




## PAPER

# Focusing on cancer patients' intentions to use psychooncological support: A longitudinal, mixed-methods study

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## Abstract

**Objective:** Distress screening programs aim to ensure appropriate psychooncological support for cancer patients, but many eligible patients do not use these services. To improve distress management, we need to better understand patients' supportive care needs. In this paper, we report the first key finding from a longitudinal study that focused on patients' intentions to use psychooncological support and its association with distress and uptake of the psychooncology service.

**Methods:** We conducted a prospective, observational study in an Oncology Outpatient Clinic and assessed distress, intention to use psychooncological support, and uptake of the psychooncology service by using the Distress Thermometer, a semistructured interview, and hospital records. We analyzed data with a mixed-methods approach.

**Results:** Of 333 patients (mean age 61 years; 55% male; 54% Distress Thermometer  $\geq 5$ ), 25% intended to use the psychooncology service (yes), 33% were ambivalent (maybe), and 42% reported no intention (no). Overall, 23% had attended the psychooncology service 4 months later. Ambivalent patients reported higher distress than patients with no intention (odds ratio = 1.18, 95% confidence interval [1.06-1.32]) but showed significantly lower uptake behavior than patients with an intention (odds ratio = 14.04, 95% confidence interval [6.74-29.24]). Qualitative analyses revealed that ambivalent patients (maybe) emphasized fears and uncertainties, while patients with clear intentions (yes/no) emphasized knowledge, attitudes, and coping concepts.

**Conclusions:** We identified a vulnerable group of ambivalent patients with high distress levels and low uptake behavior. To optimize distress screening programs, we suggest addressing and discussing patients' supportive care needs in routine clinical practice.

## KEYWORDS

cancer, Distress Thermometer, health-care delivery, needs, oncology, psychological support, psychooncology, reasons, screening, uptake

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## 1 | BACKGROUND

Cancer patients with untreated, high levels of psychosocial distress are at risk for nonadherence to cancer treatment,<sup>1</sup> reduced quality of life,<sup>2</sup> and comorbid mental disorders.<sup>3-6</sup> Psychooncological interventions can effectively reduce distress,<sup>7</sup> but many eligible patients do not take advantage of support services.<sup>8,9</sup> A third of all cancer patients show clinically significant levels of psychosocial distress,<sup>3</sup> but more than half of them do not want psychooncological support (42-75%),<sup>10-15</sup> although many patients with less distress do want support (10-44%).<sup>11,15-17</sup> Even patients who want and are offered psychooncological support do not always use these services.<sup>18</sup> Guidelines highlight the need to understand patients' supportive care needs to remove barriers and facilitate access to psychosocial services.<sup>8,18-20</sup>

Salmon et al<sup>20</sup> referring to Jonathan Bradshaw<sup>21</sup> recently brought patients' supportive care needs into focus by acknowledging that there is not only a *normative need* for support (defined by experts), indicated by an elevated distress score on the Distress Thermometer (DT) or other screening instruments, but also a *felt need* for support like a wish or desire that can become an *expressed need* for support, indicated, for example, by an expression of clear intent to use the known and available psychooncology service. Previous studies examined why a cancer patient's distress level did not always conform to their wish for support or adherence to services.<sup>10,17,18,22-25</sup> Most studies have focused on patients with high distress levels, and few used qualitative methods to understand patients' needs.<sup>26,27</sup>

We took an inductive, qualitative approach to understanding patients' supportive care needs without dividing them a priori into low- and high-distress groups. Our longitudinal mixed-methods design supplemented qualitative analysis with quantitative assessment of distress and uptake of the outpatient psychooncology service in a longitudinal mixed-methods design. We formulated 3 research questions: (1) What proportion of cancer patients intends, maybe intends, and does not intend to use the psychooncology service? (2) How are patients' intentions associated with distress and uptake of service? (3) Why do patients intend, maybe intend, and not intend to use the psychooncology service?

