



## Information needs and usage of complementary and alternative medicine in members of a German self-help group for gastrointestinal stroma tumours, sarcoma, and renal cancer



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### ABSTRACT

**Objective:** 40–50% of German cancer patients use some method of complementary and alternative medicine (CAM) and both patients and doctors often feel insufficiently informed. We examined the information-seeking behaviour and satisfaction with information on patients' interest in CAM and the therapy decision.

**Design and Setting:** An anonymous, voluntary online survey was conducted among the members of "Das Lebenshaus e.V." (House of Life), a decentralized support group for patients with gastrointestinal stroma tumours (GIST), sarcoma, and renal cancer. Data was collected from March 2015 until January 2016 using closed questions with multiple choice if appropriate and in case of ranking, a 5-point Likert scale.

**Interventions:** None.

**Main Outcome Measures:** Correlations between CAM interest, usage, information needs, sources of information and therapy decision were calculated using chi square tests for univariate analyses.

**Results:** Overall, 431 patients took part in our survey, thus return rate was 19.6%. 43.9% (n = 189) of the participants were female, 37.1% (n = 160) were male, 19.0% (n = 82) did not respond. Mean age was 59.8 years. The most common tumours were GIST (34.6%, n = 149), renal cancer (22.3%, n = 96) and sarcoma (20.0%, n = 86). 55.2% (n = 138) of the respondents were patients undergoing treatment, 19.7% (n = 85) were after treatment, 2.6% (n = 11) were relatives and 4.4% (n = 19) others while 18.1% (n = 78) did not respond.

A total of 81.8% (n = 337) of the participants were interested in CAM, but only 44.7% (n = 152) used one of the methods. Women were more commonly interested in CAM (87.2%, n = 163) and used it more often: 53.0% (n = 97) vs. 36.2% (n = 55). Information about CAM was considered important by 85.5% (n = 360) and the Internet was the most commonly used source for information about CAM (77.9%, n = 205). However, 61.4% (n = 233) were not satisfied with the information received about CAM, especially from doctors and hospitals. Patients unsatisfied with the information they had formally received about the course of their disease significantly more often used CAM (p = 0.029). Users would also make the therapy decision by themselves more often (p = 0.036). Nearly a fifth did not disclose their use to a doctor.

**Conclusions:** Dissatisfaction with received information reveals a strong need for scientific information to be available to both patients and doctors. Physicians should get special training about CAM. As the Internet is an important source, high-quality and scientific information should be portrayed on webpages easily accessible to patients.

### 1. Introduction

Cancer diagnosis is a life-threatening event. It is therefore unsurprising that patients often grasp at any possibility to potentially cure

their disease. In times of mechanized medicine and highly potent drugs, patients are also looking for gentler therapies with few or no side effects, which they hope to find in complementary and alternative medicine (CAM).<sup>1,2</sup>

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According to the definition of the National Center for Complementary and Integrative Health (NCCIH), complementary medicine is a non-conventional method used alongside traditional medical treatment, whereas alternative medicine describes the use of this treatment instead of conventional medicine.<sup>3</sup> CAM methods often promise patients to be more effective<sup>1,2</sup> or support their body's battle against cancer.<sup>1,2</sup> However, the motivations for CAM use are diverse.

CAM usage has proven to be frequent among cancer patients,<sup>4,5</sup> in Germany 40–50% of them report using some method of CAM,<sup>1,6,7</sup> with even up to 90% among breast cancer patients.<sup>8</sup>

But its use is often unknown by the doctor in charge of the treatment.<sup>9,10</sup> Additionally, many doctors and students don't feel educated enough in the field of CAM<sup>11,12</sup> while patients equally express a need for more information.

In our study the influence of information needs on the interest and the use of CAM by patients was investigated. We then examined the usage as well as disclosure to their doctors to get a better picture about the CAM users of a German non-profit organization and the motivation for their CAM use.

