

Comparing the Parenting Role Tasks in Parents of Children with Mental/Physical Disabilities

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Abstract

Background

The role of parents during childhood is very important. Imbalances in parenting roles may cause severe emotional and physical injuries in children. The current study aimed at comparing parenting role tasks in parents of children who affected to mental/physical disabilities.

Materials and Methods

In the current cross sectional study, the parenting role tasks questionnaire was completed for 230 married couples with at least one child with disability and the parents were selected by convenience sampling method. The parenting role tasks were compared between mothers and fathers. Independent t-test, chi square and analysis of variances was used to compare the scores between fathers and mothers based on studied variables including demographic variables, types of child disabilities and history of trauma and seizure.

Results

Among enrolled children, 49 (21.3%) had mental and 99 (43%) affecting to physical disabilities. A significant difference regarding the parenting role tasks between mothers and fathers; therefore, the mean score of mothers for parenting role tasks was significantly higher than that of fathers regarding different variables such as demographic data, seizure, trauma, and the type of disabilities in the child ($P < 0.001$).

Conclusion

The total score of parenting role tasks questionnaire and scores of its four subscale, including primary cares, leisure time, education and training and improving cognitive level, was higher in mothers than fathers. Our results indicated that the negative effect of children's disabilities on the balance of parental role and more pressure is bearing by mothers.

Key Words: Children, Disability, Parents, Parenting Role Tasks.

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1- INTRODUCTION

Family is a sacred institution, the main core of community, and one of the basic factors in the transmission of culture, thoughts, ethics, traditions, and emotions from one generation to another (1). Parents, as the most important persons in children's lives, play the most prominent role in facilitating the growth and development of children. The role of parents is very important for the children and their current and future lives (2, 3). Parents' role and beliefs have crucial hereditary and environmental effects, which can facilitate or inhibit the growth and development of children (1, 4, 5). As family is a social system that any disorders among the members disrupt the whole system. During the incidence of such disorders, parenting role becomes very important to resolve the problem (6, 7).

The birth of a child with disability in a family affects the destiny of all family members. Children with disabilities have lower abilities in life; they can be the cause of prosperity and happiness for themselves and families through education and training, and the opposite is also true; inappropriate educational and training methods, improper biases, and unseasonable compassion may impose heavy burden on the families (8, 9).

Parents of a child with disability show different reactions once they understand the disability and impairment of their child; from despair, hopelessness, and deny to logical exposure to the problem and decide to help and assist their child to continue and succeed in his/her life (10, 11). Since such children usually have special situations and impose different difficulties and costs to their families, if neglected by their parents, they experience irreversible mental and psychological damages, which are more stressful than the disability alone for the parents, especially the mothers. In addition, continuation of such conditions may result in family

breakdown or the isolation of the ill child and expose the family to major mental health challenges (12). Kilhofner et al. defined parenting role by occupational therapy concepts based on the model of human occupation for the first time (13). This model focuses on providing a comprehensive approach for people with different special needs through their lives. They showed the relationship between the mind and body and the influence of such relationships on motivation (as an internal factor) and implementation of activities (as an external factor) (13).

Kilhofner divided the variables into 3 subsystems including volition, habit, and performance capacity. The volition subsystem includes the source of motivation to work and constitutes of values, interests, and self-perception and self-concept. The habit subsystem includes activity in a repetitive and continuous format including habits and roles. Performance capacity subsystem includes mental and physical abilities to perform activities (14). As mentioned above, the role of parents is defined based on habits and their roles are repeated so many times that come into a habit for both parents and infants. According to this model, parents play roles based on their personal attitude and performance, and considering one role may result in negligence of others, based on the children's disabilities (15, 16).

Specific instruments were provided in this model to evaluate some roles such as laboring, parenting, teaching, studentship, etc. including Occupational Self-Assessment (OSA) and Worker Role Interview (WRI) (17, 18). Nevertheless, a standard tool was developed by Lotfi et al., in Iran, based on the human occupation model to assess parenting role and responsibilities with suitable validity and reliability to compare the engagement of parents in parenting role of disabled children (2).

Imbalances in parenting roles may cause serious mental, emotional, and physical damages to the child and family. Recent studies indicated that parents of children with special needs could not play their own roles properly. These parents spend most of their time on taking care of their ill children, which decreases their life satisfaction (19, 20). It is showed that proper relationship of family and parental response to children behavior who are affected to mental disorders could affect the sequences of disease (7). These consequences due to the disability of children is more effective in mothers' life than father due to their engagement in growth and development of children (4, 5).

