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REVIEW ARTICLE

NEUROLOGICAL REHABILITATION IN THE COMMUNITY

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There is increasing pressure on health services around the world to provide more resources and facilities in the community. This is partly as a counterbalance to the increasing cost of hospital services and partly a recognition of the importance of local health facilities. Rehabilitation has generally been a hospital-based specialty and there now needs to be a change of focus, or at least an additional focus, towards community rehabilitation. This review article summarizes some of the models of community rehabilitation and the evidence for their effectiveness. Although there is a reasonable body of evidence for both the acceptability and effectiveness of community rehabilitation there is a clear need for further research.

Key words: neurological rehabilitation, community.

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INTRODUCTION

Rehabilitation is a relatively young medical specialty. However, great strides have been made in the past few years and many countries, at least in the "developed" world, have increasing numbers of good quality rehabilitation units staffed by multidisciplinary teams of physicians, therapists and nurses, who in turn are backed by high quality training programmes. In addition, there is now a firm evidence base for the efficacy of hospital-based, post-acute rehabilitation, particularly in the context of stroke units (1, 2). However, rehabilitation has largely developed as a hospital-based specialty. This is understandable given the need for post-acute rehabilitation after such common events as stroke and traumatic brain injury. In addition, when there are relatively few specialists in the field there is an understandable tendency for such specialists to work from a single hospital base rather than their skills being diffused into the community. The same reasoning applies to therapy and nursing colleagues whose focus and training has tended to be hospital-orientated and hospital-based. Indeed it was probably essential for the specialty to develop with a hospital focus, not only to deal with the post-acute rehabilitation needs of patients but also as a means of developing centres of clinical, educational and research excellence and medico-political influence. However, there are a number of reasons why the specialty should now begin to develop a broader community outlook.

First, hospital-orientated units will not readily serve the needs of disabled people with longer-term problems. There is a clear and understandable tendency for individuals to be discharged after a few weeks or months from a hospital-based rehabilitation unit. Many such people will have residual disabilities with ongoing rehabilitation requirements and many will be poorly served by inadequate community rehabilitation resources and facilities. Second, many individuals with longer-term conditions, such as cerebral palsy, multiple sclerosis or muscle disease, will never be admitted to a post-acute hospital facility and thus rarely have access to the skilled multidisciplinary team. Third, there is a clear political agenda across most Western countries to move away from relatively expensive hospital facilities. There are many reasons for this shift but it is likely that in most countries the main cause of this refocus is the increasing expense of hospital care. Community care is, often incorrectly, perceived as being a cheaper option. However, more positively there is a political realization, supported by disabled peoples' lobbyists, that health systems should have a longer-term primary and community care focus with secondary and tertiary hospital care having a smaller share of resources than has been traditional. There is an increasing, and even urgent, need for rehabilitation specialists to be aware of this change and to work towards developing the specialty with a community orientation.

Rehabilitation will always have to argue a case for resources and to do so increasingly requires an evidence base. This article reviews some of the models and types of community rehabilitation as well as reviewing the evidence for the effectiveness of such interventions.

COMMUNITY REHABILITATION

This article will concentrate on the literature regarding community rehabilitation in the context of neurological disorders. Most of the literature in this field is about stroke rehabilitation but we have also reviewed the literature regarding other neurological disorders. There are many models of rehabilitation in the community. These range from community-based multidisciplinary teams to individual therapists or nurses working either directly in the community or working on an outreach basis from a

hospital unit. First, this review will look at some different models of multidisciplinary team working within a community setting.

Multidisciplinary teams

There appear to be two main types of community teams. The first concerns people who are already receiving hospital treatment and focuses on reducing the time of admission. These schemes are often referred to as "early discharge" schemes. The second is often referred to as "hospital at home" and this aims to provide rehabilitation in the home as a direct alternative to hospital admission. The boundaries between these two types are by no means fixed but we will use these categories to facilitate a literature evaluation.

Most publications in this field have concentrated on early discharge schemes. These schemes do not negate the need for hospital care but aim to reduce the admission time. Generally such studies have shown that early discharge teams do reduce hospital occupancy and provide a cost-effective alternative to hospital care (3–7). Most work has been done in the context of stroke. In a recent London-based study, for example, 136 people with stroke were discharged after an average stay of 12 days and received rehabilitation at home for 3 months. The control group consisted of 126 people who remained in hospital for about 18 days after their stroke and continued outpatient hospital-based treatment thereafter. The total therapy time received by each group was broadly equal but the intervention group received it at home from a team coordinated by a consultant physician. At 12 months there were no differences between the two groups with regard to activities of daily life. The authors conclude that early discharge was as clinically effective as conventional hospital care and it also reduced costs in terms of hospital stay and was acceptable to patients (4, 8).

