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A MULTI-METHOD APPROACH

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Communicating personalized risks to patients with cancer:
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Lose your dreams and you
will lose your mind

– Ruby Tuesday, The Rolling Stones

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General introduction

When someone is diagnosed with a life-threatening disease such as cancer, difficult decisions need to be made about the first treatment. For instance, men diagnosed with localized prostate cancer must decide in close consultation with their physician between surgery and several alternatives like radiotherapy or active surveillance. Similarly, women with early-stage breast cancer must decide on what type of surgery to undergo, choosing between mastectomy or breast conserving treatment such as lumpectomy combined with radiotherapy. In both cases, treatment options have comparable survival rates, but differ in the risks of adverse outcomes such as side effects or impact on quality of life[1,2]. Therefore, it is crucial that patients understand the associated risks and benefits of treatments, and that healthcare professionals use effective ways for communicating these to their patients.

However, communicating risks and other cancer statistics is an inherently difficult task. To illustrate this, imagine a 52-year-old patient, John, who has the unfortunate circumstance of being diagnosed with localized prostate cancer. He wrestles with the choice between surgery and radiotherapy, with each having its pros and cons. He visits the urologist who says to him:

> *"The chance that you will survive for five years with surgery or radiotherapy is, on average, about 95%. However, each treatment has specific risks of side effects that can impact your quality of life. As far as we know from the literature, for surgery there is a 60% risk of experiencing urinary leakage, and a 76% risk of having difficulties with erections. For radiotherapy, these side effects are not so very common, but I must say there is a higher risk of having bowel problems."*

This (fictious) example shows that discussing risk and benefit statistics is challenging for both urologist and John. The urologist can use different message formats for conveying different statistics to his patient, using numbers (e.g., percentages), words (e.g., "For radiotherapy, these side effects are *not so common*"), and relative risk descriptions (e.g., "*higher* risk of having bowel problems"). The patient, John, is being bombarded with unfamiliar statistics, such as survival rates and various risks of experiencing treatment side effects, which may be difficult to understand and appreciate, especially when having low numeracy or health literacy skills. What, for instance, does a 60% risk of urinary leakage really 'mean', and what is John supposed to do with that number? One issue that makes the communication of risks statistics even more challenging for the urologist and John is that they are typically *generic* and based on *all* patients with prostate cancer from clinical studies. However, John is not the average patient (and nobody is), and he finds it difficult to evaluate and use those generic numbers in his individual situation. Is John adequately informed? What would happen if this urologist could communicate more *personalized* risk information by utilizing unique characteristics of John such as his age, physical condition, and the type of tumor? This dissertation focuses on such personalized risk statistics, and

specifically explores how they can best be communicated to patients, and whether patients need, understand, and use those statistics when making complex decisions about treatment.

SHARED DECISION-MAKING AND PATIENT DECISION AIDS

Ideally, decisions about treatment after a cancer diagnosis should be *shared* decisions during which the healthcare professional and patient jointly decide about the course of action[3,4]. This process of shared decision-making is particularly important for patients with cancer who are facing preference-sensitive decisions, indicating that the 'best' option depends on patients' preferences and the relative weight they put on the risks and benefits. In case of the patient from the hypothetical example, all treatment options had comparable survival rates, and therefore the differences in risks of adverse effects and personal circumstances are central to his treatment choice.

Over the years, several theoretical models have been proposed to explain the process of shared decision-making, with the three-talk model prominent among them[5,6]. According to this model, shared decision-making is a collaborative approach consisting of three interconnected stages or talks between the patient and healthcare professional(s): (1) team talk, aimed at explaining the disease, possible treatment options, and potential consequences, (2) option talk, aimed at weighing all risks and benefits of treatment options using risk communication principles, together with eliciting personal preferences and values of the patient, and (3) decision talk, aimed at making a final decision about treatment in line with preferences and values of the patient. The content of each stage is summarized in Figure 1. In general, shared decision-making is associated with improved satisfaction with received care and less decisional conflict[7], and with patients being more inclined to choose less invasive treatments[8,9]. However, the process of shared decision-making is challenging as well, and patients vary in the extent to which they want to be actively involved in the shared decision-making process[10].

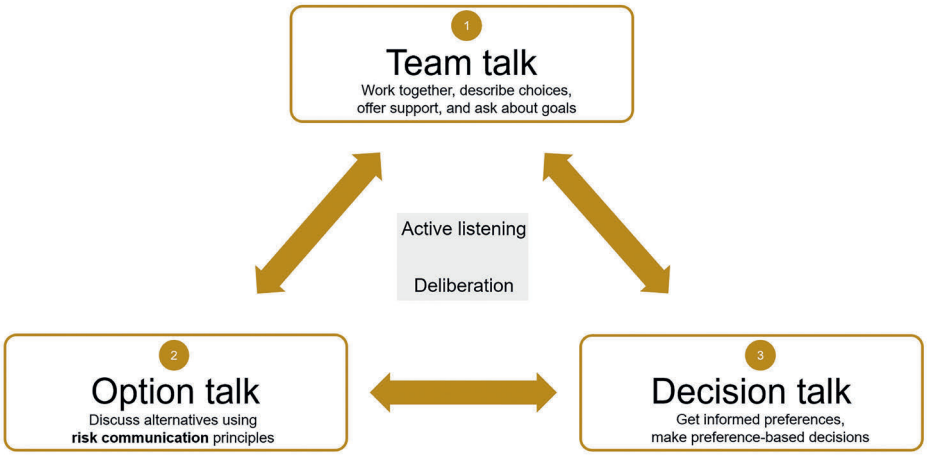

Figure 1 | Adapted version of the three-talk model of shared decision-making developed by Elwyn and colleagues[6].

Decision aids may facilitate the process of shared decision-making between healthcare professionals and their patients[11]. Decision aids are a type of decision support tool (aimed at patients and distributed by healthcare professionals) that may come in many different formats, ranging from booklets and videos to websites. The main aims of decision aids are to provide structured and balanced information about treatment options and associated outcomes such as risks of side-effects, survival, or disease recurrence, and to help patients clarify their values and preferences[12]. Moreover, decision aids should encourage patients to actively participate in the shared decision-making process with their healthcare professional[4]. A large number of randomized controlled trials show that decision aids make patients more knowledgeable about treatment options, and improve decision quality and the decision-making process[11]. Despite great promise and the increasing interest in developing decision aids, such tools tend to be generic and lack personalized information of risk and benefit statistics associated with treatment options. Moreover, the extent to which decision aids are implemented into daily clinical practice appears to be limited[4,13].

RISK COMMUNICATION

An important ingredient of shared decision-making and decision aids involves the discussion of potential risk and benefit statistics of treatment options[14,15]. Particularly the "option talk" stage often requires healthcare professionals and decision aids to communicate complex numbers such as probabilities and statistics to patients (Figure 1)[6]. The hypothetical example demonstrates that patients need to be informed about the chances of favorable outcomes (e.g., 95% five-year survival after treatment), or

about the risks of experiencing adverse outcomes (e.g., 60% risk of urinary leakage after surgery) after treatment. *Risk* is a key concept throughout this dissertation, but multiple definitions exist. This dissertation focuses on known risks, and defines risk as the objective likelihood or chance of experiencing (negative) events[16,17]. As opposed to uncertainties (i.e., unknown risks), known risks are probabilities that are based on measurable frequencies, specifically by counting the number of patients who experience side effects after treatment divided by the total number of patients who received that treatment[15]. Inspired by Lipkus, this dissertation broadly defines *risk communication* as the communication with individuals that addresses knowledge, perceptions, attitudes, and behavior related to risk and other statistics (e.g., survival)[16]. The ultimate goal of risk communication is to translate risk data (i.e., probabilities) into risk meaning (i.e., accurate perceptions and understanding), and then into risk actions (i.e., informed decision-making).

However, communicating risks and statistics during shared decision-making is a complex task that comes with several challenges[17]. First, the message format in which the risks are being presented to patients could impact their perceptions, understanding, and use: some risks come with words (e.g., "For radiotherapy, these side effects are not so common") and others with numbers. These formats, however, have several drawbacks. Communicating risks verbally, for instance, may lead to inaccurate risk perceptions, as people may have different interpretations of verbal probability statements[18,19]. In addition, when using numbers such as percentages, misinterpretations may arise as well, especially when they are being communicated without specifying the reference class. In that case, patients may have different interpretations of the risk: some believe they experience urinary leakage 60% of the time, while others think that 60% of the patients will experience the side effect[20]. A second challenge relates to the low evaluability of risks, as unfamiliar numerical information in health often lacks inherent meaning, thereby making it difficult for patients to evaluate whether they are good or bad[21]. Third and finally, some patients have inherently more difficulties than others in understanding and applying numerical information and mathematical concepts (i.e., numeracy skills)[22]. Indeed, it is much more difficult for patients than for healthcare professionals to weigh the pros and cons of different treatment options and to 'translate' risk statistics to their personal situation. Given these challenges, patients (but also healthcare professionals) might misinterpret both quantitative and qualitative risk information[23], which in some cases may even lead to different behavioral and decision-making outcomes; a scenario that is highly undesirable during shared decision-making.

To overcome these challenges, multiple risk communication guidelines and best practices have been developed for the delivery of risk and other statistical information to patients[14–16,23–28]. Regarding the first challenge (choosing the message format), a key recommendation includes the use of quantitative, numerical information whenever possible, preferably by using natural frequencies instead of percentages (e.g., "Out

of 100 patients that take this treatment, 76 may suffer from erectile dysfunction", rather than saying "76%"), as they are always specifying the reference class to which the statistics apply. In addition, following dual coding theory[29], presenting health information in multiple formats (words, numbers, and visuals) improves processing by reducing cognitive load and may therefore be helpful in promoting understanding, especially for less numerate people[30]. Consistent with this theory, several studies suggest that presenting risks in visual formats (e.g., icon arrays or "pictograms," bar graphs) improves processing and understanding[25,31,32], although evidence on which type of visual format works best is mixed[33–35]. To tackle the second challenge (low evaluability), several strategies are recommended such as using evaluative labels (e.g., telling patients how good or bad a 60% risk is) or providing comparative data on other risks (e.g., risk ladders)[15,17]. Following theory on "information evaluability"[36,37], providing such contextual information may improve evaluability by helping patients to derive meaning from unknown risk information[21]. Finally, the third challenge (individual differences) can be dealt with by recognizing limitations in numeracy, health literacy, and/or graph literacy[15,24]. For this, simplicity and targeted evaluative explanations are of utmost importance when designing risk messages[28]. Despite these major efforts in developing and using evidence-based information presentation formats for effectively communicating risks in a way that is meaningful and useful to patients, one important issue remains.

PERSONALIZED RISKS

A critical issue with risk and survival statistics communicated by healthcare professionals, decision aids, or general cancer websites for patients is that they are typically *generic* and non-personalized. This means that those statistics often represent averaged data over *all* participants with a particular type of cancer. For instance, in the case of the 52-year-old patient John diagnosed with localized prostate cancer described in the hypothetical example, the generic statistics (e.g., 60% risk of urinary incontinence, 95% chance of survival) may be of limited value since they are based on the entire group of men with (localized) prostate cancer, typically consisting of mostly substantially older men, whose data were obtained from randomized controlled trials or observational datasets. This makes it challenging for healthcare professionals and decision aids to relate generic treatment outcomes to individual patients, but also for patients like John to translate and apply the generic risk information to their individual situation, which is clearly undesirable for shared decision-making involving unique patients. Moreover, one might even ask the question whether it is ethical to provide patients with generic information based on the "average patient", given our knowledge that certain personal and clinical characteristics of patients may be associated with certain treatment outcomes[38].

With the growing emphasis on personalized medicine[39], patient centered outcome research, together with the growing availability of "big health data" (cancer registry or patient reported outcome data)[40,41], more *personalized* risks can be provided to patients. Personalization can be described as "the strategic creation, modification, and adaptation of content and distribution to optimize the fit with personal characteristics, interests, preferences, communication styles, and behaviors. It can be understood as a dynamic process, with the interactive, technological, data-mediated relationship between the sender of a personalized message and its receiver at its heart." (p. 373)[42]. In light of risk communication during shared decision-making, personalized risk estimates take into account personal (e.g., age, gender) and clinical (e.g., tumor type, stage, size, co-morbidities) characteristics that are unique to an individual patient[24], which in turn are compared with specific patient groups with similar characteristics, thereby providing patients with more specific and individualized risk information of treatment outcomes[43] (Figure 2). In the case of the 52-year-old John with localized prostate cancer, his data could be compared with a subset of comparable men, typically younger men, thereby providing more specific, personalized risks. In recent years, there has been increasing interest in the development of clinical prediction models – statistical algorithms that use patient and clinical characteristics for estimating personalized risks of health outcomes[44–48]. Even though personalized risks will likely become increasingly common in clinical practice[24], they are typically "doctor-driven" and hence not easily understandable and accessible for patients, and guidelines for effectively communicating personalized risks to individual patients are currently lacking.

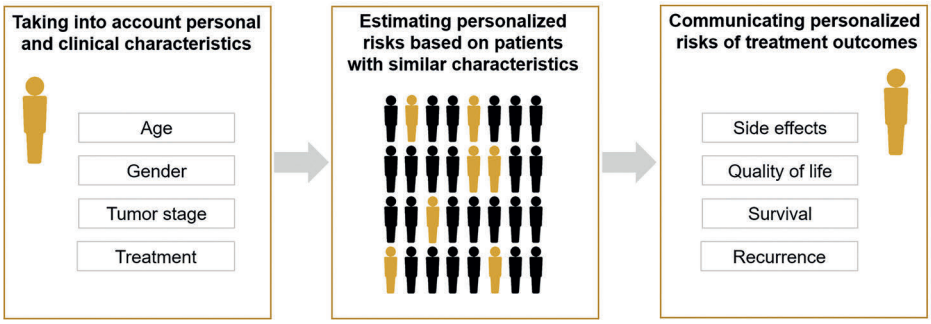

Figure 2 | Schematic representation of personalized risk information.

Personalization of health risk data fits well within research on 'tailoring' of health information, a strategy that has been applied in different health domains, such as interventions designed for smoking cessation[49,50] or for informing patients with cancer[51]. Following the elaboration likelihood model[52] and theoretical models on tailored health communication[53–56], personalized health information is typically perceived as more relevant than generic health information, which in turn increases the

likelihood that patients will process the information more deeply, resulting in better recall. Extensive research on personalization has focused on examining the effects of personalization at the level of the content to individual needs and preferences (e.g., providing pregnant women with information about the effects of smoking for their unborn child)[49], or how the information is being presented, either by adapting the mode of delivery (e.g., presenting information via texts, illustrations, and/or videos)[51] or using different message frames (e.g., adapting communication style based on people's needs)[50]. However, less attention has been paid to the effects of personalizing health risk data and other relevant statistics such as survival or recurrence rates. So far, only in the (cancer) screening context, is has been shown that personalized cancer risk information may help patients make better informed decisions, as evidenced by increased knowledge and more accurate risk perceptions[57,58]. In sum, as theory on tailoring posits that personalized health information is more likely to be considered as personally relevant and hence be read (which in turn can lead to higher levels of engagement and information recall), the question is how patients perceive, evaluate, and use personalized risk information about treatment outcomes in the context of shared decision-making.

DISSERTATION AIMS AND OUTLINE

The main aim of this dissertation is to gain insight into how personalized risks and other cancer statistics can best be communicated to patients with cancer in the context of shared decision-making about treatment. The central research question in this dissertation is **whether and how personalized risks of treatment options and cancer statistics can best be communicated to patients with cancer.** To answer this question, this dissertation consists of seven studies in total, grouped under four parts with each addressing its own aim:

(1) To review how patient decision aids currently communicate (personalized) risks of treatment options to patients with cancer;
(2) To assess patient needs and preferences for communicating personalized risks and other cancer statistics;
(3) To test the effects of different message formats and strategies for communicating personalized risks on patient's cognitive, emotional, and behavioral outcomes;
(4) To observe how healthcare professionals communicate personalized risks of treatment options to patients with cancer, and to explore how these patients, in turn, use and perceive personalized risks during treatment decision-making.

This dissertation contributes to the literature on shared decision-making, risk communication, and personalization in several ways. First, to answer the central research question and associated aims, this dissertation adopts a multimethod approach by conducting a range of different methodologies: systematic reviews,

focus groups, think-aloud observations, semi-structured interviews, a cross-sectional survey, observational, and experiments. Second, while the studies described in this dissertation are theoretically driven, the findings have broad implications for clinical practice including healthcare professionals, decision aid developers, and general cancer website, all aimed at communicating personalized risks statistics to newly diagnosed patients with cancer or cancer survivors. Third, participants in this dissertation were recruited from different samples, ranging from newly diagnosed patients and survivors from hospitals, cancer panels, and patient organizations, to healthy participants from a representative sample of the Dutch population. Fourth, to safeguard the reproducibility and reliability of this dissertation, three studies were preregistered within the Open Science Framework prior to data collection (research questions, hypotheses, and statistical analyses), and the data were made publicly available (https://osf.io/us6xb/). Fifth and finally, all chapters represent empirical studies on their own, which have been presented at international peer-reviewed conferences, and have either been published in (Chapters 2, 3, 4, 6, and 8) or submitted to international peer-reviewed journals (Chapter 5 and 7). It should be noted that those articles have their own abstract, introduction, methods, results, and discussion, and therefore some overlap in content may exist.

Following earlier work on uncertainty communication[59], the four aims of this dissertation and seven chapters are structured around Lasswell's model of communication addressing *who* communicates *what, in what form*, to *whom* and to *what effect*[60]. More specifically, factors related to the *who* are people or tools that provide the actual communication, in this case healthcare professionals and patient decision aids; factors related to *what* is being communicated are personalized risks of treatment side effects and other cancer statistics (e.g., survival rates); factors related to the *form* of the communication are different message formats (e.g., words, numbers, visuals) and contextual strategies (e.g., comparative risk information). Factors related to *whom* is being communicated include patients with cancer, cancer survivors, and healthy individuals of the general population, also addressing individual differences such as subjective numeracy, health literacy, or graph literacy skills. Finally, factors related to *what effect* personalized risk have on patients are cognitive (e.g., risk perception, (accuracy of) risk estimates), emotional (e.g., affective evaluation), and behavioral (e.g., treatment choice) outcomes. Each chapter describes one study and touches upon three or more aspects of Lasswell's model of communication (Figure 3).

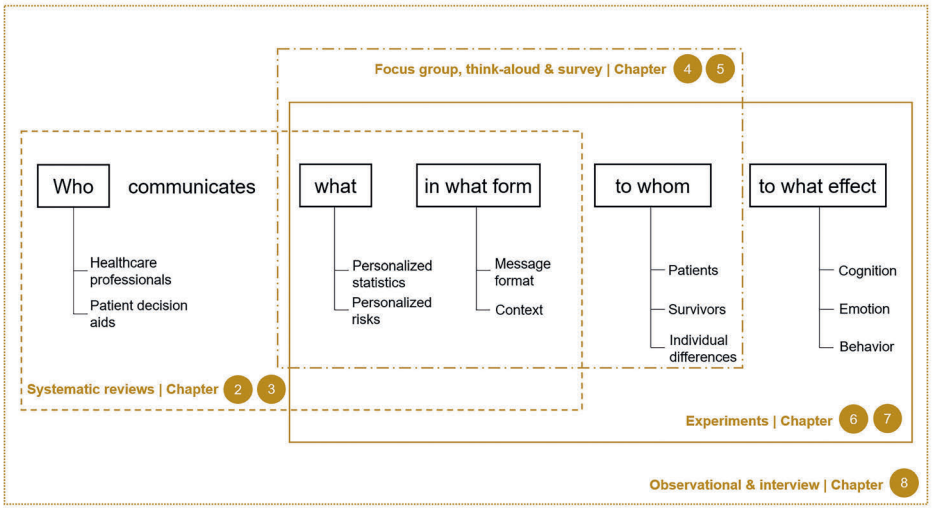

Figure 3 | Overview of studies in the context of the Lasswell model of communication[60].

PART 1:

Reviewing risk communication in decision aids – Who communicates what in what form?

This dissertation starts with two systematic reviews on (risk) communication in patient decision aids for localized prostate cancer (**Chapter 2**) and early-stage breast cancer (**Chapter 3**) treatment, in which we focused on the *who*, *what* and *in what form* components (dashed framework in Figure 3). More specifically, in both chapters the aims are to (1) make an inventory of currently available international patient decision aids ($n = 40$), and to (2) critically assess their quality in terms of information and use of communication. The information quality is assessed by means of the International Patient Decision Aids Standard (IPDAS) checklist, and the use of communication by a newly developed communicative aspects checklist, which focuses on aspects such as information presentation (e.g., which message formats decision aids use for presenting information about treatment options and associated risks of adverse effects to patients), interaction (e.g., how decision aids interact with patients to elicit their values or preferences), and personalization (e.g., to what extent decision aids provide patients with personalized risk information based on personal and disease-related characteristics).

PART 2:

Assessing patient needs and preferences – What to communicate in what form to whom?

The section that follows focuses on the question (1) whether, how, and for whom risks and other cancer statistics should be personalized, and (2) how healthcare professionals and decision aids should communicate such information to patients, thereby focusing on the *what*, *in what form*, and *to whom* components (long dashed dotted framework in Figure 3). Specifically, **Chapter 4** describes a qualitative multimethod study among breast cancer and prostate cancer survivors. First, two focus groups (n = 13) are conducted for collecting group data on survivors needs and preferences, using non-interactive sketches of what a tool for communicating personalized cancer statistics might look like. These insights serve as input for a revised interactive tool, which is designed to further explore the needs and preferences of another group of cancer survivors (n = 11) during individual think-aloud observations and semi-structured interviews. To obtain quantitative information on patient needs, **Chapter 5** describes a pre-registered cross-sectional survey on the assessment of needs for receiving personalized and generic statistical information during treatment decision-making in breast, colon, lung, and prostate cancer survivor (n = 174). In addition, it is examined how individual differences such as information coping style (actively seeking or avoiding information), subjective numeracy, or levels of anxiety, relate to these needs. Additionally, survivors' considerations for (not) wanting personalized or generic statistical information are qualitatively explored.

PART 3:

Testing different formats – Communicating in what form to whom to what effect?

This dissertation continues with two pre-registered experimental studies that examine how varying presentation formats of personalized risk information can influence people's perceptions, evaluations, and use of such risks, thereby concentrating on the *form*, *whom* and *effect* components of the communication model (solid framework in Figure 3). Specifically, **Chapter 6** reports an experimental study among patients and survivors (n = 141) recruited from a Dutch online cancer patient panel, in which the impact of personalized risks (vs. generic risks) on patients' risk interpretations is investigated, as well as through which message format (words-only vs. words and numbers combined) the risks should be best communicated. **Chapter 7** presents another experimental study, this time among healthy participants from a representative sample of the Dutch population (n = 1,807), which is aimed at (1) determining the effect of providing comparative risk information of personalized treatment outcomes on people's cognitive (risk perception and risk estimates), emotional (affective evaluations), and behavioral (treatment choice) responses; (2)

investigating whether processing of comparative risk information would be affected by whether it is presented in a numerical-only or numerical+visual format; and (3) examining whether the effects differ for people with different sociodemographics, and different levels of subjective numeracy, health literacy, and graph literacy.

PART 4:

Bringing it together during shared decision-making – Who communicates what in what form to whom to what effect?

The final study of this dissertation (**Chapter 8**) covers all components of the communication model (dotted framework in Figure 3). The aim of this study is to observe how healthcare providers, in this case urologists and nurse practitioners, communicate personalized risks of treatment side effects to newly diagnosed patients with localized prostate cancer ($n = 27$). For each patient, the consultation (concerning treatment options and associated risks) with both their nurse practitioner and urologist are audiotaped, transcribed verbatim, and coded. Relying on the coding scheme used in part 1, risk communication utterances by healthcare professionals are assessed in terms of the message formats used, how personalized risks are exactly explained to patients, and how uncertainty is revealed. Furthermore, using semi-structured interviews, it is explored whether and how these patients, in turn, perceive, understand, and use personalized risks when making a decision about treatment.

In the final chapter of this dissertation (**Chapter 9**), the general findings and theoretical implications are discussed in broader context. Based on these reflections, future directions and recommendations for both research and clinical practice are proposed to further facilitate treatment decision-making in daily cancer care, and to answer the question how best to communicate personalized risks of treatment options to patients with cancer.

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PART 1

Reviewing risk communication in decision aids

Who communicates what in what form?

2

Communication in patient decision aids for localized prostate cancer treatment: A systematic review

This chapter is based on:

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ABSTRACT

Context: Despite increasing interest in the development and use of decision aids (DAs) for patients with localized prostate cancer (LPC), little attention has been paid to communicative aspects (CAs) of such tools.

Objective: To identify DAs for LPC treatment, and review these tools for various CAs.

Materials and methods: DAs were identified through both published literature (MEDLINE, Embase, CINAHL, CENTRAL, and PsycINFO; 1990-2018) and online sources, in compliance with the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) guidelines. Identified DAs were reviewed for the International Patient Decision Aid Standards (IPDAS) criteria, and analyzed on CAs, including information presentation, personalization, interaction, information control, accessibility, suitability, and source of information. Nineteen DAs were identified.

Results: IPDAS scores varied greatly among DAs. Crucially, substantial variations in use of CAs by DAs were identified: (1) few DAs used visual aids to communicate statistical information, (2) none were personalized in terms of outcome probabilities or mode of communication, (3) a minority used interactive methods to elicit patients' values and preferences, (4) most included biased cross-tables to compare treatment options, and (5) issues were observed in suitability and accessibility that could hinder implementation in clinical practice.

Conclusions: Our review suggests that DAs for LPC treatment could be further improved by adding CAs such as personalized outcome predictions, and interaction methods to the DAs. Healthcare professionals who are using or developing such tools might therefore consider these CAs in order to enhance patient participation in treatment decision making.

INTRODUCTION

Men newly diagnosed with localized prostate cancer (LPC) are facing difficult decisions regarding treatment. They need to choose from a range of treatment options (e.g., surgery, external beam radiotherapy, brachytherapy, or active surveillance)[1], which have equivalent survival outcomes but differ in the risk of adverse outcomes[2,3]. This scenario calls for shared decision making (SDM), a three-step process by which a healthcare professional and patient (i) discuss treatment options, (ii) compare risks and benefits, and (iii) make sure that the final decision is preference-based[4,5]. SDM may involve decision aids (DAs), which are tools (e.g., booklets or websites) that provide balanced information about options and the associated risks and benefits, and help patients to clarify values and preferences and how to communicate these with their healthcare professional[6]. Today, there are hundreds of patient DAs in various health domains, ranging from cancer to heart disease[7]. Even though DAs have potential[7], systematic reviews have shown variability in the effects of DAs for LPC treatment on decisional outcomes (including decisional conflict and knowledge) and treatment choice[8–10].

An explanation for the inconsistent effects may be that DAs have been developed and implemented without taking into account the *communicative process* in which SDM occurs[11]. Classic models of this process assume that communication requires a *sender* and a *receiver* who are exchanging *information* through a certain *channel*[12]. In addition, this communication process can involve aspects such as *feedback* (i.e., the receiver's response to a message) or *noise* (i.e., anything not intended by the sender). Seen from this perspective, SDM is a similar two-way communicative process in which both healthcare professional and patient convey and receive messages through available channels in order to reach a decision regarding treatment[13]. Indeed, communication models of SDM also acknowledge the role of DAs in this communication process[14]. Therefore, it is important to look into communicative aspects (CAs) of DAs that could potentially influence elements of the communication process between healthcare professional and patient.

These CAs include, first of all, the *channels* through which DAs communicate to patients, which can either be unimodal (e.g., using text or pictures alone) or multimodal (e.g., using text with pictures or audiovisual information)[15–17]. The latter is particularly important for complex topics such as explaining surgical procedures or statistical information[18,19]. Another aspect is that DAs can signal information based on *interactions* with the patient, for instance, by clarifying values or preferences, or by providing *personalized information* for a specific receiver based on input of that receiver[20,21]. Moreover, information provided by DAs may also be less *suitable* or *accessible* because of various forms of *noise* such as complex language use (e.g., jargon), or biased presentations of risks and benefits of treatments[22]. Despite the importance

of communication characteristics of DAs, no research exists that has systematically reviewed such patient tools for LPC treatment from a communication point of view. When reviewing the quality of DAs, researchers often make use of a standardized quality checklist developed by the International Patient Decision Aids Standards (IPDAS) Collaboration[6,23]. Nevertheless, even though the IPDAS checklist is seen as the golden standard for developing and evaluating DAs[24], it is also important to consider other aspects of the communication process that are not covered by the IPDAS. Until now, only one systematic review by Adsul and colleagues has reviewed the quality of DAs for LPC treatment by using additional items related to implementation (e.g., health literacy)[25]. Although their results lead to a global understanding of the variability in characteristics and quality of DAs, more in-depth analyses of some CAs are still required to get a more complete understanding of DAs as a communicative tool in the context of SDM.

The objectives of this review are to (1) systematically identify currently available DAs for LPC treatment through both academic and online sources, (2) review these tools for IPDAS criteria and, crucially, (3) assess them on a range of aspects deemed to be important for the communication process. By doing so, this review will both update and extend previous work[25], and will also take a closer look at various CAs of DAs.

METHODS

This systematic review was reported in compliance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines[26].

Data sources and search strategy

A systematic search of *published literature* and *online sources* was performed in order to identify and obtain DAs for LPC treatment. To identify DAs through published literature, we searched the following databases: MEDLINE (via PubMed), EMBASE, Cochrane Library, The Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO. Databases were searched from 1990 to 2018. Reference lists and author names were searched to identify additional publications that met the eligibility criteria. The search strategy was developed in collaboration with an experienced research librarian, and included a combination of keywords, synonyms, and MeSH headings relating to the concepts of LPC, DAs, SDM, and treatments (Appendix A). To identify DAs through online sources, we searched two international web repositories: The Ottowa Decision Aid Library Inventory and The International Database for Support in Medical Choices (Med-Decs). An additional Internet search using Google™ was conducted in both Dutch and English for which the first 100 hits were analyzed.

Study and decision aid eligibility

Studies were included if the research was reported in a scientific journal (peer-reviewed), published between 1990 and 2018, and written in English or Dutch. Study types eligible for inclusion were (protocols of) randomized controlled trials or (quasi) experimental studies that addressed the impact of DAs as intervention on a variety of decisional outcomes or treatment choice. In addition, studies that described the developmental and/or evaluation of DAs (e.g., developmental studies, evaluation/usability testing studies, and observational studies) were also included. Target audiences of studies included newly diagnosed patients with LPC facing treatment decision making, as well as patients with early-stage or low/intermediate-risk prostate cancer. DAs developed for men with advanced prostate cancer or Prostate-Specific Antigen screening were excluded. DA formats included paper-based (e.g., hardcopy booklets, or pamphlets), web-based (e.g., Internet websites), computer-based (e.g., computer programs, CD-ROMs) or video-based (e.g., video-tape or DVD). However, DAs in the format of phone calls, online support groups, interviews, nomograms or audiotapes were excluded, since such formats could not be analyzed. Finally, only DAs that were (publicly) accessible, referred to at least two treatments, and were written in English or Dutch were included.

Study and decision aid selection

A first reviewer (RV) screened all retrieved articles for relevance based on title and abstract for initial eligibility, after which a second reviewer (GG) screened a package of 10% of the articles that consisted of a mix of included/excluded studies judged by the first reviewer (RV). The overall kappa score for inter-rate agreement was strong ($\kappa = .90$)[27]. Afterwards, disagreements were resolved through discussion or adjudication by a third person. Subsequently, two reviewers (RV, ME) independently evaluated the articles that passed the previous screening phase based on the eligibility criteria using a pre-defined criteria form ($\kappa = .96$), and disagreements were resolved through discussion and consensus between the two reviewers. Once a study had been included, one reviewer (RV) contacted the study authors for obtaining permission to request and review a copy of the DA (or to get full access to the DA).

Assessment of decision aids

The assessment of the identified DAs consisted of two parts. DAs were first reviewed for the IPDAS criteria, after which they were critically analyzed on a range of CAs. For both checklists, we carried out extensive pilot testing and discussions in order to make sure that every reviewer interpreted the items in the same way. Six teams of two coders each were responsible for reviewing one sixth of the DAs. Thus, each DA was independently assessed by two coders. Inter-rate agreements (κ) achieved by the teams ranged from .80 to .82 for the IPDAS checklist, and from .81 to .93 for the assessment of CAs.

IPDAS

The IPDAS instrument[23] consisted of 36 items divided into eight dimensions (Appendix B): information about options, outcome probabilities, clarifying values, decision guidance, development process, using evidence, disclosure and transparency, and plain language. Since not all DAs had associated studies, we decided to exclude the items related to the evaluation dimension. Response options for each criteria item were 'yes' and 'no' (coded as 1 and 0 respectively). For each DA, the number of IPDAS items met was converted to percentages of the total number of items.

Communicative aspects

Given that there was no validated CA checklist available for DAs, we developed a new checklist. We first selected aspects from the communication model by Shannon and Weaver[12] in order to determine the following seven CAs: (i) information presentation (derived from *channel*), (ii) personalization (derived from *message*), (iii) interaction (derived from *interaction*), (iv) information control (derived from *feedback*), (v) accessibility (derived from *noise*), (vi) suitability (derived from *noise*), and (vii) source of information (derived from *source of information*). We then generated a list of 76 items, which were partly derived from an existing checklist[25], and were supplemented with items from reviews about (communicative) features of DAs[28,29] and from the Suitability Assessment of Materials checklist[30]. These items were subsequently divided into the seven CAs (Appendix C).

Information presentation contained items that focused on the channels used to communicate different types of information (e.g., verbal descriptors, numbers, or visual aids), but also on how treatment comparison was realized. *Personalization* comprised items related to how the information was tailored towards the patient (e.g., tailoring outcome probabilities or content). *Interaction* contained items that concerned how the interaction between the DA and the patient was established (e.g., interaction methods used to clarify personal values and preferences), for which a distinction was made between passive (e.g., methods that did not require active participation) and active (e.g., exercises that did require active participation) interaction methods. Items relating to *information control* dealt with how the patient had control over access to information (e.g., option to only view information of interest), but also how feedback was established (e.g., summary of a patient's preferences). *Accessibility* involved items that focused on how accessible the DA was (e.g., whether the DA required login information), and *suitability* focused on how suitable the content of the DA was (e.g., presence of irrelevant illustrations). Finally, *source of information* yielded items that concerned whether and how the source of probability information was given (e.g., information about patients involved in the reported trials).

Response options for each item were 'yes' and 'no' (coded as 1 and 0 respectively; seven items needed to be recoded). Since six items were only applicable to web-based DA, the total number of items for paper-based DAs was 70, and for web-based 76. For

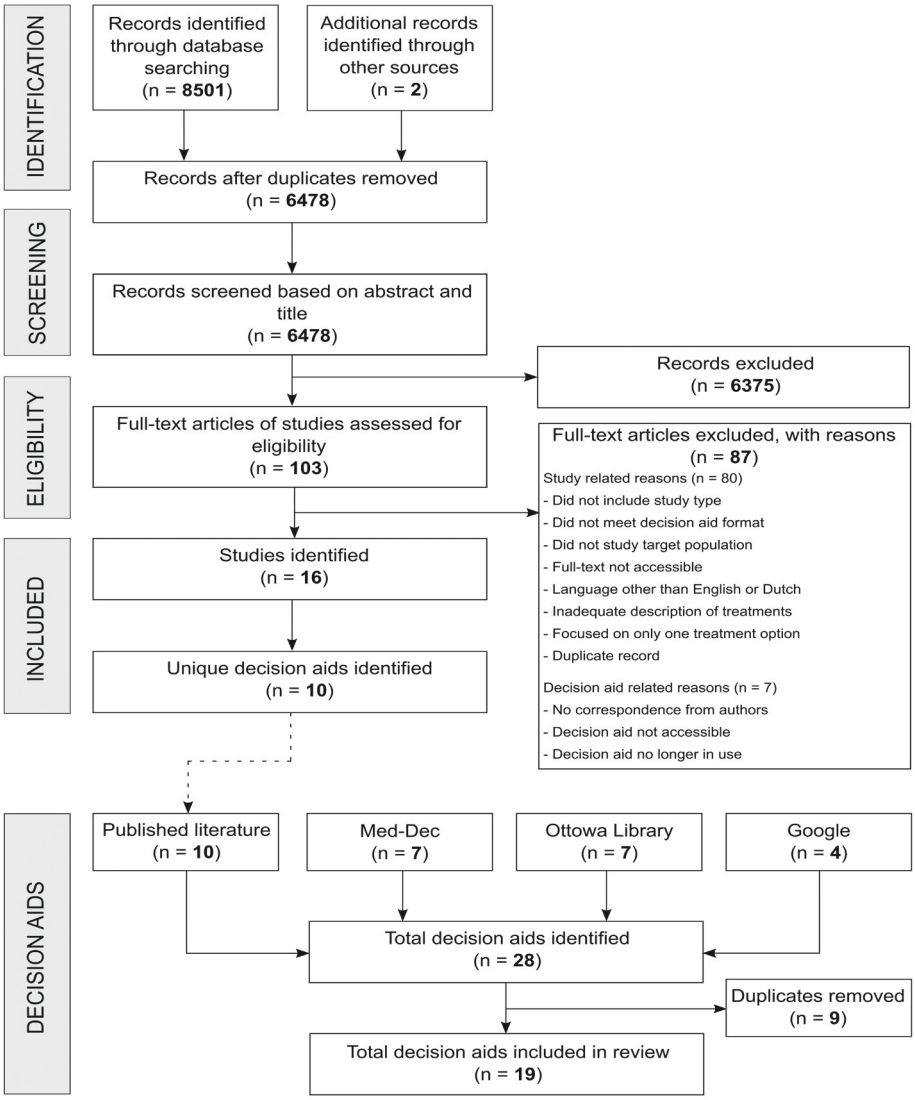

Figure 1 | Flowchart of study and decision aid selection process.

Table 1 | Summary of the decision aids included in the systematic review.

ID	Title	Organization/Authors	Country	Target audience	Publication date (last update)	Treatments discussed	Format
1	Proven best choices: Treatment options for men with low-risk prostate cancer	Institute for Clinical and Economic Review (ICER)	USA	Low risk	Unknown (Unknown)	AS, RP, BT (IMRT, PBT)	Paper
2	De keuze maken: Beslissingshulp voor patiënten met vroegtijdige stadium gelokaliseerde prostaatkanker	KU Leuven LUCAS, Isebaert31,32	BE	Localized, early-stage	Oct 2007 (Unknown)	WW, RP, EBRT, BT	Paper
3	Healing choices for men with prostate cancer	Mount Sinai Medical Center, Fox Chase Cancer Center, Diefenbach45	USA	Localized, early-stage	2008 (Unknown)	AS, RP, EBRT, BT	Web
4	Beslissingshulp voor patiënten met vroegtijdige, gelokaliseerde prostaatkanker	KU Leuven LUCAS, Schrijvers46	BE	Localized, early-stage	2010 (Unknown)	WW, RP, EBRT, BT	Web
5	Treatment choices for men with early-stage prostate cancer	National Cancer Institute	USA	Early-stage	Jan 2011 (Unknown)	AS, RP, EBRT, BT, HT (IMRT, PBT, CT)	Paper
6	Knowing your options: A decision aid for men with clinically localized prostate cancer	Agency for Healthcare Research and Quality	USA	Localized	Sep 2011 (Unknown)	AS, RP, EBRT, BT, HT (HIFU, PBT, CT)	Web
7	Keuzehulp prostaatkanker	VU Medical Center, De Argumentenfabriek, Al-Itejawi33,34	NL	Localized	Sep 2013 (Unknown)	AS, RP, EBRT, BT	Web
8	Keuzehulp voor mannen met gelokaliseerde prostaatkanker	Radboud UMC Nijmegen, KWF Kankerbestrijding, Prostaatkankerstichting, van Tol-Geerdink35,36	NL	Localized	2012 (2014)	AS, RP, EBRT, BT (HIFU, CT)	Paper

Table 1 | Continued.

ID	Title	Organization/Authors	Country	Target audience	Publication date (last update)	Treatments discussed	Format
9	Making the choice: Deciding what to do about early-stage prostate cancer	Michigan Cancer Consortium, Holmes-Rovner37	USA	Early-stage	2004 (Apr 2014)	AS, WW, RP, EBRT, BT (CT)	Paper
10	Prostate cancer treatment possibilities	National Health Service	UK	Prostate cancer	Unknown (Jan 2015)	AS, WW, RP, EBRT, BT, HT (HIFU, CT, TURP)	Web
11	Treatment choices for localized prostate cancer: A shared decision making program	Health Dialog, Arterburn38, Formica39	USA	Localized	2013 (June 2015)	AS, WW, RP, EBRT, BT (combined EBRT & BT)	Paper
12	Prostate cancer decision aid for early-stage patients	Queen's University, Feldman-Stewart40	CAN	Early-stage	Unknown (July 2015)	AS, WW, RP, EBRT, BT, HT	Web
13	Treating localized prostate cancer: A review of the research for adults	Agency for Healthcare Research and Quality	USA	Localized	Jan 2016 (Unknown)	AS, WW, RP, EBRT, BT, HT	Paper
14	P3P: Personal Patient Profile Prostate	Dana-Farber Cancer Institute, University of Washington, Berry41,42	USA	Localized	Mar 2007 (May 2016)	AS, WW, RP, EBRT, BT, HT	Web
15	Treatment choice: Prostate cancer	MAASTRO Clinic, UMC+ Maastricht	NL	Localized, low, medium, high risk	Unknown (Jan 2017)	AS, RP, EBRT, BT	Web
16	Prostaatkanker keuzehulp	Zorgkeuzelab, Cuypers43, Lamers44	NL	Localized, low, medium risk	2014 (Apr 2017)	AS, RP, EBRT, BT	Web
17	Prostate cancer: Should I choose active surveillance?	Healthwise	USA	Localized, low risk	Unknown (May 2017)	AS, RP, RT	Web

Table 1 | Continued.

ID	Title	Organization/Authors	Country	Target audience	Publication date (last update)	Treatments discussed	Format
18	Treatment options for low-risk prostate cancer	Option Grid Collaborative, EBSCO Health	UK	Low risk	Unknown (Feb 2018)	AS, WW, RP, RoP, EBRT, BT	Web
19	Prostate cancer: Should I have radiation or surgery for localized prostate cancer?	Healthwise	USA	Localized, low risk	Unknown (Apr 2018)	AS, RP, EBRT, BT	Web

Note: AS = Active Surveillance; BT = Brachytherapy; CT = Cryotherapy; EBRT = External Beam Therapy; HIFU = High Intensity Focused Ultrasound; HT = Hormonal Therapy; IMRT = Intensity-Modulated Radiation Therapy; PBT = Proton Beam Therapy; RP = Radical Prostatectomy; RoP = Robot Prostatectomy; RT = Radiation Therapy; TURP = Transurethral Resection of Prostate; WW = Watchful Waiting; Minor discussed treatments are shown in parentheses.

Table 2 | Summary of the studies included in the systematic review.

DA ID	First author, year	Country	Study design	Study population	Methods	Results
2	Isebaert, 2007[31]	BE	Evaluation study	Newly diagnosed LPC patients (*n*=50)	Patients were given a DA and were interviewed before and after the decision-making consultation.	The use of a DA led to more active involvement in treatment decision making and more information exchange between healthcare professional and patient. Also, the DA had a positive impact on the decision making process, and improved the quality of the consultation.
2	Isebaert, 2008[32]	BE	Evaluation study	Newly diagnosed LPC patients (*n*=31)	See Isebaert (2007)	See Isebaert (2007)
3	Diefenbach, 2018[45]	USA	RCT	Newly diagnosed LPC patients (*n*=369)	Patients were randomized to either the intervention group (standard consultation plus the DA) or the usual care group (standard consultation), and the study outcomes were decisional conflict and cancer-related distress.	The DA did not lead to less decisional conflict or cancer-related distress compared to the standard care condition. Patients who received the DA reported higher levels of decisional support, which was greatest for non-white minority patients and for patients with lower levels of education.
4	Schrijvers, 2013[46]	USA	Usability study	Newly diagnosed LPC patients (*n*=74)	Patients received the DA while their actual use (e.g., Frequency of page visits, time spent on each page, and use of technological features) was examined by means of web-log analysis.	Patients most frequently visited and spent most time on webpages with information about treatment options. Furthermore, patients mostly (especially aged older than 70) used features such as comparative tables, followed by value clarification tools.

Table 2 | Continued.

DA ID	First author, year	Country	Study design	Study population	Methods	Results
7	Al-Itejawi, 2016[33]	NL	Usability and evaluation study	Newly diagnosed LPC patients (*n*=5)	A participatory design (by means of focus groups, semi-structured interviews, and usability testing) was used to design a DA that met the patients' and healthcare professionals' needs.	Healthcare professionals considered medical information about treatment options and side effects as most important, while patients also found other nonmedical information (e.g., location) important to be included in the DA. Both parties expected the DA to be beneficial for the decision making process. Challenges were observed regarding the implementation of the DA into clinical practice, including barriers such as time and money consuming.
7	Al-Itejawi, 2017[34]	NL	RCT (protocol)	Newly diagnosed LPC patients	A stepped-wedge cluster RCT will be conducted to assess the effectiveness (with decisional conflict as primary measure), and cost-utility of the DA compared to usual care.	N.A.
8	van Tol-Geerdink, 2013[35]	NL	RCT	Newly diagnosed LPC patients (*n*=240)	The effect of a DA on treatment choice and whether this was affected by increased patent participation was investigated by means of an RCT. Patients were randomized to either the intervention group (treatment discussion with a specialist plus the DA) or the usual care group (only treatment discussion with specialist).	For both groups, prostatectomy was the most frequently preferred treatment, but those who received the DA were more likely to choose brachytherapy and remained undecided less frequently compared to patients with usual care.

Table 2 | Continued.

DA ID	First author, year	Country	Study design	Study population	Methods	Results
8	van Tol-Geerdink, 2016[36]	NL	RCT	Newly diagnosed LPC patients (*n*=201)	The effects of a DA on patient participation and different aspects of regret were investigated by means of an RCT. Patients were randomized to either the intervention group (treatment discussion with specialist plus the DA) or the usual care group (only treatment discussion with a specialist).	Patients who received the DA reported higher levels of patient participation. However, whether patients received the DA or usual care did not influence their levels of regret.
9	Holmes-Rovener, 2005[37]	USA	Evaluation study	Newly diagnosed LPC patients (*n*=60)	Formative evaluation methods including focus groups and surveys were used to evaluate a newly developed DA in plain language. Knowledge of patients who received the DA was compared to the knowledge of historical controls.	Patients who received the DA had more discussions with their healthcare professional about surgery, better knowledge of side effects of radiotherapy, but were less likely to be informed about their personal stage of their cancer compared to the historical controls.
11	Arterburn, 2015[38]	USA	Pre-post observational evaluation	Newly diagnosed LPC patients (*n*=117)	A pre-post observational evaluation design was used to investigate associations between DA use (DA implementation versus control group) and rates of receiving active treatment and healthcare costs.	DA implementation was associated with a lower level of receiving active treatment. However, no significant associations were found between healthcare costs in both the DA and control group.
11	Formica, 2017[39]	USA	Cross-sectional study	Newly diagnosed low-risk LPC patients (*n*=452)	A cross-sectional study was conducted to determine whether patients who received a DA had a better understanding of the rationale for active surveillance compared to patients who did not receive the DA.	Patients who received the DA had a better understanding of why active surveillance can be seen as a viable treatment option than patients who did not view the DA.

Table 2 | Continued.

DA ID	First author, year	Country	Study design	Study population	Methods	Results
12	Feldman-Stewart, 2012[40]	CAN	RCT	Newly diagnosed low- or intermediate early stage prostate cancer patients (*n*=156)	Within a multicenter RCT, Patients either received a DA with or without value clarification exercises, and at three moments (during decision making, 3 months after completing treatment, and >1 year after the decision was made) the effects of the aids were measured on decisional conflict, preparation for decision making, and decisional regret.	No differences were observed between the two groups on any outcome during decision making and 3 months after completing treatment. However, >1 year after the decision was made, patients who had received the DA with explicit value clarification exercises reported to be better prepared for decision making and to have less regret compared to patients who had received a DA without value clarification.
14	Berry, 2013[41]	USA	RCT	Newly diagnosed LPC patients (*n*=467)	A multicenter RCT was conducted to determine the effects of a DA on decisional conflict, time-to-treatment, and treatment choice. Patients were randomized to either the intervention group (a newly developed DA) or the usual care group (education material alone).	Time-to-treatment was comparable between the two groups. However, those patients who received the DA had lower levels of decisional conflict, and choose more often brachytherapy as treatment option compared to patients who only received education material.
14	Berry, 2018[42]	USA	RCT	Newly diagnosed LPC patients (*n*=276)	A multicenter RCT was conducted to determine the effect of a DA on decisional conflict. Patients were randomized to either the intervention group (a newly developed DA) or the usual care group (usual education plus links to websites), after which their decisional conflict was measured.	Patients who received the DA had lower levels of decisional conflict compared to patients who only received usual education. This effect was modified by factors such as the patients' risk level and resources.

Table 2 | Continued.

DA ID	First author, year	Country	Study design	Study population	Methods	Results
16	Cuypers, 2015[43]	NL	RCT (protocol)	Patients diagnosed with low or intermediate early-stage prostate cancer	An RCT (at the hospital level) will be conducted to assess the effectiveness (with decisional conflict as primary measure; and shared decision making and health outcomes as secondary measures) of the DA compared to usual care.	N.A.
16	Lamers, 2017[44]	NL	RCT (only intervention arm)	Newly diagnosed patients with low- or intermediate risk prostate cancer (*n*=175)	The effect of a newly developed DA on patients' preferences (and how the use of the DA could change this treatment preference) was investigated. The urologists' preferences were also asked.	After DA use, most patients preferred prostatectomy as treatment option, followed by active surveillance, brachytherapy and external beam therapy. For most patients, the DA did not change their initial treatment preference.

Note. DA = Decision aid; LPC = Localized prostate cancer; N.A. = Not applicable; RCT = Randomized controlled trial.

IPDAS

A summary of the results on the IPDAS checklist can be found in Appendix B. The percentage of IPDAS criteria met by the DAs ranged from 36% to 84% (*M* = 59%, *SD* = 12%). Ten of the 19 DAs included comparisons between positive and negative features of treatment options (53%), and 5 (26%) showed both features with equal detail. Regarding probabilities, ten DAs (53%) did not define the reference class, 11 (58%) did not mention the specified time period, and 15 (79%) did not provide balanced information about outcome probabilities. Only 2 DAs (11%) mentioned the readability levels of their aid, and most had low scores on items related to the development process (5 out of 6 items were below 50%). Figure 2 shows the IPDAS scores for each DAs, and Figure 3a displays the variation of the IPDAS scores for each dimension.

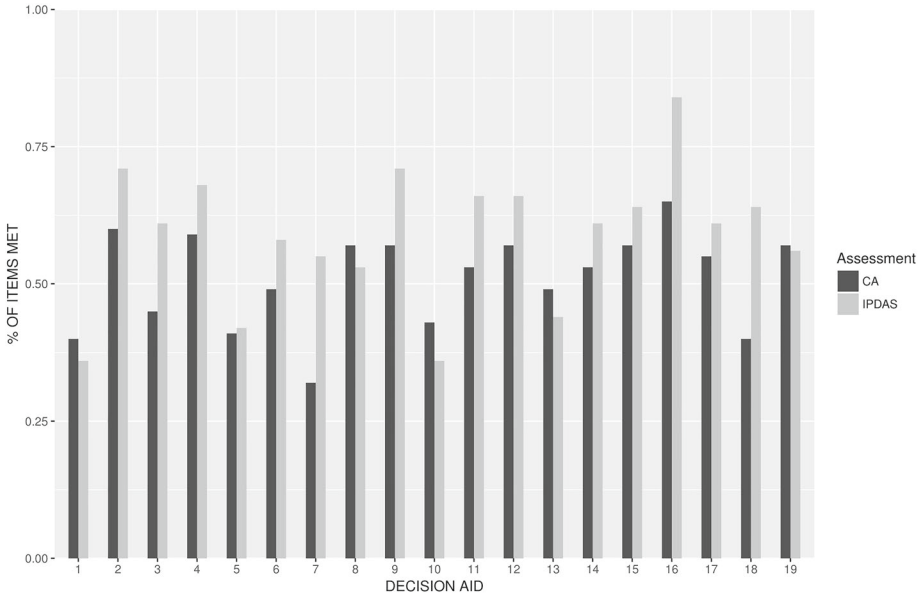

Figure 2 | Percentage of items met on the IPDAS and CA checklist for each decision aid.

Communicative aspects

A full summary of the results on the CA checklist can be found in Appendix C. The percentage of CA items met by the DAs ranged from 32% to 64% (*M* = 51%, *SD* = 9%). Figure 2 shows the CA scores for each DA, and Figure 3b displays the variation of the CA scores for each aspect.

Information presentation

All 19 DAs used absolute verbal expressions, of which 15 (79%) also used relative verbal expressions; 18 (95%) also used numerical information to convey probabilities, of which natural frequencies were most common (16; 84%) followed by absolute risks (13; 68%), percentages (10; 53%), and relative risks and number needed to treat (both 1; 5%). A minority (6; 32%) used visual aids, of which icon arrays were most frequently used (5; 26%), followed by pie and bar charts (2 and 1 respectively; 11% and 5%). The majority of the included DAs described uncertainties around probability information (15; 79%), of which all used verbal descriptions, 11 numerical ranges (73%), whilst only 1 communicated this visually (7%). Of the 16 DAs that explained disease-related factors, 4 (25%) used text-only, whilst the majority used both text and illustrations (75%). All DAs communicated the procedures of treatments verbally, of which 7 (37%) added illustrations and 3 (16%) included video clips. Furthermore, only 2 DAs (11%) presented the information in a balanced and unbiased way, 10 (53%) used roughly the same amount of text for each option, and 7 (37%) used language that was biased in favor of a specific treatment. Finally, of the 16 aids that contained positive features of treatment options, 6 (38%) provided an equal number of those features across options; whereas all aids contained negative features of options, of which 4 (21%) had an equal number of those features across options.

