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Impact of health education program on caregivers knowledge, attitude and practice toward their children with physical disability in Cheshire home, Khartoum, Sudan

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Abstract

Background: A physical disability is limitation on a person's physical functioning, dexterity stamina or mobility. A disability is a physical or mental problem that makes it difficult or impossible for a person to walk, see, hear, speak, learn, or do other important things, a physical disability is any type of physical condition that significantly impacts one or more major life activities.

The aim of the study: the study aimed to examine the impact of Health Education Program on Caregivers Knowledge, Attitude and Practice toward their Children with Physical Disability in Cheshire Home, Khartoum, Sudan.

Material and methods: This is an interventional prospective study, and it involved (113) of Caregivers for disabled children in Cheshire home in Khartoum. Data were collected by a questionnaire and an observational check list. The SPSS computer program was used for data analysis

Results: The disabled children age ranged between 1-5 yrs. The care givers were mainly the mothers. Testing the caregivers awareness before intervention showed that only (16.8%) of them were aware of the definition child physical disability. This increased after the training to (97.6%).About (93.8%) of the caregivers didn't receive any advices or instructions regarding child disability or rehabilitation. Instructions were mainly from the TV, radio, text books or magazines. Before intervention and training practice process, (92.9%) of the disabled children, were taking their meals with entire help, while (9%) of them were taking their food with a little help and (6.2%) were taking their food without any help. However, after intervention and training, about (42.5%) were completely dependent on their cares for feeding.93.8% were not able to interact with others compared to68.1%after intervention.

Conclusion: it is necessary to provide the families of disabled children with advice, direction, and provide rehabilitation appliances besides training them how to deal with their disabled children. By that they can overcome and adapt to such problem, and consequently help their disabled children to be independent as much as possible.

Keywords: activities of daily living, interaction, disability, physical disabled children

1. Introduction

A handicapped condition makes the normal function of the individual very difficult and lead to dependency. These conditions are increasing day by day due to changing life style and complicated environment. A child disability is social burden of great impact to family and community all over the world [1]. A person is considered physically handicapped if he has an impairment that substantially limits one or more of life's daily activities [2]. Disability is defined as any restriction or lack of ability to perform an activity in the normal manner[3].According to the WHO, a disability is "any restriction or lack (resulting from any impairment) of ability to perform an activity in the manner or within the range considered normal for a human being [4].

There are many different causes for physical disabilities including: genetic or inherited disorders, such as muscular dystrophy, conditions present at birth, such as spina bifida, serious illness affecting the brain, nerves or muscles, such as meningitis, spinal cord injury and Brain injury [5].

A special needs child put a great burden on the family. Marriages where there is a special needs child, involved will often become strained to the point of separation or divorce. A special need counselor can help a family deal with day-to-day issues and also prepare the handicapped child for an adult life with independence [6]. With a disability there is often depression and isolation and a counselor can help with this.

Children with physical disabilities spent three times as many days ill in bed and days spent away from a school compared to a normal child. They make 26 million more visits per years to the doctor than normal children and spent 5 million more days in the hospital annually They are limited in their daily activity for slightly more than two weeks a year, and one tenth of all children with disabilities are unable to play or attend school [7].

According to the World Report on Disability, 1 billion people have a disability; at least 1 in 10 is a child (100 million children); and 80% live in developing countries [8]. The report estimated that 15% of the world populations have disabilities, and higher-income countries have a lower prevalence of disability than lower income countries. Disability extends to influence the economy of the country and the whole world. Handicapped children are vulnerable and neglected in the society and they face many problems, including: lack of financial support, lack of educational opportunities, lack of assistive devices and person working in the field of disabilities lack knowledge and experiences. The national 2008 Sudan Census estimated the prevalence of disability at 4.8%. It also measured the number of children under 18 years at 15 million, indicating that approximately 720,000 Sudanese children have disabilities [4].

2. Materials and Methods

The Materials and Methods begins by presenting the research design, followed by setting and duration of the study, sample, sample size, data collection technique and tools, phases of the study, validity and reliability of instruments and ethical considerations.

2.1 Study design

An interventional prospective research design was used to accomplish this study**.**

2.2 Setting

Cheshire Home, Khartoum State, Sudan.

2.3 Sample: 113 Caregivers are enrolled in this study official permission was obtained from the institutions and consent from participants.

2.4 Sample size

By using spread sheet (the recommended sample size taken from population size (new cases who attended the clinic at Cheshire home) and a level of confidence of 99.0% and a margin error of 0.05%.

