Clients with stroke and non-stroke diagnoses and their guardians’ views on community reintegration status after in-patient rehabilitation

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Abstract

The aim of this study was to compare client community reintegration status following discharge from the Kachere Rehabilitation Centre (KRC), Blantyre, Malawi, in 2 consecutive years with clients versus guardian perspectives on reintegration status.

Methods

Using quantitative methods, 35 clients with stroke and non-stroke diagnoses (spinal cord dysfunction and neuropathic conditions) and 32 client guardians (the family caregivers in Malawi) were separately interviewed using the WHO Disability Assessment Schedule (WHO-DAS) 2.0 (a measure of disability due to reintegration problems back into the community). The results were analyzed using descriptive statistics and the Wilcoxon Signed-Rank Test or the Mann-Whitney U Test, as appropriate, to test for significant differences between groups. The clients’ home environments were categorized using an original checklist, the Home Observation Data Form (HOD).

Results

Moderate to severe perceived levels of disability related to reintegration difficulties were noted by clients in years 1 and 2. For those with non-stroke diagnoses, there was a significant change in year 2 results compared to year 1, but not for those with stroke diagnoses. Guardians agreed with their client’s perceptions of difficulty in year 2. Most areas of clients were taking care of household responsibilities, participating in day-to-day work or school routines, joining in community activities, and walking one kilometer per day.

Conclusions

Community reintegration challenges in suburban Blantyre, Malawi continued to plague individuals with stroke and non-stroke diagnoses for 2 consecutive years after discharge from KRC. Based on the important role guardians play during their client’s rehabilitation phase and when they return to the community, opportunities may exist to improve client perception of disability related to their reintegration status. Future studies are important to replicate these results, investigate the idea of a more important role for guardians in patient-centered care, and the relationship between motor and cognitive function and reintegration status.

Key words: stroke, spinal cord dysfunction, community reintegration, client and guardian views, Malawi

Introduction

Studies of discharged clients with neurological conditions from rehabilitation programs in the low resource countries of Nigeria, India, and Nepal reported significant community reintegration problems2-4. These problems included participation in community life1,11,12, inability to access basic needs such as food, housing, and health care. Similarly, moderate to severe levels of disability due to problems with community reintegration were noted by clients from the Kachere Rehabilitation Centre (KRC) in suburban Blantyre, Malawi, in recent years.13 Their reported difficulties were in completing tasks and responsibilities in the home and daily living routine, returning home to their former communities. They serve for varying periods of time, dependent on their client’s medical condition and sequelae and, perhaps, other social, emotional, and cultural factors. Guardians are generally female, in their late 30s, and have a close family relationship with the client (child, spouse, or parent). They have a low literacy rate and, are, generally, tenant farmers or entrepreneurs prior to their caregiver role.

Guardians provide and/or assist with a broad range of personal and self-care tasks in the formal health setting: specific medical tasks such as medication management, implementation of care instructions, and offer social-emotional support during the entire length of their client’s hospital stay and beyond within the community. They were observed to literally “live” within the specific health setting, sleep on or underneath their client’s bed, wash their clothing, and prepare and eat meals in designated areas of the hospital property. Guardians are readily available to provide daily-to-day self-care and other needs, with minimal preparation and no compensation. In the rehabilitation setting, guardians were observed to function as the client’s caregiver and family members, performing balance and mobility training, wheelchair activities, muscle strengthening, joint mobilization, self-care and personal hygiene, and simple meal preparations. In the home setting, guardians were observed to continue to assist with and provide assistance of health and daily living activities (personal needs, housekeeping, shopping, and transportation); social-emotional support is expected. Guardians attempt to fill the gaps created by their client’s medical status and help to reintegrate them back into the community. This role appears accepted as a fact of life, without question and/or the expectation of compensation. However, providing the frequently intensive strenuous and long-term support as a guardian, particularly for clients with stroke, traumatic spinal cord injury, and HIV and AIDS, adds another dimension to the life of the guardian and their relationship with their client.

