Original Article

The Relationship between the Characteristics of Mentally Retarded Persons and the Quality of life Perception of their Parents

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Abstract

Objective: The study was designed to assess the level of quality of life (QOL) in the parents of individuals with mental retardation (MR) and its relationship with the characteristics of the suffering individuals. **Study Design:** Quasi experimental research design. **Place:** The study was carried out in the Department of Psychiatry and Behavioral Sciences, Allied/DHQ Hospitals, PMC Faisalabad, Almasoom center Faisalabad and Amine Maktab special institute for mentally retarded children Lahore. **Duration of the study:** The study was conducted during July 2007 to December 2007. **Method:** 98 mothers and 91 fathers of mentally retarded individuals from public Hospitals and centers for mentally retarded children in Faisalabad and Lahore participated in this study through purposive convenient sampling technique. Quality of life was measured by WHO QOL-BREF (Validated Urdu Version) while demographic variables were recorded on a demographic sheet. The results were obtained by using analysis of variance (ANOVA) on SPSS 13. **Results:** Mothers had scored higher on QOL environment domain when their MR Child had the ability to do judgments in daily living, $F(1, 97) = 4.640$, $p < .05$. Fathers of the MR persons who can reason have scored higher on this domain ($M = 16.105$) than the fathers of the MR persons who can not reason ($M = 13.694$), $F(1, 90) = 6.692$, $p < .05$. ANOVA showed differences in the QOL scores of the fathers on psychological, $F(1, 90) = 4.819$, $p < .05$, social relationships, $F(1, 90) = 5.174$, $p < .05$ and environment domain, $F(1, 90) = 5.320$, $p < .05$ depending upon the ability of MR person to travel public transport; independent sample t test produced enough evidence to establish the effects on all four domains of QOL. **Conclusion:** In the face of the evidence of high deterioration in quality of life of the parents in absence of judgments to daily living, reasoning, and ability to travel public transport, it is to be communicated to parents and teachers of MR persons to pay more attention on the training of these skills. Further more physicians, psychiatrists, other health care professionals and members of the family are to be sensitized in identifying this disturbance in the quality of life perception in order to take measures against it so that family functioning may not be disturbed. **Key words:** Quality of life, Parents, Mothers, Fathers, Mentally retarded individuals.

INTRODUCTION

The conceptualization of mental retardation includes deficits in cognitive abilities as well as in behaviors required for social and personal sufficiency known as adaptive functioning[1]. Mental retardation may present in a range of cases; it may be exhibited as only a lower level of intellectual and adaptive functioning, or it may appear as a result of some other developmental disorder such as down's syndrome, fragile X syndrome, phenylketonuria, or other recessive gene disorders. Thirdly, mental retardation may also co morbid with other developmental disorders like autism, attention deficit hyperactivity disorder etc[2]. Mental retardation interferes markedly with the entire developmental process and many of the children affected are unlikely to become well functioning adults; the lapses left in their functioning are the responsibility of their care givers. When the parents assume this additional and essential responsibility as care givers, they become more susceptible to different psychological problems. Holroyd and Guthrie found that mothers generally feel

burdened and the family members deprived of normal family life because of the presence of a handicapped[3]. Mothers reported facing considerable difficulties balancing work and care giving responsibilities because support services rapidly declined when their child reached adolescence. Service cuts were related to the fact that adolescents are expected to be able to care for themselves, despite the fact that for many adolescents with disabilities, this is not possible[4]. A research found that three predictor blocks; child characteristics, parent's sociodemographics, and family environment accounted for 36.3% and 22.5% of parental stress and parent's psychiatric symptomatology variance respectively. Parental stress was less when the child was older; parent's reported more psychiatric symptomatology when the child showed a high level of dysfunction. Fathers who were not working had higher level of stress than fathers who were working and lower socioeconomic level was associated with greater symptom rates of cognitive disturbance, depression, anxiety, and despair among parents. Among the family environment variables, only the personal growth dimension stood out as a predictor of parental stress. An orientation toward recreational and religious pursuits, high independence, and intellectual and recreational orientations were associated with lower levels of parental stress. On the other hand, parents in achievement-oriented families showed elevated levels of parental stress[5]. Hewett noted that the moment of crisis starts as soon as the parents learn that their child is permanently handicapped[6]. Grant and Whittell found that many couples adopted a sharing caring together approach, which highlighted the importance of fathers and other males in coping roles[7]. Simerman, and colleges researched out that fathers' involvement in the lives of their young children with severe intellectual disability was highest in the areas of playing, nurturing, discipline and deciding services[8]. Parents of 1237 Swedish children later diagnosed with autism had more hospital admissions for a mental disorder than parents of a match group of normal children[9]. Researchers found that mothers of autistic children had higher levels of parenting related stress and psychological distress than mothers of children with developmental delays[10]. It is needed to explore the phenomenon in our local population because indigenous literature available is quite scarce. Current research examines the relationship between the perception of the quality of life in parents of mentally retarded individuals and different developmental, adaptive and behavioral characteristic of these individuals.

