Quality of life Among Adolescents with Physical Disability Undergoing Integrated Education

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Abstract

Research Objective - To analyse the quality of life (QoL) of adolescents with disability who attend normal school as part of integrated education. The study investigates the quality of life of disabled adolescents who attend 8-12th classes in government and aided schools in Angamaly-Perumbavoor sub-District in Kerala. The research design is descriptive in nature.25 physically disabled adolescents who attend 8th to 12th class formed the sample. Quality of life was measured using WHOQOL-BREF Scale (1997). Result Shows that majority of the disabled are having average quality of life. There is below average Psychological and environmental quality of life with disabled adolescents. The findings of the study suggest the ways to improve the quality of life of adolescents by reducing social, environmental barriers to promote integration of adolescents with disabilities in schools, family and community. To enhance the total quality of life of individuals especially the psychological and environmental quality of life by providing a disabled friendly environment at school, family and community situations.

Keywords: Physical disability, quality of life, adolescents, integration education.

Introduction

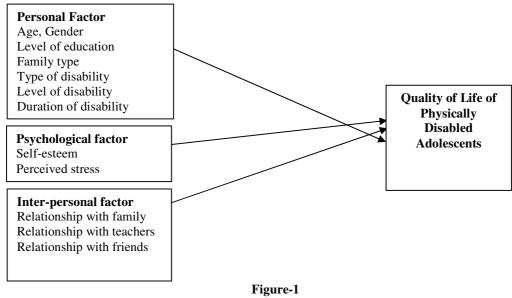
As per the study conducted by UNICEF four fifth of people having disability lives in developing countries. In India also studies have been conducted including during Census of 2001 regarding the prevalence rate of disability. In the census conducted in 2001 there are more than 2 core people with disabilities which constitute 2.13% of the total population. In the said census it is revealed that out of these people with disabilities 12,605,635 are males and 9,301,134 are females¹. These are people with visual, hearing, speech, loco motor and mental disabilities. Patel et al. (2009) using NSSO 2002 data, entered a finding that among the various disabilities prevailing in India loco motor disabilities are the most prevalent type of disabilities. The world Health Organisation has defined "Health as a complete physical, mental and social well being and not merely the absence of disease or infirmity" (WHO1983) the concept has more recently been extended to include health related quality of life. The term 'disability' has many different meanings; the Global Burden of Disease (GBD) define" Disability as loss of health, where health is conceptualized in terms of functioning capacity in a set of health domains such as mobility cognition, hearing and vision" (WHO 2004). Disability affects a person in different ways it affects his health, social relationships with family, friends and neighbours and also his independence

As the quality of life is improving in developing countries, the quality of life of a person with disability who is marginalised

and underprivileged group, studies must be made to improve the quality of life of such persons. Lack of disabled friendly environment is making the life of disabled person in misery. Social segregation of disabled persons is in the increase. Various social welfare schemes envisaged by government and other agencies are not fully successful in providing special privileges for the disabled though there is a change in approach, there is still a need for major changes so as to bring the disabled persons to the main stream of the society.

Integrated education is a result of mainstreaming movement in America. And this education concept is gaining importance all over the world. Integration only means placing in ordinary school children with special education needs. Its achievement will require the successful coordination of a whole series of transition for the handicapped ranging from early identification, to early intervention, to school program to community school program to community job and finally to community living. The ministry of human resource development (Department of secondary and higher education has been implementing a scheme of integrated education for the disabled children (IEDC) in formal schools since 1982. At present nearly 1,000,000 children with disabilities are reported to be benefitted by integrated approach through 20,000 general schools. Still there is a long way to go in realizing the objectives of education for all children with disabilities. Its full potential is yet to be explored.

