



Intellectually Disabled Children and Their Parents' Problems: Preliminary Evaluation and the Suggestion of Effective Strategies

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Abstract

Objectives: Apart from the functional problems that disability creates for the disabled, it has negative effects on parents as well. Thus, identifying these problems plays a decisive role in the health of the family. In this regard, the present study aimed to determine the psychosocial problems of the parents of intellectually disabled children (IDC) receiving services from the Iranian State Welfare Organization in Khorramabad.

Materials and Methods: Participants consisted of the parents of IDC receiving services from the State Welfare Organization of Iran, in Khorramabad during 2015. The data collection instrument was a questionnaire including demographic items and items related to psychological and social problems. The parents of 144 IDC participated in the study and completed the questionnaire via interviews at home.

Results: All parents suffered from psychosocial difficulties although, on average, mothers had more problems due to their different roles in families. Finally, a significant relationship was found between parents' education and the gender of the IDC ($P < 0.05$).

Conclusions: The impact of disability on parents depends on the severity of the disability and parents' coping skills, abilities, and capabilities.

Keywords: Intellectually disabled children, Parent problems, Preliminary evaluation, Effective strategies

Introduction

Family is a small society and a safe place for satisfying various needs of each member (1-3). In addition to creating tension, stress, and confusion in family members (4), any changes or disorders in the family and its members may disrupt the entire family system, exacerbating the disorders of family members and leading to new problems. In this regard, the birth or presence of a disabled child, especially one with intellectual disability, in each family could be a bitter and challenging event (5). Based on the definition offered by the American Psychological Association, the term "intellectually disabled" is applied to a person with an intelligence quotient (IQ) of less than 70 who has problems with coping and adjustment functions, and starts suffering from these problems before the age of 18 (6). According to the figures published by the World Health Organization, 10% to 15% of individuals in developing countries are afflicted with disabilities and between 4% and 4.5% of individuals suffer from a severe disability and thus need to receive special services (3,7). According to the Rehabilitation Center, it is estimated that 3% of the population is intellectually challenged in the United State and this figure is estimated to be about 2% in Europe. Disability is a global and rampant phenomenon

that occurs in all countries (7,8). Similarly, disability affects a large population of more than 1.5 million people in Iran, 3% of whom have severe disabilities. According to censuses taken from 2006-2011, intellectual disability was the most common among 9 forms of disability (7).

Accordingly, intellectual disability is classified into four levels after normal and borderline intelligence, including mild (an IQ between 75 and 80), moderate (an IQ between 55 and 75), severe (an IQ between 35 and 55), and profound (an IQ less than 25) intellectual disability. Individuals with profound intellectual disabilities are completely isolated and cannot communicate with the outside world (7). In this regard, Mohammadkhan-Kermanshah et al indicated that intellectual disability is associated with a failure to thrive in different dimensions. These children perform poorly in learning the expected items, and their parents' efforts to educate them fail to achieve desired results. Therefore, the intellectually disabled child adversely affects the function and structure of his/her family and causes the family to undergo physical, psychological, social, and economic tension and stress. This can disrupt the normal course of family life and cause the breakdown of the family system (8,9). In addition, the disability of one of the children has profound effects on the entire family

Received 23 June 2018, Accepted 15 November 2018, Available online 21 December 2018

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system and its various functions such that it damages the cohesion and structure of the family and can consequently lead to changes in the roles, functions, and adjustment of the family (10). Further, parents are more affected by disability compared to the other family members. Therefore, parents must undergo numerous changes to adjust and adapt themselves to the new member (5,11).

