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# Prevalence and predictors of cancer patients' unexpressed needs in the admission interview of inpatient rehabilitation

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## Abstract

**Objective:** The admission interview in oncological inpatient rehabilitation might be a good opportunity to identify cancer patients' needs present after acute treatment. However, a relevant number of patients may not express their needs. In this study, we examined (a) the proportion of cancer patients with unexpressed needs, (b) topics of unexpressed needs and reasons for not expressing needs, (c) correlations of not expressing needs with several patient characteristics, and (d) predictors of not expressing needs.

**Methods:** We enrolled 449 patients with breast, prostate, and colon cancer at beginning and end of inpatient rehabilitation. We obtained self-reports about unexpressed needs and health-related variables (quality of life, depression, anxiety, adjustment disorder, and health literacy). We estimated frequencies and conducted correlation and ordinal logistic regression analyses.

**Results:** A quarter of patients stated they had "rather not" or "not at all" expressed all relevant needs. Patients mostly omitted fear of cancer recurrence. Most frequent reasons for not expressing needs were being focused on physical consequences of cancer, concerns emerging only later, and not knowing about the possibility of talking about distress. Not expressing needs was associated with several health-related outcomes, for example, emotional functioning, adjustment disorder, fear of progression, and health literacy. Depression measured at the beginning of rehabilitation showed only small correlations and is therefore not sufficient to identify patients with unexpressed needs.

**Conclusions:** A relevant proportion of cancer patients reported unexpressed needs in the admission interview. This was associated with decreased mental health. Therefore, it seems necessary to support patients in expressing needs.

**KEYWORDS**
cancer, inpatient rehabilitation, oncology, prediction, prevalence, unexpressed needs

## 1 | BACKGROUND

In this study, we want to identify characteristics of unexpressed needs in cancer patients. Previous research shows that cancer patients face various problems that reduce their mental health and quality of life.[1,2]

However, a relevant proportion reports different kinds of unmet needs,[3-6] and having unmet needs is associated with higher psychosocial distress and lower quality of life.[7-9] Unmet needs can better be addressed if patients express them; but, if such needs are not expressed, meeting them is difficult. Therefore, we assume that one

possibility to improve treatment is a precise understanding of cancer patients' unexpressed needs to address them.

What do we know about unexpressed needs in cancer patients from previous literature? Reasons for unexpressed needs include low perceived empathy or limited time of the physician.[10] Other studies describe not expressing needs as a barrier for patients to receive appropriate support, among difficulties in recognizing their needs or negative perceptions of services available.[11,12] Further described are barriers like not being confident in psychosocial support or fear of stigmatization to use psychosocial support.[11,13,14] Overall, there are only few studies about reasons of unexpressed needs. Moreover, contents and prevalence of unexpressed needs and their associations with health-related constructs are scarcely investigated.

Associations of unexpressed needs might be helpful for a precise understanding of such needs and a better treatment. First, it should be investigated which associations exist between cancer patients unexpressed needs and quality of life. Second, the association of cancer patients' mental health and unexpressed needs might be interesting. Symptoms of depression, anxiety, and adjustment disorder are indicators of low mental health in cancer patients,[15] and many cancer patients describe to suffer from fear of cancer recurrence or progression.[16] Third, cancer patients' health literacy might be linked with their expression of needs.[17] Both positive and negative correlations are conceivable. Patients with high health literacy might not express their needs because they can cope on their own. By contrast, patients with low health literacy might not express their needs because they do not know when or how to express them. Hence, the further goal of this study is to explore possible associations between unexpressed needs in cancer patients and their quality of life, mental health, and health literacy.

