



# Photo elicitation, an approach to better understanding the patient experience with OAAs: pilot study and future implications

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Received: 21 June 2023 / Accepted: 19 October 2023

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## Abstract

**Purpose** Oral anti-cancer agents (OAAs) represent a new frontier in cancer treatment, but we do not know how well patients incorporate the strategies that they are taught for managing the side effects of OAAs into their daily lives. The purpose of this study was to understand how OAA side effects influenced patients' lives and what strategies patients used to manage them.

**Methods** The study used an interpretive descriptive design utilizing photo elicitation interviews (PEI). Two pharmacists employed at the study ambulatory oncology clinic assisted with recruitment. Participants took photos and subsequent interviews focused on talking to participants about each photo, eliciting participant perspectives describing side effects of OAAs and management strategies. A directed content analysis approach was used to analyze the transcribed interviews.

**Results** A total of nine participants were included in the study. Three themes and associated sub-themes emerged: making changes to nutritional habits due to OAA side effects (hydration and food), strategies to alleviate OAA side effects (medication and non-medication related), and methods of coping with OAA effects (intra- and interpersonal). Changing nutritional habits was an important strategy to manage OAA side effects. Medication-related strategies to alleviate OAA side effects could be nuanced and, additionally, there was wide variability in coping methods used.

**Conclusion** Patient education on OAAs and side effects is not always tailored to each unique patient and their circumstances. This study uncovered how participants devised their own distinct strategies to prevent or manage OAA side effects in an effort to help improve patients' experiences when taking OAAs.

**Keywords** Oral anti-cancer agents (OAAs) · Side effect management · Qualitative methodology · Photo elicitation interviews

## Introduction

Over 1.7 million patients are diagnosed with cancer in the USA annually, and many will be prescribed oral medications to treat their cancer. Oral anti-cancer agents (OAAs)

represent a new frontier in cancer treatment and their convenience over intravenous chemotherapy infusions is largely due to the fact that patients self-administer these agents at home. However, because they are not monitored in a controlled setting as are patients receiving intravenous chemotherapy [1], there are no clinicians immediately available to help patients as they experience a wide range of OAA side effects including nausea, vomiting, fatigue, myelosuppression, and hepatic or renal dysfunction. Clinicians strive to deliver patient-centered care and provide education on how to manage OAA [2], but there is a large gap in our knowledge as to how well patients incorporate the strategies they are taught into their daily lives.

Photo elicitation interviews (PEI) are emerging as a sound research methodology to study complex health care phenomena [3], incorporating photographs into the interview process, with the result that the visual images evoke a

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type of information that is different than information gained through discourse alone [4]. PEI have been used in cardiovascular research [5], research on families who have children and adolescents with chronic illness [6], and food routines during early adolescence [7]. However, there is a paucity of oncology research using PEI with most focused on rectal cancer [8, 9].

Oncology patients who are prescribed OAs to treat their disease represent a group for whom PEI may be especially informative. Oncology patients who do not adhere to OAA therapy as prescribed risk increased morbidity and mortality [10]. Members of our team have identified clinically worrisome patterns of patient symptoms and non-adherence in the context of OAA therapy—of 1235 patients taking OAs, 56% reported moderate to severe symptoms (e.g., fatigue, pain, and loss of appetite) [11]. Further, up to 30% of patients reported medication non-adherence to OAA therapy with symptoms as the primary reason [12], despite receiving education from oncology clinicians on evidence-based side effect management strategies. Use of PEI offers a unique perspective on patient self-management to learn about their experiences and help inform clinicians on how to educate future patients.

By reviewing pictures on side effects and management strategies, beneficial or newly discovered strategies for side effect management not currently incorporated into patient education may emerge, which may inform clinicians delivering future patient education sessions. The purpose of this study was to understand how OAA side effects influenced patients' lives and what strategies they used to manage their side effects. Additionally, this paper reports on our experience with the PEI methodology as a novel application to this population.

