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Improving online health information provision for older cancer patients

Online health information usage and its influence on patient outcomes

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Chapter 2

The effects of online health information seeking on anxiety, satisfaction, and information recall, mediated by patient participation during consultations

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Abstract

Today, many patients with cancer engage in online health information seeking (OHIS). However, not much is known about how patients differ in their amount of OHIS. In addition, OHIS might influence patient participation during a consultation with a physician, which might mediate the effects on patient outcomes. Therefore, the aim of this study was twofold. First, to provide insight into which personal characteristic and psychosocial factors affect patients' OHIS. Second, to test the hypothesis that effects of OHIS on patient outcomes are mediated by patient participation during the consultation. Patient participation was operationalized in terms of the patient's absolute word use, the patient's relative contribution in terms of word use, compared to the healthcare provider and the number of questions and assertions expressed by the patient during the consultation. Patient outcomes measured were anxiety after the consultation, satisfaction with the consultation and information recall. Participants in this study were recently diagnosed colorectal cancer patients recruited from six hospitals in the Netherlands ($N = 90$). Data was collected by means of questionnaires and audio-recorded consultations of patients with healthcare providers prior to their surgery. Results showed that younger patients, higher educated patients, patients that had a monitoring coping style and patients that experienced more cancer-related stress engaged more in OHIS. In turn, OHIS was related to patient participation in terms of the patient's absolute word use, but not in terms of the patient's relative contribution to the consultation or questions and assertions expressed. We did not find a relation between OHIS and anxiety and OHIS and recall mediated by patient participation. However, we found that patient's absolute word use significantly mediated the positive association between OHIS and patients' satisfaction with the consultation. The results indicate positive implications of OHIS for patient's care experience and thereby the importance to help patients engage in OHIS. However, the results also suggest that OHIS is only successful in increasing a single aspect of patient participation, which might explain the absence of relations with anxiety and recall. Results suggest that more beneficial effects on patient outcomes may be achieved when health care providers support patients in seeking information online

Introduction

Today, the internet hosts a growing body of easily accessible cancer-related information (McHugh et al., 2011). In line with this, patients with cancer increasingly engage in online health information seeking (from now on OHIS) (Basch et al., 2004; Castleton et al., 2011) about their illness and treatment (Barnes et al., 2017). OHIS about one's health or medical condition can contribute to feeling informed which has been positively associated with patient outcomes (Jiang & Street, 2017). For instance, better informed patients score higher on affective outcomes, e.g. they are more satisfied with their treatment (Russ et al., 2011; Street et al., 2009; Tan & Goonawardene, 2017; Weiss et al., 1996) and feel less anxious (Jiang & Street, 2017; Lambert & Loiselle, 2007; Marteau et al., 1996). Besides, OHIS can also positively influence cognitive outcomes like better information recall (Nguyen et al., 2019; Richard et al., 2017).

Although in general, patients seek for online health information (Abdul-Muhsin et al., 2017; Feathers et al., 2016; Fox & Duggan, 2013), it can be argued that the extent to which they engage in OHIS is associated with individual differences based on demographics or psychosocial characteristics (Johnson et al., 1995; Johnson, 1997). For instance, experiencing feelings of anxiety or stress regarding a medical diagnosis can result in more information needs (Posma et al., 2009) and information seeking to cope with these (Muusses et al., 2012).

Previous research did not look at the whole path from individual differences to OHIS and in turn patient outcomes, but mainly focused on either predictors of OHIS in terms of demographics and psychosocial factors (Baumann et al., 2017; Hartoonian et al., 2014; Johnson & Meischke, 1993; van Stee et al., 2018) or outcomes of OHIS (Jiang & Street, 2017; Lee et al., 2016; Linn et al., 2019; Sanders et al., 2018). More specifically, research that looked into the effects of OHIS, did not take into account what happens between OHIS and patient outcomes in terms of consultations with healthcare providers (Jiang & Street, 2017; Lee et al., 2016). This is a noteworthy omission because patients often engage in OHIS in preparation of consultations (Abdul-Mushin et al., 2017; Bol et al., 2020; Fox & Duggan, 2013), which can result in a better informed and more empowered patient who feels comfortable in taking on an active role in consultations with healthcare providers (Castro et al., 2016; Linn et al., 2019; Tan & Goonawardene, 2017). In turn, this may lead to more active patient participation during consultations (Anderson et al., 2003; Tan & Goonawardene, 2017) for example, by patients' expressing more concerns and asking more questions (Street et al., 2005).

Subsequently, patient participation can positively influence factors related to the quality of care, such as satisfaction with the consultation and understanding of health information provided (Richard et al., 2009). In addition, researchers found patient

participation to be related to lower anxiety (Clayman et al., 2015), increased satisfaction (Arora, 2003; Epstein & Street, 2007; Jackson, 2005), and improved information recall (Dillon, 2012; Richard et al., 2017). However, knowledge about whether and how the effects of OHIS on these outcomes are mediated by patient participation during the consultation is missing. Therefore, the aim of this study is to look into the demographic and psychosocial factors that can predict OHIS, but also how OHIS in turn influences patient outcomes via patient participation during consultations.

Theoretical background

Predictors of OHIS

Patients with cancer vary in the extent in which they seek for online health information. The Comprehensive Model of Information Seeking is one of the most widely adopted models discussing factors that could influence health information seeking (Johnson & Meischke, 1993). In this model, demographics and psychosocial factors are seen as important determinants of how much an individual is inclined to search for health information.

Demographics. In general, studies show that demographics such as age, education level and gender correlate with OHIS (Fox & Duggan, 2013). However, results are ambiguous. For example, some show younger individuals to seek online health information more frequently than older individuals (Ayers & Kronenfeld, 2007; Fox & Duggan, 2013; Manierre, 2015; van Weert et al., 2014), while other studies find that older adults tend to seek more information online than their younger counterparts (Rice 2006) or find no correlations with OHIS at all (Renahy et al., 2010). Frailty, or “the risk for adverse outcomes due to losses in different domains of functioning” (Schuermans et al., 2004, p. 962), is found to be related to a decline in patient’s self-management abilities, more so than chronological aging (Schuermans et al., 2004). Therefore, the level of frailty, also called biological age, might better predict a patient’s ability to engage in OHIS than chronological age. Besides, several studies show that females seek more frequently for online health information than males (Fox & Duggan, 2013; Manierre, 2015; Rice, 2006; van Weert et al., 2014), whereas other studies show no associations between OHIS and gender (Rice, 2006; Renahy et al., 2010). With respect to education level, there is some evidence that higher educated individuals seek more for online health information than lower educated individuals (Myrick & Willoughby, 2019), but other studies show no such associations (Lorence et al., 2006; Muusses et al., 2012; Renahy et al., 2010). Lastly, the tendency to search for health information online can also differ according to one’s degree of health literacy, or “the ability to perform basic reading and numerical tasks required

to function in the health care environment” (Chew et al., 2004, p. 588). As described in a review study, some studies show limited evidence that low health literate people search less frequently for health information online, compared to high health literate people, while other studies show no differences in OHIS based on health literacy (Anker et al., 2011).

