

Section 11

Discussion

Introduction

During treatment and probably a couple years past the treatment, yes, it has affected my quality of life with what I've been able to do and to achieve with regards to work, my physical activity, socializing, things like that. About we had to give up everything that I was doing for three 3 1/2 years to maybe 4 1/2 years.

Participant 024_2023AUCRT

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

This PEEK study in blood cancer includes 37 people diagnosed with CAR-T treatable blood cancer throughout Australia.

Background

Blood cancers accounted for approximately 12% of all cancers cases in Australia 2023. In 2019, 17,705 people were diagnosed with a blood cancer, a rate of 57.7 per 100,000¹. Blood cancer was diagnosed more often in men, with 9687 males diagnosed in 2019 compared to 7348 females¹. The most common type of blood cancer in Australia is non-Hodgkin lymphoma followed by multiple myeloma and chronic lymphocytic leukaemia¹, with those treatable with CAR-T therapy including B-cell acute lymphoblastic leukemia (B-ALL), Diffuse Large B-Cell Lymphoma (DLBCL) and multiple myeloma.

Blood cancer can occur at any age, acute lymphoblastic leukaemia was expected to be the most common cancer diagnosed in children 2023, however, incidence of blood cancer increases with age, and in 2019, the mean age at diagnosis was 67.2¹.

Five year survival was 69% in 2015 to 2019, survival rates are higher in younger age groups with five year survival of 90% for people aged under 40, 84% in 40–59 year olds to 69% in 60–79 year olds to 42% for those aged 80 years older¹.

Blood cancers have high hospitalisation and pharmaceutical costs, with myeloma and leukaemia rated in the top three most expensive cancers to treat in Australia².

Demographics

The demographic data we collect in the PEEK study helps us to understand how our PEEK participants compares to people in Australia, and with people that have blood cancer.

In this PEEK study, there were smaller proportions of participants that lived in major cities and higher proportions that lived in areas with higher socioeconomic status, compared to that of Australia^{3,4}. Participants lived in all Australian states and territories. There was a lower proportion of participants from NSW, while a greater proportion from Queensland compared to the proportion that live in each state⁵.

Table 12.1: Demographics

Demographic	Australia %	Blood cancer PEEK %
Live in major cities	71	57
Higher socioeconomic status (7 to 10 deciles)	40	54
New South Wales	32	16
Victoria	26	22
Queensland	20	27
South Australia	7	8
Western Australia	10	11
Tasmania	2	8
Northern Territory	1	3
Australian Capital Territory	2	5

Health status

In PEEK studies we collect information about other health conditions that participants manage, as well as health-related quality of life (with the SF36 questionnaire). The purpose of this is to have an idea of the general health of the participants in the study. We can also compare this data with the Australian population, and with other studies with blood cancer participants.

Other health conditions

The National Health Survey was conducted in 2017 to 2018, it is an Australia wide survey conducted by the Australian Bureau of statistics. Almost half of the Australian population have one chronic condition⁶. Common chronic health conditions experienced in Australia in 2017-18 were: mental and behavioural conditions (20%), back problems (16%), arthritis (15%), asthma (11%), diabetes mellitus (5%), heart, stroke and vascular disease (5%), osteoporosis (4%), chronic obstructive pulmonary disease (COPD) (3%), cancer (2%), and kidney disease (1%)⁶. The Australian Bureau of statistics reports that 10% of Australians have

depression or feelings of depression and 13.1% have an anxiety-related condition⁶.

In this PEEK study, participants had higher levels of back pain (43% compared to 16%), arthritis (27% compared to 15%), anxiety (38% compared to 13%), and osteoporosis (14% compared to 4%) compared to the Australian population. Other studies reported comorbidities in people with blood cancer, in particular, anxiety and depression of between 5 and 70% of participants⁷⁻¹⁵, and fatigue in between 44% and 91% of participants^{13,16,17}. Participants in this PEEK study had an average of 3 other conditions that they managed.

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual¹⁸. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function¹⁸.

Participants in this PEEK study completed Short Form Health Survey 36 (SF36) questionnaire, the SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function. Participants had very high scores for role functioning emotional, high scores for physical function, emotional well-being, social functioning, and pain, and average scores for role functioning physical, energy/fatigue, and general health. In contrast, other studies reported poor health related quality of life in the following domains; physical function^{13,19-21}, emotional impact^{19,20}, pain²¹, and energy/fatigue²¹

Population norms for the SF36 dimensions in Australia were assessed in the 1995 National health survey, while this was conducted 25 years ago, it can give an indication of how the blood cancer community in this PEEK study compares with the Australian population²². Compared to the Australian population, participants in this PEEK study had lower physical function, role functioning physical, energy/fatigue, and general health, they had higher scores for role functioning emotional, and social functioning, and similar scores for emotional well-being, and pain. In other studies,

compared to the general population, people with blood cancer have poorer health related quality of life²³⁻²⁸, in contrast one study described not significant differences compared to the general population²⁹.

Lower socioeconomic status, lower income and having financial difficulties were associated with poorer health related quality of life^{10,23,30-32}. In contrast, in this PEEK study participants with higher socioeconomic status had worse emotional well-being compared to those with mid to low socioeconomic status, no other significant differences were observed in subgroups for any SF36 domains in this PEEK study. Other studies described that younger age was negatively associated with health related quality of life^{30,33}, specifically emotional, cognitive and social functioning^{34,35}, and older age was negatively associated with pain, physical function, and mobility³⁴⁻³⁶. Female gender was negatively associated with health related quality of life^{30,37,38}, in particular worse physical function³³, in contrast, another study described worse health related quality of life in males.³² Having comorbidities in general was negatively associated with health related quality of life^{23,32,35,37-43}, in particular anxiety and depression^{10,17,32,35,40,42,44-49}, pain^{12,13,35,36,48-50}, fatigue^{10,12,16,37,46,51}, sleep impairments^{24,46}, poor appetite^{37,46}, muscle weakness³⁷, constipation¹⁷, hearing issues²⁴, obesity^{38,52}, and erectile dysfunction⁵³. Having a relapse and having a recent diagnosis or being in early treatment was negatively associated with health related quality of life^{23,35,49,54,55}. Some studies have described poorer health related quality of life for those undergoing treatment^{12,40,56}, while another study described poor health related quality of life while in active surveillance⁵⁷. In addition, poor health related quality of life was associated with those that had radiotherapy^{23,38}, those that have had multiple lines of treatment⁴¹, and those that were post treatment^{55,58}. A number of studies described that quality of life improved over time in patients that received cancer treatments^{32,57,59-61}, and for those in remission^{41,62}. Physical activity and social support were positively associated with health related quality of life^{26,63,64}

Key points

- Health related quality of life domains that were lower than the Australian population: physical function, role functioning physical and energy/fatigue. Social functioning and role functioning emotional were higher in this PEEK population compared to the Australian population.
- Most common comorbidities are sleep problems, back pain, and anxiety

Risks and Symptoms

In the PEEK study, information about symptoms and quality of life from symptoms before diagnosis are collected in the online questionnaire, and in the interview, participants talk about the symptoms that actually lead them to get a diagnosis. Taken together, we can get an insight into the number and type of symptoms participants get, the symptoms that impact quality of life, and the symptoms that prompt medical attention.

In this PEEK study, participants had an average of 4 symptoms before diagnosis, the most common symptoms leading to diagnosis were fatigue, back pain and none pain. The most common symptoms experienced overall (that is not necessarily lead to a diagnosis) were pain in muscle, bone and joint, fatigue, and coughs and breathlessness. In other studies symptoms leading to diagnosis included bone pain, fatigue, headaches, sleep problems, dizziness, weight loss, diarrhea, and emotional problems^{20,48,50,65}

In this PEEK study, participants had an average of 5 current symptoms, similar to another study of people with blood cancer that also averaged 5 current symptoms⁶⁶. The most common symptoms reported by participants in this PEEK study included peripheral neuropathy, fatigue, weak or damaged bones, psychological effects, and being prone to infections. Similarly, other studies described common symptoms that people with blood cancer currently experienced. Most commonly these were fatigue, back pain, nerve symptoms, breathlessness, muscle weakness, cognitive problems, emotional problems, infections, sexual dysfunction, diarrhoea and vomiting^{13,19,35,48,66-70}.

The most important symptoms to control for quality of life reported by participants in this PEEK study were fatigue, pain, lymphoedema, and fertility. The least important were heart problems, memory loss and cognitive function, and effects on bones and joints. Similarly, other studies report pain, and fatigue as the most troublesome symptoms and in contrast to the PEEK study also include cognitive problems^{67,71}.

Screening and diagnosis

Half of the participants in this PEEK study were diagnosed within 6 months of noticing symptoms. The most common diagnostic pathway was being sent to a specialist or to an emergency department by their general practitioner. Some were diagnosed during a routine check up unrelated to any symptoms. In other

studies, people with blood cancer described delays in diagnosis due to healthcare professional that were unfamiliar with symptoms, delays from referral to specialists, delays from multiple doctor visits and tests^{72,73}. Like participants in this PEEK study, other studies described that their diagnosis was unexpected, they were diagnosed through a routine check up^{74,75}

Understanding and knowledge

Absolutely nothing. I didn't even know that, you know, blood cancer could produce the sort of pain and discomfort. I didn't realize that it was blood cancer. My first thought was it's, you know, sort of a tumor. Like presentation and so I knew nothing. No, no one in my circle of friends or family have had it so I was a newbie.

