



Oncology patients' willingness to report their medication safety concerns from home: a qualitative study

Deema Bunni¹ · Grace Walters¹ · Misun Hwang¹ · Katie Gahn¹ · Heidi Mason¹ · Milisa Manojlovich¹ · Yang Gong² · Yun Jiang¹

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Abstract

Purpose Oncology patients often struggle to manage their medications and related adverse events during transitions of care. They are expected to take an active role in self-monitoring and timely reporting of their medication safety events or concerns to clinicians. The purpose of this study was to explore the factors influencing oncology patients' willingness to report adverse events or concerns related to their medication after their transitions back home.

Methods A qualitative interview study was conducted with adult patients with breast, prostate, lung, or colorectal cancer who experienced care transitions within the previous year. A semi-structured interview guide was developed to understand patients' perceptions of reporting medication-related safety events or concerns from home. All interviews were conducted via phone calls, recorded, and transcribed for thematic data analysis.

Results A total of 41 individuals participated in the interviews. Three main themes and six subthemes emerged, including patients' perceived relationship with clinicians (the quality of communication and trust in clinicians), perceived severity of adverse medication events (perceived severe vs. non-severe events), and patient activation in self-management (self-efficacy in self-management and engagement in monitoring health outcomes).

Conclusion The patient-clinician relationship significantly affects patients' reporting behaviors, which can potentially interact with other factors, including the severity of adverse events. It is important to engage oncology patients in medication safety self-reporting from home by enhancing health communication, understanding patients' perceptions of severe events, and promoting patient activation. By addressing these efforts, healthcare providers should adopt a more patient-centered approach to enhance the overall quality and safety of oncological care.

Keywords Medication safety · Adverse drug events · Health communication · Transitions of care · Patient engagement

Introduction

Cancer care has shifted significantly from inpatient to outpatient settings in the past few decades, with many patients experiencing transitions of care (TOC) from hospitals or clinics to home, which becomes an essential part of their cancer care journey [1]. However, frequent TOC among patients with cancer emphasizes the critical significance of effective communication and care coordination. Poor

communication and uncoordinated care can contribute to inadequate information sharing, increase the likelihood of adverse medication events, and ultimately lead to poor patient outcomes [2]. The National Cancer Institute defines an adverse medication event as an unfavorable sign, symptom, or disease associated with the use of a medication [3]. The advancement of cancer treatments has also led to increased prescriptions of oral anticancer agents (OAAs), which are convenient for patients and their families to manage their cancer treatments at home. However, such a care transformation requires patients and families to communicate with clinicians from home in a timely manner for proper medication and toxicity management [4]. In an observational study, the occurrence of adverse medication events in oncology patients taking OAAs was as high as 87.36% [5]. Frequently, patients have combination therapies of OAAs

✉ Yun Jiang
jiangyu@umich.edu

¹ School of Nursing, University of Michigan, Ann Arbor, USA

² McWilliams School of Biomedical Informatics, UTHHealth Houston, Houston, USA

with intravenous chemotherapy or with immunotherapy, which can increase the complexity of managing the adverse effects when patients experience TOC. Additionally, most patients with cancer have other chronic conditions, which may require them to take multiple medications concurrently with cancer medications. During TOC, these medications may be stopped, started, or changed, potentially leading to discrepancies, which may, in turn, lead to adverse medication events [6]. To achieve the goal of medication safety during TOC, patients with cancer and their families need to become “vigilant partners” in medication and toxicity self-monitoring, including timely reporting of their medication safety events or concerns to clinicians [7, 8].

Patient engagement in medication self-management is facilitated by their effective communication with well-prepared healthcare teams [9, 10]. Informed and activated patients often have the motivation, knowledge, skills, and confidence to manage their health and health care [11]. They can actively engage in communications with their healthcare teams to ask questions, gain detailed information, and voice their concerns [12]. However, it can be challenging for many patients to determine what and when to report their experiences and concerns about their medications. Some patients may fear reprisals from clinicians and hesitate to initiate their reporting from home to clinicians [13].

Various barriers and facilitators have been associated with patient engagement in healthcare interactions [14–16]. One study determined that chronic disease patients’ trust in clinicians and the perceived attitude of clinicians were among the factors that influenced their willingness to reach out to their providers during TOC [15]. In contrast, factors like negative patient-clinician interactions and intimidating healthcare settings may hinder participation [16]. To the best of our knowledge, there has been no report in the literature about factors influencing oncology patients’ willingness to report medication safety events or concerns from home, particularly from the patient’s point of view.

