Journal of Medicine, Nursing & Public Health

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ISSN: 2706-6606

Stratford Peer Reviewed Journals and Book Publishing
Journal of Medicine, Nursing & Public Health
Volume 4||Issue 1||Page 59- 72||April||2021|
Email: info@stratfordjournals.org ISSN: 2706-6606

Caregivers level of information and Access to Rehabilitation Therapy among Children with Disability, in West Bengal, India

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***How to cite this article*: Mishra, V., & Kumar, G. (2021). Caregivers level of information and Access to Rehabilitation Therapy among Children with Disability, in West Bengal, India, *Journal of Medicine, Nursing & Public Health*, Vol. 4(1), 59-72.**

Abstract

Poverty is a social condition characterized by the lack of resources necessary for basic survival or necessary to meet a certain minimum level of living standards. Thus, poverty affects ones' general social functioning but to a great extent health care**.** The effects of poverty in families of children with disabilities are very grave. The purpose of this study was to determine the influence of caregivers' level of information and caregivers' education levels, have on access to rehabilitation therapy for their children with disabilities in West Bengal, India. The study adopted a cross-sectional methodology targeting 108 caregivers which indicated that traditional cultural beliefs influenced access to rehabilitation therapy for children with disabilities. Data analysis involved descriptive statistics. The specific descriptive statistics included means and standard deviations. Witchcraft topped among traditional beliefs that were perceived to cause disability among the children. Many were aware of the nature of their child's disability and thus could seek rehabilitation therapy. The most common forms of disabilities according to the study was Cerebral Palsy and others like Autism, Paraplegia, Down Syndrome, Epilepsy, Club Feet, Mental Disability and Hydrocephalus also being recorded. Most caregivers had attained secondary level of education and primary education. With the level of education possibly implying level of awareness and understanding about the nature of disabilities, which further influence access to rehabilitation therapy. The study concludes that caregivers' level of information influences access to rehabilitation therapy for children with disabilities. Awareness training may be through seminars, church announcements and media communication through radio, televisions and newspapers. Government through Ministry of Health of India could also embark in sensitizing residents of West Bengal on disabilities and available rehabilitation therapies for children.

Key words: *Poverty, Rehabilitation Therapy, Children, Disabilities, West Bengal*

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1. Introduction

Rehabilitation has emerged as a comprehensive approach with a combination of treatment modalities that have the purpose of addressing multiple impediments and overcoming disabilities. Rehabilitation is a goal-oriented process, with the aim of enabling intellectually-disabled people to reach an optimum mental, physical and/or social functional level, thereby providing them with the tools required to change their lives (Sechoaro, Scrooby & Koen, 2014). The philosophy behind rehabilitation is that rehabilitation concentrates more on prevention or reduction of impairment of handicap than on treatment of diseases. It is grounded strongly on the belief in the empowerment of disabled persons and it identifies the individual's goals on the grounds of which a plan is developed to meet these goals (Grech, 2016). Rehabilitation plays an essential role in minimizing the impact of impairments on the activities of daily life and participation in their communities of persons with disabilities (World Health Organisation [WHO], 2011). However, access to rehabilitation therapy is influenced several factors including poverty.

Article 25 of the Universal Human Rights Declaration states that: "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control (Bright, Wallace & Kuper, 2018). It continues to direct that motherhood and childhood are entitled to special care and assistance and all children, whether born in or out of wedlock, shall enjoy the same social protection."

A caregiver who is well educated and informed about disability and understands the need for intervention approaches to disability in their children. This depicts a lack in factual information that will definitely influence access to rehabilitation. Edie & Ingstad, (2013), studies on disability and poverty, have together established a unique regional database and a baseline with comprehensive statistical information on the situation amongst individuals with disability and households with disabled members (Vadivelan, Sekar, Sruthi & Gopichandran, 2020). The studies demonstrate substantial gaps in services, for instance, assistive technology, with nearly half of those who need a device not having access to one (Kumar, Roy & Kar, 2012). Major gaps are seen on education, mental and physical health, employment, socio-economic status. According to Bunning et al 2017, information on the causes of childhood disability is not widely available across communities in low-income countries. Hence limited support services and poor access to knowledge may be contributing factors to poor access to rehabilitation.