## 2 | METHODS

We report findings from a prospective, observational study in the Oncology Outpatient Clinic of the University Hospital Basel (Switzerland). Our methods are briefly outlined below; we have described them in more detail elsewhere.<sup>28</sup>

### 2.1 | Participants

Cancer outpatients who presented for the first time and used the outpatient oncological care at the clinic were eligible when fulfilling the inclusion criteria:  $\geq 18$  years, fluent in German, not being physically or cognitively impaired in a way that impedes study participation, and having at least 1 further consultation planned with an oncologist.

### 2.2 | Standard screening and referral procedure

Based on a stepped-care model,<sup>19</sup> patients were routinely screened with the DT at their first outpatient consultation for psychosocial distress. A nurse asked patients to fill in the DT, which patients then handed to the oncologist. All patients were given written information about the outpatient psychooncology service. The service is available for free and on short notice for all outpatients. Oncologists were briefed to address psychosocial distress during the first consultation and to recommend the service to patients, based on a clinically relevant distress level ( $DT \geq 5$ ), their clinical judgment, or the patient's wish.

### 2.3 | Study procedure

Oncologists screened cancer patients for interest to participate. The study team informed interested patients about the study, obtained informed consent, and interviewed participants an average of 15 days after the first consultation. Semistructured interviews were conducted in German and over the phone or face-to-face. Interviewers (TT and 7 Master's level students) relied on a manual. They were trained to use comprehension questions, reflection, and summaries to clarify mutual understanding; to take notes on participants' answers to open-ended questions during the interview, verbatim if possible; and to make postscripts of the interviews immediately afterward.<sup>29</sup> This study complied with the Declaration of Helsinki. The local ethics committee approved the study (Ethikkommission Nordwest-und Zentralschweiz, ref. no.: EK220/13).

### 2.4 | Measures

#### 2.4.1 | Sociodemographic and clinical characteristics

Patients' sociodemographic data were recorded during the interview. Clinical data were collected from patients' medical records.

#### 2.4.2 | Psychosocial distress screening

We used the German version of the National Comprehensive Cancer Network DT to assess self-reported psychosocial distress on a visual analogue scale from 0 to 10.<sup>30</sup> The 1-item screening tool shows good reliability and validity and has a cutoff value of  $\geq 5$  for clinically significant levels of psychosocial distress (from 0 "no distress" to 10 "extreme distress").<sup>30</sup>

#### 2.4.3 | Intention and reasons for uptake of psychooncological support

We asked the participants about their prospective intention during the interview: "Do you intend to uptake the outpatient psycho-oncological support service in the next months?" The interviewer categorized the participants' responses into 3 answers (yes/maybe/no), followed by an open-ended question: "What are the reasons why you do [may/not] intend to use the outpatient psycho-oncological support service?"

## 2.4.4 | Uptake of the outpatient psychooncology service

We defined uptake as having attended at least one appointment at the outpatient psychooncology service within 4 months after study entry and retrieved this information from hospital records.

## 2.5 | Data analyses

### 2.5.1 | Quantitative analyses

We conducted descriptive analyses for sociodemographic and clinical data. To determine the association between a priori selected sociodemographic variables, which are known to predict the use of psychological support, distress, and intention, we performed a multinomial logistic regression analysis. To determine the association between intention and uptake, we performed a logistic regression analysis. Results were presented as odds ratios with 95% confidence intervals. The level of significance was set at  $P < .05$ . Analyses were conducted by using SPSS Statistics version 22.0 (IBM, Armonk/NY, 2013).

