Section 1

Introduction and methods

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Introduction

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 100,000[1]. Blood cancer was diagnosed more often in men, with 9687 males diagnosed in 2019 compared to 7348 females[1]. The most common type of blood cancer in Australia is non-Hodgkin lymphoma followed by multiple myeloma and chronic lymphocytic leukaemia[1], with those treatable with CAR-T therapy including B-cell acute lymphoblastic leukemia (B-ALL), Diffuse Large B-Cell Lymphoma (DLBCL) and multiple myeloma.

Collectively, blood cancer is 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 67.2[1].

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 older[1].

Blood cancers have high hospitalisation and pharmaceutical costs, with myeloma and leukaemia rated in the top three most expensive cancers to treat in Australia[2].

Personal Experience, Expectations and Knowledge (PEEK)

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.

The research protocol used in PEEK studies is independently driven by CCDR. PEEK studies include a quantitative and qualitative component. The quantitative component is based on a series of validated tools. The qualitative component is the result of two years of protocol testing by CCDR to develop a structured interview that solicits patient experience data and provides patients with the opportunity to provide advice on what they would like to see in relation to future treatment, information and care. The structured interview has also been designed so that the outcomes of PEEK studies can inform policy, research, care, information, supportive care services and advocacy efforts.

Position of this study

A search was conducted in Pubmed (June 12, 2023) to identify studies of blood cancer with patient reported outcomes, or patient experience conducted in the past two years worldwide. Interventional studies, meta-analysis studies, studies with children, studies conducted in developing countries, and studies of less than five participants were excluded. There were 65 studies identified of between 8 and 1861 lung cancer participants. A single study was conducted in Australia, where 13 participants were interviewed about treatment and management.

In this PEEK study 37 participants completed surveys and 33 participants completed interviews, making this one of the largest studies interviewing participants about blood cancer. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Introduction

Background

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Participants

To be eligible for the study, participants needed to have been diagnosed with a **blood cancer that is treatable by CAR-T therapy**, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study.

Ethics

Ethics approval for this study was granted (as a low or negligible risk research study) by the Centre for Community-Driven Research Ethics Committee (Reference CS_Q4_03).

Data collection

Data for the online questionnaire was collected using Zoho Survey (Zoho Corporation Pvt. Ltd. Pleasanton, California, USA, www.zoho.com/survey).

There were five researchers who conducted telephone interviews and used standardised prompts throughout the interview. The interviews were recorded and transcribed verbatim. Identifying names and locations were not included in the transcript. All transcripts were checked against the original recording for quality assurance.

Online questionnaire (quantitative)

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36) (RAND Health)[3], a modified Cancer Care Coordination Questionnaire for Patients (CCCQ)[4], the Short Fear of Progression Questionnaire (FOP12)[5], and the Partners in Health version 2 (PIH)[6]. In addition, investigator derived questions about demographics, diagnosis, treatment received and future treatment decisions making were included.

Structured Interview (qualitative)

Interviews were conducted via telephone by registered nurses who were trained in qualitative research. The first set of interview questions guided the patient through their whole experience from when symptoms were noticed up to the present day.

Questionnaire analysis

Statistical analysis was conducted using R included in the packages "car", "dplyr" and "ggplot2" (R 3.3.3 GUI 1.69 Mavericks build (7328). The aim of the statistical analysis of the SF36, CCCQ, FOP12, and PIH responses was to identify variations by blood cancer type, gender, age, location of residence, and socio-economic status. Scales and subscales were calculated according to reported instructions[3-6].

The Location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics[7].

The level of socio-economic status of participants was evaluated by postcode using the Socio-economic Indexes for Areas (SEIFA) accessed from the Australian Bureau of Statistics[8].

For comparisons by blood cancer type, a one-way analysis of variance (ANOVA) analysis was conducted. A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test. Where the assumptions for the one-way ANOVA were not met, a Kruskal-Wallis rank sum test on care was conducted with post-hoc pairwise comparisons using Wilcoxon rank sum test. When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances.

For all other comparisons between groups, a two-sample t-test was used when assumptions for normality and variance were met, or when assumptions were not met, a Wilcoxon rank sum test with continuity correction was used. Questions where participants were asked to rank preferences were analysed using weighted averages. Weights were applied in reverse, the most preferred option was given the largest weight equal to the number of options, the least preferred option was given the lowest weight of 1.

Structured interviews analysis

A content analysis was conducted using conventional analysis to identify major themes from structured interviews. Text from the interviews were read line-by-line by the lead researcher and then imported into a custom-built PEEK analysis database. Each question within the interview was individually analysed. Initial categories and definitions were identified and registered in the PEEK analysis database. The minimum coded unit was a sentence with paragraphs and phrases coded as a unit.