## Methods

### Study design

We used an interpretive descriptive study design [13] to understand, from the patient's perspective, how they experience and manage side effects of OAs. One of the tenets of interpretive description is that people who experience certain phenomena are the best source of knowledge about their experiences [13]. This principle is well-aligned with PEI where photographs that are shared between participants and researchers during an interview act as a stimulus for discussion and yield information that otherwise might not surface [3]. PEI democratize the research process because they are driven by the participant, thus reducing investigator bias [5]. We chose "auto-driven" PEI [14] whereby research participants take the pictures themselves and decide what to show researchers and what is important to them. While

a quantitative survey instrument would have reached far more patients, our research questions (i.e., how do OAA side effects influence patient lives, and what strategies do they use to manage side effects?) could best be answered using qualitative methods [15].

### Setting, sample, and recruitment

Participants were recruited from an ambulatory oncology clinic located within a large community hospital in a large urban area in the Midwest United States. Two pharmacists employed by the clinic were responsible for providing OAA education and both assisted with recruitment, using a convenience sampling technique. Pharmacists identified patients who were newly prescribed OAs, met eligibility criteria, and came to the clinic for education regarding OAA therapy. At that visit, pharmacists gave eligible patients a letter that provided basic study information and read from a short script when handing out the letters (June 24, 2021—November 11, 2021). The pharmacists returned a list of 21 eligible patients who were told to contact researchers if they were interested in participating. Only three individuals agreed to participate, leading to changes in the recruitment approach (March 7 to March 24, 2022).

Pharmacists asked patients who expressed interest for permission to share contact information with researchers. A single researcher (MM) made up to three telephone calls to 11 additional patients who had assented to contact. Once the researcher reached an interested patient, they provided in-depth information, answered questions, and obtained informed verbal consent, recruiting 6 more patients. Strategies used to improve recruitment and retention included using a differently worded message in each of the three contacts, highlighting the benefits to participation for themselves and future patients, and making it easy to return cameras (e.g., UPS pick-up service).

### Inclusion/exclusion criteria

Individuals were included if they (1) received education on a newly prescribed OAA from a pharmacist, (2) agreed to take pictures at home of things that either facilitated or hindered their ability to self-manage side effects associated with the OAA, (3) agreed to be interviewed after pictures were developed and shared with the research team, and (4) spoke and understood English. Patients were excluded if they were women who were lactating or pregnant, or did not speak or understand English.

### Data collection

We mailed each consented individual a study kit that included information on the PEI process, a disposable

camera, a copy of the informed consent document, the principal investigator's business card, and a prepaid return label so the patient could return the camera in the same box. Written instructions for taking pictures were also included, which read "Please take pictures of those things in your home that help you to manage whatever side effects you experience or keep you from managing side effects better." Once participants returned the camera, the photographs were processed by an external commercial lab. We made two copies of each picture and wrote subject ID numbers and picture numbers (#1, #2, etc.) on the back of the pictures for reference during the interview before sending one set of pictures to the participant and keeping the other set for the research team. We also received digital copies of the pictures and posted the pictures on a secure password-protected server that was accessible only to members of the study team.

We scheduled participants for an interview, which was conducted by telephone rather than in person because of COVID-19 public health restrictions in place at the time. Two researchers (MM and NW) conducted all interviews. MM is a PhD-prepared nurse researcher with expertise in interview techniques while NW is a master's-prepared research assistant with expertise in qualitative methods. The interview guide was developed by members of the research team with expertise in PEI and pharmacy (MB, EM, KF). Interview questions focused on talking to participants about each picture they took as well as asking participants to describe side effects they experienced while taking OAA and management strategies (Supplementary Information contains the interview guide). We asked participants to verify their consent at the beginning of each interview. Interviews were audio recorded, transcribed verbatim by an external transcriptionist, and redacted to remove identifying information. Participants were remunerated \$40 for their time. All documents with identifying information were destroyed at the completion of the study.

