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ORIGINAL ARTICLE

Gaps in communication between cancer patients and healthcare providers: symptom distress and patients' intentions to disclose

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Abstract

Purpose Good communication between patients and healthcare professionals (HCPs) is an important contributor to patient well-being. Few studies have focused on the gaps in communication between patients and HCPs about symptoms. This study examined patients' perspectives on symptom distress, intention to discuss symptoms, and actual symptom discussion in medical oncology visits.

Methods This was a cross-sectional descriptive study. Ninety-four patients provided demographic and clinical information and completed the Memorial Symptom Assessment Scale. Patients also answered questions about their plans for communication—and after the visit, their actual communication—with their medical team about their symptoms.

Results Patients reported many symptoms by questionnaire; however, they did not plan to discuss—nor actually discussed—most of their symptoms with their HCPs. For all symptoms, fewer than 42% of patients with the symptom intended to discuss it (except for lack of energy and pain) and less than 50% actually discussed the symptom. For bothersome symptoms, less than 42% of those with the symptom intended to discuss it (except for lack of energy) and less than 40% actually discussed the symptom. Psychological symptoms were endorsed by 24–41% of patients, depending on the symptom; however, of those endorsing a symptom, most did not discuss it with an HCP.

Conclusions Results of this study support the perception of communication gaps between patients and HCPs about symptoms. Better understanding of these gaps is needed to ensure that patient-centered care is delivered and that patients' symptoms can be appropriately managed in oncology clinics.

Keywords Memorial Symptom Assessment Survey · Cancer patients · Medical communication · Symptom reporting · Symptom bother

Introduction

The medical interview has been described as the most significant diagnostic instrument in medicine [1]. Communication between healthcare professionals (HCPs) and cancer patients has been documented as an important contributor to these patients' well-being and medical outcomes [2, 3]. Additionally, patients report that a positive interpersonal relationship and effective information exchange with HCPs are crucial aspects of cancer care [4, 5]. The quality of the relationship between cancer patients and physicians is related to patient decision-making, sense of self-efficacy, adjustment to illness, adherence to medical treatment (which influences relapse and survival), satisfaction with care, and costs of treatment [6–8]. A systematic review validated the idea that effective communication between patients and HCPs correlates with good health outcomes [7].

Symptom assessment, which can be done via interview, self-assessment surveys, and observer ratings, presents many methodological challenges. There is variability in the symptoms targeted (e.g., all symptoms, symptoms specifically related to treatment), dimensions assessed (e.g., severity, frequency), and the reliability/validity of various measures. Finally, there are differences in how particular symptoms are

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categorized. For example, the Common Terminology Criteria for Adverse Events (CTCAE) includes sexual problems under psychiatric disorders while the Memorial Symptom Assessment Scale includes sexual problems within the realm of physical symptoms [9, 10].

Some of the difficulties in cancer patient-physician communication have been characterized as barriers and unmet needs [11–13]. Communication about symptoms is complicated; however, if symptoms are not acknowledged, they cannot be addressed. From the HCP standpoint, an important barrier to communication is the short time allotted for patient visits in clinic [13]. Moreover, patients report their needs are not met when psychosocial symptoms are not discussed as part of their cancer care [13], yet this type of communication can be challenging and both patients and HCPs may wait for the other to take the lead on discussing these topics [14]. Cancer patients may not be aware that discussing their emotional issues is part of comprehensive medical care, and oncologists may worry that these discussions will be too time consuming [15]. To put this work into context, a systematic review focused on medical consultations across specialty areas suggested that patients tend to limit expression of worries, fears, and emotions in the encounter with their HCPs. In this review, physicians were found to respond in ways that discouraged patient disclosure (e.g., interrupting, minimizing, dismissing, using close-ended questions) [16]. There are no previous studies that have focused on the cancer patient's intention to discuss their symptoms with their HCP, a focus of the present study.

