

ORIGINAL ARTICLE

“That was a tip from my physician”—Gender-specific pathways of patients and relatives to outpatient psychosocial cancer counselling centres—A qualitative study

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Funding information

Deutsche Krebshilfe, Grant/Award Number: 110891

Abstract

Objective: This study aims to identify pathways patients and their relatives take to outpatient psychosocial cancer counselling centres. We had a special interest in how access for men can be eased.

Methods: Cancer patients and relatives were purposively sampled in two regions in Germany. Participants were either outpatient cancer counselling centres (OCCCs) users or non-users and participated in qualitative face-to-face interviews. We used different guidelines for users and non-users. The interviews were analysed using content analysis.

Results: One hundred and three people participated in the study. Important pathways to outpatient psychosocial cancer counselling centres for both men and women were: information about the service and its content, easy access (obtaining appointments quickly and without bureaucracy, close to home), and recommendations from another person, in particular from their treating physician. Pathways especially important for men are positive and repeated recommendations from their treating physician and other people they trust, organisation by others on the men's behalf, the Internet, the possibility to talk to a male counsellor, making it a routine in the hospital to refer distressed patients to the counselling services, and the emphasis on information sharing. Women reported more often than men that they discovered and accessed OCCCs via information material.

Conclusions: Men in particular need recommendations from others, especially from their treating physician, in order to make use of psychosocial cancer counselling. In addition, stressing the provision of information instead of exploring and expressing emotions can ease access for men to cancer counselling.

This manuscript follows the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007).

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KEYWORDS

cancer, cancer counselling service, consultation, gender, men, outpatient psychosocial cancer counselling centres, patients' needs, psycho-oncology, psychosocial

Key points

- Psychosocial services aiming to ease access for men should create gender-specific information material (flyers, websites, etc.)
- This information should especially highlight social and social-legal advice
- Referrers, usually general practitioners or oncologists, should be made aware that their recommendation plays a crucial role in male cancer patients' and their relatives' access to outpatient psychosocial cancer counselling

1 | BACKGROUND

About half of all patients with cancer as well as their relatives experience elevated levels of distress,^{1–3} both men and women. If psychosocial support is offered proactively to distressed patients in inpatient settings, the use of such services is almost equal between men and women.⁴ In outpatient settings, however, male users are under-represented, with a male-to-female ratio varying between 1:4 and 1:2.^{5,6}

At the same time, cancer treatment—and with it psycho-oncological care—is increasingly shifting to the outpatient setting.⁷ In Germany, outpatient psycho-oncological care is mainly provided by psychotherapists in private practice and outpatient psychosocial cancer counselling centres (OCCCs)⁸ and is free of charge for cancer patients and their relatives. Zeissig et al. found that about 3.0% of all cancer patients use OCCCs, about 4.7% of women and 1.5% of men.⁹ This difference between the sexes is striking. Possible explanations are that (a) men with cancer do not suffer from psychological distress as heavily as women, (b) they are equally distressed, but this is not reliably recognised in men, or (c) men tend to ignore their need for help and do not actively seek support. Studies show that the first explanation does not hold,^{3,10} but there is evidence for differential recognition of psychological distress¹¹ and help-seeking behaviour.¹² Help-seeking behaviour in men depends on more factors than in women; while women seek help from doctors if it is free of charge and no other social factors prevent them from seeing them, many socio-demographic and psychological factors cause men to seek or not seek help.^{13,14}

This is especially true for mental health care. Men with mental health concerns were repeatedly found to be half as likely to seek help from a general practitioner or mental health professional compared to women.^{15,16} They often seek psychotherapy at a stage when all other types of help have been unsuccessful and they are in a severe crisis.¹⁷

This behaviour may be related to the way they were educated. Men tend to find it more problematic than women to be dependent on the help of others.¹⁸ Gender stereotypes influence help seeking too. In some cultures, men are taught that power, dominance, competition and control are essential to proving one's masculinity.¹⁹ Male gender-stereotyping and the ideal of self-reliance may present

major barriers to help-seeking despite men suffering from fear, shame, anger, despair, etc. as much as women do.

Though gender-specific reasons for use or non-use of OCCCs are not yet well known, reasons for limited use of OCCCs in both sexes together have been found: (1) preference to self-manage, (2) already receiving help elsewhere, and (3) distress not deemed to be severe enough to warrant intervention.²⁰ To date, it is unclear whether these motives differ between men and women. This is not unlikely, given that gender stereotypes require men to be independent (self-management) and not needy (not distressed), as outlined above.

