A visit to the doctor: shared decision making supported by outcome information in chronic kidney disease

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Clinicians' and patients' perspectives on discussing outcomes during healthcare visits – Qualitative study with dyadic interviews

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Abstract

Objective

We aimed to explore patients' and clinicians' perspectives on discussing different types of outcomes during healthcare visits: clinical outcomes, patient reported outcomes (PROs), calculated prognostic outcomes and comparisons of individual patient outcomes with aggregated data.

Methods

Dyadic interviews (n = 22) with patients with breast cancer or chronic kidney disease and their treating clinician.

Results

Participants varied in their preference in what outcomes to discuss depending on: their emphasis on numerical data, perceived control over outcomes, patients' approach to uncertainty regarding the future, and the impact of outcomes on patient's motivation. Patients and clinicians agreed that avoiding information overload and enabling a trust-based patient-clinician relationship were important facilitators for discussing outcomes. The interviews revealed that assumptions from patients and clinicians about each other were not always correct. Discussion of these misassumptions led to new insights; patients realized their (non-medical) information is relevant to clinicians, and clinicians recognized they sometimes misjudge which outcomes patients wish to hear.

Conclusion & Practice implications

We identified varying preferences in discussing different types of outcomes among both patients and clinicians. The dyadic interview method proved to be effective in revealing misassumptions. Interviews revealed adverse effects of discussing outcomes, highlighting the importance of open dialogue and exploring information needs rather than assuming them.

1. Introduction

The concept of Value Based Health Care (VBHC) is increasingly being implemented in healthcare globally since its introduction in 2006[1]. VBHC entails a strategic agenda from an economic background to structure care in such a way that value in healthcare is increased. Value is determined in quality of care (measured through care outcomes) relative to the cost. Thus, information on care outcomes, in particular outcomes that matter to patients, are required to determine value of care. Since the introduction of VBHC there is an increased focus on measuring outcomes to determine value of care[2, 3]. Standard sets of patient-centred outcomes have been developed for an increasing number of conditions[4]. These outcomes can be used on an aggregated level to drive quality and process improvements[5, 6], and on the individual patient-clinician level during healthcare visits. Discussing outcomes during healthcare visits, facilitates: 1) informing patients on their health status, 2) identifying patients' problems and disease monitoring, and 3) enabling shared decision making (SDM)[6–8]. SDM entails the collaborative process between patient and clinician in making healthcare decisions[9, 10]. We distinguish four different types of outcomes that may be discussed during healthcare visits: 1) individual clinical outcomes (e. g., blood pressure or laboratory results), 2) individual patient reported outcomes (PROs)[11], 3) prognostic outcomes (e.g., estimating probability of survival or disease progression), and 4) comparisons between individual- and aggregated outcomes (e.g., comparing patients' 'experienced symptoms' to a group with similar (disease) characteristics).

These outcomes are increasingly available including their use in decision aids and PRO dashboards[12–14]. However, in daily practice their use is often limited. Potential barriers for effective use of outcomes in making medical decisions may exist in clinicians and patients having different views regarding discussing outcomes. Clinicians typically focus on the physical aspects of disease, while patients may prioritize PROs[15–19]. Additionally for prognostic outcomes, patients may be more reluctant towards discussing prognostic information than clinicians [20–22].

Understanding how patients and clinicians view different outcomes (clinical outcomes, PROs, prognostic models and comparisons with aggregate outcomes), can guide meaningful use of these outcomes during healthcare visits. Until now, studies reporting clinicians' and patients' views regarding outcome information studied these perspectives separately. However, clinicians often base their views on assumptions regarding the patient and vice versa. When the clinician's and patients' perspectives can interact directly, views can be shared and compared, potentially building new perspectives[23, 24]. Therefore, we used a dyadic approach to explore patients' and clinicians' shared and diverging perspectives on discussing various types of outcome information during consultations.

2. Methods

In this study, we conducted dyadic interviews to capture data from the interaction between patients and clinicians. In a dyadic interview, the interview was held with a patient and their treating clinician together. This approach enables participants to enrich their viewpoints by exchanging and contrasting their experiences. Existing treatment relationships serve as a shared foundation, making it easier to share and compare experiences on the topic[23, 24].

2.1.Setting and participants

Participants in the dyadic interviews included patients in follow-up care for early-stage breast cancer (BC) (N =8), women undergoing treatment for metastasized BC (N = 3), patients with chronic kidney disease (CKD) (N = 10), one patient with kidney failure receiving conservative therapy, and their treating clinicians. BC differs from CKD in that BC is a potentially curable disease depending on tumour characteristics, for which treatment is provided with the goal of achieving progression free survival. CKD is a progressive disease of nature, which lacks curative treatment. The treatment goal is slowing down kidney function decline towards kidney failure (and the need for kidney replacement therapy such as dialysis or kidney transplantation). The aim of this study was not to compare the two disease contexts, but rather to incorporate diverse clinical contexts to explore individual perspectives on discussing various types of outcomes. Participating clinicians could be nephrologists, medical oncologists, surgical oncologists or BC/ CKD nurse practitioners. Participants were all recruited from Santeon hospitals. Santeon is a hospital group of large non-academic Dutch teaching hospitals.

2.2.Participant recruitment

All clinicians were approached individually via e-mail, by telephone or in person by the researchers. Patients were recruited through their treating clinicians. To limit selection bias, a predetermined date was set on which the clinician would ask the first outpatient patient to participate in the study. If this patient was not interested, the second patient would be asked and so forth. Exclusion criteria for patients included insufficient command of Dutch of English or being cognitively impaired. Patients recruited by their clinician were contacted by a researcher (DH or EE) to further inform them about the study procedure. Informed consent was obtained from all participants.

2.3.Procedure

Before the interview, a brief online questionnaire was sent to patients to collect patient characteristics (i.e., birthyear, sex, educational level, health literacy scale)[25]. Researchers DH and EE, both experienced in qualitative research, conducted the dyadic interviews. Patients' partners/companions were welcomed to participate. To address power imbalances, researchers emphasized before the start of the interview that it should feel as a conversation between two persons, regardless of their roles, and let patients start in the interviews. Additionally, we tried to not do the interviews in consultation rooms in the hospital. When this was unavoidable due to practical reasons, we adjusted seating arrangements in the consultation rooms. Researchers minimized interference using topic cards derived from a predefined list. Participants were free to use the cards as desired, with researchers intervening only for clarification. Visual examples supported outcome discussion (see **Supplement 1**). Data was collected until both DH and EE agreed data saturation was reached (no new topics emerged). The Medical research Ethics Committees United in Nieuwegein (MEC-U), the Netherlands, assessed the study protocol to determine whether the Medical Research Involving Human Subjects Act (WMO) was applicable. In their evaluation, they concluded that the study does not fall under the scope of the WMO, as it does not involve burdensome or physically invasive procedures and requires only a limited time commitment from participants. They also concluded that the study is in congruence with the Good Clinical Practice Guidelines (W20.158).

