



Carrying on with life as a lung cancer survivor: a qualitative study of Australian survivors' employment, finances, relationships, and healthcare experiences

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Background: With novel therapies, more individuals are living longer with lung cancer (LC). This study aimed to understand the impacts of LC on life domains such as employment, finances, relationships, and healthcare needs.

Methods: Individuals 18+, diagnosed with LC, 6–24 months post-treatment were recruited through an Australian LC cohort study (Embedding Research and Evidence in Cancer Healthcare—EnRICH). Demographic, clinical, quality-of-life and distress data were obtained through the EnRICH study database. Participants completed telephone interviews. Qualitative data were analysed via Framework methods.

Results: Twenty interviews (10 females) were conducted. Most participants were diagnosed with advanced LC (Stage III =8, Stage IV =6), and were on average 17 (range, 10–24) months post-diagnosis. Four themes related to “carrying on with life” as a LC survivor were identified: (I) the winding path back to work: those working pre-diagnosis discussed challenges of maintaining/returning to employment, and the meaning and satisfaction derived from work. (II) Vulnerability versus protection: managing the financial impacts of LC: wide variations in financial impacts, some described lost income and high healthcare expenses, others felt financially protected. (III) Connection and loneliness: navigating relationships as a survivor: some experienced lost friendships due to their diagnosis, others noted more meaningful connections. (IV) Still under the umbrella: healthcare during survivorship: participants noted the importance of ongoing oncology team connection and the vital role of cancer care coordinators.

Conclusions: Many individuals living with LC want to “carry on” with life. Participants spoke of challenges and opportunities across life domains of relationships, work, and finances, and noted the importance of continued specialist healthcare throughout survivorship.

Keywords: Lung cancer (LC); novel therapy; employment; finances; qualitative

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Introduction

Background

Lung cancer (LC) is the second most common cancer in the world and remains the leading cause of cancer death (1). Whilst overall 5-year survival rates remain low (20.2% in Australia from 2014–2018) (2), recent treatment advancements such as immunotherapy (IO) and targeted therapy (TT) are producing substantial increases in survival (3). Indeed, a subset of those with advanced and metastatic LC demonstrate extended periods of disease control and progression-free survival (4), often with less toxicity and better quality of life (QoL) than individuals previously treated with palliative chemotherapy (5). LC survivors are therefore growing in numbers but remain underrepresented in qualitative survivorship research, which has historically focused on cancers with a better prognosis (6). In a meta-review of qualitative systematic reviews of cancer survivorship, our group found very few reviews and original research focusing on LC survivorship (7).

Of the qualitative LC studies published to date, some were conducted prior to the widespread availability of IO (8,9), many have focused on palliative rather than survivorship care (10,11), and others have focused on very specific survivorship issues such as exercise (12) and stigma (13). Recent studies have begun exploring the long-term physical and psychological impacts of IO and TT (14–17). However, limited attention has been given within these studies to how LC survivors manage the return to normal life and what impacts LC has on life domains such as employment, finances, and relationships.

Gaining a deeper qualitative understanding of the impacts of LC on these life domains is crucial to identify and understand specific challenges and unmet needs, and potential strategies to improve LC survivorship care. A recent quantitative study (n=292) of people with non-small-cell LC found that 43% of participants stated their LC had a “major or catastrophic” impact on their professional status, and 28% retired early because of their LC diagnosis. Almost one quarter (23%) of participants reported their household finances were severely impacted by their LC (18). Similarly, a recent population-based study of Australian cancer survivors found LC survivors had some of the lowest levels of workforce participation and highest levels of retirement due to ill health (19). A longitudinal study examining financial toxicity among people with LC currently undergoing treatment found substantial financial impacts at both diagnosis and 6 months follow-up, with substantial financial risk factors arising at 6 months for those who were employed but on sick leave (20). Lai-Kwon *et al.* (15) noted navigating issues around finances and employment amidst the uncertainty of LC survivorship was a substantial challenge for survivors, but more comprehensive qualitative exploration is needed.

Living with LC has also been found to impact family and social relationships. In a qualitative study of individuals with inoperable LC, Berterö *et al.* (21) noted that many people with LC appreciated loved one’s support but struggled with the emotional reactions of their family. Some noted changed social lives, such as hiding their diagnosis from friends or withdrawing from social circles. Studies exploring the social and relational consequences of advanced cancer are increasing (22), however few have focused on LC survivors,

Highlight box

Key findings

- Individuals living beyond a lung cancer diagnosis face substantial impacts on their work, finances, and relationships with family and friends.
- The survivorship healthcare needs of those with lung cancer are unique and nuanced, given their ongoing illness and long-term treatments.

What is known and what is new?

