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Online Health Information Seeking Before and After Oncology Consultations and its Impact on Patients' Anxiety and Uncertainty—A Longitudinal Questionnaire Study

Eline Bijlsma[1,2] | Tanja Henkel[1,2] | Annemiek J. Linn[3] | Marij A. Hillen[1,2,4] | Hanneke W. M. van Laarhoven[4,5] | Marie Jose Kersten[4,6] | Lukas J. A. Stalpers[4,7] | Mark I. van Berge Henegouwen[4,8] | Julia C. M. van Weert[3] | Ellen M. A. Smets[1,2]

[1]Department of Medical Psychology, Amsterdam UMC, Location University of Amsterdam, Amsterdam, the Netherlands | [2]Amsterdam Public Health Research Institute, Quality of Care, Amsterdam, the Netherlands | [3]Amsterdam School of Communication Research (ASCoR), University of Amsterdam, Amsterdam, the Netherlands | [4]Cancer Center Amsterdam, Cancer Treatment and Quality of Life, Amsterdam, the Netherlands | [5]Department of Medical Oncology, Amsterdam UMC, Location University of Amsterdam, Amsterdam, the Netherlands | [6]Department of Hematology, Amsterdam UMC, Location University of Amsterdam, Amsterdam, the Netherlands | [7]Department of Radiation Oncology, Amsterdam UMC, Location University of Amsterdam, Amsterdam, the Netherlands | [8]Department of Surgery, Amsterdam UMC, Location University of Amsterdam, Amsterdam, the Netherlands

Correspondence: Ellen M. A. Smets (e.m.smets@amsterdamumc.nl)

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ABSTRACT

Introduction: Patients with cancer increasingly engage in online health information seeking (OHIS), yet the impact thereof on their anxiety and uncertainty remains unclear. This study aimed to: (1) examine how, when, and why patients engage in OHIS before and after oncological consultations; (2) identify patient characteristics (sociodemographic, medical, psychological) associated with OHIS; and (3) explore the relationship between OHIS, state anxiety, and uncertainty.

Methods: Patients with various cancer diagnoses and at various phases-of-care completed three self-report questionnaires: before (T0), directly after (T1), and 2 weeks after (T2) their outpatient consultation.

Results: Half (50%) of patients ($n = 281$) engaged in OHIS. Commonly sought topics included physical complaints (T0: 57%, T2: 51%), chances of recovery after treatment and life expectancy (T0: 48%, T2: 47%), and common treatments (T0: 43%, T2: 33%). A stronger monitoring coping style, higher levels of trait anxiety, higher educational levels, and early phase-of-care were significantly associated with OHIS (all $p < 0.01$). Age, gender, health literacy, or uncertainty intolerance were not associated with OHIS (all $p > 0.05$). Seekers reported more uncertainty than non-seekers ($p < 0.001$), but OHIS was not significantly associated with state anxiety ($p = 0.642$).

Conclusion: One in two patients engaged in OHIS, particularly those who are recently diagnosed, highly educated, generally anxious or have a stronger monitoring coping style. Clinicians should not be concerned that patients' OHIS will increase patients' anxiety, as this study found no such association. As OHIS was associated with uncertainty, future research should explore whether addressing OHIS in consultations reduces uncertainty.

Eline Bijlsma and Tanja Henkel contributed equally to this work.

1 | Background

Coping with cancer presents significant challenges for patients. Patients can experience considerable emotional distress from the uncertainty associated with unpredictable symptoms, treatment effects, and the risk of recurrence [1–3]. To reduce uncertainty, patients often seek for health information [4–6]. While clinicians' opinions and expertise are highly valued [7], online resources have become the second most important source of health information [4, 8]. Online sources are increasingly available and used by patients with cancer to retrieve information about their health [9, 10].

Online resources can supplement medical consultations by addressing information needs that healthcare providers are unable to fulfill, due to time constraints or lack of skills [11, 12]. Moreover, online health information seeking (OHIS) can empower patients, particularly during the diagnostic phase, to prepare for and actively participate in consultations, by improving their disease understanding [8, 13, 14]. When treatment is discussed or has begun, new concerns may arise and online information may be consulted regarding treatment options, their efficacy, potential side effects, and how to manage work, family, and emotional wellbeing [14, 15]. Additionally, OHIS may help patients fulfill their needs for emotional or peer support [14]. Altogether, OHIS has the potential to reduce patients' uncertainty and anxiety [8, 13, 14].

Although OHIS potentially offers benefits for patients, there may also be drawbacks. The quality, clarity, and applicability of online health information varies widely, which can lead to confusion, misinformation, or information overload [6, 8]. Additionally, discrepancies between online content and clinicians' guidance may cause tension or distrust [8, 15]. Such dynamics have the potential to negatively impact the patient-clinician relationship. Clinicians may perceive a "leveling effect" in which their professional authority is undermined by online information, while patients may hesitate to raise such information out of concern that it could make the clinician feel embarrassed, challenged, or assume that the patient is overly anxious [8].

