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FACULTY OF MEDICINE

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SQ95 – Structured Questionnaire of 1995

A pilot study on the development and testing of an instrument for assessment of dependency needs of older persons in South Africa

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S Z Kalula MB. ChB. MRCP(UK)

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Declaration

I, Sebastiana Zimba Kalula, hereby declare that the work on which this thesis based is my original work (except where acknowledgements indicate otherwise), and that neither the whole work nor any part of it has been, or is to be submitted for another degree in this or any other university.

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ABSTRACT

Background

With the advent of the new government and the end of the apartheid era, the Department of Welfare investigated methods whereby the demand for equitable access to state subsidised homes for the aged might be met. It was decided to develop an instrument to assess dependency needs of older persons that might warrant admission to homes for the aged. Financial constraints dictated that only 2% of those over the age of 65 years could be institutionalised in state subsidised homes. An instrument with high specificity and sensitivity and good face and construct validity was required in order not to exclude the needy or include the undeserving in subsidised institutional care. The instrument formerly used in South Africa was designed to assess dependency needs of urban-living individuals and assumed relative affluence in contrast to the reality of the situation of the bulk of the South African population. The instrument was deficient in that it assessed only mental and physical disabilities. It did not take into account the wide disparities relating to primary needs (such as water, food, sanitation and security) that exist among communities with widely disparate socio-economic status. Since South Africa is a developing country, a significant component of the elderly population live in extreme poverty, often in rural subsistence-economy conditions. Instruments used in other countries, which assume a certain level affluence, are thus not applicable to the majority of the South African population.

It was necessary, therefore , to compile a new instrument, which could be tested on the different population groups of South Africa. Before embarking on a costly national study

of testing the new questionnaire, it was thought necessary to conduct a pilot study to iron out ambiguities and flaws. This pilot study of the new instrument, including a self-teaching manual to be used by interviewers, is the subject of the present dissertation.

Methods

The pilot study was conducted in greater Cape Town. Prior to this, a series of workshops were held at which attributes of various instruments in use in South Africa and other countries were critically examined. The instrument that was developed (called the Structured Questionnaire of 1995 - 'SQ95') has the following attributes: as theoretical framework, an inversion of Maslow's hierarchy of needs/aspirations was conceived to form a hierarchy of dependency requirements ; the instrument emphasises disability (i.e. need for assistance), rather than impairment (a disturbance in bodily function). This was achieved through a highly detailed evaluation of dependency needs relating to activities of daily living. The instrument in addition incorporates domains for the assessment of behavioural disturbances relating to mental infirmity. It contains a domain that attempts to identify cases in urgent need of evaluation for support/admission to a home for the aged; it evaluates the current care needs; it evaluates the status of primary needs (water, food, toilet and safety), community infrastructure (transport, telephone and post office), support systems available to the client (e.g. caregivers and formal and informal organisations); and it evaluates the functional status of the caregiver.

An elaborate, self-explanatory manual was complied and tested with the instrument. The purpose of the manual was to assist the interviewer in understanding the relevance and

meaning of the individual questions, with the aim of minimising inter-observer variation. An important requirement of the manual was that it would have a self teaching design for interviewers as it should be accessible for use by untrained personnel (for example in remote rural areas).

Testing the SQ95

In the pilot study, the questionnaire was tested on two samples (a total sample of 133):

(1) A randomly chosen sample of 53 elderly individuals who were living communally (in sheltered homes) under the auspices of the Catholic Welfare Development Trust's Neighbourhood Old Age Homes Project (CWDT/NOAH).

(2) Eighty randomly chosen residents at Highlands House old age home.

These residents were classified into different levels of dependency by the nursing managers of both establishments who knew the clients very well. This classification was used as the "gold standard" against which the SQ95 was validated for its classification of the residents into different levels of dependency.

Results

Significant amendments were made to the questionnaire and manual following the pilot study. Following data analysis, it appears that the instrument has no obvious flaws in the logic of its construction. There was a statistically significant relationship between the

gold standard categorisation and the classification derived from the SQ95 on dependency levels of the clients.

Conclusions

The preparatory work for this pilot study included the design and layout modifications to the original SQ95 and the writing of a comprehensive manual.

The study has been useful in providing many insights and identifying specific ambiguities and other problems related to face validity of the SQ95 in preparation for the national validation study of the SQ95. Investigations of construct validity served to reinforce the view that the theoretical framework of the SQ95 was sound and could be amenable to developing a valid scoring system from the bigger national study.

The main weakness of the pilot study was that the sample populations reflected institutionalised individuals and therefore meaningful conclusions relating to construct validity for social support system and infrastructure could not be derived.

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GLOSSARY OF ABBREVIATIONS

ADL	Activities of Daily Living
SQ95	Structured Questionnaire of 1995
CWDT	Catholic Welfare Development Trust
NOAH	Neighbourhood Old Age Homes
SHA	Subsidised Homes for the Aged
RAI-HC	Residents Assessment Instruments -Home Care
CAPS	Client Assessment Protocols
MDS-HC	Minimal Data Set for Home Care
FIM	The Functional Independent Measure
BI	Barthel Index

CHAPTER 1: INTRODUCTION

1.1 POPULATION DEMOGRAPHICS

It is well recognised that the population of almost every country in the world is ageing. Increased access to medical and other resources - one of the major successes of the 20th century - has considerably enhanced life expectancy, and several studies have shown that the mean life expectancy of a population is closely related to the level of development of the society, usually expressed in terms of per capita income and education.[1] The benefits of increased longevity may have enhanced the lives of individuals, but this steady and sustained growth of an elderly population is already posing a considerable challenge to policy makers in many societies.[1] It is anticipated that in the near future there will be an imbalance in the proportion of older to younger people, adversely affecting the dependency ratio (the ratio between people who are economically active and those who are economically dependent). The dependent group includes children, school or college students and pensioners.[2]

In most communities, the elderly are considered to be people over the age of 65 years, the most widely used criterion in industrialised societies for receipt of retirement pensions.[3] The elderly population has been further sub-classified by the known relationship between increasing age and increasing level of disability and illness. The demarcation of "older-old" has come about with the recognition that it is within the over-75 age group that increased disability and ill-health become identifiably correlated with chronological age.[3]

The factors that influence the age structure of a population are fertility and mortality and their interaction.[2] Migration has been shown to have no significant impact on either these factors.[4] Both lower birth and higher death rates in the younger age group contribute to the development of an ageing population and hence an increase in the average age, but declines in mortality contribute relatively little when compared to decreases in fertility. A decline in the birth rate decreases the number of young people and therefore increases the proportion of the old, more of whom are living longer. Clearly, a decrease in the death rate can have different impacts on the mean age depending upon the ages at which mortality decreases.[4]

World-wide, the elderly population grew by 2.8% from 1993-94, compared with a growth in the world's population of only 1.6%. The rate of growth of the elderly population is more rapid in developing than in developed countries, a developing country being one whose economy is not yet characterised by a level of industrialisation and national income sufficient to yield the domestic savings required to finance the investment necessary for further growth. Developed countries, i.e., those that are economically advanced and industrialised, include most countries in Europe, North America, as well as Japan. Among the developing countries are countries in Africa, Asia, and Latin America. It is not generally appreciated that most of the world's elderly live in developing countries. In 1990, developing countries contained over half (55%, 176 million) of the elderly, and this figure is projected to reach 68% (227 million) by the year 2025.[1]

South Africa is, at present, experiencing a phase of demographic transition in which the median age of the population is rising while the size 65+ group is gradually increasing. South Africa's median age was 20 years in 1993. It is estimated to increase to 21 years by the year 2010 and to 23 years by the year 2025.[5] It is of strategic importance that the 80+ group is increasing more rapidly than the group aged between 65 and 80 years. This trend must be taken into account in future planning in order to ensure effective rendering of services. This is essential as the need for assistance in everyday activities increases with age from 9% of persons aged 65 to 69 to 50% of the oldest old (85 and over), according to the Survey of Income and Program Participation (SIPP) carried out in the United States in 1990 and 1991 on the need for personal assistance with everyday activities.[6] (See Figure 1)

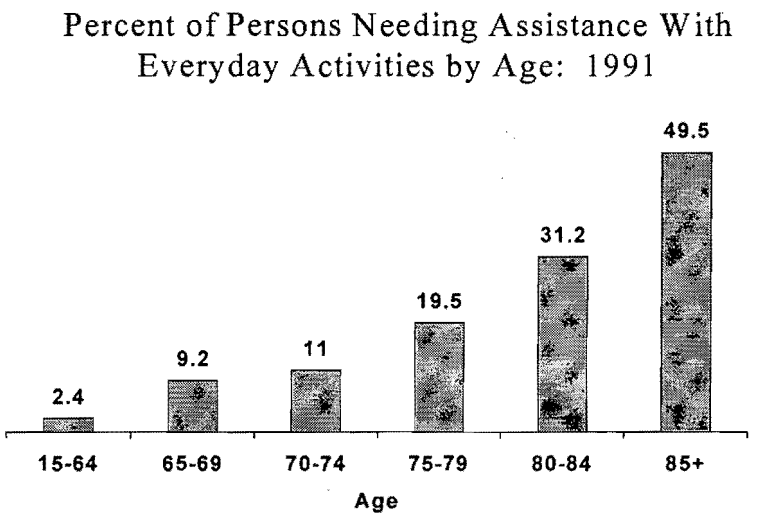


Figure 1 (Civilian non-institutional population)

Source: U.S. Bureau of the Census, 1990 and 1991 panels of Survey of Income and Program Participation (SIPP) files.

The South African figures are similar to the above. The South African Council for the Aged has endorsed estimates that approximately 7% of people aged 65-74 will need help with their personal care and activities of daily living. The proportion increases to 16% in the 75-84-year-old age group, and to 39% in the over 85-year-olds, many of whom are frail. [7] The aged population in South Africa is estimated at 1.8 million persons and will escalate to 3.4 million by the year 2015.[8]

The South African population is divided into four racial groups: white, black, coloured and Asian. The Population Registration Act passed in 1950 provided the first general definition of each group. The whites are of European descent, the blacks are described as members of the native tribes (aboriginal) of Africa, the coloureds are products of racially mixed marriages and Asians those originating mainly from the Indian subcontinent. Unfortunately these racial groupings were used as a basis for discrimination, which led to significant differences in access to education, health services, social services and in the participation in the country's economy. While the author deplores the use of racial labels, the racial groupings that were used in South Africa until recently account, to a large extent, for group differences with respect to demography, health status and requirements for social services.[9, 10]

The proportion and number of the elderly in South Africa is expected to increase in all population groups. Based on the present age structures, the whites are expected to experience an increase from 9.0% in 1995 to approximately 13% in 2015 in their elderly population and will be the oldest population group. They are followed by the most

rapidly ageing group, the Asians, with an expected increase in the percentage of the elderly from 3.8% to 8.6% for the same period. For the coloureds, the corresponding figures will be 3.7% and 6.0%. Among the blacks, the expected percentage increase in the proportion of the elderly will be from 3.1% in 1995 to 3.6% in the year 2015.[8]

Although the percentage of elderly people in the black population is lower than in the other population groups, in absolute terms there are many more blacks over the age of 65. This was evident from the 1991 census which revealed that there were 1 087 955 blacks, 474 260 whites, 111 800 coloureds and 33 819 Asians aged 65 years and over.[11]

Predictions of future population structures should be interpreted with caution. The effect of the Human Immunodeficiency virus (HIV) epidemic was not taken into account in projections of population size in the twenty-first century. The HIV epidemic may have a significant effect on the projected figures. The long-term consequences of the Human Immunodeficiency Virus infection and the Acquired Immunodeficiency Syndrome (AIDS) remain unknown. [12]

The impact of mortality from AIDS is mainly in the 15-49 year-old age group and the 0-4 year-old age group due to death from paediatric AIDS.[13] Death from AIDS also varies across the racial groups, being highest among the black population in South Africa and least among the white population. This is supported by the reported incidence of sexually transmitted disease, which is known to be closely associated with the incidence of HIV infection. The incidence of sexually transmitted disease by population group is

approximately 0.5% among the whites, 1.0% among the Indians, 10.0-15.0% among coloureds and 16.0-24.0% among blacks.[14]

The effects of AIDS/HIV might be similar to the effects of the First (1914-1918) and Second (1935-1945) World War, which affected the demographic structures of age groups in which relatively large numbers of people were killed. The population figures for the Central European countries all show such an impact. Poland has an unusually high ratio of women to men in the over 65 year-old age group reflecting gender divisions in military action. This has also been noted in Austria, and may be ascribed to the large scale on which men were killed between 1939 and 1945.[15]

1.2 ECONOMICS AND CARE OF THE ELDERLY

The rapid growth of the elderly sector of the population has health and economic implications for individuals, families and governments everywhere. With increasing age comes increasing frailty and dependency. Frailty occurs when there is diminished ability to carry out the important practical and social activities of daily living.[16] Dependency implies a relationship between a dependent individual and carer, where the dependent individual requires help on a regular basis.[17]

In developing countries, a multi-generation household is considered to be advantageous for the elderly because it provides physical and social support. In the past, dependency needs for the South African elderly were met, to mutual advantage, by relatives in their own home settings. However, South Africa, like other developing countries, is likely to

see a change in household composition during the next decade, including a decline of the extended family structure with increasing urbanisation and industrialisation. This would mean a loss of economic support and companionship for older people, unless agencies are developed to fill the gap.[18]

1.2.1 Institutionalised care

In the United States of America, the earliest institutions were for outcasts and paupers. This has contributed to their being regarded as "charitable", with the expectation that those cared for in them should be grateful and submissive.[19] They included the disabled, handicapped, aged, widows with children, orphans, the feeble minded, the mentally deranged, the chronically ill and the unemployed. Institutions came under state supervision in the United States only in the later part of the nineteenth century. During this same period, specialisation of various types of institutions occurred, leading to segregation of different groups of residents and the development of homes in their present forms. The proportion of elderly people in the general population increased rapidly in the United States only in the second half of the 20th century. This change in demography was one of the major contributing factors to growth of institutional facilities for the elderly.[20]

In the United Kingdom up to the late 1980s, a large number of frail elderly were kept in long- stay hospitals that were managed by consultant geriatricians. These facilities were usually in the oldest and poorest accommodation. There was usually no provision for single rooms and toileting facilities were inadequate. The atmosphere was oppressive and they were expensive to run. The development of National Health Service (NHS) nursing homes, which would be run by nurses, with medical care provided on call by a general practitioner, was promoted in the U.K. by the Department of Health. NHS nursing homes were intended to be small, community based units, with single rooms to promote dignity and privacy. Greater choice was opened to the frail elderly. To ensure proper use of public resources, the Community Care Act of 1990 made it clear that assessment of applicants would remain the duty of geriatric assessment teams. Such teams would have the capability to make assessments at a technical level and determine the needs and priorities at a district level that would be necessary for service distribution.[21, 22]

In South Africa, there has until recently been an unrealistic emphasis on institutional care for older persons in the white South African community. An example of this is in the Western Cape where the province is currently subsidising 133 Homes for the Aged, providing for the care of 10 718 aged persons. The racial distribution of these facilities has been, whites: 108 facilities registered to provide accommodation for 8 388 aged persons, coloureds: 25 facilities registered for 2 196 aged persons, blacks: 1 facility registered for 134 aged persons. The largest number of persons entering

institutions are the oldest old (85 years and over). Those entering at a less advanced age tend to be people who are unlikely to rely on younger family members for support.[23]

According to population figures provided by the Demographic Information Bureau (FFC, 1996) the total number of persons older than 65 years of age in the Western Cape was 259 463. This figure was estimated at 286 000 in 1997. For financial reasons, the national norm for provision of residential frail care facilities has been set at 2% of the total number of people over the age of 65 years. This is taken to be the proportion of elderly people in need of 24-hour residential care.[24] It would mean an allocation of 5 720 instead of the current 10 718 beds (of which the white community occupies 8 388) in the Western Cape. Over provision in the province has resulted in the institutionalisation of a high percentage of mobile aged persons (who could in fact be living independently in the community).[25]

In the Western Cape, the elderly population comprises 5.2% of the total population. In 1996/97 the Provincial Administration spent a total of R758 009 000 of the social services budget on the elderly group. This accounted for 37% of the total social services budget. Of the R758 009 000, an allocation of R76 726 000 was for homes for the aged.[26] Nationally, about 61% of the total welfare budget is spent on social security and social welfare services for the elderly.[27]

The over emphasis on institutional care needs to be re-evaluated. There are currently approximately 52,000 frail care beds available throughout South Africa, but most of them are unsuitable for frail care.[28]

A frail care bed is for nursing the frail elderly who generally are in need of high levels of support. This entails increased expense as an increase in number of staff is required. The facility also needs to provide amenities that are suitable for the frail elderly. The average unit cost of between R11,000 and R22,000 per annum for institutional care highlights the unaffordability of the current dispensation and the wide disparities in provider costs. The unit cost for community based services is significantly lower and varies between R250 for basic services and R2,500 per annum for more sophisticated services. [29]

Since government has responsibility for the plight of the destitute, poor and very old as well as frail persons, limited governmental resources and financial constraints mean that the available resources should be utilised most cost effectively.[30] Preparation for retirement is generally inadequate or completely lacking in South Africa; this includes a substantial proportion of those employed in the formal sector. Large numbers of South Africans are unemployed, work in the informal sector or have poorly paid jobs and, therefore, lack the means to save for retirement. There are unrealistic expectations with respect to state care for the aged and lack of public awareness of the alternative resources available from informal service providers.[31]

1.2.2. The relationship between old age homes and hospitals

In South Africa, old age homes are taking responsibility for a considerable burden of physical and mental conditions which should, ideally, be assessed and managed by health services proper in the first instance.

The presence of remediable psychiatric illnesses is often missed on assessment of an elderly person being considered for admission to an old age home. This happens frequently as such conditions are often incorrectly attributed to normal ageing. A survey conducted in July 1980 by L. Trichard, A. Zabow and L .S Gillis found that up to 75% of new admissions to certain old age homes in South Africa had a psychiatric condition: 50% suffered from dementia; 25% had depressive symptoms in association with other ailments. More than half the residents were physically stiff and weak and nearly 25% suffered from incontinence.[32] There is thus a clear need for the development of geriatric facilities that encourage the holistic management of the elderly. Better co-ordination of services between hospitals at different levels, old age homes and the community for continued medical, psychiatric and rehabilitative care of the elderly is essential.[33]

1.2.3 Disadvantages and advantages of institutional care

Disadvantages

The current dogma, as expressed in a manual produced by the Department of Welfare and Social Services (1987) is that there are several perceptible disadvantages relating to institutional care: once in an old age home, the elderly person loses autonomy; there is

lack of stimulation; to save staff time, elderly persons are usually not encouraged to help themselves. An example of this is feeding, which is less time consuming for staff than supervising the elderly while they feed themselves. Discouraging independence in the elderly is a source of demotivation, which may engender withdrawal from social activities and lead to depression and a vicious cycle of further demotivation and withdrawal.

