



A COMPARISON OF THE BURDEN AMONG IRANIAN FAMILIES OF CHILDREN WITH MENTAL, PHYSICAL, AND HARD-OF-HEARING DISABILITIES

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ARTICLE INFO

Article History:

Received 10th, September, 2013

Received in revised form 25th, September, 2013

Accepted 15th, October, 2013

Published online 28th, October, 2013

Key words:

Burden, Caregivers, Children, Mental retardation, Mothers, Hard-of-hearing, Physical disability

ABSTRACT

Background: Caregivers of children with disabilities have reported a tremendous burden in caring for these children. A number of studies have been performed on families of retarded children. The purpose of this study is to measure the burden in family caregivers of hard-of-hearing, physically disabled and retarded children in Zanjan, Iran.

Methods: The Family Burden Interview Scale (FBIS) was administered to 104 mothers of these children.

Results: Findings showed that family caregivers of these children have a great burden. Additionally, it was shown significant difference among burden of these caregivers group.

Conclusion: Caregivers of children with disabilities were at risk of tremendous burden. Further research with different and larger sample size is needed to determine deferent burden of them to provide reliable information for social and psychological centers.

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INTRODUCTION

Human beings are influenced by interactions as well as their situation in the world. The physical, social and emotional functioning of family members is deeply interdependent, with changes in one part reflected in other areas (Pilusa, 2006). The presence of a disabled family member irrevocably changes the family unit and affects all individual members. Areas that may be affected include family relationships, finances, social, recreational life, household functioning, caregiving demands and siblings (Guyard, *et al.*, 2012; Miller, Macon, Gaboda, & Cantor, 2012; Mudhovozi, Maphula, & Mashamba, 2012; Pilusa, 2006). In this context, parents as primary caregivers, are affected deeply and face different burdens (Graungaard & Skov, 2007; Guyard, *et al.*, 2012; Masterson, 2010). For example, in terms of mental burden, most caregivers of disabled children report tremendous stresses (Ambikile & Outwater, 2012; Mitchell & Hauser-Cram, 2008; Parkes, Caravale, Marcelli, Franco, & Colver, 2011; Pousada, *et al.*, 2013; Sawyer, *et al.*, 2011) which in turn causes other mental disorders such as depression (Pousada, *et al.*, 2013; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Singer & Floyd, 2006; Weiss, 2002), anxiety (Rudolph, Rosanowski, Eysholdt, & Kummer, 2003) social isolation (Lam & Mackenzie, 2002; Olsson & Hwang, 2003; Seltzer, *et al.*, 2001), and marital problems (Berge, Patterson,

& Rueter, 2006; Rajabi, Arjmandnia, & Nojani, 2012). There is also an impact on employment as seen with low rates of employment or delayed entry into the workforce (Lam & Mackenzie, 2002; Seltzer, *et al.*, 2001) among caregivers. There are few studies regarding the burdens and needs of caregivers. Controversy exists within studies about the burdens and needs of caregivers. On the other hand, professionals and policy makers need precise information regarding each type of burden and the needs of the caregivers to establish suitable intervention programs. Hence, an investigation of the burden in each group and its components seems necessary.

Mental retardation is a developmental disability that first appears in children under the age of 18 years. It is defined as a level of intellectual functioning, as measured by standard intelligence tests, that is well below average (an IQ score below 70-75). Mental retardation results in significant limitations in a person's daily living skills (adaptive functioning) and mostly persists throughout the adult life. Adaptive skills refers to skills necessary for daily life. Such skills include the ability to produce and understand language (communication); home-living skills; use of community resources; health, safety, leisure, self-care, and social skills; self-direction; functional academic skills (reading, writing, and math); and job-

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related skills (Encyclopedia of Mental Disorders). Due to the problems of the mentally retarded, they commonly rely on assistance from caregivers, which results in a different burden on caregivers (Ambikile & Outwater, 2012; Ferguson, 2002; Hedov, Annerén, & Wikblad, 2002; Mitchell & Hauser-Cram, 2008; Mudhovozi, *et al.*, 2012).

Hard-of-hearing children, as another group of disabled children, commonly have speech disorders which, in turn, cause problems in other aspects of their lives such as social, cultural, family, linguistics, academic and changes in their developmental trajectory. These problems greatly affect the family unit and results in additional burdens for family members, particularly caregivers who report high-levels of physiological disorders (Barker, *et al.*, 2009; Dehkordi, Kakojoibari, Mohtashami, & Yektakhah, 2011; Hauser, Wills, & Isquith, 2006; Rajendran & Roy, 2011).

