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Adaptation and Development of a Health Insurance Education Program for Adolescent and Young Adult Cancer Patients

Perla L. Vaca Lopez, BS,¹ Echo L. Warner, PhD, MPH,^{1,2} Austin R. Waters, MSPH,¹
Karely M. van Thiel Berghuijs, MS,¹ John S. Anderson,¹ Nicole Ray, MPH,¹ Tomoko Tsukamoto, MSN, RN,³
Heydon K. Kaddas, MPH, CPH,¹ Douglas Fair, MD, MS,^{1,4} Mark Lewis, MD,³ Elyse R. Park, PhD,⁵⁻⁷
Giselle K. Perez, PhD,⁵⁻⁷ and Anne C. Kirchhoff, PhD, MPH^{1,8}

Introduction: Adolescent and young adult (AYA) cancer patients report low health insurance literacy. We interviewed AYAs to gain their perspectives on the content and delivery of the Huntsman-Intermountain adolescent and young adult cancer health insurance (HIAYA CHAT) program.

Methods: From October 2019 to March 2020, we interviewed $N=24$ insured AYAs with cancer aged 18–39 years. Participants were recruited by study staff and social media. We elicited feedback on proposed HIAYA CHAT content including insurance terms/definitions, insurance coverage components, insurance legislation, cost management, and the suitability of the intervention delivery. Interviews were audio recorded, transcribed, and inductively analyzed using NVivo 12. We coded feedback into three categories of results: (1) delivery of HIAYA CHAT, (2) endorsements of proposed HIAYA CHAT content, and (3) recommendations to expand and improve HIAYA CHAT.

Results: Participants were 58% female, 79% non-Hispanic white, and 79% receiving cancer treatment. First, AYAs felt that three to four different content areas, each 30 minutes or less, seemed feasible and that delivery should be through an online platform. Second, participants reflected on times during their treatment when having more insurance knowledge (e.g., appeals process) would have been useful, endorsing content about insurance policies, legal protections, and legislative impacts on health care costs. Third, AYAs recommended evaluating patients' health insurance literacy before starting HIAYA CHAT and wanted concrete learning tools (e.g., sample medical bills and budgeting).

Conclusion: AYAs with cancer wanted health insurance education to include information about insurance policies and protections using tangible examples through an online delivery. Describing AYAs preferences for interventions may improve relevance and efficacy of the program.

Clinical Trial Registration: ClinicalTrials.gov Identifier: NCT04448678.

Keywords: adolescent and young adult, cancer, health insurance, insurance education, intervention, patient navigation

¹Cancer Control and Population Sciences, Huntsman Cancer Institute at the University of Utah, Salt Lake City, Utah, USA.

²College of Nursing at the University of Utah, Salt Lake City, Utah, USA.

³Intermountain Medical Oncology, Intermountain Healthcare, Murray, Utah, USA.

⁴Department of Pediatrics, Primary Children's Hospital, Salt Lake City, Utah, USA.

⁵Health Policy Research Center, Mongan Institute, Massachusetts General Hospital, Boston, Massachusetts, USA.

⁶Harvard Medical School, Boston, Massachusetts, USA.

⁷Department of Psychiatry, Massachusetts General Hospital, Boston, Massachusetts, USA.

⁸Department of Pediatrics, University of Utah, Salt Lake City, Utah, USA.

These findings were presented in part as an abstract during the 45th American Society of Preventative Oncology conference.

Introduction

CANCER IS FINANCIALLY burdensome for patients in the United States, even among the insured.^{1,2} Adolescent and young adult (AYA) cancer patients, diagnosed between the ages 15 and 39 years,³ are at risk for experiencing insurance issues and financial burden during their cancer treatment as they may lack economic stability that typically develops with age and career establishment. Compared with older adults with cancer, AYAs are more often underinsured,⁴ often have little experience navigating the health care system, and have inaccurate expectations of health insurance coverage.⁵

AYAs also have lower health insurance literacy (that is the ability to effectively use and navigate insurance to access care), which can place them at risk for further financial burden.⁶ Thus, developing an AYA-specific health insurance literacy program could improve health insurance literacy and reduce financial burden.

