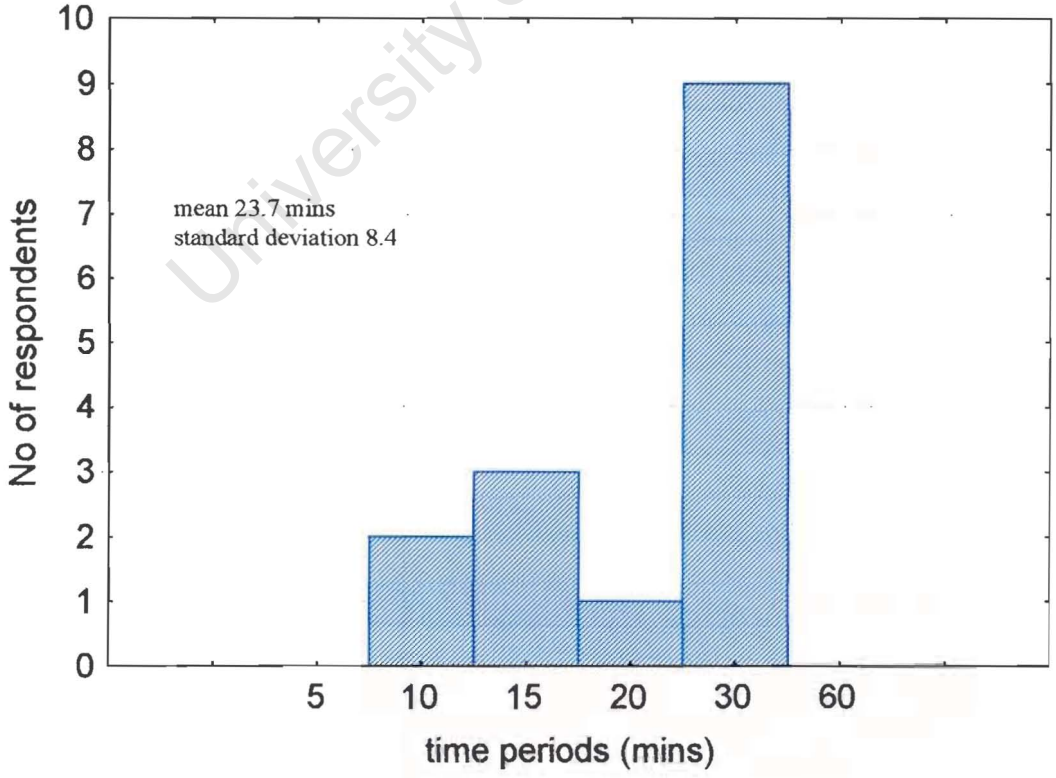


Figure 11: Income of respondents from short stay ward.

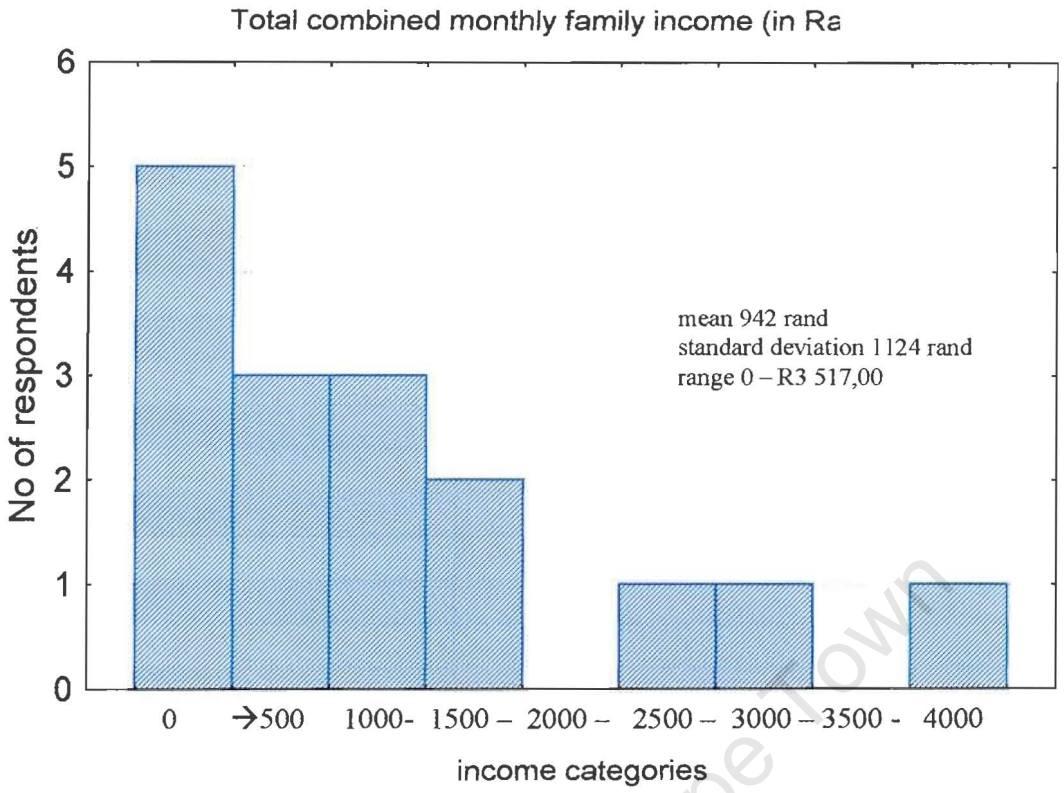
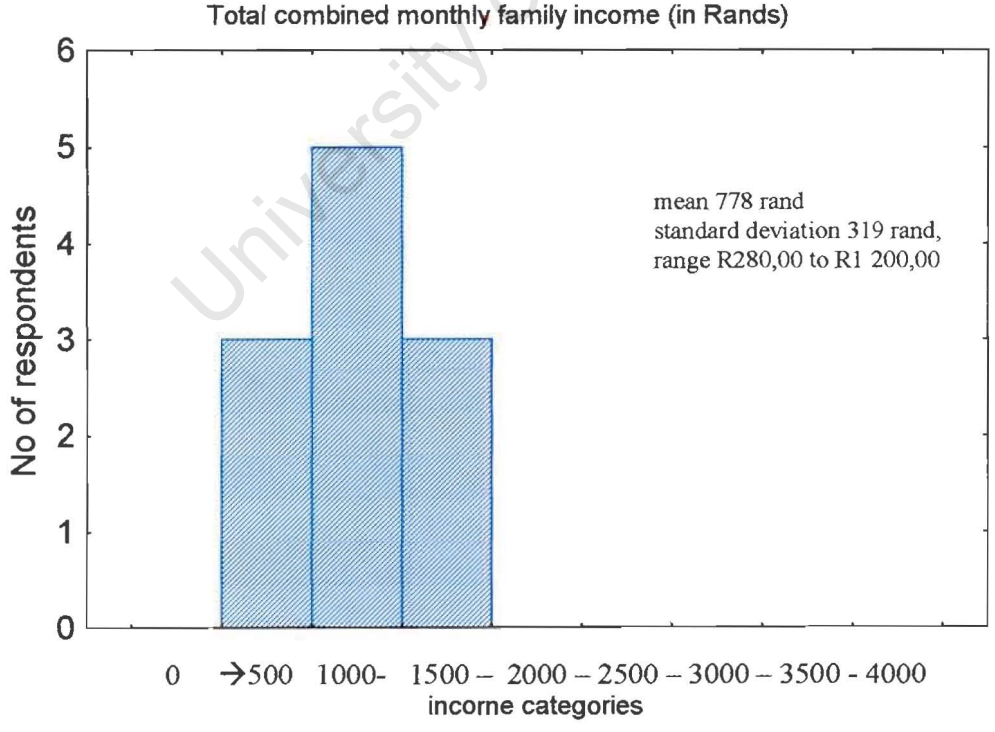


Figure 12: Income of respondents from allergy / asthma clinic.



3.2 Caregivers completing "access barrier questionnaires"

Fifty-three parents of children admitted to the Short-Stay ward for any disease were interviewed. All of the caregivers were female. 45 were the child's mother (85 %), 4 were grandmothers (7.5%), three aunts (5.7 %), and 1 the guardian at an orphanage (1.9 %). Mean age was 31.5 years. (Median 30, range 16 to 53).

Forty-one were born in a rural area (77 %). Mean duration of stay in Cape Town was 11.2 years. (Median of 7 years, range 1 month to 40 years). Excepting those born in Cape Town, the mean duration of stay in Cape Town was 8.2 years. (Median of 6 years, range 1 month to 29 years.)

There were an average of 5 occupants in the home. (Median of 4, range 2 to 12). 30 (61 %) lived in a shack made from corrugated iron or wood, 17 (35 %) in a house built from bricks, and 2 (4 %) in a flat or hostel. Whilst only 9 (19 %) of households had a telephone, 25 (51 %) were contactable by phoning a home phone, neighbour or cell-phone. 22 (45 %) described themselves as married, 5 (10 %) as separated, 2 (4 %) as divorced and 3 (6 %) as widowed. 17 (35 %) were single mothers.

Caregivers had passed a mean of 9.6 years of education (grade 9 = standard 7). (Median 10, range 0 to 17).

The home language 49 (98 %) caregivers was Xhosa, and 1 was a Sotho speaker (2 %). 12 (23 %) of caregivers claimed to speak another language; 1 Xhosa, 4 Sotho, 3 Zulu, 3 English and 2 Afrikaans.

21 (42 %) of caregivers were employed in the formal sector, informal sector or working as volunteers. The remaining 28 (58 %) were unemployed. The average total combined family income was R925 (median R640; mode R800; frequency of mode 4; lower quartile R280; upper quartile R1200)

39 (79 %) took their child to the clinic or day hospital regularly for primary care services including immunisations. 10 (21 %) utilized Red Cross War Memorial Children's Hospital for these services. 17 (34 %) acknowledged the child had consulted a traditional healer, and a further 7 (15 %) attending a church-based faith healer and 1 (2 %) a homeopath.

The demographics of the respondents who completed the "access barrier questionnaires" (group 1) were compared with those from S11 short stay ward (group 2) and parents from allergy and asthma clinic (group 3). Statistical analysis compared these groups using the ANOVAR. This is displayed as table 6. The three groups of parents were similar in all respects except for the duration of stay in the city. For this variable, there was no difference between group 1 (11.2

years) and group 2 (12.1 years), but parents of group 3 had been residing in the city for a significantly longer period (mean 20.2 years). This finding is in concert with recent data showing a marked urban-rural difference in the prevalence of allergic diseases.[63 64]

Figure 13: Age distribution of respondents completing "access barrier questionnaires"

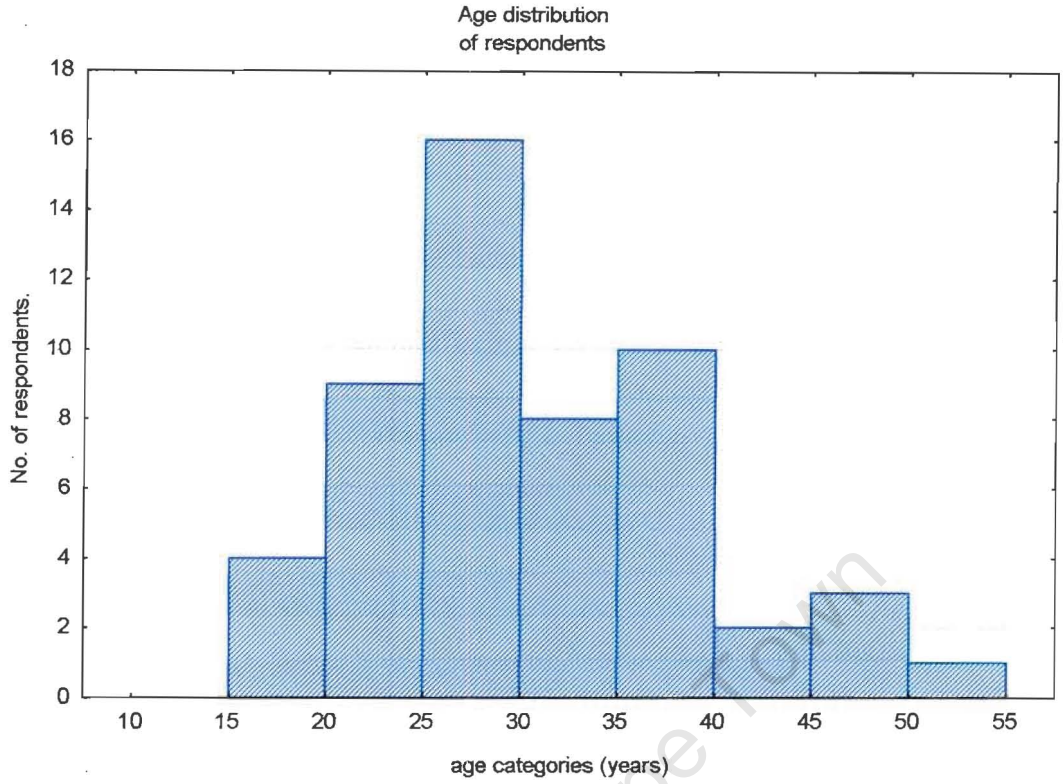


Figure 14: Duration of stay in Cape Town of respondents completing "access barrier questionnaires"

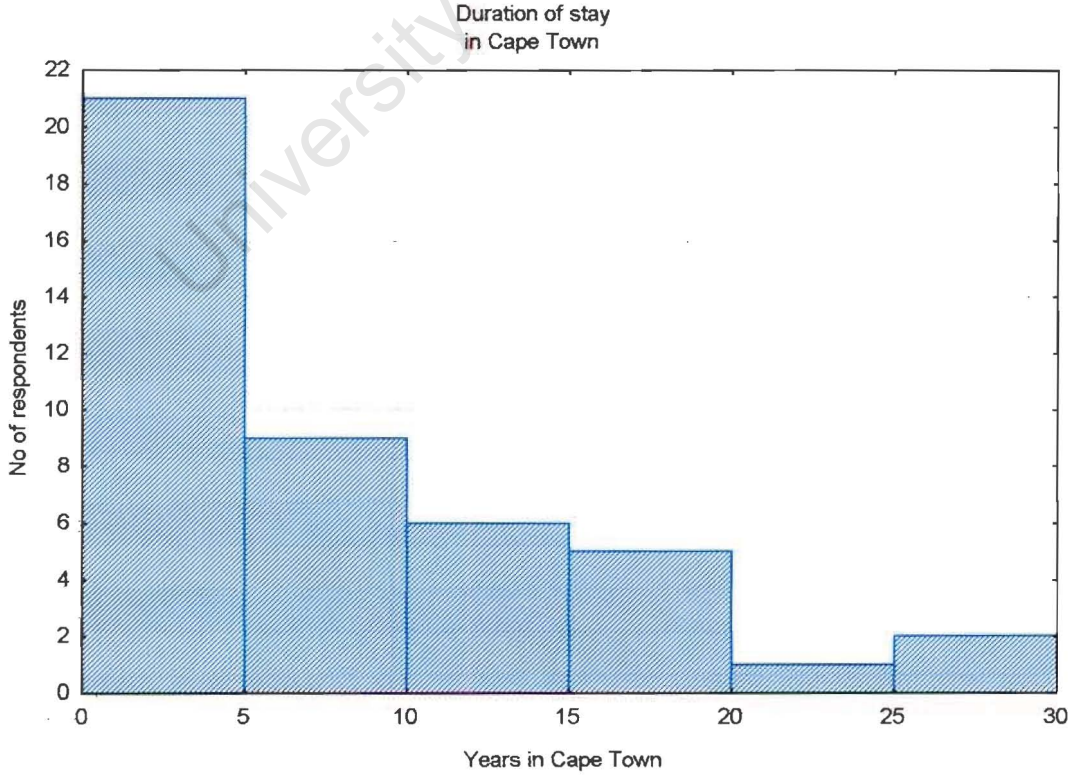


Figure 15: Type of housing of respondents completing "access barrier questionnaires"

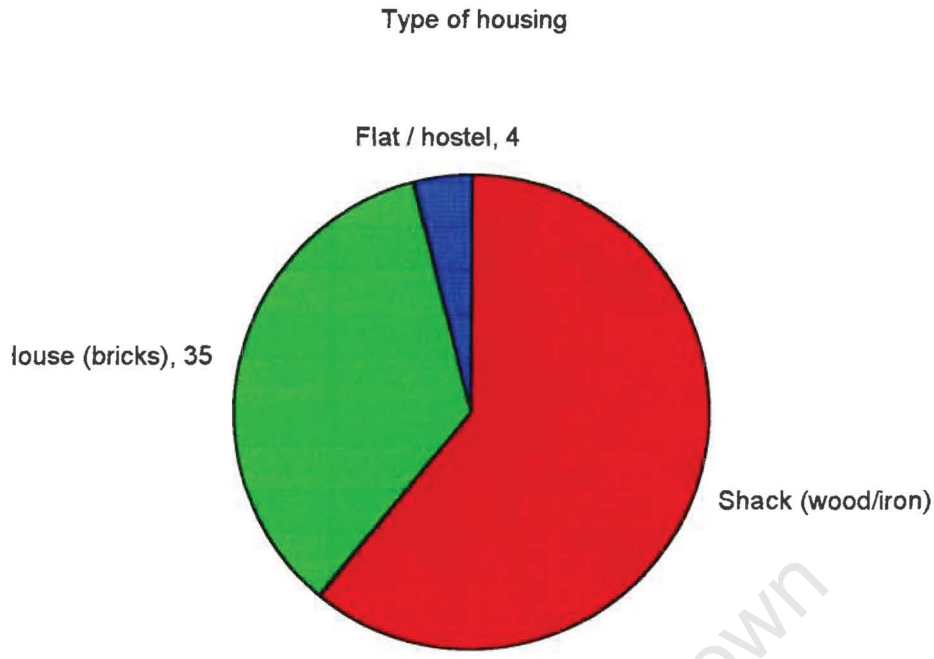


Figure 16: Marital status of respondents completing "access barrier questionnaires"

