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Associations with the quality of life of adult family members or partners (informal carers) of people with leukaemia: results from a cross-sectional online global survey

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Background: Receiving a leukaemia diagnosis and undergoing treatment impact patients and their informal carers. Our objective was to explore and quantify the impact on the quality of life (QoL) of adult family members or partners of persons living with acute or chronic leukaemia.

Methods: We conducted a global, cross-sectional online study distributed via three leukaemia patient advocacy networks. Adult informal carers completed the Family Reported Outcome Measure (FROM-16) tool. Higher FROM-16 scores indicate poorer QoL, ranging from 0 to 32, with a critical threshold of 17 indicating a "very large effect". We summarised the demographic variables and caregiving characteristics and assessed their relationships with the FROM-16 scores using Kruskal–Wallis tests with Bonferroni adjustment. Eta-squared (η^2) was used to assess the effect size.

Results: A total of 511 respondents entered the dataset: 59% (299/511) supported someone with acute leukaemia ("acute group"), whilst 41% (212/511) supported someone with chronic leukaemia ("chronic group"). The mean age of all informal carer respondents was 48.1 years [standard deviation (SD) = 13.9]. The acute group tended to be younger (mean = 43.8 years, SD = 11.8) than the chronic group (mean = 54.2 years, SD = 14.4). The majority of informal carer respondents were women (73%, 353/485). The median FROM-16 score was 14, and 38% (195/511) of the respondents scored above the critical threshold of 17. The acute and chronic leukaemia groups differed (median = 16 *vs.* 8, respectively), with a moderate-to-large effect size ($\eta^2 = 0.122$, $p = 2.92\text{E}{-15}$). Providing higher caregiving hours was associated with greater FROM-16 scores (i.e., lower QoL), with large effect sizes in both groups (acute: $\eta^2 = 0.130$, $p = 5.32\text{E}{-6}$; chronic: $\eta^2 = 0.232$, $p = 5.65\text{E}{-7}$). Giving medication was associated with moderate effect sizes (acute: $\eta^2 = 0.071$, $p = 3.98\text{E}{-6}$; chronic: $\eta^2 = 0.094$, $p = 9.56\text{E}{-6}$), whilst providing personal care showed small to moderate effects (acute: $\eta^2 = 0.036$, $p = 9.93\text{E}{-4}$; chronic: $\eta^2 = 0.092$, $p = 1.17\text{E}{-5}$).

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Conclusion: Our findings highlight a need for tailored support to reflect the differing burdens faced by informal carers of people with acute and chronic leukaemia. Policymakers and clinicians could integrate informal carer wellbeing into leukaemia care strategies, promoting holistic, family-centred support services.

KEYWORDS

caregivers, family carer burden, FROM-16, leukaemia, quality of life

1 Introduction

Leukaemia, a cancer of the blood and bone marrow, disrupts normal blood cell formation due to the uncontrolled propagation of white blood cells. Whilst acute leukaemia progresses rapidly and demands urgent intervention, chronic leukaemia typically follows a slower trajectory, requiring sustained management over time. Adult family members or friends providing unpaid care (hereafter "informal carers") play an important role in supporting the emotional, physical, and logistical needs throughout diagnosis, treatment, and survivorship. Informal carers' actions carry economic value for health systems and impact on health outcomes and experiences (1–3). In the UK, the 2021 census found that 5.8 million people provide unpaid care (4), of whom 1.1 million were estimated to be of working age and caring for people with cancer (a specific number for leukaemia was not available), at an estimated annual wage cost of £8.58 billion (5). More broadly, informal carers were estimated to contribute £184.3 billion annually to the UK economy, with an estimated 1.5 million people providing more than 50 h of care each week (6, 7). The experience of caring for someone with leukaemia is shaped by multiple factors. These include the disease subtype, the treatment intensity, the caregiving intensity, and the psychological and social contexts in which care is provided (8). Informal caregiving for people living with acute leukaemia can generate substantial multidimensional strain, altering interpersonal dynamics and adversely influencing informal carers' psychological and physical wellbeing, employment, finances, and social functioning (9).

The World Health Organization defines quality of life (QoL) "*as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns*" (10). QoL is commonly assessed using self-completion instruments, such as the World Health Organization Quality-of-Life Scale (WHOQOL-BREF) (10), the Quality of Life Scale (11), and the EuroQol 5 Dimension (EQ-5D) (12). Whilst the QoL of people with leukaemia ("patients") has been the subject of considerable research, including international surveys (13–18), the wellbeing of informal carers remains underexplored (19). Informal carer burden distress can adversely affect patient outcomes, treatment adherence, and healthcare utilisation: a 2018 systematic review of 50 studies involving patients with advanced cancer and their informal carers identified seven domains of informal carer unmet needs: information, physical, psychological, financial, cancer care service, spiritual, and social support (20). Studies have examined the QoL of informal carers to adults with leukaemia in selected populations (21–31), leaving a gap in understanding the international challenges faced by informal caregivers supporting adults with leukaemia.

1.1 Aim and objectives

Our study addresses this knowledge gap by examining informal carer-reported QoL using a validated QoL tool in an international study. By exploring how caregiving experiences differ across leukaemia subtypes and care contexts, our aim was to inform more responsive, family-centred approaches to leukaemia care. We explore the following specific study question:

> What factors are associated with informal carer QoL when supporting people with leukaemia?

2 Methods

This study analyses the caregiver data from a global, cross-sectional, online, open questionnaire hosted on the Qualtrics survey platform. The study respondents were recruited using convenience sampling via distribution by three international leukaemia patient advocacy groups to their members and by word-of-mouth. Before starting the questionnaire, the respondents were informed of the purpose of the questionnaire, that completing the questionnaire is anonymous and voluntary, and how the results would be used and reported.