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Conceptualisation of quality of life

Quality of life and disability: Quality of life of the disabled people has been the subject matter of study by various researchers all through out the world. Lack of access to health services and medical care is a major problem faced by people with disabilities and this has resulted in associated problems like muscular-skeletal and mental health. Problem, over and above the primary disability². The quality of life and psychological health are inversely related. Depression, lack of concentration, feelings of fatigue, loss of interest in daily activities, social isolation, and a sense of worthlessness were common feature of people living with disabilities. Diener et.al.³ a study among Adolescents with physical disabilities in Korea reveals that acceptance of society about their existing problem is very helpful in having a normal life for the disabled persons.

A study conducted by Centres for Disease Control and Prevention⁴, it was found that if the disabled are motivated to appraise their health situation positively the adverse impact of disability could be reduced. Kim and Kang⁵ in one of the study present that the satisfaction of having a relationship, self achievement, self worthiness, recognition are all expected by a grown up disabled person. In the case of adolescent disabled persons his self rating of health is related to various aspects, both social and psychological, which including his achievement in schools, involvement in sports and exercise, income of family psychological wellbeing, relationship with parents, self esteem etc. and quality of life is not much related to his physical well being.

Patrick⁶ in his study put forward a model for promoting quality of life of people with disabilities by giving importance to change living environment giving more opportunities to perform independence and autonomy. It is also pertinent to state that financial implications of disability in a child on the family is

also very significant Studies conducted in Delhi revealed that loco motor disabilities is causing serious financial burden on parents of the disabled children⁷. Evidence from the literature suggests that a positive self-appraisal of health may mitigate the deleterious effect of illness or disability on life satisfaction³.

Aim: To assess the quality of life (Qol) of disabled adolescents who attend integrated education

Methodology

The researcher used a descriptive design to describe quality of life of adolescents with disability who attend normal school. The universe of the study includes all physically disabled children attending general school in Angamaly-Perumbavoor Sub- District. The sample size is limited to 25. The sampling technique is purposive sampling. Researcher purposefully selected the samples from the government and aided schools in Angamaly- perumbayoor Sub- district. The samples are disabled adolescents. The loco motor disability children were the samples; both upper limb and lower limbed disability were selected as samples. The tool used was a standardised scale by World Health Organisation, the name of the scale is WHOOOL-BREF scale⁸, the scale assess the quality of life in the 4 domains like physical, psychological, social relations and environmental quality of life. The collected data was analyzed and done the percentage analysis constructed in SPSS.

Results and Discussion

The respondents include 17 males (68%) and 8 females (32%). Majority of the respondents were studying in government school 17(68%) and only 8(32%) studying in aided school. The respondents were either having upper limb disability (40%) or lower limb disability (60%).

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Table 1 elicits the level of total quality of life of adolescent children with disability. Out of 25 students 8 i.e., (72%) falls on average quality of life. The findings in the various domains in quality of life represent average level of score in physical, psychological, social relations and environment domains. Only 12% are having poor quality of life, that too in environmental and psychological domains. Another finding is that 16% are having high quality of life. The finding clearly shows the need for more intervention among adolescents with disability to improve their quality of life to attain high quality of life in physical psychological, social and environmental domains. The family, school and the community as a whole need to go hand in hand to ensure a high quality of life for the disabled adolescents in our state.

Table-2 represents the quality of life in different domains of an individual's life. The various domains assess the experiences in quality of life at their home, school and community. 72% of the total respondents comes under the average level of quality of life in environmental situations and psychological domain, whereas in the matter of social relationship (84%) are in average Qol and (76%) with average physical quality of life. There were very few respondents belongs to below average with Physical (20%) ,Psychological (4%),Social relations (16%) and environment (16%) quality of life. Only (4%)of the respondents having above average level of Physical quality of life and (12%) having above average environmental quality of life . The intervention of integrated education for disabled children has a remarkable influence in reducing stigmatisation and building self confidence and self esteem among the disabled ones. This is

true in my study also. The social workers and other professionals working for the disabled should take necessary steps to build awareness among the community regarding the strengths and capacity of those differentially able ones and the need for accepting them as a normal citizens in our country.