Participant 009_2023AUCRT

Knowledge about chronic disease before diagnosis varies between individuals. Some will gain information from family and friends with the condition, though it can result in misconceptions and misunderstandings^{76,77}. Some people will seek out information about a possible diagnosis, or explore the reasons for symptoms, before receiving a final diagnosis^{78,79} others, especially those who have symptoms for long periods before diagnosis, will gain information in terms of how to live with or adapt to symptoms they experience⁸⁰. For some people, the first time they have heard of their chronic condition is when they are diagnosed⁷⁹. At the time of diagnosis, it may be useful for the healthcare professional to talk about how much a patient knows about a condition so that appropriate information can be given, and correct misconceptions⁷⁹.

Biomarkers or genetic markers

Biomarkers can be used for diagnosis, to monitor a condition, to predict response to therapy, or to predict disease course.

In this PEEK study, more than a quarter of participants had discussions about biomarkers with their doctors. Approximately 21% had a biomarker test, and about half were interested in having a biomarker test if they had not already had one. In another study, people with blood cancer demonstrated knowledge of their test results and the importance of positive laboratory and imaging findings⁸¹.

Support at diagnosis

In this PEEK study, the majority of participants described having enough support and information at diagnosis. Another blood cancer study described that diagnosis was the time when information and support needs were greatest⁸².

Key points

- Participants have an average of 5 symptoms to manage, the most important to control for improved quality of life were fatigue, pain, lymphoedema, and fertility.

Decision making

Basically, I wasn't presented with options. I was basically told that it was so. Advanced is not quite the right word, but so far along that they had had to hit me with pretty extreme chemo early and and that happened very quickly. I have a little bit of information about what to expect from chemo, but but nothing that you told actually prepares you for how awful that can be the first course of chemo and I've I've had many was absolutely awful and that that sort of they they tweaked it and that made it more manageable so they they they changed the mix of drugs. From the first time. So I didn't have such severe reactions, you know, especially in the stomach and the, you know, nausea, diarrhea, that sort of thing. Because that was truly awful.

Participant 009_2023AUCRT

The decision-making process in healthcare is an important component in care of chronic or serious illness⁸³. Knowledge of prognosis, treatment options, symptom management, and how treatments are administered are important aspects of a person's ability to make decisions about their healthcare^{84,85}, highlighting the importance of healthcare professional communication. In addition, the role of family members in decision making is important, with many making decisions following consultation with family⁸⁶.

In this PEEK study, the majority of participants had no or very little knowledge about their blood cancer at the time of diagnosis. This was also reported in other blood cancer studies^{69,72,74,87}.

In this PEEK study, participants most commonly described their prognosis in terms of being in remission, specific medical interventions needed to manage their condition, and possible recurrence. In

other studies, people with blood cancer described their understanding of prognosis. Similar to the PEEK study, other people with blood cancer described their prognosis in terms of there being no cure and that their condition was chronic^{56,74,75,88}, they described it in terms of likely recurrence^{75,88}, that their condition could be managed with treatment⁷⁴, or that there was uncertainty around their prognosis^{87,89}. Some had difficulty understanding prognosis, especially in terms of the lack of surgical cure^{74,87}, some misunderstood or over estimated their chance of cure Hermann, #1082;Loh, #1183;O'Donnell, #1127}.

Goals of treatment and decision-making

Confidence to take part in decision-making is increased by knowledge, being prepared with relevant questions for their consultation, and summaries of previous consultations and results^{90,91}.

Participants in this PEEK study were most commonly presented with one treatment option when first diagnosed, often it was a medical emergency and urgent treatment was required. Some participants were happy to accept the approach recommended by their doctor, others participated in decision making. In other studies, people with blood cancer described varying degrees of participation in decision making from leaving it up to their doctor^{82,92,93}, shared decision making⁹³, to full participation in decision making Mian, #1070;Loh, #1183}. The amount of information was important in decision making with some describing not knowing enough to be able to make an informed decision⁸², to others feeling confident in decision making because they were well informed⁸² Mian, #1070}.

Considerations when making decisions

Look, I think for me, with this, I mean this is the first time I've ever been unwell, so I didn't have any experience to reference it to, which is so important in decision making. You know, what have you done before? Did it work, blah blah. I had nothing at all to reference this to and I was so unwell. I think that I was a very passive decision maker in that process and I really did relinquish my absolute research in that decision making space. I think I really did relinquish my decision making to the professionals around me, but in terms of it retrospectively, if I say it, if somebody said to me now I had to do something, it would be the impact of the treatment on my kids and my partner.

Participant 016_2023AUCRT

In this PEEK study, participants described their considerations when making treatment decisions. The most common considerations were the advice of their clinician, side effects, efficacy, ability to follow treatments, and quality of life.

In other studies, people with blood cancer noted a number of considerations when making treatment decisions. Some consider the efficacy and survival benefit⁹⁴⁻⁹⁹, the period of expected remission^{94,100}, the advice of their doctor^{92,99}, whether the treatment was the standard treatment or if it was personalised¹⁰¹, how the treatment was administered and how easy it was to access the treatment^{94-96,99,100} and the cost of treatment^{94,97}. The impact that the treatment has was an important consideration with people with blood cancer describing taking into account side effects^{81,92,94-97,99-101}, the impact on quality of life^{81,96,98,99,101}, the ability to function during treatment⁹⁹, and the impact on family⁹⁷.

Treatment goals

People with blood cancer have described their treatment goals, often the most important goal was to be cancer free and improve survival^{81,89}, others want to return to normality or improve quality of life⁸⁸, to be able to take part in family life⁸¹, and return to work⁸¹. Likewise, in this PEEK study, the most common treatment goals described were being cancer free or avoid recurrence, quality of life, and physical improvements.

Participation in decision making

One study described decision making over time, the majority had not changed over time as they continued to take multiple factors into consideration⁹⁹. Some noted changes, because different factors such as quality of life became more important over time or that they were more willing to treat the cancer aggressively to improve their chances⁹⁹. Similarly, in this PEEK study the majority of participants did not change decision making over time.

Key points

- Participants had little to no knowledge of blood cancer at time of diagnosis
- Advice of doctor, side effects and efficacy important considerations for treatment decision making

Treatment and healthcare provision

In this PEEK study, to get an insight healthcare access, information about access to healthcare professionals, health insurance, health system, and financial consequences from having blood cancer are collected.

Almost half of the Australian population have private health insurance with hospital cover⁶. This can be used to partially or completely fund stays in public or private hospitals. Between 2006 and 2016, the proportion of private health care funded hospitalisations in public hospitals rose from about 8% to 14%⁶. In this PEEK study, a higher proportion had private health insurance compared to the Australian population.

The majority of the participants in this PEEK study had at least some cost burden from their condition. Most commonly this was from having to take time off work, or family members needing to take time off work. Other costs included the cost of treatments, the cost of parking, travel, accommodation to attend appointments. Almost half described that a lot of the cost burden had been absorbed by the public health system. Other studies described the impact of blood cancer on personal finances. A major source of financial distress was the inability to work or having to make changes to work resulting in income loss^{87-89,102-104}. Other sources of financial stress were from the costs of treatment, management and specialist appointments^{102,105}, gap payments from public or private healthcare^{102,105}, and costs involved with treatment and management such as transport, accommodation and food¹⁰². Some described needing to get financial support from government or charities^{102,105}.

I haven't really incurred many costs at all. Some of the medications are little bit pricey, but given the big picture, they're only one \$40, \$50. My big thing for me is that I've had to leave work. It's just that sense of independence, that's all, but no other costs really that have been of a worry.

Participant 002_2023AUCRT

Allied health

Allied health is important to manage the physical, emotional, practical and financial consequences of blood cancer

Approximately two thirds of participants in this PEEK study had used allied health to manage their condition. Most commonly they had physiotherapy, advice from a dietician, psychology or counselling, and social work.

Other studies described that people with blood cancer wanted a specialised exercise program for their condition led by a physiotherapist or exercise physiologist, though less than half had access to an allied health professional for physical activity⁶⁷, and that only a quarter of people with blood cancer that were in distress received formal mental health treatment⁷

Lifestyle changes

Diet and exercise needs of people with cancer change throughout the course of their treatment and survivorship¹⁰⁶, and lifestyle changes may be made by individuals to improve treatment outcomes, improve quality of life and reduce recurrence risk factors¹⁰⁷. In this PEEK study, participants described using physical exercise for both maintaining mental and physical health, as well as maintaining a healthy diet to manage their general health.

In this PEEK study, the majority of participants (85%) had made lifestyle changes to manage their condition, they made 2 changes on average, most commonly exercise diet and reducing alcohol.

Others studies described using diet to manage side effects such as Diarrhoea, constipation, nausea and vomiting⁸⁸. Another study described that very few people with blood cancer did the recommended level of exercise, the level of exercise dropped during treatment but improved when treatment ended though did not reach pre-treatment levels⁶⁷.

Complementary therapies

Complementary therapies include taking supplements, mindfulness and relaxation techniques, massage therapy and acupuncture and many others. Complementary therapies have been reported to be used by between 40% and 80% of people with cancer, with reports of improvements in stress or side effects of treatments¹⁰⁸⁻¹¹¹. In this PEEK study, half of the participants used complementary therapies, most commonly mindfulness or relaxation techniques, massage therapy, supplements and acupuncture.

Clinical Trials

Well, I think new treatments people people should know about new treatments and should know about clinical trials. And probably the best way for this to be done would be via the treating clinician, but that certainly wasn't how my mine worked. I I had to find out about new

treatments, really the breadth of new treatments available. Not that I had to access access in the oven, but I found that out by myself.