- Some individuals with lung cancer are surviving for longer, given the increased availability of immunotherapy and targeted therapies.
- This manuscript adds insights into the ongoing life impacts of those with lung cancer, particularly the substantial challenges experienced by younger lung cancer survivors whose careers, relationships, and finances were not as well established as many older survivors.

What is the implication, and what should change now?

- Key areas of intervention to improve lung cancer survivorship include improved workplace resources, proactive screening and management of financial toxicity, support and education for loved ones in distress, and ongoing connection to the lung cancer medical team, particularly specialist lung cancer nurse coordinators.

particularly among those on novel therapies living with the illness longer term.

The concept of “resuming life” was recently explored among metastatic melanoma survivors, who may face similar challenges to LC survivors having been diagnosed with a historically poor-prognosis cancer for which recent systemic treatment developments (e.g., IO) have significantly improved prognosis and survival, at least for some. Kamminga *et al.* (23) explored experiences of 20 metastatic melanoma survivors and found that demands and expectations of oneself/others made it difficult to proceed with life as it was prior to cancer and many reported changed perspectives on life and relationships. Another study reported that many long term responders to IO/TT with LC (n=9) and metastatic melanoma (n=8) live in a “twilight zone”—neither sick nor healthy, and described the psychological, social and employment consequences of this ongoing uncertainty (24).

In summary, to date, very few studies on life domain changes and challenges have been conducted among LC survivors. With the rapid advances in LC treatment has also come the need to reconceptualise ongoing LC healthcare, away from the previous division into that targeting people with early-stage LC being treated with curative intent versus those with advanced-stage LC being treated with palliative care. We now need to better understand the longer-term care needs and preferences among the growing cohort of survivors who are living with LC, regardless of the stage of their disease (5).

Objective

Therefore, this study aimed to understand the experiences of living life with and potentially beyond LC (6–24 months post-diagnosis), including impacts on: employment, finances, relationships with family and friends, and survivorship care preferences and needs. We present this article in accordance with the COREQ reporting checklist (available at <https://tldr.amegroups.com/article/view/10.21037/tlcr-23-815/rc>).

Methods

This paper reports findings from a larger qualitative research program exploring LC survivors’ experiences. The current study focuses on survivors’ experiences of employment, finances, relationships, and healthcare. Separate data on survivors’ psychological coping and

perspectives of novel therapies are reported separately (25). Ethical approval was authorised by RPA Zone of the Sydney Local Health District Lead Human Research Ethics Committee (protocol number X16-0447). The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). Participants provided written consent to participate, and reconfirmed willingness to participate verbally prior to the commencement of the interview.

Participants

Individuals were eligible to participate in the current study if they had been diagnosed with LC (any stage), were aged 18+ years, and were 6–24 months post-completion of initial active treatment (e.g., surgery, radiotherapy, chemotherapy). Participants receiving ongoing systemic therapies (e.g., IO, TT, maintenance chemotherapy) were still eligible to participate if they were 6–24 months post-diagnosis. Participants were excluded if they were at the end-of-life, were too unwell to participate, or did not have the English language skills or cognitive capacity to provide informed consent and complete study requirements.

Participants were identified and recruited to the study through ongoing participation in a large clinical cohort study of Australian LC patients (Embedding Research and Evidence in Cancer Healthcare—EnRICH) (26). EnRICH participants who had agreed to being involved in ongoing research and matched eligibility and selection criteria were invited to participate in the current qualitative study. Eligibility criteria for the broader EnRICH clinical cohort study were: individuals ≥ 18 years presenting to identified clinical sites for the diagnosis/management of new primary LC, or first progressive disease, local recurrence or new metastasis, between June 2017 and October 2021. Purposive sampling of participants for this qualitative study was utilised to ensure diversity of experiences across characteristics such as disease stage, treatments received, QoL, and smoking status.

Recruitment

A project officer for the EnRICH cohort study (K.M.) telephoned eligible EnRICH participants to introduce the qualitative survivorship study and invite participation. Those interested in participation were contacted by the study lead (R.L-P.) who provided additional information and sent potential participants study materials (information sheet, consent form) via email or post. Three individuals

who initially consented subsequently withdrew from the study due to worsening illness. One-on-one telephone interviews were conducted by one person (R.L-P.), a female PhD qualified Research Fellow, trained in qualitative research, with a background in psycho-oncology. R.L-P. had no prior relationship with participants, and explained the study was about understanding the experiences of people living with LC.