2.4.Topic list

The topic list was developed together with a patient with CKD, a nephrologist (WB), a research coordinator- and a representative from the Dutch Kidney Patient association. The topic list included examples of four different types of outcome information specified to either BC or CKD: 1) clinical outcomes, 2) PROs, 3) prognostic estimates (estimates based on prognostic models including individual- and aggregated patient data), and 4) comparing individual patients' PRO's to aggregated PRO data. For the latter, as these kind of outcomes are not yet routinely used in todays practice, example visuals were shown in which a patient could compare their own PROs (PRO scores on physical and mental health) with a general population. To explain the concept of PRO's, example PRO questions were shown, such as 'how would you rate your quality of life?'. Prognostic estimates appropriate for the BC and CKD context were used in the interviews. In **Supplement 2** the full topic list is provided.

2.5.Data analysis

All interviews were transcribed. In this qualitative interview study we performed a deductive thematic analysis; we coded with an inductive approach within the predetermined themes of the topic list. Coding was performed independently by DH and EE. After every 2–3 interviews codes were discussed. Final codes were determined by discussion until consensus was reached. Atlas.ti 9 was used for analysis. At the end of the analysis a validity check was done with all authors. Findings are reported following the consolidated criteria for reporting qualitative research (COREQ)[26]. Per type of outcome information (clinical outcomes, PROs, prognostic estimates, comparing individual patients' PRO's to aggregated PRO data) we report patient-specific views, clinician-specific views and their shared views or misconceptions in which the patient's and clinician's view overlap or differ.

3. Results

3.1 Participant characteristics

In total, 22 interviews (N=44 participants) were conducted: 11 in BC and 11 in CKD. Interviews were live (n=16) or held via videoconferencing (n=6). The duration of the interviews was between 45-60 minutes. **Table 1** shows the participants' characteristics. Patients' health literacy scores and education levels were moderate to high. The majority of patients had known their clinician for at least 1-2 years. In CKD, most clinicians were medical specialists. In BC five medical specialists participated and six nurse practitioners.

Table 1. Patient and clinician characteristics

	CKD (n=11 interviews)	*BC (n=11 interviews)*
Patient characteristics		
Sex (female), n %	2 (18.2%)	11 (100%)
Age, median (IQR)	67 (64.0-76.0)	55 (51.0-71.0)
SBSQ score[1], median (IQR)	4.7 (4.3-5.0)	4.6 (4.7-5.0)
Education level, n(%)		
Low (ISCED [2] levels 0-2)	0	2 (18.2%)
Medium (ISCED levels 3-4)	4 (40.0%)	3 (27.3%)
High (ISCED levels 5-8)	6 (60.0%)	6 (54.5%)
Missing	1	0
How long patient has known clinician, n(%)		
< 1 year	0	3 (27.3%)
1-2 years	1 (9.1%)	5 (45.5%)

Table 1. *(Continued)*

	CKD (n=11 interviews)	BC (n=11 interviews)
3-5 years	3 (27.3%)	2 (18.2%)
>5 years	7 (63.6%)	1 (9.1%)
Clinician characteristics		
Sex (female), n%	5 (45.5%)	9 (81.8%)
Function		
Specialist [3]	10 (90.9%)	5 (45.5%)
Nurse practitioner	1 (9.1%)	6 (54.5%)

IQR= interquartile range (25th percentile – 75th percentile).

[1] *SBSQ score=Set of Brief Screening Questions (measure for health literacy), >3 is considered adequate (REF)*

[2] *ISCED= Education levels based on International Standard Classification of Education,*

[3] *= In BC, specialists were: 4 surgical oncologists, one medical oncologist and in CKD all specialists were nephrologists.*

3.2 Patients' and clinicians' perspectives on discussing different types of (outcome) information during patient-clinician healthcare visits

The interactions between patients and clinicians revealed shared and diverged views regarding discussing outcomes during healthcare visits, as well as misconceptions about each other. **Table 2** provides an overview of these findings.

Table 2: Overview of patient-specific, clinician-specific and their shared perspectives or misconceptions regarding each other on discussing outcomes during healthcare visits

		Patient-specific views	**Shared views**	**Clinician-specific views**
3.2.1 Clinical outcomes		• Clinical outcomes can give a sense of control over the disease. • Aversion to sugar-coating unfavourable results. • Clinicians should judge how much information a patient can handle based on their emotional state.	• Evaluating health = clinical outcomes + how a patient is doing/feeling. • Discussing clinical outcomes is essential for monitoring and identifying problems. • Positive feedback can provide comfort and can motivate. • Clinical outcomes are not neutral, it can provoke an emotional response. • Discussing too many clinical outcomes may result in information overload.	• Patients can be too focused on the 'numbers'. • Clinical outcomes can give a false sense of security when it is all that is focused on. • Sharing unfavorable results can demotivate and reduce commitment to treatment.
	Misconception	• Patients thought their clinician primarily focuses on clinical outcomes and disease-related outcomes, unaware that most clinicians wanted to discuss mental health as well. • Clinicians and patients sometimes focused on different treatment goals (and therefore on different outcomes), e.g. short- or long-term goals of treatment. • Patients did not always realize that next to clinical outcomes, information regarding daily life and (social) functioning is relevant for the clinician.		