Rehabilitative care, which could help to delay the onset of dependence, is usually lacking in old age homes. The daily routine in old age homes demands very little in the way of physical activity. In this respect, individualised exercise programmes would go a long way towards preventing premature physical deterioration that is related to physical inactivity. These exercises should be performed in a relaxed, pleasant atmosphere and should be non- competitive. They would be seen, thus, as a pleasant recreational activity.

Elderly people in old age homes lose opportunities for involvement in community life. It should not be forgotten that elderly people in old age homes have emotional and social as well as physical needs. They need encouragement to explore their interests, creative abilities and opportunities to express their emotions. They need to have a sense of belonging and to feel loved and appreciated. Such interventions prevent premature deterioration in physical and mental faculties. Though most elderly persons have a degree of physical and mental debilitation, there have been instances of rapid deterioration following admission to old age homes.[34]

Advantages

For the elderly person who in the community relied heavily on community services an old age home gives a sense of security. Life in the community, where one is dependent on others for most activities of daily living, can be hazardous and stressful. It creates anxiety and a sense of insecurity especially where the elderly person has to deal with different caregivers. Another source of anxiety for the elderly person is whether the caregiver will arrive on schedule.

Furthermore, an elderly person living in the community may suffer from social isolation to a greater degree than in an old age home where life is structured and some form of care is always guaranteed. [19]

1.2.4 Subsidised homes

Old age homes in South Africa are divided into categories A, B and C, depending on the fitness of the residents. The fitness of the residents is defined according to the point system on a generally used instrument based on one developed by Wicht (see annexure A)

In Category A homes, the proportion of frail, subeconomic residents may not exceed 40% of the residents that can be classified as sub economic. (Sub-economic residents are residents with inadequate finances to meet the costs of their living expenses in old age homes). In Category B homes, between 40% and 75% of the sub-economic residents

must be classified as frail or very frail. In Category C homes, more than 75% of sub-economic residents must be classified as frail and at least 50% of the residents so classified must be very frail.[35]

This categorisation of old age homes determines the amount of the subsidy payable per resident by the government. The cost per unit is lowest in a Category A home and highest in Category C homes. Government subsidies correspond to differences in running costs, which reflect the amount of care and attention required by residents in the various homes. Category C homes require a higher nurse to resident ratio than Category B homes. The higher subsidy paid to Category C homes is calculated in relation to this higher nursing staff/resident ratio.[35]

Residents are divided into three groups depending on their score on the "Wicht" assessment questionnaire for activities of self-care. The higher the score the more the care and attention required. An individual with a score of 0-9 is in group I (generally capable of independent living). Those with a score of 10-18 are in group II (frail i.e. generally requiring some assistance with activities of daily living). Individuals with a score of 19-32 are classified in group III (very frail i.e. requiring maximum support).

Most of the needs of the elderly in institutional care relate to activities of daily living (for example dressing, bathing and toileting) which do not need the skills of a registered nurse. Other activities, like pressure care, can easily be taught to aides and do not necessarily require nursing skills.[19]

1.2.5 Current and future financial implications of subsidising homes

The majority of old age homes in South Africa rely on government subsidies. In a study conducted by L. R. Tibbit in 1982 it was reported that at least 84% of residents in old age homes for whites were subsidised by the government. In one large home, the figure was up to 90%.[32] As stated earlier, there are currently 52,000 frail care beds available throughout the country. Whilst this amounts to approximately 3% of the aged population of 1.7 million, many of these beds are currently Category A accommodation and are unsuitable for conversion to Category C.[36]

With the financial constraints currently experienced in the government budget, the present system which allows institutionalisation on grounds of "social need" (i.e. not requiring physical assistance) is unsustainable. Therefore, priority must be given to homes that provide for frail older persons only. Social services for older persons who are not frail should be community based. The maximum affordable proportion of elderly that can be accommodated in subsidised homes for the aged (SHAs) has been limited to 2% of the target group. Based on the estimate that by the year 2035 there will be seven million persons over the age of 65 years, and that 2% persons would require frail care, an additional 88,000 beds will be required. This means an increase of 2,200 beds per annum. The current unescalated cost per bed is R50,000. This means that an amount of R110 million is required per annum, in order to sustain access to institutionalised care for 2% target group.[36]

An estimated 7% of the elderly among white South Africans currently reside in institutions for long-term care. Estimates of percentages from the mid-1980s of the total elderly population in institutions in developed countries vary from country to country. The highest rates occur in the world's demographically oldest countries. For the United States of America (5.7%), Austria (6.4%), Belgium (6.3%), Canada (8.7%), France (6.3%), Israel (4.0%), Japan (3.9%), Netherlands (10.9%), Sweden (9.6%), Switzerland (7.9%).[23] For the United Kingdom, the figure was 5% in 1981 and 7% in 1991.[37]

1.3 CRITERIA FOR ADMISSION TO SUBSIDISED HOMES

To ensure proper use of the limited financial and housing resources, an objective needs assessment of applicants for Subsidised Homes for the Aged (SHAs) should be performed. SHA accommodation could thus be limited to those most in need and, in addition, an opportunity would be provided for screening for unreported illness or disabilities which, if timeously and appropriately managed, might avert the need for institutionalisation. The assessment may also assist in determining the most appropriate community based support (for instances where institutionalisation is deemed not to be necessary).[38]

1.3.1 Tools for assessment

Assessment tools serve a range of functions. Some are used for screening in order to identify individuals in need of further assessment. Others, for example the Barthel Activities of Daily Living scale, which is used to diagnose and set therapeutic goals, are

for clinical management of individual patients. Yet others may be used for collecting descriptive data to identify groups with poor functioning in one or several areas and, thus, to identify high risk groups for institutionalisation. [39]

The assessment tool should not be a burden to the respondent. It should not, therefore, be long or take an excessive amount of time to complete. Also, for reasons of cost, it should not require highly trained interviewers.

Currently, the Department of Welfare uses the "Wicht instrument" for the assessment of the degree of physical and mental disability of an applicant to a home for the aged and disabled. It is based on research done by Professor C L Wicht in the Bellville region during the mid-1970s. Although it served a useful purpose for two decades, it is now hampered by intrinsic design faults.

The Wicht-instrument was designed to assess the dependency needs of urban dwellers, presuming relative affluence compared to the bulk of the South African population.(see annexure A). Another shortcoming is that it deals only with physical and mental disabilities. There is no provision for assessment of the availability or general functioning of the caregiver where one is available. Also, the current instrument attaches the same weight to each disability in the scoring process, leading to absurd anomalies in the final score. For example, an elderly person who is incontinent scores 3 points, which is the same score as for "inability to exercise". Inability to clip one's beard and toe nails scores 4 points, the same score as for being bed-bound for whatever reason, although the

intensity and urgency of care needed in these situations is totally different. Thus, the instrument lacks face or content validity. Face or content validity relates to whether the questionnaire is logical and whether the items in the instrument cover areas of interest. [39]

The Wicht-instrument also lacks provision for assessment of the availability or accessibility of primary needs, (i.e. water, food, toilet and safety) or extended support systems i.e. transport, telephone and post office. Without specific enquiry into the primary needs and availability of extended support systems, deficiencies would not be readily evident as significant elements in the dependency status of the applicant. Lack of access to primary needs and extended support systems may be common in rural and peri-urban areas. The Wicht-instrument is not suitable for use in these areas and, thus, lacks general acceptability and credibility.

CHAPTER 2:

DEVELOPMENT OF A NEW SOUTH AFRICAN DEPENDENCY QUESTIONNAIRE (SQ95)

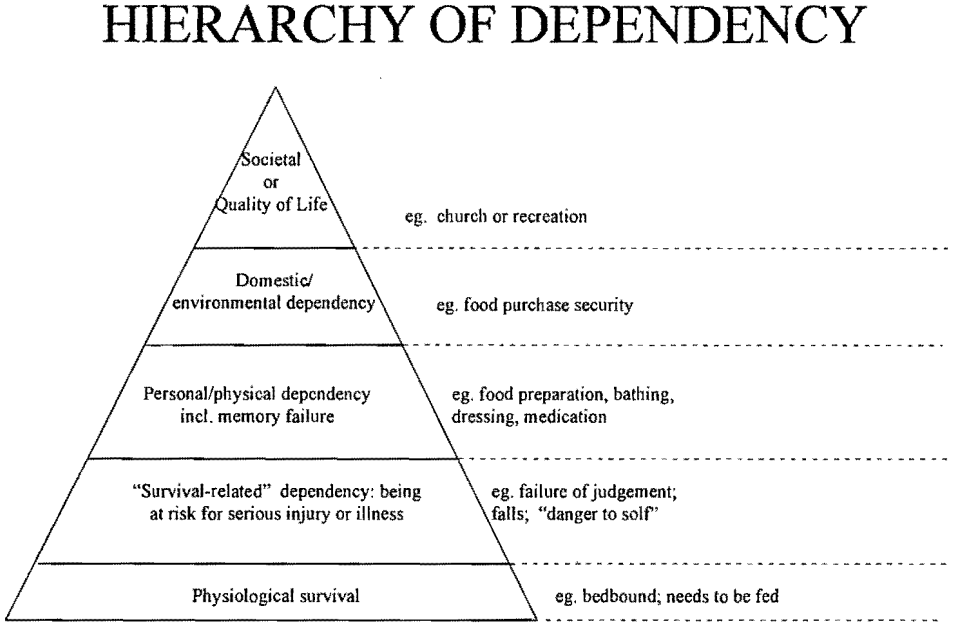
In 1995, Mr Chris van den Heever (then Head of Elderly Care in the National Department of Welfare) convened a working group in Cape Town to develop a new assessment instrument or to identify a suitable instrument for use in South Africa. In the course of a series of meetings, a variety of instruments were evaluated. After careful consideration of their merits in relation to local requirements, it was decided that a new instrument should be developed and tested in South Africa. This instrument would be used to measure the dependency needs of elderly persons to determine whether they qualified for admission to a Subsidised Home for the Aged (SHA).

It was recognised that the new instrument should satisfy the following criteria: sensitivity (i.e. it should not exclude a large percentage of individuals who deserve admission); high specificity (i.e. it should not include a large percentage of individuals who do not deserve admission); simplicity (i.e. it should not be too long or reliant on expertise or complicated calculations of scores, or on more than a minimal amount of training); appropriateness for use among all elderly populations in South Africa (i.e. urban, peri-urban and rural areas); cognisance of literacy and other measures of education; consistency with validated instruments used elsewhere in the world; focus on evaluating physical and cognitive disabilities resulting in dependency requiring SHA care, rather than conditions or diagnoses leading to such disabilities.

It should be noted that, unlike other countries, South Africa at present uses an assessment procedure that relies almost entirely on a numerical score. This approach (as against a discretionary panel approach) to the assessment of the dependency status of an applicant developed historically in the interests of nation-wide equity. It was decided to retain this approach to dependency assessments in the new political dispensation.

One of the key considerations in the point scoring system of the SQ95 was the development of a theoretical framework of dependency needs, based on an inversion of Maslow's hierarchy of human needs in related groups on five levels arranged in a form of a pyramid (figure 2). It was Maslow's view that people seek to satisfy the lowest level of needs and it is only when these are satisfied that they strive to attain the next level. Maslow held that these levels were: 1. Physiological (e.g. food, warmth, shelter, sleep), 2. Security (protection from danger and threatened deprivation of physiological needs) 3. Social (companionship, communal activities), 4. Egotistical needs (self-esteem and sense of achievement) and 5. Psychological needs (own desire for growth and development).[40]

Figure 2



This dissertation describes the pilot study that was performed to assess the instrument for face and construct validity and assess broadly its sensitivity and specificity in selecting those in need of admission to subsidised homes for the aged. A subsequent study (of which the author was a co-investigator) was performed to assess the sensitivity and specificity of the SQ95 across a nation-wide representative sample, but due to the considerable scope of that study, it is not reported here.

2.1 OTHER INSTRUMENTS EVALUATED IN DEVELOPING THE SQ95

In the following sections the key attributes of assessment instruments that have been developed elsewhere are described and critiqued.

2.1.1 The RAI-HC (Residents Assessment Instrument – Home Care).

This is a standardised instrument for evaluation of needs, strengths and preferences of elderly clients. It is used in nursing homes in the U.S.A and other countries. The RAI-HC consists of Minimal Data Set for Home Care (MDS-HC) and Client Assessment Protocols (CAPS). The MDS-HC is a screening tool for home care providers, aimed at assessing the following domains of function: health, social support and service use. It is also used to identify specific problems and risks for functional decline that would need further evaluation. These are known as "triggers". These problematic conditions are assessed in depth using the Client Assessment Protocols (CAPS).

The RAI is a clinical assessment system designed for individualised care planning. Despite the burden of paperwork perceived by the nursing leadership, it has generally been praised, with some staff noting that they were able to uncover clinical problems that would otherwise have been missed. This enables these problems to be addressed timeously, leading to a reduction in the rate of hospitalisations.[41]

The RAI-HC was formulated by a multinational group of clinicians and researchers from Canada, the Czech Republic, Denmark, England, France, Germany, Italy, Iceland, Japan, Netherlands, Norway, Spain, Sweden, Switzerland and United States.[42] Work on the Minimal Data Set for Home Care (MDS-HC) was initiated in January 1993. Thirty of the 32 items in the areas of cognition, communication, vision, mood, behaviour, ADL self-performance and continence come from version 2.0 of MDS. Of the 223 items in areas of

functional status, health status, social environment and service in the MDS-HC, 114 (47%) come from version 2.0 of MDS used in nursing homes.[43] The reliability and utility of MDS 2.0 were tested, and the weighted kappa inter-rater reliability levels were found to be 0.79, which represents excellent reliability according to standards set by Fleiss for Kappa reliability.[44] By these standards, Kappa values lower than 0.4 indicate poor reliability, values between 0.40 and 0.75 are considered adequate, and values of 0.75 and above are considered to be evidence of excellent reliability.

The RAI-HC was designed for use by a range of clinical professionals: physicians, nurses, social workers and therapists. Though it requires direct questioning of the elderly person or the caregiver it is not a questionnaire. Its reliability was tested in five countries (Australia, Canada, the Czech Republic, Japan and the United States) on clients of home care agencies as well as nursing home residents. Version 2.0 of the MDS was tested at the same time for comparison. The average weighed kappa value across the items was 0.74 for the MDS-HC and 0.75 for the MDS 2.0. The results demonstrated that the ability to obtain reliable answers to these items is not specific to the nursing home setting.[43]

The key domains assessed in the RAI-HC were:

1 Mental functioning

i. cognitive patterns including assessment of memory, cognitive skills of daily decision making and indicators of delirium (sudden onset of change in mental function)

ii. mood & behaviour patterns; that is signs of depression, anxiety, sad mood, wandering, verbal or physical abuse and aggressiveness

2. Sensory performance

i. communication disorders: (hearing, ability to understand others and making oneself understood)

ii. vision patterns (ability to see in adequate light and with glasses, if used; visual limitations and difficulties; and decline in vision compared to status 90 days before)

3. Functional performance

i. self-performance of instrumental activities of daily living (meal preparation, ordinary house work, managing finance, managing medication, phone use, shopping and transportation)

ii. self-performance of activities of daily living (e.g. eating, dressing, toileting, bathing, mobility, transfers and personal hygiene)

4. Social functioning

i client's ability to interact with others

ii. any change in social, religious, occupational or other preferred activities

iii length of periods of social isolation

5. Informal support services

i. availability of a primary and secondary informal helper

ii caregiver status

iii. extent of help (number of hours of care required)

6. Health assessment

i. continence in the last 14 day (bladder continence, use of bladder devices and bowel continence);

ii. disease diagnoses: any disease that the doctor has indicated to be present and affects client's status, requires treatments or symptom management

iii. preventive health measures taken (e.g. blood pressure monitoring, vaccinations and mammography for females; pain, falls, life style (drinking/smoking), how client feels about her general health and any fear, abuse or neglect)

iv. nutrition and hydration status (any weight change, change in food consumption and use of nutritional treatments)

v. oral health (chewing or swallowing problems and mouth pain)

vi. skin condition (bruises, rashes, pressure ulcers or presence of any other skin problems requiring therapy)

vii. medications (prescribed and over the counter medication, including a check on compliance)

7. Environmental assessment

   For hazardous and uninhabitable home and living arrangements (i.e. whether or not the client lives alone)

8. Services already being utilised by client

   For example, meal provision, support with activities of daily living, visiting nurses and social workers, physiotherapists and occupational therapists (The number of hours and minutes spent in formal care giving and planning for the care provided are noted.)[42]

The RAI-HC assessment was geared to identifying major functional, medical and social circumstances that affect the individual's quality of life, rather than dependency status. It is unsuitable for use in South Africa for several reasons:

- It cannot capture the differences in primary needs service provision that exist in South Africa, since it is designed for use in relatively affluent societies.
- It is very time consuming to administer as it takes over one hour to complete[43] and assumes a high level of competence in the person administering the instrument.
- It does not cater for conditions applicable to remote rural communities.
- It gathers much information (e.g. with respect to medical conditions) that is superfluous to the assessment of dependency status.

2.1.2 The New Zealand assessment instrument

This is similar to the RAI-HC instrument, but without as much detail. It measures disability and impairment. On completion of the assessment, the assessor is requested to recommend the level of support needed and the recommended support services.

The main domains assessed are:

i. physical function (continence, need for night care and ability to self administer medication)

ii. need for support with activities of daily living and instrumental activities of daily living

iii. sensory function and communication (vision, speech and hearing)

iv. mental functioning (detailed enquiry into memory, delusions/hallucinations, insight, orientation, mood, anxiety, behaviour and wandering)

v. social interaction, household situation (whether the client lives alone and has access to formal or informal services)

vi. ability of caregiver or family to care for client

Like the RAI-HC instrument, this instrument assumes a certain level of affluence and therefore would not be applicable to the majority of the South African population. It does not take into account the discrepancies in provision of services and basic needs that exist in this country. A strong positive feature is the caregiver component ("vi" above) which

concept was adopted in the SQ95. The comprehensive assessment of mental function was deemed too detailed for wide application in South Africa, particularly since some diagnostic detail is not directly relevant to the burden on the caregiver.

2.1.3 A British instrument

Multi- disciplinary teams in Newcastle Upon Tyne use a practical guide entitled, "A guide to assessment of the elderly" in assessing elderly people for residential care.[45] It is not clear how widely this is used in the United Kingdom.

