Understanding *ALK*+ NSCLC caregivers' psychosociological burden: Findings from the study "*Living with ALK+ cancer in France*"

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Key take aways

- **Considerably more caregivers than patients reported a major impact of *ALK*+ NSCLC on mental health.**
- **At least two-thirds of caregivers reported life-planning difficulties.**
- **Other common challenges for caregivers included fatigue, anxiety, episodes of sadness, and sleep problems.**
- **Almost three-quarters of caregivers expressed a need for more information about *ALK*+ NSCLC and its progression.**
- **This study highlights the need for more comprehensive support for caregivers of patients with *ALK*+ NSCLC to help them with the difficulties in their daily lives.**

Conclusion

The "*Living with ALK+ cancer*" study highlights the extensive challenges faced by caregivers of patients living with *ALK*+ NSCLC and emphasises the need for comprehensive support systems that address the many daily-life difficulties encountered by caregivers.

Introduction

- Anaplastic lymphoma kinase (ALK) fusion-positive (*ALK*+) adenocarcinoma accounts for up to 5% of non-small cell lung cancer (NSCLC) cases.[1-5]
- The prognosis for patients with *ALK*+ NSCLC has been drastically improved by therapeutic sequences incorporating different generations of ALK inhibitors, with median overall survival increasing from 12 months to several years.[6-9]
- Caregivers for patients with *ALK*+ NSCLC are usually family members or close friends, playing a key supportive role for patients.
  - In this supportive role, caregivers face several practical and psychological challenges; however, the specific experiences of caregivers in this setting remain underexplored.[10, 11]
- The present study evaluated the indirect impact of *ALK*+ NSCLC on caregivers and provided important insights into the unmet needs of caregivers.

Methods

- The "*Living with ALK+ cancer in France*" study was a psychosociological survey conducted in two parts:
  - A qualitative phase — designed to identify areas of interest for subsequent investigation.
  - A quantitative phase — with detailed questionnaires (on the areas of interest) for 85 patients with *ALK*+ NSCLC, 27 caregivers and 50 thoracic oncologists.
- Presented here are results for the caregiver population (n=27) in the quantitative phase.
  - The caregivers were recruited by patient associations or oncologists and were not necessarily the caregivers looking after the enrolled patients.
  - Data were collected from November 2024 to February 2025, via a self-administered 35-minute online survey.

Results

Caregiver characteristics

- Caregivers were generally female (51.9%) and aged 50–60 years (44.4%); overall mean age was 53.8 years (**Table 1**).
  - Most caregivers (85.2%) were the spouses of patients with *ALK*+ NSCLC; some caregivers (11.1%) were the children of patients.
- Caregivers reported that they provided patients with moral and psychological support (100.0% of cases); helped with everyday tasks (92.6%); and accompanied patients on hospital visits (81.5%; **Table 1**).

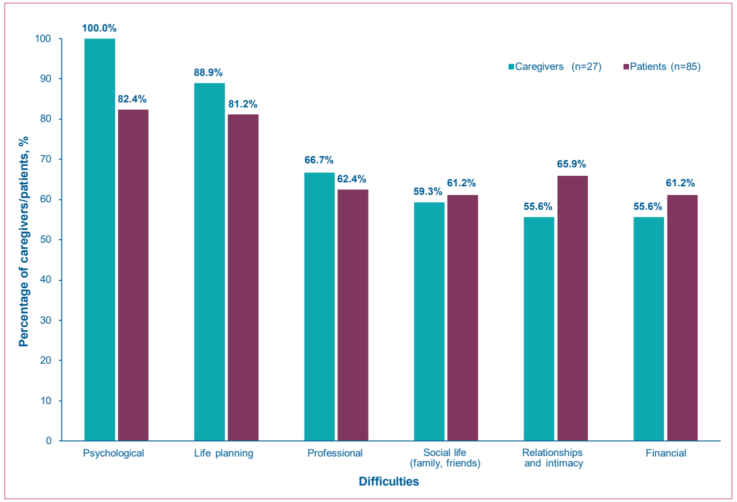
Table 1. Caregiver characteristics

Characteristic, n (%)	Caregivers (n=27)
Sex	
Female	14 (51.9)
Male	13 (48.1)
Age	
<40 years	4 (14.8)
40–49 years	4 (14.8)
50–60 years	12 (44.4)
>60 years	7 (25.9)
Primary caregiver?	
Yes, the only caregiver	21 (77.8)
One of several caregivers, but the major carer	6 (22.2)
Caregiver location	
Living in the same house as the patient	24 (88.9)
Living <30 minutes from the patient	3 (11.1)
Relationship to patient	
Spouse	23 (85.2)
Child	3 (11.1)
Friend	1 (3.7)
Family situation	
Couple with children	8 (29.6)
Couple without children	19 (70.4)
Help provided to patient	
Moral and psychological support	27 (100.0)
Everyday tasks (housework, preparing meals, etc.)	25 (92.6)
Accompanying to hospital	22 (81.5)
Talking to treating medical team	19 (70.4)
Searching for information on illness/treatments	17 (63.0)
Collecting medicines from pharmacy	14 (51.9)
Administrative tasks (e.g. making appointments, social assistance)	13 (48.1)

