

Travel habits of patients with end-stage malignant diseases: a pilot study

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Abstract

Demographic development and continuing improvements in supportive and antineoplastic therapies are reasonable predictors of increasing travel activities carried out by patients with malignant diseases. There is a lack of data on travel habits of patients with end-stage oncological diseases. We performed a multi-phased cross-sectional study to gain insights into the intersection of travel medicine and oncology. A total of 82 patients with 21 different cancer entities at a median age of 63 years completed the final questionnaire. 90.2% of all participants rated travelling as an important or very important aspect in their lives, of whom 73.2% had participated in a short- or holiday trip after the cancer diagnosis. All but one (98.8%) participant were about to plan a short- or holiday trip in the near future. Germany (home country) was the most important travel destination, 'Relaxing' and 'enjoying nature' were the most important travel motives. Fatigue and overall (medical) insecurities were major obstacles to carry out travel plans. In conclusion, a high proportion of patients enjoy travelling. Physicians and patients are encouraged to openly discuss holiday-taking in accordance with available guidelines. More research is needed to fully understand needs and obstacles at the crossroads of travel medicine and oncology.

Keywords: Cancer, palliative care, travel medicine, pre-travel advice

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Introduction

The tourism industry worldwide has experienced a steady growth in the last decades and official forecasts estimate 1.8 billion international travels by 2030 and approximately 55 million people in Germany (78% of the German population) take at least one holiday trip of 5 or more days on an annual basis ¹.

Travelers with chronic diseases are at higher risk for peri-travel illnesses, repatriation or death as exacerbation of a chronic condition might be the result of physical stress, increased alcohol consumption, dietary changes and travel-related reduced adherence to therapy ²⁻⁵. Patients with chronic diseases are thus highly encouraged

to seek pre-travel medical consultation and advice that should be tailored to the traveler's itinerary and underlying medical conditions in order to reduce the risk of travel-associated (medical) complications.

Patients with end-stage oncologic diseases are a particular subset of chronically ill travelers, because they often require frequent medical surveillance, are at high-risk for acute medical conditions and often suffer from physical, mental, and/or psychological health issues of varying severity ⁶⁻⁸. Advances in treatment options and supportive measures, however, have improved survival in many cancer entities, and long-term survival exceeding

numerous years is seen even in patients with advanced or metastatic disease (e.g. [8-11](#)).

To date, there is a lack of data on travel habits, level of information and special requirements of oncological patients, especially of those with advanced or metastatic disease. We therefore performed a multi-phased cross-sectional study to gain first insights into travel-related aspects of patients with end-stage malignant hematological or oncological diseases not amenable to curative treatment. We here report the process development and results of phases I (execution of semi-standardized interviews and item identification), II (conception of a standardized questionnaire) and III (pilot field-testing of the finalized questionnaire) of a first-in-class comprehensive questionnaire to evaluate travel habits in patients with end-stage malignant maladies.

Material and Methods:

Phase I: Semi-standardized interviews and item identification

In Q4/2016, we performed qualitative semi-standardized in-depth interviews with 10 end-stage (not amenable for curative treatment) hematological and 9 end-stage oncological patients at the José Carreras Clinical Trial Center of the University Clinic, Frankfurt am Main, Germany. Patients were approached by their treating physicians and all interviews were subsequently scheduled during a 3-week time-frame. Interviews were performed in the presence of 6 persons (two physicians, two tourism researchers and two assistant scientists). Patients were asked to give a brief overview on their disease history and their current medical condition. Explored predefined categories of interest during the interview were socioeconomic characteristics, previous travel experiences, current and future travel motives and expectations, travel preparation and mode of booking, pre-travel advice, destination requirements, medical requirements and current medical issues. Clinical information on patient and disease characteristics were additionally obtained from the patient's charts. After each interview, the interrogator team recapitulated the interview based on the written recordings and all items that were considered to be related to the intersection of holiday taking, travelling and the medical condition were extracted. Finally, after the removal of duplicates, all items identified were collected and recategorized according to the previously mentioned categories of interest in addition to "miscellaneous" items.