2.5 Data collection technique and tools

Structured interview questionnaire sheet was developed to assess caregivers Knowledge, Attitude and Practice toward their Children with Physical Disability. Observational checklist to assess their actual practices regarding their care pre intervention and post intervention.

2.6. Phases of the Study

2.6.1. Pre Intervention Phase

Baseline survey was conducted***.***

2.6.2. Intervention Phase

A course of 7 days was offered for each group, which included two lectures for three hours. The demonstration role play was used in the practical station for 6 hours in which application of care steps was applied; a total of 113 caregivers were trained.

2.6.3. Post intervention monitoring

Monitoring and supervision were carried out monthly for 6 months after the intervention to assess application of care. by the same data collector.

2.8. Ethical consideration

A written acceptance was obtained from the director of Cheshire Home Khartoum all caregivers who participate in this study was given information about the study

3. Results

Figure (1): It shows the distribution of age of the children with physical disability more than half of these children range between 1-5 yrs.

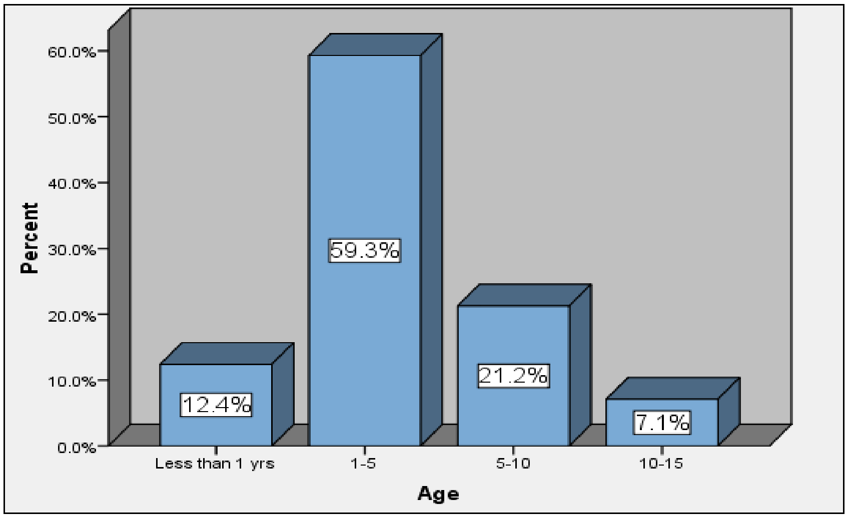

Fig 1: Age distribution of children with physical disability (n=113)

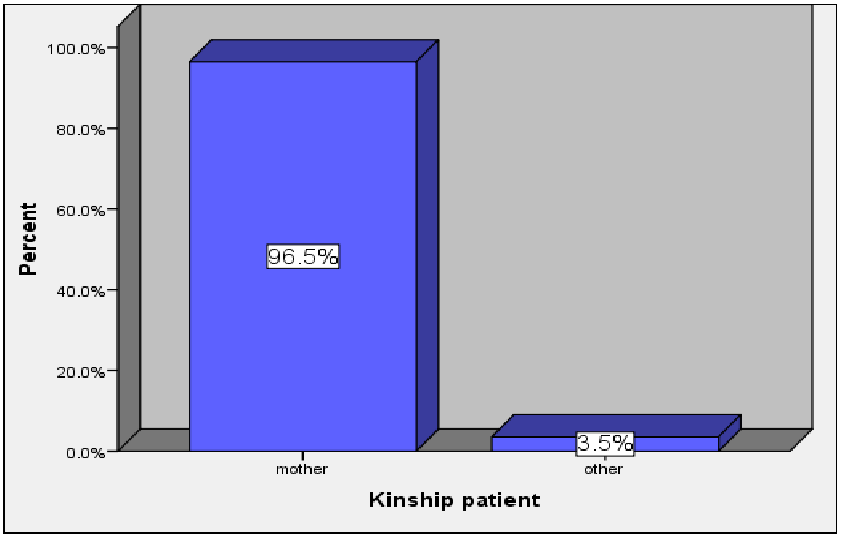

Fig 2: Distribution of study sample by relationship patient (n=113)

Figure. (1): Showed that, frequency of socio- demographic characteristics of participants, The age of the children with physical disability more than half (58.3%) of these children range between 1-5 yrs figure (1). The majority of care givers are mother of children with physical disability(95%) figure (2). About awareness of care givers regarding the definition of the child with physical disability before the study program, (16.8%) were answer the question perfectly, (83.6%) were not. But after the training program, (97.6%) percent their awareness has raised and they answer the question perfectly, while (20.4%) do not know table (1).

