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Psychosomatic Symptoms, Depression, and Anxiety among Parents and Caregivers of People With Disability

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Quantitative Study

Abstract

Background: Caring for people with disabilities creates stressful conditions and may lead to mental health problems in parents and caregivers. The aim of this study was to investigate somatic symptoms, depression, and anxiety in parents and caregivers of individuals with disability in Isfahan, Iran. This study was conducted as a joint study by Isfahan University of Medical Sciences and the University of Hamburg with financial support from DAAD.

Methods: This cross-sectional study was performed on 454 parents/caregivers of people with disabilities in Isfahan in 2019. Randomized sampling was performed and participants were selected according to the inclusion criteria. The Patient Health Questionnaire-9 (PHQ-9) (Depression), PHQ-7 (Anxiety), and PHQ-15 (Somatic) were used for data collection. Questionnaires were distributed among the participants and completed with the coordination and cooperation of the government and NGOs related to people with disability. Data were analyzed using descriptive statistics (mean and standard deviation) and analysis of variance (ANOVA) in SPSS software.

Results: The results showed that 28.4% of parents/caregivers of people with disabilities did not have any depressive symptoms and the remaining 70% experienced mild to severe levels of depressive symptoms. Regarding the level of anxiety, 30.2% showed no symptoms of anxiety and 69.8% showed mild to severe levels of anxiety symptoms. In terms of somatic symptoms, 17.8% reported no somatic symptoms and 82.2% reported mild to severe levels of somatic symptoms. Parents/caregivers differed significantly in terms of depression, anxiety, and somatic symptoms according to the type of disability.

Conclusion: The findings of the present study show that the rate of symptoms of depression, anxiety, and somatic symptoms in parents/caregivers of people with disabilities is higher than that in the general population. In addition, different types of disability can have different effects on the mental health of parents/caregivers.

Keywords: Depression; Anxiety; Somatic symptoms; Parent/Caregivers; Disability

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Introduction

Taking care of persons with disabilities is performed by parents and caregivers and it involves different, exclusive, and hard responsibilities such as punctual medication supervision, taking care of their physical, emotional, and financial needs, and helping them go to the rehabilitation center. They are burdened and suffer from stress; hence, they require help to cope with it. If the coping strategies they use to ease the burden are unhealthy and immature, they may directly affect their functions (Chadda, 2014).

Many studies have pointed out that mothers of children with developmental disabilities like intellectual disabilities (IDs), developmental delay, and physical and sensory handicap have shown noticeable signs of psychological distress. Mothers show more psychological distress or depressive symptoms (Chadda, 2014; Olsson & Hwang, 2008; Feldman, Mcdonald, Serbin, Stack, Secco, & Yu, 2007). Parents and caregivers of individuals with disabilities are at increased risk of a high level of stress and that may be the cause of the high rate of depression among them (Chi & Hinshaw, 2002; Olsson & Hwang, 2001). Previous researches have shown that psychiatric disorders are more common among caregivers of individuals with ID compared with the general population (Cooper, Smiley, Morrison, & Allan, 2007; Kobayashi, Inagaki, & Kaga, 2012). The caregiver's burden can be noticed in the procedure of illness and their hopes have been replaced by disappointment, this burden has appeared in a complete range of symptoms (Chadda, 2014).

It has been reported that mental disability causes different kinds of distress in family members, particularly in parents and mostly in mothers who suffer from psychological, physical, financial, and social distress due to the constant contact with the disabled child (Schwartz & Tsumi, 2003; Weiss, Sullivan, & Diamond, 2003; Pelchat, Lefebvre, & Perreault, 2003). However, fathers are not severely affected by the situation and show far less symptoms of psychological distress than mothers of normal children; less impact is observed on their psychological health because they are less involved (Romans-Clarkson et al., 1986; Moes, Koegel, Schreibman, and Loos, 1992; Cuskelly, Pulman, & Hayes, 1998; Hastings, 2003). Some psychiatric morbidity (depression, anxiety, and high level of distress) has been approved to be common among mothers of mentally disabled children. Overall, 35-53% of mothers of children with disabilities show symptoms of depression. There is evidence that depression and anxiety are more common in caregivers and parents of children with disability (Schwartz & Tsumi, 2003; Weiss et al., 2003). The main question here is whether the somatic symptoms in these caregivers and parents are more than that in the general population. The aim of this study was to determine the frequency of psychosomatic symptoms, depression, and anxiety among parents and caregivers of people with disability.