Personalization

The majority of the DAs (17; 89%) were tailored toward the specific stage of the prostate cancer. Tailoring towards the type of treatment, specific populations, or other prostate cancer-related factors (e.g., PSA value) only occurred in 3 (16%), 1 (5%), and 3 DAs (16%) respectively. Seven of the aids allowed (37%) patients to tailor the content of the DA. However, none of the DAs allowed patients to view probabilities based on their own situation, or to tailor information to patients' own preference for the mode of information presentation.

Interaction

Of the 16 DAs that helped patients to consider personal values and preferences, all passively asked patients to think about their personal values, and 10 (63%) used interactive methods such as weighting exercises (7; 44%) and/or sliders to assign values to preferences (4; 25%). Treatment comparison was realized by 13 aids (68%). Of these, cross-tables including positive and negative features of treatments were a key feature (11; 84%), along with verbal comparisons (9; 69%). Only 5 (39%) incorporated interactive methods such as rating or ranking exercises, and 1 (8%) provided the patient with the most suitable option on the basis of values and preferences. Finally, feedback was given in various ways. Eight DAs (42%) showed the progress of the aid, 7 (37%) provided a summary of the values and preferences, and 11 (58%) had the opportunity

to print the DA as a single document. In addition, 8 DAs (42%) provided space for note taking, and 3 (16%) included a short knowledge test.

Information control

Eleven DAs (58%) allowed patients to only receive information that they wanted to read. All except for 1 DA (95%) provided a step-by-step way to move through the DA, and 16 (84%) provided patients the opportunity to read more about a specific topic of interest. The majority (16; 84%) included the option to search for keywords by means of the "ctrl-f" function or a search bar.

Accessibility and suitability

In terms of accessibility, a total of 15 DAs (79%) were freely available on the web, and 5 (26%) required a login code to get full access. Eleven DAs (58%) reported the date of last update, and only 4 (21%) reported update frequency. The majority could be used on multiple devices (16; 84%), such as a laptop/computer or smartphone/tablet. Concerning suitability, 15 aids (79%) contained more than ten (web)pages. Of the 14 aids that contained illustrations, 8 (57%) also contained illustrations that did not have a direct link with the message being presented verbally.

Source of information

Of the 19 DAs, most included probabilities for treatment side effects and/or quality of life (15; 79%) followed by mortality rate (12; 63%) incidence rate (9; 47%) treatment after active surveillance (6; 32%) survival rate (5; 26%) progression of cancer (4; 21%) and co-morbidity (1; 5%). Only 6 DAs (32%) reported the original source of the data, of which half provided detailed information about the patients included in the data(sets) and the period of data collection.

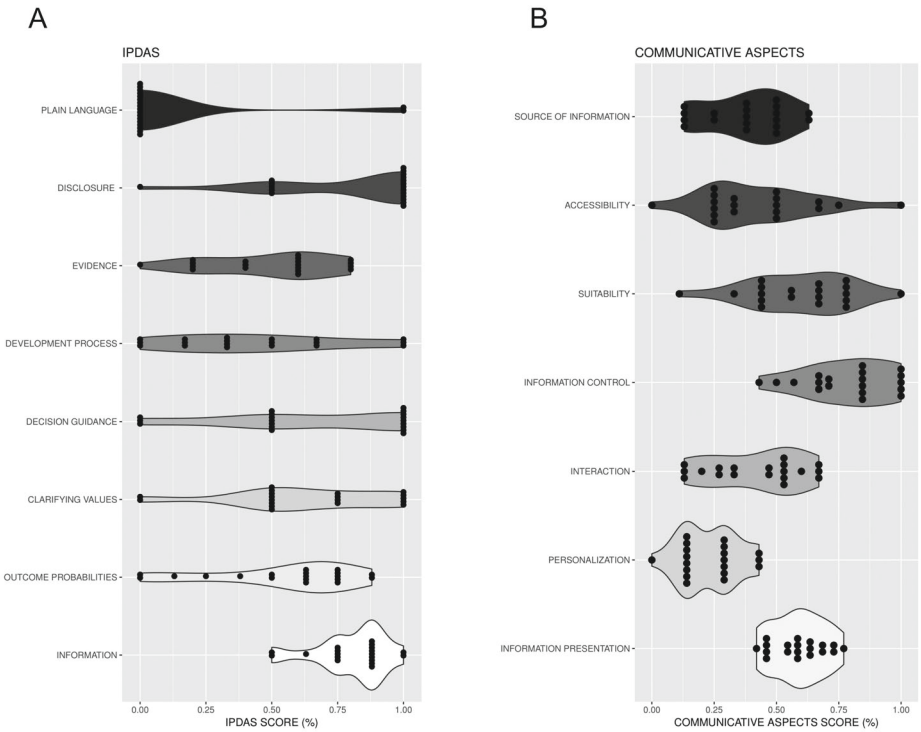

Figure 3 | Violin plots of the percentages of items met on the IPDAS checklist separated for each dimension (A), and percentage of items met on the CA checklist separated for each aspect (B). For each violin plot, dark dots represent the DAs.

DISCUSSION

In this systematic review, we identified 19 DAs for LPC treatment decision making, and reviewed them for IPDAS criteria and their usage of various CAs. Consistent with previous reviews[8–10,25], adherence to the IPDAS checklist varied substantially across DAs. Many did not adhere to good practice guidance on the presentation of outcome probabilities associated with treatment options, and also lacked substantial information regarding the development process and readability levels of the aids. More importantly, a novel finding of this review was that the use of CAs also varied substantially across DAs. Here, we will discuss some major CA shortcomings found in the DAs, and – based on insights from communication research – provide recommendations and best practices for healthcare professionals who are involved in the development or use of DA in their clinical practice (for an overview, see Table 3).

First of all, only a minority of the DAs used visual aids or other graphical methods to convey statistical information. However, given that this kind of information is often difficult to process and understand for many patients[18], various guidelines and best practices have been developed over the years how to communicate this through multiple channels[47,48]. Moreover, content-related information (e.g., LPC, procedures of treatments) was most of the time explained unimodally rather than multimodally. However, there is substantial evidence that the latter form often leads to better information recall[15–17], especially for people with lower health numeracy and health literacy skills[49]. Therefore, future DA developments should consider the possible *communication channels* (and their combination) through which different pieces of information can be explained to patients.

Another finding was that all DAs were generic and *lacked personalization,* particularly in terms of outcome probabilities (e.g., option to view statistics based on each patient's medical history) and mode of delivery (e.g., option to adjust the presentation modality). However, insights from health communication research suggest that individualized information is more likely to be considered as personally relevant (and hence, to be read) compared to generic and static information[20,21] This in-depth processing of information can lead to higher levels of engagement, which potentially encourages patients to actively participate in SDM[50]. Recent technological developments in data science and artificial intelligence offer promise for the generation of individualized risks and benefits of treatment options, and future studies should determine whether this personalized approach of DAs would also lead to improvements in LPC patients' understanding of risks[51,52].

Furthermore, only a small number of DAs contained *interactive* methods to assess patients' values and preferences, or to compare pros and cons of the available options. This aspect of interaction is particularly important for preference-sensitive decisions such as for LPC, in which there is typically no single best option. The majority of the aids incorporated interaction methods such as a side-by-side table of the positive and negative features of options. Interestingly, our analyses also demonstrated that many of these tables included biases such as an unequal number of positive and negative features of treatments, or a dissimilar amount of text for each option. Such (cognitive) biases could unintentionally influence patients' decision making[53]. It is important that such potential biases are taken into consideration during the development and use of DAs.

This review further reveals some other communicative issues that could potentially hinder the successful implementation of the DAs in clinical practice. For instance, the majority of the aids did not specify the original source of statistical information, or did not mention anything about the characteristics of the patients involved in the clinical trials. However, this information could be helpful to patients to better understand how to apply the probabilities to their own situation[54]. Furthermore, not all DAs were up-to-date and freely available to patients, some required login information to get full

access, and most were quite lengthy in terms of size, which limits their potential usage. Therefore, we recommend healthcare professionals who make use of DAs in their daily clinical practice to be aware of the *suitability* and *accessibility* of their tools for their patients. In addition, healthcare professionals who are involved in the development of DAs might consider how such tools can be dynamically updated based on new evidence and patient data in order to facilitate maintenance and implementation of the tools. Here, again, recent technological advances may be helpful.

Finally, an interesting question is whether DAs with high scores on CAs also lead to improved quality of decision making or other outcome measures of SDM. This could not be investigated in the current review, since we could not link the outcome measures of the reported trials with our assessment measures. Rather, our main focus was on conducting a systematic description of the use of CAs and IPDAS criteria by currently available DAs for LPC treatment, in order to determine its shortcomings. Nevertheless, this is an important issue, and future studies are needed in order to determine whether improved communicative characteristics of DAs in (prostate) cancer care will lead to improvements in SDM outcomes such as decisional conflict, decisional regret, knowledge, or preparation for decision making.

Table 3 | Overview of communicative issues and recommendations for healthcare professionals in the development and use of decision aids for localized prostate cancer treatment.

Communicative aspect	Issues observed in decision aids	Recommendations for healthcare professionals
Information presentation	Probability information was often communicated verbally (e.g., high chance") or numerically (e.g., "10% chance") but less visually (e.g., icon arrays).	Consider the possible communication channels through which different pieces of information can be explained to patients.
Personalization	Probability information of side effects of associated treatment options were generic and based on average statistics.	Make use of recent developments in artificial intelligence for determining individualized outcome probabilities based on patient data.
	The mode of delivery was typically fixed (e.g., only text) and could not be personalized based on patients' preferences.	Consider the individual differences in information processing by patients, and how to personalize the mode of delivery of the DAs.
Interaction	Most side-by-side displays of the pros and cons of treatment options were biased and unbalanced.	Take the potential influence of several cognitive biases in DAs into account, and its influence on treatment decision making.
	Interaction methods that elicit patients' values and preferences of treatment options were rarely used.	Provide (active) interactive exercises that help patients clarify their values and preferences.
Suitability of information	Some were quite lengthy, and most were fixed in terms of size and format.	Develop multiple formats of the DA (paper-based versus web-based), or providing variation in terms of size (short versus elaborated DAs).
Accessibility of information	Few were up-to-date and/or freely available to patients, some required login information to get full access.	Consider how DAs can be dynamically updated based on new evidence and patient data in order to facilitate maintenance and implementation of the tools.
Source of information	Original sources of probability information were most of the time unknown.	Provide reliable sources of information to help patients better understand how to apply the probabilities to their own situation.

CONCLUSION

The integration of DAs for LPC into daily clinical practice is becoming an important intervention to support patient participation in SDM[4,5,55]. Using insights from communication research and relying on technological advances in artificial intelligence research, we argue that patient DAs for LPC treatment could be further improved by taking CAs such as personalization of treatment information, interaction, and the possible channels to communicate information into account. Such improvements are not only limited to the domain of prostate cancer care, but are also useful to many other decisions in health care that do not have a single best option. We therefore believe that our findings have implications for both healthcare professionals who are making use of DAs in daily clinical practice, or who are involved in the development of such decision support tools.

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APPENDICES

Appendix A

Table A1 | Search strategy MEDLINE.

1	"Prostatic Neoplasms"[Mesh]
2	prostat*[tiab] AND neoplas*[tiab]
3	prostat*[tiab] AND cancer*[tiab]
4	prostat*[tiab] AND carcin*[tiab]
5	prostat*[tiab] AND tumour*[tiab]
6	prostat*[tiab] AND tumor*[tiab]
7	prostat*[tiab] AND metasta*[tiab]
8	prostat*[tiab] AND malig*[tiab]
9	"Prostate"[Mesh]
10	neoplas*[tiab] OR cancer*[tiab] OR carcin*[tiab] OR tumo*[tiab] OR metasta*[tiab] OR malig*[tiab] OR "Neoplasms"[Mesh]
11	#9 AND #10
12	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #11
13	"Decision Making"[Mesh]
14	"Clinical Decision-Making"[Mesh]
15	"Decision Support Systems, Clinical"[Mesh]
16	"Decision Support Techniques"[Mesh]
17	"Choice Behavior"[Mesh]
18	#13 OR #14 OR #15 OR #16 OR #17
19	(decision*[tiab] OR decid*[tiab]) AND (support*[tiab] OR tool*[tiab] OR aid*[tiab] OR instrument*[tiab] OR technolog*[tiab] OR system*[tiab])
20	decision aid*[tw]
21	Interactive health communication[tw]
22	(interacti* AND (internet OR online OR graphic* OR booklet* OR leaflet* OR tool))[tw]
23	shared decision making[tw]
24	#19 OR #20 OR #21 OR #22 OR #23
25	#18 OR #24
26	"Patients"[Mesh]
27	"Patient Participation"[Mesh]
28	"Patient Education as Topic"[Mesh]
29	"Patient Satisfaction"[Mesh]
30	#26 OR #27 OR #28 OR #29

31	#25 OR #30
32	"Prostatectomy"[Mesh]
33	prostatectom*[tiab] OR (transurethral*[tiab] AND (resection*[tiab] OR removal*[tiab]) AND prostat*[tiab])
34	#32 OR #33
35	"Radiotherapy"[Mesh]
36	radiotherap*[tiab]
37	#35 OR #36
38	"Watchful Waiting"[Mesh]
39	(Watchful*[tiab] AND waiting*[tiab]) OR (active[tiab] AND surveillance[tiab])
40	#38 OR #39
41	"Hormone Replacement Therapy"[Mesh]
42	(Hormon*[tiab] AND therap*[tiab])
43	#41 OR #42
44	treatment*[tiab]
45	"Prostatic Neoplasms/ Therapy"[Mesh]
46	#34 OR #37 OR #40 OR #43 OR #44 OR #45
47	#12 AND #31 AND #46
48	Limit 47 to (English or Dutch language and yr="1990-Current")

Appendix B

Table B1 | Results from the International Patient Decision Aids Standards (IPDAS) Checklist of the patient decision aids (*n* = 19).

Item	IPDAS dimension	Item description	*n*	%
1	Information about options	The DST describes the health condition or problem (intervention, procedure, or investigation) for which the index decision is required	19	100
2		The DST described the decision that needs to be considered (the index decision)	18	95
3		The DST describes the options available for the index decision	19	100
4		The DST describes the natural course of the health condition or problem, if no action is taken	17	89
5		The DST describes positive features (benefits or advantages) of each option	15	79
6		The DST describes negative features (harms, side effects or disadvantages) of each option	19	100
7		The DST makes it possible to compare the positive and negative features of the available options	10	53
8		The DST shows the negative and positive features of options with equal detail	5	26
9	Outcome probabilities	The DST provides information about outcome probabilities associated with the options (i.e, the likely consequences of decisions)	17	89
10		The DST specifies the defined group (reference class) of patients for which the outcome probabilities apply	10	53
11		The DST specifies the event rates for the outcome probabilities	14	74
12		The DST specifies the time period over which the outcome probabilities apply	8	42
13		The DST allows the user to compare outcome probabilities across options using the same denominator and time period	10	53
14		The DST provides information about the levels of uncertainty around event or outcome probabilities	11	58
15		The DST provides more than one way of viewing the probabilities	9	47
16		The DST provides balanced information about event or outcome probabilities to limit framing bias	4	21

Table B1 | Continued.

Item	IPDAS dimension	Item description	*n*	%
17	Clarifying values	The DST describes the features of options to help patients imagine what it is like to experience physical effects	17	89
18		The DST describes the features of options to help patients imagine what it is like to experience the psychological effects	7	37
19		The DST describes the features of options to help patients imagine what it is like to experience social effects	10	53
20		The DST asks patients to think about which positive and negative features of the options matters most to them	14	74
21	Decision guidance	The DST provides a step-by-step way to make a decision	13	68
22		The DST includes tools like worksheets or lists of questions to use when discussing options with a practitioner	12	63
23	Development process	The DST (or associated paper) mentions that the development process included finding out what clients or patients need to prepare them to discuss a decision	6	32
24		The DST (or associated paper) mentions that the development process included finding out what health professionals need to prepare them to discuss a specific decision with patients	4	21
25		The DST (or associated paper) mentions that the development process included expert review by clients/patients not involved in producing the DST	9	47
26		The DST (or associated paper) mentions that the development process included expert review by health professionals not involved in producing the DST	16	84
27		The DST (or associated paper) mentions that the DST was field tested with patients who were facing the decision	8	42
28		The DST (or associated paper) mentions that the DST was field tested with practitioners who counsel patients who face the decision	7	37

Table B1 | Continued.

Item	IPDAS dimension	Item description	*n*	%
29	Using evidence	The DST (or associated paper) provides citations to the studies selected	12	63
30		The DST (or associated paper) describes how research evidence was selected or synthesized	13	68
31		The DST (or associated paper) provides a production or publication rate	12	63
32		The DST (or associated paper) provides information about the proposed update policy	7	37
33		The DST (or associated paper) describes the quality of the research evidence used	3	16
34	Disclosure and transparency	The DST (or associated technical documentation) provides information about the funding used for development	13	68
35		The DST includes author / developer credentials or qualifications	18	95
36	Plain language	The DST (or associated paper) reports readability levels (using one or more of the available scales)	2	11

Note. DST = Decision support technology.

Appendix C

Table C1 | Results from the communicative aspects (CAs) checklist of the patient decision aids (*n* = 19).

Item	Aspect	Item description	*n*	%
1	Information presentation	Number of decision aids that included probabilistic information	19	100
		Methods used to communicate probabilistic information:		
2		Verbal		
		Absolute risks descriptions	19	100
		Relative risks descriptions	15	79
3		Numerical		
		Percentages	10	53
		Natural frequencies	16	84
		Absolute risks	13	68
		Relative risks	1	5
		Absolute risk reduction	0	0
		Relative risk reduction	0	0
		Number needed to treat/harm	1	5
4		Visual		
		Pie chart	2	11
		Bar chart	1	5
		Line graph	0	0
		Icon array	5	26
		Risk scale	0	0
5		Number of decision aids that described uncertainties around probabilities	15	79
		Methods used to communicate uncertainties:		
6		Verbal		
		Textual descriptions	15	100
7		Numerical		
		Numerical range	11	73
8		Visual		
		Confidence intervals	0	0
		Colored pictograms	1	7
9		Number of decision aids that included disease-related information	16	84
		Methods used to communicate this information:		
10		Verbal (text)	16	100
11		Visual (illustrations)	12	75
12[a]		Audiovisual (video clips) (*n*=10)	3	30
13[a]		Audio (audio clips) (*n*=10)	1	10

Table C1 | Continued.

Item	Aspect	Item description	*n*	%
14		Number of decision aids that included information about procedures of treatments	19	100
		Methods used to communicate this information:		
15		Verbal (text)	19	100
16		Visual (illustrations)	7	37
17[a]		Audiovisual (video clips) (*n*=12)	2	17
18[a]		Audio (audio clips) (*n*=12)	0	0
19		Number of decision aids that presented the information in a balanced and unbiased way	2	11
		Methods used for balanced and unbiased information:		
20		Uses roughly the same amount of text for each option	10	53
21		Displays statistics in the same way for each option (*n*=15)	10	67
22		Uses similar fonts for each option	16	84
23		Uses language that is not biased in favor of a specific option	12	63
24		Presents equal number of positive features of each option (*n*=16)	6	38
25		Presents equal number of negative features of each option	4	21
26		Keeps the order of positive and negative features constant (*n*=16)	14	88
27	Personalized information	Tailoring in general towards type of treatment	3	16
28		Tailoring in general towards specific populations	1	5
29		Tailoring in general towards PSA value or Gleason score	3	16
30		Tailoring in general towards prostate cancer stage	17	89
31		Probability tailoring	0	0
32		Mode of presentation tailoring	0	0
33		Content tailoring	7	37
34	Interaction	Number of decision aids that help patients to consider personal values and preferences	16	84
		Methods used to consider or assess values and preferences (*n*=16):		
		Passive methods		
35		Recommends patients to think about their values and preferences	16	100
		Asks patients for their personal values and preferences	10	63
		Active methods		
36		Weighting exercises	7	44
37		Sliders to assign values to preferences	4	25

Table C1 | Continued.

Item	Aspect	Item description	*n*	%
38		Number of decision aids that help allow for comparison of positive and negative features of treatment options	13	68
		Methods used to compare positive and negative features of options (*n*=13):		
39		Ranking or rating scale	5	39
40		Table to compare positive and negative features	11	84
41		Verbal comparisons	9	69
42		Discrete choice task	1	8
43		Number of decision aids that provide patient the most suitable treatment option	1	5
		Methods used to provide feedback:		
44		The decision aid shows the progress of the decision aid	8	42
45		The decision aid provides patients a summary of their values and lllpreferences	7	37
46		The decision aid permits printing as a single document	11	58
47		The decision aid provides space for note taking	8	42
48		The decision aid includes a short knowledge test	3	16
49	Information control	The decision aid allows for patients to only receive information that they want to read	11	58
50		The decision aid provides a step-by-step way to move through the decision aid	18	95
51		The decision aid provides the patient the opportunity to read more about a specific topic of interest	16	84
52		The decision aid provides access to external sources	17	89
53		The decision aid provides access to internal sources	11	58
54		The decision aid allows for patients to search for key words	16	84
55[a]		The decision aid makes it easy for patients to return to previous parts of the decision aid (*n*=12)	11	92
56	Suitability of information	The decision aid contains less than 10 (web) pages	4	21
57[a]		The decision aid contains videos with a length of less than 1 minute (*n*=4)	1	25
58		The decision aid has a conversational (writing) style	18	95
59		The decision aid has irrelevant illustrations (*n*=14)	8	57

Table C1 | Continued.

Item	Aspect	Item description	*n*	%
60	Accessibility of information	The decision aid is freely available on the web	15	79
61		The decision aid requires a login code	5	26
62		The decision aid is purely computer based	12	63
63		The decision aid requires access to internet for its use	12	63
64		The decision aid reports last update	11	58
65		The decision aid reports update frequency	4	21
66		The decision aid requires staff assistance	9	47
67		The decision aid is self-administered	18	95
68		The decision aid can be used on multiple devices	16	84
	Source of information	Types of outcome probabilities reported by the decision aid:		
69		Mortality rate	12	63
		Survival rate	5	26
70		Incidence rate	9	47
		Progression free survival	4	21
71		Treatment side effects	15	79
72		Treatment after active surveillance	6	32
		Co-morbidity	1	5
73		Number of decision aids that mentioned on which datasets the probabilistic information are based on	6	32
		Types of datasets (*n*=6):		
		Observational data	2	33
		Randomized controlled trials data	3	50
		Patient reported outcomes data	2	33
		Data combined from different studies	5	83
		Type of information about the data(sets) provided by the decision aid (*n*=6):		
74		About what scale the patient data have been collected	2	33
75		About the number of patients on which the data are based on	1	17
		About characteristics of patients on which the data are based on	0	0
76		About the period of time of data collection	1	17

Note. [a] This item does not apply to paper-based decision aids.

3

Communication in patient decision aids for early-stage breast cancer treatment: A systematic review

This chapter is based on:

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van Eenbergen, M. C.,
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van de Poll-Franse, L.V.,
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Assessing the quality and communicative aspects of patient decision aids for early-stage breast cancer treatment: A systematic review. Breast Cancer Research and Treatment, 2019; 178(1): 1-15.

ABSTRACT

Purpose: Decision aids (DAs) support patients in shared decision-making by providing balanced evidence-based treatment information and eliciting patients' preferences. The purpose of this systematic review was to assess the quality and communicative aspects of DAs for women diagnosed with early-stage breast cancer.

Methods: Twenty-one currently available patient DAs were identified through both published literature (MEDLINE, Embase, CINAHL, CENTRAL, and PsycINFO) and online sources. The DAs were reviewed for their quality by using the International Patient Decision Aid Standards (IPDAS) checklist, and subsequently assessed to what extent they paid attention to various communicative aspects, including (i) information presentation, (ii) personalization, (iii) interaction, (iv) information control, (v) accessibility, (vi) suitability, and (vii) source of information.

Results: The quality of the DAs varied substantially, with many failing to comply with all components of the IPDAS criteria (mean IPDAS score = 64%, range 31–92%). Five aids (24%) did not include any probability information, 10 (48%) presented multimodal descriptions of outcome probabilities (combining words, numbers, and visual aids), and only 2 (10%) provided personalized treatment outcomes based on patients and tumor characteristics. About half (12; 57%) used interaction methods for eliciting patients' preferences, 16 (76%) were too lengthy, and 5 (24%) were not fully accessible.

Conclusions: In addition to the limited adherence to the IPDAS checklist, our findings suggest that communicative aspects receive even less attention. Future patient DA developments for breast cancer treatment should include communicative aspects that could influence the uptake of DAs in daily clinical practice.

INTRODUCTION

In early breast cancer care, there has been rapid growth in the development of patient decision aids (DAs) to support the process of shared decision-making (SDM) between patients and their healthcare professional[1]. DAs are tools (aimed at patients and distributed by healthcare professionals) that provide information about treatment options and associated risks of side-effects and disease recurrence, and help patients clarify their values and preferences[2,3]. Moreover, DAs should encourage patients to (actively) participate in the SDM process with their healthcare professional[3,4]. Despite great promise and the increasing interest in developing DAs[1,2], the extent to which they are implemented into daily clinical practice appears to be limited[5,6].

One reason for this might be the variability in the characteristics and quality of DAs for early breast cancer treatment[7]. Assessing the quality of DAs (e.g., whether the DAs' content is reliable and evidence-based, or how they were developed and field-tested) is relevant to patients and healthcare professionals[8], since a lack of trust in or familiarity with the quality of DAs could explain why healthcare professionals do not distribute them to their patients[9]. Typically, the validated international patient decision aids standards (IPDAS) checklist is used to ensure the quality of DAs[10], and covers a variety of dimensions, ranging from information about treatment options and outcome probabilities to decision guidance and development process. Although the IPDAS is considered the gold standard for developing and evaluating DAs[11], being IPDAS compliant does not guarantee that DAs will reach the hands of patients.

We argue that another factor is the extent to which DAs pay attention to the communicative aspects. In fact, DAs include many communication aspects that may influence the use and understanding of the tools by patients and healthcare professionals, but are not covered by the IPDAS checklist[12]. These include, for instance, how DAs present information about treatment options and associated outcome probabilities to patients (e.g., only words or numbers, or in combination with visual aids)[13], or how they communicate uncertainty around statistics. Another communicative aspect is how DAs interact with patients to elicit their values or preferences (e.g., value-clarification exercise)[14], or to provide patients with personalized information based on their personal and tumor characteristics (e.g., personalized risk or survival estimates), all of which can improve patient and healthcare professional's understanding of the personal and clinical situation at hand. Furthermore, aspects like the suitability (e.g., complex language use), accessibility (e.g., only internet-based), or source of information (e.g., reliable outcome probabilities) could disturb the communication process between the DA, patient, and healthcare professional[15]. All these aspects are important elements of the communication process[16], and DAs that pay less attention to these aspects may limit their ability to be distributed by healthcare professionals and to be used and/or comprehended by patients.

Although some reviews have shown the effectiveness of DAs in early breast cancer care[1,17,18], there has been no review on the quality and use of communicative aspects among existing DAs for patients facing early breast cancer treatment decisions. Therefore, the aims of this systematic review were (1) to make an inventory of currently available patient DAs for early-stage breast cancer treatment in both English and Dutch, (2) to critically review their quality based on the IPDAS criteria, and (3) to assess to what extent they pay attention to various communicative aspects.

METHODS

This systematic review is conducted and reported in compliance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines[19].

Data sources and search strategy

A systematic search of both published literature and online sources was conducted to identify and obtain DAs for patients facing early breast cancer treatment decisions. To obtain DAs with associated studies through published literature, we searched the following databases: MEDLINE (via PubMed), EMBASE, Cochrane Library, The Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO. Given that the IPDAS checklist was launched in 2006, we searched the databases from January 2006 until March 2018. Reference lists and author names were searched to identify additional publications that met the eligibility criteria. The search strategy included a combination of keywords, synonyms, and MeSH headings relating to the concepts of breast cancer, DAs, SDM, and treatments (Appendix A). To obtain DAs without associated studies through online sources, we searched the Ottowa Decision Aid Library Inventory (https://decisionaid.ohri.ca/cochinvent.php), and Google™ (search terms "decision aid," "breast cancer," and "treatment") in both Dutch and English for which the first 100 hits were analyzed.

Inclusion and exclusion criteria

We developed inclusion and exclusion criteria for the identification of scientific studies and for decision aids. For the studies obtained through published literature, the inclusion criteria include those that were (1) reported in a scientific journal (peer-reviewed); (2) published between 2006 and 2018; (3) written in English or Dutch. Study types eligible for inclusion were (1) (non-)randomized controlled trials or experimental studies that addressed the impact of DAs as intervention on decisional outcomes or treatment choice; (2) development and/or evaluation of the DAs (e.g., protocol, developmental, evaluation, usability testing, or observational studies). Target populations of studies included newly diagnosed patients with early-stage breast cancer facing treatment decision-making.

For both DAs obtained through published literature and online sources, the following exclusion criteria applied: DAs (1) developed for women with advanced stages of breast cancer or for breast cancer screening; (2) in the format of predictive or decision-support tools (e.g., Predict-UK, Adjuvant!Online) since such tools are aimed for both healthcare professional and patients; (3) in the format of phone calls, online support groups, interviews, nomograms, or audiotapes, since such formats could not be analyzed. Finally, the following inclusion criteria applied: DAs that were (1) published between 2006 and 2018; (2) (publicly) available; (3) fully accessible (e.g., no monetary costs associated with the DA such as one time purchase, or no need to be prescribed by a certain healthcare system or healthcare professional); (4) written in English or Dutch.

Study and decision aid selection

Two reviewers (RV, KT) screened all retrieved articles for relevance based on title and abstract for initial eligibility. The overall kappa score for inter-rate agreement during the screening phase was strong ($\kappa = 0.97$)[20]. Afterwards, the few disagreements were resolved through discussion or adjudication by a third person. Subsequently, the same two reviewers independently evaluated the articles that passed the previous screening phase based on the eligibility criteria and disagreements were resolved through discussion and consensus between the two reviewers. The overall kappa score during the study eligibility phase was strong ($\kappa = 0.91$). Data extraction of the included studies and DAs were independently assessed by two reviewers.

Assessment of decision aids

The assessment of the identified DAs consisted of two parts. DAs were first reviewed for their quality according to IPDAS criteria, after which they were critically assessed on a communicative aspect checklist. Each DA was independently assessed by two coders (four coding teams in total). Inter-rate agreements (κ) achieved by the teams ranged from 0.74 to 0.86 for the IPDAS checklist (mean $\kappa = 0.81$), and from 0.76 to 0.90 for the assessment of CAs (mean $\kappa = 0.83$). The total, average inter-rate agreement was good ($\kappa = 0.82$).

Quality of decision aids

Quality of the included DAs was assessed by using the IPDAS Collaboration criteria framework. The IPDAS instrument (Appendix B)[10] consists of 36 items divided into eight dimensions: (i) information about options (items 1–8), (ii) outcome probabilities (items 9–16), (iii) clarifying values (items 17–20), (iv) decision guidance (items (21–22), (v) development process (items 23–28), (vi) using evidence (items 29–33), (vii) disclosure and transparency (items 34–35), and (viii) plain language (item 36). Since not all DAs had been evaluated in scientific studies, we decided to exclude the two items related to the evaluation dimension. Response options for each criteria item were 'yes' and

'no' (coded as 1 and 0, respectively). For each DA, the number of IPDAS items met was converted to percentages of the total number of items.

Communicative aspects of decision aids

The use of communicative aspects by the DAs was assessed by a recently developed and validated communicative aspect checklist for patient DA (Appendix C)[12]. This tumor-independent checklist consists of 76 items divided into seven CAs: (i) information presentation (items 1–26), (ii) information control (items 27–33), (iii) personalization (items 34–40), (iv) interaction (items 41–55), (v) accessibility of information (items 56–64), (vi) suitability of information (65–68), and (vii) source of information (items 69–76). Response options for each item were 'yes' and 'no' (coded as 1 and 0, respectively; seven items needed to be recoded). Since six items were only applicable to web-based DA, the total number of items for paper-based DAs was 70, and for web-based 76. For each DA, the number of communicative aspect items met was converted to percentages of the total number of items. Note that a higher communicative aspects score does not necessarily indicate a higher quality DA; it only suggests that more items from the communicative aspects checklist were taken into consideration.

RESULTS

Search results and decision aid characteristics

In total, 8073 records were identified through five databases, and four additional records through other sources (Figure 1). Screening titles, abstracts, and full-texts yielded ten eligible studies, including seven unique DAs. An additional search through online sources resulted in another 14 unique DAs, leading to a total of 21 DAs included in this review (Table 1). Ten aids originated from the United States, five from the Netherlands, five from Australia, and one from Canada. Eleven of the DAs were web based and ten were paper based. Most DAs discussed reconstruction surgery (11) and/or surgery (10; mastectomy vs. breast-conserving therapy) as treatment options, followed by (adjuvant) radiotherapy (9), systemic therapy (7; (neo)adjuvant chemotherapy and hormonal therapy), and lymph node surgery (3; axillary dissection and sentinel node biopsy). Year of last update ranged from 2008 to 2018, but most (13) had been updated in 2017 or 2018. Seven DAs had 1 or more associated studies[21–30] of which three were RCTs, five evaluation and/or development studies, and two protocol studies (Table 2).

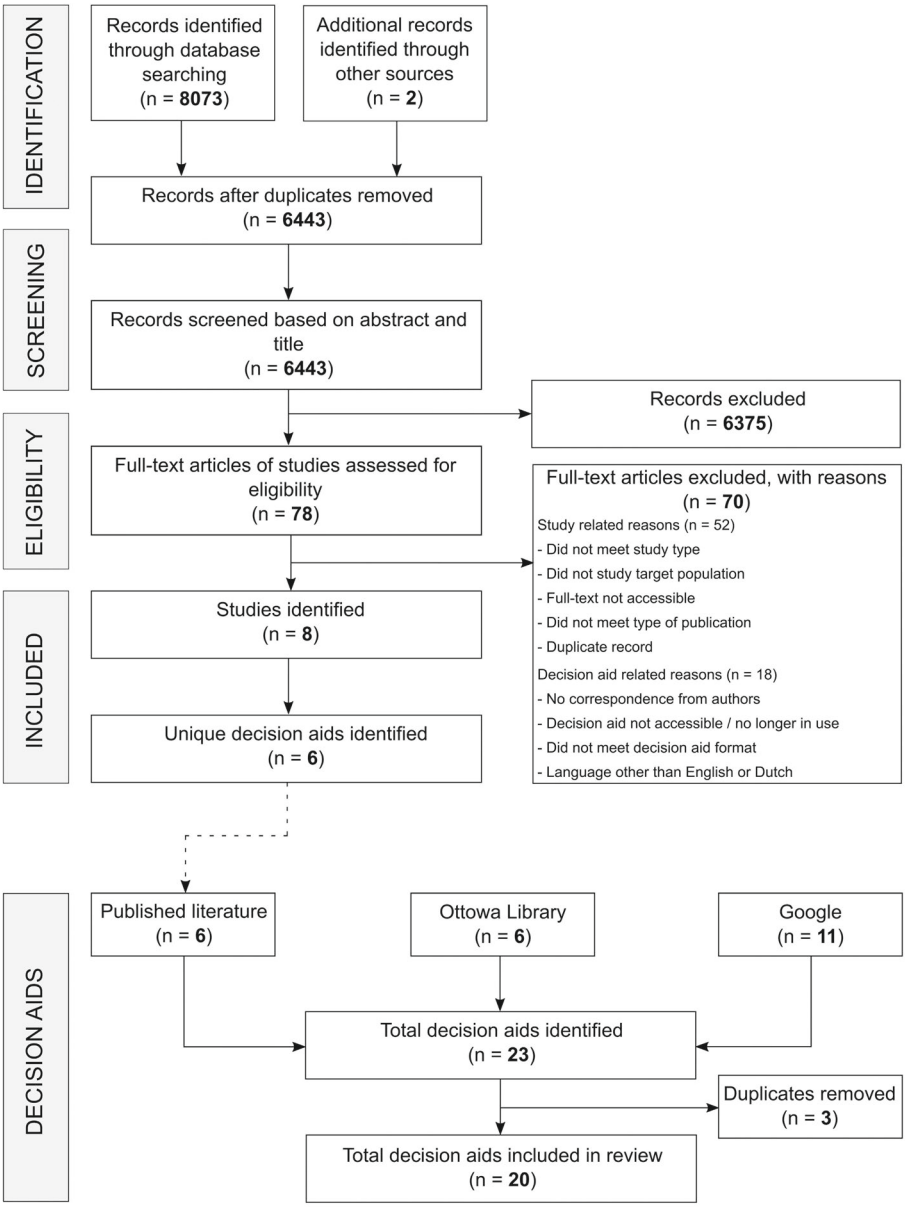

Figure 1 | Flowchart of study and decision aid selection process.

Table 1 | Summary of the decision aids included in the systematic review.

ID	Title	Organization/Authors	Country	Treatment discussed	Last update	Format
1	Mastectomy or breast conserving therapy	Harwood (2011)	AUS	BCS; Mastectomy	Aug 2008	Paper
2	Axillary dissection or a sentinel node biopsy	Harwoord (2011)	AUS	Lymph node surgery	Aug 2008	Paper
3	Understanding ductal carcinoma in situ (DCIS) and deciding about treatment	National Breast and Ovarian Cancer Center	AUS	BCS; Mastectomy; Radiotherapy; Hormonal therapy	2010	Paper
4	Frankly speaking about cancer: Breast reconstruction	Cancer Support Community	USA	Reconstruction surgery	2012	Paper
5	Surgery choices for women with DCIS or breast cancer	National Cancer Institute	USA	BCS; Mastectomy; Reconstruction surgery; Lymph node surgery	Nov 2012	Paper
6	A guide for women who are considering breast cancer treatment with chemotherapy and/or hormonal therapy before surgery	Australia and New Zealand Breast Cancer Trial Group (ANZBCTG) Zdenkowski (2016, 2018)	AUS	(Neo)adjuvant chemotherapy; (Neo)adjuvant hormonal therapy	Dec 2014	Paper
7	A patchwork of life: One woman's story. For women making breast cancer treatment decisions	Dan L. Duncan Comprehensive Cancer Center, Jabaja-Weiss (2006, 2011)	USA	BCS; Mastectomy; Reconstruction surgery; Radiotherapy; Hormonal therapy; Chemotherapy	Aug 2015	Web
8	Early-stage breast cancer: Choosing your treatment	Health Dialog	USA	BCS; Mastectomy; Reconstruction surgery; Radiotherapy; Lymph node surgery	Jul 2016	Paper

Table 1 | Continued.

ID	Title	Organization/Authors	Country	Treatment discussed	Last update	Format
9	iCanDecide	Cancer Surveillance and Outcomes Research Team, University of Michigan, Hawley (2017a, 2017b, 2018)	USA	BCS; Mastectomy; Reconstruction surgery; Radiotherapy; Chemotherapy; Hormonal therapy	2017	Web
10	Breast reconstruction: Is it right for you?	Health Dialog	USA	Reconstruction surgery	Jul 2017	Paper
11	Keuzehulp borstkanker	PATIENT+	NL	BCS; Mastectomy; Radiotherapy	Aug 2017	Web
12	Keuzehulp borstreconstructie	PATIENT+	NL	Reconstruction surgery	Aug 2017	Web
13	Breast RECONstruction Decision Aid (BRECONDA)	Breast Cancer Network Australia, Westmead Breast Cancer Institute, Macquarie University, Sherman (2016)	AUS	Reconstruction surgery	Oct 2017	Web
14	OPTIONS: What are my options for breast cancer treatment?	Wong (2011)	CAN	Radiotherapy; Hormonal therapy	Oct 2017	Paper
15	Breast cancer surgery options	Allina Health	USA	BCS; Mastectomy; Radiotherapy	2018	Paper
16	Borstreconstructie keuzehulp	Zorgkeuzelab	NL	Reconstruction surgery	Jan 2018	Web
17	Breast cancer: Should I have breast reconstruction after a mastectomy?	Healthwise	USA	Reconstruction surgery	Mar 2018	Web

Table 1 | Continued.

ID	Title	Organization/Authors	Country	Treatment discussed	Last update	Format
18	Breast cancer: Should I have chemotherapy for early-stage breast cancer?	Healthwise	USA	Chemotherapy	Mar 2018	Web
19	Breast cancer: Should I have breast-conserving surgery or a mastectomy for early-stage breast cancer?	Healthwise	USA	BCS; Mastectomy	Mar 2018	Web
20	Borstkanker keuzehulp	Zorgkeuzelab Maastricht UMC+	NL	BCS; Mastectomy; Reconstruction surgery; Radiotherapy; Chemotherapy	Oct 2018	Web
21	Borstkanker RAdiotherapie SAmen beslissen (BRASA)	MAASTRO Clinic, Maastricht University, Netherlands Cancer Institute	NL	Radiotherapy	Oct 2018	Web

Note: BCS = Breast-conserving surgery.

Table 2 | Summary of the studies included in the systematic review.

ID	First author, year	Country	Study design	Study population	Methods	Results
1,2	Harwood, 2011	AUS	Development/ Evaluation and pilot study	Development/ Evaluation study: women who had already had surgery for breast cancer (stages I and II, *n*=28) Pilot study: newly diagnosed patients with early breast cancer (stages not mentioned, *n*=11)	There were two phases of this study. The first phase involved patients evaluating the two DAs, and the second phase involved determining the effectiveness of the DAs. During both phases, study outcomes were treatment chosen, patient knowledge, decisional conflict, and satisfaction with decision-making.	Patients in the historical control group reported positive feedback on the DAs, and patients in the intervention pilot group found the DAs to be helpful. Results from the pilot study suggested a possible reduction in decisional conflict, and increase in decisional satisfaction, knowledge, and choice of axillary clearance (instead of sentinel node biopsy) in the intervention pilot group.
6	Zdenkowski, 2016	AUS	Development/ Protocol evaluation study	Newly diagnosed patients with invasive and operable breast cancer (target *n*=50)	A pre-post design will be used to evaluate the acceptability and feasibility of the DA. Primary outcomes will be acceptability and feasibility, and secondary outcomes will be decision conflict, knowledge, information and involvement preference, agreement between preferred and achieved decision.	N.A.

Table 2 | Continued.

ID	First author, year	Country	Study design	Study population	Methods	Results
6	Zdenkowski, 2018	AUS	Evaluation study (pre-post design)	Newly diagnosed patients with operable invasive breast cancer (*n*=59)	Patients first completed a baseline questionnaire (test 1), subsequently received the DA prior to consultation, and then completed a follow-up questionnaire after consultation (test 2), before surgery (test 3) and 12 months after registration (test 4). Study outcomes: as above.	The DA was found to be feasible (with most patients having accessing it) and acceptable (with the majority of the patients seeing the DAs as useful for their decision about treatment). Moreover, post-DA, decisional conflict, anxiety, and distress decreased significantly.
7	Jibaja-Weiss, 2006	USA	Evaluation study	Newly diagnosed patients with early breast cancer (stages I-IIIA, *n*=51)	Patients answered a number of questions after diagnosis, and after completing the DA. Study outcomes were patients' use of the values clarification exercise, perceived clarity of values, and decision conflict scores (low literacy version).	Over half of the participants performed the values clarification exercise. The use of the DA was associated with lower levels of decisional conflict (compared to baseline scores) and lower levels of feeling unclear about values.
7	Jibaja-Weiss, 2011	USA	RCT	Newly diagnosed patients with early breast cancer (stages I-IIIA, *n*=76)	Patients were randomized to either the intervention group (DA plus usual care) or the control group (usual care only). Study outcomes were treatment preference, breast cancer knowledge, satisfaction with decision, satisfaction with decision-making process, and decision conflict (low-literacy version).	Patients who received the DA were more likely to indicate a preference for mastectomy rather than breast-conserving surgery, were more knowledgeable and clearer about their values compared to the control group. No differences were found in satisfaction with the decision or the decision-making process between the two groups.

Table 2 | Continued.

ID	First author, year	Country	Study design	Study population	Methods	Results
9	Hawley, 2016	USA	Evaluation and pilot study	Newly diagnosed patients with early breast cancer (stage 0, I, or II, *n*=101)	Patients were randomized to either the intervention group (who viewed the DA first) or the control group (who took a survey prior to viewing the DA). Study outcomes were knowledge (about treatment options and breast cancer) and decisional appraisal.	Patients who viewed the DA first had higher scores on decisional appraisal than the control group. However, no statistically significant differences were found in knowledge about treatment options between the two groups.
9	Hawley, 2017	USA	RCT protocol	Newly diagnosed patients with early breast cancer (DCIS, or stage I-II, target *n*=222 per arm)	A two-arm RCT will be conducted to evaluate the impact of a tailored DA (intervention group) on decision quality, decision satisfaction, deliberation, and decision preparedness (as primary study outcomes) compared to the same non-tailored static DA (control group).	N.A.
9	Hawley, 2018	USA	RCT	Newly diagnosed patients with early breast cancer (stage I-II, *n*=496)	Patients were randomly allocated to the intervention group (tailored DA) or control group (non-tailored static DA). Primary study outcome was high-quality decision making (which consisted of (1) knowledge about risks and benefits of treatment options and (2) values-concordant treatment).	The use of a tailored-DA was positively associated with high-quality decisions compared to using a non-tailored DA. Patients in the intervention group had higher levels of knowledge than the control group. However, no differences were found in values-concordant treatment decisions between the two groups.

Table 2 | Continued.

ID	First author, year	Country	Study design	Study population	Methods	Results
13	Sherman, 2016	AUS	RCT	Newly diagnosed patients with early breast cancer or ductal carcinoma in situ (DCIS, stages I-III, *n*=222)	An RCT was conducted to determine the effectiveness of a DA for deciding whether to have breast reconstruction or not. Patients were randomized to either the intervention group (DA + plus standard information) or the control group (standard information). Study outcomes were decisional conflict, satisfaction with information, and decisional regret (1 and 6 months after exposure).	At both 1-and 6-month follow-up, the use of the DA was associated with lower levels of decisional conflict and higher levels of satisfaction with the information compared to the control group. There were no differences in decisional regret between the two groups.
14	Wong, 2011	CAN	Development and evaluation study	Development study: patients with early breast cancer who had already had radiotherapy (stage I, *n*=12) Evaluation study: Newly diagnosed patients with early breast cancer (stage I, *n*=36)	There were two pilot studies in this study. The first involved the development of the DA in which patients were asked to review the acceptability of the aid. The second pilot was a pre-post test aimed at examining the effectiveness of the DA on decisional conflict, knowledge, impact of event and treatment choice.	The majority of patients rated the DA as (extremely) satisfied. In comparison to the baseline scores (pre-test), patients experienced less decisional conflict and were more knowledgeable after using the DA (post-test).

Note. DA = Decision aid; N.A. = Not applicable; RCT = Randomized controlled trial.

Quality of decision aids

None of the DAs met all of the IPDAS criteria, and the total percentage of IPDAS criteria met by the DAs ranged from 31 to 92% (mean IPDAS score (*M*) = 64%, standard deviation (*SD* = 20%), see Figure 2). The seven DAs with associated studies had slightly higher IPDAS scores (*M* = 68%, *SD* = 8%) than DAs without associated studies (*M* = 63%, *SD* = 5%). The best performing DAs on the IPDAS checklist were DA12, DA14, and DA20 (Figure 3).

Most aids showed high performance on the dimensions information about treatment options, clarifying values, disclosure and transparency, and decision guidance. For instance, all DAs (100%) presented the available treatment options, with the majority of them explaining both positive and negative features of the options (95%). All aids asked patients to think about positive and negative features of the options that matter most to them (100%). Mixed performance was observed for items related to evidence, development process, and outcome probabilities. For instance, as mentioned by the DA or associated paper, almost all aids were reviewed by doctors (95%), but only half of them were reviewed by (52%) or tested with (57%) patients. Five aids (24%) did not contain any outcome probabilities. Of the aids that did contain probability information, many did not adhere to good practice guidance on communicating essential elements such as providing event rates (57%), keeping the same denominators (29%), reporting time period (43%), or uncertainty (52%). Moreover, only four DAs (19%) reported the update policy and three (14%) discussed the quality of the evidence used. Finally, regarding the dimension of plain language, only five aids (24%) reported acceptable readability levels (e.g., 8th–10th grade (Flesch-Kincaid) reading level).

		DECISION AID																				
	IPDAS ITEM	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**20**	**%**
INFORMATION	Describe condition	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●		●	●	●	●	95
	Index decision	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	100
	Describe options	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	100
	Natural course			●	●		●	●	●	●	●	●	●	●		●	●	●		●	●	75
	Positive features	●	●		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	95
	Negative features	●	●		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	95
	Fair comparison	●	●		●	●	●	●		●	●	●	●	●	●	●	●	●	●	●	●	90
	Equal details					●								●							●	15
OUTCOME PROBABILITIES	Outcome probabilities		●	●	●	●	●	●	●	●	●	●	●	●		●				●	●	75
	Reference class		●		●	●		●	●			●	●	●		●				●	●	55
	Event rates			●	●	●		●	●		●	●		●		●				●	●	55
	Time period					●		●	●	●	●			●						●	●	40
	Same denominator							●			●	●		●						●	●	30
	Uncertainty						●	●	●	●		●	●	●		●				●	●	50
	Multiple methods			●			●		●		●	●	●	●						●	●	45
	Balanced information			●				●	●		●	●		●						●	●	40
VALUES	Experience physical		●		●	●	●	●	●	●	●	●	●	●	●	●		●	●	●	●	85
	Experience psycho	●		●	●	●	●	●	●	●	●	●	●			●	●		●	●	●	80
	Experience social	●			●		●	●	●	●	●		●	●		●	●		●	●	●	70
	Matters most	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	100
DECIS GUIDAN	Step-by-step				●	●	●	●	●	●	●	●	●	●		●	●	●	●	●	●	80
	Worksheets or questions			●	●	●	●	●	●	●	●	●	●	●	●	●			●	●	●	80
DEVELOPMENT	Patients' needs			●	●		●	●		●	●	●	●	●		●				●	●	60
	Doctors' needs			●			●				●	●	●	●		●				●	●	45
	Reviewed by patients	●	●				●		●			●	●	●		●				●	●	50
	Reviewed by doctors	●	●	●	●	●	●	●	●	●	●	●	●	●		●	●	●	●	●	●	95
	Tested with patients	●	●				●		●		●	●	●	●		●				●	●	55
	Tested with doctors	●	●				●		●		●	●	●	●		●				●	●	55
EVIDENCE	Citations			●			●	●		●	●	●	●	●		●	●		●	●		60
	Selection of evidence				●		●	●				●	●	●		●	●			●		45
	Publication rate			●	●	●	●	●	●	●	●	●	●		●	●	●	●	●	●		80
	Update policy						●						●			●				●		20
	Quality of evidence						●	●						●								15
D&T	Funding			●	●		●		●		●	●	●	●		●	●	●	●	●	●	70
	Authors/developers			●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	90
PL	Plain language						●				●	●	●									20
	IPDAS SCORE (%)	**36**	**39**	**50**	**61**	**53**	**83**	**75**	**72**	**58**	**81**	**86**	**83**	**89**	**31**	**81**	**44**	**39**	**47**	**92**	**83**	

Figure 2 | The international patient decision aid standard (IPDAS) scores for each decision aid. Decis guidan: decision guidance, D&T: disclosure and transparency, PL: plain language.

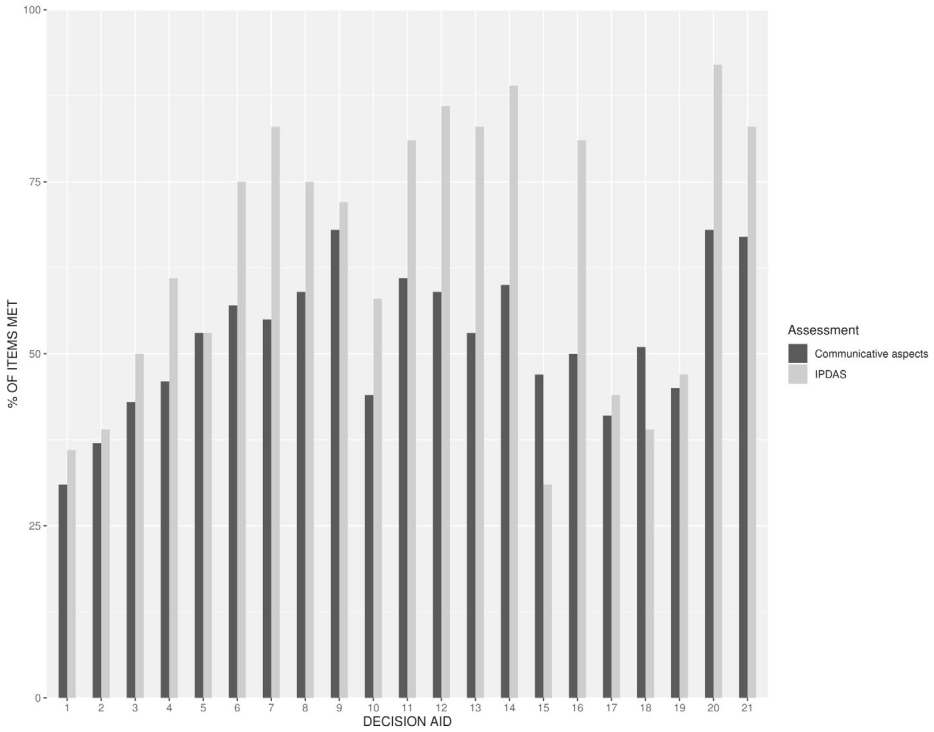

Figure 3 | Percentage of items met on the IPDAS and communicative aspects checklist for each decision aid. Decision aids are presented in chronological order (based on year of last update).

Communicative aspects of decision aids

A full summary of the results on the assessment of communicative aspects can be found in Appendix C. The overall percentage of communicative aspect items met by the DAs ranged from 31% to 68% (*M* = 52%, *SD* = 10%). The seven DAs with associated studies had similar communicative aspects scores (*M* = 52%, *SD* = 5%) compared to DAs without associated studies (*M* = 52%, *SD* = 2%). The best performing DAs on the communicative aspects checklist were DA9, DA20, and DA21 (Figure 3). In general, the majority of the aids met most items related to accessibility; mixed results were found for items with respect to information presentation, information control, interaction, and suitability of information; the least number of items met was shown for personalization and source of information (Figure 4).