Phase II: Conception of a standardized questionnaire

All categorized items identified in the in-depth interviews were re-analyzed for relevance by the scientific team including 2 tourism researchers and 2 physicians. Items that were considered of relevance by less than 2

researchers were rejected for inclusion in the questionnaire.

The construction of closed questions related to the remaining items of relevance was a multi-step process: At first, those items with complementary coverage in the German "Reiseanalyse" (RA) were borrowed and identically included into the questionnaire (n=11 items) to ensure comparability with the respective results. The RA is a research project that depicts travel patterns of the German population on an annually basis and has been performed by the "Forschungsgemeinschaft Urlaub und Reisen e.V." (FUR) since 1970 and examines more than 12,000 interviews representative of the German population every year [1](#). All remaining items (n=29) were constructed according to The European Organization for Research and Treatment of Cancer (EORTC) guidelines for developing questionnaire modules [12](#) and supporting literature [13](#). The final chapter of the questionnaire consisted of the QLQC30 quality of life EORTC module. The first construct was then reviewed by an epidemiologist and graphically optimized. The final version was pilot-tested in 10 volunteers in order to identify and solve potential problems in its administration, to identify missing or redundant issues and finally to estimate the approximate duration.

The finalized version consisted of a condensed 46-item questionnaire with an estimated processing time of 37 min (range, 29-45 min). A summary of all items in the respective categories gives Table 1.

Table 1: Item overview of the finalized questionnaire

	n	%	Cum* %
socioeconomic characteristics	6	13.0	13.0
previous travel experiences	4	8.7	21.7
current and future travel motives and expectations	3	6.5	28.3
travel preparation and mode of booking	15	32.6	60.9
pre-travel advice	4	8.7	69.6
destination requirements	5	10.9	80.4
medical requirements and current medical issues	6	13.0	93.5
miscellaneous	3	6.5	100.0
Total	46	100	

*cum %, cumulative percent

Phase III: Pilot field-testing of the finalized questionnaire

The questionnaire was field-tested in Q3, Q4/2019 at the University Hospital Frankfurt am Main, Frankfurt, Germany and at the Department of Hematology and Oncology of the Medicum Specialist Care Center, Wiesbaden, Germany. Patients were eligible to participate if they fulfilled the following criteria: age > 18 years, diagnosed with a malignant disease that has not been amenable to curative treatment for at least 3 months,

estimated life expectancy of more than 3 months, current outpatient treatment and provision of written informed consent. Medical data (histology, therapy) were collected either from the tumor documentation or, if not sufficiently documented electronically, from the paper file. Information sheets, consent forms and questionnaires were handed to the patients after routine medical contact. Patients were offered the option of taking the questionnaires home and sending them back with pre-franked envelopes. Alternatively, the questionnaires could be handed over directly to the attending physician. An e-mail address was set up for queries and to provide a general possibility of contacting the scientific team.

Statistical analysis

All variables were initially displayed descriptively (absolute and relative frequencies, mean values, proportion of missing values). Non-participants were registered in order to compare them with study participants in a non-participant analysis with regard to clinical and socio-demographic characteristics. New data was not collected in this process. The number of missing values in each variable was described using absolute and relative frequencies. Missing quality-of-life values were dealt with according to the EORTC regulations, i.e. missing items were replaced with the mean value of the scale, provided that at least half of the items of this scale had been answered. Otherwise the scale was not calculated. If cases were missing in categorical influencing variables and could not be supplemented by corresponding information from one of the available other study data sources (e.g. discharge letters), a variable value "missing" was formed. Finally, response data was clustered using k-prototypes partitioning (clustMixType 0.2-2 CITATION, R 3.6.0) on the indicated mixed (nominal, interval and ratio measurement scales) variables. Cluster prototypes were computed as cluster means for numeric variables and modes for nominal variables with focus on gender, age, quality of life, household income, travel destination countries, aspects of travel preparation, travel motives, preferred source of information and wish for medical support during travel. The number of clusters $k=5$ was determined graphically by plotting the sum of squared errors against the number of clusters $k \in [2;15]$ (elbow method)¹⁴. Additionally, we explored statistical differences between patients who had travelled after the cancer diagnosis with those who had not travelled using the Chi2 test for categorial variables. A p value below 0.05 was considered significant. Patient data used in this study were provided by the University Cancer Center Frankfurt (UCT). Written informed consent was obtained from all patients and the study was approved by the institutional Review Boards of the UCT

and the Ethical Committee at the University Hospital Frankfurt (project-number: 485-17-2018).

