

Quality of Life and Burden of Caregiving Among the Primary Caregivers of Children with Disability in Rural Karnataka

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ABSTRACT

Introduction: The primary caregiver of a child with disability has to undergo a lot of difficulties in taking care of the child. **Objective:** To assess the quality of life and burden of caregiving of primary caregivers of children with disability registered in a CBR services in rural Karnataka. **Methodology:** A cross-sectional study was done among 100 children with disability and their primary caregivers. Interview schedule including socio-demography, WHOQOL-BREF, ZBI and WHODAS was used. **Results:** Mean age of caregivers was 36.38 of which 97% were women and 82% were mothers of children with disability. Mean age of children was 11.43 years, 56% males and most common diagnosis was multiple disabilities (38%). Mean caregiver burden according to Zarit scale was 33.27 and mean burden scores were significantly different between the disability domains of the children. Mean quality of life (QOL) scores for each domain was 49.6 in physical, 60.47 in psychological, 45.67 in social and 58.44 in environmental domains. Marital status of the caregivers was significantly associated with both physical and the social domain of the QOL. Occupation of the caregiver was significantly associated with the environmental domain and the type of disability in the children significantly affected the physical domain of the QOL of the caregivers. **Conclusion:** Caregiver QOL is overall poor but it was the lowest in the physical domain and higher in psychological domain. Caregiver burden scores were high and depends on the type of disability. Importance should be given to the care of the caregivers.

Keywords: Caregiver burden, caregivers, disability, quality of life.

Introduction

“Caregiving is the process of helping another person who is unable to do so for themselves in a ‘holistic’ (physically, mentally, emotionally, and socially) manner. Caregiving is facilitated by certain character traits, emotions, skills, knowledge, time, and an emotional connection with the care recipient.^[1]” A primary caregiver is a person who consistently assumes the responsibility

for the housing, health or safety of the patient.^[2] But this becomes more difficult when there is an added burden of a morbidity-like disability in children or dementia in older people.^[3] Caregiving demands investment of more time and effort towards the specific needs of the affected individual and no two caregivers have the same work pattern.

Quality of life is the measure of a subjective assessment’s of one’s life. This shows how an individual views his/her life in terms of quality. There are lots of concepts when it comes to quality of life but the most used assessment in 4 domains viz physical, psychological, social and environmental. There are lot of psycho-social factors which add to the caregiver burden.^[4] This includes perceived less attention from the other siblings as

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the mother must spend a lot of time with the disabled one and can't attend the school functions of the other children. Due to continuous presence next to the care recipient, the caregiver will not be able to attend social gatherings such as weddings or meeting friends. Tiredness and backache are very common among the caregivers.^[5] Due to lack of training or awareness on how to manoeuvre the bedridden people, the caregivers usually adopt wrong postures and unequal weight distributions while lifting the patients.^[6,7]

Considering all these burdens which the caregiver goes through, they need utmost support from the spouse, society and the government. But the society brings in the problems like isolation, stigma and partiality towards them. When family support is not good enough, it leads to arguments and divorces.^[8,9] All these burdens combined with lack of support financially and emotionally, caregiving is considered as a thankless job. There is a dearth in literature when it comes to assessing the quality of life and caregiver burden in caregivers of disable children especially from the rural areas. So, this study was done with the objective of assessing the quality of life and burden of caregiving of primary caregivers of children with disability registered in a CBR services in rural Karnataka.

Methodology

A cross-sectional study was done among primary caregivers of children with disability who are availing the services of a community-based rehabilitation (CBR) services of the field unit affiliated to a tertiary care hospital. The study location included 4 Primary Health Centre (PHC) areas namely, Sarjapur, Anugondanahalli, Dommasandra and Lakkur which are situated within a radius of 30 kilometres from the field unit. The study sample were selected randomly from the list of children with disabilities registered under the CBR services.

The study population included the primary caregivers of children with disability availing services from the field hospital. The inclusion criteria are primary caregivers of children under 18 years of age with disability registered in the CBR services and residing in the area for at least 2 years. Primary caregivers who were not able to communicate due to severe speech and hearing impairment, intellectual impairment was excluded. The mean physical quality of life in caregivers was taken as 13.7 based on a previous study,^[10] with a confidence interval of 95% and precision rate of 10% the sample size calculated was 100 with 10% non-response rate. The children with disability were selected using a simple random sampling from the list who registered to CBR services.