The objective of this qualitative study was to understand oncology patients’ perceptions of factors that influence their willingness to report medication safety concerns from home.

Methods

Participants and settings

Potential participants were identified through the review of patient medical records. The inclusion criteria were (1) diagnosed with lung, colorectal, breast, or prostate cancers; (2) experienced TOC from hospitals or clinics to home in the past year; and (3) aged ≥ 18 years old. Purposive sampling was used to recruit participants who represented older adults and four types of cancer, given the high risk

for comorbidities and medication safety concerns in these populations [17]. Trained research staff contacted potential participants via email or phone to introduce the study and enrolled those who agreed to participate. Individual semi-structured interviews were conducted with patients with cancer who had received care at the University of Michigan’s Rogel Cancer Center, one of 72 nationally designated comprehensive cancer centers in the country. Participants who completed the interview received a \$50 gift card for their time and participation. This study was determined to be exempt by the University of Michigan Institutional Review Board (HUM00203239).

Data collection

The initial draft of the interview guide was generated based on a literature review and discussions with experts in medical oncology, patient safety, and medication adherence. To enhance methodological rigor, the staff conducted three mock interviews to test and review the interview guide before using it with participants, with appropriate updates being made throughout the process. The final guide included approximately 13 open-ended questions with guiding prompts that explored patients’ experiences with medication self-management and concerns about reporting medication safety events following transitions back home (Online Resource 1).

Interviews were conducted by 4 female research staff trained in clinical-qualitative interviewing: D.B. (pre-medical student), G.W. (pre-medical student), K.G. (BS in Biochemistry & Spanish, clinical research coordinator), A.J. (BSW, MSW, clinical research coordinator). Individual interviews were conducted over the phone between April and December 2022, and each interview lasted approximately 60 min. In-person interviews were not conducted as planned due to COVID-19 restrictions. All interviews were audio-recorded with the participants’ verbal consent and later transcribed verbatim by research staff, with any potentially identifiable personal information omitted. Interviews continued in parallel with data analysis until no new themes were generated and data saturation was reached.

Data analysis

Thematic analysis was performed with an inductive approach focusing on the participants’ experiences [18]. A.J. and K.G. individually conducted the initial line-by-line coding of the transcripts. Jointly, they developed a preliminary codebook with input from the team and used it to double code the first 25% of transcripts. Discrepancies between coders were resolved through discussions until a consensus was reached and the codebook was finalized. During the interview and data analysis phase, team meetings with an

oncology nurse practitioner, a patient safety expert, and a medication self-management researcher were held weekly to discuss emerging codes, categories, and themes, and to

reflect on the interviews to reduce potential biases for the remainder of the interviews. The discussions continued until consensus was reached about each aspect of the data analysis. Data management and analysis were conducted using NVivo software (Version 12, QRS International).

Table 1 Characteristics of participants ($N=41$)

Characteristics	No. (%)
Gender	
Male	16 (39.0)
Female	25 (61.0)
Age, mean (SD)	63.6 (10.83)
18–49	6 (14.6)
50–59	9 (22.0)
60–69	11 (26.8)
≥ 70	15 (36.6)
Race	
White	32 (78.1)
Non-White ^a	9 (21.9)
Cancer type	
Lung	10 (24.4)
Colorectal	11 (26.8)
Breast	10 (24.4)
Prostate	10 (24.4)
Taking OAs currently or previously	
Yes	26 (63.4)
No	15 (36.6)

^aNon-White includes Black or African American, Asian, or more than one race

Results

A total of 41 participants (ten for breast, lung, and prostate cancers, respectively, and 11 for colorectal cancers) had a mean age of 63.6 years (range = 44–82; standard deviation = 10.83), with 52.2% ($n=21$) of them currently taking OAs. There were more female participants ($n=25$, 61%) than males, and most of them self-reported as white ($n=32$, 78.1%) (see Table 1).

Three main themes emerged as primary factors associated with patients' willingness to report medication safety concerns from home, including (1) perceived relationship with clinicians, (2) perceived severity of adverse medication events, and (3) patient activation in self-management. There are two subthemes under each main theme, which are summarized in Table 2.

Patients' perceived relationship with clinicians

Many participants shared that their relationship with clinicians influenced their decision on whether to contact clinicians when they have concerns about their medications.

