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Understanding Quality of Life in Patients With Acute Leukemia, a Global Survey

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Purpose The Acute Leukemia Advocates Network (ALAN) sought to determine which factors are most associated with poor quality of life (QoL) in patients with acute leukemia and to determine key issues and unmet needs through administration of an online survey distributed worldwide via partner patient organizations.

Methods ALAN developed a questionnaire informed by literature review and based extensively on the hematological malignancy-specific patient-reported outcomes (HM-PRO) measure to assess the impact of acute leukemia on QoL and its relationships with patients' demographics, disease state, disease impact, and support from health care professionals. Univariate and multivariable statistical analysis was used to investigate relationships between HM-PRO scores and the other factors.

Results Of 552 respondents from 42 countries, 332 had acute myeloid leukemia, 139 had acute lymphoblastic leukemia, and 81 had acute promyelocytic leukemia (survey data collected in 2019). Younger age, female gender, and lower income were all significantly negatively associated with QoL. Weak or moderate correlations were observed between overall support, management, and impact of treatment and diagnosis of acute leukemia. Feeling isolated and having reduced ability to carry out physical or enjoyable activities were the most important individual factors, while the best predictors for QoL impact were age, gender, and income (model r^2=0.16, complete case n=449).

Conclusions Findings indicated key factors, particularly age, gender, and socioeconomic state, that clinicians responsible for the care of patients with acute leukemia should be aware of when designing support strategies. The importance of social functioning in relation to patient QoL also should be included in considerations. (*J Patient Cent Res Rev.* 2023;10:21-30)

Keywords acute leukemia; quality of life; patient-reported outcomes; PROs; social functioning

Acute leukemias (AL) are aggressive hematopoietic neoplasms with maturation arrest of either the myeloid or lymphoid lineage, leading to the clonal accumulation of abnormal cells (blasts). The acute myeloid leukemias are the most heterogeneous and may occur de novo by evolving from other myeloid malignancies or following chemotherapy or radiation therapy.[1] Treatment plans are based on type of leukemia, disease subcategorization, and patient-related factors such as age, performance status, and comorbidities.[2] Outcomes in patients with acute myeloid leukemia are highly variable, ranging from treatment-related mortality to relapse-free survival. However, resistance to treatment is common (often manifested as relapse from remission), especially in older patients. Choice of treatment ranges from purely palliative care to standard-of-care therapy to investigational therapy. Recent developments in therapies for AL include novel treatments and targeted therapy, contributing to a decrease in treatment-related mortality, and a prolongation of overall survival.[3]

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Across all AL types, measures of treatment success are increasingly becoming patient-centric, rather than focused on clinical outcomes, reflecting recognition of the significant impact of AL on patient quality of life (QoL).[4] Due to recent changes in how AL is treated, such as more intensive chemotherapy and increased used of stem cell transplants,[5] there is an urgent need for greater understanding of QoL at different points in the patient journey.[6] There is increasing support for the use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) in measuring the quality of care. Data gathered can help focus patient-centered clinical management.[7]

The Acute Leukemia Advocates Network (ALAN) is an independent global network of patient organizations dedicated to changing outcomes of patients with AL by strengthening patient advocacy. Aims of this international study, conducted by ALAN, were to understand issues important to patients and gather information on the current and emerging treatment landscape, patient experiences, and patient QoL. While there have already been high-quality studies previously conducted to assess QoL outcomes in patients with AL,[8-11] these are primarily focused on particular subsets of patients. By taking a broader view, ALAN sought to identify issues that could be addressed at a local, national, and global level.

A key step in the use of PROMs to enhance patient-centered care is the selection of assessment tools — these can be disease-specific or generic and require the appropriate focus, scope, and type of measurement to answer the research question posed. Questionnaires should ideally be validated in the population of interest and may require translation into multiple languages.[12] This study used the validated hematological malignancy-specific patient-reported outcome (HM-PRO) measure,[13] together with additional questions developed by ALAN, to determine which aspects of treatment and diagnosis have the greatest impact on patients' QoL. An initial literature review was carried out to identify areas of focus for the additional questions added to the HM-PRO for this study.

