Visualising Personalised and Comparative Risks in a Decision Aid for Breast Cancer Patients

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Abstract

Recent developments in PtDA research allow new PtDAs to be able to communicate personalised risks based on patients' personal prognosis data (e.g. size of tumor, sex, age). Notably, recent research has demonstrated that personalised risks could also be communicated to the patient in conjunction with generic information to allow for comparison (i.e., comparative risk information mode). However, it still remains unexplored whether the comparative risk information mode will outperform generic and personalized risk information mode in communicating risks. To provide a better understanding of the role of comparative risk information mode in communicating risks, the current research has investigated whether the comparative, generic, and personalized risk information modes differ in influencing the level of state anxiety and risk perception. Specifically, a between-subjects experiment (N = 167), having information mode as the independent variable (generic vs personalized vs comparative), and anxiety (mediator) and risk perception as the dependent variables, was conducted. In addition, the potential moderating effects of information coping style on the relationship between information mode and anxiety was explored. Results showed that information mode (in the order personalised, generic, comparative) did significantly heighten risk perception. However, there was no significant relationship between information mode and the level of state anxiety, while anxiety was found to significantly increase risk perception. Information coping style also did significantly moderate the effect of information mode on anxiety. Further implications that discuss the information modes and their appropriateness are discussed.

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Introduction

1 in 7 women in the Netherlands get diagnosed with breast cancer in their lifetime (kanker.nl, 2020). It is the most frequently occurring cancer in women. There are multiple treatment options that may be offered to women that have been diagnosed with breast cancer, which under certain circumstances are a choice between a mastectomy (breast removal) or lumpectomy (breast conservation). Outcomes of these treatments are comparable in terms of life expectancy, yet burden on quality of life and cosmetic results might greatly differ per patient (Savelberg et al., 2017). Not only the specific characteristics of the tumour, but also the personal preferences of the patient influence which treatment might fit them best.

Cancer patients do not want their treatment plan to exclusively be based on the current best practice according to standardized policy, but they want their unique contextual factors to influence the decision-making process as well (Thorne, Oliffe & Stajduhar, 2013). Including patients and their personal preferences and values in the decision-making process is done by Shared decision making (SDM). SDM, as opposed to physicians deciding on treatments for patients, is becoming increasingly prominent in health care practice (Elwyn et al., 2012).

The process of SDM can be facilitated with the use of patient decision aids (PtDA), which are tools to help inform and guide patients. The quality of breast cancer PtDAs varies greatly (Vromans et al., 2019a). Many are not evidence-based or personalised. Typically, the information provided in PtDAs is not based on the individual patient, but on the general population (e.g. Raphael et al., 2020; Green et al., 2004). Providing personalised information might be crucial however, since information that is tailored to a patient's clinical risk factors (versus generic information) has also been shown to increase realistic risk perception (Albada, Ausems, Bensing & Van Dulmen, 2009). In recent years, PtDAs have been developed that

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attempt to provide personalised treatment outcome communication (Hommes, Clouth, Verbeek & Kramer, 2019). However, these are not commonly studied or used in practice. Recent research found that cancer patients actually want both personalised and generic information (Vromans & Hommes, submitted). When both generic and personalised information are shown together, it allows the patient to compare their personalised risk to the average. This is called comparative information, and is still very understudied in breast cancer PtDA research.

Patients are likely to draw their own intuitive ‘gist’ representations when interpreting risk statistics (Reyna & Hamilton, 2001). These gist representations, or risk perceptions, may influence or be influenced by anxiety or worry, which are compelling emotions that impact people’s response to health risks (Trask et al., 2001). Comparative information could perhaps heighten risk perceptions by making the patient overly worried when they see that their risk estimates are higher than the general population (Fagerlin, Zikmund-Fisher & Ubel, 2007). However, this has only been found when targeted at the general (at risk) population to promote breast cancer screening, not at women who have already been diagnosed with breast cancer (e.g. Zajac, Klein & McCaul, 2006; Lipkus et al., 2000; Dillard et al., 2011). Information needs between people that are at risk of breast cancer and people that have been diagnosed with breast cancer could differ. Studies also suggest that metastatic patients who are truly interested in honest treatment information maintain hope, even when the information they are provided is not positive (Smith et al., 2010). The information coping style of a patient might thus moderate whether comparative information has a negative effect on anxiety.

Right now, PtDAs are almost exclusively developed with generic information. Recently the importance and desirability of personalising this information to the specific patient have become apparent, though still not often implemented. This research strives to discover what effect these different visual information modes (generic, personalised and comparative) in breast cancer PtDAs have on risk perception, whether this effect is mediated by anxiety, and if an information seeking coping style moderates the possible effect between risk information mode and anxiety, leading to the following RQs:

> *What are the effects of different visual information modes in a breast cancer decision aid on risk perception (RQ1)? Are these effects mediated by anxiety (RQ2)? And, does information coping style moderate the possible effect of personalized visual risks on anxiety (RQ3)?*

Theoretical Framework

In the following section some relevant theoretical background will be discussed. Firstly, a short introduction to the process of shared decision making (SDM) between the patient and health care provider, which is supported by the use of patient decision aids (PtDAs). After that, it will be explained how PtDAs can be used to help communicate potential risks of treatments to patients. It will be argued why including visual risk communication in PtDA is preferable, and that there are different information modes PtDAs can employ to communicate these risks. It will be explained how the way risks are presented in PtDA could influence a patient's risk perception, what exactly is meant by 'risk perception', and how risk perception relates to anxiety.

Shared Decision Making (SDM)

Death from breast cancer has been steadily decreasing, thanks to early diagnosis and new treatments and strategies (Carioli et al., 2017). One such strategy is for treatments to be tailored to the patient. However, personalised treatments require not only multidisciplinary scientific and technical coordination, but also the participation of the patient themselves (Levit, Nass & Ganz,

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2013). Since there are multiple clinically valid treatment options available to breast cancer patients, a decision must be made. People widely vary in their values and what matters most to them in the case of trade-offs. The suitability of the treatment options is not only dependent on their specific illness characteristics, but also on their unique preferences and circumstances (Vries, Jansen, Weert & Holland, 2019). Of course, the patient is not the only one deciding which treatment would be the best fit based on the patients' specific preferences as they work together with their doctor and other health care providers. This process of health care providers and patients sharing the decision-making process is aptly named Shared Decision Making (SDM), and becoming increasingly prominent in health care practice (Elwyn et al., 2012). It's become a cornerstone of high-quality cancer care. Elwyn et al. (2012) proposed a theoretical three step model to provide guidance in facilitating the SDM process: 1) the introduction of choice, 2) describing the patients' options, (often done by using patient decision support), and 3) helping patients explore preferences and make decisions.

By participating in decisions pertaining to their own health and well-being, SDM can make patients feel heard and empowered (Barry & Edgman-Levitan, 2012). Patients who are offered different treatment options also report less feelings of anxiety and depression (Fallowfield et al., 1994). Implementing and achieving SDM in clinical practice has been challenging though (Vries et al., 2019).

Patient Decisions Aids (PtDA)

One tool to help facilitate the SDM process are Patient Decision Aids (PtDA). PtDAs are interventions that "support patients by making their decisions explicit, providing evidence-based information about options and associated benefits/harms, and helping clarify congruence between decisions and personal values" (Stacey et al., 2017, p. 1). PtDAs are said to improve decision quality and reduce the patients' exposure to options that are not in line with their preferences or values. This makes them appropriate tools to use when considering preference-sensitive treatment options (O'Connor, Llewellyn-Thomas & Flood, 2004). They can be used before, during or after a visit with a health care provider. PtDAs can both support SDM and, without input from a health care provider, inform choice (Vries et al., 2019). An intervention review by Stacey et al. (2017) found no adverse effects of PtDAs on health outcomes or patient satisfaction. PtDAs decreased decisional conflict related to feeling uninformed, indecision about personal values, and the proportion of people who were passive in decision making. Also, they found that PtDAs reduced patients choosing major invasive surgery and instead choose more conservative options. PtDAs could thus be very helpful in the breast cancer domain, since life expectancy between mastectomy (breast removal) or lumpectomy (breast conservation) is very comparable (Savelberg et al., 2017).

Though PtDAs can be very helpful, they require meticulous development before they can be employed. Developing a PtDA is a long and arduous process which requires input from many different disciplines as well as patients (Coulter et al., 2013). PtDAs influence their users and their design should thus be carefully considered to ensure reliability (Savelberg et al., 2017). If a patient were to come across a poorly designed PtDA, it could cause them harm. When a PtDA is not considered valid by a clinician they are also unlikely to use it in their practice (Coulter et al., 2013).

Risk Communication

PtDAs can be a great tool to let patients explore and compare treatment outcomes. PtDAs should, where available, communicate quantified risk outcomes of treatments that have been garnered through research (Trevana et al., 2013). For a patient to make an informed decision, they should be made aware of relevant risks. For example, one common side effect of breast cancer treatment is fatigue, but there is considerable variability between survivors in terms of its severity and longevity (Bower et al., 2018).

However, communicating this information to the patient is quite complex. Treatment outcomes are always uncertain. In practice, often these uncertainties are not (sufficiently) communicated to the patient and thus not understood by them (Politi, Han & Col, 2007). Not only that, even when communicated correctly, uncertainty is simply difficult to comprehend and requires recognition of probability and how probability estimates work (Engelhardt et al., 2017). Health care providers might worry that bringing up these uncertainties might overly complicate matters since almost everyone, even the highly educated, do not easily understand probabilistic information (Gigerenzer, Gaissmaier, Kurz-Milcke, Schwartz & Woloshin, 2007).

According to Trevana et al. (2013) to truly be able to make an informed decision it is important for patients to understand that uncertainty is dependent on the ‘randomness’ of future events, as well as that uncertain information has limitations of reliability or adequacy. Han et al. (2011) claim that patients should be aware of the limitations of the information available to be able to make an informed decision. After all, many patients are looking for complete and truthful disclosure of statistical information after a cancer diagnosis (Fletcher et al., 2017). Still, optimal methods of communicating risks to patients, which information in what format, are still not fully understood (Trevana et al., 2013).

Personalised risk communication in PtDAs

A systematic review by Vromans et al. (2019a) on the quality and communicative aspects of PtDAs for early-stage breast cancer patients found that one communicative aspect that PtDAs often do not implement is personalised information. Typically, the information provided in

PtDAs is not based on the individual patient, but on the general population. It's hard for patients to apply statistics that are just based on the general population to their own situation.

