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NEEDS OF PARENTS CARING FOR CHILDREN WITH PHYSICAL DISABILITIES: A CASE STUDY IN JORDAN

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This study aimed at identifying the needs of families of children with physical disabilities in Jordan. The sample of the study consisted of 96 parents of children with physical disabilities whose ages ranged from 6 to 16 years old. A survey of Needs of Caring Parents was developed to achieve the purposes of this study. Results revealed that the most important needs identified by participants related to the dimensions of information and the involvement in the caring process, while the least important family needs related to the dimensions of counseling support and family support. Results also revealed that there were significant differences in the perceived needs of caring parents according to mother's vocational status (i.e., working or not working) in most of the survey dimensions. Yet, there were no significant differences in the perceived needs of caring parents that can be attributed to child's gender and age; family income range; and parents' relations with their extended family. Based on the study results, different recommendations were offered to service providers and to pre- and in-service special education teacher training. This research must be considered as a starting step in inviting institutions which provide care for the children with disabilities to focus on meeting the needs of caring parents.

Having a child with a disability can have profound effects on the family and may place a set of extra demands, challenges and burdens on the family system as well as on the disabled child. Such experience affects the dynamics of the lives of all the other members of the family in different ways during the different life-cycle stages (Kirk, Gallagher, & Anastasiow, 2000), and can be either positive or challenging. A positive experience occurs when the family members develop acceptable and appropriate attitudes toward their disabled children, and are fully aware of their strengths and weakness points, especially when they become part of the success of their disabled child (Brown & Rodger, 2009). In contrast, caring parents experience challenges when they face the stressful behavior of their child, their own feelings of incompetence and their feelings of frustration with the caring system (Brown & Rodger, 2009; Roach & Osmond, 1999).

As reported in the literature, parents caring for children with physical disabilities (PD) develop higher stress levels and lower levels of parenting satisfaction (Do Amaral, 2003; Puddy & Jackson, 2003). Moreover, parents caring for children with Physical Disabilities (PD), are at risk of developing numerous acute and long-term emotional challenges in comparison to families with no disabled children. They may express various levels and types of emotional reactions; including shock and disruption, denial, sadness, anxiety, fear, anger, and feel of guilt. They eventually go through an adjustment process, after learning to cope with having a child with disabilities and trying to work through their feelings (Johnson, 1993; Kirk et al., 2000; Neece, Kraemer, & Blacher, 2001). Yet, the time and support parents need for adjustment vary based on individual parents or families (Heward, 2006). In addition, caring parents may become forced to play additional roles as parents of children with PD. For example, in addition to their natural role, caring parents may become obliged to provide their children with intensive care, counseling, and education, support their children's behaviors, become their children's specialists, advocate for their

children's rights, act as financial providers and finally provide concerned specialists with the information they need to help them with their children's cases (Heward, 2006).

Furthermore, literature suggests that parenting a child with a disability can be demanding and create many challenges. These challenges may include: children's behavioral challenges, involvement in caring, communicating with professionals, preparation and training, and social interaction (Brown & Rodger, 2009). Adding to these, other challenges like: feelings of incompetence, feelings of anxiety, facing financial difficulties, role changes, poor social adjustment, increase in social isolation during the family's life cycle (Heather, Desmond, & Maryalice, 2006) and frustration with the care system (Murray, Maslany, & Jeffery, 2006; Roach & Orsmond, 1999). Heather et al. (2006) added that caring parents might need to deal with a number of stress sources that are created through handling daily responsibilities, such as dealing with their child's feelings about himself, and dealing with others' reactions and attitudes toward them and toward their child with PD. So, the stress parents' face affects their attitudes and makes them feel vulnerable to being criticized by others about how they deal with their child's problems (Epel, Blackburn, Lin, Dhadhar, Adler, & Morrow, 2004).

In this field, Epel et al. (2004) suggests that caring parents need to develop their abilities in stress management. Many parents proved that stress can be successfully managed. Barakat and Linney (1992) also emphasized that the mother and her child adjustment depend on the maternal response to the stress of the physical disabilities, degree of social support and the ability to foster positive mother-child interactions. Moreover, literature indicated the importance of involving parents in caring to reduce the level of stress and challenges parents face when caring for a child with physical disabilities. For example, Adams, Wilgosh, and Sobsey (1990) reported that caring for children with disabilities might have a great influence on the life of the family members depending on the degree of direct involvement in caring.

