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# Mind your words: Oncologists' communication that potentially harms patients with advanced cancer: A survey on patient perspectives

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**BACKGROUND:** Many complaints in medicine and in advanced illnesses are about communication. Little is known about which specific communications harm. This study explored the perspectives of patients with advanced cancer about potentially harmful communication behaviors by oncologists and helpful alternatives. **METHODS:** An online survey design was used that was based on literature scoping and patient/clinician/researcher input. Patients with advanced cancer (n = 74) reflected on the potential harmfulness of 19 communication situations. They were asked whether they perceived the situation as one in which communication could be harmful (yes/no). If they answered “yes,” they were asked whether they perceived the examples as harmful (yes/no) or helpful (yes/no) and to provide open comments. Results were analyzed quantitatively and qualitatively (content analysis). **RESULTS:** Communication regarding information provision, prognosis discussion, decision-making, and empathy could be unnecessarily potentially harmful, and this occurred in various ways, such as making vague promises instead of concrete ones (92%), being too directive in decision-making (qualitative), and not listening to the patient (88%). Not all patients considered other situations potentially harmful (eg, introducing the option of refraining from anticancer therapy [49%] and giving too much [prognostic] information [60%]). Exploring each individual patients' needs/preferences seemed to be a precondition for helpful communication. **CONCLUSIONS:** This article provides patient perspectives on oncologists' unnecessarily potentially harmful communication behaviors and offers practical tools to improve communication in advanced cancer care. Both preventable pitfalls and delicate challenges requiring an individualized approach, where exploration might help, are described. Although providing difficult and unwelcome news is a core task for clinicians, this study might help them to do so while preventing potentially unnecessary harm. *Cancer* 2022;128:1133-1140. © 2021 The Authors. *Cancer* published by Wiley Periodicals LLC on behalf of American Cancer Society. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

**KEYWORDS:** advanced cancer, communication, complaints, empathy, harm, information provision, patient perspective.

## INTRODUCTION

“Do no harm” lies at the heart of medicine. Harm can arise not only from medical-technical errors but also from what is historically perceived as the soft side of medicine: communication. Many complaints about medical care and in the area of advanced illness<sup>1</sup> can be traced back to communication deficits.<sup>2</sup>

However, surprisingly little is known about why many complaints in medical care are about communication. Until now, it has been unclear which specific communication behaviors have the potential to unnecessarily harm patients. Multiple studies have found that communication behaviors such as empathy, listening, reassuring, and providing tailored information have positive effects on patient-reported outcomes in (advanced) cancer.<sup>3-5</sup> We might expect that opposite behaviors could be perceived as harmful. Complaints about communication in cancer care indeed include a lack of caring and respect, incorrect information, and breakdowns in communication.<sup>6</sup>

Recently, research has addressed the clinician's perspective—but not the patient's perspective—on unnecessarily potentially harmful communication. A recent essay postulated which communication behaviors might be improper and

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harmful and suggested more appropriate alternatives (eg, referring to the patient as a disease instead of a person: “Ms X is our CHF-er” instead of “Ms X is a person with heart failure”).<sup>7</sup> Although clinicians’ viewpoints are important, individual patients’ perspectives are ultimately even more important and may differ from expert opinion<sup>8,9</sup>; nevertheless, to date, they are missing from the research.

The aim of this study was to explore the perspectives of patients with advanced cancer about potentially harmful communication behaviors by oncologists and to suggest helpful alternatives. Fulfilling this aim will provide concrete tools to help oncologists to prevent unnecessary potential harm to patients via communication at a point in their care when this is most important.

## MATERIALS AND METHODS

### *Design*

An online survey design was used. Based on the results of a scoping literature search and patient, clinician, and researcher input, an online questionnaire was created (for detailed information on the scoping process, see Supporting Appendix 1). Themes and examples of potential harmful communication and helpful alternatives in cancer care were extracted from the included articles, collated, and reviewed by the project team (which consisted of experts in cancer, palliative care, and communication and was supplemented by patient representation). The agreed-upon themes/situations and examples (eg, not supporting shared decision-making, using medical jargon, and ignoring emotions; see Supporting Appendix 2) were transformed into questions for the online questionnaire. The questionnaire was piloted on clarity/format by 2 patient representatives (J.B. and N.M.F.P.). Various changes, such as the inclusion of an example question and simplifications of questions, were made.

