



## Video reflexive ethnography as an intervention to improve oral anti-cancer agent patient education: A pilot study

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### ABSTRACT

**Objective:** Oral anticancer agents (OAAs) are associated with side effects that interfere with medication adherence, despite patient education regarding side effect management. Video reflexive ethnography (VRE) captures care processes on video that allow participants to learn from videos. The purpose of this pilot study was to assess the usefulness and impact of VRE on improving OAA education.

**Methods:** This qualitative study was conducted in a pharmacist-managed OAA clinic: two pharmacists and four patients participated. We filmed each pharmacist providing education to two patients. We conducted patient interviews and one reflexivity session with both pharmacists to learn participants' perspectives. We used thematic content analysis to analyze data.

**Results:** Two themes emerged: what patients liked/helped, and things that were unclear. Patients liked instructions on temperature taking, directions to safely handle and store OAAs. Unclear areas included knowing the timing of the worst side effects.

During the reflexivity session, pharmacists found patients' comments useful to improve their practice.

**Conclusion:** VRE was acceptable to pharmacists and patients. Pharmacists recognized VRE as a helpful technique to improve patient education on OAAs.

**Innovation:** The use of video enables participants to scrutinize and reshape their practices, making VRE a powerful innovation and adjunct to quality improvement initiatives.

### 1. Introduction

Over 1.8 million patients are diagnosed with cancer in the United States annually, and many will receive oral medications as part of their cancer treatment [1]. Oral anti-cancer agents (OAAs) are taken at home, but the wide range of side effects that patients experience may offset this convenience. In one study, a majority of patients (56%) taking OAAs reported moderate to severe side effects including fatigue, pain, nausea, and loss of appetite [2]. Further, up to 30% of patients reported medication non-adherence to their OAA therapy with side effects as the primary reason [3], despite receiving education from clinicians, such as pharmacists, about side effect management strategies. Improving how patient education on OAAs is delivered may require behavior change on the part of clinicians who do the teaching [4], to incorporate an understanding of how patients actually take these agents [4]. But improving education may also require understanding the lived experience of the patients being served, because we do not know if medication side effect management strategies are taught

in a way that patients can incorporate into their daily lives. Treatment-related side effect management remains a daunting challenge for two reasons. First, there is a large gap in our understanding of the best educational approaches that engage patients and their informal caregivers to manage treatment-related side effects effectively. Second, we have not yet explored the factors that interfere with patients' abilities to process and internalize information during education sessions for application once they are at home.

Video reflexive ethnography (VRE) is both a research method and an intervention shown to change behavior successfully in several arenas [5-7] in part because it makes complex topics visible and actionable [8]. VRE has been applied in a wide range of clinical applications including changing how intensive care unit patient care rounds are conducted [6], improving patient safety at the end of life [9], and improving the handover process from ambulance to the emergency department [5]. There are only a few studies that have used VRE as a method to improve patient education, with some studies being published separately [10-12] and other studies

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being mentioned collectively in a book on VRE more generally [13]. However, none have specifically focused on patient education related to side effect management of OAAs. VRE can address knowledge gaps in understanding the best educational methods to engage patients and caregivers in managing treatment side effects and the unexplored factors that interfere with patients' abilities to process and internalize at-home treatment information.

As an intervention, VRE allows learning and behavior change to occur through reflexivity [5]. Reflexivity generally refers to a collective process where group members collaboratively reflect on their functioning, either to evaluate what has happened or prepare for some future group action [14,15]. Another characteristic of reflexivity is that the context in which group actions occur is an important factor [15,16]. In VRE, reflexivity also includes the shared deliberation and review of video because video enables participants to frame themselves, their practices, and circumstances in new ways, thus building the capacity to change [17].

VRE is a two-step process. First, VRE captures care processes on video as they unfold in real time, representing the "ethnography" portion of the method. Second, after the videos have been edited to focus on the practice or process being examined, participants collaboratively engage in reflexivity sessions to review and discuss videos in which they participated. This step enables participants to interpret the videos jointly and consult with one another, creating opportunities to learn from the videos [17]. Video-based education has been shown to increase patients' learning [18] but VRE itself has not been used to improve patient education, representing a large gap in our knowledge of the potential utility of VRE for this purpose. The purpose of this pilot study was to assess the usefulness and impact of VRE from both patient and pharmacist perspectives in improving education to oncology patients newly prescribed OAAs.