In order to reduce the level of stress that caring parents encounter, to make their experience positive and to allow them to live gladly when raising a child with PD (Brown & Rodger, 2009), parents must recognize the various and complex needs of their child with PD (Blasco, 2001). Hence, it is necessary to help professionals gain the information they need to plan supportive services to meet parents' needs as well as the needs of their child with PD in an effective way (Brown & Rodger, 2009). Yet, literature emphasizes that only few studies have focused on identifying the needs of these parents from their realistic experience (Brown, 2007; Laan, Loots, Janssen, & Stolk, 2001). Some studies found that families of younger children with developmental disabilities perceived more needs, and despite the increasing interest they received from professionals in supporting them over the past decade, their needs are still not met (Carpenter, 2000; Ellis, Luiselli, Amirault, Byrne, O'Malley-Cannor & Taras, 2002). They also claimed that these needs increase continuously as the disabled child grows. Moreover, there were many parents who reported feeling an increasingly growing emotional and social distress (Ellis et al., 2002). According to Bromely and Blacher (1991), there is a lack of formal support presented to parents by professionals and lack of organized programs based on scientific research that survey the families' needs. Therefore, we should first understand the needs of parents of children with PD in order to be able to meet them (Murray et al., 2006).

Literature on the needs of parents caring for children with physical disabilities

Within the literature on the needs of caring parents, there is evidence that parents perceived higher needs in the area of information that they desire to receive about the status of their child (Murray et al., 2006), and how their child recognizes the world around (Brown, 2007; Gardner, 2000). Caring parents need information to plan for the future of their child with PD (Gardner, 2000). Also, caring parents need information about how to deal with behavioral problems that their children with disabilities may demonstrate. Researchers like Brown et al. (2005), Darling and Baxter (1996), and Seligman and Darling (1989), have reported that parents need information about the nature of their child's disability, as well as about the programs that best support and meet the family members' needs. Parents also reported that they need to understand the procedures of the social, health, and educational services and systems available for their children (Avery, 1999; Brown, 2007; Ray, 2005).

Buray (1999) found that there is a positive effect for providing parents with specialized training on parents' ability to raise a child with disabilities and on the attainment of skills and knowledge about the child's needs. Researchers also reported that caring parents benefit from the resources designed to help them find specialized medical and recreational services. In addition, they benefit from the programs providing information about centers of special education programs available in the local area (Redding et al., 2000; Zima, Bussing, Yang, & Belin, 2000).

Moreover, Bailey et al. (1999) found that support was considered to be more effective when it comes from formal resources. In this field, [Carpenter \(2000\)](#) and [Brown et al. \(2005\)](#) emphasized that families of children with PD need support from professionals who should understand and respect them. Yet, [McConachie \(1997\)](#) and [Mason and Linsk \(2002\)](#) pointed out that these families report lack of respect from the side of professionals who almost failed to provide them with the effective support they need. According to [Jivanjee \(1999\)](#) and [Brown et al. \(2005\)](#), caring parents report frustration as a result of the lack of organized communication between them, the medical system, the educational system and the various programs offered to their children with disabilities. Also, [Farmer, Dorsey, and Mustillo \(2004\)](#) added that the support services provided to the child and his/her parents should include coordination services to the various service systems available.

Theoretical and experimental literature emphasize that caring parents need to be deeply involved in the caring process and to work closely with professionals in the context of presenting services to their children with physical disabilities ([Banyard, Rozelle, & Englund, 2001](#)). They further need to acquire a variety of skills in order to be able to foster children with PD ([Brown, 2007](#)). Some of these skills include developing their abilities as educators, advocates and child behavioral managers ([DeRobertis & Litrownik, 2004](#); [Pithouse, Hill, Tout, & Lowe, 2002](#)), besides the essential need for mastering strong parenting skills in general ([O'Brien, Lutzler, & Campbell, 1993](#); [Puddy & Jackson, 2003](#)).

The parental stress has been found to have a strong relationship with the income of caring parents and their ability to meet their family's expenses ([Paley, O'Connor, Frankel, & Marquardt, 2006](#)). The presence of physical disabilities requires several supportive services that cost a lot of money, including medical, educational, psychological, physical and occupational services ([Reilly & Platz, 2003](#); [Vig & Kaminer, 2002](#)). Also, caring for children with disabilities requires a higher financial ability compared to caring of children without disabilities ([Able-Boone & Stevens, 1994](#), [Curran, Sharples, White, & Knapp, 2001](#); [Reilly & Platz, 2004](#); [Swann & Sylvester, 2006](#)).