2.1 Ethical approval

This study involved an anonymous, online questionnaire with no clinical intervention and, thus, minimal risk to respondents. Respondents were presented with information about the study's purpose, the voluntary nature of responding, and the intended use of their responses. Respondents were required to proceed through this information before access to the questionnaire was granted. No personally identifiable information was collected. All data were securely stored and processed per the UK General Data Protection Regulation (GDPR, 2018), the ISO 20252 and 27001 standards for social research and information security management systems, and the Market Research Society Code of Conduct.

2.2 Questionnaire technique

The questionnaire covered the following aspects: demographics, diagnosis, active monitoring (presented only to patients with chronic lymphocytic leukaemia), treatment, testing and monitoring, information and support, QoL, and views on potential new treatments. Routing was implemented to ensure that respondents were only shown questions relevant to their experience. Following review and feedback by patients, informal carers, and patient advocates, the final informal carer questionnaire had 47 questions (further information about the questionnaire design and the full questions are available as Supplement SM1 in the *Supplementary material*).

The Family Reported Outcome Measure (FROM-16) tool was included in the questionnaire and completed by informal carers about their current experience. The FROM-16 is a short (2-min completion time) validated questionnaire that assesses how an adult (over 18 years old) informal carer's QoL is affected by the patient's condition (32–35). The 16 items in FROM-16 are divided into two domains: a) emotional and b) personal and social life. With a total score range of 0–32, a higher FROM-16 score indicates a greater effect on the informal carer's QoL, with a critical threshold of 17 representing a "very large effect" on their QoL (33). Calculated FROM-16 scores classify QoL impacts as follows: 0–1 as "no effect", 2–8 as "small effect", 9–16 as "moderate effect", 17–25 as "very large effect", and 26–32 as "extremely large effect" (33).

The survey was delivered in languages for which corresponding FROM-16 translations are available. No additional translation of the instrument was undertaken for this study. However, the list of available translations is continually evolving, and some versions may not have undergone full linguistic or psychometric validation at the time of use.

2.3 Data collection

The study respondents were recruited by the Acute Leukaemia Advocates Network (ALAN), the Chronic Lymphocytic Leukaemia Advocates Network (CLLAN), and the Chronic Myeloid Leukaemia Advocates Network (CMLAN) via membership, e-mail, online forums, social media, and newsletters. The online survey (hosted on Qualtrics) was made accessible to respondents through an open QR code or web link. The questionnaire was available to be completed between 19 August 2023 and 5 January 2024 (inclusive) in one of 14 languages: Brazilian Portuguese, Chinese (simplified), Czech, Danish, Dutch, English (UK), English (USA), French, German, Hebrew, Italian, Korean, Russian, and Spanish. There were no incentives and completion was voluntary. Respondents could submit their responses without all questions completed (coded as "unanswered"). As questionnaire responses were not mandatory, item-level missing data were present across several variables. The extent of missingness varied by question, and responses coded as "unanswered" were retained and excluded on a question-by-question basis during analysis. This approach may influence subgroup estimates where the response counts are reduced.

The wider survey respondents were self-selecting people with leukaemia of any age and informal carers aged 18 years and above. In this study, we analyse the responses of informal carers.

2.4 Statistical analyses

Data were downloaded from Qualtrics and included responses from informal carers over 18 years old who completed the FROM-16 and where the diagnosis of the person for whom they provide care could be classified as acute or chronic. The FROM-16 scores were calculated using published methodology (32).

We invoked Python v3.13.11 (36) via Spyder v6.0.7 (37) to conduct data processing and analysis. We did not make statistical adjustments, as true population proportions were unknown. We summarised the demographics and reported experiences with descriptive statistics. We used inferential statistics to explore the study question. A multivariable modelling approach was considered; however, variability in the subgroup sizes and missing data limited the feasibility of robust multivariable modelling across all variables. The analysis therefore focusses on identifying associative patterns, and potential confounding is not addressed, providing a basis for future confirmatory studies.

We set the FROM-16 scores as the dependent variable using values as a discrete numeric variable. We identified demographic and variables of interest in advance of the analysis as relevant to the study question, and these were set as independent variables (all independent variables are listed in Supplement SM2 in the *Supplementary material*). We generated summary statistics for the full dataset ("overall") and for the acute and chronic subsets. We excluded "unclassifiable" responses (such as "other", "don't know", or "unanswered") on a question-by-question basis.

As the data did not meet the assumptions of standard parametric testing, such as ANOVA, we used the non-parametric Kruskal–Wallis tests with Bonferroni adjustment to mitigate the family-wise error rate within each subset of the analyses (38, 39). This is a conservative adjustment, meaning that, although true positives may be missed, false positives are less likely to be accepted. We used eta-squared (η^2) to quantify the proportion of variation in the FROM-16 scores explained by each variable. Following Cohen's criteria, the effect sizes were interpreted as small ($\eta^2 \geq 0.01$), medium ($\eta^2 \geq 0.06$), or large ($\eta^2 \geq 0.14$) (40).

Non-parametric methods were used because the distributions did not meet the assumptions required for parametric analyses. As the Kruskal–Wallis test is a one-way procedure, and there is no robust non-parametric equivalent of a two-way ANOVA, analyses were performed separately within the acute and chronic groups of informal carers. For each analysis, the p-values from the Kruskal–Wallis tests are reported, and if significant under the Bonferroni adjustment, the associated η^2 (effect size) is presented to quantify the magnitude of group differences.

With a cross-sectional design, we present the findings as associative, not causal.

3 Results

3.1 Descriptive statistics

A total of 511 respondents entered the dataset. As the question set was not forced response, different numbers of respondents provided data for demographics and variables of interest (Table 1). For the overall data, the FROM-16 scores ranged from 0 to 32, with a mean of 14.3 [standard deviation (SD) = 8.8, median

= 14, interquartile range (IQR) = 7–21], and 38% (195/511) met or exceeded the critical threshold score of 17. The variation in the denominators across analyses reflects the presence of item-level missing data, arising from the non-mandatory survey design.

