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### A novel approach to tailored communication

*Optimizing online health information for older patients*

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6

## Chapter 6

### **Fear and forget: How anxiety impacts information recall in newly diagnosed cancer patients visiting a fast-track clinic**

Nguyen, M. H., Smets, E. M. A., Bol, N., Bronner, M. B., Tytgat, K. M. A. J., Loos, E. F., & van Weert, J. C. M. (2019). Fear and forget: How anxiety impacts recall of medical information in newly diagnosed cancer patients visiting a fast-track clinic. *Acta Oncologica*, *58*(2), 182-188. doi:10.1080/0284186X.2018.1512156

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## ABSTRACT

One-day fast-track programs for cancer diagnostics and treatment planning are increasingly being implemented in health care. Fast-track programs are highly effective at reducing waiting times, and thus well received by patients and healthcare providers. However, these programs may also burden patients, as patients generally receive a lot of information from multiple healthcare providers within a short time span. This might increase anxiety and negatively impact recall of medical information in newly diagnosed patients. This study examines whether anxiety influences information recall at the moment of diagnosis, and whether this relation differs for younger and older patients. Data were collected from 78 colorectal cancer patients visiting a one-day fast-track multidisciplinary outpatient clinic. All consultations that took place were recorded on video. Anxiety was measured at baseline (T1) and immediately after consultations (T2) with the STAI-6. Information recall was assessed by telephone within 36–48 hours after patients' visit (T3) using open-ended questions. After the consultations (T2), 32% of the patients experienced clinical anxiety levels. Patients recalled ~60% of the medical information (T3). Information recall was negatively impacted by anxiety ( $\beta = -.28$ ,  $p = .011$ ), and negatively related to higher age ( $\beta = -.23$ ,  $p = .031$ ), and lower education level ( $\beta = .27$ ,  $p = .013$ ). Although older patients ( $M = 53.99$ ) recalled 11% less information than younger patients ( $M = 64.84$ ), age was not related to anxiety and did not moderate the anxiety-recall relationship. High levels of anxiety after receiving a cancer diagnosis negatively influence how much information patients remember after visiting a one-day fast-track clinic. This calls for interventions that may reduce patients' anxiety as much as reasonably possible and support patients' information recall. Researchers, practitioners, and hospitals are encouraged to continue exploring ways to optimize information provision to cancer patients in current modern healthcare.

## INTRODUCTION

Awaiting cancer diagnosis and the moment of diagnosis itself both involve high levels of anxiety for most patients (Bronner et al., 2017; Dillard, Scherer, Ubel, Alexander, & Fagerlin, 2017). High anxiety levels may hinder patients' ability to process and recall information provided by physicians (Dillard et al., 2017; Gaston & Mitchell, 2005; Stark & House, 2000). Studies have shown that cancer patients forget substantial amounts of medical information (Gabrijel et al., 2008; Jansen et al., 2008b). Regrettably, poor information recall during the early phase of diagnosis and treatment planning presents a major problem. During this uncertain phase, information needs are not only the highest among patients (Jenkins et al., 2001; Rutten, Arora, Bakos, Aziz, & Rowland, 2005), but information is also crucial for patients to make informed and shared decisions about treatment, and manage their illness (Elwyn et al., 2012; Gaston & Mitchell, 2005; Mills & Sullivan, 1999). This is, in turn, essential for a successful course of treatment and better quality of life for the patient (Fallowfield, Hall, Maguire, Baum, & A'Hern, 1994; Husson et al., 2010).

While it is generally assumed that anxiety is related to information processing in cancer patients (Fogarty, Curbow, Wingard, McDonnell, & Somerfield, 1999; Lienard et al., 2006), evidence from clinical settings on this relationship at the moment of diagnosis is lacking. Previous studies in the cancer domain have mainly examined the anxiety-recall relationship postdiagnosis or in video-vignette studies among 'analog patients', where non-cancer patients watched a bad news consultation and imagined to be the patient in the video (Jansen et al., 2008a; van Osch, Sep, van Vliet, van Dulmen, & Bensing, 2014; Visser et al., 2017). These studies often found no relation between anxiety and recall (Jansen et al., 2008a; van Osch et al., 2014; Visser et al., 2017). However, the anxiety-recall relationship is rather complex (Schwabe, Joëls, Roozendaal, Wolf, & Oitzl, 2012), and these null findings might be the consequence of the measuring moment of anxiety (e.g., post-diagnosis vs. at diagnosis) and study setting (e.g., videovignette vs. clinical setting) in previous studies.

