Disability Characteristics of Community-Based Rehabilitation Participants in Kayunga District, Uganda

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Abstract

BACKGROUND Approximately 80% of individuals with disability reside in low- and middle-income countries where community-based rehabilitation (CBR) has been used as a strategy to improve disability. However, data relating to disability severity among CBR beneficiaries in low-income countries like Uganda remain scarce, particularly at the community or district level.

OBJECTIVES To describe severity of disability and associated factors for persons with physical disabilities receiving CBR services in the Kayunga district of Uganda.

METHODS A cross-sectional sample of 293 adults with physical disabilities receiving a CBR service in the Kayunga district was recruited. Disability severity was measured using the 12-item World Health Organization Disability Assessment Schedule 2.0 (WHODAS2.0), and analyzed as a binary outcome (low: 0-9, high: 10-48). Inferential statistics using odds ratios were used to determine factors associated with impairment severity.

FINDINGS The mean WHODAS 2.0 score of persons with physical disabilities was 12.7 (standard deviation = 8.3). More than half (52.90%) of people with physical disabilities reported a high level of functional impairment. Increased disability severity was significantly associated with limited access to assistive devices (adjusted odds ratio [AOR] = 4.55, 95% confidence interval [CI]: 1.87-14.08, \(P < .001\)), and increased use of medical health care (AOR = 5.55, 95% CI: 1.84-16.79, \(P = .002\)).

CONCLUSION These findings suggest a high level of moderate to severe functional impairments in persons with physical disabilities receiving CBR in Kayunga district. These data provide support for efforts to enhance CBR’s ability to liaise with local health care, education, and community resources to promote access to needed services and ultimately improve the functional status of persons with disabilities in low-resource settings.

KEY WORDS assistive technologies, community-based rehabilitation, disability, low-and-middle income countries, WHODAS 2.0.
INTRODUCTION

Globally, approximately 15% of the world’s population lives with some form of disability, with an estimated 1 billion people experiencing disability mostly in developing countries. In Uganda, persons with disabilities account for 19% of the population. Physical impairments represent one of the primary sources of disability in Uganda overall. In Kayunga district, physical disabilities account for 25% of all disabilities.

Since the 1970s, the World Health Organization has recognized the need for expansion of community-based rehabilitation (CBR) services in low-income countries to expand access to rehabilitation services for persons with disabilities in low- and middle-income countries (LMICs). Moreover, CBR aims to enhance the quality of life of persons with disabilities; the strategy of CBR extends beyond merely managing impairments by focusing on empowering and improving livelihoods of persons with disabilities.

The International Classification of Functioning is a widely adopted conceptual framework for disability that acknowledges the interactive nature of functional capacity, activities of daily living, social role participation, and contextual factors at the level of the person and environment. Disability is fundamentally a multidimensional construct that has implications beyond health dimensions of an individual to their experiences in the different life domains, including, physical, emotional, social, and material well-being.

Instruments such as the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) have been used to measure disability and health status based on the International Classification of Functioning framework. Indeed, several studies support use of the WHODAS2.0 as a valid and reliable measure.

CBR programs have been implemented in selected Ugandan districts, including the Kayunga district, since 1991. Services can be accessed through the districts departments of community health and authorized community-based organizations (CBOs). CBR activities implemented by CBOs for persons with disabilities in Kayunga district include training of accessibility audit teams, sensitization of stakeholders, and carrying out accessibility audits in schools and recreation activities. Because of CBR, many persons with disabilities have been successfully integrated into their communities and schools.

However, challenges remain because CBR programs in Uganda lack adequate funding at the local and national level. Additionally, despite advances in CBR in some regions of Uganda, there is still a paucity of research into the characteristics and needs of those receiving CBR services in other areas. This study sought to describe the disability characteristics and associated factors in a sample of persons with physical disabilities receiving CBR services in the Kayunga district of Uganda.

METHODS

Study Setting, Design, and Study Population. This cross-sectional study was conducted between April and May 2014 in Kayunga district, and it employed quantitative data collection methods. Kayunga district is 70 km east of Kampala, the capital city of Uganda. The district comprises 2 subcounties, Bbaale and Ntenjeru, with an urbanization level of 6.7%, indicating that a large part of the community is rural. The population of Kayunga according to the 2002 national population and housing census was 297,081 people. The study population consisted of Kayunga district residents with mobility, visual, and hearing impairments who were participating in CBR services delivered through the different CBOs in the district.