In 2019, a virtual health insurance education program—HINT—(Health Insurance Navigation Tools) was being created specifically for long-term survivors of childhood cancer in the Childhood Cancer Survivor Study.^{7,8} HINT was designed as a four-session program grounded in a psychoeducational care management model. HINT was informed by Levy and Meltzer's model of the relationship between health insurance and health⁹ and the Andersen Behavioral Model of Health Services Utilization,⁹ which posits that health care use is influenced by predisposing, enabling, and need factors (e.g., demographics factors, income).

Each HINT session was planned to last 30–40 minutes and be delivered by a patient navigator. Sessions would cover topics including insurance terminology and definitions, insurance coverage components (e.g., summary of benefits [SOB]), consumer protections and expansion of insurance under the Affordable Care Act (ACA), overview of important insurance legislation (e.g., Family Medical Leave Act [FMLA]), navigating one's own plan, and cost management tools. Due to the unique health insurance needs of AYA cancer survivors, adaptation of and co-development with a health insurance education program such as HINT could produce a developmentally tailored program for providing insurance support and addressing AYAs financial worries during treatment.

In this study, we report on the adaptation of HINT for AYA cancer patients receiving patient navigation in the Huntsman-Intermountain Adolescent and Young Adult (HIAYA) Cancer Care Program. To inform the program (referred to here as HIAYA CHAT for "Let's chat about health insurance"), we conducted semi-structured interviews to explore AYA endorsements and recommendations of the existing HINT content structure as well as their preferences for intervention delivery. We report AYAs' feedback on the proposed content and delivery of HIAYA CHAT including their suggested modifications for adapting HINT for AYA patients. To the best of our knowledge, HIAYA CHAT is the first intervention designed specifically to improve health insurance and cost literacy among AYA cancer patients; thus, the feedback we elicited may be useful for future health insurance interventions for other young populations facing conditions with high medical costs.

Materials and Methods

Theoretical framework

Adapting interventions for new contexts and populations requires systematic evidence-based approaches. To describe how HINT was adapted for AYA cancer patients, we applied Movsisyan's adaptation approach, which includes a four-step process: Step 1: exploration (i.e., assess, select, and explore the intervention), Step 2: preparation (i.e., identify potential mismatches, model development, network/infrastructure establishment), Step 3: implementation (i.e., create modifications, pilot test), and Step 4: sustainment (i.e., evaluate and evolve the program).¹⁰ Herein, we describe Step 2—preparation—of the systematic adaptation of HIAYA CHAT to AYAs with cancer. This project was approved by the University of Utah Institutional Review Board (IRB No. 00091443). We report according to the COREQ guidelines (Supplementary Table S1).

Participants and recruitment

Recruitment occurred from October 2019 to March 2020. Eligible participants had health insurance, were aged 18 years or older, and received treatment at an eligible clinical site (four Utah-based hospitals that are part of the HIAYA program). Eligible participants had been diagnosed with cancer between the ages 18 and 39 years because the goal of the program is to enroll patients within the first year of diagnosis.¹¹ Recruitment occurred through HIAYA patient navigators and HIAYA social media accounts. Study staff screened potential patients and verified date of diagnosis through electronic medical records. Once eligibility was confirmed, potential participants were approached at a clinic appointment or via email/phone by study staff.

Participants were purposefully sampled to achieve equal representation of younger (18–25 years old) and older (26–39 years old) patients based on the ACA-dependent health insurance coverage cutoff age.¹² A total of 51 potential participants were contacted; 14 were unreachable and 5 declined. Of the remaining 32 AYAs, $N=24$ participated in informed consent, an online survey, and a semi-structured interview. No additional interviews were conducted after data saturation was achieved; thus, $N=8$ of the potential participants were not enrolled in the study.

