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

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Abstract

Aim
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 client 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 (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. Major areas of concern 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 problems¹⁻⁴. These problems included participation in community activities¹ and in family life², no accessible toilet or water source (unavailable within the home or difficult and or impossible to access outside the home, inadequate housing, and rugged terrain³. 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.^{5,6} Their reported difficulties were in completing tasks and responsibilities in the home and daily living routine, returning to work, accessing toilet and water sources, making friends, and participating in community activities^{5,6}. For some clients, leaving their home environment after KRC discharge was either impossible or required maximal assistance^{5,6}.

In Malawi, a low resource country of over 19 million people⁷ in southeastern Africa, guardians are devoted family members, who voluntarily provide multiple physical and psychological supports to their client within the medical setting and upon

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)⁸. They have a low literacy rate and, are, generally, tenant farmers or entrepreneurs prior to their caregiving roles⁸.

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 community⁸. 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 day-to-day self-care and other needs, with minimal preparation and no compensation. In the rehabilitation setting, guardians were observed to function as therapy extenders who reinforced 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 or provide aspects 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 client⁹⁻¹⁴.

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")⁵. The current study objectives were to compare community reintegration status in the second year with reintegration status in the prior one⁵ 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 guardians could also potentially provide more details about the specific client challenges and offer potential strategies to optimize the situation^{8,15,16}. No published studies have been noted on guardian views of reintegration status to date.

The study hypotheses were: (1) Clients with stroke and non-stroke diagnoses would perceive moderate to severe levels of disability in performing tasks related to community reintegration status over 2 consecutive years, (2) There would be no difference between client perceptions of community reintegration status in year 2 and client perceptions of community reintegration status in year 1 using the same study tools, and (3) Guardian perceptions of client community reintegration status would significantly differ from their client's perceptions in year 2.

Methods

Study sites and ethical approval

The study was conducted within client homes in suburban Blantyre in July 2014 (year 1)⁵ and July 2015 (year 2). The Institutional Review Board (IRB) at the University of Maryland, Baltimore, US, and the College of Medicine Research Ethics Committee (COMREC) in Malawi approved these studies both years.

Recruitment and enrollment

Following up on clients interviewed in year 1 and a new cohort of similar clients, the populations were clients with stroke (mainly non-hemorrhagic) and non-stroke (complete and incomplete spinal cord dysfunction due to trauma, tumor, spinal tuberculosis, Guillain-Barre Syndrome, and unknown causes), discharged within the prior two years from KRC. Sample size was determined by client availability from the chosen population, based on the year 2 inclusion and exclusion criteria (Table 1). For comparison purposes 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 all client visits 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, 22 clients were re-interviewed. There was a total of 32 guardians of varying ages who were interviewed. There were 4 clients who did not have a guardian present at the time of the interview.

Pre-morbid client occupations were farmer, student, government worker, labourer, entrepreneur, and teacher. However, many reported unemployment due to their "health condition." After rehabilitation, a few clients were able and motivated and or willing to continue running their own businesses, either partially or completely (particularly, "back-yard" farming).

Table 1: Inclusion and exclusion criteria (Year 2)

Inclusion Criteria
Over the age of 18
Diagnosis of a neurological dysfunction at time of discharge from Kachere Rehabilitation Centre
Discharged from Kachere Rehabilitation Centre more than 30 days prior to the client home visit
Able to understand the qualified interviewer/translator's (Study team leader will prescreen for this criteria)
Able to respond verbally to the qualified interviewer/translator's questions (Study team leader will pre screen for this criteria)
Lives within the designated Blantyre travel area – within 2 hours from home base for transportation considerations
Exclusion Criteria
Women of child-bearing age who by self-report state they are pregnant or suspect they might be pregnant
Expressive or receptive aphasia at discharge from Kachere Rehabilitation Centre per the healthcare record

Table 2: Gender and diagnoses of sample in Year 2

	Stroke Diagnoses	Non-Stroke Diagnoses	Unknown	Totals
Male	10	11	1	22
Female	9	5	0	14
Total	19	16	1	36

