

Health-Related Quality of Life for Primary Caregivers of Mentally ILL Patients in Kenya

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Abstract

The mentally ill patients have been shifted from institutions to home based care involving the family and the community than the straight in-hospital treatment. Consequently, the prevalence of mental illness is rising which is proportional to increased burden the primary caregivers' face that affect their HRQoL. The aim of this study was to determine the Health Related Quality of Life (HRQoL) and associated factors of primary caregivers of the mentally ill patients at the largest teaching and referral psychiatry hospital in Kenya. A correlational study was used. Systemic random sampling was used to recruit 310 caregivers of mentally ill patients in the outpatient clinic. The WHOQoL-BREF questionnaire was used to assess Caregivers HRQoL. Statistical package for social sciences version 25.0 was used for analysis. Pearson r was used to test relationships between variables and multivariate regression models were used to determine predictors of HRQoL. On quality rating 1-5, Majority (34.4%, mean 2.61 SD 1.05) of the participants reported poor HRQoL. Caregivers' marital status (r = -.292, P=0.000), relationship with the patient (r = -.166, P=0.004) and patient gender (r = -.188, P=0.001) significantly correlated with primary caregivers' poor HRQoL. Patients' review with compliance to treatment (61.5%), and health system support (r = .420, P=0.000), were significantly associated with primary caregivers' HRQoL. Specialized psychiatric and mental health professionals with policy designers to realize characteristics which impact the caregivers 'HRQoL so that intervention is done especially Psycho-education on patient care, encourage social support groups and improve health support system.

Keywords: Health Related Quality of Life, Primary caregivers, mentally ill Patients.

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Introduction

Globally, about 792 million were reported to be living with mental disorders by 2017 (Saloni Dattani et al., 2021). In Kenya, mental health is a real concern and has been ranked as the 4th in Africa and 9th globally with high numbers (1.9 million) of depressed persons leading to an increase in cases of suicides. In addition stigma and description has perpetuated mental illness and marginalization of persons and families with mental illness in Kenya (MOH, 2020). The Kenya Ministry of Health (MOH) estimates that up to 25% of outpatients and up to 40% of inpatients in health facilities suffer from mental illness. In addition, the MOH committed to decentralize mental health services by shifting the services to primary care and community level (MOH, 2021).

The mentally ill patients have been shifted from institutions to home based care involving the family and the community than the straight in-hospital treatment. Consequently, the prevalence of mental illness is rising which is proportional to increased burden the primary caregivers' face that affect their HRQoL. This due to the reorganization of mental health treatment models in the global community from hospitals to the community which has a profound, effect on the family (Noghani et al., 2016). Primary caregivers are expected to provide care to patients throughout their lifespan given that mental illness is a chronic condition (Ntsayagae, Poggenpoel, & Myburgh, 2019). Most individuals with mental illness live with their families (Leng, et al., 2018), and therefore primary caregivers play a major role in caring for persons with mental illness in various aspects (Chadda 2014).

In Kenya previously, the extended family members offered assistance of care to mentally disabled person aiding the burden of care anticipated from the nuclear family (Mbugua et al., 2011). After reorganization of mental health of shifting the services to primary care and community level, there has also been a shift of care from extended family to nuclear family, making the degree of the responsibility on mental disability greater for nuclear families (Ndetei et al; 2009, Mbugua et al; 2011).

The caregivers are either the parent, aged family members, or jobless family members of the patient who find themselves caregivers without planning for it nevertheless realize the need inevitable, further more they are never prepared for this role, and in the process of care they find it very straining (Mbugua et al; 2011). The caregiver is disadvantaged of their rights and respect that go with their occupations which lack growth as the individual continue to work obligatorily (Mbugua et al; 2011), making them a traumatized population as they have had many experiences and exposures leading to increased vulnerability to mental ill health with far reaching bearing on their health-related quality of life (Kenya Mental Health Action Plan 2021-2025). The unfavorable impact of caregiving on family caregivers' health has been reported as requiring attention (Van Wijngaarden, Schene & Koeter 2013).