It is unfortunate that PtDAs are often not personalised to the individual patient, since it is now more than ever a possibility to develop personalised PtDAs. In the current E-Health era, PtDAs are often being developed online (versus previously being paper-based), which allows PtDAs to be tailored to a patient's individual needs. Using data science and artificial intelligence on data sets of previous cancer patients can determine personalised statistical information for patients (Vromans et al., 2019b). Connecting these data sets to PtDAs would allow for PtDAs to be personalised to the individual patient. Not only do patients themselves prefer personalised information (Vromans & Hommes, submitted), there is another argument to implement these data sets into PtDAs: it would keep the information in the PtDA up to date. Cancer statistics are difficult to maintain, since there is an overwhelming amount of research being done on cancer. Breast cancer research is very saturated (Waks & Winer, 2019). Connecting breast cancer data sets to PtDAs would keep them (and their personalised information) up to date.

Combining data of the patients' personal prognosis data (e.g. size of tumor, sex, age) with, for example, a 'quality of life outcomes after treatment'-data set, would allow a PtDA to provide patients with very specific personalised information. This data could for instance be used to estimate personalised risk and outcomes or treatment consequences (Vries et al., 2019).

Comparative risk communication in PtDAs

Research by Vromans and Hommes (submitted) into statistical information needs (SIN) of cancer patients found that between generic and personalised statistics, patients consistently showed higher preference for personalised information. However, most indicated that they wanted to be shown *both* generic and personalised statistics in. One participant said: *"General*

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statistics help to put things in perspective. For example, if my personal risk of recurrence is 30%, and the general risk is 10%, I have an increased risk of 20%." (p. 13). After all, patients are looking for complete and truthful disclosure of statistical information after a cancer diagnosis (Fletcher et al., 2017). When personal and generic information is presented together, they can be compared to each other. This is called comparative information. *Generic* risk information might be 'On average, 10 out of 100 patients experience fatigue after a mastectomy', *personalised* risk information might be 'On average, 20 of 100 patients like you experience fatigue after a mastectomy' and *comparative* information show both of these statements side by side. 'How am I doing relative to other women with breast cancer?' is a question that could be answered by comparative risk information. Comparative information can be used to help patients contextualize their own risks (Han et al., 2009). A legitimate purpose for risk comparisons is giving recipients a feeling for just how large a risk is by comparing it with another.

Risk perception in PtDAs

Risk perception is an important variable to evaluate whether treatment outcome risks have been correctly communicated. Though the effect PtDAs have on risk perception of treatments is often tested (e.g. Zikmund-Fisher et al., 2008), there does not seem to be a clear consensus on what exactly is meant by risk perception. It is also not always clear what kind of risk perception is desirable to induce in patients viewing your PtDA. Sometimes studies view heightened risk perception as a positive, since women are more likely to go to breast cancer screenings if they are sufficiently worried (Yavan, Akyüz, Tosun & İyigÜn, 2010). However, this is the case for at risk women, not diagnosed women (e.g. Zajac, Klein & McCaul, 2006; Green et al., 2004; Dillard et al., 2011).

In this study, risk perceptions are estimations made by the patient about their risk of suffering certain treatment outcomes. Patients often intuitively translate risk statistics into 'gist' representations, which can impact them emotionally by for example making them worried or anxious (Zikmund-Fisher, Dickson & Witteman, 2011). A PtDA is successful when the patient gains accurate insight into their risks. It is unwanted for a PtDA to induce overly low (for some reason the patient thinks their risk is lower than it actually is) or high (for some reason the patient feels their risk is higher than it actually is) risk perceptions of treatment outcomes.

Perceiving risk and anxiety

Risk perception is often associated and hypothesised to be influenced by anxiety. According to recent theories in cognitive psychology research human beings comprehend risk in two different ways. The first is by using their 'analytic system', which includes algorithms and rules like formal logic, risk assessment and probability theory. This risk comprehension is thoughtful, effortful and takes time. The second way is by using their 'experiential system', which in many ways is the opposite. This system is quick, intuitive and people are not consciously aware of it. The experiential system links things that might be perceived as risky to emotion and affect by comparing it to previous experience. This system feels instinctive in many ways (Slovic, Peters, Finucane & MacGregor, 2005).

One such emotional response is anxiety. Anxiety braces people for threats, it engages physiological systems to prepare for a response, and recruits cognitive resources to process information pertaining to a supposed threat (Notebaert et al., 2016). Increasingly the value in these emotional responses when talking of the perception of risk has become clear. It is now recognized that this experiential system and analytic system are both active simultaneously, and that affect is actually essential to rational action. The employment of analytic thinking is guided by affect. To be able to make rational decisions, both systems are required (Slovic et al., 2005).

Best Practice: Multi-modal Risk Communication

Though there might not yet be a total consensus on what exactly is best practice in terms of risk communication in PtDAs, the PtDA checklist ‘International Patient Decision Aids Standards’ (IPDAS) does provide some guidance. According to the IPDAS communicating risk should be done using multiple methods (e.g. text, numbers, visuals).

Research has shown that visuals help people better understand and remember information. This is because graphical displays can prime automatic mathematical operations (Simkin & Hastie, 1987). For example, comparing the height of two bars might be easier and more intuitive for many people than subtraction. Graphs can summarize data and reveal patterns that people might otherwise not notice (e.g. a regression line in a scatter plot). Also, unlike presenting information in just numbers, graphs are actually better able to hold people’s attention because the display of information is concrete and visual (Lipkus, 2007).

Risk communication literature indicates that explaining risk information statistics in a multimodal way, using both non-technical language and combining this with visualizations (e.g., icon arrays, bar charts, or line graphs), is best (Garcia-Retamero & Cokely, 2017). Most current decision aids use numeric estimates such as percentages or natural frequencies, but fail to also provide patients with additional visual aids such as graphs (Vromans et al, 2019a). People with low numeracy, which affects many people, often do not correctly interpret such statistics (Buchter et al., 2014). Low numeracy is a great hindrance when presented with risk statistics while trying to weigh risk and benefits of different treatments. Without being able to effectively communicate this to them, patients cannot be truly autonomous and conscious in their decision to choose one treatment over another (Fagerlin et al., 2007; Hawley et al., 2008). According to Hakone et al. (2016) though, visualizing data can also be effective to communicate complex risk

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information to patients with low numeracy and visual literacy. Combining numbers with visual aids can help facilitate patients' grip on the information, and lead to better information recall as well (Mayer, 2005).

A certain level of graph literacy seems to be needed in order for people to be able to make meaningful interpretations and associations of the patterns that graphs depict (Garcia-Retamero & Cokely, 2017). However, as long as there are enough visual aids (e.g. simple labels and explanations to help convey meaning) provided, even people with low numeracy or graph literacy can benefit from visual risk communication (Okan et al., 2015).

Certain visualizations are more effective at representing risk communication than others though. Icon arrays and bar charts have for instance been found to be more effective than others (Hawley et al., 2008). It is also good to consistently use the same clear denominator and natural frequencies or percentages (Elwyn et al., 2009; Trevana et al., 2013).

Research model and hypotheses

Information mode and risk perception

Providing personalised information in PtDAs might be crucial and greatly improve its helpfulness, since information that is tailored to patients in a PtDA creates more realistic expectations of possible benefits and risks (O'Connor et al., 1998). It is expected that personalised statistics are more relevant to the patient and will thus be processed better by them than generic, population only, information (Vromans et al., 2019b). Information that is tailored to a patient's clinical risk factors (versus generic information) has also been shown to induce realistic risk perception (Albada, Ausems, Bensing & Van Dulmen, 2009). According to Vromans et al. (2020) tailored (personalised) risks are perceived as more personally relevant.

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Thus, it is argued that, when both information modes would show the same risk percentage, personalised risk information would induce lower risk perception than generic information. After all, a goal of a decision aid aimed at patients versus at risk population is to not induce overly high risk perceptions.

Compared to generic and personalised information, comparative information in PtDA for breast cancer patients is still very much unexplored. It has especially not been directly compared to the use of generic and personalised information in PtDAs. It is said that comparative information can be used to help patients contextualize their own risks (Han et al., 2009). Risk comparisons can also give recipients a feeling for just how large a risk is by comparing it with another. However, comparative risk information could have negative consequences. When providing patients with comparative risk information, it could bias their reactions and risk perceptions. Fagerlin, Zikmund-Fisher and Ubel (2007) found that presenting women with comparative risk information about breast cancer changed their risk perception: someone might feel compelled to choose a certain treatment because they've seen that their risk is above average and get overly worried, not thoroughly thinking through which treatment might actually fit their preferences best. However, this research like most others in this domain is targeted at the general (at risk) population to promote breast cancer screening, not at women who have already been diagnosed with breast cancer (e.g. Zajac, Klein & McCaul, 2006; Lipkus et al., 2000; Dillard et al., 2011). Research showed that people who have been diagnosed are truly interested in honest treatment information and maintain hope, even when the information they are provided is not positive (Smith et al., 2010). Still, comparative information might be upsetting when you are doing worse than other women with breast cancer. However, it has also been found that patients want all the information available, even when this information is distressing (Kehl et al., 2015).