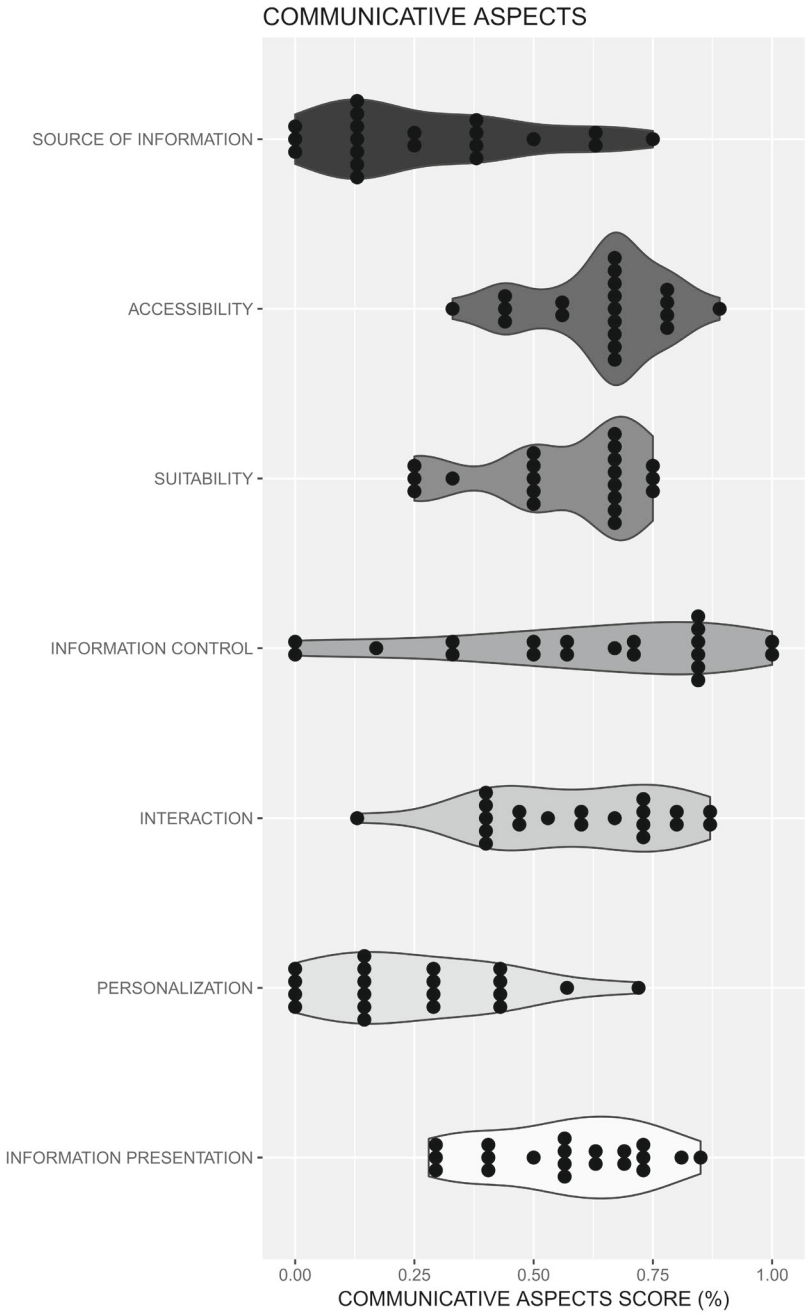

Figure 4 | Violin plots of the percentage of items met on the communicative aspects checklist separated for each aspect. For each violin plot, dark dots represent the DAs.

Information presentation

All DAs used different presentation formats for communicating outcome probabilities. Of the aids, 3 (14%) did not use any method, 2 (10%) used words-only (e.g., verbal descriptions), 6 (29%) used a combination of words and numbers, and 10 (47%) applied a combination of words, numbers, and visuals. Of the 16 aids that used numerical methods, natural frequencies were most often used (12; 75%) followed by percentages (11; 69%); for the 10 aids that used visual methods, icon arrays were the most common (9; 90%), followed by a pie chart or line graph (both 1; 10%). Of the 18 aids that communicated probability information, 14 (78%) described uncertainties around them, typically with verbal methods (13; 93%), followed by numerical ranges (8; 57%), and visually presented confidence intervals (1; 7%). Variations were also observed in presenting disease-related information (6 used text-only, 10 a combination of text and visual/audiovisual), and procedures of treatments (6 text-only, 15 a combination of text and visual/audiovisual). Finally, a significant number of DAs (19; 90%) presented information in an unbalanced way; 9 aids (43%) used more space/text for a specific treatment option, the majority provided an unequal number of positive (12; 55%) and negative features (17; 85%) across the treatment options, and of the 16 aids that included statistical information only 5 (31%) displayed such statistics in a similar way for each option.

Personalization

The majority of the DAs (14; 67%) were tailored towards the breast cancer stage (e.g., early-stage). However, tailoring towards the type of treatment (7; 33%), specific populations (3; 14%), or other breast cancer-related factors (4; 19%) (e.g., HER2 status) occurred less frequently. Five aids (24%) allowed patients to tailor the content of the DA, 3 (14%) to tailor information to patients' own preference for the mode of information presentation, and only 2 DAs (10%) allowed patients to view individualized outcome probabilities based on their own situation.

Interaction

Several interaction methods had been used by the DAs. For comparing treatment options (20; 95%), most used side-by-side tables or verbal comparisons (both 17; 85%), 6 (30%) included ranking or rating exercises, and 2 (10%) applied conjoint analysis/visual analogue scales based on patients' preferences. For clarifying patients' values, the majority (20; 95%) passively asked patients to think about their personal values, and about half used active methods such as weighting exercises (12; 60%) and/or sliders to assign values to preferences (9; 45%). Feedback was also given in different ways. Twelve aids (57%) showed the progress of the aid, 12 (57%) provided a summary of patients' values and preferences, 17 (81%) included a print option. About half (10; 48%) provided space for note taking, and 8 (38%) included a knowledge test.

Information control

Nine aids (43%) allowed patients to only receive information that they wanted to read. The majority (18; 86%) provided a step-by-step way to move through the DA, and 16 (76%) gave patients the opportunity to read more about a specific topic of interest. Only 5 aids (24%) allowed for patients to search for specific keywords or topics in the aid.

Accessibility and suitability

Regarding the suitability of information, almost all DAs (19; 90%) used a conversational (writing) style, and only 6 (29%) contained irrelevant illustrations that did not have any link with the messages being presented. Of the aids that included audiovisual material, only 1 (17%) had videos of less than 1 min. Most aids (16; 76%) were lengthy and contained more than ten (web) pages. Regarding accessibility of the aids, 16 (76%) were freely available on the web, and 5 (24%) required a login code to get full access. Thirteen DAs (62%) reported the date of last update, but only 2 (10%) reported the update frequency. All except for 1 aid could be used on multiple devices such as a laptop or smartphone, or were self-administered. Six aids (29%) required staff assistance in order to start with the aid.

Source of information

Of the 18 DAs that communicated outcome probabilities, most included probabilities for treatment side-effects (12; 67%), followed by recurrence of cancer (12; 67%). Numerical information related to survival rates (4; 22%) or quality of life outcomes (5; 28%) occurred less frequently. Only 5 DAs (28%) reported the original source of the probabilities (e.g., RCTs or population-based data), of which 3 (60%) provided detailed information about the patients included in the data (sets) and 1 (20%) about the period of data collection.

DISCUSSION

In this systematic review, we identified 21 currently available patient DAs for early-stage breast cancer treatment, and critically reviewed their quality (as assessed by the IPDAS checklist[10]) and use of communicative aspects (as assessed by a communicative aspect checklist[12]). This review shows substantial variability in the quality of the DAs, with no existing DA meeting all of the internationally agreed IPDAS criteria. Many did not adhere to good practice guidance on providing information about the development, evidence used for the content, or reporting readability levels. This limited adherence to the quality criteria has also been found among existing DAs for patients with localized prostate cancer[7,12]. Nevertheless, it is promising to see that most of the recently launched or updated DAs in our review (i.e., from 2017 onwards) have shown increased adherence to the IPDAS criteria (see Figure 3), which suggests that current DA developers and/or healthcare professionals are now taking these

criteria much more into account than in the past. At the same time, however, patients can still easily find and make use of existing low-quality DAs, which may foster low implementation rates[5,6].

We also observed that few DAs presented a thorough description of outcome probabilities of treatment options. In fact, three aids did not contain any probability information at all, and two only used verbal descriptions. Ideally, treatment decision-making is, among other elements such as patients' preferences, guided by evidence-based probabilities of treatment outcomes such as survival rates, side-effects, or quality of life after treatment[3,13]. Following the IPDAS guidelines, such outcomes may help newly diagnosed cancer patients in balancing the risks and benefits of options together with their healthcare professional, and should therefore be incorporated in DAs[31]. Moreover, from an ethical point of view, patients should be fully and adequately informed, and thus they should also be informed about outcome probabilities and their original sources[32]. The lack of statistical information for breast cancer DAs is remarkable and in contrast with DAs evaluated for men with localized prostate cancer of which all (except for one DA) contained numeric estimates regarding survival rates and side-effects of treatments[12].

The DAs that did communicate probability information showed great variability in how they communicated such statistical information. Most aids used numeric estimates such as natural frequencies or percentages, and only a few used visual aids such as icon arrays. However, several studies have shown that patients (especially with low numeracy skills) often misunderstand such statistics[33], especially when only being communicated in words[34]. Adding numbers in combination with visual aids may facilitate patients' understanding of probabilities and overcome several biases such as denominator neglect or framing effects[13]. This multimodal strategy (e.g., using both words and pictures) is also useful for communicating other treatment information (e.g., procedures of treatments), which may lead to better information recall by patients[35]. Over the years, several best practices in the communication of evidence-based outcome probabilities have been developed[13,33], and it is important that DA developers and healthcare professionals who are communicating statistical information to patients are taking these sets of guiding principles into account.

One of the more significant communicative issues found in the reviewed DAs for early breast cancer concerns the lack of personalization. For instance, all (except for two) DAs communicated average outcome probabilities based on statistics of groups of prior patients, which may be difficult to apply to the situation of individual patients[36]. Clinical decision-support tools for explaining chemotherapy survival benefits exist (e.g., Predict-UK), and can already estimate personalized outcomes based on patients' personal (e.g., age) and disease-related (e.g., tumor stage) characteristics entered by the healthcare professional. However, such tools are often difficult to understand for patients and should always be used in consultation with a healthcare professional. We therefore argue that patient DAs can be improved by incorporating patient-friendly

versions (or result pages) of such personalized clinical prediction models into existing or novel DAs. However, a prerequisite for personalizing outcomes to individual patients is the availability of robust predictive models based on large amounts of clinical data[37,38]. Recent technological advances in data science and artificial intelligence in combination with large population-based (e.g., cancer registries) or patient-reported outcome datasets offer promise for the generation of personalized treatment outcomes in DAs[12,39].

This review further reveals some potential communicative issues of early breast cancer-specific DAs that could hinder their uptake in routine clinical practice. For instance, most aids provided extensive and detailed information about the options. This may be beneficial for patients who prefer detailed information about treatment options, but may discourage patients who do not have the need, time, or capacity for this[40]. Similarly, not all DAs were easily accessible for patients due to, for instance, limited access (i.e., login code), out-datedness of information, or poor findability. These accessibility issues might be barriers for especially patients with low literacy skills, who face difficulty in finding, evaluating, and obtaining online health information[41]. Next to that, healthcare professionals may better appreciate the benefit of using and providing DAs to their patients if communicative aspects such as personalization (e.g., individualized treatment outcomes) or interaction (e.g., value-clarification exercises) are taken into account. Healthcare professionals may wonder how a limited DA can add to their advisory consult and whether a low literacy patient can take advantage of this DA. It is plausible that improving these communicative aspects of DAs will lower the barrier for healthcare professionals to distribute DAs to their patients.

Our review does have some limitations. First, most DAs were identified through online sources compared to the academic literature. Initially, we found 26 DAs with associated studies, which was comparable with the number of studies found by a related review[1]. In contrast with that review, we needed to have full access to the tools in order to accurately review their quality and communicative aspects. Hence, we could only obtain full access to a minority of those aids found through the academic sources. It should be noted, though, that this distribution of aids found via published literature or online sources is similar to distributions found in related reviews[7,12], that used a similar method for identifying and reviewing the characteristics of DAs. Another limitation is that we could not link the IPDAS and communicative aspect scores to various SDM outcomes, mostly because of the lack of data. For instance, it may be that DAs that are personalized (in terms of content, amount of information, or mode of information delivery) are seen as more personally relevant and processed more deeply by patients[42]. The benefit of this in-depth processing is that patients may acquire better knowledge about their options, which makes them better prepared for their next consultation, with more time actively involved in a SDM process[43].

CONCLUSION

SDM in early breast cancer care requires that patient and healthcare professional are both well-informed about the clinical case and personal situation at hand. DAs have been developed to facilitate this process, but their implementation in routine clinical practice remains low. This review provides insights into the variability among currently available DAs for early breast cancer treatment, and shows that both their quality and use of various communicative aspects can be improved. In addition, even though adherence to the IPDAS checklist is important for ensuring high-quality DAs, our findings suggest that DA developers should also seriously consider communicative aspects that could influence the uptake of DAs in daily practice. Our results do not only have implications for healthcare professionals who are involved in the development and use of DAs for breast cancer treatment, but also for healthcare professionals outside of breast cancer who are facing similar complex and time-consuming clinical counseling scenarios with their patients.

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APPENDICES

Appendix A

Table A1 | Search strategy MEDLINE.

1	"Breast Neoplasms"[Mesh]
2	breast*[tiab] AND neoplas*[tiab]
3	breast*[tiab] AND cancer*[tiab]
4	breast*[tiab] AND carcin*[tiab]
5	breast*[tiab] AND tumour*[tiab]
6	breast*[tiab] AND tumor*[tiab]
7	breast*[tiab] AND metasta*[tiab]
8	breast*[tiab] AND malig*[tiab]
9	"Breast"[Mesh]
10	neoplas*[tiab] OR cancer*[tiab] OR carcin*[tiab] OR tumo*[tiab] OR metasta*[tiab] OR malig*[tiab] OR "Neoplasms"[Mesh]
11	#9 AND #10
12	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #11
13	"Decision Making"[Mesh]
14	"Clinical Decision-Making"[Mesh]
15	"Decision Support Systems, Clinical"[Mesh]
16	"Decision Support Techniques"[Mesh]
17	"Choice Behavior"[Mesh]
18	#13 OR #14 OR #15 OR #16 OR #17
19	(decision*[tiab] OR decid*[tiab]) AND (support*[tiab] OR tool*[tiab] OR aid*[tiab] OR instrument*[tiab] OR technolog*[tiab] OR system*[tiab])
20	decision aid*[tw]
21	Interactive health communication[tw]
22	(interacti* AND (internet OR online OR graphic* OR booklet* OR leaflet* OR tool))[tw]
23	shared decision making[tw]
24	#19 OR #20 OR #21 OR #22 OR #23
25	#18 OR #24
26	"Patients"[Mesh]
27	"Patient Participation"[Mesh]
28	"Patient Education as Topic"[Mesh]
29	"Patient Satisfaction"[Mesh]
30	#26 OR #27 OR #28 OR #29

Table A1 | Search strategy MEDLINE.

31	#25 OR #30
32	"General Surgery"[Mesh]
33	"Mastectomy"[Mesh]
34	"Mastectomy, Segmental"[Mesh]
35	"Mammaplasty"[Mesh]
36	"Drug Therapy"[Mesh]
37	"Radiotherapy"[Mesh]
38	"Radiotherapy, Adjuvant"[Mesh]
39	#32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38
40	#12 AND #31 AND #39
41	Limit 41 to (English or Dutch language and yr="2006-Current")

Appendix B

Table B1 | Results from the International Patient Decision Aids Standards (IPDAS) checklist of the patient decision aids (*n* = 21).

Item	IPDAS dimension	Item description	*n*	%
1	Information about options	The DST describes the health condition or problem (intervention, procedure, or investigation) for which the index decision is required	20	95
2		The DST described the decision that needs to be considered (the index decision)	21	100
3		The DST describes the options available for the index decision	21	100
4		The DST describes the natural course of the health condition or problem, if no action is taken	16	76
5		The DST describes positive features (benefits or advantages) of each option	20	95
6		The DST describes negative features (harms, side effects or disadvantages) of each option	20	95
7		The DST makes it possible to compare the positive and negative features of the available options	18	86
8		The DST shows the negative and positive features of options with equal detail	3	14
9	Outcome probabilities	The DST provides information about outcome probabilities associated with the options (i.e, the likely consequences of decisions)	16	76
10		The DST specifies the defined group (reference class) of patients for which the outcome probabilities apply	12	57
11		The DST specifies the event rates for the outcome probabilities	12	57
12		The DST specifies the time period over which the outcome probabilities apply	9	43
13		The DST allows the user to compare outcome probabilities across options using the same denominator and time period	6	29
14		The DST provides information about the levels of uncertainty around event or outcome probabilities	11	52
15		The DST provides more than one way of viewing the probabilities	10	49
16		The DST provides balanced information about event or outcome probabilities to limit framing bias	9	43

Table B1 | Continued.

Item	IPDAS dimension	Item description	*n*	%
17	Clarifying values	The DST describes the features of options to help patients imagine what it is like to experience physical effects	18	86
18		The DST describes the features of options to help patients imagine what it is like to experience the psychological effects	16	76
19		The DST describes the features of options to help patients imagine what it is like to experience social effects	14	67
20		The DST asks patients to think about which positive and negative features of the options matters most to them	21	100
21	Decision guidance	The DST provides a step-by-step way to make a decision	17	81
22		The DST includes tools like worksheets or lists of questions to use when discussing options with a practitioner	17	81
23	Development process	The DST (or associated paper) mentions that the development process included finding out what clients or patients need to prepare them to discuss a decision	12	57
24		The DST (or associated paper) mentions that the development process included finding out what health professionals need to prepare them to discuss a specific decision with patients	9	43
25		The DST (or associated paper) mentions that the development process included expert review by clients/ patients not involved in producing the DST	11	52
26		The DST (or associated paper) mentions that the development process included expert review by health professionals not involved in producing the DST	20	95
27		The DST (or associated paper) mentions that the DST was field tested with patients who were facing the decision	12	57
28		The DST (or associated paper) mentions that the DST was field tested with practitioners who counsel patients who face the decision	12	57
29	Using evidence	The DST (or associated paper) provides citations to the studies selected	13	62
30		The DST (or associated paper) describes how research evidence was selected or synthesized	10	48
31		The DST (or associated paper) provides a production or publication rate	17	81

Table B1 | Continued.

Item	IPDAS dimension	Item description	*n*	%
32		The DST (or associated paper) provides information about the proposed update policy	4	19
33		The DST (or associated paper) describes the quality of the research evidence used	3	14
34	Disclosure and transparency	The DST (or associated technical documentation) provides information about the funding used for development	15	71
35		The DST includes author / developer credentials or qualifications	19	90
36	Plain language	The DST (or associated paper) reports readability levels (using one or more of the available scales)	5	24

Note. DST = Decision support technology.

Appendix C

Table C1 | Results from the communicative aspects (CAs) checklist of the patient decision aids (*n* = 21).

Item	Aspect	Item description	*n*	%
1	Information presentation	Number of decision aids that included probabilistic information	18	86
		Methods used to communicate probabilistic information (*n*=18)		
2		Verbal		
		Absolute risks descriptions	18	100
		Relative risks descriptions	12	67
3		Numerical (*n*=16)		
		Percentages	11	69
		Natural frequencies	12	75
		Absolute risks	13	81
		Relative risks	2	13
		Absolute risk reduction	1	6
		Relative risk reduction	2	13
		Number needed to treat/harm	0	0
4		Visual (*n*=10)		
		Pie chart	1	10
		Bar chart	0	0
		Line graph	1	10
		Icon array	9	90
		Risk scale	0	0
5		Number of decision aids that described uncertainties around probabilities (*n*=18)	14	78
		Methods used to communicate uncertainties (*n*=14):		
6		Verbal		
		Textual descriptions	13	93
7		Numerical		
		Numerical range	8	57
8		Visual		
		Confidence intervals	1	7
		Colored pictograms	0	0
9		Number of decision aids that included disease-related information	15	71

Table C1 | Continued.

Item	Aspect	Item description	*n*	%
		Methods used to communicate this information (*n*=15):		
10		Verbal (text)	15	100
11		Visual (illustrations)	9	60
12[a]		Audiovisual (video clips) (*n*=8)	1	13
13[a]		Audio (audio clips) (*n*=8)	1	13
14		Number of decision aids that included information about procedures of treatments	21	100
		Methods used to communicate this information:		
15		Verbal (text)	21	100
16		Visual (illustrations)	14	67
17[a]		Audiovisual (video clips) (*n*=11)	4	36
18[a]		Audio (audio clips) (*n*=11)	1	9
19		Number of decision aids that presented the information in a balanced and unbiased way	2	10
		Methods used for balanced and unbiased information:		
20		Uses roughly the same amount of text for each option	12	57
21		Displays statistics in the same way for each option (*n*=16)	5	31
22		Uses similar fonts for each option	21	100
23		Uses language that is not biased in favor of a specific option	16	76
24		Presents equal number of positive features of each option (*n*=20)	9	45
25		Presents equal number of negative features of each option (*n*=20)	4	20
26		Keeps the order of positive and negative features constant (*n*=20)	17	85
27	Information control	The decision aid allows for patients to only receive information that they want to read	9	43
28		The decision aid provides a step-by-step way to move through the decision aid	18	86
29		The decision aid provides the patient the opportunity to read more about a specific topic of interest	16	76
30		The decision aid provides access to external sources	16	76
31		The decision aid provides access to internal sources	11	52
32		The decision aid allows for patients to search for key words	5	24
33[a]		The decision aid makes it easy for patients to return to previous parts of the decision aid (*n*=11)	11	100

Table C1 | Continued.

Item	Aspect	Item description	*n*	%
34	Personalized information	Tailoring in general towards type of treatment	7	33
35		Tailoring in general towards specific populations	3	14
36		Tailoring in general towards disease factors	4	19
37		Tailoring in general towards breast cancer stage	14	67
38		Probability tailoring	2	10
39		Content tailoring	5	24
40		Mode of presentation tailoring	3	14
41	Interaction	Number of decision aids that help patients to consider personal values and preferences	20	95
		Methods used to consider or assess values and preferences (*n*=20):		
42		Passive		
		Asks patients to think about their values and preferences	20	100
		Active		
43		Weighting exercises	12	60
44		Sliders to assign values to preferences	9	45
45		Number of decision aids that help allow for comparison of positive and negative features of treatment options	20	21
		Methods used to compare positive and negative features of options (*n*=20):		
46		Ranking or rating scale	6	30
47		Table to compare positive and negative features	17	85
48		Verbal comparisons	18	90
49		Conjoint analysis / Visual analogue scale	2	10
50		Number of decision aids that provide patient the most suitable treatment option	3	14
		Methods used to provide feedback:		
51		The decision aid shows the progress of the decision aid	12	57
52		The decision aid provides patients a summary of their values and lll preferences	12	57
53		The decision aid permits printing as a single document	17	81
54		The decision aid provides space for note taking	10	48
55		The decision aid includes a short knowledge test	8	38

Table C1 | Continued.

Item	Aspect	Item description	*n*	%
56	Accessibility of information	The decision aid is freely available on the web	16	76
57		The decision aid requires a login code	5	24
58		The decision aid is purely computer based	11	52
59		The decision aid requires access to internet for its use	11	52
60		The decision aid reports last update	13	62
61		The decision aid reports update frequency	2	10
62		The decision aid requires staff assistance	6	29
63		The decision aid is self-administered	20	95
64		The decision aid can be used on multiple devices	20	95
65	Suitability of information	The decision aid contains less than 10 (web) pages	5	24
66[a]		The decision aid contains videos with a length of less than 1 minute (*n*=6)	1	17
67		The decision aid has a conversational (writing) style	19	90
68		The decision aid has irrelevant illustrations	6	29
69	Source of information	Number of decision aids that mentioned on which datasets the probabilistic information are based on (*n*=18)	5	28
		Types of datasets (*n*=5):		
		Observational data	2	40
		Randomized controlled trials data	1	20
		Patient reported outcomes data	1	20
		Data combined from different studies	1	20
		Types of outcome probabilities reported by the decision aid (*n*=18):		
70		Mortality rate / Survival rate	5	28
71		Incidence rate / Progression free survival	12	67
72		Treatment side effects	12	67
73		Quality of life	4	22
		Type of information about the data(sets) provided by the decision aid (*n*=5):		
74		About what scale the patient data have been collected	1	20
75		About the number of patients on which the data are based on	3	60
		About characteristics of patients on which the data are based on		
76		About the period of time of data collection	3	60

Note. [a] This item does not apply to paper-based decision aids.

PART 2

Assessing patient needs and preferences

What to communicate in what form to whom?

4

Exploring cancer survivor needs and preferences for communicating personalized cancer statistics from registry data: A qualitative multimethod study

This chapter is based on:

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Pauws, S. C.,
van de Poll-Franse, L. V.,
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Exploring cancer survivor needs and preferences for communicating personalized cancer statistics from registry data: Qualitative multimethod study. JMIR Cancer, 2021; 7(4): e25659.

ABSTRACT

Background: Disclosure of cancer statistics (e.g., survival or incidence rates) based on a representative group of patients can help increase cancer survivors' understanding of their own diagnostic and prognostic situation, and care planning. More recently, there has been an increasing interest in the use of cancer registry data for disclosing and communicating personalized cancer statistics (tailored toward personal and clinical characteristics) to cancer survivors and relatives.

Objective: The aim of this study was to explore breast cancer (BCa) and prostate cancer (PCa) survivor needs and preferences for disclosing (what) and presenting (how) personalized statistics from a large Dutch population-based data set, the Netherlands Cancer Registry (NCR).

Methods: To elicit survivor needs and preferences for communicating personalized NCR statistics, we created different (non)interactive tools visualizing hypothetical scenarios and adopted a qualitative multimethod study design. We first conducted 2 focus groups (study 1; $n = 13$) for collecting group data on BCa and PCa survivor needs and preferences, using noninteractive sketches of what a tool for communicating personalized statistics might look like. Based on these insights, we designed a revised interactive tool, which was used to further explore the needs and preferences of another group of cancer survivors during individual think-aloud observations and semi-structured interviews (study 2; $n = 11$). All sessions were audio-recorded, transcribed verbatim, analyzed using thematic (focus groups) and content analysis (think-aloud observations), and reported in compliance with qualitative research reporting criteria.

Results: In both studies, cancer survivors expressed the need to receive personalized statistics from a representative source, with especially a need for survival and conditional survival rates (i.e., survival rate for those who have already survived for a certain period). Personalized statistics adjusted toward personal and clinical factors were deemed more relevant and useful to know than generic or average-based statistics. Participants also needed support for correctly interpreting the personalized statistics and putting them into perspective, for instance by adding contextual or comparative information. Furthermore, while thinking aloud, participants experienced a mix of positive (sense of hope) and negative emotions (feelings of distress) while viewing the personalized survival data. Overall, participants preferred simplicity and conciseness, and the ability to tailor the type of visualization and amount of (detailed) statistical information.

Conclusions: The majority of our sample of cancer survivors wanted to receive personalized statistics from the NCR. Given the variation in patient needs and preferences for presenting personalized statistics, designers of similar information tools may consider potential tailoring strategies on multiple levels, as well as effective ways for providing supporting information to make sure that the personalized statistics are properly understood. This is encouraging for cancer registries to address this unmet need, but also for those who are developing or implementing personalized data-driven information tools for patients and relatives.

INTRODUCTION

In cancer care, many newly diagnosed patients and survivors prefer disclosure of cancer statistics and prognostic information[1–4]. For instance, patients may wish to receive information about the chances of surviving the disease (survival data), whereas others are in need of knowing the exact number of people who are diagnosed with the same type of cancer (incidence data). Such cancer statistics are increasingly being presented on the internet through various sources, such as general cancer websites for both patients and relatives[5] and healthcare professionals[6], but also in decision-support tools such as patient decision aids[7] or publicly available prediction models[8]. Cancer statistics may help increase patients' understanding of their own diagnosis, prognosis, and involvement in different stages of the shared decision-making process (e.g., option talk stage) with their clinician[9,10]. Moreover, both patients and healthcare professionals may use cancer statistics to start a conversation about complex health topics such as survival or cancer recurrence, and to discuss its role in making a decision about treatment[11]. It is therefore important that patients, relatives, and healthcare professionals have access to representative and reliable cancer statistics about topics that could contribute to informed decision making and advance care planning.

However, current cancer statistics are typically generic and population based[12–14], thereby making it hard for patients to apply the numbers to their own individual situation[15]. For instance, when a man of 50 years old is diagnosed with prostate cancer (PCa) and is asking about his life expectancy, population-based statistics about survival (which will mostly be based on substantially older men) may be of limited value. In light of the strong movements toward personalized healthcare[16], patient-centered care, and open access of "big health data,"[17,18] there has been an increasing interest in the use of population-based cancer registries for disclosing personalized cancer statistics to survivors and relatives[19]. This allows survivors to be provided with more specific statistical information of certain health outcomes by comparing their own characteristics (e.g., age, gender, type of tumor, tumor stage) with specific patient groups with similar characteristics. An illustrative example of this is the American Surveillance, Epidemiology, and End Results Cancer Survival Calculator (SEER*CSC)[11], which draws on an extensive cancer statistics database for communicating

personalized cancer statistics (cancer incidence, survival rates) in multiple formats to patients via a publicly available web-based tool. Other initiatives that used registry data or other patient-reported data in patient–clinician communication are decision-support tools for estimating personalized health statistics, such as treatment (side) effects or quality of life outcomes[8,20,21]. Given these developments, the question arises, then, what the needs and preferences for communicating personalized cancer statistics are among cancer survivors.

Present study and objectives

In this study, we focus on the disclosure of personalized cancer statistics from the Netherlands Cancer Registry (NCR), a Dutch nationwide population-based registry maintained by the Netherlands Comprehensive Cancer Organisation (IKNL). The NCR records all new cancer diagnoses and contains information about diagnosis (e.g., tumor characteristics), sociodemographic (e.g., age, gender), treatment, and vital status of millions of patients with cancer in the Netherlands since 1989[22], and primarily enables healthcare professionals, policy makers, and others to reflect on and improve cancer care and prevention in the Netherlands. Basic and generic NCR statistics such data on incidence and survival are already being provided through websites of patient organizations, hospitals, and online cancer communities (all aimed at cancer survivors and their relatives), with more detailed NCR statistics according to site, gender, age, and region being available through the web-based tool NKR-Cijfers[6] (aimed at healthcare professionals). Our main project goal is to explore whether important NCR statistics on incidence, survival, and conditional survival could be disclosed via a web-based interactive tool, in which visitors (e.g., patients or relatives) will have the opportunity to enter certain personal (e.g., age, gender) and clinical characteristic (e.g., tumor stage, years since diagnosis), with the aim of receiving personalized statistical information based on real-life patient data with similar characteristics. However, this development raises a number of questions. What types of personalized cancer statistics do cancer survivors want to receive? How should these personalized statistics be presented to patients? What potential barriers or challenges are involved in communicating personalized survival statistics to survivors via a public website? Answers to these questions will not only be useful for the development of a real-life web-based tool for displaying personalized statistics from the NCR to cancer survivors, but also for research groups outside the oncology context working on the design and implementation of similar statistical information tools based on registry or other medical data for patients and relatives.

The purpose of this study is therefore to explore the needs and preferences of breast cancer (BCa) and PCa survivors for communicating personalized cancer statistics from the NCR. Although previous research has shown that most (but not all) patients want to receive prognostic information[1–4,23], it is unclear which pieces of prognostic and statistical information patients wish to receive. Therefore, we first aim to explore

patients' need for prognostic information on a deeper level, and more specifically by investigating what type of personalized cancer risks, statistics, and probabilities patients need to receive from the NCR and other data sources. Furthermore, it is much more difficult for survivors and relatives than for healthcare professionals to translate group-based statistics to their personal situation[24,25]. For instance, some individuals have inherently more difficulties than others in understanding numeric information, even when supported with visual aids, whereas others are experiencing emotions while processing sensitive health data such as survival or mortality rates. Hence, our second aim is to examine how patients want to receive personalized statistics from the NCR. To achieve our aims, we designed different (non)interactive tools to probe participant responses on their needs and preferences.

METHODS

Overview

We conducted a multimethod qualitative study among BCa and PCa survivors (Figure 1). BCa and PCa are among the most prevalent types of cancer among men and women, respectively, which also makes it feasible to calculate personalized statistics based on a subgroup of patient data that is sizeable enough to provide statistically sound and meaningful information. Moreover, in general, the prognostic outcomes are relatively favorable for these 2 cancer types, thereby making it a suitable starting point for our initiative for disclosing personalized cancer statistics. We first conducted 2 focus groups (study 1) for collecting group data on needs and preferences of BCa and PCa survivors for communicating personalized NCR data, using noninteractive sketches of what a tool for communicating personalized statistics might look like. Based on these insights, we designed a revised interactive version of the tool, which was used to further explore the needs and preferences of another group of BCa and PCa survivors during individual think-aloud observations and semi-structured interviews (study 2). We complied with the 32-item Consolidated Criteria for Reporting Qualitative Research (Appendix 1, https://osf.io/s7keu/)[26]. Ethical approval was granted by the Research Ethics and Data Management Committee of the Tilburg School of Humanities and Digital Sciences of Tilburg University (REDC 2019-44).

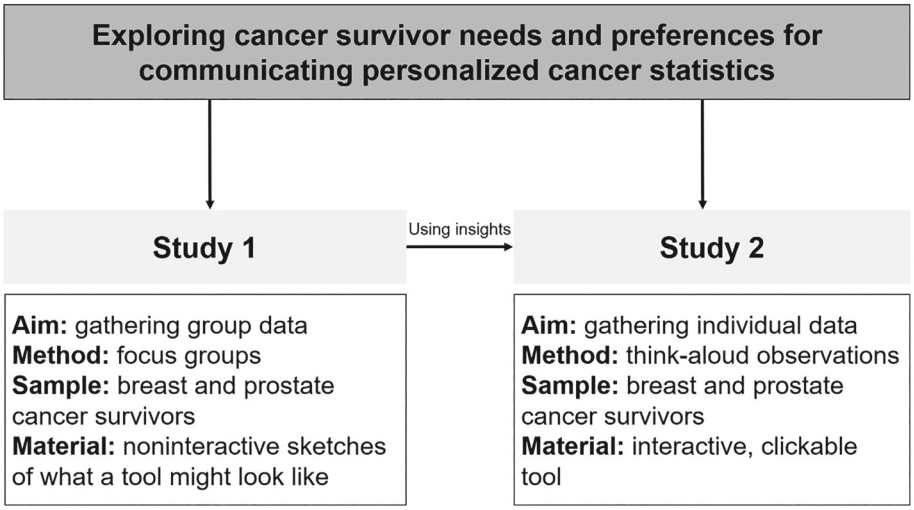

Figure 1 | Overview of studies.

Study 1: Focus groups

To explore cancer survivor needs and preferences for communicating personalized statistics from the NCR, this first study employed 2 separate focus groups (1 with BCa survivors and 1 with PCa survivors). Focus group methodology is particularly useful for exploring people's perceptions, beliefs, opinions, and attitudes about a certain topic[27].

Sampling and recruitment

For the BCa focus group, female participants were recruited from the Dutch Breast Cancer Patient Association (Borstkankervereniging Nederland [BVN]); for the PCa focus group, male participants were identified from the Dutch Prostate Cancer Foundation (Prostaatkankerstichting [PKS]). Participants were included if they were diagnosed with BCa or PCa in the past (at least 1 year after diagnosis). Each eligible participant was approached by email by one of the representatives of the BVN or PKS. Members of our research team did not have any prior relationship with the participants at study commencement, and we were unaware of who from the patient organizations were approached to participate in the focus groups. Participants were reimbursed for their time with a €15 (US $17.4) gift card (unannounced).

Materials

To elicit patients' needs and preferences, we designed noninteractive sketches of what a tool for calculating personalized statistics from the NCR might look like (Appendix 2, https://osf.io/s7keu/). This tool consisted of 3 parts: (1) patient data entry, (2) tumor data entry, and (3) output display. The patient data entry part was the same for both cancer groups (e.g., gender, year of birth), but the tumor data entry part differed between the

2 versions. The PCa version contained items such as year of diagnosis, prostate-specific antigen value, Gleason score (i.e., the aggressiveness of the cancer), and tumor stage (i.e., where the cancer is present in the body). The BCa version contained items such as year of diagnosis, tumor stage, and—in case tumor stage was unknown—metastases (i.e., whether the cancer has spread beyond the breast and nearby lymph nodes to other parts of the body). The output display showed a summary of the patient and tumor characteristics filled out by the patient, followed by the personalized absolute incidence rate of their year of diagnosis, the 5- and 10-year overall survival rate, and the conditional survival rate (i.e., survival rate for those who have already survived for a certain period[28]). All statistics were shown numerically, and the survival statistics were also shown visually in 4 different, conventional ways (i.e., icon array, pie chart, bar chart, and line graphs). Participants could also switch between the 4 types of visualization.

Data collection

We used a semi-structured topic guide for both focus groups to facilitate discussion and elicit participants' needs and preferences for the disclosure and presentation of personalized statistics from NCR data. After a round of introduction, we first explained the purpose of the project and the NCR to the participants. We then asked them to what extent they were in need of receiving the (NCR) statistics incidence, survival, and conditional survival rates in a personalized way, either at their time of diagnosis or at a later moment. After this, we posed a final question by asking what other personalized statistics they were interested in after diagnosis and treatment. During the second part of the discussion, we showed participants sketches of what such a tool could look like (Appendix 2, https://osf.io/s7keu/). Participants were asked to take a critical look at each slide and provide comments about the tool. They were also encouraged to express their needs and preferences regarding the information presented in the data entry part and the output display of the tool.

The PCa focus group was moderated by RV (male, PhD-candidate, risk communication scientist), MvE (female, health communication scientist with expertise in qualitative research), and GG (male, PhD, with expertise in clinical data science), and the BCa focus group by RV and MvE. The moderators were not known to the participants. Both focus groups lasted 90 minutes and were conducted at the IKNL in Utrecht (The Netherlands) in November 2018 (PCa focus group) and March 2019 (BCa focus group). Field notes were taken in each focus group by RV.

Data analysis

Qualitative data obtained from the focus groups were audio-recorded (with permission of the participants), transcribed verbatim, and analyzed thematically[29]. For this, we developed a deductive coding scheme based on the study objectives, discussion guide, and focus group content. First, 2 investigators (RV and MvE) developed a preliminary conceptual schema and codebook by independently reading the focus

group transcripts. The codebook was designed to capture broad coding categories of needs and preferences for (1) disclosing different types of personalized statistics, and (2) presenting personalized statistics. Then, both investigators independently coded each transcript using MAXQDA 2020 (Verbi Software)[30], and disagreements were resolved through discussion. Finally, both investigators jointly generated a report from the coded transcripts by format to identify themes. Quotes for supporting (sub) themes were translated into English.

Study 2: Think-aloud observations

Overview

A think-aloud methodology was used to further assess the needs and preferences of another group of cancer survivors for communicating personalized statistics from the NCR. This involved asking participants to verbalize their thoughts, impressions, and feelings while working with a revised, clickable, and interactive version of the tool to calculate personalized cancer statistics[31]. These revisions were based on input from cancer survivors participating in the focus group (study 1). Semi-structured interview techniques were used to allow participants to elaborate on their statements and experience with the tool, and to put them into context. The semi-structured interviews also allowed us to capture participant preferences for a specific presentation format in case the think-aloud observations would not cover this information[32].

Sampling and recruitment

Eligible participants were recruited from the same 2 patient organizations (BVN and PKS) as the first focus groups, and from a Dutch online cancer community (Kanker.nl). Participants were included if they (1) were diagnosed with BCa or PCa in the past (at least 1 year after diagnosis), and (2) had not participated in the focus groups before. The recruitment procedure was identical to the focus groups, meaning that the members of our research team did not have any prior relationship with the participants at study commencement, and we were unaware of who from the patient organization or online cancer community were approached to participate in the think-aloud observations. Participants were reimbursed for their time with a €15 (US $17.4) gift card.

Materials

We designed a clickable interactive version of the tool (for screenshots, see Appendix 3, https://osf.io/s7keu/), which allowed participants to manually enter patient and tumor characteristics, to view the associated personalized statistics, and to modify the type of visualization (i.e., icon array [as a default option], pie chart, bar chart, and line graphs) according to their preference. Based on the input from cancer survivors during the focus groups on the sketches of the tool, the following revisions were made. First, the interactive tool now started with a supporting page, including statements

such as that the statistics may contain good or bad news (taking emotional aspects into account), that the statistics were based on prior patients (taking contextual information into account), and that we could not provide exact estimates for each individual patient (taking uncertainty into account). Second, the data entry part contained explanations in plain language about certain tumor characteristics (e.g., Gleason score or tumor stage). Third, the output display was kept the same, except that we now included comparative information by providing both generic, population-based survival statistics and the personalized survival statistics altogether. Fourth, and finally, to take the survivors' preference of amount of information into account, we created 2 tool versions: (1) a short, concise version and (2) a long, detailed version. The short version only provided the raw statistics and the minimally required explanation of the statistics on the output display, which was all presented simultaneously (Figure 2). The long version contained more textual information and gave users the option to expand texts when supplementary information was needed or to see information visually (Figure 3).

All screens of the interactive tool were created using Adobe Illustrator CS6, and the tool was developed and implemented using InVision, a digital product design platform[33].

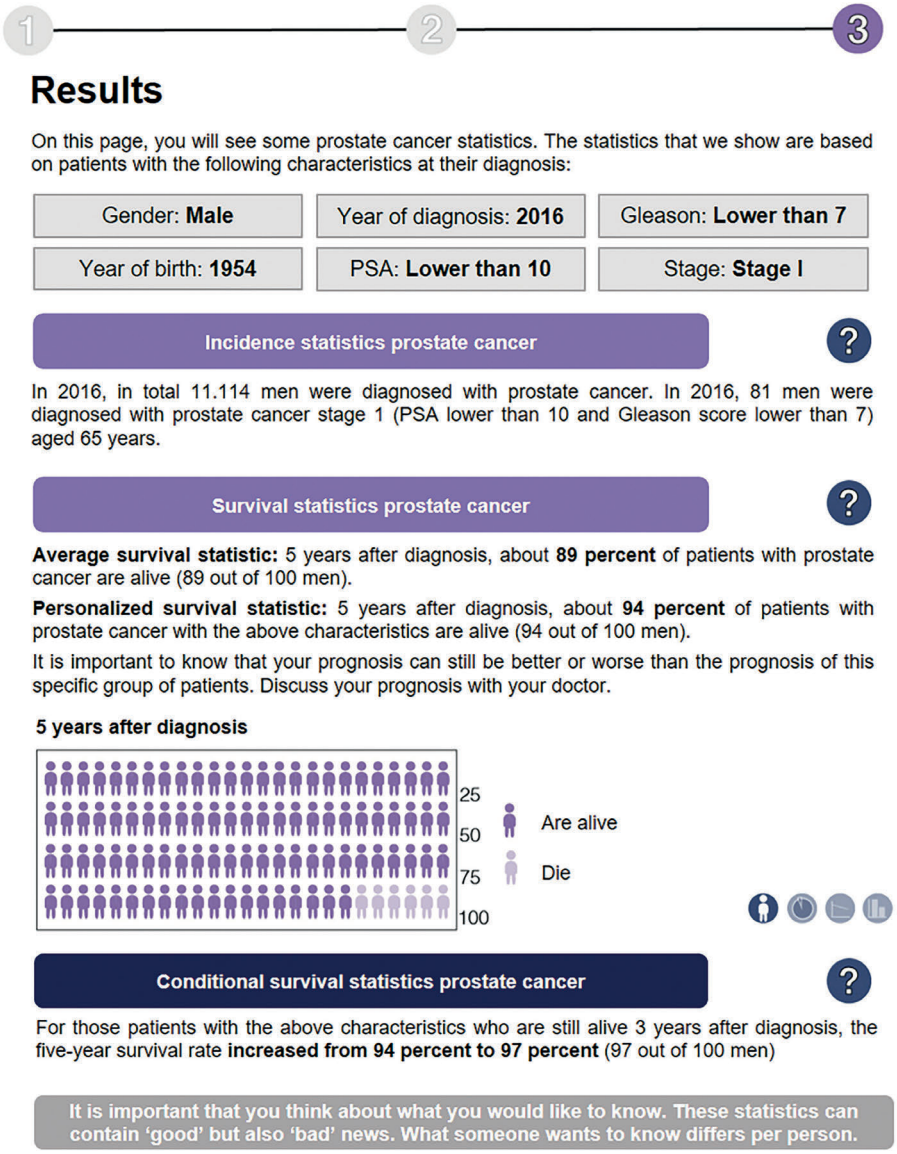

Figure 2 | Example of the output display (translated to English) in the short (concise) version of the interactive tool, communicating a favorable survival rate to PCa survivors. All information is presented at the same time. PCa: prostate cancer.

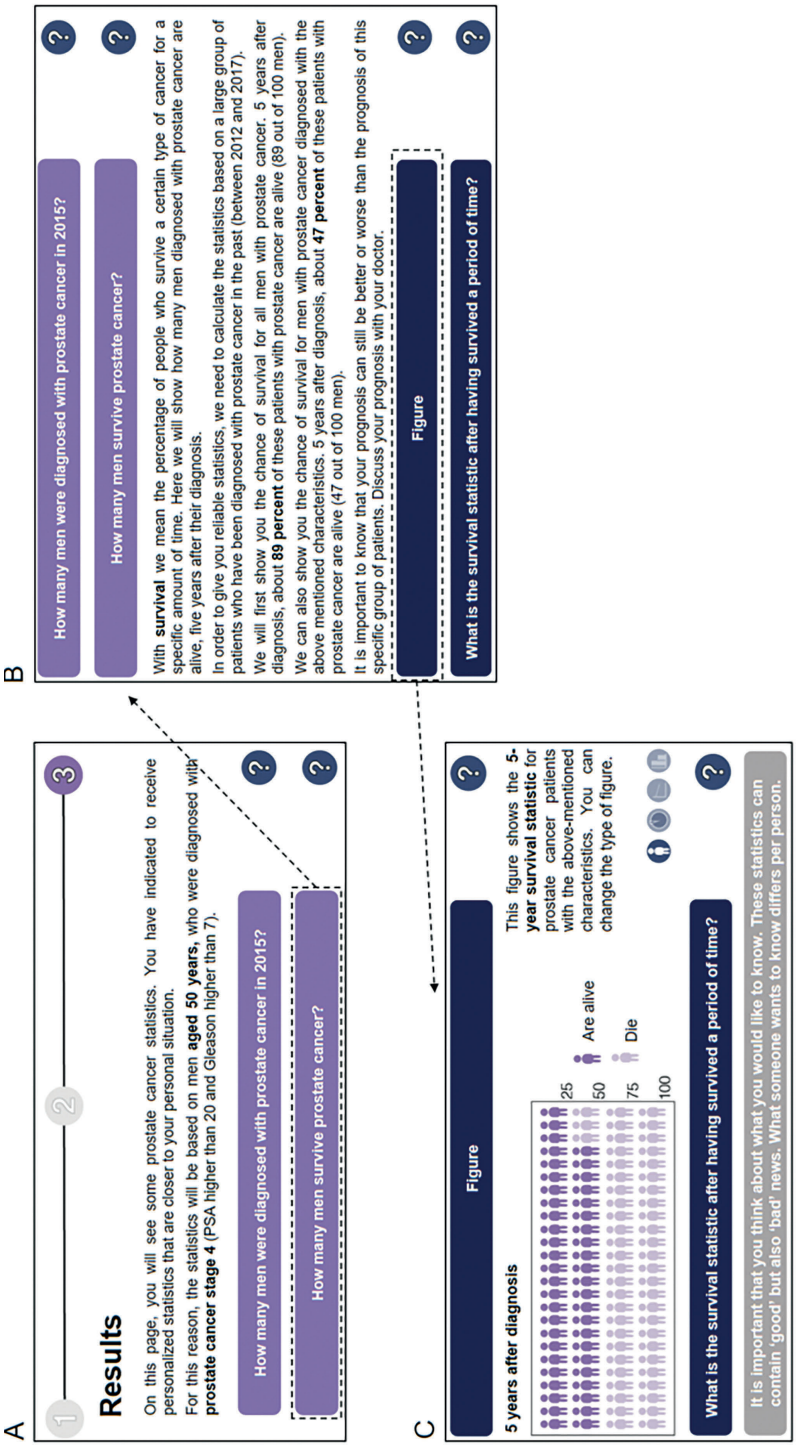

Figure 3 | Example of the output display in the long (detailed) version of the interactive tool, communicating a less favorable survival rate to PCa survivors. Participants started at the left top figure (A), and could decide what type of information they wished to see (B, C). PCa: prostate cancer.

Data collection

Each session started with an explanation of the procedure, signing informed consent, and a questionnaire that assessed sociodemographic information (age, gender, education, work, marital status, and children) and disease-related information (year of diagnosis, type of cancer). Participants were then instructed on how to think aloud. Participants were then asked to enter information into the tool and to view the results using 2 hypothetical case examples: (1) a patient with a favorable 5-year overall survival rate (89% for the BCa group and 94% for the PCa group), and (2) a patient with a less favorable overall 5-year survival rate (38% for participants with BCa and 47% for participants with PCa). Participants with PCa history would use a PCa case, and participants with BCa history would be presented with a BCa case. The case examples contained patient and disease-related information about 2 hypothetical patients[11]. We informed them that this may evoke some unpleasant memories/thoughts related to participants' own cancer (diagnostic) situation. Therefore, participants were told that (1) they always have the opportunity to withdraw their participation whenever they want to, without any negative consequences, and without providing any explanation; (2) the hypothetical personalized statistics used in this study were not real. In addition, because participants might feel anxious about reflecting on their diagnostic situation, they were referred to an online expert therapist of Kanker.nl who is specialized in dealing with cancer-related anxiety.

One case example was performed using the short version of the tool, and the other with the long version of the tool. The order and combination of the tool version with the case scenario were randomized and counterbalanced across participants. While entering the information and viewing the statistics, participants were instructed to think aloud. Prompts were used when participants fell silent (e.g., "Keep talking?"), and reassuring sounds were made to enhance thinking aloud (e.g., "Uhuh")[34].

After the think-aloud session, we conducted a semi-structured interview to provide participants with the opportunity to elaborate on statements made during the think-aloud sessions, and to further capture participants' preferences for communicating the statistics. For this, we used a semi-structured topic guide (Appendix 4, https://osf.io/s7keu/). At the end of the sessions, participants were debriefed and informed about the full purpose of the study.

The think-aloud sessions and semi-structured interviews were led by 2 interviewers, RV and a research assistant (female, research assistant in communication science with expertise in new media design). Both interviewers were not known to the participants. The sessions lasted between 21 and 67 minutes (average duration 44 minutes), and were performed at either the IKNL (in Amsterdam, Rotterdam, Utrecht, or Eindhoven) or at the participants' home. Data were collected in April and May 2019. Field notes were taken from each session by RV.

Data analysis

All think-aloud sessions and semi-structured interviews were audio-recorded (with permission of the participants), transcribed verbatim, and analyzed using content analysis[35]. For this, 2 investigators (RV and MvE) developed a deductive coding scheme based on the interview guide (Multimedia Appendix 3) and the themes and subthemes that emerged from the thematic analysis of the focus group study. The same investigators then independently coded 4 transcripts, and resolved disagreements through discussion. The remaining 7 transcripts were then coded by RV. All coding activities were performed using MAXQDA 2020 (Verbi Software)[30]. Quotes for supporting the findings were translated into English.

RESULTS

Patient characteristics

Characteristics of participants in the 2 focus groups (n for the BCa group = 9 females; n for the PCa group = 4 males) and 11 think-aloud sessions (n for the patients with BCa = 7 females; n for the patients with PCa = 4 males) are summarized in Table 1. In both groups, there were more BCa survivors than PCa survivors (69% and 64%, respectively). The participants in both groups were comparable in terms of sociodemographic and disease-related characteristics (all *p*s >.200), except for the distribution of year since diagnosis ($p = .033$), with more recently diagnosed survivors in the think-aloud group.

Table 1 | Participant characteristics for the focus groups and think-aloud observations.

Characteristics	**Study 1 Focus groups (*n* = 13)**	**Study 2 Think-aloud observations (*n* = 11)**
Gender		
Female	9	7
Male	4	4
Age at time of study, mean (SD)	59.8 (10.9)	57.1 (10.3)
<50 years	3	2
50-65 years	6	6
>65 years	4	3
Education		
Secondary education or practical education	2	4
College or applied university	6	4
University	5	3
Type of cancer		
Breast cancer	9	7
Prostate cancer	4	4
Year since diagnosis, median	9	4
0-5 years	4	7
6-10 years	3	4
>10 years	6	0
Work situation		
Work	4	5
Ill (insurance)	2	0
No work/retired	7	6
Marital status		
Married/partner	10	6
No partner	3	5
Children		
No	3	4
Yes, living with	4	2
Yes, living somewhere else	6	5

Study 1: Focus groups

Themes identified

Three themes were identified from the focus group data (Figure 4): (1) the need for personalized statistics, (2) the need for interpretation support, and (3) preference for information presentation. Subthemes are introduced below within each of the main themes' sections.

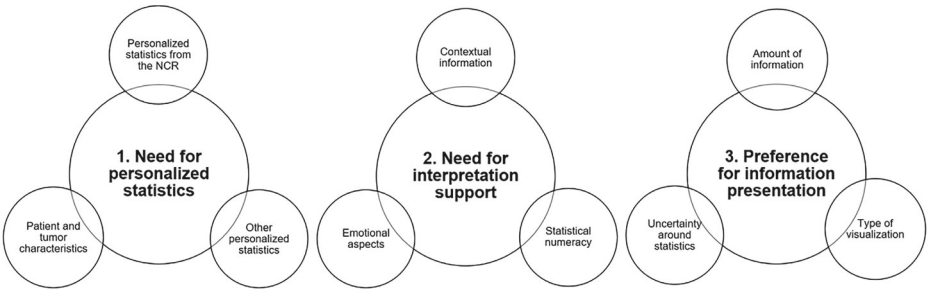

Figure 4 | Schematic representation of themes and sub-themes identified from the focus group data. NCR: Netherlands Cancer Registry.

