Adolescent and Young Adult Cancer Survivors' Valuation of Post-Treatment Recommended Care

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Purpose: Examine whether survivors of adolescent and young adult (AYA) cancer value recommended post-treatment care using focus groups and a willingness to pay (WTP) survey. WTP, a measure of value, indicates the dollar amount individuals are willing to pay to use a service.

Methods: Participants were recruited through the Utah Cancer Registry. $N=28$ survivors diagnosed with cancer at ages 15–39 and currently aged ≥ 18 participated in focus groups, and $N=4$ in phone interviews (participation rate = 50%). All participants responded to a demographic survey and WTP questions based on one-time and monthly payments for annual visits. Focus group participants responded to an open-ended question on the value of follow-up care. Interval regressions identified factors associated with WTP. Qualitative analysis summarized themes for the open-ended question.

Results: Focus group participants reported valuing follow-up care as it brings peace of mind and helps them manage their health. Yet, 38% reported not having a cancer-related visit in the previous year. Only 27% and 43% of survivors agreed to pay any one-time and monthly payments, respectively. The monthly payment mean WTP was \$41 (95% confidence interval [CI]: 31–84), equating to \$494 annually, which is greater than the mean WTP for one-time payment (\$362, 95% CI: 293–432, $p < 0.001$), suggesting that survivors may prefer monthly payments. Several factors, including being female and in better health, predicted higher WTP.

Conclusion: Many AYA cancer survivors report not visiting their doctors annually for post-treatment care despite verbally valuing care. Models that demonstrate high quality and distribute costs over time should be evaluated to encourage survivors to receive recommended care.

Keywords: adolescent and young adult, cancer, survivors, follow-up care, values, willingness to pay

Introduction

INNOVATIVE CARE MANAGEMENT strategies are required to meet the medical needs of the growing population of survivors of adolescent and young adult (AYA) cancer, defined as those diagnosed between 15 and 39 years of age.^{1–3} AYA cancer survivors are at risk for late effects, such as second cancers and heart disease, which can develop due to the original cancer or exposures to therapeutics during treatment.^{4–6} Survivors need regular follow-up care that includes a review of their medical history and previous therapies along with a physical exam.⁴ Many AYA survivors

transition from oncology care to primary care providers who may be unfamiliar with their unique risks and medical needs,^{7–9} which may result in fragmentation of care. Providing survivorship-focused care in an efficient way that incorporates survivors' preferences is an important area of ongoing research.^{10,11}

Along with asking survivors whether they value recommended care, one way of evaluating their values and preferences is to estimate willingness to pay (WTP), which is the dollar amount that individuals will pay to use a service.^{12–14} WTP is increasingly being used to understand value in healthcare,^{15–17} and preferences for cancer treatment and

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screening.^{14,18–21} Previous studies have recommended using WTP for economic evaluation of oncology products.^{22,23} To our knowledge, WTP has not been used to understand AYA cancer survivors' values of follow-up care.

WTP estimates that reflect AYA survivors' preferences for follow-up visits can help to identify potential barriers to care and inform decision-making for implementing effective AYA-focused survivorship care. AYA cancer survivors frequently report that high medical costs and lack of insurance are barriers to healthcare utilization.^{5,24} Therefore, the amount and mode of payment (e.g., paying monthly vs. annually for medical visits) may influence survivors' behavior, especially for those with limited incomes. While an annual payment may be more convenient, a monthly payment may be preferred since payments are distributed across 12 months. In addition, examining determinants of WTP, such as how socioeconomic characteristics influence valuation, can aid in identifying patient-centered strategies to promote healthcare-seeking behavior among survivors who may be at risk for foregoing recommended care.

This study reports results from focus groups and a WTP survey with AYA survivors on their valuation of recommended follow-up care. We first summarize focus group themes associated with the reasons that survivors value long-term follow-up care. Then, we estimate and compare survivors' mean WTP for paying for annual visits using two payment scenarios (i.e., once annually vs. monthly), and identify survivor characteristics that may influence WTP.

