A MULTINATIONAL QUALITATIVE STUDY

Capturing the Lived Experiences of Informal Care in Acute Leukemia

Samantha Nier
Claud Theakston
Priscila Radu
David Mott
Nadine Henderson

NOVEMBER 2025

A MULTINATIONAL QUALITATIVE STUDY

Capturing the Lived Experiences of Informal Care in Acute Leukemia

Samantha Nier
Acute Leukemia Advocates Network, Bern, Switzerland

Claud Theakston
Office of Health Economics, London, UK

Priscila Radu
Office of Health Economics, London, UK

David Mott
Office of Health Economics, London, UK

Nadine Henderson
Office of Health Economics, London, UK

OFFICE OF HEALTH ECONOMICS
& ACUTE LEUKEMIA ADVOCATES NETWORK

Please cite this report as:

Nier S., Theakston C., Radu P., Mott D., Henderson N., 2025. Capturing the Lived Experiences of Informal Care in Acute Leukemia: A Multinational Qualitative Study. OHE Grant-Funded Research Report, London: Office of Health Economics. Available at: **https://www.ohe.org/publications/capturing-the-lived-experiences-of-informal-care-in-acute-leukemia** and **https://www.acuteleuk.org/publications**

Corresponding Author:
Nadine Henderson
nhenderson@ohe.org

Funding

This research paper was commissioned and funded by the Acute Leukemia Advocates Network (ALAN) who also conceived the initial idea for this study.

Acknowledgements

The authors are grateful to Professor Hareth Al-Janabi.

About OHE Grant-Funded Research Reports

OHE Grant-Funded Research Reports are intended to provide information on and encourage discussion about a topic. They are subject to internal quality assurance and undergo at least one external peer review, usually by a member of OHE's Editorial Panel. Any views expressed are those of the authors and do not necessarily reflect the views of OHE as an organization.

If a version of the Grant-Funded Research Paper's content is published in a peer-reviewed journal, that supersedes the Research Paper and readers are encouraged to cite the journal version instead

Table of Contents

Executive Summary

Key Points

- Providing informal care to someone living with acute leukemia imposes a severe multidimensional burden, reshaping relationships and affecting mental health, physical health, career, finances, social activities and more.
- People who provide informal care (hereafter referred to as *carers*) must balance their caregiving responsibilities with these other parts of their life.
- Despite informal care sometimes putting a strain on relationships and other aspects of day-to-day life, carers voiced that they were willing to put the patient first, often to the detriment of their own wellbeing.
- Carers require practical and emotional support, including via health and social care pathways and improved flexibility from employers.
- There is a need for greater consideration of carer burden in health technology assessments to ensure treatments that reduce carer burden are properly valued.

Acute leukemia imposes a heavy toll on both patients and carers

Acute leukemia is a group of aggressive cancers that affect the blood and bone marrow. Acute leukemia progresses rapidly, requires intensive treatment and often leaves patients heavily dependent on family or friends (unpaid, informal carers) for day-to-day support. There is a lack of evidence on how providing care for people with acute leukemia affects these informal carers. Recognizing and valuing the burden of informal care is increasingly important for clinical practice, health technology assessment , and the development of interventions, support and care strategies that address both the needs of patients and carers.

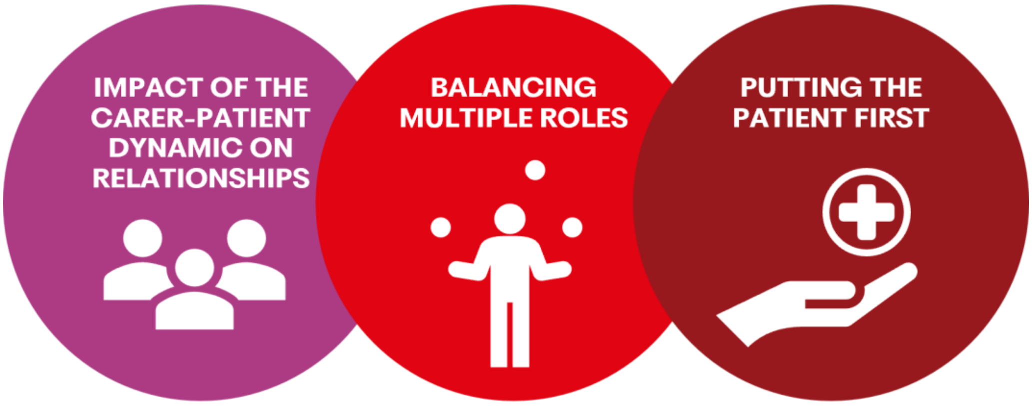
We spoke to carers in six countries

To better understand how providing informal care for an adult with acute leukemia affects carers' quality of life, we spoke to 60 informal carers, 20 from European Union countries – including 5 each from France, Germany, Italy and Spain – and 20 each from the UK and US. We asked them questions about the patient's diagnosis, how they became a carer and their experience of caregiving, as well as questions about their involvement in decision-making and which aspects of treatment they and the person they care for prefer.

Most carers reported a large impact

Over half of the carers who completed a questionnaire measuring the impact of illness on the quality of life of adult family members or partners reported experiencing a very large or extremely large impact.

We found three interlinking themes



Impact of the carer-patient dynamic on relationships

Becoming a carer introduces a new dynamic into the relationship between the carer and the person they're caring for. The journey of experiencing a diagnosis of acute leukemia and subsequent treatment can build resiliency and form stronger emotional bonds and intimacy. This was echoed in the process of facing an uncertain future together when starting treatment phases and living in the shadow of potential relapses.

Balancing multiple roles

One of the most prominent themes was the complexities of balancing existing responsibilities with the additional demands of caregiving. Carers often reported making professional and financial accommodations, such as requesting more flexibility, reducing working hours or taking a career break to enable them to devote enough time to their loved ones. Caregiving responsibilities were constant and wide-ranging, including housework, emotional support, assisting in treatment adherence, providing transport to medical appointments and performing administrative tasks. These additional tasks often meant that carers experienced role conflict, such as struggling to maintain the boundaries between their relationships to the person they care for or deprioritizing other aspects of their lives and relationships, due to competing demands on their time.

Putting the patient first

Another recurrent theme was putting the patient's needs above their own. The often-intense responsibilities and mental toll of caregiving can have a negative impact on a carer's own quality of life. Personal health, leisure activities and social interactions were frequently deprioritized. Understanding medical information about treatment options and considering decisions about their loved one's future was mentioned by some as a burden in itself. Despite the considerable and wide-ranging impact, many carers expressed that they are willing to prioritize the patient regardless of the burden on themselves.

Policy Implications

Our results demonstrate that informal caregiving imposes pressures that accumulate into a substantial, multidimensional burden. It is essential to ensure carers receive appropriate support, and that healthcare professionals and decision-makers recognize this burden.

Including carers in the clinical pathway

Improving access to targeted support could help improve carer quality of life. Practical steps could include mental health screening for carers in acute leukemia clinics and hematology wards and clear referrals to counselling, respite, and financial advice, timed to key stress points such as at diagnosis, onset of treatment, and hospital discharge. This could help to ease the strains of role conflict and prevent avoidable physical and mental health declines in carers.

Flexible workplace policy

To allow carers who are still working to continue to work while managing their caregiving responsibilities, employers should ensure that workplace policies align with what carers value most in their work environment, including accommodations such as remote working, flexible and adjustable hours, as well as formal carer leave policies.

Recognizing carers in treatment development

Therapies that shorten hospital stays, simplify dosing, or reduce toxicity can ease carers’ anxiety, improve sleep, and preserve daily routines and employment. Considering the perspectives and experiences of carers can help to ensure that, in the future, treatments and strategies developed in acute leukemia can benefit both patients and carers alike.

1. Background

Acute leukemia (AL) is a cancer of the white blood cells, which progresses rapidly and aggressively. It is characterized by the uncontrolled multiplication of malignant blood cells, leading to impairments in the function of the bone marrow (Okikiolu, Dillon and Raj, 2021). The disease is classified based on the type of malignant cells, the most common types being acute myeloid leukemia (AML) and acute lymphoblastic leukemia (ALL) (Okikiolu, Dillon and Raj, 2021). AML is most commonly found in adults, typically diagnosed at a median age of 70 years, ALL is most commonly found in children (Okikiolu, Dillon and Raj, 2021). Prognosis is largely determined by patient-related characteristics, such as age and co-morbidities, and disease-related factors such as white-cell count and genetic factors (Döhner, Weisdorf and Bloomfield, 2015).

The core treatment for people with leukemia who are fit enough to be given curative therapy consists of intensive chemotherapy, known as induction therapy, followed by consolidation, which provides an opportunity for remission, followed by maintenance therapy, which helps reduce the chances of a future relapse; maintenance therapy represents administration of less intensive, prolonged therapy after initial intensive induction-consolidation chemotherapy, and has become an emerging area of investigation in AML with recent agent approvals in this setting (Okikiolu, Dillon and Raj, 2021; Senapati, Kadia and Ravandi, 2023).

In AML, after induction chemotherapy, complete remission is seen in approximately 45%-73% of adults (Wysota, Konopleva and Mitchell, 2024). Patients who fail to achieve complete remission post two cycles of intensive induction regimen are classified as primary refractory disease and represent 20 to 30% of all newly diagnosed AML cases (Premnath and Madanat, 2023). For ALL, chemotherapy is found to be curative for 80-90% of children, but only around 40-50% of adults (Kantarjian and Jabbour, 2025). More recently, molecularly targeted drugs, novel formulation chemotherapies and immunotherapies are increasingly combined with conventional chemotherapy, particularly for those with specific mutations (Bhansali, Pratz and Lai, 2023; Lachowiez, DiNardo and Loghavi, 2023). The people not responding to this first-line therapy are known to have “refractory” disease. Similarly, in the past decade, new immunotherapies and the broader application of tyrosine-kinase inhibitors have substantially changed options for relapsed/refractory and high-risk patients (Perl et al., 2019; Shimony, Stahl and Stone, 2025).

The next step for most fit people who achieve remission is Hematopoietic Stem Cell Transplant (HSCT) (Thol and Ganser, 2020; Sun and Huang, 2022). In this procedure, patients receive a supply of healthy stem cells which aim to restore their bone marrow's function. Nevertheless, around 40% of people with AML who receive HSCT relapse following the procedure (Thol and Ganser, 2020). Despite recent advances in treatment options for leukemia, the outlook for those with relapsed or refractory AL is often poor and many subsequent treatment options are less effective compared to first-line treatments (Thol and Ganser, 2020; Raetz and Bhatla, 2012).

