Research Article

Death Anxiety Perceived Parenting Maternal Symptoms and Health-Related Quality of Life among Duchenne Muscular Dystrophy and Multiple Sclerosis Adolescents

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Abstract

Aim: Death anxiety, which may arise from the anticipation of death, includes aspects such as fear of the death process. Death anxiety in adolescents with serious or terminal illnesses was generally studied with adolescents undergoing cancer treatment. However, there have been few studies in the literature on death anxiety and the factors that may influence it in adolescents with Duchenne muscular dystrophy and multiple sclerosis. This study aims to compare death anxiety, perceived parenting, maternal psychiatric symptoms, and health-related quality of life in adolescents diagnosed with duchenne muscular dystrophy and multiple sclerosis. **Materials and Methods:** The population of the study, which is a relational screening model, consisted of 19 adolescents with muscular dystrophy and 22 adolescents with multiple sclerosis, aged between 14-17, and their mothers. Data were collected through a brief symptom inventory, death anxiety scale, quality of life scale for children, and parental attitude inventory. ANOVA, chi-square, correlation, and regression analysis analyzed data. **Results:** It was found that adolescents with muscular dystrophy had higher death anxiety, lower quality of life, less psychological autonomy from their parents, and higher psychiatric symptoms of their mothers compared to adolescents with multiple sclerosis. It has been found that death anxiety is predicted by physical functionality, psychological autonomy, and the mother's depressive symptoms. **Conclusion:** It's essential to periodically evaluate the psychiatric symptoms of DMD's mothers, especially the death anxiety symptoms of adolescents with DMD.

Keywords: Muscular Dystrophy Duchenne, Multiple Sclerosis, Death Anxiety, Adolescence

Introduction

Death anxiety, which may arise from the anticipation of death, includes aspects such as fear of the death process. In other words, it is the anxiety arising from the expected death[1]. It can be called an emotion that exists in us from the moment we are born and continues throughout our lives, has a vital role in our character development, and causes people to think that they and this world will disappear[2].

Death anxiety can be observed at an early age. According to Piaget[3], formal logical thought, which develops at about 10 to 12 years, creates the ability to consider personal ideas of death. By the time adolescents are about 14-15 years old, a complete logic will be reached; most adolescents realize that death is irreversible, permanent, and universal.

Death anxiety in adolescents is more frequently studied concerning issues such as having or not having religious beliefs[4] or after the loss of parents and siblings[5]. Death anxiety in adolescents with serious or terminal illnesses was generally studied with adolescents undergoing cancer treatment. Previous studies have shown that death anxiety is high in adolescents with cancer treatment[6]. However, death anxiety in adolescents with severe or chronic illness is a relatively under-studied topic that can cause them to confront death and can increase death anxiety over time[7].

One of these severe or chronic illnesses we are concerned about in this research are Multiple sclerosis (MS) and Duchenne Muscular Dystrophy (DMD). Multiple Sclerosis (MS), a chronic inflammatory autoimmune disease of the central nervous system, can also affect children and adolescents. It is a demyelinating disease that destroys the myelin sheath around nerve fibers[8]. Duchenne muscular dystrophy (DMD) is an inherited neuromuscular disease affecting males. DMD is diagnosed at around five years of age (at around 12-13 years of age, boys with DMD often lose the ability to walk independently; at around 15 years of age, various health complications occur-curvature of the spine, respiratory problems and risk of heart failure). These male patients' death age was around 19; however, life expectancy has increased, mainly thanks to modern Technologies[9].

MS and DMS are different diseases in terms of their causes, treatment, and fatal nature. MS is a disease with sudden onset attacks that vary considerably between individuals, and its course can vary. The uncertainty of the future is one of the most challenging issues for patients[9].

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On the other hand, DMS is a progressive disease diagnosed at an earlier age. It is a fatal disease that removes adolescents from almost every stage of normal development and social life[8]. It is known that adolescents with both diagnoses have psychological and emotional difficulties, psychological disorders, and lower health-related quality of life (HRQoL). Health-related quality of life conceptualized as a person's usual or expected physical, emotional, and social well-being being affected by a medical condition or its treatment, is reduced in both DMD[10] and MS adolescents[11].

