

Ostracism in Adolescent Cancer Patients and Predictors (OSTRACA Study): A Pilot Study of the Palliative Care Working Committee of the Turkish Oncology Group (TOG)

Adolesan Kanser Hastalarında Ostrasizm ve Prediktörleri (OSTRACA çalışması): Bir Türk Onkoloji Grubu Destek Tedaviler Çalışma Grubu Pilot Çalışması

Ali ALKAN¹, Zeynep Gülsüm GÜÇ², Gül ERGÜN³ Teoman ŞAKALAR⁴, Güliz ÖZGÜN⁵, Arzu YAŞAR⁶, Yusuf KARAKAŞ⁷, Tuğba YAVUZŞEN², Berna ÖKSÜZOĞLU⁵, Özgür TANRIVERDİ¹, Filiz ÇAY ŞENLER⁶

¹Muğla Sıtkı Koçman University School of Medicine, Medical Oncology, Muğla

²Dokuz Eylül University School of Medicine, Medical Oncology, İzmir

³Mehmet Akif Ersoy University, Faculty of Health Sciences, Department of Nursing, Burdur

⁴Erciyes University School of Medicine, Medical Oncology, Kayseri

⁵Dr. Abdurrahman Yurtaslan Training and Research Hospital, Medical Oncology, Ankara

⁶Ankara University School of Medicine, Medical Oncology, Ankara

⁷Bodrum Acıbadem Hospital, Medical Oncology, Muğla

Öz

Ostracizm, başkaları tarafından görmezden gelinmek veya dışlanmak olarak tanımlanır. Bu çalışmanın amacı, adolesan kanser hastalarında dışlanmayı değerlendirmek ve bunun prediktörlerini belirlemektir. Ergen kanser hastaları değerlendirildi. Ergenler için Ostracizm Deneyim Ölçeği'nin (OES-A) Türkçe versiyonu ve Kutcher adolesan depresyon ölçeği (KADS) kullanıldı. Ayrıca, karşılaştırma amacıyla kanser hastalığı olmayan bir adolesan kontrol grubu değerlendirildi. Aralık 2017 ve Nisan 2018 tarihleri arasında 4 farklı kanser merkezinde 52 hasta değerlendirildi. Çalışma popülasyonunda medyan OES-A skoru kontrol grubuna kıyasla daha yüksekti (23.5 vs 19.0, p=0.04). Çok değişkenli analizde, kadın olmak yüksek OES-A skorları ile ilişkilendirildi (OR: 7.4, CI (95%) 1.3-41.1, p=0.023). Üniversite öğrencisi olmak (OR: 0.16, CI (95%) 0.03-0.84, p=0.036) ve aktif olarak çalışmak (OR: 0.07, CI (95%) 0.008-0.7, p=0.031) düşük OES-A skorları ile ilişkilendirildi. Yüksek OES-A skorları ile ilişkili KADS skorları ile ilişkilendirildi (9.0 vs 7.5, p=0.16). Adolesan kanser hastaları, kanser olmayan ergenlere kıyasla daha fazla dışlanmaktadır. Kadın cinsiyeti dışlanma riski ile ilişkilendirilirken, çalışmak ve üniversite öğrencisi olmak koruyucu faktörlerdir. Ergen kanser hastalarında dışlanma daha geniş bir seride incelenmelidir.

Anahtar Kelimeler: Adolesan, Depresyon, Kanser, Ostracizm, Sosyal Dışlanma

Abstract

Ostracism is defined as being ignored or excluded by others. The purpose of the study is to evaluate ostracism in adolescent cancer patients and to determine the predictors of it. Adolescent cancer survivors were evaluated. Turkish version of the Ostracism Experience Scale for Adolescents (OES-A) and Kutcher adolescent depression scale (KADS) were used. In addition, a control cohort of adolescents without cancer was evaluated for comparison. Between December 2017 and April 2018, 52 patients were evaluated in 4 different cancer centers. The median OES-A score was higher in the study population when compared with the control cohort (23.5 vs 19.0, p=0.04). In MRA, being female was associated with high OES-A scores (OR: 7.8, CI (95%) 1.4-42.9, p=0.018). In multiple regression analysis, being female was linked to higher OES-A scores (OR: 7.4, 95% CI: 1.3-41.1, p=0.023). Being a university student (OR: 0.16, 95% CI: 0.03-0.84, p=0.036) and being actively employed (OR: 0.07, 95% CI: 0.008-0.79, p=0.031) were associated with lower OES-A scores. Higher OES-A scores were related to high KADS scores (9.0 vs 7.5, p=0.16). Adolescent cancer patients are more ostracized when compared with adolescents without cancer. While the female gender was associated with the risk of ostracism, working and being university students were protective. Ostracism in adolescent cancer patients should be studied in more extensive series.