Materials and Methods

Patient recruitment

The Utah Cancer Registry (UCR) randomly identified 200 survivors of AYA cancer ensuring they met the following criteria: (1) diagnosed between 15 and 39 years after January 1, 2006, (2) aged 18 years or older, (3) at least 1 year from diagnosis, (3) alive and current residents of Salt Lake or Washington Counties, (4) able to read and speak English, and (5) not diagnosed with non-melanomatous skin cancer or *in situ* cancer. The UCR contacted patients directly by mailing a study introductory cover letter and consent to contact form with postage-paid envelope. Patients who did not respond to the mailing within 2 weeks were contacted by phone up to three times at varying times of the day and week. Given no response, a second mail was sent. If there was no response within 2 weeks of this mailing, survivors were contacted by phone, up to three times at varying times of the day and week. Eligible survivors who provided their consent to be contacted were then contacted by our study team by calling or emailing up to six times. Participants were compensated for their time with a \$25 gift card. The University of Utah IRB approved all recruitment and study procedures.

Study procedures

After providing informed consent, participants completed a self-reported survey (containing questions on demographics, follow-up visit frequency, and general health status), participated in group discussions, and responded to the WTP questions. A few participants who could not attend our focus groups participated in phone interviews. The phone interview

participants completed the survey and WTP questions, but did not participate in group discussions. Group discussion script, survey items, and WTP questions were pilot tested with four AYA cancer survivors.

The objective of the focus group sessions was to generate discussion on valuation of recommended care. An experienced moderator facilitated the focus groups. The funnel approach, going from general to specific questions, was used to generate discussion.²⁵ After briefly describing follow-up care, participants were asked "In your opinion, do cancer survivors value follow-up visits?" Focus group script (follow-up care description, question, and probes) relating to value of follow-up care and WTP questions are presented in Supplementary Appendix (Supplementary Appendix are available online at www.liebertpub.com/jayao). Focus groups were recorded and transcribed verbatim.

Measures

The survey included questions on demographics (e.g., age at study, sex, and annual household income pre-tax) and cancer (e.g., age at diagnosis). Survivors were also asked to rate their general health by asking: "In general, would you say your health is excellent, very good, good, fair, or poor?" Response to this question was coded in a binary fashion, that is, excellent or very good versus good or fair (none of the survivors rated their health as poor). The survey also asked survivors when did they have their most recent routine check-up related to their cancer or cancer treatment (response: <3 months ago, 3–6 months ago, 6–12 months ago, 1–2 years ago, 2–5 years ago, or never).

The WTP questions were structured to elicit participants' WTP for annual visits with their treatment doctor for the next 5 years. Participants responded to two scenarios sequentially—a one-time annual payment scenario followed by a monthly payment scenario. Before responding, participants were instructed to assume that their insurance would not cover the visits (see Supplementary Appendix), and to consider their budget, to mitigate overstatement of WTP.^{26–29} In both payment scenarios, the first question asked respondents whether they would pay a dollar amount (the bid amount) for annual visits. If a respondent agreed to pay the first bid, they were directed to a follow-up question that asked if they were willing to pay double the original bid amount. Conversely, if a respondent was not willing to pay the first bid, they were directed to a follow-up question that presented half the original bid amount (this is called a double-bounded format).^{30–32} Each respondent received annual and monthly bids sequentially, where the monthly bid was 1/12th of the annual bid. Three annual bid amounts were randomized across AYA cancer survivors who participated in our focus groups and phone interviews: \$120, \$240, and \$480. The corresponding monthly bids for these annual amounts were \$10, \$20, and \$40. Consider an example here—if a respondent received \$120 as the annual bid, the monthly bid was \$10. The annual bid amounts were determined using the average cost for an office visit (approximately \$300) at the Pediatric Cancer Late Effects Clinic at the Huntsman Cancer Institute, (Salt Lake City, UT), as a benchmark. Finally, an open-ended question asked respondents to write down the most important reason that influenced their WTP decisions.

Qualitative analysis

All six focus group discussions were transcribed and then coded in NVivo Version 10. The first focus group transcript was reviewed by a researcher (S.K.) who created a coding scheme using conventional content analysis to generate a thematic structure.³³ This coding scheme was discussed with two other members of the team (E.R.Z., R.R.S.) and revised. The first transcript was then consensus coded by the three researchers using the revised coding scheme. Edits were made to the scheme based on the outcomes of the first coding. The remaining five focus group transcripts were coded independently by two researchers (E.R.Z. and R.R.S., percent agreement = 97.8%) with discrepancies resolved as a group.