The rising popularity of fast-track programs for diagnostics and treatment planning makes it especially important to study the anxiety-recall relationship in a clinical setting. These 'one-day' or 'one-stop' programs are increasingly implemented in cancer care to improve and fasten diagnostic work-up, and shorten the waiting time between staging and start of treatment (Klinkenbijn et al., 2012). Patients and providers have expressed high satisfaction with such programs (Basta, Tytgat, Klinkenbijn, Fockens, & Smets, 2016; Klinkenbijn et al., 2012; Montgomery & McCrone, 2010), but it might also negatively impact patients' information recall, as they receive a lot of information in a

short time, often from multiple providers. Relatedly, fast-track approaches may lead to elevated anxiety levels post-diagnosis as patients have little time to process their diagnosis (Montgomery & McCrone, 2010), possibly having a negative impact on information recall.

Currently, the majority of newly diagnosed cancer patients are older than 65 years, and with the growing aging population, this number is increasing worldwide (American Cancer Society, 2017b; Dutch Cancer Society, 2011). Processing and memorizing medical information is considered more challenging for older patients due to age-related decline (Brown & Park, 2003; Salthouse, 2004). Older patients are thus more at risk for poor information recall, especially within fast-track programs. However, older patients generally report lower levels of anxiety after cancer diagnosis (Linden, Vodermaier, MacKenzie, & Greig, 2012; Nelson et al., 2009) and are better able to regulate their emotions. This could free up cognitive resources and compensate for negative effects of aging on information recall (Brown & Park, 2003; Kessels, 2003). To date, the role of age in the anxiety-recall relationship has remained understudied.

This study investigates whether anxiety influences information recall at the moment of cancer diagnosis among patients visiting a one-day fast-track multidisciplinary outpatient clinic. Additionally, we examine whether age influences the anxiety-recall relationship, while controlling for other factors that might explain information recall (e.g., sociodemographic information, medical background information and information preferences).

## **METHOD**

### **Participants**

Participants were patients who were suspected of having colorectal malignancies or had received a preliminary cancer diagnosis (but awaiting information on the tumor stage) and were referred to an academic multidisciplinary outpatient clinic in the Netherlands that specializes in fast-track diagnosis and treatment planning within one day (Basta et al., 2016; Bronner et al., 2017). The inclusion criteria for participation were (a) referred for colorectal cancer; (b) 18 years or older; (c) no known cognitive impairment based on medical record (e.g., dementia); (d) Dutch language proficiency; and (e) Internet access.

## **Procedure**

The fast-track program starts with an intake consultation with a medical specialist to evaluate patients' symptoms and performance status, followed by a nurse consultation to take their medical history. Sometimes additional imaging studies are scheduled. At noon, a multidisciplinary team discusses the diagnosis and formulates a treatment plan for each patient. In the afternoon, the diagnosis and proposed treatment plan are discussed with the patient by the same doctor who conducted the intake consultation, again followed by a nurse consultation for practical treatment information. Depending on the treatment plan, patients also see a colorectal surgeon, oncologist, or radiation oncologist to discuss treatment details. On average, patients have 4–6 consultations. All consultations during the patients' visit were video recorded for this study.

Prior to visiting the fast-track clinic (1–4 days), consenting patients completed an online questionnaire to record baseline anxiety, and sociodemographic, medical background and information preferences variables (T1). Directly after their last consultation, patients filled out a questionnaire regarding anxiety at that moment (T2). Patients were contacted by telephone within 36–48 hours after their visit to assess information recall (T3).