Several patient characteristics have been reported to be associated with OHIS behavior. Higher levels of trait anxiety have been found to be associated with reduced use and/or avoidance of OHIS in patients with cancer [15]. Patients with a monitoring coping style, characterized by an active approach to seek information, acquire more knowledge about their disease through OHIS than non-seekers [16]. High monitors benefit from information that helps them understand their situation by reducing uncertainty [17] and anxiety [3]. However, patients with limited health literacy, that is, a low ability to find, understand, and use health information [18], frequently struggle to understand online health information, exacerbating rather than alleviating uncertainty or anxiety [19]. For patients with a high uncertainty intolerance, OHIS may exacerbate anxiety [20]. These conflicting findings highlight the need for further research to clarify how various psychological characteristics influence OHIS in patients with cancer, and how OHIS, in turn, affects levels of anxiety and uncertainty.

Moreover, despite growing attention to the role of OHIS in cancer care, several other important research gaps persist. While a few studies have investigated OHIS using a longitudinal design, these studies were conducted more than 5 years ago or did not specifically focus on patients with cancer [21]. Additionally, most recent studies about the association between OHIS and patient outcomes were cross-sectional, only offering insight into a single moment in time [15]. Lastly, it is important to understand which patients engage in OHIS when having a clinical consultation, their reasons for doing so, and any psychological consequences since this can provide insights for patients and clinicians in optimizing the use of the internet as a source of health information, taking into account different phases of the disease and treatment trajectory, hereafter referred to as "phase(s)-of-care".

This study aimed to examine before and shortly after oncological consultations [1] when, how, and why patients with cancer seek online health information [2]; identify associations between patient characteristics (sociodemographic, medical and psychological) and OHIS, and [3] identify to what extent OHIS (seekers vs. non-seekers) is associated with patients' anxiety and uncertainty. The results of this study may help clinicians to better support patients with their informational and emotional needs throughout different phases-of-care and support patients in terms of anxiety and uncertainty, especially in light of engagement in OHIS [8, 22].

2 | Methods

2.1 | Study Design

This analysis was part of the Inter.Com study, a longitudinal, non-interventional, study that analyzed data from questionnaires completed by patients with cancer before and after an audio-recorded oncological consultation, at an academic hospital in the Netherlands. The present study focused solely on questionnaire-based data; the analysis of audio-recordings is discussed in another article. Data were collected between September 2023 and August 2024. This study was pre-registered on the open Science Framework (OSF): https://osf.io/cjrvt, the hospital's Medical Ethics Committee granted this study an exemption to seek formal approval (J2023.0311).

2.2 | Study Sample

Patients were recruited from multidisciplinary outpatient clinics for upper gastrointestinal cancer, hematology, and radiotherapy. Inclusion criteria for patients were [1]: age ≥ 18 [2]; sufficient Dutch language proficiency; and [3] cognitive ability to provide informed consent and complete questionnaires.

We included patients across all phases-of-care: diagnostic, treatment, and follow-up phase. Phases-of-care were defined using a 12-month time criterion, to improve the likelihood of OHIS behavior. The diagnostic phase encompassed the period from the first visit to the outpatient clinic until the start of cancer treatment (up to 1 year), including diagnosis of recurrent disease (e.g., metastases). The treatment phase involved the period of undergoing treatment or receiving preparatory consultations. Patients who had been receiving treatment for over a year were excluded. The follow-up phase included patients who had completed cancer treatment within the past 12 months with no new treatment planned.

In total, 71 clinicians consulting with eligible patients at the three participating outpatient clinics were invited to participate, all provided informed consent. This included medical specialists (surgeons, medical oncologists, hematologists, gastroenterologists, radiation oncologists), residents, nurse specialists, and physician assistants.

2.3 | Procedure

Participating clinicians introduced the study to eligible patients. Those who expressed interest received information from the researchers before providing informed consent. Most patients were informed at the hospital, some were contacted by phone due to absence of the researcher or limited patient availability. Questionnaires were completed either digitally or on paper, based on patient preference, at three time points: before the consultation (T0), immediately after (T1), and 2 weeks later (T2).

2.4 | Measures

Eight cancer survivors pilot-tested the questionnaires, which raised no issues, confirming the questionnaires' suitability for the main study. To minimize recall bias, patients were asked to report their experiences from the past 2 weeks. A full overview of measures, items, response options, and reliability is provided in Supporting Information S1: Appendix A.

