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# How Do Adolescent and Young Adult Patients with Cancer Manage Their Chemotherapy-Related Symptoms at Home?

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Chemotherapy can cause many distressing side effects, potentially impacting treatment completion and quality of life in adolescent and young adult (AYA) patients with cancer. To identify ways to help mitigate chemotherapy-related symptoms, we sought to elicit barriers and facilitators to managing symptoms experienced by AYAs with cancer through interviews. Qualitative thematic analysis identified three main domains: (1) managing chemotherapy symptoms (e.g., medication, home remedies), (2) anticipating and mitigating symptoms (e.g., management of symptoms at home, anticipatory guidance), and (3) knowing when to seek care (e.g., unexpected and unusual symptoms). This study elucidated that AYAs can successfully manage symptoms at home when given the proper guidance and this could be a focus of future efforts to improve outcomes in this population. The Clinical Trial Registration number is NCT04594096.

**Keywords:** symptoms, symptom experience, treatment-related symptoms

## Background

OVER 90,000 ADOLESCENTS AND YOUNG ADULTS (AYAs) are diagnosed with cancer each year in the United States.<sup>1</sup> Despite substantial advances in cancer treatment, survival rates have not improved at the same rate as in children.<sup>2</sup> This lack of improvement can be attributed to many factors such as reduced access to cancer care, treatment side effects, and not completing planned chemotherapy.<sup>3,4</sup>

AYA patients with cancer can experience a variety of distressing treatment-related symptoms, including nausea, vomiting, and fatigue, which can be more severe than their younger counterparts.<sup>5</sup> A study by the Children's Oncology Group in patients with sarcoma demonstrated differences in treatment side effects by age, with adolescents having significantly more nausea and pain.<sup>6,7</sup> This and other studies have implicated not completing planned therapy as a possible reason for this survival disparity, which can be secondary to treatment side effects that can be more pronounced in this age group.<sup>2,3,5</sup>

A cancer diagnosis and its treatment can permeate every aspect of AYA lives.<sup>2,8</sup> A study of AYA patients with cancer

found that 96% of the participants reported managing physical and psychological symptoms as their top concern during treatment.<sup>9</sup> However, little is known about how they manage chemotherapy symptoms at home and how they perceive the need to seek care when they experience treatment side effects.<sup>10</sup> Given this, over the past two decades, a focus has been placed by the National Cancer Institute (NCI) on improving the quality of care delivered to AYA patients with cancer, including identifying avenues to improve treatment-related symptom management in this age group.<sup>11</sup>

Therefore, to address this gap in knowledge, we sought to examine what facilitates or impedes adequate self-management of symptoms experienced by AYAs during cancer treatment, including seeking help due to these symptoms. Improving symptom management in AYA patients undergoing chemotherapy could positively impact an AYA patient's treatment experience, potentially leading to improved completion of planned therapy and outcomes.<sup>6,7,10</sup> A qualitative study was performed to gain in-depth knowledge about the self-management of treatment-related symptoms experienced by AYAs with cancer.

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## Methods

### *Patient population*

Eligible patients were between the ages of 12–29 years old at diagnosis and had received at least two previous cycles of chemotherapy (to ensure that they had experience with some treatment-related symptoms) and/or were within 2 years from completion of therapy (dates extracted from electronic medical record) at the time of the interview. Non-English-speaking patients, except for Spanish, were excluded from the study.

### *Recruitment*

A purposive sample of patients who completed two or more rounds of chemotherapy was recruited from a pediatric hematology/oncology clinic. Purposive sampling increases trustworthiness and rigor of this study, as specific cases from the population were selected to participate generating in-depth information. Patients who were 29 years of age or younger were eligible to participate.<sup>12</sup>

Potentially eligible participants from the pediatric oncology clinic at the UC Davis Comprehensive Cancer Center (UCDCCC) were given general study information by clinic staff. If the patient was interested, clinic staff obtained consent from the patient to be contacted by research staff.

Research staff then confirmed patient eligibility and obtained consent from the patient or parent/guardian via telephone. If patients were under the age of 18, consent was obtained from the parent or guardian and the patient was given the option to be interviewed with a parent or guardian. All study participants were offered a \$50 gift card for their time.

### *Data collection*

In total, 18 phone interviews were conducted by C.R. between November 25, 2020 and July 8, 2021. Participants were interviewed using a semi-structured interview guide, with domains relevant to cancer treatment-related home symptom management (Supplementary Table S1). Data collection and analysis occurred concurrently and continued until data saturation was reached, with no new concepts or themes gathered.