In addition to their low HRQoL, one of the reasons that will increase the problem behaviors of adolescents with severe and chronic illnesses is their negative relationships with their parents and their caregivers' mental health problems. The relationship with parents is often examined in terms of parenting styles (i.e., authoritarian, permissive, authoritative, and neglectful) and is differentially associated with positive or negative effects on developmental outcomes, including personal and social adjustment. The authoritative style has been associated with the best socialization outcomes, such as higher levels of emotional maturity, psychosocial competence, academic performance, and fewer behavioral problems[12]. Negative parenting, such as authoritarian, permissive, or neglectful, with poor caregivers' mental health, can worsen chronically ill adolescents' problem behavior[13]. Poor mental health, including anxiety and depression, among caregivers may co-exist with poor mental and physical health in children. The effect of a caregiver's poor mental health and negative parenting attitudes on the emotions and behaviors of adolescents has been known for years[14].

In the literature so far, no research has been found that examines both parenting and the caregiver's mental health together, which are among the family factors that may affect death anxiety in adolescents with severe or chronic diseases. Moreover, the role of health-related quality of life in this relationship remains unclear.

In conclusion, this study aimed to investigate perceived parenting, caregivers' mental health, and health-related quality of life that may affect and predict the death anxiety of adolescents diagnosed with DMD and MS. We hypothesize that DMD patients with an elevated likelihood of disease progression and mortality will exhibit heightened fear of death, which will be assessed. The hypothesis posits that elevated mental symptoms in caregivers, diminished health-related quality of life, and perceived bad parenting predict death fear in both disease groups.

Materials and Methods

The ethics committee approval has been obtained from the Uludag University Clinical Research Ethics Committee (UÜ-KAEK/2023-17/8).

Participants

This causative comparison study comprises data from patients and their mothers who sought care at the hospital between January and May 2024 and consented to participate. The study sample consisted of 19 MS (5 female; 46.3 %), 22 DMD (53.7%) adolescents and their mothers (n=41). The average age of the participants is 15.51. It consists of participants aged 14 years old, 9 (22%); 15 years, 12 (29.3%); 16 years, 10 (24.4%); and 17 years, 10 (24.4%). The average age of the mothers is 44.87. Of the mothers, 36.6% had completed primary school, 58.5% had high school, and 4.2% had a university degree. 17 mothers (58.5%) have a job, and 17 (41.5%) are housewives. 18 of the mothers stated that their income was less than their expenses, 21 (51.2%) stated that their income and expenses were equal, and 2 (4.9%) mothers stated that their income was slightly more than that. 16 of the participants have 1 (39%), the other 16 have 2 (39%), 7 have 3 (17.1%) and 2 have 4 (4.9%) siblings.

Procedure

Participants were accepted to the study if they had not received psychiatric treatment before, could attend school, and had no problems with fine motor skills. Participants who agreed to participate in the research and signed the voluntary consent form were taken to the hospital's interview room, where they were informed by the psychologist and had the scales filled out. Adolescents took the Thorson-Powell Death Anxiety Scale and Parental Attitude Scale, while moms filled out the Brief Symptom Inventory and Pediatric Quality of Life Questionnaire. It took about 20 minutes for adolescents and their moms to fill out the forms. No extreme values were identified in the data; hence, no cleaning was performed. Our study was approved by the Uludag University Clinical Research Ethics Committee (2023-17/8). The research was conducted according to the Helsinki Declaration rules of good clinical practice and ethics.

Instruments

Pediatric Quality of Life Questionnaire

PedsQL is a quality of life scale developed by Varni et al. in 1999 as a result of approximately 15 years of study to measure the health-related quality of life of children and adolescents between the ages of 2-18. It is a scale that evaluates physical health, emotional, social, and school functionality. It consists of 23 items, and the lowest score that can be obtained is 0, and the highest score is 100. The higher the total score, the better the quality of life is considered. The scale in our country was adapted by Çakın Memik et al.[15].

b)The Thorson-Powell Death Anxiety Scale

Thorson-Powell (1989, 1992) developed the scale comprising 25 items prepared in a 5-point Likert format. Scores on the scale range from 0 to 100. Some items are scored reversely. The scale has four primary subscales: " anxiety about the uncertainty of death, fear of the afterlife, the dying process, and suffering, and decay and degradation; the lower the total score indicates more death anxiety. The scale in our country was adapted by Karaca and Yıldız[16].