Participant 014_2023AUCRT

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to participants include new treatment may not be as effective, and side effects.

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to participants include new treatment may not be as effective, and side effects.

A search of the Australian New Zealand Clinical Trials Registry was conducted on 17 June 2023. The search included any study that included participants with ALL, DLBCL, Mantle Cell lymphoma, and multiple myeloma, was conducted in Australia, and was open to recruitment in the last five years. A total of N studies were identified that had a target recruitment of between 12 and 3000 participants (median=255), there were 22 studies that were international, and 8 studies that were conducted exclusively within Australia. There were 9 studies that included liver cancer and other conditions. The most common types of studies were investigating drugs (n=22), other studies were investigating radiotherapy (n=3), surgery (n=2), allied health (n=1), imaging (n=1), and registries (n=1).

There were 23 studies conducted in New South Wales, 12 studies in Victoria, 13 in Queensland, 10 in South Australia, 12 in Western Australia. There were no studies conducted in Tasmania, the Australian Capital Territory, or the Northern Territory.



Figure 12.1: Distribution of clinical trials for blood cancer in Australia 2016-2021

Half of the participants in this PEEK study had discussions about clinical trials with their doctor. More than a fifth had participated in a clinical trial, and the majority of those that had not participated would participate if there was a trial appropriate for them.

Patient treatment preferences

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance.¹¹²⁻¹¹⁴ Patient preferences and priorities vary across different health issues, preferences are associated with health care service satisfaction, they refer to the perspectives, values or priorities related to health and health care, including opinions on risks and benefits, the impact on their health and lifestyle^{112,115}.

Side effects of treatment

Debilitating. So you know I probably use examples of nausea, migraine headaches those sort of things. If I was to if those something that would keep me in bed, I'd find that cruciatingly frustrating. But but yeah just it it's the the physical side of those sort of side effects is one thing. Yes, they knock you out and they put you in bed sort of thing, but that's the mental side of things that would would play on me the most in that it's if I'm experiencing severe side effects from my condition, it messes with your hope and your future outlook sort of thing, this and

belong into that sort of thing. So it's a mental battle as well as physical.

Participant 019_2023AUCRT

To help inform patient preferences in the blood cancer community, participants in this PEEK study discussed side effects, treatment administration, adherence to treatment. In this PEEK study, participants described the terms mild and severe side effects. For both mild and severe side effects, participants used specific examples to describe the terms, most commonly using aches and pain or fatigue to describe mild, and nausea or aches and pains to describe severe side effects. Other ways to describe these terms were the impact on daily activities, where mild allowed these activities and severe did not, and the ability to self manage (mild) or the need for medical intervention (severe). In other studies, people with blood cancer described side effects in terms of the impact on ability to work or do usual activities^{13,88,116}, the impact on quality of life^{41,53,116}, the duration of side effects^{59,65,88,116}, and that they considered side effects to be impact physical and mental health⁸⁸. One study described that doctors commonly underestimated the severity of side effects⁶⁸.

Self-management

Self-management of chronic disease encompasses the tasks that an individual must do to live with their condition. Self-management is supported by education, support, and healthcare interventions. It includes regular review of problems and progress, setting goals, and providing support for problem solving¹¹⁷. Components of self-management include information, activation and collaboration¹¹⁷.

Information is a key component of health self-management^{118,119}. The types of information that help with self-management includes information about the condition, prognosis, what to expect, information about how to conduct activities of daily living with the condition, and information about lifestyle factors that can help with disease management^{118,119}.

Treatment adherence

No, I've never given up. I've. I've taken it for as long as I've been under orders too. But I have. I have discussed the impact on me with the people treating me and in the case of the thalidomide, you know, I reported the, you know, the rash and I guess it was it could be regarded as a joint decision, but effectively

it was it was his decision really I I I as I said before, I really did as I was told and I think wisely.
Participant 014_2023AUCRT

In this PEEK study, participants described adhering to treatment according to the advice of their specialist or as long as prescribed, they described not giving up on any treatments, adhering to treatment as long as side effects are tolerable, needing to see test results, and as long as the treatment is working. Similarly in other studies, people with blood cancer would adhere to treatments while side effects are tolerable, according to the advice of healthcare team, and if they had enough support while undergoing treatment^{120,121}.

What needs to change to know that treatment has worked

Yes, if I can do things without being in pain. I mean if I. You know, try and walk too far. I just get very tired and and something starts to wake and I think, oh, that's enough. I can't do anymore now, you know, I just have to stop doing that. I just have to taste myself like I'm, I like working in the garden. And normally I could just work all day in the garden, but now I just do as many things as I can and then I go and take a break and you know, I sort of taste myself.

Participant 012_2023AUCRT

Participants in this PEEK study described what changes they needed to see to know that their treatment is working. Participants described needing to see evidence of stable disease/no disease progression, physical signs and symptoms disappear/reduce side effects, specific symptom reduction and return to day-to-day functionality. This is similar to descriptions in other studies, people with blood cancer described need to see physical improvement, side effects and symptoms^{19,65,81}, the ability be independent, do normal activities⁶⁵, evidence from tests and scans^{19,81}, and improvements in mental health⁸¹.

Expectations of future treatment

The way it'd be nice not to travel 3 1/2 thousand kilometers for a stem cell transplant. That would be nice. And it would be nice if they make CAR T therapy more widely available.

Participant 022_2023AUCRT

When asked what they would like to see in future treatments, PEEK participants described wanting more affordable treatments, treatments with fewer or less intense side effects, more access to new treatments

and clinical trials, and more effective or targeted treatments. In addition, they wanted more choice, transparency and discussions in relation to treatment options. In other studies, people with blood cancer described their expectations of future treatments, these included that new treatments will provide a cure, have greater efficiency and improve life expectancy^{81,88,122}. New treatments will be more targeted or personalised, and will have fewer side effects^{88,122} ^{81,123}. New treatments will consider the psychological and emotional impact and quality of life⁸⁸. New treatments will be more affordable⁸⁸, will be closer to home⁶⁵, and have less invasive or time consuming modes of administration^{65,88}.

Key points

- **Tolerance of side effects is important for treatment adherence**
- **Reduction of side effects and symptoms is an important sign to participants that their treatment is working.**

Activation (skills and knowledge)

Patient activation is the skills, knowledge, and confidence that a person has to manage their health and care; and is a key component to health self-management. Components of patient activation are support for treatment adherence and attendance at medical appointments, action plans to respond to signs and symptoms, monitoring and recording physiological measures to share with healthcare professionals, and psychological strategies such as problem solving and goal setting.

Patient activation is measured in the PEEK study using the Partners in Health questionnaire¹²⁴. On average, participants in this study had very good knowledge about their condition and treatments, they had a good ability to manage the effects of their health condition, a very good ability to adhere to treatments and communicate with healthcare professionals, and had very good recognition and management of symptoms. Other studies described that people with blood cancer had a good knowledge of their diagnosis, treatment and side effects, and symptoms associated with progression^{74,125}.

Communication and collaboration

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support^{118,119}

Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction¹²⁶⁻¹²⁹.

An expert panel identified the fundamental elements of healthcare communication that encourages a caring, trusting relationship for patient and healthcare professional that enables communication, information sharing, and decision-making¹³⁰.

Building a relationship with patient, families and support networks is fundamental to establishing good communication¹³⁰. Healthcare professionals should encourage discussion with patients to understand their concerns, actively listen to patients to gather information using questions then summarising to ensure understanding¹³⁰. It is important for healthcare professionals to understand the patient's perspective and to be sympathetic to their race, culture, beliefs, and concerns. It is important to share information using language that the patient can understand, encourage questions and make sure that the patient understands¹³⁰. The healthcare professional should encourage patient participation in decision-making, agree on problems, check for willingness to comply with treatment and inform patient about any available support and resources¹³⁰. Finally, the healthcare professional should provide closure, this is to summarise and confirm agreement with treatment plan and discuss follow up.

Communication

You need to be treated as an intelligent human being. I think there's a lot of talking down that goes on. I didn't find that so much with the nurses, just about, they were amazing. They were fantastic, but of course, they can only give out so much information. I definitely thought with the doctors, there seemed to be an assumption that you wouldn't understand what they were saying.

Participant 003_2023AUCRT

In this PEEK study, the majority of participants had overall positive communication, mostly from holistic, two way, supportive and comprehensive conversations. Negative communication was described as communication that was not forthcoming or that was limited in understanding. In other studies, people described good communication as being empathetic and optimistic^{87,131}, they described feeling equal with their healthcare professional and trusting them, in

Volume 6 (2023), Issue 4: PEEK Study in blood cancer

addition, the importance of having enough time in appointments¹³¹. Some described the value of preparing for medical appointments in improving communication¹³¹, and the benefits included more discussions about end of life care and the improvements in ability to communicate about their condition with their family and friends¹³¹. Poor communication was described as lacking empathy, lacking time and the inability to ask questions between appointments⁸⁷.

Communication and collaboration with healthcare professionals was measured in this PEEK study by the Care Coordination questionnaire¹³². Participants had good communication with healthcare professionals, they had good navigation of the healthcare system, they rated their care coordination as good, and rated their quality of care as very good.

Patient understanding of their condition and ability to seek care when needed was improved when information was delivered in a two-way exchange.^{133,134}

Expectations of future communication

Almost half of the PEEK participants were satisfied with the communication they had with healthcare professionals. Some would like communication to be more transparent and forthcoming, to have a multidisciplinary and coordinated approach, for communication to be more empathetic, to have more time to meet with their clinician and for communication to be more understandable. In other studies, people with blood cancer described their expectations of future communication. It was important that communication is respectful, had empathy, was in lay language, and took into consideration privacy and choice^{8,82}.

