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ORIGINAL ARTICLE

Comorbid mental disorders and psychosocial distress in patients with brain tumours and their spouses in the early treatment phase

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Abstract

Purpose The aim of this study was to examine the prevalence of comorbid mental disorders as well as the extent of psychosocial distress in patients with intracranial tumours and their partners during the early treatment phase. Moreover, we aimed to identify which events are experienced as most distressing in the context of the early diagnosis of brain cancer by patients and spouses.

Methods Structured clinical interviews for DSM-IV (SCID-IV) were conducted with 26 patients and their partners after the first neurosurgical treatment within the first 3 months after the detection of a brain tumour. Screening measures (NCCN distress thermometer, HADS, IES-R) were used to assess the extent of psychosocial distress as well as anxiety, depression and traumatic stress responses. Distressing experiences were assessed via a structured questionnaire and interview.

Results Thirty-eight per cent of the patients and 47% of the partners suffered from a psychiatric disorder. Most frequent diagnoses were adjustment disorder and acute stress disorder. The majority of the participants suffered from elevated psychosocial distress. Partners were equally or even more affected than the patients. For the patients, the experience most frequently described as distressing was the first detection of the tumour. The majority of the partners reported to be distressed by the fear of surgery outcomes.

Conclusions This study revealed that during this very first treatment phase, both brain tumour patients and their spouses show a high prevalence of comorbid mental disorders and psychosocial distress. The findings suggest that research and clinical efforts are needed to address the psychosocial concerns of these populations.

Keywords Intracranial tumour · Distress · Mental disorder · Patients · Spouses

Introduction

The diagnosis of cancer is an unexpected and often devastating experience for both patients and their spouses (e. g. [1, 21]). During the last years, researchers have focused on psychological distress, unmet supportive care needs and comorbid mental disorders in patients with brain tumours and their carers. It has been revealed that patients with brain tumours are particularly at risk of experiencing high emotional distress due to the severe functional and neuropsychological sequelae of the disease and the often devastating prognosis. Therefore, intracranial tumours rank among those cancer sites that result in the highest emotional burden for the concerning patients and carers (e. g. [6, 24, 28, 50]). Brain tumours are often associated with high rates of stress, anxiety and/or depression (e. g. [3, 27]) as well as a prominent reduction in health related quality of life (e. g. [15, 24, 30]). Moreover, the rate of unmet supportive care needs is high in both patients and spouses (e. g. [23). Research has demonstrated that psychological distress and comorbid mental disorders change during the course of the disease for both cancer patients and their spouses (e. g. [2, 18, 20, 33, 43]). This is due to a number of factors, amongst which rank psychological adjustment processes, changes in prognosis, treatment modalities or the patients' condition, or the exigencies of life which have to be managed in

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addition to the disease; however, research has mainly focused on the psychosocial state of this particular patient group during further disease trajectory and not included the partners.

Moreover, comorbid mental disorders have often been assessed solely via self-report questionnaires, but for the comprehensive assessment of psychological sequelae of cancer, self-report instruments should be supplemented by a structured clinical interview (e. g. [27, 47, 50]). Thus, the aim of this study was to assess psychological distress and comorbid mental disorders in both patients with intracranial tumours and their spouses during the initial treatment phase via a comprehensive psychological assessment. As brain tumour patients have seldom been studied in this early phase of the disease, we also aimed to identify those illness-related events which were experienced as distressing by both patients and partners.

Materials and methods

Subjects

Between January and September 2008, all patients with a solitary primary intracranial tumour hospitalized at the Department of Neurosurgery, University Hospital Schleswig-Holstein in Kiel, Germany, were screened by the attending neuropsychologist for the following exclusion criteria: age below 18 or over 80 years, time since diagnosis >3 months, severe medical complications and/or Karnofsky index below 50 indicating a non-satisfactory medical condition and missing patient's consent. Moreover, patients with pronounced aphasia as diagnosed via the Aachener Aphasie test (AAT) [22], the German "Golden Standard" for the diagnosis of language disorders, were excluded. Patients scoring below 23 points at the mini mental state examination (MMSE) [12] and thus with severe cognitive deficits were also excluded. Moreover, only patients whose partners also agreed to participate were included in this study. Finally, partners had to be the main caregivers of the patients.

