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QUALITY OF LIFE AND COPING STRATEGIES AMONG CARETAKERS OF MENTALLY CHALLENGED CHILDREN: A DESCRIPTIVE STUDY

Nursing

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ABSTRACT

BACKGROUND: Intellectual disability accounts for a considerable fraction of disabilities among children across the globe. These children need special care and attention from their primary caregivers. As a result, caregivers also undergo a lot of stress and depression. Studies focussing on the psychological health and quality of life in the caregivers have been scarce but are also needed so that their overall quality of life could be improved. **AIM:** To assess Quality of life and coping strategies among caretakers of mentally challenged children in the Kolhapur district of Maharashtra. **METHODOLOGY:** Quantitative, descriptive study was undertaken at a school for Mentally Challenged children comprising of primary caregivers (n=110). A structured questionnaire containing questions about quality of life and coping strategies was developed and validated by experts in the field. A pilot study (n=15) was carried out to check the feasibility of the tool. Following it, the main study was carried out by filling the questionnaire form by the participants. Correlation between variables was calculated by Pearsons's Correlation and association between variables was calculated by Chi-square test. A P-value of <0.05 was considered significant. **RESULTS:** Majority of the participants were between 30-39 years (n= 46, 41.82) and females (n=75, 68.18 %). Most common occupation was business (n=54, 49.09 %) and majority had monthly income < Rs 20,000 (n=105, 95.45%). The mean QoL score was 113.88 ± 7.49 and the mean coping strategies score was 81.3 ± 9.61. There was correlation between the QoL scores and Coping strategies scores among the caregivers of mentally challenged children (Correlation coefficient = 0.056, P-Value = 0.5548). **CONCLUSION:** The QoL and coping strategies for most caregivers for the studied data set were good. However, more studies are required in establishing independent and reliable predictors of QoL of caregivers, so that effective methods and policies could be developed for betterment of the quality of life of caregivers.

KEYWORDS

Coping Strategies, Caretakers and Mentally Challenged Children, Intellectual Disability, Quality Of Life

INTRODUCTION

Intellectual disability (ID), previously known as Mental retardation (MR), is defined as below average level of intellectual function i.e. an Intelligence Quotient (IQ) of below 70 to 75, combined with other limitations in daily activities necessary for daily living.[1] It is one of the leading developmental disabilities in children.[2] Children suffering from ID, are referred to as mentally challenged. These children face enormous problems at the physical, intellectual and social level. ID limits a child's ability to develop cognitively, physically, and emotionally as compared to other children.[3]

Mentally challenged children, especially in India are primarily managed by parents and family members. People who are closest to these children and the primary caregivers bear most brunt of their disabilities and have to adjust in several aspects according to his/her needs.[4] Caring for such children can be a physically and mentally challenging job. Thus, the impact of raising such children could be multi-fold, thereby by affecting the lives of the caregivers tremendously. Many a times, it results in compromised quality of life (QoL) of the carers too.[5,6] The Indian mental health statistics stated that the caregivers of mentally retarded children are also massively psychologically affected. In their survey, it was reported 40-75% of caregivers had substantial psychological illness as a result of their care giving, whereas as much as 15-32% had clinically diagnosable major depression. Physical health consequences, impaired immunity and a higher mortality rate, have also been anticipated in the depressed caregivers.[7]

ID, unlike physical disabilities, mostly go unnoticed until a child enters school or reaches a certain age. In the absence of knowledge about the developmental stages of a child, parents and professionals often fail in diagnosing the persisting mental disabilities. [8] Rates of ID have also been shown to vary with income group of the country of origin, the age-group of the study population. A higher prevalence has been noted among studies based on children/adolescents, than those on adults. 2 The overall prevalence of mentally challenged children across the globe is between 1-3%.[9]

While it has been reported that most families cope with the situation relatively well and continue to have a good QoL, coping with a mentally challenged child could be emotionally draining and is a highly individual process at the same time.[5] On the contrary, few evidences also suggest that some families may also find it difficult to cope up with the situation fully.[10] Coping requires a cognitive reappraisal of the situation in order to manage it properly. There could be a number of factors which affect the QoL and coping strategies of the caregivers of mentally challenged children, like severity of the disability of the child, socioeconomic status, educational status, and social support.[11] There have been a few studies regarding the QoL and coping strategies of caregivers. However, more region-based studies might be required in order to assess and improve the overall QoL of caregivers. Thus, the purpose of the present study was to assess the QoL and Coping strategies among caretakers of mentally challenged children in selected special schools at Kolhapur, Maharashtra.

