

Quality of Patient Information by Urologists Is Associated with Mental Distress in Bladder Cancer Patients

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Keywords

Bladder cancer · Cancer information · Mental distress · HADS · FBK-R23

Abstract

Aims: The study aimed to evaluate the prevalence of mental distress in patients with newly diagnosed bladder cancer, the cancer-information search behavior, and the influence of information seeking on distress. **Methods:** One hundred and one bladder cancer patients answered 2 established questionnaires (“Hospital Anxiety and Depression Scale” [HADS] and the “Fragebogen zur Belastung von Krebskranken” [FBK-R23]) for evaluation of mental distress and a self-developed questionnaire with questions concerning information seeking and socioeconomic facts. **Results:** Regarding risk group stratification, 57.4% were classified as high-risk and 42.6% as low-risk tumor-bearing patients. Analysis of mental distress showed that 23.2% had a score above the HADS-A cutoff, 25.3% above the HADS-D cutoff, and 21.4% showed a pathologic FBK-R23 score. Overall, 75% felt well informed about their illness. Risk group stratification did not correlate with HADS-A, HADS-D, or FBK-R23 score. Furthermore, active search for information or the use of the Internet did not cor-

relate with the HADS-A, HADS-D, or FBK-R23 score. However, the quality of the urologist’s information and the feeling of being informed correlated with the grade of mental distress.

Conclusion: Besides the treatment of bladder cancer, informing the patient about the disease in a psychologically wholesome manner and working together with psycho-oncologically trained psychologists are essential tasks for the treating urologist.

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Introduction

Bladder cancer (BC) is the second most common cancer of the genitourinary tract and the eleventh most diagnosed cancer worldwide [1]. BC is more common in men than in women, with respective incidence and mortality rates of 9.6 and 3.2 per 100,000 [1]. Approximately 75% of the patients with BC present with non-muscle invasive disease confined to the mucosa (stage Ta, CIS) or submucosa (stage T1), whereas 25% of the patients present in a muscle-invasive and/or primarily metastasized tumor stage [2]. In non-muscle invasive tumors, a bladder-preserving treatment is possible, but even there a high risk of

Table 1. Descriptive characteristics

<i>Section A</i>	
Age, years	
Mean	72.3
SD	9.09
Min.	48
Max.	92
Sex	
Male	76 (75.2)
Female	25 (24.8)
T-stage	
CIS	2 (2.0)
pTa	55 (54.4)
T1	23 (22.8)
T2 or higher	16 (15.8)
No data	5 (5.0)
Grading	
PUNLMP	3 (3.0)
Low grade	49 (48.5)
High grade	43 (42.6)
No data	6 (5.9)
Risk group	
Low risk	43 (42.6)
High risk	58 (57.4)
<i>Section B</i>	
Relationship	
Yes	69 (68.3)
No	28 (27.7)
Not specified	4 (4.0)
Education	
Low/intermediate	27 (26.7)
Higher	50 (49.5)
University	21 (20.8)
Not specified	3 (3.0)
Income, EUR	
<20,000	33 (32.7)
20,000–40,000	32 (31.7)
40,000–60,000	11 (10.9)
60,000–80,000	5 (5.0)
>80,000	7 (6.9)
Not specified	13 (12.9)
Center of life	
Village	16 (15.8)
Town	43 (42.6)
City	40 (39.6)
Not specified	2 (2.0)
Values are presented as <i>n</i> (%), unless otherwise stated.	

disease recurrence or progression remains, especially in high-grade tumors [3].

Mental distress experienced by patients at the time of primary diagnosis is often high, and coping strategies of patients are different when patients face the diagnosis of BC for the first time. Therefore, clinically relevant anxiety and/or depression might result from this fact. For example, Vakalopoulos et al. [4] showed that up to 23.1% of the patients with muscle-invasive BC suffer from a relevant depression. Besides, Draeger et al. [5] reported that 28%

of the BC patients, be it in a curative or palliative situation, expressed a need for psychosocial support. In line with these results is the review by Pham et al. [6]. They revealed that mental health issues, such as depression and anxiety, often coexist with a diagnosis and treatment of BC. Here, a bad prognosis is associated with a more significant psychological burden, especially after radical cystectomy. Previous studies mainly analyzed patients after radical cystectomy. In comparison, we evaluated the incidence of distress in patients with newly diagnosed BC.

