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Healthcare professionals' perspectives on the prevalence, barriers and management of psychosocial issues in cancer care: A mixed methods study

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TITLE

Healthcare professionals’ perspectives on the prevalence, barriers, and management of psychosocial issues in cancer care: a mixed methods study

ABSTRACT

This cross-sectional mixed-methods survey explores healthcare professionals’ perspective on their management of cancer patients’ psychosocial concerns, and barriers to integrate the psychosocial approach in their work. An invitation for participation was sent to 4965 inpatient and outpatient working professionals, of which 583 responded (12% response rate), and 368 fully completed the survey. The majority of respondents does not use a systematic approach to discuss patients’ psychosocial concerns, 37.5 per cent use the general question ’How are you?’, and 65.0 per cent spontaneously addresses various psychosocial aspects. Most psychosocial topics are ‘sometimes’ or ‘regularly’ discussed. Sexuality and return to work are rarely mentioned. About half of the respondents are convinced that they pay enough attention to the psychosocial well-being of cancer patients: by listening, engaging in a deeper conversation, providing advice, and through referral. Mostly patients are referred to a psychologist, a general practitioner, a social worker, a specialized nurse, or a centre for well-being and mental health. The barriers experienced, when providing psychosocial support, can be attributed to the patients, to themselves or other healthcare professionals, and to policy restrictions. These barriers should be addressed in order to enable healthcare professionals to improve the integration of the psychosocial approach in cancer care.

Keywords

Cancer care; psychosocial; multidisciplinary; healthcare professionals; survey

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INTRODUCTION

Although the survival rate of cancer has been increasing year after year, the diagnosis of cancer is still confronting for patients and their relatives. Cancer patients can experience physical, cognitive, emotional, relational, and social needs and problems. These can emerge — with a large individual variation — at each stage of the treatment process, and even after treatment completion (Boyes et al., 2012, Hisamura et al., 2018, Parry et al., 2012, Carlson et al., 2012, Schouten et al., 2016, Schouten et al., 2017, Willems et al., 2015). A wide variety of healthcare professionals (HCP) are involved. Oncologists, haematologists, and nurses are customarily involved throughout the inpatient and outpatient cancer care trajectory. In many countries, the general practitioner (GP) plays a key role in the outpatient field (Meiklejohn et al., 2016). Services from other paramedical and psychosocial disciplines are integrated to reduce patients' suffering, help patients adhere to prescribed treatments, and/or to support recovery and rehabilitation (Spence et al., 2010, Mishra et al., 2012, Korpan et al., 2011, Paccagnella et al., 2011, Lis et al., 2012, Humphris, 2008, Zebrack et al., 2008). Since cancer and related treatments have a bio-psycho-social impact (Wei et al., 2016), patients' experiences and needs can only be adequately addressed through 'Cancer Care for the Whole Patient' (Insitute Of Medicine, 2008). Hence, multidisciplinary cooperation between all these disciplines is essential to achieve an effective cancer care policy that matches with patients' experiences and care needs (Borras et al., 2014).

Over the past decade, national cancer plans have been launched to optimize cancer care, including the integration of the psychosocial approach (Grassi and Watson, 2012, Nationaal Kankerplan België, 2008). It is not the sole responsibility of psychosocial care professionals to reinforce this approach. Although psychologists and social workers are the psychosocial core disciplines involved in cancer care, all HCP involved in the care trajectory must be alert to psychosocial and other concerns to achieve comprehensive, patient-centred care. Providing a certain degree of spontaneous psychosocial support has proven to be valuable for patients (Schouten et al., 2017, Walker et al., 2003).

To optimize and further improve the integration of psychosocial aspects in cancer care, it is also important to hear the voice of the HCP involved. Therefore, the objective of this paper is to provide an understanding of HCP's perceptions of the extent to which different psychosocial topics are addressed in their contact with cancer patients, how they initiate discussions on these, and what types of care or support they provide for these issues. As well, their thoughts on potential barriers in the delivery of psychosocial care to cancer patients are described. This information can support policymakers in creating a context that enables the integration of a psychosocial approach for all HCP involved in cancer care.

