

Balancing Hope and Risk Among Adolescent and Young Adult Cancer Patients with Late-Stage Cancer: A Qualitative Interview Study

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Purpose: Previous studies have called for further research to explore adolescent and young adult (AYA) decision-making in the context of advanced cancer to understand the perspectives of this understudied population. We conducted a qualitative study with patients and providers to better understand the decision-making experience of AYA patients with advanced stages of cancer.

Methods: Semistructured qualitative telephone interviews were conducted from April 2016 to October 2016. English-speaking AYAs and healthcare providers were recruited through the social media sites Twitter and Facebook. AYAs were eligible if they were aged 18–39 years at diagnosis and self-reported having metastatic cancer; any provider who worked with AYAs with metastatic cancer was eligible. Researchers with expertise in qualitative methods conducted inductive thematic content analysis of transcribed interviews. The analyzed data were used to formulate recommendations for clinicians.

Results: Twelve AYA patients with self-reported stage IV cancer and five clinicians who care for AYAs with advanced stages of cancer were enrolled and shared their experience about AYA medical decision-making. Four primary themes emerged: (1) AYAs describe receiving unclear prognosis, (2) AYAs balance concepts of hope and risk, (3) AYAs choose aggressive treatment options, and (4) AYAs want support facing mortality. Recommendations for clinicians include clear communication about prognosis and side effects and concerted efforts to elicit patient values.

Conclusion: AYA patients and clinicians provided insights into the experiences and decision-making processes of AYA patients choosing to continue or discontinue treatment and into the areas for improvement in patient-centered oncology care. Taken together, these data provide important suggestions for clinicians caring for this vulnerable population.

Keywords: qualitative, clinical decision-making, patient-centered oncology, prognostic uncertainty, concepts of hope

Introduction

ADOLESCENT AND YOUNG ADULT (AYA) cancer patients struggle with the paradox of being diagnosed at a young age with a disease that is more common in older adults,^{1–7} a paradox magnified in AYA patients with life-limiting disease. The U.S. medical system is equipped to offer extraordinary measures to prolong life for patients with cancer⁸; hence AYA patients are faced with multiple clinical decisions when cancer has metastasized and longevity might be limited. Health services research reports increasing intensity of care near the end of life for AYA patients.^{9–11} According to a study of 663 AYA patients who were members of Kaiser Permanente in Southern California, 11% received chemotherapy

within 14 days of death and 68% experienced other interventions, including hospitalizations and ICU stays within the past 30 days of life. Owing to the nature of the population-level data, however, investigators could not elucidate patient-described reasons behind these patterns of care and called for future research to explore how and why AYAs make medical decisions at the end of life. In these critical junctures of patient care, it is also important to consider how clinical decision-making can influence unintended healthcare in the realm of patient-centered oncology, which prioritizes respect for patients' preferences, information and education, emotional support, and attention to their individual experiences.^{12,13}

The seminal AYA HOPE study has documented the healthcare needs of AYA survivors, including unmet cancer

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needs in cancer-related information and the perceived negative impacts of cancer on control over life.¹⁴ However, few studies have evaluated the unique perspectives of AYAs dying from cancer. A recent meta-analysis of 23 phenomenological studies detailed the experience of older patients with terminal cancer and focused on four main themes: trauma from the diagnosis (i.e., interruption and impact on loss and control); liminality (i.e., impact on social life, separation, and uncertainty); holding on to life (impact on coping, needs, and living with hope); and life as a cancer patient (i.e., impact on day-to-day life).¹⁵ The meta-analysis included studies with participants as young as 30 years, but did not specifically call out the unique perspectives of AYA patients who are facing mortality.

Hence, we conducted a qualitative research study to understand the values and attitudes of AYA patients with advanced stages of cancer as they made medical decisions from patient and provider perspectives. Understanding these perspectives will help identify gaps in knowledge, quality of communication, and inform interventions to improve clinical supportive care. We employed social media recruitment and engagement strategies to reach a geographically diverse sample.

