

Parents' Perception of Rehabilitation Services for their Children with Special Healthcare Needs in Helena Center in Erbil City

Zainab Abdulrahman Abdullah¹, Kareem Fatah Aziz²

¹ M.sc., Student, Community Health Nursing, College Of Nursing, Hawler Medical University,

² Assistant Professor, College of Nursing, Hawler Medical University

Abstract

Objective: First, to determine the socio-demographic characteristics; second, to identify parents' perception of rehabilitation services; and third, to find out the relationship between socio-demographic characteristics and parents' perception of rehabilitation services.

Methods: A descriptive cross sectional study was carried out. The data were collected from May 2019 to September 2019. A non-probability convenience sampling was used, and sample size of 335 parents who attending to Helena center for rehabilitation and operation children with special needs in Erbil city was calculated.

Results: The majority (around 80% or more) of the parents had positive attitudes toward the rehabilitation services provided in the center.

Conclusion: Parents of children with special health care needs in Helena Center perceived services provided to their children as family-centered.

Keywords: Rehabilitation, Children, Special Healthcare

Introduction

The Maternal Child Health Bureau (MCHB) defines children with special health care needs (CSHCN) as "those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond what is required by children generally ¹. Rehabilitation defined as "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments". The goal of rehabilitation is improvements in individual performance - for example, by improving the ability of a person's to eat and drink independently. Rehabilitation therapy means improving performance by diagnosing and treating health conditions, reducing disabilities, and preventing complications ². The main focus of Tertiary prevention in health care is to limit or reduce the consequences an existing health condition, by rehabilitation services and interventions that aim to prevent activity limitations and

to promote independence ³. Remedy is involved with restoring and compensating for the lack of functioning, and preventing or slowing deterioration in functioning in each area of a person's existence. Therapists and rehabilitation workers encompass occupational therapists, orthotists, physiotherapists, prosthetists, psychologists, rehabilitation and technical assistants, social employees, and speech and language therapists. Therapy measures include exercises, and compensatory techniques, education, assist and counseling, changes to the environment, provision of resources and assistive technology. There are three main types of rehabilitation therapy are occupational, physical and speech. Each type of rehabilitation serves a unique purpose in helping the person to reach full recovery, but all have one goal is to help the patient to return to a healthy and active lifestyle ⁴. Family-centered care is the preferred service delivery model in pediatric physical therapy. Family-centered care approaches affirm the importance of parent involvement in their child's health and rehabilitation

services. This service submission model promotes parent-provider partnerships to facilitate communication, care coordination, and access to services⁵. The origin of the word “therapy” is the Hebrew word *refua* (healing) (Origin of English word therapy, 2015). Rehabilitation therapy, a main ingredient of the Physical Medicine and Rehabilitation curing process, has an extended history. millenary of years ago the old Chinese utilize *Cong Fu*, a motion therapy, to reduce pain; the Greek physician Herodicus defined an particular system of gymnastic practice for the preventing and treatment of illness in the 5th century BCE, and the Roman physician Galen described interference to rehabilitate martial injuries in the 2nd century CE. through the midst ages, the philosopher-physician Maimonides confirmed Talmudic rules of sanitary exercising habits, in addition regimen, as preventive medication in Medical proverbs, posted between 1187-1190; and in 1569 the philologist-physician Mercurialis promoted gymnastics as each a preventive and a rehabilitative mode within the art of Gymnastics. In the eighteenth century, Niels Stenson discovered the biomechanics of human movement and Joseph Clement Tissot’s 1780 Medical and Surgical Gymnastics advanced the worth of movement as an alternate to bed rest for patients recuperating from operation, going through neurological situations, and recovering after strokes⁶. In the 19th century, the idea of neuromuscular re-schooling was suggested by means of Fulgence Raymond (1844-1910)⁷.

Methods

Design of the study

A descriptive cross sectional study was carried out to identify parents’ perception of rehabilitation services for their Children with special healthcare needs in Helena center in Erbil city.

Setting of the study

The study was carried out in Helena center for rehabilitation and operation children with special needs in Erbil city which was established since 1992.

Time of the study

The study was conducted during the period March 2019 to the November 2019. The data were collected from May 2019 to August 2019.

Sample of the study

The sample size was calculated using Epi Info-7

computer program issue. These criteria were used for sample size calculation: Population 2613, significant level 95%, prevalence of perception and satisfaction 50%, absolute precision 5%. Accordingly the sample was 335 parents who attending to Helena center for rehabilitation and operation children with special needs in Erbil city. The study sample was chosen by non-probability convenience sampling.

Inclusion Criteria

- 1- Parents who agree to be involved in the study.
- 2- Both genders (male and female).

