

BMJ Open Examining the levels of psychological support available to patients with haematological cancer in England: a mixed methods study

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ABSTRACT

Objectives The psychological impact of a haematological malignancy is well documented. However, few studies have assessed the provision of psychological support to people with these diagnoses. This study explores the extent and nature of psychological support for people diagnosed with haematological cancer to inform future service provision.

Design This study consisted of an online survey with healthcare professionals (phase 1) and qualitative interviews with patients (phase 2) and key health professionals (phase 3). A descriptive analysis of survey data and thematic analysis of interviews were conducted.

Participants Two hundred health professionals practising in England completed the survey. Twenty-five interviews were conducted with people diagnosed with haematological cancer in the past 3 years, and 10 with key health professionals, including haematologists, cancer nurse specialists and psychologists were conducted.

Primary outcome measures Level of psychological assessment undertaken with people with haematological cancer, and level and nature of psychological support provided.

Results Less than half (47.3%) of survey respondents strongly agreed/agreed that their patients were well supported in terms of their psychological well-being and approximately half (49.4%) reported providing routine assessment of psychological needs of patients, most commonly at the time of diagnosis or relapse. Patients described their need for psychological support, their experiences of support from health professionals and their experiences of support from psychological therapy services. There was considerable variation in the support patients described receiving. Barriers to providing psychological support reported by health professionals included time, skills, resources and patient barriers. Most doctors (85%) and 40% of nurse respondents reported receiving no training for assessing and managing psychological needs.

Conclusions Psychological well-being should be routinely assessed, and person-centred support should be offered regularly throughout the haematological cancer journey. Greater provision of healthcare professional training in this area and better integration of psychological support services into the patient care pathway are required.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Psychosocial support provision is under-researched in haematological cancer care and this study provides important insight into the gaps in provision of psychological support in this population.
- ⇒ A relatively large sample of health professionals completed the online survey with good representation from haematologists and nurses, from District General Hospitals and from specialist Cancer Centres across England.
- ⇒ Patients participating in the interview study included a range of haematological cancer types, treatment experiences and variation in sociodemographic characteristics.
- ⇒ A convenience sample of both health professionals and patients was used which may have led to selection bias.
- ⇒ Resource constraints meant that only 10 interviews with health professionals could be conducted.

INTRODUCTION

Haematological cancer is the fifth most common cancer in the UK, with over 40 000 people diagnosed every year, and around 250 000 people living with this type of cancer in the UK.¹ Haematological cancers are a heterogeneous group of cancers that include Hodgkin and non-Hodgkin lymphomas, multiple myeloma, myeloid and lymphoid leukaemia and other malignant disorders of the bone marrow. Some of these conditions are very acute; others are chronic.^{2 3} The symptoms of haematological malignancies are varied including enlarged lymph nodes, fatigue, unexplained weight loss, recurrent infections, influenza-like symptoms, bruising and bleeding and drenching night sweats. Common treatment options, such as bone marrow transplantation, peripheral blood cell transplantation and high-dose chemotherapy, are lengthy, invasive and often lead to debilitating side effects.⁴⁻⁷ Survival rates

for the most common types of haematological cancer have increased substantially over the past decade, with 5-year survival rates for Hodgkin Lymphoma now over 80%, non-Hodgkin's lymphoma at 65% and leukaemia and myeloma above 50%. Some types are chronic and people live with the threat of relapse, resulting in significant uncertainty about their future, higher levels of depression and anxiety and reduced quality of life.^{8–10} Some people will have no treatment and will be managed with watchful waiting; but this in itself is something that causes anxiety and distress.^{11–14} People affected by haematological cancers, therefore, often experience higher levels of psychological morbidity compared with patients diagnosed with solid tumours.¹⁵ Psychological effects can adversely affect cancer treatment, recovery and survival.^{16–20}

Previous literature reviews identified key areas of need for patients with haematological cancer, which included: support to deal with fear of recurrence; information needs; unmet needs relating to healthcare professionals' care (HCP) and family-orientated needs. This highlights the need for more widespread access to psychological support for patients with haematological cancer and for more to be done to tackle patients' fears and concerns throughout the course of their illness. The assessment and identification of unmet needs is an important step enabling the development of clinical services that support and maintain psychological well-being through treatment and into survivorship.^{9,21}

Haematologists are a regular point of contact for these survivors and not only have the opportunity to discuss psychological issues with patients but to determine who needs referring to further psychological treatment.²² Furthermore, the number of participants reporting the need for extra psychological support from a psychologist/counsellor means it is imperative that these services are available and known to those requiring them.²²

In 2019, Blood Cancer UK and the Anthony Nolan charity undertook a survey (n=1624), in collaboration with Quality Health, which aimed to explore unmet psychological needs in people diagnosed with haematological cancer.²³ Seventy-six per cent of respondents reported that their mental and emotional health had been impacted by their haematological cancer diagnosis. Of those reporting changes to their mental or emotional health, 34% were not offered psychological support, despite 24% reporting that they would have liked support during treatment, 22% reporting that they would have liked support following diagnosis and 19% reporting that they would have liked support in the first-year postdiagnosis. As a result of these findings, Blood Cancer UK commissioned the study reported here, which aimed to explore the extent and nature of psychological support provided to people diagnosed with haematological cancer.