### 2.5.2 | Qualitative analyses

We used content analysis to examine reasons for uptake of the psychooncology service.<sup>31</sup> This standardized, inductive approach analyzes qualitative data descriptively, adding a level of interpretation.<sup>32</sup> To guarantee high-quality content analyses, a team of trained researchers (AG, DZ, and TT) discussed the patients' reasons in a multistep procedure. First, we read the answers of the patients several times, divided the participants' answers into single reasons, and collected ideas about categories. Second, we gathered categories in a sample of 60 patients and refined them through an iterative process. Third, we coded reasons of all patients into categories, discussed inconsistency of assignment until consensus was reached, and assessed interrater reliability by using Cohen kappa statistics ( $\kappa$ ). Additionally, we identified main themes across categories. Analyses were conducted by using MAXQDA software version 12.2.0 (VERBI Software, Berlin, 2016).

## 3 | RESULTS

### 3.1 | Participant characteristics

Of 1240 outpatients who attended the clinic during 2013 to 2016 for an outpatient consultation, 484 were ineligible because of no further consultation, not being fluent in German, or being physically or cognitively impaired. Of all patients who attended the clinic, 756 (61%) were eligible for inclusion (Figure S1). In total,  $n = 333$  patients completed the study (Table 1).

### 3.2 | Distress, intention, and uptake of the psychooncology service

Of all participants, 53.5% showed high levels of psychosocial distress ( $DT \geq 5$ ); distress was normally distributed among all participants. Overall, 83 patients (25%) intended to use the psychooncology service (yes), 111 patients (33%) were ambivalent (maybe), and 139 patients

**TABLE 1** Participants' sociodemographic and clinical characteristics

Participants (n = 333), Unless Otherwise Stated	n	%
Age, in Years		
Mean (SD)	60.5	(14.0)
Range	19-93	
Sex		
Female	151	45.3
Male	182	54.7
Education		
Low (9th grade or less)	31	9.3
Middle (apprenticeship/high school)	186	55.9
High (diploma/university degree)	116	34.8
Living with a partner		
Yes	233	70.0
No	100	30.0
Living with children		
Yes	72	21.6
No	261	78.4
Distress thermometer <sup>a</sup>		
DT score 0-4	132	46.5
DT score 5-10	152	53.5
Time after initial cancer diagnosis, in weeks		
Median (range)	4	(0-264)
Cancer type <sup>b</sup>		
Breast cancer	67	20.1
Thoracic malignancies	59	17.7
Hematologic malignancies	51	15.3
Genitourinary cancer	28	8.4
Melanoma/skin cancer	27	8.1
Gastrointestinal (noncolorectal) cancer	22	6.6
Central nervous system tumors	16	4.8
Others	64	19.2
Treatment approach		
Palliative	128	38.4
Curative	205	61.6
Current treatments (multiple treatments possible)		
Systemic treatment <sup>c</sup>	298	89.5
Radiotherapy	109	32.7
Surgery	34	10.2
No treatment/watch-and-wait/others	21	6.3