Exclusion Criteria

- 1- Parents who refused participation in the study.

The Study Instrument

In order to collect the proper information of study, a questionnaire was designed and modified depending on extensive review of relevant literature.

Rating Scales and Scores

In order to measure the previous items accurately and statistically in part two and three, each item has been scaled by five levels of Likert scales and scored respectively as follow:

The scale is out of 100 (20 questions X 5 scores = 100). So 1 = 20, 2 = 40, 3 = 60, 4 = 80, and 5 = 100, so the category of 1 and 2 (never and rarely less than 60), sometimes (60-79), and often or always => 80

Data collection method

The data collection process has been carried out from May 2019 to August 2019. An interview technique was used, it took about 25-30 minutes for each parents. All participants were informed that the information will be kept confidential and used just for a scientific purpose.

Results

It is evident in Table 1 that the majority (around 80% or more) of the parents had positive attitudes toward the rehabilitation services provided in the center. They felt that the health care providers cooperate with the parents and pay great attention to the children without discrimination between a child and another. They answer the questions of the parents and teach them what to do at home. The only weaknesses were unavailability

of health education booklets or videos, and the other thing is that the health care providers didn't provide advice on how to contact other parents.

Table 1. Parents' perception of rehabilitation services

	Never		Rarely		Sometimes		Often		Always	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Q1	0	(0.0)	3	(0.9)	14	(4.2)	318	(94.9)	0	(0.0)
Q2	0	(0.0)	14	(4.2)	15	(4.5)	289	(86.3)	17	(5.1)
Q3	0	(0.0)	3	(0.9)	26	(7.8)	269	(80.3)	37	(11.0)
Q4	0	(0.0)	28	(8.4)	7	(2.1)	261	(77.9)	39	(11.6)
Q5	0	(0.0)	4	(1.2)	33	(9.9)	298	(89.0)	0	(0.0)
Q6	185	(55.2)	107	(31.9)	43	(12.8)	0	(0.0)	0	(0.0)
Q7	0	(0.0)	14	(4.2)	53	(15.8)	267	(79.7)	1	(0.3)
Q8	0	(0.0)	1	(0.3)	65	(19.4)	269	(80.3)	0	(0.0)
Q9	0	(0.0)	14	(4.2)	39	(11.6)	264	(78.8)	18	(5.4)
Q10	0	(0.0)	13	(3.9)	40	(11.9)	244	(72.8)	38	(11.3)
Q11	0	(0.0)	12	(3.6)	48	(14.3)	213	(63.6)	62	(18.5)
Q12	0	(0.0)	4	(1.2)	45	(13.4)	249	(74.3)	37	(11.0)
Q13	0	(0.0)	4	(1.2)	45	(13.4)	250	(74.6)	36	(10.7)
Q14	0	(0.0)	3	(0.9)	45	(13.4)	220	(65.7)	67	(20.0)
Q15	0	(0.0)	11	(3.3)	20	(6.0)	299	(89.3)	5	(1.5)
Q16	10	(3.0)	0	(0.0)	57	(17.0)	230	(68.7)	38	(11.3)
Q17	0	(0.0)	11	(3.3)	19	(5.7)	228	(68.1)	77	(23.0)
Q18	0	(0.0)	13	(3.9)	35	(10.4)	287	(85.7)	0	(0.0)
Q19	325	(97.0)	10	(3.0)	0	(0.0)	0	(0.0)	0	(0.0)
Q20	0	(0.0)	76	(22.7)	169	(50.4)	90	(26.9)	0	(0.0)

The questions of table 1:

1	To what extent do the people who work with your child make you feel as a parent you are doing a good job?
2	To what extent do the people who work with your child talk to you and tell what they are doing?
3	Do the service providers make you feel safe during a treatment session?
4	To what extent do the people who work with your child give you suggestions and ideas of things to do at home?
5	Do you feel that the service providers are supporting your child psychologically?
6	Do the service providers favor some children on others?
7	Do the service providers fully explain treatment choices to you?
8	Do the service providers give you the opportunity to participate in treatment decisions?
9	Do the service providers provide you with the opportunity to give your suggestions?
10	Do the service providers provide precise and skillful services?
11	Do the service providers treat you as an individual rather than just a parent of a patient?
12	Do the service providers listens and answers all your questions?
13	Do the service providers show an understanding of the problems that you face?
14	Do the service providers explain to you the rehabilitation plan?
15	I find cooperation from service providers.
16	Do the service providers provide information about the type of services offered at the center?
17	Do the service providers give enough information about your child condition?
18	Do the service providers explain things to you in a simple and clear way?
19	Were the information available to you in various forms, such as a booklet, video, etc.?
20	Do the service providers provide advice on how to contact other parents?

