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Research Article

Assessment of quality of life among caregivers of persons with permanent disabilities attending rehabilitation centre in H. D. Kote Taluq, Mysore district, Karnataka, India

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ABSTRACT

Background: Quality of life (QoL) is defined as “an individual’s perception of their position in life in the cultural context and in the value systems in which they live and in relation to their goals, expectations, concerns and desires. Caregivers of persons with chronic health conditions run the risk of emotional distress and poor adjustment to the demands of the patient, which in turn may adversely affect the quality of care that a person in need would receive. An assessment of quality of life among caregivers is important, for interventions targeted at rehabilitation.
Methods: A 100 caregivers of persons with disability registered under the rehabilitation program of SVYM at VMH Saragur were selected for the study. WHOQOL-BREF questionnaire was used to assess quality of life of caregivers.
Results: The Mean age of the caregivers was found to be 38.25 years with 87 (87%) females and 13 (13%) males. The mean Quality of Life of these caregivers was 71.97. Physical domain was significantly associated with income, earning capacity and duration of care. Psychological domain was associated with income and family type. Social domain was the most affected, with factors viz. Age (p-value=0.002), employment (p-value=0.02), earning capacity (p-value=0.032), education and duration of care being significantly associated. Environmental domain was associated with relation to caregiver, earning capacity (p-value=0.032), education and income. Marital status was observed to affect all the domains.
Conclusions: The Quality of Life of Caregivers was significantly affected by a multitude of factors which need to be addressed to ensure proper care of their wards. Interventions aimed at building the capacities the affected individuals as well as the caregivers would be highly beneficial to both groups.

Keywords: Caregivers, WHOQOL-BREF questionnaire and quality of life

INTRODUCTION

Disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. Disabilities are of five types namely locomotor, visual, hearing, speaking and mental disabilities.[1] The National Sample Survey Organization (NSSO) estimated the number of persons with disabilities in India at 1.8% (49-90 million), and 75% of disabled live in rural areas.[2] The physical and mental well-being of a caregiver is important for the well-being of the person receiving care. Caregivers often report significant difficulty in navigating the complex system of rehabilitation care to obtain the needed medical, mental health, educational and social services. Adverse health status of the primary caregivers could interfere with the ability to meet the needs of the care receiver, and might affect the rehabilitation.[3] An assessment of quality of life among caregivers is important for the interventions targeted at rehabilitation. This assumes importance in rural areas having limited access to rehabilitation services. Hence this study is carried out with the objective of assessing quality of life of caregivers of persons attending a rehabilitation centre.

METHODS

A Hospital based cross sectional study was conducted during the period July 2014 to December 2014. Approval was obtained from the ethics committee of JSS Medical College and Vivekananda Memorial Hospital, SVYM. Required permission was obtained from the authorities of the hospital to conduct the study. Study subjects were 100 caregivers of persons registered under “Chaitanya Vahini” programme run by SVYM Hospital, Sargur, H.D.Kote taluk. Care givers of bed ridden/seriously ill patients were excluded from the study. Sample size was estimated by using the formula ($n=4pq/l^2$), where p=prevalence of disability as per NSSO-2002=2.2%[2], with an absolute allowable error of 3%, n=95.6 rounded off to 100 study care givers. Prior informed consent in the local language Kannada was obtained from all the caregivers who were included in the study. For those who were illiterates, the consent was read out and explained to them in their language and consent was obtained by taking their thumb impression in the presence of a witness.

A pre tested and structured questionnaire was administered to all the care givers and the data was collected. Socio-demographic profile, WHOQOL-BREF an abbreviated 26-item version of the WHOQOL-100 was included in the proforma[4]. Data thus obtained was coded and entered into Microsoft excel and analysed using SPSS 22.0 Version. Descriptive statistical analysis, t test and chi-square test were applied. The statistical significance level was taken as $p<0.05$.

RESULTS

Table 1 shows association between physical domain of QOL and marital status of caregivers which was found to be statistically significant ($p<0.05$). Majority of subjects who were married were having a low mean QOL score. It also shows association between earning status of caregivers and physical domain of QOL which was found to be statistically significant ($P<0.05$).

Table 2 reveals association between psychological domain of QOL and marital status of care givers which was statistically significant ($p<0.05$). 90.9% of widows and 85.7% of widowers had lower scores. 52.5% of married caregivers were found to have lower QOL score.

Table 1: Factors affecting physical domain of QOL.

Marital status	Below mean score	Above mean score	p-value
a) Unmarried	0(0%)	4(100%)	0.001
b) Married	42(53.8%)	36(46.15%)	
c) Separated	0 (0%)	1(100%)	
d) Living as married	1(100%)	0 (0%)	
e) Widow	11(100%)	0 (0%)	
f) Widower	4(75%)	1(25%)	
Caregivers’ income			
a) Earner	29 (70.7%)	12 (29.3%)	0.032
b) Non earner	29 (49.1%)	30 (50.9%)	

Table 2: Factors affecting psychological domain of QOL.