There is no previous research to truly indicate how comparative information will perform compared to just generic or just personalised information. However, it is expected that when the personalised information is higher risk than the generic information in a comparative scenario, this might induce the highest risk perceptions. For though one's 'true' risk would be the same as in an 'only personalised'-information mode, in a comparative scenario this could be compared to a lower generic risk. As such, this leads to the following hypothesis:

> *H1: Information mode will influence risk perception in such a way that comparative (generic + personalised) visualisations induce the greatest risk perception levels followed by generic and finally personalised, which induces the lowest risk perception levels.*

Information mode and anxiety

Though one might expect that personalising risk information communicated to patients could lead to heightened worry or anxiety by making risks seem more concrete, recent meta-analysis by Edward et al. (2013) exploring this effect actually found that four out of six studies they looked into reported no significant changes in anxiety following personalised risk communication to the participants. Though insignificant, they actually found that anxiety decreased in the intervention groups. However, when generic information is shown in addition to personalised information and allows people to compare themselves to the average, it seems anxiety could become a bothersome factor. A focus study by Smit et al. (2015) explored what people's response would be to receiving hypothetical personalised risk information about skin cancer (melanoma). They presented the personalised information together with generic information, thus asking participants about comparative risk. Many participants indicated that they believed their response to the personalised information would depend on how it compared to the average generic information. As one participant put it: '… even just above the average is probably enough to frighten most people' (p. 312). Others mentioned that seeing these results might cause anxiety or depression. Of course, the group that has the highest risk of certain unpleasant outcomes is also most at risk of higher induced anxiety. Vromans and Hommes (submitted) mention that more effect studies should help identify whether presenting personalised information as higher risk (e.g. "7 out of 10 people like you experiences nausea") in conjunction with lower risk generic, population-based information ("e.g. 4 out of 10 people experience nausea") would have a negative impact on anxiety in patients. Once again, the article by Fagerlin, Zikmund-Fisher and Ubel (2007) indicates a negative effect of comparative information, in this case on anxiety. They found that that presenting women with comparative risk information about breast cancer changed their risk perception: claiming that because they have seen that their risk is above average, they will get overly worried. However, this research did not look into actual patients, but approached random women in a hospital cafeteria. They did not ask that they imagine themselves to be patients, but presented them with their own (hypothetical) risk of getting cancer. They also did not actually measure the participants' anxiety or worry; this conclusion was deduced by the authors due to the change in participants' risk perception. Still, it's quite plausible that providing patients with comparative information (especially when the patient is at higher risk than the generic, population-based information) will induce higher anxiety than when generic information is left out. This leads to the following hypothesis:

> *H2: Information mode will influence state anxiety in such a way that a comparative (generic + personalised) visualisations induce the greatest state anxiety levels followed by generic and finally personalised, which induces the lowest state anxiety levels.*

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Anxiety and risk perception

As previously mentioned, research often totes anxiety and worry as an indicator for higher risk perceptions (e.g. Fagerlin, Zikmund-Fisher and Ubel, 2007). Risk perceptions may influence or be influenced by anxiety or worry, which are compelling emotions that impact people’s response to health risks (Trask et al., 2001). According to Slovic et al. (2005), people’s risk estimates are highly influenced by their feelings: if someone’s feelings towards an action are positive, they are more likely to judge its risks as low, whereas if someone’s feelings are not positive, they tend to judge risks as high. They say that affective responses may actually mediate risk perceptions. Of course, it is not unreasonable for someone to be anxious when exploring a decision aid which informs them of their risks of treatment outcomes. Cancer is already a highly dreaded disease, as such affect towards certain (negative) treatment outcomes (e.g. pain, fatigue) might have noticeable effect on risk perceptions.

H3: Level of state anxiety will be positively associated with the level of risk perception.

Moderating effect of information coping style

Whether it is beneficial to communicate comparative risks might be contested (Fagerlin, Zikmund-Fisher & Ubel, 2007). Perhaps the negative affect comparative risk might have on risk perception by causing them anxiety would be mediated by patients’ information coping styles. Patients fare better when information is tailored to their own coping styles. There are two coping styles: monitoring (information seeking) and blunting (information avoidant). People that have a monitoring coping style are alert to negative or painful information and events. People that have a blunting coping style try to avoid this type of information. Cancer patients that have a more monitoring blunting style tend to do better when they are given more information, whereas patients that have a blunting coping style tend to do better with less information (Miller, 1995).

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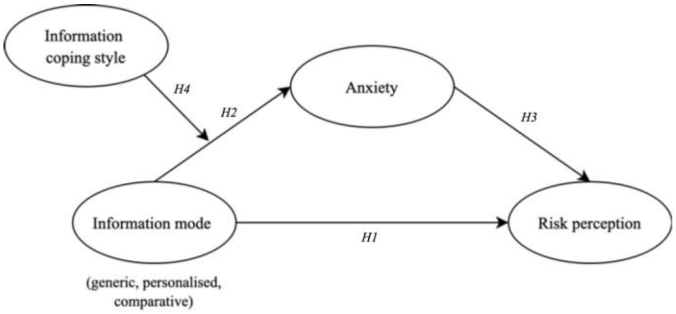
Research also showed that patients who are truly interested in honest treatment information maintain hope, even when the information they are provided is not positive (Smith et al., 2010). Vromans and Hommes et al. (submitted) found that patients with a monitoring coping style expressed a need for both personalised and generic statistical information. Patients with a monitoring coping style would thus probably prefer comparative information, showing both personalised and generic information. As such, there might be a moderating effect of a patient's information coping style on anxiety. This leads to the following hypothesis:

> *H4: Information coping style will moderate the effect of risk information mode on state anxiety.*

The research model visualising the proposed hypotheses is presented in Figure 1.

Figure 1

Research Model



Method

Design and participants

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A between-subjects experiment, where the information mode was the independent variable (generic vs personal vs comparative), was conducted to test the hypotheses proposed in this research. The generic condition functions as a control condition. In total, 181 participants were recruited for this study. Each participant was randomly assigned to one of the three conditions. However, after careful consideration of the responses some participants were deleted from the data set since they were not credible (e.g. people that spent 2 to 5 minutes, an unreasonably short time, to finish the experiment). That left 167 participant's responses. 48 participants were assigned to the generic condition, 60 to the personalised condition and 59 to the comparative condition.

The only prerequisites to take part in the study were for the participant to be female and over 18 years old. Not only does breast cancer overwhelmingly occur in women over men, cosmetic consequences (and thus choosing between a mastectomy or lumpectomy) are different for women than for men (women might be more inclined to try and preserve as much of their breasts as possible). The prototype that would be presented to the participants would also have a female-centric approach (e.g. the hypothetical patient was female). Thus, to ensure efficacy only women were approached to take part in the study.

Participants were gathered via a network sampling method. The participants were contacted via Facebook, Whatsapp, LinkedIn, email and word of mouth. By distributing via social media, it has not become a random sample. According to Casler, Bickel and Hackett (2013) distributing a questionnaire and recruiting participants via social media is a good option, since it leads to a diverse group of respondents. It is like a select convenience sample, however not representative of the entire population. This method was chosen since it is cost-effective (Battaglia, 2008).

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Sample characteristics

As previously stated, all participants were female. The overall sample of participants was quite young and highly educated. An overview of all characteristics of the participants is given in Table 1.

Table 1

Sample Characteristics

Characteristic		N	Percentage (%)
Gender			
	Female	167	100%
Age[a]			
	18-24 years old	78	46.7%
	25-34 years old	49	29.3%
	35-44 years old	14	8.4%
	45-54 years old	14	8.4%
	55-64 years old	9	5.1%
	65+ years old	3	1.8%
Education[b]			
	High school	11	6.6%
	Bachelor	57	34.1%
	Master	89	53.3%
	PhD	8	4.8%
	Other	2	1.2%
Diagnosed[c]			
	Yes	6	3.6%
	No	161	96.4%
Diagnosed loved one[d]			

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Yes	74	44.3%
No	92	55.1%
Rather not say	1	.6%

Note.

[a]Age at time of the experiment.

[b]Highest level of education or currently enrolled in level of education.

[c]Participant had previously been diagnosed with breast cancer.

[d]Participant had a loved one be diagnosed with breast cancer.

Materials

Stimuli

A prototype of a web-based PtDA was developed in collaboration with another master thesis student (Clara Coelho) for this study, providing information on quality of life data regarding breast cancer treatments (breast conserving surgery and breast removal surgery) to help patients make informed decisions during the SDM process. This data was personalised to a hypothetical patient in the *personalised* and *comparative* conditions. The prototype was developed in Adobe XD, a prototyping tool that can be used to make interactive and modern websites and apps (www.adobe.com/nl/products/xd.html). Adobe XD also allows for collaboration[1] in one file. The questionnaire was developed using the online questionnaire tool Qualtrics (www.qualtrics.com/). Both the prototype and questionnaire were developed in English.

Data Types. The personalised quality of life data used in this prototype was a fictitious hypothetical scenario, however the input data is based on two different data sets. The first is the

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[1] The prototype was developed in collaboration with Clara Coelho, who looked into the effect of interactive elements in a PtDA. As such, half of the participants viewed a prototype with interactive elements and half without. The interactivity allowed these participants to click on the pictographs to inspect more extensive information. Since participants would thus see a prototype with one of two different levels of interactivity. Interactivity was also controlled for in the analysis.

‘Patient Reported Outcomes Following Initial treatment and Long-term Evaluation of Survivorship’ (PROFILES) registry data set (Van de Poll-Franse et al., 2011). This dataset consists of reports from over 21.000 Dutch cancer patients who reported on post-treatment health-related quality of life (QoL) consequences. This data includes measures of fatigue, nausea/vomiting, pain, dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial impact. All these measures could provide valuable insight into different risks that pertain to certain treatments (e.g. women who choose breast conserving surgery might or might not report higher pain after treatment than women who had breast removing surgery). Often research into risk perception in the breast cancer domain refers to recurrence risks or risks of death (e.g. Brewer et al., 2009), whereas quality of life outcomes and risks (such as pain) occur with varying degrees in almost every person that undergoes any breast cancer treatment. As such, quality of life outcomes were chosen to be visualized in this prototype. To ensure the prototype did not become overly complex three quality of life outcomes were chosen: ‘Fatigue’, ‘Pain’ and ‘Physical functioning’ (renamed to ‘Difficulty with moving’ in the prototype for ease of comprehensibility).

The second mock-up data the prototype uses is the data which allows for *personalised* risk communication and includes the patient’s individual prognosis data such as gender, age, tumor stage, tumor size, comorbidities, examined lymph nodes etc. This information would be provided and entered into the PtDA by the patient’s health care provider. In the case of this study, a hypothetical patient with hypothetical prognosis data was used.

