ORIGINAL RESEARCH

Distress in Neuro-Oncology Patients and Its Implications for Communication

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Authors' disclosures of conflicts of interest are found at the end of this article.

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Abstract

Psychoemotional distress affects patients with cancer, including patients with a diagnosis of a malignant brain tumor. Empathy, professional expertise, and conversational skills are required to ensure successful communication with patients. The purpose of this study was to assess whether knowing the communication needs of patients would be helpful to neuro-oncologists before meeting with them. Patients in our neuro-oncology center were asked to complete the National Comprehensive Cancer Network Distress Thermometer (DT) and a study-specific questionnaire on patients' expectations for communication with the treating physician. The questions targeted issues such as attention/caring and awareness of their disease and prognosis. Importance ratings were compared between patients, with high vs. low distress scores to analyze the impact of distress on the patient's needs in physician-patient communication. A total of 81 patients completed the DT and questionnaire. One third (n = 27) had *IDH* wild-type astrocytoma, and 42 patients (51.9%) were undergoing therapy for primary or recurrent disease. Mean distress was 4.88 (standard deviation ± 2.64) in the whole cohort, and 56.8% of patients had a high distress score (≥ 5 on a 10-point scale). All issues were assessed as important or very important for communication by the majority of patients, and importance ratings increased in patients with high distress levels for most items. Mean importance ratings correlated significantly with distress scores (*p* < .001). Distress was increased in neuro-oncology patients. Patients with higher distress levels considered issues of both attention/caring and medical information about the disease as more important than patients with lower distress levels. Using distress assessment may help physicians and advanced practitioners to tailor the contents of their discussion for successful communication with patients.

Patients with cancer experience a significant burden in their daily life resulting from a variety of symptoms, such as physical or cognitive impairment, as well as fatigue. Furthermore, psychosocial stress due to prognostic awareness, disturbed social or role functioning, and a premature end to working life play a decisive role. All these factors contribute to elevated distress in cancer patients, including patients with primary or secondary brain tumors.

Distress can be measured using the Distress Thermometer (DT), a simple, self-reported tool developed by the National Comprehensive Cancer Network (NCCN) to assess distress in cancer patients on a numerical analogue scale from 0 to 10. A distress value of 5 or higher indicates the need for further support (NCCN, 2003). Additionally, the DT provides a problem list to identify potential sources of distress, including emotional, physical, practical, or family problems.

More than one third of patients with high-grade glioma have increased distress scores (Kvale et al., 2009; Renovanz et al., 2020). Impaired function is one of the reasons for elevated distress (Rooney et al., 2013). Increased distress scores indicate a reduced quality of life (Kvale et al., 2009; Hickmann et al., 2017), and distress scores of 6 or higher are associated with an increased need for supportive care in glioma patients (Renovanz et al., 2017).

Recognizing distress in patients is among the many tasks of the attending staff in an oncology unit, starting at the first point of contact. Empathic communication with the patient is of paramount importance in cancer care. However, this often poses a major challenge for not only young and inexperienced staff members, but also seasoned staff. Insufficient knowledge about the patient's needs, worries, and wishes may be one contributing factor.

Therefore, this study was performed to assess if distress affects the expectations of medical communication and care in a cohort of neuro-oncology patients. We hypothesized that higher distress leads to increased demand of attention/care, such as solicitousness, supportive care, and steadiness and reliability in the relationship to the patient, whereas lower distress levels would be associated with the wish for detailed information about the disease and treatment options. To answer this question, we performed a written survey among a heterogenous cohort of neuro-oncology patients.

PATIENTS AND METHODS

Study Design
This was a pilot project using a self-developed written survey with questionnaires for patients with primary or secondary brain tumors. Due to internal workflows at our center, we performed the interview immediately before the physician's visit, because this is generally the first person in contact with the patient in our outpatient clinic. All patients gave written informed consent for the study. The local ethics committee approved the study.

Distress Assessment
The German translation of the DT (NCCN, 2003) was used for self-reporting of distress on a numerical analogue scale from 0 to 10. Additionally, the presence of accompanying problems out of the following fields was recorded: practical (e.g., housing situation, working, insurance), familial, religious, emotional, and physical.

