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ORIGINAL ARTICLE

ASSESSING THE UNMET NEEDS AMONG CAREGIVERS OF CHILDREN WITH DISABILITIES AT THE COMMUNITY-BASED REHABILITATION CENTRES IN SELANGOR

Suriati S[1], Sharifah Zainiyah SY[2], Lye MS[2], Norlijah O[3]

[1]*Department of Basic Health Sciences, Kulliyyah of Allied Health Sciences, International Islamic University Malaysia.*
[2]*Department of Community Health, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia.*
[3]*Department of Paediatric, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia.*

ABSTRACT

Caregivers may experience the need for information, social support, a range of services and financial support in caring for children with disabilities. However, some of these needs are unmet. This study aims to determine the perceived unmet needs among caregivers of children with disabilities at the Community-based Rehabilitation centre (CBR). A cross-sectional study was carried out among a total of 337 caregivers, who were recruited from 12 CBR centres in Selangor. The unmet needs were assessed using Family Needs Survey (FNS) questionnaire, which included six subscales of needs such as need for information, social support, community services, explaining to others, financial support and family functioning. Caregivers identified the need for information that the child might receive in the future as their greatest need (94.4%) and the least was the need for getting more counseling or help in getting a job (16.3%). The mean score for the overall unmet needs was 18.67 (SD=7.623). Out of six subscales of FNS, the need for information had the highest rating which was 98.3%, followed by need for social support (93.4%), need for community services (84.0%), need for financial support (79.9%), need for family functioning (61.8%) and need for explaining to others (46.2%). The unmet needs varied within the subscales. Therefore, more effective intervention programs are needed in community-based rehabilitation centres to match or reduce those varied unmet needs in order to allow caregivers to provide better care for their children with disabilities.

Key words: *unmet needs, caregivers of children with disabilities, community-based rehabilitation centre; family needs survey.*

INTRODUCTION

In caring for children with disabilities, caregivers may experience the need for information, social and financial support, and a range of services in caring for their children[1,2,3,4,5,6]. Children's limitations related to disabilities are the reasons for the caregivers to have unmet needs. It is not surprising as disability causes both the children and their family to have additional needs[7]. These include assistance in feeding, dressing and walking in those with physical disabilities, while some children with learning disabilities may have difficulties in understanding and following the instructions given[8].

There are seven registered categories of disabilities; which include hearing, visual, physical, learning, mental, speech and multiple disabilities[9]. Registered medical officers are empowered to endorse these disabled children and to further group them into the respective categories as above. The actual number of children with disabilities in Malaysia is unavailable[10]. However, the most recent Statistic Report published by the Social Welfare Department of Malaysia in June 2009 showed that there were 261,154 registered disabled people with the Social Welfare Department in Malaysia; making up 0.93% of the Malaysian population.

Assessing the unmet needs

A considerable amount of literature has been published on children with disabilities, and one of the topics of interest was assessing the unmet needs of caregivers or parents of children with disabilities. The various categories of disabilities studied were specifically on handicapped infants[2], children with chronic health conditions[4], young children with motor or multiple disabilities[6] and children with developmental disabilities[11,12]. Even though the groups studied by the researchers were on different categories of disabilities, the outcome of these previous studies showed that most of the caregivers experienced greater need for information in caring for their children.

In one study, need for information was the greatest need among parents. It was acknowledged by more than 50% of parents of young children with handicapped condition. These parents expressed the lack of information on the following aspects: ways to teach their child, the kind of available services for the present time and in future and reading materials on how other affected parents coped with children like theirs[2] .In another study, approximately 70% of parents reported needs related to information on the services provided and to be provided for the child in the future, information about the child's disability, information on how to teach the child and information on the management of child's behavior[11]. A survey has been conducted on 84 parents of children, who were newly admitted to the therapeutic toddler class[6]. They indicated that more than 50% of parents stated that they need information regarding their child's future development, child's condition or disability and services that child might receive in the future.

Therefore, this study aims to determine the magnitude of unmet needs among caregivers of children with disabilities at the Community-based Rehabilitation centre using the Family Needs Survey (FNS) questionnaire.

METHODS

Respondent

A cross-sectional design was employed to study the unmet needs of caregivers. Sample was chosen using a simple one-stage cluster sampling method from thirty-six Community-based Rehabilitation (CBR) centres in Selangor. Out of these thirty-six CBR centres, twelve CBR centres were randomly chosen. All caregivers registered in these twelve selected CBR centres were approached for consent and recruitment into the study and they comprised of 337 caregivers. Approval to conduct the study has been obtained from the Medical Research Ethics Committee of the Faculty of Medicine and Health Sciences, Universiti Putra Malaysia and the Social Welfare Department of Malaysia. The inclusion criteria used to select the caregivers were caregivers in the presence of their children at the selected CBR centre at time of data collection, caregivers who have children with any disability aged below 18 years old and caregivers living with the child. Caregivers of children who have been identified for transfer to Special Education schools or mainstream schools with Special Education classes and not participating in the CBR's centre-based program were excluded from the study.

