

The Impact of Caregiving a Child with Cancer: A Cross Sectional Study of Experiences of Zimbabwean Caregivers

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Abstract

Background: Paediatric cancer is a global problem that has been on the rise especially in low resource settings. Children with cancer often require routine specialist medical treatment and informal caregivers are an essential resource for optimal treatment outcomes. Long-term caregiving may lead to psychosocial, physical and economic burden in informal caregivers. However, the impact of caregiving a child with cancer in low resource setting is relatively unknown.

Method: A cross sectional survey was carried out on 48 caregivers of children with cancer who were conveniently selected in Harare, Zimbabwe. Caregiver burden and HRQoL were measured using the caregiver strain index and EQ-5D respectively.

Results: Most of the caregivers were female (79.2%), educated (95.8%) and unemployed (75%). Caregivers reported high burden with mean CSI scores 7.4 (SD 2.7) and poorer HRQoL, with mean EQ-5D scores of 68.8 (21.7).

Conclusions and implications: There seem to be empirical evidence that caregiving may negatively affect health outcomes of caregivers. Therefore, there is need for routine and early screening of caregivers at risk of burden. More so, it is important to provide appropriate caregiver support services. There is also a need to develop context-specific interventions aimed at increasing caregivers HRQoL and reducing the burden of care.

Keywords: Cancer; Caregivers; Burden; Health related quality of life; Zimbabwe

Introduction

“When a family member suffers from cancer symptoms and treatment side effects, those surrounding or living with them suffer as well because they are inevitably tied to the patient” [1]. Cancer is defined as a group of diseases that is due to uncontrolled division of abnormal cells in any part of the body. Childhood cancer is a life-threatening, non-communicable condition that has been on the rise globally [2-4]. It is estimated that 100,000 children die of cancer annually and of these, 90% are from low income countries (LIC) [5]. In Zimbabwe, like in other low-income countries, the number of childhood cancers has been on the rise and is now a major public health concern [5,6]. Lifestyle changes and the HIV/AIDS pandemic have attributed to the sharp increase in the incidence of cancer and an estimated 5 000 new cases are being recorded annually in Zimbabwe [6].

Advances in medicine and technology have drastically reduced the mortality due to cancer.³ To this end, the World Health Organization (WHO) attests that the survival rates of paediatric cancers have risen up to about 75% [2,7]. Consequently, improvements in treatment have brought about transition of cancer from being a fatal to a chronic condition [8]. Cancer is associated with multiple impairments, which calls for a multi-disciplinary approach to care.

Treatment invariantly includes regular visits to specialised health-care institutions for chemotherapy, radiotherapy, surgery, rehabilitation amongst other specialist medical services [9]. Additionally, due to the complexity of the condition, family members assume an essential role in the management of children with cancer [3,10]. With the increase in costs of medical services, there is now emphasis on early discharge and self-management [1], strong shift of care from health-care settings to community care [11-15]. This consequently increases the burden of caregiving to informal caregivers [1].

An informal caregiver is defined as an individual who provide ongoing care and assistance, without pay, for a child in need of support due to physical, cognitive, or mental health conditions [16,17]. The caregiver is involved in numerous caregiving roles throughout the illness trajectory, but often do not have training for the presumed role [1,18]. The roles of the caregiver include being a legal assistant, managing medical emergencies, planning transition from home to hospital and offering psychological and social support [4,10,18].

The caregiving roles can be fulfilling in that they bring about personal satisfaction and bonding with child [18]. For mothers in the African culture, caregiving is a cultural obligation and an expected role for women. However, due to the high demands associated with providing care, it may eventually lead to burnout exhaustion, caregiver burn-out and general reduced health-related quality of life (HRQoL) and strain on the caregivers [3,10].

More often, caregiving translates to burden when the daily demands on the caregiver, are in conflict with the caregiving role and occupational roles of the primary caregiver [15]. Caregiving can affect various domains of wellbeing including spiritual, physical, social and economic [4]. Greater magnitude of burden may lead to inefficient caregiving to those affected and may eventually negatively impact on treatment of the child with cancer [4,10,19]. For instance, we hypothesize that overwhelmed caregivers are more unlikely to be compliant with treatment regimens such as attendance at scheduled appointments and administration of various medications at home.

Informal caregivers are an invaluable resource in the management of paediatric cancer and as such, their compliance and cooperation is undeniably a critical ingredient to effective management of children with cancer [18]. Many studies globally have revealed that caregiving a child with cancer is associated with poorer health outcomes in the primary caregivers [1,3,8,9,20,21]. In the Zimbabwean context, little is known about the perceived HRQoL of caregivers and the magnitude of the burden of caregiving a child with cancer. Studies on caregivers of children with CP in the same setting have revealed that long term care may be associated with depression, anxiety, lower HRQoL and high perceived burden of care [22].

