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Health Status of Adolescent and Young Adult (AYA) Cancer Survivors: Health Care Utilization Patterns and Additional Medical Expenses

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Health Status of Adolescent and Young Adult (AYA) Cancer Survivors: Health Care Utilization  
Patterns and Additional Medical Expenses

By

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DISSERTAION

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## **Health Status of Adolescent and Young Adult (AYA) Cancer Survivors: Health Care Utilization Patterns and Additional Medical Expenses**

### **Abstract**

**Background:** Adolescent and young adult (AYA; those who were diagnosed with cancer at age of 15-39 years) cancer survivors are more likely to suffer from long-term chronic conditions and psychological distress compared to AYAs without history of cancer. Engagement of AYAs in their own care through shared decision-making (SDM) can lead to better health outcomes. The associated economic impact of health status and SDM was examined in a population-representative sample of AYA cancer survivors.

**Methods:** We utilized 2011-2016 Medical Expenditure Panel Survey (MEPS) data to identify the AYA cancer survivors and an age-matched comparison population. We estimated the prevalence of health status (chronic medical conditions, psychological distress) and SDM in 2,326 AYA cancer survivors. The association between health status, SDM and medical expenditures was assessed using multivariable regression. Analyses were adjusted for age, sex, income level, insurance, health behavior, health care access, race/ethnicity, education, and marital status. Expenses were adjusted for inflation to 2016 dollars.

**Results:** The prevalence of chronic conditions, psychological distress and poor SDM was 74%, 12% and 11% in AYA cancer survivors. AYA cancer survivors with at least one chronic condition (\$2,777; 95% CI, \$480 to \$5,958), psychological distress (\$4,415; 95% CI, \$993 to \$9690) and poor SDM (\$3037; 95%CI; 109.72 to 7032.18) experienced additional annual medical expenditures. Medical expenditures associated with health status and poor SDM were more pronounced in AYA cancer survivors than adults without a history of cancer.

**Conclusions:** Chronic conditions and psychological distress in AYA cancer survivors are associated with substantial medical expenses well after cancer diagnosis. Interventions to improve SDM in AYA cancer survivors may result in lower medical expenses.

## **Introduction**

AYA cancer survivors suffer from higher risk of chronic health conditions and psychological distress than adults without a history of cancer<sup>1-3</sup>. Furthermore, AYA cancer survivors are more likely to develop unhealthy risk behaviors, including smoking, obesity, and alcohol use, than AYAs without history of cancer<sup>4</sup>. These unhealthy risk behaviors may contribute to the occurrence of chronic health conditions<sup>5</sup>.

Cancer survivorship is associated with economic burden. Having chronic conditions and psychological distress contribute to additional medical expenditure. AYA cancer survivors experience excess annual medical expenditures of \$3,170 per person in comparison to same-aged adults without a history of cancer<sup>6</sup>. Engagement of patients in their health care plan can lead to better health outcomes to the patients and cost efficiency to the health care system. Success in applying shared decision-making (SDM) can reduce unnecessary visits and increase patient adherence to medication and treatment plans<sup>7</sup>. Patients who have been involved in the decision-making process spend \$1800 less on health care annually compared to those who have not been involved<sup>8</sup>. There are multiple studies that examine cost of care in older cancer survivors<sup>9-11</sup>. However, no studies have assessed the factors associated with medical expenses and health care use among AYA cancer survivors, specifically factors associated with chronic health conditions, psychological distress, and SDM.

### Characteristics of AYA cancer survivors

AYA cancer survivor is defined in our study as someone who was diagnosed with cancer at age of 15-39 years and currently lives with, through or beyond cancer<sup>12</sup>. Compared to older adults, AYA cancer survivors have higher annual percentage increase in cancer incidence<sup>13</sup>. Moreover, AYA cancer survivors face unique challenges that differ from cancer survivors both

who are diagnosed during childhood and later in adulthood. They have their own physical, and psychological problems that pertain to the nature of the disease, its treatment, and the nature of adolescence and the early adulthood period.

The adolescence and early adulthood periods are characterized by marked changes in physical, psychological, and social development. This period, has a high rate of change in life course events (e.g., getting a new job, starting college, getting married). These changes affect the AYA survivor's future career and it is associated with many economic challenges<sup>14</sup>. Having cancer specifically affects the employment opportunities for the survivors and their caregivers, which could substantially impact the AYA receipt of appropriate survivorship care. Prior studies found that AYA cancer survivors are more likely to be unemployed or have employment disabilities that result in disadvantaged health coverage with higher premiums and low health care quality because of low coverage<sup>6</sup>.

#### Chronic medical conditions and multiple chronic conditions among AYA cancer survivors

Due to cancer treatments, including chemotherapy and radiation, young cancer survivors tend to have more long-term chronic conditions and multiple chronic conditions in comparison to adults without a history of cancer<sup>15</sup>. Among cancer survivors, 12-35% reported having one or more chronic conditions including cardiovascular disease, chronic obstructive pulmonary disease, diabetes, asthma, high cholesterol, or hypertension<sup>2</sup>.

#### Psychological distress among AYA cancer survivors

Having cancer during the developmental stage of adolescence can make AYAs more vulnerable to psychological distress<sup>16</sup>. AYA are found to have more psychological distress compared to younger-aged and older adults' survivors<sup>17</sup>. The reported prevalence of psychological distress in AYA cancer survivors has varied widely<sup>11</sup> depending on the type of measured



psychological condition<sup>18</sup>, criteria used for diagnosis<sup>16</sup>, and the type of associated cancer<sup>3</sup>. Risk factors associated with psychological distress play an important role in the psychological functioning of cancer survivors. Worse psychological distress among cancer survivors has been associated with being uninsured, unmarried, or living alone, having low education, being less than 65, and having multiple chronic conditions<sup>19,20</sup>.

#### Unhealthy risk behaviors and health care access among AYA cancer survivors

Smoking, obesity, and alcohol use are prevalent among AYA cancer survivors<sup>5</sup>. These unhealthy risk behaviors may contribute to the occurrence of many chronic conditions and psychological distress. Eating healthy, exercising regularly, and avoiding smoking play a major role in the prevention of chronic disease and reducing the cost of care<sup>21</sup>. Moreover, AYA cancer survivors are more likely to have lower health insurance coverage rates and a lack of health care access<sup>22</sup>. They reported having troubles paying their medical bills and affording care<sup>23</sup> which can lead to forgoing some essential medical care<sup>13</sup>. The lack of access to care were associated with reports of delayed care<sup>24</sup>.

#### Shared Decision-Making among AYA cancer survivors

Shared Decision Making (SDM) is an aspect of patient-centered care that ensures patient values lead all health care decisions<sup>8</sup>. Cancer survivors reported better quality of care when they are involved in the decision-making process<sup>25</sup>. Successful SDM can reduce unnecessary visits and increase patient adherence to medications and the treatment plans<sup>26</sup>. However, most health care providers do not adhere to SDM strategies<sup>27</sup>.

#### Medical expenditures and health care use associated with cancer survivorship

Cancer survivorship is associated with economic burden, as measured by health care cost, loss of productivity due to a disability, missed work days, and loss of home productivity<sup>12</sup>. AYA

cancer survivors have additional annual medical expenditures of \$3,170 per person in comparison to same-aged adults with no history of cancer<sup>6</sup>. Chronic conditions like diabetes and hypertension were associated with additional annual costs of \$3,281 and \$726 in older adult cancer survivors, respectively<sup>12</sup>. Psychological distress also was found to increase average annual medical expenditures by \$4,431 in cancer survivors of all ages<sup>28</sup>. On the other hand, patients who have been involved in SDM have been found to spend \$1800 less on health care annually than those who have not been involved<sup>8</sup>. While few studies have considered additional medical expenses associated with chronic conditions, psychological distress, and SDM among specific populations, no studies examined the factors that influence the additional medical expenses in AYA cancer survivors.

Despite that AYA cancer survivors have higher prevalence of chronic conditions, psychological distress, and healthcare utilization, no previous studies examined the factors associated with the increased cost of care in AYA cancer survivors. Therefore, we utilized the MEPS data to assess our three study objectives;

1. To assess factors associated with additional annual medical expenses and health care use in AYA cancer survivors with chronic conditions compared to AYA cancer survivors without chronic conditions.
  - a-Estimate the prevalence of chronic conditions and multiple chronic conditions among AYA cancer survivors.
  - b-Measure risk factors associated with chronic conditions among AYA cancer survivors.
  - c-Measure the additional annual medical care expenditures and health care use associated with chronic conditions among AYA cancer survivors.

d-Estimate the association between unhealthy risk behaviors, health insurance and health care access with additional annual medical expenditures in AYA cancer survivors.

2. To examine the association between psychological distress and additional medical expenditures across survivorship in AYA cancer survivors and matched adults with no history of cancer.

a- Examine the prevalence of psychological distress in AYA cancer survivors and matched adults with no history of cancer.

b-Measure the additional annual medical expenditures and health care use of psychological distress in AYA cancer survivors and matched adults with no history of cancer.

c- Measure risk factors associated with psychological distress in AYA cancer survivors and matched adults with no history of cancer.

d- Test the association between psychological distress and time since diagnosis among long-term cancer survivors.

3. To examine the role of SDM on additional medical expenditure and health care use in AYA cancer survivors matched adults with no history of cancer.

a- Examine the characteristics of AYA cancer survivors and matched adults with no history of cancer by level of SDM.

b- Study the role of SDM in patient-reported health status, health behavior, and health care access.

c-Test the association between SDM with additional medical expenditures and health care use among AYA cancer survivors and matched adults with no history of cancer.

Findings from our projects can inform survivorship care guidelines<sup>35</sup>, suggest that there is a substantial gaps in care for short- and long-term survivors, and identify the economic impact of chronic condition, psychological distress, and poor SDM among AYA cancer survivors.

## **Chapter 1: Additional medical costs of chronic conditions among adolescent and young adult cancer survivors**

### **Abstract**

**Purpose:** Adolescent and young adult (AYA) cancer survivors are more likely to have multiple chronic conditions compared to AYAs without history of cancer. The financial hardship of chronic conditions associated with cancer can substantially impact cancer survivors. We aim to assess health risk behaviors and health care access factors associated with increased medical expenses in AYA cancer survivors.

**Methods:** We utilized 2011-2016 Medical Expenditure Panel Survey (MEPS) data to identify the prevalence of chronic medical conditions, health risk behaviors and health care access in 2,326 AYA cancer survivors. The association between health risk behaviors, health care access factors and chronic conditions with medical expenditures was assessed using multivariable regression with gamma distribution and log link. Analyses were adjusted for age, sex, and race/ethnicity, education, and marital status. Expenses were adjusted for inflation to 2016 dollars.

**Results:** The majority of AYA cancer survivors (74%), who were diagnosed with cancer 10 or more years ago, had at least one chronic condition and spend an additional \$2,777 (95% CI, \$480 to \$5,958) annually compared to AYA cancer survivors with no chronic conditions. Additional annual expenses also were associated with physical inactivity (\$3,558; 95% CI, \$2,200 to \$4,606) and being unable to get care when needed (\$1,291; 95% CI, \$198 to 3,335) in AYA survivors.

**Conclusions:** Chronic conditions in AYA cancer survivors is associated with a substantial increase in medical expenses well after cancer diagnosis.

**Implication for cancer survivors:**

Getting care when needed and adopting healthy behaviors, particularly exercise, may reduce medical expenses associated with chronic conditions in AYA.

**Keywords.** adolescent and young adult cancer survivors, chronic conditions, health expenditures, healthcare use

## **Introduction**

Adolescent and young adult (AYA) cancer survivors experience multiple long-term health problems due both the effects of the cancer itself and to cancer treatments<sup>15</sup>, and are more likely to have chronic conditions in comparison to same-aged adults without a history of cancer. Chronic conditions such as cardiovascular disease, chronic obstructive pulmonary disease, diabetes, asthma, and hypertension are among these common health problems in cancer survivors<sup>5</sup>. Estimates of the prevalence of chronic conditions in AYA cancer survivors range from 12–35%<sup>4</sup>. In addition, compared to adults with no history of cancer, AYA cancer survivors are more likely to be obese and engage in risky health behaviors such as smoking, consuming alcohol, and lack of physical activity<sup>29</sup>, which may lead to increased likelihood of chronic conditions<sup>21</sup>.

Cancer has a financial impact related to health care costs, loss of productivity due to disability, and missed work days<sup>30,31</sup>. Compared to same-aged adults with no history of cancer, AYA cancer survivors have \$3,170 average higher annual medical expenditures and annual productivity losses (\$2,250)<sup>32</sup>. Not surprisingly, having chronic conditions has been found to further increase these annual medical expenditures in cancer survivors of all ages<sup>2</sup>.

