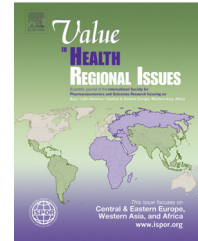




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Measuring and Valuing Informal Care for Economic Evaluation of HIV/AIDS Interventions: Methods and Application in Malawi

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ABSTRACT

Background: Economic evaluation studies often neglect the impact of disease and ill health on the social network of people living with HIV (PLHIV) and the wider community. An important concern relates to informal care requirements which, for some diseases such as HIV/AIDS, can be substantial. **Objectives:** To measure and value informal care provided to PLHIV in Malawi. **Methods:** A modified diary that divided a day into natural calendar changes was used to measure informal care time. The monetary valuation was undertaken by using four approaches: opportunity cost (official minimum wage used to value caregiving time), modified opportunity cost (caregiver's reservation wage), willingness to pay (amount of money caregiver would pay for care), and willingness to accept (amount of money caregiver would accept for providing care to someone else) approaches. Data were collected from 130 caregivers of PLHIV who were accessing antiretroviral therapy from six facilities in

Phalombe district in southeast Malawi. **Results:** Of the 130 caregivers, 62 (48%) provided informal care in the survey week. On average, caregivers provided care of 8 h/wk. The estimated monetary values of informal care provided per week were US \$1.40 (opportunity cost), US \$2.41 (modified opportunity cost), US \$0.40 (willingness to pay), and US \$2.07 (willingness to accept). **Conclusions:** Exclusion of informal care commitments may be a notable limitation of many applied economic evaluations. This work demonstrates that inclusion of informal care in economic evaluations in a low-income context is feasible.

Keywords: Africa, cost-effectiveness, economic evaluation, HIV/AIDS, informal care.

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Introduction

Informal care can be defined as a nonmarket composite commodity consisting of heterogeneous parts produced (paid or unpaid) by one or more members of the social environment of the care recipient as a result of the care demands resulting from ill health [1]. Because different health care interventions can affect the occurrence and severity of ill health, there have been a number of debates about whether and how informal care effects should be incorporated into economic evaluation studies [1,2]. Although significant methodological advancements have been made in the measurement and valuation of informal care in high- [3–5] and middle-income [2] contexts, little work has been undertaken to examine whether and, if so, how informal care can be measured and valued in low-income countries such as those in sub-Saharan Africa.

The informal care impacts associated with HIV/AIDS in Africa warrant special attention given the widespread prevalence and major development challenges associated with the disease. In 2014, 25.8 million people in sub-Saharan Africa were living with HIV, amounting to almost 70% of people living with HIV (PLHIV) worldwide [3]. PLHIV in Africa are very reliant on informal caregivers in the form of family and friends as well as on volunteers partly because of the high labor demands placed on very resource-constrained health care systems [4–6]. As countries consider how to respond to the recent 2016 World Health Organization (WHO) HIV Treatment Guidelines [4] recommendation to provide antiretroviral therapy (ART) to all PLHIV, the role of informal care provision in program decision making requires special consideration at present.

Carers of PLHIV in Africa are motivated by both intrinsic concern to support PLHIV and also some hope of receiving

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material returns for their labor in future [5]. Informal caregiving is, however, associated with negative impacts (including financial costs) to the caregiver [6,7]. The range of services provided by informal caregivers in Africa includes encouragement, keeping company, collecting water, washing clothes, preparing meals, collecting drugs from the clinics or hospitals, counseling, cultivation and harvesting of crops, and growing vegetables [8–10,17]. The consequences of HIV can therefore extend well beyond the PLHIV themselves [11–13]. As such, they should be considered when decisions are made on resource allocation whenever these are likely to result in different informal care consequences, even if they are not formally incorporated within economic evaluation analyses.

The exclusion of informal care effects from economic evaluations would, however, appear to underestimate the benefits of averting HIV infection and disease progression in which these are associated with increased informal care burdens. One of the challenges of incorporating informal care effects appears to be a lack of work on the measurement and valuation of informal care provision in low-income settings [8]. In this article, we aim to demonstrate how informal care can be measured and valued in low-income settings by estimating informal care provisions for PLHIV in Phalombe district in southeast Malawi.