It is evident in Figure 1 that the largest proportion of the couples (78.8%) scored between 60-79 % in the total perception score, and only 16.1% scored $\geq 80\%$.

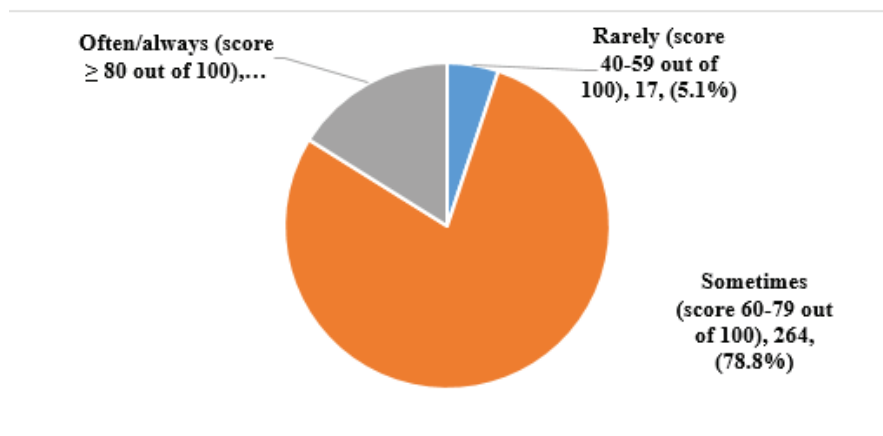


Figure 1. Overall parents' perception of rehabilitation services

Table 2 shows no significant association between the parents' perception with age of the child ($p = 0.163$), and presence of other child with special care need ($p > 0.999$). The table shows that the fathers and mothers of a female child had better perception scores than those with a male child ($p = 0.025$). Regarding the child disability, 25% of those with a child with food deformity had good perception, and 20.7% of those with a child with developmental dislocation of the hip had good perception while fewer rates were detected for the other types of deformities. It is evident in the table that 18.8% of the couples whose child was on physical therapy had higher perception scores compared with 12.6% when the child was on occupational therapy ($p = 0.025$).

Table 2. Parents' perception by child characteristics

	Rarely		Sometimes		Often		p
	No.	(%)	No.	(%)	No.	(%)	
Child age (years)							
< 3	6	(6.1)	69	(70.4)	23	(23.5)	
3-5	8	(7.0)	89	(78.1)	17	(14.9)	
6-8	2	(2.5)	68	(85.0)	10	(12.5)	
≥ 9	1	(2.3)	38	(88.4)	4	(9.3)	0.163*
Child gender							
Male	12	(8.5)	112	(78.9)	18	(12.7)	
Female	5	(2.6)	152	(78.8)	36	(18.7)	0.025
Child disability							
Cerebral palsy	1	(1.2)	75	(88.2)	9	(10.6)	
Spina bifida	9	(14.8)	45	(73.8)	7	(11.5)	
Torticollis	3	(7.3)	31	(75.6)	7	(17.1)	
Scoliosis	0	(0.0)	33	(82.5)	7	(17.1)	
Developmental dislocation of the Hip	0	(0.0)	46	(79.3)	12	(20.7)	
Foot Deformity	4	(8.3)	32	(66.7)	12	(25.0)	
Other	0	(0.0)	2	(100.0)	0	(0.0)	†
Type of rehabilitation							
Physical therapy	5	(2.6)	151	(78.6)	36	(18.8)	
Occupational therapy	12	(8.4)	113	(79.0)	18	(12.6)	0.025
Other child with special care need							
Yes	0	0.0	3	(100.0)	0	(0.0)	
No	17	5.1	261	(78.6)	54	(16.3)	> 0.999
Total	17	5.1	264	(78.8)	54	(16.1)	

*By Fisher's exact test.

†Insufficient computer memory to calculate the p value by Fisher's exact test.

Discussion

One aspect of parent satisfaction is the perception of the processes of care, which is focused on the actions of health care providers and their interaction with clients rather than the specific techniques they perform King (2004). The aim of the study was to obtain the overall perceptions of parents attending therapy services at Helena center. The results of this study suggest that most parents perceive that aspects of care relating to respectful and supportive care, coordination of care occur frequently which is similar to previous research was done in western countries Van Schie (2004). Parents report a lack of information in various forms booklet, video, etc. Similar findings have been reported in other studies. good information is necessary as a basis for FCC, provision must be sensitively tailored to parents' individual needs and capabilities. Similar to previous research, parents in our project were satisfied with services. The result of present study reveals that there is no significant statistical relationship between the parents' perception with socio-demographic regarding fathers and mothers, also there is no significant statistical relationship between the parents' perception with age of the child which is consistent with the results of Arnadottir (2012)

Conclusion

The overall results obtained in this study are important in understanding the current status of services as seen by parents. As concluded from parents' responses, there is some issues appear to be in need of improvement such as Provision of information where some parents expressed a desire for more child-specific and general information. The results also showed that parents need additional opportunities to interact with other parents. In general Parents' perceived that the services provided to their children are family-centered.

