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ORIGINAL ARTICLE

“I thought there would be more I understood”: health insurance literacy among adolescent and young adult cancer survivors

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Abstract

Background Health insurance literacy is crucial for navigating the US healthcare system. Low health insurance literacy may be especially concerning for adolescent and young adult (AYA) cancer survivors. To describe AYAs’ health insurance literacy, we conducted semi-structured interviews with AYA survivors, on and off of treatment.

Methods We interviewed 24 AYA cancer survivors (aged 18–39 years) between November 2019 and March 2020. Interviews were recorded, transcribed, and quality-checked. Using two cycles of structured coding, we explored AYAs’ health insurance literacy and examined thematic differences by policy holder status and age.

Results AYAs were 58.3% female, 79.2% non-Hispanic White, 91.7% heterosexual, and 62.5% receiving cancer treatment. Most participants had employer-sponsored health insurance (87.5%), and 41.7% were their own policy holder. Four themes emerged; in the first theme, most AYAs described beginning their cancer treatment with little to no understanding of their health insurance. This led to the three subsequent themes in which AYAs reported: unclear expectations of what their insurance would cover and their out-of-pocket costs; learning about insurance and costs by trial and error; and how their health insurance literacy negatively impacted their ability to navigate the healthcare system.

Conclusions Our findings, while requiring confirmation in larger samples and in other health systems, suggest that the health insurance literacy needed to navigate insurance and cancer care is low among US AYA survivors and may have health and financial implications. As the burden of navigating insurance is often put on patients, health insurance education is an important supportive service for AYA survivors on and off of treatment.

Keywords Health insurance · Patient navigation · Adolescent and young adult · Health insurance literacy · Cost literacy

Background

Healthcare in the US is a highly complex, expensive, and unique system, requiring patients to navigate a confusing mixture of public and private care delivery and payment structures [1–5]. Most US health insurance policies include multiple layers of complexity from provider networks and tiered prescription coverage to prior authorization and cost sharing requirements [6–8]. The 2010 Patient Protection and Affordable Care Act (ACA) expanded access to care and consumer protections [9] but also added to the complexity to the procurement and use of health insurance. Unfortunately, the burden of navigating insurance often falls on patients who may be facing debilitating, life threatening, and high-cost diagnoses, such as cancer.

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Adequate health insurance literacy — the knowledge and application of health insurance concepts — is critical for cancer patients to navigate their care and manage costs. Adolescent and young adult (AYA) cancer patients, ages 15–39 at diagnosis [10], often have minimal experience navigating healthcare as many are healthy prior to their cancer diagnosis [11]. Further, health insurance in the US is often tied to full-time benefited employment, which many AYAs may just be gaining access to when diagnosed [12], limiting their experience of choosing and understanding health insurance plans prior to a high-cost and life-threatening diagnosis. In the general population, health insurance literacy among young adults is low [13], which can mean significant cost consequences for AYA cancer patients who may not be aware that insurance provisions such as in-network providers or preauthorization can greatly affect their out-of-pocket costs [14, 15]. Not surprisingly, many AYA cancer patients report emotional distress from managing health insurance and finances during treatment [16–18].

Multiple studies have identified health insurance and out-of-pocket cost as concerns among AYAs with cancer [16–18], yet in-depth information about their understanding of health insurance and their cost management strategies as they navigate their cancer treatment is limited. Further, descriptions of how low health insurance literacy impacts financial burden among young cancer survivors is lacking. Such information is essential to developing financial and health insurance support programs for these patients. Accordingly, we conducted semi-structured interviews with AYA cancer survivors on and off active treatment. We describe AYAs' understanding of their health insurance by exploring (1) their expectations of their insurance coverage and costs during treatment, (2) insurance issues they encountered during treatment, (3) how they learned about their insurance, and (4) their understanding of their coverage and out-of-pocket costs. We then assessed whether these experiences differed by age or policy holder status.

Methods

Participants, recruitment, and data collection

Eligible participants were diagnosed with cancer as an adolescent or young adult (between the ages of 15 and 39 years), were currently 18 years of age or older, and insured at time of interview. Participants were identified through clinic schedules and an AYA patient navigator database. Though participants were required to be a minimum of 18 years of age at time of interview, some were diagnosed prior to turning 18 years of age; thus, we refer to participants in this study as AYA survivors because they were all survivors of cancer and diagnosed as an AYA. Participants were sampled according to dependent coverage age cut-off of 26 years at diagnosis, to achieve equal strata of younger (18–25 years) and older (26–39 years) survivors. Once eligibility was verified, study staff including AYA patient navigators approached the AYA survivor in clinic or via email/phone between October 2019 and March 2020. We also advertised via an AYA program's social media (Facebook and Instagram).