The main domains assessed are:

i. physical disabilities and treatable conditions adding to the disability
ii. self-care abilities (activities of daily living and instrumental activities of daily living)
iii. confusion (assessment for dementia, delirium, and depression)
iv. domestic regime (what the elderly person does on an average day)
v. accommodation and environment (includes home ownership, home safety, proximity to shops, to friends or relatives, toilet facilities, availability of bathroom with hot water, and the placement of cooking facilities in relation to disability, and whether a telephone available)
vi. household composition (who lives with the elderly person and at what stages in their lives, whether they are working or retired, approaching retirement, young, with children, etc.)

vii. carers and their problems (who the carers are and what the physical, emotional, and family stresses on the carers are)

viii. capability of the elderly client to make decisions (whether he or she understands what going into a residential home entails; what are the recent events that have led the carer to request residential accommodation, quality of social life)

The guidelines are used to assess a client's need for admission to residential care or the possibility of staying in his/her home with additional assistance. It has some similarities to the RAI- HC instrument used in the USA, except that there is no provision for assessing health problems. The instrument is unsuitable for use in SA since it offers no guidance as to its application in decision making and, instead, relies on a fairly sophisticated judgement process by a multidisciplinary team. Considerable effort is made to assess the social interactions of the client and his/her habits and routines. The instrument, thus, aims to capture information regarding the quality of life of the client beyond the basic dependency needs.

2.1.4 Multidimensional assessment instruments

Multidimensional assessment instruments combine a broad range of dimensions - physical, psychological and social - in a single instrument as opposed to measuring particular dimensions of health or dependency status. The best known among these are briefly reviewed here for their focus on elements that are relevant to dependency status assessments. The following are briefly described here: the Nottingham Health profile (NHP), the Sickness Impact Profile (SIP) and the SF - 36 (MOS Short Form 36)

The Nottingham Health Profile (NHP); (Sonja Hunt and colleagues, 1980)

This was developed in the United Kingdom as a measure of self-assessed health-related behaviour in populations. It measures levels of self-reported distress caused by pathological, social or environmental conditions.

Hunt and colleagues developed it in a general practice setting in the U. K. in 1980. It is divided into two parts:

Part I consists of 38 statements grouped into six dimensions: pain, physical mobility, sleep, emotional reactions, energy and social isolation. Respondents are requested to indicate for each statement whether they experience problems at the present. Scores for each dimension are calculated by applying a weight to each item and summing up the score for the dimension. The items were scaled for severity, using responses obtained from 1 200 outpatient interviews. A simpler, unweighted scoring system is normally used, in which the number of positive responses in each section is counted. A score of zero is given for a "No" answer and 1 for a "Yes" answer.

In Part II of the profile there are seven yes/no responses to single item questions on daily life. This section is less frequently utilised. Respondents are asked to indicate whether or not their state of health affects activities in seven areas of everyday life: the job, looking after the home, social life, home life, sex life, interests and hobbies and holidays.

A major advantage of the NHP is acceptability, as it takes 10 minutes to complete. It may be self- or interview-administered. It has been used by field-workers on different population groups both in the community and among patients. An important

disadvantage is the ceiling effects of the score (i.e. most subjects tend to score at the top of the scale with a "No" response to each item). The instrument is not a measure of health but a measure of distress caused by ill health. It is more suited for people suffering from chronic illnesses than to the general population or those suffering from minor health problems. The method of its development concentrated on ability to distinguish between groups rather than to detect change in the same individuals over time. It therefore lacks sensitivity and responsiveness. For example, if a respondent scores zero on any dimension, any subsequent improvement cannot be measured. There is lack of adequate trial data to show its responsiveness to other than gross forms of medical treatment such as heart transplant and bypass surgery.[46, 47, 48]

The four-week test-retest for reliability was reported by Hunt *et al* for 58 arthritis and 93 patients with peripheral vascular disease. Correlation coefficients for the six sections of Part I range from 0.75 to 0.88, which is satisfactory.[46, 48] (Correlation is a measure of association that indicates the degree to which two or more observations fit a linear relationship. The strength of correlation ranges from -1 to + 1. A correlation close to zero indicates no association between the observations.)

The Sickness Impact Profile (SIP)/Functional Limitations Profile (FLP), Bergner and colleagues, 1976, revised 1981.

The SIP is a measure of sickness-related behaviour alteration, as judged by an individual's perception of the impact of illness on usual daily activities. It was developed in the USA. Its objectives were to provide a broad measure of self assessed health-related behaviour. It was intended for use in health surveys, in measuring outcomes of care, in monitoring patient progress and in program planning and policy formulation.[48]

The FLP is a British version of the original SIP. It was developed for the purpose of disability studies. Its range of potential applications is similar that of the SIP. [49]

The SIP can be self- or interviewer-administered. It is lengthy and takes approximately 20-30 minutes to complete, with longer times for completion by the elderly. It has been considered too long for use in routine practice. It consists of 136 items and covers 12 dimensions: ambulation, mobility, body care and movement (which make up the physical category); social interaction, alertness behaviour and emotional behaviour (which make up the psychosocial category) and eating, work, sleep and rest, household management, recreation and pastimes and communication (which are independent categories).

Responses are weighted to give separate dimension scores from 0 (no problem) to 100 (all problems present). Scores are calculated using the weights, which represent the relative severity of limitation imposed by that item. The SIP is composed of statements such as "I have attempted suicide", I have difficulty in reasoning and solving problems",

"I do not walk at all" and "I laugh or cry suddenly", each of which covers a change in behaviour and specifies the extent of limitation. Respondents mark only items that describe them on a given day and are related to their health. The specific medical condition leading to the limitation is not taken into consideration. The respondent scores the item weight for any item endorsed. Percentage scores are calculated for categories by simply adding item values for the endorsed items, dividing by the maximum possible score for the category and multiplying by 100. For each dimension a score is similarly calculated as the sum of the positive responses out of the maximum possible score for the dimension. Apart from the dimension score, there are two sub-scores (physical and psychosocial) and a total score. Score distributions tend to be skewed to low or zero scores even in patient groups.

The instrument is problematic for elderly people because it asks the respondent to make a judgement as to whether a problem is health related or not. It may be difficult for elderly people to distinguish between the effects of ill health and natural consequences of ageing.

The SIP has been found to discriminate between ill and healthy subjects. Bergner *et al* in 1981 reported test-retest reliability of 0.88 to 0.92 in various trials. Validity trials were conducted which compared the SIP with subjective ratings made by respondents, with clinical assessments and with other assessment instruments, and showed moderate to high correlation (though this finding has been disputed in a study by Deyo and colleagues, 1983).[50, 51, 52]

The advantage of the SIP instrument is its comprehensiveness and that it includes dimensions that are especially relevant to the elderly in the community. It has also been used extensively in health care settings (including those for the elderly). Its disadvantages are its length and unsuitability for use in acute care, and it may not be very responsive to change over time in the same individual.[52, 53]

The MOS Short Form 36 (SF-36)

The SF-36 was developed as a broad based general measure of outcome in health interventions. It is an abbreviated form of a more detailed instrument, the 108-item Medical Outcomes Survey (MOS) developed by the Rand corporation in the USA (Stewart and Ware 1992). It attempts to capture aspects of health that are important to different types of patients. The instrument was shown to discriminate well between renal dialysis, diabetic, and hypertensive patients.[52, 54]

The SF-36 uses eight health scales to measure three aspects of health - functional status, well-being and overall evaluation of health. The score on each of the eight scales ranges from 0-100. Zero represents poorest health. The SF-36 health profile was developed and validated in the United States. Its validity, reliability and acceptability have also been tested in the U.K.[55]

The SF-36 has been validated and compared with the Nottingham Health Profile. The SF-36 detects positive as well as negative states of health. In six of the eight dimensions, patients are asked to rate their responses on 3- or 6-point scales rather than "Yes/No"

responses as in the Nottingham questionnaire. For each dimension, the scores are coded, summed and transformed on to a scale from 0 (worst health) to 100 (best health). The SF-36 is able to detect low-grade ill health in patients who scored 0 (good health) on the Nottingham health profile. The SF-36 is therefore more suitable for use in the community and general practice populations, which have relatively minor health problems.[54] The SF-36 has high acceptability, as it is brief (it takes 5-10 minutes to complete) and is easy to use.

Another British study by Brazier *et al* in 1992 reported good internal consistency and an excellent test- retest reliability. There was also substantial evidence of construct validity. The study was conducted as a postal survey of over 1 500 randomly selected patients aged 16-74 years. Its use for the elderly requires further validation due to a high level of missing data for the 64-70-year-olds.[56] A similar study by E.N. Andresen *et al*, in 1996, on subjects aged 66 to 98 years of age, showed high test-retest reliability and satisfactory estimates of internal consistency.[57] Normative data for Britain have been developed from a survey conducted on a general population of nearly 10 000 (broken down by age, sex, social class, long-standing illness and recent consulting).[58]

2.2 DESIGNING THE SECTION OF THE SQ95 ON ACTIVITIES OF DAILY LIVING (ADL)

Activities of Daily living are minimal functions that allow an individual to live comfortably and independently in any environment. The activities of daily living include:

eating, grooming, personal hygiene, bathing, dressing upper body and lower body, toileting, bladder management, bowel management, mobility, transfers, and communication. Social activities such as cooking, shopping and housework are not included since the ability to perform them depends heavily on other factors such as culture and domestic environment [59]

ADLs are placed half way along the scale of complexity of functioning required in the tasks of human behaviour. The latter are ranked from lowest to highest as: life maintenance, functional health, perception/cognition, physical self-maintenance (ADLs), instrumental self-maintenance and social behaviour driven by motivation to explore.[59] Lawton and Brody (Lawton and Brody, 1969) refer to the activities of daily living as "Physical Self Maintenance". This classification is important because even if an individual scores high on an ADL scale he or she is not necessarily able to function fully, owing, possibly to a handicap or disability. The distinction is difficult to draw because beyond the top mark on a scale it is not possible to measure any further improvement (i.e. if one is able to transfer, any further improvement in the ability to perform the task will not be captured) the so-called "ceiling effect".[59]

A variety of scales are used to assess ADL in the elderly. Some of these are: -

The Katz ADL score (Katz and Apkom, 1976)

This is an hierarchical scale using the principle that abilities are lost in a definite order. Thus, if one can perform one function, all the others below it in the hierarchy can be

performed. Katz showed that ability to perform more complex activities such as bathing and dressing are lost first and less complex activities such as continence and feeding are lost later. The index includes six activities: bathing, dressing, toileting, transfer, continence and feeding. Locomotion is not included. The scale has been in existence for many years but little evidence is available on either its reliability or validity.[59]

Kenny (Iversen *et al*, 1973)

This scale has very sensitive (detailed) measures in several categories, but does not include locomotion and some aspects of continence. It takes much longer to complete than the Barthel index, which is much simpler. It requires direct observation of the client. Its inter-rater reliability is high, of a similar order to the Barthel Index (see below). [59, 60]

Physical Self-maintenance Scale (PSMS): (Lawton and Brody, 1969)

This scale is not well known. Its categories include toileting, feeding, dressing, grooming, physical ambulation and bathing. Its measures do not include transfers and it does not distinguish bladder from bowel function. The PSMS has not been widely reported in the literature and there have been no predictive studies on this ADL scale.[59, 60]

Pulses Profile: (Moskowitz and McCann, 1957)

This is the only scale that includes measures of hearing and vision. Its sensitivity is low. The categories measured include a strange mixture of impairments and disability. It is primarily an indicator of impairment, described in terms of physical abnormality in a

particular category, unrelated to the actual functional impact.[61] Its test-retest reliability and validity were tested by Grange *et al* and reported to be satisfactory.[62] The study found a test-retest reliability of 0.87 and an inter-rater reliability exceeding 0.95, almost equivalent to the rates they found for the Barthel Index.

PULSES stands for: P = physical condition; U = upper limb function; L = lower limb function; S = sensory component (speech, vision, hearing); E = excretory functions; S = mental and emotional status.

The Barthel ADL Index (BI): (Florence Mahoney and Dorothea Barthel 1965 revised by Grange in 1979)

Dorothea Barthel introduced this ADL index in 1955 although it was first published in 1965. Its conceptual focus is on an individual's dependency on others for actual physical assistance. It is used to record what a client does and does not do. It aims at establishing the degree of independence from help, either verbal or physical, regardless of the underlying cause. Patients are classified into one of the three categories (dependent, performs task with assistance, independent) for each item. A person who is dependent scores zero in the relevant ADL category. Other scores reflect the time and assistance required to accomplish a task. The original scale had a score ranging from 0-100. There were some inconsistencies in the scoring. For example, someone who is independent using a wheel chair will score 5, while someone who can only walk with help and therefore is more dependent, therefore needing more caregiver time, will score 10. A total of ten items are assessed. These are feeding, toilet use, bladder function, bowel function, bathing, grooming, mobility indoor, transfer, stairs and dressing.

Collin and colleagues at the Rivermead Rehabilitation Centre in Oxford retained the original ten items but simplified the scoring system and made minor amendments to the rating instructions. This version gives a score ranging from 0 (completely dependent) to 20 (fully independent) in each category. Items are scored 0, 1, or 2, depending on the degree of assistance required by the client (except for grooming and bathing, which are scored either 0 or 1, and mobility and transfers, which are scored from 0-3). In the case of transfers, a score of 2 is given if "some assistance" is required, be it verbal or physical.[63] Granger's modification of the Barthel Index incorporates 15 items. These have been divided into a self-care sub-score that covers 9 items and mobility sub-score that covers six items. Each item is scored using a 3-point scale and scores range from -2 to 100. A score of -2 is given if one requires the help of someone else to put on a brace or an artificial limb.

With the Barthel Index, the total dependent and independent scores are distinct, but classification of persons requiring some assistance to perform a task is crude. Despite different degrees in the assistance required, all people requiring assistance are grouped together. Unlike the FIM (see below), the Barthel Index does not use percentages in its assessment of the degree of assistance required. The Barthel Index is not sensitive to change in the area where assistance is required as it fails to capture the quality and quantity of assistance.

To increase sensitivity, a modified scoring of the BI has been introduced by an Australian group of researchers (S. Shah, F. Vancaly and B. Cooper). Unlike the original BI, all 10 items have an equal number of categories. These categories are coded from 1 to 5. Category 1 is for those who are unable to perform the task, Category 2 is for those who are greatly dependent and/or unsafe in performing a task, Category 3 is for those requiring moderate help, Category 4 for those requiring minimum help and Category 5 for those who are fully independent. The slowness of an individual in performing the task is not scored lower if no human assistance is required in performing the task. The scoring depends on the weighting attached to the items as in the original BI. A total score of 100 indicates total independence, 91-99 slight dependence, 61-90 moderate dependence, 21-60 severe dependence and 0-20 suggests total dependence. The modified BI scoring system improves internal consistency and provides better discrimination of functional ability while maintaining simplicity and the same completion time for a trained assessor.[64]

The Barthel Index has good acceptability and is easy to administer. It can be administered by a doctor, nurse or any health professional and, if desired, by a carer. It takes less than five minutes to complete. The validity of the Barthel Index is well established. Its reliability has been well studied. Studies by Colin C. *et al* and by Shinar D. *et al* (in 1987) have reported high level agreement between raters and between different methods of assessment. Granger's modified version achieved good inter-rater agreement in a study by Granger, C. V. *et al*, (1979) and one by Loewen, S. C. *et al*

(1988). High levels of internal consistency were shown by Shah S. *et al*, (1989) in their study on stroke patients.[65, 66]

The predictive validity of the original Barthel Index has been tested in many studies. The Index has been shown to predict length of stay, survival and progress among stroke patients in three studies conducted by Wylie C. M *et al* in 1967.[67] Granger and colleagues, in 1979, demonstrated predictive validity for stroke patients and showed that a score of 60 was a divide between dependence and assisted independence.[60, 62, 64, 68] Although the Index is capable of showing change following rehabilitation in a stroke patient from admission to discharge, it is not able to detect subtle changes. Like most measures of function and activities of daily living, it is most suited to patients with moderate to severe disabilities. It has been used extensively for patients suffering from stroke. It has also been used for patients suffering from chronic disease leading to disability and for the elderly infirm. It is not self-administered and requires of the rater a fair knowledge of the client's abilities and circumstances. It can be used in both hospital and community settings.[69]

Gresham *et al*, 1980, compared the Barthel, Katz and Kenny scales. Independence in activities of daily living was scored in 148 Framingham Study stroke survivors using the 3 scales. They concluded that the BI performed best. Its advantages over the other two scales included its completeness, sensitivity to change, and amenability to statistical manipulation.[70] The BI is the most widely known and best of the brief assessments of

basic ADL currently available. Its limitations, like those of all other ADL scales, are the exclusion of mental, emotional, communication or family problems.[60, 71, 72]

The Functional Independence Measure (FIM)

This forms part of the Uniform Data Set for Medical Rehabilitation 1994 developed at the State University of New York. The American Congress of Rehabilitation Medicine and the American Academy of Physical Medicine and Rehabilitation developed the FIM. The Barthel index (BI) forms the foundation of the FIM. In addition to the items in the BI, the FIM has items on communication and social integration.[73]

Incorporating some of the elements of the FIM in the SQ95 was considered by the designers of the SQ95 because the FIM has been found to be the strongest scale for evaluating the need for assistance from another person in personal care tasks.[74] Like the BI, the FIM is a basic indicator of severity of disability. It measures what a person with disability is capable of doing regardless of the nature of the underlying diagnosis or impairment. It does not attempt to measure what the patient ought to be capable of doing if certain circumstances were different. The scale classifies patients into whether they can carry out an activity independently or not. If the patient is not independent, the instrument provides a score for how much assistance is required. FIM scores have been investigated in terms of time and energy required of the caregiver and may therefore be used to calculate the financial costs of caregiver provision for different levels of dependency.

The FIM has been tested since 1984 in 50 facilities across the U.S.A and has been found to have face validity. The FIM's inter-rater reliability was determined in a study in New South Wales in 1990 and found to be 0.97 among a multidisciplinary staff who had received approved training. (Lee 1992). The advantages of the FIM are that it is short and easy to administer. An assessment takes approximately 20 minutes to complete. All the items are displayed on one page. It is easy to compare scores at different phases of assessment (admission, discharge and follow-up). Any trained member of the rehabilitation team can administer it.

The disadvantages of the FIM are that it does not incorporate all activities that might need to be measured for specific purposes or for individuals with special problems. Although it is designed to be scored by any member of the rehabilitation team, some specialists may have more problems than others may in assessing particular items on the FIM. For example, a physiotherapist will find assessment of mobility easier than sphincter function, which would be easier for a nurse.[75]

The FIM has 18 items. These are grouped under six divisions, as follows:

MOTOR:

Self care:	Eating; Grooming; Bathing; Dressing Upper Body; Dressing Lower Body and Toileting
Sphincter Control:	Bladder Management (level of assistance, frequency of incontinence); Bowel Management (level of assistance, frequency of incontinence)

Transfers:	Bed; Chair, Wheelchair, Toilet; Tub, Shower
Locomotion:	Walk/Wheelchair; Stairs

COGNITIVE:

Communication:	Comprehension; Expression.
Social Cognition:	Social Interaction; Problem Solving; Memory

The scoring system in the FIM ranges between 1 and 7 for each item. A score of 7 indicates complete independence, while a score of 1 indicates total dependence. The total score can range from 18 (18 x 1) to 126 (18 x 7). The amount of effort the client expends on each task is expressed in percentages. This ranges from less than 25% in those requiring total assistance to 75% or more in those requiring minimal contact assistance.[76]

In compiling the SQ95, certain features of both FIM and BI were adopted in a modified form.