Assessment of Expectations in Physician-Patient Communication
The questionnaire was developed by authors CR and NS, and contained relevant topics in the authors' judgment. Due to the need for better clarity and relevance, we extended the questionnaire during the study. The first version (v1) contained eight items, and the second version (v2) introduced an additional item (How important is it for you that a relative is present?), resulting in nine items. These items were designed to explore the need for detailed medical information and supportive care, as well as expectations for physician-patient communication at the subsequent visit with the physician. Table 1 shows a nonbinding English translation of the questions. On a 4-point Likert scale, patients could indicate their needs by providing importance ratings for each item, ranging from "Not important" to "Very important." Answers were transformed to raw scores from one ("Not important") to four ("Very important") and used for statistical analysis. Furthermore, three questions were added

Table 1. Questionnaire on Patient Expectations for Communication With Physicians

Regarding the conversation with your doctor, how important is it for you...	Very important	Important	Less important	Not important
Item 1 ...to receive as much information as possible?	56.8%	32.1%	8.6%	2.5%
Item 2 ...to get support to cope with your illness?	22.2%	38.3%	24.7%	14.8%
Item 3 ...to understand your exact prognosis?	54.3%	24.7%	17.3%	3.7%
Item 4 ...that your doctor takes a lot of time?	44.4%	39.5%	11.1%	4.9%
Item 5 ...to get encouragement from your doctor?	35.8%	45.7%	11.1%	7.4%
Item 6 ...that appointments are kept precisely?	30.9%	43.2%	17.3%	8.6%
Item 7 ...that a relative is present?	41.8%	25.4%	19.4%	13.4%
Item 8 ...that you are seen by the doctor attending you for the most part?	45.7%	33.3%	18.5%	2.5%
Item 9 ...that the doctor enquires about your worries and fears?	13.6%	45.7%	24.7%	16.0%

to evaluate current decision-making capacity. Table 2 shows a nonbinding English translation.

Since our study was equipped to be an explorative pilot project, we performed no validation or correlation of the questionnaires.

Study Conduct

Study participants were recruited between September 2018 and December 2019 in our neuro-oncology outpatient clinic or during an in-hospital stay. The eligibility criteria were the diagnosis of a primary or secondary brain tumor independent of treatment status and the ability to give written informed consent.

Patients arriving for their medical appointment in the outpatient clinic were asked about their interest in participating by the interviewer before having any medical contact. If consent was obtained, patients received the questionnaire and were asked to complete the distress assessment and the assessment of expectations for physician-patient communication, preferably without the assistance of accompanying persons. The interviewer recorded patient characteristics, including demographics, diagnosis, treatment status, and living situation. The survey took approximately 20 minutes to complete per participant.

Statistical Analysis

Descriptive statistics are provided as mean and standard deviation and/or median and interquartile

Table 2. Questions Evaluating Decision-Making Capacity

	% of patients (n = 81)			High vs. low distress
	Yes	No	Do not know	p value
Do you feel able to make important decisions today?	82.7	6.2	11.1	0.39
Have you ever experienced medical information overload?	37.0	49.4	13.6	0.49
Do you worry about not understanding everything during the conversation?	48.1	45.7	6.2	0.54

range, as well as frequency tables. Categorical data were analyzed in contingency tables using Fisher's exact test or Pearson's chi-squared test. A mean importance rating score was calculated as the sum of the raw scores of all questions divided by the number of items; therefore, higher scores indicate higher importance. A Spearman's correlation analysis was performed correlating mean importance rating scores with individual distress levels. Significance level was set to $\alpha = .05$, and all analyses were two-sided. Due to the explorative nature of the study, no adjustment for multiple testing was performed. Statistical analyses were performed with SPSS (version 25, IBM Corp), and figures were drawn with GraphPad Prism (version 8.4, GraphPad Software, Inc.).

RESULTS

Study Cohort and Patient Characteristics
A total of 81 neuro-oncology patients were included in the study. 92.6% of patients were recruited in the outpatient clinic. Glioma was the most frequent diagnosis (72.8%). Table 3 shows details on baseline characteristics and current treatment status. All patients answered the DT and questionnaire.

