

What is the best time for psychosocial counselling from the perspective of cancer patients and their relatives?

A multi-centre qualitative study

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Abstract

Purpose: The aim of this study was to identify at what time patients with cancer and their relatives want to be informed about and receive psychosocial counselling.

Methods: In a multi-centre prospective study, both users and non-users of psychosocial cancer counselling were asked to participate in a qualitative interview about their preferences for psychosocial counselling. A second interview was scheduled 3–6 months thereafter. Interviews were transcribed verbatim and coded according to content analysis.

Results: Altogether, 61 patients and 42 relatives participated, resulting in 183 interviews (103 at t1, 80 at t2). Most often, the optimal time-point for cancer counselling was defined by the participants according to the treatment trajectory, and the most frequently mentioned preferred time-point was 'as early as possible': at the time of cancer diagnosis (mentioned in 22% of interviews with men and 10% of interviews with women). In particular, men also said that they wanted psychosocial counselling while waiting for test results (5%), at the point of returning to work and/or when under the threat of unemployment (3%). Women especially preferred this support during therapy (4%) and 'when one has the capacity for it' (4%), in terms of time and emotional capacity.

Conclusions: Healthcare providers should inform their cancer patients and the relatives about the possibilities of professional psychosocial support early on in the disease trajectory (i.e. at the time of diagnosis) and repeatedly thereafter, especially in times of uncertainty, while ensuring the patients' capacity to process information at each time-point is taken into consideration.

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KEYWORDS

counselling, gender, help-seeking, optimal time-point, preferences, timing

1 | INTRODUCTION

A cancer diagnosis usually evokes intense emotions such as fear, rage and desperation (Holland, 1989). In addition to the stress of receiving the bad news and being confronted with a potentially life-threatening disease, the often heavy treatment and potentially severe adverse events and long-lasting side effects present a challenge to which patients and their relatives have to adjust emotionally and socially. Fear of cancer recurrence, depression, sadness about changed (or lost) body functions, financial problems, feelings of utter helplessness and loss of control are common problems (Li & Cheng, 2021; Schwarz et al., 2008) not only in patients but also in relatives (Meyer et al., 2013; Pitceathly & Maguire, 2003).

A variety of psychosocial interventions have been shown to effectively support those dealing with these challenging situations (Faller et al., 2013). There are, for example, counselling, peer-led support or psychotherapy. It appears that these interventions help the patients to come to terms with cancer and to regain a sense of control in their lives by working through powerful thoughts and feelings, problem-solving and experiencing a helpful therapeutic relationship (Boulton et al., 2001; Krenz et al., 2014; Morgan & Cooper, 2015; Schwarz, 2013).

Because of the strong evidence showing the positive effects of psychosocial interventions in cancer patients, it is now standard in many countries to routinely screen all patients for increased levels of distress and to offer support to all in need, often with a stepped care approach (Grassi et al., 2012; Singer et al., 2017; Weis et al., 2014). About 9%–29% of patients make use of these services (Duggan et al., 2019; Faller et al., 2017; Kaidar-Person et al., 2017; Zeissig, Singer, Koch, Blettner, et al., 2015), although these numbers clearly differ according to healthcare system and according to the definition of 'professional psychosocial services'. The use of consultations by a psychotherapist, for example, was 11% in a German study (Singer et al., 2013) and 13% in an Australian study (Duggan et al., 2019). About 3%–9% use cancer counselling centres in Germany (Schulz et al., 2018; Singer et al., 2011, 2012; Zeissig, Singer, Koch, Blettner, et al., 2015). In the outpatient setting, there is a striking difference in usage between the sexes, where men are underrepresented with a sex ratio of about 1:3 (Curry et al., 2002; Faller et al., 2017; Salm et al., 2021; Zeissig, Singer, Koch, Zeeb, et al., 2015).