2.4.1 | Patient Characteristics

At T0, patients' sociodemographic, medical, and psychological characteristics were assessed. Sociodemographic characteristics included gender, self-identified ethnic background, educational level categorized as low, medium or high [23], and health literacy, measured using a validated three-item scale (Cronbach's alpha: 0.62) [24]. Psychological characteristics assessed included: trait anxiety using the shortened six-item version of the Dutch Trait-scale (Cronbach's alpha: 0.89) [25, 26], uncertainty intolerance using the 12-item Dutch IUS-scale (Cronbach's alpha: 0.85) [27, 28], and monitoring coping style using three items from the shortened TMSI scale (Cronbach's alpha: 0.77) [3, 29]. All were analyzed as continuous variables. Patients' age and medical characteristics type of cancer and, if applicable, treatment, time since diagnosis, treatment intent (curative/palliative/undecided) and time since start/finish most recent treatment were extracted at study entry from the electronical medical patient file.

2.4.2 | OHIS

OHIS was defined as "consulting any online health resource for health information", with web resources varying from search engines (Google) to social media and specific websites (such as the Dutch Cancer Society website). Self-reported OHIS frequency, topics, and reasons were measured at T0 and T2 using custom-designed questions (Supporting Information S1: Appendix A). Reasons for OHIS were categorized based on face-validity. Patients were grouped into seekers (engaged in OHIS at least once within the time frame of 4 weeks, either before or after the consultation) and non-seekers (never engaged in OHIS within the time frame of 4 weeks). Seekers were categorized into three subgroups: (1) those who engaged exclusively in OHIS during the 2 weeks before the consultation, (2) those who engaged exclusively in OHIS during the 2 weeks after the consultation, and (3) those who engaged in OHIS both before and after consultation. Reasons for OHIS were assessed using 13 (T0) to 20 (T2) items rated on a 5-point scale and were subsequently grouped into nine overarching categories (e.g., to prepare for the consultation or need for emotional support) based on literature [13, 27]. Mean scores were used for analysis.

2.4.3 | Anxiety and Uncertainty

Patients' anxiety and uncertainty levels were assessed at T0, T1 and T2. State anxiety was measured with the abbreviated Dutch State-Trait-Anxiety Inventory (STAI-6) (Cronbach's alpha: 0.83–0.86) [30, 31]. Level of uncertainty was measured with the validated short form of the Mishel Uncertainty in Illness Scale (MUIS) (Cronbach's alpha: 0.66–0.75) [32, 33]. For both scales, higher means indicate higher anxiety or uncertainty.

2.5 | Data Analysis

A priori power analysis indicated that a minimum of 246 participants were required to detect a small effect ($d = 0.2$, 80% power, $\alpha = 0.05$). Descriptive statistics (e.g., frequencies and distribution analyses) were conducted to explore patients' OHIS. A Wilcoxon signed-rank test was conducted to compare the frequency of OHIS before and after the consultation for patients who reported OHIS at both time points. A binary logistic regression analysis was used to determine patient characteristics associated with OHIS, comparing seekers with non-seekers. Four sequential General Estimating Equations (GEE) per dependent variable (i.e., anxiety and uncertainty) were conducted to determine to what extent OHIS before and after the consultation was associated with patients' anxiety and uncertainty. Model 1 (unadjusted) included time, OHIS, and time*OHIS interaction as predictors. Model 2 was adjusted for sociodemographic characteristics i.e., age, gender, educational level and health literacy. Model 3 was additionally adjusted for phase-of-care. The nature of patients' treatment (i.e., palliative or curative) was deliberately omitted from analyses as the treatment plan was undecided for most patients. Model 4 was fully adjusted for all previous variables, with the addition of psychological characteristics (i.e., trait anxiety, monitoring coping style, and uncertainty intolerance).

3 | Results

3.1 | Sample Characteristics

Of 432 eligible patients, 352 consented to participate (82% response rate) of whom 281 were included in analyses. Reasons for exclusion were: no consultation during inclusion (n = 47), drop-out (n = 21), non-malignant diagnosis (n = 2), and no clinician permission (n = 1). See Figure 1 for the inclusion flowchart and Table 1 for sample characteristics.

3.2 | Patients' Use of Online Health Information Before and After the Consultation