Compared to adults with no history of cancer, AYA cancer survivors were more likely to report lack of insurance and high cost of care as reasons for forgoing care compared to those with no history of cancer<sup>13</sup>. These access-to-care factors could impact the receipt of appropriate health care<sup>33</sup> and contribute to financial hardship, especially for those who suffer from chronic conditions. AYA cancer survivors face unique challenges, including cancer affecting employment opportunities, daily activities and decreasing the work productivity<sup>34</sup>, which could lead to financial problems. Given the high prevalence of chronic conditions and the increased financial hardships of AYA cancer survivors<sup>10</sup>, it is important to understand factors associated with cost of care in this population.

While studies have considered the cost of having chronic conditions in cancer survivors of all ages, no studies examined the factors associated with the cost of care in AYA cancer survivors. Therefore, we aim to examine health care access and health behavior factors associated with chronic conditions and the cost of care among AYA cancer survivors. Findings from this study can inform survivorship care guidelines<sup>35</sup> and the development of cost-effective healthcare plans to address chronic conditions in cancer survivors.

## **Methods**

### **Data**

We used the household component of 2011-2016 Medical Expenditure Panel Survey (MEPS)<sup>36</sup>, which collected data from a nationally representative sample of U.S. non-institutionalized civilians. The final response rate ranged from 53.5% to 59.3%. The sample is

taken from the panel of individuals who completed the National Health Interview Survey. The panel is surveyed for five rounds of in-person interviews and self-administered questionnaires over a period of two years. MEPS gathers comprehensive information on sociodemographic characteristics, health status, medical conditions and health care expenditures<sup>37</sup>.

## **Sample**

We identified participants who reported that they were diagnosed with cancer between 15 and 39 years of age. We considered all types of cancer, except non-melanoma skin cancers, consistent with previous studies that have not classified people with non-melanoma skin cancer as cancer survivors<sup>2,5</sup>. We identified 2,431 AYA cancer survivors. We excluded 105 participants with missing information about chronic conditions resulting in a study population of 2,326 AYA cancer survivors. Survey weights were applied to account for complex survey design<sup>38</sup>. Analysis were conducted using SAS statistical software.

## **Measures**

### **Outcomes**

Medical expenditures were calculated based on the reported health care use as dollar amount spent on ambulatory visits, inpatient nights, emergency visits, and prescription medications per year. Health care utilization was measured as the number of ambulatory visits, inpatient nights, emergency visits, and any prescribed medications, including refills, per year.

### **Main Exposures**



Chronic conditions were identified by a series of survey questions asking the participant whether a physician or other health care professional ever told them that they had heart disease, high blood pressure, high cholesterol, diabetes, asthma, emphysema, stroke, and arthritis. We estimated the prevalence of having at least one of these chronic conditions, the number of chronic conditions (0, 1, 2, 3, or >4) and each type of the chronic condition reported by the participant.

### Covariates

Sociodemographic characteristics included age, sex, education, marital status, race/ethnicity, family income, and health insurance based on participant self-report. Time since diagnosis was calculated based on the difference between age and age of cancer diagnosis. Elevated body mass index (BMI) was defined as  $>25 \text{ kg/m}^2$  and health behaviors included smoking and not exercising regularly. Access to health care measures included having a routine checkup in the past year, health insurance type (private, public, or uninsured), having usual source of care, and ability to access care when needed.

### Statistical Analysis

Descriptive statistics with chi-square tests were used to compare characteristics between AYAs with chronic conditions and AYAs with no chronic conditions. We also used unconditional logistic regression to estimate bivariate and multivariable associations between chronic conditions and health behaviors and health care access. Multivariable regression models with gamma distribution and log link were used to estimate the association of chronic conditions, health risk behaviors, and health care access to both medical expenditures and medical care use.

## **Results**

### **Characteristics of AYA cancer survivors with and without chronic conditions**

Compared to AYA cancer survivors without chronic conditions, AYA survivors of cancer with chronic conditions were more likely to be older, have public health insurance, have lower income, have less education and be non-Hispanic white (Table 1). The majority (76%) of cancer survivors were diagnosed with cancer at least 10 years before the survey (Table 2). AYAs with chronic conditions were more likely to be physically inactive (57%) compared to those without chronic conditions (41%) ( $p<0.001$ ). Despite the fact that those with chronic conditions were more likely to have a usual source of care (87% vs 73%,  $p<0.001$ ) and more likely to get routine checkup during the last year (78% vs 66%,  $p<0.001$ ), AYAs with chronic conditions were less likely to get medical care when needed (94% vs 96.5%,  $p=0.03$ ) (Table 1). Hypertension (42%), arthritis (43%) and high cholesterol (40%) were among the most common chronic conditions in survivors of AYA cancer (Table 3).

### **Factors associated with chronic conditions**

In adjusted logistic regression models, AYAs with chronic conditions were more likely to have public health insurance (OR=3.66, 95% CI 2.02 to 6.61 ), be physically inactive (OR=3.21, 95% CI 1.49 to 6.67) and receive advice to exercise (OR=4.19, 95% CI 1.98 to 8.86) than AYAs without chronic conditions (Table 4).

### **Factors associated with increased medical costs**

Having at least one chronic condition was associated with an additional average of \$2,777 (95% CI, \$480 to \$5,958) in annual medical expenditures (Table 5). Having four or more chronic condition was associated with additional \$11,178 (95% CI, \$6,325 to \$18,503) in annual medical expenditures. When looking into the expenses by each type of chronic condition, myocardial infarction was associated with the highest additional expenses (\$4,070; 95% CI, \$1,019 to \$9,454) followed by chronic bronchitis (\$3,904.76; 95% CI, \$1,039 to \$8,720), diabetes (\$3,480.22; 95% CI, \$1,417 to \$6,505) and hypertension (\$1,140.76; 95% CI, \$121 to \$2,497).

AYA cancer survivors who were physically inactive had higher annual medical expenditures (\$3,558; 95% CI, \$2,200 to \$4,606), while neither elevated BMI nor smoking were associated with significant differences in annual medical expenses. Having a usual source of care (\$687; 95% CI, \$173 to \$1,415) and regular checkups during last year (\$1,117; 95% CI, \$560 to \$1,867) were associated with increased annual medical expenses. Being unable to get care when needed was also associated with higher annual medical expenses of \$1,291 (95% CI, \$198 to \$3,335).

### **Factors associated with increased health care use**

Having chronic conditions as an AYA cancer survivor was associated with an average of 10.36 additional office visits (95% CI, 5.76 to 16.03), 0.23 additional inpatient nights (95% CI, 0.01 to 0.63), 0.44 additional emergency room visits (95% CI, 0.18 to 0.78) and use of 34.26 additional prescription medications/medication renewals (95% CI, 25.17 to 45.89) annually compared to AYA survivors of cancer without chronic conditions (Table 5). Health care use generally increased with increasing number of chronic conditions. Having one chronic condition was associated with an additional use of 7.24 prescription medications/medication renewals (95%

CI, 4.38 to 10.88), while having four or more chronic conditions was associated with increases in office visits (23.45; 95% CI, 15.70 to 33.43), prescription medications/medication renewals (63.41; 95% CI, 46.99 to 84.92), emergency room visits (0.80; 95% CI, 0.44 to 1.37) and inpatient nights (0.48; 95% CI, 0.17 to 1.10).

AYA cancer survivors who did not exercise regularly had more office visits (9.36; 95% CI, 6.80 to 11.52), more inpatient nights (0.27; 95%CI, 0.14 to 0.36), and more prescription medications/medication renewals (5.52; 95% CI, 3.95 to 6.81). AYAs with a higher BMI had less emergency room visits, but 3.44 additional prescription medications/medication renewals (95% CI, 0.44 to 7.11). Smoking was associated with less office visits, but additional emergency room visits of 0.21 (95% CI, 0.03 to 0.87).

Having a usual source of care and a checkup in the last year were associated with 3.22 (95% CI, 1.61 to 5.24) and 2.92 (95% CI, 1.62 to 4.48) additional office visits, and 2.42 (95% CI, 1.47 to 3.64) and 1.70 (95% CI, 1.19 to 3.14) prescription medications/medication renewals, respectively. AYAs who had a check-up in the last year also had additional in-patient nights and emergency department visits. Having public versus private insurance was associated with additional inpatient nights of 0.07 (95% CI, 0.01 to 0.17), emergency room visits of 0.12 (95% CI, 0.04 to 0.23) and prescription medications/medication renewals of 1.19 (95% CI, 0.61 to 1.90). However, AYAs who were unable to get care when needed had additional 3.30 office visits (95% CI, 0.69 to 7.18) and 2.01 additional prescription medications/medication renewals (95% CI, 0.63 to 4.12).

## **Discussion**

In this study, we found that chronic conditions and multiple chronic conditions were common in AYA cancer survivors and were associated with significant increases in medical expenditures and health care use. AYA cancer survivors with at least one chronic condition account for 74% of AYA cancer survivors in our study and incurred an additional \$2,777 in medical expenditures, including an average of 10 additional office visits and 34 additional prescription medications/medication renewals annually per person. Likewise, those with four or more chronic conditions, 22% of AYA cancer survivors in our study, had an average additional \$11,178 in medical expenditures, 23 additional office visits and 63 additional prescription medications/medication renewals annually per person. Myocardial infarction, chronic bronchitis, diabetes, and hypertension were among the chronic conditions with the highest cost in AYA cancer survivors. We also showed that adopting healthy behaviors might be associated with lower medical expenses, as physical inactivity was associated with additional medical expenditures and health care use. Lastly, AYAs reporting that they were unable to get care when needed had higher medical expenses and health care use. These findings are consistent with prior studies that found that delay of getting care when needed was associated with increase in cost of treatment<sup>39</sup>. Overall, the findings from our study suggest that getting care when needed and adopting healthy behaviors, particularly exercise, may reduce medical expenses associated chronic conditions. Our study is the first to estimate the medical expenses and health care use associated with multiple chronic conditions, health care access factors and health behaviors among AYA cancer survivors.

Our findings suggest that the financial cost of chronic conditions long after cancer diagnosis can be substantial among AYA cancer survivors. A previous study demonstrated that

AYA cancer survivors had \$3,170 annual expenditure compare to adults without history of cancer<sup>32</sup>. In our study, we further investigated how medical expenditures differ by chronic conditions. While estimates can vary depending on the data source<sup>40</sup>, our estimates of chronic condition expenses are comparable to estimates by other studies for older cancer survivors<sup>9,12</sup>. In addition to the number of chronic conditions, we found medical expenditures to vary by the specific type of chronic conditions, with myocardial infarction and chronic bronchitis incurring the highest annual medical expenditures of \$4,069 and \$3,900. Consistent with our findings of AYAs with diabetes and hypertension incurring additional annual medical expenditures of \$3,480 and \$1,140, previous studies found that diabetes and hypertension were associated with additional annual costs of \$3,281 and \$726 in older adult cancer survivors, respectively<sup>12</sup>. Our findings add insight about how specific and multiple chronic conditions impact the medical expenses of AYA cancer survivors.

Previous studies provided evidence that risky health behaviors are more common among AYA cancer survivors<sup>5,41</sup> and can increase the risk of acquiring chronic conditions<sup>42,43</sup>. We found that AYA cancer survivors with chronic conditions exercise less regularly than those with no chronic conditions, however, we were unable to determine whether physical inactivity contributed to the occurrence of chronic conditions or physical inactivity was due to their chronic condition. Despite this limitation, we found that AYA cancer survivors who were physically inactive had higher medical care expenditures, office visits, inpatient nights, ER visits and medication use compared to those who exercise regularly even after adjusting for chronic conditions. Our finding is consistent with a prior study that found inadequate physical activity to be associated with higher medical expenses<sup>44</sup>. We also found that elevated BMI and smoking were more common in AYA

cancer survivors with chronic conditions but were not associated with additional health care expenditures after adjusting for sociodemographic characteristics. The adverse health behaviors we observed among AYA cancer survivors with chronic conditions highlight the importance of implementing interventions to increase healthy behaviors in this population.

Previous research has demonstrated that access to health care can play an important role in improving AYA cancer survivor's health status<sup>14</sup> and decreasing cost of care<sup>45-47</sup>, especially among those with chronic conditions. We found that survivors with chronic conditions were more likely to get checkups and more likely to have a usual source of care, but less likely to access care when they needed it, suggesting that AYA cancer survivors have more health care needs than they have access to. Our findings also reveal that having a regular source of care alone might not be sufficient to provide the needed care to AYA cancer survivors with chronic conditions. Having a usual source of care and check-up in the last year were associated with higher medical expenses and health care use. Other studies found that having usual source of care had a variable effect on the cost depending on type of provider<sup>48</sup>, age, and length of chronic condition<sup>49</sup>. One study conducted in Belgium found that having a regular family physician lowers the cost of care<sup>47</sup>. In addition, in our study, being unable to get care when needed was associated with higher expenses and health care use, suggesting that access to care has consequences on health care expenses. Similarly, previous studies found that delays in getting care were associated with increased hospitalization and cost of treatment<sup>39</sup>. Providing cancer survivors with health care plans that allow them to get care when needed might be a cost-efficient way to support AYA cancer survivors.

