

REHABILITATION SERVICES FOR PERSONS AFFECTED BY STROKE IN JORDAN

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ABSTRACT

The purpose of this study was to explore the perceptions stroke survivors have of the rehabilitation services received by them in the Jordanian community. A secondary aim was to explore the impact of culture on providing appropriate services for stroke survivors.

Eighteen stroke survivors were recruited from an outpatient stroke rehabilitation programme. All 18 participants had been discharged from hospital for between one and six months. Semi-structured interviews were performed, either in the physiotherapy outpatient clinic where the affected person was attending a clinic or in their homes. Transcription of interviews carried out in Arabic and thematic analysis was also carried out in that language by transcribers who were fluent in Arabic and English, using a back-translation method. Necessary measures were taken to ensure the accuracy, reliability and validity of the data collection and analysis.

Following thematic analysis, themes arising out of the data included physiotherapy and occupational therapy support in the community, out-patient rehabilitation clinic services, community clinic services and support from families, friends and neighbours. Participants expressed satisfaction with their therapists, but there were large areas of unmet rehabilitation need for stroke survivors in the Jordanian community such as a limited availability of occupational therapy services, insufficient amount of therapy services and poor medical support.

This study presents a unique contribution to knowledge relating to the experiences of stroke survivors in a developing country, and also shows how care systems are very dependent on cultural contexts, cultural beliefs and practices.

Key words: Stroke rehabilitation, impact of culture, developing countries

INTRODUCTION

Worldwide, stroke is a leading cause of death and, for those who survive a stroke, the condition is a major cause of functional disablement (1,2). In developed countries, despite service provisions that include physical assistance and rehabilitation services, the literature indicates that there are large areas of unmet

need for stroke survivors (3,4,5). These studies however were largely carried out in developed countries, where social and economic situations differ in significant ways from those in developing countries. In developing countries, there is a paucity of information about stroke survivors and their life experiences after stroke. Also, the health and social services that are available to stroke survivors and other people with severe disability are extremely under developed.

Jordan, is one such developing country where this research is based. In Jordan, there are few rehabilitation centres for adults with disabilities and those that do exist are based in the main urban areas, necessitating travel across distances to access services. The lack of public transport renders this as a very expensive service for the average Jordanian family. As yet, very few physiotherapists work in the community in Jordan, for various economic and cultural reasons. Additionally, in Jordan, no studies have been conducted with a focus on stroke survivors and the impact of culture on their care and rehabilitation. The definition of culture used here is that of Loveland (6) who classifies culture as 'non-material' and 'material'; non-material culture including core values, beliefs and attitudes, while material culture includes architecture, clothing, food, technology and infrastructure.

It is important for health care professionals working in the community to be aware of the cultural background of their clients in terms of beliefs, behaviour and lifestyle (7). An appreciation of religious ethics surrounding health and disease may aid professionals in the challenging role of delivering care in a manner that is both appropriate and culturally sensitive (8,9). Such an appreciation will also avoid cultural clashes and conflicting expectations between providers of rehabilitation and care services and receivers of these services (10,11).

It is hoped that the findings from this project might add to the literature on community services for persons affected by stroke in less-developed countries, and provide recommendations about the provision of community services for such people in Jordan, and possibly in other developing countries in the region. Although the information presented here focuses primarily on developing countries, the findings may benefit health professionals who work with ethnic minority stroke survivors in developed countries too.

AIM

The primary aim of this study was to explore the perceptions stroke survivors have of rehabilitation in the community in Jordan. A secondary aim was to

explore the impact of culture on providing appropriate community services for stroke survivors.

METHOD

What is discussed here is part of a project looking at the implications for rehabilitation personnel of stroke care in the community. This exploratory study followed an ethnographic research design, and data were collected by means of individual semi-structured interviews with stroke survivors. Data analysis used a thematic content approach.

The study was conducted over a period of 12 months at the Outpatient Rehabilitation Centre of Al-Basher Hospital in Amman and in homes of affected persons in the rural areas of Jordan. Ethical approval was received from the Hashemite University Ethics Committee in Jordan and the School of Health Professions at the University of Brighton in the UK. There were three researchers, one male and two female, who were rehabilitation personnel but not involved in the management of participants. The male researcher had previous experience of using and analysing data from semi-structured interviews, and provided training for the two female research assistants.

