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## Prevalence and factors associated with insomnia symptoms in adolescents and young adults with cancer during the COVID-19 pandemic

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### ABSTRACT

**Objective:** The COVID-19 pandemic has been particularly distressing for adolescents and young adults (AYAs) diagnosed with cancer. High levels of distress are associated with sleep disturbances. This study examined the prevalence of insomnia symptoms in AYAs during the COVID-19 pandemic and identified factors related to greater insomnia severity.

**Design, setting, and participants:** An online survey was administered to Canadian AYAs (N = 805) diagnosed with cancer between 15 and 39 years from January to February 2021.

**Measurements:** The primary measure was the Insomnia Severity Index (ISI). Univariable and multivariable binomial logistic regression examined demographic, clinical, and psychological factors associated with significant insomnia symptoms (ISI score  $\geq 12$ ).

**Results:** Three hundred twelve (38.8%) participants reported insomnia symptoms. In the multivariable model, severe psychological distress (ie, depression and anxiety; adjusted odds ratio (AOR) = 28.75,  $p \leq .001$ ), having a pre-existing mental health condition (AOR = 1.92,  $p = .03$ ), worsened mental health during the pandemic (AOR = 1.73,  $p = .02$ ), finished cancer treatment  $\geq 1$  year ago (AOR = 1.72,  $p = .03$ ), and experiencing no changes to schooling during the COVID-19 pandemic (AOR = 2.18,  $p = .004$ ) were associated with significant insomnia symptoms. Standardized coefficients also indicated that worrying about possible disruptions to cancer care and being a homemaker/caretaker contributed to insomnia symptoms.

**Conclusions:** Nearly 40% of AYAs with cancer reported insomnia symptoms during the COVID-19 pandemic. Insomnia was associated with potentially modifiable factors such as psychological distress, highlighting possible targets for intervention.

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Public health measures designed to curb the spread of the novel coronavirus disease of 2019 (COVID-19) have caused widespread interruptions to health care, education, employment, and various aspects of social interaction for adolescents and young adults (AYAs; ages 15–39 years).<sup>1</sup> As a result, healthy young adults have reported the largest increases in anxiety, depressive symptoms, and sleep problems compared to older adults during the pandemic.<sup>2</sup> Further,

AYAs reported feeling greater levels of social isolation and loneliness during the pandemic, which is associated with greater mental health concerns.<sup>3</sup> AYAs diagnosed with cancer are more vulnerable to the psychosocial impacts of COVID-19 because of their additional risk of experiencing severe effects of COVID-19 infection and disruptions to their cancer care or survivorship supports.<sup>4</sup> Cancer centers and other support organizations worldwide have struggled to deliver comprehensive cancer care on time during this pandemic.<sup>5</sup> Subsequently, treatment interruptions, lack of in-person social and emotional support are commonly reported by AYAs.<sup>5</sup> The uncertainty associated with cancer treatment and supportive care changes has elevated the

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distress of AYAs with cancer during the pandemic.<sup>7,8</sup> Additionally, many individuals fear the risk of experiencing severe effects of COVID-19 infection and have taken increased precautions. These worries and increased social isolation may further elevate distress in this population.<sup>6</sup>

Prepandemic research demonstrates that AYAs with cancer experience distress at higher levels than their age and sex-matched peers without cancer,<sup>9</sup> a disparity that has been worsened during the COVID-19 pandemic. A recent Canadian survey reported that the odds of AYAs with cancer experiencing significant distress is 1.85 greater during the pandemic compared to AYAs with cancer prepandemic, with 68% experiencing high levels of psychological distress.<sup>6</sup> This increase in distress has also been reported AYAs with cancer in the UK, with 40% reported experiencing depression or anxiety during the pandemic<sup>10</sup>; which is greater than the reported prevalence of 15%–30% among AYAs with cancer prepandemic.<sup>9,11</sup> Similarly, in a sample of 177 AYAs with cancer, 51% reported psychological distress, with those undergoing treatment during the pandemic or completing treatment within the prior 6 months reporting the highest distress levels.<sup>12</sup> Further, 1 in 2 AYAs reported significant levels of loneliness during the COVID-19 pandemic, which was greater for AYAs who were 18–25 years old, living in urban settings, and those currently undergoing cancer treatment.<sup>13</sup> The experience of pre-existing high levels of distress in AYAs with cancer is made worse by the inability to connect with and receive support from others during the pandemic.

