



**PERCEIVED UNMET NEEDS
AMONG CAREGIVERS OF
CHILDREN WITH DISABILITIES
AT COMMUNITY-BASED REHABILITATION
CENTRE IN SELANGOR**

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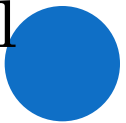
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INTRODUCTION

- Disability is covering impairments, activity limitations and participation restrictions (World Health Organization, 2009a).
 - There are seven categories of disabilities; which include hearing, visual, physical, speech, learning, mental and multiple disabilities (Community Portal for Disabled People, 2009).
 - Statistic Report (2009) shows that there are 261 154 disabled people had registered with the Social Welfare Department of Malaysia.
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PROBLEM STATEMENT

- Improvement on healthcare system increases life expectancy of children with disabilities (Martin and Colbert, 1997).
- Caregivers may experience the need for:
 - Information
 - Social support
 - A range of services
 - Financial support(Bailey and Simeonsson, 1988; Graves and Hayes, 1996; Farmer et al., 2004;).

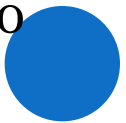


OBJECTIVES

○ General:

- To determine the perceived unmet needs among caregivers of children with disabilities at Community-based Rehabilitation centre (CBR) in Selangor.

○ Specific:

1. To determine the caregivers' socio-demographic characteristics and children's demographic characteristics.
 2. To determine the type and frequency of unmet needs of caregivers of children with disabilities according to the six subscales using the Family Need Survey (FNS) instrument.
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METHODOLOGY

| | |
|-------------------------------|--|
| Study Design | Cross-sectional |
| Study Location | 12 selected CBR centres in Selangor. |
| Study Population | Caregivers of children with disabilities who registered with the CBR centre. |
| Sampling Frame | The list of districts in Selangor. |
| Sampling Unit | The primary sampling unit in this study is the district in Selangor. |
| Sampling Method | A simple one-stage cluster sampling |
| Sample Size | 337 participants |
| Data Collection Method | Assisted self-administered questionnaire and face to face interview. |

MATERIAL

| Scale | Authors | Item | Reliability | Validity |
|---------------------------|------------------------------|---------------------------|-----------------------------|---------------------------------------|
| Family Needs Survey (FNS) | Bailey and Simeonsson (1988) | 6 subscales with 35 items | Kuder-Richardson 20 = 0.88. | A good content and construct validity |

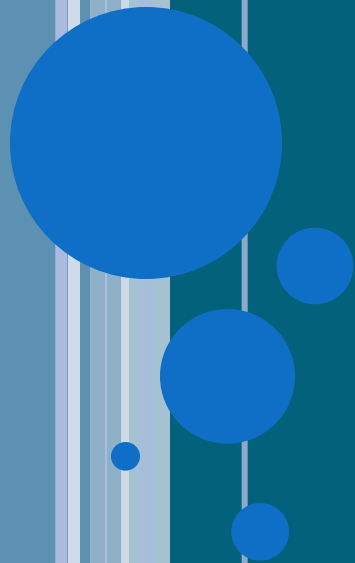


DATA ANALYSIS

| Statistical Test | Purpose |
|------------------|---|
| Descriptive | To determine the frequency distribution and percentage. |



Results & Discussion



RESPONSE RATE

Table 1 Distribution of response rate according to the districts

| District | Name of CBR centre | Number of eligible caregivers | Number of recruited caregivers | % of response rate |
|----------------|--------------------|-------------------------------|--------------------------------|--------------------|
| KUALA LANGAT | Telok Datok | 52 | 49 | 94.2 |
| | Rumah | 33 | 29 | 87.9 |
| | SayangKu | | | |
| | Tanjung Sepat | 22 | 18 | 81.8 |
| | Bukit Changgang | 16 | 15 | 93.8 |
| Suboverall | | 123 | 111 | 90.2 |
| HULU LANGAT | Semenyih | 28 | 25 | 89.3 |
| | Taman Seri Jerlok | 50 | 44 | 88.0 |
| | Suboverall | 78 | 69 | 88.5 |
| KLANG | Klang Utara | 30 | 25 | 83.3 |
| | Klang Selatan | 31 | 28 | 90.3 |
| | Suboverall | 61 | 53 | 86.9 |
| KUALA SELANGOR | Sri Cahaya | 25 | 21 | 84.0 |
| | Kuala Selangor | 15 | 9 | 60.0 |
| | Tanjung Karang | 20 | 15 | 75.0 |
| | Suboverall | 60 | 45 | 75.0 |
| SEPANG | Rumah Impianku | 15 | 10 | 66.7 |
| GRAND OVERALL | | 337 | 288 | 85.5 |

- 288 of caregivers participated in the study (85.5%).
- The response rate in each of the district ranged from 66.7% to 90.2%.