Physically disabled children have significant limitations, impairments, or delays in the physical capacity to move, coordinate actions, or perform physical activities. Their disability presents itself by difficulties in one or more of the following areas: physical and motor tasks, independent movement, and performance of basic life roles. Physical disabilities include severe orthopedic impairments or impairments caused by congenital anomalies, cerebral palsy (CP), amputations, and fractures. Children with these disabilities frequently rely on assistive devices such as wheelchairs, crutches, canes, and artificial limbs for mobility (Kirk, Gallagher, & Coleman, 2011). Because of functional limitations their daily performances, in particular educational performances, are adversely affected which leads to a high burden on caregivers (Hung, Wu, Chiang, Wu, & Yeh, 2010; Parkes, *et al.*, 2011; Siebes, *et al.*, 2007; Wiegner & Donders, 2000). Piškur and colleagues (2012) has reviewed 46 articles which showed that caregivers of children with CP tend to have high levels of stress and depression, and lower quality of life compared to parents of healthy children. Child behavior and cognitive problems, low caregiver self-efficacy and low social support are some factors consistently related to higher levels of stress and depression in their caregivers (Arango-Lasprilla, *et al.*, 2010; Piškur, *et al.*, 2012; Pousada, *et al.*, 2013; Vargus-Adams & Martin, 2009). These psychological problems may limit the role of caregivers in the management of the child's illness (Bartlett, *et al.*, 2004).

Additionally, a significant financial burden often presents among families of children with disabilities (Ambikile & Outwater, 2012; Honeycutt, *et al.*, 2003). The extra costs for disabled children for travel, domestic help, medical care, and health care expenses (hospital care, physician services, dentistry, and drugs) are worrisome. Regular, active participation by parents during all phases of treatment for the physically disabled is time-consuming. In some cases, full-time care is necessary which limits the parents' ability to earn income outside the home and reduces their financial resources (Kruse, *et al.*, 2009; Lindley & Mark, 2010; Xiong, *et al.*, 2010). A study in South India has reported the mean annual expenses of families with severely disabled children at \$254, which was significantly higher than the same annual expenses of \$181 for families with normal children. Mothers of the disabled children 21% were unemployed compared to 12% for normal children. Hence parents of disabled children needed on average an extra \$ 203 annually as social security payments from the government to meet the essential needs of

their disabled children (Kandamuthan & Kandamuthan, 2004). In a study by Xiong and colleagues (2010) families of physically and mentally disabled children required more economic assistance than normal children. Studies have shown that the more children a family had, the less economical support the family received (Honeycutt, *et al.*, 2003; Kruse, *et al.*, 2009; Xiong, *et al.*, 2010). The majority of studies that pertain to the needs of caregivers of disabled children have been conducted in Western countries (Olsson & Hwang, 2003). In Iran, there are few studies regarding the burdens of families with disabled children. Dehkordi and colleagues (2011) have shown a significant difference between stress levels of mothers of hearing-impaired children compared to mothers of other disabled and normal children in the subscales of intra-family stress, finance and business strains, stress of job transitions, stress of illness. The family is considered to be a nuclear entity in many countries, thus the disability of one of the children can often bring about adverse consequences for the family, each member and their various functions. An insight into these issues may improve quality of the interventions enabling policy makers to precisely program, manage services, and equitably divide resources dependent on the priority of each disability. Thus, this study aims to examine the total burden of each disability, the components of this burden, and the relationship between disability and burden in three groups of disabled children, namely, mentally, physically and hard of hearing.

MATERIALS AND METHODS

Participants

In this study, 104 mothers of disabled children who attended a special school in Zanjan, Iran were chosen to participate by the consensus method. There were 38 mothers whose children had mental retardation, 33 mothers of physically disabled children and 33 mothers of children with hard of hearing disorders.

Instruments

Participants completed a 24-item Family Burden Interview Scale (FBIS). This scale is comprised of 24 items grouped into 6 areas of burden: 1) financial burden 2) disruption of routine family activities 3) disruption of family leisure 4) disruption of family interactions 5) effect on physical health of others and 6) effect on mental health of others. Each item is rated on a 3 point scale, of 0 (no burden) to 2 (severe burden). Global burden was determined according to the severity of the burden experienced and rated as no, moderate and severe. Reliability of the questionnaire was verified in various studies. The internal consistency of the questionnaire according to Chronbach's alpha was estimated at 0.72. Validity assessments have shown moderate-to-strong psychometric properties. In this study consistency of the scale according to Chronbach's alpha was estimated at 0.87.

Data analysis

This study used one-way ANOVA to compare the burden subscales of financial burden, disruption of routine family activities, disruption of family leisure, disruption of family interactions, effect on physical health of others and the effect on mental health of others among the three groups. Statistical Package for the Social Sciences (SPSS 20) software package

was used for analysis of the data obtained from the study. A p-value of <0.05 was considered statistically significant.

