Prevalence and correlates of psychological distress, unmet supportive care needs, and fear of cancer recurrence among haematological cancer patients during the COVID-19 pandemic

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Abstract

Background The COVID-19 pandemic has had a disruptive effect on people with haematological cancers, who represent a high-risk population due to the nature of their disease and immunosuppressive treatments. We aimed to identify the psychological impacts of the COVID-19 pandemic on haematology patients and identify correlated factors to inform the development of appropriate supportive interventions.

Methods 394 respondents volunteered their participation in response to a study advertisement distributed online through established haematology groups. Participants completed a self-report online survey exploring well-being, psychological distress, unmet supportive care needs, and fear of cancer recurrence.

Results At least 1 in 3 respondents (35%) reported clinical levels of distress and nearly 1 in 3 (32%) identified at least one unmet need. Among respondents in remission ($n = 134$), clinical fear of cancer recurrence was reported by nearly all (95%). Unmet needs, pre-existing health conditions, younger age, financial concerns, and perceived risk of contracting COVID-19 were the dominant factors contributing to psychological distress during the pandemic. Psychological distress, lost income, perceived inadequate support from care team, perceived risk of contracting COVID-19, and being a woman were significantly associated with unmet needs. Psychological distress and concern about the impact of COVID-19 on cancer management were significantly associated with fear of cancer recurrence among respondents in remission.

Conclusion Results highlight the high psychological burden and unmet needs experienced by people with haematological cancers during the COVID-19 pandemic and indicate a need for innovative solutions to rapidly identify distress and unmet needs during, and beyond, pandemic times.

Introduction

The COVID-19 pandemic has presented many challenges for those with cancer, with members of this population subgroup at increased risk of contracting COVID-19 and experiencing severe complications or death from the virus [1]. Due to these vulnerabilities, powerful health messages have stressed the higher risk posed to cancer patients and many cancer treatments have been modified or delayed to minimise patients' exposure to COVID-19 [2]. Although these changes to usual care were designed to protect vulnerable cancer patients in the short-term, evidence is beginning to emerge of the potential long-term consequences of these actions. For example, fear of infection has resulted in many patients making their own choice to delay care, with a study conducted by the American College of Emergency Physicians during the first wave of the COVID-19 pandemic finding that 29% of the cancer patients surveyed reported they had avoided visiting the emergency department due to fears of contracting the virus [3]. In Australia, the context of the present study, cancer hospitals reported a 40% decline in patient presentations for cancer management appointments during the pandemic [4], similar to reductions reported in other

countries [5, 6]. These figures are concerning given recently published research indicates that delaying curative treatment by just one month increases cancer patients' risk of death by as much as 10% [7].

The psychological effects of limiting cancer care during the COVID-19 pandemic are likely to be significant. Community-based cancer organisations have reported an increase in the number of calls to their support lines, with many patients reporting anxiety about their risk of contracting COVID-19 [8]. Mitigating these psychological effects has thus become a health priority [9–11]. Research examining the psychological impact of the pandemic can help to inform the development of appropriate interventions, yet there is a lack of such research on people with haematological cancers. This is concerning given those with a haematological cancer represent a particularly vulnerable subgroup of cancer patients due to (i) the nature of their disease (i.e., damage to the immune system) and (ii) immunosuppressive treatments such as haematopoietic stem cell transplantation (HSCT), which places patients at increased risk of respiratory viral infections [12, 13].

In addition to the risks associated with contracting COVID-19, the pandemic has severely impacted the availability of donor stem cell products for haematological cancer patients who are planned to undergo HSCT. Finding a suitable stem cell donor is challenging and there may not be a suitable donor identified in the same country as the recipient. In Australia, over 80% of donated stem cells come from international volunteer donors [14]. Rapid border closures and flight changes have limited the availability of stem cell products, creating significant challenges for those who were planned to undergo potentially life-saving HSCT [15–17].

There are legitimate concerns about the emergence of a range of negative psychological consequences of the COVID-19 pandemic among people with haematological cancers. To inform the development of appropriate support interventions that actively mitigate the psychological consequences of the pandemic and future pandemics among haematological patients, the present study investigated (i) the prevalence of psychological distress, unmet supportive care needs, and fear of cancer recurrence among haematological cancer patients during the pandemic and (ii) correlates of these psychological factors.

