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Information Needs of Cancer Patients and Perception of Impact of the Disease, of Self-Efficacy, and Locus of Control

C. Keinki[2] · **E. Seilacher**[2] · **M. Ebel**[1] · **D. Ruetters**[2] · **I. Kessler**[2] · **J. Stellamanns**[2] · **I. Rudolph**[2] · **J. Huebner**[1]

Abstract The aim of our study was to investigate the relationship between information needs and cancer patients' perceptions of the impact of the disease, self-efficacy, and locus of control. Using a standardized questionnaire, we obtained data from patients who attended a series of lectures. The questionnaire included questions on their information needs, sources of information, satisfaction with information, and short questionnaires on self-efficacy, perception of the disease, and locus of control of reinforcement. Data was obtained from 185 patients. Our results showed that the sources of information that were most often used were physicians (84 %), print media (68 %), and the Internet (59 %); online fora (7.5 %), non-medical practitioners (9.7 %), and telephone-based counseling (8.6 %) were only used by a minority. Patients with a high perception of their own control over the disease more often used any source of information available to them and were more often interested in acquiring additional information. Higher self-efficacy was significantly associated with the need for information on all topics. Patients with a higher external locus of control significantly more often used sources of information and had significantly more need for additional information. By contrast, there were no associations with an internal locus of control. Neither external nor internal locus of control showed any associations with satisfaction with information. Information needs seem to be higher in patients with a high external locus of control and low self-efficacy. Physicians, other professionals, and institutions that provide information may take these relationships into consideration for tailoring their services to patients.

Keywords Neoplasm · Patient · Information needs · Self-efficacy · Perception of disease · Locus of control of reinforcement

Introduction

The German National Cancer Plan and similar initiatives in other Western countries are trying to enhance cancer care by improving communication and encouraging shared decision making.

A decisive requirement for shared decision making is having access to information of high quality. From the point of view of patients, the most preferred source of information is the physician [1–4]. However, several obstacles may impede communication with the physician in daily life, such as lack of time, lack of adequate rooms, and settings without interruptions and language [5]. As a result, patients have to turn to other sources of information. These sources should be low threshold and barrier free and should also address lay people with low literacy and health literacy. At the same time, oncology is a highly sophisticated subject with multiple specializations and an interdisciplinary nature. Decisions on diagnosis

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✉ J. Huebner
huebner@med.uni-frankfurt.de

E. Seilacher
seilacher@krebsgesellschaft.de

M. Ebel
ebel.desiree@gmx.de

[1] Working Group Integrative Oncology, Dr. Senckenberg Chronomedical Institute, J.W. Goethe University, Theodor-Stern-Kai 7, 60590 Frankfurt, Germany

[2] German Cancer Society, 14057 Berlin, Germany

and treatment are complex and, therefore, not easy to explain in plain language.

Parker and colleagues summarized the information needs of cancer patients in a review. According to them, patients are in need of information on the disease, symptoms, treatments, addresses of hospitals and specialized institutions, and information on current research [6]. However, in the later stages of the disease, these interests shift to long-lasting symptoms or side effects and survivorship or palliative care and symptom control [7].

Patients' willingness and ability to take part in informed consent or shared decision making may be influenced by their perception of the disease and the possibility of influencing the course of the disease. Furthermore, patients may be more inclined to engage in the process or shared decision making if they are convinced of self-efficacy. In this respect, the concept of locus of control describes whether the person perceives an ability to control what is happening by himself/herself (internal locus of control) or whether he/she feels dependent on the control of others (external locus of control).

To our knowledge, few data exist on the relationships between information needs and mental attitudes among patients with cancer. In order to learn more, we carried out a survey on participants of a series of lectures in Germany. These data may be important for clinicians and other professionals engaged in patient education to offer tailored information. Furthermore, results may be important for psycho-oncologists to better assist patients looking for and evaluating information and to provide support in the process of decision making.

Methods and Participants

The participants we surveyed were attending a series of standardized lectures on complementary and alternative medicine, which was jointly held by the German Cancer Society and a German statutory health service [8]. These institutions provide evidence-based information on the topic and address patients, their relatives, and other lay people. The talks are structured and presented by trained oncologists who are not only experts in Complementary and Alternative Medicine (CAM) but have expertise in presenting information to lay people as well. Participants are informed about the lectures by flyers of the Regional Cancer Society and the media. Additionally, patients with breast cancer who are enrolled in the disease management program of the statutory health service are directly addressed.