The quality of life (QoL) of caregivers of mental health is negatively affected. Studies in Sub-Saharan Africa have shown that 86% of caregivers of mentally ill patients generally have lower HRQoL and have reported issues such as high levels of anxiety psychosomatic problems, stress, psychological issues, societal separation, domestic struggles and severe financial problems (Sintayehu, Mulat & Yohannis, 2015; Xie, Cheng & Tao, 2016; Totsika, Hastings &Vagenas, 2016), which in turn result in poor HRQoL (Jeong, Myong & Koo, 2015).

Majority of caregivers of mentally ill patients in Kenya, receive no monetary support because of underprivileged socioeconomic status of the people, which make the caregivers defenseless as



they are not able to manage what occurs in their own lives which lowers their HRQoL (Mbugua et al; 2011). Their Sense of control is related with good physical and psychological health which miss in some of the caregivers, (Mbugua et al; 2011). The association among caregiving and health is defined normally in terms of stress. Stressors in the situation of caregiving are the trying conditions or obstacles which limit the caregivers' capacity to cope. (Mbugua et al; 2011). People with mental disorders experience unduly developed rates of incapacity and mortality which frequently lead individuals and relatives into poverty which led to poor HRQoL (Kenya mental policy 2015-2030).

It is therefore suitable to consider what is to be done about caregivers' mental health as an important component of one's HRQoL or general health. Though good advancement has been set in studying and documenting the lived involvements of primary caregivers' of mentally ill patients in Africa and Kenya (Ndetei 2009), there is not much evidence about assessing primary caregivers' HRQoL and associated factors, hence need to understand and address HRQoL and associated factors. More studies on HRQoL of primary caregivers can enlighten nurses and other health professionals on interventions that can help in decision making by policy makers that will improve primary caregivers' HRQoL and also set a baseline data for more associated studies. Consequently, the purpose of this study was to examine the socio- demographic characteristics (e.g., gender, age, education, monthly household income and relationship with the patient), patients' clinical characteristics (e.g., times of previous psychiatric hospitalization and duration of mental illness), and predictors of HRQoL of primary caregivers of people diagnosed with mental illness receiving outpatient psychiatric services at, MNTRH, Nairobi, Kenya.

Methods

The study used descriptive correlational research design. The target population was primary caregivers bringing their mentally ill patients to mental health outpatient clinic where the study was conducted in the three months of study at MNTRH. The independent variables for this study comprised social demographic caregivers' characteristics like age, gender, marital status, education, employment and income status. Patient's characteristics including age, diagnosis, readmission and treatment compliance. Health system support which comprised of Psychoeducation, Linkage to support groups/ agencies and Policies & Guidelines. The dependent variable was HRQoL for primary caregivers. This encompassed physical, mental stability, social relationship, environment and perceived health status of the primary caregivers. The researcher used systematic sampling method to obtain a sample of 310 primary caregivers who participated in the study. The WHOHRQoL-BREF questionnaire was used to assess caregivers HRQOL. Statistical package for social sciences (SPSS) version 25.0 was used for analysis. Pearson r was used to test relationships between variables and multiple regression model was used to determine predictors of HRQoL. A P < .05 was considered to be statistically significant.



Results

Sociodemographic characteristics of the participants

The average (SD) age for most caregivers was 44(13.98) years, majority of the caregivers had been the primary care giver to their mentally ill patient for an average of four years (5.19), and on average, the caregivers spend 9 (6.59) hours giving care to patient daily. Majority (52.5%) of the respondents were male and married (53.8%). Majority (35.5%) of the participants had formal education and 38.8% of the respondents were self-employed. Further, 42.5% of the respondents earned below 100 \$. In terms of relationship with patient, 19.4% of the caregivers cited that the patient was their mother.