A clinically relevant question remains as to what type of interventions the patients themselves prefer, from whom, and at what time-point during the disease trajectory—and whether this differs between the sexes. Knowing this would enable healthcare planners to optimise mental health care for cancer patients, survivors and relatives. There seems to be an overall preference for individually oriented approaches and for 'speaking over medication' (Schweer et al., 2011). For example, cancer survivors in the United States said

Implications for Practice and Policy

- Healthcare systems should ensure the possibility of continuity of mental healthcare relationships over the course of the cancer disease, so that patients can keep the same counsellor if this is preferred by them. Patients should not require one 'inpatient counsellor' and one 'outpatient counsellor' unless they wish exactly that.
- An implication for healthcare providers both in hospitals and in private practices is that they should inform their cancer patients and their relatives about the possibilities of professional psychosocial support early on in the disease trajectory (i.e. at the time of diagnosis) and repeatedly thereafter, especially before discharge from hospital (when patients lose this structured environment and go back home), when patients return to work and when the disease progresses. Whether or not they take up this offer and make use of the services is then their own decision, but they should have the opportunity to decide.

they prefer individual professional counselling compared to all other forms of psychological interventions (Arch et al., 2018). Medication was the least preferred intervention but prescribed most often in that study. Similarly, Reece et al. found that women with breast cancer prefer counselling alone over counselling plus medication and over medication alone for the treatment of depression symptoms (Reece et al., 2013). About half of all cancer patients express an intention to use professional psychosocial support (Langbecker & Yates, 2016; Nakata et al., 2020; Tondorf et al., 2018). Most of them prefer support from their oncologist or nurse, followed by a social worker or psychologist, but rarely from chaplains (Buchhold et al., 2018; Singer et al., 2009).

Very little is known, however, about patient preferences regarding the optimal timing of psychosocial counselling, despite the clinical importance of this question. What we know is that emotional distress is especially high at the time of the cancer diagnosis and at the time of disease progression (Schwarz et al., 2008; Singer et al., 2007; Stafford et al., 2015). However, this does not automatically imply that patients prefer to receive support at these times. Given the limited resources available, we must strive to offer our support to patients at the times when they are most in need of it and/or can make most use of it. This study therefore aimed to examine the preferences of cancer patients and their relatives in terms of the optimal timing of psychosocial services. We paid special attention to gender-sensitive issues in this regard (Bayer et al., 2020).

2 | METHODS

2.1 | Study design

We performed a prospective study with qualitative interviews in two cities in Germany, Mainz (Rhineland-Palatinate) and Tübingen (Baden-Württemberg). In each of the cities, there are both a university hospital and a dedicated cancer counselling centre. We contacted cancer patients and relatives of cancer patients at these four sites by displaying flyers in waiting rooms and approaching them through physicians who acted as trusted gatekeepers, asking them to participate in the study. We enrolled *users* of cancer counselling at the counselling centres, whereas *non-users* were enrolled at the hospitals. *Users* were defined as having visited a cancer counselling centre at least once, while 'visits' could be either in person (face to face) or via telephone. *Non-users* were individuals who had never used any form of counselling at a cancer counselling centre as of the time of the interview. Both users and non-users could be either patients or relatives.

Inclusion criteria were as follows: age >18 years and a histologically confirmed diagnosis of cancer (or having a relative with cancer). Exclusion criteria were as follows: no written informed consent and no elevated level of distress. This latter criterion was evaluated by handing out the distress thermometer (Roth et al., 1998) and the Hornheider Screening Instrument (Strittmatter, 1997). If individuals scored above the thresholds of either of these instruments, they were considered as having elevated levels of distress and therefore potentially in need of psychosocial counselling.

Eligible and consenting individuals were interviewed in a qualitative interview by trained researchers. The first interview (t1) was conducted at the beginning of the counselling process in users and during the first year after cancer diagnosis in non-users. After three to six months thereafter, they were interviewed once more by the same interviewer using different questions (t2).

2.2 | Sampling

Study participants were consecutively enrolled according to a sampling matrix to ensure all target groups were represented in our sample: men and women, users and non-users of cancer counselling, patients and relatives. In each cell of this matrix, we aimed to have 5–20 individuals.

2.3 | Data collection

Participants were interviewed face to face, either in the hospital or in the cancer counselling centre. In a few cases, the t2 interview was performed at the participant's home or via telephone. The participants were informed about the professional background of the interviewer, the procedures of data protection, their data access rights and about the aim of the study.

