APPLICABILITY OF A HEALTH LITERACY TEST FROM THE U.S. IN A SOUTH AFRICAN POPULATION

by

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ABSTRACT

This thesis investigates the suitability and applicability of a health literacy test from the U.S. in a black, Xhosa-speaking, South African population. The concept of literacy is a controversial one which has been much debated, as it is not easy to classify people as simply either literate or illiterate. As a result there are a number of definitions of literacy that vary with purpose and culture, but the most common one is that a person is literate if he/she can read and write. Estimating literacy from years of schooling is an inexpensive method but is also unreliable, since people generally read 3 to 5 grades below their stated educational level. This method affords little insight into the ability of patients to adequately function in a health care environment, an ability which is referred to as functional health literacy. A number of health literacy tests such as the REALM (Rapid Estimate of Adult Literacy in Medicine) test have been developed to assess this skill.

The REALM test is a word recognition test which places people into a relevant grade range estimate according to the number of words pronounced correctly. It appears to assume understanding of the word if the person is able to read that word correctly. In this project 125 black Xhosa-speaking respondents of varying educational levels who were literate in English were interviewed with the aid of an interpreter. Comprehensive demographic data were collected. Respondents were first asked to read all 66 words aloud during which time pronunciation was checked, and thereafter they were asked to explain each word.

It was found that the ability to automatically decode and read the words did not necessarily guarantee comprehension of these words. Many of the words proved to be unfamiliar to the majority of the Xhosa respondents who were able to pronounce them correctly, but could not explain them. These tended to be phonetically transparent words which were therefore more accessible to the unfamiliar reader. This research has proven to be of great value in helping identify such words which should be substituted with simpler words for use in health information materials. A number of words could neither be pronounced nor understood by the population majority and, interestingly, a small group of words could not be pronounced but were satisfactorily explained by some respondents.

The results showed an extremely poor correlation between the stated educational level and the REALM grade range estimate. This emphasizes the inappropriateness of years of formal schooling as an indicator of functional health literacy. The criteria were established for deciding cases in which the REALM test could be applied (or succeeds) and when it is inapplicable (or fails). It was found to be inapplicable in 41% of cases which clearly indicates that, in its current form, it is not a valid, reliable test to use in determining health literacy in this English second language population. It can, however, be used as a basis for the development of a more appropriate test. Recommendations for future research direction are presented and an alternative structure for a health literacy test is suggested.

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CHAPTER ONE
INTRODUCTION

Much has been learned about literacy in the past 50 years, ever since the United Nations declared it to be a basic human right along with the right to adequate food, health care and housing. After World War II, General Assembly resolution 217 A (iii) of 10 December 1948 adopted and proclaimed the Universal Declaration of Human Rights. One of the articles in the Declaration, article 26, discussed the right to education. It stated that education shall be free at least in the elementary and fundamental stages and by so doing it was hoped that these educational development efforts would expand on formal schooling [1,2]. It was assumed that higher school attendance would help to end the "scourge" of illiteracy, which is described by UNESCO (United Nations Educational, Scientific and Cultural Organization - 1988) as the "inability to use reading and writing with facility in daily life" [1,3]. But research and experience have shown that schooling does not necessarily produce literacy or the kinds of literacy that students need [1].

This idea was emphasized by the World Conference on Human Rights in Vienna (1993), which recommended that all countries should strive to eradicate illiteracy and should direct education towards the full development of the human personality and the strengthening of respect for human rights and fundamental freedoms [4]. At the International Symposium for Literacy in 1975, a unanimous declaration in Persepolis (Iran) was made that literacy is " not just the process of learning the skills of reading, writing and arithmetic, but a contribution to the liberation of man and to his full development". It should open the way to a mastery of techniques and human relations. Literacy is therefore not an end in itself, but a fundamental human right as declared by the United Nations [5].

One might have thought that food, health care and housing would be more pressing needs than literacy education, but literacy is now seen as a major tool to help address these other needs. It has been found that in addition to being important sustenance for the mind, literacy satisfies other needs in some very specific ways. Most people agree that illiteracy is a major problem in society today, therefore literacy programmes are near the top of the policy agenda of most countries in the world, irrespective of whether they are industrialized or developing countries [1].

As Morphet [6] says "Schooled literacy has become the marker of the fault line of social power". Those who do not "have it" are marked in deficit. This is supported by the Streets [7] who state that people who do not have schooled literacy are seen as being defective at the cognitive level and are suffering from the stigma of illiteracy. These people are thus functionally disempowered, in that they are unable to participate in modern life which is assumed to require a "literate orientation" e.g. people with poor literacy skills cannot read street signs, names or maps and must rely on television or radio or other people to tell them what is occurring in the world. They may also have difficulty using health care practices that are elementary to those of us who can read [8-10].

In Bourdieu's terms [11-12], schooling is where a particular "cultural capital" is acquired i.e. schooled literacy is a form of cultural capital. It is institutionally screened and validated and embedded in the norms of achievement, independence and bureaucratically appropriate conduct associated with formal settings of adulthood. However, there are other forms of literacy that do not carry the same cultural capital. These have been characterized variously as cultural resources, e.g. in the African population an older man is respected more than a younger one, even if the latter possesses "schooled literacy", and vernacular literacies, e.g. being literate in a certain

language and local or social literacies, which are acquired through social practice in settings where they are meaningful and functional [8].

This emphasizes the fact that it is impossible to think of literacy as a unitary phenomenon; hence Brian Street [13] developed 2 models called autonomous and ideological models.

1.1 Recent developments in the concept of literacy

Although literacy is regarded as being a powerful tool to have, it needs to be realized that not everybody wants to acquire reading and writing skills. Some illiterate people may feel content and comfortable with their status and may not realize the need to be literate or in fact live in a rural environment where literacy skills offer no tangible advantages.

In the past, literacy has tended to be regarded as a set of decoding and encoding skills which are isolated from the social, cultural, economic and political environments in which they are used. Children learn to decode and encode when they first attend school and their ability (and willingness) to read and write the things we would like them to read and write is generally understood to be dependent on those decoding and encoding skills. This understanding (or model) of literacy is termed the autonomous model of literacy. Research on the autonomous model tends to focus on cognition and perception and in doing so, is often highly 'technical' and is conducted in conditions intended to simulate laboratory conditions. Within this model, it has been assumed that literacy consists of a single, definable set of skills that are culturally neutral and "autonomous" in the sense that they independently generate consequences across a variety of social contexts [14].

Researchers working from an ethnographic orientation, i.e. they have spent time "in the field", in real life situations observing and interacting with the people they are researching, have built another understanding or model of literacy, termed the ideological model. Brian Street [13] has therefore replicated this kind of research. The ideological model is important as it focuses on the "socio-cultural" aspect of people. It examines people in context and looks for reasons other than the purely psychological or the physiological, for them doing what we would like to them to do (at the same time questioning the validity of what we would like them to do).

Scribner [15] who also supports the ideological model suggests 3 metaphors to describe the wide range of concepts of literacy. Literacy may be viewed as adaptation to societal expectations, the power to realize one's aspirations and effect social change or a state of grace to be attained by the well-read, cultured person. There is also a different conception of literacy, which sees it as social practices embedded in specific contexts, discourses and positions. Literacy is not simply knowing how to read and write a particular script, but being able to apply this knowledge for specific purposes in specific contexts of use in daily life [16].

The ideological model also provides reasons for people's willingness (or lack thereof) to read any kind of text other than their ability (or lack of) to read text. For example, their unwillingness to read notices and instructions, preferring instead to receive information orally. In South Africa, this model can be considered as being important in understanding why a society which is predominantly oral in nature has not easily "converted" to being literate.

Although the ideological model takes the socio-cultural background into account when assessing why people do not read, the autonomous model takes precedence in health care, as it provides us with a tool to assess the literacy skills of patients, thereby assessing their functional literacy.

1.2 Definitions of literacy

Definitions of literacy are more about what is regarded as possible than what is regarded as ideal. In 1962, UNESCO stated that "a person is literate when he has acquired 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 and whose attainments in reading, writing and arithmetic make it possible for him to continue to use these skills towards his own and the community's development" [5,17]. Almost 2 decades later (1981), UNESCO in its report simplified the definition of a literate person to "one who can both read and write a short simple statement about everyday life" [17,18]. In South Africa, definitions of literacy are complicated by the fact that knowledge of a second language, usually English is as vital for survival and development as the ability to read and write in an African language. The term 'literacy' in South Africa is often loosely used to include basic competency in English [5].

However, the concept of literacy does not imply a simple dichotomy, in other words, people cannot simply be classified as either literate or illiterate. Literacy can in truth be seen as a continuum ranging from the first formation of the letters of ones's name (pre-literate) to the ability to read and write abstract texts (highly literate). It is a controversial concept which may either be static or absolute, for example, if you are able to sign your name on the dotted line or you have completed a certain number of years at school, you are considered "literate" [5,19]. However, most would agree that literacy is not a "given"; what it is and what it does, needs to be theorized. In general terms, literacy has been socially constructed as that line which divides ignorance from knowledge and powerlessness from power [16].

Literacy can be described in a number of ways, since different skills are required for different tasks, e.g. skills for driving a car and working on a computer are all related to competency in a

special field. Literacy definitions are phrased in terms of what a person should be able to do to be considered "literate". These are:

- Able to sign his/her name
- Able to read/write a simple sentence describing one's daily activities
- Able to read and write, based on his/her self report (not based on a test)
- Able to pass a written test of reading comprehension at a level comparable to that achieved by an average student in Grade 4 according to the United States' schooling system
- Able to engage in all those activities in which literacy is required for effective functioning in his/her community [20].

UNESCO identified 3 general categories of literacy:

- *Illiterates:* these are persons that are unable to read or write in any language.
- *Semi - literates:* these persons are able to read and write in a very limited way, but since their reading and writing skills have not been permanently acquired, the semi-literate person can easily revert to a state of illiteracy.
- *Literates:* these persons have permanently acquired reading and writing skills [19].

Amongst literates, the following broad levels of proficiency can be identified:

- *Pre - literacy:* this is the first level of progress on the road to literacy. The person is beginning to acquire knowledge of the basic language and arithmetical skills, which are needed in order to master literacy. In scholastic perspective, it means functioning at about junior primary level i.e. 4 years of schooling. It is obvious that this level offers no guarantee that the basic skills are permanently established and the person can thus quite easily revert to a state of illiteracy.

- *Basic literacy:* here the acquisition of the skills of literacy is permanent at the basic literacy level, unlike at the pre-literacy level, where there is no question of regression from the skills to a level where the person must re-learn the skills. Basic literacy therefore is the level where a person can read and write a short simple communication relating to his/her everyday life. Basic skills in reading, writing and numeracy, are especially important in the health care setting, where patient participation in planning and implementing therapeutic regimens is critical for successful health outcomes [19,21].
- *Functional literacy (Career literacy):* this can be linked to a specific setting or work environment [19,22]. It incorporates reading materials that relate directly to community development and to teaching applicable or useful life skills [23]. The level of basic literacy which can be established, does not mean that the person is necessarily prepared for the demands on literacy, which are imposed by the multiplicity of occupations and community connections/links. Basic literacy is actually the pre-requisite for the attainment of the level defined as effective functional literacy. Functional literacy has been defined as anything and everything connected with basic skills education for adults and means the reader has skills at a level which matches the readability level of the work material [19]. The person thus needs to be able to read well enough to understand and interpret what he/she reads and use it as it was intended, as this will enable him/her to adequately cope in a complex society [18,23]. Functional literacy has also been described in other cases as the ability to use reading, writing and computational skills at a level adequate to meet the needs of everyday life situations such as communicating and operating a home budget [10,21-22].

Some definitions also include as part of literacy other mental skills such as numeracy and problem solving and it has also been defined as "the number of grade levels completed or the equivalent on achievement tests" [18,20]. The 1992 National Adult Literacy Survey (NALS) [24] in the U.S. adopted the following definition of literacy: "Using printed and written information to function in society, to achieve one's goals and to develop one's knowledge and potential". This definition goes beyond simply decoding and comprehending text to include a broad range of information-processing skills that adults use in accomplishing the range of tasks associated with the work, home and community contexts. The United States Congress, for example, incorporated a similar definition into the National Literacy Act of 1991, in which literacy was defined as "an individual's ability to read, write and speak in English, compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one's goals and develop one's knowledge and potential" [24-26].

From the above descriptions of the concept of literacy, it becomes clear that this is not a simple, clear-cut area of study [19]. Many would agree with Soare's [27] statement that "consensual agreement on a single definition of literacy is rather implausible" [3], although some would argue that the fact that there is no common definition for literacy does not imply that there is no need for one (Cervero 1985) [3]. Due to the many concepts or ideas involved in literacy, several investigators prefer the use of the plural term "literacies" [3].

An alternative method of defining literacy skills called the functional competency levels was introduced in the U.S. in the 1970s. This method measures the ability of people to perform literacy tasks over a range of difficulty levels. Functional competency is assessed by means of a multi-task literacy test and the results are scored on a scale of 0 to 500. The numerical data from literacy surveys can also be reported in 5 groups or levels i.e. level 1 being the lowest and level 5

the highest [28]. Adults included in Level 1 consist of those who could consistently succeed, in other words, those who at a given level of literacy have at least an 80% chance of correctly responding to a particular task, but could not succeed in Level 2 tasks. Level 1 not only includes those who could not consistently succeed with Level 2 tasks, but also those who were not literate enough in English to take the test at all. Adults in Levels 2 through 4 are consistently able to succeed with tasks at their level, but could not succeed consistently with the next more difficult level of tasks [24]. These functional competency measures are used in literacy surveys [28]. The NALS measured literacy along 3 dimensions: prose literacy, document literacy and quantitative literacy.

1.2.1 Prose literacy

Expository prose consists of printed information in the form of connected sentences and longer passages that define, describe or inform, such as newspaper stories or written instruction, whereas narrative prose tells a story but is less frequently used by adults in everyday life than by school children. Prose varies in its length, density and structures e.g. use of section headings or topic sentences for paragraphs. Literacy with prose implies that people can find information, integrate it from various parts of a passage of text and write new information related to the text. Prose literacy tasks vary in the difficulty of the demands they place on the readers. People can be assessed using literacy tasks to indicate their degree of prose literacy [24].

1.2.2 Document literacy

Documents consist of structured prose and quantitative information in complex arrays as formats arranged in rows and columns such as job applications, payroll forms, maps, tables and data forms e.g. a form for receiving medical care and graphs [24,29-30]. Literacy with documents mean that people can locate information, repeat the search as many times as needed to find all the

information, integrate it form various parts of a document and write new information as requested in appropriate places in a document. The degree of document literacy is measure in the same way as prose literacy [24].

1.2.3 Quantitative Literacy

Quantitative information may be displayed visually in graphs or charts or it may be displayed in numerical form using whole numbers, fractions, decimals, percentages or time units (hours and minutes). These quantities may appear in both prose and document form. Quantitative literacy means that people can locate quantities, repeat the search as many times as needed to find all the numbers, integrate information from various parts of a document, deduce the necessary arithmetic operation and perform arithmetic operations either alone or sequentially to numbers embedded in printed materials such as figuring a tip, completing an order form or determining the amount of interest on a loan from an advertisement. The degree of quantitative literacy is measured in the same way as prose and document literacy [24,30].

Growing numbers of individuals are expected to be able to attend to multiple features of information in lengthy and sometimes complex displays, to compare and contrast information, to integrate information from various parts of a text or document, to generate ideas and information based on what they read and to apply arithmetic operations to solve a problem. The results from surveys indicate that many adults do not demonstrate these levels of proficiency and therefore adult education programmes become increasingly important [24].

It can therefore be concluded that literacy is not a simple concept with a single accepted meaning and that it is relative rather than absolute. It does not merely involve simple reading or decoding of words, but also includes skill at comprehension and verbal reasoning ability [31]. This

therefore indicates that to test for literacy or to determine literacy levels, comprehension has to be established.

1.3 Literacy statistics in South Africa

Literacy statistics need to be approached with caution, as they are fundamentally flawed, both in that they usually make provision for only 2 categories: literate and illiterate, and are therefore insensitive to the complexities of ranges and varying types of literacy and in that they are unreliably measured. These therefore could be the reasons why estimates of the number of illiterate adults vary in South Africa as they do almost everywhere in the world [5,32-33].

When taking "no schooling" as an indication of complete illiteracy, some 24% of Black adults aged 20 and over are totally illiterate, 10% of Coloureds, 7% of Indians and only 1% of Whites [34]. From these statistics it can be seen that a considerable percentage of the population may have difficulty in reading and understanding written health care information. The percentage of black illiterates is relatively high and thus of great concern with regard to improvement and measurement of literacy.

Current discourse in South Africa tends to talk about adult basic education and training rather than literacy and Adult Basic Education and Training (ABET) has come to be defined as education and training provision for people aged 15 and over who are not engaged in formal schooling or higher education and who have an education level of less than Grade 9 (Standard 7). Table 1.1 summarizes recent figures for the basic education levels of adult South Africans aged 15 and over, using the 1995 October Household Survey and the 1996 General Population Census [34].

Table 1.1 Education levels of adult South Africans aged 15 and over

	1995 October Household Survey	**1996 General Population Census**
Number of adults (15 and over)	26.4 million (100%)	26.3 million (100%)
Full general education (Grade 9 and more)	14.3 million (54%)	13.1 million (50%)
Less than full general education (Less than Grade 9)	12.2 million (46%)	13.2 million (50%)
Less than Grade 7	7.4 million (28%)	8.5 million (32%)
No schooling	2.9 million (11%)	4.2 million (16%)

The World Factbook (1999) of South Africa reported a total literacy of 81.8% [35]. Literacy statistics in South Africa are possibly more problematic than anywhere else in the world. There are good reasons to suspect underenumeration, since some parts of the country were excluded from the most recent census (1996), i.e. no data was available from the former "independent" homelands of TBVC (Transkei, Bophuthatswana, Venda and Ciskei) [36-37]. These homelands have now been incorporated into the 9 provinces of South Africa, for example, the former Bophuthatswana is now part of the North West Province. The statistics shown in Table 1.1 indicate that there has been no decrease in the actual number or percentage of functionally illiterate adults, in fact they have been increasing and this should be of great concern. What is clear is that in both the 1995 survey and the 1996 census, about 7.5 to 8.5 million people were found to be functionally illiterate [34].

