

Health-Related Quality of Life of Caregivers of Children with Cerebral Palsy and Minor Health Problems in Zimbabwe: A Descriptive, Comparative Cross-Sectional Study

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Abstract- Background-Cerebral palsy (CP) is the most common paediatric physical disability. Children with CP often present with multiple impairments and activity limitations. This makes them often reliant on caregivers for assistance in functional activities. As CP is a lifetime condition, long term caregiving may eventually negatively affect the health related quality of life (HRQoL) of caregivers. HRQoL is context-specific, therefore, we thus set to determine the HRQoL of Zimbabwean primary caregivers of children with CP.

Method-A descriptive, comparative cross sectional design was conducted at Parirenyatwa Central Hospital, Harare Zimbabwe. We conveniently selected a sample of 29 caregivers of children with CP and 29 caregivers of children with minor health problems. Caregivers' HRQoL was measured using the EQ-5D and this was self-administered. Data were analysed using STATISTICA version 12.

Results-Most of the children (51.7%) were males, with a median age of 19 months (Q₁-Q₃: 11-31).The majority of children (69%) presented with mild severity form of CP. Most caregivers were mothers (80%), married (96.7%), and unemployed (60%) and all were literate. Caregivers of children with CP reported more problems with self-care, pain/discomfort, anxiety/depression and reported statistically significant lower HRQoL when compared to those of children with minor health problems.

Discussion and conclusion-Findings are suggestive that caregiving a child with CP may be associated with poorer HRQoL especially in the domains of self-care, pain and depression. Therefore, this calls for routine screening and measurement of HRQoL of caregivers and development of context-specific supportive interventions for caregivers to mitigate impact of the burden of caregiving.

Index Terms- Cerebral palsy, caregiver, knowledge, rehabilitation, Zimbabwe

I. INTRODUCTION

Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by

disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder".[1] CP is widely envisaged as the prototype of childhood disability, with an estimated global incidence of 2 to 3 cases per 1 000 births.[2] [3] As depicted in the definition, more often children with CP with a plethora of impairments, activity limitations and participation restrictions. As such, these children often require assistance with activities of daily such as bathing, feeding among others from informal caregivers.[4] [5] An informal caregiver is a person who is responsible for most of the day to day care of a child with CP and they are not formally remunerated for the role.

Depending on the level of severity, caregiving a child is often a life commitment.[2] [4] This may lead to the deterioration of health and health-related quality of life (HRQoL) of informal caregivers.[6] [7] [8] Further, long term caregiving has been associated with depression, anxiety, stress and low self-efficacy in primary caregivers.[9] [10] [11] It is recognised that even caregiving a typically developing child is often challenging and stressful.[12] The dynamics become even more complex if the child suffers from a long term neurodevelopmental disability/condition.[13] For instance, caregiving may lead to decreased opportunities for socialization and formal employment thus informal caregivers are more often overwhelmed by the role.[6] [14] This is more if the caregivers are of a low social standing.

Globally, with the advent of the biopsychosocial and family centred approach to care, there is now strong emphasis in development of context specific interventions aimed at increasing the HRQoL of caregivers.[6] For this to be achieved, it is paramount to determine the normative HRQoL values of caregivers. More so, HRQoL is context specific and cultural dependent, thus the need to evaluate the perceived HRQoL of Zimbabwean caregivers. An earlier study on 46 caregivers of children with CP done in Harare, Zimbabwe revealed that caregivers exhibited reported of poorer HRQoL.[6] The study design was quasi-experimental and there was no comparison made to caregivers of typically developing children or of children with minor health problems. Therefore, confounders to HRQoL were not accounted for. Henceforth, the aim of the present study was to determine the perceived HRQoL of Zimbabwean caregivers of children with CP by comparing to that of caregivers of children with minor health problems.

II. METHODS

Study design

A comparative, descriptive cross-sectional study was conducted between August 2014 and June 2015.

Setting

The study was done at Parirenyatwa Group of Hospitals (PGH) which is the largest referral centre in Zimbabwe. Caregivers of children with CP were recruited from the Rehabilitation department. This was done every Tuesday for six consecutive weeks as this was the day which CP clinics were done. The children with minor health problems were recruited at the Polyclinic at PGH. In this study, minor health problem implied those children presenting for routine health check-ups such as immunizations or suffering from non-chronic condition such as flu/cold.

Participants

Sampling and sample size calculation

Convenience sampling was used to recruit the caregivers. Assuming the mean EQ-5D VAS scores for caregivers of children with CP to be 68 (SD 17)[15] and that of caregivers of children with minor health conditions to be 65 (SD 17)[16] respectively, the minimal number of participants was 29 per group at the 95% confidence interval and 80% goal power. The sample size was calculated using the power calculator on STATISTICA version 12.