Interviews were audio-taped unless the participant preferred to have written notes instead. The questions in the interview differed slightly between users and non-users. The question regarding optimal time-points in the group of users was 'Irrespective of your current counselling—what would be the most suitable time-point for your counselling?', and in the group of non-users, it was 'If you were to use cancer counselling, what would be a suitable time-point for you?'. We did not specify who would provide the counselling because, in Germany, psychosocial cancer counselling is provided by members of different professions, for example psychologists, social workers, psychotherapists or physicians. However, it was clear from the context of the interview that we were not asking about non-professional support such as from friends or family, or about basic emotional support from the attending physician or nurse, but rather about specific psychosocial services.

There were also other questions regarding the use and non-use of psychosocial services, which are not the focus of this paper. If a participant mentioned preferences regarding the timing of services during other parts of the interview, this information was also used for this analysis.

2.4 | Analysis

All recorded interviews were transcribed verbatim using f4transkript software (dr. dresing & pehl GmbH, Marburg, Germany). The transcripts were then transferred into the software MAXQDA (VERBI GmbH, Berlin, Germany) and coded using Mayring's content analysis (Mayring, 2015). Two independent researchers read each transcript, identified text segments relevant to the research question and coded it according to a code system, which was iteratively developed and finalised after three quarters of all interviews were encoded. The code system (Table 3) consisted of five levels. First-level codes (i.e. the top level) were developed deductively, the remaining levels inductively.

2.5 | Research team

The interviews were conducted by several individuals: OB is male, a nurse and epidemiologist, and, at the time of the study, employed at the University Medical Centre in Mainz. MH is female with a degree in public health and was, at the time of the study, also employed at the University Medical Centre in Mainz. PR is a female psychologist and, at the time of the study, employed at the Cancer Counselling Centre in Tübingen. FB is male and, at the time of the study, he was a medical student at the University Medical Centre in Mainz. None of the interviewers was involved in the psychosocial care of the study participants.

OB and MH chaired the analysis process. They were supported by FB and PR plus additional people: EK is female and, at the time of the study, a student of educational science. LD is female and, at the time of the study, she studied sociology. Access to patients at the

Mainz University Hospital was enabled by JA and GH, both male and consultants in haematology.

The study was conceptualised and supervised by SS, a female psychologist, psychotherapist and epidemiologist, employed at the University Medical Centre Mainz, and by MW, a male psychologist and former head of the Cancer Counselling Centre in Tübingen.

3 | RESULTS

3.1 | Sample characteristics

We enrolled 118 eligible individuals, and 103 of them participated. Reasons for non-participation were mainly organisational issues ($n = 7$), no interest ($n = 3$), feeling too distressed ($n = 4$) and insufficient language skills ($n = 1$).

Of the participants, 54% were male, 55% were users of cancer counselling centres, and 59% were cancer patients (Table 1). The median age was 56 years (range: 22–84 years). Non-participants were, on average, nine years older than participants, and there were no other socio-demographic differences. Users of cancer counselling centres had, on average, a higher educational degree than non-users.

At t2, 80 (78%) subjects participated a second time (Table 2).

3.2 | Interview material

Altogether, 183 interviews were performed. The total duration of the audio material is 41 hr. The shortest interview took 2 min, the longest 56 min.

On the request of the participants, 14% of the interviews were not audio-taped, and only written notes were taken by the interviewer while listening to the participant.

