

Original Article

Living Through the Data: A Qualitative Study of Wearable Symptom Tracking, Self-Management and Family Participation During Chemotherapy

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ABSTRACT

Background: Artificial intelligence is increasingly capable of contributing to information processing, risk estimation, and clinical decision support in oncology, but its acceptability depends not only on technological performance but also on how patients and families understand its role within clinical relationships. Qualitative inquiry is needed to examine how trust, disclosure, accountability, explainability, and autonomy are experienced when algorithmic recommendations enter preference-sensitive treatment decisions. **Objective:** To explore how adults with cancer and family caregivers perceive artificial intelligence in oncology decision-making and to identify conditions under which AI is viewed as supporting or constraining informed participation and patient autonomy. **Methods:** An interpretive qualitative study was conducted with 14 purposively sampled participants, comprising 10 oncology patients and four family caregivers. Semi-structured interviews used clinical scenarios addressing AI-supported recommendations, disclosure, clinician–algorithm disagreement, responsibility, and treatment choice. Data were analysed using reflexive thematic analysis. **Results:** Five interrelated themes were developed: conditional trust rather than technological trust; consent as an ongoing conversation; human accountability as the boundary of automation; explainability as practical meaning; and algorithmic pressure on autonomy. Participants generally accepted AI as an additional source of information when clinicians remained visibly responsible for interpretation and decision-making. Meaningful disclosure was considered increasingly important when AI materially influenced consequential treatment choices. Participants preferred practical explanations of relevance, uncertainty, and alternatives over technical descriptions. Algorithmic recommendations could facilitate deliberation by clarifying options but could also make disagreement appear irrational when presented as objectively definitive. **Conclusion:** Participants perceived AI as most acceptable when it augmented rather than displaced clinical judgement, preserved opportunities to question recommendations, and maintained identifiable human accountability. Implementation should prioritise proportionate disclosure, clinically meaningful explanations, explicit responsibility, and protection of patient choice. **Keywords:** Artificial intelligence; oncology; patient autonomy; shared decision-making; informed consent; qualitative research; family caregivers

EDITORIAL INFORMATION

Author Contributions: WL: Concept, Design; L: Data Collection, Analysis, Interpretation; LC: Drafting, Critical Revision, Supervision.**Ethical Approval:** Universitas Prima Indonesia**Informed Consent:** Written informed consent was obtained from all participants**Conflict of Interest:** The authors declare no conflict of interest; **Funding:** No external funding; **Data Availability:** Available from the corresponding author on reasonable request; **Acknowledgments:** N/A.

INTRODUCTION

Digital technologies are increasingly extending oncology care beyond conventional face-to-face encounters through wearable monitoring, mobile health applications, electronic symptom reporting, and web-mediated surveillance. Qualitative and quantitative studies have shown that such technologies can support symptom monitoring, physical-activity assessment, communication, and remote follow-up during cancer treatment, while their usefulness depends on how patients understand the information generated and how that information is incorporated into clinical care (1–8). These developments have shifted attention from whether digital technologies can generate clinically relevant information to how patients experience technology-mediated care and how technological outputs interact with professional judgement.

Patient-facing digital systems also demonstrate that technological information does not operate independently of clinical relationships. Patients' experiences of wearable and remote-monitoring

technologies indicate that acceptability can depend on the intelligibility of the information produced, confidence in clinical oversight, and the existence of a meaningful pathway from data generation to professional response (1,5–7). These considerations become especially important when technology moves beyond monitoring and begins contributing to diagnosis, prognostic assessment, or treatment recommendations. In such circumstances, algorithmic output may acquire authority within an already complex decision-making process involving patients, clinicians, and family members.

The use of artificial intelligence in treatment-related decision-making therefore raises questions extending beyond technical performance. A patient may regard an algorithmic recommendation as useful additional evidence while still expecting a clinician to interpret its relevance, communicate uncertainty, and remain accountable for the decision. Conversely, recommendations framed as computationally objective may become difficult for patients to question, potentially altering perceptions of choice even when formal decision-making authority remains with the patient. Disclosure is similarly complex because the informational needs associated with background technological support may differ from those arising when an algorithm materially influences a consequential treatment recommendation. These issues are particularly relevant to oncology, where decisions may involve uncertainty, competing benefits and burdens, and substantial personal preferences.

