



The correlation between help-seeking behaviour, social comparison and stigma in caregivers of children with autism

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Introduction: Caregivers are one of the most important elements in the care of children with autism, that it is very essential to take into consideration their mental dimensions. This study has been conducted with the purpose of investigating the correlation between helping-seeking behaviour, social comparisons and stigma in caregivers of children with autism. **Method:** This descriptive-correlational study was conducted on 141 caregivers of children with autism referred to the autism centre since 2018 in Karaj and Tehran. Sampling method was convenience. The instruments used included the demographic characteristics and the help-seeking behaviour scale, the social comparison scale and the stigma scale. Data were analyzed using SPSS v20 software. **Results:** Most caregivers were female, aged between 36 and 45, married and had a diploma. The results also showed that there is a significant relationship between help-seeking behaviour and affiliate stigma of the caregivers of children with autism ($P = 0.046$). Also, there is a significant relationship between social comparison and affiliate stigma of the caregivers of children with autism ($P = 0.009$). **Conclusion:** considering the significant relationship between the three variables, the greater the help-seeking behavior, the amount of social comparison is higher and the amount of stigma is lower, it seems that it is better to pay particular attention to help-seeking behaviour, factors affecting it, facilitation of access to professional services such as counseling, psychological and psychiatric services, so that the person is less likely to compared himself to other people in the community and the stigma associated with the presence of the child with autism is diminished.

INTRODUCTION

Autism is one of the most chronic and complex psychological disorders in children (1,2) that its prevalence is increasing (3,4). Statistics in Iran show that, on average, 12.4 people are diagnosed with autism spectrum disorder per 10000 people (5) and this rating is 62 per 10,000 people in the world. In the United States, it is estimated that about 1% of the population under age 3 has autism spectrum disorder (6). This disorder is diagnosed based on the presence of a set of symptoms, such as quality impairment in social interactions and strange verbal communication skills, and also the existence of stereotype behaviours, movements and interests that are often strange (7-9). According to the fifth edition of the Diagnostic and Statistical Manual of Psychiatric Disorders, the above-mentioned set of symptoms, along with the minor symptoms, such as

lack of proper eye contact, the use of third-person singular pronoun instead of I, gestures and special movements, inability to establish emotional relationships and sensory problems in taste, smell and touch, and which are distinctive from birth to about three years of age, can be indicative of childhood autism, which is placed in autism spectrum disorder (10). The parents of these children face a variety of challenges and concerns (7). They face a number of problems, such as high care rates, lack of social support, high cost of treatment and rehabilitation, lack of services in the field of autism and stigma (11-12). Stigma means having a feature and characteristics that lowers the value and credibility of the individual, being labelled and attributing stereotypical thoughts to him (11) and is one of the most important problems that domestic caregivers are involved with (13). Symptoms that children exhibit due to the nature of autism disorder can cause attitudes and abusive behaviours from community members imposed to parents (14, 15), so they may feel embarrassed or blamed (14). Stigma is, in fact, a phenomenon that can be added to the family as an additional pressure, in addition to problems that arise from the nature of the autism disorder (16). The study of Rezaei Dehnavi et al., in Iran, showed that Stigma is one of the most important problems faced by mothers who have children with autism (34). Some studies have expressed that stigma can be one of the issues preventing people with mental disorders or their families from seeking