All participants received a standardized questionnaire before the start of the lecture. The survey objectives and the significance of the questionnaire for the project were explained in the introduction of the oral presentation. Participants were asked to return the questionnaire anonymously at the end of the lecture while leaving the room.

The questionnaire was derived from the first version of the pilot lectures [8]. We modified a set of questions on information needs from another questionnaire [8] and integrated further questions from three standardized international questionnaires on perception of disease, locus of control of reinforcement, and self-efficacy. The questions on CAM usage, perception of disease, locus of control of reinforcement, and self-efficacy were intended for patients only.

The questionnaire consists of seven parts:

1. Demographic data that includes gender, age, diagnosis and status (i.e., patient, relative, or other)
2. Data on information needs, such as topics, settings, and providers
3. Data concerning the usage of CAM before the lecture and the communication about this usage with professionals
4. Data on self-efficacy using a short form of the validated questionnaire from the German version of the scale developed by Schwarzer and Jerusalem (ASKU) [9–12]
5. Data on the perception of the disease using selected questions from the German version of the Brief Illness Perception Questionnaire (B-IPQ German), focusing on consequences of the disease, timelines, personal control, disease control, and coherence (understanding) [13, 14]
6. Data on the locus of control of reinforcement using the German IE-4, which differentiates between internal and external locus of control [15, 16]
7. Satisfaction with the lecture

We used closed questions, providing lists of possible answers (for example: "Do you use complementary and alternative medicine?" Options: "yes," "no," "I am not sure," and "no answer"). In cases where a rating by the participants was necessary, we prespecified answers using Likert scales (for example: "How do you rate the lecture as a whole?" Options: "very good," "good," "medium," "bad," "very bad," and "I am not sure").

According to the rules of the ethics committee at the University Hospital of the J.W. Goethe University at Frankfurt/Main, no ethics vote was necessary. IBM SPSS Statistics 20 was utilized for the data collection and analysis of frequencies and associations using chi-square tests and bivariate analyses; $p<0.05$ was considered significant.

In this article, we present data on sources of information, needs for additional information, and patients' perceptions of the impact of the disease, self-efficacy, and locus of control.

Results

Demographic Data

The questionnaire was distributed in six lectures to 384 participants. In total, 240 participants returned the questionnaire

(62.5 %). From these, 185 were patients who were undergoing or had completed cancer therapy. The demographic data and types of cancer are shown in Table 1.

Nearly two thirds of the participants were female, with breast cancer patients accounting for more than 40 %. Younger patients were less likely to attend (13.8 % below the age of 50 years), while those aged 61 years and older represented more than half of the participants (60.1 %). We also asked participants about their education, but only a minority (17 %) answered this question, so these data are not presented in this paper.

Satisfaction with Information and Sources of Information

Patients were asked about the sources of information they had used so far. Most participants said they gained information from physicians and nurses (84 %) and print media (68 %), followed by online sources (59 %). Online fora (7.5 %), non-medical practitioners (9.7 %), and telephone-based counseling (8.6 %) were only used by a minority (Fig. 1). There was no association between gender or age and the preferred source of information.

Participants were asked to rate their satisfaction with the information they had received so far on a Likert scale (where 1=“very satisfied” and 5=“not at all satisfied”). Most patients were satisfied (1 or 2; 54.3 %) with the information; only a minority was dissatisfied (4 or 5; 8.1 %). Women were significantly more often satisfied with the information than were the men ($p<0.001$). There was no association between age and satisfaction with the information received.

