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Community Based Rehabilitation And Its Impact On Quality Of Life And Psychological Well-Being Among Persons With Disability

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Abstract

Background: Community Based Rehabilitation (CBR) focuses on enhancing the quality of life of person with disabilities and their families; meeting basic needs; and ensuring inclusion and participation. In absence of such interventions person with disabilities (PWDs) may develop psychological, economic and social problems, which have an adverse effect on life satisfaction, psychological well-being and also on Quality of Life.

Objective: To assess the impact of livelihood component of CBR matrix on Psychological Well-Being and Quality of Life of PWDs.

Methods & Materials: The study comprises of 60 individuals with locomotor disability from two Blocks of Ranchi, Jharkhand, India. The impact of community-based rehabilitation (CBR) on individual's life was examined using the Socio-demographic data sheet, WHO Quality of Life (Saxena et al. 1998) and Psychological Well-Being (Dupuy, 1984). Ethical issues were followed while conducting study.

Results & Conclusion: CBR programs are also considered to be the most cost-effective approach to improve the wellbeing and increasing satisfaction level, in comparison with care in hospitals or rehabilitation centres. This model can also be used as a mental health promotion strategy for the person with disabilities. Study results will be discussed at the time of presentation.

Key Words: Community Based Rehabilitation (CBR), Mental Health, Quality of Life, Needs Satisfaction

1. INTRODUCTION

The World Health Organisation (WHO) introduced the Community-Based Rehabilitation (CBR) strategy as part of its goal to accomplish health for all by the year 2000. The Alma-Ata Conference and Declaration of 1978 on Primary Health Care (PHC) creates a new vision for providing promotive, preventive, curative and rehabilitative services for the main health problems in the community (WHO, 1978).

Many neurodevelopmental diseases which cause disability in individuals, such as cerebral palsy (CP), mental retardation (MR), Down syndrome, hearing loss (HL), and speech disorders, are congenital and affect physical, cognitive, sensory and adaptive functions during the developmental process. Moreover, the severity of disease causes variations in the daily needs of individuals and their families even in the same disability group. These disabilities cause limitations in activities and participation in adolescence and adulthood and affect the quality of life (QoL) and wellbeing in negative ways (Hetherington R, Dennis M, Barnes M, et al., 2002; Morris C, Kurinczuk JJ, Fitzpatrick R., 2005)

Persons 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. Quality of life of the disabled people has been the subject matter of study by various researchers all throughout 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. 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. in 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.

According to the Census of 2011, population consists of 2.1% disabled people, while WHO reports it to be around 2-6% (Singh R., 2011) About 4% of the population in Punjab and Jalandhar are physically challenged (Govt. insensitive to disabled children's needs., 2012) CRY (Child Rights and You) America and Child Rights, Statistics of Indian Children states that 20 out of every 1000 rural children are mentally/physically challenged, compared to 16 out of every 1000 urban children(CRY). According to United Nations International Children's Emergency Fund, there are about 600 million disabled people out of whom 150 million are children. It is estimated

that 6 to 10% of children in India are born disabled (Olivera R., 2011)

CBR is a strategy within general community development for rehabilitation, equalisation of opportunities, and social inclusion of all children and adults with disabilities (ILO, UNESCO & WHO, 2004). The CBR concept is both simple and complex in nature (ESCAP.,2003;1997). The simplicity has to do with its origins, i.e., delivery of rehabilitative services to people with disabilities in their communities. CBR's complexity is the result of the current concept of CBR programmes as multi-disciplinary, i.e., visiting people with disabilities and their families in their homes; providing appropriate information, therapy and/or training; and facilitating rights and duties of people with disabilities, family, and community members (Vanneste G., 2001).

CBR has been the focus of some form of evaluation since the first field-testing of the manual Training in the Community for People with Disabilities (Mitchell R., 1999). Early reports state that only two of the 43 countries represented by the six regional zones in which the WHO operates mentioned any evaluation and research on CBR (WHO.,1982). Earlier country reports are limited to issues such as initial consultant visits, training workshops held, and number of stakeholders involved in training. Subsequent evaluation studies presented extensive sets of data on the number of people identified with disabilities, the number of people with disabilities who received assistance, and the type of assistance (Njini L, Goerdt A, Hanekom J, et al., 1991)

Well-being is a complex construct that encompasses multiple domains such as physical and mental health, happiness, and life satisfaction. Quality of life (QOL) is defined as individuals' perception of their position in life in context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (World Health Organization Quality of Life Group.,1995). QOL has emerged as a potentially unifying concept in setting goals for services and for assessing their impact on people's everyday lives (Felce D., 1997). The unifying concept of quality of life enables service providers to reorganise resources around individuals rather than rearrange people in programme slots (Gardner JF, Nudler S and Chapman MS., 1997; Schalock R L, Brown I, Brown R, et al.,2002)

Individual QOL measures may be used for various purposes, including programme evaluation, research analysis, policy development, and meeting individualised needs (Rusch F R, H Hughes C and Hwang B., 1996).