To further explore communication about symptoms in the oncology clinic setting, we examined the following: which symptoms were most commonly reported, which symptoms patients intended to discuss with their HCP, and which were actually discussed. We examined the concordance between report of symptoms and intention to discuss them as well as the concordance between intention to discuss symptoms and actual discussion of symptoms. We also explored whether degree of symptom bother related to intention to discuss or actual discussion. Finally, we compared physical symptoms and psychological symptoms to see if there was a difference in intention to discuss and subsequent actual discussion.

Methods

Study sample

Data for this cross-sectional descriptive study was gathered for a previous research project analyzing the concordance between patients and providers on patient symptoms [17]. The study sample involved patients from three oncology outpatient clinics at a National Cancer Institute-designated comprehensive cancer center in the Midwestern USA.

Patients were eligible to participate in the study if they were older than 18 years; diagnosed with cancer at least 3 months before; had cancer stage I, II, III, or IV; and were English speakers. Patients with any psychiatric or cognitive condition that limited their ability to give consent or communicate with their medical providers about symptoms (as indicated by their oncology team) were ineligible for the study.

Procedures

This research study was approved by the Institutional Review Board of the medical school and the Protocol Review and Monitoring Committee of the cancer center (protocol number 201102137). Eligible patients were identified weekly from the clinic schedule by the oncology team (medical oncologist, nurse), using the aforementioned eligibility criteria. The research assistant approached the identified patients in the waiting room before their clinic appointment, invited participants to the study, and verified eligibility. Interested patients completed a written consent and pre-visit measures before their contact with the HCP. Patients also reported which symptoms they planned to discuss with their HCP. HCPs were informed about patients' participation in the study before their interaction with the patient. Patients were seen by their physician and may also have been seen by a nurse practitioner (NP) and/or a nurse coordinator (NC). This was determined by clinic protocol and the needs of the patient for that clinic visit. Immediately after the clinic visit, the research assistant used a structured interview to query patients about which symptoms were actually discussed with their medical team. Medical information about type of cancer and cancer stage was verified by review of the medical record.

Measures

Demographic/medical form The demographic/medical form collected patient-reported data about age, race/ethnicity, gender, education level, insurance status, type of cancer, stage of cancer, treatment status, and current medications.

Memorial Symptom Assessment Scale–Short Form (MSAS-SF) [18] The MSAS-SF—is an abbreviated version of the 32-item Memorial Symptom Assessment Scale, which has been validated in oncology populations [19]. This version of the MSAS captures symptom presence and associated distress (0–4 scale) over the past week. For four symptoms (feeling sad, worrying, feeling irritable, and feeling nervous), it measures symptom frequency (1–4 scale) rather than distress. The MSAS-SF subscales include the following: the Physical Symptom subscale (PHYS, range 0–48), the Psychological Symptom subscale (PSYCH, range 0–20), the Global Distress Index (GDI, range 0–40), and the Total Symptom Distress score (TMSAS, range 0–128). Symptoms were defined as bothersome (or

concerning) if they were reported to be somewhat, quite a bit, or very much distressing (rating of 2–4 on a 0–4 scale) or frequently or almost constantly occurring (rating of 3 or 4 on 1–4 scale)—the latter for the four symptoms noted above.

Data analysis

Descriptive statistics were used to summarize the data (mean, standard deviation, percent, and counts). Data were analyzed with SPSS version 22. Cohen's kappa coefficient was used with 95% confidence interval to evaluate concordance between (1) symptom presence and intention to discuss, (2) intention to discuss and actual discussion of symptoms, (3) endorsement of a symptom as bothersome and intention to discuss it, and (4) endorsement of a symptom as bothersome and actual discussion of it. We defined kappa agreement as follows: < 0 = less than chance agreement, 0.01–0.20 = poor agreement, 0.21–0.40 = fair agreement, 0.41–0.60 = moderate agreement, 0.61–0.80 = good agreement, and 0.81–0.99 = very good agreement. p values were used to determine statistical significance, defined as $p < 0.05$. Because of the small numbers of patients intending to discuss particular symptoms (and actually discussing symptoms), we collapsed the results across all HCPs for the kappa analysis.