Instrumentation

The participants' socio-demographics were captured using an ad-hoc demographics questionnaire. The HRQoL was measured using the EQ-5D- 3L questionnaire. The EQ-5D 3L measures HRQoL in the domains of self-care, mobility, usual activities, pain/discomfort and anxiety/depression.[17] Participants rate if they are experiencing problems in the five domains. Responses are rated on a three point Likert scale i.e. no problem=1, some problem=2 and extreme problem=3. The likert ratings are then converted to utility values through the use of EQ-5D 3L calculator. The normative values for Zimbabwe are available.[16] In the second section, participants rate their perceived HRQoL on a visual analogue scale. It is rated from zero to a hundred. The higher the rating, the higher the perceived HRQoL. The EQ-5D 3L has been demonstrated to be reliable,

validity, responsive and sensitive to detect changes in HRQoL.[16] [18] [19] The EQ-5D has also been translated into Shona, a Zimbabwe native language. The translated tool has demonstrated psychometric properties.[16] The severity of CP was captured using the gross motor classification system (GMFCS).[20] The GMFCS classifies functional ability on a five-point likert scale i.e. class one is the least affected and children in class five are more severely affected thus may require more functional assistance. It is the most commonly used tool in classification of functional ability and has been shown to be reliable, valid and responsive.[6] [20] [21]

Procedure

Ethical considerations

After getting institutional approvals, ethical permission was granted by the Medical Research Council of Zimbabwe (Ref: MRCZ/B/840). Written consent was requested from consenting caregivers for participation in the study. This was done after a verbal explanation of the rationale and aims of the study. It was emphasized that participation was on voluntary basis and that decline in participation would not affect their access to services.

Data analysis

Data analysis was performed as per protocol and we utilized the STATISTICA (version 12) and SPSS (version 22) for data analysis. Descriptive statistics were utilized to present the socio-demographics. Categorical data were analysed using the Mann-Whitney U, Chi-squared and Fishers' Exact tests.

III. RESULTS

Demographic characteristics

Study population demographics

As shown in Table 1 below, most of the children were males, n=30 (51.7%) with a median age of 19 months (Q₁-Q₃: 11-31). Children with CP were significantly older than children with minor health problems, U=280, Z=2.177 & p=0.029. Additionally, most of the children, n=20 (69%) presented with mild severity form of CP. Most of the caregivers were; mothers, n=24 (80%) married, n=28(96.7%), unemployed, n=18 (60%) and all caregivers were literate.

Table 1: Study population socio-demographics, N=58

Variable	Attribute	Caregivers of children with cerebral palsy, n=29, n(%)	Caregivers of children with minor health conditions=29, n(%)	Total N=58	Statistic	p-value
Sex of children	Male	15 (51.7)	13 (44.8)	28 (48.3)	$\chi^2=0.274$ df=1	0.600
	Female	14 (48.3)	16 (55.2)	30 (51.7)		
**Age of children	Median (Q ₁ -Q ₃)	23.0 (13.0-34.0)	13.0 (9.0-24.0)	19 (11.0-31.0)	U=280 Z=2.177	0.029
Severity of CP	Level 1	2 (6.9)			n/a	
	Level 2	12 (41.4)				
	Level 3	9 (31.0)				
	Level 4	6 (20.7)				
Sex of the caregivers	Female	29 (100)	29 (100)	58 (100)	n/a	

**Caregiver age	Mean (SD)	33. 1 (8. 5)	29 (6.0)	30.1 (7.4)	t(56)=1.074	0.288
Relationship to Child	Mother	24 (82.8)	26 (89.7)	50 (86. 2)	Fisher's Exact	0.706
	Other	5 (17.2)	3 (10.3)	8 (13.8)		
Marital status	Married	21 (72.4)	25 (86.2)	46 (79.3)	Fishers exact	0.514
	Single	5 (17.2)	2 (6.9)	7 (12.1)		
	Widowed	3 (10.4)	2 (6.9)	5 (8.6)		
Level of Education	Secondary	26 (89.7)	26 (89.7)	52 (89.7)	Fishers exact	1.000
	Primary	2 (6.9)	1 (3.4)	3 (5.2)		
	Tertiary	1 (3.4)	2 (6.9)	3 (5.2)		
Employment Status	Unemployed	18 (62.4)	21 (72.4)	39 (67.2)	Fishers exact	0.668
	Informally employed	10 (34.2)	6 (20.7)	16 (27.6)		
	Formally employed	1 (3.4)	2 (6.9)	3 (5.2)		

Results of respondents HRQoL

As compared to caregivers of children with minor health problems, caregivers of children with CP reported more problems in usual activities, p (Fishers' Exact) = 0.020,

pain/discomfort, p (Fishers' Exact) =0.041 and anxiety/depression, p (Fishers' Exact) =0.001. (See Table 2 below)