Psychosocial factors. Besides demographics, OHIS can also be explained by patients’ psychosocial characteristics such as their degree of stress or anxiety and strategies to cope with such feelings. Higher levels of fear and anxiety in cancer patients have both been associated with the tendency to avoid cancer-related information (Bol et al., 2020; Leydon et al., 2000) and with increased information needs (Eastin & Guinsler, 2006). Indeed, seeking relevant health information online might help patients to deal with the feelings of anxiety and some patients feel relieved or comforted by the information they found online (Lorence et al., 2006). However, patients with cancer differ in their need for cancer-related information (Leydeon et al., 2000), based on how they cope with a health threat: some patients prefer only a very limited amount of information (blunting coping style), while others prefer as much information as possible (monitoring coping style) (Case et al., 2005; Miller, 1987; Muris & Vries, 1994; Ong et al., 1999; Rood et al., 2015; Timmermans et al., 2006). Since results are inconsistent, more research is needed resulting in the following research question:

RQ1: Are cancer patients’ demographical characteristics (i.e. age, gender, education level, frailty and health literacy) and psychosocial characteristics (i.e. anxiety, cancer-related stress and information seeking coping style) related to OHIS?

Direct relation of OHIS and patient participation

Patient participation. OHIS may potentially better equip patients to take part in consultations with healthcare providers (Dedding et al., 2011; Hashimoto & Fukuhara, 2004). Actively participating in such consultations reflects patients’ ability and willingness to express their needs, concerns, preferences and expectations (Street & Millay, 2009). According to the Linguistic Model of Patient Participation in Care, patients need a certain repertoire of informational resources to actively communicate during medical consultations (Street & Millay, 2009). Patients that have sufficient knowledge about a topic or terminology related to the topic will discuss health issues more easily with their provider (Street et al., 1995). Therefore, the knowledge a patient possesses, which might be gained because of OHIS, influences a patients’ ability to actively communicate and is an important factor of patient participation (Castro et al., 2016; Street & Millay, 2009; Sahlsten et al., 2008).

In addition, providing patients with an opportunity to gather information, seeking online health information can empower patients by giving them the feeling they are better prepared for their consultation. This can make them confident enough to actively participate during consultations (Castro et al., 2016; Tan & Goonawardene, 2017). A recent review indeed showed that gathering online health information before a consultation resulted in patients feeling more self-assured and empowered during consultations (Tan & Goonawardene, 2017).

In conclusion, seeking health information online can prepare patients for interactions with healthcare providers by increasing knowledge and feelings of empowerment, and might therefore be a crucial predictor of patient participation. Therefore, we argue that more OHIS leads to more patient participation during a consultation with a healthcare provider.

H1: OHIS is positively related to cancer patients' participation during a medical consultation.

Indirect relation of OHIS and patient outcomes: The mediating role of patient participation

Both OHIS and patient participation are believed to be important independent factors influencing affective and cognitive patient outcomes (Street et al., 2009; Street, 2003). OHIS most likely influences these outcomes via patient participation, because it can increase patients' illness related knowledge and feeling of empowerment, leading to more patient participation (Street & Millay, 2009). Active patient participation can, in turn, positively affect factors that indicate quality of care (Street & Millay, 2009). Indeed, studies found that patient participation resulted in less anxiety (Clayman et al., 2015; Street et al., 2009), more satisfaction (Arora, 2003; Epstein & Street, 2007; Jackson, 2005), and better information recall (Dillon, 2012; Glaser & Lussier, 2017).

Anxiety. OHIS can positively influence emotional well-being in general, for example by making the patient feel less stressed (Jiang & Street, 2017) and less anxious (Lambert & Loiselle, 2007; Marteau et al., 1996; Nguyen et al., 2019). OHIS can also help patients to gain knowledge about their illness (Anderson et al., 2003), making them feel more empowered to discuss certain topics during consultations (Tan & Goonawardene, 2017), which in turn can lower their stress and feelings of anxiety. If patients experience feelings of anxiety beforehand, or because of OHIS, actively participating during the consultation gives them a chance to discuss their issues with the healthcare provider which might help decrease their anxiety.

On the other hand, in some cases OHIS can increase feelings of worry and anxiety (Baumgartner & Hartmann, 2011; Linn et al., 2019). Patients can experience confusion because of seeking health information (Anderson et al., 2003; Linn et al., 2019), which can result in feeling less comfortable to participate and more reserved acting during consultations. If a patient already feels anxious because of seeking online health information and does not actively participate during consultations, the healthcare provider may not be able to adequately address the patient’s anxiety. As a result, their anxiety may remain or increase even further. In line with this, we argue that the effect of OHIS on anxiety is mediated by patient participation during medical consultations (See Figure 2.1).

H2a: Patient participation mediates the effect of OHIS on anxiety and stress after the consultation.

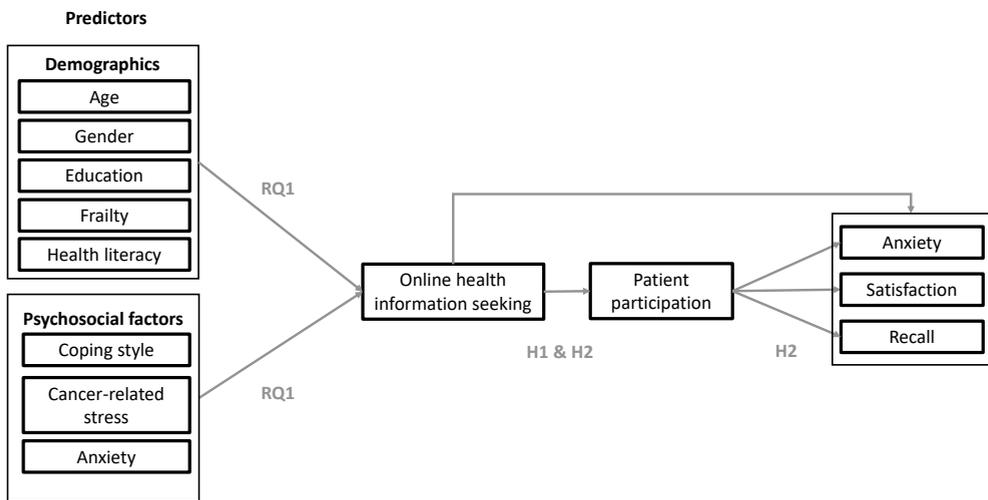


Figure 2.1. Theoretical model.