Interviews

This research used quantitative methods for data collection from 2 instruments: (1) The WHO DAS 2.0 (World Health Organization Disability Assessment Schedule)¹⁷ provided

quantitative data about perceptions of disability related to community reintegration status; and (2) An original Home Observation Data form (HOD)¹⁸ provided quantitative information about the nature of the home setting, which affects reintegration. Clients and their guardians were interviewed by an appropriately trained and qualified translator in the client’s home for the WHO DAS 2.0 and HOD. The interviews were conducted in separate rooms without any possibility of the guardians overhearing the answers of the clients and vice versa. They were delivered in English or *Chichewa* (the native dialect), according to the preference of the interviewee.

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

Item	During the past 30 days, how much difficulty did you have in:
S1	Standing for up to 30 minutes?
S2	Taking care of household responsibilities?
S3	Learning a new task, for example, getting to a new place?
S4	How much of a problem in joining in community activities?
S5	How much have you been emotionally affected by your heath?
S6	Concentrating on something for 10 minutes?
S7	Walking a long distance, such as one kilometer?
S8	Washing your whole body?
S9	Getting dressed?
S10	Dealing with people you do not know?
S11	Maintaining a friendship?
S12	Your day-to-day work/school work?

The WHO DAS 2.0 has 12 key questions, in addition to demographics and background information. It measures client perception of disability in the Activity and Participation Domains of the ICF Framework (WHO) related to performing self-care, in home and community activities (Table 3). Based on a Likert-type scale (1 to 5), 5 is the highest amount of perceived disability and 1 is the lowest. Scores range from 12-60 (least to most severe disability). The researchers designated the scores between 30 and 60 as “moderate to severe levels” of disability in year 1 and carried this parameter forward in year 2. The tool has sufficiently strong psychometric properties (validity and reliability) and has been tested with many individuals throughout the world to deem it appropriate for this study¹⁹. It was appropriate for use in Malawi due to its strong psychometrics, the prior testing process utilized by WHO, and the successful and meaningful use in year 1 of this study⁵. The HOD is an original checklist form utilized successfully in year 1 of this study (Table 4). It consists of observation categories, with assigned environmental descriptors based on the Malawi 2010 Demographic and Health Survey (MDHS)¹⁹ and the WHO DAS 2.0 questions¹⁷ The researchers observed the environment, took linear measurements, discussed the information with the guardians as needed, and completed the HOD checklist, according to the study protocol.

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

Categories	Descriptors and Results
Type of dwelling	Permanent (12); semi-permanent (1)
Floor material	Earth (1); cement (11); tile (1)
Wall material	Brick/mud (9); concrete (5)
Number of rooms	For sleeping (mean = 2.2); Others (mean = 3.4)
Number of people in home	1-8
Main sources of drinking water	Piped into dwelling (5); piped into yard (3); community pipe (1); well (1); borehole (2)
Type of toileting facility	Flush (7); pit (6)
Main sources of energy	Electricity (9); candles (1); firewood (1); charcoal (3); torch (1); lantern (1)
Household assets	Radio (8); TV (8); refrigerator (7); telephone (2); bicycle (2); car (4);, cell phone (11)
Client needs physical assistance	Yes (7); no (3)
Activities needing assistance	Self care; mobility; dressing; bathing, transportation
Person who provides physical assistance	Spouse, sibling, child, parent, paid worker
Bed nets used for malaria prevention	Yes (9); no (4)