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help and assistance in identifying, treating and following-up disorders (17-20). Caregivers of children with autism may themselves require the help of mental health professionals because of their child's symptoms. Studies have shown that this group has understood and internalized, anxiety, self-reproach, and refrain others at higher levels of experience and stigma because of the child's behavioural symptoms (9, 12, 42). Help-seeking behaviour is a behaviour that a person after awareness and accepting the problem, comes to seek help from others (18). People are not simply looking for help from mental health professionals. Statistics show that in Europe and the United States, about 52% and 74% of people with Mental Disorders do not go to treatment, and this rating is higher in low and middle-income countries (20). Generally speaking, people go through three stages to seek mental health services including identifying the problem, decision for help-seeking, and choosing the appropriate service (21, 43). Some studies have been conducted on the correlation between stigma and parental help-seeking in different groups, which show that there is a reverse relationship between these two components (22), while according to other studies, there is no significant relationship between stigma and parental help-seeking (23, 24). Therefore, it is necessary to determine the amount of support for help-seeking in the caregivers of these children so that it can be promoted if necessary. In Iran, studies have also been conducted to determine the help-seeking of people in various fields such as depression (25), sexual dysfunction (26), and cancer (27), but there has been no research related to help-seeking in caregivers of children with autism. On the other hand, individuals need information to assess their abilities and their opinions to enhance their performance and even self-esteem, and this information is obtained through social comparisons (28). Recent research has shown that the need for social comparison depends not only on the underlying conditions and characteristics of each individual, but also on his psychological state (10). Social comparisons can have positive or negative effects in individuals that this issue depends on the level of self-esteem, the existing problem, the characteristics of the people that the person compare with himself (29). Also, the nature of a mental disorder and its symptoms can affect the level of comparison that parents of children with the disorder have with others (30). The nurse is involved with the child with autism and his family in his activities and should have appropriate attitude and performance in his cares and communication with them (31, 32). As mentioned above, caregivers of children with autism live with different circumstances than caregivers of normal children, and this disorder affects their lives from a variety of dimensions. As a nurse is involved as a member of the medical team and a community-based health messenger, such as schools, associations, and health centres, there is a need for him to have a clear understanding of the psychological aspects of caregivers of child with autism that three dimensions mentioned is studied in this research. Getting the right information about the concept of stigma and its social comparison and its level in the caregivers of children with autism is necessary to be included in establishing communication between the nurse and the caregiver, but the level of the stigma and the comparison that these individuals understand due to having with the child with autism, is unknown. Also, due to the problems that arise in the presence of a member of the family with autism in the family, the psychological status of caregivers and the extent of their need and help for counselling and specialized guidance to prevent the outbreak of disorders such as depression and anxiety disorders or the treatment should be determined. With the researcher's search, studies that show the amount of help-seeking, social comparison and stigma in caregivers of children with autism and their relationship

with each other in Iranian culture were not found; therefore, this study was conducted with the purpose of determining the relationship between help-seeking variables, social comparison and stigma.

METHOD

This descriptive-correlational study was conducted on caregivers of children with autism referred to the autism centre since 2018 in Karaj and Tehran. Entry criteria included: child under the care have definite diagnosis of autism, care for the child be over the family care (father or mother) and child, not having chronic physical illness. The sampling method was convenience that was selected among caregivers who were willing to participate in the study. The instruments used included the demographic characteristics and the help-seeking scale, the social comparison scale and the stigma scale. The "Attitude toward Seeking Professional Psychological Help" scale has been made in 1995 by Fischer and Furina from a scale of the same name that was prepared by Turner and Fisher. This tool has 10 items and is graded using the Likert spectrum (0 = Disagree to 3 = Agree). This scale was translated into Persian by Tavakoli et al. in 2010 and its formal validity and its content were confirmed. (33). The scale of the "social comparison orientation" was made by Gibbons and the Bank in 1999 in order to determine the extent to which people compare themselves to others, and were implemented and validated in the United States and the Netherlands. This scale has 11 items that is designed to examine the two dimensions of the comparison of abilities (6 items) and the comparison of beliefs (5 items). This scale was first translated into Persian by Tajik Esmaeili and Hasanzadeh in 2014 and its validity was confirmed by Cronbach's alpha 0.89 and 0.86 (Tajik Esmaeili and Hasanzadeh, 2014). The scale of "affiliate stigma" is used to determine the extent of stigma in people dependent to the person with stigma (their caregivers). This tool was made by Mak and Cheung in 2008 and has 22 items, which are measured by Likert scale (1 = strongly disagree, 4 = strongly agree) and scales range from 22 to 88. The higher the gained score, the greater the amount of stigma in the individual. This scale measures 3 fields, emotional (7 items), cognitive (7 items) and behavioural (8 items). The inner consistency is 0.95 and the correlation between the 22 items is from 0.47 to 0.78. In 2011, Dehnaviet.al used this scale in their research in Iran. (34).