Half of all patients (50%) reported OHIS at least once within the time frame of 4 weeks. Among them, the majority (39%) did so in the 2 weeks before the consultation, while 29% searched in the 2 weeks following the consultation. Of all seekers, 42% reported OHIS both before and after the consultation. Search engines were the most frequently consulted resources for online health information (T0: 28%, T2: 27%), followed by websites from official institutions such as the Dutch Cancer Society (T0: 14%; T2: 18%), and hospital websites (T0: 13%, T2: 11%) (Supporting Information S1: Appendix B). Social media, online forums, and support groups were least consulted (< 10%). At both time points, the most frequently searched topics concerned physical complaints (T0: 57%, T2: 51%), chances of recovery after treatment and life expectancies (T0: 48%; T2: 47%), and (medical) treatment options (T0: 43%, T2: 33%). Alternative and/or complementary treatments (T0: 6%, T2: 6%), together with possibilities to prevent (the recurrence of) cancer (T0: 9%, T2: 6%) were searched for the least (Supporting Information S1: Appendix C). Reasons for engaging in OHIS were consistent before and after the consultation (Supporting Information S1: Appendix D for M and SD). Preparing for consultations (T0: M = 3.49, SD = 0.89; T2: M = 3.77, SD = 0.64) and active contribution to their own disease trajectory (T0: M = 3.69, SD = 1.04; T2: M = 3.81, SD = 0.0.89) were the most endorsed OHIS motives. Seeking recognition (T0: M = 1.66, SD = 0.72; T2: M = 1.71, SD = 0.58) and acting on a clinicians' recommendation (T0: M = 1.86, SD = 0.97; T2: M = 1.69, SD = 0.88) were least endorsed.

3.3 | Patient Characteristics Associated With OHIS

The binary logistic regression model to evaluate associations between covariates and OHIS showed a good fit (χ^2 [8] = 6.85, p = 0.553), and explained 35% (Nagelkerke R^2) of the variance in online seeking versus non-seeking. Trait anxiety (p = 0.003), monitoring coping style (p < 0.001), level of education (p = 0.008) and phase-of-care (p < 0.001) were significantly associated with OHIS. Patients with higher anxiety scores (Exp (B) = 3.12, 95% CI [1.5, 6.5]) or higher monitoring scores (Exp (B) = 2.52, 95% CI [1.8, 3.5]) were more likely to engage in OHIS. Compared to individuals with low education, patients with medium (Exp(B) = 2.69, 95% CI [1.3, 5.7], p = 0.010) and high education (Exp(B) = 3.29, 95% CI [1.5, 7.2], p = 0.003) were more likely to engage in OHIS. Lastly, OHIS was more frequent in patients in an earlier phase-of-care. Specifically, compared to patients in the diagnostic phase, patients in the treatment phase (Exp(B) = 0.36, 95% CI [0.2,0.8], p = 0.007) or follow-up phase

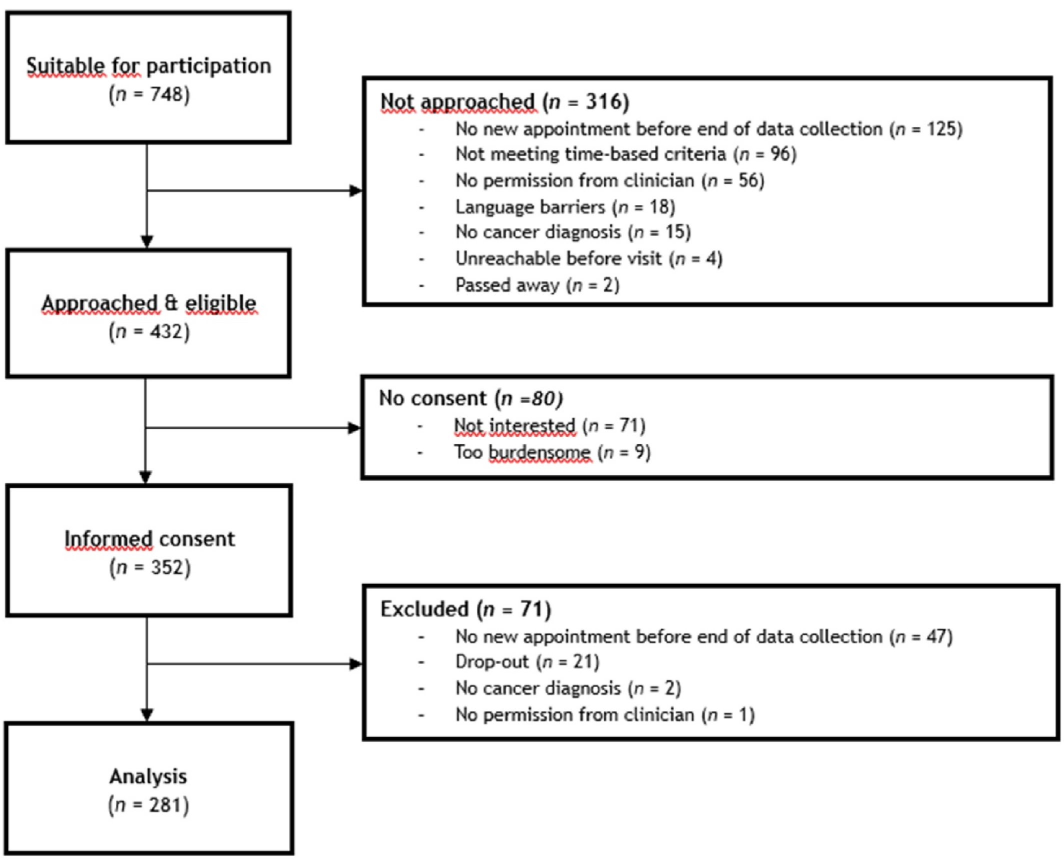

FIGURE 1 | Flowchart of study participants (inclusion process).