The process of information seeking and decision-making is often complicated and stressful for the patient, since different treatment options can be offered to BC patients, depending on the stage of the disease, the available modalities of the hospital, and the preferences of the patient. It is evident that patients with newly diagnosed cancer want to be informed and involved in the treatment decision-making process with their physician. However, physicians continue to underestimate the degree to which patients wish to be informed [7–9].

Up to now, few studies on information search behavior and the connection to psychosocial stress in BC patients after the initial diagnosis after transurethral resection of the bladder have been conducted. Therefore, the primary aim of the present study was of exploratory nature in order to identify possible associations between information about BC and mental distress after the initial diagnosis, using *inter alia* standardized and validated questionnaires (e.g., HADS-A, HADS-D, and FBK-R23).

Materials and Methods

Three hundred fifty-seven patients who have been diagnosed with BC between January 2009 and December 2016 were retrospectively identified via the hospital information system (Orbis; Agfa Healthcare, Mortsels, Belgium) of the University Hospital Frankfurt am Main, Germany. The primary purpose of the study was to assess the mental status and the information-seeking behavior of patients in the first 2 months after the initial diagnosis. At this point, patients only had transurethral resection of the bladder and no further treatment.

Extensive information about the study, a consent form, and the self-assessment questionnaire package were sent by post in 2017. Therefore, the time frame knowing about the diagnosis of BC was between 1 and 11 years.

The questionnaire package consisted of:

- The German questionnaire “Fragebogen zur Belastung von Krebskranken (FBK-R23).” The FBK-R23 is a 23-item questionnaire evaluating psychosomatic complaints, anxiety, information deficit, everyday restriction, social stress, and a sum score showing general mental distress in cancer patients. A sum score of >34 indicates a need for further psycho-oncological attention [10].
- The German version of the Hospital Anxiety and Depression Scale (HADS). The HADS is a non-cancer-specific 14-item questionnaire with 7 items assessing anxiety (HADS-A) and 7 items assessing depression (HADS-D) [11]. Here, a sum score of >8 on either scale indicates possible clinical cases of distress [12].

Table 2. Information-seeking behavior

Prior knowledge	
No knowledge	59 (58.4)
Little knowledge	24 (23.8)
Neutral or good knowledge	18 (5.9)
Active search	
No active search	32 (31.7)
Undecided	11 (11.9)
Active search	58 (57.4)
Familiar with the Internet	
Not	39 (38.6)
Undecided	7 (6.9)
Yes	55 (54.5)
Use of the Internet	
No	60 (59.4)
Yes	41 (40.6)
Use of social media	
No	96 (95.0)
Yes	3 (3.0)
Not answered	2 (2.0)
Use of TV	
No	93 (92.1)
Yes	7 (6.9)
Not answered	1 (1.0)
Use of books	
No	90 (89.1)
Yes	10 (9.9)
Not answered	1 (1.0)
Use of journals	
No	78 (77.2)
Yes	22 (21.8)
Not answered	1 (1.0)
Use of flyers	
No	64 (63.)
Yes	34 (33.7)
Not answered	3 (3.0)
Second medical opinion	
No	62 (61.4)
Yes	38 (37.6)
Not answered	1 (1.0)
Advice of pharmacist	
No	96 (95.0)
Yes	4 (4.0)
Not answered	1 (1.0)
Advice of friend/relative	
No	77 (76.2)
Yes	22 (21.8)
Not answered	2 (2.0)
Being well advised from urologist	
No	10 (9.9)
Undecided	10 (9.9)
Yes	80 (79.2)
Not answered	1 (1.0)
Being well advised from general practitioner	
No	41 (40.6)
Undecided	15 (14.9)
Yes	43 (42.5)
Not answered	2 (2.0)
Being well advised in general	
No	11 (10.9)
Undecided	14 (13.9)
Yes	75 (74.3)
Not answered	1 (1.0)
Influence of information on therapy decision	
No	39 (38.6)
Undecided	13 (12.9)
Yes	48 (47.6)
Not answered	1 (1.0)

Values are presented as *n* (%).

- A self-developed instrument to assess information-seeking behavior and socioeconomic data (Table 1, section B, and Table 2).

