

Research Paper

Correlation of Spiritual-religious Well-being and Care Burden Among Mothers of Children With Autism



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ABSTRACT

Background and Objectives: Mothers of children with autism encounter numerous challenges that can greatly impact their caregiving responsibilities. However, spiritual-religious well-being (SWB), being a fundamental aspect of human life, has the potential to alleviate a significant portion of this burden. This study aimed to explore the relationship between spiritual-religious components and care burden among mothers of children with autism.

Methods: This cross-sectional descriptive study involved 102 mothers of children with autism who sought assistance at the autism centers affiliated with the Qom University of Medical Sciences in 2022. Convenience sampling was used, and data were collected through questionnaires on demographic characteristics, SWB, and caregiving burden. Descriptive statistics and linear regression analysis were performed using SPSS software, version 22 with a significance level of 0.005.

Results: The participating mothers had an average care burden score of 75.44 ± 22.3 and a SWB score of 196.8 ± 28.3 . Linear regression analysis revealed that hope for the future and general religiosity were predictors of care burden in mothers of children with autism.

Conclusion: Mothers of children with autism experience a moderate burden of care, which is influenced by their spiritual and religious well-being. Understanding the spiritual and religious components that impact the caregiving burden can assist therapists in providing solutions to reduce stress and alleviate the burden of care for these mothers.

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Introduction

Autism spectrum disorder is a disease related to the growth of the nervous system, which is characterized by impaired social communication and repetitive behaviors [1]. The prevalence of autism has been increasing in the last two decades [2]. According to a review study conducted in 2022, one out of every hundred children in the world had an autism spectrum disorder [3]. The prevalence of autism spectrum disorder screening in the population of Iranian children is estimated at 1.9% [4].

The inability of these children to care for themselves and their dependence on their mothers represent the most critical challenges faced by mothers of children with autism. Care burden refers to the physical, emotional, and social challenges faced by caregivers of children with autism [5]. Care burden in mothers of children with autism can lead to stress and emotional exhaustion [6]. In other words, mothers with autistic children usually face a range of problems, such as significant financial burdens and ineffective treatments, resulting in a highly stressful life [7].

Xavier and Esprandio showed that the attitudes and beliefs of mothers affect the life and care of individuals with chronic disabilities. Also, among the main factors that can interfere in this care process are the quality of life (QoL), socio-economic issues, spirituality and religious beliefs, and human and cultural mutual relations [8]. Spirituality provides a framework for finding meaning and facilitates access to spiritual and religious activities [9]. La et al. [10] reported that low spirituality predicts depression in mothers of autism patients.

Spirituality and religion include various components that help individuals feel connected, find purpose, and experience meaning. In the caregiving context, these components may have implications for how mothers perceive and adapt to their responsibilities. Previous research has identified several key components of spiritual-religious well-being (SWB), including belief in a higher power, religious practices, meaning and purpose in life, hope for the future, and social support in religious communities [5].

Akkuş et al. showed that spiritual well-being components can reduce the care burden for cancer patients [11]. The results of a recent study conducted in Iran showed that the caregivers of breast cancer patients who have more spiritual intelligence experience less care burden [12]. Also, the results of another study in Turkey showed a significant negative relationship between caregiver burden and spiritual well-being [13].

In this study, spirituality is defined as “the way people seek and express meaning and purpose, and how they experience their connection to the moment, self, others, nature, and crucial or sacred things” [14]. Spirituality differs from religiosity, although the terms often overlap. Religiosity involves a personal experience established in one’s life through the beliefs, practices, and values associated with a particular religion. While some studies have examined the relationship between spirituality and care burden, fewer studies have focused on the relationship between religion and care burden [15]. Furthermore, the role of religion in our country, Iran, has been less studied, with previous research placing greater emphasis on spirituality [16]. Several studies have been conducted on the relationship between spirituality as a protective factor in reducing the care burden for various diseases [17, 18]. This article examined the relationship between spiritual-religious components and care burden in mothers of children with autism.

Methods

This descriptive-correlational cross-sectional study was conducted on family caregivers of autism patients from October to February 2012. A total of 102 mothers with autistic children were selected to participate in the research using the convenience sampling method. After obtaining ethical approval from [Qom University of Medical Sciences](#), the researchers visited the Autism Center affiliated with [Qom University of Medical Sciences](#) to obtain the phone numbers of mothers of autistic children eligible for the study. Then, the researchers contacted these mothers and invited those willing to participate in this study. Questionnaires were provided to volunteer mothers, who were asked to complete them if they agreed to participate. Completing the questionnaires took about 20 minutes.