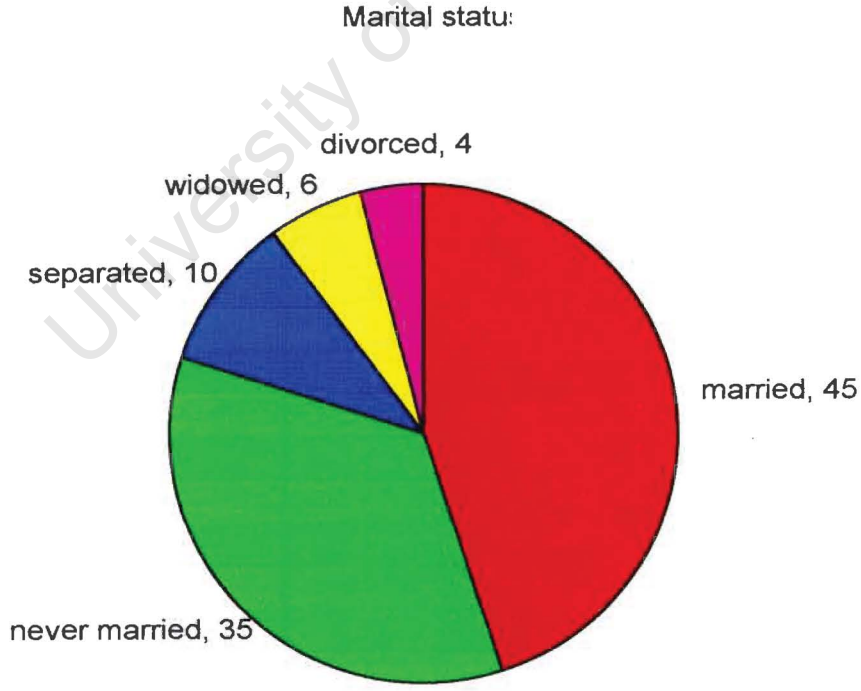


Figure 17: Education level of respondents completing "access barrier questionnaires"

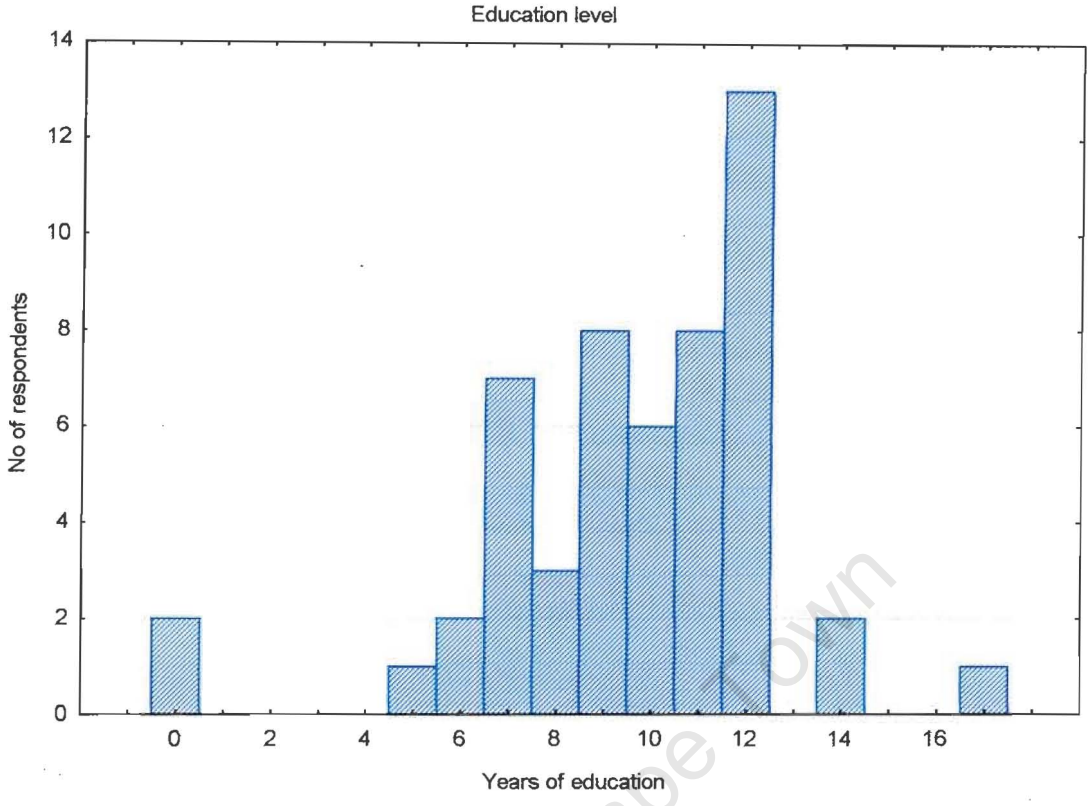


Figure 18: Income distribution of respondents completing "access barrier questionnaires"

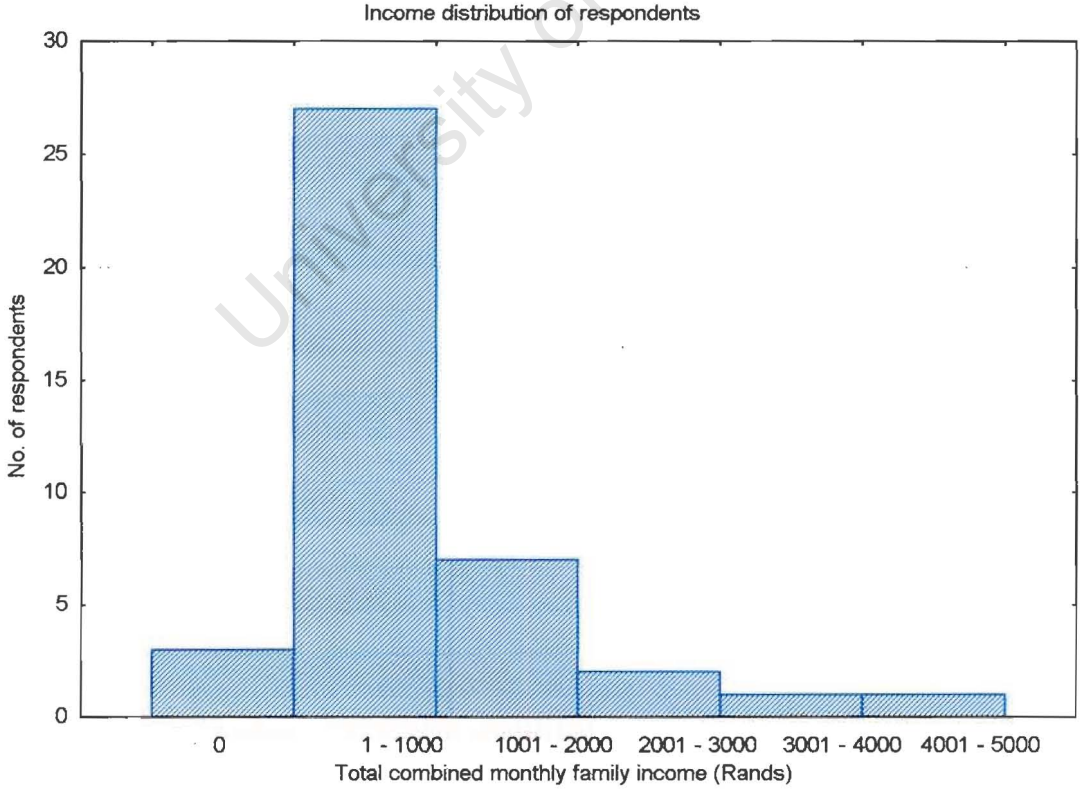


Table 6:Statistical analysis of demographics of parents who completed "access barrier questionnaires" (group 1), short stay ward (group 2) and allergy and asthma clinic (group 3).

Analysis of Variance: $p < 0.05$ = statistical significance

	SS	df	MS	SS	df	MS	F	p
Age	88.2	2	44.1	4916	80	61.5	0.717	0.491
Duration of urbanisation	1530	2	765	6973	71	98	7.790	0.0008
No of occupants per home	15.8	2	7.9	300	69	4.3	1.821	0.169
Highest educational level	19.2	2	9.6	673	79	8.5	1.125	0.330
Duration of interview	606	2	303	14839	66	224	1.349	0.267
Income level	216244	2	108122	64621342	65	994174	0.109	0.897

Chapter 4: Results

4.1 Qualitative interviews

4.1.1 Barriers to care experienced by caregivers

During the language interviews, open questions were asked about the barriers to care experienced by caregivers. The spectrum of concerns raised by the parents was used to guide the formation of the quantitative survey. Most respondents cited lack of money as the single greatest obstacle to health care. Other barriers / issues identified as problems included access to transport, caring for other dependants, rude doctors or nurses and long waiting times. Several highly personal issues were raised such as personal illness, needing to return "home" to rural areas and discord with the father of the child. There were no difference between the distribution of responses given by the two groups of parents from allergy clinic and short-stay ward.

4.1.2 Effects of disparate languages on caregivers.

During the interviews to ascertain the meaning of various words, open questions were asked about any language problems experienced by caregivers. The parent was asked how much time the doctor had spent explaining to them about the child's illness, whether they were satisfied with the communication and whether they had experienced any problems. Where caregivers had experienced problems, they were asked about the nature of the problems, perceived causes of the problems, whether that had any effects on them or their child, and what possible solutions they could suggest. Due to the open nature of the questions, a wide variety of answers were given. Although no attempt should be made to compare the responses between the two groups, the following illustrative extracts have been presented from responses given by caregivers of children in the short-stay ward and allergy clinic.

4.1.3 Effects of different languages on caregivers from short stay ward: selected excepts.

(Further excerpts contained in annexure C)

Z M

"Sometimes, English words may mean four different things, I think they mean this but then they mean something else. I'm not that well educated."

T M

"Q: When people don't understand, what effects do you think this can have on the child, when the doctor uses a word you don't understand?

A: When the child is not going to be admitted one can have a problem because one won't know how to treat the child, things like that. It's you the parent that has problems because you don't know what the child wants (needs), you understand. Another thing is when one is with the child in hospital not knowing what he has, whenever people ask what's wrong with the child one doesn't know.

Q: How can we solve this problem, so that the doctor and the mother understand each other?

A: That is going to be a difficult one because in the ward it's the mother, the doctor and the nurse. One who doesn't understand English but understands Afrikaans should be attended by a person who speaks Afrikaans. Here sometimes the nurses don't understand isiXhosa because they are coloured, so one who speaks isiXhosa should be attended by a person who speaks the language."

4.1.4 Effects of different languages on caregivers from allergy clinic: selected excerpts.

(Further excerpts contained in annexure C)

Perhaps due to past experiences, parents' expectations of doctors are not very high and they are very forgiving and understanding despite receiving discourteous service.

O L

"Q: Sisi, in your own thinking what made you misunderstand him the first time he gave you the pumps?

A: The way he explained to me, made me misunderstand him.

Q: In which particular way did he explain?

A: He used medical terms.

Q: Oh, medical terms. But you didn't ask him to explain fully.

A: I didn't ask and I felt so stupid. It created a problem, because, I think that when the doctor gives you instructions he expects you to apply them. But, when he checks up the child and discovers that you did not apply them as he instructed then he gets angry, he's also human. So we should follow instructions.

Q: Do you think that it affected the child since you did not use the medication according to the doctor's instructions?

A: Yes. I think there's need to have interpreters for people who didn't go to school, do you understand? One (a parent) will keep quiet as if she has understood because she would be afraid of the doctor shouting at her because other doctors are impatient. On the other hand doctors will think that the parent has understood or see many patients to attend to and get stressed out. Some other people are just afraid of the doctors and they will not ask, so we need interpreters.

Q: Sisi, how can we resolve a problem of a person who is in the same situation like yours, you understand and speak English well but you do not understand medical terms, how do we resolve that one when you don't really need interpreters? How do you think this person's problem could be resolved? What could be done when a doctor uses medical terms you don't understand?

A: I think there should be a demonstration; somebody should do demonstrations so that if the person doesn't understand English, then a person can learn from seeing how that is done by just observing a demonstration. When the doctor explains about puffs....

Q: When you arrived this morning did the doctor explain to you, how to use the pumps?

A: He said to me, "do you see that this child's isifuba is still tight, that means you did not use the pump the way I instructed you." He told me that I should give the child puffs in the morning and in the evening. He then gave me two pumps, one is the reliever and the other is the preventer. He told me to use the reliever when the nose is blocked and the preventer is used when the isifuba is tight so that it could be opened and be able to breathe normally.

Q: Are you now satisfied about how the doctor explained?

A: Very much."

Despite being satisfied and accepting the treatment fully, this caregiver had not received the correct information to adhere to her child's prescription correctly. The preventer pump is being used on an as-required basis, rather than regularly, and the reliever pump is being used for an incorrect indication completely.

C D

"Q: Are there times you don't understand certain words he uses?

A: There are.

Q: What do you then do.

A: I don't say anything because when I ask what the word means, he often is not able to explain, you understand.

Q: What do you think that can do to the child?

A: It can make him not to heal properly because, I didn't understand how the doctor said I should give his medicine or what he says is wrong with the child."

P M

"Q: How long does the doctor take to explain about Lubabalo's illness?

A: He takes what is enough for him; I become patient and wait, thinking maybe I'll understand even though I don't know English very well. One agrees even when one doesn't understand. Although I try to ask when I don't understand it's tough because I'm not educated.

Q: The fact that you don't understand English, what do you think that can do to the child? What damage can it cause?

A: The child won't heal properly because one didn't understand what the doctor said one should do to the child. For example, I came here and was given a pump and got to believe that it's used when **isifuba** is serious. I didn't know that there's one he should use every day, when I told the nurse she said I was wrong, I should use it all the time.

Q: Do you understand how you should use it?

A: Yes, she demonstrated very well. She told me to wait for ten minutes I had thought for six minutes.

Q: How do you think we can solve this problem?

A: It seems to me, I don't know because people's ideas are not the same...in white hospitals there are few Black people (staff), we are many Black people (patients) here. We can solve it by having someone to interpret."

On the following visit, this mother had been giving her child 10 puffs of medication through the spacer twice a day (2000 ug of budesonide twice a day). This was probably because of confusion caused by the educator getting the mother to count to 10 as a measure of how long to keep the spacer and mask on the face after administering each puff. Because of language difficulties, the mother had interpreted this demonstration as meaning she should give the child 1 puff of medication 10 times, resulting in a dose capable of causing serious side-effects.

N M

This dialogue is slightly disconcerting. It demonstrates the mother's distress, confusion and feelings of powerlessness.

"Q: How long did the doctor take to explain to you about your child's illness?

A: I don't know how to measure it because he explains and demonstrates to me. There are things he showed me. One was purple; I don't know how the other one was. He shows me how it looks like when **isifuba** is very serious and when it is right.

Q: Do you often have a problem with the language?

A: No, let me say there is something that disturbs me; often I'm not right, I often don't understand what's being said.

Q: What effects can that have on the child, the fact that you don't understand each other?

A: Sometimes he asks about things that are used for her to breathe, they ask which one she uses. According to me it's not supposed to have been given to her already but again I understand (differently) though according to the doctor…

Q: So do you have that belief that the doctor is always right?

A: Yes mama.

Q: Don't you sometimes have doubts?

A: I don't, I really believe.

Q: How can this problem be solved, the fact that mom doesn't understand the doctor very well?

A: How do I know, my child?

Q: Don't you sometimes think you would understand if things were different?

A: I don't know, please advise me."

4.1.5 Summary of effects of disparate languages on parents.

Parents from both short-stay ward and allergy clinic agree with those interviewed for the access barriers questionnaire that socio-economic difficulties are followed by language difficulties as barriers to health care for Xhosa-speaking parents. They were dissatisfied with the lack of communication between themselves and their doctors, tending to blame their own linguistic limitation rather than those of the doctors. Parents experienced difficulties in understanding English, especially medical terminology. Parents also found it difficult to ask questions or to respond to doctors questions.

Parents also reported that poor communication had negative effects on them and their children. The answers to the open questions revealed examples of these issues, e.g. the incorrect use of asthma medication including inadequate treatment and over-treatment. Parents expressed a desire to have interpreters present at all interviews and a need for doctors to speak Xhosa to improve communication.