A social relationship is a major factor which determines the quality of life of Individuals. Table-3 represents the perception of disabled adolescents towards their social relationships. Majority of the respondents are satisfied (72%) or very satisfied (28%) with the support they receive from their friends. The respondents are studying in general school as a part of inclusion education, Most of the respondents shared that their friends are very supportive during their travel to school, meeting their personal needs at school like going to bathroom, play ground etc.

But when it comes to the maintenance of relationship maintaining majority of them are neither satisfied nor dissatisfied (68%) and (24%) are fully dissatisfied with maintaining personal relationships. So it is shown that even though they are getting support from friends they couldn't maintain personal relationship. This result need to be read along with the result of psychological domain. It is found that they are not much satisfied with their appearance, they have negative feelings etc. This may result in their inability to maintain relationship. Another reason may be their friends may be concerned about their disability but may not be ready to accept them for intimate relationships.

Table-1 Fotal quality of life of adolescent person with disability

Total quanty of the of adolescent person with disability						
Sl. No	Total quality of life	Frequency	Percentage			
1	Poor quality of life	3	12%			
2	Average quality of life	18	72%			
3	High quality of life	4	16%			
	Total	25	100			

Table-2
Perception of Quality of life in Different Life Domains

Sl.No	Domains of Quality of life	Below Average	Average	Above Average	Total			
1	Physical quality of life	5(20%)	19(76%)	1(4%)	25(100%)			
2	Psychological quality of life	1(4%)	18(72%)	6(24%)	25(100%)			
3	Social relations	4(16%)	21(84%)	0	25(100%)			
4	Environment	4(16%)	18(72%)	3(12%)	25(100%)			

Table-3
Perception of Quality of Life in Social Relationships

S. No.	Social relationships	Dissatisfied	Not satisfied /dissatisfied	Satisfied	Very satisfied	Total
1	Satisfaction with personal relationships	6(24%)	17(68%)	2(8%)		25(100%)
2	Support from friends			18(72%)	7(28%)	25(100%)
3	Establishing intimate relationships	6(24%)	6(24%)	8(32%)	5(20%)	25(100%)

Table No.4 represents the perception of respondents about quality of life of their environment in which they are living. About 92% of them are dissatisfied and 8% were neither satisfied nor dissatisfied with the transportation facilities. Most of the respondents are from rural background and belongs to low socio-economic families. Most of the schools don't have school bus facilities. So they need to depend on expensive private vehicle. The existing transport facilities are not disabled friendly so it creates problem with the children This result is supported by Silver and Koopman who explains that the existing South African transport system is not easily accessible to people who are in wheel chairs. About 80% of them do not have any pocket money to meet their personal needs. But it is interesting to found that towards the safety and facilities of their living place majority are not satisfied nor dissatisfied. About 28% are dissatisfied with the leisure activities in the community. Most of the leisure activities are planned for non disabled category people. One of the respondent shared that there is a good Panchayath library in the locality, where the registration is free for disabled one. But the problem is that the library is in a four storied building. The integrated disability strategy is still in the paper, Number of barriers in environment which prevent people with disability from enjoying equal opportunities with normal people.

Perception of satisfaction in psychological domains are displayed in table-5. Majority of the respondents perceived that they are having moderate level in all the psychological factors like having enjoyment in life (64%), find meaning in their life (56%). (80%) of the respondents perceived that they have the ability to concentrate, can accept their body appearance, satisfaction with oneself (72%) and about (80%) are having moderate negative feelings. Only least number of respondents comes under very much satisfied and nobody responded as having extreme amount of satisfaction and without satisfaction .The result shows that the adolescents with disability need to go a long way to achieve high quality of life. The policy makers and administers are trying to uplift the QOL of the less privileged, through the inclusion development initiatives. More individual oriented initiatives are necessary to improve the psychological quality improvement. So schools need to facilitate services for emotional support and improve their self esteem. In Kerala most of the government schools have the service of a student councillor which has resulted in improving the conditions of student's. All the respondents are studying in general school, so they need to struggle hard to cope with the general students. This also may have strengthened them to certain extent.