Cultural issues related to the data collection process

It is usually considered appropriate to involve both men and women participants in a study, in order to ensure fair representation of the study population. In this study both men and women were included, but because of the “non-material” cultural constraints, it was necessary to recruit female research assistants to help with data collection from female participants. As survivors were interviewed privately, it was not culturally appropriate for a male interviewer to interview female survivors on his own and a female researcher had to be present as a chaperone. Other “material” cultural issues were related to the recruitment process. Participants were invited to take part in the study by means of letters. These had to be hand delivered because the postal system in Jordan does not function well and many people have no access to it. Streets are still without numbers and people receive their mail only if they have a post office box.

The interviews with stroke survivors took longer than was usual in studies carried out in developed countries, mainly for “non-material” cultural reasons. The

interviews in Jordan were usually preceded by general conversation and a cup of tea or coffee to show hospitality. Sometimes, if visitors arrived unexpectedly, the interview might have to be postponed or the researcher might have to wait until the visitors had gone, for the interview to be continued.

Participants

Recruitment of participants involved purposeful sampling. Inclusion criteria stated that participants must have experienced a stroke, been discharged from hospital and live in the community, and been identified by physiotherapists and occupational therapists as having adequate communication and cognition to participate in the interview. A total of 21 potential participants were identified as eligible for inclusion in the study, during the data collection period. The researchers approached all 21 participants to explain the purpose of the study and 18 consented to participate. One survivor was readmitted to hospital and two survivors declined to participate without giving reasons.

Procedure

After providing informed consent, each participant completed a semi-structured interview with the main researcher and one of the female research assistants. Interviews lasted between 60 to 90 minutes and were audio taped and later transcribed verbatim prior to thematic content analysis. Background demographics relevant to each participant were collected from their medical records prior to interview and included age, gender, time since stroke and the physical side of stroke.

The semi-structured interviews allowed respondents maximum opportunity to tell their stories in terms of their own values and experiences (12). Semi-structured interviews have an advantage over fully structured interviews because participants can express their views in their own words, reducing the bias imposed by closed questions (13,14). Participants were interviewed in Arabic and the tape-recorded information transcribed and analysed in that language. Measures were taken to ensure the accuracy of transcripts and the reliability and validity of the data analysis, using participant verification of accuracy of transcribed interviews (six participants), peer review of content and process of interviews and generation of themes from raw data and a back-translation method to verify translation of data from Arabic into English using two independent qualitative researchers (15).

Initially, the research team identified concepts from each transcript and coded them; these concepts were then developed into categories and similar categories were integrated into themes. The research team gave meanings and a name to each concept, category and theme.

RESULTS

Participants

In total, 18 participants were interviewed as part of the study; 14 participants were interviewed at home and 4 at a Rehabilitation Centre. Seven of the survivors were female and 11 were male, and ages ranged from 55 to 73 years. They had been discharged from hospital between one and six months, and the average time post stroke for the participants was 12.33 weeks \pm 5.29 weeks.

Three themes developed from the analysis of the raw data derived from the interviews: perceived impact of stroke, perceived needs of survivors in the community and perceived formal and informal support in the community. This paper will concentrate on the latter two, perceived needs and perceived support in the community.

Perceived formal support in the community

a) Physiotherapy and occupational therapy

Many survivors received physiotherapy in hospital, in an out-patient clinic, or at home and they were overall satisfied with their therapists. Some participants reported that they had received physiotherapy and occupational therapy after they had been discharged from hospital, but the consultant determined the number of sessions, or the stroke survivor had to terminate treatment because of financial problems in accessing transport to the clinic or inability to pay for treatment at home, or limited access from their own homes to the road. Most of the participants were satisfied with their therapists who visited them at their homes and said:

'We had a physiotherapist at home. He was good. He tried to help me. He made me sit and stand. He visits me three times a week.'