In 1990, UNESCO estimated that there were about 882 million illiterate people aged 15 and over in the world, over 800 million of whom lived in developing countries, resulting in an estimated illiteracy rate of 91% in these countries [5]. However, according to recent UNESCO figures (2000), there are 876 million illiterate adults in the world with about 98.7% of them living in developing countries [38]. The figure in the developing countries is increasing because many children are still not receiving primary schooling and are therefore adding to the numbers of

illiterate adults [5]. In comparing our statistics with those of developed countries, it can be concluded that the vast majority of illiterate adults live in "poor" countries such as those in Africa, since it has an estimated illiteracy rate of 20.8% as compared to 5% in America and only 0.9% in Europe [5,38].

Health care professionals might be aware that there is a high rate of illiteracy amongst the patients they see, but may find it difficult to identify such patients and hence regularly provide all patients with written information on prescription labels, appointment cards, consent forms and patient education pamphlets [39]. This practice poses a difficulty for adults with limited literacy skills and it may have adverse consequences on their health. Therefore it is essential that health care professionals know how widespread health literacy problems are and how to identify patients affected so that the written information can be tailored according to their literacy levels [40-41].

1.3.1 Literacy rates of urban vs. rural areas

Illiteracy rates are significantly higher in rural than in urban areas since in the former, rates for completing high school are often below those in cities [32,42]. This could be attributed to the fact that schools in rural areas serve a large geographical area and usually no transport is available to most of the students who then have to walk long distances to get there, which may affect the consistency of their attendance. Another reason is that the older children in the family are often instructed by their parents to leave school and find work in order to financially support the younger children.

The data from the 1991 Census and the research done by the Development Bank of Southern Africa (DBSA) on gender distribution of literacy skills contradicts the international trend towards higher illiteracy among women (26%) than among men (15%). The higher illiteracy rate for men

in South Africa could be due to the effects of the labour market and the migrant labour system, which encouraged men to leave school to look for work [32,38]. However, the trend changed as according to the 1996 South African census, illiteracy was higher in women (58%) than in men (41%) and it is of interest to note that this gap has decreased markedly as women now acquire higher education [34].

1.4 Literacy and the economy

Illiteracy rates have detrimental effects on the economy in general. Numerous claims have been made that a given minimum rate of literacy is a prerequisite for economic growth in developing countries. Literacy is of central importance to development and is increasingly correlated with higher income and job productivity. The social consequences of low levels of literacy in some cultures can include higher prison incarceration rates, welfare dependency and higher fertility [1]. The Riekert Report [19] found that a large percentage of the working population of South Africa, in terms of the norm of educational level only, do not possess the knowledge or skill to perform in the labour market in particular and in the economic system in general. According to the report, these people are not adequately functionally literate to cope with the normal everyday demands of the modern world with any kind of ease [19].

However, education does increase market productivity. The higher income resulting from increased market productivity should lead to increased expenditures on food, housing and medical care with improved health as a consequence [43]. The functionally illiterate are uniquely vulnerable because they are more likely to be poor, unemployed and working in jobs subject to seasonal and general economic fluctuations e.g. selling vegetables and fruit on the street pavements. They clearly occupy the lowest rung of the socioeconomic ladder [29,44]. Although low literacy is most prevalent among individuals of low socioeconomic status, individuals with

poor reading skills come from all walks of life and all socioeconomic groups [45-47]. Therefore it is important when testing for literacy that people of all socio-economic levels are tested.

1.5 Literacy and its influence on health

1.5.1 Relationship between literacy and health

Low literacy is a pervasive and under-recognized problem in health care as many health care professionals, researchers and educators may be unaware of a patient's reading or comprehension problems [39,48-49]. A negative relationship exists between literacy and health, although illiteracy has been found not to be the direct cause of poor health, in that the inability to read does not automatically make the person ill [21,26,31,44,49-53]. The health care system requires that patients be able to read, so illiteracy can be viewed as a form of lack of access to adequate health care, resulting in patients with low reading ability having difficulty accessing the health care system and understanding instructions and recommended treatments [26,54-55]. For many patients, lack of literacy skills is a major obstacle to effective health care communication and as a result low literacy has been shown to be independently associated with poor health [35,47]. The most poorly educated adults, those with the lowest literacy levels, suffer the highest rates of morbidity and mortality from chronic diseases and conditions. The fact that they can neither read nor understand the information necessary to improve their health would seem to be an important contributing factor [56]. Many poor readers feel a sense of shame regarding their inability to read, which further impairs their ability to communicate with health care providers [45].

Weiss and colleagues [57] directly tested the association between literacy and health and found that low literacy (the ability to read, write and comprehend information between fifth and eighth grade levels [26]) was significantly associated with poorer physical and psychosocial health status; the associations remained significant after adjustment for other measures of socioeconomic status, e.g. age, gender and marital status [22,45]. Patients with low literacy skills

were found to require far greater medical care than those with marginal literacy skills [44-45,53], were more likely to report their health as poor and were more likely to have been hospitalized in the previous year than people with higher literacy levels [40,45,51-52,58]. Kuh and Stirling [59] found the risk of hospitalization for diseases of the female genital system was more than twice as high for the least educated as compared with the most educated women.

Mistakes resulting from poor reading skills can lead to repeated hospitalizations and may be costing the health care industry billions of rands. Although the cost of illiteracy to the health care system is difficult to measure because of confounding socioeconomic variables, several studies in the U.S. have shown that patients with low reading skills use more health care resources [52,58].

Research to date suggests that low literacy may be an important factor associated with increased cancer risk and poor response to cancer control programs. However, the specific and potentially independent effect of literacy on cancer risk and cancer control has not been established. Fredrickson and colleagues [60] reported that lower reading ability was associated with a greater likelihood of smoking, a lower likelihood of breastfeeding and a lack of private health insurance.

People with low literacy skills may also have difficulty understanding health messages, since many educational materials use text and therefore tools for assessing patients' reading levels and the readability of educational materials may be necessary [48]. Although the strong, significant, independent association of literacy or schooling with mortality in developing countries has been confirmed by repeated studies and is given support by similar findings in the U.S., the direction of causality and the mechanisms by which literacy influences health status are less clearly established [43].

1.5.2 Literacy and maternal and infant health in developing countries

Life expectancy can be determined by several factors. After applying statistical tests to determine which factor(s) appeared to be causal, Sagan [61] found that "by far the most consistently powerful predictor of life expectancy was the prevalence of literacy". The recognition of literacy as a major determinant of health status in developing countries emerged in the literature in the late 1970s [43].

The estimated maternal mortality rate for Africa in general is 640 per 100 000. Using the Nigerian scene to illustrate his case, Harrison [62] mentioned harmful traditional customs and cultural practices, poor acceptance of antenatal care by illiterate women, and the recent difficulties posed to maternal health by "churches" and prayer houses. He made the point that the extent to which traditional cultures govern our lives is much greater without formal education than with it. Cultural literacy plays a major role here and this involves knowing how to communicate without having to explain [19,63]. Infrequently therefore, the illiterate woman is unable to resist aspects of her culture and tradition that are clearly detrimental to her health. Partly because of poverty, ignorance and superstition, illiterate women do not accept antenatal care with its proven advantages, as readily as their literate counterparts do. With no prior intentions to come to hospital, illiterate women report to health institutions only when difficulties develop during labour or when existing disease worsens. Due to the delay caused by their late presentation and the severity of the disease, these women die even before treatment can be initiated [63].

An understanding of the determinants of infant mortality is of critical importance to underdeveloped countries. Such an understanding might facilitate a reduction in fertility, since it is widely accepted that a fall in infant mortality will lead ultimately to lower fertility [64].

Preston [65] argued that "the cost-effectiveness of literacy gains in reducing mortality is so great that it may well exceed that of expenditures directed at health problems". Variables such as the educational level and occupation of the mother and father, and urban/rural residence can reduce child mortality. However, Caldwell and McDonald [66] found that parental education has a major impact when compared with income factors and access to health facilities combined. Studies from India have noted that literate mothers utilize modern health services more than do illiterate mothers and it was concluded that this was one way in which literacy led to lower infant and child mortality [43]. Low mortality rates have also been seen in Third World countries and some of their urban populations because of global biomedical science which is far more advanced than it was at the beginning of the present century [67].

Cochrane's review of studies [68] of the relationships between education and fertility concluded that education might either increase or decrease individual fertility. The decrease is greater for the educated women in urban than rural areas, but education is more likely to increase fertility in countries with the lowest level of female literacy. The explanation for this was given by Bongaarts et al [69] regarding the analysis of fertility determinants in Sub-Saharan Africa where educated, urban women, although they tend to marry later, generally abstain sexually for shorter periods after delivery and tend to replace breast-feeding earlier or altogether with milk or solid foods.

1.5.3 Literacy and chronic patients

Inadequate literacy is especially prevalent among the elderly, the population with the largest burden of chronic disease and consequently the greatest health-related reading demands. People with inadequate literacy who suffer from chronic diseases e.g. hypertension and diabetes are less likely to know the basic facts about their disease such as the range for a normal blood sugar,

symptoms of hypoglycaemia or elements of their care plan, for example what to do if they develop symptoms of hypoglycaemia [29,70]. Similarly those with hypertension and inadequate functional health literacy are less likely to know basic information about hypertension e.g. what a normal blood pressure is and are less likely to know what foods have a high sodium content [70]. Those with diabetes would be particularly disadvantaged since their self-management education relies heavily on printed instructions for meal planning, exercise, foot care and the adjustment of drug therapy [71]. The prevalence of poor reading skills may partly explain the worse health outcomes after hospital discharge of asthma patients with lower socioeconomic status [55].

Acquired Immune-Deficiency Syndrome (AIDS) is one of the "killer diseases" worldwide and as such has attracted the attention of HCPs and particularly of scientists. People living with Human Immunodeficiency Virus (HIV) and/or AIDS have to take charge of their health. A person with HIV is often on long-term, multiple drug therapy and may be required to take as many as 30 pills a day [72-73]. Since medications are often required to be taken on rigid time schedules and sometimes with certain types of food, adhering to treatment schedules poses great challenges which are exacerbated if the person has poor literacy skills [73]. It is essential to develop accessible, appropriate and comprehensible health information for such patients.

1.5.4 Literacy and noncompliance

1.5.4.1 Defining compliance and related terms

Patient compliance is difficult to define and as such alternative terms or words have been used [74-75]. It is often quantified simply as the percentage of prescribed doses taken e.g. by using a tablet count or an average dose that is about 70% of the recommended dose [74,76]. Compliance was also defined as "the extent to which a patient's drug-taking behaviour coincided with a prescribed medical regimen or health advice" [18,75,77-78]. It has been described as "the point below which the desired preventive or therapeutic result is unlikely to be achieved" [79-80]. It is

the "positive behaviour that patients exhibit when moving toward mutually defined therapeutic goals" [18].

The term "compliance" however, has been criticized for implicitly suggesting that the patient must "do as the doctor says". It has been described as the extent to which patients follow the advice given to them by health care professionals [75,81]. A good patient-physician relationship should allow for a two-way dialogue and an agreement between them to decide on the best course of action to be followed, hence the terms "concordance" and "adherence" [80-81]. It has been argued by some authors that the patients should be the ones to assess the advantages and disadvantages of prescribed therapies. Donovan and Blake [82] concluded that perhaps the issue should not be compliance, but how medical staff can understand and participate in the decisions that patients already take about their medications i.e. concordance.

The word concordance was coined to describe an approach to bringing patients into a full therapeutic partnership. Unlike compliance which involves only one person, the patient, concordance involves at least 2 people, a patient and a prescriber. The aim of concordance is to assist the patient in making an informed choice about the diagnosis and the benefits and risks of treatment [80,83].

Haynes [84] also suggested using "adherence" interchangeably with "compliance". By definition the word adherence means to stick fast to a substance, give support to agreement, opinion or party and behave according to rule or promise [85]. In pharmacy, it is understood that a patient is compliant when such patient "adheres" to all the instructions supplied by the HCP relating to the taking of the medicine [86]. It therefore appears that "compliance" and "adherence" are defined in the same way. The person is behaving according to a rule, in other words, he/she is following

someone else's orders. With concordance there is an agreement, but sometimes the patient can decide to decline taking the treatment as advised, in which case his/her rejection should not be used as the basis for his/her rejection by the HCP [83].

1.5.4.2 Extent and effects of noncompliance

Levels of compliance judged to be acceptable range from "at or near" 100% to 80%. These levels should be specified for each disease and treatment below which a patient's condition deteriorates clinically. However, such levels are often impossible to determine and so in many circumstances a generally acceptable level of compliance has to be applied arbitrarily [74]. One reviewer of the compliance literature has estimated that on average only one third of patients correctly follow HCPs directions [87] and Preece [88] has demonstrated that up to 50% of patients may not comply with their medication regimen. The reported incidence of noncompliance ranges from 4% to 92% with an average noncompliance rate for chronic drug therapy of 50% [18,75,77]. The highest noncompliance rates have consistently been found in patients with chronic disorders involving long-term treatment and in whom the illness has asymptomatic periods during which the clinical consequences of noncompliance are often delayed e.g. epilepsy [77].

Noncompliance can have serious ramifications for a person's health. The underuse of medicines may prevent the patient from obtaining optimal therapeutic benefit from the prescribed regimen resulting in poor medical outcomes, delayed recovery from or deterioration of acute illness and disease progression in chronic illness (and potentially increased morbidity) thereby preventing the HCP from effectively evaluating the efficacy of the regimen and thus leaving him/her considerably frustrated. Poor medical outcomes could also prompt dissatisfaction on the part of the patient with the health care delivery system and thus cause deterioration of the patient-physician relationship [18,75,77,79,87,89-91]. If the HCP is unaware of noncompliance,

additional medicines may be unnecessarily added to the regimen (which further increase the risk of drug-induced illness) and the patient may require an increased number of return visits to the doctor or increased hospital admissions resulting in inestimable costs. Noncompliance may result in absenteeism from work/school and decreased employment prospects all of which have adverse economic effects [18,53,75,77,89-91].

1.5.4.3 Intentional versus unintentional noncompliance

Noncompliance can be classified by patient intent (intentional or unintentional), by dosing behaviour (too much or too little of the medicine), by extent (no medication taken) and by cause (patient education e.g. patient is not instructed or did not understand how to use a medicine) [81]. In this section, the author will be discussing classification by patient intent.

Patients do not comply for various reasons and can thus be divided into either intentional or unintentional noncompliers. If the patient does not present a prescription to a pharmacist in order to obtain the medicine in the first place, he/she can be regarded as an intentional noncomplier [80]. Patients who consciously choose not to take their medicines in the way they have been told or choose to find another method of treatment are sometimes referred to as "deliberate non-compliers" [18,53,74]. Deliberate noncompliance can be in the patient's interest, for example, taking sedatives, laxatives and analgesics only when required, even if the medicines are prescribed to be taken regularly [74].

"Innocent" or unintentional failure to comply can result from a number of factors, all of which are more likely to occur with increasing complexity of the regimen i.e. the number of medicines being taken, frequency and timing of dosing [18,74-75,77,79-80,87,92]. Forgetfulness is a natural human trait; the more complicated a regimen, the more difficult it is to remember or follow. Lack

of information and/or knowledge e.g. inadequate understanding of the disease or condition and not knowing the importance of continuing with the treatment could result in failure to comply, which can be regarded as being unintentional [18,53,74-75,80,93-95]. Some of the elderly rely on their family to collect their prescriptions from doctors to be filled at pharmacies; if the people concerned are not able to do so, this may result in them being unintentionally noncompliant [96].

1.5.4.4 Reasons for noncompliance

The reason for noncompliance with medication might lie with the patient, the pharmacist or another member of the health care team, or with a combination of these people [74]. The effect of a regimen on a patient's lifestyle and the ease with which it can be accommodated into his/her daily routine could cause noncompliance. If the patient has been taking the medicine for a long time, this could result in him/her stopping the treatment on the basis that he is now well and therefore the patient thinks he does not need the treatment any more [18,75,77,79,92]. Noncompliance is a problem for all ages, however, it is clear that the normal ageing process involves a gradual decline in the cognitive abilities needed by patients in order to take their medication properly, such as visual acuity, memory, ability to understand and remember text and in their physical abilities e.g. arthritis. If the medicine container is disliked by the patient i.e. either because it is too bulky or too difficult to open, such as child resistant closures, this could result in the patient not taking the medicine [74,80,75,96-97].

Other reasons for noncompliance include poor communication between HCPs and patients, poorly organized health services, and the cost of medicines and their side effects [18,75,79-80,92-93,97]. Attitude and what the patient believes about him/herself and the illness often predicts the degree of compliance. According to the Health Belief Model developed by Becker [98], a patient is more likely to comply with the therapy when he believes that the doctor is correct, the illness can cause

him/her harm and the prescribed therapy will reduce the risk of complication or death or that his/her health will improve. If the patient does not believe in any of the points mentioned above, then he/she may not comply. It is important to recognize that providing information that is too detailed or inappropriately presented e.g. too small a font used on medication containers, may actually discourage the patient from taking the medicines [91].

1.5.4.5 Influence of low literacy on noncompliance

Low literacy and illiteracy are contributing factors to noncompliance [18,99-100]. HCPs provide a lot of written teaching material to their patients through brochures, booklets and diet lists. Unfortunately much of this literature goes unused because a significant proportion of the population might not be able to read it and therefore will fail to obtain necessary preventative and therapeutic health services [50-51,101]. The inability to read and understand written information can interfere with a patient's adherence to a recommended regimen, thus causing complications in therapy [101]. Recent studies have found that patients with extremely limited literacy skills have limited health knowledge and may not understand basic health concepts such as the purpose of a mammography or instructions to take medicine orally, on an empty stomach or 3 times a day [99]. They may also lack the reading and communication skills needed to take advantage of medical treatment that is available to them, potentially resulting in inappropriate overuse or underuse of medical services and hence practice unintentional noncompliance [44,50]. Such individuals often do not understand what a physician has said and may not be willing to ask physicians for clarification or tell them that they do not understand and hence may misinterpret health-related information that is essential to their well-being [50,99].

People with poor reading skills have difficulty analyzing instructions, which in turn inhibits their ability to formulate questions i.e. they tend to lack the necessary vocabulary to ask pertinent

questions [18,39,47,99]. One possible explanation is the lack of self-empowerment and self-efficacy that often accompanies illiteracy. People who lack self-empowerment, perceive that their life circumstances depend on external events over which they have no control and thus are unable to master the assertiveness necessary to successfully negotiate their way through an increasingly complex and bureaucratic health care system. Such individuals may fail to "take charge" of their own health situations and this may adversely affect the way in which they interact with the health care system [50-51].