Results:

Patient characteristics and sociodemographics

Table 2 depicts patient and disease characteristics of the study cohort of the phase III (field testing of finalized questionnaire). A detailed list of tumor diagnoses can be found in the supplement section (Additional File 1). A total of 82 patients with a median age of 63 years (range, 28-84 years) who were recruited in Q3, Q4/2019 participated. Only two patients denied to participate, therefore the pre-planned non-participant analysis was not carried out.

Overall, 65 patients (79.3%) lived in a permanent partnership, 65.9% of whom ($n=54$) were married. Approximately 35% ($n=29$) were academics and only 2 participants had no graduation. The average net household income was between 2.750-3000€ (range, 250€ to >5000€) monthly. Fifteen participants (18.3%) were fully- or part-time employed. All but 5 patients possessed a driver's license of whom all owned their own automobile and 65.3% of these patients felt capable of driving themselves. A disabled person's pass was owned by 67.1%. The median quality of life (QOL) evaluated with the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire EORTC-QLQ-C30 of the whole study cohort was 53.4 (standard difference, 23.3).

Table 2: Patient and disease characteristics ($n=82$)

Age (median, range)	63 years (28-84 years)	
Gender	male	47 (57.3%)
	female	32 (39.0%)
	missing	3 (3.7%)
type of malignancy	solid	47 (57.3%)
	hematologic	30 (36.6%)
	other / not classified	3 (3.7%)
median time from 1st diagnosis	missing	2 (2.4%)
	22 months	
	(3-243 months)	
ECOG* performance status	ECOG 0	22 (26.8%)
	ECOG 1	48 (58.5%)
	ECOG 2	7 (8.5%)
	ECOG 3	2 (2.4%)
	missing	3 (3.7%)
current treatment	chemotherapy	49 (59.8%)
	targeted therapy	22 (26.8%)
	watch & wait	7 (8.5%)
	other	4 (4.9%)
	missing	0 (0%)
outpatient frequency	once weekly or more	27 (32.9%)
	about twice per month	26 (31.7%)
	about once a month	11 (13.4%)
	less than one a month	7 (8.5%)
	missing	9 (11%)
previous tumor surgery	yes	20 (24.4%)
	no	60 (73.2%)
	missing	2 (2.4%)
previous radiotherapy	yes	24 (29.3%)
	no	56 (68.3%)
	missing	2 (2.4%)

*ECOG, Eastern Cooperative Oncology Group

Travel experiences and travel motives

90.2% of all participants rated travelling as an important or very important aspect in their lives and 68.3% of the phase III study cohort already participated in a median of 2 holiday trips (range, 1-20) defined as more or equal than 4 overnight stays after the tumor diagnosis. Short-trips (3 or less overnight stays) had already been undertaken by 23.2% of the study participants (median 4; range, 1-12 trips). Of those 73.2% who had participated in a short- or holiday trip at least once (n=60), 56.7% (n=34) attributed an improvement of their physical performance to this holiday. 60% (n=36) experienced an improvement of their social network bonding and a regain in overall optimism. Only one patient did not experience positive aspects

during his holiday trip. All but one (98.8%) participant were about to plan a short- or holiday trip in the near future.

The main source of travel inspiration was family and friends, followed by personal interest and the world wide web (see Figure 1A). A small proportion of patients was even encouraged by her/his oncologist or general practitioner. The most important travel motives and anticipated type of holiday were relaxing end enjoying nature. Additionally, recovering and doing “something for one’s health”, as well as being close to friends and family were important aims amongst many other motives/activities (Figure 1B).