Methods

Respondents

Eligible respondents were adults aged ≥ 18 years who currently have, or previously have had, a confirmed diagnosis of haematological cancer and had sufficient English language skills to participate without an interpreter.

Recruitment

Respondents volunteered their participation in response to a study advertisement distributed via email and/or social media platforms by established national community groups (Leukaemia Foundation), professional member societies and working groups (Victorian COVID-19 Cancer Network), and

clinical trial groups (Australasian Leukaemia & Lymphoma Group). Potential respondents were provided a link to an online information sheet, consent form, and survey. The study protocol was approved by the University of Melbourne Human Research Ethics Committee (Ref: 2057125.1).

Measures

An online cross-sectional survey was conducted from 22 July to 19 August 2020 and was used to collect the following information.

Demographic characteristics: Data on age, gender, postcode, marital status, education level, employment status, and number of dependants living in the home during the COVID-19 pandemic were collected. Residential postcode was used to classify respondents' location (Major cities/Inner regional/Outer regional/Remote/Very remote) as per the Australian Bureau of Statistics Australian Statistical Geography Standard (ASGS) [18].

Medical characteristics: Information regarding respondents' primary diagnosis, date of diagnosis, treatment, disease status, pre-existing health conditions, and type of hospital managing respondents' care was collected.

Cancer care experience: Four questions were designed by the research team to better understand the care experiences of respondents during the pandemic (see Table 1). Questions explored opportunities for family support, access to care, perceived adequacy of access to support, and ability to maintain contact with the health care team.

Financial concerns: Two items were designed to explore respondents' financial wellbeing during the pandemic, including whether they had lost income due to lockdown measures (Table 1).

Table 1. Purpose built items included in COVID-19 survey.

Topic	Items	Response options
Cancer care experience	I have had limited opportunities for family support I have been restricted in accessing care due to travel bans I have received adequate support from my care team and/or all support services I have been able to keep in good contact with my care team	5-point Likert scale of 1 ("Strongly disagree") to 5 ("Strongly agree")
Financial concerns	How do your financial concerns during the COVID-19 pandemic compare with the financial concerns you had before the pandemic? I have lost income due to the lockdown	5-point Likert scale of 1 ("Much better") to 5 ("Much worse") 5-point Likert scale of 1 ("Strongly disagree") to 5 ("Strongly agree")
Perceived risk and impact of COVID-19 on cancer management	How concerned are you about the impact of COVID-19 on your cancer management? How concerned are you about being infected with COVID-19 yourself? How concerned are you that you could give infection to your family members if you become infected with COVID-19? How concerned are you about the adequacy of measures used to prevent COVID-19 transmission in the hospital? How concerned are you about access of hospital staff to medical grade protective equipment to prevent the spread of COVID-19?	5-point Likert scale of 1 ("Not at all concerned") to 5 ("Very concerned")

Perceived risk and impact of COVID-19 on cancer management: Five questions were designed to investigate respondents' concerns about the impact of COVID-19 on their own health and their perceived risk of contracting COVID-19 (Table 1).

Psychological distress: Psychological distress was measured using the Kessler 10-item assessment (K10) [19]. Respondents indicated the extent to which they experienced each emotional state since the beginning of the pandemic using a 5-point Likert scale ranging from 1 ("None of the time") to 5 ("All the

time”). Cronbach’s alpha in this sample was 0.92, indicating a high level of internal consistency. Scores were divided into three categories representing mild (range 20-24), moderate (range 25-29), and severe psychological distress (range 30-50).

Unmet supportive care needs: Respondents’ perceived needs during COVID-19 were captured by the subdomains *Health system and Information needs* (11 items) and *Patient care and Support needs* (5 items) of the short-form Supportive Care Needs Survey (SCNS-SF34) [20]. The SCNS-SF34 had excellent internal consistency in this specific sample (Cronbach’s $\alpha = 0.97$). The SCNS-SF34 uses a 5-point scale to measure unmet need: 1 = No need – not applicable, 2 = No need – satisfied, 3 = Low need, 4 = Moderate need, and 5 = High need. In line with previous research [20], responses 1 and 2 were re-coded as 0 (“No need”) and subsequent categories were re-scored accordingly 1 (“Low need”), 2 (“Moderate need”), and 3 (“High need”).