The overall study objective was to use the questionnaire developed by ALAN to identify the key QoL indicators and drivers in this patient population. This was achieved through analyzing a series of endpoints:

1) Determine whether HM-PRO scores differ by demographic factors.
2) Determine whether HM-PRO scores differ by AL type.
3) Determine whether HM-PRO scores differ by overall support, management, and disease impact.
4) Investigate if other factors (ascertained by the more specific survey questions) affect the impact on QoL.
5) Identify the independent factors most predictive of AL's impact on QoL in order to address the unmet needs of patients, or particular patient subgroups, with AL.

METHODS

Questionnaire Development

Literature Review. To inform the questionnaire content, a literature review was conducted in April 2018 to gather insights into QoL concepts, issues important to patients with AL, and uncover any unmet patient needs. Using the search term "acute leukemia AND quality of life," English-language articles published within the prior 5 years were identified. This search strategy resulted in 340 papers for which the titles and abstracts were screened by Z.P.W. Consequently, 330 were considered to be irrelevant to this project while 10 key publications were selected for inclusion. General trends from the literature also were captured. The literature review informed recommendations for the questionnaire content that were subsequently refined and finalized by a panel of expert stakeholders, including patients, patient advocates, and clinicians.

HM-PRO Measurement Tool. Measuring QoL in AL represents a unique challenge; following a review of current QoL instruments, it was observed that the majority are not sensitive to disease-specific aspects of AL, echoing the findings of Goswami et al.[14] The recently developed HM-PRO measure was selected for assessments of QoL because it contains items specific to hematological malignancies, including aspects of physical, social, and emotional health, eating and drinking, symptoms, and side effects.[13] HM-PRO is a composite measure consisting of two parts: Part A (impact) and Part B (signs and symptoms). Both scales have a linear scoring system ranging from 0 to 100, with higher scores representing greater (negative) impact on QoL and symptom burden. The HM-PRO recall period for Part A is "at the moment" (ie, at present, today) and for Part B refers to the last 3 days.

Quality-of-Life Items Assessed. ALAN's final questionnaire consisted of 99 questions (plus some subquestions), with one section comprised of the validated HM-PRO QoL assessments,[13] and additional questions on disease, impact of treatment, and treatment management. The questionnaire was made available in 9 languages: Chinese (simplified), English, French, German, Hebrew, Italian, Portuguese (Brazilian), Russian, and Spanish. The HM-PRO tool was translated by the authors using a validated translation procedure.

Of the 99 questions in the survey, this publication focuses on questions 13–18, which ask about the overall support,

management, and impact of treatment and diagnosis of AL, and the correlation of these factors to overall QoL (determined through the HM-PRO section of the questionnaire). Questions 13–18 are itemized on an interval scale ranging from 0 to 10, where 0 represents a very bad experience (or very dissatisfied) and 10 a good experience with no problems or no negative impact. Questions 13, 14, and 16 ask about the management of the physical and emotional impact of diagnosis and treatment as well as information provided by health care professionals, whereas questions 15, 17, and 18 ask about the impact of the disease itself (Box 1). With the exception of question 16, the items in Box 1 asked patients to consider their experiences within the last month.

Box 1. Questionnaire Items Relating to Managing Impaired Quality of Life

Question 13 — management of physical symptoms and side effects by health care professionals

Question 14 — management of emotional impact by health care professionals

Question 15 — effect of acute leukemia treatment on physical and mental health

Question 16 — rating of acute leukemia information provided by or directed to by health care professionals

Question 17 — impact of acute leukemia on ability to perform meaningful activities

Question 18 — impact of acute leukemia on the well-being and lives of caregivers, friends, or family

The remainder of the questionnaire (informed by the literature search) is devoted to asking about individual factors related to disease impact, treatment regimen, and circumstances of the respondent.

Data Collection

Administration of the questionnaire used for this study occurred from February 4, 2019, to November 22, 2019, and was facilitated through use of a web-based platform that enabled electronic data capture. Patients with AL were recruited through ALAN's partner patient organizations — via email, online forums, social media, and paper flyers — with respondents from 42 countries.

