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The impact of COVID-19 on adolescents and young adults' cancer care and their wellbeing: Results from an online survey conducted in the early stages of the pandemic

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Abstract

Background: Due to the global spread of COVID-19, oncology departments across the world rapidly adapted their cancer care protocols, balancing the risk of delaying cancer treatments and risk of COVID-19 exposure. COVID-19 and associated changes may have an impact on psycho-social functioning of cancer patients and survivors. We wanted to understand the impact of COVID-19 pandemic on young people living with and beyond cancer.

Method: In this cross-sectional study, we surveyed 177 individuals, aged 18 - 39 years, about the impact of COVID-19 on their cancer care and psychological wellbeing. Participants also reported their information needs relating to COVID-19. Responses were summarized using content analysis approach.

Results: This is the first study to examine psychological functioning of young patients and survivors during the first weeks of the COVID-19 pandemic. Close to a third of respondents reported increased levels of psychological distress, and as many as 60% reported feeling more anxious than they did prior to COVID-19. More than half also wanted more information tailored to them as young cancer patients.

Conclusions: The COVID-19 pandemic is rapidly evolving and changing the landscape of cancer care. Young people living with cancer are a unique population and might be more vulnerable during this time compared to their healthy peers. There is a need to screen for psychological distress and attend to young people whose cancer care has been delayed. As the lockdown begins to ease, the guidelines about cancer care should be updated according to this population's needs.

Keywords: COVID-19; survey; depression; anxiety; information needs; adolescent cancer; young adult cancer

Introduction

COVID-19 was first identified in China, in December 2019[1] and is an infectious disease caused by the novel SARS-CoV-2 virus.[2] In most patients, COVID-19 infection results in mild symptoms such as a fever and a dry cough, but in some cases, and particularly in those with underlying health conditions and those who are immune compromised, COVID-19 can be more severe and can result in serious complications such as Acute Respiratory Distress Syndrome or even death.[3] To date, findings suggest that COVID-19 poses little threat to children and young people,[4] however, cancer patients and survivors may be a vulnerable population. Individuals undergoing active treatment or taking immunosuppressive medication are known to be at higher risk for viral infections,[5] while those in survivorship might experience distress due to changes in their follow-up care. Most young people living beyond cancer worry about cancer recurrence[6,7] and resultantly the disrupted follow-up care, which includes physical exams and screening may lead to heightened anxiety. As such, adolescent and young adult (AYA) cancer patients and survivors remain a group with unique needs during a pandemic outbreak like the current COVID-19, even though the relative risk of infection and mortality for this population have not yet been established.

Adolescents and Young Adult (AYA) cancer patients and survivors have been recognized as a unique group of patients who face different challenges and needs than their younger peers, or older adults.[8,9] In response to the global spread of the novel SARS-CoV-2, oncology departments quickly acted and adapted measures and protocols for cancer care. Most centers sought to balance the risk of delaying cancer treatment with that of exposing a vulnerable cancer patient to the virus, which resulted in a crucial reprioritization; the most essential and necessary treatments remained on schedule, while early preventative screenings, follow-up appointments, and non-essential surgeries were often delayed.[10] These changes were made rapidly and the newly devised guidelines were operationalized with increased survival in

mind, and in hopes to render the oncology centers 'pandemic proof.'[11,12] While taking such measures is necessary for successful infection control, the subsequent steps will have to involve consideration of the psychological impact of COVID-19 and related changes on cancer patients, survivors and their families.

Even though the scientific, as well as patient support communities were quick to recognize the need to provide information about COVID-19 to cancer patients,[13] the sudden increase and a plethora of resources available was not necessarily tailored to AYA patients' and survivors' needs. We do not know if the information available is adequate, and if AYAs living with or beyond cancer feel confident about making sense of and applying it.

As after any major global disaster, the COVID-19 pandemic is also likely to result in increased mental health symptomatology.[14,15] Considering that a subset of AYA cancer patients experiences significant levels of psychological distress even under normal circumstances,[16,17] it is important to recognize that worries associated with the pandemic, and any delays in life-saving treatments are likely to contribute to the anxiety in this population. Furthermore, the social distancing measures imposed to contain the spread of the infection may have unintended consequences for mental health via changes in social support, economic consequences and changes to daily routines.[18] In AYAs who are already vulnerable to experiencing distress, this may further compound their anxiety. To ensure that the needs of AYAs continue to be met during and after the COVID-19 outbreak, developing new strategies that will help manage, and attenuate worries about the COVID-19 exposure should be a priority. This effectively requires an understanding of what the needs of AYAs are in this unprecedented context.