Considering the important role of parents in children lives especially in disabled children, there were few studies on the differences in the distribution of parenting role between mothers and fathers engagement in care of children with handicap. Since, there was not found same study in Iran to compare the PRT in parents of children with handicap the current study aimed to comparing parenting role tasks in parents of children who affected to mental/physical disabilities. Therefore, the results of current study could help to balance roles, reduce the excessive responsibilities imposed to one parent, and promote parents to participate in treatment and rehabilitation of their disabled children.

2- MATERIALS AND METHODS

2-1. Study design and population

The current cross sectional study was conducted on 460 parents including 230 mothers and 230 fathers who have at least one child with physical/mental disabilities and were selected by convenience sampling method in Ghaemshahr, Joybar and Shirgah cities, Mazandaran province, North of Iran. Considering the formula for means comparison and the characteristics of parenting role tasks questionnaire based

on pilot study, the study sample size was calculated. Cochran formula was used by considering power, 0.80%, type one error 0.05, and the precision equal 0.2 as difference of scores between mothers and fathers and estimated as 154 cases in each group. Therefore, to enhance the validity of the values, 230 couples were enrolled in each of the study groups. Then, the questionnaires were collected based on the interview and completing of questionnaires.

2-2. Methods

The primary outcome in this study was the score Parenting Role Tasks questionnaire in parents of children with disability. To distribute and collect the questionnaires, a group of four trained researchers was formed. The necessary information regarding the study objectives and the way of questionnaires distribution was mentioned for maximum cooperation of selected parents. Then, the questionnaires were distributed among the parents who referred to the rehabilitation centers of studied cities for rehabilitation of their disabled children. The questionnaires were completed by one of the family members, if the parents could not read and write. It took only 20 minutes to complete the questionnaire. The healthy or disability status of children was confirmed through investigating their medical profiles. In the current study, disability was referred to as a group of permanent disabilities on different physical, sensory, and mental-psychological areas, which cause limitations or problems to the involved person in his/her daily life, compared to the other people in the society (21).

2-3. Measuring tools: validity and reliability

A standard questionnaire was used for data collection that contains two different section including demographic characteristics for child/ parents and Parenting Role Tasks (PRT) (2, 13). The

demographic section of questionnaire included age of child and their parents, type of child's disability (mental, physical, and mental-physical), history of seizure and trauma, parent's level of education (under diploma, diploma and college's degree), parent's occupation (house wife, part-time and full-time jobs), mother job and income level of family. The second section of data collection tool was the standard PRT questionnaire that was developed by Lotfi et al., for the first time in Iran at 2014 (2). It is based on the Kilhofner model of human occupation (13, 14) that defined parenting role for the first time by occupational therapy concepts. The reliability and validity was reported as good. Lotfi et al. is reported that Content validity index was 0.93 and the content validity ratio calculated as 0.80 (2). The reliability of Questionnaire in our study estimated by Chronbakh Alpha and become to 0.86.

The questionnaire was designed in four subscales including primary cares (16 items), leisure time (8 items), education and training (6 items), and improving the cognitive level (3 items). Each subscale categorized in the dimensions of tasks including ability to do work, and level of importance. It is noteworthy that the total score of each column (tasks, ability to do work, and level of importance) was divided by the number of items in each subscale. Besides, to determine the total score of parenting role tasks, the scores of 4 subscales were summed up and divided by the number of subscale (4 scores). Higher scores indicated higher abilities to do parenting role tasks and their more importance to the parents. Each question in this questionnaire could take minimum 0 and maximum 9. Therefore, the minimum and maximum of the total questionnaire varied between 0 and 297.

2.4-Ethical consideration

All participants signed the informed consent and the Ethical Committee of Arak

University of Medical Sciences approved the study protocol.

2-5. Inclusion and exclusion criteria

The inclusion criteria were including living mother and father of disabled child, having at least one child less than 7 years old with disability, age of parents between 20 to 60 years, living with the spouse during the study, and willing to participate in the study. The exclusion criteria were having a child with unclear health status or type of disability and unwillingness to participate in the study.

2-6. Data Analyses

The quantitative data were expressed by descriptive statistics as mean \pm standard deviation (SD) and the qualitative data by frequency and percentage. Inferential statistics for the qualitative data was analyzed using independent samples *t* – test, and analysis of variances were used in SPSS version 18.0. T-test was used to compare the mean score of questionnaire and dimensions between fathers and mothers as well as to assess the effect of history of seizure and trauma. Moreover, analysis of variances was used to evaluate the effect of parent's level of education (under diploma, diploma and college's degree), parent's occupation (house wife, part-time and full-time jobs) and type of child's disability (mental, physical, and mental-physical) on the parenting role tasks scores.