3.1.1 Patient demographics

The mean age of patients was 41.4 years (SD = 23.3) overall, with the acute group being younger on average (33.3 years, SD = 22.2) than the chronic group (52.7 years, SD = 19.9). Informal carers were more likely to care for male patients (56%, 267/476) than female patients (44%, 209/476).

3.1.2 Informal carer demographics

Of the informal carer respondents, 59% (299/511) supported someone with acute leukaemia ("acute group"), whilst 41% (212/511) supported someone with chronic leukaemia ("chronic group"). The mean age of all informal carer respondents was 48.1 years (SD = 13.9) (Table 1). The acute group tended to be younger (43.8 years, SD = 11.8) than the chronic group (54.2 years, SD = 14.4). The majority of informal carers responding to the survey were women (73%, 353/485). Majority of the respondents lived with the patient (84%, 414/493), almost half cared for their spouse or partner (47%, 225/474), two-thirds self-reported having an "average household income" for their country (67%, 324/483), and 43% had an undergraduate degree (202/465).

3.1.3 Care provision

Providing emotional support was the most commonly reported care activity overall (89%, 454/509) (Table 2), with similar proportions for the acute (91%, 271/299) and chronic groups (87%, 183/210). Accompanying patients on trips or to appointments (75%, 384/509) and providing support for household tasks (74%, 378/509) were the next most reported care activities. Providing personal care support was more common amongst respondents in the acute group (59%, 175/299) than the chronic group (17%, 36/210). Those in the acute group were more than three times as likely to provide care for 50 or more hours per week (52%, 138/266) compared with the chronic group (15%, 26/171).

3.1.4 Quality of information

Just over half of all informal carer respondents said that the patient's diagnosis was explained to them completely (53%, 191/363), whilst 51% (240/467) said the test results were explained completely. Of the respondents, seven-tenths (69%, 309/450) reported needing to ask for the test results to be explained. When asked what information (e.g., clinical trials, patient rights, or financial) or support (e.g., mental wellbeing, patient support groups, and buddying or befriending) they were given during the patient's treatment journey, nearly one in five (17%, 87/504) said they were not directed to any additional resources.

3.2 What factors are associated with informal caregiver QoL when supporting people with leukaemia?

The FROM-16 scores varied notably by leukaemia type (Table 1). The median FROM-16 scores for the acute group (median = 16, IQR = 11.5–23) were higher than that for the chronic group (median = 8, IQR = 5–17) (Figure 1). Aforementioned, overall, 38% (195/511) exceeded the critical threshold of 17: for the acute group, this was 47% (141/299) and for the chronic group 25% (54/212). We found a difference in the median values corresponding to a moderate-to-large effect size ($\eta^2 = 0.122$, 12.2% of the variance explained, $p = 2.92E{-}15$).

Thus, all subsequent analyses were stratified by leukaemia type to reflect the distinct informal carer experiences. Unstratified results are available in Supplement SM3 in the *Supplementary material*. With 33 variables in each family of tests for each leukaemia group, the Bonferroni-adjusted threshold for 95% significance testing is 0.05/33 = 1.52E−3.

3.2.1 Acute group

For the acute group, we identified an association between the demographic factors and the FROM-16 scores for three variables: informal carer gender, employment status, and relationship to patient (Table 3). With a moderate effect size, female respondents reported a higher median score of 17 (IQR = 13–24) compared to male respondents (median = 14, IQR = 7–19, $\eta^2 = 0.049$, $p = 1.95E{-}4$). Employment status was associated with variation in the scores ($\eta^2 = 0.068$, $p = 7.73E{-}4$), with people identifying as full-time carers who were unable to work due to their caregiving responsibilities reporting the highest median score (median = 21, IQR = 15.5–27.5). Relationship to the patient was associated with variation in the scores ($\eta^2 = 0.053$, $p = 1.24E{-}3$), with sons or daughters reporting the highest median scores (median = 20, IQR = 14–26.5).

For the other variables of interest, we could identify associations for five variables (Table 4). Increased caregiving intensity, proxied by hours of care provided per week, was strongly associated with greater FROM-16 scores, with a large effect size ($\eta^2 = 0.130$, $p = 5.32E{-}6$). Respondents providing 50 or more hours of care per week reported a median score of 20 (IQR = 14–25), whereas respondents providing less than 1 h per week reported a median of 12 (IQR = 3.75–14.5). Several care activities were linked to higher median FROM-16 scores, with moderate and small effect sizes: providing childcare (median = 20, IQR = 14–25, $\eta^2 = 0.037$, $p = 9.72E{-}4$), helping with managing finances (median = 19, IQR = 14–26, $\eta^2 = 0.056$, $p = 4.16E{-}5$), supporting personal care (median = 18, IQR = 13–25, $\eta^2 = 0.036$, $p = 9.93E{-}4$), and giving medication (median = 18, IQR = 14–25, $\eta^2 = 0.071$, $p = 3.98E{-}6$).

3.2.2 Chronic group

For the chronic group, we did not find evidence of an association for any of the demographic variables (Table 3). However, we

TABLE 1 Characteristics of the informal carer respondents and selected patient characteristics for whom they provide care, descriptive statistics, and response counts.