Therefore; we set to determine the impact of caregiving a child with cancer in the Zimbabwean context. This is essential given the change in epidemiology over the past few years as it is projected that the burden of cancer and non-communicable diseases is likely to eclipse that of infectious diseases such as HIV/AIDS [6]. Further, there is a great call to provide support services for caregivers of children with long-term health conditions. This can only be achievable if the magnitude of caregiver burden is known.

Methods

Study setting

The study was conducted at Parirenyatwa Group of Hospitals (PGH), which is in Harare, Zimbabwe. PGH is the largest referral hospital in Zimbabwe and is one of the teaching hospitals for University of Zimbabwe. PGH provides specialist medical services and it has an Oncology department where chemotherapy, radiotherapy and surgery treatments are done. It is the only public hospital where paediatric cancer chemotherapy and radiotherapy treatment are done. Caregivers of children with cancer accompany them to hospital for their treatment hence its selection as the study site.

Participants

Principal informal caregivers of children diagnosed of cancer according to patients' notes were recruited. The caregivers were supposed to have provided care for at least a month prior to the study, were caregiving a child of less than 10 years of age and were not themselves suffering from a psychiatric morbidity or a chronic health care condition such as HIV/AIDS, which would impact their HRQoL.

Sampling

In the year 2014, an average of 55 patients were treated in the paediatric oncology ward at PGH per month. Thus assuming universe of 55 and that 50% of the participants would report of caregiver

burden [22]. The minimal sample size was 48 at 0.05 alpha, design effect of one and one cluster. The sample size was calculated using StalCal function of Epi-info version 7. Caregivers were conveniently selected.

Instrumentation

An ad-hoc demographic questionnaire was utilized to capture the study population socio-demographics. Caregiver burden was measured using the CSI. The CSI is a generic, 13-item tool, which measures the perceived burden of care [23]. Caregivers responded with a Yes or a No and a response of yes is scored as one and zero is awarded for a no response.

The maximum possible score is 13 and caregivers who score seven or more are considered to be at risk of clinical distress [23-25]. The CSI has been previously used in the local settings in caregivers of children with CP and has been shown to be both valid, reliable and culturally acceptable in measuring caregiver burden [22].

Caregivers' perceived HRQoL was measured using the EQ-5D, which is a generic tool for measuring perceived HRQoL [26]. Respondents rate their health in five-domains i.e. mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The responses are ranked on a three-point Likert scale i.e. no problem=1, some problem=2 and extreme problem=3.

The ratings are transformed into a summative score through use of the EQ-5D utility calculator. Respondents also rate their overall HRQoL using a visual analogue scale (VAS) which is rated from zero up to a hundred and the higher the scale, the higher the perceived HRQoL [26,27]. The EQ-5D has been shown to be culturally acceptable, valid, reliable, stable and responsive in measuring the HRQoL of adults in the research setting [22,28].

Procedure

Ethical considerations: After obtaining institutional approval from the clinical director of PGH, we sought ethical approval from the Joint Research Ethics Committee for the University of Zimbabwe and Parirenyatwa Group of Hospitals (REF: 285/14) and the Medical Research Council of Zimbabwe (Ref: MRCZ/B/747).

Written consent was sought from caregivers who were assured that decline to participate would not prejudice their access to medical care and that participation was entirely on voluntary basis.

Data analysis: Raw data were entered on Excel and we used Statistica version 12 for data analysis. Descriptive statistics were used to present participants socio-demographics, frequencies of reported problems on the CSI and EQ-5D.

Results

Demographics

Most of the children were; males (54.2%) and most presented with Wilm's tumour, n=24(50%). All children were receiving chemotherapy. Most of the caregivers were females (79.2%), married (70.8%), unemployed (75%) and educated (95.8%) (Table 1).

	Attribute	Frequency, n%
Child's gender	Male	26 (54.2)
	Female	22 (45.8)
Child's age (months)	Mean (SD)	63.6 (34.7)
Cancer type	Leukaemia	16 (33.3)
	Wilm's tumour	24 (50.0)
	Other	8 (16.8)
Type of treatment	Surgery	20 (41.7)
	Radiotherapy	6 (12.5)
	Chemotherapy	48 (100)
Number of treatments	One	26(54.2)
	Two	18 (37.5)
	Three	4 (8.3)
Caregiver's gender	Male	10 (20.8)
	Female	38 (79.2)
Caregiver's age (ears)	Mean (SD)	34.9 (8.9)
Caregiver's marital status	Married	34 (70.8)
	Unmarried	14 (19.2)
Caregiver's employment status	Unemployed	36(75.0)
	Formally employed	8 (16.7)
	Informally employed	4 (8.3)
Caregiver's educational level	None	2 (4.2)
	Primary	6 (12.5)
	Secondary	30 (62.5)
	Tertiary	10 (20.8)
Relationship of caregiver to child	Parent	42 (87.5)
	Sibling	4 (8.3)
	Grandparent	2 (4.2)
Duration of caregiving	Less than 6 months	20 (41.7)
	More than 6 months; less than 1 year	10 (20.8)
	More than one year	18 (37.5)

Table 1: Study population socio-demographics, N=48.

