

# Psychological health of mothers caring for mentally disabled children in Qatar

Mohamed G. Al-Kuwari, MBBS, CABCM.

## ABSTRACT

**Objectives:** To compare the prevalence of psychiatric morbidity among mothers of mentally disabled children and mothers of non-disabled children, and to identify the determinants associated with psychiatric morbidity.

**Methods:** A comparative cross-sectional study was conducted in Qatar from January to June 2005 to compare the prevalence psychiatric morbidity by using the General Health Questionnaire (GHQ-12) among 195 mothers of mentally disabled children selected as a study group, and 139 mothers with non-disabled children as a comparison group.

**Results:** The prevalence of psychiatric morbidity was higher among mothers caring for mentally disabled children than mothers of non-disabled children in the comparison group. The study found the following predictors for developing psychiatric morbidity: having more than one disabled child, mentally disabled child less than 5 years of age, disabled child is first in order of birth, presence of chronic illness in addition to the mental disability, and presence of other type of disability besides the mental one. We also found that educating mothers in caring for a disabled child has a protective effect on developing psychiatric morbidity.

**Conclusion:** Mothers of mentally disabled children have poorer psychological health than mothers of non-disabled children. Shifting the rehabilitation services from child-centered to family-centered services through providing supportive services is recommended.

*Neurosciences 2007; Vol. 12 (4): 312-317*

*From the Springfield University Hospital, Wandsworth Primary Care Trust, London, United Kingdom.*

*Received 2nd February 2007. Accepted 30th May 2007.*

*Address correspondence and reprint request to: Dr. Mohamed G. Al-Kuwari, Public Health Medicine Specialist, Public Health, Wandsworth Primary Care Trust, Lupin Ward, Jasmine Tower, 61 Glenburnie Road, London SW17 7DJ, United Kingdom. Tel. +44 (208) 6825967. Fax. +44 (208) 6825936. E-mail: drmgalkuwari@hotmail.com*

The World Health Organization (WHO) reports that the overall prevalence of mental disability is 1-3%.<sup>1</sup> Literature reports that mental disability produces psychological, physical, social, and financial distress to the whole family, particularly parents, as they are virtually the only constant carers.<sup>2</sup> Mothers of those children showed more psychological distress than other member in their families, as they are the primary caregivers for their children.<sup>3,4</sup> The mothers of mentally disabled children showed significantly more psychiatric morbidity and stress than mothers of normal children, but fathers did not show the same deleterious effect on psychological health, which may be related to the differing responsibility assigned to child rearing for each parent, as the literatures showed that fathers are less involved in caregiving activities.<sup>5-8</sup> Research has revealed that psychiatric morbidity (depression, anxiety, experiencing high levels of stress) are common among mothers of mentally disabled children. Studies from different countries on parents of children with disabilities suggested that 35-53% of mothers of children with disabilities have symptoms of depression.<sup>9</sup> This study aims to compare the prevalence of psychiatric morbidity among mothers of mentally disabled children and mothers of non-disabled children in Qatar and to identify the determinants of psychiatric morbidity among mothers of mentally disabled children.

**Methods.** This comparative study was conducted between January and June 2005. The study recruited 2 groups of mothers with mentally disabled children and mothers of non-disabled children in Qatar, which is located in the Arabian Gulf with a population of more than 724,125, approximately 90% of which live in Doha. To conduct this study, permission and ethical approval was obtained from the Research Committee of Hamad Medical Corporation, and informed consent was obtained from each subject. Mothers of disabled children from 4 special education centers in Doha were selected as study groups based on the following inclusion criteria: Mothers with at least one child <15 years, diagnosed by a pediatrician as mentally disabled with a level of intelligence (IQ) <70, or has a known disease that is associated with mental disability, the mother must not have been diagnosed as a psychiatric case before her first