## Data analysis

Data analysis occurred concurrently with data collection. A directed content analysis approach [16] was used to analyze the transcribed interviews. We did not analyze any photographs. Four members of the research team (MM, NW, AB, EA) individually read each transcript and created memos of their analytic insights and interpretations. In weekly meetings, we discussed our overall impressions of each transcript and began to develop codes. We used an iterative process to compare the results of the application of codes to the transcripts until consensus was reached on the categories and criteria for inclusion of codes and documented these in a codebook. Once the codebook was finalized, we reviewed coding during team meetings, using an inductive process to develop themes, sub-themes, and associated categories. We

developed a matrix [17] to better understand the relationships among emerging themes and participants' pictures. We developed findings by meeting weekly to discuss and interpret the data in light of the original study purpose. We achieved meaning saturation after analysis of eight of the nine transcripts [18]. We used NVivo® to arrange data in ways that allowed us to see relationships and help manage the data to ensure that codes were applied consistently.

## Results

A total of nine patients participated in the study, all of them women: six were black and three were white. We did not collect information on age or cancer diagnosis. There was a total of 58 pictures taken by five participants. One participant's pictures were lost by the film developer, two participants' pictures were underdeveloped and thus unusable, and another participant agreed to the interview but did not wish to take pictures. We included this participant because she wanted to tell us her experience in using OAAs and the effect of OAAs on her life. We found that those participants whose pictures were not available were able to recall the pictures they took. The average length of time from when photos were returned to interview was 44 days (range 21–58). Interviews ranged from 28–64 min in length (mean=43:30).

Participants described making changes to their nutritional habits due to side effects of OAA, and this theme was displayed in at least one picture by all participants. Hydration and food emerged as two sub-themes. Strategies to alleviate side effects of OAA emerged as a second theme, and these included both medication and non-medication strategies. Finally, participants described various methods of coping with the effects of OAA, and these methods were implemented at intra- and interpersonal levels (see Table 1).

Overall, we found that participants developed individualized strategies to manage OAA side effects associated with liquid or food intake. Whereas all participants received education about what constituted adequate hydration in terms of the number of liquid ounces to drink, they did not receive instruction on how to do it and developed their own strategies. For example, some participants used systematic approaches, such as the participant who set up six bottles of water on her kitchen counter every day (that held the requisite number of ounces to drink), so that she would be reminded to drink some water whenever she walked by (Fig. 1). Some participants also reported taking supplemental liquids in addition to water to provide additional nutrients and electrolytes. One participant was very clear that she drank a "beverage" with each meal that was separate from and in addition to her water intake to ensure that she took in enough liquids (participant #10). Other participants reported developing a specified hydration plan and described

**Table 1** Factors influencing patients' OAA management

Sub-category	Factors	Description	Illustrative quote		
Nutrition	Hydration	Water	Importance of staying hydrated and ensuring water intake, especially to avoid complications and emergencies	Initially, I thought that I could just judge by going to the refrigerator and getting my Brita water because I thought it was purified, that I could drink that. But then I discovered that I couldn't keep up with the ounces of water that I was consuming by using that water. So, that's when I started purchasing bottled water and numbering the bottles. So, if I had five bottles numbered, which is over the amount of water that I needed to consume, I could be more sure that I was consuming the amount of water that my doctor wanted me to consume daily. (Patient 10)	
			Changes to liquid intake	Changing liquid intake to avoid or reduce side effects related to OAA	I also took a picture of my coffee... because the caffeine and the carbonation aggravate my stomach as well, so I try not to drink a lot of coffee, even though I am a coffee drinker, but I just try not to drink it every day. So, I went from drinking it every day to like, 'Okay Saturday morning and Sunday morning I'm going to treat myself to a cup of coffee,' and that generally gets me my coffee fix without irritating any symptoms with the diarrhea or anything like that. (Patient 02)
Food	Supplemental liquids	In addition to water, using liquids to take in more electrolytes and nutrients as supplements if a patient's appetite is poor or they are tired of drinking water	Alright, so when I was not eating very well, when I was on the full dose of my oral chemo, we had to resort to Pedialyte to get me some nutrients and smoothies and things like that. I don't do that anymore right now because... I don't need it... So, I kind of have that on stock now... (Patient 06)		
			Diet changes	Eating habits and patterns that have changed as a result of OAA regimen	So, as much as I love to have a full breakfast like that, I had to change over to a more bland, healthier-type breakfast and... I learned that I did better... I didn't have any diarrhea or anything like that or feeling bloated and stuff like that. (Patient 02)
			Supplementary nutrition	Back-up plans for nutrition to get sufficient calories when patients are not able to eat bigger meals	...because canned fruits help as well, but, trying to keep anything down is important. So, I should have put my Cream of Wheat [in the photo] too because... it's fortified... and smooth going down when your stomach isn't doing very well, but eating is really important and it does get difficult sometimes. (Patient 06)
	Foods to avoid	Avoiding certain foods that exacerbate side effects or make patients feel worse	I stay away from mostly dairy because that one tends to cause problems. One of the few side effects that I do have is... I mean if I'm just being blunt... really the only one I've had is diarrhea. And that's one of the main side effects, and even at that, if I watch my diet really carefully, I can avoid that completely. (Patient 04)		