Disability is an important public health problem especially in developing countries like India. The problem will increase in future because of increase in trend of non-communicable diseases and change in age structure with an increase in life expectancy (Kumar, Roy & Kar, 2012). The issues are different in developed and developing countries, and rehabilitation measures should be targeted according the needs of the disabled with community participation. In India, a majority of the disabled resides in rural areas where accessibility, availability, and utilization of rehabilitation services and its cost-effectiveness are the major issues to be considered. National Sample Survey Organization (NSSO) report and Census data of 2017 stated that its prevalence was as low as 2% in India. A recent community-based study in India by Mishra and Siddharth (2018) found the prevalence of all types of disability

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as 6.3% out of which mental disability was found to be the most common type of disability (36.7%).

Problem statement

National Sample Survey Organization (NSSO) report and Census data of 2017 stated that its prevalence was as low as 2% in India. There is very little information including publications on the causes of childhood disability, the little that is out there is filled up with medical terminologies that a common community member may not comprehend (WHO, 2011). Health practitioners are also known to do very little in giving information to parents concerning their child's disability and what to expect but keep referring them from one health provider to another which can be very frustrating and expensive (Mishra & Siddharth, 2018). Poor access to information and limited support services especially in low-income communities is one major factor that gives rise to narratives to explain the presence of disability based on cultural background (Porterfield & McBride, 2017). Such explanations affect, to a great extent, the response taken towards addressing disability with many choosing unconventional ways.

Objective of the study

To analyze the effect of caregivers level of information on disability on access to rehabilitation therapy for children with disabilities

2. Literature review

Theoretical Literature Review

Empowerment theory anchored this study. Empowerment theory was proposed by (Rappaport, 2002). Empowerment is most generally connected with different approaches to social or psychological development and the concern for local, grassroots society-based movements and programmes. The theory suggests that engagement with others to realize goals, efforts to enhance access to resources, social services and some crucial understanding of the socio-political environment, are key elements of the construct of empowerment (Rappaport, 2002).

The path of empowerment can be integrated into five gradual steps, including social disturbances existing, conscientizing, mobilizing, maximizing, and creating a new social order (Doore, 1988). Empowerment begins with the existence of disturbances by pointing out "healing illness" (Morell, 2004). Secondly, empowerment goes a notch higher by allowing the disadvantaged realize social inequality), "conscientize" themselves, and raise their power in their internal structures (Zimmerman, 2000). Thirdly, the individuals having once gotten an awareness of their limited power and the likelihood for change lead others to be part of their movement and organize in collective action (Weissberg, 1999). Power grows by organizing such joint action or power sharing with others. Fourthly, a number of authors assume a decisive moment that changes the process of organizing joint action into that of forming a new world (Shearer, 2009). This step is like "the tipping point that minimal things can make a big difference (Levitt, 2017). This "stage" can be called the maximizing step. The final stage of the path is changing old institutions and structures into new ones, or "forming" a new world or a new social order by "saving" the disadvantaged (Zimmerman & Warschausky, 1998).

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Empowerment theory is relevant to this study due to its three basic aspects. Applying this general structure to poor families with disable children indicates that empowerment includes support of poor families in accessing sources of income and equal resources allocations. Empowerment is multi-dimensional given that it arises in psychological, sociological, political, economic, and other aspects. Empowerment also takes place at a number of levels, for instance individual, group, and society. The theory is, therefore, appropriate to the study of how less fortunate groups, families in the society can be empowered by enhancing their access to sources of income and affordable social amenities like healthcare. By empowering caregivers, parents or guardians with disable children, access to rehabilitation therapy for children with disabilities in West Bengal Healthcare rehabilitation facility for the disable children can be enhanced.

Empirical Review

Zuurmond, Mahmud, Polack and Evans (2015) conducted a study, understanding the lives of caregivers of children with cerebral palsy in rural Bangladesh: Use of mixed methods. The study used mixed methods. Caregivers reported high levels of stress, anxiety, isolation, stigma, physical tiredness, and lack of time to complete everyday tasks. Knowledge and understanding about cerebral palsy was generally low. However, the study focused on disable children in Bangladesh. Access to rehabilitation therapy for children with disabilities may differ across countries.

Hussey, MacLachlan and Mji (2017) conducted a study onbarriers to the implementation of the health and rehabilitation articles of the United Nations convention on the rights of persons with disabilities in South Africa. This investigation used a qualitative, exploratory methodology. Six main categories of barriers to the implementation of the health and rehabilitation articles of the CRPD were identified. Attitude barriers including stigma and negative assumptions about persons with disabilities were seen as an underlying cause and influence on all of the other categories; which included political, financial, health systems, physical, and lack of information about the disability. Access to rehabilitation therapy for children with disabilities may differ across countries.