Selection Criteria. This study included persons with physical disabilities who were 18 years or older, receiving any 1 or a combination of CBR services as per the CBR matrix, and provided consent to participate in the study. We excluded persons with physical disabilities who had communication limitations, those who did not consent to participate in the study, and those who were out of the study area at the time of the study.

Sample Size Determination. Given that this was a study among a single group with the primary outcome expressed as a mean, the following formula for sample size estimation of 1 group mean was used: 

\[ n = \left( \frac{Z_{\alpha/2}}{\sigma} \right)^2 \frac{s^2}{d^2} \]

In the formula:

- \( s^2 \) = Standard deviation is 17.2
- \( d \) = Margin of error is 2
- \( \alpha \) = Probability of type I error (2-sided) = .05

\[ z_{0.025} = 1.96 \]

\[ n = \left( 1.96 \times 17.2 / 2 \right)^2 \]

\[ n = 284. \]
After adjusting for nonresponse at 10% (eg, 284 / 0.9), a total of 315 persons with physical disabilities were recruited in an attempt to reach a sample size of at least 284.

**Sampling Procedure.** A list of all disabled people’s organizations (DPOs) registered at the community department office was obtained at Kayunga district offices. DPOs with a CBR component were purposely selected. With the help of the district health office, each DPO with a CBR component was contacted to provide a list of all physically disabled persons eligible for the study. Physical addresses and contacts of selected persons with physical disabilities were also obtained from each DPO. Unique codes were assigned to each person with physical disabilities on the lists to make a sampling frame. Using a simple random sampling technique, 315 random numbers were generated and corresponding prospective participants were selected. Potential participants were approached with the help of the CBO officers and local leaders. The purpose of the study was then explained, individual consent was sought, and interviews were conducted thereafter.

**Data Collection.** The principal investigator and trained research assistants collected data using the 12-item short-form of the WHODAS2.0 and a structured questionnaire (Appendix 1) for associated factors (eg, sociodemographic variables, access to health care). These were face-to-face interviews with the selected participants. The tools were pretested to improve validity.

**Disability Measurement.** The WHODAS 2.0 was used to measure overall disability. This tool assesses functioning and disability in 6 life domains: cognitive, mobility, self-care, getting along, daily life activities, work/school activities, and participation. The 12-item version of the WHODAS 2.0 has been found to capture 81% variance of the 36-item version suitable for epidemiologic surveys and routine outcome assessments. Global disability was measured as a single composite score after simple sum scoring of the 12-item WHODAS 2.0. In responding to each item, participants were asked to estimate the magnitude of disability during the previous 30 days using a 5-point scale (none = 0, mild = 1, moderate = 2, severe = 3, extreme/cannot do = 4). The WHODAS 2.0 total score for each respondent ranged from 0 (low) to 48 (high). The overall intraclass coefficient for the measure was calculated at 0.98, indicating a high level of reliability. The WHODAS 2.0 has been validated in many countries and has had a high concurrent validity (specific domain correlations) after simultaneous administration with instruments (Short Form-36, WHO Quality of Life) measuring related constructs. Data Analysis. There is no agreed cut-point for identifying persons with significant disability, based on the WHODAS 2.0 scoring, but according to Andrews et al, persons scoring 10-48 are in the top 10% of the population distribution of WHODAS 2.0 scores and are likely to have clinically significant disability. Global disability scores were dichotomized into 2 groups, low disability (0-9 scores) and high disability (10-48 scores), and managed as a binary outcome.

Using STATA Version 10 (StataCorp, College Station, TX), bivariate and multivariate analyses were done to assess the relationship between each of the independent variables and the outcome variable. Crude odds ratios (ORs) at 95% confidence interval (CI) were calculated using cross tabulations. All variables with a P value < .2 at bivariate analysis as well as variables known to predict disability severity from the literature were used in multivariate analysis. A binary logistic regression analysis with a backward stepwise elimination method was done to determine the independent predictors of disability severity.