To calculate the reliability of this study, a test re-test method was used on 15 individuals and the Intraclass Correlation Coefficient of them was calculated. It should be mentioned that in this research, in addition to investigation of reliability through re-test method, the reliability was analyzed using Cronbach's alpha coefficient in the whole data. Cronbach's alpha coefficient is more than 0.7 in all scales, as a result, the research carried out have reliability. In all scales, the intra-class correlation coefficient was significant with a high probability ($P < 0.001$).

Ethical considerations

This study was approved by the Ethics Committee of Shahid Beheshti University of Medical Sciences (IR.SBMU.PHNM.1396.741). Prior to participating in the study, participants received oral and written consent.

Data analysis method

In order to analyze the data, descriptive statistics (central and dispersion indicators) and inferential statistics were used. Pearson correlation coefficient was used to examine the correlation between help-seeking, social comparison and stigma. Also, statistical regression was used to

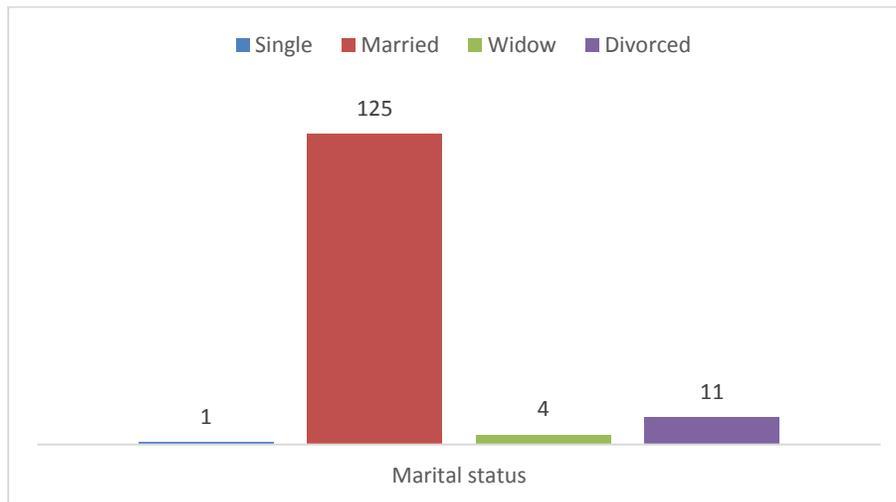


Figure 1 Marital status of participants

Table 1 Demographic characteristics of the caregivers of children with autism participating in the study

variables	gender	frequency	percentage
Gender	Female	105	74/5
	Male	36	25/5
Age	25≤	2	1/4
	26- 35	55	39
	36- 45	66	46/8
	46- 55	14	9/9
	55<	4	2/8
Marital status	single	1	0/7
	married	125	88/7
	widow	4	2/8
	divorced	11	7/8
education	Under diploma	13	9/2
	diploma	66	46/8
	bachelor	54	38/3
	Master of art or higher	8	5/7

estimate the relationships between variables. SPSS software version 20 has been used to analyze the data.

RESULTS

Participants included 141 caregivers of children with autism. Most of the caregivers were female, aged between 36 and 45, were married and had a diploma (Table 1; Figure 1).

According to the findings of the study, in terms of help-seeking behaviour, stigma and social comparisons in the caregivers of children with autism, it was determined that the score for help-seeking has the highest value, and stigma had the lowest score. This finding means that in general, people who participate in the research tend to have help-seeking and have reported less stigma compared with other variables (Table 2; Figure 2).