Statistical Analysis

Two-sample Wilcoxon rank-sum or Kruskal-Wallis rank tests were used to test for differences in scores between groups and nonparametric trend test (per Stata 11, StataCorp LLC) was used to examine differences in ordinal variables. Missing (or not applicable) answers were excluded for these tests. A P-value of <0.05 was deemed to be significant.

Correlation analysis was used to determine the direction and strength of relationships between continuous and/or ordinal measures. Spearman's rank correlation coefficient (ρ) was estimated for each pair of relevant variables. With more than 500 respondents, correlations with absolute value 0.1 or greater will always be significant at the 0.05 level. Questions whose responses had a coefficient (with HM-PRO score) greater than absolute value 0.5 were selected for further investigation. (This cut-off was chosen to limit spurious findings resulting from moderate or weak correlations.) Box plots were used to further investigate the relationships between the scores and some of the other factors that were identified as most predictive of leukemia's predictive impact on QoL (ie, with coefficient absolute value of >0.5). The left and right edges of a box mark the 25th and 75th percentiles, and the middle line represents the median.

Multivariable linear regression with backward stepwise selection (significance level of $P<0.05$ required for inclusion) was used to find the best sets of predictive factors for HM-PRO scores. Interaction terms were included to see if the relationships differed according to age group, gender, or leukemia type. A likelihood ratio test was used to assess the contribution of subgroups and interaction terms to the model. Respondents with missing values for any of the covariates were excluded from this analysis, meaning different models had different numbers of respondents. For each model we report the number (n) and a goodness-of-fit measure (r^2). Stata 11 software (StataCorp LLC) was used for the statistical analysis.

RESULTS

There were 552 respondents; reported diagnoses included acute myeloid leukemia (n=332), acute lymphoblastic leukemia (n=139), and acute promyelocytic leukemia (n=81). The highest number of respondents came from the United Kingdom (n=168), the United States (n=67), South Korea (n=41), and Sweden (n=37).

Relationships Between HM-PRO Scores, Disease Type, and Sociodemographics

The relationship between HM-PRO scores (Part A and Part B), disease type (lymphoblastic, myeloid, or promyelocytic AL) and sociodemographic factors (age, gender, income, and region) were explored (Table 1). The most common AL type was acute myeloid leukemia (60.1%), with far fewer participants diagnosed with lymphoblastic or promyelocytic AL (25.2% and 14.7%, respectively). Respondents were predominantly female (59.2%); 43.5% came from the 41–60-year age bracket, with female respondents younger, on average, than male respondents (49 vs 56 years). Most respondents were from European countries (68.8%), with those from non-

Table 1. Distribution of HM-PRO Scores and P-Values* by Disease Type and Sociodemographic Characteristics

Factor	n	Part A		Part B	
		Median [IQR]	*P*	Median [IQR]	*P*
Leukemia type			0.55		0.23
Acute lymphoblastic	139	33.1 [17.2, 52.5]		26.5 [11.8, 44.1]	
Acute myeloid	332	30.4 [16.0, 50.5]		20.6 [11.8, 38.2]	
Acute promyelocytic	81	29.2 [7.3, 51.7]		23.5 [14.7, 41.2]	
Gender			0.06		0.002
Male	222	29.3 [12.7, 49.5]		17.6 [8.8, 35.3]	
Female	327	31.4 [18.2, 53.0]		23.5 [14.7, 44.1]	
Missing	3	9.4 [0.0, 27.4]		20.6 [2.9, 23.5]	
Age in years			0.005		0.03
16–40	158	35.9 [20.5, 56.9]		23.5 [11.8, 47.1]	
41–60	240	31.3 [16.9, 51.6]		23.5 [11.8, 41.2]	
61–87	150	26.5 [11.7, 45.8]		17.6 [8.8, 32.4]	
Missing	4	43.6 [31.3, 47.5]		35.3 [29.4, 39.7]	
Income			<0.001		<0.001
Low	136	42.0 [25.0, 63.0]		29.4 [17.6, 48.5]	
Average	281	28.8 [16.1, 47.4]		20.6 [8.8, 38.2]	
High	67	22.4 [8.5, 41.7]		14.7 [2.9, 32.4]	
Not answered	68	29.0 [14.4, 49.7]		26.5 [11.8, 44.1]	
World Health Organization region			0.04		0.17
Europe	380	30.0 [14.5, 50.4]		20.6 [8.8, 39.7]	
Not Europe	163	33.3 [21.0, 53.7]		23.5 [11.8, 44.1]	
Not answered	9	25.8 [21.2, 31.0]		23.5 [11.8, 29.4]	