Methods

This cross-sectional study was extracted from a comprehensive study in Isfahan University of Medical Sciences (Psychosomatic Research Center), Iran, and the University of Hamburg, Germany. This project was implemented within a 3-year (2017-2019) interval in the format of a memorandum between the 2 universities with funding from DAAD. The study participants included 953 individuals (499 people with disabilities and 454 of their family members and caregivers) selected through random sampling method. To determine the psychosomatic symptoms and mental health status in their families, 454 participants were selected according to the list of clients in educational and rehabilitation centers and other related centers of Isfahan, Iran, in 2019. The questionnaires were completed either by going to the participants' homes, inviting them to centers related to people with disability, or inviting them to the meeting room.

Inclusion and Exclusion criteria: The inclusion criteria for the families of people with disabilities included 24 to 65 years of age, literacy, absence of serious psychiatric and neurological diseases, and lack of any disability. The exclusion criteria included unwillingness to continue participation and failure to respond to at least 20% of the items in each questionnaire.

Measuring tools

1) Demographic and disability information questionnaire

2) Patient Health Questionnaire-15: The Patient Health Questionnaire-15 (PHQ-15) was developed by Spitzer (2002). Its items include the somatization disorder/somatic symptoms of the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV). The participants were asked to rate the severity of 15 symptoms as 0 ("not bothered at all"), 1 ("a little bothered"), or 2 ("bothered a lot") for the preceding 4 weeks. Thus, the total PHQ-15 score ranges from 0 to 30 and scores of ≥ 5, ≥ 10, and ≥ 15 represent mild, moderate, and severe somatization/somatic symptoms, respectively. The validity and reliability of the PHQ-15 are high in clinical and vocational health care settings. The Cronbach's alpha of the original English version of the PHQ has been reported as 0.79-0.89 in different studies (Kroenke, Spitzer, Williams, 2002; Kroenke, Spitzer, Williams, & Lowe, 2010). In this research, the Cronbach's alpha of the PHQ-15 was 0.78.

3) Patient Health Questionnaire-9: The PHQ-9 assesses the frequency and severity of depression symptoms using 9 items scored on a 4-point Likert scale ranging from 0 (not at all) to 3 (nearly every day) (Kroenke & Spitzer, 2002). The total score of the PHQ-9 is the sum of the scores of all items and ranges from 0 to 27. The total score can be classified at a cut-off point of 10 to discriminate between minimal/mild and moderate/severe depression (Kroenke et al., 2010; Kroenke, Strine, Spitzer, Williams, Berry, & Mokdad, 2009). However, a systematic review showed that a cut-off point of 8 might increase sensitivity to depression (Manea, Gilbody, & McMillan, 2012).

4) Patient Health Questionnaire-7: The PHQ-7 measures the frequency and severity of symptoms of anxiety, specifically generalized anxiety disorder (Spitzer, Kroenke, Williams, & Lowe, 2006). It consists of 7 items that are scored on a 4-point Likert scale ranging from 0 (not at all) to 3 (nearly every day). The total score of the PHQ-7 can be classified at a cut-off point of 10 or 8 to optimize the test's sensitivity and specificity for identifying other anxiety disorders (Plummer, Manea, Trepel, & McMillan, 2016). The validity of the PHQ-7 and PHQ-9 was confirmed through a correlation of -0.32 to -0.76 with the 36-Item Short Form Health Survey (SF-36) and 0.76 with the Posttraumatic Stress Disorder Checklist (PCL-5) (Teymoori et al., 2020).

