Decision-making under risks and uncertainty: insights from patient narratives

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Abstract

Background. A cancer diagnosis forces patients into repeated decisions. Outcomes, side effects, and prognoses are hard to predict, so risks and uncertainty run through the whole process. Much research treats risk and uncertainty as objective inputs that predict behaviour, such as treatment adherence. The lived, first-person experience of them is far less understood. This experience matters for individual care. It also matters for system-level decisions on the value and funding of treatments, which assume treatments are used as intended.

Methods. This study used a qualitative design. The data were eleven published, book-length illness narratives of Dutch cancer patients. Relevant fragments were identified, organised, and analysed inductively. Thematic analysis was supported by open, axial, and selective coding. The theoretical framework combined behavioural decision theories, health psychology, and sociological approaches to illness. It was used to interpret the findings, not to predefine them.

Results. The analysis produced eight cross-cutting themes. Patients regulated threatening information by seeking it or avoiding it. They weighed risk through bodily and biographical experience rather than statistical probability. Uncertainty was cumulative and persistent. It was managed rather than resolved. Personal values set the limits of acceptable treatment. Bodily integrity and quality of life often outweighed the chance of a cure. Pre-stated values sometimes shifted abruptly under existential pressure. Whether they shifted depended on how central they were to identity. Faith, family, and identity served as anchors of meaning. Patients often acted as their own case managers when the system fell short. They alternated between trust in clinicians and personal autonomy.

Conclusion. Patients translated risk and uncertainty into personal, liveable terms. They did so by regulating information, drawing on values, and exercising agency. These findings point to cancer care that is more dynamic and more equity-oriented. They also support embedding patient experience in clinical and policy decisions.

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Introduction

Problem analysis

A diagnosis of cancer confronts patients with a series of decisions. They must decide whether to start, continue, switch, or stop a treatment, and whether to undergo surgery or different forms of therapy. Each case forces patients to weigh the prospect of cure against the side effects and disruption that treatments bring to daily life (Gleason et al., 2009; Verbrugghe et al., 2013). Treatment trajectories are often long and complex, and outcomes cannot be predicted with certainty. That makes these decisions complicated. Side effects are difficult to predict, and the prognostic information patients receive is often difficult to interpret (Han et al., 2011; Engelhardt et al., 2017). In this context, cancer care is characterised by risks and uncertainty at almost every step of the decision-making process.

In literature, risk and uncertainty have many different definitions. In this study, risk refers to the probability and severity of a specified, usually adverse, outcome (Aven & Renn, 2009). Risks are shaped not only by statistical information but also by personal experience, emotion, and values, meaning that patients evaluate and respond to risks subjectively rather than purely based on objective risk assessment (Slovic et al., 2004; Zinn, 2008). In healthcare, uncertainty comes in three forms, according to Han et al. (2011): probabilistic uncertainty (indeterminate outcomes), ambiguity (limitations or conflicting evidence), and complexity (multiple interacting factors). In oncology, these forms of uncertainty are particularly noticeable. Patients must constantly make decisions without knowing exactly how their disease or their bodies will respond to treatments. However, clinical practice guidelines are mostly based on clinical evidence and population-level statistics. As a result, they offer limited guidance on the subjective patient experience and on responses to risks and uncertainty throughout their treatment (Lugtenberg et al., 2011).

Patients' subjective experiences of conditions of risks and uncertainty have important consequences for their health-related behaviour throughout the healthcare process. Research suggests that patients' perception and response to risks and uncertainty can shape whether and how they engage with their treatment (Gleason et al., 2009; Durosini & Pravettoni, 2023). Studies on oral anticancer treatments provide an example. They suggest that adherence is influenced by patients' beliefs about the treatment, their experiences of side effects, and how they weigh the burden of treatment against anticipated benefits (Verbrugghe et al., 2013; Greer et al., 2016). More broadly, in research on cancer treatment decisions, Langmuir et al. (2023) suggest that patients report a greater treatment-related burden when experiencing high uncertainty and emotional distress around treatment choices.

This burden is further aggravated by a mismatch in decision-making roles. A patient may wish to let the physician decide, to decide together, or to decide largely on their own. When their actual role in the decision-making process differs from the one they preferred, the treatment-related burden grows (Huijgens et al., 2025). Patients attribute this burden to several other sources as well. These include uncertainty stemming from a lack of medical knowledge and the unpredictability of how their treatment and disease will develop; difficulty envisioning the severity of possible side effects; fear of making the wrong choice; and an overwhelming sense of responsibility for their own treatment (Huijgens et al., 2025).

However, much of the research on risks and uncertainty has treated them as objective inputs or predictors of a behavioural outcome, such as adherence. Before a new treatment reaches patients, manufacturers must submit a comprehensive dossier to regulators such as the European Medicines Agency. They will conduct a structured benefit-risk assessment before market authorisation (Taams et al., 2024). This assessment weighs a treatment's expected benefits against its risks. Based on that assessment, health technology assessment (HTA) bodies then inform reimbursement and coverage decisions on a national level. They do so by evaluating clinical effectiveness and cost-effectiveness, often based on quality-adjusted life year methods (Drummond et al., 2015; National Institute for Health and Care Excellence [NICE], 2013). However, these evaluations are under the assumption that treatments will be used as intended (adherence). In practice, the effectiveness of treatments is partially dependent on whether patients initiate and sustain them, and patients' willingness to do so is, among other things, shaped by their experiences with associated risks and uncertainty (Greer et al., 2016; Verbrugghe et al., 2013). This experiential dimension, how patients themselves actually experience and make sense of risks and uncertainty as a lived, evolving process, is far less known. Projected cost-effectiveness and care efficiency may therefore not be realised if patient experience is not taken into account. This is a blind spot at the intersection between patient-centred care and health policy. At the same time, multiple HTA bodies believe that patient perspectives should and will be part of HTA decision-making (Facey et al., 2010; Van Overbeeke et al., 2021). Therefore, understanding how cancer patients experience and cope with risks and uncertainty is important for individual care as well as for HTA policy decisions on funding treatments and care pathway designs.

Academic relevance

Academically, this research contributes to a more comprehensive understanding of illness experience and patient behaviour under conditions of uncertainty and risks. Traditional behavioural theories, such as bounded rationality (Simon, 1957) or Prospect Theory (Kahneman & Tversky, 1979), offer important insights into cognitive limitations and how patients diverge from rational risk calculation. However, these frameworks have been developed primarily in experimental or theoretical contexts. By complementing

such theories with patients' narratives of lived experiences – a side of healthcare which is less well understood – this study extends their application to an experiential, qualitative context, contributing empirical insights into how uncertainty and risk are coped with and navigated over the course of a healthcare process. A better understanding could bridge the gap between theory and practice for cancer patients facing risks and uncertainty by complementing existing clinical guidelines with recommendations for the adjustment of treatment policies.

Societal relevance

Societally, a deep understanding of how cancer patients experience risks and uncertainty can support more patient-centred care. Insights from patient narratives may help physicians communicate risks and uncertainty more effectively, accommodate treatment discussions to patients' values and priorities, and design care pathways that reflect the realities cancer patients face. HTA bodies increasingly recognise the need to implement patient experience data into their assessments (Facey et al., 2010; Van Overbeeke et al., 2021). Qualitative insights into how patients navigate risky and uncertain situations are able to complement quantitative evidence, supporting a more realistic treatment value, since a treatment only delivers the promised value if it is used as intended (May et al., 2014). With time, this knowledge could be a foundation for improvements in clinical guidelines and policies aimed at improving care for a growing, vulnerable patient population.

Objective

The aim of the research is to grasp the essence of how cancer patients experience and cope with risks and uncertainty throughout their healthcare pathways, while accounting for their personal values, treatment burden, and relationships with healthcare providers and the system. Drawing on published patient narratives, which give first-person, longitudinal insights into lived experiences that surveys and clinical data cannot, this study makes this experiential dimension visible. Theoretically, this extends behavioural and illness theories developed in experimental settings to lived experience. Practically, this offers a basis for clinical guidelines and HTA to manifest patient experience on which the real-world effectiveness of treatments depends.

Research questions

The main research question is:

How do cancer patients experience and cope with risks and uncertainty throughout the healthcare process?

The sub-questions for this research are:

How do cancer patients perceive and respond to risks and uncertainty in their diagnosis, treatment, and prognosis?

How do personal values and treatment burden shape the way cancer patients cope with risks and uncertainty?

How do cancer patients navigate relationships with healthcare providers and the system under conditions of risks and uncertainty?

Structure of the thesis

The remainder of this thesis is structured as follows. The theoretical framework first sets out an interdisciplinary lens used to interpret the findings, combining behavioural decision theories, health psychology and sociological approaches to illness. The research method then describes the qualitative, narrative-based design, the data collection and selection of narratives, the analytical approach, and the steps taken to support validity and reliability. The results present eight cross-cutting themes, organised under the three sub-questions. The discussion interprets these themes against the theoretical framework, draws out theoretical, practical, and policy implications, and reflects on the strengths and limitations of the study. The conclusion returns to the research questions and summarises the central contribution.

Theoretical framework

This study draws on an interdisciplinary theoretical framework to examine how cancer patients experience and cope with risk and uncertainty during their healthcare process, and how this shapes their health-related behaviour. This framework integrates behavioural decision theories, health psychology and sociological approaches to illness.

Traditional theories

The normative decision-theoretic theory of expected utility (EUT) assumes that individuals are perfectly rational and make decisions by systematically weighing the expected benefits and risks of different options to maximise their utility (Von Neumann & Morgenstern, 1947). However, empirical research shows that this theory is not applicable to patients in the real world, because they often deviate from this normative decision-making ideal (Abellan-Perpiñan et al., 2009; Starmer, 2000). This is evident particularly in oncology, where patients deal with uncertainty regarding prognosis, treatment interactions, and side effects (Han et al., 2011). Furthermore, EUT describes patients' experiences and responses to risks poorly (Reyna, 2008).

To address these limitations, this study makes use of the theory of bounded rationality. This theory suggests that decision-makers act under cognitive restraints and incomplete information (Simon, 1957). Rather than maximising their expected utility, individuals rely on heuristics, simplifications, and satisficing strategies (Simon, 1957; Tversky & Kahneman, 1974). In the case of cancer, emotional distress, uncertainty, and conflicting information further constrain analytic reasoning (Han et al., 2011; Tinetti et al., 2004). Empirical research suggests that patients with chronic conditions frequently prioritise certain outcomes such as independence or symptom relief over marginal survival gains, especially when dealing with a high treatment burden (Fried et al., 2011). Thus, bounded rationality can offer a more plausible view on how cancer patients make sense of their situation and navigate healthcare under conditions of risks and uncertainty.

Building on bounded rationality, Slovic et al. (2004) argue that individuals perceive risks more often through affective and intuitive processes rather than purely analytic calculations. Prior experiences, emotions, and framing shape the way patients evaluate risk (Slovic et al., 2004; Reyna, 2008). Prospect Theory further clarifies this by showing that individuals evaluate outcomes relative to certain reference points, often overweighting potential losses compared to gains of the same size (Kahneman & Tversky, 1979). Together, bounded rationality and Prospect Theory explain why cancer patients respond to risks and uncertainty by often diverging from statistical risk probabilities. A vividly imagined side effect can matter far more to a patient than how likely it is to be severe. A certain effect can also be experienced very differently, depending on whether it is framed as a potential loss or a potential gain. This is why patients may rely on personal experiences and values in how they navigate their healthcare process.