In the self-developed questionnaire, patients were asked about:

- their level of knowledge of BC before the diagnosis;
- whether they actively searched for information concerning BC;
- if they used the Internet or social media for information search;
- if they used TV, books, journals, or health flyers as a source for information about BC;
- if they obtained a second opinion concerning their disease by consulting a physician;
- if they asked a pharmacist, or a relative or friend for information;
- if they felt well informed at the initial diagnosis of BC;
- if they felt well informed after talking to the treating urologist or the general practitioner/family doctor, and
- if the obtained information influenced the further treatment decision;
- socioeconomic characteristics were evaluated (relationship, education, salary, center of life).

In total, 101 patients provided written consent and returned filled in questionnaires. Participants' tumor-specific data were retrospectively collected using the hospital information system Orbis. Tumor risk group stratification was done for every patient. For non-muscle invasive tumors, we used the EORTC risk calculator [3], and all muscle-invasive or advanced tumors at initial diagnosis were grouped per definition as high-risk tumors.

Statistical Analysis

The statistical analysis was performed using the IBM SPSS Statistics 23 package. Descriptive statistics were calculated for demographic and distress measures. As correlation measures for metric and ordinal data, the Spearman correlation coefficient (ρ) was calculated; for correlations between metric and dichotomous variables, the point-biserial correlation coefficient was used. Statistical tests were two-tailed with a significance level of $p < 0.05$.

The familywise error rate across the reported statistical analysis was controlled by the stringent sequential Bonferroni method. Overall, we consider this research relatively preliminary, and thus especially emphasize and discuss the uncorrected findings and encourage replication for verification [13, 14].

Results

Description of Sample Characteristics, Information Seeking, Analysis of HADS-A, HADS-D, and FBK-R23 Metrics

Of the 357 questionnaires sent, 101 (28%) were returned and included in the final analysis. Sociodemographic information about the participants is listed in Table 1. The study population had a mean age of 72 years and included 75% males and 25% females. The majority (80%) of the patients had a non-muscle invasive bladder tumor (CIS, pTa, pT1). Histopathological low grade and high grade were displayed in 48.5 vs. 42.6% of the cases. Risk stratification revealed 42.6% low-risk and 57.4% high-risk cancers. Of the participants, 69.3% were in a relationship. Higher education was mentioned by 49.5%; 20.8% had a university degree. A total of 64.4% of the pa-

Table 3. HADS and FBK-R23 descriptive statistics

	<i>n</i>	Mean	SD	Min.	Max.
HADS-A	99	5.06	3.94	0	16
HADS-D	99	5.13	4.73	0	19
FBK-R23	98	22.83	20.65	0	84

tients had a salary up to 40,000 EUR. The center of life was principally a town or a city (82.2%).

Most participants (58.4%) had no knowledge of BC when getting the diagnosis. In 57.4%, an active search for information was documented. They obtained the information through media such as the Internet (40.6%), flyers (33.7%), journals (21.8%), books (9.9%), TV (6.9%), and social media (3%), but also through friends/relatives (21.8%), pharmacists (4%), or through a second medical opinion (37.6%).

They felt well advised by the treating urologist in 79.2% of the cases. A total of 42.5% were satisfied with the information conveyed by the general practitioner, and 74.3% had the feeling of being well advised in general. The obtained information influenced the therapy decision of 47.6% (Table 2).

The metrics of the questionnaires were as follows: HADS-A displayed a mean value of 5.06 (SD 3.94). The HADS-D showed a mean value of 5.13 (SD 3.94), and the FBK-R23 had a mean value of 22.83 (SD 20.65; Table 3).

Association of HADS-A, HADS-D, and FBK-R23 with Each Other and with Clinical Parameters

HADS-A correlated with HADS-D and with the FBK-R23 sum score ($p < 0.001$, Bonferroni corrected). Furthermore, HADS-D correlated with the FBK-R23 sum score (Table 4, each $p < 0.001$, Bonferroni corrected). Neither the T-stage, grading nor risk stratification correlated with the HADS-A and HADS-D score (Table 4). T-stage did not correlate with psychosomatic complaints, anxiety, information deficit, everyday restriction, social stress, total burden, and the FBK-R23 sum score (Tables 4, 5). Also grading and risk allocation were not correlated with most of the items of the FBK-R23 (Tables 4, 5). Limitation of everyday life of the FBK-R23 correlated positively with grading ($p = 0.019$) and risk group ($p = 0.005$; Table 5).