## 2. Methods

### 2.1. Setting and participants

This qualitative study was conducted in the ambulatory oncology clinic of a large tertiary hospital in southeast Michigan in the USA that operates a pharmacist-managed OAA program. We identified this program and the two clinical pharmacists running it through our professional contacts with the hospital's pharmacy administration. The pharmacists were the only clinicians who provided education to adult patients with cancer about OAAs (e.g., medication regimen, safe OAA handling and storage, side effect management). We met with them both to describe the study, answer questions, and gauge their interest in participating. One pharmacist has been a licensed pharmacist counseling patients since July 2015, while the second has been a licensed pharmacist counseling patients since 2012.

The pharmacists or the clinic nurse reviewed the clinic schedule each week and identified patients who were scheduled for an appointment and were likely to be prescribed an OAA. Research staff attended the clinic weekly on the day when the largest number of patients were likely to be present. To be included in the study, patients had to be newly prescribed an OAA, fluent in English, and have no cognitive impairment. Patients were excluded from the study if their cancer team identified an emotionally unsettling visit (i.e., news of cancer progression or recurrence), were not fluent in English, or had cognitive impairment. Pharmacists provided a study overview to patients who met inclusion criteria. Research staff waited nearby for a pharmacist to advise that a potential study participant was interested in learning more about the study. Our goal was to recruit six patients into this pilot study. We obtained written informed consent for study participation. The study received IRB approval from the study institution (IRB #13305).

### 2.2. VRE procedures

Before the clinic was closed on March 12, 2020 due to the COVID-19 pandemic, pharmacists were filmed educating two patients each. A total of four patients participated. We set up the camera on a tripod when the

patient and caregiver (if present) were placed in a room and started the camera, then we left the room. We informed patients that their participation was voluntary and if at any time they did not wish to continue, they could say so and the pharmacist would ask us to come back in to stop recording. The pharmacist let us know when the session was finished, at which point we went into the room to stop filming and remove the camera. This allowed us to capture on film complete episodes of engagement and disengagement between patient and pharmacist.

Member checking refers to the process of presenting data to all or some participants for comment, to enhance the credibility of data analysis and participant involvement [13,19]. Member checking occurred after each video recorded session to provide pharmacists and patients with greater control, an important part of generating insightful reflexivity. Member checking entailed offering patients the opportunity to review the video of their education session while they were still in clinic. For the pharmacists, member checking involved uploading the videos into a private folder (i.e., one for each pharmacist) on a secure server for each pharmacist to view at their convenience, because they did not have time after the education session to view the videos. The only instruction given to both patients and pharmacists was, "Please review the video to make sure that it is acceptable to you."

The plan in our original VRE protocol was to visit patients at home about two to three weeks after the education session and film them as they described their OAA regimen, side effects, and how they were managing side effects. Due to pandemic-related constraints, we conducted telephone or Zoom interviews instead, depending on patient preference. Approximately two to three months after the recorded education sessions, we conducted telephone interviews with three patients and one Zoom interview with the fourth patient. The interview guide gathered information on patients' descriptions of side effects and management strategies, patients' description of their experience of the education session, and suggestions for change or clarity of sessions based on their understanding of the education session once at home. All interviews were recorded and transcribed verbatim by a proprietary service.

Next, we used the video-recorded patient education session led by the pharmacists to hold a reflexivity session. This entailed first editing the videos into short clips that showed only education on side effect management; these clips were then used as the focus of the reflexivity session. After all patient interviews were complete, one joint reflexivity session with the pharmacists was conducted on Zoom to elicit pharmacists' perspectives on the potential impact of VRE on their behaviors and on the VRE process. Both pharmacists participated. In the reflexivity session, we showed only one patient education video from each pharmacist for reflection and feedback so that the majority of time could be spent on shared deliberation and review, as is consistent with the VRE process [13]. We showed the first video where Pharmacist A did the education and asked reflexivity questions before showing the second video that involved Pharmacist B. A sample reflexivity question was, "What do you see happening here in this clip?" The Zoom reflexivity session was recorded and transcribed.