The behavioural theories addressed above explain cognitive and affective mechanisms of risk evaluation, but do not address the experience of uncertainty over time. Mishel's Uncertainty in Illness Theory (UIT), on the other hand, does this by explaining how patients construct meaning under conditions of uncertainty throughout their illness trajectory (Mishel, 1988). UIT states that uncertainty occurs when a patient fails to determine the meaning of illness-related events (Mishel, 1988). Uncertainty has a subjective meaning (appraisal) in UIT, because a patient can either evaluate it as a danger – implying harm for which coping mechanisms are used to reduce it – or as an opportunity – implying a positive outcome for which coping mechanisms are used to keep it (Mishel, 1988). Empirical studies in oncology support the distinction between danger appraisal and opportunity appraisal, showing that the former is associated with emotional distress (Mishel & Sorenson, 1991).

Mishel (1990) reconceptualised UIT to address living with continual, constant uncertainty in chronic illnesses, which is used by individuals as a starting point for a new view of life (Mishel, 1990). Probabilistic thinking – which involves accepting uncertainty as a permanent, natural part of life, rather than expecting certainty or predictability – may be the replacement of said uncertainty (Mishel, 1990). This can be relevant for cancer patients who are facing either a long treatment or have the constant possibility of recurrence (Mishel, 1990). Consequently, UIT offers a theoretical framework for understanding how uncertainty is experienced and coped with by the patient.

However, a gap in decision theories is their treatment of patient values, which are viewed as relatively stable. Prospect Theory suggests that outcomes are judged relative to certain reference points (Kahneman & Tversky, 1979), and the reconceptualised UIT describes a step-by-step move to a new view of life (Mishel, 1990). Neither describes a sudden change of internal values and standards. This is covered by the concept of response shift, a change in an individual's internal standards, values and their conceptualisation of quality of life (Sprangers & Schwartz, 1999). Response shift provides a framework for the discrepancy between patients' anticipated choices and those actually made. Personal values, however, do not guide behaviour on their own. They enter a broader motivational process that determines whether, and how, a patient act on them. A framework that link risk perception and personal values to the step from intention to behaviour is therefore needed.

The I-Change Model

How behavioural intentions translate into action is captured by the Integrated Change (I-Change) Model. This model incorporates elements from different behavioural theories to conceptualise behaviour change as a process (De Vries et al., 2005). This process consists of three phases: pre-motivational, motivational, and post-motivational (De Vries, 2017). The I-Change Model is relevant to this study because it explains the role of risk perception and information processing in shaping health behaviour, and it shows that

moving from awareness to action is not an automatic process but that it depends on motivational and practical factors (De Vries, 2017).

In the pre-motivational phase, individuals become aware of relevant health risks and cues to action. Knowledge and risk perception are central here. A patient must first recognise the existence and personal relevance of a risk before any further step can follow (De Vries et al., 2005). The I-Change Model states that awareness is affected by information factors (the quality of message, channels and sources used) and predisposing factors (e.g. behavioural, psychological, biological, and social and cultural factors) (De Vries et al., 2005). The concept of uncertainty appraisal from UIT can be linked to this phase directly, because how patients receive and interpret illness information and risks shapes whether and how they perceive personal relevance (De Vries et al., 2005; Mishel, 1988). Other research on cancer patients shows awareness of risk is not identified the same way by every patient; their ability to process prognostic information is constrained by cognitive capacity, emotional distress, and quality of information provided (Engelhardt et al., 2017; Han et al., 2011).

In the motivational phase, behavioural intentions are formed and shaped by three determinants: attitude, social influences and self-efficacy. In the context of cancer care, patients' attitude towards treatment is affected by their perceptions of associated risks and uncertainty. Research on oral anticancer drugs shows patients' beliefs about treatment are important predictors of patients' intention to adhere to prescriptions (Verbrugghe et al., 2013; Greer et al., 2016). This link between risk perception and treatment adherence can be explained by the motivational phase of the I-Change Model.

In the post-motivational phase, the translation of intention into behaviour depends on action planning, coping planning, performance skills and the ability to overcome barriers (De Vries et al., 2005). The I-Change Model shows that forming an intention is not a guarantee to behavioural change, but that ability factors (implementation plans and performance skills) are necessary to go from intention to behaviour (De Vries et al., 2005). This is in line with earlier research showing that adherence is influenced by patients' initial willingness as well as their ongoing capacity to manage treatment demands within the context of their daily life (Verbrugghe et al., 2013; Greer et al., 2016).

Clinical practice

In clinical practice, shared decision-making (SDM) is the normative model of patient-centred care (Stiggelbout et al., 2012), a collaborative process between physicians and patients, where physicians contribute medical expertise and patients their preferences and values (Charles et al., 1997). Patients report greater satisfaction (Joosten et al., 2008) and reduced decisional conflict (Stacey et al., 2017) when they are actively involved in decision-making, and SDM has the ability to improve adherence to treatment in certain clinical contexts (Joosten et al., 2008). SDM presupposes that patients are willing and

able to participate in the decision, and that their values can be elicited and used to guide the decision-making process (Charles et al., 1997). In practice, however, patients differ in how much involvement they want, and not all wish to take an active role (Levinson et al., 2005). Research shows that a mismatch between a patient's preferred role and their actual role in the decision-making process increases anxiety and decision-related burden (Gattellari et al., 2001; Huijgens et al., 2025). SDM is hard to implement under conditions of risks and uncertainty, as confronting patients with multiple options can itself create anxiety (Elwyn et al., 2009; Engelhardt et al., 2020). Yet, patients' values should guide decisions when there is no clear best treatment option (Stiggelbout et al., 2012).

Drawing on SDM, the concept of minimally disruptive medicine (MDM) focuses on aligning healthcare with patients' capacity to cope with treatment demands in everyday life (May et al., 2014; Leppin et al., 2015). MDM is directly relevant to risks and uncertainty in cancer care for two reasons. First, it reframes adherence as a function of workload, not just of motivation. It argues that healthcare guidelines may impose treatment burdens that exceed patient capacity, which complicates enacting recommended care and may reduce adherence regardless of the patient's intentions (May et al., 2014). Second, it shifts attention from the single decision to the ongoing work of being a patient. That is where much of the experience of risks and uncertainty actually plays out. In cancer care situations where risks and uncertainty are present, SDM and MDM can help explain how treatment burden and patients' capacity constraints may influence patient engagement with and adherence to recommended therapies (May et al., 2014).

SDM and MDM theorise patient-physician relationships and treatment burden (Charles et al., 1997; May et al., 2014), while saying little about how patients actually navigate the healthcare system. The concept of patient activation explains how belief, confidence, knowledge, and skills are essential for patients to manage their own healthcare process and engagement with healthcare providers and services (Hibbard et al., 2004). Patient activation is closely related to the concept of health literacy: the capacity to access, understand, and use health information (Sørensen et al., 2012), further framed by Dixon-Woods et al. (2006), who suggest that the notion of candidacy describes how patients' eligibility to care is negotiated between patients themselves and a system that may facilitate or obstruct it. Patient activation, health literacy and candidacy explain the work that patients and their families need to put in to secure timely and appropriate care, possibly resulting in uneven distribution. This reliance on self-advocacy or agency, necessary because of fragmentation in healthcare systems, may introduce a dimension of inequity since patient activation and health literacy are socially dependent (Sørensen et al., 2015). A last addition to this framework is interpersonal trust in clinicians, which shows that reliance on professional authorities and personal autonomy can coexist and alternate, rather than exist mutually exclusive (Hall et al., 2001).

Coping and meaning

UIT and its reconceptualised version offer a limited view on the coping resources patients draw on once they appraise uncertainty as either danger or opportunity (Mishel, 1988; Mishel, 1990). The Transactional Model of Stress and Coping (TMSC) distinguishes between problem-focused and emotion-focused coping and frames coping as a process that changes over time in response to situational contexts. (Lazarus, 1993). This is particularly relevant in situations where patients deal with threatening information in opposing ways, by actively seeking or avoiding it. Miller (1987) captured and described this as monitoring versus blunting coping. Monitors actively scan for and attend to threat-relevant information. Blunters, on the other hand, cope by distracting themselves from or minimising such information. Alongside cognitive coping, there are also patients who rely on religious and spiritual coping (Pargament et al., 2000). Others rely on meaning-making processes through which threatening events are given an appraised meaning first. Then they determine the fit of their appraised meaning into their global beliefs, where the extent of discrepancy between the two determines the level of distress (Park, 2010). For chronic patients, such as cancer patients, illness can create biographical disruption that destabilises their identity and urges its reconstruction (Bury, 1982). This research suggests that faith, family, and a sense of self, redefined or not, can function as an anchor during uncertain healthcare processes.

Research method

This study used a qualitative research design to investigate how cancer patients navigate their decision-making process under conditions of risks and uncertainty. A qualitative design is appropriate because the research question concerns subjective interpretations, meaning-making processes, and understanding from the point of view of the cancer patients (Green & Thorogood, 2009).

The study used patient narratives. Patient narratives provide valuable insights into lived experiences and decision-making processes. Document analysis was used to select and analyse these narratives. Document analysis is particularly suitable for exploring experiences and interpretations that can be found in textual materials (Bowen, 2009). Narrative approaches visualise illness not only as a biological condition, but also as a lived experience that unfolds over time, shaped by meaning-making processes (Kleinman, 1988; Frank, 1995). Narratives allow patients to illustrate how they combine medical information, personal values and preferences, risks, and uncertainties into a (non-)coherent decision-making process.

Data collection

Relevant documents collected and used came solely from one established narrative repository: www.patientervaringsverhalen.nl, an initiative of the Erasmus School of Health, Policy & Management. The collection is focused on personal stories and experiences, which are the basis of this research. This repository was chosen as the only source for data collection because of its broad coverage of patient narratives and this study's focus on the Dutch healthcare system. Furthermore, these narratives were made public by the authors themselves. This study used only information that was in the public narratives. Ethically, a source reference is therefore enough to respect the authors' rights.

The inclusion criteria for this study were: patients in the narratives must have been diagnosed with cancer; patients must face treatment-related risks and uncertainty; patient narratives must explicitly describe how patients either navigated their decision-making process, perceived possible risks and/or how they made trade-offs within their healthcare process; narratives may be written in both Dutch and English, but should come from Dutch patients; narratives must be in the form of a book. The narratives come from Dutch patients, so that every narrative relates to the same healthcare system – the Dutch system. Book-length narratives were preferred because, rather than shorter online narratives, they tend to offer more depth and detailed descriptions of patients' experiences.

To look for narratives that fall within these criteria, the following strategy was used. On the website of the repository, filters were used to search for possible data sources. As the illness 'cancer' was used, and as a type of content, 'book' was used. Both were always selected with either of the following themes: 'alternative', 'professional as a patient',

'health process', 'use of medicine', 'quality of care', 'informative', 'patient-friendly care', 'assertiveness', 'coordination of care', or 'shared decision-making'. The results that came forward were judged on the title, the text on the back of the cover and its availability in the university library. The last step for inclusion entailed scanning reading, looking for possible useful information to answer the main research question or the sub-questions. This process was done by reading the prologue and epilogue, looking at certain chapters based on the table of contents, and by looking for specific trigger words, such as 'risk', 'choice' or 'uncertainty'. If this information was found during scanning reading, the book was included, read in full and analysed.

