Original Article

Comparison and Examination of the Death Anxiety of Parents with and Without Having Mental Retarded Children

Abstract

Aims and Objectives: The aim of this study is to have children with and without mental retardation (MR) (diagnosed with MR), it is to compare and examine parents' death anxiety. **Materials and Methods:** The research is based on the screening model. The sample group of the study consists of 120 people in total, consisting of parents (n = 60) of children who are followed up in a private counseling and research center due to the presence of intellectual disability, and parents with typically developed children (n = 60) as the comparison group. Sociodemographic information of the participants, who could be included in the study on a voluntary basis, was filled in by the researcher using face to face interview method using the Sociodemographic Information Form, and their death anxiety levels were evaluated with the Multidimensional Evaluation Inventory for Death and Dying. In comparing the quantitative data of the study, the t test, which is the two independent variable tests, was used to analyze the difference between the two parametric groups. The relationship between the scales was tested with Pearson Correlation analysis. Multiple linear regression was used to see the effect of independent variables on the dependent variable. **Results:** As a result of the research findings, it was found that there are statistically significant differences ($P < 0.05$) between the scores of the compared groups. Death anxiety of parents with mentally retarded children was found to be higher than parents of typically developed children. **Conclusion:** This research is important in terms of providing the opportunity for cross cultural comparison and contributing to the policies to be developed on the subject..

Keywords: *Death, death anxiety, mental retardation, parents*

Zeynep Gümüs Demir[1], Kahraman Güler[2], Emel Aner Aktan[3], Deniz Sevimli[3]

[1]Department of Psychology, Faculty of Humanities and Social Sciences, Üsküdar University, [2]Department of Psychology, Faculty of Humanities and Social Sciences, Aydın University, Istanbul, Turkey, [3]Faculty of Arts and Sciences / Psychology, Dogus University, Istanbul,Turkey

Received: 25-12-2020

Revised: 13-02-2021

Accepted: 17-02-2021
Published: 30-03-2021

Orcid

Zeynep Gümüş Demir {ORCID: 0000-0003-4474-4813}

Kahraman Güler {ORCID: 0000-0002-0049-0658}

Emel Aner Aktan {ORCID: 000-0002-6781-9171}

Deniz Sevimli {ORCID: 0000-0001-8502-8843}

Address for correspondence:
Dr. Zeynep Gümüs Demir Department of Psychology, Faculty of Humanities and Social Sciences, Üsküdar University, Uskudar, Istanbul, Turkey
E-mail: Zeynep.gumus@uskudar.edu.tr

Access this article online

Website: www.jnbsjournal.com

DOI: 10.4103/jnbs.jnbs_46_20

Quick Response Code:

Introduction

Mental retardation (MR), which is among neurodevelopmental disorders, is the inadequacy of adaptive skills and behaviors according to the person's own age and culture.[1] Adaptive skills cover areas related to communication, self-care, family life, interpersonal relationships, academic skills, health, and safety. Confirmed by both clinical evaluation and an accepted measure of intelligence, it is characterized by deficiencies in intellectual functions such as reasoning, problem-solving, abstract thinking, designing, judging, learning, and experiencing at school.[2,3] MR often occurs with other developmental disabilities, and the term "mental and developmental disabilities" is used to denote the comorbidity associated with both conditions.[4]

MR could be a condition, a syndrome, or a symptom. According to the definition made by the American Mental Retardation Association (American Association on Mental Disabilities), it is a below-average intelligence function that occurs in the developmental period and is found with dysfunctions in adaptive behavior. This definition stipulates the current compliance problem and limitation in functionality in MR.[5] Along with below-average intelligence function, difficulties are experienced in communication, self-care, life at home, social skills, and social usefulness. In addition to these, it is predicted to have two or more disorders in self-orientation, health protection, academic functioning, and field of study. Causes such as hereditary factors, chromosomal abnormalities, pregnancy and birth problems, drug use during pregnancy, and close blood ties during marriage lead to the development of mental disability.[6]

How to cite this article: Demir ZG, Güler K, Aktan EA, Sevimli D. Comparison and examination of the death anxiety of parents with and without having mental retarded children. J Neurobehav Sci 2021;XX:XX-XX.

Ethics committee approval: The ethics committee approval has been obtained from the Uskudar University noninterventional research ethics committee (2018/897).