### 2.3. Data analysis

We used thematic content analysis, taking an inductive approach because so little is known about VRE in the context of OAA education related to side effect management [20]. We used conventional content analysis to derive coding categories directly from the data [21]. Two authors (MM and ART) independently reviewed each transcript, and began to develop codes. In regular meetings we discussed our overall impressions of each transcript and compared our respective codes, discussing the reasons for any discrepancies until differences were resolved to arrive at consensus on the codes. We aggregated segments of text coded under the same category before further analyzing the data to determine accuracy of coding and develop the themes. We did not develop a traditional codebook, because we did not include definitions of our codes, but rather used our detailed notes and analytic memos as a codebook and from that derived emerging themes. We also shared findings with the larger research team

**Table 1**  
Participant characteristics.

Participants	Pharmacists (n = 2)	Patients (n = 4)
Race	2 White	2 White, 2 Black
Gender	1 male, 1 female	3 male, 1 female
Cancer type		1 colon, 2 multiple myeloma, 1 chronic lymphocytic leukemia
Oral Anti-cancer Agent (OAA)		1 trifluridine and tipiracil, 2 lenalidomide, 1 palbociclib

**Table 2**  
Video data.

Video Recorded Education Sessions	
Dates	January 22, 2020 – March 4, 2020
Session duration	45 – 71 minutes; mean 66 min.
Side effect management duration	5:43 – 9:23 (minutes : seconds)

to gather their input. We did not use a qualitative software program, but instead organized our data in a Word document, given the number of participants and events recorded.

**3. Results**

Table 1 provides participant demographic characteristics and information about the cancer type and OAA, while Table 2 provides information on video data. We conducted subsequent patient telephone and Zoom interviews from April 9 to 21, 2020. Telephone interviews ranged from 24:50 to 35:07 minutes (mean 30 minutes). The Zoom reflexivity session with both pharmacists occurred in September 2020 and lasted 46 minutes.

**Table 3**  
Major themes and exemplar quotes.

Major Theme	Sub Theme	Exemplar Quote
What patients liked/what helped	Instructions on reliable and consistent temperature taking as a way to monitor for side effects	“That was very, very helpful in the beginning about taking your temperature, and we were really good about it. We both actually were taking our temperature, day and night, and I was recording them. And I could see after the first two weeks, in week three, towards the end of that week, I saw his temperature starting to go up...and when we got to 100.2, I called. And we didn't go right to the emergency room. I called...and so the oncologist on call...called me back and he said go to the emergency room... I mean, we have become huge advocates of taking your temperature. I don't understand why we don't do this all the time. I mean, it really tells a story!” – Spouse of Patient 1
	Directions for safe handling of OAAs Guidance on storing medication	“...I appreciate them telling me to make sure I handle everything with gloves.” – Patient 4 “I just really appreciate the organizer. So, it makes it one less thing for me to have to remember.” – Patient 4
Things that were unclear and other suggestions for improvement	Things that were unclear	“The one thing that we did experience that was not clear to us –and it would be the only thing that I would say needs to change in the presentation –we were feeling like weeks three and four were recovery weeks. And that's what they told us, that they were recovery weeks, and we're pretty literal about everything...Well, the fellow...came in to see us. I said I thought we were kind of on our up week because it was week three, so I thought we were recovering. And he told us, no, it's not recovering; the worst week is week three. Week three is when you are the most compromised. So, we were kind of thinking we were on the upswing and, instead, that was a critical week. We didn't do anything that was bad. I mean we still managed it...that was one thing that we didn't know. So, that's one thing I would say wasn't clear.” – Patient 1 “I think everybody has done a good job. We have no real complaints about that. The two things: one thing, I think temperatures are important, and the other thing was that third week, week three. That was the only thing. Other than that, it went well.” – Patient 2
	Proactively take anti-nausea medication	“I think [the pharmacist] did do a really good job of explaining what drug we had to take for nausea and everything else. But the difficult thing is to remind people if you are coming from infusion, that you are getting anti-nausea. So, you've got to do it on this end too.” – Patient 1
	Supplement written and oral materials	“[The pharmacist] told me some things. But, you know, everything that people tell you don't always quite register to you when they are telling you, but you get some of it, so they gave me written material. And so sometimes I'm kind of lazy about reading written material.” – Patient 2
Feeling overwhelmed		“I feel sorry for people [without health care backgrounds] because it is overwhelming when you start seeing all this. And our doctor said 'seriously, we lose more people to [not following the regimen] than to the disease because some cases, it's just too hard.' It's very hard.” – Patient 1