The Prototype. The PtDA prototype was designed to look like a website/app, to function like a clickable brochure aimed at helping patients make a choice between breast conserving and breast removal surgery. The PtDA was a dashboard (see Figure 2) where QoL data was presented

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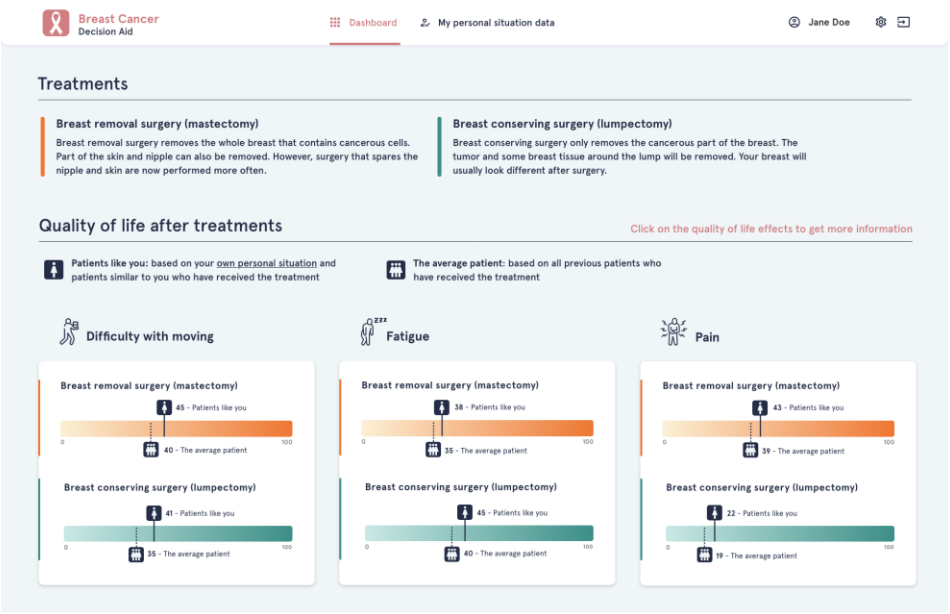
to the user in graphs. The PtDA is presented as having the ability to estimate how likely it is that a new patient will experience certain effects of the treatments, such as difficulty with moving, fatigue and pain. This estimation is supposedly based on previous patients with breast cancer (PROFILES data set). For the personalised and comparative conditions, the patient's personal situation (e.g. age, gender, size of the cancer, comorbidities) also influence the data which is presented to the user (e.g. because of someone’s age their risk of pain might be higher). The PtDA showed this data in graphs and text.

Figure 2

Prototype Dashboard (Comparative Condition)



Breast removal surgery (mastectomy)
Breast removal surgery removes the whole breast that contains cancerous cells. Part of the skin and nipple can also be removed. However, surgery that spares the nipple and skin are now performed more often.

Breast conserving surgery (lumpectomy)
Breast conserving surgery only removes the cancerous part of the breast. The tumor and some breast tissue around the lump will be removed. Your breast will usually look different after surgery.

Patients like you: based on your own personal situation and patients similar to you who have received the treatment

The average patient: based on all previous patients who have received the treatment

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Clicking on a graph in the dashboard would take the user to another page where the information in the graph is more extensively shown (see Figure 3). Text accompanying the graphs in these pages was inspired by Hommes et al.'s (2019) data-to-text cancer support tool, which also depicted personalised QoL data. For the generic condition these would be 'Out of 100 patients around 35 experience fatigue after breast removal surgery (mastectomy)', for personalised 'Out of 100 patients like you around 35 experience fatigue after breast removal surgery (mastectomy)'. In the comparative condition the two are shown side by side. This wording ('around') demonstrates the uncertainty of the data (Han et al., 2011). Guidelines by Garcia-Retamero and Cokely (2017) were used to choose the type of graphs to represent the data. The type of graph was chosen for the type of data and to ensure comprehensibility and transparency. 'Difficulty with moving', 'Pain' and 'Fatigue' were singular data comparing the efficacy of two medical treatments, thus best represented in a bar graph (Garcia-Retamero & Cokely, 2017). The styling of the singular bar graph that includes comparative information was borrowed from a similar study on visually presenting comparative cancer risks (Han et al., 2010).

Figure 3

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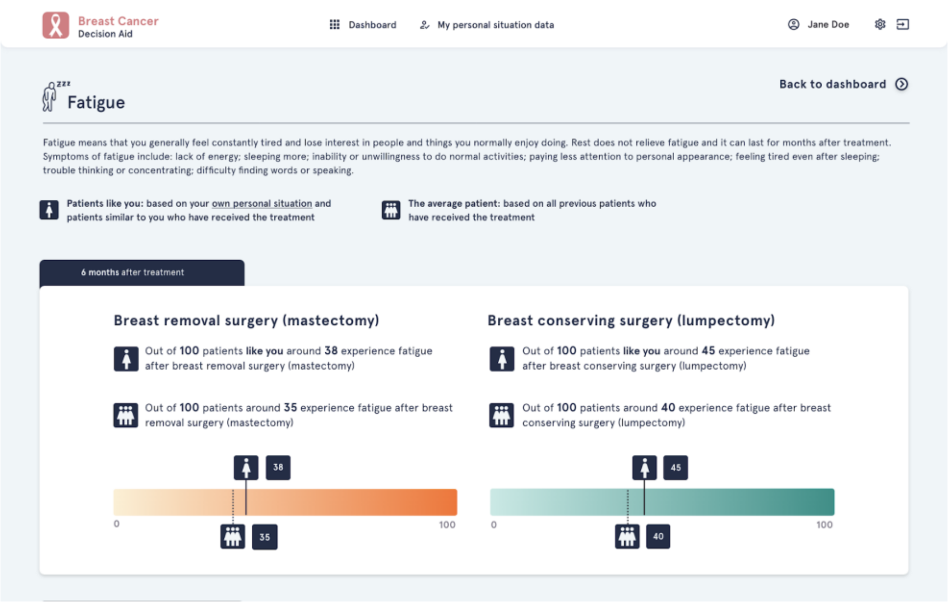
Screen when you've clicked on one of the Treatment Outcomes (Comparative Condition)



Fatigue means that you generally feel constantly tired and lose interest in people and things you normally enjoy doing. Rest does not relieve fatigue and it can last for months after treatment. Symptoms of fatigue include: lack of energy; sleeping more; inability or unwillingness to do normal activities; paying less attention to personal appearance; feeling tired even after sleeping; trouble thinking or concentrating; difficulty finding words or speaking.

Patients like you: based on your own personal situation and patients similar to you who have received the treatment

The average patient: based on all previous patients who have received the treatment

Breast removal surgery (mastectomy)

Out of **100** patients **like you** around **38** experience fatigue after breast removal surgery (mastectomy)

Out of **100** patients around **35** experience fatigue after breast removal surgery (mastectomy)

Breast conserving surgery (lumpectomy)

Out of **100** patients **like you** around **45** experience fatigue after breast conserving surgery (lumpectomy)

Out of **100** patients around **40** experience fatigue after breast conserving surgery (lumpectomy)

The graphs in the prototype present the participant with either generic (see Figure 4), personalised (see Figure 5) or comparative (see Figure 6) information. Comparative information is both generic and personalised displayed in one graph. The data was presented in the PtDA with natural frequencies (45 out of 100 patients), to make it easily interpretable (Trevana et al., 2013).

The data depicted in the different conditions was the same, except for in the comparative condition where the 'generic' information was a bit lower than the personalised information (see Figure 6). This was done since it was previously hypothesized that the comparative condition would induce higher anxiety and risk perception, and a situation where 'you' are doing worse than the generic average might induce these feelings and perceptions.

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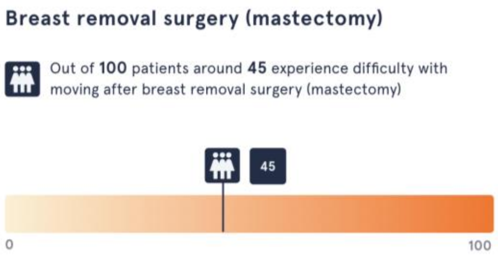
Figure 4

‘Difficulty with Moving’ in the Generic Condition

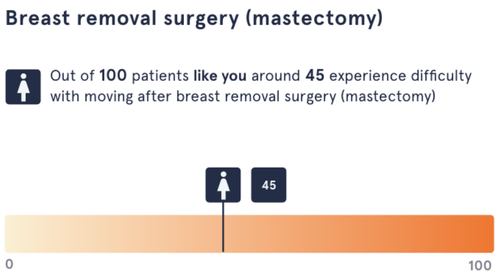


Breast removal surgery (mastectomy)

Out of **100** patients around **45** experience difficulty with moving after breast removal surgery (mastectomy)

Figure 5

‘Difficulty with Moving’ in the Personalised Condition

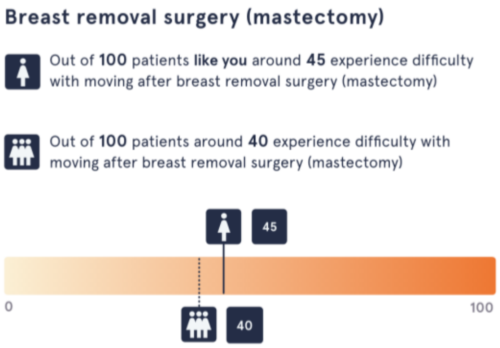


Breast removal surgery (mastectomy)

Out of **100** patients **like you** around **45** experience difficulty with moving after breast removal surgery (mastectomy)

Figure 6

‘Difficulty with Moving’ in the Comparative Condition



Breast removal surgery (mastectomy)

Out of **100** patients **like you** around **45** experience difficulty with moving after breast removal surgery (mastectomy)

Out of **100** patients around **40** experience difficulty with moving after breast removal surgery (mastectomy)

In the risk visualizations (see Figures 3, 4 and 5) there are two different icons, one for personalised information and one for generic information. The two were plainly explained to the participant as ‘**Patients like you:** based on your own personal situation and patients similar to you who have received the treatment’ for the personalised information, and ‘**The average patient:** based on all previous patients who have received the treatment’ (see Figure 7). The participant was able to click the ‘own personal situation’ to go to the ‘My personal situation page (see Figure 8). This page was also always reachable in the menu on top of the page. Here, the participant was able to see the fictitious patient that the supposed personalised information was based on.

