

The Causal Factors Associated with the Loving Care of the Mothers of Children with Multiple Disabilities

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ABSTRACT

Background: Families with disabled children need more psycho-social considerations. Motherhood care of the children with multiple disabilities is difficult. Due to its importance, the aim of this study was to investigate the causal factors affecting loving care of mothers of children with multiple disabilities.

Methods: The study used a cross-sectional method in which 75 mothers of exceptional children with multiple disabilities (physical and mental) in elementary schools in Shiraz, Iran. The data were collected through questionnaires which, besides demographical factors, evaluated the relationship between mothers' loving care of children with multiple disabilities and four other variables including purpose in life, life satisfaction, religious attitude, and sense of coherence. Mann-Whitney U was used for comparison between mothers' loving care and other variables.

Results: Results revealed that demographic variables did not have a significant relationship with loving care. In the case of social variables, there was a significant relationship between mothers' loving care and purpose in life ($P<0.001$), religious attitude ($P<0.001$), and life satisfaction ($P=0.01$).

Conclusion: Motherhood care of disabled children is a unique phenomenon which is due to attachment of mother-child situation. Nevertheless, these mothers are vulnerable and marginalized people who need more attention and social supports provided by related governmental institutions and also NGOs actors.

KEYWORDS: Health care; Mother-child relation; Disabled persons; Attachment theory

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INTRODUCTION

Having healthy children is a divine gift to a family.¹ The birth of children with defects, disabilities and incapacities leaves an adverse impact on the family and parents.²⁻⁴ Families usually take different strategies when faced with a disabled child including abandoning them, or entrusting them to orphanages or other related institutions. Yet, most families try to find a more appropriate solution which is protecting and raising the disabled child, despite all of the difficulties involved. On the other hand, taking care of children with disabilities, apart from economic costs,^{5,6} is associated with stress and psychological strains for families.⁶⁻⁸ The type of disability and the degree of its impact are indicators of the burdens that the family may go through. Meanwhile, children with multiple disabilities (accompanied with cerebral palsy and mental, bodily and motor disorders) would bring about the most pressurizing experience for families.^{9,10}

Although fathers of such children are engaged with the children's problems and issues,¹¹ mothers usually experience the most extreme pressures in caring for their disabled children.^{1,12-14} Because of this situation, such mothers possess a different psychological status from that of mothers with healthy children.¹⁵ Because children with disabilities receive different types of care, the satisfaction of such children and their parents depends on the variety of child care types.¹⁶ Thus, mothers and their children with multiple disabilities, due to the wide range of special cares needed, suffer from harshest physical and psychological strains. Whether mothers have occupational responsibilities or not is another factor affecting the situation.¹⁷ As a result, besides psychical problems of childcare,¹⁸ such mothers go through a particular type of psychological pressure.

Studies in Iran confirm poor performance and shortcoming in the families with disabled children.¹⁹ Mothers of children with disabilities suffer from depression.²⁰ Yet, there was not any study to evaluate the relationship

between psycho-social factors and loving mothers' care. The survey that was done in 2006 showed that the number of the people with disabilities was approximately 1,100,000 in Iran.²¹ Considering the importance of this critical figure and challenges with which families with disabled children are faced, the aim of this study was to evaluate the factors affecting mothers' loving care for disabled children. In fact, the study seeks to address the question why, despite numerous complications, mothers of children with multiple disabilities passionately take care of their children. The research hypothesis is that mothers' loving care of disabled children is a variable that might have a relationship with four social variables including purpose in life, life satisfaction, religious attitude, and sense of coherence. Also, the research attempts to compare the results with other related theories related to mothers' care of disabled children.

MATERIALS AND METHODS

The study was a survey (analytic and sectional) in which convenience sampling was used from Jan till Aug 2012, Shiraz, Iran. The population included all of the mothers of children with multiple disabilities in elementary schools for Exceptional Children in Shiraz city, Iran. The data collection instrument was a questionnaire with two sections; one of the sections measured demographical variables, whereas the other part measured the four social variables of purpose in life, life satisfaction, religious attitude, and sense of coherence. Experts confirmed the face validity of the variables. Motherhood loving care as dependent variable was researched in the questionnaire including 12 items about mothers' feelings and their attitude toward their care given to disabled child(ren). These items were ranged in 5 options of Lickert scale from complete agree to strongly disagree. Sense of coherence was incorporated as a Persian translated part of Antonovsky's scale. The questionnaire was translated by the researchers through the simple communicative translation method. Because the designer of the questionnaire wasn't available, we

did not use forward-backward translation. This customized questionnaire evaluated the participants' feeling and included 29 items at scale which had 5 ranges from never to always have this feeling. Validity of the all variables was confirmed; Cronbach's alpha coefficient was 0.84 for this scale.²² For the other scales, Cronbach's alpha coefficient was found 0.80.