Caregiver burden

As outlined in Table 2 below, most caregivers reported that: caregiving was inconvenient, had caused family adjustments, had resulted in changes to personal plans, had observed changes in child, reported of financial burden and were overwhelmed by the caregiving role.

Raw data were entered on Excel and we used Statistica version 12 for data analysis. Descriptive statistics were used to present participants socio-demographics, frequencies of reported problems on the CSI and EQ-5D.

Variable	Response	
	Yes (n%)	No (n%)
Sleep	20 (41.7)	28 (58.5)
Inconvenient	28 (58.5)	20 (41.7)
Physical strain	20 (41.7)	28 (58.5)
Confining	16 (33.3)	32 (66.7)
Family adjustments	22 (45.8)	26 (54.2)
Changes to personal plans	30 (62.5)	18 (37.5)
Emotional adjustments	20 (41.7)	28 (58.5)
Upsetting behaviour	16 (33.3)	32 (66.7)
Changes in child	30 (62.5)	18 (37.5)
Work adjustments	26 (54.2)	22 (45.8)
Financial strain	42 (87.5)	6 (12.5)
Overwhelmed	36 (75)	12 (25)

Table 2: Frequency of reported problems on the Caregiver strain index, N=48.

Further, the mean CSI score for the caregivers was 7.4 (SD 2.7) with range 1- 12. Most of the caregivers, n=35 (72.9%) exhibited clinical distress as they scored seven or more on the CSI.

EQ-5D summative scores, the average EQ-5D VAS and utility scores were 68.8 (SD 21.7) and 0.65 (SD 0.27) respectively (Table 4).

HRQoL

The most commonly reported problems were pain/discomfort and anxiety/depression; this is shown in Table 3 below. Further, as for the

EQ-5D Domain		Frequency (n%)
Mobility	No problem	42 (87.5)
	Some problem	6 (12.5)
Self-care	No problems	46 (95.8)
	Extreme problems	2 (4.2)
Usual activities	No problems	30 (62.5)
	Some problems	16(33.3)
	Extreme problems	2 (4.2)
Pain/Discomfort	No problems	22 (45.8)
	Some problems	24 (50)
	Extreme problems	2 (4.2)
Anxiety/Depression	No problems	20 (41.7)
	Some problems	26(54.2)
	Extreme problems	2 (4.2)

Table 3: Frequency of reported problems on the EQ-5D.

	EQ-5D VAS scores	EQ-5D utility scores
Mean (SD)	68.8 (21.7)	0.65(0.27)
Range (minimum-maximum)	60(40-100)	0.72 (0.38-1.0)

Table 4: EQ-5D summative scores.

Discussion

To the best of our knowledge, this is the first study to determine the impact of caregiving a child with cancer in the Zimbabwean context. The findings we discussed under the following headings: physical burden, psychosocial burden and economic burden.

Physical burden

Most caregivers did not report of physical burden as few participants reported of problems in mobility, self-care and usual activity. Given that the study population was relatively young, it was most unlikely that caregivers would report problems with issues such as mobility, self-care and usual activities. Additionally, most of the caregivers had been providing care to children with cancer for less than a year.

Therefore, the effects of physical burden may not have been evident yet. More so, the children were relatively young, therefore, they were unlikely to be heavy as lifting and transfers have been shown to predispose caregivers to musculoskeletal disorders such as shoulder pain and low back pain among others [29,30]. As the children become older, they may become heavier to lift and this may lead to physical burden. However, a weakness of the study was that the body mass index and level of severity and functional dependency of the children with cancer was not recorded, therefore, this is all speculation and further studies are warranted to determine the impact of caregiving on caregivers' physical health.

Psychosocial burden

Most caregivers experienced psychosocial burden with 75% reporting being overwhelmed by the role. Symptoms of burnout such as headaches, insomnia and fatigue have been reported to be prevalent amongst caregivers [4]. It has been postulated that caregivers can be negatively affected by behavioural and physical changes in the child that may be due to cancer treatment [20]. Findings from the present study also concur with the same sentiments as 62.5% reported that they were affected by changes in their children. Changes such as weight loss, alopecia among others, may lead to the feeling of anxiety amongst caregivers.