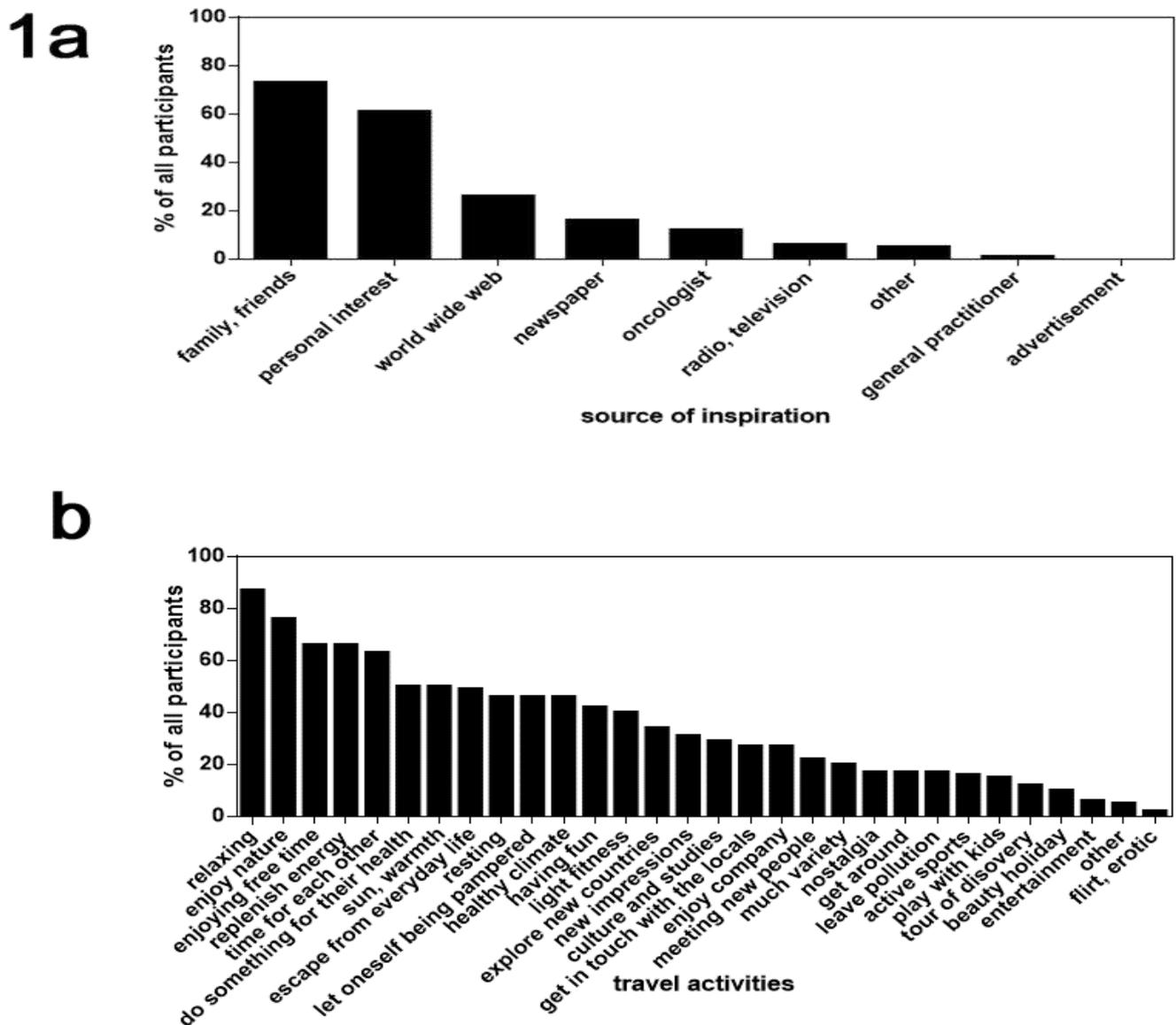


Fig. 1: Sources of inspiration (a) and preferred travel activities (b)

Travel preparation, pre-travel advice, mode of booking and destination requirements

More than half of all participants (57%) preferred all-inclusive tours and hotel travelling, whereas 37% preferred to organize their trip by means of individual bookings. The majority of participants planned their journey internet-based or sought assistance from a travel agency.