Table 2 Factors affecting patients' willingness to report medication safety concerns from home

Theme	Sub-theme	Description
Patients' perceived relationship with clinicians	The quality of communication experiences with clinicians	<ul style="list-style-type: none"> • Positive experiences with clinicians made patients feel more comfortable with continuous reporting • Negative experiences with clinicians hindered patients' initiation of contact
	Patients' trust in the clinicians' professional knowledge	Patients who had trust in the clinicians and their professional knowledge felt more comfortable reporting their medication events or concerns
Patients' perceived severity of adverse medication events	Perceived severe adverse medication events/concerns	Patients were willing to report adverse medication events that they considered to be severe
	Perceived non-severe adverse medication events/concerns	Patients were less motivated to report their experiences or concerns of adverse medication events that were not considered to be severe
Patient activation in self-management	Patients' self-efficacy in health self-management	Patients who felt confident in their abilities to manage their medications would be likely to report any medication safety events or concerns from home
	Patients' engagement in monitoring their health outcomes	Patients who have been engaged in monitoring their cancer care outcomes were motivated to report their adverse medication events, regardless of their relationship with their clinicians

One participant specified, “*I’ve got a really good relationship with the doctors that I see consistently. And I wouldn’t hesitate to ask their inputs; it’s just easier to care.*” (#36). Multiple participants shared similar feelings and experiences regarding frequent interactions with their direct care clinicians. This perception included two aspects: the quality of communication experiences with their clinicians and their trust in the clinicians’ professional knowledge.

The quality of communication experiences with clinicians

Participants considered they had good experiences in communication with clinicians when they were respected, listened to, and understood by their healthcare team. The high quality of communication, like clear explanations, strengthened their positive perception of their relationship with the clinicians and allowed for the foundation of a trusting relationship.

“I feel confident in my oncologist, you know, my medical team there. I feel like my oncologist is very clear with me, explains to me why we’re doing what, and I feel that he has the knowledge and ability to do it, which is why I see him.” (#37)

Patients’ perceived negative communication experiences with clinicians deterred them from reporting important health information from home; any dismissive or disrespectful responses eroded their confidence in the reporting process.

“I did not find reporting [concerns] to my physician helpful at all. He just pooh-poohed you and ignored you.” (#25)

Patients’ trust in the clinicians’ professional knowledge

Participants also shared that their trust and confidence in the clinicians and their knowledge and ability to prevent adverse events influenced their reporting behavior. Those who perceived an established trusting relationship were often motivated to initiate contact with the clinicians when any medication concerns arose.

“As I said before, I have a great GP. A great oncology team. I really have confidence in any contact I have with the physicians.” (#27)

“I trust that [the doctors] know what they’re doing and will always suggest and give me the treatment that they feel is the best for me and my circumstances, and that has the best opportunity to cure, treat, extend my life.” (#14)

Patients’ perceived severity of adverse medication events

Participants’ perceptions of the severity of medication events played an important role in their decision-making regarding whether to seek medical advice. Their willingness to report depended on whether they considered the medication events to be severe vs. non-severe by using their judgment.

Perceived severe adverse medication events/concerns

Participants intended to report only adverse medication events they considered severe. Different criteria were applied by different participants in their self-assessment of the severity. Some participants considered severe adverse events as those which had a significant influence on their daily lives. For example, one participant mentioned, “*If I was having something severe or that was scaring me, which I did last year because I got a bone strengthener and I was having heart palpitations and it scared me, I did send a message.*” (#9).

Participants sometimes tried to differentiate adverse effects from the “normal” ones as unanticipated. Participants reached out to their clinicians when they perceived worsening adverse effects.

“If I have something come up with a medication and it’s totally unusual, then I would let [the doctor] know.” (#35)

“Even knowing, you know, what some of the side effects could be if the side effects become more severe, I would definitely be talking to [the doctors] about “Okay, what can we do to correct this?”” (#14)

Perceived non-severe adverse medication events/concerns

Participants often perceived that an adverse event was not severe if it did not interfere with their daily life or could be resolved quickly. They did not feel the need to report these adverse events to their clinicians or they waited until they went to see their clinicians.

“If a concern is not so pressing that I don’t feel it all the time, I’m probably not going to worry about it. For instance, the day I had stomach pain, and that went away. I’m not going to report it.” (#12)

Patient activation in self-management

Activated participants, including those who were confident in their ability to self-manage their health and monitor

their health outcomes, felt comfortable reaching out to their clinicians about issues they encountered.

Patients' self-efficacy in health self-management

Participants who had strong self-efficacy in health self-management were confident in their ability to self-manage their conditions and medications and would actively report their experiences or concerns about adverse medication events.