Among the evaluations featuring QOL, one (Powell A B, Mercer W S and Harte C., 2002) used Comprehensive-QOL Scale. Another (Cummins R A, McCabe M P, Romeo Y, et al., 1994) suggests that QOL was substantially lower among people with physical disabilities who received no rehabilitation services compared to those who did receive physical rehabilitation, community-based rehabilitation, and labour market assistance. QOL scores tended to be highest, however, among those who received a combination of all three services.

CBR Matrix (WHO et al. 2010) Capability Approach (Sen, 1999). CBR programmes are considered fundamental to improve the wellbeing of people with disabilities, and for fostering their participation in the community and society at large (Cornielje, 2009; Sharma, 2007). CBR programmes are also considered to be the most cost-effective approach to improve the wellbeing of people with disabilities, in comparison with care in hospitals or rehabilitation centres (Mitchell, 1999). Little literature providing knowledge-based evaluation of the impact of CBR programmes on the well-being of people with disabilities

Alavi and Kuper (2010) identify a total of 51 studies evaluating the impact of rehabilitation for people with disabilities in Africa, Asia and Latin America (only two of these studies evaluating CBR programmes or services used a comparison group). Worldwide survey of researches and methods: literature is limited especially from an overall impact point of view. There are still no universally agreed criteria for the evaluation of CBR programmes (Finkenfugel et al., 2007)

It has been reported that although the overall burden of diseases was 20.9% in India the proportion of health expenditure was less i.e. 1% in 1990 (Murray and Lopez 1997). In the period 1998-2003, just under Rs. 1042 crore was spent by MSJE on the 'welfare of persons with disabilities' with the largest expenditure category the national institutions and corporations for disability (World Bank 2007). This represents a negligible portion of total budgetary spending. While precise comparisons are difficult, for 2000-2001 budget year, MJSE's spending on disability would account for around 0.07 percent of total Government of India expenditure, and for 2002-03, it accounted for around 0.05 percent of total. In the most recent budget year (2005- 06), the share had fallen even further to only 0.047 percent of total allocation.

2. METHODOLOGY:

2.1. Sample: The participants were 60 persons with loco-motor disability and who were having any type of assistance under CBR programmes by the NGO were selected were recruited to be the part of the study from Ranchi. Jharkhand, India. Purposive sampling technique was used.

2.2. Assessments

Socio demographic questionnaire

The information from each participant fulfilling the criteria was gathered through a detailed socio-demographic data sheet including age, gender, religion, caste, domicile, education, occupation, type of disability, and duration of assistance from CBR and NGO.

WHO Quality of Life (QOL)

The World Health Organization Quality of Life (QOL) is a measurement tool for the evaluation of quality of life. The scale includes 26 items asking about physical, psychological, social-relational, and environmental aspects of quality of life. Respondents were asked on the scale to make a subjective evaluation of their own lives using a 5-point Likert-type scale from 1(strongly disagree) to 5 (strongly agree).

It is a self-administered generic questionnaire developed in Hindi and shorter version of the WHOQOL-100 scale which was developed as a measure that would be applicable cross-culturally. It lays emphasis on subjective evaluation of the respondent's health, living condition and functioning and quality of life on the dimensions of physical, psychological, level of independence, social relations, environmental and spirituality/ religion/ personal belief. Each of these domains is treated as a separate numeric variable and higher the score, higher the quality of life. The scale has good reliability, comparable to that of WHO-QOL-100 scale ($r \geq 0.89$). It also has good content and discriminate validity.

Psychological General Well-Being

Psychological General Wellbeing Schedule (PGWS) (Dupuy,1984) measures a person's subjective well-being. It is a self-reported questionnaire and it has 22 items which have six areas. Each item has 6 point (0-5) scales. Score for each affective group = SUM (points assigned for each question in group) where: the number in square brackets represent the points assigned for selected answer. Higher score indicates good psychological general well-being in each domain.

