Where to from here: Patients of a day hospital rehabilitation programme perceived needs following stroke

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Abstract

The loss of ability to perform routine activities can result in difficulties for the stroke patient to resume their normal lifestyle. A desire to assist stroke patients after discharge prompted this pilot study into the needs of these patients during and after a program of rehabilitation at a day hospital. A longitudinal approach was used for this pilot study. The aim of the study was to identify patients’ needs pertaining to the resumption of their lifestyle, and social and emotional well-being, that emerged during the rehabilitation programme at the day hospital, on its completion and within six months of discharge from the day hospital. The study consisted of three semi-structured interviews with ten stroke patients over a period of nine to twelve months. The semi-structured interview employed open-ended questions to collect information from the participants. The interview process sought to elicit the needs of the participants during their time at the day hospital and then after discharge. It was evident from the interviews that the needs of the participants were primarily the opportunity to practice activities which could improve physical capabilities as the physical limitations placed on the participants by the stroke affected their motivation, morale and general sense of self. The day hospital was instrumental in providing participants with opportunities to learn to ‘use’ what was functioning, and therefore help the participants improve their physical capabilities. This assisted them to regain their independence. During the interviews, participants also spoke about social and emotional needs. While they received some support from interactions with the staff and other patients at the day hospital, participants stated that mostly social and emotional support came from their families. After discharge from the day hospital participants were unable to identify specific needs which they believed the day hospital could provide.

Key words: Needs, Stroke, Discharge, Rehabilitation

Introduction

A stroke is a crisis for the individual and the family (Folden 1993; Rosenthal, Pituch, Greninger and Metress 1993). The loss of function and ability to perform routine activities that are a part of everyday life can result in difficulties for the patient resuming satisfaction with their lifestyle. The emotional and physical difficulties faced by patients and their families after a stroke have been well documented in the literature (Evans, Hendricks, Haselkorn, Bishop and Baldwin 1992; Farzan 1991; Kernich and Robb 1988). The family who is a major component of the patient’s environment can be pro-active through supporting the stroke patient in their chosen activities within the home environment (Evans, Hendricks, Haselkorn, Bishop and Baldwin 1992). However, it is recognised that the ideal contribution of the family may not be forthcoming due to difficulties which the family members, themselves may face with the changes of the abilities of the stroke patient (Farzan 1991).

Regaining independence as been cited as one of the central concerns of stroke patients (Mumma 1986). To achieve this stroke patients need to re-learn about the performance capability of their body (Doolittle 1992). Many factors have been identified as contributing to improving and optimising the physical recovery of the stroke patient, which can also impact on the emotional well being of these individuals (Evans et al 1992, p 132). Much of the literature infers that recovery is analogous to improvement in physical functioning (Hafstensoottr and Gryptdonsck 1997), yet, it should not be assumed that psychosocial rehabilitation progresses simultaneously with physical rehabilitation (Farzan 1991). While considerable benefits are forthcoming from rehabilitation and education programs and family support (Kernich and Robb 1988; Thomas 1992) research has demonstrated that it is important for the patient to be active in the decisions regarding their ongoing lifestyle (Folden 1993). If patients are to be active it is important that they identify their expectations and articulate their needs.

Background

A desire to support stroke patients in their home environment after a program of rehabilitation at a day hospital prompted inquiry into the physical, emotional and social needs of these patients. Of specific interest, were health care interventions, which nurses could provide, following the completion of the rehabilitation program, to promote patients’ physical and psychosocial well being. Whereas much research has been undertaken into the immediate physical and psychological support these individuals require, this study was particularly interested in further health care support services which could be effective for patients, particularly once they had reached an understanding of their own body’s ability, that is, when they reached close to their expected optimum level of func-
tioning (Farzane 1991). Because of the learning processes involved and evidence of a plateau phase when recovery slows, researchers have expressed a need for further longitudinal studies to learn more about the long term progress of these individuals and their accompanying expressed needs and desires (Pasqurello 1990).