mentally disabled child was born. For the comparative group, 139 mothers of non-disabled children who met the following inclusion criteria were included: Mothers with children free from any mental, physical, sensory, and emotional disability, and attending the pediatric clinic in one of the selected primary health care centers. All subjects in both groups should speak and write in Arabic. Accordingly, all 223 mothers who met eligibility criteria in all 4 institutes were selected as a study group. Every mother was contacted by invitation letter from her child's educational center to attend an interview. For the comparison group, a multi-stage sampling technique was adopted as follows: in the first stage, random sampling was used to select 4 health centers out of 10 health centers located in Doha and its outskirts listed in sampling frame list. The sample size was divided proportionally between the selected health centers according to their population density. In the second stage, 5 working days from Sunday to Thursday was sorted into 2 strata (morning shift and evening shift), and from each stratum we selected one day, namely, one day morning and one day evening for each PHC center, and a cluster of mothers attending the general pediatric clinic on the selected day and shift that met the inclusion criteria of the comparison group were recruited. The 12 items General Health Questionnaire (GHQ-12) and structured questionnaire were administered to each subject. The Arabic version of the GHQ-12 was validated by El-Rufai & Daradkeh,<sup>10</sup> and the best cut-off point was 15/16 with a sensitivity of 0.88 and a specificity of 0.84. Every subject filled the GHQ-12 by herself and the total score was calculated out of 36. The questionnaire consisted of 3 parts: the first part covered maternal personal data, including: age, marital status, educational level, occupation, income, and number of disabled children she cares for. The second part covered the child's demographic data and medical history, including: age, gender, birth order, presence of other types of disability, and number of chronic health problems. Chronic health problems in this study were determined by the presence of one of the following diseases: congenital heart disease, chronic respiratory diseases, for example, bronchial asthma, cystic fibrosis, epilepsy, diabetes mellitus, chronic renal diseases, hemoglobinopathies, and childhood tumor. The third part covered utilization of supportive services such as: receiving education or training in caring for a disabled child, or participating in parental support group and counselling program, presence of a formal helper or nurse at home, and going to a rehabilitation school or day-care on a daily bases (5 days a week).

The Statistical Package for Social Sciences, version 10.00 for windows (SPSS-10) was used for data entry with appropriate coding. Mann-Whitney U test was

used for comparison of 2 means, while Chi-square was used to evaluate the difference between proportion and categorical variables. Statistical level of significance was taken as 0.05 and 95% confidence interval (CI) was calculated. The binary logistic regression was used to assess strength of association between the dependent and independent variables under study. Odds ratio (OR) and CI were calculated in logistic regression analysis.

**Results.** Out of 223 mothers of mentally disabled children that met the eligibility criteria of the study group, 197 subjects participated in the study with a response rate of 88.3%. From participating mothers, 2 cases were excluded due to their history of psychiatric illness before their disabled children were born. At the end, a total of 195 mothers of children with mental disability were assigned as a study group, and 139 mothers of non-disabled children were selected as a comparison group. Table 1 shows the socio-demographic characteristics of both the study and comparison groups. The study group was older than the comparison group ( $p < 0.05$ ), and most mothers in both groups were currently married. The educational level was lower in the study group ( $p < 0.05$ ). The prevalence of psychiatric morbidity was higher in the study group (87 [44.6%]) compared with the comparison group (26 [18.7%]) ( $p = 0.001$ ), with a total prevalence of 33.8%. Mothers of mentally disabled children with psychiatric morbidity were significantly younger (mean  $\pm$  SD = 36.15  $\pm$  6.66 years) than mothers of disabled children without psychiatric morbidity (mean  $\pm$  SD = 39.51  $\pm$  6.88 years) ( $p = 0.002$ ). Also, the percentage of psychiatric morbidity among mothers of disabled children was higher among mothers who have more than one disabled children, than those mothers who are caring for only one disabled child ( $p = 0.019$ ) as shown in Table 2. Other characteristics such as marital status, educational level, and socio-economic status did not show any statistical significance. Table 3 shows the distribution of psychiatric morbidity among mothers with mentally disabled children according to the child's characteristics. For the utilization of the supportive services designed for mothers of disabled children. The distribution of psychiatric morbidity among mothers with mentally disabled children according to their utilization of supportive services is shown in Table 4, and illustrates that psychiatric morbidity is lower in mothers who received education and training services in caring for disabled children and in mothers who sent their disabled children to school or day-care on a daily basis. However, having a formal helper or participating in support group services had no significant effect on psychiatric morbidity. The most significant predictors in the final best-fit model of logistic regression showed that mothers who have more than one disabled child

