

INFORMATIONSBEDARF VON PATIENTEN MIT SELTENEN
TUMORERKRANKUNGEN ZU IHRER ERKRANKUNG, DER
THERAPIE UND ZUR KOMPLEMENTÄREN UND
ALTERNATIVEN MEDIZIN SOWIE DEREN NUTZUNG

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1. Abkürzungsverzeichnis

1.1 Deutsches Abkürzungsverzeichnis

GfBK	–	Gesellschaft für Biologische Krebsabwehr e.V.
GIST	–	Gastrointestinale Stromatumore
KAM	–	Komplementäre und Alternative Medizin
KID	–	Krebsinformationsdienst

1.2 Englisches Abkürzungsverzeichnis

BFI-10	–	Big Five Inventory-10
CAM	–	Complementary and Alternative Medicine
IABD	–	Interest already before the diagnosis
IOSD	–	Interest only since the diagnosis
Fig.	–	Figure
NCCIH	–	National Center for Complementary and Integrative Health (USA)
SDM	–	Shared decision-making
Tab.	–	Table

2. Zusammenfassung

Eine Tumordiagnose zu erhalten ist ein schwerwiegendes Ereignis für den Patienten und geht mit einem erhöhten Informationsbedarf bei diesem einher. Dies gilt nicht nur für die konventionelle Therapie, sondern auch für Komplementäre und Alternative Medizin (KAM). Tumorpatienten informieren sich zunehmend selbstständig über ihre Erkrankung, Therapie und auch über KAM, beispielsweise im Internet. Doch gerade hier sind Informationen häufig von schlechter medizinischer Qualität. Dies ist jedoch für Patienten nur schwer zu erkennen. Problematisch ist, dass Ärzte von ihren Patienten häufig nicht darüber informiert werden, wenn diese KAM nutzen. Dies kann ernsthafte Risiken bezüglich der Behandlung zur Folge haben. Daher ist es wichtig, potentielle KAM-Nutzer besser erkennen zu können. Typische Charakteristika von KAM-Nutzern sind aus der Literatur bekannt: es handelt sich in der Tendenz um jüngere, gut gebildete, weibliche Patienten mit einem höheren Tumorstadium.

Ziel der vorliegenden Dissertation war es, ein umfassenderes Bild sowohl über den generellen Informationsbedarf von Patienten mit seltenen Tumorerkrankungen als über auch deren Informationsbedarf in Bezug auf KAM zu erarbeiten. Zudem sollte die Zufriedenheit mit den erhaltenen Informationen untersucht werden. Insbesondere sollte untersucht werden, ob Unterschiede zwischen Patienten bestanden, welche bereits vor der Tumordiagnose Interesse an KAM zeigten, und solchen, die sich erst seither dafür interessierten. Dadurch soll in der Praxis ein gezielteres Ansprechen von KAM bei Tumorpatienten erleichtert werden.

Die drei Originalarbeiten widmen sich diesen Themen mit unterschiedlichen Schwerpunkten. Sie basieren dabei auf einem gemeinsamen Datensatz. Dieser wurde mittels eines Fragebogens in einer Onlinebefragung einer web-basierten Selbsthilfegruppe für Patienten mit seltenen soliden Tumoren erhoben. Es wurden persönliche Daten, Informationen über Erkrankung und Behandlung, Interesse an KAM, deren Nutzung sowie die Big Five nach Rammstedt erfragt. Die statistische Auswertung sowie die Einschlusskriterien unterscheiden sich in den drei Publikationen leicht voneinander.

Der Schwerpunkt bei Eisfeld et al. (2020) liegt in der Analyse des *generellen Informationsbedarfs* sowie der Zufriedenheit mit verschiedenen Informationsquellen über Informationen zur Erkrankung und Behandlung und deren Einfluss auf die

Therapieentscheidung. In Bauer et al. (2018) lag das Hauptaugenmerk auf der Untersuchung des *Informationsbedarfs über KAM* und der Zufriedenheit mit diesen Informationen. Es wurde deren Einfluss auf das Interesse und die Verwendung von KAM sowie die Therapieentscheidung analysiert. Der Fokus von Dubois et al. (2019) bestand in der Untersuchung der *Unterschiede zwischen Patienten* mit Interesse an KAM vor beziehungsweise nach der Tumordiagnose.

In Einfeld et al. (2020) fand sich ein hoher Informationsbedarf und eine hohe Zufriedenheit der Teilnehmer mit den erhaltenen Informationen zu Therapie und Erkrankung (über 80 %). Jedoch zeigte sich in Bezug auf den Umgang mit Nebenwirkungen und Unterstützungsmöglichkeiten die geringste Zufriedenheit (72,0 %, resp. 70,1 %). Selbsthilfegruppen, das Internet sowie der Onkologe stellten die drei wichtigsten Informationsquellen dar.

Bauer et al. (2018) zeigten, dass das Interesse an KAM unter den Studienteilnehmern ebenfalls hoch war (81,8%), jedoch lediglich 48,3 % tatsächlich eine KAM-Methode verwendeten. Beinahe zwei Drittel waren mit den Informationen über KAM unzufrieden. Teilnehmer waren mit Informationen über KAM aus dem Internet zufriedener, als mit denen von medizinischem Personal, deren Informationen als besonders unzufriedenstellend bewertet wurden. Die wichtigste Informationsquelle über KAM stellten jedoch nicht Ärzte, sondern das Internet dar.

In Dubois et al. (2019) zeigte sich, dass die bisher bekannten Charakteristika eines KAM-Nutzers auf Patienten, welche erst seit der Tumordiagnose Interesse an KAM bekundeten, nicht zutrafen. Auch legte knapp ein Fünftel der Patienten ihre KAM-Nutzung keinem Arzt gegenüber offen.

Diese Dissertation belegt die fundamentale Bedeutung des Arztes in der Informationsvermittlung. Gerade in Bezug auf KAM sollte aktives Informieren und Hilfestellung zur Internetrecherche ein integraler Bestandteil jeder onkologischen Behandlung sein. Wie die hier vorliegenden Studien gezeigt haben ist es für den Arzt nicht trivial, potenzielle KAM-Nutzer zu identifizieren, auch da diese die Nutzung häufig nicht von selbst ansprechen. Daher sollte mit jedem Patienten die Möglichkeit der sinnvollen und risikofreien Integration von KAM in die Tumorbehandlung besprochen werden. Dies kann helfen, die Arzt-Patientenbeziehung sowie die

Patientenzufriedenheit zu verbessern und damit zu einem positiven Behandlungsverlauf beitragen.

3. Einleitung

Die Diagnose einer Krebserkrankung ist ein einschneidendes Ereignis im Leben jedes Patienten. Die ansteigende Inzidenz hat zur Folge, dass sich immer mehr Menschen mit einer potenziell lebensbedrohlichen Diagnose und der daraus resultierenden, oft belastenden Therapie auseinandersetzen müssen.

Hierdurch entsteht ein Bedürfnis nach Aufklärung und Informationen über die Erkrankung, möglichen Therapieoptionen und deren Nebenwirkungen. Bisherige Studien zeigten einen hohen Informationsbedarf von Tumorpatienten (Blanchard et al. 1988, Jenkins et al. 2001, Güleser et al. 2012, Oerlemans et al. 2012, Rudolph et al. 2015). Die Zufriedenheit mit den erhaltenen Informationen korreliert dabei mit einer höheren Lebensqualität (Davies et al. 2008, Husson et al. 2010). Ein erhöhter Informationsbedarf hingegen korreliert nachweislich mit einem verminderten Vertrauen in medizinisches Personal (Neumann et al. 2011, Pieper et al. 2015).

Wohl auch aus diesen Gründen wollen Patienten immer mehr selbst aktiv in den Prozess der Therapieentscheidung eingebunden werden (Guadagnoli und Ward 1998, Gaston und Mitchell 2005, Vogel et al. 2008, Gaisser 2012, Efficace et al. 2014). Daher stellt die partizipative Entscheidungsfindung (engl. shared decision-making, SDM) die evidenzbasierte Empfehlung für Therapieentscheidungen dar. Hierbei informiert der Arzt den Patienten über die möglichen Therapieoptionen, die finale Entscheidung treffen Arzt und Patient gemäß dessen Ansichten und Präferenzen gemeinsam. Dies verringert nachweislich das Risiko, die Therapieentscheidung im Laufe der Behandlung zu bereuen (Nicolai et al. 2016) und ist mit einem verbesserten emotional-kognitiven Outcome assoziiert (Shay und Lafata 2015).

Zunehmend stellen jedoch nicht nur Ärzte wichtige Informationsquellen über Erkrankung und Therapie dar. Immer häufiger informieren sich Patienten selbstständig im Internet (Ebel et al. 2017), aber auch über andere Medien, Verwandte und Selbsthilfegruppen (Elsner et al. 2013). Doch gerade die im Internet verfügbaren Informationen sind sehr inhomogen in Bezug auf Inhalt und Qualität der Informationen (Matthews et al. 2003, Schmidt und Ernst 2004, Brauer et al. 2010). Dies ist für Patienten jedoch meist nicht ersichtlich, da sich die Reihenfolge der angezeigten Artikel an größtenteils undurchsichtigen Suchalgorithmen sowie der Beliebtheit (Klicks), jedoch nicht an der Qualität der Informationen orientiert.

Zusätzlich zu konventionellen Behandlungsmethoden verwenden Tumorpatienten zudem zunehmend *komplementäre* und *alternative Medizin* (KAM) (Eschiti 2007). Das National Center for Complementary and Integrative Health (NCCIH) der USA definiert *komplementäre* Medizin als eine Methode, welche parallel zur konventionellen Behandlung, während *alternative* Medizin stattdessen angewandt wird (NCCIH 2016). Das NCCIH unterteilt diese weiter in biologisch basierte Produkte (Naturprodukte), wie beispielsweise Kräuter, Vitamine, Mineralien oder Probiotika, und in Körper-Geist-Praktiken, zum Beispiel Gebet, Meditation, Yoga, Entspannungstechniken oder Osteopathie.

Das Interesse an diesen Methoden unter Tumorpatienten ist hoch (Loquai et al. 2017). In verschiedenen Studien fand sich eine signifikant höhere Prävalenz der KAM Nutzung bei onkologischen Patienten im Vergleich zur Normalbevölkerung (Velicer und Ulrich 2008, Horneber et al. 2012). In Deutschland berichten 40-50% der Tumorpatienten eine oder mehrere KAM-Methoden zu verwenden (Paul et al. 2013, Huebner et al. 2014a). In einer Studie mit deutschen Brustkrebspatientinnen waren dies sogar bis zu 90% der Teilnehmerinnen (Micke et al. 2009). Auch in anderen Ländern findet sich eine ähnliche Prävalenz (Richardson et al. 2000, Eschiti 2007, Velicer und Ulrich 2008, Horneber et al. 2012).

Die Gründe für das hohe Interesse der onkologischen Patienten an KAM sind heterogen. Häufig genannte Gründe für das Interesse und die Verwendung sind das eigene Immunsystem zu stärken, selbst aktiv zu werden und den Körper im Kampf gegen die Krebserkrankung unterstützen zu wollen. Zudem erhoffen sich Tumorpatienten, durch KAM mögliche Nebenwirkungen der konventionellen Therapie reduzieren zu können. Auch wollen viele Patienten im Kampf gegen Krebs nichts unversucht lassen (Molassiotis et al. 2005, Huebner et al. 2014b, Wortmann et al. 2016). Dabei nehmen sie KAM häufig als sanfte Therapie ohne Nebenwirkungen wahr, gerade im Vergleich zur konventionellen Medizin (Singh et al. 2005).

Doch auch KAM bergen das Risiko von Nebenwirkungen. Bei paralleler Verwendung können zudem potenziell Interaktionen auftreten oder Nebenwirkungen der konventionellen Therapie verstärkt werden. Dies ist vor allem bei biologisch basierten Substanzen der Fall. Neuere Studien zeigen, dass zwischen 29% und 55% der KAM-Nutzer dem Risiko von Interaktionen ausgesetzt sind (Zeller et al. 2013, Firkins et al. 2018).

Dieses Risiko ist jedoch häufig weder Patienten noch medizinischem Personal zur Genüge bekannt (Trimborn et al. 2013). Problematisch ist auch, dass bis zu 77 % der Ärzte berichten, allgemein keine ausreichenden Kenntnisse über KAM zu haben (Henf et al. 2015). Auch ein Großteil der Medizinstudenten gibt an, nicht ausreichend über KAM informiert zu sein (Muenstedt et al. 2011).

Ein weiteres Problem besteht darin, dass Patienten ihren Onkologen zudem häufig nicht über die Verwendung von KAM informieren, dieser auftretende Symptome somit nicht einordnen kann und sie darum möglicherweise der von ihm erfolgten Therapie zuschreibt. (Saxe et al. 2008). Studien zeigten, dass zwischen 20% und 77% der Patienten mit keinem ihrer Ärzte über ihre KAM Nutzung sprechen (Robinson und McGrail 2004, Davis et al. 2012, King et al. 2015).

Daher besteht die große Notwendigkeit, Patienten, die zu einer KAM-Nutzung neigen, möglichst frühzeitig zu identifizieren. Bereits vielfach nachgewiesen ist ein Zusammenhang von soziodemografischen Faktoren und KAM-Nutzung sowohl in der Allgemeinbevölkerung (Frass et al. 2012) als auch unter Tumorpatienten (Micke et al. 2009, Nilsson et al. 2016, Toivonen et al. 2018). Der typische KAM-Nutzer ist weiblich, jünger, gut gebildet und hat ein höheres Tumorstadium (Micke et al. 2009). Zunehmend wird auch der Zusammenhang von Persönlichkeitsfaktoren und KAM-Nutzung erforscht. Meist wird hier der Big Five zugrunde gelegt (Rammstedt et al. 2014). Offenheit wurde mit einer erhöhten Verwendung von KAM assoziiert (Lo-Fo-Wong et al. 2012, Toivonen et al. 2018), jedoch ist die Datenlage bislang unzureichend und zudem widersprüchlich (Olchowska-Kotala 2013).

Die hier präsentierten Publikationen widmen sich diesen Fragen in einer speziellen Population: den Mitgliedern der gemeinnützigen Organisation „Das Lebenshaus e.V.“. Diese ist eine dezentrale Selbsthilfegruppe für Patienten mit Gastrointestinalen Tumoren (GIST), Sarkomen und Nierenzellkarzinomen, allesamt seltene solide Tumore.

Alle drei hier behandelten Publikationen beruhen auf diesem Datensatz, befassen sich jedoch mit verschiedenen Teilaspekten, welche dadurch eingehender beleuchtet werden konnten:

- Der generelle Informationsbedarf der Patienten, das Interesse an und die Verwendung von KAM in der Studienpopulation (Bauer et al. 2018)

- Der Vergleich von Patienten, die schon vor der Krebsdiagnose an KAM interessiert waren mit Patienten die erst danach Interesse bekundeten (Dubois et al. 2019)
- Die Zufriedenheit der Patienten mit Informationen über ihre Erkrankung, deren Wichtigkeit und der Einfluss auf die Therapieentscheidung (Eisfeld et al. 2020)

So soll eine umfassendere Aussage über den Informationsbedarf, die Zufriedenheit mit den Informationen sowie den Zusammenhang mit der Verwendung von komplementärer und alternativer Medizin in dem untersuchten Patientenkollektiv getroffen werden.

4. Ziele der Arbeit

Diese Arbeit verfolgt mehrere Ziele. Das übergeordnete Ziel ist es, ein umfassendes Bild sowohl über den generellen Informationsbedarf als auch den Informationsbedarf in Bezug auf KAM von Patienten mit seltenen Tumorerkrankungen (Sarkome, GIST, NCC) zu erarbeiten und die Zufriedenheit mit den erhaltenen Informationen zu erheben. Die so gewonnenen Daten können dazu beitragen, Vorhersagen über mögliche Verhaltensweisen, Einstellungen und Präferenzen zukünftiger Patienten gegenüber KAM treffen zu können. Dadurch könnten zum einen bedürfnisorientiertere Konsultationen angeboten werden, aber auch die generelle Compliance zur Therapie erhöht und potenziellen Nebenwirkungen oder Interaktionen durch KAM vorgebeugt werden.