Materials

Comorbid mental disorders

Comorbid mental disorders were assessed with the structured clinical interview for diagnostic and statistical manual of mental disorders, fourth edition (DSM-IV) (SCID) [11, 49]. The following five modules were used: major depressive disorder, adjustment disorder, acute stress disorder, posttraumatic stress disorder (PTSD) and general anxiety disorder.

Prevalence of psychiatric and stress symptoms

Current research indicates that many cancer patients and their carers are highly emotionally distressed but do not fulfil all criteria for a DSM-IV diagnosis (e. g. [16, 29, 46]). Thus, we also assessed the frequency of psychiatric and stress symptoms as reported in the SCID.

Self-report questionnaires

The following self-report questionnaires were used:

The distress thermometer (DT) is a brief screening instrument for cancer patients assessing psychosocial distress. Developed by the National Comprehensive Cancer Network in the US, the DT is a single-item 11-point visual analog scale measuring psychological distress during the past week. The DT ranges from "no distress" (0) to "extreme distress" (10). A cut-off score of ≥5 was used to identify subjects suffering from clinically relevant distress [34, 36].

The hospital anxiety and depression scale (HADS) is a widely used questionnaire for the assessment of anxiety and depression in patients with somatic complaints with good reliability and validity. It consists of 14 items, seven per subscale. Items are scored from 0 (no distress) to 3 (maximum distress). A score of 11 or above is considered to be indicative of a probable anxiety respectively depressive disorder [19, 51].

The impact of event scale-revised version (IES-R) assesses symptoms of intrusion, avoidance and hyperarousal with good reliability and validity. It consists of 22 items, seven items in each the intrusion and hyperarousal subscale as well as eight items in the avoidance subscale. Items are scored 0, 1, 3 or 5. The term "distressing event" was replaced by the term "diagnosis of the neoplasm" respectively "partner's diagnosis". For statistical analysis, the sum of intrusion and avoidance was used with a cut-off score of or above 26 to indicate at least moderate symptomatology [31, 48].

Distressing events

In a pre-study, 15 patients and six partners were interviewed about distressing events in the course of the disease. All reported events were integrated into a questionnaire in which study participants could mark those events which they experienced as distressing (multiple answers possible). The partners received a version of the questionnaire including additional events (see Table 1). All participants were asked to write down any additional distressing events in the course of the disease.

Procedure

This study has been approved by the appropriate ethics committee and performed in accordance with the ethical

Table 1 Frequency of reported events that were experienced as distressing during the course of the disease by patients (n=26) and partners (n=26)

	Patients		Partner	
	Number	Per cent	Number	Per cent
First diagnosis	20	77	18	70
Fear of surgery side-effects	17	65	20	77
Fear of opening the skull	14	54	12	46
Fear of chemotherapy	12	46	6	23
Fear of surgery in general	11	42	15	58
Uncertainty about the future	10	39	13	50
Fear of radiotherapy	10	39	6	23
Delay of the surgery	9	35	10	39
Fear of the exact histopathologic diagnosis	9	35	11	42
Waiting period prior to surgery	5	19	12	46
Doctor–patient interaction	1	4	1	4
Fear of future suffering of their partner[a]	–	–	19	73
Fear of losing their partner[a]	–	–	12	46
Helplessness in caring for their partner[a]	–	–	10	39
Fear of the progress of the disease[a]	–	–	10	39

[a] Not included in the patients version

standard laid down in the 1964 Declaration of Helsinki. Patients were tested within 5 to 14 days after the neurosurgical removal of the tumour during inpatient stay by a clinical psychologist. Partners were contacted via the patients. Written, informed consent was obtained from both before testing. The examination was performed in the following order: exploration, AAT, MMSE, SCID, DT, HADS, IES-R and questionnaire about distressing events.

Statistical analysis

Statistical analyses were performed using the Statistical Package for the Social Sciences (SPSS) version 14.0. Descriptive statistics were used to characterize the demographic and psychosocial characteristics of the study sample, the prevalence of comorbid mental disorders, the level of psychosocial distress and distressing events. Associations between variables were calculated using Spearman's correlation coefficients. Differences between patients and partners in categorical variables were calculated using binomial tests. For all other group comparisons, Wilcoxon tests were used. Two-tailed significance tests were conducted using a significance level of $p \leq 0.05$.

