

P3.399: Living with Advanced Anaplastic Lymphoma Kinase Lung Cancer – A Qualitative Study



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INTRODUCTION

Advanced Anaplastic Lymphoma Kinase Positive (ALK+) lung cancer was once a cancer with a poor prognosis

Modern targeted therapies have transformed this into a chronic disease for some patients, with PFS that can be >5 years

Studies describing the lived experience of this cohort are limited

METHODS

Qualitative Study
Advanced ALK+ lung cancer >12 months

Across Australia
N= 20

Semi-structured interviews:
In-person or via videoconference

Thematic analysis:
Recruitment until thematic saturation

Demographics	Median (years)	Range
Age	56.5	40-68
ALK Diagnosis	5.4	1.14-14.05
Treatment Exposures	First Line (n=)	Total
Alectinib	7	18
Lorlatinib	2	10
Neladalkib	0	2
Chemotherapy	5	6
Chemorads	2	2
Radiotherapy	-	8
Surgery	-	8
Lines of Systemic Therapy	n=	%
1	6	30
2	7	35
3 or more	7	35

DISCUSSION AND CONCLUSION

Actionable Take Away Message

- The lived experience of ALK+ lung cancer patients are mixed.
- Modern therapies can give quality and quantity of life to achieve some, if not all of patient’s personal goals.
- Positive experiences are counterbalanced by impacts on professional, social, physical and emotional domains.

Future Direction for Research

- Interventions that inform and support ALK+ patients and their clinicians

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RESULTS N=20

“You... feel quite alone.. being a rare cancer.. There’s so much [more attention] on [common] cancers” #9

“There’s about six of us that catch up each month just to have a morning tea and compare notes. That’s useful”. #19

“I mentioned [my symptoms] a couple of times to the doctor... it was pretty much “oh it’s probably just an allergy thing or whatever” #3

“It wasn’t a pretty time for me. It was quite dark actually” #5

“[In] the first year I was seriously depressed. I thought my life was over” #15

“When you don’t understand the systems well, you’re at a disadvantage” #9

“Although I appear healthy, there’s all these side effects that I still live with” #6

“I know... I’m gonna get hit by the bus and even the route number, I just don’t know the time” #5

“My oncologist had to write a letter to say I actually had lung cancer [as] I was starting to feel like a fraud“ #18

“It hasn’t been all that bad... I feel guilty for saying that” #16

“It’s been a gift in some ways, but obviously a curse in others” #2

“My partner’s been managing her job, the household, me and my anxiety and everything else” #16

“I wouldn’t say that my life’s difficult. It’s just different to everybody else’s” #12

“My identity’s been smashed” #13

THE LIVED EXPERIENCE OF THOSE LIVING WITH ADVANCED ALK+ LUNG CANCER

- Presentation & Diagnostic Pathway
- Early Disease Experience
- Navigating Health Systems
- Treatment
- Living with ALK as a Chronic Disease
- Feelings about ALK The “Lucky” Cancer Paradox
- Impact
- Supports Family, Friends and The Community
- Advocacy and ALK Community