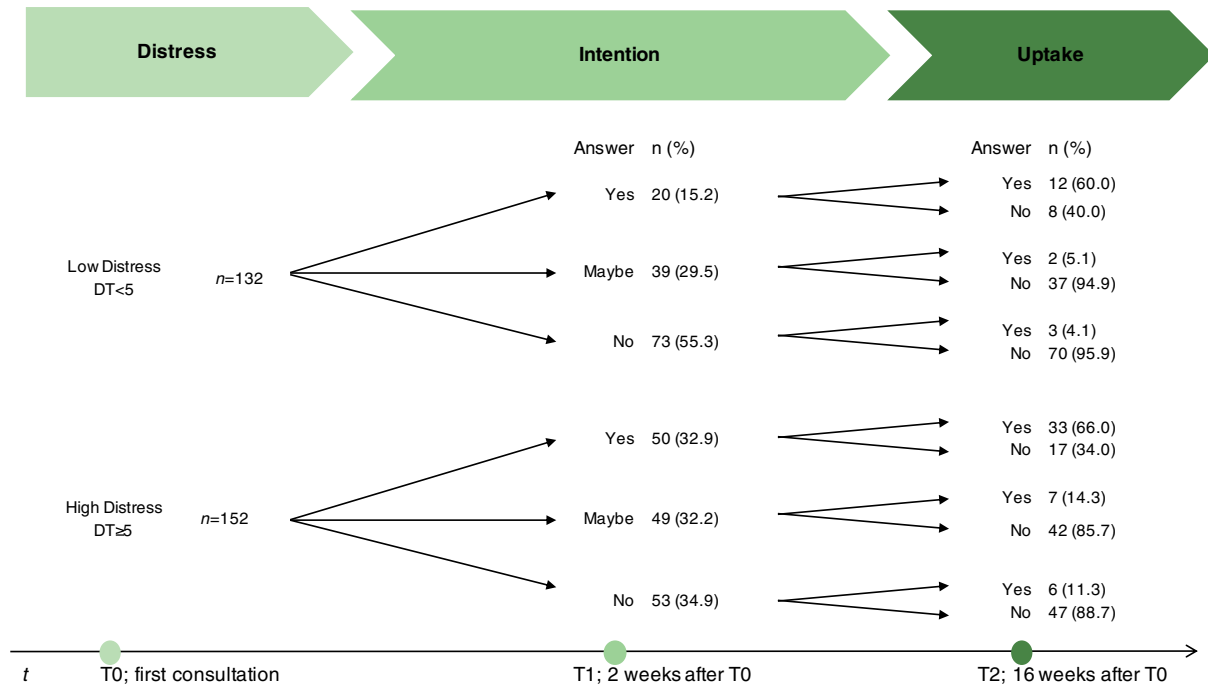
Abbreviations: SD, standard deviation; DT, Distress Thermometer.

<sup>a</sup> $n = 284$ , DT from  $n = 49$  patients missing due to nondelivery of the DT by clinical staff ( $n = 18$ ), not being provided by patients ( $n = 22$ ), and lost documents ( $n = 9$ ).

<sup>b</sup>One participant with 2 cancer types.

<sup>c</sup>Systemic treatment includes chemotherapy, immunotherapy, hormone therapy, and targeted therapy.

(42%) did not intend to use the service (no). We found high distress scores ( $DT \geq 5$ ) in 71% of patients with yes, 56% of patients with maybe, and 42% of patients with no intention. After 4 months, 77 patients (23%) had used the service at least once (54 with yes intention [65% of all yes], 13 with maybe intention [12% of all maybe], and 10 with no intention [7% of all no]). Figure 1 shows distributions of uptake stratified according to levels of distress and intentions.



**FIGURE 1** Description of patients' distress, intention, and uptake by distress level. Abbreviations: DT, Distress Thermometer; T0, screening; T1, baseline; T2, follow-up

In a multinomial logistic regression, patients with yes intention and patients with maybe intention were significantly more distressed than patients with no intention (yes: mean = 5.8 [SD = 2.4]; maybe: mean = 5.0 [SD = 2.6]; no: mean = 3.9 [SD = 2.7]). Age, sex, and education did not differ between intention groups (Table 2A). In a logistic regression analysis, patients with maybe and no intention showed significantly lower uptake behavior than patients with yes intention

(Table 2B). This result did not materially change after adjustment for sociodemographic variables (data not shown).

### 3.3 | Reasons for yes, maybe, or no intention

Patients gave a total of 734 reasons, averaging 2.2 reasons per patient (min. 1, max. 6 reasons). Content analysis identified 32 categories of