Information

Well, mostly for talking to the doctors and the nurses and then also reading the information that they give you and rereading it and then going through and thinking of questions to ask them and then asking questions. I look up a bit of stuff online, but I try to go to the things like the Queensland Health or NSW Health or the ones that are not the other, that are in Australia and that are proper medical ones as opposed to, you know, someone's crackpot theory or whatever, yeah.

Participant 006_2023AUCRT

Participants in this PEEK study described getting information from health charities, books, pamphlets and newsletter, their healthcare team, the internet and from other people with blood cancer. Other studies described information from treatment teams^{73,120}.

In terms of information that was helpful, PEEK participants found talking to their treatment team helpful, as well as hearing what to expect and other people's experiences. Likewise, other studies described information that was helpful included other people's experiences and information about what to expect⁹⁷.

I think the most helpful has been information from people who have also gone through the same thing, and their way of coping and dealing with it, small things like what to eat when you're vomiting. Yes, how you feel and what to expect from that.

Participant 003_2023AUCRT

Participants in this PEEK study most commonly described that no information was not helpful, they also described that worse case scenarios, other people's experiences and sources that are not credible are not helpful. Unhelpful information was described in other studies as information that was out of date⁹⁷, conflicting information^{97,135}, that used medical or technical language⁹⁷, that described worst case scenarios^{69,135}, and healthcare professionals that do not have time or answer questions^{69,97}.

In terms of information format preferences, people in this PEEK study had a preference for talking to someone, online information or a combination of both, written information was also a preferred format for some participants. Talking to someone was preferred because it enabled time to ask questions, it was personalised and relevant, and was supportive. Online information was preferred because of accessibility, it can be personalised and relevant, and allows for information to be digested at their own pace. Written information was preferred because it is easy to refer back to. In another study, most people with blood cancer described preferring to talk to someone to get information, other forms of information were also popular, including the internet, printed materials, and attending information sessions¹³⁶. Other studies described reasons for information preferences, a preference for speaking with some one was because they can ask questions, the information is personalised and relevant^{73,97}, and a preference for written information because they can refer back to it, take time

to digest information at own pace, add notes and help prepare for appointments^{82,97}.

In terms of information format preferences, people in this PEEK study had a preference for talking to someone, online information or a combination of both, written information was also a preferred format for some participants. Talking to someone was preferred because it enabled time to ask questions, it was personalised and relevant, and was supportive. Online information was preferred because of accessibility, it can be personalised and relevant, and allows for information to be digested at their own pace. Written information was preferred because it is easy to refer back to. In another study, most people with blood cancer described preferring to talk to someone to get information, other forms of information were also popular, including the internet, printed materials, and attending information sessions¹³⁶. Other studies described reasons for information preferences, a preference for speaking with some one was because they can ask questions, the information is personalised and relevant^{73,97} and a preference for written information because they can refer back to it, take time to digest information at own pace, add notes and help prepare for appointments^{82,97}.

Expectations of future information

Peek participants wanted future information to include more details about disease trajectory and what to expect, the ability to talk to/access to a health professional, more details about new treatments and clinical trials, more details on subgroups and specific classifications of their condition information in a variety of formats and for information to be more accessible and easy to find. In other studies, people with blood cancer described their expectations of future information, they described the need for more information about the following topics; what to expect including treatments, side effects and symptoms, and costs^{8,82,97,136-138}, psychological care^{82,136,137}, lifestyle factors including diet and exercise¹³⁶, complementary therapies¹³⁶, and peer support^{82,137}.

Care and support

The main support for me has been my family, just with taking me to appointments and to the clinic and when I had to go to hospital and things like that. I haven't had any help from outside organizations. I've had a few good friends that have come over to help me when I needed help, but other than that, we pretty much looked after ourselves.

Participant 002_2023AUCRT

Participants in this PEEK study described the support they had received for their blood cancer. Most commonly, participants had support from charities, they also found support in the clinical setting and from family and friends. The types of support included accommodation while having treatment, domestic services, financial advice and transport. There were some that did not get any support, that did not need any support, and others described the challenges of finding or accessing support. In other studies, people with blood cancer described getting support from peer support^{139,140}, their clinical team^{73,87,140}, and from family and friends^{69,73,87}. The type of support included information, emotional support, and support attending appointments^{26,87,139}, some described finding it difficult to find appropriate support^{139,140}.

Expectations of future care and support

Almost a third of PEEK participants were satisfied with the care and support received. Some would like future care and support to include a multidisciplinary and coordinated approach, they would like more access to services, more holistic care and support, more peer support and more practical support. In other studies, people with blood cancer described their expectations of future care and support, this included developing a care plan for future¹⁴¹, access to allied health to manage symptoms⁸², and the need for help accessing and navigating healthcare services⁸². They described wanting practical support, including financial help^{14,75,123}, and assistance with transport and overnight accommodation⁸². Others described the need for emotional support for themselves and for their families, and the need for peer support^{14,82,123,141}.

Anxiety associated with condition

I'm about 130 days post-transplant. I attended the clinic last week, they told me that I'm in remission or have 100% of my donors DNA. They're very happy with my results, but me as a person, I'm feeling very vulnerable, because up until a month ago, I was going to the clinic every Monday and having blood tests, and then it progressed to every fortnight. I only had one fortnightly visit and now I'm on monthly. I'm feeling really vulnerable about if something happens in between visits, because I don't know what signs to look for. I think from what I've been talking to people, that it's quite natural to feel that way.

Participant 002_2023AUCRT

The rates of depression and anxiety are higher in people with chronic conditions compared to the general population. In a meta-analysis of 20 qualitative studies, it was reported that people with chronic conditions experienced anxiety or depression as either as independent of their chronic condition or as a result of, or inter-related with the chronic disease, usually however, anxiety and depression develops as a consequence of being diagnosed with a chronic disease¹⁴².

In this PEEK study, anxiety associated with blood cancer was measured by the fear of progression questionnaire¹⁴³. The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated low levels of anxiety. A couple of studies reported that **women** had more anxiety about their condition compared to men^{33,39}. In this PEEK study, there was no significant difference in the fear of progression total score by gender, younger participants had significantly more disease related anxiety compared to older participants, and those that lived in areas with higher socioeconomic status had more disease related anxiety compared to those that lived in mid to low socioeconomic areas.

Participants in this PEEK study described feeling vulnerable during or after treatments, when experiencing side effects, when having sensitive discussion, and because of interactions with their medical team. In addition, they were most often concerned about disease progression, not being able to achieve professional and personal goals, symptoms and side effects and long term damage from treatments. In other studies, people with blood cancer described anxieties surrounding their blood cancer. A major cause of anxiety was the fear or recurrence^{9,74,82,87,135,144,145}, in addition, uncertainty about survival^{70,81}. Side effects and symptoms were also a cause of anxiety due to the impact on day to day life and the fear that it signifies a recurrence or progression^{88,116,135,144-147}. People with blood cancer worried about whether their treatment was working¹⁴⁶, undergoing treatment and going to hospital¹⁴⁵, waiting for results^{73,135}, and transitioning from patient to survivor¹³⁵.

Quality of life

No now, but I would say during the time of treatment, because I was very tired. I wanted to keep doing so much of everything that I had done prior to, but I couldn't keep up with my active children. I couldn't keep up with going out for dinners or going away on weekends. I was just too tired. When I'd go away, I'd have to take my medication with me or check my temperature. I couldn't eat certain foods. I tried not to let it get me down, but at times it would. I just used to think, "Well, it's only a short term thing. Hopefully everything goes well for long term gain." Over that period, that was very draining.

Participant 001_2023AUCRT

The majority of PEEK participants described a negative impact on quality of life from blood cancer. The impact was from the emotional strain on their family, having to manage side effects and symptoms, and having reduced social interactions. In other studies, people with blood cancer described the impact of their condition on quality of life. An important theme was the burden of living with side effects and symptoms which impacted many aspects of their life^{20,88,89,105,135,140,146,148,102,71,75,81}. They described the changes to work or education^{71,75,82,105,135}, their ability to take part in family life^{20,140,145,147}, to conduct daily activities and household tasks,^{20,30,88,89,102,145,65,71} their ability to take part in activities they enjoyed such as hobbies and sports^{30,65,71,89,102,116}, and feelings of isolation and inability to take part in social activities^{30,65,140,145}. Some described the negative impact that the burden of treatment had on quality of life^{20,140,148,102}, and costs associated with treatments and not being able to work^{105,135,147}. PEEK participants also described positive impacts from supportive relationships and bringing people together.

Activities for mental and physical health

Well, take medication, keep exercising. I still have to be very aware of who I'm mixing with because I'm sorry, I am off immunosuppressants now, but I'm still, I don't have that immunity yet. I'm also, I haven't been vaccinated for, and I can't have for quite a while yet any of the live vaccines. So I have to be very aware of besides from COVID but I don't go near anyone who may have or be carrying chicken pox, measles, mumps or Bella anything like that. So you have to be a lot more careful. I'm a lot more limited in what you do and and I'll find even before COVID well I was wearing the mask so that was a a limiting thing and I'm just trying not to get too close to people sort of always if

you're out somewhere and. You need to get to the other side of the park and there's a group of people there. You're always looking at ways to walk right away from people and not close to people. So yeah, so just things like that. Not not big, major things, I suppose.

