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Beyond the Pandemic: A Cross-Sectional Study of Hematology Cancer Patients' Unmet Needs and Experiences of Cancer Care in Ireland and the UK

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ABSTRACT

Objectives: The rising incidence of hematological cancers, novel treatments, and increased survivorship highlight the need to understand patient needs postpandemic. This study explored the experiences of individuals affected by hematological cancers in Ireland and the UK as COVID-19 restrictions lifted.
Methods: A cross-sectional descriptive survey was conducted from March 2023 to March 2024 using validated measures of distress, resilience, and unmet needs. Adults with hematological cancers were recruited online through cancer organizations and networks across Ireland and the UK. Quantitative data were analyzed using descriptive and inferential statistics, and qualitative data through thematic analysis.
Results: Ninety-two individuals completed the survey. The top unmet needs were related to tiredness, concerns about appearance, and managing others' expectations to return to "normal." Many continued to feel the pandemic's impact years later. Minimal differences in unmet needs were observed between countries, with participants reporting low distress and moderately high resilience. Thematic analysis of text responses identified three key themes: "psychological impact and self-care methods," "navigating changing cancer care delivery," and "sourcing social support," reflecting the complexities of living with and beyond hematological cancers.
Conclusions: People with hematological cancers in Ireland and the UK continue to experience distress despite moderate resilience, indicating the lasting impact of the pandemic.
Implications for Nursing Practice: Persistent unmet needs around fatigue, appearance, and societal expectations remain. The identified themes underscore the need for supportive interventions focusing on psychological coping strategies, continuity in cancer care delivery, and social support to enhance the well-being of individuals living with and beyond hematological cancers.

Background

The transition from pandemic-induced public health restrictions to a semblance of prepandemic normality presents a unique challenge for people who are affected by cancer, particularly those who are immunosuppressed.[1,2] During the COVID-19 pandemic, people affected by cancer faced a constellation of challenges that impacted their physical and psychological well-being. Many people experienced disruptions in treatment,[3-6] social isolation and additional challenges in accessing general and cancer-specific health services.[7] Nevertheless, the response to the pandemic within cancer services led to positive transformations in the delivery of care, including innovation in models of care and expansion of telemedicine, which, if sustained, have the potential to support the optimization of care services into the future.[8-10] These issues underscore the multifaceted nature of cancer care during the COVID-19 pandemic, highlighting

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Layperson Summary

What we investigated and why

We wanted to understand the needs of people with blood cancers in Ireland and the UK, and how they are coping after the COVID-19 pandemic, and what support they still need as they live longer with their diagnosis.

How we did our research

We surveyed 92 adults with blood cancers online between March 2023 and March 2024, asking about emotional well-being, coping, and ongoing support needs.

What we have found

Most people reported low distress and felt they were coping well, but many still had unmet needs. The most common issues were tiredness, concerns about appearance, and feeling pressure to act like life is “back to normal.” People also felt ongoing impacts from the pandemic. We found three key themes: how people manage their emotional health, experiences with changes in cancer care, and the need for social support.

What it means

People with blood cancers still face emotional and practical challenges long after treatment. This shows the need for better support services that focus on mental health, ongoing care, and staying connected with others.

the need for resilient healthcare systems that can adapt to unprecedented situations while providing comprehensive care.

The evolving landscape of hematological cancers regarding new treatments and outcomes, coupled with the increase in patient numbers, necessitates a deeper understanding of their needs and experiences. This understanding can facilitate effective support and improve hematology cancer care delivery as COVID-19 public health restrictions are lifted and cancer services adapt to the postpandemic period. Hematological cancers are diverse, including leukaemia, lymphoma, myeloma, and myelodysplasia syndromes (MDS). The unique pathological characteristics of hematological cancers, from presentation to prognosis, lead to diverse patient experiences, treatment approaches, and survivorship outcomes.[11-13] The volatility of the cancer diagnosis and treatment can leave patients with hematological cancers in a state of ambiguity.[14] Hematological cancers significantly impact the daily lives of affected individuals and their support networks, involving psychosocial issues such as fear of recurrence, information needs, work-related challenges, and financial concerns.[15-17] Hematological cancer patients are especially vulnerable to the effects of being immunocompromised, making them more susceptible to infection and heightened distress during the COVID-19 pandemic, necessitating precautions, such as self-isolation, to minimize the risk of complications.[4,5,18-20] Therefore, the management of hematological cancers can be challenging, requiring not only multidisciplinary but interdisciplinary healthcare to deliver comprehensive care.[21-24]

Optimal cancer care necessitates a comprehensive understanding of the needs of survivors and the factors influencing them.[25,26] The availability of care and resources for cancer survivors has progressed through the assessment of unmet needs.[27] Given disease heterogeneity and known disparities in hematological cancers, there is a limited understanding of the unmet needs and experiences faced by people with hematological cancers, a group requiring specialized care and attention.[28,29] An enhanced understanding of the needs and experiences of people with hematological cancers enables informed decision-making relating to their survivorship care.[30] Emerging evidence over the past decade has begun to advance our understanding of the needs, quality of life and patient outcomes of hematological cancers.[17,31-38] Nevertheless, the specific experiences and needs of people affected by hematological cancers during and since the pandemic have received limited attention.[39,40]

Understanding the dynamics in care for people affected by hematological cancers is crucial to the development of targeted interventions to optimize the well-being of those touched by cancer. Understanding the specific experiences of people affected by hematological cancers in the initial postpandemic period offers a unique opportunity to ensure issues in care, support, and treatment that have continued beyond the pandemic are addressed. Furthermore, initiatives implemented during the pandemic that have positively influenced care in this population can be leveraged to advance care delivery that is sensitive to the needs, preferences, and concerns of people affected by hematological cancers. This study aims to explore the experience of people affected by hematological cancers in Ireland and the UK as the public health restrictions associated with the COVID-19 pandemic were lifted.