CAREGIVERS' SOCIO-DEMOGRAPHIC CHARACTERISTICS

Table 2 Caregivers' 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 Monthly Income | | |
| ≤ RM1000 | 106 | 36.8 |
| RM 1001-2000 | 102 | 35.4 |
| RM 2001-3000 | 37 | 12.8 |
| >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 |

- Majority of respondents were:
 - Mothers (97.2%)
 - Malay (79.2%)
 - Married (99.3%)
 - Housewives (72.6%)
 - Resided in rural area (62.8%)

- Majority of respondents had:
 - Some form of education (99.3%)
 - Monthly income of below RM 2000 (72.2%).
 - Less than four children (67.7%)



CHILDREN'S DEMOGRAPHIC CHARACTERISTICS

Table 3 Children'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 | 62 | 21.5 |
| Disabilities | | |

- More than half of the respondents have:
 - Male children (58.7%).
 - Children with learning disability (53.5%).
 - Children aged below ten years old (64.9%).



Distribution of the Type and Frequency of Unmet Needs among Caregivers

Table 4 Unmet needs reported by caregivers (n=288)

| Type of Need | Respondent with unmet needs n (%) |
|--|--------------------------------------|
| Information | |
| 1 Information about my child's condition or disability | 232 (80.6) |
| 2 Information about how to handle my child's behavior | 233 (80.9) |
| 3 Information about how to teach my child | 254 (88.2) |
| 4 Information on how to play with or talk to my child | 227 (78.8) |
| 5 Information on the services that are presently available | 244 (84.7) |
| 6 Information about the services my child might receive in the future | 272 (94.4) |
| 7 Information about how children grow and develop | 266 (92.4) |
| Support | |
| 8 Someone in my family that I can talk to more about problems | 182 (63.2) |
| 9 More friends that I can talk to | 199 (69.1) |
| 10 More opportunities to meet and talk with other parents | 213 (74.0) |
| 11 More time just to talk with my child's teacher or therapist | 217 (75.3) |
| 12 Meet more regularly with a counselor (psychologist, social worker, psychiatrist) to talk about problems | 162 (56.2) |
| 13 Talk more to a minister who could help me deal with problems | 130 (45.1) |
| 14 Reading material about other parents who have a child similar to mine | 220 (76.4) |
| 15 More time for myself | 131 (45.5) |
| Explaining to Others | |
| 16 How to explain my child's condition to his or her siblings | 81 (28.1) |
| 17 Explaining my child's condition to either my spouse or my spouse's parents | 68 (23.6) |
| 18 My spouse needs help in understanding and accepting our child's condition | 69 (24.0) |
| 19 How to respond when friends, neighbors, or strangers ask questions about my child's condition | 80 (27.8) |
| 20 Explaining my child's condition to other children | 94 (32.6) |

Table 4 (Continued) Unmet needs reported by caregivers (n=288)

| Type of Need | Respondent with unmet needs n (%) |
|---|--------------------------------------|
| Community Services | |
| 21 Locating a doctor who understands me and my child's needs | 172 (59.7) |
| 22 Locating a dentist who will see my child | 174 (60.4) |
| 23 Locating babysitters or respite care providers who are willing and able to care for my child | 78 (27.1) |
| 24 Locating a day care center or preschool for my child | 166 (57.6) |
| 25 Getting appropriate care for my child during religious activity | 99 (34.4) |
| Financial Support | |
| 26 Paying for expenses such as food | 190 (66.0) |
| 27 Getting special equipment for my child's needs | 155 (53.8) |
| 28 Paying for therapy, daycare, or other services my child needs | 117 (40.6) |
| 29 More counseling or help in getting a job | 47 (16.3) |
| 30 Paying for babysitting or respite care | 83 (28.8) |
| 31 Paying for toys that my child needs | 115 (39.9) |
| Family Functioning | |
| 32 Discussing problems and reaching solutions | 100 (34.7) |
| 33 Learning how to support each other during difficult times | 128 (44.4) |
| 34 Deciding who will do household chores, child care, and other family tasks | 69 (24.0) |
| 35 Deciding on and doing recreational activities | 106 (36.8) |



PERCEIVED UNMET NEEDS

- ◉ **Highest** -> Need for information of services that the child might receive in the future (94.4%) and ways to promote child growth and development (92.4%).
- ◉ Supported by other studies: Bailey and Simeonsson (1988) and Farmer et al., (2004).
- ◉ The mean score of the overall unmet needs was 18.67 (\pm SD 7.623).

Table 5 Descriptive analysis of unmet needs in each subscale

- ◉ According to subscale:

| Subscale | % of Caregivers with Unmet Needs |
|----------------------|----------------------------------|
| Information | 98.3 |
| Support | 93.4 |
| Community Services | 84.0 |
| Financial | 79.9 |
| Family Functioning | 61.8 |
| Explaining to Others | 46.2 |



PERCEIVED UNMET NEEDS

- These findings show that:
 - Issues related to information about services becomes more important as the child gets older.
 - Explanation: caregivers concern and worry about the ongoing care for the child in the future, especially if the caregivers pass away (Lam and Mackenzie, 2002).
 - Need for information remains largely unmet
 - Explanation: caregivers failed to get help and have no idea where to acquire the information needed (Sloper and Turner, 1992).



CONCLUSION

- The unmet needs among caregivers were varied.
- More effective intervention programs are needed in CBR centre to match or reduce those varied unmet needs.



RECOMMENDATION

- The provision of information should be optimized.
- Information should be delivered in several ways.



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