Category	Measure	Overall	Acute	Chronic
Sample size (*n*)	Count	511	299	212
FROM-16 score	Range	0–32	0–32	0–32
	Mean (SD)[†]	14.3 (8.8)	16.8 (8.3)	10.7 (8.2)
	Median (IQR)[†]	14 (7–21)	16 (11.5–23)	8 (5–17)
Stated diagnosis	Acute	299	299	–
	Chronic	212	–	212
Age (patient)	Range	0-86	0-86	5-86
	Mean (SD)[†]	41.4 (23.3)	33.3 (22.2)	52.7 (19.9)
	Median (IQR)[†]	43 (21–61.5)	30 (12.5–53)	59 (39–67)
Gender (patient)	Female	209	132	77
	Male	267	143	124
Age (informal carer)	Range	21–86	22–86	21–86
	Mean (SD)[†]	48.1 (13.9)	43.8 (11.8)	54.2 (14.4)
	Median (IQR)[†]	46 (38–58)	42 (35–50)	56 (43–65)
Gender (informal carer)	Female	353	218	135
	Male	132	66	66
Country of residence	Brazil	95	70	25
	Canada	24	2	22
	China	88	80	8
	Denmark	23	14	9
	France	37	33	4
	Republic of Korea	59	49	10
	United Kingdom	35	11	24
	Other countries	126	32	94
Employment status	Full-time carer (unable to work due to caring responsibilities)	47	43	4
	Employed	285	165	120
	Retired	84	24	60
	Stay-at-home parent	42	32	10
	Unemployed	24	19	5
	Other	18	11	7
Household income	High income	54	17	37
	Average income	324	203	121
	Low income	105	65	40
Highest qualification	No formal qualifications	24	18	6
	High school qualifications or diploma	122	77	45
	University—Undergraduate	202	118	84
	University—Postgraduate	75	40	35
	Career or technical	42	23	19
Relationship to the patient	Spouse or partner	225	83	142
	Parent or guardian	160	124	36
	Son or daughter	89	71	18
	Other relationship	37	21	18
Lives with patient	Yes	414	237	177
	No	79	51	28

(Continued)

TABLE 1 Continued

Category	Measure	Overall	Acute	Chronic
Continent	Africa	14	1	13
	Asia	166	135	31
	Europe	156	73	83
	North America	55	6	49
	Oceania	15	7	8
	South America	101	73	28

† FROM-16, Family Reported Outcome Measure; SD, standard deviation; IQR, interquartile range.

identified an association for several care-related variables (Table 4). Increased caregiving intensity, proxied by hours of care provided per week, was strongly associated with greater FROM-16 scores, with a large effect size (η^2 = 0.232, p = 5.65E−7). Respondents providing 50 or more hours per week reported a median score of 19 (IQR = 11.25–23.75) compared with 3.5 (IQR = 2–6.75) for respondents providing less than 1 h of care per week. Moderate effect sizes were noted for several care activities: providing personal care was associated with a median score of 17 (IQR = 8–25.5, η^2 = 0.092, p = 1.17E−5), giving medication with a median score of 14 (IQR = 7.75–22, η^2 = 0.094, p = 9.56E−6), shopping with a median score of 12.5 (IQR = 6–21, η^2 = 0.119, p = 6.31E−7), and helping with household tasks with median score of 10 (IQR = 5–18, η^2 = 0.054, p = 7.53E−4).

Communication-related variables were significantly associated with moderate-to-large effect sizes in FROM-16 scores. Respondents who reported that the diagnosis was not explained in a way they could understand had a median score of 22.5 (IQR = 14.5–24.25) compared with 7 (IQR = 2.25–12) for respondents who felt that the diagnosis was completely explained (η^2 = 0.151, p = 6.22E−5). Respondents who always had to ask for the test results to be explained reported a median score of 18 (IQR = 7.5–23) compared with 6 (IQR = 3–10) for those who did not (η^2 = 0.121, p = 1.29E−5).

4 Discussion

Our study provides new insights into the QoL of adult informal carers supporting people living with leukaemia. Whilst previous research has described experience measurement of selected populations of informal carers, we provide a global picture of QoL using a validated tool (i.e., FROM-16) and a conservative inferential testing regime. Our findings demonstrate associations with the QoL of informal carers to people living with leukaemia, with over a third of the respondents scoring above the FROM-16 critical threshold. These findings should be interpreted in the context of a convenience sample drawn largely from advocacy-connected populations and may not fully represent informal carers outside these networks.

The acute group reported a higher psychosocial burden, but the chronic group reported challenges as well. Acknowledging this burden for all informal carers of people with leukaemia could be a foundation for effective clinical and policy responses (9). Whilst statistical significance was assessed using a conservative Bonferroni adjustment, interpretation emphasises effect sizes (η^2) and their practical relevance in understanding informal carer burden.

We found that caregiving intensity, proxied by the number of hours providing care per week, was associated with higher FROM-16 scores (i.e., greater impact on QoL), with large effect sizes observed in both acute and chronic groups. This reinforces evidence from broader cancer caregiving studies that link high time investment to emotional and social strain (19) and expands on a qualitative investigation on the lived experiences of informal carers to people living with acute leukaemia (9). Specific care activities, such as giving medication and providing personal care, were associated with higher FROM-16 scores, suggesting that the nature of the caregiving task contributes to how the burden manifests. For the acute group, associations with childcare and financial management may reflect the more disruptive and urgent nature of care. Providing shopping support was associated with greater impact on QoL in the chronic group, possibly reflecting a cumulative strain of ongoing support.

We identified several associations with notably large effect sizes (η^2), suggesting meaningful differences in informal carer burden and potential importance for care delivery. In the chronic group, almost a quarter of the variation in the FROM-16 scores was associated with the number of hours of care provided (a very large effect size). In the acute group, the hours of care provided was associated with over a 10th of the variation, representing a moderate yet meaningful effect. This demonstrates that moderate effect sizes should not be overlooked as they may reflect substantial real-world differences in informal carer burden. These differences warrant attention in service planning, for instance, identifying informal carers who may need targeted support, prioritising referrals to psychosocial services, and expanding practical or respite provision. Other factors had large effect sizes for the chronic group, including communication-related variables, such as whether the diagnosis and the test results were completely explained. This suggests a role for information quality in shaping informal carer wellbeing. For the acute group, moderate effect sizes were noted for giving medications and managing finances, highlighting areas where targeted support may be beneficial. These findings point to actionable areas where interventions could make improvements to informal carers' QoL.