Daily-life difficulties

- The bar chart in **Figure 1** shows the daily-life difficulties experienced by caregivers themselves and the daily-life difficulties reported by patients with *ALK*+ NSCLC.
  - Overall, more caregivers than patients reported that *ALK*+ NSCLC had a major impact on mental health (100.0% vs 82.4%).
- Caregivers highlighted several challenges that they experienced: fatigue (77.8%), anxiety (70.4%), episodes of sadness (66.7%), sleep problems (59.3%), insecurity (51.9%) and organisational difficulties or burnout related to caregiving (33.3%).
- Caregivers also reported difficulties with life planning (envisioning the future; 59.3%), relationships and intimacy (reduced or lost libido; 40.7%), social life (limited social contacts or friendships; 40.7%), finances (reduced income; 25.9%) and professional problems (fulfilling professional obligations; 14.8%).

Figure 1. Frequency of daily-life difficulties experienced by caregivers or patients



Supporting the patient throughout their journey

- Caregivers were always (56.0%) or often (19.0%) present during patients' follow-up visits, which occurred every 2.9 months on average.
  - However, 25.9% of caregivers (n=7) did not feel listened to by the medical team.
  - 77.8% of caregivers (n=21) reported that the patient experienced considerable anxiety with follow-up tests.
- Only 51.9% of caregivers said they received adequate support from oncologists and primary care physicians in dealing with disease impact on daily life; the corresponding proportion of patients was 84.7%.
- Caregivers considered the following support measures as being the most important:
  - More information about *ALK*+ NSCLC and its progression (74.1% of caregivers)
  - A separate hospital consultation, dedicated to nonmedical problems, for patients and caregivers (59.3%)
  - Tools and support for better training as a caregiver (59.3%)
  - Information on rights as a caregiver (59.3%).
- Support measures considered important by patients and oncologists were to:
  - Establish separate hospital consultations, dedicated to nonmedical problems, for patients and caregivers (65.9% of patients and 58.0% of oncologists)
  - Systematically provide wellness activities, such as yoga (55.3% and 60.0%)
  - Make it easier to report adverse effects to the medical team (57.6% and 52.0%)
  - Provide psychological support (51.8% and 68.0%).

References

1. Li H, Wang C, Guo C. Post-marketing safety of lorlatinib: a real-world study based on the FDA adverse event reporting system. *Front Pharmacol* 2024;15: 1385036.
2. Liu W, Huo G, Chen P. Cost-effectiveness of first-line versus second-line use of brigatinib followed by lorlatinib in patients with *ALK*-positive non-small cell lung cancer. *Front Public Health* 2024;12: 1213318.
3. Laguna JC, García-Pardo M, Alessi J, et al. Geographic differences in lung cancer: focus on carcinogens, genetic predisposition, and molecular epidemiology. *Ther Adv Med Oncol* 2024;16: 17588359241231260.
4. Barlesi F, Mazieres J, Merlio JP, et al. Routine molecular profiling of patients with advanced non-small-cell lung cancer: results of a 1-year nationwide programme of the French Cooperative Thoracic Intergroup (IFCT). *Lancet* 2016;387(10026): 1415-26.
5. Solomon BJ, Mok T, Kim DW, et al. First-line crizotinib versus chemotherapy in *ALK*-positive lung cancer. *N Engl J Med* 2014;371(23): 2167-77.
6. Solomon BJ, Kim DW, Wu YL, et al. Final overall survival analysis fom a study comparing first-line crizotinib versus chemotherapy in ALK-mutation-positive non-small-cell lung cancer. *J Clin Oncol* 2018;36(22): 2251-58.
7. Solomon BJ, Liu G, Felip E, et al. Lorlatinib versus crizotinib in patients with advanced *ALK*-positive non-small cell lung cancer: 5-year outcomes from the phase III CROWN study. *J Clin Oncol* 2024;42(29): 3400-09.
8. Mok T, Camidge DR, Gadgeel SM, et al. Updated overall survival and final progression-free survival data for patients with treatment-naive advanced *ALK*-positive non-small-cell lung cancer in the ALEX study. *Ann Oncol* 2020;31(8): 1056-64.
9. Camidge DR, Kim HR, Ahn MJ, et al. Brigatinib versus crizotinib in ALK inhibitor-naive advanced *ALK*-positive NSCLC: final results of phase 3 ALTA-1L trial. *J Thorac Oncol* 2021;16(12): 2091-108.
10. Cochrane A, Woods S, Dunne S, Gallagher P. Unmet supportive care needs associated with quality of life for people with lung cancer: a systematic review of the evidence 2007-2020. *Eur J Cancer Care (Engl)* 2022;31(1): e13525.
11. Broadbridge E, Venetis MK, Devine KA, Lee LE, Banerjee SC, Greene K. Supporting the support person: Oncologists' roles in reducing support people's uncertainty and facilitating psychological adjustment. *Psychooncology* 2024;33(3): e6313.

Conflicts of interest

J. Cadranel declares financial, personal, and advisory board interests in Amgen, AstraZeneca, BI, BMS, Janssen, MSD, Novartis, Pfizer, Sanofi and Takeda.

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