Methods

Participants

We recruited patient and provider participants through the social media channels Facebook and Twitter and through snowball sampling (Table 1). In response to Facebook and Twitter invitations to participate in the study, we were directly contacted by 40 patients. Providers engaged with our study mainly on Twitter. We reached out to nine providers who followed our study's Twitter account through direct

message on Twitter or snowball sampling from April 2016 to September 2016. We recruited AYA patients aged 18–39 years at diagnosis and who self-reported having cancer that had metastasized or advanced and could not be cured. We also invited any providers of care to that population, such as nurses, oncologists, chaplains, and social workers; only nurses and oncologists participated in this study. Participants were excluded if they did not speak English, or were not available to speak on telephone. Our study was reviewed and approved by the institutional review board at Kaiser Permanente Washington.

Participants consented to 60-minute interviews. All interviews were conducted through telephone by a PhD-level medical anthropologist (M.F.G.) or a clinical psychologist (E.J.L.) using a semistructured interview guide. The guides were designed by a PhD-level medical anthropologist (M.F.G.) in consultation with a cancer epidemiologist (K.J.W.) and psychologist (E.J.L.). Questions were open-ended and designed to elicit experiences and values related to making medical decisions and anticipated future medical decision-making in the context of advanced stages of cancer (Tables 2 and 3). Independent interview guides were developed for providers of AYAs, which elicited perspectives on care of AYA patients. Interviews were audio recorded and transcribed. Participants received a personalized thank-you card with \$50 cash for participation.

Data analysis

The research team used Atlas.ti to manage data during analysis.¹⁶ Representative interviews from each participant category were open coded by a medical anthropologist (M.F.G.) to develop the codebook.^{16,17} Then, three team members

TABLE 1. PARTICIPANT CHARACTERISTICS

Cancer type	Age at diagnosis	Age at interview	Gender	Location	Recruitment medium			
					Twitter	Facebook	Does not remember which site	Snowball sample
Breast cancer	27	39	Female	Washington	x			
Breast cancer, dx 4	36	38	Female	California			x	
Colon cancer, dx 3	24	27	Female	Illinois			x	
Lung cancer, dx 4	34	37	Female	Michigan	x			
Breast cancer, dx 3	32	34	Female	Washington			x	
Breast cancer	31	32	Female	Texas	x			
Breast	30	34	Female	California	x			
Anaplastic large cell lymphoma	Not captured	Not captured	Female	New York	x			
Classic Hodgkins lymphoma	26	32	Female	California		x		
Pancreatic cancer	29	31	Male	Oregon	x			
Anaplastic thyroid cancer in abdomen and colon	25	31	Female	Oregon			x	
Breast cancer, dx 4	31	33	Female	Washington	x			
Oncologist, GI cancer			Male	Texas	x			
Preoperative nurse			Female	Ohio				x
Hospice nurse			Female	Indiana	x			
AYA nurse navigator			Female	Ohio				x
AYA RN			Female	Ohio	x			

Gray shading differentiates provider participants from patient participants.

AYA, adolescent and young adult; dx, stage at diagnosis; GI, gastrointestinal; RN, registered nurse.

TABLE 2. KEY INFORMANT INTERVIEW GUIDE—PATIENT

Medical treatment history	Could you share with me your cancer diagnosis, type of cancer, and treatment received to date?
Medical decisions made	Could you tell me about your last visit to the doctor or hospital, in which you had to make a decision about your healthcare? When you made the decision you described above, what goals and priorities were important to you?
Medical decisions anticipated	I would like to shift now to talking about how you see decision-making in your future, understanding that your perspective may shift in time, or even as you talk about it with me, and that's ok. As you think about your future medical care, what types of decisions do you anticipate making?
Medical decision-making by treatment type	Now I'd like to talk with you about some of the specific types of care that are commonly available to people with advanced stages of cancers: chemotherapy, surgery, and hospice care. We're interested in knowing how patients make decisions about these specific types of care. Given where you are, as you look into the future, how do you anticipate making decisions about <i>chemotherapy</i> ? What conversations have you had with your doctor and/or others about the impacts of chemotherapy on quality of life versus prolonging life? Given where you are, as you look into the future, how do you anticipate making decisions about <i>surgery</i> ? What conversations have you had with your doctor and/or others about the impacts of surgery on quality of life versus prolonging life? Given where you are, as you look into the future, how do you anticipate making decisions about <i>comfort care or hospice care</i> ?
Advice to a friend making similar medical decisions	I would like to ask you to imagine that you are giving advice to a friend with late-stage cancer who is making difficult medical choices. How would you counsel him or her? What things would you advise them to consider?
Invitation to share further thoughts	Are there any other thoughts you have about making decisions about your medical care that you would like to share with me?