METHODS

Design

A mixed methods study, following an explanatory sequential design was used, consisting of an online survey for

HCPs (phase 1) and qualitative interviews with patients (phase 2) and key stakeholders (phase 3).

Survey and interview development

The survey was informed by the 2019 Blood Cancer UK/Anthony Nolan survey findings,²³ the wider evidence-base and expert stakeholder input from patients and HCPs. A draft version was shared with the Blood Cancer UK Clinical Advisory Panel for comment and pilot tested with a small group (n=5) of clinicians (haematologists and nurse specialists). Following this, minor survey modifications were made prior to its distribution to eligible health professionals through Qualtrics, an online survey platform.²⁴

The survey addressed the following topics: how the psychological needs of patients were assessed and addressed by HCPs; the perceived level of need for support; access to and availability of specialised psychological support; the referral process, waiting times, perceived gaps in support provision and training/educational needs of staff. The survey also included free text space for respondents to add any extra information relating to the provision of psychological support for patients with haematological cancer.

A patient interview topic guide was developed in collaboration with the Blood Cancer UK patient representatives' panel and was also informed by the literature. This included questions on patients' experiences of psychological support they had received from their healthcare team or counselling or psychological therapy services, how helpful this had been and at what stage in the care pathway they had needed support. A key stakeholder topic guide was developed in collaboration with the Blood Cancer UK Clinical Advisory Panel and included questions on what psychological services were offered, when they were offered and what the perceived barriers were to providing and accessing these services.

Study population

HCPs based in England and working with adult patients with haematological cancer were eligible to participate in the survey. HCPs working with paediatric, teenage and young adult patients with haematological cancer were excluded on the basis that service provision for these groups differed from adult populations.

Adults diagnosed with haematological cancer who had responded to the previous Blood Cancer UK survey and indicated willingness to participate in future research were eligible to participate in the interview study. This included people at any stage along the care pathway. A sample of key stakeholders, comprising HCPs from the National Health Service (NHS) and cancer charities, involved in the psychological care of patients were invited to interview.

Recruitment and data collection

Invitations to participate in the study were sent to clinicians listed on Blood Cancer UK mailings lists and to

multidisciplinary team (MDT) leads across England who were asked to share it with team members, both within Specialist Cancer Centres and District General Hospitals (DGHs). The invitations were sent from Blood Cancer UK and were cosigned by a consultant haematologist and advisor to Blood Cancer UK.

The survey was also widely promoted, including through the British Haematology Society Annual Conference, and Blood Cancer UK's Twitter account, with a link to the online survey landing page provided. The survey was open from 5 November 2020 to 25 February 2021.

A random sample of respondents to the Bloodwise/Anthony Nolan 2019 survey who agreed to be contacted for further studies were invited to express interest in taking part in the interview study. They were also asked to provide some demographic and clinical information to enable a purposive selection of a range of participants. A purposive sample of respondents in terms of haematological cancer diagnosis, treatment received, age group and gender was then invited to take part in an interview study. Two hundred and sixty invitations were sent out and 69 individuals responded. From this group, a purposive sample of 31 individuals was invited to be interviewed and 25 took part. Telephone Interviews lasted approximately 1 hour and were transcribed verbatim by a professional transcriber.

Data analysis

Survey data were downloaded from Qualtrics,²⁴ the online survey software used, into SPSS V.24²⁵ and a descriptive analysis was undertaken. Differences between haematology doctor and nurse responders were explored as well as differences between those respondents based in a cancer centre versus those in a DGH. For the latter comparison, as some individuals indicated multiple places of work, only those who indicated solely cancer centre or DGH were included in the analysis. Where differences were found these have been presented. Differences have not been significance tested as the sample was not random and, therefore, testing would not be meaningful. Qualitative data were analysed thematically using the Framework Approach.²⁶ The qualitative software NVivo was used to manage the data analysis process.²⁷

A sequential explanatory design was used to combine the data from the quantitative and qualitative data.^{28–30} Combined data are presented as themes and subthemes.

Patient and public involvement

Blood Cancer UK patient representatives' panel and two further patient representatives were involved in the design of the study, development of all patient-facing materials used and write up of the paper. Blood Cancer UK helped with recruitment of health professionals and patients and were integral to the dissemination of the findings.

RESULTS

Two hundred and twenty-eight surveys were completed. Twenty-eight were excluded for the following reasons: completed by patients (n=23), completed by health professionals not caring for haematological cancer patients (n=4) and completed by a teenage and young adult nurse (n=1). Two hundred surveys were therefore included in the analysis. The participant characteristics of survey responders are summarised in [table 1](#).

Twenty-five patients and 10 health professionals were interviewed. Participant characteristics are reported in [tables 2 and 3](#), respectively.

Sample quotes from the health professional interviews and open-text comments are presented in [table 1](#) and sample quotes from the patient interviews are presented in [table 2](#), both available as online supplemental file 1. The survey and topic guide are available as online supplemental file 2. A combined summary of survey and interview findings is presented below as themes and subthemes.

