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Investigating the Relationship between Caregiver Burden and Demographics among the Mothers of Children with Intellectual Disability

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ABSTRACT

Mothers have been introduced as the best source to care for the children with intellectual disability; however, they have faced many problems such as caregiver burden. The current study was conducted to determine the relationship between caregiver burden and demographics among the mothers of children with intellectual disability supported by Elahi Rehabilitation Center. This is a descriptive-correlation study in which the convenience sampling method was used to select 60 mothers of children with intellectual disability at Elahi Rehabilitation Center in Quchan. All of the subjects met the inclusion criteria. The data collection tools were the demographics questionnaire and Caregiver Burden Inventory (CBI). Then SPSS 20 was employed to analyze data. According to the research findings, the mean of caregiver burden score was 76.93 (22.70) for mothers. This score was above the average level in 51.70% of mothers. Moreover, there was no statistically significant relationship between caregiver burden and the demographics of mothers except for an underlying disease among children. Different demographics of mothers of children with intellectual disability did not influence the level of caregiver burden in most cases. The physical and emotional impacts of caregiving were probably greater than individual differences. It is advised to conduct this study on more subjects.

Key words: Caregiver; Burden; Children; intellectual Disability

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INTRODUCTION

Intellectual disability is a series of disorders which cause cognitive limitation[1]. Due to complications and high prevalence, it is considered one of the common growth disorders, insofar as its prevalence is 3% in the general population. Approximately, there are 1200000 intellectually disabled individuals in Iran [2]. In addition to the high prevalence, the intellectually disabled individuals may show misbehaviors with a large number of emotional and mental problems in comparison with the general population[1]. Basically, intellectual disability is accompanied by growth failure in different physical, mental, developmental, social and educational aspects. The intellectually disabled children are weak at learning the expected tasks, and parents usually fail to train them in new skills and inhibit inappropriate behaviors, a fact which requires more efforts to make parents accept and adapt to the reality in comparison with normal children[3]. Furthermore, caregivers face more familial challenges including heavy financial burden and physical-mental problems[4]. Larson (2014) believes that dealing with the daily limitations and stress of life can negatively influence the health and welfare of caregivers of children with disability, and mothers experience more stress[5]. A mother is the first person who makes contacts with a child directly. Feelings of guilt and fault or frustration and deprivation resulting from the abnormality of children can make her dissociable and unwilling to communicate with the environment. These feelings can also make her feel less self-esteemed, inferior, valueless and sorrowful, a fact which leads to low self-esteem and depression threatening her mental health [6]. The mothers of children with intellectual disability may become completely frustrated and worried about their children's problems after emerging negative feelings about their abilities to fulfill goals and lose hope[7]. Sadat Hosseini (2014) believes that women form 75% of familial caregivers, a fact which results in their depression due to the interference of the caregiving responsibility with other household responsibilities[8]. One of the negative outcomes of taking care of an intellectually disabled child, which has been taken into account for the last few years, is the caregiver burden, also referred to as the caregiver pressure in some references[9]. By definition, it refers to physical, mental, financial and social problems which a patient's family members experience[10]. Khajavi (2011) states that the increased levels of caregiver burden can have various consequences for caregivers such as reducing care for a patient or abandoning a patient, a fact which makes the conditions of a patient worse[11]. Therefore, caregiver burden is very problematic for patients and their families. Since it is not known as a disease and has a hidden nature, both the patient and caregiver suffer from difficulties[12].

Given the high prevalence of intellectual disability[2]and the side effects on children [1, 3] resulting in many problems for families and mothers in particular[4-7], it causes caregiver burden and reduces their care for children [9, 11]. This study was conducted to determine the relationship between caregiver burden and demographics among the mothers of children with intellectual disability. It was also meant to identify the effective individual factors in order to present solutions to cope with this problem.

MATERIALS AND METHODS

This is a descriptive-correlation study in which the statistical population included all the mothers of intellectually disabled children supported by Elahi Rehabilitation Center in Quchan. They all met the inclusion criteria which were having an intellectually disabled child, elementary school educations and a parent-child relationship. The exclusion criteria were illiteracy, a stepmother-child relationship and unwillingness to participate in the study. The data collection tools included a demographics questionnaire, which was confirmed by reviewing books and papers and consulting with 10 professors of Zabol University of Medical Sciences. Moreover, the test-retest method was employed to evaluate the validity and reliability of this questionnaire which contained 13 items pertaining to the demographics of mothers including age, place of residence, marital status, number of children, number of children with intellectual disability, educational attainment, job, income, the child's age and gender, an underlying disease of the child or mother and the years of caregiving.