RESULTS

Table one shows that families of children with physical disabilities, mental retardation and hard-of-hearing bear a heavy mental burden. Among these three groups, families of children with physical disabilities in the five sub scales of financial burden, disruption of family leisure, disruption of family interactions, effect on physical health of others and effect on others' mental health showed the highest amount of mental pressure. In the disruption subscale of routine family activities, families of mentally retarded children had the maximum burden. According to Table 2 there was no significant difference between these three groups in terms of the cited subscales as well as general pressure. The pressure noted in the mentally retarded and physically disabled groups in these subscales was much higher than that observed in the hearing impaired group. Therefore, all three groups were compared together and the difference is significance.

Table 1 Means, Standard Deviations of three groups

Type of disability		M	SD
Mental retardation		7.05	6.54
Speech disorder	Financial burden	6.87	2.14
Physical disability		8.6	3.47
Mental retardation	Disruption of routine family activities	4.44	3.79
Speech disorder		2.78	3.69
Physical disability		4.63	2.13
Mental retardation	Disruption of family leisure	4.34	6.72
Hard-of-hearing		2.03	1.97
Physical disability		3.12	2.6
Mental retardation	Disruption of family interactions	4.39	2.39
Hard-of-hearing		3.75	3
Physical impairment		5.54	4.24
Mental retardation	Affect on physical health of others	2.13	5.82
Hard-of-hearing		1.24	1.37
Physical impairment		2.3	1.55
Mental retardation	Effect on mental health of other	3.86	3.05
Hard-of-hearing		2.93	1.63
Physical impairment		3.93	1.47
Mental retardation	Total burden	26.23	24.61
Hard-of-hearing		19.63	10.84
Physical impairment		28.15	11.54

M= Mean, SD= Standard Deviation

DISCUSSION AND CONCLUSION

The health and well-being of children have a direct impact on families' health and well-being(Murphy, *et al.*, 2011; Pilusa, 2006). Thus, living with a disabled child adversely affects a family's life, bringing problems in various domains such as impacts on time, expenses, work, relationships within the family, as well as social, physical and psychological health (Guyard, *et al.*, 2012; Lukens, Thorning, & Lohrer, 2002; Mudhovozi, *et al.*, 2012). Policy makers and professionals should create sufficient interventions and programs, as well as manage resources and services. To achieve this purpose, it is necessary to investigate different burdens experienced by caregivers of disabled children(Navidian & Zaheden, 2008). Mental retardation, hard-of-hearing and physical impairments are prevalent disabilities among children (Burkhard, 2011; Sethi, Bhargava, & Dhiman, 2013) which impacts differently on their Physical and mental health(Baker, *et al.*, 2003; Brown & Turner, 2010; Crowe, 2003; Rajabi, *et al.*, 2012; Sethi, *et al.*, 2013) and consequently impacts their caregivers (Gau, Chiu, Soong, & Lee, 2008; Mudhovozi, *et al.*, 2012; Navidian & Zaheden, 2008; Pilusa, 2006).This study has determined the burden of the three groups of disabled children's' caregivers, showed the relationship between their type of disability and the burdens, and compared the burdens of these three groups.

The present research has shown that caregivers of disabled children were faced with different burdens of care. This study also showed that caregivers of physically disabled, retarded and hard-of-hearing children had a high amount of burden for which there was no significant difference in burden among these groups. Our findings were consistent with many research (Ambikile & Outwater, 2012; Baker, *et al.*, 2003; Barker, *et al.*, 2009; Bartlett, *et al.*, 2004; Brownlie, *et al.*, 2004; Dehkordi, *et al.*, 2011; Guyard, *et al.*, 2012; Hauser, *et al.*, 2006; Hedov, *et al.*, 2002; Hintermair, 2006; Honeycutt, *et al.*, 2003; Hung, *et al.*, 2010; Lam & Mackenzie, 2002; Rudolph, *et al.*, 2003; Sawyer, *et al.*, 2011; Seltzer, *et al.*, 2001; Shearn & Todd, 2001; Singer & Floyd, 2006; Vecchio, Cybinski, & Stevens, 2009; Xiong, *et al.*, 2010).

