

# FOSTERING COMMUNITY DEVELOPMENT

## UTILISING DOMICILIARY PHYSIOTHERAPY AS A TOOL

■ M J Futter, MSoc Sc (Administration & Planning), Physiotherapy Department, University of Cape Town

### INTRODUCTION

David Korten defines community development as "a process by which the members of a society increase their personal and institutional capacities to mobilise and manage resources to produce sustainable and justly distributed improvements in their quality of life consistent with their own aspirations"<sup>1</sup>. The most important goal of this development is the growth of the people concerned in order to realise more of their potential<sup>2</sup>. Community involvement in health care is a very good way of motivating grass-roots people to participate in decision-making and action which affect their lives<sup>3,4</sup>.

As a result of improved medical technology, increased life expectancy, decreased hospital stay and the current growth in the population the need for physiotherapy rehabilitation services is constantly increasing<sup>5,6</sup>. However, there are insufficient physiotherapists to provide the necessary therapeutic intervention services. This means that many disabled people are not able to achieve their potential functional capacity and thus the quality of life within their families, communities and society at large is affected negatively. By failing to achieve their maximum functional level the burden to their families and the community is increased<sup>7</sup>.

Caregivers are the most important persons in the rehabilitation of chronically disabled relatives. Once they are discharged from hospital, the responsibility falls entirely on the caregivers at home who spend a large portion of the day looking after the disabled person<sup>8,9</sup>.

### SUMMARY

Following a request from the Manenberg community a domiciliary physiotherapy programme was established in order to improve the quality of life of the severely disabled persons and their caregivers living in the area.

Emphasis was placed on the community development process to encourage the participants to take responsibility for their own rehabilitation needs.

Forty-three disabled persons were provided with rehabilitation regimens and their caregivers were trained in the physiotherapy management of their relatives until maximum benefit had been achieved.

Measurements of the functional level before and after the intervention showed a significant improvement even though the injury or onset of disease had occurred from two years to eleven years previously.

This improvement demonstrated that the caregivers, many of whom were functionally illiterate, were competent at performing the physiotherapy techniques required to rehabilitate their disabled relatives.

**Key words:** caregiver training, rehabilitation, empowerment

The study was set up at the initiative of the Manenberg Health Project Committee (MHPC). They requested that the Physiotherapy Department, University of Cape Town assist them with effecting an improvement in the care of the severely disabled members of their community. A partnership was thus developed between the Physiotherapy Department and the MHPC. The disabled were provided with rehabilitation programmes and their caregivers were trained in basic physiotherapy techniques by final year students under supervision of teaching staff. In turn the students gained experience in rehabilitation of long-term patients and in teaching caregivers to do simple physiotherapy techniques and how to manage their relatives within the home environment.

### AIM OF THE STUDY

The aim of the study was to investigate the effectiveness of a domiciliary physiotherapy programme that

- a) provided long-term severely disabled persons with rehabilitation regimens
- b) trained the caregivers in the physiotherapy management of their disabled relatives.

The emphasis was placed on capacity building of the individuals involved and not on providing statistical evidence of the various disabilities or personal details of the caregivers.

### PARTICIPANTS

Manenberg is a low-cost housing estate, situated on the Cape Flats 25 kilometres from Cape Town. The majority of the people have a standard four or less education and only 37.45% of the population earned an income during 1991<sup>10</sup>. Housing facilities in this suburb are very limited. Thirty-seven percent of the dwellings have to share outside toilets with three other dwelling units and have no bath or shower provided. The average number of people living in a two bedroomed unit ranges between eight and 15<sup>11</sup>.

The subjects in the study comprises 43 bedbound or housebound individuals and their caregivers. The ages of the disabled ranged from 22 years to 73 years with a mean of 50 years. The predominant number fell into the 61 - 70 age group. This is to be expected since the largest group of participants suffered from cerebra-vascular accidents (CVA's) (Table I).