Keywords: Adolescent, Depression, Cancer, Ostracism, Social exclusion

Introduction

The word "Ostracism" originated around 500 B.C. in Greece. Athenians used shards of clay

	ORCID No
Ali ALKAN	0000-0002-8253-5046
Zeynep Gülsüm GÜÇ	0000-0001-8960-2208
Gül ERGÜN	0000-0002-1292-2040
Teoman ŞAKALAR	0000-0003-2749-9414
Güliz ÖZGÜN	0000-0002-9575-8214
Arzu YAŞAR	0000-0002-0545-1383
Yusuf KARAKAŞ	0000-0003-0205-4590
Tuğba YAVUZŞEN	0000-0001-9375-8133
Berna ÖKSÜZOĞLU	0000-0002-2756-8646
Özgür TANRIVERDİ	0000-0002-0598-7284
Filiz Çay ŞENLER	0000-0002-7156-4650

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Adres / Correspondence : Ali ALKAN

Muğla Sıtkı Koçman University School of Medicine, Medical Oncology, Muğla

e-posta / e-mail : alkanali@yahoo.com

(Ostraca) to vote and decide whether a community member was banished. The term has been used to define "being ignored and excluded" (1-3). It critically impacts one's sense of belonging, self-worth, autonomy, and meaningful presence (4). The enduring impact of long-term ostracism is profound and destructive (1). In addition, it leads to a collapse in psychological drive and functioning, manifesting in suicidal thoughts or actions, eating disorders, depression, and a sense of hopelessness. Even short-term exposure has been associated with emotional stability and anger (5). Suppose one is exposed to ostracism in the short term. In such instances, there are notable rises in blood pressure and cortisol levels, alongside increased activation of dorsal anterior cingulate cortex which is a part of brain associated with responses to physical pain (6, 7).

Furthermore, research on ostracism has uncovered correlations with depression, physical health issues, and even mortality rates (8, 9).

During adolescence, a pivotal stage of development, individuals grapple with understanding themselves within the social sphere. Experiencing exclusion during this period can lead to a range of behavioral issues and emotional disturbances. Ostracism among adolescents specifically has detrimental effects on anxiety levels, self-esteem, sense of belonging, perceived control, and the pursuit of meaningful existence (10, 11). Moreover, it serves as a social risk factor contributing to the intensification of depressive symptoms during early adolescence (12).

In addition to the problems of cancer itself and its consequences on social life, cancer patients are prone to psychosocial issues, such as social exclusion and social disconnection (13). Adolescent cancer patients are unaware of social failure after a cancer experience. The type of the tumor, younger ages, neurotoxic medications, and educational status have been associated with impaired social interactions (14). Social exclusion is a significant problem that is usually ignored or not discussed. Kim et al. demonstrated that 49.7% of adolescent cancer survivors experienced social exclusion in school (15). In addition, exclusion and victimization were associated with higher depressive symptoms. According to data on adolescent and adult cancer patients, we hypothesized that adolescent cancer patients are also prone to ostracism. The aim of this pilot study was to evaluate ostracism among adolescent cancer patients and identify the factors that contribute to it.

Material and Method

The multicenter study was carried out by the Palliative Care Working Committee members of the Turkish Oncology Group (TOG) in four oncology centers in Turkey. The study protocol received approval from the Ethical Committee of the Institution and the study followed the ethical guidelines set in the 1964 Declaration of Helsinki. All the participants gave their informed consent to be included in the research.

Participants

Between December 2017 and April 2018, the patients who admitted and evaluated in outpatient clinic were included. Patients between the ages of 14-24, had cancer diagnosis, and ones who were in remission, were invited. In this pilot study, we aimed to study patients under remission to exclude the psychosocial distress related to the process of therapy and its complications, which could be an important confounder. In addition, the patients with a clinical suspicion of recurrence of neuropsychiatric illness (active psychotic symptoms or severe suicidal

ideation and/or intent) causing difficulty participating in the survey and who were illiterate were excluded. A control cohort was studied to compare the group's results with those of healthy adolescents. The university students at Mehmet Akif Ersoy University were invited to the study. The adolescents between 18-22 were invited, and those diagnosed with cancer were excluded.