The need for appropriately written information is compounded by the fact that patients forget about one-half of oral instructions within 5 minutes after receiving them. An example of unintentional noncompliance which illustrates some of the concepts discussed above follows: a man who lived at home with his family was discharged from hospital after recurrent congestive heart failure. A cardiologist instructed him to take digoxin 0.125mg PO, alternating with 0.25mg PO every other day. The patient stated that he understood the directions and was given written instructions for reference. At the next visit his digoxin level was well above therapeutic range. He had been taking both pills every day instead of alternating the doses. He still had the written directions in his wallet, but admitted that he could not read them stating, "I don't want anyone to know. They'll think I'm stupid" [9,47]. This failure to retain information combined with inappropriate reading levels may contribute to decreased compliance and increased morbidity [102].

1.6 Functional health literacy

1.6.1 Definition of health literacy

The concept of health literacy surfaced from a rising concern among healthcare providers and adult education practitioners about the number of patients who do not possess the literacy skills needed to maintain a healthy lifestyle. It is defined as a patient's ability to read and comprehend

health-related materials such as prescriptions, patient information leaflets, medication labels and directions or home health care [21,29,103]. Williams et al [104] have defined functional health literacy as a range of basic skills necessary to function in the health care environment. Adults who function at the lowest literacy level find it difficult to understand the instructions of the medical care providers and read consent forms and instructions on prescription labels, whereas individuals with limited English proficiency have cultural and language barriers that hinder their understanding of the healthcare system [103]. The National Health Education Standards define health literacy as "the capacity of an individual to obtain, interpret and understand basic health information and services and the competence to use such information and services in ways which are health enhancing" [26].

Health care professionals have been concerned for many years about the reading difficulty of commercially developed patient education materials, many of which are written at or above the ninth-grade reading level. Several authors have emphasized the importance of the ability of patients to both read and understand the educational materials provided [105].

The assumption that the last grade level completed equals literacy skills is likely to be erroneous, as the grade level does not necessarily give an estimate of functional health literacy, studies of which have been limited by the lack of inappropriate testing instrument [21,105]. Comprehension is dependent upon reading skills, rather than on grade completed and the actual reading ability has often been found to be below the reading level indicated by literacy tests. This problem is highlighted by the finding that to read the instructions on over-the-counter contraceptives, an individual would have to be able to read at the eleventh-grade level [105].

1.6.2 Characteristics of low-literate patients

People with poor literacy vary greatly and usually many are older and did not complete high school [46]. Given the high percentage of illiterate adults in South Africa, many patients may have difficulty reading and understanding all types of health information materials such as discharge instructions, medication labels, patient education materials, consent forms or health surveys [39]. According to the Living Standards and Development (LSDS) data, 58% of all South Africans who seek care for an illness do so in the private sector, therefore 42% seek care in the public health care centres [106]. It can almost be guaranteed that of the latter, the majority are Africans, as the demographics of people with poor literacy skills suggest that they represent a significant proportion of health care consumers who visit health departments, primary care facilities and community–based health centres [107]. These people as has already been noted, have poorer health, higher medical expenses and an increased number of hospital and outpatient visits compared with those who have a higher literacy level [108].

Even though they may not be aware of it, health care professionals encounter patients with limited literacy on a daily basis and should not assume that their patients know how to read and are able to understand written instructions [52,108]. Many persons with poor reading skills are ashamed and have developed methods for concealing their illiteracy and in some situations, patients' inability to read or write or understand directions for medications is rarely obvious and as a result it might never be discovered [33,40,51-52,54,108-110].

1.6.3 Low-literate patients and health care information

Illiteracy can be deadly and thus HCPs need to know the patients they serve [9,111]. Assessing and thereby knowing patients' literacy skills can be used to guide HCPs in selecting and developing appropriate educational materials i.e. "tailoring" health care information towards their

literacy levels, however little has been done to explore the impact of illiteracy on health care [21,39]. For example, if the average reading level of patients in a day hospital is below the ninth-grade level, standard patient educational materials, which are generally written at a high school or tertiary level, will rarely be useful [39]. The reading abilities of most patients in public settings have been shown to be much lower than the required reading levels of written materials such as vaccine information pamphlets [112].

Parents are the care providers for their children and therefore should be able to read and understand written paedriatic information to do this effectively. Unfortunately many patient education materials are written at too high a reading level for a large number of parents i.e. eighth grade or higher and some findings have suggested that written instructions below seventh grade level may be needed for parents [101,112]. Child health care will be compromised if physicians incorrectly assume that all parents can read and understand health-related materials [113].

Current materials contain an excessive amount of information that most patients do not find useful, so the idea is to write for the desired health behavior, rather than for high-level knowledge [112]. This is highlighted by one study where a 5- to 7- year discrepancy was found between the reading comprehension of the average public clinic patient and the ability levels needed to read most patient education materials [114].

1.6.4 Assessing reading skills of low-literate patients

When a patient can neither read nor understand medication instructions, HCPs must try to find creative ways to communicate [39,111]. Assessment of patients' reading skills is useful to HCPs in clinical settings. Aggregate testing rather than individual testing of patients provides HCPs in a clinic or hospital system with a profile of their patients' reading levels [39]. Simply asking

patients if they can read is not a sufficient assessment of their skills, as many adults with poor literacy skills successfully conceal this from others. The easiest way to find out how literate a person is would be to ask him/her how many years of schooling have they completed, but it is not sufficient to ask patients about their education level (highest grade completed in school), because although there is a relationship between education and literacy, reading skills cannot be accurately predicted from educational attainment [39-40,115]. It needs to be remembered that years of schooling may reflect what people have been exposed to, but gives no guarantee of the acquisition of literacy skills, which are highly perishable if there are no regular opportunities to read and write. Hence, while there may be some who progress from illiteracy or semi-literacy as a result of informal learning opportunities in society, there are many more who relapse from literacy into illiteracy [5,17].

Surveys have shown that people read 3 to 5 grades lower than the years of schooling completed [9,28,116]. Literacy level is both a better indicator of what a person learned in school and of a person's ability to acquire new knowledge and cope with societal demand. Future studies of education and health should use literacy as their measure of educational attainment, since literacy skills may be a stronger correlate to health status than education level [39,58]. In fact, several studies have linked literacy level independent of educational attainment to health status, knowledge, behaviours and costs [39].

1.7 Readability of patient education materials

Information leaflets, pamphlets, brochures and medication and discharge sheets are examples of the many types of patient education materials provided in health care facilities as an adjunct to verbal instructions and information sharing by health care professionals [57]. Written materials complement verbal explanations by providing a reference point once a patient leaves the health-

care setting, as well as providing additional information that is aimed at increasing a patient's understanding of a particular subject [101]. They provide information about the patients' health, disease process, drug and treatment regimen and how they can take care of themselves when they get home, without having to use drugs. Therefore it is imperative that patients be able to read and understand the literature given to them; their reading abilities must match the reading levels of the written material [57,101-102].

Most health information however is written for a reading level beyond tenth grade comprehension [51,56]. Many studies that compare the reading difficulties of health materials with the skills of the reading public indicate that there is a broad gap between the readers and the materials. These studies have shown that the reading level of patient education materials ranges from the ninth- to twelfth-grade levels and therefore they are not written at an appropriate reading level for the target populations [56,101,117-118]. Swanson and colleagues [119] compared the readability levels of written instructions for different types of contraception. Package inserts had the most difficult readability (Grades 9 to 11), followed by generic (standard) instruction sheets (Grade 8). The latter were still outside the reading range of most of the target population. Swanson et al therefore suggested that authors of generic instruction sheets should try to inform health providers regarding the reading level needed to understand those materials, so that they could be given to the appropriate patients and also that drug companies be mandated, maybe by the Food and Drug Administration to write product inserts at an appropriate reading level.

Information in patient information leaflets should be aimed at the fifth grade level or lower. People at all levels of literacy and education, even those with well-developed reading skills, prefer easy-to-read materials and understand them better, since materials written at a higher level tend to lower understanding and clarity [9,46,51,79,101,120-121].

Many attempts have been made to suggest comprehensive guidelines for the development of more readable health education publications with the main emphasis being placed on text simplification [9,45]. Randomized studies to evaluate the effects of simplifying the text of health education literature to make it more readable consistently report some improvement in comprehensibility. Studies of patients who were randomly assigned simply written or more difficult pamphlets on bronchoscopy, warfarin, medication for depression and antismoking education found that patients assigned the simpler pamphlet scored significantly higher on various indices of comprehension. Two of these studies also reported that simplifying the text resulted in greater comprehension for both good and poor readers, improved overall medical compliance, enhanced the wellness of patients and reduced the cost of caring by preventing illness and limiting hospitalization [45,115].

The results of the randomized study of patients receiving 2 versions of a pamphlet on cervical cancer and condyloma indicated that effective use of illustrations and text style can improve comprehension for poor readers. These results suggest that attention to other aspects of readability such as text style and the use of illustrations can make fairly difficult text (seventh – eighth grade reading level) more accessible to poor readers [45]. Another strategy that has been considered in simplifying health education materials was to rewrite them [115].

1.7.1 Readability assessment methods

Health educators and medical providers have been persistently concerned with the evaluation of the readability of printed health education materials as it has been recognized that people's health depends partly on their ability to read and understand medical information [45,122]. Readability is expressed as the reading ease or difficulty of the materials and is quantified by readability formulae [117]. These are procedures most frequently used to evaluate health education materials and calculate the required reading level in grade-level equivalents [45]. They offer health care

professionals a convenient and easy-to-use method to assess the reading difficulty and comprehension of most printed materials [28,101,108,123-124].

Readability formulae used to evaluate a variety of health education materials include the SMOG, Flesh or Flesh-Kincaid, Dale Chall, Fry, and Gunning's Fog Index (FOG) [45,101]. These formulae are based on 2 factors: word difficulty and sentence length [28,117]. The greater the number of multi-syllable words, the greater the reading difficulty and also the longer the sentences, the greater the reading difficulty [28]. Most commonly used formulae are the SMOG, Fog and Fry readability tests. Recently, health-care providers have begun using these formulae to evaluate written materials for target populations [101].

The SMOG formula is a simple formula using the number of polysyllabic words in a set number of sentences to calculate an approximate grade level of reading ability. It theoretically measures the reading grade level needed to assure complete comprehension i.e. 100% as opposed to that needed to read text with a general comprehension of only 50% to 75% [101,125].

The Fog Readability Test uses average sentence length and the percentage of polysyllabic words to estimate a grade reading level [101]. For example grade level = (number of words/number of sentences + number of three-syllable words) x 0.4 [45]. This index requires that 75% of persons reading at a given grade level be able to understand the text.

The Fry Readability Test looks at the ratio of the number of syllables per 100 words to the number of sentences per 100 words. The Fry is based on 50% comprehension at a given grade level i.e. it is not necessary to test the readability of every word and sentence [28,101,116].

Readability formulae however have a number of disadvantages:

i) They make no allowances for the presence of ambiguous words or phrases which may reduce the comprehensibility of the leaflet [67] and

ii) Although the numbers obtained may be useful for statistical analysis i.e. estimating the "grade levels" of patient information materials, they may not indicate whether a given passage is understandable for a given group of patients i.e. patients' knowledge of the subject area or the concept level of the text [67,100].

Improving the quality of a patient's recovery as well as enhancing compliance with follow-up care often depends on well written and easy-to-understand materials. Readable literature is not an option, but a requirement. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) in the U.S. mandates that patients be informed. One JCAHO standard states that teaching should be provided in a comprehensible manner that takes literacy, educational level and language into consideration [9,26,47,54]. Readability and comprehension of written instructions are essential for patients to receive proper medical care and therefore simpler, easy-to-read materials written in the everyday language of the target population are essential [39,126].

1.8 Communicating with the low-literate patient

Ideally, every patient should be tested and then given written material specifically matched to his/her reading level. However, a more realistic goal is to devise literature that can be used by as many patients as possible. It can also be argued that all patients should be screened with a formal test at their initial medical evaluation, since illiteracy is such a common concept [9,124]. But once the abilities of patients in a particular unit or setting have been assessed, a general range of reading levels can be identified. The reading level of patient information materials should be adjusted as low as possible to reach the maximum number of patients without giving up important

information. Some HCPs may feel that patients with higher reading levels might object to information several grades below their reading level, but people actually prefer material that is simpler to read and research has demonstrated that regardless of a patient's reading level, simply worded material offers the best communication [9,52].

Patients with low literacy skills, in particular, need to be able to understand oral and written information about their medical conditions, follow written information and numerical directions regarding their therapeutic regimens and, in order to do this they need simple instructions [21,39,52]. Such people rely on oral explanations, demonstrations of tasks and visuals [22,28]. It is often best for providers to demonstrate desired skills e.g. using an asthma inhaler, rather than having patients read about the skills. Furthermore, HCPs should then have the patient demonstrate the skills to ensure they have been adequately understood. This "show me" technique applies to many health care behaviours in addition to specific manual skills like inhaler use. Health care providers should not assume low-literate patients can read the instructions on medication bottles, rather they should ask the patient to "show me" how to take the medication [39,54,124,127]. The active voice is more effective than the passive voice e.g. a statement such as "Take one tablet before each meal" will be more effective than "it is better if this medication is taken before meals" [9]. Careful restating of patient instructions can also be highly effective [52].

Compassion is essential in detecting and dealing with illiterate persons, who may be greatly ashamed of their handicap [52]. However, the only way to fairly evaluate the usefulness of printed materials as a component of community health education among high-risk groups is to develop materials that can be read and understood by the target population [126]. Information is best presented in clear, short sentences; long sentences and paragraphs should be avoided whenever possible [100,128,124]. When caring for patients with limited literacy, HCPs must use

creative approaches including audio- and videotapes (can be used for television-literate people) and picture books to teach or obtain informed consent [22,39-40,47,51,57,110,129]. Videotapes may provide useful education for patients with low literacy levels, but this technology is expensive and may prove impractical for use on a large scale in public clinics. One-on-one oral instruction may be the most effective way of communicating with the low-literate patients, but it is labour intensive and time consuming [28,115]. These videos should only be used in addition to regular patient education activities not as the sole source of patient education [47]. Audio- and videotaped health instructions are not popular in South Africa, but they need to be considered.

The use of pictograms in pharmacy has been receiving increased attention over the past few years, possibly due to an increased awareness of the needs of special patient populations such as the low-literate [86,130]. Their success as a communication aid in pharmacy however, depends first on a rigorous design and testing process and secondly on their diligent application by HCPs trained in their usage [53]. Pictograms can also be helpful aids in understanding and remembering leaflet information and thus should accurately show what the patient is supposed to do [28,53,100,131]. The brain has more access routes and greater storage capacity for pictorial images than for words. Therefore details that might otherwise be lost can be constructed through visual association [28]. Pictures/pictographs/pictograms as they are alternately called, should be simple line drawings and clear and specific to the message so that poor readers can use them as clues to understand the information [9,130]. Peter Houts [52] once stated "Cued recall is far more effective than simple verbal instructions. By giving the patient a picture as a reminder, recall rates can go from 15% to 85%, hence the saying "a picture is worth a thousand words" [28]. Pictures should not be designed to convey the message by itself, but to complement a health care provider's instructions i.e. should always be accompanied by a comprehensive verbal explanation and thus will serve as a reminder to both the pharmacist and the patient [52-53, 86,130,132].

It is essential for the pharmacist or the HCP to ensure that the patient understands, remembers and complies with medical instructions, as this forms part of the pharmaceutical care plan, a relatively recent pharmacy practice model, which holds pharmacists responsible for assuring that drug therapy is used appropriately to achieve positive patient outcomes [41,99,133].

CHAPTER TWO
APPROACHES TO HEALTH LITERACY MEASUREMENT

2.1 The need for assessing health literacy

Illiterate patients require more intensive, specialized counselling to ensure their understanding of health instructions. However, a major problem lies with identifying these patients [134]. In order to do so, a quick, non-threatening test should be devised that can effectively evaluate the reading level. Although it is impractical to screen all patients for illiteracy, the first group that should be targeted is the patient with multiple medical problems who is at highest risk for complications due to mistakes with medicines and diagnostic tests [52,134]. A primary goal of most reported research that has made use of word recognition and/or comprehension tests has been to estimate the overall level of literacy of patient populations [45].

The Health Literacy Project (HLP) in the U.S. agrees with this statement, as it does not recommend testing individual patients unless health education interventions are being specifically tailored to that patient [39]. However, the HLP recommends that the reading grade levels of patients should not to be recorded in medical records due to potential ramifications for employment or job security. They feel that if health care providers test patients' literacy skills, they need to be sensitive to patients' concerns and potential embarrassment and ensure that the testing results will be confidential [39]. However, grade-level placement can have a few advantages:

i) It makes it easier for the practitioner to specialize his/her counseling for the patient

ii) It also allows researchers to more specifically evaluate an individual's literacy level for better use in evaluations and analysis [135].

Two basic approaches to measuring literacy have been described:

- *Direct assessment* which allows us to determine literacy levels based on performance in a test or on literacy tasks given by an examiner, and
- *Indirect assessment* which allows us to determine literacy from "proxy" information that is known to be (indirectly) related to literacy such as number of years of schooling [136].

2.2 Indirect assessment of health literacy

This is a cheap and practical method. Literacy statistics internationally are usually based on levels of formal education and rely on the assumption that there is a good correlation between school education and literacy [137]. The problem with these statistics is that they cannot accommodate people who have never attended a formal school but have improved their literacy skills through adult literacy programmes [37]. Researchers have found that one cannot assume that a specified number of years of schooling will result in the same literacy level for all individuals as a number of variables such as quality of education and attitude of parents towards education will influence the learner [32,37]. In fact in one study in the U.S., people with a high school education were found to possess poor reading skills, limited vocabulary, little knowledge of health issues and a weak ability to acquire and use new knowledge [29]. It has also been found that grade completion may not positively correlate with patients' reading skills since occupations and recreational habits may promote or impede the maintenance of reading skills [102].

2.3 Direct assessment of health literacy

Readability measurement is a direct assessment method and involves testing a patient's ability to "transcode a series of kinesthetic symbols," i.e. to translate words into meaning, and it tests the patient's ability to understand what he/she has translated or comprehended [102].

