Assessment of Health-Related Quality of Life and its Associated Factors in Family Caregivers of Children with Lymphoma at a National Hospital in Central Malawi

Patrick GMC Phiri^{1,2,*}, Alfred Owino Odongo¹, John G Kariuki¹

ABSTRACT

Background: The health-related quality of life (HRQoL) HRQoL continues to be understudied among family caregivers with chronically ill children especially in developing countries like Malawi. Aim: This study aimed to assess health-related guality of life and determine the sociodemographic factors associated with the health-related quality of life of caregivers of children with lymphoma at a referral hospital in Malawi. Materials and Methods: A cross-sectional study was carried out at a referral hospital in Malawi, and 107 caregivers were recruited. The Medical Outcomes Study Questionnaire 36-Item Short Form was used to collect data which were analysed using SPSS Version 25. Results: All 107 targeted participants were assessed. Both the physical health component and the mental health component mean scores were low (M=50.63, SD=11.86 and M=45.51, SD=11.95, respectively). Time since diagnosis of the child's cancer accounted for significant differences in both the physical and mental health components' mean scores (F(2, 104)=5.030, p=0.002 and F(2, 104)=5.030, p=0.006, respectively). The caregivers >41years old, those who were married, those who were employed, and caregivers whose children were diagnosed >12 months were among those more likely to report a better physical health perception compared to those without these characteristics. Conclusion: The health-related quality of life of the caregivers at the referral hospital was severely impaired. The findings suggest that caregivers of children with lymphoma have the potential to develop more serious mental and physical health problems; hence, interventions to mitigate the burden of caring for children with lymphoma are needed.

Keywords: Family caregivers, Health-related quality of life, Lymphoma, Physical health, Mental health, Medical outcomes questionnaire, Central hospital, Malawi.

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INTRODUCTION

Despite making some progress in childhood cancer care, the burden of cancer on family members remains critically significant in Malawi. In 2018, almost 87.7% of children with cancer, including those with lymphoma, received most of their treatment at home after stabilisation.1 The presence of co-morbidities, treatment abandonment, high default rates, and loss to follow-up all contribute to longer treatment durations for children diagnosed with cancer, including those affected with lymphoma.² Coupled with the continuation of home care and treatment, the time and effort required to care for a child with lymphoma can result in high levels of stress for caregivers.3 These aspects of care have implications for family caregivers' health-related quality of life (HRQoL), which is the degree of happiness and satisfaction with life and the perception of the impact that illness and its adverse effects have on one's life.4 Current literature concludes that with careful measurement, HRQoL can be a major predictor

of the patients', family caregivers', and healthcare workers' health. $^{\!\!\!\!\!^{4,5}}$

Consensus exists on the importance of family caregivers and their influence on clinical outcomes and the well-being of children with cancer.6 Family caregivers are the first line of support for children with cancer.7 Thus, caregivers need to be a part of the HRQoL equation if lymphoma care is to improve.^{6,7} Given that research on cancer and HRQoL has mainly focused on children alone7,8 and with little or no evidence on assessing the HRQoL of family caregivers of children with lymphoma, there is a critical absence of empirical information on the HRQoL of both caregivers and their children with lymphoma. More importantly, in Malawi, suboptimal outcomes indicative of poor HRQoL in caregivers of children with lymphoma have been reported. For instance, Stanley et al.1 reported that some caregivers of children with lymphoma enrolled at one of the central hospitals abandoned the treatment

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of their children due to anxiety and loss of hope, which are two of the characteristics of impaired quality of life in family caregivers. Yet, despite this evidence, the full scale of the effect of caring for children with lymphoma has not been studied in Malawi, let alone the HRQoL of family caregivers. This study sought to (1) determine the HRQoL of caregivers caring for children with lymphoma; (2) identify differences in the domains of HRQoL among family caregivers based on the time since diagnosis (i.e., between one and six months, seven and 12 months, and more than 12 months); and (3) identify the association between caregivers' socio-demographic characteristics and the domains of HRQoL among family caregivers of children with lymphoma at national hospital in Central Malawi.