Recently, researchers have focused on the psychological needs of parents caring for children with PD and how to meet them through providing them with the counseling support they need ([Carpenter, 2000](#)). According to [Murray et al. \(2006\)](#), the needs of caring parents which were most perceived as unmet related to counseling support. Counseling is considered helpful to parents as a formal supportive service. It helps them deal with stress and learn how to react to the behaviors of their physically disabled children. Furthermore, through counseling, parents learn how to manage their time and interact with their other children without PD ([Mason & Linsk, 2002](#); [Brown et al., 2005](#)). [Laan, Loots, Janssen, Stolk \(2001\)](#) have also shown that many parents feel that having counseling support is very useful.

The type of support (i.e., formal and informal) are considered very important needs perceived by caring parents having children with disabilities according to literature. Formal group support comes from governmental support ([Reilly & Platz, 2003](#)), community-based services ([Buelow, 2007](#)), training ([Burry, 1999](#); [Myers, 1992](#)), teachers and schools ([Laurence, Webb, Okundaye, & Hafner, 2003](#); [Paley et al., 2006](#)) and from the educational system ([Evans, Scott, & Schulz, 2004](#)). [Redding, Fried, and Britner \(2000\)](#) reported some of the benefits of this type of support. These benefits included feeling understood and acceptable by others, learning new parenting skills, interacting with them and giving them the opportunity to exchange their feelings and concerns with people who can observe and understand them. In contrast, [Duvdevany and Abboud \(2003\)](#) found that informal social resources of support were related to parental well-being and that support presented to families from their friends, neighbors and other family members is crucial in determining their quality of life. [Boaz and Muller \(1994\)](#), however, provided powerful evidence proving that the need for long-term nursing is remarkably reduced when families receive both types of support (i.e., formal and informal).

Existing literature supports the notion that caring parents need various types and levels of support in order to cope with the presence of one or more children with PD. Such support includes: training, responsive professionals, respect, counseling services, comprehensive material support, information, community resources, social support from the community, financial support, an accommodating school system and good relationships with social workers ([Seligman & Darling, 1989](#); [Brown et al., 2005](#); [Murray et al., 2006](#); [Schormans, Coniega, & Renwick, 2006](#)). [Armstrong and Kerns \(2002\)](#) reported that the need for health/medical information, professional support, community network support and involvement in the child's care were most likely to be unmet for families of children with physical disabilities.

To summarize, families of children with physical disabilities face several challenges and difficulties that affect their long-term quality of life. There is an observed relationship between the life quality of the family having a child with PD and the extent to which their needs are met. But despite the increased awareness of the importance of meeting the needs of children with disabilities, the awareness of meeting the needs of their caring parents is still limited. This, in turn, highlights the importance of identifying and determining the needs of families having physically disabled children. These needs should be addressed based on scientific research methods to enable providing families with the supportive services needed.

Significance of the study

Caring parents who foster children with physical disabilities undergo particular challenges which, in turn, may create many needs for the family that should be met. Meeting the needs of these parents may help in upgrading their quality of life which would, in turn, help in elevating the quality of life for the whole society. Research should gear more attention to identify the needs of parents having physically-disabled children. These efforts can be beneficial in building an efficient database to identify parents' needs and determine the unmet ones. This study, therefore, adds to the existing literature through exploring the particular needs of Jordanian parents caring for children with PD.

Furthermore, identifying the needs of caring parents can help the concerned institutions to generate possible solutions to meet parents' needs through planning the supportive services and developing the quality of these services. Institutions can benefit from the results of this study as they can take perceived families' needs into consideration when planning services for those families in order to increase the efficiency of existing services (Marray et al., 2005).

Study objectives

This study aimed at identifying the needs of parents caring for a child or more with physical disabilities using a sample survey of those identified as being engaged in caring of such children. Specifically, the objectives of this study aim to define the needs of parents of children with physical disabilities in Jordan, and to find out to what extent the needs of these parents are being met, and to determine the best ways to meet the needs from the caring parents' perspective. Therefore, this study implemented surveying techniques that include close- and open-ended questions to answer the following questions:

1. What is the level of needs of parents caring for children with physical disabilities in Jordan?
2. What are the most and least important needs identified by parents caring for children with physical disabilities in Jordan?
3. Are there significant differences among the dimensions of needs according to the following demographic variables: gender of the child, age of the child, mother's vocational status, family income and parents' relations with their extended families?
4. What are the suggestions of parents caring for children with PD that they think would best help meet their unmet needs?

Methodology

Population and sample

The population of the study included parents at the Hashemite area in Al-Zarqa city, who have children with physical disabilities in public schools, including movement disabilities, during the academic year 2008/2009. A list of disabled children was obtained from the Ministry of Education in Jordan to determine the population frame of the study. A list stating the numbers of all children with disabilities and their schools in Al-Zarqa city was also obtained. According to the list, the target population was (132) children with physical disabilities. A random sample of (72) children with physical disabilities was drawn from the established population frame, which represented approximately (46 %) of the population.