2.3.1 Informal assessment

Some clinicians have developed informal methods to determine if a patient has sufficient reading skills to understand written information. One common straightforward method is for the health care provider to simply ask open-ended questions concerning what patients understand about what they have read. For example, the University of New England Health Literacy Center in Maine suggests saying, "You know, I give out these instructions so many times a day, I sometimes overlook something. Would you tell me what you have learned so I can be sure you understood everything?" Other quick checks involve asking patients to read a form, a prescription medicine label or asking them specific questions about instructions they have received [39]. Another way of finding out a patient's reading skill level is to simply hand him/her a written material upside-down; most readers will reorient the page, whereas those with a reading handicap may not [52,110]. However, the problem with this is that one may embarrass the patient and thus loose their trust and the patient may seek health care elsewhere.

2.3.2 Formal assessment

Formal assessments of literacy skills in health care settings can be divided into 2 categories: word recognition tests and comprehension tests [39]. Both word recognition and comprehension tests are used in health education research and practice to estimate the reading ability (literacy) of individuals. There is considerable debate as to whether both types of tests should be used. "Batteries" of reading tests used in schools to evaluate students generally include both word recognition and comprehension sections and both convey important information to instructors about different aspects of a student's development [45].

2.3.2.1 Word Recognition Tests

Word recognition tests in which individuals read aloud from a list of individual words are useful predictors of general reading ability. In administering this test, the examiner presents a patient with a list of words that vary in difficulty from easy to complex. Reading of words continues until the patient encounters words he or she cannot pronounce. These tests do not measure reading comprehension or interpretation *per se*, but only the ability to recognize, or read and pronounce individual words. The rationale behind word recognition tests is that if patients have trouble pronouncing words, which is a beginning-level reading skill, they are likely to have difficulty with comprehension, which is a higher order skill. If the difficulty occurs in reading simple words from the list, comprehension is likely to be limited. In health care settings, word recognition tests are essentially used as proxies for comprehension tests.

Reading recognition tests are quick and easy to score; they are easy to administer, they require less training to administer and interpret and are appropriate measures to identify low-level readers [39,45]. These tests can alert clinicians to the possibility that their patients may have difficulty with printed educational materials. Those who score very poorly may also have trouble with oral provider-patient communication. Examples of such tests are the WRAT-R or WRAT-3 test (Wide Range Achievement-Revised) and the REALM test (Rapid Estimate of Adult Literacy in Medicine) [22,39,45,51].

2.3.2.2 Comprehension Assessment

Comprehension tests assess a patient's ability to understand text written at different levels of difficulty, but require more time and skill to administer than word recognition tests. Such assessments can be useful in both clinical research and in developing and testing the comprehensibility of written educational materials. They are not, however, practical for routine

assessments of literacy skills in clinic settings. Examples of such tests are the Cloze technique [28] and the Test of Functional Health Literacy in Adults (TOFHLA) [39].

2.4 Commonly used health literacy tests

2.4.1 TOFHLA Test (Test of Functional Health Literacy in Adults)

The test consists of 2 parts: reading comprehension and numeracy [21]. It uses written forms e.g. medical labels or forms explaining Medical aid rights and responsibilities. It measures the patient's ability to read and understand 3 prose passages; preparation for an upper gastrointestinal tract radiograph series, the patient's rights and responsibilities section of a Medicaid application form and a standard hospital informed consent form [29,138]. The test also measures the patient's numeric literacy skills and the ability to interpret and act on forms, medication directions and other forms of communication that are typical in health care settings [120]. It takes about 22 minutes to administer and the content validity is good, as text forms commonly encountered in health care settings are used [21,39].

The Reading Comprehension section is a 50-item test using the modified Cloze procedure [21]. The Cloze test was developed by Taylor in 1953 and was designed in such a way that every fifth word is deleted from a 250-word passage and the reader's task is to fill the gaps with the exact replacements. The patient's reading ability is estimated based on the number of words correctly identified. The assessment is based on the assumption that better readers will understand the context of the text and be able to fill in the missing words in the text [39].

The Cloze procedure and the WRAT-R often are used together to obtain a more complete assessment of an individual's reading ability. Here health information leaflets can be used e.g. a

passage on hypertension or asthma. The test therefore assesses the "literacy fit" of a specific material to a specific patient [28,45].

In the case of the TOFHLA test, every fifth to seventh word in a passage is omitted. The reader selects from 4 possible choices, one of which is correct and 3 of which are similar but grammatically or contextually incorrect. Passages were selected from instructions for preparation for an upper gastrointestinal tract radiograph series, the patient rights and responsibilities section of a Medicaid application form and a standard hospital informed consent form. The Numeracy section is a 17-item test using actual hospital forms and labeled prescription vials. It tests a patient's ability to comprehend directions for taking medicines, monitoring blood glucose, keeping clinic appointments and obtaining financial assistance. Patients are presented with cue cards or labeled prescription bottles and asked to respond to oral questions regarding information about the cards or bottles. The numeracy score is multiplied by a constant 2.941 to create a score ranging from 0 to 50. The sum of the sections yields the total score, which ranges from 0 to 100. The classification and interpretation of scores from the TOFHLA test are described in Table 2.1 [21,58,138].

Table 2.1 Classification of scores from the TOFHLA test

Score	Literacy level
0 - 59	*Inadequate health literacy* (patients often misread the simplest materials, including prescription bottles and appointment slips; the Medicaid rights and responsibilities passage is not comprehended)
60 - 79	*Marginal literacy* (patients struggle to read more difficult numerical information and prose passages such as financial screening questions and they also misread instructions such as those indicating the taking of medications on an empty stomach. They can read the Medicaid passage, but the informed consent passage is not understood)
75 - 100	*Adequate literacy* (patients successfully complete most of the tasks required to function in the health care setting, but still may have difficulty comprehending the most difficult numerical tasks and informed consent documents)

2.4.2 MART test

One of the direct measurements or word recognition tests specifically developed for use with patients in the medical setting is the Medical Achievement Reading Test (MART). The test is designed to resemble a prescription label in order to more accurately determine a patient's ability to read medical information as it is typically presented. The MART is a new test that has not yet been validated with diverse patient populations [45].

2.4.3 WRAT test

The WRAT has been widely normalized with thousands of subjects throughout the U.S. The current version, the WRAT-Revised or WRAT 3 has been divided and restandardized to enable the development of 2 equivalent forms (tan and blue) that allow for pre- and posttesting. Each of the 2 forms contains 3 subsets: reading recognition, spelling and arithmetic [28,39].

The reading subtest consists of letter reading i.e. naming 15 letters of the alphabet and word reading i.e. pronouncing 42 words [39]. The patients read aloud from a list of these 42 words arranged in progressive difficulty. The more words they can pronounce correctly, the higher the reading skill [28]. The WRAT-R generates several types of scores, which range from 1 to 57. These scores can be converted to grade-equivalent reading levels ranging from preschool to post-high school and are often most useful for use in clinical settings. The WRAT-R test usually takes 3 to 5 minutes to administer and score, although an inexperienced examiner may take longer [39].

2.4.4 REALM test (Rapid Estimate of Adult Literacy in Medicine)

Health care professionals have looked to the field of education for instruments to screen patient reading ability as the common standardized decoding and comprehension reading tests are not practical for use in busy primary care and public health settings. These tests are too lengthy or not applicable for medical settings. For example, previous research by Murphy et al [139] found that patients were not receptive to taking the Slosson Oral Reading Test (SORT) or the WRAT-R. Patients felt uneasy about having to read so many words on the SORT-R and older patients found the print size too difficult to read. Readers with limited skills became rapidly frustrated with the difficulty of the initial items on the WRAT-R and often failed to complete the test. These findings therefore suggest that the WRAT-R and the SORT-R are not appropriate tests for adult patients whose reading levels are below ninth grade. The Peabody Individual Achievement Test-Revised (PIAT-R) was well received by patients, but its length and high cost limit its use in busy public clinics [139]. Hence the REALM test was developed.

The REALM test is supposed to be a rapid screening instrument designed to identify those patients who have difficulty reading common medical and lay terms (for body parts and illnesses) that are routinely used in primary care patient education materials [45,140].

The original REALM test consisted of 125 words and it was completed by a total of 207 adults in 6 primary care clinics, together with the SORT and the reading recognition and comprehension sections of the PIAT-R [141]. In response to requests from researchers and clinicians, the REALM was revised and shortened to 66 words and both these versions have been validated [139-141].

The REALM is a reading recognition test that measures a patient's ability to pronounce words of increasing difficulty. The authors claim that it is unique among reading recognition tests as all test words are commonly used lay terms, which makes the test particularly useful for estimating literacy skills in medical settings [45,140]. A test such as this therefore focuses on determining literacy as related to the ability to function in a health care environment, whereas a problem with a survey such as the National Adult Literacy Survey [40] is that it does not include health-related items and therefore it cannot determine how many people cannot read adequately enough to function in a health care setting [40]. The test should take approximately 1 to 2 minutes to administer and is designed to estimate the reading level below Grade 9, as above that level the assumption is made that the patient will be functionally literate. It is formally available in English, although a Spanish version has been developed for research purposes [134,140].

A problem with using the REALM test translated into Spanish is that the Spanish language has fairly regular phoneme-grapheme correspondence i.e. one sound is usually represented by one letter and vice versa. If one learns the letters and the sounds they represent in Spanish, it is relatively easy to pronounce words correctly, but in most cases the low-literate patients have not necessarily understood what they have "read". This could also be happening with English readers [134]. The REALM test should therefore only be used in its original English form, since when translated it does not serve the original purpose.

The REALM test consists of 3 lists of 22 words each. Words are arranged in order of increasing difficulty with List 3 being the most difficult, i.e. they are arranged according to number of syllables and pronunciation difficulty [139-140]. Patients are asked to read aloud as many words as they can, beginning with the first word in the first column. If patients are unable to pronounce several consecutive words, they are asked to look down the list and pronounce as many of the remaining words as they can. It appears to assume understanding if the patient can do pronounce them correctly [140]. Dictionary pronunciation is the scoring standard, with reading ability being an indicator of functional literacy skills [39,49].

The grades are estimated according to the number of words pronounced correctly. The grade estimate is useful in determining the type of health care information which may be read and understood as shown in Table 2.2 [49,139-140].

Table 2.2 Grade Range Estimates from the REALM test

Words pronounced correctly	Grade range estimates	The kind of health care information that the patient may/may not be able to read.
0 – 18	Grade 3 and below	May not be able to read most low-literacy materials. May need repeated oral instructions to enhance compliance. Materials are composed primarily of illustrations or audio or videotapes and it may be helpful if a health worker is present during their use.
19 – 44	Grades 4 – 6	May need low-literacy materials and may not be able to read prescription labels. In this case participative methods such as demonstration or discussion can be used, i.e. one-on-one counseling for adequate understanding.
45 – 60	Grades 7 – 8	May struggle with most currently available patient education materials. Material (both oral or written) should not be too simple (e.g. first grade) or too complex.
61 – 66	Grade 9 and above	Should be able to read most patient education materials. These individuals should be able to converse with their doctors about matters of lifestyle.

2.4.4.1 Validation of the REALM test

Content validity was built into the REALM test by selecting words from education materials and forms used in the Louisiana State University hospital clinics. Criterion validity was evidenced by high correlations between the REALM and the SORT-R (0.96, $p < 0.0001$), the PIAT-R (0.97, $p < 0.0001$) and the WRAT-R 0.88, $p < 0.0001$) [139]. A linear regression analysis, using REALM raw scores to predict the raw scores from the SORT-R, was conducted to establish the grade range estimates of the REALM. Grade equivalents reported for the SORT-R were used as a guide to determine the REALM grade range estimates. The SORT-R was selected as a standard of comparison for the REALM because it is a widely used, nationally (U.S.) standardized test. Both the REALM and the SORT-R showed a high concentration of words at low reading levels [139].

2.4.5 Advantages and limitations of health literacy tests

In the health care environment, results from the REALM test are considered to be more valid than data from adult literacy surveys as the REALM test uses medical and health related words and as a result is favoured by many members of the National Work Group on literacy and health in the U.S. [51]. However, it does not test the ability to read and understand numbers, which is referred to by literacy experts as numeracy and quantitative literacy [21,28]. It takes less time to administer than the TOFHLA test i.e. 2 to 3 minutes compared to 22 minutes for the TOFHLA test and thus can be used when patient compliance with reading medication instructions is a problem [28,47]. Most literacy tests in medical settings are used only for detection of low literacy, unlike the REALM test which also diagnoses reading and learning problems [39]. When the reading and learning problems of the population have been identified or diagnosed, the REALM test can aid in the development of user-friendly handouts or patient education materials [9].

With the original test, the print is large and the font size used is larger than the prescription labels and information in patient education materials [135]. This was done so that the test would appear less threatening to the respondents. However, this could lead to an overestimation of a patient's ability to read a medicine label e.g. a patient may be able to read words on the REALM test because of its larger type size, but be unable to read the same medication instructions on a medicine label due to its smaller type size. The scoring is simpler than the others, but fails to place individuals into specific grade levels. Rather it converts the patient's raw score into grade range estimates, not considering that a patient with a third-grade reading ability would require different counselling than a patient with a preschool reading ability or a person who has not attended school at all. This information of grade range estimates provided by the REALM test is

generally sufficient, since in health care settings patients need only be categorized as poor, midrange or high-level readers [39].

The TOFHLA is a tool which facilitates a more comprehensive assessment of functional health literacy. It tests a patient's ability to read prose as well as phrases containing numbers using real materials from the health care setting. Prose-reading and numeracy skills which are an essential component of functional health literacy, are both tested by the TOFHLA test. However the TOFHLA test requires up to 22 minutes to administer and therefore it is more useful as a research tool than a clinical tool [21]. It takes a long time to administer and this is not ideal in the heath care setting where the system is overburdened with a heavy patient load and insufficient staff.

The WRAT-R is appropriate for use with individuals aged 5 - 74 [39]. The major limitation of the WRAT-R is its difficulty level for populations of poor readers, such as those who seek care in publicly funded health clinics. The words on the WRAT-R, which are presented in ascending order of difficulty, rapidly become difficult for low-level readers making many such patients give up quickly. The patients may feel anxious as the test requires them to continue saying words aloud until 10 consecutive items or words are missed or mispronounced [28,39]. Almost a third of the words are above a ninth-grade reading level and even HCPs struggle with some of the words. The complexity of the test can be reduced by using a modified scoring method which allows patients to quit after 3 consecutive words have been missed. However, when using this method, the test may lose accuracy for assigning grade equivalents and it should then only be used as an estimate of higher or lower reading ability [39].

The author required a health literacy test which was simple and could be administered in a short period of time. Taking into consideration the above discussion of health literacy tests, the REALM test was chosen instead of the others.

2.4.6 Description of the literature search

The literature search involved accessing information from a number of diverse but relevant areas. The areas searched included literacy and its relevance in a health context, tools used to assess literacy and health literacy, health information materials and their assessment, development and assessment of pictograms, pictograms in health, communication with low-literate patients and intercultural communication.

A literature search was conducted in the computerized databases MEDLINE (1966 – 1999) and International Pharmaceutical Abstracts (1970 – 1999). A number of different search engines were used to search the World Wide Web: these included Yahoo, Google and Metacrawler. The following search terms and phrases were used: literacy, health literacy, health and illiteracy or low literacy, literacy tests, pictograms, pharmaceutical pictograms, pictograms and health, visuals and health, health and culture, readability and drug information. Journals containing relevant information were identified and an individual search was done on all issues of that journal if it was available on the Web.

Authors of selected papers were contacted via e-mail and further references were requested from them. The reference list of each relevant article was examined for further pertinent references. This search of the literature was ongoing for the duration of the project (January 1999 – October 2000).

CHAPTER THREE
METHODOLOGY

3.1 Introduction

The preceding chapters established the background and context of this research project. The concept and definitions of illiteracy and the extent of this problem, both nationally and internationally, were discussed. The link between literacy and health was explored with particular reference to low-literate populations. Much of the research in these areas and in the development and assessment of health literacy tests has been conducted in the U.S. However, it is in the developing world with its unacceptably high illiteracy levels and subsequent serious implications for health, that research such as this is urgently needed.

Although the number of years of schooling has been shown to be a poor indicator of reading ability, it is still widely used, as it is regarded as an inexpensive assessment method and is easy data to collect. HCPs have identified the need to determine or measure patients' literacy levels more accurately and as a result, literacy tests have been developed, one of them being the REALM test which has been widely used in the U.S.

In this chapter the aims and objectives of this research and the methods by which these were addressed are presented.

3.2 Aims and objectives

The main aim of this study was to assess the applicability and suitability of the REALM test in a representative South African population. The objectives were:

1. To determine whether the REALM test could be applied to a Xhosa population for whom English was a second language.

2. To investigate the relationship between stated educational level and the REALM grade range estimate obtained from both the reading and understanding scores.
3. To determine whether the stated educational level correlates with the expected REALM grade range estimate.
4. To identify words in the REALM test which were understood by an acceptable proportion of the respondents.

3.3 Study site

The study was conducted in Grahamstown, a small town in the Eastern Cape, one of the 9 South African provinces. According to the latest census report (1996), the Eastern Cape's population of about 6.3 million is the third largest in the country, with 2.9 million being male and 3.3 being female. Thirty-seven percent of the province's population live in urban areas, whereas 63% live in non-urban areas. The population consists of 86.4% African (Black), 7.4% Coloured, 0.3% Indian (Asian), 5.2% White and 0.7% "unspecified or other" [142].

The interviews were conducted among the Xhosa population which is one of the 9 black ethnic groups in South Africa, with the highest concentration being in the Eastern Cape i.e. 83.8% of the population in this province speak IsiXhosa. IsiXhosa is also the second most commonly spoken home language in South Africa after IsiZulu [142].

The Eastern Cape is one of the poorest provinces, its unemployment situation being among the worst in the country. Development is restricted by poor infrastructure, poorly resourced local government structures and a shortage of skilled people. A large proportion of the economically active population in the rural areas are migrant workers who work on the mines in other parts of the country [143-144]. It is therefore not surprising to find that 20% of the Eastern Cape's

population aged 20 and over have had no schooling at all with only 5% holding a tertiary qualification [142].

The majority of the interviews took place in Rhini (Grahamstown's township). Before they commenced, the sisters and nurses of local primary health care clinics were contacted. The objectives of the project were discussed with them and their permission was obtained to interview selected patients. The interviews were conducted in clinics or in the respondents' homes. They were conducted at several locations: Joza location Extensions 1, 2 and 7, Masithandane Centre in Joza, Settlers Day Hospital, Rhodes University Campus, N.G. Dlukulu Clinic Extension 7, Joza Location A- and B-block, Assumption Clinic Extension 2 and Fingo Village.