A second researcher verified the codes and definitions, and the text was coded until full agreement was reached using the process of consensual validation. Where a theme occurred less than 5 times it was not included in the study results, unless this result demonstrated a significant gap or unexpected result.

Data analysis and final reporting was completed in August 2023.

Position of this study

A search was conducted in Pubmed (June 12, 2023) to identify studies of blood cancer with patient reported outcomes, or patient experience conducted in the past two years worldwide (Table 1.1). Interventional studies, meta-analysis studies, studies with children, studies conducted in developing countries, and studies of less than five participants were excluded. There were 65 studies identified of between 8 and 1861 lung cancer participants.

There were 19 studies that collected information by interview of between 8 and 72 participants. There were 6 studies focused on quality of life[9-14], 6 studies focused on treatment and management[15-20], 5 studies that focused on decision making[21-25], a single study that focused on care and support[26], and a single study that focused on information and communication[27].

There were 2 studies that collected information by focus group, on study of 18 participants was focused on quality of life[28], and one study of 8 participants was focused on decision making[29].

There were 44 studies that collected data by survey of between 15 and 1861 participants.There were 30 studies focused on health-re;ated quality of life [30-58],
4 studies focused on quality of life[28,59-61],
4 studies focused on expectations[29,62-64],
3 studies focused on decision making[65-67],

3 studies focused on treatment and management[68-70], a single study focused on care and support[71], and a single study focused on information and communication[72]

A single study was conducted in Australia, where 13 participants were interviewed about treatment and management. In this PEEK study 37 participants completed surveys and 33 participants completed interviews, making this one of the largest studies interviewing participants about blood cancer. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Table 1.1: PEEK position

Author, year	Location	Interviews	Survey	Focus	PEEK Section							
					2: Health status, co-morbidities	3: Symptoms & Diagnosis	4: Decision making	5: Treatment & management	6: Information & communication	7: Care &support	8: Quality of life	9 Expectations
Hodge, 2022[15]	USA	72	72	Treatment and management	X			X				X
Bates-Fraser, 2023[9]	USA	21 (21 carers)	0	Quality of life							X	
Howell, 2022[27]	UK	35 (10 carers)	0	Information and communication		X			X		X	
McCaughan, 2023[16]	UK	35 (10 carers)	0	Treatment and management		X			X	X	X	
Blejec, 2023[21]	USA	29	0	Decision making			X	X	X	X		
Hoppe, 2022[10]	USA	28	0	Quality of life					X		X	X
Amonoo, 2022[26]	USA	25	0	Care and support						X		
Janssens, 2021[22]	Multinational	24	0	Decision making			X				X	
Borregaard Myrhøj, 2022[23]	Denmark	12 (11 Carers)	0	Decision making			X					
van Lieshout, 2022[17]	The Netherlands	23	0	Treatment and management				X				
Nathwani, 2022[11]	USA	22	0	Quality of life		X		X			X	
Dombeck, 2023[24]	USA	21	0	Decision making			X					
Crowder, 2022[12]	USA	20	0	Quality of life							X	
Crawford, 2022[13]	USA	20	0	Quality of life		X					X	X
Mian, 2023[25]	Canada	18	18	Decision making			X					
Bixby, 2023[18]	USA	18	0	Treatment and management				X				
Colton, 2022[19]	Australia	13	13	Treatment and management	X						X	
Booker, 2023[20]	Canada	8 (4 carers)	0	Treatment and management				X			X	
Vena, 2023[14]	USA	8	0	Quality of life		X			X	X	X	
Cheng, 2022[28]	USA	18*	0	Quality of life							X	

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Wilson, 2022[29]	Canada	8*	0	Decision making			X	X			X
Wu, 2022[30]	USA	0	1861	HRQOL	X						
Ullrich, 2023[31]	USA	0	1703	HRQOL	X						
Ullrich, 2023[31]	USA	0	1703	HRQOL	X						
Baum, 2023[71]	Germany	0	1551	Care and support	X					X	X
Mayo, 2022[59]	Canada	0	1160	Quality of life							X
Strouse, 2022[32]	USA	0	980	HRQOL							
Lohmann, 2022[33]	Germany	0	922	HRQOL	X						
Sharman, 2020[34]	USA	0	889	HRQOL	X						
LeBlanc, 2022[35]	USA	0	690	HRQOL	X						
Gatopoulou, 2022[36]	Multinational	0	514	HRQOL	X			X			
Bridges, 2023[62]	Canada	0	339 (73 carers)	Expectations							X
Janssens, 2022[63]	Multinational	0	393	Expectations							X
Ribbands, 2023[65]	USA	0	377	Decision making							
Ludwig, 2022[37]	Multinational	0	330	HRQOL	X	X					
Quinn, 2022[38]	Germany	0	330	HRQOL	X	X					
Tervonen, 2023[66]	Multinational	0	300	Decision making			X				
Barata, 2023[68]	USA	0	249	Treatment and management				X			X
Lepretre, 2021[39]	France	0	219	HRQOL	X			X			
Ashaye, 2022[67]	USA	0	201	Decision making			X				
Chantziara, 2022[40]	Multinational	0	186	HRQOL	X					X	
Sleurs, 2021[41]	Multinational	0	186	HRQOL	X					X	
O'Donnell, 2022[42]	USA	0	180	HRQOL	X	X					
Rensen, 2022[43]	Netherlands	0	139	HRQOL	X						
Pemberton-Whiteley, 2023[44]	Multinational	0	139	HRQOL	X					X	
Park, 2022[45]	South Korea	0	132	HRQOL	X					X	
Ribbands, 2023[46]	USA	0	132	HRQOL	X	X					
Damen, 2022[64]	The Netherlands	0	122	Expectations	X						X