### *Ethics*

The study was approved by the Ethical Committee of Psychology Research of Leiden University (2020-09-22-L.M.vanVliet-V1-2643).

### *Participants and Recruitment*

Eligible patients were 18 years old or older with advanced (incurable) cancer and sufficient Dutch language skills. Initially, we included only women with incurable breast cancer. To increase recruitment numbers, eligibility criteria were widened.

From June to November 2020, patients were recruited via channels of patient organizations (eg, the Dutch Breast Cancer Association [BVN], the Dutch Federation of Cancer Patient Organizations [NFK], and kanker.nl). Social

media advertisements could be freely shared. Participants from previous studies were also approached if they had consented to being contacted again. The advertisement (which either was sent directly to patients with incurable cancer or clearly stated that this was the eligible group) included a link to the online study, and after interested patients read the information letter and provided electronic informed consent, they could access the questionnaire.

### *Background Characteristics*

Sociodemographic characteristics (eg, age and education) and medical information (eg, cancer type and prior/current treatments) were assessed.

### *Harmful and Helpful Communication*

Patients were presented with 19 situations that could potentially entail unnecessarily harmful communication (grouped under decision-making, information provision, and empathy; see Supporting Table 1 and Supporting Appendix 2). These situations were accompanied by an example of potentially harmful communication and an alternative of potentially helpful communication. First, patients were asked whether they thought that this was a situation in which communication could be harmful (yes/no). If they replied “yes,” they were asked whether they thought that the examples provided were indeed 1) harmful (yes/no) or 2) helpful (yes/no). In open-ended questions, they could then provide additional suggestions and/or experiences of harmful and helpful communication per situation and, lastly, in general. To assess participants’ views on 2 topics (discussing the option of refraining from anticancer therapy and giving information about life expectancy), we included both a situation in which the discussion of these topics could be rated as potentially harmful and a situation in which the nondiscussion of these topics could be rated as potentially harmful, and we provided mirrored harmful/helpful examples.

### *Data Analysis*

First, background characteristics were described. Second, the extent to which potentially harmful situations and their potentially harmful and helpful suggestions were perceived as such was described. Quantitative analyses were performed with SPSS version 25. Third, open-ended questions were qualitatively analyzed according to the principles of content analysis<sup>10</sup> and were supported by ATLAS.ti software. In the first step (deduction), one of the researchers (J.W., who was supported by L.M.V.V.) read through and coded all data for correspondence with the categories identified (displayed in Supporting Appendix 2). Two researchers (J.W. and L.M.V.V.) together created new coding unities for data that did not fit within the existing

categories (step 2: induction). In the third step, the lists of categories were grouped under higher order headings, and in the fourth step (abstraction), these were summarized qualitatively (see the Results section) and integrated with the quantitative results of the survey (see Supporting Table 1) in a final table (see Supporting Table 2). Situations that <33% of the patients assessed as potentially harmful were not included in the final table (based on the RAND appropriateness method<sup>11,12</sup>). This table and interim analyses were reviewed and discussed with the coauthors (who had backgrounds in psychology, communication, medicine, and patient representation) to prevent a 1-sided interpretation of the data. Preferred Reporting Items for Systematic Reviews and Meta-Analyses, Strengthening the Reporting of Observational Studies in Epidemiology, and Consolidated Criteria for Reporting Qualitative Research guidelines were followed for reporting.

## RESULTS

### Participant Characteristics

Seventy-four of the 90 patients who started the questionnaire answered the communication questions and were included in our analyses. The background characteristics of these 74 patients are summarized in Table 1. The mean age of the patients was 57 years (SD, 9.06 years).