**Ethical Considerations.** We obtained approval from Makerere University School of Public Health Higher Degrees of Research and Ethics Committee. All the study tools were administered in a language best understood by the participants (English, Luganda, or sign language), who then provided written consent for participation in the study. To ensure privacy and confidentiality, we used unique codes on the questionnaires.

**RESULTS**

**Demographic Characteristics.** Out of the 315 sampled participants, 293 adults with a mean age of 43.2 years (SD = 16.1) participated in the study (response rate of 93%). Seven percent of the randomly selected prospective participants did not respond because they were not in the study area for the duration of the study.

Tables 1 and 2 summarize the social demographic characteristics of the respondents and other study variables. The mean WHODAS 2.0 score of the study sample was 12.68 (SD = 8.3, range 0-48). A total of 138 participants scored 0-9 (47.10%) and 155 (52.9%) scored 10-48.

**Factors Associated with Disability Severity.** Tables 3 and 4 display results of bivariate and multivariate analyses. For multivariate analysis, we used backward stepwise logistic regression to come up with
adjusted odds ratios and a model representing the independent predictors of increased disability. When factors were fitted in a logistic regression model for multivariate analysis, 100% (n = 293) of respondents were retained in the analysis. Factors found to be independently associated with an increased likelihood of reporting more severe disability after controlling for confounders were: spending 8-15 years in school (OR = 2.51, 95% CI: 1.09-5.75, \( P = .030 \)) compared with those who spent 0-7 years in school, lack of access to assistive devices (OR = 4.55, 95% CI: 1.87-14.08, \( P = .000 \)) compared with those with access, and using conventional medical health care (OR = 5.55, 95% CI: 1.84-16.79, \( P = .002 \)) compared with those who opted for traditional healers. Factors that were significantly associated with a reduced likelihood of reporting more significant disability included being widowed (OR = 0.02, 95% CI: 0.00-0.29, \( P = .005 \)), being a homemaker (OR = 0.07, 95% CI: 0.00-0.72, \( P = .024 \)), and being unemployed (OR = 0.08, 95% CI: 0.00-0.72, \( P = .05 \)).

### DISCUSSION

Disability is a global health concern that differentially affects LMICs.\(^3\) CBR provides a mechanism for providing rehabilitative services for individuals with disabilities in LMICs who would otherwise not have access to them because of health systems gaps and human resource limitations. In Uganda, CBR programs are faced with a challenge of resource allocation, whereby many CBR programs lack adequate budget allocations at the local and national level.\(^3\) Uganda’s national policy on disability does not explicitly elaborate on how interventions relating to disability will be funded,\(^9\) which makes commitment to disability interventions difficult, leading to
inequities in the health and education sectors as suggested by the present study.

The present study found that more than half of the persons with disabilities who were receiving CBR services reported significant disability as measured by the 12-item WHODAS 2.0. Our results suggest that there is significant unmet need with regard to assistive devices even among those receiving CBR. Specifically, lack of access to assistive devices was associated with increased odds of functional impairment. This is an important finding because it reflects current international initiatives aimed at realizing the promise of the United Nations Convention on the Rights of Persons with Disabilities in LMIC settings. For example, the World Health Organization has convened the Global Cooperation on Assistive Technology (GATE) with a vision to provide affordable assistive products to all who need them around the world.20 The GATE initiative aims to address challenges to assistive device access in places like the Kayunga district of Uganda by identifying potential interventions at the levels of policy, products, personnel, and service provision.

These findings also indicate that individuals experiencing significant physical disability reported higher medical utilization than those without physical disability. The CBR framework was designed to meet basic needs of persons with disabilities and their families, while promoting inclusion and participation across domains. CBR programs are not intended or able to provide specialized medical care (eg, physiatry) or advanced rehabilitative services akin to those commonly available through interdisciplinary clinics found in high-income countries. As a result, it is likely