Our findings suggest a need for differentiated support strategies. The acute group may benefit from targeted respite services and

TABLE 2 Response counts for the caregiving activities and experience measures.

Category	Measure	Overall	Acute	Chronic
Sample size (*n*)	Count	511	299	212
Caregiving activities provided	Emotional support	454	271	183
	Communication	302	191	111
	Household tasks	378	232	146
	Personal care	211	175	36
	Collect prescriptions	264	183	81
	Providing transport	276	189	87
	Accompanying on trips or appointments	384	245	139
	Giving medication	215	163	52
	Childcare	127	105	22
	Managing finances	186	133	53
	Shopping	271	175	96
	Other support	23	10	13
Hours providing care per week	Less than 1 h	38	8	30
	1–4 h	60	19	41
	5–9 h	60	29	31
	10–19 h	48	25	23
	20–35 h	43	29	14
	36–49 h	24	18	6
	50+ hours	164	138	26
Diagnosis explained in a way informal carer could understand	Yes, completely	191	125	66
	Yes, to some extent	145	94	51
	No	27	15	12
Patient had treatment for their leukaemia	Yes	461	287	174
	No	47	11	36
Informal carer involved as much as they should have been in decisions about care	Yes, definitely	311	206	105
	Yes, to some extent	115	65	50
	No	21	11	10
Patient currently undergoing regular testing or monitoring	Yes	476	277	199
	No	31	22	9
Test results explained to informal carer in a way they could understand	Yes, completely	240	144	96
	Yes, to some extent	195	115	80
	No	32	13	19
Informal carer has to ask for test results to be explained	Yes, always	80	57	23
	Yes, sometimes	229	135	94
	No	141	71	70
Given or directed to:				
Information	Information received	343	219	124
	Information not received	161	78	83
Support	Support received	325	216	109
	Support not received	179	81	98
Support or information	Support or information received	417	267	150
	No support or information	87	30	57

TABLE 3 **Kruskal–Wallis tests of association between the FROM-16 scores and key demographics for caregivers providing support to patients with acute and chronic leukaemia[a].**

Key demographics	Acute group				Chronic group			
	n	Median (IQR)	*p*[c]	η^2[b]	*n*	Median (IQR)	*p*[c]	η^2[b]
Age (patient) (years)			2.80E−02				2.76E−01	
0–17	95	20 (15–25)			15	8 (3.5–12)		
18–25	36	15 (11.75–21)			15	9 (3.5–20.5)		
26–35	36	16 (11.75–19)			15	9 (4–17)		
36–45	35	15 (11–20)			21	12 (6–25)		
46–55	32	15 (6.75–22)			27	15 (6–22)		
56–65	37	14 (8–26)			59	9 (5–15)		
66–75	22	15.5 (6.75–21.75)			36	7 (2.75–10.5)		
76 and over	6	13 (8.25–22.25)			24	9.5 (3.75–16)		
Gender (patient)			4.20E−03				3.21E−01	
Female	132	14.5 (9–22)			77	7 (4–14)		
Male	143	17 (13–24.5)			124	9 (5–17)		
Age (informal carer) (years)			2.93E−02				2.49E−02	
18–25	7	21 (15–28.5)			4	20 (17.75–22)		
26–35	70	17 (13.25–23)			23	8 (5–16.5)		
36–45	112	17.5 (13–23)			38	10 (4.25–18.5)		
46–55	63	15 (12–24)			38	8 (5.25–17.75)		
56–65	32	12.5 (5.75–20.5)			58	9 (5.25–15.75)		
66–75	10	14 (6–20.5)			37	8 (5–15)		
76 and over	5	7 (6–12)			13	3 (2–6)		
Gender (informal carer)			1.95E−04	0.049			7.49E−02	
Female	218	17 (13–24)			135	10 (5–18.5)		
Male	66	14 (7–19)			66	7 (3.25–14)		
Country of residence			4.97E−01				4.19E−02	
Brazil	70	17 (12.25–23)			25	10 (6–18)		
Canada	2	13 (13–13)			22	4.5 (1–14.5)		
China	80	16 (12.75–21.25)			8	21 (14–23)		
Denmark	14	13.5 (9–16)			9	9 (3–11)		
France	33	17 (13–24)			4	22 (17.25–23.25)		
Republic of Korea	49	16 (11–23)			10	7 (0.25–18.5)		
United Kingdom	11	7 (5–23)			24	8 (5.75–10.25)		
Other countries	32	21.5 (10.5–29.25)			94	7 (5–15)		
Employment status			7.73E−04	0.068			1.21E−02	
Full-time carer (unable to work due to caring responsibilities)	43	21 (15.5–27.5)			4	22 (20.5–25.25)		
Employed	165	16 (11–22)			120	8 (3–17)		
Retired	24	11.5 (5.75–15.25)			60	7 (4–12.5)		
Stay-at-home parent	32	17.5 (13.75–24)			10	7.5 (5.25–14.5)		
Unemployed	19	16 (13.5–27.5)			5	17 (10–21)		

(Continued)