Institutional ethics committee approval for the study was obtained. Written informed consent was taken before starting the interview. Interview included questions on socio-demography, Quality of life using WHOQOL-BREF, Caregiver Burden using the Zarit Burden Scale and WHODAS to assess the degree of disability in the child. The Zarit Burden scale^[11] contains 22

items. All three structured interview schedules were translated into Kannada using the standard procedure and back-translation were done to ensure quality. General Health of the caregiver was assessed and one-time measurement of Blood Pressure with Omron HEM - 7124 digital sphygmomanometer. The data was entered in Microsoft Excel and analysed with IBM SPSS version 20. The descriptive statistics are analysed using means, standard deviations and proportions. The associations are done using nonparametric tests like Chi-square tests Mann Whitney U test and Kruskal Wallis tests.

Results

In the 100 primary caregivers interviewed, their mean age was 36.38 (SD: 12.15) years in which three fourths of them were between 21 to 40 years. Almost everyone (97%) were females who are either mothers (82%) or grandmothers (11%). The fathers (3%) and aunts (4%) comprise the rest of the caregivers. Taking an arbitrary income cut off of INR 10,0000, 72% of the study population were having a family income of less than 10,000 per month. Among the caregivers, 90% were Hindu by religion, 81% were married and 15% were widowed. They belonged to a nuclear family (52%), three generation family (36%) and joint family (12%). They have completed middle and high school education (60%) and most are not gainfully employed (65%) while the rest are involved in farming or unskilled work.

On doing the health check-up of the caregivers the most common complaint was tiredness (13%) and backpain (12%). On one-time blood pressure measurement, 85% had normal levels. Among the children with disability, the mean age was 11.43 (SD: 4.58) years with 56% of them were males. Based on the primary diagnosis of the child, 38% were having multiple disabilities and 34% had intellectual disabilities [Table 1]. Using the WHO disability assessment scale, the mean disability score of the children in the study was 57.31 ± 24.49. This WHODAS scores were significantly higher among children with multiple disabilities (*P* < 0.001) [Table 2].

Based on the WHOQOL Bref Scores of the caregivers [Table 3], the mean scores in Physical domain was 49.66 ± 9.5; Psychological domain was 60.47 ± 8.8; Social domain was 45.67 ± 20.28 and Environmental domain was 58.44 ± 14.75. On comparing mean domain scores across various categories of socio-demographic

Table 1: Primary Diagnosis of the Children with Disability in the Study Along with the Corresponding Caregiver Burden Scores (n=100)

Diagnosis	Male (%)	Female (%)	Total
Hearing Impairment	6 (54.5)	5 (45.5)	11
Locomotor Difficulties	8 (53.3)	7 (46.7)	15
Mental Retardation	18 (52.9)	16 (47.1)	34
Multiple Disabilities	23 (60.5)	15 (39.5)	38
Speech Problems	0	1	1
Visual Impairments	1	0	1

Table 2: The WHODAS Disability Scores and the Zarit Caregiver Burden Scores for the Different Disability Diagnostic Domains

Diagnosis	WHODAS scores Median (IQR)	P**	Caregiver Burden Scores* Median (IQR)	P**
Hearing Impairment	29.9% (27.9-32.2)	$P < 0.001$	26 (22-40)	$P = 0.02$
Locomotor Difficulties	49.1% (36.3-55.6)		28 (18-33)	
Mental Retardation	52.3% (42.1-71)		33.5 (23.5-40.25)	
Multiple Disabilities	81.3% (60-94.7)		34.5 (29-49)	
Speech Problems	36.41%		38	
Visual Impairments	27.82%		18	

*Caregiver burden scores assessed through the Zarit Burden Scale for each of the diagnosis

**Kruskal Wallis test

Table 3: Quality of Life of the Caregivers

WHOQOL Domains	Mean Score	Std Dev
Physical	49.66	9.5
Psychological	60.47	8.8
Social	45.67	20.28
Environmental	58.44	14.75

variables [Table 4], the physical domain scores were significantly associated with the marital status ($P = 0.002$) of the caregiver and the disability diagnosis ($P = 0.04$) of the child. The psychological scores were associated with religion ($P = 0.003$) while the social domain scores were associated with how the caregiver is related to the child ($P = 0.005$) and their marital status ($P < 0.001$). The environmental domain scores were significantly associated with income of the family ($P = 0.003$) and the occupation of the caregiver ($P = 0.004$).

Based on the Zarit Caregiver burden, the mean score was 33.27 ± 13.03 with 56% of the caregivers having mild burden and 25% with moderate burden and 2% with severe burden [Table 5]. The burden scores were significantly associated with the disability domain of the child ($P = 0.02$) with more burden among caregivers of children with multiple disabilities. The burden categories are not significantly associated with any of the socio-demographic factors or disability domains.

Discussion

Almost all the caregivers were female (97%) and are mothers (82%) with fathers comprising 3% which is comparable to a study by Basaran^[12] which had 94.4% caregivers as mothers of the children with disability, fathers were 2.1% and others were 3.5%. The mothers were the caregivers in almost all families because the onus of taking care of the child and running the family is on the female members, especially wives. When the child is born, sometimes the mothers must give up her job and dedicate her time for the child.