Theme 1: Need for personalized statistics

Participants reported the needs for receiving personalized statistics from the NCR as well as other personalized statistics, and also on how to establish this by taking several patient and tumor characteristics into account.

Personalized statistics from the NCR. All participants found the (5- and 10-year) survival rate the most important statistic from the NCR. However, at their time of diagnosis, participants wanted to know their personalized survival chance based on their own situation. Participants mentioned that a personalized survival rate seems more relevant and useful to know than the generic or average survival rate, and that characteristics such as tumor stage and lymph nodes involvement could have a significant impact on survival rates.

> *"You really want to know your personalized survival chances for your own type of cancer. So, if you are having a T4-stage cancer, you want to know the survival rate for that specific situation." [P04, aged 71 years]*

For the personalized incidence rate, participants found this type of information to be important, especially because this may help them know how many other patients like them have this specific disease and whether it is something rare or not. Being aware

of the high or low incidence rate could also "help patients to see where they are in the bigger picture" [P04]. However, there were also participants who did not really see the added value of this statistic, especially because they already had been diagnosed with cancer and cannot really change this diagnosis.

> *"You have already been diagnosed with breast cancer. So, what does it matter that other people also have breast cancer?" [B04, aged 55 years]*

Finally, when showing personalized conditional survival rates, participants with BCa and PCa both initially found the term difficult to understand and rather confusing. However, after explaining the concept in more detail and showing them what it might look like in the tool, participants agreed that this type of statistical information might be useful to communicate. Participants mentioned that communicating the personalized conditional survival statistic "can be very reassuring and psychologically beneficial for patients" [P3]. Another participant said:

> *"For instance, in the case of triple-negative for breast cancer, after having survived the first three years, your survival chance increases enormously! This could be very interesting and important to communicate [to patients]." [B03, aged 57 years]*

Other personalized statistics. Participants' need for disclosing other personalized statistics based on NCR or other data sets spanned a broad range. Participants expressed a need for receiving information about personalized risks of treatment outcomes, such as the likelihood of experiencing treatment side effects.

> *"I would have liked to know my [personalized] risk of experiencing a side effect after treatment, and whether this risk would change over time or not." [P01, aged 72 years]*

Moreover, participants reported the need for personalized statistical information about cancer recurrence, risk of cancer in the family, and impact on quality of life such as physical, cognitive, and psychosocial functioning. Furthermore, participants with BCa in particular wanted to receive statistics on the chances of getting metastatic cancer, whereas participants with PCa specifically expressed a need for treatments chosen by other patients with PCa over time and performance statistics of different hospitals.

Patient and tumor characteristics. Participants had several comments on the characteristics that patients should fill out, and simultaneously expressed their need for extending this with other patient and tumor features. In both groups, participants voiced concerns about asking for a patient's tumor stage, because most of the participants were unfamiliar with the term.

"Based on my education materials from 2012, I can see that I received information about tumor grade and HER2, but not about my tumor stage." [B04, aged 55 years]

Moreover, for the metastatic feature, patients found it important to indicate whether the tumor had spread to the lymph nodes or to other parts of the body. Participants therefore suggested providing clear explanations of the patient and tumor characteristics. Additional features proposed by the PCa survivors were information about a person's health status and information about comorbidity. Additional features requested by BCa survivors were tumor grade, HER2 status, and specific types of BCa such as triple negative. Finally, both groups asked for a feature dealing with a person's family history of cancer (i.e., genetics).

Theme 2: Need for interpretation support

Both PCa and BCa survivors identified challenges that could hinder the correct interpretation of the personalized cancer statistics by future users, and expressed the following needs for supporting patients with this.

Contextual information. Both groups of participants expressed their wishes to see supplementary information that should accompany the personalized statistics. For instance, they commented that the current survival rates are actually better than those that were displayed by the tool, because patients with newly diagnosed cancer can benefit from advances in treatment options.

"It is important to mention that all statistics here are about the past and are based on former treatment options. You should really communicate this to users…So the current statistics can only be more positive." [B01, aged 50 years]

Furthermore, some BCa survivors thought that providing comparative information such as the chance of 10-year cancer recurrence related to the chance of getting cancer for the first time. Similarly, the participants with PCa stated that the 5- and 10-year survival statistics for patients with cancer should be placed in context by comparing them with the survival rates of people who do not have cancer.

"Providing the survival rate for the norm population would be very useful. The survival rate of the normal population isn't that great as well. If I see a 10-year survival rate of 21 percent for PCa patients [with stage 4], what does this 21 percent mean, and how does it compare [to the normal population]?" [P03, aged 67 years]

Statistical numeracy. Several participants expressed their concerns about communicating personalized statistics to patients with low health or numeracy skills. They considered it important to explain that the personalized survival rates are still

average statistics, and that supplementary information is highly needed especially for those patients who are lacking prior knowledge in statistics.

> *"It is important that these statistics are not communicated in a scientific manner, but instead in a way that is understandable for those who do not have a background in statistics." [P02, aged 79 years]*

Emotional aspects. Participants emphasized the importance of taking emotional aspects such as anxiety into account that may be evoked by viewing information about survival rates. Especially in the scenario with the less favorable survival statistic, some participants found the information shocking and uneasy to see and offered suggestions for adding warning statements about this.

> *"I think it would be a good idea to advice people to see this information together with someone else. I could imagine that some people may find this [statistical] information emotionally difficult to interpret…Something like a disclaimer." [B05, aged 41 years]*

However, other participants did not experience this, and felt that disclosing personalized statistical information via this tool is of utmost importance for those who need it to become well informed, even though the statistics could be bad and provoke negative emotions. They felt that this would not destroy patients' hope, but instead would create a more realistic picture.

> *"Those people who want hope will not read this [personalized statistical information]. I think that if you have the [statistical] information, it should become available for everyone." [B01, aged 50 years]*

> *"I have searched for statistical information all night long. Having that knowledge [statistical information] makes me feel calm." [B06, aged 63 years]*

Theme 3: preference for information presentation

While viewing the tool, participants reported their preferences for presenting the personalized cancer statistics in terms of type of visualization, amount of information, and uncertainty around statistics.

Type of visualization. Regarding the different types of visualization that we used for communicating the survival rates, almost all PCa and BCa survivors expressed a preference for the icon arrays. However, 1 participant with PCa commented that the icon arrays increased levels of anxiety because "they seemed too personal" [P03]. Overall, participants found the option to switch between different types of visualization valuable and helpful.

Amount of information. In both groups, participants shared their views on whether we should give users a conscious choice of what information they would like to see, for instance, by giving them the option to expand texts when supplementary information about specific terms or statistics is preferred. Some participants argued that this would then satisfy both users who want detailed or supplementary information about the statistics and users who want to see as little as possible. This was also true for showing the visualizations by default, or providing patients the option to decide for themselves whether they want to see the information visually or not.

> *"I was thinking of the graphic. Do you always want to show this to all patients, regardless of the type? You could also first show them the textual information, and then give them the option to view the information in a graphic, and which type of graphic. Because…what if the survival rate turns out to be very low. Then the icon arrays can very confrontational." [B01, aged 50 years]*

Uncertainty around statistics. Not all participants were aware of the imprecision of the statistics (i.e., epistemic uncertainty), and they had conflicting views on whether or not we should disclose and communicate this. Some participants thought it might be too difficult and confusing to communicate, whereas others stated it may help patients understand that the statistics are less reliable and could be no more than an indication of what could happen. The participants with BCa showed a preference for communicating this kind of uncertainty only when calculating survival rates for small groups (e.g., patients with BCa with triple-negative), or when the statistics were relatively poor (e.g., less favorable survival rate). As one BCa survivor put it:

> *"Here [sees a 5-year survival rate of 44% for a stage 4 BCa patient] you want to know the variation, because it may give the patient hope. If you have a poor statistic, but you see that the range is big, then you may think that you could still be on the positive side of the range. Whereas if you have a good statistic, then providing a range becomes less relevant." [B03, aged 57 years]*

This concludes the findings of the focus groups. In the next section, we will discuss the results from the think-aloud observations, which allow us to get a better insight into what cancer survivors might actually think and feel when confronted with personalized cancer statistics.

Study 2: Think-Aloud Observations

Overview

The results of the think-aloud observations are presented below, structured around the 3 main themes that were identified from the focus group data (need for personalized statistics, need for interpretation support, and preference for information presentation). Table 2 displays an overview of the main results obtained during the think-aloud observations.

Need for personalized statistics

Overall, most participants (*n* = 9) mentioned that receiving the personalized survival rate was very valuable, of which 7 mentioned that they would use this tool after their diagnosis, and 2 only after a few years after diagnosis. Participants showed less interest in the information about cancer incidence, and 3 were even surprised by the personalized incidence rate, because they expected this statistic to be much higher. Similar to the focus group study, almost all participants (*n* = 10) greatly appreciated the conditional survival rates, especially when initially being confronted with a less favorable survival rate. As participants put it, while thinking aloud:

> *"Well, I think this [conditional survival rate] is very valuable… Indeed, if you have survived some years after diagnosis, you are no longer part of the group of patients that died, so from that moment your chances of survival increase enormously. [B03, aged 45 years]"*

> *"Yes, I get it. The survival rate increased from 47 percent to 87 percent. Well, then I am a real survivor! 87 out of 100 men, that's high, isn't?" [P01, aged 68 years]*

However, similar to the focus group, 6 participants expressed their need for adding more clinical characteristics and treatment history to the tool for better personalizing the statistics.

Need for interpretation support

All participants found the supporting statements at the start of the tool very helpful and important, as they may help users become better prepared for receiving and interpreting the statistics. However, 3 participants explicitly mentioned that we should not use labels by telling users that the numbers they will see will be good or bad news. One participant commented, while thinking aloud:

> *"I do not think that you can decide for someone else whether something is good or bad news. That is not up to you. It is also relative. I mean, if you see this [survival rate] you may think it's good news, but I may think it's bad news." [B05, aged 50 years]*

The same participant offered suggestions for replacing "good or bad news" with "favorable or less favorable than expected" [B05].

Participants also experienced and expressed a mix of positive and negative emotions while viewing the personalized statistics. The majority of the participants (*n* = 9) expressed positive emotions such as a sense of hope, while viewing the conditional survival rates (*n* = 8), or the favorable survival rate. However, 7 participants were "shocked" or felt "uneasy" when seeing the less favorable survival rate in comparison with the favorable generic survival rate. Those participants were surprised that so few people would survive after 5 years with these specific characteristics.

> *"Oh god, this [less favorable personalized survival rate] is still after five years. Well this number is very different from the generic statistic [generic, population-based survival rate]. Pff, that really sucks!" [B02, aged 60 years]*

Nevertheless, participants found it important to disclose the less favorable survival rates as well to create a realistic and fair picture. Some patients (*n* = 5) found that emotions should be taken into account, but at the same time commented that those who do not want to see the personalized statistics will not visit the tool.

> *"I did not experience any feelings, but I am also a rationally and realistically oriented person. I know some women who don't want to see this kind of information, but the question is whether they will look for these statistics at all." [B03, aged 45 years]*

Furthermore, participants had mixed views on the comparative information between the personalized and generic, population-based statistics. This view typically depended on whether the personalized survival rate was above or below the generic statistic. Some participants (*n* = 5) found the less favorable survival rate confronting when it was shown in comparison with the favorable generic survival rate. However, when participants' personalized survival rate was higher than the average, others (*n* = 5) thought it was supportive:

> *"The [generic] survival rate is 89 percent… Oh well, that is a lot. Survival rate for patients with the above characteristics is 94 percent. Okay, so my prognosis is better than the average [prognosis]. Well that's good news." [P03, aged 60 years]*

> *"This [seeing both personalized and generic survival rate] is fine, and seems like an added value to me. This way, you can see whether you are below or above the average survival rate." [P04, aged 69 years]*

Participants further expressed concerns about terminology used in the tool. For instance, 7 participants were not familiar with the term "tumor stage," but rather with alternative features such as TNM stage or the presence of metastases or not. Participants further recommended to avoid complex terms such as "incidence" or "conditional survival" (Figure 2), and preferred the tool version in which these terms were explained in plain language (Figure 3).

Preference for information presentation

Participant preferences for visualizing the personalized survival rates were in line with those of participants in the focus group, with the majority preferring icon arrays ($n = 6$), followed by pie ($n = 4$) and bar charts ($n = 1$). However, participant reactions to the "human aspect" of the icon arrays varied, with some appreciating the pictographs since the survival rates are about people, while others expressed concerns that they were too confronting. Despite this variation in preferences and (emotional) reaction, most participants appreciated the function of tailoring the type of visualization ($n = 8$).

> *"I didn't like to be confronted with this figure [icon array], because 38 percent [chance of survival]...Here you should have the option to switch between figures. When the percentage was displayed by means of a pie chart, I experienced it as less shocking than when it is presented with pictographs. I think here you should be able to make a choice in how you want to see it." [B01, aged 54 years]*

Furthermore, regarding the amount of information, most participants preferred the short and concise result page of the tool ($n = 10$). Participants typically commented that they primarily used the tool to see statistics and survival rates as soon as possible, and therefore expected to see numerical information rather than large pieces of text. Almost half expressed a preference for tailoring the amount of information and expanding the text for certain topics (e.g., complex terms, supplementary information about the NCR) if desired ($n = 5$). Again, this was mostly preferred by participants who were shocked by the less favorable survival rates. Finally, 5 participants appreciated the verbal descriptions of uncertainty around the statistics that we presented as part of the supporting statements, and 2 participants wanted to see confidence intervals.

Table 2 | Overview of statements made by participants during the think-aloud sessions (*n* = 11).

Item	*n* (%)
Need for personalized statistics	
Mentioned that receiving personalized survival rate is valuable.	9 (82)
Showed less interest in (personalized) incidence rate	11 (100)
Appreciated the conditional survival rates	10 (91)
Wanted more clinical characteristics and treatment history for specifying statics even further	6 (55)
Need for interpretation support	
Found the supporting statements helpful and important	11 (100)
Would not recommend using verbal labels for interpreting statistics (e.g., to tell patients they will receive "good or bad" news)	3 (27)
Experienced positive emotions (e.g., sense of hope) while viewing the personalized statistics	9 (82)
Experienced negative emotions (e.g., shocked) while viewing the personalized statistics	7 (64)
Mentioned that both favorable and unfavorable personalized statistics should be disclosed	11 (100)
Found comparative information confronting when their personalized statistics were below average	5 (45)
Appreciated comparative information when their personalized statistics were above average	5 (45)
Preference for information presentation	
Preferred icon arrays for displaying personalized survival rates	6 (55)
Preferred pie charts for displaying personalized survival rates	4 (36)
Preferred bar charts for displaying personalized survival rates	1 (9)
Appreciated the function of tailoring the type of visualization	8 (73)
Preferred a short and concise result page	10 (91)
Expressed a preference for tailoring the amount of information	5 (45)
Appreciated verbal descriptions of uncertainty around personalized statistics	5 (45)
Wanted to see confidence intervals along with the personalized statistics	2 (18)

DISCUSSION

Principal findings

This study aimed to explore needs and preferences of cancer survivors for communicating personalized statistics from a Dutch nationwide population-based registry, the NCR[22]. We developed different versions of a tool that allows patients to enter personal and disease-related characteristics for determining personalized incidence, survival, and conditional survival rates. We applied a qualitative multimethod study approach, by collecting group data through focus groups and individual data via think-aloud observations combined with semi-structured interviews.

Our study suggests that the majority of our selective sample of cancer survivors (in both the focus group study and think-aloud sessions) have a desire to receive personalized cancer statistics. Survivors expressed an overarching desire for especially receiving tailored survival rates and conditional survival rates; they showed less interest in the personalized incidence rate, but they still thought it could be useful for some patients. Overall, the majority expressed intention to use the tool for viewing personalized statistics, regardless of the outcome. Furthermore, survivors wanted to receive a range of personalized statistics, such as personalized risk information about treatment outcomes (e.g., side effects, survival, recurrence rate, or quality of life). These results support previous findings that most (but not all) patients want detailed and individualized information about their prognostic situation[2–4,36,37], with especially a strong need for personalized (conditional) survival rates and treatment outcomes (e.g., risks of side effects, quality of life, or recurrence rates).

When it comes to communicating personalized statistics to patients, we found that survivors expressed a need for being provided with supporting information that should help correctly interpreting the statistics. For instance, in both focus groups and think-aloud observations, cancer survivors mentioned the importance of adding contextual information (e.g., explaining the influence of treatment on survival over time, providing comparative information including generic, population-based statistics), which should help put the personalized statistics into perspective[38,39]. Next to that, survivors in the focus groups reported that they processed personalized survival statistics emotionally, and were viewing the information under the influence of emotions such as feelings of distress. Indeed, this was captured during the think-aloud observations, in which some participants were confronted by the less favorable survival statistic compared with the favorable generic survival statistic. Reminding or preparing patients about this was found to be helpful, although the use of specific interpretation labels such as “good” or “bad” news were strongly discouraged. At the same time, we observed that the disclosure of conditional survival rates had a positive effect on cancer survivors’ sense of hope, which is in line with previous work on the link between hope and disclosure of prognostic information[36].

Regarding the preference of cancer survivors for presenting the personalized statistical information, participants expressed an overarching preference for simplicity and conciseness. They found it important that the key information (survival rates) was immediately visible to them. Although some participants wished to see more information about the details of the statistics, others did not appreciate this. This challenge of finding a balance between fully informing patients about the statistics while not simultaneously overwhelming them by providing too much information has also been found elsewhere[40,41]. There were survivors who appreciated the option to tailor the amount of information, by extending texts when more detail was preferred[42], or by choosing whether or not one wants to see the visual representation of the survival statistic. Finally, regarding the type of visualization, most participants preferred the pictographs, which is in line with previous research[43], although some found the use of pictographs inappropriate and frightening for communicating survival rates[44]. We further found that the option to switch between different types of visualization was greatly appreciated by our participants, which may therefore solve the variety in presentation preferences among cancer survivors[45].

Strengths and limitations

A strength of this study is that we employed multiple rigorous qualitative methods (focus groups and think-aloud observations combined with semi-structured interviews) that complied with reporting standards[26]. The focus groups (study 1) allowed us to gather group data on cancer survivors' needs, preferences, and perceptions about disclosing personalized cancer statistics, while the think-aloud observations (study 2) revealed spontaneous thoughts and feelings of survivors while being confronted with personalized statistics. At the same time, the think-aloud method has sometimes been criticized regarding its validity and reliability[46,47], as it may be cognitively demanding for participants to complete a task while simultaneously verbalizing their thoughts, opinions, and feelings. However, following previous research[32], we partially tackled this issue by conducting semi-structured interviews after the think-aloud sessions during which participants could elaborate on their verbal statements and experiences with the tool. Even though we conducted all studies with cancer survivors (who have experience with being confronted with a cancer diagnosis), we had to make use of hypothetical case examples instead of participants' own patient and tumor characteristics. This may have limited the ecological validity of the results, and may have influenced the emotional processes that patients did (or did not) experience while interacting with the tool.

Another limitation is that we recruited (active) cancer survivors involved in online cancer communities or patient organizations. It has been demonstrated that this selection of cancer survivors may not be fully representative of the general cancer population, as they are typically somewhat higher educated and make more extensive use of the internet[48]. Several studies suggest that lower education is associated with

lower eHealth use[49]. Furthermore, we did not measure participants' health literacy or numeracy skills, although some participants in our study expressed their concerns about communicating statistics to patients with low health or numeracy skills. Therefore, supplementary information or advice to discuss the results with clinician is highly needed especially for those patients who are lacking prior knowledge in statistics, or who may have less education. Despite this shortcoming, our interactive tools did comply with best practices and risk communication guidelines for communicating statistical information to the general public[24,50–53], and their content was developed by using a plain language approach (e.g., using everyday language, and using logically structured and focused information)[54]. A related limitation is that we only included BCa and PCa survivors, which makes it challenging to generalize our results to other oncology populations and those patients in active treatment. However, a recent study showed that internet use and wishes for online health information and statistics do not differ between patients with different cancer types[48]. Nevertheless, for future developments and eventual release of a possible real-life web-based NCR tool, it is important to test the understanding of the tool also among the general cancer population, preferably with variation in terms of cancer type, educational background, health literacy, and numeracy skills.

Implications and future directions

Our results contribute to the rapidly expanding field of personalized risk communication and tailored health communication, as they further enhance our understanding of how and why we should make efforts in disclosing and communicating personalized risks statistics from registry data to patients. For instance, our data provide support for a novel recommendation of allowing users to modify the type of visualization in line with their preferences. Over the years, several best practices and communication guidelines have been developed for the delivery of risk and statistical information to patients[24,50–53,55], particularly with an emphasis on searching for a single-best strategy. However, preferences for certain visualizations may vary between individuals[56], and therefore tailoring the type of visual aid toward the user's preference may be a promising additional risk communication strategy to consider. Another novel finding of our study is that some of the risk communication guidelines for communicating generic, population-based statistics may yield unexpected effects when they are used for communicating risks or statistics that are personalized. For instance, icon arrays—a recommended type of visualization for explaining risks and statistics—were preferred by most participants in our study (consistent with other studies[57,58]), but they also evoked feelings of distress as they became too personal to some patients[44]. Therefore, systematic knowledge about how patients will perceive and process visual aids that communicate personalized risks statistics is needed, as well as future investigations about the effects of tailoring the type of visual aid or the amount of information on associated risk perception and comprehension outcomes.

Furthermore, our results are encouraging for research into needs and preferences of patients with cancer with respect to personalized information provision and the disclosure of big health data[11,17]. The majority of our sample expressed a need for receiving personalized statistics on different topics before and after their initial treatment, ranging from survival rates to risk information about treatment side effects. We therefore recommend further development and implementation of data-driven personalized decision aids and disease risk prediction models (either based on registry, clinical, or patient-reported outcome data) in and outside The Netherlands[8,11,15,20,21], and support their availability to patients and healthcare professionals in daily routine practice and to laypersons on the internet. At the same time, this development comes with several challenges, which may explain why some (personalized) cancer statistics are not currently available to the general public. For instance, some additional items for personalizing survival statistics as requested by participants are not readily available within the Dutch registry (e.g., information on genetic factors or comorbidity). Relatedly, increasing the number of items in this case may lead to smaller subgroups, which in turn may lead to uncertain and less reliable personalized statistics. As such, the utility of and preference for personalized statistics may differ markedly depending on how reliable the information is, and further exploration on these aspects is highly warranted.

The results of our study also have a number of novel practical implications for the design and implementation of personalized, data-driven information support tools for cancer survivors (Textbox 1). We have shown that making such tools available to patients and the general public comes with several challenges such as avoiding technical language that is needed to describe statistical or medical terms, making sure that all patients will correctly interpret the statistical information, and not overwhelming them with visualizations that display less favorable survival outcomes. A key lesson from our qualitative studies is that there does not seem to exist a single perfect communication format for the delivery of personalized cancer statistics. We therefore believe that many of the issues identified with our potential NCR tool could be solved by applying a number of different personalization techniques, such as tailoring the amount of information (e.g., expanding text boxes for those who want detailed and supplementary information)[42], or tailoring the type of visualization in line with patient preferences. Furthermore, as some patients may experience difficulties with correctly interpreting the statistical information, several strategies could be taken into account such as the provision of contextual information about the statistics, or comparative information by showing average statistical outcomes of other patients.

Finally, although it has been shown that personalized statistics are typically perceived as more relevant[25], and hence better processed than generic information[59,60], our findings suggest that tool developers should not underestimate the role of affect in this process[61]. We observed that some participants processed statistical information emotionally, and expressed to be confronted by the less favorable survival rates. Making web-based prediction tools publicly available to patients and relatives thus

faces the challenge of avoiding discouraging patients with less favorable survival rates of prognosis from having hope. This is especially challenging for tools that rely on automatically generated textual explanations, for instance produced by robot writers that cannot easily provide contextual information in a similar way as a doctor can do during a consultation[62]. However, in line with previous information needs studies, our participants indicated that for those patients who really want honest prognostic information the levels of hope will maintain, even when the news is bad[37]. We recommend tool developers to provide supporting or preparatory information about the emotional aspects, and to find ways on how to tailor automatically generated sentences and explanations on poor prognosis and treatment outcomes to patients.

CONCLUSION

The majority of our sample of cancer survivors expressed a desire for receiving personalized cancer statistics such as specific and relevant data on survival and conditional survival. This is encouraging for those who are developing personalized information tools for patients that are drawing on cancer registry data or other medical databases, especially in an era of personalized healthcare and open access of big health data. Presenting personalized statistics to the public remains challenging and calls for tailoring strategies, as cancer survivors in our study demonstrated variation in their preferences for communicating the statistics. As a result of these findings, our research group is currently developing a real-life web-based tool that communicates personalized NCR statistics, which will be further evaluated among different stakeholders including patients, relatives, and healthcare professionals. Given the valuable information generated in collaboration with cancer survivors, we suggest that this approach and findings can be used to design data-driven personalized information (and decision-support tools) tools for patients with cancer and other disease conditions.

Textbox 1 | Recommendations for the development of tools that communicate personalized health statistics to the public.

The need for personalized statistics
Regarding the type of statistics:

- Consider communicating personalized survival statistics together with conditional survival statistics.
- Communicate not only statistics about personalized cancer incidence, but also about survival, conditional survival, and treatment outcomes (e.g., side effects, quality of life).
- Consider and evaluate multiple patient (age, gender, lifestyle), and clinical (disease stage, tumor characteristics) characteristics for tailoring the statistics.

The need for interpretation support
Regarding difficulties with interpreting personalized statistical information:

- Provide contextual information about the statistics and use clear explanations on the intended use.
- Consider communicating comparative information by showing statistics of the average patient in addition to the personalized statistics.
- Use plain and appropriate language and make sure that data entry characteristics are known by patients (or at least provided by their healthcare professionals).
- Regarding emotions or feelings of distress that may arise while viewing (less favorable) statistics:
- Prepare patients for the less favorable survival statistics via reminders or warning statements.
- Avoid using evaluative labels such as '"good" or '"bad" survival statistics.

Preferences for information presentation
Regarding variation in preference for type of visualization:

- Incorporate multiple types of visualization for displaying the statistical information.
- Allow patients to modify the type of visualization according to their preference.

Regarding variation in preference for amount of information:

- Keep the amount of information short and concise.
- Allow patients to tailor the amount of information, for instance, by incorporating the option to expand text for showing detailed information.

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5

Assessing cancer survivor needs for personalized and generic statistical information: A cross-sectional survey

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ABSTRACT

Background: When healthcare providers discuss treatment options with their patients, communicating in numbers is inevitable. In this pre-registered study, we assessed cancer survivors' need for generic (population-based) versus personalized (tailored towards patient/tumor characteristics) statistical information after their diagnosis. We examined how information coping style, subjective numeracy, and anxiety levels of survivors relate to these needs and identified statistical need profiles. Additionally, we qualitatively explored survivors' considerations for (not) wanting statistical information.

Methods: Cancer survivors' need for statistics regarding incidence, survival, recurrence, side effects and quality of life were assessed. For each of these topics, survivors were asked to think back to their first cancer diagnosis and to indicate their need for generic and personalized statistics on a 4-point scale ('not at all'-'very much'). Associations between information coping style, subjective numeracy, and anxiety with need for generic and personalized statistics were examined with Pearson's correlations. Statistical need profiles were identified using Latent Class Analysis. Considerations for (not) wanting statistics were analyzed qualitatively.

Results: Cancer survivors ($n = 174$) had a higher need for personalized than for generic statistics ($p < .001$, $d = 0.74$). Need for personalized statistics was associated with higher subjective numeracy ($r = .29$) and an information-seeking coping style ($r = .41$). Three statistical need profiles were identified (1) a strong need for both generic and personalized statistics (34%), (2) a stronger need for personalized than for generic statistics (55%), and (3) a little need for both generic and personalized statistics (11%). Considerations for wanting personalized cancer statistics ranged from feelings of being in control to making better informed decisions about treatment. Considerations for not wanting statistics related to negative experience with statistics and to the unpredictability of future events for individual patients.

Conclusions: Despite limited disclosure of personalized statistics in clinical practice, it appears that most cancer survivors want personalized statistics during treatment decision-making. Subjective numeracy and information coping style seem important factors influencing this need. We encourage further development and implementation of personalized decision support technologies in oncological care to support patients in treatment decision making.

INTRODUCTION

When patients diagnosed with cancer discuss treatment options with their healthcare provider, communicating in numbers is inevitable. Ideally, healthcare providers discuss both statistics related to outcomes of treatments (e.g., survival benefits, cancer free survivorship) and the risks of adverse effects (e.g., side effects, impact on quality of life) in order to facilitate shared decision-making[1,2]. However, it might be hard for patients to apply statistics to their individual situation, since those are often *generic* and based on *all* patients diagnosed with a certain type of cancer[3,4]. So, when a 45-year-old man, for example, is diagnosed with prostate cancer, generic statistics may be of limited value since they are derived from the entire group of prostate cancer patients, consisting of mostly substantially older men, whose data was obtained from randomized controlled trials or observational datasets. With the increased availability of medical and patient reported outcome data, more *personalized* statistics can be provided by comparing individual patient and disease characteristics (e.g. tumor type, stage, age, gender) with specific patient groups with similar characteristics, thereby providing patients with more specific and personalized probability information of a certain outcome[5,6]. In the case of the 45-year old male with prostate cancer, his data could be compared with a subset of comparable men, typically younger ones, which in turn may lead to more accurate risk perceptions and informed decision-making[7].

However, there is also a potential downside to this: since the statistics are more personally relevant for the 45-year-old male, they might conceivably also induce more anxiety in him, especially when the numbers are not positive, and perhaps, for this reason, the more generic statistics would be preferred. In truth, we know very little about who would want personalized statistics under which circumstances, and the increasing availability of this kind of information raises a number of new as yet unanswered questions. Do all patients want to receive statistics, or do they only want personalized instead of generic ones (or vice versa)? And are these different needs related with any personal or psychosocial characteristics?

However, assessing patients' statistical information needs is challenging, especially since communicating statistics (and especially personalized ones) in clinical practice remains limited[8,9]. Healthcare professionals often do not communicate such numbers due to time constraints[10], data unavailability[11,12], unreliable data (selection bias in observational data), or fear of disrupting patients' hope[13]. Additionally, clinical decision-support systems that use personalized data to inform decisions are often not rigorously tested, which means that the impact on patient care remains unknown[14]. Even if clinical support systems are evaluated, this happens in their specific clinical context, making it difficult to draw general conclusions about the usage of personalized data in healthcare[15]. In the same vein, most decision aids for patients with cancer facing treatment decisions do not contain personalized statistics either, or do not contain any numerical information at all[16–18]. This makes it difficult to assess whether and in what

circumstances patients are open to receiving personalized statistics during treatment decision-making.

Even though several survey studies repeatedly suggest that patients have a desire for receiving prognostic information in general[19,20], there has been no detailed investigation into patients' need for specifically receiving personalized numbers and statistics for a range of different outcomes. A recent qualitative study found suggestive evidence that majority of cancer patients want to receive personalized cancer statistics such as survival rates or treatment side effects risks[21], but a more systematic and quantitative analysis is lacking. Therefore, the first aim of this study is to quantitatively assess whether or not patients have a need for personalized or generic statistics after a cancer diagnosis. Based on previous research regarding patients' (prognostic) information needs, we hypothesize that there is a need for both generic (H1a) and personalized (H1b) statistics.

If we assume that personalized statistics are available to both healthcare providers and patients, there are several challenges to overcome, both in consultations and (online) patient decision aids. First, patients differ in how much information they want to receive, also known as *information coping style*[22]. Some patients want all available information (information-seekers), whereas others prefer to receive little or no information (information-avoiders). Information avoiders may show more decisional regret[23], and experience more psychological distress than information seekers[24,25]. This poses a challenge: should healthcare providers simply provide all patients with more personalized statistics? This does not seem to be the solution: patients only report better quality of life and less anxiety if their information needs are congruent with what they received[26]. This difference in information coping style may also influence whether patients want to receive generic and/or personalized statistics for (treatment) decisions. We expect that information-seekers would want both generic and personalized statistics, whereas information-avoiders prefer to avoid both.

Second, interpreting risks and probabilities seems to be problematic for many[27]. At the same time, we cannot avoid numbers as risk communication research strongly recommends to communicate risks in numbers (e.g. "1 out of 10 people experience side effect X") instead of words-only (e.g. "it is unlikely")[4,28–30]. That is why *subjective numeracy* should be considered when investigating the need for personalized and generic statistics. Research has shown that people who have low subjective numeracy, perceive a lower quality of doctor-patient communication which could have an effect on the decisions they make because they interpret risks differently[31,32]. Patients with lower (subjective) numeracy also tend to prefer a less active role in shared decision-making[33]. We expect that people with higher subjective numeracy have a higher need for personalized statistics than those with lower subjective numeracy.

Finally, as patients diagnosed with cancer often experience *anxiety*, which can in turn influence their general need for information, we expect that anxiety will also be related to cancer patients' need for especially personalized statistics. Some studies

found that patients who are more anxious may have lower needs in receiving statistical information that is too anxiety provoking (e.g., unfavorable survival or recurrence rates) which can help them preserve hope[19,20]. However, others found the opposite, by showing that patients with higher anxiety scores wanted to know more prognostic information[34]. Overall, we expect that the need for especially personalized statistics would be negatively related with higher levels of anxiety. Since evidence on the relationship with generic and personalized needs and all these factors (information coping style, subjective numeracy, and anxiety) is scarce, no formal hypotheses were formulated. These all relate to the second aim of our study: to explore different patient factors that could influence their need for generic and personalized statistics.

The third aim of this study is to identify statistical need profiles. Similar to earlier research, we seek to explore the more complex patterns underlying patients' needs for generic and personalized statistics into statistical needs profiles[35]. We expect that there might be several factors (cancer type, age, information topic, anxiety, information coping style, numeracy, gender) that could all have an impact on to what degree patients want to receive generic and/or personalized statistics[21,35–37].

Our fourth and final aim is to explore reasons people have for (not) wanting to receive personalized or generic statistical information after a cancer diagnosis. It is currently unknown what reasons patients have for not only receiving personalized statistics, but also why they still want generic statistics. Knowing more about the underlying factors (aim 2) and views (aim 3) could help doctors identify those patients that might want personalized or generic statistics, and those that do not. All hypotheses and expectations were pre-registered within the Open Science Framework prior to data collection (https://osf.io/qv35z/).

METHODS

Sample and procedure

In April 2020, 664 cancer survivors with breast, colon, lung or prostate cancer were invited to participate. Cancer survivors were recruited from a Dutch panel (Kanker.nl) and completed the questionnaire online. Participants eligible for participation received an invitation to enter the study via e-mail. Participation was voluntary and no reminders were sent out to avoid overburdening the panel. Sociodemographic, disease-related questions, and statistical information needs (SIN) were assessed in a newly developed questionnaire, also examining information coping style, subjective numeracy and anxiety level and lasted about 20 minutes. The complete questionnaire (Dutch and English) is publicly available (https://osf.io/qv35z/).

Measures

Socio-demographic and clinical factors

Demographic and clinical variables included age, gender, education level, marital status, having children, employment status, tumor type, year of diagnosis, and primary treatment(s).

Need for personalized and generic statistics

The need for personalized and generic statistics was assessed by a newly developed SIN-instrument. First, an explanation of the difference between a personalized and a generic statistic was provided, followed by a control question to check whether participants understood the difference ($n_{\text{wronganswer}}$ = 8/174 (4.6%)). Respondents were then asked to think back to their first cancer diagnosis, and to indicate whether they would have wanted to receive generic and/or specific statistical information regarding: the absolute cancer incidence number (1 item), survival rate (2 items; 5 and 10 year survival rate), treatment-related survival rate (2 items; 5 and 10 year), recurrence rate (2 items; 5 and 10 year), risk of treatment side effects (1 item), and impact of treatment on quality of life (4 items; physical, emotional, cognitive, and social functioning). The selection of topics was based on the needs and preferences of prostate and breast cancer survivors assessed during focus groups[21], and on earlier comparable studies[19,20,36]. All items relating to generic statistical needs were combined to create one average generic-SIN score, and all items relating to personalized statistical needs were used to create an average personalized-SIN score.

For each topic, respondents indicated their need for generic (α = .88) and personalized statistics (α = .87) on a 4 point scale (1 = 'not at all', 2 = 'a little', 3 = 'quite a bit', 4 = 'very much'). These answer categories were taken from the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire[38]. Each question was clarified with an example, and the questions about the need for personalized statistics included a reminder of what was meant with the term 'personalized'/'specific' (Figure 1). The examples did not include any real data (e.g., the numerator was left out: "… out of 100"), as this might bias participants' responses. The questionnaire also included an open question where respondents could indicate why they would (not) want to receive personalized/generic statistics The order of personalized and generic statistic items was counterbalanced per topic across all participants. The questionnaire was developed by a team of (health) communication researchers, medical experts in oncology, and a statistician. The instrument was pre-tested[1] among five patients with cancer regarding understandability, length, clarity and possible missing topics.

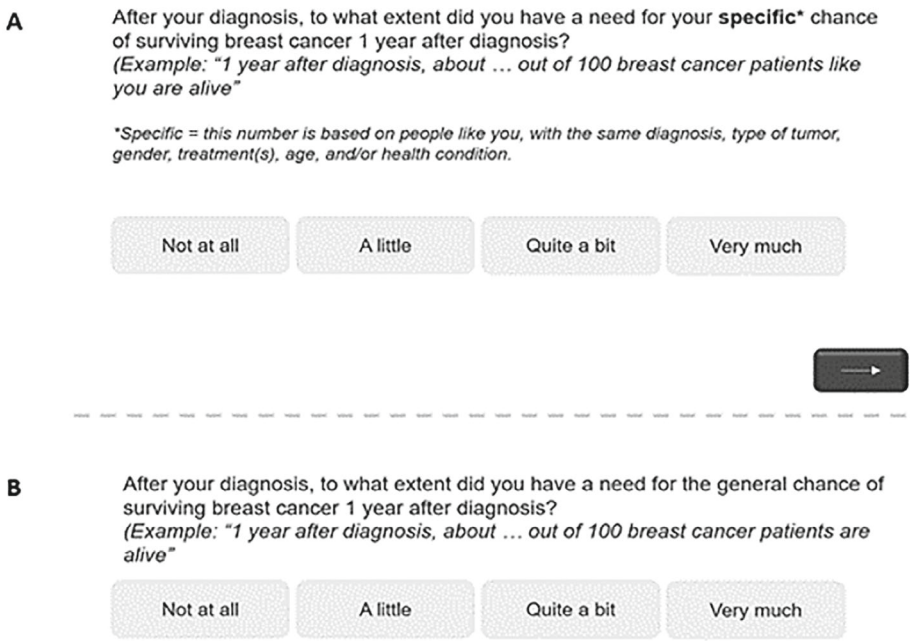

Figure 1 | Example items for breast cancer survivors that assess their need for personalized (A) and generic (B) statistics regarding their 1-year survival rate (shown on separate pages).

Information coping style, subjective numeracy, and anxiety level

Information coping style was measured with a validated shortened version of the Threatening Medical Situations Inventory[39]. Two styles are distinguished: a monitoring ("information-seekers") and a blunting information coping style ("information-avoiders"). Assessment was based on two hypothetical descriptions of threatening medical situations, followed by six items assessing to what degree they identify with the statements measured on a 5-point scale (1 = 'not applicable at all' and 5 = 'very applicable'). The internal consistency of the blunting (α = .67) and monitoring (α = .74) subscales were moderate to good. An information style score was calculated by subtracting the blunting subscale score from the monitoring subscale score, with a higher score indicating a monitoring/information seeker coping style (and a lower score a blunting/information-avoider style)[40–43]. The scales were unrelated to each other (Pearson's product moment correlation = -.08).

Subjective numeracy was assessed with the validated, 8-item Subjective Numeracy Scale (SNS)[44,45], which examines quantitative ability and preference for numerical information measured on a 6-point scale (1 = 'least numerate' and 6 = 'most numerate') (α = .88). We used the Dutch version of the SNS [46,47]. The mean subjective numeracy score was determined by computing the average score of the eight items, with higher scores indicating higher subjective numeracy.

Anxiety level was assessed with a validated Dutch version of the Anxiety-subscale of the Hospital Anxiety and Depression Scale (HADS) questionnaire[48]. HADS consists of 7 items measured on a 4-point scale (0 = 'not at all' and 3 = 'mostly') (α = .88). Scores were summed, with higher scores representing higher anxiety levels.

Statistical analyses

We used separate one sample t-tests (test-value: 2^2) to determine whether cancer survivors had a need for generic statistics and a need for personalized statistics. Comparisons *between* the need for personalized versus generic statistics were tested with separate paired-sample t-tests. For the calculation of effect sizes, Cohen's *d* was computed, where a *d* of 0.2 represents a small, a *d* of 0.5 a medium, and a *d of* 0.8 a large effect size[49]. We also included confidence intervals. Associations between need for generic and personalized statistics, and information coping style, subjective numeracy, and anxiety level were assessed with Pearson's correlation coefficients.

An exploratory three-step latent class analysis (LCA) was conducted to identify statistical information needs' profiles of cancer survivors[50]. All SIN-items (i.e., items on incidence, recurrence, survival, and quality of life) were included as indicators (measurement level was specified as ordinal). The number of classes increased until model fit was sufficient as assessed by the Bayesian Information Criterion (lowest BIC selected), Akaike's information criterion (lowest AIC selected), Consistent AIC (CAIC), and bivariate residuals (lower than 10). The assumption of local independence was relaxed if beneficial for model fit. To compare the classes, differences in information coping style, anxiety level, numeracy, and demographic variables were investigated with Wald tests using the three-step adjustment to account for uncertainty in the classification [50,51]. Confidence intervals and *p*-values are reported.

The statistical analyses were performed using SPSS statistical software (version 24.0). Tests were 2-sided and considered statistically significant at $p < .05$, and adjusted for multiple testing using the Bonferroni correction.

Exploratory qualitative analysis

We qualitatively analyzed the open-ended question using a deductive thematic analysis[52]. The main purpose of this analysis was to capture broad coding categories for people's views on (not) wanting generic and/or personalized statistics. We excluded responses that were off topic or that we could not interpret. One researcher (SH) coded each comment, and final themes were discussed between two researchers (SH, RV). Illustrative comments reflecting these themes are included in the results.

Ethical statement

Ethical approval was granted by the Research Ethics and Data Management Committee (REDC) of the Tilburg School of Humanities and Digital Sciences of Tilburg University (REDC 2020-148a). All methods were carried out in accordance with relevant guidelines

and regulations, and the survey protocol was approved by the ethics committee (REDC). All participants gave their digital consent to participate, and the ethics committee approved the use of digital signatures.

RESULTS

Sample characteristics

Out of 644 cancer survivors who were invited to participate since they were a member of the Kanker.nl panel, 204 (32%) clicked on the link to launch the survey. Of those, 184 (29%) agreed to participate by giving informed consent. Of those participants, 174 (27%) continued beyond the sociodemographic part of the survey (Figure 2) and were included in the analyses on SIN. In total, 159 (25%) participants completed the whole questionnaire. Other studies that used the same patient panel had similar response rates[46]. The mean age of the participants was 60.2 years (*SD* = 9.1, median = 60.7) and 59 percent was female (Table 1). The majority of participants (57 percent) had a college/university degree. The mean time since diagnosis was 5.89 years (*SD* = 9.46, median = 3.50).

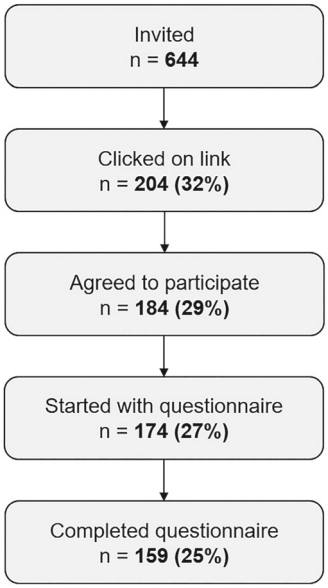

Figure 2 | Flowchart of the data collection process.

Table 1 | Participant characteristics (*n* = 174).

Characteristics	*n*	%
Gender		
Female	103	59
Male	71	41
Age at time of survey, mean (SD)	60.2 (9.1)	
<50 years	26	15
50-65 years	90	52
>65 years	58	33
Education		
Low[a]	15	9
Medium[b]	59	34
High[c]	100	57
Tumor		
Breast	67	39
Colon	40	23
Lung	21	12
Prostate	46	26
Years since first diagnosis, mean (SD)	5.9 (9.5)	
0-5 years	101	58
>5 years	73	42
Work situation		
Work	56	32
Insurance (ill)	17	10
No work/retired	101	58
Marital status		
Married/living together	138	79
Partner, not living together	2	1
No partner	34	20
Children		
No	50	29
Yes, living with/ living somewhere else	124	71

Note. [a] = Primary and (low levels of) secondary school; [b] = Secondary school (higher levels) or practical education; [c] = College and university; SD = standard deviation.

Need for personalized and generic statistics

Overall, there was a need for both personalized statistics ($M = 3.14$, $SD = 0.73$), $M_{dif} = 1.14$, $t(173) = 20.63$, $p < .001$, $d = 1.56$, 95% CI [1.04,1.25], and generic statistics[3] ($M = 2.70$, $SD = 0.72$), $M_{dif} = 0.70$, $t(173) = 12.74$, $p < .001$, $d = 0.97$, 95% CI [0.59,0.81]. For each topic, there was a stronger need for personalized than for generic statistics (all *p*s < .001, Table 2). Survivors expressed the highest need for receiving the personalized non-treatment related survival rate and risk of treatment side effects, and the lowest need for the generic cancer incidence statistic. Based on distribution scores (Figure 3), there was a clear preference for personalized over generic statistics (with variation in interest for different topics), but there were also some survivors who did not want anything (but even those would rather have personalized than generic numbers). Most survivors (56%) preferred to receive personalized statistical information from their physician, as well as from the internet ($n = 97$), whereas 25% ($n = 44$) preferred to receive this from their physician only, and 16% ($n = 28$) via the internet only. Furthermore, there were no difference in statistical information needs according to time since initial diagnosis, for both generic ($t(172) = -0.027$, $p = .979$, $M_{dif} = -0.003$, 95% CI [-0.22,0.11]) and personalized statistics ($t(172) = -0.181$, $p = .409$, $M_{dif} = -0.020$, 95% CI [-0.24,0.20]).

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Table 2 | Cancer survivors' needs for personalized and generic statistics (mean and standard deviations), compared for each topic.

	Type of statistic[a]					
Topic	**Personalized**	**Generic**	***t***	***df***	***d***	**95% CI**
Cancer incidence	2.60 (1.05)	2.15 (0.90)	7.25*	173	0.55	[0.34, 0.60]
Survival rate (non-treatment related)	3.38 (0.84)	2.94 (0.94)	7.20*	172	0.56	[0.35, 0.60]
Survival rate (treatment-related)	3.27 (0.95)	2.75 (0.96)	7.96*	169	0.61	[0.42, 0.68]
Recurrence rate	3.26 (0.98)	2.75 (0.98)	8.20*	166	0.65	[0.40, 0.64]
Risk of side effects	3.32 (0.87)	2.94 (0.93)	6.51*	165	0.51	[0.28, 0.50]
Quality of life	3.13 (0.81)	2.69 (0.81)	8.56*	162	0.66	[0.35, 0.54]

Note. [a] = Rated on a 4-point scale (1 = 'not at all', 2 = 'a little', 3 = 'quite a bit', 4 = 'very much'); * $p < .001$.

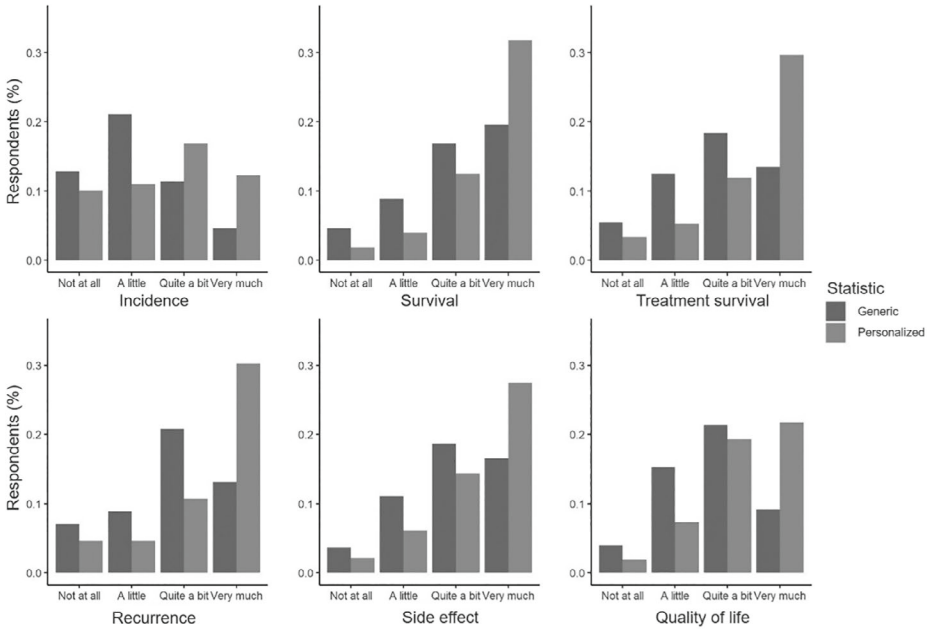

Figure 3 | Distribution of needs scores for generic and personalized statistics across topics.

Associations with information coping style, subjective numeracy, and anxiety level

Cancer survivors' needs for personalized statistics was positively associated with their need for generic statistics ($r = .67$, $p < .001$). With regard to the information coping style ($M = 3.01$, $SD = 0.53$), survivors who scored higher (information-seekers) had a higher need for personalized ($r = .41$, $p < .001$) and generic ($r = .37$, $p < .001$) statistics than participants who scored lower (information-avoiders). Furthermore, the need for personalized statistics was positively related with subjective numeracy ($M = 4.73$, $SD = 0.97$; $r = .29$, $p < .001$). There was no significant association between the need for generic statistics and subjective numeracy ($r = .11$, $p = .181$). Additionally, there was no significant association between survivors' anxiety level ($M = 5.33$, $SD = 4.02$) and their need for personalized statistics ($r = -.05$, $p = .564$) nor with their need for generic statistics ($r = -.07$, $p = .409$).

Statistical need profiles

With the exploratory LCA, three SIN profiles were identified (Figure 4). Survivors in the first SIN profile ("high SIN") had a strong need for both generic and personalized statistics ($n = 60$; 34.0%), for each SIN topic (except for incidence rate). The biggest group of survivors are in the second profile ("medium SIN", $n = 95$, 55.0%), in which survivors had "a little/quite a bit of" need for generic statistics and "quite a bit" of

need for personalized statistics. Survivors in the third profile ("low SIN", $n = 19$, 11.0%) showed "a little" need for both generic and personalized statistics.

Across all profiles, personalized statistics were valued as more important than generic statistics. Additionally, information provided on incidence and social functioning scored lowest on both generic and personalized SIN. There were significant differences in information coping style between the classes, with the highest scores in the first profile (indicating information-seekers), followed by the second profile, and the third profile (Wald = 24.03, $p < .001$). We observed no significant differences in terms of sociodemographic characteristics, clinical characteristics, anxiety level, and numeracy skills (see Additional File 1 for characteristics of and comparisons between SIN profiles).

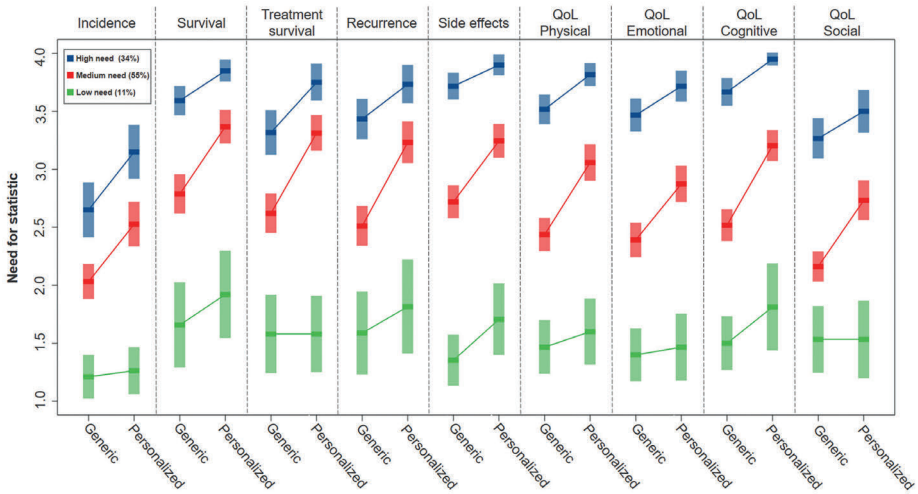

Figure 4 | Statistical need profiles for the three classes identified using latent class analysis. The x-axis indicates the need for generic and personalized statistical information, separated for each statistical topic (QoL = Quality of Life). The y-axis indicates respondents' needs score, measured on a 4-point scale (1 = 'not at all', 2 = 'a little', 3 = 'quite a bit', 4 = 'very much'). For each class, means and 95% confidence intervals are shown.

Exploring views on statistical information needs

Based on comments from 98 respondents, we identified seven themes that summarize considerations people have for (not) wanting personalized and/or generic statistics. Almost half ($n = 48$) mentioned that receiving personalized statistics would give them a feeling of being somewhat in control in turbulent times. They mentioned it would help them to create a better picture of what life would be like after diagnosis, make plans for the future, better understand their disease, and manage expectations. One participant said:

"It gives you a tool from which you can be motivated to take action or not. A tool to deal with a situation that is life-threatening." [Woman aged 53, lung cancer]

That feeling of wanting to be in control is shared by many of the participants and seems to be related to wanting to be in charge of the decision-making process. Many note the importance of receiving (specific) numbers to make informed decisions about treatments, but also decisions after treatments can be based on this kind of information:

"[…] You want to sort of remain in control of your life and be prepared. If I know that I have an 80 percent chance of being alive 15 years after diagnosis, then I feel more at ease than knowing it's only 30 percent. This also causes you to make different decisions." [Woman aged 48, breast cancer]

Some also commented on the difference between personalized and generic statistics ($n = 17$). Many wanted to receive both types of statistics in order to compare them. This would help them with interpreting the numbers better and feeling even more in control about their own life after diagnosis.

