

Coping in Mitchell's Plain: A Qualitative Analysis of a Group of Handicapped Elderly in the Community

— LT Coetzee, J Katzenellenbogen, K Rendall

Mrs LT Coetzee

Dept of Biomedical Engineering
University of Cape Town
OBSERVATORY
7700

Ms J Katzenellenbogen

Centre for Epidemiological
Research in South Africa

Ms K Rendall

Dept of Occupational Therapy
University of Western Cape

Curriculum vitae

Tandi Coetzee studied at UCT and qualified with a BSc Physiotherapy in 1986. This article is part of a Master's Thesis for which she is registered through the Department of Biomedical Engineering at UCT. She is married to Nicol and they have 2 children. Tandi is practising part time with a focus on neurological rehabilitation.

Summary

This is a qualitative (or health-orientated quality of life) analysis of a group of 9 handicapped elderly people, all with locomotor disabilities, living in a specific community. It shows that the traditional medical method whereby these patients go to a health centre to receive rehabilitative intervention from medical staff who do not personally go to the environment from which their patients come, is insensitive and inappropriate to the individual's needs. This small group illustrates how they live and cope with multiple handicaps in their home environment. All 9 had 3 or more impairments leading to a range of disabilities with different needs. The restrictive, overcrowded environment complicates conventional mobility methods for independence in and around the home; this in turn leads to greater dependence on their care-givers.

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KEYWORDS:

Aged; Handicapped; Disability Evaluation; Devices; Rehabilitation; Quality of Health Care.

Introduction

Life expectancy has slowly increased over the years. The conventional tools for measuring health by life expectancy and mortality rate, are no longer regarded as adequate indicators of real health status. In the context of chronic diseases and

extended life span, a traditional medical diagnosis has become insufficient on its own. It is also necessary to consider disabilities related to activities of daily living, and its interrelationship with the broader environment.¹

Handicap occurs as a result of disabilities and/or disease (impairment) and is a limitation in the fulfilment of a role that is normal for an individual in his own environment.²

This article discusses a qualitative, or a health-orientated quality of life analysis of a group of handicapped elderly people with locomotor disabilities living in a specific community. As a qualitative approach was used, the meaning and interpretation was analysed rather than emphasizing measurements and statistical analysis. Through qualitative study, data collection and concept generation often occur simultaneously, the one complementing the other.³ Out of a large study these elderly were grouped together because some common themes manifested specific to this age group. The series described in this study was selected from a community-based survey done in Mitchell's Plain in 1989, to determine the prevalence of all disabilities.

Mitchell's Plain is a dormitory town, 25 km from Cape Town, with a population of approximately 350 000 people. This town was established for so-called "coloured" people when they were relocated from the central Cape Town area, 13 years ago, as a result of the Group Areas Act. This is a young developing community with 36,1% of the population under the age of 15 years.

... Handicapped Elderly

Methods

A random, stratified, proportional cluster sampling technique was used to select the study population. House to house visits were conducted by therapy assistants using a screening questionnaire, based on that used by the WHO.⁴ This was to identify people with impairments and disabilities. A person was identified as being *disabled* when there was a

All were receiving pensions and lived as dependants with families

limitation, or an inability to perform an age-appropriate activity. The elderly were classified as disabled when they were unable to care for themselves without assistance, thus selecting "disabled" people with handicaps for activities appropriate to the expectations of the elderly. Those people identified as disabled had follow-up visits at home by trained therapists and a structured questionnaire covering ICDH categories, was administered.⁵ (International Classification of Impairment, Disabilities and Handicaps). For people with locomotor problems, additional observations were done by a physiotherapist looking at aspects of the environment, home accessibility, and the assistive equipment in use. All the disabled elderly were over the age of 70 years. The sample yielded no disabled people between 65 and 70 years.

Results

The population of 2 424 people sampled, yielded 24 over the age of

70 years with 9 who were disabled. These 9 people will be discussed under i) Socio-demographic Profile, ii) Physical Mobility and iii) Functioning.