In Newcastle upon Tyne Rodgers et al. (3) described 92 individuals who were medically stable at 72 hours post-stroke and were allocated randomly into two groups; one received early hospital-supported discharge and the other conventional care. The median length of stay in hospital was 13 days for the early discharge group and 22 days for the control group. The community-based team was involved with individuals for a median of 9 weeks whilst the control group continued to receive hospital and then standard outpatient rehabilitation as required. At 3 months there were no differences between the two groups in terms of functional ability, handicap, health status, carer stress, re-admission rate and mortality. However, the early discharge group did participate more in activities of daily living than the control group. The cost analysis also illustrated that the cost of the discharge team was balanced by reduced costs following shorter length of hospital stay (9).

Similar conclusions were reached in Stockholm (10). This was a similarly designed study whereby the early discharge group received 3–4 months of continued rehabilitation at home. At 6 months follow-up there were no statistically significant differences in patient outcome (11). However, a more detailed analysis suggested a positive effect of home rehabilitation on social activity, activities of daily living, motor capacity, manual dexterity and walking. Death and dependence in activities of daily living was only 24% in the intervention group compared with 44% in the control group. Obviously there was a reduction in hospital days from an average of 29 days in the control group to just 14 days in the home rehabilitation group. Whilst these studies are quite positive it is worth pointing out the relatively small sample sizes. Larger multi-centre trials with longer follow-up are required to assess the generalizability of the results and longer-term cost effectiveness.

Hospital at home schemes act as an alternative to hospital admission. They are defined as "a service that provides active treatment by health care professionals, in the patients' home, of a condition that otherwise would require acute hospital inpatient care, always for a limited period" (12). There are very few studies that have assessed the efficacy of such schemes in a multidisciplinary context. Early work by Wade et al. (13) gave 96 general practitioners in a district in the south-west of England the opportunity to refer acute stroke patients to a nurse led multidisciplinary home care service. Forty-nine of the general practitioners agreed to participate. The acute stroke patients of the remaining 47 general practitioners formed the control group and had access to standard hospital and community services. The GP continued to make all clinical decisions. A large number of people were recruited (over 400 in each group) and at the end of 6 months the authors found no difference in functional recovery and emotional adjustment in the survivors of stroke or any difference in the stress level in the carers. Whilst it was encouraging that post-acute rehabilitation could be provided in the community without apparent detriment to the patient it is now somewhat doubtful that such studies are ethical given the evidence that suggests that people are better served by acute admission to a stroke unit (2). In a slightly different context Pozzilli et al. (14) compared hospital at home care with routine hospital care for people with multiple sclerosis. The home care multidisciplinary team included three neurologists, a urologist, a psychologist, a specialist in rehabilitation medicine, a physiotherapist, a nurse, a social worker and a coordinator. Access to the team was via a telephone operator who would in turn contact the appropriate specialist to arrange a home visit. At 1 year follow-up there was an increase in client satisfaction with the hospital at home care. However, there were no significant differences in health outcome between the two groups. It was felt that this form of intervention was popular with the clients and led to substantial savings. The authors also point out that it would be unwise to conclude that such schemes always reduce costs, because they open resources to people who would not otherwise be receiving any health care assistance. However, it does seem preferable for people with longer-term conditions to be managed at home, if this produces similar health outcome, rather than going through the unnecessary trauma and cost of a hospital admission.

In a recent study (7), 199 people were referred to a hospital at home scheme by their GP, albeit largely for cardiovascular and respiratory diagnoses. One hundred and two were allocated randomly to the hospital at home scheme and the rest allocated to standard hospital inpatient care. The hospital at home scheme ran

for a maximum of 14 days for each person and provided between 4 and 24 hours of care a day through a team of nurses, physiotherapists, occupational therapists, generic health care workers and a cultural link worker. The scheme was nurse led but the GP maintained medical responsibility. At the 3 months follow-up there were no clinically or statistically significant differences in outcome. This again demonstrates that a good quality, community-based, multidisciplinary rehabilitation team is capable of producing the same satisfactory outcomes as a hospital-based unit.

Whilst these early studies have shown some promising results regarding outcome, acceptability and cost effectiveness there is certainly much more work that needs to be done to assess the full impact of a multidisciplinary rehabilitation team working in a community setting. A number of studies make the point that better coordination and communication between team members may have produced a more effective service. Is there evidence of the efficacy of such co-ordination by means of a care manager or key worker?