**P-values for differences were obtained using Wilcoxon rank-sum test, Kruskal Wallis rank-sum test, or nonparametric trend test. Missing responses were not included in these tests.*

HM-PRO; hematological malignancy-specific patient-reported outcome measure; IQR, interquartile range.

European countries significantly younger, on average (39 vs 53 years). There were no other apparent differences between regions.

There was no evidence for significant differences between the leukemia types and QoL scores for either part of HM-PRO (P=0.55 for Part A and P=0.23 for Part B). However, younger age, female gender, and lower income were all significantly associated with both worse impact (Part A) and worse symptoms (Part B). Part A scores also were significantly lower in Europe, indicating a lower negative impact on QoL aspects in these countries.

Relationships Between HM-PRO Scores, Overall Support, Management, and Disease Impact

The relationship between HM-PRO scores and questions 13–18 of the ALAN questionnaire was assessed to identify the correlation between overall support, management, and impact of treatment and diagnosis of AL (Figure 1). Answers were mostly positive (median score 6–8 out of a highest possible score of 10), with the highest medians (ie, 8) resulting for questions that referred to the management of physical symptoms by health care professionals (question 13) and information provided by health care professionals (question 16). The question that asked about impact on caregivers, friends, or family (question 18) had the lowest median (ie, 6) and the largest interquartile range.

The responses to questions 13–18 were all either weakly or moderately negatively correlated with scores for both parts of HM-PRO (-0.37 to -0.66 for Part A, and -0.32 to -0.56 for Part B). Correlations to HM-PRO Part A and Part B were also similar for each question (Table 2), indicating that low HM-PRO scores are associated with good experiences and vice versa. Several of the individual questions were moderately or highly (positively) correlated with one another — eg, management of physical symptoms (question 13) correlated with management of emotional impact by health care professionals (question 14) and impact on performing meaningful activities (question 17) correlated with impact on friends and family (question 18), with correlation coefficients of 0.77 and 0.72, respectively.