Diagnosis of cancer is often a catastrophic to caregivers [4,20]. It is often associated with a lot of anxiety, fear and at times depression [4]. As such, support is of paramount importance. However, in the context of the local setting, due to the scarcity of health-care personnel, caregivers may not be afforded the support necessary for them to cope with the diagnosis and subsequent management throughout the disease trajectory. We also speculate that cultural beliefs as to the causes of cancer may lead to depression in caregivers. In Zimbabwe and Africa in general, cultural myths and beliefs such as witchcraft and maternal promiscuity as causative agents of illness are still prevalent [31-33]. There is also evidence that depression is endemic in informal caregivers [33,34]. As most caregivers were unemployed, most would

thus struggle to search means for economic survival and at the same time assume the caregiving role. This role conflict may lead to depression which may increase with the passage of time [17,33].

Most caregivers (62.5%) in this study found caregiving inconvenient. Caregivers usually find less time for socializing with friends and family due to inadequate time as caregiving is often a full-time "career" [21]. This is more so in low resource settings where there is scarcity of respite services. Decreased opportunities for socialization may eventually lead to decrease in social networks yet social support has been demonstrated as one of the key buffers to the effects of burden of care [8,35]. More often, due to cultural obligations, women may feel obliged to provide care to their children and consequently overlook their own health which may further exacerbate the amount of perceived burden of care.

Findings from the present study are also in concordance with literature that stipulates that caregivers usually exhibit anxiety when the child is receiving active treatment [8,21]. Treatment modalities such as chemotherapy are associated with multiple side effects such as vomiting, pain among others and these may increase caregivers/anxiety. We also postulate that anxiety about the treatment outcomes may also lead to anxiety in caregivers. Othoman et al also echo are the same sentiments, they reported that the caregivers were anxious especially when the child was receiving active treatment [36]. However, in their study the level of anxiety was lower in caregivers who were knowledgeable of cancer.

Economic burden

There is a consensus that caregiving a child with cancer often leads to financial/economic burden [17,21]. Similarly, in this study, 87.5% of the caregivers reported financial burden. In the Zimbabwean context, factors such as high costs in diagnostic procedures such as MRIs and CT scans may attribute to the high cost. In addition, most of the caregivers had to travel from various parts of the country to seek specialist medical services at PGH. Consequently, some of the caregivers would thus require money for temporary accommodation and this might have resulted in financial burden. A study by Saifan et al in Jordan also echo the same sentiments in that out-of-pocket expenses like transport, food, accommodation and medical test expenses all combined lead to financial burden [21]. Further, with the collapse of social services, escalating health costs and high unemployment rate, caregivers are faced with colossal economic challenges in financing care for their children [33]. Even for caregivers with health insurance cover, most health insurers pay for services up to a certain threshold, which is most often not adequate in most cases to meet all expenses thus transferring the burden to caregivers.

On the same wavelength, a study on 354 caregivers of children of with cancer to determine the effects of place of residence or travel time to therapy on that burden in the United States also shares the same sentiments. The key findings were that caregiving a child with cancer was associated with high financial burden as some caregivers missed

work as they had to attend clinics, some had to relocate to remote settings to cut on cost of living and in extreme cases, some had to resign from formal employment [9]. To this end, one only wonders at the magnitude of economic burden of caregivers of children with cancer living in low resource settings such as Zimbabwe where economic challenges are unspeakable.

Conclusion, Implications and Recommendations

The weaknesses of the study were a small sample size, use of generic outcome measurements and as the study was cross sectional in nature, causality could not be established. Further, participants were drawn from one institution and this was a threat to the external validity of the study findings. In light of these limitations, there seems to be empirical evidence that caregiving a child with cancer may be associated with high caregiver burden and poorer HRQoL. Therefore, it thus becomes important to develop interventions for buffering the impact of caregiving, as the efficacy of treatment regimens may be heavily dependent on the health and the HRQoL of informal caregivers. This is especially important in low resource settings where there is scarcity of respite care services.

As this was an exploratory study, there is need of future studies that employ large sample sizes, longitudinal designs to determine the changes in burden of care/HRQoL along the trajectory of the disease process. Further, there is also need to develop context-specific and culturally appropriate tools for routine screening of caregivers' perceived burden of care. It is also important to early identify caregivers who may exhibit signs of clinical distress so that they may be referred for support at an early stage. There is also an urgent call for rehabilitation professionals to be actively involved in paediatric oncology given the evolving burden of cancer in the Zimbabwean setting.

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