As part of the reflexivity session, we shared deidentified patient feedback with the pharmacists in the form of two major themes that we supported with patient quotes: what patients liked/what helped, and things that were unclear and suggestions for improving education sessions. We also included two minor themes that provided insights into the education session from the patient perspective that did not align with the two major themes. Table 3 displays themes, sub-themes, and exemplar quotes.

**3.1. Patient feedback – what patients liked/what helped**

Data reported in this section came from patient comments on video recordings. Patients reported many positive takeaways from the OAA educational sessions. Instructions on reliable and consistent temperature taking as a way to monitor for side effects, directions for safely handling OAAs, and guidance on storing medication and the pharmacist-provided medicine organizer were viewed favorably by patients. Other patient comments highlighted the usefulness of the medication organizer and safe handling information given to them by the pharmacists. Some of the OAAs were recommended to be taken after breakfast, and patients appreciated getting advice on how to remember to take the OAA after breakfast:

*“I appreciate saying that pills should be given as ‘breakfast dessert’. You have to emphasize have a good lining in the stomach of food so you don't damage the stomach, because it has been working out.”*

[– Patient 4]

**3.2. Patient feedback – things that were unclear and other suggestions for improvement**

Data reported in this section also came from patient comments on video recordings. Patients described potential areas of improvement within the educational sessions such as subject areas where they felt additional and clearer information could have been included. Specifically, self-

management of OAA therapy could have been enhanced by knowing when to expect the worst side effects (often around week three) and this was unclear to at least two patients.

Another potential area of improvement was understanding that taking anti-nausea medication proactively could help. One patient, who had taken intravenous (IV) chemotherapy previously, did not realize that anti-nausea medication had been infused with the IV chemotherapy, so initially did not understand the need to take oral anti-nausea medications proactively with OAAs. The patient thought that a reminder from the pharmacist would have helped to be proactive in managing nausea associated with the OAA:

*"I think [the pharmacist] did do a really good job of explaining what drug we had to take for nausea and everything else. But the difficult thing is to remind people if you are coming from infusion, that you are getting anti-nausea. So, you've got to do it on this end too."*

[ - Patient 1 ]

While pharmacists conveyed information through oral and written means, at least one patient did not derive benefit from either approach. Although this patient did not make a specific suggestion to improve the education, the feedback suggests that oral and written methods may need to be supplemented to have a wider impact.

### 3.3. Patient feedback – minor themes

Patient feedback yielded two minor themes that did not align with the major themes: feeling overwhelmed and the need for candor with oncologists. For example, while not specifically related to what patients liked or what could be improved, patients reported feeling overwhelmed by the information provided.

Whereas patients might not normally confess dietary indiscretions to a primary care or family physician, having a cancer diagnosis may have prompted some patients to tell their oncologist everything, in case it affected the treatment or outcome of their cancer. For example, a patient who was also struggling with obesity and high blood pressure, felt they had to tell the physician about stopping at a fast-food restaurant and eating hamburgers because the oncologist needed to know everything that was going on, *"no holding back, you know."* – Patient 2

### 3.4. Pharmacist reflection on patient feedback

During the pharmacists' reflexivity session, pharmacists were not surprised by patients' comments and found them useful in reflecting on their patient interactions. Both pharmacists agreed with patient feedback on education session improvement opportunities. Particularly, they agreed that these sessions can be overwhelming for patients and that making the information more focused would be a useful improvement strategy. Identified strategies included removing unnecessary or less discussed information from education materials, providing more explanation of potential side effects, and doing a better job of contrasting OAAs with intravenous treatment plans delivered in the infusion center.