To adapt and better prepare for any future outbreaks, it is important to understand the impact of the novel SARS-CoV-2 on AYAs cancer care and their wellbeing. The aim of this study was 1) to gather initial evidence of the impact of COVID-19 on AYA cancer patients' and survivors' psychological well-being and cancer care, and 2) to understand where they

received the information about the pandemic and how satisfied they were with the resources on COVID-19.

In order to provide the future readership with context, **Figure 1** provides an overview with all the relevant dates and facts known to the authors at the time of writing this article (May 12, 2020).

[INSERT FIGURE 1: Global and UK COVID-19 context at the time of this study.]

Method

This anonymous cross-sectional survey was an extension of an ongoing longitudinal study exploring the predictors of psychological well-being and holistic recovery in AYA cancer patients. The original study protocol and COVID-19 survey material can be viewed at the following link: https://osf.io/ncpv8/. This study has been approved by the Medical Sciences Inter-Divisional Research Ethics Committee at the University of Oxford (R61437/RE005).

Data were collected using Qualtrics, a secure online survey software, via an anonymous link distributed on social media outlets and online via patient organizations' web posts or newsletters. Participants were provided brief information about the study, eligibility criteria, and the current aims; understanding what was the COVID-19 impact on their cancer care and wellbeing. The survey had two equal arms: a Slovenian and an English, accessible to anyone who was able to read and respond in English. Participants were all cancer patients or survivors aged between 18 and 39 years, diagnosed with any form of malignant cancer at age 10 or later.

Measures and survey description

Demographic and Medical information

Participants reported their age, gender, geographical region, and current living arrangement. They also reported their current health status, treatment status, whether or not

they had a pre-existing mental health condition or other chronic illness, or if they were taking any immunosuppressant medication (i.e. steroids).

Psychological distress

Psychological distress was measured using the Patient Health Questionnaire for Depression and Anxiety (PHQ-4), a 4-item measure of the frequency of two anxiety and two depressive symptoms on a 4-point Likert scale from 0 (not at all) to 3 (nearly every day). Reliability and validity of the brief PHQ-4 scale have been established in general and clinical populations, and a score of 3 or above on either sub-scale, and a total score of 6 or above is indicative of clinically relevant distress.[19,20] Cronbach's α for PHQ-4 in our study was 0.84, and 0.83 and 0.78 for anxiety and depression subscales, respectively.

COVID-19: impact on care and information resources

Respondents self-reported if and how the pandemic related events disrupted their cancer treatment and care, what the pandemic impact was on their psychological well-being, where they received the information about the novel SARS-CoV-2, and how satisfied they were with the information available on a scale from 0 (least satisfied/trustworthy) to 10 (most satisfied/trustworthy). (See https://osf.io/ncpv8/)

Analysis

The analyses were conducted in R (Version 3.6.3)[21] using the following packages: ggplot2 (Version 3.3.0),[22] dplyr (Version 0.8.5),[23] psych (Version 1.9.12.31)[24] and papaja (Version 0.1.0.984).[25]

Survey data were analysed in an exploratory and descriptive manner in order to provide preliminary evidence of the impact of the COVID-19 pandemic on the subjective well-being

of cancer patients. We also reported self-reported COVID-19 impact on individuals' cancer treatment protocols.

Qualitative responses were analysed using content analysis approach.[26] The approach has been described as suitable for mixed method research, allowing for a more positivistic approach to analysis and phenomena description.[27] Two researchers (UK, SR) independently read and coded all of the responses to open-ended questions about COVID-19 impact on cancer patients and caretakers' psychological well-being. The researchers coded responses, both deductively by organizing them around the present study aims and survey questions, as well as inductively by devising a list of categories to describe impact on cancer care and the most common worries from participants' descriptions. The formulated categories were refined and operationalized into a coherent list upon which all qualitative responses were mapped. The inter-rater reliability for this procedure was 96%. Lastly, the classification of responses was checked by a third author, and discrepancies were resolved in a consensus meeting. All illustrative quotes in the main body are from different participants.