Figure 7

Icons Explaining the Personalised and Generic Information (here both in the comparative

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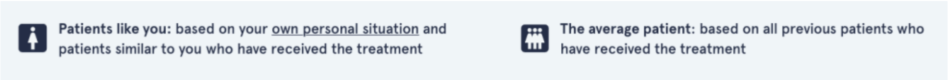
condition)

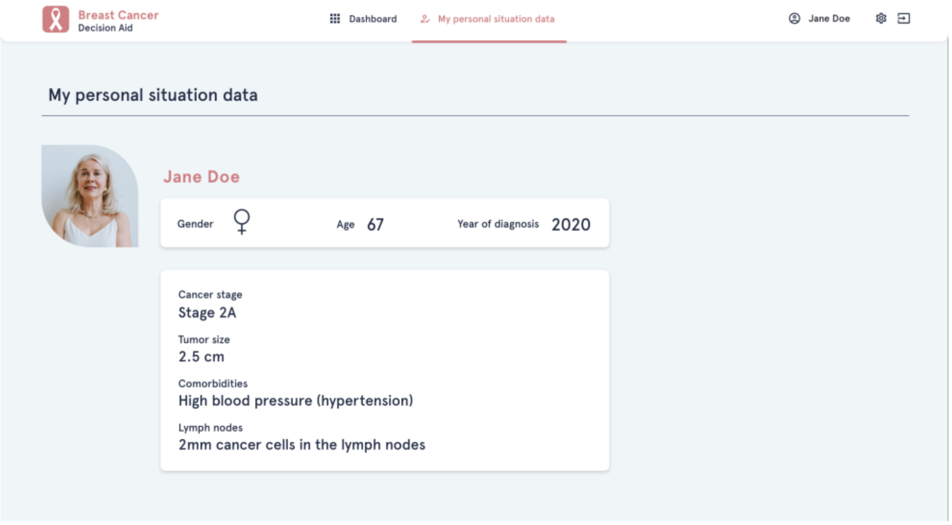


Patients like you: based on your own personal situation and patients similar to you who have received the treatment

The average patient: based on all previous patients who have received the treatment

Figure 8

'My Personal Situation'-Page (only in personalised and comparative conditions)



My personal situation data

Jane Doe

Gender ♀

Age 67

Year of diagnosis 2020

Cancer stage
Stage 2A

Tumor size
2.5 cm

Comorbidities
High blood pressure (hypertension)

Lymph nodes
2mm cancer cells in the lymph nodes

Measures

Anxiety. The State-Trait Anxiety Inventory (STAI) was used to measure anxiety (Marteau & Bekker, 1992). The STAI is the most often used measurement tool when measuring anxiety in response to decision aids (Green et al., 2004; Osaka & Nakayama, 2017). It has also previously been directly post-experiment in decision aid research (Bekker, Hewison & Thornton, 2004).

The STAI State scale assesses how people feel at a particular moment in time. A shortened 6-item (e.g. ‘I am worried’, ‘I am tense’) form was used to measure State anxiety (Marteau & Bekker, 1992). Statements were rated on a 4-item scale (1 = Not at all, 4 = Very much so). The State scale score is composited to one State anxiety score.

Risk Perception. Risk perception is measured quite differently across the board and often measures one’s risk perception of getting a disease rather than treatment consequences. The way risk perception is measured is also dependent on the content of the risks. Thus, there is no one tried and true method to measure risk perception. As such, risk perception in this study as a measurement was adapted from items in similar studies. Items were adapted from Lee, Shin, Kawaja and Ho (2016) and Zikmund-Fisher et al. (2008). Participants responded to each question on a 5-point Likert scale. Since there were multiple treatments and multiple QoL outcomes, to ensure validity all items referred to only one treatment (mastectomy) and one QoL outcome (Pain). The four items were ‘If you were to choose to have a breast removal operation (mastectomy), how likely do you think you would be to experience pain[2]?’ (1 = Not at all likely, 2 = A little likely, 3 = Moderately likely, 4 = Quite likely, 5 = Extremely likely), ‘If you were to choose to have a breast removal operation (mastectomy), how likely do you think you would be to experience pain, as compared to the average person who had this operation?’ (1 = Not at all likely, 2 = A little likely, 3 = Moderately likely, 4 = Quite likely, 5 = Extremely likely), ‘Taken all together, how worried would you be about experiencing pain if you had a breast removal operation (mastectomy)?’ (1 = Not at all worried, 2 = A little worried, 3 = Moderately worried, 4 = Quite worried, 5 = Extremely worried), ‘Taken all together, how common do you think

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[2] In the questionnaire these four Risk Perception items also included ‘6 months after treatment’ (e.g. “how likely do you think you would be to experience pain 6 months after treatment?”) since the prototype included 3 timelines which were in place for Clara Coelho’s research.

experiencing pain is for people who have had a breast removal operation (mastectomy)?' (1 = Not at all common, 2 = A little common, 3 = Moderately common, 4 = Quite common, 5 = Extremely common). Risk perception is the mean of these four items.

Information Coping Style. Information coping style was measured with the shortened Threatening Medical Situations Inventory (TMSI). This shortened scale has been validated in the cancer domain (Ong et al., 1999). Monitoring versus blunting style scales have been extensively used in cancer research, looking into the way patients cope with their health situation and either seek or avoid potentially anxiety-inducing information about cancer (Miller, 1995). The TMSI presents the participant with two health-related hypothetical situations such as 'vague suspicious headache complaints' and 'choosing for uncertain heart surgery'. These situations are followed up with three monitoring (e.g. ''I plan to ask the specialist as many questions as possible") and three blunting statements (e.g. "For the time being I try not to think about unpleasant outcomes"). The participant indicates how applicable the statements would be for them in the hypothetical situation on a 5-point Likert scale (1 = 'not at all applicable to me', 5 = 'strongly applicable to me'). Blunting and monitoring scores are calculated by averaging all relevant items.

Control variables. Some control variables[3] were checked to see if they influence the study design as well. Graph literacy was checked for using the Subjective Graph Literacy Scale (Garcia-Retamero, Cokely, Ghazal & Joeris, 2016). Another control variable was previous knowledge and familiarity with breast cancer, measured by questions 'Have you ever been diagnosed with breast cancer?' ([0] = has no loved ones that have been diagnosed with breast cancer; [1] = has loved ones that have been diagnosed with breast cancer) and 'Have any of your

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[3] As mentioned, 'Interactivity' from Clara Coelho's study was also checked for as a control variable.

loved ones ever been diagnosed with breast cancer?' ([0] = participant has not been diagnosed with breast cancer; [1] = participant has been diagnosed with breast cancer).

Reliability of scales. In order to ensure the validity of our measures, their internal consistency reliability (Cronbach's Alpha) was assessed. The Anxiety (STAI) scale had a Cronbach's Alpha of 0.838, the Perceived risk (PRISK) scale had a Cronbach's Alpha of 0.767, the Graph Literacy (GL) scale had a Cronbach's Alpha of 0.905, the Monitoring Information Coping Style (ICS-M) scale (minus ICS3) had a Cronbach's Alpha of 0.719, all which indicated high internal consistency reliability.

Procedure

Participants were asked to open the questionnaire on a laptop or desktop to ensure consistency and because the prototype was designed to work as a desktop website. The questionnaire opened with an introduction to the research. Since participants might not have any experience with breast cancer, decision aids or possible treatments and their treatment outcomes, a short explanation was given about these topics and how one might feel about these as a breast cancer patient. It was then explained that they would be exploring and evaluating a decision aid app. Participants were asked to imagine themselves to be a breast cancer patient while doing so, to imagine that they had been diagnosed and now faced the difficult choice of deciding between breast conserving treatment and breast removal surgery. They were made aware that these two treatments have very similar life expectancy outcomes, but differ in other quality of life consequences where importance of factors might differ between patients. The participants were told that the information they would be seeing in the decision aid would be fabricated. In the *comparative* and *personalised* conditions, the fictitious patient ('Jane Doe') would also have fabricated individual prognosis data that was previously entered by her health care provider.

Participants were informed that there were no expected risks associated with the research, that they could stop at any time without having to give a reason, and that their responses would be anonymously processed and stored.

After giving their informed consent, confirming they were female and over 18 years old, participants were first asked to answer demographic questions (e.g. age, highest level of education). Then, participants would be given a link to one of the three different decision aid conditions. The link opened the decision aid in a new tab. They were told to keep this tab open at all times during the experiment so they would be able to go back and forth between the questionnaire and the decision aid. Participants were asked to take their time to explore the decision aid, and to then return to the questionnaire and get back to answering questions.

After familiarising themselves with the decision aid, they were informed they would be answering some questions to gain insight into their experience. Participants were also continuously asked to answer as if they were a breast cancer patient themselves. Right after exploring the decision aid the participants would be asked about their risk perception. To ensure participants would be looking at the correct information in the decision aid while answering questions, they were asked to go to the page about ‘Pain’ and shown a screenshot of the correct page. They were then asked if they were on that page, and if they answered ‘Yes’ they could go on. After that, they were asked to answer some questions regarding how they felt while interacting with the prototype. Here, the STAI words were introduced with the questions ‘When thinking about the decision aid, how did you feel while exploring it?’. Next were the Graph Literacy and Information Coping Style questions. The questionnaire ended with some optional, mostly open-ended questions: ‘How would you describe your experience with the decision aid?’, ‘How difficult was it to understand the information in the decision aid (1= extremely difficult; 5

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= extremely easy)?', 'Based on the information given, which treatment would you prefer (Breast conserving surgery (lumpectomy) or Breast removal surgery (mastectomy))?', 'Why did you choose this treatment?' and 'Is there something else you would like to add?'.

Participants were thanked for their participation and debriefed on their contribution to the research and what was investigated.

Analyses

Analyses were conducted with the partial least squares (PLS) approach. This conduction was done using the WarpPLS 6.0 analytical software (Kock, 2017). This approach was chosen since the PLS structural equation modeling (PLS-SEM), unlike the covariance-based structural equation modeling (CBSEM), does not require normality assumptions in the data, allowing for smaller sample sizes (Marcoulides & Saunders, 2006). PLS-SEM also allows a nomological network of variables, providing a more integrative estimation of correlations between variables (Streukens, Wetzels, Daryanto, & De Ruyter, 2010). This makes it a more preferable approach over more traditional analytical approaches such as the analysis of variance (ANOVA).

Results

Data inspection and validity of scales

In order to do parametric tests, the Likert scale questions were interpreted as interval variables (Norman, 2010). Not all statements are normally distributed according to the Shapiro-Wilk (sample size <1000), but this is largely due to the size of the sample (N = 167). According to the central limit theorem, it can be said that since the sample size is greater than 30, the distribution of the sample means can be regarded as normally distributed (Burns & Burns, 2008). Also, results were yielded using the PLS-SEM method, which as previously mentioned does not require normality assumptions (Marcoulides & Saunders, 2006). All variables indicated a skewness between -1 and 0, and kurtosis between -1 and 1. According to Hair et al. (2010) and Bryne (2010), data can be considered to be normal if skewness is between -2 to +2 and kurtosis is between -7 to +7. Thus, these results are deemed acceptable. See Table 2 for the descriptive statistics of the three conditions.