The parents of these children were contacted and informed about the study purposes. They were further assured that their responses will be kept confidential and anonymous. Demographic data of the sample are shown in Table 1.

Instrumentation

In order to assess the needs of caring parents of children with physical disabilities from parents' point of view in Jordan, the researchers developed a survey instrument named *Scale of Needs of Caring Parents*. The researchers first reviewed theoretical and experimental literature related to the families of children with disabilities and their reactions to physical disabilities and any other type of physical disabilities (Carpenter, 2000; Kirk et al., 2000; Redding et al., 2000; Blasco, 2001). Moreover, sections of the

questionnaire were identified and the items were distributed on them. Moreover, the researchers carefully studied items included in previous experimental literature. Then, the researcher put the final frame of the items, so that each of them was designed to identify caring parents' perceived needs.

Table 1. Demographics of the Sample

Variable	Level	Frequency	Percent %
Gender of child	Male	38	56.7%
	Female	34	53.3%
Age of child	(6-8) years	14	21%
	(9-11) years	21	31.3%
	(12-14) years	19	28.4%
	(15-16) years	13	19.4%
	No answer	6	9%
Income range	Less than 150	21	31.4%
	(151-300)	37	55.2%
	More than 300	3	4.5%
Parents' relation with their extended family	No answer	9	13.4%
	No relation	25	36.3%
Mothers vocational status	Relation	33	49%
	No answer	10	10.4%
	Working	41	42.7%
	Nonworking	45	46.8%

The instrument used to collect data in this study was composed of 60 items in the primary frame, divided into three sections. The first section represented a demographic questionnaire inquiring on the characteristics of the family members; such as: age, gender, income level and level of education. The second section was rated using a five Likert-type scale, with five indicating *strongly needed* and one indicating *strongly unneeded*. This section consists of six subscales: (a) Information; (b) Counseling Support; (c) Involvement in Caring; (d) Community Services; (e) Family Support; (f) Professional Support and Training. The third section of the questionnaire was an open-ended question soliciting ideas and suggestions for better service delivery to parents caring of children with PD to meet their unmet needs.

Correcting the scale

A five-point scale was used to rate the participants' performance with the following findings: the value three on this scale represents the middle value of this scale. The degree ranging between 2.5 to 3.49 represents the mean degree on the scale and lies in the category of average degree of needs. So, the authors identified one category lower than this category and another category higher than it. The range (3.5-5) represents the highest degree of needs, while the degree ranging from 1 to 2.49 represents the lowest degree of needs.

Checking the validity and reliability of the instrument

The researchers translated the questionnaire into Arabic after initially preparing it in English. Then, both the Arabic and English copies were proofread by a language specialist, who made some modifications on a number of items included in the instrument. In order to ensure the validity of instrument, the researcher first proved logical validity; also, ensured the validity of the Arabic version of the instrument by consulting a group of six referees specialized in special education at several Jordanian universities about it. Their role was to confirm whether the content of the instrument was accurate and adequate in terms of language clarity, to check the relevance of each item to the main section it is related to in the questionnaire and to provide any additional comments or corrections. Changes recommended by the validation panel and those identified as needed during the pilot test were taken into consideration to modify the instrument by omitting, adding or rephrasing some items, decreasing the number of items from 60 to 51, distributed on the previous six subscales.

In order to estimate the reliability of the questionnaire, internal consistency measures were computed using the Cronbach's alpha method for each domain and for the total domains. Thus, the reliability coefficients were: 0.90 for needs related to Information Support, 0.91 for Counseling Support, 0.84 for Personality Traits and Motives for Caring, 0.82 for Involvement in Caring, 0.81 for Community Support, 0.92 for Family Support, 0.86 for Training and Professional Support and 0.73 on the total score. These results indicate that the reliability coefficients were satisfactory for the purpose of the study.

Data collection

Data were collected from parents of physically disabled students in the public and private schools during the academic year of 2008/2009. Data were collected from (64) caring parents. To ensure a representative sample, a certain percentage of caring parents from the Ministry of Education in Jordan were involved.

Data analysis

Demographic data were summarizing the research participants and their responses regarding their disabled children. All responses on the scale of family needs were coded, entered into the computer and analyzed using the Statistical Package for Social Sciences (SPSS). The data collected were analyzed and then expressed through means and standard deviations. The t-test for an independent sample and one-way analysis of variance (ANOVA) were used as the main statistical techniques in the study.