Sechoaro, Scrooby and Koen (2014) studied effects of rehabilitation on intellectually-disabled people-a systematic review. Studies on the effects of rehabilitation on intellectually disabled people were selected systematically, appraised critically for methodological quality and summarized. Rehabilitation interventions indicated good outcomes with regard to intellectually disabled people. Findings showed that people with mild to moderate intellectual disabilities improved in terms of activities of daily living (ADL) after rehabilitation. Improvement was noted in ADL, self-care skills, communication skills and cognitive achievements. Communication skills led to improved access to information regarding rehabilitation on intellectually-disabled people. However, the current study specifically focuses on disable children.

Landry, Rama, Harris, Madison, Parekh, Banks and Wijesinghe (2015) conducted a study exploring the factors that influence the perceptions of disability: a qualitative study of mothers of children with disabilities at a community-based rehabilitation centre in Sri Lanka. A descriptive qualitative research design was employed. Thirteen semistructured interviews were conducted with participants receiving rehabilitation services at a community-based facility. Three major themes emerged from the analysis: (i) level of family, community support and information support; (ii) spiritual and cultural interpretations of disability; and

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(iii) outcomes of rehabilitation services. Perceptions of disability appeared to be strongly influenced by the social, community and spiritual/cultural support structure in which the mothers lived. In particular, the support from the participant's spouse emerged as a primary factor exerting strong influence on perception, and future outlook, among the participants. Engagement in community-based rehabilitation programming also reinforced positive perceptions, created a sense of hope among participants regarding their child's future, and established aspirations for future education and employment opportunities alongside social integration.

3. Materials and Methods

The study shall adopt cross-sectional study, from May to June 2020. Cross-sectional study was used to gather information on a population at a single point in time. The study was conducted in West Bengal Healthcare rehabilitation facility for the disable children in India targeting 108 children with disabilities. Census of all the 108 children with special needs shall be undertaken as the study population is small and manageable. Primary data were collected using semi-structured questionnaires. Caregivers were asked to fill questionnaires on behalf of the sick/disable children. Data analysis was undertaken using Statistical Package of Social Science (SPSS) version 23 for analysis. Descriptive statistics including frequency, percentages and mean were employed during data analysis.

4. Results and Discussion

108 questionnaires were administered and a total of 76 questionnaires were duly filled and returned representing 70.4% response rate. This response rate is considered satisfactory to make conclusions for the study. According to Bailey (2000), a response rate of 50% is adequate while a response rate greater than 70% is very good.

4.1 Demographic characteristics of participants

4.1.1 Parent/care giver demographic information

The study presented the demographic information of parents/caregivers that included gender, age, caregiver and area of residence were investigated. The results are presented in table 1.

Table 1: Parent/care giver demographic information

Parent/care giver demographic information		[Frequency, Percent]
Gender	Male	[20, 26.3%]
	Female	[56, 73.7%]
Age	Below 18 years	[2, 2.6%]
	18-24 years	[14, 18.4%]
	25-30years	[26, 34.2%]
	36-40years	[13, 17.1%]
	40-50years	[14, 18.4%]
	Above 50years	[7, 9.2%]
Caregiver	Biological parent	[62, 81.6%]
	Guardian	[13, 17.1%]
	Children's Home	[1, 1.3%]
Caring of the child	Alone	[38, 50%]
	With Partner	[30, 39.5%]
	With Parents/Family	[5, 6.6%]
	Other	[3, 3.9%]

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Results in Table 1 show that majority of caregivers (73.7%) were females who could be mothers, grandmothers, sisters or aunties, involved in taking care of the child with disability. Male caregivers also participated but to a small extent.

It was also established that majority of parents/caregivers were aged 24-50 years. This is considered an age where most people are either parents/caregivers or act as guardians. It was also noted that majority of caregivers (81.6%) were biological parents with only 17.1% being guardians while 1.3% were in children homes.

Demographic results further show that a majority of caregivers were taking care of the child with disability alone, without a partner and only 39.5% had partners. The results imply that most children with disabilities were being cared for by single parent/guardian as attributed by a huge proportion of participants.

4.1.2 Child Demographic information

This study presents the demographic information of the children with disabilities, including characteristics of their gender, age, cause of disability and nature of the disability as is presented in table 2.

