



Review Article

The neglected burden of caregiving in low- and middle-income countries

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Abstract

Background: The number of persons with disability worldwide is estimated at more than one billion, and low- and middle-income countries (LMIC's) have particularly high prevalence. The consequences of disability have garnered growing attention, but the burden of caregiving for persons with disease or disability remains largely unquantified especially in LMIC's.

Objective: The goal of this paper is to report the results of a review of literature on caregiving in LMIC's, describing the characteristics of caregivers and of persons with disease or disability for whom care is provided, and the burden of caregiving in several domains.

Methods: We reviewed electronically available literature up to March 2012. Data were extracted pertaining to the following categories: caregiver demographics, caregiving activities, psychological burden, social burden, financial burden, physical burden, and time burden.

Results: Our review demonstrates that there is considerable and neglected burden on caregivers in LMIC's in physical, psychological, social, time, and financial realms. Existing literature is limited by the small volume of published research available on this topic, diverse methodologies, and lack of consensus on how to define and measure caregiver burden. However the evidence is clear that there are adverse consequences that arise as a result of the role of caregiver in this setting.

Conclusions: In light of the mounting evidence of the significant burden placed on caregivers of persons with disease and disability, it is imperative that the opportunity be taken to ensure that evidence informs best practice and policy in order to provide the support and services necessary to make an impact. © 2014 Elsevier Inc. All rights reserved.

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The global estimate of prevalence of disability in those 15 years and older was 10% in the 1970's,¹ and the most recent estimates have increased to 15.6%–19.4%.^{2,3} When people of all ages are included, the estimate stands at more than one billion.⁴ The World Report on Disability integrates the best available evidence on global disability and describes the negative consequences that disability has on the health, educational achievements, and economic opportunities of persons with disability. It indicates that the number of people living with disability is growing rapidly, that low income countries face a higher prevalence of disability, and that unmet needs including access to services and programs precludes many from participating in their family units and society.⁴

State support and privately paid assistance are often unavailable or unaffordable for persons with disability, so the provision of care and assistance often comes from within the family or community. The burden of caregiving often falls onto unpaid family members or friends of the person requiring care, especially in developing countries.^{5,6}

Caregivers themselves experience increased stress and disease burden,⁷ but the evidence of this comes almost exclusively from investigations done in high income countries. Less data on the burden of caregiving in low- and middle-income countries (LMIC's) are available related to people with diseases or disabilities that often have caregiving needs (schizophrenia, dementia, HIV/AIDS, spinal cord injury, stroke, and traumatic brain injury).^{8–17} The needs of persons with disease or disability in LMIC's have been inferred from high income countries, but the assumption that the caregiving experience is similar in both contexts ignores the many added challenges associated with caregiving in LMIC's.⁹

The assumption that traditional societies have sufficient support systems to meet the needs of persons with disease and disability has recently been challenged. Social structures are shifting as the support systems of traditional

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societies are weakened by migration and urbanization, the nuclearization of families, the growing prevalence of dual career families, and the devastation of communities by global pandemics like HIV/AIDS.^{18–22} Caregivers in LMIC's face structural challenges that may add to their hardships: medical, educational, and social services are often insufficient, health care budgets are limited, there is a shortage of health care workers, and food insecurity may exist.^{23–27}

The overarching goal of this paper is to understand the way that caregiving for persons with disease or disability has been studied in LMIC's. Our specific objectives were to: 1) perform a literature review regarding caregiving related to disease and disability in LMIC's, 2) describe the characteristics of caregivers that have been reported, and 3) describe the characteristics of persons with disease or disability for whom care is given in the LMIC context. We hope that the presentation of this information will garner attention on caregivers and stimulate a global dialog on their needs in LMIC's.

Methods

We reviewed electronically available literature without limit to publication date, up to March, 2012. Searches were performed in MEDLINE (Ovid), PubMed Plus, Scopus, EMBASE, PsycINFO, and Web of Knowledge databases. Gray literature was searched using Google Scholar, Eldis, and Digital Dissertation. Search terms were related to caregiving and to LMIC's as follows: *caregiv**, *carer**, *developing countr**, *developing nation**, *underdeveloped countr**, *underdeveloped nation**, *less developed countr**, *less developed nation**, *third world countr**, *third world nation**, *resource poor setting**, *limited resource setting**, *resource limited setting**, *low income countr**, *low income nation**, *poor countr**, *poor nation**, *least developed countr**, and *least developed nation** – where “*” denotes truncation. See [Appendix 1](#) for an example of a database search query.

Studies were included if available in English. Studies which provided original data regarding the burden of caregiving were included if they data was collected from one or more LMIC as defined by the World Bank Atlas method (2012 gross national income per capita of $\leq \$1035$ – $\$12,615$).²⁸ Studies were included if caregiving was for persons with chronic diseases or disabilities, and otherwise excluded (i.e. subjects were malnourished children, orphans without chronic illness or disease, drug abusers, or elderly but otherwise healthy persons). Intervention trials were excluded as this was a review of descriptors of caregiving and not an evaluation of interventions.

Studies were initially screened by title and abstract, and full texts of the relevant articles were obtained. The primary author-extracted data and created spreadsheets in Microsoft Excel that allowed data to be compiled

categorically. Data pertaining to the caregiver demographics and what activities of caregiving were performed were extracted. Data pertaining to the burden that caregivers experienced were determined to most often fall into five main domains and are presented in this paper accordingly: psychological burden, social burden, financial burden, physical burden, and time burden. Study design and methods of quantifying burden utilized by each publication were also extracted. Reference lists of included literature were used to identify additional studies that met inclusion criteria.

To indicate the quality of the studies, selected criteria from the Critical Review Form—Qualitative Studies scale were applied (version 2.0) to each study.^{29,30} The criteria were: 1) method(s) used (participant observation, interviews, document review, focus group, or other), 2) Was the process of purposeful selection described?, and 3) Was procedural rigor used in data collection strategies?

Results

We identified 1898 studies by searching the databases and seven more through other sources. After removing duplicates 695 papers remained. Further screening according to our inclusion and exclusion criteria resulted in 51 papers being included in this review ([Fig. 1](#)).

These 51 studies encompassed fifteen specific medical diagnoses of persons being cared for ([Table 1](#)). The most common medical diagnosis of persons being cared for was HIV/AIDS, reported in 15 studies (29%), followed by dementia and Alzheimer's disease (18%). 14% of studies did not specify the medical diagnoses of participants – often instead describing the persons being cared for as mentally disabled, physically disabled, or chronically ill older people. Other common diagnoses were schizophrenia (12%) and cerebral palsy (8%). More studies concerned mental health conditions (39%) than chronic infectious diseases (33%) or chronic neurologic diseases (16%).

Data from 33 countries were included in the 51 studies ([Table 1](#)). The most common were India (20%), China (16%), Brazil (12%), and Nigeria (10%). Caregivers from countries in the Americas were more frequently included in studies than any other World Health Organization (WHO) region, though this was influenced by a small number of studies conducted by one collaborative research group that included data collection sites in primarily in Latin American countries.^{9,16,31}

All the studies that met inclusion criteria were published in the last twenty years, but nearly half of all publication (49%) were published in the five years preceding this literature search. The frequency of publication decreased for each preceding five year period.

We used the Critical Review Form – Qualitative Studies to assess the quality of studies. 98.0% of studies used

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