Condition	Number (n = 43)
Respiratory	2
Quadriplegia	7
Paraplegia	2
Hemiplegia	20
Head injury	9
Hemiplegia/Amputation	3

The length of time from the onset of disability to the first home visits on the programme ranged from two years to 11 years with a mean of 4.65 years so that many of the participants actually fell into younger age groups at the time of injury or onset of disease.

Twenty-nine participants were totally bedridden, nine were able to move from room to room with the assistance of a helper and five were able to walk with some form of walking aid.

The caregivers were either immediate family members or part of the extended family who lived in the same dwelling as the disabled person and whose responsibility it was to care for the relative. Eight percent of the caregivers were male and 92% female.

## METHODOLOGY

The study was carried out by means of action research. This method of research is frequently used in business and the social sciences. The approach differs from other forms of research as it is conducted in the community setting and is committed to collaboration between the researcher and participants of a project. It studies real-life situations and programmes and makes no attempt to manipulate the variables<sup>12</sup>.

As the object of this study was to foster community development it engaged capacity building of the participants by incorporating the members of the family in the planning, implementation, analysis and evaluation of the programme. The principal tool used was non-formal education, based on the MHPC's felt need for the participants to acquire the necessary knowledge and skills to deal with their physical problems. By using action research as the form of inquiry it allowed incremental improvements to be made to the project as soon as shortcomings were identified. When clients are participants in research rather than "subjects" they are more likely to be familiar with and able to contribute to the practical problems involved with the implementation of projects<sup>13</sup>.

The disabled were identified to some extent by community leaders and posters in community centres, but the majority joined the programme by means of snowballing.

The programme was conducted over two years and involved 42 final year students. As part of their community experience requirements they each spend three mornings per week for four weeks in Manenberg. Two students and a member of teaching staff visited the home of a patient. They completed a comprehensive questionnaire and performed a full assessment which included functional, stress and socialisation scales of measurement. For the purposes of this article only the functional assessment is included as the questionnaire comprises 14 pages and would have been too long to include. The functional ability was measured by scoring 14 different basic activities of daily living according to the amount of assistance the individual required (Table II).

Daily activity	Independent (4)	Independent with aids (3)	Independent with assistance (2)	Dependent (1)
Feeding				
Toilet use				
Washing/bathing				
Dressing/grooming				
General bed mobility				
Sitting				
Getting in and out of bed				
Sit to stand				
Mobility from room to room				
Mobility from room to toilet				
Kitchen activities				
Climbing stairs/ramp				
Getting in and out of transport				
Walking outside				
TOTAL SCORE (56)				

The participants were educated in detail about the medical condition affecting the disabled and realistic goals were set for their functional achievement. It was explained to them that treatments would not be carried out on a daily basis as a service, but that the intention was to teach the caregivers how to assist them to achieve their maximum potential of independence. The disabled were taught exercises and functional activities to be carried out with the assistance of their relatives. Demonstrations of the required physiotherapy techniques were given to the caregivers and they were taught how to perform these effectively themselves. Techniques that were found necessary to be taught most frequently were passive movements, positioning for stroke victims, transfers, maintenance exercise regimens, assisted walking and personal back care.

Participants were encouraged to contribute to problem solving regarding the promotion of functional independence of the patient. For example, they made suggestions regarding the arrangement of the furniture so that the disabled could walk around the house independently by holding onto the furniture as the space in most of the houses was too confined to accommodate walking frames or crutches. They were also informed about local resources available and taught how to utilise them. By approaching the City Council Housing Office they were able to have handrails added or altered to facilitate negotiation of steps and also to have ramps built for ease of access for wheelchair users.

Visits took place more frequently initially (two or three times per week), whilst the caregivers' techniques and management needed to be monitored and the regimens of the disabled needed to be progressed. Thereafter, they took place as frequently as was necessary. This varied between once per week and once per month to meet their individual needs and as their rate of progress demanded. "Home-work" to be carried out by the participants was given in the

form of diagrams as the majority of them were functionally illiterate.