Results

Participants

During the period between April 6 and May 12, 2020, 177 AYA cancer patients and survivors participated in the study and completed at least 80% of the survey. Of those, 39 were from the Slovenian arm and 138 from the English arm. Participants' demographic and medical information is presented in **Table 1**. On average, cancer patients were 29.33 ($SD = 6.17$) years old. A third [57 out of 177] of responders were in active treatment at the time of the study, 14% [24 out of 177] completed treatment within the previous 6 months, and 54% [96 out of 177] completed their cancer treatment more than 6 months ago. Of the latter, 14 (15%) individuals were still taking immunosuppressive medication.

[INSERT TABLE 1: Demographic and Medical information of participants]

COVID-19 impact on cancer care

Forty-five percent [79 out of 177] of AYA cancer patients reported that COVID-19 had an impact on their cancer treatment or care, and 21% [38 out of 177] reported no impact at the time, but worried that there might be.

According to the short answers, the analyses revealed six categories of most commonly reported changes in cancer care. These categories were: follow-up appointments being postponed or cancelled, appointments carried out over the phone or virtually, cancer treatment and/or surgery being postponed, having to be alone during the treatment, reduced access to medicine, and changes in treatment protocols, such as reduced blood-work or oral instead of intravenous chemotherapy.

COVID-19 impact on psychological well-being

Over a third of AYA participant scored in the clinical range for psychological distress. Individuals undergoing treatment or within 6 months of treatment completion, on average, reported higher levels of psychological distress. Symptoms of anxiety were more common than depressive symptomatology. The mean scores and proportions of participants scoring in the clinical range of psychological distress are reported in **Table 2**.

Additionally, participants were asked how they felt compared to before the pandemic. Sixty-two percent [109 out of 177] of respondents reported feeling more anxious than before, 34% [52 out of 177] reported feeling the same, and 9% [16 out of 177] reported feeling less anxious than before. The proportion of individuals feeling more anxious was the same for those currently in treatment, as well as those who have completed treatment over 6 months ago (see Supplementary material).

[INSERT TABLE 2: Psychological distress among AYAs]

The short responses revealed that the most common concerns among the AYAs related to COVID-19 and their health status were not being sure how big of a risk COVID-19 posed for them, how their body would react to the infection, anxiety about experiencing serious complications if they were to catch the virus, and having their cancer care delayed. However, individuals also reported impact on mood, as well as worries about their family members, returning to "the normal" and finances. The categories and examples of participants' responses can be viewed in Table 3.

[INSERT TABLE 3: Categories of content on COVID-19 impact on psychological wellbeing]

Moreover, physical distancing measures imposed by many authorities resulted in social isolation with 52% [90 out of 173] of AYAs reported feeling more isolated than prior to the pandemic. On the other hand, 39% [68 out of 173] reported feeling about the same, and 9% [15 out of 173] reported feeling less isolated than before, and better understood by their friends and family.

"Even though I am still as isolated as I was when going through treatment and recovery, I find I feel less isolated than before because now my friends and family understand a lot better how it feels."

The qualitative responses highlighted that despite an increase in social interactions online, many individuals missed a more intimate human connection with others. While a few individuals reported having more time for themselves and their families, others reported that the isolation made them more anxious, depressed, and claustrophobic. Their needs as cancer patients were felt to have become secondary:

"People are so concerned with COVID-19 that they don't care about my cancer anymore."

For some, isolation also acted as a trigger, reminding them of their cancer:

"It makes me feel like I am in the first steps of my treatment all over again."

COVID-19 information resources and satisfaction

Participants were asked what sources they relied on for obtaining information related to the COVID-19 pandemic. The majority of respondents [159 out of 172] relied on a minimum of 2 different sources, with the general news being most read [135 out of 172], followed by social media [used by 109 out of 172]. Less than a third [46 out of 172] relied on cancer support groups and patient organizations for COVID-19 specific information. Individuals in different illness phases reported relying on the same information resources. Satisfaction and trustworthiness of the available information related to COVID-19 were perceived to be moderate, 6.2/10 and 6.1/10 respectively, with individuals currently undergoing treatment reporting least satisfaction and trustworthiness for the available information (see Supplementary material for breakdown by treatment status).