Interview guide and measures

The interview was pilot tested before fielding with six AYA cancer patients and survivors to ensure relevant information and community centeredness. The sections explored in the interview included demographics, financial support, obtaining and understanding current coverage, plan experiences and satisfaction, cost conversations with providers, and review of the proposed HIAYA CHAT materials. This study focuses on the feedback received on HIAYA CHAT content. Through a 59-item online survey, we collected demographics (e.g., treatment status, gender, education), the health insurance literacy measure (21 items, scores range 0–84, higher scores indicate higher levels of health insurance literacy),¹³ treatment status, diagnosis type, and age at diagnosis.

Data collection

After completing the online survey, participants were emailed a PDF outline of the proposed HIAYA CHAT content to assess for the interview. Semi-structured interviews were conducted over the telephone by A.R.W. and K.v.TB. HIAYA CHAT content included information on insurance terms/definitions (e.g., deductible, co-insurance, and premium), insurance coverage components (e.g., SOB), insurance legislation (e.g., the ACA, FMLA), and cost controlling mechanisms (e.g., cost conversations with providers, budgeting, insurance appeals). Thematic saturation was achieved when little new information relevant to the research question emerged from the interviews,¹⁴ which was determined through discussion and consensus of the research team members with experience in qualitative research. The interviews were audio recorded, transcribed, and quality checked for discrepancies. A \$20 gift card was given to thank each participant for their time and contribution.

Data analysis

Qualitative data were analyzed in NVivo 12 through two cycles of structured coding to identify: (1) recommendations about the delivery of HIAYA CHAT, (2) endorsements of proposed HIAYA CHAT content, and (3) recommendations to expand and improve HIAYA CHAT content. Structured coding is a method of inductive qualitative analysis where codes are created to label content that is relevant to particular overarching question. Structural coding is especially useful for examining feedback across multiple participants to identify commonality and differences.¹⁵

During first cycle coding, free form memos were recorded to capture the coder's thought processes and to identify ambiguous or difficult to describe content for discussion with authors. A draft of an unconstrained matrix was created, P.L.V.L. and J.S.A. coded five (20%) randomly selected interviews into the unconstrained matrix, which ultimately consisted of two major categories endorsements and recommendations. In second cycle coding, five randomly selected interviews were categorized into endorsements and recommendations of the intervention content.

All coding was reviewed by three authors (P.L.V.L., E.L.W., A.R.W.), and one additional code was made for feedback on the delivery of the intervention to ensure fit of data and rectify inconsistencies. For these five interviews, coding discrepancies were documented and resolved through coder consensus at weekly meetings; a final coding scheme was created and applied to the remaining interviews. Discrepancies in coding were discussed and revised through consensus. The final categories included the following: (1) delivery: feedback about the format, timing, and technical aspects of delivering the intervention content to future AYAs; (2) endorsements: statements of affirmation or confirmation; and (3) recommendations: content participants felt should be added or changed in the intervention material. Descriptive demographics and cancer statistics were calculated in Stata 14.

Results

On average, the interviews lasted 32 minutes (range: 15–55 minutes). Participants who were aged 18–25 years were on average 20.5 years old and those who were aged 26–39 years

were on average 31.7 years old. Nearly half were female (58.3%), non-Hispanic White (79.2%), and on treatment (65.2%, Table 1). Most had private insurance (83.3%); 41.7% were the policyholder, whereas 45.8% had insurance through their parents and 12.5% had a spouse. Average health insurance literacy scores were 55.63 (SD: 10.06, range 0–84; with scores <60 denoting low insurance literacy, not shown in Table).

Feedback on the overall concept of HIAYA CHAT was largely positive (“I would schedule [the intervention] right now.”) with many participants offering strong endorsements of the proposed intervention content, citing their own previous inexperience with health insurance as a primary factor and through sharing stories of their personal struggle to navigate the health insurance landscape. Participants shared that as young adults their cancer diagnosis was their first intimate interaction with the health system and had minimal if any prior experience using their health insurance. Participants supported the need for an intervention that addresses health insurance literacy for AYA cancer patients.