Statistical analysis

Summary statistics of survivor demographics (sex, age at study, age at diagnosis, marital status, and annual household income) and health-related (general physical health: excellent/ very good vs. good/fair, and number of days during the previous 30 days when survivor's physical health was not good) characteristics were computed. We also summarized information on the most recent visit to doctor's office related to their cancer or cancer treatment.

An interval regression was used to examine WTP.^{19,34} For each individual, WTP intervals for one-time and monthly payment scenarios were created using their responses to the first and follow-up bid amounts as: (1) $WTP \geq 2 \times BID$ (response: yes to both the first bid and second higher bid), (2) $BID \leq WTP < 2 \times BID$ (yes to first bid and no to second higher bid), (3) $BID > WTP \geq BID/2$ (no to first bid and yes to second lower bid), and (4) $WTP < BID/2$ (no to both the first and second lower bids). The interval regression models the probability that the actual WTP lies within these specified intervals. Independent variables included demographic and health-related factors mentioned above. Coefficients of this regression indicate by how much WTP varied across independent variable categories. The predicted values from this regression were used to estimate the mean WTP and 95% confidence intervals (CIs). For comparison purposes, the mean monthly payment was multiplied by 12 to compute annual WTP resulting from the monthly scenario. A paired *t*-test was used to compare the annual mean from one-time and monthly payment scenarios.

We also summarized the most important reasons that participants gave for their WTP responses according to the first bid response in both the payment scenarios. Quantitative analyses were conducted in Stata 13.0 (StataCorp LP, College Station, TX).

Results

Study sample

Figure 1 presents information on our study sample. Of the 200 survivors of AYA cancer who met our study criteria and were identified by the UCR, 69 did not respond and 10 declined to participate, and the UCR was unable to deliver mailings to 57 individuals making them ineligible. Our team contacted the 64 eligible participants who provided their consent—28 participated in one of six focus groups from March to August 2015 (four focus groups in Salt Lake City, UT and two in St. George, UT), and four survivors who were

FIG. 1. Flow diagram for study sample. ^aPlease see the text for our study criteria.

unable to attend focus groups participated in phone interviews. Therefore, the sample size for our study was 32 (participation rate = 50%). Of the survivors contacted by our study team, 2 declined and 30 were lost to follow-up.

Survivor characteristics

Over half of the participants were female, 53.1% were 19–30 years of age (Table 1). 43.7% were diagnosed with cancer at ages 21–30, 31.3% at 15–20 years, and 25.0% at 31–37 years. The majority of the survivors were non-Hispanic White ($n = 28$, 87.5%), and 68.7% ($n = 22$) were working full time, 15.6% ($n = 5$) were working part time, 6.2% ($n = 2$) were unable to work due to disability/extended illness, and 9.4% ($n = 3$) were not seeking work as they were caring for home/family (not reported in the table).

Over 50% reported their general physical health as excellent or very good and 46.9% as good or fair. On average, survivors reported close to 4 days (standard deviation = 6.8) in the previous month when their physical health was not good. Thirty-four percent reported having a cancer-related doctor's visit in the previous 6 months, 28% 6–12 months ago, 28% in 1–2 years ago, and 10% 2–5 years ago (not reported).

Value of follow-up care

Themes from the focus group discussions fell into two areas: personal versus provider reasons (Table 2). Personal reasons included feeling that follow-up care would bring peace of mind. Survivors felt reassured after a follow-up visit confirmed that their cancer had not returned or spread. One survivor described this as: “I think, also, it's that peace of mind that it allows, where you live a life where you're consumed with the what-ifs, but having the follow-up visits kind

TABLE 1. CHARACTERISTICS OF SURVIVORS OF ADOLESCENT AND YOUNG ADULT CANCER

<i>Demographics</i>	<i>N (%)</i>
Sex	
Male	14 (43.7)
Female	18 (56.3)
Age at study (years)	
19–30	17 (53.1)
31–45	15 (46.9)
Age at diagnosis (years)	
15–20	10 (31.3)
21–30	14 (43.7)
31–37	8 (25.0)
Marital status	
Married	16 (50)
Single, never married or separated	16 (50)
Annual household income (\$)	
≤25,000	9 (28.1)
25,001–50,000	7 (21.9)
50,001–100,000	10 (31.3)
>100,000	6 (18.6)
Physical health	
General Physical Health	
Excellent or very good	17 (53.1)
Good or fair	15 (46.9)
Days of poor physical health in the previous month, mean (SD)	3.75 (6.8)

SD, standard deviation.

of reassures you ... that the cancer has subsided and it's not continuing to spread."