The staff of the day hospital was aware of the literature discussing social loneliness, isolation and depression (Astrom, Adolfsen and Asplund 1993; Whitney, Burns, Frederic and Lowery 1994) and was keen to introduce measures physical and/or social and emotional that they believed could assist these individuals. The staff was aware that during the period at the day hospital patients had the opportunity to learn and practice skills and to communicate with staff and other patients. The staff was particularly interested in whether stroke patients favoured the development of a support group for companionship and to talk and learn further about adjustments imposed by the stroke. Social support has been reported as having a positive impact on recovery of functional status following stroke (Glass, Malchat, Belyea, and Feussner 1993).

Aim

The aim of the study was to identify patient's physical, emotional and social needs on return to their home environment at the completion of a period of rehabilitation and six months afterwards.

Method

This longitudinal pilot study consisted of three semi-structured interviews with ten stroke patients over a period of nine to twelve months. The interviews were conducted with patients firstly, when they were discharged from an acute care facility and commenced at the day hospital, secondly, at the completion of the rehabilitation programme and, finally, approximately six months after they had been discharged from the day hospital to their home environment. A semi-structured interview using open-ended questions was employed to collect information. The open-ended questions were directed to learn more about the needs of these patients, that is, what they believed could assist them following completion of the program and on their discharge. Approval for the study was sought from the relevant ethics committee of the hospital.

Sample

Patients selected for the study were ten stroke patients who fitted the eligibility criteria and who started at the day hospital within two months of the study commencing. The inclusion criteria were: diagnosis of stroke; admission to a rehabilitation programme; ability to speak English; and no cognitive dementia. Cognitive dementia was assessed by the mini-mental exam (MMSE) consists of 11 items that are summed to create a mental score (Folstein, Folstein, McHugh 1988). A score from 0 to 30 is obtainable. The score of twenty is typically used as a cut off for grouping subjects as having or not having cognitive impairment (Folien 1993 p.164). The mini-mental state for the participants ranged from 22 to 30.

All the participants approached consented to partake in the study. The mean age of the sample was 69.2 years. There were five males and five females in the study. All lived in their own home and received support from family, government and/or community groups. Participants had a fair degree of independence when at home thereby able to manage by themselves with support.

Data Collection

This pilot study consisted of three semi-structured interviews with ten stroke patients over a period of nine to twelve months. Stroke patients were approached within the first three weeks of admission to the rehabilitation program at the day hospital and asked whether they would be willing to discuss their needs that would promote their well being. Participants were assured that their responses would be kept confidential and that they could decline to participate in the interview process at any time.

The first interview was undertaken within the first three weeks of each participant's commencement of the rehabilitation program at the day hospital (this was after a period of admission as an inpatient when the participant was first diagnosed with stroke). The second interview was undertaken within the last few weeks of the rehabilitation program and the third interview approximately six months after completion of the program.

The first and second interviews were conducted face-to-face with patients during their routine visits to the day hospital. The interviews were conducted in a quiet location separate from the activities of the day hospital. The open-ended questions were written on the interview schedule that the interviewer read to the participants. The participants' responses were recorded in note form on the interview schedule. The interviews typically ranged from half an hour to one hour depending on the degree to which participants wanted to elaborate on and clarify their responses. In the first two interviews information was obtained about participants needs.
to promote their well being. The first question was directed to start the participant talking about the stroke and asked "How has the stroke affected you?". This was perceived to be important because it gave insight into their situation and provided a background for the needs that the participants were encouraged to discuss. The following questions focused on what the participants hoped to achieve and what they anticipated their needs were to achieve these goals. Participants were encouraged to talk about possible emotional and social support as well as their physical needs. In order to learn about what they wanted to achieve participants were asked questions about what they enjoy; 'how did they prefer to spend their time', 'what was important to them' and what did they like doing'. To learn about what participants anticipated their needs were to achieve these goals, they were asked about the limitations that presently stop them from partaking in their chosen activities. The interview focused on the limitations and patients' needs to 'get around' the problem.