**TABLE 2** Associations among sociodemographic variables, distress, and intention as well as intention and uptake

(A) Multinomial Regression Analysis of Sociodemographic Variables and Distress on Intention									
	Intention Yes vs No <sup>a</sup>			Intention Maybe vs No <sup>a</sup>			Intention Yes vs Maybe <sup>b</sup>		
	B (SE)	OR [95% CI]	P Value	B (SE)	OR [95% CI]	P Value	B (SE)	OR [95% CI]	P Value
Distress (DT 0-10)	0.28 (0.06)	1.32 [1.17-1.49]	<.001**	0.17 (0.06)	1.18 [1.06-1.32]	.003*	0.11 (0.06)	1.12 [0.99-1.26]	.078
Age	-0.02 (0.01)	0.98 [0.96-1.00]	.107	-0.01 (0.01)	0.99 [0.97-1.01]	.406	-0.01 (0.01)	0.99 [0.97-1.01]	.410
Sex (0 = male, 1 = female)	0.19 (0.32)	1.21 [0.65-2.24]	.553	0.20 (0.29)	1.22 [0.69-2.14]	.497	-0.01 (0.33)	0.99 [0.52-1.88]	.980
Education (0 = low, 1 = high)	-0.14 (0.33)	0.87 [0.46-1.66]	.672	-0.11 (0.30)	0.90 [0.50-1.62]	.722	-0.03 (0.34)	0.97 [0.50-1.88]	.924
(B) Logistic regression analysis of intention on uptake									
	B (SE)		OR [95% CI]		P Value				
Intention yes vs no <sup>a</sup>	3.18 (0.40)		24.02 [10.95-52.71]		<.001**				
Intention maybe vs no <sup>a</sup>	0.54 (0.44)		1.71 [0.72-4.07]		.22				
Intention yes vs maybe <sup>b</sup>	2.64 (0.37)		14.04 [6.74-29.24]		<.001**				

Note. (A) Model  $\chi^2$  (8) = 28.94,  $P < .001$ ,  $n = 284$ , Nagelkerke  $R^2 = 0.110$ . Education was dichotomized into "low/medium" (less than ninth grade/apprenticeship/high school) and "high" (diploma/university degree). (B) Model  $\chi^2$  (2) = 100.66,  $P < .001$ ,  $n = 333$ , Nagelkerke  $R^2 = 0.395$ .

Abbreviations: B, Beta coefficient; SE, standard error; OR, odds ratio; CI, confidence interval; P value, significance level; DT, Distress Thermometer.

<sup>a</sup>Reference group no intention.

<sup>b</sup>Reference group maybe intention.

\* $P < .05$ .

\*\* $P < .001$ .

**TABLE 3** Ranking order of categories of reasons for patients' (yes/maybe/no) intention to use the psychooncology service (n = 333)

Intention		Yes (n = 83)			Maybe (n = 111)			No (n = 139)		
Rank	Categories	% (n)	Rank	Categories	% (n)	Rank	Categories	% (n)		
1	[ATT1] Yes/psychooncologist is an expert	40% (33)	1	[DIS1] Maybe/fear of deterioration	46% (51)	1	[SUP2] No/social support (family and/or friends)	45% (62)		
2	[COP1] Yes/support as means for empowerment and self-help	30% (25)	2	[SUP2] No/social support (family and/or friends)	25% (28)	2	[DIS8] No/subjective emotional and physical well-being	33% (46)		
3	[DIS1] Yes/fear of deterioration	25% (21)	3	[DIS8] No/subjective emotional and physical well-being	24% (27)	3	[ATT9] No/psychologists are not helpful	19% (27)		
4	[COP4] Yes/information and counseling	19% (16)	4	[DIS5] Maybe/uncertainty of current situation	14% (16)	4	[COP10] No/self-determination	19% (26)		
5	[DIS2] Yes/bad news/shock	18% (15)	5	[DIS2] Maybe/bad news/shock	12% (13)	5	[COP9] No/self-management	14% (20)		
6	[ATT6] Yes/recommendation	13% (11)	5	[ATT7] No/information is helpful and sufficient	12% (13)	6	[DIS7] No/favorable prognosis	13% (18)		
7	[COP2] Yes/talking as catharsis	12% (10)	6	[DIS3] Maybe/uncertain medical situation	10% (11)	7	[SUP1] No/physician as main supporting partner	12% (16)		
8	[ATT2] Yes/become acquainted with the psychooncologist	11% (9)	7	[COP9] No/self-management	9% (10)	8	[DIS1] Maybe/fear of deterioration	11% (15)		
8	[COP5] Yes/disburden family	11% (9)	7	[COP4] Yes/information and counseling	9% (10)	9	[COP8] No/talking is not helpful	10% (14)		
8	[DIS4] Yes/burdened family	11% (9)	10	[COP7] No/positive thinking	9% (13)	10	[COP7] No/positive thinking	9% (13)		
9	[ATT4] Yes/positive experience with psychological support	10% (8)								