Participant 006_2023AUCRT

In this PEEK study, participants described the activities they do for their physical and mental health. They described the importance of being physically active, complying with treatment, self care (more rest, accepting help and pacing themselves), understanding their limitations, maintaining a healthy diet, mindfulness or meditations, socialising with family and friends, hobbies, consulting a mental health professional, and maintaining a normal routine. This similar to what has been reported in other studies people with blood cancer; the importance of social support, family and friends, and engaging in activities and remaining social^{89,145,149}, others the importance of routine, normality, keeping busy and distracted^{89,135,145,149}, and of mindfulness, spirituality and accepting their condition Koll, #1166;Crowder, #1156;Hermann, #1082;Maatouk, #1085;Raphael, #1111}. People with blood cancer described the importance of adhering to their treatment, seeking medical attention, and being informed about their condition Crowder, #1156;Andres-Jensen, 2020 #1048;Raphael, #1111;Hermann, #1082;Koll, #1166}, and others had made lifestyle changes including diet, exercise, reducing alcohol and quitting smoking to maintain mental and physical health^{116,145,150}.

Burden

Well, probably not not as much now as it was. I mean it definitely was when I was was really unwell because they had to do everything. Now it's more just I suppose they've got that extra burden of they've just got to make sure that they don't get me sick or. That sort of thing, just just being more careful with with those things. So I have to remind them and I have to make sure and say okay, yeah, well, yes, we know we've been vaccinated for chicken pox, but they could still get it slightly and pass it on to me. So I have to be very aware of that. But I'm not a burden now in that, yeah, I cook, I cook, I cook the meals, I clean the house. I yeah. Go with my husband for his appointment. So I do whatever. So I'm I'm sort of almost almost normal, just with just the fact that I'm more tired and have to be a bit more cautious with stuff.

Participant 006_2023AUCRT

The majority of participants in this PEEK study felt that their condition was a burden on their family, for some, this was temporary or only during treatment. For others, the burden was from the mental and emotional strain placed on their family, and the extra household duties and responsibilities that their family must take on. Likewise, other studies describe the emotional impact on family^{89,146}, and the extra responsibilities others took on and having to rely on others^{140,146}. In one study, participants noted that they did not want to be a burden and worried about being able to look after themselves⁸⁷.

Relationships

I don't think so. They, my siblings worry like crazy and. Some of our friends do worry, no matter how I try to assure them not to. So it's that's nice. Sometimes it's it's too much. But the attention. But I keep saying I'm not going to die, I'm not going to die. I'll let you know if I'm going to die. My brother-in-law had Hodgkin's died last year from really the side effects of all the treatments he had 40 years ago. Years ago, his heart gave out, his arteries, gave out everything just but he had a good life and he was well all that time. So yeah, it's it's nice that that they care so much.

Participant 036_2023AUCRT

PEEK participants described a mix of positive and negative impacts on relationships as a result of their diagnosis. Positive impacts included family relationships being strengthened, and well-meaning and supportive relationships. Negative impacts were from dynamics of relationships changing due to anxiety, exacerbations or physical limitations of condition, and from suffering, that is people not knowing what to say or do and withdrawing from relationships. In other studies, people with blood cancer described the negative impact that blood cancer had on their relationships. This was from people being dismissive or not understanding their condition, especially when in remission^{69,116}, being socially isolated because of treatments, side effects and risk of infections^{71,88,116,138,146}, not being able to fully participate in family life¹³⁸, and the financial impact¹⁰². Some described that their condition had brought their family and relationships closer together¹⁰².

References

1. Australian Institute of Health and Welfare. (2023). Cancer data in Australia. Retrieved from <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia>.
2. Merollini KMD, Gordon LG, Ho YM, Aitken JF, Kimlin MG. Cancer Survivors' Long-Term Health Service Costs in Queensland, Australia: Results of a Population-Level Data Linkage Study (Cos-Q). *Int J Environ Res Public Health* 2022; **19**(15).
3. Australian Bureau of Statistics, 2016, Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia, 2016, 'Postal Area, Indexes, SEIFA 2016 ', data cube: Excel spreadsheet, cat. no. 2033.0.55.001, viewed 24 October 2019, <https://www.abs.gov.au/AUSSTATS>.
4. Australian Bureau of Statistics. (2020). Regional population, 2018-19 financial year. Retrieved March 4, 2021, from <https://www.abs.gov.au/statistics/people/population/regional-population/2018-19>.
5. Australian Bureau of Statistics. (2020). National, state and territory population, June, 2020. Retrieved March 4, 2021, from <https://www.abs.gov.au/statistics/people/population/national-state-and-territory-population/jun-2020>.
6. Australian Bureau of Statistics 2017-18 National Health Survey (NHS). Accessed from <https://www.abs.gov.au/statistics/health/health-conditions-and-risks/national-health-survey-first-results/latest-release>.
7. Marte C, George LS, Rutherford SC, et al. Unmet mental health needs in patients with advanced B-cell lymphomas. *Palliat Support Care* 2022; **20**(3): 328-33.
8. Damen MDC, Westerweel PE, Levin MD, Pelle AJ. Unmet supportive care needs, anxiety and depression in haematology patients during watch-and-wait. *Psychooncology* 2022; **31**(2): 176-84.
9. Brice L, McErlean G, Donovan C, et al. Fear of cancer recurrence following allogeneic haematopoietic stem cell transplantation (HSCT) for haematological malignancy: A cross-sectional study. *Eur J Oncol Nurs* 2020; **49**: 101845.
10. Bellali T, Manomenidis G, Meramveliotaki E, Minasidou E, Galanis P. The impact of anxiety and depression in the quality of life and psychological well-being of Greek hematological cancer patients on chemotherapy. *Psychol Health Med* 2020; **25**(2): 201-13.
11. Castelli L, Elter T, Wolf F, et al. Sleep problems and their interaction with physical activity and fatigue in hematological cancer patients during onset of high dose chemotherapy. *Support Care Cancer* 2022; **30**(1): 167-76.
12. Maatouk I, He S, Hummel M, et al. Patients with precursor disease exhibit similar psychological distress and mental HRQOL as patients with active myeloma. *Blood Cancer J* 2019; **9**(2): 9.
13. Jespersen E, Nielsen LK, Larsen RF, Moller S, Jarlbaek L. Everyday living with pain - reported by patients with multiple myeloma. *Scand J Pain* 2021; **21**(1): 127-34.
14. Lennmyr EB, Karlsson K, Abrahamsson M, et al. Introducing patient-reported outcome in the acute leukemia quality registries in Sweden. *Eur J Haematol* 2020; **104**(6): 571-80.
15. Posluszny DM, Bovbjerg DH, Syrjala KL, Agha M, Dew MA. Correlates of anxiety and depression symptoms among patients and their family caregivers prior to allogeneic hematopoietic cell transplant for hematological malignancies. *Support Care Cancer* 2019; **27**(2): 591-600.
16. Ullrich CK, Baker KK, Carpenter PA, et al. Fatigue in Hematopoietic Cell Transplantation Survivors: Correlates, Care Team Communication, and Patient-Identified Mitigation Strategies. *Transplant Cell Ther* 2023; **29**(3): 200 e1- e8.
17. Park SY, Kim Y, Hong H. Patient-reported distress and problems among elderly patients with hematological malignancy in Korea. *Support Care Cancer* 2022; **30**(11): 9019-27.
18. 36-Item Short Form Survey (SF-36) Scoring Instructions. n.d. https://www.rand.org/health/surveys_tools/mos/36-item-short-form/scoring.html (accessed 10 February 2017).
19. Nathwani N, Bell J, Cherepanov D, et al. Patient perspectives on symptoms, health-related quality of life, and treatment experience associated with relapsed/refractory multiple myeloma. *Support Care Cancer* 2022; **30**(7): 5859-69.