In the German health care system, more than half of all cancer patients make use of a 3-week inpatient rehabilitation program after the termination of acute treatment.[18] The German Statutory Pension Insurance finances this program for all cancer patients to reduce long-term impairments. At the patients' arrival, a physician conducts a comprehensive admission interview. Hence, this interview is a key element for patients to express and for physicians to identify needs. However, patients may perceive high stress, which may prevent them from expressing all possible needs. A substantial number of patients report unmet needs at beginning and end of rehabilitation, whereby patients' supportive care needs during inpatient rehabilitation may lead to improved quality of life.[19]

The main goal of our study ("UNSAID" study) is to explore cancer patients' unexpressed needs in the admission interview. In the first part of the study, we used qualitative interviews with patients and health professionals to investigate possible reasons for patients' not expressing needs in the admission interview. Results showed a great variety of reasons, for example, limited time in the admission interview, shame, or nonempathic behavior of the physician.[20] However, it is unclear how many patients might not express all relevant needs, and hence, physicians may not initiate appropriate interventions. In this second part of our study, we had four aims: (a) to identify the proportion of cancer patients with unexpressed needs in the admission interview of inpatient rehabilitation, (b) to examine topics of unexpressed needs and reasons

for not expressing them, (c) to explore associations between not expressing needs and sociodemographic variables, clinical variables, health-related variables, and patients' evaluations of the admission interview, and (d) to examine whether patients not expressing needs may be identified using sociodemographic, clinical, and health-related information typically available in the admission interview.

## 2 | METHODS

This study was approved by the Ethics Committee of the Medical Faculty, University of Würzburg (ref: 71/17), registered on WHO International Clinical Trials (DRKS00012998) and performed in accordance with the Declaration of Helsinki. All participants provided written informed consent.

### 2.1 | Design, patients, and recruitment

We conducted a questionnaire survey with cancer patients attending a 3-week inpatient rehabilitation program at one oncological rehabilitation center. Besides written informed consent, patient inclusion criteria comprised diagnosis of breast, prostate, or colon cancer, and age of 18 years or older. Exclusion criteria included a lack of German language skills and severe, uncorrected visual impairment. A few days after arrival, a physician asked all eligible patients during the recruitment period to participate and provided written information. Upon agreement, patients received the questionnaire during the last week of their stay. Moreover, a study assistant selected data from initial routine diagnostics. Thus, we obtained data from both beginning (T0) and end (T1) of participants' rehabilitation stay.

### 2.2 | Measures

#### 2.2.1 | Unexpressed needs

Based on the results of the first study part,[20] we developed a questionnaire to assess cancer patients' unexpressed needs in the admission interview of inpatient rehabilitation (Supporting Information Supplement A and B). We asked patients at T1 to remember the admission interview. First, we asked patients to rate the following item: "In the admission interview, I expressed all my concerns and distress". Response options were (a) absolutely not true, (b) rather not true, (c) rather true, and (d) absolutely true. Second, we asked patients to rate their own situational condition, physician behavior, and setting. Third, we assessed 22 reasons for patients' not expressing needs, which we selected based on the most prominent reasons of the first study part. Fourth, we assessed 10 possible topics of unexpressed needs, which we also selected based on most prominent topics of the first study part. Finally, we asked patients about their satisfaction with the admission interview and treatment during acute care and rehabilitation.

## 2.2.2 | Health-related variables

To assess correlates of unexpressed needs, the following measures with good reliability and validity were used.

### Quality of life

We assessed quality of life using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30).[21] Items are rated mainly on a 4-point Likert scale, ranging from 1 (not at all) to 4 (very much). The EORTC-QLQ C30 comprises five functioning scales (physical, role, cognitive, emotional, and social functioning), three symptom scales (fatigue, pain, and nausea and vomiting), and a global health and quality of life scale. Further comprised are several single-item measures. Scales are transformed into a range of 0 to 100. Higher scores in functioning scales reflect better health status, whereas higher scores in symptom scales reflect lower health status (Cronbach's alpha: physical functioning = 0.75, role functioning = 0.81, cognitive functioning = 0.85, emotional functioning = 0.92, social functioning = 0.69, fatigue = 0.88, nausea = 0.59, pain = 0.89, global health, and quality of life = 0.90).

### Depression and anxiety symptoms

We used the Patient-Health-Questionnaire-4 (PHQ-4) to capture symptoms of depression and generalized anxiety.[22] This 4-item ultra-brief self-report questionnaire consists of a 2-item depression scale (PHQ-2) and a 2-item anxiety scale (GAD-2). Patients assess depressive and anxiety symptoms over the last 2 weeks on a 4-point Likert scale, with the response options (a) not at all, (b) several days, (c) on more than half the days, and (d) nearly every day. For each subscale, items are summed up to form a sum score ranging from 0 to 6 (Cronbach's alpha: PHQ-4 = 0.85, PHQ-2 = 0.79, GAD-2 = 0.79).