Variable	Mean	S.D
Age in years	43.79	13.98
Being the primary care giver to the mentally ill patient in years	3.92	5.19
Time in hours spent giving care to patient daily	9.11	6.59
Gender		
Male	157	52.5
Female	142	47.5
Marital status		
Married	161	53.8
Single	104	34.8
Widowed	34	11.4
Education level		
None at all	11	3.7
Primary school	64	21.4
Secondary school	106	35.5
College	84	28.1
University	34	11.4
Employment status		
employed	187	62.5
Unemployed	65	21.7
Other	47	15.7
Average monthly income(USD)		
< 100	127	42.5
100-200	81	27.1
300-400	48	16.1
500-600	23	7.7
>700	20	6.7
Relationship to the patient		
Siblings	83	27.7
Parents	76	25.4
Children	66	22.1
Spouse	29	9.7
Other	45	14.9



Patients' characteristics

Majority of the patients were aged 40(20.05), were male (56.9%) and single (49.2%). Most patients (61.5%) were unemployed and had secondary school (39.1%) level of education. Schizophrenia (31.8%) and substance abuse (29.8%) were the most common diagnosis. Most patients (61.5%) were taking oral medication and compliant to treatment (65.2%). Family members (35.8%) and insurance (30.4%) paid for the treatment. Patients (49.8%) attend clinic and (33.4%) had never been re-admitted in a psychiatric Hospital in the last six months.

Variable	Mean	S.D	
Age in years	39.68	20.52	
	Ν	%	
Gender			
Male	170	56.9	
Female	129	43.1	
Marital status			
Married	68	22.7	
Single	185	61.9	
Widowed	46	15.4	
Highest education level			
None at all	44	14.7	
Primary school	60	20.1	
Secondary school	117	39.1	
College	51	17.1	
University	27	9	
Employment status			
Employed	72	24.1	
Unemployed	184	61.5	
Other	43	14.4	
The diagnosis of the patient			
Schizophrenia	95	31.8	
Mood disorders	52	17.4	
Personality disorders	44	14.7	
Substance abuse	89	29.8	
Others	19	6.4	
Treatment compliance by the patient			
Yes	195	65.2	
No	104	34.8	
Mode of payment for the patient medication	on/treatment		
Self	26	8.7	

Table 2: Patients Characteristics

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Parents	60	20.1	
Insurance	91	30.4	
Family members	107	35.8	
Friends	15	5	

Health System Support

Majority (81.6%), of the caregivers reported not receiving follow up from health personnel, (67.9%) never received psycho education, (83.3%) never received linkage to support agencies and (74.2%) never received guidelines on how to take care for the mentally ill patient.

Relationship between Caregivers' characteristics and HRQoL

Age of the caregiver (r=-.158**, P=0.006) was negatively and statistically significantly correlated with physical health. Caregiver marital status was negatively and statistically significantly correlated with physical health (r=-.171**, P=0.003), mental health (r=-.125**, P=0.031), social relationships (r=-.292**, P=0.000) and environmental health (r=-.284**, P=0.000). Caregiver relation with the patient and physical health (r=-.166**, P=0.004), social relationships (r=-.130**, P=0.024), was negative and significant. Time caregivers spend with patient was negatively and statistically significantly correlated with physical health (r=-.159**, P=0.006). This means that the caregivers' age, marital status, relation with the patient and time spent with patient impacted them negatively which lowered their HRQoL. These are again the variables which are the predictors of physical health.

Caregiver education level was positively and statistically significantly correlated with physical health (r=.185**, P=0.001), social relationships (r=.236**, P=0.000), and environmental health (r=.384**, P=0.000). Caregiver average monthly income was positively and statistically significantly correlated with physical health (r=.134**, P=0.021), mental health (r=.164**, P=0.004), social relationships (r=.313**, P=0.000), and environmental health (r=.434**, P=0.000). This showed that caregivers who were well educated and had good income either through employments or some busyness were impacted positively which means they were able to address their needs of daily living and that their patients which improved their HRQoL.

Relationship between Patients' characteristics and QoL

Patient gender was negatively and statistically significantly correlated with physical health of the caregivers (r= -.188**, P=0.001). Patient age was negatively and statistically significantly correlated with physical health of the caregivers (r=-.153**, P=0.008), and social relationships (r=-.113**, P=0.05). Patient marital status was negatively and statistically significantly correlated with physical health of the caregivers (r=-.133**, P=0.021), and social relationships (r=-.128**, P=0.027).