20. Jean-Baptiste M, Gries KS, Lenderking WR, Fastenau J. Symptom burden and health-related quality of life impacts of smoldering multiple myeloma: the patient perspective. *J Patient Rep Outcomes* 2020; **4**(1): 95.
21. Ficko SL, Pejša V, Zadnik V. Health-related quality of life in Croatian general population and multiple myeloma patients assessed by the EORTC QLQ-C30 and EORTC QLQ-MY20 questionnaires. *Radiol Oncol* 2019; **53**(3): 337-47.
22. Australian Bureau of Statistics 1995, National Health Survey: SF36 Population Norms, Australia, 1995. cat. no. 4399.0, ABS, Canberra.
23. LeBlanc MR, Bryant AL, LeBlanc TW, et al. A cross-sectional observational study of health-related quality of life in adults with multiple myeloma. *Support Care Cancer* 2022; **30**(6): 5239-48.
24. Wu NL, Phipps AI, Krull KR, et al. Long-term patient-reported neurocognitive outcomes in adult survivors of hematopoietic cell transplant. *Blood Adv* 2022; **6**(14): 4347-56.
25. Esser P, Kuba K, Mehnert A, et al. Quality of life in survivors of hematological malignancies stratified by cancer type, time since diagnosis and stem cell transplantation. *Eur J Haematol* 2018; **101**(3): 340-8.
26. Aili K, Arvidsson S, Nygren JM. Health related quality of life and buffering factors in adult survivors of acute pediatric lymphoblastic leukemia and their siblings. *Health Qual Life Outcomes* 2021; **19**(1): 55.
27. Gotze H, Kohler N, Taubenheim S, Lordick F, Mehnert A. Polypharmacy, limited activity, fatigue and insomnia are the most frequent symptoms and impairments in older hematological cancer survivors (70+): Findings from a register-based study on physical and mental health. *J Geriatr Oncol* 2019; **10**(1): 55-9.
28. Hutchinson AD, Thompson E, Loft N, Lewis I, Wilson C, Yong ASM. Cognitive late effects following allogeneic stem cell transplantation in haematological cancer patients. *Eur J Cancer Care (Engl)* 2021; **30**(5): e13448.
29. Ruark J, Mullane E, Cleary N, et al. Patient-Reported Neuropsychiatric Outcomes of Long-Term Survivors after Chimeric Antigen Receptor T Cell Therapy. *Biol Blood Marrow Transplant* 2020; **26**(1): 34-43.
30. Pemberton-Whiteley Z, Nier S, Geissler J, et al. Understanding Quality of Life in Patients With Acute Leukemia, a Global Survey. *J Patient Cent Res Rev* 2023; **10**(1): 21-30.
31. Coughlin SS, Ayyala DN, Stewart JL, Cortes JE. Social needs and health-related quality of life among hematologic cancer survivors. *Support Care Cancer* 2022; **30**(11): 8919-25.
32. Brice L, Gilroy N, Dyer G, et al. Predictors of quality of life in allogeneic hematopoietic stem cell transplantation survivors. *J Psychosoc Oncol* 2021; **39**(4): 534-52.
33. Cheon J, Lee YJ, Jo JC, et al. Late complications and quality of life assessment for survivors receiving allogeneic hematopoietic stem cell transplantation. *Support Care Cancer* 2021; **29**(2): 975-86.
34. Geue K, Gotze H, Friedrich M, et al. Perceived social support and associations with health-related quality of life in young versus older adult patients with haematological malignancies. *Health Qual Life Outcomes* 2019; **17**(1): 145.
35. Georges GE, Bar M, Onstad L, et al. Survivorship after Autologous Hematopoietic Cell Transplantation for Lymphoma and Multiple Myeloma: Late Effects and Quality of Life. *Biol Blood Marrow Transplant* 2020; **26**(2): 407-12.
36. Osaki K, Morishita S, Takami S, et al. Quality of life of patients with hematological malignancies and factors affecting health state utility values. *Support Care Cancer* 2022; **30**(6): 5319-27.
37. Kamal M, Wang XS, Shi Q, et al. Symptom burden and its functional impact in patients with "symptomatic" relapsed or refractory multiple myeloma. *Support Care Cancer* 2021; **29**(1): 467-75.
38. Corella Aznar EG, Ayerza Casas A, Carbone Baneres A, Calvo Escribano MAC, Labarta Aizpun JI, Samper Villagrasa P. Quality of life and chronic health conditions in childhood acute leukaemia survivors. *Med Clin (Barc)* 2019; **152**(5): 167-73.
39. Paunescu AC, Copie CB, Malak S, et al. Quality of life of survivors 1 year after the diagnosis of diffuse large B-cell lymphoma: a LYSA study. *Ann Hematol* 2022; **101**(2): 317-32.
40. Meier C, Taubenheim S, Lordick F, Mehnert-Theuerkauf A, Gotze H. Depression and anxiety in older patients with hematological cancer (70+) - Geriatric, social, cancer- and

treatment-related associations. *J Geriatr Oncol* 2020; **11**(5): 828-35.

41. Lepretre S, Touboul C, Flinois A, et al. Quality of life in adults with acute lymphoblastic leukemia in France: results from a French cross-sectional study. *Leuk Lymphoma* 2021; **62**(12): 2957-67.

42. Kim SH, Kim I, Koh Y, Shin D, Hong J, Seo KS. The importance of physical function in patients with multiple myeloma for improving quality of life. *Support Care Cancer* 2020; **28**(5): 2361-7.

43. Fukushima T, Nakano J, Ishii S, et al. Influence of Hemoglobin Level on Muscle and Physical Functions, Activities of Daily Living, and Quality of Life in Patients With Hematological Malignancies. *Integr Cancer Ther* 2019; **18**: 1534735419842196.

44. Kang HY, Choi EY. Factors influencing quality of life in patients with multiple myeloma. *Contemp Nurse* 2019; **55**(2-3): 109-21.

45. Papathanasiou IV, Kelepouris K, Valari C, et al. Depression, anxiety and stress among patients with hematological malignancies and the association with quality of life: a cross-sectional study. *Med Pharm Rep* 2020; **93**(1): 62-8.

46. Senf B, Grabowski K, Spielmann N, Fettel J. Quality of life and distress assessed with self and external assessment screening tools in patients with hematologic malignancies attending treatment in an acute hospital. *Qual Life Res* 2020; **29**(12): 3375-85.

47. Zaleta AK, Miller MF, Olson JS, et al. Symptom Burden, Perceived Control, and Quality of Life Among Patients Living With Multiple Myeloma. *J Natl Compr Canc Netw* 2020; **18**(8): 1087-95.

48. Suzuki N, Okuyama T, Akechi T, et al. Symptoms and health-related quality of life in patients with newly diagnosed multiple myeloma: a multicenter prospective cohort study. *Jpn J Clin Oncol* 2022; **52**(2): 163-9.

49. Ramsenthaler C, Gao W, Siegert RJ, Edmonds PM, Schey SA, Higginson IJ. Symptoms and anxiety predict declining health-related quality of life in multiple myeloma: A prospective, multi-centre longitudinal study. *Palliat Med* 2019; **33**(5): 541-51.

50. Ludwig H, Bailey AL, Marongiu A, et al. Patient-reported pain severity and health-related quality of life in patients with multiple myeloma in

real world clinical practice. *Cancer Rep (Hoboken)* 2022; **5**(1): e1429.

51. Hofer F, Koinig KA, Nagl L, Borjan B, Stauder R. Fatigue at baseline is associated with geriatric impairments and represents an adverse prognostic factor in older patients with a hematological malignancy. *Ann Hematol* 2018; **97**(11): 2235-43.

52. Marriott CJC, Beaumont LF, Farncombe TH, et al. Body composition in long-term survivors of acute lymphoblastic leukemia diagnosed in childhood and adolescence: A focus on sarcopenic obesity. *Cancer* 2018; **124**(6): 1225-31.

53. Micas Pedersen S, Nielsen TH, Gang AO, et al. Sexual dysfunction is highly prevalent in male survivors of malignant lymphoma. *Sex Med* 2023; **11**(2): qfad021.

54. Sleurs C, Musoro J, Rowsell A, et al. Sociodemographic and Medical Determinants of Quality of Life in Long-Term Childhood Acute Lymphoblastic Leukemia Survivors Enrolled in EORTC CLG Studies. *Cancers (Basel)* 2021; **14**(1).

55. Jensen CE, Vohra SN, Nyrop KA, et al. Physical Function, Psychosocial Status, and Symptom Burden Among Adults with Plasma Cell Disorders and Associations with Quality of Life. *Oncologist* 2022; **27**(8): 694-702.

56. O'Donnell EK, Shapiro YN, Yee AJ, et al. Quality of life, psychological distress, and prognostic perceptions in patients with multiple myeloma. *Cancer* 2022; **128**(10): 1996-2004.

57. Trevino KM, Martin P, Chen Z, Leonard JP. Worsening Quality of Life in Indolent Non-Hodgkin Lymphoma and Chronic Lymphocytic Leukemia Patients in Active Surveillance: A 12-Month Longitudinal Study. *Clin Lymphoma Myeloma Leuk* 2022; **22**(2): 82-8.

58. Engelhardt M, Ihorst G, Singh M, et al. Real-World Evaluation of Health-Related Quality of Life in Patients With Multiple Myeloma From Germany. *Clin Lymphoma Myeloma Leuk* 2021; **21**(2): e160-e75.

59. Lindberg A, Eskelund CW, Albertsson-Lindblad A, et al. Pre-treatment health-related quality of life parameters have prognostic impact in patients >65 years with newly diagnosed mantle cell lymphoma: The Nordic Lymphoma Group MCL4 (LENA-BERIT) experience. *Hematol Oncol* 2022; **40**(1): 22-30.