Table 2: *(Continued)*

		Patient-specific views	Shared views	Clinician-specific views
3.2.2 PROs		• For effective use of PROs a good patient-clinician relationship is needed because it lowers the threshold to discuss symptoms.	• PROs can help in: prioritizing patients problems and needs, evaluating disease progress, understanding symptoms, preparing consultations, discussing symptoms that patients might not feel comfortable to bring up themselves • Downsides: PROMs do not always include the right questions, regular conversation without PROs may suffice. • PROMs need to be concise and specific. • Consultations may take longer.	• Risk of information overload when discussing both clinical information and PRO's . • Increase in number of symptoms to discuss with patients because of PROs.
	Misconception	• Patients thought PROs are mainly for the clinician, while clinicians argued it can help patients as well in preparing and bringing up (sensitive) topics. • Patients argued not to need PROs for themselves (they already know their problems), but did not always realize the PROs matter to clinicians as well. • Patients assumed clinicians were already aware of most of their problems (making PROs unneeded), but clinicians often expressed a need for more insight in patients’ symptoms and functioning. • Patients often thought it is a burden for the clinician when patients share complaints that do not relate to their expertise, but clinicians countered they want to know and get a holistic view to provide best care. • Clinicians thought filling out PROs is a burden for patients, but patients were more than willing to fill it out when asked (and if intended for use as part of care).		

Table 2: *(Continued)*

		Patient-specific views	Shared views	Clinician-specific views
3.2.3 Prognostic estimates		• Predictions help to cope with the uncertain future. • The preference for receiving predictive information may change over time. • When calculated predictions are inaccurate, they may negatively impact life choices.	• Discussing predictions is particularly important when something can still be changed/improved. • Predictions may stimulate motivation in treatment. • Predictive information may be difficult to hear/process. • Its best to share predictive information based on estimates, without exact numbers.	• It is difficult to determine which patients want to hear predictions, and in what level of detail. • Predictions may lag behind recent developments. • Patients can cling too much to predictions. • Explaining predictions is challenging. Graphical support may help.
	Misconception	• Clinicians tend to assume they know whether patients want to hear predictions and do not always check these assumptions. However, patients varied from wanting to hear even negative predictions to patients not wanting to hear predictions at all. Made assumptions were not always correct. • Some patients expect clinicians to estimate whether they are (emotionally) ready to hear predictions.		
3.2.4 Comparing individual PROs to aggregated PRO data		• Doing worse than others when comparing on PROs is difficult to process. • Knowing what others choose in treatment decisions could be a useful comparison of data. • Some patients had no interest in comparisons, because: every individual trajectory is unique, they value the opinion of the clinician over the data-comparisons, or worry comparisons are invalid because of comorbidity. • Comparisons may affect patients' own symptom experience.	• Comparing an individual patient to aggregated PRO data helps inform what symptoms to expect and it can guide treatment decisions. • Doing better than others on PROs motivates.	• Sharing data on comparisons with others on PROs adds to being as transparent as possible.
	Misconception	• Some clinicians tended to share such comparisons because transparency of available knowledge was considered important, but not all patients wanted to receive such information and expressed it may even negatively affect them.		

3.2.1 Clinical outcomes

When patients primarily mentioned **physical aspects** when considering evaluation of their health during the interviews, different clinicians responded that **mental aspects** were also important. From their conversations it became clear that both considered clinical outcomes essential for **disease monitoring** and **timely identification of problems**. Both clinicians and patients stressed the importance of **positive feedback**, reporting 'good' clinical results, because it can provide comfort and it can motivate patients. Clinicians mentioned that **negative feedback in clinical outcomes** could demotivate patients to commit to their treatment(s).

Patients varied in focusing on clinical outcomes and 'numbers' versus qualitative information such as 'how they are feeling'. Those without symptoms often prioritized clinical outcomes during healthcare visits. In one discussion, a clinician noted that a patient that preferred clinical outcomes, focused too much on 'the numbers' (**Box 1**). This discussion highlights the patient's need to feel a sense of control over their kidney function decline. Discussing kidney function (eGFR) is the ultimate measure for patients in gaining insight into their disease progress. However, the clinician responds that focusing too much on the kidney function can hinder exploring other important factors related to (progress of) CKD. The clinician adds that patients may misinterpret kidney function when they lack an understanding of the overall course of the kidney function. As a result, patients may perceive the decline both as more stable ('*false sense of security*' or less stable '*shaken because of small decline*') than observed over time by the clinician.

Box 1 (CKD), ***p=patient, c=clinician***

P: I think- from my perspective, I only want to know to what extent the kidneys no longer function properly and what can be done about that.

C: That is actually what I very often hear in the discussions I have with patients when they come to see me, because that's the first thing they want to know, what is the kidney function? Whereas, I understand that, I really do, that that's important to them, but I always try to look beyond just that number. And to also see if people do indeed have health problems associated with poor kidney function, especially when that points towards the need for dialysis. (...) And even though I really try to emphasise in those discussions with patients that that number is really not the only thing that matters, you often see that patients latch on to that number. That's actually one of the things they always want to know about first.
P: Of course, because that's what you always notice. I'm now at an eGFR (kidney function) of 32 and I have this and I have that. So that's clear. But well, I- In the end, it's about what you can do with it.

C: And it sometimes also gives people sort of a false sense of security, because- Or perhaps false sense of security is not the right way to say it, but sometimes people's kidney function is one or two per cent lower and it upsets them tremendously, whereas that's just a variation in the measurement itself. On the one hand that number is something they latch on to, but I try to get them to look beyond just that number.

Another clinician pointed out to their patient, that when patients focus a lot on 'medical numbers', it can hinder the clinician in adequately assessing the patients' **social network and daily life functioning**. The patient responded to never have realized that this was important information as well (**Box 2.**)

Box 2 (CKD), ***p=patient, c=clinician***

C: I have to know about your overall fitness as well. There is sometimes a huge urge to zoom in on the numbers, whereas I actually want to know about the combination, about how you do things and what you're able to do in your daily life, combined with the numbers. You are the sort of person who quickly wants to know about those numbers, I recognise that.

P: That's true. Because for me, that shows you immediately where I stand. That's what I want to know. That's just how it is.

C: Well, but I think that sometimes I would like to have a slightly better idea of how people are doing at home. I don't always have a clear insight with everyone into what they actually can and cannot do at home. So that's something I would sometimes like to know more about.

P: Yes, sure. And the home situation, I never thought about that. So, but I don't mind talking about that.

In CKD interviews, clinicians and patients often had **differing views on treatment goals,** leading them to focus on different outcomes. When discussing reasons for prescribing medication (e.g. blood pressure or anti-diabetic drugs), clinicians emphasized the long-term goal of slowing kidney function decline, whereas patients were more focused on immediate goals such as lowering blood pressure or losing weight, without considering the broader picture. Patients did not always seem to be aware of the connection between these treatments and the goal of slowing kidney function decline. Several CKD clinicians reported difficulties in effectively communicating this information to patients.