The increased distress caused by the COVID-19 pandemic may place AYAs with cancer at a greater risk for poor sleep and insomnia symptoms.<sup>14,15</sup> Sleep quality and quantity have important implications for physical health, psychological well-being, and immunity, making it a priority area of investigation and intervention to improve the overall well-being of AYAs with cancer.<sup>16,17</sup> To date, little is known about sleep disruption among AYAs with cancer during the COVID-19 pandemic. Compared to prepandemic, Zhou et al<sup>18</sup> noted decreased insomnia severity among AYA cancer survivors during the pandemic attributable to increased opportunities for sleep. However, their sample was small (N = 35), and the study was conducted at the beginning of the pandemic, thus not capturing the impact of prolonged social disruption. Other studies in cancer survivors outside the AYA age range have not reported significant changes in sleep quality or disorders during the COVID-19 pandemic.<sup>19</sup> Again, study samples were small (Ns < 50), and sleep was measured with a single question, which might not capture all aspects of sleep. Understanding what factors increase the risk of insomnia can help identify individuals or subgroups of AYAs diagnosed with cancer who require additional interventions to combat insomnia during this pandemic.

The overall objective of the current paper was to explore the experience of insomnia among AYAs diagnosed with cancer using data from a Canadian survey (ICOVIDAYA<sup>4</sup>) conducted after 10 months of pandemic restrictions. Our specific aims were 2-fold. First, we sought to estimate the prevalence of insomnia symptoms among AYAs with cancer, including individuals currently undergoing treatment and those in the survivorship phase. Second, we sought to examine what demographic, clinical, psychosocial, and COVID-19 pandemic-related factors are associated with an increased odds of insomnia symptoms among AYAs with cancer.

## Participants and methods

### Study design and participants

The current study analyzed data from a national cross-sectional survey of AYAs with cancer designed to explore the impact of the COVID-19 pandemic on this population (the ICOVIDAYA survey<sup>4</sup>). Participants diagnosed with any type or stage of cancer during the

ages of 15–39 years, residing in Canada, and currently 18 to 39 years old were eligible for the survey. Participants were primarily recruited with help from Young Adult Cancer Canada (YACC) and other AYA cancer support groups throughout Canada using social media posts. Anonymous data was collected between January and February 2021 via an online survey offered in both French and English. Participants completed a digital informed consent form before accessing the survey and could receive a \$10 e-gift card for their participation. Ethical approval was obtained from the University of Manitoba Research Ethics Board (HS: 24501). One thousand sixty-three individuals completed the ICOVIDAYA survey. One hundred twenty-eight participants were excluded because they did not report their current age, and 130 individuals were excluded because they were older than 39 years (n = 258 excluded from the final sample).

### Measures

#### Dependent variables

The Insomnia Severity Index (ISI) was used to measure the severity of participants' insomnia symptoms, their impact on daily functioning, and any associated distress during the previous 2 weeks.<sup>20</sup> The ISI has been validated for use with patients with cancer, including AYA cancer survivors.<sup>21</sup> The measure consists of 7 items (eg, "How worried/distressed are you about your current sleep problem") rated on a 5-point Likert scale ranging from 0 (eg, "Not at all worried") to 4 (eg, "Very much worried"). Items were summed to provide a total score of insomnia severity ranging from 0 to 28. As recommended for research purposes, we classified participants with scores < 12 as having no insomnia symptoms and those with scores ≥ 12 as having insomnia symptoms.<sup>21</sup> The ISI has demonstrated excellent sensitivity and specificity in community and clinical samples to detect and classify the presence of insomnia.<sup>20</sup> Internal consistency was good in the current sample (Cronbach's  $\alpha = 0.72$ ).

#### Independent variables

Participants answered various questions to measure relevant sociodemographic, clinical characteristics, and the impacts of the COVID-19 pandemic. Sociodemographic and clinical variables were categorized into the following: age, gender (men, women), relationship status (single, in a committed relationship), race/ethnicity (White, Black, Indigenous, or a Person of Color [BIPOC]), rural-urban status (urban, rural/remote dwelling) employment status (student, employed, homemaker/caretaker, collecting disability or unemployment insurance, other), personal income in the year 2020 in CAD (<\$20,000/year, \$20,000–\$40,000/year, \$40,000–\$60,000/year, \$60,000+/year), cancer type (solid [non-CNS tumors], hematological malignancies, brain cancer), time since cancer diagnosis, cancer treatment status (undergoing treatment, finished less than 1 year ago, finished ≥ 1 year ago), prepandemic mental health condition (yes, no), pre-existing chronic health condition (yes, no).