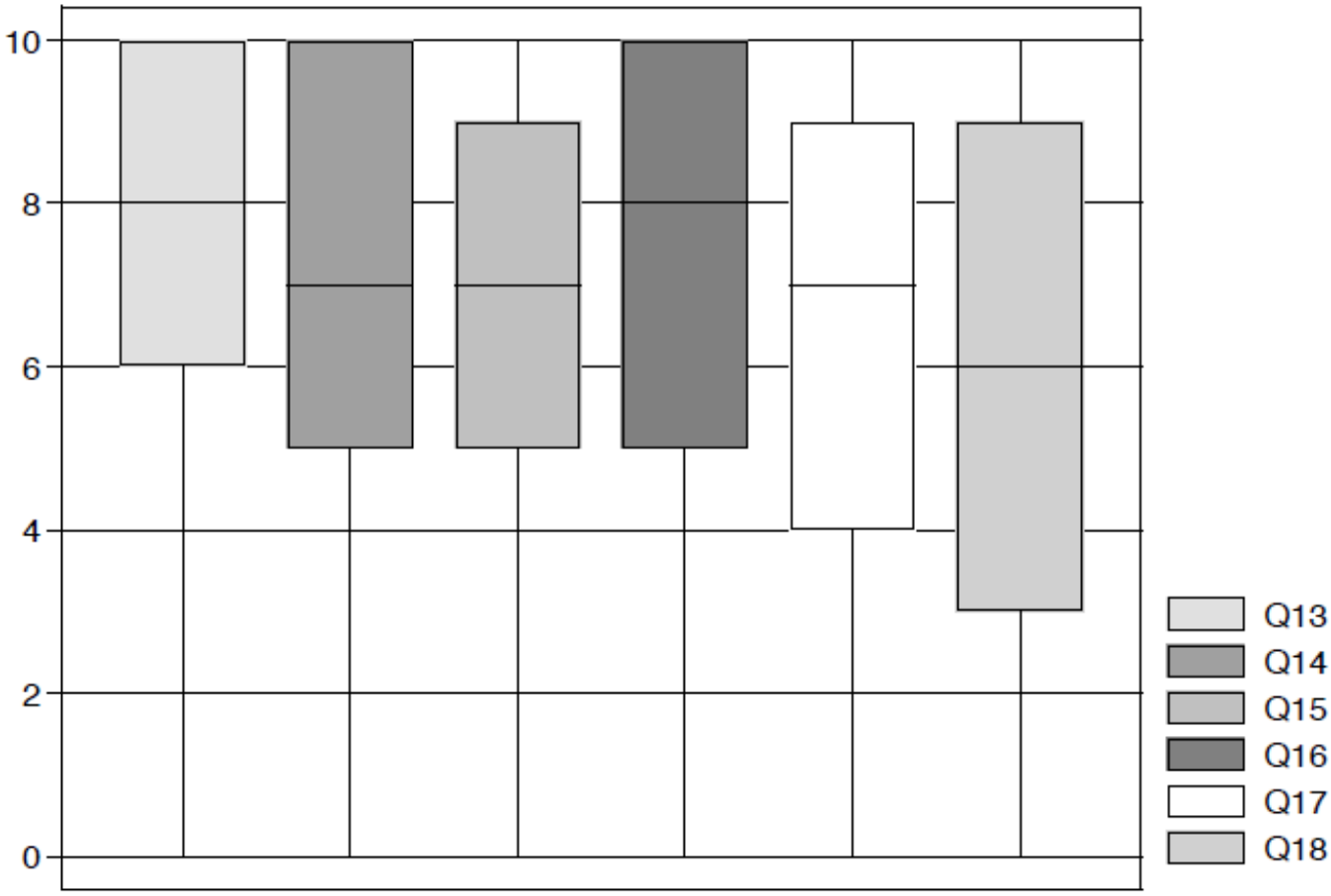

Figure 1. *Boxplots showing distributions for questions 13–18 (Q13–Q18). Q13 — management of physical symptoms and side effects by health care professionals; Q14 — management of emotional impact by health care professionals; Q15 — effect of acute leukemia treatment on physical and mental health; Q16 — rating of acute leukemia information provided by or directed to by health care professionals over the last month; Q17 — effect of acute leukemia on ability to perform meaningful activities; Q18 — negative impact of acute leukemia on the well-being and lives of caregivers, friends, or family. For all questions, scales ranged from 0 (bad) to 10 (good).*

The question around patients' ability to perform meaningful activities (question 17) had the strongest (moderate) correlations with both HM-PRO parts. Among the three questions relating to service provision, management of emotional impact (question 14) showed the strongest relationship with both Part A (impact) and Part B (symptoms) of the HM-PRO (correlation coefficients of -0.43 and -0.35, respectively).

Relationships Between HM-PRO Part A Scores and Other Factors

The relationship between HM-PRO scores and other questions from the ALAN questionnaire (ie, those other than questions 13–18) was also assessed. Correlation analysis was feasible for data that were ordinal, which applied to most responses. Many of the questions were either weakly or moderately correlated with HM-PRO Part A scores. Items with an absolute correlation coefficient greater than 0.5 were: question 35 — "feelings of isolation caused by AL diagnosis in the last month" (ρ=-0.67); question 73 — "ability to carry out physical activities in the last month" (ρ=0.58); and question 76 — "ability to carry out hobbies and enjoyable activities in the last month" (ρ=0.58).