Only 24% [42 out of 173] of respondents reported receiving direct communication regarding COVID-19 from their oncologists or health care teams, majority (64%) of whom was undergoing treatment at the time of this study. Over half of the participants, 56% [96 out of 170] reported wanting more information about how to cope with the pandemic (see Supplementary material for breakdown by treatment status). Furthermore, 35% [60 out of 172]

of AYAs would have preferred information about COVID-19 tailored to their needs as young cancer patients and survivors.

"It would be nice to have something to read designed with me in mind." (Female, 32)

On the other hand, a few individuals reported that having more information would be overwhelming, and some reported the need for information specifically for mental health resources for cancer patients during a pandemic.

Discussion

Evidence to-date suggests that young people are at lower risk for contracting the novel SARS-CoV-2 virus or developing serious complications from it,[4,28] however, youth living with and beyond cancer might be at an increased risk because due to the compromised immunity resulting from illness and/or cancer late-effects.[5,29] Moreover, changes in cancer care protocols may increase the levels of anxiety and uncertainty not only for those undergoing active treatment, but also for individuals in the long-term care. Our cross-sectional study of youth living with and beyond cancer, conducted in the initial weeks of the COVID-19 pandemic, found that 3 in 10 AYAs experienced increased levels of psychological distress, with anxiety being more prominent than depressive symptomatology. As many as 6 in 10 AYAs reported feeling more anxious during the COVID-19 pandemic than they had been previously.

Higher levels of distress during a pandemic outbreak might be expected[14] and a variety of psychological problems such as panic disorder, anxiety, and depression due to COVID-19 pandemic have already been observed in general population.[30] It may be that this is compounded for cancer patients, given the salience of risks to their health and their

vulnerability due to immunosuppression. The themes driving anxiety and worry for our participants were predominantly related to physical health and cancer-related concerns. A recent study of Italian adolescent cancer patients and survivors revealed that both groups worried about contracting the virus, and felt personally at risk for severe complications, with survivors reporting more worry than those in follow up care.[31] When stratified by treatment status, our results revealed the highest levels of anxiety in those who have completed treatment within the past 6 months, followed by those in treatment at the time of the study. We speculate that this may in part be due to the uncertainty often experienced upon treatment completion, when individuals often have to wait for scans before remission can be confirmed. These treatment transitions can be burdensome for patients.[9,32] The first few months after treatment are also often marked by frequent follow up appointments, all of which were likely postponed or cancelled due to the current pandemic. The added uncertainty is likely to contribute to anxiety symptoms.

The lowest levels of clinically elevated psychological distress were present in those off treatment, for whom the care was also least impacted by the pandemic and associated events. Nevertheless, a high proportion of those off treatment also reported feeling more anxious now than compared to the times prior the pandemic.

The social impact of the disease containment measures has been considerable. Most governments and authorities across the world have imposed physical distancing as a way to slow the spread of the virus within communities. For many, these measures resulted in social isolation, which can result in increased feelings of loneliness and further contribute to the feelings of low mood and anxiety.[33] The majority of our participants recounted being familiar with isolation measures due to their cancer experience. For some AYAs, de novo isolation acted as a negative reminder of their illness, while on the other hand, almost 10% reported feeling less anxious and isolated compared to the time prior the pandemic. The qualitative

responses revealed that this may be due to the fact that they felt better understood, spent more time with their families, or even found more time for themselves.

Research to date suggests that AYAs with cancer like to be involved in their care and need tailored, age-appropriate information about their cancer, care, late-effects, and resources.[34,35] Only a quarter of our participants reported receiving direct communication related to COVID-19 from their health care providers and we demonstrated that more than half of AYAs would like to have received more information on how to cope during the COVID-19 pandemic, specifically, information tailored to them as young cancer patients and survivors. Regardless of the time passed since diagnosis, the most common worry was knowing the extent of the risk for contracting the virus and how their body would react if they were to contract the infection.