"I need the generic statistics to put my personalized statistics into perspective." [Man aged 65, lung cancer]

Although many might want personalized statistics, some also comment on the (un) availability of data and the tough spot they are in because of that ($n = 9$). As one participant put it:

"In 1995, these data were unavailable. There were only data about strictly medical consequences of amputation and radiation ... There is much more information now and I think that could have helped me to - with the social, emotional and societal issues I ran into because of the cancer – not ask myself again and again where all of these issues came from." [Woman aged 58, breast cancer]

The importance of receiving more personalized statistics is also stressed by this participant:

"Because I am relatively young to have rectum cancer, I have the idea that the numbers are not totally representative for my situation. Because, how much percent of people die from underlying issues? If you are 70 and you add 5 years, then the chances of dying are higher anyway than for someone who is 40 … That's why I would find it very useful to know the numbers aimed at my age group." [Woman aged 38, colon cancer]

There were some people who were dissatisfied with the statistics they were given (*n* = 6). For example, one participant noted:

> *"I would really like to know what my chances are. Doctors give me little specific information, but only generic information. I did ask for it though, but I never received any answers. It almost looks like they can't say anything about it. That's very frustrating." [Man aged 71, prostate cancer]*

There was a small group of people that can be classified as statistics-lovers (*n* = 13), who commented that they prefer numbers rather than words by saying:

> *"The words 'little' or 'rarely' do not tell me anything. Percentages tell me a lot more and are more specific." [Woman aged 59, lung cancer]*

> *"The more information I receive, the better. Information in terms of numbers is typically short and powerful and tells me more than just words." [Man aged 74, prostate cancer]*

In contrast, there was also a group of people that did not want specific numbers at all (*n* = 15), for instance because they felt the numbers did not tell them much since "everybody is unique". Or, as one participant put it:

> *"I'm not really fond of predictions or results, every person is different and what happens to you happens to you … nothing you can do about it." [Woman aged 68, colon cancer]*

Additionally, some participants had negative experiences with statistics, or they did not want to know everything about their future because they "live day by day". This seems especially true for those who had metastatic cancer:

> *"In my process, statistics often gave a wrong indication, both in a positive and in a negative way. With that, the available numbers have created a false (un)certainty, which is there still." [Man aged 54, colon cancer]*

> *"Personally, I would not want specific numbers. I have metastatic prostate cancer. The PSA-levels are increasing, but I remain positive and optimistic. I would absolutely not want to know what my expectations are or the remaining time I still possibly have. Now I can live with this quite well and would absolutely not want that this whole situation would affect my emotions." [Man aged 63, prostate cancer]*

DISCUSSION

Our findings highlight that most people in our selective sample diagnosed with cancer want to receive statistical information on different health outcomes[19,20,36], and especially personalized statistics adjusted to their personal and tumor characteristics[21,53]. However, currently such statistics are not personalized in clinical practice and patient decision aids[16–18]. In line with previous research[20,36], personalized survival outcomes, risks of side effects, and recurrence rates are deemed most relevant by patients or cancer survivors, followed by quality of life statistics. Ironically, survivors showed little need for the cancer incidence statistic, while this number is communicated the most in patient decision aids[16–18]. As such, there seems to be a discrepancy in what patients actually want to receive and what they often get.

Furthermore, information-seekers expressed a stronger need for both personalized and generic statistics than information-avoiders. The association between SIN and subjective numeracy was partly found; survivors with higher subjective numeracy showed more need for receiving personalized statistics, but not for generic statistics. This indicates the importance of distinguishing between these two types of statistics. It seems that people who perceive themselves as being good with numbers also view personalized numbers as more important. Future studies could focus on whether those patients also estimate their risks more accurately when receiving personalized statistics. No association was found between anxiety and SIN. Since we measured how anxious people felt in the past two weeks, it could still be that receiving personalized numbers affects anxiety induced by the personalized format. One might argue that the group most at risk for induced anxiety levels are those that receive the worst news. However, researchers have demonstrated that most metastatic cancer patients prefer to have as much information as possible, regardless of the severity of the outcome[13,54–56]. More effect studies could help identify the boundaries of providing personalized statistics, especially when their personalized outcome paints a worse picture than the generic outcome[57].

In addition, we identified three statistical need profiles based on cancer survivors' answers on the SIN items. Besides the well-known distinction between the information-seeker ("high SIN"; 34%), characterized by a strong need for both personalized and generic statistics, and the information-avoider ("low SIN"; 11%), characterized by low statistical information needs, a third group showed to be the largest group within our sample of cancer survivors. This group ("medium SIN"; 55%) showed a somewhat different pattern, characterized by a medium need for generic statistics, but a strong need for personalized statistics. Survivors with both a strong need for personalized and generic statistics were characterized by a high information-seeking coping style. Our findings build on existing studies that identified patient profiles based on information needs [35,58], and also show that the majority of our sample want to receive statistics related to personalized treatment outcomes.

Our study also explored reasons patients might have for preferring (personalized) statistics. Almost half of our sample commented that personalized statistics would let them feel more in control. This could be explained by the 'locus of control' theory[59], which refers to "the perception that events are determined by one's own behavior (internal control) or by such outside forces as other people or fate (external control)"[60]. Even though patients were diagnosed with cancer (external control), receiving personalized statistics could lead to patients feeling more empowered and actively involved in the decision-making process (internal control). Research has shown that experiencing internal control can have a positive impact on how anxious or depressed people feel[61]. With respect to people who want to receive both generic and personalized statistics to compare information, research has highlighted the positive effects of including such comparative risk information[62,63], although the effects of including comparative risk information may vary between contexts and individuals[57,64]. Finally, to shed more light on people who have a low need for receiving statistics, some patients with metastatic expressed no need for statistics, as they would feel less motivated. However, this is not automatically true for all metastatic cancer patients as many still want to be thoroughly informed[34]. Taken together, this explorative analysis calls for a more in-depth interview study on the reasons why patients might not want to receive personalized (statistical) information.

Strengths and limitations

This study provides the first comprehensive assessment of cancer survivors' needs for receiving statistics after diagnosis, while distinguishing between generic and personalized statistics. We did not focus on *how* patients want to receive such information (e.g., verbal, numerical, visual)[65]. Especially since cancer survivors wanted to receive personalized statistics about quality of life in a numerical format, more research should be dedicated to how to present such subjective data[66]. We also bear in mind that we measured subjective numeracy rather than objective numeracy. Although the two concepts are highly related[45], subjective numeracy also takes into account how people feel about their skills so there is a possibility people over- or underestimate their numerical abilities.

Additionally, in our study we assumed that data would be readily available for all of the topics and cancer types, while this is not necessarily the case in clinical practice. Moreover, understanding uncertainty around statistics is challenging, especially when communicating personalized statistics as reference groups decrease[6]. This, in turn, means that a personalized risk might be less reliable from a statistical perspective. However, even simple patient characteristics ('tumor type' or 'age') could be used to personalize outcomes[66] and most studies on communicating personalized risks for cancer screening found positive results[67]. What the effects are of discussing personalized risks about side effects, diagnosis or quality of life in general should be

studied more thoroughly, but individual patient tools that communicate personalized risks about cancer could yield positive results[9,68,69].

Finally, our sample consisted of (active) cancer survivors involved in online cancer communities or patient organizations. This selection may not represent the general cancer population, as they are educated and demonstrate higher levels of internet use[70,71]. However, it is interesting to note that there was still a group of blunters (i.e., information-avoiders) in our sample. In order to gain a comprehensive assessment of the statistical needs of cancer patients, future research should be inclusive of the full range of (newly diagnosed) cancer patients. Furthermore, in line with current practices, the cancer incidence statistic was the only statistic that was not presented as a rate, which could be a reason for the lower interest.

Implications

Our results are encouraging for research into patient needs with respect to personalized information provision and the disclosure of health risk data[66,72,73]. Most cancer survivors in our sample reported a strong need for receiving personalized statistics on different topics, ranging from survival rates to quality of life information. In practice, the need for personalized statistics can change depending on phase of the disease, with newly diagnosed patients wanting (personalized) statistics on survival, patients in the decision-making stage wanting such numbers for side effects and risk of recurrence and patients after the treatment phase wanting information on quality of life[74]. Our results are also useful for further development and implementation of data-driven personalized decision aids and (web-based) risk prediction models in oncology[66,72,73,75,76]. Moreover, the empirical findings contribute to the rapidly expanding fields of personalized medicine[77], individualized medical decision-making [5], patient-centered care, and shared decision-making [2]. As some participants reported, personalized statistics should not replace generic statistics, but instead should preferably be communicated in combination. This way, patients can make better sense of the personalized statistics and learn how they compare to the average, population-based statistics[78].

The findings also shed light on possible contributing factors such as a patient's information coping style or subjective numeracy. Based on our qualitative analysis, we can see that patients might want personalized statistics, both personalized and generic statistics, or no statistics at all. By asking individual patients if they would want to receive (personalized) statistics, healthcare professionals could empower patients to become more aware of the kind of role they want to play in their decisions. Our results suggest that a patient's information coping style could be an important indicator if both generic and personalized statistics should be provided. Additionally, people with high subjective numeracy also express a stronger need for personalized statistics. Both characteristics of patients could be part of an online decision aid that patients fill out

before entering a consultation, so that healthcare professionals can effectively tailor the type of statistics that they want (or do not want) to disclose to individual patients.

CONCLUSION

We found that the majority of our sample of cancer survivors expressed a strong need for receiving personalized statistics on different topics during treatment decision-making. Information coping style and subjective numeracy seem to be important factors for determining whether a patient wants to receive personalized statistical information. Our results encourage further development and implementation of data-driven personalized decision aids and risk prediction models in oncology practice care to help patients making well-informed and shared decisions about treatment.

FOOTNOTES

[1] Based on patients' feedback on our questionnaire during the pre-test, we made the following changes. We first added two questions: (1) "how satisfied are you with the information you received during your treatment process" as some of the patients mentioned they were already satisfied and this may affect their need for personalized statistics, and (2) "Imagine that you would be able to receive these specific numbers, how would you want to receive them? 1: Through my doctor during a consultation, 2: Through the internet, 3: Both through my doctor during a consultation as well as via the internet, 4: I do not want to receive specific numbers.", as this might influence their willingness to receive personalized statistics. Second, we added an explanation to the control question: "Mind you, for the sake of this research we presume that all data are available. Even if you have a rare form of cancer, we are interested to know if you have a need for these specific numbers.", as one of the pre-tested patients noted that they had a rare form of cancer so questions might not apply to them. Finally, we revised the phrasing of some questions (e.g., for the demographic question on work status "incapacitated" was changed to "temporarily incapacitated", and for the 5-year-recurrance items that accidentally talked about "1-year recurrence" was changed into "5-year recurrence").

[2] When we started with the design of our SIN-questionnaire, we initially used a 5-point scale (ranging from 1 as "none at all" to 5 as "very much"). However, after careful expert evaluation we thought it would be better to use a 4-point scale as it would be clearer what the score "2" meant. We also included verbal meanings to the scales (i.e., "1: not at all", "2: a little", "3: quite a bit" to "4: very much") for each item, to help respondents better interpret the answer options. Unfortunately, we mistakenly still put a test-value of 3 in our pre-registration within the Open Science Framework. As our aim was to identify whether or not people have a need for personalized and generic statistics,

a test score of 2 would be better since "a little" need already indicates that there is a need. We therefore changed our pre-registered analysis.

[3] There was a medium ordering effect of the need for general statistics ($t(159) = 2.02$, $M_{dif} = 0.23$, $p = .045$, $d = .31$, 95% CI [0.01,0,45]) with people who answered questions about generic statistics before personalized statistics scoring higher on their general statistical needs ($M = 2.83$, $SD = 0.68$) than people who answered questions about personalized statistics first ($M = 2.61$, $SD = 0.75$). Since distribution between conditions was equal, this did not impact the results.

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PART 3

Testing different formats and strategies

Communicating in what form to whom to what effect?

6

Communicating personalized risk information of cancer treatment side effects: Only words or also numbers?

This chapter is based on:

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ABSTRACT

Background: The increased availability of patient reported outcome data makes it feasible to provide patients personalized risk information of cancer treatment side effects. However, it is unclear how such information influences patients' risk interpretations compared to generic population-based risks, and which message format should be used to communicate such individualized statistics.

Methods: A web-based experiment was conducted in which participants (n = 141) read a hypothetical treatment decision-making scenario about four side effect risks of adjuvant chemotherapy for advanced colon cancer. Participants were cancer patients or survivors who were recruited from an online Dutch cancer patient panel. All participants received two personalized risks (of which the reference class was based on their age, gender and tumor stage) and two generic risks conveying the likelihood of experiencing the side effects. The risks were presented either in words-only ('common' and 'very common'), or in a combination of words and corresponding numerical estimates ('common, 10 out of 100' and 'very common, 40 out of 100'). Participants' risk estimates, risk accuracy, and risk perceptions were primary outcomes. Perceived personal relevance and perceived uncertainty were secondary outcomes.

Results: Personalized risks were estimated as higher and less accurate than generic risks, but only when they were presented in words; Such differences were not found in the verbal and numerical combined condition. Although personalized risks did not impact participants' risk perceptions, personalized risks were perceived as more personally relevant than generic risks in both message formats. Finally, personalized risks were perceived as less uncertain than generic risks, but only in the verbal-only condition.

Conclusions: Considering current interest in the use of personalized decision aids for improving shared decision-making in oncology, it is important that clinicians consider how personalized risks of treatment side effects should be communicated to patients. We recommend both clinicians who communicate probability information during consultations, and decision aid developers, that verbal descriptors of personalized risks should be supported by numerical estimates of risks levels, to avoid overestimation of risks.

INTRODUCTION

After a cancer diagnosis, most patients want to be fully informed about the possible treatment options and the associated risks of side effects to support a well-informed treatment decision-making process[1,2]. For instance, colorectal cancer patients eligible for chemotherapy should be informed about the chances of experiencing adverse effects such as neuropathy or changes in smell and taste. Such risk statistics are typically communicated by the clinician during a consultation and/or incorporated into tools such as patient decision aids[3], and are therefore an essential part of shared decision-making[4]. However, patients often have difficulty understanding and interpreting risks[5], especially those patients with low numeracy or health literacy skills[6], which can further influence treatment decision-making[7,8]. Due to advances in artificial intelligence and personalized medicine, there has been rapid growth in the development of personalized risk communication tools in cancer care[9–12], with the aim to provide patient's risk information about treatment side effects based on their personal clinical and sociodemographic characteristics. Despite great promise of such individualized data-driven tools[13], it is unclear whether (1) personalized risks influence risk estimates and perceptions and lead to more or less accurate risk estimates compared to generic risks, and (2) which message format should be used to communicate such individualized statistics to patients.

Typically, risk information about possible treatment side effects is generic and mostly based on the "average patient", such as information presented in randomized controlled trials or patient reported outcome reports[14]. Such average statistics make it hard to relate outcomes to individual patients[15], particularly because they often do not contain a clear description of to whom the risk estimates refer (i.e., the reference class) and may therefore be a factor in the misunderstanding of the risk information about treatment side effects[16]. *Personalized* risk information of side effects adjusted to the clinical (e.g., tumor stage) and sociodemographic (e.g., age, gender) characteristics of an individual patient may increase the perceived personal relevance of risk information, thereby increasing the likelihood that patients will process the personalized information with more deliberation, consideration, and evaluation[17,18]. In fact, several studies have shown that personalized risk estimates may improve the accuracy of patients' estimations of probabilities and may increase their risk perceptions in both the general health context[19] as well as in the domain of cancer risk and screening[20,21]. Therefore, personalizing side effect risks may be an effective communication strategy for enhancing the accuracy of patients' risk estimates and for increasing risk perceptions.

An important consideration for clinicians, health educators and patient tool developers is through which *message format* they should communicate personalized risk statistics, using for instance verbal and/or numerical formats[15]. Verbal risks can be expressed via descriptions such as rare, likely, or very common. The European

Commission provided guidelines on using particular verbal descriptors associated with corresponding numerical estimates (Table 1)[22]. The problem is that such phrases are often interpreted in different ways by different patients, typically causing overestimations of the actual occurrence of the side effect[23–26]. Another way of communicating risks is through combining verbal information with numerical estimates, such as percentages, probabilities, or natural frequencies[22,26]. Although experimental studies have consistently shown that a combination of verbal and numerical formats of generic risks are estimated as lower and perceived as less likely to occur than verbal descriptions alone[23–27], it is not known to what extent such results apply to personalized risks. It is important to study this, as recent studies suggest that verbal risk labels without accompanying numerical information are still frequently used by oncologists[28] or incorporated in patient decision aids for communicating personalized risks of treatment side effects[29–31].

Table 1 | Verbal descriptors of side effects risks and their corresponding numerical probabilities as recommended by the European Commission[22].

Verbal descriptor	Corresponding numerical frequency interval
Very common	May affect more than 1 in 10 people (≥1/10)
Common	May affect up to 1 in 10 people (≥1/100 to <1/10)
Uncommon	May affect up to 1 in 100 people (≥1/1000 to <1/100)
Rare	May affect up to 1 in 1,000 people (≥1/10000 to <1/1000)
Very rare	May affect up to 1 in 10,000 people (<1/10000)
Not known	Frequency cannot be estimated from the available data

Present study and hypotheses

In the present study, we will examine the impact of personalization (personalized vs. generic risks) and message format (verbal-only vs. verbal and numerical combined format) of risks of cancer treatment side effects on cancer patients' risk interpretations. We will use risk estimates, risk accuracy, and risk perception as primary outcome variables. First, regarding the influence of personalization, we expect that risks that are personalized will lead to higher risk perceptions (i.e., perceived as more likely to occur) than generic risks[20,32].

H1: Compared to generic risks of treatment side effects, personalized risks will be perceived as more likely to occur.

Second, given the growing importance of replication research in the empirical sciences for improving the reproducibility of earlier study's results[33], we attempt to conceptually replicate previous findings on the effect of message format on peoples' risk interpretations. Previous studies have consistently shown that people viewing

generic risk information in a verbal-only format estimate the probability as higher and less accurate[23,25], and perceive these risks as more likely to occur than people viewing risks in a verbal and numerical combined format[23–26]. We expect this impact of message format to persist for personalized risks as well.

H2: Compared to risks of treatment side effects presented in a verbal and numerical combined format, risks presented in a verbal-only format will be estimated as (a) higher) and (b) less accurate, and (c) perceived as more likely to occur.

Third, regarding the combined effect of personalization and message format, we assume that personalized risks expressed as words and numbers combined should improve peoples' estimated risk accuracy even more compared to generic risk information[19–21]. This is because especially in this situation, people should have less reason to deviate from the actual personalized risk statistic being communicated.

H3: Compared to generic risks of treatment side effects, personalized risks will be estimated as more accurate than generic risks, but only when the risks are presented in a verbal and numerical combined format.

Finally, we will assess perceived personal relevance and perceived uncertainty of the risk information as secondary outcome measures, for which we propose the following two hypotheses:

H4: Personalized risks of treatment side effects will be perceived as more personally relevant than generic risks, regardless of the message format.

H5: Personalized risks of treatment side effects will be perceived as less uncertain than generic risks, regardless of the message format.

METHODS

Study design

We used a 2 (personalization: personalized vs. generic) × 2 (message format: verbal-only vs. verbal and numerical combined) × 2 (probability rate: low vs. high) mixed design, with repeated measures on the first and third factor. Participants were randomly assigned to one of the two message format conditions. We included probability rate as a methodological variable to investigate whether the effects of personalization and message format are similar for high and low probability rates[25]. We used risk estimates, risk accuracy, and risk perception as primary outcome variables, and perceived personal relevance and perceived uncertainty as secondary outcome variables.

Participants

Native Dutch adults between the ages of 18 and 70 who had been diagnosed with cancer in the past were selected from the scientific panel of the online cancer community platform Kanker.nl to participate in our study. We selected people who had been in a similar health situation before, since they are better able to imagine the given scenarios (compared to, for instance, a student sample), thus enhancing the generalizability of our results[34]. Patients who were diagnosed with colorectal cancer in the past were excluded from participation due to prior personal experience. As part of the pre-registered analysis (https://osf.io/ygchx), power calculations were conducted prior to data collection to determine our sample size using the program G*Power 3.1[35]. Previous meta-analyses have indicated small effect sizes for personalization effects on risk perception[36], and medium effect sizes for message format effects on risk estimates and risk perception[23]. To detect a small effect (effect size $f = 0.10$) with a $2 \times 2 \times 2$ mixed design, a sample of 136 participants was needed (power = 0.8, $\alpha = 0.05$). We therefore aimed for a minimum of 136 participants.

Stimulus materials

All participants received two personalized and two generic risk statistics for the occurrence of four possible side effects after adjuvant chemotherapy including fatigue, neuropathy, taste and smell changes, and diarrhea, respectively. Personalization was established by manipulating the *reference class* (i.e., denominator) to which the risk statistic applies. More specifically, personalized risks contained a reference class based on participants' reported gender (male or female), age group (in 5-year bins between 15 and 69 years), and tumor stage (advanced colon cancer as stated in the scenario). For example: 'This side effect is common (occurs in 10 out 100 men like you, aged between 65 to 69 years with advanced colon cancer)" (Table 2). Generic risks descriptions were fixed and included a reference class that was not personalized on patient and tumor characteristics. For example: "This side effect is common (occurs in 10 out of 100 people)" (Table 2).

Half of the participants received the risk only in words (verbal-only condition), and the other half in a combination of words and numbers (verbal and numerical combined condition). Within the verbal-only condition, we selected the verbal descriptors 'common' (*vaak* in Dutch) for representing a low probability rate and 'very common' (*zeer vaak* in Dutch) for representing a high probability rate. Following the recommendations proposed by the European Commission, we used the corresponding natural frequency estimates '10 out of 100' for representing a low probability rate and '40 out of 100' for representing a high probability rate[3,5,15,22]. To exclude the possible effect that a specific side effect could influence higher risk estimates, the combination of personalization, probability rate and type of side effect was randomized, as well as the order of personalized and generic risks in combination with the probability rate.

Table 2 | Development and structure of the risk information about the likelihood of occurrence for each experimental condition.

	Verbal-only condition		**Verbal and numerical combined condition**	
	Generic	**Personalized**	**Generic**	**Personalized**
Low probability rate	This side effect is common	This side effect is common in [gender] like you, aged between [age group] years with advanced colon cancer	This side effect is common (occurs in 10 out of 100 people)	This side effect is common (occurs in 10 out of 100 [gender] like you, aged between [age group] with advanced colon cancer)
High probability rate	This side effect is very common	This side effect is very common in [gender] like you, aged between [age group] with advanced colon cancer	This side effect is very common (occurs in 40 out of 100 people)	This side effect is very common (occurs in 40 out of 100 [gender] like you, aged between [age group] with advanced colon cancer)

Note. The risk information was presented in Dutch to the participants.

Procedure

Data collection took place in May 2019. A representative of Kanker.nl sent a link of our web-based experiment to participants of the cancer patient panel. When entering the online experiment, an introductory text was shown, followed by questions on background and medical characteristics. The reported gender and age group were subsequently used for personalizing the reference class of the personalized risk information. Participants then read a short scenario in which they imagined being diagnosed with advanced colon cancer and discussing adjuvant chemotherapy as a treatment option with their doctor. We chose colon cancer as the disease context because both men and women can be diagnosed with this form of cancer (versus, for example, prostate cancer). This allowed us to include gender as a personalization factor of the risk information. Participants were told that they were receiving a decision aid from their doctor including information about four possible side effects after adjuvant chemotherapy. Each description consisted of three elements: the name of the side effect, a short description of the side effect, and risk information about the likelihood of experiencing the side effect. This was followed by the assessment of the primary and secondary outcome measures. In the final part of the experiment, we measured participants' subjective numeracy skills and prior history with chemotherapy and/or one of four mentioned the side effects. Participants were then debriefed about the main purpose of the experiment and thanked for their participation.

Measures

Primary outcome measures

We had three primary outcome measures for measuring risk interpretations, based on the meta-analysis by Büchter and colleagues[23] and the studies by Knapp and colleagues that we attempted to replicate[24,25]. First, *risk estimates* was assessed using the question "What do you think is the probability **you** will experience this side effect", measured as a percentage between 0 and 100[24]. Second, the *risk accuracy* determined by computing the absolute difference between the actual risk of each side effect occurring and each participant's estimated risk of that side effect occurring. Scores closer to zero were therefore more accurate (for similar reasoning, see[21,25]). Third, *risk perception* was assessed using the question "How likely is it that **you** will experience this side effect?", measured on a 6-point scale, with 1 as 'not likely at all' and 6 as 'very likely'[23,24].

Secondary outcome measures

We also included two secondary outcome variables. First, *perceived personal relevance* was assessed using the items "The risk information about the side effect was made personally for me" and "The way how the risk information was being presented was relevant to me" (measured on a 5-point scale, with 1 as 'strongly disagree' and 5 as 'strongly agree')[32]. Second, *perceived uncertainty* was assessed by asking the question "How uncertain do you think is this likelihood of experiencing this side effect after chemotherapy?", measured on a 6-point scale, with 1 as 'not at all' and 6 as 'extremely'[37].

Individual difference measures

Individual differences in subjective numeracy were assessed by the Subjective Numeracy Scale (SNS[38]), which is an 8-item self-assessment for determining participants' quantitative ability and preferences for receiving numerical information (measured on a 6-point scale, with 1 as 'least numerate' and 6 as 'most numerate'). The SNS has proven to be a valid and reliable measure, and correlates strongly with objective numeracy measures[39]. For the current study, we used the Dutch version of the SNS[40]. The mean subjective numeracy score was determined by computing the average score of the eight items.

Statistical analyses

We conducted a 2 (within-subjects: personalization) × 2 (between-subjects: message format) × 2 (within-subjects: probability rate) mixed-model multivariate analysis of variance (MANOVA)[1]. The dependent variables were our three primary outcome measures; risk estimates, risk accuracy, and risk perception (see Appendix A for full results). If applicable, significant interaction effects were further analyzed by means of simple effect analyses. As an additional exploratory analysis, we controlled for

individual differences by conducting a separate mixed-model multivariate analysis of covariance (MANCOVA) with subjective numeracy skills and prior history with chemotherapy and/or one of the side effects as covariates. For this exploratory analysis, only results that deviate from the pre-registered MANOVA analysis were reported (Appendix A). For our two secondary outcome measures, we conducted two separate mixed-model ANOVAs, with repeated measures on the first and third factor. The dependent variables were perceived personal relevance and perceived uncertainty. Data on patient and tumor characteristics for the two message format conditions were compared using chi-square tests for categorical variables and t-tests for continuous variables. All statistical analyses were performed using SPSS version 24.0 (IBM Corporation, Somers, NY, USA). Tests were two-sided and considered statistically significant at $p < .05$. The study design, hypotheses, and analysis plan were pre-registered prior to data collection and analysis within the Open Science Framework (https://osf.io/j74dt/). Ethical approval was granted by the Research Ethics and Data Management Committee of the Tilburg School of Humanities and Digital Sciences of Tilburg University (ID REDC.2019.26).

RESULTS

Participants

Out of 825 people who were invited to participate, 188 (23%) clicked the link to launch the survey. Of those, 171 (91%) continued beyond the informed consent page, and 141 (75%) fully completed the survey (Figure 1). All completed cases were analyzed. Completion rates were consistent across experimental conditions (73% in the verbal-only condition, 77% in the verbal and numerical combined condition). The mean age of participants was 57.3 years ($SD = 7.4$), and the participants in both message format conditions were comparable in terms of sociodemographic and disease-related characteristics (all $ps > .10$, Table 3).

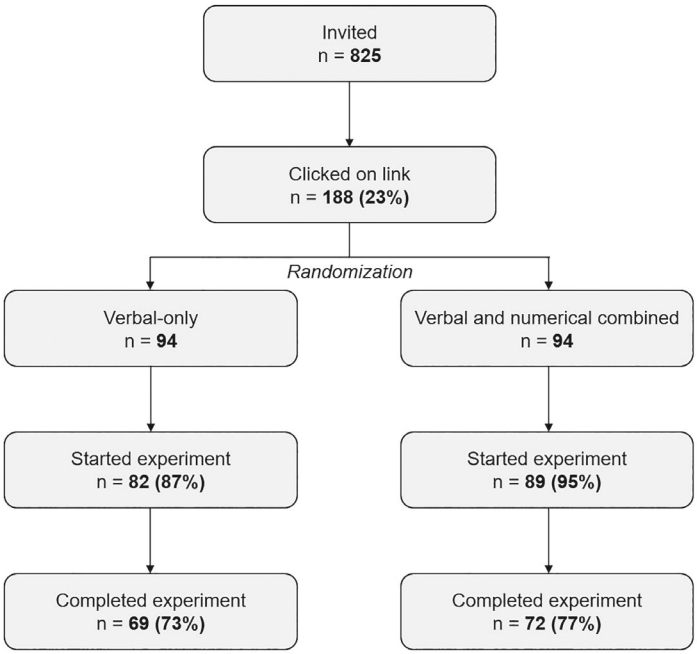

Figure 1 | Flowchart of the data collection process.

Table 3 | Participant characteristics by message format condition.

	Verbal-only (*n*=69)		Verbal and numerical combined (*n*=72)		
Characteristics	***n***	**%**	***n***	**%**	***p***
Gender					
Female	45	35	46	36	
Male	24	65	26	64	.869
Age at time of experiment, mean (SD)	57.72 (7.29)		56.83 (7.50)		.469
<50 years	8	11	13	18	
50-65 years	44	64	49	68	
>65 years	17	25	10	14	.201
Education					
Primary school	8	11	12	17	
Secondary school	17	25	24	33	
College/University	44	64	36	50	.255
Tumor					
Breast	22	32	22	31	
Hematological [a]	13	19	8	12	
Urological [b]	10	15	13	18	
Gynecological [c]	7	10	10	14	
Head and neck	4	6	6	8	
Lung	2	3	4	5	
Skin	3	4	2	3	
Gastroenterological [d]	3	4	2	3	
Other [e]	3	4	4	5	
Unknown	2	3	1	1	.912
Years since diagnosis, mean (SD)	6.48 (6.89)		5.01 (4.22)		.133
0-5 years	43	62	52	72	
6-10 years	12	17	13	18	
11-15 years	8	12	5	7	
>15 years	6	9	2	3	.318
Treatment(s)					
Surgery	48	70	48	67	.712
Radiotherapy	40	58	35	49	.266
Chemotherapy	40	58	37	51	.433
Immunotherapy	13	19	11	15	.574
Hormone therapy	18	26	24	33	.347
Other	16	23	13	18	.451

Table 3 | Continued.

	Verbal-only (*n*=69)		Verbal and numerical combined (*n*=72)		
Characteristics	***n***	**%**	***n***	**%**	***p***
Prior experience side effects					
Fatigue	55	80	49	68	.116
Neuropathy	29	42	26	36	.471
Smell and taste changes	30	44	27	38	.470
Diarrhea	14	20	11	15	.436
None of the above	7	10	9	13	.659
Subjective numeracy, mean (SD) [f]	4.51 (0.81)		4.64 (0.86)		.384

Note. [a]Lymphoma, Leukemia, Multiple myeloma; [b]Prostate, bladder; [c]Uterus, cervix, ovary; [d]Esophageal, anus, GIST, gall bladder, but excluding colorectal cancer; [e]Brain, renal cell, undifferentiated pleomorphic sarcoma, neuroendocrine tumor; [f] α = .82; SD = standard deviation.

Effects on primary outcome measures

In both message format conditions, participants' estimated risks strongly correlated with the accuracy of their estimated risks ($r_{\text{verbal-only}}$ = -.984, $p < .001$, $r_{\text{verbal+numerical}}$ = -.943, $p < .001$) and risk perceptions ($r_{\text{verbal-only}}$ = .820, $p < .001$, $r_{\text{verbal+numerical}}$ = .738, $p < .001$), which, in turn, strongly correlated with participants' risk accuracy ($r_{\text{verbal-only}}$ = -.813, $p < .001$, $r_{\text{verbal+numerical}}$ = .728, $p < .001$).

Effects of personalization

There was a significant main effect of personalization on the risk estimates and risk accuracy. Personalized risks were estimated as higher, $F(1, 125) = 6.25$, $p = .023$, $\eta_p^2 = .04$, and less accurate, $F(1, 125) = 6.25$, $p = .014$, $\eta_p^2 = .05$, than generic risks (Table 4a and 4b). However, in contrast to our hypothesis (H1), there was no significant main effect of personalization on risk perception, indicating that personalized risks were not perceived as more likely to occur than generic risks, $F(1, 125) = 1.79$, $p = .183$, $\eta_p^2 = .01$. It should be noted that these personalization effects were not found when controlling for individual differences in numeracy and prior history with the side effects (Appendix A). Overall, the effects of personalization did not depend on the probability rate (all *F*s < 1).

Effects of message format

As hypothesized, there was a significant main effect of message format on risk estimates, $F(1, 125) = 69.82$, $p < .001$, $\eta_p^2 = .36$, risk accuracy, $F(1, 125) = 64.26$, $p < .001$, $\eta_p^2 = .34$, and risk perception, $F(1, 125) = 30.27$, $p < .001$, $\eta_p^2 = .20$. The results therefore

suggest that risks presented in a verbal-only format were estimated as higher (H2a), less accurate (H2b), and perceived as more likely to occur (H2c) than risks presented in a verbal and numerical combined format. These message format effects were also found when controlling for individual differences (all *p*s < .001; Appendix A), and were more pronounced for low probability rates (all *p*s < .001).

Interaction effects between personalization and message format

There was a significant interaction effect between personalization and message format on risk accuracy, $F(1, 125) = 7.82$, $p = .006$, $\eta_p^2 = .06$. Simple effect analysis showed that personalized risks were estimated as less accurate than generic risks in the verbal-only condition, ($p < .001$), but not in the combined condition ($p = .833$). This is in contrast to our hypothesis (H3), for which we expected personalized risks to be estimated as more accurate compared to generic risks, but only when expressed as words and numbers combined. There was also a similar significant interaction effect on risk estimates, $F(1, 125) = 7.21$, $p = .008$, $\eta_p^2 = .06$. Simple effect analysis revealed that personalized risks were estimated as higher than generic risks in the verbal-only condition ($p = .001$), but not in the combined condition ($p = .789$). Overall, these significant interaction effects were found for both probability rates, and when controlling for individual differences (Appendix A). Finally, there was no significant interaction effect between personalization and message format on risk perception, $F(1, 125) = 1.79$, $p = .183$, $\eta_p^2 = .01$. Figure 2 displays the distribution of estimations of probabilities (and the mean risk estimates) given by participants for each experimental condition.

Effects on secondary outcome measures

As hypothesized (H4), participants perceived personalized risks as more personally relevant than generic risk information about side effects, $F(1, 123) = 19.11$, $p < .001$, $\eta_p^2 = .13$ (Table 4a and 4b). This effect of personalization occurred regardless of message format conditions, $F(1, 123) = 2.36$, $p = .127$, $\eta_p^2 = .02$, and probability rate, $F < 1$. Regarding perceived uncertainty, there was a significant interaction effect between personalization and message format, $F(1, 113) = 6.23$, $p = .014$, $\eta_p^2 = .05$. Simple effects analysis showed that personalized risks in the verbal-only condition were perceived as less uncertain than generic risks ($p = .007$), but not in the verbal and numerical combined condition ($p = .436$), which partly confirms H5. Finally, risks with low probability rates were perceived as more uncertain than risks with high probability rates, $F(1, 113) = 11.01$, $p < .001$, $\eta_p^2 = .09$.

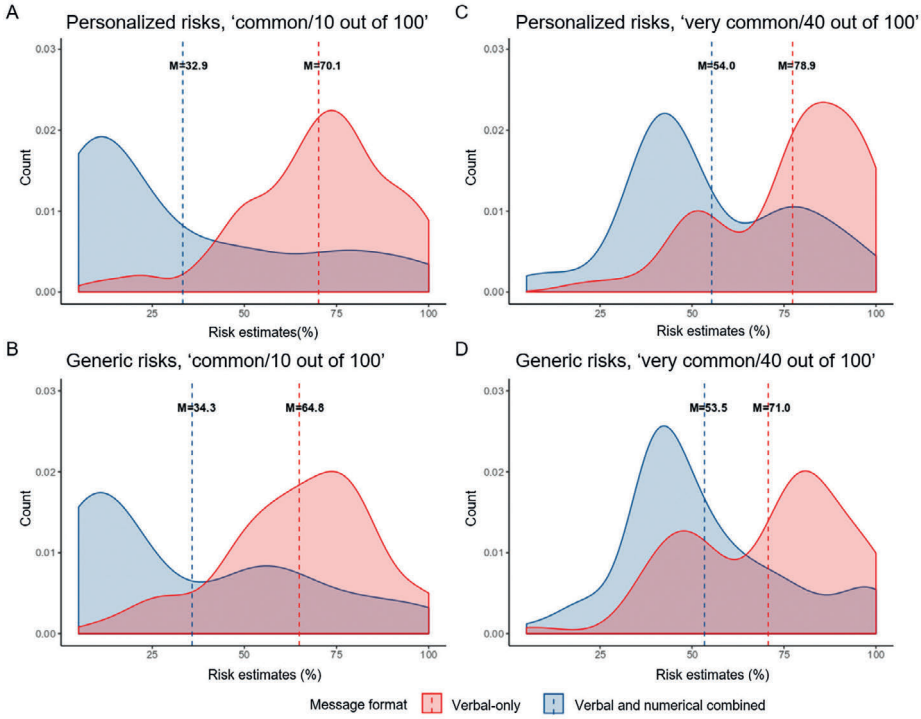

Figure 2 | Comparisons of distribution risk estimates between verbal-only (red) and verbal and numerical combined (blue) message formats for (A) low probability personalized risks and (B) low probability generic risks, and for (C) high probability personalized risks and (D) high probability generic risks. The dotted lines represent the average estimated risks.

Table 4a | Participants' mean scores (with standard deviations within parentheses) on the primary and secondary outcome measures as a function of personalization (personalized vs. generic risks) and message format (verbal-only vs. verbal and numerical combined) for low probability rate risks.

	Verbal-only "common"			**Verbal and numerical combined "common, 10 out of 100"**		
Measures	**Generic**	**Personalized**	**Total**	**Generic**	**Personalized**	**Total**
Primary measures						
Risk estimates[1] (in %)	64.8 (20.1)	70.1 (19.6) [a**]	67.5 (19.8)	34.3 (29.9)	32.9 (30.8)	33.6 (30.4)[c***]
Risk accuracy[2] (in %)	54.8 (20.1)	60.1 (19.6) [a***]	57.5 (19.9)	24.9 (29.4)	23.7 (30.2)	24.3 (29.7)[c***]
Risk perception[3]	4.41 (1.09)	4.46 (1.01)	4.49 (1.05)	3.25 (1.52)	3.23 (1.57)	3.24 (1.55)[c***]
Secondary measures						
Perceived personal relevance[4]	3.16 (0.74)	3.46 (0.81) [a***]	3.34 (0.78)	3.19 (0.97)	3.40 (0.91) [b***]	3.30 (0.94)
Perceived uncertainty[5]	2.90 (1.19)	2.59 (1.19) [a*]	2.75 (1.19)	3.13 (1.50)	3.31 (1.47)	3.18 (1.49)

Note. [1] "What do you think is the probability you will experience this side effect" (percentage between 0% and 100%); [2] The absolute difference between the actual risk of each side effect occurring and each participant's estimated risk (scores closer to zero are more accurate); [3] "How likely is it that you will experience this side effect?" (1 = not likely at all, 6 = very likely); [4] "The risk information about the side effect was made personally for me" and "The way how the risk information was being presented was relevant to me" (1 = strongly disagree, 5 = strongly agree, α = .87); [5] "How uncertain do you think is this likelihood of experiencing this side effect after chemotherapy?" (1 = not at all, 6 = extremely); [a] Mean differs significantly compared to generic risk within verbal-only risk condition; [b] Mean differs significantly compared to generic risk within verbal and numerical combined condition; [c] Mean differs significantly compared to total verbal-only risk; * $p < .01$, ** $p = .001$, *** $p < .001$.

Table 4b | Participants' mean scores (with standard deviations within parentheses) on the primary and secondary outcome measures as a function of personalization (personalized vs. generic risks) and message format (verbal-only vs. verbal and numerical combined) for high probability rate risks.

	Verbal-only "very common"			**Verbal and numerical combined "very common, 40 out of 100"**		
Measures	**Generic**	**Personalized**	**Total**	**Generic**	**Personalized**	**Total**
Primary measures						
Risk estimates (in %)	71.0 (21.1)	78.9 (18.1) [a**]	74.9 (19.1)	53.5 (22.3)	54.0 (21.9)	53.7 (22.1) [c***]
Risk accuracy (in %)	32.1 (19.5)	39.6 (16.7) [a***]	35.8 (18.1)	17.4 (19.3)	17.9 (18.7)	17.7 (19.0) [c***]
Risk perception	4.73 (1.07)	5.02 (0.98)	4.87 (1.03)	4.23 (1.22)	4.28 (1.21)	4.26 (1.22) [c***]
Secondary measures						
Perceived personal relevance	3.16 (0.74)	3.47 (0.80) [a***]	3.39 (0.77)	3.34 (0.89)	3.47 (0.86) [b***]	3.40 (0.88)
Perceived uncertainty	2.55 (1.30)	2.41 (1.37) [a*]	2.48 (1.34)	2.73 (1.20)	2.91 (1.36)	2.82 (1.28)

Note. [a] Mean differs significantly compared to generic risk within verbal-only risk condition; [b] Mean differs significantly compared to generic risk within verbal and numerical combined condition; [c] Mean differs significantly compared to total verbal-only risk; * $p < .01$, ** $p = .001$, *** $p < .001$.

DISCUSSION

Main findings

The current study demonstrates that message format matters when communicating personalized risk information of treatment side effects. We found that communicating personalized side effect risks leads to higher and less accurate risk estimates compared to generic risks, but only when the risks were communicated using words-only. Such differences were not found in the combined verbal and numerical condition. This suggests that communicating about side effect risks in words-only allows patients to overestimate and even inaccurately estimate their personalized risks[15,41,42]. Moreover, patients may take these individualized verbal risk labels as too personal, which in turn may lead to overestimations of the risks. However, these personalization effects could not be found for risk perception, which may underscore that increases in risk estimations do not necessarily translate into increases in risk perceptions. Furthermore,

we replicated the message format effect for Dutch verbal risk labels. More specifically, we showed that risks presented in a verbal-only format are estimated as higher and less accurate, and perceived as more likely to occur than risks presented in a combined verbal and numerical format[23,25,26].

However, personalized risks in a verbal and numerical combined format did not lead to more accurate risk estimates compared to generic numerical risk information[19–21]. A possible explanation for this might be that the personalized and generic risks were shown separately and did not contain any comparative risk information. As a result, patients could not see their own risk score for a particular side effect in comparison with scores of other patients, especially for determining whether they were above or below average[43,44]. Although there is currently a debate about whether comparative risk information should be provided to patients[45,46], such communication strategy could improve people's estimations and perceptions of probability information in the context of personalized versus generic risks of side effects[19].

Finally, in both message formats, personalized risks are perceived as more personally relevant than generic risks, which is in line with past studies on tailoring effects in health communication[32]. In addition, this shows that by manipulating the reference class of probability outcomes our manipulation of personalization was successful. We further found that when risks were presented only by means of verbal descriptors, personalized risks were perceived as less uncertain than generic risks. This suggests that personalized risks in the verbal-only condition were estimated as higher, and therefore perceived as more certain to occur.

Limitations and suggestions for future research

A first limitation is that the research design uses a hypothetical decision-making scenario instead of a real decision-making scenario in our experimental design. To partially compensate for this, our sample consisted of cancer patients and survivors who were recruited from a Dutch cancer patient panel. Often, scenario-based experimental studies on effective risk communication strategies are conducted in student samples (for an overview, see[18]), who may not be familiar with a medical decision-making situation and may have different perceptions of risks and probability information about cancer[23,47]. Although the use of cancer patients in our experiment contributed to the ecological validity of the results, future research to confirm our findings in a real-world treatment decision-making situation would be advisable.

Another limitation is that we personalized the risks based on a limited number of patient characteristics in a non-interactive way, to keep the experiment manageable and the results generalizable. Clinical prediction models in oncology settings typically utilize a larger variety of patient and tumor characteristics in decision-making (e.g., TNM-stage, the specific use of chemotherapy, or comorbidities) that is more extensive than we have dealt with in our study. Using such an interactive prediction modelling tool in which participants can enter their own personal and disease-related

characteristics and see the impact of each characteristic on their personal risk could influence patients' risk perception[48]. Despite this limitation, the personalized risks in our study were perceived as more personally relevant compared to the generic, population-based risks.

Finally, we only compared risks communicated through words or a combination of words and numbers, and did not consider the potential added value of visual aids as another message format. A plethora of research suggests that visual aids may increase understanding and perception of risk information[3,15,42,49,50]. For instance, bar charts may help to display the distinction between personalized and generic risks, and pictographs may communicate the number of people with similar characteristics that may experience the side effect compared to the number of people from the general population[15]. Therefore, it is suggested to investigate the impact of personalized risks through visually presented information compared to, for instance, numerical descriptions of risks.

Implications

Despite these limitations, our findings have implications for research and practice. First, in line with guidelines and best practices for communicating complex medical data and risks in daily clinical practice and patient decision aids[3,15,42,51], our results offer support for the recommendation to avoid verbal descriptions without numbers since they may lead to inaccurate risk estimates. Our findings suggest that this recommendation may become even more relevant when the risks are personalized and adjusted to sociodemographic and clinical characteristics of patients. This finding is useful for clinicians who discuss risks, health data, and other probability information during consultations in general with their patients and relatives, and especially for clinicians who are using modern decision-support systems (e.g., clinical prediction models) for estimating and communicating individualized treatment outcomes to patients. In addition, in light of the growing emphasis of personalized medicine[52], shared decision-making[4,53], and the promising approaches of the delivery of personalized risk information through patient-centered decision aids[9–12], our results contribute to the empirical evidence on how best to communicate personalized risks to individual patients[54,55].

CONCLUSION

When communicating personalized risk information of treatment side effect to patients, using a combination of words and numbers will lead to more accurate risk estimates than when using words only. Although we found no evidence that personalization of numerical risks leads to even more accurate risk estimates, doing so with verbal labels alone may have a negative impact on patients' (accuracy) of risk estimates. Given the strong movements toward personalized medicine and patient-

centered healthcare, future research will have to determine whether other ways of presenting personalized risk information, such as comparative risk information or visual aids promote effective communication of personalized risks during cancer treatment decision-making.

FOOTNOTES

[1] According to our pre-registration (https://osf.io/j74dt/), our main analysis consisted of a 2 (personalization: personalized, generic) × 2 (message format: verbal-only, verbal and numerical combined) mixed-model multivariate analysis of variance (MANOVA) with repeated measures on the first factor. However, we decided to include probability rate as a methodological variable in our study design, which resulted in a 2 × 2 × 2 mixed-model MANOVA. This MANOVA was initially stated as an exploratory analysis in our pre-registration, but has now become the main analysis in this study.

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APPENDICES

Appendix A

Description: For our main analysis, we conducted a 2 (within-subjects: personalization) × 2 (between-subjects: message format) × 2 (within-subjects: probability rate) mixed-model multivariate analysis of variance (MANOVA)[1]. The dependent variables were our three primary outcome measures; risk estimates, risk accuracy, and risk perception. If applicable, significant interaction effects were further analyzed by means of simple effect analyses. As an exploratory analysis, we controlled for individual differences by conducting a separate 2 (within-subjects: personalization) × 2 (between-subjects: message format) × 2 (within-subjects: probability rate) mixed-model multivariate analysis of covariance (MANCOVA) with subjective numeracy skills and prior history with chemotherapy and/or one of the side effects as covariates. The dependent variables were risk estimates, risk accuracy, and risk perception.

Table A1 | Main and interaction effects on primary outcome measures, resulting from a 2 (personalization: personalized, generic) × 2 (message format: verbal-only, verbal and numerical combined) × 2 (probability rate: low, high) mixed-model MANOVA with repeated measures on the first and third factor.

	Primary outcome variables								
	Risk estimates			**Risk accuracy**			**Risk perception**		
Main/Interaction Effects	***F***	***p***	η_p^2	***F***	***p***	η_p^2	***F***	***p***	η_p^2
Personalization	5.32	**.023**	.041	6.25	**.014**	.048	2.40	.124	.019
Message format	69.82	**<.001**	.358	64.26	**<.001**	.340	30.27	**<.001**	.195
Probability rate	72.71	**<.001**	.368	93.59	**<.001**	.428	65.86	**<.001**	.342
Personalization × Message format	7.21	**.008**	.055	7.82	**.006**	.059	1.79	.183	.014
Message format × Probability pate	15.17	**<.001**	.108	26.33	**<.001**	.174	12.91	**<.001**	.094
Personalization × Probability rate	< 1	-	-	< 1	-	-	< 1	-	-
Personalization × Message format × Probability rate	< 1	-	-	< 1	-	-	< 1	-	-

Note. [a] *df* = 1, 125; Significant results are given in **bold.**

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Table A2 | Main and interaction effects on primary outcome measures, resulting from a 2 (personalization: personalized, generic) × 2 (message format: verbal-only, verbal and numerical combined) × 2 (probability rate: low, high) MANCOVA with repeated measures on the first and third factor.

	Primary outcome variables								
	Risk estimates			**Risk accuracy**			**Risk perception**		
Main/Interaction Effects	***F***	***p***	η_p^2	***F***	***p***	η_p^2	***F***	***p***	η_p^2
Personalization	1.04	.310	.009	1.60	.209	.002	0.28	.598	.002
Message format	63.43	**<.001**	.348	59.28	**<.001**	.333	27.13	**<.001**	.186
Probability rate	1.64	.203	.014	4.55	**.035**	.037	2.03	.157	.017
Personalization × Message format	7.32	**.008**	.058	6.70	**.011**	.053	2.03	.157	.017
Message format × Probability pate	11.45	**.001**	.088	21.14	**<.001**	.151	9.00	**.003**	.070
Personalization × Probability rate	< 1	-	-	< 1	-	-	< 1	-	-
Personalization × Message format × Probability rate	< 1	-	-	< 1	-	-	< 1	-	-

Note. [a] *df* = 1, 125; [b] *df* = 1, 119; [c] Individual difference in numeracy, prior history with chemotherapy, and prior history with one of the side effects serve as covariates; Significant results are given in **bold.**

7

Explaining personalized risk information of treatment outcomes: Does providing comparative risk information matter?

This chapter is based on:

Vromans, R. D.,
Pauws, S. C.,
van de Poll-Franse, L. V.,
& Krahmer, E. J.

Effects of comparative information when communicating personalized risks of treatment outcomes: Web-based experimental study. Manuscript submitted for publication.

ABSTRACT

Background: In recent years, there has been considerable interest into personalized risks of treatment outcomes. However, personalized risks lack inherent meaning and therefore are difficult for patients to evaluate. We examined the effects of providing comparative data of the average person's risk when discussing personalized risks on people's cognitive, emotional, and behavioral responses.

Methods: 1807 participants from a representative sample of the Dutch population received personalized risks of treatment side effects in three different health scenarios. Participants either received only their own personalized risk statistic, or with comparative data indicating that their risk was below or above average. Furthermore, we examined whether the effects would be influenced by message format (natural frequencies with or without icon arrays) and individual differences (subjective numeracy, health literacy, and graph literacy). Primary outcomes were risk estimates, risk perception, and affective evaluations. Secondary outcomes were perceived personal relevance and treatment intention.

Results: Providing comparative risk information did not influence participants' risk perceptions, affective evaluations, nor their intention of choosing the treatment. However, participants who were told that their personalized risks were above average, estimated their own risk as lower than participants who received the same personalized risks that were below average or that were without any comparative data. Message format and individual differences did not influence people's responses to comparative data. Although less numerate participants had less accurate risk estimates overall and were less likely to take over the personalized risk they were provided with compared to highly numerate participants, both numeracy groups preferred to receive comparative data in addition to the personalized risks.

Conclusions: Comparative data of the average person's risk can be used by people for estimating their own risk, without negatively impacting their risk perceptions, affective evaluations, or treatment intentions. Healthcare professionals and decision aid developers can consider providing comparative risk information for helping people make sense of their personalized risks of treatment outcomes.

INTRODUCTION

Communicating probability information about risks and benefits of health interventions or treatment options to patients is becoming an essential part of modern-day health care and shared decision-making[1,2]. In light of the growing emphasis on personalized medicine, patient-centered care, and open access of "big health data"[3–5], there has been rapid growth in the development of personalized risk information tools for patients in different health contexts[6], ranging from, for example, cardiovascular diseases to the oncology setting[7–9]. These tools are aimed at providing patients personalized risks and health statistics that take into account several personal and clinical characteristics of unique patients. These personalized risks are – compared to generic risks – perceived as more personally relevant[10], which increases the likelihood of them being better processed and understood by patients[11–13].

Even though personalized risks may be more useful and relevant for a patient than generic, average-based ones, a critical problem is that they still have low evaluability: they are often unfamiliar to patients, lack inherent meaning, and therefore make it difficult for patients to evaluate whether they are 'good' or 'bad'[14]. Following theory on "information evaluability"[15,16], single risk statistics presented in isolation are generally difficult to evaluate by people and are sometimes even ignored. However, providing contextual information may improve evaluability of personalized risks by helping patients to derive meaning from unknown risk information[14]. Examples of contextual strategies include using evaluative labels (e.g., telling patients how good or bad a 70% risk is) or providing comparative data on other risks (e.g., risk ladders)[1,17].