Fear of cancer recurrence (FCR): Respondents who had completed treatment and were in remission were asked to complete the 9-item *Severity* subscale of the Fear of Cancer Recurrence Inventory (FCRI) [21]. This subscale evaluates the severity of intrusive thoughts associated with respondents’ fears about the possibility that cancer could return or progress on a 5-point Likert scale ranging from 1 (“Not at all”) to 5 (“A great deal”). The accepted cut-off score for clinical FCR is 13. The FCRI had acceptable internal consistency in this sample (Cronbach’s $\alpha = 0.77$).

Data analysis

Survey data were collected in Qualtrics and de-identified prior to being exported to SPSS (V26.0, IBM SPSS) for analysis. Descriptive statistics (e.g., frequencies, means, and standard deviations) were calculated. Univariate linear regressions were conducted to identify potential correlates of psychological distress, unmet supportive care needs, and FCR. All variables significant at $p < 0.05$ were subsequently included in multiple linear regression models to determine their relative contribution to each of the dependent variables. Moderation analyses were carried out to further identify high risk groups and explored the effects of gender (1 = men, 2 = women), location (1 = major cities, 2 = regional), age (treated as continuous), marital status (1 = single, 2 = married/defacto), education (1 = < tertiary, 2 = tertiary), and employment status (1 = employed, 2 = unemployed).

Results

Respondent characteristics

A total of 394 respondents aged 16 to 84 years (mean $\pm$ standard deviation (SD): 60.4 years $\pm$ 12.8) participated in this study (See Online Resource 1 for the sample characteristics table). Respondents were evenly divided between major cities (50%) and regional areas (50%). The ratio of men (53%) to women (47%) was relatively even and most were married (71%). Lymphoma (34%) and leukaemia (27%) were the most common haematological cancers reported. Over half (53%) of all respondents had received a

haematological cancer diagnosis within the previous three years. In terms of stage of treatment, 43% were currently receiving ongoing, or maintenance treatment while 37% were in remission.

Psychological distress, unmet supportive care needs, and fear of cancer recurrence

Descriptive statistics for the dependent variables of psychological distress, unmet supportive care needs, and FCR are presented in Table 2. Thirty-five percent of respondents ($n = 138$) had elevated scores on the Kessler Psychological Distress scale, with 17% reporting scores suggestive of mild distress, 8% reporting scores suggestive of moderate distress, and 9% reporting scores suggestive of severe distress. Overall, 32% ($n = 128$) of respondents reported experiencing at least one unmet moderate or high need; 28% reported at least one unmet moderate or high need in the Health system and Information domain and 24% reported at least one unmet moderate or high need in the Patient care and Support domain. The most prevalent unmet needs were (i) having access to professional counselling (15%), (ii) being given information about test results as soon as feasible (15%), and (iii) being treated like a person (15%). Of those who had completed treatment and were in remission ($n = 134$), all respondents reported some degree of FCR, with 95% reporting clinical FCR.

Table 2. Prevalence of psychological distress, unmet supportive care needs, and fear of cancer recurrence.

Psychosocial factors	Mean $\pm$ SD	n (%)
Psychological distress	19.5 (7.1)	–
Mild (20 – 24)	–	68 (17.3)
Moderate (25 – 29)	–	33 (8.4)
Severe (30 – 50)	–	37 (9.4)
Unmet supportive care needs	1.5 (3.3)	–
Health system and information	–	109 (27.7)
Patient care and support	–	95 (24.1)
Fear of cancer recurrence	23.5 (6.6)	–
Normal (< 13)	–	7 (5.2)
Clinical FCR (≥ 13)	–	127 (94.8)

Financial concerns

In terms of financial wellbeing during the pandemic, 26% of respondents had lost income and 29% indicated their financial concerns had been worse compared to the period before the outbreak.