Unlike Italian adolescents,[31] our AYA participants consumed most of the news related to the pandemic via general news sources, followed by social media outlets. This difference may be due to the older age of our sample. The fact that AYAs received most information from general news sources could also explain the reported need for more tailored information. The utility of social media as a way to deliver reliable information, as well as interventions to AYA cancer communities is gaining traction and could pave the way for an eHealth approach to oncological AYA care.[36] Preliminary evidence supports the feasibility and acceptability of online psychosocial interventions for AYAs in treatment[37] or early post-treatment phases,[38] however, future research should carefully evaluate if online support and digital approaches to care respond equally well to the needs of AYAs living with and beyond cancer.

Strengths and Limitations

While the global reach and early data collection add the largest contribution to the growing body of knowledge about the COVID-19 pandemic, there are several limitations that limit the generalizability of our work. Our sample size was relatively small, highly heterogeneous,

mostly female, and with most responses submitted from North America and Europe. While a geographically diverse sample offers broad and preliminary insights into COVID-19 related concerns of AYAs globally, it also limits generalizability due to the diverse health care systems, time-lags between peaks of the pandemic across different countries, and measures taken to prevent the spread of COVID-19.

Participants were a self-selected group who responded to the online study post, and we collected only minor, though relevant details relating to their medical and cancer history. Moreover, the survey was cross-sectional in nature and psychological distress was assessed using a very brief measure, and relied on short answer questions, to which many individuals provided responses with limited context and detail. We relied on retrospective self-report of changes in psychological distress since the advent of COVID-19, which are subject to reporting biases. Nevertheless, have provided important preliminary evidence, which offers invaluable directions for the future research on the impact of COVID-19, and also captured the experiences of this vulnerable population in the early weeks of the COVID-19 pandemic. Our sample included respondents at different stages of cancer treatment and beyond.

Clinical implications

The COVID-19 pandemic is rapidly evolving, and we learn new details every day. Even though the disruptions in our daily routines and health care systems pose many challenges, therein lie many opportunities for improvement of AYA cancer care in the future. The current situation highlights the continued need to screen for psychological distress and attend to those who might be experiencing distress even under normal circumstances. Finding ways of doing this whilst providing follow-up care remotely is particularly important within the current ways of working, and the brief PHQ-4 used in this study may offer a promising way to monitor psychological distress in clinical contexts.

The health care teams should actively engage and provide relevant and reliable information about COVID-19 for cancer patients and survivors, as well as information about any mental health resources. This will be important as the lockdown measures begin to ease in the coming months. Individuals whose care was delayed should receive adequate support so that they follow through with their appointments and continue the necessary treatment. While attending to those who are undergoing treatment or just recently completed it has been a priority, our results emphasize that the needs of long-term survivors should not be overlooked, as many may be experiencing higher levels of distress due to their illness history.

Telemedicine and eHealth might offer a favorable approach for some AYAs, however, in scaling them up, we have to ensure we do not leave behind those with limited access to digital technologies.