Data analysis

The key data were collected per the WHO DAS 2.0 protocol¹⁷ and analyzed using the WINSTAT Statistics Add-In for Microsoft Excel (version 2009.1) and simple Excel calculations for the mean scores. The non-parametric Wilcoxon Signed-Rank Test was chosen to determine: the significance of the differences between the response scores: (1) For the same clients in year 1 compared to year 2, and (2) In year 1 compared to year 2 for clients with stroke diagnoses and those with non-stroke diagnoses. Use of this test assumed the following: (1) a distribution of differences between paired observations were neither normal nor symmetrical, (2) use of ordinal data, (3) paired observations that were independent of each other, (4) difference scores that were from a continuous distribution, and (5) the independent variable consisted of two related groups. The Mann-Whitney *U* Test for non-parametric statistics was chosen to determine the significance of the differences between the response scores of the clients and guardians in year 2. Use of this test made the same assumptions as the Wilcoxon except that there were two unrelated groups. The level of significance was set *a priori* at 0.05. The HOD data were summed by category.

Results

Over a 2-year period, an average of 57.1% of clients perceived moderate to severe levels of disability related to difficulties with reintegration into their home and community settings (DAS 2.0 scores between 30 and 60). This is in comparison to 60.7% in year 1⁵ of this study and 50.0% in year 2. Perceived difficulties in year 1, as in year 2, were in several key areas of activity and participation: taking care of household responsibilities, participating in day-to-day

work or school routine, joining in community activities, and walking one kilometer. Home Observation Data, particularly related to the frequent location of water sources and pit latrines outside the home, supported the WHO DAS 2.0 results.

In year 2, there was a significant relationship between the perceived level of disability and the neurological condition itself. That is, for the group with non-stroke diagnoses in year 2, there were less severe perceptions of disability but not for the group with stroke diagnoses. In both years, environmental barriers seriously impeded reintegration as reinforced by the HOD data. The need for mobility devices and/or reinforcement of training, part-time employment, and/or socializing opportunities were noted throughout the interviews. There was no significant difference in perceived disability based on WHO DAS 2.0 scores by the guardians compared to the clients, echoing client observations about the reintegration challenges from the home and community environments.

Comparing group perceived disability scores, in year 1, clients had a mean WHO DAS 2.0 score of 31.6. In year 2, their mean score was 29.0. This change was statistically insignificant (Table 5). Clients with stroke diagnoses in year 1 (n=12) had WHO DAS 2.0 mean scores of 31.2. In year 2, it was 28.5, but the difference was statistically insignificant (Table 6). For the clients with non-stroke diagnoses, comparing group scores in year 1, 10 clients had a mean WHO DAS 2.0 score of 32.1. In year 2, the mean was 29.7. This difference was statistically significant (Table 7). Comparing group scores for all clients in year 2 (n=36), the mean WHO DAS 2.0 score was 30.8, compared to the guardians (n=32) mean score of 31.4. This difference was statistically insignificant (Table 8).

This study’s results supported the researcher’s hypothesis, which stated that there would be moderate to severe levels of perceived disability related to community reintegration status over two consecutive years. There was a difference when comparing results in year 1 and 2 for those clients with stroke diagnoses, but not for those with non-stroke diagnoses. For the latter group, reintegration difficulties were noted, but the clients showed a significant improvement between years 1 and 2. Guardians agreed with their clients on perceived levels of disability in year 2 for the entire year 2 cohort.

Reintegration barriers, interior and exterior to the client homes and surrounding community, presented ongoing perceived challenges for a significant number of clients (supported by their guardians), based primarily on their “health condition (per the WHO DAS demographic list),” but also because of their home environments. In a relatively “suburban Blantyre setting,” lack of solid pathways surrounding many homes, distant and or primitive water/toileting sources (wells with pumps or pit latrines), narrow doorway entrance steps without railings, and limited or distant public transportation were frequent. Within the home, narrow doorways, lack of railings, door sills between rooms, living areas crowded with non-moveable furniture, and tiny bathrooms (when present) were not uncommon. Some client/families were sufficiently resourceful to make adaptations to the environment to meet some, if not all, of the client’s needs. For many clients, returning to their prior work was impossible due to both the client’s motor and perhaps mental status (including sadness and depression), but also due to the seemingly lack of employer support for modified or part-time work duties, or architectural adaptations to the work environment, as is

more common in developed countries for individuals who are ability-challenged. Lack of adequate personal adaptive equipment and mobility devices and limited or no local community rehabilitation follow-up services post KRC discharge compounded this situation. Wheelchair users and those clients requiring mobility devices appeared to experience greater challenges.