Patient education level was positively and statistically significantly correlated with social relationships of the caregivers (r= $.155^{**}$, P=0.007), and environmental health (r= $.302^{**}$, P=0.000). Medication payment was positively and statistically significantly correlated with physical health of the caregivers (r= $.115^{**}$, P=0.047), and their mental health (r= $.136^{**}$, P=0.018). Patient review was positively and statistically significantly correlated with mental health of the caregivers (r= $.256^{**}$, P=0.000), their social relationships (r= $.136^{**}$, P=0.005), and environmental health (r= $.203^{**}$, P=0.000).



Relationship between Health system support and QoL

Health system support was positively and statistically significantly correlated with physical health of the caregivers (r= $.225^{**}$, P=0.000), mental health (r= $.124^{**}$, P=0.032), social relationships (r= $.263^{**}$, P=0.000), and environmental health (r= $.420^{**}$, P=0.000).

	Health system support		Physical health	Mental health	Social relationshi p	Environment al health
Health						
system support	Pearson Correlation	1	.225**	.124*	.263**	.420**
	Sig. (2-tailed)		0.000	0.032	0.000	0.000
Physical						
health	Pearson Correlation		1	.587**	.691**	.646**
	Sig. (2-tailed)			0.000	0.000	0.000
Mental health	Pearson Correlation			1	.610**	.506**
	Sig. (2-tailed)				0.000	0.000
Social						
relationship	Pearson Correlation				1	.737**
	Sig. (2-tailed)					0.000
Environment						
al health	Pearson Correlation					1
	Sig. (2-tailed)					

Table 3: Relationship between Health system support and QoL

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Multivariate Regression Analysis

Caregivers' marital status (β = -.075, P= 0.019), relation with patient (β = -.027, P= 0.002), time spent with patient (β = -.015, P= 0.008), patient's gender (β =-.005, P= 0.02), patient's marital status (β = -.101, P= 0.006) had a negative and significant influence on physical health of primary caregivers. Patient gender (β = 0.303, P= 0.000), bill payment (β = 0.076, P= 0.011), health system support (β = 0.225, P= 0.000) had a positive and significant influence on physical health of primary caregivers. The adjusted R squared revealed that jointly, caregiver characteristics, patient characteristics and health system support accounted for 20.1% of changes in the physical health of primary caregivers.

Caregivers' relation with patient ($\beta = -.016$, P= 0.047) had a negative and significant influence on mental health of primary caregivers. Bill payment ($\beta = 0.074$, P= 0.008), patient review ($\beta =$ 0.124, P= 0.000), health system support ($\beta = 0.104$, P= 0.043) had a positive and significant influence on mental health of primary caregivers. The adjusted R squared revealed that jointly,



caregiver characteristics, patient characteristics and health system support accounted for 10.3% of changes in the mental health of primary caregivers.

Caregivers' average monthly income ($\beta = 0.099$, P= 0.042), age ($\beta = 0.01$, P= 0.006), bill payment ($\beta = 0.075$, P= 0.038), health system support ($\beta = 0.262$, P= 0.000) had a positive and significant influence on social relationships of primary caregivers. Caregivers' marital status ($\beta =$ -0.16, P= 0.000), relation with patient ($\beta = -0.047$, P= 0.000), patient marital status ($\beta = -0.103$, P= 0.021) had a negative and significant influence on social relationships of primary caregivers. The adjusted R squared revealed that jointly, caregiver characteristics, patient characteristics and health system support accounted for 24% of changes in the social relationships of primary caregivers.

Caregiver's age ($\beta = 0.005$, P= 0.027), highest education level ($\beta = 0.082$, P= 0.017), average monthly income ($\beta = 0.083$, P= 0.006), patient highest education level ($\beta = 0.089$, P= 0.001), health system support ($\beta = 0.264$, P= 0.000) had a positive and significant influence on environmental health of primary caregivers. Caregivers' marital status ($\beta = -0.08$, P= 0.001), relation with patient ($\beta = -0.014$, P= 0.029). The adjusted R squared revealed that jointly, caregiver characteristics, patient characteristics and health system support accounted for 36.9% of changes in environment health of primary caregivers.