4.1.6 Effects of different languages on doctors: selected excerpts.

(Further excerpts contained in annexure C)

The language interviews included open questions about any language problems experienced by the doctors. The doctor was asked what proportion of time they spoke Xhosa to the parents who could not speak English, whether they were satisfied with the communication and if they had experienced any problems. Where doctors had experienced problems, they were asked what those problems were, what the perceived causes of the problems were, whether that had any effects on them or the caregiver and their child, and what possible solutions they could suggest. A wide range of answers were received to these open questions.

The majority of doctors stated that their ability to communicate in Xhosa was limited and aimed mainly to ask questions requiring "yes" or "no" answers. Understanding parents' responses in Xhosa was usually beyond their capabilities.

Dr J.N

This doctor is very aware of the difference between rapidly obtaining a history in an acute situation and counselling a patient fully about an illness. He finds that outside of the emergency situation, an interpreter is necessary for any quality of communication. He has an acute awareness of the barriers facing parents from disadvantaged backgrounds, both in terms of their access to health care and their experience of being in the hospital. He conceives of the power differential between patients and doctors to be central to understanding the nature of the barriers they experience. He states that the non-verbal communication and the manner in which one communicates may be central to achieving the goal of setting the patient at ease, facilitating a better relationship and improved communication.

"A: I think my Xhosa is based around strictly very medically oriented Xhosa based around symptoms and signs using single words and short phrases relating to rapidly obtaining a history from a patient as to the acute problem which I use as a sort of a screen before asking an interpreter to actually explain some of the things, so it sort of gives me a start. Then I use that as a basis to examine somebody and start directing their management.

I am not going to be able to give them much coherent feedback. I can extract some information but I'm not really able to express in Xhosa.

Q: You said one of the reasons for the problem that you have with communication is that the parents are very disempowered, and don't feel that they are able to ask questions of the doctors. Do you feel that that is the major factor?

A: I think it is an important factor - it's a disempowering situation to have a sick child in the hospital. You don't have information, you're constantly scared, you are not sure whether you are in the right place, the people you're not familiar with. In the acute emergency situation I think the sort of medical power relations as well as the language, social and cultural power relations come into it: you're a physician perhaps in a white coat, you're a white male, middle class and your patient is a poor black mother with a child who might feel she can get into trouble.

And by the time I get to see her she might already have come through a barrage of fairly brusque clerks, nurses, hospital admin to get there and then its only now that I get there, so that by then she might not feel in a position of confidence, her child is sick, she might have issues of disclosure, so she comes to it with an experience, perhaps a negative experience of the hospital...in fact, the few Xhosa words I use is actually an attempt to try to slightly ease that power differential.

Q: Do you feel that the service that we provide to our parents does suffer because of the communication problems, and if so, how?

A: Yah, I think it definitely does, although I think some of it is a fault of omission rather than an active failing, and that is that because of these power and language relations oftentimes there isn't the assertiveness on the part of the patient or the doctor to make that communication happen, and allow not just the transfer of information, but the communication to explain enough of what is going on, get feedback, reflect back, counsel, all those aspects of true communication. Those aspects are often overlooked and don't happen for some obvious reasons, and that's sometimes the cause of failed treatment, failed adherence, discontent, and errors – medical errors."

Dr LKR

This doctor is very concerned about the relationship between herself and her patients. She mentions that an understanding of the cultural aspects of a disease may be necessary before we are able to address the patient's concerns and that this may be a barrier between patients and doctors.

"Q: What are the reasons or causes for this problem with communication that we have?

A: Well I think the biggest reason is that we as doctors haven't taken initiative to relate to the people in their first language so that we understand the context that they are coming from. We try to understand as fully as possible but if you haven't immersed yourself into it, you don't actually know what they are worried about and you also have to take into context the cultural aspect of a disease, what their belief of the disease is. I think we could do a lot on our part to make more effort to learn the language, basic skills but then also we need to learn more about the culture.

Q: Are you saying this should be a compulsory part of medical training?

A: If you are going to be practicing in the country, Yes."

Dr LM

This doctor experiences difficulties with communication due to lack of language skills. Additional barriers are time constraints and concerns over the adequacy of translation.

"Q: Are you satisfied with the way that you communicate with your Xhosa speaking parents?

A: Not always, sometimes I really feel limited. You can ask a lot of yes-no questions. Sometimes they think you can speak Xhosa and they go off on a whole long thing and that makes it difficult because sometimes you do catch some of the words. I think if you do speak to them in Xhosa they try to be more approachable. My vocabulary as such is not extensive; it's not big enough...

A: ...instead of the examination and the whole interview taking twenty minutes, well more or less, you now have to get someone to translate and then it takes double, twice that amount of time because obviously you ask the translator a question, the translator ask them a question, they answer. It's a three-way conversation and the person in between can't always give the exact translation of what's been said. So then you don't always get the proper history as well, I think."

Dr LC

This doctor has concerns about her ability with communication due to language deficiencies. She mentions possible drawbacks with using interpreters that they may paraphrase and distort questions, answers and explanations. She also mentions cultural differences between herself and her parents and thinks the solution to address these barriers is to learn more Xhosa language and culture.

"Q: Doctor I would like us to talk about the conversation you have with the patients are you satisfied with the conversation between you and your patients.

A: No.

Q: Why not?

A: Because I don't have a big enough vocabulary so I can't ask everything that I want to and often if you give the impression that you can speak, then you tend to get a lot more back in response and you can't actually understand what's being answered. I can't explain enough as much about things as I would like to. I use an interpreter but I also use pictures and drawings. But the problem with interpreters is, I sometimes think they directly translate and they sometimes say "I" for patients and sometimes you find out that you give a long explanation and they will only say two or three words...

Q: They do paraphrasing ... taking what they think is important. Which may not be?

A: Sometimes that may not be...so that's also not optimal. I mean after long explanations and they say two words and then you wonder if they said everything that you wanted to communicate.

Q: How do you deal with that where your instinct tells you that this might not be what you said?

A: I sometimes go back to explain again and ask the interpreter if they actually said this. I go back and try make sure.

Q: When you are going through this period of having a communication breakdown between yourself, the patient and an interpreter; what effect does it have on a child?

A: I think, perhaps children don't generally look after themselves, so the care that they get is from the person who brings them to hospital, so if they don't have a proper understanding of the disease and the implications it has for the child then the care of the child might be compromised. If they don't fully know what to do at times of emergency, or what the dangers are, the health of the child is highly compromised.

Q: Have you come across a case like that before where the health of the child has been compromised through misunderstanding?

A: I don't know about this, because the other thing is that its much more complicated than that. Its all very well to explain in the Western setting hospital what's best for the child because the person you are telling it to has got other beliefs about what other things are better for the child, and that can also influence it. I had a case of a child with severe, severe asthma, who came in in status, you know, almost dying. She was brought in by her father who was Rastafarian and he'd been in numerous times and had things explained over and over again yet he'd not been giving any medication because he believed herbal remedies were better. So, I think it's not only the language but also the concepts you believe. The one way of doing it is for all doctors to learn to speak Xhosa better if that's what your patients are and another thing that would be important to know more about the Xhosa culture and social things and explain what the different concepts of disease are and try to incorporate that in our understanding because if we have our understanding things may not be the same as the way they understand it."

Dr PR

This doctor has some important insights into the necessity of communication being a repetitive two-way interchange of information. Constant checking of the quality of the exchange is necessary for good communication. He has some fairly radical views on the problems and their solutions.

"Q: You wouldn't regard yourself as someone proficient in Xhosa?

A: No, I'm not...like when I call out patients' names in the waiting room the mothers often don't know what I'm saying. We put different emphasis on different syllables.

Most often I use a couple of individual words when I'm taking a history rather than when I'm giving a diagnosis. In the case of taking a history the information is kind of gleaned and I can interpret the information along with what I see in the child, but if I'm giving information out it's a completely different thing. I can't be sure, given that I'm talking about things to do with the sickness or maybe medical terms or so on, I can't be sure what the mother takes in, and I'm aware that when you work through an interpreter one isn't actually sure that what you're telling the interpreter is what the interpreter is telling the mother.

I think that it has to do probably with the precision of the words that one uses. I mean the translation from the English to the Xhosa. I think even if I would learn to speak Xhosa, my Xhosa would not be as rich as the person to whom I'm talking. And, when I'm using words I would only have a choice between very few words and so I could easily choose the wrong words. I think second language speakers, speaking to first language speaker will always have that sort of problem and so I don't see it as necessarily as a problem sitting with an interpreter. I see it as a problem that I'm not in fact a Xhosa. I've got a registrar at the moment who is a Xhosa, now I'm sure that when he speaks to another Xhosa the message gets through because he can pick up from the questions she asks whether the interpretation is correct or not. I mean that's what I do when I speak English to someone who speaks English. I say something and then I listen to what they say back then it's quite clear to me from what they say back if they've understood what I've meant them to understand or not. I don't think communication is an easy thing at all. If you've got two first language speakers its already difficult, if any one of you is a second language speaker then you've really got problems.

Q: Okay. Basically you are saying some of the communication problems that the doctors experience when speaking with Xhosa speaking patients could be solved by introducing or exposing doctors as early as possible to the Xhosa language?

A: Well if you can do it at the age of three or four years before they've even thought about doing medicine yes I think that would help. I've heard many medical students complain about how difficult they found it and I haven't seen many medical students actually using Xhosa much. The solution is to only train Xhosa speaking people to be doctors then we wouldn't have that problem at all.

Q: What about the current doctors, who cannot speak Xhosa, what could be done in that case?

A: Not much except wait for them to die."

Dr Le M

This doctor is somewhat older than the others. He feels that communication issues are subsidiary to the patient getting the correct treatment. His solution is a simple vocabulary booklet which he could refer to to ask questions of his patient. His focus is almost entirely on using Xhosa as a tool to get an adequate history in order to make the correct diagnosis. Counselling the patient was not mentioned.

"Q: On a scale of 1 – 10 where would you place yourself in Xhosa?

A: 1 if that! I know a few words. I think in the future, one should be able to speak more Xhosa, and I think perhaps it would be a good idea. You know an older person has difficulty picking up a language; it's easier for a young person, so I think Xhosa should be taught till matric or Std 8. For those of us who haven't been taught at school there should be a thin booklet at all our clinics, in all our hospitals, with basic questions that we ask patients and the basic information we can give them. Not a thick book, it can be up to 10 pages for most patients.

Q: Are there any problems in communication in your Xhosa speaking parents.

A: The problem is either they understand or they don't understand. I may have great problems in communicating but on the whole not.

Q: Why not?

A: When it's something outside the common illnesses - like to explain a temper tantrum or a breath holding attack instead of a fit. It's too complicated. Is the child having a fit or isn't the child having a fit. Then I would have to call in an assistant to take a good history. I sometimes even have Xhosa speaking doctors who refer someone in here with what they say is a fit and I decide it's not a fit. You've got to take an accurate detailed history, and you need someone who can speak Xhosa well.

Q: How do we avoid communication problems?

A: Improve my knowledge of Xhosa and to have gone to school to learn Xhosa. We need a thin booklet for all medical doctors."

4.1.7 Summary of doctors' concerns

The majority of doctors were aware of the difficulties patients face with access to health care. These included structural, social, cultural and language barriers faced by parents once they accessed the medical system. Most doctors agreed that language barriers are a significant problem, affecting their ability to elicit a reliable history, explain the nature of their patients' illnesses, and counsel them if necessary. They believed that poor communication could adversely affect the quality of the care they provide, which in turn could impact negatively on the patient.

All doctors were concerned about their inability to communicate effectively with parents. They acknowledged their limited Xhosa language skills, and often confined themselves to greeting in Xhosa and asking basic questions to elicit yes/no answers. They seldom used interpreters for history taking, regarding the use of interpreters to be more necessary during counselling of the parent.. They believe adequate communication for history taking may be within their reach with further training in Xhosa language skills. One doctor suggested a vocabulary and phrase book would help achieve this goal.

Most doctors utilized interpreters when more in-depth history or parental counselling was required. Doctors raised concerns about the efficacy of interpreters in certain cases. They were concerned about inaccurate histories and the loss of control over the interview process. They tended to portion blame on the interpreter for these problems, rather than conceptualising it in terms of a problem in communication between the triad of patient, intermediary and doctor. Only few doctors utilized recognised strategies to improve communication via an interpreter such as reflection and rephrasing, (such strategies do form part of many doctors first-language communication). A minority of doctors also believed, somewhat naively, that improving their ability to speak Xhosa and knowledge of Xhosa culture would enable them to communicate in all settings obviating the need for interpreters.

4.2 Access barrier questionnaires

4.2.1 Barriers to health care

Parents were asked about barriers to health care using open ended questions and selection from lists. They were asked to enumerate the single most important obstacle and to define the three most important obstacles. They also were asked yes / no questions regarding specific barriers that may have prevented them from bringing their children for medical care. This use of multiple methodologies (triangulation) is used to elicit a rich picture of the range of problems experienced. The following data in the text (and presented in tables) reflects the number (and percentage) of respondents who cited firstly the single most important problem and the three most important problems, using two methodologies i.e. open questions, and selecting from lists.

When asked (on open questioning) to define the single biggest obstacle to good health care for their children, 42 (86 %) of respondents cited financial problems, 5 (10 %) cited transport problems and only one patient cited language difficulty (2%). The full range of responses is listed in table 7.

When asked (on open questioning) to list the three biggest everyday obstacles to good health care, 64 % of answers received were "lack of money." Transport difficulties reflect 15 % of responses and other social and structural difficulties reflect 17 % of responses. Language factors still only reflect 4 % of responses. The factors listed impeding good health care are displayed in table 8.

When asked to select (from a pre-formed list) the single or three greatest obstacles to getting medical care for their child, the responses covered a wider range of answers. With this methodology, financial problems are reflected in a far lower proportion of caregivers responses. Fourteen parents (28 %) selected financial issues as the single greatest obstacle to health care and financial issues were selected as 27 % of responses to being one of the three greatest obstacles to health care. With this methodology, language issues were selected about half as frequently as financial issues as obstacles to access to health care. This is then followed by social and cultural issues. When taken together, language, social and cultural issues were selected as frequently as socio-economic and transport issues as being barriers to access for quality care. (25 and 19 of single greatest obstacles respectively; 44 and 47 of three greatest obstacles respectively) These data are shown in tables 9 and 10.

32 (65 %) caregivers said there had been a specific occasion when they had not bought their child in to seek medical attention because there had been a factor that had prevented them from doing so, the most common reasons (selected from a pre-formed list) were overwhelmingly related to socio-economic difficulties and are listed in table 11.

Table 7: Problems cited in responses to the open question: "What is the single biggest obstacle you have faced in getting medical care for your child?"	Number	Percent
Lack of money	42	84
Problems with transport	5	10
Inability to speak English	1	2
Difficulty getting time off work	1	2

Table 8: Problems cited as a responses to open question: "List three normal day to day problems you have faced in getting medical care for your child."	Number	Percent
Money	34	68
Transport	8	16
Waiting time	3	6
Referral system	2	4
Poor English skills	1	2
Inability to get off from work	1	2
Caring for other dependants	1	2
Lack of access to a telephone	1	2
Not being told the diagnosis	1	2
Personal illness	1	2

Table 9: Problems selected from a list reflecting "the single greatest obstacle you have ever faced in getting medical care for your child"	Number	Percent
Difficulty paying medical bills	14	28
Doctors and staff who don't speak Xhosa	8	16
Rude or discourteous doctors or nurses	6	12
Difficulty understanding explanations of the child's illness	6	12
Long waiting time for the doctor	6	12
Lack of interpreters	5	10
Difficulty arranging transportation	3	6
Difficulty taking time off work	1	2
Inconvenient doctor's working hours	1	2

Table 10: Problems selected from a list reflecting "the three greatest obstacles you have ever faced in getting medical care for your child"	Number	Percent
Difficulty paying medical bills	29	58
Doctors and staff who don't speak Xhosa	16	32
Rude or discourteous doctors or nurses	14	28
Difficulty arranging transportation	14	28
Difficulty understanding explanations of the child's illness	11	22
Long waiting time for the doctor	9	18
Difficulty taking time off work	4	8
Inconvenient doctor's working hours	4	8
Difficulty making an appointment	4	8
Doctors and staff who don't understand your culture and background	3	6

Table 11: Number (and percent) of parents who answered affirmative to yes / no questions regarding specific factors that had prevented them bringing their child for a consultation.	Number	Percent
I didn't think I could afford it	19	38
Lack of transportation	16	32
Hospital being too far	8	16
Long waiting times to see the doctor	7	14
I Work and the hours are inconvenient	7	14
Difficulty getting an appointment	7	14
I felt doctors and staff would not understand my culture and background	2	4
Doctors and other staff do not speak Xhosa	1	2

4.2.2 Communication

Caregivers claimed that doctors spent an average of 16 minutes explaining their child's illness to them. (Median and mode 10 minutes). Four caregivers claimed doctors had spent no time explaining to them, and 4 that doctors had spoken to them for an hour.

Of the last discussions with a doctor, 45 (92 %) had been in English, 2 (4 %) in Xhosa, 1 (2 %) in English and Xhosa and 1 (2 %) in Afrikaans. Of the discussions not in the caregiver's home-language, 10 (21 %) had interpreters present; the remaining 19 (79 %) did not. Thus 94 % of interviews were conducted in a language unfamiliar to the patient.