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METHODS

Design, setting, and participants

To reach a large group of HCP a cross-sectional mixed-method survey study design was used, in which both quantitative and qualitative data were collected. For aspects for which for which prevalence's were explored we chose to work with closed-ended questions, resulting in quantitative data. To give participants the change to give their personal reflections or experiences on certain topics that could not be quantified we chose to work with open-ended questions, resulting in qualitative data.

The multidisciplinary sample of HCP was recruited in the inpatient and outpatient healthcare context in the north-east part of Belgium. An attempt was made to reach all HCP serving the regional population of cancer patients, and so an exhaustive approach in recruitment was used. Medical doctors, nurses, healthcare assistants, psychologists, social and spiritual workers, dieticians, pharmacists, physical, occupational, and lymphedema therapists were invited to participate (recruitment details in Supplementary file 1).

HCP working with cancer patients in the *inpatient* context were recruited from the five (medium to small) acute care hospitals in the region (all in urban area). Medical directors and heads of departments were contacted to obtain the permission to recruit participants from their hospital, and to plan the distribution of the survey.

HCP working in the *outpatient field* were recruited trough professional associations and discipline-specific networks. We obtained the cooperation of GP- and physical therapist circuits, home care and home nursing services, health insurance services and discipline-specific professional associations. Regional coordinators and chairpersons assisted in distributing the survey.

There were no restrictions regarding age, gender, professional discipline, duration of career or job time spent working with the cancer patient population, as these were all included as variables in the study.

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Material

Participants were queried on a wide range of psychosocial topics, with a subdivision based on the Cancer Rehabilitation Evaluation System (CARES) (Schag and Heinrich, 1990, Schouten et al., 2016) (Survey questionnaire in Supplementary file 2). Multiple choice (MPC), matrix table (MT), and open-ended (OE) questions were used to collect data on the following five topics:

1. Socio-demographic and professional characteristics $^{\text{MPC, OE}}$;
2. Prevalence of psychosocial topics addressed in contacts with cancer patients $^{\text{MT}}$;
3. Care offered to cancer patients in case of psychosocial problems $^{\text{MT}}$;
4. Referral policy for psychosocial problems $^{\text{MT}}$;
5. Potential barriers experienced in the delivery of psychosocial care or support for cancer patients $^{\text{MPC, OE}}$.

The questionnaire was pilot-tested in a group of 10 HCP from eight disciplines. Based on their feedback, adjustments and linguistic refinements were made.

Procedure

All HCP received the same e-mail explaining the study objective, information on the informed consent procedure, and a Qualtrics-weblink to complete the survey. A time frame of 14 days was provided to complete the survey. Participants were actively recruited in October and November 2016. In early December, a reminder was sent with a request for non-responders to indicate why they chose not to participate. No further incentives were used. The online survey was closed at the end of December 2017.

Data-analysis

Only data of fully completed surveys were used for analysis; In this way the obtained insights on all explored aspects were based on the same sample. In this sample there were no missing data, since we worked with an answer obligation to get to the next question in Qualtrics.

Descriptive statistics were used to summarize participant characteristics. Frequencies and percentages were computed for participants' responses to MPC and MT questions on 'Prevalence and addressing of psychosocial topics in patient-professional contact', 'Psychosocial support or care provided', and 'Referral policy'. We planned to perform subgroup analysis based on the several disciplines of HCP if subgroups were large enough to come to meaningful analyses.

Data from two open-answer questions on 'personal or general shortcomings or barriers in the provision of psychosocial care or support' was subjected to thematic analysis (Braun and Clarke, 2006). Several main themes and subthemes derived from the analysis of participants' answers in this analysis, and participants' quotes were coded accordingly in NVivo (Table 3 in results section). Findings were not checked with participants afterwards.