Marital status	Below mean score	Above mean score	p-value
a) Unmarried	0 (0%)	3 (100%)	0.006
b) Married	41 (52.5%)	37 (47.5%)	
c) Separated	0 (0%)	1 (100%)	
d) Living as married	1 (100%)	0 (0%)	
e) Widow	10 (90.9%)	1 (9.1%)	
f) Widower	6 (85.7%)	1 (14.3%)	

Table 3 reveals association between social domain of QOL and age of care givers. People above the age of 36 years were having lower QOL score compared to those in the younger age category. Also shows association between social domain of QOL and marital status of caregivers which was found to be significant statistically ($p<0.05$). Caregivers who were unmarried, separated, widow and widower were having lower QOL. It also reveals association between literacy status of care givers and social domain of QOL which is significant statistically ($p<0.05$). Illiterate caregivers had lower QOL score in comparison to who had primary education. It reveals association between social domain of QOL and family size which was found to be significant statistically ($p<0.05$).

Caregivers in a family of more than 6 persons have lower mean score compared to other families which was found to be statistically significant ($p<0.05$). Table also shows social domain of QOL was affected by the earning capacity of caregivers. Non-earning caregivers were having lower QOL score compared to caregivers who had some source of income which was found to be statistically significant ($p<0.05$). Association between type of disability the caregiver was dealing and the social domain of QOL which was significant statistically ($p<0.05$).Association between social domain of QOL and duration of care was found to be significant statistically (p<0.05).

Table 3: Factors affecting social domain of QOL.

Age (years)	Below mean score	Above mean score	p-value
Below 18	1(20%)	4(80%)	0.02
19-25	5(33.3%)	10(66.6%)	
26-35	10(35.7%)	18(64.3%)	
36-45	17(62.9%)	10(37.1%)	
Above 45	16(64%)	9(36%)	
Marital status			
Unmarried	2(50%)	2(50%)	0.000
Married	30(38.4%)	48(61.6%)	
Separated	1(100%)	0(0%)	
Living as married	1(100%)	0(0%)	
Widow	11(100%)	0(0%)	
Widower	4(80%)	1(20%)	
Education			
Illiterate	34(65.3%)	22(34.7%)	0.006
Primary school	14(36.8%)	24(63.2%)	
Secondary school	1(33.3%)	29(66.7%)	
Above secondary school	0(0%)	3(100%)	
Family size			
2	22(46.8%)	25(53.2%)	0.021
3-5	20(44.4%)	25(55.6%)	
>6	7(87.5%)	1(12.5%)	
Caregivers’ income			
Earner	23(46.9%)	26(53.1%)	0.017
Non earner	36(70.5%))	15(29.5%)	
Disability			
Cerebral palsy	6(27.2%)	16(72.8%)	0.009
Hearing loss	1(12.5%)	7(87.5%)	
Physically handicapped	25(60.9%)	16(39.1%)	
Mentally retarded	9(64.2%)	5(35.8%)	
Blind	4(36.3%)	7(63.7%)	
Stroke	4(100%)	0(0%)	
Duration of care giving			
Below 5 years	15(30.6%)	34(69.4%)	0.020
Above 5 years	26(50.9%)	25(49.1%)	

Table 4 reveals association between environmental domain of QOL and marital status of caregivers observed to be significant statistically (p<0.05). 58.9% of illiterate caregivers were found to have lower QOL score and 63.2% of care givers who had primary school education had higher QOL score. Table shows statistical significant association between environmental domain of QOL and relation to care receiver (p<0.05). Association between environmental domain of QOL and duration of care giving was significant statistically (p<0.05).

Table 4: Factors affecting environmental domain of QOL.

Marital Status	Below mean score	Above mean score	p-value
Unmarried	1(25%)	3(75%)	0.005
Married	33(42.3%)	45(57.7%)	
Divorced	0 (0%)	1(100%)	
Separated	1(100%)	0(0%)	
Widow	10(90.9%)	1(9.1%)	
Widower	6(75%)	2(25%)	
Education			
Illiterate	33(58.9%)	23(41.1%)	0.010
Primary school	14(36.8%)	24(63.2%)	
Secondary school	0(0%)	3(100%)	
Above secondary school	1(33.3%)	2(66.7%)	
Relation to care receiver			
Parents	34(54.8%)	28(45.2%)	0.025
Spouse	11(50%)	11(50%)	
Offspring	0(0%)	3(100%)	
Others	3(23.7%)	10(76.3%)	
Duration of care giving			
Below 5 years	35(57.3%)	26(42.7%)	0.022
Above 5 years	13(33.3%)	26(66.7%)	

Table 5 shows that as the duration of care giving increases there is a deterioration of physical and social domains of QOL. This is reflected as statistically significant negative correlation between duration of care giving and QoL domains i.e. physical & social.

Table 5: Correlation between domains of QOL and duration of care.