(i) Socio-demographic profile:

In this group of 9 there were 7 females and 2 males. All of them, except one, had schooling of up to two years and all had done some form of domestic or unskilled work during their working life. One had completed school and had done semi-skilled labour. All in this group were receiving pensions and lived as dependents of their families in council-built homes.

(ii) Physical Mobility:

Physical mobility is dependent on (a) the type(s) of impairment leading to a disability or disabilities, (b) the specific environment and (c) the particular assistive equipment available to the individual.

a) Impairments:

Impairment can be defined as a loss or an abnormality of a psychological, physiological or anatomical structure

A very sociable person who would like to visit

(or function) that could result in a *disability* which is a restriction (or lack of ability) to perform an activity within the range considered normal for a human being.² A major feature of disablement in this group was the presence of *multiple impairments*, as illustrated by the following two

people. (Pseudonyms are used throughout.)

Aziza is a lady 79 years of age, who was involved in a motor vehicle accident 10 years ago, and then developed severe arthritis. She is very hard of hearing, has had an ocular impairment since a school-

The housing structure posed a real problem

going age and presently has cataracts. She walks with great difficulty, needing assistance.

Gabiba is an 86 year old lady with poor eyesight, is hard of hearing and suffers from severe arthritis. She also fell and fractured her hip 8 years ago. She is crippled by pain from the arthritis and moves slowly about the house holding onto furniture.

It is clear that the majority of these elderly people had three or more impairments. One does expect a high incidence of hearing and visual impairment* in this age group, but when these are added to other impairments, it makes it so much more disabling: a combination of poor eyesight, reduced hearing ability and restricted locomotion, (in the form of arthritis or a cerebral vascular accident which all of them had), is extremely disabling. All the people in this group were assisted, or had to have proxy reporting for this interview due to a communication handicap. The proxy reporting did not negatively influence the data, but rather improved the quality of information as it was mostly the caretakers doing the reporting. It was

... Handicapped Elderly

also interesting to note that all the disabled people had caretakers available for the interviews, which suggests that they needed full time supervision. Thus, multiple impairments in this group was associated with greater dependance on their caretakers.

b) Environment:

The environment, especially the housing structure, posed a real problem, as illustrated by the following example:

Anne, 80 years old, who is wheelchair-bound, lives in a single storey council-built house with four stairs leading to the front door. An impractical sunken-lounge-effect was created by adding a little wall at the entrance to the lounge with two stairs leading up and another two stairs leading down. Her bedroom can only be accessed through this lounge and therefore is inaccessible by wheelchair. The standard council-size bathroom cannot accommodate a wheelchair at all.

When asked about extending the bathroom, (as there were household members with building skills), it was pointed out that the house was semi-detached and the bathroom could only be extended lengthwise and not in its width, which would still make it inaccessible for a wheelchair. The bathroom leads off the kitchen which is furnished with a table and chairs. Thus her wheelchair is confined to the entrance area of the house. Her 52 year old niece carries her to the bedroom, to the lounge and/or to the bathroom when necessary. This family with their sunken lounge, demonstrates

how one can manipulate an environment to meet one's own aesthetic needs, but it also demonstrates the lack of insight (or motivation) to adapt the environment to accommodate the disabled.

All the people in this group live in an environment which is restrictive: all live in simplex or duplex council-built homes with tiny rooms and most lived in double storey homes, where the standard design dictates that the living and kitchen areas are downstairs and bedrooms with bathroom are upstairs. The standard

The conventional tools for measuring health by life expectancy and mortality rate, are no longer adequate indicators of health status

bathroom is very narrow and has a bath, basin and toilet with very little space to move. All the council homes are semi-detached with the neighbour's bathroom adjacent, which makes extensions difficult or very expensive. All the homes are small and often very densely furnished, restricting the full use of assistive devices such as wheelchairs and walkers.

c) Assistive Equipment:

All 9 people were either using assistive equipment for locomotion, or were in need of some aid as illustrated in the following situations:

Jan uses a walking stick assisted by a tripod bar stool, (or a person, when available!) to move around the house. He solved the problem

of the instability with just a walking stick by using a barstool. He received the walking stick from a tertiary hospital at no cost and it is still in good repair. He expressed the need for a wheelchair as he is a very sociable person and would like to use the wheelchair to visit the neighbours. (After evaluation by a professional, a wheelchair and walking frame was recommended for Jan.)