Methods

Study Design and Sample

A cross-sectional descriptive study was conducted. Participants were recruited online through cancer organizations and support groups across Ireland and the UK between March 2023 and March 2024. This study adhered to the Strengthening the Reporting of Observation Studies in Epidemiology (STROBE) guidelines.[41] Adults (aged 18 years and over) living with or beyond a diagnosis of leukaemia, lymphoma, myeloma, or MDS, who had experienced care during the COVID-19 pandemic and could provide informed consent to participate in a survey were eligible to participate. A convenience sampling strategy was utilized, recruiting participants via cancer organizations and support groups. Cancer charities and support groups across Ireland and the UK used various approaches to disseminate study information to potential participants via email newsletters or bulletins, social media pages, or printed posters in their physical spaces. The study was also advertised by the research team members’ professional and organizational social media profiles (Facebook, X, and LinkedIn) to share with cancer research networks. The survey was accessed through an online participant information leaflet via a link or QR code. The questionnaire was anonymous; however, participants were asked to indicate their consent to participate before completing the online questionnaire. Ethical approval for the study was obtained from the University Research Ethics Committees (Reference: LS-22-35-Drury).

Data Collection

Validated questionnaires were selected for this study, guided by the results of previous qualitative research conducted by the team.[19,20] The study questionnaire aimed to explore participants’ perceptions of changes to continuity of care, perceived risks, or benefits of new methods of care delivery implemented during and since the COVID-19 pandemic, information needs, and worries about cancer relating to COVID-19, as well as questions about their unmet needs, distress, resilience, and demographic characteristics. This study aims to provide a snapshot of patient-reported well-being and support needs during this transitional period, rather than a retrospective or longitudinal evaluation of the pandemic’s full course. People with hematological cancers participated in a single, anonymized questionnaire comprised of self-report demographic questions (eg, age, gender, cancer type, time since diagnosis, country of origin, country of healthcare, and other relevant factors), and validated measures of distress, resilience, and unmet needs.

Identification of an individual's psychological needs is fundamental to developing a plan to manage needs.[42] The National Comprehensive Cancer Network Distress Thermometer (NCCN-DT)[43] facilitated screening self-reported distress in different settings across Ireland and the UK. Participants reported their level of distress over the past week on the NCCN-DT, a one-item visual analogue scale (0 meaning no distress and 10, extreme distress). The DT has been validated across different cancer types, settings, cultures, and countries.[44-47] The Problem List asked participants, "Have you had any concerns about any of the items below in the past week, including today?", selecting all that apply to physical, emotional, social, practical, spiritual/religious or other concerns.[48]

The 2-item Connor–Davidson Resilience Scale (CD–RISC-2) evaluated the resilience of participants on a 5-point Likert scale (0, "not true at all," to 4, "true nearly all of the time") via two items, "able to adapt to change" and "tend to bounce back after illness or hardship."[49] The sum of both items (range of 0-8) is calculated to provide an overall CD-RISC-2 score; higher scores reflect higher levels of resilience.

The 30-item Survivor Unmet Needs-Short Form (SF-SUNS) measures the degree of unmet need as perceived by an individual over the past month.[50,51] Unmet needs are assessed from the following four domains: information needs (3 items), work and financial needs (8 items), access and continuity of care needs (6 items), and coping, sharing, and emotional needs (13 items).[51] Unmet needs ranged from no unmet needs (0) to very high unmet needs (4) on the SF-SUNS. Scores from domains are generated by adding each item score and dividing by the total number of domain items.[50] SF-SUNS derives from the original 89-item SUNS and is validated for cancer survivors one to 5 years postdiagnosis and has been tested with hematological populations,[51,52] and has demonstrated reliability and validity.[35,53] All Cronbach's alphas were >0.85 showing strong internal consistency for all four domains and intraclass correlations >0.9 indicate the SF-SUNS is reliable in measuring levels of unmet need.[50]

COVID-19-specific questions were adapted from previous research.[54] A 13-item questionnaire to understand COVID-19's impact on cancer patients' distress in everyday life consisted of a 4-point Likert scale (1, "not at all," to 4, "very much"), with some binary (yes/no) response choices and optional text responses (eg, Would you like more information? If yes, what kind of information?).

Data Analysis

The descriptive analyses of (1) levels of unmet needs, (2) distress scores, and (3) resilience scores were conducted. Using SPSS (v.28), the unmet needs domain scores were calculated by summing the scores for all items and dividing by the number of nonmissing responses for that domain. The most prevalent "high/very high" unmet needs were ascertained from the percentage of participants reporting this level of unmet need for each of the 30 items, ranked from high to low. Univariate analyses of subgroups at risk of (1) higher unmet needs, (2) higher distress scores, and (3) lower resilience were conducted. Nonparametric tests, such as the Mann–Whitney *U* test and the Kruskal–Wallis *H* test, were carried out to investigate associations between the outcomes of interest (unmet needs, distress, and resilience) and subgroups (age, gender, residence, country, and cancer type). These subgroup analyses were exploratory, consistent with the descriptive and cross-sectional nature of the study. Relevant statistical assumptions were upheld. Missing values were minimal in the dataset. Narrative responses to open-text questions about care experiences during and after the pandemic were analyzed using a broad, inductive approach to thematic analysis in NVivo 14. Codes were grouped into subthemes and then synthesised into higher-level themes, allowing categories to emerge directly from participant responses to provide contextual insights into the needs and experiences of people with hematological cancers.

Results

Characteristics of Participants

Ninety-two participants completed the questionnaire on their care in Ireland and the UK during the pandemic. Their sociodemographic details are available in Table 1.

All participants received their care in their country of residence. Participants were predominantly female (65.9%, *n* = 36), and of white ethnicity (97.6%, *n* = 83), residing in urban settings (60.0%, *n* = 51), and ranged in age from 25 to 81 years (mean = 56 years, SD = 12.00). While the UK and Ireland operate public health services, 41.2% (*n* = 35) hold private health insurance. At the time of the survey, half of the participants were employed (51.1%, *n* = 47), 31% were retired (31.5%, *n* = 29), and few were unable to work (7.6%, *n* = 7), in education (1.1%, *n* = 1) or unemployed (1.1%, *n* = 1). Participants reported their working hours since their cancer diagnosis; some worked fewer hours (28.3%, *n* = 26), some worked their usual hours (26.1%, *n* = 24), and others were not working (34.8%, *n* = 32). However, the number of participants who retired since their cancer diagnosis increased by 19.5% for this sample. Participants were diagnosed with leukemia (40.2%, *n* = 37), lymphoma (30.4%, *n* = 28), myeloma (17.4%, *n* = 16), and MDS (4.7%, *n* = 4). Time since diagnosis ranged from one to 22 years; 33.7% were three to 5 years postdiagnosis. During the pandemic, participants reported receiving cancer treatment (65.2%, *n* = 60) or follow-up care (47.8%, *n* = 44), with 40 participants receiving both. Thirty-seven participants reported follow-up care and surveillance. Most participants received chemotherapy (59.8%, *n* = 55), immunotherapy (30.4%, *n* = 28), targeted therapy (15.2%, *n* = 14), or radiotherapy (15.2%, *n* = 14); many participants received multiple therapies. Overall, 61.2% of participants (*n* = 53) reported one or more comorbidities.

