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COMMUNITY BASED OCCUPATIONAL THERAPY IN CHILDREN WITH EPILEPSY AND ASSOCIATED CO-MORBIDITIES IN RURAL AREAS OF MAHARASHTRA, INDIA

Neurology

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ABSTRACT

AIMS, OBJECTIVES: To study and understand the role of occupational therapy in community based rehabilitation of children with epilepsy and associated co-morbidities in Maharashtra, India.
METHODS: The data from the "Free epilepsy detection and treatment camps", conducted by National Health Mission and Epilepsy Foundation in different districts of Maharashtra in the years 2011-2019, were retrospectively analyzed.
RESULTS: Results indicated the trends in the children with epilepsy(N=2973) in terms of comorbidities and the intervention provided. Future implications were also discussed.
CONCLUSION: This study gives an insight into the role of occupational therapist in community based rehabilitation of children with epilepsy and associated co-morbidities in Maharashtra, India

KEYWORDS

Community Based Rehabilitation, Occupational Therapy, Children, Epilepsy

INTRODUCTION

In spite of a well planned primary healthcare system in place, it is seen that there is disproportion of healthcare resources (manpower & materials) i.e. greater availability and accessibility in urban regions and lesser in rural areas. The availability and accessibility issues in rural areas are further magnified by poverty, illiteracy, increasing population etc which act as barriers to healthcare. But times are changing, and the conditions of the rural regions are improving as evident from the Census 2011. Beyond these socio-cultural underpinnings, a major barrier to rehabilitation of individuals with disability is the lack of health seeking behaviors, of caregivers which needs to tackled.

World Federation of Occupational Therapists (WFOT) in its recent position paper[1] has mentioned about rethinking of professional priorities in terms of their social responsibility towards individuals with disability and has also urged that Occupational Therapy professionals look beyond individual therapies and re-conceptualize their roles in influencing a much required change in the healthcare system by working on projects based of social models for eg: Community Based Rehabilitation (CBR).

According to Government of India Census 2011 Maharashtra stands, second with its 35 districts in terms of population in India. It has population of 11.24 crore and the total number of disabled persons is 1.6 million of which and 60% are children. One of the major causes for disability in children is Epilepsy. Epilepsy is second largest neurological condition, affecting children. It presents with multiple disabilities in the motor, cognitive and behavioral areas. In India the prevalence of epilepsy in children is ~5 out of 1000 children and imposes a heavy burden on children themselves, their families and also on healthcare systems. Children with epilepsy (CHW) need rehabilitation programs in consideration of the epilepsy itself as well as the multiple disabilities it causes[2].

CBR is a concept that was developed by the World Health Organization (WHO) in the 1970s so as to improve the availability and access of healthcare to all individuals. From the time of conception the "CBR" has undergone many a changes from being a concept to a policy to a program. It is interpreted differently in different countries, health sectors etc i.e. a door to door survey and rehabilitation program, outreach programs in the form of rehabilitation camps , activities that lead to providing equal opportunities, protecting rights, community integration of individuals with disability etc.

In this research project we have studied through the experiences of a community out-reach program in rural areas of Maharashtra in the year 2011-19, and the role of Occupational Therapy in Community Based Rehabilitation (CBR) of Children with Epilepsy (CWE) and associated comorbidities.

AIM OF STUDY

To study the role of occupational therapy in community based rehabilitation of CWE and associated comorbidities.

METHODS

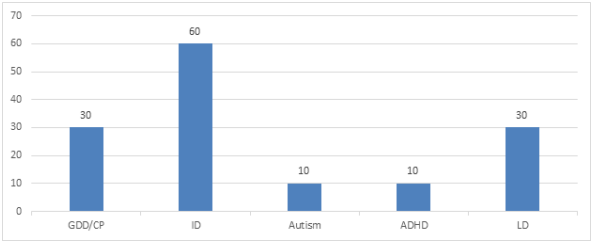
Background: In India, the National Rural Health Mission developed (NRHM) in 1983 now renamed National Health Mission (NHM) is a government body which works at the national and state levels towards fulfilling the needs of Persons with Disabilities(PWD) in rural areas. Epilepsy Foundation (EF) is a Non Government Organization working towards the children and adults with epilepsy. The NHM and the EF in collaboration are working on the CBR projects of persons with epilepsy across the different regions in Maharashtra. They have undertaken OUT-REACH programs (an important model of CBR) so as cater to a larger population over a larger area. These programs are conducted in the form of one-two day "Epilepsy Detection and Treatment Camps". Comprehensive evaluation and intervention is carried out at the camps by an expert team of Neurologists, Pediatricians, Psychologists, Occupational therapists, Physiotherapists and Speech Therapists. The camps are conducted at the civil hospitals located at the region. The community workers publicize about the camp in all the nearby regions and get an approximate estimate of the prospective camp attendants, prior to the actual camps. On the day of the camp the patients come on their own or are accompanied by various community workers. After initial registration they are directed to the neurologists and pediatricians who diagnose them, prescribe investigations &/ medications and refer them to appropriate therapies. The patients referred to Occupational Therapy are assessed by direct observation as well as interview of the caregiver / community worker and provided appropriate intervention using various frames of references. The data reports collected during the camps are given to the patients as well as a copy is retained by the camp team. In this study, the field notes from the camps conducted in the year 2011-2019 were studied retrospectively to understand the role of Occupational Therapy in community based rehabilitation in CWE and associated comorbidities.