The aim of this study was therefore to identify gender-specific reasons for using OCCCs by better understanding the pathways used by men versus women.

2 | METHODS

2.1 | Study design

We performed a qualitative study. Users and non-users of OCCCs were enrolled at two university cancer centres and adjacent counselling centres in Rhineland-Palatinate and Baden-Wuerttemberg, Germany. To capture a broad range of experiences, we used a purposive sampling strategy guided by a matrix. This matrix included men and women, outpatient psychosocial cancer counselling service users and non-users, cancer patients and relatives of cancer patients (Table 1). Our goal was to enrol 5–20 participants for each cell of the matrix, following the principle of maximum variation sampling.²¹ We enrolled users via OCCCs and non-users via the cancer outpatient departments of the university hospitals. Without prior selection, counsellors of OCCCs approached all users during their first visit and asked them to participate in the study. During appointments at the University Cancer Centre Mainz or in the Radio- and Haemato-oncology Departments (University Hospital Tübingen), we approached cancer patients who had been diagnosed within the last year and their accompanying relatives. After thorough interview training, we conducted baseline interviews (t1) with all eligible and consenting participants. Three to 6 months after the first interview, the same

TABLE 1 Number of interviews per time point and group

	Non-users of outpatient cancer counselling centres				Users of outpatient cancer counselling centres				Total
	Patients		Relatives		Patients		Relatives		
	Men	Women	Men	Women	Men	Women	Men	Women	
Interview at baseline (t1)	13	12	12	9	20	16	6	15	103
Follow-up interview (t2)	7	9	9	7	15	16	4	13	80

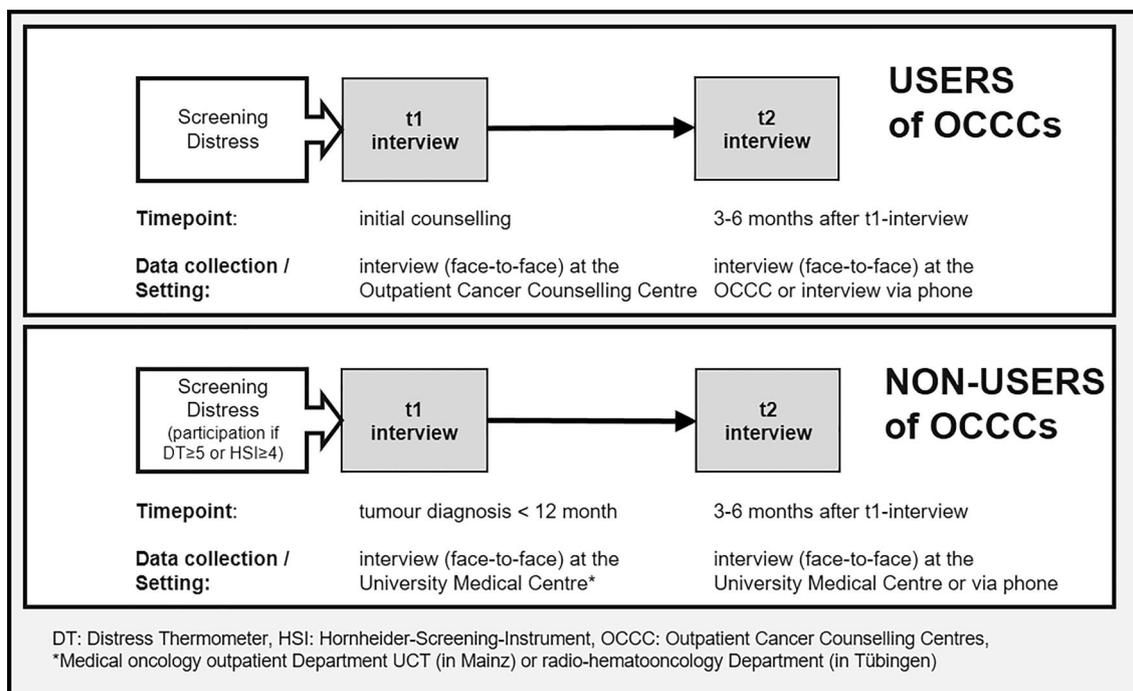


FIGURE 1 Study design and inclusion criteria

interviewers asked participants for a second interview (t2) using slightly different questions (Figure 1).