Perceived risk and impact of COVID-19 on cancer management

Regarding the perceived adequacy of measures used to prevent transmission of COVID-19 in hospitals, 61% of respondents expressed some degree of concern (32% 'a little bit concerned', 15% 'moderately concerned', 8% 'quite concerned', 6% 'very concerned'). Regarding their concerns about access of hospital staff to protective equipment to prevent COVID-19 transmission, 62% of respondents reported some degree of concern (29% 'a little bit concerned', 13% 'moderately concerned', 9% 'quite concerned', 11% 'very concerned'). When asked how concerned they were about the impact of COVID-19 on their cancer management, 70% respondents reported some degree of concern (33% 'a little bit concerned', 19% 'moderately concerned', 12% 'quite concerned', 6% 'very concerned').

Cancer care experience

During the COVID-19 pandemic, 35% of respondents indicated they had limited opportunity for family support, and 21% had been restricted in accessing care due to travel bans. Regarding their care team, the majority of respondents felt they had maintained good contact (80%) and received adequate support (71%).

Factors associated with psychological distress

Online Resource 2 presents the factors found in univariate regression analyses to be significantly associated with psychological distress during the pandemic. These factors were entered simultaneously in a multiple regression model (adjusted $R^2 = .37$, $F(11, 324) = 18.63$, $p < .001$; Table 3). Six of the factors remained significant, collectively explaining 35% of the variance in psychological distress. Specifically, unmet needs, pre-existing health conditions, younger age, financial concerns, perceived risk of contracting COVID-19, and living in a regional area were associated with greater psychological distress during the pandemic.

Table 3. Multiple linear regression model assessing the factors associated with psychological distress, unmet supportive care needs, and fear of cancer recurrence.

Variable	B [95% CI]	SE	β	<i>p</i>	<i>R</i> ²
Psychological distress					.37
Total unmet needs	0.17 [0.11, 0.24]	.03	.25	.000	
Number of pre-existing health conditions	1.32 [0.84, 1.80]	.24	.25	.000	
Age	-0.11 [-0.17, -0.06]	.03	-.20	.000	
Financial concerns	1.82 [0.97, 2.64]	.43	.20	.000	
Perceived risk of contracting COVID-19	0.21 [0.02, 0.39]	.09	.12	.027	
Location (1 = Major cities, 2 = Regional)	-1.29 [-2.53, -0.05]	.63	-.09	.041	
Concern about impact of COVID-19 on cancer management	0.53 [-0.09, 1.15]	.32	.09	.096	
Limited opportunity for family support	0.31 [0.03, 0.64]	.17	.08	.077	
Marital status (1 = Single, 2 = Married)	-1.12 [-2.53, 0.28]	.71	-.07	.117	
Restricted access to care	0.18 [0.17, 0.52]	.18	.05	.324	
Lost income	0.09 [0.26, 0.44]	.18	.02	.887	
Unmet supportive care needs					.22
Psychological distress	0.38 [0.22, 0.54]	.08	.27	.000	
Lost income	0.69 [0.17, 1.21]	.26	.13	.009	
Adequate support from care team	0.94 [0.24, 1.64]	.36	-.13	.009	
Perceived risk of contracting COVID-19	0.33 [0.04, 0.62]	.15	.13	.025	
Gender (1 = Men, 2 = Women)	2.14 [0.17, 4.09]	.99	.11	.034	
Concern about impact of COVID-19 on cancer management	0.86 [0.13, 1.84]	.50	.10	.089	
Age	-0.03 [-0.11, 0.05]	.04	-.04	.469	
Financial concerns	0.26 [-1.10, 1.62]	.69	.02	.703	
Fear of cancer recurrence					.29
Psychological distress	0.27 [-0.12, 0.44]	.08	.28	.001	
Concern about impact of COVID-19 on cancer management	1.48 [0.48, 2.47]	.50	.25	.004	
Perceived risk of contracting COVID-19	0.29 [0.00, 0.58]	.15	.17	.051	
Age	-0.04 [-0.12, 0.03]	.04	-.09	.254	
Total unmet needs	0.01 [-0.12, 0.13]	.06	.01	.921	

B, unstandardized regression coefficient; CI, confidence interval; SE, standard error; β , standardized regression coefficient

Moderation analyses revealed that (i) age moderated the relationship between financial concerns and psychological distress ($B = 0.09$, 95% CI = 0.03, 0.16, $t = 2.72$, $p = .007$), such that the association between financial concerns and distress was stronger in younger people compared to older people, and (ii) marital status moderated the relationship between perceived risk of contracting COVID-19 and higher psychological distress ($B = -0.55$, 95% CI = -0.91, -0.18, $t = -2.94$, $p = .004$), such that the association between perceived risk of COVID-19 and distress was higher among those who were single compared to those who were married.