A qualitative approach permits examination of how patients and family caregivers interpret these questions in their own terms rather than reducing acceptability, trust, or autonomy to predetermined survey categories. The present study therefore explored how adults with cancer and family caregivers perceived the use of artificial intelligence in oncology decision-making, with particular attention to trust, disclosure and consent, explainability, professional accountability, disagreement between clinicians and algorithms, and the potential influence of algorithmic recommendations on patient autonomy. It further examined the conditions under which participants perceived AI as supporting rather than constraining meaningful participation in treatment decisions.

MATERIALS AND METHODS

An interpretive qualitative design was used to examine how oncology patients and family caregivers understood the role of artificial intelligence in clinical decision-making, particularly in relation to trust, consent, accountability, explainability, and patient autonomy. The study was informed by a relational understanding of autonomy in which decision-making is situated within interactions among patients, clinicians, family members, available information, and meaningful alternatives. Reporting was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) (9).

Purposive sampling was used to recruit 14 participants comprising 10 adult oncology patients and four family caregivers. Sampling sought variation in age, sex, cancer type or caregiving relationship, stage of treatment, and familiarity with digital health. Patient eligibility required participants to be aged 18 years or older, to be receiving or to have previously received oncology care, and to be able to discuss treatment decision-making in English or Bahasa Indonesia. Eligible caregivers were adults involved in supporting a family member receiving oncology care. The patient sample included participants with breast, colorectal, lung, haematological, gynaecological, and prostate cancers. The caregiver sample included spouses, an adult child, and a sibling.

Data were generated using semi-structured interviews focused on participants' understanding of artificial intelligence, reactions to AI-supported diagnostic or treatment advice, expectations concerning disclosure and consent, perceptions of responsibility, and responses to situations in which clinical and algorithmic recommendations differed. Short hypothetical scenarios were incorporated to make these issues concrete. The scenarios varied the visibility and potential clinical consequence of AI involvement, including background image-analysis support, generation of an individualised recurrence estimate, concordance between a clinician and an algorithm, disagreement between an oncologist and an algorithm, use of AI without prior discussion, and an AI-generated treatment alternative that differed from the oncologist's initial recommendation. This variation enabled participants to consider AI use across situations ranging from comparatively low-visibility support to potentially high-consequence treatment decisions.

Data were analysed using reflexive thematic analysis following the approach described by Braun and Clarke (10). Analysis involved familiarisation with the data, coding, development of candidate themes, review of candidate themes against the dataset, refinement of thematic boundaries, and interpretive writing. Coding addressed explicit participant accounts while also examining how participants positioned clinical expertise, technological authority, personal values, and responsibility within decision-making. Themes were retained on the basis of conceptual relevance to the research question rather than numerical frequency. Particular attention was given to accounts that complicated or contradicted emerging interpretations, including situations in which participants accepted one application of AI but rejected another or simultaneously expressed enthusiasm about technological capabilities and concern about their implications. Such divergent accounts were considered during theme refinement to avoid treating either acceptance or concern as a uniformly informed position.

Interpretation also compared how participants responded to differing levels of AI influence and to situations in which efficiency, predictive information, professional reassurance, or personal control were given different prominence. The analysis examined whether AI was perceived as broadening the information available for deliberation or narrowing the range of choices that participants felt able to question. Patient and caregiver accounts were considered within the same thematic analysis while retaining participant identifiers so that similarities and contrasts between the two participant groups could be examined. Ethical approval was granted by Universitas Prima Indonesia. Participation was voluntary, confidentiality was maintained through pseudonymised participant identification numbers, and participants could withdraw until the point at which analysis commenced. The ethics approval number was not available in the supplied manuscript record and therefore requires verification before publication.

