



ALAN

Acute Leukemia Advocates Network

**BEYOND THE BLOOD COUNT:
USING QUALITATIVE RESEARCH TO TRANSFORM HEMATOLOGY CARE**

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www.acuteleuk.org

Disclosure

- No conflict of interest



About ALAN

<https://youtu.be/pbLUEXdgBsE>



- ALAN is:
 - an independent global network of patient organisations
 - dedicated to changing outcomes of patients with acute leukemia
 - by strengthening patient advocacy
- **64** member organisations from **60** countries
- It aims to:
 - build capacity in the members of the network - deliver tailored services to acute leukemia patients and carers on the national level
 - join forces between organisations across countries – e.g. on the policy and research level
- ALAN is hosted under the umbrella of the [Leukemia Patient Advocates Foundation](#) (LePAF), a patient-led non-profit foundation based in Switzerland.



A multinational qualitative study



- 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.
- We spoke to 60 informal carers:
 - 20 from European Union countries – including 5 each from France, Germany, Italy and Spain
 - 20 from the UK and
 - 20 from the US.
- We asked them questions about
 - the patient's diagnosis,
 - how they became a carer and their experience of caregiving,
 - their involvement in decision-making
 - their quality of life (inclusion of FROM-16) and
 - which aspects of treatment they and the person they care for prefer

Methods (1/2)



- **Preparatory research**

- Literature review known as a rapid evidence assessment using Google Scholar and PubMed 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
- 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.
- The key findings from the literature review were instrumental in shaping both the discussion guide and the overall approach to the study

- **Study population**

- Adult (18 years or older) carers of an adult patient with a diagnosis of acute leukemia (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 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

- **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 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.

Methods (2/2)



- **Study design**

- We used interpretive qualitative methodology to guide the use of semi-structured interviews
- 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
- 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.

- **Data analysis**

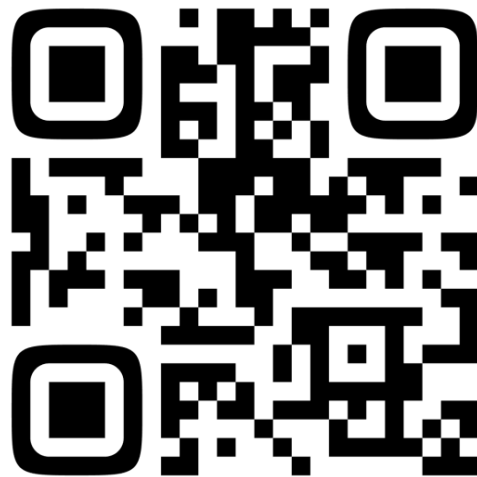
- The interview transcripts were analyzed using NVivo, a qualitative data management platform.
- Analysis of interviews was conducted using a reflexive thematic approach to identify key themes and insights. This involved generating succinct labels (codes) that capture and evoke important features of the data that might be relevant to addressing the research question,
- 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.
 - 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

Demographics and carer experience



Characteristic		N (%)
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%)
Employment status	Full time	28 (46%)
	Part time	13 (22%)
	Not working	12 (20%)
	Retired	7 (12%)
Relationship (the patient is the carer's ...)	Parent	23 (38%)
	Partner	22 (37%)
	Sibling	9 (15%)
	Child	3 (5%)
	Other	3 (5%)
Patient's time of acute leukemia diagnosis	Less than 6 months ago	7 (12%)
	Between 6 and 11 months ago	13 (22%)
	Between 1 and 3 years ago	16 (27%)
	More than 3 years ago	22 (37%)
	Missing	2 (3%)

Access the full study report here



Meet Sarah



Young professional caring for her father with AML



Working full-time while caregiving



Experiencing panic attacks, sleeping 4 hours/night

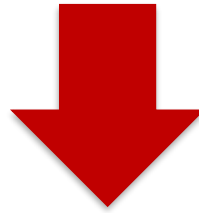


“I have difficulties breathing often, but I try not to show it. I sleep less or almost nothing. I have to physically move him around, my back has been affected.” – Sarah

The hidden burden



"In your treatment plans, have you ever asked: 'How is this affecting the person giving the medications at home?'"



Clinical excellence requires understanding the full ecosystem of care

e.g in acute leukemia*, 58% of informal caregivers reported experiencing a **very large or extremely large impact** of illness on their quality of life, 47% reported working full-time while caregiving and 15% reported no support network.

What Qualitative Research Reveals That Numbers Cannot



Quantitative

- What happens
- How many
- Statistical significance
- Measurable outcomes

"58% report severe burden"

Qualitative

- Why it happens
- How it feels

"I had to stop working"

Quantitative tells us burden is severe.
Qualitative research tells us *why, how, and what to do about it.*

"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."

Three Interlinking Themes



Impact of the Carer-Patient Dynamic Relationship

Relationships transform—deepening intimacy while creating role conflict



Balancing Multiple Roles

Professional, financial, and caregiving demands create impossible trade-offs



Putting Patient First

Carers become lay experts while sacrificing their own wellbeing



Impact of the Carer-Patient Dynamic Relationship

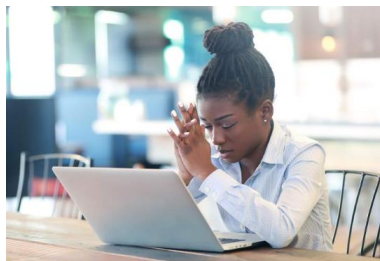


Research finding:

- Deepens emotional closeness and mutual commitment
- Face uncertainty together
- Creates role conflict: partner → nurse, parent → patient
- Strains intimacy and family dynamics

Implication:

The "partner" becomes "nurse"— role conflict affects treatment adherence



“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”

“Our relationship almost didn’t survive. We came close to separating. Our lives have changed drastically”



Balancing Multiple Roles

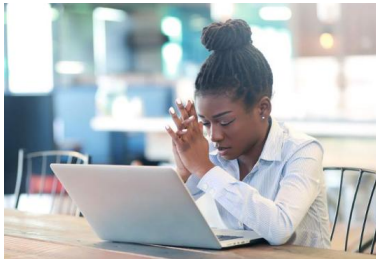


Research finding:

- Making professional and financial accommodations
- Providing constant and multi-faceted care
- 47% working full-time + constant caregiving = impossible math

Implication:

Early retirement, pawned businesses, depleted savings



“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.”