Results

Of 125 patients approached in the oncology clinic, 103 consented to participate (82% response rate). Nine of the consented patients were not included in the study as they were determined to be ineligible after consenting ($n = 3$) or failed to complete study measures ($n = 6$). Therefore, 94 patients provided data for this study (75% of the total approached). Table 1 shows the demographic and clinical data for the participants. Participants attended clinics for three types of cancer: breast ($n = 32$) gastrointestinal ($n = 35$), and lung ($n = 27$). Patients were more likely to be white, educated, and female. Most patients had stage IV disease; however, breast cancer patients were more likely to have stage II disease.

Table 2 shows the MSAS-SF results for participants. The maximum number of symptoms reported by any patient was 27 (of a possible 32 symptoms), and the minimum number was 0. Patients reported 9.52 symptoms on average (SD = 6.10). The average number of bothersome symptoms was 5.8 (SD = 4.8). The average PHYS score was 9.9 (SD = 7.0, range = 2–31). The average PSYCH score was 6.4 (SD = 4.4, range = 1–18). The average GDI score was 10.4 (SD = 6.9, range = 1–29). The average TMSAS score was 19.7 (SD = 13.8, range = 1–64). Patients reported intention to discuss 3.2 symptoms on average (SD = 2.9, range = 0–12); however, they actually discussed $X = 2.7$ symptoms (SD = 3.9, range = 0–32) with their physicians, $X = 0.6$ symptoms (SD = 1.6, range = 0–8) with nurse coordinators, and $X = 1.5$ symptoms (SD = 2.8, range = 0–15) with nurse practitioners.

We defined the most common symptoms as those endorsed by 38% or more of patients. The eight most commonly reported symptoms were lack of energy, pain, worrying, cough, dry mouth, feeling drowsy, change in the way food tastes, and difficulty sleeping. Patients were most likely to intend to discuss with their HCPs pain, lack of energy, and numbness/tingling (20% or more of patients with this symptom intended to discuss it). Patients were most likely to actually discuss with their HCPs pain, lack of energy, cough, and nausea (20% or more of patients with this symptom actually discussed it). Some symptoms were discussed in clinic despite patients not endorsing the symptom, specifically nausea and pain (20.9% and 22.4% reported discussion, respectively).

We examined concordance between (1) endorsing a symptom and intending to discuss it and (2) intending to discuss a symptom and actually discussing it. Regarding the first type of concordance, there was very good agreement between endorsing dizziness and intending to discuss it, good agreement between endorsing hair loss and intending to discuss it, and moderate agreement between endorsing weight loss and intending to discuss it; however, none of these results was statistically significant. Concordance was low for the remaining symptoms, and the results were statistically significant only for these symptoms: mouth sores, worrying, and feeling irritable. Regarding the second form of concordance, there was good agreement between intending to discuss the symptom "problems urinating" and actually discussing it, and this result was statistically significant. There was moderate concordance for 15 other symptoms (see Table 3). All of the kappa scores were statistically significant, except for the symptoms problems with sexual interest/activity and weight loss.

With regard to symptom bother, lack of energy, pain, worrying, feeling sad, and feeling nervous were identified as bothersome by 30% or more of participants. Over 50% of patients who endorsed these symptoms as bothersome reported intention to discuss them in clinic: mouth sores, pain, itching, diarrhea, sweats, and numbness/tingling. Although worrying and feeling sad were among the more common bothersome symptoms, only 13% of patients intended to discuss their worrying and 13% intended to discuss feeling sad. In terms of actual discussion of bothersome symptoms, at least 50% of patients who reported these symptoms as bothersome also discussed them with their HCPs: pain, nausea, diarrhea, swelling of arms/legs, difficulty swallowing, constipation, cough, and vomiting. Worrying, feeling nervous, and feeling sad were least likely to be actually discussed with HCPs despite being among the more common bothersome symptoms.