CHAPTER 3: EVALUATION OF THE SQ95

3.1 COMPONENTS OF THE SQ95

The SQ95 is divided into 3 sections, as follows

A. REGISTRATION DETAILS: BACKGROUND AND IDENTIFICATION DETAILS

i. identity of the interviewer, including occupation

ii. the place where the interview took place

iii. the identity of the person who gave information during the interview

iv. identification and background information of the client

v. details regarding the client's next of kin/caregiver

vi. details of total household income

vii. client's current accommodation

viii. family composition within client's household

B. ASSESSMENT OF DEPENDENCY NEEDS

i. "absolute criteria" for admission of the client to a frail care facility (intended to identify the obviously deserving cases and minimise delays in admission)

ii. "secondary criteria" for admission to subsidised home accommodation, addressed under the following sub-headings:

- need for professional nursing care which covers pressure care
- specialised care (such as wound dressings or a need for frequent injections

or any other therapy that cannot be managed in the community)

- need for frequent night care.

The motivation for the latter categories was that the need for professional care or frequent night care could place an excessive burden on the client's relatives (or other caregivers) and should be a relatively important consideration with respect to admission to a SHA.

- need for assistance with activities of daily living (see above discussion in relation to the Barthel Index and FIM)
- client's mental functioning with emphasis on whether he/she is a danger to others or him/herself (assessing behavioural disturbances and not cognitive function as such)

Apart from the elements entailing direct assessment of caregiver and professional support requirements, the SQ95 includes several sections aimed at assessing the physical infrastructure and social support systems available to the client. These are important considerations in SA, where there is a statutory requirement for equitable provision of services to frail elderly persons, which can only be achieved if the wide disparities with respect to infrastructural developments are taken into account.

- primary needs (water, food, toilet facilities and safety measures) available to client, particularly in remote rural areas and in peri-urban areas.

  The combination of poor access to primary needs and mild to moderate physical disabilities may constitute grounds for admission to a SHA.

- domestic needs (home maintenance, laundry, garden maintenance, shopping and business matters)

  This item, which played a significant part in the Wicht instrument, is somewhat out of keeping with other items that address factors more directly linked to frailty and survival.

- availability of extended support systems/needs (transport, telephone and post office)

  This item is of similar relevance to the assessment of dependency and the primary needs item, though at a less basic level in terms of Maslow's hierarchy.

- support systems available to client (formal and informal)

  Assessment of currently used and potential support systems is important since harnessing such systems more effectively may allow the client to remain at home.

- general functioning of the caregiver.

  Although a caregiver may have functioned adequately as the client's support in the past, this item seeks to identify possible breakdown in the future.

C. CONCLUSIONS

- recommendations: (a) urgency for the need of admission to a home for the aged (b) need for support services
- need for client to appeal against the recommendations

Section C was not assessed in this study, as this section is mainly for administrative purposes than assessment of the dependency status of clients.

3.2 AIM AND OBJECTIVES OF THE PILOT STUDY

AIM

To evaluate the SQ95 as a new screening tool in the assessment of elderly persons, who may require admission to Subsidised Homes for the Aged (SHAs).

OBJECTIVES

- To derive a format of the SQ95, which would be appropriate for use in a large- scale, decentralised survey. This required the elimination of components which were of purely administrative relevance and a layout which would be readily amenable to coding and transcription

- To evaluate the SQ95 (i.e. its derivative) in terms of face validity and construct validity

- To assess broadly the sensitivity and specificity of the SQ95 in selecting clients who are deserving of admission to subsidised homes for the aged

- To develop and test a manual as a companion to the SQ95, which would enable relatively inexperienced health workers to use the SQ95 in a standardised fashion

3.3 METHODS

3.3.1 STUDY DESIGN

The clients on whom the Pilot study was performed were allocated into categories by the nursing directors at Highlands House (HH-described below) and the Catholic Welfare Development Trust/Neighbourhood Old Age Homes (CWDT/NOAH – described below). This was taken to reflect the "true" dependency status of the clients. The interviewer used the SQ95 as a means of classifying clients' dependency status – the "test" status of clients

3.3.2 Sample Selection

The project was based in greater Cape Town. Two groups of clients were evaluated:

i. a group comprising elderly people living in sheltered housing and thus "at risk" of requiring admission to a SHA in the near future.

ii. clients who were living in an old age home. Some of these were, by consensus of the senior staff, unable to care for themselves due to physical or cognitive disabilities.

Others were there for "social reasons", eg. lack of an alternative secure environment, but were still living independently.

The first group was comprised of approximately 100 clients of all races and religious groups living in sheltered care homes under the auspices of the Catholic Welfare Development Trust (CWDT). They were also under the medical supervision of the Geriatric Unit of Groote Schuur Hospital. The second group consisted of 122 residents of Highlands House, a private old age home within the Greater Cape Town area.

iii. From these two groups, four sub groups were selected for the study: an "at risk group" of 53 (i.e. at risk of requiring admission to a SHA in the near future) were randomly selected residents of the CWDT communal homes (SQ95 evaluation of this group explored the specificity of the instrument.) and three other subgroups from Highlands House. At the time of the survey, Highlands House had 280 residents in total. The Nursing management was asked to provide us with 122 names, stratified into different categories of function as assessed by senior personnel of the home, as follows:

i. those that were clearly totally dependent on the support services that the home provides and with whom family could not have been expected to cope. (Total of 15 names.)

ii. those who were in the home for purely "social reasons". These residents did not have disabling cognitive or physical conditions, and were in the home because of lack of social support structures in the community where they came from.
(Total of 31 names.)

iii. those who were in the home because of physical or cognitive disability or both, but were not in frail care (ie. not totally dependent). These were sub-classified into two groups:

a) those who could have continued living in the community with unskilled aid provided twice daily for one hour (20 names). An example of this group is an elderly person who is not able to do his/her own shopping and cleaning but is able to prepare simple meals.

b) those who could have continued living in the community with unskilled aid provided on a continuous day and night basis (56 names). These were individuals who need assistance with toileting, cooking of meals and dressing. An example of this would be an individual who is cognitively impaired but is kept continent with regular toileting.

From the 122 names supplied a total of 80 names were randomly selected from each of the three categories. The 80 names were typed out on a single sheet in random order.

Conceptually, the above groups fall into three categories:

- The severely frail group

SQ95 has *inter alia* been specifically designed to enable the easy identification of the clients who "obviously" qualify for admission to SHAs, ie. those clients that satisfy the "absolute criteria" in the SQ95. These criteria include being bed-bound, mentally disabled with incontinence or having a chronic medical condition requiring professional care. The clients in this group explored the sensitivity of the "absolute criteria" of SQ95.

- The Cumulative Score group (total dependency score).

These are clients who require SHA care according to the cumulative score from SQ95. These clients were, by the consensus of senior personnel, said to require SHA care and were unlikely to cope in sheltered care environments but did not satisfy the "absolute criteria" of the SQ95. The study explored the construct validity and sensitivity of the cumulative score component of SQ95.

- The "Control group"

Clients in this category were in Highlands House not for reasons of physical or cognitive frailty but for "social reasons". These served as a further group of negative controls. This group and the "at risk" (at risk of requiring admission to a SHA in the near future) group from CWDT, provided the basis for estimating the specificity of SQ95.

Acceptable levels of sensitivity and specificity of the SQ95 were not set for the pilot study but for the national study the levels were set at 95% and 85% respectively.

3.3.3 The Questionnaire and manual

Questionnaire

The original questionnaire was designed after a series of discussions held by the group that convened in Cape Town in 1995. The first few versions of the SQ95 were assessed on a pre-pilot basis by health and welfare professionals with extensive experience in the assessment of dependency needs of elderly persons. After each of the pre-pilot studies, some changes were made to the questionnaire. Ambiguities were ironed out and the need recognised for a detailed manual.

Manual

A manual, to be used as a companion to the questionnaire, was compiled by the author of this study (Annexure C). The purpose of the manual was to assist the interviewer in understanding the relevance and meaning of individual questions, with the aim of minimising inter-observer variation. It was designed as a self-teaching device.
Before compiling the manual, the author interviewed some of the individuals who had participated in the design of the SQ95 regarding their views on the intended relevance and meaning of the individual items.

The section in the manual dealing with activities of daily living was based on the guidelines for using the FIM and the Barthel Index. The Occupational therapy department of Groote Schuur Hospital, University of Cape Town, provided further guidance.

The interviewer employed to conduct the pilot study was requested to read through the manual before starting the fieldwork. The interviewer was not required to observe the client perform the task, as a subjective report was acceptable. Alterations to the manual were made in the light of input from the interviewer following interviews with a trial group of 10 clients.

3.3.4 Administration of the questionnaire-based survey

Owing to financial restrictions, there was only one interviewer trained for administration of the questionnaire. She was deliberately kept unaware of the different categories of dependency described above. She did not know which clients fell in which categories on the randomised lists that she was given.

After self-training by reading through the manual, she field-tested the questionnaire on 10 clients. After the 10 clients had been interviewed, any difficulties and misunderstandings were discussed with the author before the fieldwork proceeded.

The fieldwork was done in three phases:

- Highlands House - interview with clients (total of 32 interviews).
- Highlands House - interview with staff and obtaining information from medical records (total of 79 interviews).

- CWDT - interview with clients (total of 53 interviews).

One questionnaire was used per client except for some clients from Highlands House for each of whom two questionnaires were used. The reason for this was to compare information obtained from the client with that obtained from the medical personnel and medical notes. Answers were number coded and the relevant number was entered in the appropriate box (see annexure B)

3.3.5 Data collection and analysis

Data collection commenced in March 1996 and was completed in June 1996. The spread in time was due to the fact that the interviewer had to carry out the interviews during times that were suitable for both her and the clients. If a client was unavailable, the interviewer had to call again for another appointment.

The data were analysed using the STATISTICA package; version 5 (1997), manufactured by Statsoft. Spearman's rank correlation coefficient was used to measure correlation for ordinal variables. Association between a binary and ordinal variable was assessed using Kruskal Wallis Median test for analysis of variance. This was used to test for a difference in the median score of items in the different 'gold standard' classification groups. Two by two tables were constructed to calculate differences in proportion of dependent clients from the different categorisations. Where appropriate kappa statistic was calculated as a measure of degree of agreement between SQ95 and gold standard classification.

Sensitivity and specificity of the SQ95 questionnaire was calculated using two by two tables.

In the interpretation of the statistical tests, values of $p<0.05$ were deemed to be significant.

Strategy for analysis

i Evaluation of internal consistency (construct, face validity) of the questionnaire

ii Sensitivity: It is important to evaluate cases that are frail that were not identified by SQ95 - why were they missed?

iii Specificity: Was an unacceptably high proportion of clients who do not need OAH care categorised as "frail" by the SQ95?

3.3.6 Ethical considerations

Consent to perform the study was obtained from the Ethics and Research Committee of the University of Cape Town (UCT) Medical Faculty. The management of the relevant old age home and CWDT were approached for approval. Individual clients (where possible) were verbally consulted before commencement of the interview on the understanding that no action would be taken to the client's disadvantage based on the results of the questionnaire. Confidentiality was assured in all cases. The data will be stored in the Department of Geriatrics, UCT for at least five years after completion of the study.

4. RESULTS

4.1. Sample size and Demography

i. Except for section 5, sections 1-9 of the questionnaire were not analysed because these sections were designed mainly for administrative purposes. These sections deal with background information and personal details of the client. : (see annexure B).

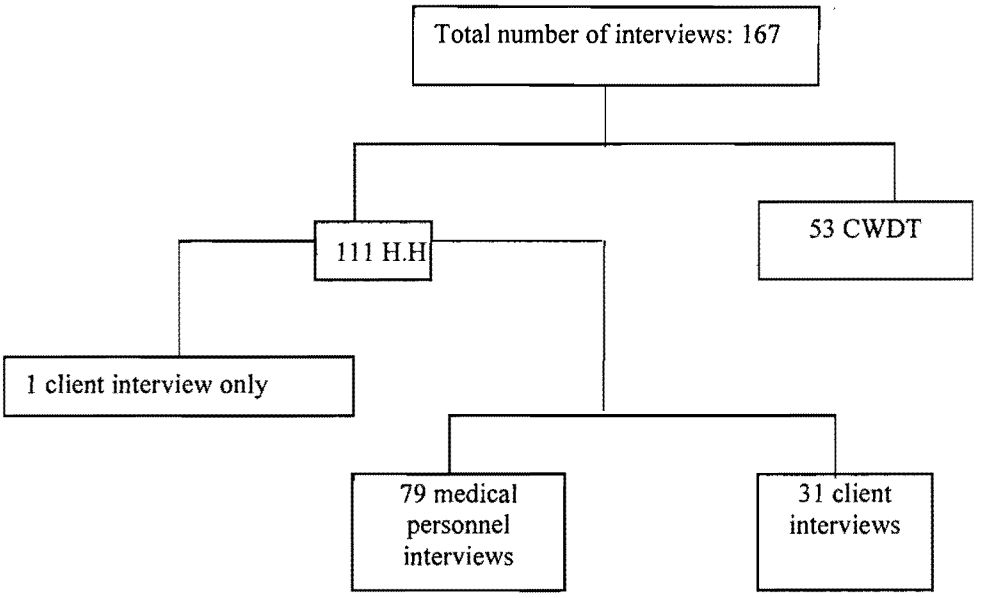


Figure 3. Number of interviews and sampled populations

A total of 133 people were included in the sample. There were 164 interviews since two interviews were assigned to some clients from Highlands House.

The age distribution was as shown in Table 1 below. As expected, the elderly population in sheltered housing was much younger than that in the institution. There

were 37 (27.8%) clients aged 85+ in Highlands House old age home as compared to 5 (3.7%) in sheltered housing.

The population studied consisted of 47 persons of mixed ancestry (coloureds) and 86 whites. Of these, 103 (77.4%) were women and 30 (22.6%) were men; 75 (56%) were widowed, 40 (30%) were single, 10 (8%) were divorced and 8 (6%) were married. (See Table 2).

All 133 clients could speak English. 51 could speak Afrikaans, 1 Xhosa and 1 Hebrew.

TABLE 1. Age distribution of the study population

AGE GROUP	HIGHLANDS HOUSE Total in age group & percentage of total number of clients	CWDT-NOAH Total in age group & percentage of total number of clients
50-59	3 (2.3%)	0 (0%)
60-64	1 (0.7%)	4 (3.0%)
65-74	12 (9.0%)	24 (18.1%)
75-84	27 (20.3%)	20 (15.0%)
85+	37 (27.8%)	5 (3.8%)
TOTAL	80 (60.1%)	53 (39.9%)

TABLE 2. Demographic characteristics

	Number	%
Gender		
Female	103	77.4
Male	30	22.6
Marital status		
Widowed	75	56.4
Single	40	30.1
Divorced	10	7.5
Married	8	6.0
Race		
White	86	64.7
Coloured	47	35.3

4.2. Specific components of the questionnaire and assessment of construct and face validity

In what follows, reference will be made to sections or items which refer to specific components of the present pilot study version of the SQ95 (see Annexure B).

Section 10.1 (Absolute criteria for admission to an old age home)

The absolute criteria for admission to a subsidised home for the aged are being bed-bound, being mentally disabled with urinary and/or bowel incontinence or having a chronic high-risk medical condition requiring continuous nursing care.

Four (3%) persons satisfied these criteria for admission into an old age home (see Table 3).

TABLE 3. Clients meeting absolute criteria for admission to an old age home

Bedbound	1	
Chronic medical conditions	3	- 1 Leukaemia and blind
		- 1 Chronic schizophrenia
		- 1 Severe Parkinson's disease

When data from clients meeting the absolute criteria for admission to old age homes was analysed for performance of other activities of daily living (ADL), the following features were found: they all needed help with feeding except the client with schizophrenia, who was able to eat independently. The latter's mental state was kept stable with regular monitoring by psychiatrists. She required the help of one person for bathing and personal hygiene and could only take medication with help and supervision. Two of the remaining three clients were totally dependent on one person in all ADL. The client with Parkinson's disease needed assistance with all ADL except that he could eat independently with aid devices.

When comparing "absolute criteria" for admission with mental functioning, no meaningful comment could be deduced from this data since there was only one client with dementia who was on regular psychotropic drugs that maintained her mental state under reasonable control. This client also happened to be bed-bound, which qualified her for admission to the institution.

Section 10.2 (secondary criteria for admission to a SHA)

This section consists of sections assessing the following:

i. quantifiable specialised or high intensity care needs

ii. dependency reflected in ADL and access to resources

The data recorded under 'i' above fell under "pressure care", "specialised (professional) care" and "night care".

Pressure care (item 10.2.1) was required by 10 clients, all of whom were in the old age home (see Table 4).

TABLE 4. Clients in need of pressure care and intensity of care required

Intensity of care required	Number of client
1-3 times / day	6
Every 4 hours	3
Every 2 hours	1

When need for pressure care was compared with mobility score under the section recording ADLs (item 13.8), 9 (90%) of the 10 clients needed some assistance with mobility. Of the 9, 1 required supervision, 1 required the help of one person, 6 required the help of two and 1 was totally immobile. A review of questionnaires of these individuals revealed that these were the same clients who were in need of pressure care.

Seven clients required specialised nursing care (item 10.2.2). One of these was said to have severe electrolyte disturbance and weight loss. The cause for this was not stated and she was not on any medication. Of the remaining 6, 1 required eye care though no specific diagnosis was given, 3 required simple dressings for leg ulcers, 1 needed dressings for a pressure sore and one required dressings that could not be managed in the community (see Table 5).

TABLE 5. Specialised care

Type of care required	Number of clients
Maintenance of electrolyte balance	1
Eye care	1
Wound dressing	5

Specialised care did not correlate with dependency in ADL except for medication (as a nurse in the old age home routinely gave this).(See table 6).

TABLE 6. Correlation between specialised care and dependency in ADL

ADL	Spearman rank (r)	p value
Eating	- 0.06	0.49
Dressing upper body	0.02	0.79
Dressing lower body	0.02	0.85
Personal hygiene	0.13	0.14
Bathing	0.11	0.21
Toileting	- 0.08	0.34
Medication	0.19	0.006
Mobility	- 0.02	0.81
Transfers	0.02	0.86
Communication	- 0.06	0.49

Night care (item 10.2.3) of the questionnaire. In all, 62 were recorded as requiring night care, 50 of whom required care only once a night. The night care in most of these cases consisted of medication given at bedtime by a nurse. Of the remaining 12, 11 required attention regularly 3 times per night and 1 was described as "usually awake, restless disturbs others" (see Tables 7).