Finally, patients and clinicians agreed that **'numbers' (i.e., clinical outcomes) are not neutral:** they can provoke a certain emotional response. However, patients **discouraged "sugar-coating" of the results**. Different clinicians mentioned that they try to estimate the amount of unfavourable information their patient can tolerate. One patient with CKD reacted to this by saying they expected their clinician to do so as he considered it 'part of the job' to sense what information to tell based on the emotional state the patient is in.

3.2.2 PROs

Participants' opinions on PROs varied. While some clinicians actively promoted PROs, others were unconvinced of their usefulness and reluctant to use them in practice. The patients' opinions showed similar contrasts. When clinician and patient agreed on views regarding PROs, they reinforced each other's perspective.

Clinicians and patients who shared positive attitudes towards PROs, mentioned several benefits. They emphasized that PROs can help **prioritize patients' most important problems and needs**. When measured over time, PROs are valuable for **evaluating disease progress**, especially in chronic conditions like CKD, where changes may occur gradually and go unnoticed. Additionally, PROs can help patients **understand the symptoms** of their disease and **prepare** themselves for healthcare visits, as exemplified in **Box 3.**

Box 3 (BC), ***p=patient, c=clinician***

P: And I personally experienced those PROMs as that it really forces you to take pause and reflect, what does it feel like to me? How do I experience it? Where do I stand? It is actually not that bad or should I in fact change something because I actually feel a bit less in certain areas. That's where it helps.

In interviews where both participants expressed skepticism about PROs, they reinforced each other's arguments against their use. In one CKD interview, clinician and patient preferred discussing topics through regular conversation than using PROs to set the agenda. They mentioned that, based on their experience, PRO-questionnaires **do not always include the right questions** for the situation making them difficult to fill out. They also expressed being fatigued with today's '**survey-culture'.**

Several clinicians also warned of **potential information overload** for patients due to the challenge of balancing both PROs and clinical information during the healthcare visits. A patient with CKD responded in agreement and assumed clinicians are more than capable of efficiently exploring symptoms of patients without using PROs (**Box 4**).

Box 4 (CKD), ***p=patient, c=clinician***

C: So yes, there is that- That's also what makes me a bit hesitant to hand out many of them. Because they have so many PRO questions and like I just said, you already discuss so many things. And if you don't do anything with them [PRO's], then I feel- Then it's unfair towards patients, so you really need to pay attention to what you do with them. So you should indeed to be very aware of that, what do I want to use it for? And what- And then pick out a few things that you can do something about. I certainly think that for some people, especially those who don't easily share issues without being asked, it can have a lot of added value. But I can also imagine that it does indeed add another big chunk of information and that people don't always have the time or are not always willing to discuss it all.

P: Personally, I feel it would actually be a semi-substitute for the conversation, and I feel the conversation is more important than those forms. (...) And I think that a professional would already know those kind of things [of PROs]; questions like: do you have health issues regarding these areas? you suffer from that, that or that? That takes just two seconds, I would think. But, well. Perhaps that's me being old fashioned, but so be it.

In other interviews clinicians were enthusiastic about PROs and presented counterarguments to patients' hesitations. In one interview, a patient states that discussing PROs was unnecessary, because this person was already aware of their own symptoms and quality of life. However, the clinician emphasized that this information was also important for the treating clinician. Additionally, patients who argued that a good conversation was enough were countered by clinicians, who pointed out that PROs help **structure the conversation and facilitate discussion of sensitive topics (Box 5).**

Box 5 (CKD), ***p=patient, c=clinician***

P: Sometimes I struggle with it quite a bit, thinking: what do they mean by that? And I'll admit it, I don't always enjoy filling in all those questionnaires. It feels like a chore. But of course it's very important for you.

C: What do you find stupid about it? Is it having to complete the questions, or the time it takes?

P: It's just that I think we could simply discuss it during the appointment instead. But of course for you it works better to have everything on paper.

C: But- Because as you say, we could discuss it when we get to it, but if I were to ask you a frank question in our conversation, such as if you have had problems sometimes, say, in your sexual functioning, you might say no, not all, everything is fine. Whereas if you had filled in the questionnaire at home, you might have answered, yes, sometimes; and then I would have said, I understand that you occasionally have difficulties- Would you like to get something for that or can we discuss that? Or I would use different words to refer to it, because then you would have to, in one way or another, when you're sitting in front of the doctor- We know that people sometimes sort of sweep things under the carpet or would rather not discuss them, even though it might be very important for that patient. You wouldn't be afraid to tick a box in the form, but in the consulting room you would-

P: Not mention it.

C: Not bring it up. I believe that is what those questionnaires are for, right?

Multiple patients expressed concerns about **limited consultation time** and the **fear of burdening** their **clinician** by discussing PROs unrelated to their medical expertise. Some clinicians agreed, feeling that they 'cannot fix everything'. However, other clinicians argued that discussing 'minor problems' or issues outside their expertise can offer a better **overall understanding of the patient**, helping to deliver the best care and make necessary referrals (**Box 6**).

Box 6 (CKD), ***p=patient, c=clinician***

C: As a doctor, you hear about a great number of health problems from patients, most of which you actually cannot fix. And that creates the risk of raising false expectations, because as a doctor you can lower the blood pressure, but many other health problems you cannot do all that much about. But on the other hand, I do think that as a doctor I can help people better when I have a better understanding of what is going on exactly. And I do think that it's important that patients also have proper insight into what exactly you can do with it.

While clinicians often mentioned that completing PROMs could be burdensome for patients, many patients, including those who were initially uncertain about the value of PROMs, said they would be willing to do so if their clinician asked. According to one clinician, 'framing' PROMs as part of routine care (e.g., resembling a blood test) and explaining their relevance is key to encourage patient willingness to complete them.

3.2.3 Prognostic estimates

Most patients, particularly those with BC, preferred to hear personalized predictions, because **uncertainty about the future can be challenging to cope with**. Clinicians noted that they often make assumptions about whether patients want to hear specific prognostic information, but the interviews revealed that these assumptions were not always accurate (**Box 7**).