Folgende Teilziele werden im Einzelnen verfolgt:

- a. Es soll zunächst der generelle Informationsbedarf und die Zufriedenheit mit verschiedenen Informationsquellen über Informationen zur Erkrankung und Behandlung herausgearbeitet werden.
- b. Daraufhin soll der Informationsbedarf über und die Zufriedenheit mit KAM sowie der Einfluss der erhaltenen Informationen und der Zufriedenheit auf das Interesse und die Verwendung von komplementären und alternativen Methoden untersucht werden.
- c. Ein weiteres Ziel dieser Arbeit ist es, den Einfluss von soziodemografischen und Persönlichkeitsfaktoren sowie den persönlichen Gründen für das Interesse auf die KAM-Nutzung herauszuarbeiten.
- d. Von großem Interesse sind besonders die Unterschiede in der Zufriedenheit mit den erhaltenen Informationen und der KAM-Nutzung bei Patienten, die bereits vor der Diagnose Interesse an KAM zeigten im Vergleich zu denen, die sich erst danach für dieses Thema interessierten.
- e. Zudem soll in diesem Patientenkollektiv der Einfluss der genannten Faktoren auf die Art der Therapieentscheidung (allein, Arzt oder partizipativ) ebenso wie die Offenlegung der KAM-Nutzung gegenüber Ärzten untersucht werden.

Zur Datenerhebung bestand eine Kooperation mit dem Verein „Das Lebenshaus e.V.“. Mit weiteren wissenschaftlichen Stellen bestanden keine Kooperationen.

5. Publizierte Originalarbeiten

5.1 „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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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).^{1,2}

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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.³ CAM methods often promise patients to be more effective^{1,2} or support their body's battle against cancer.^{1,2} However, the motivations for CAM use are diverse.

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

But its use is often unknown by the doctor in charge of the treatment.^{9,10} Additionally, many doctors and students don't feel educated enough in the field of CAM^{11,12} 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,^{1,2,7} patients' information needs, information seeking behaviour, and communication^{13,14} as well as from a validated psychological inventory.¹⁵

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.¹⁵

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 %
Gender		
Female	189	43.9
Male	160	37.1
No response	82	19.0
Age (years)		
≤ 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
Education		
Basic education ^a	33	7.7
Secondary education ^b	76	17.6
Higher education ^c	166	38.5
No response	156	36.2
Category		
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
Type of tumour		
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 ^d	17	3.9
No response	80	18.6

^a Certificate of Secondary Education.

^b General Certificate of Secondary Education.

^c High school/college/university degree.

^d 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

interested in the topic.

The overall interest in CAM methods was very high, both among users and non-users: 96.8% (n = 152) of those who had already used it and 71.6% (n = 136) who had not, were interested in CAM (p < 0.001).

Overall, interest was higher in women than men (87.2%, n = 263 vs. 76.9%, n = 120). However, 54.5% (n = 85) of the male patients only became interested in CAM after their diagnosis, whereas 55.1% (n = 103) of the women had already been interested beforehand (p < 0.001).

Higher education not only correlated with a higher interest in CAM, but also with a significantly higher interest even before cancer diagnosis, whereas patients with a lower education also had lower levels of interest and they more commonly only became interested in CAM after their diagnosis. Globally, interest in CAM was the highest in patients with a higher education (p = 0.017).

3.3. Reasons for interest in CAM

Patients reported different aims with CAM. A total of 57.5% (n = 248) wanted to strengthen their immune system, 58.0% (n = 250) wanted to strengthen their body's own power. Less often cited reasons were to detoxify (23.2%, n = 100) or as a cure for cancer (23.4%, n = 101) (Fig. 1).

Women significantly more often named to “strengthen the immune system” and “strengthen the body's own forces” as well as “detoxify” when asked about their reason for interest in CAM. However, men were more interested in CAM in order not to leave nothing undone: 60.3% (n = 73) vs 54.3% (n = 89, p = 0.005). There was no significant correlation between reasons for CAM use and the level of education.

Patients who had already been interested in CAM before the cancer diagnosis had a wider range of reasons to use it (strengthen immune system 87.5% (n = 126) vs. 80.1% (n = 121); strengthen body's own forces 90.3% (n = 130) vs. 78.1% (n = 118); to detoxify, 37.5% (n = 54) vs. 29.8% (n = 45)). Patients interested since their diagnosis were rather more commonly interested in CAM as a cure for cancer (35.1%, n = 53 vs. 31.3%, n = 45) and to leave nothing undone: (65.6%, n = 99 vs. 49.3%, n = 71) (p < 0.001).

All reasons for interest in CAM - except for not leaving anything undone - were named significantly more often by participants who were or had been using CAM. However, respondents not using CAM significantly more often stated they were interested in CAM not to leave anything undone: 65.7%, n = 90 vs 50.7%, n = 77 (p = 0.001).

3.4. Importance of information about CAM

There was a very high need for information. In our survey, 98.8% (n = 417) considered information about their disease and treatment very or rather important, so did 97.9% (n = 410) about information on

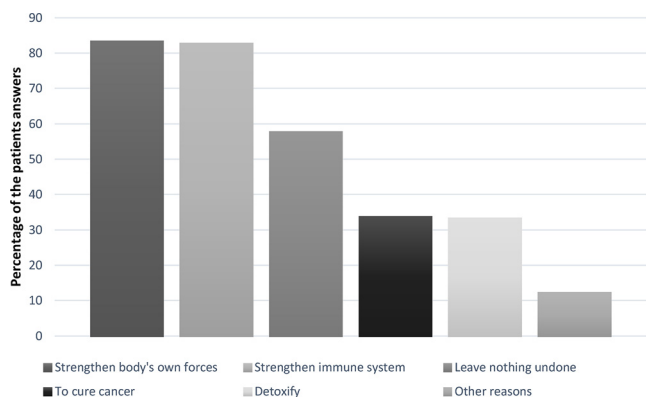


Fig. 1. Reasons for interest in CAM (N = 300).

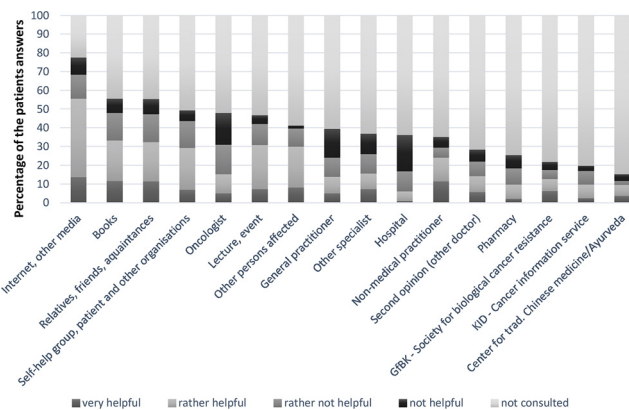


Fig. 2. Sources of information on CAM and its rating by the participants (N = 288).

possible side effects.

Information on CAM was considered important by 85.5% (n = 360). Of those, 66.9% (n = 241) considered them very important. Only 14.5% (n = 61) did not find it important.

Information about CAM was important to both men and women, but women were significantly more interested than men: 88.3%, n = 166 vs. 79.6%, n = 125 (p = 0.027).

In our study, the Internet was the most commonly used source of information about CAM: 77.9% (n = 205) of the patients used it, more than half (55.9%, n = 147) also considered the information very or rather helpful. Other frequently used sources were books (56.0%, n = 145), relatives and friends (55.8%, n = 145), as well as self-help groups (49.8%, n = 128). Almost half of the patients consulted their oncologist for information about CAM (48.2%, n = 123). Interestingly, patients were especially unsatisfied with the information they received from the hospital and other doctors: 67.6% (n = 83) of them were unsatisfied with CAM information from their oncologist and even 82.5% (n = 76) said so about the information from the hospital (Fig. 2).

The importance of information about CAM significantly correlated with more frequent consultation of non-medical practitioners (p = 0.007) (German: Heilpraktiker; a non-academic profession approve by the state who are allowed to diagnose and treat diseases without involvement of a physician) and the GfBK (Society for Biological Cancer Defence, an association of diverse professionals committed to a broad range of complementary and alternative medicine) (p = 0.020) for information about the disease and treatment.

Also, the less helpful the respondents considered the information about the disease and treatment provided by the oncologist, the more important they found information about CAM therapies (p = 0.028).

The use of the Internet for information about CAM was significantly more common in younger patients (< 35 years; p = 0.043). They also considered the Internet significantly more helpful than older ones (p = 0.043).

Women consulted relatives (p = 0.022), non-medical practitioners (p < 0.001), and centres of Traditional Chinese Medicine (p = 0.004) significantly more often with respect to CAM and were also more satisfied with the information they received compared to male patients (p = 0.022).

Older patients were significantly less satisfied with the information about CAM provided by their oncologist, but at the same time also consulted an oncologist significantly less often than younger patients (both p = 0.002).

3.5. CAM usage

About half of those interested in CAM (43.8% of all participants, n = 152) stated they had already used or were currently using a method of CAM (p < 0.000).

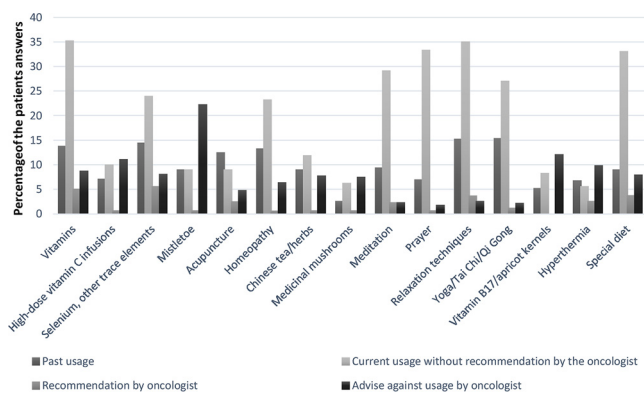


Fig. 3. Usage of different CAM methods and respective oncologist's advice about these methods (N = 279).

The most frequently used CAM methods overall were relaxation techniques (50.2%, $n = 99$), vitamins (48.9%, $n = 103$), Yoga/Tai Chi/Qi Gong (42.3%, $n = 80$), and special diets in 41.9% ($n = 80$) (Fig. 3). With respect to currently most used methods the numbers were similar: vitamins (35.2%, $n = 77$), relaxation techniques (35.0%, $n = 69$), prayer (33.3%, $n = 58$), and special diets (33.0%, $n = 63$). Patients also consulted the oncologist more often about these methods. The oncologist most often recommended selenium or other trace elements (5.5%, $n = 11$), vitamins (5.0%, $n = 11$), as well as special diets (3.7%, $n = 7$). The CAM methods most advised against were mistletoe therapy (22.2%, $n = 40$), vitamin B17/apricot kernels (12.0%, $n = 19$), high-dose vitamin C infusions (11.0%, $n = 19$), and hyperthermia (9.8%, $n = 16$).

CAM use significantly correlated with gender: 53.0% ($n = 97$) of the women had already used CAM, in comparison to 36.2% ($n = 55$) of the men ($p = 0.002$). Younger patients used CAM significantly more often than older patients ($p = 0.033$).

A higher education not only significantly correlated with a higher interest in CAM ($p = 0.017$), but also with a higher usage of CAM methods ($p = 0.007$).

Using CAM methods significantly correlated with dissatisfaction with the information about the course of disease ($p = 0.029$) and how to deal with side effects ($p = 0.003$). A significantly higher use of CAM was found in patients who consulted their relatives ($p = 0.001$), non-medical practitioners ($p < 0.001$), centres of Traditional Chinese Medicine ($p < 0.001$) as well as the GfBK ($p < 0.001$) or books ($p < 0.001$) for information about the disease and treatment. It was high in patients satisfied with the obtained information, but still even significantly higher in unsatisfied patients compared to those who did not consult these sources ($p < 0.001$).

3.6. Influence of satisfaction with information

Overall satisfaction with information about the disease and the comprehensibility of the information was very high in our survey, more than 80% ($n = 345$, $n = 347$) stated to be satisfied. However, satisfaction with information about possible support such as self-help groups, about side effects, and how to deal with it was considerably lower. It was the lowest for CAM methods: only 7.6% ($n = 29$) were very satisfied with the information about CAM, but 43.2% ($n = 164$) were rather and 18.2% ($n = 69$) even very unsatisfied.

Patients who were less satisfied with the information provided also showed significantly more interest in CAM methods. This was valid for information about their disease in general ($p = 0.012$), possible support ($p = 0.014$), the course of the disease ($p = 0.002$), type of therapy ($p = 0.021$), effects of cancer medication ($p = 0.001$), and how to deal with their side effects ($p = 0.022$), as well as information about CAM methods ($p < 0.001$).

Using CAM methods also significantly correlated with

dissatisfaction with the information given by the oncologist about the course of disease ($p = 0.029$) and how to deal with side effects ($p = 0.003$). Yet, there was no significant correlation between the use of CAM and the satisfaction with the information about the disease, the comprehensiveness of the information, possible support, and the type of therapy of the disease, the effects of the cancer medication and its possible side effects, nor with information about CAM itself.

3.7. Involvement in therapy decision

When asked about how the final decision about their treatment was established, 12.3% of the patients stated they made this decision by themselves, in 17.2%, it was the doctor's decision, but for the majority of 70.4%, it was a consensual one made together with their physician.

Patients using CAM significantly more often made the decision about the therapy alone and less often as a consensual one or by the doctor when compared to non-users ($p = 0.036$).

3.8. Disclosure about CAM use

Almost one third (28.1%, $n = 121$) of the participants informed their oncologist about their CAM use, 24.1% ($n = 104$) shared this information with their general practitioner (GP) and 8.4% ($n = 36$) did so with another specialist, 2.8% ($n = 12$) did not recall if or who they told about their usage. However, a total of 14.8% ($n = 64$) of the participants did not confide in any doctor.

Patients with lower education significantly more often disclosed using CAM to their oncologist and other physicians while patients with a higher education more often did to their general practitioner ($p < 0.001$).

4. Discussion

In our survey, we found more than 80% of the patients interested in CAM, yet only about half of them used some CAM method. Over half of those not interested still considered information on CAM important. While satisfaction with information on the disease was high, satisfaction with information about CAM was very low. The Internet was the most commonly used source of information about CAM and considered helpful by about half of the participants. Interest in CAM was higher in patients who were less satisfied with the information on their disease. As our survey demonstrates, CAM is a highly relevant topic in cancer patients who do not feel sufficiently informed.

The prevalence of CAM usage is in line with other data from Germany^{6,7} and from other countries.^{16–18} Also, the higher interest and user rate in female participants, younger patients, and well-educated patients^{16,19–22} is consistent with other studies. These correlations are especially highly significant for gender and education. One explanation is that these groups are more proactive with respect to participation in therapy. Another explanation could be a general trend towards alternative methods in society. Furthermore, men seem to have a more practical reason to use CAM as they highly significantly more often marked "not leaving anything out" as reason.