Table 1 Demographic data and type of cancer

Demographic data		Number of patients (%)
Status	Patient, current treatment	116 (62.7)
	Patient, after treatment	69 (37.3)
Gender	Male	54 (29.0)
	Female	121 (65.4)
	No answer	10 (5.4)
Age	≤50 years	25 (13.5)
	51–60 years	52 (28.1)
	61–70 years	55 (29.7)
	71–80 years	43 (23.3)
	81 years and above	4 (2.2)
	No answer	6 (3.2)
Type of cancer	Breast cancer	80 (43.2)
	Prostate cancer	19 (10.3)
	Colorectal cancer	12 (6.5)
	Other gastrointestinal cancers	15 (8.1)
	Gynecological cancers	6 (3.2)
	Leukemia and lymphoma	9 (4.9)
	Lung cancer	6 (3.2)
	Melanoma	6 (3.2)
	Others	29 (15.7)
	No answer	3 (1.6)

Need for Additional Information

In the next section, participants were asked to choose several items from a list of additional information topics. Complementary medicine was chosen most often (56 %), followed by nutrition (39 %). Palliative care was only marked by 15 % (Fig. 2). There were no associations between these topics and gender or age.

Perception of Disease, Locus of Control of Reinforcement, and Self-Efficacy

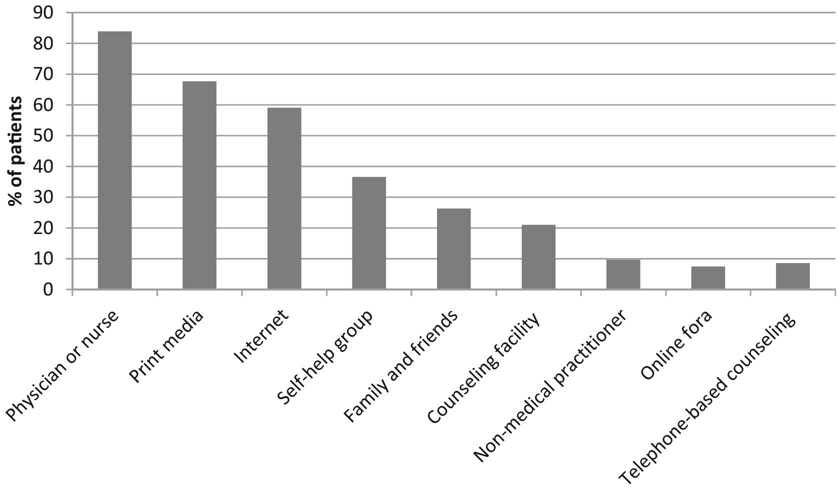
In this section, patients were first asked to rate the impact of the disease on their life (see Brief Illness Perception Questionnaire; Table 2). More than two thirds of the patients rated this impact as “medium” or “high” (5–10). Nearly three quarters of them believed that the disease would last for a while or for the rest of their lives (5–10). Perception of individual control on the disease was low for nearly half of the patients (1–4); less than 10 % had a high perception of control (8–10). Regarding the usefulness of the therapy against the cancer, more than 90 % rated it as “medium” to “strong” (5–10), and nearly half of them marked it as “strong” (8–10). A strong feeling of coherence (8–10) was only reported by about a third of the patients, and nearly 20 % rated it as low (1–4).

Patients who had a high perception of own control of the disease significantly more often used any source of information available to them (all $p<0.001$) and were more often interested in additional information on all topics (all $p=0.01$). Meanwhile, a feeling of coherence did not correlate with sources of information or information needs.

The next questions concerned self-efficacy (ASKU). Out of 185 patients, 93 (50.3 %) answered all items on the subscale. Taking all patients into account, the mean was 3.86 and the standard deviation was 0.66. The results from all patients as well as for male or female patients apart did not differ significantly from those from a random sample from Germany who were given the same questionnaire by the developers of the questionnaire [12]. There was no association between perceived self-efficacy/satisfaction and information/sources of information used. However, higher self-efficacy was frequently associated with the need for information for all topics (all $p<0.001$).

The final questions addressed the locus of control of reinforcement using the IE4 instrument, in order to evaluate the internal and the external locus of control. Considering the internal locus of control, the arithmetic mean was 7.34 with a standard deviation of 1.42; for external locus of control, it

Fig. 1 Sources of information of the cancer patients (several answers were possible)



was 5.06 and 1.52, respectively. These results were higher than those of the healthy adults who participated in the validation study (internal locus of control was 4.12 with a standard deviation of 0.81; external locus of control was 2.56 with a standard deviation of 0.96) [16]. Patients with a higher value for external locus of control used lay sources of information significantly more and had a higher need for additional information (all $p=0.001$). By contrast, there were no associations between information needs and information seeking and internal locus of control. Neither external nor internal locus of control showed any association with satisfaction with information.