Most of the families (72%) had a monthly income of less than 10,000 Rupees. This corresponds to less than 32 Rupees per capita per day which is the rural cut-off for the poverty line.^[13] In rural Karnataka, 24.5% of the population are below the poverty line according to CBHI, 2015.^[14] The study participants were very reluctant to divulge information related to properties

and were also unable to quote an average monthly income. So, the arbitrary cut-off of Rs. 10,000 was taken. The families in the study are agriculture dependent and the income is seasonal as well as dependent on a lot of other external factors. The low income also contributes to the financial burden of caregiving as well as dents the healthcare received for the child.

More than two thirds of the caregivers were currently married (81%), 15% were widowed and 3% were separated. Basaran^[12] showed that 92.3% of the caregivers are currently married and few studies showed that divorces are more prevalent among the parents of a disabled child.^[18,9] The nuclear families with children with disability have put more burden on the caregiver as there was no one to help in sharing the caregiving when compared to joint families or 3 generation families where grandmothers and aunts are significantly contributing to the caregiving of the child. Majority of the caregivers have studied up to middle school (30%) or high school (30%) but 29% of them were uneducated. Education plays a role in lot of factors contributing to the disability of the child like age at marriage, child spacing and consanguinity among others. Also, an educated mother will cope up better in caregiving as she can plan and make use of available resources.

Caregivers are considered as invisible patients because the constant work and care takes a toll on their health. In a study done by Brehaut^[15] on the caregivers of the children with cerebral palsy, 7.1% had elevated blood pressures. In our study, the elevated blood pressures were not associated with caregiver burden or the domain of disability. The most common health complaint among the caregivers is tiredness (13%) followed by back pain (12%) and headache 9 (5%). The main reason for backpain in caregivers could have been due to most of them adopting wrong postures^[6,7] and methods when mobilising a bedridden child, especially while picking up the child from bed, transporting the child and other lifting activities.

Even though disability is prevalent across age groups, children under 18 years of age were more affected both physically and mentally. Children with multiple disabilities mostly don't make it into adulthood. The average age of the children with disability in our study was 11.43 ± 4.5 years which ranged between 2 to 18 years. The most common domain in the disability was multiple disabilities (38%) followed by mental

Table 4: Significant Associations Between Socio Demography and QOL Domains Using Kruskal Wallis Test* and Mann Whitney U Test**

Variable		Median (IQR)			
		Physical	Psychological	Social	Environmental
Relation	Mother	50 (44,56)	63 (56,69)	50 (31,56)	63 (50,69)
	Father	38	56	44	63
	Grandmother	38 (38,44)	56 (56,63)	25 (19,50)	56 (44,56)
	Aunt	53.5 (44,63)	59 (51.5,67.5)	62.5 (51.5,78)	59.5 (56,63)
<i>P</i> *		0.012	0.638	0.005	0.363
Income	<10,000	48 (44,56)	59 (56,69)	50 (25,56)	56 (45,63)
	>10,000	52 (46,61)	63 (56,69)	58 (31,69)	66 (56,75)
<i>P</i> **		0.184	0.106	0.070	0.003
Marital Status	Married	50 (44,56)	63 (56,69)	50 (37.5,69)	63 (50,69)
	Divorced	44 (38,44)	56 (56,63)	25 (6,31)	50 (44,63)
	Widowed	38	63	25	56
	Unmarried	44	63	56	63
<i>P</i> *		0.002	0.698	0.00	0.332
Occupation	Housewife	50 (41,56)	63 (56,69)	50 (31,62.5)	56 (50,69)
	Clerical, Shop, farmer	50 (44,63)	63 (56,69)	50 (47,69)	69 (63,75)
	Skilled	47	69	47	59.5
	Semi-skilled	50	69	50	41
	Unskilled	44	56	50	41
<i>P</i> *		0.886	0.095	0.109	0.004
Disability Domains	Hearing Impairment	56 (44,63)	63 (56,69)	50 (31,75)	63 (56,75)
	Locomotor Impairment	56 (44,56)	56 (56,63)	50 (50,56)	63 (50,75)
	Mental Impairment	50 (44,56)	63 (56,63)	50 (31,59)	63 (50,69)
	Multiple Impairment	34 (34,56)	56 (56,69)	35 (35,56)	56 (48,63.5)
	Speech Impairment	44	56	46	56
	Visual Impairment	44	63	44	50
<i>P</i> *		0.04	0.794	0.573	0.409

*Kruskal Wallis test, **Mann Whitney U test

Table 5: Caregiver Burden in the primary caregivers

Burden Level	Proportions %
No burden	17
Mild	56
Moderate	25
Severe	2

retardation (34%) and locomotor difficulties (15%). In the Indian Census on Disability^[16] of 2011, there was 8% multiple disabilities, 6% mentally retarded and 20.3% with locomotor difficulties.