Identifying Factors Predicting Leukemia's Impact on Quality of Life

Linear regression models with Part A (impact) as outcomes were constructed, using the variables identified as the most important (ie, those with the strongest correlations, excluding questions 13–18) as covariates. Since many of the questions are interrelated, a separate analysis was carried out for each set of factors. Age, gender, income, and leukemia type were included in

Table 2. Correlations* Between HM-PRO Part A and Part B Scores and Questions 13–18 (Q13–Q18)

	Part A score	Part B score	Q13	Q14	Q15	Q16	Q17	Q18
Part A score	1.00							
Part B score	0.63	1.00						
Q13	-0.37	-0.32	1.00					
Q14	-0.43	-0.35	0.77	1.00				
Q15	-0.50	-0.48	0.56	0.56	1.00			
Q16	-0.40	-0.35	0.66	0.66	0.52	1.00		
Q17	-0.66	-0.56	0.44	0.42	0.57	0.47	1.00	
Q18	-0.57	-0.46	0.38	0.41	0.53	0.38	0.72	1.00

**Pairwise Spearman's rank correlation coefficients.*

all models, together with relevant interaction terms, to determine whether the effects might differ between the different subgroups. The best predictors for QoL impact (HM-PRO Part A) were age, gender, and income (model r^2=0.16, complete case n=449).

Overall Support, Management, and Disease Impact

In this section, questions 13–18 were added to the previously developed linear regression models. Management of physical symptoms and side effects by health care professionals (question 13), management of emotional impact by health care professionals (question 14), effect of AL treatment on physical and mental health (question 15), and impact of AL on ability to perform meaningful activities (question 17) were all independently related to HM-PRO Part A (P=0.011). Age (P=0.65) and gender (P=0.19) were not significant covariates in this model, although income (P<0.001) remained as such. There was a significant interaction (P=0.03) between the impact of AL on the ability to perform meaningful activities (question 17) and the type of leukemia, indicating that the relationship between this item and the Part A score was weaker for the acute lymphoblastic leukemia group.

Thus, the final model included questions 13, 14, 15, and 17; income; and the interaction term between leukemia type and question 17. This model produced an r^2 of 0.53 (n=430).

Three items: feelings of isolation caused by AL diagnosis in the last month (question 35); ability to carry out physical activities in the last month (question 73); and ability to carry out hobbies and enjoyable activities in the last month (question 76) were each added to the first model (which included age, gender, and leukemia types) to determine their predictive power. These items were all independently related to QoL impact per HM-PRO Part A (P<0.001 for all). There were no significant interactions between these items or between each and age, gender, or leukemia type. Age and gender changed to nonsignificant (P=0.55) when these questions 35, 73, and 76 were added to the model, but the significance of income remained (P=0.03). To investigate further, each question was added to the model in turn. The most noticeable effect was that the P-value of age increased from 0.002 to 0.74 when feelings of isolation (question 35) was added to the model. This model (with questions 35, 73, 76, and income [n=462]) was the most predictive for Part A (impact) of HM-PRO (r^2=0.59).

DISCUSSION

Demographic Factors

The demographic factors most related to poorer QoL were younger age, female gender, and lower income, with no evidence of significant differences in QoL between the leukemia types, or based on region, despite the diverse health care systems represented.

Previous studies have illustrated that women with cancer report a higher incidence of cancer-related fatigue and depressive symptoms compared to men,[15] and there is evidence to suggest that this holds true with hematological malignancies. Sztankay et al reviewed gender differences in QoL for those with hematological malignancies, citing lower global QoL, impaired physical, emotional and social functioning, and poor adjustment in the occupational domain for female patients.[16] The reasons for these differences are not fully understood but may be attributed to higher pain perception and increased potential for depression in women, both of which are predictive factors for QoL.[17-19] However, it should also be considered that QoL differences by gender may reflect the variations that are present in the general population.[20] Our

study adds to the limited data, indicating that poorer QoL is more likely for female patients with acute leukemia.

The relationship between income and health is well documented, with poverty associated with worse health outcomes.[21] Studies of cancer survivors often report positive correlations between income and health-related QoL, with high-income patients not only more likely to survive cancer but to enjoy better QoL as survivors.[22] Identifying the causes of this disparity is complex, and beyond the scope of this paper, particularly as the study encompassed data from multiple countries with different social and health care systems.