Table 1: Knowledge of the care givers regarding the definition of children with physical disability before and after intervention

	Pre intervention		Post intervention	
	No	%	No	%
Know	19	16.8%	90	79.6%
Don’t know	94	83.2%	23	20.4%
Total	113	100%	113	100%

P value<.000 Chi-Square=89.33

Table.(2):Illustrated the present of Participants attending course Before education program, (93.8%) of the care givers didn’t receive any advices or instructions regarding child disability or rehabilitation, while (6.1%) of them got some instructions and directions from the TV, radio, text books or magazines. but after the education program all of study group(100%) received the advice.

Table 2: Distribution of care givers regarding receiving advice from the Cheshire home (n=113)

	Pre intervention		Post intervention	
	No	%	No	%
Received advice	7	6.2%	113	100%
Don’t received	106	93.8%	0	0%
Total	113	100%	113	100%

P value<.000 Chi-Square=1.996

Table. (3): Showed the source of information for most participants as shown from the table. Home exercises practice: Before the education program, those who practice physical treatment exercise at home were (80.5%), yet, after the study program, the percentage has raised to (99.1%) and consequently a positive impact improvement has occurred on the concerned child.

Table 3: Performance of care givers regarding practicing exercises at home (n=113)

	Pre intervention		Post intervention	
	No	%	No	%
Practice physical exercise at home	91	80.5%	112	99.1%
Don’t practice	22	19.5%	1	.9%
Total	113	100%	113	100%

Chi-Square=21.346 P value<.000

Table.(4):Present the percent Father’s treating his disabled child, the majority (95.5%) of the fathers, treat their disabled children perfectly and carefully, while only four point four (4.4) percent of them do not care about their children. This may attribute to their frustration and depression, or to their negligence of how to deal with them, however, after they received more advices and instructions, the objective has been realized, that means, all fathers are treating their disabled children normally and properly the same like the well normal child.

Table 4: Distribution of the father's treating their disabled child (n=113)

	Pre intervention		Post intervention	
	No	%	No	%
Know	108	95.6%	113	100%
Don’t know	5	4.4%	0	0%
Total	113	100%	113	100%

P value<.024 Chi-Square=5.113

Table.(5):Illustrate the present of participants The manner of a disabled child feeding, Before intervention and training practice process (92.9%) of the disabled children, were taking their meals with an entire help, while only (9%) of them were taking their food with a little help and (6.2%) were taking their food without any help. However, after intervention and training practice of a child feeding manner, using special tools, the situation has improved, whereas, the percentage of those who were eating with an entire help, has dropped to (42.5%) and who were eating with a little help has raised to reach (51.3%).

Table 5: Distribution of manner of disabled child feeding (n=113)

	Pre intervention		**Post intervention**	
	No	**%**	**No**	**%**
with entire help	105	92.9%	48	42.5%
with little help	1	.9%	58	51.3%
without help	7	6.2%	7	6.2%
Total	113	100%	113	100%

P value<.000 Chi-Square=76.303

Table. (6): Illustrated the present of Participants knowledge about the disabled child playing.

Table 6: Distribution of disabled child playing from2011-2013) (n=113)

	Pre intervention		**Post intervention**	
	No	%	No	%
with entire help	106	93.8%	28	24.8%
with little help	6	5.3%	78	69.0%
without help	1	9%	7	6.2%
Total	113	100%	113	100%

Pvalue<.000 Chi-Square=1.116

Table (7): Showed the total distinguishes three categories of the disabled children playing as follows: before the training program there were (93.8%) playing with an entire help, (5.3%) playing with a little help, while (9%) were playing without any help. After the training program practicing, the situation has changed as follows: (24.8%) play with an entire help, (69%) play with a little help, while the percentage of those who were playing without help, has dropped to (6.2%). It is noticeable that the significance of this training is that, it helps strengthening the muscles of the child extremities and consequently joining, combining, and communicating others. Regarding the disabled child communication with others, before the training program, (93.8%) were not able neither to communicate with others, nor to give attention around them, while only (6.2%) were able to do so. After the training program and intervention, the situation has improved, whereas, the proportion of those who were able to communicate and to give attention around them has raised to (68.1%).

Table 7: Distribution of disabled child regarding communication with other (n=113)

	Pre intervention		**Post intervention**	
	No	%	No	%
communicate	7	6.2%	77	68.1%
Non communicate	106	93.8%	36	31.9%
Total	113	100%	113	100%

P value<.000 Chi-Square=92.840

4. Discussion

Introduction The study included 113 questionnaires which was filled by the researcher and trained person working at Cheshire disabled children care center, the data was collected from the care givers of the physical disabled children who attended the education program regularly.