2.2 | Screening instruments

Potential participants were screened for distress using the Distress Thermometer (DT), a visual analogue scale from 0 to 10, and the Hornheide Screening Instrument (HSI).²² On the DT, ≥ 5 points were indicative of distress, as was ≥ 4 on the HSI (Figure 1). If either one of the instruments indicated distress, the patient or relative was considered to be distressed. In non-users, only distressed patients were asked to participate in the qualitative interviews. This was done to improve comparability between users and non-users, assuming users of psychosocial counselling services to be more distressed than the average cancer patient.

2.3 | Interview procedures

We developed an interview guide to elicit respondents' narratives. The guide comprised open-ended questions and was developed for

the purpose of this study, based on conceptual considerations and clinical experience. It was subsequently pilot tested in five patients.

There were different questions for users and non-users of OCCCs. The questions about the pathways to cancer counselling are compiled in Figure 2. If necessary to maintain the flow of the conversation, other questions could be inserted or the wording changed.

The interviews were conducted face-to-face, in exceptional cases by telephone. In the vast majority of interviews, only the interviewer and the participant were present. In a few cases, a third person, generally the spouse, attended the interview. Interviews were audio-recorded. If participants did not agree to be recorded, written notes were taken to document the answers.

2.4 | Research team

The interviews were performed by a total of seven interviewers. Five interviewers were female, two were male. Two interviewers were researchers at the University Hospital Mainz (one public health scientist and one epidemiologist), two were psycho-oncologists at the University Hospital Tübingen (both

Users of Outpatient Psychosocial Cancer Counselling Centres (OCCCs)	Non-Users of Outpatient Psychosocial Cancer Counselling Centres
"What brought you to the OCCC today?"	"Under what circumstances would you make use of cancer counselling?"
"How did you find out about the OCCC?"	"What would the counselling service have to look like for you to make use of it?"
"What circumstances made it easier or supported you to come to the OCCC?"	
"What should a cancer counselling centre look like so that it is more accessible to men in particular?"	

FIGURE 2 Interview questions on the topic of pathways to cancer counselling

psychologists), two were counsellors at the counselling centre Tübingen (one psychologist and one social worker), and one was a medical student at the University Hospital Mainz. The entire study team in Mainz completed an interview training session before starting the interviews. The interviewers were not involved in counselling the respondents and briefly introduced themselves and their occupations.

2.5 | Data analysis

All audio files were recorded and transcribed verbatim. The transcripts were not submitted to the participants again. The content of the transcripts was then analysed using Mayring's content analysis.²³ Coding of interviews was performed by at least two researchers. Interviews were first coded separately by each researcher. All text segments relevant to the research question were coded according to a category system that was developed iteratively and completed after coding three quarters of all interviews. The main categories were generated deductively based on major topics of the interview guideline. The remaining code levels were generated inductively and structured in up to three sublevels. Qualitative data analysis was performed using MaxQDA for Windows version 12.0 (VERBI Software).

3 | RESULTS

3.1 | Description of the sample

One hundred and three individuals participated in the study: 57 users and 46 non-users. Of them, 51 were male, 52 were female, 61 were cancer patients and 42 were relatives. The median age was 56 years (range: 22–84 years). The proportion of highly distressed participants (DT ≥ 5) was slightly higher in the group of non-users of OCCCs (87% in non-users vs. 74% in users; Table 2).

We conducted 183 interviews with a total duration of 41 h audio material. In 14% of the cases, respondents preferred written notes instead of audio-recording. Eighty participants (78%) also took part in the second interview (t2).

3.2 | Pathways

We identified five major pathway categories.

3.2.1 | First pathway: Organisational issues

Easy access turned out to be central in this category. In particular, compatibility with working times, short-term appointments, and proximity to a counselling centre were frequently mentioned both by men and women.

- ¹: Ok. What circumstances have made it easier or more supportive to come?
- P²: [...] the open consultation times, because I could just go without calling, without having to have an appointment really, rather I simply, when I had the feeling, now I go, I just did it. That was good.
(Female, cancer patient [breast], user, 31 years)

Men repeatedly requested that outpatient psychosocial cancer counselling service should be an integral part of the oncological therapy. For example, one man emphasised that an appointment for cancer counselling should be made automatically, as is the case with other oncological treatments.

- P: [...] now you get set a port and then you are called, we mediate the port op and then it could be just as good, yes, we now arrange the first counselling appointment and then please go here and there. And then it works [...]
(Male, cancer patient [carcinoma of unknown primary], user, 55 years)

Another male interviewee said that man-to-man counselling was a potential pathway for men to outpatient psychosocial cancer counselling service.