TABLE 3 Continued

Key demographics	Acute group				Chronic group			
	n	Median (IQR)	p^{c}	η^{2b}	n	Median (IQR)	p^{c}	η^{2b}
Other	11	14 (10.5–19.5)			7	15 (8–23)		
Household income			3.51E−02				1.45E−02	
High income	17	14 (8–17)			37	7 (3–12)		
Average income	203	16 (11–24)			121	8 (5–16)		
Low income	65	17 (14–25)			40	14 (5.75–21.5)		
Highest qualification			5.19E−01				3.79E−01	
No formal qualifications	18	14.5 (9.25–16)			6	8 (2.75–14.75)		
High school qualifications or diploma	77	16 (12–23)			45	8 (5–19)		
University—Undergraduate	118	17 (11–23)			84	7 (3–14.25)		
University—Postgraduate	40	14.5 (13–22.25)			35	10 (4.5–17)		
Career or technical	23	16 (12.5–24.5)			19	10 (7.5–18.5)		
Relationship to the patient			1.24E−03	0.053			6.05E−01	
Spouse or partner	83	15 (10–20)			142	8 (4–15.75)		
Parent or guardian	124	17 (13–23)			36	10 (5–17.5)		
Son or daughter	71	20 (14–26.5)			18	11 (6–17)		
Other relationship	21	10 (7–16)			16	6 (4.5–7.5)		
Lives with patient			2.73E−02				1.32E−01	
Yes	237	17 (12–23)			177	9 (5–17)		
No	51	14 (6–19)			28	6.5 (3–14)		
Continent			5.39E−01				4.74E−01	
Africa	1	9 (9–9)			13	6 (5–14)		
Asia	135	16 (12–22.5)			31	13 (3–21)		
Europe	73	16 (9–24)			83	8 (5–15)		
North America	6	14 (13–20.25)			49	7 (4–15)		
Oceania	7	27 (13–30)			8	4 (0.75–12.75)		
South America	73	17 (12–23)			28	10 (5.75–18.25)		

Testing was within the group, not between the groups.
FROM-16, Family Reported Outcome Measure; *IQR*, interquartile range.
[a] Response number is shown as n. Median values and interquartile range (IQR) are reported, and the p-values for the Kruskal–Wallis test are given.
[b] Eta-squared (η^2) indicates the effect size and is presented where variables are deemed to have a statistically significant difference in the median values within groups.
[c] Bonferroni-adjusted alpha = 0.05/33 = 0.0015 = 1.52E−3.
Statistical tests were conducted within subgroups, not between acute and group groups.

financial guidance, reinforcing calls from a qualitative study (9), whilst the chronic group may require sustained emotional and logistical support. The significant associations between caregiving roles and QoL highlight the importance of recognising informal carers as integral members of the care team.

4.1 Comparison with the wider FROM-16 literature

Our findings align with broader evidence from the FROM-16 literature, which has demonstrated psychosocial and practical burdens on family members across a range of conditions (8, 41–45). Validation work across several languages and settings further demonstrates the measure's robustness and sensitivity to diverse informal carer experiences (32, 46–48). Our findings contribute to this evidence base by providing an international description of informal carer burden in leukaemia using FROM-16.

4.2 Implications for policy and practice

Our findings have implications for clinical practice. Clinicians can play a key role by proactively engaging informal carers, ensuring clear communication, and facilitating access to support services. The FROM-16 is a brief, generic instrument that enables clinicians to systematically capture the impact of a patient's illness on informal carers, an aspect of care that can be overlooked in routine clinical

TABLE 4 **Kruskal–Wallis tests of association between the FROM-16 scores and caregiving activities and experience measures for caregivers providing support to patients with acute and chronic leukaemia[a].**

Variables	Acute group				Chronic group			
	n	Median (IQR)	p^c	η^{2b}	n	Median (IQR)	p^c	η^{2b}
Caregiving activities provided								
Emotional support	271	16 (12–23)	8.73E−01		183	8 (4–15.5)	1.10E−01	
Does not provide this	28	15.5 (7–23)			27	13 (5.5–22)		
Communication	191	17 (12–24)	3.70E−02		111	10 (5–19)	7.42E−03	
Does not provide this	108	15 (9–22)			99	7 (2.5–12.5)		
Household tasks	232	16 (12–24)	6.28E−02		146	10 (5–18)	7.53E−04	0.054
Does not provide this	67	16 (7.5–21.5)			64	6 (3–10)		
Personal care	175	18 (13–25)	9.93E−04	0.036	36	17 (8–25.5)	1.17E−05	0.092
Does not provide this	124	14 (9–20.25)			174	7 (4–14)		
Collect prescriptions	183	17 (13–25)	5.99E−03		81	11 (5–19)	2.72E−02	
Does not provide this	116	15 (9.75–20)			129	8 (4–15)		
Providing transport	189	16 (12–25)	2.95E−01		87	12 (5–19)	1.12E−02	
Does not provide this	110	16 (10.25–22)			123	7 (4–13.5)		
Accompanying on trips or appointments	245	16 (12–24)	2.17E−01		139	10 (5–18.5)	5.75E−03	
Does not provide this	54	16 (7.5–22)			71	6 (3–11.5)		
Giving medication	163	18 (14–25)	3.98E−06	0.071	52	14 (7.75–22)	9.56E−06	0.094
Does not provide this	136	14 (8–20)			158	7 (3–14)		
Childcare	105	20 (14–25)	9.72E−04	0.037	22	14.5 (7.75–24.75)	6.35E−03	
Does not provide this	194	15 (10–22)			188	8 (4–15.25)		
Managing finances	133	19 (14–26)	4.16E−05	0.056	53	14 (6–20)	3.92E−03	
Does not provide this	166	15 (9–21)			157	7 (4–14)		
Shopping	175	17 (12–24.5)	9.27E−02		96	12.5 (6–21)	6.31E−07	0.119
Does not provide this	124	16 (10–22)			114	6 (3–10.75)		
Other support	10	16 (11.25–25)	9.23E−01		13	10 (6–15)	8.28E−01	
Does not provide this	289	16 (12–23)			197	8 (5–17)		
Hours providing care per week			5.32E−06	0.130			5.65E−07	0.232
Less than 1 h	8	12 (3.75–14.5)			30	3.5 (2–6.75)		
1–4 h	19	13 (7.5–15.5)			41	7 (5–13)		
5–9 h	29	15 (7–19)			31	10 (6–18.5)		
10–19 h	25	14 (9–18)			23	8 (3.5–17.5)		
20–35 h	29	15 (13–21)			14	12.5 (5.25–19)		
36–49 h	18	14 (10.5–25)			6	14.5 (9.5–20.25)		
50+ h	138	20 (14–25)			26	19 (11.25–23.75)		