A total of 51 eligible AYA survivors were screened and contacted by the study team. Of these 51, 14 were unable to be contacted, and 5 declined participation. Among the 32 remaining AYA survivors, 24 participated (12 younger and 12 older) in an interview at which point thematic saturation was reached and no further interviews were conducted. The remaining 8 potential participants were informed they would be contacted for subsequent aims of the study as eligible. Recruitment occurred iteratively with analysis until the interviewers (ARW and KM) and study team confirmed that data saturation had been achieved [19, 20]. Participating AYA survivors provided informed consent, completed a demographic and health insurance survey, and participated in a semi-structured interview over the phone. Interviews on average lasted 32 minutes.

Interview guide development

The guide was developed by the study team to elicit AYA survivors' experiences with understanding and using their insurance coverage, their health insurance expectations and satisfaction, health insurance issues while navigating cancer treatment, their understanding of cost components of their healthcare, and feedback on a health insurance education intervention. The interview guide was piloted with 6 AYA survivors to ensure applicability and patient centeredness. The analysis presented here focuses on participant understanding of their health insurance, coverage, and out-of-pocket costs; expectations of their coverage and costs; issues using their insurance to access healthcare; and how they learned about their insurance.

Qualitative analysis

Interviews were recorded, transcribed, and quality-checked with audio to address discrepancies. Data were analyzed using an inductive thematic analysis approach consisting of two cycles of structured coding in NVivo 11 [21, 22]. First cycle coding used sentence-by-sentence coding of 20% of the interviews; the resulting codes were then condensed into a coding scheme [22]. To refine the structure, an additional 20% of interviews were coded, resulting in a finalized coding scheme. To test inter-coder reliability, ARW and KM double-coded an additional 20% of the interviews to identify coding discrepancies [22]. All interviews were then coded into the coding scheme sentence by sentence by ARW and KM. To identify differences in health insurance literacy and perceptions of health insurance, after all interviews were coded, thematic content areas were stratified by age (younger vs. older) and policy holder (own policy holder vs. dependent).

Survey items and analysis

Prior to the interview, participants filled out a brief survey with demographic factors, health insurance information, and the health insurance literacy measure (HILM). The HILM is a 21-item validated tool designed to capture health insurance and cost literacy with 4 sub-sections including confidence choosing ($\alpha = 0.93$), comparing plans ($\alpha = 0.96$), confidence using ($\alpha = .0.93$), and being proactive ($\alpha = 0.80$). The HILM composite score ranges from 0 to 84 with higher scores indicating greater literacy. HILM scores and descriptive statistics were calculated by age strata (18–25 years, 26–39 years) using STATA 14.2 [23].

Results

Participants ($N = 24$) were nearly split by gender (female 58.3%), primarily heterosexual (91.7%), non-Hispanic White (79.2%), and had at least some college education (91.6%). Less than half of participants were the policy holder of their health insurance (41.7%), and many were receiving treatment at the time of the interview (65.2%). Most AYA survivors were close to their original diagnosis date with a range of 0–6 years and a median time since diagnosis of 1 year. The mean age of survivors at diagnosis was 25.7 (SD, 6.8; range, 15–39); at diagnosis, younger survivors were a mean age of 20.5 (SD, 3.0; range, 15–25), and older survivors were a mean age of 31.7 (SD, 4.4; range, 26–39). Most demographics were similar between younger and older survivors except for education and policy holder status, as older survivors had more education and were more commonly their own policy holder. Overall, the mean HILM score was 55.6 (SD, 10.1; range, 31–75) [23]; younger AYAs had a mean HILM score of 53.9 (SD, 11.1), and older AYAs had a mean HILM score of 57.3 (SD, 9.1) (Table 1).

Thematic analysis resulted in four distinct themes regarding AYA survivors' experience with health insurance (Fig. 1). Theme one, low health insurance literacy, describes how participants commonly began their cancer treatment with low knowledge and confidence of health insurance and costs. This directly led to the three remaining themes: in theme two expectations of out-of-pocket costs: "a rude awakening," survivors reported unclear expectations of what their insurance would cover and their out-of-pocket costs. In theme three, learning about health insurance and out-of-pocket costs, most survivors reported learning about insurance and costs by trial and error throughout their cancer treatment. Finally, theme four, challenges navigating healthcare and insurance systems, explores how low health insurance literacy affected participants' ability to navigate the healthcare system, particularly during treatment. Upon stratified review of thematic content, few differences were observed by age group or policy holder status. Thus, results are described in aggregate unless otherwise noted.

