

# Sexual, psychological, interpersonal well-being and (unmet) supportive care needs of couples after a gynecological cancer treatment

Dalex Pernelle<sup>1</sup>, Koheellee Kaneez<sup>1</sup>, Undurraga Malinverno Manuela<sup>2</sup>, Petignat Patrick<sup>2</sup>, Aerts Leen<sup>2,\*</sup>

<sup>1</sup>Faculty of Medicine, Geneva University, 1206 Geneva, Switzerland

<sup>2</sup>Department Obstetrics and Gynecology, Geneva University Hospitals, 1205 Geneva, Switzerland

\*Correspondence: [Leen.Aerts@hcuge.ch](mailto:Leen.Aerts@hcuge.ch) (Aerts Leen)

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**Objectives:** To assess the sexual and psychosocial functioning of couples after a gynecological cancer treatment and their (unmet) supportive care needs. **Methods:** Patients treated for a gynecological cancer at the Geneva University Hospitals in Switzerland between January 2012 and September 2019 and their partners completed self-reported validated questionnaires on anxiety, depression, sexual function, relationship satisfaction, sexual communication and (unmet) supportive care needs. **Results:** Sixteen couples participated in the study. Mean age was 59.5 (range 46–72) for women and 63 (range 50–76) for men. The mean duration since treatment was 3 years (range = 1–7). 38% of women and 33% of men reported moderate to high levels of anxiety whereas 18, 75% of women and no men suffered from moderate to severe depression. Sixty percent of patients reported a sexual dysfunction and 40% reported significant sexual distress. Eighteen percent of men reported an erectile dysfunction and 33% reported a significant sexual distress. Whereas most couples were satisfied about their relationship, difficulties in sexual communication were expressed. Receiving psychological support, information and help with the changes in the sexual life were the most widely supported care needs. Although the highest domains of unmet needs were in the informational, relational and physical domain, more than 50% of couples reported unmet needs in the sexual domain. **Conclusion:** Gynecological cancer negatively affects the psychosexual well-being of couples. Support during and after treatment should take psychological and sexual aspects and the partner perspective into account.

## Keywords

Gynecological cancer; Sexual function; Psychological well-being; Couple relationship; Unmet supportive care needs

## 1. Introduction

Improvements in diagnostic techniques and advances in treatment modalities for gynecological cancer have contributed to an increased survival over time [1]. More women and their partners are living with sexual and psychological effects of cancer and its treatment.

Over the past decade, a growing body of research has shown that disruptions to the sexual and psychosocial function following gynecological cancer are common and that

they greatly impact the patient's well-being. Psychological issues include fear of cancer recurrence, feelings of uncertainty about their future, anxiety and depression [2]. In addition, self-awareness changes may occur, such as altered experience as a woman (e.g., loss of attractiveness, changes in appearance) [3, 4]. Body image can be impaired through disfiguring changes in appearance and functioning [5, 6]. Furthermore, the physical side effects (e.g., fatigue and pain), may alter self-confidence and participation in social roles [7].

Symptoms of the gynecological cancer itself, including fatigue, abdominal pain and post-coital bleeding can impact women's ability to engage in sexual activities. It has been argued that disruptions to sexual well-being are more likely to be related to the effects of the gynecological cancer treatment, including anatomical changes such as vaginal shortening, reduced vaginal elasticity or clitoral removal [8, 9]. Previous research has shown that women with gynecological cancer reported disruptions in sexual function, including changes to sexual desire, arousal, vaginal lubrication, genital sensitivity, orgasm, and sexual satisfaction [9]. Sexual disruptions are frequently reported as one of the key issues that women are concerned about after diagnosis and treatment [10].

There has been increasing recognition that the impact of cancer is not limited to the individual patient but that it also affects the partner's well-being. To date, little is known on the impact of a gynecological cancer on the partner's quality of life. Since gynecological cancer highly impacts the patient's sexual function, and sexuality and intimacy are inter-subjective experiences, one could assume that partners also struggle with changes in their intimate relationship.

Open communication about sexual concerns is required to adapt to changes in sexual life. Often, talking about sex with one's partner may be difficult. Studies have found that patients receive little information on the impact of the cancer on their sexual functioning so that they feel ill-equipped to manage, and unprepared to cope with the changes to their sexual life [11].