We describe three different categories of feedback about adapting HIAYA CHAT for AYAs with cancer, including (1) delivery of HIAYA CHAT, (2) endorsements of proposed HIAYA CHAT content, and (3) recommendations to expand and improve HIAYA CHAT content. Specific examples of endorsements and recommendations for HIAYA CHAT are shown in Table 2.

TABLE 1. ADOLESCENT AND YOUNG ADULTS PARTICIPANT SOCIODEMOGRAPHICS

Sociodemographic	N = 24	
	n	%
Age at survey, years		
18–25	12	50.0
26–39	12	50.0
Treatment status		
On treatment	15	65.2
Off treatment	8	34.8
Gender		
Male	10	41.7
Female	14	58.3
Education		
College graduate or higher	8	33.3
Some college	14	58.3
High school education or less	2	8.3
Race/ethnicity		
Non-Hispanic White	19	79.2
Hispanic White	4	16.7
Non-Hispanic racial minority	1	4.2
Sexual orientation		
Sexual minority	2	8.3
Heterosexual	22	91.7
Health insurance status at survey		
Private insurance	20	83.3
Public insurance	4	16.7
Health insurance policy holder		
Self	10	41.7
Parent	11	45.8
Spouse	3	12.5

TABLE 2. ENDORSEMENTS AND RECOMMENDATIONS ON THE FEASIBILITY, DESIGN, AND DELIVERY OF HIAYA CHAT

<i>Subcategory</i>	<i>Endorsement</i>	<i>Supportive quote</i>	<i>Recommendation</i>	<i>Supportive quote</i>
Format	Participants agreed that three to four different content areas seemed achievable considering the amount of information in HIAYA CHAT. The order of content areas made sense pertaining to the content each session had.	<p>“I think four is good, three or four. I feel like less than that would be too packed, [too] much information per time.”</p> <p>“I think obviously having the basics first just to be able to understand the more complicated things. But I think it’s all in a good order.”</p>	Participants recommended for content areas to be about 30 minutes long.	“I think four session 30-minute sessions is pretty solid.”
Feasibility of online setting	Most participants affirmed that online delivery would be more convenient and less likely to add to treatment schedule burden; however, some preferred face-to-face as an option.	“I think it would be nice to do it [over Zoom] just because that way it wouldn’t make your treatment visit longer.”	Participants preferred for HIAYA CHAT to be online as patients felt that it would be less likely to add another burden to their busy schedules. The need for engaging material was deemed additionally important when the material is delivered over telehealth platforms.	<p>“If there is a video that you can watch or if you can Skype and do something because you are feeling crappy. You can’t drive, you don’t have transportation that day or whatever, I think that would make it a little bit easier.”</p> <p>“I do think in-person would probably more interesting [and] easier to pay attention to.”</p>
Review material	Printed review material was seen as helpful mainly for sharing information with others/caregivers.	“It would be nice to have something to show my wife so we could talk about it after.”	Participants did not want “homework” or any assignments to complete between each content area.	“I’d be wary of anything that feels like homework, especially for teenagers.”
Timing of delivery	The importance of delivering HIAYA CHAT before treatment was highlighted.	“[HIAYA CHAT] probably isn’t much use after you’ve already done treatment so [delivery] sooner rather than later is probably better.”	Immediately after cancer diagnosis, scheduling can be hectic and participants expressed doubt material would be well received at that time.	“There’s just like a lot of moving parts after getting that cancer news. I wouldn’t have wanted to do like a whole insurance thing at that point.”
In-session material	N/A	N/A	Participants were asked for their opinion whether there should be things to work on in-between content areas (e.g., homework) and if so, how would they frame it. Most said that they would call it a worksheet insurance or insurance map but not homework.	“Maybe frame it in like, ‘In order to make the next session productive, we’d ask that you look at this worksheet.’”

