

Introduction

There is a need to understand the perspectives and preferences of informal carers of people with acute leukemia. This evidence will help inform the understanding of the burden on informal carers in this context and potentially inform the evaluation of treatments now and in the future.

The Acute Leukemia Advocates Network (ALAN), in collaboration with The Office of Health Economics (OHE), are running a qualitative preference study using semi-structured interviews to:

- Elicit carer's greatest concerns regarding their burdens in providing informal care
- Explore carer's treatment priorities for the people that they provide care to and
- Understand the extent to which carer's concerns about the burden on themselves may relate to their treatment priorities.

Aim

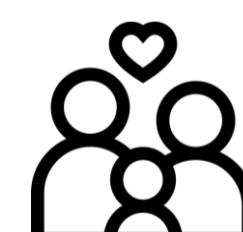
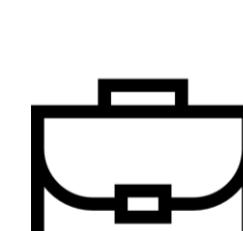
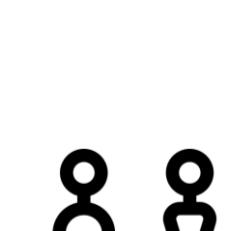
This qualitative preference study was conducted to understand the perspectives and preferences of informal carers of people with acute leukemia.

Methods

- After a literature review known as a rapid evidence assessment, a total of 60 virtual one-to-one semi-structured interviews with caregivers were conducted.
- Ethical approval was obtained prior to recruitment. Demographic information and responses to the Family Reported Outcome Measure (FROM-16) were collected prior to the interview.
- The interviewers used an interview guide to explore the burdens of providing care, carer's treatment priorities and the interaction between these topics. Given the flexible approach, not all respondents were asked the same questions.
- Analysis of interviews was conducted using a reflexive thematic approach to identify key themes.

Results (I)

A total of 60 informal carers took part in the study, with the following demographic information:

	UK	USA	France	Germany	Italy	Spain
	20 (33%)	20 (33%)	5 (8%)	5 (8%)	5 (8%)	5 (8%)
	Parent	Spouse	Sibling	Child	Other	
	4 (7%)	31 (52%)	23 (38%)	2 (3%)	2 (3%)	
	Full-time	Part-time	Not working	Retired	Unknown	
	23 (38%)	13 (22%)	10 (17%)	7 (12%)	7 (12%)	
	18 to 30	31 to 50	51 to 70	>71		
	4 (7%)	31 (52%)	23 (38%)	2 (3%)		
	Male	Female				
	28 (47%)	32 (53%)				

The hours spent on caregiving varied, with **57% of caregivers (31/54) saying they provide "constant care"** or more than 5 hours per day. The most quoted responsibilities included: housework, emotional support, taking the patient to medical appointments, helping with treatment, hygiene, accompanying in physical activities and administrative tasks.

“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.”

Understanding of the perspectives and preferences of informal carers of people with acute leukemia: insights from a qualitative study

Samantha Nier¹; Nadine Henderson², Priscila Radu², Claud Theakston², David Mott²

1. Acute Leukemia Advocates Network; 2. The Office of Health Economics

Key messages

- The impacts on individuals as a result of caring for a loved one through diagnosis and treatment of acute leukemia are **considerable and broad-ranging**.
- Carers often play a **supportive role** in treatment decision-making. In general, they prefer treatments with less burden on the patient and themselves but are **willing to make sacrifices** to ensure the patient's needs come first.
- This study highlights the multifaceted burdens faced by informal carers of people with acute leukaemia and underscores the **importance of considering their perspectives in treatment evaluations** and care strategies.

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Results (II)

Impacts on quality of life varied based on personal circumstances and experiences, but can be categorized into the following themes:



Emotional burden: Carers expressed a range of emotional impacts as a result of the diagnosis and treatment of acute leukemia, including worry, frustration, helplessness, regret, resentment and fear. Some carers reported feeling obligated to care for their loved one (23/60).

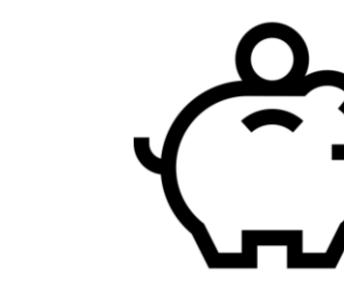


Mental burden: Carers also reported feelings of anxiety and depression

Carer's own health: Some carers reported negative impacts on their own health as a result of the caregiving burden (e.g., difficulties with sleep, doing less exercise, mental and physical fatigue).

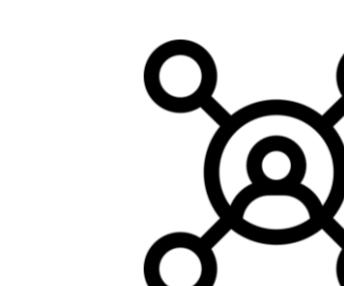


Professional impact: Carers often expressed a professional impact (62% [37/60]) and this was seen through a variety of avenues, including requesting more flexibility from their current job, cutting down working hours, taking a career break, leaving the workforce, retiring early and learning new skills or changing jobs to enable them to work from home.

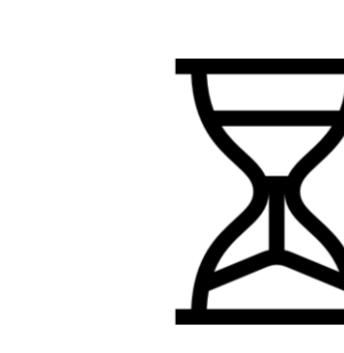


Financial impact: Changes to working hours and jobs were often associated with a negative financial impact. Many carers reported a financial impact (53% [32/60]) due to medical insurance, treatment, transportation parking and covid-19 testing. Some carers reported other avenues of receiving financial support, such as from family, online charitable collections, savings and pawning.

“So, since then, I guess there have been times I had to either stop working or decrease my hours, which as far as my finances go, yes, those have taken some major dips as well, because of the amount of care that has been needed.”



Social impact: Most carers reported a negative impact on their social life due to their caregiving responsibilities (68% [41/60]) e.g., not being able to attend social gatherings because of time constraints or fatigue. Carers also expressed that speaking to friends and family had also become a chore or no longer being invited



Time burden: Many carers expressed that their caregiving responsibilities were time-consuming (48% [29/60]) and some carers mentioned that caregiving felt like an additional job or being on call 24/7. Many felt that they no longer had time for themselves

Impact of treatment decision-making

- 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, often alongside responsibilities such as advocacy and treatment management. Carers often defer to medical practitioners and the patients to ultimately make decisions.
- Views were generally split between whether having an involvement in treatment decision-making was a burden or not.

Conclusion

Becoming a carer can have a significant impact on quality of life (Emotional burden, Mental burden, Carer's own health, Professional impact, Financial impact, Social impact and Time burden); carers often feel as though they are balancing multiple roles.

Carers often play a supportive role in treatment decision-making. In general, they prefer treatments with less burden on the patient and themselves but are willing to make sacrifices to ensure the patient's needs come first.



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