Instruments

The assisted self-administered questionnaires used in this study were in both Malay and English languages. Nine items captured caregivers' characteristics, such as the primary caregiver of the child, gender, race, marital status, occupation, family average monthly income, number of children, education level and geographical location. In addition, three items related to the caregiver's child were assessed such as child's age, gender and type of disability. The Family Needs Survey (FNS) was socio-culturally adapted and used in this study to assess the unmet needs of a family of children with disabilities[2]. It is a 35 item scale and is composed of six subscales: information, social support, community services, explaining to others, financial support and family functioning. Scores range from 0-35 and higher scores represent more unmet needs. In the present study, the Cronbach's alpha is 0.91 overall, with subscales ranging from 0.74 to 0.88 and it showed a good face and content validity. In other studies, it has demonstrated an adequate reliability (Kuder-Richardson 20 = 0.88)[4], a satisfactory test-retest reliability (r = 0.67 for mothers and 0.81 for fathers), and a good content and construct validity[2].

The original version of FNS is in English language. However, majority of the respondents were Malays. Therefore, the FNS was translated into Malay language using forward translations.

Statistical analysis

Results were analyzed using the SPSS software. Descriptive statistics was used to describe the frequency distribution of caregiver's socio-demographic characteristics, child's demographic characteristics and the unmet needs.

RESULTS

Respondents

Overall, 288 (85.5%) caregivers agreed to participate in this study. The distribution of child's demographic characteristics is shown in Table 1.

More than half of the respondents have male children (58.7%), children aged below ten years old (64.9%) and have children with learning disability (53.5%).

Moreover, the majorities were mothers (97.2%), married (99.3%), Malays (79.2%) and housewives (72.6%), living in rural area (62.8%) and almost 70% reported a family average monthly income of below RM2000 (Table 2).

Table 1. Distribution of respondents by their child's demographic characteristics (n = 288)

Characteristics	Frequency (n)	Percentage (%)
Gender		
Male	169	58.7
Female	119	41.3
Age (years)		
< 0	1	0.3
1-4	44	15.3
5-9	142	49.3
10-14	70	24.3
15-17	31	10.8
Type of Disability		
Hearing	3	1.0
Visual	1	0.4
Physical	66	22.9
Mental	0	0.0
Speech	2	0.7
Learning	154	53.5
Multiple Disabilities	62	21.5

Table 2. Distribution of respondents by socio-demographic characteristics (n = 288)

Characteristics	Frequency (n)	Percentage (%)
Relationship		
Mother	280	97.2
Others	8	2.8
Gender		
Male	0	0
Female	288	100
Race		
Chinese	32	11.1
Indian	28	9.7
Malay	228	79.2
Marital Status		
Married	286	99.3
Divorced	2	0.7
Occupation		
Government servant	43	14.9
Private sector	24	8.3
Self-employed	12	4.2
Housewife	209	72.6
Family Average Monthly Income		
≤ RM1000	106	36.8
RM 1001-2000	102	35.4
RM 2001-3000	37	12.9
>RM 3000	43	14.9
No. of Children		
1-4	195	67.7
5-9	89	30.9
≥10	4	1.4
Education Level		
No education	2	0.7
Primary	39	13.5
Secondary	196	68.1
Tertiary	51	17.7
Place of Residence		
Rural	181	62.8
Urban	107	37.2

Cited unmet needs among caregivers
The distribution of respondents by the type of need is presented in Table 3. The mean score of the overall unmet needs was 18.67 (SD=7.623). It indicates that the caregivers have around 18 unmet needs on average; out of the 35 items of unmet needs in FNS. Approximately 90% of caregivers rated at least one or more unmet needs. This high percentage of unmet needs shows that the caregivers needed help to look for more information, support, community services and financial support, and needed help in family functioning and explaining to others about the child's condition.

All of the items related to the need for information were rated as needed help by more than 70% respondents. Other than the need for more information about the services that the child might get in the future, respondents also reported that they needed more information about the child's development and growth (92.4%), the way to teach the child (88.2%), handle the child's behavior (80.9%) and play or talk to the child (78.8%), current services available for the child (84.7%) and information about the child's condition (80.6%).