Box 7 (Metastatic BC), ***p=patient, c=clinician***

C: To show this [personalized prediction regarding survival rate], that's just such a hard reality. And fortunately that is not true in most cases, but I do notice that with, with those patients [that have negative prospects] I tend to do show that less often- what I, we, do when we know the prospects are very poor, then I keep- sometimes I withhold it from them for a bit, until they have seen the oncologist, because they will discuss it with the patient anyway. I notice that I do that, but if people ask for it, then I will obviously show it, but then I just don't like doing it, I just hate it, it's so shit.

P: But even if the outlook is, er, poor or, er, five years-

C: Would you still like to see it?

P: Yes, then I would still want to know.

C: Fair enough, so I-

P: Then I could take it into account.

C: Fair enough, so I am actually too much in the habit of assuming what the patient in front of me would want, because even if you have a very poor prognosis, some people absolutely don't want to know about it, but others actually prefer to know what they can expect.

Different BC patients explained that their desire to receive prognostic outcomes, such as 'survival', depended on when the outcomes were shared, and that these **preferences could change over time (Box 8)**.

Box 8 (BC), ***p=patient, c=clinician***

C: If people in the beginning say, no, I don't want to know survival outcomes, would you advise to bring it up again at a later time or to leave it at that?

P: I would say yes, you should, because people's perspectives can change over time. Looking at myself, with the studies, for example; in hindsight, I feel that I would have wanted to do that. So I get it that you may not want to know about it in the beginning, but you may want to know halfway through. So you can always offer it again.

In CKD, several patients mentioned wanting to know predictions about disease progression only **if they could still take action to prevent it**. For some, these predictions acted as a 'wakeup call' to commit to their treatment. CKD clinicians explained that they often use predictions as a **motivator** for patients. However, when a patient cannot take steps to improve their prognosis, communicating prognostic estimates can have a negative impact and **discourage** them, according to both a CKD- and BC clinician (**Box 9**).

Box 9 (CKD), ***p=patient, c=clinician***

P: I seize every moment of life, so no, I wouldn't want to know [calculated risk on the need for kidney replacement therapy in 2 and 5 years]. Then I would build my life around the prospect of those two or five years. No, I don't want to do that. Let me just enjoy each day. Would you recommend it to anyone?

C: Well, if the model contains elements you can actually influence, it could be helpful. For example: if it includes smoking, it would be possible to show a particular percentage depending on whether or not someone smokes, perhaps it might motivate them to quit.

P: Well, yes.

C: Yes, that would be useful, but I think it's very difficult. Particularly with something like a decline in kidney function. That is actually also what you basically said. You can give people a whole lot of information, but if they actually have no influence on what happens, that can really only have a very negative effect.

Some patients preferred not to receive any prognostic estimates. Both CKD and BC patients emphasized that every patient is unique, and therefore, **predictions may not be accurate** for the individual. Patients also expressed concerns that incorrect prognostic estimates could **significantly impact their life choices and how they experience life (Box 10)**.

Box 10 (CKD), ***p=patient, c=clinician, p1= patient's partner***

C: Would you want to know about such as a prediction [calculated risk on the need for kidney replacement therapy in 5 years]?

P: I don't know if I would want to, to know about such a prediction.

P1: But, well, it would of course create a bit more clarity if you were going to start with dialysis, if that were necessary.

P: Yes, but it's a prediction, sort of like the weather forecast. And you would base your whole outlook on it, telling yourself that you can expect to be left with a certain number in five year's time. But things may turn out differently. Plus, I personally don't feel the need to know about it. It would consume far too much of your life and, you also want to have a normal life aside from it.

Acknowledging the varying patient preferences, CKD and BC clinicians expressed difficulty in deciding how much prognostic information to disclose. Clinicians either asked patients before sharing such information or, more often, made their **own judgment** about whether patients wanted to know **(Box 11).**

Box 11 (BC), ***p=patient, c=clinician***

C: With some patients, they very clearly don't want to know about things [predictions regarding mortality], so then I just don't tell them, or when you, when you sense that someone doesn't- But okay, that's of course a bit subjective, that I then think I can sense that, but that's why I deliberately don't tell some women about certain things. That, those are never really important things, because then, with those I know you're expected to-

P: Over the course of the conversation you get a sense of, er-

C: You get a bit of a sense of what their needs are, so to say. That's what I hope, I hope that I am able to do that.

Many clinicians opted to discuss disease prospects in a more '**general way'** rather than providing patients with probabilities and exact numbers, because patients may cling too much on the latter. This view was often shared by the patient.

3.2.4 Comparing individual PROs to aggregated data

Opinions on the usefulness of comparing individual patient's PROs to those of a group of comparable patients varied. Several clinicians found such a comparison helpful to inform patients about **disease prospects,** including expected symptoms. Patients felt it would be useful to **understand the symptoms** they experienced. Patients explained that they used it as a global reference, for motivation or to guide treatment decisions. Whether a patient was performing better or worse than the reference group seemed to affect their preference for hearing comparisons based on aggregated data. Both patients and clinicians agreed that **doing better can be motivating**, while some BC patients remarked that **doing worse can be difficult to hear and demotivating,** especially when they don't know how to improve their PROs. This led some patients to wanting to avoid hearing the comparisons.

Other patients also did not want to compare themselves to aggregated data, as they believed: **every individual's disease experience is unique.** They valued the opinion of the clinician over the comparisons with aggregated data. Some patients believed that such comparisons could negatively affect their own symptom experience. A patient added that it may depend on **personality traits** whether patients see added value in the comparisons. When this was brought up in an interview, the clinician came to realize that such comparisons may not suit everybody, and realized they needed to check whether patients want to receive such information before discussing it.

Box 12. Reflections on doing dyadic interviews

- Power imbalances may exist between a patient and their treating clinician. This may go two ways; patients feeling less empowered compared to the clinician who has medical knowledge and guides their treatment, and clinicians may feel limited in expressing themselves freely to maintain a good patient-clinician relationship and being professional and polite. Considering the potential power imbalances, we noticed the following:
  - Clinicians often let the patient respond first, perhaps they did not want to 'overrule' them.
- Both parties frequently spoke up and did not seem to hold back when they disagreed with each other. This was more evident in some interviews than others. Overall, we do think there was room for both to share honest opinions.
- Patients did not look for confirmation with their clinician when they stated something.
- Patients were often not convinced by clinicians in a discussion or when there was disagreement.

- We do think there was room for both to share honest opinions, as even critical remarks regarding the other were sometimes shared (both ways).

