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Why Do Adult Patients With Cancer Not Seek Help for Their Depressive Symptoms? The Role of Illness Perceptions, Coping, and Social Support

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Background: Up to 75% of cancer patients with depressive symptoms do not make use of psychological care.

Objective: To examine how perceptions of and coping with depressive symptoms and perceived social support in adults with cancer are associated with their need for psychological care, concurrently and over time.

Methods: In this longitudinal study, 127 participants who received a cancer diagnosis in the past 5 years, experienced at least moderate depressive symptoms, and were not receiving psychological help, completed 2 self-report questionnaires (3 months apart) including the brief Illness Perception Questionnaire and brief Coping Orientation to Problems Experienced Inventory and Social Support List.

Results: Participants with stronger belief in the efficacy of psychological care and more likely to use avoidant coping reported a greater need for psychological care at both data points. Social support was not significantly associated with perceived need for psychological care.

Conclusions: Stronger perceived treatment control and greater use of avoidant coping were significantly associated with a greater perceived need for psychological care.

Implications for practice: People with cancer may benefit from being informed about the efficacy of depression treatment. Furthermore, health care professionals should be aware that avoidant coping may complicate psychological care seeking for a group of adults with cancer experiencing depressive symptoms and having a need for psychological care.

Foundational: Illness perceptions and coping mechanisms can predict cancer patients' need for psychological care. Providing information about treatment options and its efficacy, together with targeting avoidant coping may increase adequate decision-making and possibly the uptake of psychological care.

Keywords: cancer, coping, depression, illness perceptions, need for care, social support

Introduction

Many adults experiencing cancer also experience symptoms of depression during or after cancer treatment due to this serious illness and its intensive treatment.¹ Although prevalence rates of depressive symptoms vary, approximately a quarter of adult patients with cancer report depressive symptoms, with the odds of becoming depressed being up to 5 times higher in patients with cancer than in the general population.²⁻⁴ Given the possible impact of depressive symptoms on treatment nonadherence and poorer quality of life,⁵⁻⁸ it is important for health care professionals to identify depression in patients with cancer and intervene in time. Oncology nurses have a crucial role in providing comprehensive patient care, detecting psychological distress,

and providing an initial supportive response.^{9,10} Clinical guidelines are in place to routinely use a screening instrument for depressive symptoms in clinical care to identify patients with depressive symptoms and guide them to effective evidence-based psychological treatments.¹¹⁻¹⁴ Still, the uptake of psychological care for depressive symptoms is low: around 25%.^{15,16} A systematic review concluded that not perceiving a need for psychological care is one of the most important factors in not seeking care for depressive symptoms amongst patients with cancer.¹⁷ What underpins this lack of need for care remains unclear.¹⁷

Conceptual Framework

The Common Sense Model of Self-Regulation (CSM) assumes that a perceived need for care can be explained by several factors.^{18,19} First, need for care can be explained by patients' *illness perceptions* about their symptoms. These perceptions concern aspects such as the cause, impact, controllability, duration, and course of the illness.²⁰ Illness perceptions subsequently induce patients' *coping responses* to deal with problems (eg, seeking information, active problem-solving) and to regulate emotions (eg, seeking emotional support, acceptance) or to deal with the issue in a less adaptive, more passive or avoiding way (eg, denial, avoidance). A recent systematic review indeed found that illness perceptions and coping with cancer are strong predictors of perceived need for cancer care.²¹

Most studies in patients with cancer that have used the Common Sense Model focused on patients' perceptions of and coping with *cancer*.²²⁻²⁴ Consequently, very little is known about these patients' perceptions of and coping with *depressive symptoms* and if these are related to a perceived need for care. To date, only a handful of studies have examined illness perceptions of and coping with depressive symptoms in adults with

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cancer,²⁵ with some evidence that illness perceptions predict a perceived need for psychological care.^{26,27}

Patients' need for care can also be influenced by their social environment, although little is known about this relationship in patients with cancer.^{28,29} Findings about the influence of significant others on need for care have been inconsistent. Some studies have found that receiving social support from friends and family *decreases* the perceived need for professional help, since help is already being received.³⁰ Other studies concluded that social support from family and friends can *increase* help-seeking, when friends and family motivate patients to do so.³¹ One study found that lower levels of social support were related to a higher referral wish for psychological care in patients with cancer.³²

Given the low uptake of psychological care in depressed cancer patients and to optimize psycho-oncological care, understanding of patients' psychological care needs, need to be expanded. This may provide more insight into factors that can be targeted to optimize patients' decision-making about the uptake of psychological care. This study aimed to examine whether and how patients' perceptions of depressive symptoms, their coping with depressive symptoms and their perceptions of social support are related to their need for psychological care, both at the same time and three months later.