It has been reported that mental problems such as somatic complaints, depression, and anxiety disorder are more common in parents with mentally retarded children compared to other parents.[7] In a meta-analysis examining 162 studies on the mental and physical health of caregivers of children with special needs, 23 different factors that may have an impact on the health of caregivers have been identified. It has been reported that social determinants, caregiver-related variables, characteristics of the disabled child, family characteristics, and support factors can affect caregiver health.[8] On the other hand, an increasing number of studies indicate a relationship between parent coping strategies and mental health.[9,10]

Families of children with special needs may face stigma and social isolation.[11] Social isolation is an important issue that needs to be addressed, experienced by mentally retarded children and their parents, and can cause depression. Families using rehabilitation, mental health, or general health services are thought to have a very high probability of financial loss, job change, and sleep disturbance.[8] The level of disability, problematic behaviors, caregiver health, social and individual characteristics affect the quality of life of caregivers and children with MR. It has been reported that there is a relationship between social support and parental stress management and resilience, and the stress and depression levels of mothers who think that they receive little support increase.[12] Social services of countries are effective on the stress levels of families with mentally retarded children. The level of competence of services is an important determinant. It is thought that there is a relationship between social support and parental stress management and resilience.[10]

Death is a phenomenon that has occupied the minds that have been understood throughout human history.[13] The desire to live and to survive drive is the greatest inspiration of man. What provides this is the fear created by the reality of death in man. This fear enables the person to make quick and instant decisions in the face of any threat perception and to survive by activating the whole organism.[14] The perception of death as creepy, frightening, and desperate stems from the psychological structuring of the human being. Existential theorists have argued that the main source of anxiety is death anxiety.[15] As a multidimensional concept, death contains many dynamics within it. The philosophical, religious, moral, legal, social, emotional, and mystical dimensions of death are the results of trying to understand the phenomenon of death since the existence of humanity.[16] Some of these dimensions include the anxiety of the unknown, the fear of losing or leaving loved ones behind, the belief that death can be painful, the feeling of unfinishedness, and the sadness created by the fact that no longer exists. Death anxiety is universal. Denying death, challenging it, wanting or accepting death are attitudes that can develop in the face of death.[17]

The number of children with special needs mental deficiency is showing 29% according to data Turkey Statistical Institute.[18] New regulations are made to increase the quality of life of children with special needs and caregivers around the world. This issue is on the agenda of many countries' health and social policies. In this context, any research that will raise awareness will serve public health. Those with mental disabilities among children with special needs show significant individual differences among themselves. A better understanding of the mentally disabled individuals and their families requires new social policies and global structuring. The insufficiency of social policies created to benefit disadvantaged groups can cause negative consequences. Death anxiety experienced by parents with mentally retarded children is considered as one of these negative consequences. Among the concerns of parents who have a disabled child are the belief that no one will take care of their children after death, and the lack of social facilities and support.[19]

One of the reasons for this study is that death anxiety has an important place in human life for whatever reason. In this study, it was aimed to compare the death anxiety of parents with and without mentally retarded children and to investigate the relationship with sociodemographic variables. Death anxiety-related research both in Turkey investigating the death anxiety of parents of mentally retarded children is limited, although there are very few studies in the world. Ongoing research on individuals with special needs is important for the development of new policies and services.

Methods

The ethics committee approval has been obtained from the Uskudar University noninterventional research ethics committee (2018/897).

Sample

The sample group of the study consists of 120 people in total, consisting of parents of children (n = 60) who are followed up in a special guidance and research center due to mental disability, and parents with children who do not show mental disability (n = 60) as the comparison group. The individuals in the study and comparison groups were informed by the researcher about the study and their written consent was obtained that they agreed to participate in the study. The sample of the study consisted of people selected on the basis of appropriate sampling methods and volunteering. Participants' response times ranged from 15 to 20 min. Inclusion criteria for the study group of the research; being a parent with a child with special needs, being over the age of 18, not having a permanent psychiatric disorder with continuing treatment, having literacy and mental competence to understand reading, and being volunteer. Although the inclusion criteria are the same for the comparison group of the study, there is

a condition of having a parent with a child without any disability.

Measurement instruments

Sociodemographic information of the participants, who could be included in the study on a voluntary basis, was filled in by the researcher using face-to-face interview method using the Sociodemographic Information Form, and their death anxiety levels were evaluated with the Multidimensional Evaluation Inventory for Death and Dying.