**Table 1** - Distribution of socio-demographic characteristics of the study and comparison groups.

Socio-demographic characteristics	Study group (N=195)	Comparison group (N=139)	Total (N=334)
	n (%)	n (%)	n (%)
Maternal age (mean+ SD)	38.0±6.9	33.9±6.4	
<i>Current marital status</i>			
Currently married	184 (94.4)	133 (95.7)	317 (94.9)
Unmarried (divorced/widowed)	11 (5.6)	6 (4.3)	17 (5.1)
<i>Educational level</i>			
Primary	34 (17.4)	7 (5.0)	41 (12.3)
Intermediate	21 (10.8)	11 (7.9)	32 (9.6)
Secondary	60 (30.8)	42 (30.2)	102 (30.5)
University and further	80 (41.0)	79 (56.8)	159 (47.6)
<i>Occupational status</i>			
Working or studying	60 (30.8)	54 (38.8)	114 (34.1)
Housewife	135 (69.2)	85 (61.2)	220 (65.9)
<i>Total monthly income in Qatari Riyals</i>			
<5,000	56 (28.7)	34 (24.4)	90 (26.9)
5,000-9,999	64 (32.8)	40 (28.8)	104 (31.1)
10,000- 14,999	38 (19.5)	40 (28.8)	78 (23.4)
≥15,000	37 (19.0)	25 (18.0)	62 (18.6)

**Table 2** - Distribution of psychiatric morbidity among mothers with mentally disabled children according to their characteristics.

Maternal variable	Presence of minor psychiatric morbidity	
	Psychiatric cases n (%)	Non-psychiatric cases n (%)
<i>Marital status</i>		
Currently married (n=185)	82 (44.3)	103 (55.7)
Currently not married (n=10)	5 (50.0)	5 (50.0)
<i>Educational Level</i>		
Primary (n=34)	9 (26.3)	25 (73.5)
Intermediate (n=21)	9 (42.9)	12 (57.1)
Secondary (n=60)	32 (53.3)	28 (46.7)
University (n=80)	37 (46.3)	43 (53.7)
<i>Occupational status</i>		
Working or studying (n=60)	30 (50.0)	30 (50.0)
Housewife (n=135)	57 (42.2)	78 (57.8)
<i>Monthly income in Qatari Riyals</i>		
<5,000 (n=56)	23 (41.1)	33 (58.9)
5,000- 9,999 (n=64)	34 (53.1)	30 (46.9)
10,000- 14,999 (n=38)	16 (42.1)	22 (57.9)
≥15, 000 (n=37)	14 (37.8)	23 (62.2)
<i>Number of disabled children within the family*</i>		
One (n=175)	73 (41.7)	102 (58.3)
Two or more (n=20)	14 (70.0)	6 (30.0)

\* $\chi^2 = 4.723$ , degrees of freedom = 1,  $p$ -value=0.019

**Table 3** - Distribution of psychiatric morbidity among mothers with mentally disabled children according to their children's characteristics.

Child's variable	Presence of minor psychiatric morbidity	
	Psychiatric cases n (%)	Non-psychiatric cases n (%)
<i>Children's age*</i>		
<5 years (n=42)	28 (66.7)	14 (33.3)
5-9 years (n=56)	18 (32.1)	38 (67.9)
10-14 (n=97)	41 (42.3)	56 (57.7)
<i>Child's gender</i>		
Male (n=117)	50 (42.7)	67 (57.3)
Female (n=78)	37 (47.4)	41 (52.6)
<i>Child's birth order<sup>†</sup></i>		
1st (n=51)	32 (62.7)	19 (37.3)
2nd (n=27)	14 (51.9)	13 (48.1)
3rd or more (n=117)	45 (38.5)	72 (61.5)
<i>Child's diagnosis</i>		
Down's syndrome (n=83)	31 (37.4)	54 (62.6)
Cerebral palsy (n=62)	33 (53.2)	30 (46.8)
Autism (n=17)	7 (41.2)	11 (58.8)
Other diseases (n=33)	19 (57.6)	14 (42.4)
<i>Presence of other disability<sup>‡</sup></i>		
Yes (n=91)	52 (57.1)	39 (42.9)
No (n=104)	39 (37.5)	65 (62.5)
<i>Number of child's chronic illnesses<sup>§</sup></i>		
No chronic illness (n=109)	37 (33.9)	72 (66.1)
One chronic illness (n=61)	37 (60.7)	24 (39.3)
Two or more chronic illnesses (n=25)	19 (76.0)	6 (24.0)