Unmet Needs

The mean SF-SUNS subdomain scores ranged from 1.05 to 1.42, with the coping, sharing, and emotional needs domain achieving the highest score overall (Table 2).

The top five unmet needs items with the highest mean scores included, "dealing with feeling tired" ($\bar{x}$ = 1.91, SD = 1.22; 85.3%, *n* = 64), "dealing with changes in how my body appears" ($\bar{x}$ = 1.57, SD = 1.23; 78.7%, *n* = 59), "dealing with people who expect me to be back to normal" ($\bar{x}$ = 1.56, SD = 1.26; 77.3%, *n* = 58), "dealing with not being able to feel normal" ($\bar{x}$ = 1.55, SD = 1.17; 80.0%, *n* = 60), and "dealing with feeling stressed" ($\bar{x}$ = 1.51, SD = 1.02; 82.6%, *n* = 62), Table 3. Similarly, the top five "high/very high" unmet needs items included "dealing with feeling tired" (28%, *n* = 21), "finding someone to talk to who understands and has been through a similar experience" (22.7%, *n* = 17) and "dealing with changes in how my body appears" (22.7%, *n* = 17), "dealing with people who expect me to be 'back to normal'" (20.0%, *n* = 15), "paying household bills or other payments" and "dealing with not being able to feel 'normal'" (18.7%, *n* = 14, respectively). Younger participants (under the median age of 57 years) had statistically significantly higher unmet work and financial needs than those above the median age (>58 years), Z = –0.2.11, *P* = .035. There were no other statistically significant associations between clinical or sociodemographic characteristics and unmet needs domains (*P* =≥ .05), Appendix A.

Distress and Resilience

Distress levels were on average low (mean = 3.78, SD = 2.55) and resilience scores were moderately high (mean = 5.80, SD = 1.75)

TABLE 1
Summary Sample Characteristics (*N* = 92)

Variable	*n*	%
Country (*N* = 92)		
Ireland	43	46.7
England	27	29.3
Scotland	8	8.7
Northern Ireland	7	7.6
Wales	7	7.6
Cancer care received in the same country (*N* = 92)		
Yes	92	100
Hematological cancer (*n* = 85)		
Lymphoma	28	30.4
Hodgkin lymphoma	*9*	*9.8*
Non-Hodgkin lymphoma	*19*	*20.7*
Leukaemia	37	40.2
Chronic leukaemia (CLL, CML)	*32*	*34.8*
Acute leukaemia (ALL, AML)	*4*	*4.3*
Myeloma	16	17.4
Myelodysplastic syndrome	4	4.3
Time since diagnosis (range 1-22 y) (*n* = 85)		
1-3 y	20	21.7
3-5 y	31	33.7
5-10 y	22	23.9
10+ y	12	13.2
Cancer treatment received during COVID (*n* = 85)		
Cancer treatment	60	65.2
Chemotherapy	*55*	*59.8*
Immunotherapy	*28*	*30.4*
Targeted therapy	*14*	*15.2*
Radiotherapy	*14*	*15.2*
Stem cell transplant	*7*	*7.6*
Watchful waiting	*6*	*6.5*
Surgery	*4*	*4.3*
Clinical trial	*1*	*1.1*
Follow-up	44	47.8
Surveillance	36	39.1
Gender (*n* = 85)		
Female	56	65.9
Male	29	34.1
Age (*n* = 85)		
Mean = 56 y (*SD* = 12). Median = 58 y. Range = 25-81 y		
Ethnicity		
White	83	97.6
Other (eg, Asian, Mixed)	2	2.4
Residence		
Rural	34	40.0
Urban	51	60.0
Employment status (at time of survey) (*n* = 85)		
Employed (full-time/part-time)	47	51.1
Retired	29	31.5
Student	1	1.1
Unemployed	1	1.1
Unable to work	7	7.6
Working hours (since cancer) (*n* = 85)		
Fewer hours	26	28.3
More hours	3	3.3
Usual hours	24	26.1
Not working	32	34.8
Employment status (before cancer) (*n* = 85)		
Employed (full-time/part-time)	71	77.2
Retired	11	12.0
Student	1	1.1
Unemployed	1	1.1
Unable to work	1	1.1
Comorbidities (*n* = 80)		
0	31	38.8
1	33	41.2
2 or more	16	20.0

TABLE 2
Unmet Needs Domain Scores

Domain (range 0-4)	Mean	SD
Unmet information needs (INF)	1.06	0.92
Unmet work and financial needs (FIN)	1.12	0.96
Unmet needs for access and continuity of care (ACC)	1.05	0.88
Unmet coping, sharing, and emotional needs (COP)	1.42	0.87

(Table 4), without much variation between country, cancer type, gender, age, or residence (Appendices B and C).

Participants reported multiple concerns across the NCCN problem list (Table 5); 126 physical concerns, 118 emotional concerns, 118 practical concerns, 102 social concerns and 86 spiritual concerns. For physical concerns, the most reported issues were sleep (54.9%, 45 responses), memory or concentration (42.7%, 35 responses), and loss or change of physical abilities (35.4%, 29 responses). The three highest-ranked emotional concerns were worry or anxiety (57.3%, 47 responses), changes in appearance (31.7%, 26 responses) and loss of interest or enjoyment (24.4%, 20 responses). For practical concerns, taking care of myself (37.0%, 30 responses) and taking care of others or work (29.2%, 24 responses, respectively) were the three highest ranked by participants. Social concerns related to none (34.2%, 28 responses), relationships with spouse or partner (29.3%, 24 responses), and relationships with friends or coworkers (20.7%, 17 responses). For spiritual concerns, 60% reported no concerns (63.4%, 52 responses); others reported concerns with a sense of meaning or purpose (18.3%, 15 responses) or regarding death, dying, and the afterlife (17.1%, 14 responses). There were no statistically significant differences between distress scores and sociodemographic or clinical characteristics (*P* =≥ .05), Appendix D.