Sociodemographic information form

With the form prepared by the researcher, information such as gender, age, marital status, number of children, physical-mental illness, and employment status was questioned and filled in by the researcher with a face-to-face interview.

Multidimensional evaluation inventory for death and dying

The inventory measure death anxiety and death acceptance of the validity and reliability study in Turkey by Zorlu and Ünübol were made in 2018,[13] the scale was adapted to Turkish. The scale has two dimensions as fear and acceptance. The ratio of explaining the total variance of the fear subscale is 43.44%, and the reliability coefficient of Cronbach is 0.950. The explanation rate of the total variance of the acceptance subscale is 50.21%; Cronbach's reliability coefficient is 0.678. The factor distribution of the subscales is different from the original scale. Subscale names have been adapted according to Turkish culture. According to these results, it has been shown that the Turkish Form of ÖÇDE-F is a scale with high validity and reliability.[13]

Data analysis

While analyzing the data obtained in this study, the data were entered into the computer as numerical expressions and statistical analyzes were made using the IBM Corp. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp, Released 2017. Before starting the analysis, the data were examined in terms of normal distribution. It was observed that all scales showed normal distribution in the control of Kurtosis-Skewness values performed

Table 1: Distribution of the sample by demographic variables

	Frequency (%)	
	Without having children with MR diagnosis	**Having children with MR diagnosis**
Gender		
Male	30 (50.0)	30 (50.0)
Female	30 (50.0)	30 (50.0)
Total	60 (100.0)	60 (100.0)
Age		
25-35	17 (28.3)	11 (18.3)
36-45	21 (35.0)	23 (38.3)
46-55	1 (1.7)	16 (26.7)
55 and above	2 (3.3)	1 (1.7)
Total	41 (68.3)	51 (85.0)
Missing	19 (31.7)	9 (15.0)
Total	60 (100.0)	60 (100.0)
Education		
Secondary school	5 (8.3)	32 (53.3)
High school	10 (16.7)	16 (26.7)
Undergraduate	20 (33.3)	2 (3.3)
Graduate	10 (16.7)	5 (8.3)
Total	45 (75.0)	55 (91.7)
Missing	15 (25.0)	5 (8.3)
Total	60 (100.0)	60 (100.0)
Marital status		
Single	1 (1.7)	0 (0)
Married	54 (90.0)	58 (96.7)
Divorced	5 (8.3)	2 (3.3)
Total	60 (100.0)	60 (100.0)
Religion		
Muslim	59 (98.3)	60 (100.0)
Missing	1 (1.7)	
Total	60 (100.0)	

MR: Mental retardation

for the analysis of normality distribution in the sample group of research variables. Since the values in all scales and subscales are between −2 and +2, it shows a normal distribution. In the analysis applied, 95% reliability level was taken as basis. In order to analyze the difference between the two parametric groups in comparing quantitative data, two independent variables tests, the *t*-test, were used. The relationship between the scales was tested with Pearson Correlation analysis. Multiple linear regression was used to see the effect of independent variables on the dependent variable. For statistical significance, $P < 0.05$ was taken.

Results

This section contains the findings obtained from the demographic information form prepared by the researcher.

As seen in the table [Table 1], 50.0% of the group without MR children were male, 50.0% were female, 28.3% were between the ages of 25 and 35, 35.0% were between the ages of 36 and 45, 1.7% were between the ages of 46 and 55, and 3.3% are 55 years or older. About 8.3% of this group are secondary school graduates, 16.7% are high school graduates, 33.3% are university graduates, 16.7% are graduate and above, 1.7% are single, 90.0% are married, 8.3% are divorced, 98.3% are Muslim. In the group with MR children, 50.0% male, 50.0% female, 18.3% between 25 and 35 years old, 38.3% between 36 and 45 years old, 26.7% between 46 and 55 years old, 1.7% 55 years and above, 53.3% secondary school graduate, 26.7% high school graduate, 3.3% university graduate, 8.3% master's and above, 96.7% married, 833% divorced, and 100.0% of the participants are Muslim.

As seen in the table [Table 2], the mean of the Fear Sub-Dimension is 2.11 (standard deviation [SD] = 0.68), the average of the Acceptance Sub-Dimension is 3.38 (SD = 0.60), the average of the Insurgency Sub-dimension is 1.41 (SD = 0.63), and its average is 2.55 (SS = 0.83).