This notion goes along with CAM usage being highly associated with non-scientific sources such as relatives, non-medical practitioners or centres of Traditional Chinese Medicine.¹

However, the gap between interest in CAM and its actual use was surprisingly large: only about half of those interested in the topic also actually used CAM methods. To our opinion, the underlying reasons might be manifold: patients could be generally interested, but still trust their doctors to choose the best therapy for them or have more trust in academic medicine than CAM methods. They might also still be undecided whether to use it, as there is a lack of objective, scientific information on the subject. Moreover, as already Molassiotis and colleagues argued in 2005 they might not be able to afford a CAM therapy, as it often involves privately paying for it.²¹

In our survey, the Internet was the most commonly used source on CAM, especially among younger patients, who are more familiar with web-based information-seeking.²³ Patients prefer its easy accessibility, low costs and possibility of easily exchanging experiences with other patients. However, information on the Internet is of very variable content and quality.^{24–26}

When looking at the satisfaction with the information about CAM from different sources, patients were especially unsatisfied with the information they received from the hospital, the oncologist, or other doctors. One reason could be that healthcare professionals often don't feel sufficiently informed about CAM^{11,12} as there is a general lack of scientific information on the subject. Most importantly, patients dissatisfied with the information provided by the oncologist about their disease and treatment found information about CAM significantly more important. There might be two quite different reasons for this phenomenon. For one, the information from the oncologist might have been unsatisfactory, thus leaving the patient looking for alternatives. Another explanation might be that the association of a high interest in CAM correlates with higher needs for information in general or leads to some scepticism towards conventional medicine that is difficult to overcome. Additionally, dissatisfaction with the information about the course of the disease and how to deal with side effects was highly significantly associated with higher CAM usage. The dissatisfaction may lead to disappointment in academic medicine and an increased usage of alternative methods.

CAM users made the decision about the therapy significantly more often by themselves and less often as a shared decision or as a decision by the doctor. This could be due to the stronger dissatisfaction with the information provided and less trust in the doctor's advice as a result. It is also possible that patients using CAM want to feel more active, more in control, and take their fate into their own hands.² Yet, in an earlier study, we have shown that CAM usage is associated with less perception of self-efficacy.¹⁴ Accordingly, feeling disappointed by the physician and having low trust in one's own forces might be a leading motivator for using CAM. In fact, often CAM methods are offered as an absolute chance for healing without risks.²⁷

Nearly a fifth of patients in our study either did not recall whether they informed a doctor on using CAM or reported that they had not done so. With respect to side effects or interactions,²⁸ this missing information put patients at serious risk²⁹ to which the physician may not react adequately.

4.1. Limitations

One limitation of our survey is the return rate of about 20%, which is in line with other online surveys. Additionally, it seems likely that more patients who are familiar with web-based information-seeking returned the online questionnaire. Accordingly, we cannot say if the results are representative for all the members of the House of Life or all patients with respective diseases.

Furthermore, having actively made contact and joined the self-help group, the participants already demonstrated a high interest in information on the disease and possible treatments. The high levels of activity and information needs are therefore unsurprising.

Another potential bias is the fact that the majority of the participants showed a higher education which goes along with higher interest in CAM.^{16, 19–21}

Last but not least, the questionnaire was not validated, yet, it is a merger of several instruments which have been used in different patient groups and which have provided consistent results in several other surveys.

5. Conclusions

There is an urgent need for high quality, trustworthy information about CAM that is easily accessible to patients. Objective information

on CAM should be portrayed on reliable websites to appropriately inform patients about CAM methods, possible side effects, and interactions according to current research. Doctors should know about these websites to recommend them to their patients.

Additionally, there is a need for training for healthcare professionals on CAM in general.

This training should not only be offered to oncologists, but to all doctors and especially general practitioners. It should not only include information about effects, side effects, and interactions, but also about communication on CAM with patients. Doctors should actively address the patient's interest and ask for potential CAM use in order to recommend suitable and safe CAM methods. Better communication about the oncological treatment and side effects in addition to actively informing about CAM and its reasonable integration into the treatment regimen might lead to better adherence to the conventional treatment and thus improve outcomes.³⁰

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Conflict of interest

The authors declare that they have no conflict of interest.

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5.2 „Importance of and Satisfaction with Information about Their Disease in Cancer patients”

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Importance of and Satisfaction with Information about Their Disease in Cancer Patients

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Abstract

To learn more about information needs and satisfaction with provided information among cancer patients and whether dissatisfaction with information has any association with how therapy decisions are made. An online survey was conducted during March 2015 and January 2016 by the German non-profit patient organization “Das Lebenshaus e.V.” among their members with rare solid tumors. A total of 338 records was analyzed. The majority found information on their disease important and was satisfied with the provided information. The participants were less satisfied with the information concerning management of side effects than with other aspects of information ($p < .001$). Support groups, lectures, and the oncologist were rated as the most helpful sources of information followed by a second opinion and media. Participants who were dissatisfied with the information more often made the decision on the treatment alone by themselves ($p < .001$). Our results show a high satisfaction with disease-related information among our study participants. Improvements could be made by offering more information on the management of side effects and by giving more information about support groups, reliable websites, and other helpful media.

Keywords Patient information needs · Satisfaction with information · Shared decision-making · Patient support groups · Patient lectures

Introduction

Cancer incidence is rising over the last years. As cancer belongs to the leading causes of death worldwide, it confronts a patient with a life-threatening diagnosis and its therapy is often stressful. Information about the disease, its therapy, and side effects are therefore crucial for the patient. Being satisfied with the provided information is related to a better health-related quality of life [1]. Former studies could show that anxiety and depression are associated with dissatisfaction with information [2, 3]. Therefore, providing cancer patients with the information they need should be given high priority.

There are multiple sources for patients to gain information about their disease. The internet has become one of the most important sources of information on health issues and its use has increased significantly during the last years [4, 5]. Cancer patients prefer the physician as source of information are not only using the internet for gathering information on their disease and treatment but also to find support and exchange with other persons affected [6, 7]. Need of information is inversely associated with trust in physicians and nurses [8]. Furthermore, patients want to be involved in the decision on how much information is provided [9].

Shared decision-making (SDM) is the recommended decision model in evidence-based medicine with the physician giving input in a form of information and the patient formulating his preferences and weighing different treatment options based on the information provided and considering his preferences.

Several studies have shown that people with lower education and less literacy and numeracy less often engage in SDM [10]. This might be due to less confidence in their own ability to understand the information provided and to draw adequate conclusions. Moreover, patients with lower education may be less confident in discussing with the authority physician.

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SDM leads to less decisional regret [11]. Decisional regret is an important concept in oncology especially with respect to unsuccessful treatments and (long-lasting) side effects. Decisional regret leads to less satisfaction with life and less quality of life. Accordingly, SDM is an important means to increase patients' quality of life [12].

Besides education and literacy, the subjective feeling of having received satisfying information might be an important prerequisite for patients to engage in SDM. In order to learn more on this association, we decided to set up a survey among patients with rare tumors who might less often find sufficient information. We decided to conduct an online survey with the members of the organization "Das Lebenshaus e.V." (in English "House of Life") to learn more about their information needs, satisfaction with provided information, and perceived helpfulness of different sources of information.

This organization is a German non-profit self-help organization for patients with rare solid tumors.

Methods

Study Design and Sample

This survey was conducted during March 2015 and January 2016 by the German nonprofit patient organization "Das Lebenshaus e.V." All members were asked via email to participate in the online survey. Participants were informed that the study was voluntary and anonymous.

Questionnaire

The online survey consisted of a standardized questionnaire which was developed by the working group Prevention and Integrative Oncology based on a questionnaire on Complementary and Alternative Medicine (CAM) developed by this group [4, 13] and integrated the Big Five questionnaire on personality traits [14]. The questionnaire consisted of 4 sections and 13 questions:

- Information needs and satisfaction with information
- Interest and use of CAM
- Personality traits according to the Big Five by Rammstedt et al. [14]
- Personal data (age, gender, type of cancer...)

We used closed questions and in case of rating a Likert Scale.

For this article, we analyzed the data about information needs and satisfaction with information. The data about the interest and use of CAM and the correlations with the Big Five personality traits will be published separately.

Ethics

An ethical approval of this anonymous online survey was not necessary according to the rules of the ethics committee of the J.W. Goethe University at Frankfurt.

Statistics

Data sets were excluded if the participant had no oncologic disease (e.g., relative) or if there was no answer on this question.

For statistical analysis, Likert Scale responses were grouped into two categories. The categories very and rather important were grouped into important and rather and very unimportant into unimportant. Additionally, the categories very and rather satisfied were grouped into satisfied and rather and very dissatisfied into dissatisfied. Furthermore, very and rather helpful were grouped into helpful and rather not helpful and not helpful into not helpful.

Data were analyzed using IBM SPSS Statistics 25 for Windows. To analyze differences in the frequency of categorical variables, the chi-squared test was used. A significant chi-squared test suggests that the frequencies are not equally distributed. To know which categories contribute most to a significant chi-squared test, the residuals were calculated for each cell of the contingency table. The residuals are the differences in expected and observed frequencies. A negative residual indicates that the frequency in that cell is smaller than expected if frequencies were equally distributed between categories. A positive residual indicates that the frequency is bigger than expected. For better comparison, the residuals were *z*-standardized. Standardized residuals above ± 1.96 represent a significant ($p < .05$), above ± 2.58 a very significant ($p < .01$), and above ± 3.29 a highly significant ($p < .001$) difference between expected and observed frequencies.

Results

Demographics

Of 2199 members of "Das Lebenshaus e.V.," who were asked to participate in the survey, 431 answered our online questionnaire (return rate 19.6%). All in all, we could analyze 338 records. Demographics are shown in Table 1. Fifty-four percent of patients were female (53.6%) and forty-five male (45.3%). Median age was 59.8 years (SD 11.8 years). Detailed demographics are shown in Table 1.

The participants replying to our questionnaire showed many different tumors (Table 1). As expected, the most common tumors were GIST's, RCC's, and sarcoma. Other cancer types were gynecological cancer (ovarian and breast cancer), hematologic cancer (lymphoma, chronic myeloid leukemia),

Table 1 Participant demographics (*n* = 338)

Gender	Total	In %
Female	181	53.6
Male	153	45.3
No answer	4	1.2
Age		
≤ 35	12	3.6
36–50	51	15.1
51–65	157	46.4
66–80	113	33.4
≥ 80	2	0.6
No answer	3	0.9
Education		
Basic education*	33	9.8
Secondary education**	74	21.9
High school/college/university degree	158	46.7
No answer	73	21.6
Category		
Patient under treatment	241	71.3
Patient post treatment	97	28.7
No answer	0	0
Cancer type		
GIST	138	40.8
Renal cell carcinoma	86	25.4
Sarcoma	86	25.4
Gynecologic cancer	3	0.9
Hematologic cancer	3	0.9
Urologic cancer	2	0.6
Solitary fibrous tumor	2	0.6
Malignant melanoma	1	0.3
Other***	16	4.7
No answer	1	0.3

*Certificate of secondary education, **general certificate of secondary education, ***more than one type of tumor or tumor not specified

urologic cancer (bladder cancer and urothelial carcinoma), solitary fibrous tumor, and malignant melanoma. If the tumor was not specified or the participant had more than one tumor, it was classified as other.

Importance of Information and Satisfaction with Information

A clear majority found information about their disease, therapy (anti-cancer therapies), and side effects very important (Fig. 1). Less than 2% found the information rather unimportant or very unimportant.

Most of the participants were satisfied with the information concerning their disease (Fig. 2). More than 80% of the people were very satisfied or rather satisfied with information about the disease in total (83.6%) and the comprehensibility of

information (85.2%). More than 70% were very satisfied or rather satisfied with the information on the course of the disease (73.1%), treatment (anti-cancer therapies) (77.3%), effects of cancer medication (75.4%), side effects (72.0%), and additional support (70.1%).

To analyze if subjects were equally satisfied with all 8 information aspects (see Fig. 2) or if there were some aspects the patients were significantly less/more satisfied than with others, a chi-squared test was used. For the test, the two positive categories (very satisfied/rather satisfied) and the two negative categories (rather dissatisfied/very dissatisfied) were each grouped together into two remaining categories (satisfied vs. dissatisfied). Using a chi-squared test, it was examined if these two categories (satisfied and dissatisfied) were equally distributed among the 8 questions of the different information aspects. Indeed, the chi-squared test was highly significant ($\chi^2(7) = 74.84, p < .001$) meaning that subjects were not equally satisfied with all information aspects. In detail, by calculating the standardized residuals, we could see that the participants were significantly more dissatisfied when asked about the management of side effects ($z = 5.1, p < .001$) than expected if they were equally satisfied with all information aspects. Furthermore, for the aspects “general information about disease” and “comprehensibility of information,” the participants were less dissatisfied than expected ($z = -3.2, p < .01$ and $z = -3.8, p < .01$ respectively).

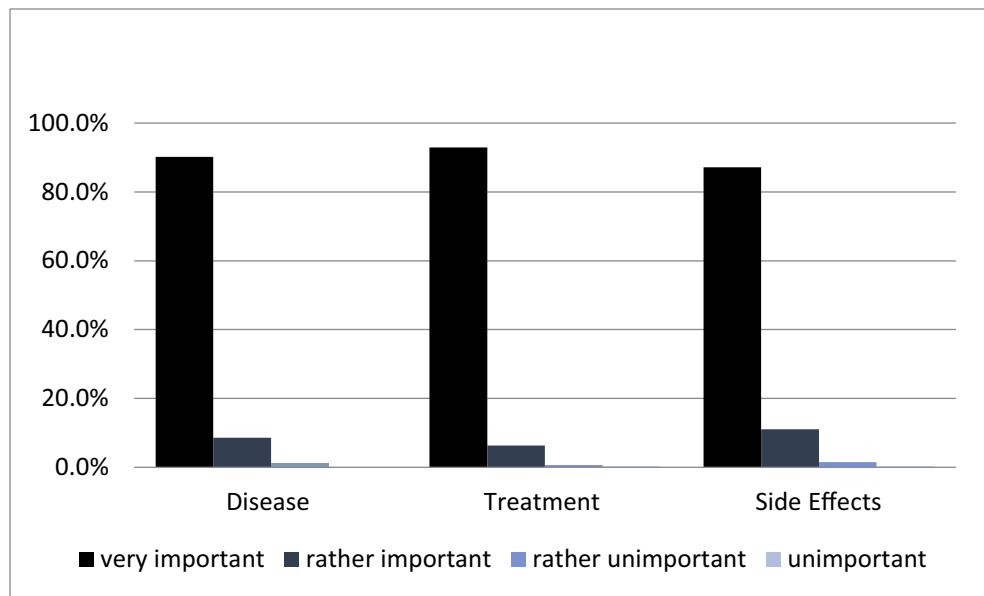
There were no significant differences for gender ($\chi^2(1) = 1.028, p = .375$) and patient category ($\chi^2(1) = 0.020, p = 1.000$) concerning satisfaction with information. Instead, we could see a significant difference between the educational levels concerning satisfaction with information. Participants with a basic education were less satisfied with the information about the disease in total ($\chi^2(2) = 7.124, p = .028$) and information about support ($\chi^2(2) = 6.864, p = .031$) than participants with a higher education.

To analyze if dissatisfaction with information was equally distributed among patients with the three different cancer types (GIST, sarcoma, and RCC) a separate chi-squared test was used for every information aspect. Table 2 shows a significant *p* value for every information aspect. This means that patients of the different cancer types differed in their dissatisfaction with information. Over all information aspects, the absolute number of dissatisfied sarcoma patients as well as the percentage of dissatisfied sarcoma patients was higher than in the other cancer types.

GIST gastrointestinal stromal tumor, *RCC* renal cell carcinoma

For every information aspect, the number of dissatisfied participants is shown. Percentages represent the amount of dissatisfied participants within the total number of participants with GIST’s, RCC, or sarcoma who answered that question.

Fig. 1 Importance of information about the disease, treatment, and side effects



Helpfulness of Information from Different Sources

The members of “Das Lebenshaus e.V.” assessed the helpfulness of different sources of information. The chi-squared test showed that there were significant differences in the perceived helpfulness between the different sources of information ($\chi^2(10) = 337.999, p < .001$). Among the 16 sources support groups, the internet and the oncologist were the top three (Fig. 3).

Peer support groups or other patient’s organizations were rated as the most helpful sources of information. 81.4% rated this group of information sources as very helpful or rather helpful. Also, the information from other people affected by

the disease was evaluated as helpful by 75.7% while information from relatives, friends, and acquaintances was rated as helpful by only 41.5%.

The internet and other media were rated as the second most helpful sources of information with 80.7% evaluating it as very or rather helpful.