Where an interpreter was present, caregivers identified 9 (90 %) as nurses and 1 (10 %) as strangers. No caregiver identified an interpreter as a professional interpreter. It is important to note, however, that this reflects the patients perception, and the true proportions of nurses, lay-people or interpreters that was used for interpretation is unknown. When interpreters were present, 6 (60 %) of caregivers were satisfied with the performance of the interpreter, 4 (40 %) were not.

Only 15 (31 %) of caregivers said they were satisfied with the amount and nature of the communication with the doctor. Thirty four (69 %) were dissatisfied or had experienced problems. The most common cited problem (64 %) was failure to understand English, especially specific words or medical terminology. 26 (53 %) of caregivers said that in the previous discussion with the doctor there had been occasions when the doctor had said something to them but they had not understood. 15 (31 %) stated that the doctor had failed to understand what they had said in Xhosa. 19 (39 %) stated that they had wanted to ask a question but had been to too anxious or afraid to ask.

Figure 19: Duration of doctors' interviews

with respondents completing "access barrier questionnaires"

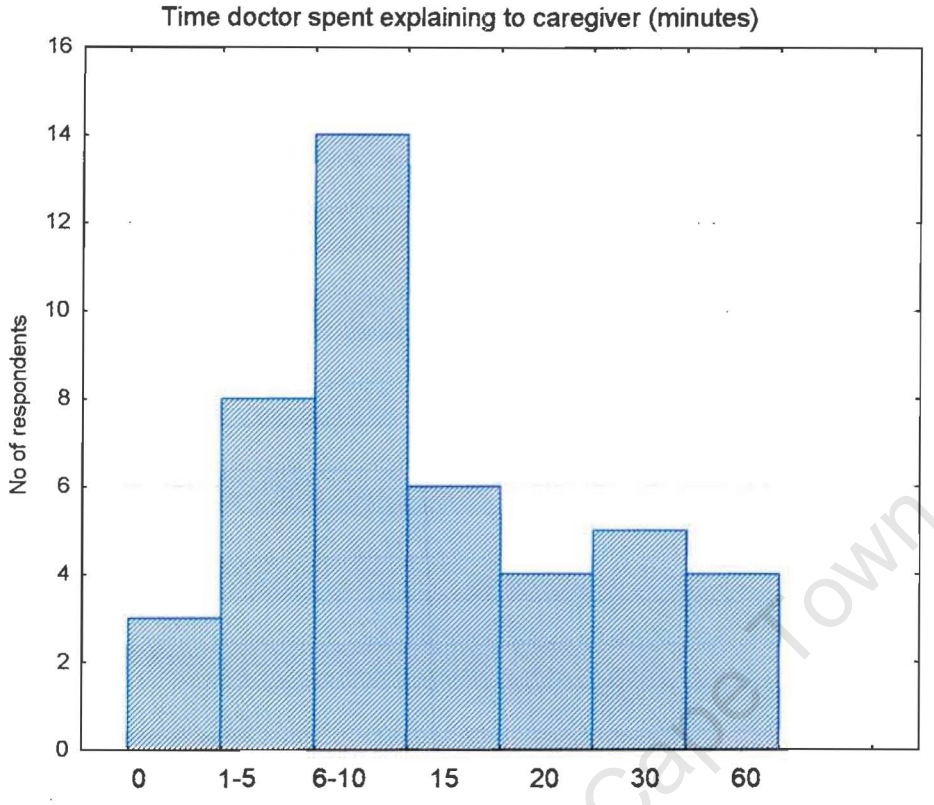
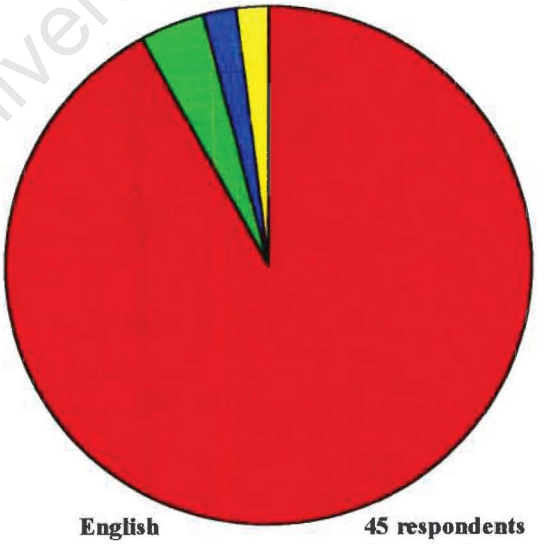
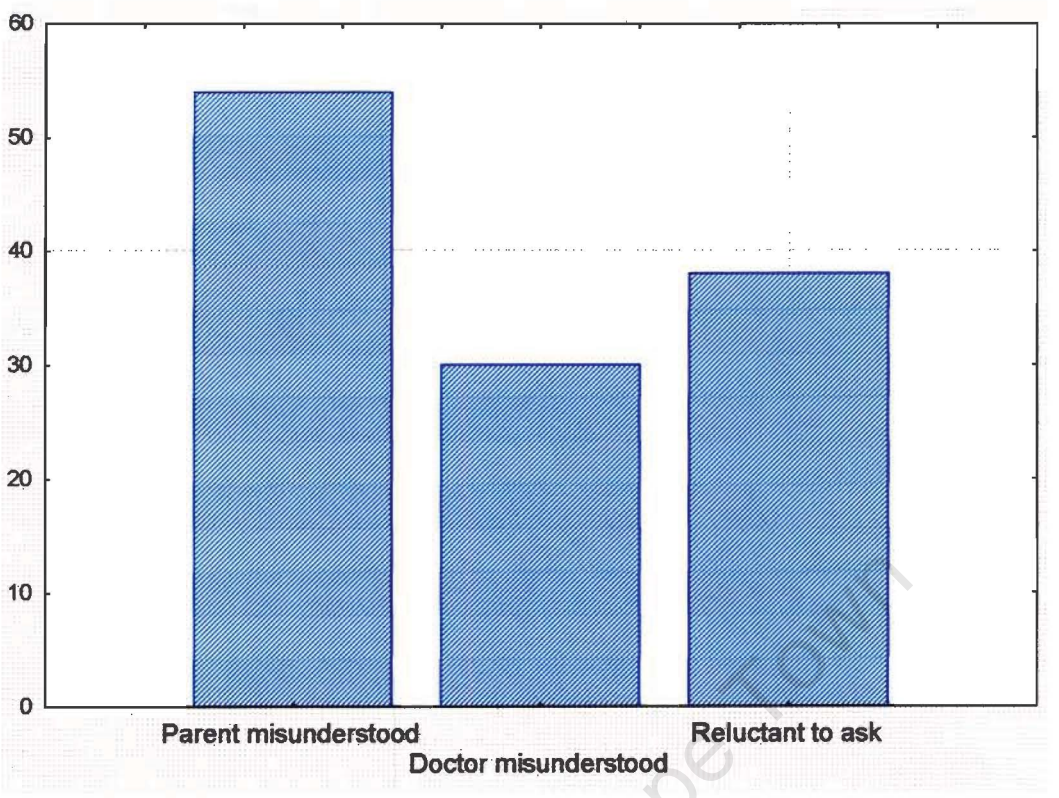


Figure 20: Language distribution of previous doctor's interview with caregiver.



Red:	**English**	**45 respondents**
Green:	**Xhosa**	**2 respondents**
Blue:	**English + Xhosa**	**1 respondent**
Yellow:	**Afrikaans**	**1 respondent**

Figure 23: Patterns of communication problems



4.2.3 Consequences of poor communication.

22 (45 %) of caregivers were concerned about the possible negative effect of poor communication on them or their children. 14 parents (28 %) believed poor communication could have a direct effect on their child's health. 6 (12 %) parents believed poor communication could adversely affect their understanding of the disease and the medication use. Negative consequences of poor communication (on open questioning) cited by the caregivers are listed below in table 12.

On open questioning, 11 (22 %) caregivers said there had been a specific adverse effect on their child from doctors or other staff not speaking Xhosa. These comprised direct adverse effects on their children's health. Most commonly cited adverse effects are displayed in table 13.

4.2.4 Solutions for breakdown in communication

When asked what parents do when they feel that there is a breakdown in communication a number of answers were volunteered. The most common response was a request for an interpreter (39 % of responses), however 7 (21 %) of parents responding to this question said they would simply keep quiet and follow instructions. The full range of responses is listed in table 14 .

32 (65 %) of caregivers said the solution to communication problems was that interpreters should be present or made available for every consultation. 7 (14 %) of caregivers said that the solution was for doctors to speak Xhosa. When asked directly whether doctors should learn Xhosa as part of their medical training, 47 (96 %) of caregivers answered in the affirmative.

Table 12 Number (and percentage) of problems cited by respondents as possible negative consequences of poor communication (on open questioning)	Number	Percent
Poor health care	6	12
The child not getting better or getting worse	6	12
Being unable to understand what the treatment is or how to use medication	4	8
Being given the wrong treatment	2	4
Not being able to understand the cause of the illness	2	4
The doctor getting the wrong history	1	2
Getting cross	1	2
The child getting anxious	1	2

Table 13 Number (and percentage) of specific negative outcomes experienced by respondents as consequences of poor communication (on open questioning)	Number	Percent
Incorrect or inappropriate medicines were given	4	8
The child was misdiagnosed	3	6
I did not understand the doctors explanations and gave the wrong medicines	2	4
The child received poor medical care	2	4

Table 14 Spectrum of caregivers' responses to what they do when experiencing communication problems (on open questioning)	Number	Percent
Ask for interpreter	13	26
Ask doctor	8	16
Nothing / keep quiet / get cross	6	12
Ask nurses	5	10
Concentrate on the instructions	1	2

Chapter 5: Discussion

5.1 Barriers to care for patients

5.1.1 Effects of socioeconomic issues on caregivers

Xhosa speaking parents often experienced problems to access health care. Socioeconomic factors, location of health facilities and language (and culture) differences were the major reasons for this. Most interviews were conducted in a language in which the patient was not proficient without an interpreter. Parents were dissatisfied at the lack of communication between them and the attending doctor. Certain parents were too apprehensive to ask questions. Parents expressed concern about the possible negative impact of poor communication on the health of their children. Specific examples were revealed in the qualitative interviews of adverse effects on children resulting from poor communication.

The barriers to health care access in this study differ somewhat from those reported by Flores et al[13] among Hispanic parents in the U.S.A. In my study socio-economic issues are cited more frequently than language and cultural issues as barriers to access care, which is more marked when caregivers are asked open questions than when they select from lists. In Flores' study, caregivers claimed that language problems were the biggest obstacle preventing them from accessing good medical care (26%), followed by financial issues (20 %) and long waiting times at the doctor's office (15%). However, in Flores' study, when parents experienced a barrier severe enough to cause them to decide not to bring a child in for medical care, financial issues were cited by 34 %, transportation by 21 %, excessive waiting time by 17 % and lack of cultural understanding by staff by 11 %. Other studies have also shown the overriding effects of economic factors, such as lack of health insurance or inadequate income on lowering utilisation rates for physician and preventative services by children of minority groups in the USA. Non-financial barriers relate to physician supply (especially availability of language and culturally compatible doctors), transportation difficulties and lack of child care facilities. [10] [14]

Although they may be less well off than their English speaking counterparts in the U.S.A, the material barriers to health care suffered by the Hispanic population Flores studied are less severe than those experienced by the Xhosa speaking population I studied. The financial and structural barriers faced by the population I studied are far greater than those experienced by the Hispanic population, and this may account for the greater emphasis placed on these problems by my study group. The socio-demographic characteristics of the respondents reveal that many are living in peri-urban townships, some in squatter camps, with a high proportion of unemployment, single mothers and low total monthly family incomes. Money was cited by almost all respondents on open questioning (82 %) and ranked on closed

questioning as the single greatest obstacle to health care. Access to transport – either through lack of available transport or perhaps due to the cost of having to pay for "taxis" – is a second major concern raised by parents during open questioning. When caregivers were asked to recall specific times when they did not bring their child in for medical care, again structural and economic issues were foremost with linguistic and cultural issues hardly featuring at all.

5.1.2 Effects of different languages on caregivers

In addition to the structural and financial barriers to health care, differences in language and culture are also seen as major issues of concern. When asked to select the single greatest obstacle to health care from a pre-formed list, money issues remains the primary concern, with lack of transport being less prominent (7^{th} place!) Issues of language and communication (25 respondents) collectively overshadowed the concern with money (19 respondents). When asked to select the three greatest obstacles to health care from a pre-formed list, socio-economic issues are ranked 1^{st} and 4^{th} most frequently, with issues of language and communication ranked 2^{nd} and 3^{rd} most frequently.

This may stem from a central finding of my research, showing that 94 % of interviews were conducted in English or Afrikaans, and in only 21 % of these interviews was an interpreter present. There is thus both a lack of formal interpreters as well as underutilisation of these interpreters within the hospital.

69 % of caregivers were dissatisfied or had experienced problems, with understanding the doctor or the doctor not understanding them. Significantly, in the context of power between doctors and patients, over $1/3^{rd}$ had been too anxious or afraid to ask questions. Parents listed a number of concerns with the effects of poor communication. 22 % of parents polled in this study were able to cite specific examples where they believed poor communication had adversely affected the health of their children. This is very similar to the 20 % of parents who believed poor communication affected their children's health in the study by Flores et al[13]. In addition the parents' concerns about poor medical care, misdiagnosis and incorrect medication use are very similar in the two studies. Parent's perceptions of adverse effects of poor communication in the two studies are compared in table 15.

Concerns raised by caregivers over the effects of poor communication included difficulties with counselling them about their children's illness, continued appropriate care at home and compliance with medication. Concerns were raised about possible misdiagnosis, inappropriate medications, inadequate involvement of the patient and provision of information, reduced compliance and follow up, reduced patient satisfaction and reduced patient understanding of diagnoses and medication.

Table 15: Adverse effects of communication: Comparison of two studies.		
Adverse affect	This study	Flores
Incorrect or inappropriate medicines were given	8 %	5 %
The child was misdiagnosed	6 %	6 %
I did not understand the doctors explanations and gave the wrong medicines	4 %	0
The child received poor medical care	4 %	8 %
Inappropriate hospitalisation	0	1 %
Any adverse affect	22 %	20 %

5.1.3 Caregivers' expectations and assertiveness.

The propensity to complain about linguistic and socio-cultural issues may be dependant upon the expectations one has for these needs being met – which depends upon one's politicisation as well as past experiences of the medical system and other components of general society. When Xhosa-speaking respondents were asked about their reactions to lack of communication with doctors, 21 % said they do nothing (keep quiet), get cross or simply obey instructions. This probably reflects the extent of the disempowerment and frustration felt by patients due to the inequities between them and their doctors. These inequities based on knowledge, race, status and language are the legacy of the apartheid era. These inequities are probably responsible for the attitudes of patients to their doctors as well as doctors to their patients.

In addition, lack of power and assertiveness may account for the differences that the method of questioning seems to have on the types of responses given. With open questioning, respondents must volunteer a specific problem that has preventing them from accessing quality health care. It could be construed by the respondent as being "rude" to complain about service within the hospital and difficulties in communication with the doctor. It may be more polite or require less assertiveness to "complain" of socio-economic obstacles. When asked to select from lists, however, the option of selecting a language, cultural or service related problem is presented. With this methodology respondents may feel it is "allowed" for them to respond with these concerns. Although this may have been minimised by the use of Black African researchers speaking Xhosa, it is possible that the effects of cultural and language differences on doctor-patient relationships and researcher-patient relationships may be profound (as discussed below).

5.2 Differences between doctors and parents.

5.2.1 Culture

Culture refers to learned, accumulated experience of humans, and a group's culture refers to those socially transmitted patterns of behaviour characteristic of that particular social group[65]. Culture refers to what people do, as well as to what they think. "A culture" is always a composite of individuals, an abstraction that is an analytical simplification of the behaviour and ideas of a group. This abstraction cannot take on concreteness and serve as an entity or a causal agent. Culture does not "adapt to a harsh environment" or "cause people to go on vision quests" or "value individuality" or any other characteristic. Despite this, cultural codes do govern our everyday behaviour.

Culture often describes the role relations between people, terms of address and systems of respect. In this way, persons with different culture may interact in different ways, within their group, and between the groups.

5.2.2 Styles of reasoning.

In the descriptions of problems, Xhosa parents were more inclined to give examples, use long stories and to repeat themselves. Some of this may have to do with the foreign concept of an "interview" versus a "discussion" or "conversation", but power differential and lower proficiency in English were not causes as these interviews were conducted in Xhosa by Xhosa interviewers. This may, however, be related to the educational level of any person, rather than simply confined to Xhosa speakers.

5.2.3 Power

Another consideration that must be borne in mind when analysing parents' descriptions of their satisfaction or problems with the hospital, is the propensity of Xhosa speakers not to complain about the services that they are receiving. A number of parents indicated that "the doctor is always right" and that "the doctors are here to help us". These parents were very reluctant to blame the doctors or the hospital for problems they were experiencing, and many parents took the blame on to themselves by saying "it is because I am not educated that I cannot understand." I believe these answers expose the extent of the inequality of power relations between doctors and patients. The factors that underpin these relations are differences in race, age, gender and knowledge, as well as situated factors such as unfamiliarity with the environment, and the vulnerability that stems from their child's illness or trauma. Doctors are located at the top of a health services hierarchy encompassing doctors, nurses and patients[30]. Crawford constructed the language difficulties between patients and doctors in terms of this power differential. She wrote that:

"doctors are the "eye" that probes the patient's body; they ask closed ended questions in relation to a body of knowledge largely inaccessible to the patient, and they are the undisputed possessors of the master narrative in the biomedical discourse. The patients are positioned at the bottom, largely passive bodies whose own version or narrative of their illness is not considered central to the process of diagnosis and formulation of a realistic treatment strategy. The nurses ... where a wide gulf of social class, race, language and gender frequently separates doctor from patient, occupy a conflicted and ambivalent position intersecting the space between them."