To collect the samples, a statistical survey was conducted on children with multiple disabilities based on data in Department of Education of Shiraz. According to the findings, in 2012, 120 children with multiple disabilities studied at an elementary level in exceptional children's schools. All of these mothers were included in the study and there were not any exclusion criteria. After making inquiries of administrators in Department of Education of Shiraz, it was found that a number of these students had dropped out of school; also, some mothers did not tend to fill out the questionnaires. Therefore, 20 mothers weren't available and 15 people didn't return the questionnaires. Finally, 75 questionnaires were completed, after the parents expressed their verbal consent. Following calculation of the frequency and means of the data, to conduct the analysis, we used a number of tests. Because distribution of mothers' loving care wasn't normal, we used Mann-Whitney U for comparison between mothers' loving

care with the child's gender and age, mothers' education, fathers' education, number of children, and number of disabled children in the family. Pearson's correlation coefficient was used to detect the association between mothers' loving care and purpose in life, life satisfaction, religious attitude, and sense of coherence. In this research, SPSS 17 at the 0.05 level of significance was used. It should be mentioned that this research was approved by the ethics committee of university.

RESULTS

Descriptive analysis of the data revealed that 24 mothers had male children, whereas 24 had female children. Out of this sample, 43 students were older than 10 years of age and 32 of them were younger than 10 years of age. As far as the parent's education level was concerned, 41.3% of mothers and 42.5% of fathers had secondary school diploma (according to Iran's education system). Most of the families (55.4%) had less than two children, and 53.4% of them had more than one disabled child. Table 1 illustrates the demographical specifications of the participants.

To achieve the aims of the research, inferential analysis was conducted to determine the relationship between the dependent variable and independent variables. Thus, the relationship between independent

Table 1: Frequency distribution of demographical variables

Variable		Frequency	Percentage
Child gender	Male	51	68%
	Female	24	32%
Child age	10>	43	57.3
	10≤	32	42.7
Mothers' education	Illiterate	16	21.3
	Secondary school diploma	31	41.3
	High school diploma	25	33.3
	BA or beyond	3	4
Fathers' education	Illiterate	14	19.2
	Secondary school diploma	31	42.5
	High school diploma	19	26
	BA or beyond	9	12.3
Number of children	1	41	55.4
	2≥	34	44.6
Number of disabled children in family	One child	50	66.6
	>1	25	33.4

variables (demographical and social) and the dependent variable (mothers' loving care for disabled children) was investigated. In the case of demographical factors, statistical results revealed that there was no significant relationship between the gender of disabled children and childcare they received ($P=0.84$). That is, no matter the child was male or female, s/he received motherly care. Furthermore, no significant relationship was found between disabled children's age (divided into two groups of older or younger than 10 years of age) and mothers' loving care ($P=0.84$).

Kruskal–Wallis test also showed that there was no relationship between the education level of mothers ($P=0.18$) and that of fathers ($P=0.39$) and loving care for children. Also, the number of children in the family (total number) and the number of disabled children in the family did not show any statistical significance (Table 2).

As to sociological variables, Pearson's correlation coefficient showed that there was a positive and significant correlation ($P<0.05$) between purpose in life, religious attitude, life satisfaction, and mothers' loving care for disabled children. Yet, sense of coherence did not show any significance in the correlation. That is, mothers' social relations with others and their association to others or isolation from

them did not affect their child care (Table 3).

DISCUSSION

The aim of this study was to investigate the causal factors affecting the mothers' loving care for children with multiple disabilities, in Education Department for Exceptional Children, Shiraz, Iran. The results of the research showed that there was not any significant relationship between demographical variables and mothers' loving care. That is to say, children's age, gender and number of disabled children in a family did not show any association with mothers' loving care. Given the cultural and social context of the Iranian society and also the importance of such concepts as mother and motherly love in this context, the present research confirmed the hypothesis that age, gender, and number of disabled children would not affect the mothers' childcare. Thus, it can be argued that mothers have a specific attachment to their children, and that motherly love is an innate attribute not affected by demographical variables.