Participant responses to the CD-RISC-2 showed varying levels of ability to adapt to change and bounce back after illness or hardship (Table 6).

A Kruskal–Wallis *H* test showed that there was a statistically significant difference in resilience scores between different countries, $\chi^2(4) = 9.86$, *P* = .043, the highest levels of resilience were observed among those that reside in Ireland (mean rank = 49.11), followed by Wales (38.83), England (35.41) and Scotland (29.12). Highly significant differences in resilience scores between cancer types were found, $\chi^2(3) = 13.87$, *P* = .003, with a mean rank resilience score of 51.63 for myeloma, 46.24 for leukaemia, 32.00 for lymphoma, and 16.00 for MDS.

Participants' Reflections on Cancer and the Pandemic

The responses to questions about COVID-19 from participants with hematological cancers were integrated and grouped according to identified patterns of meaning. Theme one, psychological impact and self-care methods; theme two, navigating changing cancer care delivery, and theme three, sourcing social support reflects the perspectives of individuals who experienced the pandemic with a hematological cancer diagnosis (Fig.).

Psychological Impact and Self-Care Methods

Health Risk Averse captured COVID as an unwanted addition to the fears surrounding a cancer diagnosis for people with hematological cancers. *"Fearful of illness as cancer (and treatment) presents enough challenges to the mind and body"* (P75FNI). For this cohort, this was exacerbated by active treatment, preparation for stem cell transplant, and compromised immune systems. Participants (89%) reported they were distressed regarding COVID-19. Open-text responses from 41 participants provided further insight into specific factors contributing to experiences of distress during COVID-19, including being "*afraid of mixing with others*" (P050FNI) and being "*a vulnerable person*" (P22FE). Additionally, almost three-quarters of participants reported that they are still distressed by the current situation regarding COVID-19 (73.9%, *n* = 54).

Balancing Risks and Quality of Life described the efforts to consider safety versus daily living. People with hematological cancers had increased awareness of the potential consequences of infection

TABLE 3
Level of Unmet Needs by SF-SUNS Item (*N* = 75)

SF-SUNS item	Domain	Mean (SD)	None	Low-Mod	High-very high
			n (%)	*n* (%)	*n* (%)
Finding information about complementary or alternative therapies	INF	0.85 (1.07)	39 (52.0)	28 (37.3)	8 (10.7)
Dealing with fears about cancer spreading	INF	1.15 (1.06)	28 (37.8)	40 (54.1)	6 (8.1)
Dealing with worry about whether the treatment has worked	INF	1.17 (1.14)	28 (37.3)	38 (50.7)	9 (12.0)
Worry about earning money	FIN	1.27 (1.19)	26 (34.7)	36 (48.0)	13 (17.3)
Having to take a pension or disability allowance	FIN	1.11 (1.21)	33 (44.0)	32 (42.7)	10 (13.3)
Paying household bills or other payments	FIN	1.25 (1.26)	28 (37.3)	33 (44.0)	14 (18.7)
Finding what type of financial assistance is available and how to obtain it	FIN	1.20 (1.30)	33 (44.0)	29 (38.7)	13 (14.1)
Finding car parking that I can afford at the hospital or clinic	FIN	0.96 (1.29)	41 (54.7)	24 (32.0)	10 (13.3)
Understanding what is covered by my medical insurance or benefits	FIN	0.85 (1.12)	40 (53.3)	30 (40.0)	5 (6.7)
Knowing how much time I would need away from work	FIN	0.89 (1.18)	42 (56.0)	25 (33.3)	8 (10.7)
Doing work around the house (cooking, cleaning, home repairs, etc.)	FIN	1.17 (1.08)	22 (29.3)	45 (60.0)	8 (10.7)
Having access to cancer services close to my home	ACC	0.88 (1.04)	34 (45.3)	34 (45.3)	7 (9.3)
Getting appointments with specialists quickly enough (oncologist, surgeon, etc.)	ACC	1.05 (1.11)	28 (37.3)	39 (52.0)	8 (10.7)
Getting test results quickly enough	ACC	1.19 (1.12)	24 (32.0)	40 (53.3)	11 (14.7)
Having access to care from other health specialists (dieticians, physiotherapists, occupational therapists)	ACC	1.19 (1.16)	26 (34.7)	39 (52.0)	10 (13.3)
Making sure I had enough time to ask my doctor or nurse questions	ACC	1.01 (1.11)	29 (38.7)	38 (50.7)	8 (10.7)
Getting the healthcare team to attend promptly to my physical needs	ACC	0.99 (1.06)	28 (37.3)	41 (54.7)	6 (8.0)
Telling others how I was feeling emotionally	COP	1.45 (1.15)	16 (21.3)	47 (62.7)	12 (16.0)
Finding someone to talk to who understands and has been through a similar experience	COP	1.48 (1.25)	19 (25.3)	39 (52.0)	17 (22.7)
Dealing with people who expect me to be “back to normal”	COP	1.56 (1.26)	17 (22.7)	43 (57.3)	15 (20.0)
Dealing with people accepting that having cancer has changed me as a person	COP	1.48 (1.16)	18 (24.0)	45 (60.0)	12 (16.0)
Dealing with reduced support from others when treatment has ended	COP	1.17 (1.19)	28 (37.3)	36 (48.0)	11 (14.7)
Dealing with feeling depressed	COP	1.01 (1.01)	27 (36.0)	42 (56.0)	6 (8.0)
Dealing with feeling tired	COP	1.91 (1.22)	11 (14.7)	43 (57.3)	21 (28.0)
Dealing with feeling stressed	COP	1.51 (1.02)	13 (17.3)	52 (69.3)	10 (13.3)
Dealing with feeling lonely	COP	1.15 (1.11)	25 (33.3)	42 (56.0)	8 (10.7)
Dealing with not being able to feel “normal”	COP	1.55 (1.17)	15 (20.0)	46 (61.3)	14 (18.7)
Trying to stay positive	COP	1.21 (.93)	19 (25.3)	51 (68.0)	5 (6.7)
Coping with having a bad memory or lack of focus	COP	1.44 (1.15)	17 (22.7)	45 (60.0)	13 (17.3)
Dealing with changes in how my body appears	COP	1.57 (1.23)	16 (21.3)	42 (56.0)	17 (22.7)