\* $\chi^2 = 12.01$ , degrees of freedom (df) = 2,  $p$ -value=0.002, <sup>†</sup> $\chi^2 = 9.73$ ,  
df = 2,  $p$ -value=0.008, <sup>‡</sup> $\chi^2 = 5.08$ , df = 1,  $p$ -value <0.05,  
<sup>§</sup> $\chi^2 = 20.63$ , df = 2,  $p$ -value=0.001

**Table 4** - Distribution of psychiatric morbidity among mothers with mentally disabled children according to their utilization of supportive services.

Supportive service	Presence of minor psychiatric morbidity	
	Psychiatric cases n (%)	Non-psychiatric cases n (%)
<i>Presence of nurse or formal assistant to care for disabled child</i>		
Yes (n=48)	26 (54.2)	22 (45.8)
No (n=147)	62 (42.2)	85 (57.8)
<i>Receiving education and training on caring for a disabled child*</i>		
Yes (n=84)	29 (34.5)	55 (65.5)
No (n=111)	58 (52.3)	53 (47.7)
<i>Participating in counselling and support group activities</i>		
Yes (n=72)	25 (34.7)	47 (65.3)
No (n=123)	62 (50.4)	61 (49.6)
<i>Child goes to school or day-care daily†</i>		
Yes (n=131)	49 (37.4)	82 (62.5)
No (n=64)	45 (70.3)	19 (29.7)

\* $\chi^2 = 5.38$ , degrees of freedom (df) = 1,  $p$ -value=0.02,  
 † $\chi^2 = 13.63$ , df = 1,  $p$ -value=0.001

were approximately 4 times as likely to develop psychiatric morbidity as compared to mothers with one disabled child (OR=4.3, 95% CI=1.6-13.4). Mothers were approximately 3 times more likely to develop psychiatric morbidity if their mentally disabled children were first in order of birth (OR=2.8, 95% CI=1.3-6.0). Mothers of children with more than one disability were approximately 3 times more likely to develop psychiatric morbidity than those of children with mental disability only (OR= 2.7, 95% CI=1.3-5.3), while those who have mentally disabled children with chronic illness were approximately 2 times more likely to develop psychiatric morbidity (OR=2.2, 95% CI=1.1-4.4). Being a mother of a mentally disabled child below 5 years of age increased the risk for developing psychiatric morbidity by 2 times compared to mothers of older children (OR= 2.0, 95% CI=1.1-4.2). However, receiving training and education in caring for disabled children reduced the risk for psychiatric morbidity (OR= 0.3, 95% CI=0.1-0.6).

**Discussion.** This comparative cross-sectional study was designed to compare the psychological health status of mothers caring for mentally disabled children with mothers of non-disabled children in the Qatari society. In the present study, the prevalence of psychiatric morbidity was significantly higher among mothers of children with mental disability than mothers of non-disabled children.

This difference in prevalence of psychiatric morbidity among mothers caring for mentally disabled children was demonstrated in different studies. In a British study<sup>9</sup> the difference in prevalence was slightly smaller. It was 35% for mothers of mentally disabled children and 25% for comparison mothers by using GHQ. Also, using different psychometric tools showed similar difference in a Swedish study.<sup>11</sup> Consistent with previous research in different parts of the world; the prevalence of psychiatric morbidity among mothers with mentally disabled children was within the reported range. It was similar to the prevalence reported among Turkish,<sup>12</sup> Asian British,<sup>13</sup> and Swedish mothers,<sup>14</sup> slightly higher than the prevalence among British mothers,<sup>9</sup> and lower than the prevalence among Icelandic mothers.<sup>15</sup> Although the difference between the studies was very small, such a difference should be expected due to different types of psychometric tools used, difference in the age of children, setting of the study, geographical variation that implies difference in culture, economic status, and health care service. In general, this result indicates that mothers caring for mentally disabled children in the Qatari society have similar psychological distress that mothers in different parts of the world faced. The mothers experienced various degrees of psychological distress due to parental reaction towards irreversibility of the intellectual disability, social stigma, anticipation of future, and caring demand.<sup>16</sup>