Table 1 (continued)

Sub-category	Factors	Description	Illustrative quote
Therapeutic interventions Medication	Over-the-counter medications	On advice of doctor or patient-initiated use of over-the-counter medications to help manage side effects of OAA	...if the diarrhea did...come about, I would take Imodium... Now it seems like the liquid worked better than the pills, worked faster than the pills. So, that's what I did to cope with it...I just discovered that to me that the liquid worked better than the pills. (Patient 02)
	Prescription medications	Provider prescribed medication to help with side effect management	And it's the Norco, so that's one of the prescribed pills from the doctor...for me...to help manage my everyday pain...so the one that I have is like kind of perforated in the middle, so I actually just pop it in half and I take half of the pill, because half of the pill...I can still function...it takes the edge off to where I'm still can do my normal, everyday functions. (Patient 14)
	Medication adherence	Strategies for and by patients who take OAA to help with adherence to medication	...in order to identify what I'm taking on a daily basis and when I'm taking it, we came up with a system. My daughter...she's a craft junkie, and she had a lot of colored sheets of paper and we decided that if we used a different color craft paper for each day and on the days that I would take my chemo, the time I would put on it, the date that I was going for chemo, the time that I was going for chemo, and what other medications I was taking on that day. The oral chemo would be listed on it, the infusion time would be listed on it, and the supplements that I was taking at a given time would be listed on it... (Patient 10)
Non-medication therapies	Therapies in response to OAA side effects	Objects, behaviors, or activities that patients used to bring relief from side effects of OAA	Um, the nausea isn't that horrible, so I mean it's uncomfortable, but I-I usually drink like maybe Vernors or Coke. I sip on that and that helps. (Patient 16) I like candles, they're soothing for me. (Patient 16)
	Preventive therapies	Strategies for and by patients to prevent side effects from occurring or to limit the impact of side effects	Vinyl pull-on briefs helped me to feel secure when I'm going away from home, because you never know if you're going to have diarrhea or what and you certainly don't want to have a feeling that you have voided in your clothes...in your underwear and...it's just the feeling of security that you feel secure. So, I always, when I'm going out to the doctor, I would put them on over my briefs, just for a sense of feeling secure. (Patient 10)
Coping mechanisms			