Data collection

As part of the EnRICH cohort study, demographic, clinical, and outcome data [including patient reported outcome (PRO) measures] are collected at diagnosis, 3-, 6-, and 12-month post-diagnosis and annually thereafter, up to 5-year follow-up. Demographic measures include data on age, gender, marital status, education country of birth, income, employment status, and remoteness of residence based on postcode. Clinical information includes date of diagnosis, tumour stage, histological type [small cell lung cancer (SCLC)/non-small cell lung cancer (NSCLC)], treatments received and dates, comorbidities, and smoking status. Two validated PRO measures were utilised: (I) European Organisation for Research and Treatment of Cancer Core Quality of Life questionnaire (EORTC-QLQ)-C30, a 30 item cancer-specific measure of QoL with scores ranging from 0–100 (higher scores represent higher QoL) (27); and (II) National Comprehensive Cancer Network (NCCN) Distress Thermometer with scores ranging 0–10 (10= most distress; ≥ 5 = clinical levels of distress) (28).

The semi-structured interview schedule was developed and iteratively revised by authors, who have expertise across psycho-oncology, LC clinical care, qualitative research and implementation science. Questions explored participants' lives since LC diagnosis and treatment, with a focus on post-treatment physical, psychological, social, and lifestyle changes and concerns. Interviews averaged 54 minutes (range, 27–97 minutes) and were audio-recorded and transcribed verbatim. Post-interview notes were documented after each interview. Depth and sufficiency of concepts/themes was considered after each interview, and regularly discussed by R.L-P., P.B., and N.M.R. After interview 16, authors determined that new information was rarely adding meaningful data. Participants 17–20 were purposively sampled for diverse and underrepresented characteristics, however new themes or subthemes were not identified. After 20 interviews, our coding team (R.L-P., P.B.,

and N.M.R.) felt confident that we approached meaningful thematic saturation as described by Saunders *et al.* (29).

Data analysis

Demographic, clinical, and PRO data underwent descriptive analysis using Microsoft Excel 2016. Qualitative interviews were analysed using Framework methods (30,31): (I) familiarisation with interview data by repeated listening, re-reading, and note-taking; (II) generation of independent initial thematic frameworks by separate authors (R.L-P., P.B., N.M.R.) based on three transcripts (15%), iterative discussion of themes and subthemes, and confirmation of coding scheme with independent analysis of an additional two transcripts by R.L-P., P.B., and N.M.R.; (III) coding of all data by R.L-P. according to the agreed coding scheme; (IV) organisation of themes and quotes into a Framework matrix, managed via MS Word and Excel; (V) identification, mapping, and interpretation of patterns and relationships between themes, participants, and participant characteristics using the coding framework.

Rigour was addressed through use of multiple strategies, such as (I) detailed review of transcripts to establish integrity of interview and transcription procedures; (II) collaborative coding of 25% of transcripts by different team members to ensure consistency between coders and a comprehensive list of themes and subthemes, and (III) use of rich direct quotes from participants to ensure accurate and fitting interpretation of data. See [Table S1](#) for full details of rigour using COREQ checklist for reporting qualitative research (32).

Results

Quantitative

Twenty LC survivors completed an interview. Mean age was 69 years (range, 30–84 years) with even numbers of males/females participating. Half of participants were married/partnered, with the remaining either widowed, divorced or never married. Just under half of participants ($n=8$) were currently working. Most participants were diagnosed with advanced LC (Stage III =8, Stage IV =6). Of the six people diagnosed with early stage (I/II) disease, two reported subsequent disease progression. Participants were on average 17 months post-diagnosis (range, 10–24 months) and had received multiple treatments over that time, including radiotherapy ($n=11$), chemotherapy ($n=10$), or

Table 1 Participant demographics, clinical data, and patient reported outcomes (n=20)

Characteristics	Values
Demographics	
Age (years), mean [range]	69 [30–84]
Female, n (%)	10 (50.0)
Marital status, n (%)	
Married/living with partner	10 (50.0)
Widowed	5 (25.0)
Single (never married)	3 (15.0)
Divorced	2 (10.0)
Education, n (%)	
Intermediate certificate/year 10	6 (30.0)
Leaving certificate/year 12	3 (15.0)
Technical certificate/diploma	4 (20.0)
University degree	6 (30.0)
Not reported	1 (5.0)
Employment status, n (%)	
Currently working	8 (40.0)
On leave	1 (5.0)
Retired	11 (55.0)
Country of birth, n (%)	
Australia/New Zealand	15 (75.0)
Europe	3 (15.0)
United Kingdom	2 (10.0)
Location of residence [†] , n (%)	
Metropolitan	14 (70.0)
Regional	6 (30.0)
Clinical data	
Stage at first diagnosis, n (%)	
I	2 (10.0)
II	4 (20.0)
III	8 (40.0)
IV	6 (30.0)
Time since diagnosis (months), mean [range]	17 [10–24]
Histological type, n (%)	
Non-small cell lung cancer	18 (90.0)
Small cell lung cancer	2 (10.0)