## **Dependent variable**

**Information recall.** Recall of information from the consultations was measured at T3 using the protocol of the Netherlands Patient Information Recall Questionnaire (NPIRQ; Jansen et al., 2008b). Thirteen standardized open questions about often discussed topics were asked to every patient (i.e., about the proposed treatment plan; treatment goal; logistic planning of treatment; possible risks and side effects of treatment; tips about nutrition, fatigue, weight, and stool; reasons for contacting the nurse and contact information). To improve the validity of the recall measure, a maximum of five additional open questions were formulated tailored to the specific case of each individual patient, based on the videotaped consultations (e.g., about details of treatment; additional medical tests; revalidation information). The correct answers were also derived from the videotaped consultations. Each answer as provided by the patient during the interview was scored as not recalled (0), partially recalled (1) and completely recalled (2). Patients could receive a maximum of 18 questions in total. However, because the number of discussed topics varied across patients, not all standardized open questions were applicable to all patients. According to the NPIRQ guidelines, a standardized score was calculated by taking the percentage correctly recalled information, based on the total sum score (range 2–22) and maximum obtainable recall score (range 4–34; from now

on referred to as 'information density'). Two researchers double coded 15% of the recall answers ( $n = 14$ ), showing good intercoder reliability (mean  $\kappa = .816$ ,  $p < .001$ ).

### **Independent variables**

**Age.** Chronological age was measured at baseline as a continuous variable. For comparisons between age groups, a distinction was made between younger (0;  $<65$ ) and older patients (1;  $\geq 65$ ). The majority of new colorectal cancer incidences occurs in patients aged 65 years and older (Siegel et al., 2017), and this cut-off has also been employed in previous studies considering aging and cancer (Yancik & Ries, 2000).

**Anxiety.** Anxiety was measured (T1 and T2) with the short 6-item version of the Spielberger State-Trait Anxiety Inventory (STAI-6; Marteau & Bekker, 1992; van der Bij, de Weerd, Cikot, Steegers, & Braspenning, 2003). Patients rated the degree to which they were currently experiencing anxiety on a scale ranging from 1 (not at all) to 4 (very much so) (T1,  $\alpha = .83$ ; T2,  $\alpha = .85$ ). The items reflect the presence (tense, upset, worried) or the absence (calm, relaxed, content) of anxiety at that moment. The total scores were recorded based on the guidelines to scores from 20 to 80, with scores higher than 44 as the cut-off for clinical anxiety levels (Bronner et al., 2017).

### **Control variables**

The following variables were considered relevant for explaining information recall and therefore considered as control variables.

**Sociodemographics.** Patients' gender and education level were measured. Education level was dichotomized as lower (primary education, general secondary education, middle vocational education) and higher levels (higher vocational education, university).

**Medical background.** We recorded whether patients came in for a second opinion (no = 0, yes = 1), and whether patients participated in the national colorectal cancer screening (no = 0, yes = 1). Frailty, which refers to functioning in the physical, cognitive, social, and psychosocial domain, was assessed with the 15-item Groningen Frailty Indicator (GFI; Schuurmans, Steverink, Lindenberg, Frieswijk, & Slaets, 2004; Steverink, Slaets, Schuurmans, & Van Lis, 2001). A sum score was calculated (range 0–15), with higher scores indicating higher frailty levels. Quality of life was measured with two items from the EORTC Quality of Life Questionnaire (QLQ-C30; Aaronson et al., 1993), for example "how would you rate your overall health during the past week?" measured on a 7-point scale

ranging from 1 (very bad) to 7 (excellent; Pearson's  $r = .80, p < .001$ ). The treatment goal (palliative or unclear = 0; curative = 1) and suggested treatment modality (surgery only = 0; chemotherapy or radiation therapy = 1) were derived from the medical file.