The objectives of this study were to compare client perceptions of disability related to community reintegration status over 2 consecutive years and to compare client versus guardian views. In the year 1 study, there were moderate to severe perceptions of disability from environmental barriers (“narrow passageways within, surrounding, and leading to their homes, rough and hilly terrain, water sources outside the home, lack of cars, and long distances to markets and places of worship”). The current study objectives were to compare community reintegration status in the second year with reintegration status in the prior one to identify similarities and differences between the results, looking for changes over time. Interviewing guardians, who work closely with their clients during the in-patient rehabilitation phase, and post discharge, could verify or refute client perceptions, and add to the body of reintegration literature. These guidelines could also potentially provide more detail about the specific client challenges and offer potential strategies to optimize the situation.4-5 No published studies have been noted on guardian views of reintegration status to date.

Study sites and ethical approval

Following up on clients interviewed in year 1 and a new cohort of clients interviewed in year 2, every effort was made to re-interview the cohort of clients interviewed in year 1. The clients that were not re-interviewed had either died, moved from the area, or were not available.

Using a consecutive sampling approach, a cohort of new clients in year 2 was identified from a population of 20 discharged rehabilitation clients, who met the protocol’s inclusion criteria. For clients in year 2, the guardian, if available and willing, was also interviewed, according to the study protocol. There was no control group in this study. There was a total of 36 clients interviewed (22 males and 14 female) in year 2, ranging in age from 27 to 91 years, with a mean age of 55 years. There were 19 clients with stroke diagnoses, 16 had non-stroke diagnoses and 1 diagnosis was unknown (Table 2). From the original year 1 cohort, 32 clients were re-interviewed. There was a total of 32 guardians of varying ages who were interviewed. The year 2 cohort were in their late 30s, and have a close family relationship with the client (child, spouse, or parent). They have a low literacy rate, and, generally, tenant farmers or entrepreneurs prior to their caregiver role.

Table 1: Inclusion and exclusion criteria (Year 2)

| Inclusion Criteria | Exclusion Criteria |
|-------------------|-------------------|
| Over the age of 18 | Women of child-bearing age who by self-report state they are pregnant or under 18 years of age |
| Diagnosis of a neurological dysfunction at time of discharge from Kachere Rehabilitation Centre | Epileptic or expressive aphasia at discharge from Kachere Rehabilitation Centre per the healthcare record |

Table 2: Gender and diagnoses in sample at Year 2

| Stroke Diagnoses | Non-Stroke Diagnoses | Unknown | Total |
|------------------|----------------------|--------|-------|
| Male             | 10                   | 11     | 22    |
| Female           | 9                    | 5      | 14    |
| Total            | 19                   | 16     | 35    |

Interviews

This research used quantitative methods for data collection from 2 instruments: (1) The WHO DAS 2.0 (World Health Organization Disability Assessment Schedule)2 provided

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Table 3: DAS 2.0 key questions with scoring key (Years 1 & 2)

Table 4: Home observation data (HOD) form categories, descriptors, and results for 13 client homes (Year 2)

Table 7: WHO DAS Scores in years 1 and 2 for clients with non-stroke diagnoses

Table 8: WHO DAS Scores for clients and guardians in year 2 (Using Mann-Whitney U Test)

Discussion

These results support the sparse number of prior studies in low resource communities within and outside Malawi on community reintegration problems, primarily due to environmental barriers. While motor function may have been a factor in other studies and clearly very important to the level of client independence and skills in performing reintegrative activities, this factor was beyond the scope of this study. However, the WHO DAS 2.0 demonstrated its potential efficacy. The WHO DAS 2.0 was designed as an observation tool to provide subjective measures that are consistent with the client's own perceptions of disability. The tool measures the impact of disability on the client's daily activities, and it can be used to monitor the progress of clients over time. The WHO DAS 2.0 also provides a standardized method for comparing disability levels and identifying the areas of greatest need for intervention. Additionally, the tool is adaptable to different cultural contexts, making it a valuable tool for assessing disability in diverse populations. Given the importance of community reintegration, it is crucial to continue researching and developing tools like the WHO DAS 2.0 to better understand and address the challenges faced by individuals with disabilities in Malawi and other low resource communities. Future research should focus on implementing and evaluating interventions to improve community reintegration in these settings.
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Conflicts of interest
The authors state no conflicts of interest in this research or for the development of the manuscript.

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