The results of many studies suggest that parents with intellectually disabled children (IDC) suffer from extensive stress and anxiety compared with other parents (6,8,9,12,13). These psychological problems may be due to the concerns of parents about their children's future problems, the severity of the intellectual disability, high financial costs, shattered dreams, pitiful glances and behaviors of other people, wrong beliefs of the society, the lack of adequate information, limited access to education and rehabilitation services, and the contrast related to the existence of other children (14). The presence of these factors together puts a lot of psychological strain and stress on parents, which affects their personal and family lives. The experiences of all relevant authorities in the world show that families not only play the greatest role in the rehabilitation of the disabled but also they are the best place for the growth and development of the intellectually disabled in many cases. The effects of the presence of intellectually handicapped children in the family can be enormous. For instance, financial responsibilities, the disruption of the conjugal life, social isolation, and the reduction of the time that parents should spend with their healthy children are known as stressful factors in families (13,15). Furthermore, the presence of an intellectually disabled child is a crushing pressure on parents. In other words, this indicates the death of all their hopes and dreams for what their child might have become and points to the fact that their lives will never be as comfortable and free as it used to be (5,11,16). The extra care that some children with disabilities impose on their parents affects their interactions as well. The occurrence of disability in children can further lead to great emotional disorders and economic problems in the family so that all family members experience crises due to the presence of the disabled individual. Moreover, family relationships become cold and strained, and the social relationships of the family become limited. Additionally, other children develop emotional and social problems and, in general, the mental health of the family which is the guarantor of children's health and personal-social capital is jeopardized severely. Although these families experience greater stress, they are better adjusted (17,18). Researchers argue that children with intellectual disabilities have many needs and are less able to deal with their own problems because of their disability, and this leads to a relative to complete dependence of the disabled on their parents, especially their mothers. Therefore, their disability becomes a constant source of pressure, stress, and tension (3,5,8,13,19).

Accordingly, there is a need for evaluating the problems that the parents face since the intellectual disability of the children can cause significant problems for the parents. Previous evidence shows that the mothers of children with intellectual disability have to deal with many problems. Thus, the identification of their problems and the related factors can help support institutions and guide the families. In this regard, a descriptive and cross-sectional study was designed and carried out to identify the psychosocial problems of parents of IDC referring to the State Welfare Organization of Iran, in Khorramabad.

Materials and Methods

Setting and Participants

This descriptive and cross-sectional study aimed to determine the psychosocial problems of the parents of IDC referring to the State Welfare Organization of Iran, in Khorramabad. In addition, the study sought to determine the relationships among these problems and some individual characteristics, followed by comparing the problems of the parents and providing effective solutions in this regard. The studied population of this study included the parents of 1781 IDC including 247, 588, 623, and 323 children with mild, moderate, severe, and profound intellectual disability, respectively. These children received services from the State Welfare Organization of Iran, the Khorramabad branch, had intellectual disability records in this organization and attended rehabilitation centers on a daily basis. Among these, the parents of 144 IDC (the couple sample) were chosen using the systematic random sampling method. The inclusion criteria were: being under the coverage of the State Welfare Organization of Iran, both parents (mother and father) being alive, living with each other in one place, and keeping the intellectually disabled child in the family.

Procedure

Data Collection Instrument

The data collection instrument was a questionnaire consisting of three parts. The first part consisted of 16 questions about the individual and social information of the child and the parents, including parental age, parental education level, employment status and occupation, monthly family income, parental age at the birth of the disabled child, the age of the disabled child, along with the disabled child's birth order and gender. Further, the other data encompassed the time duration of the child's disability, the consanguinity of parents, the presence of another handicapped child in the family, the disabled child's school attendance status, and the coincidence of physical disability, as well as the intellectual disability and the type of physical disability, the level of intellectual disability, and the level of physical disability. Furthermore, the second part consisted of 26 questions regarding parent's psychological problems and the third part included 12 questions about the social problems of the parents. The

questionnaires were completed by a clinical psychologist using face-to-face interviews at home.

Validity Confirmation of the Questionnaire

To assess the validity of the questionnaire, content validity was used such that the questionnaire was sent to 10 faculty members of Lorestan University of Medical Sciences and their opinions and comments were taken into consideration in its revision. Its reliability for each area (social and psychological problems) was determined using the correlation coefficients ($r = 0.80$), followed by organizing the answers to the questions on a 4-point Likert-type scale. Initially, the coefficients were determined as coefficient 3 = always, coefficient 2 = often, coefficient 1 = seldom, and 0 = never. For each questionnaire, the scores of psychological and social problems were determined separately and their sums were determined accordingly. The questionnaires were completed in one session using interviews at participants' homes.