Low health insurance literacy

AYA survivors commonly expressed a lack of understanding about their health insurance and costs that they first experienced during their cancer treatment. For most participants, cancer was their first high-cost experience with the healthcare system. This lack of knowledge ranged from not understanding the purpose of health insurance, as a whole, to more granular topics including appeals, provider networks, and how coverage translates to out-of-pocket costs. One survivor stated "I thought there was going to be more that I understood [about health insurance], but I think that's it. Yeah, I just know that there was a deductible." This confusion was shared by another survivor who stated: "I think health insurance is completely confusing. I would say, knowing the copay structures [is something I don't understand well]. I still haven't figured that out."

It was common for survivors to use insurance terminology incorrectly throughout the interview when discussing their experiences. Terms that the researchers interpreted as being used incorrectly most often were *deductible*, *coinsurance*, and *out-of-pocket maximum*. While insurance was deemed confusing by most participants, younger survivors who were not their own policy holder used more health insurance terms incorrectly compared to older survivors who were typically their own policy holder.

Expectations of out-of-pocket costs: "a rude awakening"

Nearly all survivors were surprised by their treatment costs and how little their insurance covered. One survivor stated, "I don't know what I thought, but I had never really dealt with insurance, so I was like, 'Oh, we pay every month. We pay a pretty good amount,' so I thought we were just going to be covered and everything's going to be awesome. It was just like a rude awakening." Another survivor reported: "I'm shocked. Absolutely shocked. It [Out-of-pocket costs] can bury somebody."

Several survivors had experienced their insurance denying certain aspects of their cancer treatment, which they did not expect. These experiences included denials for surgeries, genetic testing, and out-patient prescription medications. While most denials experienced by survivors were successfully appealed, a few participants paid out-of-pocket

Table 1 Sociodemographic and health insurance factors by age among adolescent and young adult (AYA) cancer survivors ($N = 24$)

	Total ($N = 24$)		Age at diagnosis			
			Younger AYAs (15–25 years) ($N = 12$)		Older AYAs (26–39 years) ($N = 12$)	
	N	%	*N*	%	*N*	%
Treatment status[a]						
On treatment	15	62.5	6	50.0	9	81.8
Off treatment	8	33.3	6	50.0	2	18.2
Gender						
Male	10	41.7	6	50.0	4	33.3
Female	14	58.3	6	50.0	8	66.7
Education						
College graduate or higher	8	33.3	1	8.3	7	58.3
Some college	14	58.3	9	75.0	5	41.7
High school education or less	2	8.3	2	16.7	0	0
Race/ethnicity						
Non-Hispanic White	19	79.2	9	75.0	10	83.3
Hispanic White	4	16.7	2	16.7	2	16.7
Non-Hispanic racial minority	1	4.2	1	8.3	0	0
Sexual orientation						
Sexual minority	2	8.3	1	8.3	1	8.3
Heterosexual	22	91.7	11	91.7	11	91.7
Health insurance status at survey[b]						
Private insurance	21	87.5	10	83.3	11	91.7
Public insurance	5	20.8	1	8.3	4	33.3
I don't know	1	4.2	1	8.3	0	0
Health insurance policy holder						
Self	10	41.7	1	8.3	9	75.0
Spouse	3	12.5	0	0	3	25.0
Parent	11	45.8	11	91.7	0	0
	Mean	SD	Mean	SD	Mean	SD
Health insurance literacy measure (HILM)	55.6	10.1	53.9	11.1	57.3	9.1

[a] Missing $N = 1$

[b] Percentages add up to more than 100% as some participants had more than one health insurance coverage type (i.e., public and private)