**Table 1** (continued)

Sub-category	Factors	Description	Illustrative quote
Intrapersonal coping	Finding Comfort	Psychological support to help oneself feel better mentally, emotionally, physically, and spiritually	I read a lot of different books. I have one book that's called <i>Commanding Your Morning</i> , and it just kind of helps you get a good sense of direction in the morning...spiritually and physically, it helps you just kind of focus through the day and helps you actually realize that...I can command my morning to be what I want it to be which transcends through the day. (Patient 02)
	Coping with Changes	Actions taken by patients to handle lifestyle changes that occur due to side effects of OAA	...your skin is peeling and your-your feet...at the bottom of your feet is peeling, so I just don't want to be exposed to anything. So, since I can't go [to the nail salon], we got the foot bath so that I can do...soak my feet at home and just have some type of foot care that I can do on my own. (Patient 14)
	Distraction	Taking a patient's mind off of side effects, diagnosis, or boredom	Yeah, those are video games. Those help me keep my mind off of everything. If I'm playing a video game...I forget what's going on...and it distracts me. (Patient 16)
Interpersonal coping	Support from others	Human connection or support that brought relief or helped to reduce stress for patients	Yeah, they're very supportive. Even though my grandfather and my father [are] not here anymore, they were very supportive and helpful in my battle. My brother is very supportive. My husband is here every day, of course, and my son is here throughout the week, so it is a very special picture because they're very supportive of me. (Patient 14)
	Self-disclosure to others	Patients' decisions on what information or emotions to share and who to share them with	My scrapbook is very, very precious to me... I actually became real emotional because I talked about the day that I got the call and when I found the lump myself, and how long I had been putting it off because I felt something not good in my spirit about it, but my friends encouraged me to just go ahead and get it done and so I put that in there, the backstory of everything. (Patient 02)
	Care-oriented interactions	Interactions with health care providers to obtain or share information related to OAA/cancer management	I had a...before I even started, I had a really long phone conversation with one of the nurses who handles the [oral chemo] and we went through everything just step by step from the very beginning...So, in all honesty, I was very well informed. (Patient 04)





**Fig. 1** Numbered bottles of water to ensure adequate hydration

how they learned to increase their liquid intake only after suffering the consequences of dehydration and having to go to an urgent care facility specifically for oncology patients.

Food was also an important sub-theme. Participants described diet changes to avoid side effects such as diarrhea, how they supplemented their food intake when their appetites declined, and how they learned to avoid certain foods altogether. None of the participants mentioned how the advice they received during OAA education took into account their unique dietary habits. Participants often used trial and error to find foods that were palatable or minimized gastric upset. Participants turned to informal sources, such as Facebook groups, for suggestions on hydration and food. In one instance, a man in a grocery store checkout aisle noticed on the conveyor belt canned fruit that belonged to the man checking out groceries in front of him. The two started a conversation about canned fruit and discovered that both of their wives were cancer survivors who turned to canned fruit to meet nutritional needs when other foods were unpalatable. Food texture became an important consideration for many participants, such as the participant who turned to Cream of Wheat when she could not eat a full meal because it was “smooth going down when your stomach isn’t doing very well, but eating is really important” (participant #6).

Participants described both medication and non-medication-related strategies to alleviate side effects of OAA. Medication strategies included non-prescription medication, prescription medication to help with side effect management, and strategies to facilitate adherence to OAAs. Similar to nutrition, participants individualized strategies to alleviate OAA side effects. Some participants showed us pictures of complex color-coded paper reminders of when to take medication and described their “system” during the interview (patient #10). Other participants described how they used electronic aids such as the reminder applications on their smart phones, although they did not take any pictures of these aids.



**Fig. 2** Color-coding scheme to help adhere to medication regimen

Sometimes over-the-counter medications were recommended by clinicians to help control side effects, but one participant discovered that the formulation of a medication recommended by the pharmacist (i.e., pill) did not work as quickly as another (i.e., liquid). Participants did not always take analgesic medications as prescribed, cutting back on doses because they caused somnolence and interfered with daily functioning. Some preferred non-prescription options for mitigating side effects such as insomnia, as the one participant who preferred to take melatonin because she liked to “try natural ways of doing things versus getting prescriptions from the doctor” (participant #14).

Participants were creative in devising ways to adhere to what were sometimes complex medication regimens. One participant, in collaboration with her daughter, devised a color-coding scheme to remind herself of medication doses and times and took a picture of it (Fig. 2). This and other strategies were helpful because although participants were given pill organizers for their medication, the organizers did not come pre-filled so participants and family members had to fill the organizers on a weekly or bi-weekly basis. Some participants admitted missing OAA medication doses occasionally but believed that they received adequate education on how to make up for missed doses. In some cases, participants were taking a lower dose of OAA than originally prescribed because of the severity of their side effects. One participant told us, “Oh, and it does create anxiety when they lower your dose, and you think, I can’t hack it. I’m going to die sooner...you know, you have all these negative thoughts that creep in when you can’t handle it like a man, you know, so...” (participant #6).