Limitations of the study

The small size of the sample may not be representative of the population of parents caring for children with physical disabilities. Therefore, the results may not be generalized to all of Jordan. However, the sample size in this study was similar to sample sizes reported in other studies (Able-Boone & Stevens, 1994; White & Knapp, 2001).

Results

This study was an attempt to explore the needs of parents caring for children with physical disabilities from the parents' perspectives. In what follows, we present the results of the research questions set for this study.

Results of the first research question

The first research question addressed the level of needs identified by parents who care for children with physical disabilities. In order to answer this research question, means, standard deviations and ranks were used as shown in Table 2.

Table 2. Participants' Ratings on the Overall Family Needs Scale and on its Six Dimensions

Dimensions	Rank	Mean	Standard Deviation
Involvement in Caring	1	4.43	0.42
Information	2	4.37	0.51
Professional Support and Training	3	4.15	0.60
Community Support	4	4.11	0.58
Counseling Support	5	3.52	0.77
Family Support	6	3.23	1.06
Total		3.91	0.53

As shown from Table 2, the total mean of participants' ratings for the overall scale was 3.91, which lies in the category of average degree of needs. With regard to the means and standard deviations for the six dimensions of the caring family needs' scale, the dimension of *Involvement in Care* had the highest mean score of 4.43 with a standard deviation of 0.42; lying in the category of high degree of needs, while the *Family Support* dimension had the lowest mean of 3.23 with a standard deviation of 1.06; lying in the category of average degree of needs. This result indicates that, overall, participants have a high degree of estimated needs that if met would enable them better raise their disabled children.

Moreover, means of participants' ratings for other dimensions of the scale lie in the category of *high degree of needs*. These means were 4.37 (SD = 0.51), 4.15 (SD = 0.60), 4.11 (SD = 0.58) and 3.52 (SD = 0.77) for the dimensions of information, professional support and training, community support and counseling support respectively.

Results of the second research question

To answer the second question concerning determining the most and least important needs identified by parents caring for children with physical disabilities in Jordan, means and standard deviations for each of the 50 items were calculated, where the mean values ranged from (2.60) to (4.65). The items were then

ranked. Table 3 shows the ten items that were rated by participants as the most important needs of families of physically disabled children. Their means ranged from (4.43) to (4.65). Four items of those that had the highest rating were from the information dimension, whereas three items were from the involvement in care dimension, one item from the community support dimension and one from the counseling support dimension.

Table 3. The Most Important Needs Identified by Families of Physically Disabled Children.

No.	Item(I need to...)	Rank	Mean	SD	Dimension
36-	Have specialists follow up and supervise my child with special performance	1	4.65	0.45	Involvement in Caring
8-	Get enough information about future services my child with special need might need.	2	4.63	0.56	Information
4-	Be told what the suitable learning environment of my child and the rules of safety are.	3	4.59	0.49	Information
43-	Raise the society awareness about children with special needs.	4	4.58	0.63	Community Support
10-	Have complete information about my child's physical problem (e.g. weakness, headache, problem with hearing).	5	4.55	0.55	Information
13-	Help develop my child's abilities to depend on himself/herself according to his/her optimal limit.	6	4.52	0.77	Counseling Support
5-	Know the resources and local organizations that offer assistance on how to deal with my child with special needs.	7	4.5	0.63	Information
39-	Know my role in the learning process of my child.	8	4.5	0.68	Involvement in Caring
38-	Have complete information on my child's problem with thinking (e.g. memory, confusion).	9	4.47	0.70	Involvement in Caring
35-	Coordinate and cooperate with a specialist concerning methods of taking care of my child with special needs.	10	4.47	0.64	Involvement in Caring

Furthermore, one can observe from Table 3 that the highest mean score was 4.65 for item 36 (Have specialists follow up and supervise my child with special performance), which belongs to the involvement in caring dimension. Ranked as second is item eight from the information dimension that represent the need of parents to *get enough information about future services their child with disability might need* with mean score of 4.63. With regard to the community support dimension, the data indicated that the needs that were identified by parents as most important was the need to *raise the society awareness about children with disabilities*, with a mean score of 4.58. While parental need for *help to develop their child's abilities to depend on himself according to his optimal limit* was identified as most important in the counseling support dimension with a mean score of 4.54.

Table 4 shows the ten items that were rated by participants as the least important needs of families of physically disabled children and which ranged from (2.54) to (3.54). As observed from Table 4, four items were from the counseling support dimension, five were from the family support dimension and one item was from training and professional support dimension.