- Participants were enthusiastic about the interviews and having a 'different' conversation with each other.
- Multiple 'light-bulb-moments' arose from the interaction between participants, because they were able to directly reflect on each other's statements. These findings were particularly relevant and cannot be achieved using individual interviews.
- Using question cards proved effective in maintaining the conversation between the two participants while allowing the researcher to remain minimally involved in the interaction.
- The dyadic interviews appeared to strengthen the patient-clinician relationship by juxtaposing their perspectives and allowing them to hear each other's reasoning, fostering a deeper mutual understanding.

4. Discussion and conclusion

4.1. Discussion

We aimed to better understand what meaningful use of outcome information during healthcare visits entails. To achieve this, we conducted dyadic interviews to study both patients' and clinicians' perspectives on different types of outcome information, including outcomes, PROs, prognostic estimates, and comparisons of individual PROs to aggregated data. The interviews uncovered that assumptions about one another were not always accurate. Addressing these misconceptions sparked new insights: patients realized that their non-medical information holds value for clinicians, while clinicians recognized that they sometimes do not correctly assume which outcomes patients prioritize hearing about.

We identified variability in the preferences of both patients and clinicians regarding which outcomes were considered important to discuss during healthcare visits. This individual variability is in line with earlier research regarding outcomes [20,22]. For patients, preferences depended on their verbal assertiveness in raising topics and whether they needed PROMs for this end and their strategies for coping with uncertainty about the future. In addition, patients who emphasized that 'every individual is different' focused less on predictions and comparisons with others based on aggregated data, compared to those with a less individualistic perspective. Regarding prognostic outcomes, patients' preferences in receiving the outcomes was also determined by the patients' ability to change the outcomes.

In this study we identified a difference between patients with a focus on numerical outcomes and patients who focused more on qualitative outcomes, such as how they are feeling. In CKD interviews, some patients fixated on the kidney function (measured with eGFR) overshadowing other important topics of conversation including overall functioning and treatment goals to slow down kidney function decline. Patients were also not always aware of the treatments related to slowing down kidney function decline (e.g., blood pressure regulation). Rather than a misalignment in views regarding which outcomes CKD clinicians and their patients consider important, it highlights a knowledge gap within CKD patients. Use of additional information tools for patients to better understand the treatment goals related to slowing down kidney function decline may be helpful.

Although less evident, clinicians also differed in the emphasis on numerical outcomes. An explaining factor for this difference may be the numeric-self efficacy (one's own confidence in numerical data). In Peters et al., they found that people with lower subjective numeracy were less motivated in numeric tasks and had more negative reactions to numbers [27]. This relates to both clinicians who provide numerical information and patients who receive it. Clinicians and patients with higher numeric-self efficacy may tend to numerical outcomes more than when having lower numeric-self efficacy. Additionally, patients may react differently to provided numerical information depending on their level of numeric-self efficacy. Thus, differences in numeric-self efficacy should be acknowledged, as they can influence how numerical information is interpreted and applied in medical decision making [28].

Another important finding was the identified assumptions of patients and clinicians regarding each other. The dyadic interviews enabled participants to directly respond to each other's statements, which revealed that these assumptions were not always accurate. Three main misconceptions will now be discussed. First, patients were often unaware that the information they can provide, such as preferences, daily life circumstances, and social functioning were valuable alongside clinical information. In a review by Joseph Williams et al., they explain that this believe hinders shared decision making. Efforts should be made to help patients recognize that their lived experiences are important[29]. A genuine curiosity among clinicians to gain a holistic understanding of their patients will support this effort. Second, patients did not always realize that PROs could benefit them personally, not just help clinicians monitor disease. In discussing PROs during interviews, these patients realized they could use them to prepare for healthcare visits. Clinicians often assumed PROs were burdensome for patients, as often mentioned in literature [30], however patients refuted this during the interviews.

Patients expressed a willingness to complete PROs, particularly when they were relevant to their care. Moreover, patients had realistic expectations about discussing PROs, considering time constraints and their clinician's ability to offer care outside the scope of their specialization. Third, clinicians did not always correctly assume their patient's information needs, particularly regarding prognostic outcomes. Clinicians mentioned to judge per patient what outcomes to share with them, but some patients disagreed with their judgment (e.g. not wanting to hear the outcomes). During these conversations, clinicians realized that sharing certain outcomes could have unforeseen negative effects, and not every patient wants to hear them. Importantly, patients added that they may change their view over time about whether they want to receive outcome information.

4.2 Practice implications

This study has several implications for clinical practice. First, our findings identified different factors that contribute to effective use of outcome information: 1) clinical outcomes alone do not suffice to understand patients' overall health status and patients should be made aware that their lived experience is important to discuss, 2) when using PROs, the goal of its use should be clear to both clinicians and patients, 3) information-overload should be avoided, in particular when both PROs and clinical outcomes are discussed, and 4) patients' individual information needs vary and should be explored by clinicians rather than assumed.

A key strength of this study is the method of dyadic interviewing. This method proved highly effective for thoroughly exploring diverse perspectives. By facilitating direct reactions to each other's arguments, the dyadic interviews enabled participants to generate new insights. Shared opinions were reinforced, while conflicting views prompted the emergence of new arguments or clarification of differences. Future research on diverse topics regarding both the perspective of patient and clinician could similarly benefit from employing this method.

This study has several limitations. Although we aimed to minimize power imbalances during interviews, we cannot exclude the possibility of social desirability bias affecting the candour of patients and clinicians. However, our observations suggest that this bias was probably limited, as both parties openly discussed 'negative' aspects of certain outcome information and frequently disagreed with each other. Secondly, outcome information based on comparisons with aggregated data was not yet routinely used in consultations, and therefore discussion of this topic was abstract despite visual examples. Thirdly, there may have been some residual selection bias as clinicians were responsible for selecting participating patients, which could have influenced the results despite efforts to mitigate this bias. Fourthly, health literacy scores of patients included in this study were high as well as the average education levels. This may limit generalizability of the results. Additionally, we did not test the illness understanding of participating patients. Illness understanding may affect which outcomes patients prefer to (not to) discuss. Lastly, patient input into the study's topic list was derived only from CKD patients and not BC patients. Furthermore, although noted in the COREQ guidelines, we did not perform validity checks with all participants.