"I feel confident that if I'm feeling side effects, I would contact somebody, so I feel safe as far as managing." (#8)

Activated participants did not seem to solely rely on their clinicians for information on managing their conditions. They felt at ease around their clinicians and comfortable to self-advocate.

"I would say the majority of the information that I've taken in, and the confidence that I've received from it has been from my own research and not necessarily what I've been provided by my physician." (#19)
"I'm comfortable around doctors, I just have a certain level of ease maybe where they don't scare me, they put their pants on one leg at a time just like me, and I respect their knowledge. But this is my house, and I, you know, advocate for myself." (#22)

Patients' engagement in monitoring their health outcomes

Participants who had strong concerns about their cancer care outcomes (i.e., life or death) and monitored their health status changes were proactive in seeking medical advice and reporting any alarming symptoms in their condition. They recognized the importance of timely self-reporting and considered it vital to the preservation of their health, sometimes regardless of whether they had built a connection with the clinicians yet.

"No matter who my doctor was, I would report my issues because I am concerned about my health." (#1)
"Because they're my doctors and I have a body or a physical condition that's going to kill me, and the only way to deal with it is letting them know what's happening with my body and listen to whatever they have to say." (#39)

Discussion

Oncology patients and their families are expected to play an active role in medication self-management during transitions of care. However, it can be challenging for many patients and families to engage in self-monitoring and timely reporting

of their medication safety events or concerns during TOC. This study identified three main factors that were associated with oncology patients' willingness to report their medication safety concerns from home. Patients' perceived relationship with their clinicians was the primary factor that influenced their decision to report their concerns. The other two factors included patients' perceived severity of medication events and patient activation in self-management. Oncology patients, despite being advised to report adverse medication events, may have personal perceptions, or limitations that affect their decision to report. These findings shed light on the understanding of oncology patients' needs for support in safely managing their medications at home.

It is not surprising that oncology patients perceived that their relationship with their clinicians was a determinant of their reporting of medication safety events to clinicians. Although not solely focused on oncology, the literature has demonstrated that the quality of the patient-clinician relationship can significantly impact patient satisfaction and engagement in their care [19]. It also suggests that establishing and nurturing a good patient-clinician relationship is vital in promoting effective health communication and enhancing the overall patient experience [20]. The current study provides further evidence that a positive relationship between patients and clinicians could foster a sense of collaboration and empower patients to take an active role in managing their medications, including timely reporting of medication safety events and concerns [21].

The foundation of the general patient-clinician relationship has been addressed to consist of four key elements: *trust*, *loyalty*, *regard*, and *knowledge*, which are mutually referenced between patients and clinicians [22, 23]. A synthesis of qualitative literature identifies these four elements as the result of patients' ongoing experiences with their physicians [22]. For the current study, *regard* seems to be most relevant to the perspectives that oncology patients shared. For example, patients who perceived a greater sense of *regard* from their clinicians, such as through the act of being listened to, attributed that to a positive communication experience. Mutual *regard* indicates that the patient and clinician have mutual respect and liking for each other as individuals [23]. This translates into a good patient-clinician relationship with transparent communication between both sides, which is crucial for accurate diagnosis, effective treatment planning, and overall healthcare management [24]. Conversely, a perceived lack of connection or poor communication can lead to disengagement and non-adherence to medical recommendations [25]. Barriers to open communication with the clinicians appeared with oncology patients who previously encountered negative experiences when reporting their medication safety concerns. This is congruent with findings from previous studies in which negative healthcare interactions limited patient participation and led both oncology and

non-oncology patients to withhold information out of fear of being misunderstood, embarrassed, or facing repercussions which can hinder accurate diagnosis and compromise overall patient health outcomes [26, 27]. Building a positive relationship with oncology patients through effective patient-clinician communication promotes patient-centered cancer care.

Moreover, mutual trust in the patient-clinician relationship indicates that the patient has faith in the clinician's professional knowledge and competence in providing care, and the clinician has trust in the patient's beliefs and engagement in self-management such as self-reporting of symptoms [23]. In this study, oncology patients' beliefs in their clinicians' expertise and recommendations enabled them to feel more comfortable reporting medication safety events and concerns. There are a vast number of studies confirming the significance of experiences and trust when examining the impact of the patient-clinician relationship on patient self-reporting behaviors [19, 22, 23, 28]. Consistent with existing literature, oncology patients in the current study identified that their medication safety reporting behavior was influenced by the trust they had in their clinicians.