However, pharmacists were careful to highlight how some improvements may not be possible due to factors beyond the pharmacists' control. Use of rooms and the time allotted for educational sessions was a major factor as they could not occupy rooms for extended time periods, limiting the thoroughness of the teach-back method they preferred to use. For example, Pharmacist A recognized that preloaded pill boxes would be helpful for patients but may not be possible due to time constraints on pharmacists.

Both pharmacists proposed changes to the education to make it more efficient and have a stronger impact on the patient starting OAA therapy. During the reflexivity session, both pharmacists gleaned from the videos opportunities for immediate improvement. Both pharmacists liked using creative language to help patients remember when to take medication, so that instead of using pharmacy-laden language such as "take one pill after breakfast" they could use the term "breakfast dessert." After hearing from

patients how helpful this term was, both pharmacists saw the value in using creative language to improve retention. Pharmacists were struck by the lack of visual aids and thought that preparing and using more visual aids for patients (i.e., PowerPoint slides and other illustrations) would be helpful. Both pharmacists noticed that they looked at the educational materials they were each holding rather than making eye contact with patients. And since each consultation room was equipped with a computer and monitor screen, it would be easy to load visual aids on the computer and look at the material together.

### 3.5. Pharmacist reflections on VRE as a practice improvement strategy

Both pharmacists found the video-recording process to be acceptable during patient interaction and reported no interference with their usual workflows. Overall, VRE was recognized by pharmacists as a helpful technique to observe, reflect upon, and improve educational sessions for patients moving forward with OAA therapy. They found the VRE method helpful to understand their own behaviors and proposed the possibility of using cell phone cameras to record sessions to continue reflection without researchers present.

After watching the videos, pharmacists identified behaviors that they could change. These behaviors included: speaking more clearly, asking more follow-up questions to gather more information from patients, and looking at documents less while looking at patients/caregivers more. Further, Pharmacist A noticed that they were not giving the patient enough time to provide input during the session and reflected:

*"They [patient and spouse] did a lot of back-and-forth talking and I noticed that I tried to keep talking ...I probably should have paused and let them finish what they were saying...that is something I would definitely change."*

Pharmacist B reflected that more nuanced information could have been provided, and gave the example of temperature taking, which is crucial for monitoring for possible infection. One's temperature will vary depending on the device and body site used (e.g., mouth, ear, armpit), so what is considered a fever will vary as well, and patients need to know that information to monitor their temperatures effectively:

*"...related to measuring temperatures with an ear device saying that, you know, that depending on the device, the temperature, what is considered a fever can vary depending on this specific device. So I should have elaborated on that."*

## 4. Discussion and conclusion

### 4.1. Discussion

In this pilot study we assessed the usefulness and preliminary impact of VRE from both patient and pharmacist perspectives in improving education to oncology patients taking OAAs. Because of the COVID-19 pandemic, we recruited four of the six patients originally planned. Video recording actual events as they occur in real time promotes collectively exploring and discussing events, thereby facilitating participants' learning of how to reshape their practice and the practice context [22]. The purported benefits of VRE became apparent in our pilot study when during the reflexivity session pharmacists commented on aspects of their practice, the practice context, and the way they delivered educational content (e.g., voice too soft, interrupting patients, not making eye contact).

Both pharmacists noted that computer monitors in clinic rooms could be used to display visual information for the patient, and serve as a focal point for discussion, in this way offering another medium to complement more traditional verbal and written information. Such an approach might have been helpful for one of the patients in our study who neither heard everything that was told to them nor read materials that were given. While probing to understand why the patient did not find either written or verbal information helpful was beyond the scope of our project, cancer

information overload provides one possible explanation [23]. Feeling overwhelmed was mentioned by patients in our study, and is consistent with the definition of cancer information overload, “feeling overwhelmed by the amount of cancer-related material in the information environment.” [23] Ways to reduce cancer information overload may include the use of multi-education strategies. For example, the use of multi-modal strategies and teach-back were effective in one study where pharmacists provided medication information in the Emergency Department, where information overload is also likely to occur [24]. Another strategy could be to enhance the educational experience and confidence in managing side effects by reiterating main teaching points and conducting a side effect check at a future clinic follow-up visit.