(Continued)

TABLE 4 Continued

Variables	Acute group				Chronic group			
	n	Median (IQR)	p[c]	η^2[b]	*n*	Median (IQR)	p[c]	η^2[b]
Diagnosis explained in a way informal carer could understand			7.52E−02				6.22E−05	0.151
Yes, completely	125	17 (12–24)			66	7 (2.25–12)		
Yes, to some extent	94	16.5 (13–22.75)			51	14 (7–19)		
No	15	24 (15.5–28)			12	22.5 (14.5–24.25)		
Patient had treatment for their leukaemia			5.70E−01				2.94E−01	
Yes	287	16 (12–23)			174	9 (5–17)		
No	11	16 (8.5–21)			36	7 (5–12)		
Informal carer involved as much as they should have been in decisions about care			8.25E−01				8.14E−02	
Yes, definitely	206	16 (12–24)			105	9 (4–16)		
Yes, to some extent	65	16 (11–22)			50	10 (5–19)		
No	11	14 (12.5–21.5)			10	15 (11.75–22)		
Patient currently undergoing regular testing or monitoring			4.89E−01				6.56E−01	
Yes	277	16 (11–23)			199	8 (5–16)		
No	22	16 (13–24.75)			9	12 (3–25)		
Test results explained to informal carer in a way they could understand			4.06E−01				1.92E−03	
Yes, completely	144	16 (9–23)			96	7.5 (3–12)		
Yes, to some extent	115	16 (13–23)			80	9.5 (5–19)		
No	13	20 (12–23)			19	16 (6–21.5)		
Informal carer has to ask for test results to be explained			3.73E−01				1.29E−05	0.121
Yes, always	57	16 (11–23)			23	18 (7.5–23)		
Yes, sometimes	135	17 (13–24)			94	10 (5–17.75)		
No	71	16 (9.5–22)			70	6 (3–10)		
Given or directed to:								
Information			4.87E−01				5.72E−01	
Information received	219	16 (11–23)			124	9.5 (5–16)		
Information not received	78	17.5 (13–23)			83	7 (4–19)		
Support			3.33E−01				4.07E−01	
Support received	216	16 (11–23)			109	8 (5–15)		
Support not received	81	17 (12–25)			98	9 (4.25–19)		
Support or information			6.37E−01				8.96E−01	
Support or information received	267	16 (11–23)			150	9 (5–16)		
No support or information	30	15.5 (12–27.75)			57	7 (3–19)		

Testing is within the group, not between the groups.

FROM-16, Family Reported Outcome Measure; *IQR*, interquartile range.

[a] Response number is shown as *n*. Median values and interquartile range (IQR) are reported, and the *p*-values for the Kruskal–Wallis test are given.

[b] Eta-squared (η^2) indicates the effect size and is presented where variables are deemed to have a statistically significant difference in the median values within groups.

[c] Bonferroni-adjusted alpha = 0.05/33 = 0.0015 = 1.52E−3.

Statistical tests were conducted within subgroups, not between acute and group groups.

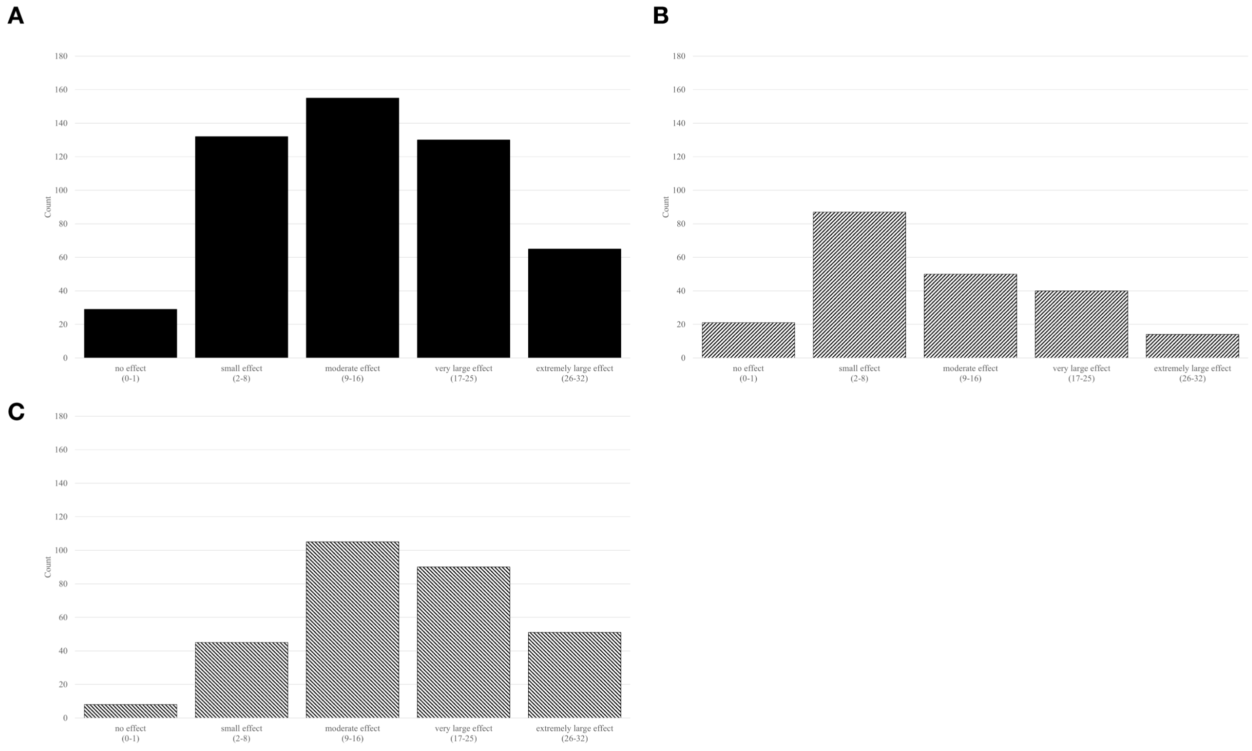

FIGURE 1
Distribution of the Family Reported Outcome Measure (FROM-16) scores overall **(A)** and in the acute **(B)** and chronic **(C)** groups.