Primary goal of this study is to assess the sexual, psychological and relational functioning of the gynecological cancer patient and her partner after treatment. This studies goal is to increase our understanding about the (unmet) supportive care needs of couples and after their cancer treatment, including their emotional, sexual and social well-being.

## 2. Materials and methods

### 2.1 Participants

Woman who had a surgical or medical treatment for a gynecological cancer at the Geneva University Hospitals in Switzerland between January 2012 and September 2019 were contacted by a medical student (PD) involved in the research project. All partners were recruited via the patients and were not directly contacted. The inclusion criteria for couples were: (1) couple of whom the women had a treatment for a gynecological cancer at the Geneva University Hospitals in Switzerland between January 2012 and September 2019; and (2) being in the same committed, monogamous relationship since the gynecological cancer diagnosis. Exclusion criteria included: (1) age less than 18; (2) not being able to read and understand French; (3) patients having a relapse of the gynecological cancer; and (4) patients or partners being diagnosed with another type of cancer.

### 2.2 Procedure

Patients and partners both received a questionnaire package by mail at their home address. The package included (1) a consent form; (2) an investigator-derived questionnaire on socio-demographics, medical and relationship history; (3) validated self-reported questionnaires on sexual, psychological and interpersonal functioning; and (4) an investigator-derived questionnaire on (unmet) supportive care needs. If no completed questionnaires were received within four weeks a reminder phone call was performed. All subjects gave their informed consent for inclusion before they participate in the study. The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the local Ethics Committee (approval number: 2017-01733, date: 28/03/2018).

### 2.3 Outcome measures

#### 2.3.1 Descriptive variables

Participants completed questionnaires on demographics, medical history and relationship status and sexual activity. Information on the gynecological cancer and treatment was obtained from patient records.

#### 2.3.2 Psychological function

Anxiety was assessed by using the Trait Anxiety subscale of the Spielberger State-Trait Anxiety Inventory (STAI) [12]. This 20-item, well-known, and widely used measure has demonstrated very good psychometric properties in clinical and non-clinical populations. Cronbach's alpha for the present sample was 0.89. The minimum score is 20 and the maximum score is 80. Higher scores indicate higher levels of anxiety. STAI scores are classified as "no or low anxiety"

(score 20–37), "moderate anxiety" (score 38–44), and "high anxiety" (score 45–80).

The Beck Depression Inventory II (BDI II, 21 items) was used to assess the presence and severity of symptoms of depression [13]. Each item rates on a four-point intensity scale. Higher scores indicate higher depression symptoms. Scores between 0 and 13 indicate minimal depression, scores between 14 and 19 indicate mild depression, scores between 20 and 28 indicate moderate depression and scores between 29 and 63 indicate severe depression. Cronbach's alpha for the present sample was 0.86.

#### 2.3.3 Sexual function

Gynecological cancer survivors who were sexually active completed the Female Sexual Function Inventory (FSFI). The FSFI is a self-report 19-item measure assessing sexual functioning in women such as sexual arousal, orgasm, sexual satisfaction and discomfort experienced during sexual activity. The minimum score is 4 and the maximum score is 95. Higher scores indicate better sexual function, and lower scores indicate more impaired sexual function, whereas a score of  $\leq 26.5$  is used as a cut-off score for a clinical sexual dysfunction. This measure has a high internal consistency (i.e., high inter-item correlation for the six domains), and validity among several samples of women with sexual difficulties [14]. Cronbach's alpha for the present sample was 0.98.

Partners who were sexually active completed the 15-question International Index of Erectile Function (IIEF). The IIEF is a validated investigation for the assessment of erectile function, orgasmic function, sexual desire and intercourse satisfaction [15]. The minimum score is 0 and the maximum score is 90. Higher scores indicate better sexual function and lower scores indicate more erectile dysfunction. Cronbach's alpha for the present sample was 0.97.

Both partners completed the Female Sexual Distress Scale, a 12-item measure designed to assess sexually related personal distress. Although designed for women, items are gender non-specific and could pertain to both women and men. The minimum score is 0 and the maximum score is 52. Higher scores indicate more sexual distress. This measure has demonstrated high internal consistency, test-retest reliability, discriminate validity and construct validity [16]. Cronbach's alpha for the present sample was 0.97.