The questions asked in the second interview were similar to the first interview, namely, what the participant hoped to achieve and what did they believe their needs were to achieve this, as the aim of the second interview was, similar to the first interview, namely to identify the participants needs. The final interview conducted over the phone was approximately six months after discharge from the day hospital. The interviews were conducted to further identify if the day hospital could be of assistance to the participants, in particular, if they could specify needs and interventions that were not previously realised prior to their discharge from the day hospital. As participants generally did not describe their circumstances at home as problematic these interviews were often only ten to twenty minutes. Data obtained from the interviews were grouped into themes.

Results

During the first interview when participants were asked how the stroke had affected them, all the participants chose to focus on the limitations imposed by the stroke. Some of these restrictions were described as follows:

"Life is very different; my daily routine is disturbed; my concentration is short and I now need to lie down".

"I do not use my right hand" and "I would like to know ways of getting around using my right hand".

"I cannot straighten my right arm and I am unable to use a knife".

Eight of the ten participants at the first interview spoke about how it affected their morale: One woman, who took much pride in the cleanliness of her home, became quite depressed as she was unable to clean as much as she would like "because of the disability of my arm I am unable to do the house work; it gets me down", one man who was the full-time carer for his wife became very disappointed when he found that he could no longer undertake this role: "The stroke has contributed significantly to my loss of independence - I am no longer able to care for my wife who is almost blind...", another man who was still active in the workforce prior to the stroke was concerned because he was no longer able to enjoy his trade, ceramic tiling, he stated, "It is frustrating not to be able to pick up things and use my left hand; ultimately I wish to return to tiling"; a further participant said that he "felt like an invalid because he was unable to care for himself...", while another said "I know I just can't do things. I have lost motivation...".

One woman who realised she could not return to the things that she enjoyed stated that she "would like to learn a new hobby, for example, sewing"

At this first interview all the participants stated that one of their major needs was to regain some degree of function - whether it be to resume previous function or whether it was to learn alternate ways to achieve what they could previously achieve. All the participants felt that the day hospital was assisting them to achieve this, their greatest need. As one participant stated "further therapy was the best thing to assist him now". At this first interview participants were focused on resuming functional ability and seldom expressed other needs.

At the second interview the positive contribution of the day hospital to fulfill the existing needs of the stroke patients was evident. It was obvious through comments such as:

"With my time at the day hospital my function has improved..." and "I like coming to the day hospital as I am able to practice doing things".

One man stated he was impressed with his time at the day hospital because he had learnt "...how to transfer from furniture and to handle equipment". This opportunity was very important in helping him "...return to normal...".

The woman concerned about undertaking housework was feeling much relieved as she gradually learnt how to attend to housework. From her teaching at the day hospital she was learning ways to position herself to undertake tasks, for example, sitting to clean the bathroom etc.

In relation to their ongoing needs participants discussed in the second interview that they would be
satisfied if they were able to achieve a "reasonable level of functioning". This reasonable level seemed to be determined by them being able to enjoy activities to they pursued prior to the stroke or discover new activities that provided similar enjoyment.

All participants during the second interview indicated that there had been an improvement in their functioning while they attended the day hospital. This improvement was significant in raising their self-esteem. On leaving the day hospital some of the participants felt robbed of the opportunity to continue practising and improving their capacity to undertake activities that assisted toward their independence. During this second interview six of the participants spoke of the advantages of meeting up with other people at the day hospital, however, their prime need, which was met, was the opportunity to practice and improve skills for everyday living. Over half the participants spoke about either social or physical isolation and their need for interaction with significant others. When discussing these emotional concerns participants spoke primarily of their extended family. Usually it was a spouse or son or daughter who accommodated these needs.