Table 1 (continued)

Table 1 (continued)

Characteristics	Values
Current disease status, n (%)	
Early stage, no evidence of recurrence	3 (15.0)
Recurrent	2 (10.0)
Locally advanced or metastatic	15 (75.0)
Treatments received [‡] , n (%)	
Lung resection	8 (40.0)
Chemotherapy	10 (50.0)
Radiotherapy	11 (55.0)
Immunotherapy	10 (50.0)
Targeted therapy	4 (20.0)
Patient reported outcomes	
Quality of life (EORTC-QLQ-C30), mean [range], 14 SD	72 [33–94], 14
Distress (NCCN Distress Thermometer), mean [range], SD	3 [0–10], 3

[†], based on postcode of residence; [‡], most participants have received more than one treatment. EORTC-QLQ, European Organisation for Research and Treatment of Cancer Core Quality of Life questionnaire; SD, standard deviation; NCCN, National Comprehensive Cancer Network.

novel therapy such as IO (n=10) or TT (n=4). Global QoL scores ranged from 33–94 [mean =72, standard deviation (SD) =14] while distress scores ranged 0–10 (mean =3, SD =3). Further demographic and clinical characteristics are shown in *Table 1*.

Qualitative

Four overarching themes were identified: (I) the winding path back to work; (II) vulnerability versus protection: managing the financial impacts of LC; (III) connection and loneliness: navigating relationships as a survivor; and (IV) still under the umbrella: healthcare during survivorship.

Theme 1: the winding path back to work

Of those participants in paid employment prior to diagnosis, all had either stopped or reduced work during periods of initial active treatment due to logistics, fatigue, or a desire to focus on their health. What happened after initial treatment finished varied widely. A few participants, particularly with earlier stage illness, and/or with an office-based role, had

reengaged with paid work easily, transitioning back to their previous roles with minimal disruption. Others were not able to return to their original employment because of physical function constraints or because the logistics of receiving ongoing treatments due to their advanced stage of disease (e.g., IO) were incompatible with work schedules. One participant had to move to a more junior role because fatigue and pain made them physically unable to do their previous role. These changes led to uncertainty about their career future. A few participants remained on extended leave or had retired early. For some, this was their own decision, with one participant's diagnosis prompting a re-evaluation of life goals and a focus on priorities outside work. However, others involuntarily stopped working either because they were physically unable or they felt unwanted by their workplace.

"I took two weeks off for recovery from surgery, three weeks recovery from the chemo... After that, it's just almost kind of like back to normal. I don't see a difference."—male, 50–59 years, early-stage LC.

"Work-wise, the doctor said... "You can't travel. You have to be here every three weeks."... In terms of work, that was it. I haven't worked since the diagnosis."—male, 50–59 years, late-stage LC.

"[Career goals] are on hold at the minute. I did get my certificate and I did all my placements. But at the moment I'm not physically capable of doing a job like that."—female, 60–69 years, late-stage LC.

The attitudes and actions of the employer and broader workplace appeared to significantly impact how/whether some LC survivors reengaged with work. Some employers kept in touch with participants throughout treatment, took an interest in their wellbeing, invited them back to work, and supported them with leave arrangements. Some employers also made changes to the work or schedule to accommodate survivors' needs. However, other participants expressed negative experiences with their workplace which made returning to work difficult. One survivor's employer showed little interest in his return to work which resulted in him taking early retirement. Another survivor's workplace could not easily accommodate part-time arrangements to enable ongoing treatment.

"They said, "Don't start at 7 o'clock in the morning, we've got something for you to do at 8 or 9. Come in, if you feel a bit tired, just let your supervisor know and sign off and go home again". It was open ended and very generous of them. They said, "How would you like to work your way in?"—male, 60–69 years, early-stage LC.

"I had the intention to stay [working]... The decision [to stop working] mainly is that the boss didn't show any interest. I thought I was a valuable asset in the company. In the long run you start thinking, "Well, they don't need me."—male, 70–79 years, late-stage LC.

Many participants discussed numerous benefits of working such as enjoying getting out of the house, feeling productive, connecting with colleagues, and reconnecting with their passions. Some of those unable to work expressed sadness at the loss of income, identity, purpose, and connections.

"Oh, I absolutely love it [work]. It gets me out of the house. It gets me feeling better about myself...I get to socialise. I get to interact. I get to use my brain."—female, <50 years, late-stage LC.

"I miss the [work] environment. I miss the [clients] and working with other staff. If I get the "all clear" I'm definitely going to go back in some capacity even if it's voluntary. I don't want to sit around doing nothing."—female, 60–69 years, late-stage LC.