4.3. Conclusion

In conclusion, conducting dyadic interviews with patients and clinicians revealed a variation in individual preferences for discussing different types of outcome information during healthcare visits. For patients, these variations were partly shaped by the level of disease insight (being able to link outcomes to their disease status), but also personal traits such as how to cope with uncertainty about the future and verbal assertiveness in raising topics during healthcare visits (for which PROMs were considered helpful). The dyadic interview method proved to be effective in revealing misconceptions between patients and clinicians. Patients were not always aware that their information was important to discuss, and clinicians sometimes misjudged their patient's information needs. Through genuine curiosity in one another and open dialogue such incorrect assumptions can be avoided. Exploring (information) preferences, rather than assuming them, is key.

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Supplement 1 – Examples provided of outcome information during the interviews.

1A.Examples of patient reported outcome measures (PROMs), used in both CKD and BC interviews.

For both breast cancer and CKD, examples of PROM-questions regarding physical and mental health were shown:

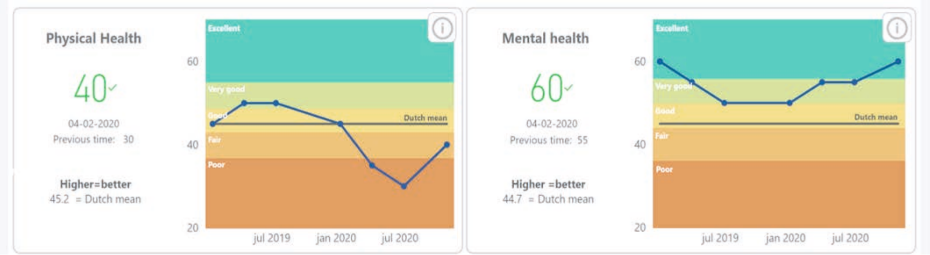
How would you rate your overall pain levels: 0 (no pain) until 10 (worst imaginable pain)

How would you rate your overall tiredness?
- none
- mild
- moderate
- severe
- very severe

How would you rate your overall quality of life?
- poor
- fair
- good
- very good
- excellent

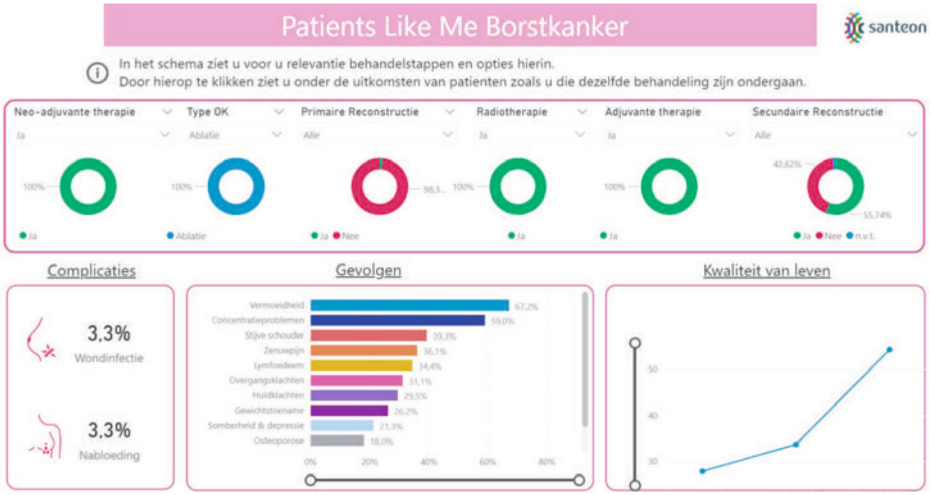
1B. Examples provided of individual PROs to aggregated PRO data used in both CKD and BC interviews

For patient-aggregated data comparisons examples included comparing patient individual mean PROM scores on physical and mental health with the mean scores of the Dutch population, visualized in a graph.



1C. Example of comparing individual PROs to aggregated data used in BC interviews.

A visual (in Dutch) of a Santeon – made dashboard was shown that visualizes the complications, effects (patient reported/PROs) and quality of life of patients grouped per therapy modality.


Patients Like Me Borstkanker

In het schema ziet u voor u relevantie behandelstappen en opties hierin.
Door hierop te klikken ziet u onder de uitkomsten van patienten zoals u die dezelfde behandeling zijn ondergaan.

Neo-adjuvante therapie: Ja
Type OK: Ablatie
Primaire Reconstructie: Alle
Radiotherapie: Ja
Adjuvante therapie: Ja
Secundaire Reconstructie: Alle

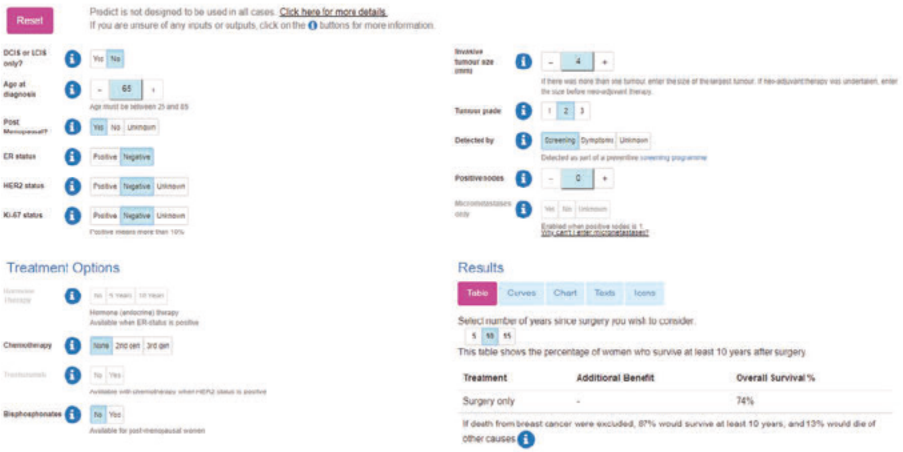
1D. Example of a prediction model used in CKD interviews

The Kidney Failure Risk Equation was used as a model that predicts risk of progression to kidney failure (and needing kidney replacement therapy such as dialysis). This model provided the following information:

The chance on kidney failure and needing kidney replacement therapy in two years = ... %
The chance on kidney failure and needing kidney replacement therapy in five years = ... %

1E. Example of a prediction model used in BC interviews

The visual example of a prediction model in breast cancer was the PREDICT (https://breast.v3.predict.cam/tool) for breast cancer prognostic model predicting survival with/without adjuvant systemic treatment.



Predict is not designed to be used in all cases. Click here for more details.
If you are unsure of any inputs or outputs, click on the ⓘ buttons for more information.