Health professionals' views on the provision of psychological support

Perceived importance of psychological support

Less than half 47.3% (79/167) of survey respondents strongly agreed/agreed that their patients were well supported in terms of their psychological well-being. Open-text responses also reported a perceived gap in service provision, with HCP respondents indicating a lack of prioritisation for psychological services, national variation in service provision and a general lack of resources (see [table 1](#) in online supplemental file 1).

Of 68.9% (102/148) of respondents reported that providing psychological support was definitely part of their role. More nurse respondents (86%, 75/87) held this view, compared with doctors (44.9%, 31/69).

HCPs perceived those patients at most risk of emotional problems were patients with previous mental health problems (56.5%, n=113), patients with recurrence (51%, n=102), patients with young children (43.5%, n=87) and patients with low levels of social support (42.5%, n=85).

Reported barriers to HCPs providing psychological support to patients were lack of time (69%, 138) and lack of resources (59.5%, 115). Over a third of participants (35%, 70) felt that patient factors (eg, patient reluctance) were also barriers to the provision of support, with open-text comments from clinical nurse specialists (CNS) identifying that patients were sometimes reluctant to disclose their emotional needs.

Assessment and monitoring

Half (49.4%, 89/180) of survey respondents agreed/strongly agreed that the psychological needs of their patients with haematological cancer were routinely assessed, with nurses more likely to strongly agree/agree with this statement than doctors (55.1%, 54/98 vs 43.2%, 32/74). This view was endorsed by more respondents based in a cancer centre than those based in a DGH (55.1%, 43/78 vs 44.2%, 31/70). Psychological

Table 1 Survey participant characteristics

	N	%
Gender		
Female	136	75.1
Male	44	24.3
Prefer not to say	1	0.6
Missing	19	–
Clinical role		
Doctor	75	37.5
Consultant haematologist	67	33.5
Consultant oncologist	2	0.01
Specialist registrar	3	0.02
Clinical fellow	3	0.02
Nurse	104	52.0
Nurse specialist/advanced Nurse practitioner	57	28.5
Haematology or oncology Sister/deputy sister	10	0.05
Haematology or oncology Staff nurse	25	0.13
Other nurse for example, cancer practice educator, research nurse	12	0.06
Other (including allied health professionals and psychologists)	21	10.5
Years of experience in haematological oncology		
0–5 years	45	24.9
6–10 years	40	22.1
>10 years	96	53.0
Missing	19	–
Place of work (NB some participants indicated multiple responses)		
Cancer centre	95	47.5
District general hospital	83	41.5
Primary care	5	2.5
Other	16	8.0
Geographic location		
Yorkshire & Humber	10	5.7
West Midlands	10	5.7
North East	13	7.4
South East Coastal	14	8
East Midlands	14	8
South West	16	9.1
South Central	19	10.9
East of England	21	12
North West	26	14.9
London	32	18.3
Total	175	100%

Continued

Table 1 Continued

	N	%
Missing	25	–

NB, some participants had more than one treatment.

assessments were most often undertaken (*always/nearly always/often*) at the time of diagnosis (70.1%, 122/174) and disease progression/relapse (65%, 110/169).

Clinical judgement was most often used for assessing psychological needs (77.6%, 121/156, endorsed *always/*

Table 2 Patient interviewee characteristics

	N	%
Gender		
Male	10	40
Female	15	60
Age group		
≤40 years	0	0
41–65 years	15	60
>65 years	10	40
Marital status		
Married	20	80
Single	3	12
Co-habiting	1	4
Divorced	1	4
Ethnicity		
White British	24	96
Indian	1	4
Haematological cancer type		
Chronic lymphocytic leukaemia	6	24
Hairy cell leukaemia	1	4
APL	1	4
Acute myeloid leukaemia	1	4
Hodgkin lymphoma	1	4
Non-Hodgkin lymphoma	9	36
Multiple myeloma	2	8
Essential thrombocythemia	3	12
Myelofibrosis	1	4
Treatment		
Watch & wait	6	
Chemotherapy	14	
Stem cell therapy	3	
Radiotherapy	1	
Immunotherapy	1	
Other	3	

APL, Acute promyelocytic leukaemia.

Table 3 Key stakeholder characteristics

Role	Place of work	Location
Nurse specialist	Cancer Centre	South East
Nurse specialist	District General Hospital	South East
Nurse specialist	District General Hospital	London
Nurse specialist (transplant services)	District General Hospital	South East
Consultant haematologist	District General Hospital	South East
Consultant haematologist	Cancer Centre	Yorkshire & Humber
Consultant haematologist	District General Hospital	South West
Psychotherapist	Cancer Centre	London
GP	Primary Care	London
Centre lead	Maggie's Centre	West London

GP, General Practitioner.

nearly always/often), with the use of Holistic Needs Assessment (HNA) tool (always/nearly always/often) reported by 45.5% (91/163) of participants. In open-text responses, HCPs noted that the HNA was a useful tool for helping patients to open up about their concerns (see [table 1](#) in online supplemental file 1).