Care management

An Italian study (15) involved 200 elderly people already receiving conventional care services in the community. These people were randomly allocated either to an intervention group that provided integrated medical and social care with care management or to a control group that received the services as before. The care manager supervised individualized care plans, monitored service provision and coordinated input. The care manager had a managerial role but it was the local GP who still held clinical responsibility. Individuals in the care management programme had less admission to hospital after 1 year follow-up and if such admission was necessary then it was appropriately delayed, in comparison with the control group. The care management group also had improved physical functioning as well as fewer GP home visits.

In the Swedish early discharge study (10), one therapist was assigned to the role of care manager for each client. The individual was responsible for coordinating discharge procedure, most of the home therapy, the rehabilitation team and for contacting the appropriate neurologist. This study produced a positive outcome in terms of increased rate of social activity, activities of daily living, motor capacity, manual dexterity and walking. Evidence is sparse but common sense dictates that if there is a multidisciplinary team then such team needs coordinating. It also seems preferable for the patient to have a single point of contact through whom access can be obtained to other team members and other resources and facilities.

The individual therapist in the community

A number of studies of community rehabilitation have looked at the efficacy of individual therapeutic input, primarily occupational therapy or physiotherapy, as opposed to the impact of the full multidisciplinary team. Young & Forster (16–18) have done much work on this subject. In one study they compared day hospital attendance and home physiotherapy for people with stroke after discharge from hospital. The individuals attended the day hospital for 2 days a week or received home treatment from a community physiotherapist. One hundred and twenty-four people were recruited and 108 were fully assessed at 6 months. Both arms of the study showed significant improvement in functional abilities between discharge and 6 months but the improvements were significantly greater for those treated at home. This was despite the fact that those treated at home received less actual therapy.

In a similar study 327 people who were discharged from medical or geriatric wards were allocated randomly into two groups (19). One group received domiciliary rehabilitation at home from a physiotherapist, occupational therapist and other relevant professionals. The other group received hospital-based rehabilitation in both an outpatient and day unit setting. At 6 months the outcome was similar for both groups in terms of functional disability, perceived health, social engagement and life satisfaction. In a study by Gilbertson et al. (20), a 6-week domiciliary intervention programme by an occupational therapist increased activities of daily living at 8 weeks compared with routine follow-up but this difference was not maintained at 6 months. However, an increased level of satisfaction was reported in the intervention group at 6 months. The results in these studies are typical of the literature as a whole. Home therapy seems generally as efficacious as hospital or day unit based therapy but most studies show patients' preference for home therapy.

There is still controversy over whether therapy contacts always need to be conducted by qualified therapists. A visit once a week by an occupational therapist and/or physiotherapist who prescribed a programme of exercise and activities to be carried out by the patient for up to 3 months was compared with standard outpatient day hospital therapy in a New Zealand study (21). The programme was devised in collaboration with the patient. At 3 months there was no significant difference in neurological and physical function and activities of daily living between the two groups. The study concluded that physical rehabilitation under the regular supervision of qualified therapists but conducted by the patients themselves was as effective as having the individual attend a hospital outpatient department.

Nursing intervention

Nurse practitioners have been evaluated as primary care providers for more than 25 years (22) but there is a shortage of large-scale, randomized trials that compare nurse practitioners with physicians or therapists. A meta-analysis of 38 studies indicated a trend to suggest that nurse practitioner care is equivalent to or sometimes better than care provided by a physician (23). However, many studies lack methodological rigour and often use poor or untested outcome measures. Most studies have assessed the role of the primary care nurse and have not concentrated on the field of neurological rehabilitation. However, one study by Forster & Young (24) was able to go some way to remedy this situation. They randomly assigned 240 elderly individuals who had recently had a stroke and were living at home to an intervention group or a control group. Both groups received

the usual treatment and services provided by hospital and community staff but only the intervention group received additional visits by a specialist outreach nurse over a period of 12 months. A minimum of 6 visits in the first 6 months by the specialist outreach nurse was shown to be as effective as the standard treatment in terms of perceived health, social activities and stress among carers. In the intervention group, those with milder disabilities had a small improvement in social activities. Thus, the study was unable to distinguish any major benefits of a specialist nurse input although the authors did conclude that personalized support, practical help, information and counselling were factors that were found to be of particular value to the patients in the nurse group. Comparable outcomes were noted in a study (25) that compared a home programme of rehabilitation for individuals with moderately severe traumatic brain injury against a standard inpatient programme. An initial 5-day multidisciplinary evaluation at home and medical treatment as appropriate was followed by provision, by a psychiatric nurse, of guidance on home activities as well as weekly telephone contact, as part of an 8-week home programme. In this study those with less severe injuries tended to do better when treated in the home programme whereas the more severely injured people did better in the hospital-based programme.