Theme 2: vulnerability versus protection: managing the financial impacts of LC

The level of financial distress resulting from reduced work/income and increased medical expenses varied widely. Some participants experienced very few financial impacts. These participants were typically older, retired and described themselves as being financially "comfortable". Others, particularly younger participants, reported significant financial costs that continued to profoundly impact their lives, identity, and sense of autonomy. For example, one participant had to change her living arrangements and move back in with her parents, another had to reluctantly borrow significant amounts of money from his elderly parents to meet living expenses.

"I have had to come back to [city] and live with my parents. And that was quite rough on me because I had originally left because I felt that my family was quite toxic."—female, <50 years, late-stage LC.

"Not being able to go out to earn an income, is also the hard part. I've worked all my life... I find it hard to rely on my husband's money. And if I buy things for myself, I feel guilty because I'm buying it out of his money"—female, 50–59 years, early-stage LC.

Some participants felt protected from the impacts of reduced work during survivorship due to support such as income protection insurance or government disability or older age pensions. Some perceived this income support

as fraught with conditions and caveats and reported being fearful of losing these benefits, while others found the process to be relatively easy.

“I’ve been on two years of income protection. It’s not [equivalent to previous income], but it’s paid our mortgage. And [insurance company] are not too keen on paying it, they’ve tried to kick me off about eight times”—male, 50–59 years, late-stage LC.

“[Financial security] has been helped by the fact that my insurance actually paid out my salary. I get the same salary I used to get, which is pretty big, without having to go to work... I was expecting to be tortured, but in fact they came to the party pretty quickly.”—male, 60–69 years, late-stage LC.

During treatment, several participants reported experiencing very few out of pocket costs because they were treated in the public hospital system via universal healthcare or on a clinical trial. Several noted feeling *“thankful for being born in Australia and being treated under the public health system”*. Some participants’ healthcare teams also made special arrangements to ensure they did not incur out of pocket expenses if they could not meet them. Participants acknowledged other forms of financial support such as food vouchers or medical reimbursements, however this was usually only provided reactively if they spoke up about financial hardship. Other participants described increased medical expenses, particularly for medications or if they were treated in the private healthcare system. For some, there had been no disclosure of the costs they would incur. One participant reported her reason for attending a private cancer clinic was because she was not made aware of her options and was fearful of being put *“on some 2-year waiting list while the cancer was growing away in my lungs”* via the public healthcare system. Some participants reported substantial impacts to their savings as a result of medical expenses.

“I find that if you ask, you can get help with it. I wasn’t necessarily offered help with it upfront, but it is there if you ask”—female, 70–79 years, late stage LC.

“When I went for my very first treatment, the accounts woman came out and said she would be submitting an account for \$6700. And I said, “I don’t have that much money in a working account. No one has advised me that I’m going to have to pay that””—female, 70–79 years, late stage LC.

“[Universal healthcare] didn’t pay for [medication] so that was in the beginning every day \$130 or something... so my savings went down quick smart. Towards the end, I took a bit out of my superannuation to stay on top of things.”—male, 70–79 years, late stage LC.

Despite initial active treatment being finished, many

participants highlighted ongoing healthcare expenses related to their LC, such as attending general practitioner (GP) appointments or accessing allied healthcare services such as physiotherapy or psychology. Some described high transport and parking costs when accessing healthcare. Participants had varying capacity to meet these costs, with some unable to afford allied health treatments or medications and, therefore, going without.

“In [regional town] we have had to pay for the [GP] and it’s \$90 a bit. I can’t afford that. I’ve gone off a lot of my medication because I can’t afford it.”—female, 50–59 years, early stage LC.

“With the ongoing health issues, at the moment the public weight loss clinic isn’t accepting anyone. So I would have to go private and pay that. And none of that is rebatable. I have to see an exercise physiologist just for exercise.”—female, <50 years, late stage LC.

Theme 3: connection and loneliness: navigating relationships as a LC survivor

Participants described varying impacts of LC on their relationships with family and friends. Some survivors spoke about how their diagnosis had improved or deepened relationships, particularly with family members. For many, their family (often spouses and/or adult children) were heavily involved in their ongoing care and were regarded as an important source of emotional support. Several noted that family gave their life meaning, and for some their cancer had further clarified this. A few survivors described greater appreciation of time with loved ones, particularly with children and grandchildren. This sentiment was expressed across both early and late-stage survivors.

“I’ve got a wonderful husband who’s very, very positive and he says we’ll get through it, and if we don’t get through it, he’ll be there for me.”—female, 70–79 years, late stage LC.

“I think I enjoy [parenting] more now. I probably take in the moments of parenting more consciously, being more in the present. I’m very conscious of little moments of happiness and spending time with [children].”—male, 50–59 years, early stage LC.