Discussion

In this survey, we asked 185 cancer patients about their satisfaction with information, the sources of information they used, and topics for additional information they were in need of.

While half of the patients were satisfied with the information they received, nearly half were not. In fact, 8 % of the participants were dissatisfied, a fact that points to the need for better information for patients. Considering that most information is provided by physicians, it is of utmost importance to improve communication between healthcare professionals and patients. One of the goals of the National Cancer Plan is to provide training to improve the communication skills of medical students and physicians. Other sources of information also are available to patients. Yet, most of these sources either do not comply with the requirements of evidence-based information [17–19] or are produced for people with high health literacy [20].

There may be several reasons why women were more often satisfied with the information they received than men—for one, women with breast cancer may have specific informational needs [21]. Moreover, a large proportion of the participating women had breast cancer, and in Germany, most breast cancer patients are treated in disease management programs. These structured programs have an informative character,

Fig. 2 Need for additional information concerning different topics (several answers were possible)

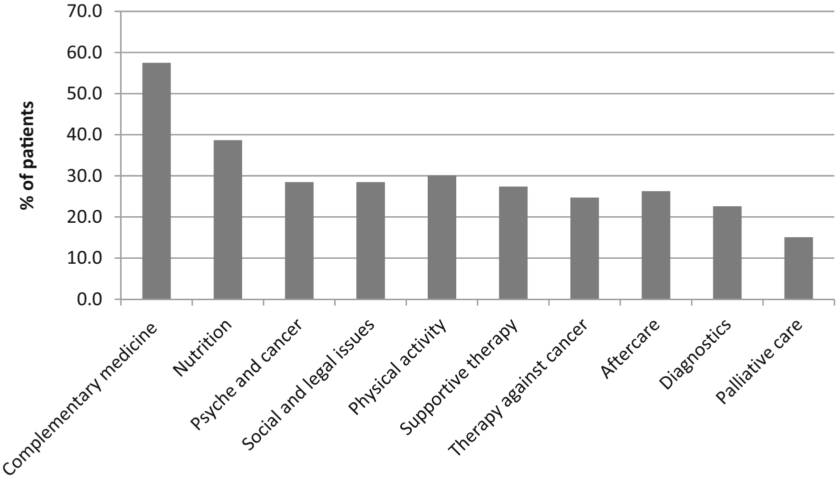


Table 2 Results of the brief illness perception questionnaire

VAS	Number of patients (%)				
	Strength of impact on daily life (VAS 0=none at all to 10=strongest possible) (%)	Timeline of the disease (0=only for a short time to 10=for all lifelong) (%)	Perception of individual control (0=none to 10=very strong) (%)	Perception of usefulness of the therapy against the disease (0=not at all to 10=very strong) (%)	Coherence (0=I do not understand at all to 10=I very clearly understand the disease) (%)
0	4 (2.2)	7 (4.5)	14 (8.2)	1 (0.6)	7 (4.1)
1	5 (2.8)	3 (1.9)	17 (9.9)	2 (1.2)	3 (1.8)
2	16 (9.0)	5 (3.2)	19 (11.1)	3 (1.8)	7 (4.1)
3	25 (14.0)	10 (6.5)	27 (15.8)	7 (4.2)	16 (9.4)
4	22 (12.4)	13 (8.4)	20 (11.7)	12 (7.2)	13 (7.6)
5	24 (13.4)	14 (9.1)	39 (22.8)	30 (18.0)	27 (15.8)
6	24 (13.4)	9 (5.8)	13 (7.6)	13 (7.8)	12 (7.0)
7	33 (18.5)	7 (4.5)	9 (5.3)	26 (15.6)	25 (14.6)
8	9 (5.1)	8 (5.2)	5 (2.9)	31 (18.6)	25 (14.6)
9	6 (3.4)	2 (1.3)	4 (2.3)	14 (8.4)	17 (9.9)
10	10 (5.6)	76 (49.) 4	4 (2.3)	27 (16.2)	19 (11.1)

which may explain why more women were satisfied with the information than men.