**Information preferences.** Monitoring coping style assesses the degree to which patients seek or avoid information in a threatening medical situation, and was measured with a 3-item, 5-point scale, ranging from 1 (not applicable to me at all) to 5 (very applicable to me), derived from the Threatening Medical Situation Inventory (TMSI; e.g., "I intend to get as much information as possible about my treatment"; Miller, 1987; van Zuuren, de Groot, Mulder, & Peter, 1996). A total sum score was computed, with higher scores indicating higher monitoring coping style ( $\alpha = .76$ ). Information preference was measured with an adapted item of the Information Satisfaction Questionnaire (Thomas, Kaminski, Stanton, & Williams, 2004), assessing whether patients prefer to receive: (a) as much information as possible, both positive and negative, (b) as much information as possible, both positive and negative, but bit by bit, (c) not much information and (d) only positive information. The items were dichotomized by merging category b, c and d into "not all information (at once)" (0) vs. "as much information as possible, both positive and negative" (1).

### **Statistical analyses**

A three-stage linear regression model was estimated to examine the relationship between anxiety and age, and information recall. The baseline model (Model 1) included the control variables. To reduce the number of predictors, only variables which were at least marginally correlated with information recall were included in the model ( $p < .10$ ; see Table 6.1; for a similar procedure see Zandbelt, Smets, Oort, Godfried, & de Haes, 2004; Zandbelt, Smets, Oort, Godfried, & de Haes, 2006). Furthermore, we controlled for the information density by including the maximum obtainable recall score in the model, as this reflects the number of information entities that were discussed during the consultation (see also 'Dependent variable'). Anxiety (as measured directly after the diagnosis and treatment planning consultations at T2) and age (continuous) were added as predictors in Model 2, and the interaction between anxiety and age was included in Model 3. All analyses were repeated with anxiety at baseline (T1) to examine whether baseline anxiety levels prior to visiting the fast-track clinic were relevant for the effect of anxiety at diagnosis on information recall. Assumptions of linearity, normality, homoscedasticity, independent errors (Durbin-Watson = 2.00), and multicollinearity (VIF < 10) were met for all variables. Standardized coefficients (betas) are reported for comparisons of predictive power.

## RESULTS

### Sample characteristics

In total, 219 patients visited the fast-track clinic from November 2014 through November 2015. Of these patients, 180 could be reached by telephone and were informed about the purpose of the study (i.e., to gain insight into information provision at the clinic). A total of 91 patients (51%) consented to participate in the study. Due to drop-out and missing data, a total of 78 patients (43%) were included in the final analysis. An overview of participant inclusion and reasons for non-response is presented in Figure 6.1. The majority of participating patients were male (65.4%) and lived together with a partner, children or other family member (82.0%). All patients received a cancer diagnosis. The majority received a curative treatment plan (73.1%) and was advised to undergo surgery without additional chemotherapy or radiation therapy (69.2%). All patient characteristics are shown in Table 6.1.

### Anxiety and recall of medical information

The average anxiety score after consultations (T2) was 42.05 ( $SD = 12.21$ ), with no differences between younger and older patients,  $t(76) = -1.47, p < .146$ . Thirty-two percent of patients experienced clinical anxiety levels ( $>44$ ) at T2. On average, patients recalled 60% of the information provided during the diagnostic and treatment planning consultations ( $SD = 16.88$ ; range = 22.22–100.00). Information about treatment logistics (i.e., the where, when and duration of treatment) was recalled best with 83% ( $SD = 25.70$ ), while recommendations for daily life (e.g., about weight, stool, diet, and when to contact the nurse) were recalled poorest with 43% ( $SD = 33.28$ ). Older patients ( $M = 53.99, SD = 17.74$ ) recalled on average 11% less information than younger patients ( $M = 64.84, SD = 14.61$ ),  $t(76) = 2.96, p = .004$ .