2.3. Procedure

To conduct this study permission was taken from NGO named Chotanagpur Sanskritik Sangh based in Ranchi. Jharkhand, India. Researcher followed inclusion and exclusion criteria while recruiting samples. Persons with loco-motor disability were recruited for the study once they provided with their written informed consent to the researcher. Information was collected in direct face-to-face interviews. Further WHO Quality of Life and Psychological Well-Being was administered. Ethical guidelines were followed while conducting study.

2.4. Data analysis

The data obtained were analyzed with Statistical Package for Social Sciences-version 16.0 for Windows® (SPSS Inc., Chicago, IL, USA).

The PGWB and WHO QOL score was used for analysis. The socio-demographic characteristics (age, income and duration of assistance form CBR) and outcome variables (mean score of QOL and PGWB) were correlated with mean score using Pearson's correlation analysis.

3. Results

Table 1: Frequency and % of participants Socio demographic Information (Categorical variables)

S. No.	Domain	Responses	Frequency (%)N=60
1	Gender	Male	25 (41.7)
		Female	35 (58.3)
2	Religion	Hindu	27(45.0)
		Muslim	15(25.0)
		Christian	9 (15.0)
		Sarna	9 (15.0)
3	Occupation	Agriculture activities	32 (63.3)
		Self employed	20 (13.3)
		Service	8 (23.3)
4	Domicile	Rural	28 (46.7)
		Semi-Urban	32 (53.3)
4	Socioeconomic status	Lower	35 (58.3)
		Middle	22 (36.7)
		Higher	3 (5.0)
5	Type of the family	Nuclear	48 (80.0)
		Joint	12 (20.0)
6	Education	Primary	32 (53.3)
		Secondary	20 (33.3)
		Above	8 (13.3)

Table 1 shows that majority of the respondents were female 35 (58.3%) most of respondents from Hindu religion 27(45.0%). Majority of the persons with disability were engaging in agriculture 32 (63.3%). Most of the respondents were belongs to semi urban domicile 32 (53.3), 35 (58.3%) of respondents from lower socio-economic status, 42(70.0%) most of the persons with disability belongs to nuclear family 48 (80%), most of the respondent's education were up to primarily level 32 (53.3%).

Table 2: Mean and Standard Deviation scores on Socio demographic details of (continuous variables) PGWB and QOL

Variable	Mean (SD)N=60
Age	30.60 (5.97)
Family income	4120.04 (1721.31)
Duration of assistance from CBR	3.23 (1.75)
Physical QOL	19.36 (4.34)
Psychological QOL	16.50 (4.01)
Social QOL	10.51 (2.94)
Environmental QOL	16.70 (4.06)
Total score of QOL	**63.08 (8.81)**
Anxiety	16.88 (2.35)
Depressive mood	11.45 (1.91)
Positive wellbeing	15.33 (2.74)
Self control	10.45 (1.62)
General health	12.53 (1.83)
Vitality	14.23 (2.06)
Total score of PGWB	**80.88 (7.49)**

Table 2, shows that mean and SD scores of age of the respondents was 30.6 (SD 5.9), income per month of respondents were 4120 (1721), duration of assistance from CBR was 3.23 (1.75) years, the mean and SD score of Physical QOL was 19.36 (SD 4.34), psychological QOL was 16.50 (4.01), social QOL was 10.52 (2.94), environmental QOL was 17.70 (4.06), Overall Quality of Life (QOL) mean score was ***63.08*** (8.81) and the mean and SD of anxiety domain was 16.88 (2.35), depressive mood was 11.45 (1.91), positive wellbeing 15.33 was (2.24), self-control was 10.45 (1.62), general health was 12.53 (1.83), vitality was 14.23 (2.06), Overall psychological general wellbeing mean score was 80.88 (7.49).

Table 3: Correlation between total QOL mean score and other variables (n=60)

Variable	Pearson's R	p value
Age	-.074	0.574
Duration of assistance of CBR	0.104	0.429
Income of the family (per month)	0.002	0.991
Physical QOL	0.713	0.001**
Psychological QOL	0.574	0.001**
Social QOL	0.527	0.001**
Environmental QOL	0.458	0.001**

** P<0.01 Correlation is significant

Table 3 shows that there was significant positive correlation between: physical QOL domain with overall QOL (r= 0.713; p<0.001), psychological QOL domain with overall QOL (r= 0.574; p<0.001), social QOL domain with overall QOL (r= 0.527; p<0.001), environmental QOL domain with overall QOL (r= 0.458; p<0.001).