Both partners completed the Dyadic Sexual Communication Scale measuring the sexual communication in the couple [17]. This measure is a 13-item scale that assesses partners' perceptions of their communication processes around sexual problems. It has demonstrated good reliability and a uni-factorial structure. The total score is sum across items with higher scores indicating lower participants' perception of the communication process encompassing the sexual relationship. The minimum score is 13 and the maximum score is 78. Cronbach's alpha for the present sample was 0.81.

**Table 1. Socio-demographic characteristics.**

	Patient	Partner
	n = 16	n = 16
Age (years)	59.5 ± 12.8	63 ± 13.2
Place of birth (%)		
West Europe	93.75	87.5
East Europe	6.25	0
United-States of America or Canada	0	0
Africa	0	0
Asia	0	6.25
Australia	0	0
Middle East	0	0
South America	0	6.25
Years of schooling (years)	15 ± 3.2	15 ± 5.1
Monthly personal income (%)		
<3000 CHF	35.7	6.25
3000–5000 CHF	35.7	25
5000–10000 CHF	21.4	31.25
>10000 CHF	7.1	37.50

Values are presented in percentages or mean ± standard deviation.

### 2.3.4 Relational function

Both partners completed the Couple Satisfaction Index [18], a 32-item measure of relationship satisfaction. The minimum score is 0 and the maximum score is 161. Higher scores indicate higher levels of relationship satisfaction. This measure demonstrates strong convergent validity with other well-known relationship satisfaction measures, and has been used with a sample of participants spanning the relationship spectrum (e.g., dating, engaged, married). Cronbach's alpha for the present sample was 0.95.

### 2.3.5 Supportive care needs

Patient and their partners completed a self-report questionnaire on (unmet) supportive care needs, developed by our research team. The questionnaire was developed based on the available literature, by contacting experts in the field and take into account their comments. The questionnaire consisted of 26 questions evaluating 6 distinct need domains: (1) physical support (e.g., pain management); (2) emotional support and existential survivorship care (e.g., anxiety, loss of control); (3) care on sexual well-being (e.g., changes in sexual feelings); (4) partner relationship support (e.g., family concerns, communication between the couple); (5) social support (e.g., home management, finances, impact on family); and (6) provision of information (e.g., access to professional counselling). The supportive care needs during the gynecological cancer treatment and the actual supportive care needs were evaluated by the question 'Do/Did you have a need?'. To determine whether a need was unmet the following question was asked: 'Did you receive the necessary help to deal with this need?'

**Table 2. Patient's medical history.**

	Patient	Partner
	n = 16	n = 16
Gynecological cancer (%)		
Vulvar cancer	0	
Cervical cancer	25 (4/16)	
Stage I	50 (2/4)	
Stage II	25 (1/4)	
Stage III	0	
Stage IV	25 (1/4)	
Uterine cancer	62.5 (10/16)	
Stage I	80 (8/10)	
Stage II	0	
Stage III	10 (1/10)	
Stage IV	10 (1/10)	
Ovarian cancer	12.5 (2/16)	
Stage I	0	
Stage II	0	
Stage III	100 (2/2)	
Treatment (%)		
Surgical treatment	93.75	
Chemotherapy	37.5	
Radiotherapy	18.75	
Time since end of treatment (%)		
0–1 years	25 (4/16)	
1–2 years	18.75 (3/16)	
2–3 years	31.25 (5/16)	
3–4 years	6.25 (1/16)	
4–5 years	0	
5–6 years	12.5 (2/16)	
6–7 years	6.25 (1/16)	
Menopausal status (%)		
Pre-menopause	12.5	
Post-menopause	87.5	
Other drug use (%)		
Steroid hormones	6.25 (1/16)	
Antihypertensive	63.6 (7/11)	87.5 (7/8)
Cholesterol-lowering drug	18.2 (2/11)	25 (2/8)
Antidiabetic	18.2 (2/11)	25
Antidepressants	9 (1/11)	0
Anxiolytic	9	0
Parasympathomimetic	9	12.5 (1/8)
Other	18	50

Values are presented in percentages or mean ± standard deviation.

### 2.4 Statistical analysis

All data were analyzed using SPSS version 21 (IBM Corp, Armonk, NY, USA). Percentages or mean and standard deviations were used to describe the characteristics of the sample and scores. Pearson correlations were conducted to examine the relationship between variables. The level of significance was set at  $p < 0.05$ .