(M.F.G, E.J.L., and T.B.) each coded sample interviews from each participant category to ensure trustworthiness.^{18,19} Codes were further refined through team-coding sessions and discussion until group consensus on meaning was reached for every code.^{16,20} M.F.G. recoded all interviews with the finalized codebook to identify key themes and quotes. Themes that emerged were categorized into domains.¹⁶ We focused the analysis for this article on themes that represent the AYA experience of *medical decision-making*. The entire research team reconvened to summarize the data and synthesize them into clinical recommendations.

Results

In this qualitative study, we conducted a total of 17 semistructured in-depth interviews: 12 with AYA patients and 5 with AYA healthcare providers. All patient participants were in their 20s and 30s, the majority were women, and had cancers involving the pancreas, colon, breast, sarcoma, lymphoma, and thyroid. Providers included nurses and oncologists (Table 1).

Overall themes

We identified four major themes that describe the clinical decision-making of AYA patients and their practice of balancing hope of increased survival against the risk of debilitating cancer treatment and life-limiting disease. Identified themes include (1) unclear prognosis, (2) balancing concepts

of hope and risk, (3) choosing the most aggressive treatment option, and (4) facing mortality.

Unclear prognosis

Both patients and providers stated that communication from medical team to patient about prognosis was ambiguous. Patients described not being able to fully understand the purpose of their treatment in relation to their prognosis. One patient said, "It's unclear if my treatment is palliative or for cure purposes. My surgeon even referred to hope that this can be a chronic disease, something you live with and manage your whole life" (*Female, 27, colon cancer*). Without having a clear understanding about their prognosis, making medical decisions for AYA patients was especially difficult. Another patient said, "I've never been told that I'm terminal, so I have always felt like I've got a little bit of buffer there" (*Male, 31, pancreatic cancer*). This patient later said that absent a terminal diagnosis, he was not willing to discuss making medical decisions about hospice or palliative care.

Balancing hope and risk amid uncertain treatment outcomes

As patients make medical decisions about additional cancer treatment, weighing known risks of side effects against uncertain benefits, they carefully balance concepts of hope and risk. With limited data about treatment efficacy in the AYA population to make informed decisions, patients and clinicians make their best guesses about additional treatment.

TABLE 3. KEY INFORMANT INTERVIEW GUIDE—PHYSICIAN

Medical background	Could you share with me your medical specialty, and the types of care you provide?
Medical decisions made	Could you tell me about a recent consultative visit with a patient, in which he or she had to make a decision about his or her healthcare? When he/she made the decision you described above, what goals and priorities did you have for your patient's care?
Medical decisions anticipated	I would like to shift now to talking about how you see decision-making in your patient's future. As you think about your patient's future medical care, what types of decisions do you anticipate him/her to make?
Medical decision-making by treatment type	Now I'd like to talk with you about some of the specific types of care that are commonly available to people with advanced stage cancers: chemotherapy, surgery, and hospice care. Given where your patient is, as you look into the future, how do you anticipate making recommendations about second- or third-line <i>chemotherapy</i> or experimental trials? What conversations have you had with your patient and/or his or her caregivers about the impacts of chemotherapy on quality of life versus prolonging life? Given where your patient is, as you look into the future, how do you anticipate making recommendations about <i>surgery</i> , such as surgery to remove metastasis or palliative surgery to alleviate pain? What conversations have you had with your patient and/or others about the impacts of surgery on quality of life versus prolonging life? Given where your patient is, as you look into the future, how do you anticipate making recommendations about <i>hospice care</i> ?
Advice to a colleague with patients making similar medical decisions	I would like to ask you to imagine that you are giving advice to a colleague caring for a young adult with late-stage cancer who is making difficult medical choices. How would you counsel him or her?
Invitation to share further thoughts	Are there any other thoughts you have about making recommendations about care for young adults with advanced cancer that you would like to share with me?