Most people with AL present with symptoms related to inadequate blood cell production, such as fatigue, frequent bruising or infection, but some cases are asymptomatic, only detectable by laboratory abnormalities (Okikiolu, Dillon and Raj, 2021). Nevertheless, patients' experience of living with AML features symptoms such as fatigue, weakness and shortness of breath, leading to significant impacts on their lives such as anxiety, reduced ability to function normally, and limited involvement in social and family life (Tomaszewski et al., 2016; ALAN et al., 2024). Common symptoms in people living with ALL can include unexplained fevers and unusual bleeding (Terwilliger and Abdul-Hay, 2017). As such, patients with AL often rely heavily on family members or friends as informal carers (Grover et al., 2019).

There is little evidence on carer burden for those providing informal care for people living with AL. Some recent evidence has shown that carers of patients with AL and other forms of leukemia or hematologic malignancies face considerable humanistic and economic burdens, particularly related to financial strain, emotional distress and disruption of family relationships, often as a result of providing practical support (Oliva et al., 2025; Yucel, Zhang and Panjabi, 2021). Many carers of people with hematologic malignancies report post-traumatic stress disorder, significant sleep problems and moderate-to-poor health-related quality of life (HRQoL) (Oliva et al., 2025; Yucel, Zhang and Panjabi, 2021).

1.1 Study Objectives

This study explores the impact of informal, unpaid caregiving on carer quality of life (QoL) and various aspects of day-to-day life, as well as carer involvement in decision making and their perspectives on and experiences with treatment options.

Obtaining a better understanding of the burden on carers of people with AL, as well as their views about AL treatment, can be useful for the development and appraisal of new treatments, as it enables a more accurate representation of the burden of the disease beyond that on the patient. The implications of this research can add to the body of evidence supporting the importance of carers’ perspectives in Health Technology Assessment (HTA) and how carer burden should be considered when assessing the value of new health technologies (Mott, 2018; Mott et al., 2023).

2. Methods

2.1 Preparatory research

To obtain an initial understanding of the existing research into carer perspectives and preferences in the context of AL, we conducted a literature review known as a rapid evidence assessment (REA). A REA provides a systematic approach to evidence gathering but places specific restrictions on the scope of the search to allow a focused review in a limited timeframe. The searches were conducted using Google Scholar and PubMed and sought to identify studies that had elicited the perspectives of informal carers of people with a diagnosis of AL, hematological malignancies or cancer more broadly, using qualitative research.

A total of 23 studies were identified from which key insights were extracted to inform the design of the planned study. Of these, 11 studies focused specifically on AL and blood cancers, with only one addressing the carer burden associated with ALL specifically. An additional 10 studies examined carer burden in the context of cancer more broadly. The remaining two studies, though focused on other diseases, were included due to their relevant methodological contributions. Of the 23 studies, 13 were primarily qualitative, with the majority (10) employing semi-structured interviews. Complete interview guides were available for three of these, and partial guides or topic outlines were accessible for another three. The remaining 10 studies comprised literature reviews, case studies, evidence syntheses, and quantitative research.

The key findings from the literature review were instrumental in shaping both the discussion guide and the overall approach to the study. The literature specific to ALL and AML predominantly focused on the experiences and burdens faced by carers, including those who were bereaved (McCaughan et al., 2019). Most of these studies employed semi-structured interviews, with some also collecting data using validated instruments such as the Family Burden Interview (FBI) (Pai and Kapur, 1981) and the Carer Strain Index (CSI) (Robinson, 1983; Sullivan, 2002). Commonly reported themes included emotional distress, unexpected changes in the patient's condition, facilitators and barriers to caregiving, and the broader impact of caregiving on family dynamics. Example questions used in these studies included: "*What do you wish you had known?*", "*What else might have been helpful?*" (Tan et al., 2023), and "*What has been challenging?*" (Fisher et al., 2021).

Literature addressing other types of cancer explored similar themes but also placed particular emphasis on carer preferences regarding the location of care and end-of-life experiences (Ozdemir et al., 2021; Lee et al., 2015; Poor et al., 2022; McCaughan et al., 2019). Additional recurring themes included recognition of the carer as a key member of the care team (Bechthold et al., 2023), discordance in treatment preferences between patient and carer, and the importance of social connectedness (Bechthold et al., 2023; Fisher et al., 2021; Ozdemir et al., 2021). These studies typically involved both carers and patients through semi-structured interviews and surveys. Example questions for patients and carers respectively included: "*If you had to make a choice now, would you prefer treatment that extends life as much as possible, or would you want treatment that gives you minimal pain and discomfort?*" and "*If you had to recommend a treatment to (Patient) now, would you recommend a treatment that extends life as much as possible, or would you recommend a treatment that focusses on relieving pain and discomfort as much as possible*?" (Ozdemir et al., 2021).

2.2 Study population

Adult (18 years or older) carers of an adult patient with a diagnosis of AL (irrespective of when the diagnosis was made or the current remission status), who lived in the UK, US, France, Germany, Italy, or Spain at the time of the interview, were eligible. Any relationship to the patient was considered acceptable, including partners, other family members or friends. Bereaved carers of an AL patient were excluded on the grounds that this would likely generate themes beyond the scope of the study objectives and could potentially cause undue distress for interviewees.

The minimum sample size by country included 20 participants each from the UK and USA, and five participants from each of the remaining countries (France, Germany, Italy and Spain). Given that evidence suggests that more informal carers are women and we added a 20% minimum quota for male carers.

Country	**UK**	**US**	**France**	**Germany**	**Italy**	**Spain**
No of interviews	**20**	**20**	**5**	**5**	**5**	**5**

2.3 Recruitment

A specialist recruitment agency that connects patients and carers with researchers, identified participants and scheduled virtual interviews. For all English-speaking interviews, members of the OHE team (NH, PR, CT) conducted the interviews. For all non-English-speaking interviews, an interviewer working on behalf of the recruitment agency conducted the interviews (having received training from the OHE team) in the primary local language of the participant's country of residence. All interviews were recorded, transcribed, and where necessary, translated into English. The transcripts were the key output of these activities.

2.4 Study design

We used interpretive qualitative methodology to guide the use of semi-structured interviews to elicit the views of carers of people living with AL, information on their QoL and impact of caregiving, their involvement in decision making and their perspectives and priorities with regards to treatment options. Data for this study were collected from June to September 2024. Study design, data collection and analysis were conducted in accordance with the CASP Qualitative Checklist (Critical Appraisal Skills Programme, 2018), ensuring transparency in sampling, researcher-participant relationships, ethical oversight, data saturation and analytic coherence. Interview guides were reviewed by patient advocates from the Acute Leukemia Advocates Network (ALAN) to ensure they were appropriate for the study's objectives.

Baseline data on each participant, including demographics, caregiving status, employment status and Family Reported Outcome Measure (FROM-16) questionnaire, were collected by the recruitment agency ahead of the interviews (Golics et al., 2014). The FROM-16 is a 16-item questionnaire that assesses the impact of a person's health condition on the quality of life of their adult family members or partners (Golics et al., 2014). It can measure the secondary burden of disease on family members, informing clinical decisions and research across various medical conditions. The FROM-16 has two domains: Emotional (6 items, max score 12) and Personal and Social Life (10 items, max score 20). Each item has three response options (not at all, a little, a lot), scored 0-2 points. The total score ranges from 0 to 32, with higher scores indicating greater impact on the family member's quality of life. The validated score bands are: 0-1 (no effect), 2-8 (small effect), 9-16 (moderate effect), 17-25 (very large effect), and 26-32 (extremely large effect). The FROM-16 has demonstrated high internal consistency, reproducibility, construct validity, and responsiveness to change (Golics et al., 2014).

The interviews lasted for around 60 minutes and were conducted online. The interviews were semi-structured based on an interview guide with three main sections: (1) diagnosis/becoming a carer, (2) experience of caregiving, and (3) treatment preferences/decision-making. The interview guide was developed based on the objectives of the study and findings of the rapid evidence assessment. If the patient was currently in remission, we asked participants to consider their experiences when the person they care for was receiving active treatment. The English language interview questions can be found in the Appendix.

As this is reflexive qualitative research, we acknowledge the potential for interviewer bias, whereby the interviewer's language, tone, or personal background may have influenced participant responses. To reduce bias, we used a standardized interview guide. Interviewers were trained to encourage open-ended responses and to minimize prompts that could suggest preferred answers. Researchers reflected on their own assumptions and documented potential points of influence during the analytic process, in line with best practices for reflexivity in qualitative research.

2.5 Data analysis

The interview transcripts were analyzed using NVivo, a qualitative data management platform. Analysis of interviews was conducted using a reflexive thematic approach to identify key themes and insights as outlined by Braun and Clarke (2006). This involved generating succinct labels (codes) that capture and evoke important features of the data that might be relevant to addressing the research question. Three of the authors (PR, CT and NH) each coded a proportion of the transcripts, given the large number of interviews conducted. Working on the same NVivo project/file, updating a codebook and ongoing dialogue between the researchers allowed the team to code concurrently. To ensure consistency of approaches, each of the team reviewed a subset of transcripts coded by another author and resolved any differences through discussion. Next, we conducted a process of generating and refining themes, where themes are defined as patterns of shared meaning underpinned by a central concept or idea.

2.6 Ethical considerations

Ethical approval was obtained from City St George's, University of London (formerly City, University of London) Economics Research Committee (ETH2324-1660). All the participants were provided with a participant information sheet and informed consent form (ICF) which was collected by the recruitment agency in writing and consent was further confirmed verbally at the beginning of the interview. Consent for anonymized quotations to be included in any future publication was obtained in the ICF.

3. Results

3.1 Demographics and carer experience

We conducted semi-structured interviews with 60 carers –20 from each of the UK and USA, and 5 from each of France, Germany, Italy and Spain. There was a near-even split between the genders, with 43% male and 57% female carers interviewed. The majority (82%) of carers lived in the same household as the patient. A small majority of carers (52%) were aged between 31 and 50, while 40% were aged between 51 and 70, 5% were under 30 and 3% were over 70. The majority of participants (60%) were in employment (47% full-time; 13% part-time). Lastly, most carers were either caring for a parent (38%) or their partner (37%). A smaller proportion of carers were caring for their sibling (15%), their child (5%) or another relation (5%).