Brief Symptom Inventory (BSI)

Developed by Derogatis (1992), BSI is a 5-point Likert-type scale. It consists of 5 sub-dimensions and a total of 53 items: anxiety, depression, negative self, somatization, and hostility. The score that can be obtained from the scale varies between 0 and 212. The higher the total score indicates, the more severe the psychiatric symptoms. The scale in our country was adapted by Şahin and Durak[17].

Parental Attitude Scale

Developed by Rhoades and O'Leary (2007) , the scale consists of 3 subscales: acceptance involvement, control, and psychological autonomy dimensions. The acceptance/interest dimension measures how loving, caring, and participatory children perceive their parents to be. The control dimension aims to measure how children perceive their parents as controlling. The psychological autonomy dimension aims to measure the extent to which parents apply democratic attitudes and to what extent they are encouraged to express the child's individuality. The items in the first and third dimensions are evaluated on a

4-point Likert-type scale, the first two in the second dimension are evaluated on a 6-point Likert-type scale, and the remaining items are evaluated on a 3-point Likert-type scale. When some items scored reversely, lower points indicate negative parenting attitudes. The scale in our country was adapted by Yılmaz[18].

Statistical analysis

Statistical analyses were performed using version 22 of IBM SPSS software. Statistical significance was set at p≤.05. The groups (DMD and MS) were analyzed using the t-test, Pearson correlation test, and linear regression analysis since the kurtosis analysis revealed that the data were regularly distributed.

First, diagnosed groups were compared for the death anxiety, caregivers' mental health, health-related quality of life, and perceiving parenting using the t-test. Second, the Pearson correlation analysis launched between death anxiety and health-related quality of life, maternal psychiatric disorders, and perceived parenting scores. Finally, regression analysis was carried out in cases where the relevant variables had a substantial linear relationship and followed a normal distribution.

Results

The scores and standard deviations that the participants obtained from the independent variables are shown in Table 1 in this section.

According the results there were significant differences between the diagnosed group in terms of death anxiety and caregivers' mental health. Death anxiety scores DMDs' has significantly greater about the uncertainty of death, (t=10.67, p≤.000) fear of the afterlife, (t= 6.89, p≤.000) the dying process and suffering, (t=8.95, p≤.000) and decay and degradation, (t=4.50, p≤.000).

There were also statistically significant differences in DMD's caregivers' mental health according to MS. DMD' mothers had more depression (t=-10.49, p≤.000), anxiety (t=-6.96, p≤.000), hostility (t=9.65, p≤.000), somatization (t=-8.22, p≤.000) and negative-self (t=8,79, p≤.000) symptoms.

When the diagnosed groups' quality of life was compared, significant differences were found in their social, emotional, and physical functionality and school-related functioning. DMS' social, (t=-9.90, p≤.000), emotional (t=-4.48, p≤.000), physical (t=-11.38, p≤.000) school-related functioning, (t=-5.79, p≤.000) funcitoning were significantly lower.

Table 1: The average scores and standard deviations of the participants from the dependent variables