(continued)

TABLE 2. (CONTINUED)

<i>Subcategory</i>	<i>Endorsement</i>	<i>Supportive quote</i>	<i>Recommendation</i>	<i>Supportive quote</i>
Patient navigator relationship	Participants unanimously endorsed the use of existing patient navigators to deliver HIAYA CHAT.	“I really love and trust [patient navigator name]. She was there the same day I got my diagnosis and visited every treatment appointment.”	N/A	N/A
Individuals tailoring	There was strong support for sections that addressed the participant’s actual insurance plan/situation.	“I really would like them to just hold my hand through my own insurance plan and tell me exactly what I need to know.”	Participants recommended that base-level insurance knowledge be assessed, and delivery adjusted, to meet deficits.	“If someone already knows about like insurance terms and stuff going through all that one by one is going to be really boring for them.”

HIAYA CHAT, Huntsman-Intermountain Adolescent and Young Adult Cancer Care Program “Let’s chat about health insurance.”

Delivery of HIAYA CHAT

One of the strongest recommendations was for established AYA patient navigators to administer the intervention. It was clear that navigators had robust rapport with most participants and were seen as a valuable member of the patient’s oncology team. A participant stated, “I feel like throughout this whole process [cancer treatment], sometimes it feels like [healthcare providers] just give me info, but no one really cares. But, this [HIAYA CHAT], it actually feels like people care.” Participants believed that HIAYA CHAT would provide new information that they would not receive elsewhere. AYAs valued the option of an online navigation format as it would be more convenient and less likely to add to another burden (e.g., scheduling, travel).

Participants (more often the older participants) recommended measuring patients’ level of health insurance literacy before starting HIAYA CHAT because they felt that those with higher literacy may not need to go through all the basic insurance terminology, which is covered in HIAYA CHAT. In this case, participants recommended a “condensed version” of insurance terms and definitions. Furthermore, participants recommended terms and definitions be presented in an engaging interactive format, citing boredom as a primary factor. One participant stated, “Health insurance isn’t exactly something that most teenagers are excited about.”

Endorsements of proposed HIAYA CHAT content

The majority of participants felt frustrated by trying to understand their health insurance. Thus, many endorsed the idea of learning common health insurance terms, particularly to address the “wordiness,” as one participant put it, of their insurance plan. The most endorsed content was budgeting tools with cost calculators to help estimate out-of-pocket costs. The majority of participants thought the content on insurance coverage components (e.g., SOB) would position them to get the most use out of their insurance.

Content about the ACA was overwhelmingly accepted; several participants felt that understanding ACA insurance protections would improve their health insurance use and

decision-making. As one participant stated, “All you ever hear about [the ACA] is what they say in the news so it’s honestly kind of tough to actually know what it even is.” Another strongly endorsed topic related to the ACA was the right to appeal coverage decisions. Multiple participants discussed frustrating experiences with having claims rejected and not knowing how to file appeals. One participant expressed, “I remember this one time when my insurance told me they weren’t going to pay for [a diagnostic scan]. The fear that I was going to get stuck with some crazy expensive bill was real and at the time I had no idea there was anything to do about that.”

Recommendations to expand and improve HIAYA CHAT content

Content on insurance terms and definitions. Participants felt that the content should be age-specific. This included recommending that younger participants be given less information on health insurance terms and definitions to avoid boredom and potential intervention attrition. There was some concern that having insurance terms and definitions first would dissuade participation in the other, more interactive or “exciting” HIAYA CHAT content. Participants felt that the list of terms and definitions was comprehensive.