A few participants, particularly those who did not have family living close by, spoke about unexpected support they received from friends or neighbours during their treatment, which deepened relationships and made them appreciate the significant people in their lives.

“I’ve had my friends... drive me to and from the hospital and I was allowed to stay [at friend’s house] and not stress about accommodation, I was very lucky that I had a good support group around me.”—female, 60–69 years, late stage LC.

“I live in an apartment by myself in a wonderful complex. I’ve got several friends here. I’ve got one neighbour who’s a very close friend and helps me a lot... It is quite a community. When I was first diagnosed with lung cancer, a young family [neighbours] gave me a [meal delivery] voucher. So I’m extraordinarily lucky to have that as my home environment.”—female, 70–79 years, late stage LC.

Whilst many participants experienced benefits to their relationships, some also described challenges. Many expressed ongoing concerns about their family members’ coping, with several survivors describing how the anxiety of family regarding their health and capabilities was exhausting and overbearing. A couple of participants reported worrying more about their family than themselves and found this emotionally draining. This was expressed by both early and late-stage survivors, and across all age groups.

“[Partner] is very worried about me all the time. And kind of almost to the point of smothering me. I definitely want to be there for them emotionally, but I can’t just be dealing with them crying about everything every day.”—female, <50 years, late stage LC.

“I’m worried about them [adult children] being worried, so that starts a cycle and I am just a wreck.”—female, 70–79 years, late stage LC.

Several participants spoke of important relationships becoming strained or distant after their LC diagnosis, for a number of reasons. For some, the stress of diagnosis caused loved ones to withdraw, others described increased friction because of their physical limitations or mood, and some believed lack of support or concern from a loved one impacted the relationship in the long term. A few participants with late-stage diagnoses revealed they had lost friendships because their friends did not know how to cope with the “*impending doom*” of LC or had experienced loss before and wanted to avoid it again. A young LC survivor expressed social isolation, feeling that their old friends “*had moved on with their lives*”. Many participants experienced both positive and negative relational impacts, with the contrast between these highlighting negative outcomes.

“I’ve got a partner, she’s been very attentive and understands so much of it. But any stress in a relationship, like this, makes it worse... She says I’m scratchy and itchy and irritable.”—male, 70–79 years, early stage LC.

“I’ve got two [adult children] that I’ve only seen three times in the last six years. They’re not there for me. But my other daughter has always been here for me, she’s really supportive and loving... [Other adult children] don’t do anything... they didn’t even ring me.”—female, 70–79 years, late stage LC.

“There’s been the people whose instant reaction was “what can I do to help?”, “Can I do this?”... Then there’s the people who found out and I haven’t seen them again. Some people have definitely changed when they found out I’ve got cancer, they disappeared.”—female, 70–79 years, late stage LC.

“I do notice on the periphery a change in some people who are very dear friends, who do now look at me like “dead man walking”. There is a psychological change that happens to people when they know there’s an impending doom around.”—male, 50–59 years, late stage LC.

A few participants with late-stage LC also discussed how their ongoing survival was defying the expectations of others, with a couple of participants describing how friends or family were pleasantly surprised at how well they were coping and how good they looked. But for some participants, “*looking so well*” led to negative impacts, such as some family members now holding unrealistically high expectations of their capability, particularly around the home, or withdrawing support.

“People have said to me, “Well, you’ve got stage IV lung cancer but you don’t look like it.” And I said, “Am I supposed to look like I’m half dead, like what were you expecting?” People’s perception of what it is that lung cancer should look like, [they think I] should be lying on a bed, dying [laughs]”—female, 70–79 years, late stage LC.

“I had family here at Christmas time. And that annoyed me a bit. They think I’m Wonder Woman because I very rarely get sick. They just look at me as if I’m fine.”—female, 70–79 years, late stage LC.

Participants also spoke about their own struggles acknowledging their cancer with others. Some tried to reassure their friends they were doing well, as they did not want pity or sympathy. A couple of participants did not want to disclose their cancer diagnosis to their broader social network, preferring to keep it private. One participant discussed finding it challenging making new friends, as she did not know if/when to disclose the LC diagnosis.

“I don’t think people give me a lot of sympathy because I tell them usually that I think I’ve dodged a bullet. I don’t want people sort of thinking, “Ob you poor thing.”—male, 50–59 years, late stage LC.

“I had that massive fear of going out to meet people because... it’s almost like a shame in the sense of having the cancer... I’m concerned that people will pull away knowing that I have cancer because they don’t want to deal with it... I felt quite alone in that sense... I don’t know whether they want to take on a friend and then have a friend die on them.”—female, <50 years, late stage LC.