METHOD

Participants

98 mothers and 91 fathers of mentally retarded persons participated in this study through purposive convenient sampling technique. The sample has been taken from Department of Psychiatry and Behavioral Sciences, Allied/DHQ Hospitals, PMC Faisalabad, Almasoom center Faisalabad and Amine Maktab special institute for mentally retarded children Lahore.

INSTRUMENTS

Validated Urdu Version of WHO QOL-BREF[11] was used to assess the Quality of life perception of the parents. Child characteristics were recorded on a separate performa that measured the presence or absence of the developmental, intellectual, adaptive, social and emotional characteristics of the MR persons.

PROCEDURE

Research protocol was presented to Ethical Review Committee of the Punjab Medical College. After the approval, raters were recruited who were internee psychologists. They were trained in the administration of instruments. Raters approached the parents of MR persons in above mentioned centers with the help of their staff. After informed consent was taken, data were collected on prescribed Performa and QOL-BREF. Multivariate Analysis of Variance was computed by using SPSS 13.0.

RESULTS

Results showed that presence of three characteristics are very important in sustaining the QOL perception of the parents of MR persons. These important skills are judgment to daily living, reasoning, and ability to travel public transport. ANOVA showed differences in scores of mothers on environmental domain of QOL depending upon the restlessness, $F(1, 97) = 4.901$, $p < .05$ and ability of MR person to do judgments of daily living, $F(1, 97) = 4.640$, $p < .05$. Independent sample t test nullified the differences on restlessness but it produced enough evidence to establish the effects on judgment to daily living (see table 1). Mothers had scored higher on QOL environment

domain when their MR Child had the ability to do judgments in daily living. Analysis of variance also showed difference in scores of mothers on physical health domain of QOL depending upon the weight and social responsiveness of the child $F(1, 97) = 3.98$, $p < .05$ and $F(1, 97) = 4.497$, $p < .05$ respectively. Because of the small difference between the means, independent sample t test was applied that nullified the observed significance (see table 1). Differences were found in QOL scores of the mothers on social relationship domain depending upon the MR person's ability to travel public transport, $F(1, 97) = 5.126$, $p < .05$ and apply academic skills, $F(1, 97) = 6.509$, $p < .05$. Independent sample t test nullified the difference on both of the variables (see table 1). Differences were also found in QOL on psychological health and environment domain depending upon whether the MR person can reason or not, $F(1, 97) = 4.300$, $p < .05$ and $F(1, 97) = 6.371$, $p < .05$ respectively but independent sample t test nullified the differences (see table 1). Difference was found in QOL scores of fathers on physical health domain depending upon that MR person can reason or not, $F(1, 90) = 6.692$, $p < .05$. Fathers of the MR persons who can reason have scored higher on this domain ($M = 16.105$) than the fathers of MR persons who can not reason ($M = 13.694$). Independent sample t test proved the statistical significance (see table 2). ANOVA showed differences in the QOL scores of fathers on psychological, $F(1, 90) = 4.819$, $p < .05$, social relationship, $F(1, 90) = 5.174$, $p < .05$ and environment domain, $F(1, 90) = 5.320$, $p < .05$ depending upon the ability of MR person to travel public transport; independent sample t test produced enough evidence to establish the effects on all four domains of QOL. QOL scores of the fathers were significantly higher on all four domains when their MR Child had ability to travel public transport (see table 2). Effect of the stubbornness of MR person was found to be statistically significant on physical health domain of QOL of the fathers of MR persons, $F(1, 90) = 5.231$, $p < .05$. But independent sample t test nullified the effect (see table 2). Effect of the self support of the MR person is statistically significant on social relationship domain of QOL of fathers, $F(1, 90) = 3.873$, $p < .05$. But t test could not produce enough evidence to establish the results (see table 2). The effect of MR person's ability to use tools, $F(1, 90) = 3.827$, $p < .05$ and being socially responsive, $F(1, 90) = 4.761$, $p < .05$ were found to be significant on the environment domain of QOL of fathers in the Analysis of Variance but the evidence could not be retained in independent sample t test (see table 2).

