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Psychosocial experiences of young adults diagnosed with acute leukemia during hospitalization for treatment

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Abstract

The diagnosis of cancer for anyone is a time of fear and uncertainty. For young adults (YA) diagnosed with acute leukemia (AL) there are the additional challenges related to lengthy aggressive in-hospital treatment, multiple concurrent symptoms and decreased wellbeing. The purpose of this study was to explore the experiences of YAs with AL undergoing induction chemotherapy. This study used a nested qualitative longitudinal design with a convenience sample. Qualitative data was collected using semi-structured interviews and participants were invited to maintain journals. The semi-structured interviews were audiotaped, transcribed and loaded into Atlas.ti for analysis. Common themes and categories were verified and used to disseminate the findings. Seven YA, mean age 32 (+/- 4) years participated in this study. Three thematic classifications emerged: *Getting Through*, *Supported yet Isolated*, *Information Exchange Preferences*, that detail how these YA processed and coped during treatment. The findings from this study provide important insights for nurses regarding coping mechanisms that YA apply, which included relying on technology and social media platforms. Additionally, the YAs in this study discussed their need for information. The findings from this study may provide insights for clinicians currently caring for YA with AL, while also directing future palliative care research endeavors.

Keywords

Acute Myeloid Leukemia; Acute Lymphoblastic Leukemia; Psychosocial needs; Young Adults; Supportive Care Needs; Qualitative Methods

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Acute leukemia's (AL) are an aggressive group of hematologic cancers that require emergent and intensive treatment for survival. In young adults (YAs) defined as those ages 18-39, a growing subset of the population, the incidence of hematologic cancers such as AL has increased,¹ while survival rates have been significantly lower when compared with other age groups.² Ultimately, survival trends indicate that the YA diagnosed with AL continue to have a poor prognosis.²⁻⁴

Treatment for AL includes intense induction chemotherapy, which is defined as the first treatment for a disease, and requires individuals to spend as many as four to six weeks hospitalized most often in an academic medical center, for both treatment and treatment-related complications, such as neutropenia, anemia, and thrombocytopenia.⁴ If remission is achieved with induction chemotherapy, consolidation treatment then begins. Consolidation treatment includes 6-days of hospitalization once a month for at least 3-4 months or stem cell transplantation, if necessary and if available. For the YA's diagnosed with AL, the treatment paradigm over the past decade has changed where they are now treated with even more intense regimens.^{3,5} Thus, the abrupt and intense period of treatment and extended hospitalization may further contribute to the stress of the current life-threatening situation.⁶⁻⁸ During this time it is not uncommon for individuals with AL to experience negative consequences of the disease and treatment (infections, hemorrhage, symptoms such as fatigue, shortness of breath, disturbed sleep, anorexia) without yet knowing if the treatment was effective.^{9,10}

Current evidence has shown that adults undergoing treatment for AL experience numerous concurrent symptoms and a decreased quality of life when compared with other cancers.¹¹⁻¹³ The diagnosis of AL in the YA adds another level of complexity to their current life circumstance and unique developmental needs.^{7,8} These individuals are at a critical point in their life where they are initiating important developmental milestones, such as going to college, beginning careers, getting married, or beginning families. The diagnosis of AL for YAs is in essence a paradox where they see their emerging capabilities while they may fear diminishing possibilities as they are forced to consider the possibility of their own mortality.¹⁴

Resources that specifically address the unique experiences and palliative care needs of the YA are limited.¹⁵ Yet, palliative care with its unique communication skills and interdisciplinary team approach, can provide or bridge invaluable resources necessary to provide the requisite personalized support to the YA patient.^{15,16} However, while many professional oncology organizations have called for the inclusion of palliative care in conjunction with initial chemotherapy treatment, many barriers still exist that limit AL patients access to early and even late palliative care.^{16,17} Additionally, given the uniqueness of AL in the YA population, there is a dearth of research that has examined the unique psychosocial experiences and palliative care needs of the YA during hospitalization and induction treatment for AL.^{18,19}

The purpose of this paper is to examine the experiences of YAs diagnosed with AL who are actively receiving induction chemotherapy, to better direct the care delivered by oncology

and palliative care clinicians. The data for this analysis was collected within a larger mixed-methods study that examined the supportive care needs of adults receiving treatment for AL.