We applied the STROBE (for observational quantitative studies) (Tong, Sainsbury and Craig, 2007) and COREQ (for qualitative studies) (von Elm et al., 2007) guidelines for reporting as far as applicable to this study.

Ethical considerations

Participants were informed that the collected information would be kept confidential and that the questionnaire was anonymous. There were no incentives provided for completing the questionnaire. A full proposal outlining all study methods and stages was reviewed by the Medical Ethics Committee of Hasselt University and the ethical committees of all participating hospitals (Jessaziekenhuis, Ziekenhuis Oost-Limburg, Sint-Fransiscus ziekenhuis, Regionaal ziekenhuis Sint-Trudo, Mariaziekenhuis Noord-Limburg), who granted permission for the study to proceed (ref. CME2015/633).

RESULTS

Participants

The invitation for participation was sent to 4965 HCP (608 inpatient, and 4357 outpatient), of which 583 responded (12% response rate), and 368 surveys were fully completed.

Only 35 of the invited HCP provided a reason for not participating in the study: 'no interest in participating' (8.6%); 'lack of time' (22.9%); 'not applicable to me, since I never or rarely work with cancer patients' (54.3%); another not specified reason (14.3%).

The mean age in the sample was 43 years (sd = 11.51, range 21-81), the mean years of professional experience was 18 years (sd 11.39, <1-47), and 23.9 percent of the participants was male. Further information on socio-demographic and professional characteristics is displayed in Table 1.

QUANTITATIVE DATA

Prevalence and addressing of psychosocial topics in patient-professional contact

The majority of HCP indicated that most of the psychosocial topics were '*sometimes*' or '*often*' addressed in contact with cancer patients (Figure 1). There were three topics that

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deviated from this tendency. Thoughts about the disease, treatment, and recovery were more frequently discussed with patients. In contrast, sexuality, and resumption of work were clearly less often discussed. Similar response tendencies were found when comparing the answers from HCP providing inpatient and outpatient care.

A minority of the participants (1.9%) use a systematic approach to address psychosocial concerns: checklists to assess patients' well-being (n=5) and patient-reported outcome tools (n=2) are used. The vast majority of HCP do not use a systematic approach. A minority (2.7%) believe that addressing psychosocial issues is not part of their job; 37.5% percent use the general question *'How are you?',* so patients can bring up any psychosocial problems themselves if desired; 56.0% percent spontaneously address various psychosocial aspects when exploring cancer patients' well-being.

Psychosocial support or care provided

Half of the HCP (51.9%) believe he or she *'usually'* provides enough attention to the psychosocial needs of cancer patients. Nine percent indicated they '*always*' do so, 29.6 percent '*sometimes*'. A small portion of the HCP (9%) reported '*never*' giving sufficient attention to the psychosocial needs of patients.

The three most prevalent types of care and support offered are: listening (38.5%), a more in-depth conversation or advice (29.4%), and referral (19.3%). The use of brochures (written information) in response to psychosocial concerns or problems is limited (4.0%). Other care or support actions — as questioned — are used even less. A similar response tendency was found when comparing the answers from HCP in inpatient and outpatient care. Further details are displayed in Supplementary file 3.

Referral policy

Tables with quantitative referral details for all psychosocial topics are listed in Supplementary file 4, the main findings are discussed below and displayed in Table 2.

Referral towards inpatient HCP or services

In the inpatient field, patients are most frequently referred to a hospital-based psychologist (20.7%), social worker (17.4%), or specialized nurse (10.8%). The options '*Inpatient referral is not applicable to me'* (18.0%) and '*I do not refer, I provide care or support for this aspect myself*' (9.0%) complete the top five.

Referral to outpatient HCP or services

In the outpatient field, patients expressing psychosocial concerns or problems are mostly referred to the GP (18.3%), psychologist (14.5%), or centres for well-being and mental health (12.6%). The options to '*I do not refer, I provide care or support for this aspect myself*' (11.2%) and 'O*utpatient referral is not applicable to me*' (11.0%) complete the top five.