### *Data analysis*

All interviews were audio recorded, transcribed verbatim, and uploaded to the qualitative data analysis software Dedoose. Transcripts were de-identified before being uploaded to Dedoose for coding. Data were coded both inductively and deductively using thematic analysis within a constructionist paradigm. A constructionist paradigm allows for researchers to uncover subjective meanings associated with participants' experiences.<sup>13–15</sup>

Two research team members (H.N. and E.A.) independently and openly coded two transcripts and then met to discuss what was found and to research intercoder agreement. Peer debriefing is often used in qualitative research to increase credibility in the findings. A tentative list of codes and their definitions were discussed and used to code the remainder of the transcripts.<sup>16</sup> Once all transcripts were coded,

H.N. and E.A. met regularly to discuss the coding process and began analyzing within and among each transcript. Codes were then collapsed into categories and then into themes and subthemes (Table 2).

This study was approved by the University of California Davis Internal Review Board.

## Results

A total of 28 eligible patients were approached and 18 were successfully enrolled in the study (2 declined, 2 died before interview, and 6 did not respond after initial contact). Among the 18 participants, 17 completed the interview individually whereas 1 participant completed the interview with their guardian.

Among the 18 participants, 61% were females (Table 1). The majority of the participants were full-time students, living with family members, and had insurance coverage during their chemotherapy treatment. Approximately 55% of the participants had public insurance and were the policy holders. The majority of the participants were referred to the UCDCCC by their primary care physician or chose the hospital due to convenience of close proximity. The majority of cancer diagnoses (55%) were solid tumors such as soft tissue sarcoma, germ cell tumor, and osteosarcoma.

Most of the participants experienced similar symptoms such as nausea, tiredness, bone pain, and loss of appetite due to chemotherapy. From the patient interviews, we identified three main themes: managing symptoms at home, not needing medical assistance, and seeking medical intervention. The themes, subthemes, and corresponding quotes are displayed in Table 2.

### *Theme 1: managing symptoms at home*

This theme summarizes the variety of methods used by participants to manage chemotherapy symptoms at home, including taking medications, utilizing home remedies, and sleeping and resting. One of the most common methods to treat chemotherapy symptoms was medication. The majority of the participants used anti-nausea medicine such as Zofran during their chemotherapy treatment. Some of the participants were recommended by their physician to use anti-nausea medication as a preventive measure where they would take the medicine before their treatment session, then continue until after a couple of days of the chemotherapy.

One participant mentioned going through a trial-and-error process to figure out which combination of medicine worked best for them to combat the nausea. A few participants recounted using homemade remedies such as teas and candy to treat nausea and mouth sores. Participants also reported using sleep as means to getting through the pain and nausea caused by the chemotherapy. Participants also described sleeping and resting as a way to handle weakness and drowsiness during the treatment.

### *Theme 2: anticipating and mitigating symptoms*

Study participants reported multiple reasons for not seeking medical help to treat chemotherapy symptoms in-between appointments, including receiving instructions on what symptoms to expect and how to treat them. Participants

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

<i>Characteristics</i>	<i>Total participants n = 18</i>
Current age (years), median (range)	18 (13–25)
Age at diagnosis, median (range)	16 (12–24)
Sex	
Female	11
Male	7
Highest education completed	
Some school	9
High school or equivalent	5
Some college or associates	4
Hispanic or Latino	
Yes	7
No	11
Race	
Asian	1
Black or African American	2
White	10
Other <sup>a</sup>	5
School or employment status just before diagnosis	
Employed	3
Student	12
Both employed and student	1
Unemployed	2
Type of cancer	
Hematologic	8
Solid	10
Chemotherapy regimens	
Cytarabine, daunorubicin, dexamethasone doxorubicin, mercaptopurine, methotrexate, peg-asparaginase, vincristine	5
VDC/IE	2
MAP	3
Ifosfamide/Doxorubicin	2
BEP	2
Brentuximab Vedotin+AVD	1
Doxorubicin, Vincristine, Peg-Asparaginase, Methotrexate	1
ABVE-PC	1
Bevacizumab, Nivolumab	1
Treatment duration, median (range)	11 months (4–36)
Insurance	
Private	8
Public	10
Receiving emotional support	
Family and friends	14
Counseling	1
Self	3
Receiving financial support	
Family and friends	13
Self	2
Other <sup>b</sup>	3

<sup>a</sup>Mixed, Hispanic, no answer.

<sup>b</sup>GoFundMe, government.