### 3. Results

#### 3.1 Sample characteristics

In total, 179 couples were contacted. Of those, 106 were eligible for the study. 51 couples agreed to participate. We received completed questionnaires of 16 couples (RR: 15%). The socio-demographic characteristics and medical history are presented in Tables 1,2. 75% of couples were married, 18.7% were co-habiting and 6.3% were not-cohabiting but in a stable partner relationship. The mean duration of the present relationship was 31.5 years (range = 5–45 years, SD = 15.3). The majority of the couples were sexually active (68.75%). Of those not being sexually active (n = 5/16), one couple reported primary dyspareunia as the reason of sexual inactivity, while the other couples reported being sexually inactive because of a male sexual dysfunction (one erectile dysfunction and three unspecified male sexual dysfunctions).

#### 3.2 Psychological functioning

Women had a mean score of 35.79 (SD = 8.93) on the STAI while men had a mean score of 34.4 (SD = 8.64). Six women (37.4%) and five men (33.3%) were suffering from moderate to high levels of anxiety. The BDI showed a mean depression score of 10.1 (SD = 9.1) for women and 5.38 (SD = 4.19) for men with 18.75% of women and no men suffering from moderate to severe depression.

#### 3.3 Sexual and relational functioning

As shown in Table 3, the FSFI mean score ( $25.22 \pm 7.44$ ) was in the clinical range of female sexual dysfunction. Sixty percent (9/15) of patients reported a sexual dysfunction. Forty percent of women reported significant sexual distress. Eighteen percent of men reported an erectile dysfunction. Thirty-three percent of men reported significant sexual distress. The mean score on the Couple Satisfaction Index was comparable between patients and partners, with 2 women (13.33%) and 5 men (31.25%) reporting relationship dissatisfaction. No significant difference was seen between patients and partners in terms of dyadic sexual communication.

#### 3.4 Relationship between psychological, sexual and relational well-being

In women, anxiety was positively correlated with depression,  $r(16) = 0.006, p < 0.05$ . Sexual distress was positively correlated with depression,  $r(15) = 0.023, p < 0.05$  and with the total FSFI score,  $r(15) = 0.045, p < 0.05$ . The total FSFI score was also positively correlated with the Dyadic Sexual Communication score,  $r(15) = 0.012, p < 0.05$ .

In men, sexual function was positively correlated with sexual communication,  $r(15) = 0.029, p < 0.05$ , and sexual distress was negatively correlated with relationship satisfaction,  $r(15) = 0.038, p < 0.05$ .

#### 3.5 Supportive (unmet) care needs

As shown in Table 4, 38.1% of women expressed supportive care needs in the psychological domain, followed by 33.5% in the relational, 32.2% in the sexual, 31.8% in the physical, 23.7% in the informational and 18% in the practical domain

**Table 3. Sexual and relational functioning.**

	Patient n = 15	Partner n = 16
Female sexual function index		
Total score	25.22 ± 7.44	
FSFI desire	3.24 ± 1.11	
FSFI arousal	3.99 ± 1.24	
FSFI lubrication	4.47 ± 1.59	
FSFI orgasm	4.4 ± 1.54	
FSFI satisfaction	4.28 ± 1.77	
FSFI pain	4.84 ± 1.34	
International Index of Erectile Function		
Erectile function		21.9 ± 7.4
Orgasmic function		6.8 ± 2.6
Sexual desire		6.5 ± 1.7
Intercourse satisfaction		9.9 ± 3.8
Overall satisfaction		7.7 ± 2.0
Sexual Distress Scale	15.67 ± 17.05	11.71 ± 10.97
Couple Satisfaction Index	129.13 ± 26.24	129.81 ± 26.31
Dyadic Sexual Communication Scale	52.79 ± 14.99	50.8 ± 11.21

Values are presented in percentages or mean ± standard deviation.

during treatment. After treatment, women expressed supportive care needs in the following domains: 23.5% in the relational, 22.3% in the sexual, 22% in the psychological, 21.3% in the informational, 17.2% in the physical, and 8.7% in the practical domain.

During treatment, they reported unmet needs in the informational domain (89%), followed by the physical (60.8%), sexual (52.5%), relational (33%), psychological (24.4%) and practical domain (16.7%). After treatment, 71% of the unmet needs were in the relational domain, 68.4% in the physical, 68.2% in the sexual, 64% in the informational, 42% in the psychological, and 16.7% in the practical domain.