The determination of predictors of psychiatric morbidity among mothers caring for mentally disabled children gives a clear picture of the association between independent variables and psychiatric morbidity after controlling for confounders, to help health professionals in identifying those mothers who need special attention to reduce their risk of psychological distress and restore their psychological well-being. In this study, some determinants were identified as predictors of psychiatric morbidity among mothers of mentally disabled children. Most of these predictors were child related. The strongest predictor for psychiatric morbidity was having more than one disabled child. The possibility of having maternal psychiatric morbidity increases as the number of disabled children caring for within the family increases. Mothers caring for 2 or more disabled children have a higher prevalence of psychiatric morbidity than mothers caring for only one disabled child. A similar finding was reported by Firat.<sup>12</sup> In agreement with a British study,<sup>9</sup> the current study concludes that the presence of physical disability is considered as predictor of psychiatric morbidity among mothers of mentally disabled children, but in this study the OR of this predictor was higher than that found in the British study (2.7 compared to 1.6). This association was reported by many studies,<sup>9,17-19</sup> which can be attributed to the degree

of child dependency on the mother in daily activities of life, for example, toileting, bathing, feeding, clothing, and mobility, which increase the burden of caring. It has been reported that caring for children with multiple disabilities increases the maternal caregiving hours.<sup>20</sup> The presence of chronic illness in the mentally disabled child was also found to be one of the predictors for psychiatric morbidity. The finding agreed with reports by other researchers.<sup>19,21</sup> This association can be explained by the well-documented observation that chronic illness can cause stress for the mother of the child slightly lower than that caused by disability.<sup>21</sup> Also, chronic illness increases the caregiving burden in terms of appointments, medication, and life style modification.<sup>20</sup> In addition, some chronic illnesses associated with mental disability are life-threatening illnesses, for example, congenital heart diseases, which increased parental burden. Furthermore, having a child below 5 years of age with mental disability is considered to be one of the predictors of maternal psychiatric morbidity. The study showed psychiatric morbidity more prevalent among mothers of preschool age mentally disabled children (<5 years) than mothers of children aged 5-9 years, however, this level returns to an increase among mothers of older children aged 10-14 years. Glidden and Schoolcraft<sup>22</sup> reported this trend of 2 peaks of distress in early childhood and adolescence stage in their longitudinal study.<sup>22</sup> It is well documented that there are defined transformational points for high distress for both parents of a mentally disabled child (period after diagnosis, school entry, adolescence).<sup>23</sup> The highest level of psychiatric morbidity among mothers of preschool mentally disabled children was reported in a Korean study.<sup>24</sup> This finding can be attributed to the pathway of coping process (shock, denial, depression, acceptance, and adaptation) and in these years, mothers will be in the early stage of this process and when adaptation will take place varies according to many factors in the personality and social environment. For instance, it has been found that the period just after diagnosis of a disabled child is characterized by more intense parental psychological distress.<sup>25</sup> Therefore, health professionals recommend early intervention for parental distress in this period.<sup>26</sup> Another explanation can be added that children <5 years of age are less likely to go to school or day care on a daily basis, as they go to an early intervention unit twice a week for 2 hours only accompanied by their mothers. So, they stick to their mothers for the whole day, and as a result of that burden increase, mothers do not have spare time for themselves. This explanation is supported, as it has been found by some researchers that maternal caregiving time increases as the child's age decreases.<sup>21</sup> However, the second increase in prevalence of psychiatric morbidity among mothers of children aged 10-14 years can refer

to the needs of the adolescence period in mentally disabled children, for example, behavioral changes, and controlling the child becomes more difficult as the child becomes older, and parental anticipation of the child's future. Receiving information on the disability and training in caring for a mentally disabled child reduces the risk of developing psychiatric morbidity in mothers of mentally disabled children, meaning that such an intervention has a preventive effect for psychiatric morbidity in those mothers. Many studies showed that providing adequate information on child disability and the availability of services along with caring skills training of dealing with a disabled child has a great impact on reducing the psychological distress among mothers of disabled children.<sup>27-30</sup> Taanila et al<sup>31</sup> found that Finnish parents, who received information and advice in caring for their disabled children, reported positive feelings toward caring for their children. Such an intervention may clarify the ambiguity of the situation and the future through the given information about the disability. In addition to that, it helps mothers to cope faster through the caring skills taught to them.