Another promising contextual strategy for improving evaluability of personalized risk information is by adding *comparative risk information* of the average person's risk to the patient's individual risk estimate. In line with Festinger's social comparison theory[18], patients often report that they want to see their own risk score for a particular outcome in comparison with scores of other patients[19,20], especially for determining whether they are above or below average[21]. When personalized risks are presented with other data (e.g., the average risk), people are better able to interpret even unfamiliar risks because both types of risks serve as a reference for each other, which enables people to evaluate the "goodness" or "badness" of the risk information[17].

However, a much-debated question is whether patients should be provided with comparative risk information at all. According to some, comparative statements should not be communicated (or at least with caution), since such data could unintentionally influence patients' cognitive (e.g., risk perception), emotional (e.g., affective evaluation or levels of worry), and subsequent behavioral (e.g., decision-making) responses[22–26]. For instance, people who are above average risk may feel more worried and compelled to take a treatment, even though this may not always be the best option based on rational decision analysis. To others, however, patients should always be informed about whether their personalized risk is above or below average, since most patients

will make such comparisons on their own anyway[24,25]. In this case, the provision of context would be useful for correcting inaccurate beliefs and risk perceptions. However, little is known about interpretations that people derive from comparative information and whether this may depend on what type of comparative data are communicated and in what specific health decision context[17,27]. Therefore, the first aim of this study is to examine people's cognitive, emotional, and behavioral responses to comparative risk information in the context of communicating personalized risk information of treatment side effects.

Importantly, the communication of comparative risk information may be influenced by various factors, including the way in which comparative data is communicated[26]. Arguably, the most common way to communicate risks in healthcare is through numerical estimates such as percentages or natural frequencies (e.g., "5 out of 100 persons like you will experience this treatment side effect"), but such formats are often misinterpreted by less literate and numerate patients. Consistent with dual coding theory[28], adding visual representations of statistical data such as icon arrays (or pictographs) to numerical information can influence people's understanding and perceptions of risk, but also health-related decisions, and might therefore be a better strategy for communicating personalized risks with comparative data[1,29,30]. However, pictographs have also been shown to have the highest affective impact through automatic associations (e.g., the color red associates with danger) compared to numerical-only estimates, which in turn may impact risk perceptions, affective evaluations, and treatment decision-making[31–33]. Especially in a situation when a patient's personalized risk is above average, communicating this both numerically and visually may cause people to be unintentionally worried about the information, which may be emphasized even more when displayed visually. As such, an important unanswered question is whether people's responses to comparative information might be influenced by the message format.

The aim of the present study is threefold: to (1) to determine the effect of providing comparative risk information of personalized treatment outcomes on people's cognitive (risk perception and risk estimates), emotional (affective evaluations), and behavioral (decision-making) responses; (2) to investigate whether processing of comparative risk information would be affected by whether it is presented in a numerical-only or numerical+visual format; and (3) to examine whether the effects differ for people with different sociodemographics, and different levels of subjective numeracy, health literacy, and graph literacy. We tested three pre-registered hypotheses (https://tiu.nu/osf/q2dcz):

H1: Participants receiving personalized risks that are above average (i.e., receiving relatively less favorable risk information) will report higher (a) risk estimates, (b) risk perceptions, and (c) affective evaluations than participants viewing the same

personalized risks that are below average (i.e., receiving relatively favorable risk information) or without any comparative risk information.

H2: Participants receiving personalized risks presented in a numerical+visual format will show higher (a) risk estimates, (b) risk perceptions, and (c) affective evaluations than participants viewing the same personalized risks presented in a numerical-only format.

H3: Participants receiving personalized predictions that are above average and that are presented in a numerical+visual format will report higher (a) risk estimates, (b) risk perceptions, and (c) affective responses compared to other combinations of message format and comparative risk information.

METHODS

Study design and sampling

In a large scale experiment, participants were presented with three different health scenarios and personalized risk information of treatment side effects in six different formats, for which we adopted a 3 (comparative risk information: personalized-risk only, personalized risk above average, personalized risk below average) × 2 (message format: numerical-only, numerical+visual) between-subject design. Participants were randomly assigned to one of the six experimental conditions. We used risk estimates, risk perception, and affective evaluation of the risk information as primary outcomes, and perceived personal relevance and treatment intention as secondary outcomes. Ethical approval was granted by the Research Ethics and Data Management Committee of the Tilburg School of Humanities and Digital Sciences of Tilburg University (ID REDC.2019.26a).

A representative sample of the Dutch population (age ≥ 16) was recruited through CentERdata's Longitudinal Internet Studies for the Social Sciences (LISS) panel. This panel consists of 5,000 households in the Netherlands, comprising approximately 7,500 individuals, and represents a true probability sample of households drawn from the population register by Statistics Netherlands[34]. Households that could not otherwise participate are provided with a computer and Internet connection. Panel members complete online questionnaires every month for which they receive financial compensation. In addition, the LISS panel yearly collects data on panel members' sociodemographics and health status, among other core topics, which allows for researchers to add these data to their survey data. As part of the pre-registration (https://tiu.nu/osf/q2dcz), power calculations were conducted in order to determine our sample size using the program G*Power 3.1.9.2[35]. To detect a small effect for the primary measures with a 3 × 2 between-subject design, a sample of 1269 participants was calculated to be needed for the experiment (power = 0.9, α = .05). However, given

that we were interested in exploring individual difference measures, we aimed for a total of 1800 participants (300 per experimental condition).

Materials

Health scenarios and personalized risk information

Participants read three health scenarios and treatment information in a randomized order: chemotherapy for advanced colon cancer, medication for increased cholesterol levels, and surgery for skin cancer. We selected these scenarios to represent various diseases, treatment options and associated side effects, as well as for variation in the actual probability estimate of experiencing a potential side effect. In each scenario, participants were asked to imagine being diagnosed with that specific disease and that they were given a website from their doctor including information about treatment and its associated side effects. After each scenario text, participants received personalized risk estimates of experiencing a treatment side effect, which was always a fictitious number and held constant for each participant across the experimental conditions. Participants were informed that the risk information was personalized based on their reported gender, age, and specific information about the disease as stated in the scenario. For colon cancer, the risk of experiencing neuropathy after chemotherapy was 38%. For increased cholesterol, the risk of gastrointestinal complaints after medication was 25%. For skin cancer, the risk of inflammation of the skin surrounding the wound after surgery was 17%.

Comparative risk information

Participants either received their personalized risk estimate without comparative data (personalized risk-only condition), or they received their personalized risk together with a lower generic risk (i.e., personalized risk above average condition) or together with a higher generic risk (i.e., personalized risk below average condition). A generic risk was defined as the risk for *all people* of *all ages* diagnosed with *all forms of colon/ skin cancer or all cholesterol levels*. We intended to vary the risk difference between the personalized risks and the generic risks in the three health scenarios. Therefore, these risk differences were +/- 20% for the colon cancer scenario, +/- 15% for the increased cholesterol scenario, and +/- 10% for the skin cancer scenario, respectively.

Message format

Half of the participants received the risk only in numbers (numerical-only format) using natural frequencies (e.g., 38 out of 100 men like you). The other half received the risk in a combination of natural frequencies and visual aids using icon arrays (numerical+visual format). As recommended by Zikmund-Fisher and colleagues[36], the icons included a matrix of 100 restroom icons displayed in different colors to represent the number of individuals with (red) or without (grey) experiencing the

side effect. Figure 1 displays example stimuli for all six experimental conditions, shown for male participants receiving risk information about experiencing neuropathy after chemotherapy for advanced colon cancer.

Figure 1 | Structure of stimulus material within the 3 [comparative risk information: personalized risk-only, personalized risk above average, and personalized risk below average] × 2 [format: numerical-only, numerical+visual) between-subject design, shown for male participants receiving risks about neuropathy after chemotherapy for colon cancer. Participants either received their personalized risk without comparative data, or they received their personalized risk together with a lower generic risk or together with a higher generic risk.

Measures

Primary measures

We had three primary outcome measures. First, *risk estimates* was measured using the question "What do you think is the probability **you** will experience this side effect" (measured as a percentage between 0 and 100)[10,37]. Second, *risk perception* was measured with two items ("How likely do you think you would be to experience this side effect after treatment?" and "How big do you think is the chance that you would be to experience this side effect after treatment?", Cronbach's α = .85) measured on 5-point scales, with 1 as 'not likely at all'/'not big' and 5 as 'very likely'/'very big')[10,37]. Third, *affective evaluation* of the risk information was measured with three items ("How frightening/worrisome/serious do you think the information about this side effect was?", Cronbach's α = .90) measured on a 5-point scale, with 1 as 'not frightening'/'not worrisome'/'not serious' and 5 as 'very frightening'/'very worrisome'/'very serious'[31].

Secondary measures

We also included two secondary outcomes. First, *perceived personal relevance* was measured using two items ("The risk information about the side effect was made personally for me" and "The way how the risk information was being presented was relevant to me", Cronbach's α = .85) measured on 5-point scales, with 1 as 'strongly disagree' and 5 as 'strongly agree'[11]. Second, *treatment intention* was measured using the question "Based on the information that you just read, how likely it is that you will choose this treatment?" measured on a 5-point scale, with 1 as 'not likely at all' and 5 as 'very likely'[31].

Individual difference measures

Subjective numeracy was assessed by the Subjective Numeracy Scale (SNS[38]), which is an 8-item self-assessment for determining participants' quantitative ability and preferences for receiving numerical information (measured on a 6-point scale, with 1 as 'least numerate' and 6 as 'most numerate', α = .87). All eight items were presented in a randomized order. The SNS has proven to be a valid and reliable measure, and correlates strongly with objective numeracy measures[39]. For the current study, we used the Dutch version of the SNS[10,40]. The mean subjective numeracy score was determined by computing the average score of the eight items, with higher scores indicating higher numeracy skills.

Health literacy was measured with the 13-item version of the Short Assessment of Health Literacy in Dutch (SAHL-D[41]). Participants were exposed to multiple choice questions in a randomized order in which they had to select the accurate meaning of health-related words. Each answer was coded as 1 (correct) or 0 (incorrect). A sum score was calculated (range: 0–13) with higher scores representing higher health literacy skills.

Graph literacy was assessed with the 4-item version of the Graph Literacy Scale in Dutch[42–44], presenting different types of graphs and questions (two open-ended and two multiple choice, in a randomized order) about understanding the information in the graphs. Each answer was scored 1 (correct) or 0 (incorrect). A sum score was calculated (range: 0–4) with higher scores representing higher graph literacy skills.

Background measures

Demographic data (i.e., age (groups), gender and educational level) were extracted from the LISSPANEL database. Educational level was categorized as follows, based on guidelines from CBS Statistics Netherlands 2013[45]: lower (i.e., primary education, preparatory secondary vocational education), medium (i.e., higher secondary general education or pre-university education, secondary vocational education), and higher level of education (i.e., higher vocational education, university). Next to that, we also controlled for prior (indirect) experience with the three diseases and/or treatments and/or side effects that were used in the experimental study.

Need for personalized risks and comparative data

We assessed participants' need for receiving their personalized risks of treatment outcomes with the item "Imagine that you're being informed about potential risks of a treatment. In general, to what extent do you have a need for knowing your personalized risk of experiencing treatment side effects?" (measured on a 4-point scale, 1 = not at all, 2 = a little, 3 = quite a bit, 4 = very much). Participants' need for comparative data was assessed with the item "Imagine that you're being informed about your personalized risks of experiencing side effects after treatment. Would you also want to know what your personalized risk is compared to the average risk?" (answer options: 1 = yes, always, 2 = yes, but only when my personalized risk is better than average, 3 = yes, but only when my personalized risk is worse than average, 4 = no, I don't want to know).

Statistical analyses

Following the pre-registration, we conducted three separate two-way multivariate analyses of covariance (MANCOVAs; one for each health scenario) with risk estimates, risk perception, and affective evaluation as dependent variables, and comparative risk information and message format as the independent variables. We controlled for demographic characteristics (age, gender, education) and individual difference measures (numeracy, health literacy, and graph literacy) by entering them as covariates. If applicable, significant interaction effects were further analyzed by means of simple effect analyses. For comparative risk information, we used pre-specified contrasts to assess whether personalized risks above average yielded higher levels of (a) estimated risks, (b) perceived risks and (c) affective evaluations compared to the other two comparative strategies.

For the secondary outcome measures, we conducted separate two-way ANCOVAs, with perceived personal relevance and treatment intention as dependent variables, and comparative risk information and message format as the independent variables, and the same demographic characteristics and individual difference measures as control variables.

As an exploratory analysis, we examined whether participants' need for personalized risk information and comparative whether the effects of comparative risk strategies on people's estimated probabilities may be depended on numeracy. For this, we converted numeracy into a binary variable consisting of less (SNS ≤ 4) and highly (SNS ≥ 4) numerate people[46], and subsequently tested its association with specific probability estimates (e.g., accurate response, fifty-fifty response) using chi-square tests for the different comparative risk strategies.

Data on sociodemographic characteristics and individual difference scores for the (1) respondents and non-respondents, and for the (2) six experimental conditions were compared using chi-square tests for categorical variables and ANOVAs for continuous variables. All statistical analyses were performed using SPSS version 24.0 (IBM Corporation, Somers, NY, USA). Tests were two-sided and considered statistically

significant at $p < .05$. The study design, hypotheses, exploratory objectives, and analysis plan were pre-registered prior to data collection and analysis within the Open Science Framework (https://tiu.nu/osf/q2dcz).

RESULTS

Sample characteristics

Out of 2,409 people who were invited to participate, 1,807 (75%) clicked the link to launch the survey. Of those, 1753 (97%) fully completed the survey (Figure 2). Completion rates were high across experimental conditions (range = 90%–99%), and only completed cases were analyzed. Fifty-four percent of the sample was female, and the mean age of participants was 53.9 years (*SD* = 18.3, range = 16–95 years). Overall, this sample was largely representative of the Dutch population[1]. There were no differences between respondents and non-respondents when comparing gender and education (Table 1). However, non-respondents were on average younger (*p*s < .001). Finally, the participants in all six experimental conditions were comparable in terms of sociodemographic characteristics, numeracy, health literacy, and graph literacy skills (all *p* values >. 590, Table A1, Appendix A).

Table 1 | Sociodemographic characteristics of respondents and non-respondents.

	Respondents (*n* = 1807)		**Non-respondents (*n* = 602)**		
Characteristics	***n***	**%**	***n***	**%**	***p*-value**
Gender					
Female	980	54	333	55	
Male	827	46	269	45	.644
Age, mean (SD)	53.9 (18.3)		40.7 (17.0)		< .001
15-24 years	142	8	104	17	
25-34 years	199	11	156	26	
35-44 years	213	12	124	21	
45-54 years	277	15	85	14	
55-64 years	356	30	68	11	
> 65 years	620	34	65	11	< .001
Education[a]					
Lower[b]	472	26	130	22	
Medium[c]	600	33	214	36	
Higher[d]	729	41	256	42	.084

Note. [a] = Missing data for nine participants; [b] = Primary education, preparatory secondary vocational education; [c] = higher secondary general education or pre-university education, secondary vocational education; [d] = higher vocational education, university; SD = standard deviation.

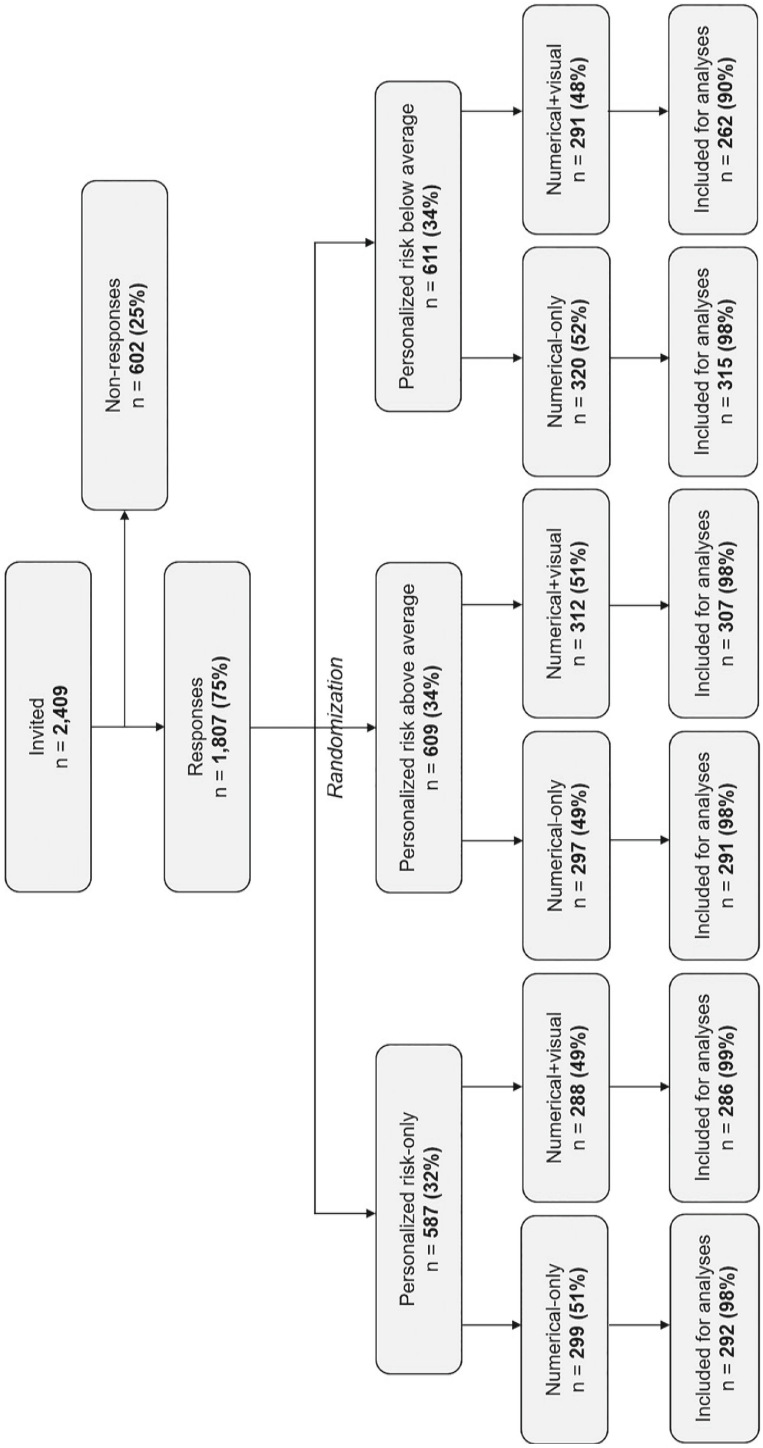

Figure 2 | Flowchart of the data collection process.

Effects on primary and secondary outcomes in the colon cancer scenario

Descriptive statistics for the primary and secondary outcomes in the colon cancer scenario are shown in Table 2, and all test statistics can be found in Appendix B (Table B1). There was a significant effect of comparative risk information on people's estimated risks, $F(2, 1741) = 8.27$, $p < .001$, $\eta_p^2 = .009$. Participants who received personalized risks that were above average reported significantly lower probability estimates than participants who received the same personalized risks that were below average ($p < .001$) or that were without any comparative risk information ($p = .008$) (Figure 3a). However, there were no significant main effects of comparative risk information on perceived risk, affective evaluations, perceived personal relevance, or treatment intention (all *p*s > .182). Overall, these (non-)effects of comparative risk information did not depend on the message format (all *p*s > .120). Furthermore, there was no effect of message format on people's estimated risks, perceived risks, affective evaluations, or perceived personal relevance (all *p*s > .834). However, participants who received risk information in a numerical-only format were more likely to take the treatment compared to participants who received the information in a numerical+visual format ($F(1, 1741) = 4.04$, $p = .045$, $\eta_p^2 = .002$).

Table 2 | Participants' mean scores on the primary and secondary outcomes in the colon cancer scenario across all experimental conditions.

	Personalized risk-only			Personalized risk above average			Personalized risk below average		
Outcomes	**Numerical -only**	**Numerical +visual**	**Total**	**Numerical -only**	**Numerical +visual**	**Total**	**Numerical -only**	**Numerical +visual**	**Total**
Primary outcomes									
Risk estimates	42.4 (17.9)	40.7 (16.4)	41.5 (17.2)	38.0 (15.5)	39.9 (17.1)	39.0 (16.3)[a***]	42.8 (16.6)	43.0 (17.0)	42.9 (16.8)
Risk perception	3.04 (0.81)	3.04 (0.82)	3.04 (0.81)	3.04 (0.85)	3.11 (0.81)	3.08 (0.83)	2.09 (0.76)	3.03 (0.82)	3.06 (0.79)
Affective evaluation	3.23 (0.96)	3.16 (0.94)	3.20 (0.95)	3.22 (0.97)	3.22 (0.96)	3.22 (0.96)	3.21 (0.94)	3.28 (0.92)	3.24 (0.93)
Secondary outcomes									
Perceived personal relevance	2.97 (0.95)	2.92 (0.86)	2.95 (0.90)	2.97 (0.96)	3.09 (0.97)	3.04 (0.96)	3.07 (0.92)	3.00 (0.90)	3.04 (0.91)
Treatment intention	3.63 (1.13)	3.55 (1.03)[b*]	3.59 (1.08)	3.53 (1.07)	3.47 (1.09)[b*]	3.50 (1.08)	3.62 (1.10)	3.47 (1.03) [b*]	3.55 (1.07)

Note. Standard deviations within parentheses; Control variables include age, gender, education, subjective numeracy, health literacy, and graph literacy; [a] Mean differs significantly compared to total personalized risk-only and personalized below average conditions; [b] Total numerical+visual format differs significantly compared to total numerical-only format; * $p<.05$, ** $p<.01$, *** $p<.001$.

Effects on primary and secondary outcomes in the increased cholesterol scenario

Descriptive statistics for the primary and secondary outcomes in the increased cholesterol scenario are shown in Table 3, and all test statistics can be found in Table B2 (Appendix B). The pattern of results for the effects of comparative risk information are almost similar to that of the first health scenario. There was a significant effect of comparative risk information on people's estimated risks, $F(2, 1741) = 3.65$, $p < .026$, $\eta_p^2 = .004$. Participants who received personalized risks that were above average reported significantly lower probability estimates than participants who received the same personalized risks that were below average ($p < .010$) or that were without any comparative risk information ($p = .048$) (Figure 3b). Again, there were no significant main effects of comparative risk information on perceived risk, affective evaluations, or treatment intention (all *p*s > .244). However, there was a significant main effect of comparative risk information on perceived personal relevance ($F(2, 1741) = 3.73$, $p = .024$, $\eta_p^2 = .004$), with participants perceiving personalized risks that were below average as more personally relevant than personalized risks without comparative data ($p = .022$). Similar to the previous scenario, these (non-)effects of comparative risk information did not depend on the message format (all *p*s > .083).

Furthermore, there was a significant main effect of message format on risk perception ($F(1, 1741) = 5.47$, $p = .019$, $\eta_p^2 = .003$) and affective evaluation ($F(1, 1741) = 4.20$, $p = .041$, $\eta_p^2 = .002$). Participants in the numerical+visual format reported lower levels of perceived risk and affective impact of the risk information compared to participants who received the same personalized risks in a numerical-only format. There were no significant main effects of message format on risk estimates, perceived relevance, or treatment intention (all *p*s > .681).

Table 3 | Participants' mean scores on the primary and secondary outcomes in the increased cholesterol scenario across all experimental conditions.

	Personalized risk-only			Personalized risk above average			Personalized risk below average		
Outcomes	**Numerical -only**	**Numerical +visual**	**Total**	**Numerical -only**	**Numerical +visual**	**Total**	**Numerical -only**	**Numerical +visual**	**Total**
Primary outcomes									
Risk estimates	31.4 (18.8)	29.6 (18.1)	30.5 (18.4)	27.7 (16.8)	29.2 (17.9)	28.4 (17.4)[a*]	31.3 (18.6)	31.0 (18.8)	31.2 (18.7)
Risk perception	2.60 (0.88)	2.44 (0.85)[b*]	2.52 (087)	2.51 (0.80)	2.50 (0.85)[b*]	2.50 (0.83)	2.57 (0.88)	2.46 (0.90)[b*]	2.52 (0.89)
Affective evaluation	2.41 (0.98)	2.33 (0.90)[b*]	2.47 (1.01)	2.40 (0.98)	2.35 (0.96)[b*]	2.37 (0.94)	2.50 (1.03)	2.43 (0.97)[b*]	2.38 (0.97)
Secondary outcomes									
Perceived personal relevance	2.80 (0.98)	2.72 (0.95)	2.76 (0.97)	2.79 (0.94)	2.93 (1.02)	2.86 (0.98)	2.95 (0.96)	2.87 (1.00)	2.91 (0.98)[c*]
Treatment intention	3.38 (1.15)	3.46 (1.18)	3.42 (1.16)	3.34 (1.15)	3.27 (1.16)	3.31 (1.16)	3.32 (1.21)	3.34 (1.21)	3.33 (1.21)

Note. Standard deviations within parentheses; Control variables include age, gender, education, subjective numeracy, health literacy, and graph literacy; [a] Mean differs significantly compared to total personalized risk-only and personalized below average conditions; [b] Total numerical+visual format differs significantly compared to total numerical-only format; [c] Mean differs significantly compared to total personalized risk-only condition; * $p<.05$, ** $p<.01$, *** $p<.001$.

Effects on primary and secondary outcomes in the skin cancer scenario

Descriptive statistics for the primary and secondary outcomes in the skin cancer scenario are shown in Table 4, and all test statistics can be found in Table B3 (Appendix B). The pattern of results for the effects of comparative risk information are almost similar to that of the other two health scenarios; there were again no significant main effects of comparative risk information on people's perceived risks, affective evaluations, or treatment intentions (all *p*s > .272). However, this time, there was no effect of comparative risk information on participants' estimated risks, $F(2, 1741) = 1.28$, $p = .279$, $\eta_p^2 = .001$. Furthermore, similar to the previous scenario, there was a significant main effect on perceived personal relevance ($F(2, 1741) = 3.26$, $p = .039$, $\eta_p^2 = .004$), with participants perceiving personalized risks that were below average as more personally relevant than personalized risks without comparative data ($p = .034$). Overall, these (non-)effects of comparative risk information did not depend on the message format (all *p*s > .099).

Furthermore, similar to the second scenario, there was a significant main effect of message format on affective evaluation ($F(1, 1741) = 10.15$, $p = .001$, $\eta_p^2 = .006$). Participants in the numerical+visual format reported lower levels of affective impact of the risk information compared to participants who received the same personalized risks in a numerical-only format. Again, there were no significant main effects of message format on risk estimates, risk perception, perceived relevance, or treatment intention (all *p*s > .062).

Table 4 | Participants' mean scores on the primary and secondary outcomes in the skin cancer scenario across all experimental conditions.

	Personalized risk-only			Personalized risk above average			Personalized risk below average		
Outcomes	**Numerical -only**	**Numerical +visual**	**Total**	**Numerical -only**	**Numerical +visual**	**Total**	**Numerical -only**	**Numerical +visual**	**Total**
Primary outcomes									
Risk estimates	24.4 (18.7)	22.3 (16.9)	23.4 (17.9)	22.0 (16.8)	24.0 (19.5)	23.0 (18.2)	24.1 (16.8)	25.0 (19.1)	24.5 (17.9)
Risk perception	2.16 (0.85)	2.06 (0.77)	2.11 (0.81)	2.18 (0.79)	2.09 (0.89)	2.13 (0.84)	2.14 (0.77)	2.13 (0.90)	2.14 (0.83)
Affective evaluation	2.45 (0.98)	2.25 (0.89)[c**]	2.36 (0.94)	2.37 (0.99)	2.23 (0.99)[c**]	2.30 (0.99)	2.44 (1.00)	2.35 (1.04)[c**]	2.40 (1.02)
Secondary outcomes									
Perceived personal relevance	2.71 (1.00)	2.59 (0.96)	2.65 (0.98)	2.68 (0.96)	2.79 (1.07)	2.73 (1.02)	2.80 (1.02)	2.78 (1.02)	2.79 (1.02)[a*]
Treatment intention	3.74 (1.17)	3.82 (1.14)	3.78 (1.16)	3.69 (1.18)	3.72 (1.18)	3.70 (1.18)	3.69 (1.20)	3.76 (1.14)	3.72 (1.17)

Note. Standard deviations within parentheses; Control variables include age, gender, education, subjective numeracy, health literacy, and graph literacy; [a] Mean differs significantly compared to total personalized risk-only condition; [b] Total numerical+visual format differs significantly compared to total numerical-only format; * $p <. 05$, ** $p < .01$, *** $p < .001$.

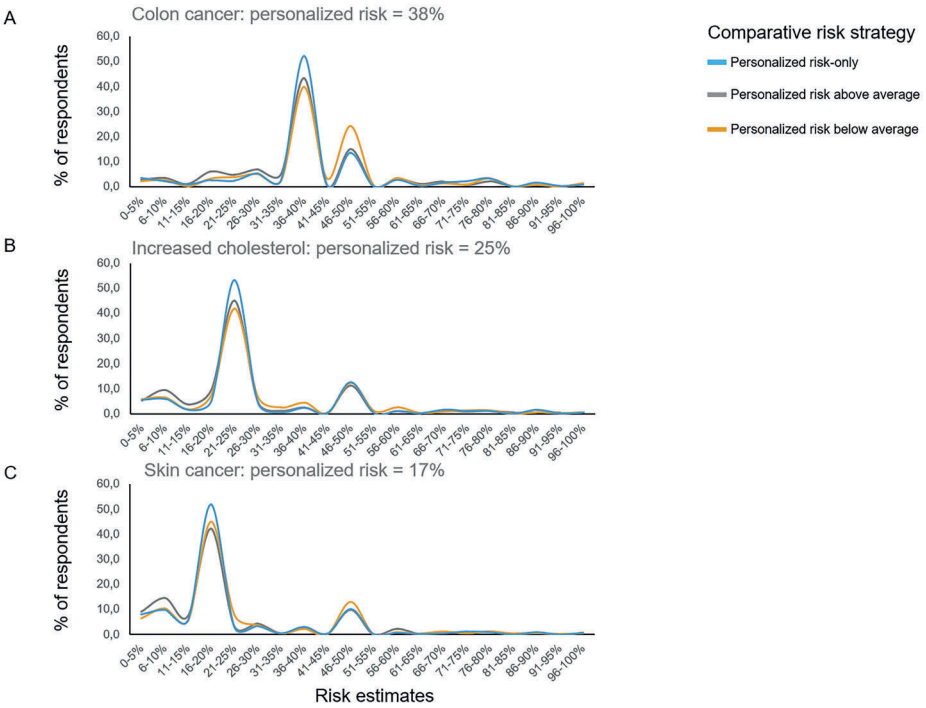

Figure 3 | Risk estimates as a function of comparative risk strategy, shown for all three health scenarios.

Exploratory findings: individual differences and need for personalized risks

We observed some important differences between people with different subjective numeracy skills on a range of different measures. First, regardless of message format or comparative risk strategy, less numerate people had less accurate risk estimates and were less likely to take over the personalized risk they were provided with compared to highly numerate participants in all three health scenarios ($\chi^2_{skincancer}(1, 1784) = 153.25$, $p < .001$; $\chi^2_{cholesterol}(1, 1784) = 142.20$, $p < .001$; $\chi^2_{coloncancer}(1, 1784) = 158.08$ $p < .001$). Moreover, less numerate people were more likely to estimate their risk as 50% percent compared to highly numerate people ($\chi^2_{skincancer}(1, 1784) = 35.81$, $p < .001$; $\chi^2_{cholesterol}(1, 1784) = 44.59$, $p < .001$; $\chi^2_{coloncancer}(1, 1784) = 18.16$, $p < .001$).

Even though our sample showed great interest in receiving personalized risk information of treatment side effects (70.6% reported to have quite a bit or very much need, 22.5% a little need, and 6.9% no need at all), less numerate people also showed less interest in wanting personalized risks ($M = 2.72$, $SD = 0.99$) than highly numerate people ($M = 3.19$, $SD = 0.86$); $t(1673) = 10.43$, $p < .001$, $d = 0.51$). If people were being provided with their personalized risk score, the majority also wanted to receive comparative risk information (73.5%), whereas some only wanted to receive comparative data when their personalized risks were better (7.4%) or worse (11.7%),

and few did not want to receive comparative data (7.4%). However, both less (65%) and highly (78.1%) numerate people showed great need for receiving comparative risk information.

DISCUSSION

In this experimental study among a representative sample of the Dutch population, the main findings were threefold. First, we found that comparative data of the average person's risk can be used by people for estimating their own personalized risk, without negatively impacting their risk perceptions, affective evaluations or treatment intentions. Second, we found that processing of comparative risk information was not influenced by whether it was presented via numbers-only (i.e., natural frequencies) or combined with visual information (i.e., colored icon arrays). Third, the effects and processing of comparative risk information did not differ for people with varying sociodemographic characteristics (age, gender, education) and different levels of subjective numeracy, health literacy, and graph literacy skills.

These findings are in contrast with our pre-registered hypothesis (H1) and previous research on this topic[22–26]. People who received contextual information indicating that their personalized risk was above the average, generic risk did not report higher risk perceptions and did not evaluate the information as more frightening or worrisome compared to people who received the same personalized risks that were below average or without any comparative risk information. A possible explanation for these contrasting results could be that our study investigated the effects of comparative risk data in the context of personalized side effect risks of treatment options, whereas previous research was carried out in the screening context, emphasizing the (reducing) the risk of getting a certain disease such as breast or colon cancer[23,26]. However, our results do corroborate with researchers who are in favor of disclosing comparative risk information[47,48], and are also strengthened by the fact that the vast majority of our sample reported a high need for receiving comparative data when being provided with personalized risk information of treatment options, which was also found by Fagerlin and colleagues[23].

One unanticipated finding was that, on average, people's risk estimates were influenced by comparative risk information, but in the opposite direction of our hypothesis (H1). We expected that people's risk estimates would – jointly with their risk perceptions and affective evaluations – be increased when showing people that their personalized risk is above average. In general, even when people are being provided with numerical risks, they tend to overestimate their own risk estimate[10,49,50]. In two out of three health scenarios, people used the average risk for determining their own risk score: They reported on average lower risk estimates when being provided with relatively less favorable risk information (i.e., being above average), and higher risk estimates when being provided with more favorable risk information (i.e.,

being below average). These results suggest that people do not ignore comparative risk information when estimating their own risk. In addition, distributions plots of people's risk estimate revealed that most people take over the personalized risk score they were provided with, thereby demonstrating accurate risk estimates. However, exploratory analyses revealed that less numerate people were more likely to estimate their own risk as "fifty-fifty" and less likely to take over their personalized risk score compared to highly numerate participants. Empirical studies have shown that "fifty-fifty" responses may represent answers such as "don't know", especially among less educated and numerate people[51,52]. Although people's responses to comparative risk information did not depend on numeracy skills, the different risk estimates patterns of less numerate people may invite further research to specially examine whether providing comparative data in addition to personalized risks may be beneficial or detrimental for especially less numerate people.

The results found for comparative risk information did not depend on whether risks were communicated via natural frequencies or combined with colored icon arrays. However, regardless of comparative risk strategy, in two out of three scenarios, numbers combined with visual information were evaluated as less affective compared to numerical risks without visual information. It has been suggested that some graphical formats, such as icon arrays or pictographs, may be affect-inducing formats through automatic associations (e.g., the color red may be associated with danger), which may have an impact on people's risk perceptions and emotional responses[32,33]. Our result, which is the opposite of our expectation (H2), can thus possibly be explained by the fact that these health scenarios contained lower risk estimates, and therefore presented icon arrays displaying less people affected by the risks in red (and therefore more nonaffected people in grey). Overall, these findings did not depend on whether risks were presented with or without comparative risk information (H3), nor on people's graphical literacy skills.

The findings in this study should be considered in light of several strengths and limitations. This study is an improvement over previous research, specifically by utilizing a large representative sample of the Dutch population. This allowed us to examine the effects of comparative risk information, while testing influential factors such as message format, and controlling for several individual difference factors including numeracy, health literacy, and graph literacy. Other strengths are that we tested the effects across three different health scenarios, and that we pre-registered our hypotheses and statistical analysis plan before data collection. However, the findings of this study are limited to the use of hypothetical treatment decision-making scenarios; even though this is a common research strategy, a general limitation of this method is that we cannot be sure whether results fully generalize to participants experiencing real consequences of their perceptions and decisions[27]. Whether our findings are similar or different in real-world clinical settings and decision-making

contexts should be investigated in future research to ensure the generalizability of our results.

We believe that our study results have implications for both research and practice. First, the empirical findings directly add to two recently published review articles on communicating outcome probabilities as part of the 2021 evidence update for the International Patient Decision Aids Standards (IPDAS) Collaboration[1,6]. These reviews particularly highlight (1) the need for more systematic research on the usage and effects of personalized risk estimates in the context of treatment decision-making[6], but also emphasized (2) the importance of communicating risk estimates in context and evaluative labels including strategies such as comparative risk information for helping people make sense of their health risks[1]. By experimentally testing different presentation format for conveying health risks that are personalized towards the user characteristics, and taking into account the variability in numeracy, health literacy, and graph literacy skills, the results of our study will make an important contribution to field of risk communication in patient care and shared decision-making. Moreover, our results and experimental set-up may also be relevant for researchers in other health contexts who are facing similar treatment decision-making scenarios in which the communication of comparative or personalized risk estimates plays an important role.

Second, our findings also have practical implications for the design of personalized decision support tools for patients who are making a decision about treatment. Particularly, our results may help decision aid developers who wish to personalize risk estimates within their tools. Knowing the conditions under which circumstances, for instance, comparative information and visual displays such as icon arrays are most associated with risk perception, worry, or treatment decision-making might help the design of effective personalized health communication tools. This will help patients to become more involved in shared decision-making with their doctor, so that they can jointly make a well-informed decision about treatment.

CONCLUSION

Shared decision-making requires effective risk communication about evidence-based outcome probabilities of treatment options to patients in a clear and balanced way[1,2]. Considerable efforts have been put into personalized risk estimates and integrating them in patient decision aids, but this does not necessarily mean that patients can easily make sense of such risks. Despite the ongoing debate, our results suggest that healthcare professionals can consider providing comparative data (e.g., the average person's risk) when communicating personalized risk estimates of treatment side effects. Our experimental results show that comparative risk information can be used by people for especially estimating their own risk, without negatively impacting their risk perceptions, affective evaluations, or treatment intentions. Future research is needed to confirm our findings in other health contexts and real-world decision-

making scenarios, but also to seek out which people are particularly sensitive and potentially influenced by the provision of comparative risk data.

FOOTNOTES

[1] Our sample was slightly older than the mean age (49.5 years) of the Dutch population, $M_{diff} = 4.47$, 95% CI [3.64, 5.32], $t(1806) = 10.42$, $p < .001$), and represented slightly more females than those in the Dutch population (50.7%) in 2020 according to Statline.

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APPENDICES

Appendix A

Table A1 | Sociodemographic characteristics and individual difference scores by experimental condition.

	Personalized risk-only		Personalized risk above average		Personalized risk below average		
	Numerical-only (*n*=299)	Numerical+ visual (*n*=288)	Numerical-only (*n*=297)	Numerical+ visual (*n*=312)	Numerical-only (*n*=320)	Numerical+ visual (*n*=291)	*p*-value
Gender (%)							
Female	157 (53)	154 (54)	170 (57)	169 (54)	178 (56)	152 (52)	
Male	142 (47)	134 (46)	127 (43)	143 (46)	142 (44)	139 (48)	.817
Age, M (SD)	52.7 (18.5)	54.2 (17.7)	54.6 (18.7)	53.4 (18.4)	55.1 (18.3)	53.5 (18.0)	.662
15-24 years	29 (10)	21 (7)	24 (8)	23 (7)	22 (7)	23 (8)	
25-34 years	35 (12)	25 (9)	35 (12)	41 (13)	32 (10)	31 (11)	
35-44 years	35 (12)	38 (13)	26 (9)	37 (12)	42 (13)	34 (12)	
45-54 years	45 (15)	42 (15)	46 (16)	49 (15)	43 (13)	52 (18)	
55-64 years	56 (18)	71 (24)	55 (18)	54 (18)	70 (22)	50 (18)	
> 65 years	98 (33)	91 (32)	111 (47)	108 (35)	111 (35)	101 (35)	.802
Education (%)							
Lower[a]	80 (27)	81 (28)	73 (25)	80 (26)	80 (25)	78 (27)	
Medium[b]	100 (33)	85 (30)	102 (35)	105 (34)	108 (34)	100 (35)	
Higher[c]	119 (40)	121 (42)	121 (40)	126 (40)	131 (41)	111 (38)	.980
Numeracy[d], M (SD)	4.01 (1.12)	4.20 (1.01)	4.13 (1.10)	4.19 (1.10)	4.09 (1.04)	4.15 (1.07)	.688
Health literacy[d], M (SD)	9.56 (2.76)	9.38 (2.82)	9.59 (2.88)	9.53 (2.63)	9.57 (2.70)	9.62 (2.97)	.935
Graph literacy[d], M (SD)	2.01 (1.06)	1.98 (1.06)	2.06 (1.01)	2.01 (1.05)	2.10 (1.05)	2.09 (1.14)	.590

Note. [a] = Primary education, preparatory secondary vocational education; [b] = higher secondary general education or pre-university education, secondary vocational education; [c] = higher vocational education, university; [d] Missing data for twenty-five patients; M = Mean; SD = standard deviation.

Appendix B

Table B1 | Main and interaction effects on primary outcome measures resulting from a 3 × 2 MANCOVA and on the secondary outcome variables resulting from two separate 3 × 2 ANCOVAs for the colon cancer scenario.

	Primary outcome variables									Secondary outcome variables					
	Risk estimates			Risk perception			Affective evaluation			Perceived personal relevance			Treatment intention		
Main/Interaction Effects	*F*	*p*	η_p^2	*F*	*p*	η_p^2	*F*	*p*	η_p^2	*F*	*p*	η_p^2	*F*	*p*	η_p^2
Comparative risk information [a]	8.27	**<.001**	.009	0.16	.854	.000	0.22	.801	.000	1.71	.182	.002	1.60	.202	.002
Message format [b]	0.00	.952	.000	0.01	.925	.000	0.02	.896	.000	0.04	.834	.000	4.04	**.045**	.002
Comparative risk information × Message format [a]	1.88	1.53	.002	0.94	.389	.001	0.90	.406	.001	2.12	.120	.002	0.32	.728	.000

Note. [a] *df* = 2, 1741; [b] *df* = 1, 1741; Covariates include age, gender, education, subjective numeracy, health literacy, and graph literacy; Significant results are given in **bold**.

Table B2 | Main and interaction effects on primary outcome measures resulting from a 3 × 2 MANCOVA and on the secondary outcome variables resulting from two separate 3 × 2 ANCOVAs for the increased cholesterol scenario.

	Primary outcome variables									Secondary outcome variables					
	Risk estimates			Risk perception			Affective evaluation			Perceived personal relevance			Treatment intention		
Main/Interaction Effects	*F*	*p*	η_p^2	*F*	*p*	η_p^2	*F*	*p*	η_p^2	*F*	*p*	η_p^2	*F*	*p*	η_p^2
Comparative risk information [a]	3.65	**.026**	.004	0.04	.960	.000	1.32	.267	.004	3.73	**.024**	.004	1.41	.244	.002
Message format [b]	0.11	.741	.000	5.47	**.019**	.003	4.20	**.041**	.002	0.17	.681	.000	0.03	.854	.000
Comparative risk information × Message format [a]	1.36	.258	.002	1.16	.314	.001	0.91	.404	.001	2.50	.083	.003	0.62	.540	.001

Note. [a] *df* = 2, 1741; [b] *df* = 1, 1741; Covariates include age, gender, education, subjective numeracy, health literacy, and graph literacy; Significant results are given in **bold**.

Table B3 | Main and interaction effects on primary outcome measures resulting from a 3 × 2 MANCOVA and on the secondary outcome variables resulting from two separate 3 × 2 ANCOVAs for the skin cancer scenario.

	Primary outcome variables									Secondary outcome variables					
	Risk estimates			Risk perception			Affective evaluation			Perceived personal relevance			Treatment intention		
Main/Interaction Effects	*F*	*p*	η_p^2	*F*	*p*	η_p^2	*F*	*p*	η_p^2	*F*	*p*	η_p^2	*F*	*p*	η_p^2
Comparative risk information [a]	1.28	.279	.001	0.22	.803	.000	1.30	.272	.001	3.26	**.039**	.004	1.05	.351	.001
Message format [b]	0.03	.853	.000	3.50	.062	.002	10.15	**.001**	.006	0.20	.653	.000	1.03	.310	.001
Comparative risk information × Message format [a]	2.32	.099	.003	0.35	.702	.000	0.47	.628	.001	1.60	.202	.002	0.04	.965	.000

Note. [a] *df* = 2, 1741; [b] *df* = 1, 1741; Covariates include age, gender, education, subjective numeracy, health literacy, and graph literacy; Significant results are given in **bold**.

PART 4

Bringing it together during shared decision-making

Who communicates what in what form to whom to what effect?

8

Communication, perception, and use of personalized risks in prostate cancer treatment-decision making: An observational and interview study

This chapter is based on:

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ABSTRACT

Background: We investigated how healthcare professionals communicate personalized risks of treatment outcomes (i.e., risks adjusted to patient and clinical characteristics) to patients with localized prostate cancer during consultations, and explored how these patients perceive and use such risks during treatment decision-making.

Design: Consultations of 27 patients (concerning treatment and associated risks) were performed by the nurse practitioners and urologists and were audiotaped, transcribed and coded. Patients were then interviewed to explore their perceptions and use of their personalized risks of urinary incontinence after prostatectomy. Interviews were qualitatively analyzed using thematic analysis.

Results: HPs explained personalized risks by discussing risk factors, which was appreciated and recalled by patients. Personalized risks were typically communicated both numerically and verbally (70%). When using numbers, HPs always used percentages, but rarely used natural frequencies (14%). Uncertainty was disclosed in only 34% of consultations. One-third of patients used personalized risks in their treatment decision-making by either switching to another treatment or sticking to their initial preference.

Conclusions: Patients value and use personalized side effect risks during treatment decision-making. When communicating personalizes risks, healthcare professionals are advised to use natural frequencies but also to move beyond the provision of specific numbers by providing context. Clearly explaining the relationship between risk factors and personalized risk estimates may help patients understand and recall those.

INTRODUCTION

Men newly diagnosed with localized prostate cancer (PCa) are facing difficult decisions regarding treatment. They need to choose from a range of options including robot-assisted radical prostatectomy (RARP), external beam radiotherapy, brachytherapy, or active surveillance[1], which have equivalent survival outcomes but differ in the risks of side-effect[2,3]. For instance, RARP is associated with urinary incontinence and radiotherapy with bowel problems, which can have a serious negative effect on PCa survivors[4]. It is therefore important that patients are well informed about treatment side-effect risks during the shared decision-making (SDM) process[5]. Numerical risks (e.g., probabilities that patients will experience any adverse event) are ideally communicated by the urologist and/or nurse practitioners (NPs) during a consultation and in tools such as patient decision aids[6]. However, these risks are typically generic and based on the "average patient", which makes it difficult for patients to understand and translate those risks to their individual situation[7–10].

In light of the growing emphasis on personalized healthcare and outcome probabilities in clinical practice during SDM[11,12], it has become more feasible to provide patients with *personalized risk information* about treatment outcomes such as side effects[13]. These personalized risks take into account patient (e.g., age) and clinical characteristics (e.g., tumor stage) that are unique to an individual patient, and are therefore perceived as more relevant than generic, non-personalized risks[14,15]. Even though personalized risks will likely become increasingly important and common in clinical practice[13], guidelines for *how* healthcare professionals (HPs) can best communicate them to patients are lacking[16,17]. Which message formats do HPs currently use for explaining personalized risks, for instance via words-only, numerical, or graphical formats? Do HPs disclose uncertainty around the personalized risks, and if so, which type(s) and how? Furthermore, it is currently unclear how patients perceive personalized risks and uncertainty, and also whether, how, and why they use personalized risks during treatment decision-making[18]. It is crucial to study, as previous research has shown that personalized risks may impact patients' risk perceptions and medical decisions[19–21], which could even depend on how they are communicated[15,22].

In this study, we explore the communication of personalized risks of urinary incontinence in the context of PCa treatment decision-making. We focused on the Continence PREDiction tool (CPRED) that predicts the personalized risks of urinary incontinence 6-months post-RARP, based on clinical characteristics[23]. Both NPs and urologists in the Netherlands Cancer Institute (NCI) / Antoni van Leeuwenhoek (AvL) hospital are currently using CPRED during consultations with patients[19], thereby making it a suitable context for observing the actual communication of personalized risks to newly diagnosed patients. The aim of this study was to investigate how HPs communicate personalized risks (i.e., urinary incontinence) to PCa patients during

consultations, and to explore how these patients, in turn, perceive and use their personalized risk during treatment decision-making.

METHODS

Design

This study consisted of an observational study of audiotaped consultations between HPs and patients and semi-structured interview study with patients. The study protocol was reviewed by the Institutional Review Board of the NCI / AvL hospital (IRBd20-285) and was exempted from medical ethical review, according to the Dutch Medical Research Involving Human Subjects Act (WMO). Before the recording/interview, all patients signed written informed consent.

Patient sample

Between December 2020 and March 2021, newly diagnosed patients with localized PCa from the NCI/AvL hospital, eligible for RARP as a treatment option and fluent in the Dutch language, were recruited by the NP at the start of their consultation in which information was given about the available treatment option(s). We aimed for a total of 30 patients, distributed equally among the three CPRED categories (low, intermediate, and high).

Personalized risk information

The CPRED model was used to determine the personalized risk of urinary incontinence after RARP for each individual patient[19,23]. CPRED predicts the chance of full recovery of urinary incontinence (as defined by the International Consultation on Incontinence Questionnaire – Short Form[24]) based on the preoperative membranous urethral length (MUL) and the inner levator muscle distance (ILD), which are derived from an MRI of the patient's prostate in an earlier clinical examination. Longer MUL and shorter ILD predict higher chance of continence recovery[23]. During the multidisciplinary team consult, the parameters are entered in to the clinical prediction model, which produces a CPRED score consisting of a percentage describing the chance of continence recovery (i.e., no diaper or inlay use and no involuntary urine loss) within 6 months after RARP, with higher CPRED scores indicating higher chances of recovery[19,23]. We distinguished three CPRED risk categories: high (0%–40%), risk (41%–60%), and low (61%–100%)[19].

Procedures and data collection

Consultations

Each patient had two consecutive consultations on the same day (standard procedure): one with the NP, followed by one with the urologist. In both consultations, patients were given information about the outcome of the multidisciplinary team consult

(in which the patient was not a part of), the available treatment option(s), and associated risks of side-effects including their personalized CPRED score. In case a patient considered radiotherapy, he could schedule a meeting with the radiologist on that same day. Note that these radiation oncology consultations were not part of the current study and were therefore not recorded. Both NPs and urologists recorded their consultations themselves using an Olympus VN-541PC voice recorder, and they were explicitly instructed to perform their consultation as usual. Patients were told that the study aimed to investigate information provision during consultations about treatment options. The concepts of personalized risks and CPRED were not introduced. After the second consultation, patients either made a decision about treatment together with their urologist, or they called the urologist at a later moment to jointly make a final decision about treatment.

Patient interviews

After a patient had made a final treatment choice, he was interviewed by RV. These interviews were held 20 days after the consultations (*SD* = 11 days), but they were always scheduled between a patient's final treatment choice and the actual treatment. Due to the COVID-19 situation, interviews were held via telephone, which were recorded using an Olympus VN-541PC voice recorder. The interview protocol (Appendix A, see https://osf.io/c8zbx) started with questions about patients' general experience with the consultations, followed by questions about perceptions of their personalized CPRED score, uncertainty around CPRED, and the role of CPRED in their decision were asked. After the interview, we assessed patients' subjective numeracy skills using the Dutch version of the Subjective Numeracy Scale[15,25].

Coding and analyses

Consultations

Consultations were analyzed directly from audio. All fragments in which either the NP and/or urologist communicated a patient's CPRED score were identified, marked, and analyzed using a predefined code scheme (Appendix B, see https://osf.io/c8zbx). This code scheme was based on research on communicative aspects of patient decision aids for communicating risks[7–9] and on a related observational study[26]. We first coded the *message format* that was used to convey the CPRED score. If verbal information was used, we coded whether this was an absolute and/or a relative risk description. If numerical information was used, we coded whether percentages and/or natural frequencies (e.g., 10" out of 100 patients like you") were used, and whether these numerical estimates were presented as absolute and/or relative risks. We then coded how the CPRED score was *explained* to patients, by focusing on the disclosure of the CPRED model and its predictor variables, the period over which the CPRED scores applied, the defined group (reference class) for which the CPRED scores applied,

and the emphasis on the personalization of the risk. We finally coded which types of *uncertainty* around CPRED were disclosed, focusing on aleatory uncertainty (i.e., unpredictability of single events) and epistemic uncertainty (i.e., imprecision of risk estimates and their applicability to a specific patient). Two independent raters (RV and research assistant) coded the same five (10%) consultations, and the inter-rate agreement was high (87%). Any discrepancies were resolved in consensus meetings. As the agreement between coders was good, one rater (RV) only coded the remaining consultations. All coding analyses were performed using Microsoft Excel.

Patient interviews

Interviews were audio recorded, transcribed verbatim, and coded using a deductive thematic analysis procedure within an essentialist/realist framework[27,28]. First, three researchers (RV, EK, SP) familiarized themselves with the qualitative data by independently reading the interview transcripts, taking notes, and marking ideas for coding. Based on these insights, as well as the study objectives, interview protocol, and interview content, (RV) systematically coded key features of each transcript using MAXQDA software[29], and collated these into potential themes, which, in turn, were refined and relabeled where necessary through discussions with (RV) and (EK, SP). Finally, (RV) defined and refined each theme and generated the report by selecting illustrative extracts, which were translated into English.

RESULTS

Patient and consultation characteristics

Thirty-four eligible patients were asked to participate in the study and 27 agreed to participate (79%). Of these patients, all consultations with their NP were audio taped successfully. However, for three patients, their consultation with the urologist was not audio taped by accident, bringing the total number of recorded consultations to 51. Patients were on average 66 years old (range: 47-78) (Table 1). Most of the patients opted for RARP as a final treatment option. Urologists and NPs discussed the personalized risk in 50 consultations (98%). For one consultation, the risk was not discussed because the patient already opted for active surveillance.