Financial Disclosure: There is no financial disclosure.

Conflict of Interest: None to declare.

Ethical Clearance: All experimental protocols were approved under the Faculty of nursing and all experiments were carried out in accordance with approved guidelines.

References

1. McPherson M, Arango P, Fox H. A new definition of children with special health care needs. *Pediatrics*. 1998; 102(1): 137–140.
2. Swedish disability policy: services and care for people with functional impairments: habilitation, rehabilitation, and technical aids. 2006.
3. Patrick DL. Rethinking prevention for people with disabilities Part 1: a conceptual model for promoting health. *American Journal of Health Promotion*. 1997; 11(4):257–260.
4. Pendleton H, Schultz W. Pedretti's Occupational Therapy-E-Book: Practice Skills for Physical Dysfunction. Elsevier Health Sciences. 2017.
5. O'Neil ME, Ideishi R, Nixon-Cave K. Care coordination between medical and early intervention services: family and provider perspectives. *Fam Syst Health*. 2008; 26:119–134.
6. Dreeben O. Development of the physical therapy profession. *Introduction to Physical Therapy for Physical Therapist Assistants*. Sudbury, MA: Jones and Bartlett. 2007: 3-22.
7. Conti AA. Western medical rehabilitation through time: a historical and epistemological review. *Sci World J*. 2014(2014): 432506.
8. American Nurse Association. *Pediatric Nursing: Scope and Standards of Practice*, (2nd ed.). Silver Spring, MD. 2015.
9. Arnadottir U, Egilson S. Evaluation of therapy services with the Measure of Processes of Care (MPOC-20): The perspectives of Icelandic parents of children with physical disability. *Journal of Child Health Care*. 2012; 16(1): 62-74.
10. Association of Rehabilitation Nurses (2014). *ARN Position Statement - The Essential Role of the Rehabilitation Nurse in Facilitating Care Transitions*. Chicago, IL: Author.
11. Cohn E. Parents' experiences in the waiting room of an occupational therapy clinic. *American Journal of Occupational Therapy*. 2001; 55: 167–174.
12. Dickens K, Matthews L, Thompson J. Parent and service providers' perceptions regarding the delivery of family-centred paediatric rehabilitation services in a children's hospital. *Child: Care, Health and Development*. 2011; 37: 64–73.
13. Dyke P, Buttigieg P, Blackmore A. Use of themeasures of process of care for families (MPOC-56) and service providers (MPOC-SP) to evaluate family-centred services in a paediatric disability

- setting. *Child: Care, Health, and Development*. 2006; 32(2): 167–176.
14. Hummelinck A, Pollock K. Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Education and Counseling*. 2006; 62: 228–234.
 15. King G, King S, Rosenbaum P. Evaluating health service delivery to children with chronic disabilities and their families: Development of a refined measure of processes of care (MPOC-20). *Children's Health Care*. 2004; 33: 35–57.
 16. Origin of English word therapy. Edenics. <http://edenics.net/english-word-origins.aspx?word=THERAPY>. Accessed on April 24, 2015.
 17. Pasquina PF, Bryant PR, Huang ME, Roberts TL, Nelson VS, Flood KM. Advances in amputee care. *Archives of physical medicine and rehabilitation*. 2006; 31;87(3): 34-43.
 18. Raghavendra P, Murchland S, Bentley M. Parents' and service providers' perceptions of family-centred practice in a community-based paediatric disability service in Australia. *Child: Care, Health, and Development*. 2007; 33(5): 586–592.
 19. Sheikh L, O'Brien M, McCluskey-Fawcett K. Parent preparation for the NICU-to-home transition: staff and parent perceptions. *Child Health Care*. 1993; 22: 227–239
 20. Simms R, Cole FS. The many roles of family members in “family- centered care”--part II. Interview by Deborah Dokken. *Ped nurs*. 2007; ;33(1): 51-2.
 21. Van Schie P, Siebes R, Ketelaar M, Vermeer A. The measure of processes of care (MPOC): Validation of the Dutch translation. *Child: Care, Health, and Development*. 2004; 30: 529–539.
 22. Williams L. The many roles of families in family-centered care--Part III. *ped nursing*, 2007;33(2): 144-6.