Furthermore, treatment can have systemic effects and have serious implications on quality of life. Participants expressed varieties of hopes, including hope that there would soon be a treatment breakthrough, hope to be cancer-free, and hope to be able to be with children or start a family (Table 4).

They also expressed the difficulties of trying to make treatment decisions amid uncertainty. Illustrative quotations include, "I always think of it like a chess game, right? That eventually I'm going to lose and the cancer's going to win, but I want to keep the game going as long as possible, and I don't want to use up all my pieces yet. Things are changing right now, so we're all sort of playing this game together and making it up as we go along" (*Female, 37, lung cancer*). A woman with breast cancer told us, "I don't want to be sitting in a bed, having some hospice nurse feeding me through a tube, you know? (tearful) But my husband's like, 'what if you do the surgery and everything goes great, and we get another year?' What do I do? Where is the right call? What am I willing to go through? What am I willing to put my family through?" (*Female, 32, breast cancer*).

Choosing the most aggressive treatment option to prolong life

Patients stated that they were willing to take bigger risks with oncology treatment because of their youth, including choosing the most aggressive treatment options, taking the

maximum doses of chemotherapy and other treatment medications, and willing to participate in experimental treatments. "I started out with the highest dose possible and [my doctor] said 'I knew you would want that, I knew you'd ask for it.' I have two small kids, so I'm willing to take bigger risks than maybe some other patients might be willing to take. But I also have to balance the quality of that time" (*Female, 39, breast cancer*). "I'm young enough and I'm strong enough that if there's anybody that can make this work in, it's gotta be me, right? I'm giving them the most healthy, strong specimen to work with, so I felt like if there's anybody that can tolerate all this, then that's me" (*Male, 31, pancreatic cancer*).

Participating in additional cancer treatment can have a profound impact on the immediate futures of patients and their families, including side effects, diminished quality of life, and financial and emotional burden. Patients expressed concern about the effects of aggressive treatment on family. "When the drug I'm on stops working, there's a couple clinical trials that would be the logical next step. But the question will be: is travel worth it, and how much of a strain does that put on my family, both time-wise and financially?" (*Female, 37, lung cancer*). "So how far do I go? How many more chemo sessions am I willing to do? I'm young and I can handle it better than older adults, but I also never want to be that person that's compromising their quality of life so much just because they're trying to live a few more months" (*Female, 27, colon cancer*).

TABLE 4. TYPES OF HOPE DESCRIBED BY PARTICIPANTS

Hope for treatment breakthrough	You think you're going to die in a year and you meet someone with a very similar diagnosis who's been alive for 5–7 years and you're like, "okay, I'll take that." If I can hold onto hope till then, who knows what treatment is going to come up after that?— <i>Female patient with stage IV breast cancer, 34a</i> I sometimes latch onto that same hopeful thought about Phase 1 or 2 trials being the miracle cure. That makes it easier to administer meds that I otherwise know are going to be really hard to tolerate. I think you have to have some element of hope as you're giving those meds.— <i>Provider, AYA RN</i>
Hope to be cancer free	I want it gone completely out of my body. I don't want any kind of residue of cancer, tumor markers, I want it all gone. I know that's so wild, huh? That's very radical just to think that that could even be possible, but I swear, it's going to happen. It's got to happen.— <i>Female patient with stage IV breast cancer, 38</i>
Hope to be able to be with children/start a family	All I want to be here is for my son. My quality of life is in length and longevity so they're trying to get me to live as long as possible.— <i>Female patient with stage IV breast cancer, 33</i> I really wanted to have a family, my husband really wanted to have a family. We decided to go ahead and find an egg donor and a surrogate so that we can still have a family, despite all this crap.— <i>Female patient with stage IV breast cancer, 34b</i>

34a and 34b are different patients of the same gender, age, and cancer type.