Data analysis method: Descriptive data such as the status of somatic complaints, depression, and anxiety of people with disabilities and their families were analyzed and displayed using descriptive statistical methods such as mean and standard deviation and frequency distribution. Moreover, analysis of variance (ANOVA) was used to compare the mental health and somatic symptoms of people with disabilities and their families according to the type of disability and SPSS software (version 23, IBM Corp., Armonk, NY, USA) was used for the statistical analyses.

This study with the scientific code 298062 has been approved by Isfahan University of Medical Sciences and has received the ethics code IR.MUI.MED.REC.1398.214 from the ethics committee. Figure 1 show consort flowchart.

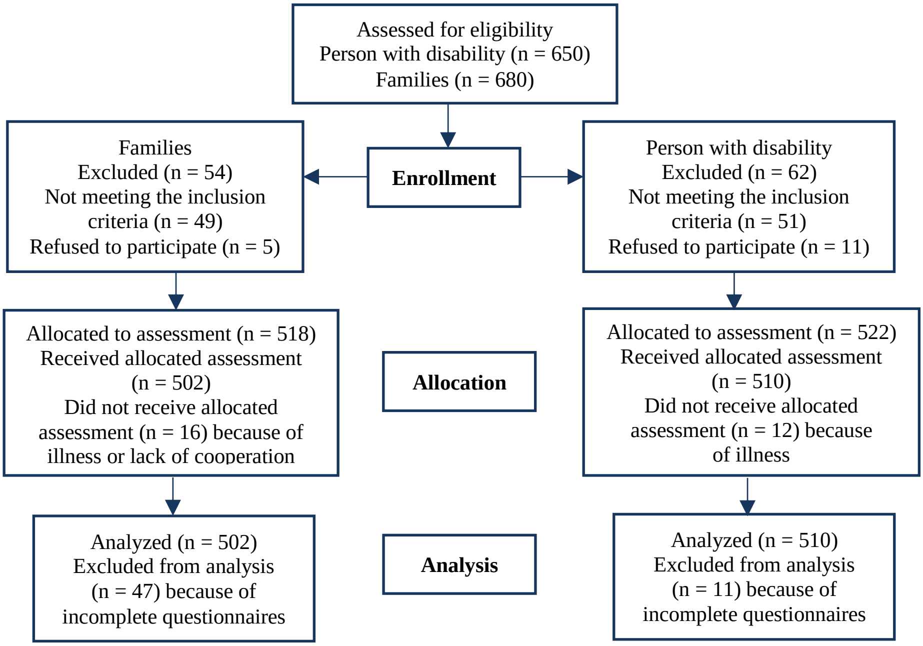

Figure 1. The Consort Flowchart of assessment of persons with disability and their families

Results

From among 454 parents/caregivers of people with disabilities, 449 completed the questionnaires. The mean age of the participants was 46.4 ± 10.4 years, 52% of them were women, and 86.3% were married. The other demographic characteristics of the studied subjects are presented in table 1.

Table 1. Demographic characteristics of the study population (n = 449)

Demographic Characteristics	Value
Age (Mean ± SD)	46.4 ± 10.4
Sex (Female) [n (%)]	268 (59)
Marital Status [n (%)]	
Married	391 (86.3)
Single	40 (8.8)
Divorce/etc.	7 (1.5)
Education [n (%)]	
Illiterate	10 (2.3)
Under diploma	224 (50.6)
Diploma	126 (28.5)
Upon diploma and BA	80 (18.1)
MA and more	2(0.5)
Type of disability [n (%)]	
Blind	94 (20.7)
Deaf	27 (5.9)
Sensorimotor	36 (7.9)
Mental	102 (22.5)
Missing	195 (43)
Psychological Symptoms (Mean ± SD)	
Depression	8.38 ± 4.10
Anxiety	8.15 ± 4.38
Somatic Symptoms	10.36 ± 4.9

Table 2. Mental health of parents and caregivers of people with disability

Status	None	Mild	Moderate	Moderately Severe	Severe	Missing
Depression	129 (28.4)	156 (34.4)	150 (33)	12 (2.6)	3 (0.7)	4 (0.9)
Anxiety	137 (30.2)	160 (35.2)	136 (30)	-	14 (3.1)	7 (1.5)
Somatic symptom	81 (17.8)	139 (30.6)	155 (34.1)	-	76 (16.7)	3 (0.7)

Data are presented as n (%).