TABLE 7. Number of clients requiring night care and the frequency of care

Frequency per night	Number of clients
1	50
3	11
More than 3 times	1
Total	**62**

Table 8 shows medical conditions in those that required night care.

TABLE 8. Need for night care and specific medical conditions

Intensity of need for night care	Number (%)	Medical condition
Once per night	50.(80.7)	Administration of medication
Three times per night	11 (17.7)	2 bed-bound
		2 Parkinson's disease
		1 dementia
		1 brain surgery for tumour
		2 depression
		1 poor eyesight
		2 stroke
More than three times per night	1 (1.6)	1 dementia
Total	62 (100)	

Comparing the need for night care with ADLs, it was noted that, of the 12 requiring night care three times or more per night, 3 required assistance with eating. Of these, 2 had Parkinson's disease and 1 was blind. Assistance with dressing was needed by 7. There was a strong association between night care and need for assistance with dressing ($p = 0.004$). There was also a strong association between night care and the need for assistance with personal hygiene ($p < 0.00$), with 9 (75%) of the 12 individuals requiring regular night care also requiring at least one person to assist them with personal hygiene. By contrast, 25 (20.7%) of the 121 individuals not requiring night care needed the assistance of at least one person for personal hygiene. The association between the need for regular night care and need for assistance with bathing was equally strong, with 9 (75%) of the 12 requiring assistance while 28

(23.1%) of the 121 not requiring night care needed the assistance of at least one person for bathing (p = 0.001). There was an equally strong correlation between night care and need for assistance with toileting (r 0.32, p < 0.00). There was a highly significant association between regular night care and the need for assistance with transferring (p < 0.00) and mobility (p < 0. 00). There was no correlation between need for regular night care and need for assistance with communication (r 0.11, p 0.22).

Overall, there was good correlation between need for night care and dependency in ADL except for eating and communication. (See Table 9).

TABLE 9. Correlation between night care and ADL

ADL.	Spearman Rank r	P value
Eating	0.14	0.12
Dressing upper body	0.27	0.001
Dressing lower body	0.25	0.004
Personal hygiene	0.34	< 0.00
Bathing	0.28	0.001
Toileting	0.32	<0.00
Medication	0.53	< 0. 00
Mobility	0.37	< 0.00
Transfers	0.33	< 0.00
Communication	0.11	0.22

The correlation between night care and mental behaviour (item 14.1) was good. Of the 12 individuals who required regular night care, 5 (41.7%) exhibited abnormal

mental behaviour (r 0.23, p= 0.007). On the whole, this section demonstrates construct validity of the questionnaire since frail elderly people requiring night care are usually physically dependent and therefore show dependency in ADL.

Section 11 (Medical conditions causing dependency)

This section is does not measure dependency levels. It is, however, helpful in identifying the causes of dependency in the clients and therefore in planning for levels of staffing at the receiving old age home. Of the total of 133 clients, 106 did not have specific medical conditions causing dependency. All those with specific medical conditions causing dependency were from the old age home. Of the total of 80 clients from the old age home, 27 (33.8%) had medical conditions causing dependency. The type and frequency of these medical conditions is shown in table 10.

TABLE 10. Number of clients presenting with specific medical conditions causing dependency.

Specific medical condition	Number and percentage of affected clients
Dementia	9 (33.3)
Stroke	4 (14.8)
Severe arthritis	3 (11.1)
Chronic schizophrenia	3 (11.1)
Parkinson's disease	2 (7.4)
Blindness	2 (7.4)
Mental sub-normality	1 (3.7)
Epilepsy	1 (3.7)
Leukaemia	1 (3.7)
Amputation	1 (3.7)
TOTAL	27 (100)

Clients with specific medical conditions causing dependency generally required assistance in ADL. Of the 164 interviews, 32 had a medical condition causing dependency and 132 had no medical condition causing dependency. There was a higher proportion of clients with a medical condition causing dependency, needing assistance with ADL than those without a medical condition causing dependency. See Table 11

TABLE 11. Comparing proportions of clients with medical dependency and those without medical dependency requiring ≥ level 3 assistance in ADL (N = 164)

ADL	Med. Dep. +ve (n=32)	Med. Dep. -ve (n = 132)	P value
Eating	0.09	0.0	< 0.00
Dressing upper body	0.41	0.03	< 0.00
Dressing lower body	0.47	0.03	< 0.00
Personal hygiene	0.84	0.22	< 0.00
Bathing	0.84	0.27	< 0.00
Toileting	0.34	0.0	< 0.001
Medication	0.97	0.59	<0.00
Mobilisation	0.28	0.0	< 0.00
Transfer	0.38	0.02	< 0.00
Communication	0.09*	0.0	< 0.00

Med. Dep. +ve = Medical condition causing dependency present
Med. Dep. -ve = Medical condition causing dependency absent

As stated in the section on night care (10.2.3), 12 clients required night care 3 times or more per night. Of these 12, 9 (75%) had specific medical conditions causing dependency.

The 4 clients requiring pressure care every 4 hours or more all came from this group of clients.

Two of the 7 clients requiring specialised care had specific medical conditions causing dependency. One had a stroke and the other had dementia. For both these clients, the specialised care required was ulcer dressing.

Section 12: (Other medical conditions)

This section was included in order to gain knowledge of the clients' medical health. This could help plan medical services that would be required by the clients.

Table 12 shows the most frequently reported medical conditions

TABLE 12. Medical conditions most frequently reported by the 133 clients

Medical condition	Number of clients	Percentage
Hypertension	45	33.8
Arthritis	33	24.8
Depression	17	12.8
Angina	15	11.2
COAD/asthma	13	9.8
Diabetes mellitus	9	6.8
Cancer	5	3.8

COAD = Chronic obstructive airways disease.

Depression, which is not unusual among institutionalised individuals, was the third most commonly reported medical condition occurring in 17 persons (12.8%).[77]
It should be noted that most of these persons had more than one medical condition.

Section 14.1 (Mental behaviour)

Analysis of this section showed good correlation with the degree of dependency. Of the 9 individuals reported as exhibiting abnormal behaviour, 7 had dementia as their medical cause for dependency. Two of the 9 exhibited abnormal behaviour that was a danger to themselves and to others. There were 6 other clients with abnormal behaviour. A number of these were reported as having early dementia, but this was

not recorded as the medical cause for dependency. As mentioned earlier, most of these clients were on medication (some of which was behaviour modifying) and hence had not been exhibiting abnormal behaviour at the time of the survey. Comparing the results in this section with those of the ADL (section 13), there was significant correlation between mental functioning and dependency in all ADL except communication. See Table 13.

TABLE 13. Dependency in Activities of Daily Living in clients exhibiting abnormal behaviour

ADL	Spearman Rank r	P value
Eating	0.33	< 0.00
Dressing upper body	0.50	< 0.00
Dressing lower body	0.48	< 0.00
Personal hygiene	0.49	< 0.00
Bathing	0.40	< 0.00
Toileting	0.36	< 0.00
Medication	0.42	< 0.00
Mobility	0.38	< 0.00
Transfers	0.48	< 0.00
Communication	0.02	0.74

On the whole, analysis of section 14.1 (mental behaviour) in relation to other sections recording related information regarding physical or cognitive functioning, supported satisfactory construct validity of the questionnaire.

4.3 ASSESSMENT OF SPECIFICITY AND SENSITIVITY

Establishment of sensitivity and specificity of an instrument is often hampered by absence of a gold standard. Many areas that are assessed, such as social functioning, are subjective and hence comparing an instrument with a gold standard may be inappropriate.[78]

The secondary objective of this pilot study was to develop an analytical strategy to broadly test the sensitivity and specificity of the questionnaire before proceeding with the national study. For this section, clients were allocated to different categories according to their level of dependency by the nursing managers of Highlands House old age home and of the sheltered housing (NOAH/CWDT) and this was taken to be the "gold standard". The classification of the client's dependency levels as determined by the SQ95 was then compared to the "gold standard" (or "true" level of dependency).

Kruskal Wallis test was used to test for a difference in the median score on ADL, pressure care, specialised care, night care, absolute criteria for admission and mental behaviour across the different 'gold standard' defined classification groups. There was a highly significant difference in the median scores in the different groups except for specialised care and communication. There was not enough variation in the data to show a significant difference between "absolute criteria" and the "gold standard" classification. There were 4 individuals who satisfied the absolute criteria for admission to SHA, these were all from category 1(dependent group) See Table 14.

TABLE 14. Comparison between SQ95 classification on individual items/sections and *a priori* categorisation of Highlands House old age home residents. (n=111 interviews)

	P value (Kruskal Wallis Median Test)
ADL: Eating	0.000
ADL: Dressing upper body	0.000
ADL: Dressing lower body	0.000
ADL: Hygiene	0.000
ADL: Bathing	0.000
ADL: Toileting	0.000
ADL: Medication	0.000
ADL: Mobility	0.000
ADL: Transfers	0.000
ADL: Communication	0.134
Pressure care	0.000
Specialised care	0.963
Night care	0.000
Absolute criteria	1.000
Mental behaviour	0.000

Communication showed no variation between the groups because it is not necessarily impaired even among the frail individual. The other reason was that the interviewer misinterpreted the meaning of communication as well as that of specialised care.

Kappa statistic of agreement was calculated for different combinations of gold standard classification groups and that of the SQ95 dependency levels using two by two tables.

Agreement was poor between the gold standard classification and SQ95 in the following items: bathing, medication, communication, specialised care, night care and mental behaviour. Table 15 shows actual and kappa agreement of the dependent and social groups in the dependency ratings of the SQ95. Kappa agreement of the dependent and group 3a, dependent and group 3b (not shown in the table) showed similar results.

Group 1 = Dependent, 2 = social admission, 3a = minimum community support, 3b = maximum community support.

For calculation of Kappa statistic SQ95 ADL level ≤2 classified as no assistance, ADL level ≥3 classified as requiring assistance. For pressure care, specialised care and night care those requiring any kind of support were compared with those requiring no support. For mental behaviour level ≤2 was classified as normal while mental behaviour ≥3 was classified as abnormal. (See annexure B).

Kappa greater than 0.75 represents excellent agreement, below 0.40 represents poor agreement 0.40 – 0.75 represents intermediate to good agreement.[44]

Table 15. Agreement between SQ95 and "gold standard" categorisation of Highlands House old age home residents.

	Group 1 versus group 2
	(Actual % agreement) Kappa
ADL: Eating	(88%) 0.40
ADL: Dressing upper body	(92%) 0.72
ADL: Dressing lower body	(92%) 0.72
ADL: Hygiene	(73%) 0.40
ADL: Bathing	(67%) 0.33
ADL: Toileting	(74%) 0.74
ADL: Medication	(26%) 0.04
ADL: Mobility	(94%) 0.74
ADL: Transfers	(97%) 0.88
ADL: Communication	(85%) 0.23
Pressure care	(84%) 0.44
Specialised care	(80%) 0.05
Night care	(59%) 0.20
Absolute criteria	(89%) 0.49
Mental behaviour	(81%) 0.21

Example

Eating

	Gold standard		
	Gold 1	Gold 2	Total
SQ95 ≥ 3	3	0	3
SQ 95 ≤2	8	55	63
Total	11	55	66

Gold 1 =dependent, Gold 2= social

Actual agreement = (3+55) / 66 = 0.88

Kappa = {(11 * 3) /66 + (55* 63) / 66 } / 66 = 0.80

(0.88 – 0.80) / (1.0 – 0.80) = 0.40

Since the Highlands House clients received comprehensive services and care, several sections in the SQ95 were irrelevant to this group. These sections included "Primary needs" (section15), "Domestic needs" (section 16), "Extended Support Systems/Needs" (section 17). "Support Systems available to Client" (section 18) and "General Functioning of Care giver" (section 19).

The "true" dependency status categorisation ("gold standard") of the sheltered housing population was divided into only two categories (namely, either 'independent' or 'requiring support'), as this population was comprised of clients who lived in the community. The former category was designated fully independent in all aspects of activities of daily living. Individuals in the second category required some support with certain tasks. The association between individual items and the severity of dependency needs by *a priori* classification (gold standard) showed good correlation. The results showed that none met absolute criteria for admission into a home for the aged. None required pressure care, night care, or specialised care. All were independent with respect to eating, dressing, mobility and transfers. Only medication (see Table 16) criteria under ADL showed significant dependency (r 0.59, $p<0.001$) for medication dependency. The instrument showed satisfactory sensitivity but less adequate specificity for this aspect of ADL. Out of a population of 53, 1 (1.9%) required assistance with personal hygiene, 3 (5.7%) required assistance with bathing. Of these 3, 2 were classified as being fully independent according to the "gold standard". One required an aid device for the toileting criteria (wore a pad for urinary incontinence). This was the same individual who needed assistance with

personal hygiene, bathing and administration of medication. She is clearly at risk of institutionalisation.

In the sheltered housing population (NOAH/CWDT), there was significant association between the *a priori* category (gold standard) and the SQ95 classification on domestic needs, laundry ($p< 0.001$), shopping ($p<0.001$) and business tasks ($p= 0.023$), home maintenance ($p< 0.001$))- see Tables 17 - 20. Garden maintenance was not relevant, as none of this sample was required to maintain a garden. Six clients, according to the "gold standard" classification needed assistance with domestic needs.

Tables 16-20 CWDT/NOAH, correlation between the "gold standard" categorisation and SQ95 classification on medication dependency and domestic needs.

Table 16. Medication dependency

	Gold Standard categorisation		
SQ95 Classification	Independent	require support	Total
Independent	42	1	43
Need supervision	5	5	10
Total	47	6	53

Sensitivity 89.4% and specificity 83.3%; Actual agreement = 89%; Kappa = 0.56

Table 17. Laundry

	Gold Standard categorisation		
SQ95 Classification	Independent	require support	Total
Independent	46	2	48
Need supervision/support	1	4	5
Total	47	6	53

Sensitivity 97.9% and specificity 66.7%; Actual agreement = 94%; kappa = 0.70

Table 18. Shopping

	Gold Standard categorisation		
SQ95 Classification	Independent	require support	Total
Independent	46	2	48
Cannot perform task	1	4	5
Total	47	6	53

Sensitivity 97.7% and specificity 66.7%; Actual agreement = 94%; Kappa = 0.70

Table 19. Business Tasks

	Gold Standard categorisation		
SQ95 Classification	Independent	require support	Total
Independent	37	2	39
Need supervision/support	10	4	14
Total	47	6	53

Sensitivity 78.7% and specificity 66.7%; Actual agreement = 77%; kappa = 0.29

Table 20. Home Maintenance

	Gold Standard categorisation		
SQ95 Classification	Independent	require support	Total
Independent	47	3	50
Need supervision/support	0	3	3
Total	47	6	53

Sensitivity 100% and specificity 50%; Actual agreement = 94%; Kappa = 0.64

4.4. Results of the double assessment carried out on some clients of the Highlands house old age home.

The inclusion of this part in the study though not part of the objectives of the study was to compare the reliability of information obtained from clients to that obtained from nursing personnel.

A comparison of the two interviews across all the basic ADL, Pressure care, Night care and Specialised care as well as Mental functioning showed significant similarities except for night care ($p<0.001$), personal hygiene ($p<0.027$), bathing ($p<0.007$). Table 21 shows the actual differences in the responses between the two groups. Most clients thought they were independent as regards personal hygiene and bathing, but the nurses thought otherwise. Clients thought they required frequent attention at night but nurses thought they did not. (See table 21).

Table 21. Items that revealed significant differences between the client's and nurse interview.

Item	Client interview	Nurse interview
Night care		
none needed	0	1
once per night	4	29
Three times or more	28	1
Personal hygiene		
Independent	25	13
independent with devices	1	1
needs supervision	4	10
Needs help of one person	2	7
Bathing		
Independent	24	10
independent with devices	1	1
needs supervision	3	9
Needs help of one person	4	11

4.5. AMENDMENTS TO THE SQ95 QUESTIONNAIRE AND MANUAL IN LIGHT OF THE PILOT STUDY

The pilot study revealed a number of ambiguities and redundancies in the instrument with respect to the goals of the planned nation-wide evaluation. These are listed in Annexure D.

Overall, the questionnaire was made more user-friendly and was pre-coded for data entry in the computer to minimise error during transcription.

5. DISCUSSION

As has been observed in studies elsewhere in the world, this pilot study showed that the clients in an old age home tended to be much older than those in sheltered accommodation.[79] The 85+ age group formed 27.8% of the population of the old age home and 3.76 % of the population in sheltered housing. The majority were female (77.4%) and widowed (75%).

The interview was conducted in the language that the client was most proficient in. Communication in our study was not a major problem because our interviewer was proficient in English, Afrikaans and Xhosa, which are the languages commonly spoken in the Cape Town area (the study location).

5.1. Methodological considerations

As stated earlier, this was a pilot study to assess the validity, sensitivity and specificity of the original questionnaire. Validity refers to the extent to which a

measure actually measures what it is meant to measure. A measure lacks validity if an observer or instrument repeatedly measures characteristics of the same individual above or below the real value.

5.2 The questionnaire and the manual

In its revised form, the SQ95 is user friendly and the coding of the results has been simplified to reduce the likelihood of error during transcription. Sections have been included to the questionnaire to cover the diverse conditions under which the South African population lives. An attempt has been made to make the manual a self-teaching instrument for interviewers, to increase standardisation of the responses from clients. The manual is no doubt still ambiguous in some respects and will require further refinement. Though the interviewers are encouraged to read the manual before using the questionnaire, there are those who might feel that this is not necessary. A brief self-test may be helpful for such interviewers, chiefly to highlight their need to become fully familiar with the manual.

5.3. Interviewer and population sample

A major weakness of this pilot study was that it was tested on only one interviewer. This means that we have only one opinion with respect to the face validity as perceived by a field worker. The user friendliness and comprehensibility of the SQ95 and the manual could have been better assessed if more field workers were exposed to it. Another weakness is that the study did not include severely impoverished or rural

subjects and therefore sections 15 (Primary needs), 16 (Domestic needs) and 17 (Extended support systems/needs) were not tested in the communities where they would have had most relevance. These aspects will be addressed by the main national study.

5.4. Assessment of Face validity

This refers to the extent to which the measure or questionnaire makes logical sense. The pilot study covered in detail this aspect of the SQ95.

Sections 1-9 deal with background information of the client. After correction of ambiguities in some questions, no flaws in these sections were identified. There were no reports of misunderstandings.

A possible source of confusion was identified in sub-section 10.2.2 (Specialised care). This was demonstrated to require a better definition in the manual as it led to confusion on the classification of individuals. Those who were classified as needing specialised care, only needed simple dressings which, with training and good community medical services, a caregiver could manage.

Another source of confusion might lie in sections 11 and 12, Medical Conditions Causing Dependency and Other Medical Conditions. It should be recognised that this was intended only to give the assessors an idea of the health status of the client. It may also give the institutions an idea of the medical support clients might require. It was not intended to contribute to the dependency score, since the underlying principle of the SQ95 is that dependency status should be evaluated regardless of its cause.