The ages of the physical disabled children range between one to five years, and the majority of their care givers are their mothers, and that is good for the benefit of these children.

Before the educational program the care givers had poor knowledge about the definition, types, causes and treatment of physical disability and how to deal properly with their children, about three quarter of them were entirely have no knowledge of the above variable, however, after the educational program their knowledge was improved among all of them. As it is necessary for the care givers of the physical disabled children to obtain good knowledge that relevant to their children, and that was conformed with study done by (Dikman & Gordon, in New Yourk 1985) [9].

The majority of study group(93.8%) did not received any advice at Cheshire home, however, after the educational program, the whole study group (100%) have received the advice regarding their disabled children care, how to deal properly and how to help them in performing their daily activities. Whereas the parents of physical disabled children if there were not received advice so early at time of diagnosis will suffer from psychological stress and complicated crisis which may not be overcome, hence it needs support and help accept that problem, as stated by (Bailey, A.B.& Smith,S.W. in USA 2000) [10]. Therefore it is necessary to consider and provide psychological support and advice in order to save and help their children. This fact correspond with study done by (Albrecht, in New Yourk 1995) [11] in which reveal that, a family which received a psychological support immediately after the diagnosed of disabled child, will be able to adapt it easily and consequently able to help their disabled child. This study showed that all study group had recognized the importance of the therapeutic exercise at home, and positive effect as it revealed sign on their disabled children, and they start doing it regularly. The result show that the majority of the fathers of disabled children (95.6%) treated their children with more consideration and care, while about (4.4%) of study group do not care of their disabled children, either because they are disappointed or ignorant that mean they don't know the proper method of dealing with them. However after the advice there was significant improvement the whole study group tend to treat their disabled children normally equal with their normal children, this good and positive impacts on both the disabled and normal children. However the over care of the disabled child, may limit his activities and self dependence as well, beside it may also encourage the normal children to become jealous and with discrimination psychological problems. This fact correspond with study done by (Macks & Reeve in USA, 2007 [12] in which they demonstrate that the disabled children's brothers suffer jealousy and psychological disturbance due to more parent's care toward the disabled children compared to them.

Regarding a disabled child eating and drinking method, the study showed that before the training program, the majority of disabled children were taking their meals, drinking water and other liquid with an entire help from the care givers, while after the training program, the outcomes were improved the majority of disabled children eat and drink with little help. When the care givers subjected to special training deal with the correct and appropriate position and the used of special equipments help to do that. This conformed with study done by (Deborah French, in France 2013) [13] in which he emphasized that the use of special eating and drink equipments, is very important to help disabled child to learn good eating and drinking skills. Before the training program and intervention many family were not practicing playing with their disabled child, however, after the intervention, they recognized the role of playing for disabled child since it strength muscles and help him/ her to communicate and contact with other. This result agree with study done by (Macy Kaiser in UK 2001) [14] to which showed that when families play with their disabled child it builds stronger sense of families. says Dana Battaglia, outreach clinical coordinator at The Eden II Programs and a visiting professor at Adelphi University in Garden City. Children who do not participate may suffer a lack of flexibility in their language later in life, meaning they could be unable or find it difficult to express themselves. "Practice," says Schwartz, also helps children learn basic social skills. Regarding the disabled child communication with other there was positive change has occurred after they were taught simple sign and pictures. (Pennington L, Goldbart J, Marshall J in USA 2004) [15]. stated that “Picture cards may be used to help the patient remember everyday objects and increase his vocabulary. The patient might use picture boards of everyday activities or objects to communicate with others”.

5. Conclusion

The study concluded that: All study group received advices that helped them taking care for their disabled children and became compliant in physical therapy treatment. There was improvement the knowledge of the care givers of disabled children about disability, types, causes and rehabilitation has increased, and most disabled child’s mothers helped by the family members. All fathers acting normally toward their disabled children and their brothers and sisters are treated them normally and play with them. After the education and training program most of physical disabled children are eating and drinking fluid and other liquid with less help, and easier for them to communicate with others. Unfortunately there is no change in speaking skills and bowel and bladder control.

6. Recommenations

The researcher recommends the following: Frequent supportive psychotherapy counseling of care givers. Training courses for caregivers of physical disabled children regarding the proper and perfect methods of doing the physical exercises at home efficiently. Propose regular parent meeting in the center for exchange experience and skill as well.

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