TABLE 1 Sample characteristics

	Men $n = 51$ $N (%)$	Women $n = 52$ $N (%)$	Total $n = 103$ $N (%)$
Patient or relative			
Cancer patient	33 (65%)	28 (54%)	61 (59%)
Relative of a cancer patient	18 (35%)	24 (46%)	42 (41%)
Age at interview (in years)			
Median [range]	56 [25–84]	57 [22–78]	56 [22–84]
Cancer site ^{a,b}			
Respiratory system	8 (16%)	7 (13%)	15 (15%)
Central nervous system or eye	3 (6%)	5 (10%)	8 (8%)
Intestinal tract	4 (8%)	6 (12%)	10 (10%)
Gynaecological tumours	4 (8%)	14 (27%)	18 (17%)
Male genital tumours	4 (8%)	0 (0%)	4 (4%)
Urinary tract	5 (10%)	0 (0%)	5 (5%)
Haematological malignancies	13 (25%)	11 (21%)	24 (23%)
Skin	1 (2%)	2 (4%)	3 (3%)
Head and neck	4 (8%)	2 (4%)	6 (6%)
Other	5 (10%)	5 (10%)	10 (10%)
Educational level			
≤Compulsory school	15 (29%)	17 (33%)	32 (31%)
Post compulsory school, below university level	10 (20%)	13 (25%)	23 (22%)
University level	23 (45%)	21 (40%)	44 (43%)
Unknown	3 (6%)	1 (2%)	4 (4%)
Time since first diagnosis (in years)			
Mean, SD (standard deviation)	1.9 (4.5)	3.4 (5.9)	2.7 (5.3)

^aMultiple entries possible.

^bIn relatives: refers to disease of the cancer patient.

	Non-users of counselling				Users of counselling				Total
	Patients		Relatives		Patients		Relatives		
	Men	Women	Men	Women	Men	Women	Men	Women	
t1	13	12	12	9	20	16	6	15	103
t2	7	9	9	7	15	16	4	13	80

Note: t1 = Baseline, t2 = 3–6 months later.

TABLE 2 Number of interviews per time-point and group

TABLE 3 Suitable and unsuitable time-points for cancer counselling from the perspective of cancer patients and relatives, stratified by gender

Level 2	Level 3	Level 4	Interviews with men n = 86 N (%)	Interviews with women n = 97 N (%)
Suitable time-points	Treatment associated time-points	Diagnosis/beginning	19 (22%)	10 (10%)
		Waiting for test results	4 (5%)	1 (1%)
		Therapy	1 (1%)	4 (4%)
		During inpatient rehabilitation	1 (1%)	0 (0%)
		After inpatient rehabilitation	1 (1%)	3 (3%)
		Aftercare/before follow-up tests	2 (2%)	1 (1%)
		Dying/death	1 (1%)	4 (4%)
	Work related time-points	Threat of unemployment	1 (1%)	0 (0%)
		Return to work	2 (2%)	2 (2%)
		Whenever problems arise	2 (2%)	0 (0%)
	In case of unexpected events	Severe cognitive problems	1 (1%)	1 (1%)
		Disease progression	1 (1%)	2 (2%)
		Early, before problems arise	1 (1%)	0 (0%)
		When one has the 'capacity' for it	2 (2%)	4 (4%)
Unsuitable time-points	Treatment associated time-points	Diagnosis/beginning	1 (1%)	1 (1%)
		Before entering hospice	1 (1%)	0 (0%)

Note: Displayed are the number and percentage of documents (interviews, both from t1 and t2) where the category was coded. Level 1 is 'Time-points' and refers to all the codes, and it is therefore not mentioned in the table.

3.3 | Preferred time-point(s) for cancer counselling

When discussing the preferred time-points, a few participants also mentioned time-points they find unsuitable for support. Therefore, under the first-level code *time-points*,¹ we created two second-level codes: *suitable* and *unsuitable time-points*.

3.3.1 | Suitable time-points

Most often, the optimal time-point for cancer counselling was defined by the participants according to the *treatment trajectory* (Table 3). Among these, the time-point most often mentioned as suitable by the participants was 'as early as possible', that is *at the time of the cancer diagnosis* (mentioned in 22% of the interviews with males and in 10% with females). Most of these did not express that support should be offered only at the beginning, but rather from

the beginning onwards. Participants also expressed reasons for this preference, for example that they felt lost and in despair at that time and needed help from a professional person. Another reason mentioned was that it is helpful to start a relationship with the counsellor at the beginning of the disease trajectory so that this trusting relationship can hold the patient during times of crises later on.

For me it was important that I went relatively early to counselling, while I still had it together health-wise. Before the chemotherapy and all that or the radiation started, so to speak. That was very important in order to establish something or to receive support right at the beginning, because that is when the uncertainty was the biggest. And the shock was still there. And that was really important at the beginning. And now, during the further course [of the disease] of course ... that I, that through that I..., in a

manner of speaking, that they know me and we trust each other, it is of course very important that the contact person is always the same over the course of the disease. So that this [relationship] is effective, so to speak. That secure feeling just cannot be there at the beginning. It first has to be developed. And the time was there [for creating this secure feeling in the relationship with the counsellor]. And also, this support, with highs and lows, that just needs, yeah, time and trust. And that has to be established. And that that happens at the beginning, as early as possible, all the better, yes.