Approximately half (52.7%, 78/148) of respondents reported generally providing written information to patients about managing the psychological impact of haematological cancer (always/often). More than half (55%, 110/164) reported having access to in-house specialised psychological support. Referrals to these services were reportedly triggered by clinician opinion (52%, 104), patient request (47.5%, 95), relatives' request (37%, 74) or screening guidelines (14%, 28). In the interviews, CNSs identified the importance of being able to readily access specialist services for patients with more complex needs.

Role division

Seventy seven per cent (153/165) of respondents indicated that nurse specialists were commonly (always/nearly always or often) involved in providing emotional/psychological support. Interviews with health professionals confirmed the reality of this role division with the primary role of the consultant haematologist reported as being to focus on medical care, while the provision of psychological support to patients was mainly within the remit of the CNS. In some settings, CNSs had support workers within their team who helped provide psychological support to patients.

Training and confidence

Overall, less than one-third (31%, 62/162) of survey respondents felt confident/very confident in providing psychological support to patients, whereas 32% (52/162) felt not very/not at all confident. Fifty-five per cent of nurses (47/86) felt confident/very confident in providing

psychological support compared with only 17% of doctors (12/70), and 15% (13/86) of nurses felt not very/not at all confident compared with 53% (37/70) doctors.

Most doctors (85.3%, 64/75) and 39.4% (41/104) of nurses reported they had received no training for assessing and managing psychological needs. In the interviews, respondents reported a perceived lack of training for HCPs and felt that additional training would be beneficial. Haematologists reported relying on their clinical judgement to assess psychological problems having not received any specific training.

Twenty-four per cent of all nurse respondents (25/104), and 42.1% (24/57) of CNSs/advanced nurse practitioners reported having received Level Two Psychological Support training, as recommended in National Institute for Health and Care Excellence (NICE) guidance on the provision of supportive and palliative care for adults with cancer (NICE, 2004).

Overall, 19% (28/163) of respondents reported that their organisation had implemented guidance on providing psychological support to patients. Respondents based in a cancer centre were more likely to report this than respondents based in a DGH (25.4%, 18/71 vs 15.6%, 10/64).

Models of care

In the interviews, HCPs provided insights into what they perceived as some good models of psychological support. For example, one respondent described the success of embedding a psychologist within the haematology transplant service. The process involved a baseline assessment being conducted on all patients referred for transplant, with further support tailored to meet needs, including further psychologist support if required. The rationale for this model was to identify problems early and help prevent patients presenting with more severe psychological symptoms such as post-traumatic stress disorder at a later stage.

Another respondent described a model within a large tertiary centre of having psychotherapy support completely embedded within the Haem-oncology Service. Any patient could be referred to the psychotherapy service from any member of the multidisciplinary care team or could self-refer. Family members could also be referred or self-refer. Patient and family members could have as many sessions as they found useful. The respondent described how over time awareness and appreciation of psychological services had grown within the multidisciplinary team and this was now fully integrated. The service was also able to offer training and support to MDT members. Support workers were employed by one cancer clinic to help provide emotional and practical support. They were seen as beneficial as they were able to look at the whole picture from a slightly non-medical perspective.

A more informal approach of assessment for psychological need was adopted by a cancer charity offering emotional support and practical advice at the hospital site. People diagnosed with cancer were navigated to the

charity by the health professionals. Psychological assessment was conducted by a cancer support worker who was trained to level 2 in emotional support. This meant they were trained to screen patients with cancer for psychological and other concerns, including through the use of HNA, as well as providing basic psychological assessment and interventions. This sometimes led to a one to one session with a clinical psychologist, group support with a clinical psychologist, or for those with mild psychological needs, peer support and activities such as yoga and mindfulness.

Patient experiences and views

Three main themes emerged from the interviews with patients: need for psychological support; experiences of psychological support by the healthcare team and experiences of counselling or specialised psychological therapy services. Selected quotes are reported in [table 2](#) in online supplemental file 1.

Need for psychological support

Participants' views regarding the importance of psychological support varied. Some patients felt that this should be offered routinely to all patients at diagnosis and then be available as required throughout the cancer pathway. Others felt that this support should be offered a few weeks after diagnosis. For some, the end of cancer treatment was the time of greatest need for psychological support.

Some participants reported that they did not need formal support services, indicating that they were able to cope and find the support they needed themselves. Others indicated a reluctance to seek or accept formal support, as they felt it indicated that they were not coping, and they were keen to self-manage their own emotions. Other participants reported they had not needed psychological support, but their interview accounts suggested that they had struggled at times and may have benefited from support had it been offered sensitively.

Experiences of psychological support from the healthcare team

Considerable variation was reported in the extent to which participants reported having been offered psychological support from their healthcare team. Exceptional care from HCPs was reported by some, both professionally and attitudinally. In contrast, some individuals reported not being offered any emotional support, regardless of whether they perceived a need for it.