The oncologist was rated the third most helpful source of information. 79.5% found the information they got from their oncologist very helpful or rather helpful. In contrast, only 29.3% evaluated the information from their general practitioner as helpful. More than half of the participants sought a second opinion (62.4%), 76.4% of them found the information they got helpful. The web pages “Krebsinformationsdienst”

Fig. 2 Satisfaction with information about different topics concerning cancer, *e.g., peer support groups, **comprehensibility of information

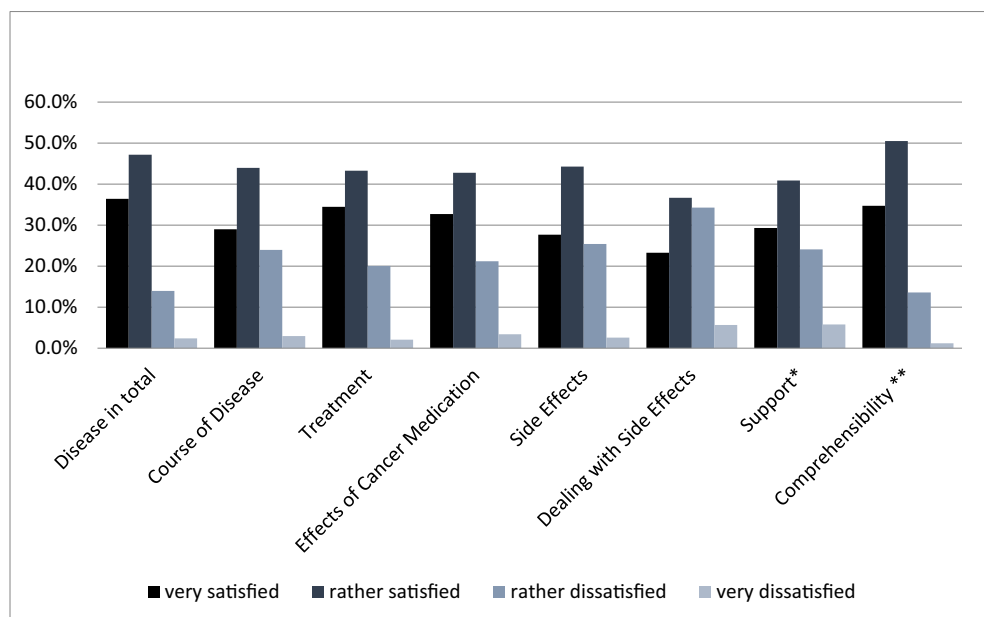


Table 2 Comparison of dissatisfaction with information between different cancer types (*n* = 307; GIST 137 patients, RCC 85 patients, sarcoma 85 patients)

Dissatisfaction with information about	GIST <i>n</i> (%)	RCC <i>n</i> (%)	Sarcoma <i>n</i> (%)	<i>p</i> value
Disease in total	10(7.3%)	12(14.1%)	26(30.6%)	<i>p</i> < .001
Course of disease	21(15.4%)	26(30.6%)	35(41.2%)	<i>p</i> < .001
Treatment (anti-cancer therapies)	18(13.4%)	20(23.8%)	27(32.5%)	<i>p</i> = .004
Effects of cancer medication	22(17.6%)	13(16.5%)	30(42.9%)	<i>p</i> < .001
Side effects	32(25.6%)	14(17.7%)	29(37.2%)	<i>p</i> = .021
Dealing with side effects	44(35.5%)	27(33.8%)	38(52.1%)	<i>p</i> = .034
Support (e.g., self-help group)	30(22.6%)	20(23.5%)	36(43.9%)	<i>p</i> = .002
Comprehensibility of information	10(7.5%)	14(16.3%)	19(22.6%)	<i>p</i> = .006

(KID, a German evidence-based information service for cancer patients) and “Gesellschaft für Biologische Krebsabwehr” (a German society which provides information on complementary and alternative medicine without a strict scientific commitment) were consulted by 32.0% and 22.6% and rated as helpful by 56.6% and 43.1% respectively.

Decision About Treatment

The participants were asked about the way the final decision about their treatment was established. 11.8% of the participants made this decision alone, for 17.2%, the doctor decided on the treatment alone but for the majority of 71.0%, it was a shared decision.

We found a significant association between dissatisfaction with information and the patient making the decision about

treatment alone. Participants who were dissatisfied with the information about the disease in total significantly more often reported that they made the decision all by themselves ($\chi^2(2) = 16.673, p < .001$). This association could be demonstrated for all different categories of information except information about dealing with side effects. On the other hand, participants who were satisfied with the information about possible support less likely made the decision all alone ($\chi^2(2) = 21.620, p < .001$). The same effect was found for satisfaction with information about the course of the disease ($\chi^2(2) = 24.923, p < .001$) and satisfaction with information about the therapy ($\chi^2(2) = 22.790, p < .001$).

Participants with sarcoma more often made the decision alone by themselves ($z = 3.9, p < .001$) and participants with GIST less often reported that they made the decision about treatment alone ($z = -2.1, p < .001$).

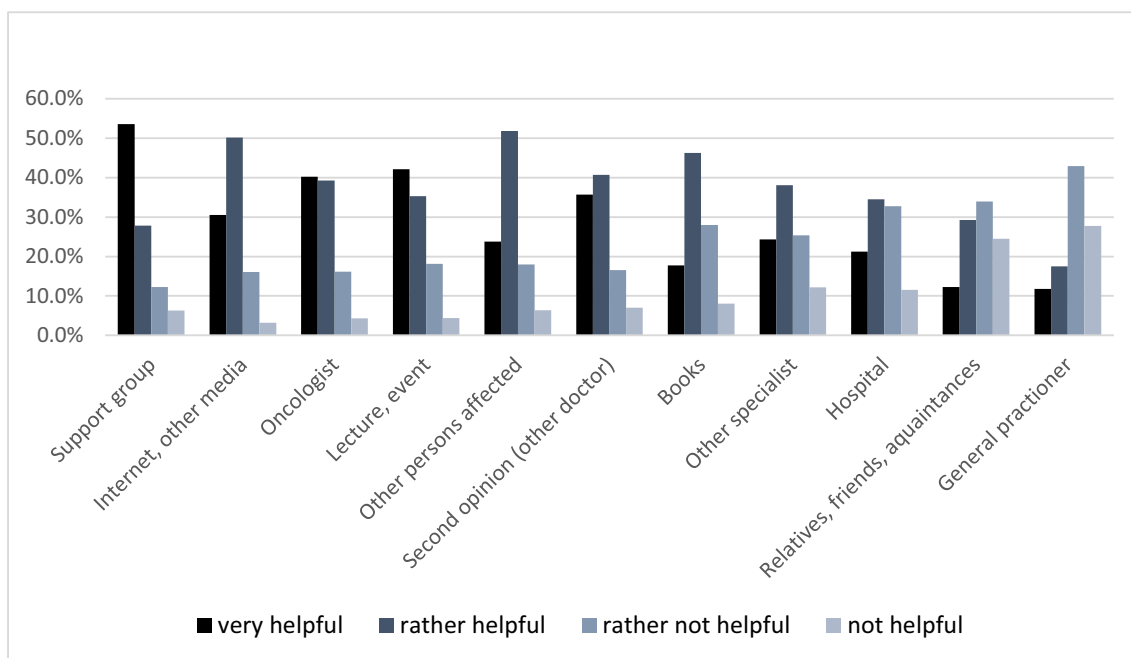


Fig. 3 Evaluation of the helpfulness of information from different sources

Discussion

Performing an online survey about the information needs and satisfaction with information on cancer patients with different rare solid tumors, we could show that the clear majority found information on their disease, treatment, and side effects very important. Former studies about different cancer types had shown similar results [15–18]. Regarding satisfaction with the provided information, we could see a high satisfaction with the information about the disease in general, treatment, support, and the comprehensibility of information. Other studies with cancer patients on the satisfaction with information also showed that the majority was satisfied with the received information [4, 13, 19, 20], although there are still areas for improvement regarding information about support groups and financial support [19]. In our study, we could see that the participants were less satisfied with the information about how to deal with side effects ($p < .001$). For breast cancer patients, a need for more information on side effects and their treatment has been shown before [21, 22]. Our group has shown that breast cancer as well as prostate cancer patients on endocrine therapy often do not feel informed on side effects and their management. Moreover, in case of side effects, most physicians did not respond to complaints and nearly no patient reported on any active steps taken by the physician in charge [23, 24]. Additionally, management of side effects is also rated as a weak point by patients getting a second opinion [25].

Physicians and health care workers should therefore not only give information about the possible side effects but also about possible strategies to deal with them. Beside information from their physician, the internet and other media offer a chance for additional support. For example, a web-based self-management for cancer survivors can have a small-to-moderate effect on fatigue, depression, anxiety, and quality of life as a review could show [26]. In fact, the internet may offer education and motivation to get active as a patient. Empowerment of patients may also make them more consequent in the discussion of real side effects and in their demand of help.

Generally, we could see a high importance of the internet and other media for cancer patients to get helpful information concerning their disease. Study members evaluated the internet even a little more helpful as the information from their oncologist. Only 5.6% did not consult the internet. Our findings are similar to a former German study regarding information needs of cancer patients. In that survey, the physician, support groups, and the internet were also regarded the most important sources of information [13, 16]. Other studies showed a wide range of cancer patients seeking information on their disease in the Internet between 27 and 80% with rising numbers over the time [4, 5, 27, 28]. Yet, the high rate of internet use among our study participants may be because we performed an online questionnaire. Therefore, people

without internet access could not attend our study. Former studies assumed that the more patients are dissatisfied with the information they got, the more they are using the internet on health-related issues [29, 30].

The internet provides an easy access to information. As everyone can easily upload information in the internet, the web pages about cancer differ widely and range from medical supervised webpages to webpages about alternative therapies without any scientific foundation. For patients, it is hard to tell both apart. As ranking of websites by the most often used search engines is not by quality at all, most patients will find rather less serious websites [31]. Also, in our survey, we found that only a minority of patients knew the evidence-based website of the KID. Accordingly, a helpful tool might be lists of reliable web pages, books, lectures, and events presented by the doctor.

Participants evaluated support groups as the most helpful source of information. Cancer peer support groups are known to provide multiple benefits such as emotional support and exchange of information about the disease, treatment, and side effects [32]. Our study showed that the perceived helpfulness of the information patients get from support groups is even a little higher than from the internet and their oncologist. Consulting a peer support group should therefore be discussed with every cancer patient and information on support groups should be given. More and more support groups also provide information on their websites or are in part or completely organized in the Internet [33].

Despite the oncologist being evaluated only as the third most helpful source of information, the conversation between patient and the oncologist is essential. Only the oncologist may present the information that is relevant to the individual patient. Yet, most patients also find a simultaneous support by the general practitioner important [34]. The general practitioner should be more integrated in the patient-physician communication. Especially in the treatment of side effects he might take over important tasks.

Our findings showed that participants with a basic education were less satisfied with the perceived information about the disease in general and information about support than participants with a higher education. It is known from other studies that patients with a higher education tend to seek more information on different channels as it is known from younger patients compared to older [8, 35–37]. Other studies did not show an association between education and information needs [38]. Nevertheless, when offering information to a patient, the physician should be aware whether his patient can use and understand it. An adaptation to the health and ehealth literacy of the patient may greatly improve patient satisfaction with the information and therefore with the patient-physician communication.

Regarding the cancer type, participants with a sarcoma were more dissatisfied with the information about their

disease and participants with a GIST less dissatisfied ($p < .001$). We could not find any study that addresses information needs and satisfaction with information in patients with GIST, sarcoma, or RCC. As this is the first study to describe that patients with a sarcoma are more dissatisfied with the information about their disease than patients with a GIST or RCC, it is hard to draw any conclusion. One explanation might be that within this group of patients, diverse entities are subsumed. Accordingly, evidence is even lower than for other rare cancers and only few specialized centers exist.

Shared decision-making has a strong influence on quality of life and reduces regret of decision [12, 39, 40]. Moreover, a physician-controlled decision is associated with less reported quality of care [41]. Shared decision-making is the preferred form of younger, female, and highly educated patients [39, 42]. In our survey, those who were more satisfied with the provided information indicated significantly more often that the decision about the therapy was a shared decision. From this, one might derive that the provision of patient-centered information is not only an ethical issue but may lead to essential improvements in cancer care. Moreover, as information may improve adherence, an indirect effect on survival may be postulated [23, 24]. More studies on the topic of satisfaction with information in patients with rare tumors should be made.

Limitations

The study design of an online research is clearly limited. The return rate was about 20% which might not be representative of all members of the House of Life. Additionally, there were missing answers. Furthermore, our cohort is not representative for all patients with the studied cancer types because participants engage in an internet-based support group and actively search for information and support on this web page. Patients who do not want to participate in a support group and do not actively look for information might answer the questions differently. Furthermore, we did not assess the quality of the information provided and the fact that patients are receiving their information from a variety of sources could be associated with a variety of quality, too. In addition to the missing content quality, there is also no information about formal quality (e.g., quality assurance processes or updating policies). Since both may have an influence on the satisfaction with information, content and formal criteria of the sources of information should be examined in further investigations. Results of this investigation are not suitable for improving patient information as no reasons for dissatisfaction with the information were requested. As density of information and support services between patients with rare and common tumors may vary and

this may have an impact on satisfaction, both groups should be examined in a comparative manner in the future.

Conclusion

Despite a high satisfaction with disease-related information among our study participants, we could show that there are still areas for improvement. Especially, more information on the management of side effects should be given. More attention should be paid regarding information provision for less-educated patients. Our results indicate that it is important to inform a patient about different information sources especially about support groups, reliable websites, and other helpful media. Making a patient satisfied with the information about his disease might lead to patient empowerment for a higher engagement in decision-making with direct and indirect consequences on quality of cancer care, quality of life, and even survival.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

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5.3 „Not all cancer patients with an interest in CAM are the same. Differences between patients with a CAM interest prior to the cancer diagnosis and those with first-time interest since diagnosis”

Clara Dubois, Hannah Eisfeld, Fabienne Bauer, Thorsten Schmidt, Karin Kastrati, Andreas Hochhaus, Jutta Hübner

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Not all cancer patients with an interest in CAM are the same. Differences between patients with a CAM interest prior to the cancer diagnosis and those with first-time interest since diagnosis



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ABSTRACT

Objectives: The aim was to assess differences in age, gender, education and personality (Big Five) between cancer patients already interested in CAM prior to the diagnosis and cancer patients only interested in CAM since their diagnosis.

Design: 323 members of the support and information platform “Lebenshaus e.V.” with gastrointestinal stromal tumours (GIST), renal cell carcinomas (RCC) and sarcomas participated in an online survey.

Main outcome measures: Interest in CAM prior to cancer diagnosis, CAM interest since diagnosis, CAM use and disclosure of CAM use to doctors.

Results: 39% were already interested in CAM before the diagnosis and 40.6% were first interested in CAM after their diagnosis. 44.9% stated a current/past CAM use. Female gender and high education were significant predictors for interest in CAM before the diagnosis and general CAM use. The Big Five did not become significant predictors. Predictors were different for patients interested in CAM before the diagnosis and patients only interested since the diagnosis. Sarcoma patients were significantly more likely to be interested in CAM after the diagnosis than patients with GIST. Disclosure of CAM use could not be predicted by sociodemographic variables and personality.

Conclusion: Known predictors for interest in CAM such as female gender, higher education and younger age do not seem to apply in cancer patients with no prior CAM affinity. This result together with a high CAM prevalence raises the importance of addressing CAM in all cancer patients for a need-oriented treatment and to avoid side effects and interactions with conventional treatment.