Results

Sample characteristics

The study population consists of 26 patients and their partners. The number of patients meeting the exclusion criteria was 47. Participants and non-participants did not differ in terms of age, gender or tumour stage (p values> 0.2). The first language of all the participants was German. None of the patients had started chemotherapy or radiotherapy at the time of testing. Table 2 provides more detailed information of the participants' attributes.

Comorbid mental disorders

The prevalence of comorbid mental disorders based on the SCID was 38% for patients and 47% for partners. None of the participants received more than one SCID diagnosis. Acute stress disorder was most prominent in the patient group with 19%. The most frequent diagnosis in the partner group was adjustment disorder (31%). Table 3 provides more details.

Prevalence of psychiatric and stress symptoms

Results indicate that especially partners show a high incidence of psychiatric and stress symptoms (e. g. sleeping disorders, decreased concentration or fatigue). Figure 1 provides more details.

Self-report questionnaires

The majority of both patients (73%) and partners (85%) described relevant psychosocial distress in the DT. On average, patients reached a score of 6.0 (SD=2.6; CI=2.8–9.2) in the DT and partners of 6.58 (SD=2.0; CI=3.38–9.78). The mean HADS anxiety score was 5.04 (SD=4.7; CI=1.57–8.51) in patients and 8.77 (SD=3.4; CI=5.3–12.24) in their partners, whereas the depression scores were 3.77 (SD=4.0; CI=1.32–6.22) for patients respectively

Table 2 Demographic and medical characteristics of the patients (n=26) and their partners (n=26)

	Patients [n (%)]	Partners [n (%)]
Sex		
Female	13 (50)	13 (50)
Male	13 (50)	13 (50)
Age		
Range	26–77	26–75
Mean	59.04	57.12
Education		
Elementary school	10 (38)	13 (50)
Junior high school	8 (31)	4 (15)
High school certificate/university degree	8 (31)	8 (31)
Current employment status		
Retired	12 (46)	9 (35)
Working outside the home	13 (50)	12 (46)
Working inside the home	1 (4)	3 (12)
Marital status		
Married	22 (85)	22 (85)
Living with partner	4 (15)	4 (15)
Children		
None	6 (23)	9 (35)
<18 years	3 (12)	4 (15)
≥18 years	17 (65)	13 (50)
Type of tumour		
Meningeoma	12 (47)	
Astrocytoma	4 (15)	
Glioblastoma	5 (19)	
Other	5 (19)	
Tumour malignancy		
WHO-grade I (benign)	12 (46)	12 (46)
WHO-grade II + III (semi-benign/semi-malign)	8 (31)	8 (31)
WHO-grade IV (malign)	6 (23)	6 (23)
Time since brain tumour diagnosis		
<1 month	19 (73)	
1–3 months	7 (27)	

6.46 (SD=3.7; CI=4.01–8.91) for partners. The mean sum of intrusion and avoidance described in the IES-R was 23.38 (SD=16.2; CI=6.88–39.88) for patients and 27.0 for partners (SD=15.1; CI=10.5–43.5). Percentage of patients and partners meeting the respective cut-off scores in either of the self-report instruments can be seen in Table 4.

Comparison of patients and partners

The frequency of patients and partners receiving an SCID diagnosis did not differ. Also, no differences in the respective frequencies were found in the DT, the HADS depression score or the IES-R; however, more partners than patients met the cut-off score of the HADS anxiety scale (see Table 5 for details).

Comparisons of the raw scores in the self-report measures revealed that partners described themselves as both more anxious (p=0.001) and depressed (p=0.014). Regarding the DT (p=0.311) and the IES-R (p=0.264), no differences were found between patients and partners.

Correlations in the self-report measures between patients and partners were maximal of medium height (range from 0.148 to 0.488) and did not reach statistical significance (p> 0.1) with the exception of the HADS anxiety scores (p= 0.011).

Distressing events in the context of the early diagnosis and treatment of an intracranial tumour

Table 1 shows the frequency of distressing events in the course of the disease that were reported by patients and their partners. The majority of patients (77%) experienced the first diagnosis of a brain tumour as distressing, followed by the fear of surgery side-effects (65%). The most frequently reported distressing experiences by the partners were the fear of surgery side-effects (77%) as well as the fear of future suffering of their partner (73%).