ABVE-PC, Adriamycin, Bleomycin, Vincristine, Etoposide, Prednisone, Cyclophosphamide; AVD, Adriamycin, Vinblastine, Dacarbazine; BEP, Bleomycin, Etoposide, Cisplatin; MAP, Methotrexate, Adriamycin, Cisplatin; VDC/IE, Vincristine, Doxorubicin, Cyclophosphamide/Ifosfamide, Etoposide.

reported feeling comfortable managing symptoms independently, utilizing various methods to control their symptoms at home.

For some patients, managing symptoms included finding a routine that worked for them, such as “medicated mouthwash and lidocaine, and frequent brushing and flossing about three times a day,” to help with mouth sores. Some of the participants were also prepared by the health care team on how to manage these symptoms by getting explicit instructions on how to treat their symptoms at home.

The list of symptoms and instructions on how to manage those symptoms served as anticipatory guidance that helped the participants anticipate their potential symptoms as well as how to mitigate them. Many participants felt there was no need to reach out to their providers because of the explicit instructions they had received beforehand.

### *Theme 3: knowing when to seek care*

The majority of participants expressed that they called the nurse line or sought medical care if they experienced any new symptoms or if the symptoms were unexpected or unusual such as “new skin blotches.” Some participants indicated that persistent symptoms or the prolonged duration of some of the symptoms might also push them to seek medical care. Almost all the participants stated they would go to the emergency room (ER) if they had a fever. Similarly, some of the participants had unplanned visits to the ER due to blood clots.

### **Discussion**

This study provides insight into the self-management of symptoms experienced by AYA patients during cancer treatment, including when they sought care for their symptoms. Overall, participants felt they were able to successfully manage their symptoms at home with anticipatory guidance from their medical team. However, they also identified unexpected and unusual symptoms or specific symptoms where they had instructions to seek medical care (e.g., fever) as barriers to managing symptoms at home.

Little is known about how AYA patients manage their symptoms, and our study findings highlight that AYA patients can successfully manage symptoms at home, but there continue to be instances when there is a need to seek medical care.

This study found that AYA patients will seek care for unusual or unexpected symptoms. This is consistent with previously reported literature that patients seek health care services due to uncertainty about the seriousness of their symptoms.<sup>17</sup> Different interventions to improve anticipatory guidance in the literature include education regarding possible treatment side effects to reduce negative expectations of treatment affects and tools to cope with physical and emotional pain related to treatment.<sup>18,19</sup>

Based on our findings and existing literature, it appears that increased education could improve patients’ awareness of possible symptoms that are within the realm of what can be expected and when to reach out for help. This could help optimize a patient’s time at home and avoid unnecessary trips to the ER and exposure to other illnesses in this immunocompromised and vulnerable patient population.

TABLE 2. THEMES AND SUBTHEMES WITH QUOTES

Themes	Subthemes	Quote 1	Quote 2
Managing chemotherapy symptoms	Medication	“I feel like I probably had about 10 different kinds of anti-nausea medication.”	“Yeah. I took Tylenol a lot. I mean, it was not like an excessive amount, but whenever the doctor would say it was safe, I would try to take it.”
	Sleep and rest	“I usually slept through a lot of the pains that I had. Yeah. I slept a lot during my treatments to try to get through them.”	“If I was nauseous, I’d usually just try to sleep.”
	Home remedies	“I think they’re called the Pepacol candies. . . . But I remember those would help sometimes with the nausea, that and ginger chews for when I either couldn’t take more Zofran, or I just didn’t want to. Probably, I had a lot of, what is it, the Gleabana juice and a lot of soups just because I figured if I couldn’t keep anything down, I may as well make it easier.”	“And aromatherapy in terms of lavender or Doterra, which is essential oils, has this one called Serenity that we really like, and also it has another one that’s called – I don’t know – like, Tamer that helps with nausea and then they have a ginger like . . . Yeah, gumdrops sort of thing that you can suck on that . . . Heating pads, ice, audiobooks. . .”
Anticipating and mitigating symptoms	Successfully managing symptoms at home	“I just kept up with all of my medication that would stop the nausea before it got too bad and they never got to the point of where they were too severe.”	“So, it was just a lot of the communication with my nurse practitioner – sorry, nurse coordinator that helped me really establish that cycle and really know how to listen to my body and know what medications work for what and how they were gonna work.”
	Anticipatory guidance	“I don’t think I really needed to. They gave me a list of things that I should do if I was experiencing any of the symptoms.”	“And, my doctor warned me about a lot of stuff, and I read the pamphlet that they gave me, and it named off some of the stuff. So, everything that was posted on there – I didn’t get everything that happens on there, but everything that I did end up going through was mentioned to me.”
Knowing when to seek care	Unexpected and unusual symptoms	“Whenever I feel something new, like something that I’ve never felt before, I usually call because I’m just like oh, this is new to me. I don’t know that this could mean. I might think it’s something small, and it could turn out to be something much bigger.”	“Yeah. I think it was my second round, I had these red dots popping up on my body. And, we didn’t know what they were. So, I ended up calling the nurse line, and they said it’s fine. It happens. It was from a reaction to one of the drugs I was given.”
	Persistent symptoms	“Really, I guess, just a fever or if I was sick any other way, like, if I couldn’t stop throwing up or something like that. But usually, we just call for a fever. Sometimes feeling really tired.”	“And I went to the hospital for that. And I had a migraine that had lasted for a week and a half.”
	Unplanned visits to the hospital/ER	“When I had that infection I wasn’t admitted to the hospital, but I did have to stay the day in the infusion center in an isolated room with antibiotics because of the infection”	“So, my throat was very tender and the doxorubicin kind of stripped away all the healing cells that were inside my throat and it ended up making it raw to where I couldn’t eat or drink anything because it burned so much and I ended up going to the hospital and staying there for about 10 days because I was being treated – because I couldn’t ingest anything through my mouth.”