Having a strong relationship with members of the healthcare team with sensitive, empathetic communications and well co-ordinated, consistent care was perceived to be important to the psychological well-being of patients and their families. All respondents referred to at least some contact with a nurse, although it was not always possible to differentiate whether this was with a CNS. Some respondents described receiving excellent nurse led support throughout their journey which helped them emotionally. Others described being provided with nurse

contact details, but being reluctant to make contact, perceiving either that the nurses were too busy, that dealing with psychological concerns was not their remit, or that they could only legitimately make contact during the period when they were receiving treatment. Some described feeling dissatisfied with the nursing support they had received, either because they found it difficult to access the nurse, felt that the nurse did not have time to deal with their psychological well-being concerns, or in some cases, that nurses did not have the required knowledge.

Many patients had been provided with leaflets and information at the time of diagnosis, although some felt that more written information would have been helpful. Some talked about the importance of being well informed about their disease, reporting that this helped them to cope emotionally.

Experiences of counselling and psychological therapy services

Some participants were referred to counselling services. Most of those who received one-to-one counselling reported finding it helpful, being a chance to talk to a neutral person about their anxieties and concerns. Participants described value in being able to 'offload' to someone whose job it was to listen, rather than feeling they were burdening friends and family. However, some respondents experienced long waiting times for counselling, so that when it was available, it was no longer appropriate. For others, counselling did not meet patients' needs or expectations

For example, one participant who was on a watch and wait regime found that the counsellor they saw had limited understanding of the nuances of haematological cancer treatments, while another described how their expectations of professional support were misplaced. Group counselling was offered in some clinics, but a few respondents did not find these group counselling sessions useful due to the mix of treatment stages and age ranges of participants. No participants had received therapy from the NHS Improving Access to Psychological Therapy (IAPT) services.

DISCUSSION

This study has highlighted substantial variation and gaps in the assessment and management of psychological distress in patients with haematological cancer in England. This is in keeping with previous research which has identified that haematological patients often display unmet needs and distress.^{9 21} In line with these studies, less than half of HCP respondents in our survey believed that their patients were well supported in terms of their psychological well-being. This is an important issue to address as appropriate psychological support interventions have been shown to have beneficial outcomes for haematology patients in terms of reducing anxiety, depression and quality of life.^{31 32}

The UK NICE guidance on the provision of supportive and palliative care for adults with cancer³³ states that at level 2, guided by HNAs, HCPs should be detecting and assessing psychological distress. Level 2 trained clinicians should also be able to: offer focused interventions designed to enhance self-care skills and perception of control; improve ability to adjust to life situations; problem solve and provide enhanced psychological information.³³ The beneficial outcomes of comprehensive nurse counselling were reported in a recent systematic review. The review found that patients valued nurse presence and availability, a trusting nurse–patient relationship, a holistic approach, human touch and continuity of care and that this was beneficial to their healing experience.³⁴ In line with these findings, in our study, many patients reported being able to cope with the support of their clinical team, illustrating that psychological distress and patient concerns can often be addressed and resolved by HCPs with the right attributes and training.

Assessing and managing psychological issues is mainly under the remit of CNSs who are significantly under-resourced and, as a result, often struggle to deliver this psychological support role.³⁵ Macmillan's most recent workforce census demonstrated worrying vacancy rates across CNS roles in England, with significant geographic variation.³⁶ They report a need for an additional 2500 specialist cancer nurses, an increase of 84%. By 2030, the gap between patient need and workforce capacity will have grown to 3700 nurses, an increase of 123% over the number of CNS's in place at the time of the most recent census.³⁶ This highlights the importance of capacity and capability building for CNS's to ensure that psychological support is available to patients across the cancer trajectory.

Previous studies have reported that the provision of patient education could be a substantial modifiable factor in improving illness perception and reducing psychological distress.³⁷ The theoretical framework provided by the Common Sense Self-Regulatory Model offers a systematic approach to better understanding the relationships between variables that influence psychological distress and can be used to better understand distress in patients with haematological cancer. The model assumes that when people receive stimuli such as a cancer diagnosis, cancer progression or symptoms, they form an illness perception. People's past experiences with illness and sociocultural contexts such as support from families and HCPs are also suggested as factors affecting illness perceptions.³⁸ Lee *et al* reported that satisfaction with patient education significantly influenced illness perception in patients diagnosed with gastric cancer. This finding is in accordance with previous studies on patients with breast cancer, head and neck cancer and colorectal cancer.^{39–43} Therefore, HCPs need to evaluate patients' perception of cancer immediately after diagnosis and, if necessary, to provide patient education to correct misperceptions about the illness. HCPs could assess psychological distress and illness perception after patients' cancer diagnosis using simple instruments such as the National

Comprehensive Cancer Network Distress Thermometer or Brief Illness Perception Questionnaire.^{44 45} Doing so could increase the chances of detecting patients who need interventions.