Results

The results showed that the mean age of the fathers was 50.42 ± 1.32 , 36.2%, 86.1%, and 18.1% of whom were illiterate, employed, and government employees, respectively. Moreover, the youngest and the oldest ages of fathers at the time of the birth of the disabled child was 20 and 56 years, respectively. Additionally, the mean age of the mothers was 43.67 ± 9.13 , 47.3%, 9.7%, and 8.3% of whom were illiterate, employed, and teachers, respectively. Similarly, the youngest and oldest ages of mothers at the birth of the disabled child was 14 and 45 years, respectively. The age of the disabled child varied from 1 to 42 years. In terms of the birth order of the intellectually disabled child, 30.6% of them were first-born. In addition, 66.7% of all disabled children were males and the duration of disability varied from 1 year (2.8%) to 42 years (1.4%). In investigating the number of consanguineous marriages, it became clear that 30.6% of

parents were relatives and 11.1% of them had more than one disabled child at home. Based on the results, 47.2% of the parents indicated that their disabled child attended the school, 45.8% of whom attended special schools. The level of participants' intellectual disability is presented in Table 1.

According to the data, 43.1% of the parents reported that their child suffers from no physical disabilities while 56.9% of them asserted that their child has both types of disability. In terms of the level of physical disability, the majority of the children had a moderate physical disability and only 5.6%, 5.6%, and 9.7% of them had mild, very severe, and severe physical disabilities, respectively. As regards the type of physical disability, 23.6% had motor impairments, 5.6% were deaf, and 1.4% were blind. The mean scores of parents' problems are shown in Tables 2 and 3.

Regarding the severity of social problems, 80.6% of fathers and 69.4% of mothers had moderate intensity social problems. In terms of the severity of psychological problems, 63.9% of fathers and 65.3% of mothers had moderate intensity psychological problems. The results of the Chi-squared test showed that there is a significant relationship between the total psychosocial problems of both parents and the level of education of the mother ($P = 0.013$). Additionally, there were significant relationships among the child's gender ($P = 0.014$), age, the coincidence of intellectual and physical disability, the severity of the intellectual disability, the duration of the disability of the child, and the number of handicapped children in the family with parents' social and psychological problems ($P = 0.05$).

Discussion

The results of the present study showed that the family of an IDC have many social and psychological problems and face different educational, financial, and emotional problems in caring for the child. All these problems put

Table 1. The Relative Distribution of the Intellectual Disability Level of Handicapped Children

Level of Intellectual Disability	Mild	Moderate	Severe	Profound	Total
Relative frequency (%)	12.5	51.4	30.6	5.6	100

Table 2. The Mean and SD of Parents' Social and Psychological Problems

Problems	Mother		Father		The Lowest Problem Score		The Highest Problem Score	
	Mean	SD	Mean	SD	Mother	Father	Mother	Father
Social	1.54	0.69	1.43	0.74	0.0	0.0	3	3
Psychological	1.46	0.55	1.36	0.55	0.16	0.12	2.64	2.76

Note. SD: Standard deviation.

Table 3. The Mean and SD of Parents' Social and Psychological Problems

Problems	Mean	Standard Deviation	The Lowest Problem Score	The Highest Problem Score
Social	0.72	± 1.49	0.0	3
Psychological	1.41	± 0.56	0.12	2.76

pressure on parents and can destroy the peace and stability of the family, and consequently affect their adjustment. The results of a study by Fadakar Sogheh et al (8) regarding determining the problems of families with handicapped children demonstrated that more than half of the studied participants had emotional and social difficulties, and the severity of these problems represented a significant relationship between the disabled child's gender, family income, and the level of intellectual disability.