Eight survivors thought that the amount of physiotherapy they received was not enough: *'The consultant decided I needed 10 sessions of physiotherapy and they terminated my treatment after that. If I could get more therapy I might improve. I feel am getting worse and worse since they terminated my therapy.'*

b) Clinics

Out-patient rehabilitation clinics were provided for stroke survivors in need of physiotherapy and occupational therapy. Survivors showed satisfaction with the rehabilitation out-patient services they received, but stated that they preferred to have their therapy at home. Only two male participants would have preferred to have their physiotherapy at an out-patient clinic:

'Physiotherapists at [named clinic] use equipment such as springs, pulleys, shoulder wheels. How can you provide these at home? They are very useful tools.'

Only one female survivor mentioned being visited by an occupational therapist (OT), and again was very pleased with their services: *'[Named OT] was very good. She helped me to move my fingers and showed my daughter how to help me dressing and undressing because I have shoulder pain.'*

When asked about follow-up after discharge from hospital, all survivors responded that there were no follow-ups at all from their doctors or other health professionals after treatment had stopped. They also reported that no explanation as to why the help was stopped, was ever given. The following comment sums up their feelings: *'When I was discharged from [named hospital] after four weeks they referred me to a physiotherapist. They decided there would only be 10 sessions for me, so now we have to find a private physiotherapist.'*

Some survivors reported positively on the support received by rehabilitation physicians in the clinics. For example, one male survivor said: *'[Named physician] examined me, looked at my standing and my walking and referred me to the pathology lab for further tests.'*

Other nine participants were dissatisfied with the interaction with their physicians: *'He didn't touch me or examine me. He was busy chatting with others about other issues, and he said 'OK, we will give you 10 physiotherapy sessions.'*

All the survivors reported that they had to visit the hospital again to see their consultant for a review, and many were dissatisfied with and discouraged by the way they were treated: *'The clinic was so crowded with no privacy and in his clinic there was no chair available for me to sit on.'*

c) Community clinic services

All survivors reported that they had community clinics in the area where they lived and that they used the general practitioner (GP) services in the clinic to

provide them with medication, mainly for high blood pressure and diabetes. They identified two types of community clinics: one run by the Ministry of Health; the other by non-governmental organisations ((NGOs). None of the survivors mentioned having had a home visit from a GP from the local community clinic: 'I never had any home visit by GP , I used to go to see the GP in his clinic and the GP checked my blood pressure and prescribed medication for me.'

The majority of male and female survivors reported that the GP clinics offered nothing for stroke survivors: 'The clinic in our area has nothing for my disease, no exercises, and no medical examination. They can only help you with medication or take your blood pressure.'

DISCUSSION

The study has highlighted a number of issues relating to the rehabilitation services for stroke survivors in the community. Of particular importance were the limited availability of rehabilitation services and the impact of both "material" and "non-material" culture on levels of service provision.

Availability of services

The formal support identified by survivors included existing services such as physiotherapy at home and in out-patient clinics, occupational therapy in out-patient clinics, and specialist rehabilitation clinics and consultant clinics. The majority of the survivors reported using state (government) services because all the survivors in this study were selected from state hospitals.

Survivors were satisfied with their physiotherapists, the only health professionals providing services for survivors at home in Jordan, which accords with what has been reported in other studies (16,17). The majority of both male and female survivors preferred to receive therapy at home. This preference was also reported in other studies (18,19); and for similar reasons, except in these studies travel was provided without cost. Stroke survivors in this study preferred home-based physiotherapy over out-patient physiotherapy because of transport problems and costs, and elimination of waiting time in out-patient clinics.

However, female survivors in the current study preferred to be treated at out-patient clinics rather than in their homes. One possible explanation for this preference may be that the majority of physiotherapists in Jordan are men, and in Jordanian culture women avoid being treated by men unless it is absolutely

necessary. Furthermore, female therapists work mainly in out-patient clinics and do not go into people's homes, especially if the person requiring therapy is a man. If a female survivor has no access to out-patient clinics because of transport or her economic situation and is not willing to be treated by a man in her home, then her therapy may be terminated or she may seek help from non-professional and traditional healers.