Distress in Neuro-Oncology Patients
The mean distress score in the cohort of 81 patients was 4.88 ± 2.64, with a median distress score of 5 (interquartile range: 3–7; Figure 1). The distress scores ranged from 0 to 10. Fifty-seven percent (46/81) of patients had high distress, defined as a score of ≥ 5. Patients with high distress did not differ from patients with lower distress regarding age ($p = .54$), performance status ($p = .45$), diagnosis ($p = .36$), treatment status ($p = .21$), or presence of an accompanying person ($p = 1.0$).

Factors Influencing Distress
The DT assessment provides additional data of accompanying problems within the last week prior to scoring (NCCN, 2003). Seventy of eighty-one (86.4%) patients reported physical problems, and 57/81 (70.4%) described emotional problems. Practical or family problems were reported in 22.2% and 4.9% of patients, respectively.

Patient Expectations of Communication
All patients ($n = 81$) answered the questionnaire and rated the importance of different items for the

Table 3. Patient Demographics (n = 81)	
	n (%)
Sex	
Female	37 (45.7)
Male	44 (54.3)
Age	
≤ 50 years	28 (34.6)
51–70 years	42 (51.8)
> 70 years	11 (13.6)
KPS	
90-100	58 (71.6)
70-80	21 (25.9)
< 70	2 (2.5)
Diagnosis	
Glioblastoma/astrocytoma, *IDH* wt	27 (33.4)
Astrocytoma, *IDH* mt	21 (25.9)
Oligodendroglioma	11 (13.6)
CNS - lymphoma	8 (9.9)
Other primary brain tumor	10 (12.3)
Brain metastases	4 (4.9)
Time since diagnosis	
≤ 12 months	28 (34.6)
13-60 months	27 (33.4)
> 60 months	26 (32.0)
Treatment status	
Primary therapy ongoing	25 (30.9)
Treatment of recurrence	17 (21.0)
Follow up	39 (48.1)
Site of study participation	
Outpatient clinic	75 (92.6)
In-hospital stay	6 (7.4)
Accompanying person present	
Yes	52 (69.3)
No	23 (30.7)

subsequent appointment with the treating physician. These items regarding expectations for physician-patient communication are detailed in Table 1. Fourteen patients answered the first version of the questionnaire with items one to six and eight to nine, and 67 patients answered the second version of the questionnaire that included item seven.
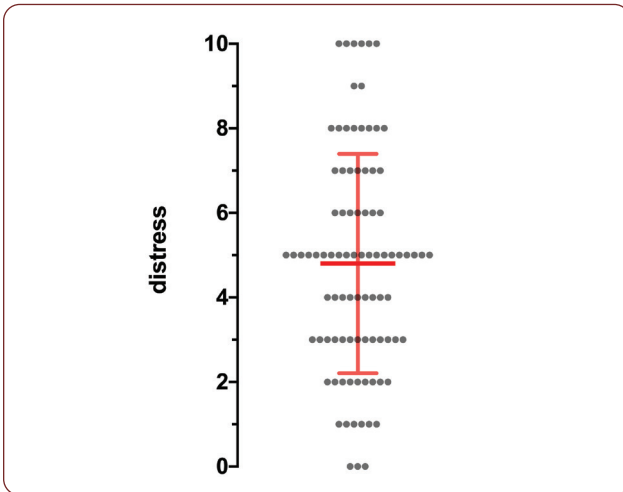
Figure 1. Distribution of distress scores.

All items were rated as important or very important by the majority of patients (Table 1). More than half of patients reported item 1 (How important is it for you to receive as much information as possible?) and item 3 (How important is it for you to understand your exact prognosis?) to be very important. Across all items, no more than 16% of patients rated any item as not important.

The additional questions evaluating decision-making capacity revealed that 82.7% of patients felt capable to make decisions, 48.1% were concerned about potential difficulties in understanding the information provided by the physician, and 37.0% patients had experienced medical information overload.