ER, emergency room.

Although there are many studies that assess how different interventions can be helpful in managing chemotherapy symptoms, there are limited studies that show how patients manage these symptoms at home.<sup>4,20,21</sup> In addition, there are even fewer studies reporting symptom management for the AYA population with chemotherapy symptoms.

In this study, patients managed their symptoms from chemotherapy at home with minimal interventions from their health care team. The majority of the participants used medication, sleep, diet changes, and use of home remedies to manage the symptoms. However, more research is still needed on the efficacy of home remedies and natural products that some patients might utilize to relieve chemotherapy side effects.<sup>22,23</sup> Therefore, there needs to be an open communication between AYA patients and their physicians about the use of natural remedies to manage symptoms at home.

This study identified that some patients would delay or avoid seeking care, because they did not want “to bother” their health care team with expected symptoms that they were instructed that they may experience. This has been previously reported in the literature reviewing why people avoid medical care.<sup>24</sup> In the era of a global pandemic, it is also reasonable that patients would avoid seeking medical care in a hospital setting.

Although not reported widely, one of the participants cited delaying seeking care due to the coronavirus disease 2019 (COVID-19) pandemic. The COVID-19 pandemic has led to delayed and avoidance of medical care due to risks of complications or unavailable medical.<sup>25,26</sup> This can be of concern given that patients with cancer are immunocompromised and can be at higher risk of complications and worse outcomes from COVID-19.<sup>27</sup> Efforts should be made to ensure that patients feel safe seeking medical attention when necessary. Telemedicine could be used to bridge this communication gap, especially in this technologically savvy, AYA patient population.

### Limitations

Although we were able to include participants with a wide range of diagnoses, our study is limited to participants recruited from one institution, which may limit generalizability. Similarly, our participants largely had access to health care insurance and financial assistance through family, which may not be representative of all the AYA patients with cancer.

Lastly, these patients were treated in a pediatric setting, which can sometimes offer more support than the adult oncology setting, which may not make the results of the study generalizable to the whole of the AYA population. However, thematic saturation was reached during these interviews, which provided in-depth information into the management of chemotherapy symptoms by AYA patients with cancer from the perspective of the patients themselves, of which there is limited data.

### Conclusion

Study findings demonstrate that the majority of participants reported adequately managing symptoms at home with medication, rest, and home remedies. In addition, anticipatory guidance provided by their health care team prepared them for the potential treatment side effects they could experience. This study also highlights that experiencing unexpected symptoms could result in seeking medical care, which was complicated by the COVID-19 pandemic.

Future efforts should identify ways to provide anticipatory guidance as a potentially effective way to decrease unplanned visits. In addition, future studies should investigate the feasibility, acceptability, and effectiveness of virtual medical appointments to reduce delays and avoidance of medical treatment due to outbreaks of diseases, such as COVID-2019, that result in disrupted in-person medical care.

### Authors' Contributions

Conception and design: H.N., E.A., E.C.A.-V., M.G., and M.M. Financial support: E.A. Administrative support: E.A., M.M. Provision of study materials or patients: E.A., M.M. Collection and assembly of data: H.N., C.R., C.C., M.G., and E.A. Data analysis and interpretation: H.N., E.C.A.-V., M.G., T.K., and E.A. Article writing: H.N., E.A., E.C.A.-V., C.R., and T.K. Final approval of article: all authors. Accountable for all aspects of the work: all authors.

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No competing financial interests exist.

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### Supplementary Material

Supplementary Table S1

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