Others felt that follow-up visits helped in managing their health and to provide early detection of other health conditions that may develop as a result of their cancer or cancer therapy. This was described by one survivor as a way of

feeling in charge of their health as: "It's a proactive way of making sure that we are safe. For me, my cancer is really latent and probably the easiest to beat, but the problem is how I control my health."

A related idea was the need to have better guidance for future concerns. Specifically, visits helped survivors identify potential side effects: "Yeah, the beneficial thing about follow-up visits is you don't really know how to expect or anticipate the side-effects that come from cancer, and so as you're experiencing those, through follow-up, the doctors are able to help you overcome those challenges."

Survivors also reported provider-related reasons for valuing follow-up care. The most salient reason was sharing a good relationship with their providers, which extended beyond clinical relationship to a key source of social support: "I don't mind going back and seeing the people that I spent a lot of time with because it's kind of like a little close family to me."

Some survivors indicated that they valued follow-up care because they felt their doctor did a good job of providing recommended care, which increased their confidence. One survivor stated that during his visits, "[the doctor] would always go back to the cancer institution's recommended scheduled visits, and what they recommend based on my diagnosis. It kind of took out the emotion of it, and it was this is why they recommend it, this is why we prescribe it." That is, clear recommendations from providers were a key to survivors' feeling as though they had good guidance for their healthcare after treatment ended.

Willingness to pay results

For the one-time payment scenario, 26.7% agreed to pay both the first and second bids and 13.3% refused to pay both the bids. In the monthly payment scenario, 43.3% agreed to pay both the first and second bids and 13.3% refused to pay both the bids. Based on the regression results, the mean WTP for the annual payment was \$362.8 (95% CI: 293.3 to 432.4). The mean for the monthly payment was \$41.2 (95% CI: 30.6 to 83.8), which equates to \$494.3 (95% CI: 416.8 to 571.8) annually. The 12-month mean from one-time and monthly payment scenarios were statistically different ($p < 0.001$).

Female survivors were willing to pay more for one-time and monthly payment plan than males (Table 3: annual = 175.9, 95% CI: 10.9 to 340.9, $p = 0.04$; monthly = 24.4, 95% CI: 4.8 to 43.9, $p = 0.02$). Survivors who rated their health as good/fair were also willing to pay more (annual = 251.1, 95% CI: 65.9 to 436.4, $p = 0.01$; monthly = 22.9, 95% CI: 0.5 to 45.4, $p = 0.05$) than those who rated their health as excellent/very good. Greater time, since the last check-up, had a negative influence on WTP, meaning that survivors who had cancer-related visits more recently had higher WTP (annual = -138.1, 95% CI: -222.4 to -53.7, $p = 0.001$; monthly = -11.3, 95% CI: -21.6 to -1.1, $p = 0.03$). No other variables, including time since diagnosis, were related to WTP.

Of participants who refused to pay the first bids, common reasons included income constraint (Table 4: 33.3% vs. 37.5% for one-time and monthly payments, respectively), and that the visits were costly (13.3% vs. 12.5% for one-time and monthly payments, respectively). Twenty percent of those who refused to pay the first bid in one-time payment scenario reported that they felt that they were at low risk for health problems or visits were unnecessary.

TABLE 2. THEMATIC STRUCTURE FOR VALUE-BASED DISCUSSIONS

<i>Themes</i>	<i>Explanation</i>
Personal	
Peace of mind	Follow-up visits help in detecting the recurrence or spread of cancer. To know that cancer is not recurring or spreading is reassuring.
Physical health	Follow-up visits help in managing physical health and identifying (i.e., early detection) late effects of chemotherapy and cancer.
Provider specific	
Relationship with providers	Survivors share a good relationship with their providers (doctor or nurse). Therefore, they value follow-up visits.
Adherence to medical guidelines	Follow-up visits are beneficial as doctors follow recommended medical guidelines, which increases survivors' confidence in these visits.