	MS			DMD		
	Mean	**Kurtosis**	**Sd**	**Mean**	**Kurtosis**	**Sd**
***Uncertainty of death**	20.28	-0.83	3.53	10.95	1.07	1.83
***Fear of the afterlife**	17.31	0.70	4.29	10.54	1.13	1.56
***The dying process and Suffering**	10.10	-0.52	2.64	4.59	-0.30	1.09
***Decay and degradation**	13.05	-1.13	3.06	9.45	-0.34	0.95
****Social functionality**	2.63	-0.71	2.88	10.00	1.19	1.90
****Emotional functionality**	6.73	-0.10	3.41	10.22	-0.20	1.23
****Physical functionality**	6.26	-0.16	6.10	22.63	0.26	2.68
****School-related functioning**	5.28	-0.71	2.88	9.58	1.19	1.73
*****Acceptance-involvement**	22.89	-0.63	4.49	24.59	-0.25	3.55
*****Control**	11.00	0.74	2.00	11.09	0.79	1.57
*****Psychological autonomy**	16.89	-0.82	3.54	7.68	0.76	2.90
******Depression**	7.89	-0.74	4.81	28.22	1.21	7.15
******Anxiety**	7.10	1.01	5.57	19.18	0.85	5.50
******Hostility**	4.47	-0.92	3.02	13.09	-0.30	2.68
******Somatization**	5.42	0.74	3.54	15.36	-0.59	4.07
******Negative-self**	5.36	-1.03	2.92	17.90	0.69	5.57

MS: Multiple Sclerosis; DMD: Duchenne Muscular Dystrophy

*Death anxiety sub-scales; **Health-related quality of life sub-scales; *** Parenting Attitude sub-scales;****Caregivers' mental symptoms

When perceived parenting was compared, acceptance-involvement (t=-1.35, p= .18) and control (t=-.16, p= .87) weren't significant but psychological autonomy, (t=9.16, p≤.000) was found significant difference. DMD participants perceive that they have less psychological autonomy from their parents than MS.

Before proceeding with the regression analysis, Table 2 displays the findings of the correlation analysis between death anxiety and health-related quality of life, maternal psychiatric disorders, and perceived parenting scores.

The correlation analysis results show a strong link between death anxiety and negative quality of life, high mother psychiatric symptoms, and low perceived parental acceptance and psychological autonomy.

Table 2: Relationship levels between death anxiety and dependent variables.

		PhysicalF1	EmotionalF1	SocialF1	School-relatedF1	Anxiety2	Depression2	Hostality2	Negative-Self2	Somatization2	Acceptance3	PsychologicalA3	Control3
	Pearson Correlations	-,78*	-,56 *	-,70*	-,67*	-,67*	-,75*	-,71*	-,74*	-,70*	-,31**	,68*	-,07
Death Anxiety	**Sig.**	,00	,00	,00	,00	,00	,00	,00	,00	,00	,05	,00	,64

*p≤.05; **p≤.00

[1]Health-related quality of life subscores, [2]Caregivers' mental symptoms scores, [3]Perceived parenting subscores

To find out how much of the variance of the total score of death anxiety can be explained by HRQoL, a regression analysis backward method was conducted. It was found that quality of life-related to physical functioning (PF) predicts a total score of death anxiety. PF significantly explained 60% of the variance in total death anxiety (F(1.39)=58.84, p≤.000). It was found that PF significantly contributed to the model (t=-7.67, p≤000, R^2=.60; Durbin-Watson=2.54). Thus, death anxiety is high in children with poor physical functioning.

Table 3: Health-related quality of life as a predictor of total death anxiety

	Model	B Std.	Error	Beta	t	Sig.
1	Physical functioning	-,861	,357	-,552	-2,413	,021
	Emotional functioning	,735	,843	,151	,871	,389
	Social functioning	-,566	,572	-,169	-,989	,329
	School functioning	-1,306	,741	-,279	-1,762	,087
2	Physical functioning	-,691	,298	-,443	-2,321	,026
	Social functioning	-,718	,543	-,215	-1,323	,194
	School functioning	-1,036	,671	-,222	-1,544	,131
3	Physical functioning	-,951	,226	-,610	-4,207	,000
	School functioning	-1,063	,677	-,228	-1,570	,125
4	Physical functioning	-1,210	,158	-,775	-7,671	,000

In step 4 of the regression analysis, the variable that predicts death anxiety is quality of life related to physical function.

In the regression analysis conducted to find out which mental health symptoms of the mother predicted total death anxiety, only the mother's depression level was found to be predictive. Mothers' depression significantly explains 56% of the variance in total death anxiety (F=50.44, p≤.000) . It was found that mothers' depression significantly contributed to the model (t=-7.02, p≤000, R^2=.56). Thus, death anxiety is high in children whose mothers have high depression symptoms.