| Table 3. Bivariate and Multivariate Analysis of Disability Severity Associated Factors |
|---------------------------------|--------|--------|--------|
| Variables                          | High (10-48) | Low (0-9) | Crude Odds Ratio (COR) 95% CI | Adjusted Odds Ratio (AOR) 95% CI | P  |
| Marital status                      |          |        |         |          |  |
| Never married                      | 28(18)  | 28(20) | 1  |          | 1   |
| Currently married                  | 81(52)  | 84(61) | 1.04 (0.56, 1.90) | .961 |
| Separated                          | 28(18)  | 25(18) | 0.89 (0.42, 1.89) | .768 |
| Widowed                            | 18(12)  | 1(1)   | 0.55 (0.00, 0.44) | .006 |
| Work status                        |          |        |         |          |  |
| Paid work                          | 3(2)    | 7(5)   | 1  |          | 1   |
| Self-employed                      | 101(65) | 104(75)| 0.44 (0.11, 1.75) | .245 |
| Nonpaid work                       | 6(4)    | 4(3)   | 0.28 (0.04, 1.82) | .185 |
| Student                            | 7(5)    | 8(6)   | 0.49 (0.09, 2.65) | .408 |
| Housekeeping                       | 14(9)   | 7(5)   | 0.21 (0.42, 1.09) | .064 |
| Unemployed                         | 24(15)  | 8(5)   | 0.14 (0.03, 0.69) | .015 |
| Years in school                    |          |        |         |          |  |
| 0-7                                | 116(75) | 81(59) | 1  |          | 1   |
| 8-15                               | 36(23)  | 51(37)| 2.03 (1.21, 3.39) | .007 |
| ≥16                                | 3(2)    | 6(4)   | 2.86 (0.69, 11.79) | .145 |
| CBR type                           |          |        |         |          |  |
| private                            | 95(61)  | 73(53)| 1  |          | 1   |
| Government                         | 12(8)   | 29(21)| 3.14 (1.50, 6.58) | .002 |
| Both                               | 48(31)  | 36(26)| 0.97 (0.57, 1.65) | .93 |
| Assistive device access            |          |        |         |          |  |
| Yes                                | 48(31)  | 19(14)| 1  |          | 1   |
| No                                 | 107(69) | 119(86)| 2.80 (1.55, 5.08) | .001 |
| Health care type                   |          |        |         |          |  |
| Traditional                        | 37(24)  | 8(6)   | 1  |          | 1   |
| Conventional                       | 115(74) | 126(91)| 5.07 (2.26, 11.33) | .000 |
| Others                             | 3(2)    | 4(3)   | 6.17 (1.14, 33.11) | .034 |

CBR, community-based rehabilitation; CI, confidence interval.
* Statistically significant (P < .005).
that specialized rehabilitative medicine care remains inaccessible to participants in the present study given known human resource and health systems limitations in the local setting. In this way, the positive relationship between disability severity and medical utilization observed in this study provides not only an indication of current functional status but also likely reflects gaps in the overall health system infrastructure. Trouble finding physicians who understand their disabilities, difficulty obtaining information about available services, and lack of clarity about referral pathways have previously been identified as specific barriers to specialized health care access experienced by persons with disabilities. This would suggest that although modern medical health care may be chosen to maintain and restore the health of persons with disabilities, existence of structural, equipment, and attitudinal barriers in the Ugandan health care settings may compromise the quality of health care that they are able to access. Such barriers may underscore our finding that traditional healers remain very commonly used by persons with physical disabilities. Furthermore, greater severity of disability has often been associated with a lower educational level. The results of this study could be interpreted to suggest otherwise. However, it is important to note that most mainstream schools in Uganda do not provide accessible information (eg, sign language, braille, or audio formats) and persons with disabilities admitted to higher education institutions may have to pay out of pocket for any communication services they need. The lack of accessible information in schools has been linked to poor literacy and high dropout rates for persons with disabilities. These challenges extend across educational levels because sub-Saharan universities rarely consider admitting students with disabilities to specific programs of their choice. Unfortunately, the present study did not directly assess the highest level of education successfully completed. However, our finding that a relatively high proportion of participants with significant disabilities reported having spent more years in school may be an indirect indicator of limitations in the local school environment’s ability to adapt and provide effective accommodations for students with disabilities.