TABLE 1 | Sample characteristics (N = 281).

Patient characteristics	N (%)/M (SD)
Sociodemographic	
Gender (female), n (%)	93 (33%)
Age in years, M (range)	66.06 (26–87)
Level of education, n (%)	
Low	78 (28%)
Medium	99 (35%)
High	102 (37%)
Ethnic background	
Dutch	265 (95%)
Surinamese	3 (1%)
Moroccan	2 (1%)
Other	9 (3%)
Health literacy, M (SD), range	2.03 (0.72), 1–4.67
Medical	
Phase-of-care, n (%)	
Diagnostic	119 (42%)
Treatment	90 (32%)
Follow-up	72 (26%)
Type of cancer, n (%)	
Esophageal	115 (41%)
Stomach	54 (19%)
Hematological	53 (19%)
Breast	11 (4%)
Bone	10 (4%)
Prostate	8 (3%)
Lung	8 (3%)
Colorectal	4 (1%)
Oral	3 (1%)
Other	15 (5%)
Type of treatment, n (%)—Multiple responses possible	
Combination of chemo-, radiotherapy and surgery	79 (25%)
Radiotherapy	54 (16%)
Immunotherapy	40 (12%)
Chemotherapy	40 (12%)
Surgery	35 (9%)
Stem cell transplant	17 (5%)
Combination of chemotherapy and radiotherapy	13 (4%)
Combination of chemotherapy and stem cell transplant	7 (2%)
Combination of radiotherapy and hormone therapy	3 (1%)
Undecided	36 (11%)
Other	11 (3%)
Treatment intent: Palliative versus curative, n (%)	
Curative	107 (38%)
Palliative	62 (22%)
Undecided	112 (40%)
Cancer history, n (%)	
First cancer diagnosis	214 (76%)
Recurrence of cancer	67 (24%)
Psychological	
Trait anxiety, M (SD), range	1.55 (0.46), 1–3.33
Uncertainty intolerance, M (SD), range	2.60 (0.62), 1–4.58
Monitoring coping style, M (SD), range	3.19 (1.00), 1–5

Note: Education was grouped as follows: low (no education, primary school, lower vocational education), medium (secondary general education, secondary vocational education, higher general and preparatory scientific education), high (higher vocational education, university).

(Exp(B) = 0.17, 95% CI [0.1, 0.4], $p < 0.001$) were less likely to engage in OHIS. Age, gender, uncertainty intolerance, nor health literacy were significantly associated with OHIS.

3.4 | Associations Between Patients' OHIS and Their Anxiety and Uncertainty

3.4.1 | State Anxiety

The unadjusted model (Model 1) showed a significant main effect of OHIS on anxiety (Wald χ^2 [1] = 11.305, $p < 0.001$), and a significant effect of time on patients' levels of anxiety (Wald χ^2 [2] = 16.338, $p < 0.001$). Overall, anxiety levels were higher among seekers compared to non-seekers ($B = -0.13$, SE = 0.04, $p < 0.001$). Anxiety levels changed over time, with the highest levels before the consultation ($B = -0.04$, SE = 0.04) and lowest directly after the consultation ($B = -0.03$, SE = 0.02). The interaction between OHIS and time was not significant (Wald χ^2 [2] = 0.95, $p = 0.621$), indicating no differences between seekers and non-seekers in how anxiety changed over time (see Figure 2). When controlling for sociodemographic variables (i.e., age, gender, level of education and health literacy) (Model 2) and for phase-of-care (Model 3), the main effects of OHIS and time on anxiety remained significant ($p < 0.05$). However, when adding psychological characteristics (i.e., trait anxiety, uncertainty intolerance, monitoring coping style) to the fully adjusted model (Model 4), only time remained significantly associated

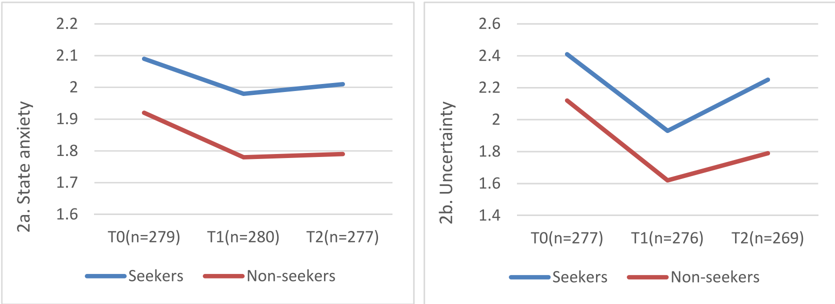

FIGURE 2 | Anxiety (2a, left) and uncertainty (2b, right) before the consultation (T0), after the consultation (T1) and 2 weeks after consultation (T2) for seekers and non-seekers. Higher mean scores indicate higher anxiety and uncertainty.