Methods

This analysis represents a nested qualitative longitudinal study using a convenience sample of YA, who had enrolled in a larger mixed methods study that included adults 18 years of age and older undergoing treatment for AL. All YA in this study were between the ages of 18 and 39, diagnosed with AL (either acute myeloid leukemia or acute lymphocytic leukemia), hospitalized for induction chemotherapy, and able to read and write in English. The University of Pittsburgh Institutional Review Board approved this study.

Procedures

Participants were recruited from the inpatient hematology oncology unit of a quaternary academic medical center. The Hematology Oncology Clinical Trials Nurse Coordinator was notified by the clinical team of any potential participants that met inclusion criteria. Potential participants who agreed to speak with a member of the study team were then introduced to the study and provided informed consent.

Demographic data including age, gender, race, education level, occupation/employment were collected at baseline. A member of the study team collected information regarding: AL diagnosis (type, date), treatment, laboratory results, referral services, and cytogenetic disease risk profiles from participant's medical record.

All YA completed semi-structured interviews at enrollment and again at hospital discharge, to determine if and/or how participants needs, insights, changed over the four to six weeks of hospitalization. An interview guide that included semi-structured questions were used to elicit information regarding the participants psychosocial experience during the treatment process and their support networks. Examples of questions asked included "How are you feeling?"; "What are some of your worries about treatment for your cancer?"; How do you cope with your worries?"; Do you know what palliative/supportive care is? If so, what are your thoughts about it?"; "How do you see the next year evolving for you?". Interviews took place in the patient's private hospital room and were recorded using a digital audio recorder. Interviews lasted anywhere from 15-30 minutes. The YA were also provided a paper journal that allowed them to maintain a journal about their experience while hospitalized. Participants who chose to journal were asked to write at least once week, detailing their experience, challenges, worries.

Data Analysis

Qualitative descriptive analysis with inductive thematic development guided this analysis.²⁰ The analysis of both interviews and journals was a multi-step process. First the recorded interviews were transcribed verbatim. Journal entries were also transcribed from the hard-copy journals verbatim. Transcriptions were then reviewed and audited for accuracy by the Principal Investigator (TAA). Once accuracy was confirmed the transcriptions were loaded into Atlas.ti for analysis. Transcripts were read and then re-read to achieve data immersion.

²¹ Analysis of the transcripts was then completed line-by-line and preliminary inductive

codes were assigned for appropriate lines of data. Next, data reduction occurred where common categories and emerging themes were reviewed and developed by Principal Investigator (TAA). Consensus was achieved through the study team by having a second investigator with experience in YA oncology and qualitative methodology (JKM) review the primary data, coding strategy, reduction of data through categories and eventual themes. Methods to ensure scientific rigor and trustworthiness of the data analysis included aspects of demonstrating (1) credibility (iterative questioning to ensure study questions were framed to answer the research question), frequent debriefing with study investigators), (2) transferability (contextual review), (3) dependability (maintaining a word document of any audits to detail study related decisions), and (4) confirmability (investigator triangulation).²²

Results

Sample Description

Seven YA's participated in semi-structured interviews. Two journals were returned. The participants who returned their journal followed the instructions and journaled at least once a week throughout their hospitalization. The mean age of participants was 32 (+/- 4) years, mean length of hospitalization was 30 (+/- 9.7) days, and one of the participants received a palliative care consult during their induction treatment. Sample characteristics are presented in Table 1.

Three thematic classifications emerged from the transcripts. These themes characterized the YA's processing of their AL diagnosis and subsequent protracted hospitalization: *Getting through, Supported yet Isolated, Information Exchange Preferences*. Additional excerpts of the thematic data are found in Table 2.

Getting Through—Approaches to coping to new significant life-threatening diagnosis such as AL is an important consideration for anyone, especially a young adult. In this study, many participants shared how they were able to cope with the diagnosis of leukemia as well as the extended time in the hospital.

Some participants did their best to remain positive during their treatment.

"Uh, I think I've kind of coped with it well. I kind of, I don't know, I ignored it at first, but I don't know, I guess after I dealt with it I didn't really have any bad days".- 04i discharge

"I'm just trying to stay positive right now. I'm just trying to stay like really positive and-and just not be nervous, because I am nervous about the whole thing-but I'm trying not to be. [laughter]; I'm just going to try to stay positive."- 05 enrollment

"...I worry that I won't recover, but I don't really think like that. I'm gonna go home, I'm gonna recover and I'm gonna live a long happy life with my family so I'm a power-of-positive-thinking person. Yes I have leukemia, but--it's not going to kill me. -08 enrollment

"I'm just real positive on how everything is going. I'm confident in the chemo and I'm hoping to get out of her soon." - 10 enrollment

At the same time, remaining positive as participants went through the initial weeks of treatment at times could be challenging. These challenges were more readily expressed in journal writings, rather than during the interview process.