The inclusion criteria included the age of over 18 years, being the legal mother of the child, being responsible for the child’s care, living in Qom City, the ability to communicate and respond, a definite diagnosis of the child’s autism by a specialist doctor, and consent to participate in the project. The exclusion criteria included the presence of psychological problems and chronic physical illnesses in the mothers and incomplete responses to more than half of the questions in the questionnaire.

In this study, the questionnaires assessing demographic characteristics, SWB, and care burden were used to achieve the research objectives.

The demographic characteristics questionnaire included the child's age, mother's age, child's gender, economic status, number of children, mother's education level, mother's employment status, marital status, and age at which autism was diagnosed.

Care burden inventory (CBI)

Novak and Gest created this questionnaire to measure the objective and subjective burden of caregiving. This questionnaire has 24 questions and five subscales: Time-dependent care burden, developmental care burden, physical care burden, social care burden, and emotional care burden. It is scored based on a five-point Likert scale from completely disagree [1] to completely agree [5]. Accordingly, the scores for this questionnaire range from 24 to 120. In the study of Novak and Gest, the validity and reliability of this questionnaire were measured in mothers, with Cronbach's α for the different subscales ranging from 73% to 87% [19]. The validity and reliability of this tool in Iran were examined by Shafizadeh et al. The Pearson correlation coefficients for the relationship between the scores obtained from the CBI and the Beck anxiety inventory (BAI) and Beck depression inventory (BDI) were 0.69 and 0.49, respectively, confirming concurrent validity. Cronbach's α for CBI was 0.91, with values ranging from 0.78 to 0.92 for its subscales [20].

SWB questionnaire

The initial version of the scale (2005) was made by Untrainer, and after revision and necessary corrections, its final version was introduced in 2007 [21]. This questionnaire consists of 48 questions and six subscales, including hope for the future, forgiveness, experience of meaning and purpose, general religiosity, belief in the hereafter, and hope in God. Each sub-scale contains eight questions, and the responses are based on a six-point Likert scale, ranging from completely disagree (one) to completely agree (six). Sixteen questions are reverse graded. The total score of the scale is obtained from the sum of the scores of the subscales, with a minimum score of 48 and a maximum score of 288. Higher scores indicate higher religious biological well-being. The creators of the questionnaire reported the internal consistency of the entire scale as 89%. The reliability of the Persian version of the questionnaire was reported to be 81% by Alilu et al., which was confirmed [22]. In the present study, the validity of the scale was checked by Cronbach's α method, yielding a value of 79%.

Descriptive statistics (frequency, frequency percentage, Mean \pm SD) were used for data analysis using SPSS software version 22. Also, Pearson's correlation coefficient was used to examine the correlation between the research variables. A linear regression analysis was used to predict the factors affecting care burden. The level of significance for all tests was set at $P < 0.05$.

Results

The mean age of the participants was 35.1 ± 5.8 years, and the age range was between 18 and 41 years. Also, 96% of the participants were currently living with their spouses, and 84.3% were housewives.

The mean care burden score of the samples was 75.44 ± 22.3 , with the highest care burden related to the dimension of time-dependent care burden (19.6 ± 4.3), and the lowest care burden related to the dimension of physical care burden (12.27 ± 4.9). Among the dimensions of the SWB questionnaire, the highest score was related to the dimension of general religiosity (39 ± 0.9), and the lowest score was related to the dimension of hope for the future (25.9 ± 7.3). Table 1 presents the mean scores of the research variables.

Table 2 presents the relationship between SWB components and care burden in the research samples. A significant inverse correlation was observed between most components of SWB and the care burden components. The highest correlation is found between evolutionary care burden and hope for the future ($r = -0.697$, $P = 0.000$), while the lowest correlation is related to time-dependent care burden and the experience of meaning and purpose ($r = 0.921$, $P = -0.005$).

The variables of the SWB questionnaire included in the regression model, specifically hope for the future ($P = 0.0001$) and general religiosity ($P = 0.003$), were identified as predictors of care burden in mothers of children with autism. This indicates as hope for the future and general religiosity increase, the care burden in mothers of children with autism decreases (Table 3).