(ID MO028, male, user, patient, time-point t2)

Another time-point, that is actually closely related to the beginning of treatment, was while **waiting for test results**. The extreme uncertainty that patients and relatives feel during these times leads to feelings of helplessness and creates a need for support.

How do I handle this disease? How do I manage the upcoming examinations? And above all, the corresponding test results. How do I deal with the waiting time, which is sometimes also really considerable, ... and if nothing happens. The waiting time until the examination and the waiting time until the results are there, these were often terrible days.

(ID TL021, male, user, relative, t2)

Participants also underlined the need for help once the treatment and the stay in the rehabilitation clinic are over, when they are at home and face all the problems in daily life.

Maybe also another contact after discharge. Some kind of contact, be it written or otherwise. Because many problems first crystallize when you are at home again, when you are trying to master your daily life again, what doesn't work or maybe what doesn't work the way you had hoped.

(ID MO032, male, user, patient, t1)

Another aspect that participants took into account was related to their *work*, be it the **threat of unemployment or return to work**.

Then at a time point, when for me it became more likely that the disease had been beaten, yes, I was helped in that I managed to get a foot in the door again professionally.

(ID TA001, male, user, patient, t2)

In contrast—and sometimes in addition—to these a priori defined time-points, some participants expressed their wish to receive psychosocial support later on, **when they have the 'capacity' for it**.

Capacity here meant either time or emotional capacity to deal with the emerging distressing topics.

I mean, depending on the situation, you are involved with an operation or chemo or something. You have to take that into account; can I go somewhere right now or will that overwhelm me and so on. So I think there certainly are no right or wrong time-points.

(ID TL019, female, user, patient, t2)

Another group of statements underlined that counselling should be provided **when unexpected events** happen, not according to the treatment schedule. These unexpected events were either not specified or the participants referred to the progression of the disease.

Yes, if, of course, my wife's condition deteriorated considerably, then... because then... I would have even less time then to take care of yet something else, right?

(ID TR001, male, non-user, relative, t1)

Another unexpected event mentioned twice by participants was severe cognitive problems (**confusion**) of their relatives.

Yes of course, I mean, that is just the way the situation is at the moment. That you partially don't even know how you should react. The way my mother in part ... she really had problems. At times she was talking nonsense and, yeah, just really really difficult, yeah. And that was certainly a motivation here.

(ID MM022, male, user, relative, t1)

3.3.2 | Unsuitable time-points

There were also a few voices (1%) saying that there is a lot of information to be processed at the time of the cancer **diagnosis**, and thus, this time was considered as unsuitable, not because counselling is not necessary but because the patients and relatives feel overwhelmed by too much information to be processed or too many appointments at that time.

Because that was, yeah, we were overrun with all of it. We got the news in November. Directly after my wife was operated on. Then in rehab. And so there was absolutely no time at all for any kind of consultation.

(ID TA003, male, user, relative, t2)

One patient said that the time **before entering hospice** would be too late to start with psychosocial counselling because it is too late for building a trusting relationship with the counsellor. This would have made it difficult for him to accept psychological counselling (his

own experience had been different, he had been offered and had used counselling earlier on), although he thought that counselling regarding socio-economic topics was still possible at that time.

I would not do that in a situation when a person is physically weak and ... is about to go hospice, and then starts to look and gets counselling. I think that could not be as effective. It would maybe be more of a formal check in point, but this feeling of 'I can trust this person and feel like I am in good hands and am understood', then it is not an issue anymore. Rather, it is simple then and can be more, okay, what are the addresses, which hospice, ... how will it be arranged financially. And these formal things. And maybe the person at that moment can't completely come to grips with this. Rather a relative has to be there, who looks as well. In this way, it would be a totally different consultation.