with state anxiety (Wald χ^2 [2] = 14.228, $p = < 0.001$), while the main effect of OHIS disappeared (Wald χ^2 [2] = 0.216, $p = 0.642$) (see Table 2 for model summaries).

3.4.2 | Uncertainty

The unadjusted model (Model 1) showed a significant main effect of OHIS (Wald $\chi^2 = 22.33$, $p < 0.001$) on uncertainty, indicating that seekers reported significant higher levels of uncertainty than non-seekers ($B = -0.23$, SE = 0.05, $p < 0.001$). This model also revealed a main effect of time on uncertainty (Wald $\chi^2 = 102.21$, $p < 0.001$), indicating that time significantly predicts uncertainty levels, regardless of OHIS. Uncertainty decreased from before to immediately after the consultation and increased again in the 2 weeks after the consultation (Figure 2b). The interaction between OHIS and time was not significant (Wald $\chi^2 = 4.98$, $p = 0.083$), indicating that changes in uncertainty over time were similar between seekers and non-seekers (see Figure 2). These effects remained consistent when accounting for sociodemographic characteristics (i.e., age, gender, level of education, health literacy, Model 2), phase-of-care (Model 3) and psychological characteristics (i.e., trait anxiety, uncertainty intolerance, monitoring coping style, Model 4). In the fully adjusted model, OHIS (Wald $\chi^2 = 8.46$, $p = 0.004$) and time (Wald $\chi^2 = 108.28$, $p < 0.001$) showed significant main effects. Table 3 summarizes all model findings.

4 | Discussion

The present study examined online health information seeking (OHIS) among patients with cancer before and after their consultation, and its association with anxiety and uncertainty. OHIS was common: about half of patients sought information at least once, primarily via search engines, to explore symptoms, life expectancy, and treatment options. Online sources used, topics searched for and reasons for OHIS were similar before and after consultations. Key reasons for OHIS included to prepare for the consultation and active involvement. Patients with a stronger monitoring coping style and higher trait anxiety, with a medium-to-high level of education, and at an early phase-of-care, were more likely to engage in OHIS. Seekers reported greater uncertainty than non-seekers, even after adjusting for covariates. Health literacy, phase-of-care, and uncertainty intolerance were significant covariates for OHIS, partially explaining patients' uncertainty. OHIS was not associated with patients' anxiety.

These findings both support and extend existing research on OHIS. The proportion of patients engaging in OHIS is lower than previously reported (73%–89%) [9, 10], this likely reflects methodological differences. Previous studies with patients with cancer have used retrospective designs and broad, undefined timeframes, often using general questions such as "Have you ever searched for information about cancer online?" [9, 10]. In contrast, the present study employed a longitudinal approach with a clearly defined time frame surrounding an oncological consultation, providing a more targeted and time-sensitive perspective. Given that half of patients engaged in OHIS, our findings underscore the relevance of OHIS in the context of consultations and oncological care in general.

Our findings on the online resources used, largely align with prior research, showing that patients with cancer primarily rely on search engines and official websites [9]. However, unlike earlier research [34], we found limited use of social media. This may reflect sample characteristics: our heterogenous group included all ages, genders, and diagnoses, not specific subgroups like younger woman with breast cancer, who are more likely to use social media [34]. Thus, formal information sources rather than social media appear more commonly used by the general cancer patient population.

Patients in our study most frequently reported preparing for consultations and actively engaging in one's own disease trajectory as reasons for OHIS. These findings align with recent research indicating that patients use OHIS primarily to bolster their sense of empowerment and for informational support [14], rather than for emotional support [27]. Few patients in our sample reported searching for alternative or complementary treatments, contrasting with previous research in Poland [35], which found that patients with cancer used OHIS highly for information about complementary and alternative medicine. Notably, the present sample was composed predominantly (95%) of patients with a Dutch ethnic background. The discrepancy in OHIS reasons may reflect cross-national and cultural differences in healthcare systems and patient behavior.

Consistent with prior research, we found positive associations between OHIS and trait anxiety [15], monitoring coping style [16], and educational level [16, 36], and a negative association with phase-of-care [15]. This highlights the importance of accounting

TABLE 2 | GEE models on state anxiety.