We also examined concordance for intention to discuss bothersome symptoms and actual discussion of those symptoms (see Table 3). There was very good concordance for

Table 1 Demographics and clinical characteristics for cancer patients

Cancer type	Total ($n = 94$)	GI ($n = 34$)	Breast ($n = 33$)	Lung ($n = 27$)
Age, *n* (%)				
23–49	19 (20.4)	5 (14.7)	12 (36.4)	2 (7.7)
50–69	56 (60.2)	24 (70.6)	17 (51.5)	15 (57.7)
70–86	18 (19.4)	5 (14.7)	4 (12.1)	9 (34.6)
Gender, *n* (%)				
Female	66 (70.2)	16 (47.1)	32 (97.0)	18 (66.7)
Race/ethnicity, *n* (%)				
White	69 (73.4)	21 (61.8)	26 (78.8)	22 (81.5)
Black/AA	22 (23.4)	11 (32.4)	7 (21.2)	4 (14.8)
Asian	2 (2.1)	1 (2.9)	0 (0)	1 (3.7)
Other	1 (1.1)	1 (2.9)	0 (0)	0 (0)
Education, *n* (%)				
High school	12 (12.8)	3 (8.8)	6 (18.2)	3 (11.1)
High school grad/GED	22 (23.4)	10 (29.4)	7 (21.2)	5 (18.5)
Some college	24 (25.5)	11 (32.4)	6 (18.2)	7 (25.9)
Technical college	3 (3.2)	3 (8.8)	0 (0)	0 (0)
Bachelor's	16 (17.0)	3 (8.8)	7 (21.2)	6 (22.2)
Master's/Doctoral	15 (16.0)	4 (11.8)	6 (18.2)	5 (18.5)
Other	1 (1.1)	0 (0)	0 (0)	1 (3.7)
Insurance, *n* (%)				
Private	36 (38.3)	12 (35.3)	15 (45.5)	9 (33.3)
Medicare	31 (33.0)	11 (32.4)	8 (24.4)	12 (44.4)
Medicaid	12 (12.8)	4 (11.8)	4 (12.1)	4 (14.8)
Self pay	3 (3.2)	2 (5.9)	0 (0)	1 (3.7)
Other, not working	12 (12.8)	5 (14.7)	6 (18.2)	1 (3.7)
Cancer stage, *n* (%)				
I	9 (9.6)	1 (2.9)	7 (21.2)	1 (3.7)
II	22 (23.4)	6 (17.6)	13 (39.4)	3 (11.1)
III	23 (24.5)	9 (26.5)	7 (21.2)	7 (25.9)
IV	38 (40.4)	16 (47.11)	6 (18.2)	16 (59.3)

these symptoms: changes in skin, problems urinating, dizziness, difficulty swallowing, swelling of arms/legs, and feeling irritable; however, the kappa was statistically significant only for swelling of arms/legs and feeling irritable. The level of agreement was good for hair loss and numbness/tingling in hands/feet; the kappa was significant for hair loss, and marginally so for numbness/tingling in the hands/feet. There was moderate agreement for 12 symptoms (see Table 3), but the kappa was statistically significant only for pain.

Finally, we examined patients' intentions to discuss and actual discussion of psychological symptoms (see Fig. 1). A number of the more common bothersome symptoms (identified by more than 30% of participants) were psychological in nature: worry, feeling sad, and feeling nervous. However, participants did not intend to discuss these symptoms (see Table 2), and indeed they were not discussed. For example, worry is a psychological symptom that was relatively common (endorsed by 42% of participants), but only 6% of participants intended to discuss it with their HCPS and only 5% actually discussed it. Similarly, "problems with sexual interest/activity" was endorsed by 14 patients, but only one patient intended to discuss it with their HCPs.