Distress and Patient Expectations

To evaluate the correlation of high distress levels with patient expectations for physician-patient communication, we divided the cohort into patients with high distress (distress score ≥ 5, n = 46) and low distress (distress score ≤ 4, n = 35), and compared importance ratings between both groups. Patients with high distress scores rated most items significantly more important (Table 4). For example, receiving as much information as possible was important or very important for 80% of patients with a low distress score, compared with 95.7% for patients with a high distress score (p = .021). The difference did not reach statistical significance for items three (understanding the exact prognosis), seven (presence of a relative), and

Table 4. Distress Scores and Expectations for Communication				
Rating: Very important or important	**All patients, %** **(n = 81)**	**High distress, %** **(n = 46)**	**Low distress, %** **(n = 35)**	**High vs. low distress, p value**
Regarding the conversation with your doctor, how important is it for you...				
Item 1 ...to receive as much information as possible?	88.9	95.7	80.0	**.035**
Item 2 ...to get support to cope with your illness?	60.5	73.9	42.9	**.006**
Item 3 ...to understand your exact prognosis?	79.0	87.0	68.6	.056
Item 4 ...that your doctor takes a lot of time?	84.0	93.5	71.4	**.013**
Item 5 ...to get encouragement from your doctor?	81.5	89.1	71.4	**.050**
Item 6 ...that appointments are kept precisely?	74.1	87.0	57.1	**.004**
Item 7 ...that a relative is present?	67.2 (45/67)	72.5 (29/40)	59.3 (16/27)	.30
Item 8 ...that you are seen by the doctor attending you for the most part?	79.0	86.8	71.4	.17
Item 9 ...that the doctor enquires about your worries and fears?	59.3	69.6	45.7	**.041**

eight (being seen by the physician attending for the most part). Interestingly, 89% (41/46) of accompanied patients rated the presence of a relative as important or very important, compared with only 15% (3/20) of unaccompanied patients ($p < .001$).

Correlation of Mean Importance Rating and Distress

A mean importance rating score from all items was calculated as described previously, with higher values indicating a higher mean importance rating. Individual distress levels and mean importance rating scores were significantly correlated (Spearman's $r_s = .43$; $p < .001$; see Figure 2).

Decision-Making Capacity

Regarding the additional questions on decision-making capacity, the majority of patients felt able to make decisions at the appointment. Nearly half of the patients had experienced an overload of medical information and were concerned about not understanding everything during the conversation with the physician. There were no significant differences between patients with high and low distress scores (Table 2).
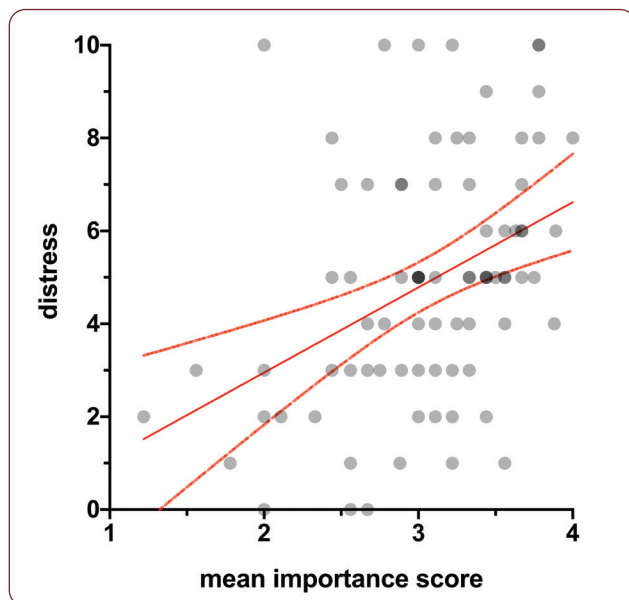

Figure 2. Scatter plot of individual mean importance scores and distress. Mean importance score is calculated for each patient as the sum of raw scores of all questions divided by number of items; higher mean importance score indicates higher importance ratings given. Red line is linear fit with standard deviation.

DISCUSSION

Our cohort of patients represented an average population at our neuro-oncology center, and distress was a relevant issue. Following the NCCN Guidelines, the more than half of patients with a distress score of 5 or higher should therefore be further evaluated for the need for psychosocial support. The mean distress in our cohort is in line with larger studies of high-grade glioma patients (Renovanz et al., 2020), emphasizing that distress is not limited to patients with high-grade glioma but also affects patients with other primary or secondary brain malignancies.