Similarly, the results of studies by Fairthorne et al (6) and Ahmadi et al (5) on the mental and psychological problems of mothers after the birth of their IDC confirm the results of the present study. In this regard, Fairthorne et al reported that after the birth of an IDC, the mother is gradually encountered with numerous mental and emotional problems that become extremely severe over time, which is due to the pressure of caring for the disabled child (6). The mean monthly care and rehabilitation costs are considerable issues in this respect. In other words, the presence of a handicapped child imposes extra expenses on the family. Given that rehabilitation expenses are not covered by insurance organizations in Iran, the economic problems of this group of families are even more pronounced compared to the other families. Although the findings of the present study showed that 100% of these individuals benefited from the insurance services offered by the State Welfare Organization of Iran, more than 90% of them were not under the coverage of supplemental insurance plans. According to participants, many necessary rehabilitation and care services are not covered by regular insurance plans and not fully provided by the rehabilitation group of the State Welfare Organization of Iran and insurance organizations. Thus, families experience many financial pressures, all of which put mothers at the epicenter of these problems. Therefore, it seems necessary that the provision system of therapeutic and rehabilitation services to the disabled be improved by the State Welfare Organization of Iran. In the present study, more than one-third of parents had consanguineous marriages although this rate was 53.3% in the studies by Taghizadeh and Asadi, as well as Dadkhah et al (3,12). This difference could be because of the awareness and health literacy of marrying couples about the consequences of consanguineous marriages as a result of information and training offered by the media, health and treatment centers, along with the State Welfare Organization of Iran. The results of a study by Shahri et al revealed that consanguineous marriage was the most important factor leading to disabilities and the occurrence of genetic illnesses (20). Accordingly, children born in such families need more specialized care in addition to routine care since the risk of chronic diseases is extremely higher in them in comparison with healthy children. Therefore, caring for these children is a highly difficult task and points to this reality that the presence of an IDC strongly affects the mother's physical and mental health

and reduces their resistance against various diseases and thus increases disease incidence rates among these children (5,8).

The results of this research are not consistent with the findings of Dini-Torki et al that demonstrated no significant difference between the stress levels and the psychological functioning of families with intellectually disabled and handicapped children and families with normal children (21). This inconsistency can be attributed to the different beliefs and values in different societies. According to Khabaz et al, more mentally healthy individuals hold deeper beliefs (22). The results of the present study suggested that the parents of IDC had many psychological problems among which, worry and anxiety were the most prominent. The results of other studies by Ahmadi et al (5) and Fadakar Sogheh et al (8) showed that the parents of IDC experience more stress compared to those with normal children, and symptoms like tiredness, aggression, disappointment, and chronic sadness can be observed in the parents of such children. In addition, the results of the comparison of parents' problems represented that mothers had more psychological problems than fathers, but this was not a statistically significant difference. The results of some studies by Khayatadeh Mahani (23), Ahmadi et al (5), Dadkhah et al (12), and Fairthorne et al (12) support our results. The parents of IDC often experience tension and anxiety. The evidence shows that mothers are more influenced by the condition of their children compared to the other members of the family. This may be due to the fact that mothers are more involved in their children's problems and are under more pressure.

Moreover, the results of the present study indicated that both parents suffer from social problems. The most prominent social problems in families are related to the presence in public places and gatherings, recreation, and trips. In this regard, the results of other studies revealed that the presence of an IDC influences the social situation of a family. On the one hand, the family reduces or cuts off its social relationships with others because of providing services to and being more involved with the IDC and embarrassed about having a disabled child, who displays inappropriate behaviors and behavioral disorders, on the other hand. Therefore, family members become socially isolated and withdrawn and get less involved in social activities, and this leads to more social problems in families (5,8,21).

Based on the results of the present study, a significant relationship was found between the level of parents' education and their social and psychological problems ($P = 0.013$) so that mothers with less education (illiterate and elementary school) had more social and psychological problems although the share of psychological problems was more considerable. These results are in line with those of some other studies (5,12), indicating that parents' higher educational attainment levels lead to their further adjustment with the disability of their children (1,5,12).