### Quantitative Results

Supporting Table 1 shows the quantitative results of the survey, that is, the extent to which various communication situations were perceived as potentially harmful communication. The following situations were perceived as the most potentially harmful: discussing the end of anti-cancer therapy without mentioning what is still possible (85%), not listening to the patient (88%), and making vague promises (92%). Focusing on the occurrence of side effects (31%) was perceived as the least potentially harmful. Views varied on the potential harmfulness of behaviors regarding the amount of information (60% perceived too much as harmful, and 65% perceived too little as harmful) and the option of refraining from anticancer therapy (49% perceived discussion as harmful, and 44% perceived nondiscussion as harmful). See Supporting Table 1 for patients' perceptions of potentially harmful and helpful examples.

### Qualitative Results

The qualitative results are based on the open-ended responses to the survey, that is, patient-reported data about what patients perceived as potentially harmful

**TABLE 1.** Background Characteristics

Characteristic	No. (%)
Sex	
Female	68 (92)
Male	6 (8)
Marital status	
Married	52 (70)
Single	22 (30)
Education	
Lower	16 (22)
Intermediate	20 (27)
Tertiary	37 (50)
Missing	1 (1)
Occupation	
Paid job	19 (26)
Disabled/sick leave	32 (43)
Houseman/housewife	5 (7)
Retired	15 (20)
Other <sup>a</sup>	3 (4)
Ethnicity	
Dutch	64 (87)
Western immigrant	5 (7)
Missing	5 (7)
Type of cancer <sup>b</sup>	
Breast	58 (78)
Colon	2 (3)
Lung	5 (7)
Kidney	2 (3)
Prostate	2 (3)
Other <sup>c</sup>	9 (12)
Treatments currently receiving <sup>b</sup>	
Chemotherapy	19 (26)
Radiotherapy	4 (5)
Hormone therapy	40 (54)
Immunotherapy	13 (18)
Operation	1 (1)
Symptom-oriented treatment	24 (32)
Tumor-oriented treatment possible but refrained from	2 (3)
Tumor-oriented treatment impossible	1 (1)
Other <sup>a</sup>	13 (18)

<sup>a</sup>Unspecified.

<sup>b</sup>Multiple options possible.

<sup>c</sup>Other included ovarian, pancreatic, bladder, esophageal, unknown cancers; cholangiocarcinoma; eye melanoma; and leiomyosarcoma (n = 1 for each).

communication behaviors and helpful alternatives. Patients reported that communication might be potentially harmful in relation to 1) information provision, 2) prognosis discussion, 3) decision-making, and 4) empathy. In terms of helpful communication, many patients commented about the importance of asking questions and exploring patients' needs and preferences.

### Information provision

When information is being provided, communication can be potentially harmful in various ways. First, it can be harmful if information is provided without acknowledging the emotional impact instead of giving the patient some time and exploration space. Second, harm might be experienced when oncologists make vague or even false promises rather than specific promises; this leaves patients

feeling unsettled and insecure. Third, when jargon is used instead of plain language, this can result in difficulty in understanding the situation. Fourth, providing either too much information (which is confusing and overwhelming) or too little (leaving the situation unclear) can be harmful. Helpful communication includes clear, honest, and concrete information and at the same time explores patients' preferences and tailors information provision accordingly:

Harmful vague promise: "Not responding to questions you pose via the electronic record. Not calling back at all. Or saying you'll be called on Friday and then not having time, so you end up spending the whole day waiting." (ID-1021)

Helpful promise: "They should always say when they'll call back. If you don't know when they're going to call, that causes a lot of stress because you're waiting." (ID-1049)

Approach to tailoring information: "Of course there are some people who want to discuss all the test results. A doctor should know or ask whether that's what the patient wants." (ID-1051)

### Prognosis

Patients' perceptions about the potential harmfulness of discussing prognostic information varied. Some found it harmful if (specific) prognostic information was provided because this sort of information is inherently uncertain. Others found it harmful if no or vague prognostic information was provided. Asking patients about their preferences might be helpful. If a prognosis is discussed, it may be helpful to stress the uncertainty for an individual and to take prognostic discussions step by step and mention (positive) outliers:

Harmful lack of prognostic information: "Just saying nothing really isn't on. Certainly when you're just hearing it [for the first time]." (ID-1032)

Harmful specific prognostic information: "Mentioning time frames is tricky. You may get it wrong." (ID-1074)

Helpful exploration: "To what extent is it important for that individual patient to have an indication about their life expectancy? Tailor the answer accordingly, without compromising the reality." (ID-1045)

### Decision-making

Where decision-making was concerned, being too directive was perceived as potentially harmful (eg, using

words such as "you must"). It might be helpful to provide a rationale and to discuss alternative treatment options, including pros and cons. Patients differed as to whether oncologists should provide proactive advice and who should make the final decisions:

Harmful being directive: "You must start your chemo within a certain time." (ID-1014)

Helpful rationale: "[The doctor explaining] \*why\* they advise this, would make the communication less harmful." (ID-1045)

Patients varied in their perceptions about the potential harmfulness of discussing the option of refraining from further aggressive anticancer therapy. Some found it harmful to discuss this while there was still aggressive anticancer treatment available because it took away hope. Others found it harmful if it was not discussed because they felt that it should be presented as an option. If the matter was discussed, patients found it particularly harmful if the oncologist talked in terms of "nothing to be done." Approaches considered helpful were those that focused on what was still possible, stressed that the patient would be continuously supported, and discussed all available options with their pros and cons:

Harmful discussion: "No treatment gives you no hope of living longer—yet hope is what you so badly want, only at the end of the trajectory I would not want any more treatment." (ID-1040)

Harmful no discussion: "All options should be discussed and explained, even if that is difficult." (ID-1020)

Helpful: "I will continue to help you." (ID-1065)

### Empathy

Various behaviors that revealed a lack of empathy were perceived by patients as potentially harmful. These behaviors included 1) not responding to emotions (eg, ignoring them), 2) not listening to the patient (eg, ignoring or downplaying reported complaints), 3) providing premature reassurance, 4) not seeing the patient as a person (eg, focusing only on medical facts) or an individual (eg, not using the patient's name), and 5) complimenting patients on looking good without checking if that matches how they feel. The overarching helpful approach was exploration: exploring patients' emotions, complaints, worries and feelings, psychological functioning, and (unmet) needs. A patient should be seen as a person behind the disease:



Harmful compliment: “In daily life it’s already pretty annoying that everyone is constantly saying you look great. A doctor should know that that’s just on the outside.” (ID-1020)

Helpful compliment: “It’s fine to give compliments. But make sure to conclude with an open question.” (ID-1043)

Harmful not responding to emotions: “Always harmful: ignoring the patient’s reaction.” (ID-1051)

Helpful exploring of emotions: “Are you worried about....? Would you perhaps find it helpful to talk about it with our department’s psychological support counsellor?” (ID-1045)

### Exploration—ask the patient

In line with the aforementioned helpful exploration of patients’ preferences regarding (prognostic) information provision and emotions and needs, exploration seemed an overall precondition for helpful communication. It was deemed helpful if oncologists ask questions and explore 1) what patients already know, 2) what their main (treatment-related) aims and preferences are, 3) what symptoms and complaints they have, 4) whether they have understood the information provided, and 5) whether they have any additional questions:

Helpful: “Asking what the patient themselves view as a possible solution and taking that as the starting point for advice or further discussion.” (ID-1060)

Helpful: “Always probe further. Maybe the patient’s complaints come from an underlying problem.” (ID-1074)

### Table Creation

Quantitative and qualitative results were integrated into a final table depicting the main themes and subthemes of potentially harmful communication, including explanations and concrete harmful/helpful examples (see Supporting Table 2).