Factors associated with unmet supportive care needs

Online Resource 2 presents the factors found in univariate analyses to be significantly associated with unmet supportive care needs during the COVID-19 pandemic. These factors were entered simultaneously into a multiple regression model (adjusted $R^2 = .22$, $F(8, 331) = 12.89$, $p < .001$; Table 3). Five of the factors remained significant, collectively explaining 22% of the variance in unmet supportive care needs. Psychological distress, lost income, perceived inadequate support from care team, perceived risk of contracting COVID-19, and being a woman were found to be significantly associated with greater unmet supportive care needs during the pandemic.

Moderation analyses revealed that (i) gender moderated the relationship between psychological distress and unmet needs ($B = 0.45$, 95% CI = 0.18, 0.73, $t = 3.25$, $p = .001$), such that the association between psychological distress and unmet needs was stronger in women than in men, and (ii) age moderated the relationship between lost income and unmet needs ($B = -0.05$, 95% CI = -0.09, -0.00, $t = -2.06$, $p = .039$), such that the association between lost income and unmet needs was stronger in younger people compared to older people.

Factors associated with fear of cancer recurrence

Online Resource 2 presents the factors found in univariate analyses to be significantly associated with higher FCR during the COVID-19 pandemic among respondents in remission. These factors were entered simultaneously into a multiple regression model (adjusted $R^2 = .29$, $F(5, 120) = 11.21$, $p < .001$; Table 3). Two of the factors remained significant, collectively explaining 28% of variance in FCR. Specifically, psychological distress and concern about the impact of COVID-19 on cancer management were associated with greater FCR during the pandemic. No significant moderators were identified.

Discussion

This study aimed to identify the psychological issues experienced during the COVID-19 pandemic by haematological cancer patients and to identify correlated factors to inform the development of appropriate interventions. In this cross-sectional study we found a high prevalence of psychological distress and unmet supportive care needs, which was much higher than results obtained from two previous studies involving Australian haematology patients during non-pandemic times [22, 23]. Developing innovative solutions to screen for distress and unmet needs and responding to these needs in a timely manner is crucial, especially during pandemic times when face-to-face clinical care is limited.

FCR was particularly prominent among respondents in the present study, with nearly all (95%) of those in remission reporting clinical levels of FCR. While FCR is arguably one of the most common issues among cancer survivors, the prevalence among this sample is significantly higher than that previously seen in survivors of solid cancers and haematological cancers in non-pandemic times [24, 25]. Given FCR is associated with high rates of depression and greater health care utilisation [26] and does not appear to abate over time [27], haematological cancer patients may benefit from (i) greater validation of their

concerns and (ii) enhanced routine screening to determine the severity of FCR and the need for specialised treatment of FCR. A single-item screening instrument has recently been developed for this purpose [28]. Due to its brevity, the tool can easily be used in clinical follow-ups and may be better suited to the time and resource constraints of health professionals, many of whom are managing additional workload demands as results of the pandemic.

Unmet needs emerged as a key contributor to psychological distress among those surveyed in the present study. These findings are in line with previous research reporting positive associations between unmet needs and psychological morbidity among haematological cancer patients [29]. The widespread disruptions to accessing cancer care services during the pandemic may explain why 'having access to professional counselling', 'being given information about test results as soon as feasible', and 'being treated like a person' were the three highest ranked needs in this study. Moreover, the pandemic has likely heightened these needs due to travel restrictions posing additional barriers to accessing care, which was a concern reported by at least one in five (21%) respondents in this study. Our results suggest that attending to these needs among haematological cancer patients constitutes a potential means of reducing psychological distress.