- I: What would the offer have to look like so that it would be more accessible to men in particular?
- P: I think men's groups could be a thing, because I think men would probably like to discuss things like that with men, I suppose.
(Male, relative, user, 39 years)

TABLE 2 Sample characteristics

	Users (N = 57) n (%)	Non-users (N = 46) n (%)	Overall (N = 103) n (%)
Status (patient/relative)			
Patient	36 (63.2)	25 (54.4)	61 (59.2)
Relative	21 (36.8)	21 (45.6)	42 (40.8)
Participation			
Baseline (t1)	57	46	103
Follow-up (t2)	48 (84.2)	32 (57.1)	80 (77.7)
Sex			
Female	31 (54.4)	21 (45.7)	52 (50.5)
Male	26 (45.6)	25 (54.3)	51 (49.5)
Age in years			
Mean (standard deviation)	50.9 (12.1)	63.0 (11.8)	56.3 (13.4)
Median [range]	53.5 [22.6–78.0]	65.2 [26.9–84.9]	56.9 [22.6–84.9]
Psychological distress			
High distress (≥ 5 points on the Distress Thermometer)	42 (73.7%)	40 (87.0%)	82 (79.6%)
No/low distress (< 5 points on the Distress Thermometer)	6 (10.5%)	6 (13.0%)	12 (11.7%)
Missing	9 (15.8%)	0	9 (8.7%)
Cancer site^{a,b}			
Respiratory system	3 (5.3)	12 (26.1)	15 (14.6)
Central nervous system	7 (12.3)	1 (2.2)	8 (7.8)
Intestinal tract	8 (14.0)	2 (4.4)	10 (9.7)
Gynaecological tumours	14 (24.6)	4 (8.7)	18 (17.5)
Male genital tumours	3 (5.3)	1 (2.2)	4 (3.9)
Urinary tract	3 (5.3)	2 (4.4)	5 (4.9)
Haematological malignancies	10 (17.5)	14 (30.4)	24 (23.3)
Skin	2 (3.5)	1 (2.2)	3 (2.9)
Ear/nose/throat or head/neck	3 (5.3)	3 (6.5)	6 (5.8)
Other	4 (7.0)	6 (13.0)	10 (9.7)
Stable partnership			
Yes	37 (64.9)	33 (71.8)	70 (68.0)
No	15 (26.3)	9 (19.6)	23 (23.3)
Unknown	5 (8.8)	4 (8.7)	9 (8.7)
Children			
Yes	40 (70.2)	32 (69.6)	72 (69.9)
No	15 (26.3)	12 (26.1)	27 (30.1)
Unknown	2 (3.5)	2 (4.3)	4 (3.9)
Educational level			
\leq Compulsory school	10 (17.5)	22 (47.8)	32 (35.0)
Post compulsory school (below university level)	12 (21.1)	11 (23.9)	23 (22.3)
University level	31 (54.4)	13 (28.3)	44 (42.7)
Unknown	4 (7.0)	0	0

^aMultiple entries possible.^bIn relatives it refers to the disease of the cancer patient.

3.2.2 | Second pathway: Information

Information on the existence and a detailed description of the service was also a pathway to OCCCs for both sexes. A male participant particular considered information about cancer counselling to be a potential pathway for men to the OCCCs.

- I: Is there anything you would say: This is how one should design the offer so that it is more accessible to men?
- P: I believe the key lies solely in the explanation [of what the service is]. - I mean, we have so many types of media, whether TV, newspapers, magazines or medical flyers. I believe explaining is the most important aspect.
(Male, relative, non-user, 72 years)

Most patients and relatives found their way to OCCCs via leaflets that they either found in hospitals or received from healthcare professionals. For women, information materials played a more important role than for men.

3.2.3 | Third pathway: Self-initiative

A high level of self-initiative was mentioned to be another pathway to OCCCs, but mainly by women.

- P: [...] in that case I became active and searched or kept my eyes open [...].
(Female, relative, user, 33 years)

The spontaneous and self-initiated search on the Internet or in social networks was a frequently mentioned pathway to OCCCs, which was mentioned more often by men.

- P: Yes, you would have to look it up on the Internet.
(Male, relative, non-user, 70 years)

3.2.4 | Fourth pathway: Referral from a trusted person

Referral by another person was the most commonly mentioned pathway to outpatient psychosocial cancer counselling service for both sexes. The most frequently mentioned person in this respect was the treating physician.