MATERIALS AND METHODS

The Quantitative, descriptive study was undertaken at a school for Mentally Challenged children in Kolhapur, Maharashtra. The study population consisted of caregivers of Mentally Challenged children's whose children were studying at special school. A total of 110 caregivers were selected by non-probability, convenient sampling technique. Caregivers who knew either English or the vernacular language were included in the study, whereas caregivers who were mentally ill or not present during data collection were excluded from the study.

After an extensive review of literature, referring the books and journals as well as discussion with the guide and experts in field, the study tool (questionnaire) was developed. The questionnaire contained three sections. Section A comprised of questions related to the socio-demographic variables like Age in year, Gender, Religion, Marital Status, Educational qualification, Occupational status, Monthly Income, Number of Children. Section B contained questions on QoL Assessment scale to assess the Quality of Life among caretakers of mentally challenged children. It consists of 30 Statements on QoL, which was categorised into Positive and Negative Statements based on the five-point Likert scale. [12] They were scored 112-150 for good, 71-111 for bad, and 30-70 for poor QoL respectively. Section C comprised of questions relating to the coping Strategies among the caregivers and was also according the five-point Likert scale. Based on the answers, the participants were scored 80-120, 40-79 and 0-39 as good, bad and poor respectively.

The tool was sent to 20 experts in field and modifications were made considering the suggestions. The study was then piloted over a small sample size (n=15), at a school for mentally challenged children located at Panhala, Kolhapur after obtaining a formal permission from the concerned authority. Informed consent was obtained from the

participants. The questionnaire tool was distributed, and the responses were collected from the participants. The reliability score was calculated by using Cronbach's alpha formula.

The main study was conducted from 16/02/2018 up to 28/02/2018, between 10.15 am to 5.00 pm and the responses of the participants were collected in the same procedure as in the pilot study. Average time given to each sample was 30 minutes approximately. A total of 10 participants were selected per day for data collection, which continued for 11 days. Following this, the recorded data was analysed. Descriptive data analysis was performed on MS-Excel. Correlation between variables was calculated by Pearsons's Correlation and association between variables was calculated by Chi-square test. A P-value of <0.05 was considered significant.

RESULTS

The reliability score in the pilot studies was 0.71 for QoL and 0.78 for coping strategies. This proved that the questionnaire tool designed to measure the QoL and Coping strategies were reliable and consistent.

In the main study, majority of the participants were between 30-39 years. Moreover, a considerable fraction of the caregivers were females (n=75, 68.18 %). Also, more than half of the participants (n=60, 54.55 %) were Hindus. All the participants were married, with children. Most caregivers (n=74, 67.27 %) had two children. Also, 54.5 % of them had attained a minimum of secondary education. Most common occupation was business and majority had monthly income < Rs 20,000.

Variables	Sub-Categories	Frequency	%
Age in years	20-29	36	32.73%
	30-39	46	41.82%
	40-49	28	25.45%
	50 & above	0	0.00%
Gender	Male	35	31.82%
	Female	75	68.18%
Religion	Hindu	60	54.55%
	Christian	0	0.00%
	Muslim	13	11.82%
	Others	37	33.64%
Marital Status	Married	110	100.00%
	Divorced	0	0.00%
	Single Parent	0	0.00%
	Separated	0	0.00%
Educational Qualification	Illiterate	3	2.73%
	Primary	16	14.55%
	Secondary	60	54.55%
	Higher Secondary	31	28.18%
	Graduate	0	0.00%
Occupational Status	Unemployed	27	24.55%
	Business	54	49.09%
	Private Sector	23	20.91%
	Government Servant	6	5.45%
Monthly income in rupees	Less than 10,000	51	46.36%
	10,001 - 20,000	54	49.09%
	20,001 - 30,000	5	4.55%
	30,001 - 40,000	0	0.00%
Number of children	One	28	25.45%
	Two	74	67.27%
	Three	8	7.27%
	More than Three	0	0.00%

The mean QoL score was 113.88 ± 7.49. The It was good and average for 74 and 36 participants respectively (Figure 1). Similarly, the mean coping strategies score was 81.3 ± 9.61 and were good and average for 63 and 47 participants respectively (Figure 2). No participant scored poor in either the QoL scoring or the coping strategy scoring.

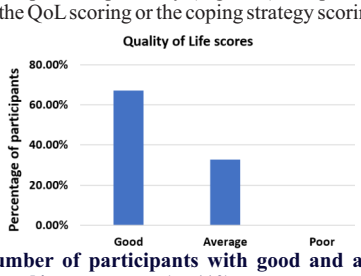

Figure 1. Number of participants with good and average QoL scores, expressed in percentage (n=110)

Figure 2. Number of participants with good and average coping strategy scores, expressed in percentage (n=110)

We could not find any correlation between the QoL scores and Coping strategies scores among the caregivers of mentally challenged children (Correlation coefficient = 0.056, P-Value = 0.5548). There was a significant association between QoL scores and marital status (P<0.05). However, there were no associations between QoL scores and other sociodemographic parameters like age, gender, qualification, occupation and monthly income. Likewise, no statistically significant association between coping strategies score and any sociodemographic variable is reported.