The referral frequencies of the outpatient and inpatient subgroup contributing to this general tendency are displayed in Supplementary file 2..

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QUALITATIVE DATA

Shortcomings or barriers in the provision of psychosocial support or care

The open-ended questions show that 51.4% of the sample experience shortcomings and barriers in the provision of psychosocial care or support to cancer patients. Thematic analysis revealed that some barriers are specific to the HCP, others can be attributed to the healthcare system, or are situated at the patient-level. The main themes and subthemes that resulted from the thematic analysis are displayed as headings and subheadings in Table 3 with participants' example quotes, and presented in italic font in the discussion below.

Barriers at the patient-level

Sometimes patients have *no need* for extra help and manage themselves or with support from their context, others are in denial and *do not accept* psychosocial or supportive care.

Healthcare professionals' shortcomings

HCP often experience a *lack of opportunity to discuss psychosocial aspects* with their patients. Limited contact, lack of privacy, and lack of time and workload play a major role in this.

Participants expressed feeling *having insufficient knowledge or education* to effectively meet the psychosocial needs of cancer patients. Medical, oncological, and psychological knowledge is mentioned, as well as knowledge of emotional, financial, palliative aspects, and return to work.

Consequently, participants think that *more HCP with the appropriate education and training* are needed to optimally support cancer patients in the care process.

Problems with communication are frequently mentioned as a barrier for good supportive care provision. Sometimes patients are not consulted and informed enough by HCP about the diagnosis, implications of treatment or prognosis. HCP themselves also experience poor information transfer, limited multidisciplinary and transmural consultation and cooperation.

HCP experience several *barriers in the referral for psychosocial or supportive care*. Referral is complicated by a limited awareness of referral options. Hence, patients often receive insufficient information regarding the available care or support options. When a referral to psychosocial services is made, there are long waiting times before patients receive actual care. Some HCP felt that their own psychosocial or paramedical care offer is not recognized and valued by other HCP, resulting in limited referral of patients.

Some participants experience *their own emotional vulnerability* as a difficulty. As cancer patients are often supported by HCP over several years, there can be a strong inter-human relationship. The feeling of impotency is also mentioned, as well as the fear that one can never fulfil the expectations related to psychosocial concerns.

A *lack of empathy* for the patients' situation is experienced by some HCP, who believe they could provide better psychosocial support had they had a personal experience with cancer.

Barriers in the healthcare system

Participants indicate that the healthcare *financing system* is mainly based on a 'fee for service system', and the time available for patients is sometimes limited. *There is no funding for*

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certain psychosocial care aspects, so *patients need to pay for it themselves*. It is conceivable that this has an impact on the accessibility of the care needed.

In several areas, *the psychosocial or supportive care offer is experienced as limited or unclear*. To HCP, there seems to be no general systematic approach in cancer care for topics like emotional and sexual functioning, pain relief, social, financial, spiritual issues, rehabilitation, and return to work. Participants experience a limited access, availability or continuity in psychosocial or supportive care across the different phases in the care process. Sometimes the opposite is experienced: an oversupply and competition in supportive care options offered by several disciplines or patient advocacy organisations.

HCP mention several *shortcomings in routine support and follow-up of patients*. There is too little attention for home support, information on financial consequences and reimbursements, contact with buddies, and support for patients' relatives and minor children. Some participants speak of the need for a permanent care coordinator, who patients, but also the different HCP involved, can address in case of questions, discussion and organization of care.

The *paperwork* that needs to be done when supportive care is applied for is often perceived as burdensome and time-consuming, both for patients and for HCP.

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DISCUSSION

In this study, a multidisciplinary group of HCP was surveyed regarding their perspective on the prevalence of psychosocial issues in patient-HCP interactions, the types of care they provide themselves, their referral policy, and potential barriers in the delivery of psychosocial care.