### The anxiety-recall relationship

The baseline model with control variables only (Model 1) revealed a significant relationship between education level and information recall, such that those with higher education levels recalled more information than those with lower education levels ( $\beta = .31, p = .006$ ). None of the other control variables explained variance in information recall. Extending this model with anxiety and age (Model 2) significantly improved the model ( $\Delta R^2 = .12, p = .005$ ; total adjusted  $R^2 = .26$ ), and showed that anxiety was the strongest predictor of information recall ( $\beta = -.28, p = .011$ ), followed by education level ( $\beta = .27, p = .013$ ), and age ( $\beta = -.23, p = .031$ ). Higher levels of anxiety, as well as higher age and lower education levels, were associated with poorer information recall. Testing the interaction

effect (Model 3) provided no evidence for the moderating influence of age on the anxiety-recall relationship, suggesting that older patients do not differently recall information as a result of their experienced anxiety compared to younger patients. Controlling for anxiety at baseline (T1) in the regression models yielded similar results. The regression models are summarized in Table 6.2.

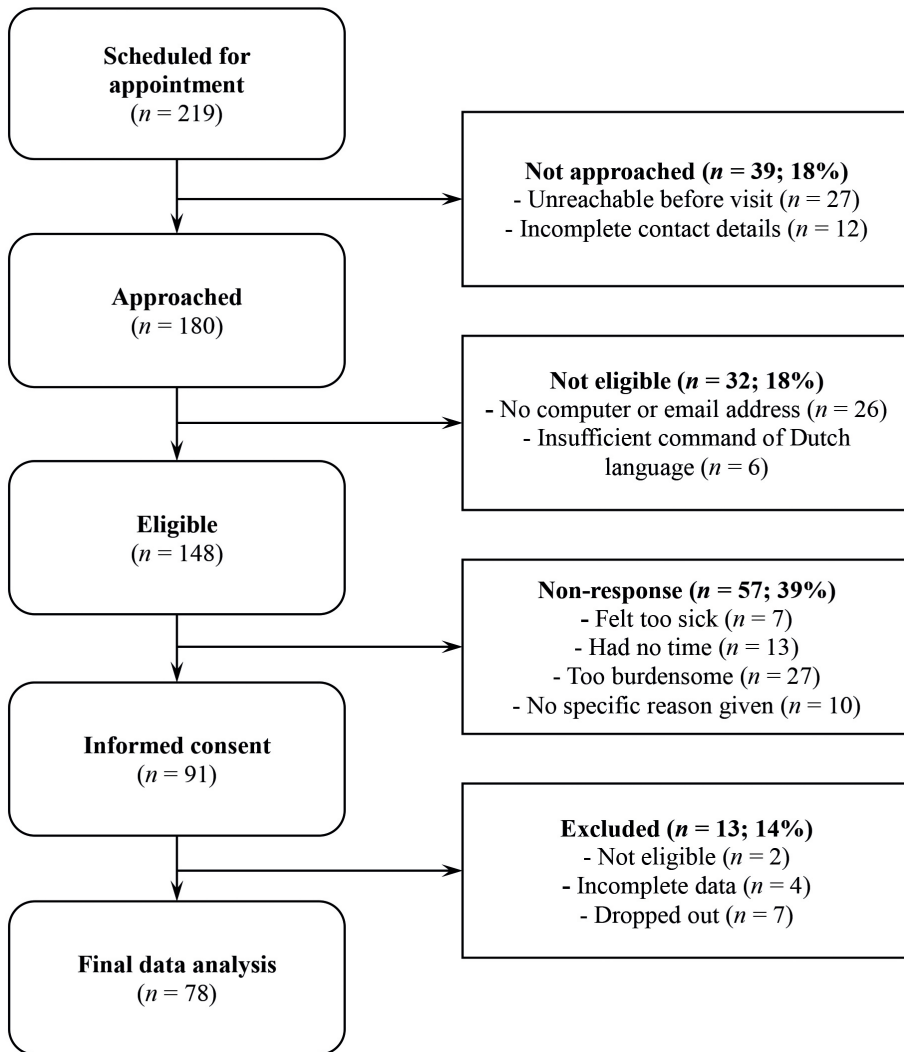


Figure 6.1. Flow diagram of patient inclusion.

