Exploring the lived experiences of lung cancer patients attending a nurse-led follow-up clinic: A qualitative study

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Abstract

Background: Lung cancer causes approximately 48,000 new diagnoses and 35,000 deaths each year in the UK, making it the leading cause of cancer mortality (UK NSC, 2022; Cancer Research UK, 2024). International guidelines consistently recommend routine surveillance for at least five years following curative-intent treatment (ASCO, 2021:, NCCN 2025, ESMO: 2023; NICE 2024). Nurse-led follow-up clinics play a key role in delivering this care, offering holistic, patient-centred support, symptom management, and continuity while alleviating pressure on consultant-led services (De Leeuw & Larsson, 2013; NHS Long Term Plan, 2019). Despite policy endorsement and growing service provision, limited research explores how lung cancer patients experience nurse-led follow-up, particularly within local contexts

Research Design: Participants were adults who had undergone curative intent, lung cancer treatment and were within the five year follow-up period at a nurse-led clinic. Purposive sampling was used to capture a range of experiences across treatment backgrounds and follow up stages.

Data Collection and Analysis: Guided by an interpretivist paradigm and adopting an inductive qualitative design, semi-structured interviews were conducted to generate rich, in-depth accounts of participants' experiences. A phenomenological approach reinforced the study, enabling exploration of how participants perceived and made meaning of their follow-up care. Data were analysed using Braun and Clarke's (2006) six-phase thematic analysis, supporting the identification of patterns of meaning grounded in participants' lived experiences.

Findings: Five themes were identified: navigating the treatment journey, emotional response, communication and information, feeling supported, and continuity of care. Participants described nurse led care as providing clear and reassuring communication, offering valued continuity with familiar clinicians, and ensuring accessible support through responsive contact routes. Holistic care that addressed emotional, practical, and psychological needs was central to participants' sense of safety, confidence, and wellbeing throughout survivorship. Overall, the findings suggest that nurse led clinics offer a unique relational and integrative model of care that extends beyond clinical surveillance alone
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Conclusion: The study demonstrates that nurse led lung cancer follow up delivers highly valued, person-centred care that meets both clinical and holistic needs. It addresses the research question by illustrating how communication, continuity, accessibility, and holistic support shape patient experience. The findings support further investment in advanced nursing roles and highlight opportunities for future research to refine and strengthen survivorship pathways.

Introduction

Recurrence rates remain high across all stages, and survivors have a lifelong increased risk of second primary lung cancers (SPLCs) (Stirling *et al.,* 2021). Structured post-treatment surveillance enables earlier detection of recurrence and SPLCs, allowing retreatment with curative intent and improved survival outcomes (Schneider *et al.,* 2020; Stirling *et al.,* 2021). Structured follow-up visits are advised to ensure early detection and timely management of recurrence and late treatment related toxicities (NICE, 2024). This systematic surveillance is crucial for improving survival outcomes, maintaining quality of life, and facilitating the management of ongoing physical and psychosocial issues (World Health Organization (WHO). 2017; Zebrack, 2024).

Increasing numbers of lung cancer survivors, combined with rising patient complexity, have placed growing pressure on consultant-led outpatient services; rendering traditional follow-up models increasingly unsustainable (Thomas, 2023). In response, nurse-led follow-up clinics have emerged as a clinically and operationally effective model for delivering flexible, patient-centred, and cost-efficient care that aligns with evidence based surveillance schedules. These clinics offer holistic assessment, timely symptom management, psychosocial support, and continuity of care, particularly during the critical five-year post treatment period (De Leeuw and Larsson, 2013).

National strategies, such as the NHS Long Term Plan (2019), advocate for the expansion of advanced nursing roles to improve accessibility, continuity, and quality of care while reducing strain on acute and consultant-led services. In alignment with these priorities, local healthcare initiatives have introduced nurse-led lung cancer follow-up clinics designed to provide structured, protocol driven care that addresses patients' clinical, emotional, and supportive needs.

The SPIDER framework provided a structure approach to guide development of the research question towards understanding meaning rather than measuring variables, ensuring consistency between the philosophical foundations and practical execution of the study (Cooke, Smith, and Booth, 2012).

Research Question Aim and Objectives

Research Question: How do lung cancer patients in the five-year follow-up period perceive the quality of care provided through a nurse-led clinic?

Research Aim: To explore and critically evaluate the livid experiences and perceptions of individuals receiving follow-up in the lung cancer nurse led clinic.