Approximately 80% of the respondents considered booking their holidays spontaneously or at short notice (1-3 months ahead). Regarding the influencing variables of journey organization, the overall costs were rated most

important for travel planning (55%), followed by the opportunity for personal consultation such as a 24h helpdesk (49%), and cancellation conditions (46%). Special requirements at the travel destination are shown in Figure 2. With regards to medical support, approximately half of all participants (47.6%) considered to actively choose a destination that provided some form of medical care, however, only 6% got in touch with the local medical team at the travel destination before travelling. Of note, only 6% wished to have their journey accompanied by a health care professional.

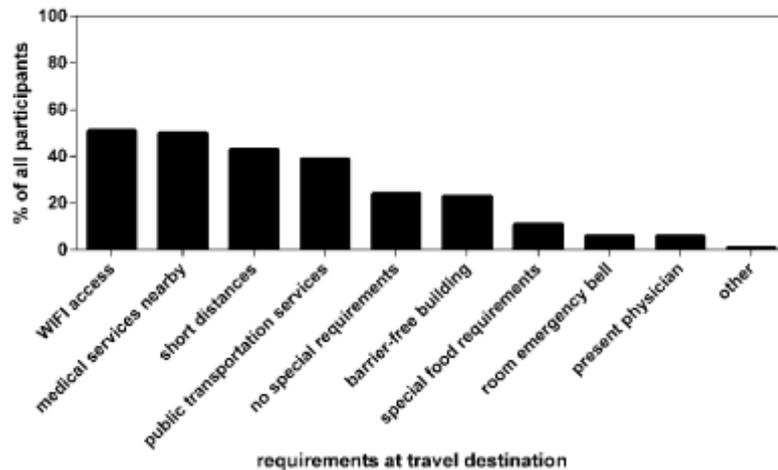


Fig. 2: Perceived requirements at the travel destination

Pre-travel sources of information and advice were mainly sought internet-based (> 60%). 42% of all participants considered consulting their oncologist for pre-travel advice, approximately 30% considered consulting their general physician. The majority of participants had not considered seeking any professional (travel-agency, physician) pre-travel counseling (53.6%). Among those who had considered seeking medical pre-travel advice, items rated most important by the participants were “evaluation of general fitness” (>60%), “organization of

medical support in the case of emergency” (44%), “translation of medical information into language of the destination country” (24%) and “customs and medication import” (20% of all participants). Aside from general travel advice (see above), the patient’s level of information regarding specific aspects was self-rated as low (see Figure 3) and 30% of all participants did not see the need for medical pre-travel counseling while also perceiving a lack of opportunities for pre-travel medical counseling.

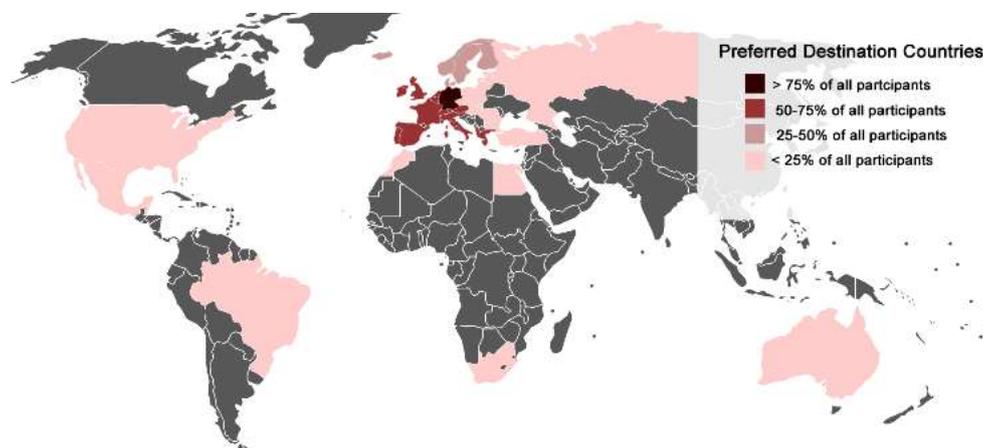


Fig. 3: Preferred destination countries of all questionnaire participants.