Table 2: Child Demographic information

Child Demographic information		**[Frequency, Percent]**
Gender of the child	Male	[36, 47.4%]
	Female	[40, 52.6%]
Age of the child	Less than 3 year	[23, 30.3%]
	4-6 years	[29, 38.2%]
	7-10 years	[15, 19.7%]
	Over 10 years	[9, 11.8%]
Cause of disability	Born with	[55, 72.4%]
	Acquired after birth	[21, 27.6%]

Results in table 2 above show that majority of the children with disabilities (52.6%) were female while 47.4% were males. The results imply that most females were disposed to disability compared to male, though this might dependent on several other issues that were not under investigation in this study. Most of the children with disabilities (38.2%) were aged 4-6 years and 30.3% were aged 3 years and below. The study also indicated that majority of children (72.4%) were born with disabilities or acquired them at birth. Caregivers' responses further indicated that the type of disability that was common in West Bengal was physical disability as presented in figure 1.

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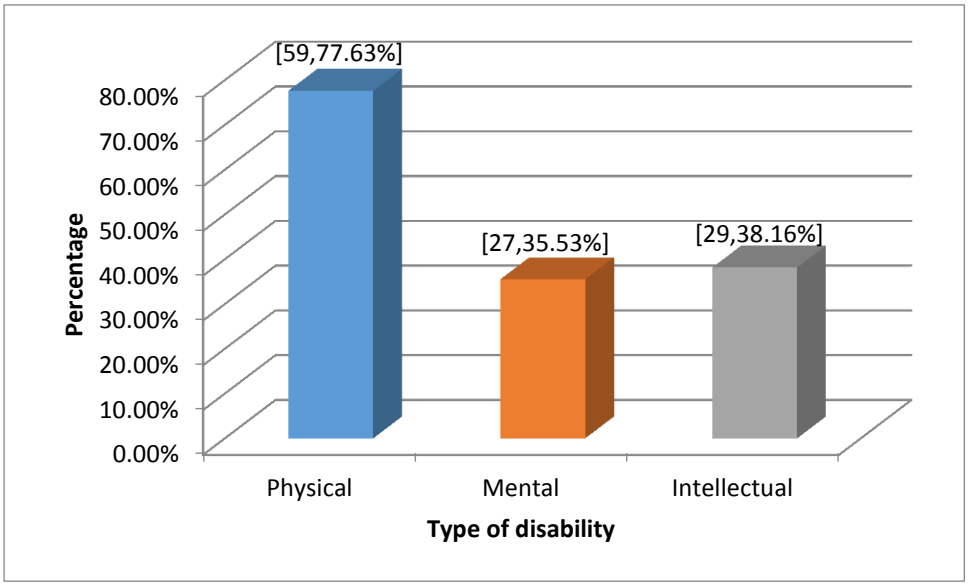

Figure 1: Type of disability

Figure 1 show that a majority of the children (77.63%) had physical disabilities, 35.53% had mental or learning disabilities while 38.16% had intellectual or cognitive impairment. The results imply that the most common forms of disabilities among children seeking rehabilitation therapy in West Bengal had physical disabilities. These included limb deformities and the lack of physical developmental milestones appropriate to age.

4.2 Caregivers level of information and Access to Rehabilitation Therapy

The main objective of the study was to analyze the effect of caregivers' level of information on disability and access to rehabilitation therapy for their children with disabilities. Caregivers' access to factual information about disabilities and management of day to day activities including medication required influenced their abilities and need of seeking rehabilitation therapy. These results are presented in the subsequent sections using pie charts, bar graphs and a table. Figure 2 shows caregivers' level of information.