Independent variables & covariates	Model 1 Estimates (SE)	Model 2 Estimates (SE)	Model 3 Estimates (SE)	Model 4 Estimates (SE)
Intercept	0.71 (0.02)	0.43 (0.14)**	0.71 (0.14)***	0.20 (0.14)
Non-seeking = 0 (vs. seeking = 1, ref group)	−0.13 (0.04)***	−0.12 (0.04)***	−0.08 (0.04)*	−0.03 (0.03)
Time (1 = Before consultation), ref group: 3 = 2 weeks after consultation	0.04 (0.03)	0.03 (0.02)	0.03 (0.02)	0.03 (0.02)
Time (2 = After consultation), ref group: 3 = 2 weeks after consultation	−0.03 (0.02)	−0.03 (0.02)	−0.04 (0.02)	−0.04 (0.03)
Non-seeking × time 1 (before consultation)	0.04 (0.03)	0.04 (0.03)	0.04 (0.03)	0.04 (0.03)
Non-seeking × time 2 (after consultation)	0.02 (0.03)	0.03 (0.03)	0.02 (0.03)	0.03 (0.03)
Age		0 (0.02)	0 (0)	0 (0)
Gender		0.16 (0.03)***	0.14 (0.03)***	0.09 (0.02)***
Education		−0.05 (0.02)*	−0.02 (0.02)	0 (0.02)
Health literacy		0.09 (0.02)***	0.08 (0.02)***	0.06 (0.02)***
Phase-of-care			−0.13 (0.02)***	−0.11 (0.02)***
Trait anxiety				0.21 (0.04)***
Uncertainty intolerance				0.07 (0.03)**
Monitoring coping style				0 (0.01)
QIC (Quasi likelihood under independence model criterion)	93.038	92.030	86.104	82.001

Note: Dependent variable: State anxiety.
*$p < 0.05$.
**$p < 0.01$.
***$p < 0.001$.

for psychological traits alongside sociodemographic and medical characteristics in OHIS research. Contrasting with previously reported studies, is the absent association between OHIS and sociodemographic characteristics. Prior studies have linked OHIS to younger age [16], and female gender [36]. Our study results initially seemed similar, but when controlling for relevant variables, these associations were no longer significant. This could indicate that prior research overlooked relevant characteristics, or that OHIS is becoming more universal and no longer related to young age or gender. Consequently, relying solely on sociodemographic profiles to identify patients' likelihood to engage in OHIS may be of limited clinical value; psychological and medical characteristics should be considered as well.

In our study, OHIS was not associated with anxiety after adjusting for relevant covariates, whereas previous studies reported OHIS to be associated with either increased [19, 20] or reduced [8] anxiety. However, none of these studies employed a longitudinal design with such a diverse population of patients with cancer as the current study. Our results suggest that OHIS solely may not drive anxiety. Instead, individual psychological traits (e.g., trait anxiety, uncertainty intolerance) and clinical characteristics, such as the phase-of-care, may be more influential. Notably, OHIS was consistently associated with higher uncertainty, even after controlling for patient characteristics. This contrasts with earlier studies suggesting that OHIS may reduce uncertainty [8]. Higher uncertainty may result from a mismatch between patients' expectations and their actual OHIS experiences, particularly when facing complex or distressing information. A recent study showed that patients engaging in OHIS tended to avoid information when exposed to complex medical terminology, unexpected findings, or confrontational search results (e.g., severe treatment side effects) [14]. This avoidance may manifest in closing the website or ending their OHIS session completely, potentially leaving patients equally or more uncertain compared to before their online search. Guidance in OHIS by clinicians might help these patients [14], although it is uncertain if, and how, this guidance is associated with uncertainty in patients. Therefore, further research should explore how oncological consultations can mitigate uncertainty.

4.1 | Clinical Implications

This research highlights the prevalence of OHIS among patients with cancer and, consequently, the importance of addressing OHIS during consultations, as approximately half of patients engage in OHIS around their oncological consultation. Our findings suggest need for (more) guidance on symptoms, prognosis, and treatment, as these topics are searched for most. By recommending trustworthy websites, clinicians could provide patients with access to accurate, comprehensive health information that supplements the consultation content. Importantly,

TABLE 3 | GEE models on uncertainty.