Table 2 Comparison of burden among caregivers of physically disabled, mentally disabled and hard of hearing children

Family of	subscales	F	DF	p	
Mental retardation	Financial burden	1.448	2,101,103	0.24	>0.05
Hard-of-hearing					
physical impairment					
Mental retardation	Disruption of routine family activities	3.14	2,101,103	0.048	> 0.05
Hard-of-hearing					
physical impairment					
Mental retardation	Disruption of family leisure	2.37	2,101,103	0.098	>0.05
Hard-of-hearing					
physical impairment					
Mental retardation	Disruption of family interactions	2.54	2101103	0.083	> 0.05
Hard-of-hearing					
physical impairment					
Mental retardation	Effect on physical health of others	0.786	2,101,103	0.458	> 0.05
Hard-of-hearing					
physical impairment					
Mental retardation	Effect on physical health of others	2.106	2,101,103	0.127	> 0.05
Hard-of-hearing					
physical impairment					
Mental retardation	Total burden	2.204	2,101,103	0.116	> 0.05
Hard-of-hearing					
physical impairment					

In the current study, caregivers of all three groups had high burdens in the financial burden, disruption of routine family activities, disruption of family leisure, disruption of family interactions, effect on physical health of others, effect on mental health of others, and in total burden. There was no relationship between type of disability and burden. The presence of disabled children in a family is burdensome. Caregivers from all three groups have shown high financial burden in the financial subscale which was consistent with other studies. Honeycutt et al. (2003) stated that caregivers of disabled children commonly faced financial expenses such as travel, domestic help, medical and health care (hospital care, physician services, dentistry, and medications). Regular, active participation by caregivers during all phases of treatment are time-consuming. Disabled children need full-time care that limits the ability of caregivers to earn income outside the home, leading to a decrease in their financial resources (Ambikile & Outwater, 2012; Honeycutt, et al., 2003; Kruse, et al., 2009; Lindley & Mark, 2010). Although all three groups have shown high amounts of financial burden, the physically disabled group scored the highest. Caregivers of physically disabled children not only pay for their children's routine medical expenses, however due to the functional limitations of these children, caregivers have additional expenditures for special devices which are expensive. For example, special wheelchair lifts and vans to transport physically disabled children can range in price from \$5000 to \$30000 (Honeycutt, et al., 2003; Steele & Davies, 2006; Xiong, et al., 2010). The functional limitation of such children requires full time care that decreases the hours a caregiver can work, therefore affecting the entire family's financial well-being (Heck & Makuc, 2000).

Furthermore, family members preoccupied with financial burden may be distracted and less attentive to the child's care needs (Kristjanson, et al., 1998). The financial burden may have a long-term impact on the financial security, quality of life, and future well-being of the entire family (Miedema, Easley, Fortin, Hamilton, & Mathews, 2008). The results of this study indicated that all three groups of caregivers showed high disruption in their activities, leisure time and interactions, which was consistent with other studies (Ambikile & Outwater, 2012; Lam & Mackenzie, 2002). Caregivers of disabled children have to assist their children in activities of daily living, which include feeding, dressing, lifting, and transporting. This leads to fatigue and neglect of the caregiver's own routine activities and leisure time. Day-to-day care of disabled children limits both the caregiver's time and their own routines. This research confirmed studies by researchers who stated that while caregivers consistently concentrated on fulfilling the needs of their disabled children the caregivers did not spend time for themselves (Perkins & Haley, 2010). As a result, caregivers experience exhaustion and fatigue. This fatigue is the source of unwillingness to participate in social activities, relations with friends, and interactions with others. Finally, this trend in life can lead to mental and physical problems in caregivers. Lam et al. (2002) found that caregivers of retarded children have devoted more time to child care and spent less time on social activities which in turn increased their risk for mental and physical problems (Ambikile & Outwater, 2012; Dehkordi, et al., 2011; Hedov, et al., 2002; Hintermair, 2006; Lukens, et al., 2002; Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002;

Piškur, et al., 2012; Rudolph, et al., 2003; Sawyer, et al., 2011; Seltzer, et al., 2001; Shearn & Todd, 2001; Siebes, et al., 2007; Singer & Floyd, 2006; Vecchio, et al., 2009; Weiss, 2002; Wiegner & Donders, 2000).

Some findings have shown that a number of disabled children have high amounts of behavior problems that adversely affected caregivers mental health (See: Baker, et al., 2003; Barker, et al., 2009; Gau, et al., 2008; Mudhovozi, et al., 2012; Pousada, et al., 2013; Raina, et al., 2005; Rajabi, et al., 2012). In the disruption of routines activities subscale, caregivers stated that behavior problems of their children not only affected their own mental health, but it also adversely affected other family members. According to the results of this study, it can be stated that a high amount of burden exists among caregivers of physically disabled, retarded and hard of hearing children that can be attributed to their special needs. The results reinforce the need to decrease caregiver burden and has highlighted the importance of policy maker's attention in order to provide sufficient interventions and services to families of disabled children. Limitations of this research included the small number of participants, as the population of families with disabled children in Zanjan is small. Zanjan is a small city compared to other cities in Iran which does not have suitable resources and services for disabled children and their caregivers. Hence the caregivers of disabled children lack adequate services. Therefore, generalizing the results of the present study needs caution.

Acknowledgments

The authors of the present research wish to express special thanks to the mothers of these children who took time from their busy lives to take part in this study.

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