TABLE 1: DEMOGRAPHICS SUMMARY

CHARACTERISTIC		COUNT (n=60)	PERCENTAGE
Gender	**Female**	34	57%
	Male	26	43%
Living with patient	**Yes**	49	82%
	No	11	18%
Age	**18 to 30**	3	5%
	31 to 50	31	52%
	51 to 70	24	40%
	71 or above	2	3%
Working status	**Full time**	28	47%
	Part time	13	22%
	Not working	12	20%
	Retired	7	12%
	Parent	23	38%

CHARACTERISTIC		COUNT (n=60)	PERCENTAGE
Relationship (the patient is the carers…)	**Partner**	22	37%
	Sibling	9	15%
	Child	3	5%
	Other	3	5%
The patient was diagnosed with AL…	**Less than 6 months ago**	7	12%
	Between 6 and 12 months ago	13	22%
	Between 1 and 3 years ago	16	27%
	More than 3 years ago	22	37%
	Missing	2	3%

A table of individual participant characteristics can be found in the Appendix.

Most patients had symptoms before diagnosis, including fatigue, weakness, fever, pains and swelling, bruising, and frequent infections. However, many carers had reported that the diagnosis was unexpected. There was variation in the time since diagnosis; 12% had been diagnosed less than 6 months ago, 22% had been diagnosed between 6 and 12 months ago, 27% had been diagnosed between 1 to 3 years ago, and 37% had been diagnosed over 3 years ago.

There was some variation in how carers reported their experience and satisfaction with the healthcare system. While the majority reported positive experiences, generally attributed to their perception that they received the right amount of information and involvement from healthcare professionals (HCPs), a significant minority reported mixed or negative experiences. Carers who reported negative experiences said that it was generally driven by delayed diagnosis, insufficient information and the feeling that HCPs were being prescriptive in that they would insufficiently involve the carers in treatment decisions, or a failure to consider multiple treatment options.

3.2 FROM-16 questionnaire scores

Responses to the FROM-16 questionnaires indicate a significant carer burden in AL. When considering the total score bands based on responses to the 16 items, over half of our sample (n=35, 58%) indicated a substantially large carer burden, with 38% (n=23) reporting a "very large" effect and 20% (n=12) reporting an "extremely large" effect. 40% (n=24) reported a "moderate" effect. None of the carers (0%) included in our sample reported a "small" FROM-16 effect (Table 2). A single (n=1, 2%) FROM-16 questionnaire was missing.

When splitting the results between the two domains, we observed that carers reported a slightly greater impact on their emotional well-being than on their personal and social lives. Note that each FROM-16 item has three response options ("not at all", "a little", "a lot"), scored 0-2 points. The average FROM-16 emotional score was 7.5 out of 12 (63%), while the FROM-16 personal score averaged 11.5 out of 20 (57%). This is consistent with interview findings which revealed that emotional strain remains a dominant theme in carers' experiences.

TABLE 2: FROM-16 QUESTIONNAIRE RESULTS

FROM-16		**COUNT (n=60)**	**PERCENTAGE**
Severity score band	**Small**	0	0%
	Moderate	24	40%
	Very large	23	38%
	Extremely large	12	20%
	Missing	1	2%

Source for score bands: (Golics et al., 2014)

3.3 Thematic analysis

Thematic analysis of the interview transcripts generated three main themes related to the impacts on carer quality of life: (1) impact of the carer-patient dynamic on relationships, (2) balancing multiple roles, and (3) putting the patient first. Themes and sub-themes are outlined in Table 3.

TABLE 3: THEMES & SUB-THEMES

THEME	SUBTHEME	EXEMPLARY QUOTE
Impact of the carer-patient dynamic on relationships	Resiliency and intimacy in relationships	*"I think it has really reinforced our commitment to one another, so I'd say it's improved in a positive way."* **UK12: Patient's Male Partner**
	Facing uncertainty together	*"You just don't know what to expect every day and going into this blindly and every day you're making decisions or trying to figure out what to do and what not to do. It's a guessing game"* **US17: Patient's Male Partner**
Balancing multiple roles	Making professional and financial accommodations	*"Well, I had to put my job on ice, I've taken some time off work in order to stand by him. My whole life is on ice for now."* **IT2: Patient's Daughter**
	Providing constant and multi-faceted care	*"I mean, it was just all day. He would set up camp on the couch when he was at home or go to bed and he couldn't do anything, so I had to clean, cook, provide him with food, keep the kids away, make sure he was mentally okay, emotionally okay."* **US1: Patient's Female Partner**
	Experiencing role conflict	*"Personally, we struggle with the patient/caregiver versus husband/wife thing a little bit. It's hard to… We definitely were in the just patient/caregiver mode for quite a few years and now, we're starting to get back into where, okay, we can feel like husband and wife again a little bit."* **US4: Patient's Female Partner**
Putting the patient first	Becoming an advocate and expert in leukemia	*"I will also always do my own research, just to see what else is out there and clinical trials and all of that."* **US2: Patient's Daughter**

THEME	SUBTHEME	EXEMPLARY QUOTE
	Overlooking own needs at the detriment of personal quality of life	*"I would definitely put my well-being behind that of my mother. First, I would make sure that everything goes well and that she is doing well, and then I can look at the impact on myself."* **DE5: Patient's Daughter**
	Limited freedom & social isolation	*"I lost a lot of friends because I couldn't keep up socially. Even… I love to play basketball and go to the gym, but ever since last year, it's been really difficult to do all that."* **UK5: Patient's Son**
	Considering consequences of future treatment decisions	*"I want the best for him and I'm on board with it and I'm involved in that decision, […]. It affects me 'cause I want the best for him in that regard."* **US9: Patient's Sister**

3.3.1 Impact of the carer-patient dynamic on relationships

Resiliency and intimacy in relationships

The impact of diagnosis and treatment of AL can have varying effects on a carer's relationship with their loved one. Across settings, carers frequently reported that the demands of AL drew families closer. Shared adversity fostered stronger emotional bonds, increased openness, and a renewed appreciation of everyday moments. This sense of mutual commitment often served as an internal motivator that sustained carers through demanding periods. While most find that the shared experience strengthened their relationship, others find that it imposes a strain. Nevertheless, the majority of carers suggested that their relationship with the patient had improved.

> *"We're facing this issue together has brought this sense of unity, because we communicate more now very openly about the fears, hopes, the feelings about the plans for the future and our daughter. […] The times that I probably should have*

> *been at work, now we spend it together. So, I'd say it's really improved in closeness, more intimacy."*
> **UK3: Patient's Male Partner**

For those looking after their partner, some couples experienced significant relational strain, and a minority reported being on the brink of separation. A number of carers also reported problems with sexual intimacy.

> *"Our relationship almost didn't survive. We came close to separating. Our lives have changed drastically"*
> **FR3: Patient's Male Partner**

Some carers reported concerns about the impact of the diagnosis and treatment on their children. Carers were worried about the psychological impact of witnessing their family member experience side effects and pain associated with treatment. Other concerns included spending less quality time together as a family, not being able to provide sufficient support, children developing mental health disorders such as anxiety, and children being forced to become more independent and take on additional responsibilities.

> *"I'm also worried about my daughter who is also affected. She has the same panic attacks I have, often at school."*
> **DE4: Patient's Female Partner**

> *"I worry about not raising my child properly, because he's seeing all this going on. I worry about the lasting effects of stress on him."*
> **UK7: Patient's Daughter**

For those caring for a parent, child or other relative, the experience of caregiving can still impact a carer's relationship due to the time and effort required.

> *"My fiancée will say I have a second wife because I'm always with him. Like I told you, it affects my relationship, but like I told you, she's also understanding."*
> **UK10 Patient's Brother**

Facing uncertainty together

Carers reported the significant impact of uncertainty around treatment symptoms, achieving remission and planning for the future in general. For many, living "in the shadow" of a relapse or treatment complication dominated daily life. Carers described organizing routines around hospital visits, infection control, and real-time clinical updates, demonstrating a common, prevailing mindset of short-term planning. Carers reported the necessity of living week to week or day to day, without thinking about long-term plans like vacations and retirement. The uncertainty of the future also has a knock-on effect on carers' freedom and personal lives.

> *"Also, being aware that you live one day at a time. You don't have to make huge plans for the future because you never know what might happen."*
> **IT3: Patient's Daughter**

Uncertainty also manifests in the very short term, especially during periods of active treatment, due to the side effects of treatment and the consequent mental health impacts.

> *"It can be quite random. It'll be a day where he'll wake up and he's completely depressed about the whole thing"*
> **UK11: Patient's Male Partner**

3.3.2 Balancing multiple roles

Making professional and financial accommodations

Carers often expressed a professional impact due to becoming a carer; this was seen through a variety of avenues, including requesting more flexibility from their current job, cutting down working hours, taking a career break, leaving the workforce, retiring early and learning new skills or changing jobs to enable them to work from home.

> *"That's why I had to give up my job and just be a main carer, and make sure she's okay, because that's my main priority at the moment."*
> **UK18: Patient's Daughter**

> *"I've had to find a job that's flexible, so working from home more and being a bit more flexible for going to appointments. So, having an employer that understands that has been quite important because I can't get to the office every day."*
> **UK9: Patient's Son**

> *"I quit my job, and my job is just my husband, honestly."*
> **US4: Patient's Female Partner**

Changes to working hours and jobs were often associated with a negative financial impact. Decisions were framed as trade-offs between income security and being physically present. Some carers reported other avenues of receiving financial support, such as from family, online charitable collections, and using their savings.

> *"Yes, it did definitely have a big financial impact. So, I just have to make do with what we have. I took early retirement and collect social security."*
> **US17: Patient's Male Partner**

> *"I used my savings. And I also used my business. I pawned it a little."*
> **ES1: Patient's Male Partner**

More than half of the carers we spoke to reported significant financial impacts, such as increased outgoings due to medical insurance, treatment, transportation, parking and COVID-19 testing. Some carers expressed that they would like to leave their jobs to care for their loved one full-time but could not for financial reasons.