Satisfaction. Generally, better informed patients are more satisfied with their healthcare process (Fogel et al., 2002; Nguyen et al., 2019; Street et al., 2009; Weiss et al., 1996). Russ and colleagues (2011) found that patients who sought online health information were more satisfied with the information given by the provider during a consultation when compared to patients who did not seek online health information.

A reason for this increase in satisfaction can be that seeking for online health information before a consultation gives the patient a feeling of being prepared for the consultation (Tan & Goonwardene, 2017). Online information can help patients

anticipate the discussion of certain topics during consultations or to consider possible treatments that will be proposed (Czaja et al., 2003). Knowing what to expect during the consultation can result in more active participation, for example, expression of questions or expectations. These can subsequently be addressed by the healthcare provider, resulting in more satisfaction with the consultation. In line with this, patients are more satisfied when providers are supportive of their search for online health information (Bylund et al., 2010; Hay et al., 2008). Therefore, it can be argued that OHIS leads to more satisfied patients through increased patient participation.

However, as discussed before, OHIS can also cause confusion, thereby inhibiting active patient participation. As a result, issues relevant to the patient may not be addressed in which case patients can feel disappointed and less satisfied with the consultation. Accordingly, research showed that when the online findings do not match with the information discussed during the consultation for example regarding diagnosis or treatment options, this can result in a less satisfied patient (Ahluwalia et al., 2010). Therefore, we argue that the effect of OHIS on satisfaction with the consultation is mediated by patient participation (Figure 2.1).

H2b: Patient participation mediates the effect of OHIS on satisfaction with the consultation

Recall. When patients engage in OHIS before a consultation and this leads to more participation during the consultation, this is likely to improve recall of the information discussed (Dillon, 2012; Harrington et al., 2004; Richard et al., 2017; Sansoni et al., 2015; van Weert et al., 2011). One of the reasons for the positive association between OHIS, participation and recall is that repetition of the same information can improve information recall (Kreps, 2017; Watson & McKinstry, 2009). When patients search for online health information before the consultation and discuss the same information during the consultation by actively participating, this leads to a repetition in exposure to that information. In addition, the exposure to a first piece of information can prime the interest for a second similar piece of information (Voorveld et al., 2011). Because this double exposure to the same kind of information stimulates deeper information processing, it is expected to positively influence information recall (Dijkstra, 2002; Epstein, 1994).

Besides, it can be argued that patients who participate more actively during the consultation by asking more questions and expressing more concerns will receive more information from healthcare providers, and are also more likely to understand the rationale and recommendations of the provider (Street & Millay, 2009). Moreover, actively participating patients are more involved and therefore also process the information they

receive during the consultations in an active manner. This active, deeper processing of information can result in better information recall (Petty & Cacioppo, 2018). Thus, we argue that the effect of OHIS on recall of the information provided during the consultation is mediated by patient participation (Figure 2.1).

H2c: Patient participation mediates the effect of OHIS on information recall.

Method

Design

A study was conducted in six Dutch hospitals among newly diagnosed colorectal cancer patients. All patients received the standard procedure of care provided by the hospitals without any alterations by the researchers. All newly diagnosed patients that were planned to receive surgery were approached to participate in the study. Consenting healthcare providers (surgeons and specialized nurses) and patients signed an informed consent form. Study participants received a consultation with a surgeon or specialized nurse in preparation for their surgery. This consultation was audio-recorded, transcribed, and content coded. Besides, data was collected by means of questionnaires before and after the consultation.

This study was registered with Trialregister.nl, NTR5919, and received ethical approval by the Review Board of the Amsterdam School of Communication Research (2017-PC-7979) and the medical ethical review boards of the hospitals that participated in the study (METC-nr: 13-061). The data collection to answer the research questions and hypotheses for this study was part of a larger investigation including multiple measurement moments.

Procedure and participants

Participants were (a) newly diagnosed colorectal cancer patients, (b) that were planned to receive surgery (possibly in combination with an other treatment) who had (c) sufficient command of the Dutch language; (d) were able to read, and (e) had no cognitive impairment according to their medical record (i.e. dementia); and (e) who had provided written informed consent.

Once the consultation with the surgeon was scheduled, a specialized nurse or medical secretary asked the patients if they wanted to receive study information. Patients that agreed to being contacted about this study were approached, approximately 3 days before the consultation, by the study coordinator via phone to explain what study

participation would entail. Consenting patients received additional information and the first online questionnaire (T1) via e-mail. Patients were asked to complete the first questionnaire one day before their consultation.

The scheduled consultation was recorded (T2a) and two days thereafter the patients received the second questionnaire partly via e-mail (T2b) including standard questions that were the same for all patients. Patients were also approached via telephone two to three days after the consultation by the research assistant or researcher (T2c) to assess recall using recall questions that were tailored to the consultation.

The final sample consisted of 90 patients in total seen by 23 healthcare providers (surgeons and specialized nurses) in six Dutch hospitals. During the study, 346 patients were reported as suitable for participation by the specialized nurses or medical secretaries of the hospitals. 285 patients were successfully approached to participate in the study. The other 61 patients either did not meet the inclusion criteria or could not be reached due to organizational or technical difficulties. Of the 285 patients that were successfully approached, 119 consented to participate in the study. As 29 of the consenting patients did not fill out the first questionnaire before the consultation, a total of 90 patients could be properly included in the final analyses. Between the first and following questionnaires a number of patients dropped out resulting in 72 consultation recordings, 67 responses on T2b and 63 responses on T2c. For more details about the drop-out process see Figure 2.2.