3- RESULTS

Among children enrolled in the current study, 119 (51.7%) were female and 49 (21.3%) had mental and 99 (43%) affecting to physical disabilities. Moreover, 82 (35.7%) had affected to both of mental physical disabilities. The history of seizures and trauma was reported in 40.4% and 3.5% respectively. Caring from disabled child with by mothers in 97.4% and 3.9% reported that having other disabled child (**Table.1**).

According to the results in **Table.2**, the mean score of total score of parenting role tasks and its subscales including primary cares, leisure time, education, and training, improving cognitive level of mothers were significantly higher than (total of 129 score) of fathers ($P < 0.001$). Moreover, our results indicated that the mean total score of the questionnaire was significantly higher in mothers than fathers ($P < 0.001$).

The mean score of Subscales of questionnaire including primary cares, leisure time, education, and training and improving cognitive of the parenting role tasks questionnaire based on different dimensions of each subscale is provided in **Table.3**. Our results showed the scores of tree dimensions of each subscales including duty scope, ability and importance from 4 subscales of questionnaire were significantly higher in mothers than fathers. Nevertheless, when the mean total score of role tasks questionnaire and its subscales compared between fathers and mothers, the means was significantly higher in mothers in all

dimensions and subscales ($P < 0.001$). However, in stratified analysis (**Table.3**) the mean scores of all dimensions and subscales of questionnaire was higher in mothers than fathers ($P < 0.001$).

The stratified analysis conducted based on the total score of the questionnaire and its subscales to compare the mean score of fathers and mothers according to the some studied variables such as seizure history, trauma history, and type of child disability. Independent sample t-test showed that there was no significant difference in mean score of role tasks in mothers/fathers separately, based on the seizure history and trauma history ($P > 0.05$).

In addition, analysis of variance showed that there was no significant difference in mean score of all dimensions and subscales of questionnaire ,including primary cares, leisure time, education and training and improving cognitive level, in mothers and fathers based on the type of child disability ($P > 0.05$).

Table 1: Demographic characteristics of disabled children that participated in study

Demographic Variables		Frequency`	Percent
Gender	Boy	111	48.3
	Girl	119	51.7
Abnormality	Mental	49	21.3
	Physical	99	43
	Both Mental and Physical	82	35.7
History of seizures	Yes	93	40.4
	No	137	59.6
History of trauma	Yes	8	3.5
	No	162	70.4
	Unknown	60	26.1
Mother education	Under diploma	82	35.7
	Diploma	102	44.3
	College	46	20
Father education	Under diploma	72	31.3
	Diploma	103	44.8
	College	55	23.9
Mother job	Homemaker	208	90.4
	Staff	21	9.6
Income level	Low	49	21.3
	Moderate	158	68.7
	High	23	10
Caring from disabled child	Mother	224	97.4

	Nurse/Other	6	2.6
Having other disabled child	Yes	9	3.9
Caring from other disabled child	Yes	6	2.6

Table-2: Comparing the Mean \pm Standard Deviation of Total Score of the Parenting Role Tasks Questionnaire and the Subscales in father and mother of Both Groups of the Study

The mean score of	Father	Mother	P-value
Primary Cares	27.59 \pm 23.2	101.96 \pm 20.92	<0.001
Leisure Time	18.8 \pm 9.79	34.49 \pm 13.29	<0.001
Education and Training	7.66 \pm 9.7	36.46 \pm 15.5	<0.001
Improving Cognitive Level	5.67 \pm 4.7	13.51 \pm 6.7	<0.001
Total Score	56.81 \pm 38.91	186.33 \pm 45.4	<0.001

Table-3: Comparing the Mean \pm Standard deviation of parenting role tasks questionnaire based on total scores and subscale of each demotion (1)