According to respondents, a variety of psychosocial topics is addressed in HCP-patient contacts. This is done rather spontaneously and not according to a systematic approach. However, without a systematic approach, attention for, and detection of patients' psychosocial problems will vary (Arora, 2003). Previous studies have demonstrated that HCP do not always make a good estimate of patients' psychosocial distress or needs (Mitchell et al., 2011). Patients on their part, often wait for the HCP's initiative to discuss certain topics (Taylor et al., 2011). We found that sexuality and return to work issues are rarely covered. Other studies suggest that sexuality issues are discussed less because of taboo or feelings of shame related to the topic (Vermeer et al., 2016). Return to work issues are less prominent during the active treatment phase, yet become an important issue later in the phase of cancer survivorship (Stergiou-Kita et al., 2014).

The majority of respondents (67.9%) provide spontaneous psychosocial support to cancer patients by listening, engaging in a more in-depth conversation, or giving advice. Further they refer mainly to psychologists, social workers, specialized nurses, centres for well-being and mental health, and the GP. In this study, as well as in other studies, the GP is perceived as a central figure in primary care — with an important role in the follow-up of cancer care (Meiklejohn et al., 2016). A considerable proportion of the HCP working in the inpatient field have indicated that referral to outpatient care options was not applicable for them. The same idea exists amongst in the outpatient field working HCP regarding inpatient referral. In other words, participating HCP do not seem to be inclined to do transmural referrals.

Our findings regarding experienced barriers are in line with other studies. Lack of time and resources, inadequate interdisciplinary communication and cooperation, limited knowledge of and familiarity with psychosocial well-being and care options were found to be barriers for

HCP to integrate the psychosocial approach in routine care (Fagerlind et al., 2013, Dilworth et al., 2014, Wei et al., 2017). As found in the study of Travado et al. (Travado et al., 2015), HCP feel that the existing financing system of cancer care, and the (lack of) coordination in the psychosocial approach induce thresholds. Nurses could, for example, have a more explicit role in detecting, working with, and referring for psychosocial needs of cancer patients, integrated in a multidisciplinary team approach (Ercolano, 2017). However, for this the task allocation and inter-disciplinary attunement need to be discussed. The challenges integrating the psychosocial approach are not specific to cancer care, these could partly be explained by the fragmentation in primary care and limited transdisciplinary communication and collaboration (Vannieuwenborg et al., 2015).

This study had some limitations. Firstly, the response rate (12%) was low. In an attempt to obtain a representative sample and avoid selection bias, we tried to recruit all HCP serving the population of cancer patients to a greater or lesser extent. After all, each HCP is a care provider and potential referrer for these patients. Recruitment was especially difficult in the outpatient field because of the fragmentation that characterizes primary care, and the lack of visibility regarding specializations. Our exhaustive approach in recruitment probably led to the invitation of HCP for whom our study topic was not relevant, since they rarely or never work with cancer patients. This presumption is confirmed as 54.3% of the non-responders, of whom we have information, indicated not participating for this reason. Secondly, as most surveys, our survey has the potential for selection bias. We used an exhaustive approach to prevent bias in recruitment, however self-selection bias cannot be prevented. HCP who have more affinity with the psychosocial topic could have been more inclined to participate in this survey (Podsakoff et al., 2003). Thirdly, we planned to do a subgroup analysis to detect potential differences between different disciplines of HCP. However, due to the limited response rate subgroups were judged to be not large enough to perform meaningful subgroup analyses. Fourthly, findings from the survey were not discussed with participants afterwards. However, after completion of this study a larger survey was conducted commissioned by the Flemish Minister for Health, Welfare and Family, and the resulting insights were similar to the ones obtained in the current study (Daly 2017).