Content on insurance components. Insurance components in HIAYA CHAT include SOB, explanation of benefits, insurance cards, and bills. Participants expressed difficulty comprehending bills that were related to their treatment and recommended showing an example of these different documents to help differentiate and understand them. One participant stated, “Maybe you could show them just a fake bill or something so they can read that, too. So, they can understand the bill, who pays what.” Another participant expressed that AYAs may not have much experience dealing with health insurance and they could easily “Get overwhelmed or frustrated with a bill that has 15 providers on it for a procedure.” Participants suggesting including information on how to access, read, and understand their SOB, because soon after their cancer diagnosis they found

TABLE 3. RECOMMENDATIONS AND SUPPORTIVE QUOTES FOR HIAYA CHAT CONTENT PERTAINING TO COSTS FOR PATIENTS

<i>Subcategory</i>	<i>Recommendation</i>	<i>Supportive quote</i>
Budgeting	Participants recommended budgeting tools based on their previous experiences with using Excel, apps, and smart phones.	“[I’m a] accounting major, so I just have an Excel spreadsheet.”
Communication	Participants expressed the importance to communicate with their health care team because they can help with financial assistance programs.	“[Don’t] be afraid [to communicate with your healthcare team]—just everyone just needs to ask questions.”
Health insurance utilization	Participants mentioned the importance to emphasize there are ways to reduce costs and to make sure patients do their research and see if there is an insurance plan that may suit them better.	“It’s going to be expensive [cancer treatment], but knowing there’s other ways to reduce those costs, that would be amazing.” “Make sure they’re well aware of what they’ve got [in their insurance plans].”
Other	Participants expressed the importance of making sure patients know that cancer treatment can be expensive and having cancer can be a long process but that there are ways to reduce costs.	“[There are] opportunities or other ways to get help with payment if your health insurance doesn’t cover something.”

HIAYA CHAT, Huntsman-Intermountain Adolescent and Young Adult Cancer Care Program “Let’s chat about health insurance.”

themselves having to use their insurance more frequently than before, and often they needed help interpreting this documentation.

Content on insurance-related legislation. Participants wanted to learn strategies to reduce health care costs, manage finances during cancer, and have insurance coverage, but were unaware of how insurance-related legislation could factor into this. Participants generally supported learning about health insurance- and employment-related laws, such as the ACA, FMLA, Consolidated Omnibus Budget Reconciliation Act (COBRA), and Americans with Disabilities Act (ADA). However, there was an explicit need to connect this legislation to their needs as a cancer patient. Participants did not want to learn about parts of laws that they perceived did not apply to them and that younger patients may be less likely to engage with policy-related material. Participants recommended that content about health care legislation, such as the ACA, be tailored by age. To this point, one interviewee stated, “I’m not trying to dis on learning about history, and acts, and politics, and things, which this is, and it’s important, but being able to communicate that to potential teenagers would be the trick.”

Participants also recommended that the HIAYA CHAT material be approached in a manner that presented facts about legislation and avoided commentary about the policies being “good” or “bad” given the political climate surrounding the ACA.

Content on cost sharing. Participants felt that insurance cost sharing discussions should cover how to address costs with health care teams and ways that providers can help patients navigate cost sharing with their insurance. Participants recognized the value of their health care teams advising them in managing their costs. One participant stated, “When I talked to [patient navigator] about money she came back to me the next week with this whole plan about how we were going to make sure [my out-of-pocket-cost] was covered.”

Many participants felt when they initiated conversations about finances, their health care team had gone out of their way to help with the appeals process and ameliorate health insurance confusion. Participants remarked how learning to communicate with their health care team about costs was important, but difficult: “It was pretty hard for me to talk to my doctor about costs because it felt like I was being ungrateful for all they were doing for me.”

Content on managing out-of-pocket costs. Participants wanted HIAYA CHAT to include tools for budgeting, using health insurance and communicating with their health care team. They preferred budgeting that incorporated day-to-day expenses such as rent, food, utility bills, and living expenses in addition to cancer treatment costs. Additional examples of the recommendations received for HIAYA CHAT are shown in Table 3.