TABLE 3. INTERVAL REGRESSION RESULTS FOR WILLINGNESS TO PAY

	One-time payment			Monthly payment plan		
	Coefficient	95% CI	p	Coefficient	95% CI	p
Sex						
Male (ref)						
Female	175.9	10.9 to 340.9	0.04	24.4	4.8 to 43.9	0.02
Age at study (years) ^a	135.9	−56.2 to 328.0	0.17	4.5	−17.5 to 26.6	0.40
Marital status						
Married (ref)						
Single, never married, or separated	42.8	−151.2 to 236.8	0.67	−2.8	−25.4 to 19.8	0.81
General physical health						
Excellent or very good (ref)						
Good or fair	251.1	65.9 to 436.4	0.01	22.9	0.5 to 45.4	0.05
Days of poor physical health in the previous month ^a	−10.7	−23.0 to 1.6	0.09	−1.1	−2.6 to 0.3	0.13
Last check-up (years) ^a	−138.1	−222.4 to −53.7	0.001	−11.3	−21.6 to −1.1	0.03
Time since diagnosis ^a	21.6	−29.6 to 72.7	0.41	−0.9	−7.2 to 5.4	0.78

An interval regression was used to identify predictors of WTP. The dependent variable was a censored WTP variable, which was created using participant responses to the first and follow-up question. Regression coefficients indicate by how much WTP varied across independent variable categories. For example, on average, female survivors were willing to pay approximately \$176 more than their male counterparts as annual one-time payment toward follow-up care. Income was excluded from both regressions since its marginal effect on WTP approached 0. Bold values are statistically significant at alpha=0.05 level.

^aAge at study and last check-up were included as linear terms. Days of poor physical health in the previous month and time since diagnosis (age at study−age at diagnosis) were included as continuous variables.

CI, confidence interval; WTP, willingness to pay.

TABLE 4. REASONS THAT INFLUENCED WILLINGNESS TO PAY

Themes	%
One-time payment	
Individuals who agreed to pay the first bid (N=15, 50.0%)	
Follow-up visits are important (7)	46.7
Cost is affordable (2)	13.3
Would pay the lower amount (2)	13.3
Money over health (1)	6.6
Individuals who refused to pay the first bid (N=15, 50.0%)	
Income constraint (5)	33.3
Minimal risk or unnecessary visits (3)	20.0
Cost vs. benefit decision (2)	13.3
Costly (2)	13.3
Monthly payment plan	
Individuals who agreed to pay the first bid (N=23, 74.2%)	
Cost is affordable (10)	43.4
Easy to pay than one-time (6)	26.1
Follow-up visits are important (3)	13.0
Comfortable as I can leave the payment plan any time (2)	8.7
Individuals who refused to pay the first bid (N=8, 25.8%)	
Income constraint (3)	37.5
Costly (1)	12.5
Need personalize care (1)	12.5
Not required (1)	12.5

We asked respondents an open ended question about the most important reasons that influenced their response WTP question. In this table, we summarize themes separately for those who agreed and refused to pay the first bids for annual one-time payment and monthly payment plan.

Discussion

This study used two methods (focus groups and WTP survey) to understand AYA cancer survivors' valuation of post-treatment recommended care in a single state in the United States. Survivors reported that they value having access to follow-up care as it brings peace of mind and helps them to better manage their health. In our focus group discussions, survivors who reported good relationships with their healthcare providers indicated valuing follow-up care, and providers' adherence to recommended medical guidelines increased survivors' confidence. While our focus groups indicated that survivors value follow-up care, 38% reported that they had no cancer-related visits in the previous year. Our assessment begins to identify both survivor-specific factors and healthcare-related gaps that may prevent AYA survivors from seeking recommended care.