Table 2

Descriptive statistics

	Condition	Mean	N	SD
Perceived risk	Personalised	3.22	60	.68
	Generic	3.41	48	.64
	Comparative	3.39	59	.64
Anxiety	Personalised	2.97	60	.88
	Generic	3.06	48	.78
	Comparative	3.07	59	.86

In order to ensure the construct validity of our measures, for each indicator their internal consistency reliability (Cronbach’s Alpha) and their item loadings for each indicator were assessed. PLS-SEM was employed to test the validity of the measures. The analysis was based on the method by Shin et al. (2019). All items’ loadings except for one were above 0.5 and statistically significant with a *p*-value of below 0.001 (see Table 3), indicating a good reliability (Kock, 2017). One item (ICS3) from the Monitoring Information coping style scale had an insufficient item loading score (0.293). This item was “I decide to first inquire with other authorities and doctors”, which could be argued is quite a bit more ‘extreme’ of an action to take than some of the other statements in this scale (e.g. “I intend to ask the specialist as many questions as possible”), since it could imply a distrust in your current health care provider. As such, it was deemed appropriate to leave out this statement during analyses. As previously mentioned, all measures were found to have a Cronbach’s Alpha above 0.7, indicating high internal reliability.

Table 3

Item loadings

STAI	Item loading	PRISK	Item loading	GL	Item loading	ICS-M	Item loading
STAI1	(.75)***	PRISK1	(.85)***	GL1	(.88)***	ICS1	(.67)***
STAI2	(.71)***	PRISK2	(.73)***	GL2	(.87)***	ICS4	(.66)***
STAI3	(.75)***	PRISK3	(.72)***	GL3	(.88)***	ICS8	(.79)***
STAI4	(.82)***	PRISK4	(.80)***	GL4	(.84)***	ICS10	(.73)***
STAI5	(.67)***			GL5	(.80)***	ICS11	(.57)***
STAI6	(.76)***						

Note. STAI, State Anxiety Inventory; PRISK, Perceived risk; GL, Graph literacy; ICS-M, Monitoring information coping style.

*** $p < .001$.

Hypotheses testing

PLS-SEM was conducted to examine the significance of the causal paths that were posited in the structural model (H1-H4). The variable information mode was dummy-coded as personalized = [1], generic = [2] and comparative = [3]. See Figure 9 for a holistic view of the PLS-SEM results.

Information mode and risk perception

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H1 posited that information mode would influence risk perception in such a way that comparative (generic + personalised) visualisation induce the greatest risk perceptions followed by generic and personalised, where personalised would induce the lowest risk perceptions. Consistent with this prediction, the PLS-SEM results indicated that information mode (in the order personalised, generic, comparative) significantly increased risk perception in a breast cancer PtDA ($\beta = .13$, $p < .05$). The results were in support of H1.

Information mode and anxiety

H2 posited that Information mode would influence state anxiety in such a way that comparative (generic + personalised) visualisation induce the greatest state anxiety followed by generic and personalised, where personalised would induce the lowest state anxiety. Contrary to this prediction, the PLS-SEM results indicated that information mode was not significantly positively associated with anxiety in a breast cancer PtDA ($\beta = .06$, $p = .23$). Thus, H2 was not supported.

Anxiety and risk perception

H3 posited that Level of anxiety would be positively associated with the level of risk perception. Consistent with this prediction, the PLS-SEM results indicated that anxiety was indeed significantly positively associated with risk perception in a breast cancer PtDA ($\beta = .21$, $p < .01$). The results were in support of H3.

Moderating effect of information coping style

H4 posited that Information coping styles moderated the effect information mode of risk information has on anxiety. No significant effect was found between information mode and anxiety (H2), and no significant moderating effect was found either ($\beta = .00$, $p = .48$). Thus, H4 was not supported.

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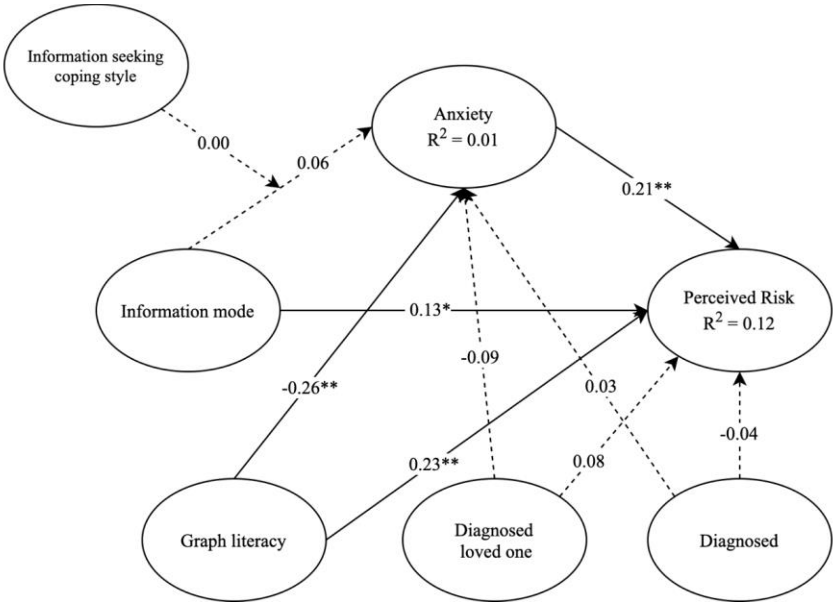
Control variables

Some control variables[4] were checked to see whether these factors might have had an effect on the independent variables. Of these variables, having a loved one diagnosed with breast cancer or being diagnosed yourself were both found to have no significant effect on the independent variables. Graph literacy had a negative significant relationship with state anxiety ($\beta = -.26$, $p < .01$) and a positive relationship with risk perception ($\beta = .23$, $p < .01$). That means that the higher the participant’s graph literacy, the lower their state anxiety and the higher their risk perception were.

Figure 9

PLS-SEM results.



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[4] ‘Interactivity’ from Clara Coelho’s study was found to have no effect on both anxiety and risk perception.

Note. Solid lines indicate significant paths and dashed lines indicate non-significant paths. *p < .05, **p < .01.

Additional findings

Participants gave some extra insight into their experience with the decision aid during the final part of the questionnaire, where the open-ended questions ‘How would you describe your experience with the decision aid?’ and ‘Is there anything else you would like to add?’ were asked.

Generally, in each of the three conditions most answers were short and positive. Some thoughts that were shared by many of the participants were that the decision aid was “Easy to use”, “Good”, “Easy to understand”, “Interesting”, “Helpful”, “Understandable”, “Informative” and “Clean” in any of the three conditions.

Participants’ view on visualising information

An assumption was made for this research based on previous research that visualising information in decision aids would be helpful and preferred (Garcia-Retamero & Cokely, 2017; Vromans et al, 2019a). Overall, participants seemed very positive about the visual information in the decision aid. One participant said “the visualisation of the information really makes it comprehensible”, another said they “really liked the simple way complex data was represented” and it was also mentioned that “it was easy to quickly see what the results were in different situations.” Participants found the decision aid “easy to navigate and to interpret the data that was presented” and “easy to navigate, visually appealing and very clear comparisons”. They said the decision aid had a “Very smooth interface, [was] intuitive and provid[ed] good-sized bites of information”, and was “clearly visualised and explained. I liked the visuals and look/feel of the aid.”. One participant said: “I like that you wanted to go for a graphical approach with fewer text!”

Participants’ positive interest in comparative information

Interestingly, though yet unaware of the purpose of the research, many participants mentioned the type of information they perceived in the decision aid and indicated an interest in comparative information.

Especially notable was that many of the participants in the *personalised* condition indicated that they felt generic information was ‘missing’. As one participant put it: “I missed the average data in comparison to my personal data, because that would make it easier to interpret.” Others said “Maybe at the end I would think that what I wanted to see was the average success of both treatments. it's difficult to put myself in such shoes, I think that is something very scary and difficult to imagine, at least to me” and “I thought at first that I could slide the image of the little lady around, to see how likely I was to experience this kind of pain compared to others.”. One participant also mentioned that seeing average data next to the personalised data might also make them worry less: “It was fine! I would like to see what is 'usual' in a situation like that so that you can worry less.” Another participant mentioned that they “… would welcome additional information about other patients' recovery and experience (how did they rate their levels of pain/fatigue difficulty moving, etc.).”

Participants in the *comparative* condition also seemed positive about the comparative information they viewed in the decision aid. As some participants put it: “I liked that I could see what happened to the average number of people and what happened to people that were similar to myself”, “I like how it took your particular unique situation into account.”, and “It is very helpful to see the difference between the average patient and patients like me. It puts it in perspective”. One participant even said that the decision aid was “Easy to use and gives you facts in a quite neutral way (I stay calm, even though it is about me)”, implying that they did not find the comparative information worrisome even though the personalised information was higher risk than the generic information.

It seemed participants had a clear interest in experiences of other women. For example, someone said the decision aid “feels incomplete, I would like to see more explications or experiences from people in my age group.” Others mentioned “Maybe I would like to have some feedback (like quotes) from patients like me about their experience with each treatment” and “Might also be good to add a forum or something like that where other women can share their experiences and support each other through this difficult process.” Knowing what other people went through seemed valuable. As one participant put it: “It is always a good thing to know what the experiences are of other women in the same situation.”

Discussion

This research strove to investigate what the effects are of different types of visual information modes (generic, personalised and comparative) in a PtDA on risk perception (H1), whether these effects are mediated by feelings of anxiety (H2), and whether an information seeking coping style would moderate (H4) the possible effect information mode has on anxiety (H3).

In line with our prediction, information mode was significantly related to heightened risk perceptions (H1). This seems to support the scarce previous research that indicated that comparative information would induce high risk perceptions (Fagerlin, Zikmund-Fisher and Ubel, 2007), whereas personalised information would low risk perceptions (Vromans et al., 2019b).

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However, it was predicted that this effect would be mediated by anxiety (H2). According to Fagerlin, Zikmund-Fisher and Ubel (2007), comparative information induces high risk perceptions by making people overly worried when they see that their own risk is higher than the generic risk. However, the prediction that information mode would heighten anxiety was not validated by this research. At this moment, the fact that comparative information might be anxiety-inducing is the main argument previous research totes as to not be in favour of designing breast cancer PtDA with comparative information (Fagerlin, Zikmund-Fisher and Ubel, 2007). Thus, the fact that this effect could not be confirmed by this research seems to be in favour of a comparative information mode.

Another prediction that was supported in this research was that higher anxiety would induce higher risk perceptions (H3). These findings are in line with previous research, which found that if someone’s feelings towards an action are positive, they are more likely to judge its risks as low, whereas if someone’s feelings are not positive, they tend to judge risks as high (e.g. Tripp & Milne, 1995; Slovic et al., 2005). This effect was also quite a bit higher than the effect of information mode on risk perception in this study.