Theme 4: still under the umbrella: healthcare during survivorship

Participants described the importance of maintaining connection to the oncology team as they navigated living life with/beyond the LC. This maintained connection appeared equally important to those with early and late-stage LC, and across age groups. Those receiving ongoing IO/TT still had regular appointments with the medical oncology team. Even if treatment had ceased, most participants were still in contact with at least one cancer specialist. Many strongly emphasised the value of specialist LC nurses/cancer care coordinators, as their “go-to person” providing ongoing information, coordination, support, and access to continuity of care. Some participants also noted appreciation of the allied health members of the cancer care team, including social workers, psychologists, dieticians, and physiotherapists. One participant expressed very positive experiences about a cancer survivorship fitness program. Some participants noted they did not feel they needed to utilise the allied health services but appreciated having them offered and their ongoing availability if needed. Participants also appreciated ongoing regular surveillance from the cancer care team, and if part of a clinical trial, the extra scrutiny that increased scans (required as part of the trial) provided. However, access to care coordination, and a connection with the cancer care team were not experienced by all participants. Some felt unable to have their questions answered and felt shuffled between teams.

“[Lung cancer nurse] is invaluable because, it’s a psychological thing... you know you can e-mail her anytime, you can call her. It gives you a security blanket you can just call. There’s someone there to listen and call and guide you through those extremely complex [situations].”—male, 50–59 years, late stage LC.

Participants reported mixed experiences of their GPs. For some, their GP was a trusted medical advisor and confidante, however, most reported they were not routinely involved in survivorship care. Some reported difficulty with the flow of information between specialists and their GP and felt responsible for keeping the GP informed. Some participants had little awareness about how much their GP knew about their diagnosis or how much information specialists had sent to the GP. Several acknowledged that they rarely visited their GP, usually only for prescriptions or referrals. Others did not have a regular GP, attended medical centres instead, or their GPs had retired/moved away and they had not found a replacement.

“Well, [GP] mainly reassured me that the treatment I’m having is probably the best I can have for my needs. He’s another

layer of support... I’ve had him for about 30 years.”—male, 70–79 years, late stage LC.

“I don’t think I really have a GP because when my wife passed away I’ve never been to a doctor again. So with the blood test I went to the medical center. So I haven’t got really a relationship with him”—male, 70–79 years, late stage LC.

Discussion

Key findings

This study provides insight into the challenges and opportunities faced by people carrying on with life beyond a LC diagnosis. After treatment had finished, or as they adapted to long-term therapies (IO/TT), survivors described the unique experience of living with a cancer with a now somewhat uncertain prognosis. Participants noted an array of LC impacts across life domains such as work, finances, and relationships, with some experiencing substantial ongoing disruption.

Participants in our study experienced substantial work disruptions and ongoing career impacts. While more than half of participants had retired prior to diagnosis, those still in paid employment at diagnosis described the need, capacity, and desire to continue working. One in five people diagnosed with LC are of typical working age (under 65 years) in Western countries (2,33). A few survivors in our study reported an easy return to their previous role after treatment completion. However, more reported substantial challenges such as feeling unwanted or forgotten by their employer or being physically unable to perform previous work duties. A need for ongoing contact and workplace support were reported as key facilitators of work reengagement, which aligns with previous research among LC survivors (15), advanced colorectal cancer survivors (34) and a meta-review of qualitative studies addressing employment among cancer survivors (35). One study did note that LC survivors reported a need for more support navigating employment issues (15). While general return to work resources are provided by peak cancer support bodies (36,37), our study and others (34,38) demonstrates that the challenges for LC survivors in workforce reengagement require a more targeted approach. Development and dissemination of resources to support employers and workplaces with ongoing connection and workplace adjustments for people living with LC remains a key priority.

We found that some LC survivors face substantial

financial impacts of their disease, despite Australia's universal healthcare and relatively high levels of social support. These challenges were particularly pronounced among younger survivors of working age who had significant financial responsibilities (e.g., mortgage, dependent children) and were living on a reduced income due to employment changes. These experiences align with other research that reports being a younger age (<65 years) cancer survivor is associated with worse financial burden (39). Those who had already retired typically reported less financial distress as they often had lower expenses (e.g., owned their home), had financial reserves, and had superannuation or an existing pension as uninterrupted income. These findings are novel and prompt a need for programs that facilitate work reengagement to alleviate financial stress, as well as improved access to professional support (such as a financial navigator or planner) for financial management and recovery (40).