Table 4: Correlation between PGWB mean score and other variables (n=60)

Variable	Pearson's R	p value
Age	0.073	0.579
Duration of assistance of CBR	-0.089	0.498
Income of the family (per month)	0. .009	0.945
Anxiety domain	0.459	0.001**
Depressive mood	0.630	0.001**
Positive wellbeing	0.538	0.001**
Self-control	0.613	0.001**
General health	0.663	0.001**
Vitality	0.735	0.001**
Correlation between vitality domain of PGWB and Age		
Age	0.305	0.018*

* P<0.05 Correlation is significant.
** P<0.01 Correlation is significant

Table 4 shows that there was significant positive correlation between: anxiety domain with overall PGWB (r= 0.459; p<0.001), depressive mood domain with overall PGWB (r= 0.630; p<0.001), positive wellbeing domain with overall PGWB (r= 0.538; p<0.001), self-control domain with overall PGWB (r= 0.613; p<0.001) general health domain with overall PGWB (r= 0.663; p<0.001) vitality domain with overall PGWB (r= 0.735; p<0.001). the vitality domain mean score was significant positive correlation with age (r= 0.305; p<0.018).

Table 5: Correlation between total QOL and PGWB mean score and other variables (n=60)

Variable	Pearson's R (QOL)	p value	Pearson's R (PGWB)	p value
Age	-.074	.574	.073	.579
Duration of assistance of CBR	.053	.686	-.089	.498
Income of the family (per month)	.002	.991	.009	.945

Table 5 shows that there was no correlation between: QOL and PGWB with other variables (age, duration of assistance of CBR and income of family (per month).

4. DISCUSSION

The current study found that all the domains of QOL and PGWB were positively correlated with each other. The mean scores of QOL and PGWB indicates that persons with disability having good quality of life and psychological general wellbeing. The key finding was that positive correlation between vitality (the capacity to live and develop) domain of PGWB and age, which means persons with disability had less age possessing more vitality. Surprisingly there was no significant impact between duration of assistance from Community based rehabilitation with quality of life and psychological general belling among person with disability.

Many studies have reported that persons with disability having good quality of life due to acceptance of society about their existing problem is very helpful in having a normal life for the disabled persons (Diener eat al., 1999). A study conducted by Centres for Disease Control and Prevention in the year 1989 found that if the disabled are motivated to appraise their health situation positively the adverse impact of disability could be reduced. Current study also shows that persons with disability having good quality of life it was also found in study conducted by Abraham (2013). Evidence from the literature suggests that a positive self-appraisal of health may mitigate the deleterious effect of illness or disability on life satisfaction.

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. Present study findings reveals that persons with disability having adequate psychological wellbeing it may due to the assistance of CBR or other factors.

In current study the mean score of PGWB among persons with disability shows adequate psychological general well-being. The same findings were seen in study conducted by Burns et al. There was evidence that good work appears to help to improve mental health wellbeing and employment rate for people with mental health problems. Individual Placement and Support (IPS) was also recognised in the literature as an effective rehabilitation programme for severe mental health problems (Burns et al., 2007)

Finally, the current study found that all the domains of QOL and PGWB were positively correlated with each other, which shows that physical, psychological, social and environment develops overall quality of life among persons with disability. Anxiety reduced, not be depressive mood, positive wellbeing, self-control, general health and vitality also develops the psychological general wellbeing among persons with disability.

5. CONCLUSION:

The current study indicates that CBR activities or programmes need to reach more effectively towards persons with disability, only the duration of assistance may measure the impact of CBR, it would have taken into particular areas to assess impact of community based rehabilitation. 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. Rehabilitation of the loco-motor disabled would not be complete unless the physical rehabilitation is accompanied by their psycho-social rehabilitation.

The effect of disabilities on the suffering of an individual depends on the way person reacts and adjusts to their unusual or changes in life situation. The common reactions of an individual to their disabled condition are: feelings of inferiority, self-devaluation, fear, hostility, resignation and a tendency to accept the role of a recluse to mitigate these problems. Many international organizations vary in their approach to the management and treatment of disabled people's needs: for example the WHO promotes a medical rehabilitation approach to disability issues; UNESCO promotes inclusive education policies; the International Labor Organization (ILO) has a policy of including disabled people in their employment; UNICEF focuses on prevention of impairment in children through health and immunization programmes.

Ongoing research programmes on disability are limited in India. Although, one of the objectives of National Policy for PWD and the RPWD Act is to support the research in prevention and management of disability. Also, the major focus is on the social upliftment along with monetary benefits such as job opportunities, exemption from taxes, pensions, etc. and providing rehabilitation facilities to especially challenged individuals.

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