> *"A lot of our funds are going to insurance. […] We're paying more, […] much more than usual, before he was diagnosed."*
> **US16: Patient's Female Partner**

Providing constant and multi-faceted care

Carers reported a multitude of tasks and responsibilities, with routines extending well beyond emotional support to include medication management, transport, household tasks, administrative paperwork, and clinical monitoring. Many carers expressed that their caregiving responsibilities were time-consuming, which in turn meant that their routines were disrupted as well as reducing their ability to travel or take holidays. Almost all carers interviewed described themselves as the main carer. Although most suggested that they had some level of additional support, for example, from other family members, a small number reported having no support.

> *"My wife… I've got a couple of grown kids, they help their uncle out. A couple of his friends, we've got a good tag team."*
> **US14: Patient's Brother**

> *"Everyone always shows a lot of understanding and says, "I can understand, no problem", but nobody ever thinks to come round and help or anything like that."*
> **DE5: Patient's Daughter**

As part of their responsibilities as carers, participants reported several activities that they would not have performed before, and which affected their personal lives.

> *"Normally most of the things that I do, I wasn't doing before, so most of the household tasks and stuff like that, I wasn't the one doing them, but now I had to start working part-time so I could have time to actually take care of her, the household, my daughter, personal care, and also her medical management."*
> **UK3: Patient's Male Partner**

The most commonly quoted responsibilities included: housework, emotional support, taking the patient to medical appointments, helping the patient with treatment, hygiene, accompanying in physical activities, administrative tasks and advocacy, with fewer people mentioning monitoring and visiting the patient in the hospital as primary responsibilities.

> *"Practical tasks are like going food shopping, arranging the appointments for blood tests or for the swab that she had to do when she was doing the chemo, taking her to the hospital, picking her up, seeing the doctor, picking up medical prescriptions, standing by her as well."*
> **IT5: Patient's Daughter**

> *"On a typical day, I get him up, have to help him get washed usually, I have one of those showers you can hold on, so I help shower […] then I help him get dressed, it's hard for him to move a little bit, but he can do some himself, […], then I do all the cooking and cleaning because he can't do any of that. I keep up on all the appointments."*
> **US14: Patient's Brother**

> *"Okay, in a typical week, basically I do everything. How can I say? Cook, I clean for him, I help him get around, I take him to basically all appointments. When he needs to go to the store or whatever, I provide the transportation. Whenever he has any questions, which I don't know, I do the online research or the reading, or I'll basically reach out to the transfusion nurse and ask follow up questions."*
> **US18: Patient's Nephew**

The number of hours spent on caregiving varied considerably, from some carers saying they provide "constant care" whereas others reported spending less than two hours a day. Some carers mentioned that caregiving felt like an additional job or being on call 24/7.

> *"He [the patient] would set up camp on the couch when he was at home or go to bed and he couldn't do anything, so I had to clean, cook, provide him with food, keep the kids away, make sure he was mentally okay, emotionally okay. So, didn't really ever stop."*
> **US1: Patient's Female Partner**

> *"Every day, every minute of the day. I had to sleep in another bedroom, 'cause I was disturbing him, and I had to do everything for him"*
> **UK14: Patient's Female Partner**

> *"When she was still having treatment? I would say I was on standby 24 hours a day. I mean, practically I was probably giving her about 7 or 8 hours [of care]."*
> **UK20: Patient's Sister**

Many felt that they no longer had time to themselves, which also reflected in the 'Limited freedom & social isolation' sub-theme. Another commonly mentioned impact was the time commitment associated with medical appointments and transportation.

> *"Because during all his treatments, his chemotherapy, his fever, he was hospitalized […] that means two hours of travel each way."*
> **FR2: Patient's Female Partner**

Experiencing role conflict

Many interviewees experienced some level of role conflict during their time as carers; for some, taking on this additional role meant that they had less time and energy to devote to other existing aspects of their lives. For some interviewees, caregiving responsibilities often competed with other roles and demands on their time. Some found it difficult to simultaneously be a partner and carer, for example, and many reported having to mentally switch between roles, using terms like "caregiver mode" and "partner mode" to reflect different mindsets.

> *"It feels like my role has shifted from being a wife to a nurse, or even a maternal figure, which I don't like at all."*
> **FR2: Patient's Female Partner**

> *"Personally, we struggle with the patient/caregiver versus husband/wife thing a little bit. It's hard to… We definitely were in the just patient/caregiver mode for quite a few years and now, we're starting to get back into where, okay, we can feel like husband and wife again a little bit."*
> **US4: Patient's Female Partner**

> *"Well, my birthday card said 'to my loving carer', put it that way."*
> **UK14: Patient's Female Partner**

> *"She needs to stay occupied. I feel that I have another child, to be honest with you, that I'm responsible for, to entertain, to be a taxi."*
> **US12: Patient's Daughter**

3.3.3 Putting the patient first

Becoming an advocate and expert in leukemia

Many carers reported actively researching additional information on AL, either for personal interest or to complement what information they have been given by the HCPs. These carers felt they had to rapidly develop disease-specific knowledge, routinely engaging clinicians, organizing appointments, and seeking second opinions. They valued clear, jargon-free communication and preferred interactions with HCPs that recognize carers as active partners rather than passive supporters.

Some carers had the responsibility of administering treatment or ensuring treatment adherence.

> *"I read through the information. I went privately to a meeting without him, so I could get the insights that I needed via the doctors etc. They basically informed me of all of the different types of leukemia there is and what one he has, etc., and what I need to look out for, as symptoms etc., like that."*
> **UK11: Patient's Male Partner**

> *"We lived 45 minutes away from the hospital and I was to administer 14 drugs and learn about all the scheduling and all of that. At the height being completely terrified and overwhelmed by what was happening and the risk of doing something wrong was… It was traumatizing in a way that I can't express really because I didn't sleep."*
> **US3: Patient's Mother**

> *"I'm in the room all the time so when the doctor is talking, he's really talking to me. […] because he knows basically that I'm sort of the one that needs to absorb all of this information. My mother is also relying on me to remember everything that the doctor has said."*
> **US8: Patient's Son**

The level of input of carers in treatment decision-making was variable, some had no involvement, some felt they had a supportive role, some felt like joint decision-makers and others felt they were the main decision-maker. Carers generally had a supportive role in making treatment decisions, alongside responsibilities such as advocacy and treatment management. Carers often reported deferring to medical practitioners and the patients to ultimately make decisions.

> *"No, I wasn't involved. However, they always told me what the treatments entailed."*
> **FR4: Patient's Mother**

> *"If there were more treatment options and we had to consider them, then of course it would be fine to talk it with her as she is the main affected one. And also, to help her to choose. If we have to choose and we can help her, then maybe we can tell her what would be best for her. But in the end, the last decision is hers."*
> **ES3: Patient's Sister**

> *"I would say more than personally involved. I'm really, totally involved and probably, my mother is relying on me really to even make the decision."*
> **US8: Patient's Son**

Views were generally split between whether having an involvement in treatment decision-making was a burden or not.

> *"She just lets me make the decisions. She doesn't really want to make any decisions and it was the same… my dad had dementia and she left everything to me, and we would sit there in these meetings and she'd say, "No my daughter makes all the decisions". So, is it a burden? I don't feel it a burden."*
> **UK13: Patient's Daughter**

> "I felt a bit overwhelmed. I was like: "This is my mother's life." What am I supposed to say? It doesn't feel nice when you have to make decisions about someone else's life."
> **DE5: Patient's Daughter**

Overlooking own needs at the detriment of personal quality of life

Personal health, leisure, and social connections were frequently deprioritized. Carers viewed self-care as secondary to the patient's needs yet acknowledged cumulative fatigue and emotional strain. Indeed, the majority of carers reported that their quality of life had decreased since becoming a carer. Female carers were more likely than male carers to report specific aspects of caregiving that impacted their quality of life and were more likely than male carers to experience worsened quality of life.

Carers expressed a range of emotional impacts as a result of the diagnosis and treatment of AL. These include: worry, frustration, helplessness, regret, resentment and fear.

> *"The burden has grown a lot bigger, I think. I'm forever alert; I'm very tense; stressed out; mentally charged I may say. And those panic attacks, I suffer a lot from them I must admit."*
> **DE4: Patient's Female Partner**

Some carers reported feeling obligated to care for their loved one. Some of these carers referred to cultural expectations to care for their loved ones.

> *"It's simply my duty. It's something I have to do. It's like … I don't love doing it but I don't have a choice."*
> **DE2: Patient's Female Partner**

> *"In our culture [...], we have to look after our parents […] so, we see that as a blessing."*
> **UK6: Patient's Son**

Carers of individuals with AL reported experiencing elevated levels of anxiety and depression, often stemming from the emotional burden of caregiving, uncertainty about disease progression, and the demands of navigating complex medical systems.

> *"As a caregiver, I felt down, I felt depressed."*
> **UK10: Patient's Brother**

> *"Emotionally, it has added a significant mental load […] with anxiety, stress, and worry."*
> **FR2: Patient's Female Partner**

> *"I guess my mental health probably wasn't great looking back"*
> **UK19: Patient's Daughter**

Some carers reported negative impacts on their own health as a result of the caregiving burden, these included difficulties with sleep, doing less exercise, mental and physical fatigue.

> *"I have difficulties breathing often, but I try not to show it. You sleep less or almost nothing. You have to physically move him around, my back has been affected."*
> **IT3: Patient's Daughter**

> *"My health and fitness definitely deteriorated. My weight gained, so quality of life in terms of, I suppose, my physical health was not good."*
> **UK19: Patient's Daughter**

A handful of carers expressed that the diagnosis of AL had made them more likely to get medical check-ups and testing.

Only a minority of carers mentioned that they actively used support groups, and generally found them helpful. The majority, however, felt that they could not regularly attend such group meetings for logistical reasons, lack of awareness, or not finding much use in them. Many felt that it was easier to engage with other carers through self-directed online groups.

Limited freedom & social isolation

Many carers reported a negative impact on their social life due to their caregiving responsibilities. This mainly manifested through not being able to attend social gatherings because of time constraints or fatigue.

> *"Going out is no longer an option. I haven't been on holiday for a while either. It's just not possible. That's why my own private life has basically been reduced to zero."*
> **DE5: Patient's Daughter**

> *"I lost a lot of friends because I couldn't keep up socially."*
> **UK5: Patient's Son**

> *"I golfed and played some sports […] I cut most of that stuff out. I'm trying to figure out how to get back into that and take care of my wife at the same time."*
> **US17: Patient's Male Partner**

Some carers also expressed that speaking to friends and family had become a chore or were no longer being invited to social gatherings. These restrictions on travel and social engagement often result in shrinking already suboptimal support networks.