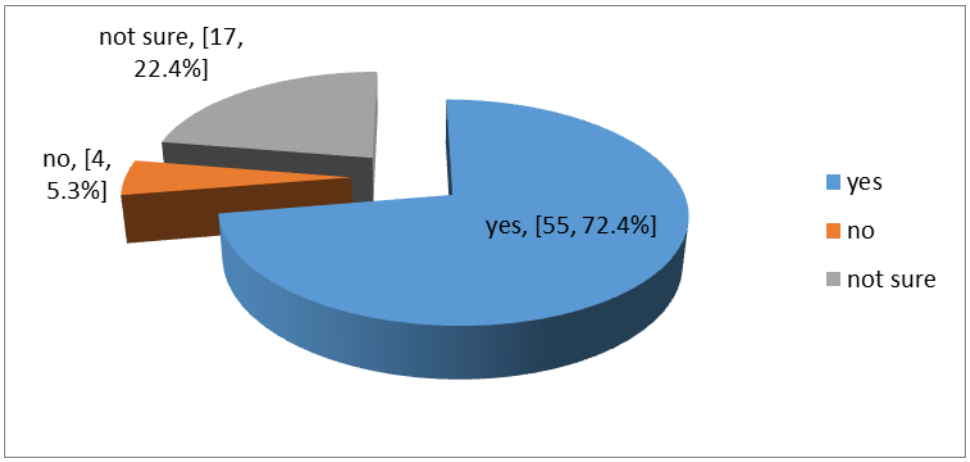

Figure 2: Awareness on the nature of child's disability

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Results in table 2 showed that majority of the caregivers (72.4%) were aware of the nature of their child's disability, 22.4% were not sure while 5.3% were totally unaware. The results imply that most caregivers' were aware of the nature of their child's disability and were able to name it but did not necessarily translate to better access to rehabilitation services. Masasa (2012), who conducted a study on cultural beliefs towards disability revealed a general lack of awareness on disability. Despite parents knowing the nature of disability, it came out from the study that many did not really have facts or understood their children's conditions. Table 3 outlines the nature of disabilities as mentioned by respondents.

Table 3: Nature of disability

Nature of disability	[Frequency, Percent]
Cerebral Palsy	[22, 40%]
Hydrocephalus	[1,1.8%]
Spina Bifida	[1,1.8%]
Autism	[4,7.3%]
Paraplegia	[5,9.1%]
Mental Disability	[2,3.6%]
Down Syndrome	[5,9.1%]
Hydrocephalus	[2,3.6%]
Epilepsy	[4,7.3%]
Club Feet	[3,5.5%]
Rickets	[2,3.6%]
Polio	[1,1.8%]
Filled wrongly	[1,1.8%]
Burns	[1,1.8%]
Attention Deficit Hyperactive Disorder (ADHD)	[1,1.8%]

The results in table 3 show that the most common forms of disabilities were Cerebral Palsy. Other forms of disabilities in West Bengal included Autism, Paraplegia, Down syndrome, Epilepsy, Club feet, Mental Disability and Hydrocephalus. Understanding the nature of disability is essential in seeking rehabilitation therapy. It enables caregiver to visit the appropriate medical facility to seek specific care required for the particular condition. It saves time, expenses and stresses associated with moving from one medical facility to another and seeking alternative therapies that may not work. The study further sought to identify whether caregivers knew of other rehabilitation centers apart from in West Bengal where they could seek similar or specialized care for their children. The results are presented in figure 3.

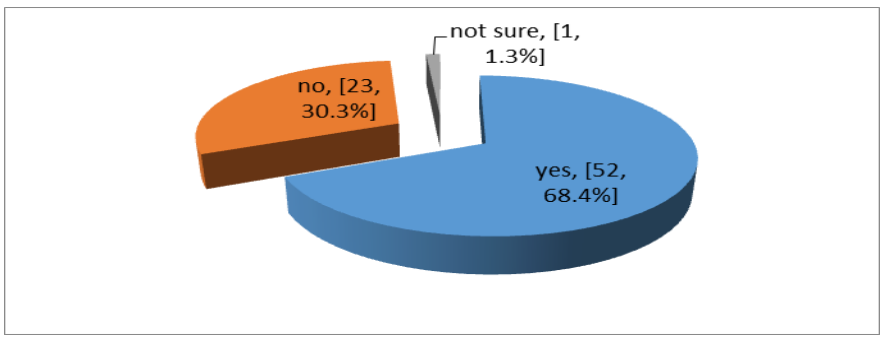

Figure 3: Other treatment or rehabilitation centers where caregivers can access help for the child

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Results in figure 3 shows that majority of caregivers (68.4%) knew other rehabilitation centers where they could seek treatment apart from in West Bengal. It was also revealed that 30.3% of caregivers did not know of any other rehabilitation centers to seek treatment apart from in West Bengal. This is a significant number considering it involves the health care and well-being of children. Knowing other rehabilitation centers is important in accessing rehabilitation therapy for children with disabilities in that it allows for a more holistic intervention with specialized care where needed. In relation to this, caregivers were asked to list those other rehabilitation centers they knew. Caregivers were also asked to indicate whether they are able to manage the therapy needs of the child at home or in the absence of a medical practitioner and the results are as presented in figure 4.