Questions regarding the experiences with the COVID-19 pandemic were logically developed for the purposes of this study using Likert scale. They were refined by the virtual engagement of co-investigators and AYAs with lived experiences of cancer. The self-reported impact of the COVID-19 pandemic was collapsed into the following: impacts to school (yes, no), work (yes, no), finances during the pandemic (same, better, worse than prepandemic), psychological well-being (same, better, worse than prepandemic), physical activity (no change, more, less physical activity during the COVID-19 pandemic), family (same, better, worse than prepandemic), friend relationships (same, better, worse than prepandemic), substance misuse (no substance misuse, no change, increase, or decrease in substance misuse during the pandemic). We defined COVID-19 impacts to schooling/education as having to quit school entirely, transitioning entirely to virtual schooling, blended learning, or other specified impacts.

Impacts to employment were defined as having to quit work, being laid off, or temporary layoff but have since resumed work. Finally, negative impacts to cancer treatments during the pandemic were defined as changes to treatment protocol, delay or cancellation of diagnostic testing, treatments, follow-up appointments, or other support services, and reduced access to clinical trials.

The Kessler Psychological Distress Scale (K10) was used to measure symptoms of anxiety and depression over the past month.<sup>22</sup> The K10 consists of 10 items (eg, “During the last 30 days, about how often did you feel hopeless?”) rated on a 5-point Likert scale ranging from 1 (“None of the time”) to 5 (“All of the time”). Items are summed to create a total score ranging from 10 to 50. Total scores < 20 indicate no presence of distress, scores ranging from 20 to 24 suggest mild distress, 25 to 29 suggest moderate distress, and scores greater than 30 indicate severe distress.<sup>22</sup> The K10 has previously been used with AYAs diagnosed with cancer.<sup>9</sup> Cronbach’s alpha was 0.75 within the current sample.

Perceived loneliness and social isolation were evaluated with a 3-item loneliness scale developed from the UCLA Loneliness Scale.<sup>23</sup> Participants responded to items (eg, “How often do you feel that you lack companionship?”) on a 3-point Likert scale ranging from 1 (“Hardly Ever”) to 3 (“Often”). Items are summed with scores of  $\geq 6$ , indicating loneliness.<sup>24</sup> Acceptable measures of reliability and validity have been obtained for this measure.<sup>23</sup> The 3-item loneliness scale has been used to measure social isolation during the COVID-19 pandemic in young adults with cancer.<sup>25</sup>

#### Sample size

Approximately 8000 AYAs with a cancer diagnosis are engaged in the AYA support networks across which this survey was distributed. Based on the estimated insomnia prevalence of at least 30% among AYAs with cancer during this pandemic, we determined that the number of individuals required to determine the prevalence of insomnia with a 95% confidence interval with 5%, 4%, and 3% margin of error will be 311, 475, and 807, respectively. Power calculations were conducted with Epitools (<http://epitools.ausvet.com.au>).

#### Statistical analysis

Descriptive statistics were used to describe the demographics and clinical characteristics of the sample. Binomial logistic regressions were used to explore the factors associated with insomnia symptoms during the COVID-19 pandemic among AYAs diagnosed with cancer. Measures with established clinical cut-offs were used categorically to ease interpretations and better disseminate the results of the current analysis. First, univariable binomial logistic regressions identified variables associated with insomnia symptoms (scores of  $\geq 12$  on the ISI). Next, variables with significant (ie,  $p \leq .05$ ) univariable regressions were simultaneously entered into a multivariable logistic regression model. Box-Tidwell transformations were used to ensure linearity to the logit for continuous predictors. If the assumption of linearity to the logit was violated, the continuous variable was supplemented for its natural logarithm.<sup>26</sup> Next, multiple linear regressions were used to test for multicollinearity among variables included in the multivariable logistic regression model. Variance inflation factors for all variables were under 4, suggesting minimal collinearity. Finally, we calculated standardized regression coefficients to determine the predictors with the greatest effect on the presence of insomnia symptoms in AYAs with cancer.<sup>27</sup> All analyses were conducted in SPSS Version 27.