Research Objectives:

1. To explore lung cancer patients' experiences of follow-up care within a nurse-led clinic over the five-year survivorship period.
2. To identify key aspects of care (communication, continuity, accessibility, holistic support) that influence patients' satisfaction with their care.
3. To explore how they describe their communication, continuity, accessibility and holistic support.
4. To explore the extent to which the nurse led clinic meets their needs.
5. To provide insight to support generating evidence-based recommendations for enhancing the delivery and quality of nurse-led follow-up services for lung cancer patients.

Research Design

Paradigm:
Interpretivist The study is situated within an interpretivist paradigm, which assumes that reality is socially constructed and that meaning is created through individuals' interactions and experiences (Schwandt, 1994; Lincoln et al., 2011). Interpretivism is appropriate for this research as it seeks to understand how patients make sense of, and attribute meaning to their experiences of nurse-led lung cancer follow-up care. Rather than attempting to measure outcomes or test hypotheses, the focus is on understanding subjective perspectives and the context in which care is experienced.

Research Approach:
Inductive An inductive approach supports the study, as patterns, themes, and meanings are intended emerge from the data rather than being imposed a priori. This approach supports the generation of rich, descriptive insights grounded in participants' accounts and is consistent with both qualitative research and interpretivist assumptions.

Methodology:
A qualitative research methodology was selected to enable an in-depth exploration of patients' experiences, emotions, perceptions, and interpretations of nurse-led follow-up care. Qualitative research is particularly suited to healthcare research where complex human experiences cannot be adequately captured through quantitative methods alone (Silverman, 2016).

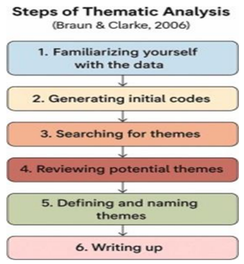
Specifically, a phenomenological methodology was adopted. Phenomenology is concerned with exploring and describing individuals' lived experiences and how they perceive and interpret those experiences (Moustakas, 1994; Creswell and Poth, 2018).This methodology is appropriate as the study seeks to understand what it is like for patients to attend a lung cancer nurse-led follow-up clinic, focusing on aspects such as communication, continuity of care, emotional support, and the meaning attributed to nurse-led encounters. Phenomenology enables the researcher to foreground participants' voices while remaining attentive to context and meaning-making.

Data collection Methods:
Semi structured interviews were used because they allow participants to describe their experiences in their own words and provide rich, detailed data. Face-to-face interviews were chosen to support rapport, observe non-verbal cues, and ensure comfort and privacy. Interviews were held in a private clinic room and lasted 45–60 minutes to allow depth without causing fatigue. All interviews were audio-recorded with consent to ensure for transcribing

Sample:
Purposive sample of 6 participants with lung cancer who had completed primary treatment was recruited and met the inclusion and exclusion criteria

Inclusion	Exclusion
Adults (18+) with lung cancer	Palliative care
Completed primary treatment	Significant cognitive impairment
≥3 months attending nurse-led clinic	Under 18 years

Data Analysis Method: Data were analysed using Braun and Clarke's (2006) six phase approach to thematic analysis.



Quality Assurance and Ethical Issues:
This study followed rigorous ethical standards to protect participants' rights and wellbeing. Ethical approval was obtained through the RGU the School of Health Ethics Review Panel (SERP) and the Jersey Health Research Ethics Committee. Participants gave fully informed, voluntary consent and were reminded of their right to withdraw at any time. Confidentiality was ensured through anonymisation and secure data handling. A risk assessment and support pathways were in place for anyone discussing sensitive experiences.

Overall, the study prioritised the principles of research ethics (Creswell and Creswell, 2018). autonomy, beneficence, non maleficence, and justice to ensure safe, responsible, and ethical research practice.

Findings

Five key themes were identified that capturing both the practical and emotional aspects of participants' experiences across their cancer journey. Clear communication, continuity of care and support emerged as key themes

1. Navigating the Treatment Journey

"In the back of my mind, I think I already knew, because you said likely cancer"

"You talked me through travel, surgery what to expect so much panic and just knowing what was going on it was so nice to feel secure and safe and how well organised things"

"I went to Southampton for PET scan, which unfortunately I'm very claustrophobic and I just couldn't go through with it. I felt terrible because I've just wasted a lot of people time"

"I was advised there were three things I could do, I could wait until it was my time, or to go to Southampton or I could go private special blood test. CNS arranged an appointment with the consultant oncologist, took my bloods and spent for a special test find the DNA"

2. Emotional Responses

"CT Biopsy which I hated, I hated, but you did tell me all about the procedure still horrible. It was scary I couldn't breather something went wrong really frightening"

"Talked me through travel, surgery what to expect so much panic and just knowing what was going on it was so nice to feel secure and safe and how well organised things, always kind, smiling, positive"

"I then needed a PET scan off-island. It was a long day and I was scared, but you arranged for my friend to travel with me. That meant everything. I didn't want to be alone."