Table-1

Independent sample t test on the QOL scores of the mothers

QOL-DOM	Child characteristics	n	X	t	Sig.
Physical	Normal birth weight	41	13.35	1.396	.166
	Under weight	57	14.19		
Social	Able to travel public transport	18	15.11	1.858	.072
	Not able to travel public transport	80	13.83		
Physical	Socially responsive	45	13.66	-0.544	.588
	Not socially responsive	53	13.99		
Social	Able to apply academic skills	37	14.77	1.727	.087
	Not able to apply academic skills	61	13.64		
Psychological	Can reason	47	13.48	.378	.706
	Cannot reason	51	13.29		
Environmental	Can reason	47	13.53	.591	.556
	Cannot reason	51	13.25		
Environmental	Do judgment of daily living	42	13.93	2.083	0.04*
	Cannot Do judgment of daily living	56	12.98		
Environmental	Restless	62	13.12	-1.635	.105
	Not restless	36	13.85		

* significant at 0.05

df = 96, 2 tailed

Table-2

Independent sample t test on the QOL scores of the fathers

QOL-DOM	Child characteristics	n	X	t	Sig.
Physical	Can reason	44	15.69	3.727	.000** *
	Cannot reason	47	13.88		
Physical	Stubborn	63	14.86	.536	.595
	Not stubborn	28	14.53		
Physical	Can travel public transport	17	16.13	2.748	.011*
	Cannot travel public transport	74	14.44		
Psychological	Can travel public transport	17	16.10	2.894	.008**

	Cannot travel public transport	74	14.12		
Social	Can travel public transport	17	16.39	2.504	.020*
	Cannot travel public transport	74	14.18		
Environmental	Can travel public transport	17	15.06	2.176	.039*
	Cannot travel public transport	74	13.63		
Social	Self Supported	32	15.46	1.90	.061
	Not Self supported	59	14.12		
Environmental	Able to use tools	41	14.44	1.809	.074
	Not able to use tools	51	13.46		

* Significant at 0.05 **significant at 0.01
***significant at 0.001
df = 89, 2 tailed

DISCUSSION

Results have shown that the QOL of the parents of the MR persons is statistically high on the domains of physical health and environment because of the presence of the skills of judgment to daily living, reasoning and ability to travel public transport. Presence of the ability of judgment to daily living in MR person is seen to be importantly associated with the quality of life score of their mothers on environment domain. The MR persons who have a sense to judge the affairs of daily life rightly pose less vigilance on the part of the mothers since they are usually primary care givers[4]. In case of MR Child, mothers have to look after their child more vigilantly if his/her sense of judgment is impaired. The prolonged and additional responsibility lowers their QOL perception. This tells that interaction between parent and child needs to be life long and hectic for the care giver or parents.

Ways and extent of the interaction between child and the family is important in determining the load of stress on parent because of the presence of an MR Child in the family. This may lower their QOL perception as the fact has been established by previous researches that such child is taken as a long standing stress. Leland and Smith while summarizing the impact of a mentally retarded child in the family, state that the crucial importance of interactions between the child and the family, and the community starts right from the birth of the mentally retarded child in the family and extends throughout the life[12]. Crnic, Friedrich and Greenberg opined that the birth and continuing care of mentally retarded children are often stressful experiences for family members as these children's difficulties inevitably touch the lives of those around them[13].

Presence of this ability assumes that the child is able to take his responsibility on to his own shoulders as for as his immediate daily environment is concerned. The perception of the mothers that their handicapped child is safer and comfortable enhances a sense of better QOL perception in them on environmental domain. This hints at reciprocity between the mothers QOL perception and nature of characteristic of MR person affecting it. This reciprocity is also confirmed by previous research findings[14]. Fathers' perception of QOL on physical health is also affected by MR person's ability to reason. If reasoning ability is intact, fathers scored higher on physical health domain of QOL and vice versa. Presence of this characteristic seems crucial in sustaining QOL perception of fathers on physical health domain. When the MR person can reason, fathers sense them safe in their physical environment since this characteristic guarantees to safe guard their children from the physical hazards that in turn increase their own perception of QOL on physical health domain. This reciprocity between characteristic of MR person and sense of well being of the parent pertaining to that very characteristic has already been observed in other researches[14].

Ability of MR persons to travel public transport is importantly associated with better QOL scores of their fathers on physical, social, psychological, and environment domain. When an MR person is able to help himself on public transport, it gives satisfaction to the fathers and lightens their responsibility as well; as in our society fathers are thought to be responsible for the out door affairs of their children. Since researches say that moment of crisis starts right after birth and extends through out life, fathers feel them selves bound to the out door responsibilities of their MR child and this perception holds an everlasting situation[6, 12]. In such a situation if an MR person can help himself independently in public transport, it releases their fathers from the burden of responsibility and from the burden of the perception of long standing duration of the responsibility that in turn sustains their QOL perception on all four domains.

CONCLUSION

Skills like reasoning, judgment to daily living, and ability to travel public transport are found to be very important in differentiating the perception of QOL in the parents of MR children as deteriorated or not. Hence while training MR persons in home or in special schools, emphasis should be paid on the development and training of these skills. Further more physicians, psychiatrists, other health care professionals and members of the family are to be sensitized in identifying this disturbance in the quality of life perception in order to take measures against it so that family functioning may not be disturbed.

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