Note. Categories are only listed above 9% of patients reporting (all categories are shown in Table S1). %, percentage of patients in this group reporting this category.

patients' reasons and 4 main themes. Interrater reliability was strong to moderate ( $\kappa = 0.70-0.89$ ).<sup>33</sup> Table S1 contains a detailed description of all categories and number of reasons per group.

Four main themes emerged across groups: attitude (ATT), coping (COP), distress (DIS), and support (SUP). *Attitude* includes categories that describe patients' opinions about psychooncological support. *Coping* includes different strategies that patients say they used to handle a situation. *Distress* consists of several categories that describe either subjective distress or well-being as a reason for uptake or decline of support. Formal and informal support includes categories that describe support needs of patients.

Patients with a yes intention wanted to consult psychooncologists mainly because (1) they considered the psychooncologists to be experienced experts [ATT1], (2) they wanted support for self-empowerment [COP1], and (3) they wanted to prepare for potential physical or mental deterioration [DIS1]. Patients with no intention generally (1) felt supported enough by family and friends [SUP2], (2) reported mental and physical well-being [DIS8], and (3) did not think psychological support would be helpful [ATT9]. Ambivalent patients (maybe) combined reasons for and against support, and they often described a potential situation in which they would consider taking advantage of support services (ie, if-then thinking): (1) They wanted to use support if their physical or mental condition deteriorated [DIS1], (2) they currently felt supported enough [SUP2], and (3) they felt physically and emotionally well [DIS8]. Other reasons are listed in order of rank in Table 3 and Table S1.

## 4 | DISCUSSION

To the best of our knowledge, this study is the first longitudinal, observational study with prospective data along the distress screening pathway assessing cancer patients' distress, intention, and uptake of the psychooncology service focusing on patients' intentions by using mixed methods.

Our study had 3 key findings. First, with a trichotomous assessment of health-care service needs (yes/maybe/no), we identified a considerable number of ambivalent patients (33%), who had high mean distress levels but were less likely to use services. Second, we found an association between level of distress and patients' intentions, but 67% of patients with a high distress level did not intend to use support immediately. Third, qualitative analyses revealed different motives of ambivalent patients and patients with no or yes intention.

In line with previous research,<sup>13,15,22,34</sup> we found that the level of distress, but not age, sex, or education, was associated with the intention to use psychooncological support. However, about 35% of patients with high distress levels did not intend, whereas 45% of patients with low distress levels intended or maybe intended to use support. The general assumption that high distress equates with a need for support is based on a diagnostic model that recognizes patients who are at risk for mental disorders.<sup>20,35</sup> Predefining a cut-off value is a normative standard helpful for screening, but it must be used carefully, because we screen for *normative need* but not, per se, for patients' *felt or expressed needs*.<sup>20</sup>

Intention predicted uptake behavior, but 7% of patients with no intention used the service, and 35% of patients with an intention had not used the service after 4 months. Uptake behavior in ambivalent patients was low (12%). Further studies need to explore the barriers between intention and uptake.<sup>18</sup>

In the interview, patients with no intention emphasized social support and well-being, which supported our quantitative result on low distress values and aligned with previous research on highly distressed patients who declined support.<sup>10</sup> Patients' negative attitudes about psychological support and their strong emphasis on self-determination and self-management may indicate a patient concept avoiding help-seeking behavior, which is common in mental health-care settings.<sup>10</sup>