The consanguineous marriage of paternal cousins had the highest frequency in this study, which corroborates with the results of other studies (20,24,25). In their study, Nemati and Asadi found that consanguineous marriage plays an important role in the incidence of intellectual disability because of recessive genes, therefore, the awareness of the couples regarding the consequences of this kind of marriage and receiving genetic counseling is crucial (25). Hajiesfandiary et al also showed that the consanguineous marriage of maternal cousins has the highest frequency among the parents of exceptional children (26). Thus, it is important to pay attention to this point that the birth of a child for parents at any age and condition is a stressful factor, and if this child is born with a type of disability or a combination of disabilities, the psychological, social, and economic pressures on the family increase even more (5) such that this pressure influences and changes the relationships with relatives. Putting an emphasis on separating and hiding the disabled child from relatives, neighbors, and acquaintances leads to loneliness for all family members, and this, in turn, inflicts irreparable psychological damage to the family (5,27). Therefore, the presence of an IDC limits the social relationships of families, and the more severely a child is intellectually disabled, the more limited the free time and social relationships of the parents would be (8,27). In the present study, more than half of the participants stated that their social relationships with their relatives and neighbors had been negatively affected as well. Thus, it seems that passing through this crisis requires repairing and improving roles, infrastructures, and familial lifestyles so that to establish proper adjustments. To this end, families need all-round help and comprehensive support. In the present study, a significant relationship was found between the level of intellectual disability and the presence of multiple disabilities (i.e., the coincidence of mental and physical disabilities) with the social and psychological problems of the parents, which is in conformity with the results of other studies (5,1,8). Accordingly, in families with severely IDC, the disabled child requires more attention in terms of rehabilitation and care, and this issue leads to his/her permanent dependence on his/her parents, especially the mothers. On the other hand, the IDC irrational behavior and noise makes the home a stressful environment for family members, as a consequence of which the views and attitudes of family members and other people become negative regarding the disability of the child, which, in turn, leads to more emotional problems in the families. The findings of the present study showed that the parents of IDC suffer from considerable social and psychological problems. Therefore, measures should be taken to support the parents, especially to emotionally support mothers in order to reduce the psychological tension and stress that they experience. This leads to an increase in their success in dealing with the problems of their IDC in addition to feeling more psychologically calm and relaxed. Based on

the results of the present study, psychological and social problems were extensively higher in low-income families. Similarly, Abasi et al found that a good economic status is an important factor in the mental health of the parents (28), which was confirmed by Fadakar Sogheh et al (8). According to the findings of the present study, there are significant relationships among the variables of parents' education, income, the level of intellectual disability, and the coincidence of intellectual and physical disabilities with both the psychological and social problems of the parents. Thus, health and welfare policymakers can try to ameliorate the problems caused by the presence of a disabled child in the family via codified planning and initial needs assessment and to prevent such problems. Additionally, they can offer fundamental solutions with accessible planning and consequently enhance the health of families and society. Eventually, providing care and rehabilitation facilities at homes and in rehabilitation centers in order to improve the health of the children and their parents can be an effective step in reducing the problems of families with IDC.

Limitations

The present study was of a cross-sectional type. It is recommended that longitudinal studies be conducted on this issue. In addition, the lack of the full cooperation of most parents was one of the serious limitations of the present study such that they did not permit the authors to examine the conditions of the households and the families.

Conclusions

The findings of the present study showed that the parents of IDC are affected by considerable psychosocial problems. Therefore, measures should be taken to support such parents, especially emotional support.

Conflict of Interests

The authors have no conflict of interests to declare.

Ethical Issues

To follow ethical considerations, information was recorded without the names of the participants, and the consent and willingness of the parents were obtained before filling the questionnaire and those who were unwilling to participate were excluded from the study. Before starting data collection, the names of families with IDC were identified in coordination with the State Welfare Organization in Khorramabad and collaboration with rehabilitation centers. Then, the parents were contacted via phone calls, and the consent of both parents was obtained for the study. Eligible participants were selected using the random sampling method from among these couples. This study was approved by the Ethics Committee of Lorestan University of Medical Sciences with the registration number of IR.LUMS.REC.1389.1198.

Financial Support

This study was supported by Lorestan University of Medical Sciences.

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