As can be understood from the table [Table 3], as a result of the independent group *t*-test conducted to determine

Table 2: Descriptive statistics of the multidimensional evaluation scale for death and dying

Subscales	*n*	Minimum	Maximum	$\bar{X}$	SD
Fear	120	1.04	4.00	2.11	0.68
Acceptance	120	1.43	4.00	3.38	0.60
Rebellion	120	1.00	4.00	1.42	0.63
Denial	120	1.00	4.00	2.55	0.83

SD: Standard deviation

Table 3: Results of the independent group *t*-test conducted to test the significance of the difference between the scores of the multidimensional scale of death and death and its subdimensions according to the group variable of the sample

	n	$\bar{X}$	SS	*t*	SD	*P*
Fear						
Having children without MR	60	1.98	0.54	−2.112	118	0.037
Having children with MR	60	2.24	0.78			
Acceptance						
Having children without MR	60	3.44	0.62	1.018	118	0.311
Having children with MR	60	3.33	0.59			
Rebellion						
Having children without MR	60	1.19	0.27	−4.149	118	<0.001**
Having children with MR	60	1.64	0.79			
Denial						
Having children without MR	60	2.35	0.68	−2.711	118	0.008**
Having children with MR	60	2.75	0.92			

**P<0.01, ***P<0.001. MR: Mental retardation, SD: Standard deviation

Table 4: Results of the independent group *t*-test conducted to test the significance of the difference between the scores of the multidimensional scale of death and dying and its subdimensions according to the group variable of the sample (female)

Group	*n*	$\bar{X}$	Ss.	*t*	SD	*P*
Fear						
Having children without MR	30	2.03	0.59	−1.634	58	0.108
Having children with MR	30	2.31	0.73			
Acceptance						
Having children without MR	30	3.45	0.75	1.149	58	0.255
Having children with MR	30	3.24	0.67			
Rebellion						
Having children without MR	30	1.22	0.30	−1.917	58	0.060
Having children with MR	30	1.48	0.70			
Denial						
Having children without MR	30	2.62	0.71	−0.289	58	0.774
Having children with MR	30	2.68	0.92			

**P<0.01, ***P<0.001. MR: Mental retardation, SD: Standard deviation

Table 5: Results of the ındependent group t-test conducted to test the significance of the difference between the scores of the multidimensional scale for death and dying and its subdimensions according to the group variable of the sample (male)

Group	*n*	$\bar{X}$	Ss.	*t*	SD	*P*
Fear						
Having children without MR	30	1.94	0.49	−1.343	58	0.185
Having children with MR	30	2.18	0.83			
Acceptance						
Having children without MR	30	3.43	0.46	0.104	58	0.917
Having children with MR	30	3.42	0.48			
Rebellion						
Having children without MR	30	1.17	0.23	−3.878	58	<0.001**
Having children with MR	30	1.79	0.86			
Denial						
Having children without MR	30	2.08	0.54	−3.771	58	<0.001**
Having children with MR	30	2.82	0.93			

**P<0.01, ***P<0.001. MR: Mental retardation, SD: Standard deviation

whether the scores of the sample group from the Fear Sub-Dimension differ significantly with respect to the group variable, It has been determined that there is a statistically significant difference at the P < 0.05 level between the groups because the group with MR children got more points. No statistically significant difference was found at the $P > 0.05$ level from the results of the independent group *t*-test performed to determine whether the scores of the sample group from the Acceptance Sub-Dimension differ significantly according to the group variable.

As can be understood from the table [Table 3], as a result of the independent group *t*-test conducted to determine whether the scores of the sample group from the Rebellion Sub-Dimension differ significantly according to the group variable, It has been determined that there is a statistically significant difference at the P < 0.05 level between the groups because the group with MR children got more points. As a result of the independent group *t*-test performed to determine whether the scores of the sample group from the Denial Sub-Dimension differ significantly according to the group variable, a statistically significant difference was found at the $P < 0.05$ level between the groups, since the group with an MR child got more points.

As can be seen from the table [Table 3], there was no statistically significant difference at the level of $P > 0.05$ from the results of the independent group *t*-test conducted to determine whether the scores of the sample group from the Fear Sub-Dimension differ significantly according to the group variable. No statistically significant difference was found at the $P > 0.05$ level from the results of the independent group *t*-test conducted to determine whether the scores of the sample group from the Acceptance Sub-Dimension differ significantly according to the group variable.