The main limitation of our survey was that the sample was not representative due to the recruitment at lectures, which were announced by the local cancer societies. At some places, self-help groups helped invite patients to the lectures; in other places, advertisements were placed in the local media. Furthermore, the public health insurance, which sponsored the lectures, invited breast cancer patients treated in regional disease management programs; people who are insured by this organization are known to be well educated.

Furthermore, the setting of a lecture hall tends to attract patients who are in better physical condition and who have higher literacy and health literacy. The topic of the lectures, complementary medicine, may have further helped to draw highly educated female patients, as this is the demographic group most engaged with complementary medicine [22, 23]. On the other hand, we compared the demographic data with those from a former survey where we addressed participants at different low-threshold information seminars for cancer patients and found similar demographic data [24].

Regarding the sources of information, the usage of the internet is higher than in other surveys and higher than our own data from former surveys [8, 25]. This may be due to the high literacy levels of the audience that attended these lectures. Yet, there were no differences with relation to gender or age. As many patients feel unsettled upon using the internet [26], an easily accessible web-based network could be established by institutions engaged in evidence-based patient information, a network that patients would feel safe to navigate. Such a web-based network, which may also produce printable information or distribute print material, would be of high relevance and could also integrate websites from self-help groups. By contrast, counseling facilities and telephone-based counseling seem to be less important less important.

Considering the need for additional information, the high scores for complementary medicine must be discussed considering the setting of a lecture on this topic. It is important to realize that the highest rated topics are nutrition, psyche, cancer, social and legal issues, and physical activity. While diagnostics and treatments are discussed with the physician, cancer centers may engage in a structured information dissemination for these topics. Most of the participants were patients with breast cancer, most of whom were treated in certified breast cancer centers that offer psycho-oncological and social care for any patient perioperatively. However, even this subgroup is in need of further information. Information must be provided during the entire duration of the treatment and during aftercare and should not be concentrated at the start of the treatment when patients are facing diagnosis for the first time.

Finally, turning to the results on perception of the disease, self-efficacy, and locus of control, some important results may be summarized.

Patients with a higher value for the external locus of control significantly more often used any source of information available to them and were more often interested in additional information on all topics. This could be due to their efforts to understand and get control over the disease. In fact, patients who had a high perception of own control of the disease also reported high information needs. By contrast, there were no associations between internal locus of control or self-efficacy and information needs or information seeking. This may be due to higher levels of satisfaction among these patients with the information provided by the physician. Yet, we cannot derive from our data an association between internal locus of control or self-efficacy and satisfaction with information.

Accordingly, we have to assume that patients with higher internal locus of control or self-efficacy have lower information needs, as they rely on their own internal strength. By contrast, information may be needed and used to control or manipulate external forces by those who are less convinced of their internal power. On the other hand, one could argue that patients with a high internal locus of control or self-efficacy may feel less control over the cancer, which might entail fewer needs of information. On the other hand, our data confirm a strong association between internal locus of control or self-efficacy and perceived control on the disease. More research is needed to understand the relationship between the concepts of control or self-efficacy and the information needs of cancer patients in order to better customize information delivered to patients.

Most cancer patients are in high need of information and use diverse sources. Various forms of media offer relevant information, but the quality of information as well as usability and visibility must be enhanced. Furthermore, structured information, as provided in disease management programs, may enhance patient satisfaction with information. As patients have diverse perceptions of self-efficacy and control and since information needs differ with these perceptions, tailored information considering and respecting these differences are mandatory. In order to combine these needs with quality, usability, and visibility, further research is needed to more deeply understand patients' needs.

Physicians and other professionals that intend to provide information on diagnosis and treatment of cancer or survivorship issues may consider that patients with a high need for additional information may be those with a weak perception of control and self-efficacy. Providing facts may not alleviate the problem, and psycho-oncological support may be helpful. Furthermore, physicians should be aware of these patients being more likely to use additional sources of information, which may lead to misinformation and misunderstanding in case of low-quality sources, which may call for additional discussion.

Conflict of Interest The authors declare that they have no competing interests.

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