In conclusion, listening to the voice of HCP is needed to further improve care for cancer patients. A variety of psychosocial topics are discusses during patient - HCP interactions, and often care is given in line with the patient’s needs. However, half the HCP believe that not enough attention is paid to the psychosocial needs of cancer patients — for some leading to feelings of impotency. The main barriers in providing psychosocial support to cancer patients are: limited knowledge in order to optimally support the patient in coping with their experiences, inadequate (interdisciplinary) communication and collaboration, and a lack of time and resources to integrate the psychosocial approach in routine inpatient and outpatient care. The psychosocial approach in cancer care seems to depend more on the individual approach of HCP than on the healthcare system. As a result of the financing system, the accessibility of specific psychosocial care aspects could be under pressure. Explicit detection of psychosocial needs is missing and the response to those needs, from a team perspective and an integrated approach, is not yet common practice. A more explicit approach of psychosocial needs for cancer patients can also provide important insights for training, continuing education and support of the involved HCP.

CONFLICTS OF INTEREST

Authors declare to have no conflicts of interest.

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ABBREVIATIONS

CARES: Cancer Rehabilitation Evaluation System

GP: General practitioner

HCP: Healthcare professional(s)

MPC: multiple choice

MT: matrix table

OE: open-ended

PRO: Patient Reported Outcome

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TABLES

TABLE 1. Socio-demographic and professional characteristics sample.

	Participants (N=368)	
Characteristics	n	%
Professional context		
Inpatient	124	33.7
Outpatient	219	59.5
Both inpatient and outpatient	25	6.8
Timing of HCP involvement in the care trajectory		
In the diagnostic phase	196	53.3
Between diagnosis and start of treatment	227	61.7
During intensive treatment (S, CT, RT,…)	277	75.3
During follow-up or maintenance	273	74.2
Inpatient professional discipline		
Medical doctor specialised in cancer treatment	7	1.9
Medical doctor with other specialty	13	3.5
Nurse	66	17.9
Nurse specialist	15	4.1
Healthcare assistant	1	0.3
Psychologist	16	4.3
Social worker	8	2.2
Pastoral worker	3	0.8
Dietician	7	1.9
Physical therapist	4	1.1
Lymphedema therapist	3	0.8
Occupational therapist	4	1.1
Other	4	1.1
Outpatient professional discipline		
General practitioner	41	11.1
Medical doctor with other specialty	1	0.3
Home nurse	76	20.7
Healthcare assistant	40	10.9
Psychologist	7	1.9
Dietician	3	0.8
Physical therapist	27	7.3
Occupational therapist	3	0.8
Lymphedema therapist	7	1.9
Pharmacist	2	0.5
Health insurance service (social work,…)	23	6.3
Centre for social welfare (social work,…)	8	2.2
Other	6	1.6

Abbreviations: N number of participants, S Surgery, CT chemotherapy, RT radiotherapy.

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TABLE 2. Referral of intra- and outpatient healthcare professionals for several psychosocial issues.

Referrals to inpatient HCP or service[a]			**Referrals to outpatient HCP or service**[a]		
	By Int. HCP[b]	**By Ext. HCP**[c]		**By Int. HCP**[b]	**By Ext. HCP**[c]
	n (rank)	n (rank)		n (rank)	n (rank)
MD cancer treatment	142 (7th)	136 (6th)	General practitioner	361 (1st)	599 (1st)
MD other specialty	48 (8th)	24 (12th)	MD with other specialty	22 (12th)	45 (11th)
Nurse	180 (6th)	101 (8th)	Home nurse	144 (7th)	198 (8th)
Specialist nurse	350 (3rd)	200 (5th)	Physical therapist	16 (13th)	45 (11th)
Psychologist	648 (1st)	418 (2nd)	Lymphedema therapist	-	5 (13th)
Social worker	494 (2nd)	394 (3rd)	Dietician	-	6 (14th)
Pastoral worker	234 (4th)	118 (7th)	Psychologist	280 (3rd)	473 (4th)
Dietician	21 (11th)	21 (13th)	Pharmacist	29 (11th)	11 (12th)
Physical therapist	16 (12th)	32 (11th)	Centre for well-being and MH	190 (4th)	498 (2nd)
Lymphedema therapist	3 (14th)	3 (14th)	Medical insurance service	171 (5th)	271 (6th)
			Centre for social welfare	147 (6th)	258 (7th)
Other discipline	26 (10th)	62 (10th)	Other discipline	57 (9th)	180 (9th)
No referral, own care offer	195 (5th)	271 (4th)	No referral, own care offer	124 (8th)	487 (3rd)
Not applicable for me to refer	40 (9th)	914 (1st)	Not applicable for me to refer	289 (2nd)	297 (5th)
No referral, issue not a point of attention for my discipline	10 (13th)	90 (9th)	No referral, issue not a point of attention for my discipline	51 (10th)	103 (10th)