Mental Health Status of Parents/Caregivers of People with Disability: According to the PHQ-15 cut-off point, 16.7% and 34.1% of the participants had severe and moderate somatic symptoms, respectively. Based on the cut-off point of the PHQ-7, 3.1% and 30% of participants showed severe and moderate anxiety symptoms, respectively. According to the PHQ-9 cut-off point, 0.07%, 2.6%, and 33% of subjects, respectively, showed severe, moderately severe, and moderate depression symptoms (table 2).

Depression, Anxiety, and Somatic Complaints in Parents/Caregivers in Terms of the Type of Disability: According to the results of data analysis presented in table 3, the severity of depression, anxiety, and somatic symptoms of parents/caregivers varies in terms of the type of disability ($P < 0.05$). Post hoc tests were used to determine significant differences between groups in terms of the type of disability of children and the results are presented in table 4.

Parents/caregivers of people with blindness differed significantly from those of people with spinal cord injury (SCI) in terms of depression and anxiety ($P < 0.001$). Moreover, a significant difference was observed between parents/caregivers of people with sensory-motor disability and blindness in terms of the severity of anxiety and somatic symptoms ($P < 0.001$). In addition, a significant difference was observed between parents/caregivers of people with SCI and parents/caregivers of deaf individuals in terms of severity of anxiety ($P < 0.005$).

As seen in figure 2, the mean score of depression in parents/caregivers of deaf children is higher than other groups. In contrast, the mean scores of somatic symptoms of parents/caregivers of people with sensory-motor disability are higher than other groups.

Discussion

The present study findings showed that, based on the cut-off points of PHQ versions, the level of depression, anxiety, and somatic symptoms in parents/caregivers is higher than the general population of Iran (Ebrahimi, Seyed mirramazani, & Hosseini, 2020). According to the results presented in table 2, about 70% of the participants had mild to severe depression and anxiety, and up to 80% of these people suffered from mild to severe somatic symptoms, and the prevalence of these severe symptoms is higher than those in the general population (Sadock, Sadock, & Ruiz, 2017).

Table 3. Analysis of variance of means of depression, anxiety, and somatic symptoms in parents and caregivers based on type of disability of family members

Status	Blind	Deaf	SCI	Sensorimotor	Mental	F	P
Depression	6.60 ± 2.83	6.98 ± 4.07	8.40 ± 4.92	7.60 ± 5.01	8.36 ± 5.21	4.17	0.002
Anxiety	7.63 ± 3.39	7.42 ± 4.99	8.39 ± 4.59	8.98 ± 5.97	8.22 ± 4.96	2.63	0.03
Somatic symptoms	7.79 ± 3.17	7.37 ± 4.74	8.75 ± 5.3	10.71 ± 5.66	9.42 ± 5.37	12.53	0.001

SCI: Spinal cord injury
Data are presented as mean ± standard deviation (SD)

Table 4. Tukey's honestly significant difference test results for group differences

Groups	Depression	Anxiety	Somatic symptoms
Blind			
Deaf	0.37	-0.37	0.41
Spinal cord injury	-1.79*	-1.79*	-0.95
Sensorimotor disability	-1.00	-1.00*	-2.91*
Mental disability	-1.76*	-1.76*	1.63
Deaf			
Spinal Cord Injury	-1.41	-1.41*	1.37
Sensorimotor injury	-0.62	-0.62	3.33*
Mental disability	-1.38	-1.38	2.05
Spinal Cord Injury			
Sensorimotor injury	0.79	0.79	-1.96*
Mental disability	0.03	0.03	1.28