	Physica	al Health		Mental Health			Social Relationships			Environmental Health		
	В	t	Sig.	В	t	Sig.	В	t	Sig.	В	t	Sig.
(Constant)	2.388	6.938	0.000	2.287	7.208	0.000	1.672	3.995	0.000	1.177	4.546	0.000
Caregivers' age	0.001	0.182	0.856	0.003	1.143	0.254	0.01	2.781	0.006	0.005	2.23	0.027
Caregivers' marital status	-0.075	-2.354	0.019	-0.039	-1.319	0.188	-0.16	-4.16	0.000	-0.08	-3.44	0.001
Caregivers' highest education level	0.013	0.283	0.777	-0.022	-0.526	0.6	0.03	0.546	0.585	0.082	2.401	0.017
Caregivers' average monthly income	0.017	0.429	0.668	0.026	0.693	0.489	0.099	2.043	0.042	0.083	2.75	0.006
Caregivers' relation with patient	-0.027	-3.127	0.002	-0.016	-1.996	0.047	-0.047	-4.459	0.000	-0.014	-2.196	0.029
Time spent with patient	-0.015	-2.679	0.008	-0.004	-0.819	0.413	-0.006	-0.867	0.387	-0.007	-1.68	0.094
Patient's gender	0.303	3.778	0.000	0.112	1.518	0.13	0.095	0.977	0.329	0.097	1.613	0.108
Patient's gender	-0.005	-2.333	0.02	-0.002	-1.161	0.247	-0.004	-1.513	0.131	-0.001	-0.603	0.547
Patient's marital status	-0.101	-2.761	0.006	-0.05	-1.488	0.138	-0.103	-2.315	0.021	-0.015	-0.548	0.584
Bill payment	0.076	2.564	0.011	0.074	2.691	0.008	0.075	2.087	0.038	0.019	0.838	0.403
Patient highest education level	0.001	0.032	0.974	0.024	0.701	0.484	0.04	0.888	0.375	0.089	3.214	0.001
Patient review	0.019	0.538	0.591	0.124	3.865	0.000	0.045	1.06	0.29	0.039	1.497	0.135
Health system support	0.225	4.032	0.000	0.104	2.029	0.043	0.262	3.864	0.000	0.264	6.286	0.000
Adjusted R2	0.201			0.103			0.24			0.369		

Table 4: Multiple Regression Model



Predictors of HRQoL

The adjusted R squared revealed that jointly, caregiver characteristics, patient characteristics and health system support accounted for 20.1% of changes in the physical health, 10.3% in the mental health, 24% in the social relationships and 36.9% in environment health of primary caregivers.

Discussion

The results revealed that caregiver gender, bill payment, health system support had a positive influence on physical health of primary caregivers. This implied that QoL was better for male compared to female caregivers. Contrary, Basheer et al. (2015) found that female caregivers had a poor QoL characterized by psychological distress. The HRQoL on physical health zone of caregivers would also improve if there was follow up from health personnel, psycho education, linkage to support agencies and guidelines on how to take care for the mentally ill patient. Hasan et al. (2014) indicated that psycho-educational intervention had a positive effect on psychological outcomes and caregivers' wellbeing. Wang and Bishop (2019) noted that social support was significantly associated with the caregivers' HRQoL.

Furthermore, caregiver marital status, relation with patient, time spent with patient, patient's gender, and patient's marital status had a negative influence on physical health zone of primary caregivers 'HRQoL. This implied that the HRQoL for caregivers who were married was better compared to the single, widowed, divorced and separated. Similarly Maruyama and Galynker (2010) established that married caregivers indicated lower prevalence of depressive symptoms, anxiety and, mental fatigue. The findings also implied that the HRQoL for caregivers who were parents to the patient were more affected compared to other relatives. The results further indicated that the more time spent with patient, HRQoL for caregivers deteriorates. The results revealed that HRQoL for caregivers was poor with female patients compared to male patients. In addition, the findings indicated that HRQoL for caregivers was better with married patients compared with single, widowed, divorced and separated patients.

The findings indicated that bill payment, patient review, and health system support had a positive and significant influence on mental health of primary caregivers' HRQoL. The findings meant that HRQoL for caregivers was better when bills were paid by other people other than patient' parents. The results also implied that patient review improved the HRQoL for caregivers. The results further denoted that mental health of caregivers would improve if there was follow up from health personnel, psycho education, linkage to support agencies and guidelines on how to take care for the mentally ill patient. Hasan et al. (2014) indicated that psycho-educational intervention had a positive effect on psychological outcomes and caregivers' wellbeing. On the other hand, caregiver relation with patient had a negative and significant influence on mental health of primary caregivers. This implied that the HRQoL for caregivers who were parents to the patient was more affected compared to other relatives.