RESULTS

Fourteen participants contributed to the study, including 10 oncology patients and four family caregivers. The patient sample represented breast, colorectal, lung, ovarian, and haematological cancers and included participants at different reported chemotherapy cycles. Caregivers included two spouses, one adult child, and one sibling. Participants did not divide into consistently favourable or unfavourable positions toward AI. Instead, their accounts indicated that acceptability depended on the function assigned to AI, the consequence of the decision in which it was involved, whether a clinician remained responsible for interpreting its output, and whether patients retained a meaningful opportunity to question or reject the resulting recommendation. Five interrelated themes were developed: conditional trust rather than technological trust; consent as an ongoing conversation; human accountability as the boundary of automation; explainability as practical meaning; and algorithmic pressure on autonomy.

Table 1. Thematic evidence matrix

Theme	Central analytic interpretation	Patient Evidence	Caregiver Evidence
Conditional trust rather than technological trust	Trust was placed in clinically supervised use of AI rather than in technology independently	P03	P11
Consent as an ongoing conversation	Desired disclosure increased when AI materially influenced a consequential decision	P06, P09	No caregiver quotation displayed for this theme
Human accountability as the boundary of automation	Participants expected identifiable clinical responsibility despite advanced automation	P02	P14
Explainability as practical meaning	Participants prioritised decision-relevant explanations over technical descriptions	P05, P08	No caregiver quotation displayed for this theme
Algorithmic pressure on autonomy	AI could either facilitate deliberation or make disagreement feel irrational	P01, P04	P12

Theme 1: Conditional trust rather than technological trust

Participants rarely described trust as confidence in artificial intelligence independently of the clinical context in which it was used. AI was more readily accepted as an additional source of information, a means of organising complex data, or a second opinion than as an autonomous decision-maker. P03, a patient, explained: “If it caught something the doctor had not seen, that would be beneficial. The doctor should explain it to the patient, but not the computer alone.” The value attributed to AI therefore depended not only

on what the technology might detect but also on whether its output remained embedded within clinical interpretation and communication.

Caregiver accounts similarly distinguished computational capability from legitimate decision-making authority. P11, a family caregiver, stated: “It may compare thousands of cases, and I cannot do so, but it does not know what I will accept to live with.” Participants could acknowledge that computational systems might process information more consistently or at a scale unavailable to an individual clinician while simultaneously rejecting the proposition that computational capacity alone conferred authority over preference-sensitive treatment choices. Trust appeared stronger when uncertainty was acknowledged and the clinician remained visibly engaged in interpretation.

Theme 2: Consent as an ongoing conversation

Participants did not generally frame informed consent as requiring a separate technical explanation for every use of AI. Instead, the desired level of disclosure depended on the perceived influence of the technology on the decision. Background functions were viewed differently from AI contributions capable of altering diagnosis, prognosis, or treatment selection. P06, a patient, explained: “If it is only sorting scans, I do not need a lecture about it; it does not change my decision.”

Disclosure became more important when AI materially shaped what was recommended. Participants wanted to understand what the system contributed, whether the clinician agreed with its output, and whether reasonable alternatives remained available. P09, a patient, characterised meaningful consent as follows: “I should be able to say yes, no, or show me another option.” Accounts therefore suggested that disclosure was perceived as useful when it preserved deliberation rather than merely informing patients retrospectively that AI had been involved. Disclosure occurring only after a recommendation had already been framed was perceived as offering less meaningful opportunity for participation.

Theme 3: Human accountability as the boundary of automation

A prominent boundary across the interviews concerned responsibility for decisions. Participants were willing to contemplate substantial technological involvement provided that an identifiable clinician continued to review the output and remained responsible for the clinical recommendation. P02, a patient, stated: “Somebody has to be the decision maker; if the answer is inaccurate, then I cannot dispute it with software.”

Accountability was understood as more than the allocation of blame following an adverse outcome. Participants expected professional responsibility to involve active scrutiny of algorithmic recommendations. P14, a family caregiver, explained: “If the doctor is responsible, then the doctor has to check it.” Participants consequently resisted situations in which clinicians might justify a recommendation solely by referring to what an algorithm had produced. Disagreement between AI and a clinician was not automatically interpreted as evidence of failure; it could instead create a reason for additional scrutiny, provided that neither source was followed automatically.