Based on a comparative analysis of the Hospital Anxiety and Depression Scale (HADS) and the DT in 150 brain tumor patients, a cutoff score of 6 or higher was proposed to be optimal for identifying patients with distress (Goebel & Mehdorn, 2011). It should be noted that although the mean distress score was 5.73, as much as 64% of the cohort reported neither a relevant extent of anxiety nor depression. Given the plethora of further possible influencing factors on distress despite anxiety or depression, the proposed cutoff score of 6 seems too restrictive and must be interpreted with caution. Therefore, employing a cutoff score of 5 for identification of high distress and thereby following the NCCN Guidelines seemed reasonable in our cohort.

Patients most frequently reported emotional and physical problems within the week before study participation, so their distress was probably mostly influenced by these factors. This was expected in light of the high emotional burden and associated neurologic deficits related to a brain tumor diagnosis (Coomans et al., 2019).

Our study revealed that patients' needs and expectations for attention and care, but also for detailed information about their disease, were generally high. Thus, our initial hypothesis of higher needs for attention and care and lower demands for detailed information in patients with high distress could not be proved. On the contrary, the proportion of patients with a substantial need to know details about their disease and prognosis was even increased in patients with high distress levels. This corresponds to observations by others in the literature (Applebaum et al., 2018; Forst et al., 2020; Sharma et al., 2021). Physicians and advanced practitioners should address this issue during the course of the disease.

Only a few patients judged the queried issues as not important. This could indicate the presence of prior knowledge or that a person does not wish to be confronted with their disease and prognosis. Although this must be respected, personnel could periodically enquire about these needs.

Taken together and in the consideration of the design of this study, the distress score assessment seems unsuitable to determine whether the physician should place particular emphasis on attention/caring or focus on information transfer about the disease, treatment, and prognosis. All issues were important or very important for more than half of the patients in view of physician-patient communication. In cases of high distress, the needs were even more pronounced, whereas in cases of low distress, fewer issues remained important. This refers above all to information quantity, support on coping strategies, spending time during the appointment, and organizational procedures (e.g., item six: "How important is for you that appointments are kept precisely?"). Following this, an assessment of distress before a visit with patients (and relatives) may be helpful to prepare for the setup and extent of the visit. The physician or advanced practitioner could address certain issues and emphasize or postpone others. Moreover, knowledge about the patient's distress level would allow for initiation of adequate supportive care measures, which is relevant to the entire staff of an oncology unit.

IMPLICATIONS FOR ADVANCED PRACTITIONERS

Due to the internal workflows at our center, we selected elements of physician-patient communication. However, the topic of our study applies not only to physicians, but also to advanced practitioners, nursing staff, care workers, and others making up the interdisciplinary teams working in oncology units. The necessity to respond to reported needs should be self evident and therefore concerns everyone who comes in contact with oncology patients. Patients' distress and needs have implications not only for communication with patients, but also for the setting of an in-hospital stay and the outpatient clinic. It is important to ensure sufficient time and resources, and a reliable organization of appointments. A consistent team of personnel, flexible time slots, involvement of relatives, and reliability in organizational matters are essential to successfully manage patients' distress in a joint effort. Concepts of outreach work or scouting guidance by social workers or psycho-oncologists represent an essential element of patient-centered care. Multidisciplinary teamwork also means that oncology care must include a holistic view. Furthermore, the need for support by social workers and psycho-oncology therapy often continues after the end of chemotherapy or radiation therapy, indicating that a return to normal life is not automatic after treatment for cancer ends. Thus, constant supportive care with attention to individual needs can only be performed by sufficiently funded interdisciplinary teams.

LIMITATIONS

This study has several limitations. First, the small sample size may hamper generalization. Nevertheless, the mean distress level is comparable to larger studies, and the study size was sufficient to draw meaningful conclusions for patient-centered care and successful physician-patient communication. Second, the questionnaire was designed arbitrarily without claim of completeness and was used without prior validation. Despite this, the responses obtained in this cohort point to clinically meaningful importance. The most serious limitation may be the missing assessment of patient-reported outcome measurements, such as health-related quality of life, anxiety, and depression, which was outside the focus of this work and should be addressed in further studies.