### Study Limitations

There are several noteworthy limitations of the present study. This was a cross-sectional study that by design did not establish a causal relationship between disability severity and its determinants. The absence of a comparison sample of others without CBR support limits the ability to make inferences about CBR’s influence on disability severity. The study is also limited by its use of a self-report tool in assessing functional limitations and by having the sample restricted to those already receiving CBR. In addition, this study included only those with physical impairments. As a result, it is not representative of the general population of CBR clients, which includes a broader range of impairment domains. Furthermore, a few findings of this study contrast those commonly reported in the literature and as a result warrant a cautious interpretation. For example, we found a relationship between more years of education and increased likelihood of disability, which is not consistent with the larger body of empirical study. Additional research is needed to clarify and contextualize this discrepancy.

| Table 4. Independent Predictors of Disability Severity of Persons With Physical Disabilities Receiving CBR After Controlling for Confounders |
| --- |
| Variable | Independent Variable Category | Adjusted Odds Ratios AOR (95% CI) | P |
| Marital status | Never married Ref | | |
| | Widowed | 0.02 (0.00, 0.29) | .005 |
| Work status | Paid work Ref | | |
| | Housekeeping (maids) | 0.07 (0.00, 0.72) | .024 |
| | Unemployed | 0.08 (0.00, 0.72) | .025 |
| Years in school | 0-7 Ref | | |
| | 8-15 | 2.51 (1.09, 5.75) | .030 |
| CBR type | Private Ref | | |
| | Government | 5.12 (1.87, 14.08) | .001 |
| Use assistive devices | Yes Ref | | |
| | No | 4.55 (2.06, 10.04) | .00 |
| Health care type | Traditional Ref | | |
| | Conventional (medical) | 5.55 (1.84, 16.79) | .002 |

CBR, community-based rehabilitation; CI, confidence interval.
CONCLUSION

CBR has enhanced the availability of basic rehabilitative care in resource-limited areas. Uganda’s overall growing body of disability policies and longstanding CBR presence provide pathways to narrowing these implementation gaps. However, additional studies are required to establish the effect of CBR services on disability severity and associated outcomes. This study highlights continued implementation gaps with regard to improving overall disability among CBR beneficiaries. It is recommended that CBR organizations liaise with persons with disabilities and their allies to minimize barriers to assistive device access. Furthermore, measures should also be taken to increase successful inclusion in mainstream educational settings as Uganda strives toward realization of the rights of persons with disabilities.

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APPENDIX 1: QUESTIONNAIRE

World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) This questionnaire contains the interviewer-administered, 12-item version of WHODAS 2.0.

Section one: Face sheet

| F.1 | Respondent identity number |
| F.2 | Interviewer identity number |
| F.3 | Assessment time point (1, 2, etc) |
| F.4 | Interview date | Day........ | Month............. | Year.......... |
| F.5 | Living situation at time of interview | Independent in community 1 | Assisted living 2 | Hospitalized 3 |

Section 2: Demographic and background information This interview has been developed to better understand the difficulties people may have due to their health conditions. The information that you provide in this interview is confidential and will be used only for research. The interview will take 5-10 minutes to complete.

Even if you are healthy and have no difficulties, I need to ask all of the questions so that the survey is complete. I will start with some background questions.

| A.1 Record sex as observed | Male 1 | Female 2 |
| A.2 How old are you now? | Years............. |
| A.3 How many years in all did you spend studying in school, college or university? | Years............. |
| A.4 What is your current marital status? (Select the single best option) | Never married 1 | Currently married 2 | Separated 3 | Widowed 4 |
| A.5 Which describes your main work status best? (Select the single best option) | Paid work 1 | Self-employed 2 | Non-paid (volunteer or charity) 3 | Student 4 | Keeping house/homemaker 5 | Unemployed (health reasons) 7 |
Section 3: Measuring disability severity: WHODAS 2.0 12 item coded questions (example of filled questionnaire with hypothetical scores)