1. Introduction

1.1. Relevance of CAM use in cancer patients

The use of complementary and alternative medicine (CAM) has gained increasing popularity over the last two decades with an estimated overall 12-month prevalence of 32.2%.¹ According to an international systematic review cancer patients show an even higher prevalence of 43%² and spend significantly more money on CAM than the general population.³ Cancer patients use CAM to strengthen themselves and their immune system, enhance their (emotional) well-being, manage side effects of conventional cancer treatment and do everything

possible to fight the disease.^{4–6} They most frequently use biologically-based CAM such as vitamins, trace elements and phytotherapy, as well as prayer and relaxation techniques.^{3,6} The high prevalence of CAM in cancer patients is important for health care professionals since it goes along with information needs⁷ and the risk of potential interactions with conventional cancer therapy.^{8,9} Many users consider CAM to be a non-toxic treatment¹⁰ which is soft, without side effects and less aggressive than conventional drugs.¹¹ Yet, some CAM can indeed have side effects⁹ or increase side effects of conventional cancer therapy.¹² Some biologically-based methods can potentially affect the efficacy of anticancer drugs and jeopardize a therapy.^{8,13,14} In fact, a recent study in German oncologic practices revealed that 54.9% of the patients using

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CAM were at risk of possible interactions.¹⁵ Interactions and negative side effects become particularly dangerous when patients and doctors do not know about them or when patients do not disclose using CAM. Yet, nondisclosure rates are high ranging from 20% to 77% in cancer patients.^{16–18}

1.2. Predictors for CAM use

Several studies have investigated sociodemographic predictors for the use of CAM in the general population¹ but also among cancer patients.^{19–21} In both groups gender (women > men), age (younger > older) and education (higher > lower) significantly predicted the use of CAM. In patients with cancer tumour type, stage (higher > lower) and smoking behaviour (non-smokers > smokers) were identified as additional predictors.¹⁹ Recently, interest has risen in individual characteristics and personality traits as predictors for CAM. Personality is known to influence general health behaviour. Most research on personality and health behaviour has applied the five-factor model of personality.²² High conscientiousness and low neuroticism have been associated with better health behaviour both in people with and without cancer²³ and high conscientiousness even with a lowered mortality risk.^{24,25} Further, the factor openness has been found to predict the use of all types of CAM except manipulative body-based methods in the general population.²⁶ However, research on personality and CAM use in cancer patients is scarce. One study with breast-cancer patients in the Netherlands found that only high openness was associated with the use of CAM.²⁷ The association between openness and CAM use could be confirmed in a Canadian breast-cancer sample.²⁰ Yet, a third study from Poland found contrasting results.²⁸ In the sample with heterogeneous cancer types low openness was associated with CAM use together with high extraversion and high neuroticism. In summary, there are only few studies in different cancer samples with contrasting results about the role of personality in CAM use.

These different results might be explained by the heterogeneity of the cancer populations in the studies. There might be a significant difference between cancer patients who were already open for CAM before the diagnosis and cancer patients who's interest in CAM was first triggered by the cancer diagnosis. Cancer patients who are familiar with CAM might simply transfer CAM to their new health situation. Hence, one can expect similar predictors for interest in CAM in this group as in the general population. Yet, little is known about those who only become interested in CAM because of the life-threatening disease. So far, studies have not differentiated between these two cancer populations.

1.3. Research question

Knowing relevant predictors for CAM use in cancer patients is important for health care professionals to ensure need-oriented consultation and information, prevent negative interactions and improve compliance with conventional cancer therapy. The aim was to clarify conflicting findings by assessing known factors (sociodemographic variables and tumour type) and the Big Five as potential predictors for interest in CAM already before the diagnosis (IABD), for interest in CAM only since the diagnosis (IOSD), for general CAM use and for disclosure of CAM to doctors.

2. Methods

2.1. Participants & material

Participants were members of the German non-profit organization “Das Lebenshaus e.V.” (English: house of life). The organization offers information and support for people with rare forms of solid tumours mainly gastrointestinal stromal tumours (GIST), renal cell carcinomas (RCC) and sarcomas. All 2199 members were asked via email to participate in an online survey and 431 replied. Participation was

Table 1
Sample Characteristics.

Characteristics	n (%)
Age, M (SD)	59.36 (12.23)
Gender	
women	171 (53.6)
men	148 (46.4)
Education	
basic	29 (11.4)
middle	71 (28.0)
high	154 (60.6)
Cancer type	
GIST	131 (40.7)
RCC	84 (26.1)
Sarcoma	83 (25.8)
Others	24 (7.5)

Notes: Education levels were allocated the following way. Basic means elementary school or main school, mid-level stands for comprehensive school and high-level refers to a high school degree or academic.

voluntary and anonymous. Data sets completed by relatives and data sets with more than 50% missing answers were excluded from the analyses leaving 323 entries. Information on characteristics of the study sample can be found in Table 1. The survey consisted of four different sections on general and CAM-specific information needs, CAM, personality and personal data such as age, gender and education. The data on information needs and satisfaction about information, general prevalence of CAM and reasons for the use of CAM were published separately^{29,30}.

2.2. CAM

Participants were asked if they were already interested before the diagnosis, only since the diagnosis or not at all and if they currently or ever used CAM. Disclosure of CAM was assessed by presenting a list of different kind of doctors (oncologist, general practitioner, specialist, other, and none) and asking patients to tick off the ones they talked to about their CAM use.

2.3. Personality

The BFI-10³¹ a 10-item version of the 44-item BFI³² was used to measure the Big Five. Each dimension was assessed by two items on a 5-point-scale. The BFI-10 has been tested on different study populations with acceptable results concerning reliability and validity.³¹ Yet, internal consistency in this data set was low to very low (Table 2).

2.4. Statistical analyses

Analyses were conducted in SPSS (version 25). Several multiple logistic regressions were run to test if sociodemographic variables (age, gender and education), tumour type and personality predicted the different dependent variables: interest already before the diagnosis (IABD), interest only since the diagnosis (IOSD), and CAM use (present or past) and disclosure of CAM. To assess the predictive value of the predictors Odds Ratios (OR) were calculated in the logistic regressions. An OR above one implies a positive relationship between the predictor and the dependent variable. An OR below one indicates a negative association.

2.5. Ethical vote

According to the rules of the ethics committee at the Goethe University Frankfurt an ethical approval for this anonymous online survey was not necessary.

3. Results

Tests of multicollinearity were run for all predictors in the logistics

Table 2
Description, mean (M), standard deviation (SD) and internal consistency (α) of the Big Five dimensions.

factor	low level	high level	Cronbach's α	M (SD)
openness	conservative, cautious	imaginative, curious	.16	3.36 (0.88)
consciousness	careless, unworried	effective, organized, perfectionist	.45	3.97 (0.75)
extraversion	reserved, timid	social	.58	3.29 (0.91)
agreeableness	competitive, antagonistic	cooperative, friendly, compassionate	.18	3.16 (0.70)
neuroticism	self-confident, calm	emotional, sensitive	.58	2.82 (0.89)

Table 3
Model parameters for interest in CAM before diagnosis (IABD) and interest in CAM since diagnosis (IOSD).

model parameters	Interest in CAM before diagnosis (IABD)			Interest in CAM after diagnosis (IOSD)		
	OR	CI	p	OR	CI	p
constant	0.53		.771	0.02		.063
women vs. men	4.07	1.63 – 10.16	.003	0.38	0.14 – 1.04	.060
education middle vs. higher	0.39	0.15 – 0.98	.045	1.39	0.54 – 3.58	.496
education basic vs. higher	0.46	0.11 – 1.95	.290	1.69	0.48 – 6.00	.415
age	0.96	0.95 – 1.02	.436	1.00	0.97 – 1.04	.892
RCC vs. GIST				2.01	0.79 – 5.12	.142
Sarcoma vs. GIST				6.88	1.93 – 24.49	.003
Others vs. GIST				1.66	0.38 – 7.21	.509
extraversion	1.01	0.64 – 1.60	.970	1.23	0.78 – 1.94	.382
agreeableness	1.44	0.78 – 2.67	.247	1.41	0.78 – 2.55	.256
consciousness	0.73	0.42 – 1.23	.271	0.87	0.49 – 1.56	.642
neuroticism	1.28	0.80 – 2.06	.299	1.69	0.96 – 2.96	.070
openness	1.40	0.87 – 2.25	.161	1.62	1.00 – 2.62	.050
N	141			141		
Chi ² (df)	29.54 (9)			21.15 (12)		

Notes: N = number of cases included in the analyses, OR = Odds Ratio; CI = Confidence Interval, df = degrees of freedom. Significant ($p < .05$) and nearly significant p-values ($p < .10$) are highlighted in bold font.

regressions. The VIF (variance inflation factor) ranged between 1.09 and 1.55 indicating that multicollinearity was not an issue.³³

3.1. Interest in CAM before and since the cancer diagnosis

39% of the participants stated they were interested in CAM already before the cancer diagnosis (IABD). 40.6% were only interested in CAM since the cancer diagnosis (IOSD) and 18.6% were never interested in CAM. The aim was to identify general predictors for IABD and IOSD. The first model with IABD as the dependent variable was highly significant, $\chi^2(9) = 29.54, p = .001$ (Table 3). Women were more interested in CAM before the diagnosis than men (OR = 4.07, confidence interval [CI] = 1.63–10.16, $p = .003$). Patients with mid-level education were significantly less interested than participants with higher education (OR = 0.39, CI = 0.15 – 0.98, $p = .045$). None of the Big Five were significant predictors. Subsequently, we analysed IOSD. Having a sarcoma was the only significant predictor in this model (Table 3). The odds of being interested in CAM only since the diagnoses were 6.88 times higher in sarcoma patients than in patients with GIST (OR = 6.88, CI = 1.93–24.49, $p < .01$). Gender only approximated statistical significance and changed its direction. Women were less likely to be interested in CAM only since the diagnosis than men (OR = 0.38, CI = 0.14–1.04, $p = .06$). None of the Big Five factors were significant. However, openness (OR = 1.62, CI = 1.00–2.62, $p = .05$) and neuroticism (OR = 1.69, CI = 0.96–2.96, $p = .07$) approached significance.

3.2. CAM use

44.9% stated they currently/ever used at least one form of CAM. 50.8% stated they never used CAM. The use of CAM was significantly predicted by most known sociodemographic predictors (Table 4). Women were more likely than men to use CAM (OR = 2.41, CI = 1.32–4.72, $p = .010$). Mid-level educated patients were less likely

Table 4
Model parameters for the logistic regression with general CAM use before and after diagnosis as the dependent variable.

model parameters	OR	CI	p
constant	0.30		.916
women vs. men	2.41	1.23–4.72	.010
education middle vs. high	0.37	0.17–0.67	.002
education basic vs. high	0.34	0.13–0.90	.030
age	0.98	0.95–1.00	.079
extraversion	1.15	0.82–1.62	.414
agreeableness	1.22	0.80–1.86	.361
consciousness	0.86	0.57–1.28	.448
neuroticism	0.97	0.69–1.42	.990
openness	1.15	0.82–1.63	.424
N	231		
Chi ² (df)	38.13 (12)		.000

Notes: N = number of cases included in the analyses, OR = Odds Ratio; CI = Confidence Interval; df = degrees of freedom. Significant ($p < .05$) and nearly significant p-values ($p < .10$) are highlighted in bold font.

than highly educated patients to use CAM. Yet, likeliness of CAM use did not significantly decrease with rising age (OR = 0.98, CI = 0.95–1.00, $p = .079$). None of the Big Five significantly predicted CAM use.

3.3. Disclosure of CAM use

18.3% patients stated they did not inform any doctor about their CAM use and 3.4% did not remember whether they disclosed it or not. 34.1% informed their oncologist, 28.8% their general practitioner and 10.2% talked with a specialist about their CAM use. A total of 161 cases could be included in the logistic regression with disclosure as a dichotomous variable. Disclosure to an oncologist, general practitioner or specialist was coded as disclosure and agreement to the statement “I did not talk to any doctor about my CAM use” was coded as non-disclosure.

The model was not significant ($\chi^2(9) = 3.26, p = .953$) and none of the predictors (sociodemographic variables, Big Five) significantly predicted disclosure.

4. DISCUSSION

4.1. Summary

This study examined sociodemographic variables, tumour type and personality as predictors for the interest in CAM (before and since the diagnosis), CAM use and disclosure of CAM to doctors in cancer patients. The percentage of CAM users was 44.9%. Interest in CAM was equally high ranging from 39% before diagnosis and 46.6% after diagnosis. Similar numbers have been found in other German cancer samples before.^{19,34–36} 21.7% did not disclose their CAM use to any doctor or did not remember leaving possible side effects and interactions non-detected.

4.2. Sociodemographic variables

Consistent with numerous previous studies in cancer patients^{5,37–39} and the general population,¹ female gender predicted IABD and CAM use. Higher education could also be confirmed as a predictor for IABD and general CAM use.^{1,5,21,37,40} High education associated with high socio-economic status comes along with more financial resources to spend on CAM which can be expensive and are often not paid by health insurance.³ Additionally, this group might have greater knowledge about CAM and health in general combined with an increased willingness and ability to inform themselves about their disease and possible treating options. No association could be found for age, interest in CAM (before and since diagnosis) or CAM use. This result contradicts the well-established association between younger age and increased use of CAM.^{1,5,19,39,40} This might be explained by the relatively old age of the study participants with a median of 59.36 years.

4.3. Tumour type

Several studies found varying CAM rates between patients with different types of cancer.^{19,41} Yet, this might be an artefact of gender since most found higher rates in breast-cancer patients. In this study, using regression analyses gender was controlled and tumour type remained a predictor for general CAM use and IOSD. Sarcoma patients were significantly more likely to be only interested since the diagnosis than patients with GIST. This result is in line with a study in which RCC patients were among the more frequent users of CAM compared to other types of cancer.¹⁹ The different number and effectiveness of conventional treatments might be an explanation for differences between the GIST, RCC and sarcoma. Sarcomas are treated with a variety of different treatments making it difficult to find consistent information. This might increase uncertainty and the need for alternative or additional treatments such as CAM. This explanation is compatible with our finding that sarcoma patients in the same sample were least satisfied with information provided by their doctors.³⁰ By contrast, there has been a vast progress in therapies for GIST. This might give GIST patients a bigger sense of security and confidence in the current treatment. The role of uncertainty and heterogeneity in the cancer treatment should be further examined as potential predictor for the use of CAM.

4.4. Personality

It is likely that people with a high level of openness are curious to experience other forms of medicine as shown in the healthy population²⁶ and some cancer populations.^{20,27} Further, it might be that neurotic cancer patients are more anxious and insecure about the disease and its treatment rising the willing to use additional methods to increase their sense of control.²⁸ In this study, none the Big Five

predicted neither the interest in CAM (before and since diagnosis) nor CAM use. Openness and neuroticism approximated significance as predictors for the interest in CAM triggered by the cancer diagnosis though (higher levels of openness and neuroticism increased the likelihood for CAM interest). One explanation for the missing statistical significance might be the low internal consistency of the BFI-10 in this sample. Hence, the results on personality in this study need to be interpreted cautiously. Further research on personality and CAM with more reliable instruments than the BFI-10 are needed.

4.5. Effect of the cancer diagnosis

There was a pattern of changing predictors between interest in CAM already before the diagnosis (IABD) and interest only since the diagnosis (IOSD) indicating a potential diagnosis-predictor interaction. Gender and education were both not significant anymore in IOSD and changed the direction. Further, high openness and high neuroticism became nearly significant predictors in IOSD but not in IABD. The differences between IABD and IOSD indicate that patients who were already interested in CAM before the cancer diagnosis differ from patients who only became interested because of the diagnosis. It is known that people generally increase the use of CAM after a cancer diagnosis⁴² because they want to use everything available to fight the disease. Yet, it is also possible that a cancer diagnosis also changes attitudes and the general awareness towards CAM in those who were sceptical or not interested in CAM before. Our results indicate that known characteristics for CAM users might not be representative for all cancer patients for the interest in CAM. Patients who only become interested in CAM because of their cancer might be at risk for not being addressed with information about CAM since they do not match the scientifically established stereotype of the young educated female cancer patient.