DCIS or LCIS only? Yes [✓ No]
Age at diagnosis: 65
Age must be between 25 and 85
Post Menopausal? [✓ Yes] No Unknown
ER status: Positive [✓ Negative]
HER2 status: Positive [✓ Negative] Unknown
Ki-67 status: Positive [✓ Negative] Unknown
Positive means more than 10%

Invasive tumour size (mm): 4
If there was more than one tumour, enter the size of the largest tumour. If neo-adjuvant therapy was undertaken, enter the size before neo-adjuvant therapy.
Tumour grade: 1 [✓ 2] 3
Detected by: [✓ Screening] Symptoms Unknown
Detected as part of a preventive screening programme
Positive nodes: 0
Micrometastases only: Yes No Unknown
Enabled when positive nodes is 1.
Why can't I enter micrometastases?

Treatment Options

Hormone Therapy: No 5 Years 10 Years
Hormone (endocrine) therapy
Available when ER-status is positive
Chemotherapy: [✓ None] 2nd gen 3rd gen
Trastuzumab: No Yes
Available with chemotherapy when HER2 status is positive
Bisphosphonates: [✓ No] Yes
Available for post-menopausal women

Results

Select number of years since surgery you wish to consider.
5 [✓ 10] 15
This table shows the percentage of women who survive at least 10 years after surgery

Treatment	Additional Benefit	Overall Survival %
Surgery only	-	74%

If death from breast cancer were excluded, 87% would survive at least 10 years, and 13% would die of other causes

Supplement 2 – Topic list used

During this dyadic-interview, or duo-interview, we ask you, as patient and healthcare provider, to have a conversation with each other about different types of information shared during a healthcare visit.
Here is how the duo-interview works:
In front of you are cards with questions related to the condition for which you as a patient are being treated by your healthcare provider. The cards are color-coded by theme. One of you picks a card at a time and reads the question out loud. You may each take a moment to think about your answer to the question. If you like, you can write your thoughts down. Then, you will discuss the question with each other. You may ask each other follow-up questions and spend as much time on each card as you wish. Once you feel the question has been sufficiently discussed, you can move on to the next card.
The aim is for the conversation to take place mainly between the two of you, while I, as the interviewer, stay in the background as much as possible. Of course, you can always ask me questions if anything is unclear. I may also occasionally explain certain definitions during the conversation.

Theme 1: Which outcomes?

Card 1:

What does **'good health'** look like for you as a patient?

Explanation: We ask you as a healthcare provider to think about that good health looks like for this particular patient. For the following cards, we will also ask you to answer the questions with this specific patient in mind.

Alternative phrasing/clarification:

To the patient: Describe what good health looks like for you.

To the healthcare provider: Describe what you think good health looks like for this patient.

Card 2:

Which information do you need to know how it is going with your condition?

Alternative phrasing/clarification:

To the healthcare provider: What information do you need in order to understand how this patient's condition is progressing?

Card 3:

Which information do you need to determine whether a treatment is successful?

Try to think of a treatment recently started.

Alternative phrasing/clarification:

To the healthcare provider: On which factors do you determine whether a treatment for this patient was successful?

Card 4:

What information do you sometimes feel is missing after a consultation? In other words, what is not discussed that you would find useful?

Theme 2: Clinical outcomes and PROMS

Explanation (by the interviewer)

Results/effects of provided care (treatment outcomes) can be discussed in different forms: clinical- or medical- outcomes and outcomes reported by patients themselves. Clinical outcomes derive from the healthcare provider and include things like blood test results or blood pressure measurements. Next to these clinical outcomes, outcomes exist that say something about how a patient is feeling or doing. Only the patient him/herself can provide this information. These outcomes are called patient reported outcomes or PROMS. PROMs are collected by questionnaires send to the patient to fill out. Example of PROM-topics include level of fatigue, level of pain or emotional well-being.

What kind of information is mainly discussed during conversations between you two during healthcare visits?

Additionally:

- Are PROMs sometimes discussed?

- Is information sometimes visualized during the healthcare visit?

Card 5:

Which information do you need to determine the effects of a treatment?

(try to think of a recently started treatment).

Alternative phrasing/clarification:

To the healthcare provider: Which information do you need to determine potential effects of a treatment of this patient?

Card 6:

What can discussing both medical information and patient-reported information during the consultation lead to? Can you think of any positive and negative effects of each?

Explanation (by the interviewer)

Sometimes we can compare information of one patient to information of a group of patients with similar characteristics (such as age and sex) and similar condition. You can compare your scores on clinical information or PROMs to the other patients.

[A visual example is shown.]

What do you think of this kind of information?

Card 7:

You as a patient, did you ever experience being compared to a group of similar patients? If so, what kind of information was the comparison about?

Alternative phrasing/clarification:

To the healthcare provider: Do you ever use comparisons of information of the patient to a group of patients?

Card 8:

Discuss with each other whether you find it useful to discuss such comparisons of yourself to a group of similar patients? Why or why not?

Alternative phrasing/clarification:

To the patient: Would you want to compare information about yourself with a similar group of patients? Why or why not?

To the healthcare provider: Do you find it useful to compare this kind of information across similar patients? Why or why not?

Card 9

Which information would you like to compare with a group of similar patients, and why?

Additionally: Is there information that you would absolutely not wish to compare with a group of similar patients, and why?

Alternative phrasing/clarification:

To the patient: In what aspects would you like to compare yourself with a group?

To the healthcare provider: What information from this patient would you find useful to compare with a group?

Theme 3: prediction model

(Explanation by the interviewer)

For CKD:

Calculation programs exist that, based on information about you, such as kidney function, age, and sex, can predict something about your condition. For example, the chance on needing kidney replacement therapy in a few years. A prediction like that calculated on information of you is called a prediction model. A prediction is always an estimate; just like a weather forecast, it may not always be accurate.

For BC:

Calculation programs exist that, based on information about you, such as, age, sex, tumour characteristics, can predict something about your condition. For example, the chance on survival in 5 or 10 years. A prediction like that calculated on information of you is called a prediction model. A prediction is always an estimate; just like a weather forecast, it may not always be accurate.

[A visual example is shown]

Card 10

Are such predictions ever discussed in the consultation room between you?

Card 11

Would you like to know such a prediction?

Closing remarks:

-Thank you!

-Any feedback for the researcher?