Discussion

The present study was conducted to investigate the relationship between SWB and care burden in mothers of children with autism, with a particular focus on identifying the components of SWB that contribute to reducing care burden. Our results showed that SWB is a crucial factor in reducing the care burden in mothers of children with autism. Among the studied spiritual-religious com-

Table 1. Scores of the SWB questionnaire and CBI in mothers of children with autism

Variables	The Mean Percentage of the Maximum Obtainable Score (%)	Range of Changes in the Scale Scores	Mean±SD
SWB	81	288-48	28.3±196.8
Public religiosity	77	8-48	39.0±9.9
Forgiveness	55	8-48	10.6±30
Hope for the future	58	8-48	9.9±31.26
Belief in the afterlife	64	8-48	7.3±33.5
Hope in God	45	8-48	7.3±25.9
Experience meaning and theme	72	8-48	10±37.1
Time-dependent care burden	73	5-25	4.3±19.6
Evolutionary care burden	57	5-24	6.3±15.96
Physical care burden	51	4-20	4.9±12.27
Social care burden	57	5-18	4.8±12.42
Emotional care burden	54	5-23	7.5±14.83
Total care burden	69	24-97	22.3±75.44



ponents, hope for the future appeared as the most crucial factor in reducing the care burden, and a significant negative correlation was observed between hope for the future and the care burden. This result is consistent with that of Kuang et al., indicating the importance of hope in promoting resilience and coping in mothers of children with disabilities [23]. Hope for the future has been proven to increase psychological resilience. Individuals who maintain a positive outlook and envision a better future are more likely to cope with the challenges and stresses

associated with caregiving. This adaptability enables them to manage the care burden more effectively [24]. In addition, hope for the future serves as a motivational force for mothers [25], empowering them to adopt effective coping strategies. When mothers maintain a positive perspective and anticipate favorable outcomes, they are more inclined to engage in proactive problem-solving, seek support, and identify resources that can help alleviate the care burden.

Table 2. Correlation between components of spiritual-religious health and care burden in mothers of children with autism

Variables	Emotional Care Burden	Social Care Burden	Physical Care Burden	Evolutionary Care Burden	Time-dependent Care Burden
Public religiosity	-0.428**	-0.435**	-0.299*	-0.476**	-0.159
Forgiveness	-0.35**	-0.267*	-0.236*	-0.371**	-0.138
Hope for the future	-0.561**	-0.612**	-0.554**	-0.697**	-0.373**
Belief in the afterlife	-0.231*	-0.13	-0.185	-0.149	-0.135
Hope in God	-0.138	-0.177	-0.128	-0.15	-0.095
Experience meaning and theme	-0.169	-0.174	-0.153	-0.166	0.005

*P<0.05, **P<0.01



Table 3. Regression results of religious-spiritual health components in explaining care burden

Variables	P	t	Coefficient β	Standard Error	B
Public religiosity	0.003	-3.03	-0.33	1.16	-3.53
Forgiveness	0.38	0.87	0.09	0.75	0.65
Hope for the future	0.0001	-4.72	-0.53	11.06	-5.02
Belief in the afterlife	0.07	1.91	0.22	1.38	2.64
Hope in God	0.78	0.27	0.03	1.08	0.29
Experience meaning and purpose	0.81	0.23	0.02	1.12	0.26

In addition, in the present study, general religiosity could significantly predict care burden. Hatefi et al. proved the relationship between care burden and religious beliefs among mothers in families with individuals who have chronic diseases [26]. Religion and spirituality can provide a sense of meaning and purpose in life. Alshammari et al. found that individuals who perceive caregiving as having deeper meaning or who align their caregiving with their religious beliefs experience lower levels of caregiving burden [27]. Religiosity can provide a framework that helps mothers view their role as part of a higher purpose, leading to a more positive and meaningful caregiving experience. Additionally, religious beliefs and practices foster feelings of hope, optimism, and trust in a higher power. These factors can positively influence mothers' ability to cope with caregiving burdens, maintain their well-being, and persevere during challenging times.