**Table 6.1.** Patient characteristics (N = 78).

Variable	n	%	Mean (SD)	Range
<i>Independent variables</i>				
Age**			62.41 (9.08)	27.90–81.37
Anxiety T1 (possible range 20–80)			43.98 (10.22)	23.33–73.33
Anxiety T2* (possible range 20–80)			42.05 (12.21)	20.00–76.67
<i>Control variables</i>				
<i>Sociodemographic information</i>				
<i>Gender</i>				
Male	51	65.4		
Female	27	34.6		
<i>Education level**</i>				
Lower	42	53.8		
Higher	36	46.2		
<i>Medical background variables</i>				
Frailty (possible range 0–15)			2.54 (1.95)	0–8
Quality of life (possible range 1–7)			4.90 (1.37)	1.00–7.00
<i>Second opinion</i>				
No	65	83.3		
Yes	13	16.7		
<i>National cancer screening*</i>				
No	52	66.7		
Yes	26	33.3		
<i>Treatment goal</i>				
Palliative	21	26.9		
Curative	57	73.1		
<i>Treatment modality</i>				
Surgery only	54	69.2		
Chemo- and/or radiation therapy	24	30.8		
<i>Information preferences</i>				
Monitoring coping style (possible range 3–15)			10.64 (2.58)	3–15
<i>Information preference</i>				
Not all information (at once)	27	34.6		
As much information as possible	51	65.4		
<i>Consultation characteristics</i>				
Information density (maximum obtainable recall score)			18.92 (5.61)	4–34

Note. Significant correlations with information recall are indicated with asterisks.

†  $p < .10$ . \*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

**Table 6.2.** Regression models assessing the relation between anxiety, age and information recall

	Model 1 $\beta$ , $p$ -value	Model 2 $\beta$ , $p$ -value	Model 3 $\beta$ , $p$ -value
<i>Control variables</i>			
High education level (vs. low education level)	.31, .006	.27, .013	.27, .013
National cancer screening (vs. no)	-.18, .102	-.15, .156	-.15, .158
Information density (maximum obtainable recall score)	.04, .690	-.05, .613	-.05, .611
<i>Independent variables</i>			
Anxiety		-.28, .011	-.20, .764
Age		-.23, .031	-.19, .599
<i>Interactions</i>			
Anxiety $\times$ Age			-.09, .907
$R^2$	.15	.26	.26
$\Delta R^2$		.12	.00
Sig. $\Delta F$		.005	.907

Note.  $N = 78$ . Model 1 shows a simple linear regression model assessing the relationship between control variables and information recall. Model 2 expands upon Model 1 by adding anxiety and age to the model. Model 3 expands upon Model 2 by adding the interaction between anxiety and age to the model.  $R^2$  indicates the explained variance of the model (adjusted);  $\Delta R^2$  shows the change in  $R^2$  by adding predictors in Model 2 and 3; Significant  $\Delta F$  shows whether the difference in  $F$ -value for adding anxiety and age to the second model and the interaction between anxiety and age to the third model is significant.

## DISCUSSION

This study examined the anxiety-recall relationship in cancer patients at the point of diagnosis in a fast-track clinic setting. This study is one of the first to provide evidence from a clinical setting that highly anxious patients remember less information from diagnosis and treatment planning consultations. Remarkably, patients forget ~40% of the information that was provided by their healthcare providers. While older patients recalled less information than younger patients, age did not influence the anxiety-recall relationship. This suggests that post-diagnosis anxiety has the same impact on information recall in both younger and older patients. Together, these findings present important implications for clinical practice.

## **Clinical implications**

Fast-track programs in cancer diagnosis and treatment planning are a good solution to reduce waiting times (Klinkenbijn et al., 2012) and it is impossible to imagine modern health care without such approaches. However, it remains important to be aware of the possible implications for patients such as elevated anxiety and poor information recall. Providing interventions to limit anxiety as much as possible is desirable for optimal information transfer, but given the emotional impact of a cancer diagnosis high anxiety levels will nevertheless remain. Therefore, strategies to enhance information recall could be a more realistic starting point. Encouraging patients to bring a companion or to record the consultation can improve information recall (Brandes & van Weert, 2017; Jansen et al., 2010a). Additional tailored patient education materials, such as pre- and post-consultation websites and brochures, can be used to prepare patients for intensive fast-track trajectories as well as to recap information that is often forgotten (e.g., recommendations for daily life). Good preparation may reduce anxiety as well as increase the likelihood that patients remember more information. Furthermore, physicians could use recall-promoting behaviors such as repetition and summarize information to improve patients' information recall (Silberman, Tentler, Ramgopal, & Epstein, 2008). Finally, additional follow-up appointments could be scheduled, allowing for more time to discuss treatment details with the patient. Such strategies and interventions could enhance patients' information recall, support them in making informed and shared decisions, as well as help patients manage their disease during treatment.