Domains	R	p
Physical	-0.250	0.012
Psychological	-0.013	0.899
Social	-0.274^{**}	0.006
Environmental	0.192	0.055

DISCUSSION

1. Mean QOL

Total 100 caregivers were interviewed and the mean Quality of Life of these caregivers was 71.97. Mary Lícia de Lima and Jair Lício Ferreira Santos established in their study done in Brazil that being a caregiver affects the QOL adversely.[5]

2. QOL according to age

In this study it was observed that, Social domain of QOL was found to be significantly associated with age. (P=0.002) Pedro Schestatsky, et al. observed similar results in their study in Brazil. Environment, Physical and Psychological domains of QOL had been found not to be significantly affected by age, non-significant with age, which is in line with the results of the present study.[6] In a study done by Abdel W Awadalla in 2007, it was found that caregivers with higher age had higher QOL score.[7]

3. QOL according to sex

In the present study the mean QOL score was almost same among males and females and there was no statistically significant difference in these groups ($p>0.05$). Diego Mugno had concluded in his study that mothers had lower QOL score compared to fathers.[8]

4. QOL according to marital status

In present study it was observed that caregivers who are married had better QOL score than other caregivers. It was statistically significant in all 4 domains. It may be attributed to the fact that majority of caregivers are married in present study. Similar results were found in a study done by Asmahan F Alshubaili and Jude U Ohaeri who reported that caregivers who were married had higher QOL score.[9]

5. QOL according to type of family

In the present study mean QOL of caregivers did not vary significantly with type of family. Pedro Schestatsky et al observed positive co-relation between physical domain score and number of people living in same house in Brazil.[6]

6. QOL according to educational level

In the present study it was observed that caregivers with higher education had better QOL as compared to caregivers with lesser education. This finding was statistically significant in social and environment domain ($p<0.05$). Rebecca G concluded in her study that education was significantly associated with QOL score of caregivers.[10]

Education was also found affecting QOL score in a study conducted by Abdel W Awadalla.[7]

Contrary to the above findings, Asmahan F Alshubaili and Jude U Ohaeri observed in their study that lower education was associated with lower QOL score.[9] Daniel Fu Keung Wong observed that caregivers with lower educational status had more difficulties and lower score of QOL.[11] Ruzanna ZamZam and Marhani Midin noted in their study that higher educational status was associated with higher QOL score.[12]

7. QOL according to occupational status

In the present study the mean QOL was lower among homemakers and daily-wage labourers (coolies) in comparison to caregivers engaged in other occupation. This was statistically significant (p-value < 0.02).

Asmahan F Alshubaili and Jude U Ohaeri observed in their study that caregivers engaged in higher skill work had higher QOL score.[7]

8. QOL according to earning capacity of caregiver

The study revealed that the caregivers who were earning had lower QOL score compared to those who were not earning. It was found statistically significant in physical and environment domain (p-value=0.032).

9. QOL according to total family income

In present study it was found that caregivers with lower family income had lower QOL score compared to caregivers with higher family income. It was found statistically significant in physical, psychological and environment domain. Asmahan F Alshubaili and Jude U Ohaeri in their study observed that caregiver’s unemployment and hence total family income was associated with lower QOL.[9]

10. QOL according to family size

The present study revealed that caregivers with a family size of 3 to 5 members had higher QOL score and was statistically significant in social domain.

11. QOL according to relation of caregiver to disabled person

In present study it was observed that mothers and fathers had lower QOL score compared to other relations and was statistically significant in environment domain (p-value=0.025). Diego Mugno observed in his study that mothers had lower QOL than fathers.[8] Asmahan F Alshubaili and Jude U Ohaeri observed in their study that parents had higher QOL score than the spouse caregivers.[9] Abdel W Awadalla also had similar findings in his study conducted in Kuwait.[7]

12. QOL according to type of disability

The present study revealed that the people who were caregivers for physically handicapped persons had significantly lower QOL score that those of people caring for other disabilities.

13. QOL according to duration of care giving

In present study it was observed that people who were caregivers for more than 5 years had lower QOL score compared to others. It was found to be statistically significant in social domain. In a study conducted by Abdel W Awadalla it was observed that duration of care giving was not associated with QOL of caregivers.[7] Ruzanna ZamZam and Marhani Midin observed in their study that duration of caregiving was significantly associated with QOL score. It is in line with findings of our study.[12]

Eloise H. Tew and Sharon L observed that lower QOL scores were associated with duration of caregiving.[13] Sandeep Grover's study findings suggest that longer duration of care giving was associated with lower QOL scores.[14]

14. Correlation between social domain of QOL and duration of care

As the duration of care giving increases there is a deterioration of physical and social domains of QOL. This is reflected as statistically significant negative correlation between duration of care giving and QOL i.e. physical and social domains.

CONCLUSION

Mean domain score for physical, psychological, social and environmental domains were 88.12, 72.48, 33.08 & 94.2 respectively. There were significant difference in QoL score according to marital status, caregiver's income, educational levels, family size, type of disability, duration of care giving and relation to disabled persons. In conclusion, the quality of life is a multidimensional concept. This assumes more importance in rural areas having poverty & limited access to rehabilitation services. Therefore intervention targeted rehabilitation approach is required. Social assistance from governmental and non-governmental organizations to both care givers and disabled people are need of the hour to improve their Quality of Life.

Limitation

Hospital based study; hence the results cannot be generalized to the population. More female study subjects in comparison to males.

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