Our results highlight the increased financial hardship faced by haematology patients during the COVID-19 pandemic. At least one in four respondents indicated they had lost income as a result of the pandemic and had increased financial concerns. Lost income was associated with greater unmet needs, while financial concerns were associated with greater psychological distress. These associations underscore existing literature suggesting financial stress is a relatively powerful predictor of distress among haematological cancer patients, who are particularly vulnerable to these difficulties due to the expensive and prolonged nature of treatments such as HSCT that can lead to extended time away from work [30, 29, 31]. This study also found that the associations between (i) financial concerns and psychological distress and (ii) lost income and unmet needs were stronger in younger people compared to older people, indicating that this subgroup of patients may benefit most from additional support in accessing financial assistance. Validated screening tools, such as the 11-item COST-FACIT [32], may assist clinicians with identifying those patients at high risk who may benefit from additional financial advocacy resources and referral to targeted interventions.

This study found evidence of positive associations between perceived risk of contracting COVID-19 and both psychological distress and unmet needs, with the association between perceived risk and distress stronger among single persons. Additionally, a positive association was observed between concern about the impact of COVID-19 on cancer management and FCR among respondents in remission. In Australia, messages communicating the dangers of COVID-19 have led to unintended declines in patient presentations for cancer management appointments [4]. Several community-based cancer organisations have already taken proactive steps to help restore the delivery of cancer care through social media campaign initiatives. For example, the "Don't delay" and "Here for you" campaigns encourage patients to follow-up on health concerns and access cancer support [33, 34]. Our results suggest this messaging should reassure patients about the safety of clinical facilities and inform them of the availability and

effectiveness of telehealth appointments [35]. This may help to reduce fears of contracting COVID-19 and restore much needed cancer care.

Building upon previous research [36], the present study found higher levels of distress amongst regional compared to urban respondents. In recent years, there have been increased efforts to enable access to cancer services for regional haematological cancer patients, since much of their needed care is only offered in urban treatment centres [37]. However, unwarranted variation in care for regional patients is an issue that continues to demand action, which has likely heightened during the pandemic due to travel restrictions posing additional barriers to accessing care.

Limitations

Several study limitations need to be considered. First, an eligibility requirement that respondents have sufficient English language skills is likely to have prevented the participation of individuals from culturally and linguistically diverse (CALD) backgrounds. Future research considering the needs of these individuals is critical. This is particularly important given the rapid uptake of telehealth consultations, which are less suited to CALD patients and may exacerbate inequalities that are already apparent in cancer care [14, 36]. Second, the present findings should be interpreted with caution due to the potential for bias resulting from our self-selection recruitment method. Third, as this study was cross-sectional, causative links cannot be assumed and require further investigation in prospective studies. Finally, this study did not include detailed questions about patients' perspectives or experiences resulting from receiving care via telehealth. A qualitative study examining the perceived value of telehealth during the COVID-19 pandemic is currently ongoing.

Conclusion

The present study appears to be one of the first to explore the prevalence and correlates of psychological distress, unmet needs, and FCR in haematological cancer patients during the COVID-19 pandemic. Results indicated that respondents experience high levels of distress and unmet needs, and that the majority in remission experience clinical FCR. These findings highlight the need for supportive interventions to assist haematological cancer patients to better manage distress, unmet needs, and FCR, which is particularly important during pandemic times when face-to-face clinical care is limited. The correlated factors identified in this study can be used to inform the development of appropriate support interventions and target those most in need, including financial concerns, lost income, younger age, living in a regional area, perceived risk of contracting COVID-19, and concern about the impact of COVID-19 on the management of haematological cancers. It is hoped that the present findings encourage much-needed efforts to minimise major disruptions to cancer care and mitigate the longer-term psychological impact on people with haematological cancers.

Declarations

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Conflict of interest: The authors declare that they have no conflict of interest in this work.

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the University of Melbourne Human Research Ethics Committee (Ref: 2057125.1) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Consent to participate: Informed consent was obtained from all individual participants included in the study.

Consent for publication: Participants provided informed consent regarding publishing their data.

Data availability: The data that support the findings of this study are available upon request from the corresponding author.

Code availability: N/A

Author contributions: All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Nienke Zomerdijs, Michelle Jongenelis, and Camille E. Short. The first draft of the manuscript was written by Nienke Zomerdijs and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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