Association of Information Seeking with Mental Distress

The level of information before knowing the diagnosis of BC did not correlate with HADS-A ($p = 0.748$), HADS-D ($p = 0.692$), or the FBK-R23 sum score (Table 4, $p = 0.294$). Active search for information, the use of the Internet, social media, television, books, journals, or information flyers also did not correlate with the HADS-A or

HADS-D score (Table 4). Use of social media did correlate positively with fear, social stress ($p < 0.001$, Bonferroni corrected), the value of total stress, and the FBK-R23 sum score (Tables 4, 5). Active search for information, the use of the Internet, television, books, journals, or information flyers did not correlate with FBK-R23 (Tables 4, 5).

There are significant negative correlations between the quality of the urologist's information with HADS-A and psychosomatic problems, fear, lack of information, social stress, the value of total stress, and FBK-R23 sum score (Tables 4, 5). Information of the general practitioner did not correlate with the HADS-A or HADS-D score. Concerning the different items of FBK-R23, only lack of information correlated negatively with information of the general practitioner. The feeling of being informed correlated negatively with HADS-A, HADS-D, and all items of FBK-R23 (Tables 4, 5). The influence of information on therapy did not correlate with HADS-A or HADS-D (Table 4). Regarding FBK-R23, the influence of information on therapy correlated negatively with lack of information, the value of total stress, and the FBK-R23 sum score (Tables 4, 5).

Association of Socioeconomic Parameters with Mental Distress

Age, gender, education, steady relationship, and center of living (city vs. country) did not correlate with HADS-A and HADS-D scores. The level of gross annual income was negatively associated with the HADS-A score (-0.215 ; $p = 0.046$). Gender, education, gross annual income, steady relationship, and the center of living did not correlate with the FBK-R23 score. Age correlated negatively with anxiety in the FBK-R23 score (-0.241 ; $p = 0.017$).

Discussion

A cancer diagnosis can be life-changing. In addition to physical complaints, especially psychological distress is a big challenge for patients. In particular, in the immediate period after diagnosis, patients experience a high burden, to which they can respond with different stress symptoms [15–17].

In this study, we analyzed how stressful a newly diagnosed BC diagnosis is for patients, how patients inform themselves, and how much such information is associated with mental distress. The sociodemographic structure of our study population meets the expectations of this group of patients and can, therefore, be regarded as a typical sample. For example, a high proportion of patients with a positive smoking history (72.5%) [18, 19] is in the range as was expected.

Table 4. Correlation of clinical parameters and parameters of information with HADS-A, HADS-D, and FBK-R23 sum score

	HADS-A	HADS-D	FBK-R23 sum score
HADS-A ¹	–	0.659 (<0.001*)	0.733 (<0.001*)
HADS-D ¹	0.659 (<0.001*)	–	0.708 (<0.001*)
FBK-R23 sum score ¹	0.733 (<0.001*)	0.708 (<0.001*)	–
T-stage ¹	0.113 (0.278)	0.112 (0.284)	0.047 (0.657)
Grading ¹	–0.018 (0.865)	0.057 (0.586)	0.146 (0.166)
Risk ¹	0.025 (0.808)	0.076 (0.456)	0.173 (0.088)
Information before ¹	–0.033 (0.748)	–0.040 (0.692)	–0.107 (0.294)
Active information search ¹	0.022 (0.826)	–0.117 (0.249)	–0.054 (0.597)
Use of the Internet ²	0.029 (0.777)	0.120 (0.235)	0.015 (0.882)
Use of social media ²	0.192 (0.060)	0.132 (0.198)	0.240 (0.018*)
Use of TV ²	0.125 (0.220)	0.017 (0.865)	0.124 (0.224)
Use of books ²	–0.050 (0.626)	–0.166 (0.102)	–0.132 (0.196)
Use of journals ²	0.157 (0.123)	–0.082 (0.420)	0.035 (0.735)
Use of flyers ²	0.200 (0.051)	0.138 (0.180)	0.161 (0.118)
Information urologist ¹	–0.257 (0.011*)	–0.155 (0.127)	–0.237 (0.019*)
Information general practitioner ¹	–0.045 (0.663)	–0.162 (0.114)	–0.122 (0.233)
Feeling well informed ¹	–0.323 (<0.001*)	–0.332 (<0.001*)	–0.338 (<0.001*)
Influence of information on therapy ¹	–0.178 (0.080)	–0.152 (0.135)	–0.200 (0.048*)

Bold indicates correlation is significant at alpha corrected by the sequential Bonferroni method. * $p < 0.05$. ¹ Spearman correlation coefficients. ² Point-biserial correlation coefficients.

