



Contents lists available at ScienceDirect

Disability and Health Journal

journal homepage: www.disabilityandhealthjnl.com

Caregiving for Uganda's elders with disability: Using cross-sectional surveillance data to identify healthcare service gaps in low- and middle-income settings

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ARTICLE INFO

Article history:

Received 7 June 2017

Received in revised form

22 December 2017

Accepted 27 December 2017

Keywords:

Caregiving

Elderly

Disability

Low-and-middle-income countries

Uganda

ABSTRACT

Background: Disability is highly prevalent in low-and-middle-income countries (LMICs), but there is a relative dearth of disability and caregiving research from LMICs.

Objective: To examine type and severity of disability experienced by individuals 60 years and older, caregivers and type of caregiving assistance, and the interrelationships between sociodemographic factors involved in Uganda.

Methods: Data was collected from two Eastern Ugandan districts using the WHO Disability Assessment Schedule 2.0. Data on availability of caregiver was analyzed for 816 participants with disability. Group comparisons and regression analyses examined differences based on caregiver availability.

Results: Approximately 66% of individuals with disability had a caregiver. The mean age of those with a caregiver (74.7 ± 8.9 years) was statistically significantly ($p = .0004$) higher than that of individuals without caregiver (72.4 ± 8.2 years). Significant differences based on caregiver availability were found relative to sex ($p = .009$), age ($p \leq .001$), education level ($p \leq .001$), occupation ($p \leq .001$) and head of household status ($p \leq .001$). The most frequent types of disability were related to vision (78.4%) and ambulation (71.7%). Caregiving most often fell to family members. Logistic regression results showed that individuals over the age of 80 years were 2.51 times more likely to have a caregiver compared to those 60–69 years ($p \leq .001$). Those in the highest wealth quintile were 1.77 times more likely to have a caregiver. **Conclusions:** Findings demonstrate gaps in caring for aging individuals with disabilities in LMICs and highlight the importance of understanding caregiver access in generating effective healthy aging initiatives and long-term care systems.

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Introduction

The concept of disability has evolved to be thought of as a dynamic interaction between a person with a chronic health condition, activities of daily living, ability to participate in important

social roles, and the physical as well as social environment within which they live.¹ According to 2011 World Health estimates, there are more than one billion people in the world with a disability.² The most recent global estimates find that between 15.6 and 19.4% of all individuals 15 years and older experience some form of disability. Approximately 80% of individuals with disabilities live in low- and middle-income countries (LMICs), demonstrating the disproportionate effect of disability on resource-limited environments. Multinational studies have found rates of disability to be positively correlated with age among those older than 50 years residing in LMICs,³ presenting empirical and practical challenges as the

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international life expectancy has increased.⁴

Data on disability and caregiving in low-income countries remains under-developed. Research infrastructure in LMICs is crucial for planning and implementing systems to support healthy aging and disability reduction.⁵ Lack of data is problematic because not only does disability affect individuals with chronic health conditions, but often the responsibility of caregiving falls upon family members or others in the immediate community thereby creating a much larger effect on system-level health promotion efforts in LMICs.

Uganda provides a prime example. The East African country remains one of the poorest in the world,⁷ and one with significant health system challenges. Uganda has a conspicuous gap in the availability of disability data. A 2001 population census estimated the prevalence of all disabilities in the Ugandan population to be roughly 4%; however, recent research has indicated that this may be a significant under-estimation.⁶ Uganda spent approximately 9.5% of its gross domestic product on healthcare in 2011,⁸ with estimates indicating that the country has just one physician per 10,000 population and that only about 57% of the population has access to a health care facility within 5 km of home.⁹ However, rural communities have much lower health access that close to home with some districts as low as 7%.

In response to the need for population-based data on disability and in pursuit of enhanced health promotion initiatives, two Demographic Surveillance Sites have been established in Uganda. In Eastern Uganda, the Iganga-Mayuge Demographic Surveillance Site (IM-DSS) conducts research on non-communicable diseases and health systems across parts of two districts. The aims of this paper are to examine the type and severity of disability experienced by those over 60 years and older, characterize individuals who receive caregiving and types of assistance provided, and evaluate socio-demographic factors influencing disability and caregiving in the Iganga and Mayuge districts.