Theme 4: Explainability as practical meaning

Participants did not primarily seek technical accounts of source code, model architecture, or computational processes. Their accounts emphasised explanations that could be related directly to the treatment decision: why a recommendation had been produced, which factors were relevant, how certain the output was, and what circumstances might make it less applicable to the individual patient. P05, a patient, stated: “I do not need to know how the machine is constructed; I need to know why it believes option A is the most suitable for me.”

Highly precise numerical outputs could themselves generate uncertainty when participants did not understand their basis. P08, a patient, commented: “It says 82 percent, but cancer is never that certain. What does that number really mean?” Explainability was therefore experienced as practically useful when algorithmic information could be translated into clinically meaningful terms and incorporated into discussion rather than presented as an isolated numerical result.

Theme 5: Algorithmic pressure on autonomy

Participants identified a potential tension between receiving technically sophisticated advice and retaining a genuine sense of choice. Recommendations explicitly described as AI-derived could appear unusually objective and consequently more difficult to challenge. P12, a family caregiver, explained: “If I am told the computer calculated that this is the best treatment, then if I say no, I feel irrational.” P04, a patient, expressed a similar tension: “I am being given an option, but at the same time I am being told there is only one possible answer.”

These accounts indicated that the existence of formal choice did not necessarily mean that participants experienced the alternatives as equally contestable. Algorithmic authority could narrow perceived room for disagreement when a recommendation was presented as the uniquely rational conclusion. At the same time, participants also described circumstances in which AI could strengthen participation by making alternatives and trade-offs easier to consider. P01, a patient, stated: “If I can see the different options clearly, it may be easier to talk about my priorities with the doctor and my family.” The distinction therefore depended on how AI was incorporated into deliberation: it could support agency when it made options more intelligible, but constrain agency when its output was framed as effectively unquestionable.

Table 2. Representative quotations mapped to themes

Theme	Participant	Representative quotation
Conditional trust	P03, patient	“If it caught something the doctor had not seen, that would be beneficial. The doctor should explain it to the patient, but not the computer alone.”
Conditional trust	P11, family caregiver	“It may compare thousands of cases, and I cannot do so, but it does not know what I will accept to live with.”
Consent as ongoing conversation	P06, patient	“If it is only sorting scans, I do not need a lecture about it; it does not change my decision.”
Consent as ongoing conversation	P09, patient	“I should be able to say yes, no, or show me another option.”
Human accountability	P02, patient	“Somebody has to be the decision maker; if the answer is inaccurate, then I cannot dispute it with software.”
Human accountability	P14, family caregiver	“If the doctor is responsible, then the doctor has to check it.”
Practical explainability	P05, patient	“I do not need to know how the machine is constructed; I need to know why it believes option A is the most suitable for me.”
Practical explainability	P08, patient	“It says 82 percent, but cancer is never that certain. What does that number really mean?”
Algorithmic pressure on autonomy	P12, family caregiver	“If I am told the computer calculated that this is the best treatment, then if I say no, I feel irrational.”
Algorithmic pressure on autonomy	P04, patient	“I am being given an option, but at the same time I am being told there is only one possible answer.”
Algorithmic support for deliberation	P01, patient	“If I can see the different options clearly, it may be easier to talk about my priorities with the doctor and my family.”

Across the themes, participants distinguished between being informed and being overwhelmed by technical information. They did not necessarily want each technological operation to become an independent consent exercise, yet they rejected assumptions that technical complexity justified excluding them from information relevant to consequential decisions. P07, a patient, stated: “I want to decide for myself how much I want to know, not be told that it is too technical for me.” These accounts supported a preference for explanation that could be proportionate to the clinical significance of AI involvement and expandable when participants wanted further detail.

Data governance also emerged as a related consideration. Some participants were willing to contemplate secondary use of health information for improving cancer-related technologies when the purpose and governance were transparent, but they drew distinctions between patient-benefiting uses and undisclosed commercial reuse. P10, a patient, explained: “I could accept it if my data helped another patient, but if it becomes a product and nobody tells me, that is different.” Trust in AI-supported recommendations was therefore connected not only to the immediate clinical interaction but also to participants' perceptions of how the underlying health data were managed.