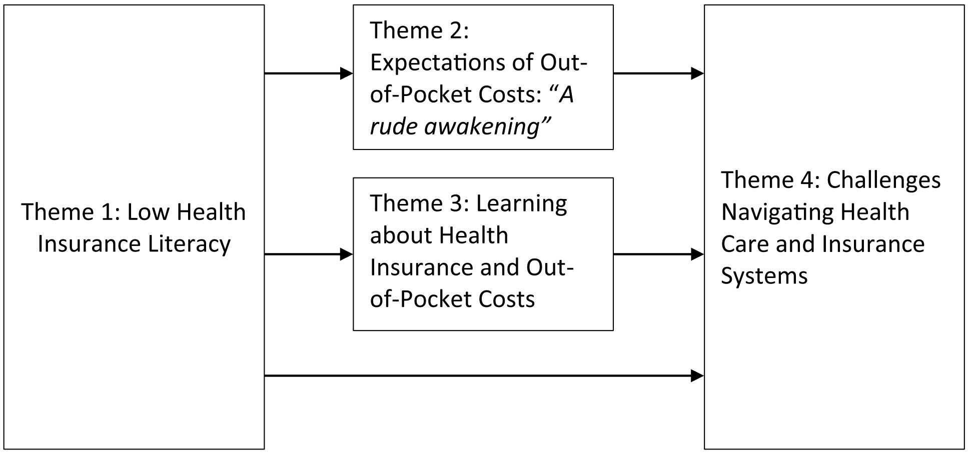

Fig. 1 Adolescent and young adult cancer survivors' health insurance literacy, costs, and healthcare

for denied services (discussed further in theme four: navigating the complexity of the healthcare system and insurance). Female survivors sometimes expressed dissatisfaction about the lack of insurance coverage for fertility preservation; this was not an issue described by male participants.

Interestingly, a minority of survivors expressed that they expected their treatment to be more expensive than it was. They were pleasantly surprised that their out-of-pockets costs were lower than anticipated. Survivors who thought their insurance was going to cover less than it did expressed similar levels of insurance knowledge as those who experienced high out-of-pocket costs.

Learning about health insurance and cost

Prior to their cancer diagnosis, only a few survivors reported ever being taught about health insurance, such as from a parent. However, more AYAs reported learning about health insurance through trial and error during treatment. A survivor shared, “I think I understand it [health insurance] a little better. Just as I’ve gone to more doctor’s appointments like I found I understand it a little bit more.” Learning through experience was particularly common for older AYA survivors who were their own policy holder. One older AYA survivor shared how they gained a better understanding of how different plans can impact their out-of-pocket costs, stating “So, yes, now that I’ve gone through cancer the next time I go and buy [health insurance] I’ll have to look at so many factors that I just found I never considered before.”

AYA survivors reported seeking information on health insurance from a variety of sources including asking family, friends, and coworkers; searching online, including on their insurer’s website; and asking healthcare providers directly. In general, survivors found the process of obtaining information about their specific insurance to be arduous. Thus, they commonly enlisted caregivers to help them seek information about their health insurance. One survivor shared “Honestly, my husband, he loves to do research and so he calls a lot of people and calls around and stuff and he enjoys that. So, luckily I have him, but if I didn’t I’d be screwed.”

When seeking information regarding health insurance, it was difficult for survivors to find trustworthy and accurate information. One older AYA survivor shared their experience with a health insurance broker informing them that a health share, which often does not cover cancer care costs, would be their best option: “The first guy [broker] that helped us got me on one that didn’t actually cover anything. It was a [health] share. So, I had to actually wait an extra month longer than my doctor wanted to wait [to begin treatment].” Another survivor reported picking a high deductible plan that resulted in higher out-of-pocket costs during treatment, because a co-worker recommended it: “I actually asked the women that I work with what they do because they have families, and they know a little bit more about [health insurance].”

Challenges navigating the healthcare and insurance systems

Challenges navigating healthcare occurred for survivors, from scheduling appointments to filing appeals to their insurer for their cancer treatment. These circumstances often stemmed from difficulty using their insurance, knowing what was covered, and understanding where they could go for healthcare. For example, some survivors reported not understanding how to find out which providers, hospitals, or systems were in-network for their specific insurance plan. Several survivors reported delaying appointments when diagnosed because they were not sure if their insurance would cover their appointment, service, or provider. One survivor reported not being unable to confirm whether their provider was in-network from either their insurer or their hospital resulting in multiple delays to the start of treatment. As a result, they missed care: “Yeah, so lately when I don’t know because I don’t really know who to ask, so I’ll just cancel the appointment.” Another survivor discussed having to delay surgery due to an issue with coverage and the potential implications: “And so, we don’t know, but there’s potential that if I would have had surgery earlier, then it wouldn’t have spread to my lymph nodes, and I could have avoided chemotherapy.”