Methods

The study was approved by the Institutional Review Board of [REDACTED FOR PEER REVIEW] and the Uganda National Council of Science and Technology. The data collection procedures have been described in previous publications.^{6,10} The IM-DSS regularly collects a variety of health and demographic data on all individuals in the Iganga and Mayuge districts, including data on births and deaths, migration, and access to health services as well as other relevant socioeconomic and education data. However, until this study, only limited data regarding disabilities was collected through the IM-DSS.

Using a screening instrument for physical disability in February 2009, adults aged 18 years and older with physical disabilities ($n = 2018$) were identified in the IM-DSS population. To further characterize physical disability in the region, a cross-sectional survey was carried out between November 2009 and March 2010. Two survey instruments were implemented as module A and module B. The intent of module A was to identify individuals with disabilities during each round of data collection. Module B was administered to disabled individuals identified in module A. The aim of module B was to capture more in-depth data regarding the individual's disability as well as caregiver data.

Module B used the 36-item interviewer-administered version of the WHO Disability Assessment Schedule 2.0 (WHODAS 2.0). The instrument is based on the International Classification of Functioning (ICF) framework, and evaluates six areas of disability: understanding and communicating, getting around, self-care, getting along with people, life activities and participation in society.^{11,12} The WHODAS 2.0 instrument lacks insight into aspects of the

disability experience such as the cause and duration, impact on next of kin or caregiver, and potential interventions that could be administered to alleviate the disability. These three additional domains were appended for the purposes of this study.

The WHODAS instrument was translated into Lusoga (the local language) using a standard translation-back-translation protocol.¹³ The instrument was administered by trained field assistants at the individual level. The questions in the survey use a 30-day reference. There are five possible answer choices for each question, ranging from 1 (none) to 5 (extreme/cannot do). These scores are then added up for each domain, as well as across domains, resulting in domain-specific and total scores. These scores are all standardized on a scale of 0–100 using Item Response Theory, in order to ensure comparability across different settings.^{11,12} The higher the score, the greater the degree of disability represented.

Statistical analysis

The outcome of interest in this study was caregiver availability. Age, marital status, educational level, occupation and wealth quintiles were taken as categorical variables. Six types of disabilities were assessed; vision, hearing, walking, upper body mobility, self-care and communication. Severity of disability was calculated based on scores of module A for each type of disability and was grouped as mild, moderate and severe. Wealth quintiles were developed using household assets including house, vehicles, furniture, electrical appliances and agricultural equipment. Wealth quintiles went from lowest to highest. The analysis was done using STATA version 12.¹⁴

Comparison was done for caregiver availability and characteristics of individuals with disability using Pearson chi square test for categorical variables. Simple and multivariate logistic regression was done to look at the association of caregiver availability with variables including sex, age group, marital status, educational level, occupation, wealth quintiles and severity of disability.

Of the 2018 adults aged 18 years and older with physical disabilities, data on caregiver was available for 1472 (72.9%) adult individuals with disability. Since this paper focuses on individuals 60 years and older, the analysis was conducted on a sample of 860 out of 1472 individuals with disability.

Results

Of the 860 individuals with disability 60 years and older, data on availability of caregiver was available for 816 individuals. About 66.3% ($n = 541$) individuals had a caregiver. The mean age of those with a caregiver (74.7 ± 8.9 years) was statistically significantly (p -value .0004) higher than the mean age of individuals disability without caregiver (72.4 ± 8.2 years). Majority of those with a caregiver were females (67.8%, $n = 367$). Around half of those with caregiver were widowed (46.4%, $n = 251$). More than 60% ($n = 338$) of the individuals with disability had no education. Most of those with a caregiver were either self-employed (48.1%, $n = 260$) or unemployed due to health reasons (44.7%, $n = 242$). More than 60% ($n = 321$) of the individuals with disability belonged to lower two wealth quintiles. About 72.8% ($n = 394$) of those with a caregiver were head of their household. On comparison of demographic characteristics of participants with and without caregiver, significant difference between the two groups were found based on sex (p -value .009), age group (p -value <.001), education level (p -value <.001), occupation (p -value <.001) and head of household (p -value <.001; Table 1).

The most frequent type of physical disability was visual (78.4%, $n = 674$), walking (71.7%, $n = 617$), upper body mobility (41.9%, $n = 360$), hearing (39.8%, $n = 342$), self-care (22.7%, $n = 195$) and

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