Apart from physical disability, this study did not find any effect of other predictors reported by other studies such as poverty, autism, lone parent, ethnicity, and gender of the disabled child.<sup>9,14</sup> This difference in predictors may be attributed to differences between the communities. Also, it failed to find any effect for some interventions such as support groups or counselling. Although mothers caring for mentally disabled children who participate in psychological support activities, such as paternal support groups or counselling, showed a low prevalence of psychiatric morbidity compared to mothers who did not participate in such activities, such an effect was not significant in logistic regression analysis. However, several studies reported that support groups reduce maternal depression and showed significant improvement in the psychological well-being of mothers.<sup>31-34</sup> In Qatar, support groups and counselling programs are newly established programs in one center only, therefore, it may need some time to be effective or the content of this program may not consider the need of the mothers. In addition, the design used in this study was unsuitable to evaluate the effect of interventions.

In conclusion, we found that psychiatric morbidity was higher among mothers of children with mental disability than mothers of non-disabled children. The strongest predictor for psychiatric morbidity is having more than one disabled child. Whereas, receiving education and training in caring for a mentally disabled child has a preventive effect. Based on these conclusions, the rehabilitation institutes should shift their services from child-centered to family-centered services by increasing awareness of health

maintenance organizations and rehabilitation centers on the importance of involving families in their services through providing psychological assessment for mothers and offering family psychological support service units within the institutes. Educational activities for parents on parenting a disabled child, the availability of services, and how to utilize them. All these services should start once the mentally disabled child is born to help the parents in coping, and should be extensively provided for mothers at more risk to develop psychiatric morbidity, such as mothers of children with multiple disabilities and chronically ill, as well as mothers of more than one disabled children and those with preschool age disabled children.

**Acknowledgment.** Sincere thanks to all rehabilitation centers and special educational schools in the State of Qatar for their cooperation in this study.