Discussion

While this study replicates previous research showing that cancer patients have high symptom burden, both physical [20–22] and psychological in nature [21, 23], it further establishes that patients have limited intentions to discuss their symptoms and the frequency of actually discussing symptoms with their HCPs is lower yet, even for bothersome symptoms. Thus, these results indicate that patients do not always intend

Table 2 Memorial Symptom Assessment Scale–Short Form: symptom data

Symptom	*n* (%)*									
	Patients who endorsed symptom		Intend to discuss		Discussed with MD		Discussed with NC		Discussed with NP	
Difficulty concentrating	22	(23)	9	(10)	4	(4)	0	(0)	1	(1)
Pain	52	(55)	31	(33)	34	(36)	7	(7)	16	(17)
Lack of energy	64	(68)	31	(33)	25	(27)	5	(5)	15	(16)
Cough	38	(40)	15	(16)	13	(14)	3	(3)	8	(9)
Changes in skin	15	(16)	9	(10)	7	(7)	2	(2)	3	(3)
Dry mouth	37	(39)	8	(9)	5	(5)	1	(1)	2	(2)
Nausea	32	(34)	12	(13)	22	(23)	4	(4)	10	(11)
Feeling drowsy	36	(38)	13	(14)	11	(12)	3	(3)	6	(6)
Numbness/tingling in hands/feet	31	(33)	20	(21)	9	(10)	3	(3)	6	(6)
Difficulty sleeping	36	(38)	15	(16)	10	(11)	1	(1)	6	(6)
Feeling bloated	19	(20)	6	(6)	3	(3)	1	(1)	2	(2)
Problems urinating	6	(6)	2	(2)	3	(3)	1	(1)	1	(1)
Vomiting	12	(13)	4	(4)	6	(6)	1	(1)	4	(4)
Shortness of breath	30	(32)	7	(7)	8	(9)	2	(2)	6	(6)
Diarrhea	20	(21)	7	(7)	10	(11)	3	(3)	7	(7)
Sweats	24	(26)	10	(11)	8	(9)	2	(2)	4	(4)
Mouth sores	11	(12)	6	(6)	2	(2)	0	(0)	0	(0)
Problems with sexual interest/activity	14	(15)	1	(1)	1	(1)	0	(0)	0	(0)
Itching	11	(12)	7	(7)	6	(6)	2	(2)	3	(3)
Lack of appetite	29	(31)	8	(9)	7	(7)	2	(2)	6	(6)
Dizziness	21	(22)	8	(9)	3	(3)	3	(3)	5	(5)
Difficulty swallowing	13	(14)	4	(4)	4	(4)	2	(2)	3	(3)
Change in the way food tastes	36	(38)	11	(12)	5	(5)	1	(1)	5	(5)
Weight loss	23	(25)	4	(4)	6	(6)	1	(1)	1	(1)
Hair loss	29	(31)	8	(9)	6	(6)	0	(0)	0	(0)
Constipation	12	(13)	8	(9)	6	(6)	1	(1)	8	(9)
Swelling of arms/legs	10	(11)	7	(7)	11	(12)	5	(5)	3	(3)
Don't look like myself	15	(16)	2	(2)	1	(1)	0	(0)	1	(1)
Feeling sad	32	(34)	4	(4)	3	(3)	0	(0)	2	(2)
Worrying	39	(42)	6	(6)	5	(5)	0	(0)	1	(1)
Feeling irritable	23	(25)	6	(6)	3	(3)	1	(1)	1	(1)
Feeling nervous	31	(33)	8	(9)	5	(5)	0	(0)	2	(2)

to discuss their symptoms with their medical team, even when those symptoms are particularly bothersome.