Table 5: WHO DAS Scores in Years 1 and 2 for same clients (Using Wilcoxon Signed-Rank Test)

	n	mean	SD
year 1	22	31.6	±12.8
year 2	22	29	±12.3

Significant difference (Z=1.98; p=0.04)

Table 6: WHO DAS Scores in years 1 and 2 for clients with stroke diagnoses

(Using Wilcoxon Signed-Rank Test)

	n	mean	SD
year 1	12	31.2	±13.4
year 2	12	28.5	±12.5

No significant difference (Z=0.98; p=0.32)

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

(Using Wilcoxon Signed-Rank Test)

	n	mean	SD
year 1	10	32.1	±12.8
year 2	10	29.7	±12.7

Significant difference (Z=0.98; p=0.02)

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

	n	mean	SD
Clients	36	30.8	±12.6
Guardians	32	31.4	±12.4

No significant difference (Z=-0.98; p=0.921)

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, this study’s researchers informally observed greater client challenges in navigating various home and community environments when using wheelchairs and/or other mobility devices, or for those clients seemingly in need of new devices or review of correct usage strategies. Guardians provided a few more details on their clients’ reintegration problems but few offered suggestions to improve the situation. The same problems were identified in both study years and by all participants in the studies.

Study Limitations

Study limitations included a small sample and one of convenience based on the study’s inclusion and exclusion criteria and timeframe, the inherent bias with a client self-assessment, the presence of depressive symptoms (particularly in those with stroke), other personal biases, and misinterpretation or misunderstandings of information and instructions (due to cognitive or emotional function, level of education, and experiences), and assumptions made with the use of the particular non-parametric test. This study did not formally address client motor or cognitive function and the potential relationship with reintegration status.

For both client groups involved in this study, the WHO DAS 2.0 provided information on their “reality,” through subjective perceptions of difficulty when engaging in various daily living activities and integration within the community. These results surprised the researchers. However, as an explanation, it is possible that clients with non-stroke diagnoses may have had spontaneous physical improvement from year 1 to year 2. While the group with stroke represented only individuals with the diagnosis of stroke, they tended to be older than the group with non-stroke diagnoses, and were perhaps beyond the optimum time-frame for rapid motor recovery. The group with non-stroke diagnoses represented individuals with inflammatory-type conditions that could improve significantly spontaneously and relatively quickly, such as paraparesis from Guillain-Barre Syndrome or spinal infections. The client-guardian agreement may have been an expression of the *reality* for both groups, and perhaps, not exaggerated by the clients as the researchers had expected.

Conclusions And Recommendations

Consideration should be given to the guardians’ role in “patient-centered” care, particularly for bridging the gap between the rehabilitation and home environments.¹⁵ Important to a complete picture for rehabilitation discharge preparation are details about the environment itself (room sizes, doorway openings, location of water sources and plumbing, barriers to access outside the home’s perimeter and beyond, etc.) and the availability of community resources. Timely and realistic attention to the potential need for home modifications, to implement modifications, or locate alternate housing arrangements, would be helpful.

Guardians would benefit from knowledge about the course and potential level of expected client recovery from the neurologic condition, the changes in personality that might accompany the condition, and setting realistic goals and expectations for the client. They may also benefit from professional social-emotional support to assist them with their new or newer role as full-time caregiver for a person with ability challenges. While this role is usually accepted in Malawi, it is not innate. For some guardians, the experience may be totally new, unexpected, unsupported, out of context, and lifelong. Comprehension of the enormity of the task is variable. However, appropriately educated, supported, and prepared guardians may provide a key to maximizing client community reintegration status and, ultimately, quality of life for both the client and guardian.

Future studies, with a larger sample, are important to replicate these results as well as to 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.

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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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