This study also suggests that oncology patients' self-assessment of the severity of adverse events is related to their willingness to report medication safety concerns from home. That is, patients mainly reported the adverse events they considered severe. This finding is consistent with previous studies in which patients with non-cancer diseases also tended to be less likely to report their mild side effects [29, 30]. Possible interpretations for such reporting behaviors are that some patients may be afraid of receiving additional treatment for those mild symptoms, do not want to bother their clinicians with mild side effects that they think they can tolerate, or anticipated the side effects [31, 32]. During TOC, when oncology patients and their families often assume the responsibility to self-monitor and assess any medication safety events, many of them may not have the knowledge or guidance to determine the severity of the events or when to report, which highlights the potential need for self-management skill training. A review article recommends clinicians assess patients' recall, comprehension, and health literacy, indicating a patient-centered approach to communication in which a shared decision-making process is established can promote patient engagement and improve the quality of care [31, 33].

In this study, patient activation has been emphasized as a significant personal factor that contributes to patients' willingness to share their medication safety concerns with clinicians. This finding is understandable as activated patients are more likely to have the knowledge, skills, and confidence to manage their health, including their medications at home. Patient activation has been constantly linked to improved patient engagement in health communication [34]. Previous

literature has highlighted the association between patient activation and the patient-clinician relationship, as well as patients' initiation of self-reporting, which is important for the early identification of medication safety concerns when patients transition back home [21, 35, 36]. The current study suggests promoting patients' self-efficacy in self-management to empower and engage patients in adverse event monitoring and reporting [37].

This qualitative study has improved the understanding of oncology patients' perceptions of self-reporting adverse medication events from home and identified major factors that are associated with patients' willingness to report. Clinicians should be aware of these factors and proactively address them in their interactions with patients to encourage reporting and ensure medication safety. Understanding the factors influencing patient engagement in reporting medication safety events from home is vital as it serves as the foundation for developing systematic strategies aimed at fostering active participation in healthcare decisions. By identifying these factors, healthcare providers can tailor interventions to address specific barriers and facilitate open communication with patients, ultimately enhancing patient safety and improving healthcare outcomes [38].

Several limitations should be considered. First, study participants were from a single cancer center and the findings may be unable to cover all potential influencing factors. Second, the study included only patients with four common cancer types, potentially overlooking unique experiences and concerns regarding medication safety and reporting from individuals with less common cancer types, such as kidney or blood cancer. Additionally, the interviews took place over the phone instead of in-person, which may have impacted the ability to establish rapport with the participants. There was also an overrepresentation of female (61%) and white (78.1%) participants which may influence the diversity of the perspectives captured in the interviews. Lastly, it is possible that some participants were reluctant to provide negative feedback about their clinicians. Considering these situations, interviewers relied on posing hypothetical scenarios to obtain the participants' perspectives on certain issues, which may not capture the full depth of real experiences.

Conclusion

The findings of the study help clarify the challenges that oncology patients face when managing their medications at home and their need for support in medication safety event self-monitoring and reporting. As indicated, the patient-clinician relationship emerged as a main factor influencing patients' reporting behaviors, which can potentially interact with other factors for patients' willingness to report. From a clinical perspective, these findings

underscore the importance of fostering strong patient-clinician relationships and creating environments that encourage open communication about medication safety concerns. Furthermore, this study highlights the need for continued research to explore the complex nature of patient-reporting behaviors and the effectiveness of interventions aimed at promoting patient engagement in medication safety event reporting.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00520-024-08565-5>.

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Author contributions D.B.: Conceptualization, Data curation; Formal analysis, Writing—original draft.

G.W.: Conceptualization, Data curation; Formal analysis, Writing—original draft.

M.H.: Formal analysis, Writing—review & editing.

K.G.: Project administration, Data curation; Formal analysis, Writing—review & editing.

H.M.: Formal analysis, Writing—review & editing.

M.M.: Formal analysis, Writing—review & editing.

Y.G.: Funding acquisition, Conceptualization, Writing—review & editing.

Y.J.: Funding acquisition, Conceptualization, Project administration, Methodology, Formal analysis, Supervision, Writing—review & editing.

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Data availability The data from this research study are not publicly available due to reasons of confidentiality. Data are located in protected access data storage at the University of Michigan, with any identifying information omitted.

Declarations

Ethics approval The study was reviewed and determined to be an exempt study (category #2) by the University of Michigan Institutional Review Board (HUM00203239) and conducted in accordance with the Declaration of Helsinki.

Consent to participate Oral informed consent was obtained from every individual patient participating in this study.

Competing interests The authors declare no competing interests.

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