Many AYA cancer survivors struggle with having adequate health insurance coverage<sup>23,50,51</sup>. We observed that AYA cancer survivors with chronic conditions were more likely to have public insurance than those with no chronic conditions, a finding that may relate to their eligibility for Medicaid based on their disability/chronic condition or to their ability to obtain insurance through the Affordable Care Act by removing the preexisting condition rule and decreasing the rates of coverage denial<sup>51</sup>. This finding also may be related to the worse health status observed among those with lower socioeconomic status and public health insurance<sup>52</sup>. In our study, we found that survivors with public insurance have higher expenses, more emergency room visits, and more inpatient nights compared to those with private health insurance even after adjusting for chronic conditions. These findings may relate to AYAs with public insurance having more access to care difficulties that may lead to worse outcomes and large out of pocket expenses<sup>52</sup> compared to those with private insurance. Prior studies have found that those with public insurance are more likely to have a fair or poor health status, experience delays in receiving care<sup>24</sup>, and have unmet medical needs<sup>53,54</sup>. The severity of chronic conditions, which can affect health expenditure substantially<sup>55</sup> but are not available in the MEPS data, could also be contributing to these differences and should be the focus of future research.

Some limitations of this study include the potential self-reporting biases with under or over-reporting of responses to some survey questions. However, many studies have demonstrated that self-report methods are well correlated with more objective measures<sup>56</sup>. An additional limitation is that AYAs with more aggressive cancers, which are associated with higher expenses are less likely to survive to participate in the survey<sup>57</sup>. However, our population included long term cancer survivors who had the opportunity to develop chronic conditions. Our study did not capture all



types of chronic conditions, such as autoimmune conditions<sup>58</sup>, Alzheimer's disease<sup>59</sup> or epilepsy,<sup>60</sup> which have been associated with higher medical costs in previous studies. Yet, we have included the top 12 most common chronic conditions. Lastly, our study did not capture quality of care, which could impact medical expenses, or other important costs, including the productivity loss, care giver/childcare, or transportation costs, that are important aspects to include in future research.

## **Conclusion**

AYA cancer survivors are an understudied population<sup>51,61,62</sup> compared to older adults<sup>2,30,63,64</sup> and face many long-term complications from their cancer treatment, including chronic conditions. AYA cancer survivors who suffer from chronic conditions had significantly greater medical expenses and health care utilization. The findings from our study suggests that getting care when needed and adopting healthy behaviors, particularly exercise, may reduce medical expenses associated with chronic conditions. Prevention strategies might not only address cancer survivor's health needs, but also decrease the risk of chronic conditions and their associated medical expenses. Future studies should focus on how sociodemographic factors, such as income, race/ethnicity, and health insurance interact to influence the cost of chronic conditions and how preventive behavioral risk factors and health care access impact care in longitudinal studies.

Table 1. Demographic characteristics of adolescent and young adult cancer survivors with and without chronic conditions: Medical Expenditure Panel Survey, 2011 to 2016

Characteristics	AYA cancer survivors with chronic conditions (N=1685)	AYA cancer survivors without chronic conditions (N= 641)	P-value
	N (weighted%)	N (weighted%)	
Age			<0.001
18-29	113 (6.14)	120 (18.14)	
30-39	281 (15.xx)	250 (37.52)	
40-49	440 (24.36)	176 (27.82)	
50-64	550 (36.10)	81 (13.80)	
65 or older	279 (17.88)	11 (2.70)	
Sex			0.5
Male	338 (23.90)	131 (21.85)	
Female	1342 (76.09)	510 (78.14)	
Race/ethnicity			<0.001
Hispanic	278 (9.26)	158 (16.49)	
Non-Hispanic white	874 (79.15)	292 (75.13)	
Non-Hispanic black	196 (6.53)	51 (4.47)	
Non-Hispanic Asian	29 (1.13)	16 (1.98)	
Non-Hispanic other	57 (2.93)	10 (1.75)	
Education			0.01
Less than high school	446 (38.10)	158 (35.03)	
High school graduate	403 (35)	131 (26.71)	
Some college or more	270 (26.90)	128 (38.26)	
Marital status			0.36
Married	758 (55.46)	331 (58.77)	
Not married	780 (44.54)	252 (41.23)	
Health insurance			<0.001
Private	896 (61.86)	412 (74.17)	
Public	607 (29.62)	122 (12.89)	
Uninsured	177 (8.52)	107 (12.95)	
Income			0.01
Poor	414 (15.97)	131 (13.22)	
Near poor	121 (6.30)	33 (3.27)	
Low income	269 (14.4)	82 (10.5)	
Middle income	446 (25.52)	200 (32.95)	
High income	430 (37.80)	195 (40.04)	
BMI and Health behavior			
Physical inactivity	900 (56.90)	3232 (40.78)	<0.001
Elevated BMI >25	1177 (67.10)	381 (56.22)	0.001
Smoking	417 (25.66)	128 (22.14)	0.2
Advice on health behavior			
To stop smoking	308 (70.16)	65 (51.57)	0.002
To exercise regularly	963 (56.99)	203 (32.76)	<0.001
To eat healthy	806 (47.98)	125 (20.21)	<0.001
Health care access			
Usual source of care	1398 (86.78)	452 (73.47)	<0.001
Get care when needed	1764 (93.93)	716 (96.50)	0.03
Checkup last year	1277 (77.89)	408 (66.25)	<0.001

BMI=Body Mass Index calculated body weight in kg/height in m<sup>2</sup>

Table 2. Characteristics of adolescent and young adult cancer survivors with and without chronic medical conditions: Medical Expenditure Panel Survey, 2011 to 2016

Characteristics	AYA cancer survivors with chronic conditions (N=1685)	AYA cancer survivors without chronic conditions (N= 641)
	N (weighted %)	N (weighted %)
<b>Cancer site*</b>		
Bladder	11 (0.70)	< 5
Brain	9 (1.69)	< 5
Breast	198 (12.57)	76 (11.15)
Cervix	474 (32.90)	173 (21.86)
Colon	56 (2.94)	19 (1.76)
Leukemia	10 (1.72)	6 (1.52)
Lung	17 (2.07)	< 5
Lymphoma	52 (4.42)	35 (5.45)
Melanoma	106 (9.26)	61 (10.94)
Other	497 (28.26)	167 (26.55)
Prostate	10 (1.70)	<5
Throat	< 5	<5
Thyroid	25 (3.9)	14(8.5)
<b>Time since diagnosis</b>		
0-4	175 (10.86)	187 (31.85)
5-9	195 (12.73)	132 (22.96)
10-19	344 (26.31)	146 (29.43)
>=20	646 (50.09)	81 (15.76)

\*Percentages sum to greater than 100% as a result of some individuals reporting more than one cancer diagnosis.

Table 3. The distribution of chronic conditions in adolescent and young adult cancer survivors: Medical Expenditure Panel Survey, 2011 to 2016

Type of chronic condition	N (weighted %) *
Congestive heart disease	172 (7.16)
Myocardial infarction	173 (6.79)
Angina	149 (5.35)
Other heart disease	384 (17.82)
Hypertension	967 (41.75)
Diabetes	295 (11.91)
Arthritis	954 (42.75)
Asthma	433 (17.54)
Emphysema	136 (5.99)
Chronic bronchitis	170 (6.40)
High cholesterol	880 (39.77)
Stroke	213 (8.31)
Number of chronic conditions	N (weighted %)
0	641 (26.10)
1	532 (22.80)
2	394 (17.91)
3	276 (11.65)
≥4	548 (21.54)

\*Percentages sum to greater than 100% as a result of some individuals reporting more than one chronic condition.

Table 4. Associations of health care and health behaviors with the likelihood of having a chronic condition among adolescent and young adult cancer survivors: Medical Expenditure Panel Survey, 2011 to 2016

Characteristics	Unadjusted		Adjusted†	
	Odds ratio of chronic condition (95%CI)	P-value	Odds ratio of chronic condition (95%CI)	P-value
<b>Health care access</b>				
Checkup last year	1.44 (1.05-1.99)	0.025	0.64 (0.23-1.78)	0.38
Public vs private insurance	2.51(1.71-3.71)	<0.0001	3.66 (2.02-6.61)	<0.001*
Having usual source of care	2.19 (1.54-3.10)	<0.0001	0.81 (0.26-2.55)	0.72
Unable to get needed care	2.04 (1.19-3.57)	0.01	1.09 (0.40-2.94)	0.88
<b>BMI and Health behavior</b>				
Elevated BMI>2	1.45 (1.07-1.95)	0.01	0.63 (0.27-1.46)	0.27
Physical inactivity		<0.0001	3.21 (1.49-6.67)	0.004*
Smoking	1.22 (0.85-1.75)	0.29	0.90 (0.38-2.14)	0.81
<b>Doctor's Advice</b>				
To exercise regularly	1.27 (0.68-2.35)	0.45	4.19 (1.98-8.86)	<0.001*
To eat healthy	3.99 (1.85-8.61)	0.0005	1.76 (0.64-4.84)	0.26
To stop smoking	1.23 (0.55-2.76)	0.62	0.57 (0.12-2.77)	0.47

†Models adjusted for associated variables in the table and age, sex and race/ethnicity, marital status, education poverty level and time since diagnosis.

\*Statistically significant adjusted odds ratios (p<0.05).

BMI=Body Mass Index calculated as body weight in kg/height in m<sup>2</sup>

Table 5. Additional medical care expenditures and use among adolescent and young adult cancer survivors: Medical Expenditure Panel Survey, 2011 to 2016

	Additional Total Medical Expenses \$ (95%CI)	Additional Office Visits N (95%CI)	Additional Inpatient Nights N (95%CI)	Additional Emergency Room Visits N (95%CI)	Additional Prescription Medication N (95%CI)
At least one chronic condition					
chronic conditions	\$2,776.86* (\$480.91-\$5958.98)	10.36* (5.76-16.03)	0.23* (0.01-0.63)	0.44* (0.18-0.78)	34.26* (25.17-45.89)
Number of chronic conditions					
One condition	-111 (-1033.7-1204.12)	2.30 (-0.39-5.67)	0.02 (-0.07-0.19)	0.06 (-0.02-0.19)	7.24* (4.38-10.88)
Two condition	1823.88* (230.81-4156.19)	7.96* (3.64-13.54)	0.12 (-0.02-0.41)	0.13* (0.02-0.31)	13.94* (9.42-19.78)
Three conditions	935.08 (-650.30-3506.07)	5.37* (0.99-11.35)	0.11 (-0.04-0.47)	0.31* (0.11-0.64)	20.95* (13.56-31.12)
Four or more	11,177.87* (6324.92-18502.82)	23.45* (15.70-33.43)	0.48* (0.17-1.10)	0.80* (0.44-1.37)	63.41* (46.99-84.92)
Type of chronic condition					
CHD	\$513.32 (-1052.22 -3356.53)	1.62 (-3.35-9.25)	-0.03 (-0.04-0.13)	0.06 (-0.03-0.20)	2.27 (-1.02-7.19)
MI	\$4,069.6* (1018.86-9453.50)	3.8 (-1.43-11.65)	0.20* (0.02-0.57)	0.06 (-0.01-0.18)	2.12 (-1.01-6.72)
Angina	\$1,505.50 (-525.54-5223.73)	-1.40 (-5.24-4.41)	0.17 (-0.00-0.56)	0.03 (-0.04-0.14)	3.64 (-0.22-9.49)
Other heart disease	\$834.55 (-204.42-2263.78)	1.17 (-1.52-4.52)	0.02 (-0.05-0.15)	0.08* (0.02-0.17)	0.81 (-0.87-2.93)
Hypertension	\$1,140.76* (121.23-2496.53)	1.92 (-0.69-5.11)	0.11* (0.01-0.27)	0.098* (0.03-0.17)	7.32* (4.66-10.55)