This study highlights that HCPs lack training and confidence in assessing and providing psychological support, highlighting the need for consistent, up to date training to be implemented and consistently reviewed by all staff who are regularly providing care to patients with haematological cancer. Such training could be delivered within undergraduate courses for health professionals and updated through continuing professional development accredited courses. This suggestion is reinforced by a systematic review which evaluated the effectiveness of the different training methods used to impart skills relating to psychological practice, with a variety of HCPs trained in communication, diagnostic and referral skills. Findings showed that, in most studies, the psychological skills of the staff who had received training improved.⁴⁶

Participants diagnosed with haematological cancer also described good communication and well-coordinated care as important to their emotional well-being as well as continuity in HCPs caring for them. Positive communications and interactions with HCPs have been shown to increase patient satisfaction with care and care quality and yet are often sacrificed due to busy clinical caseloads and other pressures.⁴⁷ It is important to recognise the added value of protecting time between patients with haematological cancer and HCPs to discuss options for psychological support provision, when and how to access this support and how this support can be reviewed and sustained.

In some cases, support may be required through formal referrals to counselling or psychological therapy services,³⁴ although HCPs in this study reported practical barriers including geographical locations of services, with regional cancer centres often requiring long-distance travel and long waiting lists after referral to psychological support services. These barriers have been recognised, with waiting times for psychological support during the COVID-19 pandemic reaching record rates.^{48 49} Timely access to good-quality psychological therapy provision is essential and although the UK Government has made good progress with its IAPT programme, there is still much to do before all people with psychological issues receive the crucial help and support they need.³³ More collaboration and communication between service providers and improved signposting for mental well-being services is needed not just within the NHS but to all services offered by relevant charities and voluntary groups.⁵⁰

Patient barriers to seeking psychological support reported in our study included the ongoing stigma surrounding accessing psychological services, patients' levels of education as well as patient gender.^{51–53} A service where psychological support options are discussed routinely with all patients and carers should be offered.³⁴ Patients are not always aware of their support needs and



the role of HCPs can be to raise awareness, thus improving patients' quality of life and emotional well-being.

Furthermore, some patients were reluctant to seek or accept support, as they felt it indicated that they were not coping. This confirms previous work suggesting that strategies of concealment, stoicism and avoidance can contribute to negative adjustment, information deficits and social isolation in patients with cancer.^{54 55} These strategies are also problematic if used excessively or rigidly because they leave people vulnerable by being less able to access support networks.⁵⁶ Such maladaptive coping strategies have shown to increase distress, and health professionals need to identify such strategies and address them with their patients.

This study has highlighted useful models of psychological care currently available within some UK cancer services. Embedding specialist psychological services within haematological cancer services may help to facilitate a culture change within services leading to greater recognition of the importance of ensuring that this aspect of care is properly addressed. Informal and third-sector sources of support are important to many patients and strong collaborations in this area should be encouraged and developed.

Strengths and weaknesses

A relatively large number of HCPs took part in the online survey across England, with good representation from haematologists and nurses, from DGH's and specialist cancer centres. However, the survey sample is a convenience sample and cannot be considered representative of all HCPs caring for patients with haematological cancer. As no denominator was available from this convenience sample, it was not possible to impute values, so a descriptive analysis has been presented. Similarly, while the patients participating in the interview study included a range of haematological cancer types, treatment experiences and variation in sociodemographic characteristics, it was a convenience sample and, therefore, may not be representative of all patients with haematological cancer. Convenience sampling may have led to selection bias. The study population was under-represented in terms of ethnicity with all participants but one (who reported as Indian) reporting as White English/Welsh/ Scottish/ Northern Irish/British. The sample population was also all over the age of 40. Similarly, while we sought to include a range of key health professionals in phase 3 of the study, resource constraints meant that only 10 interviews could be conducted.

CONCLUSION

Haematological cancer patients may have greater psychological issues than those with solid tumours due to the uncertainty of treatment outcomes for liquid tumours. Patients should have timely access to a range of psychological support according to need throughout the cancer pathway. In many cases, adequate psychological support can be provided by health professionals delivering cancer

care. However, this requires HCPS to have access to education, training and supervision that enables them to develop the skills and confidence to identify emotional problems and provide psychological support as well as recognising when referrals to psychiatric services needed. Cancer Nurse Specialist (CNS) capacity building is needed, and increased resources for specialist support for those patients who require that level of input. Where possible, embedding counselling and psychological therapy services within haematological cancer services could be helpful for those with complex needs by helping to facilitate a culture change within these services and leading to greater acknowledgement of the importance of this aspect of care. Collaborations with charities offering psychological support should be supported and developed.