> *"I used to interact with people a lot, but I don't know, I've gone a bit quiet, kind of thing. I've just gone into myself […] I'm too tired to even talk to somebody about it, kind of thing. Sometimes it's nice to talk, but then, I just shut myself down"*
> **UK8: Patient's Daughter**

Considering consequences of future treatment decisions

For many carers, the prospect of having to make future treatment decisions carries a mental toll; these concerns mainly relate to the impact on the patient, the possibility of losing their loved one and sometimes the continued responsibilities associated with caregiving.

> *"My biggest concern is that when we go for the next examinations, they will say that everything has been in vain, and that the cancer has spread and that it is coming to an end."*
> **DE5: Patient's Daughter**

Concerns about the future may be present even when the patient is in remission, particularly in the time immediately before routine appointments to monitor recurrence.

> *"It's just until you have these six months appointments, [...] and it gets to that appointment day, and it becomes a bit, as it increases, the white blood cells, it's like a bit of a waiting game. And it's been a long wait, but nothing's happened, but it does feel like every six months we're going to get bad news."*
> **UK9: Patient's Son**

When asked about concerns for the future, some expressed concerns about their own future but this was mainly secondary to the well-being of the patient.

> *"My biggest concern is my mum [...] what's going to happen. How long this is going to go on for. Yeah, my biggest concern is my health as well, at the same time. But yeah, more than my health, is my mum."*
> **UK8: Patient's Daughter**

To explore treatment preferences for life extension versus quality of life, we asked carers to proxy-report the treatment perspectives of the patients they care for. Responses were evenly split, with roughly half indicating a preference for quality of life and half for life extension. While these proxied patient views may not wholly align with the true preferences of the patient, they nevertheless allow us to explore treatment experience discordance and carers' perceptions of differences in preferences. Importantly, most carers thought that their preferences would align with the wishes of their loved ones. However, we found significant treatment preference discordance, with carers much more strongly prioritizing treatments that improve patient quality of life over life extension. These preferences were often influenced by the age of the patient, the presence of children or grandchildren, wishes to maintain dignity and avoidance of pain or suffering. Some carers had already discussed this hypothetical situation with their loved ones.

> *"The thing is, this is not a life anymore at a certain point because her treatment is really hard."*
> **ES2: Patient's Sister**

> *"I think he'd be more about extending life, because of his grandkids, and he does talk about – he has mentioned something about that, which was nice to hear"*
> **UK7: Patient's Daughter**

3.4 Differences by demographic information

Although the three core themes cut across all 60 interviews, their intensity and practical consequences varied by demographic context, particularly gender.

Women had larger average FROM-16 scores (19.4) compared to men (18.2), indicating that the impact of caregiving on the emotional as well as personal and social life of female caregivers was slightly greater than that reported by men. Additionally, women were more likely to report "very large" or "extremely large" scores than men, with 21 women reporting these scores compared to 13 men.

Similarly, in our interviews, women generally reported lower QoL, listing a greater number of caregiving responsibilities and associated QoL impacts. Partners most commonly experienced role conflict. Employed full-time carers articulate the highest tensions between professional & financial accommodations and providing constant care. They value employer flexibility, remote working, predictable appointment schedules, and remote consultation options. This is particularly true for younger carers, where career impact is often front-of-mind. Social life curtailment is felt as a sharp lifestyle change. Middle-aged carers often juggle multiple dependents (children, ageing parents), experiencing role conflict and financial strain. Older carers often mentioned physical limits and fatigue more than financial concerns.

3.5 Impact of COVID-19

The post-lockdown impact of the COVID-19 pandemic was generally perceived as positive by carers, primarily due to the broader acceptance of flexible working hours and remote work arrangements. These changes provided greater autonomy, enabling carers to better balance employment responsibilities with caregiving duties. However, for individuals whose diagnosis or treatment occurred during the pandemic, the experience was largely negative. Key concerns centered on the heightened risk of infection for those receiving care. Moreover, hospital policies, particularly restrictions on visitors, contributed to increased anxiety among both carers and patients.

4. Discussion

4.1 Overview of principal findings

This multinational qualitative study of 60 informal carers for adults with AL demonstrates the significant impact on carers' quality of life. Indeed, over 58% of respondents scored in the highest two FROM-16 score bands; indicating a 'very large' to 'extremely large' burden, suggesting that many carers of people with AL could be deemed by clinicians to be at risk of requiring additional support services (Shah et al., 2023). Reflexive thematic analysis revealed three interlinking themes that explain this burden:

1. The carer-patient dynamic reshapes relationships: often deepening emotional closeness but sometimes straining intimacy and widening family roles.
2. Balancing multiple roles: carers routinely juggle employment, household management, and complex clinical tasks, generating financial pressure and role conflict.
3. Putting the patient first: carers become 'lay experts' and advocates, frequently at the expense of their own physical, emotional and social well-being.

Together, these findings show that AL caregiving imposes simultaneous relational, practical and personal pressures that accumulate into a substantial, multidimensional burden.

4.2 Findings in context

Our findings corroborate and extend prior research in AL and other hematological and solid cancers, which consistently highlight a severe, multifaceted carer burden. Large cross-sectional surveys exploring carer burden in AL in India reported markedly high burden, anxiety and depression when social support and financial buffers were thin, echoing our participants' accounts of curtailed income and leisure (Kumari et al., 2018; Grover et al., 2019). A scoping review of 71 studies confirms these patterns across AML and other hematological malignancies, documenting uniformly poor HRQoL, large out-of-pocket costs and a scarcity of tailored supports, gaps echoed by our respondents (Yucel, Zhang and Panjabi, 2021). A recent 27-country survey of 571 family members likewise found that 40% reported a tangible decline in their own quality of life, most commonly emotional distress and disrupted eating habits (Oliva et al., 2025). While our findings suggested many carers felt sufficiently informed and involved in treatment decisions, a significant minority felt the opposite. Oliva et al. (2025) found comparable communication gaps: 15% of family members in their study felt the diagnosis should have been conveyed more sensitively, nearly 30% judged it outright “insensitive,” and 55% still wanted clearer written information from their clinic. Such experiences can needlessly exacerbate carer burden. The multifaceted carer burden manifests in our three interconnected themes.

4.2.1 Impact of the carer-patient dynamic on relationships

Our findings mirror broader research highlighting that while caregiving can strain intimacy and alter partner dynamics, it often deepens emotional closeness and mutual support. While caregiving can provide elements of purpose and closeness, one study suggests these are usually only present while workload, costs, and financial/psychological pressures remain manageable (Grover et al., 2019). Family members frequently provide day-to-day emotional support in addition to household, transport and finance tasks (Oliva et al., 2025). Couples frequently navigate shared emotional burdens, including grief, uncertainty, and fears about recurrence (Mullis et al., 2024). Indeed, a synthesis of carers’ experiences in hematological cancers noted that carers’ fear for the future is pervasive (Cormican and Dowling, 2023), signaling a need for better support in coping with uncertainty.

4.2.2 Balancing multiple roles

A number of studies exist in the broader literature in caregiving for AL and blood cancer, which also explore the challenges associated with role conflict in the family system, round-the-clock care and associated financial challenges. One qualitative study noted a similar theme, highlighting the challenges of “juggling act of competing roles in the family system” (Fisher et al., 2021). Our study, however, delves deeper into how this role conflict manifests, exploring the challenges associated with balancing the role of carer with an individual's other social roles, including not only their pre-existing relationships and family system, but also professional responsibilities and the broader social circle.

Additionally, there is some literature corroborating our findings on the potential for significant professional impacts and associated financial toxicity. For example, it has been reported that caregiving in AL frequently derails careers; carers cut hours or exit employment, accruing significant financial strain (Yuen and Wilson, 2021; Qiu and Wu, 2024). Oliva et al. (2025) quantified these pressures: one-third had to cut work hours or leave employment and nearly half reported direct financial hardship. Additionally, our findings support others who note that regular, around-the-clock care and vigilance bring fatigue, sleep debt and health decline, reinforcing our respondents’ descriptions of self-care erosion (Mullis et al., 2024; Qiu and Wu, 2024).

These patterns can be situated within Pearlin's Stress Process Model of Family Caregiving, which distinguishes primary stressors (the patient's illness), secondary role strains (conflicts among work, family and self-care) and the carer's appraisal of these (Pearlin et al., 1990; Adelman et al., 2014). Our theme of balancing multiple roles maps onto the model's secondary stress processes, showing how employment and financial pressures compound the primary stressor of AL. These findings highlight the need to recognize the significant challenge associated with taking on additional social caregiving roles, roles which can often benefit others at the expense of the individual.

4.2.3 Putting the patient first

Our results resonate with other literature demonstrating that carers overwhelmingly prioritize patient QoL and wishes when participating in treatment choices. A recent survey of cancer carers found that they place the highest importance on patient-centered factors, quality of life, physical and emotional well-being, and the patient's wishes, when participating in treatment decision-making (Bechthold et al., 2023). A study by Ozdemir et al. (2021) in Singapore, including 285 advanced-cancer patient-carer dyads, found that treatment-preference discordance was common (60%) and demonstrated that carers with significant treatment preference discordance with their respective patient are associated with worse carer burden and lower caregiving esteem. They also found that when discordance occurred, 57% of carers opted for a balanced ("moderate life extension + symptom management") approach, only 23% favored pure symptom management, and 20% endorsed maximal life extension; nearly half of the patients, by contrast, chose maximal life extension (Ozdemir et al., 2021).

We found that carers may not sufficiently consider their own health and lives due to considering the patient they care for and may be unwilling to consider themselves in decision-making. When asked directly, many carers reported that they did not consider themselves when making decisions. However, there may be discrepancies between how this question was answered and carers' overall concerns for the future and prioritization of patient QoL over life extension. Several participants in our study rejected the term "burden". Despite discussing the considerable time and effort associated with caregiving, many carers reported that their loved one was not a burden to them. This sentiment has been captured in other settings, such as dementia care (Nguyen et al., 2021). Self-perceived carer burden may also differ by the ethnicity of the carer (Parveen, Morrison and Robinson, 2011; Fenton et al., 2022). While we did not collect demographic data relating to ethnicity specifically, we note that a small number of our interviewees did explicitly mention the importance of their religion and culture in framing their attitudes towards caregiving, particularly the importance of self-sacrifice to provide for the needs of others. Exploring this further could be an avenue for future research.

