

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

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Received date: July 29, 2014, **Accepted date:** August 20, 2015, **Published date:** August 25, 2015

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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

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)

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. Sympto

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- community-based rehabilitation in community development. *Community Health (Bristol)* 1: 24-29
- 33 Van der Mark EJ, Verrest H (2014) Fighting the odds: strategies of female caregivers of disabled children in Zimbabwe. *Disabil Soc* 29: 1412-1427.
- 34 Patel V, Abas M, Broadhead J, Todd C, Reeler A (2001) Depression in developing countries: lessons from Zimbabwe. *Br Med J* 322: 482-484.
- 35 Munsell PE, Kilmer RP, Cook JR, Reeve CL (2012) The effects of caregiver social connections on caregiver, child, and family well-being. *Am J Orthopsychiatry* 82: 137-145.
- 36 Othman A, Mohamad N, Blunden S (2011) Factors Related to Parental Well Being in Children with Cancer. *Int Conf Soc Sci Humanit IPEDR* 5: 255-260.