Participants described non-medication strategies as being either in response to OAA side effects or to prevent side effects. Strategies in response to OAA side effects included taking naps or using lotions infused with essential oils such as lavender. Other strategies included wearing vinyl briefs when going out to prevent soiling their clothes and

socializing earlier in the day, when energy stores were not yet depleted.

The final theme was methods of coping with OAA side effects and these included both intrapersonal and interpersonal approaches. There was wide variability in the coping mechanisms participants used. Participants described several intrapersonal strategies for coping with side effects and these included finding comfort, coping with lifestyle changes, and distraction. Coping with lifestyle changes included finding alternatives to enjoyable activities that had to be curtailed because of side effects or the risk of side effects. One participant, who previously went to a spa regularly for pedicures, found that using a footbath at home was an acceptable alternative (Fig. 3). Distraction took the form of television watching or playing video games. Participants also talked about their underlying cancer diagnosis and how they managed to cope with the effects of their disease. Several participants told us that they found comfort in reading spiritual or motivational books. One participant worked to maintain a positive attitude saying, "...Every time I try to get depressed... I try to turn that around and think positive" (participant #18).

At the interpersonal level, most participants described their need for support from others. While some participants depended on a wide circle of family and friends to provide support, others placed limits on how much to self-disclose about their disease or side effects, and to whom. Participants also spoke about care-oriented interactions with providers as providing support, but these were fundamentally different from other forms of support because these interactions tended to be structured and focus exclusively on OAA management and side effects. Participants told us about the importance of their support networks, including how essential relationships were because they brought emotional and social fulfillment. For example, participants did enjoy socializing and maintaining contact with friends but did not always disclose to their friends how they were feeling or provide details on their treatment. Two participants felt

abandoned by their friends and struggled to cope with both the cancer and the side effects of OAAs. For one participant, this resulted in maladaptive coping: "So, I do drugs to forget about...everything. About the cancer, about my depression, about being alone all the time. I have no friends. You know, no one has checked up on me at all" (participant #16).

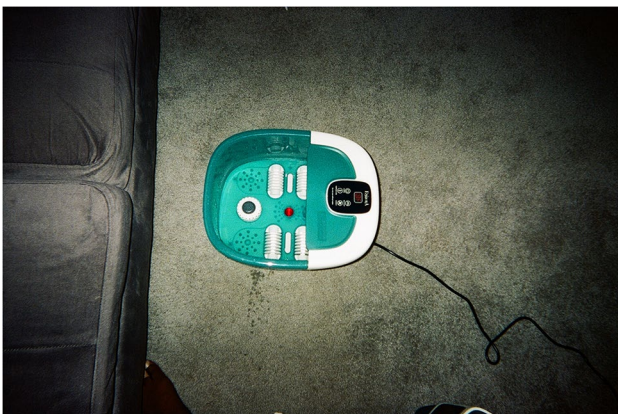
## Discussion

The purpose of this qualitative study was to use PEI methodology to understand how OAA side effects influenced patients' lives and what strategies they used to manage side effects. We identified three major themes and several sub-themes within each. PEI was an appropriate methodology for our research question because we were interested in the effect of OAA from the patient's perspective [3].

Quantitative survey studies have reported suboptimal adherence to OAA regimens [11, 12], but can only speculate on why this might be because they did not include the perspectives of patients themselves. A quality improvement project at one community practice site was successful in reducing the number of patients who discontinued their OAA on their own to zero (from 48%) in part by providing patient education on drug-specific self-care guidelines [19].

Participants described how they developed their own solutions to the problem of managing OAA side effects; providers can enhance their education offerings by incorporating what our participants told us (e.g., canned fruit, Cream of Wheat as an alternative nutritional source). While solutions are known and shared among patients, they may be hidden from providers unless patients' unfiltered and frank perspectives are shared. PEI helped us capture these perspectives so that we can now disseminate them to the medical community. Participants were shy or reluctant to give suggestions to providers about how to improve education [20]; however, they had no trouble talking about their own experiences possibly because of the patient-driven PEI approach.