The prediction that an information seeking (monitoring) coping style would moderate the effect information mode might have on anxiety (H4) was also not supported in this research. This effect was expected because previous research indicated that patients fare better when information is tailored to their own coping styles, and cancer patients that have a more monitoring blunting style tend to do better when they are given more information, compared to patients that have a blunting coping style who tend to do better with less information (Miller, 1995). However, since this effect was not supported, it might indicate that it is not necessary for PtDA to fit their information mode to the individual patient.

The control variable graph literacy was found to have a significant effect on both risk perception and anxiety. Interestingly, the effect on anxiety was negative (indicating that participants who rated themselves to have high graph literacy reported lower anxiety), whereas the effect on risk perception was positive (indicating that participants who rated themselves to have high graph literacy reported higher risk perception). Especially the positive effect on risk perception is notable here, perhaps indicating that in this research, with the information visualised in the PtDA, higher risk perception was more ‘accurate’ since these individuals should more accurately be able to interpret the data. After all, higher graph literacy allows one to make meaningful interpretations when interpreting graphs (Garcia-Retamero & Cokely, 2017).

The main finding of this research, that there seems to be a significant influence of information mode and anxiety on risk perception, should be considered. It could be argued that these results indicate both ‘good’ and ‘bad’ things about the use of comparative information in a PtDA. There is no real consensus in breast cancer PtDA research on whether it is a good or a bad thing to induce higher risk perceptions. In research where the target audience are at risk women who should go to breast cancer screenings (versus the current study’s target audience of diagnosed patients), it is often seen as a success when risk perceptions are heightened and people are thus encouraged to go to screenings (e.g. Yavan, Akyüz, Tosun & İyigÜn, 2010). It might make people take action to prevent or stop certain ill-advised behaviours. On the other hand, as this research indicates, a predictor for higher risk perception seems to be someone’s anxiety. Of course, it is not unreasonable for someone to be anxious when exploring a decision aid which informs them of their risks of treatment outcomes. However, it could also be argued that making diagnosed patients overly anxious about treatments is not desirable, since they are unlikely *not* to undergo any treatment.

Still, risk perception itself is a complicated measure, since there is no ‘true’ risk to measure it against. Risk perceptions are not exact percentages, but mere intuitive ‘gist’ representations formed by the patient (Reyna & Hamilton, 2001). PtDA should strive to induce ‘accurate’ risk perceptions, which in the case of this study might be higher risk perceptions. This would be supported by the fact that in this study, higher graph literacy was positively associated with higher risk perceptions (Garcia-Retamero & Cokely, 2017). In the case of the comparative information mode in this study, where you could actually see that your risk is higher than average, it might be quite logical that risk perception would be higher than in the other two conditions, because ‘your’ risk was actually higher than the average. So, comparative information would perhaps have been ill-advised if it not only heightened risk perceptions, but did so by making the patient overly anxious (Fagerlin, Zikmund-Fisher and Ubel, 2007). Of course, it is preferable for patients to stay calm and accept their situation rather than to be overly anxious about the future. However, no significant effect was found between information mode and anxiety. Thus, it cannot yet be confirmed that the use of comparative information is truly unwise and that, in the future, designers should not include comparative information in PtDAs. On the contrary, many participants in the open-ended questions of the questionnaire expressed the fact that they would like to be able to compare themselves to others. This supports previous research by Vromans & Hommes et al. (submitted), that found that statistical information needs of cancer patients include both generic and personalised information. This interest in comparative information was especially the case in participants assigned to the personalised information mode condition. In the generic information mode condition, participants were ignorant to the fact that such a new possibility of predicting one’s own outcomes based on their personal situation was a possibility. But, in the personalised condition, many participants indicated that they felt the ‘average’ to compare themselves to was missing. Though not that many personalised decision aids are available to the public as of yet, a big reason for that is the fact that decision aids can take many years to develop (Coulter et al., 2013). Based on the fact that recent research is very positive about the personalisation of PtDAs (Vromans et al., 2019a), it could be expected that personalised PtDA might eventually become the norm. However, this research could support other recent research that indicates that, now that personalised information is a possibility, comparative information could possibly be even more preferable in breast cancer PtDAs (Vromans & Hommes, submitted).

Limitations and future directions

Some limitations must be mentioned when considering the results of this research. One limitation was the type of participants that were approached in this study. Though participants were asked multiple times to imagine that they were considering the decision aid as a diagnosed breast cancer patient, participants were recruited via convenience sampling. In reality only 6 out of 167 participants had ever been diagnosed with breast cancer themselves. Though this was checked for as a control variable and no significant effect was found, 6 participants would be too few to truly rule out that results would not have been different if the participants were actual diagnosed patients. There could also be a difference between previously diagnosed (and recovered) patients versus patients that are going through treatment decision making at the moment of consulting a PtDA. Results might be different if actual (current) breast cancer patients would have taken part in the experiment. The fact that no significant effect was found of information mode on anxiety and that the effect on risk perception was rather low, could be explained by the participants not being nearly as invested or affected by the different information modes (especially comparative information) as actual diagnosed breast cancer patients would be.

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Though a stronger investment might also not immediately mean that comparative information would be wholly inappropriate. Actual patients might open a PtDA while anxious and expecting the worst, overestimating their risks. Showing them that their estimates are worse than average would be what they are already expecting. This way, the ‘unknown’ is explicated and women will better understand their true situation. After all, research indicates that patients who are truly interested in honest treatment information maintain hope, even when the information they are provided is not positive (Smith et al., 2010).

The pool of participants was also quite young (most were student age), while the median age for women to get diagnosed with breast cancer is 62 years old (National Cancer Institute, 2021). Older women might feel less at ease using an app to help them in their decision-making process. The participants were also almost exclusively highly educated, which is often not indicative of the population. However, it is said that in general breast cancer patients are actually fairly highly educated. However, this mostly due to the fact that this group is more likely to go to screenings, where the cancer is actually detected (Aarts, 2012).

Another limitation was that the prototype of the PtDA that was presented to the participants was quite complex. During the design of the PtDA, meticulous thought went into making it seem like an already valid and usable product. When asking people what their ‘experience’ with the PtDA was like, and how anxious they were while exploring it, it seemed valuable and logical to present such a complete product. It seemed reasonable that a seemingly usable product would invoke stronger emotions than a static image of a graph would. However, this means that there might be external factors (outside of information mode) that influenced the results. Though care was taken to ensure that the PtDA was identical in everything but the information mode for each condition, there might still be unaccounted for effects. For example, the fact that two participants would not only compare themselves against the average (in the comparative condition), they would also compare the risk to the risk of the other treatment and other treatment outcomes, since the prototype presented two different treatment with each three different treatment outcomes.

It should also be mentioned that information mode was simply seen as three different types of ways to show information to patients, no manipulation check was done to see which of the conditions for example felt most personal or personally relevant. Possibly the perceived level of personalisation could have affected the results, future studies might consider measuring this as a manipulation check.

In this research in the comparative condition the patient had a higher risk of certain treatment outcomes compared to the average patient. However, were the situation the other way around, perhaps other interesting findings could be discovered. For example, what would be the effect of comparative information on risk perception if one is informed that their risk is lower than that of the average patient? Could patients feel overconfident and perceive their high risk as low because their risk is lower than the average patient? These would have to be explored in future research.

In that same line of thought, the difference between the hypothetical patient and the average patient was very small in this research. So, if this gap were bigger, more troubling results could be found about the effect of comparative information on risk perception and anxiety. Still, previous research indicated that it was especially those (metastatic) patients without promising expected treatment outcomes that want all the information available, even when this information is distressing (Kehl et al., 2015).

Future research could also expand on how to best include visual risk information in breast cancer PtDAs. Though most participants seemed quite positive about the graphical approach, Some criticism came up as well. One participant said that they were missing some more concrete visualisations of the outcomes: “Maybe I would have liked to see what the breast could look like after a lumpectomy. Not as in a real-life image but perhaps a visualisation. I do not know what it looks like. It may influence my decision.” This was also reiterated by others participants who said “[the decision aid] was disappointing, I expected more information and also pictures. I can imagine what a mastectomy would look like but I have no visuals of a lumpectomy” and “I would also be interested in visual aid: what would my chest look like after each operation?”. These possibilities could be further explored.

In conclusion, the current research added to the positive support of the personalisation of breast cancer PtDAs (Vromans et al., 2019b), and while it also did cautiously support that comparative risk information might induce higher risk perceptions than either generic or personalised information, this does not per se indicate that it is not also a contender for good risk communication design. Comparative information should still be considered by future PtDA designers and further investigated in future research.

Practical implications

- When considering the design of a personalised breast cancer PtDA, it could be helpful to show patients comparative information to help them contextualize their own risks.
- Especially when people know risk information is based on their own personal situation, they are interested in the risk of the general population as well.

- The addition of visual (graphical) information to PtDA was well-received and should be more often considered to be implemented in PtDA.
- Previous findings in breast cancer PtDA research that are geared towards the at-risk population should not immediately be considered relevant to PtDA geared towards diagnosed patients.

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Appendix

Appendix A

Breast Cancer Decision Aid Questionnaire

Introduction

A decision aid on quality of life after breast removal surgery (mastectomy) or breast conserving surgery (lumpectomy) for breast cancer patients

Dear participant,

We ask you to participate in our online study for our master theses. Please take your time to read the following information before deciding to participate in the study.

What is this research about?

During breast cancer treatment, women often have to make difficult decisions. One of those decisions could be to have breast conserving or breast removal surgery. Breast conserving surgery removes only the tumor from the breast, while breast removal surgery removes the entire breast with the cancer. Often these two treatments have a similar life expectancy, so there are other factors that will determine which treatment each patient will choose. For example, the expected quality of life after treatment is very important to many women. This includes how you feel physically and emotionally after treatment, or how the treatment can affect your social life and financial status.

The decision aid app

In this study we would like to test an app (a kind of clickable brochure) which aims at helping

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patients make a choice between breast conserving and breast removal surgery. This decision aid estimates how likely it is that a new patient will experience certain effects of the treatments, such as difficulty with moving, fatigue and pain. This estimation is based on a lot of data about previous people with breast cancer [comparative/personalised conditions:] and the patient's personal situation (e.g. age, gender, size of the cancer, comorbidities).[/] The decision aid shows these effects of treatments in pictures (graphs).