## References

- World Health Organization. Mental health around the world, world health day 2001. Geneva: WHO; 2001.
- Schwartz C, Tsumi A. Parental involvement in the residential care of persons with intellectual disability: The impact of parents' and residents' characteristics and the process of relocation. *Journal of Applied Intellectual Disabilities* 2003; 16: 285-293.
- Weiss JA, Sullivan A, Diamond T. Parent stress adaptive functioning of individuals with developmental disabilities. *Journal on Developmental Disabilities* 2003; 10: 129-135.
- Pelchat D, Lefebvre H, Perreault M. Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *J Child Health Care* 2003; 7: 231-247.
- Romaans-Clarkson SE, Clarkson JE, Dittmer ID, Flett R, Linsell C, Mullen PE, et al. Impact of a handicapped child on mental health of parents. *Br Med J (Clin Res Ed)* 1986; 293: 1395-1397.
- Moes D, Koegel RL, Shreibman L, Loos LM. Stress profiles for mothers & fathers of children with autism. *Psychol Rep* 1992; 71 (3 pt 2): 1272-1274.
- Cuskelly M, Pullan L, Hayes A. Parenting & employment decision of parents with a preschool child with disability. *Journal of Intellectual & Developmental Disability* 1998; 23: 319-332.
- Hastings RP. Child behavior problems and partner mental health as correlates of stress in mothers and fathers of children with severe autism. *J Intellect Disabil Res* 2003; 47 (Pt 4-5): 231-237.
- Emerson E. Mothers of children & adolescents with intellectual disability: social and economic situation, mental health status & the self-assessed social and psychological impact of the child's difficulties. *J Intellect Disabil Res* 2003; 47 (Pt 4-5): 385-399.
- Daradkeh TK, Ghubash R, El-Rufaie OE. Reliability, validity, and factor structure of the Arabic version of the 12-item General Health Questionnaire. *Psychol Rep* 2001; 89: 85-94.
- Olsson MB, Hwang CP. Depression in mothers and fathers of children with intellectual disability. *J Intellect Disabil Res* 2001; 45 (pt 6): 535-543.
- Firat S, Diler RS, Avcı A, Seydaoglu G. Comparison of psychopathology in the mothers of autistic and mentally retarded children. *J Korean Med Sci* 2002; 17: 679-685.
- Emerson E, Robertson J, Wood J. Levels of psychological distress experienced by family carers of children and adolescent with intellectual disabilities in an urban conurbation. *Journal of Applied Intellectual Disabilities* 2004; 17: 77-84.
- Olsson MB, Hwang CP. Sense of coherence in parents of children with different developmental disabilities. *J Intellect Disabil Res* 2002; 46 (pt 7): 548-559.
- Guethmundsson OO, Tomasson K. Quality of life and mental health of parents of children with mental health problem. *Nord J Psychiatry* 2002; 56: 413-417.
- Pelchat D, Ricard N, Bouchard J-M, Perreault M, Saucier J-F, Berthiaume M, et al. Adaptation of parents in relation to their 6-month-old infant's type of disability. *Child Care Health Dev* 1999; 25: 377-397.
- Manuel J, Naughton MJ, Balkrishnan R, Paterson Smith B, Koman LA. Stress and adaptation in mothers of children with cerebral palsy. *J Pediatr Psychol* 2003; 28: 197-201.
- Slooper P, Turner S. Risk and resistance factors in adaptation of parents of children with severe physical disability. *Child Psychol Psychiatry* 1993; 34: 167-188.
- Silver EJ, Westbrook LE, Stein RE. Relationship of parental psychological distress to consequences of chronic health conditions in children. *J Pediatr Psychol* 1998; 23: 5-15.
- Bouma R, Schweitzer R. The impact of chronic childhood illness on family stress: a comparison between autism and cystic fibrosis. *J Clin Psychol* 1990; 46: 722-730.
- Brust JD, Leonard BJ, Sielaff BH. Maternal time and the care of disabled children. *Public Health Nurs* 1992; 9: 177-184.
- Glidden LM, Schoolcraft SA. Depression: its trajectory and correlates in mothers rearing children with intellectual disability. *J Intellect Disabil Res* 2003; 47 (pt 4/5): 250-263.
- Hastings R, Beck A. Practitioner Review: Stress intervention for parents of children with intellectual disabilities. *J Child Psychol Psychiatry* 2004; 45: 1338-1349.
- Yim SY, Moon HW, Rah UW, Lee IY. Psychological characteristics of mothers of children with disabilities. *Yonsei Med J* 1996; 37: 380-384.
- Hill-Smith AJ, Hollins SC. Mortality of parents of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 2002; 15: 18-27.
- Pelchat D, Lefebvre H. A holistic intervention programme for families with a child with a disability. *J Adv Nurs* 2004; 48: 124-131.
- Law M, Hanna S, King G, Hurley P, King S, Kertoy M, et al. Factors affecting family-centered service delivery for children with disabilities. *Child Care Health Dev* 2003; 1: 1-10.
- Redmond B, Richardson V. Just getting on with it: Exploring the service needs of mothers who care for young children with severe/profound and life-threatening intellectual disability. *Journal of Applied Research in Intellectual Disabilities* 2003; 16: 205-218.
- Kelly B, Monteith M. Supporting disabled children and their families in Northern Ireland: A research and policy review. London (UK): National Children's Bureau & Joseph Rowntree Foundation; 2003.
- Taanila A, Syrjälä L, Kokkonen J, Järvelin M. Coping of parents with physically and/or intellectually disabled children. *Child Care Health Dev* 2002; 28: 73-86.
- Taanila A, Järvelin MR, Kokkonen J. Parental guidance by doctors and nursing staff: parents view of initial information and advice for families with disabled children. *J Clin Nurs* 1998; 7: 505-511.
- Singer GH, Irvin LK, Hawkins N, Cooley E. Evaluation of community-based support service for families of persons with severe handicaps. *Journal of the Association for Persons with Severe Handicaps* 1998; 14: 312-323.
- Schultz CL, Schultz NC, Bruce EJ, Smyrnios KX, Carey LB, Care CL. Psychoeducational support for parents of children with intellectual disability: An outcome study. *International Journal of Disability, Development and Education* 1993; 40: 205-216.
- Baine S, Rosenbaum P, King S. Chronic childhood illness: what aspects of caregiving do parents value? *Child Care Health Dev* 1995; 21: 291-304.