Study Population: N= 2973 (from 75 camps between June 2011-June 2019)

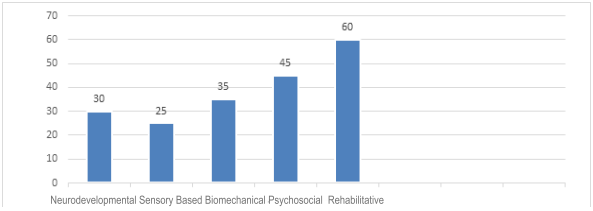
Evaluation: All children who were referred to occupational therapy by neurologists and pediatricians after diagnosis were evaluated by direct clinical neuropediatric observation checklist and Caregivers(CG) & / Community Health (CHW) interview.

Intervention: As per the evaluations each child was provided with intervention in the form of CGs/CHWs training, referral to local professionals, home program handouts, prescription of positioning , mobility and low cost aids.

RESULTS



Graph 1: Percentage of Comorbidities (N=2973)



Graph 2: Percentage of Frames of References Used for Intervention (N=2973)

DISCUSSION

ROLE OF OCCUPATIONAL THERAPY

In mildly/ moderately affected children a restorative approach was used, and in severely/profoundly affected children a maintenance/ compensatory approach was used. Interventions provided were based on the following Frames Of References(FORs).

A)Occupational Performance Training (Graph 2)

1)Neuro Developmental: was used for children with Global Developmental Delay/ Cerebral Palsy / Hemiplegia etc using methods like joint compressions and weight bearing in developmental positions. Development of normal milestones, posture and movement were also facilitated.

2)Sensory Based: Sensory Processing Disorders(SPD) and Sensory Modulation Disorders (SMD) were seen in many cases of CP, Autism, ADHD, Scholastic Backwardness etc. The underlying reasons for the sensory seeking / avoidant behaviors were explained. Simple easy to follow sensory diet using natural materials for eg: fresh air walks, swinging on swings tied to tree branches, natural textures grass, sand, natural clay to make arts and crafts, outdoor play etc to reduce hyperactivity and sensory preoccupations were suggested.

3)Biomechanical: Many children with motor developmental delay were found to have developed contracture, deformities and inability to maintain erect postures due to lack of motor control. Stretching exercises were taught. They were provide with diagrams & designs of making low cost aids (eg: positioning splints, seating devices, standing devices, crutches, canes, wheelchairs). Some who wanted to buy custom made aids were referred to nearby surgicals.

4)Psychosocial: Many problem behaviours existed in the children. Functional Behavioural Analysis (FBA) and Positive Behavioral Supports (PBS) like tangible items , star charts were taught understand to handle behaviours at home and school that were hindering learning of skills.

5)Rehabilitative: The seizures themselves, anti epileptic medications, and the comorbidities may reduce the child's ability to learn and the child may be denied the opportunity to practice by parents and teachers. They might often restrict a child's play, schooling and social life, either through the fear that the child will injure himself, or to avoid the embarrassment caused by the child having a seizure in public. Consequently epilepsy considrebly affects the acquisition of skills, and an occupational therapist can offer these individuals opportunity to learn and practice the skills they lack[3].

The following describes occupational performance areas , intervened using the rehabilitative FOR and also mentions verbatims by the CGs to get a qualitative subjective understanding.

Activities of Daily Living

"I make him wear clothes to save time"

ADL was one of the major areas of dependence, firstly because children were lacking the sensory motor and cognitive skills for the same, and secondly due to lack of time the caregivers preferred to let their children be dependent. CGs were taught forward chaining and backward chaining techniques,making of some low cost adaptive aids like universal cuffs, handling techniques for energy conservation.

Work -School/Vocational

"I don't send my child to school"

Many children were not attending school at all. Many of them had attended school for a while and then were withdrawn post epileptic attacks/ due inability to cope with academics etc. And many CGs were unaware of the facilities of inclusion in normal as well as special schools available for persons with disabilities. They were explained about the same were encouraged to enroll their children in school. Those children who were attending schools were also not functionally literate i.e. basic reading writing, counting, telling time, money management etc and were not at par with the peers. CHWs were trained in Functional Behavioural Analysis(FBA), Positive Behavioural Supports (PBS), importance of resource rooms, multisensory teaching methods, Individualized Education Program (IEP). Parents who could be potential shadow teachers to the children at school were also trained. For the adolescents age groups vocational counseling was provided and referral to the local special schools and vocational training centers for enrollment.