Gabiba has two walking sticks which she also received from a tertiary hospital, also at no cost, but she never uses them. She also has a walking frame, which she received from a secondary care hospital, and this is only useful on a very even surface outside the house. It is too clumsy to use inside, so she uses the furniture for support instead. She also requested a wheelchair to improve her mobility in the neighbourhood and for other outings.

Marlene, aged 74, is able to move around the house independently, but when going out to see friends in the neighbourhood, she needs assistance to get out of the house and to cross the road. She asked for an "ysterhand" (a walking stick) to give her the confidence and mobility to go out independently.

These three persons show clearly the need for assistive equipment to make them mobile, but also the importance of prescribing appropriate equipment sensitive to the environment and the individual's specific needs.

Only one person had appropriate assistive equipment and that she inherited from her husband. She had no need for more aids or further intervention.

... Handicapped Elderly

Four of the nine (4/9) people needed wheelchairs; of these four (4), two (2) already possessed chairs: the first had just received a wheelchair from a social worker but had no idea how it functioned. The second person was using a child size wheelchair which she received from

They needed full time supervision

neighbours many years ago. This chair was in bad state of repair, with flat tyres, broken foot plates and damaged armrests. She was ingeniously using an old cupboard door over the armrests as a lap-tray. After the home assessment the therapist recommended wheelchairs to the same people who expressed the need for one. These chairs were all predominantly needed for outside use. Wheelchairs used for mobility outside the home and longer distances in the partially ambulant person, was also reported by York.⁶ With the overcrowding and structural problems of the council-built homes, conventional wheelchairs are not practical for inside use. A chair on casters which can convert into a commode, should be investigated further for inside use.

Seven (7) people had walking sticks; three (3) used them regularly, indicating that these were appropriate for these individuals' needs. Of the walking sticks that were in use, one was privately bought, the second inherited from a husband and the third was received from a sister at the Day Hospital on her request. This shows the important role of the person's own initiative and

responsibility taken in deciding on a particular aid. The other four (4) walking sticks were all still in good repair but inappropriate for the people's needs. A real problem has been identified in the way that aids are being supplied. The aids supplied by institutions far removed from the community, are mostly not appropriate, and are insensitive to the needs of the locomotor disabled.

Looking at these three aspects, (the type of disability, the person, the environment and assistive equipment), it shows that they are inter-related and all are crucial in determining the quality of physical mobility of these people.

The interacting of the above mentioned processes can also be understood within the theoretical framework of the systems approach (Biomatrix). The biomatrix, the web of life, is the network of all living things on earth, with processes defined as series of controlled and interrelated events having a specific purpose. One process cannot be isolated from the rest of the life matrix in which all processes are interrelated.⁷

Functioning as an Individual, a Family Member or a Community Member

Functioning as an Individual (Self-care)

Self-care was chosen as a means by which to screen for "handicap" in this age group, as an age-appropriate activity of daily living. For all nine (9) people there was some form of assistance needed in the area of self-care. Those with moderate disabilities, needed some assistance with washing and often with

grooming. The more severely affected people also needed assistance with transfers. Neither of the two people with wheelchairs could access the bathroom or accommodate a wheelchair in the bathroom. Two families independently had a self-engineered bath board to assist them with transfers and with bathing. This eases the burden of the helper and makes the elderly person less dependent and more confident in caring for him- or herself.

Functioning as a Family Member (Dependence)

Families often have to take the responsibility on themselves to care for their disabled, elderly relatives, as there are no homes or home-help-services available for this community.

Old Jan, 92 years old, is living with his daughter who has taken care of him for ten years since his stroke. She would like to "put him in a home, as he needs someone at home for him all the time".

The patient's own initiative and choice of a particular aid

Anne, whom you have met before, has only been with her niece for one year. She moves to different family homes every few months.