These findings also show that there is an inverse and significant relationship between help-seeking an affiliate of caregivers of children with autism ($P = 0.046$). This means that the more the help-seeking in caregivers of children with autism, the less stigma this group reports. Due to the fact that the correlation is very low and closes to zero, the relationship between the two scales is very slight. Also, there is a significant relationship between social comparison and affiliate stigma of the caregivers of children with autism ($P = 0.009$). The correlation is 0.22, which means that the two scales of social comparison and affiliate stigma have a positive linear relationship of 0.22. There is a significant

relationship between help-seeking and social comparison of caregivers of children with autism ($P = 0.025$). The correlation is 0.19, which means, help-seeking and social comparisons have a positive linear relationship of 0.19. Here too, since the correlation is very low and close to zero, the relationship between the two scales is very slight (Table 3).

The above table shows that both help-seeking and social comparison variables became significant against the affiliate stigma of the caregivers of children with autism participating in the study ($P = 0.009$, $P = 0.002$).

The number of -0.58 means that with the constancy of other variables, by increasing one unit in the help-seeking scale, on average, 0.58 units of the affiliate stigma scale are reduced and the number of 0.47 means that with an increase in the scale of social comparison, on average, 0.47 units of dependent stigma scale increases.

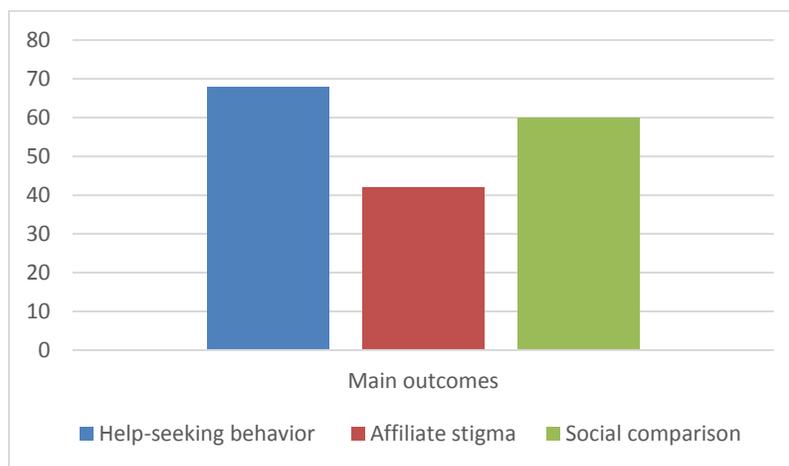
Simply put, it is predicted that with the increase in help-seeking behaviours, the amount of stigma in the caregivers of children with autism will be reduced. In contrast, increasing social comparisons lead to increased stigma in the target population.

DISCUSSION

Concerning the help-seeking and correlation, there is relationship between this component and the stigma in the caregivers of children with autism. The results showed that the mean and standard deviation of the help-seeking in this group was ($5/0 \pm 20.5$), that this result is in accordance with the study of Al-Mutairi et al., so that in their study, the

Table 2 Distribution of help-seeking rates, affiliate stigma and social comparisons in caregivers of children with autism

variable	average±standard deviation	Average of percentage	Range
Help-seeking behavior	5/0 20±/5	68/3	0 -30
Affiliate stigma	13/4 49±/7	42	22 -88
Social comparison	7/4 37±/2	59/5	11 -55

**Figure 2** Main outcomes of study**Table 3** Determining the Relationship of help-seeking and Social Comparison in Caregivers of Children with Autism

Variable		Social comparison	Affiliate stigma	Help-seeking behaviour
Help-seeking behavior	correlation	* 0.19	* -0.17	1
	p-value	0.025	0.046	
Affiliate stigma	correlation	* 0.22	1	* -0.17
	p-value	0.009		0.046
Social comparison	correlation	1	* 0.22	* 0.19
	p-value		0.009	0.025

Table 4 Investigation of the relationship between help-seeking and social comparison with the affiliate stigma of the caregivers of children with autism participating in the study

Variable	correlation	Standard deviation	p-value
intercept	44.1	8	<0.001
Help-seeking behavior	-0.58	0.2	0.009
Social comparison	0.47	0.1	0.002

average percentage of help-seeking has been reported 50.9%, and in the results of this study, which was performed on mothers following childbirth, it is stated that postpartum depression has a reverse relationship with the rate of help-seeking, that is, the more help-seeking behaviour increases, depression will decrease (35). A research in the United States is on Asian students have been done that the findings show that the more willingness to help-seeking in psychological disorders, the person will have less stigma toward this issue (36), which is consistent with the findings of the present study.