5.2.4 Language differences

There are many aspects to differences between languages. Mostly due to the phonological differences[66] between Xhosa and English, Xhosa is not the easiest of languages to master. Despite this, one need not speak it perfectly to be understood, and the study of Xhosa is a fascinating and rewarding enterprise, with the potential to greatly enhance relationships between English and Xhosa speakers.

5.2.4.1 Phonology

5.2.4.1 (a) Different individual sounds

There is a finite set of meaningful sounds which appear in human languages. Not all of these sounds appear in any given language, i.e., each language has its own finite subset of meaningful sounds. For example, clicks have no meaning in English, but they are part of Xhosa. Clicks are derived from the Khoisan family of languages which has a series of clicks. A few languages that came into extensive contact with the Khoisan have adopted some: Zulu has the most (about a dozen), Xhosa has nine, Sotho only one.

5.2.4.1 (b) Combinations of sounds

Only certain clusters of consonants are permissible in a language, and this varies between languages. This can cause considerable difficulties with pronunciation of non-native languages. For example, Chinese speakers may mispronounce p-r combinations even though both sounds are common individually in the language. An example in Xhosa is the difficulty English speakers have in pronouncing the cluster of t and y as in the word "utywala" (alcohol).

5.2.4.1 (c) Aspiration

Compare, for example, the [p] in *pill* of that of *spill*. You should be able to detect a short burst or puff of air after the [p] in *pill* that is absent in *spill*. That puff of air is called aspiration. Despite the phonetic difference in aspiration, speakers of English usually consider the [p] in *pill* and *spill* to be the "same" sound. This is because the difference between the aspirated sound and the unaspirated sound never conveys meaning in English.

English is like Xhosa, in that both English and Xhosa speakers produce aspirated and unaspirated stops. But in Xhosa, aspiration can be used to signal meaning contrast.

Xhosa	English
Tata (aspirated):	take
Tata (not aspirated):	father

5.2.4.1 (d) Tone

Tone assumes various levels of importance in different languages. In most languages, intonation is critical in distinguishing sentence types, mood or questioning. In some languages, it may differentiate singular and plural forms or serve grammatical functions. In others, including Xhosa, it has a lexical function, where words have different meanings depending on tone. Examples where tonal differences may impact on medical workers include the tonal differences in "ulusu" meaning either "skin" or "tripe", and "ithanga" meaning either "thigh" or "pumpkin".

5.2.4.2 Structure

The structure of the Xhosa language is very different from that of English. Probably the most important and obvious difference is the process whereby multiple words can be created from a root by the insertion of a prefix, suffix or infix. Xhosa "laces" words together, whereas English has separate words, e.g.:

*Ndi*ngugqirha Smith	2 words	*U*ndincedile	1 word
I am Dr Smith	4 words	*You* me have helped	4 words

This lacing together is not only limited to adding different words together to create added meaning. Different word forms differentiate tense, gender and number of a single root word. In addition, different word forms may change a word from its noun to verb form and imply aspects such as causation.

Verb forms with added meaning.

A further characteristic of Xhosa is the extended semantics of the verb system, by the insertion of prefixes, suffixes or infixes. Verbs with a causative ending [isa] reflect an outside force doing something else, for example "ukubona" meaning "to see" and "ukubonisa" meaning "to show" i.e. "to cause to see". Another familiar example is "ukuncanca" "to suck" (on the breast) and "ukuncancisa" "to breast feed".

5.2.4.3 "Styles" of language.

Other differences between parents and doctors may affect their use of language. Chief among these is age and gender. Age-based variation in language is quite common. Forms such as words or styles of speech used by older persons may be lost or disappear among younger people.[67] Some of this is tied to disappearing technologies, concepts or explanatory models that are not shared by or less prevalent among younger people. Examples within English include the words "antimacassar" and "icebox" and slang terminology such as "pops" or "sonny". Gender differences in English are relatively subtle when compared to Xhosa. In English it is usual for more polite forms to be used by women, for example to use "pee" to refer to urination, rather then the word "piss". In Xhosa, "hlonipha" or "politeness" refers to a stricter form of limitation of women's speech.

Chapter 6: Conclusions and recommendations

6.1 Conclusions

Xhosa-speaking parents experience significant barriers to optimum health care. Socio-economic issues are most important in our setting, but patients also encounter significant difficulties in communication with doctors. A lack of same-language medical practitioners and interpreters leads to the majority of interviews being conducted in a language the patient cannot fully understand. Patients are dissatisfied with the lack of communication between themselves and doctors and have difficulty understanding doctors. Doctors are also concerned about the difficulties in communication between them and their patients. Doctors need to be trained in communication and effective use of interpreters.

6.2 Recommendations for the training of doctors

Strategies to increase doctors' awareness of African languages and culture include recruiting more Black African doctors, training doctors in language skills during their training, and training qualified doctors in communication theory, language skills and the effective use of translators.

In South Africa, the demographics of the intake of doctors into medical school has changed, reflecting a desire to recruit more Black African doctors. In addition, many medical schools are making the learning of an African language as part of their medical training. The University of Cape Town's medical school places great emphasis on these issues.

Among the goals of UCT medical school's new focus on outcomes based education includes changing the emphasis of medical education from a doctor centred, disease oriented approach to a patient centred, holistic approach. Active and contextual learning is favoured over the passive transfer of information, and the setting has been changed from one focussing almost exclusively on tertiary hospital services to including primary care and community settings. Among the planned changes to course content is the reduction of the medical curriculum to a five-year program at certain medical schools (UCT still prefers a 6 year course) with the extra compulsory year of internship added to the current community service year leading to a total of 7 years training. New courses are included in year 1 entitled "becoming a professional" and "becoming a medical professional". Year 2 to 2 ½ introduces students to problem-based learning and the study of normal structure and function as well as pathophysiology. Year 2 ½ to 3 introduces clinical skills such as history taking, confidence building, basic examination techniques and clinical reasoning. Throughout the medical training, learning techniques are employed to bring people together in smaller groups so as to expose them to people of

different cultures, in order that they can explore each other's personal views on health, social welfare and human rights issues.

A specific course on health communication will commence on 13th July 2004 for third year medical students (semester 6) at UCT. An introductory lecture will cover the extent of the problem, and outcomes of tutorials are effective working with an interpreter, increasing cultural awareness in an interview and facilitating effective communication in specific vulnerable populations such as those with different languages, mental handicap, speech disability and deafness.

It is hoped that medical students will benefit from these courses and be better prepared to deal with the difficult communication issues that will face them in their future careers.

For those doctors who have graduated before implementation of the new curriculum, awareness of these issues should be communicated in medical journals. Each institution should be encouraged to recruit more interpreters and train doctors on how to utilise their services optimally. Courses in "indigenous languages" at hospitals may increase the language skills of doctors, encourage greeting, enhance communication for diagnosis and systems review, and expose doctors to cultural issues that may make them more sensitive towards their patients. In intervention studies in the USA, Mazor[20] assessed the effects of teaching Spanish to doctors. His study showed that it decreased the use of interpreters, increased patient satisfaction and did not adversely affects patient outcome. Thus, teaching doctors different languages (at a basic level) may enable more optimal use of interpreters (a limited resource) and increase patient satisfaction. Institutions should consider publishing limited word-lists (with English translations) for doctors with greetings and systemic enquiry, and recommend local texts, such as the excellent book by Kirsch, Skorge and Matsiliza[66] which more fully cover medical communication. A short medical Zulu dictionary is available online at http://www.jwolfe.clara.net/WebPages/ZuluDict.htm. A CD Rom produced by a Capetonian company, African Voices, provides an entertaining and easy way of picking up the basic and intermediate Xhosa language skills. " Speak Xhosa With Us" is available at most bookstores or directly from the company (email: avoice@iafrica.com.)

6.3 Guidelines for communicating effectively.

Communication is not simple. Communicating with patients in one's own language is not easy. Communicating with a patient from another culture and language group can be challenging. Communicating with such a patient through the use of an interpreter can be difficult. The following guidelines may help. (Tables 16 and 17.)

Table 16

6.3.1 General guidelines for doctor-patient interactions.[i]

1. Develop alternatives to taking histories via direct questions. Use a conversational, open ended style.
2. Use related questions, repeat questions with different phrasing.
3. Emphasise through repetition.
4. Invite correction and induce the discussion of alternatives.
5. Pursue seemingly unconnected issues the patient raises. These may lead to crucial information or uncover difficulties with understanding or translation.
6. Come back to an issue if you suspect a problem and get a negative response.
7. Provide instructions in form of a written list.
8. If alternatives exist, spell them out.
9. Ask parents to repeat back or re-explain what you have discussed.

Table 17

6.3.2 Guidelines for monolingual providers in a cross-cultural environment

1. Unless you are thoroughly effective and fluent in the target language, always use an interpreter.
2. Learn basic words and sentences in the target language. Asking interpreters about words or comments that have not been translated prompts attention to detail.
3. Utilize dictionaries of languages used by your patient population. Be aware that brief "definitions" provided by translating dictionaries only serve as labels.
4. Become familiar with special terminology used by patients. Specific beliefs, practices and traditions are often referred to by indirect language or special terms.
5. Check the quality of translated health-related material by having them back-translated.
6. Meet with interpreters on a regular basis.
7. Evaluate the interpreter's style and approach to the patients.
8. Be patient.

[i] All guidelines modified (by re-organising into categories) from Putsch[i68]

6.3.3 Jargon.

Jargon words should be avoided. If a definitive diagnosis is being made and one wishes to explain fully to the parent the biomedical explanation of a specific disease, careful explanation, appropriate for the level at which you wish the parent to understand should be made. The help of interpreters will be essential. Parents should be encouraged to reflect on what has been explained to them, and information repeated a number of times if necessary. Questions should be encouraged. A complete understanding of jargon words will still not be appropriate or possible.

Wherever possible, let parents use their own words, and record them diligently, exactly as the parent uses them. If parents use a word such as asthma or wheeze, clarify what it means to them, and document that as well.

Doctors interested in communication with their patients realise that employing medical jargon is unlikely to lead to effective communication. Doctors, however, are less likely to pay attention to which idiom they use when they speak "in terms understandable to the patient." Expressing concepts in "a more familiar idiom" may yield little useful information or lead to additional misunderstandings. Often such a claim is used as an excuse to provide inadequately detailed simplistic or simply untrue explanations to patients in a way that serves no better to educate or counsel their patients in the cause, effects, treatment or prognosis of their illness. Dictionary "equivalents" of English medical words may not be understood in equivalent terms, and these labels often obscure true communication rather than aid it. Non-African doctors thus need some ideas of the cultural mores of their patient and the explanatory models they use to conceptualise their perceptions of illness. The re-negotiation of the patient's explanatory model for their illness is a critical part of the healing process, and necessitates knowledge of those models likely to be held by one's patients.

6.4 Recommendations for the use of interpreters

Insufficient interpreters are employed by the Red Cross War Memorial Children's Hospital, and the hours in which they are available do not cover the important times at night when severely ill children are admitted. In addition, doctors need to be encouraged to use interpreters more, and need training in the effective use of interpreters. (Table 18). Interpreters are not only translators, but also cultural brokers between parents and doctors. Including (and trusting) the interpreter as a valued member of the team will improve communication providing the doctor is skilled in using an interpreter and the interpreter has sufficient field knowledge in the area being covered. Interpreters' input and comments should be sought. Despite this, the conversation should be seen as primarily being between the doctor and the parent, with the interpreter as a facilitator, not a prime participant. Doctors should be aware of common interpreter errors such as omission, addition, condensation, substitution and role exchange[55]. Errors with names and numbers may commonly occur.

Table 18

6.4.1 Guidelines for the effective use of interpreters.

1. Use all the guidelines above for doctor-patient interaction.
2. Address your patient directly. Avoid directing all your commentary to or through an interpreter.
3. Avoid using family members as interpreters.
4. Be certain the interpreter is thoroughly involved with the patient during an interview
5. Be certain the interpreter knows what you want.
6. Use language and explanations that the patient can understand and the interpreter can handle. Use short questions and comments. Avoid technical terminology and professional jargon.
7. Give time for the interpreter to interpret your words. When lengthy explanations are needed, break them up and have them interpreted piece by piece in straightforward, concrete terms.
8. Make allowance for terms that may not exist in the target language. Do not use terms that could be misinterpreted in the other language without clarifying exactly what you mean.
9. Try to avoid ambiguous statements and questions.
10. Avoid indefinite phrasing using "could", "might", "if" and "maybe". These may be mistaken for actual agreements or firm approval for an idea or course of action.
11. Avoid abstractions, idiom, similes and metaphors.
12. Ask the interpreter to comment on the patient's word content and emotions.

6.5 Recommendations for further research

Further studies are warranted to explore patient barriers to care, communication difficulties, language differences and differences in explanatory models.

A major barrier to health care may be parent illiteracy and discordance between the understandability of patient advice material, questionnaires, consent forms and medication instructions.[38 41 42] Studies looking at parents' degree of literacy and asking them to explain written questionnaires, consent forms, instructions and medication details would reveal where parents have difficulties with these, and guide attempts to improve them. Such studies have been done in other settings and study instruments validated to allow rapid assessment of these problems.[39 40]

In order to establish the nature of communication between doctors and parents, direct observational studies would be required. This approach has been used to reveal inadequacies in communication[24 25 30 31 32 33 49], and such studies offer similar advice on how to further deal with these problems.

A study similar to Mazor[20] et al, who showed the effects of a short course in Spanish on the use of interpreters, patient satisfaction and patient outcome, could be done to assess whether the Xhosa classes currently offered at Red Cross War Memorial Children's hospital actually improve doctor-parent communication and parent satisfaction. Such a study would give impetus to making such courses strongly recommended or even compulsory for all non-Xhosa speaking doctors (and other health workers) within the institution.

Much work has recently been done on medical communication, and some medical schools have incorporated teaching on communication into their curricula. One hopes that this will help those graduates form "that special bond … that only comes through language."[37]

Further data from the interviews looking at patients' and doctors' definitions of medical terminology in English and Xhosa has been analysed and will be submitted toward a doctoral thesis in linguistics at UCT in 2005.

Annexure A:

Questionnaire used as basis for qualitative interviews (Chapter 2.4.1)

Questionnaire for qualitative interviews

Hello , I am .....

We are doing a study to find out, how you and your doctor talk to each other. To do this, we need to ask you some questions. We really want to know what you actually think. We don't want you to tell us what you think we want to hear. This is not a test of how much you know, we want to find out what you think and believe, so that we can address any concerns you may have.

But first we need to ask you a few questions about yourself:

Name

Age

Gender

Place of residence

Place of birth

How long since a rural area

What other languages do you speak

Level of formal schooling

How many times has your child been in hospital for the same problem

How long has a doctor or nurse has spent explaining your child's problem.

Now I want to talk about the conversation you have with your doctors.

Are you satisfied with the conversation between you and the doctor?

If not why?

Are there problems in communication?

What are the problems in communication?

What are the reasons /causes for the problem?

What effect does this have on you/your child?

What are possible solutions

Now I want to find out what you believe about your child's chest problem, and what the words you use mean. There is no right or wrong answer to these questions. We don't want to test how much knowledge you have, we are really interested in finding out what you think about these things. We need you to be as complete as possible with your answers, and tell us everything, if it fits in with what doctors think and even if it doesn't fit in with what doctors think. Remember, we want to know what YOU believe.

What is wrong with your child?
If you had to give this a name, what would it be?
What do you mean when you use this word?

What does this sickness do to your child?
How does it work?
What parts of the body are most affected?
What are the biggest problems the sickness causes for your child?

How serious is it?
How long does it take?
What happens then?

What do you think has caused " X"?
How does one get "x"? .
Why do you think it started when it did?

What kind of people get "x"
Is it the same in different kind of people?
Are there different types of "x"

What can someone with "x" do about it?
What kind of treatment do you think you should receive?
What are the most important results you hope to receive from the treatment?

Now we need to compare the way you use this word to the way you use other words to see if they are the same or if they are different? If they are different we want to know how they are different. You mentioned the word "y"

Does it mean exactly the same thing?
Is it similar to "x"? How does it differ?
Are the any other word referred to or included in the definition?
Are there any other different meanings / senses of the word?

List of terms

Chest diseases:	Isifuba, asthma, I-esma, isifuba somoya, pneumonia, inyumoniya Ingqele
Signs	wheezing, ukutswina, ukuminxana, tight chest shortness of breath, iphika coughing, ukukhohlela
Infectious diseases:	intsholongwane, germs, infection, usuleleko
Upper respiratory signs/ illnesses:	flu, ifiva, umkhuhlane, a "cold" imifinya,

Are there any other words which you feel are related or important. Explain these terms too, please.