(ID MO028, male, user, patient, t2)

3.4 | Gender differences

When analysing the quotes separately by gender, we found that men more often underlined the need to receive support—or information about the possibility of support—as early as possible. They often preferred a proactive offer of psychosocial help at that time. This can be exemplified by the following quote from one of the interviews with a male patient who also explicitly stated the need to 'break the inhibition' that men often have regarding the use of psychosocial counselling.

In my case, where I was completely blindsided by the situation. There are just so many impressions, questions, helplessness, that are suddenly running through your head that at first you just don't have any head space for something like that. If you get something [e.g., a flyer] handed over right away, 'listen, there is someone who can take care of you, who can help you etc.', I think that would break this inhibition at the beginning considerably.

(ID MM023, male, user, patient, t2)

Women, in contrast, more often asked for flexible approaches, for example when they had the time and/or the emotional capacity to deal with problems. They thus underlined the necessity that professional help is offered according to their individual needs.

Another difference was that men, more often than women, expressed their need for support while waiting for test results, whereas women more often mentioned the time during treatment as an important time-point for counselling.

However, overall, there were only few gender differences regarding preferences for the timing of psychosocial counselling.

4 | DISCUSSION

This study set out to examine the preferences of cancer patients and relatives of cancer patients concerning the time-point for psychosocial counselling during the disease trajectory, taking into account potential gender differences.

The main finding is that the most suitable time-point for introducing counselling, from the perspective of the patients and relatives, is at the time of the cancer diagnosis. This is in line with findings that distress is highest at that time (Bergerot et al., 2015; Schwarz et al., 2008; Singer et al., 2007; Stafford et al., 2015; van Beek et al., 2020). There is a high need for information at that time, which frequently is not satisfied—especially as cancer care is becoming very complex and the capacities for processing all this information on the part of the patients is limited too. It is a challenging task for clinicians to offer as much information as needed but not too much, just at the right time and in just the right amount for this particular patient. In a busy clinic, this is not always possible, but it should at least be aimed for.

In our clinical experience, and also based on the interviews from this study, not only the clinicians but also the patients are very busy with their treatments, with logistics, information processing and recovery at the beginning, and quite a few do not want a lot of psycho-oncological support. However, they are happy when they are informed and have the chance to get to know the psycho-oncologist. They can then fall back on the contact later if necessary.

Informing the patients and relatives about available psychosocial services enables shared decision-making. This is not only important when it comes to oncological care (De Vries et al., 2014; Ernst et al., 2011; Gattellari et al., 1999; Kunkel et al., 2000; Nicolai et al., 2016) but also in regard to psychosocial services. In that sense, informing patients is more than just putting a flyer in their 'hospital information folder' (although this is better than nothing), but means talking to them about the different services and telling them what they can and cannot offer because they often do not know what the services entail (Engesser et al., 2019) or have misconceptions about them (Bayer et al., 2022).

Providing this information and contact at the beginning does not imply that counselling should be offered only then. Instead, it should start at that time and then be offered continuously because there are also other times of elevated distress, for example during chemotherapy (Reece et al., 2013), while waiting for test results (Parker et al., 2016), and at times of disease progression (Briest et al., 2015). These time-points were also mentioned by our study participants as important for receiving psychosocial counselling. They also mentioned situations when they face returning to work or are discharged from the hospital as times where they need support. We assume that this is related to a reduction in feeling safe/secure once patients lose the structured environment an inpatient stay provides.

Another important aspect that was mentioned is that support should be offered whenever unexpected or distressing events

occur, such as disease progression. That implies that the provision of counselling should not only be related to certain time windows during the disease trajectory but should be offered flexibly whenever needed.

Regarding gender, we found that women seem to prefer flexible approaches and men tend to prefer a clear offer of and/or information about counselling at the time of first cancer diagnosis. Participants from both sexes underlined the overwhelming situation at that time, but men more often seem to prefer a proactive offer of psychosocial help at that time because they feel 'inhibited' to actively seek help. This is in line with findings that men use psychosocial services less frequently than women despite their need for it (Curry et al., 2002; Faller et al., 2017; Salm et al., 2021; Zeissig, Singer, Koch, Zeeb, et al., 2015).