Section 13, Activities of Daily Living, explores dependency in the basic non-nursing needs. There were no difficulties with these items except for 'Communication', which did not show good correlation where it was meant to do so. For example, clients with blindness or dementia were reported as having no problems with communication. This could have arisen from misunderstanding of the question by the interviewer and the person being interviewed. Communication covers speech, sight and hearing. This means that although an individual with dementia can speak, his /her speech is not normal if his/her speech content is incoherent. This item has to be made clearer in both the SQ95 and the manual to improve the face validity.

Another anomaly is the inclusion of a section on Mental Functioning (section 14), given that Activities of Daily Living should conceivably include all functional impairments/dependencies. The logic of the designers of the SQ95 was as follows: there is high prevalence of cognitive impairment among the dependent elderly and this symptom complex imposes an extra burden on caregivers and nurses alike; also, the basic ADL assessments do not capture behaviour disturbances including antisocial behaviour; further, the scoring system, which was generalised (with some difficulty) for all ADLs, could not readily be extended to include behaviour disturbances associated with mental infirmity. It may thus be concluded that, on the whole, the SQ95 has a satisfactory level of face validity, which may be improved if the aforementioned recommendations were incorporated.

As a further evaluation of dependency status related to environmental factors, primary needs (section 15) and domestic needs (section 16) are assessed. Support systems (sections 17 and 18) and likelihood of the current caregiver being able to cope with the dependant (section 19) are assessed. As mentioned in the foregoing discussion of results, most of these were not assessed, as a large percentage of our sample was from an institution where all the necessary support was provided.

5.5. Assessment of Construct validity

Construct validity is "the extent to which a particular measure relates to other measures consistent with theoretically derived hypotheses concerning the concepts that are being measured." [80] In this situation, other variables are used that are believed to be associated with the characteristic under study. For example being cognitively impaired may interfere with the maintenance of personal hygiene or handling of business but not with mobility. As another example: if one is investigating the prevalence or impact on health of depression, one would inquire about sleep pattern, change in appetite, interest in hobbies, which are known to alter if one is depressed.[81, 82]

It has been demonstrated in the results that there is very high correlation (which is statistically significant) between a variety of items used in the assessment of dependency status.

Despite the small and rather biased sample, we were able to show that the clients who satisfied the absolute criteria (section 10.1) for admission were dependent in almost all ADL (section 13). We purposely did not explore these severely dependent clients in detail since this is the least problematic part of the assessment in general. Analysis of the clients requiring pressure care revealed that these comprise 90% of the clients requiring help with mobility. In the analysis of need for night care, clients requiring night care 3 times or more per night either had severe dementia or had a significant physical disability. They were also significantly dependent in most ADL except communication. Communication showed poor correlation (r 0.11, p 0.22) and may have been misinterpreted by the interviewer. As a result of this, the interpretation of communication has been amended in the manual.

Pressure care (item 10.2.1)

Pressure care is required in situations where mobility is reduced.

Pressure care involves lifting and turning several times a day in order to prevent development of pressure sores. For those clients who have already developed pressure sores, there would also be a need for wound care. Such needs are usually beyond the capacity of one caregiver, and an untrained carer will not usually be able to meet such demands. In institutions, carers work in shifts and can therefore cope better with the situation. If a family member had to take up such a heavy burden, it would quickly lead to "burn out" of the carer. Though numbers were too small for meaningful statistical calculations, the association between need for pressure care and

need for assistance with mobility was good, supporting the construct validity of the questionnaire.

Specialised care (item 10.2.2)

Clients requiring specialised care did not show dependency in ADLs ($p>0.05$) as might have been expected. This was because only 7 clients required specialised care. Of the 7, 5 required dressing of ulcers. These would not have required institutional care had community services been adequate. These clients not surprisingly were independent in ADL. Therefore, specialised care did not show significant association with dependency in ADL. If the sample size were larger, it would have probably given a different result.

Night care (item 10.2.3)

This was defined as any care required between 22.00 and 06.00 hours. This was then graded into the average frequency per night. There was good correlation between need for night care and dependency in ADL except for eating ($r = 0.14$, p 0.12) and communication (r 0.11, p 0.22) This is because feeding oneself is one the least sophisticated of the ADLs. As stated earlier, communication appears to have been misinterpreted by the interviewer. Again, the number of clients requiring night care 3 times per night was only 12. This figure is small and results should be interpreted with caution. However, despite the small sample the results make good sense in that clients in need of night care had the following conditions: dementia, stroke, poor

eyesight, and some were bed-bound. Such clients would be expected to be dependent in ADL as demonstrated in the data capture of the SQ95, supporting its construct validity.

Mental behaviour

Of the 15 clients with abnormal behaviour, only five had behaviour that was cause for concern. These 5 were all dependent in all ADL except communication. What was surprising was that these individuals were also dependent in mobility as well as transfers. The explanation for this could be that these individuals were not only mentally but also physically frail.

5.6 Comments on sampling and sample size

As stated earlier, due to the nature of the populations studied, certain features of the questionnaire (SQ95) were not explored for construct validity. Since 60% of the study population was already institutionalised, the environmental factors in sections 15 (Primary Needs), section 16 (Domestic Needs), section 17 (Extended support systems / needs), section 18 (Support systems available to the client) and section 19 (General functioning of the caregiver) could not be explored for construct validity. The rest (40%) of the elderly population was in sheltered housing. These, unlike a population normally living in the community, had an organised formal social support

system. Another confounding factor was that the accommodation of the NOAH/CWDT sub-group had been modified to suit the elderly residents in respect of primary and domestic needs and extended support systems/needs. Therefore, exploration of these aspects did not cover the different environmental factors we would expect to find in the South African population.

Since sections (15 to 19) deal with the domains of clients' living arrangements, their assessment was severely hampered by the sample population in this pilot study. The items in these sections are largely independent of the client's functioning in terms of ADL and mental functioning or dependency on professional nursing care or other professional care allied to medicine. Correlation, hence, is not expected to occur between these domains. Physical dependency does not depend merely on physical capabilities but also on the proximity of different amenities. Sections 15-19 were included so that environmental factors may be taken into consideration in assessment of a client. A client with limited or inaccessible primary, domestic, or extended support systems would qualify for institutionalisation with a lesser degree of dependency than a client who had access to all these facilities.

Another problem is that the sample contained rather few clients with dependency needs who were living in the community. Most of clients assessed from sheltered housing (CWDT/NOAH) were fully independent, leaving only 3 clients needing some assistance in certain aspects of ADL and 6 clients requiring assistance with domestic needs. The sample from the old age home (Highlands House) had only 4

clients meeting the absolute criteria for admission to an old age home; this, however, was a due to deliberate bias in the sampling frame, since construct validity for the 'absolute criteria' was deemed very unlikely to be faulty.

5.7. Sensitivity and specificity

There were no set acceptable levels of sensitivity and specificity for the pilot study as this analysis would to be dealt with in detail in the national study that will have a much larger and more variable sample.

However, testing the sensitivity and specificity of SQ95 showed good correlation between dependency classification by nursing managers ("gold standard") and that of the SQ95. The clients who were classified as being dependent by nursing managers were shown by the SQ95 to satisfy the absolute criteria for institutionalisation. The numbers were too small for meaningful statistical analysis. On Kruskal Wallis test, the SQ95 showed that the dependency levels in the different 'gold standard' classification groups differed. There was a difference in the need for pressure care ($p<0.00$) kappa of 0.44 and night care ($p<0.00$) but poor kappa statistic of 0.20. Giving medication at night to clients who were not truly dependent contributed to the poor kappa agreement. The need for specialised care did not differ in the different gold-standard classification groups, $p = 0.963$ and kappa =0.05. This was the same result as that obtained in testing the construct validity of the SQ95. As stated in that

context, the clients needing specialised care were independent except that the majority required dressings for leg ulcers.

Dependency in activities of daily living as identified by SQ95 corresponded highly with the classification according to the gold standard, the "true" dependency status. The dependency levels were statistically different in the different groups (figure 14) except for communication ($p = 0.134$ and kappa = 0.23). This was due to the misinterpretation of the meaning of communication as discussed under testing of validity of the questionnaire. Kappa was poor for bathing (0.33) and medication (0.08) because clients in old age homes are given assistance in these activities where it would normally not be warranted. The very low kappa values in some instances (night care: 0.20, specialised care: 0.05 especially) are not unexpected in that the 'gold standard' represents a 'summary statement' by the nursing managers of whether or not the client needs institutional care. The discrepancies in many instances appear to indicate that (i) either the nurse managers' view is not upheld by objective assessment or (ii) data collected are wrong. The nursing managers' "gold standard" classification had some bias in that their classification used the old scoring system where similar weight was given to activities that had different implications on survival (eg. same score for urinary incontinence and for inability to shave). Data collected on specialised care and communication was wrong due to misinterpretation of their respective meaning. We should also bear in mind that the kappa statistic is very sensitive (unstable) when there are small numbers in some of the groups and this is the case for those SQ95 questions for which there are very poor kappa values. Kappa for dressing (0.72), toileting (0.74), mobility (0.74) and transfers (0.88) were

good, presumably because even in the old age home clients would get assistance in these activities when they are really deserving. There was poor agreement for mental behaviour (0.21) because of the small numbers of those with mental behavioural problems among those who were classified as being dependent. Most of the clients were physically but not mentally frail.

The SQ95 is designed to be a composite score so even though, in this particular data set, there was little discriminatory ability in some sections of the SQ95 (for example specialised care) evidence of dependency would be picked up by other sections of the SQ95.

As expected, clients from the old age home showed a higher dependency level than those from sheltered housing. Of the 53 clients from the CWDT/NOAH sheltered housing, only 3 clients were classified as requiring assistance. These 3 all required assistance with bathing. Only 1 of the 3 needed assistance with toileting and personal hygiene. The nursing managers classified this client as being dependent. The other 2 required only minimal assistance with bathing and hence nursing managers classified them as independent. This degree of dependency might not have been obvious to the nursing managers as the clients share the residences and do assist each other in some minor tasks.

The acceptable sensitivity and specificity levels for the pilot study were not set, as it was not a representative sample. The acceptable sensitivity and specificity levels for the national study, which doesn't form part of this report, were set at 95% and 85% respectively. The sensitivity was set at a higher level than the specificity because it

was thought that including a few less needy persons was better than excluding the needy from admission to SHA.

All the clients from sheltered housing required assistance with medication. However, this only involved collecting medication from dispensary, which was at a different site from the clinic. There was good correlation between the "true" dependency status and the SQ95 regarding domestic needs: home maintenance (sensitivity 100%, kappa 0.64), laundry (sensitivity 97.9%, kappa = 0.70), shopping (sensitivity 97.7%, kappa 0.70 and business tasks had a low sensitivity 78.7% and poor kappa agreement 0.29, Specificity was low for all the domestic needs (50-68%). Medication dependency had sensitivity of 89.4%, specificity of 83.3% and kappa = 0.56. Kappa was good for all domestic needs except for business tasks. The low specificity was due to the small sample size, there being only 6 clients from CWDT/NOAH who required assistance with domestic needs.

All clients from the old age home had domestic tasks done for them by the nursing staff. The specificity and sensitivity on this section was therefore not assessed for this sub-population.

The 7 level dependency assessment was adequate but it would have been better defined thus improving the specificity and sensitivity if the quality and quantity of dependency were defined using percentage of assistance required as in the FIM.[73] This was not adopted as it requires a certain level of sophistication from the

interviewer and the respondent. This would have created problems for sectors of South Africa where such levels of sophistication may not be readily available.

5.8. Assessment of sources of information: Client-based vs. Nurse-based interviews

Information obtained from the client interviews and interviews from the nursing staff at the old age home was similar except for information on need for night care, personal hygiene and bathing. More clients than were considered by the nursing staff reported that they required night care. The nurses interviewed were daytime nurses and not night nurses. This could have contributed to the discrepancy, although in theory information is handed over between the different shifts.

As regards bathing and personal hygiene, most clients thought they could perform these activities independently while the nurses thought otherwise. The difference may possibly be due to clients feeling that they could do these independently if they were left to themselves. It seems likely that nurses tend to assist clients in order to speed up the process. This was reflected in the poor kappa statistic for bathing, personal hygiene and night care. An open question besides the closed ones used in the SQ95 might have given a clearer answer.

5.9. Amendments to the SQ95 questionnaire and the manual in the light of the pilot study

Despite using only one interviewer, a number of amendments were made both to the manual and questionnaire. It is hoped that further amendments will be made after the national study, which will examine all these aspects in greater detail before the SQ95 is adopted for use as an assessment instrument for admission to old age homes.

5.10 Comments on the results of the study

From data analysis it appears that the SQ95 has no obvious flaws in the logic of its construction. Apart from its focus on what the client can do, it allows for assessment of the environment in which the client lives and assessment of how the carer is coping with the situation.

Clients in the HH old age home and the CWDT/NOAH centre were housed according to their dependency level. The different levels of dependency were obvious to the interviewer and this would have biased the phrasing of the questions, as the likely answers were obvious to her. Though there were 7 different levels of assessment of the required level of assistance, in an environment where clients were obviously frail, the line of questioning would be biased towards eliciting how dependent the client was than how much independent she/he was.

The nurses working in institutions have a biased view of a person's level of dependency as they generally assist clients even when they are capable of performing

a task. So the 'gold standard' classification does not truly reflect the dependency status but it was the best tool available.

The study would have had more weight if it had included community dwelling persons without formal social support. A larger sample would have had more variability in the results and therefore made more sense of the analysis. These goals will hopefully be achieved in the national study.

6. CONCLUSION

The preparatory work for this pilot study included design and lay-out modifications to the original SQ95 and the writing of a comprehensive manual: these aspects were tested during the pilot study, leading to many helpful insights and identified areas of ambiguity requiring attention prior to the nation-wide validation study. The pilot study has been useful in identifying specific ambiguities and other problems related to face validity of the SQ95 in preparation for the national study. Investigation of construct validity served to reinforce the view that the theoretical framework of the SQ95 was sound and could be amenable to developing a valid scoring system.

The main weakness of the pilot study was that the sample populations reflected institutionalised individuals and therefore meaningful conclusions relating construct validity for social support systems and community infrastructure could not be derived. Despite the small homogenous sample there were no obvious sensitivity and specificity flaws. There was good construct and face validity for the sections where data were available.

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ANNEXURE A

DEPARTMENT OF WELFARE / DEPARTEMENT VAN WELSYN

ASSESSMENT OF THE DEGREE OF PHYSICAL AND MENTAL DEBILITY OF AN APPLICANT/RESIDENT: HOME FOR THE AGED OR DISABLED

BEOORDELING VAN DIE GRAAD VAN FISIEKE EN GEESTELIKE VERSWAKKING VAN 'N APPLIKANT/INWONER: TEHUIS VIR BEJAARDES OF GESTREMDES

Name of applicant/resident:
Naam van applikant/inwoner: .....

Date of birth:
..... Geboortedatum: .....

Record the points of the relevant description in the corresponding block.
Vul die punte van die toepaslike beskrywing in die ooreenstemmende blokkie in.

	Points Punte	Assessment Beoordeling 0	1	2	3	4
1. MOBILITY • BEWEEGLIKHEID						
a. Moves independently, with or without appliances. Beweeg onafhanklik, met of sonder hulpmiddels.	0					
b. Moves with the aid of a walking stick, walking frame, wheel-chair with partial support or supervision. Beweeg met behulp van 'n kierie, loopraam, rolstoel met gedeeltelike hulp of toesig.	2					
c. Moves only when aided by staff. Beweeg slegs met behulp van die personeel.	3					
d. Bedridden and totally dependent upon assistance. Must be transferred from bed/chair/bed. Bedlêend en totaal afhanklik van hulp. Moet oorgeplaas word van bed/stoel/bed.	4					
2. PERSONAL HYGIENE • PERSOONLIKE HIGIËNE						
2.1 Care of hands, face and feet Versorging van hande, gesig en voete						
a. Completely independent. Heeltemal selfstandig.	0					
b. Requires supervision. Benodig toesig.	1					
c. Requires assistance, e.g. nailcutting. Benodig hulp bv. knip van naels.	2					
d. Totally dependent. Heeltemal afhanklik.	3					
2.2 Oral care • Mondsorg						
a. Completely independent. Heeltemal selfstandig.	0					
b. Requires supervision to care for teeth. Benodig toesig met tandversorging.	1					
c. Requires assistance with care of teeth. Benodig hulp met tandversorging.	2					
d. Totally dependent. Requires care with aid of mouth tray. Heeltemal afhanklik. Benodig versorging met behulp van mondblad.	4					
2.3 Bath/shower • Bad/stort						
a. Completely independent. Heeltemal onafhanklik.	0					
b Requires encouragement and supervision. Benodig aansporing en toesig.	1					
c. Requires assistance. Benodig hulp.	2					
d. Dependent – must be bathed. Afhanklik – moet gebad word.	3					
2.4 Beard & hair care • Baard- en haarversorging						
a Completely independent. Care results in neat appearance. Safe to shave alone. Heeltemal onafhanklik. Versorging gee netjiese voorkoms Veilig om self te skeer.	0					
b. Requires supervision. Benodig toesig.	1					
c. Requires assistance. Benodig hulp.	2					
d. Totally dependent. Heeltemal afhanklik.	3					
3. EATING/DRINKING CAPABILITIES EET- EN DRINKVERMOËNS						
a. Completely independent. Heeltemal selfstandig.	0					
b. Requires supervision. Benodig toesig.	1					
c. Requires partial assistance e.g. to cut meat, butter bread and/or must be encouraged to eat. Benodig gedeeltelike hulp bv. om vleis te sny, brood te smeer en/of moet aangemoedig word om te eet.	2					
d. Totally dependent upon assistance. Heeltemal afhanklik van hulp.	3					
e. Dependent on tube feeding. Afhanklik van buisvoeding.	4					
4. CLOTHING • KLEDING						
a. Dresses/undresses completely independent. Trek heeltemal selfstandig aan en uit.	0					
b. Requires supervision for dressing/undressing. Benodig toesig vir aan- en uittrek.	1					
c. Requires assistance to dress/undress e.g. with buttons, zips, shoelaces etc. Benodig hulp met aan- en uittrek bv. met knope, ritssluiters, skoenveters, ens.	2					
d. Totally dependent. Heeltemal afhanklik.	3					
5. SIGHT • GESIGSVERMOË						
a. Sight good or impaired but able to function independently. Gesigsvermoë goed of verswak maar nog in staat om selfstandig te funksioneer.	0					
b. Sight poor – requires partial assistance. Gesigsvermoë swak – benodig gedeeltelike hulp.	1					
c. Blind – totally dependent on assistance. Blind – heeltemal afhanklik van hulp	3					
6. HEARING GEHOOR						
a. Hearing good to reasonable to deaf but able to function independently. Gehoor goed tot redelik tot doof maar nog in staat om selfstandig te funksioneer.	0					
b. Hearing poor to deaf: communicates with difficulty and/or is a disturbance to others. Gehoor swak tot doof: kommunikeer met moeite en/of is 'n steurnis vir ander.	1					
c. Hearing poor to deaf – a risk to him/herself and for others. Gehoor swak of doof – 'n risiko vir hom-/haarself en/of andere.	3					