The visits continued until the teaching staff member considered the disabled and caregiver had gained maximal benefit from the assistance provided. The number of visits each participant received ranged from three to 26. The reassessment was then done. This was performed by a different pair of students doing their community rotation under supervision of a different member of the teaching staff. A second questionnaire was completed and the functional, stress and socialisation levels were measured for the second time.

During the two years that the study was being conducted the researcher held regular monthly meetings with the MHPC to evaluate, monitor and make incremental changes to the programme where necessary.

## FINDINGS

Wilcoxon's signed rank test was performed on the functional scores to compare the group before and after the intervention programme.

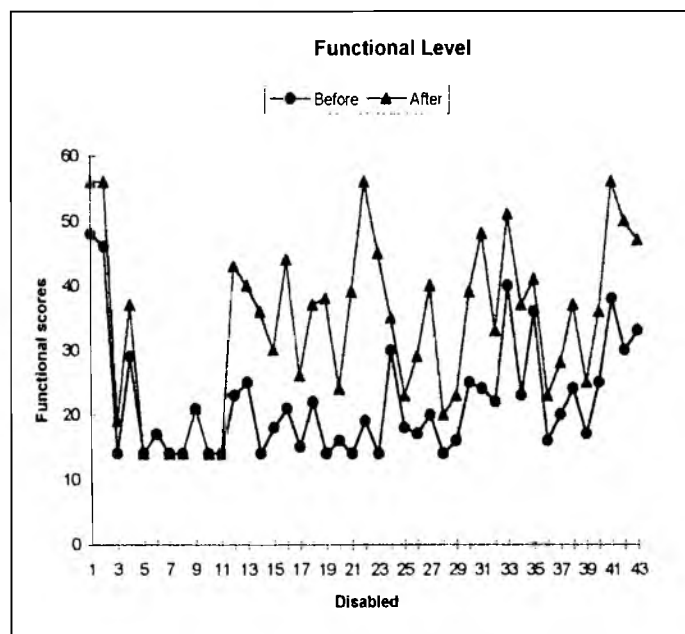


Figure 1: Functional level before and after programme

As can be seen in Table III there was a significant improvement in the functional level ( $p < 0.0001$ ). This improvement is presented graphically in Figure 1.

Functional improvement occurred in the majority of patients irrespective of the length of time since disablement. It was achieved even amongst the disabled who had developed moderately severe contractures.

In spite of the fact that some of the individuals had been fully rehabilitated in hospital and their caregivers had been taught physiotherapy techniques prior to their relatives' discharge many of them had regressed since being at home. As the caregivers had not been able to adapt the techniques learned in hospital to their home environments they had discontinued them. Adaptations to the techniques were essential due to the lack of space in the dwellings and the uneven ground surfaces of the environment. Similar stud-

ies conducted in the United Kingdom concluded that the best place to train the caregivers to ensure successful implementation of the rehabilitation programmes learned in hospital is the home environment<sup>14,15</sup>.

Table III: Functional level scores before and after programme

	Functional Score			Functional Score	
	Before	After		Before	After
1	48	56	23	14	45
2	46	56	24	30	35
3	14	19	25	18	23
4	29	37	26	17	29
5	14	14	27	20	40
6	17	17	28	14	20
7	14	14	29	16	23
8	14	14	30	25	39
9	21	21	31	24	48
10	14	14	32	22	33
11	14	14	33	40	51
12	23	43	34	23	37
13	25	40	35	36	41
14	14	36	36	16	23
15	18	30	37	20	28
16	21	44	38	24	37
17	15	26	39	17	25
18	22	37	40	25	36
19	14	38	41	38	56
20	16	24	42	30	50
21	14	39	43	33	47
22	19	56			
n = 43			p < 0.0001		

Fifty percent of the disabled who were bedridden or unable to walk at the beginning of the programme were in possession of functional appliances that they had never used. These had been supplied by the hospitals prior to their discharge. Reasons given for not having used the appliances included

- the house was too small in which to manipulate the wheelchair
- there was insufficient space to negotiate between the furniture in the house and the ground surface outside was of soft sand and the crutches sank into the soil
- they had never been taught how to use the walking aid in the hospital and were afraid to use it in case they fell
- they had regressed and could no longer walk
- the wheelchair had been provided for use outside, but the patient lived on the first floor of the block of flats and was unable to negotiate the stairs to reach ground level.