“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].”

Putting Patient First

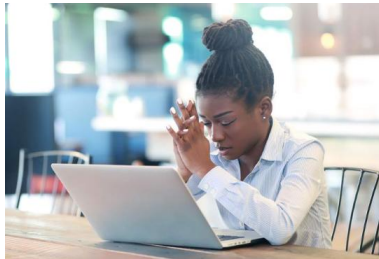


Research finding:

- Becoming an advocate and expert in leukemia
- Overlooking own needs at the detriment of personal quality of life
- Limited freedom & social isolation
- Treatment preference discordance—carers prioritize quality of life, patients want life extension

Implication:

Many carers become "lay experts" but sacrifice their own health



“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.”

“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...It was traumatizing.”

Why This Matters for YOUR Practice



Better Treatment Decisions

- Understanding carer burden helps predict non-adherence
- Treatment simplification benefits patients and families
- Consider home capacity when choosing regimen
- Treatments reducing hospital stays simplify doctoring measurable carer benefits

Identifying Hidden Risk Factors

- Carer

Design Patient-Centered Care

- Mental health screening for carers at key points
- Clear referral pathways to counseling
- Flexible appointment scheduling

Qualitative research transforms abstract "patient-centered care" into concrete clinical actions.

What would you miss ?



Burden severity?

Quantitative:

58% report very large/extremely large burden

Qualitative:

"Every day, every minute of the day. I had to sleep in another bedroom, 'cause I was disturbing him"

Context?

Quantitative:

Demographics: age, gender, relationship

Qualitative:

"In our culture, we have to look after our parents... so we see that as a blessing"

Treatment impact?

Quantitative:

Grade 2 fatigue in 45% of patients

Qualitative:

"He would set up camp on the couch... he couldn't do anything"

Qualitative:

"I quit my job, and my job is just my husband, honestly"

The power of qualitative methods



The Problem with Quantitative-Only Approaches:

- Clinical trials measure: survival rates, response rates, adverse events
- They often miss: daily lived experience, what makes life worth living, treatment burden

Qualitative research doesn't
replace quantitative—it
completes the picture.

Quantitative

Numbers → What

meaning, cultural
nuances, actionable insights

Tomorrow in your clinic



Level 1 (Easy):

- Add one question to your consultations: *"How is caring for [patient name] affecting you?"*
- Provide written information about carer support resources
- Acknowledge carer presence in consultations

Level 2 (Intermediate):

- Screen carers for burden using PRO tools like FROM-16 (takes 2 Min)
- Discuss treatment preferences with both patient AND carer
- Consider carer capacity when choosing between treatment options

Level 3 (Advanced):

- Advocate for routine carer assessment in your institution
- Collaborate with qualitative researchers on your own projects
- Present carer impact data in tumor boards

For Your Research Career



Mixed Methods Studies

- Combine quantitative outcomes with qualitative patient experience
- Example: Clinical trial + patient interviews about treatment burden*

Implementation Science

- Identify gaps qualitative methods could fill in your subspecialty
 - Use qualitative methods to understand barriers and facilitators
- Example: Why do carer support programs fail or succeed?*

Patient Partnership

- Collaborate with advocacy groups like ALAN
- Example: Co-design research questions that matter to patients*

Three Key Takeaways



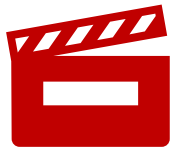
See beyond the patient

Family impact is clinical outcome



Value qualitative evidence

Stories inform where numbers cannot



Act on insights

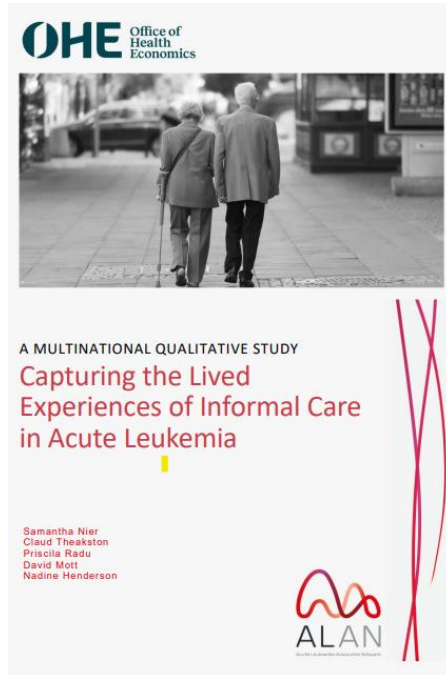
Small changes in practice = meaningful reduction in suffering

The carers you never see are in every room with every patient.

Qualitative research makes them visible.

What will you do differently knowing what you know now?"

Access the full study report here



https://acuteleuk.org/wp-content/uploads/2025/11/ALAN-Report_Capturing-the-Lived-Experiences-of-Informal-Care-in-Acute-Leukemia.pdf



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