### Adjustment disorder symptoms

We evaluated adjustment disorder symptoms using the Adjustment Disorder New Module 20 (ADNM-20).[23] Patients rate on a 4-point Likert scale, ranging from 1 (never) to 4 (often), how often they have experienced different adjustment symptoms during the past 2 weeks. Items are summed up to a sum score ranging from 0 to 80. Cronbach's alpha in our data was 0.94.

### Fear of progression

Fear of progression was assessed with the short form of the Fear of Progression Questionnaire (FoP-Q-SF).[24] Patients rate items on a 5-point Likert scale, ranging from 1 (never) to 5 (very often). Items are summed up to a sum score ranging from 0 to 60, with higher scores indicating higher levels of fear of progression. Cronbach's alpha in our data was 0.89.

### Health Literacy

Health literacy was measured using the German short-short version of the European Health Literacy Survey (HLS-EU-Q6).[25] It comprises six items, which can be assigned to a conceptual model with four dimensions (finding, understanding, assessing, and applying) and three domains (disease care, prevention, and health promotion). Items are rated on a 4-point Likert scale, with higher values indicating better health literacy. They are averaged into a total score (range: 1-4). Cronbach's alpha in our data was 0.80.

## 2.2.3 | Sociodemographic and clinical characteristics

We assessed sociodemographic characteristics (gender, age, marital status, having children, education level, employment status) by patients' self-reports and clinical characteristics (cancer type, stage of cancer: primary vs recurrent, treatment situation: curative vs palliative) from patients' charts.

## 2.2.4 | Measurement points

We obtained data at both beginning (T0) and end (T1) of inpatient rehabilitation, with a time gap of 3 weeks between both measurement occasions. At T0, only data on depression (PHQ-2), anxiety (GAD-2), and emotional functioning (EORTC-QLQ C30, subscale) were available from routine diagnostics. Hence, we only captured information usually available in the admission interview. At T1, we assessed all measures as described above. Thus, we assessed symptoms of depression, and general anxiety, and emotional functioning twice, at T0 and T1, and all other health-related variables solely at T1. Due to organizational reasons we evaluated characteristics of unmet needs and patients' perceptions of the admission interview retrospectively at T1.

## 2.3 | Statistical analysis

To answer research questions 1 and 2, we computed descriptive statistics (means, frequencies) with 95% confidence intervals. To answer research question 3, we computed bivariate correlations using Spearman correlation coefficients. Correlations coefficients of 0.1/0.3/0.5 were regarded as small/medium/large.[26] To answer research question 4, we computed ordinal logistic regression models.[27] Not expressing needs, measured as a 4-point ordinal variable, was the dependent variable. Predictors were included in two steps. In the basic model (model 1), we included clinical (diagnosis) and sociodemographic (age, sex, and education) variables. In further models (models 2a-2c), we additionally included health-related variables assessed at T0 (depression, anxiety, and emotional functioning). For each predictor, we conducted an independent model. We report odds ratios, including 95% confidence intervals and Nagelkerkes $R^2$. In all analyses, we considered a two-sided $P < .05$ as statistically significant. We used IBM SPSS Statistics (Version 25.0.0.1) and R (Version 3.6.1).