As can be understood from the table [Table 4], no statistically significant difference was found at the level of $P > 0.05$ from the results of the independent group *t*-test, which was conducted to determine whether the scores of the sample group from the Rebellion Sub-Dimension differ significantly according to the group variable. No statistically significant difference was found at the level of $P > 0.05$ from the results of the independent group *t*-test performed to determine whether the scores of the sample group from the Denial Sub-Dimension differ significantly according to the group variable.

As can be seen from the table, there was no statistically significant difference at the level of $P > 0.05$ from the results of the independent group *t*-test conducted to determine whether the scores of the sample group from the Fear Sub-Dimension differ significantly according to the group variable. No statistically significant difference was found at the $P > 0.05$ level from the results of the independent group *t*-test conducted to determine whether the scores of the sample group from the Acceptance Sub-Dimension differ significantly according to the group variable.

As it can be understood from the table [Table 5], as a result of the independent group *t*-test conducted to determine whether the scores of the sample group from the Rebellion Sub-Dimension differ significantly according to the group variable, there is a statistically significant difference at the $P < 0.05$ level between the groups because the group with MR children got more points has been determined. As a result of the independent group *t*-test conducted to determine whether the scores of the sample group from the Denial Sub-Dimension differ significantly according to the group variable, a statistically significant difference was found at the $P < 0.05$ level between the groups because the patient group received more points.

Discussion

In this study, the death anxiety of parents with and without MR was compared and examined. Although there are many studies on parents of children with intellectual disabilities (Burke and Stelter, 2019; Lee *et al.*, 2016),[4,7,12,20-22] few studies are related to parents' death anxiety.[19] As a result of the study, it was found that the fear, rebellion, and denial subscales of the death anxiety scale of parents with mentally retarded children were significantly higher than parents without mentally retarded children. The findings of the research support the results of the research by Oktar and Yıldız[19] examining the death anxiety of mothers with mentally disabled children. Parents with mentally retarded children are thought to have a fear of dying before their children. This finding can be explained by the possibility of death anxiety in parents due to the inadequacy of official or private support systems that can care for children with special needs.

Another finding of this study is the gender difference between the results of the subscales. No significant difference was found in the fear, acceptance, denial, and rebellion subscales of the mothers with and without mentally retarded children. However, the denial and rebellion subscale scores of the fathers with mental retarde children were found to be statistically significantly higher than the healthy group. The importance of father–child interaction in child development is known (Davys *et al*., 2016). In this context, it is important to examine the death anxiety of fathers as well as mothers. The difference between fathers' and mothers' attitudes regarding their children with disabilities could be related to the fact that the primary caregivers are mostly mothers and they can spend more time with their children than fathers. Behavioral theory suggests that exposure may reduce anxiety, have a therapeutic effect, and avoidance will reinforce fear. In addition, it is thought that gender difference may be effective in experiencing and expressing emotions.

The adequate and quality social support that parents receive from official institutions has a positive effect on

their quality of life.[23] The meta-analysis results of Scherer *et al*.[4] provide evidence that parenting a mentally retarded child is associated with high levels of depressive symptoms. It has been suggested that if the mentally retarded child has comorbid disabilities, the risk of depression, which presents a mixture of physical and cognitive impairments, may increase.[4] In the study of Marquis *et al*.[8] examining 162 studies on the mental and physical health of caregivers of children with disabilities, many different factors that could have an impact on the health of these caregivers were identified. Social determinants, individual caregiver variables, characteristics of the disabled child, family characteristics, and support systems are among these factors. Raising a mentally retarded child includes stressors such as stigma, financial burden, need for constant care, and behavioral problems that arise in children.[24] In addition, it has been reported that parents may be at a greater risk of depression and anxiety due to stress factors such as increased caregiver demands and financial burden.[4]

In the study of Gogoi *et al*.,[7] the psychological responses of parents with mentally retarded children were examined. It was found that anxiety and depression levels were higher and their quality of life was lower than mothers with healthy children. As people with mental and developmental disabilities live longer, they may need not only disability-related support but also services related to aging adults.[25] However, families often provide such support themselves, due to the inadequacy of most service delivery systems.[26] Although future planning should include every family member, very few families of mentally retarded people make future planning. The main reason for this is that future planning can cause stress due to the uncertainty of the future.[21] Moreover, as parental stress can negatively affect children, supporting the well-being of parents can contribute to supporting children's development in a positive way.