Methods

Study Design

We used longitudinal data from 2 online self-report assessments, 3 months apart, to study our research question. Participants could be at different stages in their cancer treatment, as long as they received a diagnosis in the past 5 years, enabling us to collect a representative sample of the cancer population. Previous research has shown that depressive symptoms can change over the course of 3 months, making it likely that need for psychological care might also change in this period.³³ The rationale for the 3-month period between the 2 assessments was therefore both content-related (eg, sufficient time for a possible change in need for psychological care, yet also constraining the likelihood of other events that may influence care needs) and for pragmatic reasons (eg, planning and available resources for carrying out the project). The Medical Ethical Committee of the University Medical Center Groningen stated that the study was non-WMO complicit (2017/064).

Participants and Procedure

Eligible participants were adults, able to complete questionnaires in Dutch, who received a cancer diagnosis in the past 5 years, and experienced at least moderate levels of depressive symptoms (patient health questionnaire [PHQ-9] ≥ 10). Previous research has shown that the optimal PHQ-9 cutoff score for detecting patients with a possible depression is a score of 10 or higher.^{34,35} We decided to follow this recommended cutoff score, since we were interested in identifying patients experiencing elevated levels of depressive symptoms who were not seeking or receiving psychological care. We focused on patients experiencing depressive symptoms, to be able to ask them how they perceived and coped with these symptoms. An exclusion criterion for participation in the study was currently receiving psychological care, for instance from a psychologist or nurse practitioner. Patients were recruited by Kantar TNS, a large research agency with an extensive respondent panel. Eligible participants received an information letter and informed consent form. Participants received a monetary incentive from Kantar TNS.

Measures

Demographic Variables, Cancer Characteristics, and Depression Score

Demographic (gender, age, education, employment status, and partner status) and cancer-related variables (type, treatment, and time since diagnosis) were all obtained with single self-report questions at baseline. Depressive symptoms were measured with a sum score on the PHQ-9: a validated and widely used, nine-item self-report questionnaire (answers ranging from 0 "not at all" to 3 "almost every day") representing DSM-V symptoms for Major Depressive Disorder.³⁴

Need for Care

The primary outcome variable was perceived need for care, measured with the question: "Would you currently like to receive psychological care?" which could be answered with "yes" or "no." This question was measured both at baseline and at follow-up.

Illness Perceptions

Illness perceptions were measured at baseline using the Dutch version of the validated and often-used brief Illness Perception Questionnaire that was adjusted to the illness at hand: depressive symptoms.^{36–38} Instead of using "illness," we asked about "these problems" which referred to a summary of depressive symptoms reported earlier (when scoring an item of the PHQ-9 1 or higher), thereby using a personalized approach. The questionnaire consists of 8 items—each about one illness perception—that can be answered on an 11-point scale ranging from 0 (low) to 10 (high).

Coping

Coping was measured at baseline using the brief COPE consisting of 14 two-item subscales about the use of a certain coping strategy when faced with problems.³⁹ We used the similar personalized approach as in the brief IPQ. Items could be answered with 4 response categories ranging from "I haven't been doing this at all" (1) to "I've been doing this a lot" (4). Scores for the subscales consisted of sum scores of the 2 affiliated items.³⁹ We performed a principal component factor analysis with Varimax rotation to reduce the number of variables that needed to be included in our analyses, as has previously been done.^{40,41} We found 3 factors: (1) approach coping (active coping, positive reframing, planning, humor, acceptance, self-distraction, and religion), (2) support seeking coping (instrumental support, emotional support and venting), and (3) avoidant coping (denial, substance use, behavioral disengagement, and self-blame). Cronbach's Alpha's were .75, .79, and .60, respectively.