Using WTP provided an innovative measure of strength of survivors' preferences associated with follow-up care. We estimated survivors' WTP for annual visits with their treatment doctor using two payment scenarios—one-time payment and monthly payment plan. On average, survivors were willing to pay \$362 as one-time annual payment and over \$41 as monthly payment (\$494 for 12-month period). The monthly plan yielded a higher annual WTP than the annual payment, perhaps because survivors feel more comfortable paying when the amount is spread over time. In fact, many survivors reported that the monthly plan was affordable and easy to handle, and could also act as a reminder to schedule visits. These findings suggest that medical facilities targeted to survivors should examine the impact of flexible payment mechanisms in an attempt to encourage survivors to receive regular medical care. A study reported that patients with diabetes show higher rates of testing and goal attainment under

pay-for-performance care than routine care.³⁵ We suggest that care models that distribute costs over time and demonstrate high quality should be examined for improving adherence to follow-up care among AYA survivors.

Survivors' WTP for one-time and monthly plans varied by factors, such as sex, self-reported physical health, and time since their last medical check-up. Research studies may need to focus on identifying and addressing the reasons why male survivors may be less likely to value follow-up care. Survivors who reported excellent or very good physical health had significantly lower WTP compared with those who stated their health was fair or good. This is likely a result of health confidence. Survivors who believe that they are healthy may not see the need to visit their provider on a regular basis. Finally, survivors who had recently received survivor-focused care indicated a higher WTP. These results imply that targeting resources toward encouraging survivors with self-reported excellent or very good health at their last visit and those who have not seen their providers in a long time may be important to ensuring the long-term health of survivors.

Among those who refused to pay the initial bids, one-fifth believed that visits were unnecessary or they were at minimal risk of future complications, and close to 15% reported that the benefits of visits did not outweigh the costs. These results indicate that survivor-perceived effectiveness of recommended care may influence their willingness to attend visits with their providers. Therefore, it is crucial that providers effectively communicate the need for post-treatment surveillance with survivors who may be at a high risk of developing late effects. Again pay-for-performance care models that incorporate quality and effectiveness may help survivors receive recommended care.

Many AYA survivors (38% in our sample) forego annual follow-up cancer care, yet reasons for this behavior are not adequately understood. In a national study conducted before the implementation of the Affordable Care Act, 21% of AYAs with cancer were uninsured and close to 44% of survivors aged 20–29 years reported cost-related barriers to medical care.²⁴ In our sample, almost all the survivors were insured, eliminating insurance as the influential factor. However, paying for visits may be a greater problem for uninsured survivors. Although the Affordable Care Act is expected to reduce the proportion of uninsured cancer survivors,³⁶ the lack of Medicaid expansion in 19 states means that low income survivors will still lack affordable or quality health insurance. We encourage future studies to investigate whether WTP estimates are influenced by insurance status.

A few limitations are worth noting. Our data are self-reported and we had a modest participation rate. However, an AYA cancer-related study reports a similar response rate.³⁷ Self-reported values may exceed true WTP.³⁸ Yet we took precautionary measures to reduce the magnitude of this bias such as reminding respondents about their budget constraints and describing the scenarios as if they were real and consequential.^{38–40} Although we took care to recruit participants from both Salt Lake and Washington counties, to represent both urban and rural patients, all our study participants were English speaking, and data were from a single state that may limit the generalizability of our findings. Due to a small sample size, we could not conduct analyses by cancer type, diagnosis age, or time since diagnosis. We recommend that future studies evaluate values associated with follow-up care

due to differences in age at diagnosis and study, language (e.g., English vs. Spanish speaking), and cancer diagnosis across states in the United States. Furthermore, participants' previous experiences with co-payments may have influenced WTP estimates, which we were unable to control for in our analysis. Future studies should examine the differences in WTP by implementing these scenarios across independent random samples. Many of the current limitations arise due to a limited budget and the experimental work using focus groups, and both could be addressed in a full implementation of such a WTP study.

In summary, survivors of AYA cancer in our focus groups reported that they value recommended post-treatment care. This was an experimental study and we recommend that future studies implement value-based studies for examining follow-up care barriers among AYA cancer survivors in other geographic regions across the United States for detailed examinations. Healthcare facilities may be able to help vulnerable survivors by providing a monthly payment plan for visits, like those now being implemented for preventive care.⁴¹ Cost effectiveness of such an approach should be examined.

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Author Disclosure Statement

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