Table 4 also shows that item 46 *Reinsure that my strong negative feeling toward my child is usual*, which belongs to the counseling support dimension obtained the lowest mean score of 2.54 with a standard deviation of 1.2. In relation to the same dimension, item 23 *Be helped by someone to get rid of my shy feelings relevant to my child handicapness* takes the second lowest rank with a mean score of 2.60. With regard to the family support dimension, the data indicated that the lowest needs related to this dimension was item 47 that represents parents needs to support their normal child to adapt to their disabled brothers/sisters, while the item that represents parents need for help to develop a method to cope with their child's needs had the lowest degree of needs in the training and professional support dimension with a mean score of 3.50.

Results of the third research question

The third research question in this study investigates whether there are significant differences among the dimensions of families' needs ascribed to the following demographic variables: gender of disabled child, age of disabled child, family economic level, mother's vocational status and parents' relations with their extended families.

Table 4. The Least Important Needs Identified by Families of Physically Disabled Children

No.	Item(I need to)	Rank	Mean	SD	Dimension
46	Reinsure that my strong negative feeling toward my child is usual.	1	2.54	1.4	Counseling Support
23	Be helped by someone to get rid of my shy feelings relevant to my child handicapness.	2	2.60	1.3	Counseling Support
47	Support my normal children to adapt to the status of their brothers/sisters with special needs.	3	2.98	1.2	Family Support
31	Be helped and assisted to clarify the status of my child to my family members.	4	3.00	1.3	Family Support
33	Be helped prepare myself for worse situations.	5	3.15	1.2	Counseling Support
18	Be assisted to help my spouse accept my child's status.	6	3.18	1.4	Family Support
19	Be assisted to minimize the psychological burden resulting from the child's suffering.	7	3.24	1.2	Counseling Support
49	My family needs assistance in knowing their responsibilities and duties.	8	3.28	1.2	Family Support
50	My family needs amusement.	9	3.33	1.2	Family Support
53	Develop a method to cope with my child's needs.	10	3.50	1.2	Training and Professional Support

T-test for independent samples was used to examine the differences in means among children's gender (i.e., females and males), parents' relations with their extended families and the mother's vocational status (i.e., working or non-working). The results of the t-test show that there were no significant differences at the (0.05) level between family needs according to gender of child with physical disabilities. However, Table 5 illustrates that there were significant differences at the (0.05) level between parents who belong to extended families and those who do not, only in the dimension of family support, where the differences were in favor of parents who do not belong to extended families.

Table 5. The Differences between Participants Who Belong to Extended Families and Those Who Do not on the Dimension of Family Support

Dimension	Relationship	N	Mean	Std. Deviation	t	df	P
Family's Support	No	25	3.60	1.2	2.0	56	.04*
	Yes	33	3.06	.79			

Significant at $p < 0.05$

Moreover, results of t-test, reported in Table 6, show that there were significant differences at the (0.05) level between family needs according to whether the mother of the child with physical disabilities is working or not. These differences appeared in the overall mean for the scale and in the dimensions of Counseling Support, Community Support, Family's Support and Professional and Training Support, which were in favor of working mothers. However, in the information dimension, the differences were in favor of nonworking mothers.

On the other hand, one-way analysis of variance was utilized to identify whether the variances of the three levels of child age and the four levels of family's income were equal or significantly different. One-Way Analysis of Variance showed that there were no significant differences among participants' ratings of their needs that can be attributed to the variable of age of children with physical disabilities (1991-1993; 1994-1996; 1997-2000). There were also no significant differences which can be attributed to the variable of family income range (less than 150; 150-300; more than 300) at the (0.05) level of significance for all the dimensions measured by the scale.

Results of the fourth research question

In order to understand how caring parents of children with PD would like their needs be met, we have added an open-ended question to the family needs scale asking participants how they think their needs could be met in suitable ways. Thirty six respondents out of 70 completed this question. Fourteen suggestions were identified through content analysis of the participants' responses. These suggestions are presented in table 7 according to how frequent they were mentioned by participants.

Table 6. The Differences between Working and Non-Working Mothers of Children with Physical Disabilities on Each Dimension of the Scale and on the Scale as a Whole

Dimension	Career	N	Mean	Std. Deviation	T	df	P
Information	Working	41	4.3355	.53470	-2.102*	43	.041*
	Nonworking	45	4.9038	.07365			
Counseling Support	Working	41	3.6541	0.79082	2.343*	43	.024*
	Nonworking	45	2.6695	0.94213			
Community Support	Working	41	4.1867	0.57105	3.464*	43	.001*
	Nonworking	45	3.1343	0.68769			
Family Support	Working	41	3.4688	0.98993	3.610*	43	.001*
	Nonworking	45	1.6250	0.75000			
Professional Support and Training	Working	41	4.2266	0.53701	4.511*	43	.000*
	Nonworking	45	3.0000	0.12856			
Total	working	41	4.0022	0.51418	3.204*	43	.003*
	nonworking	45	3.1380	0.52354			