Another issue identified by survivors was that the amount of treatment received was not enough. Ten treatment sessions were seen as appropriate by doctors and physiotherapists, whatever the outcome for the person undergoing treatment. This has also been reported in studies, such as Partridge (16). She suggested that one-third of stroke survivors in her study in the United Kingdom sought additional help from private physiotherapists, because they were dissatisfied with the amount of physiotherapy provided by the National Health Service (NHS). In the Jordanian situation this limitation of treatment is part of the "material" cultural impact on services, possibly due to limited resources for health and prescriptive medical relationship between medics and rehab personnel.

None of the survivors reported receiving occupational therapy at home. However, one survivor received occupational therapy at an out-patient clinic and was content with that service. The lack of occupational services at home can be explained by the limited availability of these services in general, in Jordan. This is still a new profession and there are only a few trained OTs, mostly female, in the whole country (20). Here is seen the impact of both "material" and "non-material" culture.

Communication with health professionals

The majority of survivors had communication problems with doctors and therapists working in clinics. Partridge (16), in a study in the United Kingdom, suggested that stroke survivors were dissatisfied with physiotherapists who did not listen to them. This suggests that the problems in communication between survivors and medical staff are not limited to the Jordanian settings only.

In Jordan, doctors' name badges are written in English and the medical records, including discharge notes which are designed to give information to affected persons, are in English rather than Arabic. This confuses the affected persons and may lead to poor communication between them and the staff, as well as denying them access to important information. It is also likely that the affected persons and their families are not involved in decisions relating to their treatment.

The importance of this involvement has been demonstrated in other studies (21,22). Partridge (16) also suggested that good communication was seen by therapists as essential for establishing a good therapeutic relationship.

Impact of culture on the provision of rehabilitation services

In any culture, there are both positive and negative features. The majority of Jordanians are Muslims and the influence of Islam affects every aspect of society.

Gender issues: From the findings of this study, gender issues demonstrated a substantial impact on the provision of rehabilitation services, in particular for women with stroke. Survivors consistently agreed that there was clear discrimination against women survivors of stroke.

Customs around physical contact between men and women in Islam influence the care given to female stroke survivors in Jordan. In general, only male therapists work with survivors in their homes in Jordan, so the therapy available to women survivors in their homes will be limited, resulting in the treatment being terminated or the affected person seeking help from traditional healers. In either case, the possibility of further complications or the slowing down of progress is possible. Women with disabilities face less favourable treatment than men in the same situation. There is an urgent need to address the implications of gender issues in Jordan, to identify unmet needs and to change cultural attitudes. One way of improving the situation of women with disabilities could be by increasing the number of female therapists and making it possible for them to work in the community.

Limitations

Necessary measures were taken to ensure the accuracy, reliability and validity of the data collection and analysis. However, for a number of reasons the findings of this project must be interpreted with caution.

The purposive sampling procedures applied in this study decrease the generalisability of the findings. All participants were selected from the city of Amman. A further study involving a sample of participants from other parts of Jordan might lead to different findings. Additionally, stroke survivors were selected from in-patient hospital medical records so the study excluded up to 40 per cent of possible participants who were not admitted to hospital (23). The study also excluded up to 30 per cent of potential participants by not including persons with severe dysphasia (24).

CONCLUSION

The current study was unique and elicited a new body of evidence about the life experiences of Jordanian stroke survivors after discharge from hospital. The findings from this study will inform service providers and planners about the needs of stroke survivors, and will contribute to the development of appropriate formal community care for these people. This study presents a unique contribution to knowledge relating to the experiences of stroke survivors in a developing country and also shows how rehabilitation services are very dependent on cultural contexts, cultural beliefs and practices.

The findings of this study will have some important recommendations for the provision of care services for stroke survivors both in Jordan and, more widely, in other developing countries in the region. This study has explored important issues facing health care providers - specifically physiotherapists and occupational therapists in delivery of culturally appropriate care. Thematic analysis of semi-structured interview data suggested that there are large areas of unmet rehabilitation needs for stroke survivors in the community, such as a limited availability of occupational therapy services, insufficient physiotherapy services and poor medical support. Although these findings are limited by the small, local nature of the study, trends have emerged that warrant further study.

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