3. Communication and Information

"You always seem to explain it to me; you will decipher for me"
"Nurse always there for me, if I need to talk, I could phone, if I was worried about anything. Very kind"

"Just way you describe everything to me and tell me what's going on and let me understand, Explain to me, my next stage will be, what's going to go on from there, the CNS absolutely fantastic, very kind, very welcoming, she relaxed me. She made me feel relaxed with how she approached things, I was given all the details that I needed"

"You always explained things clearly and never rushed me"

"You explained everything at my level of understanding not all the medical terms simple language, and that made the whole journey far less frightening"

4. Feeling Supported

"Nurse always there for me, if I need to talk, I could phone, if I was worried about anything. very kind"

"You were somebody was there for me, never felt like you were trying to push me out the door, You listened to everything I needed to say, They were really supportive and helpful with any questions that I had, I felt listened to even when I was anxious, the nurse put me at ease, which was really lovely"

"If we just phone and ask for you, you always phone us back, always just get us in to see you if I have any worries or concerns"

"You reassured me when I panicked or started imagining the worst"

5. Continuity of Care

"Nurse always there for me, if I need to talk, I could phone, if I was worried about anything. Very kind"

"Follow up the next five years? I'm going to see a nurse that I can talk to just as I would to my own friends"

"Generally, thank you for everything. I really hope my follow-up continues with you"

Limitation

The qualitative design provided in-depth insight into patients lived experiences; however, findings are specific to a single service context and may not reflect experiences in other settings. Qualitative studies aim for depth rather than generalisation, and transferability depends on the reader's judgement of contextual similarity (Marshall and Rossman, 2016). Insider researcher positioning may also have shaped participant responses and interpretation. Although reflexive strategies were used, subjectivity is understood as inherent to qualitative research rather than a flaw (Braun and Clarke, 2006). These limitations do not detract from the value of the study but highlight the importance of context.

Conclusion

Findings demonstrate that the value of nurse-led care extends far beyond clinical surveillance. Participants consistently described the clinics as a vital source of psychological reassurance, clear communication, and emotional containment during a period often marked by uncertainty and fear.

Relational continuity emerged as particularly important. Repeated contact with a familiar nurse fostered trust, confidence, and a sense of being genuinely known and understood qualities that enhanced patients' feelings of safety throughout their cancer journey. Accessibility to timely advice between appointments further supported self-management and reduced anxiety when new symptoms or worries arose.

The nurse-led clinic was experienced as a holistic space where emotional, practical, and clinical needs were addressed together. This integrated, person-centred approach helped patients adjust to life after treatment and contributed significantly to their overall wellbeing.

The study demonstrated that nurse-led follow-up delivers not only efficient and acceptable care but a deeply relational model that supports long-term recovery. These insights highlight the central contribution of advanced nursing roles in shaping follow-up pathways that meet the full spectrum of patient needs beyond treatment.

Recommendations

1. Strengthen communication:
Introduce consistent communication structures for results and follow-up discussions, supported by written or digital summaries and clear visual aids to enhance understanding and reduce anxiety.

2. Prioritise continuity of care:
Adopt a named-nurse or micro-team model and optimise scheduling systems to ensure patients see a familiar clinician wherever possible. Strengthening relational continuity will enhance trust and clinical accuracy.

3. Improve accessibility and flexibility:
Maintain responsive advice lines or digital platforms with defined response expectations. Offer flexible appointment formats, including face-to-face, telephone, and video, to match clinical need and patient preference.

4. Embed holistic and psychosocial assessment:
Incorporate routine needs screening throughout follow-up and ensure findings inform multidisciplinary planning. Strengthen referral pathways to psycho-oncology, pulmonary rehabilitation, welfare support, and community services.

5.Support workforce development:
Provide APNs and CNSs with protected time for advanced training in communication, survivorship, and psychological assessment. Monitor caseloads to protect relational care, reduce burnout, and sustain high-quality, person-centred practice.

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References