4.3 Implications

Our findings have implications for clinical practice, policymaking, future research and evolving health-technology-assessment (HTA) methods that increasingly recognize family spillover effects.

AL imposes a significant, multidimensional burden on carers. Our reflexive themes highlight the impact of the carer-patient dynamic on relationships, requiring carers to balance multiple roles, often causing them to neglect their own health as a result of putting the patient first. The themes reveal substantial unpaid labor, productivity losses and quality-of-life decrements that extend beyond the patient, pointing to under-recognized societal costs. Many of these impacts are also demonstrated by our quantitative findings: 58% of respondents scored in the top two FROM-16 bands, indicating a very-to-extremely large impact on their quality of life, and indicate and quantify what HTA agencies may consider a "substantial carer effect". Acknowledging this burden is the foundation for effective clinical and policy responses.

Proactive, tailored support for carers is required. As many carers place their own needs last and underuse formal services, there remain challenges in implementing appropriate interventions. Some practical steps could include routine psychosocial screening in hematology clinics, clear referral routes to counselling, respite and financial advice, and employer policies enabling flexible or remote working and protected leave. Offering these resources at predictable stress points in the care pathway, such as at diagnosis, onset of treatment, and hospital discharge, could help to ease the strains of role conflict and prevent avoidable physical and mental health declines in carers.

Treatments developed to benefit patients can also create measurable health spillovers in carers. It is important to recognize the spillover effects of disease and medical treatments in HTA, both positive and negative. For example, treatments that shorten hospital stays, simplify dosing or minimize toxicities can yield direct and indirect benefits for carers, such as reduced anxiety, better sleep, and preserved family routine, as well as financial and economic gains through sustained employment and productivity. Failing to count these spillovers in cost-effectiveness analyses risks systematically undervaluing innovations and supportive care services that benefit carers as well as patients.

Evidence of carer impacts should be included in HTA. Many HTA agencies are becoming increasingly willing to consider carer burden. For example, in the UK, the National Institute for Health and Care Excellence (NICE) considers carer burden, either quantitatively using utilities or through qualitative deliberation where quantifiable evidence is lacking, provided there is evidence to show the effect on carers is substantial

(NICE, 2022). However, in practice, only a small proportion of NICE technology appraisals had included carer HRQoL impacts, and these are often limited to a number of conditions, such as pediatric and rare diseases (Pennington, 2020; Kanters et al., 2024). Our mixed-methods data provides that evidence on the carer burden associated with AL. The qualitative insights reported here can guide deliberations by committees when marginal survival benefits must be balanced against quality-of-life considerations.

Across Europe, methodologies have historically varied by country, though the new EU Joint HTA process is moving toward greater harmonization. There is often limited inclusion of carer QoL considerations, often focusing on costs rather than QoL/Quality Adjusted Life Years (QALYs). While some countries consider the societal perspective, others see carer effects as optional. As NICE is recognized as an influential HTA body (Henderson et al., 2023), greater inclusion of carer burden in UK appraisals may set a precedent for upcoming potential EU joint assessments and ICER’s modified societal analyses, accelerating a carer-inclusive approach to value determination. Despite these measures, carer benefits are often not fully captured in cost-effectiveness analyses. Given this, the use of rich qualitative data can be used to fill the evidence gap and ensure carer impacts and preferences are taken into consideration. To ensure this inclusion, there is a continued need for the generation of more robust and generalizable data.

There remain significant data limitations. Data on carer QoL is rarely collected in clinical trials, and there is a paucity of data that can be used in HTA. Increased efforts should be made to generate robust data, including trial-based and longitudinal studies tracking how burden evolves across treatment phases, and other forms of real-world evidence. Additionally, patient and carer preference data can help to inform treatment development and reimbursement decisions. Further areas of research could focus on the appropriateness of the use of carer-specific measures in HTA and potentially explore mapping between measures such as CarerQol and FROM-16 to generic preference-based measures such as EQ-5D-5L. The generation of further robust data, both quantitative and qualitative, will enable more accurate modelling of family spillovers as well as deliberative processes in HTA, and can incentivize innovative interventions that matter most to carers and patients alike.

4.4 Strengths and limitations

To our knowledge, this is the first large multinational study exploring the perspectives and experiences of carers of adults with AL across Europe and North America. We primarily use in-depth reflexive thematic analysis, while also collecting a standardized burden measurement (FROM-16). Based on the questionnaire, this allows us to demonstrate quantitatively that burden is reported as severe across diverse health-systems, and qualitatively, why: caregiving deepens intimacy while simultaneously creating role conflict; treatment decisions impose additional emotional labor; and burden is stratified by gender, employment and life-stage, with women and full-time workers particularly strongly affected.

We note a number of limitations to our study. Firstly, one (n=1) FROM-16 questionnaire was incomplete and omitted from the final results. Additionally, thirteen questionnaires were missing responses to a single question. FROM-16 guidelines state that if one question is left unanswered, this is scored 0, and the scores are summed and expressed as usual out of a maximum of 32 (Cardiff University, 2025; Golics et al., 2014), therefore these responses were included. One of these participant questionnaires would have seen their burden category get worse (from very large to extremely large) if the participant had answered “a little” (score = 1) to this missing question. Five of these questionnaires would have required a response of “a lot” (score = 2) to change the category. Therefore, our FROM-16 responses may be a slight underestimate of carer burden.

Secondly, there are some limitations to our collection of demographic information. For example, in addition to the omission of ethnicity, no data on income or rural/urban living of the carers were collected. These characteristics may have an impact on the extent and manifestation of carer burden. Additionally, due to the larger number of younger, fully employed carers, our sample may not be fully representative.

Finally, because all three coders are English-speaking and coded English transcripts translated from the original language, there is the potential for some loss of meaning and nuance in interviews from non-Anglophone countries. However, as each non-English-speaking country was smaller in sample size than the US and UK, the effect of this on overall findings is likely negligible. Given the small sample size, country-level insights could not be extracted for these markets. Nonetheless, the analysis is intended to provide an overarching view rather than a comparative assessment across countries. As mentioned in the methods, some degree of interviewer bias is possible, and should be considered when interpreting findings.

5. Conclusion

Caring for an adult with acute leukemia places a heavy, wide-ranging burden on families. Across six countries, nearly six in ten carers told us the illness had a very large or extreme impact on their lives. Our thematic analysis explains why. First, the carer–patient dynamic reshapes relationships, often deepening closeness, but sometimes straining intimacy and family roles. Second, carers routinely juggle multiple roles: employment, household management and complex health tasks, with clear financial pressure and time loss. Third, most put the patient first, sacrificing their own health, sleep, social life and leisure to keep treatment on track.

These pressures add up. Carers described constant vigilance, limited freedom to plan for the future, and a persistent anxiety about relapse. Women and those working full-time reported particularly sharp trade-offs. While many felt informed and included by clinicians, a sizeable minority did not, and practical supports were patchy or hard to access.

A number of things can be done to ease these pressures. Hematology services should routinely assess carer needs, with simple pathways to counselling, respite and financial advice at predictable pinch points: diagnosis, treatment start and hospital discharge. Employers should offer flexible work, remote options and protected leave so carers are not forced to choose between income and care. Health technology assessors should consider carer impacts such as time, wellbeing and productivity when judging the value of treatments, especially those that shorten hospital stays, simplify dosing or reduce side-effects.

Carers are essential partners in care. Recognizing their contribution, and designing services, workplaces and treatment decisions that reduce avoidable strain, will improve life not only for patients, but for the families who stand behind them.

6. References

Adelman, R.D., Tmanova, L.L., Delgado, D., Dion, S. and Lachs, M.S., 2014. Caregiver burden: a clinical review. *JAMA*, 311(10), pp.1052–1060. 10.1001/jama.2014.304.

ALAN, CMLAN, CLLAN and Picker, 2024. *Global Leukemia Experience Survey 2023 Report*. [online] Picker Institute Europe. Available at: https://acuteleuk.org/wp-content/uploads/2024/10/P-101824-Global-Leukemia-Experience-Survey-2023-Report-FINAL.pdf [Accessed 27 Aug. 2025].

Bechthold, A.C., Azuero, A., Puga, F., Ejem, D.B., Kent, E.E., Ornstein, K.A., Ladores, S.L., Wilson, C.M., Knoepke, C.E., Miller-Sonet, E. and Odom, J.N., 2023. What Is Most Important to Family Caregivers When Helping Patients Make Treatment-Related Decisions: Findings from a National Survey. *Cancers*, 15(19), p.4792. 10.3390/cancers15194792.

Bhansali, R.S., Pratz, K.W. and Lai, C., 2023. Recent advances in targeted therapies in acute myeloid leukemia. *Journal of Hematology & Oncology*, 16(1), p.29. 10.1186/s13045-023-01424-6.

Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), pp.77–101. 10.1191/1478088706qp063oa.

Cardiff University, 2025. *Family Reported Outcome Measure (FROM-16)*. [online] Cardiff University. Available at: https://www.cardiff.ac.uk/medicine/resources/quality-of-life-questionnaires/family-reported-outcome-measure [Accessed 24 July 2025].

Cormican, O. and Dowling, M., 2023. The hidden psychosocial impact of caregiving with chronic haematological cancers: A qualitative study. *European Journal of Oncology Nursing*, 64, p.102319. 10.1016/j.ejon.2023.102319.

Critical Appraisal Skills Programme, 2018. *CASP Qualitative Research Checklist*. Available at: https://casp-uk.net/casp-checklists/CASP-checklist-qualitative-2024.pdf .

Döhner, H., Weisdorf, D.J. and Bloomfield, C.D., 2015. Acute Myeloid Leukemia. *New England Journal of Medicine*, 373(12), pp.1136–1152. 10.1056/NEJMra1406184.

Fenton, A.T.H.R., Ornstein, K.A., Dilworth-Anderson, P., Keating, N.L., Kent, E.E., Litzelman, K., Enzinger, A.C., Rowland, J.H. and Wright, A.A., 2022. Racial and ethnic disparities in cancer caregiver burden and potential sociocultural mediators. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, 30(11), pp.9625–9633. 10.1007/s00520-022-07367-x.