Travel distance, mode of travelling and destination countries

Approximately one-fourth of all participants defined the maximum tolerable travel distance as equal or less than 4 hours, 35% of all study participants felt convenient with travel distances above 6 hours. Approximately three-fourths of all participants rated 1-2 weeks of travelling as optimal. Most individuals would plan their holiday trip by car (80.5%), plane (57.3%) or train (47.6%) and 18.6% could imagine to tour by ship. The most important characteristics for the selection of the transport mode were travel speed, comfort and flexibility, whereas pricing and environmental friendliness were less important. Figure 3 displays the target countries for holiday trips. Approximately 90% of all participants choose their home country Germany as their main travel destination, however, 22% also chose long-distance travelling as a viable option, e.g. to South-Africa or transatlantic flights.

Difficulties in the realization of travel request

Finally, all participants were asked to enumerate potential and formerly experienced difficulties regarding the realization of their travel ideas. Amongst other problems, fatigue (59%), overall insecurity (34%), absence of adequate travel insurances (27%) and further symptoms related to the malignant disease as well as drug side effects (approximately one-third each) were most frequently named.

Subgroup analysis

We compared patients who had already taken part in a short- or holiday trip after tumor diagnosis (travelers) with those who had not yet done so (non-travelers). There were no significant sociodemographic differences between these subgroups (Table 3). Pricing was more often rendered as an important aspect ($p=0.02$) when planning a holiday trip by non-travelers and non-travelers were less likely to book a long-distance trip by airplane ($p=0.01$). Additionally, non-travelers more frequently preferred a nearby physician in the case of medical emergency ($p=0.01$). Participation in health and wellness activities was rated more important in the non-traveler subgroup ($p=0.02$). Further, patients who had not travelled since the tumor diagnosis were more often fully employed ($p=0.048$), and were more often in possession of a disabled person's pass ($p=0.02$). Additionally, there was a trend towards inferior QOL in non-travelers (56.5 ± 22.7 vs 45.0 ± 23.6 ; $p=0.06$). There were no significant differences regarding the average household income.

Table 3: Comparison of travelers with non-travelers (n=82)

	travellers	no travelers	p value
Male Gender	31/56	16/26	0.86
solid malignancy	34/56	13/26	0.52
under chemotherapy	33/56	16/26	0.87
previous radiotherapy	18/56	6/26	0.52
previous surgery	19/56	1/26	0.79
ECOG* 0,1	47/56	23/26	0.42
QLQ-C30 score	56.5 ± 22.7	45.0 ± 23.6	0.06

*ECOG, Eastern Cooperative Oncology Group

Discussion:

There is only limited scientific exploration of the intersection of malignant diseases and holiday taking, and there is a lack of evidence to guide health care providers and patients ¹⁵. We therefore conducted this exploratory study to create and validate a first-in-class comprehensive travel habits questionnaire in order to evaluate travel habits in patients with end-stage malignant diseases.

The overall interest in travel activities of our study cohort was high and 73.2% had already participated in a short or holiday trip after the diagnosis of advanced or metastatic cancer and all but one patient were in the process of planning future travel activities, irrespective of socioeconomic factors. The vast majority of patients attributed positive aspects to prior travelling after the diagnosis, which is in line with a pilot study performed by Hunter-Jones et al in 2003, who interviewed 24 cancer patients about their reflections upon holiday taking ¹⁶. In most patients, perceived benefits of travel seem to outweigh travel-related stress and exertion. In addition, we found a trend to improved QOL in patients who already engaged in travelling after the cancer diagnosis and although this association does not prove a causal relationship, previous data and ours suggest a potential impact that needs further scientific addressing. Following these arguments, physicians need to be aware of potential conflicts that might hamper the patient's travel intentions. In our cohort, overall insecurities as well as medication and disease-related symptoms were among the most frequently named issues that require review by the treating physician. The fact that 67.1% of the included patients owned a disabled person's pass reflects the need for pre-travel advice and careful consideration of the patient's physical impairment and possible anxieties. As 46.4% of the patients actively chose destinations that showed some form of medical care, but at the same time only few (6%) wished to be accompanied by a health care professional the golden threshold between the availability of medical care and the possibility of switching off from

“hospital life” needs to be individually determined for each patient. In general, it is of importance to minimize potential risks by careful planning including professional pre-travel advice. Although concrete pre-travel advices for oncological patients are mostly derived from related non-malignant diseases (e.g. COPD guidelines for patients suffering from lung-cancer), few overarching recommendations exist that should be considered ¹⁷, especially when preparing for international travelling.