Another data collection tool was the caregiver burden 24-item inventory, developed by Novak and Guest in 1989[13]. There are five subscales in this questionnaire: time dependence caregiver burden (items 1-5) indicating a period of time which a caregiver spends taking care of a patient; developmental caregiver burden (items 6-10) indicating the burden imposed on a caregiver during different periods of life development of a patient; behavior; physical caregiver burden (items 11-14) showing the physical burden and burnout caused while taking care of a patient; social burden (items 15-19) stating the social aspects of a caregiver's life which is influenced while taking care of a patient; and emotional burden (items 20-24) indicating the emotions and feelings of a caregiver's life affected while taking care of a child. This questionnaire measures caregivers with a five-point Likert scale (from completely false to completely true). In other words, subjects select one of the followings to respond to each item: completely false (1), false (2), almost true (3), true (4) and completely true (5). The validity and reliability of the caregiver burden inventory were confirmed in foreign and domestic studies. Abbasi*et al*. (2013) used the content validity to determine the validity of this inventory and found out that the content validity index was 91.8%, 90.2% and 93.6% in terms of relevance, clarity and simplicity, respectively. It was 93.6% in total. Evaluating the reliability, they utilized the internal cohesion method to show that the total alpha coefficient of the scales was 0.90 and the alpha coefficients of subscales ranged from 0.76 to 0.82[12]. McClary *et al* (2007) used Cronbach's alpha for each of the subscales (time-dependence, developmental, physical, social and emotional caregiver burdens) to report that the reliability of the questionnaire varied from 0.69 to 0.87, and the total Cronbach's alpha was 0.80[14].

According to the results of a pilot study, the size of sample was estimated 60 individuals with Stata 11. Using the convenience sampling method, the research subjects were selected after making sure that they met the inclusion criteria and granted oral and written consents. Then the demographics questionnaire and CBI were distributed among them to fill out. The quantitative and qualitative variables were described with mean (SD) and frequency (percentage), respectively. The Spearman and Pearson correlation tests were employed to determine the relationships of quantitative variables. Moreover, the independent *t*-test and one-way ANOVA were utilized to investigate the relationships between qualitative variables and caregiver burden. SPSS 22 was employed for the statistical analysis, and p-value was considered significant below 0.05. The ethical considerations were complied with such as the confidentiality of information and the patient right to quit study at any research steps.

RESULTS

In this study, there were 60 mothers with intellectually disabled children. According to the results, the mean of age was 40.98±8.74, and they were divided into different age groups including 21-30 (7%), 31-40 (24%), 41-50 (21%) and 51-60 (8%). The mean and standard deviation of children age, number of children, number of children with intellectual disability and the years of caregiving were 8.77±3.64, 2.93±1.36, 1.2±1.3 and 8.93±3.4. Moreover, 60% of the children were female, and 48.3% of them had physical diseases. In addition, 81.7 of mothers were married, and 85% of them were housewives. Furthermore, 20% of them had physical diseases, and 85% lived in the city. The majority of them (51.7%) were literate, and only 25% of them had diplomas or higher degrees.

According to the findings, the mean of caregiver score was 76.93±22.70 for mothers. This score was above the average level in 51.70% of the mothers.

The Spearman and Pearson correlation tests were used to investigate the correlation between the score of caregiver burden and each of the demographics of research subjects such as a mother's age (p=0.207), a child's age (p=0.783), the number of children (p=0.546), the number of intellectually disabled children (p=0.745), the years of caregiving (p=0.589) and income (p=0.413) (Table 1).

Table 1: The Relationship between the Qualitative Characteristics of Research Subjects and Caregiver Burden Score

Variable	Correlation Coefficient	P-Value
Mother's age	0.165	0.207
Child's age	0.036	0.783
Number of Children	0.079	0.546
Number of Intellectually Disabled Children	0.043	0.745
Years of Caregiving	0.71	0.589
Income	0.108	0.413

According to Table 2, the findings of the independent *t*-test and one-way ANOVA indicate the difference in the mean of caregiver burden score for the research subjects based on marital status (p=0.1), educational attainment (p=0.1), employment status (p=0.3), place of residence (p=0.8), mother's underlying disease (p=0.8), child's gender (p=0.6) and child's underlying disease (p=0.003) (Table 2).