Data analysis

Whilst reading, fragments of text possibly relevant to the objective of this study were highlighted using five colours. Each colour represented a provisional domain (choice, risk, uncertainty, perception, other), in order to give the data a preliminary structure during collection. After all data were collected, the data fragments were manually typed into Excel and structured by colour code. Manually typing the fragments allowed the researcher to revisit the data. It also allowed the researcher to reconsider whether each highlighted text fragment genuinely contributed to the objective of this study.

During this step, some of the text fragments were removed from the dataset. A fragment was excluded when it did not contain relevant information on the perception of, response to, or coping with risks and uncertainty. Examples include passages that were purely descriptive of medical procedures, without any link to how the patient experienced risks, uncertainty, or a medical decision. Text fragments were long because context was included in them. Before coding, some text fragments were shortened or summarised, so as to make the data clearer for the coding process. No value of text was lost during this process.

Data were coded inductively. Inductive coding allowed for new concepts, themes or patterns to emerge from the data (Braun & Clarke, 2006). The theoretical framework was deliberately not used as a coding scheme during the analysis, in order to allow these themes and patterns to emerge without being constrained by predefined theoretical categories. The theoretical framework served two other purposes instead: first, it was used as background knowledge to help find data relevant to the objective; second, the theoretical framework was used to interpret the data after the coding process to make sense of the patterns identified.

Data were analysed by using thematic analysis, which is appropriate to identify patterns across textual data while still allowing flexibility (Braun & Clarke, 2006**)**. The analysis was done according to the six stages described by Braun and Clarke (2006): familiarisation with the data, initial coding, searching for themes, reviewing themes, defining and naming themes, and producing the report. For the initial coding, data were analysed

using open, axial and selective coding based on the Grounded Theory from Glaser & Strauss (1967). This method was not the main analysis strategy, but functioned merely as a structural framework for the raw data. The use of open-to-selective coding served a practical purpose. It provided a clear progression from descriptive (open) codes through relational (axial) codes to selective codes, without the explicit aim of generating formal grounded theory. The codes were first grouped into five domains. Through subsequent thematic analysis, these domains were refined into eight cross-cutting themes that address the three sub-questions. Combining these two strategies is methodologically justified because thematic analysis and Grounded Theory share a considerable overlap in their coding procedures, and thematic analysis leaves room for the researcher not to commit to the full theoretical implications of Grounded Theory (Braun & Clarke, 2006).

During the process of data analysis, the research question and sub-questions were refined based on the characteristics of the data. The original formulation focused on explicit reasoning behind medical decision-making and benefit-risk trade-offs by patients, but once the coding process was finished, the data proved to be insufficient to answer the original questions.

The original research question was: "*How do cancer patients navigate medical decision-making under conditions of multiple risks and uncertainty?"* The original sub-questions were: 1. "*How do cancer patients perceive and prioritise different types of risks?"; 2. "How do cancer patients interpret (and cope with) uncertainty in the healthcare process?"; 3. "How do cancer patients' personal values and preferences shape benefit-risk trade-offs?"*

Instead, the data turned out to be better suited to examine patients' experiences of risks and uncertainty, and how they navigated these, rather than the underlying thoughts and explicit reasoning for their decision-making processes. This adjustment is justified by the iterative nature of qualitative research, in which the research question and data are aligned through a reflexive process (Braun & Clarke, 2006).

Validity and reliability

Validity and reliability in qualitative research are difficult to determine, which is why Golafshani (2003) argues that these concepts must be redefined within a naturalistic paradigm, where trustworthiness is used as a measure of quality instead of statistics. For this study, reliability was therefore conceptualised as dependability, which refers to consistency of the research process rather than repeatability. Dependability was supported through the iterative nature of the coding process itself. Codes were continuously revised throughout the analysis as new patterns and themes emerged, reconsidering earlier interpretations. Central to rigorous thematic analysis, this continuous moving back and forth between data and codes made sure that the final

coding structure was grounded in a thorough engagement with the data (Braun & Clarke, 2006).

In qualitative research, validity is often conceptualised as credibility and trustworthiness (Golafshani, 2003). Golafshani (2003) emphasises that the credibility of the research depends heavily on the researcher's transparency and methodological rigour, because in qualitative research "the researcher is the instrument" (Patton, 2001, as cited in Golafshani, 2003). Throughout the data analysis, notes were made to record emerging patterns, making the reasoning behind analytical choices partially traceable. In addition, the supervisor reviewed the coding and thematic structure during the process, serving as an external check on the consistency of the interpretations. These measures together aimed to enhance both the dependability and credibility of this study.

Results

This chapter presents the findings of an inductive analysis of eleven published illness narratives of cancer patients, comprising a total of 108 coded fragments. The included narratives are listed in Table 1.

Table 1: Included patient narratives (N)

Code	Title	Author	Year	Type of cancer
N1	Anneke	Anneke Booij	2013	Breast cancer
N2	Opnieuw geboren	Sjaak Slangen	2018	Soft tissue sarcoma
N3	Naadloos van zorgverlener naar patiënt	Laura Klop	2018	Breast cancer
N4	De kwetsbare patiënt	Paul Goderis	2014	Thyroid carcinoma
N5	Prostaatkanker	Henri Pieter	2014	Prostate cancer
N6	Gevangen in de zorgketen	Walter Stolz	2014	Meningeal tumour
N7	Borstkanker	Jenny Oude Egberink	2019	Breast cancer
N8	Sterkte met je tumor!	Paula Bakhuis	2014	Lymphoma / breast cancer / lung cancer
N9	Mondig ziek zijn	Mariëtte Moors-Mommers	1988	Breast cancer
N10	Obsessie in relatie met kanker	Adri Smits	2024	Lymphoma
N11	Nooduitgang	Harrie Keusters	2015	Rectal cancer

Those 108 fragments have been coded into eight selective codes that correspond with the cross-cutting themes of the analysis. The selective codes fall under five different, overarching domains. The selective codes, domains, and their corresponding sub-question (SQ) are presented in Table 2.

Table 2: Selective codes and overarching domains

Selective codes	SQ	Domain
Defence against and regulation of threatening information	SQ1	Risk perception & uncertainty
Subjective and cumulative risk perception	SQ1	Risk perception & uncertainty
Decision-making under uncertainty	SQ1	Decision-making & choice
Body, quality of life and treatment burden as a value-based limit	SQ2	Values, identity & coping
Autonomy, identity and meaning-making as guiding values	SQ2	Values, identity & coping
Coping and the dynamic re-evaluation of values under pressure	SQ2	Values, identity & coping
Trust and shared decision-making in the treatment relationship	SQ3	Relationship with healthcare providers
Patient agency and system barriers	SQ3	Information & autonomy

The analysis identified repetitive mechanisms and patterns across the data through constant comparison. The findings are organised by the three sub-questions of this study and presented as eight cross-cutting themes (Table 3). The themes are explained and supported by examples and quotes. Supporting quotes are shown in the original language, followed by a self-translated version.

Table 3: Overview of the eight themes, their corresponding sub-question (SQ), and the core finding of each theme

Sub-question	Theme	Core finding of the theme
SQ 1	1. Two opposing routes to control	Both information-seeking and information-avoiding served as a control mechanism
SQ 1	2. Risk weighed through subjective experience	Probabilities are interpreted not through statistics, but through lived experience
SQ 1	3. Cumulative and constant uncertainty	Uncertainty accumulates across the healthcare process; doubt arises even after good news
SQ 2	4. Shifting values under existential pressure	Preferences at the start may change throughout the healthcare process
SQ 2	5. Bodily integrity and quality of life prevail	Treatment burden and disfigurement become a decisive criterion, even over cure
SQ 2	6. Anchors of meaning and coping mechanisms	Beliefs and coping mechanisms against continual uncertainty
SQ 3	7. The patient as their own case manager	Self-operation emerges where the system fails, raising the risk of inequality
SQ 3	8. Trust and autonomy fluctuate	Surrender and self-direction alternate within the same relationship

Perception and response to risks and uncertainty

Theme 1. Two opposing routes to control – seeking versus avoiding information

Across the narratives, patients pursued the same goal: getting a sense of control over an uncontrollable situation. They reached for it along two opposing routes. One route was information-seeking; the other was information avoidance and denial. The seeking route took several forms. One patient searched relentlessly for everything about breast cancer (N7). Another wanted to know as much as possible, so as not to be taken by surprise (N4). A third prepared questions to ask during consultations (N6). A fourth studied the national guidelines independently to reach a firm treatment position (N5). These fragments show patients seeking information consciously. In each case, the patient used information to gain insight into diagnosis, prognosis, or treatment, and to prepare for what might come.

Seeking, in other words, was a way of trying to convert an uncertain situation into one the patient could feel some grip on.

The avoidance route took equally varied forms. One patient pushed his stoma information booklet to the back of a drawer because he could not bear the idea of a stoma at all (N11). Another lived with a visible lump in her breast for over two years without seeing a doctor (N7). A third experienced the diagnosis as if it concerned someone else, in a state of dissociation (N4). A fourth selectively completed half-heard sentences from his physician, building himself a 'wall of certainty' (N10). These fragments show that some patients actively avoid information by distancing themselves from it. They did not want to know about what might happen in order to feel a sense of control over the situation. Where the seekers reduced uncertainty by confronting it, these patients managed it by keeping it at a distance. Both protected a sense of control. The seekers did so by increasing knowledge, while the avoiders did so by limiting exposure.

The two routes were not mutually exclusive at the individual level. Some patients clearly leaned towards seeking, such as the one who studied the guidelines (N5) or the one who prepared questions (N6). One leaned towards avoidance (N10). Yet the same patient could draw on both. One patient (N7), for instance, searched exhaustively for information at one stage, while she avoided seeking a diagnosis altogether at an earlier stage. This pattern is why the analysis placed seeking and avoidance under the same selective code. A patient is not necessarily either a seeker or an avoider. Seeking and avoiding information are strategies serving the same purpose.

Theme 2. Risk weighed through subjective experience – body, biography, and personal logic

Patients tended to interpret probabilities through lived experience. Several considerations outweighed the numerical risk: the severity of anticipated side effects, prior bodily harm, the irreversibility of an intervention, and a sense of 'it cannot hurt to try'. For one patient, a five percent chance of cancer cells in her lymphatic system was reason enough to irradiate the armpit. The same patient grew wary of her leg prosthesis after an earlier spontaneous hip fracture, reasoning from her own body that it would not be good for her bones (N1). For another, the severity of the expected side effects prompted a move to an alternative treatment. He had the options of a medicine with severe side effects that could possibly reduce his tumour to limit the risks in case of a surgery, or he could go for palliative treatment in the form of radiotherapy and embolisation. He chose the latter (N4). For a third, the decisive factor was the irreversibility of radiotherapy, which would have ruled out surgery later on. He chose to undergo a risky surgery first, bearing in mind that radiotherapy would always be an option if surgery was not sufficient (N5). These fragments show a pattern of patients weighing their risks subjectively. Numerically, five percent is not a big chance, but for the patient in N1, it was too big a chance to take the risk and not irradiate. For the patient in N4, the

physicians were looking for a cure, which may have been possible with medication and then surgery. However, the side effects were too severe for him, so he chose palliative treatment over the chance of a cure. Risks were judged by perceived bodily consequence, not by probability.