Annexure B:

"Access barrier questionnaire" used to elicit and record caregivers' socio-economic and demographic data and difficulties with access to quality health care.

(Chapter 2.4.2)

ACCESS BARRIER QUESTIONNAIRE

Date: _____

Name : _____ Surname : _____

Sex: ___M ___F
Age: ____

1. Date of Birth: _____
2. Relationship to child of person being surveyed: _____
3. Place of birth : _____ Place of residence : _____
4. Is there a phone at home : _____ Number : _____
5. How long have you lived in the city : _____
6. How many brothers and sisters does the child live with? ____
7. How many people live with you in your home? _____

Is your home a Shack (wood and zinc) house (bricks) other

8. What is your marital status?
   - ☐ 1 = Married, living with spouse
   - ☐ 2 = Married, separated from spouse
   - ☐ 3 = Divorced
   - ☐ 4 = Widowed
   - ☐ 5 = Never Married
   - ☐ 6 = Common law marriage
   - ☐ 7 = Other
9. What is your highest level of education completed :_____
10. Occupation : _____
11. How would you rate your ability to speak English?
    - ☐ Very well
    - ☐ Well
    - ☐ Not very well
    - ☐ Not at all
12. What is the primary language spoken at home? _____
13. What other languages are spoken ? _____

14. Where do you take your child for check-ups and vaccinations? _____

15. Where did you usually used to take your child when he/she is sick?

- ☐ traditional healer
- ☐ clinic
- ☐ local hospital
- ☐ private doctor
- ☐ emergency room
- ☐ other - Where? _____

16. When last did you take your child to see a traditional healer ?

17. When last did you or a family member go to a traditional healer ?

18. What illness is the child suffering from? _____

19. The child is where ? Ward S11 : _____ Allergy Clinic : _____

20. How many times has the child been here before with the same problem ?

21. How much time did the last doctor spend with you explaining about the child's illness ?

22. Was that time long enough ? _____ yes _____ no

23. What language did that doctor speak ? : _____

24. Was an interpreter present ? : ___ yes ___ no Professional Nurse Family Stranger

25. Are you satisfied with the conversation you had with your doctor ?

26. Were there problems with communication ?

27. What was the problem with communication ?

28. Was there on this occasion instances where

You said or asked something to the doctor but the doctor did not understand ? __ yes ___ no
The doctor said or asked something but you did not understand ? ___ yes ___ no
You were too anxious or nervous to say or ask something that you wanted to ? __ yes __ no

29. What effect did this have on you or your child ?

30. What do you do when you have problems with communication ?

31. What are the possible solutions to this problem ?

32. Do you feel you understand fully the meanings of the words that the doctor uses for the illness he / she says your child has ? ___ yes ___ no

33.(If an interpreter was present) Were you satisfied with the interpreter during this conversation ?
___ yes ___ no

34. What are the normal day to day problems you have faced in getting medical care for your child? _____

35. What is the single greatest obstacle you have faced in getting medical care for your child?
_____

36. Have you ever not brought your child in for health care because doctors and other staff did not speak Xhosa? ___ yes ___ no

37. Have you ever not brought your child in for health care because you didn't think you could afford it?
___ yes ___ no

38. Have you ever not brought your child in for health care because you felt that doctors and other staff wouldn't understand your culture and background? ___ yes ___ no

39. Have you ever not brought your child in for health care because of transportation difficulties?
___ yes ___ no
If yes, for what reason? _____

40. Have you ever not brought your child in for health care because the health care facility was too far away from where you live? ___ yes ___ no

41. Have you ever not brought your child in for health care because it was too difficult to make an appointment? ___ yes ___ no
If yes, why (no telephone/money, number always busy, waiting time for appointment too long, clerk/secretary did not speak Xhosa, etc.?) _____

42. Have you ever not brought your child in for health care because you would have to wait too long to see the doctor? ___ yes ___ no

43. Have you ever not brought your child in for health care because you work and the doctor's office hours were inconvenient? ___ yes ___ no

44. Are there any other important obstacles you have encountered in trying to get appropriate health care for your child? _____

45. Do you think that your child ever received poor medical care in the past because doctors and other staff did not speak Xhosa? ___ yes ___ no

46. Do you think your child was ever misdiagnosed because doctors and other staff did not speak Xhosa? ___ yes ___ no

47. Do you think your child was even given incorrect or inappropriate medication because doctors and other staff did not speak Xhosa? ___ yes ___ no

48. Do you think there were times where you did not understand the doctors explanation of how to give the medicines resulting in a possibility that the wrong medicines or amount of medicines could be given ? _____ yes _____ no

49. Do you think your child was ever inappropriately hospitalized in the past because doctors and other staff did not speak Xhosa? ___ yes ___ no

50. Do you think doctors should learn Xhosa as part of their medical training ? _____ yes _____ no

51. Which of the following have been the **three** most important obstacles you have faced in getting medical care for your child:

- ☐ Doctors and staff who don't speak Xhosa.
- ☐ Doctor's and Staff who don't understand your culture and background.
- ☐ Lack of interpreters
- ☐ Inconvenient doctor's office hours
- ☐ Difficulty making an appointment
- ☐ Long waiting time at the Doctor's office
- ☐ Difficulty arranging transportation to the Doctor's office
- ☐ Difficulty paying medical bills
- ☐ Difficulty taking time off from work
- ☐ Rude and/or discourteous doctors or nurses
- ☐ Difficulty understanding explanations of your child's illness
- ☐ Difficulty understanding how to give your child's medication

52. Which of the following is the single greatest obstacle you have ever faced in getting medical care for your child:

- ☐ Doctors and staff who don't speak Xhosa.
- ☐ Doctor's and Staff who don't understand your culture and background.
- ☐ Lack of interpreters
- ☐ Inconvenient doctor's office hours
- ☐ Difficulty making an appointment
- ☐ Long waiting time at the Doctor's office
- ☐ Difficulty arranging transportation to the Doctor's office
- ☐ Difficulty paying medical bills
- ☐ Difficulty taking time off from work
- ☐ Rude and/or discourteous doctors or nurses
- ☐ Difficulty understanding explanations of your child's illness
- ☐ Difficulty understanding how to give your child's medication

53. What was your total combined family income during the past month. _____

Note : rate the respondents ability to speak English?

- ☐ Very well
- ☐ Well
- ☐ Not very well
- ☐ Not at all

Did the respondent "hlonipha" yes no

Annexure C:

Excerpts from qualitative interviews (Chapter 4.1.3 – 4.1.6)

All interviews supplied on disc

Caregivers from short stay ward

1) ZN
2) NT
3) NN

Caregivers from allergy clinic

4) VB
5) BM
6) NT

Participating doctors

7) Dr LM
8) Dr JN
9) Dr LKR
10) Dr PR
11) Dr LeM

Caregivers from short stay ward

1) ZD

This example illustrates the extent of the lack of communication between doctors and parents and the measures taken by this mother to facilitate some limited communication.

Q: Has it ever occurred in some instances that you want to ask the doctor something, but experience difficulties because of the problem, knowing that you would phrase yourself better in Xhosa? What do you do when such a situation arises?
A: Yes, because I'm not a Mlungu. I try expressing myself in a manner that the doctor would understand.
Q: Do you think the doctor has a problem sometimes because he only speaks English?
A: He understands, Even though I may have a problem with the tense, he's able to understand what I'm trying to say.
Q: Does he speak Xhosa at all?
A: No, they don't speak Xhosa.
Q: Not even a little bit?
A: No, they don't.
Q: So you were saying you don't have a problem with the communication at all, you can hear and are able to express yourself. However there are moments whereby you feel you are not quite expressing yourself well enough in English as you would in Xhosa. How then do you solve this problem?
A: I do try, as much as I know that what I'm saying is incomplete in order for him to understand. I basically summarised (what I say) unlike if I were to speak in my own language .The information is therefore not complete as it would have been in Xhosa, in order for him to be able to understand.
Q: What do other parents say here at Red Cross?
A: There was one at the ward whom I explained what the doctor was saying to.
Q: She couldn't understand a thing and you interpreted for her?
A: Yes, it wasn't complicated. The doctor wanted to know when she was admitted and she said on Sunday but she didn't know how to say so in English.
Q: So you are actually saying that there are parents who can't speak English and that it helps to have an interpreter?
A: Yes, it helps but sometimes doctors want to explain to the patients personally.
Q: So what do you think should be done in a case where the doctor can't speak Xhosa properly?
A: I don't know what can be done, because it may not be possible to have an interpreter when the doctors are very busy. I've only seen two Black doctors and maybe they can't interpret all the time... I don't know whether it's early or late for the doctors to learn Xhosa.
Q: Do you mean while they are training?
A: So that they are able to communicate because most patients here speak Xhosa.

2) NT

Q: So did you say the communication between you and the doctor is satisfactory?
A: You mean when he speaks English and I can't understand?
Q: Yes
A: For instance yesterday he wanted to know if my child does take or has ever taken treatment for TB before, I couldn't quite understand what he was saying, He dropped the subject and carried on with what I could understand. Thereafter when he was done we got out into another entrance where there was a Xhosa speaking nurse. He then called me and the nurse therefore explained that the doctor was asking if the child has taken treatment for TB. She asked me in Xhosa and I told her he hasn't.
Q: And then, when you don't understand each other properly, what damage could that cause?
A: There could be damage to the child and I won't be able to understand yet I could agree as if I can understand yet cannot, that's the damage that could happen.
Q: So how can we solve this problem?
A: I don't know if it could be solved right now, or else there could be an interpreter to interpret for me because I don't understand.

3) NN

This mother is aware that her major problem is in responding to the doctor. She initially claims she understands the doctor well but in her last sentence accedes that she may misunderstand some questions too.

Q: You understand everything he says?
A: Yes, I do but I'm unable to speak.
Q: What do you do when you have to answer?
A: I often answer whatever question he's asking.
Q: In isiXhosa or English?
A: In English, though doubting that I answered well.
Q: What effects can that have on the child?
A: It may happen that I said the wrong thing…that I didn't answer what he was asking but what I thought he was.

Caregivers from allergy clinic

4) VB

Some of the assessment of the time spent speaking to the mother includes the whole of the diagnostic process, rather than the counselling. This misunderstanding may account for the parents who said the doctor spent an hour explaining their child's illness to them.

Q: Sisi, how much time can you say a doctor or a nurse spends with you, explaining the illness of your child, or what will happen after taking the treatment?
A: It's not much, maybe thirty minutes.
Q: Thirty minutes?
A: Yes, trying to explain to me what the problem is or ask me to go back to the X-ray and taking some stuff back to him. He will try to check what's wrong with the child and they will explain to me the problem of the child.
Q: Let us talk about how you and your doctor communicate about the problem of the child and what will happen to the child. Sisi, are you satisfied by how your doctor speaks to you?
A: I am satisfied, because they try by all means to make sure that you are satisfied. Yes, there's nothing one can do if she (the parent) doesn't understand English it becomes difficult. I understand it but it becomes difficult for me to ask questions, like I would want to know if this is the situation what's going to happen? But, if s/he (the doctor) is telling me that the problem is this and that, I understand and I'm satisfied.
Q: Even if s/he explains in English?
A: Yes. I understand and am satisfied but it's hard for me to ask questions... I do have problems, sometimes when I want to ask or explain something to him and it becomes difficult because I don't have much English vocabulary.
Q: Do you think that the doctor has a problem in communicating with you?
A: To the ones I've been with none of them showed any problem because they do not go to the Black nurses to ask for help because they could not understand me. He would write what I tell him and will write down anything I say.
Q: According to you, how can such a problem be solved?
A: I think each and every doctor should have an interpreter who would explain what the person is saying because when you speak the doctor writes and maybe he is not writing what you are saying because he is not going to show you anyway.
Q: If, he's not writing what you are saying what could he be writing?
A: I am just saying when they don't have interpreters and they do not understand what you are saying, and not being able to have a two-way dialogue with you.
Q: Sisi, when there is that problem between the doctor and the parent, how do you think that can be solved?
A: It could be solved by what I'm saying that doctors must have interpreters on their side to interpret for people who cannot speak English, do you understand? That will satisfy the person who has come to the doctor and the doctor as well.
Q: When you think about this problem, do you think that can put the child at a risk? Do you think that could endanger the way in which the child is treated by the doctor?
A: It can endanger the child because when the child gets the prescription by a doctor who speaks English talking to someone who does not understand English, she may give the

child the incorrect measurement which could be more than what the doctor prescribed because of the misunderstanding. In that way you endanger the child's life and that is why it is important to have somebody who will help with Xhosa because not all of us went to school.

5) BM

I'm able to understand him in some parts, in some I don't.
Q: What do you do when you don't understand him?
A: I keep quiet, I'm uneasy to ask because I don't know his language.
Q: Do you sometimes have difficulty understanding some English words?
A: Yes, I sometimes do.
Q: What effects can this have on the child, because you don't understand each other?
A: He won't get treated properly.
Q: How can we solve this communication problem?
A: We can solve it by doctors learning isiXhosa.

6) NT

I was satisfied but not fully because our languages are different. I don't understand him completely and he also doesn't understand me completely. When one's talking to the doctor about their child's illness, one wishes they could understand what he sees and wishes there were someone like them who could speak their language. To be able to speak to your heart's content and also able to understand what the doctor wants.
Q: What made you to be satisfied?
A: What made me satisfied is that Sinethemba got the rash tablets that he has to take at night. The fact that the new doctor looked at the folder and he told me about the tablets. The fact that he also had a personal interest because he wrote on the folder that I should fetch again in March because the medicines he gave were for a month. He said he won't give me more than that; I should come back again in March. What I don't know is whether he understood me. I asked if it was necessary for me to bring Sinethemba with in March since his next appointment is on the 4th of April, because he said I should take the folder and go to the Pharmacy. So I'm saying I don't know whether we understood each other on that, you understand?
Q: So you do have problems because of the different languages, like you said.
A: We do have a great deal.
Q: Which are the most important ones, is it when you are talking about the medicines or when talking about the illness?
A: The most important one to me is, this child has to come back every three months, previously it was every month and then it was changed to three months. Now since you also want to hear about his progress, I wish it were possible to talk to someone who can understand me. Starting from the nurses, we don't understand each other because they are coloured. I wish from the nurses, when one is asked how many times the child gets **ukuminxeka** a week or month or how many times do I take him a day, I wish I could be sure because what worries me is to be sure... that is what I'm saying, I can hear (understand) is **weak.** It may so be that you don't hear (understand/note) it. That is my problem. Even with you as the doctor you wish you can talk directly and am able to

understand (the patient). Unlike hearing (understanding) here and there because that affects my child's health.
Q: Do you think an interpreter is the one that can solve this problem?
A: Yes, because when I'm really struggling or when he is experiencing great difficulties, I'm totally not able to understand this language (English).

Participating doctors

7) Dr LM

Most doctors stated that their ability to communicate in Xhosa was rudimentary and aimed mainly at asking questions with "yes" or "no" answers. Understanding parents' responses is beyond their abilities. In this regard, the third answer given by this doctor is particularly revealing.

Q: Are you satisfied with the way that you communicate with your Xhosa speaking parents?
A: Not always, sometimes I really feel limited. You can ask a lot of yes-no questions. Sometimes they think you can speak Xhosa and they go off on a whole long thing and that makes it difficult because sometimes you do catch some of the words. I think if you do speak to them in Xhosa they try to be more approachable. My vocabulary as such is not extensive, it's not big enough and also it's like saying " I is hungry" kind of thing in English. I don't know if that answers your question.
Q: I think what you are saying is that your grammar is not good enough?
A: Oh, the grammar is not that great and the vocab is not big enough. So if that was a bit bigger and expansive we wouldn't have such a big problem.
Q: Besides the problems that you specifically have with the language, what other problems do you feel that you experience in communication? With your parents?
A: Except for not really understanding them?
Q: So the other thing is that you don't understand what *they* are saying?
Dr: Because I have said previously, you say one word or two words in Xhosa and they think you are fluent in it and give you huge long answers.
Q: And you said it makes you frustrated and what did you say, you are not able to find out the problems?
A: Ja, you can't get behind to exactly what the problem is. You know, you don't always get to know what the problems are because you don't have that proper communication. Now at three o'clock in the morning there's not always someone around to translate.
Q: So the problem also has to do with time.
A: Ja, of course so instead of the examination and the whole interview taking twenty minutes, well more or less, you now have to get someone to translate and then it takes double, twice that amount of time because obviously you ask the translator a question, the translator ask them a question, they answer. It's a three-way conversation and the person in between can't always give the exact translation of what's been said. So then you don't always get the proper history as well, I think.
Q: So you are not happy with translators?
A: It depends, at one of the hospitals I worked we had a full time translator and she was trained in medical terminology so that was great. And if you used a sister most of the times also they know the terminology so it is a bit easier for them to translate but I think sometimes using a sister makes it a bit difficult because they will jump to conclusions in the history that is given, so if the mother says "my child is coughing blood" or "my child coughed and blood came out", they will say it is haemoptysis, but it is not always haemoptysis it might be haematemmesis. But they assume. So I think you get led in the examination.

Q: You talked about trained interpreters and sisters. Do you use anybody else for interpreting?
A: Parents, obviously, other parents that you've spoken to and you know can speak English very well. And then we use security guards sometimes in non-confidential matters, you know like what is wrong coughing and other things, is there anyone with TB at home.