- I: What brought you here today to the outpatient psychosocial cancer counselling centre?
- P: Well, it was a tip from the physician treating me, who explained to me very briefly about the cancer centre and told me that counselling is actually covered for all sorts of areas that are significantly influenced by the disease.
(Male, cancer patient [Non-Hodgkin-Lymphoma], user, 55 years)

A female participant explicitly emphasised the need of a trusting physician-patient-relationship, especially in times of a serious illness such as cancer.

- I: [...] but I think that the doctor can achieve a lot, because I think if you are in such a situation with such a disease, the relationship with the doctor is completely different to when as if I go there because I have a headache or something else. That's why I believe that the doctor can steer this relatively accurately, because I think the patient surrenders to the doctor anyway, [...].
(Female, cancer patient [bowel], user, 67 years)

For some men, it was not the provision of information itself that was decisive, but rather the approaches. For example, a male cancer patient suggested both an active approach during a hospital stay and a written inquiry after discharge.

- P: [...], this direct discourse within the clinic, but maybe also again after discharge. A written or in whatever form kind of inquiry.
(Male, cancer patient [kidney], user, 57 years)

Other healthcare professionals, but also friends, relatives, acquaintances, and other patients were mentioned as playing an important role, especially their positive recommendation. Many men felt that testimonials from other men could be an incentive for men to use OCCCs.

- P: [...] this word-of-mouth recommendation works just fine. This is similar to a restaurant, I can walk by it ten times and say, ah yes, looks ok, but I'm not going in there. But if five friends from my circle of friends say that it's great, it doesn't matter what it looks like, I'll go in there anyway. And I think that's exactly the same here.
(Male, cancer patient [lung], user, 29 years)

3.2.5 | Fifth pathway: Public image

Many respondents, women and men, emphasised that in order to ease access for men, OCCCs should be associated with the image of providing information rather than dealing with psychological problems. Therefore, psychological or emotional content should not be primarily mentioned. For example, a young cancer patient stated that men often were afraid to acknowledge and address problems.

- I: And could you think of something that would make it easier for other men to come here?
- P: [...] somehow put the information a bit in the foreground, that the actual consultation, or where I think the man might be afraid of, of whatever because that is not a problem for me, so this attitude, that somehow you can integrate that in such a conversation somehow [...] because nobody will admit it, it's even harder for younger people, because everyone is the strongest and the biggest. That's what I think: that is one should do it more on this information story.
(Male, cancer patient [lung], user, 29 years)

A similar statement regarding psychological help was made by a wife about her husband. She emphasised that counselling on psychological issues would be difficult for her husband.

- P: I now imagine my husband, as far as the psychological side is concerned, it gets more difficult [...] As far as the pure help is concerned, such as a certificate of disability, advice, how is it going on financially and such things, I think he is absolutely not averse to come, yes. That would be ok for him.

(Female, relative, user, 58 years)

4 | DISCUSSION

This study identified key issues associated with access of patients and relatives to psychosocial cancer counselling centres in the outpatient setting. We found both gender-specific and general pathways.

Information about the service and its content, easy access, referral by a trusted person, in particular by the treating physicians, were mentioned as important pathways to outpatient counselling for both sexes. These results are in line with a large population-based survey which found that doctors were named as the most important contact for questions about cancer.²⁴ Rosenberger and colleagues reported that the most common pathway to OCCCs was a doctor's recommendation.²⁵ A recent study from Switzerland has shown that the active recommendation of an oncologist in particular has a major influence on the use of psycho-oncological support.²⁶ General practitioners and oncologists play a key role in providing information on cancer and as a pathway to OCCCs. Our study adds that a doctor's recommendation for psychosocial support can facilitate the path to OCCCs for both men and women.

In addition to pathways that are relevant for both sexes, we also found gender-specific pathways. Our results suggest that men attach great importance not only to recommendations by physicians, other healthcare professionals, friends, relatives, acquaintances and other patients, but they have to be formulated positively and multiple times. Beyond that, some men recommended a routine integration of psychosocial cancer counselling service into cancer therapy. Men obviously need more external prompts to seek advice, which is in line with prior evidence.^{4,27} More women than men found their way to OCCCs on their own initiative in our study. This could be because women are more used to dyadic relationships and are more often able to accept counselling. In addition, there are socialisation factors that mean that women are more inclined to use affective processes and contextual thinking with the motives of caring and helping to solve problems.²⁸ This may be one reason why women are generally over-represented in the outpatient setting.⁶ Another explanation could be that the counselling services have been mainly aimed at women since the beginning and are still practised by women significantly more often than men.²⁹