## 3 | RESULTS

## 3.1 | Sample characteristics

The final sample included 449 cancer patients (Supporting Information Supplement C and D). Mean age of participants was 58.8 years

| Prevalence of unexpressed needs | n | % | 95%-CI |
|---|---|---|---|
| In the admission interview, I expressed all my concerns and distress | | | |
| Absolutely not true | 17 | (3.8) | 2.4%-6.1% |
| Rather not true | 90 | (20.3) | 16.8%-24.3% |
| Rather true | 207 | (46.4) | 42.1%-51.4% |
| Absolutely true | 129 | (29.1) | 25.1%-33.5% |
| **Topics of unexpressed needs** | **n** | **%** | **95%-CI** |
| Fear of cancer recurrence | 205 | 45.7 | 41.1%-50.3% |
| Physical changes and treatment side effects | 154 | 34.3 | 30.1%-38.8% |
| Fear of the further course of the disease | 132 | 29.4 | 25.4%-33.8% |
| Financial security | 80 | 17.8 | 14.6%-21.6% |
| Sexuality | 75 | 16.7 | 13.5%-20.4% |
| Concerns regarding professional future | 69 | 15.4 | 12.3%-19.0% |
| Confrontation with death | 64 | 14.3 | 11.3%-17.8% |
| Partnership problems | 52 | 11.6 | 8.9%-14.9% |
| Workplace problems | 50 | 11.1 | 8.5%-14.4% |
| Family problems | 40 | 8.9 | 6.6%-11.9% |

(SD = 12.8; range 23-89) and n = 284 (63.3%) were female, n = 320 (71.6%) were married or living with a partner, n = 350 (78.1%) had children, n = 121 (27.7%) had received basic school education, and n = 218 (48.9%) were employed. Breast cancer was diagnosed in n = 238 (53.0%), prostate cancer in n = 134 (29.8%), and colon cancer in n = 77 (17.1%) of patients. In n = 407 (90.6%), this was a primary cancer.

## 3.2 | Unexpressed needs

Overall, n = 17 (3.8%) patients stated that it was "absolutely not true" having expressed all needs and burdens in the admission interview, n = 90 (20.3%) answered "rather not true", n = 207 (46.7%) "rather true" and n = 129 (29.1%) "absolutely true," respectively (Table 1).

Most frequent unexpressed needs were disease-specific topics in a narrow sense: Fear of cancer recurrence (n = 205; 45.7%), physical changes and treatment side effects (n = 154; 34.3%) or fear of the further course of the disease (n = 132; 29.4%). These were followed by financial security, sexuality, concerns regarding professional future, confrontation with death, partnership problems, workplace problems, and family problems (Table 1).

Patients indicated a wide range of reasons for not expressing needs (Figure 1). We present reasons sorted by patient-related, physician-related, and setting-related areas. The most frequent patient-related reasons were being focused on physical consequences of cancer, distress became evident only later during rehabilitation, not knowing about the possibility to talk about distress in the admission interview, and having a general difficulty in talking about feelings. Among physician-related reasons, patients rated the physician not

asking about distress as the main barrier. Among setting-related reasons, 14% of patients rated a lack of time as a main barrier.

## 3.3 | Correlates of not expressing needs

Not expressing needs in the admission interview was not significantly associated with socio-demographic characteristics (sex, age, diagnosis, having a partner, having children, education level, employment status, rehabilitation type, stage of cancer). Statistically significant small-to-medium correlations were found with several health-related outcomes at the end of inpatient rehabilitation, including lower quality of life, higher levels of depression and anxiety, adjustment disorder, fear of progression, and health-literacy. Furthermore, not expressing needs was significantly associated with subjective assessments of the admission interview. Medium to strong correlations were found with patients' evaluation of the admission interview. Patients with unexpressed needs more often perceived that the physician had less time, that the atmosphere was unpleasant, that they felt less understood, and that they were less satisfied in general with the admission interview (Supporting Information Supplement E).