Eight items in the subscale of need for social support were endorsed by greater than one third of the respondents. The greatest need was for reading materials (76.4%), followed by need for support from the child's teacher or therapist (75.3%), support from other parents (74%), support from friends (69.1%), support from family members (63.2%), support from counselors (56.2%), need for more time for themselves (45.5%) and need for support from religious person (45.1%). The most frequently chosen unmet needs for services were dental services (60.4%), medical services (59.7%) and day care centre services (57.6%). For financial support, approximately 70% of respondents needed help in paying for expenses of the child. In contrast, respondents reported less than 45% for all items in both of the subscales of the need to explain to others and family functioning.

Table 3. Unmet needs scores reported by caregivers (n=288)

Type of Need	Respondent n (%)	Mean ± SD
Information		
Information about my child's condition or disability	232 (80.6)	2.67±0.726
Information about how to handle my child's behavior	233 (80.9)	2.65±0.778
Information about how to teach my child	254 (88.2)	2.79±0.612
Information on how to play with or talk to my child	227 (78.8)	2.64±0.753
Information on the services that are presently available	244 (84.7)	2.77±0.600
Information about the services my child might receive in the future	272 (94.4)	2.92±0.383
Information about how children grow and develop	266 (92.4)	2.89±0.419
Social Support		
Someone in my family that I can talk to more about problems	182 (63.2)	2.32±0.978
More friends that I can talk to	199 (69.1)	2.49±0.855
More opportunities to meet and talk with other parents	213 (74.0)	2.60±0.763
More time just to talk with my child's teacher or therapist	217 (75.3)	2.62±0.731
Meet more regularly with a counselor (psychologist, social worker, psychiatrist)	162 (56.2)	2.33±0.864
Talk more to religious person who could help me deal with problems	130 (45.1)	2.04±1.011
Reading material about other parents who have a child similar to mine	220 (76.4)	2.65±0.698
More time for myself	131 (45.5)	2.02±1.044
Explaining to Others		
How to explain my child's condition to his or her siblings	81 (28.1)	1.54±1.025
Explaining my child's condition to either my spouse or my spouse's parents	68 (23.6)	1.49±0.963
My spouse needs help in understanding our child's condition	69 (24.0)	1.39±1.016
How to respond when others ask about my child's condition	80 (27.8)	1.67±0.947
Explaining my child's condition to other children	94 (32.6)	1.73±0.997
Community Services		
Locating a doctor who understands my child's need	172 (59.7)	2.30±0.935
Locating a dentist who will see my child	174 (60.4)	2.33±0.926
Locating babysitters who are willing and able to care for my child	78 (27.1)	1.38±1.153
Locating a preschool for my child	166 (57.6)	2.15±1.096
Getting appropriate care for my child during religious activity	99 (34.4)	1.69±1.068
Financial Support		
Paying for expenses such as food	190 (66.0)	2.42±0.911
Getting special equipment for my child's needs	155 (53.8)	2.14±1.086
Paying for therapy, daycare, or other services my child needs	117 (40.6)	1.80±1.160
More counseling or help in getting a job	47 (16.3)	1.14±1.075
Paying for babysitting or respite care	83 (28.8)	1.42±1.192
Paying for toys that my child needs	115 (39.9)	1.79±1.135
Family Functioning		
Discussing problems and reaching solutions	100 (34.7)	1.74±1.054
Learning how to support each other during difficult times	128 (44.4)	1.96±1.038
Deciding who will do household chores, child care, and other family tasks	69 (24.0)	1.51±0.998
Deciding on and doing recreational activities	106 (36.8)	1.80±1.054

DISCUSSION

The results are consistent with the previous studies of assessing unmet needs among caregivers of children with disabilities. For example, need for information remains largely unmet[2,4,5]. The present study shows that the need for information is the most frequently reported unmet need, in which it mainly represents the caregivers of the lower income group. Parents need to be informed about the child's disability, diagnosis and services available for them[7].

Specifically, the present study indicates that the most frequently cited need among caregivers is the need for information about services that the child might receive in the future. This finding is supported by other studies who stated that parents are more likely to get information about services for their child in the future and in fact, it was the highest unmet need among the other needs[2,4,5,11,12]. This finding shows that issues related to child's future becomes more important as the child gets older; suggesting that information regarding future services available to the children is often required by caregivers. A possible explanation is the caregivers are concerned and worried about the ongoing care for the child and in the future, especially if the caregivers pass away[13,14].

Besides getting more information related to services in the future, the present study also shows that the caregivers would like to get more information about; their child's growth and development, child's condition, how to handle the child's behavior, how to play, talk or teach their child as well as services presently available for their child. Caregivers reported that they have difficulty obtaining information or have little access to the information they needed because they failed to get help and have no idea where to acquire the information needed[15]. In other study, one of the parents expressed this statement during the interview: "*It's hard to find out what you may need, what resources are available, what you can do, or what the state can do for your child*" (p. 173)[16]. They were left feeling frustrated with the unavailability of information related to the care of their child.