Most of the participants when questioned about the usefulness of a type of support group did not consider it a high priority. Some participants said, possibly, while others felt more comfortable receiving support from family and close friends. This was the case for all, except one younger participant who had very little family support; she clearly expressed a keen desire for a support group. Alternatively, one participant stated that he "...will miss people when he goes however if does not really wish to come back; unless of course, it was absolutely necessary".

When participants were asked about further needs to achieve their desired goals they were not able to clearly express their needs rather they talked about what was presently fulfilling their needs. During the discussions patients inferred that on discharge the facilities that they required would be in place and they would no longer need assistance from the day hospital.

The third interview conducted over the phone approximately six months after completion of the rehabilitation program asked the participants about their needs subsequent to their discharge. In particular, needs they believed could be fulfilled by the day hospital. The participants were asked again about whether they would be interested in a support group.

Only six of the ten participants could be contacted by telephone six months later. Although phone numbers were obtained at the outset of the research participants circumstances changed. The difficulty in contacting patients could possibly be attributed to alternate living arrangements to accommodate lifestyle changes necessitated by the patient’s condition. This is similar to other studies of stroke patients that have reported high dropout rates. One reason has been the fragility of the population (Mann, Hurten, Tomita, Charvat 1995, p.64).

The participants during the follow-up telephone interview generally described their ongoing lifestyle as satisfactory. They expressed gratitude for the opportunity to learn skills, particularly from the Occupational Therapist and Physiotherapist at the day hospital and most of them explained how they believed it was important for them to continue practising skills. However, the six participants who could be contacted, six months later, did not believe they had any needs that could be provided by the day hospital. Participants spoke of family and other networks that were able to cater for their needs. While one participant said she would be interested to hear if something was "going on" she did not believe it was necessary for her to continue well being.

During this third interview all patients stated that they had accommodated to the limitations imposed on them by the stroke. While some accommodations were possible through a change in how tasks were performed, other accommodations involved help from community agencies. In either case participants believed their needs were being met.

Limitation

As the sample size in this study was small, the results are limited in their generalisability. It was a specific sample who prior to the rehabilitation programme were identified as being able to function in their own home. Also, the participants were appreciative of what had been done for them. Often such a population group who is appreciative of the service provided is not attuned to requesting services or alternatively is not knowledgeable about opportunities available to them.

The use of the telephone as the medium for communication during the third and final interview possibly limited the quality of the information obtained. It was difficult to draw on non-verbal cues and encourage the participants to be expressive when the researcher is not face-to-face with the participants.

Conclusion

The results from this study indicate that overall participants needs were being met through the activities of the day hospital. In particular, patients appreciated the opportunity to learn about
how to perform routine tasks with the imposed limitations of the stroke and to practice these tasks. All of the participants were able to learn tasks so as to function with a reasonable degree of independence. With the acquisition of independence patients believed that their needs had been fulfilled. After discharge from the day hospital patients were unable to articulate any specific needs. Patients spoke about being grateful for the opportunity afforded to them. That is, the opportunity to learn and practice skills, however they believe it was their responsibility after discharge to maximise their situation. The participants from this study indicate that the present operations of the day hospital are satisfying patients needs. This finding maybe a result of the degree of success in facilitating the participants in returning to a reasonable level of function. It needs to be acknowledged that a different group of stroke patients whose satisfaction with their ongoing lifestyle was not as great may desire further input of services from the day hospital.

The discussions with the participants in this study suggest that the period of rehabilitation at the day hospital provides an excellent period of transition for patients. While attending the day hospital patients are able to adjust slowly to their home circumstances with continued input from health professionals. Accordingly, they can gradually identify and cater for their needs. This interim phase enables patients to organise both physical and emotional support from both formal and informal sources to facilitate enforced lifestyle adjustments. It was possibly because of the participants’ resourcefulness during this period that they believed that they had no further needs with which the hospital could assist them.

References


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