## 3.4 | Prediction of not expressing needs

In regression analyses, the ordinal-dependent variable was not having expressed needs in the admission interview. The basic model (model 1) showed that age, sex, education level, and diagnosis were no significant predictors for not expressing needs (Supporting Information Supplement F). Furthermore, we conducted three independent models
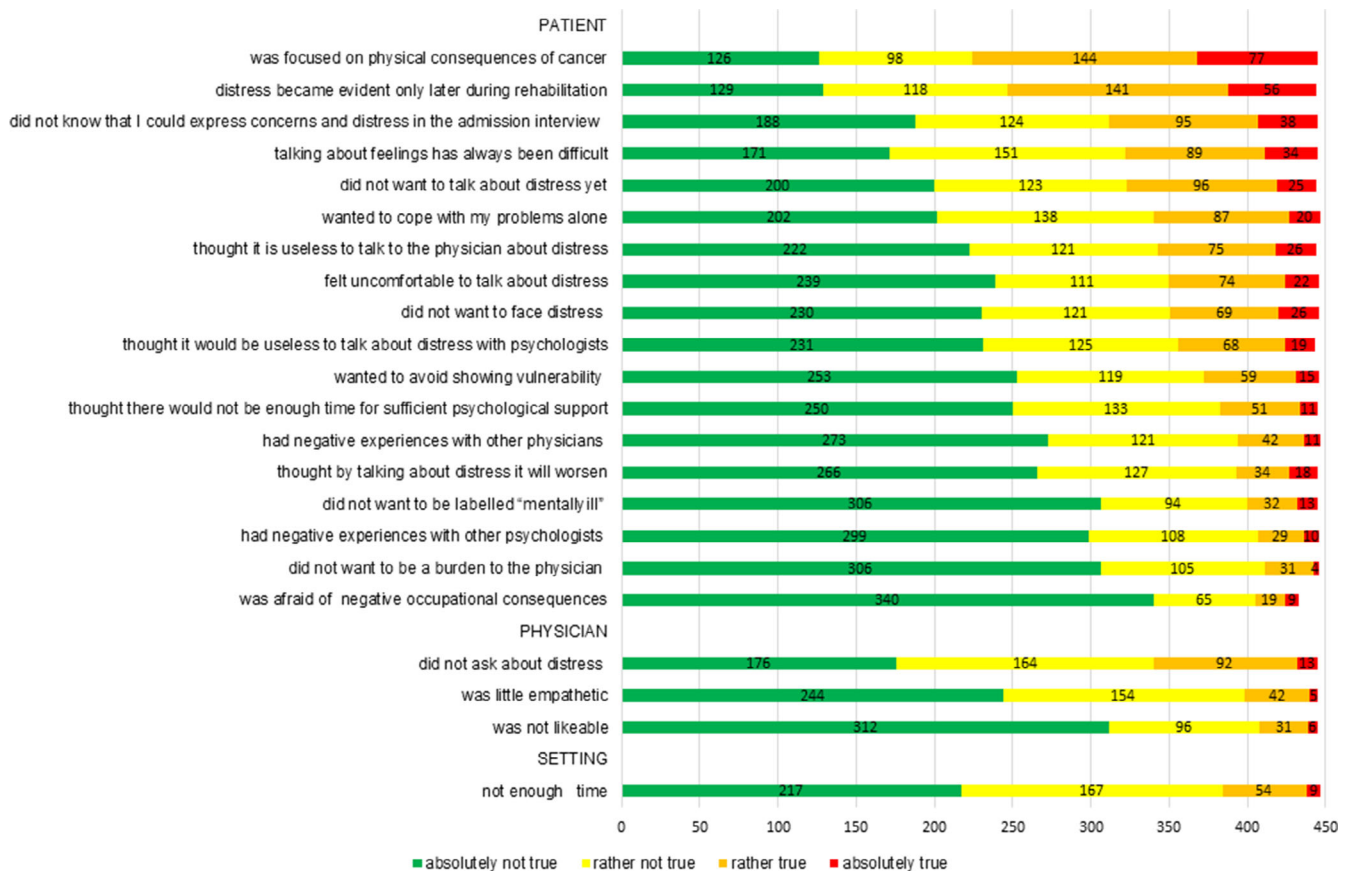
**FIGURE 1** Absolute frequencies of cancer patients' reasons for not expressing needs

(models 2a-2c), including the predictors of the basic model and additional health-related variables as further possible predictors measured at T0. We included depression (model 2a), anxiety (model 2b), and emotional functioning (model 2c), respectively. Depression (OR = 0.759, Nagelkerkes $R^2$ = .057, $P$ < .01) was a significant predictor for not expressing needs in the admission interview. Anxiety (OR = 0.839, Nagelkerkes $R^2$ = .034, $P$ = .106) and emotional functioning (OR = 1.002, Nagelkerkes $R^2$ = .034, $P$ = .104) were no significant predictors.