Hypothetical scenario

For this online study, we would like to ask you to imagine that you have recently been diagnosed with breast cancer. You are faced with the choice of undergoing breast removal or breast conserving surgery. The treatments have a similar life expectancy. There is no wrong choice, it depends on your preferences. What your quality of life after treatment will be can influence this choice. Your healthcare provider has recommended that you review this quality of life decision aid so you can compare the two treatments. [comparative/personalised conditions:] The decision aid works based on fictitious (fake/invented) patient data. So you will see predictions for a fictitious patient. This patient is 67 years old and has Stage 2A breast cancer. This way, you can imagine which data would be needed for the outcomes of the decision aid. The fictitious data was supposedly entered by the fictional patient's healthcare provider.[/]

What does participating in this research entail?

If you decide to participate in this study, we ask that you do so on a computer or laptop. We are interested in gathering data from female participants. You will first be asked to complete a questionnaire with general questions (such as your education level and age). Then you will be asked to explore a [comparative/personalised conditions:] personalised [/] breast cancer decision aid app. After exploring the decision aid app, you will answer questions about your experience

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with the decision aid app and questions related to self-evaluation. If you agree to participate, participation takes approximately 20 minutes in total. It is important to know that there are no right or wrong answers, we are only curious about your own experiences.

Are there any risks associated with the research?

As far as is known, there are no risks associated with the study. It is important to know that you can stop at any time without having to give a reason. You may have questions about the information after your participation, or you may be upset by the information about quality of life after treatment. You can always contact the researchers with all your questions (see bottom of this page for contact information).

What happens to my data?

Your data will be processed completely anonymously and will be used with the utmost care only for this research. The collection of your data is done according to the new AVG rules (General Data Protection Claims). The committee for "Research Ethics and Data Management" of Tilburg University (Tilburg School of Humanities and Digital Sciences) has granted permission to carry out this research.

The results of this research will be presented at conferences and possibly published in medical (scientific) journals. However, we will never display the results in such a way that you could be identified. The anonymised data will be stored for ten years in a secure system at Tilburg University. We may remove your information from the file at any time, up to the time this study is published. Please do not hesitate to contact us.

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If you have any remarks or complaints regarding this research, you may also contact the Research Ethics and Data Management Committee of TSHD via tshd-redc@tilburguniversity.edu.

Can I withdraw at any time?

Yes, participation in this study is completely voluntary and without obligation. You have the right to decide not to participate in this study. This has no further negative consequences for you. For any comments or complaints about this study, you can also contact the "Research Ethics and Data Management Committee" of Tilburg School of Humanities and Digital Sciences via tshd.redc@tilburguniversity.edu.

With kind regards,

Clara Coelho (c.lealmacedopirescoelho@uvt.nl) & Maryse van Dalen (m.l.vandalen@uvt.nl)

Informed Consent

A decision aid on quality of life after breast removal surgery (mastectomy) or breast conserving surgery (lumpectomy) for breast cancer patients

If you want to participate in this study, you can give your consent below. Your participation in this study is completely voluntary. During the study you have the right to withdraw at any time, for any reason and without any adverse consequences.

If you agree to participate, please indicate:

- That you understand what participating in this study entails;

- That you understand that you can ask any questions regarding this research that you want;
- That you are older than 18 years;
- That you have read all the information;
- That you understand that you may withdraw at any time without giving a reason;
- That you understand that you can have your data deleted without giving a reason until the time of publication;
- That you agree that the anonymised data will be stored for ten years;
- That you agree that the data can be used for further scientific research or scientific publications;
- That you agree that anonymous data may be shared with other researchers.

- I agree to participate and start the study.
- I do not agree and do not want to participate in the study.

Demographic questions

What is your age?

- 18-24
- 25-34
- 35-44

- 45-54
- 55-64
- 65-74
- 75+

With which gender do you identify the most?

- Man
- Woman
- Other

Answer other than Woman > Thank you for your interest in this study. However, we are only gathering data of women at this time.

What is your highest level of education? If you are currently enrolled, select that one.

- None
- Primary school
- High school
- Bachelor
- Master
- PhD
- Other:

Have you ever been diagnosed with breast cancer?

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- Yes
- No
- Rather not say

Have any of your loved ones ever been diagnosed with breast cancer?

- Yes
- No
- Rather not say

On the next page you will get the link to the decision aid app. Please keep this questionnaire tab and the decision aid app tab open at all times as you will be asked to go back and forth between the two. Please take your time to explore the decision aid app. Afterwards, return to the questionnaire and get back to answering the questions.

[next page]

Here is the link to the decision aid app.

<link>

Please keep this questionnaire tab and the decision aid app tab open at all times as you will be asked to go back and forth between the two.

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Post-Questionnaire

Now that you have had the time to explore the decision aid, we would like to gain some insight into your experience. We ask you to imagine that you are being asked these questions as a person with a breast cancer diagnosis.

In the decision aid app, go to the page about “Pain” to answer the following questions.

Are you on this page?

(screenshot Pain 6mthns)

Risk Perception

The following questions are about your perception of the treatment effects you see in the decision aid app. Please select the answers you feel most reflect your experience as if you were a breast cancer patient.

If you were to choose to have breast removal surgery (mastectomy), how likely do you think you would be to experience pain 6 months after treatment?

(1 = Not at all likely, 2 = A little likely, 3 = Moderately likely, 4 = Quite likely, 5 = Extremely likely).

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If you were to choose to have breast removal surgery (mastectomy), how likely do you think you would be to experience pain 6 months after treatment, as compared to the average person who had this operation?

(1 = Not at all likely, 2 = A little likely, 3 = Moderately likely, 4 = Quite likely, 5 = Extremely likely).

Taken all together, how worried would you be about experiencing pain if you had breast removal surgery (mastectomy) 6 months after treatment?

(1 = Not at all worried, 2 = A little worried, 3 = Moderately worried, 4 = Quite worried, 5 = Extremely worried).

Taken all together, how common do you think experiencing pain is for people who have had breast removal surgery (mastectomy) 6 months after treatment?

(1 = Not at all common, 2 = A little common, 3 = Moderately common, 4 = Quite common, 5 = Extremely common).

The following questions relate to how you interacted with the decision aid app and how you felt while interacting with it. We ask you to imagine that you are being asked these questions as a person with a breast cancer diagnosis.

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STAI-State anxiety scale Short-version (Marteau & Bekker, 1992)

The following words can be used to describe someone's emotional state. Read each word and select the extent to which they apply to how you felt while exploring the decision aid. There are no right or wrong answers. Do not spend too much time on one word but give the answer which seems to describe your feelings best. (Scale of 1-5; 1 = not at all / very slightly, 2 = a little, 3 = moderately, 4 = quite a bit, 5 = extremely)

When thinking about the decision aid, how did you feel while exploring it?

1. Tense
2. Upset
3. Worried
4. elaxed (reverse coded)
5. Content (reverse coded)
6. Calm (reverse coded)

The following section pertains to your personal preferences and identity.

Graph literacy

Health information is commonly presented in the form of graphical visualizations, the following questions pertain to how comfortable you are with interpreting this kind of information. Answer the following questions by selecting the most applicable option to you:

_ How good are you at working with bar charts? (1= extremely bad; 5= extremely good)

_ How good are you at working with line plots? (1= extremely bad; 5= extremely good)

_ How good are you at working with pie graphs? (1= extremely bad; 5= extremely good)

_ How good are you at inferring the size of a bar in a bar chart? (1= extremely bad; 5= extremely good)

_ How good are you at determining the difference between 2 bars in a bar chart? (1= extremely bad; 5= extremely good)

Information coping style

The following situations describe events that you may have experienced or that you may well imagine. Each situation is followed by a few statements. These concern thoughts and ideas that people may have in such a situation. Try to imagine that you are in such a situation and indicate for each statement to what extent it would apply to you in these situations. There are no right or wrong answers.

1. Suppose you have had headaches and felt dizzy for some time. You are at the doctor's office and he tells you that he does not fully trust it and that you have to see the specialist for a rather tedious examination. Please indicate for all statements to what extent they apply to you? (1 = not at all applicable to me 2 = not very applicable to me 3 = somewhat applicable to me 4 = quite applicable to me 5 = very applicable to me)

a. I intend to ask the specialist as many questions as possible.

b. I think it will all be fine.

c. I decide to first inquire with other authorities and doctors.

d. I intend to read about headaches and dizziness.

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e. I try to think as little as possible about unpleasant things for the time being.

f. I'm not worried: such an examination is not as bad as having a headache all the time.

2. Suppose you have problems with your heart. You are with the specialist and he recommends surgery. He tells you that you will have to wait four months and that it is not certain whether the operation will really help. Please indicate for all statements to what extent they apply to you? (1 = not at all applicable to me 2 = not very applicable to me 3 = somewhat applicable to me 4 = quite applicable to me 5 = very applicable to me)

a. I assume the operation will help me.

b. I decide to study heart surgery as much as possible.

c. I intend to do as many fun and useful things as possible for the coming months.

d. I will investigate whether there is a chance that the operation will have negative results.

e. I decide to contact other patients with the same problem for information.

f. I think: "it will all be okay".

Additional Questions

The following questions reflect your overall experience with the decision aid.

How would you describe your experience with the decision aid?

How difficult was it to understand the information in the decision aid (1= extremely difficult; 5 = extremely easy)?

Based on the information given, which treatment would you prefer?

- Breast conserving surgery (lumpectomy)
- Breast removal surgery (mastectomy)

Why did you choose this treatment?

Is there something else you would like to add?

Debriefing

Thank you for participating in this study.

Your contribution to this research

With this study, we attempted to understand the best way to visualize quality of life information for people with breast cancer. Thanks to your contribution, we now better understand whether certain presentation techniques are desirable and effective. Thank you again for that.

What was investigated?

There were two elements of focus in this study. Firstly, insights were gathered on the influence of interactive elements on your understanding of the health risks presented. You were either able to explore an interactive (with hover elements, clicking and a slider) or a static decision aid app.

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In the questionnaire we were then able to understand whether the interactive elements or the lack of them helped you understand the information presented better or not.

Secondly, the information in the decision aid app was presented as personalised (based on specific data), generic (based on means), or both shown together. We wanted to know if presenting the information in these three different ways would affect your anxiety and risk perception of the data. For example, would it be bothersome for the patient to see that they have worse expected outcomes than other patients?

Other questions were used to characterize you personally and to understand whether certain personality traits affected your understanding of the information. Finally, we were also interested in your overall experience with the decision aid and how you would choose a treatment based on the information presented.

Do you want to stay informed about this study or do you have any questions?

Do not hesitate and send an email to one of the researchers Clara Coelho, c.lealmacedopirescoelho@uvt.nl and/or Maryse van Dalen, m.l.vandalen@uvt.nl).

With kind regards,

Clara Coelho en Maryse van Dalen