## DISCUSSION

Though recognizing that providing difficult and unwelcome news is a core task of clinicians, this study aimed to explore the perspectives of patients with advanced cancer about potentially harmful communication behaviors by oncologists and to suggest helpful alternatives. Our results provide an overview of mainly female breast cancer patient perspectives of how communication can be unnecessarily potentially harmful in the areas of (prognostic) information

provision, decision-making, and empathy. The results reveal preventable behaviors and delicate challenges on which patients’ views varied, and they identify the exploration of each individual patient’s needs and preferences as a precondition for helpful communication. Potential harm can be prevented if patients’ double communication needs are met: their need to know and understand (ie, their need for information and informed decision-making) and their need to feel known and understood (ie, their need for empathy and being seen as a person).<sup>13-15</sup>

Within oncologists’ core tasks of honestly informing and supporting patients, our study highlighted several potentially harmful behaviors that would be relatively easy to prevent. These behaviors center around empathy (eg, informing without empathy, not listening) and concreteness (medical jargon, vague promises) and largely overlap with a recent overview article of communication challenges in advanced cancer.<sup>16</sup> From previous studies, we know that oncologists sometimes miss opportunities to show empathy,<sup>17,18</sup> and this might increase patients’ anxiety.<sup>3,19</sup> If oncologists do not succeed in successfully displaying empathy in advanced cancer care consultations, this can negatively affect patients’ feelings of satisfaction and their information recall.<sup>4,17,20</sup> These findings highlight the need for oncologist-expressed empathy, which can ensure the prevention of unnecessary potential harm. Empathy can be demonstrated by behaviors such as NURSE (naming, understanding, respecting, supporting, and exploring emotions) responses,<sup>13,21</sup> providing space after breaking bad news,<sup>22</sup> using questions to make patients feel heard,<sup>21</sup> and listening<sup>23</sup> to establish patient-centered cancer care.<sup>24</sup> The other area in which patients perceived preventable harmful behavior was communication lacking concreteness. It is known that (even well-educated) patients can misunderstand medical terminology<sup>25</sup> and information provided,<sup>26-28</sup> and the uncertainty of vague promises (eg, “I will call you tomorrow”) can increase patients’ anxiety.<sup>29</sup> These findings highlight the opportunity for oncologists to check whether a patient has understood the information provided (“teach-back”<sup>30</sup>) and to provide a concrete call appointment, including a timeslot, to prevent unnecessary harm.

Other delicate challenges require an individualized approach in our era of ever-increasing precision medicine (eg, how much [prognostic] information to provide, how directive to be in the decision-making process, and how to introduce, or not introduce, the topic of refraining from anticancer therapy). Where the amount of information is concerned, our findings overlap with previous results reporting that both too much information (being overwhelming and confusing<sup>21,31</sup>) and too little information

(leaving the situation unclear and increasing anxiety<sup>32</sup>) may be perceived as potentially harmful. Prognostic preferences particularly vary.<sup>33,34</sup> Most patients, but not all, want to receive (some) information.<sup>35,36</sup> Checking patients' (prognostic) information preferences, which can change over time,<sup>37,38</sup> seems essential,<sup>21,39</sup> and tailoring can be achieved with questions such as "Would you like to talk about what this (scan) result means?"<sup>40</sup> When it comes to the decision-making process, a paternalistic decision-making style<sup>21</sup> especially may be perceived as potentially harmful, although patients vary on how actively they want to be involved in decision-making.<sup>41</sup> What might be helpful here is to emphasize to patients that people vary and again to ask about their preferences.<sup>21</sup> Lastly, it remains unclear whether patients perceive it as potentially harmful to discuss, or harmful not to discuss, the option of refraining from anticancer therapy. In clinical care, oncologists do not always discuss it<sup>42</sup> and quickly focus on additional treatment options,<sup>43</sup> perhaps because they see it as an inferior option,<sup>44</sup> which is at odds with their duty to discuss all possible treatment options.<sup>45,46</sup> Although the option of no aggressive anticancer treatment needs to be carefully introduced at a certain point in time, patients in our study and other studies<sup>33,47</sup> seemed to disagree on whether it should be discussed early (ie, while there is still aggressive anticancer treatment available) or not. Moreover, most patients in our study agreed that it was harmful if oncologists mentioned that there was nothing to be done. This suggests that the harmful blow of raising the option of refraining from anticancer therapy could perhaps be softened by focusing on what is still possible (eg, symptom-oriented treatments) and providing reassurance that the patient will not be abandoned.