#### Missing data

Missing data were minimal in the current sample ranging from 0% to 2% on all variables of interest. In addition, all participants

responded to the dependent variable. Given missing data was < 10%, missingness was handled by SPSS defaults (ie, listwise deletion).<sup>28</sup>

## Results

### Demographics and clinical characteristics

Participants were 805 AYAs diagnosed with cancer living in Canada. Participants ranged in age from 18 to 39 years, with a mean of 30.27 years ( $SD = 5.27$ ). Male and female gender was roughly proportional in the survey (55.5% vs. 44.5%). Most participants were white (95.6%), in a committed relationship (60.1%), were employed (65.5%), and lived in an urban center (75.5%). Seventy-six percent of participants reported having a solid, noncentral nervous system tumor, and one-third (33.0%) were actively undergoing treatment. One hundred eighteen participants (14.8%) disclosed the presence of a pre-existing mental health condition. Additional demographic and clinical characteristics of the sample are summarized in [Table 1](#).

### Factors associated with insomnia in AYAs with cancer during COVID-19

Collectively, 38.8% (95% confidence interval [CI] 35.4%, 42.2%) of AYAs with cancer met or exceeded the cut-off for insomnia symptoms ([Table 2](#)). More women (40.3%) and BIPOC participants (48.4%) reported moderate/severe insomnia symptoms than men (37.5%) and white participants (38.1%), respectively. However, differences were nonsignificant (ie,  $p > .05$ ). Significantly more participants in the survivorship phase of cancer care (ie, finished cancer treatments) reported experiencing moderate/severe insomnia symptoms (42.6%), compared to participants actively receiving treatment (30.2%;  $\chi^2(1) = 11.44$ ,  $p = .001$ ,  $V = 0.12$ ). Separate univariable logistic regressions identified factors associated with insomnia ([Table 3](#)). Independent variables with significant univariable regressions were entered into the multivariable binomial logistic regression model. The multivariable regression model was significant,  $\chi^2(30) = 205.39$ ,  $p < .0005$ . The Hosmer-Lemeshow test was not significant ( $\chi^2(8) = 14.20$ ,  $p = .08$ ) suggesting the model was a good fit. The multivariable model correctly identified 72.5% of cases; sensitivity was 57.2%, specificity was 82.6%, positive and negative predictive values were 68.4% and 74.6%, respectively.

After adjusting for other covariates variables, individuals who experienced mild, moderate, or severe levels of psychological distress during the pandemic were at 4 (adjusted odds ratio [AOR] = 4.11 [CI 1.44, 11.73],  $p = .01$ ), 14 (AOR = 41.34 [CI 5.23, 39.32],  $p \leq .001$ ), and nearly 29 times (AOR = 28.75 [CI 10.27, 80.45],  $p \leq .001$ ) greater odds of experiencing significant insomnia symptoms, respectively. Having a pre-existing mental health condition before the COVID-19 pandemic or experiencing a worsening of psychological well-being during the pandemic increased the odds of experiencing significant insomnia symptoms by nearly 2 times (pre-existing mental health condition: AOR = 1.92 [1.06, 3.48],  $p = .03$ ; worse psychological well-being during the pandemic: AOR = 1.73 [1.08, 2.77],  $p = .02$ ). Longer time since finishing treatment increased the odds of experiencing moderate to severe insomnia symptoms (AOR = 1.72 [1.06, 2.78],  $p = .03$ ). Individuals who identified with multiple employment categories (eg, a full-time student, who also works part-time), were at lower odds of experiencing significant insomnia symptoms (AOR = 0.36 [0.15, 0.87],  $p = .02$ ). Compared to those who experienced COVID-19-related changes to their education, participants who did not experience school disruptions were at greater odds to have insomnia symptoms (AOR = 2.18 [1.29, 3.71],  $p = .004$ ). At the multivariable level, age, rural-urban status, pandemic impacts on employment, personal income, pandemic impacts on finances, chronic health conditions, loneliness, or changes to substance misuse were

**Table 1.**  
Descriptive statistics for demographic and clinical details of N = 805 adolescents and young adults with cancer