Social Support

Social support interactions and deficit were measured at baseline using the 8-item subscale "emotional support with problems" from the Social Support List Interactions and Discrepancies (SSL-I and SSL-D).⁴² Social support interactions were measured by summing the scores of the interaction scale answers: seldom or never (1), now and then (2), regularly (3), very often (4). Discrepancy scores—I miss it (1), I do not really miss it, but I prefer more (2), exactly the right amount (3), it happens too often (4)—were reversed and summed, with higher scores indicating a greater deficit. Cronbach's alpha's were .88 and .84, respectively.

Statistical Analyses

We calculated means and percentages for demographic variables, cancer characteristics, perceived need for care at baseline and follow-up, illness perceptions, coping, and social support. We conducted chi-square tests and independent T-tests to examine differences between patients with and without a perceived need for care, both at baseline and at follow-up. Binomial logistic regressions were used to examine the associations with need for care of the variables, which were significantly different between the 2 groups. All analyses were performed using SPSS Statistics 25.

Results

Participants

We approached 2549 patients for study participation, with 321 patients (12.6%) not responding to the study call. This resulted in 2228 patients being screened of which 469 patients

received their cancer diagnosis over 5 years ago. A large group had low to mild levels of depressive symptoms (1491 patients) and 66 patients already received psychological care at that moment. One third of the remaining eligible sample did not give informed consent for participating in the study, leading to a final sample of 127 participants at baseline. The follow-up assessment was completed by 107 respondents. Demographic and cancer characteristics are shown in Table 1 and correspond to samples studied in previous research.^{32,43} Supplemental Digital Appendix A, available at <http://links.lww.com/CR9/A1> shows the predictors and care needs of the follow-up sample, which did not differ significantly from the sample at baseline.

Predictors of Need for Care at Baseline and Follow-up

Of the 127 participants, 17 perceived a need for care at baseline (13%). Regarding illness perceptions, participants (n = 110) not perceiving a need for care perceived lower treatment

Table 1.
Demographic Variables and Cancer Characteristics

Variable	Total (N = 127)	Need for Care (N = 17)	No Need for Care (N = 110)
Gender (% female)	56.7	64.7	55.5
Age (mean ± SD years)	61.4 ± 12.3	56.7 ± 14.1	62.1 ± 11.9
Education (%)			
Low	24.4	11.8	26.4
Middle	45.7	52.9	44.5
High	29.1	29.4	29.1
Unknown	0.8	5.9	0.0
Employment (%)			
Retired	36.2	23.5	38.2
Paid job	23.6	29.4	22.7
Inability to work	21.3	5.9	23.6 ^d
Doing the household	11.8	29.4	9.1
Other ^a	7.0	11.8	6.4
Partner status (%)			
Married or registered partnership	64.6	70.6	63.6
Single	15.0	11.8	15.5
Living together	7.9	5.9	8.2
Other ^b	12.5	11.7	12.7
Cancer type (%)			
Breast	24.4	47.1	20.9
Skin	19.7	17.6	20.0
Male reproductive organs	12.6	17.6	11.8
Digestive system	9.4	5.9	10.0
Urinary tract	7.9	0.0	9.1 ^d
Respiratory tract	7.1	5.9	7.3
Female reproductive organs	6.3	5.9	6.4
Hematology	5.5	0.0	6.4 ^d
Other ^c	12.6	11.8	12.6
Cancer treatment (%)			
Surgery	64.6	52.9	66.4
Chemotherapy	36.2	11.8	40.0 ^d
Radiotherapy	34.6	64.7	30.0 ^d
Hormone therapy	24.4	23.5	24.5
Immunotherapy	7.1	11.8	6.4
Other	9.4	5.9	10.0
Current treatment state (%)			
Active	34.6	17.6	37.3
Finished	52.0	47.1	52.7
Planned	13.4	35.3	10.0
Time since diagnosis (mean ± SD years)	3.54 ± 1.38	3.24 ± 1.48	3.58 ± 1.36
Total depression score (PHQ-9) (mean ± SD)	14.39 ± 4.22	14.65 ± 2.69	14.35 ± 4.42

Abbreviation: PHQ-9, patient health questionnaire.

^aSearching paid work, receiving education, being incapacitated for work and doing voluntary work.

^bWidow/widower, divorced, and having a partner but not living together.

^cEndocrine, head/neck, central nervous system, and sarcoma.

^dSignificant difference ($P < .05$) between subgroups.