Procedures/Measures

After outpatient visits, the patients were invited to study. Suitable patients were assessed through either in-person interviews or online questionnaires. We sent an invitation e-mail to participants, and they filled out the survey online. To assess the factors associated with ostracism, the risk factors defined in the literature have been described and studied. The questionnaire included questions on demographic information, sociocultural background (such as presence of siblings and monthly household income), comorbidities, educational background, parental employment status, history of psychiatric admissions, and details about primary illnesses. To evaluate the ostracism, the Ostracism Experience Scale for adolescents (OES-A) was used (2). The OES-A is an 11-item self-report instrument that uses a five-point Likert scale to evaluate two subtypes of ostracism: exclusion and ignorance. Exclusion is social rejection and inappropriate actions a group performs against an individual. (e.g., physical or verbal aggression, behavioral disruption, gossip spreading) can lead to exclusion. Ignorance is social neglect and doesn't display the behaviors that elicit active exclusion(2). The total score from 11 items ranges between 11 and 55, with higher scores indicating a greater level of ostracism experienced. Mercan (16) and akin et al. (17). The test showed validity with an internal consistency reliability coefficient of 0.93 for the ignored subscale, .90 for the excluded subscale, and .89 for the overall scale. In addition, to assess the effects of ostracism depressive symptoms, the Adolescent depression scale (KADS) was used. KADS is an 11-item self-report scale for assessing depression, with each item scored from 0 to 3 based on the frequency of symptom occurrence: 0 (hardly ever), 1 (much of the time), 2 (most of the time), and 3 (all of the time). The total score, ranging from 0 to 33, is the sum of the scores for all 11 items(18). A questionnaire evaluated the characteristics of the control cohort, and OES-A was used to assess the level of ostracism.

Statistical analysis

The baseline characteristics of the patient group were described using frequencies and proportions for dichotomous and categorical variables. Normality testing was performed by evaluating histogram, using Skewness/ Kurtosis results and Kolmogorov- Smirnov/ Shapiro-Wilk tests. After evaluation all those results, distribution of numerical

Table 1. Characteristics of patients and control cohort

Characteristics	With cancer (52) n (%)	Without cancer (206) n (%)
Median age (range)	21 (14-24)	20 (18-22)
Age<21	23 (44.2)	
Male	31 (59.6)	117 (56.8)
Educational status		
in university	23 (44.2)	
other	29 (55.8)	
Living in		
City center	44 (84.6)	175 (84.9)
Other (town, village...)	8 (15.4)	31 (15.1)
Living		
With parents	40 (76.9)	149 (72.3)
With friends/dormitory	12 (23.1)	57 (27.7)
Parents alive	42 (80.8)	195 (94.7)
Parents divorced	2 (3.8)	8 (3.9)
Educational status- father		
Illiterate	6 (11.5)	0 (0)
Primary school	8 (15.4)	115 (55.8)
Middle school	13 (25.0)	6 (2.9)
High school	11 (21.2)	48 (23.3)
University	14 (26.9)	37 (18.0)
Educational status- mother		
Illiterate	7 (13.5)	8 (3.9)
Primary school	1 (1.9)	136 (66.0)
Middle school	20 (38.5)	11 (5.3)
High school	6 (11.5)	37 (18.0)
University	12 (23.1)	14 (6.8)
Sibling present	50 (96.2)	199 (96.6)
Household income (monthly)		
Less than 2000tl	20 (38.3)	82 (39.8)
More than 2000tl	32 (61.5)	124 (60.2)
Working full/part-time	9 (17.3)	23 (11.2)
Time to follow up (range), months	45 (3-267)	
Long follow-up (≥45 months)	26 (50)	
Diagnosis		
Bone- soft tissue malignancy	15 (28.8)	
CNS malignancy	11 (21.2)	
Testis/ Ovarian malignancy	13 (25.0)	
Hematological malignancy	4(7.7)	
Other	9 (17.3)	
Comorbidity present	14 (26.9)	
History of Psychiatry Admission	8 (15.4)	
History of antidepressant/ antipsychotic	5 (9.6)	

data was determined and further analysis was performed. The Kruskal-Wallis test was employed for univariate analysis of predictors of OES-A scores. A median score of 23.5 was used to categorize OES-A scores into high and low groups. Age was divided based on the median age of 21 into two groups: <21 and ≥21. The income parameter was categorized as low or high according to the average wage in Turkey (2000 Turkish liras). The length of follow-up was classified as long or short, based on the median follow-up time of 45 months. The factors associated with OES-A scores were tested by Mann-Whitney U test and the factors associated with high OES-A scores were analyzed using Chi-square test. Parameters with a p-value of less than 0.10 were further explored in multiple regression analysis(MRA). Variables such as female sex, age under 21, university student status, active

employment, and low income were examined using a logistic regression model in the MRA. All analyses were performed using SPSS 22.0 for Windows (IBM Corp., Armonk, NY). *P*- value of less than 0.05 was considered as statistically significant. Power analysis was not performed at the beginning of the study. A posterior power analysis was performed and calculated. The G*Power 3.1.9.2 program was used to perform the power analysis and the frequency of high OES-A cancer patients were used for calculation. Post hoc power was found to be 92.4% with 0.3 effect size.