Common cancer-related symptoms—such as lack of energy [24, 25], pain [22, 25], and nausea [25]—were the symptoms patients most often discussed with their HCPs in this study. The existing literature suggests that lack of energy [26, 27] and pain [28, 29] are the physical symptoms most commonly underreported by patients and therefore untreated. However, in this study, they were the symptoms that patients most often intended to report and, indeed, those that were most often actually discussed with their HCPs, in comparison with other symptoms. One explanation for these results may be that patients find it easier to discuss symptoms which they perceive to be typical cancer symptoms, or it may be that HCPs are more likely to ask about the most common cancer-related symptoms. Our study did not assess who initiated the discussion about symptoms. Consistent with HCP-initiated discussion, patients reported some discussion about symptoms (e.g., nausea and pain) even though they did not endorse having the symptoms.

Patients were unlikely to discuss some physical symptoms with their HCPs, such as dry mouth and changes in sense of taste. Further study is needed to explore reasons for this communication gap. For instance, prior research has suggested

Table 3 Symptom reporting concordance

Symptoms	Overall symptoms and intention to discuss		Intention to discuss symptoms and actual discussion		Intention to discuss and actual discussion when symptom is bothersome	
	Cohen's kappa	*p* value	Cohen's kappa	*p* value	Cohen's kappa	*p* value
Difficulty concentrating	0.06	0.69	0.39	< 0.01**	0.40	0.39
Pain	− 0.05	0.44	0.49	< 0.01**	0.53	< 0.001***
Lack of energy	0.02	0.69	0.40	< 0.01**	0.26	0.13
Cough	0.00	0.97	0.34	< 0.01**	0.44	0.09
Changes in skin	− 0.07	0.68	0.39	< 0.01**	1.00	0.16
Dry mouth	− 0.01	0.89	0.38	< 0.01**	0.39	0.17
Nausea	− 0.01	0.86	0.46	< 0.01**	0.53	0.09
Feeling drowsy	− 0.04	0.70	0.41	< 0.01**	0.37	0.15
Numbness/tingling in hands/feet	− 0.01	0.99	0.55	< 0.01**	0.70	0.05
Difficulty sleeping	0.03	0.82	0.45	< 0.01**	0.44	0.09
Feeling bloated	− 0.13	0.21	0.47	< 0.01**	0.25	0.47
Problems urinating	− 0.07	0.62	0.66	< 0.01**	1.00	0.16
Vomiting	− 0.70	0.74	0.39	< 0.01**	N/A	N/A
Shortness of breath	− 0.16	0.11	0.39	< 0.01**	0.42	0.27
Diarrhea	− 0.17	0.13	0.42	< 0.01**	0.57	0.12
Sweats	− 0.13	0.25	0.55	< 0.01**	0.40	0.13
Mouth sores	− 0.52	< 0.05*	0.23	< 0.001***	N/A	N/A
Problems with sexual interest/activity	0.01	0.93	− 0.01	0.91	0.00	1.00
Itching	0.09	0.52	0.49	< 0.01**	0.17	0.71
Lack of appetite	− 0.05	0.45	0.29	< 0.01**	0.40	0.16
Dizziness	0.83	0.62	0.39	< 0.01**	1.00	0.16
Difficulty swallowing	0.10	0.51	0.29	< 0.01**	1.00	0.16
Change in the way food tastes	0.04	0.51	0.33	< 0.01**	0.44	0.08
Weight loss	0.44	0.56	0.11	0.22	N/A	N/A
Hair loss	0.70	0.27	0.38	< 0.01**	0.79	< 0.001***
Constipation	− 0.07	0.54	0.49	< 0.01**	0.57	0.12
Swelling of arms/legs	0.01	0.95	0.42	< 0.01**	1.00	< 0.05*
Don't look like myself	− 0.13	0.24	0.42	< 0.01**	N/A	N/A
Feeling sad	− 0.13	0.06	0.26	< 0.001***	N/A	N/A
Worrying	− 0.13	< 0.05*	0.32	< 0.01**	0.00	1.00
Feeling irritable	− 0.22	< 0.05*	0.58	< 0.01**	1.00	< 0.01**
Feeling nervous	− 0.13	0.17	0.42	< 0.01**	0.41	0.11