MATERIALS AND METHODS

This was a cross-sectional study which used stratified random sampling technique to recruit family caregivers.⁸ The family caregivers were first divided into three strata based on their time since diagnosis. Subgroup 1 was comprised of caregivers whose children were diagnosed between one and six months, Subgroup 2 was comprised of caregivers whose children were diagnosed between seven and 12 months, and Subgroup 3 was comprised of caregivers whose children were diagnosed more than 12 months. The sample size was determined to give adequate precision for estimating the parameters of interest using the formula below⁹ and 107 participants were recruited.

$$N = \frac{z_{a/2}^2 * p(1-p) * DEFF}{d^2}$$

Ethical clearance was sought from Mount Kenya University (MKU/ ERC/1803/#876) and the National Health Sciences Research Committee of Malawi (21/09/1793). The participants were informed of the risks and benefits of the study through a written information sheet, and the participants who agreed to participate in this research signed a written consent form immediately before data collection started. Data from both male and female caregivers were collected face to face using the Medical Outcomes Study Questionnaire 36-item Short Form (SF-36).¹⁰

The primary outcome variables were the physical health component (PHC) and the mental health component (MHC) of the SF-36. Data were collected on the eight HRQoL dimensions that form the PHC and the MHC on the SF-36.10,11 The physical functioning dimension measures the extent to which individuals' physical health status limits their physical activities, whereas the physical role function dimension measures the extent to which individuals' physical status interferes with their daily health activities.¹² The general health dimension measures individuals' perception of their health status at present compared to four weeks prior and how this aspect interferes with their performance of daily activities.¹² The bodily pain dimension measures the presence of pain and how individuals' pain interferes with their performance of daily activities. The vitality dimension measures individuals' general feeling of strength or tiredness, while the emotional role function measures emotional problems and how these interfere with individuals' work and daily activities.¹³ The social functioning dimension measures how individuals' emotions interfere with their social activities. The last (general mental health) dimension measures individuals' presence or absence of emotional aspects, such as anxiety and depression.

The different dimensions of the SF-36 are scored on a Likert scale with different levels, except physical health which is scored as "Yes" or "No." To calculate the final score, each score is transformed into a 0 to 100 score (Supplementary Material 1 and 2), and the lower the score, the poorer the HRQoL.^{12,14} In this study, the socio-demographic variables of the caregivers, such as age, gender, marital status, education level, occupation, household income, relationship with the child, area of

residence (rural or urban), time since diagnosis, period of treatment, religion, cultural group, number of children, and distance from the nearest hospital, were added.

Data were analysed using SPSS Version 25. One-way ANOVA was employed to examine the differences in time since diagnosis and the scores in the PHC and the MHC domains, which were the primary outcomes of HRQoL. Multiple linear regression analysis was used to determine whether socio-demographic characteristics were significantly associated with the primary outcomes of HRQoL as previously described. Categorical variables were recoded to dummy variables first before performing linear regression analysis.¹⁵ All statistical tests were set to two-sided, and the level of statistical significance was set at 0.05. The PHC and MHC domains were the dependent variables, whereas the socio-demographic characteristics of the caregivers were the independent variables.^{14,15}

Supplementary Material 1: Step 2: Components of SF-36 and their domains or components.

The 8 Components		Items Item # SF-36		Components
1	Physical functioning	10	3 4 5 6 7 8 9 10 11 12	Physical Health Components
2	Physical role function	4	13 14 15 16	
3	Bodily pain	2	21 22	↓
4	General health	5	1 33 34 35 36	
5	Vitality	4	23 27 29 31	Mental Health Component
6	Emotional role limitation	3	17 18 19	Ļ
7	Social Functioning (social role)	2	20 32	v
8	General mental health	5	24 25 26 28 30	

Supplementary Material 2: Step 1-SF-36 Scoring Criteria and Recoding of Items to transformed scores between 1 and 100.

Item numbers	Original response category	Recode original response to
1, 2, 20, 22, 34, 36	1	100
	2	75
	3	50
	4	25
	5	0
3, 4, 5, 6, 7, 8, 9, 10, 11, 12	1	0
	2	50
	3	100
13, 14, 15, 16, 17, 18, 19	1	0
	2	100
21, 23, 26, 27, 30	1	100
	2	80
	3	60
	4	40
	5	20

	6	0
24, 25, 28, 31	1	0
	2	20
	3	40
	4	60
	5	80
	6	100
32, 33, 35	1	0
	2	25
	3	50
	4	75
	5	100

RESULTS

A total of 107 participants were targeted and 107 participants were recruited, representing a 100% response rate. The ages of the participants ranged from 18 to 63 years old, with a mean age of 31.4 years (SD=9.35). Most of the participants were between 21 and 30 years old, and 48.6% were married. The characteristics of the sample are presented in Table 1. The results showed that there was a higher mean score for the physical functioning component (M=56.00, SD=15.13), while the general mental health component was the least scored (M=38.82, SD=10.02). Whereas, the PHC had a higher mean score (M=50.63, SD=11.86) compared with MHC (M=45.51, SD=11.95), as presented in Table 2.