| In the past 30 days, how much difficulty did you have in: | None | Mild | Moderate | Severe | Extreme or cannot do |
|----------------------------------------------------------|------|------|----------|--------|---------------------|
| S.1 Standing for long periods such as 30 minutes?         |      |      |          |        |                     |
| S.2 Taking care of your household responsibilities?       |      |      |          |        |                     |
| S.3 Learning a new task, for example, learning how to get to a new place? |      |      |          |        |                     |
| S.4 How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can? |      |      |          |        |                     |
| S.5 How much have you been emotionally affected by your health problems? |      |      |          |        |                     |
| S.6 Concentrating on doing something for ten minutes?      |      |      |          |        |                     |
| S.7 Walking a long distance such as a kilometre [or equivalent]? |      |      |          |        |                     |
| S.8 Washing your whole body?                              |      |      |          |        |                     |
| S.9 Getting dressed?                                      |      |      |          |        |                     |
| S.10 Dealing with people you do not know?                 |      |      |          |        |                     |
| S.11 Maintaining a friendship?                            |      |      |          |        |                     |
| S.12 Your day-to-day work/school?                         |      |      |          |        |                     |

WHODAS disability score = sum of scores.
NB: *Scale of 0 (none) to (extreme or cannot do), *Range of scores: 0 to 48.

Section 4: Other determinants of disability severity of persons with physical disabilities receiving CBR

a. Type of impairment?
   1. Mobility
   2. Visual
   3. Hearing
   4. Other specify ...........................................

b. Nature of impairment?
   1. Spinal cord injury
   2. Amputation
   3. Cerebral palsy
   4. Musculoskeletal injury
   5. Other specify.................................

c. Cause of impairment?
   1. Congenital
   2. Disease
   3. Road traffic
   4. Other specify.................................

d. What type of CBR organization do you receive care from?
   1. Private / NGO
   2. Government CBO
   3. Both private and government
   4. Other, specify........................................

e. Have you had any form of vocational training?
   1. Yes
   2. No

If yes, what type of training? .........................
f. Are you a member of any community development group that provides you with any form of assistance?
   1. Yes
   2. No

   If Yes, specify .................................................................

g. Do you find ease receiving medical treatment from the community health facilities?
   1. Yes
   2. No

   If not, why? .........................

h. What type of health care do you often seek?
   1. Traditional medicine
   2. Conventional medical treatment
   3. Other specify.................................

i. Do you have access to any form of assistive devices?
   1. Yes
   2. No

j. Do you get support from any of your family members?
   1. Spouse and children
   2. Parents / guardians
   3. Other relatives
   4. None
   5. Other specify.............

k. What is your family size (number)? .........................

l. What type of rehabilitation therapy do you access?
   1. Physiotherapy
   2. Occupational therapy
   3. Counselling
   4. None
   5. Other specify ......................

m. Have you been assigned to a CBR worker?
   1. Yes
   2. No

n. How often are you visited by a CBR worker?
   1. Daily
   2. Monthly
   3. Weekly
   4. Other specify ......................
APPENDIX 2: EXAMPLE OF WHODAS2.0 SIMPLE SUM SCORING METHOD

| In the past 30 days, how much difficulty did you have in: | None | Mild | Moderate | Severe | Extreme or cannot do |
|----------------------------------------------------------|------|------|----------|--------|---------------------|
| S.1 Standing for long periods such as 30 minutes?          | 0    | 1    | 2        | 3      | 4                   |
| S.2 Taking care of your household responsibilities?       | 0    | 1    | 2        | 4      |                     |
| S.3 Learning a new task, for example, learning how to get to a new place? | 0    | 1    | 2        | 3      | 4                   |
| S.4 How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can? | 0    | 1    | 2        | 3      | 4                   |
| S.5 How much have you been emotionally affected by your health problems? | 0    | 1    | 2        | 4      |                     |
| S.6 Concentrating on doing something for ten minutes?      | 0    | 1    | 2        | 3      | 4                   |
| S.7 Walking a long distance such as a kilometre [or equivalent]? | 0    | 1    | 2        | 3      | 4                   |
| S.8 Washing your whole body?                              | 0    | 1    | 2        | 4      |                     |
| S.9 Getting dressed?                                      | 0    | 1    | 2        | 3      | 4                   |
| S.10 Dealing with people you do not know?                 | 0    | 1    | 2        | 4      |                     |
| S.11 Maintaining a friendship?                            | 0    | 1    | 2        | 4      |                     |
| S.12 Your day-to-day work/school?                         | 0    | 1    | 2        | 3      | 4                   |

WHODAS score (0-48 scale) = sum of scores =12.

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