Variable		N (%)
<b>Demographic variables</b>		
Age (years)	<i>M (SD)</i>	30.3 (5.3)
Gender	Men	445 (55.5)
	Women	357 (44.5)
	Gender variant/ nonconforming	2 (0.2)
Relationship status <sup>a</sup>	Single	318 (39.8)
	In a committed relationship	484 (60.2)
Race/ethnicity	White	770 (95.6)
	BIPOC <sup>b</sup>	35 (4.4)
Province/territory	Atlantic <sup>c</sup>	169 (21.0)
	British Columbia	88 (10.9)
	Central Canada <sup>d</sup>	222 (27.6)
	Prairies <sup>e</sup>	233 (28.9)
	Territories <sup>f</sup>	93 (11.6)
Rural-urban status	Urban	605 (75.5)
	Rural/remote	196 (24.5)
Employment status	Student	72 (8.9)
	Employed	527 (65.5)
	Homemaker/caretaker	39 (4.8)
	Collecting disability/ unemployed	123 (15.3)
	Other <sup>g</sup>	44 (5.5)
Personal income	<\$20,000	57 (7.5)
	\$20,000 to <\$40,000	115 (15.2)
	\$40,000 to <\$60,000	195 (25.8)
	\$60,000+	389 (51.5)
<b>Clinical variables</b>		
Cancer type	Solid tumors	615 (76.4)
	Hematological malignancies	155 (19.3)
	Brain	35 (4.3)
Time since diagnosis (years)	<i>M (SD)</i>	4.2 (3.7)
Treatment status	Currently undergoing treatment	265 (33.0)
	Finished <1 year ago	290 (36.0)
	Finished >1 year ago	241 (31.0)
Pre-existing mental health condition	Yes	118 (14.8)
	No	676 (85.2)
Chronic health conditions	Yes	192 (23.9)
	No	613 (76.1)

<sup>a</sup> In and relationship includes common law, married, and committed relationships vs. single, which includes divorces, widowed, or single.

<sup>b</sup> BIPOC = Black, Indigenous, or Person of Color. This category includes individuals who self-identified as any race/ethnicity other than White, including those identifying with multiple ethnic groups.

<sup>c</sup> Newfoundland and Labrador, Nova Scotia, New Brunswick, Prince Edward Island.

<sup>d</sup> Quebec, Ontario.

<sup>e</sup> Manitoba, Saskatchewan, Alberta.

<sup>f</sup> Nunavut, Northwest Territories, Yukon.

<sup>g</sup> Other includes those who identify with multiple categories or identified "other" employment status.

not associated with moderate or severe insomnia symptoms ( $p > .05$ ).

Exploration of standardized coefficients revealed experiencing distress during the pandemic was the largest contributor to increased insomnia symptoms among AYAs with cancer (mild distress:  $\beta = 20.20$ ; moderate distress:  $\beta = 36.62$ ; severe distress:  $\beta = 47.09$ ). The following largest contributors to moderate/severe insomnia symptoms were being concerned about possible changes to treatment plans ( $\beta = 13.78$ ), being a homemaker or caretaker ( $\beta = 8.94$ ), having a pre-existing mental health condition ( $\beta = 5.90$ ), and not experiencing COVID-19-related disruptions to schooling ( $\beta = 5.63$ ). On the other hand, identifying with multiple employment categories contributed to decreased insomnia symptoms among AYAs with cancer ( $\beta = -11.94$ ). Additional standardized coefficients are listed in Table 3.

**Table 2.**  
Descriptive statistics for patient-reported outcome measures of N = 805 adolescents and young adults with cancer

Variable		Statistic
<b>Insomnia severity</b>	<i>M (SD)</i>	10.6 (4.2)
	No insomnia symptoms	493 [61.2%]
	Insomnia symptoms (ISI $\geq 12$ )	312 [38.8%]
	ISI scores $\geq 8$	632 [78.5%]
<b>Psychological distress</b>	<i>M (SD)</i>	26.7 (6.3)
	No distress	95 [11.8%]
	Mild distress (K10 20–24)	163 [20.2%]
	Moderate distress (K10 25–29)	297 [36.9%]
	Severe distress (K10 $\geq 30$ )	250 [31.1%]
<b>Loneliness</b>	<i>M (SD)</i>	5.7 (1.4)
	Not lonely	384 [47.7%]
	Lonely (UCLA3 $\geq 6$ )	419 [52.0%]

ISI, insomnia severity index; K10, 10-item Kessler Psychological Distress Scale; UCLA3, 3-item University of California, Los Angeles Loneliness Scale.