## 4 | DISCUSSION

As a prerequisite of optimal treatment, patients should express their needs to receive interventions addressing these needs. In this study, we examined the prevalence and predictors of cancer patients' unexpressed needs in the admission interview of inpatient rehabilitation. A considerable proportion of patients reported unexpressed needs, despite intensive screening for psychosocial needs in the recruiting clinic. Unexpressed needs included cancer-specific issues, followed by other psychosocial problems like financial security or sexuality. Reasons for not expressing needs were widespread. Not expressing needs in the admission interview was not associated with sociodemographic characteristics, but with lower quality of life and mental health at the end of rehabilitation. Patients with higher levels

in not expressing needs perceived to a lesser degree that the physician had enough time or that the conversation atmosphere was pleasant, felt less understood, and were less satisfied with the admission interview. Depression showed a statistically significant, but only small correlation, and is therefore not sufficient to identify patients with unexpressed needs.

About a quarter of cancer patients indicated not having expressed all their needs in the admission interview. However, more patients reported specific unexpressed topics. Hence, we can assume that there are still more patients with at least one unexpressed need. In comparison, the prevalence of unmet needs in cancer patients is thoroughly examined.[4-6,28-32] For example, a study from the UK found that 61% of breast cancer survivors had at least one unmet need, and 18% had more than five unmet needs.[4] In a sample of gynecological cancer survivors, 43% of respondents had at least one moderate- or high-level unmet need.[28] In a study with older adults with cancer, 45% of those with social support needs reported having at least one unmet need.[29] Thus, compared to the prevalence of unmet needs in cancer patients, our results suggest that the prevalence of unexpressed needs may be at least a quarter or higher. Furthermore, the screening procedures in the recruiting clinic are well developed compared to others, which might also contribute to a possible underestimation of unexpressed needs in our study.

Fear of cancer recurrence was the most frequently reported unexpressed need in this study. It is also one of the most commonly

reported concerns and unmet needs.[9] Although those fears and worries about recurrence or progression may be an understandable reaction to cancer, they can be highly detrimental.[16] It is a risk factor for higher depression, lower quality of life, and problematic daily functioning. Previous research showed that cancer survivors on average show no significant change in fear of cancer recurrence over time.[33] Hence psychological interventions reduce those fears in cancer patients,[34] expression of needs in this area should be facilitated for better allocating patients according to their needs.

Patients reported various reasons for not expressing needs. The most frequent patient-related reasons were that the physical consequences of cancer had priority in the admission interview, that some concerns became evident only later during their stay, and that patients were not aware that they could express their concerns in the admission interview. Hence, we can assume that patients discussed other, more prominent issues and needs in the admission interview and therefore did not express other needs.[12] We might surmise that for some patients the admission interview, after all, is not the ideal time point to express psychosocial needs. This may be underlined by associations between patients' not expressing needs with feeling nervous or troubled. It is only later in inpatient rehabilitation that patients may calm down after the acute treatment. Physical problems may ameliorate and recede. Just on the day of the admission patients experience lots of new impressions, maybe rush, meet new people, say good-bye to their family and home. Moreover, they meet their attending physician for the first time. Hence, we may assume talking about needs further in inpatient rehabilitation or even after might help patients to express needs. Anyway, in this very situation, the physician-patient-communication appears to be crucial.[10,11,20] A considerable amount of patients does not know about the possibility to talk about special needs and burdens in the admission interview.[12,13] Physicians' empathic demand might tackle this.[10,11,20] Patients then may decide on their own if the admission interview is the right time to talk about different kinds of needs or if they prefer waiting for further possibilities in the ongoing treatment.

In contrast to previous studies about unmet needs, we found no associations between not expressing needs and sociodemographic and clinical characteristics, such as cancer type, age, or education level.[3,9] Our results thus indicate that unexpressed needs may occur independently of these characteristics. However, further studies about the impact of cancer type and treatment setting on needs expression would complete this picture. Beyond that, not expressing needs at the beginning of rehabilitation was associated with lower quality of life and lower mental health at the end of rehabilitation. This finding is in line with previous studies about unmet needs.[7,9] However, these results do not allow for a causal interpretation. Either not expressing needs in the admission interview might decrease quality of life, mental health or suffering from poor quality of life, or mental health might cause patients not to express needs. Overall, long-term data must be collected to investigate whether these correlations persist after the end of rehabilitation.