Very little conventional rehabilitation equipment was found to be necessary as household furniture frequently proved to be more relevant in promoting function than the expensive equipment used in hospital departments.

The participants' responses to the question "What do you understand by the term stroke" in the questionnaire demonstrated that they had very little understanding of the medical condition affecting them/their relative, its causes

and how to avoid preventable complications. This was due, in part, to the fact that many of the disabled had never received any form of rehabilitation. It may also have been as a result of them not being exposed to any form of education by the health professionals at the time of discharge from hospital or due to misunderstanding of the explanations given on the part of the family. A great deal of confusion arose when they were questioned on the length of time they had received physiotherapy treatment in hospital. Many patients were unable to distinguish between physiotherapy and occupational therapy. Others claimed they had never received physiotherapy in spite of being in a spinal unit for five months and yet they were aware of stretching, skin care and how to transfer from bed to wheelchair.

Working in isolation of other members of the health team caused a great deal of frustration as their expertise was frequently essential in order for the physiotherapy treatment to be maximally effective. For example, one of the stroke patients could not be treated for several weeks as he had a severe attack of gout and his knee joints were too painful for him to weightbear. He had no transport of his own and no money to get himself to the Day Hospital in order for the doctor to prescribe the necessary medication. The services of a social worker, doctor and nursing sister were essential in order to have this aspect of his management dealt with expeditiously so that his physiotherapy treatment could continue unimpeded.

## DISCUSSION

There may very well be an optimum period of time for improvement of function, but that does not mean that rehabilitation should not be attempted on the basis that the injury or onset of disease occurred a substantial time ago.

A major problem working within a community like Manenberg on a long-term basis would be to sustain work satisfaction and motivation among the physiotherapists. This is largely due to the isolation from colleagues and less-than-ideal environment, for example, standard of hygiene in which to practise. The constant demands of using initiative to stimulate the participants to solve their own problems was also stressful as there were no other health workers with whom the problems could be shared.

Time management was found to be the main difference between the physiotherapy practised in hospitals as opposed to that within the Manenberg community. This applied specifically to the amount of time spent in dealing directly with the disabled and the time spent on activities which provided support for them and their families. These activities included education of the participants regarding their medical conditions, assessing and teaching them how to manage them as well as monitoring their progress and providing psychological and emotional support. Liaison with the City Council for minor alterations to the dwellings was also very time consuming.

## IMPLICATIONS FOR PHYSIOTHERAPY

The value of physiotherapy education in the manage-

ment of the disabled and their families in rehabilitation cannot be overemphasised. This is particularly so in a country where there are insufficient resources to provide services in rehabilitation centres to everybody in need. By spending time on this aspect prior to discharge the disabled and their families can be taught how to take responsibility for their own health needs.

Follow-up home visits ensure that hours of rehabilitation in hospital are not wasted by being discontinued on discharge. Visits done soon after discharge can ensure that the disabled have the opportunity of reaching their maximum functional ability within their families and their caregivers can be provided with the necessary skills to effectively achieve and maintain this in the environment in which they need to perform them.

This is also a means of ensuring that only appropriate appliances are prescribed and that they are returned when no longer required.

The home visit is a means of providing emotional support to the families during the initial period after hospitalisation when they most need it.

## CONCLUSION

A domiciliary physiotherapy programme is an effective means of providing rehabilitation for long-term severely disabled people. Their level of functional ability increased significantly, regardless of the length of time from the onset of disease or injury.