A recurring suggestion for overcoming the aforementioned delicate challenges seems to be to explore each individual patient's needs and preferences. We found that exploration was helpful not only for addressing patients' varying information preferences but also as a means to make communication more helpful in general (eg, by exploring what patients know, want to know, and understand and what they are aiming for). This reflects the essence of patient-centered care: receiving care and information tailored to each individual's needs and preferences.<sup>48,49</sup> Two key skills are noteworthy and valuable for making communication more helpful: asking and listening.<sup>21,23</sup> Although these recommendations are certainly not new (see Back<sup>16</sup>) in clinical care, physicians sometime encounter difficulties in exploring patients' preferences when discussing difficult topics, and patients sometimes do not dare to ask questions (the collusion principle).<sup>21,50</sup>

Our study has limitations. First, our sample was limited in terms of quantitative sample size and representativeness (mainly female patients with breast cancer participated). This limits the generalizability of the results, although the cancer type was not related to the perceived potential harmfulness of situations (data not shown). Second, although there were no comments about patients strongly disagreeing with specific situations/examples, we could have asked for this specifically. Third, a more nuanced answer scale trying to distinguish harm from preferences could have yielded different results. Fourth, inclusion was based on self-assessment, so despite various safeguards, patients without incurable cancer could have participated. Lastly, insight is lacking into how often potentially harmful behaviors occur and what their effects are on patient-reported outcomes. Future studies should overcome these limitations and disentangle which specific behaviors can negatively influence which patient outcomes and for which patients. These insights can be used to observe clinical interactions in a standardized way and, more importantly, to improve clinical care (eg, via evidence-based training) to ultimately benefit patients. Existing training courses that offer a good starting point for this training include VitalTalk<sup>51</sup> and the Serious Illness Guide from Ariadne Labs.<sup>52</sup>

In conclusion, we provide a unique patient perspective on oncologists' unnecessarily potentially harmful communication behaviors and offer practical tools to overcome them in advanced cancer. We describe both preventable pitfalls (eg, *patient vs Ms X*) and delicate challenges requiring an individualized approach (eg, introducing the option of refraining from anticancer therapy) where exploration might help. Although providing difficult and unwelcome news is a core task of clinicians, our study might help them in doing so while preventing unnecessary potential harm.

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## CONFLICT OF INTEREST DISCLOSURES

Liesbeth M. Van Vliet is a board member of the Dutch Society for Psychosocial Oncology (unpaid) and a deputy national representative for the European Association for Communication in Healthcare (unpaid). The other authors made no disclosures.

## AUTHOR CONTRIBUTIONS

**Janine Westendorp:** Investigation, data curation, project administration, formal analysis, writing—original draft, and writing—review and editing. **Andrea W. M. Evers:** Conceptualization, analysis, and writing—review

and editing. **Jacqueline M. L. Stouthard:** Conceptualization, analysis, and writing—review and editing. **Janneke Budding:** Conceptualization, analysis, and writing—review and editing. **Elsken van der Wall:** Conceptualization, analysis, and writing—review and editing. **Nicole M. F. Plum:** Conceptualization, analysis, and writing—review and editing. **Mirjam Velting:** Conceptualization, analysis, and writing—review and editing. **Anneke L. Francke:** Conceptualization, analysis, and writing—review and editing. **Sandra van Dulmen:** Conceptualization, analysis, and writing—review and editing. **Tim C. olde Hartman:** Conceptualization, analysis, and writing—review and editing. **Liesbeth M. Van Vliet:** Conceptualization, funding acquisition, data curation, supervision, project administration, formal analysis, writing—original draft, and writing—review and editing.

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