Results

Demographics

Between December 2017 and April 2018, 70 patients with a diagnosis of cancer were invited, and

Table 2. Factors associated with OES-A scores and high OES scores in adolescents with cancer

Characteristics	OES-A score (median, range)	p	OES-A high n (%)	p
Sex				
Male (n=31)	19.0(11-41)		11 (35.5)	
Female (n=21)	28.0(12-36)	0.008	15 (71.4)	0.011
Age				
<21 (n=23)	25 (11-41)		15 (65.2)	
≥21 (n=29)	21 (11-36)	0.182	11 (37.9)	0.046
Educational status				
in university (n=14)	18.5 (11-30)		7 (30.4)	
other (n=38)	27.0 (11-41)	0.011	19 (65.5)	0.012
Living in				
City center (n=44)	24.0 (11-36)		24 (54.5)	
Other (town, village...) (n=8)	17.5 (11-41)	0.103	2 (25.0)	0.121
Living				
With parents (n=40)	22.0(11-41)		22 (46.8)	
Others (n=12)	35.0 (18-36)	0.012	4 (80.0)	0.173
Both parents alive (n=42)	23.0 (11-41)		21 (50.0)	
One/two parents dead (n=10)	20.5 (16-36)	0.776	5 (50.0)	0.632
Parents divorced				
Yes (n=2)			1 (50.0)	
No (n=50)	NC		25 (50.0)	0.755
Educational status- father				
Illiterate (n=6)	28.5 (21-41)		5 (83.3)	
Primary school (n=8)	21.0 (15-32)		4 (50.0)	
Middle school (n=13)	23.0 (11-36)		6 (46.2)	
High school (n=11)	19.0 (17-32)		4 (36.4)	
University (n=14)	22.5 (11-30)	0.482	7 (50.0)	0.281
Educational status- mother				
Illiterate (n=7)	28.0 (21-41)		6 (85.7)	
Primary school (n=1)	25.0 (15-36)		1 (100)	
Middle school (n=20)	18.5 (16-32)		12 (60.0)	
High school (n=6)	20.0 (11-27)		2 (33.3)	
University (n=12)	17.5 (11-30)	0.086	2 (33.3)	0.592
Sibling				
Present (n=50)			26 (52.0)	
Absent (n=2)	NC		0 (0)	0.247
Household income (monthly)				
Low (<2000tl) (n=20)	28.0 (11-41)		15 (75.5)	
High (>20000tl) (n=32)	21.0 (11-32)	0.029	11 (34.4)	0.005
Working full/part-time (n=9)	19.0 (11-30)		1 (11.1)	
Not working (n=43)	25.0 (11-41)	0.08	25 (58.1)	0.012
Follow-up				
Long (n=26)	26.0 (12-36)		14 (53.8)	
Short (n=26)	21.0 (11-41)	0.153	12 (46.2)	0.394
Diagnosis				
Bone- soft tissue malignancy (n=15)	21.0 (11-40)		5 (33.3)	
CNS malignancy (n=11)	25.0 (11-36)		7 (63.6)	
Testis/ Ovarian malignancy (n=13)	23.0 (15-30)		6 (46.2)	
Hematological malignancy (n=4)	28.0 (20-29)		3 (75.0)	
Other (n=9)	21.5 (16-32)	0.534	4 (50)	0.983
History of Psychiatry Admission				
Present (n=8)	21.0 (11-41)		5 (62.5)	
Absent (n=43)	26.5 (19-32)	0.235	21 (47.7)	0.354
History of antidepressant/ antipsychotic				
Present (n=5)	20.0 (19-32)		2 (40.0)	
Absent (n=47)	23.5 (11-41)	0.624	24 (51.1)	0.501

52 (74.2%) patients participated in 4 different cancer centers. In addition, 206 adolescents without a history of cancer were evaluated as a control cohort. The analysis of characteristics of patients with cancer showed a median age of 21 (14-24), 40.4% of them were female, and most of them were university

students (23, 44.2%) (Table 1). While 96.2% had at least one sibling, 3.8% had parents divorced. 17.3% of them were actively working part-time or full-time. Soft tissue/ bone tumors (28.8%) and germ cell tumors (25.0%) were the most common diagnoses, and median follow-up was 45 months (3-267). In

addition, 14 (26.9%) had at least one comorbidity, and 8 (15.4%) had a history of psychiatry admission.