practice. With a 2-min completion time, the FROM-16 could be used to provide insights into the patient's social and caregiving context and to facilitate structured discussions about emotional burden, coping, and support needs. This could help identify families at risk of distress and could be used to inform shared decision-making for more holistic patient care and to measure the impact of new treatments on the QoL of informal carers. Advocacy groups may find the study results helpful in calling for provision of differentiated services for carers of patients with acute and chronic leukaemia, particularly in developing informal carer-support mechanisms, informing regulatory priorities, and ensuring that implementation strategies reflect these realities.

4.3 Limitations and strengths

Whilst our survey was available in 14 language variations and promoted globally, the sample may not fully represent informal carers in regions with limited Internet access or weaker advocacy infrastructure. Although all survey languages corresponded to available FROM-16 translations, not all versions may have undergone full linguistic or psychometric validation. This may affect cross-cultural comparability and the interpretation of scores across language groups. Cultural norms, family roles, expectations of health, and perceptions of QoL vary across countries, as do healthcare systems and the availability of formal support services. Responses were concentrated in several countries, including Brazil, China, and the Republic of Korea, and this may influence the reported QoL and should be considered when interpreting cross-country variations. These contextual differences may shape informal carer experiences in ways not fully captured and limit the generalisability of our findings.

Our use of convenience sampling via leukaemia advocacy networks may have introduced selection bias, with respondents potentially more engaged or burdened than the broader informal carer population. Digitally excluded individuals may be underrepresented. Experiences in low-resource or non-network populations may differ and be underrepresented. These factors may limit the generalisability of the findings to the broader population of informal carers.

Our cross-sectional design limits causal inference: the observed associations between caregiving characteristics and QoL should not be interpreted as directional or causal. Needs and perceptions may evolve over time and were not detectable by our study, which is an inherent limitation of the cross-sectional design.

As our questionnaire was self-reported and completed online, the responses may be subject to recall bias or social desirability bias, and non-mandatory items resulted in missing data that may have influenced some subgroup analyses. Missing data arose from non-mandatory responses and were handled through item-level exclusion. This may reduce the precision of some subgroup estimates due to smaller denominators. Bias may arise if non-response is associated with caregiver characteristics or experiences, particularly in subgroup analyses.

Methodological work has enabled mapping the FROM-16 scores to EQ-5D utilities; however, the application of such economic modelling was beyond the scope of this study (49). Future studies may consider integrating these approaches to support health economic evaluation and could apply multivariable modelling approaches and longitudinal designs to identify independent predictors of informal carer QoL, controlling for confounding, and explore changes over time across diverse settings.

Nevertheless, the study has strengths: it is an international, multilingual survey focussing on the QoL of adult informal carers to people living with leukaemia. The use of the validated FROM-16 instrument enables a consistent and structured assessment of the impact of disease on family members across diverse settings. The large sample size and the inclusion of respondents from multiple countries enhance the breadth of perspectives captured. Stratified analysis by acute and chronic leukaemia provides clinically meaningful insights into differences in the caregiving burden associated with distinct disease trajectories. The use of non-parametric methods appropriate to the data distribution, alongside conservative Bonferroni adjustment, reduces the likelihood of false-positive findings. Reporting and interpreting effect sizes (η^2) facilitate understanding of the magnitude and practical relevance of the observed associations.

5 Conclusions

This international study highlights the substantial and variable impacts of leukaemia on the QoL of informal carers, with the acute group reporting greater burden than the chronic group. Caregiving intensity, proxied by the number of hours of care per week, and specific care tasks, particularly personal care and medication management, were associated with greater impacts on informal carer QoL. These findings suggest a need for tailored support strategies that recognise informal carers as integral to leukaemia care. Integrating informal carer needs into care pathways, improving communication, and ensuring access to emotional and practical support may help in providing family-centred care, with implications for clinical practice, service design, and policy, whilst recognising that the study reflects a convenience sample and may not fully represent all informal carers.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation. Contact ALAN (info@acuteleuk.org) to discuss access to data.

Ethics statement

This study involved an anonymous, online questionnaire with no clinical intervention, and thus minimal risk to respondents. Respondents were presented with information about the study's purpose, the voluntary nature of responding, and the intended use of their responses. Respondents were required to proceed through this information before access to the questionnaire was granted. No personally identifiable information was collected. All data were securely stored and processed per the UK General Data Protection Regulation (GDPR, 2018); ISO 20252 and 27001 standards for social research and information security management systems; and the Market Research Society Code of Conduct.

Author contributions

AP: Writing – original draft, Writing – review & editing, Conceptualization, Formal Analysis, Software, Visualisation. SN: Conceptualization, Funding acquisition, Supervision, Writing – review & editing. SG: Conceptualization, Funding acquisition, Methodology, Project administration, Supervision, Validation, Writing – original draft, Writing – review & editing. SS: Conceptualization, Supervision, Validation, Writing – review & editing.

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Conflict of interest

SS is a joint copyright owner of the FROM-16: Cardiff University receives royalties for some uses.

The remaining author(s) declared that this work was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The author SS declared that they were an editorial board member of Frontiers, at the time of submission. This had no impact on the peer review process and the final decision.

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