One breast cancer narrative shows this pattern in an unusual way (N7). She tried apricot kernels, reasoning, 'if it does not work, it does not hurt'. However, she chose breast amputation over breast-conserving surgery, because the latter required irradiation that risked affecting her lungs (N7). These choices seem inconsistent because she embraced an unproven remedy but rejected an established treatment. These are not necessarily comparable risks weighed against each other. They are two applications of a single criterion. The apricot kernels carried, in her appraisal, no bodily downside. The irradiation necessary for a breast-conserving surgery carried an unacceptable bodily cost, even when the alternative was breast amputation (N7). This is why the fragment matters for the theme. It shows that the decisive consideration was the perceived consequence for her own body, not objective risk calculation. The inconsistency dissolves once risk is read as a subjective and biographical judgement, which is exactly what the theme claims.

Theme 3. Cumulative and constant uncertainty

Uncertainty was not experienced as a single event. It accumulated across the healthcare process. One prostate cancer patient described this explicitly (N5):

"Opnieuw werden we dus opgezadeld met een dilemma, met nieuwe onzekerheden, met nieuwe angst over de toekomst, enzovoorts. De rollercoaster bleef maar in beweging." (Pieter, 2014)

"Again, we got burdened with a dilemma, with new uncertainties, with new fears about the future, and so on. The rollercoaster kept on moving." (translation)

The image of a rollercoaster that 'just kept moving' captures the core of this theme. Each resolved question opened a new one. Uncertainty was renewed and not removed. The same patient also wrote that it does not matter if you irradiate or not, there is always a chance for the cancer to come back (N5). For another patient, a favourable result produced unease rather than relief. Physicians told her that radiotherapy would be possible instead of surgery because her tumour had shrunk enough. She wondered whether radiotherapy would be sufficient, while already bracing herself for an amputation. Her doubt persisted despite the positive outcome. Later, she reframed her incurable disease as a chronic illness. She did so to live with it for as long as possible, even when her cardiac function declined, narrowing down her options (N1). This fragment is analytically important because it shows that uncertainty can survive good news. It arose from the gap between what patients expected and what they were told. Both patients told their stories of how each point in their trajectories came with more or new

uncertainty. Uncertainty was embedded throughout the trajectory, spanning diagnosis, treatment, and prognosis.

In Theme 1, patients controlled which information they received. Contrastingly, in Theme 3, several patients sought to manage ongoing uncertainty by controlling its timing. One patient postponed an operation in order to build confidence before committing (N11). In another narrative, a patient trialled a drug for three months. He did so because he could then revisit the decision, knowing its performance and side effects (N4). These fragments were not viewed as attempts to resolve uncertainty. Rather, they were viewed as ways to live with it. That distinction is the point. It is a way of living on a rollercoaster that never stops.

Personal values and treatment burden

Theme 4. Shifting values under existential pressure

Patients' preferences before diagnosis could collapse once the prospect of death became real. The will to live superseded earlier beliefs. This was clearest in a lymphoma narrative. There, the patient's prior intention not to be treated gave way at the decisive moment (N10):

Ik zou me zeker niet laten behandelen. Kwaliteit van leven, daar zou ik voor kiezen. En dan nu? 'Ja, natuurlijk.' (Smits, 2024)

"I would certainly not undergo treatment. Quality of life, that is what I would choose. And now? 'Yes, of course.'" (translation)

The contrast is the point: an earlier 'certainly not' against an immediate 'yes, of course'. The patient started his trajectory with a personal value that was overturned the moment it was tested. He wrote that his attachment to life proved stronger than all his prior beliefs. However, this reversal was not a rule. One patient refused all treatment in order to stay true to herself (N8). A third opted for quality of life and comfort over irradiation, accepting the risk of his cancer coming back (N5). Comparable situations thus produced opposite choices. Side by side, these fragments suggest a boundary condition. Whether a patient's personal value held or shifted depended on how central it was to the patient's sense of self. In the fragments where the value was central, it held even under existential pressure. Where it was more a general preference than a part of identity, it was the first thing to give way.

Theme 5. Bodily integrity and quality of life prevail

Several patients drew a line at which mutilation, loss of function, or an unbearable treatment burden became unacceptable. This happened sometimes, even at the cost of a chance of a cure. One rectal cancer patient preferred the experimental route of a clinical trial to avoid a stoma and the permanent mutilation it brings (N11). Another patient declined a potentially curative operation because it would have cost him the

ability to walk (N4). One breast cancer patient deliberately chose a lower medication dosage (N9). Another said treatment should continue only as long as the side effects remained bearable, with the ability to communicate as the lower boundary of a life still worth living (N6). These fragments show that patients sometimes make decisions setting a value-based limit on their treatment. It was set not by the probability of cure, but by what the patient deemed acceptable. Based on this interpretation, bodily integrity and quality of life served as decisive criteria in their own right.

Theme 6. Anchors of meaning and coping mechanisms

Beyond individual decisions, patients needed something to hold on to in order to endure the trajectory at all. Two kinds of resources recur across the coded fragments. The first is a durable anchor of meaning that tells patients why their situation is bearable. The second is an active coping mechanism that helps them get through the process day by day. The anchors drew on what already mattered before the illness. Faith in God gave one breast cancer patient support and stability (N1). Another found the same stability in his Calvinist background (N10). A third held that whatever one believes in is best and treated the illness as an occasion for identity change. She promised herself that she would 'really live' from then on (N7). Two other patients explicitly stated that their children were the reason to keep going. The first was a mother of three young children, who stated that she moved heaven and earth to be able to see her kids grow up. The second patient stated that it was his partner and his own kids that made him keep fighting (N2). Coded individually, these are different beliefs. Grouped, however, they share a function. They worked less as decision rules than as reasons to keep going.

The second resource concerned the management of distress itself. Coping took several forms in the narratives. One patient opted for stoicism: she chose not to report all of her physical pain but to endure it. She also used anticipatory grieving as a coping strategy to soften the potential blow of her dying (N1). Another patient turned to mindfulness, focused on her breathing, and went for long walks. This made her waiting time in between chemotherapy sessions manageable (N7). A patient with a thyroid carcinoma chose to let go of his 'illusion of control' (N4):

Controle willen hebben over zaken waar wij helemaal geen controle over hebben, leidt tot grote teleurstelling en meer onzekerheid. Daarom was het voor mij beter te erkennen dat ik de loop der dingen niet bepaal." (Goderis, 2014)

"Wanting to control things we cannot control at all leads to big disappointments and more uncertainty. That is why it was better for me to acknowledge that I do not determine the course of things." (translation)

These responses look very different from one another, but what unifies them is their effect. Each way of meaning and each coping mechanism provided the patient with a stable foundation. From that foundation, the surrounding uncertainty became liveable,

something they deemed necessary to endure their trajectories. The theme, therefore, does not name a set of beliefs or coping mechanisms. It names the function those beliefs and mechanisms served: anchoring the self against continual uncertainty.

Navigating relationships with providers and the system

Theme 7. The patient as their own case manager

Where coordination, access, or reimbursement fell short, patients and their families took charge. This agency was partly chosen and partly forced. One patient laid down in front of his general practitioner's reception desk to force a much-needed earlier appointment. He also negotiated with his physician over how to phrase his 'passage problem', so that the liquid food he actually needed would be reimbursed (N2). In another narrative, a husband drove his wife to hospital appointments himself. The hospital-funded taxi carried several patients at once as a cost-containment measure. Therefore, the taxi was often late, and driving her to the hospital himself was more than twice as fast as the taxi (N6). A breast cancer patient phoned the hospital herself because her radiotherapy was postponed for over two weeks, while she only had three days of delay. She thereby brought her radiotherapy appointment forward by a week (N3). A prostate cancer patient circumvented a system barrier by contacting a physician abroad. In the Netherlands, a patient needs a specialist's referral for an MRI scan, but in "B", as he called it, he got an MRI scan the following day (N5). One rectal cancer patient drew the general conclusion, applied to his own situation. He stated that it was the patient's own initiative that determined whether he reached the appropriate centre of care. It was on his own initiative that he ended up in Maastricht, where he could participate in a clinical trial, so as to try to prevent him from getting a stoma (N11).

These fragments were all coded as patient agency against the system. They show that, in order to receive timely and appropriate care, patients too often need to take matters into their own hands. In each case, the patient's effort compensated for a failure of the system to coordinate or grant access on its own. If appropriate care depends on the patient's own initiative, some patients are more likely to fall through the cracks. These are the patients who are less assertive, less able to advocate for themselves, or less supported. A patient acting as their own case manager is therefore more than resourcefulness. It is also an indicator of an underlying inequity. Within this inequity, the system rewards those patients who are already best equipped to navigate it.

Theme 8. Trust and autonomy fluctuate

Patients alternated between surrendering to their physician and reclaiming their own direction. This often happened within the same relationship. Trust did not necessarily displace autonomy; it coexisted with it. One breast cancer patient surrendered completely (N3):

"Ik vind het prima. Zij zullen wel weten wat goed voor mij is. Ik geef me helemaal over."
(Klop, 2018)

"I am fine with it. They will know what is good for me. I surrender completely."
(translation)

However, the same patient refused to wear a cooling cap during chemotherapy. She also decided, on her own, to stop taking a medicine, on the basis of how her body felt (N3). In another narrative, a husband was relieved to be spared the decision of his wife's medication dosage, only to adjust it himself that same evening (N6). The contrast within each case is the core finding of this theme. Complete surrender and self-direction were not fixed roles. They were roles a patient could fluctuate between. What allowed them to coexist was a particular kind of trust. That trust was built, firstly, through person-centred recognition: being treated as a person rather than a number (N7), or a general practitioner phoning his patient spontaneously, so that she did not feel forgotten (N3). Secondly, it was built through honesty, for instance, when a patient accepted that no one could ever be certain in cancer care, yet she still believed her physician (N9). Another patient repeatedly discussed the actual necessity of hospital admission with his physician when he had a fever, and then autonomously declined it on multiple occasions (N5). These fragments are why trust is linked to participation. When there was trust between a patient and their physician, it enabled the patient's own agency. It allowed them to take their preferred role in the patient-physician relationship.

Discussion

Interpretation of the findings

This study examined how cancer patients experience and cope with risks and uncertainty throughout the healthcare process, drawing on eleven published illness narratives. The analysis generated eight cross-cutting themes, summarised in the results section. One interpretive thread runs through them and is further expanded in the sections below. Patients did not treat risks as objective, and they also did not expect uncertainty to be resolved. Instead, patients tended to interpret risks in personal and bodily terms, whilst finding ways to live with and act under uncertainty that continued throughout the healthcare process. The narratives brought into view the dimension that population-level evidence, clinical guidelines, and the reimbursement decisions based on them tend to leave out. That dimension is the experiential, first-person side of care that was identified in the introduction. The sections below discuss each sub-question in turn. For each finding, an explanation is provided on how the results link to the theoretical framework. Each interpretation is tied back to the specific narratives it came from, identified by their corresponding code (N1-N11).

Perception and response to risks and uncertainty

Patients regulated threatening information through two opposing strategies: active seeking and deliberate avoidance (Theme 1). The function of Theme 1 is linked to UIT, which holds that the appraisal of uncertainty as danger motivates coping that aims to reduce it (Mishel, 1988). The narratives show that this mechanism runs along both routes. The seekers used information to get a grip on the situation, with one patient studying national guidelines intensively to set himself up with a firm treatment position (N5). The avoiders deliberately kept information at a distance, with one patient selectively finishing half-heard sentences to build himself a ‘wall of certainty’ (N10). These two behaviours are opposites of each other, but they serve the same function. Both seeking and avoiding information restored a sense of control under a danger appraisal. That shared function connects the data to UIT, and it sharpens the theory rather than merely confirming it. In UIT, a danger appraisal points to reducing uncertainty, and both seeking and avoiding information serve that function.