N/A = agreement above that expected when independence is zero. At least one variable in each two-way table upon which measures of association are computed is a constant

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$

that patients may be unwilling to discuss some physical symptoms because of their uncertainty that doctors will have an intervention, doubt about the efficacy of an intervention, unwillingness to take additional medications, or discomfort with "complaining" [30]. These concerns may also be related to the symptoms that patients expressed intention to discuss yet did not do so (feeling bloated, lack of energy, sexual interest, dry mouth, worrying, feeling drowsy, and itching).

The low level of concordance between presence of symptoms and intention to discuss them may be related to the degree of bother associated with symptoms. If participants experience a symptom but do not find it to be bothersome, they may not feel the need to discuss it. For bothersome symptoms, the higher levels of concordance between intention to discuss and actual discussion suggests that the more patients were bothered by their symptoms, the greater intention they had

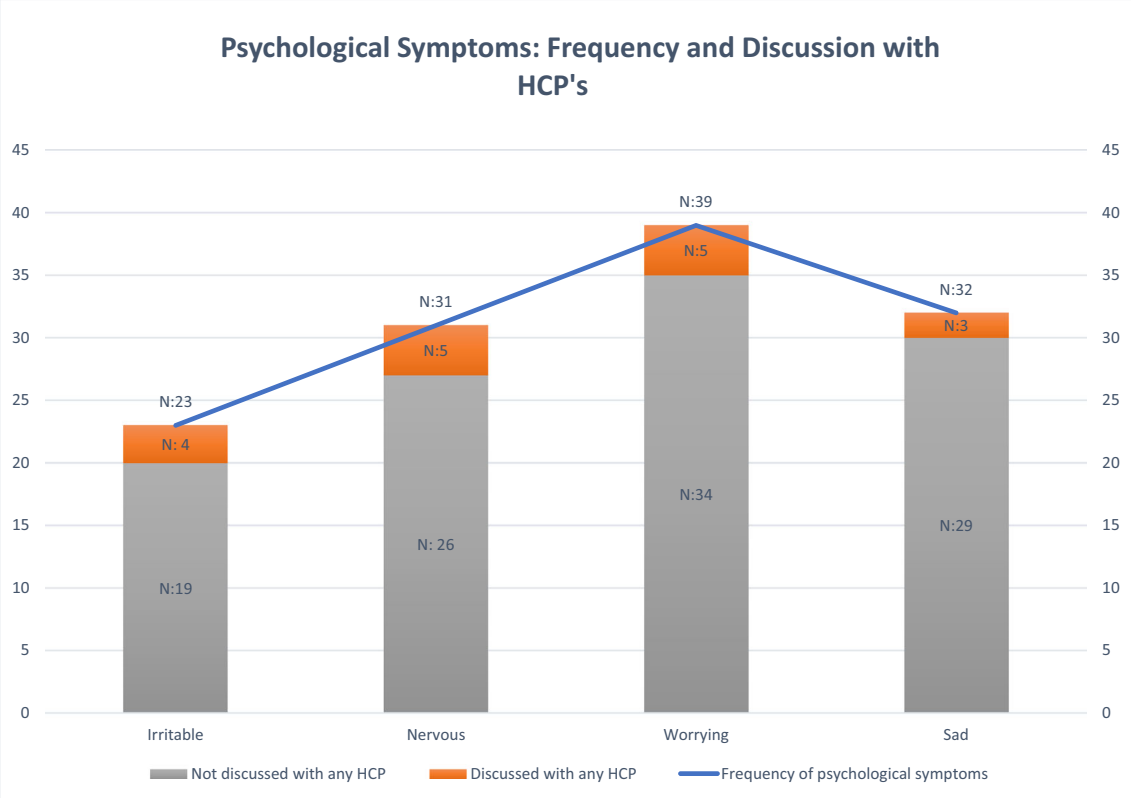

Fig. 1 Psychological symptoms: frequency and discussion with HCP's

to discuss them and the more likely they were to actually discuss them.