Table 2: Frequencies of responses on the EQ-5D, N=58

EQ-5D dimension	Attribute	Caregivers of children with cerebral palsy n=29, n (%)	Caregivers of children with minor health conditions n=29, n (%)	Total, n (%)	Statistic	p-value
Mobility	No problems	21 (72.4)	25 (86.2)	46 (79.3)	Fishers Exact	0.179
	Some problems	7 (24.1)	4 (13.8)	11 (19.0)		
	Extreme problems	1 (3.4)	0	1(1.7)		
Self-care	No problems	20 (69.0)	23 (79.3)	43 (74.1)	$\chi^2=0.360$ df=1	0.549
	Some problems	9 (31.0)	6 (20.7)	15 (25.9)		
Usual activities	No problems	16 (55.2)	25 (86.2)	41 (70.7)	Fishers Exact	0.020
	Some problems	12 (41.4)	4 (13.8)	16 (27.6)		
	Extreme problems	1 (3.4)	0	1 (1.7)		
Pain/discomfort	No problems	8 (27.6)	17 (58,6)	25 (43.1)	Fishers Exact	0.041
	Some problems	16 (55.2)	11 (37,9)	27 (44.8)		
	Extreme problems	5 (17.2)	1 (3,4)	6 (12.1)		
Anxiety/ depression	No problems	12 (41.4)	24 (82. 8)	36 (62.1)	Fishers Exact	0.001
	Some problems	12 (41.4)	5 (17.2)	17 (29.3)		
	Extreme problems	5 (17.2)	0	5 (8.6)		

Further, as compared to caregivers of children with minor health problems caregivers of children with CP rated their HRQoL to be lower on the EQ-5D VAS scale, $t(53)=-5.3$, $p<0.001$. (See Table 3 below)

Table 3: EQ-5D summative scores, N=58

EQ-5D summative score	Attribute	Caregivers of children with cerebral palsy n=29	Caregivers of children with minor health conditions n=29	Statistic
EQ-5D VAS score	Mean (SD)	70.5 (11.5)	85.0 (9.0)	$t(53)=-5.3$ $p<0.001$
	Median(Q ₁ -Q ₃)	70 (65-80)	85 (80-90)	
	Range (min-max)	45 (50-95)	30 (70-100)	
EQ-5D utility score	Mean (SD)	0.057 (0.219)	0.069 (0.258)	U=419.5 Z=-0.08 p=986
	Median	0	0	
	Range (min-max)	0-1	0-1	

IV. DISCUSSION

Most of the children were males which is in concordance with literature which stipulates that CP is more prevalent in males as opposed to girls.[22] Further, there was a spread of levels of severity of CP as measured by the GMFCS, therefore the sample was representative of the children with CP. All the caregivers were mothers. In the African context, the responsibility of caregiving is left almost entirely to females.[7] Further, the high literacy and unemployment status is representative of adult females in Zimbabwe. Official statistics of the Zimbabwean population peg the unemployment rate and literacy rates for women at 87.8% and 98% respectively.[23] Thus results may be generalizable to other caregivers in the research setting.

Mobility and self-care

The study population consisted of relatively young caregivers, with a mean age of 30.1 (SD 7.4) years, thus problems with mobility and self-care were very unlikely. The present findings are comparable to findings from a study to determine the HRQoL of caregivers of children with CP in the same research setting. In their study, Dambi and Jelsma (2014) found the proportions of reported problems with problems in mobility and self-care to be 32.6% (n=15) % and 21.7% (n=10) respectively.[6]

Usual activities, pain & discomfort

Caregivers of children with CP reported experiencing problems in usual activities. This may emanate from pain as result of providing assistance in functional activities.[24] This claim is further substantiated by the fact that most of the caregivers also complained of pain and discomfort. As CP is a life time condition and depending on the level of severity, the level of assistance required by the children may lead to pain and discomfort.[2] [4] [24] More so, almost similar studies have reported musculoskeletal problems such as low back pain and shoulder pain to be common in informal caregivers.[5] [24] [25] For instance, in lifting children with CP, some of the caregivers may end up utilizing unsafe lifting techniques leading to low back pain.[6] [25] [26] This is further compounded by increasing

in age , weight and severity of CP which may thus require increased physical excursion in providing functional assistance.[25] [27]

As caregivers were from a low resource setting, most if not all of them, would not have been taught on safe lifting and transfer techniques and were unlikely to afford purchasing mobility aids such as wheelchairs. Therefore, caregivers were more likely to be at a high risk of developing musculoskeletal conditions which could have resulted in chronic pain. For instance, shoulder pain incurred during lifting and transfers may lead to activity limitations in dressing. This “forced” immobilization may then lead to the alterations of the biomechanical structures in the joint structures which further leads to more pain thus perpetuating a vicious cycle. Additionally, most of children with CP mainly present with spasticity of limbs.[28] This poses challenges on the caregiver especially in providing care and during lifting and transfers thus may result in more complains of pain/discomfort.