4.6. Disclosure

Non-disclosure rates of CAM use are relatively high in cancer patients^{16–18} and were at least 18.3% in this sample. This is a source for concern due to the risk of side effects^{8,9,12} and negative interactions with conventional cancer therapy.^{8,13,14} Disclosure of CAM to doctors could neither be predicted by sociodemographic variable nor by personality. Other studies discovered the main reasons for non-disclosure were anticipation of a negative response from the doctor, concern that the physician did not know about CAM, the fact that the doctor did not ask about it and the patient's belief that CAM was not relevant to conventional therapy.^{17,18} Therefore, we assume that disclosure depends less on personal characteristics of the patient and more on knowledge about CAM and communication style between doctor and patient. Most patients would like to have more information about CAM preferably from their doctor.⁷ However, physicians are usually not the first source of information about CAM and only come after family, friends and media.^{5,36} Most doctors and medical students are not confident to inform about CAM because of missing knowledge and training.^{16,43} While medical school is based on the principle of scientific evidence, patients often use non-scientific sources and feel told off if doctors refer to some CAM as not evidence-based. Oncologists should use an open, understanding and non-judgmental discussion style,⁴⁴ talk about side effects and interactions, try to communicate evidence-based medicine and routinely ask about CAM use even when the patients do not address it themselves. Further research is needed to identify communication styles best suitable for the discussion of CAM with cancer patients.

4.7. Limitations

Reaching participants online excludes those with limited access or internet aversion which might be especially common among older cancer patients. Around 80% did not reply and approximately 17% of

the responders needed to be excluded because of filling in less than 50% of the questionnaire. There might be systematic differences between repliers and non-repliers. Furthermore, it is possible that members of the “Lebenshaus e.V.”, a platform for information and support, are special with regards to their personality, information needs and interest in CAM. Also, the sample of patients with rare solid tumours is not representative of most cancer types. It is a valuable addition to the majority of studies in breast cancer samples though. A relevant point of criticism is the low internal consistency of the personality dimensions and especially openness in this study. Therefore, all results concerning personality need to be interpreted with caution. Further research using questionnaires with more than 10 items are necessary.

4.8. Conclusion

This study is among the first to examine the potential difference between cancer patients with a prior interest in CAM and patients who's interest in CAM is triggered by the diagnosis. In the latter, known predictors for interest in CAM and CAM use do not seem to apply. While prior CAM interest and general CAM use was associated with younger age, higher education and female gender, patients with CAM interest only since the diagnosis were not associated with the same factors. We conclude that information about CAM should not only be addressed at young educated female cancer patients but also at a broader group of cancer patients. Further, the results of this study suggest that the treatment of rare tumours with heterogeneous and less effective therapies such as sarcomas might increase insecurity raising the interest in additional treatments such as CAM. Providing comprehensible information for this group might be particularly important. A relevant aim was to predict non-disclosure of CAM to doctors due to the potential health risk of side effects and interactions with conventional cancer treatment. Yet, no predictors for disclosure of CAM use could be identified. Therefore, we assume that personal characteristics such as age, gender, education and personality play only a minor role in CAM disclosure. Instead, non-disclosure might be more effected by missing knowledge about potential interactions and side effects both on the side of patients and doctors. Doctor communication style might be another essential factor in disclosure. Doctors should communicate openly and appreciatively, be trained in CAM, talk about side effects and interactions and routinely ask about interest in CAM after the cancer diagnosis.

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6. Diskussion

Mit den drei präsentierten Originalarbeiten wurden Informationsbedarf und -suchverhalten der Mitglieder von „Das Lebenshaus e.V.“ im Allgemeinen sowie in Bezug auf KAM untersucht. Im Folgenden werden die Ergebnisse anhand der unter „Ziele der Arbeit“ genannten Fragenstellungen diskutiert.

a. Genereller Informationsbedarf und Zufriedenheit mit Informationen

Nahezu alle Teilnehmer dieser Studie bewerteten Informationen über ihre Erkrankung, deren Behandlung und möglichen Nebenwirkungen als sehr wichtig. Ein hohes Informationsbedürfnis von Tumorpatienten wurde bereits in zahlreichen Studien demonstriert (Blanchard et al. 1988, Jenkins et al. 2001, Güleser et al. 2012, Oerlemans et al. 2012).

Konsistent zur Literatur fand sich eine hohe Zufriedenheit mit den generellen Informationen zu Erkrankung und Behandlung sowie deren Verständlichkeit (Llewellyn et al. 2006, Rudolph et al. 2015, Ebel et al. 2017). Im Vergleich dazu waren die Teilnehmer unzufriedener mit Informationen über mögliche Unterstützungsmöglichkeiten, Nebenwirkungen und deren Management. Diese Beobachtung wird durch sowohl durch deutsche als auch internationale Studien untermauert (Llewellyn et al. 2006, Wuensch et al. 2015, Jung et al. 2016). Somit zeigt sich ein hoher Bedarf nach mehr und qualitativ hochwertigen Informationen über Unterstützungsmöglichkeiten, Nebenwirkungen sowie deren Management.

In dieser Dissertation erwiesen sich Selbsthilfegruppen, gefolgt von Internet und Onkologen als meistgenutzte und am hilfreichsten bewertete Informationsquellen. Auch in anderen Studien werden Ärzte, Selbsthilfegruppen und das Internet als die wichtigsten Bezugsquellen beschrieben (Güleser et al. 2012, Rudolph et al. 2015). Es ist bekannt, dass Selbsthilfegruppen für Tumorpatienten eine wichtige emotionale Unterstützungsmöglichkeit darstellen (van den Borne et al. 1986) und den Austausch über krankheitsbezogene Informationen und Erfahrungen ermöglichen (Hübner et al. 2013). Dies geschieht auch zunehmend über das Internet.

Nicht nur die Möglichkeit, sich sofort unkompliziert zu vernetzen und mit anderen Betroffenen austauschen zu können, ist ein Grund für den immer wichtiger werdenden Stellenwert des Internets in der Informationsbeschaffung. Das Internet wird auch für Recherchen zu Gesundheitsfragen immer häufiger genutzt (Nagler et al. 2010, Powell

et al. 2011, Stern et al. 2012, Kowalski et al. 2014, Nayir et al. 2016, Ebel et al. 2017). Internet und andere Medien rangierten unter den Studienteilnehmern an zweiter Stelle der hilfreichsten Informationsquellen, noch vor dem Onkologen (Eisfeld et al. 2020). Dies lässt sich zum einen durch die zunehmend verbreitete generelle Nutzung des Internets erklären (ITU 2005-2017), zum anderen durch die schnelle, einfache und kostengünstige Art und Weise, Informationen zu erhalten.

Da das Internet größtenteils ungeprüfte Informationen bietet, sollte Tumorpatienten Hilfestellung bei der Internetrecherche erhalten. Denn jeder Nutzer kann Informationen unabhängig von der Richtigkeit ins Internet stellen und verbreiten, die Qualität ist somit sehr variabel (Eysenbach et al. 2002, Brauer et al. 2010) und häufig unseriös bis falsch (Matthews et al. 2003, Liebl et al. 2015). Die Nutzer können dies jedoch meist nicht oder nur schwer unterscheiden, was erhebliche Risiken birgt und bei Befolgen ernsthafte Konsequenzen zur Folge von haben kann (Weisbord et al. 1997, Hainer et al. 2000). Wenn Informationen im Internet denen des Arztes widersprechen, kann zudem das Vertrauen in den Arzt verringert werden oder verloren gehen. Dies könnte zu einem Therapieabbruch führen.

Da die Reihenfolge der Anzeige nicht von der Qualität der Informationen, sondern von der Beliebtheit und Anzahl der Aufrufe sowie durch Bezahlungssysteme und undurchsichtige Suchalgorithmen geprägt ist, verwenden die meisten Patienten häufig unseriöse Webseiten (Liebl et al. 2015). Am wahrscheinlichsten verwenden sie die ersten Hits, die ihnen von der genutzten Suchmaschine vorgeschlagen werden, ohne nach Hintergrundinformationen über die Quellen und Autoren zu suchen (Eysenbach und Köhler 2002). In Studien zeigte sich, dass die Qualität der Internetseiten zwar höher eingeschätzt wird, wenn diese von staatlichen Institutionen oder offiziellen Organisationen angeboten wird, aber auch danach, wie verständlich die Informationen sind und ob die Seite subjektiv seriös erscheint (Marshall und Williams 2006, Schwartz et al. 2006). Internetseiten mit hochwertigen Informationen haben zudem häufig eine schlechte Sichtbarkeit (Liebl et al. 2015). Eine US-amerikanische Studie mit Studenten des Gesundheitswesens belegte, dass selbst diese oftmals Probleme hatten, zuverlässige Informationen im Internet von falschen zu unterscheiden und verlässliche Quellen zu finden (Ivanitskaya et al. 2006).

Daher kommt hier gerade Ärzten eine Schlüsselrolle zu, denn diese stellen weiterhin eine der wichtigsten Informationsquellen für Patienten dar. Onkologen rangierten hier

nach Selbsthilfegruppen und dem Internet an dritter Stelle. Gerade auch angesichts der Informationsflut im Internet ist der Arzt-Patienten-Kontakt von großer Bedeutung: nur Ärzte können dem Patienten aufzeigen, welche der Informationen für ihn im speziellen relevant sind und welche der Vielzahl an Therapiemöglichkeiten die Beste für ihn ist. Das zeigt sich auch in der hohen Zufriedenheit mit den Informationen zu Erkrankung und Therapie des Onkologen (80%). Zudem können Ärzte proaktiv die Internetrecherche besprechen und Hinweise auf Webseiten mit seriösen Informationen, wie zum Beispiel dem Krebsinformationsdienst (KID) geben, um es Patienten zu ermöglichen, sich umfassend und seriös zu informieren.

Im Vergleich mit dem Onkologen waren die Teilnehmer mit den Informationen des Hausarztes über Erkrankung und Therapie unzufriedener, diese fanden nur 30 % hilfreich. Die wichtige Rolle der gleichzeitigen Betreuung durch den Hausarzt wurde für Tumorpatienten gezeigt (Lang et al. 2017). Diese erklärt sich durch die oft jahrelange Betreuung des Patienten und Kenntnis der psychosozialen Situation sowie der Komorbiditäten. Daher sollte dieser neben dem Onkologen noch stärker in die Tumorbehandlung und Arzt-Patientenkommunikation eingebunden werden. Insbesondere wäre ein Ausbau der Kommunikation über Nebenwirkungen und deren Management hilfreich, da gerade hier die Zufriedenheit niedriger war und dem Hausarzt oftmals die Verlaufskontrollen und Nachsorge obliegen.

Diese Forschungsarbeit zeigt zudem, dass ein spezielles Augenmerk auf bildungsschwächere Patienten gelegt werden sollte. Diese zeigten sich deutlich unzufriedener mit Informationen über die Erkrankung im Allgemeinen sowie mögliche Unterstützungsmöglichkeiten als Teilnehmer mit höherem Bildungsstand (Eisfeld et al. 2020). Eine Ursache könnte die Tatsache sein, dass Bildungsferne häufig weniger Informationen beziehen und dafür weniger unterschiedliche Quellen verwenden (Rutten et al. 2005, Matsuyama et al. 2011, Pieper et al. 2015, Finney Rutten et al. 2016, Faller et al. 2016). Mögliche Verständnisschwierigkeiten, verminderte Lese- oder Schreibkenntnissen oder geringere Gesundheitskompetenz kommen ebenso als Ursachen in Betracht. Somit sollten speziell auf diese Gruppe zugeschnittene vereinfachte Informationen sowohl von Ärzten vermittelt, als auch auf verlässlichen, gekennzeichneten Internetseiten bereit gestellt werden. Dies ist insbesondere von großer Relevanz, als dass ein Drittel der Deutschen dieser Gruppe zugeordnet werden kann (höchster Schulabschluss: Hauptschulabschluss) (Bundesamt 2018).

b. Informationsbedarf KAM, Zufriedenheit und Nutzung

Die Ergebnisse dieser Forschungsarbeit demonstrieren ein sehr hohes Interesse an KAM; über 80 % der Teilnehmer waren an diesem Thema interessiert. Dies sind deutlich höhere Werte als die bisheriger Studien (Huebner et al. 2016, Loquai et al. 2017). Bezüglich der KAM-Nutzung zeigte sich jedoch eine große Lücke zwischen den an KAM Interessierten und den tatsächlichen Nutzern: lediglich die Hälfte gab an, tatsächlich eine KAM-Methode zu verwenden oder verwendet zu haben, die Prävalenz der KAM-Nutzung war 44 %. Diese stimmt sowohl mit bereits in Deutschland (Paul et al. 2013, Ebel et al. 2015, Loquai et al. 2017) als auch weltweit erfolgten Studien überein (Richardson et al. 2000, Eschiti 2007, Velicer und Ulrich 2008, Horneber et al. 2012, Elsner et al. 2013).

Unterschiedliche Ursachen für diese Diskrepanz sind denkbar: die größtenteils fehlenden wissenschaftlichen Daten könnten Interessierte von einer Nutzung abhalten und zum kritischen Hinterfragen von KAM führen. Es ist auch vorstellbar, dass sie darauf vertrauen, dass Ärzte für sie das bestmögliche Therapiekonzept erstellen oder ein höheres Vertrauen in die konventionelle Medizin haben. Möglicherweise wurde ihnen auch von einer Nutzung abgeraten. Ein weiterer wichtiger Grund für die Entscheidung gegen die KAM-Nutzung stellt auch die Tatsache dar, dass die Kosten für die Behandlungen meist nicht von Krankenkassen übernommen werden (John et al. 2016), sondern vom Patienten selbst getragen werden müssen (Molassiotis et al. 2005, Elsner et al. 2013). Diese Kosten schwanken in der Literatur von wenigen bis mehreren hundert Euro pro Monat (Schönekaes et al. 2003, Nagel et al. 2004, Eschiti 2007, Naing et al. 2011).

Obwohl die Hälfte der Interessierten kein KAM verwendete, bewertete eine Mehrheit von 85,5 % Informationen über KAM als sehr wichtig oder eher wichtig. Selbst die Hälfte der Nicht-Interessierten befand diese für wichtig. Jedoch war die Zufriedenheit mit Informationen über KAM im Vergleich zu den anderen Informationen mit deutlichem Abstand am niedrigsten; fast zwei Drittel zeigten damit unzufrieden. Dies unterstreicht den enormen Informationsbedarf von Tumorpatienten zu diesem Thema.

Gerade Patienten, die unzufrieden mit den erhaltenen Informationen waren, zeigten ein höheres Interesse an KAM. Insbesondere bewerteten Patienten Informationen über KAM häufiger als wichtig, wenn diese die Informationen des Onkologen über Erkrankung und Behandlung nicht hilfreich fanden. Mehrere zugrundeliegende

Ursachen sind vorstellbar: einerseits könnte die Unzufriedenheit mit den Informationen dazu führen, dass sich Patienten eher nach Alternativen zu der dort vorgeschlagenen Behandlung umsehen. Umgekehrt könnte ein höheres Interesse an KAM auch mit einem vom Beginn an erhöhten Informationsbedarf einhergehen und daher Patienten trotz des Erhalts objektiv ausreichender Informationen subjektiv unzufrieden zurücklassen. Zudem ist auch eine ungenügende Qualität der Informationen ein möglicher Grund für ein höheres Interesse an KAM.

Es ist ebenso vorstellbar, dass ein hohes Interesse an KAM mit einer generell skeptischen Haltung gegenüber der konventionellen Medizin einhergeht und daraus eine höhere Unzufriedenheit mit den Informationen des Arztes resultiert. Die Unzufriedenheit mit der Medizin könnte wiederum zu einer erhöhten Anwendung von KAM-Methoden führen. Tatsächlich war Unzufriedenheit mit Informationen über den Verlauf der Erkrankung und dem Management von Nebenwirkungen im Allgemeinen als auch speziell vom Onkologen in der präsentierten Untersuchung mit einer signifikant höheren KAM-Nutzung assoziiert. Weitere Untersuchungen werden benötigt, um derartige Zusammenhänge zu erfassen.