In a study by Tup et al. in a population of 2,227 Australian parents, 88.6% of parents presented high levels of stress, emotional and behavioural problems, and stated that these problems have occurred after playing a parental role. It was also found that about 60% of people prefer informal help-seeking (friends and family) to help-seeking by expert advice, and informal help-seeking from mental health professionals, the portions of counselling (45.9%), drug treatment (34 / 3%) and cognitive therapy is (26.4%) (37). A qualitative study in Iran on help-seeking that has investigated depressed women that ultimately found two matching patterns for help-seeking; first, seeking social support such as getting help from families, neighbours, and religious authorities and second; seeking the specialized support by mental health

professionals such as psychologist and counsellor (25). In both recent studies it is stated that, stigma associated with help-seeking of mental health professionals can influence the choice of type of help-seeking pattern, and individuals prefer informal support as a result of their concern about stigma referring to psychologists, that can be indicative of the reverse relationship between stigma and help-seeking. In another study, the results of which are similar to the findings of the present study, Rinders et al. Carried out a study on people in two regions where suicide rate is low in one and high in the other, and found that in areas where suicide is less, people have a positive attitude toward help-seeking and experience less stigma and shame than people in other area. They also found that perceived stigma has reverse relationship with help-seeking (38). On the other hand, the research conducted by Lali, et.al in a population of students showed that general stigma does not have any impact on the level of help-seeking of people in the future, while like the present study, stigma prevents them from help-seeking them against psychological problems (39). The results of Damster et al. contradict the results of the research, as the study showed that the more the stigma is, the more parents are willing to help-seeking in the form of training classes. Also, the more parents understand and experience more

stigma, they are more likely to take care of their children and seek help from professionals (22).

Concerning the determination of the correlation between the level of help-seeking and social comparison in the caregivers of children with autism, the results showed that there is a significant and direct correlation between these two variables, so the greater the amount of help-seeking, the more social comparison will be. In this regard, Newman article can be referred, which yields a different result from the research carried out by the researcher. In this paper, students act to seek help in academic affairs, and it is stated that social comparisons can have both positive and negative impact on student help-seeking. If the person has a positive social comparison and seeks to resolve his problems through social comparison, his help-seeking behaviour helps to improve his condition. If it is possible for a person to consider help-seeking behaviour along his or her weakness, and because he does not compare himself with others, he does not turn to help-seeking behaviours (40). Also in Hodges and Dieb's research, social comparisons frequently occur in self-help groups, which in some cases are effective and lead an individual to seek help from other parents who have similar conditions (29). In relation to determining the correlation between social comparison and stigma, Peterson et al. research can be noted, which is consistent with the research carried out by researchers, shows that the more stigma that a person understands and internalizes, the person experiences more social comparisons (41).

CONCLUSION

By investigating three parameters of help-seeking, stigma and social comparison in caregivers of children with autism, who are generally parents, it was found that there are significant relationships between all three parameters. Considering that the results of this study in the group mentioned has shown that the greater the amount of help-seeking, the more the amount of social comparison and the amount of stigma is lower, it seems that it is better to pay particular attention to the concept of help-seeking, factors affecting it, facilitate access to professional services such as counseling, psychological and psychiatric services, so that the person is less likely to compare himself to other people in the community and the stigma associated with the presence of the child with autism is diminished. Regarding the results of this study, the importance of stigma and label in the target group has been revealed, so that this component has a direct impact on the level of social comparison of the individual, and the more caregiver internalized the stigma the more he compares with other people and this is a potential factor for disrupting individual mental health. With effective understanding and attention to concepts such as help-seeking, stigma and social comparisons in the caregivers of children with autism, we can hope that there will be less conflicts in the future in the individual and the family.

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