Diabetes	\$3,480.22* (1416.89-6505.28)	5.09* (0.96-10.45)	0.06 (-0.03-0.22)	-0.02 (-0.05-0.04)	10.08* (6.05-15.28)
Arthritis	\$628.05 (-124.31-2828.13)	4.99* (2.09-8.44)	0.01 (-0.02-0.24)	0.10* (0.03-0.18)	4.16* (2.22-6.48)
Asthma	\$1,064.66 (-58.82-2606.98)	5.55* (1.99-9.96)	-0.004 (-0.05-0.10)	0.05* (0.00-0.12)	5.61* (2.90-9.02)
Emphysema	\$330.50 (-1273.74-3445.13)	-5.22 (-7.88- - 1.12)	-0.07 (-0.12-0.06)	-0.03 (-0.08-0.05)	3.17 (-0.59-13.36)
chronic bronchitis	\$3,904.76* (1039.27-8719.58)	9.68* (3.08-19.04)	0.31* (0.08-0.77)	0.08* (0.00-0.40)	5.62* (1.60-11.37)
High cholesterol	-\$628.01 (-1239.4-29.85)	1.20 (-1.18-4.06)	-0.05 (-0.09-0.02)	-0.01 (-0.02-0.21)	0.98 (-0.55-2.86)
Stroke	\$612.67 (-791.81-2892.94)	1.62 (-2.27-6.97)	0.16* (0.02-0.42)	0.11* (0.02-0.23)	4.10* (0.78-8.72)
BMI and Health Behavior					
Elevated BMI>25	625.24 (-1371.28-3209.77)	-1.24 (-4.72-2.88)	-0.09 (-0.24-0.15)	-0.02* (-0.13- -0.10)	3.44* (0.44-7.11)
Physical inactivity	3557.80* (2199.85-4606.19)	9.36* (6.80-11.52)	0.27* (0.14-0.36)	0.11 (-0.45-0.19)	5.52* (3.95-6.81)
Smoking	-805.59 (-2789.97-1912.62)	-7.85* (-10.66- -4.47)	-0.06 (-0.23-0.25)	0.21* (0.03-0.87)	1.29 (-1.58-4.88)
Health care access					
Checkup last year	1117.95* (560.84-1867.08)	2.92* (1.62-4.48)	0.10* (0.01-0.27)	0.17* (0.06-0.35)	1.70* (1.19-3.14)
Public vs private Insurance	568.14* (137.21-1154.62)	0.88 (-0.10-2.07)	0.07* (0.01-0.17)	0.12* (0.04-0.23)	1.19* (0.61-1.90)
Unable to get needed care	1290.74* (197.88-3334.80)	3.30* (0.69-7.18)	0.003 (-0.06-0.14)	0.06 (-0.04-0.25)	2.01* (0.63-4.12)
Having usual care	687.12* (173.25-1415.16)	3.22* (1.61-5.24)	0.02 (-0.04-0.14)	-0.04 (-0.08-0.03)	2.42* (1.47-3.64)

All models were adjusted for the variables presented in the table and age, sex, race/ethnicity, marital status, education, and time since diagnosis. All measures reported were per person per year.

†Chronic conditions include coronary heart disease (CHD), angina, myocardial infarction (MI), and other unspecified heart disease, asthma, high blood pressure, high cholesterol, diabetes, arthritis, stroke, and emphysema.  
\*Statistically significant estimates ( $p < 0.05$ ).

## **Chapter 2: Psychological distress and associated additional medical expenditure in adolescents and young adult cancer survivors**

### **Abstract**

**Background:** Adolescent and young adult (AYA) cancer survivors experience psychological distress often because of cancer and its treatment. However, no prior studies evaluated the additional medical expenditures and health care utilization associated with psychological distress in AYA cancer survivors.

**Methods:** AYA cancer survivors and a comparison matched group of adults with no history of cancer were identified from 2011-2016 Medical Expenditure Panel Survey (MEPS) data. Medical expenditures and health care utilization were evaluated using multivariable regression models.

**Results:** AYA cancer survivors ( $n=1,757$ ; 11.5%) were more likely to have psychological distress compared to adults with no history of cancer ( $n=5,227$ ; 5.8%). Psychological distress prevalence persisted high many years after diagnosis, with 11.2% reporting distress  $\geq 20$  years after cancer diagnosis. AYA cancer survivors with psychological distress were more likely to smoke and have chronic conditions, and less likely to exercise regularly compared to AYAs with no history of psychological distress. AYA cancer survivors with psychological distress have additional annual medical expenses (\$4,415; 95% CI, \$993 to \$9690), office visits (2.80; 95% CI, 0.23 to 6.15), and use of prescription medications/medication renewals (11.58; 95% CI, 5.70 to 19.47) than AYA cancer survivors without psychological distress. Additional annual medical expenses of



psychological distress were \$2,600 higher in AYA cancer survivors than adults without history of cancer (\$1,802; 95% CI, \$440 to \$3,791).

**Conclusion:** Our results highlight the substantial economic burden associated with psychological distress in AYA cancer survivors.

**Implication:** Our research informs survivorship care plans and interventions that address the psychological needs for AYA cancer survivors.

**Keywords.** adolescent and young adult cancer survivors, psychological distress, health expenditures, healthcare use, health behavior

## **Introduction**

Adolescent and young adult (AYA; those who were diagnosed with cancer when 15-39 year old) cancer survivors are more likely to experience psychological distress compared to adults with no history of cancer<sup>65,66</sup>. Psychological distress in cancer survivors can be expressed as depression, anxiety, panic attacks, post-traumatic stress disorder, cancer worry, or anger<sup>16,67,68</sup>. The reported prevalence of psychological distress in AYA cancer survivors has varied widely<sup>11</sup> depending on the type of measured psychological condition<sup>18</sup>, criteria used for diagnosis<sup>16</sup>, and the type of associated cancer<sup>3</sup>.

Psychological distress has been found to impact quality of life and health status of cancer survivors<sup>69-72</sup>. Worse psychological outcomes have been found among cancer survivors without health insurance, those who are unmarried or live alone, who have chronic conditions or who smoke<sup>19,20</sup>. In addition, sociodemographic characteristics, such as female gender<sup>73</sup>, younger age, and lower education, were associated with psychological distress in both healthy adults and cancer

survivors; however, associations between distress and sociodemographic characteristics were stronger in cancer survivors<sup>19</sup>. Expenses associated with psychological distress in cancer survivors can be substantial. Psychological distress was found to increase average annual medical expenditures by \$4,431 in cancer survivors of all ages<sup>28</sup>. Distress was not only associated with expenses, but also associated with increased health care utilization in cancer survivors of all ages<sup>74</sup>

AYA cancer survivors encounter unique challenges pertaining to their age of diagnosis, including managing long-term impacts on health, disturbance of social life, and challenges with employment and health insurance<sup>33</sup> that can exacerbate psychological distress<sup>75</sup>. Despite younger cancer survivors experiencing higher prevalence of psychological distress<sup>19</sup>, no prior studies have examined the cost associated with psychological distress in AYA cancer survivors. Therefore, we estimated the health care expenditures and health care utilization associated with psychological distress in AYA cancer survivors. Moreover, we examined the relation of psychological distress with sociodemographic characteristics, health care access and health factors.

## **Methods**

### **Data Sources**

We used the household component of 2011-2016 Medical Expenditure Panel Survey (MEPS)<sup>36</sup>, which collected data from a nationally representative sample of U.S. non-institutionalized civilians. The sample is taken from the panel of individuals who completed the National Health Interview Survey, with a final response rate of 53.5%-59.3%. The panel is surveyed for five rounds of in-person interviews and self-administered questionnaires over a

period of two years. MEPS gathers comprehensive information on sociodemographic characteristics, health status, medical conditions and health care expenditures<sup>37</sup>.

### **Study population**

We identified participants who reported that they were diagnosed with cancer between 15 and 39 years of age. We considered all types of cancer, except non-melanoma skin cancers, consistent with previous studies that have not classified people with non-melanoma skin cancer as cancer survivors<sup>2,5</sup>. We identified 2,431 AYA cancer survivors. We excluded 350 participants with missing information about psychological distress resulting in 2,081 eligible AYA cancer survivors. We used this sample to estimate the weighted prevalence of psychological distress in AYA cancer survivors by time since diagnosis. For the comparison group, we used propensity score matching methods to identify our population for adults with no history of cancer. There were 118,564 adults without a history of cancer who were eligible. We matched on age $\pm$  2 years, sex whether male or female, and race/ethnicity whether Hispanic or non-Hispanic white, Black, Asian, or other. We conducted unconditional logistic regression to obtain the propensity score, which is the predicted conditional probability of being AYA cancer survivor based on the matched covariates. We used the propensity score to get 3 matched adults with no history of cancer for each AYA cancer survivor using the greedy matching process in SAS<sup>76</sup>. In the matched analysis, we excluded 324 due to missing information on race/ethnicity, a matching factor, resulting in 1,757 AYA cancer survivors and a matched sample of 5,227 adults with no history of cancer included.

### **Measures**

#### **Outcomes**

Medical expenditures were calculated based on the reported health care use as dollar amount spent on ambulatory visits, inpatient admissions, emergency visits, prescription medications averaged per year and adjusted for inflation up to the year of 2016 using Personal Health Care Expenditure Price Index. Additional medical expenses for psychological distress reflect expenditures above those for AYA cancer survivors without psychological distress. Health care utilization was measured as the number of ambulatory visits, inpatient nights, emergency visits, and prescribed medications, including refills, per year.

#### Psychological distress

Psychological distress was assessed using Kessler (K6) item questionnaire (Endicott, 1984). It shows consistency when measuring distress across multiple sociodemographic population and has been validated as a screening tool for clinically significant psychological distress. The participants were asked how often they felt so sad nothing could cheer them up, nervous, restless, or fidgety, hopeless, that everything was an effort, or felt worthless in the past 30 days (all of the time, most of the time, some of the time, a little of the time, or none of the time). Scores were summed to generate a total symptom score with scores  $\geq 13$  indicating clinically significant distress.

#### Covariates

Sociodemographic characteristics included age, sex, education, marital status, race/ethnicity, family income, and health insurance based on participant self-report. Time since diagnosis was calculated based on the difference between age at survey and age of cancer diagnosis. Measures of access to health care included having a routine checkup in the past year,

health insurance type (private, public, or uninsured), having a usual source of care, and ability to access care when needed. Elevated body mass index (BMI) was defined as  $>25 \text{ kg/m}^2$  and adverse health behaviors included smoking (currently smoke) and not exercising regularly (not meeting the guidelines of 150 minutes/week). Chronic conditions were identified by a series of survey questions asking the participant whether a physician or other health care professional ever told them that they had coronary heart disease (CHD), angina, myocardial infarction (MI), other unspecified heart disease, high blood pressure, high cholesterol, diabetes, asthma, chronic bronchitis, emphysema, stroke, and arthritis. We produced a binary variable of having at least one or more of these chronic conditions and added it to our model.

### **Statistical Analysis**

Descriptive statistics with chi-square tests were used to compare characteristics of those with and without psychological distress for AYA cancer survivors and adults without a history of cancer. We used unconditional logistic regression to estimate bivariate and multivariable associations of psychological distress with sociodemographic characteristics, health care access, and health factors. Weighted analysis was conducted to compare psychological distress in AYA cancer survivors by time since diagnosis to adults with no history of cancer (Supplemental Figure 1). Multivariable regression models, with gamma distribution and log link were used to estimate the association of psychological distress with medical expenditures. Multivariable regression models, with negative binomial distribution and log link were used to estimate office-based visits and prescription medication use including refills. Two-part zero inflation negative binomial models were used to estimate the number of inpatient nights and emergency room visits because a large percentage of AYAs did not use these services. All models were adjusted for chronic conditions, age at survey, sex, race/ethnicity, education, marital status, income, insurance,

exercise, body mass index, and smoking status. All descriptive statistics and regression models were conducted separately for AYA cancer survivors and on a matched sample of adults without a history of cancer. All analyses were conducted using SAS statistical software (version 9.4).

## **Results**

### **Prevalence of psychological distress among AYA cancer survivors and non-cancer participants**

Among 1,757 AYA cancer survivors, 11.5% reported having psychological distress, while among the 5,227 matched adults with no history of cancer, 5.8% reported having psychological distress. Psychological distress in AYA cancer survivor remains significantly increased long after cancer diagnosis, with 11.2% reporting distress  $\geq 20$  years after cancer diagnosis (Figure 1). Psychological distress did not differ by the time from diagnosis or by the malignancy diagnosis.

### **Characteristics of AYA cancer survivors with and without psychological distress**

In AYA cancer survivors, higher psychological distress was observed in females, those with lower income, unmarried, or having public versus private insurance (Table 1). Smoking and physical inactivity were more common in AYA survivors with psychological distress. AYA cancer survivors with psychological distress were more likely to have a checkup in the last year but also report being unable to get care when needed. In addition, adults without a history of cancer who had psychological distress were more likely to have a higher BMI than those without psychological distress.