Table 1 | Patient ($n = 27$) and consultation ($n = 51$) characteristics.

Patient characteristics	***n***	**%**
Age at time of interview, mean (SD)	66.4 (7.8)	
< 50 years	1	4
50-59 years	5	18
60-69 years	9	33
> 70 years	12	44
Education		
Primary/secondary school	6	22
Practical education	8	30
College/applied university	5	18
University	8	30
Gleason score		
6	8	30
7	18	66
8	1	4
Continence PREDiction (CPRED) score		
Low (0-40%)	9	33
Intermediate (41-60%)	8	30
High (61-100)	10	37
Initial treatment preference		
Radical prostatectomy	12	44
External beam radiotherapy	2	8
Brachytherapy	7	26
No preference	6	22
Final treatment choice		
Radical prostatectomy	15	56
External beam radiotherapy	6	22
Brachytherapy	4	15
Active surveillance	2	8
Work situation		
Work	9	33
Ill (insurance) / partial work	2	8
No work/retired	16	59
Marital status		
Married	17	62
Not married / partner living together	8	30
Partner not living together / no partner	2	8
Children		
Yes	19	70
No	8	30

Table 1 | Continued.

Subjective numeracy, mean (SD)	**4.79 (0.87)**	
Lower numeracy (SNS ≤ 4)	6	21
Higher numeracy (SNS ≥ 4)	21	79
Consultation characteristics		
Duration of consultations in minutes, median (range)	21 (6-42)	
Treatment discussed during consultation		
Radical prostatectomy	51	100
External beam radiotherapy	51	100
Brachytherapy	27	53
Active surveillance	13	25

Consultations: Current practice for communicating personalized risks

Table 2 displays how many times different aspects occurred during the consultations, including exemplar quotes. The personalized risk of urinary incontinence was typically communicated via a combination of words and numbers (70%), and occasionally via words-only (16%) or numbers-only (14%). When risks were communicated via numbers, HPs always communicated absolute risk statistics using percentages, which were sometimes combined with natural frequencies (19%). The reference class was mentioned in only 20% of the consultations, and the lack of this led to ambiguous statements (e.g., "*We think that you will have full urinary control for 98 percent")* related to whom the risk refers to (e.g., X percent of the time versus X percent of men like you). When risks were communicated via words, HPs often used absolute verbal descriptors of the risks (e.g., *"That chance is very small"* or *"That's a plausible risk"*), or verbal labels to indicate whether the risk is good or bad (e.g., *"That's not very favorable"* or "*That score is actually quite good, we are really happy with that"*).

In 68% of the consultations, HPs explicitly mentioned that the risk they communicated was personalized and based on a statistical model (e.g., *"We have calculated your personal risk using a model…"*). For instance, as one urologist put it:

> *"For my previous patient, I could say that his risk of urinary incontinence was about 1 or 2 percent. That man will not experience urinary incontinence, of course. But I cannot say this to you. That is the reason why we calculate these personalized risks, because these risks differ from person to person. If I would tell you that your risk is about 15 or 20 percent, then I am informing you in a way that is too positive."*

When explaining a patient's personalized risk, HPs almost always referred to the length of the patient's MUL (92%), mostly combined with the ILD (66%). The degree of urinary incontinence was explained in 74% of consultations, and the period over which the CPRED score applied in 94% of the consultations. Finally, in 34% of the consultations

some type of uncertainty was disclosed. Aleatory uncertainty was communicated in 16% of the consultations, and epistemic uncertainty in 28% of the consultations. For instance, one urologist explicitly said that the individualized risk only applied at the group level.

> *"We work with statistics, but for you it will be either yes or no. We work with probabilities that are based on a group of patients. The only thing that matters for you is whether you will experience it or not. That will always be the difference."*

Table 2 | Frequency of communicative aspects discussed by healthcare professionals during consultations with their patients.

Communicative aspect	*n*	%	Exemplar quote(s)
Formats used for communicating personalized risks			
Verbal: absolute risk descriptions	41	82	"That prediction [CPRRED score] is actually **not that great.**" "The chance that you will stay incontinent after the removal of the prostate is **very low.**" "That score is actually **quite good**, we are really **happy** with that."
Verbal: relative risk descriptions	10	20	"Your risk of urinary incontinence is **higher** than the average risk of all men." "For you, this overall risk of urinary incontinence does not make sense, because your risk is **lower**."
Numerical: percentages	42	84	"We think for **55 percent** that you will be dry 6 months after surgery. So that means that there is a **45 percent chance** that you will lose some urine 6 months after surgery."
Numerical natural frequencies	8	16	"For surgery, the chance that you will recover from urinary incontinence is 28 percent. **So, when you have 10 men like you with the same anatomy and the same length of your membranous urethral, 3 of them will not experience** any urinary loss. However, **7 will experience** some form of incontinence."

Table 2 | Continued.

Communicative aspect	*n*	%	Exemplar quote(s)
Aspects used for explaining personalized risks			
CPRED predictor: urethra length (MUL)	46	92	"We know that there are **two factors** that could influence your recovery from urinary incontinence." "That is **the membranous urethral length** and the **distance between the pelvic floor muscles**. These two can be measured from the MRI-scan, and in your case, these outcomes are favorable."
CPRED predictor: distance between pelvic floor muscles (ULD)	33	66	"Here are some muscles, the **pelvic floor muscles**. You need to tighten these muscles consciously, and to exercise more consciously to get those muscles on strength. But, there is also another factor and that one related to the **length of the urethra.** The longer the urethra, the faster you will recover."
Reference class for which the CPRED scores apply	10	20	"So, you have 10 **men like you, with exactly the same anatomy and the same length of the urethra**. Of those 10 men, 3 will…"
Time period over which the CPRED scores apply	47	94	"These two factors will give a percentage, and it turns out that we think that the chance that you will not experience any urinary loss **6 months after surgery** is 28 percent."
Degree of urinary incontinence	37	74	"When you'll lose some urine, you'll probably have some **drops of urine loss**, especially when coughing or sneezing." "That varies quite a lot. In the beginning you'll lose **some more urine**, but at a certain point you'll only lose **some drops or a splash of urine** with certain efforts, for instance when getting up."
Reference to (CPRED) prediction model	34	68	"If your urethra is a bit shorter, then you'll have a higher chance of urinary leakage for a longer period of time, and **we have calculated** this chance for you. **We use a sort of calculator for that**." "We think that the chance that you will fully recover from incontinence **is estimated** at around 44 or 45 percent."

Table 2 | Continued.

Communicative aspect	*n*	%	Exemplar quote(s)
Emphasize that risk is personalized	34	68	"However, I will not provide you with generic risk information, because **I have personalized risk information for you**. **This information is for you,** and not for your neighbor or for the next patient. Because for them I will have a different risk." "For my previous patient, I could say that his risk of urinary incontinence was about 1 or 2 percent. That man will not experience urinary incontinence, of course. But I cannot say this to you. **That is the reason why we calculate these personalized risks**, **because these risks differ from person to person.** If I would tell you that your risk is about 15 or 20 percent, then I am informing you in a way that is too positive."
Types of uncertainty disclosed			
Aleatory uncertainty (first-order)	8	16	"I **cannot guarantee** that [that will happen] for you." "I **cannot say that** that [urinary incontinence] **will not happen.**"
Epistemic uncertainty (second-order)	14	24	"The chance that you will recover within 6 months, so that you will be dry, is **between 20-25 percent.**" "But **whether it will happen to you individually is also difficult to say**. It could just as well be that you will experience no problems at all after this treatment. " "The problem is that we are working with percentages, **statistics that apply for the whole group.** But for you **as an individual it will always be yes or no."**

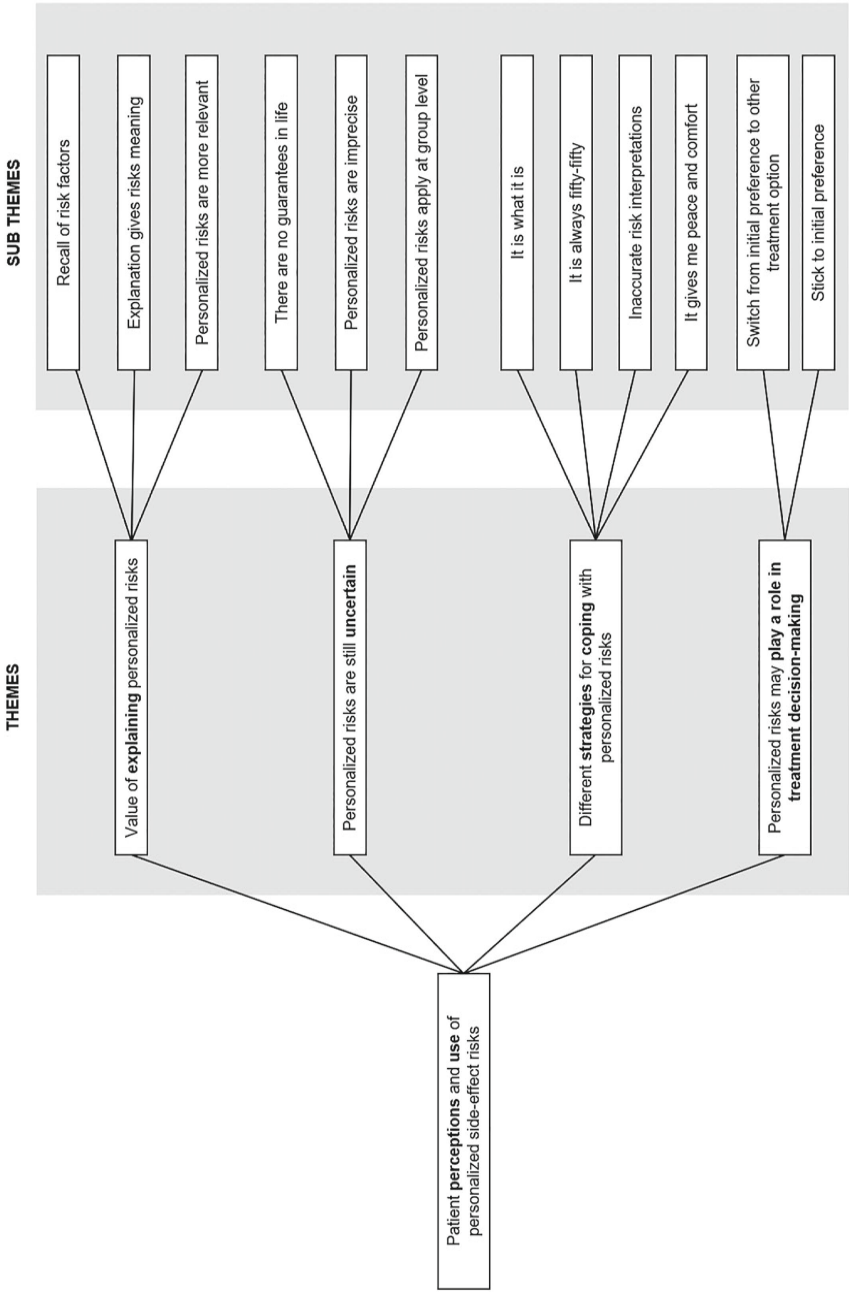

Figure 1 | Overview of the four themes identified in the 27 semi-structured interviews.

Patient interviews: Patient perceptions and use of personalized risks

Four themes related to patients' perceptions and use of personalized risks were identified (Figure 1). Exemplar quotes for each subtheme are presented in text and displayed in Table 3.

Theme 1: Value of explaining personalized risks
A first theme related to patients' appreciation for explaining their personalized risk. Eighteen patients (67%) recalled their CPRED score, and most referred to the MUL and occasionally to the ILD. As one participant put it:

> *"No, I really liked the explanation of the risk, because it became clearer to me. If someone says that my risk of incontinence is 75 percent, then you will typically forget to ask why that is.* ***But now it was clear to me what the problem was*** *[length of the urethra],* ***so I could better understand the risk.*** *I liked this style of communication." [P20, CPRED 23%, aged 73, highly numerate]*

Relatedly, patients said that these explanations provided context to the risks and put things into perspective. Given that these risk calculations were based on unique patient characteristics, patients mentioned increased perceptions of personal relevance, such as the feeling that the risks really applied to their individual situation (*"It felt really personal"* [P6, CPRED 55%, aged 60, highly numerate]). Patients also suggested to hand out a piece of paper to patients displaying the risk score and its explainable factors.

Theme 2: Personalized risks are still uncertain
A second theme related to patients' perceptions of uncertainty about personalized risks. Regarding aleatory uncertainty, patients mentioned that personalized risks are still unable to predict single events. Patients said that there are no guarantees in life and that their HPs can never say whether something will happen to them in the future, even though the risks are personalized. One patient said that you could just as well be on the other side of the coin:

> *"The doctor made very clear that 86 percent of the patients will be fine and that the other 14 percent will not be fine.* ***But you know, these are all statistics.*** *If you are part of that 14 percent, then that would be inconvenient, even though that 86 percent sounds good." [P1, CPRED 86%, aged 72, highly numerate].*

Regarding epistemic uncertainty, patients noticed that personalized risks are still imprecise. They commented that the risks are based on past observations, which can be summarized into a single risk statistic, but will never be exact. *"The more information you gather"*, one patient said, *"the more precise the prediction becomes"* [P25, CPRED

27%, aged 76, highly numerate]. Other patients thought that their personalized risk still applied at the group level. These two components of epistemic uncertainty (i.e., imprecision of personalized risk estimates and their inapplicability to a specific patient) were also expressed by this patient:

> *INTERVIEWER: "Do you think that this number is very specific, or could it also be something around…?"*
>
> *PATIENT: "No, around is also fine.* ***It cannot be 100 percent sure*** *that my score is 25 percent."*
>
> *INTERVIEWER: "What do you mean exactly with it cannot be 100 percent sure?"*
>
> *PATIENT: "Well, my risk was about 25 percent,* ***but it could just as well be 15 or 10 percent.*** *It can never be certain,* ***because every human being is unique."*** *[P24, CPRED 25%, aged 57, less numerate]*

Theme 3: Different strategies for coping with personalized risks

The third theme related to patients' different strategies for coping with and interpreting their personalized risks. There were patients who were quite attached to their risk, which gave them feelings of peace and comfort, or could serve as an indication of what could happen in the future. However, other patients took their risk for granted and mentioned that one cannot do that much about it ("It is what it is"). Others tried to simplify their risk, by translating the probability outcome into a fifty-fifty outcome (i.e., it will happen, or it will not). As this patient put it:

> *"Well, in the end it's about you and whether you will experience it.* ***So, then it will be reduced to a personal dichotomy, eh, yes or no.*** *So yeah, this is how probabilities work, and we will never know in advance how it turns out for you." [P3, CPRED 48%, aged 78, highly numerate]*

In contrast, others were relieved that their own personalized risk was not close to fifty percent but close to zero or one hundred percent, which facilitated risk processing.

> *"They expressed that [risk of incontinence] in a percentage, and for me that was 90 percent. Honestly,* ***I was quite happy with that one, because it was such a clear outcome****. If it would have been fifty-fifty, then you really need to think about it." [P2, CPRED 11%, aged 72, highly numerate]*

Six patients (22%) had inaccurate risk interpretations by assuming that the risk referred to the degree of urinary leakage.

*"Yes, but after 6 months there will be **about 80% little or no urinary leakage.**" [P7, CPRED 80%, aged 71, highly numerate]*

Theme 4: personalized risks may play a role in treatment decision-making

The fourth theme indicated that personalized risks may play a role in treatment decision-making. For nine patients (33%), their personalized risk score had a decisive role in their decision-making. These patients received a high or intermediate risk of incontinence (CPRED range: 11%-50%) and therefore switched from RARP (as initial preference) to other treatments.

"Yes, that was the main reason, that side-effect [urinary incontinence] after surgery. In a certain situation, my urethra could contribute to being incontinent. 28 percent continent, and 72 percent incontinent. This made me to opt for radiotherapy." [P23, CPRED 28%, aged 75, highly numerate]

Other patients within this group used this personalized risk as a confirmation for excluding RARP as a treatment option in the decision process. Patient who did not use the personalized risks (67%) during treatment decision-making valued reasons such as tumor removal or other side-effects (erectile dysfunction or bowel problems).

Table 3 | Exemplar quotes of all subthemes during the semi-structured interviews with patients.

Theme	Subtheme	Exemplar quote(s)
Value of explaining personalized risks	Recall of risk factors	"Yes, the doctor gave me a percentage and said that **my urethra was too short.** It would have been better **if I would have had a longer urethra.** But he said there is nothing I can do about that, because it is just the way how I am built physically." [P9, CPRED 44%, aged 57, highly numerate] "They looked at my anatomy, like how my body was built. It has something to do with the **pelvic floor** and **the length of your urethra…**I think that was useful, because it was based on my anatomy. Very clear and pleasant." [P6, CPRED 55%, aged 60, highly numerate]
	Explanation gives risk meaning	"Yes, in a consultation some information can be put into perspective. If you receive [generic] risks in a booklet, that is a bit too confronting, like this is it. **But when you have a conversation about it, then that personalized risk can be explained** … In the end I was quite happy with the consultation, because it felt better than after reading the booklet with the generic risks." [P21, CPRED 28%, aged 47, highly numerate]
	Personalized risks are more relevant	"Yes, they explained that [CPRED score] **for my specific situation**, like **based on my data**." [P10, CPRED 98%, aged 66, highly numerate]

Table 3 | Continued.

Theme	Subtheme	Exemplar quote(s)
Personalized risks are still uncertain	There are no guarantees in life	"The doctor made very clear that 86 percent of the patients will be fine and that the other 14 percent will not be fine. **But you know, these are all statistics.** If you are part of that 14 percent, then that would be very inconvenient, even though that 86 percent sounds good." [P1, CPRED 86%, aged 72, highly numerate]
	Personalized risks are imprecise	"Well, if they say that out of 100 people 31 will experience something, **that could just as well be 30.** With that respect, **I have no idea how accurate those studies are**. But so far, I always had a pure feeling about the percentages that I received." [P27, CPRED 67%, aged 68, less numerate]
	Personalized risks apply at group level	"That [personalized] risk estimate applies to the entire population in that particular study. **It does not say anything about you as an individual…**It says something about what they have seen in and experienced with thousand other patients, but that number does not say anything about me… every human body is unique." [P22, CPRED 94%, aged 75, highly numerate]
Different strategies for coping with personalized risks	It is what it is	"No, **these are just the facts**, you cannot hide them. And you shouldn't do that anyway…**You should accept, it is what it is.** I you want to get treated for the problem, there are always risks. You can't rule that out. You need to face it." [P25, CPRED 27%, aged 76, highly numerate] "You know, you need to choose between two evils. It [urinary incontinence] is not comfortable, but having cancer is way worse. So, if you want to get rid of it [cancer], then **you need to accept that risk.** I may be very sober, but also realistic." [P11, CPRED 98%, aged 59, less numerate]
	It is always fifty-fifty	"Well, if you have a risk of 50 percent, then it's easy. **Then is either yes or no**." [P24, CPRED 25%, aged 57, less numerate]
	Inaccurate risk interpretations	"The doctor said **the degree of incontinence will be about 60 percent,** so yeah we discussed that." [P9, CPRED 44%, aged 57, highly numerate]
	It gives me peace and comfort	"I find it [CPRED score] **all reassuring.** Because you never want to be that exception who gets something. But I don't think those percentages are weird**. I think they are important**." [P27, CPRED 67%, agreed 68, less numerate] "Well, if you say there is a 30% chance of something, then you get something different. If the risk is below 5%, then I think is sounds more positive. **That will give me some reassurance**." [P7, CPRED 80%, aged 71, highly numerate]

Table 3 | Continued.

Theme	Subtheme	Exemplar quote(s)
Personalized risks may play a role in treatment decision-making	Switch from initial preference to other treatment option	PATIENT: "Yes, after 6 months, the chance that I would recover [from urinary incontinence] was 12 percent." INTERVIEWER: "What were your thoughts at that moment?" PATIENT: "Well, I'm 52 years old, so I will not take that risk. I had two weeks to think about my decision, but, I did not have to wait so long. So, I immediately called the hospital and told them that I wanted radiotherapy." [P17, CPRED 12%, aged 52, less numerate]
	Stick to initial preference	"It had something to do with the urethra, which was too short, and then the risk of incontinence was above average. However, I didn't want surgery anyways, **so this** [low CPRED score] **was added to that** [line of reasoning]." [P18, CPRED 43%, aged 71, highly numerate]

DISCUSSION

Given that personalized treatment information is increasingly available and entering clinical care, we observed how HPs (in a urology setting) communicate personalized risks of incontinence after RARP and how patients perceive and use these numbers in their treatment decision-making. Evaluation of audio-recorded consultations revealed that HPs often explained the risk by discussing key factors of the prediction model that contributed to patients' personalized risk. Patients appreciated personalized risks and their explanations, which helped them make sense of their own risk data and perceive them as relevant. HPs often used a combination of words and numbers to convey risks; If numbers were used, HPs always used percentages and, in a few instances, natural frequencies. When integrating the observational data with the interview data, some patients (22%) misinterpreted the percentage risk score, by assuming that they would experience urinary leakage in X percent of the time. Therefore, our study supports the recommendation of using natural frequencies for communicating personalized risk estimates[30–32], since percentages do not always specify the reference class or population for whom the personalized risks apply[33]. Finally, HPs hardly disclosed uncertainty around personalized risks.

For one-third of the patients their personalized risk of urinary incontinence may have played a role in their treatment choice, which aligns with previous research conducted in a prospective (but not randomized) setting[19]. These patients typically opted for RARP as a preferred treatment choice before the consultation, and either switched to another option (due to a relatively less favorable personalized risk) or sticked to RARP as initial preference (due to a relatively favorable personalized risk). Other patients within this group used their personalized risk as a confirmation for

excluding RARP. There were also patients who did not use their personalized risk of urinary incontinence and valued other reasons such as tumor removal (especially with the thought that radiotherapy would still be possible), or put more weight on side-effects such as erectile dysfunction or bowel problems[34]. These findings are in line with previous findings that most (but definitely not all) patients value an desire personalized risk information about treatment outcomes[14,18]

An important observation was that HPs typically communicated the personalized side-effect risk score along with discussing the clinical risk factors (e.g., the patient's urethra length) that contributed to that risk estimate. The interviews revealed that these short explanations helped patients understand why they are at risk and the relationships between risks factors and their personalized side-effect risk. Furthermore, HPs used different contextual strategies for explaining the risk, such as providing verbal evaluative labels whether a score was high or low, or comparative data of the average person's risk. Following theory on information evaluability[35,36], it is challenging for patients to know whether their personalized risk is good or bad, which also makes patients tend to ignore single risk statistics[37]. Although these contextual strategies may be useful for helping patients making sense of personalized statistics[14,38], they can also unintentionally create emotional meanings that may or may not be useful, and should therefore be used with caution[6,39].

The disclosure of uncertainty around personalized risks was limited and discussed in only one-third of the consultations, which is consistent with related observational studies on predicting and communicating individual disease outcomes in the breast cancer or genetic cancer screening context[26,40]. However, contrary to those studies, aleatory uncertainty (i.e., the fundamental indeterminacy or randomness of future events) was communicated less often by HPs than epistemic uncertainty (i.e., the adequacy, reliability, or credibility of personalized risks). It could be that HPs did not want to overwhelm their patients with uncertainty information or to impair the trustworthiness of the information. However, personalized risks, whether related to treatment side effects, survival rates, or recurrence rates, are all based on prediction models of (a subset of) population-level data, and hence always yield some form of epistemic uncertainty [6], but these uncertainties were hardly shared with patients. Whether HPs should communicate uncertainty around risks at all is a topic of debate[26,41]. Some scholars are in favor for ethical or transparency reasons[42,43], whereas others believe that uncertainty may lead to undesired psychological responses[44,45]. Interestingly, when looking at the interview data, some patients still perceived these probabilities as imperfect or inapplicable to individual patients. These perceptions could be explained by the fact that patients do not really experience risks or probabilities, but instead experience single outcomes[41]. That is, even though a patient may receive a risk of, for example, 12 percent of urinary incontinence, for that patient the outcome eventually happens, or it does not happen. This also aligns with patients applying different strategies for coping with and interpreting their personalized risk

estimates[46]. To some, personalized risks gave them feelings of peace, comfort, and control[14,47,48], while others tried to simplify their personalized risk, by translating the probability score into a fifty-fifty outcome (i.e., it will happen, or it will not), which could also mean "don't know"[49].

Some limitations need to be addressed. Our study was mono-center, which means that our observations provide a snapshot of how personalized risks are being communicated in a specific clinical setting. Although most of our findings corroborate with similar observational studies [26,40], more observational research is needed in other clinical contexts with larger cohorts and a diverse sample of HPs. Furthermore, we focused on the communication of a specific treatment outcome (i.e., urinary incontinence) and ignored other risks such as erectile dysfunction that were discussed by the NPs and urologists, and we also did not observe radiation oncology consultations. Finally, we recorded two follow-up consultations with the NP and urologist, which means that patients received their personalized risk and explanation twice. Note that, our focus was not on comparing both types of consultations with each other, but rather on getting general insights into current practices of HPs in their communication of these risks.

We believe that our findings have three broad clinical implications. First, we recommend HPs to move beyond the risk estimate and put some effort in explaining what role each risk factor plays in determining the risk, which may help patients better understand why they are (not) at risk and recall their own estimate. Second, patients may use personalized risks in their treatment decision-making, which highlights the need for training HPs in clearly communicating these risks in the context of SDM[50]. We believe that some general risk communication techniques can be easily practiced during clinical practices[6], such as the use of natural frequencies instead of percentages, but we are also aware that tasks such as communicating different types of uncertainty demand more training[13]. Third, our results are relevant for those developing decision aids that are drawing on medical or patient reported outcome data, and who are facing similar challenges regarding the reliability, accuracy, and credibility of personalized risks. It remains for future research to addresses these challenges, and to investigate how best to help patients translate personalized risks and uncertainty information into better informed decision-making[13].

CONCLUSION

While this study demonstrates the value of personalized risk information during shared decision-making about treatment, it also emphasized that risk communication should move beyond providing patients with just specific and precise numbers. Providing contextual information by explaining how personalized risks are determined may help patients understand and recall those. Given that patients may use personalized risks in their treatment decision-making highlights the need for skills training for HPs in clearly communicating these risks.

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9

General discussion and conclusion

When newly diagnosed patients with cancer are making a decision about the first treatment, it is important that they are being well-informed about all possible treatment options and associated risks and benefits[1,2]. However, communicating risks is an inherently complex task. The growing emphasis on personalized healthcare and increased availability of cancer registry data and patient reported outcome data offer promising opportunities to provide patients with personalized treatment risks (i.e., risks that take into account personal and clinical characteristics of individual patients) during shared decision-making[3–5]. This dissertation looked at the needs, preferences, communication, perceptions, interpretations, and use of personalized risks of treatment outcomes for patients with cancer in the context of shared decision-making about treatment. The central research question in this dissertation was **whether and how personalized risks of treatment options and cancer statistics can best be communicated to patients with cancer.** To answer this central question, this dissertation addressed the following four aims which are structured around Lasswell's model of communication addressing *who* communicates *what, in what form*, to *whom* and to *what effect.*

(1) To review how patient decision aids currently communicate (personalized) risks of treatment options to patients with cancer;
(2) To assess patient needs and preferences for communicating personalized risks and other cancer statistics;
(3) To test the effects of different message formats and strategies for communicating personalized risks on patient's cognitive, emotional, and behavioral outcomes;
(4) To observe how healthcare professionals communicate personalized risks of treatment options to patients with cancer, and to explore how these patients, in turn, use and perceive personalized risks during treatment decision-making.

In this final chapter, the main findings of the studies reported in this dissertation are summarized, separately for each aim, after which they will be integrated in light of the central research question. This is followed by a discussion of the strengths and limitations of the study methods, the theoretical implications for risk communication research, and practical implications for clinical practice. Finally, directions for future research are proposed.

MAIN FINDINGS

Part 1: Reviewing risk communication in decision aids – Who communicates what in what form?

This dissertation started with two systematic reviews on the quality of information and use of communication in currently available patient decision aids for localized prostate cancer (**Chapter 2**) and early-stage breast cancer treatment (**Chapter 3**). For both types of cancer, decision aids ($n = 40$) were systematically identified through both published academic literature and online sources. Their quality was assessed

using the International Patient Decision Aids Standards (IPDAS) checklist, and their use of communication was assessed by focusing on personalization, information presentation, interaction, information control, accessibility, suitability, and source of information. The quality varied greatly among the prostate (mean IPDAS compliance rate = 59%, range: 36-84%) and breast cancer (mean IPDAS compliance rate = 64%, range: 31-92%) decision aids. More importantly, substantial variations in the use of communication by decision aids were found as well. Almost all were generic and non-personalized, particularly in terms of communicating about statistics and risks of treatment outcomes. Six decision aids (15%) did not include any risk information at all or only communicated these via verbal descriptions. Decision aids that did contain numerical risks showed great variability in how they communicated these to patients (typically using natural frequencies followed by percentages), and about half presented multimodal risk descriptions by combing numbers with visuals (typically icon arrays or pictographs). These reviews also revealed some other communicative issues relating to interaction, suitability, and accessibility that could hinder successful implementation of decision aids in daily clinical practice. Taken together, **Chapters 2** and **3** demonstrate that currently available decision aids for localized prostate cancer and early-stage breast cancer treatment vary substantially in their quality, and further suggest that they could be improved by taking various communication aspects into account, with the integration of personalized risk estimates of treatment outcomes most prominent among them.

Part 2: Assessing patient needs and preferences – What to communicate in what form to whom?

The second aim of this dissertation was to assess (1) whether, how, and for whom risks and other cancer statistics should be personalized, and (2) how these statistics in turn should be communicated to patients by taking into account their preferences. First, using a qualitative multimethod study design (**Chapter 4**), breast cancer and prostate cancer survivor needs and preferences were explored for disclosing and presenting personalized statistics from a large Dutch nationwide population-based data set, the Netherlands Cancer Registry (NCR). To elicit survivor needs and preferences, different (non)interactive tools were created in which patients had the opportunity to enter personal (e.g., age) and clinical (e.g., tumor stage, year of diagnosis) characteristics, with the aim of receiving personalized cancer statistics about incidence and survival rates. Overall, participants in both focus groups (n = 13) and think-aloud observations (n = 11) expressed a need to receive personalized statistics (e.g., survival, conditional survival, risks of side effects) from a representative source. Personalized statistics were considered more relevant and useful than generic statistics. When it comes to communicating personalized statistics to patients, it was found that patients needed support for correctly interpreting the personalized statistics and putting them into perspective, for instance by adding contextual or comparative information of

the average person's survival. In addition, while thinking aloud, some participants processed (less favorable) survival statistics emotionally, which calls for supporting or preparatory information about emotional aspects. Overall, participants preferred simplicity and conciseness, and the ability to tailor the type of visualization and amount of (detailed) statistical information according to personal preferences.

Chapter 5 described a quantitative study on assessing patient needs for receiving personalized statistical information after a cancer diagnosis ($n = 174$). In this pre-registered cross-sectional survey, cancer survivors were asked to think back to their first cancer diagnosis and to indicate to what extent they would have wanted to receive generic (population-based) and personalized statistics for a range of different cancer statistics: cancer incidence rates, survival rates, risk of treatment side effects, risk of cancer recurrence, and treatment impact on quality of life. It was also studied how individual differences (information coping style, subjective numeracy, and anxiety levels) related to these needs, whether statistical need profiles could be identified, and what participants' considerations were for (not) wanting statistical information. The results showed that, for each topic, the participants had a higher need for receiving the personalized statistics than the generic ones. This need for personalized statistics was associated with higher subjective numeracy skills and an information-seeking coping style. Furthermore, three statistical needs profiles were identified: patients having a (1) strong need for both personalized and generic statistics (34%), (2) stronger need for personalized than for generic statistics (55%), and (3) a little need for both personalized and generic statistics. Participants' considerations for wanting personalized cancer statistics related to feelings of being in control or making better informed decisions about treatment, while considerations for *not* wanting statistics were about the unpredictability of future events for individual patients or negative experience with statistics in the past. Overall, results of **Chapters 4** and **5** suggest that the vast majority of patients and survivors – especially those with higher numeracy skills and an information-seeking style – have a desire to receive personalized statistics such as risks of side effects and survival rates after a cancer diagnosis.

Part 3: Testing different formats – Communicating in what form to whom to what effect?

This dissertation continued with two pre-registered experimental studies among a sample of cancer patients and survivors ($n = 141$) and a sample of healthy participants that was representative for the Dutch population ($n = 1{,}807$). The main aim of these experiments was to examine how varying message formats and contextual strategies for communicating personalized risks can influence people's cognitive, emotional, and behavioral outcomes. The first experiment, presented in **Chapter 6**, tested the impact of personalized risks (vs. generic risks) on patients' cognitive outcomes (e.g., perceived risk, (accuracy) of estimated risk, perceived relevance, and perceived uncertainty), as well as through which message format (words-only vs. words and numbers

combined) the risks should be best communicated. Participants were instructed to imagine that they had been diagnosed with advanced colon cancer and to discuss four different side effects of adjuvant chemotherapy with their healthcare professional. All participants received two personalized risks (of which the reference class was based on their self-reported age, gender and tumor stage) and two generic risks conveying the likelihood of experiencing the side effects. Furthermore, half of the participants received this likelihood only in words ('common' and 'very common'), and the other half in a combination of words and corresponding natural frequencies ('common, 10 out of 100' and 'very common, 40 out of 100'). The results showed that personalized risks were estimated as being higher and less accurate than generic risks, but only when they were presented in words. Such differences were not found in the verbal and numerical combined format. Personalized risks were also perceived as more personally relevant (in both message formats) than generic risks.

The second experiment **(Chapter 7**) examined the effect of providing contextual risk information on people's cognitive (perceived risk, estimated risk, perceived relevance), emotional (affective evaluation), and behavioral (treatment intention) outcomes when communicating personalized risks (11%). Furthermore, it was tested whether the results would be affected by the message format (numerical-only vs. numerical+visual format) and individual differences (sociodemographics, subjective numeracy, health literacy, and graph literacy skills). Participants from a representative sample of the Dutch population were presented with three health decision-making scenarios and personalized risk estimates of treatment side effects. Participants only saw their personalized risk without comparative data, or with comparative data of the average person's risk, which was either higher or lower than their own risk. The results indicated that the provision of comparative risk information did not influence participants' risk perceptions, affective evaluations, nor their intention of choosing the treatment. However, participants who were told that their personalized risk was above average estimated their own risk lower than participants who were told that their risk was below average or who received no contextual information at all. Message format (natural frequencies with or without icon arrays) and individual differences did not influence people's responses to comparative data, but less numerate participants were more likely to estimate their own risk as "fifty-fifty" compared to highly numerate participants. The majority indicated a preference for personalized risk information, and both numeracy groups desired comparative data in addition to their personalized risks. In sum, **Chapters 6** and **7** suggest that personalized risks are perceived as more relevant than generic risks, and that different message formats (verbal, numerical, and visual), contextual strategies (providing comparative data), and individual differences (numeracy) may impact how these risks are perceived and interpreted – although the effects can be subtle and sometimes in an unexpected direction.

Part 4: Bringing it together during shared decision-making – Who communicates what in what form to whom to what effect?

This dissertation concluded with a study (**Chapter 8**) aimed at exploring actual use of personalized risks of treatment outcomes by healthcare professionals and newly diagnosed patients during shared decision-making about treatment for localized prostate cancer. More specifically, this study observed how urologists and nurse practitioners communicated personalized risks of incontinence after surgery to their patients, and how these patients ($n = 27$), in turn, perceived and used these numbers in their treatment decision-making. Evaluation of audio-recorded consultations revealed that healthcare professionals often explained the risk by mentioning key factors of the prediction model that contributed to patients' personalized risk. Furthermore, healthcare professionals often used a combination of words and numbers to convey risks. If numbers were used, healthcare professionals always used percentages and, in a few instances, natural frequencies. During semi-structured interviews, it was found that patients appreciate these explanations, which help them make sense of their personalized risks and perceive them as relevant. Some patients (22%) misinterpreted the percentage risk score, by assuming that they would experience urinary leakage in X percent of the time. Although disclosure of uncertainty around personalized risks was limited, some patients still perceived these as imperfect or inapplicable to specific patients. Finally, patients expressed different strategies for coping with their personalized risk, and about one-third used these risks in their treatment decision-making by either switching to another treatment option or sticking to their initial preference. In conclusion, **Chapter 8** demonstrates that simple explanations of how personalized risks are determined may help patients understand and recall those risks, and further suggests that they can have a decisive role in treatment decision-making.

ANSWERING THE CENTRAL RESEARCH QUESTION

The central research question addressed in this dissertation was **whether and how personalized risks and other cancer statistics can best be communicated to patients with cancer.** The following three overarching findings contribute to answering this question.

(1) The results of this dissertation indicate that the vast majority of people diagnosed with cancer want to receive statistical information on different health outcomes, and particularly personalized statistics adjusted to their personal and clinical characteristics. However, it was also observed that such statistics are not personalized in currently available patient decision aids for treatment decisions, which means that there currently is a discrepancy in what patients want to receive (i.e., personalized risk statistics) and what they often get (i.e., generic, non-personalized risk statistics). Patients find personalized risks useful and more

relevant than generic risks, which calls for the integration of such information in patient decision aids and clinical consultations.

(2) When presenting personalized risks to patients, they can be best presented numerically using natural frequencies (e.g., 8 of out 100 patients like you) combined with verbal descriptors (e.g., this risk is *common*) and/or visual displays (e.g., icon arrays), while verbal-only formats should be avoided given their variable and inaccurate risk interpretations. In addition, providing contextual information – a strategy that is strongly desired by patients – increases information evaluability and can help patients derive meaning from their personalized risk information, without negatively impacting their risk perceptions or affective evaluations. Examples include disclosing comparative risk data or explaining the relationship between risk factors and personalized risk outcomes.

(3) Importantly, whether and how personalized risks can best be communicated to patients strongly depends on individual differences in terms of information coping style and subjective numeracy skills. For instance, those patients who are not actively seeking for detailed information (i.e., information avoiders) and who are less numerate may have less desire for numerical personalized risks estimates. Moreover, compared to highly numerate patients, less numerate patients typically have higher risk estimates perceptions and may benefit from simple and clear explanations on how personalized risks should be interpreted and used.

Overall, this dissertation has demonstrated the value and clinical usefulness of personalized risk statistics among patients, and further suggests that communicators should carefully choose appropriate message formats and contextual strategies that align with the needs, preferences, and information processing styles of unique individual patients, with the aim of promoting informed decision-making in the treatment of cancer.

STRENGTHS AND LIMITATIONS

The studies presented in this dissertation have both strengths and limitations. This dissertation provides the first comprehensive assessment of the communication of personalized risk estimates in cancer care by adopting a multimethod approach consisting of rigorous qualitative (focus groups, think-aloud observations, semi-structured interviews) and quantitative (systematic reviews, experiments, and observations) methodologies. In addition, in light of the growing emphasis on replication research to improve the reliability and reproducibility of empirical study results[6], three studies in this dissertation were pre-registered within the Open Science Framework, with research questions, hypotheses, and statistical analyses all specified and registered prior to data collection. However, most studies in this dissertation are limited to the use of hypothetical treatment decision-making scenarios (**Chapters 4**, **5**, **6**, and **7**) instead of a real decision-making scenario (**Chapter 8**), which challenges the

generalizability of the results into actual clinical practice. Obviously, when someone is diagnosed with cancer, that person often experiences anxiety and distress, which in turn can have an influence on information processing and decision-making. To partially compensate for this, participants were recruited from different samples, including newly diagnosed patients with cancer from hospitals, cancer survivors from Dutch cancer panels and major patient organizations, and healthy participants from a representative sample of the Dutch population. It should be noted, though, that cancer survivors recruited from the cancer panel may not represent the general cancer population, as they are typically highly educated and demonstrate higher levels of internet use[7]. Moreover, the scope of this dissertation was limited to the treatment decision-making context in an oncology setting. Therefore, future studies are needed to replicate our experimental and observational findings in other health-related medical decision-making contexts, possibly also focusing on other outcome measures (e.g., understanding).

THEORETICAL IMPLICATIONS

This dissertation has several theoretical implications for research on shared decision-making, risk communication, and personalization. These are discussed below.

Integrating personalized risks into the three-talk model of shared decision-making

A first theoretical contribution of this dissertation relates to the three-talk model of shared decision-making, proposed by Elwyn and colleagues[1], and more specifically the 'option talk' which involves the communication of evidence-based risk and benefits of treatment options. Arguably, the discussion of risks is a hallmark of an informed decision, which is defined as "a reasoned choice made by a reasonable individual using *relevant* information about the advantages and disadvantages of all the possible courses of action, in accord with the individual's beliefs"[8]. This dissertation suggests that personalized risks and cancer statistics are perceived as more relevant and may therefore promote more informed decision-making. Moreover, personalized risks help increase patients' understanding of their individual diagnostic situation and support patients in initiating conversations about complex topics such as survival and health-related quality of life. Indeed, substantial evidence from randomized controlled trials in the screening context demonstrates that personalized risk communication helps patients to make well-informed choices to participate in screening or not[9]. The current dissertation is therefore relevant for improving the three-talk model of shared decision-making by introducing the concept of *personalized* risk communication as a valuable and integral part of the option talk for promoting informed shared decision-making.

Applying fundamental principles of risk communication to personalized risks

Second, the studies and findings presented in this dissertation contribute to our understanding of risk communication and perception in a medical decision-making context. Over the years, several best practices and recommendations have been formulated on how best to communicate risk statistics and health data to patients[5,10–18]. Although these fundamental principles are extremely useful and important, almost all experimental work on risk communication is based on generic and non-personalized risks, while only a few studies investigated the optimal method for communicating personalization in risk information within the treatment decision-making context. As such, little evidence exists to what extent such guidelines apply to personalized risks. This dissertation has made a first step to fill that research gap and provided a deeper insight into the communication of personalized risk statistics to patients. Some of the recommendations seem to be applicable to both types of risks (e.g., verbal-only message formats led to more variable interpretations) or provide additional evidence for using one (e.g., natural frequencies are especially useful for personalized risks, since they make the personalized reference class more explicit). Interestingly, there are also novel findings that require attention. For instance, compared to generic risks, it was generally found that personalized risks (1) are perceived as more relevant, (2) evoke higher interests for comparison with other risk data, (3) call for explanations and disclosure of contributing factors, and (4) embody different types of uncertainty that may (or may not) be disclosed. Therefore, this dissertation is relevant to the theory of risk communication because it shows that many of the traditional recommendations are generally applicable to both type of risks, but crucially highlights the added value of personalized risks.

Rethinking the role of contextual information when communicating personalized risks

Third, this dissertation sheds new light on our understanding of the provision of contextual information for improving patients' evaluation of unfamiliar personalized risk statistics. The results from both needs assessments (**Chapters 4** and **5**) and the experimental study (**Chapter 7**) show that people generally want comparative data about the average person's risk or survival rate when being provided with their personalized risk. Moreover, the observational study (**Chapter 8**) revealed that healthcare professionals frequently use such comparisons when discussing a patient's personal risk, while the experimental results demonstrate that comparative data do not necessarily change people's risk perceptions, affective evaluations, and treatment choice (**Chapter 7**). These findings have important implications for theory on "information evaluability"[19,20], which posits that single risk statistics presented in isolation are generally difficult to evaluate by people and are sometimes even ignored. However, when personalized risks are presented with the average risk, people are better able to interpret even unfamiliar risks because both types of risks serve as a

reference for each other, which enables people to evaluate the "goodness" or "badness" of the risk information. Information evaluability of personalized risk information can thus be improved by adding contextual information about the average person's risk or by explaining crucial personal or clinical factors that determined the personalized risk.

These findings also contribute to the ongoing scientific debate on whether and in what specific health context patients should be provided with comparative risk information or not. According to some, comparative data should not be communicated or at least used with caution, since such information could unintentionally make patients feel more worried, overwhelmed, or confused, especially when the average risk is more favorable than their personal one[21–25]. Presumably for this reason, the IPDAS Collaboration recommends using contextual information with caution[11]. To others, however, patients should always be informed about whether their personalized risk is above or below average, since most patients will make such comparisons on their own anyway[26,27]. In this case, providing context would be useful in correcting inaccurate beliefs and risk perceptions. Importantly, what this dissertation adds is that the interpretations which people will derive from comparative information may depend strongly on what type of comparative data is communicated and in what specific health decision context. The current dissertation focused on communicating comparative risk data in the context of *informing* patients about personalized side effect risks of treatment options, while previous research was carried out in the screening context, emphasizing the risk of getting a certain disease such as breast or colon cancer[22,25]. As such, armed with the knowledge of previous research and the current dissertation, the effect of providing comparative risk or risk factor information needs to be evaluated in the context of the risk communication goal and personal health situation at hand.

Understanding personalized risks through the lens of theory on tailoring

Fourth and finally, this dissertation aimed at getting a better understanding of patient perceptions of personalized risks and other cancer statistics. Throughout this dissertation, it was consistently found that personalized risks were perceived as more relevant than generic risks, especially when patients were being informed about personal (e.g., age) and clinical factors (e.g., type of tumor, anatomical features) that contributed to the risk score. This finding complements previous theoretical work on tailored health communication[28–30] – and in a broader sense aligns with principles derived from the elaboration likelihood model[31] – which jointly posit that personalized or tailored information is more likely to be seen as personally relevant and, consequently, to be processed and read. It is often assumed that increased personal relevance is part of the key theoretical mechanisms underlying the positive effects of personalization on outcomes such as recall of information, risk perception, and intention to change behavior[32,33]. Although experimental work presented in this dissertation did not show difference in risk perception or recall of risk estimates

between personalized and generic risks (**Chapter 6**), the observational study (**Chapter 8**) did reveal that 67% of patients recalled their personalized risk score and, in some cases (33%), even used this information when making a decision about treatment. As such, this dissertation is relevant for theories on tailored health communication, as it shows that a new type of content (health risk data) in a particular health context (treatment decision-making in cancer care) shows similar effects on important variables such as perceived personal relevance. At the same time, however, more empirical research is needed to develop theory-based models of the mechanisms involved in understanding the effectiveness, processing, recall, and use of personalized health risk data in a medical decision-making context.

PRACTICAL IMPLICATIONS

The findings of this dissertation also have broad implications for clinical practice, including patient decision aid developers, healthcare professionals, and general website about cancer. All practice recommendations – based on insights obtained from this dissertation – are summarized in Table 1. Even though there may be some overlap, these recommendations will be discussed separately.

Recommendations for decision aid developers

To start, the findings have two direct implications for the design of web- or computer-based patient decision aids and especially those who are integrating personalized risk estimates or other cancer statistics. First, patient decision aids should not only adhere to the IPDAS guidelines (to safeguard the quality of the decision aids), but they should also pay attention to different communication aspects. Of particular importance is the integration of personalized treatment information, which means that the content of risks and benefits of treatment options in decision aids is personalized based on personal and clinical characteristics of unique patients. In recent years, there has been an increasing interest in the development of clinical prediction models – statistical algorithms that use patient and clinical characteristics for estimating personalized risks of health outcomes[3,34–37]. However, such models are typically "doctor-driven" (i.e., characteristics need to be entered by healthcare professionals) and are hence difficult to understand for patients and should therefore always be used in consultation with a healthcare professional. Some clinical prediction models have been translated for patients and are publicly available on the internet, such as the Predict-UK tools for newly diagnosed patients with breast cancer[35,36] and prostate cancer[37]. For patient decision aids designers, it is therefore recommended to integrate patient-friendly versions or result pages of clinical prediction models into currently available or newly developed decision aids. However, it should be noted that a prerequisite for personalized risk information is the availability of large amounts of clinical data and validated prediction models[4,38]. Luckily, recent developments in data

science and artificial intelligence combined with the increased availability of large population-based (e.g., the Netherlands cancer registry[39]) or patient reported outcome (e.g., PROFILES registry[40]) datasets offer promising opportunities for integrating personalized treatment outcomes into decision aids[41].

Second, when integrating personalized risks in decision aids, this dissertation provides insights into how such personalized risks can best be presented to individual patients. For instance, a key lesson is that there does not seem to exist a single perfect communication format for the delivery of personalized risks. Given the inevitable variation in needs, preferences, numeracy, health literacy, and graph literacy skills among patients, decision aid developers may consider potential personalization strategies at multiple levels. These include the possibility to adapt the type of visual display (e.g., choosing between icon arrays, bar graphs, or line graphs) or the amount of risk information (e.g., expanding text boxes for those who want detailed and supplementary information) according to patients' preferences. Furthermore, to assist patients with lower numeracy or health literacy skills, it is highly recommended to add contextual information or advice on how to interpret the personalized risks. Finally, when integrating patient-friendly or simplified clinical prediction models into patient decision aids, developers should always carefully test patients' ability to understand and input the data characteristics. If those are too complicated, it may be better that they are entered by the healthcare professional. Overall, these recommendations for the communication of personalized risks in decision aids could be added to the recently launched evidence update of the IPDAS guidelines on communicating probability information to patients[5,11].

Recommendations for healthcare professionals

The findings also have two specific practical implications for healthcare professionals who are discussing personalized risk and probability information with their patients in daily clinical practice. First, the results of this dissertation may help healthcare professionals decide whether or not to disclose personalized risk statistics to patients. The two needs studies described in this dissertation (**Chapters 4** and **5**) suggest that many patients want to receive personalized statistics, yet there are still few who do not wish to receive statistics at all. Patients' information coping style and subjective numeracy skills could play an important role in determining whether someone wants to receive (personalized) statistical information during a consultation; patients who generally look for detailed information about their disease and consider themselves "good with numbers" benefit from being provided with personalized risk information of treatment outcomes. When discussing risk and benefit statistics of treatment options with patients, healthcare professionals could, for instance, ask patients in advance whether they also want to receive specific numbers. Alternatively, self-report measures for assessing information coping style and subjective numeracy can be added to

(existing) screening questionnaires, especially since patients consider these instruments as less intimidating and less burdensome compared to mathematical exercises.

Second, some findings of this dissertation are relevant for helping healthcare professionals *how* best to communicate personalized risk information to their patients. Discussing all possible strategies for communicating risks goes beyond the scope of this section, but there are two simple strategies that are noteworthy. First, it is highly recommended to communicate risks in a numerical format (instead of verbal-only format), and preferably via natural frequencies ("16 out of 100 men like you will experience this side effect after treatment X") instead of percentages ("16%"), while keeping the denominator as simple and consistent as possible. The advantage of using natural frequencies for personalized risks is that they always specify a reference class, which in turn helps patients to realize that their risk statistic is based on similar patients and therefore applies to their situation. Second, this dissertation has highlighted the importance of *explaining* a personalized risk statistic to a patient by providing contextual information that goes beyond the risk statistic. For instance, when a 52-year-old men diagnosed with localized prostate cancer is being told that his personalized risk of erectile disfunction after surgery is about 26 out of 100, it would be helpful if his urologist also explains how that risk was determined and how it compares to the average risk ("Your risk is lower than the average risk, which is 76 out of 100). This is related to your younger age, but also to the favorable position of the tumor within the prostate, which allows us to spare some nerves"). This way, patients will understand the relationship between risk factors and their personalized risk, and whether they can do something about it or not. In sum, whenever a percentage score rolls out of a prediction model, healthcare professionals are advised to put some effort in translating that number into a simple representation that may help patients to derive meaning from their personalized risks and therefore make consultations more time efficient.

Recommendations for disclosing personalized cancer statistics on the Internet

Third and finally, the results from this dissertation could be useful to those who are interested in disclosing general cancer statistics on general cancer websites for patients and relatives. Most patients with cancer desire personalized risks and cancer statistics, such as specific and relevant data on survival and treatment side effects. This is encouraging for those who are developing personalized information tools for patients that are drawing on cancer registry data or other medical databases, especially in an era of personalized health care and open access of big health data. However, disclosing sensitive health to the public remains challenging, let alone statistics that are personalized towards the situation of individual patients. These include avoiding technical language that is needed to describe statistical or medical terms, making sure that all patients will correctly interpret the statistical information, and not

overwhelming patients with visualizations that display less favorable outcomes that may discourage patients from having hope.

As a result of the findings presented in this dissertation, a real-life web-based tool "Cijfers op maat" will be launched in 2022 on the Dutch website https://kanker.nl, which will communicate personalized rather than generic cancer statistics. These personalized statistics are derived from the Netherlands Cancer Registry, for patients with breast, colon, lung, and prostate cancer. In line with this dissertation's findings, the latest version of this tool (Figure 1) presents personalized statistics while keeping the information and data entry characteristics short and concise. Moreover, note that the tool specifies the reference class to whom the statistics apply, and provides context by explaining the gist meaning of conditional survival outcomes. Based on the recommendation of this dissertation research, other suggestions such as tailoring the type of visualization, providing comparative survival data, and adding natural frequencies to percentages are currently being considered. This tool will hopefully contribute to patients' understanding of their own diagnostic situation and may facilitate involvement in the shared decision-making process with their healthcare professional.