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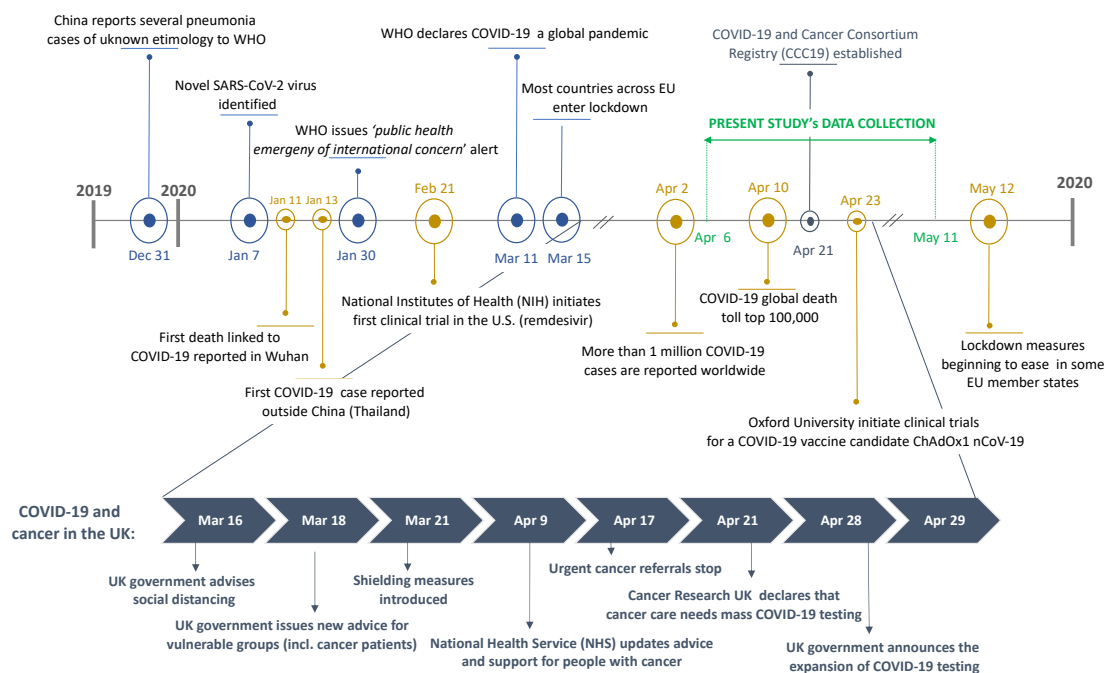
Figure captions

Figure 1: **Global and UK COVID-19 context at the time of this study.**
This figure aimed at providing future readership with COVID-19 context at the time of writing (May 12, 2020). By mid-March, most countries across Europe began nation-wide lockdowns. At the beginning of April, most cancer centers began adapting their treatment protocols. By late April COVID-19 a Cancer Consortium Registry was established with currently over 100 participating institutions globally reporting results about COVID-19 outcomes in cancer patients. There are currently several vaccine trials which have already began testing in healthy human participants.

Table 1
Demographic and Medical information of participants

Variable	*n*	%	*M* (SD)	Range
Age	177	100	29.33 (6.17)	[18 - 39]
Gender				
Female	154	87		
Male	20	11		
Prefer not to answer	3	2		
Region				
North America	93	53		
Central and South America	2	1		
Europe	78	44		
Middle East	1	1		

Africa	0	0
Asia	1	1
Oceania	3	2
Living arrangement		
Alone	24	14
Shared house	13	7
Partner only	45	25
Parents	20	11
Family	72	41
Other	4	2
Treatment status		
Undergoing treatment	57	32
Completed within 6 months	24	14
Completed more than 6 months ago	96	54
Immunosuppressant medications		
Yes	41	23
No	122	69
Prefer not to answer	14	8

Table 1 continued

Variable	*n*	%	*M* (SD)	Range
Mental health diagnosis				
Yes	66	37		
No	108	61		
Prefer not to answer	3	2		

Table 2
Psychological distress among AYAs

		Anxiety	Depression	Total
	n	*M* (*SD*)	*M* (*SD*)	*M* (*SD*)

	n			
Total sample	177	2.61 (1.94)	1.92 (1.71)	4.53 (3.29)
Undergoing treatment	57	2.84 (1.89)	2.07 (1.69)	4.91 (3.22)
Completed within 6 months	24	3.54 (2.02)	2.29 (1.90)	5.83 (3.60)
Completed more than 6 months ago	96	2.24 (1.87)	1.73 (1.66)	3.97 (3.15)

		Anxiety	Depression	Total
	n	*n* (%)	*n* (%)	*n* (%)
Total sample	177	56 (32%)	34 (19%)	51 (29%)
Undergoing treatment	57	20 (35%)	10 (18%)	17 (30%)
Completed within 6 months	24	12 (50%)	6 (25%)	12 (50%)
Completed more than 6 months ago	96	24 (25%)	18 (19%)	22 (23%)

Note. PHQ-4 items are rated on a 4-point Likert scale ranging from 0 to 3. The upper half of the table contains means and *SD*, while the bottom half contains number and proportion of individuals scoring in the clinical range.