Joan has been living with her daughter for two years, and feels very isolated as all her friends are still in Stellenbosch. She had to leave her home there due to her disabling arthritis.

The onset of a disability seems to

... Handicapped Elderly

force the elderly to move in with relatives. Others, who have been disabled for many years, are moved around to different family homes. This moving around of the handicapped to different homes, has also been noted by the Community

The majority had 3 or more impairments

Occupational Therapy Service working in Mitchell's Plain (COTS) as an aspect of concern.⁸ The dynamics within the family often have to change to accommodate the locomotor disabled dependent family member.

Functioning in the Community

The disabled elderly are still part of society but what social contact do they have?

Gabiba, with both sensory and motor impairments often enjoys visitors at home, and gets out to visit others by car only, or goes to church when she feels well enough. Her church leader also pays regular visits to her at home when she is unable to attend church. She needs assistance to get out of the house but requires a private car for transport. The family does not have a car or a telephone in the house, and any social contact for her is a big effort.

Many of the elderly felt that their disability has affected their social life. By living in family homes they do become part of the social activities at home, but the rest of the family often feels burdened as their own social life outside the home is restricted due to

the dependence of the live-in elderly member. Those people who belong to religious groups are visited at home by their religious leaders, in many instances as often as three times a month. Those with telephones at home and with a minor communication disability, use the telephone regularly to contact their own friends and relatives. The majority of the visitors to the home are friends of the family, not necessarily their particular friends, but the elderly who are living with their relatives and not in institutions, are naturally exposed to much more social interaction.

The next person demonstrates clearly the complexity with which many themes interact on the disablement process.

Aziza has severe visual and hearing loss and is crippled with arthritis. She is unable to climb stairs or even walk independently, and lives in a double storey council-type

To prescribe appropriate equipment sensitive to the environment and the individual's specific needs

house with her daughter. With any flair-up of her arthritis, she is limited to the top storey of the house as this is where her bedroom and the only bathroom of the house are situated. Because of the confined space in the bedroom, and the size of the bathroom, her newly acquired wheelchair cannot be used upstairs. The wheelchair can also not move about down-

stairs in the living area due to the furniture arrangement and the small space available. Her wheelchair was used as an armchair instead. The caretaker was overjoyed when shown that the wheelchair could actually fold up, and had many other functions as well! The wheelchair was ordered

Moves about the house, holding onto furniture

and delivered by a social worker two weeks prior to our visit, but Aziza had been taken for a walk only once since acquiring the wheelchair. Her caretaker carried her outside, put her into the chair, took her for a walk and carried her back inside. She cannot care for herself: she needs help with dressing, with toileting and bathing. In the bathroom the family had devised a bath board to assist with transfers, which enables them to still get her into the bath. The daughter said that she found it difficult to cope by herself as her mother needs total care, and this she found too demanding as she has to run the household as well. She felt she needed extra domestic help to cope with the situation. When feeling better, the elderly mother gets out to visit friends once a month. She also reported that people only tend to visit her when she is ill. She felt her disability affected her contact with other people. When asked how she felt about the company she had, she felt happy with it. Their home however has no phone. Her religious leader does pay her visits at home on a regular basis.

... Handicapped Elderly

Conclusion

For the purposes of this paper, different themes were dealt with separately, and illustrated by vignettes. These themes are all so interlinked that in order to do a true quality of life assessment, the person must be assessed considering all aspects of life as in a systems approach, and Aziza clearly illustrates this.

Multiple impairments complicate the disablement process and lead to different disabilities and handicaps. These need different or unique solutions, sensitive to the specific needs of the person in his own family and social environment. A traditional medical diagnosis, while very useful as a starting point, is reductionistic; and hereby real depth and meaning is lost.

Qualitative analysis was used as "measurement is not the goal, but rather knowing and understanding."⁹ An interview in the home environment gives a better understanding of the person's needs, where the person comes from and how the person has to cope. To assist the elderly handicapped to greater independence and better quality of life, health care workers need to go to the living environment of the person, listen to him and be sensitive to all the aspects of this particular individual's life.

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Footnote

* Visual impairment was defined as experiencing difficulty even with using glasses.