Table 4: Caregivers' mental health as a predictor of total death anxiety.

	Model	B	Std. Error	Beta	t	Sig.
1	Anxiety	,244	,576	,136	,424	,674
	Depression	-,576	,403	-,467	-1,428	,162
	Hostility	-,815	,882	-,287	-,924	,362
	Negative self	-,552	,619	-,291	-,892	,378
	Somatization	,303	,899	,129	,338	,738
2	Anxiety	,324	,519	,180	,624	,536
	Depression	-,519	,362	-,422	-1,433	,161
	Hostility	-,662	,747	-,233	-,886	,381
	Negative self	-,581	,605	-,307	-,959	,344
3	Anxiety	-,524	,359	-,425	-1,457	,153
	Depression	-,482	,683	-,170	-,705	,485
	Negative self	-,366	,494	-,193	-,741	,464
4	Depression	-,653	,307	-,530	-2,129	,040
	Negative self	-,461	,472	-,244	-,977	,335
5	Depression	-,925	,130	-,751	-7,102	,000

In step 5 of the regression analysis, the variable that predicts death anxiety is the depressive symptoms of caregivers.

Finally, the prediction of psychological autonomy and acceptance as dimensions of parental attitudes, which have a linear relationship with death anxiety, were examined, and it was observed that only psychological autonomy predicted death anxiety. Psychological autonomy significantly explains 46% of the variance in total death anxiety, (F=33.65, p≤.000). It was found that psychological autonomy significantly contributed to the model (t=5.41, p≤000, R^2=.46). Thus, death anxiety is high in children with low psychological autonomy from their parents.

Table 5: Perceived parenting dimensions as a predictor of total death anxiety

	Model	B	Std.Error	Beta	t	Sig.
1	Acceptance involvement	-,362	,451	-,100	-,802	,428
	Psychological autonomy	1,694	,325	,649	5,211	,000
2	Psychological autonomy	1,778	,306	,681	5,801	,000

In step 2 of the regression analysis, the variable that predicts death anxiety is the psychological autonomy from parents.

Discussion

In this study, the differences between death anxiety, perceived parenting, caregivers' mental health, and quality of life among adolescents diagnosed with DMD and MS were investigated, and it was also suggested that mothers' high psychiatric symptoms, low health-related quality of life and perceived negative parenting could predict death anxiety.

The results showed that adolescents diagnosed with DMD had higher death anxiety and lower social, emotional, school-related, and physical quality of life than adolescents with MS, and their mothers' psychiatric symptoms were more severe. When looking at perceived parenting, it was found that there was a difference only in terms of psychological autonomy, which means adolescents with DMD had less psychological autonomy than their parents.

Earlier studies point to common psychosocial problems in young men with DMD. These problems are related to life planning and preparation for the end of life. For example, the inability to talk about sensitive topics (impending death, physical and psychological features of the disease) may be a protective factor for male patients (delaying the risk of disturbing family members). However, death and fear of death can occur in the event of sudden deterioration of health, death of another male patient with DMD, or severe medical intervention [10].

DMD is a disease that is diagnosed earlier and progresses worse than MS. Children with DMD have lived with this disease for a more extended period than those with MS. They are particularly vulnerable to more severe physical disabilities [19]. Although the adolescents with DMD who participated in the study can use their hands and arms, they all use wheelchairs. It is logical that their physical quality of life was worse than the MS group and predicted death anxiety more. Progressive physical losses may increase anxiety about death and dying. This might also means they depend more on their mothers, and their care burden is more significant. Mothers also know that they may lose their children if a new treatment is not found. This care dependency and uncertainty of the future may explain the high number of psychiatric symptoms of mothers with children with DMD. Earlier studies show that caregivers of children with DMD deal with the stressors associated with one family member's progressively disabling and terminal disorder [20]. Moreover, parents of children with DMD reported having a major depressive episode than the general population [21]. According to Landfeldt et al. [22] caregivers with DMD children were moderately or highly anxious or depressed.