On the other hand, investigating sociological variables showed that there was a relationship between religious attitude and loving care. This finding confirms that strategy of adaptability was associated with religion in parents with

Table 2: Relationship between demographical variables and mothers' loving care for disabled children

Variable		Mean	P value
Child gender	Male	44.228.04±	0.84
	Female	44.6811.31±	
Child age	10>	44.317.89±	0.96
	10≤	44.4210.69±	
Number of children in family	2≥	33.931.87±	0.31
	2<	34.092.04±	
Number of disabled children in family	One child	33.542.82±	0.43
	1<	21.833.08±	

Mann-Whitney U test is less than $P=0.05$ level of significance

Table 3: Correlation among sociological variables and mothers' loving care for disabled children

Variable	r value of Mothers' loving care	P value*
Purpose in life	0.58	<0.001
Religious attitude	0.52	<0.001
Life satisfaction	0.42	0.01
Sense of coherence	0.22	>0.05

*Sig. $P<0.05$

disabled children.² Also, a research in Kuwait, which is similar to Iran in terms of religiosity, showed that religious beliefs had an adaptive role in parents of children with disabilities.²³ In fact, it could be argued that the more the strategy of adaptability is used, which is associated with religious concepts, the more the mother's psychological capacity will be in protecting her disabled child or children. As religiosity has a main role in coping strategies of disabled people such as women with breast cancer,²⁴ mothers of disabled children cope with this situation and continue loving care of their children.

Another finding of the study was the association of life satisfaction and mothers' loving care. Although numerous studies have addressed life satisfaction of mothers' of with disabilities, the literature does not seem to include any research specifically concentrating on the relationship between this variable and mothers' loving care. Apparently, although life satisfaction might be felt lower in mothers of disabled children, compared to mothers of healthy children, at any rate, life satisfaction represents an important role in childcare. That is because when the mother is reasonably satisfied with life, she will enjoy higher levels of motivation to provide care to her child. Another research finding revealed that those with higher levels of emotionality are more satisfied with life.²⁵ Thus, there is a correlation among mothers' emotions and feelings, life satisfaction, and care for the disabled child.

The important finding of the present study was that purpose in life did not only have a significant relationship with mothers' loving care, but also it showed the highest coefficient as a predictor for such care. Generally speaking, purpose in life is a strong conceptual construct that affects many issues including care for disabled children. As Schaefer et al. point out, purpose in life predicts both health and longevity, suggesting that the ability to find meaning from life's experiences, especially when confronting life's challenges, may be a mechanism underlying resilience.²⁶

As far as meaningfulness is concerned, life is a multifaceted construct which is shaped in different directions and involves a broad perspective of values such as purpose in life, important goals in life, and spirituality.²⁷ It was shown that purpose in life had a significant impact on such children's interpersonal relations.²⁸ Results of the present study confirm this finding. Given the cultural and religious context of the Iranian society, and given the fact that there was a significant relationship between religious orientation and child care, it can be concluded that there is a correlation among religion, purpose in life, and child care, in such a way that religious concepts can constitute a specific approach to life, affecting the mother's care for her child.

As far as the sense of coherence and its impact on care for disabled children are concerned, it was shown that the sense of communication had a significant relationship with coping strategies of mothers of autistic children.²⁹ The results of the present study rejects this findings, although it supports the fact that social norms were an obstacle to motherly care of patients with brain injury, and that such norms only imposed a peripheral role on the mothers.³⁰ The "stigmas" are an obstacle to disabled people.³¹ Customarily, social stigmas in developing countries are barriers to disabled children and their families, specifically affecting psychosocial status of mothers. Considering the cultural and social context of Iran, it can be argued that such mothers possess lower levels of sense of coherence, which, if enhanced, can considerably contribute to their care of their disabled children.

From theoretical consideration as to motherhood loving care, there are three approaches which could be discussed. First, theory of individuals' preferences, values, and rational economic choices³² defines parenthood care of children as a cost-benefit issue. The new household economy and individualization show rational choice of social actors about their behavior.³³ These theories related to an important social theory

called rational choice theory. In this theory, people are seen as spurred by the needs or objectives that express their 'preferences'. They act inside particular, given requirements and on the premise of the data that they have about the conditions under which they are acting.³⁴ This theory utilizes a particular and smaller meaning of "rationality" basically to imply that an individual goes about as though adjusting expenses against advantages to arrive at action that maximizes personal advantage.³⁵

This theory can't explain motherhood loving care of disabled child because this is a difficult, exhausting, and high cost care. It not only doesn't include any objective and preference for mothers, but it is the cause of many psychosocial and physical problems for them. Even if it is accepted that religious beliefs are rewards in the hereafter, it can't be satisfied for some mothers. Also, as the study showed, having children with multiple disabilities leads to mother's social isolation and she will be deprived of social rewards and preferences. Therefore, rational choice theory can't explain motherhood loving care. In other words, rational and economic approaches which are based on rational economic choices and individual preference include poor approaches to explain this reality.