The narratives extend this account in a second way. It turns out that both strategies could be employed by the same patient at different moments in the healthcare process. One patient avoided by not going to the doctor with a lump in her breast for over two years, yet she searched relentlessly for every bit of information on breast cancer at a later stage (N7). To explain this, Miller’s (1987) monitoring-versus-blunting distinction can be applied. Miller (1987) treats monitoring and blunting as situational styles rather than as constant traits. TMSC adds to this by suggesting that coping is a process shifting over time in response to the situation (Lazarus, 1993). Taking Miller’s (1987) and Lazarus’

(1993) findings together, they explain why one person could move between the established routes as the trajectory changed. The findings also nuance the pre-motivational phase of the I-Change Model (De Vries et al., 2005). In that phase, processing information is deemed a route towards awareness of health risks. Although the seekers used information as a route towards awareness, the avoiders used information processing as a defence against it.

Patients consistently weighed risks through subjective measures rather than through statistical probabilities (Theme 2). These measures included the severity of side effects, prior bodily harm, the irreversibility of an intervention, and a 'cannot hurt to try' mentality. This is exactly at which point EUT fails for real patients, already anticipated for by the theoretical framework (Von Neumann & Morgenstern, 1947; Reyna, 2008). Three behavioural theories predict why probability matters less than subjective measures. First, bounded rationality predicts a reliance on heuristics when information is overwhelming and emotionally charged (Simon, 1957). Second, the affect heuristic predicts that a vividly imagined consequence carries more weight for a patient than the actual consequence (Slovic et al., 2004). Third, Prospect Theory predicts that outcomes are evaluated relative to a personal reference point, where potential losses weigh more than equivalent gains (Kahneman & Tversky, 1979). One case shows all three at work. A breast cancer patient tried apricot kernels, yet chose amputation over breast-conserving surgery (N7). Although the risks do not seem comparable, it is the thought process that brings value. For her, the kernels had no downside, even though she knew nothing about them, and their working is unestablished. The irradiation that the surgery required carried an unacceptable downside, while this is an established treatment. The potential that irradiation captured her lungs weighed more than the chance of a cure, whilst saving her breast. Together, these findings suggest that cancer patients do not calculate risks; they feel it and frame it through personal experience. Thereby, they make their subjective appraisal the logic by which they navigate risks in the healthcare process.

Patients also experienced uncertainty as something that was continual and accumulated over time (Theme 3). They did not experience their uncertainty being resolved. This links directly to the reconceptualised UIT, and how that theory explains living with continual uncertainty (Mishel, 1990). The strongest supporting evidence for this is that even good news was not able to resolve uncertainty. One breast cancer patient had favourable results from her tumour-removing surgery, which were that radiotherapy was sufficient. However, she met these results with unease rather than relief, because she already braced for an amputation (N1). The discrepancy between her expectations and the reality created a new form of doubt. This is in line with one of UIT's antecedents: event congruence, the fit between a patient's expectation and what actually happens (Mishel, 1988). Uncertainty was not a result of the objective situation, but the result of a mismatch. The reconceptualised UIT predicts a response to this situation as well: probabilistic thinking, in which uncertainty is accepted as being a natural and continuous

part of life, not something that is eliminated (Mishel, 1990). The narratives show some patients enacting this. Instead of eliminating their uncertainty, they managed its timing in order to live with it. One patient postponed surgery to build confidence before committing (N11), while another patient trialled a drug for three months so he could monitor its effects and revisit his decision later (N4). These were not attempts to remove uncertainty. They represented ways of living with a continuous, unending process. This perspective connects the finding to prior work. Uncertainty was described as a persistent, shifting feature of advanced cancer before by Langmuir et al. (2023). The present narratives add a longitudinal, first-person view, in which uncertainty is not merely endured. It is actively managed through information regulation.

Personal values and treatment burden

Pre-stated patient values could be revised under existential pressure for some, while for others, they held firm (Theme 4). This challenges a core assumption of the decision-theoretic models in the theoretical framework, which treat preferences as relatively stable. It also complicates SDM, which assumes that patient values can be obtained and then used to guide a decision (Charles et al., 1997). This finding is better explained by response shift, a change in a patient's internal standards, values and the conceptualisation of quality of life throughout the illness trajectory (Sprangers & Schwartz, 1999). Prospect Theory's relative reference points (Kahneman & Tversky, 1979) and UIT's 'new view of life' (Mishel, 1990) are similar ideas that allow values to move. Neither, however, captures how abruptly the change occurs at the decisive moment. The clearest case of this phenomenon is the lymphoma patient, whose 'certainly not' intention reversed at the decisive moment to 'yes, of course' (N10). Response shift entails exactly this sudden internal switch. The results also indicate why this happened to some patients but not to others. Values appeared to be held when they were central to the patient's identity, as seen in (N8), where one patient refused all treatment to stay true to herself. Where the value was more of a general preference than a part of the real identity, the value shifted. This boundary condition links the finding to biographical disruption and the self-reconstruction in illness (Bury, 1982). Following the I-Change Model, the instability sits in the motivation phase, in which attitudes and values are assumed to shape intention (De Vries et al., 2005). The narratives suggest that these inputs can be reconfigured at a decisive moment, in such a way that the intention which forms there reverses the one the patient voiced earlier.

Bodily integrity and quality of life functioned as a limit on acceptable treatment (Theme 5). Some patients declined potentially curative surgery to preserve function or avoid mutilation, as when one patient refused a potentially curative surgery to protect his ability to walk (N4). This fits MDM and its core attention to treatment burden and a patient's personal capacity (May et al., 2014; Leppin et al., 2015). It also confirms the bounded rationality finding that patients prioritise independence and/or symptom relief over marginal survival gains when faced with a high treatment burden (Fried et al., 2011). The

findings also extend MDM. Because MDM is largely workload-oriented, it focuses on the daily effort treatment demands. The refusals found in the narratives of Theme 5 were often driven less by the daily demand of treatment than by meaning. They were driven by what mutilation or functional loss would do to the patient's sense of self (Bury, 1982). The limit was set by identity, not merely by daily burden.

Patients sustained themselves through anchors of meaning and coping mechanisms (Theme 6). The type of resource links the data to theory. The results separate two functions that the decision-theoretic and appraisal models – bounded rationality, SDM, and UIT – do not distinguish. The first function is a durable anchor of meaning, a reason to make the situation bearable. For one patient, it was faith in God that sustained her (N1), while for two others, their children made them keep fighting (N2; N9). The anchors align with the meaning-making model, in which a threatening event is integrated with a person's global beliefs. (Park, 2010). They also fit within the religious and spiritual coping idea of Pargament et al. (2000). The second function is the active management of distress in the moment. One patient used anticipated grief in order to soften the pain of her dying in advance (N1). This falls under emotion-coping in TMSC (Lazarus, 1993). Another patient deliberately let go of the 'illusion of control', reasoning that trying to control the uncontrollable would only end up in more distress (N4). The decision-theoretic and appraisal models mention whether patients cope, not actually how they cope. The wider coping-and-meaning lens from the theoretical framework distinguishes a durable anchor from a temporary approach. That distinction shows why the wider lens is necessary.

Navigating relationships with providers and the system

In relation to the wider system, patients and their families repeatedly took charge where coordination, access or reimbursement fell short. They acted as their own case manager (Theme 7). This finding sits outside the decision-focused core of the theoretical framework. SDM and MDM theorise the patient-physician relationship and burden of treatment, but say little about navigating a fragmented organisation such as a hospital (Charles et al., 1997; May et al., 2014). Three system-level accounts fit the data better. First, patient activation, which describes the belief, knowledge, and confidence of a patient to manage their own care (Hibbard et al., 2004). Patient activation was evident in N3, when the patient stopped a treatment on her own decision. Second, health literacy, which describes the capacity to access, understand, and use health information (Sørensen et al., 2012). Health literacy was evident in N2 when the patient negotiated with his physician about his 'passage problem', so as to claim reimbursement for fluid food. Third, candidacy, which describes a patient's eligibility for care as something continually negotiated with a system that may help or hinder it (Dixon-Woods et al., 2006). Candidacy was evident in N5 when the patient circumvented the Dutch national referral barrier by arranging an MRI scan abroad. These acts provide empirical support for the post-motivational phase of the I-Change Model, which states that performance skills and the ability to overcome barriers translate intention into behaviour (De Vries et al.,

2005). The findings raise an equity concern that the framework can explain. Patient activation and health literacy are not evenly distributed, but they are socially patterned (Sørensen et al., 2015). If timely and appropriate care depends on self-advocacy, the patients with the least activation or literacy are more likely to fall through the cracks. Following this interpretation, the system rewards the patients who are best equipped to navigate it. On their own, SDM and MDM cannot address this inequity.

Finally, patients moved between surrendering to clinical authority and claiming personal autonomy, sometimes within the same narrative (Theme 8). This finding extends SDM. SDM largely treats decision roles as fairly stable and frames difficulty as a mismatch between preferred and actual roles (Gattellari et al., 2001; Huijgens et al., 2025). The narratives in this study suggest that these roles are dynamic instead. The literature on interpersonal trust explains this pattern. Trust can enable a patient's agency rather than displace it (Hall et al., 2001). One patient surrendered completely to her physician in one matter, but she refused a cooling cap and stopped a medicine on her own judgement within the same trajectory (N3). Trust in her physician did not displace her autonomy. It was a condition under which she could exercise it. The mismatch framing assumes a single preferred role, while these narratives suggest that the more demanding task is to track a role that keeps moving.

Theoretical implications

Taken together, the findings support and extend the theoretical framework. They provide experiential support for behavioural accounts of risk perception (Themes 2 and 3) and for UIT's account of coping with uncertainty (Theme 1). They also reveal three areas where the theoretical framework's established decision-theoretic models fall short, and where the wider lens is necessary. First, patient values are not stable inputs. They can shift throughout the illness trajectory, sometimes abruptly. The decision-theoretic models cannot accommodate this, so response shift is needed to explain it (Theme 4). Patient values shape how they experience and cope with risks and uncertainty, which has implications for the decision-making process. Second, coping is not captured by appraisal alone. The theoretical framework's meaning-making and coping perspective is required to interpret how, not merely whether, patients cope (Theme 6). The way patients give meaning to and cope with risks and uncertainty also has implications for the decision-making process. Third, decision-making takes place within a system with certain shortcomings. Patients must actively navigate these systems themselves. SDM and MDM overlook this, so the concepts of patient activation, health literacy, and candidacy bring it into view. This also raises an equity concern (Theme 7).

Furthermore, the I-Change Model deserves a separate note, because this study used it in a particular way. The model was built to explain behaviour change, yet this study used it as a structure to examine how patients evaluate options under conditions of risk and uncertainty. Following that interpretation, all three phases were found within the themes:

information regulation in the pre-motivational phase, the (in)stability of personal values in the motivational phase, and system navigation in the post-motivational phase. However, rather than progressing through these stages linearly, patients moved back and forth among them. These observations are offered as interpretive extensions suggested by the narratives, not as a test of the theories. This study was not designed to confirm, qualify or refute these models. It was designed to map patients' lived experiences in relation to risks and uncertainty in the healthcare process. The contribution of this study is to show where each theoretical lens helps and where its limits are.

One cross-cutting pattern emerged from all eight themes: patients look to regain control of both the risks and uncertainty they faced. They did so not by resolving them, but by shaping them into personal, liveable situations. Patients weighed risks subjectively through bodily consequences rather than numerical probabilities, while they tried to manage uncertainty rather than resolve it. This reframes the theoretical framework's central focus on discrete decisions as moments within a continuous process of self-management.