“I find the word cancer so hard to say out loud. It is a struggle to think about yourself having that deadly “c” word. The TV ads for Cancer Centers of America are becoming difficult to watch. I find myself changing the channel to avoid hearing about cancer or cancer treatment.”—22 journal

For this individual just hearing the word cancer grew difficult at times, further reminding him of his diagnosis, isolation in the hospital and the lack of control he currently had both over his surroundings as well as his health.

Supported Yet Isolated—Treatment for AL occurs within an academic medical institution, due to the high intensity chemotherapy and life-threatening complications that may occur with an impaired immune system. Thus, it is not uncommon for individuals to travel from hours away for treatment. This distance from home may make it very difficult for families to visit the hospital which ultimately, may leave the individual receiving treatment feeling isolated.

Participants discussed this feeling of confinement within the hospital:

“I do not love the IV. I feel tied to the bed. I know I’m not, but it’s the feeling.”— 04 enrollment

“I am watching the TV show OZ, it is about life in a max security prison. Minus locking down the door to my room this has slowly become like prison. Granted, the nurses don’t carry guns and clubs. Also. I can really do as I please, but I find this team like the parole board and the warden always controlling your outcome ... I am not in control of my life it is in somebody else hands.” 22 journal

Then all of the YA participants discussed the role of family, friends, technology and social media as important methods of support during their treatment.

“I have tons of friends on Facebook, believe it or not, and it’s amazing how many people are supportive in that way, you know, just sending get well wishes. I can’t imagine going through this like ten years ago whenever stuff like that wasn’t around..”—04 enrollment

Some identified that they seemed much younger when compared to the other patients they observed on the hospital unit where they were treated.

“My family is very supportive. Friends, I have about a hand-just a handful of, like, good friends that are there... I did feel like I was, like, the only young person over there, ‘cause I’d seen a bunch of old people...”—24 enrollment

The detailed experiences that the participants shared, provides insight into the challenges that a long hospitalization poses for the YA while illuminating how technology can assist with the challenges.

Information Exchange Preferences—Communication is an important skill for health care providers that can facilitate rapport and build trust with patients. This is especially true when providers are tasked with delivering life-changing information. The YA in this study quite frequently discussed the delivery of information as they discussed their experience during induction chemotherapy treatment. Participants openly shared what they wanted to hear from their healthcare team, and what they thought was helpful, such as:

“I want to hear about positive things, like mostly success stories. You know? So, I know there’s not that many [nervous laugh], but- um, I’m determined to be one.”

–05 enrollment

“A lot of times with the process, you would get a lot of overview: This is what’s going to happen, but we don’t know exactly the day; or we don’t have a timeframe on it.”–22 discharge

Some, participants discussed how they would have liked to have more information and/or clearer information:

“...I look a lot of stuff up online because it is not explained to me by the team here at the hospital...” –22 journal entry

“I wish I would have known of the psychological support options maybe in the beginning.”–05 discharge

“Sometimes I would kind of wonder-you know, I wanted more information than I got. You know, or I’d have to, like, pull information.”- 22 discharge.

The excerpts from these YA’s illustrate how the information they received affected their experiences, as well as both their desire for and framing of information they want to receive.

Discussion

This study highlights the strength, struggles and emotional oscillation that YA who are undergoing a new or recurrent diagnosis of AL may experience during the rapid transition from initial diagnosis to induction chemotherapy treatment and prolonged hospitalization. Research findings of older adults with AL have identified similar psychological struggles, and have begun to highlight the need for palliative care referrals to this disease group.^{23,24} Only one of the participants in this study received a palliative care consultation during their enrollment in this study. This is unfortunately not an uncommon finding. Patients with hematologic malignancies are far less likely to receive a palliative care consult as providers have reported that they believe these services are only for end of life or they have a desire to control even the palliative care that is provided to their patients.¹⁷ Yet, incorporation of palliative care early in the treatment course, especially for the YA population, may provide critical trust and personalized support that is necessary, especially when navigating challenging and life-threatening diseases such as AL.¹⁶ Given, the ground breaking research that continues to illustrate the moderate to severe concurrent physical and psychological symptoms that patients with AL experience, it is anticipated that patients with hematologic malignancies will increasingly experience referrals to palliative care services.