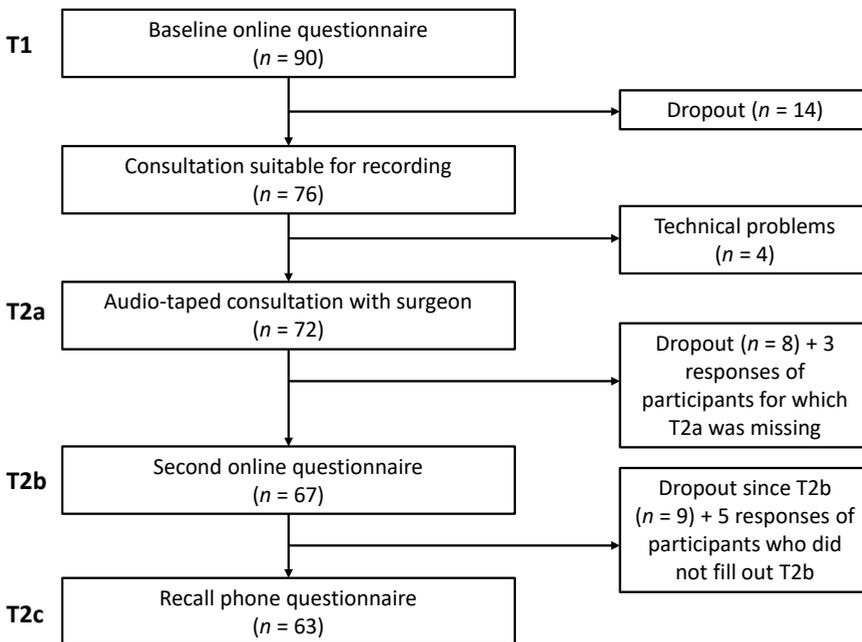


Figure 2.2. Flowchart of inclusion and drop-out.

Measures T1

Demographics. Socio-demographic information was obtained in the first questionnaire with questions regarding age, gender, education level, living situation, and internet usage. Three categories were formed for education level (low, middle and high). Besides, hospital records were used to obtain medical information about the patients' diagnosis and treatment.

Frailty. Frailty was measured using the Groningen Frailty Indicator (GFI) (Schuurmans et al., 2004). This scale contains 15 items about physical functioning (mobility, multiple health problems, fatigue, and vision or hearing problems), cognitive functioning, social functioning, and psychological functioning (feelings of depression or anxiety). The total score could range from 0–15, but in this study patients scored from 0–11 ($M = 2.80$, $SD = 2.45$), with a higher score indicating being more frail (Schuurmans et al., 2004).

Health literacy. A three-item questionnaire was used to measure health literacy (Chew et al., 2004). Items addressed one's ability to obtain and read medical information and to fill out medical forms on a 5-point scale ($\alpha = .62$). The total score ranged from 1–5, with a higher score meaning higher health literacy ($M = 4.26$, $SD = .71$).

Anxiety (pre-consultation). Anxiety was measured at T1 with the short Dutch version of the State-Trait Anxiety Inventory (STAI-6) (Marteau et al., 1996; van der Bij et al., 2003). Patients rated to which degree they were currently experiencing anxiety on a 4-point scale ranging from 1 (not at all) to 4 (very much so). Higher scores on the scale indicate higher levels of anxiety. Patients scored on average 1.95 ($SD = .55$), with scores ranging from 1 to 3.67. Cronbach's alpha was good ($\alpha = .82$).

Cancer-related stress. Cancer-related stress was measured at T1 with a subscale of the Dutch version of the Impact of Events Scale (Pieterse et al., 2005; van der Ploef et al., 2004), comprising seven items ($\alpha = .84$). Participants rated the items on a 4-point Likert scale (1 = 'not at all', 2 = 'rarely', 3 = 'sometimes', 4 = 'often'), with a higher score meaning higher levels of cancer related stress. Scores ranged from 1–3.71 and patients scored on average 2.03 ($SD = .70$).

Monitoring coping style. Monitoring coping style was measured with the adapted shortened version of the Threatening Medical Situation Inventory was used at T1 to measure monitoring coping style (Bronner et al., 2018; van Zuuren et al., 1996). The scale consisted of three items measuring monitoring intentions regarding the patients own medical situation. Items addressed intentions to (1) look for information within the threatening situation; (2) go deeply into the situation by reading about it; and (3) get information from the healthcare provider ($\alpha = .82$). Participants responded to the statements with answer options ranging from 1 ('not at all applicable to me') to 5 ('very much applicable to me') and scored on average 3.46 ($SD = 1.07$), with a higher score indicated higher monitoring intentions.

OHIS. Based on previous research (Muusses et al., 2012), patients were asked to indicate on a 5-point Likert scale how often they had used the internet for seeking information about their illness or treatments options before the consultation (T1). Answer options were 1 ('did not use'), 2 ('used very little'), 3 ('used sometimes'), 4 ('used regularly') and 5 ('used often'). Patients on average scored 2.23 ($SD = 1.32$).

Measures T2a

Patient participation. The audiotaped consultations were transcribed and manually coded by a research assistant using three measures representing patient participation. This operationalization is in line with methods used in previous research (Ford et al., 2000; Schinkel et al., 2015; Russel & Stiles, 1979; Zandbelt et al., 2007). First, the absolute contribution of the patient to the consultation was measured with the patient's absolute word count. Second, the patient's relative contribution was measured by calculating the ratio of the number of words used by the patient compared to the number of words used by the healthcare provider. For these two measures the coding process existed of counting all words used by the patient and the healthcare provider (Schinkel et al., 2015; Zandbelt et al., 2007). Third, the number of questions and assertions expressed by the patient during the consultation was coded by using a codebook developed based on the method described by Street and Millay (Street & Millay, 2009). (See Appendix A for the complete codebook). Ten percent of the dataset was double coded by a second independent coder resulting in an acceptable intercoder reliability ($\kappa = .764, p < .001$).

Measures T2b

Anxiety (post-consultation). Anxiety was measured post-consultation (T2b) in the same manner as pre-consultation (T1). Patients on average scored 1.80 ($SD = .66$). Cronbach's alpha was good ($\alpha = .86$).