Play/Leisure

For children who preferred solitary play (mainly sensory preoccupations) positive play behaviors, engaging with sensory toys, playing with CGs were taught. Seating and standing devices were prescribed to participate in simple reaching for toy activities for severely disabled. Group play and Social Skills Training methods were taught to the CGs and CHWs

B) Capacity Building/Task Shifting- Training of CGs & CHWs

As there is an acute shortage of clinical personnel and healthcare professionals, it is practically impossible for the existing Occupational Therapists to cater to the entire children with epilepsy and associated disabilities on a direct basis. But this can be done on a indirect basis by task shifting and training of the CGs and CHWs to tackle various issues like feasibility, accesibility, availability & sustainability.

"It's difficult to comprehend this stuff I am just a daily wage labourer at a farm"

Feasibility: The CGs had difficulty understanding the home program. Therefore they were explained in a simple local language. The handouts with diagrams shall help them in continuing with the home program.

"Hospital is at a distance of 130 kms from our village,there is no facility of exercises in the local dispensary"

Accessibility & Availability: The overall number of therapists in the rural areas does not match the population needs for rehabilitation. And to overcome this deficit of manpower task shifting and capacity building was essentially carried out i/f/o training of CGs & CHWs (teachers, special educators, volunteers, anganwadi workers, ASHA, incharges of various vocational institutions/ special schools). Group training was provided through direct demonstration as well as through power point presentations. This helped in serving a larger population in a shorter time.

"We used to attend therapy earlier now we don't"

Sustainability: Over a period as the disability sets in and CGs loose interest and belief in therapy. The CGs were convinced to at least attend therapy sessions once in a few months at civil hospitals, to obtain home program and follow the same back home. They were referred to the nearby PHC/ Civil Hospital or to local private occupational therapy practitioner for follow up. Similar was the case with assistive technology, many CGs had some assistive devices provided to them by previous camps which they stopped using after a while. The importance of the same was explained to the CGs and the CHWs was explained to them in terms of positive impact on the family[4] as follows.

- Autonomy : degree to which the child needs help to perform activities.
- Disposition: degree to which the child is content during the day

- Effort: degree of exertion needed to assist the child
- Function: degree to which the child has voluntary control over his or her own actions
- Respite: degree to which the parent needs relief from caregiving
- Social and Family Interaction: degree to which the child interacts with others
- Supervision: degree to which the child requires attention from family members
- Well-being / Safety: degree to which the parent is worried about the child's well being and safety.

C) Telerehabilitation Followup

The followup for some children those who required it, was provided through telerehabilitation

FUTURE IMPLICATIONS

Education And Job Opportunities

Westcott and Whitecombe (2003)[5] asserted that occupational therapists need to develop the educational agenda, so that the profession has a real impact to make on health and social care in the world . Thebeault (2006)[6] expressed there is need to expose students to the realities of global issues such as poverty , that compromise health and limit access to meaningful occupation. Very few job positions of OT in PHC's and Civil hospitals are there in Maharashtra especially in rural areas of which again many remain vacant. Developing skill and interest in OTs to take up such opportunities in CBR is important.

Advocacy, Capacity & Resource Building

Giving information regarding available schemes, policies and Resource is also an important role of OTs. All the CHWs in the NHM can attend the camps regularly, be in contact with the camp team so that the further intervention can be appropriately handed over to the PHC/ Civil hospitals and to the CHWs for regular follow ups. Infrastructure requirement of special schools, low cost aid manufacturing units, day care centres, vocational training centres, sheltered workshops was evident through CGs and CHWs intervews. These can be only developed with strong government and non government organization's backing.

Vision To Tread New Paths

"If……the vision and courage to tread new paths are lacking, then the danger is that more conferences will be held, more declarations will be written, more slogans devised, and still 98% of the disabled population will remain totally unaware of the concern being voiced on their behalf" [O'Toole 1995, page 319][7]

Occupational therapy interventions are not merely concerned with restoring physical functioning, access to occupation is necessary for survival, wellbeing , community participation and the exercise of citizenship. Through the position papers on CBR produced by the World Federation of Occupational Therapists(WFOT), and the vision statement of American Occupational Therapy Foundation[8], it appears that Occupational Therapists recognize both a universal right to occupation and their professional responsibility to work towards its realization, by means of advocacy , training, and listening to and working with people. CBR promotes the role of occupational therapy in working with communities towards enabling access to occupation for all.[9] Thus the role of Occupational Therapy in community based rehabilitation is important and more number of Occupational Therapists should consider this as an avenue of practice.

CONCLUSION

This study gives an insight into the role of occupational therapy in community based rehabilitation of children with epilepsy in the rural areas of Maharashtra. It also provides many future implications in this area.

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