There are a few health care studies that use PEI, with similarities to our own [5, 6, 21]. In a PEI study with 20 rectal cancer patient survivors, seeking support and information was a sub-category of coping, similar to our category of coping mechanisms [8]. The focus of the study was on the emotional experiences of rectal cancer survivors, whereas we sought to learn about pragmatic and concrete strategies oncology patients used to manage side effects of OAA therapy. In another PEI report using the same sample of rectal cancer survivors, patients described the impacts of treatment [9]. Dietary changes and gastrointestinal-related needs were a prominent finding, similar to what we found. Despite study differences, patients' experiences and information shared by



**Fig. 3** Foot bath as a way to cope with a lifestyle change



them are important for providers to incorporate and prioritize in patient education methods and materials.

Interestingly, none of the studies described above mentioned sharing photographs with clinicians, although there could be benefit from having clinicians view photos taken by patients at home. One possible application of PEI would be for patients to upload images directly into their patient portal for clinicians to view and intervene, if needed. Several papers have been published that describe how to conduct PEI and provide pragmatic guidance [6, 22, 23].

PEI as a method has strengths and limitations. Strengths of PEI include the patient-centric view not only on OAA management but also on daily life. The pictures prompted discussions that provided a more in-depth and detailed look at the day-to-day journey of participants managing side effects of OAA and living with cancer. Interestingly, participants also wanted to talk about cancer and its effects on mortality, not just OAA. PEI as a methodology has applications beyond OAA and could be used to reveal a broad, birds-eye view of the lived experience of oncology patients, as has already been done for rectal cancer survivors [8, 9]. There was nothing vague in what participants told us. They were all very clear and, in some cases, revealed intimate details about their lives (e.g., one participant's frank discussion of substance use). Although we did not get pictures from all participants, interviews were still rich and participants were able to recall what was in the pictures. There were several lost or unreturned cameras, which represented an unexpected research expense.

Our study has several important limitations. Although fairly diverse in relation to race, all participants were women and their experiences might not reflect the perspectives and priorities of male patients. Participants were selectively chosen by two pharmacists who ran the OAA clinic and may have been more receptive to the PEI process. All participants came from a single ambulatory oncology clinic in a large urban city in the Midwest and may not reflect the wider population of patients who are prescribed OAA therapy for their cancer. There may have been some recall bias because of the length of time between picture taking and interview.

## Conclusion

The PEI methodology provided rich information about patients' experiences in managing side effects associated with OAA therapy. Whereas cancer patients receive detailed education on the specific OAA being prescribed and information on how to manage side effects in general, strategies are not necessarily tailored to each unique patient and their circumstances, nor do they include suggestions on how to cope. Our participants devised their own distinct strategies to prevent or manage OAA side effects and also turned to

family, friends, and social media for guidance on how to overcome bothersome side effects. The potential for PEI to uncover other aspects of the experience of living with cancer is vast.

**Supplementary information** The online version contains supplementary material available at <https://doi.org/10.1007/s00520-023-08128-0>.

**Author contribution** M.M. and N.W. conducted all interviews. M.M., N.W., A.B., and E.A. conducted all data analysis. M.M. wrote the main manuscript text. N.W. prepared Figs. 1, 2 and 3 and Table 1. All authors reviewed and edited the manuscript.

**Funding** Support for this project came from the School of Nursing Translational Seed Award, with donor funds provided by Janet Gatherer Boyles and the estate of Dr. Jo Horsley.

**Data Availability** The data that support the findings of this study are available on request from the corresponding author, [MM]. The data are not publicly available due to their containing information that could compromise the privacy of research participants.

## Declarations

**Ethics approval** The study was approved by the institutional review board (IRB) of the researchers' university (HUM00189828) and the participating health system ceded review to the university IRB under the Streamlined, Multisite, Accelerated Resources for trials IRB Reliance platform (SMART IRB) agreement terms. The study was conducted in accordance with the Helsinki Declaration as revised in 2013.

**Consent to participate** Verbal informed consent was obtained from all participants. Additionally, the study received a waiver of documentation of informed consent.

**Competing interests** The authors declare no competing interests.

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