to them, which led to *“more isolation”* (P05MI), *“being extra careful”* (P10FI), and *“shielding”* (P26FE). The attempts to avoid COVID-19 extended to their families and friends as there were *“strong concerns for interruption of treatment and cross-infection from others”* (P14MW). Awareness of public hygiene practices was reported due to the inherent risk of infection for this group, *“more aware of health risks”* (P64FS) and *“more aware of poor hygiene of others”* (P71MNI). However, the increased public awareness of the associated risks for vulnerable groups empowered some participants with hematological cancers to voice their hygiene concerns to others, *“I feel like I can tell others to be more hygienic, hand wash etc, because of COVID”* (P63FS).

The resumption of **regular activities** was a return to normal. Eating, exercising, and sleeping were highlighted by several participants as methods for self-care. The pandemic provided some hematological cancer patients psychological respite as there was time to rest and focus on self-care, *“COVID gave time to realise you need to rest you need to mind yourself to give yourself the best chance”* (P66MS).

Navigating Changing Cancer Care Delivery

The **Unmet Needs Arising from Changes in Clinical Care** for people with hematological cancers and their loved ones cannot be underestimated, *“I had to attend appointments by myself and was unable to have visitors in hospital” (P20FE)*, “*the loneliest time of our lives.”* (P55FI, see Fig., subtheme 2.1). Over 80% of participants would have liked more information related to the pandemic (82.2%, *n* = 60). Participants reported it would have been most helpful to have more information on the psychological or emotional aspects of living with and after cancer (48.6%, *n* = 34), followed by the physical aspects of living with and after cancer (45.7%, *n* = 32) and information or advice for family, friends, and carers (41.4%, *n* = 29), *N* = 70.

TABLE 4
Distress and Resilience Scores

	N	Mean	SD	Median	Min	Max
Distress (0-10)						
NCCN-DT	81	3.78	2.55	3.00	0	9
Resilience scores (0-8)						
CD-RISC-2	81	5.80	1.75	6.00	2	8

The Logistics of Healthcare Delivery were challenging during the pandemic. An altered normal was experienced by participants as physical and environmental changes to care were apparent as care moved online or over the phone, “*there were a lot of changes. I had telephone calls instead of meetings”* (P72FW). Overall, 63% of participants reported having one or more care appointments postponed during the pandemic (63.0%, *n* = 46); maintaining the usual frequency of their visits was reported as important (94.0%, *n* = 73). Participants understood the challenges for healthcare professionals during the pandemic, as it was unknown territory, *“in fairness, they were not able to provide answers to questions that they did not know”* (P75FNI). Participants largely reported government measures and healthcare services responses to the pandemic as appropriate (>82.0%, *n* = 73); however open-text responses voiced negative views on governance across countries (*“the government are ignoring people like me” (P02FI); “we were asked to shield by the government and have now been completely abandoned by them” (P45ME).*

Preventative Measures included social isolation and adherence to guidelines. Participants reported multiple vaccine administrations (up to eight). Half of the participants felt they could access sufficient support from healthcare professionals to address their health-related problems in the past few weeks of completing the survey (53.4%, *n* = 39). Similarly, half of the participants responded “*not at all*” to worries about accessing care at the hospital in the past few weeks (52.1%, *n* = 38). Almost two-thirds of participants reported hospital staff did everything they could to provide support during or since their cancer treatment “*all of the time*” (61.4%, *n* = 43), but recognized

TABLE 5
NCCN Distress Problem List Responses (*N* = 82)

Choices	Response percent	Response count
Physical concerns		
Pain	28.05	23
Sleep	54.88	45
Tobacco use	1.22	1
Substance use	1.22	1
Memory or concentration	42.68	35
Sexual health	10.98	9
Changes in eating	17.07	14
Loss or change of physical abilities	35.37	29
None	18.29	15
Emotional concerns		
Worry or anxiety	57.32	47
Sadness or depression	20.73	17
Loss of interest or enjoyment	24.39	20
Grief or loss	12.20	10
Fear	15.85	13
Loneliness	13.41	11
Anger	12.20	10
Changes in appearance	31.71	26
Feelings of worthlessness or being a burden	13.41	11
None	14.63	12
Social concerns		
Relationship with spouse or partner	29.27	24
Relationship with children	14.63	12
Relationship with family members	18.29	15
Relationships with friends or coworkers	20.73	17
Communication with healthcare team	14.63	12
Ability to have children	10.98	9
None	34.15	28
Practical concerns		
Taking care of myself	36.59	30
Taking care of others	29.27	24
Work	29.27	24
School	3.66	3
Housing	10.98	9
Finances	24.39	20
Insurance	6.10	5
Transportation	4.88	4
Childcare	4.88	4
Having enough food	1.22	1
Access to medicine	4.88	4
Treatment decisions	26.83	22
None	25.61	21
Spiritual or religious concerns		
Sense of meaning or purpose	18.29	15
Changes in faith or beliefs	4.88	4
Death, dying, or afterlife	17.07	14
Conflict between beliefs and cancer treatments	0.00	0
Relationship with god	2.44	2
Ritual or dietary needs	0.00	0
None	63.41	52

pandemic-related issues which hindered the quality and organization of clinics and services, including *"capacity problems"* (P63FS), "*staffing, resources and pressures*" (P20FE), and *"less time to discuss details of care"* (P37FI). One-third of respondents believed their general practice did everything they could to support them "all of the time" (34.3%, *n* = 24). Twenty participants provided further contextualizing information regarding general practice, "*they couldn't cope with demand*" (P71MI) and "*the long wait or difficulty to get appointments*" (P28FE).