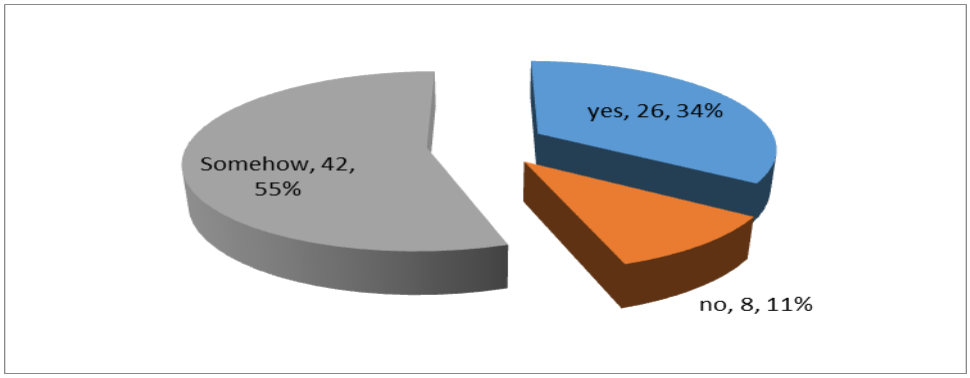

Figure 4: Ability to meet the therapy needs of the child at home

The results in figure 4.14 show that 55% of caregivers were somehow able to manage the therapy needs of their child at home or in the absence of a medical practitioner, 34% were fully able while 11% were not in a position to. The results are a clear indication that most caregivers are not in a position to manage the needs of rehabilitation alone the absence of qualified medical practitioner. This implies that caregivers may need more support through trainings and awareness creation disability management at home. Concerning if caregivers understood their children's medication and whether they were able to administer the medicines at home or in the absence of a medical practitioner, majority said yes and the results are presented in figure 5.

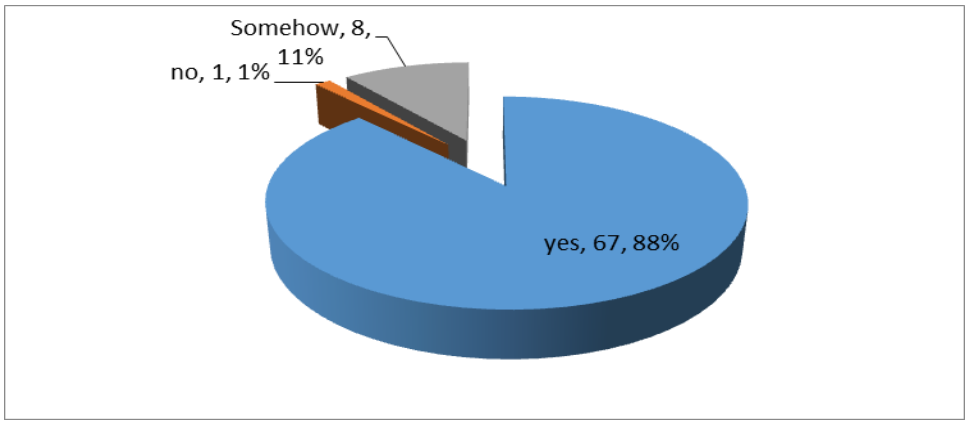

Figure 5: Understanding of child's medication and ability to administer the medicines in the absence of a medical practitioner

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Results in figure 5 shows a majority of caregivers (88%) who understood their children's medication and were able to administer the medicines at home in the absence of a medical practitioner. Understanding the child's medication and the ability to administer the medicines in the absence of a medical practitioner is considered essential in enhancing rehabilitation therapy for children with disabilities. Caregivers response on if they were aware of the frequency of therapy plan required for their children's development, their results were as presented in figure 6.