Note. $p < 0.05$

Table 7. Content Analysis of Identified Ways to Meet Participants' Needs

Way	Frequency
Receiving support from professionals and dealing with them as partners.	10
Organizing the services available.	10
Receiving support from schools and medical centers.	8
Providing children with physical disabilities with comprehensive services.	8
Coordination	7
Financial assistance.	7
Recreation services.	5
Training parents on how to develop the abilities of their children with physical disabilities.	4
Forming groups of parents	3

Ranked according to their frequency, receiving support from professionals and dealing with them as partners, organizing the services available, receiving support from schools and medical centers, and providing children with physical disabilities with comprehensive services were the suggestions that had the highest frequency indicating their importance to all participants involved in the study.

Parents involved in the study had commented on the approach of delivering the professional support for family members and for children with physical disabilities children. One respondent whose son had physical disabilities commented: *I need an effective support to develop the abilities of my child with physical disabilities.* Another respondent mentioned, *Supportive services to my family in addition to supportive counseling to my child with physical disabilities would be useful.* He added: *I think professionals must arrange monthly workshops for families to help them and their children.*

Information parents receive was another area of concern, as one respondent wrote, *I do not have enough information about my child's situation*. Another said, *I want to know more about the appropriate environment to educate my child with physical disabilities*. Another respondent indicated, *It is useful to know what my child's future looks like, and what the available services which can help him are*.

Discussion

This study aimed at determining the needs of parents caring for children with physical disabilities in Jordan. Study results revealed that the mean score on the overall scale of caring parents' needs was (3.91) indicating that parents, on average, have a high degree of needs. This result could be due to the fact that caring parents who responded to the study scale were not provided with enough services and support in different areas (emotional, social, health, physical and intellectual aspects) that help them and their children with physical disabilities. This result is similar to those of previous researchers like Brown et al. (2005), Carpenter (2000), Ellis et al. (2002), and Seligman and Darling (1989) which suggested several areas that frame the unmet needs of parents caring for children with PD including: training, responsive professionals, respect, counseling services, formal and informal support, comprehensive material support, information availability, community resources and support, financial support, an accommodating school system and good relationships with social workers.

Ranked as their top priorities, parents identified their need to be involved in the caring process of their disabled children and their need for detailed information about the future of their children with PD, as well as the available services offered to them, in addition to the most secure educational environment that will meet their children's needs. This must be coupled with information about the problems their children encounter. Results, also, indicate the parents' need to participate in delivering services and identify their roles and responsibilities within the designated team. Those perceived needs could be explained through professionals' misunderstanding to the roles of parents in the caring process, in addition to the fact that some professionals may believe that parents' participation conflict with their roles and as a consequence, they may fail to provide necessary information for parents. This result is in harmony with the results reported by previous studies (e.g., Brown et al., 2005; Darling & Baxter, 1996; Hudson & Levasseur, 2002; Seligman & Darling, 1989).

The perceived need for support and training from professionals occupied the third dimension in participants' ratings to their most important areas of identified needs. This result indicates that caring parents need training and support to become more aware of their children's weakness and strength points and how best to meet them. This result is also in agreement with the findings of many studies indicating that caring parents are frustrated as a result of the lack of professionals' support and coordination (Brown et al., 2005; Jivanjee, 1999). Yet, when these parents received training, they reported fewer child behavior problems and lower stress (Amaral, 2003; Burry, 1999; Feldman & Werner, 2002).

Community support occupied the fourth dimension among the most important areas of identified needs by participants. This may be explained in light of the lack of community awareness of disabilities in general and of children with PD in specific. As shown from other studies in this area, there is a need for a variety of community programs for children with disabilities. For example, Zima et al. (2000) and Brown et al. (2005) indicated that there is a persistent need for transitional services to help children and their parents cope with the transition from school to community, and from childhood to adulthood.

On the other hand, family support and counseling support dimensions were ranked as the least important areas of identified needs. This could be the case as the vast majority of families in Jordan belong to extended families that provide encouragement and support to caring parents. Moreover, extended families strengthen the emotional aspect and help parents develop positive characteristics needed to cope with the disabilities of their children.

As for the most and least ten important needs of families of children with physical disabilities, results indicate that four of the ten most important needs belong to the information dimension, while five are from the involvement in caring dimension and one is from the community support dimension. These results suggest that all caring parents who responded to our scale placed special emphasis on the importance of getting understandable and honest information about their child status, future, and available services. The results also denote the important to raise the society awareness about these children and their abilities.