Even though anxiety at cancer diagnosis is inevitable, dealing with patients' anxiety may still support them in memorizing medical information. Clinicians are often aware of the anxiety that goes with cancer diagnosis, but find it difficult to evaluate how anxious individual patients are and to tailor their communication style accordingly (Stuij et al., 2018). Asking patients directly about their anxiety and discuss patients' emotional distress may be a good first step. Additionally, screening for elevated anxiety levels (e.g., the short Distress Tool; Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008) may help clinicians tailor their communication, for example by structuring and repeating information and using checks for understanding, thereby supporting patients in processing medical information during the consultation. While the latter communication strategies could benefit all patients, they become particularly important when dealing with highly anxious patients. Moreover, addressing anxiety during the consultation might prevent patients from being too overwhelmed to process information. Video-vignette studies have shown that physicians' effective communication can lower patients' anxiety and enhance their ability to recall medical information (Fogarty et al., 1999; Jansen et al., 2010b; Medendorp, Visser, Hillen, de Haes, & Smets, 2017; van Osch et al., 2014).

For example, being compassionate or giving reassurance can reduce anxiety (Fogarty et al., 1999; van Vliet, van der Wall, Plum, & Bensing, 2013). Similarly, giving a minimal encouragement ('hmm') or using trust-conveying communication can improve information recall (Jansen et al., 2010b; Medendorp et al., 2017). These communication strategies take up little time, but could make a significant difference for highly anxious patients.

### **Limitations and future research directions**

This study examined the anxiety-recall relationship within the context of a fast-track program, but the findings might not be unique to fast-track contexts. Future research may address whether a negative anxiety-recall relationship exists in other trajectories as well. Furthermore, as variations in the time of measurement might lead to different conclusions on the anxiety-recall relationship (Schwabe et al., 2012), this should be carefully considered when comparing results across studies.

The limited sample size and sample heterogeneity should also be acknowledged. Although all patients went through the same fast-track program, the sample also included patients who visited the fast-track clinic for a second opinion. As these patients had already received their diagnosis, the anxiety-recall relationship could have been different for this group. However, anxiety may be not only caused by the diagnosis in itself, but also by the uncertainty of the tumor stage and consequent treatment plan. A post-hoc analysis in which second opinions ( $n = 13$ ) were excluded showed a similar, slightly stronger effect of anxiety on recall ( $\beta = -.32, p = .005$ ), demonstrating the robustness of our findings. Finally, although a fair proportion of variance in information recall was explained by our model, it is important to consider other potentially relevant factors in explaining information recall (e.g., future time perspective, anger after receiving a cancer diagnosis; Bol et al., 2018).

### **Conclusion**

This study showed that high levels of anxiety after receiving a cancer diagnosis negatively influence how much medical information patients remember after visiting a one-day fast-track clinic for diagnosis and treatment planning. Research scholars and clinicians should work collaboratively to identify ways to optimize information provision to cancer patients in highly emotionally charged clinical settings such as fast-track clinics.

## **ADDITIONAL INFORMATION**

### **Ethics approval and informed consent**

Both the ethical review board of the Academic Medical Center and the institutional review board of the Amsterdam School of Communication Research approved the study protocol (reference numbers W13\_053 #13.17.0069 and 2014-CW-110). All patients and healthcare providers gave written informed consent for participating in the study, for video recording their consultations, and for analyzing and publishing the collected data in a way that the data will never be retraceable to individual patients or healthcare providers.