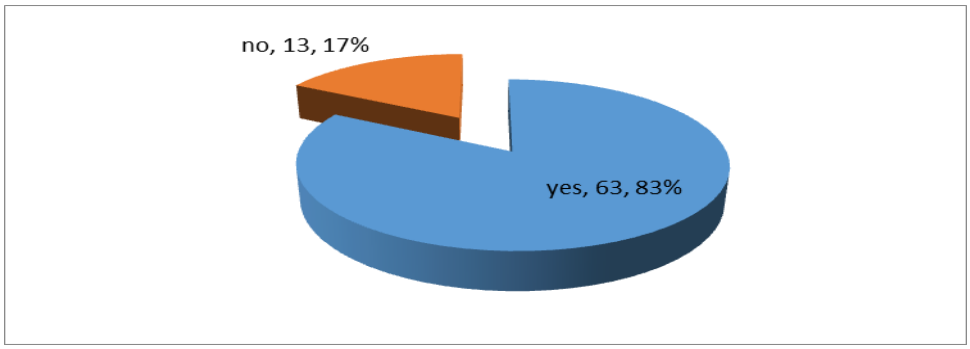

Figure 6: Awareness on the frequency of therapy plan required for child's development

Results in figure 4.16 showed that a larger number of caregivers (83%) are aware of the frequency of therapy plan required for their child's development. These results imply that awareness of specific therapy plan is essential in facilitating rehabilitation therapy. Caregivers were further requested to indicate how they came to know about in West Bengal Healthcare rehabilitation facility for the disable children and a majority learned about the project from other beneficiaries of the project as indicated in figure 7.

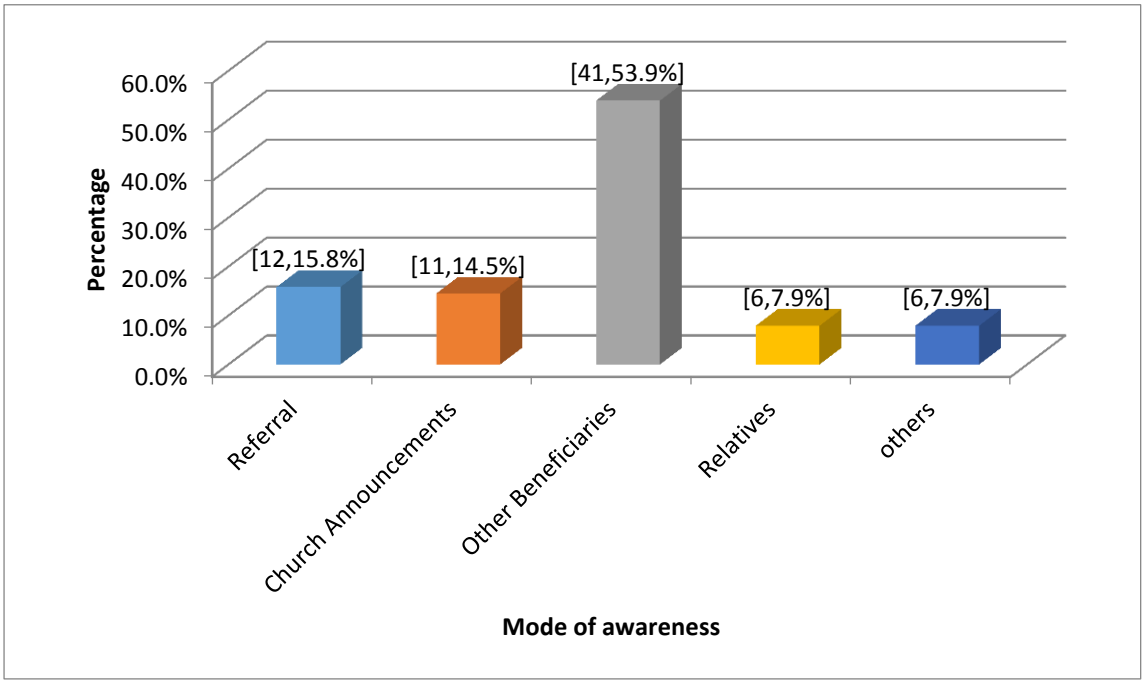

Figure 7: Mode of awareness

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The results in figure 7 show that 53.9% of caregivers came to know about in West Bengal Healthcare rehabilitation facility for the disable children through other beneficiaries. It was also established that most other caregivers knew about in West Bengal Healthcare rehabilitation facility for the disable children through referrals from other facilities, church announcements and even relatives. Caregivers also learned of the project from neighbours, community health volunteers and health workers. These groups of persons are important in passing out information on community health issues and where to access services. On the question of the duration of time they have been benefiting from in West Bengal Healthcare rehabilitation facility for the disable children, caregivers responses are as indicated in figure 8.