Studies have indicated that, in the general cancer population, patients report worse health-related QoL with increasing age in the domains of physical and cognitive functioning, but they perform better with domains related to mental health, such as social and role functioning.[23,24] There is some evidence to suggest that QoL for those with acute leukemia improves with increased age,[25] however, this finding was not conclusive. Younger patients may be more likely to have a lower income, as they are more likely to be in the early stages of their career and potentially have higher living costs (such as the need for child care). Therefore, the relationship between poverty and QoL may be further exacerbated in younger AL populations.

Results from our study suggest that the relationship between age and poorer QoL could be due to how younger patients with acute leukemia experience isolation. This would echo the findings of Geue et al, who reported younger age had a negative impact on emotional, social, and cognitive function in patients with hematological malignancies and also that younger patients had a higher level of perceived negative social support than older patients.[26] It is not clear from the study as to the cause of the feelings of isolation. Certainly, there are issues relating to the AL treatment pathway that may necessitate a period of physical isolation due to aggressive chemotherapy and/or long stays in hospital. However, there also may be a situation where patients wish to withdraw from family and friends so as not to cause worry or because they don't feel that others can relate to their experiences as a cancer patient.[27-29] Patients may experience isolation after treatment has finished when they may no longer have the regular contact and support from health care professionals.[29] Some articles reference Erickson's development theory and hypothesize that young people have more social contacts from different areas of life than older people, leading to the potential for "higher detrimental interactions" in younger patients than for older patients.[26] This evidence underpins the notion that social support can have a positive impact on survival in acute myeloid leukemia[30] and other cancers. Thus, we believe addressing the issue of isolation and social support should be a consideration in treatment decision-making and beyond, particularly as prevention of feelings of isolation in younger patients may be relatively easily addressed, as compared to identifying solutions to deep-seated gender and economic inequalities, which are far more complex.

Disease Impact and Support Needs

All factors relating to disease impact and support from health care professionals were significantly related to QoL. Different aspects of support from health care professionals, including those related to treatment, appear to be independently related to QoL impact, as does ability to carry out meaningful activities. Question 15 is ambiguous, as it could be related to treatment by caregivers or from chemotherapy. In any future iterations of the questionnaire, this should be made more specific.

The results from questions 18 and 17, respectively, showed that patients gave a slightly worse score for the impact their AL had on others (caregivers, friends, and family) than the impact it had on themselves, albeit with greater variability. There are numerous studies that have reported the negative impact cancer has on the QoL of caregivers, friends, and family of patients with cancer.[31,32] In particular, recent studies by Yu et al and Wang et al provided evidence about the negative impacts leukemia and AL have on the QoL of family caregivers, although these studies were limited to China.[25,33,34] What is interesting here is that our scores come from the perspective of the patients themselves rather than that of the caregiver, friend, or family member. "Self-perceived burden" in patients with hematological malignancies is an understudied subject, and given its potential to impact a patient's interactions with others and psychological well-being, we would reiterate the recommendations of Simmons that called for further studies into the role of caregiver/family burden in mental/emotional well-being and QoL.[35]

Implementation by Caregivers

Identification of the demographic most at risk of worsening QoL following an AL diagnosis (younger patients, particularly women and those on lower incomes) will enable targeting of practical strategies to both measure and reduce the impact on QoL in these patients. For example, reducing feelings of isolation by setting up or signposting patients to targeted support groups (eg, female-only or age-specific) and ensuring patients with low income receive relevant financial advice. Additionally, with the potential link between income and

survival, subsequent studies investigating adjustments to treatment regimens in low-income populations may be required. Measuring the success of such strategies, as well as elucidating the impact of specific treatments on QoL, will require the incorporation of regular QoL surveys in these patient groups.

Limitations of Analysis

The fact that this is a convenience sample, recruited via patient organizations, and with most participants coming from the United Kingdom or United States may lead to potential bias (eg, responses on support from health care professionals may depend on the health care culture of each respective country, particularly without standardization of treatment regimens across health systems). The sample may not be representative of patients with AL as a whole; however, this study still gives us a valuable insight into some of the factors that are important regarding QoL for those with AL.