ANNEXURE A

Points Punte	Assessment Beoordeling			
0	1	2	3	4

7. TREATMENT / BEHANDELING

7.1 Medication / Medikasie

a. Uses medicines independently as and when required. Gebruik medikasie onafhanklik soos benodig. — 0

b. As "a" but monthly control necessary. Medicines must be ordered for resident. Soos "a" maar maandelikse kontrole nodig. Medisyne moet vir inwoner bestel word. — 1

c. Medicines must be administered, requiring specialised assistance. Medisyne moet toegedien word. Gespesialiseerde hulp word benodig. — 3

7.2 Care of pressure areas / Versorging van drukplekke

a. Not required. Geen benodig. — 0

b. At least three times a day. Ten minste 3 keer per dag. — 1

c. Every 4 hours. Elke 4 uur. — 2

d. Every 2 hours. Elke 2 uur. — 3

8. TOILET HABITS / TOILETGEWOONTES

a. Selfsufficient. Complete control of functions. Selfversorgend. In volle beheer van funksies. — 0

b. Selfsufficient, but experience problems with stress or mild incontinence. Requires encouragement to practice bladder control. Requires supervision with use of toilet.. Selfversorgend maar ondervind probleme met druklek of geringe inkontinensie. Benodig aanmoediging vir blaasbeheer oefeninge. Benodig toesig met toiletgebruik. — 1

c. Periodic accidents with no prior preventative measures. Periodieke ongelukke sonder voorafgaande voorsorgmaatreels. — 2

d. Requires catheter and/or colostomy care. Benodig kateter en/of kolostomie sorg. — 3

e. Total urine and faecal incontinence. Totale urien- en ontlastingsinkontunensie. — 4

9. THERAPEUTIC ACTIVITIES / TERAPEUTIESE AKTIWITEITE

e.g. handiwork, exercises, guidance councelling, socialising, handling of money
bv. handwerk, oefening, voorligting, sosialisering, hantering van geld

a. Requires no motivation or support. Benodig geen motivering of ondersteuning. — 0

b. Requires 15-3- minutes support per day. Benodig 15-30 minute ondersteuning per dag. — 1

c. Requires 30-60 minutes support per day. Benodig 30-6- minute ondersteuning per dag. — 2

d. Requires support in excess of 60 minutes per day. Benodig ondersteuning vir meer as 60 minute per dag. — 3

10. MENTAL CONDITION / GEESTESTOESTAND

a. Memory good – no support required. Geheue goed – benodig geen ondersteuning nie. — 0

b. Failing memory e.g. no recollection of where clothing or articles were placed. Gebrekkige geheue bv. geen herinnering waar kledingstukke of artikels geplaas is nie. — 2

c. Serious loss of memory/confused/anti-social behaviour or aggressive. Ernstige geheueverlies/verward/antisosiale gedrag of aggressief. — 4

Point Punte	Assessme. Beoordeli		
0	1	2	3

10.2 Emotional support / Emosionele steun

Counselling and/or support
Beraad en/of ondersteuning

a. No support required. Geen ondersteuning benodig. — 0

b. Requires support 15-30 minutes per day. Benodig ondersteuning 15-30 minute per dag. — 2

c. Requires support in excess of 30 minutes per day. Benodig ondersteuning vir meer as 30 minute per dag. — 3

10.3 Communication capability / Kommunikasievermoë

a. Normal communication. Normale kommunikasie. — 0

b. At times unable to communicate desires/needs. Soms onvermoë om begeertes/behoeftes bekend te maak. — 1

c. Total absence of communication. Algehele afwesigheid van kommunikasie. — 2

10.4 Orientation / Oriëntasie

In respect of time, place and person
Ten opsigte van tyd, plek en persoon

a. Normal. Normaal. — 0

b. At times disorientated. Ten tye gedisoriënteerd. — 1

c. Often disorientated, restless, wanders. Dikwels gedisoriënteerd, rusteloos, dwaal rond. — 2

d. Continuously disorientated, but does not disturb other residents. Gedurig gedisoriënteerd, maar steur nie die ander inwoners nie. — 3

e. Total disorientation. Goes astray/must be attended /disturbs others/apathetic. Totale disoriëntasie. Verdwaal/moet opgepas word /steur ander/apaties. — 4

10.5 Comprehension / Begripsvermoë

a. Good ability to follow simple instructions and to understand motives and situations. Goeie vermoë om eenvoudige opdragte te volg en motiewe en situasies te verstaan. — 0

b. Able to follow simple instructions, but poor understanding of motives and situations. In staat om eenvoudige opdragte te volg, maar swak begrip van motiewe en situasies. — 1

c. Poor ability to follow simple instructions and poor understanding of motives and situations. Swak vermoë om eenvoudige opdragte te volg en swak begrip van motiewe en situasies. — 2

d. Unable to follow either simple instructions or understand motives and situations. Nie in staat om eenvoudige opdragte te volg en motiewe en situasies te begryp nie. — T

KEY TO SCORE - SLEUTEL TOT PUNTETELLING

Points/Punte	Care/Versorging	Group/Groep
0 - 11	Self Care/Selfversorgend	1
12 - 27	Moderate Care/ Matige Versorging	2
28 & over 28 & meer	Maximum Care Maksimale Versorging	3

GROUP CLASSIFICATION - GROEPINDELING

Assessment Beoordeling	Date Datum	Group Groep	Signature Handtekening	Capacity Hoedanigheid
1st/1ste				
2nd/2de				
3rd/3de				
4th/4de				

ANNEXURE B

Survey Number | | | | | 4

Official use only

ASSESSMENT FOR ADMISSION TO HOMES FOR FRAIL PERSONS / SUPPORT NEEDS FOR OLDER / DISABLED PERSONS

1.	**ORGANISATION**			6
2.	**ASSESSOR [INTERVIEWER]**			8
	OCCUPATION			10

3.	**PLACE OF ASSESSMENT** 1 = Own dwelling 2 = Home for Aged 3 = Sheltered accommodation 4 = Community centre 5 = Hospital 6 = Clinic 7 = Other specify	11

4.	**SOURCE OF INFORMATION**		
	1 = Person self (client)	Yes = 1; No = 2	12
	2 = Caregiver		13
	3 = Family member		14
	4 = Social worker		15
	5 = Medical Personnel		16
	6 = Other specify		17

5.

CLIENT'S PERSONAL DETAILS	S = surname, MN = middle name, FN = first name		
SURNAME	S	MN	FN
FULL NAME			20
ADDRESS			
TEL No			
GENDER M = 1, F = 2			21
DATE OF BIRTH:	Y Y Y Y	M M	D D 29
Age			32
MARITAL STATUS 1 = Married, 2 = Widowed, 3 = Single, 4 = Divorced, 5 = Separated			33
RACE (for statistical purposes)			
1 = Black, 2 = Coloured, 3 = White, 4 = Asian, 5 = Other specify			34
HOME LANGUAGE			35
SECOND LANGUAGE			36
1 = English, 2 = Xhosa, 3 = Afrikaans, 4 = Zulu, 5 = Tswana, 6 = Pedi, 7 = Sesotho, 8 = Venda.			
9 = Swazi, 10 = Shangaan, 11 = Ndebele, 12 = Other specify			

6.

DETAILS REGARDING NEXT OF KIN / CAREGIVER			
NAME	Age of next of kin/caregiver		38
	Age unknown = 99		
ADDRESS			
TEL No: Work	Home		
RELATIONSHIP			39
1 = Spouse			
2 = Son / daughter			
3 = Brother / sister			
4 = Other specify			
5 = No carer / next of kin			

7.

SOURCE OF INCOME	40
1 = Disability grant	
2 = Old Age Pension	
3 = War Veteran's	
4 = Other (Private)	
5 = None	
GROSS INCOME / MONTH	41
0 = None, 1 = R1-R499, 2 = R500-R999, 3 = R1000-R1999, 4 = >R2000	
Number of financial dependants if any	42

8.

ACCOMMODATION	43
1 = House owner	
2 = House tenant	
3 = Flat owner	
4 = Flat tenant	
5 = Retirement complex (sheltered housing with access to social services)	
6 = Private Home for the Aged	
7 = Guest House / Private hotel	
8 = CPOA Home	
9 = Housing scheme (subsidised housing without social support)	
10 = Tribal (rural traditional housing)	
11 = Farm labourer	
12 = Other specify	

9.

FAMILY COMPOSITION (in household of the client)		
Lives in an old age home	Yes = 1, No = 2	44
Lives alone		45
With spouse		46
With children/child		47
With other family members (eg sister, niece, nephew, grandchild etc)		48
With other elderly		49
With non family (friends)		50
Rural extended family		51
Specify number of persons in household if not in Old Age Home		52

10. **ASSESSMENT OF DEPENDENCY NEEDS**

10.1 **ABSOLUTE CRITERIA FOR ADMISSION (see manual)** 53

1 = bedbound

2 = mentally disabled with total incontinence

3 = chronic high risk medical conditions requiring continuous nursing care

4 = none of the above

10.2 **SECONDARY CRITERIA FOR ADMISSION** (need for professional care)

10.2.1 **Pressure care** 54

1 = nil needed

2 = 1 to 3 x per day

3 = Every 4 hours

4 = Every 2 hours

10.2.2 **Specialised care** 55

1 = requires no care/dressings

2 = simple, daily treatment of dressings

3 = requires complicated treatment of dressings more than 3 x per day

10.2.3 **Night care** (22h00 - 06h00) 56

1 = no or infrequent night care required

2 = regular, 1 x per night care required

3 = requires attention 3 x per night regularly

4 = usually awake, restless, disturbs others

11. **MEDICAL CONDITIONS CAUSING DEPENDENCY** 57

1 = severe arthritis

2 = stroke

3 = amputation

4 = severe chronic obstructive airways disease

5 = end stage cardiac (heart) failure

6 = end stage renal (kidney) failure

7 = end stage liver failure

8 = dementia

9 = Other specify

12. **OTHER MEDICAL CONDITIONS** Yes = 1, No = 2

Cancer	58
Diabetes mellitus	59
Angina	60
Hypertension	61
Arthritis	62
Other specify	63

13. **ACTIVITIES OF DAILY LIVING (Read manual for criteria)**

13.1	Eating	64
13.2	Dressing - upper body	65
13.3	Dressing - lower body	66
13.4	Personal hygiene	67
13.5	Bathing	68
13.6	Toileting	69
13.7	Medication	70
13.8	Mobility (Locomotion)	71
13.9	Transfers (bed, chair, wheelchair)	72
13.10	Communication	73

1 = Fully independent

2 = Independent with aid devices

3 = Needs supervision, but manages on own

4 = Needs regular supervision and help with certain tasks

5 = Needs help of one person

6 = Needs help of two persons

7 = Needs continuous care

If client requires to wear a pad or needs a catheter because of incontinence and manages them on their own score 2. If they need supervision score 3.

Survey Number | | | | | 4

14.1 **MENTAL FUNCTIONING (Read manual for criteria)** 5

1 = No support required

2 = Observes acceptable social standards

3 = Behaviour is unusual but does not offend others or endanger self

4 = Behaviour disturbing to others at times but not a danger to self or others

5 = Continuous uncontrollable, demanding behaviour

6 = Behaviour dangerous / risk to him/herself / other people

14.2 **Psychiatric assessment necessary** Yes = 1, No = 2 6

15. **PRIMARY NEEDS (Read manual for criteria)**

15.1 Water 7

15.2 Food 8

15.3 Toilet 9

15.4 Safety 10

1 = available

2 = limited

3 = inaccessible / dangerous

4 = not available

16. **DOMESTIC NEEDS (Read manual for criteria)**

16.1 Home maintenance 11

16.2 Laundry 12

16.3 Garden maintenance 13

16.4 Shopping 14

16.5 Business 15

1 = Independent

2 = With support / supervision

3 = Needs a person to do these tasks

4 = Not applicable (eg client in old age home)

17. **EXTENDED SUPPORT SYSTEMS / NEEDS (Read manual for criteria)**

17.1	Transport	16
17.2	Telephone	17
17.3	Post Office	18

1 = Available
2 = Limited
3 = Inaccessible / dangerous
4 = Not available

18. **SUPPORT SYSTEMS AVAILABLE TO CLIENT** 19

1 = Support system (spouse, family, friends) functioning well
2 = Support systems available but not functioning well
3 = Living alone with access to other support systems (family, friends)
4 = Only formal support systems
5 = Support system available, but exploitation / abuse / neglect suspected
6 = No support system available

19. **GENERAL FUNCTIONING OF CAREGIVER** 20

1 = Caregiver fully in control of the situation
2 = Requires additional support
3 = Not healthy / aged / disabled
4 = Requires continuous support / help
5 = Total incapacity to provide care
6 = Total burnout
7 = Not applicable - client already in an old age home

Date of completion of questionnaire:	Y	Y	Y	Y	M	M	D	D 28

Please comment on any problems you may have had in administering the questionnaire on this client:

Signature of interviewer:

MANUAL FOR SQ95

SQ95: Structured Questionnaire of 1995

ASSESSMENT FOR ADMISSION TO HOMES FOR OLDER PERSONS and/or SOCIAL SUPPORT SERVICE REQUIREMENTS

SECTION 1 REGISTRATION DETAILS (Please ensure that all sections are answered)

Section 1. ORGANISATION:

Refers to the organisation that supports the client or the old age home in which the client is resident.

Section 2. ASSESSOR: write your name here.

Occupation of interviewer: write your trained profession (if appropriate) e.g. nurse, OT, physiotherapist, social worker etc.; if you do not have formal training, write "LAY" in the relevant boxes.

Section 3. PLACE OF ASSESSMENT

Please indicate where the assessment is being done, e.g. sheltered accommodation or community centre (club) or client's own home (the home in which the client lives).

Section 4. SOURCE OF INFORMATION

Note that we want the best possible assessment of the client. So, if you think it is necessary to speak to people other than the client (e.g. caregiver) to fully assess his/her dependency, please do so. Make crosses.

Section 5. CLIENT'S PERSONAL DETAILS: Complete as indicated. (Note: "Race" is included for statistical purposes only: this should be determined by asking the client: "What is your 'race'?")

Section 6. DETAILS REGARDING NEXT OF KIN OR CAREGIVER: If the client is institutionalised or cared for by a professional organisation, details of the next of kin (if known) should be recorded. If the client is not institutionalised, details of the caregiver should be recorded. If no next of kin or caregiver is known, Code "5"

Section 7. SOURCE OF INCOME: Please indicate client's source of income, e.g. Disability grant, 'Old Age Pension' (State pension), or Private pension, Civil service pension, Police pension etc. If source of income is unknown please code "9".

Gross income: This refers to the client's total monthly income or the total income of the couple (if applicable). If gross income is unknown please code "9"

Section 8. ACCOMMODATION: This refers to the client's current accommodation. Tick the appropriate alternatives.

"Retirement complex" refers to housing where individuals live independently but have easy access to social services.

"Housing scheme" refers to an owner of a house that forms part of a subsidised housing scheme, without any support system.

"Tribal", refers to rural, traditional housing arrangements.

Other: If the client's accommodation is not listed, please specify in writing.

Section 9. FAMILY COMPOSITION: This question is asked to establish the number of people living in the same dwelling as the client.

"Other elderly" refers to a non-family member who is of the client's age group.

"Extended family" refers to different generations of the same family living in the same dwelling or groups of dwellings.

"Rural extended family" refers to living arrangements where support is derived from family members more distant than first degree relatives (brothers, sisters, parents or children).

SECTION 10: ASSESSMENT OF DEPENDENCY NEEDS

This section deals with assessment of support needs for the client.

In subsection 10.1, each of the criteria reflects a need for urgent evaluation for admission to a home for the aged. The remainder of the form should still be completed since the information will provide a more complete picture of the client's circumstances.

10.1. ABSOLUTE CRITERIA FOR ADMISSION AND NEED FOR URGENT EVALUATION

1. A client who is bed-bound due to severe physical illness or frailty.
2. A severely mentally disturbed client with total incontinence of bladder and/or bowels.
3. A client with one or more chronic high risk conditions requiring continuous nursing care. Examples of medical conditions requiring continuous nursing care are: End stage lung disease requiring

oxygen, a brittle diabetic requiring insulin or a poorly controlled epileptic.

10 2. SECONDARY CRITERIA FOR ADMISSION

This section deals with conditions that may, when taken into consideration as a totality, justify the client's admission into a home for the aged. It is divided into sections. The first deals with verifiable need for skilled care or a heavy burden of unskilled care. Subsequent sections attempt to compile a profile of the client's care needs in relation to the presence or absence of resources in and around the client's accommodation and the extent to which the caregivers are able to cope with the client's needs.

10.2.1-10.2.3. NEED FOR SKILLED CARE OR A HEAVY BURDEN OF UNSKILLED CARE

This subsection records situations where skilled care, specialised care, night care (including pressure care) or a heavy burden of non-professional care is required. This would include situations where pressure care, daily dressings are necessary or where a client suffers continuous uncontrolled disturbing behaviour during the night. The care demands resulting from these conditions be such that the caregiver is unlikely to manage the client even with support from community services (e.g. community sister).

Section 11. MEDICAL CONDITIONS CAUSING DEPENDENCY: List here those conditions that are deemed to be the cause(s) of dependency or lead to the client requiring skilled care. If there are none please code "0".

Section 12. OTHER MEDICAL CONDITIONS: Indicate in this section any underlying medical conditions other than those causing dependency. This information will give an idea to the receiving old age home on the required medical attention to the client.

Section 13. ACTIVITIES OF DAILY LIVING (ACTIVITIES OF SELF CARE)

Note: In the SQ95 no attempt is made to measure impairment or to categorise impairments. Considerable effort is made to gather information on disability and caregiver needs (dependency). Thus, *the effect of any specific physical impairment is expressed as its consequent disability/dependency.* (If one considers visual impairment as an example, it is possible to measure the severity of impaired vision accurately; but what is really important is whether the client's visual impairment renders him dependent on others for care and if so the amount of care that is required. It will be seen, therefore, that apart from the relevance of vision with respect to communication, there is no specific section dealing with the effects of loss of eyesight. The reason for this is that the implications of blindness would automatically be incorporated in the need for assistance with dressing, mobility, eating etc. Similarly, there is no specific item dealing for example with arthritis, or the loss of one arm, etc. We know that in older persons there are often several causes of dependency with respect to certain activities of daily living - again, the specific cause of impairment is not important here, but rather the degree of disability/dependency.)