## Discussion

To our knowledge, this is the first study to examine insomnia symptoms during the COVID-19 pandemic in a large sample of AYAs diagnosed with cancer. The prevalence of insomnia symptoms was 38.8%. The prevalence and mean score of the ISI for AYAs in this sample ( $M = 10.61$ ) is higher than what was reported by another study in young adult cancer survivors early in the COVID-19 pandemic (Zhou et al<sup>18</sup>; 34.3% with insomnia symptoms,  $M = 7.0$ ). Notably, the study by Zhou et al<sup>18</sup> used a lower cut-off for the ISI than the current one (ISI scores  $\geq 8$  vs.  $\geq 12$ , respectively). Using an ISI cut-off score  $\geq 8$  as per Zhou et al,<sup>18</sup> nearly 79% of study participants experienced mild insomnia symptoms. These results demonstrate that insomnia is a significant concern for a sizeable proportion of young adults with cancer during the COVID-19 pandemic. Considering the association of sleep disturbances with a heightened risk of cancer-related morbidity and mortality,<sup>17</sup> continued research is required to monitor insomnia symptoms among AYAs with cancer as the world learns to live with the COVID-19 virus.

In our study, AYAs who experienced significant psychological distress at any level or reported having a pre-existing mental health condition had greater odds of experiencing insomnia. Those reporting the highest levels of distress, representing 31% of the sample, were at 28 times greater odds of reporting insomnia symptoms. There is a well-established bidirectional relationship between psychological distress and sleep disruption.<sup>29</sup> AYAs already report higher levels of distress than their peers without cancer and older adults with cancer,<sup>9</sup> which has worsened during this pandemic.<sup>6</sup> Given such a robust bi-directional association of psychological distress with insomnia, it is essential that cancer and community support organizations routinely screen AYAs with a cancer diagnosis for psychological distress, including assessment for insomnia. Screening can help provide tailored sleep and psychosocial support to those distressed or who have a pre-existing mental health diagnosis.

The pandemic has impacted cancer care delivery, and hospital policies were altered rapidly to protect patients and healthcare workers during this pandemic. While these changes to healthcare services worked for some, they led to uncertainty and increased distress for others.<sup>8</sup> Although not statistically significant, results of the current

**Table 3.**  
Factors associated with insomnia symptoms (ISI scores  $\geq 12$ ) in adolescents and young adults with cancer during the COVID-19 pandemic