Abbreviations: HCP healthcare professional; Int. inpatient, Ext. outpatient; MD medical doctor; MH mental health.

[a] The order of the HCP in this table corresponds to the sequence of the multiple choice options in the survey.

[b] For inpatient HCP: N = 124.

[c] For outpatient HCP: N = 219.

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TABLE 3. Themes resulting from the thematic analysis and example quotes - Barriers in the provision of psychosocial care or support to cancer patients

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Barriers specific to patients

Absence of needs

“Not all patients are in need for support.”

Denial

“Often there are psychologic barriers in patients.”

“Sometimes it is difficult to have a deeper conversation with the patient or the partner due to denial of the problem.”

Healthcare professionals’ shortcomings

Lack of opportunity to discuss psychosocial aspects

“Not enough time, too much workload, not enough experience… it's not pleasant to start a conversation with a patient and then after 2 minutes you have to interrupt the conversation to react on the call of another patient.”

Having insufficient knowledge or education

“Help for emotional pain, coping with the diagnosis...often I don’t know how to help patients with this.”

Problems with communication

“Patients are insufficiently informed about their disease and prognosis. For poor prognosis, sometimes the ‘truth-communication’ is inadequate.”

“Sometimes I don’t get enough information on the patient’s situation: mostly only the referral for the physical aspect without information on the psychosocial well-being”

Barriers in the referral for psychosocial or supportive care

“Ignorance about offered services that would be useful for a patient to be referred to”

“Sometimes referral does not go smoothly, or there is a waiting time, which can be very stressful for people”

Their own emotional vulnerability

"The feeling sometimes to be powerless in situations…that you cannot do enough for clients."

Lack of empathy

“It is difficult to understand patients’ needs. Only when you are confronted with it yourself you can better indulge yourself in the thoughts and experience of the patient”

Barriers in the healthcare system

Financing system

“There is no opportunity for me as a doctor to take sufficient time .... in fact I do most of the work (in time ...) for free, in between…and this with the following consideration: although without financial compensation, there is a lot of gratitude from patients for the time that I spend on it.”

“Often I want to refer to a psychologist, but patients have to pay the full costs themselves”

The psychosocial or supportive care offer is experienced as limited or unclear

“There is a lack of understanding by the National Health Service concerning the resumption of work, the psychological burden of the disease is often underestimated.“

“There is sufficient psychological support during admission for surgery in the hospital (nursing, psychologist, social worker, breast nurse) but too little follow-up post-surgery, usually this is done at the request of the patient and not systematically.”

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Shortcomings in routine support and follow-up of patients

" Concerning the financial aspect…often people don't know where they stand and what they can do. Also concerning care and support people usually don't know what the possibilities are and where they can request it."

"Care for minor children of cancer patients seems insufficiently structurally embedded to me. And aftercare, after the death of the parent. I think there is too little attention for this ..."

Paperwork

"All the hassle of paperwork that long or serious illness entails."