Discussion

The United States health insurance system is very complex and requires attentive navigation by cancer patients while simultaneously managing the difficulties of their disease.⁵ We conducted interviews with AYA cancer patients to gain their perspective on how to adapt a virtual, four-session health insurance education navigation program, that was originally designed for pediatric cancer survivors, to aid in navigating health insurance during their cancer. AYAs highly valued the proposed content in the intervention, HIAYA CHAT, because they felt that it had the potential to increase their insurance knowledge and help them optimize their insurance use. Many participants specifically wanted to learn about policies pertaining to pre-existing conditions, employment protections, and insurance access as well as the insurance claims and appeals process. Participants suggested some modifications to the content and delivery of HIAYA CHAT, specifically ensuring that HIAYA CHAT content is appropriate across the wide AYA age range, which includes teenagers and young adults.

Not surprisingly, participants noted that learning about health insurance was “boring” but essential as a cancer patient. To address this, they suggested providing tangible examples to reinforce learning concepts such as health care bills. Participants felt that tailoring HIAYA CHAT to individual needs and insurance plans could be more engaging than a one-size-fits-all approach. Other ideas to increase engagement were to make HIAYA CHAT more interactive through things such as budgeting tools, role-playing with the patient navigator, and information on cost conversations with health care providers. Effective efforts to increase young adults’ engagement in other interventions have emphasized using digital platforms that include automated and communicative functions and access to peer support.¹⁶ Tailoring the intervention using AYA learning or developmental theories, such as Arnett’s emerging adulthood, could also be applied in future health insurance education interventions to increase engagement, appeal, and retention of program content.¹⁷

In addition to being a way to increase engagement, participants wanted guidance on how to have cost conversations with providers and how to apply budgeting resources for both cancer-related expenses as well as living expenses. Cost conversations with providers can help reduce out-of-pocket costs, connect patients with financial assistance programs and other resources that cancer patients may not be fully aware of.¹⁸ Participants were typically unsure of how or when to talk about insurance and costs with providers, potentially because AYAs have minimal prior experience using their health insurance and navigating costs,^{6,19} so having opportunities to role-play cost conversations during HIAYA CHAT was well received. Based on this feedback, we included an additional module on assertive communication with providers in the cost sharing section of the intervention content.

To increase the relevance and fit, participants suggested tailoring certain sections of HIAYA CHAT based on AYAs’ health insurance literacy, age, and life stage. In an earlier report from this same sample, we found that the younger AYA participants had lower health insurance literacy than older. Thus, educational programs that are designed for cancer patients in this age range may need to consider within-group differences in health insurance literacy.² Indeed, targeted intervention material that is designed specifically for AYAs who are no longer on their parent’s health insurance plans and who are financially independent may be drastically different compared with AYAs who rely on their parents for insurance and financial support.

Key takeaways were finding greater confusion around insurance terminology for younger AYAs and that older AYAs thought that measuring insurance literacy before the intervention could be useful for tailoring materials. Therefore, adapting the intervention to address in-group differences among AYA cancer survivors or to consider differences by life stage (e.g., transitioning from dependent coverage to their own employer plan) may have more success than a one-size-fits-all approach.

The delivery of HIAYA CHAT via videoconference (i.e., Zoom) was strongly endorsed by the majority of study participants. A preference for online programs among AYAs has been observed in previous research because they often use digital technology to manage their health care needs, such as through smartphone apps, social media, and websites.²⁰ As digital natives, AYAs are particularly well positioned to benefit from digital interventions,²¹ but how these are im-

plemented in clinical settings and with patient navigators still requires further feasibility and acceptability testing.

Digital interventions may also ameliorate geographic barriers to participation, which is of particular concern for cancer centers with large catchment areas, and may help address disparities faced by AYAs in rural locations.²² However, as rural communities often face more limited access to internet coverage, future efforts should track and evaluate how internet access may limit participation or potentially exacerbate disparities. While these interviews were conducted before the COVID-19 pandemic, our findings are reinforced by the high feasibility and acceptability of telehealth services during the pandemic.¹⁶

In the absence of significant policy overhaul to simplify accessing and paying for care, increasing patient health insurance literacy is one of the few modifiable factors influencing accessibility and affordability of cancer care.²³ Despite the volume of the literature describing health insurance concerns, issues accessing care, and financial toxicity for cancer patients,²⁴ previous work to increase health insurance literacy among cancer patients has been limited despite cancer being one of the most expensive chronic diagnoses.¹ We are aware of only one intervention to teach cancer patients about health insurance, and this did not focus on the specific needs of AYAs.²⁵ Thus, addressing the feedback received during this interview supports ongoing efforts to improve AYAs health insurance literacy and, ultimately, protect AYA cancer patients from potentially unnecessary costs during cancer treatment.