Other AYAs reported receiving medical services without knowing if those services would be covered. One older AYA survivor reported receiving surgery prior to receiving confirmation of preauthorization. They shared “We didn’t find out [if it was covered] though until after my surgery. So, we were just like, ‘Well, we’re doing the surgery regardless if we’re going to pay a gazillion dollars.’ And then, they just came back and told us they were going to pay half, which was awesome, but also sad at the same time because it’s a really expensive bill.” Another younger AYA survivor shared that they were referred to see an oncofertility specialist prior to starting their treatment and did not realize that their insurance would not cover the costs: “They just wouldn’t cover any of it [fertility preservation] and it’s expensive, the consult visits, like I spent a couple of hundred just to go hear about it. I was like, ‘Oh, heck no.’”

Furthermore, most survivors reported having claims denied and difficulty navigating the appeals process. Some survivors reported receiving a letter with their bill informing them that they could appeal. One survivor stated, “So I did have some appeal thing come up and I was confused because I was getting paperwork about it [that I didn’t know what to do with].” Others found out about appeals from their providers. A minority of survivors reported paying out-of-pocket for denied services and medications. Additionally, for many survivors, it was difficult and stressful coordinating an appeal between the insurer and the hospital. One survivor shared their frustration, saying "It was just a lot of back-and-forth. We would call the insurance… it always felt like they honestly weren't working on it or we were talking to someone new always… and then, we would call the hospital and we would get frustrated too just because they'd want to talk to our insurance. And, it was just a hot mess."

Discussion

Young adults often have low health insurance literacy and minimal experience with the healthcare system [11, 13]. AYAs who struggle to understand and use their health insurance could face debilitating out-of-pocket costs. In our qualitative study of survivors of AYA cancer with access to patient navigation, we found that survivors struggled with understanding their insurance coverage and costs. Moreover, some made the difficult decision to delay cancer care because they did not know what was covered by their insurance plan. Many participants struggled with accessing important consumer protections, such as appeals, that could help them to manage their costs. At the same time, consistent with our findings, costly but critical services like oncofertility care remain unaffordable even for insured AYAs, specifically female survivors or survivors who have a uterus as fertility preservation procedures are much more costly for this group [25]. While these findings should be interpreted cautiously due to our limited sample, our study points to a critical need to further research on how insurance knowledge may hinder access to care for AYA cancer survivors.

AYAs in our study reported substantial gaps in understanding of their own health insurance policies, as well as health insurance in general. The average health insurance literacy measure scores of the younger (53.9) and older (57.3) AYAs were lower than an insured, general population sample (63.5) [26]. While older AYAs who were often their own policy holder reported a greater understanding of their health insurance, nearly all AYAs in the study reported health insurance literacy below the general population mean [26]. This finding warrants future research to understand AYA cancer survivors' health insurance literacy on the population-level and highlights the importance of health insurance education among the AYA cancer population. Further, future inquiry should explore the associations between low health insurance literacy and potentially severe outcomes such as delaying care and increased out-of-pocket costs among AYA survivors.

Very few AYAs in our study reported ever being taught about health insurance prior to their diagnosis. Rather, they learned by trial and error during their cancer treatment, which was often confusing and expensive. This experiential learning along with AYAs' stage of life (e.g., still in college, obtaining financial independence) [27, 28] may leave them vulnerable to additional financial burden during and after their cancer. Current models of financial burden among AYA cancer survivors suggest that AYA financial burden may have a "ripple effect" impacting survivors' quality of life, morbidity, and mortality after treatment [29]. Our findings in the context of this model suggest that patient-level interventions to increase AYA survivors' health insurance literacy may alleviate short-term and long-term financial burden experienced by AYAs. Further, oncology care teams could assist AYA survivors in navigating their health insurance by initiating conversations about coverage of services, budgeting, and managing out-of-pocket costs [30]. However, some providers may also require education to feel fully equipped to facilitate such conversations [31].

Some AYAs delayed treatment and cancelled appointments because they did not know if services were covered by their health insurance. At least one participant even delayed the start of their treatment due to being enrolled in a health share that did not cover cancer care during the diagnostic process. Among all AYAs' higher rates of being underinsured and uninsured are key drivers in delays to diagnosis, which in part likely contributes to the lower survival rates among this age group [32]. In our study, helplessness and fear of high out-of-pocket costs were expressed by many AYAs who were unable to find out if their care was going to be covered by their insurance. Some AYAs in our study reported receiving care without receiving prior authorization or knowing if their insurance would cover the care. Receiving high-cost cancer care without receiving notification of if those services will be covered enters AYAs into potentially avoidable and financially devastating situations. Our study suggests that the complexity of using insurance contributes to disparities for AYAs.