The study showed that the dimension of general religiosity had the highest mean score among the spiritual-religious components studied. This indicates that mothers of children with autism may turn to religion as a source of comfort and support in their caregiving roles. This result is consistent with a previous study that highlighted the importance of religious coping in promoting psychological well-being among mothers of children with disabilities [28]. Data analysis showed that hope for the future received the lowest mean score among spiritual-religious components measured among mothers of autistic children. These results show that mothers may face challenges in maintaining hope and optimism regarding their children's future outcomes. The prospect of their children growing up in society can be a source of anxiety and uncertainty [29], potentially contributing to a lower score in hope for the future. Given that hope for the future was identified as a crucial predictor of caregiv-

ing burden in this study and received the lowest score among the components of SWB, it is essential to design interventions aimed at increasing hope in mothers of children with autism. These interventions could include strategies, such as goal setting, positive thinking, fostering realistic expectations, and promoting resilience.

The results of this study showed that the care burden for mothers of children with autism falls within the medium range. This finding is consistent with the study conducted by Shrestha et al. in Nepal [30]. This result can be explained by the fact that the continuous care of an autistic child is associated with psychological stress, frustration, and depression, all of which can impact the mental health of mothers and contribute to their care burden [31]. Autistic children present significant challenges for their mothers. Following a diagnosis of autism, mothers encounter substantial issues related to their children's symptoms and the need for special, long-term care [32]. Parents must simultaneously meet their own needs and those of their children, leading to increased pressure across all physical, emotional, social, and economic dimensions, as well as changes in their lives resulting from their caregiving roles [33]. It is important to note that the average range of caregiving burden reported in this study does not capture the individual variation in burden experienced by mothers. The caregiving burden is a multifaceted construct that is influenced by various factors, including the child's level of functioning, available social support, financial resources, and access to health-care services. Future research should examine these factors to gain a more comprehensive understanding of the caregiving burden experienced by mothers of children with autism.

The results of this study showed that the time-dependent care burden received the highest possible score. This finding suggests that mothers of children with autism face significant challenges related to time management and disruptions in their daily schedules. The demanding nature of caring for children with autism often requires constant attention and supervision, leaving mothers with limited time for self-care, personal activities, and social interactions. For example, Saccà et al. [34] examined the experiences of mothers in caring for children with autism and found that the need for time was the central theme in their narratives. The authors emphasized that mothers feel constantly pressured due to the demands of constant supervision, participation in therapy sessions, and managing the child's daily schedule. Also, Estes et al. [5] found that higher levels of time-related caregiving burden were associated with increased maternal stress and depressive symptoms among mothers of children with autism. These results underscore the importance of considering the time-related caregiving burden in interventions and support programs for mothers of autistic children. Conversely, the physical care load received the minimum possible score in this study, suggesting that the mothers participating in this research may have access to support services or interventions that help alleviate their physical care burden.

Our study highlights the importance of considering SWB as a potential factor in reducing the caregiving burden in mothers of children with severe autism. It provides crucial insights for designing effective interventions and support systems by identifying specific components of SWB that contribute to alleviating the caregiving burden. Future studies are needed to further examine the relationship between SWB and caregiving burden in this population, as well as to design interventions that promote SWB as a means to reduce stress and caregiving burden.

The present study also had limitations. It was conducted only in the autism centers of Qom City. Additionally, this study focused exclusively on caregivers of children with autism, while examining the burden experienced by caregivers of individuals with diabetes, chronic obstructive pulmonary disease, mental disorders, Alzheimer's disease, and cancer could also provide valuable information. Another limitation was using a self-report tool for data collection, which may introduce bias.

It is suggested that future studies evaluate more effective factors influencing caregiver burden and assess the effectiveness of psychological interventions in improving the caregiving burden and the QoL of caregivers.

Ethical Considerations

Compliance with ethical guidelines

In the current study, all ethical considerations were observed. This study was approved by the Ethics Committee of [Qom University of Medical Sciences](#) Qom, Iran (Code: IR.MUQ.REC.1401.063).

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Authors' contributions

Study design: Maedeh Maarefi and Zahra Taheri-Kharami; Sampling: Maedeh Maarefi and Elham Abbasi; Statistical analysis: Zahra Taheri-Kharami; Writing the original draft: Zahra Saboohi; Supervision, review and editing: Zahra Taheri-Kharami and Masoud Hasanzand-Amouzadeh.

Conflict of interest

The authors declared no conflict of interest.

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