Men also more often mentioned the need for counselling during times of uncertainty while waiting for test results. The differences were not large, and it could be that this was simply due to chance. If, however, the findings indeed relate to a true gender difference in preferred timing of counselling, one possible explanation is that maybe men find it especially difficult to deal with a situation where they are forced to do nothing while at the same time the threat is intense. This can result in severe distress related to helplessness especially when there is a tendency to deal with threatening situations by 'doing something'. There is evidence that such an 'activity-oriented' coping style is more present in men than in women (Bayer et al., 2020; Danielsson et al., 2011). Overall, however, differences between men and women were not striking.

Here, we would like to mention some of the limitations of our study that might have had an impact on the results. First, this study was conducted in Germany and our participants experienced the German healthcare system. It might be difficult to extrapolate from our results to other healthcare contexts. The German healthcare system is characterised by a strict separation between the inpatient and outpatient sectors, with different reimbursement schemes. As a consequence, patients have different doctors, nurses and counsellors in the two sectors. This could have led to the emphasis our study participants placed on this issue. Another characteristic of the German system is that health insurances pay for psychotherapy, which is not common in many other countries. As of recently, they also pay for services at cancer counselling centres. But even before, users of counselling centres never had to pay for the services; they were funded by various other sources. This could have influenced our results insofar as patients and relatives do not have to worry about how they could finance their consultations, which could make it easier for them to say that they want counselling 'as early as possible'.

Second, the participants clearly knew that we were conducting a study on cancer counselling. They may have sensed that the interviewers have a positive view of psychosocial counselling. The interviewers received training to reduce this potential bias, but when reading the interview transcripts, we found that this was not entirely removed. The answers regarding what time-points are best suited for counselling were probably not affected by this, but we cannot rule it out completely.

Third, this is a qualitative study, which means that we must be careful not to equate the frequency of certain codes as evidence of the frequency of this preference in the entire population of cancer patients. For that, we would need quantitative studies, which could be a subsequent research project. Another limiting point is that the patients included in this study had different types of cancers with different prognoses and treatments and also had different doctors who had informed them differently about psychosocial counselling. We did this on purpose to capture diverse experiences; however, it also implies that we cannot make inferences for certain groups of patients or relatives.

In summary, most participants underlined the need for counselling 'as early as possible' with the possibility to create a long-lasting trusting relationship, where help can be retrieved flexibly whenever needed. This is in contrast to how health care is currently organised in Germany, where we face a strict separation between the inpatient and outpatient settings (Singer et al., 2018). This system prevents health personnel in the hospital from caring for patients once they are discharged and, vice versa, health providers in cancer counselling centres or in private practices cannot continue their care when the patient is referred to a hospital. This creates repeated separations from mental healthcare providers for the patients, as well as often a loss of information each time a person crosses the 'line' between the sectors. Of course, this 'line-crossing' can also present a chance for a new and fresh beginning if experiences in the hospital or in the clinic / counselling centre / private practice have been bad and a patient wants a new start with a new counsellor.

5 | IMPLICATIONS

An implication of our study for policy decisions is that healthcare systems should ensure the possibility of continuity of mental healthcare relationships over the course of the cancer disease, so that patients can keep the same counsellor if this is preferred by them. Patients should not require one 'inpatient counsellor' and one 'outpatient counsellor' unless they wish exactly that.

An implication for healthcare providers both in hospitals and in private practices is that they should inform their cancer patients and their relatives about the possibility of professional psychosocial support early on in the disease trajectory (i.e. at the time of diagnosis) and repeatedly thereafter, especially before discharge from hospital (when patients lose this structured environment and go back home), when patients return to work and when the disease progresses. Whether or not they take up this offer and make use of the services is then their own decision, but they should have the opportunity to decide.

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CONFLICT OF INTEREST

There are no financial conflicts of interest.

ETHICAL APPROVAL

The study protocol was approved by the responsible Ethics Committee of Rhineland-Palatinate and has been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

DATA AVAILABILITY STATEMENT

The quantitative data that support the findings of this study are available from the corresponding author upon reasonable request. The qualitative data are not publicly available to protect the privacy of the patients and relatives.

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ENDNOTE

¹ Categories of the code system are marked with bold italics.

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