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REFERENCES

- Blood cancer UK statistics on blood cancer. 2021 Available: <http://bloodcancer.org.uk/understanding-blood-cancer>
- Sant M, Allemani C, Tereanu C, *et al*. Incidence of hematologic malignancies in Europe by morphologic subtype: results of the HAEMACARE project. *Blood* 2010;116:3724–34.
- Campo E, Swerdlow SH, Harris NL, *et al*. The 2008 WHO classification of lymphoid neoplasms and beyond: evolving concepts and practical applications. *Blood* 2011;117:5019–32.
- Engert A, Plütschow A, Eich HT, *et al*. Reduced treatment intensity in patients with early-stage Hodgkin's lymphoma. *N Engl J Med* 2010;363:640–52.
- Bonifant CL, Jackson HJ, Brentjens RJ, *et al*. Toxicity and management in CAR T-cell therapy. *Mol Ther Oncolytics* 2016;3:16011.
- Cheson BD, Bennett JM, Grever M, *et al*. National cancer institute-sponsored Working group guidelines for chronic lymphocytic leukemia: revised guidelines for diagnosis and treatment. *Blood* 1996;87:4990–7.
- Albrecht TA, Rosenzweig M. Management of cancer related distress in patients with a hematological malignancy. *J Hosp Palliat Nurs* 2012;14:462–8.
- Hashmi S, Carpenter P, Khera N, *et al*. Lost in transition: the essential need for long-term follow-up clinic for blood and marrow transplantation survivors. *Biol Blood Marrow Transplant* 2015;21:225–32.
- Barata A, Wood WA, Choi SW, *et al*. Unmet needs for psychosocial care in hematologic malignancies and hematopoietic cell transplant. *Curr Hematol Malig Rep* 2016;11:280–7.
- Swash B, Hulbert-Williams N, Bramwell R. Unmet psychosocial needs in haematological cancer: a systematic review. *Support Care Cancer* 2014;22:1131–41.
- Klemm P. Late effects of treatment for long-term cancer survivors: qualitative analysis of an online support group. *Comput Inform Nurs* 2008;26:49–58.
- Allart-Vorelli P, Porro B, Baguet F, *et al*. Haematological cancer and quality of life: a systematic literature review. *Blood Cancer J* 2015;5:e305:5:..
- Hall A, Lynagh M, Bryant J, *et al*. Supportive care needs of hematological cancer survivors: a critical review of the literature. *Crit Rev Oncol Hematol* 2013;88:102–16.
- Allart P, Soubeyran P, Cousson-Gélie F. Are psychosocial factors associated with quality of life in patients with haematological cancer? A critical review of the literature. *Psychooncology* 2013;22:241–9.
- Boyes AW, Girgis A, D'Este C, *et al*. Flourishing or floundering? prevalence and correlates of anxiety and depression among a population-based sample of adult cancer survivors 6months after diagnosis. *J Affect Disord* 2011;135:184–92.
- Zhu J, Fang F, Sjölander A, *et al*. First-Onset mental disorders after cancer diagnosis and cancer-specific mortality: a nationwide cohort study. *Ann Oncol* 2017;28:1964–9.
- Linden W, Vodermaier A, Mackenzie R, *et al*. Anxiety and depression after cancer diagnosis: prevalence rates by cancer type, gender, and age. *J Affect Disord* 2012;141:343–51.
- Clinton-McHarg T, Paul C, Boyes A, *et al*. Do cancer helplines deliver benefits to people affected by cancer? A systematic review. *Patient Educ Couns* 2014;97:302–9.
- Abuelgasim KA, Ahmed GY, Alqahtani JA, *et al*. Depression and anxiety in patients with hematological malignancies, prevalence, and associated factors. *Saudi Med J* 2016;37:877–81.
- Gheihman G, Zimmermann C, Deckert A, *et al*. Depression and hopelessness in patients with acute leukemia: the psychological impact of an acute and life-threatening disorder. *Psychooncology* 2016;25:979–89.
- Tsatsou I, Konstantinidis T, Kalemikerakis I, *et al*. Unmet supportive care needs of patients with hematological malignancies: A systematic review. *Asia Pac J Oncol Nurs* 2021;8:5–17.
- Raphael D, Frey R, Gott M. Psychological support requirements of haematological cancer survivors: how can health professionals meet their needs? *Psychol Health Med* 2021;26:832–44.
- Bloodwise/anthony nolan report. psychological needs of blood cancer patients; 2018.
- Qualtrics (2021), Provo, Utah, USA. n.d. Available: <https://www.qualtrics.com>
- IBM Corp. IBM SPSS statistics for windows, version 24.0. Armonk, NY: IBM Corp; 2016. Available: <https://www01.ibm.com/support/docview.wss?uid=swg21476197>
- Gale NK, Heath G, Cameron E, *et al*. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:117–9.
- QSR International Pty Ltd. NVivo (released march 2020). 2020. Available: <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>
- Rossmann GB, Wilson BL. Number and words: combining quantitative and qualitative methods in a single large-scale evaluation study. *Eval Rev* 1985;9:627–43.
- Tashakkori A, Teddlie C. Mixed methodology: combining qualitative and quantitative approaches. applied social research methods series. In: *Handbook on mixed methods in the behavioral and social sciences* 46. Thousand Oaks, CA: Sage, 2003:
- Creswell JW, Clark VLP, Gutmann M, *et al*. Advanced mixed methods research designs. In: Tashakkori A, Teddlie C, eds. *In Handbook on mixed methods in the behavioral and social sciences*. Thousand Oaks, CA: Sage, 2003: 209–40.
- Swash B, Bramwell R, Hulbert-Williams NJ. Unmet psychosocial supportive care needs and psychological distress in haematological cancer survivors: the moderating role of psychological flexibility. *Journal of Contextual Behavioral Science* 2017;6:187–94.
- Bryant J, Mansfield E, Hall A, *et al*. The psychosocial outcomes of individuals with hematological cancers: are we doing enough high quality research, and what is it telling us? *Crit Rev Oncol Hematol* 2016;101:21–31.
- National Institute for Health and Care Excellence (NICE) Guidance. Improving supportive and palliative care for adults with cancer. cancer service guideline [CSG4]; 2004.
- Tay LH, Ong AKW, Lang DSP. Experiences of adult cancer patients receiving counseling from nurses: a qualitative systematic review. *JBIR Database System Rev Implement Rep* 2018;16:1965–2012.
- Henry R. The role of the cancer specialist nurse. *Nursing in Practice* 2015.
- Macmillan Cancer Support. Addressing the gap - highlighting the need for growing the specialist cancer nursing workforce. 2020. Available: https://www.macmillan.org.uk/_images/addressing-the-gap-report_tcm9-358808.pdf
- Lee JY, Jang Y, Hyung W. Mediating effect of illness perception on psychological distress in patients with newly diagnosed gastric cancer. *Cancer Nurs* 2022.
- Leventhal H, Diefenbach M, Leventhal EA. Illness cognition: using common sense to understand treatment adherence and affect cognition interactions. *Cogn Ther Res* 1992;16:143–63.
- Gibbons A, Groarke A, Sweeney K. Predicting general and cancer-related distress in women with newly diagnosed breast cancer. *BMC Cancer* 2016;16:935.
- Zhang Z, Yang L, Xie D, *et al*. Illness perceptions are a potential predictor of psychological distress in patients with non-muscle-invasive bladder cancer: a 12-month prospective, longitudinal, observational study. *Psychol Health Med* 2020;25:969–79.
- Zhang N, Fielding R, Soong I, *et al*. Illness perceptions as predictors of psychological distress among head and neck cancer survivors: a longitudinal study. *Head Neck* 2018;40:2362–71.
- McCorry NK, Dempster M, Quinn J, *et al*. Illness perception clusters at diagnosis predict psychological distress among women with breast cancer at 6 months post diagnosis. *Psychooncology* 2013;22:692–8.
- Miceli J, Geller D, Tsung A, *et al*. Illness perceptions and perceived stress in patients with advanced gastrointestinal cancer. *Psychooncology* 2019;28:1513–9.
- Roth AJ, Kornblith AB, Batel-Copel L, *et al*. Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer* 1998;82:1904–8.
- Weinman J, Petrie KJ, Moss-morris R, *et al*. The illness perception questionnaire: a new method for assessing the cognitive representation of illness. *Psychology & Health* 1996;11:431–45.
- Garzonis K, Mann E, Wyrzykowska A, *et al*. Improving patient outcomes: effectively training healthcare staff in psychological practice skills: A mixed systematic literature review. *Eur J Psychol* 2015;11:535–56.