Clinical identification of comorbid mental disorders and psychosocial distress

For implementation in daily practice, the application of a structured clinical interview as well as of a variety of supplemental questionnaires might not be feasible. Thus, we evaluated the capability of the applied screening instruments for the detection of psychological comorbidity. Every participant who had received an SCID diagnosis was also classified as suffering from relevant psychosocial distress by the DT (sensitivity=100%). For the other questionnaires, sensitivities regarding the ability to identify patients with psychiatric morbidity as diagnosed via the SCID were considerably lower with 46% for the HADS anxiety score, 18% for the HADS depression score and 77% for the sum of intrusion and avoidance as reported in the IES-R; however, the specificity (true negative classifications) of the DT was considerably low with 30% so that a cut-off of ≥6 might be more applicable in certain settings (sensitivity=86.4%, specificity=43%) (see Goebel & Mehdorn, submitted).

Discussion

Clearly, the diagnosis of a brain tumour can be the source of psychosocial distress in patients and partners. Psychosocial distress and comorbid mental disorders are often not

Table 3 Comorbid mental disorders of the patients (n=26) and their spouses (n=26)

	Patients		Partners	
	Number	Per cent	Number	Per cent
Acute stress disorder	5	19	3	12
Adjustment disorder	4	15	8	31
Major depressive disorder	1	4	1	4
Posttraumatic stress disorder	0	0	0	0
Generalized anxiety disorder	0	0	0	0
Total	10	38	12	47

diagnosed in cancer patients und thus not properly treated despite the existence of effective treatments (e. g. [37]) and might impede patients' quality of life as well as compliance. So far, little is known about the emotional state of patients with brain tumours and their spouses in the early treatment phase of the disease. Thus, the aim of this paper was to assess psychiatric morbidity and psychosocial distress in patients and partners as well as the association of both. Because of the discrepancy of prevalence estimates between self- and clinically administered ratings, we used a comprehensive test battery consisting of a combination of SCID and self-report questionnaires. Finally, we focused on the subjective experiences of the patients and partners within the first few months after receiving the diagnosis during the very first treatment phase of the disease trajectory.

The present study shows both a high prevalence of comorbid mental disorders and high psychosocial distress levels in patients with intracranial tumours. Altogether, 38% of the patients received an SCID diagnosis. The most frequent diagnosis of patients was acute stress disorder with 19%. In the self-report questionnaires, about three quarters of the patients described relevant psychosocial distress in the DT and half-described relevant intrusion and avoidance in the IES-R. Anxiety and depression via the HADS were less frequently reported.

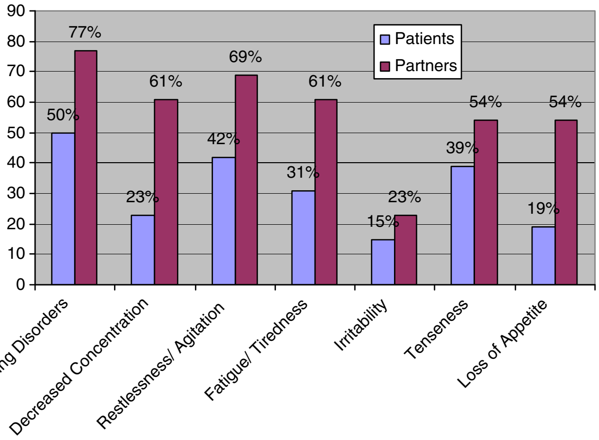

Fig. 1 Frequency of psychiatric/stress symptoms often observed in relation with a tumour diagnosis

In partners, the most frequent psychiatric diagnosis according to the SCID was adjustment disorder with about 30%. Altogether, almost half of the partners received an SCID diagnosis. Regarding the self-report questionnaires, partners reported similar subjective experiences in most measures with the exception of higher HADS anxiety scores.