Definitions (These are very important; bear them constantly in mind!)

'Supervision' *means 'keeping an eye on the client to ensure that a task is being done, and may include prompting or coaxing the client verbally - it does not include physically assisting the client.*
'Helping' *means that physical contact with the client is required or help in using an aid that the client normally uses is required.*

NOTE: The interviewer is not required to observe the client perform the activity; a subjective report from the client or carer is acceptable.

13.1 Eating: includes the use of suitable utensils to bring food to the mouth, chewing and swallowing once the meal is presented in the customary manner.

1. Fully independent
   The client can eat a plate of food without any help.

2. Independent with aid devices:
   The client eats independently but requires use of specially adapted cutlery to cut the food, or spread butter etc.

3. Needs supervision but manages on his own:
The client manages to feed or drink by him/herself (with or without an assistive device) but needs constant prompting throughout the meal otherwise the meal is not fully eaten.

4. Needs regular supervision and help with certain tasks:
The client needs assistance with associated tasks such as cutting up food, adding salt or pepper to food, opening cartons of milk, adding sugar or milk to tea and pouring liquids, but the client does contribute to the task.
(Note that any help needed in getting to his/her food or bringing food to the client is a feature of mobility; this section simply determines whether the client is independent with respect to feeding him/herself.)

5 Needs help of one person: Client needs to be fed.

6. Does not apply to feeding - do not fill in this block.

7. Needs continuous care. Client not able to eat or drink and relies on other means of feeding such as gastrostomy or nasogastric feeding and does not administer the feeds him/herself.

13.2-13.3. Dressing:

These notes refer to both the 'upper body' and 'lower body' sections of the questionnaire, which are to be filled in separately.

This includes dressing and undressing as well as applying and removing prosthesis or orthosis where applicable. An orthosis is a device applied to or around the body in the case of physical impairment or disability.

1. Fully independent:
Client dresses and undresses independently including getting clothing from drawers, wardrobes, etc. and manages to put on all garments, manages zips, buttons, press studs and can tie shoe laces and is able to apply or remove prosthesis or orthosis when applicable.

2. Independent with aid devices
Client requires special adaptive fastenings such as velcro or an assistive device to dress or takes more than reasonable amount of time to get dressed or undressed.

3. Needs supervision but manages on own
Client requires supervision e.g. watching and prompting, or setting out clothes or dressing equipment.
(Note that any help needed in getting to clothes or bringing clothes to the client is a feature of mobility; this section simply determines whether the client is independent with respect to dressing.)

4. Needs regular supervision and help with certain tasks
Client requires regular supervision and help in dressing and undressing, but client does co-operate and tries to assist with dressing and undressing. Requires assistance with fastening clothing such as zips, buttons, bra, shoes, etc.

5. Needs help of one person
Client needs physical assistance for most aspects of dressing and undressing, but is able to participate to some degree with putting on and/or removing clothing.

6. Needs help of two people
Client is dependent in all aspects of dressing and is unable to participate in the activity.

7. Does not apply to dressing.

13.4. Personal Hygiene

This includes mouth care and denture care, washing of hands and face, shaving, combing or brushing hair.

1. Fully independent
Client performs the above tasks independently and performs them safely.

2. Independent with aid devices.
Client needs aid devices (e.g. an adapted comb) for personal hygiene.

3. Needs supervision but manages on his/her own or with minimal assistance
Client requires supervision e.g. watching or prompting, otherwise the tasks are not completed.
(Note that any help needed in getting to items needed for hygiene or bringing such items to the client is a feature of mobility; this section simply determines whether the client is independent with respect to performing his/her own tasks of hygiene.)

4. Needs regular supervision and help with certain tasks
Client needs supervision and assistance with some tasks, e.g. setting out equipment, opening a tap, applying toothpaste to a toothbrush, or opening containers.

5. Needs help of one person
Client needs assistance with almost all aspects of hygiene, but is able to participate to some degree with personal hygiene.

6. Client is dependent in all aspects of personal hygiene and is unable to participate in the activity.

7. Does not apply to hygiene - do not fill in this box.

13.5. Bathing

This includes washing, rinsing and drying the body from the neck down *excluding the back*; may be either in a bath, a shower, a basin or sponge/bed bath.

1. Fully independent
Client is fully independent with bathing. Can get in and out of the bath or shower, can sit down in the bath and stand up from sitting; he/she can reach the taps and turn taps on and off and is able to wash and dry himself.

2. Independent with aid devices
Client can perform the above task but needs an aid device, e.g. long handled sponge, special board to sit on or aid devices to open and close taps.

3. Needs supervision but manages on his/her own
Client baths/showers independently but needs prompting to enable him/her to complete the task.
(Note that any help needed in getting to the bath or bringing a basin to the patient is a feature of mobility; this section simply determines whether the client is independent with respect to using the bath/basin.)

4 Needs regular supervision and help with certain tasks.
Client needs some help with certain tasks, e.g. with getting in and out of the bath or supervision is required for safety, e.g. adjusting water temperature or setting out equipment for bathing.

5. Needs help of one person
Client is dependent on the help of one person in all aspects (e.g. transfer to a bath tub or shower and needs help with washing and drying, but is able to participate to a minimal degree.

6. Needs help of two persons
Client dependent on 2 persons for some (or all) aspects of bathing.

13.6. Toileting

Includes getting on and off the toilet, maintaining hygiene of private parts and adjusting clothing before and after using the toilet.

1. Fully Independent
Client is able to perform all tasks of toileting safely.

2. Independent with aid devices
[Bedpans, commodes, urinals, pads, catheters and a raised toilet seat or bars fitted on sides of the toilet are aid devices.]
A client is independent in toileting with some aid devices and, in addition, the client is able to empty and clean the aids where applicable.

3. Needs supervision but manages on his own
Client manages on his own, but needs some prompting to carry out the task. (Note that any help needed in getting to the toilet or bringing a

commode to the patient is a feature of mobility; this section simply determines whether he/she is independent with respect to using the toilet/bedpan/commode.)

4. Needs regular supervision and help with certain tasks.
Client needs supervision for safety and needs assistance in getting on and off the toilet and emptying or cleaning the toilet, commode or bedpan where applicable.

5. Needs help of one person
Client needs assistance of one person in all aspects of toileting, i.e. with getting on and off the toilet, adjusting clothing, and cleaning of the private parts as well as emptying and cleaning the bed pan where applicable.

6. Needs support of two people
Client needs assistance of two people in all aspects of toileting, e.g. a client with stroke and obesity or severe joint deformities with stiffness.

7. Needs continuous care
Client needs assistance in all aspects of toileting and he/she is incontinent of both urine and stool.

13.7. Medications

Includes opening containers, counting the tablets according to prescribed dosage, taking the medication or tablets in correct amounts or administering injectable medications where applicable.

1. Fully independent
Client can safely administer his/her own medication and control it independently, that is, he/she remembers when to take his/her medicines and when to request renewal of his/her stock.

2. Independent with aid devices.
Client uses special devices to open pillboxes, or uses a pill dispenser or other aid device.

4. Needs regular supervision and help with certain tasks
Client needs to be watched for safety and needs physical help for certain tasks, e.g. going up stairs, going into public places or walking long distances.

5. Needs help of one person
Needs constant help of one person for all aspects of mobility, but is able to contribute.

6. Needs help of two persons
Needs help of two persons for all aspects of mobility.

7. Does not apply

13.9. Transfers

Includes transferring from bed to a chair or wheelchair and back with safety.

1. Fully independent
Needs no help or assistive devices.

2. Independent with aid devices
Devices (bed hoist, special handles etc.) are necessary, but can be handled by client without any help.

3. Needs supervision but manages on own
If client needs prompting, coaxing etc., without the supervisor physically having to help the client.

4. Needs regular supervision and help with certain tasks.
Client needs supervision for safety and needs physical assistance e.g. to steady a chair, etc.

5. Needs help of one person
Client always needs assistance of one person for transfers, but is able to contribute to some extent.

6. Needs help of two persons
Client needs two persons to transfer him/her safely.

7. Does not apply.

13.10. Communication

This includes intelligible/sensible communication through speech, hearing and vision (sign language or some other visual method of communication).

1. Fully independent
Independent in communication.

2. Independent with aid devices
Independent when using hearing aids, speaking devices.

3. Does not apply to communication - do not fill in box.

4. Needs regular supervision and help with certain tasks
Client requires assistance with communication or guidance/directions in public places.

5. Needs help of one person
Client needs one person to assist in communication in public places because of speech or hearing disorder.

6. Does not apply to communication.

7. Needs continuous care
May apply to clients with two or more communication deficits (e.g. blind and deaf etc.) or where client's attempts at communication are wholly ineffective.

SECTION 14. MENTAL FUNCTIONING

This section deals with the assessment of behavioural disturbances due to impairment of the client's mental function.

1 No support required
Client has normal memory and mood and requires no support.

2 Observes accepted social standards with support
Client has poor memory but behaviour is normal except that he/she requires regular reminders of certain tasks.

3 Behaviour is unusual but does not offend others or endanger self (self-explanatory).

4 Behaviour disturbing to others at times but not a danger to self or others.
E.g., client has loss of memory associated with the repetitive questions and restlessness.

5 Continuous, uncontrollable demanding behaviour
Client is constantly seeking attention, shouting in an uncontrollable manner, but is not a danger to self or others.

6 Behaviour dangerous/risk to him/herself or to other people
Client's life is endangered by confusion, paranoia and mental illness or he/she is a threat to the safety of others.

Would a formal psychiatric assessment be beneficial?
State your opinions (with input from professionals if necessary).

SECTION 15. Primary Needs

This section applies only to community dwelling clients and it records information regarding the accessibility of water, food, toilet and safe shelter for the client. Make a cross in the 'Not applicable' box if the client is currently institutionalised.

15.1. Water

This deals with the accessibility of water to the client.

Available
The source of water supply is readily available to the client, i.e. tap water within the house and there are no physical obstructions.

Limited
The source of client's water supply is outside the house; or inside the house, but up or down one or more flights of stairs.

Inaccessible/dangerous
Client has to walk more than 50 metres to get to the nearest tap.

Not available
Client has to rely on a water supply from a river or well which involves walking a long distance.

15.2. Food

Available
Shops and other sources of food are easily accessible, i.e. within easy walking distance.

Limited
Shops and other sources of food are accessible but can only be reached with difficulty.

Inaccessible/dangerous
Shops and other sources of food are at a distance and client or caregiver requires to use public transport to get basic food requirements.

15.3. Toilet

Available
Toilet facilities are within easy reach for client i.e. within the house.

Limited
A toilet is nearby the dwelling, but the client can get to it without difficulty.

Inaccessible/Dangerous
Toilet facilities are available but are not readily accessible to the client.

Not Available
No formal toilet structure within 100 metres of the patient's dwelling.

15.4. Safety

This includes security, fire safety and structural safety of dwelling as determined by the interviewer.

Available
Client's dwelling is secure with adequate door and window locks. His/her cooking facilities do not represent a fire hazard. The client's dwelling (including stairs) is structurally sound.

Limited
Client's dwelling is secure but there is a fire hazard (e.g. loose wiring, use of candles or other open fires) or the dwelling structure may be unsafe.

Inaccessible/dangerous
Client's home has inadequate security and does not offer reasonable protection against intruders.

Not Available
No security or safety measurement apparent.

Section 16. Domestic needs

16.1.Home maintenance

This includes maintaining a home in a clean condition.

Independent
Client is able to maintain the dwelling and its surrounding in good condition.

With support/supervision
Client is able to maintain the home but needs support for labour intensive tasks.

Needs a person to do these tasks.
Client not able to maintain the dwelling in a clean and hygienic state.

16.2 Laundry

This includes washing, drying, ironing and putting away of clothing items.

Independently
Client is able to perform the task independently and safely.

With support/supervision.
Client needs assistance with some tasks e.g. hanging clothing on the cloth line and putting them away in the wardrobe.

Needs a person to do these tasks
Client not able to perform any of the laundry tasks.

16.3 Garden maintenance

This includes maintenance of the grounds around the dwelling and/or a garden patch for growing vegetables.

Independent
Client is able to maintain the garden in good condition.

With support /supervision
Client is able to do simple jobs in the garden e.g. watering the garden or planting seedlings but needs help with the labour intensive duties like lawn mowing or digging.

Needs a person to do these tasks
Client is not able to maintain the garden.

16.4 Shopping

This includes getting to the shops, choosing the required items and taking them home.

Independent
Client is able to shop without assistance.

With support/supervision
Client is able to shop but requires assistance with certain tasks. For example, he/she is not able to carry the shopping home or he/she is poorly sighted and needs assistance with choosing the correct items.

Needs a person to do the task
Client not able to shop.

16.5 Business

This includes banking, getting pension money or a disability grant, paying bills and letter writing.

Independent
Client is able to manage business matters independently.

With support/supervision
Client needs assistance with some business matters, e.g. the paying of bills or collecting pension money (see section 17.3).

Needs a person to do the task.
Client not able to perform any business tasks.

SECTION 17. COMMUNITY INFRASTRUCTURE

These are facilities that are necessary to the elderly person for him/her to cope in the community. Make a cross in the 'Not applicable' box if the client is currently institutionalised.

17.1. Transport (public or private)

Available
The client has ready access to private or public transport.

Limited
Transport is available in the vicinity, but some distance from the dwelling.

Inaccessible/dangerous
Client relies on public or other transport but it is relatively inaccessible or in a dangerous area.

Not available
No transport available.

17.2. Telephone

Available
Client has a telephone available in his/her own dwelling.

Limited
Telephone not available in the client's dwelling but readily accessible in the vicinity.

Inaccessible/dangerous
Not within walking distance or only available in a dangerous area.

Not available
No telephone service in the area.

17.3. Post Office or pension pay-out point

Available
Easily accessible.

Limited
Not readily accessible in the vicinity.

Inaccessible/dangerous
Not within walking distance or in a dangerous area..

Not available
Not available in the community where the client lives.

SECTION 18. SUPPORT SYSTEMS AVAILABLE TO CLIENT

This represents a social network system that helps the client meet his/her needs.

1. Support systems functioning well
Client lives with spouse who is in good health or lives with a member of the family who is very supportive or has very supportive friends.

2. Support system available but not functioning well
A spouse, family member or friend is available but is not very supportive to the client or unable to support the client effectively.

3. Living alone with access to other support systems
Client lives alone but has support from family or friends who are easily accessible.

4. Only formal support system
Client's only support system is from professional organisations, e.g.. social worker, district nurse or from clubs or the church.

5. Support system available but exploitation/abuse/neglect suspected.
For example: physical, financial or psychological abuse.

6. No support system available
Client lives alone and has no support from family, friends, social welfare, clubs or church etc.

SECTION 19. GENERAL FUNCTIONING OF CARE GIVER

1. Caregiver fully in control of the situation
The caregiver is providing adequate care to the client and him/herself.

2. Caregiver requires some support
The caregiver is managing well but needs some support for care giving (e.g. counselling).

3. Not healthy/aged/disabled/emotionally frail
Caregiver is frail or other factors are present which may lead to an inability to provide support.

4. Requires continuous support/help
Caregiver needs to employ a carer to provide the necessary support in the community.

5. Total incapacity to provide care
Caregiver is unable to provide care due to personal, physical or mental infirmity.
(e.g. care-giver who is her/himself developing a dementing illness and is not capable of rendering the necessary support).

6. Total burn out
Caregiver is physically and emotionally exhausted, placing the client at risk.

Manual written by: Dr S Kalula, Prof. S Louw, Mrs D Regensberg, Mrs K Brodrick

AMENDMENTS TO THE SQ95 QUESTIONNAIRE AND MANUAL IN LIGHT OFTHE PILOT STUDY

In section 5, the wording "Personal details" was changed to "Client's personal details", as it was not clear whose personal details were required. Race was included for statistical purposes and marital status was thought to be part of the essential information. Religion and Identity Number were excluded, as they did not contribute anything to the data required for the survey.

In section 7 (Source of income): "Disability" was changed to "Disability grant"

In section 8 (Accommodation): the options of house; flat; tenant and owner were changed to: house owner; flat owner; house tenant; flat tenant. "Retirement complex" was expanded to include sheltered housing with access to social services and housing scheme stands for subsidised housing without social support. "Tribal housing" was expanded to "Rural traditional housing".

In section 9: "Family composition" was changed to "Family composition in household of client", thus making it more specific. The answer format to each alternative was changed to "Yes/No", as the client may be with spouse, children etc. in the same household. For data analysis, it was appropriate that every alternative be answered. "With other family" was made explicit by adding examples like sister, nephew, grandchild etc.

Illness/other problems: this was taken out as it produced data that was not amenable to statistical analysis. It was replaced by "Medical conditions causing dependency" and "Other medical conditions", allowing for a total of 8 of the most common causes of

dependency and 5 other common medical conditions. Both these had the alternative "Other specify" so the list could be expanded in light of other commonly reported medical conditions.

In section 10: "Assessment" was changed to "Assessment of Dependency Needs" to make it more explicit. "Absolute criteria" in this section was changed to "Absolute criteria for admission". "Mentally disabled and total incontinence" was changed to "Mentally disabled with total incontinence" as it was envisaged that both conditions had to be present for immediate admission to an old age home. The alternative "None of the above" was included so that every client could have a response to the question. "Secondary criteria for admission" was made more explicit by the addition of (need for professional care) and "Need for night care" was specified as "Night care from 22.00 hours- 06.00hours".

In section 13 (Activities of Daily Living): "Dressing" was divided into "Dressing upper body" and "Dressing lower body" as these require different skills. "Mobility" was divided into "Mobility" and "Transfers" as separate categories. To make it more explicit, "Communication" in the manual was broken down into sight, hearing and speech (comprehension and expression). Use of catheter or pad for management of incontinence was confusing. A scoring system depending on whether or not the client could manage these independently was, therefore, included in the questionnaire.

In section 14.1 (Mental functioning): the alternatives:

i. No support required

ii. Observes accepted social standards.

Were not initially explained to the interviewer, who had problems deciding into which of the two alternatives a client with normal behaviour fitted. The second alternative was changed to "Observes accepted social standards with support". The manual was amended accordingly to include an explanation of the meaning of the above alternatives.

In section 15 (Primary needs): the options "Limited" and "Inaccessible" were vague and confusing for the interviewer. Thus, changes were made to the manual, specifying approximate distance in metres and kilometres from the client's dwelling to the source of his/her food, water and toilet.

In section 16 (Domestic needs): The option "Not applicable" was added to the questionnaire for clients who were already in an old age home. This was done so that every client would have a response to every question.

In section 17: "Physical support system/needs" was changed to "Extended support system/needs". To take account of telephone, transport and post office, i.e. facilities that help the elderly person cope in the community.

In section 18: "Natural support system" was changed to "Support system available to client" to make it more explicit.

In section 19 (General functioning of the caregiver): the option "Not applicable" was added for clients who were already institutionalised.