While financial toxiburden can result in serious implications such as bankruptcy [33, 34], our findings suggest that neither acute nor long-term financial impacts of treatment were at the forefront of most AYAs' decision-making during treatment. This finding can be contextualized in AYAs' developmental stage of life [27, 28], specifically, being in the process of gaining financial independence. AYAs in our study were commonly surprised by their cost of cancer care. Those who had aged out of dependent coverage may encounter the perfect storm of a lack of experience with healthcare systems, low health insurance literacy, unclear expectations of their out-of-pocket costs, and minimal consideration of financial impact of care, leaving them highly vulnerable to financial toxburden. These findings are consistent with the literature that indicates AYAs are at a high risk of financial burden [35, 36] but expand on the different facets of health insurance and health insurance literacy that have the ability to impact AYAs' financial toxiburden.

Health insurance education is an important avenue to supporting AYA cancer patients which should involve key stakeholder such as insurers, health systems, providers, patients, and care partners. Health insurers should deploy plan structures that are easier for consumers to understand and navigate. The consumer experience with insurers is often complicated. The burden is placed on patients to navigate their plans, during a time when getting care quickly can be critical. For example, the intent of cost sharing mechanisms such as copayments and deductibles is for patients to be cognizant of their healthcare utilization; however, such mechanisms can make it confusing for patients to understand what they may have to pay for and can even deter patients from receiving needed care [37]. Beyond large-scale structural changes to the health insurance system, our findings suggest that clinic- and patient-level health insurance literacy interventions may be key to improving AYAs' quality of care and mitigating long-term financial issues [38, 39]. Further, our study suggests younger AYAs may be less knowledgeable about health insurance but may be more likely to be protected financially as a dependent on parental coverage, while older AYAs may be at higher risk of experiencing severe financial outcomes due to poor understanding of their health insurance, suggesting that services may need to be tailored by age.

Limitations

Our study has certain limitations. No currently uninsured AYAs were included in the sample as our focus was on health insurance literacy. The lack of health insurance is a major barrier to receiving cancer care and can lead to much more severe financial outcomes. Further, our sample was small, fairly homogenous (i.e., non-Hispanic White), and generally well-educated, limiting the representation of perspectives from more diverse populations. Lastly, our analysis only included patient-reported descriptions of their out-of-pocket costs rather than actual cost data. Future studies should include patients actual out-of-pocket cost data in comparison with their perceptions of their out-of-pocket costs.

Conclusion

High medical financial burden is experienced by AYA cancer survivors across the world, even among those in countries with universal insurance and payment models [40]. Our findings explore how health insurance literacy — which is a critical skill for navigating the complex US healthcare system — affects AYA survivors' cancer care experiences, financial toburden, and treatment adherence. Most of our participants reported that they had very low health insurance literacy. As a result, AYAs in our study skipped appointments, delayed care, and reported receiving high-cost services without notification of coverage. These potentially dangerous and financially devastating responses to navigating complex health systems may be mitigated with system-level changes to insurance complexity. However, larger population-level studies focusing on the impacts of health insurance literacy are needed. To our best knowledge, health insurance literacy among AYA cancer survivors has not been explored in other countries with different payment structures; future inquiry should explore the influence of health insurance literacy on financial burden and treatment adherence among AYA survivors in other countries. Beyond larger changes to health insurance policy, testing patient-based health insurance education interventions may increase their ability to successfully navigate health systems, use their insurance to the fullest, and avoid unnecessary out-of-pocket costs.

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Author contribution All authors contributed to project conceptualization and methodology. ARW, KM, PLVL, and ACK were responsible for project administration. ARW, KM, HK, ACK, and ELW were responsible for formal analysis and visualization. ERP and ACK provided supervision. ARW was responsible for writing—original draft. All authors were responsible for writing—review and editing.

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Data availability N/A.

Code availability N/A.

Declarations

Ethics approval Ethics approval was provided by the University of Utah Institutional Review Board (IRB#00091443).

Consent to participate All participants participated in the informed consent process prior to participating in the study.

Consent for publication All data is reported in aggregate and is deidentified; thus, consent to publish was not obtained from participants.

Conflict of interest The authors declare no competing interests.

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