## **Health care access, health factors and sociodemographic characteristics associated with psychological distress**

In multivariable models, AYA cancer survivors with psychological distress were more likely than AYA cancer survivors without psychological distress to have public health insurance (vs private; OR=5.90, 95% CI 3.14 to 11.09), exercise less regularly (OR=2.22, 95% CI 1.16 to 4.17), smoke (OR=3.37, 95% CI 1.89 to 6.04), have chronic conditions (OR=2.98, 95% CI 1.19 to 7.46) and be unmarried (add OR and 95% CI) (Table 2). Associations were similar, but of lower magnitude, in multivariable models among matched adults without a cancer history (Supplemental Table 1).

## **Additional medical expenditure and health care utilization associated with psychological distress**

AYA cancer survivors without psychological distress had an average of \$5,324 (95% CI, \$3,275 to \$8,653) in annual medical expenditures (Supplemental Table 2). In these AYA cancer survivors, psychological distress was associated with an additional \$4,415 (95% CI, \$993 to \$9,690) in annual medical expenditures (Table 3). Psychological distress in an AYA cancer survivor also was associated with an average of 2.80 additional office visits (95% CI, 0.23 to 6.15), and use of 11.58 additional prescription medications/medication renewals (95% CI, 5.70 to 19.47) annually compared to AYA survivors of cancer without psychological distress. In matched adults without history of cancer, psychological distress was associated with an additional \$1,802 (95% CI, \$440 to \$3,791) in annual medical expenditures, 4.77 additional office visits (95% CI, 2.27 to 7.96), and use of 10.73 additional prescription medications/medication renewals (95% CI, 6.25 to 16.56) annually.

## **Discussion**

In our analysis of the nationally representative MEPS data, we found that prevalence of psychological distress in AYA cancer survivors was two times higher than that observed in adults with no history of cancer, consistent with other recent population-based studies of cancer survivors<sup>28,65</sup>. In addition, Psychological distress was associated with increased healthcare utilization and additional medical expenditures. AYA cancer survivors with psychological distress had an additional \$4,415 in annual medical expenditures, compared to \$1,802 in additional medical expenditures among adults without a history of cancer. Our study is the first to estimate the additional medical expenses and health care utilization associated with psychological distress in AYA cancer survivors. We also found that AYA cancer survivors with psychological distress were more likely to have chronic conditions, smoke, exercise less regularly, and have public insurance or be uninsured compared to those with no psychological distress, highlighting the need to consider behavioral factors and health insurance type when addressing psychological distress in AYA cancer survivors. Overall, the high prevalence of psychological distress emphasizes the importance of developing strategies that address long term psychological morbidities associated with cancer and its treatment.

Psychological distress, in our sample, was found to be increased in AYA cancer survivors compared to those without cancer and it persists long (>20 years) after cancer diagnosis. Psychological distress can occur due to immediate stressors related to worries about treatment of current cancer<sup>11,77-79</sup> or long-term side effects<sup>67,80</sup>, consistent with our findings of higher psychological distress among those with chronic conditions. Previous studies have found that



depression, anxiety, and posttraumatic stress disorder are among the major psychological disorders in long-term AYA cancer survivors who were an average of 12 years from cancer diagnosis<sup>20,70</sup>. In addition, psychological distress was found to be higher in cancer survivors than among people with other chronic conditions<sup>19</sup>, highlighting the importance of screening and interventions to reduce psychological distress in AYA cancer survivors, especially those who have chronic conditions.

Previous studies found that cancer negatively impacts finances in AYA cancer patients<sup>75,81</sup>. In our study, we found that psychological distress was associated with additional medical expenditures in both AYA cancer survivors and adults with no history of cancer. However, the costs associated with psychological distress in AYA cancer survivors were higher than the costs incurred by adults with no history of cancer. Our estimates of cost were adjusted for factors associated with psychological distress, including chronic conditions, health behaviors and sociodemographic factors. Previous studies found that the high cost of care was associated with delay in getting care in AYA cancer survivors<sup>13</sup>. We also found that office-based visits and prescription medication use/refills were significantly higher in AYA cancer survivors with psychological distress compared to those without psychological distress. Our medical care expenditure and healthcare utilization findings are consistent with prior studies<sup>28</sup>. Psychological distress was associated with higher mental and physical health care utilization in cancer patients<sup>82,83</sup> and depression was associated with emergency room and office-based visits up to one year post diagnosis and the cost associated with depression remained high up to eight years after diagnosis<sup>84</sup>. Depression also was found to be associated with higher medical expenditure<sup>85</sup>.

Together, these findings highlight the magnitude of economic burden and healthcare utilization associated with psychological distress in AYA cancer survivors.

We found that AYA cancer survivors with higher psychological distress were more likely to have public or no insurance, smoke, be physically inactive and be unmarried. Consistent with our findings, psychological distress has been found to be associated with being a current cigarette smoker and having public or no insurance in AYA cancer survivors<sup>65</sup>. Psychological distress in cancer survivors could be related to the impact of cancer on physical health, social life, employment opportunities or insurance coverage<sup>20</sup>. Our study results suggest that health behaviors and potential issues with health insurance should be addressed in AYA cancer survivors with psychological distress. For example, physical activity interventions have been found to benefit the psychological health of AYA cancer survivors<sup>86,87</sup>. In addition to physical activity interventions, psychotherapeutic and psycho-educational interventions can improve psychological outcomes in pediatric and AYA cancer survivors<sup>88</sup>, as psychological distress is influenced by the level of coping, beliefs<sup>23</sup> and attitude toward cancer<sup>89</sup>. Psychological interventions, especially those using cognitive behavioral therapy, have been found to be cost effective in improving health status compared to usual care in cancer patients<sup>90</sup>.

Health care expenses and utilization outcomes associated with psychological distress in cancer survivors were less frequently studied compared to quality-of-life measures<sup>91</sup>. Our findings highlight the importance of including psychological surveillance and treatment in survivorship care plans of AYA cancer survivors. Specifically, the American Society of Clinical Oncology recommends that survivorship care plans acknowledge that survivors often face

emotional or mental health issues, advise those experiencing any of these issues to address them with their oncology or primary care provider and provide a list of local and national resources developed at individual sites<sup>92</sup>. Multiple indicators of high quality psychologic care have been identified among cancer survivors, including the availability of psychological health care professionals, following evidence -based treatment plans and early referral to psychoeducational counseling<sup>91</sup>.

Several limitations of our study need to be recognized. First, we were not able to examine causal relationships for factors associated with psychological distress, as this is a cross-sectional study, but were able to assess its association with medical expenditures and healthcare utilization. Cancer stage, severity, and type of treatment were not included in the analysis, as the survey lacked this information. Previous studies found that treatment type was found to be associated with psychological distress and depressive symptoms<sup>17,93</sup>. We did not have information regarding specific psychological disorders so were unable to consider these associations in our study. However, the Kessler psychological distress questionnaire has high sensitivity and specificity in screening for psychological distress in cancer survivors<sup>94</sup>. Furthermore, our study estimated the total medical expenditures and healthcare utilization by type of service in addition to the roles of health care access, health behavior, BMI, and sociodemographic characteristics in relation to psychological distress for a very vulnerable population of AYA cancer survivors. Future research should focus on conducting longitudinal studies to explore underlying factors leading to psychological distress.

## **Conclusion**

Psychological distress is common in AYA cancer survivors, persists long after cancer diagnosis, and is associated with significant medical expenditures as well as health care utilization. The results from our study suggest that there is a substantial need for psychological care intervention for short- and long-term AYA cancer survivors. Employing survivorship care plans that acknowledge psychological needs by screening to identify those with psychological distress and referring survivors to treatment or interventions can mitigate the impact of psychological distress in AYA cancer survivors<sup>68</sup>.

Table 1. Characteristics of adolescent and young adult (AYA) cancer survivors and adults\* with no history of cancer by psychological distress, Medical Expenditure Panel Survey 2011-2016

Characteristics	AYA cancer survivors with psychological distress (N=202, 11.50%)	AYA cancer survivors without psychological distress (N= 1555, 88.50%)	P-value	Adults with psychological distress and no history of cancer (N=301, 5.76%)	Adults without psychological distress or history of cancer (N=4926, 94.24%)	P-value
	N (%)	N (%)		N (%)	N (%)	
Age			0.14			0.20
18-29	20 (9.90)	159 (10.23)		32 (10.63)	524 (10.64)	
30-39	49 (24.26)	353 (22.70)		64 (21.26)	1177 (23.89)	
40-49	63 (31.19)	417 (26.82)		83 (27.57)	1294 (26.27)	
50-64	55 (27.23)	413 (26.56)		94 (31.23)	1305(26.49)	
65 or older	15 (7.43)	213 (13.70)		28 (9.30)	626 (12.71)	
Sex:			0.03			0.05
Male	29 (14.36)	322 (20.71)		46 (15.28)	985 (20.00)	
Female	173 (85.64)	1233 (79.29)		255 (84.72)	3941 (80.00)	
Race/ethnicity:			0.10			0.07
Hispanic	46 (22.77)	326 (20.96)		58 (19.27)	1071 (21.74)	
Non-Hispanic white	117 (57.92)	943 (60.64)		178 (59.14)	2964 (60.17)	
Non-Hispanic black	26 (12.87)	199 (12.80)		43 (14.29)	614 (12.46)	
Non-Hispanic Asian and other	13 (6.44)	87 (5.59)		22 (7.31)	277 (5.62)	
Education:			0.11			0.08
Less than high school	57 (45.97)	420 (45.50)		90 (48.65)	1305 (43.41)	
High school graduate	47 (37.90)	285 (30.88)		62 (33.51)	945 (31.44)	
Some college or more	20 (16.13)	218 (23.62)		33 (17.84)	756 (25.15)	
Marital status:			<0.00			<0.001
Married	70 (39.33)	746 (53.52)	1	112 (45.71)	2698 (60.59)	
Not married	108 (60.67)	648 (46.48)		133 (54.29)	1755 (39.41)	
Health insurance:			<0.00			<0.001
Private	61 (30.20)	930 (59.81)	1	121 (40.20)	3156 (64.25)	
Public	119 (58.91)	446 (28.68)		130 (43.19)	1015 (20.60)	
Uninsured	22 (10.89)	179 (11.51)		50 (16.61)	746 (15.14)	
Income:			<0.00			<0.001
Poor	93 (46.04)	322 (20.71)	1	108 (35.88)	808 (16.40)	
Near poor	21 (10.40)	93 (5.98)		23 (7.64)	240 (4.87)	
Low income	31 (15.53)	233 (14.98)		58 (19.27)	765 (15.53)	
Middle income	45 (22.28)	446 (28.68)		82 (27.24)	1512 (30.69)	
High income	12 (5.94)	461 (29.65)		30 (9.97)	1601 (32.50)	
Smoking			<0.00			<0.001
Yes	103 (53.09)	340 (22.30)	1	93 (31.42)	724 (14.94)	
No	91 (46.91)	1185 (77.70)		203 (68.58)	4123 (85.06)	
Exercise regularly			<0.00			<0.001
Yes	61 (30.20)	728 (47.24)	1	94 (31.65)	2301 (47.00)	
No	141 (69.80)	813 (52.76)		203 (68.35)	2595 (53.00)	
BMI			0.21			0.002
≤25	54 (26.73)	5483 (31.06)		79 (26.25)	1719 (34.90)	
>25	148 (73.27)	1072 (68.94)		222 (73.75)	3207 (65.10)	

Checkup last year			0.06			0.02
Yes	162 (81.00)	1140 (74.95)		222 (74.75)	3296 (68.35)	
No	38 (19.00)	381 (25.05)		75 (25.25)	1526 (31.65)	
Having usual care			0.16			0.90
Yes	172 (85.75)	1258 (81.53)		232 (77.59)	3762 (77.26)	
No	29 (14.43)	285 (18.47)		67 (22.41)	1107 (22.74)	
Unable to get care when needed			<0.00			<0.001
Yes	33 (16.43)	77 (4.96)	1	40 (13.33)	165 (3.36)	
No	169 (83.66)	1475 (95.04)		260 (86.67)	4753 (96.64)	

\*Matching (3 adults with no history of cancer to each AYA cancer survivor) based on age, sex and race/ethnicity

Table 2. Association of psychological distress with access to health care, health factors and sociodemographic characteristics among AYA survivors of cancer: Medical Expenditure Panel Survey, 2011 to 2016