Increasing the quality of life of children with special needs and their families is among the important parameters of public health.[27] This topic has created a growing research area in recent years in all countries of the world.[28] A good understanding of the factors that shape the quality of life of this disadvantaged group can inform the development of better policies and better practices to support families. While many studies have defined the quality of life of these families in the last decade,[29-33] some of them are more among these families. Attempted to identify the cluster of factors that could contribute to higher quality of life (Zuna *et al*., 2010).[34-37]

All families, including those affected by disability, deserve a high quality of life. Mentally disabled individuals have lived an isolated life for centuries. Functional service programs are needed to be socially acceptable and social integration.[38] In a study conducted to determine the difficulties and family burden experienced by the families of children with intellectual disability, 48.8% of the mothers stated that they did not have anyone to help care for their children, they felt disappointed, surprised, shocked, desperate, anger and guilty, and blamed others. In the same study, it was reported that mothers had suicidal thoughts, 28.1% experienced depression, most of them looked at their future with anxiety and thought that their burdens were too heavy to bear.[39] It is known that social support has an effect on the life satisfaction of families with children with special needs, seeking help, coping with depression, and stress.[40] In this context, determining the need for support of parents with mentally disabled children as a part of the society, increasing the quality of life with the services to be provided, and trying to eliminate all concerns including death anxiety are within the scope of social responsibility.

Among the positive features of the study are the adequacy of the number of cases, the acceptable ratio of women to men in the sample group, and the use of the scale whose validity and reliability have been made in our country. Additionally, conducting a research in one institution with participant living in the same city, studying limited number of factors related to death anxiety can be included in the study as limitations. The necessary support can be provided by ensuring the integration of children with mental disabilities and their families into society, increasing their quality of life, developing necessary health and social policies, and increasing research that will draw attention to this issue.

It is beneficial to prepare and implement various psychosocial support programs such as making new regulations on social and health policies in order to reduce the death anxiety of families, providing some social security for disabled children, providing support for caregiver problems of their children, and managing stress.

Patient informed consent

Informed consent was obtained.

Ethics committee approval

The ethics committee approval has been obtained from the Uskudar University Noninterventional Research Ethics Committee (2018/897).

Financial support and sponsorship

No funding was received.

Conflicts of interest

There are no conflicts of interest to declare.

Author contribution subject and rate

Zeynep Gümüş Demir (50%): Design the research, data collection, and analyses and wrote the whole manuscript.

Kahraman Güler (20%): Contributed with on research design and analyses

Emel Aner Aktan (10%): Supervised the article write-up.

Deniz Sevimli (20%): Contributed with comments on research design and slides interpret