60. Chantziara S, Musoro J, Rowsell AC, et al. Quality of life of long-term childhood acute lymphoblastic leukemia survivors: Comparison with healthy controls. *Psychooncology* 2022; **31**(12): 2159-68.
61. Wright R, Oremek M, Davies D, et al. Quality of Life following Allogeneic Stem Cell Transplantation for Patients Age >60 Years with Acute Myelogenous Leukemia. *Biol Blood Marrow Transplant* 2020; **26**(8): 1527-33.
62. Strouse CS, Larson MC, Ehlers SL, et al. Long-Term Health-Related Quality of Life of Autologous Hematopoietic Cell Transplantation Patients and Nontransplant Patients With Aggressive Lymphoma: A Prospective Cohort Analysis. *JCO Oncol Pract* 2022; **18**(7): e1069-e80.
63. Lohmann B, Kuba K, Gotze H, Mehnert-Theuerkauf A, Heyne S, Esser P. Partnership, sexuality, and fertility-related communication: findings from a register-based study among long-term hematological cancer survivors. *Support Care Cancer* 2022; **31**(1): 26.
64. Servadio M, Cottone F, Sommer K, Oerlemans S, van de Poll-Franse L, Efficace F. Physical activity and health-related quality of life in multiple myeloma survivors: the PROFILES registry. *BMJ Support Palliat Care* 2020; **10**(4): e35.
65. He J, Duenas A, Collacott H, et al. Patient Perceptions Regarding Multiple Myeloma and Its Treatment: Qualitative Evidence from Interviews with Patients in the United Kingdom, France, and Germany. *Patient* 2021; **14**(5): 613-23.
66. Stamm SL, Spichiger E, Pabst T, Bachnick S, Jeitziner MM. Symptom prevalence and health-related quality of life in patients undergoing autologous stem cell transplantation - A longitudinal observational study. *Eur J Oncol Nurs* 2021; **53**: 101997.
67. Nicol JL, Woodrow C, Burton NW, et al. Physical Activity in People with Multiple Myeloma: Associated Factors and Exercise Program Preferences. *J Clin Med* 2020; **9**(10).
68. Quinn B, Ludwig H, Bailey A, et al. Physical, emotional and social pain communication by patients diagnosed and living with multiple myeloma. *Pain Manag* 2022; **12**(1): 59-74.
69. Cuffe CH, Quirke MB, McCabe C. Patients' experiences of living with multiple myeloma. *Br J Nurs* 2020; **29**(2): 103-10.
70. Shaheen NA, Alqahtani M, Alawbthani NS, Thomas A, Alaskar A. Chemotherapy-Induced Peripheral Neuropathy and its Impact on Health-Related Quality of Life among Multiple Myeloma Patients: A Single-Center Experience. *Indian J Palliat Care* 2020; **26**(4): 506-11.
71. Crawford R, Gries KS, Valluri S, et al. The patient experience of relapsed refractory multiple myeloma and perspectives on emerging therapies. *Cancer Rep (Hoboken)* 2022; **5**(11): e1603.
72. Howell DA, Hart RI, Smith AG, Macleod U, Patmore R, Roman E. Disease-related factors affecting timely lymphoma diagnosis: a qualitative study exploring patient experiences. *Br J Gen Pract* 2019; **69**(679): e134-e45.
73. Vena JA, Copel L, McDermott-Levy R. Lived Experiences of Young Adults With Lymphoma During Acute Survivorship. *Cancer Nurs* 2023; **46**(1): E11-E20.
74. Howell DA, McCaughan D, Smith AG, Patmore R, Roman E. Incurable but treatable: Understanding, uncertainty and impact in chronic blood cancers-A qualitative study from the UK's Haematological Malignancy Research Network. *PLoS One* 2022; **17**(2): e0263672.
75. Bennink C, van der Klift M, Scheurer H, Sonneveld P, Duijts SFA. Perspectives on returning to work of multiple myeloma patients: A qualitative interview study. *Eur J Cancer Care (Engl)* 2021; **30**(6): e13481.
76. Lewis SA, Noyes J, Mackereth S. Knowledge and information needs of young people with epilepsy and their parents: Mixed-method systematic review. *BMC Pediatr* 2010; **10**: 103.
77. Zahradnik A. Asthma education information source preferences and their relationship to asthma knowledge. *J Health Hum Serv Adm* 2011; **34**(3): 325-51.
78. Attfield SJ, Adams A, Blandford A. Patient information needs: pre- and post-consultation. *Health Informatics J* 2006; **12**(2): 165-77.
79. Schulz GB, Grimm T, Buchner A, et al. Benefits and Complications during the Stay at an Early Rehabilitation Facility after Radical Cystectomy and Orthotopic Ileum Neobladder Reconstruction. *Urol Int* 2019; **103**(3): 350-6.
80. Roddis JK, Holloway I, Bond C, Galvin KT. Living with a long-term condition: Understanding well-being for individuals with thrombophilia or

asthma. *Int J Qual Stud Health Well-being* 2016; **11**: 31530.

81. Janssens R, Lang T, Vallejo A, et al. Patient Preferences for Multiple Myeloma Treatments: A Multinational Qualitative Study. *Front Med (Lausanne)* 2021; **8**: 686165.

82. Herrmann A, Mansfield E, Tzelepis F, Lynagh M, Hall A. Use of the supportive care framework to explore haematological cancer survivors' unmet needs: a qualitative study. *BMC Health Serv Res* 2020; **20**(1): 1062.

83. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsy JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; **284**(19): 2476-82.

84. Barnes S, Gardiner C, Gott M, et al. Enhancing patient-professional communication about end-of-life issues in life-limiting conditions: a critical review of the literature. *J Pain Symptom Manage* 2012; **44**(6): 866-79.

85. Fellowes D, Wilkinson S, Moore P. Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database Syst Rev* 2004; (2): CD003751.

86. Lamore K, Montalescot L, Untas A. Treatment decision-making in chronic diseases: What are the family members' roles, needs and attitudes? A systematic review. *Patient Educ Couns* 2017; **100**(12): 2172-81.

87. McCaughan D, Roman E, Sheridan R, et al. Patient perspectives of 'Watch and Wait' for chronic haematological cancers: Findings from a qualitative study. *Eur J Oncol Nurs* 2023; **65**: 102349.

88. Parsons JA, Greenspan NR, Baker NA, McKillop C, Hicks LK, Chan O. Treatment preferences of patients with relapsed and refractory multiple myeloma: a qualitative study. *BMC Cancer* 2019; **19**(1): 264.

89. Hermann M, Kuhne F, Rohmoser A, Preisler M, Goerling U, Letsch A. Perspectives of patients with multiple myeloma on accepting their prognosis-A qualitative interview study. *Psychooncology* 2021; **30**(1): 59-66.

90. Griffin SJ, Kinmonth AL, Veltman MW, Gillard S, Grant J, Stewart M. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners: a

systematic review of trials. *Ann Fam Med* 2004; **2**(6): 595-608.

91. Wetzels R, Harmsen M, Van Weel C, Grol R, Wensing M. Interventions for improving older patients' involvement in primary care episodes. *Cochrane Database Syst Rev* 2007; (1): CD004273.

92. Mian O, Puts M, McCurdy A, et al. Decision-making factors for an autologous stem cell transplant for older adults with newly diagnosed multiple myeloma: A qualitative analysis. *Front Oncol* 2022; **12**: 974038.

93. Loh KP, Xu H, Back A, et al. Patient-hematologist discordance in perceived chance of cure in hematologic malignancies: A multicenter study. *Cancer* 2020; **126**(6): 1306-14.

94. Fifer SJ, Ho KA, Lybrand S, Axford LJ, Roach S. Alignment of preferences in the treatment of multiple myeloma - a discrete choice experiment of patient, carer, physician, and nurse preferences. *BMC Cancer* 2020; **20**(1): 546.

95. Eriksson J, Landfeldt E, Ireland S, Jackson C, Wyatt E, Gaudig M. Stated preferences for relapsed or refractory mantle cell lymphoma treatments in Sweden and Germany. *Future Oncol* 2020; **16**(13): 859-68.

96. Ashaye A, Thomas C, Dalal M, et al. Patient preferences for frontline therapies for Philadelphia chromosome-positive acute lymphoblastic leukemia: a discrete choice experiment. *Future Oncol* 2022; **18**(17): 2075-85.

97. Foster J, Moore H, Preussler JM, et al. Information Needs for Treatment Decision-making of Hematopoietic Cell Transplant Patients 65 Years or Older and Caregivers. *J Cancer Educ* 2020; **35**(4): 651-60.

98. Ribbands A, Boytsov N, Bailey A, Gorsh B, Luke E, Lambert A. Drivers of physician decision-making and patient perspectives across lines of therapy in multiple myeloma in the USA. *Future Oncol* 2023; **19**(22): 1549-62.

99. Dombeck C, Swezey T, Gonzalez Sepulveda JM, et al. Patient perspectives on considerations, tradeoffs, and experiences with multiple myeloma treatment selection: a qualitative descriptive study. *BMC Cancer* 2023; **23**(1): 65.

100. Wilke T, Mueller S, Bauer S, et al. Treatment of relapsed refractory multiple myeloma: which new PI-based combination treatments do patients prefer? *Patient Prefer Adherence* 2018; **12**: 2387-96.