In this study, patients were least likely to intend to discuss psychological symptoms and sexual difficulties, even though psychological symptoms were among the most bothersome symptoms. These results support previous research indicating that patients tend not to communicate about psychological symptoms [31]; consequently, the psychological burdens of cancer often go unaddressed [15, 32]. For example, in a study about supportive care needs of patients with cancer, five of the ten most frequently endorsed unmet needs were in the psychological realm: fears about cancer spreading, fears about cancer returning, concerns about the worries of those close to them, uncertainty about the future, and concerns about the ability of loved ones to cope with caregiving [32]. Patients may elect not to report psychological symptoms because they believe doctors are not familiar with how to address psychological concerns or because they believe their doctors have a negative attitude toward emotional problems [31, 33].

A possible contributor to these results is social desirability bias. Social desirability response bias is a common tendency for people to present a favorable image of themselves by providing socially acceptable responses to questions [34, 35]. In this case, patients may believe that sexual and/or psychological problems are not directly related to their disease and thus not relevant in this setting [34]. Previous research has documented that cancer patients tend not to share their psychological problems with their doctors because they fear a negative reaction [31]. As for sexual symptoms, in a previous study of ovarian cancer patients, only 25% of physicians and 19% of nurses discussed psychosexual issues with their patients [36]. Perhaps patients are following the lead of their HCPs in terms of what is acceptable to discuss in the clinic setting.

This study has several limitations. First, it is a descriptive study based on a convenience sample and therefore the findings may not be generalizable. Second, the sample demographics were somewhat homogenous as the majority of the patients were female, white, and educated. As one of the clinics utilized was a breast cancer clinic, this biased the sample toward more females. Given the research suggesting that women are better reporters of symptoms than men [37–40], these results may underrepresent problems with communication about symptoms in the clinic setting. Third, these results are extracted from a self-report measure; therefore, data was subject to social desirability bias and other demand characteristics, which may affect the validity of the findings. Using a research assistant (rather than a member of the patient's medical team) to gather this data may have mitigated the social desirability effects. Fourth, asking patients about their symptoms and their intentions to discuss them prior to the clinic visit may have influenced what they discussed with their

HCPs, although it seems this would have biased the results toward higher concordance levels. Finally, while patients were interviewed immediately after the clinical encounter, we were unable to verify their report of whether or not symptoms were actually discussed in that encounter and did not ask who brought up specific symptoms (the patient or the HCP). Future research could include recordings of the clinical encounters in order to document who brought up specific symptoms and to verify whether they were discussed. It would also be helpful to gather qualitative data on patients' decision-making about symptom disclosure.

Conclusions

To our knowledge, this is one of the first descriptive studies to examine patients' perspectives on symptom bother, their intentions to discuss symptoms with their HCPs in medical oncology visits, and whether the discussion took place. The results draw attention to the phenomenon that cancer patients do not intend to discuss many of their symptoms in the clinic setting, and these discussions do not happen even when the symptoms are bothersome. Further investigation is necessary to explore why cancer patients do not share their symptoms, and qualitative studies may be helpful in identifying factors influencing these decisions. Particular attention may need to be paid to factors related to the discussion of psychological and sexual symptoms with HCPs as these conversations seem particularly difficult for patients. Facilitation of symptom reporting may need to come in the form of explicit permission from the medical team or perhaps through availability of different means of communicating about symptoms, such as electronic reporting. As symptom reporting is important for appropriate symptom management, which is related to patient well-being and overall quality of life, this is an important area for future research.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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