For the participants in this study without the support of a palliative care team, it was clear that trying to navigate and maintain a positive outlook was important. All participants reported that they were satisfied with the care that was provided by the staff. Other work has documented that this level of satisfaction in care contributed to their positivity towards the healthcare experience.²⁵

These data illustrate the unique challenges that the YA may experience during a protracted AL hospitalization that typically lasts four to six weeks. YA may have an especially difficult time with the AL diagnosis, as treatment requires admission to an academic medical center that may be a long distance from home, extended hospitalization for treatment and management of treatment-related effects which often leads to feelings of isolation, the older age of other patients on the oncology unit and a perceived lack of understanding from unit staff related to psychosocial needs and impact of their illness.²⁶ YA who receive treatment on a unit specializing and focusing on care of YA patients may benefit in a variety of ways, including “boosting morale” and providing an avenue for peer support that this specific population needs.^{18,27,28}

Information delivery was another challenge for this population. Our findings suggest, while patients at points received valuable information by their providers, they had a strong desire for additional information and alternative information delivery modalities. The findings from this study are similar to another recent study conducted in the YA population, where it was found that unmet needs regarding information on their cancer and support services were common.¹⁸ These findings contrast findings from a recent systematic review, that examined the treatment decisions of older adults in oncology, and identified that older adult oncology patients often preferred to make decisions based on recommendation of their provider, rather than a need for more information and a need to take an active role in healthcare decisions.²⁹ One explanation for these differences may be that the emerging YA generations have been exposed to large amounts of electronic information throughout their lives. Thus, their needs and desires regarding information may vary from the older culture, training and expectations of the providers delivering their care.

The role of social media in YA's lives, including navigating a new cancer diagnosis, has been increasingly documented over the past decade. From blogging to Instagram to Facebook, social media platforms are documented as a source of inspiration, comfort, and ultimately connection for YA's.^{30–32} The YA in this study, also spoke frequently about the important role social media played during their hospitalization. Sites such as Facebook can serve as a method to update close family and friends all at once, while also seeing notifications and notes of encouragement as needed. While it is unclear if social media use among YA is different than that of older adults and pediatrics patients with cancer or that of the parent or caregiver, it may be important and appropriate for nurses to evaluate their patients interest and use of social media. Nurses may be able to provide guidance to their patients regarding potential benefits (connection, support, knowledge) and risks (loss of privacy, unintended intense emotions) when their YA patients are considering using social media during their cancer journey. Publications are currently emerging that may provide support and knowledge for both YA patients and nurses on various social media platforms.³²

Limitations of this study need to be acknowledged. Generalizability of the findings from this study are limited by the sample (size and age) and methodology. Only two individuals returned their journals. Two individuals chose not to write in a journal and the other participants, opted to not return for personal reasons. Enrollment in this study was through a convenience sample of YA who were hospitalized and diagnosed with AL. Additionally, there were no YA minorities that participated. The interesting findings from this study warrant further investigation. For instance, it may be important to explore differences in information shared through interviews versus journals. Unfortunately, since only two journals were returned this was not possible. However, at least one of the participants did use their journals to write a darker evaluation of their experience when compared to the interview discussion that they provided. Additionally, future studies should explore experiences and needs of the YA including the entire age range 18-39 years, examining differences in supportive care needs among the various developmental stages within the YA group.

Conclusion

YAs undergoing treatment for cancer and specifically AL, have a high degree of stress and psychosocial needs and these needs may be enhanced during prolonged periods of initial hospitalization and treatment. It is anticipated that in the future YA's including those with AL, will be increasingly cared from by palliative care clinicians. Thus, the findings from this study may help to inform strategies to deliver personalized supportive care for the YA patients with AL, especially as the involvement of palliative care in this population continues to expand. Additionally, in this understudied population, more research is needed to further understand the specific needs of YAs hospitalized for the treatment of AL. Specifically, mixed methods research that expands on the physical and psychological experiences during treatment that may influence health-related quality of life both now as well as in the future are imperative. Research that builds from foundational knowledge gained from studies such as this one has the potential to lead to a personalized palliative care intervention to improve the delivery of care for YA diagnosed with AL.