DISCUSSION

Taking care of mentally retarded children poses a lot of stress and trauma in the caregivers. Previous data suggests that a considerable fraction of these caregivers suffer from a psychological illness, and clinically diagnosable depression. The amount of psychological, emotional and financial burden these parents go through is enormous.[7] Major depression can also lead to plethora of other disorders like, fatigue, disturbed sleep pattern, increased rate of heart diseases, etc.[13] This fact has stirred up the need to assess the QoL among the primary caregivers of mentally retarded children, and the factors they depend on. The present study was undertaken among caregivers in a school for special children.

Herein, most of the caregivers were females, unlike Shekhawat et al, who showed males as the primary caregivers.[4] It has been demonstrated that when females are the main caregivers of the patient, they have a poorer QOL in comparison to other family members.[14] Similar trend was also reported by Chandravanshi et al. The prevalence of depression among these mothers was a whopping 79 %. They also showed that having MR children affected both urban and rural women equally, irrespective of the residential background.[15] A study by Raina et al reported that both physical and mental state of caregivers of children with cerebral palsy are affected.[16] The religion of most participants was Hindu, which is primarily due to the population make-up of the region under study, the finding is similar to Chandravanshi et al.[15]

Several studies have shown that continued physical, emotional, and economic burden affects caregivers life negatively.[17,18,19] Herein, most patients had a good QoL, which is heartening to note. This further suggests that the caregivers of these MR children did not feel any burden while taking care of them. Alternatively, it could also mean that the caregivers might feel uncomfortable in expressing their lack in QoL in a general survey or to a stranger. None of the caregivers were highly educated. The maximum level of education attained was higher secondary. Shekhawat et al have found that the level of education was significantly positively correlated with QoL score in all the domains, and that better education had a positive impact on the overall QoL.[4] However, we did not find any association between the QoL and the educational status of the caregiver. The other most important determinant of the QoL of caregivers is the financial status and family income, as reported by Lin et al.[18] Lower socioeconomic status of families has been shown to be associated with more stress because of poor availability of resources.[20] Herein, as most of the participants belonged to low economic background, it is logical to assume that they might have to deal with some level of stress. However, there was no significant association between the economic class and QoL. A plausible explanation could be a fear of judgement among the participants. It was suggested that a combination of stress, health and household income factors are independent and most potential variables for assessing QoL among caregivers of MR children.[18] We also did not observe any significant association between the

occupation and QoL, although a participant's occupation has often taken as a factor for determining respondent's social class and is identified as a predictor of social life.[21]

Additionally, data suggests that most participants had good coping strategies against stress experienced while dealing with MR children. Also, surprisingly, no significant association between the coping strategies and the studied socio-demographic variables. Coping strategies have been broadly classified into three strategies and comprise of problem-focused coping (active coping, planning, instrumental support, and religion scales); active emotional coping (venting, positive reframing, humor, acceptance, and emotional support scales); and avoidant emotional coping (self-distraction, denial, behavioural disengagement, self-blame, and substance use scales).[22] Previous studies advocate the importance of family support and cohesion for emotional release, and better spouse communication with spouse contributing to better coping. The parents also felt that a realistic outlook of the child's disability and acceptance, better facilitated them to cope.[11] An inverse relationship between psychological stress and positive coping strategies have been reported by Venkatesh et al.[23] In addition, greater religiosity has been correlated with better coping in parents of MR children. A study by Rammohan et al opined that the style of problem solving, and strength of religious belief and faith in god were significant predictors of well-being among the caregivers, especially in India.[24]

The study on a whole showed that the QoL and coping strategies of the caregivers for the studied data set were good. Also, it was surprising to see that there were no significant associations between the socio-demographic variables and QoL. Both QoL scores and coping strategies were good, implying that the caregivers did not feel MR children as a burden, and had developed effective coping mechanism to deal with stress. In addition, it could also imply that participants were uncomfortable in sharing their experiences and stress to a general audience. As the socio-economic status of most caregivers were low, there is a need to implement strategies to work for the betterment of the psychosocial health of the caregivers, not only the ID children. The estimation of QoL in different domains (Physical health, psychological health, social relationship, and environment) is missing in the study, which could be potential limitation of the study. Although the psychological health of the caregivers is extremely essential, the studies relating to it are very scarce. More studies are required in establishing independent and reliable predictors of QoL of caregivers. There is a need for the healthcare providers to assess the QoL of caregivers on regular basis. Also, as financial status is an important predictor, more help from NGOs and other organizations will help in improving the overall QoL in caregivers of MR children.

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None

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