The results showed that the time since diagnosis variable accounted for significant differences in the PHC domain's mean scores (F(2, 104)=5.030, p=0.002), in which the caregivers whose children's diagnosis was given more than 12 months reported a higher PHC mean score. The time since diagnosis variable also accounted for significant differences in the MHC domain's mean scores (F(2, 104)=2.342, p=0.006), in which the caregivers whose children were diagnosed more than 12 months reported higher mean scores (Table 3).

Compared with the caregivers <20 years old, those who were >40 years old were more likely to experience better physical health (β =122.833, p<0.001). Compared with single caregivers, those who were married were more likely to report better physical health (β =40.332, p<0.001). The caregivers whose children had >12 months of lymphoma treatment were less likely to experience better physical health (β =-10.073, p=0.026) compared with those who had <6 months of lymphoma treatment. Moreover, those who lived >8 kilometres away from the hospital were less likely to have better physical health (β =-6.980, p=0.038). Compared with being a sister, brother, grandparent, cousin, or other family member in relation to the child, the caregivers who were parents of children with lymphoma were less likely to experience optimal physical health (β =-103.524, p=0.042).

Regarding the MHC the caregivers who were \geq 41 years old were more likely to experience optimal mental health compared with those <20 years old (β =66.643, p<0.001). Compared with the male caregivers, the female caregivers in this study were less likely to report an optimal mental health experience (β =-195.444, p<0.001), whereas the caregivers who were separated were also less likely to report optimal mental health (β =-56.842, p=0.29). Lastly, the caregivers who were parents of children suffering from lymphoma were less likely to report a better mental health experience compared with those who were sisters, brothers, cousins, or other family members (β =-34.647, p<0.001), as shown in Table 4.

Table 1: Demographic characteristics of study participants.					
Socio-demographic characteristics	Subgroup	Frequency (%)			
Age (years)	<20	9 (8.4)			
	21-30	50 (46.7)			
	31-40	21 (19.6)			
	>40	27 (25.2)			
Gender	Male	17 (15.9)			
	Female	90 (84.1)			
Marital status	Single	22 (20.6)			
	Married	52 (48.6)			
	Separated	20 (18)			
	Widowed/widower	13 (12.1)			
No. of Children	1-4	90 (84.1)			
	5-10	17 (15.9)			
Education level	None	0 (0.0)			
	Primary	70 (65.4)			
	Secondary	30 (28.0)			
	University	7 (6.5)			
Religious denomination	Catholic	38 (35.5)			
	CCAP	34 (31.8)			
	SDA	11 (10.3)			
	Pentecostals	13 (12.1)			
	Moslem	11 (10.3)			
Cultural background	Chewa	30 (28.0)			
	Tumbuka	24 (22.4)			
	Yao	33 (30.8)			
	Lhomwe	20 (18.7)			
Occupation	Farmer	13 (12.1)			
	business	58 (54.2)			
	Formal employment	36 (33.6)			
Time since diagnosis	Up to 6 months	50 (46.7)			
	7 to 12 months	37 (34.6)			
	Above 1 year	20 (18.7)			
Place of treatment	Admitted	52 (48.6)			
	Attending Clinic	55 (51.4)			
Period on treatment	Up to 6 months	54 (50.5)			
	7 to 12 months	45 (42.1)			
	Above 1 Year	8 (7.5)			
Residence	Rural	53 (49.5)			
	Urban	18 (16.8)			
	Semi-urban/District town	36 (33.6)			
Distance to Hospital	<8 Kilometres	39 (36.4)			
	>8 Kilometres	68 (63.6)			
Monthly income (US\$)	<\$100.00	45 (42.1)			
	\$100-200	33 (30.8)			
	\$201-300	29 (27.1)			
Relationship with the Child	Sister/Brother/Cousin	24 (22.4)			
	Parent	63 (58.9)			
	Grandson/daughter	20 (18.7)			

Data are presented as frequency (percentage); \$= United States Dollar

Table 2: Mean scores on 8 components of HRQoL on the SF-36.									
	Descriptive Statistics								
	HRQoL Component	Ν	Mean	SD					
1	Physical Functioning	107	56.82	15.13					
2	Physical Role Function	107	48.83	45.45					
3	Bodily Pain	107	42.00	13.78					
4	General Health	107	54.86	11.60					
5	Vitality	107	42.05	11.16					
6	Emotional Role Limitation	107	51.87	9.96					
7	Social Function	107	49.30	16.18					
8	General Mental Health	107	38.82	10.02					
	Total Physical Health Component (1-4)	107	50.63	11.86					
	Total Mental Health Component (5-8)	107	45.51	11.95					

Table 3: Physical Health Component and Mental Health Component mean scores by time since diagnosis KCH Hospital.