Independent variables & covariates	Model 1 Estimates (SE)	Model 2 Estimates (SE)	Model 3 Estimates (SE)	Model 4 Estimates (SE)
Intercept	0.81 (0.03)	0.33 (0.19)	0.68 (0.17)	0.21 (0.19)
Non-seeking = 0 (vs. seeking = 1, ref group)	−0.23 (0.05)***	−0.25 (0.04)***	−0.20 (0.05)***	−0.17 (0.04)***
Time (1 = Before consultation), ref group: 3 = 2 weeks after consultation	0.07 (0.03)**	0.08 (0.03)**	0.07 (0.03)**	0.07 (0.03)**
Time (2 = After consultation), ref group: 3 = 2 weeks after consultation	−0.15 (0.03)***	−0.16 (0.03)***	−0.16 (0.03)***	−0.16 (0.03)***
Non-seeking × time 1 (before consultation)	0.10 (0.05)*	0.10 (0.05)*	0.11 (0.05)*	0.11 (0.05)*
Non-seeking × time 2 (after consultation)	0.06 (0.05)	0.07 (0.05)	0.07 (0.05)	0.07 (0.05)
Age		0 (0)**	0 (0)	0 (0)
Gender		0.04 (0.04)	0 (0)	0 (0.03)
Education		−0.03 (0.03)	0 (0.03)	0.02 (0.02)
Health literacy		0.10 (0.03)***	0.10 (0.02)***	0.08 (0.02)***
Phase-of-care			−0.15 (0.02)***	−0.14 (0.02)***
Trait anxiety				0.04 (0.04)
Uncertainty intolerance				0.17 (0.03)***
Monitoring coping style				−0.01 (0.02)
QIC (Quasi likelihood under independence model criterion)	131.037	130.859	122.297	119.127

Note: Dependent variable: Uncertainty.
*$p < 0.05$.
**$p < 0.01$.
***$p < 0.001$.

our finding that patients' online searching and anxiety were not associated, provides preliminary evidence that clinicians may not need to be overly concerned that addressing patients' OHIS—or encouraging them to search for information online—will increase patients' anxiety, as this study found no association between online searching and increased anxiety levels. In fact, addressing OHIS during consultations may help identify and fulfill patients' emotional and/or informational needs and reduce uncertainty, empower patients, and support their coping efforts. Understanding the psychological impact of OHIS, particularly its association with anxiety and uncertainty, is a key step for developing patient-centered guidance on safely and effectively navigating online information. In summary, integrating discussion of OHIS into oncological consultations is a low-risk approach to support patients in their needs as they navigate an uncertain future.

4.2 | Study Limitations

Although this study yielded valuable insights, several limitations should be considered. Patient recruitment depended on clinician referral. Some clinicians may not have referred patients in vulnerable situations, thereby introducing selection bias. Additionally, most participants were of Dutch origin, as sufficient proficiency of the Dutch language was an inclusion criterion, limiting generalizability to patients with other ethnic backgrounds. Although the risk of recall bias was minimized by asking patients to reflect on the past 2 weeks, the study relied on self-report, including retrospective assessments of OHIS and emotional experiences. OHIS behavior was assessed using a self-developed, non-validated questionnaire, which may not have captured the full scope of OHIS behaviors and warrants cautious interpretation of the findings. Additionally, non-seekers were not asked to explain their reasons for abstaining from OHIS, which could have produced valuable insights into the association between OHIS and anxiety and uncertainty. Moreover, the follow-up period of 2 weeks after the consultation is likely too short to capture the full trajectory of OHIS behavior and its psychological effects. Lastly, whether OHIS was discussed during the consultation was not considered while discussion of online health information may influence patients' perspectives, feelings, and interpretations of such information, highlighting an important direction for future research.

4.3 | Conclusion

This study provides valuable insights into OHIS behavior of patients with cancer around oncological consultations, which has implications for both clinical practice and research. Over half of patients engaged in OHIS, mainly for information on symptoms, prognosis, and treatment. OHIS was more prevalent among patients with stronger monitoring coping style, higher trait anxiety levels, higher educational levels, and in an early phase-of-care. However, it was unrelated to other sociodemographic characteristics. These findings challenge the assumption that OHIS is associated with patients' age and gender. OHIS seekers reported consistently more uncertainty than non-seekers. Future research should examine how online health information is discussed during clinical encounters and how such discussions affect uncertainty. In an era where searching online for health information is common among patients with cancer, this study underscores the importance of guiding such practices, to best support patients and clinicians in leveraging the internet as a supplementary source of information alongside the oncological consultation.

Author Contributions

Eline Bijlsma: investigation, data curation, methodology, project administration, writing – original draft. **Tanja Henkel:** investigation, data curation, methodology, project administration, writing – original draft. **Annemiek J. Linn:** conceptualization, funding acquisition, writing – review and editing. **Marij A. Hillen:** conceptualization, funding acquisition, writing – review and editing. **Hanneke W. M. van Laarhoven:** resources, writing – review and editing. **Marie Jose Kersten:** resources, writing – review and editing. **Lukas J. A. Stalpers:** resources, writing – review and editing. **Mark I. van Berge Henegouwen:** resources, writing – review and editing. **Julia C. M. van Weert:** conceptualization, funding acquisition, writing – review and editing, supervising. **Ellen M. A. Smets:** conceptualization, funding acquisition, writing – review and editing, supervising.

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