Limitations

This study has limitations. Most AYAs were non-Hispanic White, and therefore, important differences in cultural values around health care, health costs, and structural determinants may not be described. We only enrolled insured AYAs and had a small number of publicly insured AYAs in the study due to our recruitment locations. The health insurance literacy needs may differ for publicly insured patients compared with individuals with a private health insurance plan. Thus, we are now organizing to pilot test HIAYA CHAT in a sample of Medicaid-insured AYAs. All our participants were enrolled in a Utah health insurance plans or received their cancer care in Utah; as insurance plan structure differs by state due to variable Medicaid eligibility and premium discounts for Marketplace plans, preferences for participants in other states may be different.

Due to the complexity of insurance terminology, the average reading level of the intervention content materials was at approximately a 10th grade reading level. We worked closely with a health educator throughout the development of the materials and the vast majority of the high literacy words in the materials were insurance terms; we made a strong effort to simplify all other content, but future work in this area should focus on enhancing the comprehensibility of the HIAYA CHAT material. Additionally, AYAs who were willing to participate in this study may have more interest and knowledge about health insurance compared with those who did not enroll.

Conclusions

Our results constitute an important step to address health insurance literacy disparities among AYAs with cancer.

Iterative modification based on patient feedback can improve the patient-centeredness of HIAYA CHAT and address real-world barriers to participation in randomized controlled trials. By identifying potential mismatches program content, such as participants' desire for budgeting tools and cost conversation coaching, we documented specific suggestions for adapting HIAYA CHAT to address AYAs specific needs. Other modifications that arose from our results related to the duration of intervention, tangible examples of health care bills, and technology-based delivery of the intervention. In taking this important step to modify HIAYA CHAT by eliciting AYA cancer patient's opinions and advice about the intervention content and delivery, we potentially preempted challenges to intervention feasibility and acceptability.¹⁰

Acknowledgments

The authors appreciate the support from the patients who participated in the study. We thank Emily Measom for assistance in collecting materials, resource checking, and for quality checking interview audio transcripts. We also thank Junko Fowles for providing feedback on the material content.

Authors' Contributions

All authors contributed to the study conception and design and material preparation. Participant recruitment and data collection were performed by P.L.V.L., K.vTB., A.R.W., N.R., T.T., and A.C.K. Data analysis was performed by P.L.V.L., A.R.W., J.S.A., and H.K.K. with oversight from E.L.W. The first draft of the article was written by P.L.V.L., and all authors commented on previous versions of the article. All authors read and approved the final article.

Research Involving Human Subjects

This research was approved by the University of Utah Institutional Review Board, and the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Informed Consent to Participate

Verbal informed consent was obtained from all individual participants before the interview who were included in the study.

Data Availability

The data generated in this study are available upon request from the corresponding author.

Disclaimer

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Author Disclosure Statement

No competing financial interests exist.

Funding Information

This work was supported by the National Cancer Institute of the National Institutes of Health under Award Number R01CA242729-01 (Kirchhoff, PI) and T32CA078447 (Warner). Travel Funding provided by the National Institutes of Health grant P30CA042014 (Ulrich, PI).

Supplementary Material

Supplementary Table S1

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Address correspondence to:

Perla L. Vaca Lopez, BS

Cancer Control and Population Sciences

Huntsman Cancer Institute at the University of Utah

2000 Circle of Hope

Salt Lake City, UT 84112

USA

Email: perla.vacalopez@hci.utah.edu