Characteristics	Unadjusted		Adjusted*	
	Odds of having Psychological distress OR (95%CI)	P-value	Odds of having Psychological distress OR (95%CI)	P-value
<b>Access to health care</b>				
Checkup last year	1.12 (0.69-1.79)	0.64	0.90 (0.43-1.86)	0.76
Public vs private insurance	5.67 (3.51-9.16)	<0.001	5.90 (3.14-11.09)	<0.001
Uninsured vs private	3.67 (1.66-8.13)	0.002	5.32 (1.79-15.77)	0.003
Unable to get needed care	2.89 (1.58-5.30)	<0.001	1.74 (0.87-3.49)	0.12
Having usual source of care	1.13 (0.61-2.11)	0.69	1.31 (0.70-2.46)	0.39
<b>Health factors</b>				
Exercise regularly	0.44 (0.29-0.67)	0.0001	0.45 (0.24-0.86)	0.016
Elevated BMI>25	1.13 (0.71-1.80)	0.60	0.82 (0.39-1.71)	0.59
Smoking	4.51 (2.98-6.84)	<0.001	3.37 (1.89-6.04)	<0.001
Chronic conditions	1.97 (1.09-3.56)	0.02	2.98 (1.19-7.46)	0.02
<b>Sociodemographic characteristics</b>				
Sex (female vs male)	1.56 (1.03-2.35)	0.03	1.58 (0.73-3.41)	0.24
<b>Education</b>				
Less than high school	Ref		Ref	
High school graduate	1.22 (0.80-1.84)	0.36	1.15 (0.61-2.18)	0.67
Some college or more	0.68 (0.40-1.15)	0.15	0.76 (0.30-1.92)	0.56
<b>Marital status (Unmarried vs married)</b>				
	1.77 (1.29-2.44)	<0.001	1.85 (1.04-3.31)	0.04
<b>Race/ethnicity</b>				
Non-Hispanic White	Ref		Ref	
Hispanic	1.14 (0.79-1.64)	0.49	1.66 (0.73-3.78)	0.22
Non-Hispanic black	1.05 (0.67-1.65)	0.82	1.03 (0.51-2.08)	0.93
Non-Hispanic Asian and other	1.20 (0.65-2.23)	0.55	1.09 (0.39-3.04)	0.87

\*Models adjusted for age, time since diagnosis, and other covariates in the table

Table 3. Additional medical expenses, health care use and medications for psychological distress in AYA cancer survivors and matched\* adults with no history of cancer: Medical Expenditure Panel Survey, 2011 to 2016

	AYA cancer survivors Mean (95%CI)	P-value	Adults with no history of cancer Mean (95%CI)	P-value
Total expenses \$	\$4415.49 (993.43-9689.85)	0.006	\$1802.44 (439.65-3790.60)	0.005
No. of additional Office based visits	2.80 (0.23-6.15)	0.03	4.77 (2.27-7.96)	<0.0001
No. of additional Inpatient nights	0.19 (-0.36-1.08)	0.56	0.12 (-0.33-0.82)	0.65
No. of additional Emergency room visits	0.23 (-0.11-0.68)	0.21	-0.003 (-0.32-0.41)	0.98
No. of additional Medication number	11.58 (5.70-19.47)	<0.0001	10.73 (6.25-16.56)	<0.0001

All models adjusted for age, sex, race and ethnicity, education, marital status, income, insurance, exercise, body mass index, smoking status, and chronic conditions

\*Matching (3 adults with no history of cancer to each AYA cancer survivor) based on age, sex and race/ethnicity



### **Chapter 3: Shared decision-making, medical expenditures, and health care utilization among adolescent and young adult cancer survivors**

#### **Abstract**

**Background:** Engagement of patients in their own care can potentially lead to better health outcomes, especially for the vulnerable population of adolescent and young adult (AYA) cancer survivors who experience psychological distress and chronic conditions more often than non-cancer patients. However, no prior studies examined the association between decision sharing and health outcomes, medical expenditures, and health care utilization in AYA cancer survivors.

**Methods:** AYA cancer survivors (n=1,162) and a comparison group of matched adults with no history of cancer (n=2,954) was identified from 2011-2016 Medical Expenditure Panel Survey (MEPS) data. Medical expenditures and health care utilization associated with shared decision making (SDM) were evaluated using multivariable regression models.

**Results:** AYA cancer survivors were more likely to report poor SDM compared to adults with no history of cancer (Odds Ratio=1.31, 95% Confidence Interval (CI): 1.06 to 1.62). AYA cancer survivors with poor SDM were more likely to report poor mental and physical health compared to AYAs with good SDM. AYA cancer survivors with poor SDM had \$3,037 (CI: \$110 to \$7,032) in additional annual medical expenses and 4.86 (CI: 2.00 to 8.52) in additional office visits compared with AYA cancer survivors with optimal SDM, even after adjusting for chronic conditions and psychological distress.

**Conclusion:** Our results highlight the substantial economic burden associated with poor SDM in AYA cancer survivors.

**Implication:** Our research suggests that interventions to improve SDM in AYA cancer survivors may contribute to patient's positive perception about their health and result in AYAs seeking fewer medical services resulting in lower medical expenses.

**Keywords.** adolescent and young adult cancer survivors, Shared decision making, health expenditures, healthcare use, health behavior

## Introduction

Adolescent and young adult (AYA) cancer survivors are at an increased risk of physical and psychosocial late effects of cancer treatment<sup>61</sup> and are more likely to use health care services than adults without a history of cancer<sup>95</sup>. More generally, physician-patient communication is essential for delivering appropriate information about diagnoses and in making decisions about treatment plans<sup>96</sup>.

Shared Decision Making (SDM) involves educating patients on the available evidence for care options and weighing this against their preferences<sup>7</sup>. SDM is a part of patient-centered care that improves doctor patient communication and ensures that the patient's values lead all health care decisions instead of the physician dictating patient care. Engagement of patients in their own care can lead to better health outcomes for the patients and greater cost efficiency for the health care system<sup>8</sup>. Cancer survivors have reported better quality of care when they are involved in decision making<sup>25</sup>.

Effective doctor-patient communication can also ensure receiving timely care for cancer patients<sup>97</sup>. Successful SDM can reduce unnecessary visits and increase patient adherence to medications and the treatment plans<sup>26</sup>. Moreover, patients who have been involved in decision making have been found to spend \$1800 less on health care annually than those who have not been involved<sup>8</sup>. Despite the Affordable care Act (ACA) encouraging use of SDM in health care<sup>98</sup>, many health care providers do not adhere to SDM principles<sup>27</sup>.

Although studies have assessed the importance of SDM for improving quality of care and lowering health care expenditures in adults with specific chronic conditions, including diabetes and atherosclerosis<sup>99,100</sup>, no studies have examined these associations in AYA cancer survivors, a group with a higher prevalence of chronic conditions, psychological distress, and healthcare

utilization<sup>5,32</sup>. Therefore, our aim is to examine access to care, health status, perceived health, and health behaviors associated with SDM as well as the association of SDM with health care utilization and medical expenditures in AYA cancer survivors.

## **Methods**

### **Data Source**

We used the household component of the 2011-2016 Medical Expenditure Panel Survey (MEPS)<sup>36</sup>, which collected data from a nationally representative sample of U.S. non-institutionalized civilians. The final response rate ranged from 53.5% to 59.3%. The sample is taken from the panel of individuals who completed the National Health Interview Survey. The panel is surveyed for five rounds of in-person interviews and self-administered questionnaires over a period of two years. MEPS gathers comprehensive information on sociodemographic characteristics, health status, medical conditions, and health care expenditures<sup>37,101</sup>.

### **Study population**

We identified participants who reported that they were first diagnosed with cancer between 15 and 39 years of age, as done previously<sup>32</sup>. We considered all types of cancer, except non-melanoma skin cancers, consistent with previous studies that have not classified people with non-melanoma skin cancer as cancer survivors<sup>2,5</sup>. We identified 2,431 AYA cancer survivors. As done previously<sup>100</sup>, we excluded participants with no usual source of care, BMI<18.5 and those with person survey weight =0. For the comparison group, we used propensity score matching methods to identify our population for adults with no history of cancer. There were 118,564 adults without a history of cancer who were eligible. We matched on age  $\pm 2$  years, sex (male, female), and race/ethnicity (Hispanic of any race, non-Hispanic white, non-Hispanic Black, non-Hispanic Asian, other). We conducted unconditional logistic regression to obtain the propensity score,

which is the predicted conditional probability of being AYA cancer survivor based on the matched covariates. We used the propensity score to identify 3 matched adults with no history of cancer for each AYA cancer survivor using the greedy matching process in SAS<sup>76</sup>. In the matched analysis, we excluded participant with missing information on matching factors, resulting in matched sample of 2,954 adults with no history of cancer.

## **Measures**

### **Outcomes**

Medical expenditures were calculated based on the reported health care use as dollars spent on ambulatory visits, inpatient nights, emergency visits, and prescription medications per year. Additional medical expenses reflect additional expenditures above those for AYA cancer survivors with optimal shared decision. Health care utilization was measured as the number of ambulatory visits, inpatient nights, emergency visits, and any prescribed medications, including refills, per year.

### **Shared decision-making measures**

Shared decision making was measured using a self-administered questionnaire adapted from Consumer Assessment of Healthcare Providers and Systems Clinician and Group (CAHPS-CG) survey which is a widely used survey to assess patient experiences in health care. A total score out of 12 was given for each participant. The score was based on 4 questions about patient doctor SDM. Questions include: 1) how often healthcare providers explained things in a way that was easy to understand? (2) how often providers showed respect for what you had to say? (3) how often providers spent enough time with you? (4) how often providers listened carefully to you? The responses provided on a 4-point Likert scale: 1-never, 2-sometimes, 3-usually, and 4-always. We combined never and sometimes based on the method used by previous studies<sup>7</sup>. The final

composite SDM scores ranged from 4 to 12, which were used to categorize an overall assessment of SDM, classified as “poor” (4-7 points), “average” (8-11 points), and “optimal” (12 points).

#### Covariates

Sociodemographic characteristics included age at survey, sex, education, marital status, race/ethnicity, health insurance based on participant self-report, and family income based on the poverty statistics developed by the Current Population Survey as percentage of the applicable poverty line (based on family size and composition). Income was categorized as poor (<100%), near poor (100% to <125%), middle income (125% to <200%), middle income (200% to <400%), and high income ( $\geq$  400%). Time since diagnosis was calculated based on the difference between age at survey and age of cancer diagnosis. Elevated body mass index (BMI) was defined as  $>25$  kg/m<sup>2</sup> and health behaviors included current smoking and not exercising regularly, defined as not meeting the guidelines of 150 minutes/week. Access to health care measures included health insurance type (private, public, or uninsured) and unable to get needed care (unable to receive or delay in receiving needed treatment).

Chronic conditions were identified by a series of survey questions asking the participant whether a physician or other health care professional ever told them that they had coronary heart disease, angina, myocardial infarction, other unspecified heart disease, high blood pressure, high cholesterol, diabetes, asthma, chronic bronchitis, emphysema, stroke, or arthritis. We classified participants as having at least one or more of these chronic conditions versus none. Psychological distress was measured using Kessler (K6) item questionnaire<sup>94</sup>. The participants were asked how often they felt so sad nothing could cheer them up, nervous, restless, or fidgety, hopeless, that everything was an effort, or felt worthless in the past 30 days (all of the time, most of the time, some of the time, a little of the time, or none of the time). Scores were summed to generate a total

symptom score, with scores  $\geq 13$  indicating clinically significant distress. Perceived mental and physical health were measured by asking each person to rate their health (excellent, very good, good, fair, poor) and categorized as poor/fair and at least good (good, very good and excellent).

### **Statistical Analysis**

Descriptive statistics with chi-square tests were used to compare characteristics of AYAs with optimal vs average vs poor SDM. We also used multinomial logistic regression to estimate bivariate and multivariable associations between having poor and average SDM (versus optimal) with health behaviors and health care access. Multivariable regression models with gamma distribution and log link were used to estimate medical expenditures. As done previously<sup>2</sup>, multivariable regression models with negative binomial distribution and log link were used to estimate office-based visits and prescription medication use including refills. Two-part zero inflation negative binomial models were used to estimate the number of inpatient nights and emergency room visits because a large percentage of AYAs did not use these services. All models were adjusted for chronic conditions, age at survey, sex, race/ethnicity, education, marital status, income, insurance, exercise, body mass index, and smoking status. All descriptive statistics and regression models were conducted separately for AYA cancer survivors and on a matched sample of adults without a history of cancer. Analyses were conducted using SAS statistical software (version 9.4).