Providers also expressed concern over aggressive treatment regimens. "I can't tease out [if] we really do a good enough job of letting them know about the impact of some of these [treatments] long-term? Or do we just gloss over them ourselves, because we understand that this is the only thing that will hopefully cure—I don't know. When you see someone really struggling with long-term effects, it does make you wonder. And again, that's the quality of life issue, right? Like what does it mean to you, what do you think you can live with, deal with, endure, and when is it not worth it anymore?" (*Nurse provider 4*).

When is it time to let go? Dealing with mortality as a young person

AYA patients were at times able to accept their mortality before their doctor and family. Such patients described how hard it was to make the decision to end treatment. There were often other options suggested by providers that they were encouraged to try. The following quotations illustrate this theme. "When I talked about ending treatment, [my doctor] was like 'if that's what you really want to do, we can set you up with hospice. But please talk to the neurosurgeon, at least a consult. I know there's more that we can do for you.' I want to be here, but I'm exhausted at this point" (*Female, 32, breast cancer*). "Doctors don't understand because they want you to live. And my partner and family members, they were like no—you have to fight, because they want you to live. I think in a way they also don't understand. It's very state-bound knowledge that only really you can understand" (*Female, 31, thyroid cancer*).

Of course, not all AYA patients are ready to discontinue treatment before their providers recommend stopping. Some providers described the difficulty of AYA patients coming to the realization that they wanted to end treatment. "The younger patients can't really see that [they are nearing the end of their treatment options]. They keep going. They have to come to that in their own heart, to say okay, I'm dying, and this isn't how I want to live" (*Hospice nurse*).

Some patients stated that it is important to speak to a professional therapist while making medical decisions and facing mortality. "I think it's really important to see someone like a therapist in young adult cancer. It's not like I have these serious issues, just that it is serious and you're making a lot of these decisions and there's a lot of concerns—like I'm not ready to die, how can I manage this? I still need to live my days as best as I can. And I think a therapist can really help you manage your thoughts and feelings regarding that. Because it's a mental battle too, it's not just physical" (*Female, 27, colon cancer*).

Synthesis and clinical implications

Taken together, our data suggest three key opportunities for clinicians in supporting AYA patients: (1) clear communication about prognosis, (2) taking time to connect with patients and elicit their values, and (3) shared decision-making with evidence to support clinical decisions and acceptance of patient preferences and choices.

Discussion

Our research is among the first to examine the perspectives and values of AYA patients with advanced stages of cancer who are making clinical decisions, as well as the perspectives of the clinicians who provide care to them. We innovatively recruited participants through social media channels to access a national sample and to connect with AYA patients in the space they use to discuss their illness. Our primary finding is that AYA populations struggle to balance their hopes against the risks of their continued treatment. In aligning AYA oncology care toward patient-centeredness, these patients' experiences suggest that eliciting patient values is an important part of patient care,¹² as is clear patient-provider communication and connectedness between patients and providers.^{13,21,22}

Like other studies that documented an unmet need for cancer-related information for AYA patients,^{14,23,24} our participants reported that it was difficult to make decisions about medical treatments because there were very few

treatment efficacy studies conducted within their population. The lack of cancer-related information for AYAs negatively impacts their health-related quality of life.^{14,24} Understanding the impact of treatment and side effects is critical for informed patient-centered care and support of patient shared decision-making.