Table 5. Correlation of clinical parameters and parameters of information with single items of the FBK-R23

	Psychosomatic problems	Fear	Lack of information	Limitation of everyday life	Social stress	Value of total stress
T-stage ¹	0.039 (0.707)	–0.020 (0.851)	–0.018 (0.864)	0.142 (0.176)	–0.037 (0.727)	0.049 (0.638)
Grading ¹	0.071 (0.500)	0.028 (0.792)	0.100 (0.348)	0.245 (0.019*)	0.093 (0.379)	0.149 (0.156)
Risk ¹	0.099 (0.333)	0.063 (0.538)	0.105 (0.308)	0.284 (0.005*)	0.087 (0.393)	0.173 (0.089)
Information before ¹	–0.049 (0.633)	–0.064 (0.529)	–0.155 (0.132)	–0.127 (0.213)	–0.079 (0.440)	–0.105 (0.305)
Active information search ¹	0.030 (0.771)	–0.032 (0.752)	–0.104 (0.313)	–0.103 (0.312)	–0.041 (0.685)	–0.055 (0.591)
Use of the Internet ²	–0.044 (0.668)	–0.027 (0.790)	–0.005 (0.958)	0.054 (0.595)	0.059 (0.566)	0.006 (0.955)
Use of social media ²	0.187 (0.067)	0.269 (0.008*)	0.047 (0.649)	0.171 (0.094)	0.356 (<0.001*)	0.240 (0.016*)
Use of TV ²	0.158 (0.121)	–0.004 (0.968)	0.101 (0.325)	0.079 (0.442)	0.157 (0.123)	0.117 (0.252)
Use of books ²	–0.093 (0.362)	–0.184 (0.070)	–0.156 (0.130)	–0.075 (0.463)	–0.060 (0.559)	–0.135 (0.185)
Use of journals ²	0.150 (0.140)	–0.049 (0.633)	0.012 (0.910)	–0.008 (0.934)	0.023 (0.819)	0.035 (0.735)
Use of flyer ²	0.245 (0.016*)	0.068 (0.508)	0.055 (0.601)	0.098 (0.344)	0.106 (0.306)	0.147 (0.153)
Information urologist ¹	–0.136 (0.183)	–0.230 (0.023*)	–0.338 (<0.001*)	–0.120 (0.241)	–0.205 (0.043*)	–0.238 (0.019*)
Information general practitioner ¹	–0.117 (0.255)	–0.029 (0.777)	–0.202 (0.048*)	–0.157 (0.125)	–0.004 (0.973)	–0.123 (0.232)
Feeling well informed ¹	–0.276 (0.006*)	–0.238 (0.018*)	–0.382 (<0.001*)	–0.226 (0.025*)	–0.317 (0.001*)	–0.335 (0.001*)
Influence of information on therapy ¹	–0.169 (0.096)	–0.129 (0.204)	–0.259 (0.011*)	–0.196 (0.052)	–0.060 (0.555)	–0.202 (0.046*)

Bold indicates correlation is significant at alpha corrected by the sequential Bonferroni method. * $p < 0.05$. ¹ Spearman correlation coefficients. ² Point-biserial correlation coefficients.

While in general, about 30% of all cancer patients are considered severely distressed; this rate appears to be lower (about 20%) in prostate cancer patients [20]. Our cohort of BC patients seems to be similar to prostate cancer patients, since the most substantial part of BC patients are elderly men, and the share of patients in this study with a relevant level of mental distress was between 20 and 30%

(23.2% [HADS-A], 25.3% [HADS-D], and 21.4% [FBK-R23] of the patients with a score above the cutoff).

Patsou et al. [21] showed a correlation between income, education, and tumor stage with depressive symptoms and anxiety. Besides, Jeong and An [22] reported that in gastric cancer patients, age correlated with depression and anxiety correlated with income. Analysis of so-

ciodemographic factors revealed that in our cohort, age and income correlated negatively with anxiety.