3.4 Study population

The research sample was chosen to include a cross-section of the local black population who have English as their second language. As mentioned previously, the majority of the black population in this part of the country have IsiXhosa as their first language. This population is fairly representative of the average patient population who is likely to have problems accessing and understanding health care information in this country and as a result 125 Xhosa respondents from a variety of educational backgrounds (ranging from no schooling at all to tertiary level education) were tested.

Patients attending the clinics and people accompanying the patients were approached and were invited to participate in the project. Respondents were also approached in their homes and were invited to participate. All respondents had to be over 18 years of age and were required to have some reading ability in English. They all have IsiXhosa as their home language.

3.5 Development of the research instrument

A questionnaire (Appendix A) consisting of 2 sections was developed. It elicited demographic data such as age, sex and educational level. Initially the latter data was collected in 6 categories; none (no education at all), Grades 1 - 4, Grades 5 - 7, Grades 8 - 10, Grades 11 - 12 and tertiary level. In South Africa the duration of formal schooling is 12 years: 3 years in junior primary school (Grades 1 - 3), 4 years in senior primary (Grades 4 - 7), 3 years in junior secondary (Grades 8 - 10) and finally 2 years in senior secondary school (Grades 11 - 12). Respondents of all educational levels were tested. Language proficiency was evaluated in IsiXhosa, English, Afrikaans and any other African languages. This data was collected to determine the respondents' communication and reading skills in the commonly used languages in South Africa.

Data regarding place of residence and employment status was also collected. Reder [145] found that literacy practices were organized into domains of activities such as those of the church, school, work and governance. He also found that the social roles of the literacy specialists in the church and in the schools were quite different and that these differences could have a profound influence on the choices individuals make about acquiring their literacy skills in certain settings. Therefore the respondents' employment status and place of residence could have had a bearing on their ability to read and explain the words. The ability to tell time from either a clockface or a digital watch or both was assessed as this is a basic indicator of numeracy literacy.

Approval for the study was obtained from the Rhodes University Departmental Ethical Standards Committee. The questionnaire was first piloted on a random sample of 6 Xhosa adults. The purpose of the pilot study was to validate the questionnaire and to assess the need for its revision. As a result of the pilot study, modifications were made to the questionnaire and additional questions were included. The educational levels were split up into 14 categories instead of 6.

This allowed greater flexibility in subsequent grouping of educational levels and ensured that a sufficient number of respondents were included in each category. Provision was made for the possibility of respondents not being able to pronounce a REALM test word correctly, but being able to explain it, which was an unexpected and a surprising result.

An interpreter was required as my first language is Sesotho, another of the 9 black languages in South Africa and although I am able to speak and understand some IsiXhosa, it was not sufficient for this process since my rudimentary knowledge of IsiXhosa only enabled me to communicate at a relatively basic level.

3.6 Training of the interpreters

In South Africa, medical interpreting is both an important and a problematic issue. Multilingualism and multiculturalism are emerging and are promoted with 11 languages now officially recognized instead of the former 2 official languages of English and Afrikaans [146-147]. The Constitution also guarantees the right of all South Africans to be served in the language of their choice and in principle what should be included in official usage of languages is "not only the right to express oneself and to communicate, but also the right to demand to understand, to be understood and served in the language or languages used" [147-148]. Seleskovitch [149] describes interpreting as more than the oral translation of words, but a process involving also the uncovering of meaning to make the message explicit to others. Baker [150], Bell [151] and Newmark [152] point out in their respective discussions that interpreting is a complex task which involves mediation between languages, cultures and people in particular contexts. The 2 interpreters used in the study were both black and IsiXhosa was their home language i.e. they were of the same culture as that of the respondents.

Both of the interpreters had a tertiary education; one was a qualified teacher and the other had received training from a technikon. Initially they were required to complete the questionnaire themselves in the presence of my supervisors as this is an important component in training interpreters for a specific task. The necessity of accurately reporting the exact answers given by the respondents was emphasized. It is often found that interpreters do not faithfully communicate the full message or interpretation to the interviewer because they may selectively disregard potentially important components of a response. This may compromise the results since their perception of the relative importance of issues may differ from that of the interviewer. Bearing in mind the above comments, the following points were emphasized when training the interpreters:

i) The interpreters had to make sure that the respondents felt comfortable and at ease before commencing with the interview, as any reservations about the interview could influence their responses

ii) The interpreters should not be critical or judgemental in their communication with the respondent and should provide a safe, uncritical forum for the respondents to answer the questions.

iii) The interpreters were instructed to accurately and faithfully translate the complete communication between the respondent and myself.

3.7 The interview process

The same approach was used each time when approaching and recruiting potential respondents. The interpreter was instructed to say the following: "Good morning/afternoon, my name is .....and I stay in .....here in Rhini. Here with me is Lebo Lecoko from Rhodes University, Pharmacy Department. She is doing a project for her studies and I was wondering if you would be interested in assisting her. But first, could you tell us if you can read English or not because

we have medical words from a health test that you will need to read aloud in English and thereafter explain in IsiXhosa". If the respondent agreed to participate, the interpreter would then continue and say: "The interview will not take a long time, make yourself comfortable and relax. You can take as long as you need to complete the test. Before we start with the test, I would like to ask you a few questions about yourself".

The respondent was first required to provide demographic information including age, educational level and language proficiency. During this phase of the interview, the ability to tell time from either a conventional clockface or a digital watch or from both was determined.

The pronunciation and understanding of the words of the REALM test by the respondents was determined after the demographic data was obtained. The words were printed using Arial 14-font bold typeface (defined as the minimum print size used in books for the visually impaired [96]) onto a card which was covered with adhesive plastic. This font was chosen as the words were clearly legible from an acceptable reading distance even for a person with slightly impaired vision and it also gave the test a "friendly" and unthreatening appearance, since using a simple typeface in large bold print with contrasting colours for text and background on good quality paper can make a difference for someone with poor sight [153]. Each of the 3 lists was printed on a separate card. The reason for having separate lists was to try and minimize any confusion resulting from respondents scanning the whole test, being overwhelmed by the large number of words and losing concentration. However in the U.S., the original test is administered with all 66 words on one page and only pronunciation is assessed. Since our objective was to evaluate the applicability of the REALM test in a population for whom English is their second language, understanding could not be assumed if the word was merely pronounced correctly, but had to be assessed as well.

The respondents were asked to read aloud as many words as they could from List 1, beginning with the first word. On completion, they went back to explain the meaning of each word. The same process was followed for Lists 2 and 3. If the respondents were unable to read or pronounce several successive words in one list, they were asked to scan the rest of the list and pronounce those words that they could. The correct pronunciations and explanations were marked with a plus sign (+). The mispronunciation, incorrect explanations and "do not know" were marked with a minus sign (-). The total scores were added together after the interviewing process was completed. The reading time for each list was noted as unobtrusively as possible with the use of a stopwatch. However, the time to explain the meaning of the words was not noted. Respondents were then thanked and were given a small honorarium (R10) at the end of the interview.

3.8 Analysis of data

The decision had to be made when the REALM test was successful or when it failed. As already noted in Section 2.4.4, the test appears to work on the assumption that if the patient can pronounce the word, there is a strong possibility that the word has also been understood. The results from this study were categorized into 4 cases as follows:

Table 3.1 Cases indicating success and failure of the REALM test

Case #	Correct pronunciation	Correct explanation or understanding	Succeeds/fails
1	Yes	Yes	succeeds
2	No	No	succeeds
3	Yes	No	fails
4	No	Yes	Fails

Both Cases 1 and 2, in which the respondents could both pronounce and understand the words or could neither pronounce nor understand the words, present 2 clear-cut situations where our results

concur with the assumption made in the REALM test. In these cases, we considered the REALM test as being appropriate to use, so we classified it as succeeding. In Case 3, words were pronounced correctly, but were not understood, which contradicts the assumption made in the REALM test. In Case 4, a most interesting case, the words could not be pronounced, but their meaning was satisfactorily explained. These latter 2 cases contradict the assumption made in the REALM test and therefore the test is classified as having failed. Case 4, was introduced after the pilot study, when it was discovered that there were some respondents who could not read the words, but could explain them.

Correct pronunciation of words can be a highly subjective measure. This (correct pronunciation) was based on dictionary pronunciation, but as respondents were all English second-language speakers, it was essential to allow some flexibility to cater for the influence of a Black language on the pronunciation of the English words. Consistency in assessing the correct pronunciation was maintained as only one interviewer (myself) conducted all the interviews. My pronunciation was also assessed in the presence of my supervisors, when I trained the interpreters. An advantage was the fact that I have the same cultural background as the respondents, matriculated at an English-medium school and obtained my degree at an English-medium university. I found this to be valuable in appreciating the nuances in pronunciation and coming to a final decision.

3.9 Statistical Analysis

BMDP Statistical Software programmes were used for the analysis of the data. A chi-square test (Pearson) was used to test the association between the respondents' stated educational level and other variables (reading and understanding scores as derived from the REALM test).

CHAPTER FOUR
RESULTS

4.1 Introduction

Readability is the first step in ensuring that patients understand patient package inserts and use them to improve their medication-taking behaviour and health care decision-making. These findings however call into question the ability of writers and distributors of patient package inserts to write medication and health information at a level that the majority of patients can read [154]. Practitioners need to be become aware of the discrepancy between the level of the written materials and the reading level of their patient [101,128].

It is important for practitioners to understand that the reading level of patients cannot be easily judged by their appearance or necessarily by their educational achievement, hence the need for a literacy test, preferably a quick and non-threatening one. Health care is a technical field and most patients are not familiar with the terminology or many of the concepts and in view of the rapid development in health care, the need for readable materials is even more pressing [101].

In order for patient-directed materials to serve their purpose, the literacy of a patient population should be surveyed in order to adjust the reading level of written material and enable the patients to participate in self-care activities [116,155]. It must be recognized that patients may be able to read or sound out the words, but this ability does not automatically ensure comprehension of the written word. Hence in this project understanding as well as pronunciation of the words was determined in the assessment of the REALM test.

4.2 Demographic Characteristics

A total of 125 respondents were interviewed and their demographic results are presented in Table 4.1. Respondents were all black Xhosa-speaking adults from Grahamstown in the Eastern Cape. Sixty percent of the respondents were females. Since the interviews were conducted either at the respondents' homes or at local primary health care clinics in the area, the likelihood of finding a female respondent was greater, since females traditionally are more likely to stay at home and act as the main caregivers. They are also reported as having a higher illiteracy rate than males [34] and many of them may be unemployed. This imbalance in gender does not affect the results, since all the respondents were categorized according to educational levels. Almost 93% of the respondents were between 21 and 65 years of age.

The majority of respondents were from the township in Grahamstown east (Rhini), with only one respondent from Grahamstown central and one from a farm outside Grahamstown. About 71% of the respondents were unemployed and this was not surprising since unemployment in the Eastern Cape has long been among the worst in South Africa [143]. Of the respondents who were employed, most of them were unskilled workers who earned a low income e.g. "assistants" in offices, gardeners and cleaners. Only 1 respondent was employed in his professional capacity in the educational field as a teacher. Five respondents who were in the "other" category were either students or pensioners.

The language proficiency of the respondents was determined in both their mother tongue (IsiXhosa) and in English (Table 4.1). The column "Listen only" indicates that the respondent could only understand the language, but could not respond after being spoken to. The second column, "Listen and speak," indicates that the respondent could understand and communicate, but

could not read that language. The last column indicates the highest level of proficiency as the respondent could understand, speak and read the language.

Table 4.1 Demographic characteristics (N = 125)

Characteristic	Number (%)
Sex	
Male	50 (40.0)
Female	75 (60.0)
Age (yrs)	
<21	6 (4.8)
21 – 40	65 (52.0)
40 – 65	51 (40.8)
>65	3 (2.4)
Educational level	
Grade 3 and below	30 (24.0)
Grades 4 – 6	30 (24.0)
Grades 7 – 8	30 (24.0)
Grade 9 and above	35 (28.0)
Occupation	
Labourer	12 (9.6)
Domestic worker	5 (4.0)
Education	1 (0.8)
Unemployed	89 (71.2)
Self-employed	13 (10.4)
Other	5 (4.0)
Language proficiency	
Xhosa: Listen only	0 (0.0)
Listen and speak	1 (0.8)
Listen, speak and read	124 (99.2)
English: Listen only	4 (3.2)
Listen and speak	1 (0.8)
Listen, speak and read	120 (96.0)

As expected, all respondents were able to communicate in their home language with only one respondent reporting being unable to read IsiXhosa. The respondents were included in the study on the basis that they were able to read English, therefore the inclusion of the 5 respondents who

claimed that they could not read English requires explanation. Although they initially denied being able to read English, it was found that once the interview progressed, they were in fact able to read the words of the REALM test. The reason for this "denial of their ability" could be that they felt threatened by the educational level of myself and the interpreter and therefore lacked the self-confidence to submit to the test. These 5 respondents did not have much formal education i.e. they were all below Grade 8 and the word "test" may have intimidated them. However, it is interesting to note that all 5 respondents were able to read the words of the REALM test and one of them actually took less than the target time of 3 minutes. On the other hand it is not surprising that one of them took the longest time to read the words i.e. 22 minutes.

The groupings of educational level were done according to the categories referred to in the REALM test i.e. no formal education to Grade 3, Grades 4 to 6, Grades 7 to 8 and Grade 9 and above. Each group consisted of 30 respondents, except for the last one (Grade 9 and above) which included 35 respondents.

4.3 Results from the REALM test

As already noted the REALM test consists of 3 lists, each list consisting of 22 words arranged in order of increasing difficulty from List 1 to List 3. The REALM test grades the literacy skills according to the number of words pronounced correctly such that a person pronouncing 0 to 18 words correctly would be graded as Grade 3 and below, a person pronouncing 19 to 44 words correctly would be graded as Grade 4 to 6, a person pronouncing 45 to 60 words correctly would be graded as Grade 7 to 8 and finally a person pronouncing 61 to 66 words correctly would be graded as Grade 9 and above. Within each individual list, the number of words pronounced and explained satisfactorily were also classified into groupings i.e. 0 to 6 words, 7 to 14 words, 15 to 20 words and finally 21 to 22 words. Both the reading and understanding performance of the 125

respondents were determined. Reading performance was judged in terms of correct pronounciation as determined by the author. The results for the individual lists are shown in Table 4.2.

Table 4.2 Reading performance for individual lists (22 words per list)

Number of words	N (%) with correct pronunciation (N = 125)		
	List 1	List 2	List 3
0 – 6	9 (7.2)	22 (17.6)	22 (17.6)
7 – 14	32 (25.6)	39 (31.2)	31 (24.8)
15 – 20	36 (28.8)	37 (29.6)	34 (27.2)
21 – 22	48 (38.4)	27 (21.6)	38 (30.4)

With reference to List 1, a small number of respondents (7.2%) pronounced only between 0 to 6 words correctly whereas 38.4% of the respondents could pronounce almost all the words correctly. A higher number (17.6%) scored in the lowest category (0 – 6 words) for Lists 2 and 3, but for both Lists 1 and 3, more respondents were able to pronounce more words correctly. This statement however, does not hold true for List 2 resulting in the list apparently being the more difficult list for this population. In List 3, 30.4% of the respondents were able to pronounce almost all the words correctly, but only 21.6% were able to do the same with List 2, again emphasizing the apparently greater difficulty of this list.

Table 4.3 Understanding performance for individual lists (22 words per list)

Number of words	N (%) with correct understanding (N = 125)		
	List 1	List 2	List 3
0 – 6	39 (31.2)	70 (56.0)	91 (72.8)
7 – 14	68 (54.4)	43 (34.4)	29 (23.2)
15 – 20	16 (12.8)	11 (8.8)	5 (4.0)
21 – 22	2 (1.6)	1 (0.8)	0 (0.0)

However, the understanding performance (Table 4.3) resulted in a rating of the 3 lists of words in the same order as suggested by Davis et al [140] i.e. increasing order of difficulty from List 1 to List 3. List 3 is undoubtedly the most difficult, since none of the respondents were able to understand all of the 22 words which appeared in this list.

Table 4.4 Overall reading and understanding performance for all three lists (66 words)

Number of words	**N (%) of respondents (N = 125)**	
	Correct pronunciation	**Correct understanding**
0 – 18	15 (12.0)	67 (53.6)
19 – 44	39 (31.2)	48 (38.4)
45 – 60	31 (24.8)	10 (8.0)
61 – 66	40 (32.0)	0 (0.0)

When examining the overall reading and understanding performance (Table 4.4), it can be seen that the respondents performed better with the pronounciation of the words than with the understanding of the words. This is especially noticeable in the highest category (61 – 66 words) where 32% could read almost all the words of the REALM test but not one respondent was able to explain the meaning of those words.

Table 4.5 Time taken to read all 66 words

Time (mins)	**N (%)**
< 3	58 (46.4)
3 – 5	23 (18.4)
> 5 – 10	33 (26.4)
> 10	11 (8.8)

The time taken to read the test ranged from 40 seconds to 22 minutes and 18 seconds, (Table 4.5). The table shows that almost half of the Xhosa-speaking respondents were able to read the REALM test in less than 3 minutes. This is in keeping with the intended time to complete the test

in its original format, as Davis et al [140] had designed it to be administered in 2 minutes or less and thus serve as a rapid method of determining the literacy level of patients. However, more than 50% of this study population did take longer than the desired 3 minutes to read these 66 English words. At the same time, it can be noted than almost two-thirds of the respondents managed to complete the REALM test in less than 5 minutes, which should still be acceptable for a quick health literacy test.

4.4 Assessing the applicability of the REALM test

In assessing whether the REALM test could be meaningfully applied in this South African population, we had to decide on the conditions under which it worked (or was successful) and those cases when it was inapplicable (or unsuccessful). The results were categorized into 4 cases as discussed in Section 3.8 (Worked No.1 and Worked No.2; Failed No.1 and Failed No. 2).

The next step was to try and determine the maximum failure rate which would be acceptable and still enable the REALM test to be used reliably in this population. The REALM test is a tool that is used to estimate literacy skills and for it to be a valid, data-gathering instrument it should be proven to be reliable and acceptable. The acceptance criteria we established were that it should "work" for individual words for at least 80% of the respondent population and this should be the case for not less than two-thirds of the words (44 out of 66 words).

Table 4.6 reflects the words of List 1 in the order in which they appear in the REALM test. Highlighted areas illustrate results pertaining to at least 50% of the population. This was as arbitrary number which was chosen to allow for comparison between cases where at least half the population was involved. From the highlighted areas in the first column (Worked No.1) it can be seen that only 10 words were pronounced correctly and understood by more than half the study

population. Success in pronouncing and explaining the words decreased dramatically in the latter third of the list with the exception of the word "asthma". Six of the 12 words were so unfamiliar to this population that less than 5% succeeded in pronouncing these words correctly and understanding them. The word "fat" was the easiest word as 92.8% of respondents could both read and explain it.