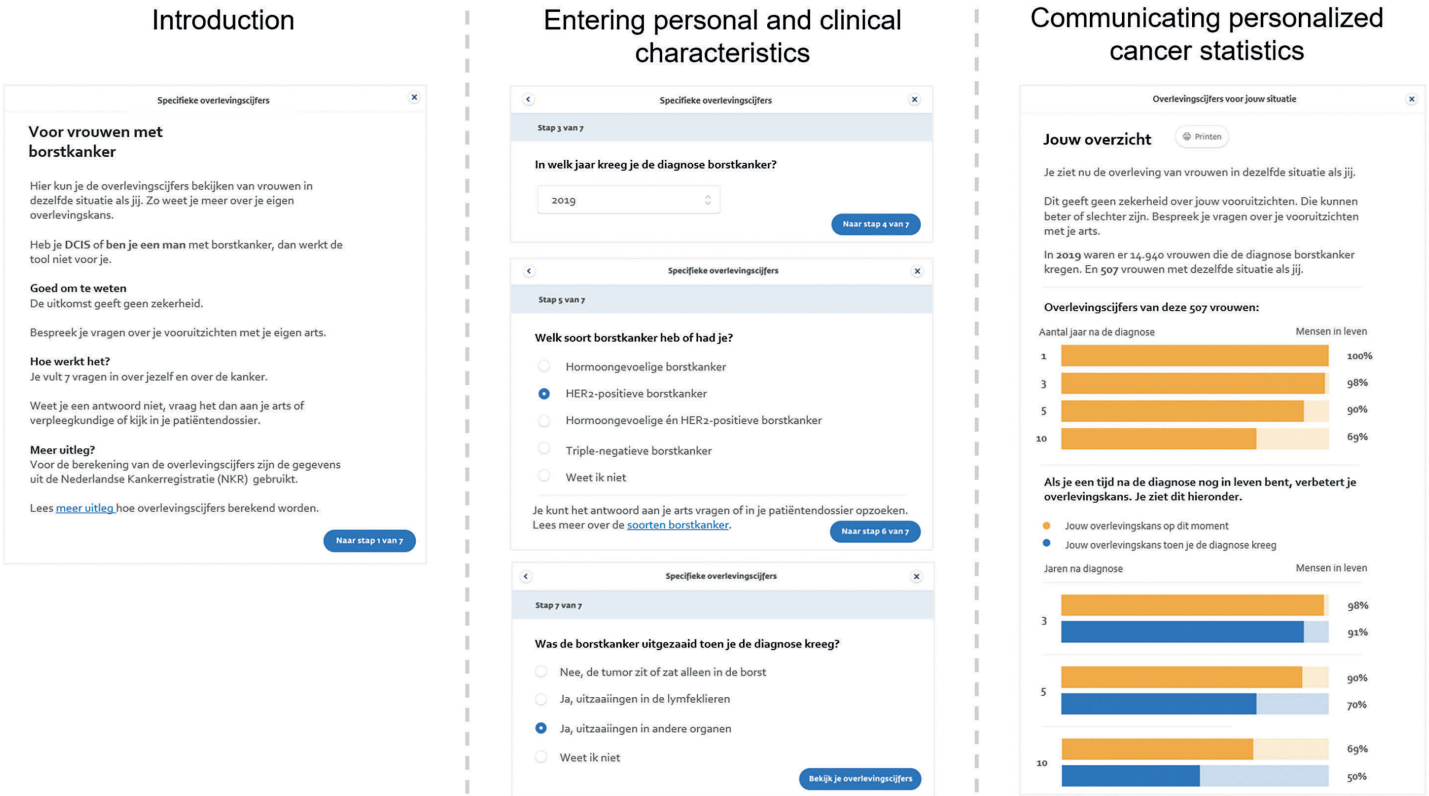

Figure 1 | Illustrative screenshots of the latest version of the tool "Cijfers op maat" on the Dutch website https://kanker.nl for communicating personalized cancer statistics about cancer incidence and (conditional) survival.

Table 1 | Overview of practice recommendations for healthcare professionals, decision aid developers, and general cancer websites when communicating personalized risks and other cancer statistics to patients or survivors.

Topic	Recommendation	Based on chapter(s)
What to communicate?		
Type of risk	Consider the integration of personalized risks and benefits of treatment options	2–7
	Consider the communication of personalized patient reported outcomes on quality of life	2–5, 8
Type of cancer statistics	Consider disclosing personalized (conditional) survival statistics	4, 5
Data entry characteristics	Make sure that patient and clinical characteristics that serve as data entry for determining personalized risks are familiar and easy to understand by patients	4
In what form to communicate?		
Message format	Use numerical risk formats, combined with either verbal or visual formats	4, 6, 7
	Avoid using verbal-only formats, since they may lead to inaccurate risk interpretations	2, 3, 6
	Preferably use natural frequencies (e.g., 10 out of 100)) since they always specify the reference class (which is especially beneficial for personalized risks)	2, 3, 8
	Avoid using percentages-only (and preferably translate percentages into natural frequencies), since they are unclear to what class the risks refer to	8
	When using visual formats, use icon arrays for expressing part-whole relationships	4
Contextual information	Provide contextual information about the personalized risks and use clear explanations on the intended use	4, 5, 7, 8
	Consider communicating comparative information (e.g., of the average person's risk or survival rate) to help patients make sense of their personalized risk	4, 5, 7, 8
	Explain a patient's personalized risk by drawing attention to crucial factors that determine that risk (e.g., specific patient or clinical characteristics), since this may lead to better recall and understanding of the risks	4, 8
	Consider using evaluative labels (e.g., high or low risk), but avoid labels such as "good" or "bad" for evaluating survival statistics	4

Table 1 | Continued.

Topic	Recommendation	Based on chapter(s)
Communicating to whom?		
Individual differences in information coping style	Patients with an information-seeking style may benefit from receiving personalized statistics, while patients with an information-avoiding style may not	5
	Check in advance whether patients want detailed and personalized numerical risk information or not; consider the possibility to tailor the amount of information	4
Individual differences in information processing	Recognize individual differences in risk information processing, specifically variations in numeracy, health literacy, and graph literacy skills	4–8
	Provide additional support (visual displays or explanations) to less skilled patients	4, 5, 7
	In general, keep the risk information short, simple, and concise	4, 8
Individual differences in preference for presentation	Recognize variation in preference for type of visualization and the amount of information	4
	Consider incorporating multiple types of visual displays or the possibility to modify the type of visualization or amount of information according to a patient's preference	4, 8
Communicating to what effect?		
Cognition	Be aware that the way how personalized risks are presented (verbally, numerically, of visually) may impact how patients interpret, perceive, and use those risks (see message format for recommendations)	6–8
	Keep in mind that personalized risks are perceived as more personally relevant than generic risks by patients, which in turn may lead to better recall and use of information	4, 5, 6, 8
Emotion	Recognize that some patients may experience emotions or feelings of distress while processing sensitive health data such as (less favorable) survival or mortality rates; prepare patients for these less favorable outcomes	4, 8
	Realize that to some patients want personalized risks to feel more comfortable in the decision-making process	4, 5, 8
Behavior	Be aware that personalized risks may be used by patients in their treatment decision-making; to some, it could even be a decisive factor determining their treatment choice	5, 8

DIRECTIONS FOR FUTURE RESEARCH

Several important questions remain to be answered. Therefore, based on the findings of this dissertation, this section discusses the following three directions for future research: (1) dealing with uncertainty around personalized risks, (2) testing the clinical impact of personalized risks on treatment and shared decision-making outcomes, and (3) exploring novel contextual strategies for explaining personalized risks.

Dealing with uncertainty around personalized risks

First, the findings of this dissertation raise intriguing questions regarding the disclosure and communication of uncertainty associated with personalized risk estimates. Although personalized risks seem to estimate patients' "true" risk of experiencing treatment outcomes, they are not perfect and always yield some form of uncertainty[42]. The science of uncertainty distinguishes two types of uncertainty: aleatory and epistemic uncertainty. The first type, aleatory uncertainty, indicates that future events such as experiencing treatment side effects are simply hard to predict (e.g., "There are no guarantees in life"). The second type, epistemic uncertainty, refers to limitations in the reliability and accuracy of personalized risk estimates (e.g., "The risk could also be 50% or 70%") or their applicability to a specific patient (e.g., it remains unknown who eventually will experience which outcome)[43,44]. When reviewing and observing current practices, the results of the dissertation indicate that decision aids and healthcare professionals hardly disclose different types of uncertainty to patients, which corroborates earlier observational studies [45,46]. However, whether uncertainty around personalized risk estimates should be communicated at all to patients is a topic of debate[18,45]. Some scholars believe that different levels of uncertainty around personalized risks statistics should always be disclosed to patients for ethical reasons. For example for the sake of transparency or helping patients prevent them from attributing an unrealistic degree of certainty to risk estimates[47,48]. Others believe that such uncertainty information may overwhelm patients and lead to negative psychological responses and undesired outcomes such as increased risk perceptions or levels of worry[25,43]. Interestingly, this dissertation found that some patients still asked for disclosing uncertainties around personalized survival statistics (**Chapters 4 and 5**), or perceived personalized risks of treatment outcomes still as imperfect or inapplicable to individual patients (**Chapter 8).** These perceptions could be explained by the fact that patients do not really experience risks or probabilities, but instead they experience outcomes. Nevertheless, no clear guidance exists today on how best to inform patients about uncertainty around personalized risk and benefit estimates[11,44]. Therefore, systematic knowledge about how uncertainty associated with personalized risk estimates of treatment outcomes is currently being communicated to and processed by patients is needed. Also, future research on the effects of different types

of uncertainty of personalized risks on patients' cognitive, emotional, and behavioral outcomes is required.

Testing the clinical impact of personalized risks

A second area for future research relates to testing the effectiveness of personalized risk information on several treatment decision-making outcomes in daily clinical practice. Most of the outcomes reported in this dissertation were found in the experimental and non-clinical setting. There are studies that suggest that personalized risk information of treatment outcomes may impact certain treatment decision-making outcomes in the domain of prostate cancer care, although evidence is scarce[37,49]. For instance, a recent multicenter randomized controlled trial conducted in the United Kingdom showed that the provision of personalized risk information to patients (using the Predict prostate cancer tool) led to lower levels of decisional conflict and better-informed decision-making about treatment[37]. Also, a Dutch prospective study compared patients receiving generic risk information (historical control cohort) with patients receiving personalized risk information (prospective cohort)[49] and found that patients who receive relatively less favorable personalized risk estimates of experiencing urinary incontinence after surgery are more likely to reconsider their initial treatment preference and to eventually opt for another treatment like radiotherapy – a result that aligns with the observational and qualitative findings (**Chapter 8**). However, this study was limited in that the type of risk information was not tested in a fully randomized controlled setting, and longitudinal data on the possible effects were lacking. Future studies could therefore focus on the impact of personalized risk estimates (integrated in for instance decision aids or risk communication tools used during consultations) on treatment decisions in a real-world clinical setting, and also on the effects of personalized risks on patient's decisional regret and potentially unmet expectations in the long-term[50].

Exploring novel contextual strategies for explaining personalized risks

One of the key findings of this dissertation relates to the added value of providing contextual information when discussing personalized risk information with patients. Nevertheless, it remains challenging to understand and evaluate personalized data (with or without contextual data), especially for patients with poor numeracy skills who may not wish to receive numerical information at all. Therefore, future research is invited to further examine novel strategies that may help facilitate (less numerate) patients to derive meaning from personalized risk statistics. A first interesting candidate strategy for adding context to personalized risk statistics is using narratives, which are short stories or testimonials that illustrate how previous patients experienced certain health outcomes, usually told from a first-person perspective[10]. Narratives have been an important component of patient decision aids[51], and less numerate people tend to be more focused on narratives than statistical information[52]. More importantly, like

health risk statistics, testimonials can also be personalized based on specific patient factors (e.g., age, gender, or type of treatment), indicating that patients would receive more relevant narratives that share experiences of similar patients, thereby increasing both perceived relevance and evaluability of the information among patients. A second possible strategy for optimizing context surrounding personalized risks could be to tailor the amount of contextual information. Congruent with the concept of tailoring the amount of information[53], context could be selected intentionally based on patients' specific information needs rather than providing patients with all possible contextual information[54]. Empirical research is needed to explore and test the preceding strategies, thereby guiding the communication of personalized risks to ensure that the risks are meaningful of patients with different numeracy levels.

GENERAL CONCLUSION

By employing multiple rigorous qualitative and quantitative methods, this dissertation explored whether and how personalized risks of treatment outcomes and other statistics can best be communicated to patients with cancer in the context of shared decision-making about treatment. Although decision aids have been developed to support the process of risk communication during shared decision-making, the findings revealed that they tend to be generic and lack personalized information about treatment outcomes. However, this dissertation has found that most patients desire personalized risk and prognostic information during treatment decision-making, especially those with an information-seeking style and higher numeracy skills. Certain message formats (e.g., natural frequencies combined with verbal descriptors or icon arrays) and contextual strategies (e.g., providing comparative risk data or explaining the relationship between risk factors and risk outcomes) are important for effectively communicating personalized risks to patients. At the same time, special attention is required for patients who are having more difficulties than others with interpreting numerical information. Finally, personalized risks are typically perceived as more relevant than generic risks and can also play a key role in a patient's treatment choice. Overall, these findings have broad theoretical implications for research on risk communication, shared decision-making, and personalization, as well as practical implications for healthcare professionals and decision aid developers to help patients make sense of their own personalized health risks data. In conclusion, this dissertation demonstrates the value and usefulness of personalized risk information during shared decision-making, but also emphasizes the need for moving beyond the provision of detailed, specific, and individualized risk statistics. Instead, communicators should select appropriate message formats and contextual strategies that align with the needs, preferences, and information processing styles of unique individual patients, to promote informed decision-making in the treatment of cancer.

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APPENDICES

Summary (Nederlandse samenvatting)

Wanneer bij iemand de diagnose kanker is vastgesteld, moet er vaak een moeilijke beslissing worden genomen over de behandeling. Hierbij is het belangrijk dat een patiënt duidelijke en volledige informatie ontvangt over de voor- en nadelen van alle mogelijke behandelopties. Om verschillende opties te vergelijken moeten kansen en risico's afgewogen worden, maar deze statistieken zijn vaak lastig te begrijpen voor niet-medici. Daarnaast is het communiceren van risico's en andere statistieken over kanker ook een complexe en moeilijke taak voor zowel artsen als keuzehulpen. Deze keuzehulpen zijn hulpmiddelen voor patiënten in de vorm van brochures, websites, of apps waarbij de voor-en nadelen van bepaalde opties tegen elkaar worden afgewogen. Stelt u zich een 52-jarige patiënt voor, John, bij wie gelokaliseerde prostaatkanker is ontdekt. Hij worstelt met de keuze tussen operatie en radiotherapie, die beide zowel voor- als nadelen hebben. Hij bezoekt de uroloog die tegen hem zegt:

> *"De kans dat u met een operatie of radiotherapie over vijf jaar nog leeft, is gemiddeld zo'n 95%. Elke behandeling heeft echter specifieke risico's op bijwerkingen die van invloed kunnen zijn op uw kwaliteit van leven. Op basis van de literatuur weten we dat er bij een operatie 60% kans is op urineverlies en 76% kans op erectieproblemen. Bij radiotherapie komen deze bijwerkingen niet zo vaak voor, maar ik moet zeggen dat er een hogere kans is op darmproblemen."*

Dit (fictieve) voorbeeld laat zien dat het bespreken van risicostatistieken een uitdaging is voor zowel de uroloog als John. De uroloog kan verschillende vormen (formats) gebruiken om statistieken en kansen aan zijn patiënt te communiceren. Ze maakt in dit geval gebruik van getallen (bijv. percentages), woorden (bijv. "Voor radiotherapie komen deze bijwerkingen *niet zo vaak* voor") en relatieve risicobeschrijvingen (bijv. "*hogere kans* op darmproblemen"). De patiënt, John, wordt overspoeld met voor hem onbekende statistieken, zoals overlevingspercentages en risico's op het ervaren van bijwerkingen van de behandeling, die wellicht lastig te begrijpen en te interpreteren zijn. Wat betekent bijvoorbeeld 60% kans op urineverlies en wat moet John met dat getal?

Een nog uitdagender probleem is dat de risicostatistieken doorgaans generiek zijn en gebaseerd zijn op alle patiënten met prostaatkanker uit medische studies. John is echter niet de gemiddelde patiënt (en niemand is dat), en hij vindt het moeilijk om die generieke cijfers toe te passen op zijn eigen situatie. Is John voldoende geïnformeerd? Wat zou er gebeuren als de uroloog meer *gepersonaliseerde* risico-informatie zou communiceren door rekening te houden met unieke kenmerken van John, zoals zijn leeftijd, fysieke conditie en het type tumor?

Dit proefschrift richt zich op dergelijke gepersonaliseerde risicostatistieken en onderzoekt hoe deze het beste aan patiënten met kanker kunnen worden gecommuniceerd en of patiënten deze statistieken nodig hebben, begrijpen en gebruiken bij het nemen van complexe beslissingen over een behandeling. Dit proefschrift gaat in op de volgende vier doelen die zijn gestructureerd rond Lasswell's

communicatiemodel, waarbij wordt aangegeven *wie wat* communiceert, in *welke vorm*, *aan wie* en met *welk effect*:

(1) Het kritisch evalueren en beoordelen hoe huidige keuzehulpen (gepersonaliseerde) risico's van behandelopties communiceren aan patiënten met kanker (hoofdstuk 2 en 3);
(2) Het beoordelen van de behoeften en voorkeuren van patiënten voor het communiceren van gepersonaliseerde risico's en andere kankerstatistieken (hoofdstuk 4 en 5);
(3) Het testen van de effecten van verschillende formats en strategieën voor het communiceren van gepersonaliseerde risico's op de cognitieve, emotionele en gedragsuitkomsten van de patiënt (hoofdstuk 6 en 7);
(4) Observeren hoe zorgverleners gepersonaliseerde risico's van behandelingsopties communiceren aan patiënten met kanker, en onderzoeken hoe deze patiënten gepersonaliseerde risico's waarnemen en gebruiken tijdens de besluitvorming over de behandeling (hoofdstuk 8).

OVERZICHT VAN STUDIES EN BELANGRIJKSTE BEVINDINGEN

Deel 1: Kritisch evalueren van huidige keuzehulpen – Wie communiceert wat in welke vorm?

Dit proefschrift begon met twee literatuurstudies (*systematische reviews*) over de kwaliteit van informatie en het gebruik van communicatie in keuzehulpen voor de behandeling van prostaatkanker (**hoofdstuk 2**) en borstkanker (**hoofdstuk 3**). Voor beide soorten kanker werden keuzehulpen (n = 40) systematisch geselecteerd via zowel gepubliceerde academische literatuur als online bronnen (zoals Google). Hun inhoudelijke kwaliteit werd beoordeeld met een checklist die gemaakt is door medisch specialisten en onderzoekers en waarin regels staan waaraan goede keuzehulpen zouden moeten voldoen (de *International Patient Decision Aids Standards (IPDAS) checklist*). Omdat *IPDAS* geen rekening houdt met *hoe* risico's worden gecommuniceerd, werd er een nieuwe checklist ontwikkeld - de *Communicatieve Aspecten checklist* - om de kwaliteit van de communicatie te beoordelen op het gebied van personalisatie, informatiepresentatie, interactie, informatiecontrole, toegankelijkheid, geschiktheid en informatiebron. We vonden dat de inhoudelijke kwaliteit van de keuzehulpen sterk verschilde voor zowel prostaat (gemiddelde IPDAS-score = 59%, minimum en maximum scores: 36-84%) als borstkanker (gemiddelde IPDAS-score = 64%, minimum en maximum scores: 31-92%). Belangrijker nog is dat ook op het gebied van de communicatie, de keuzehulpen nogal verschilden. Bijna alle keuzehulpen waren generiek en dus niet-gepersonaliseerd, en met name de statistieken en risico's waren generiek. Zes keuzehulpen (15%) bevatten helemaal geen risico-informatie of communiceerden deze alleen via woorden. Keuzehulpen die wel nummers bevatten, verschilden erg in de manier waarop ze deze aan patiënten communiceerden (meestal met behulp van *natural frequencies* ("1 op de 10") gevolgd door percentages

("10%")), en ongeveer de helft presenteerde risico's door getallen te combineren met visualisaties (meestal *icon arrays* of pictogrammen). De **hoofdstukken 2** en **3** laten samen zien dat de beschikbare keuzehulpen voor gelokaliseerde prostaatkanker en vroeg-stadium borstkanker aanzienlijk variëren in kwaliteit, en tonen verder aan dat ze verbeterd zouden kunnen worden door rekening te houden met communicatieve aspecten, met als meest belangrijke aspect het integreren van gepersonaliseerde risico's van behandeluitkomsten. Maar willen patiënten dit wel?

Deel 2: Het beoordelen van behoeften en voorkeuren van patiënten - Wat in welke vorm aan wie communiceren?

Met behulp van een combinatie van verschillende kwalitatieve onderzoeksmethoden (**hoofdstuk 4**) werd onderzocht wat de behoeften en voorkeuren van overlevenden van borst- en prostaakanker waren voor het ontvangen van gepersonaliseerde statistieken. Hiervoor werden verschillende (interactieve) tools ontwikkeld waarin patiënten de mogelijkheid hadden om persoonlijke (bijv. leeftijd, geslacht) en medische (bijv. tumorstadium, jaar van diagnose) kenmerken in te voeren, om zo uiteindelijk gepersonaliseerde statistieken over incidentie (hoe vaak de kanker voorkomt) en overleving te ontvangen. Over het algemeen gaven deelnemers in beide focusgroepen (n = 13) en hardop-denk observaties (n = 11) aan dat ze behoefte hadden aan gepersonaliseerde statistieken (bijv. overleving, conditionele overleving, risico's op bijwerkingen), met name omdat ze gepersonaliseerde statistieken relevanter en nuttiger vonden dan generieke statistieken. Bij het communiceren van gepersonaliseerde statistieken aan patiënten bleek wel dat patiënten ondersteuning nodig hadden om de statistieken correct te interpreteren en in perspectief te kunnen plaatsen, bijvoorbeeld door contextuele informatie toe te voegen of de persoonlijke statistieken te vergelijken met gemiddelden. Daarnaast verwerkten sommige deelnemers hardop-denkend overlevingscijfers op een emotionele manier (vooral als de uitkomst minder gunstig was), wat om ondersteunende of toelichtende informatie vraagt. Over het algemeen gaven de deelnemers de voorkeur aan eenvoud en beknoptheid, en ze wilden ook de mogelijkheid om het type visualisatie en de hoeveelheid (gedetailleerde) statistische informatie aan te kunnen passen aan hun persoonlijke voorkeuren.

Hoofdstuk 5 beschrijft een kwantitatief onderzoek naar de behoefte van patiënten voor het ontvangen van gepersonaliseerde statistische informatie na een kankerdiagnose (n = 174). In een online vragenlijst werd aan overlevenden van kanker gevraagd terug te denken aan hun eerste kankerdiagnose en aan te geven in hoeverre ze generieke en gepersonaliseerde statistieken hadden willen ontvangen voor een reeks verschillende statistieken: incidentiecijfers, overlevingscijfers, risico's op bijwerkingen van de behandeling, risico's op terugkeer van kanker en invloed van de behandeling op de kwaliteit van leven. Er werd ook onderzocht hoe individuele verschillen (*informatiecopingstijl* (of iemand informatie opzoekt of liever vermijdt),

numerieke vaardigheden (hoe goed iemand is met getallen) en angstniveaus (hoe angstig iemand zich voelt)) verband hielden met deze behoeften, en wat de overwegingen van deelnemers waren om al dan niet statistische informatie te willen ontvangen. De resultaten toonden aan dat de deelnemers voor elk onderwerp een grotere behoefte hadden aan het ontvangen van de gepersonaliseerde statistieken dan de generieke. Deze behoefte aan gepersonaliseerde statistieken ging samen met hogere numerieke vaardigheden en een informatie-zoekende copingstijl. Overwegingen van deelnemers om gepersonaliseerde kankerstatistieken te willen, hadden betrekking op gevoelens van controle of het nemen van beter geïnformeerde beslissingen over behandeling, terwijl overwegingen om geen statistieken te willen, betrekking hebben op de onvoorspelbaarheid van toekomstige gebeurtenissen voor individuele patiënten of negatieve ervaringen met statistieken in het verleden. Over het algemeen laten de resultaten van **hoofdstukken 4** en **5** zien dat de overgrote meerderheid van de patiënten en overlevenden—vooral degenen met hogere numerieke vaardigheden en een informatiezoekende copingstijl—een wens hebben om gepersonaliseerde risicostatistieken te ontvangen bij het maken van een keuze over een behandeling.

Deel 3: Testen van verschillende formats – Communiceren in welke vorm aan wie met welk effect?

Dit proefschrift ging verder met twee experimentele onderzoeken onder (1) een steekproef van patiënten met kanker en overlevenden (n = 141) en (2) een steekproef van gezonde deelnemers die representatief was voor de Nederlandse bevolking (n = 1.807). Het eerste experiment, gepresenteerd in **hoofdstuk 6**, testte de invloed van gepersonaliseerde risico's (vs. generieke risico's) op de cognitieve responses van patiënten (bijv. risicopercepties, (nauwkeurigheid van) risicoschattingen, waargenomen relevantie en waargenomen onzekerheid), evenals via welk format (alleen woorden versus woorden en cijfers gecombineerd) de risico's het beste gecommuniceerd moeten worden. De deelnemers kregen de opdracht om zich voor te stellen dat ze de diagnose darmkanker hadden gekregen en om vier verschillende bijwerkingen van chemotherapie te evalueren. Alle deelnemers kregen twee gepersonaliseerde risico's (waarbij personaliseren gedaan werd op basis van hun leeftijd, geslacht en tumorstadium) en twee generieke risico's die de kans op het ervaren van de bijwerkingen aangaven. Daarnaast kreeg de helft van de deelnemers deze kansen alleen in woorden gepresenteerd (bijv. 'deze bijwerking komt *vaak* voor bij manen zoals u'), en de andere helft in een combinatie van woorden en bijbehorende *natural frequencies* (bijv. 'deze bijwerking komt *vaak* voor, bij 10 van de 100 mannen zoals u'). Uit de resultaten bleek dat gepersonaliseerde risico's hoger en minder nauwkeurig werden ingeschat dan generieke risico's, maar alleen wanneer ze in woorden werden gepresenteerd. Dergelijke verschillen werden niet gevonden in het gecombineerde

format. Gepersonaliseerde risico's werden ook als meer persoonlijk relevant ervaren (in beide formats) dan generieke risico's.

Het tweede experiment (**hoofdstuk 7**) onderzocht het effect van het geven van contextuele risico-informatie op de cognitieve (risico percepties, risicoschattingen, waargenomen relevantie), emotionele (affectieve evaluatie) en gedragsmatige (behandelingsintentie) responses van mensen bij het communiceren van gepersonaliseerde risico's. Verder werd er gekeken of de resultaten zouden worden beïnvloed door het format (alleen numeriek vs. numeriek + visueel format) en individuele verschillen (socio-demografische kenmerken (zoals leeftijd en opleiding), numerieke vaardigheden, gezondheidsvaardigheden (hoe goed je gezondheidsinformatie kunt snappen) en grafiek-vaardigheden (hoe goed je bent in het aflezen van grafieken)). Deelnemers kregen drie scenario's voor het nemen van gezondheidsbeslissingen en gepersonaliseerde risicoschattingen van bijwerkingen van de behandeling te zien. Deelnemers zagen of (1) alleen hun gepersonaliseerde risico zonder het gemiddelde risico, of ze zagen zowel hun eigen gepersonaliseerde risico als het gemiddelde risico, dat (2) hoger of (3) lager was dan hun eigen risico. De resultaten gaven aan dat het verstrekken van gemiddelde risico-informatie geen invloed had op de risicopercepties, affectieve evaluaties en behandelintenties. Deelnemers die te horen kregen dat hun persoonlijke risico bovengemiddeld was, schatten hun eigen risico echter lager in dan deelnemers van wie hun risico onder het gemiddelde lag of die helemaal geen contextuele informatie ontvingen. Presentatieformat (*natural frequencies* met of zonder pictogrammen) en individuele verschillen hadden geen invloed op de reacties van mensen die beter of slechter scoorden dan gemiddeld. De meerderheid gaf een voorkeur aan voor gepersonaliseerde risico-informatie, en wilden naast hun gepersonaliseerde risico's ook het gemiddelde risico ontvangen. Samengevat laten de **hoofdstukken 6** en **7** zien dat gepersonaliseerde risico's als relevanter worden beschouwd dan generieke risico's, en dat verschillende formats (woorden of getallen), contextuele strategieën (of je we of niet het gepersonaliseerde risico met het gemiddelde risico vergelijkt) en individuele verschillen (numerieke vaardigheden) een impact kunnen hebben op hoe deze risico's worden waargenomen en geïnterpreteerd – hoewel de effecten subtiel en soms in een onverwachte richting kunnen zijn.

Deel 4: Samenbrengen tijdens samen beslissen – Wie communiceert wat in welke vorm aan wie met welk effect?

Dit proefschrift werd afgesloten met een studie (**hoofdstuk 8**) waarbij werd gekeken hoe urologen en verpleegkundig specialisten gepersonaliseerde risico's van urineverlies na een operatie aan hun patiënten communiceerden, en hoe deze patiënten (n = 27) deze risico's waarnamen en gebruikten bij hun besluitvorming over de behandeling. Hiervoor werd een voorspellingsmodel gebruikt, een tool die persoonlijke voorspellingen maakt over het risico op urineverlies op basis van

enkele patiëntgegevens. Evaluatie van de opgenomen consultaties bracht aan het licht dat zorgverleners het risico vaak uitlegden door de belangrijkste factoren van het voorspellingsmodel te noemen die bijdroegen aan het persoonlijke risico van de patiënt. Bovendien gebruikten zorgverleners vaak een combinatie van woorden en cijfers om risico's over te brengen. Als er gebruik werd gemaakt van getallen, gebruikten zorgprofessionals altijd percentages en in enkele gevallen *natural frequencies*. Tijdens semigestructureerde interviews bleek dat patiënten deze uitleg waarderen, en het ze hielp hun persoonlijke risico's te begrijpen en ze als relevant te beschouwen. Sommige patiënten (22%) interpreteerden de procentuele risicoscore verkeerd door aan te nemen dat ze in X procent van de tijd urineverlies zouden ervaren (terwijl het ging om de kans *op* urineverlies, niet om de *hoeveelheid* van urineverlies). Hoewel het communiceren van onzekerheid rondom gepersonaliseerde risico's beperkt was, beschouwden sommige patiënten deze nog steeds als onzeker of niet van toepassing op specifieke patiënten. Ten slotte gaven patiënten verschillende strategieën aan om met hun persoonlijke risico om te gaan, en ongeveer een derde gebruikte deze risico's bij hun besluitvorming over de behandeling door ofwel over te schakelen naar een andere behandelingsoptie of vast te houden aan hun oorspronkelijke voorkeur. **Hoofdstuk 8** laat zien dat een eenvoudige uitleg over hoe gepersonaliseerde risico's worden bepaald, patiënten kan helpen deze risico's te begrijpen en zich deze te herinneren, en toont aan dat ze een beslissende rol kunnen spelen bij het nemen van beslissingen over de behandeling.

CONCLUSIE

Door gebruik te maken van verschillende kwalitatieve en kwantitatieve onderzoeksmethoden, werd in dit proefschrift onderzocht *of* en *hoe* gepersonaliseerde risico's van behandeluitkomsten en andere statistieken het beste kunnen worden gecommuniceerd aan patiënten met kanker in de context van gedeelde besluitvorming over behandeling. Hoewel er keuzehulpen zijn ontwikkeld om het proces van risicocommunicatie tijdens gedeelde besluitvorming te ondersteunen, bleek uit onze bevindingen dat ze meestal generiek zijn en geen gepersonaliseerde risico-informatie bevatten. Dit proefschrift heeft echter aangetoond dat de meeste patiënten persoonlijke risico- en prognostische informatie wel degelijk willen ontvangen tijdens de besluitvorming over de behandeling, vooral degenen met een informatie-zoekende copingstijl en hogere numerieke vaardigheden. Bepaalde formats (bijv. *natural frequencies* in combinatie met verbale descriptoren of pictogrammen) en contextuele strategieën (bijv. het verstrekken van vergelijkende risico-informatie of het uitleggen van de relatie tussen risicofactoren en risico-uitkomsten) zijn belangrijk voor het effectief communiceren van gepersonaliseerde risico's aan patiënten. Tegelijkertijd is er speciale aandacht nodig voor patiënten die meer moeite hebben met het interpreteren van numerieke informatie. Ten slotte worden gepersonaliseerde

risico's doorgaans als relevanter gezien dan generieke risico's en kunnen ze ook een sleutelrol spelen bij de behandelkeuze van een patiënt.

Over het algemeen hebben deze bevindingen brede theoretische implicaties voor onderzoek naar risicocommunicatie, gedeelde besluitvorming en personalisatie, evenals praktische implicaties voor zorgverleners en ontwikkelaars van keuzehulpen om patiënten te helpen hun eigen gepersonaliseerde gezondheidsrisico's te begrijpen. Samengevat toont dit proefschrift de waarde en het nut aan van gepersonaliseerde risico-informatie tijdens gedeelde besluitvorming, maar het benadrukt ook de noodzaak om verder te gaan dan het verstrekken van gedetailleerde, specifieke en geïndividualiseerde risicostatistieken. In plaats daarvan moeten communicatoren (zoals artsen, verpleegkundigen en keuzehulpontwikkelaars) geschikte formats en contextuele strategieën selecteren die aansluiten bij de behoeften, voorkeuren en informatieverwerkingsstijlen van unieke individuele patiënten, om uiteindelijk geïnformeerde besluitvorming bij de behandeling van kanker te bevorderen.

List of publications and presentations

JOURNAL PAPERS INCLUDED IN THIS THESIS

1. **Vromans, R. D.,** Tillier, C. N., Pauws, S. C., van der Poel, H. G., van de Poll-Franse, L. V., & Krahmer, E.J. (2022). Communication, perception, and use of personalized side-effect risks in prostate cancer treatment decision-making: Observational and interview study. *Patient Education and Counseling*.
2. **Vromans, R. D.,** Pauws, S. C., van de Poll-Franse, L. V., & Krahmer, E. J. (under review). *Effects of comparative information when communicating personalized risks of treatment outcomes: Web-based experimental study.* Manuscript submitted for publication.
3. **Vromans, R. D.**[†]**,** Hommes, S.[†], Clouth, F.J., Lo-Fo-Wong, D., Pauws, S.C., Verbeek, X., van de Poll-Franse, L.V., & Krahmer, E.J. (under review). *Need for numbers: Assessing cancer patients' need for personalized and generic statistical information*. Revised manuscript submitted for publication.
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[†] Joint first authorship

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1. **Vromans, R. D.,** Linn, A., Maru, N., Pabian, S., Krahmer, E. J., & Bol, N. (under review). *Comparing and Predicting COVID-19 Risk Perceptions Across Adjacent Regions in the Netherlands and Belgium: A Cross-Sectional Survey Among University Students*. Revised manuscript submitted for publication.
2. van Eenbergen, M. C., **Vromans, R. D.,** Tick, L. W., Vreugdenhil, A., Krahmer, E. J., Mols, F., & van de Poll-Franse, L.V. (2022). Comparing survivors of cancer in population-based samples with those in online cancer communities: Cross-sectional questionnaire study. *JMIR Cancer, 8*(1), e19379.

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1. Bol, N., **Vromans, R. D.,** van Wezel, M. M. C., van Weert, J. C. M., & Krahmer, E. J. (2022, May). Who Does (Not) Adhere to COVID-19 Preventive Measures? Identifying Subgroups Based on Risk Perceptions and Media Use in a Dutch Population-Based Sample. Paper will be presented at the *72nd Annual International Communication Association Conference,* Paris, France.
2. van der Linden, L., **Vromans, R. D.**, & Krahmer, E. J. (2022, May). To suspend or not to suspend? Analyzing online responses to the mixed messaging regarding the suspension of AstraZeneca's COVID-19 vaccine in the Netherlands. Paper will be presented at the *72nd Annual International Communication Association Conference,* Paris, France.
3. **Vromans, R. D.,** Bol, N., van Wezel, M. M. C., & Krahmer, E. J. (2022, February). "R" you getting this? Testing effects of different visual displays for explaining the COVID-19 reproduction number to the general public. Abstract will be presented at the *Etmaal van de Communicatiewetenschap 2022*, Brussels, Belgium.
4. Hommes†, S., **Vromans†, R. D.,** Krahmer, E. J., Bol, N., & Antheunis, M. L. (2022, February). Breaking the silence: An experimental and interview study investigating the usefulness of communicating personalized predictions about life after emergencies. Abstract will be presented at the *Etmaal van de Communicatiewetenschap* 2022, Brussels, Belgium. † Joint first authorship
5. **Vromans, R. D.,** Pauws, S. C., van de Poll-Franse, L. V., & Krahmer, E. J. (2021, November). Communicating personalized side effect risks of treatment options: The role of comparative risk information. Abstract presented at the *European Conference on Health Communication 2021,* Virtual.
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12. **Vromans, R. D.,** Bol, N., van Wezel, M. M. C., van Weert, J. C. M., & Krahmer, E. J. (2021, October). Identifying Subgroups at Risk for Non-Adherence to COVID-19 Preventive Measures Based on Risk Perceptions and Media Use: A Latent Profile Analysis. Abstract presented at the *43rd Annual Conference of the Society for Medical Decision Making,* Virtual. **[LEE B. LUSTED AWARD CANDIDATE]**
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17. **Vromans, R. D.,** Pauws, S. C., Bol, N., van de Poll-Franse, L. V., & Krahmer, E. J. (2020, June). (Not) Taking it Personal: An Experimental Study into the Effects of Personalization and Message Format on the Interpretation of Cancer Treatment Side Effect Risks. Abstract presented at the *18th Biennial European Conference of the Society for Medical Decision Making*, Berlin, Germany. **[TOP-RATED ABSTRACT]**
18. Hommes, S., **Vromans, R. D.**, Clouth, F.J., Verbeek, X., Vermunt, J., Pauws, S. C., van de Poll-Franse, L.V., de Hingh, I., & Krahmer, E.J. (2020, June). Communication in decision aids for stage I-III colorectal cancer patients: A systematic review. Abstract presented at the *18th Biennial European Conference of the Society for Medical Decision Making*, Berlin, Germany.
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TiCC PhD Series

1. Pashiera Barkhuysen. Audiovisual Prosody in Interaction. Promotores: M.G.J. Swerts, E.J. Krahmer. Tilburg, 3 October 2008.
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6. Fritz Reul. New Architectures in Computer Chess. Promotor: H.J. van den Herik. Co-promotor: J.W.H.M. Uiterwijk. Tilburg, 17 June 2009.
7. Laurens van der Maaten. Feature Extraction from Visual Data. Promotores: E.O. Postma, H.J. van den Herik. Co-promotor: A.G. Lange. Tilburg, 23 June 2009 (cum laude).
8. Stephan Raaijmakers. Multinomial Language Learning. Promotores: W. Daelemans, A.P.J. van den Bosch. Tilburg, 1 December 2009.
9. Igor Berezhnoy. Digital Analysis of Paintings. Promotores: E.O. Postma, H.J. van den Herik. Tilburg, 7 December 2009.
10. Toine Bogers. Recommender Systems for Social Bookmarking. Promotor: A.P.J. van den Bosch. Tilburg, 8 December 2009.
11. Sander Bakkes. Rapid Adaptation of Video Game AI. Promotor: H.J. van den Herik. Co-promotor: P. Spronck. Tilburg, 3 March 2010.
12. Maria Mos. Complex Lexical Items. Promotor: A.P.J. van den Bosch. Co-promotores: A. Vermeer, A. Backus. Tilburg, 12 May 2010 (in collaboration with the Department of Language and Culture Studies).
13. Marieke van Erp. Accessing Natural History. Discoveries in data cleaning, structuring, and retrieval. Promotor: A.P.J. van den Bosch. Co-promotor: P.K. Lendvai. Tilburg, 30 June 2010.
14. Edwin Commandeur. Implicit Causality and Implicit Consequentiality in Language Comprehension. Promotores: L.G.M. Noordman, W. Vonk. Co-promotor: R. Cozijn. Tilburg, 30 June 2010.
15. Bart Bogaert. Cloud Content Contention. Promotores: H.J. van den Herik, E.O. Postma. Tilburg, 30 March 2011.
16. Xiaoyu Mao. Airport under Control. Promotores: H.J. van den Herik, E.O. Postma. Co-promotores: N. Roos, A. Salden. Tilburg, 25 May 2011.
17. Olga Petukhova. Multidimensional Dialogue Modelling. Promotor: H. Bunt. Tilburg, 1 September 2011.
18. Lisette Mol. Language in the Hands. Promotores: E.J. Krahmer, A.A. Maes, M.G.J. Swerts. Tilburg, 7 November 2011 (cum laude).

19. Herman Stehouwer. Statistical Language Models for Alternative Sequence Selection. Promotores: A.P.J. van den Bosch, H.J. van den Herik. Co-promotor: M.M. van Zaanen. Tilburg, 7 December 2011.
20. Terry Kakeeto-Aelen. Relationship Marketing for SMEs in Uganda. Promotores: J. Chr. van Dalen, H.J. van den Herik. Co-promotor: B.A. Van de Walle. Tilburg, 1 February 2012.
21. Suleman Shahid. Fun & Face: Exploring Non-Verbal Expressions of Emotion during Playful Interactions. Promotores: E.J. Krahmer, M.G.J. Swerts. Tilburg, 25 May 2012.
22. Thijs Vis. Intelligence, Politie en Veiligheidsdienst: Verenigbare Grootheden? Promotores: T.A. de Roos, H.J. van den Herik, A.C.M. Spapens. Tilburg, 6 June 2012 (in collaboration with the Tilburg School of Law).
23. Nancy Pascall. Engendering Technology Empowering Women. Promotores: H.J. van den Herik, M. Diocaretz. Tilburg, 19 November 2012.
24. Agus Gunawan. Information Access for SMEs in Indonesia. Promotor: H.J. van den Herik. Co-promotores: M. Wahdan, B.A. Van de Walle. Tilburg, 19 December 2012.
25. Giel van Lankveld. Quantifying Individual Player Differences. Promotores: H.J. van den Herik, A.R. Arntz. Co-promotor: P. Spronck. Tilburg, 27 February 2013.
26. Sander Wubben. Text-to-text Generation Using Monolingual Machine Translation. Promotores: E.J. Krahmer, A.P.J. van den Bosch, H. Bunt. Tilburg, 5 June 2013.
27. Jeroen Janssens. Outlier Selection and One-Class Classification. Promotores: E.O. Postma, H.J. van den Herik. Tilburg, 11 June 2013.
28. Martijn Balsters. Expression and Perception of Emotions: The Case of Depression, Sadness and Fear. Promotores: E.J. Krahmer, M.G.J. Swerts, A.J.J.M. Vingerhoets. Tilburg, 25 June 2013.
29. Lisanne van Weelden. Metaphor in Good Shape. Promotor: A.A. Maes. Co-promotor: J. Schilperoord. Tilburg, 28 June 2013.
30. Ruud Koolen. Need I say More? On Overspecification in Definite Reference. Promotores: E.J. Krahmer, M.G.J. Swerts. Tilburg, 20 September 2013.
31. J. Douglas Mastin. Exploring Infant Engagement. Language Socialization and Vocabulary. Development: A Study of Rural and Urban Communities in Mozambique. Promotor: A.A. Maes. Co-promotor: P.A. Vogt. Tilburg, 11 October 2013.
32. Philip C. Jackson. Jr. Toward Human-Level Artificial Intelligence – Representation and Computation of Meaning in Natural Language. Promotores: H.C. Bunt, W.P.M. Daelemans. Tilburg, 22 April 2014.
33. Jorrig Vogels. Referential Choices in Language Production: The Role of Accessibility. Promotores: A.A. Maes, E.J. Krahmer. Tilburg, 23 April 2014 (cum laude).
34. Peter de Kock. Anticipating Criminal Behaviour. Promotores: H.J. van den Herik, J.C. Scholtes. Co-promotor: P. Spronck. Tilburg, 10 September 2014.
35. Constantijn Kaland. Prosodic Marking of Semantic Contrasts: Do Speakers Adapt to Addressees? Promotores: M.G.J. Swerts, E.J. Krahmer. Tilburg, 1 October 2014.

36. Jasmina Marić. Web Communities, Immigration and Social Capital. Promotor: H.J. van den Herik. Co-promotores: R. Cozijn, M. Spotti. Tilburg, 18 November 2014.
37. Pauline Meesters. Intelligent Blauw. Promotores: H.J. van den Herik, T.A. de Roos. Tilburg, 1 December 2014.
38. Mandy Visser. Better Use Your Head. How People Learn to Signal Emotions in Social Contexts. Promotores: M.G.J. Swerts, E.J. Krahmer. Tilburg, 10 June 2015.
39. Sterling Hutchinson. How Symbolic and Embodied Representations Work in Concert. Promotores: M.M. Louwerse, E.O. Postma. Tilburg, 30 June 2015.
40. Marieke Hoetjes. Talking hands. Reference in Speech, Gesture and Sign. Promotores: E.J. Krahmer, M.G.J. Swerts. Tilburg, 7 October 2015
41. Elisabeth Lubinga. Stop HIV. Start Talking? The Effects of Rhetorical Figures in Health Messages on Conversations among South African Adolescents. Promotores: A.A. Maes, C.J.M. Jansen. Tilburg, 16 October 2015.
42. Janet Bagorogoza. Knowledge Management and High Performance. The Uganda Financial Institutions Models for HPO. Promotores: H.J. van den Herik, B.A. van de Walle. Tilburg, 24 November 2015.
43. Hans Westerbeek. Visual realism: Exploring Effects on Memory, Language Production, Comprehension, and Preference. Promotores: A.A. Maes, M.G.J. Swerts. Co-promotor: M.A.A. van Amelsvoort. Tilburg, 10 February 2016.
44. Matje van de Camp. A link to the Past: Constructing Historical Social Networks from Unstructured Data. Promotores: A.P.J. van den Bosch, E.O. Postma. Tilburg, 2 March 2016.
45. Annemarie Quispel. Data for all: Data for all: How Professionals and Non-Professionals in Design Use and Evaluate Information Visualizations. Promotor: A.A. Maes. Co-promotor: J. Schilperoord. Tilburg, 15 June 2016.
46. Rick Tillman. Language Matters: The Influence of Language and Language Use on Cognition. Promotores: M.M. Louwerse, E.O. Postma. Tilburg, 30 June 2016.
47. Ruud Mattheij. The Eyes Have It. Promotores: E.O. Postma, H. J. Van den Herik, and P.H.M. Spronck. Tilburg, 5 October 2016.
48. Marten Pijl. Tracking of Human Motion over Time. Promotores: E. H. L. Aarts, M. M. Louwerse. Co-promotor: J. H. M. Korst. Tilburg, 14 December 2016.
49. Yevgen Matusevych. Learning Constructions from Bilingual Exposure: Computational Studies of Argument Structure Acquisition. Promotor: A.M. Backus. Co-promotor: A. Alishahi. Tilburg, 19 December 2016.
50. Karin van Nispen. What Can People with Aphasia Communicate with their Hands? A Study of Representation Techniques in Pantomime and Co-Speech Gesture. Promotor: E.J. Krahmer. Co-promotor: M. van de Sandt-Koenderman. Tilburg, 19 December 2016.
51. Adriana Baltaretu. Speaking of Landmarks. How Visual Information Inuences Reference in Spatial Domains. Promotores: A.A. Maes and E.J. Krahmer. Tilburg, 22 December 2016.

52. Mohamed Abbadi. Casanova 2, a Domain Specific Language for General Game Development. Promotores: A.A. Maes, P.H.M. Spronck, A. Cortesi. Co-promotor: G. Maggiore. Tilburg, 10 March 2017.
53. Shoshannah Tekofsky. You Are Who You Play You Are. Modelling Player Traits from Video Game Behavior. Promotores: E.O. Postma, P.H.M. Spronck. Tilburg, 19 June 2017.
54. Adel Alhuraibi. From IT-BusinessStrategic Alignment to Performance: A Moderated Mediation Model of Social Innovation, and Enterprise Governance of IT. Promotores: H.J. van den Herik, B.A. van de Walle. Co-promotor: S. Ankolekar. Tilburg, 26 September 2017.
55. Wilma Latuny. The Power of Facial Expressions. Promotores: E.O. Postma, H.J. van den Herik. Tilburg, 29 September 2017.
56. Sylvia Huwaë. Different Cultures, Different Selves? Suppression of Emotions and Reactions to Transgressions across Cultures. Promotores: E.J. Krahmer, J. Schaafsma. Tilburg, 11 October 2017.
57. Mariana Serras Pereira. A Multimodal Approach to Children's Deceptive Behavior. Promotor: M. Swerts. Co-promotor: S. Shahid. Tilburg, 10 January 2018.
58. Emmelyn Croes. Meeting Face-to-Face Online: The Effects of Video-Mediated Communication on Relationship Formation. Promotores: E.J. Krahmer, M. Antheunis. Co-promotor: A.P. Schouten. Tilburg, 28 March 2018.
59. Lieke van Maastricht. Second language prosody: Intonation and rhythm in production and perception. Promotores: E.J. Krahmer, M.G.J. Swerts. Tilburg, 9 May 2018.
60. Nanne van Noord. Learning visual representations of style. Promotores: E.O. Postma, M. Louwerse. Tilburg, 16 May 2018.
61. Ingrid Masson Carro. Handmade: On the cognitive origins of gestural representations. Promotor: E.J. Krahmer. Co-promotor: M.B. Goudbeek. Tilburg, 25 June 2018.
62. Bart Joosten. Detecting social signals with spatiotemporal Gabor filters. Promotores: E.J. Krahmer, E.O. Postma. Tilburg, 29 June 2018
63. Yan Gu. Chinese hands of time: The effects of language and culture on temporal gestures and spatio-temporal reasoning. Promotor: M.G.J. Swerts. Co-promotores: M.W. Hoetjes, R. Cozijn. Tilburg, 5 June 2018.
64. Thiago Castro Ferreira. Advances in natural language generation: Generating varied outputs from semantic inputs. Promotor: E.J. Krahmer. Co-promotor: S. Wubben. Tilburg, 19 September 2018.
65. Yu Gu. Automatic emotion recognition from Mandarin speech. Promotores: E.O. Postma, H.J. van den Herik, H.X. Lin. Tilburg, 28 November 2018.
66. Francesco Di Giacomo. Metacasanova: A high-performance meta-compiler for domain-specific languages. Promotores: P.H.M Spronck, A. Cortesi, E.O. Postma. Tilburg, 19 November 2018.

67. Ákos Kádár. Learning visually grounded and multilingual representations. Promotores: E.O. Postma. Co-promotor: A. Alishahi, G.A. Chrupala. Tilburg, 13 November 2019.
68. Phoebe Mui. The many faces of smiling: Social and cultural factors in the display and perception of smiles. Promotor: M.G.J. Swerts. Co-promotor: M.B. Goudbeek. Tilburg, 18 December 2019.
69. Véronique Verhagen. Illuminating variation: Individual differences in entrenchment of multi-word units. Promotor: A.M. Backus. Co-promotores: M.B.J. Mos, J. Schilperoord. Tilburg, 10 January 2020 (cum laude).
70. Debby Damen. Taking perspective in communication: Exploring what it takes to change perspectives. Promotor: E.J. Krahmer. Co-promotores: M.A.A. Van Amelsvoort, P.J. Van der Wijst. Tilburg, 4 November 2020.
71. Alain Hong. Women in the Lead: Gender, Leadership Emergence, and Negotiation Behavior from a Social Role Perspective. Promotor: J. Schaafsma. Co-promotor: P.J. van der Wijst. Tilburg, 3 June 2020.
72. Chrissy Cook. Everything You Never Wanted to Know about Trolls: An Interdisciplinary Exploration of the Who's, What's and Why's of Trolling in Online Games. Promotores: J. Schaafsma, M.L. Antheunis. Tilburg, 22 January 2021.
73. Nadine Braun. Affective Words and the Company They Keep: Investigating the interplay of emotion and language. Promotor: E.J. Krahmer. Co-promotor: M.B. Goudbeek. Tilburg, 29 March 2021.
74. Yueqiao Han. Chinese Tones: Can You Listen with Your Eyes? The Influence of Visual Information on Auditory Perception of Chinese Tones. Promotor: M.G.J. Swerts. Co-promotor: M.B.J. Mos, M.B. Goudbeek. Tilburg, 18 June 2021.
75. Tess van der Zanden. Language Use and Impression Formation: The Effects of Linguistic Cues in Online Dating Profiles. Promotor: E.J. Krahmer. Co-promotores: M.B.J. Mos, A.P. Schouten. Tilburg, 22 October 2021.
76. Janneke van der Loo. Mastering the Art of Academic Writing: Comparing the Effectiveness of Observational Learning and Learning by Doing. Promotor: E.J. Krahmer. Co-promotor: M.A.A. van Amelsvoort. Tilburg, 1 December 2021.
77. Charlotte Out. Does Emotion shape Language? Studies on the Influence of Affective State on Interactive Language Production. Promotor: E.J. Krahmer. Co-promotor: M.B. Goudbeek. Tilburg, 16 December 2021.
78. Jan de Wit. Robots that Gesture, and their Potential as Second Language Tutors for Children. Promotor: E.J. Krahmer. Co-promotor: P.A. Vogt. Tilburg, 28 January 2022.
79. Ruben Vromans. Communicating Personalized Risks to Patients with Cancer: A Multi-Method Approach. Promotores: E.J. Krahmer, L.V. van de Poll-Franse, S.C. Pauws. Tilburg, 8 July 2022.

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spijt van deze laatste toevoeging, haha). Ik wil je bedanken voor je onvoorwaardelijke steun en liefde. Je leert me wat leven is. Aan dit boekje komt binnenkort een eind, maar ik hoop dat we nog oneindig veel leuke hoofdstukken mogen toevoegen aan ons bijzondere liefdesverhaal. Ik hou van je!

Ruben Vromans
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About the author

ABOUT THE AUTHOR

Ruben Daniël Vromans was born on November 23, 1993 in Gilze-Rijen, the Netherlands. After graduating pre-university education at the Mgr. Frencken College in Oosterhout in 2012, he started with a Bachelor in Communication and Information Sciences at Tilburg University. After graduating his bachelor's degree in 2015 (with distinction), he did a Research Master in Linguistics and Communication Sciences at Tilburg University and Radboud University Nijmegen (joint program), with a graduation internship at the Max Planck Institute for Psycholinguistics on inhibitory control and speech production. In 2017, he completed his Research Master (cum laude) and subsequently started his PhD research at Tilburg University and the Netherlands Comprehensive Cancer Organisation (IKNL). His doctoral research focused on communicating personalized risks to patients with cancer during shared decision-making about treatment. During his PhD, he was also involved in an NWO-Corona Fast-track data project on investigating people's risk perceptions, media use, and their adherence to COVID-19 protective behavior, and in a ZonMw Topzorg project on communicating personalized outcomes to trauma patients (in collaboration with the Elisabeth Twee-Steden Hospital). Ruben is currently working as an Assistant Professor in the Department of Communication and Cognition and Tilburg University. He will further study how people think and feel about health risks and how they can best be communicated in order to help people make sense of their personalized health risks data.