Time since diagnosis	Physical Health Component Domain				Mental Health Component Domain			
	Mean	SD	F Statistic	Р	Mean	SD	F Statistic	Р
<6 Months	47.05	11.09	F (2, 104) =5.03	.002	44.43	11.51	F (2, 104) =2.342	.006
7-12 Months	50.07	12.08			46.23	13.01		
>12 Months	55.60	12.54			49.69	10.95		

SD=Standard Deviation; F=F statistic; PHCD=Physical Health Component Domain; MHCD=Mental Health Component Domain; P=p-value

Table 4: Associations between Physical Health and Mental Healt
domain mean scores and the Caregivers' socio-demographic
characteristics.

Background characteristics	Physical Health Domain Score		Mental Health Domain Score			
	β	SE	<i>p</i> -Value	β	SE	p-Value
Age (years)						
<20 (Ref)						
21-30	-45.951	85.255	.591	30.779	33.153	.355
31-40	2.276	20.409	.911	43.636	58.904	.115
>41	122.833	10.208	<.001	66.643	11.575	<.001
Gender						
Male (Ref)						
Female	11.379	15.202	.456	-195.444	47.429	<.001
Marital status						
Single (Ref)						
Married	40.332	10.519	<.001	38.411	22.015	.084
Separated	-27.572	60.364	.649	-56.842	25.653	.029
Widow/Widower	-74.193	66.572	.268	33.842	28.291	.234
No. of Children						
1-4 (Ref)						
5-10	64.863	75.980	.395	62.156	119.264	.603
Education level						
None (Ref)						
Primary	8.952	22.517	.692	-45.951	85.255	.591
Secondary	24.583	19.612	.213	32.276	20.409	.101

University	21.784	26.924	.420	12.583	31.135	.066
Religious						
denomination						
Catholic (Ref)						
CCAP	-185.992	113.746	.104	-65.098	47.741	.174
SDA	-194.080	117.454	.100	-62.461	47.529	.190
Church of Christ	24.309	14.058	.087	-55.057	49.078	.263
Pentecostals	-55.057	49.078	.263	423.333	158.127	.008
J/ Witness	-135.000	158.127	.394	-36.667	66.074	.580
Cultural						
background						
Tumbuka (Ref)						
Chewa	15.405	18.392	.403	18.071	26.157	.491
Yao	8.707	17.222	.614	17.371	24.781	.485
Lhomwe	23.000	17.516	.191	12.905	28.302	.649
Occupation						
Farmer (Ref)						
Business	1.962	72.114	.978	47.822	46.037	.304
Formal	29.833	16.621	.076	28.708	10.611	.031
Employment						
Time since						
diagnosis						
≥6 months (Ref)	40 417	(2.02.1	112	0.555	2 000	014
/-12 months	48.417	62.924	.443	-9.5//	3.880	.014
Over 12 Months	13.933	9.797	.727	8.482	4.883	.048
Place of						
Admitted (Pef)						
Attending clinic	10 252	22.021	120	169 002	27 790	< 001
Pariod on	-10.235	22.921	.420	100.092	37.709	<.001
treatment						
<6 months (Ref)						
7-12 months	19,150	62.044	.758	3,975	39,791	026
Over 12 Months	-10.073	4.538	.027	-47.410	20.456	.022
Residence	101070	1000	1027	1,1110	201100	1022
Rural (Ref)						
Urban	-27,305	30.532	373	-10.983	19.427	573
Semi-Urban/	-158.030	126 141	012	-13 565	11.078	224
District	150.050	120.111	.012	10.000	11.070	.221
Distance to Hospital						
<8kms (Ref)						
>8kms	-6.980	3.356	.038	38.167	48.547	.434
Monthly income	-41.095	38.285	.286			
<\$100.00 (Ref)						
USD\$100-200	18.443	16.789	.275	41.095	38.285	.286
\$201-300	81.764	38.305	.035	46.175	87.350	.060
Relationship with the Child						
Sister/Brother/						
Cousin (Ref)	102.254	50 114	0.12	24.647	10 (02	< 0.01
Parent	-103.254	50.114	.042	-34.647	10.683	≤.001
Grandson/ daughter	-4.856	21.008	.818	-10.080	13.673	.737

Ref=Reference categorical value; No. children=Number of Children; CCAP= Church of Central Africa Presbyterian; SDA=Seventh Day Adventist; SE=Standard Error.