The pandemic led to limitations in the everyday lives of people with hematological cancers, participants (*n* = 35) described the **Impact on** socializing, such as *"social life was hit bad"* (P64FS). Participant illustrations (Fig.) showed that social distance from family and friends and the disinfection routines associated with someone who contracted COVID were distressing experiences for participants. **Support Went Online** as there was an increased shift toward electronic forms of communication, as face-to-face was restricted, leading to reduced socialization *"I no longer actively participate in my local community and most of my socializing with friends is done via WhatsApp"* (P43FI). **Internal and External Supports** reflected the wide-ranging but individualized supports that people with hematological cancers relied on. Internal forms of social support from family and friends were instrumental in caring for hematology cancer patients during the pandemic, "*I have a wonderful husband and a group of close friends, so I feel very cared for*" (P55FI*)*. External support came from cancer charities and support groups, as well as some healthcare professionals. Overall, 18% of participants (*n* = 13) reported they were given enough support from community services (eg, public health nurse, home help), while 45% of participants reported they did not need help from health or social services (*n* = 32). Half of the participants attended cancer support group meetings (52.9%, *n* = 37), and all but one of 35 participants found them useful (97.2%, *N* = 36). The overall support and care of hematology cancer patients varied, with only one-third of participants reporting they had an up-to-date written care plan (32.9%, *n* = 23). Participants reported they had a named nurse (64.8%, *n* = 46), named doctor (72.9%, *n* = 51), or specified a specific contact (56.3%, *n* = 40) for their cancer concerns (eg, specific nurse, medical team, or cancer support group. One participant from Wales advocated for hematological cancer patients by writing letters to politicians, "*Write letters to MPs. . . As no other group of people would be left to fight for themselves like this!"* (P42FW).

Discussion

This study underscores the importance of recognizing and addressing unmet care needs among hematological cancer patients in Ireland and the UK, particularly in the wake of the COVID-19 pandemic. This research provides specific findings that enhance our understanding of the unmet needs, distress, and resilience of people with hematologic cancers. Higher unmet needs were related to tiredness, appearance, and societal expectations to "return to normal." Evidence from the past decade shows that tiredness remains a consistent problem for people with hematological cancers,[55-58] indicating that despite advancements in treatment, cancer-related fatigue continues to require targeted interventions and investment in supportive services. While our findings on fatigue and appearance-related concerns are consistent with prepandemic studies,[59-61] the pandemic may have intensified these unmet needs by amplifying social isolation, reducing access to in-person support, and increasing health-related anxieties. Our findings align with broader literature indicating that while spiritual concerns remain low among hematological cancer patients,[16] a wide range of physical, psychological, social, and health system unmet needs persist during survivorship.[62] These findings suggest that postpandemic service recovery should prioritize fatigue management programs, psychosocial interventions, and reintegration support to address enduring unmet needs while maintaining infection control measures for this vulnerable group.

This study has found that almost three-quarters of people living with or after hematological cancer in Ireland and the UK continue to experience distress related to COVID-19, and between 44.0% and 85.3% experience unmet needs but low distress and moderately high resilience. While healthcare responses may have varied between jurisdictions, participants across Ireland and the UK have similar experiences of unmet needs and distress. However, differences were noted in resilience as participants from Northern Ireland and Scotland had significantly lower scores than those from England, Wales, and Ireland. People with lymphoma had significantly lower resilience scores than leukaemia and myeloma.

This study provides novel insights into how hematological cancer participants continued to feel distressed even years after the pandemic's peak. The findings show that people with hematological cancers were health risk averse due to the known inherent consequences of infection to their compromised immune systems, which

TABLE 6
CD-RISC-2 Item Responses and Univariate Analysis of Total Scores

Item	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time	Response count
I am able to adapt to change	0.00% (0)	6.10% (5)	26.82% (22)	36.59% (30)	30.49% (25)	82
I tend to bounce back after illness or hardship	0.00% (0)	6.10% (5)	30.49% (25)	31.71% (26)	31.71% (26)	82
CD-RISC-2 total score ($N = 81$)			*n*	Mean rank	Test statistics	*P* value
By age[a]						
Under the median age (<57 y)			37	41.45	$Z = -0.160$	.873
Over the median age (>58 y)			44	40.63		
By gender[a]						
Female			53	43.58	$Z = -1.39$	.166
Male			28	36.13		
By residence[a]						
Rural			33	37.32	$Z = -1.19$	.232
Urban			48	43.53		
By country[b]						
Ireland			28	49.11	$\chi^2(4) = 9.86$	**.043**[*]
England			23	35.41		
Scotland			8	29.19		
Northern Ireland			6	29.00		
Wales			6	38.83		
By cancer type[b]						
Leukaemia			35	46.24	$\chi^2(3) = 13.87$	**.003**[*]
Lymphoma			27	32.00		
MDS			4	16.00		
Myeloma			15	51.63		

[*] **$P \le .05$.**
[a] Mann–Whitney *U* tests for binary categorical variables.
[b] Kruskal–Wallis *H* tests for more than two categorical variables.

was not new but amplified by the pandemic. These safety concerns made living a normal or fulfilling life challenging. This became easier as restrictions lifted; however, pre- or postpandemic, infection control remains of importance for people with hematological cancers. The psycho-social and emotional support provided by family and friends during a hematological cancer journey was reported as highly beneficial; this was most noticeable in their inherent loss due to restrictions related to the pandemic (eg, no visitors allowed or participants attending appointments alone). These findings reinforce the need for future approaches to developing physical care environments and infection control policies to prioritize the psycho-social needs of people with hematological cancers.