Similarly, positive attitudinal aspects, knowledge, and coping concepts were important for patients with an intention (yes). Attitudinal aspects and knowledge are relevant to support-seeking behavior.<sup>24,36,37</sup> Many of these patients had precise ideas of what they wanted and would get when asking for psychooncological support, which indicates that mental health literacy, knowledge, and patient empowerment is an important aspect for service use.<sup>8,25</sup>

However, attitudes, experiences, or knowledge about support services played a negligible role for most ambivalent patients (maybe). Ambivalent patients stated reasons for and against support: Fears and uncertainties were described as well as resources and well-being. Patients reported a lot of if-then thinking and seemed to be open to using the service at a later stage. In our clinical experience, a clear treatment plan, medical appointments, and a focus on going through the medical treatment psychologically stabilize patients. Dekker et al<sup>38</sup> argued that an increased distress level might indicate "adaptive emotional responses, which facilitate coping with cancer" instead of a maladaptive process. Further studies are needed.

Our study offers a novel, in-depth qualitative analysis of patients' supportive care needs, which revealed a threefold intention (yes/maybe/no) and a divergent pattern of motives for declining psychooncological support. Intention is relevant here because 67% of highly distressed patients did not want to make immediate use of the psychooncology service, but only 35% of these had no intention, and 32% were ambivalent (maybe).

Our study has several strengths. First, to our knowledge, it is the first study to monitor uptake behavior of patients after expressing supportive care needs in a longitudinal study. Second, we qualitatively analyzed patients' needs, a crucial extension of previous studies. Third, we assessed a large sample of cancer patients in the early phase of treatment with equal representation of men and women.

## 5 | STUDY LIMITATIONS

Our limitations are as follows: First, due to the large number of study participants, we decided against audio records. Instead, we used the qualitative method of taking notes during the interview and writing reflective postscripts afterward.<sup>29</sup> We countered possible interviewer bias by relying on a detailed interviewer manual and closely supervising interviewers. Second, this was a single center study. Our sample was representative for our clinic and other outpatient oncological settings that use a stepped-care model and integrate psychooncological

care (eg, Comprehensive Cancer Centers). Third, oncologists did not inform 13% of all eligible patients about the study, 28% of eligible patients did not want more information about the study, and 12% refused to participate after being informed. We adopted a recruitment strategy where the consultant oncologist recruited the patients because it offered several advantages. Oncologists are the first and closest contact for outpatients, it is a naturalistic setting, and being invited by a physician to participate in a psychooncological study might reduce the stigma to accept the invitation. But there is also a risk of bias if oncologists are more inclined to inform interested, approachable patients about the study, or to invite patients with spare time, or who they judged healthy enough to participate.

## 6 | CLINICAL IMPLICATIONS

It is essential to integrate patients' supportive care needs into the clinical distress screening pathway. Patients with an ambivalent intention to use support might go unrecognized in clinical practice because supportive care needs are usually captured with a dichotomous response format.<sup>13</sup> We propose to assess the supportive care needs of patients by using a trichotomous response format (yes/maybe/no) at the same time as assessing psychosocial distress with the DT. The needs of highly distressed patients who do not intend to use support services (no) might be better met if approaches to these patients focused on reducing stigmatization and enhancing self-determination. In contrast, it might be better to address the needs of highly distressed, ambivalent patients (maybe) by taking an "if-then" approach to discussions about service uptake. Taking the right approach to meet the needs of each patient group could optimize psychooncological health-care delivery. Supportive cancer care should also always include providing detailed information to all patients about the work psychooncologists do and the benefits of psychooncological treatments.

## 7 | CONCLUSION

Our study reveals patients' subjective needs linked to psychosocial distress and uptake of a psychooncology service in cancer outpatients by using mixed methods. We identified a vulnerable group of ambivalent patients. To optimize distress screening programs, we suggest that patients' supportive care needs should be addressed and discussed in routine clinical practice.

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### CONFLICT OF INTEREST

The authors declared no conflicts of interest. G.M. was a consultant for Janssen Research & Development, LLC.

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#### SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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