Table 2.
Means of Illness Perceptions, Coping and Social Support

Variable	Total Group (N = 127)	Need for Care (N = 17)	No Need for Care (N = 110)
Illness perceptions (mean ± SD)			
Consequences	6.92 ± 1.74	7.24 ± 1.79	6.87 ± 1.74
Timeline	6.89 ± 2.22	7.06 ± 1.20	6.86 ± 2.34
Personal control	4.76 ± 2.32	4.76 ± 1.89	4.75 ± 2.38
Treatment control	4.32 ± 2.57	6.94 ± 1.82	3.91 ± 2.43 ^a
Identity	6.45 ± 1.89	7.41 ± 1.66	6.30 ± 1.88 ^a
Concern	6.10 ± 2.31	7.24 ± 1.60	5.93 ± 2.35 ^a
Coherence	6.44 ± 2.02	5.82 ± 1.88	6.54 ± 2.03
Emotional representation	6.38 ± 2.17	7.35 ± 1.58	6.23 ± 2.22 ^a
Coping (mean ± SD)			
Approach	4.34 ± 0.90	4.45 ± 0.91	4.33 ± 0.90
Support seeking	3.70 ± 1.18	4.39 ± 1.40	3.59 ± 1.12 ^a
Avoidant	3.30 ± 0.97	3.96 ± 1.12	3.20 ± 0.91 ^a
Social support (mean ± SD)			
Interactions	17.54 ± 5.24	19.35 ± 5.34	17.26 ± 5.20
Deficit	12.94 ± 4.09	14.00 ± 3.04	12.77 ± 4.22

Illness perceptions ranged from 0 to 10. Coping factors ranged from 2 to 8. Social support interactions and deficit ranged from 8 to 32 and 8 to 24, respectively.

^aSignificant difference ($P < .05$) between subgroups.

Table 3.
Predictive Value of Illness Perceptions and Coping on Need for Care

Variable	B	SE	Odds Ratio	95% CI
Illness perceptions				
Treatment control	.474 ^a	.153	1.606	1.190, 2.167
Identity	.152	.239	1.164	0.729, 1.859
Concern	.041	.225	1.042	0.670, 1.620
Emotional representation	.060	.211	1.061	0.702, 1.606
Coping				
Support seeking	.253	.247	1.288	0.794, 2.089
Avoidant	.629 ^b	.321	1.877	1.001, 3.518

The outcome variable is perceived need for care.

Abbreviation: CI, confidence interval.

^aSignificant at $P < .01$.

^bSignificant at $P < .05$.

control ($t(125) = -6.1, P < .001$), less strongly identified their symptoms as being part of depression ($t(125) = -2.3, P = .012$), were less concerned about ($t(125) = -2.9, P = .003$) and less emotionally influenced by their symptoms ($t(125) = -2.0, P = .023$), compared to those who did perceive a need for care (see Table 2). There were no significant differences between those with and without a care need in the perceptions of consequences, duration, personal control, and coherence. With respect to coping, participants without a perceived need for care used significantly less support seeking ($t(125) = -2.7, P = .004$) and avoidant coping ($t(125) = -3.1, P = .001$), compared to those with a perceived need for care. We found no significant difference between the 2 groups regarding the use of approach coping, social support interactions, and perceived social support deficits.

We performed a logistic regression analysis (see Table 3) including all 6 variables that significantly varied between the group that perceived a need for care at baseline and the group that did not perceive a need for care. Results showed that higher treatment control and a greater use of avoidant coping were associated with a stronger perceived need for care. Thus, participants perceiving treatment to be effective and those more likely to use avoidant coping to manage their symptoms reported a greater need for care. The odds ratio's (OR) indicated that for every point increase in treatment control and avoidant coping, the likelihood of having

a need for care increased by 1.6 and 1.9 times, respectively. It should be noted that for avoidant coping, the confidence interval was relatively wide, which reduces the precision of the OR.

Change Over Time

A logistic regression analysis with baseline predictors and need for care at follow-up as outcome showed similar results as before, with higher treatment control ($B = .333, SE = .120, OR = 1.396, 95\% CI [1.103, 1.766]$) and greater use of avoidant coping ($B = .663, SE = .301, OR = 1.941, 95\% CI [1.075, 3.504]$) both significantly associated with stronger perceived need for care.