Table 4.6 Performance of the REALM test for List 1. (Highlighted areas indicate more than 50% of the respondents in those specific categories)

	N (%) of respondents in the different categories (N = 125)			
List 1	**Worked No.1[1]**	**Worked No.2[2]**	**Failed No.1[3]**	**Failed No.2[4]**
Fat	**116 (92.8)**	3 (2.4)	6 (4.8)	0 (0)
Flu	**109 (87.2)**	11 (8.8)	5 (4.0)	0 (0)
Pill	62 (49.6)	4 (3.2)	59 (47.2)	0 (0)
Dose	28 (22.4)	24 (19.2)	**73 (58.4)**	0 (0)
Eye	**87 (69.6)**	18 (14.4)	4 (3.2)	16 (12.8)
Stress	41 (32.8)	24 (19.2)	60 (48.0)	0 (0)
Smear	22 (17.6)	31 (24.8)	**72 (57.6)**	0 (0)
Nerves	54 (43.2)	24 (19.2)	40 (32.0)	7 (5.6)
Germs	**67 (53.6)**	25 (20.0)	31 (24.8)	2 (1.6)
Meals	**78 (62.4)**	13 (10.4)	32 (25.6)	2 (1.6)
Disease	**66 (52.8)**	30 (24.0)	29 (23.2)	0 (0)
Cancer	**82 (65.6)**	27 (21.6)	13 (10.4)	3 (2.4)
Caffeine	30 (24.0)	52 (41.6)	43 (34.4)	0 (0)
Attack	**67 (53.6)**	22 (17.6)	36 (28.8)	0 (0)
Kidney	**70 (56.0)**	20 (16.0)	32 (25.6)	3 (2.4)
Hormones	6 (4.8)	36 (28.8)	**83 (66.4)**	0 (0)
Herpes	6 (4.8)	26 (20.8)	**93 (74.4)**	0 (0)
Seizure	2 (1.6)	**76 (60.8)**	47 (37.6)	0 (0)
Bowel	6 (4.8)	29 (32.2)	**90 (72.0)**	0 (0)
Asthma	**70 (56.0)**	29 (23.2)	23 (18.4)	3 (2.4)
Rectal	5 (4.0)	38 (30.4)	**81 (64.8)**	1 (0.8)
Incest	6 (4.8)	46 (36.8)	**73 (58.4)**	0 (0)

[1] Worked No.1 = words correctly pronounced and correctly explained
[2] Worked No.2 = words incorrectly pronounced and could not be explained
[3] Failed No.1 = words correctly pronounced but could not be explained
[4] Failed No.2 = words incorrectly pronounced but could be correctly explained

The word "seizure" appeared to present particular problems as it was only pronounced and explained correctly by 2 out of 125 respondents (1.6%) and it was the word that the largest number of respondents (60.8%) were unable to either pronounce or explain correctly in the second column. This has serious implications when considering the development of patient information materials for conditions such as epilepsy.

The highlighted areas in the third column (Failed No.1) indicate words that the majority of this study population could pronounce but could not understand. A person administering the REALM test and only checking for pronunciation would therefore be "fooled" into assuming that this population has some familiarity with these words, whereas they are not understood well at all. Certain words in this list should be used with caution when talking to patients and these are "herpes" and "bowel", as they "failed" in about 75% and 72% of the study population respectively. The word "dose" is a relatively simple one and represents a familiar concept to HCPs and to many patients. However from Table 4.6 it is obvious that the Xhosa adult has great difficulty understanding this concept as this word "failed" in more than half the respondents.

"Failed No.2" presents an interesting scenario, as in this case although respondents could not pronounce the words, they were able to explain them satisfactorily. A particularly noticeable word here is "eye", which 12.8% of the respondents were unable to pronounce, but which they could explain. In most cases it was pronounced as "ear".

Table 4.7 presents results from List 2. The increased difficulty of List 2 when compared with List 1 is illustrated in the results, in that only 4 words in List 2 as opposed to 10 words in List 1 were correctly pronounced and understood (Worked No.1) by more than half the study population, indicating the more difficult nature of List 2. A greater number of words could neither be

pronounced nor explained by more than half of the respondents in List 2 than List 1 (4 words and 1 word respectively). The word "haemorrhoids" presented particular problems as not one respondent was able to read and understand it (Worked No.1) and it was the word that the largest number of respondents (77%) could neither pronounce nor understand (Worked No.2). This would indicate that using an alternative, simpler word should be tested e.g. "piles".

Table 4.7 Performance of the REALM test for List 2. (Highlighted areas indicate more than 50% of the respondents in those specific categories)

	N (%) of respondents in the different categories (N = 125)			
List 2	**Worked No.1[1]**	**Worked No.2[2]**	**Failed No.1[3]**	**Failed No.2[4]**
Fatigue	7 (5.6)	**79 (63.2)**	38 (30.4)	1 (0.8)
Pelvic	11 (8.8)	43 (34.4)	**71 (56.8)**	0 (0)
Jaundice	5 (4.0)	**66 (52.8)**	54 (43.2)	0 (0)
Infection	58 (46.4)	15 (12.0)	52 (41.6)	0 (0)
Exercise	**88 (70.4)**	25 (20.0)	10 (8.0)	2 (1.6)
Behaviour	53 (42.4)	40 (32.0)	32 (25.6)	0 (0)
Prescription	35 (28.0)	40 (32.0)	50 (40.0)	0 (0)
Notify	37 (29.6)	44 (35.2)	43 (34.4)	1 (0.8)
Gallbladder	19 (15.2)	52 (41.6)	54 (43.2)	0 (0)
Calories	8 (6.4)	29 (23.2)	**88 (70.4)**	0 (0)
Depression	26 (20.8)	39 (31.2)	60 (48.0)	0 (0)
Miscarriage	**77 (61.6)**	25 (20.0)	17 (13.6)	6 (4.8)
Pregnancy	**95 (76.0)**	20 (16.0)	2 (1.6)	8 (6.4)
Arthritis	42 (33.6)	50 (40.0)	27 (21.6)	6 (4.8)
Nutrition	31 (24.8)	34 (27.2)	60 (48.0)	0 (0)
Menopause	5 (4.0)	43 (34.4)	**77 (61.6)**	0 (0)
Appendix	**72 (57.6)**	18 (14.4)	33 (26.4)	2 (1.6)
Abnormal	52 (41.6)	26 (20.8)	47 (37.6)	0 (0)
Syphilis	16 (12.8)	52 (41.6)	57 (45.6)	0 (0)
Haemorrhoids	0 (0)	**96 (76.8)**	29 (23.2)	0 (0)
Nausea	9 (7.2)	**84 (67.2)**	31 (24.8)	1 (0.8)
Directed	62 (49.6)	25 (20.0)	37 (29.6)	1 (0.8)

[1] Worked No.1 = words correctly pronounced and correctly explained
[2] Worked No.2 = words incorrectly pronounced and could not be explained
[3] Failed No.1 = words correctly pronounced but could not be explained
[4] Failed No. 2 = words incorrectly pronounced but could be correctly explained

Three words in List 2 as opposed to 7 words in List 1 could be pronounced correctly but were not understood by more than 50% of the respondents (Failed No.1). This was expected since List 2 is more difficult than List 1, thus fewer words in List 2 were correctly pronounced but could not be explained by this study population.

Nine words in List 2 (Failed No.2) could not be pronounced correctly by a small percentage of the respondents, although their correct meaning was explained. Of particular note is the word "pregnancy", which 6.4% of the respondents could explain but not pronounce. It is possible that words such as "miscarriage" and "pregnancy", which commonly appear on posters in local primary health care clinics have "primed" the respondents and while they were unable to pronounce these words, they were able to explain them possibly because patients associate the visual grapheme with the experiences women encounter.

List 3 was, according to Davis et al [140] the most difficult and our findings substantiate this claim (Table 4.8). Only 2 words were both correctly pronounced and explained (Worked No.1) by at least half the respondents namely, "emergency" and "sexually". Interestingly, there were fewer words (2 words) in List 3 (Worked No.2) which were pronounced incorrectly and were misunderstood by more than half the population than were found in List 2 (4 words). We would have expected that there would be more such words in List 3, due to it being the most difficult list.

A significant proportion of the words in List 3 (9 out of 22 words) were correctly pronounced, but could not be explained by more than half the population. In this situation the REALM test administrator would erroneously accept that the respondents could understand these words.

Table 4.8 Performance of the REALM test for List 3. (Highlighted areas indicate more than 50% of the respondents in those specific categories).

List 3	N (%) of respondents in the different categories (N = 125)			
	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]
Allergic	39 (31.2)	31 (24.8)	55 (44.0)	0 (0)
Menstrual	52 (41.6)	37 (29.6)	34 (27.2)	2 (1.6)
Testicle	23 (18.4)	38 (30.4)	63 (50.4)	1 (0.8)
Colitis	0 (0)	26 (20.8)	99 (79.2)	0 (0)
Emergency	65 (52.0)	28 (22.4)	31 (24.8)	1 (0.8)
Medication	47 (37.6)	18 (14.4)	60 (48.0)	0 (0)
Occupation	30 (24.0)	43 (34.4)	52 (41.6)	0 (0)
Sexually	67 (53.6)	38 (30.4)	19 (15.2)	1 (0.8)
Alcoholism	53 (42.4)	40 (32.0)	29 (23.2)	3 (2.4)
Irritation	12 (9.6)	36 (28.8)	77 (61.6)	0 (0)
Constipation	15 (12.0)	30 (24.0)	80 (64.0)	0 (0)
Gonorrhoea	15 (12.0)	58 (46.4)	52 (41.6)	0 (0)
Inflammatory	2 (1.6)	32 (25.6)	91 (72.8)	0 (0)
Diabetes	41 (32.8)	51 (40.8)	25 (20.0)	8 (6.4)
Hepatitis	1 (0.8)	50 (40.0)	74 (59.2)	0 (0)
Antibiotics	20 (16.0)	47 (37.6)	58 (46.4)	0 (0)
Diagnosis	19 (15.2)	63 (50.4)	43 (34.4)	0 (0)
Potassium	19 (15.2)	46 (36.8)	60 (48.0)	0 (0)
Anemia	3 (2.4)	31 (24.8)	91 (72.8)	0 (0)
Obesity	10 (8.0)	45 (36.0)	70 (56.0)	0 (0)
Osteoporosis	1 (0.8)	63 (50.4)	61 (48.8)	0 (0)
Impetigo	0 (0)	33 (26.4)	92 (73.6)	0 (0)

[1] Worked No.1 = words correctly pronounced and correctly pronounced
[2] Worked No.2 = words incorrectly pronounced and could not be explained
[3] Failed No.1 = words correctly pronounced but could not be explained
[4] Failed No. 2 = words incorrectly pronounced but could be correctly explained

Diabetes is one of the most common chronic diseases internationally. Thus one would expect that the majority of the study population would be familiar with the word. However, from Table 4.8 it can be seen that only 32.8% of the respondents were able to read and understand it and 6.4% could explain the word but not pronounce it correctly (Failed No.2).

When examining the 3 lists together (Table 4.9) it can be seen that List 1 is marginally more successful than the other 2 lists i.e. the REALM test "works" with more than 80% of the

respondents for a larger number of words. This could be due to the fact that the respondents are more familiar with the words in this list and as already indicated by Davis et al [140] it is the least difficult list.

According to the pre-determined criteria for the acceptability of the REALM test (Section 4.4), it exhibited a poor overall performance as the test only "worked" for 8 out of the 66 words (Table 4.9). When looking at the overall results from 8250 cases (i.e. 66 words x 125 respondents), the REALM test "failed" in 41% of cases. Both these results indicate that, in its present form, the REALM test is an unacceptable method for assessing the health literacy of Xhosa people in South Africa. A number of words in the REALM test are course for concern regarding their inclusion in written patient education materials.

Table 4.9 Overall performance of the REALM test

List 1	Performance of REALM test		List 2	Performance of REALM test		List 3	Performance of REALM test	
	Succeeds	Fails		Succeeds	Fails		Succeeds	Fails
Fat	95.2	4.8	Fatigue	68.8	31.2	Allergic	56.0	44.0
Flu	96.0	4.0	Pelvic	43.2	56.8	Menstrual	71.2	28.8
Pill	52.8	47.2	Jaundice	56.8	43.2	Testicle	48.8	51.2
Dose	41.6	58.4	Infection	58.4	41.6	Colitis	20.8	79.2
Eye	84.0	16.0	Exercise	90.4	9.6	Emergency	74.4	25.6
Stress	52.0	48.0	Behaviour	74.4	25.6	Medication	52.0	48.0
Smear	42.4	57.6	Prescription	60.0	40.0	Occupation	58.4	41.6
Nerves	62.4	37.6	Notify	64.8	35.2	Sexually	84.0	16.0
Germs	73.6	26.4	Gallbladder	56.8	43.2	Alcoholism	74.4	25.6
Meals	72.8	27.2	Calories	29.6	70.4	Irritation	38.4	61.6
Disease	76.8	23.2	Depression	52.0	48.0	Constipation	36.0	64.0
Cancer	87.2	12.8	Miscarriage	81.6	18.4	Gonorrhoea	58.4	41.6
Caffeine	65.6	34.4	Pregnancy	92.0	8.0	Inflammatory	27.2	72.8
Attack	71.2	28.8	Arthritis	73.6	26.4	Diabetes	73.6	26.4
Kidney	72.0	28.0	Nutrition	52.0	48.0	Hepatitis	40.8	59.2
Hormones	33.6	66.4	Menopause	38.4	61.6	Antibiotics	53.6	46.4
Herpes	25.6	74.4	Appendix	72.0	28.0	Diagnosis	65.6	34.4
Seizure	62.4	37.6	Abnormal	62.4	37.6	Potassium	52.0	48.0
Bowel	28.0	72.0	Syphilis	54.4	45.6	Anemia	27.2	72.8
Asthma	79.2	20.8	Haemorrhoids	76.8	23.2	Obesity	44.0	56.0
Rectal	34.4	65.6	Nausea	74.4	25.6	Osteoporosis	51.2	48.8
Incest	41.6	58.4	Directed	69.6	30.4	Impetigo	26.4	73.6

[1] Numbers are in percentages, highlighted areas indicate more than 80% of the respondents.

4.5 Correlations between educational level and variables measured

The REALM test classifies each person into a "grade range estimate" depending on their ability to pronounce a certain number of words correctly. This grading is totally independent of their stated educational level and is an estimate of literacy.

Table 4.10 Correlation between stated educational level and REALM grade range estimate obtained from reading score

Stated Educational Level	N (%) of respondents in each REALM grade range estimate			
	0 – 18 words	19 – 44 words	45 – 60 words	61 – 66 words
Grade 3 and below	11 (36.7)[1]	18 (60.0)	1 (3.3)	0 (0)
Grades 4 - 6	0 (0)	13 (43.3)	9 (30.0)	8 (26.7)
Grades 7 - 8	4 (13.3)	3 (10.0)	12 (40.0)	11 (36.7)
Grade 9 and above	0 (0)	5 (14.3)	9 (25.7)	21 (60.0)

[1] Highlighted areas indicate the predicted REALM grade range estimate for the majority of respondents at each stated educational level

The 4 categories of grade range estimates were discussed in Section 2.4.4. Table 4.10 presents the relationship between the respondents' stated educational level and the grade range estimates they achieved in the REALM test after reading the words. The highlighted areas indicate the categories into which the majority of respondents would have been expected to fall according to the original REALM test. The group with the lowest educational level (Grade 3 and below) performed better than anticipated, with the majority (60%) falling into the second grade range estimate (19 – 44 words) as opposed to the predicted lowest one of 0 to 18 words. This could be attributed to the fact that some of these respondents said that they were "royal readers" i.e. although they did not go to school, they were taught by their parents at home or acquired their reading skills in some other informal manner.

Respondents in the second and third educational level (Grades 4 – 6 and Grades 7 – 8 respectively) fell into the expected grade range estimate for pronunciation and in those respondents with the highest education, the predicted and the actual observed results were in good agreement, with 60% of the study population in that category falling between 61 and 66 words. The overall reading performance was thus better than expected.

Table 4.11 Correlation between stated educational level and REALM grade range estimate obtained from understanding score

Stated Educational Level	N (%) of respondents in each REALM grade range estimate			
	0 – 18 words	19 – 44 words	45 – 60 words	61 – 66 words
Grade 3 and below	29 (96.7)[1]	1 (3.3)	0 (0)	0 (0)
Grades 4 - 6	16 (53.3)	14 (46.7)	0 (0)	0 (0)
Grades 7 - 8	10 (33.3)	18 (60.0)	2 (6.7)	0 (0)
Grade 9 and above	11 (31.4)	16 (45.7)	8 (22.9)	0 (0)

[1] Highlighted areas indicate the predicted REALM grade range estimate for the majority of respondents at each stated educational level

The relationship between the educational level and the REALM grade range estimate resulting from testing understanding of the words was also investigated (Table 4.11). It would be expected that the majority of the respondents would fall into the areas highlighted in this table, however this was the case only with those respondents in the lowest educational level. Almost all of those with Grade 3 and below (29 out of 30) were able to explain only the expected number of words and thus fell into the predicted grade range estimate of 0 to 18 words.

Less than half of the respondents (46.7%) in the second educational level fell into the expected grade range estimate (19 – 44 words) as opposed to 53.3% who did worse than expected and fell in the lowest estimate of 0 to 18 words. There were only 2 out of the 30 respondents (6.7%) in the third educational level (Grades 7 – 8) who achieved the expected grade range estimate of 45

to 60 words. This small percentage (6.7%) indicates the importance of determining understanding of the words.

The group consisting of respondents with the highest level of education (Grade 9 and above) is an interesting one, as almost a third of the respondents fell into the lowest grade range estimate (0 – 18 words). It was expected that the majority of these respondents would have a much higher understanding, since some of them have a tertiary education. However, not even one respondent had a grade range estimate of 61 to 66 words. This could be partially accounted for by the fact that English is not their first language.

It is clear that the respondents with the highest education fared much worse than their U.S counterparts with the same educational level. The REALM test would not have shown this if administered in the "normal" way (only testing for pronunciation), since 60% of the respondents with Grade 9 and above fell in the predicted highest grade range estimate (61 – 66 words) for pronunciation. However none of them (Grade 9 and above) achieved this high category for understanding.