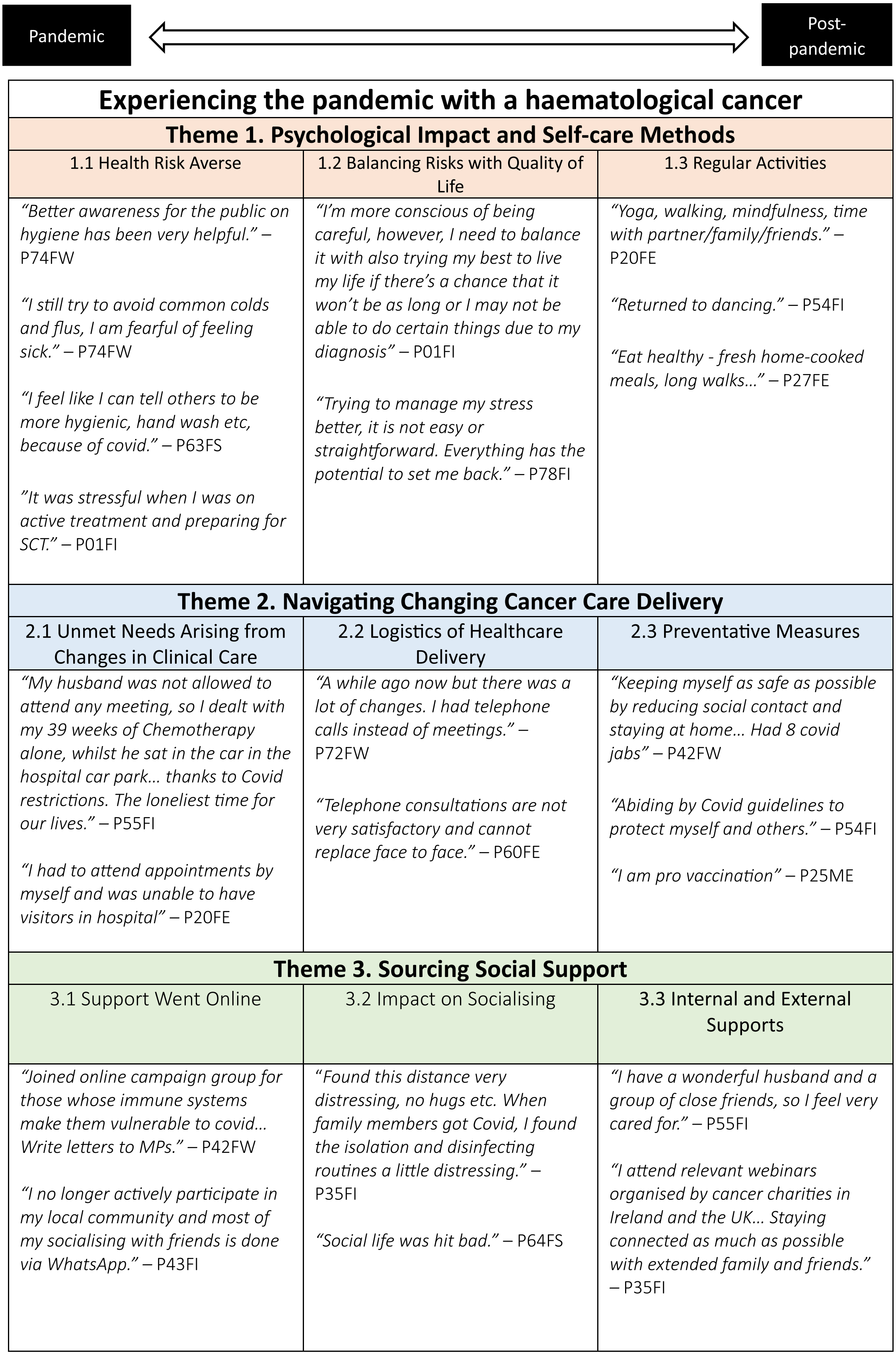
Previous longitudinal evidence suggests that cancer patients experience heightened distress initially at diagnosis, which improves within 12 months.[63] This current study contributes to the body of evidence by highlighting the difficulties associated with the pandemic experience, its restrictions, and complications across the spectrum of care, which require due consideration.

Clinical Implications

Patients' experiences of care during and after the pandemic varied, with some reporting feeling well-supported and others struggling to access care or receive sufficient support. Infection prevention will continue for people with hematological cancers, given their immunocompromised status and ongoing infection-related anxieties. However, ensuring that policies, including during health crises, incorporate patient perspectives on balancing safety and psychosocial well-being will enhance the overall quality of cancer care for individuals living with hematological cancers. This reflects findings from other studies for better integration of psychosocial support within infection control.[62,64] Many patients reported having a named nurse or doctor to contact about their concerns, underlining the importance of personalized care in improving patient satisfaction and outcomes. Additionally, the acceptance and understanding many patients had toward healthcare professionals navigating an unprecedented period of uncertainty indicates a strong foundation for partnership in care planning moving forward.

A single site in Ireland successfully implemented strict screening procedures to allow systemic anticancer treatment to be delivered as planned during the pandemic[65]; while the profound adverse impact of COVID-19 was found on the entire cancer patient pathway in Northern Ireland.[66] Similar to findings from Australian hematological cancer patients,[39] telehealth care was perceived as less personal by participants across Ireland and the UK. However, it must be noted that many of these telehealth services were provided temporarily or in their infancy. As telehealth expands, efforts should focus on preserving personal connections and patient-centered communication to ensure care remains supportive while flexible. Low levels of distress and high resilience were also found in studies of care experiences during COVID-19 for people living with cancer in Ireland (distress levels, $\bar{x} = 3.4$, SD = 2.2; and resilience $\bar{x} = 6.5$, SD = 1.6)[19,20] and in Switzerland (distress levels, $\bar{x} = 2.9$, SD = 2.5; and resilience $\bar{x} = 7$, SD = 1.3). This study found that participants from Ireland and the UK reported postponed appointments for their cancer care as a result of the pandemic; this contrasts with findings from Switzerland in which patients with melanoma, breast, lung or colon cancer on active treatment at the time of the COVID-19 pandemic did not experience delays or disruptions in their cancer treatment.[67] This contrast highlights the role of healthcare system structures and crisis management strategies in ensuring the continuity of cancer care during a pandemic. The uninterrupted treatment in Switzerland, despite the pandemic, suggests that targeted approaches can preserve essential cancer services even under crisis conditions, whereas the postponements in Ireland and the UK underscore the need for robust contingency planning to prevent treatment delays that may impact cancer outcomes during future healthcare disruptions.