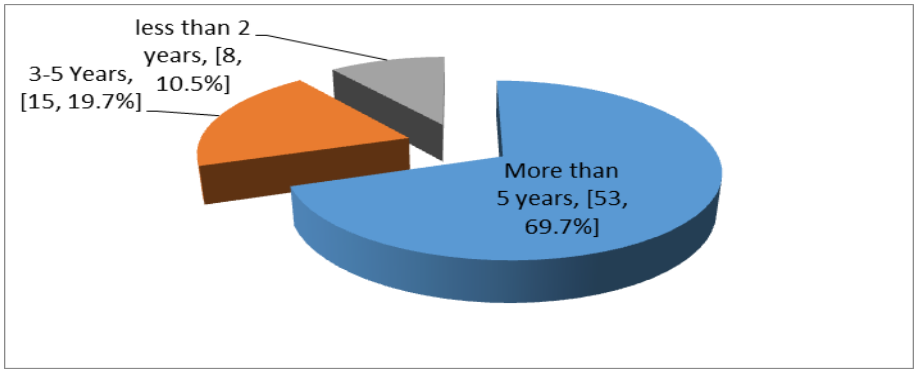

Figure 8: Time duration that have you have benefitted from West Bengal Healthcare rehabilitation facility for the disable children

Results in figure 8 showed that majority of caregivers (69.7%) have been benefiting from West Bengal Healthcare rehabilitation facility for the disable children for more than 5 years. The results imply that West Bengal Healthcare rehabilitation facility for the disable children has been very instrumental in offering rehabilitation therapy for children with disabilities and also indicating the retention level of beneficiaries and the relevance of the project. On level of information and how it influence access to rehabilitation therapy for children with disabilities in West Bengal Healthcare rehabilitation facility for the disable children. The results are as presented in figure 9.

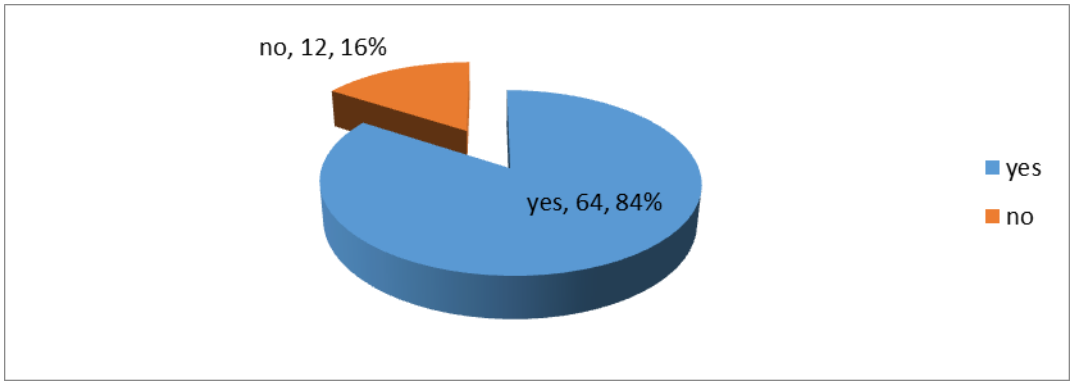

Figure 9: Caregivers' level of information about disability and access to rehabilitation therapy for children with disabilities

The results in figure 9 show that majority of caregivers (84%) were informed about disability and access to rehabilitation therapy for children with disabilities. The results imply that most caregivers have adequate information regarding various forms of disabilities that would further facilitate the need for interventions.

5. Conclusion

The study concludes caregivers' level of information influence access to rehabilitation therapy for children with disabilities. Caregivers' level of information is pertinent when seeking rehabilitation therapy for persons with disabilities particularly as in the context of the study.

6. Recommendations

The study recommends for continuous awareness training among caregivers so that they focus more on proper management of the conditions rather than looking back into the retrogressive beliefs in traditions and superstitions that may hinder them to seek medically proven healthcare attention for their child/children with disabilities. Awareness training may be done through seminars, church announcements and media communication through radio, televisions and newspapers to not only inform those affected but also to sensitize the community on issues of disability as many caregivers were having a first time experience with disability and lacked factual information. Government through Ministry of Health of India could also embark in sensitizing residents of West Bengal on disabilities and available rehabilitation therapies for children.

Increase public awareness and understanding of disability. Governments, voluntary organizations, and professional associations should consider running social marketing campaigns that change attitudes on stigmatized issues such as HIV, mental illness, and leprosy. Involving the media is vital to the success of these campaigns and to ensuring the dissemination of positive stories about persons with disabilities and their families.

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