In those participants where physical improvement was not possible their quality of life was enhanced by the increased level of understanding that their families acquired. Caregivers who were educated about the medical conditions of their relatives gained the confidence to know when to encourage independence and when to accept the fact they were not able to be more independent. This ensured that they did not have unrealistic expectations of them.

Because of the broad nature of the work, experienced and mature physiotherapists who are familiar with the resources in the community are essential to initiate and implement the individual programmes. This involves counselling of family members, teaching the disabled and their families how to utilise local resources, liaising with other health disciplines and collaborating with other sectors dealing with health matters in the community. However, once intervention programmes had been established the caregivers were found to be competent at implementing the physiotherapy techniques and the maintenance programmes of their disabled relatives themselves. This could be observed by the improvement in functional ability that the patients demonstrated as the physiotherapists only planned the intervention programmes, but the caregivers had to carry out the day-to-day rehabilitation techniques themselves. By being so empowered they became self-sufficient in managing the daily rehabilitation and maintenance requirements of their disabled relatives.

Although community development per se was not measured the amount that took place during this study can be inferred from the level of physical improvement achieved

in the disabled. This occurred as a result of the increased capacities of the disabled and of the caregivers to manage their relatives effectively themselves.

In order for the rehabilitation of disabled to be successful, a community interdisciplinary team approach is essential. Members of the team should incorporate doctors, nurses, occupational therapists, speech therapists, social workers, psychologists and community rehabilitation workers. Although physiotherapy is only a component of the team it forms an integral part, but is limited unless the other members of the team are available.

For final rehabilitation of long-term severely disabled to be successfully achieved home visits are essential to provide the physiotherapist with comprehensive knowledge of the environment, family situation and rehabilitation needs of the individual. This cannot be envisaged and planned for from a hospital or outpatient department. Without home visits months of expensive physiotherapy in hospital are often wasted. Patients are unable to adapt the rehabilitation techniques learned in the spacious gym or ward to the limited area of the home environment nor are they able to substitute expensive equipment used in hospital with simple appliances from the home. Assistance from the physiotherapist in the form of one or two home visits is crucial if the functional level of the disabled is to be maintained after discharge from hospital.

## REFERENCES

1. Korten D C. People-Centred Development Forum. In: Louw, Lionel R. Process and Pre-requisites Necessary for the Successful Implementation and Management of Community Development Projects. *Social Work* 1993;29(2):94-99.
2. Korten D C, Klauss R. *People-Centred Development*. Hartford, Conn. Kumarian Press 1984.
3. Adams R. *Self-help, Social Work and Empowerment*. MacMillan, London 1990.
4. Rifkin S B. The Role of the Public in the Planning, Management and Evaluation of Health Activities and Programmes, including Self-care. *Social Science and Medicine* 1981;15A:377-386.
5. Condie E. A Therapeutic Approach to Physical Disability. *Physiotherapy* 1991;77(2):72-77.
6. Menon P B M. Developing Community-Based Rehabilitation Services for the Disabled by the Primary Health Care Approach. *International Rehabilitation Medicine* 1984;6:64-66.
7. Sharman E M. The Problems of a Rehabilitation Service. *Physiotherapy* 1972;58:209.
8. Gloag D. Needs and Opportunities in Rehabilitation. *British Medical Journal* 1985;290 February:368-372.
9. Putterhill J S, Disler P B, Jacka E *et al*. Coping with chronic illness. Part II. The carer. *South African Medical Journal* 1984;65:891-894.
10. Central Statistical Services. Official Population Census. Pretoria, South Africa 1991.
11. Manenberg Housing Estate Office.
12. Susskind E C, Klein D C. *Community Research: Methods, Paradigms and Applications*. Praeger 1984.
13. Van Vlaenderen H, Nkwinti G. Community-based Research in Black Rural Communities. Paper delivered at PASA Conference, Port Elizabeth 1990.
14. Frazer F W. *Rehabilitation within the Community*. Faber and Faber 1982.
15. Forster A, Young J. The Role of Community Physiotherapy for Stroke Patients. *Physiotherapy* 1990;76(8):495-496.