The findings indicated that caregivers' monthly income, age, bill payment, and health system support had a positive and significant influence on social relationships of primary caregivers and their HRQoL. This implied that the higher the monthly income, the better the social relationship of caregivers and improved HRQoL. Results also indicated that the older the caregiver, the better their social relationships. Magana et al. (2017) found that the young caregivers in age were predictive of advanced stages of developing depressive symptoms because of caring for adult patients with schizophrenia among the Latino people. Further, social relationships of caregivers https://doi.org/10.53819/81018102t3033



were better when bills were paid by other people apart from the patient's parents which improved their HRQoL. The results further denoted those social relationships of caregivers would improve if there was follow up from health personnel, psycho education, linkage to support agencies and guidelines on how to take care for the mentally ill patient. Hasan et al. (2014) indicated that psycho-educational intervention had a positive effect on psychological outcomes and caregivers' wellbeing.

On the other hand, results revealed that caregivers' marital status, relation with patient, and patient marital status had a negative and significant influence on social relationships zone of primary caregivers' HRQoL. The finding denoted that HRQoL for caregivers who were married was better compared to the single, widowed, divorced and separated. Maruyama and Galynker (2010) established that married caregivers indicated lower prevalence of depressive symptoms, anxiety and, mental fatigue. Contrary, Caqueo et al. (2014) found that caregivers who were married exhibited severe depressive symptoms as compared to the single counterparts. The result also implied that the QoL for caregivers who were parents to the patient was more affected compared to other relatives. In addition, the results implied that social relationships of caregivers was better with married patients compared with single, widowed, divorced and separated patients.

The findings indicated that caregiver's age, highest education level, monthly income, patient highest education level and health system support had a positive and significant influence on environmental health zone of primary caregivers' HRQoL. The study findings implied that the older the caregiver, the better the environmental health. According to Wong et al. (2016), caregivers who were younger in age (less than 25 years old) were displeased with mental health facilities thus had worse HRQoL. Results also imply that the higher the educations level of caregivers, the better the environmental health. Malysia et al. (2014) found out that caregivers with post graduate education level indicated improved HRQoL. Further, an increase in caregiver monthly income would lead to improvement in their environmental health. In addition, the findings implied that environmental health of caregivers would be better if the patient had proper education. The findings further implied that environmental health of caregivers and guidelines on how to take care for the mentally ill patient. Wang and Bishop (2019) noted that social support was significantly associated with the caregivers' HRQoL.

On the other hand, the findings indicated that caregivers' marital status and relation with patient had a negative and significant influence on environmental health area of primary caregivers' HRQoL. This revealed that environmental health of caregivers who were married was better compared to the single, widowed, divorced and separated. Maruyama and Galynker (2010) established that married caregivers indicated lower prevalence of depressive symptoms, anxiety and, mental fatigue. The result also implied that the environmental health of caregivers who were parents to the patient was more affected compared to other relatives

Limitations

No cultural, or emotional situations were considered among the caregivers throughout the study. Also there was time and monetary limitations to do the study. Therefore, more research needs to



be done considering culture, emotional situations of caregivers during the study with enough time and finance.

Conclusion

The study concluded that the caregivers' social demographic like age, marital status, relation with the patient and time spent with patient were negatively correlated with their HRQoL. Review of patients, compliance to medication, Social and health system support were positively correlated with HRQoL.

Recommendations

Specialized psychiatric and mental health professionals with policy designers to realize characteristics which impact the caregivers 'HRQoL so that interventions are done especially Psycho-education on patient care, patient review, the importance of treatment compliance, encourage social support groups and improve health support system especially follow up through home visting to enhance their HRQoL which will translate to quality care of the mentally ill patients.

Declaration of competing interest

This research had no competing interests and was the researcher's original work which had not been offered for a master's degree in any other university.

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