Ostracism scores and the predictors of ostracism

The median OES-A scores were 23.5 (range: 11.0-41.0) for adolescents with cancer and 19.0 (range: 11-49) for the control cohort ($p=0.040$). Further analysis of OES-A scores in adolescents with cancer revealed median scores of 16.0 (range: 6-30) for the exclusion subscale and 6.0 (range: 5-13) for the ignorance subscale (Table 2). Factors associated with higher ostracism included female sex (71.4% vs. 35.5%, $p=0.011$), age under 21 (65.2% vs. 37.9%, $p=0.046$), and low household income (75.5% vs. 34.4%, $p=0.005$). Conversely, patients working full/part-time (11.1% vs. 58.1%, $p=0.012$) and university students (30.4% vs. 65.5%, $p=0.012$) experienced less ostracism. In MRA, being female was linked to higher OES-A scores (OR: 7.4, 95% CI: 1.3-41.1, $p=0.023$). Being a university student (OR: 0.16, 95% CI: 0.03-0.84, $p=0.036$) and being actively employed (OR: 0.07, 95% CI: 0.008-0.79, $p=0.031$) were associated with lower OES-A scores. Additionally, higher OES-A scores correlated with higher KADS scores (9.0 vs. 7.5, $p=0.166$) (Table 3).

Table 3. Multiple regression analysis of factors associated with high OES-A scores in adolescents with cancer

	High OES-A scores		
	OR	CI (95%)	p
Female	7.4	1.3-41.1	0.023
Being university student	0.16	0.03-0.84	0.036
Working	0.07	0.008-0.79	0.031
Low income	3.2	0.6-16.2	0.152
Age <21	1.5	0.3-7.0	0.565

Discussion

In this study, we aimed to evaluate the level of ostracism in adolescent cancer patients and identify the predictors of ostracism. To the best of our knowledge, this is the first data on ostracism in cancer patients. We concluded that OES-A scores were higher in adolescent cancer patients compared to adolescents without a history of cancer. Female adolescent patients were found to be at higher risk of ostracism, while being employed and being university students appeared to be protective factors against ostracism.

Adolescence is an essential period of time for psychological development. During this period, individuals have healthy social relations and understand and improve their perspectives. However, adolescents are socially more sensitive and have unique problems; exposure to ostracism and social exclusion can cause irreversible issues (19). Being a group member in adolescence is essential, so being excluded from the group may result in disappointment, psychological stress and

sorrow. In addition, social isolation and problems in getting touch with the social group may cause numerous behavioral problems and emotional disturbances (20). The ostracism in adolescents and its effects on adolescents have been studied in numerous studies. We found more OES-A scores in our study population than in the control cohort. The comparison with the historical data was difficult because of the data presented in the previous studies (11, 21). The survey by Gurler et al. found that younger adolescents are more ostracized. We also saw similar data, but there was statistical significance in MRA and correlation analysis (11). The studies on ostracism have not found gender as a risk factor for ostracism (21). Unlike the previous data, we demonstrated that gender is an essential predictor of ostracism. Female adolescents with cancer were exposed to a 7.4-fold increased risk of ostracism. Previous data has shown income level as a risk factor for social exclusion (22). In our study, low income was associated with a 3.2-fold increased risk of ostracism ($p=0.15$). However, there are many determinants of socioeconomic parameters, and a more specific study can clarify them. Consistent with the literature, studies with adolescents showed a positive correlation between ostracism scores and depression (23, 24). As a clinical impact of ostracism, we evaluated KADS scores and found worse depression scores in ostracized adolescents. Some of the literature has shown social exclusion as a risk factor for cyber addiction (25). As a part of clinical impacts, we evaluated the impacts of social media exposure on ostracism. However, there was no correlation between them.

The study has inevitable limitations. Firstly, because we evaluated patients with questionnaires, the data were subjective. In addition, some of the participants completed the survey online. There was no previous data about ostracism in cancer patients. So, further analysis could be done using the median score of OES-A. There is a limited number of adolescent cancer patients who are in remission. So, we could reach only 52 patients. Due to the limited number of patients, we couldn't further evaluate the effects of "working" and "being a university student."

Conclusion

The study found that OES-A scores were higher than those of adolescents without cancer. While female adolescent patients are more prone to ostracism, working and being university students were protective against ostracism. Ostracism in adolescent cancer patients should be studied in a more extensive series with a control group of non-cancer patients.

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Conflict of interest statement

The authors have nothing to declare

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