Category	Definition	Example
General anxiety	Broad statements and descriptions of anxiety and worries that are not specified or described in detail	*"My anxiety levels tend to be quite high. I had felt like I had my anxiety under control, but this situation has thrown me off."*
Health anxiety	Broad statements about worries of own health, hypochondria, includes concerns about individuals' mental health and illness triggers	*"I worry that my current health problems will not be taken as seriously in the healthcare system as they were before."*
Loneliness	Mentions of lacking support, feeling low and sad due to isolation, feelings of loneliness	*"Whereas I was isolated prior to the global lockdown, I was still able to have the physical support of my family given that they were healthy. I have now lost that, making navigating cancer treatment all the more lonely."*
Low mood	Broader descriptions of low mood or morale, depression	*"Increased feelings of depression and overeating."*

Disruptions	Refers to the impact on mental health and wellbeing due to disruptions in daily living and activities	*"My biggest source of happiness was my job and not being able to see my students is heartbreaking."*
Death/dying	Explicit mentions about dying and mortality	*"I am constantly worried that if I fall sick, I will end up dying considering my cancer history and weak immune system."*
Worry about COVID-19 – self	Worries about how one's body would react to COVID-19, worries about severe complications due to COVID-19, including worries about receiving adequate care if they contracted COVID-19	*"I am worried that if I caught it, I would be one of the ones that do not do well as I have had radiation to my spleen and still have low lymphocytes."*
Worry about COVID-19 – others	Worries about close individuals or family members contracting the virus	*"Mostly worried about family/elder members of the family wanting to get outside more."*
Cancer care	Changes and disruptions in cancer care, which are unfavorable; worry about continuing with care and going to the hospital where many people are infected	*"I worry about what stage my cancer will be when they are finally able to do my surgery/treatment."*
Return to normal	Concerns about how to return to normal, what normal will look like; worries about returning back to work	*"Going back to work eventually stresses me."*
Finance	Direct financial impact from job loss or disruption; loss of insurance	*"I have lost my job, risk losing my insurance, and will be in active treatment until late summer."*

Table 3: Categories of content on COVID-19 impact on psychological wellbeing

SUPPLEMENTARY MATERIAL – Breakdown by treatment phase

	Better than before N (%)	Same as before N (%)	More anxious than before N (%)
Undergoing treatment (n = 57)	7 (12%)	14 (25%)	36 (63%)
Completed within 6 months (n = 24)	2 (8%)	9 (38%)	13 (54%)

Completed more than 6 months ago (n = 96)	7 (7%)	29 (30%)	60 (63%)

Table 1: Table showing the proportion of individuals feeling more anxious or distressed now, compared to the time prior to the pandemic, stratified by treatment phase

	Received info about COVID N (%)	Did not receive info about COVID N (%)
Undergoing treatment (n = 57)	27 (47%)	30 (53%)
Completed within 6 months (n = 23)	4 (17%)	19 (83%)
Completed more than 6 months ago (n = 91)	11 (10%)	82 (90%)

Table 2: Table showing the proportion of individuals who received direct communication about COVID-19 from the health care team by treatment phase

	Want more information N (%)	Don't want more information N (%)	Not sure N (%)
Undergoing treatment (n = 56)	33 (59%)	13 (23%)	10 (18%)
Completed within 6 months (n = 23)	13 (57%)	4 (17%)	6 (26%)
Completed more than 6 months ago (n = 91)	50 (55%)	16 (18%)	25 (27%)

Table 3: Table showing the proportion of individuals who would have wanted more information about COVID-19, stratified by treatment phase

	COVID-19 Information sources	Satisfaction (mean)	Trustworthiness (mean)
Undergoing treatment (n = 57)	General news (n = 44) Medical Professionals (n = 43) Social Media (n = 37)	6/10	5.8/10
Completed within 6 months (n = 23)	General news (n = 22)	6.3/10	6.5/10

	Medical Professionals (n = 14) Social Media (n = 12)		
Completed more than 6 months ago (n = 91)	General news (n = 69) Social Media (n = 60) Medical Professionals (n = 44)	6.3/10	6.2/10

Table 4: Table showing the most commonly used information resources for COVID-19, and reported satisfaction and perceived trustworthiness of these resources, stratified by treatment phase
NOTE: Satisfaction and trustworthiness are rated on a scale from 0 (least satisfied/trustworthy) to 10 (most satisfied/trustworthy).