Satisfaction with consultation. To measure patient satisfaction with the consultation (T2b), the five-item 'Patient Satisfaction Questionnaire' was used (Blanchard & Ruckdeschel, 1986). Items address to which extent the patient was satisfied in terms of needs that were met by the surgeon, if the patient felt actively involved during the consultation, the information received during the consultation, the emotional support received during the consultation, and the interaction during the consultation in general ($\alpha = .80$) (Zandbelt et al., 2007). All answer options were used ranging from 1 ('not satisfied at all') to 5 ('completely satisfied') and patients scored on average 4.39 ($SD = .58$).

Measures T2c

Information recall. To measure information recall, the Patient Information Recall Questionnaire (NPIRQ) (Jansen et al., 2008) was used as protocol to compose the questions. The correct answers to the questions were (parts of) statements provided by the surgeon during the consultation. Therefore, the answers were literally derived from the transcribed consultations. Answers provided by the patients were scored as 0 (not recalled), 1 (partially recalled) and 2 (completely recalled). If the patient did not recall the information, there were two other answer options: “this information was not discussed” and “this information was discussed, but I can’t remember the details”, both resulting in a score of 0 (Jansen et al., 2008).

In line with the NPIRQ guidelines, a sum score was constructed by calculating the percentage of the obtained recall score (range 6%–100%) relative to the maximum achievable score (2–26 points), with higher scores indicating better recall. Patients scored on average 60% ($SD = .19$). 10% of the cases ($n = 7$) was double coded by two independent coders to check intercoder reliability (mean $\kappa = .71$, $p < .001$) (Hayes & Krippendorff, 2007).

Statistical analyses

The analyses are based on a two-step process, in line with previous research investigating patient participation (Zandbelt et al., 2007). First, correlations between demographic and psychosocial variables and outcome variables were tested. The variables that significantly correlated with the outcome measures at a significance level of .10 were selected for follow-up analyses as control variables. Second, multivariate regression analyses were carried out to test whether demographic variables (age, gender and education level) and psychosocial factors (frailty, coping style, stress, and anxiety before the consultation) were related to OHIS (RQ1) and if OHIS was related to patient participation (number of words used by the patient during the consultation, relative contribution a patient had in the consultation in terms of word count ratio, and number of questions and assertions expressed) (H1). For the mediation effects in H2a, H2b and H2c, regression analyses, using PROCESS, model 4 (Bodie & Dutta, 2008) were conducted. In addition, to determine whether the relation between OHIS and the outcome variables differed depending on clustering within healthcare providers, multi-level analyses were carried out if the dependent variable correlated with healthcare provider (Hox et al., 2017).

Results

Sample

Age of patients' included in the final analyses ranged from 39 to 88 years ($M = 69.93$, $SD = 9.93$) and about two third was male (65.6%). Half of the patients (55.1%) had a medium education level. Patients' health literacy was relatively high among patients ($M = 4.25$, $SD = .71$) and they were not frail on average ($M = 2.80$, $SD = 2.45$). Almost half of the patients (45.6%) indicated they did not use the internet, 12.2% used the internet very little, 21.1% used the internet sometimes, 15.6% used the internet regularly and 5.6% used the internet often before the consultation. Non-response analyses revealed that participants did not differ compared to non-participants regarding gender ($F = 2.92$, $p = .097$), but were on average significantly younger ($M = 69.75$, $SD = 9.93$) than patients who did not wish to participate ($M = 73.15$, $SD = 10.30$) ($F = 7.24$, $p = .008$). Background information of the participants is given in Table 2.1.

Table 2.1. Sample characteristics

Background variables	Patients	Total (N) ¹
Demographic information		
Age (years), mean (SD)	69.93 (9.93)	90
Gender		
Male, <i>n</i> (%)	59 (65.6%)	90
Female, <i>n</i> (%)	31 (34.4%)	
Education level		
Low, <i>n</i> (%)	24 (27.3%)	88
Medium, <i>n</i> (%)	45 (51.1%)	
High, <i>n</i> (%)	19 (21.5%)	
Health background information		
Health literacy ² , mean (SD)	4.25 (.71)	90
Frailty ³ , mean (SD)	2.80 (2.45)	90
Psychosocial information		
Coping style ⁴ , mean (SD)	3.46 (1.07)	90
Online health information seeking behaviour		
Never, <i>n</i> (%)	41 (45.6%)	90
Very little, <i>n</i> (%)	11 (12.2%)	
Sometimes, <i>n</i> (%)	19 (21.1%)	
Regularly, <i>n</i> (%)	14 (15.6%)	
Often, <i>n</i> (%)	5 (5.6%)	

1. *N* refers to the entire population under study and *n* refers to a sample population under study. Not all cells add up to 100% owing to missing data.

2. A higher score indicates higher levels of health literacy (maximum range 1–5; reported range 1–5).

3. A higher score indicates higher frailty (maximum range 0–15; reported range 0–11).

4. A higher score indicates a higher information monitoring coping style (maximum range 1–5; reported range 1–5).

Patient participation

Recorded consultations ($N = 72$) lasted between 4:26 minutes and 46:40 minutes with an average duration of 20:19 minutes ($SD = 7:47$). The amount of words spoken during these consultations ranged from 488 words to 6824 words ($M = 2657$, $SD = 1307.89$). Patients spoke a minimum of 29 words and a maximum of 1347 words ($M = 472.57$, $SD = 295.46$), while healthcare providers spoke at least 386 words and at the most 5124 ($M = 1998.83$, $SD = 991.93$). Patients scored a relative contribution to the consultation of 19.2% on average with a range from 3.4% to 43.5% ($SD = 8.20$), hence the ratio of healthcare providers ranged from 56.5% to 96.6%, with an average of 80.8% ($SD = 8.20$).

At least one question was asked by 69 patients and 55 patients expressed at least one assertion. The number of questions ranged from 1 to 35 per consultation ($M = 6.44$, $SD = 6.36$) and the number of assertions ranged from 1 to 10 per consultation ($M = 2.30$, $SD = 1.92$). This results in a total number of questions and assertions ranging from 1 to 37 ($M = 7.96$, $SD = 7.03$).

Predictors of OHIS

Demographics ($N = 90$). The correlation analyses showed that age was negatively related to OHIS ($r = -.29$, $p = .005$), suggesting that an increase in age is associated with less OHIS. Education level and OHIS were positively correlated ($r = .37$, $p < .001$), suggesting that higher educated patients engage more in OHIS. No significant correlations were found between OHIS and gender ($r = .01$, $p = .911$), frailty ($r = -.10$, $p = .353$), and health literacy ($r = .15$, $p = .144$) (see Table 2.2).