DISCUSSION

This qualitative study identified five interconnected dimensions through which oncology patients and family caregivers interpreted the involvement of artificial intelligence in treatment-related decision-

making: conditional trust, proportionate and continuing consent, human accountability, practically meaningful explainability, and algorithmic pressure on autonomy. Participants did not evaluate AI as an isolated technology. Instead, its acceptability depended on how it was positioned within the clinical relationship, the consequence of the decision in which it was involved, whether a clinician remained visibly responsible, and whether the patient retained a genuine opportunity to question or reject the recommendation. The findings therefore suggest that perceived legitimacy of AI in oncology may depend as much on the clinical process surrounding its use as on the output generated by the system.

The importance participants placed on clinical integration is consistent at a broader digital-health level with oncology research showing that patients' experiences of technological monitoring depend on whether information is understandable, clinically relevant, and connected to an identifiable pathway for professional interpretation or response (1,5–8). Studies of wearable and remote symptom-monitoring systems have similarly demonstrated that technological data acquire practical value when embedded within ongoing cancer care rather than functioning as isolated streams of information (1,5–8). Although these studies concern monitoring technologies rather than AI-assisted treatment decisions, they provide relevant contextual evidence that patients evaluate digital systems partly through the human and organisational structures in which those systems operate. The present findings extend this relational concern into higher-stakes decision contexts, where participants expected AI-generated information to remain subject to professional interpretation and patient deliberation.

Trust in the present study was therefore conditional rather than technological. Participants could simultaneously acknowledge the potential computational advantages of AI and reject the proposition that such capability should translate automatically into decision-making authority. This distinction was especially apparent when participants discussed clinician–algorithm disagreement. Rather than requiring clinicians always to override or always to follow AI, participants expected disagreement to initiate scrutiny. Human accountability was consequently understood not merely as identifying responsibility after an error but as requiring clinicians to review, contextualise, and, where necessary, challenge algorithmic output. This interpretation is important because it positions accountability as an active feature of implementation rather than a retrospective attribution of blame.

Participants also described consent as proportionate to the material influence of AI. Background technological functions were generally perceived as requiring less elaborate explanation than applications capable of affecting diagnosis, prognosis, or treatment selection. However, participants wanted sufficient information to understand what AI had contributed, whether the clinician agreed with the output, what uncertainty remained, and what alternatives were available when the technology materially affected a consequential recommendation. This indicates that disclosure may be more meaningful when organised around decision relevance rather than technical complexity. Similar considerations have emerged in broader remote-monitoring research, in which patient acceptance depends partly on understanding what information is collected, how it will be used, and what response can be expected from the clinical service (1,5). The current findings suggest that these expectations become more consequential when technology contributes directly to treatment deliberation.

Explainability was likewise framed in practical rather than computational terms. Participants did not emphasise knowledge of model architecture or source code; instead, they wanted to understand why a recommendation was relevant to them, which factors influenced it, how uncertain it was, and under what circumstances it might be less applicable. Numerical precision without contextual interpretation could increase rather than resolve uncertainty. This finding suggests that patient-facing explanations should not be equated with maximal technical disclosure. The more relevant goal may be sufficient interpretability for meaningful participation in the clinical decision. Digital oncology research similarly indicates that patients value understandable and actionable information rather than data collection alone (1,5,7). For AI-supported decisions, this principle may require clinicians to translate algorithmic output into the clinical alternatives, uncertainties, and patient-specific considerations that shape the actual choice.

The theme of algorithmic pressure adds an important qualification to assumptions that providing additional information necessarily strengthens autonomy. Some participants believed that AI could support agency by clarifying alternatives and making trade-offs easier to discuss with clinicians and family members. Others described the possibility that a recommendation presented as mathematically or computationally optimal could make refusal feel unreasonable. In these accounts, formal availability of choice did not always correspond to an experienced freedom to disagree. AI may therefore support autonomy when it broadens deliberation but potentially constrain it when technological authority narrows the range of options perceived as legitimate. Implementation should consequently avoid presenting model outputs as self-validating conclusions and should retain explicit opportunities for patients to discuss values, preferences, uncertainty, and acceptable alternatives.