The Malawian HIV program has pioneered a number of HIV treatment scale-up strategies since replicated by other countries, including the ambitious program to attain universal access to ART started in 2004 [9] and the Option B+ approach to prevention of mother-to-child transmission of HIV that commenced in 2011 [10]. At present, the program in Malawi is implemented through a public and private health care system consisting of 724 HIV testing and counseling sites and 713 ART sites [11]. HIV treatment follows Malawian national guidelines that were most recently revised in 2014 [14]. The need for health care particularly in HIV treatment is very high, with only 71% of adults and 42% of children (<15 years) eligible for HIV treatment accessing ART [11]. Delivery of HIV/AIDS services is severely hindered by serious financial and human resource constraints [12]. To mitigate these, Malawi employs community health worker cadres and works in partnership with nongovernmental organizations to implement a standardized supportive supervision and mentorship program under the guidance of the Ministry of Health national program [13]. Many community-based organizations and support groups support the needs of PLHIV.

Malawi is presently updating its National Health Operational Plan, which includes planning for HIV/AIDS. The choice of health care interventions in the Malawian health sector is primarily based on an essential health care package that lists priority interventions on the basis of assessment of cost-effectiveness studies, mainly drawn from the international literature [12]. These studies, however, rarely consider informal care effects, and it appears that such effects are also not considered when determining the essential health care package.

Methods

Study Design

The study was undertaken in Phalombe district located in southeast Malawi as part of the Lablite ART implementation project [13] between November 2013 and August 2014. Data were collected from caregivers of PLHIV who were accessing care at Holy Family Mission Hospital and from five public primary care health facilities (Chitekesa, Mpasa, Nkhulambe, Phalombe, and Sukasanje).

We aimed to recruit 50 PLHIV in each of the following categories: patients who had not had a clinical event more serious than those characterized in WHO stages 1 or 2 in the last

3 months; patients with a WHO stage 3 event in the last 3 months; and patients with a WHO stage 4 event in the last 3 months. We hypothesized that more serious cases would require more care. A research nurse restaged PLHIV for whom we did not have information about their WHO stage in the last 3 months. PLHIV were recruited consecutively in each category until the target numbers were reached. All identified PLHIV were requested to identify their primary caregivers (guardians) who were interviewed at their homes.

The protocol and the data collection tools (Refer to Questionnaire) were approved by the National Health Sciences Research Committee. All individuals consented to participate in the study.

Measuring Informal Care Time

On the basis of the features of rural African societies, which include low literacy levels and a concept of time based on the natural changes in a day (e.g., sunrise, meals, and sunset) as opposed to the Western concept based on a clock [15], and the challenges of using the diary and recall methods [16], we used a modified diary to measure informal care time. The modified diary divided the day into natural time periods (e.g., waking up time to sunrise) and respondents were asked to recall their time allocation to different activities within each of the periods during the previous day (Refer Questionnaire). This differs from the standard diary that divides the 24-hour day into equal time periods, such as 15 minutes [16]. Informal care activities included escorting the PLHIV to the hospital, collecting drugs for the PLHIV, encouraging the PLHIV, collecting water for the PLHIV, washing clothes for the PLHIV, preparing meals for the PLHIV, and keeping the PLHIV company [14,18–19]. The Malawi HIV/AIDS program formally expects the guardians/informal carers to support patients with most of these activities [9,14]. Respondents were asked on how many of the last 7 days they had spent any time on each activity. Time allocated by an individual carer to an informal care activity in a week was estimated by assuming that the previous day was typical and by multiplying hours spent during that day on an activity by the number of days any time had been spent on the same activity in the previous week. Total informal care hours in a week were estimated by summing the time allocated to all informal care activities.

Valuing Informal Care

Methods of estimating monetary values of informal care are classified into revealed preference and stated preference methods [1]. Revealed preference methods involve the measurement of informal care time and its valuation by using market wages (opportunity cost method) or the market prices of close substitutes, such as paid care workers (the proxy good method) [1,20]. The opportunity cost method is widely used because it is pretty straightforward to apply, but its application is challenging in societies that have a high proportion of self-employed individuals such as small-scale farmers who do not have monetary wages. It is also challenging to apply to full-time housewives/husbands and retired persons [1]. Studies in such situations have used the official minimum wage [2,18]. We, however, expect official minimum wages to bias the opportunity cost of time for individuals who decide not to join the labor market because they perceive the market wage as being lower than their opportunity cost of time. For example, a university graduate who does not accept a job that is offering the official minimum wage would likely have higher opportunity cost of time than the minimum wage. It is reasonable to assume that an individual will accept a job if the wage offer exceeds the reservation wage [21]. Similarly, if an individual's education status and assets from which they generate income are very low, their opportunity cost of time may

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