Caregivers cited the backpain, tiredness, easy fatiguability, difficulty to keep up the energy levels throughout the day as main issues which reflects on the physical domain of the QOL. The caregiver burden puts a lot of strain mentally also as they are depressed or constantly worrying about the child. When the caregiver spends most of the time with the child and inability to attend social gatherings like marriages or other functions owing to the inability to leave the child alone at home, the social domain is affected in QOL. The environmental domain is affected by the socio-economic status of the family and the support from the community in terms of transportation and availability of healthcare facilities.

Quality of life was not associated with gender of the caregiver. This shows that the father and the mother are equally affected in their QOL when they are the primary caregivers. The relation of the caregiver to the disabled child is significantly associated with physical ($P = 0.012$) and the social ($P = 0.005$) domain of the QOL. When the caregiver is an aunt, she felt her QOL is worse and this may be since she may not have the bond with the child which a mother or father would have which makes them adjust and tolerate few things.

Marital status of the caregiver was significantly associated with both physical ($P = 0.002$) and the social ($P = 0.001$) domain of the QOL. The warmth and support of the spouse is always an important factor in the health of the caregiver. Currently married caregivers had better QOL scores in physical domain because the caregiving activities might have got distributed to a certain extent. The social domain scores were better in married caregivers because the shared caregiving gives them an opportunity to have better social interactions like attending social gatherings like marriages or time to meet friends and relatives.

The domain of disability especially the multiple disability domain in the children significantly affected the physical domain ($P = 0.04$) of the QOL of the caregivers. Some domains like multiple disabilities and locomotor difficulties have an

increased demand in caregiving around the clock with a constant oversight on whether everything is alright with the child every ten minutes. The QOL scores were negatively correlated with the level of disability in the study by Basaran.^[12]

The mean caregiver burden scores in this study according to the Zarit scale was 33.27 ± 13.03 . In studies involving caregivers of adults, the mean Zarit caregiver burden scores were 26.2 in breast cancer caregivers^[17] and 33.59 for geriatric caregivers.^[18] This shows that caregiver burden is more for caregivers of children with disability because of various reasons like children as such needs extra care, children with disability cannot communicate their needs and problems, added burden of running around for healthcare among others. Also, caregiving requires the undivided time of a person that it is a luxury to have a financially productive job which leads to poor quality of life leading to a vicious cycle.^[19]

This is because children with multiple disabilities have difficulties in communicating their needs and problems which make it very difficult for the caregiver to perceive whether everything is normal or not. Combined with chronic bedridden conditions and bedsores; constant need of monitoring, lifting and mobilising the child and the fact that the child is completely dependent on the caregiver makes the caregiver burden significantly higher.^[20] In the study by Lucia^[21] on caregivers of mental disorder patients, the burden scores were significantly associated with age, religion and health condition of the caregivers. The prevalence of depression among caregivers is around 37% and directly proportional with the caregiver burden.^[22]

It is proven that the caregiver burden of the parents and the resulting mental stress leads to parent-child conflict and how close the parent is to the child.^[23] It is important to invest in caring for these caregivers with psychological education, skills training and therapeutic counselling to reduce burden and increase quality of life.^[24] Primary care is the accessible and affordable healthcare for a majority of these people but disability or community-based rehabilitation in the primary care level is left to be desired more. Community health workers are the masters in running the show at primary level and these caregiver issues should be addressed through them.

Recommendations

Awareness should be created on the importance of caregiver health and the need for sharing of the responsibility of caring for the child. The caregivers should be given regular health check-ups and monitoring of blood sugar levels and blood pressures. They should be made aware of the schemes and monetary benefits available for the disabled child which they can avail to take care of the health expenses of the child. Creating opportunities for the caregivers to work from home like small scale industries which operate at household levels like cooking food for parcels or tie flowers for garlands or tailoring should be started. Also, to promote social support which is proven to reduce caregiver burden and the resulting depression to an extent.^[22]

Conclusions

Quality of life (QOL) scores were less than normal in all domains with the physical and social domains affected the most. The relationship of the caregiver to the child, their marital status, income, occupation all plays a significant role in the quality of life of the caregivers. Mothers alone cannot take care of the child with special needs all through the day. Almost two thirds of the caregivers have some burden of caregiving. The mean burden scores were significantly different between the disability domains of the children with the burden being the highest among the caregivers of children with multiple disability. Education and training on how to care for the back of caregivers when lifting the children and mobilising them. Marital status is also an important factor associated with QOL and marriage counselling is a must for couples with disabled children right from the childbirth so that they support one another in caring for the child instead of blaming each other.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

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