Fisher, C.L., Mullis, M.D., Kastrinos, A., Wollney, E., Weiss, E.S., Sae-Hau, M. and Bylund, C.L., 2021. “Home wasn’t really home anymore”: Understanding caregivers’ perspectives of the impact of blood cancer caregiving on the family system. *Supportive Care in Cancer*, 29(6), pp.3069–3076. 10.1007/s00520-020-05811-4.

Golics, C.J., Basra, M.K.A., Finlay, A.Y. and Salek, S., 2014. The development and validation of the Family Reported Outcome Measure (FROM-16)© to assess the impact of disease on the partner or family member. *Quality of Life Research*, 23(1), pp.317–326. 10.1007/s11136-013-0457-y.

Grover, S., Rina, K., Malhotra, P. and Khadwal, A., 2019. Caregiver Burden in the Patients of Acute Myeloblastic Leukemia. *Indian Journal of Hematology and Blood Transfusion*, 35(3), pp.437–445. 10.1007/s12288-018-1048-4.

Henderson, N., Brassel, S., O’Neill, P., Allen, R., Largeron, N. and Garau, M., 2023. *NICE enough? Do NICE’s Decision Outcomes Impact International HTA Decision-making?* [Consulting Report] Available at: https://www.ohe.org/publications/nice-enough-do-nices-decision-outcomes-impact-international-hta-decision-making/ .

Kantarjian, H. and Jabbour, E., 2025. Adult Acute Lymphoblastic Leukemia: 2025 Update on Diagnosis, Therapy, and Monitoring. *American Journal of Hematology*, 100(7), pp.1205–1231. 10.1002/ajh.27708.

Kanters, T.A., Hezik-Wester, V. van, Boateng, A., Cranmer, H., Kvamme, I., Santi, I., Al-Janabi, H. and Exel, J. van, 2024. Including carer health-related quality of life in NICE health technology assessments in the United Kingdom. *Health Economics, Policy and Law*, pp.1–13. 10.1017/S1744133124000124.

Kumari, R., Kohli, A., Malhotra, P., Grover, S. and Khadwal, A., 2018. Burden of caregiving and its impact in the patients of acute lymphoblastic leukemia. *Industrial Psychiatry Journal*, 27(2), pp.249–258. 10.4103/ipj.ipj_75_18.

Lachowiez, C.A., DiNardo, C.D. and Loghavi, S., 2023. Molecularly Targeted Therapy in Acute Myeloid Leukemia: Current Treatment Landscape and Mechanisms of Response and Resistance. *Cancers*, 15(5), p.1617. 10.3390/cancers15051617.

Lee, J.E., Shin, D.W., Cho, J., Yang, H.K., Kim, S.Y., Yoo, H.S., Jho, H.J., Shin, J.Y., Cho, B., Park, K. and Park, J.-H., 2015. Caregiver burden, patients' self-perceived burden, and preference for palliative care among cancer patients and caregivers. *Psycho-Oncology*, 24(11), pp.1545–1551. 10.1002/pon.3827.

McCaughan, D., Roman, E., Smith, A.G., Garry, A.C., Johnson, M.J., Patmore, R.D., Howard, M.R. and Howell, D.A., 2019. Perspectives of bereaved relatives of patients with haematological malignancies concerning preferred place of care and death: A qualitative study. *Palliative Medicine*, 33(5), pp.518–530. 10.1177/0269216318824525.

Mott, D.J., 2018. Incorporating Quantitative Patient Preference Data into Healthcare Decision Making Processes: Is HTA Falling Behind? *The Patient - Patient-Centered Outcomes Research*, 11(3), pp.249–252. 10/gdtkc6.

Mott, D.J., Schirrmacher, H., Al-Janabi, H., Guest, S., Pennington, B., Scheuer, N., Shah, K.K. and Skedgel, C., 2023. Modelling Spillover Effects on Informal Carers: The Carer QALY Trap. *PharmacoEconomics*. [online] 10.1007/s40273-023-01316-0.

Mullis, M.D., Wollney, E.N., Bylund, C.L., Campbell-Salome, G., Wright, K.B., Sae-Hau, M., Weiss, E.S., Rajotte, M. and Fisher, C.L., 2024. "A Caregiver's Marriage": The Impact of Blood Cancer on the Spousal Connection. *Cancer Care Research Online*, 4(2), p.e055. 10.1097/CR9.0000000000000055.

Nguyen, H., Nguyen, T., Tran, D. and Hinton, L., 2021. "It's extremely hard but it's not a burden": A qualitative study of family caregiving for people living with dementia in Vietnam. *PLOS ONE*, 16(11), p.e0259788. 10.1371/journal.pone.0259788.

NICE, 2022. NICE health technology evaluations: the manual.

Okikiolu, J., Dillon, R. and Raj, K., 2021. Acute leukaemia. *Medicine*, 49(5), pp.274–281. 10.1016/j.mpmed.2021.02.004.

Oliva, E.N., Ionova, T., Nier, S., Pemberton-Whiteley, Z., York, N., Costello, D. and Salek, S., 2025. Disease and treatment burden in patients with leukaemia: family members/partner perspective. *Frontiers in Hematology*, [online] 4. 10.3389/frhem.2025.1570055.

Ozdemir, S., Ng, S., Malhotra, C., Teo, I., Finkelstein, E.A., and COMPASS Study Group, 2021. Patient–Caregiver Treatment Preference Discordance and Its Association With Caregiving Burden and Esteem. *Innovation in Aging*, 5(3), p.igab020. 10.1093/geroni/igab020.

Pai, S. and Kapur, R.L., 1981. The burden on the family of a psychiatric patient: development of an interview schedule. *The British Journal of Psychiatry: The Journal of Mental Science*, 138, pp.332–335. 10.1192/bjp.138.4.332.

Parveen, S., Morrison, V. and Robinson, C.A., 2011. Ethnic variations in the caregiver role: A qualitative study. *Journal of Health Psychology*, 16(6), pp.862–872. 10.1177/1359105310392416.

Pearlin, L.I., Mullan, J.T., Semple, S.J. and Skaff, M.M., 1990. Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist*, 30(5), pp.583–594. 10.1093/geront/30.5.583.

Pennington, B.M., 2020. Inclusion of Carer Health-Related Quality of Life in National Institute for Health and Care Excellence Appraisals. *Value in Health*, 23(10), pp.1349–1357. 10.1016/j.jval.2020.05.017.

Perl, A.E., Martinelli, G., Cortes, J.E., Neubauer, A., Berman, E., Paolini, S., Montesinos, P., Baer, M.R., Larson, R.A., Ustun, C., Fabbiano, F., Erba, H.P., Stasi, A.D., Stuart, R., Olin, R., Kasner, M., Ciceri, F., Chou, W.-C., Podoltsev, N., Recher, C., Yokoyama, H., Hosono, N., Yoon, S.-S., Lee, J.-H., Pardee, T., Fathi, A.T., Liu, C., Hasabou, N., Liu, X., Bahceci, E. and Levis, M.J., 2019. Gilteritinib or Chemotherapy for Relapsed or Refractory FLT3-Mutated AML. *New England Journal of Medicine*, 381(18), pp.1728–1740. 10.1056/NEJMoa1902688.

Poor, E., Ya-Ning, C., Iadonisi, K., Tan, K.R. and Bryant, A.L., 2022. Exploring Experiences of Bereaved Caregivers of Older Adult Patients With Acute Myeloid Leukemia. *Clinical journal of oncology nursing*, 26(2), pp.135–139. 10.1188/22.CJON.135-139.

Premnath, N. and Madanat, Y.F., 2023. Paradigm Shift in the Management of Acute Myeloid Leukemia—Approved Options in 2023. *Cancers*, 15(11), p.3002. 10.3390/cancers15113002.

Qiu, M. and Wu, Y., 2024. Understanding the experience of family caregivers of patients with leukemia: a qualitative analysis of online blogs. *Humanities and Social Sciences Communications*, 11(1), p.374. 10.1057/s41599-024-02830-y.

Raetz, E.A. and Bhatla, T., 2012. Where do we stand in the treatment of relapsed acute lymphoblastic leukemia? *Hematology*, 2012(1), pp.129–136. 10.1182/asheducation.V2012.1.129.3800156.

Robinson, B.C., 1983. Validation of a Caregiver Strain Index. *Journal of Gerontology*, 38(3), pp.344–348. 10.1093/geronj/38.3.344.

Senapati, J., Kadia, T.M. and Ravandi, F., 2023. Maintenance therapy in acute myeloid leukemia: advances and controversies. *Haematologica*, 108(9), pp.2289–2304. 10.3324/haematol.2022.281810.

Shah, R., Finlay, A.Y., Salek, S.M., Nixon, S.J., Otwombe, K., Ali, F.M. and Ingram, J.R., 2023. Meaning of Family Reported Outcome Measure (FROM-16) severity score bands: a cross-sectional online study in the UK. *BMJ Open*, 13(3), p.e066168. 10.1136/bmjopen-2022-066168.

Shimony, S., Stahl, M. and Stone, R.M., 2025. Acute Myeloid Leukemia: 2025 Update on Diagnosis, Risk-Stratification, and Management. *American Journal of Hematology*, 100(5), pp.860–891. 10.1002/ajh.27625.

Sullivan, M.T., 2002. Caregiver Strain Index (CSI). *Journal of Gerontological Nursing*, 28(8), pp.4–5. 10.3928/0098-9134-20020801-03.

Sun, W. and Huang, X., 2022. Role of allogeneic haematopoietic stem cell transplantation in the treatment of adult acute lymphoblastic leukaemia in the era of immunotherapy. *Chinese Medical Journal*, 135(8), pp.890–900. 10.1097/CM9.0000000000001898.

Tan, K.R., Chan, Y.-N., Iadonisi, K., Poor, E., Betancur, S., Jung, A., Sagester, K., Coppola, S., Pergolotti, M., Kent, E.E., Schwartz, T., Richardson, D. and Bryant, A.L., 2023. Perspectives of caregivers of older adults with acute myeloid leukemia during initial hypomethylating agents and venetoclax chemotherapy. *Supportive Care in Cancer*, 31(1), p.95. 10.1007/s00520-022-07565-7.

Terwilliger, T. and Abdul-Hay, M., 2017. Acute lymphoblastic leukemia: a comprehensive review and 2017 update. *Blood Cancer Journal*, 7(6), p.e577. 10.1038/bcj.2017.53.