There were many aspects of the education that patients liked, including monitoring for side effects by taking one’s temperature, as well as directions for safely handling and storing OAs. These strengths may have been enhanced by the face-to-face delivery of the education. However, many aspects of patient education have changed because of pandemic-related restrictions, and face-to-face instruction in the future may not occur for all patients. Fortunately, research has shown that computer-based education may be an acceptable alternative, and may result in higher knowledge levels than face-to-face education [25].

#### 4.1.1. Limitations

We acknowledge the following study limitations. The education provided by participating pharmacists represents the practice standard of one institution, limiting the generalizability of our findings to other settings. However, the strengths of VRE to change practice by bringing into conscious awareness one’s habits so that they can be examined for improvement opportunities has been well documented in the literature [7,12,26,27]. Different OAs have different side effects and we did not keep track of differences in education based on the type of OA, limiting our ability to learn how education may have differed for various OAs. Finally, we did not conduct follow-up VRE sessions with pharmacists as is recommended [13] to learn whether or not their practice actually changed or whether any changes were sustained as a result of participating in this study.

#### 4.2. Innovation

There are several innovative aspects to our project. Although the use of video for education and training purposes has been well established, we have extended the applicability of video feedback to a novel situation. VRE is a relatively new methodology and has not previously been applied to the topic of improving patient education related to OAs, so in this pilot study we have explored new territory for the utility of VRE. Moreover, data from this pilot study suggest that practice improvements for pharmacists emerged using VRE, which may not have occurred otherwise. In unsolicited comments, both pharmacists told us that they could video record sessions for review and reflection, to improve their practice. Although we did not guide the pharmacists to do this, training clinicians to use VRE methods would be a promising innovation for care delivery improvements, particularly in the complex setting of cancer care delivery. VRE researchers apply the phrase “planned obsolescence” to the process of teaching clinicians how to use their cell phone cameras to film a clinical practice in need of change and follow the VRE method without researcher input or presence. “Insiders” or those who work in the clinical environment and are interested in practice improvement have video recorded their own practice and that of their colleagues [8]. The use of video thus enables participants to scrutinize and reshape their practices [12], making VRE a powerful innovation and adjunct to quality improvement initiatives that seek to change clinical practice.

#### 4.3. Conclusion

This VRE study engaged pharmacists in examining their practice and its effect on patients taking OAs. While our pilot study was conducted with

fewer patients than originally planned, our findings suggest that VRE was acceptable to pharmacists who drew insights from watching videos of the education sessions they conducted and subsequent patient interviews. Patients also accepted and appreciated the opportunity to share their thoughts regarding OAA education. After reviewing videos and hearing patients’ feedback, pharmacists identified ways that education could be improved. The reflexivity session with pharmacists gave them an opportunity to jointly discuss their practice, and possibly strengthen their approach for future patients.

#### CRedit authorship contribution statement

**Milisa Manojlovich:** Conceptualization, Validation, Formal analysis, Writing – original draft, Writing – review & editing, Project administration, Funding acquisition. **Amna Rizvi-Toner:** Validation, Formal analysis, Investigation, Writing – review & editing. **Ryan DasGupta:** Validation, Writing – review & editing. **Karen Farris:** Formal analysis, Writing – review & editing. **Chris Friese:** Formal analysis, Writing – review & editing. **Diana Kostoff:** Validation, Writing – review & editing. **Emily Mackler:** Formal analysis, Writing – review & editing. **Vanessa Millisor:** Validation, Writing – review & editing. **Marita G. Titler:** Formal analysis, Writing – review & editing.

#### Declaration of Competing Interest

The authors have no competing interests to declare.

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#### Appendix A. Supplementary data

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