Despite Australia's universal healthcare, many participants reported substantial out-of-pocket healthcare costs. Similar to previous findings, some participants with healthcare insurance who opted to be treated via the private hospital system incurred sizeable and unexpected financial costs (39). Participants also reported significant expenses during survivorship incurred from GP appointments, allied healthcare treatments, transport/parking, and medications. Numerous calls to action have been made for: (I) improved early identification of cancer survivors experiencing financial toxicity; (II) greater transparency in disclosing future financial impacts and options, and (III) financial support of cancer survivors in financial distress. However, limited implementation of these measures into routine care has been reported to date (20,39-41).

Participants described the significant relational impacts of LC. Many reported some close relationships had strengthened, but others had become strained or lost. Participants expressed concern about their family members' distress, were exhausted by loved ones' anxiety, and were saddened when family/friends withdrew from the relationship (perhaps due to anticipatory grief). Research consistently demonstrates that family members of people with cancer experience high levels of emotional distress (42), and that patient and family carer mental health and coping are interdependent. A longitudinal study found family members' mental health at baseline significantly influenced patient mental health 3 months later (43). These findings underscore the importance of distress screening and established pathways for psychological support for the loved

ones of people with cancer (44), particularly among LC populations given the high levels of distress among both patients (45) and their carers (46).

Additionally, some participants with late-stage LC in our study also reported relationship friction due to mismatched expectations about their physical capabilities/limitations. Other studies of long-term responders to novel therapies have similarly reported experiences of those who do not fit the traditional "sick" role (15,23). Inclusion of family members or significant others in medical consultations and information about the ongoing and late effects (that may not be outwardly visible) could create a better understanding of the needs and limitations of survivors in the longer term. A review of social support among people with LC found significant associations between the level of support received from loved ones and higher patient QoL (47). Interventions assisting people affected by LC to navigate relationship challenges during survivorship are needed.

LC survivors report unique ongoing physical and emotional needs, particularly those with advanced LC receiving IO/TT (14,15,25). The survivorship care model used in early-stage and curative cancers may not be wholly applicable; nor may palliative care, as some LC survivors will experience long term disease control (5). Petrillo *et al.* (14) described this as the unique "foot-in-both-worlds" experience of LC survivors. Limited research attention has been given to the rapidly changing landscape of LC treatments, survival and survivors' ongoing healthcare needs (16). Participants in our study expressed their strong preference for ongoing contact with their oncology team, and several highlighted the immense value of their LC nurse coordinator, who acted as a primary point-of-care, for information and support. The value of nurse-led survivorship care has been well established among breast, prostate, gynaecological, and colorectal cancers (48), however ours is one of the first studies to describe the beneficial role of the LC nurse specialist in survivorship. Research to establish the optimal ongoing care pathways for LC survivors, and action to improve access to LC nurse specialists, is urgently needed in Australia (3). Our study provides foundational evidence for further research.

Strengths and limitations

A key strength of this study is recruitment via the EnRICH cohort study which resulted in a broad array of participants who varied on demographic and clinical characteristics, such as age, marital status, education, employment, cancer stage,

and treatments received. This recruitment strategy also allowed for insights into different healthcare experiences, as participants were not recruited from a single treatment centre and resided in both metropolitan and regional areas. However, one potential limitation is that sites where recruitment to EnRICH occurred were all tertiary specialist tertiary cancer centres and, therefore, may offer better than standard support structures during episodes of care, such as through the role of the specialist LC nurse coordinator at some, but not all, centres. Despite this, our study fills a notable void, with Lai-Kwon *et al.* (15) calling for future qualitative LC studies to be conducted among survivors with a broad range of demographic and clinical characteristics.

Important limitations of this study must however be acknowledged. Despite purposively sampling for variability in distress/QoL, participants in our study reported higher QoL than has been reported in other studies of LC survivors (49). Additionally, most participants were of Caucasian background or European born. Future research should focus on those who have high levels of distress, lower QoL, and those who are from culturally and linguistically diverse backgrounds, as these survivors may face unique challenges. Additionally, given our study's focus on life domains such as relationships, employment, and healthcare, another limitation may be that we did not capture the attitudes of family/friends, employers, and health professionals. Our study demonstrates that many survivors place great value and reliance on these important stakeholders, and future LC survivorship research should aim to capture their experiences and attitudes.

Conclusions

While treatment and survival advancements are having an undeniably positive impact on people with LC, more survivors than ever before are navigating the unique challenges of life with LC across work, finances, and relationships. In our study, impacts were felt most by younger LC survivors, whose careers, relationships, and finances were not as well established as many older survivors. Key areas of intervention include improved workplace resources for LC survivors, proactive screening and management of financial toxicity, and support and education for loved ones in distress. LC survivors described a strong desire to stay connected with their cancer healthcare team, particularly the specialist LC nurse. As treatments and survival continue to improve, researchers,

clinicians, and policymakers must remain aware of the unique challenges faced by those carrying on with life as a LC survivor.

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Footnote

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