Figure 4.1 presents a graphic representation of the relationship between the REALM grade range estimate of both correct pronunciation and understanding and the percentage of respondents, according to their stated educational level. It shows a comparison between reading and understanding results obtained for the stated educational levels.

Fig 4.1 Percentage of respondents with correct pronunciation and understanding of words in the four REALM grade range estimates

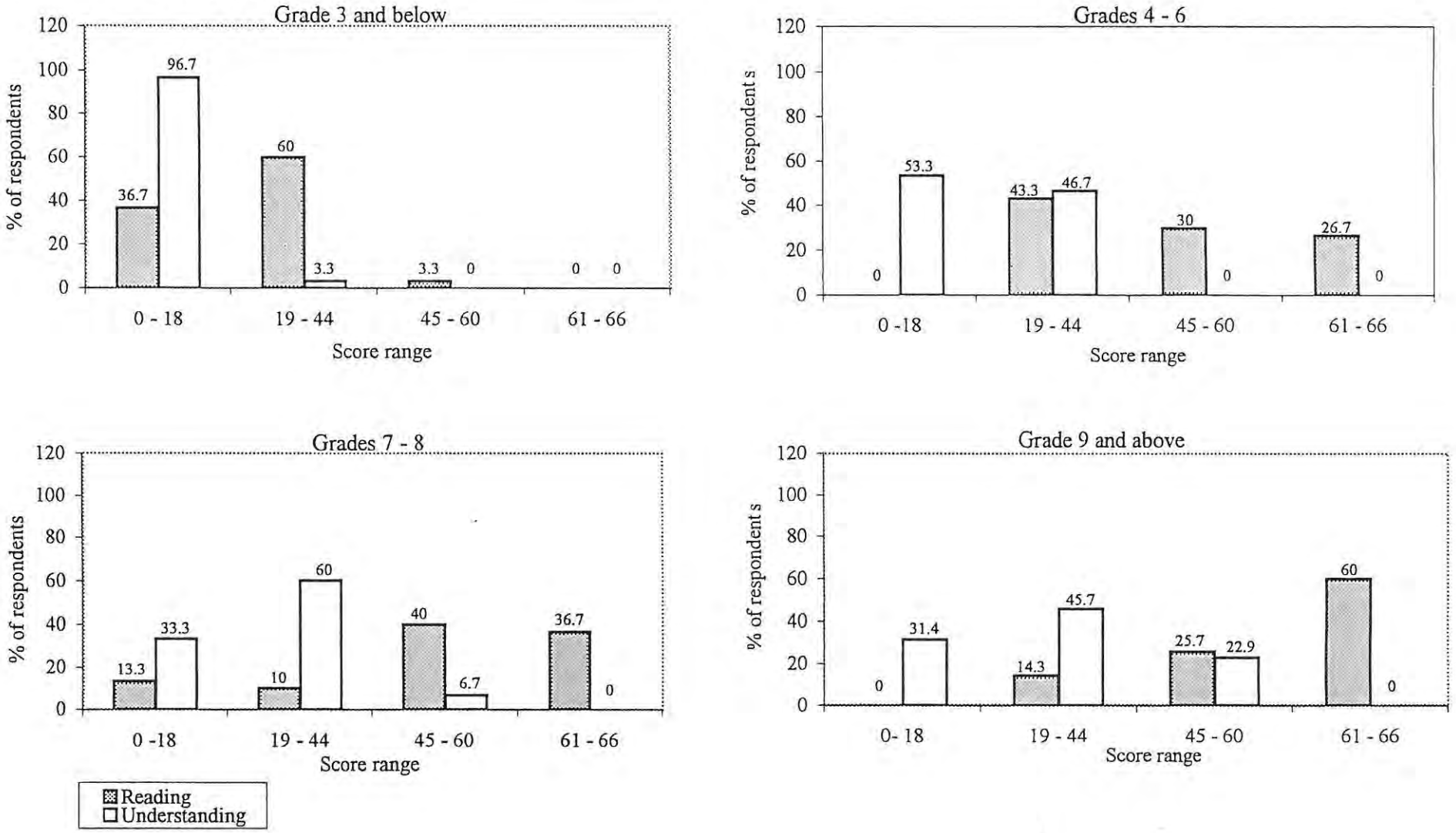


Table 4.12 Average reading and understanding grades for the combined population

	N (%) of respondents in each REALM grade range estimate (N = 125)			
	(Grade 3)	**(Grades 4 – 6)**	**(Grades 7 – 8)**	**(Grade 9)**
	0 – 18 words	**19 – 44 words**	**45 – 60 words**	**61 – 66 words**
Reading grade	15 (12.0)	39 (31.2)	31 (24.8)	40 (32.0)
Understanding grade	66 (52.8)	49 (39.2)	10 (8.0)	0 (8.0)

It was expected that the number of respondents in the stated educational level category would correspond with those in the reading grade and understanding grade categories, e.g. 30 respondents had Grade 3 education or below; it would therefore be expected that these 30 respondents would be able to pronounce and explain between 0 – 18 words correctly as this, in terms of the REALM test, would then classify their grade range estimate as being of Grade 3 or below. In the last 2 categories of the reading grade (45 – 60 words and 61 – 66 words), it was found that there were 31 and 40 respondents respectively and these numbers correspond fairly well with the number of the respondents in these stated educational levels i.e. 30 and 35 respondents respectively. However, a contradiction was observed in the same categories of the understanding grade, in that there were only 10 respondents in Grades 7 – 8 and none in Grade 9 and above as opposed to the 30 and 35 respondents interviewed in the stated educational level category.

These results clearly indicate that the ability to pronounce a word correctly provides us with very little insight as to whether the meaning of the word is actually comprehended.

CHAPTER FIVE
DISCUSSION

5.1 Introduction

Literacy has been reported as being a powerful tool for coping in life. It is a critical factor in interacting with others in a complex way and, of course, in promoting the health of a population because literacy affects health and health affects educational attainment, both of which are influenced by the social and economic context of a society. However, the relationships among these variables change as a country moves through mortality transitions or stages of health development. The prevalence of high literacy stimulates and facilitates modernization or complexity in health care and this sophistication increases the demand for patients' literacy and comprehension [43].

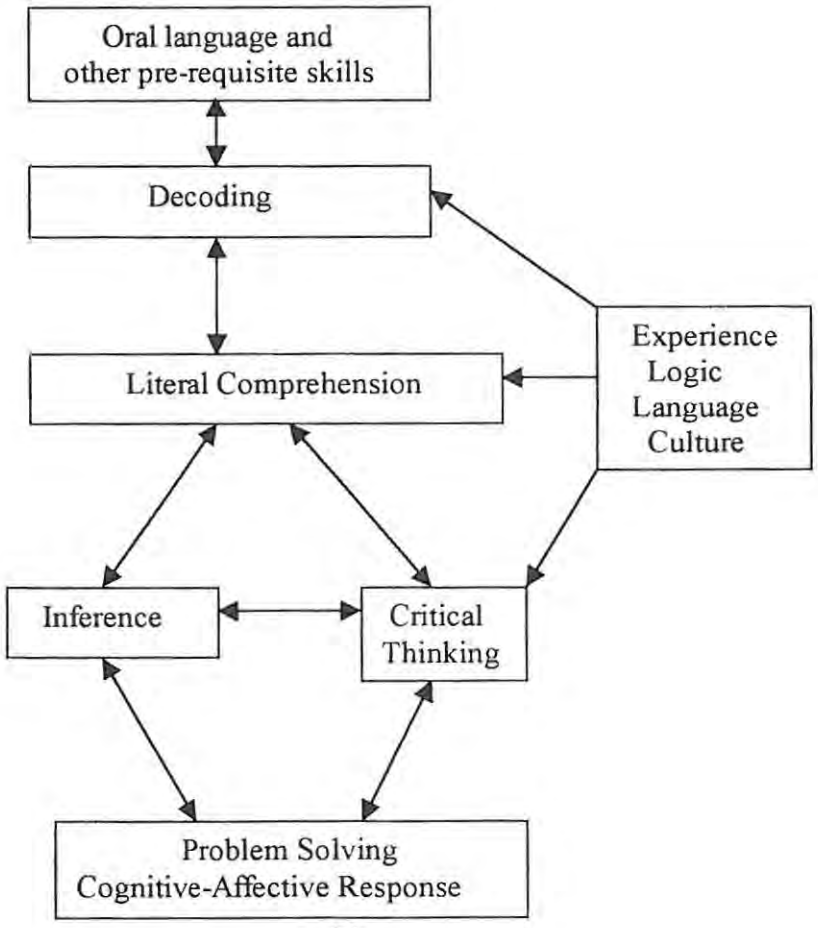
Unfortunately, global literacy has not progressed at the same rate and many people with low literacy skills are finding it increasingly difficult to operate in the health care environment. Such people are often shy to admit their lack of literacy skills and as a result have developed methods of concealing their illiteracy [33,40,51-52,54,108-110]. In some situations people may claim that they can read but, when challenged, they fail to display an acceptable reading ability. Paradoxically, there are also those who state that they cannot read, but who are in fact able to do so. This was demonstrated in our study by 5 respondents who claimed that they could not read, but who actually completed the test in less than 22 minutes.

5.2 Reading and comprehension

The reading process is a complex one as shown in Figure 5.1. It involves a merging of both language and thinking cognition with what is commonly thought of as reading. Oral language is the base for reading. In order to read, a shift must be made from speech to print using a process

called decoding i.e. being able to pronounce written letters and words correctly [28,156]. Reading and comprehension however, call on different skills. Word recognition is a higher order skill (Figure 5.1) which entails decoding of words and is measured by the REALM test [28,112]. Automatic decoding is also essential for the understanding of words [157] and this is the phenomenon on which the REALM test appears to be based. However, the results from our study indicated that decoding of words does not necessarily mean that those words will be understood as 32% of the study population could read between 61 and 66 words correctly and none of them could explain the same number of words. This phenomenon is also contradicted by the fact that in our study population, we had respondents who could not decode the words *per se*, but were able to explain them (Case 4 in Table 3.1).

Fig 5.1 Modified version of levels in the reading process [28]



Understanding or comprehension (literal) shows how much the patient understands from reading i.e. grasping the meaning of the message [28,108]. It has also been described as a "process in which the reader constructs meaning interacting with text, through a combination of prior knowledge and previous experience" [158]. It is a step beyond decoding the words and many readers with low literacy skills interpret words literally [28]. Low-level readers may be able to pronounce words, yet not comprehend their meanings [112] e.g. many respondents in our study could pronounce words such as "herpes" and "bowel" correctly, but were unable to explain them. This shows that even though a person may possess adequate decoding skills, understanding and interpretation is not guaranteed [18]. Therefore, if in doubt about the REALM test results, HCPs can verify the patient's understanding by asking them to explain some of the words [108].

Of all the literacy skills needed in health care, reading comprehension is the most important. Most studies have not assessed patients' reading comprehension because of time constraints and other practical limitations imposed by the medical setting. Assessing patient comprehension is a necessary prerequisite to facilitating patient cooperation with medical instructions [114]. Reading recognition tests cannot be used to assess patient understanding of words or concepts, it is thus important to determine whether these tests can be effectively substituted for measurement of comprehension [45,114].

Research that examines the association between word recognition and comprehension in patient populations is rare and the published research to date reports only moderate correlations between measures of word recognition and comprehension. The results from our study also substantiate this fact in that there was no significant correlation between respondents' reading and understanding of the words. The applicability of health literacy tests in health care settings is an

important issue with respect to measuring literacy, hence our test to determine the respondents' understanding of the words [45].

Cultural perception is a variable that may affect literal comprehension, decoding and critical thinking. Heath [159] states that cultural milieu affects the ways in which children learn to use language. She describes culture as learned behaviour and language habits as part of that shared learning e.g. the word "moon" can be an ambiguous one in the Sotho culture. When a Sotho woman is menstruating, she refers to herself as being "at the moon". On reading the word "moon", she may then interpret it in an incorrect way, because of her social context.

A relationship has been found between reading speed and comprehension i.e. as reading speed increases, so does the level of comprehension. If people cannot decode easily, then they cannot read fluently at a reasonable speed. If words are read laboriously, one at a time, it becomes extremely difficult to comprehend the meaning of whole sentences. Readers have to be able to read fast in order to make sense of the point. The more slowly a reader reads, the more difficult it is to understand the text because comprehension is lost in the effort to decode the written symbol [157]. Our results concur with this, as the relationship between the time taken to read the words and understanding was an inversely proportional one i.e. the longer the respondents took to read the words, the lower their level of comprehension ($r = 0.69$; $p < 0.0001$).

This relationship does not appear to have been taken into consideration by Davis et al [140] in determining the grade range of the REALM test. I feel that this variable should be considered in determining reading level, particularly as a highly significant correlation between reading time and comprehension was found in these results. The relationship could be of even greater importance in an English second-language population.

5.3 Why an English health literacy test in South Africa?

Literacy in all the national languages is totally impractical in South Africa, where there are 11 official languages. Nevertheless, the actual practice and discourse of the politicians makes it clear that English is undoubtedly considered as the dominant, socially powerful language [146].

The REALM test was administered in English for a number of reasons: The original test is administered and available in English. In a study conducted in the U.S. in an attempt to translate the REALM test into Spanish, it was found that because of the regular phoneme-grapheme correspondence in the language i.e. one sound being represented by one letter and vice versa, respondents engaged in word calling without understanding what they were reading [134]. This also occurs with the Xhosa language and other black languages as these languages were transformed into written languages relatively recently by the missionaries during the 19th and early 20th centuries. Other reasons for conducting the test in English are that in South Africa the majority of pharmacists speak English either as a first or a second language and most health information is currently available either in English or Afrikaans.

The results obtained therefore may have been affected by the fact that respondents were not tested in their home language. On the basis of what is known about the treatment of reading, particularly the fact that proficiency in reading goes together with the reader's ability to read with meaningful anticipation, it can be set as a condition that in order to become literate in a target language, the reader must have a command of the spoken language. Language is an integral part of the personality and the culture of a person. It is therefore self-evident that an illiterate person, if confronted with a totally foreign language medium, will experience considerable problems in learning to read and write that particular language. From a linguistic and an educational

viewpoint, it is therefore desirable that a person should first be made literate in his/her national language or mother tongue [19].

The availability of most written medical information in only 2 languages (English or Afrikaans) has been criticized in a letter to a popular magazine. In the letter, the person stated that the absence of other languages was insensitive and did not reflect black people's economic contribution. He wondered whether the health of these people meant anything to the pharmaceutical manufacturers since they did not bother to incorporate the indigenous languages into patient information leaflets [160].

There is no doubt that it is the right of patients to receive health care information in their home language. However, it is totally impractical to print it in all 11 languages and it would also have major cost implications. Written health information could possibly be made available in English and 2 other black languages such as IsiZulu and Sesotho. The reason for using English is that it is more socially accepted and is often used to determine literacy in this country [5,146]. The black languages in Southern Africa can be classified into 2 groups i.e. Nguni and Sotho; therefore it would seem sensible to have one language from each of the 2 groups. Since, when a person understands IsiZulu, there is a great possibility that he/she will also understand IsiXhosa and related languages such as IsiNdebele and also that a good understanding of Sesotho might guarantee an understanding of languages like Setswana and Sepedi or vice versa.

5.4 Expected versus observed results after administration of the REALM test

A number of research studies have found that the level of education correlates poorly with reading ability [100,161]. In the study, in investigating the relationship between educational level and reading scores, a good correlation was found for all educational groups except those of Grade

3 and below (Table 4.10). Although most research has found that patients with the lowest level of education are more likely to encounter significant difficulties with reading written materials, in our study they performed better than expected.

Surveys in the U.S. have shown that people read 3 to 5 grades lower than the years of schooling completed [9,28,116]. This relationship is confounded in developing countries where there is widespread illiteracy and where a large proportion of people tend to acquire literacy skills in an informal manner. Generally, we tend to look at formal education only, disregarding the fact that people can acquire literacy through apprenticeship learning. This is a process of acquiring skills informally in everyday activities from peers and/or relatives. There is also data that indicates that lack of formal training opportunities and socio-economic pressures in South Africa have led to on-the-job or informal apprenticeship learning in various work and community contexts [8]. There is also an increase in urbanization; people are moving from scarcely populated rural areas to densely populated towns and cities seeking job opportunities and they are therefore more exposed to written words and modern technology. The need for survival forces people to acquire skills informally, referred to as communal-literacy [8] e.g. those who sell fruit and vegetables on the street pavements and taxi drivers are required to have numeracy skills.

Only the respondents with Grade 3 and below understood the number of words anticipated by the corresponding REALM grade range estimate. The other 3 groupings i.e. Grades 4 – 6 to Grade 9 and above, performed worse than was expected in that they fell in the lower REALM grade range estimate. Our results concur with the notion that grade level does not necessarily give an estimate of functional health literacy, and therefore the assumption that literacy skills equal the last grade level completed is likely to be erroneous [21,105].

Our results showed a distinct lack of a relationship between reading ability and comprehension, although in some research it is indicated that comprehension is dependent upon reading skills rather than on grade completed [105]. In a study that showed that education is no guarantee of understanding, Mustard and Harris in the U.S. [162] asked 54 college freshmen to attempt to interpret actual prescription labels. Only 49% of the students interpreted the labels correctly and even those who answered correctly were confident about their answer only 12% of the time.

5.5 Applicability of the REALM test as indicated by the study

One of the objectives of this study was to assess whether the REALM test is transferable to another country, in this case to the Xhosa population in South Africa. The criteria for acceptance or rejection of the REALM test were discussed in Section 3.8. We also decided that 80% was an acceptable level to assure the reliability of the REALM test as a health literacy test for our Xhosa respondents.

When looking at the 3 lists of words (Table 4.9), it can be noted that the REALM test "worked" (Cases 1 and 2) for only 8 words for more than 80% of the respondents. With regard to Case 1 (Table 3.1), the respondents use most of these words on a regular basis i.e. they encounter them frequently. Words such as "pregnancy", "exercise", "miscarriage" and "cancer" are usually used as English words, as opposed to being translated into the relevant black language; hence their familiarity to most of the respondents. In Case 2, where the respondents could neither pronounce nor explain the words correctly, it is not surprising to find words such as "seizure", "haemorrhoids" and "fatigue", as these words are difficult to sound out.