Psychosocial factors ($N = 90$). In addition the correlation analyses showed that cancer-related stress was positively correlated to OHIS ($r = .36$, $p < .001$), implying higher stress levels can result in more OHIS. There was a marginally significant positive correlation between anxiety before the consultation and OHIS ($r = .18$, $p = .076$), suggesting that patients who report higher anxiety levels might engage more in OHIS. Regarding coping style, a positive correlation was found ($r = .45$, $p < .001$), meaning patients with higher levels of monitoring coping style engaged more in OHIS (see Table 2.2).

Regression analyses ($N = 90$). To test whether these variables predict OHIS, a regression analyses was carried out including all possible predictors that significantly correlated with OHIS (age, education level, cancer-related stress, anxiety before the consultation and coping style). Results showed that education level ($b = .54$, $p = .002$), cancer-related stress ($b = .48$, $p < .001$), and coping style ($b = .41$, $p < .001$) were positively associated with OHIS. Thus, higher educated patients, patients experiencing more cancer-related stress and patients with higher levels of a monitoring coping style more frequently

engaged in OHIS. There was no relation anymore between age and OHIS ($b = -.01, p = .239$) and between anxiety before the consultation and OHIS ($b = .08, p = .742$) based on the multivariate regression. To answer RQ1, education level, cancer-related stress and monitoring coping style are positively related to OHIS.

Relation between OHIS and patient participation during consultation ($n = 71$)

The correlation analyses showed that gender was significantly related to number of words used by the patient ($r = -.23, p = .005$) and number of questions and assertions expressed by the patient ($r = -.26, p = .003$), suggesting that males used less words and expressed less questions and assertions than females. Coping style was also positively related with number of words used by the patient ($r = .37, p = .004$), indicating that patients with a more monitoring coping style used more words (see Table 2.2). There were no significant correlations between the other variables and number of words used, the relative contribution a patient had in the consultation in terms of word count ratio, or number of questions and assertions expressed by the patient.

Regression analyses were carried out to test the relation between OHIS and patient participation outcomes. Based on the correlation analyses, gender and coping style were included as control variables for the regression analyses regarding number of words used by the patient, gender was included as control variable for the regression regarding number of questions and assertions expressed. No variables were included as control variables in the regression regarding relative contribution of the patient.

Results showed OHIS was positively related to the number of words used by the patient during the consultation ($b = 50.58, p = .004$), when controlling for gender and coping style. The relation between OHIS and the patient's relative contribution a patient had in the consultation in terms of word count ratio was also significant ($b = 1.99, p = .017$). OHIS was not related to the number of questions and assertions expressed ($b = .167, p = .185$), when controlling for gender. In other words, patients who engaged more in OHIS, used more words during the consultation and had a larger relative contribution to the conversation, but did not express more questions and assertions. Regarding H1, we can conclude that OHIS is associated with some, albeit not all indicators of patient's participation during consultations.

Relation between OHIS and anxiety, satisfaction and recall, mediated by patient participation

The correlation analyses ($N = 90$) showed that gender ($r = -.23, p = .005$), frailty ($r = -.44, p < .001$), anxiety before the consultation ($r = -.60, p < .001$), and cancer-related stress ($r = -.51, p < .001$) were significantly related to anxiety after the consultation. Gender

was also significantly related to number of words used by the patient ($r = -.23, p = .005$) and number of questions and assertions expressed by the patient ($r = -.26, p = .003$), while coping style was also positively related with number of words used by the patient ($r = .37, p = .004$) (see Table 2.2). These variables were included as control variables in the regression analyses regarding anxiety after the consultation. Healthcare provider was only significantly related to satisfaction with the information ($r = -.23, p = .005$). However, multi-level analyses showed the relation between OHIS and satisfaction was not dependent on healthcare provider ($F = -.04, p = .347$). There were no significant correlations between the other variables and satisfaction with the information or information recall. Therefore, no control variables were included in the regression analyses regarding satisfaction and recall.

Anxiety ($n = 64$). When controlling for gender, frailty, anxiety before the consultation and cancer-related stress, OHIS was not related to anxiety after the consultation ($b = .07, p = .176$). Regarding patient participation, number of words used by the patient ($b = -.00, p = .228$), the patient's relative contribution in terms of word count ratio ($b = .01, p = .740$) and number of questions and assertions expressed by the patient ($b = .01, p = .211$) were also not related to anxiety after the consultation. There was no significant mediation of OHIS on anxiety after the consultation via number of words used by the patient, relative contribution of the patient to the consultation or number of questions and assertions (see Table 2.3), thus H2a must be rejected.

Satisfaction ($n = 64$). OHIS was marginally negatively related to satisfaction with the consultation directly ($b = -.10, p = .078$), suggesting the more a patient engaged in OHIS, the less satisfied the patient was with the consultation. The number of words used by the patient was positively related to satisfaction with the consultation ($b = .001, p = .005$), meaning the more words a patient used, the more satisfied a patient was. The patient's relative contribution in the consultation in terms of word count ratio was marginally negatively related to satisfaction ($b = -.02, p = .063$), suggesting the higher the relative contribution of the patients (and therefore automatically the lower the contribution of the healthcare provider), the less satisfied the patient was. There was no significant relation between the number of questions and assertions expressed by the patient and satisfaction ($b = -.01, p = .139$). The indirect relation between OHIS and satisfaction, via the number of words used by the patient was also significant ($b = .05, 95\% \text{ CI} = .0053, .1158$). This means that patients who engaged in OHIS used more words during the consultations, which in turn was positively related to more satisfaction with the consultation. Therefore, H2b is partly supported.