Subscales of questionnaire	Dimensions of each subscale	Father	Mother	P-value
Primary care	Duty scope	4.41 \pm 3.68	14.16 \pm 1.94	0.0001
	Ability rate	11.45 \pm 8.97	42.37 \pm 11.54	0.0001
	Importance rate	11.86 \pm 10.9	45.34 \pm 9.25	0.0001
leisure time	Duty scope	2.87 \pm 1.46	5.2 \pm 2.04	0.0001
	Ability rate	6.53 \pm 4.29	14.42 \pm 6.29	0.0001
	Importance rate	6.43 \pm 2.23	14.86 \pm 6.05	0.0001
Education and Training	Duty scope	1.19 \pm 1.5	5.33 \pm 1.9	0.0001
	Ability rate	3.2 \pm 3.9	14.55 \pm 7.25	0.0001
	Importance rate	3.31 \pm 4.43	16.56 \pm 7.03	0.0001
Cognitive improving	Duty scope	0.9 \pm 0.78	2.01 \pm 0.92	0.0001
	Ability rate	2.46 \pm 2.0	5.51 \pm 2.9	0.0001
	Importance rate	2.31 \pm 2.04	5.98 \pm 3.14	0.0001

4- DISCUSSION

The current study aimed at comparing the parenting role tasks subscales, level of ability to do work, and level of importance of such tasks between mothers and fathers of children with mental-physical disabilities in Ghaemshahr, Joybar and Shirgah cities, Mazandaran province, Iran. By comparing the level of importance and the quality of the tasks performed by mothers and fathers, the differences between the roles can be recognized, which results in assisting the parents of such children to play their roles better. Results of the current study indicated that the mean scores of primary cares, leisure time, education, and training, improving

cognitive level, and the total score of parenting role tasks, based on demographic data and clinical status of children, were significantly higher in mothers than fathers. In the other word, mothers of children with disabilities spend a lot of time per day to take care of their children ($p < 0.001$). There was a significant correlation between different subscales of parenting role tasks and the total score of the questionnaire, and the role of mothers in leisure time was significantly more than the fathers. Based on our results, some items of leisure time subscales and also all items of improving cognitive level subscale are usually perform by mothers. These items are telling stories, reading books, talking and playing with the child at

home as well as using educational programs on TV, radio, internet, and books, in addition to consultation with specialists, participation in educational programs, meetings at kindergarten and clinics to assist the child. Since the mothers are not responsible for living costs, and have more presence at home, rehabilitation centers, and kindergartens they work better this roles than the fathers.

On the other hand, parents of children with disabilities deal with different problems that result from disabilities of their children such as financial costs, paying more attention and spending money on some care subscales and neglect other subscales such as leisure time. Some items in leisure time subscale including participation in extra-curricular classes, going on trips and entertainment places impose financial burden to the families that is impossible for most of them (22, 23). Results of the current study indicated that the mean score of primary cares, leisure time, education and training, and improving cognitive level subscales and the total score of the parenting role tasks questionnaire, based on seizure, trauma, and disability status of the child, were significantly higher in mothers than fathers ($p < 0.001$). According to the results, the presence, or absence of seizure, trauma, and even type of disability in the child (mental, physical, or both of them) had no effect on reducing the pressure imposed to mothers and in all cases, mothers bear a great part of caregiving.

Another result of the current study was the correlation between the score of tasks realm and the score of primary cares subscale in fathers and such a correlation in mothers was observed between the score of level of ability to do work and primary cares subscales. These results indicated that fathers were merely aware of their tasks in primary cares and their ability in this subscale was insignificant. Accordingly, it seems that this shortage

was in association with the introverted character, financial concerns about the present and future costs of the child, and high probability of depression in fathers. In contrast, mothers showed high ability in such tasks, but it results in more physical problems for the mothers as they play the main role in taking care of their children and have more physical contacts with them (24, 25).

In the subscales of leisure time and education and training, the level of importance and tasks scores had the highest and lowest correlations, respectively. It seems that parents were aware of the importance of leisure time and education and training programs for their children, but they could not play their roles properly due to the high workload of mothers, fathers' less presence at home, and also the definition of common-low on such tasks as maternal duties. Lack of financial means resulted in weakness in dealing with the matters such as buying toys, books, and educational toys in education and training subscale, and going on trips and entertainment programs in the leisure time subscale. However, due to mental disorders in such children, training the skills such as personal hygiene, social behaviors, cognitive-perceptual concepts, and practically motor skills beyond the ability of such children were impossible and were omitted accordingly from the parenting tasks.

Regarding the improvement of cognitive level subscale, fathers showed the highest correlation with the tasks and mothers with the level of importance, which indicated the awareness of fathers regarding their own roles. However, due to the main role of mothers in taking care of their children and financial concerns of fathers about living costs and spending most of their time and income on these cases, the reduced role of parents in the other subscales can be justified largely. The highest and lowest correlations with the

total score of parenting role tasks were observed in the primary roles and improving cognitive level subscales and indicated that having a child with disabilities affects the parenting role tasks negatively. In a way, that meeting one of these subscales (such as primary cares) results in negligence of other subscales (such as improving the cognitive level).