Correlation analysis of numerous questions (data trawling) can lead to spurious results. To avoid this, only those aspects with a ρ of absolute value greater than 0.5 were selected for further investigation. However, this approach could have led to some important relationships being missed. Some questions were not ordinal, or included few respondents, so these too could have been missed.

Linear regression was considered to be the most appropriate for identifying independent factors but may have not been the best model for the (non-normally distributed) data. However, residuals from the models appeared to be roughly normally distributed, which meant that the results (and r^2 values) should be reasonably reliable. Since this was an exploratory analysis, no attempt was made to impute missing values, therefore some models had less observations than others.

CONCLUSIONS

Our study provides evidence of the issues relating to quality of life for patients with acute leukemia. By identifying the key factors that relate to worse QoL, finite health care resources can be directed where they are most needed, such as providing techniques or signposting patients to support groups to deal with social isolation and improving access to relevant financial help and advice. We strongly recommend that clinicians be mindful of the importance of social functioning to QoL, particularly patient experiences relating to worries about friends and family and isolation, when designing care and support plans. Patient organizations and charities can provide a wide range of supportive resources, and we encourage health care professionals to direct patients to disease-specific groups whenever appropriate.

Patient-Friendly Recap

- Patient-centered approaches to caring for individuals with acute leukemia should take into account potential impact on quality of life.
- The Acute Leukemia Advocates Network and its partner organizations surveyed patients worldwide to identify factors most associated with the experience of living with this cancer.
- Younger patients, women, and those with low income reported worse quality of life than their counterparts. Feelings of social isolation and barriers to physical activity were noted to be the most impactful issues.
- When treating patients with acute leukemia, clinicians should keep in mind the importance of social functioning and connect patients to resourceful and applicable support groups.

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Author Contributions

Study design: Pemberton-Whiteley, Bradley. Data acquisition or analysis: Pemberton-Whiteley, Bradley. Manuscript drafting: Bradley. Critical revision: Pemberton-Whiteley, Nier, Geissler, Wintrich, Verhoeven, Christensen, Salek, Oliva, Ionova.

Conflicts of Interest

Z.P.W. reports: employment by Leukaemia Care; equity ownership of Patient Evidence; consultancy for Acute Leukemia Advocates Network (ALAN), Amgen, Astellas, Bristol-Myers Squibb, Celgene, Incyte, Janssen, Novartis, and Pfizer; advisory board membership for ALAN and CML Advocates Network; speakers bureau for Amgen, Bristol-Myers Squibb, Gilead, Jazz, Novartis, and Pfizer. S.N. reports: consultancy role for ALAN. J.G. reports: advisory roles and consultancy on patient engagement to Amgen, Alnylam, Bayer, Biomarin, Boehringer, Gilead, Janssen, Novartis, Pfizer, Roche, Servier, Sanofi, Takeda, and UCB; board membership of ALAN, CML Advocates Network, Leukaemia Patient Advocates Foundation, and LeukaNET. S.W. reports: board membership of ALAN; MDS UK organizational grants from and/or honoraria for advisory board role from Novartis, Janssen, and Takeda. B.V. reports: board membership of ALAN. R.C. reports: board membership of LYLE; advisory roles and consultancy for Bristol-Myers Squibb, Takeda, Roche, Pfizer, Janssen, Novartis, and Autisme 4700DK. S.S. reports: educational grant from GSK plc, Merck Group, and Dr Wolff; travel support and consultancy from Agios; joint copyright holder of HM-PRO. E.N.O. reports: advisory roles and consultancy for Bristol-Myers Squibb, Novartis, Amgen, Appelis, and Alexion; speakers bureau for Bristol-Myers Squibb and Novartis. T.I. reports: advisory roles and consultancy for

Bristol-Myers Squibb, Takeda, and Amgen; principal investigator in sponsor-initiated studies; speaker bureau for Takeda. J.B. reports: employment by IQVIA.

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