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Study	Country		Sample	Category					
Suzuki, 2022[47]	Japan	0	106	HRQOL	X	X			
Yusuf, 2022[48]	USA	0	104	HRQOL	X				
Jensen, 2022[49]	USA	0	98	HRQOL	X	X			
Micas Pedersen, 2023[50]	Denmark	0	88	HRQOL	X	X			
Paunescu, 2022[51]	France	0	69	HRQOL	X		X		X
Trevino, 2022[52]	USA	0	64	HRQOL	X				
Wang, 2021[53]	USA	0	60	HRQOL	X	X			
Castelli, 2022[54]	Germany	0	58	HRQOL	X				
Coughlin, 2022[55]	USA	0	53	HRQOL	X				
Lindberg, 2022[69]	Multinational	0	51	Treatment and management	X		X		
Stamm, 2021[56]	Switzerland	0	47	HRQOL	X	X			
Biran, 2021[57]	USA	0	42	HRQOL	X				
Osaki, 2022[58]	Japan	0	32	HRQOL	X				
Nakajima, 2022[72]	Japan	0	16 (14 carers)	Information and communication				X	
Marte, 2022[60]	USA	0	26	Quality of life	X		X		X
Ochagavía Sufrategui, 2023[70]	Spain	0	23	Treatment and management	X		X		
Bennink, 2021[61]	Netherlands	0	15	Quality of life					X

HRQOL = Health related quality of life
*Focus groups

Abbreviations and terminology

ASGS	The Australian Statistical Geography Standard from the Australian Bureau of Statistics, defines remoteness and urban/rural definitions in Australia
CCDR	Centre for Community-Driven Research
dF	Degrees of Freedom. The number of values in the final calculation of a statistic that are free to vary.
f	The F ratio is the ratio of two mean square values, used in an ANOVA comparison. A large F ratio means that the variation among group means is more than you'd expect to see by chance.
HER2	Human epidermal growth factor receptor 2
FOP	Fear of Progression. Tool to measure anxiety related to progression
IQR	Interquartile range. A measure of statistical dispersion, being equal to the difference between 75th and 25th percentiles, or between upper and lower quartiles.
p	Probability value. A small *p*-value (typically ≤ 0.05) indicates strong. A large *p*-value (> 0.05) indicates weak evidence.
PEEK	Patient Experience, Expectations and Knowledge
PIH	Partners in Health
SD	Standard deviation. A quantity expressing by how much the members of a group digger from the mean value for the group/
SEIFA	Socio-Economic Indexes for Areas (SEIFA) ranks areas in Australia according to relative socio-economic advantage and disadvantage. This is developed by the Australian Bureau of Statistics.
SF36	Short Form Health Survey 36
t	t-Statistic. Size of the difference relative to the variation in your sample data.
Tukey HSD	Tukey's honestly significant difference test. It is used in this study to find 7significantly different means following an ANOVA test.
W	The W statistic is the test value from the Wilcoxon Rank sum test. The theoretical range of W is between 0 and (number in group one) x (number in group 2). When W=0, the two groups are exactly the same.
X^2	Chi-squared. Kruskal-Wallis test statistic approximates a chi-square distribution. The Chi-square test is intended to test how likely it is that an observed distribution is due to chance.

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.   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.

4.   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.

5.   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.

6.   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.

7.   Australian Bureau or Statistics (2021) Australian Statistical Geography Standard (ASGS) Edition 3
Reference period
July   2021   -   June 2026https://www.abs.gov.au/statistics/statistical-geography/australian-statistical-geography-standard-asgs. ASGS.

8.   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.

9.   Bates-Fraser LC, Mills J, Mihas 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.

10.   Hoppe R, Winter MA, Graap K, Albrecht TA. Impact of a Hematologic Malignancy Diagnosis and Treatment on Patients and Their Family Caregivers. *Oncol Nurs Forum* 2022; **49**(5): 445-53.

11.   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.