J/Witness= Jehovas' Witness

DISCUSSION

This study demonstrated that the HRQoL of the caregivers at the current setting was severely impaired. These findings support the notion that overall, the caregivers' HRQoL was affected by the burden of caring for a child with lymphoma. Compared with the findings of Lim *et al.*¹⁶ who compared HRQoL in six countries (Singapore, Iran, Turkey, the United Kingdom, the United States, and Canada), the caregivers' PHC and MHC mean scores ranged from 60 to 93 in those studies. In the current study, the PHC mean score was 50.63 (*SD*=11.86), while the MHC mean score was 45.51 (*SD*=11.95). When rating HRQoL using the SF-36, Konstantinou *et al.*¹⁷ explained that mean scores of 50 or lower represented severe impairment of one's HRQoL. Given that the SF-36 also acts as a diagnostic tool for individuals' HRQoL^{4,12-17} the current findings suggest that caregivers of children with lymphoma at this national referral hospital had a severe form of impaired HRQoL.

The time since diagnosis accounted for significant differences in the PHC and MHC domains' mean scores. These findings were further supported by multiple linear regression analysis. For example, the caregivers whose children were diagnosed >12 months were more likely to experience better mental health (β =8.482, p=0.048) compared with those who were diagnosed <12 and <6 months, respectively. Thus, the current findings confirmed the diagnostic nature of the SF-36 as a measure of individuals' HRQoL at different times of the disease. The current findings also confirmed the findings of Tsai et al.18 who also reported that the parents of children with cancer diagnosed within the first months experienced enormous psychological stress, which affected both their physical and mental health well-being. In the analysis of the psychosocial impact of the diagnosis of cancer on children, families, and the community, Gorman¹⁹ claimed that parents usually experienced stress, trauma, and anxiety in the first months of living with the diagnosis. Conversely, those who were diagnosed more than 12 months had developed stringent coping mechanisms.¹⁷⁻¹⁹ Previous literature has concluded that the improvement in HRQoL mean scores as time elapses may also be due to the treatment outcomes of the child.¹⁸⁻²⁰ Nevertheless, the findings of this study imply that the lymphoma diagnosis impacted the caregivers more in the first six months of diagnosis. Thus, interventions to mitigate this early impact are needed as early as the child is diagnosed with cancer.

The study found that caregivers who were >41 years old were more likely to have better PHC mean scores compared with those who were younger. The association between caregivers' age and HRQoL has been reported in previous studies.²⁰ The factors attributing to this finding have not been well documented in previous literature on caregivers' HRQoL. However, literature has suggested that older caregivers who are >40 years old are more mature, have experienced some stress in the past, are more optimistic, and have a greater capacity to manage stressors owing to their experiences, although they may be physically challenged.²¹ The preceding findings support the current results. However, the real contribution of older age to positive HRQoL for caregivers should be further studied in current settings.

The current study's findings support the notion that gender is an important determinant in caregivers' perception of HRQoL, as described in other professions such as nursing and teaching²² For instance, the female caregivers were more likely to be linked to poor HRQoL compared with their male counterparts. Rosler-Schidlack *et al.*¹² explained that female caregivers tend to experience more subjective care burden due to their demanding social roles. In the nursing profession, for example, some literature has concluded that female nurses tend to experience difficulties in work-life balance and have multiple roles compared with male nurses, which affects their coping styles.¹⁹⁻²² Interestingly,

Svedding²³ and Rodriguez *et al.*²⁴ suggested that the influence of gender on poor health as reported in females compared with males in most families may stem from the fact that most men do not traditionally admit to suffering from poor health conditions due to their masculinity compared with women.