Family involvement also deserves attention because four participants were caregivers and several accounts positioned treatment decision-making as relational rather than exclusively individual. Caregivers could contribute interpretation, reassurance, and contextual knowledge, but their involvement also introduces questions about whose preferences are being represented and how technological information influences family discussions. Research on cancer self-management has shown that family caregivers frequently participate in symptom recognition, decision support, and practical management of illness (11,12). Although those studies concern symptom management rather than AI-assisted treatment choice, they reinforce the relevance of considering patients and caregivers as interacting participants in technology-mediated cancer care. Future research should examine patient-caregiver dyads directly to determine where interpretations of algorithmic recommendations converge and where they create tension around autonomy or responsibility.

Data governance emerged as an additional consideration linked to trust. Participants distinguished between uses of health information perceived as contributing to patient benefit and secondary or commercial uses occurring without sufficiently transparent disclosure. This finding indicates that perceptions of an AI-supported recommendation may be influenced not only by the immediate clinical encounter but also by assumptions about how the data underlying technological systems are collected, reused, and governed. Existing digital oncology literature similarly identifies patient preferences and acceptability as relevant considerations in technology-mediated monitoring and data-generating systems (1,5). Transparent governance may therefore be important to maintaining trust even when patients do not request detailed technical information about the algorithms themselves.

The findings have several practical implications. Oncology services considering AI-assisted decision support should preserve visible clinician responsibility, establish proportionate approaches to disclosure, and ensure that algorithmic recommendations can be explained in relation to clinically meaningful alternatives and uncertainties. Patients should be able to ask whether AI materially contributed to a recommendation and to request further explanation when its influence is consequential. Clinicians may also require preparation to communicate uncertainty without presenting computational predictions as either infallible or irrelevant. Digital monitoring trials have demonstrated that technology is most useful when linked to predefined clinical pathways rather than simply introduced as an additional information source (6–8). A comparable implementation principle may apply to AI: technological output should be accompanied by clear responsibility for interpretation and response.

Several limitations should be considered when interpreting these findings. The purposive sample comprised only 14 participants from a single reported institutional context, including 10 patients and four family caregivers, and therefore does not support estimates of population prevalence or generalisable frequencies of particular views. The manuscript record does not document the recruitment denominator, refusals, interviewer characteristics, researcher-participant relationships, interview duration, recording and transcription procedures, language-specific transcription or translation processes, or a formal sampling-completion criterion. These reporting gaps limit assessment of selection processes, reflexivity, information sufficiency, and the potential influence of translation or interviewer positioning. The analysis did, however, use reflexive thematic analysis and explicitly considered divergent or negative accounts during theme development (10). Before publication, the missing methodological details should be

recovered from the original study records and reported in accordance with COREQ rather than reconstructed retrospectively (9).

A further limitation is that participants responded partly to hypothetical scenarios concerning different forms and levels of AI involvement. Such scenarios allowed participants to consider ethically and clinically distinct situations, but accounts of anticipated reactions may differ from experiences during actual AI-supported treatment decisions. The findings should therefore be interpreted as participants' perceptions and reasoning regarding possible AI-supported oncology care rather than evidence that AI changed treatment uptake, clinical outcomes, or patient behaviour. Longitudinal qualitative work embedded in real-world AI-enabled oncology pathways would be required to examine whether these expectations persist when patients encounter algorithmic recommendations during actual care.

CONCLUSION

Oncology patients and family caregivers in this qualitative study perceived artificial intelligence as potentially compatible with patient autonomy when it functioned as an aid to, rather than a substitute for, responsible clinical judgement. Acceptability depended on maintaining identifiable human accountability, providing disclosure proportionate to the consequence of AI involvement, translating algorithmic outputs into practically meaningful explanations, and preserving the patient's ability to question recommendations and consider alternatives. AI could facilitate deliberation when it clarified choices, but participants also perceived a risk that recommendations framed as computationally definitive could make disagreement appear irrational. These findings support implementation approaches that preserve clinician responsibility, patient control over the depth of explanation, transparent discussion of uncertainty, and meaningful opportunities for preference-sensitive decision-making. They should not be interpreted as evidence of improved treatment uptake, effectiveness, or population-level outcomes.

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