8) Dr JN

This doctor is very aware of the difference between rapidly obtaining a history in an acute situation and counseling a patient fully about an illness. He finds that outside of the emergency situation, an interpreter is necessary for any quality of communication. He has an acute awareness of the difficulties facing parents from disadvantaged backgrounds, both in terms of their access to health care and their experience of being in the hospital. He states that the non-verbal communication and the manner in which one communicates may be central to achieving the goal of setting the patient at ease, facilitating a better relationship and improved communication.

I think my Xhosa is based around strictly very medically oriented Xhosa based around symptoms and signs using single words and short phrases relating to rapidly obtaining a history from a patient as to the acute problem which I use as a sort of a screen before asking an interpreter to actually explain some of the things, so it sort of gives me a start. Then I use that as a basis to examine somebody and start directing their management. So its not really an ideal situation and often it's a combination of a spattering of English from the patient, and a spattering of Xhosa from me and we get a short history and then expand it with an interpreter if it's a complex problem
Q: So what would you feel that you need to get an interpreter for?
A: I think that most of the answers that I am getting I getting are yes or no answers so what I am really looking for is more detail of a particular symptom in terms of associated factors, duration, severity and then also things about the background history of a patient. The non-medical things or like what their environment is like, and also to sort of council the patient in a non-medical way to explain some feedback ... I am not going to be able to give them much coherent feedback. I can extract some information but I'm not really able to express in Xhosa.
Q: Would you say that you are satisfied with the communication that you have between yourself and your patient?
A: Is this Xhosa speaking patients who don't speak English?
Q: Yes
A: No, it's never really satisfactory. It's a stopgap; it's a very brief attempt at getting information.
Q: What problems do you experience specifically with that group of people.
A: The problem that comes to mind is that as a group of people often people who don't speak English are very disempowered. So they don't actually assert themselves very much in terms with coming forward with information and even if they did in Xhosa I wouldn't really be able to understand them, so the fact that I can use a few Xhosa words or phrases to get information from them is practical and useful but it is actually not very good for the relationship because it kind of perpetuates the fact that I just ask short questions and they answer them so its not a true dialogue and apart from that its very

limited, I am not getting a clear picture of the problem, I am getting a few basic ideas of the problem. I have to say that if patients really don't have any English or Afrikaans I would want to have an interpreter there. So we're talking about more in an acute, emergency situation where it's necessary for me to get a very rapid basic history.
Q: If there is an interpreter present do you find that that solves the problem completely or they are still problems with the interpreter?
A: I wouldn't say it solves it completely but it goes a long way to solving it. You never quite know exactly what's going on in the interaction between the interpreter and the patient. You can not rely on other cues, non verbal cues, and you can provide a bit of reflection and feedback, and re-emphasise things in different ways, so it goes quite along the way but I'm sure it doesn't solve all the problems.
Q: You said one of the reasons for the problem that you have with communication is that the parents are very disempowered, and don't feel that they are able to ask questions of the doctors. Do you feel that that is the major factor?
A: With the problem with the communication? I think it is an important factor. I think its not – it's a disempowering situation to have a sick child in the hospital. You don't have information, you constantly scared, you are not sure whether you are in the right place, the people you're not familiar with. I'm talking about now the emergency intake situation, rather than the clinic where its more familiar, you might have met the patient before and they are more at ease, in which case there are far more greeting cues and familiarity cues. In the acute emergency situation I think the sort of medical power relations as well as the language, social and cultural power relations come into it. So there are a number of factors that are mitigating against communication.
Q: What medical power relation?
A: I mean the obvious ones: you're a physician perhaps in a white coat, you're a white male, middle class and your patient is a poor black mother with a child who might feel she can get into trouble.
Q: So she feels that she's disempowered and she can't ask questions because of her whole social and cultural and historical thing?
A: I think that comes into it. And by the time I get to see her she might already have come through a barrage of fairly brusque clerks, nurses, hospital admin to get there and then its only now that I get there, so that by then she might not feel in a position of confidence, her child is sick, she might have issues of disclosure, so she comes to it with an experience, perhaps a negative experience of the hospital. So I try to consider that and perhaps take it into account what she's come through in the hospital, and I try to disarm that but I'm aware that there's already a big differential, and in fact, the few Xhosa words I use is actually an attempt to try to slightly ease that power differential.
Q: Do you find that it does put people more at ease?
A: Yes, the fact that I'm just able to say hello, how are you, and sort of ask a few basic things and questions which goes to familiarity and I normally generate a smile or just a vague sense of acceptance.
Q: Did you study any Xhosa during your training?
A: Yah, we did have some Xhosa for medical student classes.
Q: Did you feel that that helped you?
A: Yah, I think it did at the time, one got a little bit more proficient with the language at the time because you were formally doing classes and lectures and doing homework. But what I use now is probably only a small proportion of what we were taught. I probably should refer to the book more than I do – but it's really quite a low ceiling in what I can

get with my Xhosa from the patient and its actually preferable that I get an interpreter. Whereas if I worked in an area where that isn't access to that then I'd be actually obliged to extend my Xhosa a little bit, particularly in things like counselling...its nearly always essential to get a counsellor in.
Q: Do you think it should be compulsory to learn an African language in a medical school in South Africa?
A: I'm not sure about compulsory, I think it's a very good thing. I'm not sure it should be compulsory, but I think it would be a very valuable thing to learn within the curriculum. Like most things its only when you need it that it actually contributes to your ability to do your work and the enjoyment of your work that you realise that its particularly useful, but I think it is a good thing to learn Xhosa in Cape Town because if you're in Natal it wouldn't really make sense.
Q: Are there any other possible solutions to the communication problems that we have in the hospital?
A: I think that the manner with which one communicates is very very important whether you're doing it through English via an interpreter or via the little bit of Xhosa that you have. But that's sort of another area, but the way in which you try to come across, and the way that you communicate with the patient both in verbal and non verbal terms, whether its in their language or your own language, I think they can a sense of a dialogue rather than a top-down situation, which is inevitable but which you can minimise.
Q: Do you feel that the service that we provide to our parents does suffer because of the communication problems, and if so, how?
A: Yah, I think it definitely does, although I think some of it is a fault of omission rather than an active failing, and that is that because of these power and language relations oftentimes there isn't the assertiveness on the part of the patient or the doctor to make that communication happen, and allow not just the transfer of information, but the communication to explain enough of what is going on, get feedback, reflect back, counsel, all those aspects of true communication. Those aspects are often overlooked and don't happen for some obvious reasons, and that's sometimes the cause of failed treatment, failed adherence, discontent, and errors – medical errors.

9) Dr LKR

This doctor is very concerned about the relationship between herself and her patients. She mentions that an understanding of the cultural aspects of a disease may be necessary before we are able to address the patient's concerns.

Q: Now in terms of the conversation that you have with your patients or your parents, are you satisfied with the conversation that you have with them?
A: Depending on how much they understand me, if they don't understand me I am not really satisfied because I don't really feel I am making the contact that I want to make.
Q: So sometimes you feel that your parents don't understand you?
A: Yes, I do feel that and if that is the case then I do ask for help.
Q: What other problems do you have with communication, besides for them not only understanding?
A:I think education wise, if you are asking basic questions and the person doesn't really understand the impact of the question. They understand the question but they don't actually know how to answer it back, then they just sort of have long gaps of silence and

we both get very anxious or tense that the silence is taking place sort of thing, that things are not getting answered. I think more on a part impatience on my part because I want to get answered or I need to be there....
Q: So in terms of the effect that these problems have, first of all parents don't understand what you are saying, so that might have an impact on them? What impact does that have?
A: Well I think it makes them anxious that they are not being understood and that their problem is not going to be addressed. That when it comes to management afterwards, that they sort of hand over totally to you. They will hand over responsibility totally because there isn't that two-way – this is exactly what I am going to do, do you agree with it? The patient autonomy is taken away because of it.
Q: So it has an impact on the way the patient feels and it affects the nature of how well you can do your job. You said you think that the parents sometimes believe that the health of their child will suffer?
A: I think that, Yah well, not that it will suffer but that perhaps the whole picture will not be seen in context.
Q: Okay, so there are problems with your diagnosis if you can't communicate properly.
A: Yes, there will be. Sometimes what you find is the presenting complaint and you get sidetracked with something that you do know about and you only realise later that the thing that they are most anxious about you haven't actually addressed because you didn't take enough notice of it. What I find usually is that the doctors read the referral letter and they take the presenting complaint from the referral letter on the basis that the other doctor has already assessed the child and they will make the assessment on that letter and not always clarify. Sometimes you pick up the presenting complaint hasn't actually come to the full.
Q: So you think sometimes in fact because you don't understand the language you can miss what it is that the person is actually there for?
A: Yes, definitely.
Q: So do you think that it does influence our quality of care?
A: Yes it does in a small percentage. The majority of the time you are on the right track. You do miss out, yes.
Q: What are the reasons or causes for this problem with communication that we have?
A: Well I think the biggest reason is that we as doctors haven't taken initiative to relate to the people in their first language so that we understand the context that they are coming from. We try to understand as fully as possible but if you haven't immersed yourself into it, you don't actually know what they are worried about and you also have to take into context the cultural aspect of a disease, what their belief of the disease is. They might think the child might present with vomiting and they might think the child swallowed a frog and you haven't taken that into consideration because you don't understand where they are coming from. I think we could do a lot on our part to make more effort to learn the language, basic skills but then also we need to learn more about the culture.
Q: So when do we need to do that?
A: I think it needs to be introduced during Medical School and we need to put it in practice.
Q: Are you saying this should be a compulsory part of medical training?
A: If you are going to be practicing in the country, Yes.
Q: Okay. I was about to ask you what possible solutions there would be. Are there any others besides for making speaking an African language compulsory?

A: I think on that ground you can relate much better to your patients. That would solve the biggest problem.

10) Dr PR

This doctor has some important insights into the necessity of communication being a repetitive two-way interchange of information. Constant checking of the quality of the exchange is necessary for good communication. He has some fairly radical views on the problems and their solutions.

Q: You wouldn't regard yourself as someone proficient in Xhosa?
A: No, I'm not. I tried three times to learn to speak Xhosa, and I found it very difficult. I tried the tapes and I went to a course at the university, but for some reason, Xhosa is a difficult language for me to learn.
Q: During that period was there any course offered in Xhosa or any other African languages?
A: Yes there were voluntary courses, I tried them and I was too stupid, I just could not make it. I think for me the only white people who speak good Xhosa are people who grew up in the Eastern Cape.
Q: But at least you can pronounce it, you can pronounce it well. At least you are not saying Kosa.
A: I should be saying X-hosa, like when I call out patients' names in the waiting room the mothers often don't know what I'm saying. We put different emphasis on different syllables.

Most often I use those words, a couple of individual words when I'm taking a history rather than when I'm giving a diagnosis. In the case of taking a history the information is kind of gleaned and I can interpret the information along with what I see in the child, but if I'm giving information out it's a completely different thing. I can't be sure, given that I'm talking about things to do with the sickness or maybe medical terms or so on, I can't be sure what the mother takes in, and I'm aware that when you work through an interpreter one isn't actually sure that what you're telling the interpreter is what the interpreter is telling the mother.
Q: So you are saying that relying on interpreters a lot may be problematic itself in terms of getting the right information across and getting the right response?
A: Definitely it can be a problem, and hopefully part of the problem is resolved because I see the mother not just once but on several occasions.
Q: What do you think causes that misinterpretation from the interpreter, seeing that the person whom you are using for interpreting is the health care worker who may be familiar with the medical terms?
A: I think that it has to do probably with the precision of the words that one uses.
Q: You mean the English words or the Xhosa words?
A: I mean the translation from the English to the Xhosa. I think even if I would learn to speak Xhosa, my Xhosa would not be as rich as the person to whom I'm talking. And, when I'm using words I would only have a choice between very few words and so I could easily choose the wrong words. I think second language speakers, speaking to first language speaker will always have that sort of problem and so I don't see it as necessarily as a problem sitting with an interpreter. I see it as a problem that I'm not in fact a Xhosa.

I've got a registrar at the moment who is a Xhosa, now I'm sure that when he speaks to another Xhosa the message gets through because he can pick up from the questions she asks whether the interpretation is correct or not. I mean that's what I do when I speak English to someone who speaks English. I say something and then I listen to what they say back then it's quite clear to me from what they say back if they've understood what I've meant them to understand or not. I don't think communication is an easy thing at all. If you've got two first language speakers its already difficult, if any one of you is a second language speaker then you've really got problems.
Q: So, basically one of the problems that you've experienced is that you relay the information to the interpreters and he being the first language speaker of Xhosa can actually talk to the parent, but then the response from the interpreter that you get from the parent may not be accurate?
A: Yes, exactly. I think that this discussion we are having now is an iterative discussion. I'm saying something and you're coming back with what you understand from what I'm saying, and then I can correct that. You and I can only do it because we share the same language and actually the same lexicon. The same set of words that we can choose from, and that makes it easier to understand each other. But, when I'm talking to an interpreter there are just too many differences and it becomes problematic.
Q: Doctor, are you saying that the problem with the words that are used between doctors, patients and interpreters may in the long run cause problems for diagnosis?
A: I think there is no problem with diagnosis but probably with understanding what the diagnosis is all about, and then later on understanding of what to do about it. I'll give you an example, if you ask a Xhosa mother "how many bottles do you give your baby a day?" She will tell you how many she gives during the daytime, and unless you say "and at night…?" . And that has got to do with presumably Xhosa grammar or whatever, whereas if you ask an English speaking woman "how many bottles do you give your baby a day?" she will tell you how many including the night time. So there are subtleties. There must also be things that are not so subtle too. And I'm not sure what we can do about that, beyond me having grown up in the Eastern Cape, and speaking Xhosa from when I was little.
Q: I think you can easily go to the Eastern Cape to speak more Xhosa as you have earlier suggested (both laughing). At the moment what do you think could be the possible solution to this problem?
A: I think that the first thing is that people be aware that there is a problem.
Q: Which people?
A: Doctors. I think doctors have to be aware. This is the product that I'm trying to deliver is trying to be a doctor. Doctors have to be aware of the pitfalls and of the difficulties in communication in general, and one has to spend more time. You have to spend more time because, you have to make it part of a process. I'm talking about communicating a diagnosis now, so you communicate that diagnosis now you say what you want to say to the mother and….
Q: Let's just say maybe you're telling me my child has pneumonia then you must relay that to a Xhosa speaking person who does not understand English at all?
A: Yeah so I'll explain a little bit about fever, ushushu, and how something is happening in the lung and try and keep it as simple as possible, not because I think the person is stupid but because I think these things are complicated. So, through an interpreter try to send that message through and then to prolong the process, maybe ask the mother some questions. You put across the information you want to through the interpreter and then

you need to ask some questions, through the interpreter, to establish whether the important elements of what you were trying to put across were understood. There are certain critical parts that she has to understand about the pneumonia. And unfortunately, our time is a very expensive thing.
Q: So, this critical factor that the mother has to understand about the child's illness say to a mother who doesn't speak English at all, so you are saying that in many cases doctors only rely on interpreters for this message to get through?
A: I think that what a doctor would do is give this information to the interpreter and see that the interpreter is speaking to the mother and might not go the extra step of checking to see whether the important parts of the information has actually gone through.
Q: What effect could this have on a child, if maybe the information that has been received by the doctor through the interpreter was incorrect? What effect would that have on a child?
A: Well it depends on the extent of what's wrong with the child, with what were dealing with. It could be very serious.
Q: Is there a case where a child has been wrongly diagnosed?
A: Mh-h m-h (yes).
Q: Is there a case where that happened, because of the wrong information that has been given to you by interpreters?
A: It could easily happen if there was a language problem, that a very important piece of information didn't come through. Unless the doctor asked the question. I think probably at the end not being able to speak a particular language means that you have to ask more questions and be more careful to get what you want.
Q: Okay. Basically you are saying some of the communication problems that the doctors experience when speaking with Xhosa speaking patients could be solved by introducing or exposing doctors as early as possible to the Xhosa language?
A: Well if you can do it at the age of three or four years before they've even thought about doing medicine yes I think that would help. I've heard many medical students, even though I haven't discussed this with them, complain about how difficult they found it and I haven't seen many medical students actually using Xhosa much. I'm not sure if they are still giving Xhosa now at medical school. The solution is to only train Xhosa speaking people to be doctors then we wouldn't have that problem at all.
Q: What about the current doctors, who cannot speak Xhosa, what could be done in that case?
A: Not much except wait for them to die.

11) Dr Le M

This doctor is somewhat older than the others. He feels that communication issues are subsidiary to the patient getting the correct treatment. His solution is a simple vocabulary booklet which he could refer to to ask questions of his patient. His focus is almost entirely on using Xhosa as a tool to get an adequate history in order to make the correct diagnosis. Counselling the patient was not mentioned.

Q: On a scale of 1 – 10 where would you place yourself in Xhosa?
A: 1 if that! I know a few words. I think in the future, one should be able to speak more Xhosa, and I think perhaps it would be a good idea. You know an older person has difficulty picking up a language; it's easier for a young person, so I think Xhosa should

be taught till matric or Std 8. For those of us who haven't been taught at school there should be a thin booklet at all our clinics, in all our hospitals, with basic questions that we ask patients and the basic information we can give them. Not a thick book, it can be up to 10 pages for most patients. In the day hospital the Xhosa speaking sister takes the history and then presents the patient to you and then you thoroughly examine the patient and then if you are not happy with the history and what you find, if it doesn't add up then the sister will help you even further with communicating with the patient so that the patients gets the best opinion.