Cases 3 and 4 (Table 3.1) are cases in which the REALM test was considered to have failed. A regular correspondence between grapheme and phonetic pronunciation was apparent for the

words listed in Case 3 (Table 3.1). Respondents were using phonetic cues based on phonological patterns with which they are familiar. This method therefore helped them to decode unfamiliar words such as "colitis", "inflammatory", "bowel", "herpes", "anemia" and "impetigo". The letters of the words were easy to sound out and this helped with decoding, although the entire meaning was not grasped. Knowing a set of words does not mean that the meaning of the whole text will be understood. Words often have to be seen in different contexts to ensure their understandability [157].

In Case 4, the words were either incorrectly pronounced or were not attempted at all, but their meaning was satisfactorily explained. For example, with words such as "eye" and "diabetes", the respondents could tell me what they meant but could not pronounce them. The English language contains many words like these which are not phonetically "transparent" i.e. their pronunciation cannot be easily guessed. In this case the respondents are probably recognizing the whole visual symbol e.g. the Coca-Cola sign is a universally familiar, easily recognizable sign and most people know what message it communicates, even though they may not be able to actually read it.

This is supported by a report from the Media Research and Training Unit of Rhodes University [163] which states that the reason for all the faces and emblems in South Africa is because there are many illiterate people who cannot read, but are very good at decoding symbols. People can identify a Shoprite store (one of the local supermarkets), because they can recognize the Shoprite logo, although they may not be able to read the word. In developing information materials therefore, we need to realize that people may possess competencies other than those similar to the cognitive skills associated with schooled literacy [8].

From the above discussion, it can be seen that the REALM test in its current form cannot be applied to measure health literacy in this country, especially in a population of whom English is a second language. This is demonstrated by words such as "calories", "herpes" and "colitis" which proved to be inappropriate and unfamiliar with our study population and will therefore need to be replaced. However, there are certain words from the REALM test which were just as unsuccessful, but need to be used e.g. "dose", "hepatitis", "menopause" and "anemia". Although the REALM test proved to be inapplicable in its original form, it can however be used as the basis for developing a modified and more relevant test for use with a South African patient population.

However, it needs to be remembered that although availability of health literacy tests is of importance in providing HCPs with the information to help them select materials and teaching methods most appropriate for each patient, testing the literacy skills of every patient might not be ideal for a number of reasons. Firstly, unless the HCPs are trained to apply appropriate teaching methods for each reading level, they cannot make effective use of the patients' literacy records. Secondly, some low literacy patients may elect to seek medical service elsewhere upon learning of the literacy test and lastly, it adds to the cost of the health care system [28].

5.6 Strategies for developing understandable patient education materials

Developing and using written health information poses a great challenge, particularly with current advances in health care technology. As the need for information increases, comprehensive written material is essential if patients are to participate in self-care activities. All too often however, health information is complex and full of medical jargon [155] and therefore requires a higher order of literacy skills in order to be interpreted. Many seemingly simple medical words which are readily understood by an educated layperson, may still remain part of medical jargon to the person with low literacy skills. This point was demonstrated very clearly in this study by

words such as "dose", "smear" and "medication", which could be regarded as simple and familiar concepts to HCPs and many patients, but from Tables 4.6 and 4.8 respectively it can be seen that the Xhosa adult does not seem to understand them.

On the other hand, we cannot dispense with medical jargon since the process of substituting simple words for these words is not easy, especially in a low-literate population who also only have English as a second language. In the substitution process, we have to consider cultural differences and literacy limitations [28]. In an African culture, for example, people tend to be too shy to pronounce the word "rectal" because of its association with body functions and will also have difficulty explaining it. A word such as "hormones" pertains to substances inside the body which cannot be seen. Understanding of this word relies on a basic knowledge of the physiology of the body, the knowledge which is far beyond many low-literate patients. Therefore the concept of this word is extremely difficult to communicate, as the content is absent.

A gap has been identified between patients' reading level and the level of written health information and it has been noted that all patients prefer easy-to-read materials irrespective of their educational level [9,46,51,56,101,117-119,121,128]. In order to simplify patient education materials and to avoid the use of unnecessary medical jargon, a number of strategies can be followed to develop understandable materials. Firstly, the development of patient education materials should be done in collaboration with target populations to gain insight into their culture, knowledge, beliefs and concerns about the problem to be addressed [53].

HCPs should be involved in all aspects of the design process and should represent a range of cultures thereby representing a multicultural approach. This could assist in identifying words which may/may not be acceptable in certain cultures. Information and illustrations in these

materials should be culturally relevant i.e. use language(s) and terminology commonly used by the target population e.g. a primary health care clinic that primarily serves black patients should ideally distribute materials written in the relevant black language which contain culturally sensitive illustrations [9,51]. Linguists can help with the identification of words that maybe simple to sound out, but are relatively difficult to understand and can suggest simpler, more appropriate words as a substitute. Materials targeted for low-level readers should therefore substitute more commonly used, understandable words for complex, unfamiliar words.

The words to be used in these materials should first be tested for comprehension as it is often difficult to predict whether a word may or may not be understood merely from correct pronunciation i.e. preliminary information should be collected to identify the comprehension level of individual words in the population [105]. This was often confirmed in our study e.g. almost 80% of the respondents were able to pronounce the word "colitis" correctly, but were unable to explain it. It can therefore be seen that some of the words from the REALM test would be inappropriate for use in patient education materials for our Xhosa respondents.

In deciding on layout and the general appearance of the information material, large fonts should be used and the layout should incorporate substantial amounts of blank (white) space to make the text look easy to read [9].

5.7 Respondents' attitude

The respondents were all kind, interested and willing to participate in the research. Once we had interviewed a couple of respondents, we found that the "bush telegraph" had worked very efficiently in the township. People knew about us before we could introduce ourselves formally.

The respondents' houses were generally very basic and simple. Many of these houses consisted of 1 or 2 rooms with only minimal furniture, some were shacks made of wattle and daub with mud floors. Only a few of them had electricity. Despite their circumstances, we were usually offered something to drink from the little that they had. Some of the respondents thought that by writing their names and addresses down, we were going to offer them employment. The majority of the respondents who had poor literacy skills were so interested in learning more that they asked us to give them English classes. Fortunately we were able to refer them to adult education programmes. We encountered no hostility or resistance in our interviews with the respondents.

5.8 Limitations of the REALM test and the study

We all have expectations of the message a particular piece of text holds. It is these expectations along with the context of the words that help us to make sense of the meaning. With the REALM test however, the words exist in "isolation" i.e. they are not used in contexts and this could have had affected the respondents' ability to explain them correctly. It has been found that scores improve when use is made of contextualized comprehension.

Only one ethnic group in South Africa was tested and all respondents were from the same geographical site which was an urban setting. The majority of respondents were at the lower end of the socioeconomic scale. Caution would therefore have to be exercised in extrapolating these results to other ethnic groups and to people living in different settings such as in the many isolated, rural areas of the country.

CHAPTER 6
CONCLUSION

This research has shown that the unmodified REALM test is an unsatisfactory method of assessing functional health literacy in a Xhosa population. These results could be extrapolated to predict that this test is also unlikely to be applicable in other English second language populations. The results illustrated the unreliability of using stated level of education as a predictor of literacy skills. This was substantiated by the extremely poor correlation between the stated educational level and the REALM grade range estimates obtained from the reading and understanding scores. One of the most useful outcomes of the project was the finding that this method of testing literacy using individual health related words, enables the identification of those words which can then be used with a satisfactory degree of confidence when developing written health information material for a population of varying educational and literacy skills.

Ours is the first research group to introduce the concept of health literacy testing to South Africa and to attempt to determine the health literacy skills of a selected target population. Given the high rate of illiteracy in this country as well as the varying range of literacy skills, the need for this type of testing would appear to be of great importance. This is particularly relevant in English second language speakers of high educational levels in whom good literacy skills would be anticipated but who, in this study, displayed surprisingly poor comprehension of many of the words.

In light of the findings of this project the following directions for future research are recommended. The Constitution of South Africa guarantees the right of all its citizens to be served and understood in the language of their choice [147-148]. English and Afrikaans still remain the languages in which most health care information is provided in this country although

significant progress is being made in meeting the diverse language needs of its multicultural population. As health information in black languages becomes increasingly available, consideration should be given to testing health literacy in these languages rather than only in English.

The REALM test was not administered in the home language of the respondents and this will undoubtedly have had a bearing on their performance. This project was conducted in people who speak Xhosa which is one of the Nguni languages. The research should be duplicated in selected different black ethnic groups, particularly in one of the Sotho languages, as well as in any other English second language speakers, whose home language may be for example Afrikaans or Urdu. This is necessary in order to extrapolate results to all South Africans who do not have English as their first language.

The structure of the REALM test could be modified to include 2 sections; the first section would be similar to its current form, but could be shorter, in that it would include medical words (possibly 2 lists of 20 words each) which were to be read and their pronunciation checked. The additional section could consist of a short passage of health related text with selected words missing. A few different options could be offered for these words with the respondent being required to choose the most appropriate one. This type of literacy test would then test both reading and comprehension, as an overall understanding of the text is required in order to choose the correct word. The test must be quick, easy to administer and easy to score as these are essential attributes for any test which is to be used in the fast-paced health care environment where time is at a premium.

Globally much work still needs to be done in addressing the health information needs of patients, particularly for patients in developing countries who encounter problems accessing health information as a result of inadequate literacy skills. This research has illustrated the danger of assuming literacy skills based on formal education and has indicated both the need for including simple, understandable text in health information material and the necessity of evaluating draft written material in the target population before its final preparation and distribution.

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APPENDIX A

TESTING LITERACY LEVEL USING THE REALM TEST

(REALM - rapid estimate of adult literacy.on medicine)

NAME OF INTERVIEWER: _____

TEST SITE: _____

Name of respondent: _____

1	2	3

SECTION 1: DEMOGRAPHICS

1.1 Sex

Male[1]	Female[2]		4

1.2 Age

<21[1]	21-40[2]	40-65[3]	>65[4]		5

1.3 Race

Black[1]	White[2]	Coloured [3]	Indian[4]		6

1.4 Home Language

Xhosa[1]	English[2]	Afrikaans[3]	Sesotho[4]	7	8

1.5 Language proficiency

	listen[1]	speak[2]	read [3]		
Home Language					9
English					10
Afrikaans					11
Specify:_____ Other					12

1.6 Highest qualification

None[1]	Sub A[2]	Sub B[3]	Std 1[4]	Std 2[5]	Std 3[6]	Std 4[7]
Std 5[8]	Std 6[9]	Std 7[10]	Std 8[11]	Std 9[12]	Std 10[13]	Tertiary[14]

13 14 [ ][ ]

1.7 Place of residence

Suburbs [1]	Township [2]	Farm [3]
Hostel [4]	Other [5]	

[ ] 15

Specify: _____

1.8 Where about is this place? (Specify the province)

16 17 [ ][ ]

Eastern Cape [1]	Free State [2]

1.9 Are you currently employed?

Yes[1]	No[2]

[ ] 18

1.10 Where are you working now?

Clerical[1]	Farm[2]	Labourer[3]	Domestic[4]	Education[5]
Shop assistant[6]	Hospital worker[7]	Self-employed[8]	Unemployed[9]	Other[10]

19 20 [ ][ ]

1.11 Can you tell time from a clock face?

Yes[1]	No[2]	Digital time only [3]	Both[4]

[ ] 21

1.12 Apprehension factor

a. At a family gathering are you the "centre of attraction"? (when you are not around,people feel "like" the party has not started yet)

Yes[1]	No[2]

[ ] [*26]

b. When at family gatherings/bible groups do you

Tell stories[1]	Listen to stories[2]	Both[3]

[ ] [*27]

c. When being asked a question by a teacher/employer/doctor, do you feel

Confident to answer[1]	Scared to answer in case you make a mistake[2]

[ ] [*28]

* numbers on the last page

RAPID ESTIMATE OF ADULT LITERACY IN MEDICINE
(REALM)

List 1 Reading	Understanding	**List 2** Reading	Understanding	**List 3** Reading	Understanding
1) fat _____	_____	23) fatigue _____	_____	45) allergic _____	_____
2) flu _____	_____	24) pelvic _____	_____	46) menstrual _____	_____
3) pill _____	_____	25) jaundice _____	_____	47) testicle _____	_____
4) dose _____	_____	26) infection _____	_____	48) colitis _____	_____
5) eye _____	_____	27) exercise _____	_____	49) emergency _____	_____
6) stress _____	_____	28) behaviour _____	_____	50) medication _____	_____
7) smear _____	_____	29) prescription _____	_____	51) occupation _____	_____
8) nerves _____	_____	30) notify _____	_____	52) sexually _____	_____
9) germs _____	_____	31) gallbladder _____	_____	53) alcoholism _____	_____
10) meals _____	_____	32) calories _____	_____	54) irritation _____	_____
11) disease _____	_____	33) depression _____	_____	55) constipation _____	_____
12) cancer _____	_____	34) miscarriage _____	_____	56) gonorrhea _____	_____
13) caffeine _____	_____	35) pregnancy _____	_____	57) inflammatory _____	_____
14) attack _____	_____	36) arthritis _____	_____	58) diabetes _____	_____
15) kidney _____	_____	37) nutrition _____	_____	59) hepatitis _____	_____
16) hormones _____	_____	38) menopause _____	_____	60) antibiotics _____	_____
17) herpes _____	_____	39) appendix _____	_____	61) diagnosis _____	_____
18) seizure _____	_____	40) abnormal _____	_____	62) potassium _____	_____
19) bowel _____	_____	41) syphilis _____	_____	63) anemia _____	_____
20) asthma _____	_____	42) haemorrhoids _____	_____	64) obesity _____	_____
21) rectal _____	_____	43) nausea _____	_____	65) osteoporosis _____	_____
22) incest _____	_____	44) directed _____	_____	66) impetigo _____	_____
Time: _____		Time: _____		Time: _____	

Total Time: _____

* Reading Score: _____

* Understanding Score: _____

Grade: _____
(number of years completed at school)

* enter this data on the last page

2.1 Reading performance (the number of words pronounced correctly)

List 1

0 - 6 [1]	7 - 14 [2]	15 - 20 [3]	21 - 22 [4]		22

List 2

0 - 6 [1]	7 - 14 [2]	15 - 20 [3]	21 - 22 [4]		23

List 3

0 - 6 [1]	7 - 14 [2]	15 - 20 [3]	21 - 22 [4]		24

Overall

0 - 18 [1]	19 - 44 [2]	45 - 60 [3]	61 - 66 [4]		25

2.2 Understanding of the words

List 1

0 - 6 [1]	7 - 14 [2]	15 - 20 [3]	21 - 22 [4]		26

List 2

0 - 6 [1]	7 - 14 [2]	15 - 20 [3]	21 - 22 [4]		27

List 3

0 - 6 [1]	7 - 14 [2]	15 - 20 [3]	21 - 22 [4]		28

Overall

0 - 18 [1]	19 - 44 [2]	45 - 60 [3]	61 - 66 [4]		29

2.3 Length of time it takes to read the test

≤3 mins [1]	>3 - 5 mins [2]	>5 - 10 mins [3]	> 10 mins [4]		30

2.4 Reading score

0 - 18 [1] (≤3rd grade)	19 - 44 [2] (4th - 6th grade)	45 - 60 [3] (7th - 8th grade)	61 - 66 [4] (≥9th grade)		31

2.5 Understanding score

0 -18 [1] (≤3rd grade)	19 - 44 [2] (4th - 6th grade)	45 - 60 [3] (7th - 8th grade)	61 - 66 [4] (≥9th grade)		32

2.6 The number of words the patient could read, but could not understand.
(indicates failure of REALM test).

List 1

none[1]	≤3 [2]	4 - 7 [3]	8 - 11 [4]	≥12 [5]		33

List 2

none[1]	≤3 [2]	4 - 7 [3]	8 - 11 [4]	≥12 [5]		34

List 3

none[1]	≤3 [2]	4 - 7 [3]	8 - 11 [4]	≥12 [5]		35

Overall

none[1]	≤3 [2]	4 - 7 [3]	8 - 11 [4]	≥12 [5]		36

2.7 Success/failure of REALM test for individual words.

37
1

- "Worked No. 1" means cannot read and cannot understand.
- "Worked No. 2" means can read and can understand.
- "Failed No. 1" means can read, but cannot understand.
- "Failed No. 2" means cannot read, but can understand.

LIST 1:

1. fat	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		38
2. flu	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		39
3. pill	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		40
4. dose	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		41
5. eye	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		42
6. stress	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		43
7. smear	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		44
8. nerves	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		45
9. germs	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		46
10. meals	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		47
11. disease	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		48
12. cancer	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		49
13. caffeine	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		50
14. attack	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		51
15. kidney	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		52
16. hormones	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		53
17. herpes	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		54
18. seizure	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		55
19. bowel	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		56
20. asthma	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		57
21. rectal	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		58
22. incest	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]		59

LIST 2:

23. fatigue	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	61
24. pelvic	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	62
25. jaundice	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	63
26. infection	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	64
27. exercise	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	65
28. behaviour	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	66
29. prescription	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	67
30. notify	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	68
31. gallbladder	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	69
32. calories	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	70
33. depression	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	71
34. miscarriage	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	72
35. pregnancy	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	73
36. arthritis	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	74
37. nutrition	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	75
38. menopause	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	76
39. appendix	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	77
40. abnormal	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	78
41. syphilis	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	79
42. haemorrhoids	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	80
43. nausea	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	1
44. directed	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	2

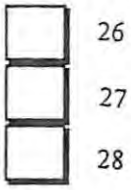
3

3

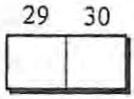
LIST 3:

45. allergic	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	4
46. menstrual	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	5
47. testicle	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	6
48. colitis	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	7
49. emergency	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	8
50. medication	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	9
51. occupation	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	10
52. sexually	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	11
53. alcoholism	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	12
54. irritation	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	13
55. constipation	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	14
56. gonorrhea	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	15
57. inflammatory	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	16
58. diabetes	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	17
59. hepatitis	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	18
60. antibiotics	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	19
61. diagnosis	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	20
62. potassium	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	21
63. anemia	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	22
64. obesity	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	23
65. osteoporosis	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	24
66. impetigo	Worked No.1[1]	Worked No.2[2]	Failed No.1[3]	Failed No.2[4]	25

1.12 Apprehension Factor (see page -2-)



- Total Reading Score (see page -3-)



- Total Understanding Score (see page -3-)

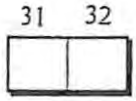


Fig 4.1 Percentage of respondents with correct pronunciation and understanding of words in the four REALM grade range estimates