		Univariable logistic regression analysis		Multivariable logistic regression analysis		
		Odds ratio [95% CI]	<i>p</i>	Adjusted odds ratio [95% CI]	<i>p</i>	Standardized coefficient ( $\beta$ )
<b>Age</b>		0.97 [0.94, 0.99]	.01	0.99 [0.95, 1.02]	.45	-0.01
<b>Gender</b>	Men (ref)	1				
	Women	1.13 [0.85, 1.50]	.42			
<b>Race</b>	White (ref)	1				
	BIPOC	1.52 [0.74, 3.12]	.25			
<b>Rural-urban status</b>	Urban (ref)	1		1		
	Rural/remote	1.48 [1.07, 2.04]	.02	1.41 [0.88, 2.25]	.15	2.19
<b>Relationship status</b>	In a committed relationship (ref)	1		1		
	Single	1.57 [1.18, 2.10]	.002	1.49 [1.00, 2.24]	.05	2.22
<b>Employment status</b>	Employed (ref)	1		1		
	Student	1.73 [1.05, 2.83]	.03	1.00 [0.45, 2.25]	.99	0.04
	Homemaker/caretaker	1.40 [0.73, 2.69]	.31	1.95 [0.73, 5.21]	.18	8.94
	Unemployed	0.76 [0.50, 1.15]	.20	1.03 [0.54, 1.96]	.94	0.22
	Other <sup>a</sup>	1.13 [0.61, 2.12]	.70	0.36 [0.15, 0.87]	.02	-11.94
<b>Personal income in year 2020</b>	<\$20,000	1.58 [0.90, 2.77]	.11	1.32 [0.56, 3.12]	.53	3.25
	\$20,000-\$40,000	1.30 [0.85, 1.99]	.23	1.65 [0.89, 3.06]	.12	4.22
	\$40,000-\$60,000	1.65 [1.16, 2.34]	.005	1.47 [0.93, 2.30]	.10	2.35
	\$60,000+ (ref)	1		1		
<b>Time since cancer diagnosis</b>		0.95 [0.91, 0.99]	.01	0.89 [0.66, 1.21]	.46	-0.46
<b>Cancer type</b>	Solid tumors (ref)	1				
	Hematological malignancies	1.12 [0.78, 1.61]	.53			
	Brain tumors	0.73 [0.35, 1.52]	.40			
<b>Treatment status</b>	On treatment (ref)	1		1		
	Completed treatment <1 year ago	1.56 [1.10, 2.22]	.01	1.46 [0.94, 2.28]	.10	2.28
	Completed treatment $\geq 1$ year ago	1.91 [1.33, 2.75]	.001	1.72 [1.06, 2.78]	.03	3.56
<b>Pre-existing mental health conditions</b>	No (ref)	1		1		
	Yes	2.67 [1.79, 3.98]	<.001	1.92 [1.06, 3.48]	.03	5.90
<b>Pre-existing chronic Health conditions</b>	None (ref)	1		1		
	One or more conditions	1.64 [1.18, 2.29]	.003	1.02 [0.63, 1.65]	.95	0.11
<b>Psychological distress</b>	None (ref)	1		1		
	Mild (K10 20-24)	3.456 [1.39, 8.63]	.01	4.11 [1.44, 11.73]	.008	20.20
	Moderate (K10 25-29)	11.62 [4.93, 27.40]	<.001	14.34 [5.23, 39.32]	<.001	36.62
	Severe (K10 $\geq 30$ )	20.48 [8.63, 48.60]	<.001	28.75 [10.27, 80.45]	<.001	47.09
<b>Loneliness</b>	Not lonely (ref)	1		1		
	Lonely (UCLA3 $\geq 6$ )	2.22 [1.66, 2.97]	<.001	0.91 [0.61, 1.35]	.64	-0.52
<b>Pandemic's impact on psychological well-being</b>	None (ref)	1		1		
	Better	0.845 [0.60, 1.21]	.36	1.11 [0.70, 1.75]	.67	0.63
	Worse	1.83 [1.27, 2.62]	.001	1.73 [1.08, 2.77]	.02	3.52
<b>Pandemic's impact on schooling</b>	Yes impact (ref)	1		1		
	No impact	3.17 [2.20, 4.56]	<.001	2.18 [1.29, 3.71]	.004	5.63
<b>Pandemic's impact on employment</b>	Yes impact (ref)	1		1		
	No impact	1.46 [1.04, 2.06]	.03	1.245 [0.73, 2.12]	.42	1.60
<b>Pandemic's impact on physical activity</b>	No change (ref)	1				
	More physically active	1.06 [0.73, 1.53]	.78			
	Less physically active	1.29 [0.92, 1.79]	.14			
<b>Pandemic's impact on family relationships</b>	None (ref)	1				
	Better	0.83 [0.56, 1.23]	.35			
	Worse	1.04 [0.69, 1.56]	.87			
<b>Pandemic's impact on relationships with friends and peers</b>	None (ref)	1				
	Better	0.70 [0.47, 1.04]	.07			
	Worse	1.05 [0.71, 1.55]	.82			
<b>Pandemic's impact on finances</b>	None (ref)	1		1		
	Better	1.91 [0.81, 4.49]	.14	1.22 [0.40, 3.67]	.73	-3.83
	Worse	0.64 [0.43, 0.94]	.02	0.61 [0.35, 1.09]	.10	2.98
	None (ref)	1		1		

(continued)

Table 3. (Continued)

		Univariable logistic regression analysis		Multivariable logistic regression analysis		
		Odds ratio [95% CI]	<i>p</i>	Adjusted odds ratio [95% CI]	<i>p</i>	Standardized coefficient ( $\beta$ )
<b>Pandemic's impact on treatment and follow-up appointments</b>	No impact, but concerned about	1.75 [0.86, 3.53]	.12	2.62 [0.92, 7.49]	.07	13.78
	Impacts	1.69 [1.22, 2.35]	.002	1.40 [0.83, 2.37]	.21	2.42
<b>Pandemic's impact on substance misuse</b>	No substance misuse (ref)	1		1		
	No change	1.89 [1.28, 2.80]	.001	1.08 [0.60, 1.93]	.80	0.60
	Increased substance misuse	2.33 [1.33, 4.07]	.003	1.24 [0.58, 2.64]	.58	2.20
	Decreased substance misuse	1.21 [0.83, 1.76]	.33	0.83 [0.47, 1.46]	.52	1.44

ISI, insomnia severity index; K10, 10-item Kessler Psychological Distress Scale; UCLA3, 3-item University of California, Los Angeles Loneliness Scale; BIPOC, Black, Indigenous, or a Person of Color.