- 47 Street RL, Spears E, Madrid S, *et al.* Cancer survivors' experiences with breakdowns in patient-centered communication. *Psychooncology* 2019;28:423–9.
- 48 Royal College of Psychiatrists. Two-fifths of patients waiting for mental health treatment forced to resort to emergency or crisis services. 2020. Available: <https://www.rcpsych.ac.uk/news-and-features/latest-news/detail/2020/10/06/two-fifths-of-patients-waiting-for-mental-health-treatment-forced-to-resort-to-emergency-or-crisis-services>
- 49 Mind we still need to talk: a report on access to talking therapies. 2013. Available: https://www.mind.org.uk/media-a/4248/we-still-need-to-talk_report.pdf
- 50 Mental Health Foundation Scotland. Supporting the emotional and mental health needs of people with cancer. 2018. Available: <https://www.mentalhealth.org.uk/sites/default/files/mh-needs-people-with-cancer.pdf>
- 51 Carolan CM, Smith A, Davies GR, *et al.* Seeking, accepting and declining help for emotional distress in cancer: a systematic review and thematic synthesis of qualitative evidence. *Eur J Cancer Care (Engl)* 2018;27:e12720.
- 52 Dilworth S, Higgins I, Parker V, *et al.* Patient and health professional's perceived barriers to the delivery of psychosocial care to adults with cancer: a systematic review. *Psychooncology* 2014;23:601–12.
- 53 Nekolaichuk CL, Cumming C, Turner J, *et al.* Referral patterns and psychosocial distress in cancer patients accessing a psycho-oncology counseling service. *Psychooncology* 2011;20:326–32.
- 54 Brunton L, Booker J, Molassiotis A. Making sense of symptoms in men with prostate cancer: a longitudinal qualitative exploration. *Int J Urol Nurs* 2012;6:107–14.
- 55 Matheson L, Boulton M, Lavender V, *et al.* Dismantling the present and future threats of testicular cancer: a grounded theory of positive and negative adjustment trajectories. *J Cancer Surviv* 2016;10:194–205.
- 56 Bilsker D, Fogarty AS, Wakefield MA. Critical issues in men's mental health. *Can J Psychiatry* 2018;63:590–6.