12.   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).

13.   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.

14.   Vena JA, Copel L, McDermott-Levy R. Lived Experiences of Young Adults With Lymphoma During Acute Survivorship. *Cancer Nurs* 2023; **46**(1): E11-E20.

15.   Hodge A, Sheean P, O'Connor P, et al. Exploring health behaviors and the feasibility of a lifestyle intervention for patients with multiple myeloma. *Support Care Cancer* 2022; **30**(12): 9771-9.

16.   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.

17.   van Lieshout R, Lize N, Tick LW, et al. Nutrition-related problems, nutritional support practices and barriers to adherence to nutritional guidelines during intensive treatment for acute myeloid leukemia: Patients' and hematology nurses' perspectives and experiences. *Clin Nutr ESPEN* 2022; **48**: 446-55.

18.   Bixby TJ, Brittle CJ, Mangan PA, Stadtmauer EA, Kallenbach LR. Patient Perceptions of CAR-T Therapy in the USA: Findings from In-Depth Interviews. *Oncol Ther* 2023: 1-10.

19.   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).

20.   Booker R, McLennan AIG, Beattie S, Stajduhar KI, Sawatzky R. Integrating Palliative Care in Hematopoietic Stem Cell Transplantation: A Qualitative Study Exploring Patient, Caregiver, and Clinician Perspectives. *Oncol Nurs Forum* 2023; **50**(3): 313-23.

21.   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.

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

23.   Borregaard Myrhoj 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.

24.   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.

25.   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.

26.   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.

27.   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.

28.   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.

29.   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.

30.   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.

31.   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.

32.   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.

33.   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.

34.   Sharman JP, Cocks K, Nabhan C, et al. Longitudinal health-related quality of life in first-line treated patients with chronic lymphocytic leukemia: Results from the Connect((R)) CLL Registry. *EJHaem* 2020; **1**(1): 188-98.

35.   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.

36.   Gatopoulou X, Iraqi W, Morgan K, et al. The Burden of a Multiple Myeloma Diagnosis on Patients and Caregivers in the First Year: Western European Findings. *Clinicoecon Outcomes Res* 2022; **14**: 731-53.

37.   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.

38.   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.

39.   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.

40.   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.

41.   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).

42.   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.

43.   Rensen N, Steur L, Grootenhuis M, et al. Parental Sleep, Distress, and Quality of Life in Childhood Acute Lymphoblastic Leukemia: A Longitudinal Report from Diagnosis up to Three Years Later. *Cancers (Basel)* 2022; **14**(11).

44.   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.

45.   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.

46.   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.

47.   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.

48.   Yusuf ARS, Heiling HM, Deal AM, et al. Longitudinal Analysis of Patient-Reported Cognitive Function in Multiple Myeloma. *Clin Lymphoma Myeloma Leuk* 2022; **22**(12): 920-7.

49.   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.

50.   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.

51.   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.

52.   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.

53.   Wang XS, Srour SA, Whisenant M, et al. Patient-Reported Symptom and Functioning Status during the First 12 Months after Chimeric Antigen Receptor T Cell Therapy for Hematologic Malignancies. *Transplant Cell Ther* 2021; **27**(11): 930 e1- e10.

54.   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.

55.   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.

56.   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.

57.   Biran N, Zhai W, Jensen RE, et al. Patient-reported outcomes following autologous stem cell transplant for patients with multiple myeloma. *EJHaem* 2021; **2**(3): 488-92.

58.   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.

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

60.   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.

61.   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.

62.   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.

63.   Janssens R, Lang T, Vallejo A, et al. What matters most to patients with multiple myeloma? A Pan-European patient preference study. *Front Oncol* 2022; **12**: 1027353.

64.   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.

65.   Ribbands A, Boytsov N, Bailey A, Gorsh B, Luke E, Lambert A. Real-world patient-reported outcomes and concordance between patient and physician reporting of side effects across lines of therapy in multiple myeloma within the USA. *Support Care Cancer* 2023; **31**(6): 371.

66.   Tervonen T, Duenas A, Collacott H, et al. Current Health State Affected Patient Preferences More Than Disease Status: A Discrete Choice Experiment in Multiple Myeloma. *Value Health* 2023; **26**(6): 909-17.

67.   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.

68.   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.

69.   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.

70.   Ochagavia Sufrategui M, Gil Lemus MA, Yanez San Segundo L, et al. [Translated article] Adherence

and quality of life in patients with chronic lymphocytic leukemia treated with oral antineoplastic drugs. *Farm Hosp* 2023; **47**(2): T69-T74.

71.   Baum J, Lax H, Lehmann N, et al. Patient-reported patterns of follow-up care in the 'Aftercare in Blood Cancer Survivors' (ABC) study. *J Cancer Res Clin Oncol* 2023.

72.   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.