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FIGURES

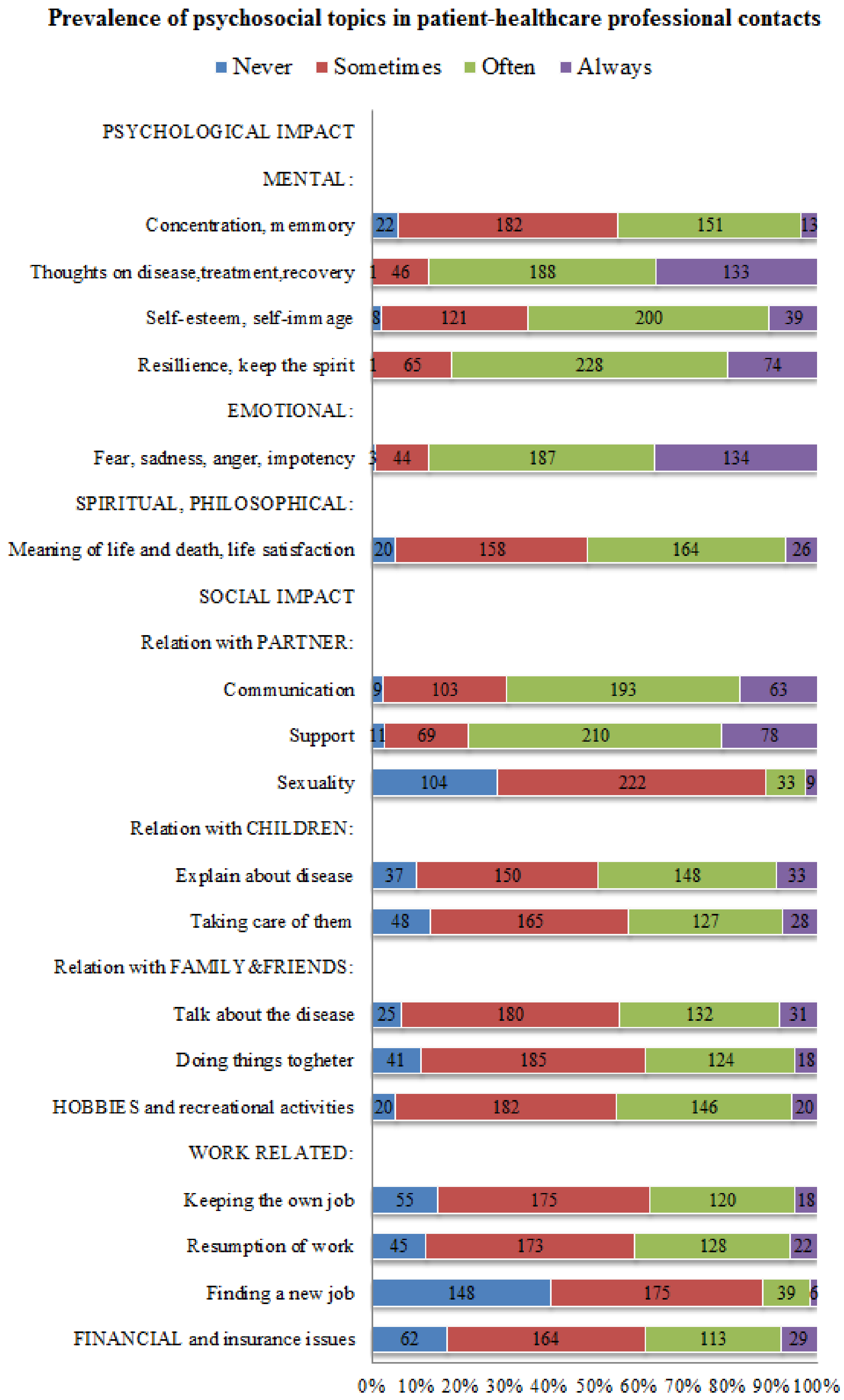

Figure 1 Prevalence of psychosocial topics in patient-healthcare professional contacts.

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