In general, estimated prevalences are about 20–50% for comorbid mental disorders in cancer patients (e. g. [7, 8, 14, 18, 33]). Thus, our data indicate that brain tumour patients in this early treatment phase are at a similar risk of experiencing psychiatric morbidity. Previous research has indicated that the psychosocial burden of brain tumour patients is even higher compared to patients with other forms of cancer (e. g. [6]). These studies, however, mainly focused on patients in later stages of the disease. Thus, the further development of the psychological state of patients with intracranial tumours should be explored in future studies. This is of special importance considering the high incidence of traumatic stress responses in our sample. Acute stress disorder was introduced in the DSM-IV to describe psychological stress reactions within the initial month after experiencing a traumatic event with the aim of identification those individuals who would subsequently develop PTSD. The DSM-IV also recognized, for the first time, that traumatic stress reactions such as PTSD may be precipitated by life-threatening illness. This development has contributed to greater focus in recent years on the issue of stress reactions following cancer (e. g. [25]); however, to date only few studies have assessed acute traumatic stress responses in adult cancer patients (e. g. [26, 32, 33]). Reported prevalences range from 5% to 33% and are thus again comparable to our data. The relationship between acute and posttraumatic stress responses is still controversial. Thus, until now no predictors have been identified which allow the early identification of brain tumour patients at risk for the development of PTSD.

There is little information about the prevalence of adjustment disorders. Only one large study focusing on

Table 4 Number and percentage of patients ($n=26$) and partners ($n=26$) meeting the respective cut-off scores in the applied self-report measures

	Cut-off score	Patients meeting the cut-off score		Partners meeting the cut-off score	
		Number	Per cent	Number	Per cent
NCCN-DT	≥5	19	73	22	85
HADS anxiety	≥11	3	12	10	39
HADS depression	≥11	1	4	4	15
IES-R Σ I+A	≥26	13	50	13	50

the general population has included adjustment disorder with depressed mood among their diagnoses. The investigators found a very low prevalence of <1% [9]. In patient samples, prevalences range from about 5–20% [45]. Thus, our data indicate that a considerably high proportion of brain tumour patients and especially their partners suffer from adjustment disorders. To date, the clinical value of the current diagnosis of adjustment disorder remains controversial (see [45] for a review). Inconsistent clinical descriptions, inadequate differentiation from other disorders and the lack of psychometrically validated diagnostic instruments rank amongst the reasons for this. Future studies should focus on the differentiation between AD and subthreshold manifestations of psychological distress in clinical settings (e. g. [13]).

Previous studies in patients with intracranial tumours reported levels of distress between 28% and 52% [27, 30]. In our sample, 73% of the patients reported high levels of distress. This might be due to the acute setting and short time interval between receiving the diagnosis and psychological assessment in our sample. Keir and colleagues [27] for example found that patients who had received the diagnosis within the last year reported more items of concern in the DT than patients who had been living longer with the disease. Again, the development of psychosocial distress should be explored in future studies, especially whilst considering predictors for long-term distress. Regarding the prevalences of significant anxiety (12%) and depression (4%) in the HADS, previous studies have reported similar results for patients with brain cancer [1, 41]. Also, the discrepancy of high prevalences in the DT and low prevalences in the HADS has been reported before [1, 24, 27, 41]. It was hypothesized that this is due to the fact that the DT measures distress without the often normal sensed stigmatization, whereas the HADS patients might have chosen socially acceptable rather than accurate responses; however, it could also be hypothesized that patients in this acute state mainly suffer from unspecific emotional reactions whereas specific psychiatric disorders might not develop until later stages of the disease trajectory. This is supported by the high levels of unspecific psychiatric and stress symptoms as reported in the SCID. Moreover, the high prevalence (50%) of significant symptoms of intrusion and avoidance in the IES-R is in concordance with this interpretation as it has been suggested that the IES-R measures diffuse emotional distress and adjustment problems rather than PTBS symptoms (e. g. [33, 39]).

Another aim of this study was to elucidate the relation between the emotional state of the patients and their partners. Our data demonstrated consistently that spouses suffer similarly or even more likely from psychiatric morbidity. This is consistent with previous studies in patients with (brain) cancer and has, for example, been attributed to the added burden of managing familial and everyday life demands alone (e. g. [4, 24, 29, 43]); however, in contrast to previous studies (e. g. [17, 20, 29]), associations between patients and partners regarding the reported psychological sequelae are rather small in our sample and only significant for the HADS anxiety score. Again, this might be due to the early treatment phase and the specific hospital setting.