Both patients and providers in our study described AYA patient experiences with aggressive treatments when cure is not the goal of treatment. Aggressive treatment among AYAs at the end of life has been observed in multiple populations.^{9,10} These rates of aggressive treatment are similar to those observed among older adults (>65 years).^{25,26} Mack et al. conducted medical record reviews of 111 AYA Kaiser Permanent members and found that as patients entered the last 30 days of life, almost half changed their initial preference, with a few wanting life-prolonging care and many preferring comfort care. These results indicate a shifting need of care for AYA patients near the end of life to which their clinicians need to be attuned. Many patients in our study stated that they chose the most aggressive or very aggressive treatment options because of their youth, pressure from their family, their desire to have more time with their loved ones, and, for those who are parents, with their children, or reluctance to decline treatments offered by their providers. These findings are similar to others that suggest that patients defer to physicians during clinical discussions or to the hopes and expectations of loved ones.^{27–29} It is interesting to note both patients and providers may be hesitant about pursuing aggressive treatment for AYA patients with metastatic cancer, and yet it happens anyway. Several studies have explored how patient and provider cultural roles can drive oncology and end-of-life therapies.^{30,31} Future research could explore patient and provider cultural roles and aggressive treatment in the context of AYA patients in the United States. One of our patients mentioned viewing his body as a specimen given to providers to work with, highlighting the transactional nature of healthcare. Future studies could explore this further by looking at patient agency in oncology care.

Furthermore, quality of life is a key recognized need within this population. We found, as did other studies, that substantial proportions of AYAs are not getting all of their psychosocial needs met regarding communication support and psychological distress.^{32,33} Some of our patients stated that access to a professional therapist is important when making medical decisions and facing mortality. Many patients are using social media and the internet to access psychosocial support and health-related information.^{34–37} Future research could explore how and why AYA patients are using social media for support and for medical decision-making.

Strengths and limitations

Our study has several strengths, including the use of social media to recruit a national sample and representation from a variety of cancer types in a primarily 25–35-year-old population. Our goal was to begin to understand patient perspectives with the intent to further design research and potential interventions to address identified unmet needs. However, our study is not without limitations. We did not interview patients <18 years, and the views expressed might not reflect the views of older teens. We only collected participant perspectives from one male participant. Further-

more, we did not collect specific data on clinical details, such as prognosis, prior treatment, or communication, and we acknowledge that communication needs and patient values change over time. However, our intent was to capture a rich snapshot of AYAs care experience when faced with life-limiting illness.

Taken together, our results can help inform future work in developing interventions in patient and clinician communication, risk communication, and defining AYA support programs at cancer centers. Our results align with National Comprehensive Cancer Network guidelines³⁸ and suggest that the following would be helpful for providers to consider:

- Provide information about treatment risks and side effects: universally, AYA patients report a general lack of clinical information about the risks and side effects of treatment to inform decisions about whether to continue or decline the offered treatment.³³ This finding highlights the importance of including AYA patients in observational and clinical trials to document clinically observed and patient-reported outcomes.
- Talk about quality of life versus prolonging life in terms of aggressive treatment and intervention options.³⁹ Some patients hope for more time, that is, *quality* time, some are willing to endure toxic treatments for family, whereas others worry about the impact of treatment on family members and loved ones. Clinicians may help patients understand the risks and effects of treatment on their remaining time and on the quality of that time.
- Longitudinally elicit patient experiences and values. Patient-centered oncology care depends upon knowing patients' values regarding treatment at the end of life and goals for quality of life.^{21,22} Identifying patient values, preferences, and needs allows clinicians to provide the information most helpful for decision-making, including when to end treatment. Clinicians may then feel more confident in making their clinical recommendations.
- Provide support for AYA patients facing mortality.⁴⁰ Advanced stages of cancer often come with distress about mortality, and AYAs need the corresponding support. Providers can suggest psychosocial support for patients who want to discuss their mortality with their family and medical teams, especially as it affects their decision-making, including the support of social workers, psychologists, psychiatrists, and religious leaders.

This study is one among the few to capture the specific voices of AYAs with advanced stages of cancer. AYAs experience prognostic uncertainty, describe choosing aggressive treatment options, and balance various hopes against the risk of side effects that may negatively impact quality of life. Knowing and negotiating the right time to end treatment and active interventions are difficult for both patients and their providers. Clinicians have an opportunity to support AYAs by connecting with them and eliciting their values, and by being kindly candid about prognosis and treatment benefits and risks and uncertainties. Ultimately, interventions designed to improve clinical care and to meet the needs of AYAs with advanced stages of cancer are needed.

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