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Table 1:

Sample Characteristics

Participant	Age (yrs)	Gender	Diagnosis	Disease Status	Cytogenetic Risk	Length of Hospitalization	Palliative Care Consult
#4 *	30	Female	AML	New	Intermediate	29 days	No
#5	36	Female	AML	Relapse	Intermediate	47 days	No
#8	35	Female	ALL	New	Favorable	32 days	No
#10	26	Male	ALL	New	Favorable	29 days	Yes
#13	35	Male	AML	Relapse	Intermediate	27 days	No
#22 *	28	Male	AML	New	Intermediate	32 days	No
#24	25	Female	ALL	Relapse	Favorable	14 days	No

* Returned journals at completion of the study

Table 2.

Additional Excerpts of Exemplary Themes

Getting Through	Feeling Supported	Level of Information/Communication
<p>"...for me I'm a pretty easy going guy... I mean it sounds weird, nothing is really a big deal for me. Even when they told me at first, I was like, I treated it like a broken arm. Ok let's fix it and get on with it. I take it all with a grain of salt. No reason worrying about it, that just makes you worse. Every day is a good day, you know what I mean? Every day I'm kind of just like the same old same old." –131 dc</p> <p>"You know, I could worry about everything into the future and try to figure out how I'm gonna fix it, but sometimes it's just easier to go, okay, well, this days done, and we'll just figure out the next one. So, you know, I have more of that philosophy now than when I was first checked into the hospital, where everything was a worry, everything was a concern- ... I just learned one day at a time and, you know, not to dwell on the negative." –22 dc</p> <p>"I am slowly starting to lose my sense of humor. It is hard when you can not find the humor in the world or things around you." –22 journal</p> <p>"I am not tired of being here (the hospital) because I know this is the only place I can get healthy. I have a great view (the city), my nurses, aides, and doctors are all awesome, caring and friendly and the food is pretty good. I told my mom that if it weren't for the leukemia, chemo, pills and blood-taking, this would be like a vacation. I guess it's all about your outlook on life and how you handle the bumps in your road." – 04 journal</p>	<p>"I have my family, I have my friends, I have a huge network of people praying. We keep in touch on Facebook... everyone's up to date, it helps them as much as it helps me." –05 enrollment</p> <p>"my sisters, are real close, and real involved... They're both nurses, so they watch out for me, and some friends, too, you know, who are nurses-my buddy's wife is a nurse... So, I mean, you know, I kind of talk to the same people all the time" –13 enrollment</p> <p>My mother and I would make bets on what time the bag would end and we called them chemo bets. She was a lot better at guessing." –04 journal</p> <p>"I struggle to want to stay in touch with the world outside... tons and tons of cards, tons and tons of texts... I text my sister twice a day... it's different when you're my age, you're 28, and Facebook and all of the social media and texting and e-mail are so common that, you know, you just kind of-you just kind of get overwhelmed by it" –22 discharge</p>	<p>"Say, this is what's wrong with you, and this is what we have to do. Maybe not so much how it would turn out, because my doctor where we live, said he doesn't really deal with percentages, and things like that, so there's no guarantees, and he says, but you're young and you're healthy, and so you're not curable, he calls it healable, you're able to be healed. So he kind of, I don't know, I guess the percentages would be scary, if he would have said them anyway. [laughs] Considering they're not really all that high, the ones that I've heard" –04 enrollment</p> <p>"I didn't really like how they told me. From when I went to Emergency Room to maybe 45 minutes after I got blood work done, a doctor pretty much came in and said, "You have leukemia." He flat-out just came in and said, "You have leukemia." Gave me a tissue, and started explaining. I didn't really like that at all, I knew that something was wrong, but to just come out and say like that, it was just shocking. It was a lot to take in. I would have liked him to say, not so much that I have leukemia, that I could possibly, or not even said it, that, said we'd like to send you upstairs to get more testing. And not have said something, let somebody else tell me-not tell me in a tiny emergency room." –10 enrollment</p> <p>"You don't know what is happening- you think you're dying" –08 enrollment</p> <p>"Sometimes it feels like I'm on "Grey's Anatomy... one person usually a doctor comes in and they give a couple comments, and that's pretty much it. Then you do spend some more time with, like, the certified nurse practitioner, and every once in a while, the fellow will come in and explain a little more to you, but it's almost like the communication process is: "We don't want to tell you because then you start feeling positive and we know it's going to bad again... for somebody who's going through it for the first time... it's kind of overwhelming... For me, my education level's there. I understand what you're talking about, you know, but sometimes it takes me a minute to process it..." –22 enrollment</p>