While written or printed materials (brochures, leaflets, etc.) played an important role for women, for men it was the Internet. In Europe, the proportion of men using the Internet is still higher than that of women (84.9% vs. 80.3%), although these figures have been converging in

recent years.³⁰ Maybe anonymous and unimpeded information gathering, as is possible on the Internet, is more important for men than for women. A specific offer for men, such as man-to-man counselling, was also mentioned. Positive examples are already firmly established in other sectors beyond the psychosocial counselling centres and can serve as role models for the outpatient setting.^{31,32}

Moreover, the well-known role stereotypes, according to which seeking help for men is considered a weakness,²⁷ were confirmed in a variety of statements of the participants. For men, the image of a counselling service is decisive. In this context, it also seems to be important not to emphasise the psychological aspects of the service offer in the first place. Instead, information transfer and social-legal advice should be highlighted for men to ease access for them. Indeed, study results suggest that men are more sceptical than women about psychological help.³³ However, our results also underline that men want to talk about their emotions and experiences; they just may need other pathways to find the trust and courage to do so.

Another point to be taken into consideration is that men and women may differ in terms of support preferences or even regarding the effectiveness of certain services. Cancer counselling is not the only option for both patients and relatives, men and women, to receive emotional support. Indeed, many prefer such support from their doctors and nurses in the hospital or community.³⁴ Whether psychosocial services have gender-specific effects is another open question. A systematic review of 15 randomised trials for the treatment of unipolar depression found that the evidence is inconclusive so far: some studies found better effects in men, some in women, and many found no differences.³⁵ An interesting finding from a survey among about 3000 depressed individuals who had received various types of support was that psychotherapy was described as equally effective by men and women whereas counselling was reported to be helpful more often by women.³⁶

4.1 | Study limitations

Due to our sampling matrix, which consisted of eight groups (Table 1), a comparatively high number of participants were included in this qualitative prospective study. This generated a large and complex dataset. On the one hand, this enriched the content, but on the other hand, it was a great challenge to work out the most important statements without generalising too much.

We enrolled non-users of cancer counselling centres in two university hospitals and users of OCCCs in the same towns, which may have led to a selection of participants. However, the aim of our purposive sampling was not to reproduce representativeness of the German cancer population but to capture a wide range of perspectives according to the principle of maximum variation sampling.²¹

An important limitation of this study is that it was conducted exclusively in Germany. A special feature of the German health system is that the outpatient and inpatient sectors are strictly separated, as are their funding and actors (doctors, nurses,

counsellors, and psychotherapists). This strict separation also means that the transition from the inpatient to the outpatient sector with its different actors can be a major challenge for people affected by cancer. However, access to OCCCs in Germany is straightforward as no formal referral from a doctor is required. A generalisation of the results to other health care systems is therefore only possible to a limited extent. However, we assume that some aspects mentioned by our study participants regarding pathways to psychosocial support services are similar in other health care contexts and can be relevant to ease gender-specific access to cancer counselling.

4.2 | Clinical implications and conclusions

This study highlights the need to establish pathways to outpatient psychosocial cancer counselling service that are tailored for men. This includes the creation of gender-specific information as well as organisational conditions. Provision of information and social and social-legal advice should be highlighted for men, whereas psychological aspects should be less emphasised. In addition, a gender-specific design of the different information channels such as flyers and websites is recommended. A central aspect is to make the referrer, generally the general practitioner or oncologist, aware that a recommendation on their part plays a crucial role in the access of male cancer patients and relatives to outpatient psychosocial cancer counselling service.

ACKNOWLEDGEMENTS

The study was funded by the German Cancer Aid (grant number # 110891). The funding body had no influence on the design of the study, the collection, analysis, and interpretation of data, or in writing the manuscript.

CONFLICT OF INTEREST

The authors declared no conflicts of interest.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The study was carried out in accordance with the Declaration of Helsinki and Good Clinical Practice guidelines. The Ethical committees of Rhineland-Palatinate (reference number 837.248.14 - 9487-F) and of the University Medical Centre of Tübingen (reference number 525/2014BO2) approved the study. All participants provided written informed consent.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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ENDNOTES

¹ I = Interviewer.

² P = Participant.

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How to cite this article: Billaudelle F, Bayer O, Hechtner M, et al. "That was a tip from my physician"—Gender-specific pathways of patients and relatives to outpatient psychosocial cancer counselling centres—A qualitative study. *Psychooncology.* 2022;31(6):1022-1030. <https://doi.org/10.1002/pon.5893>