Separated caregivers were more likely to experience poorer MHC mean scores. Research on the relationship between caregivers' HRQoL and being a married or separated caregiver is not well documented from the caregivers' perspective. One study on general quality of life concluded that married caregivers (men 40 to 69 years old and women >40 years old) experienced a better quality of life than those without partners.²¹ Han et al.²¹ accredited this finding to versatility, positive encounters, and backing from each spouse. While the current study demonstrated that the longer the time since the diagnosis was made, the better the PHC and MHC mean scores, in contrast, the longer the children received treatment, the worse the caregivers' HRQoL. Whereas Tsai et al.¹⁸ explained that while caregivers gradually come to terms with the diagnosis of cancer between three and six months and then cope after 12 months, their optimal perception of physical health and mental health may continue to be affected by the length of treatment, leading to relapses in anxiety and depression. Fear of recurrence of the disease and myths and the fear of the unknown have also been attributed to caregivers' impaired HRQoL following a long period of treatment.¹⁹⁻²⁴ Stanley et al.1 suggested providing hospital home visits to inform homebased care and linking families to community-based support groups as possible interventions to mitigate these negative experiences.

Caregivers who attend clinics are more likely to experience better mental health than those with children who are admitted to the hospital ward. Although commuting from home may be burdensome to both the caregivers and their children, it is suggested that at-home, caregivers are able to attend to household chores, look after their other children, and engage in community activities, which has the potential to promote better HRQoL.^{1,24} Given the health benefits, attending a clinic as a way of continuing treatment is a commendable strategy that should be promoted.

In this study, a significant association between living in semi-urban district towns and physical health was identified. It is worth noting that apart from ease of transportation, most urban district towns and rural areas share similar conditions in Malawi, such as poor health facilities that are often understaffed, underfunded, and under-resourced.25 Several studies on the sociology of health and disparities in health care have documented the important contribution of living in rural, semiurban, and urban areas to one's health status.²⁶ For example, studies on low income and developing countries have shown that rural residents are most likely to experience poor health and lower survival rates. The United for Sight Report on Global Health²⁷ reported that people in rural and semi-urban areas are often more unlikely to have the quickest access to a healthcare centre, well-trained physicians and nurses, and palliative care services for the chronically ill compared with those in urban areas. This unlikelihood of quick access to healthcare facilities is compounded by the distance to clinics, which is usually beyond the stipulated distance according to different healthcare policies.28 Thus, the poor physical health reported in the current study may have been attributed to the overall lack of access to adequate healthcare services in semi-urban and rural areas in Malawi. Given the nature of the current findings, a policy framework that includes strategies and interventions that address disparities in HRQoL in rural, semi-urban, and urban areas should be developed by healthcare officials in Malawi.

As demonstrated, the caregivers who earned between US\$201 and US\$300 were more likely to have a better physical health experience compared with their counterparts who earned less. In quantitative

terms, the relationship between income and caregivers' HRQoL has not been directly addressed in recent studies on caregivers. However, similar findings have been reported in nursing studies. For example, Ali *et al.*²⁹ reported that having a higher income was significantly associated with nurses' better HRQoL. However, Ali *et al.*²⁹ did not specify the income ranges of the nurses and the relationship to their physical and mental health. As such, one cannot reliably conclude that financial resources are important for better physical and mental health, especially for caregivers. It is imperative that more research is carried out in other settings and countries to identify and compare the relationship between income and caregivers' HRQoL.

Having a child with lymphoma is likely to limit the optimal HRQoL of caregivers as found by the current study. In support, some previous studies have documented that families are affected when a child is diagnosed with cancer.³⁰ However, literature indicating who among the family was the most affected was not evident. While the current evidence is relatively new to the literature on caregivers' HRQoL, it suggests that the HRQoL of caregivers who are the parents of a child with lymphoma are most affected compared with those who are grandparents, cousins, brothers, and sisters. However, the lack of previous studies on this issue requires that the current findings be interpreted and generalised with caution, hence the need for more studies on this important variable.

This study demonstrated that religion may play a role in one's optimal experience of HRQoL. For instance, the current findings showed that being a member of the Pentecostal church was more likely to be associated with better mental health. In their review, Panzini et al.³¹ observed proof of the relationship between religion and personal satisfaction in investigations of medical services, which revealed that medical care staff who practiced strict religiosity scored better on quality of life. In the case of Pentecostalism, its contribution to caregivers' quality of life was partially ascertained by Kohrsen³² who claimed that Pentecostalists believe that the Holy Spirit can gift them with specific awards, such as spiritual healing, prophecy of their disease, and reversal of demonic powers that come with the disease. Thus, it is believed that Pentecostalism aids in coping. While this may partially explain why Pentecostals were likely to be associated with significantly better mental health, the findings from this study found limited evidence on the influence of religious denominations on the caregivers' HRQoL to date. Nevertheless, the influence of religion has the potential to integrate religious-related practices in interventions, such as making scheduled programs for religious prayers and religious visitations in hospitals to enhance caregivers' coping mechanisms.