<sup>a</sup> Other includes those who identify with multiple categories or identified "other" employment status

study suggest that worrying about the possibility of changes to treatment and survivorship care, more so than actual disruption in care, was important for the development of insomnia. Individuals may ruminate on possible changes to treatment and the subsequent impact on their health, thus leading to increased stress. Perceived stress is central to the existing models which explain the development and maintenance of insomnia.<sup>30</sup> The experience of stress can cause significant presleep arousal, which can precipitate and perpetuate insomnia. Additional analyses are required to understand better the relationship between and possible mediators of insomnia severity and worries about changes to care. Unsurprisingly, stress caused by the COVID-19 pandemic may be driving insomnia symptoms among AYAs with cancer. Without early identification, insomnia frequently becomes a chronic disorder,<sup>31</sup> highlighting the importance of screening and access to treatment.

Few demographic and clinical variables were associated with significant insomnia during the COVID-19 pandemic. However, greater time since completing treatment was associated with greater odds of experiencing insomnia. While cancer treatments (eg, chemotherapy, radiation) may directly contribute to insomnia symptoms, these tend to be short-term side effects of treatment.<sup>32</sup> When temporarily disturbed sleep persists past treatment completion and is combined with maladaptive coping strategies, insomnia becomes rapidly reinforcing and may turn chronic. Other research suggests that insomnia is one of the longest-lasting symptoms reported by cancer survivors.<sup>33</sup> Even 5 years after their diagnosis, women with breast cancer experience greater sleep problems despite rating their quality of life to be equal to or better than peers without cancer.<sup>34</sup> This highlights the need for improved access to evidence-based interventions for insomnia in AYA survivorship care.

Engaging in multiple forms of employment emerged as a protective factor for experiencing insomnia. Although these individuals represented only 6% of the study sample, this finding may suggest that diversification of responsibilities may have provided structure and routine during the pandemic, which is essential in maintaining good mental health.<sup>12</sup> In comparison, students not experiencing impacts from the pandemic on their education were at an increased odds of experiencing insomnia symptoms. Although pivoting to virtual learning may have been associated with loneliness,<sup>12</sup> the expectation to maintain prepandemic academic functioning may have caused significant health-related and performance anxiety.

### Limitations

Several unique limitations of our study must be considered while interpreting its findings. The ISI assesses the severity of insomnia symptoms in the past 14 days and does not assess for hours of sleep

or duration of insomnia symptoms. Considering that insomnia symptoms can wax and wane, our results cannot be used to estimate the number of participants meeting the diagnostic criteria for insomnia disorder, which requires insomnia symptoms to be present for at least 3 months. Further, the use of medications to aid with sleep was not assessed, which may have led to underestimating insomnia symptom prevalence. The primary recruitment method involved self-referral, and despite best efforts to recruit a representative sample, several groups remain underrepresented. The sample was mainly white, employed, from urban areas, and had little representation from gender-diverse groups. Due to small group sample sizes, we could not conduct subanalyses for gender nonconforming, BIPOC, and multiple races/ethnicities. Likewise, less than 10% of the current sample identified as students without other forms of employment. Given small subgroup sample sizes, the findings of the current study for those groups should be interpreted with caution.

Additionally, the survey was conducted using an online survey tool and required access to both a computer and a reliable internet connection. As a result, individuals from a lower-income household with limited access to internet services may not have had access to participate. Further, given that participants could self-refer to the study, participants may have self-selected not to participate if they experienced severe distress or insomnia. Future studies should seek to confirm the current findings in more diverse and inclusive populations as the COVID-19 pandemic continues.

### Conclusions

This study is the first to demonstrate that nearly 40% of Canadian AYAs with cancer experienced insomnia symptoms during the COVID-19 pandemic. Experiencing psychological distress during the COVID-19 pandemic significantly increased the odds of experiencing insomnia. Insomnia is associated with increased risk of developing and worsened recovery from many mental health disorders in the general population.<sup>35</sup> Specifically in cancer survivors, insomnia is further associated with impaired quality of life,<sup>36</sup> problems with cognitive function,<sup>37</sup> and cancer-related fatigue.<sup>38</sup> Our results add to the growing recognition that the impact of cancer on AYAs does not end with the completion of treatment.<sup>39</sup> In order to improve overall well-being and recovery from cancer, greater access for AYAs with cancer to evidence-based interventions to manage insomnia and support their mental health is desperately needed, and even more so during the COVID-19 pandemic.<sup>40</sup>

### Declaration of conflict of interest

The authors have no conflicts of interest to declare.

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## Data availability statement

The datasets generated and/or analyzed during the current study are available from the corresponding author on request.

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