Furthermore, we wanted to evaluate if the real clinical threat caused by the cancer stage is associated with experienced mental distress. In general, the first diagnosis of cancer is initially a shock [23, 24], but remarkably in the current study, there was no correlation between the clinical but scientific risk group, one could call it “the real threat” and the level of mental distress. Is this because of the not sufficient information was conveyed by the doctor? Or is cancer just cancer? Meaning that the patient does not realize the tumor stage or even neglects this prognosis-defining fact. Vrinten et al. [25] showed that cancer fear and psychosocial stress interact to produce disengagement with cancer-related information. Chae [26] described that cancer information overload, accompanied by confusion and stress about cancer information, causes cancer information avoidance.

Studies have shown a gap of cancer information seeking between low and high socio-economic statuses [27–29]. Educated patients seek to have more information about their disease. This may result in more active participation in medical decision-making, to be satisfied with their medical services, to engage in healthy lifestyle behaviors, and to ultimately achieve better health outcomes and a reduced stress level [30]. The Internet, in general, plays a crucial role in information finding. Even the older generation is becoming more and more familiar with the use of the Internet. In the present study, 40.6% of the patients used the Internet in their search for information. This is in line with a recent study of Corrales et al. [31], who analyzed the use of the Internet for research in breast cancer patients. They reported that 46% of their patients used the Internet for information about their condition. Different studies already showed that the Internet search for information may be confusing [32] and may increase the disease-specific anxiety [33]. In the Corrales study, the HADS anxiety subscale score was higher for those who used the Internet versus those who did not. In contrast, in our study, the use of the Internet for information seeking was not associated with the HADS-A and HADS-D scores. In general, the Internet search for cancer information may be complicated, but with more and more cancer societies launching reliable and easy-to-understand guideline-based cancer information sites (European Association of Urology, American Association of Urology), the quality of information may increase with the result of soothing the mind [34].

A relevant finding of this study is that the level of information given by the treating urologist is essential for the patients, since the level of information analyzed by the FBK-R23 influenced the therapy decision of the patients significantly. Here, the level of information correlated

furthermore with psychosomatic complaints, anxiety, information deficit, everyday restrictions, social stress, total stress value, and the sum score in FBK-R23.

Davison et al. [7] and Davison and Breckon [8] have reported similar results for patients with prostate cancer. They analyzed the role men assumed with their physician in treatment decision-making, factors influencing their decision, and information preferences. They concluded that the urologist’s recommendation for treatment continues to be one of the most critical influences on the treatment decision. The type and amount of information men want are dependent on their health information-seeking behavior, with younger men being more active concerning treatment decision-making compared to older men.

A limitation of the current study is that patients were asked at different time points about their feeling they had after they have been told to have BC. The diagnosis of BC was made between 2006 and 2016, and questionnaires were sent to the participants in 2017. Therefore, the time frame knowing about the diagnosis of BC was between 1 and 11 years. For that reason, bias is likely since patients might remember the situation from a different point of view. For example, if the disease is healed now, patients might remember that they felt less anxiety than patients who had progressive disease.

Another question that should be raised is if the correlation between patient’s level of information and psychological distress is causal or not. Previous studies showed that the patient’s level of information influences psychological distress [35, 36]. Nevertheless, the question remains to which extent the psychological distress influences the patient’s level of information. A patient who knows how to cope with the burden associated with the disease could be less emotionally influenced by it, and it might be easier for him to follow attentively, to ask the right questions, and to interact problem-oriented with the practitioner. On the other hand, when the doctor communicates with a mentally stressed patient, the socio-emotional level of conversation becomes more important so that the patient may receive less disease- and therapy-specific information.

Conclusions

The diagnosis of BC often creates mental distress. Frequently, patients associate the diagnosis with a death sentence. The urologist should not only decide about the therapy, but he is also supposed to be the conductor who orchestrates a holistic cancer management system, including offering psycho-oncological support if necessary.

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Statement of Ethics

The investigation was approved by the local Ethics Committee of the Goethe University Frankfurt/Main, Germany (project No.: 428/14). Informed consent was obtained from all individual participants included in the study.

Disclosure Statement

The authors have no potential conflicts of interest to disclose.

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