CONCLUSION

The current findings showed evidence supporting the notion that caregivers of children with lymphoma, like any other cancer or chronic illness, are affected by disease burden. Moreover, the study established that the time since the child was diagnosed with cancer accounted for significant differences in both the PHC and MHC domains' mean scores of the caregivers. This implies that the time since diagnosis is an important consideration when studying HRQoL in caregivers. As the current study identified multiple factors and socio-demographic characteristics associated with the caregivers' HRQoL compared with previous studies, it found that no one factor or setting conclusively determined the caregivers' overall HRQoL. Further studies, such as cross-sectional studies on the HRQoL of other key populations whose presence has a direct bearing on caregivers' HRQoL such as children, are needed. More randomised controlled trials to test the effectiveness of some psychosocial interventions, such as problem-solving skills training, psychoeducation, psychosocial counselling, and hospital-based support

groups, on reducing caregivers' anxiety and depression and improving their HRQoL are vital in Malawi.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

REFERENCES

- Stanley CC, Westmoreland KD, Itimu S, Salima A, Van der Gronde T, Wasswa P, et al. Quantifying bias in survival estimates resulting from loss to followup among children with lymphoma in Malawi. Pediatr Blood Cancer. 2017;64(6):e263-70. doi: 10.1002/pbc.26370, PMID 27896944.
- Dozzo M, Donnis MP, Scattolin A, Maino E, Bassan R. Burkitt's lymphoma in adolescents and young adults: Management challenges. Adolesc Health Med Ther. 2016;11:11-29.
- Jensen RE, Arora NK, Bellizzi KM, Rowland JH, Hamilton AS, Aziz NM, et al. Health-related quality of life among survivors of Hodgkin lymphoma. Cancer. 2013;119(3):672-80. doi: 10.1002/cncr.27781, PMID 22951588.
- Litwin MS. Health-related quality of life. In: Penson DF, Wei JT, editors. Clinical research methods for surgeons. Humana Press; 10.10.1007/978-1-59745-230-4_13. doi: doi.
- Vlachioti E, Matziou V, Perdikaris P, Mitsiou M, Stylianou C, Tsoumakas K, et al. Assessment of quality of life of children and adolescents with cancer during their treatment. Jpn J Clin Oncol. 2016;46(5):453-61. doi: 10.1093/jjco/hyw009, PMID 26889049.
- Klassen AF, Raina P, McIntosh C, Sung L, Klaassen RJ, O'Donnell M, *et al.* Parents of children with cancer: Which factors explain differences in healthrelated quality of life. Int J Cancer. 2011;129(5):1190-8. doi: 10.1002/ijc.25737, PMID 21064097.
- Dix DB, Klassen AF, Papsdorf M, Klaassen RJ, Pritchard S, Sung L. Factors affecting delivery of family-centred care in pediatric oncology. Pediatr Blood Cancer. 2009;53(6):1079-85. doi: 10.1002/pbc.22168.
- 8. Rosner B. Fundamentals of statistics. 8th ed. Australia: Cengage Learning; 2011.
- Setia MS. Methodology series module 3: cross-sectional studies. Ind J Dermatol. 2016;6(3):261-4. doi: 10.4103/0019-5154.182410.
- Ware JE, Sherburne CD, The MOS. 36-item short-form health survey (SF-36). Conceptual framework and item selection. Med Care. 1992;30:473-83.
- Ware JE, Kosinski M, Dewey JE. How to score version two of the SF-36 rand Health Survey. Hays Arch Phys Rehab. 2002;83(2):1189-201.
- Rösler-Schidlack B, Stummer H, Ostermann H. Health-related quality of life of family caregivers' evidence from Hesse. J Public Health. 2011;19(3):269-80. doi: 10.1007/s10389-010-0369-z.
- Kobayashi K, Nakagami-Yamaguchi E, Hayakawa A, Adachi S, Hara J, Tokimasa S, et al. Health-related quality of life in Japanese children with acute lymphoblastic leukemia during and after chemotherapy. Pediatr Int. 2017;59(2):145-53. doi: 10.1111/ped.13092, PMID 27422759.
- Kuerten BG, Brotkin S, Bonner MJ, Ayuku DO, Njuguna F, Taylor SM, et al. Psychosocial burden of childhood sickle cell disease on caregivers in Kenya. J Pediatr Psychol. 2020;45(5):561-72. doi: 10.1093/jpepsy/jsaa021, PMID 32374404.
- Morozova O, Levina O, Uusküla A, Heimer R. Comparison of subset selection methods in linear regression in the context of health-related quality of life and substance abuse in Russia. BMC Med Res Methodol. 2015;15:71. doi: 10.1186/ s12874-015-0066-2, PMID 26319135.
- Lim HA, Tan JY, Chua J, Yoong RK, Lim SE, Kua EH, et al. Quality of life of family caregivers of cancer patients in Singapore and globally. Singapore Med J. 2017;58(5):258-61. doi: 10.11622/smedj.2016083, PMID 27090600.
- Tsai MH, Hsu JF, Chou WJ, Yang CP, Jaing TH, Hung IJ, et al. Psychosocial and emotional adjustment for children with pediatric cancer and their primary caregivers and impact on health-related quality of life during the first six months. Qual Life Res. 2013;22(3):625-34. doi: 10.1007/s11136-012-0176-9, PMID 22528241.
- Gorman LM. The psychosocial impact of cancer on individuals, family, and society. In: Oncology Nursing Society, editor. Oncology Nursing Society; 2009;1-21.
- Rensen N, Steur LM, Schepers SA, Merks JH, Moll AC, Kaspers GJ, et al. Gender-specific differences childhood cancer. Pediatr Blood Cancer. 2019;66(7):e27728. doi: 10.1002/pbc.27728, PMID 30916456.
- Han KT, Park EC, Kim JH, Kim SJ, Park S. Is marital status associated with quality of life? Health Qual Life Outcomes. 2014;12:109. doi: 10.1186/s12955-014-0109-0, PMID 25104276.
- Sarafis P, Rousaki E, Tsounis A, Malliarou M, Lahana L, Bamidis P, et al. The impact of occupational stress on nurses' caring behaviors and their healthrelated quality of life. BMC Nurs. 2016;15:56. doi: 10.1186/s12912-016-0178-y, PMID 27708546.
- 22. Routes J, Costa-Carvalho BT, Grimbacher B, Paris K, Ochs HD, Filipovich A, et al. Health-related quality of life and health resource utilization in patients