For men, the majority of supportive care needs expressed during treatment were in the psychological domain (32.9%), followed by the sexual (30.7%), physical (26.5%), informational (14.7%), practical (14%) and relational domain (11%). After treatment, 28.3% of the supportive care needs were in the sexual domain, while 17.4% were in the psychological, 12.3% in the informational, 11.5% in the relational, 7.8% in the practical, and 5.3% in the physical domain.

During treatment they reported unmet needs in the relational (100%) and the informational domain (100%), followed by the sexual (81.3%), psychological (57.3%), physical (45.8%) and practical domain (33%), while after treatment 100% of the unmet needs were in the relational and informational domain, followed by 78.5% in the sexual, 64.1% in the psychological, 50% in the physical, and 12.5% in the practical domain.

**Table 4. (Unmet) supportive care needs.**

Physical function Female	Care need during treatment	Care need after treatment	Unmet need during treatment	Unmet need after treatment	Physical function Male	CN	CN2	UN	UN2
Difficulties in pain control	13	13	100	100	Difficulties in pain control	39	14	60	100
Fatigue	53	13	50	100	Fatigue	33	7	40	100
Trouble sleeping	20	20	67	67	Trouble sleeping	13	0	50	0
Memory/concentration difficulties	40	27	67	75	Memory/concentration difficulties	21	0	33	0
Bladder or bowel problem	33	13	20	0					
Psychological function F	CN	CN2	UN	UN2	Psychological function M	CN	CN2	UN	UN2
Anxiety	47	20	14	33	Anxiety	33	17	60	100
Depression	20	7	0	0	Depression	14	0	100	0
Sadness	53	27	25	50	Sadness	33	15	40	100
Fear of cancer progression	47	33	14	27	Fear of cancer metastasis	47	21	43	33
Fear of death	27	27	25	50	Fear of death	53	31	50	50
Loss of control	33	20	60	67	Loss of control	21	21	33	66
Physical modification	40	20	33	67	Physical modification	29	17	75	100
Sexual function F	CN	CN2	UN	UN2	Sexual function M	CN	CN2	UN	UN2
Sexual impact	40	20	50	67	Sexual impact	40	21	83	66
Desire modification	33	27	80	75	Desire modification	27	17	75	100
Dyspareunia/fear to hurt	33	13	20	50	Dyspareunia/fear to hurt	36	31	80	75
Sexual changes	27	27	50	75	Sexual changes	31	31	75	75
Sexual communication	27	27	75	75	Sexual communication	21	39	100	80
Intimacy	33	20	40	67	Intimacy	29	31	75	75
Relationship F	CN	CN2	UN	UN2	Relationship M	CN	CN2	UN	UN2
Family and partner concern	20	20	33	67	Family and partner concern	15	15	100	100
Communication	27	27	33	75	Communication	7	8	100	100
Practical issues F	CN	CN2	UN	UN2	Practical issues M	CN	CN2	UN	UN2
Activities and hobbies	27	13	25	50	Activities and hobbies	21	15	66	50
Home management	27	13	25	0	Home management	7	8	0	0
Money	0	0	0	0	Money	7	8	0	0
Information F	CN	CN2	UN	UN2	Information M	CN	CN2	UN	UN2
Quality of life	29	14	100	100	Quality of life	14	15	100	100
Specialist access	21	21	67	67	Specialist access	7	7	100	100
Nursing support	21	29	100	25	Nursing support	23	15	100	100

Values are presented in percentages.

#### 4. Discussion

The aim of the present study was to examine the sexual, psychological and relational functioning of couples after a gynecological cancer treatment and to assess their (unmet) supportive care needs.

In the current study 38% of women reported moderate to high levels of anxiety. These findings are in line with the results of cross-sectional studies in ovarian and cervical cancer patients [6, 19] and are higher than levels found in the general female population [2]. Thirty-three percent of men reported moderate to high levels of anxiety. Similar levels of anxiety have been reported in previous studies assessing the psychological well-being of partners of cancer patients [20]. These findings are not surprising as couples are suddenly faced with a serious and unexpected threat that creates uncertainties about the future. The mean depression score in our study is in line with the findings of previous prospective controlled studies in gynecological cancer patients [21, 22]. Interestingly, levels of depression were similar to levels reported in the general female population [23]. Previous research has shown that although patient's levels of depression are increased during and immediately after cancer treatment, patients with a cancer survival time greater than 1-year report levels of depression that do not differ from the general population. A possible explanation is the "response shift" phenomenon: when confronted with a life-threatening disease patient may adjust their internal standards and values, based on which they evaluate their general well-being. In the current study none of the partners were suffering from moderate or severe depression. These findings are comparable with the results of a cross-sectional study assessing the psychological well-being of partners after a treatment for gynecological cancer showing that during cancer follow-up, partners were significantly less depressed than their spouses [24].