In addition, considering the significant difference in the level of ability and importance of parenting role tasks in the two groups with disabled children, the higher abilities of mothers to do their parenting roles and giving more values to such tasks can be understood. There was a significant difference in the total score of parenting role tasks between the groups, which indicated the negative effect of having a child with disability on the effective execution of parenting role tasks in parents. Different studies indicated the negative effect of disabled children on the other family members, especially regarding psychological adjustment, and showed that mothers of children with disabilities experience higher degrees of anxiety, depression, and other mental complications that probably result from the fact that they deal more with the problems of their children and endure more pressures (26-30).

A study conducted on families in the USA reported that 80% of caregiving tasks were performed by the mothers, while fathers spent much lower time on items such as feeding, bathing, but more time on some others such as playing and school homework. A study conducted in 2015 reported that mothers of children with autism disorder, based on DSM-IV criteria for autism spectrum disorders (ASDs), need more supports on the cases not being met by the fathers (31). Results of a study (24) showed a significant difference regarding the general health status between the parents of healthy children and these ones with children cerebral palsy in the

total score and the scores of following subscales: physical symptoms, anxiety, sleep disorder, depression, and social performance disorder. The results of their study were consistent with those of the studies conducted on the parents of children with cerebral palsy (24). In Iran mothers constitute 85% of the caregivers of children with cerebral palsy; in the developing countries that families have limited resources, such situations cause parents, especially mothers, not to meet other aspects of life properly (32), which threatens their quality of life and health status and indicates that more attention should be paid to this group of the community (33).

As mentioned above, previous studies generally evaluated parents without differentiating mothers and fathers, or even the mothers alone were evaluated. Although mothers deal more with taking care of the children with disabilities, considering the impact of disabled child on the mental status of the father and consequently disruption of father's role in supplying living costs, evaluating the status of fathers was of great importance and the current study aimed to meet such a gap(23, 34). Parents of the children with disabilities have problems and weaknesses in performance and compatibility; hence, they need consultation and educational services, socio-mental and financial-welfare supports (22) by changing parenting styles and balancing the parenting role tasks to reduce the stress, improve mental health, and increase the quality of life in parents, especially mothers of children with disabilities.

Lack of cooperation of rehabilitation clinics, difficulties in accessing the families interested to cooperate with the study, lack of similar studies conducted based on the parenting role tasks questionnaire in Iran, spending much time on finding access to the families, and competing the questionnaires were some

of the study limitations. Finally, further investigations on the parenting role tasks of parents of children with disabilities focusing on the type of disability and assessing different and effective variables on how to do the parenting role tasks are recommended.

5- CONCLUSION

The results of the current study indicated that the lack of balance in parenting role tasks between mothers, fathers, and imposing more responsibilities on mothers. The total score of parenting role tasks questionnaire and scores of its four subscale, including primary cares, leisure time, education and training and improving cognitive level, was higher in mothers than fathers. Our results indicated that the negative effect of children's disabilities on the balance of parental role and more pressure is bearing by mothers. Therefore, in families with disabled children, mothers are at the exposure of different health threatening challenges and problems and prone to severe and even inevitable damages that need urgent and more consideration of authorities and disability policy makers to provide suitable substrates to enhance mental health in parents, especially mothers. To overcome this crisis, it is necessary to reform the roles, structures, and life style of the family to make proper compatibility. Since parents play a significant role in rehabilitation of such children and problems of parents result in improper achievement of rehabilitation goals, by resolving such problems as much as possible, achievement of rehabilitation goals, especially occupational therapy, is facilitated which is an effective step to increase the success and performance of such children.

6- CONTRIBUTION OF AUTHORS

AR; Contributions to the conception or design of the work; analysis, and

interpretation of data and Final approval of article.

SY; Contributions to the conception or design of the interpretation of data for the work; and Final approval of the article.

MK; Contributions to the conception or design of the work and Final approval of the article.

AS.A; Contributions the acquisition and analysis of data for the work and Drafting the article.

HA; Contributions to the conception or design of the work; interpretation of data for the work; and Final approval of the article.

FR; Contributions to the conception or design of the work; interpretation of data for the work; and Final approval of the article.

AM; Contributions to the conception or design of the work analysis, or interpretation of data for the work; and Final approval of the article.

7- CONFLICT OF INTEREST

There is no conflict of interest.

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