The third aim of this study was the identification of those illness- and treatment-related events that were experienced as distressing by patients and partners. For about three quarters

Table 5 Comparison of frequencies of receiving a diagnosis in the different diagnostic instruments

		Number	Relative frequency	*P*
SCID	Patients	10 of 26	0.385	0.754
	Partners	12 of 26	0.462	
NCCN DT	Patients	19 of 24	0.792	1.0
	Partners	20 of 24	0.833	
HADS anxiety	Patients	3 of 26	0.115	0.016*
	Partners	10 of 26	0.385	
HADS depression	Patients	1 of 26	0.038	0.375
	Partners	4 of 26	0.154	
IES-R Σ I+A	Patients	10 of 26	0.385	1.0
	Partners	11 of 26	0.423	

NCCN National Comprehensive Cancer Network

*$p<0.05$

of the patients, the first notification of the diagnosis was experienced as distressing followed by fears about the surgery and surgery side-effects as well as the final diagnosis and prognosis and possible future treatment. These data are (with the exception of the specific anxiety regarding the neurosurgical treatment) comparable to those reported by Mehnert and Koch [33] in a large sample of patients with breast cancer. Spouses reported similar distressing events. Many partners also reported future-related anxieties in terms of fear of future suffering of their partner or loosing him/her. Moreover, about 40% of the partners described themselves as distressed due to feeling helpless in caring for their partner.

It should be noted that there were no negative side-effects regarding the anaesthesiological or neurosurgical treatment in any of our patients. Thus, the surgery-related fears have been proven to be objectively unfounded; however, they were still recalled by patients and spouses despite the retrospective interview. Previous research has indicated that preoperative anxiety is frequent in surgical patients in general and neurosurgical patients in particular (e. g. [5, 40]). Preoperative anxiety influences the physical and psychological outcome (e. g. depression, satisfaction, pain, hospital stay) and is thus important to assess—especially as there is a multitude of quick and successful interventions for the reduction of preoperative anxiety (e. g. [10]); however, although the Amsterdam preoperative anxiety and depression scale [35] has been successfully used in the neurosurgical setting [40], until now no questionnaire for the assessment of specific preoperative anxiety has been validated in patients with intracranial tumours.

Our study offers the strengths of the comprehensive assessment of psychological sequelae of brain tumours via both a structured clinical interview and a combination of standardized questionnaires. Moreover, the assessment of the belonging partners has been reported for the first time in this early stage, specific setting and the diagnosis of an intracranial tumour; however, this study also has different limitations. First, all partners were recruited through patients. Thus, the sample might be biased towards well-functioning partners and couples and therefore not be representative (see [20]). Second, the sample size is rather small. The main reason for the exclusion of patients was that they were not living with a partner as the focus of this paper was not only the patients' psychological state but also the spouses' as well as the interaction of both. Thus, all widowed or single patients were excluded which, again, probably leads to non-representative results for the whole population of brain tumour patients.

In summary, comorbid mental disorders and psychosocial distress are of high relevance in this population and setting. Thus, our findings highlight the necessity of a routine psychological screening for distress in patients and spouses in the early phase of this disease and its treatment in order to identify relevant supportive care needs. In our sample, the DT proved to be an appropriate screening instrument. High levels of distress and unmet supportive care needs of patients with brain cancer and their partners should be identified quickly and patients and spouses should be informed about appropriate treatment options; however, despite the remarkably high level of psychological comorbidity, to date there is a striking lack of research regarding the value of medical, psychological or rehabilitative treatment in brain tumour patients and their families (e. g. [38, 42, 44]). Our study emphasizes the necessity of future research in these fields.

Conclusions

Both patients with an intracranial tumour and their spouses suffer from high rates of psychosocial distress and psychiatric morbidity during the very first stage of the disease and its treatment. Negative psychological sequelae in partners were by trend even higher than in patients themselves. Moreover, the assessment of distressing events provided information about specific support needs of spouses, for example regarding the helplessness in caring for their partner. Thus, future studies should focus on the further development of psychiatric morbidity as well as the identification of early risk-factors regarding the development of long-term distress for both patients and partners. Moreover, partners should be considered in the development of specific and targeted interventions—not only for their own sake, but also in their function as important source of support for the patient with brain cancer.

Conflicts of interests None.

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