CONCLUSION

In this cohort of neuro-oncology patients, increased distress levels corresponded to higher needs of both attention/caring and medical information about the disease, and its assessment may help inform successful communication with patients. ●

Disclosure
The authors have no conflicts of interest to disclose.

References

Applebaum, A. J., Buda, K., Kryza-Lacombe, M., Buthorn, J. J., Walker, R., Shaffer, K. M., D'Agostino, T. A., & Diamond, E. L. (2018). Prognostic awareness and communication preferences among caregivers of patients with malignant glioma. *Psycho-Oncology, 27*(3), 817–823. https://doi.org/10.1002/pon.4581

Coomans, M. B., Dirven, L., Aaronson, N. K., Baumert, B. G., Van Den Bent, M., Bottomley, A.,...Taphoorn, M. J. B. (2019). Symptom clusters in newly diagnosed glioma patients: Which symptom clusters are independently associated with functioning and global health status? *Neuro-Oncology, 21*(11), 1447–1457. https://doi.org/10.1093/neuonc/noz118

Forst, D., Quain, K. M., Landay, S., Anand, M., Kaslow-Zieve, E., Mesa, M. M.,...Temel, J. S. (2020). Perceptions of prognosis and goal of treatment in patients with malignant gliomas and their caregivers. *Neuro-Oncology Practice, 7*(5), 490–497. https://doi.org/10.1093/nop/npaa021

Goebel, S., & Mehdorn, H. M. (2011). Measurement of psychological distress in patients with intracranial tumours: The NCCN distress thermometer. *Journal of Neuro-Oncology, 104*(1), 357–364. https://doi.org/10.1007/s11060-010-0501-5

Hickmann, A.-K., Hechtner, M., Nadji-Ohl, M., Janko, M., Reuter, A. K., Kohlmann, K.,...Renovanz, M. (2017). Evaluating patients for psychosocial distress and supportive care needs based on health-related quality of life in primary brain tumors: A prospective multicenter analysis of patients with gliomas in an outpatient setting. *Journal of Neuro-Oncology, 131*(1), 135–151. https://doi.org/10.1007/s11060-016-2280-0

Kvale, E. A., Murthy, R., Taylor, R., Lee, J. Y., & Nabors, L. B. (2009). Distress and quality of life in primary high-grade brain tumor patients. *Supportive Care in Cancer, 17*(7), 793–799. https://doi.org/10.1007/s00520-008-0551-9

National Comprehensive Cancer Network. (2003). NCCN Clinical Practice Guidelines in Oncology: Distress management. https://www.nccn.org/professionals/physician_gls/pdf/distress.pdf

Renovanz, M., Hechtner, M., Janko, M., Kohlmann, K., Coburger, J., Nadji-Ohl, M.,...Hickmann, A. K. (2017). Factors associated with supportive care needs in glioma patients in the neuro-oncological outpatient setting. *Journal of Neuro-Oncology, 133*(3), 653–662. https://doi.org/10.1007/s11060-017-2484-y

Renovanz, M., Hickmann, A. K., Nadji-Ohl, M., Keric, N., Weimann, E., Wirtz, C. R.,...Coburger, J. (2020). Health-related quality of life and distress in elderly vs. younger patients with high-grade glioma-results of a multicenter study. *Supportive Care in Cancer, 28*(11), 5165–5175. https://doi.org/10.1007/s00520-020-05354-8

Rooney, A. G., McNamara, S., Mackinnon, M., Fraser, M., Rampling, R., Carson, A., & Grant, R. (2013). The frequency, longitudinal course, clinical associations, and causes of emotional distress during primary treatment of cerebral glioma. *Neuro-Oncology, 15*(5), 635–643. https://doi.org/10.1093/neuonc/not009

Sharma, A., Fruth, B., Barrera, C., Farfour, H. N., Mrugala, M. M., Edwin, M. K.,...Porter, A. B. (2021). How much time do we have? Longitudinal perception of prognosis in newly-diagnosed high grade glioma patients and caregivers compared to clinicians. *Journal of Neuro-Oncology, 152*(2), 313–323. https://doi.org/10.1007/s11060-021-03700-2