References

1. Kamstra A, van der Putten AA, Maes B, Vlaskamp C. Exploring spontaneous interactions between people with profound intellectual and multiple disabilities and their peers. J Intellect Dev Disabil 2019;44:282-91. https://doi.org/10.3109/13668250.2017.1415428.
2. Birliği AP. Ruhsal bozuklukların tanımsal ve sayımsal elkitabı. In: Köroğlu E, (Çev. Ed.). Beşinci Baskı (DSM-5) Tanı Ölçütleri Başvuru Elkitabı. Ankara: Hekimler Yayın Birliği; 2013. Isbn 10: 9753001983.
3. Görmez A, Kırpınar İ. Prevalence of psychiatric disorders in adults with mental retardation and related factors. Anatolian Journal of Psychiatry 2017;18:338-43. doi: 10.5455/apd.239795.
4. Scherer N, Verhey I, Kuper H. Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. PLoS One 2019;14:e0219888. https://doi.org/10.1371/journal.pone.0219888.
5. Tassé MJ, Luckasson R, Nygren M. AAIDD proposed recommendations for ICD–11 and the condition previously known as mental retardation. Intellect Dev Disabil 2013;51:127-31. https://doi.org/10.1352/1934-9556-51.2.127.
6. Yavuz F. Encounters of Families with Mentally Disabled Children A Study on the Problem of Social Exclusion. Mugla: Unpublished Master's Thesis, Sıtkı Koçman University Institute of Social Sciences; 2016. https://tez.yok.gov.tr/UlusalTezMerkezi/tezSorguSonucYeni.jsp.
7. Gogoi RR, Kumar R, Deuri SP. Anxiety, depression, and quality of life in mothers of children with intellectual disability. Open J Psychiatry Allied Sci 2014;8:71-5. http://dx.doi.org/10.5958/2394-2061.2016.00046.X.
8. Marquis S, Hayes MV, McGrail K. Factors affecting the health of caregivers of children who have an intellectual/developmental disability. J Policy Pract Intellect Disabil 2019;16:201-16. https://doi.org/10.1111/jppi.12283.
9. Biswas S, Moghaddam N, Tickle A. What are the factors that influence parental stress when caring for a child with an intellectual disability? A critical literature review. Int J Dev Disabil 2015;61:127-46. https://doi.org/10.1179/2047387714Y.0000000043.
10. Zaidman-Zait A, Mirenda P, Duku E, Vaillancourt T, Smith IM, Szatmari P, *et al*. Impact of personal and social resources on parenting stress in mothers of children with autism spectrum disorder. Autism 2017;21:155-66. https://doi.org/10.1177%2F1362361316633033.
11. Park CL, Masters KS, Salsman JM, Wachholtz A, Clements AD, Salmoirago-Blotcher E, *et al*. Advancing our understanding of religion and spirituality in the context of behavioral medicine. J Behav Med 2017;40:39-51. DOI 10.1007/s10865-016-9755-5.
12. Marquis SM, McGrail K, Hayes M. Mental health of parents of children with a developmental disability in British Columbia, Canada. J Epidemiol Commun Health 2020;74:173-8. http://dx.doi.org/10.1136/.
13. Zorlu F, Ünübol H. The multidimensional orientation toward dying and death inventory (MODDI-F): factorial validity and reliability in a Turkey sample, 2018;19:39-46. doi: 10.5455/apd.300390.
14. Jong J. Death anxiety and religion. Curr Opin Psychol 2020;40:40-4.
15. Osborne JW. An existential perspective on death anxiety, retirement, and related research problems. Can J Aging 2017;36:246-55. https://doi.org/10.1017/S0714980816000465.
16. Qiu Q, Fang Y, Lin X. Analysis of death anxiety of undergraduates and influencing factors. J Shanghai Jiaotong Univ (Med Sci) 2015;35: 1512–15. [doi: 10.3969/j].
17. Bianco S, Testoni I, Palmieri A, Solomon S, Hart J. The psychological correlates of decreased death anxiety after a near-death experience: The role of self-esteem, mindfulness, and death representations. J Humanist Psychol 2019;1-24. https://journals.sagepub.com/pb-assets/Icons/author-info-1498649887747.png.
18. TÜİK. Özürlülerin Sorun ve Beklentileri Araştırması. Ankara: Türkiye İstatistik Kurumu Matbaası; 2011. Available from: https://www.tuik.gov.tr/.
19. Oktar MN, Yıldız R. Zihinsel engelli çocuğu olan annelerin ölüm kaygısı ile sosyal politikalara güven ilişkisi. Akademik İncelemeler Dergisi 2019;14:463-98. DOI: 10.17550/akademikincelemeler.478213.
20. Boehm TL, Carter EW. Family quality of life and its correlates among parents of children and adults with intellectual disability. Am J İntellect Dev Disabil 2019;124:99-115. https://doi.org/10.1352/1944-7558-124.2.99.
21. Burke M, Arnold C, Owen A. Identifying the correlates and barriers of future planning among parents of individuals with intellectual and developmental disabilities. Intellect Dev Disabil 2018;56:90-100. https://doi.org/10.1352/1934-9556-56.2.90.
22. Feldman MA, Aunos M. Recent trends and future directions in research regarding parents with ıntellectual and developmental disabilities. Curr Dev Disord Rep 2020;7:173-81. https://doi.org/10.1007/s40474-020-00204-y.
23. Boehm TL, Carter EW. A systematic review of informal relationships among parents of individuals with intellectual disability or autism. Res Pract Persons Severe Disabil 2016;41:173-90. https://doi.org/10.1177%2F1540796916657339.
24. Woodman AC, Mawdsley HP, Hauser-Cram P. Parenting stress and child behavior problems within families of children with developmental disabilities: Transactional relations across 15 years. Res Dev Disabil 2015;36C: 264-76. https://doi.org/10.1016/j.ridd.2014.10.011.
25. Lee CE, Burke MM, Stelter CR. Exploring the perspectives of parents and siblings toward future planning for individuals with intellectual and developmental disabilities. Intellect Dev Disabil 2019;57:198-211. https://doi.org/10.1352/1934-9556-57.3.198.
26. Burke MM, Fish T, Lawton K. A comparative analysis of adult siblings' perceptions toward caregiving. Intellect Dev Disabil 2015;53:143-57. https://doi.org/10.1352/1944-7558-120.5.395.
27. Schippers A, Zuna N, Brown I. A proposed framework for an integrated process of improving quality of life. J Policy Pract Intellect Disabil 2015;12:151-61. https://doi.org/10.1111/jppi.12111.
28. McKenzie K, Milton M, Smith G, Ouellette-Kuntz H. Systematic review of the prevalence and incidence of intellectual disabilities: Current trends and issues. Curr Dev Disord Rep 2016;3:104-15. DOI 10.1007/s40474-016-0085-7.
29. Bertelli M, Bianco A, Rossi M, Scuticchio D, Brown I. Relationship between individual quality of life and family quality of life for people with intellectual disability living in Italy. J Intellect Disabil Res 2011;55:1136-50. https://doi.org/10.1111/j.1365-2788.2011.01464.x.
30. Boehm TL, Carter EW, Taylor JL. Family quality of life during the transition to adulthood for individuals with intellectual disability and/or autism spectrum disorders. Am J İntellect Dev Disabil 2015;120:395-411. https://doi.org/10.1352/1944-7558-