Thol, F. and Ganser, A., 2020. Treatment of Relapsed Acute Myeloid Leukemia. *Current Treatment Options in Oncology*, 21(8), p.66. 10.1007/s11864-020-00765-5.

Tomaszewski, E.L., Fickley, C.E., Maddux, L., Krupnick, R., Bahceci, E., Paty, J. and van Nooten, F., 2016. The Patient Perspective on Living with Acute Myeloid Leukemia. *Oncology and Therapy*, 4(2), pp.225–238. 10.1007/s40487-016-0029-8.

Wysota, M., Konopleva, M. and Mitchell, S., 2024. Novel Therapeutic Targets in Acute Myeloid Leukemia (AML). *Current Oncology Reports*, 26(4), pp.409–420. 10.1007/s11912-024-01503-y.

Yucel, E., Zhang, S. and Panjabi, S., 2021. Health-Related and Economic Burden Among Family Caregivers of Patients with Acute Myeloid Leukemia or Hematological Malignancies. *Advances in Therapy*, 38(10), pp.5002–5024. 10.1007/s12325-021-01872-x.

Yuen, E.Y.N. and Wilson, C.J., 2021. The Relationship between Cancer Caregiver Burden and Psychological Outcomes: The Moderating Role of Social Connectedness. *Current Oncology*, 29(1), pp.14–26. 10.3390/curroncol29010002.

7. Appendix

7.1 Interview guide

Diagnosis/Becoming a carer

1. What is your relationship with the person that you care for?*
    a. [Probe]“Were you living together at the time of diagnosis?”
    b. [If not] “Are you living together now?”
    c. [Probe] “Are you the main caregiver?”
2. Are you currently working?
3. When did they first receive their diagnosis of acute leukemia?*
4. What led to the diagnosis?*
    a. [Probe] “What kind of symptoms had they been experiencing?”
5. Were you with the patient on the day of diagnosis? Did you expect the diagnosis of acute leukemia?
6. Is the person you care for currently undergoing active treatment?
    a. [Probe] First line versus maintenance versus in remission/relapses
7. What was your experience with the healthcare system? Do you feel you were well informed about the condition and the treatment options?
    a. [Probe] “Were you provided or directed to sources of information?”
    b. [Probe] “How did the doctor/healthcare professional describe the treatment options available?”
    c. [Probe] “To what extent are you involved in treatment decisions”
8. Do you feel you have been sufficiently involved in decisions?*
    a. Would you like to be more involved?

Experience of caregiving

9. Could you describe your caregiving responsibilities on a typical day?
    a. [Probe] Examples, ensuring they take their medication, cooking, cleaning
10. What are the main impacts/changes to your life that have resulted from becoming a carer/caregiver?
    a. [Probe] e.g., Financial, Emotional, Your own health, Work/Professional
11. How has your relationship with the person you care for changed?
12. How have your other relationships and social life changed since becoming a carer?
    a. [Probe] “Have you felt isolated since becoming a carer”?
13. Do you feel you have sufficient support/a supportive (social) network?
14. Are you in contact with support groups/patient organizations?
15. How would you rate your quality of life now compared to before the diagnosis?
16. Can you estimate how many hours per week you spend providing care and support to the patient when they were undergoing treatment?
17. What is your biggest concern going forward?
18. [If not already expressed feelings of anxiety] Do you feel worried/anxious about the future?

Treatment preferences/decision-making

19. What do you consider to be the most important features of a new treatment?
20. What are your views on the treatment of acute leukemia?

    a. [Probe] e.g., improved survival, treatment response/remission, improved quality of life, tolerable side effects, impact on carer/family members, affordability
    b. [Probe] What aspects of the treatment experience had the biggest impact on the person that you care for?
    c. [Probe]Is this what also had the biggest impact on you? If not, what was it?

21. If the person that you care for were to need further treatment in future, what would be your greatest concerns about the treatment?
    a. [Probe] Are there any specific side effects that the person that you care for would want to avoid above all others? Do you think that these align with your own concerns?
    b. [Probe] Would the person that you care for want to prioritize life-extension or quality of life in a new treatment? Do you share this perspective?
    c. [Probe] {Acknowledge any already suggested} Do you think that your views on future treatment differ [in any other ways] to the views of the person that you care for? If so, why?
22. To what extent do you contribute to the person you care for's treatment decisions?
    a. [Probe] Do you feel that having to consider treatment options and make treatment decisions is a personal burden?
23. If further treatment were needed in future, to what extent might you consider the potential impact on yourself when discussing options with the person that you care for?
    a. [Probe] Do you think that if [x burden] were improved/alleviated, you would still feel the same way?

That brings me to the end of my questions. Is there anything that we didn't discuss about your experience that you'd like to add?

7.2 Demographics

TABLE 4: FULL PARTICIPANT DEMOGRAPHICS

PARTICIPANT ID	COUNTRY	SEX	RELATIONSHIP*	AGE	WORKING STATUS	LIVING WITH PATIENT
DE1	Germany	F	Sibling	51 to 70	Part time	No
DE2	Germany	F	Partner	51 to 70	Full time	No
DE3	Germany	M	Sibling	51 to 70	Retired	No
DE4	Germany	F	Partner	31 to 50	Full time	Yes
DE5	Germany	F	Parent	31 to 50	Part time	Yes
ES1	Spain	M	Partner	51 to 70	No	Yes
ES2	Spain	F	Sibling	51 to 70	Part time	Yes
ES3	Spain	F	Sibling	31 to 50	Part time	Yes
ES4	Spain	F	Partner	51 to 70	Part time	Yes
ES5	Spain	M	Partner	70 or above	Retired	Yes
FR1	France	M	Partner	31 to 50	Full time	Yes
FR2	France	F	Partner	31 to 50	Full time	Yes
FR3	France	M	Partner	31 to 50	Full time	Yes
FR4	France	F	Child	31 to 50	Part time	Yes
FR5	France	F	Child	51 to 70	Retired	No
IT1	Italy	M	Parent	31 to 50	Full time	No
IT2	Italy	F	Parent	51 to 70	Full time	Yes
IT3	Italy	F	Parent	31 to 50	No	Yes
IT4	Italy	M	Parent	31 to 50	Full time	No
IT5	Italy	F	Parent	51 to 70	Full time	No
UK1	UK	M	Partner	51 to 70	Retired	Yes
UK2	UK	M	Partner	51 to 70	Full time	Yes
UK3	UK	M	Partner	31 to 50	Part time	Yes
UK4	UK	M	Friend	31 to 50	No	Yes
UK5	UK	M	Parent	31 to 50	Part time	Yes
UK6	UK	M	Parent	31 to 50	Full time	Yes
UK7	UK	F	Parent	31 to 50	Part time	No
UK8	UK	F	Parent	31 to 50	No	Yes
UK9	UK	M	Parent	31 to 50	Full time	No
UK10	UK	M	Sibling	31 to 50	Full time	Yes
UK11	UK	M	Partner	51 to 70	No	Yes
UK12	UK	M	Partner	31 to 50	Part time	Yes
UK13	UK	F	Parent	51 to 70	Full time	No
UK14	UK	F	Partner	70 or above	Retired	Yes
UK15	UK	F	Parent	31 to 50	No	Yes
UK16	UK	F	Partner	51 to 70	Part time	Yes

PARTICIPANT ID	COUNTRY	SEX	RELATIONSHIP*	AGE	WORKING STATUS	LIVING WITH PATIENT
UK17	UK	F	Partner	31 to 50	Full time	Yes
UK18	UK	F	Parent	18 to 30	No	Yes
UK19	UK	F	Parent	31 to 50	Full time	Yes
UK20	UK	F	Sibling	51 to 70	Retired	Yes
US1	USA	F	Partner	31 to 50	Full time	Yes
US2	USA	F	Parent	31 to 50	Part time	Yes
US3	USA	F	Child	51 to 70	Full time	Yes
US4	USA	F	Partner	51 to 70	No	Yes
US5	USA	M	Partner	51 to 70	Full time	Yes
US6	USA	M	Parent	31 to 50	No	No
US7	USA	M	Parent	18 to 30	Full time	Yes
US8	USA	M	Parent	51 to 70	Full time	Yes
US9	USA	F	Sibling	51 to 70	Full time	Yes
US10	USA	M	Partner	51 to 70	Full time	Yes
US11	USA	F	Parent	31 to 50	No	Yes
US12	USA	F	Parent	31 to 50	No	Yes
US13	USA	F	Parent	31 to 50	Full time	Yes
US14	USA	M	Sibling	51 to 70	Full time	Yes
US15	USA	M	Other (Grandparent)	18 to 30	Full time	Yes
US16	USA	F	Partner	51 to 70	No	Yes
US17	USA	M	Partner	51 to 70	Retired	Yes
US18	USA	M	Other (Uncle)	31 to 50	Part time	Yes
US19	USA	F	Sibling	31 to 50	Full time	Yes
US20	USA	M	Parent	31 to 50	Full time	Yes

NOTE: 1 *THE PATIENT IS THE CARER'S...

About OHE

With over 60 years of expertise, the Office of Health Economics (OHE) is the world's oldest independent health economics research organisation. Every day we work to improve health care through pioneering and innovative research, analysis, and education.

As a global thought leader and publisher in the economics of health, health care, and life sciences, we partner with Universities, Government, health systems and the pharmaceutical industry to research and respond to global health challenges.

As a government-recognised Independent Research Organisation and not-for-profit, our international reputation for the quality and independence of our research is at the forefront of all we do. OHE provides independent and pioneering resources, research and analyses in health economics, health policy and health statistics. Our work informs decision-making about health care and pharmaceutical issues at a global level.

About ALAN

The Acute Leukemia Advocates Network (ALAN) is an independent global network of patient organisations, dedicated to changing outcomes of patients with acute leukemias by strengthening patient advocacy in that area. We aim to maximise the capacity of members within the network to allow us, together, to deliver tailored services to acute leukemia patients and carers on the national level. All whilst joining forces between organisations on the policy and research level across countries.

ALAN is hosted under the umbrella of the Leukemia Patient Advocates Foundation (LePAF), a patient-led non-profit foundation based in Switzerland. As a foundation we connect leukemia patient organizations on all continents to strengthen advocacy work. The mission is to improve the lives and survival of patients affected by leukemia as well as their relatives by supporting leaders in providing help and support.

NVOEMBER 2025