Recall ($n = 63$). Analyses showed no significant correlation between OHIS and information recall ($b = -.02, p = .283$). Besides, there was no significant relation between number of words used by the patient ($b = .00, p = .008$), the patient's relative contribution

Table 2.2. Correlation matrix

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Age ^a	-																
2. Gender	.021	-															
3. Education level ^b	-.057	.038	-														
4. Health literacy	.039	.074	.220*	-													
5. Frailty	-.157	-.002	-.183	-.295**	-												
6. Anxiety (pre-consultation)	-.286**	-.016	-.113	-.041	.461**	-											
7. Cancer-related stress	-.294**	-.156	-.020	-.045	.203	.554**	-										
8. Coping style	-.205*	-.099	.231*	.112	-.115	.013	.198	-									
9. Healthcare provider	.096	-.172	-.275**	-.097	-.162	.119	.109	-.061	-								
10. Consultation time	-.043	.079	-.056	-.076	-.250*	.088	.060	.127	.509**	-							
11. OHIS	-.289**	.012	.369**	.151	-.096	.183	.361**	.453**	-.100	.143	-						
12. Patient participation (word count)	-.061	-.229*	.099	.020	-.131	.142	.082	.336**	.392**	.525**	.326**	-					
13. Patient participation (relative contribution)	-.074	-.103	.086	.077	.111	.039	-.003	.168	-.062	-.156	.220	.547**	-				
14. Patient participation (questions & utterances)	.065	-.258*	.147	-.076	-.034	.147	.114	.223	.285*	.330**	.176	.633**	.295**	-			
15. Anxiety (post-consultation)	-.067	-.231*	-.144	-.124	.435**	.601**	.511**	.152	.085	-.031	.238*	.187	.166	.278*	-		
16. Satisfaction	.134	-.200	-.174	-.044	-.151	-.169	-.121	-.127	.227	.141	-.191	.086	-.178	.005	-.360**	-	
17. Recall	-.105	.021	.080	-.126	.073	.150	.161	-.176	.081	.061	.016	.208	.139	.040	.018	.345**	-

Note. ^a Gender was dummy coded into 1 = female, 2 = male. ^b Education level was dummy coded into 1 = low, 2 = medium, 3 = high.

* $p < .05$. ** $p < .01$. *** $p < .001$.

to the consultation ($b = .00, p = .921$), the number of questions and assertions expressed ($r = -.00, p = .587$) and information recall. In addition, there was no significant mediation of OHIS on information recall via one of the patient participation measures (see Table 2.3). This means that H2c needs to be rejected.

Table 2.3. Mediation analyses

Relations	<i>b</i>	<i>se</i>	<i>LLCI</i>	<i>ULCI</i>	<i>t</i>	<i>p</i>
Effect of OHIS on						
Word count	68.9740	27.8861	13.1535	124.7945	2.4734	.0163
Word count ratio	1.9918	.8473	.2958	3.6879	2.3508	.0222
Questions and assertions	.7349	.6469	-.5601	2.0299	1.1360	.2606
Anxiety	.0666	.0517	-.0369	.1701	1.2890	.2028
Satisfaction	-.1029	.0560	-.2149	.0091	-.18377	.0712
Recall	-.0203	.0189	-.0581	.0175	-1.0747	.2870
Anxiety predicted by						
Word count	-.0003	.0003	-.0009	.0004	-.7810	.4381
Word count ratio	.0141	.0096	-.0051	.0333	1.4679	.1478
Questions and assertions	.0051	.0117	-.0184	.0286	.4365	.6642
Mediation via word count	-.0174	.0231	-.0385	.0540		
Mediation via word count ratio	.0280	.0219	-.0196	.0694		
Mediation via questions & assertions	.0038	.0162	-.0470	.0225		
Satisfaction predicted by						
Word count	.0008	.0004	.0001	.0015	2.2207	.0302
Word count ratio	-.0223	.0109	-.0442	-.0005	-2.0487	.0449
Questions and assertions	-.0087	.0139	-.0365	.0191	-.6246	.5346
Mediation via word count	.0529	.0283	.0053	.1158		
Mediation via word count ratio	-.0319	.0254	-.0925	.0068		
Mediation via questions & assertions	-.0068	.0162	-.0268	.0416		
Recall predicted by						
Word count	.0002	.0001	.0000	.0004	1.6737	.0996
Word count ratio	.0004	.0036	-.0068	.0076	.1033	.9180
Questions and assertions	-.0025	.0047	-.0119	.0069	-.5359	.5941
Mediation via word count	.0131	.0091	-.0029	.0333		
Mediation via word count ratio	.0004	.0051	-.0092	.0127		
Mediation via questions & assertions	-.0015	.0043	-.0084	.0101		

Note. Abbreviations: Number of words used = Number of words used by the patient. Relative contribution = relative contribution of the patient in terms of words used by the patient compared to words used by the healthcare provider. Question & assertions = number of questions and assertions expressed by the patient.

Discussion

Review of findings

The aim of this study was twofold. First, this study examined which demographic and psychosocial factors could predict OHIS of newly diagnosed cancer patients. Second, it was investigated how OHIS subsequently relates to patient participation during consultations and how this in turn affects patients' anxiety, satisfaction, and information recall. Regarding demographic factors, the results showed that patients with higher levels of education are more inclined to engage in OHIS. With respect to psychosocial factors, higher levels of cancer-related stress are associated with more OHIS and patients having a monitoring coping style also engage more in OHIS. In turn, OHIS was positively related to patient participation in terms of number of words used by the patient during the consultation and a patient's relative contribution in the consultation, but not to the number of questions and assertions expressed.

The negative direct relation between OHIS and satisfaction shows that more OHIS leads to less patient satisfaction. Additionally, the number of words used by the patient was related to higher levels of satisfaction with the consultation, whereas the patient's relative contribution in the consultation was related to lower levels of satisfaction. The results also showed a positive indirect relation between OHIS and satisfaction via number of words used by the patient, meaning that patients who engaged more in OHIS used more words during the consultation which in turn was positively related to satisfaction with the consultation. Based on these results a careful conclusion can be drawn that OHIS can lead to both more and less satisfaction with the consultation, depending on the mediation of number of words used by the patient.

Our results indicate that not all patients engage in OHIS. Especially lower educated patients search less health information online. This is in line with previous research in which education is shown to influence OHIS positively (Lenhart & Horrigan, 2003). Hence, concerns raised almost 20 years ago by Lenhart and colleagues (Cegala et al., 2007; Street et al., 2005) regarding the digital divide still appear to be valid. Since our findings suggest OHIS is related to patient participation and satisfaction with the consultation, it can be seen as problematic that a group of patients does still not engage in OHIS.