120.5.395.

31. Caples M, Sweeney J. Quality of life: A survey of parents of children/adults with an intellectual disability who are availing of respite care. Br J Learn Disabil 2011;39:64-72. https://doi.org/10.1111/j.1468-3156.2010.00619.x.
32. Hastings RP. Do children with intellectual and developmental disabilities have a negative impact on other family members? The case for rejecting a negative narrative. Int Rev Res Dev Disabil 2014;50:165-94. https://doi.org/10.1016/bs.irrdd.2016.05.002.
33. Reynolds MC, Gotto GS, Arnold C, Boehm TL, Magaña S, Dinora P, *et al*. National goals for supporting families across the life course. Inclusion 2015;3:260-6. https://doi.org/10.1352/2326-6988-3.4.260.
34. Giné C, Gràcia M, Vilaseca R, Salvador Beltran F, Balcells-Balcells A, Dalmau Montala M, *et al*. Family quality of life for people with ıntellectual disabilities in C atalonia. J Policy Pract Intellect Disabil 2014;12:244-54. https://doi.org/10.1111/jppi.12134.
35. Foley KR, Girdler S, Downs J, Jacoby P, Bourke J, Lennox N, *et al*. Relationship between family quality of life and day occupations of young people with Down syndrome. Soc Psychiatry Psychiatr Epidemiol 2014;49:1455-65. DOI 10.1007/s00127-013-0812-x.
36. Kyzar KB, Turnbull AP, Summers JA, Gómez VA. The relationship of family support to family outcomes: A synthesis of key findings from research on severe disability. Res Pract Persons Severe Disabil 2012;37:31-44. https://doi.org/10.2511%2F027494812800903247.
37. Vilaseca R, Gràcia M, Beltran FS, Dalmau M, Alomar E, Adam-Alcocer AL, *et al*. Needs and supports of people with intellectual disability and their families in Catalonia. J Appl Res Intellect Disabil 2017;30:33-46. https://doi.org/10.1111/jar.12215.
38. Ioanna D. Independent living of individuals with intellectual disability: A combined study of the opinions of parents, educational staff, and individuals with intellectual disability in Greece. Int J Dev Disabil 2020;66:153-9. https://doi.org/10.1080/20473869.2018.1541560.
39. Balcı S, Kızıl H, Savaşer S, Dur Ş, Mutlu B. Zihinsel engelli çocuğu olan ailelerin yaşadığı güçlüklerin ve aile yükünün belirlenmesi. Psikiyatri Hemşireliği Dergisi 2019;10:124-30. DOI: 10.14744/phd.2018.05657.
40. Yildirim G, Ertekin Pinar S, Ucuk S, Duran Aksoy O, Ersan EE. The effect of training given to parents with mentally disabled children on their life satisfaction self-stigma of seeking help depression and stress-coping styles. Int J Soc Psychiatry 2020;66:279-91. https://doi.org/10.1177%2F0020764020903750.