Discussion

This study aimed to improve our understanding of why many adults with cancer and depressive symptoms perceive a low need for psychological care. We identified 2 patient groups more likely to report such low care need: (1) those who thought more negatively about the efficacy of psychological treatment and (2) those who were less likely to use avoidant coping to manage their symptoms of depression. These 2 factors were significantly associated with need for psychological care at the same time, but also predicted patients' care needs 3 months later.

The key finding was that participants who reported less faith in the efficacy of depression treatment perceived lower care needs, than those who believed depression treatment to be efficacious. As several depression treatments have proven to be effective,^{11,12} this low perceived efficacy of treatment might point to a lack of adequate information or misperceptions about the efficacy of depression treatment in some adults with cancer. Informing adults with cancer about the efficacy of the different options of psychological treatment for depressive symptoms may optimize their informed decision-making regarding care uptake. More research is needed to examine how to best inform these patients on the options and possible benefits of psychological treatment. In addition, more in-depth qualitative research is needed to better understand these patients' perceptions of the efficacy of psychological treatment for depressive symptoms.

Participants who were more likely to use avoidant coping were also more likely to report a greater need for care for depressive symptoms, than those less likely to use avoidant coping. Such avoidant coping may express itself by denying problems or substance use and might make it more difficult to seek and find ways to receive psychological care, even when such care is perceived to be needed. Screening patients on depressive symptoms and referring those with depressive symptoms and a need for care to support services might thus not be sufficient, as their avoidant behavior may impede care uptake. Health care providers could, therefore, explicitly discuss avoidant coping tendencies and barriers in psychological care uptake with their patients.

Over time, we found similar results: lower faith in depression treatment efficacy and lower use of avoidant coping were associated with lower psychological care needs 3 months later, showing that these findings were robust over time.

We found no evidence for a role of social support in explaining participants' need for care. Previous research found that social support could have both positive and negative influences on perceived need for care.^{30–32} Future research is needed to examine moderators of the relationships between support and care needs. Such research may shed light on situations, persons, or under what conditions each of the directions of the relationship prevails.

Strengths

A strength of our study was our homogeneous sample in terms of symptom severity, which is relevant in the context of examining care needs.^{4,32} Another strength lies in the personalized instructions for the brief IPQ and brief COPE. This allowed us to ask questions about perceptions and coping related to the patient's unique combination of depressive symptoms.

Limitations

A limitation of the study is, as a result of the small group that perceived a need for care, it may have been more difficult to draw statistical inferences about differences among the two groups. However, the assumption of linearity of the logit was met for all included predictors. We checked for outliers in our data. Together with the fact that we did find significant effects in our analyses, study results do provide answers to our research questions. Another limitation of the study is that only the direct relationships between the predictors and need for care were tested, since our sample size did not allow us to analyze the complete model in one overall analysis. Future research is needed to analyze the overall model, including all assumed relationships among the variables included, and more thoroughly test possible mediational and temporal associations among illness perceptions, coping and social support, and need for care. Future research could also include a longer timeframe to study the longitudinal effects of illness perceptions, coping, and social

support on perceived need for psychological care more in-depth. Moreover, it could include stigma as an additional predictor, since previous research has shown this to be an important aspect in seeking psychological help.⁴⁴ A third limitation might be that, although an accepted approach, perceived need for care was measured with one item.³² Measuring need for care with a more extensive set of questions (ie, the Perceived Need for Care Questionnaire)⁴⁵ might be a more valid assessment.

Practice Implications

Cancer patients with depressive symptoms who have negative beliefs about psychological treatment efficacy are less likely to perceive a need for care. Health care providers can assist patients by providing psychoeducation about the options and efficacy of depression treatment and hereby optimize informed decision-making in the uptake of care. Moreover, health care providers should be aware that depressed cancer patients with a perceived need for care might show avoidant coping, and that this might hamper an adequate dealing with depressive symptoms and care uptake.

Conclusion

One reason for cancer patients' low need for psychological care is a low perceived treatment efficacy. Another possible reason for low care uptake is that cancer patients with a need for care who are avoidant in their managing of problems, do not seek or accept psychological care.

Data Supplements

Supplemental digital content for this article is available at <http://links.lww.com/CR9/A1>.

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