### **Results**

#### **Characteristics of AYA cancer survivors and adults with no history of cancer**

Table 1 show that AYA cancer survivors who reported poor SDM were more likely to be uninsured or have public health insurance vs those with optimal SDM (8% and 47% vs 4% and 34%;  $p < 0.001$ ). In addition, they were more likely to smoke (29% vs 22%;  $p = 0.06$ ), report not

getting care when needed (1% vs 4%;  $p<0.001$ ), have psychological distress (25% vs 12%;  $p<0.001$ ) and perceive their mental (36% vs 16%;  $p<0.001$ ) and physical health (51% vs 30%;  $p<0.001$ ) as poor/fair. Similar results were found in the matched sample of adults with no history of cancer. Further, in adults without a history of cancer, those with poor SDM were less likely to exercise regularly, more likely to be of Hispanic race/ethnicity, and more likely to have lower income compared to those with optimal SDM.

### **Shared decision making in AYA cancer survivors**

Compared to matched adults without history of cancer (11.44%), AYA cancer survivors were more likely to report poor SDM (14.11%, Figure 1). The odds of reporting poor SDM was 1.31 (95%CI; 1.06 to 1.62) times higher in AYA cancer survivors compared to adults without a history of cancer after adjusting for age, sex and race/ethnicity, education, and income.

### **Association between shared decision making and health status**

In multivariable models, the odds of reporting poor SDM (vs optimal) were higher in AYA cancer survivors with psychological distress than those without psychological distress OR= 3.10 (95% CI 1.44 to 6.72) (Table 2). Moreover, AYA cancer survivors who perceived their physical health as at least good were less likely to report poor SDM (OR=0.52, 95% CI 0.27 to 0.97). Among adults without history of cancer, results were similar for psychological distress and perceived physical health (Table 3). In addition, those who were unable to get care when needed were more likely and those who perceived their mental health as at least good were less likely to report poor SDM.

### **Shared decision making, medical expenditures and health care utilization**



AYA cancer survivors with optimal SDM had an average of \$7,896 (95%CI, \$5,707 to \$10,925) in annual medical expenditures and 8.36 (95%CI, 6.60 to 10.58) annual office visits (Table 4). Additional health care expenditures of \$3,037 (95%CI; \$110 to \$7,032) and office visits of 4.86 (95%CI; 2.00 to 8.52) were found in those who reported poor (vs optimal) SDM. Adults without a history of cancer had an average of \$3,726 (95%CI, \$2,889 to \$4,807) in annual medical expenditures and 5.90 (95%CI, 4.88 to 7.13) annual office visits (Table 5). Similar to AYA cancer survivors, higher medical expenditures and increased office visits were observed among those without a history of cancer who reported poor SDM, we found that they have an additional \$2,242 (95%CI; \$1,036 to \$3,753) for poor SDM than those with optimal SDM and use more 2.38 (95%CI 1.08 to 3.93) office visits.

## **Discussion**

In our nationally representative study, we found that poor SDM was higher in AYA cancer survivors compared to adults without a history of cancer. AYA cancer survivors with psychological distress and those who perceive their physical health as poor/fair were more likely to report poor SDM, findings that were similar in our analyses of adults without a history of cancer. In addition to having higher medical expenditures and office visits than adults without a history of cancer, medical expenditures, and office visits among AYA cancer survivors with poor SDM were substantial. Specifically, AYA cancer survivors with poor SDM spent an additional \$3000 and had 5 additional office visits per year compared to those with optimal SDM. Our findings are consistent with previous studies that identified good doctor patient communication to reduce referrals and diagnostic tests, improve patient perception about their health<sup>102</sup>, and lower the cost of care<sup>27</sup>.

We found a higher prevalence of poor SDM in AYA cancer survivors compared to adults without a history of cancer, findings that are consistent with previous studies on cancer patients of all ages<sup>103</sup>. One explanation for this poorer SDM is that cancer survivors are more likely to have physical and psychological health problems that need more time, explanation, and attention compared to adults without a history of cancer. However, after adjusting for both chronic conditions and psychological distress, poor SDM remained higher in AYA cancer survivors, highlighting the need to improve SDM in this population. We also observed that poor SDM was associated with increased medical expenditures and office visits among AYA cancer survivors in our study. Further, for those reporting poor SDM, AYAs expenditures and health care office visits were higher compared to adults without history of cancer. These findings are supported by a previous study that found poor SDM to be associated with both higher health care utilization and health care expenditures among patients who visited a primary care physician<sup>104</sup>.

The Institute of Medicine has emphasized the importance of SDM in cancer patients as a part of patient centered care due to the complexity of treatment plans, limited of evidence for many treatment options, and treatment options having tradeoffs of risks and benefits that can greatly change by patient preferences and values<sup>105</sup>. The SDM model provides an alternative model to the paternalistic informed models previously used that focus on one direction of information exchange from doctor to patient<sup>106</sup>. A key characteristic of SDM is a stepwise process where both patient and physician share the information and agree on the treatment plan<sup>26 108</sup>. Patient satisfaction with radiation treatment were found to be highly correlated with perceived SDM among cancer patients<sup>109</sup>.

We found that having psychological distress was highly associated with reporting poor SDM in AYA cancer survivors. This finding may relate to patient satisfaction, as studies have

identified psychological factors, specifically anxiety, to be strong determinants of patient satisfaction in patients with atraumatic painful upper extremity<sup>26</sup> or among cancer patients<sup>103</sup>. A systematic review of several studies suggested that psychological distress should be accounted for when collecting patient reported measures of care satisfaction<sup>110</sup>. In addition, those who perceived that they are in at least good physical health were less likely to report poor SDM in our study. These findings are consistent with a study that found involvement in treatment decisions to be associated with higher social and physical functioning among women with breast cancer<sup>111</sup> and a systematic literature review that identified effective doctor patient communication to be associated with better emotion regulation of patient, perceived satisfaction, and better recovery<sup>112</sup>. Moreover, effective doctor patient communication has been found to reduce patient anxiety and reduce the need for future visits or unnecessary tests<sup>102</sup>. However, to date, interventions among physicians and patients to increase SDM has not shown any promising improvement in the reported and measured use of SDM in health care settings<sup>113</sup>.

Compared to adults without a history of cancer, AYA cancer survivors were more likely to have higher medical expenditures and more office visits even with optimal SDM. This may be explained by AYA cancer survivors being more likely to have serious and multiple chronic conditions<sup>32</sup> and/or more severe psychological distress<sup>29</sup> than adults without history of cancer which can increase medical expenses and health care use<sup>15</sup>. Having long term chronic conditions has been significantly correlated with higher expenses and office visits in AYA cancer survivors<sup>95</sup>. Because of high healthcare costs, a previous study found that AYA cancer survivors are more likely to forgo medical care compared to those with no history of cancer<sup>5</sup>.

Some limitations to this study include that this study is cross-sectional, so we were not able to confirm any of the temporal relations between exposures and outcomes. Instead, future

longitudinal studies are needed to elucidate the casual relationships. SDM and other measures in this study were based on self-report, which might be subject to recall and information bias and driven by one bad experience. However, self-reported measures have been validated as a measure of patient experience in health care<sup>114</sup>. Even though SDM is frequently reported in the literature, there is no standard or unified measure across studies. The self-reported measure also might be affected by the participants psychological status, which we attempted to minimize by considering psychological distress in our analysis. Despite these limitations, our study used MEPS data which is population-based and provides a representative sample of the population. It also provides measurable insight on the potential economic outcome of applying SDM in medical settings and included a comparison population of matched adults without history of cancer.

## **Conclusion**

The prevalence of poor SDM is higher in AYA cancer survivors than adults without a history of cancer and associated with higher medical expenditures and more office visits even after adjusting for chronic conditions and psychological distress. In addition, those with at least good mental and physical health were less likely to report poor SDM. These findings suggest that interventions to improve SDM among AYA cancer survivors may contribute to patient's positive perception about their mental and physical health and may result in AYAs seeking fewer medical services resulting in lower medical expenses. This study highlights the importance and the potential economic and health benefits of adapting optimal SDM while caring for AYA cancer survivors.

Table 1. Characteristics of adolescent and young adult (AYA) cancer survivors and (1:3) matched sample of adults with no history of cancer by shared decision making (SDM), Medical Expenditure Panel Survey 2011-2016

Characteristics	Shared decision making AYA Cancer survivors			P value	Shared decision making Adults with no history of cancer			P value
	Poor N=164 (11.41%)	Average N=491 (42.97%)	Optimal N=507 (45.62%)		Poor 338 (11.44%)	Average 1248 (42.25)	Optimal 1368 (46.31)	
Age				0.08				0.12
18-29	18 (10.98)	37 (7.54)	39 (7.69)		30 (8.88)	94 (7.53)	87 (6.36)	
30-39	43 (26.22)	107 (21.79)	82 (16.17)		62 (18.34)	227 (18.19)	257 (18.79)	
40-49	41 (25.00)	119 (24.24)	139 (27.42)		100 (29.59)	301 (24.12)	336 (24.56)	
50-64	42 (25.61)	148 (30.14)	164 (32.35)		105 (31.07)	396 (31.73)	442 (32.31)	
65 or older	20 (12.20)	80 (16.29)	83 (16.37)		41 (12.13)	230 (18.43)	246 (17.98)	
Sex:				0.08				0.99
Male	39 (23.78)	98 (19.96)	83 (16.37)		56 (16.57)	206 (16.51)	225 (16.45)	
Female	125 (76.22)	393 (80.04)	424 (83.63)		282 (83.43)	1042 (83.49)	1143 (83.55)	
Race/ethnicity:				0.95				0.01
Hispanic	30 (18.29)	89 (18.13)	101 (19.92)		57 (16.86)	199 (15.95)	191 (13.96)	
Non-Hispanic white	103 (62.80)	313 (63.75)	313 (61.74)		221 (65.38)	840 (67.31)	922 (67.40)	
Non-Hispanic black	23 (14.02)	60 (12.22)	68 (13.41)		34 (10.06)	133 (10.66)	193 (14.11)	
Non-Hispanic Asian and other	8 (4.88)	29 (5.91)	25 (4.93)		26 (7.69)	76 (6.09)	62 (4.53)	
Education:				0.62				0.28
Less than high school	43 (42.16)	138 (46.78)	129 (43.73)		87 (40.47)	332 (42.13)	359 (42.29)	
High school graduate	38 (37.25)	88 (29.83)	91 (30.85)		79 (36.74)	235 (29.82)	252 (29.68)	
Some college or more	21 (20.59)	69 (23.39)	75 (25.42)		49 (22.79)	221 (28.05)	238 (28.03)	
Marital status:				0.48				0.15
Married	73 (50.34)	238 (55.48)	244 (52.47)		181 (58.58)	704 (62.97)	798 (64.56)	
Not married	72 (49.66)	191 (44.52)	211 (47.53)		128 (41.42)	414 (37.03)	438 (35.44)	
Health insurance:				<.001				0.04
Private	74 (45.12)	304 (61.91)	314 (61.93)		210 (62.13)	880 (70.51)	951 (69.52)	
Public	77 (46.95)	155 (31.57)	172 (33.93)		100 (29.59)	287 (23.00)	336 (24.56)	
Uninsured	13 (7.93)	32 (6.52)	21 (4.14)		28 (8.28)	81 (6.49)	81 (5.92)	
Income:				0.25				0.02
Poor	48 (29.27)	102 (20.77)	99 (19.53)		67 (19.82)	182 (14.58)	193 (14.11)	
Near poor	10 (6.10)	36 (7.33)	31 (6.11)		24 (7.10)	60 (4.81)	67 (4.90)	
Low income	27 (16.46)	72 (14.66)	70 (13.81)		53 (15.68)	161 (12.90)	183 (13.38)	
Middle income	38 (23.17)	136 (27.70)	148 (29.19)		96 (28.40)	360 (28.85)	399 (29.17)	
High income	41 (25.00)	145 (29.53)	159 (31.36)		98 (11.44)	485 (38.86)	526 (38.45)	
Smoking				0.06				0.001
Yes	46 (28.93)	97 (19.92)	110 (22.18)		72 (21.62)	172 (13.94)	190 (14.12)	
No	118 (71.07)	394 (80.08)	397 (77.82)		266 (78.38)	1076 (86.06)	1178 (75.88)	
Exercising regularly				0.80				0.006
Yes	98 (59.76)	280 (57.14)	298 (58.78)		188 (55.79)	727 (58.44)	714 (52.27)	
No	66 (40.24)	211 (42.86)	209 (41.22)		150 (44.21)	521 (41.56)	654 (47.73)	
BMI				0.40				0.20
>25	113 (68.90)	362 (73.73)	359 (70.81)		239 (70.71)	821 (65.79)	926 (67.69)	
≤ 25	51 (31.10)	129 (26.27)	148 (29.19)		99 (29.29)	427 (34.21)	442 (32.31)	
Getting care when needed				0.001				<.001
Able	19 (11.59)	31 (6.31)	19 (3.75)		25 (7.40)	43 (3.46)	26 (1.90)	
Unable	145 (88.41)	460 (93.69)	488 (96.25)		313 (92.6)	1205 (96.54)	1342 (98.10)	
Chronic conditions				0.65				0.11
None	30 (18.29)	106 (21.59)	103 (20.32)		236 (69.82)	882 (70.90)	910 (67.11)	
>1	134 (81.71)	385 (78.41)	404 (79.68)		102 (30.18)	366 (29.10)	458 (32.89)	
Psychological distress				<.001				<.001
Yes	39 (25.32)	55 (11.60)	58 (11.60)		51 (15.50)	68 (5.62)	62 (4.65)	
No	125 (74.68)	436 (88.40)	449 (88.40)		287 (84.50)	1180 (94.38)	1306 (95.35)	