## 2. Materials and methods

### 2.1. Study population

All members of the German non-profit organization Das Lebenshaus e.V. (House of Life), a decentralized support group for patients with gastrointestinal stroma tumours (GIST), sarcoma, and renal cancer, were asked via email to participate in our online survey between March 2015 and January 2016. Participation in the survey was voluntary and anonymous.

### 2.2. Questionnaire

A standardized questionnaire was developed by experts from the working group Prevention and Integrative Oncology of the German Cancer Society and patient advocates from the self-help group Das Lebenshaus. The questionnaire was merged from standardized questionnaires the working group has developed for CAM,<sup>1,2,7</sup> patients' information needs, information seeking behaviour, and communication<sup>13,14</sup> as well as from a validated psychological inventory.<sup>15</sup>

It is comprised of 13 questions and divided into 4 sections:

- 1) Personal data (age, gender, type of tumour, level of education, patient or relative)
- 2) Information on the disease and treatment
  - General information needs
  - Satisfaction with information
  - Source/provider of information
- 3) Interest in CAM
  - Reasons for interest
  - Current use of CAM
  - Source/provider of information
  - Information about CAM usage shared with doctor
  - CAM method used most often and opinion of oncologist on its use
- 4) Personality traits according to the Big Five by Rammstedt et al.<sup>15</sup>

We used closed questions with multiple choice if appropriate and in case of ranking, a 5-point Likert scale. During the data analysis phase, it was not always necessary to specify the full scale of possible responses and in those cases the results were simplified. For instance, “very” and “rather satisfied” were combined into “satisfied”; likewise, “rather” and “very unsatisfied” became “unsatisfied”.

Data about general information needs and the correlations with the Big Five personality traits will be published separately.

**Table 1**

Demographical data of the participants (N = 431).

	Total (n)	in %
<b>Gender</b>		
Female	189	43.9
Male	160	37.1
No response	82	19.0
<b>Age (years)</b>		
≤ 35	13	3.0
36–50	54	12.5
51–65	164	38.1
66–80	118	27.4
≥ 80	2	0.5
No response	80	18.6
<b>Education</b>		
Basic education <sup>a</sup>	33	7.7
Secondary education <sup>b</sup>	76	17.6
Higher education <sup>c</sup>	166	38.5
No response	156	36.2
<b>Category</b>		
Patient under treatment	238	55.2
Patient post treatment	85	19.7
Relative	11	2.6
Other	19	4.4
No response	78	18.1
<b>Type of tumour</b>		
GIST	149	34.6
Renal cancer	96	22.3
Sarcoma	86	20.0
Gynaecologic cancer	5	1.2
Hematologic malignancy	3	0.7
Urologic cancer (except renal cell carcinoma)	2	0.5
Solitary fibrous tumour	2	0.5
Malignant melanoma	1	0.2
Others <sup>d</sup>	17	3.9
No response	80	18.6

<sup>a</sup> Certificate of Secondary Education.

<sup>b</sup> General Certificate of Secondary Education.

<sup>c</sup> High school/college/university degree.

<sup>d</sup> More than one type of tumour or tumour not specified.

### 2.3. Approval from ethics committee

According to the rules of the ethics committee of the J.W. Goethe University at Frankfurt, no ethical vote was necessary for this anonymous survey.

### 2.4. Statistics

Analysis of chi-square tests for univariate analyses was carried out using IBM SPSS Statistics 23. The level of significance was  $p < 0.05$ .

## 3. Results

### 3.1. Demographic data

The questionnaire was distributed to the 2199 members of the House of Life. Overall, 431 members took part in our survey, thus the return rate was 19.6%. 43.9% of the participants were female, 37.1% were male, 19.0% did not respond. Mean age was 59.8 years. Detailed demographical data can be seen in [Table 1](#).

### 3.2. Interest in CAM

A majority of the participants (81.8%,  $n = 337$ ) were interested in CAM; 39.3% ( $n = 162$ ) of the participants had been interested before having cancer, whereas 42.5% ( $n = 175$ ) only showed interest in CAM since the diagnosis. Only 18.2% ( $n = 75$ ) of the participants were not

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