In addition to more information, the present study also shows that the caregivers would like to get more social support especially supports from other parents with similar condition. Besides support, they would like to read materials about other parents' situations. Findings from the current study are consistent with other studies, where parents scored higher for support related to other parents of children with chronic conditions and disabilities[2,4,5]. There are several aspects to be underlined in order to explain these unmet needs for support. One of the aspects includes the perception of caregivers about the similarity of the situation experienced by them. Perceived similarity is one of the elements in bi-directional relationship[17]. Bi-directional relationship occurs between new parents of children with disabilities and supporting parents who also have children with conditions similar to those of the new parents. The same challenges and common experiences faced by support givers and support recipients establish the similarity between them. Caregivers appreciate this support because they often benefit from sharing experience in caring for their child[8]. They feel emotionally supported[18] and feel stronger to survive and obtain more resolutions from this sharing experience[14].

For community services, caregivers in the present study claimed that they needed help to locate doctors and dentists, who understand their child's health needs and who are able to give treatment to their child. These findings are consistent with the findings of other study who found that services related to medical care were often been reported by parents in caring for the child[1]. These unmet needs suggest that the number of service providers and professionals is not sufficient in providing care to these children. Although the availability of professionals who are involved in the care of children with disabilities in Malaysia has improved, the problem here is one of misdistribution[10]. Furthermore, the services offered for children with disabilities and their families are insufficient and priority is not given to them in terms of medical development. Thus, an immediate action towards overcoming these issues is needed.

Need for financial support is also a significant concern. Most caregivers in this study needed financial help to pay for expenses related to their child's condition. For example, they need to buy food, special equipment or devices and pay for the services obtained for their child. These findings suggest how important financial support to caregivers is in caring for their children with disabilities. Similar finding can be found in other studies too. Caring for a child with disabilities causes an increase in economic burden over time[3,7,19]. The fact that two-third of the caregivers earn less than RM2000 could have compounded further the need for financial support.

Need for explaining to others, although reported much less frequently in the present study, still exists for a substantial number of caregivers. Caregivers cited "*how to explain to other atypical children about the child's condition*" as their primary need for explaining to others. Other study also found that almost half of parents in their study needed help in explaining about their child's disability to other atypical children[2]. This finding suggests that caregivers needed help to explain about their child's disability to other unaffected children. One possible explanation for this is because they found that their child is being rejected by the other children. For example, parents feel that their child has been excluded from the other children because the children dislike playing with their child[20]. Parents would appreciate it if their child can be accepted into the community and thus giving the opportunity for the child to play happily with their peers. Similarly with the need for explaining to others, caregivers were less likely to report unmet needs in the area of family functioning. This finding was very similar to those found by other researchers[4]. However, out of four items listed, caregivers reported greatest need for help in learning the way to support each family member during difficult times. This finding suggests that a good support system is important in maintaining family function.

As caring for children with disabilities is related to caregiver's negative emotions such as stress, anxiety, depression and isolation, assessing for unmet needs among caregivers and planning programmes to reduce or match the unmet needs are urgently needed. The provision of information should be optimized and delivered in several ways. For example, distributing a booklet at the time of diagnosis or during the general health surveillance and later after the diagnosis might help to optimize the information of caregivers. In this era of information technology advances, producing a booklet should not be difficult and should come in handy. Furthermore, there are many issues related to services such as the availability, accessibility, coordination and monitoring of services. Therefore, new development and new directions of services should be initiated and services must be responsive to the needs of the families. One potential strategy to increase the support system of caregivers is to provide a family support group. Implementing the family support network to caregivers could give them more strength to survive in caring for the child. Since the respondents for the present study were mothers, it is recommended to encourage father to participate in the future studies because the unmet needs from the parental perspectives might differ somewhat and thus, could broaden the findings in the field of study.

Limitations of the study

Only mothers participated in present study. Parental perception towards unmet needs is important too because they are also the primary caregiver of the child. In addition, the unmet needs can only be ascertained from caregivers who enrolled the child with CBR centre. Therefore, it limits the finding of unmet needs among caregivers of children with disabilities.

CONCLUSION

In conclusion, the unmet needs among caregivers of children with disabilities varied within the subscales; with the need for information was the most frequently reported unmet needs followed by help to look for more social support, community services and financial support. The least frequent were help in family functioning and the way to explain to others about the child's condition. Since this is the first study of its kind in Malaysia, therefore the information obtained about the unmet needs of the caregivers of children with disabilities at the CBR centers can be used to enrich the present programs provided by the Social Welfare Department to develop appropriate interventions, improvement of provision of comprehensive care services and sourcing of resources for caregivers of children with disabilities.

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