with primary immunodeficiency disease prior to and following 12 months of immunoglobulin G treatment. J Clin Immunol. 2016;36(5):450-61. doi: 10.1007/s10875-016-0279-0, PMID 27091140.

- Rensen N, Steur LMH, Schepers SA, Merks JHM, Moll AC, Kaspers GJL, et al. Determinants of health-related quality of life proxy-rating disagreement between caregivers of children with cancer. Qual Life Res. 2020;29(4):901-12. doi: 10.1007/s11136-019-02365-9, PMID 31820207.
- Rodriguez E, Perez-Penaranda A, Losada-Baltar A. Relationships between quality of life and family function in caregiver. BMC Fam Pract. 2011;12:1-19.
- Oyama Y, Fukahori H. A literature review of factors related to hospital nurses' health-related quality of life. J Nurs Manag. 2015;23(5):661-73. doi: 10.1111/ jonm.12194, PMID 25807874.
- Eberhardt MS. The importance of place of residence: Examining health in rural and nonrural areas. Am J Pub Health. 2014;94(10):1682-6.
- 27. United for sight. Module 2: What are health disparities? p. module2.htm/2017.

Sight.org. Urban-rural health. Available from: http://www.United for.

- Milton A. Rural versus urban access to healthcare services. Soc Health. Sep 2009;14-21.
- Ali A, Rasheed A, Naz S. Health-related quality of life of nurses working in tertiary care hospital of Karachi. Pak J Med Sci. 2020;36(3):490-5. doi: 10.12669/ pjms.36.3.1267, PMID 32292458.
- Eiser C, Varni JW. Health related quality of life symptom reporting: Similarities and differences between children and their parents. Eur J Pediatr. 2013;172(10):1299-304. doi: 10.1007/s00431-013-2049-9, PMID 23715654.
- Panzini RG, Mosqueiro BP, Zimpel RR, Bandeira DR, Rocha NS, Fleck MP. Quality of life and spirituality. Int Rev Psychiatry. 2017;29(3):263-82. doi: 10.1080/09540261.2017.1285553, PMID 28587554.
- Koehrsen J. When sects become middle class: Impression management among middle class Pentecostals in Argentina. Sociol Relig. 2017;78(3):318-39. doi: 10.1093/socrel/srx030.

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