*P < 0.001

These findings indicating the high levels of depression, anxiety, and somatic symptoms in parents/caregivers of people with disability support the findings of Resch, Elliott, and Benz (2012), which showed that these individuals suffer from higher levels of anxiety, depression, and somatic symptoms. Our results are consistent with the findings of previous studies indicating that parents of children with developmental disabilities have more mental stress, poorer psychological status, and greater somatic problems than parents with normal children (Fritz, 2020). Although the prevalence of psychological problems in caregivers and parents of people with disabilities was higher than the general population, the extent of these problems varied according to disability, which is discussed below.

Mental Health of Parents/Caregivers in terms of Disability Type: The severity of depression in parents/caregivers of people with mental disability and SCI was significantly higher than other groups of participants. These findings are consistent with the results of the study by Kayili (2018) that showed significant differences in depression levels of parents of children with different types of disability. According to our findings, it seems that persons with mental disability and decrease function in all life areas are regarded as a kind of social stigma for the family, this leads to feelings of hopelessness, despair, shame, and social avoidance. Although the parents/caregivers of blind children face many problems, their child can have occupational, educational, social abilities, and even access to higher levels of education such as the doctorate degree.

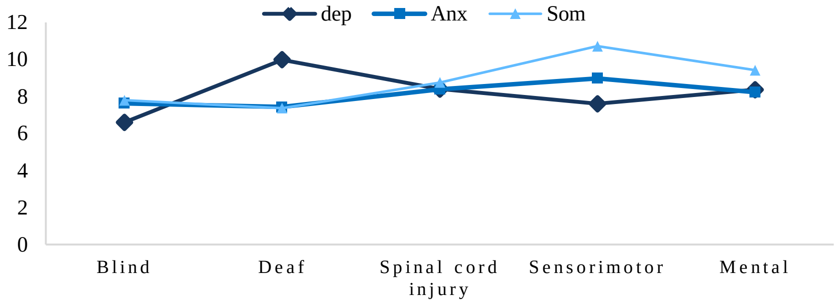

Figure 2. Comparison of means of depression, anxiety, and somatic symptoms in parents/caregivers based on type of disability of the family member

Furthermore, our findings revealed that parents/caregivers of persons with SCI suffer from a higher severity of depression than other groups. This result is consistent with the findings of Simpson, Anderson, Jones, Genders, and Gopinath (2020). Based on our finding, SCI seems to be a stressful event that occurs for an individual and his/her family and suddenly transforms a healthy and efficient person into a person with disability in all areas of life; hence, depression emerges as an inevitable psychological reaction.

Our findings also revealed higher anxiety in parents/caregivers of individuals with sensory-motor and mental disability, and SCI, and these findings support the findings of Lynch and Cahalan (2017). It seems that these parents/caregivers experience more insecurity and uncertainty due to their conditions. The findings also showed that the severity of somatic symptoms in parents/caregivers of individuals with sensory-motor disability is higher than other groups. It can be inferred from the findings of this study that the somatic complaints and health concern of parents/caregivers are related to type of disability. According to the study by Krishnan, Sood, and Chadda (2013), the family members of an individual with a major problem with sensory-motor symptoms focus on the physical condition of their family member, and this results in an increase in somatic complaints in these caregivers.

Conclusion

In general, parents/caregivers of persons with disability suffer from depression, anxiety, and somatic symptoms more than the general population in Iran. Moreover, families of individuals with sensory motor and mental disability, and SCI are more at risk of psychological problems than other groups.

Suggestions: Based on the findings, it is suggested that mental health screening of parents/caregivers be performed through questionnaires and clinical interview, and the people who are at risk of psychiatric disorders be referred for treatment and the necessary preventive measures be performed for others.

Limitations: The most important limitation of this research was that only self-assessment questionnaires were used to determine mental health, so it is suggested that clinical interview be used for a definitive diagnosis in future studies.

Conflict of Interests

Authors have no conflict of interests.

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