101. Fiala MA, Vij R, Wildes TM. A Mixed-Methods Study of Stem Cell Transplantation Utilization for Newly Diagnosed Multiple Myeloma. *Clin Lymphoma Myeloma Leuk* 2019; **19**(9): e521-e5.
102. LeBlanc MR, LeBlanc TW, Leak Bryant A, Pollak KI, Bailey DE, Smith SK. A Qualitative Study of the Experiences of Living With Multiple Myeloma. *Oncol Nurs Forum* 2021; **48**(2): 151-60.
103. Jackson G, Galinsky J, Alderson DEC, et al. Productivity losses in patients with newly diagnosed multiple myeloma following stem cell transplantation and the impact of maintenance therapy. *Eur J Haematol* 2019; **103**(4): 393-401.
104. Devilli L, Garonzi C, Balter R, et al. Long-term and quality of survival in patients treated for acute lymphoblastic leukemia during the pediatric age. *Hematol Rep* 2021; **13**(1): 8847.
105. Wilson M, Thavorn K, Hawrysh T, et al. Engaging Patients and Caregivers in an Early Health Economic Evaluation: Discerning Treatment Value Based on Lived Experience. *Pharmacoeconomics* 2022; **40**(11): 1119-30.
106. Doyle C, Kushi LH, Byers T, et al. Nutrition and physical activity during and after cancer treatment: an American Cancer Society guide for informed choices. *CA Cancer J Clin* 2006; **56**(6): 323-53.
107. Chelf JH, Agre P, Axelrod A, et al. Cancer-related patient education: an overview of the last decade of evaluation and research. *Oncol Nurs Forum* 2001; **28**(7): 1139-47.
108. Roberts D, McNulty A, Caress AL. Current issues in the delivery of complementary therapies in cancer care--policy, perceptions and expectations: an overview. *Eur J Oncol Nurs* 2005; **9**(2): 115-23.
109. Oh B, Butow P, Mullan B, et al. The use and perceived benefits resulting from the use of complementary and alternative medicine by cancer patients in Australia. *Asia Pac J Clin Oncol* 2010; **6**(4): 342-9.
110. Beatty LJ, Adams J, Sibbritt D, Wade TD. Evaluating the impact of cancer on complementary and alternative medicine use, distress and health related QoL among Australian women: a prospective longitudinal investigation. *Complement Ther Med* 2012; **20**(1-2): 61-9.
111. Molassiotis A, Xu M. Quality and safety issues of web-based information about herbal medicines in the treatment of cancer. *Complement Ther Med* 2004; **12**(4): 217-27.
112. Kim C, Armstrong MJ, Berta WB, Gagliardi AR. How to identify, incorporate and report patient preferences in clinical guidelines: A scoping review. *Health Expect* 2020; **23**(5): 1028-36.
113. Cronin RM, Mayo-Gamble TL, Stimpson SJ, et al. Adapting medical guidelines to be patient-centered using a patient-driven process for individuals with sickle cell disease and their caregivers. *BMC Hematol* 2018; **18**: 12.
114. Sleath B, Carpenter DM, Slota C, et al. Communication during pediatric asthma visits and self-reported asthma medication adherence. *Pediatrics* 2012; **130**(4): 627-33.
115. Ross CK, Steward CA, Sinacore JM. The importance of patient preferences in the measurement of health care satisfaction. *Med Care* 1993; **31**(12): 1138-49.
116. Andres-Jensen L, Larsen HB, Johansen C, Frandsen TL, Schmiegelow K, Wahlberg A. Everyday life challenges among adolescent and young adult survivors of childhood acute lymphoblastic leukemia: An in-depth qualitative study. *Psychooncology* 2020; **29**(10): 1630-7.
117. In: Adams K, Greiner AC, Corrigan JM, eds. The 1st Annual Crossing the Quality Chasm Summit: A Focus on Communities. Washington (DC); 2004.
118. Grande SW, Faber MJ, Durand MA, Thompson R, Elwyn G. A classification model of patient engagement methods and assessment of their feasibility in real-world settings. *Patient Educ Couns* 2014; **95**(2): 281-7.
119. Taylor SJC, Pinnock H, Epiphaniou E, et al. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS - Practical systematic Review of Self-Management Support for long-term conditions. Southampton (UK); 2014.
120. Ailawadhi S, Swaika A, Advani P, et al. Awareness of myeloma care and the global impact of treatment: An international internet-based prospective study. *J Oncol Pharm Pract* 2022; **28**(2): 425-33.
121. Blejec S, Cytryn R, Yagnik R, Bickell NA, Lin JJ. Facilitators of Multiple Myeloma Treatment: A Qualitative Study. *Oncol Nurs Forum* 2023; **50**(3): 372-80.

122. Bridges S, Fowler S, McLaughlin L, et al. How should multiple myeloma research change in a patient-oriented world? Findings and lessons from the pan-Canadian myeloma priority setting partnership. *Res Involv Engagem* 2023; **9**(1): 60.
123. Lamore K, Bourdeau C, Alos N, et al. Contributing Factors of Unmet Needs Among Young Adult Survivors of Childhood Acute Lymphoblastic Leukemia with Comorbidities. *J Adolesc Young Adult Oncol* 2021; **10**(4): 462-75.
124. Petkov J, Harvey P, Battersby M. The internal consistency and construct validity of the partners in health scale: validation of a patient rated chronic condition self-management measure. *Qual Life Res* 2010; **19**(7): 1079-85.
125. Simensen VC, Smeland KB, Kiserud CE, et al. Survivors' knowledge of their diagnosis, treatment and possible late adverse effects after autologous stem cell transplantation for lymphoma. *Acta Oncol* 2019; **58**(9): 1315-22.
126. Williams S, Weinman J, Dale J. Doctor-patient communication and patient satisfaction: a review. *Fam Pract* 1998; **15**(5): 480-92.
127. Stewart M, Brown JB, Boon H, Galajda J, Meredith L, Sangster M. Evidence on patient-doctor communication. *Cancer Prev Control* 1999; **3**(1): 25-30.
128. Stewart M, Brown JB, Donner A, et al. The impact of patient-centered care on outcomes. *J Fam Pract* 2000; **49**(9): 796-804.
129. Glasgow RE, Davis CL, Funnell MM, Beck A. Implementing practical interventions to support chronic illness self-management. *Jt Comm J Qual Saf* 2003; **29**(11): 563-74.
130. Makoul G. Essential elements of communication in medical encounters: the Kalamazoo consensus statement. *Acad Med* 2001; **76**(4): 390-3.
131. Borregaard Myrholm C, Novrup Clemmensen S, Sax Rogind S, Jarden M, Toudal Viftrup D. Serious illness conversations in patients with multiple myeloma and their family caregivers-A qualitative interview study. *Eur J Cancer Care (Engl)* 2022; **31**(1): e13537.
132. Young JM, Walsh J, Butow PN, Solomon MJ, Shaw J. Measuring cancer care coordination: development and validation of a questionnaire for patients. *BMC Cancer* 2011; **11**: 298.
133. Farias AJ, Ornelas IJ, Hohl SD, et al. Exploring the role of physician communication about adjuvant endocrine therapy among breast cancer patients on active treatment: a qualitative analysis. *Support Care Cancer* 2017; **25**(1): 75-83.
134. Salgado TM, Quinn CS, Krumbach EK, et al. Reporting of paclitaxel-induced peripheral neuropathy symptoms to clinicians among women with breast cancer: a qualitative study. *Support Care Cancer* 2020; **28**(9): 4163-72.
135. Raphael D, Frey R, Gott M. The nature and timing of distress among post-treatment haematological cancer survivors. *Eur J Cancer Care (Engl)* 2019; **28**(1): e12951.
136. Pulewka K, Strauss B, Hochhaus A, Hilgendorf I. Clinical, social, and psycho-oncological needs of adolescents and young adults (AYA) versus older patients following hematopoietic stem cell transplantation. *J Cancer Res Clin Oncol* 2021; **147**(4): 1239-46.
137. Nakajima S, Kamibeppu K. Quality of life and informational needs for allogeneic hematopoietic stem cell transplant among patients and their caregivers visiting long-term follow-up clinic. *Blood Cell Ther* 2022; **5**(2): 35-44.
138. Panjwani AA, Marin-Chollom AM, Pervil IZ, et al. Illness Uncertainties Tied to Developmental Tasks Among Young Adult Survivors of Hematologic Cancers. *J Adolesc Young Adult Oncol* 2019; **8**(2): 149-56.
139. Amonoo HL, Harnedy LE, Deary EC, et al. Peer support in patients with hematologic malignancies undergoing hematopoietic stem cell transplantation (HSCT): a qualitative study. *Bone Marrow Transplant* 2022; **57**(8): 1277-86.
140. Henckel C, Revette A, Huntington SF, Tulsy JA, Abel GA, Odejide OO. Perspectives Regarding Hospice Services and Transfusion Access: Focus Groups With Blood Cancer Patients and Bereaved Caregivers. *J Pain Symptom Manage* 2020; **59**(6): 1195-203 e4.
141. Barata A, Abrams HR, Meyer C, et al. What do patients think about palliative care? A national survey of hematopoietic stem cell transplant recipients. *Blood Adv* 2023; **7**(10): 2032-41.
142. DeJean D, Giacomini M, Vanstone M, Brundisini F. Patient experiences of depression and anxiety with chronic disease: a systematic review and qualitative meta-synthesis. *Ont Health Technol Assess Ser* 2013; **13**(16): 1-33.
143. Hinz A, Mehnert A, Ernst J, Herschbach P, Schulte T. Fear of progression in patients 6 months

after cancer rehabilitation-a- validation study of the fear of progression questionnaire FoP-Q-12. *Support Care Cancer* 2015; **23**(6): 1579-87.

144. Mayo SJ, Brennenstuhl S, Panesar P, Bryant AL. Patterns of Concerns Among Hematological Cancer Survivors. *Cancer Nurs* 2022; **45**(6): 447-56.

145. Crowder SL, Sauls R, Redwine L, et al. Mindfulness in Adolescent and Young Adult (AYA) Patients Undergoing Hematopoietic Stem Cell Transplantation (HSCT): A Qualitative Study. *Cancers (Basel)* 2022; **14**(11).

146. Cheng R, Scippa K, Locke FL, Snider JT, Jim H. Patient Perspectives on Health-Related Quality of Life in Diffuse Large B-Cell Lymphoma Treated with Car T-Cell Therapy: A Qualitative Study. *Oncol Ther* 2022; **10**(1): 123-41.

147. Richter J, Sanchez L, Biran N, et al. Prevalence and Survival Impact of Self-Reported Symptom and Psychological Distress Among Patients With Multiple Myeloma. *Clin Lymphoma Myeloma Leuk* 2021; **21**(3): e284-e9.

148. Bates-Fraser LC, Mills J, Mihos P, et al. "A lot to manage and still have some kind of a life": How multiple myeloma impacts the function and quality-of-life of Black-White patient-caregiver dyads. *J Am Geriatr Soc* 2023.

149. Koll TT, Semin JN, Coburn RA, et al. Returning to life activities after hematopoietic cell transplantation in older adults. *J Geriatr Oncol* 2020; **11**(2): 304-10.

150. Colton A, Smith MA, Broadbent S, Rune KT, Wright HH. Perceptions of Older Adults with Hematological Cancer on Diet and Exercise Behavior and Its Role in Navigating Daily Tasks. *Int J Environ Res Public Health* 2022; **19**(22).