In contrast, the ten least important needs identified by participants indicate that four needs belong to the dimension of counseling support, five needs belong to the dimension of the family support, and finally one need belongs to the dimension of training and professional support. The distribution of these ten needs can be accounted for through the possibility that participants received support from their own family members and the support needed for their normal children to adapt to the status of their brothers/sisters with special needs.

These results suggest that all participants emphasized that they can, with a modest degree, cope with the physical disabilities of their children and that family members can tolerate children with physical disabilities and accept them without any negative feelings. Results also indicate that family needs of help to cope with their disabled children are less important compared to other needs mentioned in the study's scale. Moreover, family members can adjust with their physically disabled children in consistency with their logical raising thinking.

As for the significant differences among dimensions of families' needs due to the selected demographic variables, results revealed that there are no statistically significant differences among caring parents' needs attributable to gender of child, age of child, parents' economic level and whether they belong to an extended family or not, except on the family support dimension as there were statistically significant differences in favor of parents who do not have extended families. This means that caring parents share the same views towards their needs when caring for children with PD regardless of their child's age, gender, or even their own variation. It also indicates that most caring parents firmly believe that their needs are unmet in an effective manner.

The results of the study also signify that there are statistically significant differences on the dimensions of the study survey in favor of working mothers, except for the information dimension, where the differences were in favor of nonworking mothers. This result may be due to the possibility that working mothers, because of the limited time they could spend in caring of their children with physical disabilities, they need more support from both formal and informal support systems compared with non-working mothers. Furthermore, working mothers need to send their child with PD to centers for more hours. So, they experience more challenges throughout their search to provide their child with excellent services which may not be efficiently available in their area.

The final question of this study relates to the suggestions that parents think can best meet their needs. The results indicated that the two frequently mentioned ways to meet the parents' needs as recognized by parents themselves are: (1) receiving support from professionals, and (2) having more service resources available to their children with physical disabilities. These responses indicate that caring parents may not be aware of the services available in community. On the other hand, parents believe that the available services lack organization to be more efficient and comprehensive in developing different activities to meet their children's needs and exploit their capacities through training and caring.

In lieu of previous discussion, we can conclude that the parents' needs can be met through providing them with information about the service system available. In addition, there seems to be a necessity for providing individual case management or service networks in order to help families have an access for those available services. This is so, because the service system in Jordan is complicated and their might be difficulty for parents in accessing those services. On the other side, caring parents have little knowledge and experience about service system. As a result, professionals must have holistic and comprehensive information about the available programs, services and financial resources, and this can be achieved through the availability of the case management system.

Conclusion and Implications

In the present time, decision makers should focus on the role of parents caring for children with PD as part of the whole community progress plan. Through organized studies and scientific research, we can build an efficient database to identify these parents' needs and determine the unmet ones. This, would in turn, help concerned institutions to generate possible solutions by planning the needed supportive services and developing the quality of these services. Therefore, we should determine caring parents' needs, especially the unmet ones, before developing the services or enhancing the already existing ones. In addition, we can aid family members by improving the quality of their life from several aspects. Caring parents who foster children with physical disabilities experience particular challenges, such as stress, anxiety, isolation and financial difficulties. These challenges may raise many needs which should be met.

Several implications can be drawn from this research. The results of this study suggest that caring parents have many needs preventing them from providing their physically disabled children with effective care. In order to assist these parents and upgrade their children's life as well as their own, we recommend that all service providers be aware of the necessity of meeting caring parents' needs while providing services for children with PD. They also need to know how to develop a welcoming atmosphere that enables them to work closely with parents and communicate with them in effective and friendly ways. All service systems should also work together to identify the needs of these parents and put an effort to meet parents' needs and eradicate all the barriers they face to enable them provide the best for their disabled children. From a different angle, parents of children with physical disabilities and the institutions that provide services for them should be presented with a financial support by various ministries and resources to enable parents meet their needs and the need of their child with disability. Furthermore, Jordanian universities and colleges should offer new courses for specialists including social workers, counselors, early education teachers, special education specialists, nurses, and doctors that provide training on parent involvement and the best strategies to provide comprehensive services for these children and their parents.

From a theoretical standpoint, the scope of the future research should be expanded to look at the needs of caring parents who have children with other disabilities and to investigate the effect of other demographic variables. Furthermore, qualitative research can add in-depth information about the perspectives of parents caring for children with PD. This research is hoped to be seen as a starting point for overcoming the barriers facing services presented to children with PD and their families.

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