On the other hand, child care assessments are one part of mothers' value systems, and in turn these arise in specific social and geographical contexts.³² This value system is related to another concept and theory called attachment theory. This is a psychoanalytical theory which explains how individuals react inside connections when harmed, differentiated from friends and family, or seeing a risk.³⁶ According to J. Bowlby who is known as the father of attachment theory, the mother consequently has a bond to the kid on the grounds that she conveyed it for 9 months; however, early contact is essential in shaping solid bonds between them.³⁷ Bowlby concluded that the newborn child and youthful youngster ought to experience a warm and consistent association with his/her mom (or

perpetual mother substitute) in which both discover fulfillment and pleasure and that not to do as such may have critical and irreversible emotional wellness outcomes, were both dubious and persuasive. Given this relationship, feelings of blame and nervousness (attributes of dysfunctional behavior when in abundance) would grow in a composed and direct way. Commonly amazing feelings would be directed and get to be agreeable to the control of the tyke's creating identity. He expressed, it is this perplexing rich and remunerating association with the mother in the early years, differed in incalculable courses by relations with the father and with kin, that youngster therapists and numerous others now accept to underlie the advancement of character and emotional well-being.³⁸ Therefore, mother has experienced growing another human beings during 9 months and after birth she is caring of her child during ongoing times. This leads to formation of mother-child relationship which becomes richer and more complex over time.

Another theory that can be discussed is theory of human caring which was presented by J Watson in nursing discipline. Care in this theory is an ethical-moral-philosophical values-guided foundation which forms caring-healing modalities. Therefore, nurses were informed by a deeper vision and ethical commitment to the human dimensions of caring in nursing-the art and human science context. Accordingly, nursing care includes humanistic-altruistic values, loving-kindness and equanimity for self and others, cultivating sensitivity to oneself and others, and cultivating one's own spiritual practices on one hand and systematic use of scientific (creative) problem-solving caring process, promoting trans personal teaching-learning, and allowing for existential phenomenological dimensions in another.³⁹ Nursing care in this view is a package of science, art, and love.

Comparison of these three theories shows that attachment theory is more powerful than other theories. As mentioned, motherhood care of multiple disabled children is difficult and exhausting, not to mention its high cost.

Such care can't include any preference. Although the theory of human caring, is a novel idea, it can't explain all dimensions of motherhood loving care of disabled child. According to this view, human caring includes two beneficiaries, self (care provider) and others (care giver). However, motherhood care of disabled children is a care which one person (disabled child) benefits of it. In this critical care, them other only dedicates and her body and soul weaken during caring of child. Therefore, she doesn't pay any attention to herself. She doesn't pay any attention to her costs, vulnerability, and interests. She ignores many of her needs and thinks about her child (ren). On the other hand, this kind of caring doesn't have any relationship with scientific modalities as Watson has mentioned. Therefore, motherhood loving care of disabled child is a specific care which is related to her attachment and affiliations to her disabled child. This form of care is holistic and is related to motherhood loving.

We can't know all dimensions of this specific relationship, care, and phenomena, but we can help these vulnerable humans to identify the factors related to this type of care. According to results, policymakers of social institutions, especially Social welfare Organization, as well as institutions affiliated with the Health System, are recommended to consider the triad of variables including religious orientation, purpose in life, and life satisfaction, and to enhance plans in this regard. Also, they have to consider the social isolation of these mothers and take measures to develop their social relationships so that their sense of coherence can be promoted.

The strength of this study was consideration of the problems of mothers having children with multiple disabilities as a vulnerable group in the context of Iran. Researchers also recommend that in-depth qualitative as well as quantitative studies on such mothers should be conducted studies, especially in the context of Iran.

Due to lack of related research on this topic in Iran, we did not find any available data to

compare our findings with. Because of this, it was challenging for the researchers to explore the background of the problem in the country in specific detail.

CONCLUSION

Mothers of disabled children are vulnerable and marginalized individuals. Having disabled children is an additional pressure for them and their families. Because disabled children need permanent care, mothers should take care of their children until the end of life. This is a boring and repetitive care which leads to mothers' mental and physical fatigue. The most important factor in continuity of this grueling care is motherly love. Findings of this research revealed that life satisfaction, purpose in life, and religious orientation had a significant association with loving care of mothers with disabled children. Theoretical discussion shows that attachment theory better than the other theories (rational choice theory and theory of human caring) can explain this critical form of care. Therefore, Policy makers of Welfare Organizations and the Health System are recommended to focus on this variable as an important and effective factor.

Conflict of Interest: None declared.

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