The main source of information and consultation in our study were family and friends or web-based services. Professional advisors like physicians or a travel agency were involved in less than 50% of all participants, underscoring the need for creating more awareness within professionals. In line with this, Mikati et al. performed a retrospective analysis in patients with a history of cancer and showed that international travel is common among this population, visiting friends and families as well as tourism being the most important purposes for travelling. However, merely ~50% of all participants reported seeking pre-travel advice from a health care provider ¹⁸. Similar patterns were confirmed in another survey among (autologous and allogeneic) stem cell transplant (SCT) recipients ¹⁹. The high proportion of internet-based consultation in our survey, however, offers the possibility to present relevant information material at exposed websites.

Representative data on travel habits of the German population are annually published by the FUR. Unfortunately, specific subgroups are only explored on cost-intensive request and, more importantly, published results are mainly focused on commercial aspects limiting the scientific value for practical physicians ¹. It is one of the strengths of our questionnaire that specific questions were designed in accordance to this large representative survey to perform comparative analyses with the FUR data. However, due to the limited number of cases in our study, we have not included a comparative presentation in this manuscript.

Our study has some limitations. First, albeit a multitude of patients with different cancer entities were included (n=21, see supplement), epidemiologically important cancer entities such as gynecologic tumors are underrepresented here. An upcoming multi-centric study (Phase IV) aims to generate representative results in the near future. And second, all information provided by the participants are at risk for recall bias and only reflect the current opinion of the patient, which is the main reason why we did not ask for self-reported travel habits prior to the cancer diagnosis. Finally, in light of the recent COVID19 pandemic, travel habits of cancer patients may undergo transformation into yet unknown directions.

Conclusions:

Travel is an important aspect of life in patients with end-stage malignant diseases. A high proportion of patients enjoys national and international travelling and most patients experienced positive aspects related to travelling. Disease- and medication-related issues are potential impediments that might hamper travel intentions. Professional pre-travel advice, however, is currently only sought by a minority of patients. In conclusion, physicians and patients are encouraged to openly discuss holiday plans in accordance with available guidelines. More research is needed into this scientifically understudied intersection of travel medicine and oncology.

Highlights

What Is Already Known?

Demographic development and continuing improvements in supportive and antineoplastic therapies are reasonable predictors of increasing travel activities carried out by patients with malignant diseases. There is a lack of data on travel habits of patients with end-stage oncological diseases.

What Does This Study Add?

The study shows that patients with malignant diseases enjoy travelling. Physicians and patients are encouraged to openly discuss holiday-taking in accordance with available guidelines. More research is needed to fully understand needs and obstacles at the crossroads of travel medicine and oncology.

Declarations:

Ethics approval and consent to participate

Written informed consent was obtained from all patients and the study was approved by the institutional Review Boards of the UCT and the Ethical Committee at the University Hospital Frankfurt (project-number: 485-17-2018).

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

JSt reports personal fees from Bristol-Myers & Squibb, personal fees from Novartis, outside the submitted work. MSe reports personal fees from Lilly, personal fees from Astra-Zeneca, personal fees from Bristol-Myers & Squibb, personal fees from Merck Sharp & Dohme, personal fees from Pfizer, personal fees from Takeda, personal fees from Roche, personal fees from AbbVie, personal fees from Boehringer-Ingelheim, personal fees from Celgene, personal fees from Novartis, outside the

submitted work. All remaining authors have declared no conflicts of interest.

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Author Contribution

JSt., SKo, Oba, and KWe conceived and planned the study. JBi, Oba, OHe, FEI, JVi, Oba, SHo, NHo, CBr, HSe, Awe, SBa, SSh, MAh and MSe carried out the study, participated in patient interrogation and/or participant recruiting. KWe, MAh and SKo contributed to the interpretation of the results. All authors provided critical feedback and helped shape the research, analysis and manuscript.

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