Anxiety/depression

As compared to caregivers of children with minor health problems, caregivers of children with CP reported of suffering from anxiety/depression. This is in accordance to literature which posits long term caregiving a child with CP is likely to be associated with anxiety [11] [29] [10], depression [11] [10] [9] [30], low self-efficacy [31] [32] and stress in primary caregivers [33] [34] [35] . Additionally, the demands of caregiving may be overwhelming which may lead to depression in the caregivers.[6] For instance, the need for routine specialist medical services may lead to financial burden which may then evolve into depression.[36] [37] The prevailing socio-economic situation in Zimbabwe may compound the financial burden in the caregivers. For instance, with the “dearth” of social services and escalating health care costs, caregivers are faced with a daunting task of footing the out of pocket medical expenses.[38] Further, as most of the caregivers were unemployed, this could lead to depression in caregivers as they have to juggle between informal tasks for survival and meeting the financial obligations of caregiving.

Further, there is still a lot of stigma and discrimination in society towards disabilities especially in low income countries. [39] [40] [41] For instance myths such as CP being caused by witchcraft and maternal promiscuity are still prevalent.[42] [43] [44] [45] A recent study has revealed that disabled people are the

most marginalized and discriminated in the Zimbabwean society.[38] The study further stipulates that mothers, who are the primary caregivers in most instances, bear the brunt shed by society. Therefore, the fact that caregivers with CP reported more of depression was unsurprising.

Over the past few decades the family centered approach has evolved as the yardstick/gold standard in provision of neuro-rehabilitation services.[46] This model of care is hinged on provision of support to the caregivers in addition to providing therapy for children with CP. [43] [46] Nowadays, there is now consensus that there is a great need to support caregivers once diagnosis of CP is made.[47] Diagnosis is often accompanied by feelings of helplessness, grief, guilty, among others.[48]As such support in form of counselling sessions and provision of knowledge may help to mitigate the anxiety associated with the diagnosis.[47] [48] This “ideal” model of care also requires adequate human resources for its implementation, this may not be so in low resource settings. For instance, due to human resources shortages, caregivers may not be given the support they require when the child is diagnosed of CP. This lack of support may lead to anxiety which may then evolve to depression which may then manifest as low perceived HRQoL in the caregivers.

Summative HRQoL indices

Results from the summative scores of the EQ-5D were inconclusive i.e. there was a significant difference in caregivers perceived HRQoL on the EQ-5D VAS scale whilst the EQ-5D utility summative score did not yield any statistically difference. This may pose the question of the discriminative ability of the EQ-5D summative scores. Nevertheless, as stipulated in literature, caregivers of children with CP are more likely to report of lower HRQoL as compared to the general population [30] or to caregivers of typically developing child [7] [49] or caregivers of children with minor health problems. [50] This may be attributed to the demands of caregiving especially where there is no formal/structured support to alleviate the burden of care.

V. CONCLUSION

Results of the present study need to be interpreted with caution due to methodological limitations. Firstly, given the cross sectional and descriptive nature of the study, causality cannot be inferred. Additionally, confounders to HRQoL were not accounted for as randomization was not feasible. More so, other variables such as social support which have been demonstrated to be strong predictors to HRQoL[13] [14] [51] were not captured and this would have given a holistic of the caregivers' HRQoL. More so, children with CP were statistically significantly older than children with minor health problems and this potentially acted as a confounder to caregivers' physical health. For instance, older children were bound to be heavier thus resulting in greater report in pain in caregivers thus may have ultimately negatively affected the HRQoL of caregivers.

Notwithstanding the limitations, the study findings were in concordance with literature which stipulates that long term caregiving may lead to lower/poorer HRQoL in informal, primary caregivers of children with CP. As such there is need to provide supportive interventions for the caregivers to mediate the effects of caregiver burden. Large scale studies are also needed to establish the normative HRQoL values of caregivers.

Additionally, there is a great need to constantly assess caregivers' HRQoL so as to detect those caregivers who may need support early. Special emphasis should be on the screening for musculoskeletal pain, anxiety and depression. Further, large scale, longitudinal studies which also include caregivers who reside in rural areas must be done to ascertain the perceived HRQoL states of caregivers. This is more important as most of the research on caregivers' HRQoL has been done in urban settings in high income countries and as such its generalizability to low income countries and rural settings may be questionable.

COMPETING INTERESTS

'The author(s) declare that they have no competing interests'.

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