Die Unzufriedenheit mit aus medizinischen Quellen erhaltenen Informationen über KAM war insgesamt hoch. Von großer Relevanz ist neben der erwähnten hohen Unzufriedenheit mit jenen vom Onkologen (67,6 %) auch die Hausärzten (64,3 %) oder Krankenhäusern (82,5 %). Eine mögliche Ursache hierfür wäre, dass sich medizinisches Personal nicht ausreichend über KAM informiert fühlt und keine ausreichende Weiterbildung diesbezüglich besteht, wie die Ergebnisse mehrerer Untersuchungen nahelegen (Muenstedt et al. 2011, Trimborn et al. 2013, King et al. 2015). Zudem fehlen größtenteils seriöse Daten zu den verschiedenen KAM-Methoden (Huebner et al. 2013b, Kutschan et al. 2020, Huebner et al. 2013a). Es ist möglich, dass diese Unsicherheit auch vom Patienten bemerkt wird. Weiter ist anzunehmen, dass Patienten bei Ärzten höhere Anforderungen an die Qualität der Informationen stellen, während eine schlechtere Qualität bei anderen Quellen wie dem Internet bekannt und eher akzeptiert sein dürfte. Das Maß an Unzufriedenheit könnte besonders deshalb so groß ausgefallen sein, weil diese Erwartung enttäuscht wurde. Zudem könnten Mediziner komplementären und alternativen Methoden ablehnend gegenüber eingestellt sein und so für den Patienten nur ungenügende Informationen anbieten.

Die am häufigsten genutzte Informationsquelle über KAM waren jedoch nicht Ärzte, sondern das Internet. Zudem zeigten sich mehr als die Hälfte der Patienten (56 %) damit zufrieden, also deutlich zufriedener als mit Informationen von Ärzten. Hinsichtlich der im Internet über KAM erhaltenen Informationen und dem Stellenwert des Internet für den Informationsbezug stellen sich selbstverständlich erneut dieselben Probleme wie bereits unter *Abschnitt a.* diskutiert. Gerade in Bezug auf KAM ist die Qualität und der Inhalt dieser Informationen jedoch besonders variabel (Schmidt und Ernst 2004, Broom und Tovey 2008, Verhoef et al. 2009, Brauer et al. 2010) und häufig unwissenschaftlich bis potenziell schädlich (Walji et al. 2004, Brauer et al. 2010). In einer Analyse englischsprachiger Seiten mit Informationen über KAM zeigte sich, dass in hohem Maße wissenschaftlich fragwürdige Aussagen über die Wirkung getroffen und Nebenwirkungen negiert wurden (Matthews et al. 2003). Selbst die Informationen auf Internetseiten von amerikanischen Tumorzentren waren stark heterogen und nur von mittlerer Qualität (Brauer et al. 2010). Die hohe Zufriedenheit der Patienten mit den Informationen über KAM deutet darauf hin, dass dieses Problem von ihnen nicht erkannt wird. Dies setzt die Patienten dem Risiko von unerwünschten Wirkungen, Nebenwirkungen und Interaktionen aus.

Problematisch ist zudem, dass seriöse Webseiten wie die des KID nur einer Minderheit der Teilnehmer bekannt waren. Hierauf sollte aktiv im Patientengespräch hingewiesen werden und Informationsmaterial bereitgestellt werden, um Fehlinformationen durch Recherche auf unwissenschaftlichen Webseiten vorzubeugen.

c. Einfluss von soziodemografischen Faktoren, dem BFI-10 und dem Interesse an KAM

Die Auswertung der soziodemografischen Daten zeigte sich im Einklang mit der Literatur. Die deutlich häufigere Verwendung von KAM unter Frauen und gebildeteren Patienten wurde bereits vielfach nachgewiesen (Richardson et al. 2000, Molassiotis et al. 2005, Miller et al. 2009, Heese et al. 2010, Elsner et al. 2013, Firkins et al. 2018) und besteht auch bei Patienten, die keine Krebserkrankung haben (Frass et al. 2012). Zudem scheinen beide Gruppen aktiver nach krankheitsbezogenen Informationen zu recherchieren und eine größere Auswahl an Informationsquellen zu verwenden (Eakin und Strycker 2001, Rutten et al. 2005, Beckjord et al. 2008, Matsuyama et al. 2011, Pieper et al. 2015, Finney Rutten et al. 2016), möglicherweise um nach Wegen zu suchen, selbst aktiv etwas zur Therapie beitragen zu können. Eine erhöhte KAM-

Nutzung von jüngeren Patienten ist ebenfalls in der Literatur nachgewiesen (Molassiotis et al. 2005, Micke et al. 2009, Frass et al. 2012, Hamilton et al. 2013), war in der hier demonstrierten Studien jedoch nur in einer (Bauer et al. 2018) von zwei Studien signifikant (siehe Abschnitt f.). Diesem hohen Bedürfnis nach Informationen und KAM-Nutzung sollte von Ärzten aktiv begegnet werden, indem auf seriöse Informationsmöglichkeiten und zum Therapiekonzept passende Methoden verwiesen wird.

Auch hinsichtlich der Ursachen für das Interesse an KAM zeigten sich Unterschiede zwischen den Geschlechtern: Männer gaben häufiger an, Interesse an KAM zu haben, um nichts unversucht lassen, während Frauen häufiger angaben, das Immunsystem und ihren Körper stärken oder entgiften zu wollen. So scheinen Männer eine eher zweckorientierte Herangehensweise an KAM zu haben, während Frauen eher einen ganzheitlichen Therapieansatz verfolgen (Leiser 2003, Warriner et al. 2014).

In dem untersuchten Patientenkollektiv fand sich weder eine Korrelation der 5 Persönlichkeitsfaktoren mit dem Interesse an KAM noch deren Verwendung. Obwohl in einer Studie aus den USA hohe Gewissenhaftigkeit und niedriger Neurotizismus mit einem besseren Gesundheitsverhalten korrelierten (Rocheffort et al. 2018) und sich in weiteren Studien bei erhöhter Offenheit eine höhere KAM-Nutzung fand (Lo-Fo-Wong et al. 2012, Nilsson et al. 2016), sind Daten zu Tumorpatienten bislang rar und teilweise widersprüchlich (Olchowska-Kotala 2013). Daher wären weiterführende Untersuchungen bezüglich eines potenziellen Einflusses von Persönlichkeitsfaktoren mit geeigneten Instrumenten sinnvoll, um mögliche weitere Vorhersagewerte über KAM-Nutzer evaluieren zu können.

d. Unterschiede im Interesse bereits vor vs. erst nach der Diagnosestellung

Unseres Wissens nach untersucht diese Arbeit als eine der ersten mögliche Unterschiede zwischen Patienten, welche sich bereits vor der Diagnosestellung für KAM interessierten und solchen, die dies erst nach der Diagnose taten. Hier zeigte sich, dass sowohl Frauen als auch gebildetere Patienten bereits vor der Diagnose häufiger interessiert waren. Dies könnte an den bereits unter Abschnitt c. diskutierten Faktoren liegen, sowie möglicherweise an einer höheren Bereitschaft, Fähigkeit und Möglichkeit, sich über Therapieoptionen zu informieren.

Hingegen traf dieses bekannte Profil des KAM-Nutzers nicht mehr auf Patienten zu, welche erst nach der Diagnose Interesse an KAM entwickelt hatten: Hier zeigten Männer häufiger Interesse. Dies ließ sich jedoch nur in einer Studie nachweisen (Bauer et al. 2018), in einer zweiten fand sich dagegen keine signifikante Korrelation (Dubois et al. 2019), (siehe Abschnitt f.). Bezüglich der Bildung fand sich ebenfalls keine Signifikanz mehr. Aus der Literatur ist bekannt, dass sich Interesse und Nutzung von KAM nach einer Tumordiagnose erhöhen (Velicer und Ulrich 2008). Daher ist gut denkbar, dass sich angesichts dieses potenziell lebensbedrohlichen Ereignisses die Sichtweise von Personen ändert, die nicht dem KAM-Stereotyp (jung, weiblich, gut gebildet) entsprechen und KAM zuvor möglicherweise skeptisch gegenüber eingestellt waren. Hierzu würde passen, dass sowohl das generelle Patientenkollektiv als auch besonders Männer mit Interesse nach der Diagnose häufiger angaben, nichts unversucht lassen zu wollen und KAM häufiger als Heilmittel gegen Krebs zu verwenden.

Dadurch, dass nach einer Tumordiagnose bislang bekannte Charakteristika für KAM-Nutzer nicht mehr zutreffend zu sein scheinen, ist das Risiko höher, nicht durch ihren Arzt nicht über KAM aufgeklärt und informiert zu werden. Somit könnten diese Patienten häufiger unerwünschten Nebenwirkungen und Interaktionen ausgesetzt sein, welche wiederum vom Arzt schlechter eingeordnet werden können. Weitere Studien zu Unterschieden von zwischen Interesse vor und nach der Tumordiagnose sowie der resultierenden KAM-Nutzung werden benötigt, um diesen Aspekt eingehender zu beleuchten.

e. Einfluss auf Therapieentscheidung, Offenlegung KAM-Nutzung

Die Art der Therapieentscheidung korreliert maßgeblich mit der Zufriedenheit der Teilnehmer mit den erhaltenen Informationen. Unzufriedene, aber auch KAM-Nutzer fällten sie statistisch deutlich häufiger allein, wobei es deutliche Überschneidungen der beiden Gruppen gab. Durch Unzufriedenheit könnte Misstrauen in den ärztlichen Rat entstehen und zu einer alleinigen Therapieentscheidung führen. Mit den Informationen zufriedene Patienten berichteten dagegen häufiger über eine partizipative Entscheidungsfindung (Shared Decision-Making, SDM).

Eine weitere mögliche Ursache für eine alleinige Therapieentscheidung durch den Patienten kann jedoch auch das Bedürfnis sein, selbst aktiver zu werden und die Dinge selbst in die Hand nehmen und besser kontrollieren zu wollen (Huebner et al. 2014b).

Dennoch deuten die Ergebnisse darauf hin, dass ein besonderes Augenmerk auf die Zufriedenheit mit den Informationen gelegt werden und Patienten nach ihrer Zufriedenheit gefragt werden sollten, um eine partizipative Entscheidungsfindung zu ermöglichen. Nachweislich kann so ein Bereuen der Therapieentscheidung verhindert (Brown et al. 2012, Efficace et al. 2014, Kashaf und McGill 2015) und so möglicherweise Therapieabbrüche oder die alleinige Verwendung von alternativer Medizin vorgebeugt werden.

Auch hinsichtlich KAM sollte eine partizipative Entscheidungsfindung erfolgen. Unerwünschte Nebenwirkungen oder Interaktionen können durch den behandelnden Arzt nur schwer eingeordnet werden, wenn er nicht über die KAM-Nutzung des Patienten informiert ist. Diese können zudem fälschlicherweise der konventionellen Therapie zugeschrieben werden und womöglich zum Therapieversagen oder -abbruch führen. Dies kann dadurch erschwert werden, dass Patienten häufig die Verwendung von KAM dem Arzt gegenüber nicht offenlegen (Robinson und McGrail 2004, Davis et al. 2012, King et al. 2015). In dieser Forschungsarbeit fanden sich leicht voneinander abweichende Raten der Nicht-Offenlegung der KAM-Nutzung: 14,8 % in Bauer et al. vs. 18,3 % in Dubois et al. sprachen mit keinem Arzt über ihre KAM-Nutzung. Dies ist gerade im Vergleich zur Literatur gering, wo sich teilweise deutliche höhere Raten zwischen 20 % und 77 % fanden (Robinson und McGrail 2004, Davis et al. 2012, King et al. 2015).

Gerade der Onkologe jedoch wurde nur von einem Drittel, der Hausarzt nur von einem Viertel der Teilnehmer informiert. Mögliche Ursachen für die Nicht-Offenlegung können Angst vor Zurückweisung sein oder die Annahme, Ärzte seien diesen Methoden gegenüber negativ eingestellt oder nicht darüber informiert. Es konnte gezeigt werden, dass Patienten annahmen, KAM sei nicht für die Therapie relevant oder das Thema nicht ansprechen, weil der Arzt nicht aktiv danach gefragt hatte (Tasaki et al. 2002, Robinson und McGrail 2004, Davis et al. 2012).

Daher ist es von großer Wichtigkeit, dass Ärzte dieses Thema selbst ansprechen, um die Therapie möglichst gut aufeinander abstimmen und mögliche Nebenwirkungen und Interaktionen einordnen zu können.

f. Diskussion der Methoden und Limitationen

Die in dieser Dissertation vorgestellten Ergebnisse zeigen, wie wichtig hochwertige Informationen über KAM im Internet und von Ärzten für Tumorpatienten sind. Aus der Methodik und den Ergebnissen ergeben sich jedoch einige Limitationen.

Generell ist anzunehmen, dass eine selektive Stichprobe vorliegt, weshalb die Ergebnisse nicht ohne Weiteres auf alle Mitglieder des Vereins oder die Population aller Tumorpatienten mit den genannten Erkrankungen übertragbar sind. Es ist ferner davon auszugehen, dass die Teilnehmer, auch aufgrund der Onlinebefragung, im Vergleich zu Nicht-Teilnehmenden eher internetaffin und besonders am Thema der Befragung interessiert waren und somit der hohe Stellenwert des Internets als Informationsquelle überschätzt sein könnte.

Hinsichtlich der Stichprobe zeigte sich zudem eine Überrepräsentation von Frauen und gebildeteren Patienten. Da in diesen Gruppen bereits ein erhöhtes Informationsbedürfnis sowie eine höhere KAM-Nutzung nachgewiesen ist, könnte dies zu einer Verzerrung der Ergebnisse im Vergleich zur Gesamtpopulation der Tumorpatienten geführt haben. Auch haben die Mitglieder bereits durch den Beitritt in die Selbsthilfegruppe ein erhöhtes Interesse an Informationen und eine besondere Aktivität bewiesen, was eine Erklärung für das insgesamt sehr hohe Informationsbedürfnis sein könnte. Darüber hinaus wurde speziell eine Gruppe mit seltenen soliden Tumoren untersucht, sodass die Ergebnisse nicht ohne Weiteres auf andere Tumorarten übertragbar sind. Gerade hier sind Informationen oft rar und die Ungewissheit könnte zu einer größeren Unzufriedenheit führen. Studien zur Gegenüberstellung von seltenen und häufigen Tumoren wären sinnvoll, um mögliche Unterschiede herausstellen und somit besser auf die unterschiedlichen Bedürfnisse eingehen zu können.

Statistisch ist zu beachten, dass die Ergebnisse bezüglich einer signifikanten KAM-Nutzung von jüngeren Patienten sowie einer vermehrten Nutzung durch Männer nach der Tumordiagnose nicht konsistent erscheinen. Hier zeigte sich in einer der Auswertungen ein signifikantes Ergebnis (Bauer et al. 2018), während sich in einer zweiten keine Korrelation nachweisen ließ (Dubois et al. 2019). Zudem fanden sie leicht unterschiedliche Raten der Offenlegung der KAM-Nutzung: 14,8 % vs. 18,3 %. Dies dürfte an der unterschiedlichen statistischen Auswertung (Chi-Quadrat vs. lineare Regression) in den drei Studien liegen. Zudem wichen die Stichproben leicht

voneinander ab, da teilweise unterschiedlich mit statistischen Ausreißern und Inklusionskriterien umgegangen wurde. Dennoch zeigten sich in allen drei Artikeln in der überwiegenden Mehrheit konstante und vergleichbare Ergebnisse.