The current study showed that 60% of the sexually active patients reported a sexual dysfunction and 40% experienced significant sexual distress. These results are in line with previous research showing that women who are confronted with a gynecological cancer are at risk for sexual dysfunctions [21, 25]. Partners of women with a gynecological cancer also reported a disruption in their sexual function. Eighteen percent of the sexually active partners reported an erectile dysfunction compared to 7% in the general population [26]. Thirty-three percent reported significant sexual distress. The consequences of the cancer and its treatment force couples to redefine their sexual relationship, to explore alternative possibilities with regard to sexual behavior [27]. Lack of information and couple's challenges to communication about sexual issues may lead to lack of understanding of the situation and distress whereas an open and constructive communication enhances better coping with the new sexual life [28, 29]. Women and partners reported that talking about sexual concerns and wishes is one of the most difficult issues in cancer recovery [29, 30]. These findings are supported by the results of our study showing that although most couples were

satisfied about their partner relationship, difficulties were encountered in sexual communication. Finally, the positive associations between the psychological well-being, relationship satisfaction and sexual function and distress are in line with the current bio-psycho-social model of human's sexuality.

In the current study, supportive care needs were identified in all domains. In line with other studies [31–34] receiving psychological support and receiving information and help with the changes in the sexual life were the most widely supported care needs of couples during and after treatment. The highest domains of unmet needs during and after treatment were in the informational, relational and physical domain. In addition, more than 50% of patients and partners reported unmet needs in the sexual domain.

Our study has some limitations. First, the results are limited by the small sample size and low response rate. This may be due to the large package of questionnaires and by our reliance on a mail-back procedure. The limitations of our study include a response bias since people who feel confident about talking about sexuality have usually less sexual problems. Thirdly, to measure the presence of (unmet) supportive care needs, we used a newly developed questionnaire. These limitations notwithstanding, the present study is unique in presenting findings about the psychosocial and sexual function of both the gynecological cancer survivor and her partner and their (unmet) supportive care needs.

Replication of the study in a prospective way and with a larger sample would increase our knowledge about how sexual concerns and supportive care needs for the couple evolve over time. Furthermore, it would allow to assess predictors of psychosocial and sexual distress and of couple's care needs.

The findings show that not only information about the course of the illness and its treatment should be provided, but that psychosexual issues should be addressed during and after treatment. By opening and facilitating the discussion about sexuality and intimacy, as well as providing information that normalizes a wide range of sexual changes and intimate practices, rebuilding sexual life after cancer diagnosis and treatment will be facilitated. Effective psychosocial and sexual support must be provided for both the patient and her partner so they can both express their feelings and worries. It can involve psychosexual education such as effects of cancer and its treatment on sexuality (i.e., desire, arousal) but also on the physical well-being (i.e., fatigue, memory and concentration difficulties). This way, prevention can be made and help can be brought if patient and partner meet these difficulties. Since healthcare provider's workings in oncology often feel uncomfortable addressing sexual issues appropriately [10], communication about sexual health issues should be included in their education and training. Interdisciplinary work between clinicians, nurse practitioner and psychologist should be revalued.

## 5. Conclusions

The current findings show that gynecological cancer and treatment negatively affects the psychological and sexual well-being of the patient and her partner. Support during and after treatment should go beyond the physical aspects of the cancer treatment and should take psychological and sexual aspects and the partner perspective into account.

## Author contributions

Category I, Conception and Design—AL, KK; Category I, Acquisition of Data—AL, DP; Category I, Analysis and Interpretation of Data—AL, DP; Category II, Drafting the Article—AL, DP; Category II, Revising it for Intellectual Content—AL, DP, UMM, PP; Category III, Final Approval of the Completed Article—DP, KK, UMM, PP, AL.

## Ethics approval and consent to participate

The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the local Ethics Committee (approval number: 2017-01733, date: 28/03/2018).

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## Conflict of interest

The authors declare no conflict of interest.

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