Practical and policy implications

The findings have several implications for practice. Patients differed in how they wished to engage with information; therefore, clinicians might tailor the timing and amount of information to a patient's own regulation style, rather than assuming that more information is always better (Theme 1). Because values are prone to change, preferences are best revisited at multiple points during the trajectory rather than elicited once. This would align SDM with response shift (Themes 4 and 8). Benefit-risk conversations should give explicit weight to treatment burden and to bodily- and identity-related meanings of interventions, aligning with MDM (Theme 5). Because patients also weigh their options through anchors of meaning such as faith or family, these conversations should also include such resources since they are part of how patients define what counts as benefit and risk (Theme 6). Most pressingly, strengthening navigation support and care coordination, and paying attention to patients with lower activation or health literacy could reduce an unnecessary and avoidable source of inequity (Theme 7).

These patterns also bear on how the value of cancer treatments is assessed at the system level. HTA and the cost-effectiveness analyses that inform reimbursement typically assume that treatments are used as intended (Drummond et al., 2015). The narratives show repeatedly that they are not: patients limit dosage to protect quality of life, decline or discontinue treatments on grounds of bodily integrity or burden, and they sometimes only obtain timely care through self-advocacy (Themes 4, 5 and 7). Each of these is a mechanism of the efficacy-effectiveness gap: the divergence between effects established in trials and those realised in everyday practice (Eichler et al., 2011). These mechanisms imply that cost-effectiveness estimates that rest on treatment adherence as intended, may misstate a treatment's real-world value. The point of this implication is

not to quantify experience, but to incorporate qualitative patient-experience evidence of this kind into value assessment and care-pathway design. This is in line with recent calls to embed patient perspectives in HTA (Facey et al., 2010; Van Overbeeke et al., 2021).

Strengths and limitations

This study has several strengths and limitations. Its use of published illness narratives offered rich, longitudinal, first-person accounts across the whole trajectory — a perspective less accessible through cross-sectional or clinical data. At the same time, these narratives are a self-selected source. Their authors are likely to be relatively articulate, reflective, and disproportionately survivors. This may over-represent agency and meaning-making, and under-represent more passive or less health-literate patients. There is a particular irony here for the equity argument of Theme 7: the patients most disadvantaged by a system that rewards self-advocacy are also the least likely to have written such narratives. The accounts are also retrospective and written for publication. Another limitation follows from the type of data. Because the narratives were written and published independently of this study, the data were fixed. The researcher could not ask follow-up questions on ambiguous passages. He could also not request elaboration on the narratives. The analysis was therefore bounded by what each author chose to write down, not for the purpose of this study but for their own. Being shaped by hindsight and the conventions of storytelling, the narratives may impose coherence on what was lived as a messier, more uncertain process. Some of the agency and meaning they convey may therefore be partly a product of narration. The way narratives were identified may have shaped the themes, too. The search relied on thematic filters such as shared decision-making, assertiveness, and coordination of care. These filters may have predisposed the dataset toward the very experiences of self-advocacy and role negotiation that emerged as themes.

A further limitation concerns the scope of the study itself. As mentioned in the ‘research method’ section, the research question and sub-questions were adjusted during the analysis. The focus of the study moved away from the explicit reasoning behind an individual’s benefit-risk decisions and towards the experience of risks and uncertainty. This had an empirical reason: the narratives did not contain enough explicit information on the reasoning behind decisions; therefore, the study cannot support the original aim. This restructuring is in line with iterative qualitative research (Braun & Clarke, 2006). Consistent with the aims of qualitative research, the goal was analytic transferability rather than statistical generalisability. Dependability and credibility were supported by iterative coding and supervisor review (Braun & Clarke, 2006; Golafshani, 2003). Even so, a single analyst conducted the coding, and other researchers might have clustered the material differently.

Future research

Future research could address these limitations and build on the findings. The design of this study was only able to reconstruct value change after it had already happened (Theme 4). Prospective, longitudinal interview studies are therefore needed to observe response shift in oncological decision-making as it unfolds. The narrative sample of this study overrepresented articulate survivors, which left the equity concern of Theme 7 untested. Future research could recruit beyond the articulate survivor. That means including patients with lower activation or health literacy, and those who did not author narratives. Such work would test whether system navigation actually differs across groups. Finally, this study put aside its aim for explicit benefit-risk reasoning behind decision-making processes. Mixed-methods designs could link information-regulation styles and patient activation to decisional and clinical outcomes. This would help translate these qualitative insights into concrete guidance for tailoring information and support.

Conclusion

This study set out to understand how cancer patients experience and cope with risks and uncertainty throughout the healthcare process. It did so by analysing eleven published patient narratives. Its central conclusion is that, for these patients, risks and uncertainty were translated into personal, liveable terms. Throughout the trajectory, patients were looking to regain a sense of control. They did so through three recurring levers: they regulated the information they took in, they used personal values as a compass for what was worth enduring, and they exercised agency in their relationships with clinicians and the wider system.

The first sub-question asked how patients perceive and respond to risks and uncertainty. Patients did so in subjective and biographical terms. They weighed prior experience, side effects and irreversibility more heavily than statistical probabilities. Depending on the situation, they either sought threatening information or avoided it. Uncertainty itself was perceived as cumulative and persistent, rather than confined to discrete moments. The second sub-question asked about the role of personal values and treatment burden and how they shape the way cancer patients cope with risks and uncertainty. Both strongly shaped how patients coped: bodily integrity and quality of life set limits on what treatment was acceptable and what risks they were willing to take. Anchors such as faith, family, and identity sustained patients in their uncertainty. Pre-stated values could also shift under existential pressure. Whether they did so, however, depended on how central they were to the patient's sense of self. The third sub-question concerned how patients navigate their relationships with providers and the wider system. Patients did so dynamically. They alternated between trust and autonomy. Where coordination in or access to the system fell short, they frequently acted as their own case managers. This reliance on self-advocacy exposed an underlying inequity.

This study contributes in two ways. First, it demonstrates these mechanisms in naturalistic, first-person accounts. Second, it shows where established theories reach their limits. The proneness of values, the work of meaning-making, and the navigation of a fragmented system are not well addressed by SDM, MDM, or decision-theoretic models alone. Taken together, the findings call for a cancer care approach more focused on equity and on ongoing, dynamic processes than on discrete events. They call for an approach that engages with how patients integrate subjective experiences with risks and cope with uncertainty over time, rather than focusing solely on decisions made at isolated moments.

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Appendices

Appendix A

Boek	Fragment (verkort)	Open code	Axiale code
▸ ***Risicoperceptie & onzekerheid***			
Obsessie in relatie met kanker	Ontkenning verwijst de angst naar de verstopte vergetelheid. Vrees is vreselijk dus beter om te vluchten.	Ontkenning als eerste reactie op risico	Vermijding en ontkenning als afweer tegen bedreigende informatie
Obsessie in relatie met kanker	Ik zit alle halve zinnen aan te vullen naar wat voor mij wenselijk is... een muur van zekerheid creëren.	Selectief horen wat geruststelt; 'muur van zekerheid' bouwen	Vermijding en ontkenning als afweer tegen bedreigende informatie
Anneke	Koorts, maar geen zin in ziekenhuis. Uiteindelijk toch gebeld, het kon echt niet meer.	Uitstellen van hulp zoeken ondanks risicosignalen	Vermijding en ontkenning als afweer tegen bedreigende informatie
Anneke	Kanker is zo grillig dat voor geen enkele patiënt een vast protocol te volgen is.	Onvoorspelbaarheid van kanker als bron van onzekerheid	Onzekerheid als constant en cumulatief kenmerk van het traject
Anneke	Huiverig om prothese te gebruiken door eerdere spontane botbreuk; inschatting eigen risico.	Eigen risico-inschatting op basis van eerdere ervaringen	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
Anneke	Oksel bestralen: kans niet zo groot (~5%), maar aanwezig. Een verstandige keuze.	Kleine kans als voldoende reden voor preventieve behandeling	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
Anneke	Paul en ik hadden ons gericht op amputatie als zelfbescherming — het goede nieuws gaf onzekerheid.	Goed nieuws roept onverwacht nieuwe twijfel op	Onzekerheid als constant en cumulatief kenmerk van het traject

Anneke	Prognose onduidelijk, maar niet meer te genezen is duidelijk. Strategie: chronische ziekte ervan maken.	Herkadering van ongeneeslijke ziekte als chronisch	Onzekerheid als constant en cumulatief kenmerk van het traject
Anneke	Doorgaan met chemo is te riskant door hartproblemen. Oncoloog: hart rust geven, dan verder kijken.	Behandelstop door nieuw risico; gezamenlijke afweging	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
Anneke	Hart kan Herceptin niet aan. Er zijn nog wel chemo's mogelijk maar niet ideaal.	Beperking van behandelopties door bijwerking	Onzekerheid als constant en cumulatief kenmerk van het traject
Anneke	Bestraling gaat voorlopig niet door — starten met behandeling was anders 4 weken vertraagd, onaanvaardbaar.	Tijdsrisico van uitstel weegt zwaarder dan risico bestraling	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
Anneke	Kankercellen in borst weg; onrustige voorlopercellen worden met radiotherapie weggehaald — toch twijfel.	Twijfel ondanks positieve uitslag: is radiotherapie echt voldoende?	Onzekerheid als constant en cumulatief kenmerk van het traject
Nooduitgang	Het voorstel was de operatie niet nu uit te voeren maar te wachten tot januari — meer vertrouwen opbouwen.	Wachten om zekerheid te vergroten voor definitieve beslissing	Onzekerheid als constant en cumulatief kenmerk van het traject
Nooduitgang	Zo opgelucht dat de risicovolle endeldarmamputatie verder uit zicht was — zo snel mogelijk tekenen.	Enorme opluchting bij vermijden van hoogrisico-ingreep	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
Nooduitgang	Ik wilde niet bij de stomaclub horen, dus ik gooide het informatieboekje ver onder in de la.	Ontkenning van mogelijke uitkomst als bescherming	Vermijding en ontkenning als afweer tegen bedreigende informatie

Naadloos van zorgverlener naar patiënt	Bestraling zal ook longen raken. Kan dan met prednison behandeld worden. Dat zien we dan wel weer.	Acceptatie van bijkomend risico met laissez-faire houding	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
Naadloos van zorgverlener naar patiënt	Als ik hier veel last van heb moet de dosis van de chemokuur aangepast worden.	Begrip van dosis-bijwerkingverband; bewust van het mechanisme	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
De kwetsbare patiënt	Medicijn had gezien de bijwerkingen niet de voorkeur.	Bijwerkingsprofiel als doorslaggevende factor	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
De kwetsbare patiënt	Drie maanden uitproberen — dan aan de hand van resultaat en bijwerkingen opnieuw bekijken.	Proefperiode als strategie om onzekerheid te reduceren	Onzekerheid als constant en cumulatief kenmerk van het traject
De kwetsbare patiënt	Regelmatig betrapte ik me erop dat ik dacht dat het om een derde ging en niet om mijzelf.	Dissociatie als reactie op diagnose	Vermijding en ontkenning als afweer tegen bedreigende informatie
Prostaatkanker	Als je kiest voor bestralen kan er later niet meer worden geopereerd. Als je kiest voor opereren kan er later bestraald worden.	Irreversibiliteit van behandelkeuze als doorslaggevend risico	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
Prostaatkanker	Opnieuw een dilemma, nieuwe onzekerheden, nieuwe angst. De rollercoaster bleef in beweging.	Opeenvolgende onzekerheden als emotionele belasting	Onzekerheid als constant en cumulatief kenmerk van het traject
Gevangen in de zorgketen	Wie garandeert dat de afstemming klopt? Ik heb besloten haar toch maar zelf te rijden.	Wantrouwen in zorgafstemming leidt tot zelf de regie nemen	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica

Gevangen in de zorgketen	Marjolijn zo ernstig achteruitgegaan dat we haar veiligheid niet langer konden garanderen.	Veiligheidsrisico als aanleiding voor opname-eis	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
Borstkanker	Mijn long wordt zo goed als zeker geraakt — toch besluit ik geen bestraling te doen.	Bewuste aanvaarding van risico om andere reden	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
Borstkanker	Ik loop al meer dan twee jaar met een knobbel en weet al die tijd dat ik borstkanker heb.	Jarenlange vermijding van diagnosebevestiging	Vermijding en ontkenning als afweer tegen bedreigende informatie
Borstkanker	Patiënt probeert anthroposofische maretaktherapie. Krijgt koorts en rode plekken van de injecties. Patiënt wil het via drankampullen innemen, maar voordat ze dat kan, belandt ze in het ziekenhuis. Genoeg reden om te stoppen.	Alternatieve therapie naast reguliere zorg	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
Borstkanker	Ik heb mijn twijfels, maar bestel de pitten toch: baat het niet, schaadt het ook niet.	Laag-drempel experiment bij twijfelachtige remedie	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
Mondig ziek zijn	Met het idee: het zal wel niets zijn, maar ik wil toch dat ernaar gekeken wordt.	Voorzorgshalve hulp zoeken ondanks verwachting van niets	Subjectieve risicoweging vanuit ervaring, lichaam en eigen logica
▸ ***Besluitvorming & keuze***			
Obsessie in relatie met kanker	Vertel me liever wat mijn kansen zijn… Maar wie neemt eigenlijk welke gok?	Willen weten van prognose; behandelbeslissing onder druk	Beslissen onder onzekerheid: overleg, intuïtie en tijdsdruk
Obsessie in relatie met kanker	Ben ik een sukkel geweest toen ik ja zei? … Geworden tot	Spijt en twijfel na behandelbeslissing	Twijfel, spijt en zelfrechtvaardigi

	slachtoffer, onzeker, twijfelend over keuzes.		ng na de beslissing
Anneke	Gekozen voor uitstellen operatie en starten met chemo — geen invloed op prognose, maar tumor wordt beter operabel.	Gezamenlijke beslissing over behandelvolgorde	Beslissen onder onzekerheid: overleg, intuïtie en tijdsdruk
Anneke	Bestraling eerst niet door — 4 weken wachten vonden we niet aanvaardbaar.	Actief verwerpen van behandeloptie op basis van tijdsrisico	Beslissen onder onzekerheid: overleg, intuïtie en tijdsdruk
Anneke	Overstap naar Taxol — escape-chemo. Amper tijd om na te denken.	Beslissing onder tijdsdruk zonder ruimte voor overweging	Beslissen onder onzekerheid: overleg, intuïtie en tijdsdruk
Opnieuw geboren	De onderzoeken bieden geen mogelijkheden, maar ze willen een jonge man niet zomaar opgeven. 'Doet u maar wat u denkt.'	Delegeren van beslissing aan arts bij ontbreken van opties	Ervaren keuzevrijheid en de grenzen daarvan (van keuze tot schijnkeuze en overgave)
Naadloos van zorgverlener naar patiënt	Chemotherapie, bestralingen en hormoontherapie — besloten omdat het weefsel agressief is.	Agressiviteit van tumor als kader voor behandelintensiteit	Beslissen onder onzekerheid: overleg, intuïtie en tijdsdruk
De kwetsbare patiënt	Wij besloten behandelvoorstel af te wachten alvorens te vragen naar alternatieven.	Strategisch wachten voor een betere onderhandelingspositie	Beslissen onder onzekerheid: overleg, intuïtie en tijdsdruk
Prostaatkanker	Als opereren nog kan, kies ik voor opereren in B en niet in X.	Ziekenhuiskeuze op basis van vertrouwen en expertise	Beslissen onder onzekerheid: overleg, intuïtie en tijdsdruk
Prostaatkanker	Da Vinci-methode: preciezer, minder pijn, snellere genezing — ik koos voor deze behandelvorm.	Kiezen voor modernste technologie op basis van risico-batenafweging	Beslissen onder onzekerheid: overleg, intuïtie en tijdsdruk
Prostaatkanker	Uren wikken en wegen, voor- en nadelen, met anderen gesproken…	Uitgebreid overlegf beslissingsproces	Beslissen onder onzekerheid: overleg, intuïtie en tijdsdruk

	Uiteindelijk besloten niet te bestralen nu.		
Gevangen in de zorgketen	Had ik in mijn dagboek verkeerde cijfers genoteerd om een therapie te rechtvaardigen waarin ik niet geloofde?	Zelfreflectie op eigen motivatie bij twijfelachtige keuze	Twijfel, spijt en zelfrechtvaardiging na de beslissing
Gevangen in de zorgketen	Wij eisten onmiddellijke stopzetting van alle behandelingen.	Familie neemt regie over bij achteruitgang patiënt	Ervaren keuzevrijheid en de grenzen daarvan (van keuze tot schijnkeuze en overgave)
Sterkte met je tumor	Als je zo'n ziekte hebt, dan is er maar één kant die je op kunt gaan: naar voren. Je hebt geen keuze.	Ervaren onvermijdelijkheid van doorzetten	Ervaren keuzevrijheid en de grenzen daarvan (van keuze tot schijnkeuze en overgave)
Mondig ziek zijn	Ik hoefde hierover niet lang na te denken en heb besloten het te laten doen.	Snelle decisiviteit bij heldere keuze	Beslissen onder onzekerheid: overleg, intuïtie en tijdsdruk
Waarden, identiteit & coping			
Obsessie in relatie met kanker	Machteloosheid verdrongen door dwars te zijn; weigering de situatie te accepteren.	Verzet als uitdrukking van verlangen naar autonomie	Autonomie en eigen regie als sturende waarde
Obsessie in relatie met kanker	Hoe vaak heb ik gezien wat chemo een mens aandoet. En nu ga ik het zelf ervaren. Zelf gewild, volmondig toegestemd.	Weloverwogen instemming met zware behandeling	Coping bij existentiële dreiging: acceptatie, stoïcisme, overgave en heroverweging van waarden
Obsessie in relatie met kanker	De calvinistische dogmatiek uit mijn jeugd dwingt me het onoverkomelijk te	Calvinistische opvoeding stuurt acceptatie van het onvermijdelijke	Identiteit, geloof en relaties als zingevend anker

	accepteren; die opvoeding wint.		
Obsessie in relatie met kanker	Ik zou me zeker niet laten behandelen. Kwaliteit van leven, daar zou ik voor kiezen. En dan nu? 'Ja, natuurlijk.'	Discrepantie tussen vooraf gestelde waarden en daadwerkelijke keuze	Coping bij existentiële dreiging: acceptatie, stoïcisme, overgave en heroverweging van waarden
Obsessie in relatie met kanker	Ik bad kort, niet om een gunstige uitslag maar om rust in mijn lijf. En ik werd rustig.	Gebed als bron van rust	Identiteit, geloof en relaties als zingevend anker
Obsessie in relatie met kanker	Mijn hang aan het leven is sterker dan al mijn eerdere overtuigingen.	Levenswil overstijgt eerdere waarden	Coping bij existentiële dreiging: acceptatie, stoïcisme, overgave en heroverweging van waarden
Anneke	Patiënten moeten goed weten welke medicijnen gestopt kunnen worden. Ik heb dat zelf geregeld.	Zelfmanagement van medicatie als autonomie-uiting	Autonomie en eigen regie als sturende waarde
Anneke	We leven in het nu en proberen alvast te rouwen zodat het later niet als verrassing komt.	Anticiperend rouwen als coping	Coping bij existentiële dreiging: acceptatie, stoïcisme, overgave en heroverweging van waarden
Anneke	We geloven in God en ondervinden kracht om te vechten; ik geloof in een Hemel en een leven na de dood. Daar houd ik me aan vast.	Geloof in God als bron van kracht en houvast	Identiteit, geloof en relaties als zingevend anker
Anneke	We leven duidelijk in het hier en nu en maken mooie herinneringen voor later.	Genieten van het heir en nu en herinneringen maken als coping	Coping bij existentiële dreiging: acceptatie, stoïcisme,

			overgave en heroverweging van waarden
Anneke	Ik meld niet alles. Ik doorsta het gewoon.	Onderapportage van klachten als copinggedrag	Coping bij existentiële dreiging: acceptatie, stoïcisme, overgave en heroverweging van waarden
Opnieuw geboren	Desalniettemin is deze relatie, naast mijn eigen kinderen de reden geweest te blijven knokken en de wil vast te blijven houden om te overleven.	Persoonlijke relatie als motivatie voor behandelcontinuering	Identiteit, geloof en relaties als zingevend anker
Nooduitgang	Het woord experiment klonk als muziek. Geen stoma, geen verminkingen — op het scherpst van de snede.	Voorkeur voor experimentele behandeling vanwege lichamelijke integriteit	Lichamelijke integriteit, kwaliteit van leven en behandellast als grens
Nooduitgang	Naast positief blijven denken was conditie opbouwen het enige dat ik zelf kon doen.	Actief zelfmanagement (conditie opbouwen) als gevoel van controle	Autonomie en eigen regie als sturende waarde
Naadloos van zorgverlener naar patiënt	Ik vertel dat ik geen ijskap ga gebruiken. Heb me erin verdiept en er goed over nagedacht.	Weloverwogen weigering van aanbevolen maatregel	Autonomie en eigen regie als sturende waarde
Naadloos van zorgverlener naar patiënt	Na vijf dagen stop ik met de Mepitel, omdat ik het gevoel heb dat ik alles afsluit.	Stoppen met behandeling op basis van lichaamsgevoel	Autonomie en eigen regie als sturende waarde
Naadloos van zorgverlener naar patiënt	Ik vind het prima. Zij zullen wel weten wat goed voor mij is. Ik geef me helemaal over.	Bewuste overgave aan medisch gezag als coping	Coping bij existentiële dreiging: acceptatie, stoïcisme, overgave en heroverweging van waarden

Naadloos van zorgverlener naar patiënt	Ik haal medicijnen op tegen misselijkheid en verstopping. Ik slik alles zoals het hoort.	Strikte therapietrouw als verantwoordelijkheidsgevoel	Coping bij existentiële dreiging: acceptatie, stoïcisme, overgave en heroverweging van waarden
De kwetsbare patiënt	Volledige genezing mogelijk maar ten koste van loopfunctie. Ik besloot te vragen naar andere behandelmogelijkheden.	Lichamelijke integriteit boven curatieve kans	Lichamelijke integriteit, kwaliteit van leven en behandellast als grens
De kwetsbare patiënt	Alle deskundigen: operatie verdient voorkeur maar niet ten koste van loopfunctie — palliatieve behandeling.	Consensusbeslissing rond functionele grens	Lichamelijke integriteit, kwaliteit van leven en behandellast als grens
De kwetsbare patiënt	Schrijven in de derde persoon hielp me afstand te nemen en me te richten op wat ik wél begreep.	Afstand nemen via schrijven in de derde persoon (coping)	Coping bij existentiële dreiging: acceptatie, stoïcisme, overgave en heroverweging van waarden
De kwetsbare patiënt	Kwaliteit van leven verbetert niet als je niet blijft zoeken naar de oorzaak, maar wel als belangrijke waarden nastreeft.	Belangrijke waarden nastreven i.p.v. oorzaak zoeken (acceptatie)	Coping bij existentiële dreiging: acceptatie, stoïcisme, overgave en heroverweging van waarden
De kwetsbare patiënt	Controle willen hebben over het oncontroleerbare, leidt tot grote teleurstelling en meer onzekerheid. Het was voor mij beter te erkennen dat ik de loop der dingen niet bepaal.	Loslaten van de 'illusie van controle' als coping	Coping bij existentiële dreiging: acceptatie, stoïcisme, overgave en heroverweging van waarden