In der Auswertung wurden bei geringen Antwortzahlen je Item häufig verschiedene Antwortkategorien für die Chi-Quadrat-Tests zusammengefasst: aus *eher wichtig* und *sehr wichtig* wurde zum Beispiel *wichtig*. Dies war möglich, da die Analysen explorativ durchgeführt wurden. Bei zukünftigen, eher hypothesen-testenden Verfahren könnten auch für diese Fragen Regressions- oder Pfadanalysen genutzt werden, die die Einflüsse der Variablen untereinander sichtbar machen können, ähnlich wie dies in den Analysen der Persönlichkeitsfaktoren erfolgte (Dubois et al. 2019). Darüber hinaus konnte die Auswertung von Frage 9 nur deskriptiv erfolgen, da im Onlinefragebogen statt einer Zweifachantwort lediglich eine Einfachantwort möglich war. Die deskriptive Statistik stellt bei Verwendung der jeweiligen Methode somit nur die Hälfte der eigentlichen Antwort der Nutzer dar. Eine Aussage zur Verwendung der verschiedenen KAM-Methoden und der Meinung des Onkologen hierzu kann somit nicht getroffen werden.

Bei den Fragebogendaten sind – wie immer bei retrospektiven Selbsteinschätzungen - Erinnerungsfehler und kognitive Verzerrungen möglich. Die Teilnahmequote der hier berichteten Studien lag bei 20 %. Eine solche Quote liegt im niedrig-normalen Bereich für Onlinebefragungen (Cook et al. 2000, Manfreda et al. 2008, Daikeler et al. 2019).

Der BFI-10 zeigte zudem in dieser Stichprobe eine schlechte interne Konsistenz. Bei einer Replikation sollte daher ein ausführlicheres Big-5-Inventar genutzt werden, um so klarere Zusammenhänge zwischen den Persönlichkeitsfaktoren und der KAM-Nutzung herausarbeiten zu können.

Um konkreten Verbesserungen insbesondere in Bezug auf das Management von Nebenwirkungen und Unterstützungsmöglichkeiten zu ermöglichen, wären zudem weitere Studien zu den Gründen der Unzufriedenheit mit den jeweiligen Informationen sinnvoll.

7. Schlussfolgerungen

Die in dieser Dissertation vorgestellten Ergebnisse unterstreichen die essentielle Rolle des Arztes in der Vermittlung von Informationen an Tumorpatienten. Zwar zeigte sich eine hohe Zufriedenheit mit den Informationen über die Erkrankung und Therapie im Allgemeinen, jedoch besteht hinsichtlich möglicher Unterstützungsmöglichkeiten und dem Management von Nebenwirkungen noch Verbesserungsbedarf. Diese Themen sollten vom Arzt routinemäßig angesprochen werden, um dem Patienten Möglichkeiten aufzuzeigen, selbst aktiv werden zu können. Informationsmaterial zu passenden und seriösen Gruppen sollte jedem Tumorpatienten ausgehändigt werden. So kann zur Stärkung der Gesundheitskompetenzen und zur häufigerer partizipativer Entscheidungsfindung beigetragen werden, was wiederum die Compliance erhöhen und sich so positiv auf die Lebensqualität auswirken kann.

Insgesamt wäre eine engere Einbindung des Hausarztes in die Tumorbehandlung sinnvoll. Da dieser häufig die ambulanten Nachsorgen übernimmt, ist dies gerade in Bezug auf das Management von Nebenwirkungen wichtig. Da die Zufriedenheit mit den vom Hausarzt erhaltenen Informationen jedoch gering war, sollten – gerade angesichts der Vielzahl an unterschiedlichen Tumoren und Therapien – speziell auf die hausärztliche Versorgung zugeschnittene Handlungsempfehlungen für die jeweiligen Tumorentitäten erstellt werden. Zudem sollten die Verbesserungsmöglichkeiten von Informationen über Management von Nebenwirkungen und Unterstützungsmöglichkeiten weiter untersucht werden.

Hinsichtlich der immer bedeutender werdenden Rolle des Internets ist es zudem außerordentlich wichtig, dass Ärzte selbst aktiv Hilfestellung zur Online-Recherche geben. Die Patienten sollten auf seriöse Webseiten hingewiesen werden, welche qualitativ hochwertige Informationen über ihre Erkrankung und Therapie enthalten. So könnte Risiken durch Falschinformationen vorgebeugt werden.

Da das Internet die wichtigste Quelle von Informationen über KAM darstellte, besteht gerade hier ein dringender Bedarf nach seriösen Informationen. Diese sollten möglichst direkt auf den Internetseiten der Krebszentren bereitgestellt werden und über Wirkung, Nebenwirkungen sowie Interaktionen informieren. Zudem wäre es sinnvoll, eine für Patienten leicht ersichtliche Kennzeichnung (Label) von wissenschaftlich geprüften und hochwertigen Internetseiten zu erstellen. Dies wäre

auch für die konventionelle Tumorthherapie sinnvoll. Hierfür ist eine weitere intensive Forschung zu den vielen unterschiedlichen KAM-Methoden, deren Wirkungen, Nebenwirkungen und Interaktionen mit konventionellen Therapien dringend vonnöten.

Angesichts der hohen Nutzerraten und dem noch höheren Interesse an KAM, ist es essentiell, dass Ärzte dieses Thema nach der Krebsdiagnose routinemäßig ansprechen und seriöses Informationsmaterial bereithalten. Es sollte zum Standard gehören, dass Tumorpatienten im Gespräch aktiv auf die Probleme unseriöser Internetquellen hingewiesen und gleichzeitig auf seriöse Quellen verwiesen werden, um Interaktionen, unerkannten Nebenwirkungen oder gar Therapieabbrüchen vorzubeugen.

Als eine der ersten Studien konnten wir zeigen, dass gerade Patienten, die erst nach der Diagnose Interesse an KAM zeigten, nicht den bislang nachgewiesenen Charakteristika entsprechen. Daher ist dringend empfehlenswert, jedem Tumorpatienten standardmäßig Informationen über KAM anzubieten. So lassen sich im Idealfall partizipativ Methoden finden, welche sinnvoll in die Therapie eingebunden werden können.

Es ist alarmierend, dass sich Tumorpatienten mit den im Internet erhaltenen Informationen über KAM zufriedener zeigten, als mit solchen von Ärzten. Um eine integrative Behandlung zu gewährleisten, ist ein spezielles Training über KAM notwendig, da sich ein Großteil des medizinischen Personals nicht ausreichend dazu informiert fühlt (Muenstedt et al. 2011, Trimborn et al. 2013, King et al. 2015). Dieses sollte für Onkologen und weiterbehandelnde Ärzte angeboten werden. Hier sollte besonders auf Nebenwirkungen und Interaktionen mit der konventionellen Behandlung eingegangen werden. Zudem sollte auf Webseiten mit zuverlässigen Informationen hingewiesen werden. Ebenso wäre es sinnvoll, Informationsbroschüren über KAM zu erstellen, welche von den Ärzten ausgehändigt werden können. Hier sollte das Bildungsniveau der Patienten berücksichtigt werden, um auch schlechter gebildete Patienten zu erreichen.

Insgesamt weisen die in dieser Dissertation dokumentierten Studien darauf hin, dass sich das standardmäßige Informieren über KAM, deren sinnvolle und risikofreie Integration in die Behandlung, sowie das Wissen um die jeweiligen verwendeten Methoden positiv auf die Arzt-Patientenbeziehung und die Zufriedenheit des Patienten

auswirken können. Zudem könnte durch Vorbeugen von Nebenwirkungen, Interaktionen oder Therapieversagen die Compliance und möglicherweise das Outcome verbessert werden. Daher sollten aktive Informationen über KAM und deren integrative Nutzung sowie Hilfestellung zur Internetrecherche ein standardmäßig integrierter Bestandteil jeder onkologischen Behandlung sein.

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9. Anhang

9.1 Fragebogen

Umfrage zur Informationsvermittlung und Nutzung von Komplementären Therapien unter Krebspatienten

1. Wie wichtig sind Ihnen Informationen...	sehr wichtig	eher wichtig	eher unwichtig	sehr unwichtig
... zu Ihrer Erkrankung?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... zu Ihrer Therapie?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... zu Methoden der Naturheilkunde und/oder komplementären (ergänzenden) und/oder alternativen Therapien?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... zu Nebenwirkungen Ihrer Therapie?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Wie zufrieden sind Sie im Allgemeinen	sehr zufrieden	eher zufrieden	eher unzufrieden	sehr unzufrieden
... mit Informationen zu Ihrer Erkrankung insgesamt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... mit der Verständlichkeit dieser Informationen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... mit Informationen über weitere Unterstützungsmöglichkeiten (z.B. Selbsthilfegruppen, soziale Dienste)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... mit Informationen zum Verlauf Ihrer Erkrankung?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... mit Informationen über die Therapie Ihrer Erkrankung?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... mit Informationen über die Wirkung der verordneten Krebsmedikamente?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... mit Informationen über die Nebenwirkungen der Behandlung?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... mit Informationen über den Umgang mit den Nebenwirkungen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... Informationen zu Methoden der Naturheilkunde und/oder komplementären (ergänzenden) und/oder alternativen Therapien?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Wie sehr haben Ihnen Informationen zu Ihrer Erkrankung und Therapie geholfen, die Sie aus folgenden Quellen erhalten haben?

	sehr gehoffen	eher gehoffen	wenig gehoffen	nicht gehoffen	nicht gefragt
Hausarzt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Onkologe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anderer Facharzt:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Krankenhaus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Apotheke	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Selbsthilfegruppen, Patienten- und andere Organisationen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet und andere Medien	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Verwandte, Bekannte, nahestehende Personen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Heilpraktiker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Zentrum für trad. Chines. Medizin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GfBK - Biologische Krebsabwehr	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vortrag / Veranstaltung	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
KID - Krebsinformationsdienst	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bücher	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Meinung (anderer Arzt)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anderere Betroffene	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sonstige: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Wie stark fühlten Sie sich bei der endgültigen Entscheidung zur Therapie mit einbezogen?

- ich habe diese Entscheidung alleine getroffen
- mein Arzt und ich haben diese Entscheidung gemeinsam getroffen
- mein Arzt hat diese Entscheidung für mich getroffen

5. Interessieren Sie sich für komplementäre Medizin?

- ja, schon vor meiner Krebserkrankung
- nein
- ja, erst seit ich Krebs habe

Bitte beantworten Sie die weiteren Fragen nur, wenn Sie hier mit ja geantwortet haben!

6. Warum interessieren Sie sich für Methoden der Naturheilkunde und/oder komplementären (ergänzenden) und/oder alternativen Therapien? (mehrere Antworten sind möglich)

- Immunsystem stärken
- körpereigene Kräfte stärken
- entgiften
- als Heilmittel gegen Krebs
- Um nichts unversucht zu lassen
- andere Gründe (bitte auflühren):

7. Von wem haben Sie Informationen zu Methoden der Naturheilkunde und/oder komplementären (ergänzenden) und/oder alternativen Therapien erhalten und wie haben Ihnen diese geholfen?

	sehr gehoffen	eher gehoffen	wenig gehoffen	nicht gehoffen	nicht gefragt
Hausarzt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Onkologe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anderer Facharzt:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Krankenhaus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Apotheke	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Selbsthilfegruppen, Patienten- und andere Organisationen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet und andere Medien	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Verwandte, Bekannte, nahestehende Personen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Heilpraktiker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Einrichtung Trad. Chines. Medizin/ Einrichtung für Ayurveda	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GfBK - Biologische Krebsabwehr	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vortrag / Veranstaltung	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
KID - Krebsinformationsdienst	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bücher	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Meinung (anderer Arzt)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anderere Betroffene	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Nutzen Sie derzeit oder haben Sie bereits komplementäre Therapien angewandt?

ja
 nein

9. Wenn Sie aktuell Methoden der Naturheilkunde und/oder der komplementären (ergänzenden) und/oder alternativen Medizin nutzen, welche sind dies? Was hat Ihr Onkologe dazu gesagt?

	Habe ich früher einmal angewendet	Nehme ich derzeit ein /wende ich derzeit an	Nicht mit Onkologen gesprochen	Dazu hat mir Onkologe geraten	Davon hat mir mein Onkologe abgeraten	Dazu hat Onkologe nichts gesagt
1. Vitamine						
2. hochdosierte Vitamin-C-Infusionen						
3. Selen und andere Spurenelemente						
5. Mistel						
7. Akupunktur						
8. Homöopathie						
9. Chinesische Kräuter / Tees						
10. Heilpilze						
11. Meditation						
12. Gebet						
13. Entspannungsverfahren						
14. Yoga / Tai Chi / Qi Gong						
15. Vitamin B17; Aprikosenkerne						
16. Hyperthermie						
17. Besondere Ernährung (bitte nennen)						
18. Sonstiges, bitte eintragen						

10. Haben Sie die Anwendung dieser Methoden Ihren Ärzten mitgeteilt? Wenn ja, wem? (Sie können mehrere Antworten ankreuzen):

- Meinem Onkologen
- Einem anderen Facharzt; und zwar:.....
- Meinem Hausarzt
- Keinem Arzt
- Ich kann mich nicht erinnern

11. Welche Medikamente gegen die Tumorerkrankungen bekommen Sie aktuell?

12. Wie Menschen mit Information umgehen, hängt auch von der eigenen Veranlagung ab, deshalb möchten wir Sie bitten auch diese Fragen zu beantworten. Inwieweit treffen die folgenden Aussagen auf Sie zu?

	Trifft überhaupt nicht zu					Trifft voll und ganz zu
	1	2	3	4	5	
Ich bin eher zurückhaltend, reserviert	1	2	3	4	5	
Ich schenke anderen leicht Vertrauen, glaube an das Gute im Menschen.	1	2	3	4	5	
Ich bin bequem, neige zur Faulheit.	1	2	3	4	5	
Ich bin entspannt, lasse mich durch Stress nicht aus der Ruhe bringen.	1	2	3	4	5	
Ich habe nur wenig künstlerisches Interesse.	1	2	3	4	5	
Ich gehe aus mir heraus, bin gesellig.	1	2	3	4	5	
Ich neige dazu, andere zu kritisieren.	1	2	3	4	5	
Ich erledige Aufgaben gründlich	1	2	3	4	5	
Ich werde leicht nervös und unsicher.	1	2	3	4	5	
Ich habe eine aktive Vorstellungskraft, bin fantasievoll.	1	2	3	4	5	

13. Zum Ende des Fragebogens möchten wir Sie bitten, ein paar Angaben zu Ihrer Person zu machen:

Zu welcher Personengruppe gehören Sie?

Patient, zur Zeit in Behandlung

Angehöriger

Patient, nach der Behandlung

Sonstiges

Alter: _____

Tumorart: _____

Bildungsabschluss: _____

Geschlecht: männlich weiblich

VIELEN DANK FÜR IHRE MITWIRKUNG!

9.2 Ehrenwörtliche Erklärung

Hiermit erkläre ich, dass mir die Promotionsordnung der Medizinischen Fakultät der Friedrich-Schiller-Universität bekannt ist,

ich die Dissertation selbst angefertigt habe und alle von mir benutzten Hilfsmittel, persönlichen Mitteilungen und Quellen in meiner Arbeit angegeben sind,

mich folgende Personen bei der Auswahl und Auswertung des Materials sowie bei der Herstellung des Manuskripts unterstützt haben: Prof. Dr. Jutta Hübner, Clara Dubois, Dr. Hannah Eisfeld, Dr. Thorsten Schmidt, Prof. Dr. Andreas Hochhaus sowie Karin Kastrati.

die Hilfe eines Promotionsberaters nicht in Anspruch genommen wurde und dass Dritte weder unmittelbar noch mittelbar geldwerte Leistungen von mir für Arbeiten erhalten haben, die im Zusammenhang mit dem Inhalt der vorgelegten Dissertation stehen,

dass ich die Dissertation noch nicht als Prüfungsarbeit für eine staatliche oder andere wissenschaftliche Prüfung eingereicht habe und

dass ich die gleiche, eine in wesentlichen Teilen ähnliche oder eine andere Abhandlung nicht bei einer anderen Hochschule als Dissertation eingereicht habe.

Weimar, 11.09.2020

Unterschrift des Verfassers

9.3 Danksagung

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