A recent study in the north-east of England (26) compared a nurse practitioner, trained in the management of dystonia and the administration of botulinum toxin injections, with a hospital-based outpatient service. The nurse practitioner was found to be as good at or, in some aspects, better than the service provided by medical staff in the outpatient clinic.

Other aspects of community rehabilitation

Two other studies stand out in the literature, which do not readily fit into our previous categorization.

The first examined the role of a referrals facilitator between primary care and the voluntary sector and this was shown to result in clinically important benefits compared with standard GP care (27). This system appeared to reduce anxiety and improved ability to carry out everyday activities and had positive effects on feelings about general health and quality of life. This is an exploratory study but nevertheless may have implications with regard to further studies in this area. It emphasizes the potential for better coordinated involvement of voluntary agencies, particularly providers of information and peer support, in the context of community rehabilitation.

The second study described a hospital discharge scheme for elderly people using care attendants to accompany individuals home on the first day and provide up to 12 hours of support for the ensuing 2 weeks (28). This scheme showed a reduced hospital readmission rate but there were no significant differences between the two groups in physical independence, morale or in death rates. The care attendants provided practical care and coordinated help from family, friends and statutory services. Once again this study shows the potential role of a coordinator in the provision of formal and informal support services.

LESSONS FROM THE SOUTH

We should not forget that whilst community rehabilitation in the developed world is in its infancy developing countries have been using the community-based rehabilitation (CBR) approach for at least 20 years (29). The concept was developed around the idea that family members are the best resource for assisting with the daily needs of disabled people. However, the concept has been adjusted and developed in different countries and different cultures and there is no universally accepted definition (30, 31). Some projects are expert based, outreach programmes from local hospitals. Other CBR programmes have grown from within the community. The latter programmes tend to focus on disabled persons groups who develop an identity in the local community and work towards economic self-sufficiency. Many projects involve utilising the skill of local, multipurpose health workers who have undergone relatively brief periods of rehabilitation training. CBR projects in developing countries are obviously working in very different economic and cultural circumstances but nevertheless some lessons from the past 20 years of CBR development could be applied in the more developed world (32).

The first very clear lesson is that for a project to have acceptance by and meaning for the disabled population there must be participation of people with disabilities. A related lesson is that for community projects to work then the local community should participate as much as possible. This might mean that the physical base for a community rehabilitation service should be in a local community centre. Alternatively it may mean that disability awareness information should be available in the vicinity, such as in local schools or through local employers. Northern countries can also make good use of volunteers. Volunteering has a long tradition in many countries. Perhaps the major lesson to be learnt from CBR projects in the South is flexibility. The role and remit of a local community project needs to remain flexible and the service will often need adjusting as experience develops. Rigidity of thought and management style are to be actively discouraged. It is also helpful to avoid unnecessary professional boundaries. Community rehabilitation team members should be prepared, within reasonable limits, to work outside their own traditional professional roles. Finally, the most successful CBR projects in the South have been those that have not only provided health input but have also provided a broader educational role and acted as an information resource, not only for the disabled people and their families but the local community.

CONCLUSIONS

Most of the studies reviewed have shown that community rehabilitation in whatever form is at least as effective as the traditional alternative of hospital care. However, it is also clear that there are many gaps in our knowledge and much further work to be done. In particular much of the work has been done within Europe and needs to be replicated in different community and cultural settings from other parts of the world. However, it is

initially reassuring that community rehabilitation teams can provide a similar level of rehabilitation outcome to hospital-based teams. Many studies, not surprisingly, also find that patients and their carers prefer delivery of care within the home setting. It would be wrong to suggest that community rehabilitation should replace post-acute hospital-based rehabilitation units. There is now overwhelming evidence of the efficacy of such units, particularly in the context of stroke. However, it is clear that rehabilitation must continue to be provided in the longer term and that hospital-based units cannot provide such a function. The speciality of rehabilitation must begin to look outside hospital-based care and move towards a more holistic provision of services within the community. There is certainly no evidence that any particular form of community rehabilitation is preferable and no hard evidence that could be used to determine the membership or style of working of a rehabilitation team. It would appear that teams working purely in the community are generally as efficacious as those using a hospital outreach model. There is evidence from some studies that individual therapists working in the home can also provide a good outcome. However, it is also clear that coordination is needed between the clinicians as well as between the team and the disabled person and family. There are many different models and styles of working. Such a patchwork of services is probably appropriate and reflects the different resources and facilities of community and primary care services in different countries. There will be no single model for community rehabilitation. This review has made it very clear that the literature of efficacy and cost effectiveness is sparse and generally poor. There is no doubt that there is an urgent need for more vigorous and thorough evaluation of various community schemes. However, this should not discourage rehabilitationists from taking a positive role in the development of community-based initiatives.

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