Our results show different relations between the different measures of patient participation and OHIS. First, our results seem to suggest that patients who engage in OHIS are inclined to use more words during the consultation, which in turn results in more satisfaction with the consultation. This mediation might occur regardless of the reaction of the healthcare providers. However, satisfaction with the consultation might also be influenced by the interplay between the patient and the healthcare provider. For example, patient participation can elicit facilitating responses in the healthcare provider

resulting in the healthcare provider discussing more information during consultations (Fallowfield & Jenkins, 2006; Hack et al., 2005; Puts et al., 2012). On the other hand, the healthcare provider may disregard the input of the patient which is more in line with studies that have shown healthcare providers to insufficiently meet the patient's needs (Cegala et al., 2007; Fallowfield & Jenkins, 2006; Hack et al., 2005). If the relative contribution of the patient is higher it could mean that even though the patient uses more words, the healthcare provider does not respond to the patient's input. This could explain why an increase in the patient's relative contribution to the consultation relates to a decrease in satisfaction with the consultation.

Second, the undemonstrated relation between OHIS and the expression of questions and assertions contradicts previous research suggesting that OHIS facilitates patients to express needs and concerns (Diviani et al., 2015; Flanagan et al., 2016; Langille et al., 2010). One reason for this could be that online health content is often incorrect, incomplete, biased (Diviani et al., 2015) and usually experienced by patients as difficult to comprehend (Diviani et al., 2015; Flanagan et al., 2016; Langille et al., 2010). If patients engage in OHIS but find information that confuses them, this might inhibit their expression of questions or assertions. In particular, if patients do not feel empowered and confident during the consultation, they might ask less questions and express less assertions. It might also be possible that patients did not find the right information to support them in asking questions or expressing assertions or that OHIS fulfilled patients' information needs and already answered questions patients had. This could all have resulted in patients asking less questions during consultations. On the other hand, finding ambiguous information online could also result in patients asking more questions during the consultation in an attempt to take away their confusion. We swiftly examined the content of the transcripts to get a better understanding of the differences in relations between OHIS and the separate indicators of patient participation. The transcripts showed that patients who used more words, but did not express more questions and assertions, mostly engaged in small talk and discussed side issues unrelated to their ongoing situation. This implies that patients who are more active in OHIS are also more active during consultations in terms of using more words, but the information they found online did not seem to empower them enough to express treatment-related questions or assertions.

We expected that OHIS would result in less anxiety after the consultation (H2a), via more patient participation, but our results did not support this. The fact that OHIS did not influence the expression of questions and assertions might explain why we also did not find an indirect relation between OHIS and anxiety via patient participation, since feelings of anxiety could not be partly dismantled by discussing them with the healthcare provider.

The aforementioned line of reasoning may also explain why OHIS did not lead to better information recall, indirectly via patient participation. By not expressing questions

or assertions, but just talking more about other subjects, more information was added to the consultation. The amount of information this added to the consultation could have overshadowed the most important information about the diagnosis and treatment. Previous research has shown that the amount of information discussed during the consultation can negatively influence recall of the information discussed (Jansen et al., 2008).

Strengths

This study is, as far as we are aware, the first to show a significant mediation of OHIS on satisfaction with the consultation, via patient participation. Established models regarding the influence of OHIS on patient participation mainly focused on either via which ways patient participation can be increased by OHIS, for example by increasing knowledge and feelings of empowerment (Street, 2003) or how patient participation can influence patient outcomes (Cegala et al., 2007; Street et al., 2005; Zandbelt et al., 2007). Our findings help to connect and extend these models by linking these two processes together, considering both the influence of OHIS on patient participation and in turn the relation between patient participation and patient outcomes.

A distinguishing feature of this study are the participants. Including newly diagnosed cancer patients is challenging due to the emotional burden the patients face. Therefore, another strength of this study is that we succeeded to collect this data in a vulnerable population. The fact that this is a multicenter study with participating patients being treated in one of six Dutch hospitals, made inclusion of the patients even harder. Even though this is beneficial for the external validity of the study, differences occurred in the recruitment process between the hospitals and inclusion was more troubled in some hospitals than in others resulting in varying inclusion rates between hospitals.

Limitations and future research

First, patient participation was operationalized by means of quantitative measures only. Therefore, we could only draw conclusions based on the quantity of patient participation and not regarding the quality of patient participation. Future research should also qualitatively address patient participation during consultations to get more insight into the content of patient participation. Besides, only the utterances of the patients were analyzed. The utterances of healthcare providers were only included in terms of relative contribution to the consultation but not in terms of content. Since it seems plausible that patients' communication is dependent on the interplay between the partakers in that consultation (Lenhart & Horrigan, 2003; Street et al., 2005; Zandbelt et al., 2007), it is advised to analyze behavior of all parties taking part in the consultation in future research. In addition, only behavioral measures were used in this study to measure patient

participation. Adding measures of perceived participation would be a valuable addition and is therefore recommended for future research.

A limitation that could have influenced the relations with information recall is that in this study, the number of recall questions was based on the amount of information the patient received from the healthcare provider during the consultation. This means that the more information was provided, the more recall questions the patient had to answer. Not only the amount of information provided is known to be negatively related to the ability to correctly recall this information (Brandes et al., 2015; Epstein et al., 2018), but also a higher number of questions can mean a higher chance of making mistakes. The researchers of this study deliberately chose to tailor the recall questions to the consultations of each separate patient, because asking a fixed set of recall questions meant asking questions about topics that were not discussed with the patient which was seen as unethical. In future studies, researchers can decide on asking a maximum number of questions per topic in the case of long consultations.

Lastly, since our results show that OHIS does not lead to expressing questions or utterances, we encourage researchers to further investigate the effects of other types of online health information, for example online tools specifically developed and offered to patients. Previous research has shown that online health information developed and offered to a specific patient population, including preparatory tools such as question prompt lists or information tailored to the patients' situation can be effective in increasing patient participation (Brandes et al., 2015; Langille et al., 2009).

Practically, since we see a relation between some measures of patient participation and satisfaction, but not all, this study shows the importance of providing patients with the right tools to search for online health information that stimulates participation by means of expressing questions and utterances during consultations. Especially because OHIS can also increase worry and confusion (Anderson et al., 2003; Baumgartner & Hartmann, 2011; Linn et al., 2019), healthcare providers are advised to guide patients with clear instructions on how to search for information online. For example, hospitals could provide patients with flyers including information about which websites are reliable and which websites are not.

Conclusion

This study showed that younger patients, higher educated patients, patients that experience more cancer-related stress and patients that have a monitoring coping style are more likely to engage in OHIS. OHIS is positively related to the patient's absolute contribution during a consultation, which in turn results in the patient being more satisfied with the consultation. The results are an important addition to established models regarding the influence of OHIS.