This study also found that mothers' depression predicted death anxiety in their children, unlike other psychiatric symptoms. Kulas [23] found that mothers with DMD had high symptoms of depression and anxiety. However, they did not receive psychiatric treatment or therapy and explained this due to not needing it or financial reasons. Similarly, none of the mothers participating in this study had received any psychiatric treatment before. It can be argued that mothers' symptoms are not noticed between caregiving and daily living tasks. In our country, it is expected to think that it would be selfish for someone to take care of themself when their child is so ill [24].

Similar studies show that the quality of life is low in DMD [25] and that declines in physical functions negatively affect the quality of life. The progression of the disease/declines in physical ability may cause the child to realize that he is not getting better or he is getting worse and might become more preoccupied with thoughts about death. Therefore, it is not surprising that the health-related quality of life physical functioning is the one that most predicts death anxiety. However, death and dying are not openly discussed topics in Turkiye. The subject of death is always something that is avoided and denied. Especially the situation of terminally ill children and adolescents is a subject that is always rejected, even if asked, but always given hope. It is tough to see practices such as making peace with one's death, talking about what one wants to do before death, or saying goodbye. Moreover, in Turkiye, families do not want this issue to be discussed with their children [26]. Therefore, this might mean that children with DMD are afraid of dying but cannot talk about it.

Finally, when we examined perceived parenting, we found that adolescents with DMD had less psychological autonomy from their parents. This dimension is to what extent the parents practice democratic attitudes and to what extent they are encouraged to express the child's individuality. Although there is no previous research on this subject, the fact that they see their children as less competent or in need of help and that they perform many of their tasks instead of them may have relegated the children's individuality and autonomy, causing this results.

It is important to note that the findings in this study do not indicate that adolescents with MS have a high quality of life, have low death anxiety, perceive their parents more positively, and that their mothers do not have psychiatric symptoms. It indicates that adolescents with MS and their mothers experience fewer difficulties than adolescents with DMD and their mothers. It is known that adolescents with MS and their parents have difficulties when compared to the healthy control group [27,28].

Death anxiety is frequently observed in diseases with poor prognosis, and various therapeutic methods are used when working with these patients. Several evidence-based treatments, including dignity therapy, meaning-centered psychotherapy, acceptance and commitment therapy, and cognitive-behavioral therapy, address psychological, social, spiritual, and existential issues at the end of life [29]. But, in cultures that rarely use words such as death and dying, dignity-based approaches develop much more slowly. In these cultures, like ours, patients' true feelings about illness and death are often ignored and they do not receive adequate support to develop their sense of dignity [30]. As a result of this actual situation, it seems very difficult for DMD patients to receive help in accepting death and dying with dignity. In Turkiye, the limited number of therapeutic approaches generally applied to cancer patients [31] are rarely applied to DMD patients.

To the best of our knowledge, this is Turkiye's first study on the topic. However, only a small number of participants could be reached because the study was only carried out in one location. In order to generalize the findings and look into how other variables can predict the fear od death, it would be advantageous for future research to include a larger sample size.

Conclusion

In conclusion, this study found that the health-related quality of life of adolescents with DMD was more negative than that of adolescents with MS, who experienced more death anxiety and did not have psychological autonomy from their parents. DMD mothers had severe mental health symptoms. The death anxiety could be predicted by physical functioning, psychological autonomy, and mothers' depression symptoms. Considering that the children and their mothers participating in this study have not received psychiatric treatment before, it is essential to periodically evaluate the psychiatric symptoms of DMD mothers, especially the death anxiety symptoms of adolescents with DMD, and provide psychological support.

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Patient informed consent

Patient informed consent was obtained.

Ethics committee approval

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Conflict of interest

There is no conflict of interest to declare.

Author contribution subject and rate

- Arzu Çırpan Kantarcıoğlu (70%): Design the research, data collection, and analyses and wrote the whole manuscript. Organized the research and supervised the article write-up.
- Rabia Tütüncü Toker (%30): Contributed with comments on research design and slides interpretation. Contributed with comments on manuscript organization and write-up.

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