No								
Perceived mental health				<.001				<.001
Poor/fair	59 (35.98)	94 (19.14)	82 (16.17)		67 (19.82) 271 (80.18)	141 (11.31) 1106 (88.69)	114 (8.33) 1254 (91.67)	
At least good	105 (64.02)	397 (80.86)	425 (83.83)					
Perceived physical health				<.001				<.001
Poor/fair	84 (51.22)	163 (33.20)	153 (30.18)		109 (32.25) 229 (67.75)	220 (17.67) 1027 (82.36)	195 (14.26) 1172 (85.74)	
At least good	80 (48.78)	328 (66.80)	354 (69.82)					

Figure 1. Cancer status by shared decision making (SDM) using 1:3 matched sample, Medical Expenditure Panel Survey 2011-2016

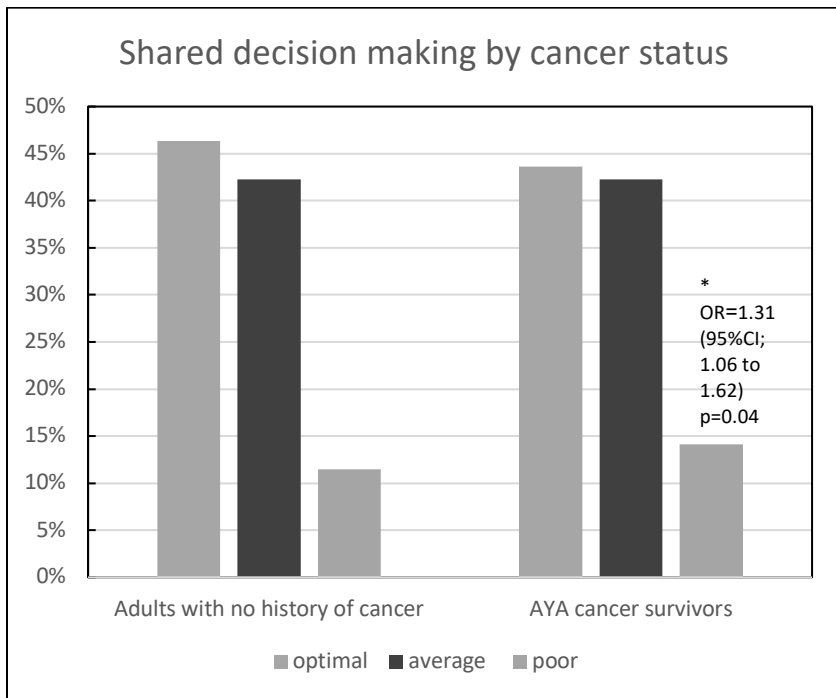


Table 2. Association of average and poor (vs optimal) shared decision making with access to health care and health factors among AYA cancer survivors: Medical Expenditure Panel Survey, 2011 to 2016

	SDM Unadjusted OR			SDM Adjusted OR		
	Optimal	average	poor	Optimal	average	poor
<b>BMI and health behavior</b>						
Smoking	Ref	0.87 (0.64-1.18)	<b>1.43 (0.96-2.14)</b>	Ref	1.02 (0.63-1.66)	0.55 (0.26-1.14)
Not exercising regularly	Ref	0.94 (0.73-1.20)	1.04 (0.73-1.49)	Ref	0.88 (0.60-1.30)	1.09 (0.61-1.92)
BMI>25	Ref	1.16 (0.88-1.53)	0.91 (0.62-1.34)	Ref	1.06 (0.71-1.60)	1.07 (0.58-1.96)
<b>Access to care</b>						
Insurance	Ref			Ref		
Public insurance vs private		0.93 (0.71-1.22)	<b>1.90 (1.31-2.75)</b>		0.90 (0.57-1.42)	1.88 (0.99-3.57)
Uninsured vs private		1.57 (0.89-2.79)	<b>2.63 (1.26-5.49)</b>		1.44 (0.57-3.62)	2.79 (0.86-9.06)
Unable to get care when needed	Ref	1.73 (0.96-3.11)	<b>3.36 (1.74-6.52)</b>	Ref	2.09 (0.84-5.23)	2.25 (0.72-7.01)
<b>Health status</b>						
Chronic conditions	Ref	0.93 (0.63-1.26)	1.13 (0.73-1.79)	Ref	0.88 (0.53-1.48)	1.26 (0.57-2.77)
Psychological distress	Ref	1.00 (0.67-1.48)	<b>2.58 (1.64-4.07)</b>	Ref	1.49 (0.79-2.80)	<b>3.10 (1.44-6.72)</b>
<b>Perceived health</b>						
Perceived mental health as at least good		0.82 (0.59-1.13)	<b>0.34 (0.23-0.51)</b>	Ref	0.94 (0.54-1.65)	0.52 (0.26-1.03)
Perceived physical health as at least good		0.87 (0.67-1.14)	<b>0.41 (0.29-0.59)</b>	Ref	1.31 (0.74-2.32)	<b>0.52 (0.27-0.97)</b>

Bold indicate statistical significance of  $p \leq 0.05$



Table 3. Association of average and poor (vs optimal) shared decision making with access to health care and health factors among (1:3) matched adults without history of cancer: Medical Expenditure Panel Survey, 2011 to 2016

	SDM Unadjusted OR			SDM Adjusted OR		
	Optimal	average	Poor	Optimal	average	Poor
<b>BMI and health behavior</b>						
Smoking	Ref	0.99 (0.79-1.23)	<b>1.68 (1.24-2.27)</b>	Ref	0.97 (0.69-1.37)	1.33 (0.83-2.14)
Exercise less regularly	Ref	<b>1.28 (1.10-1.50)</b>	1.15 (0.91-1.46)	Ref	1.17 (0.93-1.47)	1.02 (0.72-1.44)
BMI>25	Ref	0.92 (0.78-1.08)	1.15 (0.89-1.50)	Ref	0.78 (0.61-1.00)	1.06 (0.72-1.56)
<b>Access to care</b>						
Insurance Public insurance vs private	Ref	0.92 (0.77-1.10)	<b>1.35 (1.03-1.76)</b>	Ref	1.07 (0.79-1.45)	1.25 (0.80-1.96)
Uninsured vs private		1.08 (0.78-1.49)	1.57 (0.99-2.47)		0.91 (0.55-1.50)	0.63 (0.27-1.51)
Unable to get care when needed	Ref	<b>1.85 (1.13-3.02)</b>	<b>4.12 (2.35-7.23)</b>	Ref	<b>2.12 (1.05-4.27)</b>	<b>2.68 (1.11-6.47)</b>
<b>Health status</b>						
Chronic conditions	Ref	<b>1.19 (1.01-1.41)</b>	1.13 (0.88-1.47)	<b>Ref</b>	<b>1.44 (1.10-1.90)</b>	0.93 (0.62-1.40)
Psychological distress	Ref	1.22 (0.86-1.74)	<b>3.76 (2.54-5.57)</b>	Ref	1.18 (0.68-2.05)	<b>3.50 (1.88-6.52)</b>
<b>Perceived health</b>						
Perceived mental health as at least good		<b>0.71 (0.55-0.93)</b>	<b>0.37 (0.27-0.51)</b>	Ref	<b>0.61 (0.40-0.93)</b>	<b>0.55 (0.32-0.96)</b>
Perceived physical health as at least good		<b>0.78 (0.63-0.96)</b>	<b>0.35 (0.27-0.46)</b>	Ref	0.97 (0.68-1.39)	<b>0.41 (0.26-0.66)</b>

Bold indicate statistical significance of  $p \leq 0.05$

Table 4. Additional medical expenses, health care utilization and medications for shared decision making in AYA cancer survivors: Medical Expenditure Panel Survey, 2011 to 2016

	Reference	Additional	
	Optimal	Average	poor
Expenses	\$7895.91 (5706.72-10,924.90)	\$334.57 (-1270.28-2328.16)	<b>\$3036.64 (109.72-7032.18)</b>
Office visits	8.36 (6.60-10.58)	1.26 (-0.22-3.01)	<b>4.86 (2.00-8.52)</b>
Emergency room	1.57 (1.07-2.32)	0.08 (-0.3-0.62)	0.21 (-0.29-0.92)
Inpatient nights	1.13 (0.56-2.31)	0.13 (-0.34-0.88)	0.11 (-0.42-1.05)
Medication refill	18.08 (13.85-23.60)	<b>-3.13 (-5.69—0.03)</b>	0.91 (-3.73-7.05)

Bold indicate statistical significance of  $p \leq 0.05$

Table 5. Additional medical expenses, health care utilization and medications for shared decision making in matched (1:3) adult without history of cancer: Medical Expenditure Panel Survey, 2011 to 2016

	Reference	Additional	
	Optimal	Average	poor
Expenses	\$3726.04 (2888.52-4806.86)	361.51 (-178.18-982.82)	<b>2242.16 (1036.33-3752.56)</b>
Office visits	5.90 (4.88-7.13)	<b>2.19 (1.38-3.08)</b>	<b>2.38 (1.08-3.93)</b>
Emergency room	1.39 (0.98-1.96)	-0.09 (-0.36-0.25)	0.27 (-0.17-0.85)
Inpatient nights	1.88 (0.99-3.57)	-0.33 (-0.75-0.24)	-0.35 (-0.86-0.42)
Medication refill	14.40 (11.70-17.72)	1.14 (-0.62-3.13)	2.39 (-0.56-5.97)

Bold indicate statistical significance of  $p \leq 0.05$

## Conclusion

In this dissertation, we used Medical Expenditure Panel Survey data (MEPS), a nationally representative sample of U.S. non-institutionalized civilians, to examine the medical expenditure and healthcare use associated with the health status of AYA cancer survivors at a population-based level. AYA cancer survivors face long-term complications from their cancer treatments, including chronic conditions and psychological distress, and they are more likely to report poor SDM compared to adults with no history of cancer. Fewer studies have addressed the needs of AYA cancer survivors<sup>51,61,62</sup> compared to older adults<sup>2,30,63,64</sup>. We had the advantage of gaining access to confidential and recent data regarding the age of cancer survivors which allowed us to include more participants and use updated data.

Our results from the first project showed that most long-term cancer survivors (74%) had at least one chronic condition and that the estimated average of additional expenses associated with chronic conditions was \$2,777. The results also showed that physical activity and access to care significantly correlated to the cost of care. Getting care when needed and adopting healthy behaviors, particularly exercise, may reduce the medical expenses associated with chronic conditions.

The findings from our second project showed that psychological distress prevalence was high among long-term cancer survivors compared to adults with no history of cancer even after 20 years of surviving cancer. It also showed that smoking and exercising less regularly were associated with higher psychological distress. Moreover, psychological distress accounted for higher expenditures and higher prescription medication/refills among this population. Employing survivorship care plans that acknowledge psychological needs by screening to identify those with psychological distress and referring survivors to treatment or interventions can mitigate the impact

of psychological distress in AYA cancer survivors<sup>68</sup>.

Our third project highlighted the poor Shared Decision Making (SDM) among cancer survivors compared to matched adults with no history of cancer. AYA cancer survivors who had good mental and physical health were less likely to report poor SDM. We found that AYA cancer survivors who reported poor SDM had significantly greater medical expenses and health care utilization. Interventions to improve SDM among AYA cancer survivors may contribute to patients' positive perception about their mental and physical health and may result in AYAs seeking fewer medical services resulting in lower medical expenses.

Our findings emphasize the potential economic and health benefits of survivorship plans that target preventing chronic diseases and screening for psychological distress as well as adopting optimal SDM while caring for AYA cancer survivors. Future longitudinal studies are needed to examine how sociodemographic disparities, including income, race/ethnicity, and health insurance, interact to influence the cost of care. Studies should also explore underlying risk factors leading to chronic conditions, psychological distress, and poor SDM, and they should assess how preventive behavioral risk factors and health care access affect care among the AYA cancer survivors.

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