Table-4
Perception of Quality of life in Enviormental Situations

Sl.No	Environmental Factors	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Total		
1	Transportation Facilities	23(92%)	2(8%)		25(100%)		
2	Conditions in the living place		22(88%)	3(12%)	25(100%)		
3	Opportunity for leisure	7(28%)	18(72%)		25(100%)		
4	Availability of information for daily living	16(64%)	9(36%)		25(100%)		
5	Pocket money to meet personal needs	20(80%)	5(20%)		25(100%)		
6	Safety in daily life		11(44%)	14(56%)	25(100%)		

Table-5
Perception towards satisfaction in psychological domains

S. No	Psychological factors	A little	Moderate	Very Much	Total
1	Enjoyment in life	9(36%)	16(64%)		25(100%)
2	Meaning to your life	8(32%)	14(56%)	3(12%)	25(100%)
3	Ability to concentrate	5(20%)	20(80%)		25(100%)
4	Accept bodily Appearance	6(24%)	16(64%)	3(12%)	25(100%)
5	Satisfaction with oneself	4(16%)	18(72%)	3(`12%)	25(100%)
6	Negative feelings	5(20%)	20(80%)		25(100%)

Table-6
Perception of quality of life towards physical health

Sl.No	Physical health	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied	Total
1	Energy to everyday life		9(36%)	15(60%)	1(4%)	25(100%)
2	Ability to get around	6(24%)	12(48%)	5(20%)	2(8%)	25(100%)
3	Ability to perform daily activities		9(36%)	16(64%)		25(100%)
4	Satisfaction with sleep		8(32%)	11(44%)	6(24%)	25(100%)
5	Capacity to work		9(36%)	15(60%)	1(4%)	25(100%)

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Table-6 depicts the perception of quality of life towards physical health. Majority of the respondents are satisfied or very satisfied with their physical health. About 24% were dissatisfied and 48% without any perception towards the ability to get around. It may be due to the environmental limitations for the disabled persons in our society. It is interesting to note that majority of them are satisfied (60%) with their capacity to work and (60%) satisfied with their energy to everyday life. More than half of the respondents (64%) were satisfied with their ability to perform daily activities. There are students who are very satisfied with energy for life (4%), ability to get around (8%) satisfied with their sleep (24%) and capacity to work (4%). The inclusion policies and the disabled friendly interventions in educational initiatives improve the opportunity for participation in all walks of life to some extent. We cant say that this inclusion concept eliminates the stigma and negative reactions towards people with disability, but this result was entirely different from the findings of other studies. Here the respondents are satisfied with their energy and their physical health even though they have problems in their physical conditions.

Road Ahead: The perception of disabled towards their quality of life is in the average level. It is due to many factors like physical, psychological, enviormental social relationship etc .But one of the major factor is that these students are in the integrated education system. That is why there is high quality of life with social relationship and physical health. But the lack of satisfaction in environment and psychological realm may be due to lack of support and improper implementation of integration education system. There are so many parents who do not avail the integration services. They need to be informed about the said services and should prompt them to make use of them for their special wards. Social work intervention is having ample scope at individual, group and community level to ensure good life situation for the people with disability.

Conclusion

The study reveals the self perception of disabled adolescents who undergone integration education in normal school. The physical health and social relations domain is having good quality, whereas the Psychological and environmental domain shows dissatisfaction to many of the components. The integration education system has a major role in improving the psychological and social relationship domains. The integration system washed away the misconceptions and discrimination towards the people with disability. The disabled adolescents expressed the barriers in environment which affect their quality of life. The government needed to take initiatives to make our state a disabled friendly state.

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