Prostaatkanker	Wetenschappelijk nooit aangetoond dat kousen bijdragen aan voorkomen trombose — na paar dagen gestopt.	Eigen evidence-based redenering over bijwerkingspreventie	Autonomie en eigen regie als sturende waarde
Prostaatkanker	Of je nou wel of niet bestraalt, er blijft altijd kans dat kanker terugkeert. Gekozen voor kwaliteit en comfort.	Restrisico accepteren; kwaliteit van leven als kernwaarde	Lichamelijke integriteit, kwaliteit van leven en behandellast als grens
Prostaatkanker	Weer wilde men mij opnemen. En weer hield ik dat tegen.	Herhaaldelijk weigeren van opname; eigen regie bewaren	Autonomie en eigen regie als sturende waarde
Gevangen in de zorgketen	Marjolijn accepteert radio- en chemotherapie zolang de bijwerkingen 'draaglijk' zijn. Anders stopzetten.	Vooraf gestelde grens aan behandelbelasting	Lichamelijke integriteit, kwaliteit van leven en behandellast als grens
Gevangen in de zorgketen	Zodra communicatie met omgeving niet meer mogelijk is, is er geen zinvol leven meer.	Communicatievermogen als grens voor zinvol leven	Lichamelijke integriteit, kwaliteit van leven en behandellast als grens
Gevangen in de zorgketen	Waarom nam ik niet op tijd het besluit over te schakelen naar palliatieve zorg? Omdat ik niet wilde accepteren.	Niet-acceptatie blokkeert tijdige beslissingsomschakeling	Coping bij existentiële dreiging: acceptatie, stoïcisme, overgave en heroverweging van waarden
Borstkanker	Ik krijg de keus tussen amputatie of borstbesparende operatie. Door alles wat ik gelezen heb, besluit ik geen bestraling te doen.	Uitgebreide zelfstudie leidt tot afwijking van standaardadvies	Autonomie en eigen regie als sturende waarde
Borstkanker	Omdat ik tijdens de eerste behandeling niet misselijk ben geweest, vind ik het	Eigen ervaring overstijgt voorgeschreven protocol	Autonomie en eigen regie als sturende waarde

	onzin Dexamethason in te nemen.		
Borstkanker	Letten op ademhaling, medidatie-oefeningen en veel wandelen maakt wachten op volgende chemokuur draaglijk.	Mindfulness als bewuste strategie bij onzekerheid	Coping bij existentiële dreiging: acceptatie, stoïcisme, overgave en heroverweging van waarden
Borstkanker	Datgene waar je in gelooft is het beste.	Geloof als epistemisch principe bij behandelkeuze	Identiteit, geloof en relaties als zingevend anker
Borstkanker	Mijn leven is veranderd. Ik ga nu echt leven, niet meer zoals anderen van mij verwachten.	Ziekte als aanleiding voor identiteitstransformatie	Identiteit, geloof en relaties als zingevend anker
Sterkte met je tumor	Geen operatie, geen chemo, geen bestraling. Voor mij hield dat in dat ik trouw zou blijven aan mezelf.	Volledige afwijzing behandeling als authenticiteitskeuze	Identiteit, geloof en relaties als zingevend anker
Sterkte met je tumor	Jij bent als enige de baas over je lichaam — je mag als dictator beslissen.	Radicale patiëntautonomie als norm	Autonomie en eigen regie als sturende waarde
Mondig ziek zijn	Op mijn 34e borstkanker. Drie kleine kinderen. De vooruitzichten waren slecht. Hemel en aarde bewogen.	Kinderen als motivatie om behandeling te ondergaan	Identiteit, geloof en relaties als zingevend anker
Mondig ziek zijn	Psychomotore therapie: opnieuw een verhouding aangaan met het eigen lichaam, het vertrouwen herstellen.	Herstel van vertrouwen in het eigen lichaam na ziekte	Identiteit, geloof en relaties als zingevend anker
Mondig ziek zijn	Mayke wilde niet maximale dosis vanwege nadelen. Daarna vier goede jaren gehad.	Bewuste dosisbeperking voor kwaliteit van leven	Lichamelijke integriteit, kwaliteit van leven en behandellast als grens

▸ *Relatie met zorgverleners*			
Obsessie in relatie met kanker	Een derde persoon bij zo'n gesprek, liefst met kennis van zaken en niet te emotioneel betrokken.	Advies voor betere beslissingsondersteuning	Gedeelde besluitvorming en participatie als gewaardeerde norm
Anneke	We hebben een prettig contact met de oncoloog en kunnen zelf ook meedenken.	Actieve participatie in behandelplan als kernwaarde	Gedeelde besluitvorming en participatie als gewaardeerde norm
Nooduitgang	Zo was het protocol, zo was het afgesproken en zo deed ik het ook.	Protocol als leidraad; conformiteit aan medische afspraak	Vertrouwen in arts en protocol als basis voor instemming en geruststelling
Naadloos van zorgverlener naar patiënt	Zij bespreekt oncologie-revalidatie; samen besluiten we dat dit voor mij nu niet nodig is.	Gedeeld besluit op basis van individuele situatie	Gedeelde besluitvorming en participatie als gewaardeerde norm
Naadloos van zorgverlener naar patiënt	De huisarts belt 's ochtends; dat doet erg goed - het gevoel dat je niet vergeten wordt.	Spontaan telefoontje van huisarts ervaren als persoonlijke betrokkenheid	Vertrouwen in arts en protocol als basis voor instemming en geruststelling
Gevangen in de zorgketen	Ik had me gerustgesteld gevoeld, hoefde zelf niet na te denken. 's Avonds toch het advies opgevolgd.	Tijdelijke overgave aan arts gevolgd door eigen afweging	Vertrouwen in arts en protocol als basis voor instemming en geruststelling
Borstkanker	Het is mijn lichaam. Ik word benaderd als mens en niet als nummer.	Erkenning als individu als basisvoorwaarde voor vertrouwen	Vertrouwen in arts en protocol als basis voor instemming en geruststelling
Mondig ziek zijn	Ze hadden gezegd dat het over was. Niemand weet ooit iets zeker, maar ik geloofde hen wel.	Vertrouwen in arts ondanks inherente onzekerheid	Vertrouwen in arts en protocol als basis voor instemming en geruststelling

▸ *Informatie & autonomie*			
Anneke	Graag meer willen weten over bestralingsmogelijkheden en -kansen.	Onvervulde informatiebehoefte	Informatie zoeken als controle-instrument bij onzekerheid
Anneke	Bestraling uitgesteld wegens volle chemoafdeling — ik ga bellen.	Actief opkomen voor eigen zorgplanning	Patiëntagentschap: actief navigeren en afdwingen in het zorgsysteem
Opnieuw geboren	Op maandagmorgen ga ik voor de balie liggen om spoed af te dwingen, uiteindelijk belt de dokter zelf met de specialist.	Radicale assertiviteit om toegang tot zorg te forceren	Patiëntagentschap: actief navigeren en afdwingen in het zorgsysteem
Opnieuw geboren	Ik ga naar een goed bekendstaande homeopathische arts. Waarom voel ik me dan zo ziek?	Zoeken naar alternatieve verklaring bij onverklaarde klachten	Patiëntagentschap: actief navigeren en afdwingen in het zorgsysteem
Opnieuw geboren	En als u gewoon opschrijft dat ik een volledig passageprobleem heb? Goed, het wordt voorgeschreven.	Onderhandelen met arts om vergoeding te verkrijgen	Patiëntagentschap: actief navigeren en afdwingen in het zorgsysteem
Nooduitgang	Alle informatie over het onderzoek gaf veel vertrouwen; langzaam beginnen we voorkeur voor experimenteel scenario te ontwikkelen.	Informatieverstrekking vergroot vertrouwen en stuurt voorkeur	Systeembarrières, informatiekloof en (gebrek aan) transparantie
Nooduitgang	Luc en ik concluderen dat het eigen initiatief van de patiënt bepalend is of je in Maastricht terechtkomt.	Ongelijkheid in toegang afhankelijk van patiëntinitiatief	Systeembarrières, informatiekloof en (gebrek aan) transparantie
Naadloos van zorgverlener naar patiënt	Ik bel een oedeemtherapeut — dit lijkt me beter dan een fysiotherapeut.	Zelf hogere kwaliteit zorg regelen	Patiëntagentschap: actief navigeren en

			afdwingen in het zorgsysteem
Naadloos van zorgverlener naar patiënt	Vandaag bel ik het Erasmus waarom bestralingen twee weken later beginnen, terwijl er maar drie dagen vertraging was. Uiteindelijk week eerder mogelijk.	Actief opvolgen en aanvechten van planning	Patiëntagentschap: actief navigeren en afdwingen in het zorgsysteem
De kwetsbare patiënt	Ik wilde er zoveel mogelijk over weten — sterke behoefte om niet verrast te worden.	Informatie zoeken om verrassing te vermijden	Informatie zoeken als controle-instrument bij onzekerheid
De kwetsbare patiënt	Opnoemen van behandelmogelijkheden schiep verwachtingen die later bijgesteld moesten worden.	Vroege informatie schept verwachtingen die later moeten worden bijgesteld	Systeembarrières, informatiekloof en (gebrek aan) transparantie
Prostaatkanker	Mijn conclusie: volgens Nederlandse richtlijnen zou een operatie nog net mogelijk moeten zijn.	Zelfonderzoek om behandelopties te beoordelen	Informatie zoeken als controle-instrument bij onzekerheid
Prostaatkanker	In Nederland mag huisarts een CT-scan alleen in bijzondere situaties aanvragen — weinig keus. Rede genoeg voor mijn vrouw om het ziekenhuis in B te raadplegen.	Systeembarrière beperkt diagnosemogelijkheden	Systeembarrières, informatiekloof en (gebrek aan) transparantie
Gevangen in de zorgketen	Niemand had ons verteld over spierverzwakking als bijwerking van Dexamethason.	Informatiekloof over bijwerkingen	Systeembarrières, informatiekloof en (gebrek aan) transparantie
Gevangen in de zorgketen	Voor het overleg had ik vier vragen voorbereid.	Gestructureerde voorbereiding op medisch gesprek	Informatie zoeken als controle-instrument bij onzekerheid

Borstkanker	Ik blijf als een bezetene zoeken naar alles over borstkanker, vooral complementaire therapieën.	Intensief informatie zoeken als autonomie-uiting	Informatie zoeken als controle-instrument bij onzekerheid
Mondig ziek zijn	Ik heb de specialist gevraagd of er ook andere behandelingen waren.	Actief vragen naar alternatieven	Informatie zoeken als controle-instrument bij onzekerheid