Participants expressed a desire for more information on coping with the psychological and emotional aspects of living with and after cancer. The survey findings, including the contextual understanding provided by open-text comments, are consistent with wider literature on patients with hematological cancers who made drastic changes to their lives in line with government recommendations for shielding to reduce their risk of exposure to the virus during the COVID-19 pandemic.[5] The findings of this study regarding the experience of care during and post the pandemic reflect the findings of another study in which hematology cancer patients who experience



Pandemic ⟷ Post-pandemic

Experiencing the pandemic with a haematological cancer

Theme 1. Psychological Impact and Self-care Methods

1.1 Health Risk Averse	1.2 Balancing Risks with Quality of Life	1.3 Regular Activities
“Better awareness for the public on hygiene has been very helpful.” – P74FW *“I still try to avoid common colds and flus, I am fearful of feeling sick.”* – P74FW *“I feel like I can tell others to be more hygienic, hand wash etc, because of covid.”* – P63FS *”It was stressful when I was on active treatment and preparing for SCT.”* – P01FI	*“I’m more conscious of being careful, however, I need to balance it with also trying my best to live my life if there’s a chance that it won’t be as long or I may not be able to do certain things due to my diagnosis”* – P01FI *“Trying to manage my stress better, it is not easy or straightforward. Everything has the potential to set me back.”* – P78FI	*“Yoga, walking, mindfulness, time with partner/family/friends.”* – P20FE *“Returned to dancing.”* – P54FI *“Eat healthy - fresh home-cooked meals, long walks…”* – P27FE

Theme 2. Navigating Changing Cancer Care Delivery

2.1 Unmet Needs Arising from Changes in Clinical Care	2.2 Logistics of Healthcare Delivery	2.3 Preventative Measures
“My husband was not allowed to attend any meeting, so I dealt with my 39 weeks of Chemotherapy alone, whilst he sat in the car in the hospital car park… thanks to Covid restrictions. The loneliest time for our lives.” – P55FI *“I had to attend appointments by myself and was unable to have visitors in hospital”* – P20FE	*“A while ago now but there was a lot of changes. I had telephone calls instead of meetings.”* – P72FW *“Telephone consultations are not very satisfactory and cannot replace face to face.”* – P60FE	*“Keeping myself as safe as possible by reducing social contact and staying at home… Had 8 covid jabs”* – P42FW *“Abiding by Covid guidelines to protect myself and others.”* – P54FI *“I am pro vaccination”* – P25ME

Theme 3. Sourcing Social Support

3.1 Support Went Online	3.2 Impact on Socialising	3.3 Internal and External Supports
“Joined online campaign group for those whose immune systems make them vulnerable to covid… Write letters to MPs.” – P42FW *“I no longer actively participate in my local community and most of my socialising with friends is done via WhatsApp.”* – P43FI	*“Found this distance very distressing, no hugs etc. When family members got Covid, I found the isolation and disinfecting routines a little distressing.”* – P35FI *“Social life was hit bad.”* – P64FS	*“I have a wonderful husband and a group of close friends, so I feel very cared for.”* – P55FI *“I attend relevant webinars organised by cancer charities in Ireland and the UK… Staying connected as much as possible with extended family and friends.”* – P35FI

FIG. Thematic map representing the three themes that reflect experiencing the pandemic with a hematological cancer. Sourcing social support.

critical illness may view it as a small part of a larger treatment pathway, and so quality of life is impacted by this rather than the acute episode.[68] Therefore, dealing with COVID-19 became a part of living with and beyond hematological cancer for participants who may experience many of these concerns independent of a pandemic (eg, fear of infection, adapting lifestyle to minimize risks).

Limitations

This study provides important insights into the postpandemic experience for people with hematological cancers, rather than focusing on the response to the pandemic or a comparative policy analysis between countries. Despite efforts made to reach eligible hematology cancer patients across Ireland and the UK, the sample size is small yet comparable to similar studies.[69-72] However, the online reach of hematology cancer patients appears limited, in comparison to registry-based or direct recruitment via hospital sites.[73-75] Collectively, the standardized and open-ended questions on the questionnaire offer a comprehensive picture of the postpandemic survivorship experience. These instruments capture participants' current experiences and do not provide longitudinal insight. Growing evidence highlights the impact of the watch-and-wait approach for patients with indolent hematological cancers, with one-third reporting unmet needs.[76] The convenience sampling strategy and online recruitment approach may limit this research's generalizability. A minority of this sample reported they were under watchful waiting procedures during COVID-19, limiting the understanding of the impact for this specific group. Similarly, this study presents some limited understanding of patients with myelodysplastic syndromes with significantly lower resilience scores than other hematological cancers, but their low participation rate limits this finding. This builds on limited evidence for this group, as many patients with MDS have lower-risk diseases and are managed by existing treatments or a watch-and-wait strategy; there is no standard care for the majority of these patients; many are not candidates for approved treatments or experience relapse after first-line treatment and require further therapy.[77,78]

Conclusion

This study provides an understanding of the experience of people affected by hematological cancers in Ireland and the UK as the public health restrictions associated with the COVID-19 pandemic were lifted. This study provides a comprehensive understanding of the unmet needs, distress, and resilience of hematological cancer patients in Ireland and the UK, particularly in the context of the COVID-19 pandemic. The findings highlight the critical areas where healthcare systems can better support these patients, emphasizing the importance of addressing both physical and psychosocial needs. The ongoing distress related to COVID-19 underscores the need for continued vigilance and support for this vulnerable population. Future policies and interventions should focus on enhancing information dissemination, maintaining continuity of care, developing optimal physical environments for cancer care, and fostering resilience among hematological cancer patients to improve their overall quality of life.

Declaration of competing interest

The authors have none to declare.

CRediT authorship contribution statement

Vanessa Boland: Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Project administration, Formal analysis, Data curation. **Liz O'Connell:** Writing – review & editing, Writing – original draft, Project administration. **Orlaith Cormican:** Writing – review & editing, Writing – original draft, Project administration. **Karen Campbell:** Writing – review & editing, Writing – original draft, Project administration. **Maura Dowling:** Writing – review & editing, Writing – original draft, Project administration. **Amanda Drury:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Project administration, Methodology, Funding acquisition, Conceptualization.

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Supplementary materials

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