Table 2: The Relationship between the Qualitative Characteristics of Research Subjects and Caregiver Burden

Variables		M (SD)	Test	p-Value
Marital Status	**Widowed** **Married** **Divorced**	89.60±18.22 88.33±18.14 74.24±23.04	One-Way ANOVA	0.1
Educational Attainment	**Literacy** **Junior High-School** **Diploma** **Higher**	82.13±23.16 67.50±22.54 73.18±19.41 68.75±27.28	One-Way ANOVA	0.1
Job	**Housewife** **Office Worker**	75.78±23.28 83.44±18.91	Independent t-Test	0.3
Place of Residence	**Urban** **Rural**	76.67±23.14 78.44±21.22	Independent t-Test	0.8
Mother's Underlying Disease	**Yes** **No**	7.33±29.15 77.83±21.07	Independent t-Test	0.5
Child's Gender	**Male** **Female**	75.25±20.13 78.06±24.47	Independent t-Test	0.6
Child's Underlying Disease	**Yes** **No**	85.59±20.88 68.84±21.59	Independent t-Test	0.003

DISCUSSION

This study indicate that the mothers of intellectually disabled children are under caregiver burden; however, there was no statistically significant relationship between caregiver burden and their demographics (age, place of residence, marital status, number of children, number of children with intellectual disability, educational attainment, job, income, mother's underlying disease and years of caregiving), and only a child's underlying disease resulted in a statistically significant difference. In this section, the research results are discussed. However, it should be mentioned that no similar papers have been found despite searching into foreign and domestic papers. Therefore, the researcher has referred to some studies which might be different from the current study.

According to the findings, the mothers of intellectually disabled children were under caregiver pressure because of taking care of their children. Probably, a child's high and full-time dependence on mother in all affairs influenced the results. Bartolo*et al*. (2001) indicated that there was an inverse and significant relationship between caregiver burden and patients' functional independence[10]. Chang *et al*. (2010) showed that the caregivers who took care of their patients more hours during the day experienced higher caregiver burden and had lower mental health [15]. Abbasi*et al*. (2013) indicated that the caregivers of patients needing more care experienced more caregiver burden[12]. All of the abovementioned findings are consistent with the results of the current study.

Other studies indicate the lack of a relationship between the demographics of mothers with caregiver burden and showed that only a child's underlying disease was effective. Probably, a child's independence on mother after been affected with an underlying disease and the excessiveness of caregiving needs resulted in this finding. Motaharian *et al*. (2015) indicated that the demographics of caregivers of hemophilic children were not significantly related to caregiver burden[16]. Leiknes *et al*. (2015) showed that the demographics of caregivers of patients with Parkinson's disease were not significantly related to caregiver burden[17]. These findings are consistent with the current study. Although both of these studies are different from the current study in terms of statistical population, they have been compared due to the similarity of results. In this regard, Loureiro*et al*. (2013) did not find any significant relationships between caregiver burden and the demographics of the caregivers of the elderly such as age and marital status[18]. Despite different statistical populations, their study is consistent with the current study. However, since they reported that there was a significant relationship between caregiver burden and educational attainment ($p=0.046$) and that caregivers of lower educations experienced higher caregiver burden[18], their study is different from the current study. Probably, differences in dividing the educational attainments, statistical population and research tools influenced these results. Costa *et al*. (2015) did not report any significant relationships between caregiver burden and marital status among the caregivers of the elderly[19]. Despite a different statistical population, their study is consistent with the current one. However, they reported a statistically significant relationship between caregiver burden and educational attainment, insofar as older caregivers having lower educations experienced more caregiver burden[19], a fact which is inconsistent with the current study. Probably, different research tools, statistical population and the classification of age and educational groups influenced this result. At the end of their study, Ratnawati *et al*. (2014) did not find any relationships between caregiver burden and job, educational attainment and marital status among schizophrenic patients[20]. Despite a different statistical population, their study is consistent with the current study. However, they reported that caregiver burden was significantly related to age and economic status[20]. Probably, different statistical population and the classification of age groups and different criteria for economic status influenced this result. In another study, Daniel (2012) did not find any significant relationships between caregiver burden and any of the demographics except for income [21], a fact which is consistent with the current study. However, different economic criteria were the cause of the observed difference.

In the current study, the time constraints of sampling did not allow the researcher to use a larger sample. Since other studies reported different results, it is advised to conduct this study on a larger sample.

CONCLUSION

The research results indicated that the problems which the mothers of children with intellectual disability faced would put them under caregiver burden. In other words, mothers experienced almost the same caregiver burden, although they had different demographics, except for the mothers of children who suffer from another underlying disease other than intellectual disability. The increased care required for these children would probably increase the caregiver burden on the mothers. In other words, caregiver burden would probably influence the demographics of mothers, too. Therefore, it is suggested that officials make efforts in order to reduce the caregiver burden on these mothers.

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