Q: In terms of the language itself or the message you get from the sister may not be the same as the message that was sent by the patient? Maybe they paraphrase it or leave out information you might be interested in hearing.

A: I don't think so. The patients get a very good deal. If you have got a concerned doctor who takes a good history with the help of an interpreter if necessary and he examines thoroughly and takes time to speak to the patient, I think the patients gets a good deal. I think the majority of patients are interested in being examined properly or having their children examined properly than anything else. If there are too many patients, the problem is you can't spend any time with them.

Q: Do you speak Xhosa at all to the Xhosa speaking patients?

A:(shows paper) Ungunina. Unguyisa C
Molo Mama
Molo tata Ok.
I speak Zintsu zizingaphi.

} Difficult to make out what this means due to poor accent and nonsensical words.

I can ask most of the questions that are necessary and they can reply, say "ewe" or not or whatever. Here in the hospital I don't have to call the interpreters so often. Firstly there are too few of them around and when you need them you can't get hold of them. On Thursday morning we have sisters who can help me and if they are busy there are other Xhosa speaking adults around who also speak and who are only too willing to come in and lend a hand with interpreting.

Q: When you use another adult do you feel the information you would get is accurate?

A: I think so, yes they would. When it comes to psychiatric problems or domestic problems its different. The person may not want to tell the stranger to tell you.

Q: Are you satisfied in the communication with you and your patients?

A: Yes, in the context of children. Not with adults where most things are private. For children the common things are gastroenteritis or RTI's but now we've got the terrible HIV epidemic which brings both of those things in so…right ho!

Q: Are there any problems in communication in your Xhosa speaking parents.

A: The problem is either they understand or they don't understand. I may have great problems in communicating but on the whole not.

Q: Why not?

A: When it's something outside the common illnesses - like to explain a temper tantrum or a breath holding attack instead of a fit. It's too complicated. Is the child having a fit or isn't the child having a fit. Then I would have to call in an assistant to take a good history. I sometimes even have Xhosa speaking doctors who refer someone in here with what they say is a fit and I decide it's not a fit. You've got to take an accurate detailed history, and you need someone who can speak Xhosa well.

Q: When you do have those problems what effect does it have on the child?

A: I try to be sure of what it is I am doing before I treat. I am not someone who just goes bang bang bang on the chest and then gives medicines. That's not medicine, that useless.

When I treat someone it's after a thorough history and a thorough examination and I am sure I am treating the right problem. If I can't be sure the patient understands I get an interpreter or a sister or someone from the waiting room. I find sometimes that people haven't been using their medicines or their pumps but I don't find that just in Xhosa speaking patients, it occurs in English and Afrikaans speaking patients.
Q: How do we avoid communication problems?
A: Improve my knowledge of Xhosa and to have gone to school to learn Xhosa. We need a thin booklet for all medical doctors.

Annexure D: Presentations of research at congresses

Abstract: 2003 World Allergy Organisation Congress (Vancouver)

Poster: 2003 World Allergy Organisation Congress (Vancouver)

Abstract: 2004 World Asthma Congress (Bangkok)

Power point presentation: Presented at the following meetings:

2003 Research Day Institute of Child Health (University of Cape Town)

2004 World Asthma Congress (Bangkok)

2004 SANPAD Congress (South Africa-Netherlands Research Programme on Alternatives in Development, Johannesburg)

2004 Intercultural Communication – The linguistic challenges of diversity. (Dept of Linguistics, University of Stellenbosch)

Abstract for poster presentation at World Allergy Organisation Congress. Vancouver 2003.

Differences in definitions of respiratory medical terminology exacerbates language barriers between doctors and non-English speaking patients.

This qualitative study assessed patient's barriers to care, communication between doctors and patients and definitions of medical terminology of doctors and patients who speak different languages.

Subjects were parents whose children were admitted for chest disease, parents of children at allergy clinic for asthma and doctors. Doctors were English speaking; parents spoke Xhosa (an indigenous African language).

In-depth semi-structured interviews utilized a cross-cultural "explanatory model" framework. Usage and definitions of common respiratory terms was elicited from the three groups in English and Xhosa. Demographic data was collected, and a list of words and their definitions generated. Contrastive linguistic analysis was used to establish single or multiple "senses" of words for each group. The usage of the words between the three groups was compared. A questionnaire was completed by caregivers assessing their perceptions of barriers to access to care for their children.

Differences were found between groups in the frequency with which they could not define words at all, the range of definitions, and the number of "senses" of the words. Terms were identified that have "consistency" in their usage within each group, in contrast to those with multiple "senses". Terms were identified with cross-group "concordance" in their definitions. Terms were classified into linguistic categories.

Language differences and discordant definitions of medical terminology adversely effect communication in medical milieu, leading to reduced patient satisfaction and non-compliance.

P-6-36

Differences in definitions of respiratory medical terminology exacerbates language barriers between doctors and non-English speaking patients.

Levin M.E.

Red Cross War Memorial Childrens Hospital, Cape Town, South Africa

Language, ethnicity and culture are inextricably entwined. Where differences exist in these domains between health professionals and patients, communication may be significantly affected. Poor communication can lead to longer visits, higher admission rates, less acceptance of treatment, lower follow up rates and reduced patient satisfaction. Lack of data about barriers to patient care and language usage in South African hospitals hinders the evolution of strategies aimed at addressing these problems.

This qualitative study assessed **1) patient's barriers to care, 2) communication between doctors and patients and 3) definitions of medical terminology of doctors and patients who speak different languages.** Subjects were 17 parents whose children were admitted for chest disease, 16 parents of children at allergy clinic for asthma and 8 doctors. Doctors were English speaking; parents spoke Xhosa (an indigenous African language).

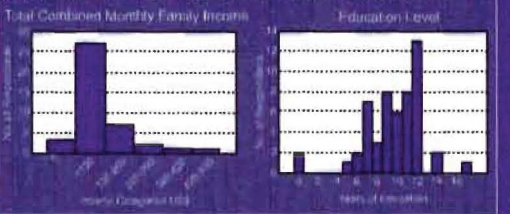
In-depth semi-structured interviews utilized a cross-cultural "explanatory model" framework. Usage and definitions of common respiratory terms was elicited from the three groups in English and Xhosa. Demographic data was collected and a list of words and their definitions generated. Contrastive linguistic analysis was used to establish single or multiple "senses" of words for each group. The usage of the words between the three groups was compared.

Differences were found between groups in the frequency with which they could not define words at all, the range of definitions, and the number of "senses" of the words. Terms were identified that have "consistency" in their usage within each group, in contrast to those with multiple "senses". Terms were identified with cross-group "concordance" in their definitions. Terms were classified into linguistic categories.

1) Barriers to care experienced by 51 Xhosa-speaking parents. Socio-economic factors were of prime importance.

Single greatest obstacle to health care
Language issues are 2nd in importance after socio-economic.

Difficulty paying medical bills	14
Doctors and staff who don't speak Xhosa	8
Rude or discourteous doctors or nurses	8
Difficulty understanding explanation of the child's illness	8
Long waiting time for the doctor	8
Lack of interpreters	5
Difficulty arranging transportation	3
Difficulty taking time off work	1
Inconvenient doctor's working hours	1

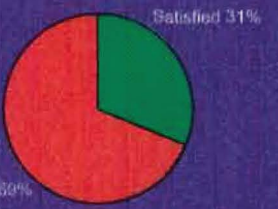


2) Communication problems experienced by 51 Xhosa-speaking parents. Lack of same language practitioners and interpreters leads to patient dissatisfaction and misunderstandings.

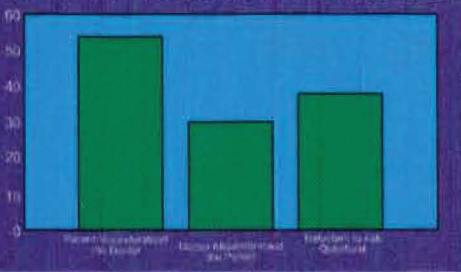
Language of previous Communication with Doctor

Proportion of Interviews with Interpreter

Satisfaction with Communication



Problems in the Discussion with the previous Doctor



3) Language differences ranged from completely different definitions of word meanings (fever is a disease with coughing and coryza to Xhosa speakers, not a raised body temperature) to differences in perceived cause, effect, prognosis and treatment. Culture specific explanations of illness included inggala: the "cold-hot" theory of disease, idliso: poisoning via food and xakaxa: mucus buildup since birth.

Concordance or discordance between definitions of terms

Doctors could not define 8 out of the 10 Xhosa words
Parents were unable to define "wheeze", "tight chest" and "shortness of breath".

Of the remaining 10 terms

5 had clinically-significant discordance in meaning	3 had minor differences	2 terms were used concordantly
Asthma	Flu	Coughing
Cold	Germs	Ukukhohlela
Fever	Infection	
Isifuba		
Pneumonia		

CONCLUSIONS :

Socioeconomic issues are followed by language issues as barriers to medical care for Xhosa-speaking children. Parents have little access to same language practitioners or translators. Parents are dissatisfied with the communication between themselves and their doctors and experience significant problems with understanding doctors, speaking in English and asking questions.

Language differences and discordant definitions of medical terminology adversely effect communication in medical milieu, leading to reduced patient satisfaction and non-compliance. Doctors need to be trained in communication, the use of interpreters and the meanings of medical terms in other languages. Interpreters should be more widely accessible. Culturally different explanations of disease may account for some of the discordance of definitions.

Thanks to Prof E Wainberg, Prof C Molala, Prof L Swartz, Prof R Kaschula and especially Ms Thami Makubalo and Mr Nkululeko Mabandla

Research funded by ALLSA, UCT and GlaxoSmithKline

Abstract for oral presentation at World Asthma Congress. Bangkok 2004.

Culture specific models of illness exacerbate barriers between doctors and patients in South Africa.

Objectives: To assess
- Patient's barriers to care
- Communication between doctors and patients
- Definitions of medical terminology of doctors and patients
- Culture specific models of illness

In Xhosa speaking African parents and English or Afrikaans speaking European doctors.

Methods :
This qualitative study utilised semi-structured questionnaires to elicit barriers to patient's care from 53 Xhosa speaking parents whose children were admitted to the short stay ward.

In-depth semi-structured interviews were conducted on 33 Xhosa speaking African parents whose children were admitted for chest diseases and 8 English or Afrikaans speaking doctors. The interviews utilized a cross-cultural "explanatory model" framework. Interviews elicited barriers to care, language problems experienced by subjects, the usage and definitions of common respiratory terms in English and Xhosa and models of disease causation, course and treatment. A list of words and their definitions was generated and contrastive linguistic analysis was used to establish single or multiple "senses" of words for each group.

Results:
Financial and socioeconomic issues were closely followed by language difficulties as the greatest barriers to care experienced by Xhosa speaking parents.

Parents are dissatisfied with the communication between themselves and their doctors. A significant proportion of Xhosa-speaking parents experience difficulties with understanding their doctor, making themselves understood and asking questions. Parents experience difficulty with understanding the words used by doctors and medical terminology. Words are used differently by parents and doctors.

Culture specific explanatory models of illness included Ingqele : a variant of the cold-hot theory of disease, Xakaxa : mucus that was not removed at birth building up and causing asthma and Idliso : poisoning via food.

Conclusions

Language differences, discordant definitions of medical terminology and culture specific explanatory models of disease adversely effect communication in medical milieu, with adverse effects on quality of care and reduced patient satisfaction.

Culture - specific models of illness & Barriers between doctors and patients in South Africa

Mike Levin
Red Cross Hospital

Rationale

Ethnicity ↔ Culture

Language

Communication

longer visits, higher admission rates, less acceptance of treatment, lower follow up rates and reduced patient satisfaction.

Overview

Qualitative study → patient's barriers to care
communication between doctors and patients
definitions of medical terminology

2 Parts → Barriers to care & communication
Medical terminology & culture

Barriers to care

A questionnaire was developed based on a similar study in Spanish speaking patients in North America.

Parents perceptions of barriers to care.

Open ended questions
Closed ended questions
Selection from lists

Administered to 53 parents in short stay ward.

Xhosa speaking researchers.

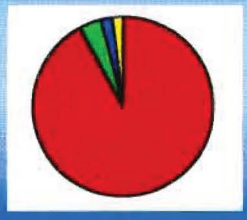
Single greatest obstacle

Difficulty paying medical bills	14
Doctors and staff who don't speak Xhosa	8
Rude or discourteous doctors or nurses	6
Difficulty understanding explanation of the child's illness	6
Long waiting time for the doctor	6
Lack of interpreters	5
Difficulty arranging transportation	3
Difficulty taking time off work	1
Inconvenient doctor's working hours	1

Single greatest obstacle

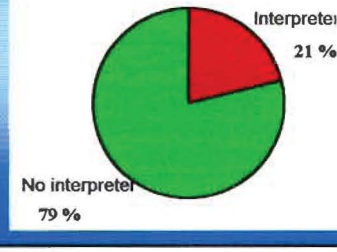
Difficulty paying medical bills	14
Doctors and staff who don't speak Xhosa	8
Rude or discourteous doctors or nurses	6
Difficulty understanding explanation of the child's illness	6
Long waiting time for the doctor	6
Lack of interpreters	5
Difficulty arranging transportation	3
Difficulty taking time off work	1
Inconvenient doctor's working hours	1

Language in interview

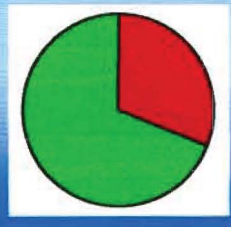


English	92 %
Xhosa	4 %
English / Xhosa	2 %
Afrikaans	2 %

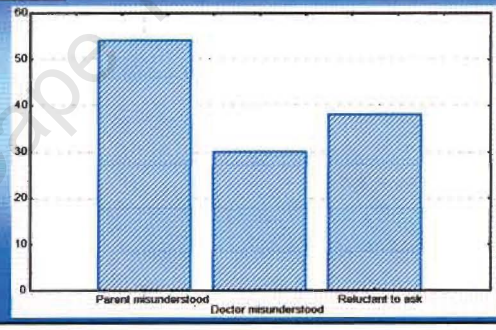
Non-Xhosa Interviews



Satisfaction



Problems in consult



Summary : Barriers

Language & cultural issues are second in importance after socio-economic issues, taken overall are most frequent.

Same language interviews are very uncommon.

Interpreters are underutilised.

Parents are dissatisfied with the quality of communication.

Parents experience significant problems.

Communication problems cause sequelae.

Causes of miscommunication

In-depth semi-structured interviews – open ended questions

Cross-cultural, non judgmental framework.

41: Large number for qualitative research

Doctors were English speaking
Parents spoke Xhosa.

Medical terms

Usage and definitions of common respiratory terms in English and Xhosa.

List of words and their definitions generated.

Contrastive linguistic analysis was used to establish single or multiple "senses" of words for each group.

The use of the words between the groups was compared.

Medical terms : Results

The frequency with which groups could not define words at all.

The range of definitions

The number of "senses" of the words

Terms were identified that were "consistent" in their usage within each group, in contrast to those with multiple "senses".

Terms were identified with cross-group "concordance" in their definitions.

Doctors

Unable to define	Able to define
8 out of 10 Xhosa words	2 out of 10 Xhosa words
	Isifuba Definition differs from parents
	Ukukhohlela Definition agrees with parents

Parents

Unable to define	Able to define
3 of 12 English words	9 of 12 English words
tight chest wheeze	6 : Major differences in definitions of doctors
shortness of breath	2 : Minor differences in definitions of doctors
	1 : Concordance between parents and doctors "Coughing"

Language differences: culture

Differences in meaning
or perceived cause, effects, prognosis, treatment

Discordant terms – minor - Flu
germs
infection

Discordant terms – major - Asthma
Cold
Fever
Isifuba
Pneumonia

Cultural models

- Ingqele: Cold enters the body → pneumonia
- Idliso: Poisoning via food → TB
- Xakaxa: Mucus from birth → asthma

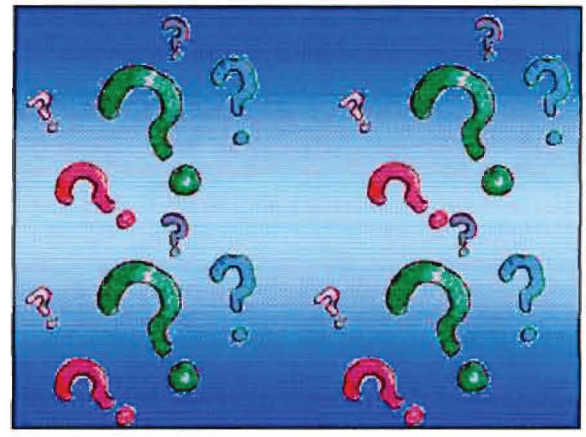
Conclusions

Language differences and discordant definitions of medical terminology adversely effect communication.

This leads to reduced patient satisfaction and non-compliance.

Culturally different explanations of disease accounts for some of the discordance of definitions.

Doctors should be trained in communication
use of interpreters
cross – language/ cultural
meanings of medical terms



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