We used regression analysis to identify patients with unexpressed needs using predictors usually available in the admission interview on a routine basis. Patients with higher depressive symptoms assessed at the beginning of rehabilitation had a higher risk of not expressing needs, but the correlation was small. Based on those results, it seems not yet possible to predict unexpressed needs with information usually available in the admission interview. Hence, unexpressed needs may be a new phenomenon that current assessment instruments do not yet cover.[21,22,35,36] Therefore, it might be helpful to ask patients directly for specific needs to facilitate their expression and to develop screening instruments targeting such needs.

## 4.1 | Limitations

This study has several limitations. First, we assessed unexpressed needs in the admission interview retrospectively about 2 weeks after the interview had taken place. Future studies might assess unexpressed needs directly at the beginning of rehabilitation could thus prospectively examine whether not expressing needs predicts objective and subjective health outcomes. Second, we did not capture all health-related outcomes already at the beginning of rehabilitation, for example, health literacy, as this was not part of the standard diagnostics. Therefore, we may have overseen potential predictors for not expressing needs. Third, recall bias is possible, due to the order of items in the questionnaire and due to effects of the rehabilitation treatment which may alter patients' priorities. Fourth, it seems possible that the multiple and partially overlapping reasons for not expressing needs provided to patients could have been tiring and affected their evaluation of unexpressed needs. Fifth, we cannot make assumptions about the individual influence of different physicians' behavior, because we did not capture that information. Finally, due to a monocentric design, local specifics might limit the generalizability of our results. Nevertheless, we assume this point to be no major restriction. Patients expressed global needs and reasons, not clinic-specific ones. Furthermore, the treatment procedures of inpatient rehabilitation clinics in the German pension insurance system are mainly standardized. Since screening in the recruiting clinic is more extensive than required, we rather assume that our findings underestimate the phenomenon of unexpressed needs.

## 4.2 | Clinical implications

A large group of patients does not express their needs during admission in inpatient cancer rehabilitation. This is associated with treatment outcome. What may be the clinical implications? First, it seems necessary to improve physician-patient-communication. Patients should be provided with explicit information that talking about various needs in the admission interview is possible. Empathic conversation might help patients to express their needs. Second, needs might be addressed continuously during inpatient rehabilitation and even after. Meanwhile, physical problems might have improved, the physician-patient-relationship might be more dependable, and patients with a

general difficulty in talking about feelings might be more open. Third, the resource-problem must be tackled. More time or more staff could facilitate the expression of needs. Allocating needs assessment in specific domains to other professions could support physicians. For example, one possibility might be establishing a mandatory psychological admission interview. Besides, the structure of the admission interview is determined to a large extent by the funding institution. More resources would have to be provided. Fourth, a reliable prediction of unexpressed needs is not yet possible. Depressive symptoms at the beginning of rehabilitation might be a potential hint but must be interpreted cautiously. Furthermore, question prompts for patients or structured guidelines for physicians might be effective in dealing with unexpressed needs, not only in the admission interview, but also in other settings. Altogether, the aim should not be to cope with all psychosocial needs in the admission interview or inpatient rehabilitation, but rather to identify a risk group and initiate possible treatments, even after rehabilitation.

## 4.3 | Conclusion

A considerable number of cancer patients report not expressing their needs in the admission interview of inpatient rehabilitation. Not expressing needs is associated with lower treatment outcomes. Cancer-specific issues are most frequently not expressed. Depression at the beginning of rehabilitation is not sufficient to predict cancer patients' not expressing needs in the admission interview. Together, it seems necessary to improve the identification of patients with unexpressed needs and to facilitate needs expression to ensure optimal care in cancer.

### CONFLICT OF INTEREST
The authors report no conflict of interest.

### DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available from the corresponding author upon reasonable request.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.