An Investigation of the practical supportive care needs in lung cancer: survivors, family caregivers and health professionals' perspectives





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Introduction

- Lung cancer survivors (LCSs) often experience lower Quality of Life (QOL) compared to other types of cancer survivors (Dagnelie et al., 2007; Sugimura & Yang, 2006).
- Family caregivers (FCGs) of these survivors are impacted by the stress of cancer diagnosis and survivorship, leading to reduced QOL, particularly where their LCS is experiencing anxiety or depression due to low QoL themselves (Tan et al., 2018).
- Such issues for LCSs and their FCGs highlights that these groups' supportive care needs (SCNs) are not being met.
- SCNs can be defined as the need to support one who has a disease or or illness to increase their QOL through early treatment and preventing the symptoms of the disease of side-effects of treatment (Berman et al., 2020).
- One important SCN, Practical needs, can be broadly defined as the need to
 maintain wellbeing in areas pertaining to finance, employment/education and
 transport to healthcare (Jiang et al., 2022). While there is some literature on LCSs
 experiencing financial struggle after treatment (Vijayvergia et al., 2015), issues
 maintaining current career development stage (Paraponaris et al., 2010) and
 transport issues getting to treatment (Baggstrom et al., 2011), such needs are less
 documented but equally apparent in FCGs (Utz & Warner, 2022). There is also a
 gap surrounding non-informational practical SCN research and intervention for both
 LCSs and FCGs.





Aims

 To identify the key practical supportive care needs of LCSs and their FCGs, from the perspective of LCSs, their FCGs and HPs involved in their care, and the extent to which they were being met in current health services.

Methods

- We conducted in-depth interviews with 13 LCSs (8 females, average age: 67 ½ years), 9 FCGs (7 females, average age: 47½ years) and 19 Health Professionals (HPs) who supported individuals living with, and after, lung cancer across Ireland.
- Participants were recruited via a range of approaches, including print and social media campaigns from the research team, funding body and supportive care charities in Ireland, and targeted recruitment of HPs through hospital settings.
- Interviews were audio-recorded and transcription was prepared for reflexive thematic analysis (Braun & Clarke, 2019).



REFERENCES

- Baggstrom, M. Q., Waqar, S. N., Sezhiyan, A. K., Gilstrap, E., Gao, F., Morgensztern, D., & Govindan, R. (2011). Barriers to Enrollment in Non-small Cell Lung Cancer Therapeutic Clinical Trials. *Journal of Thoracic Oncology*, 6(1), 98–102. https://doi.org/10.1097/JTO.0b013e3181fb50d8
- Berman, R., Davies, A., Cooksley, T., Gralla, R., Carter, L., Darlington, E., Scotté, F., & Higham, C. (2020). Supportive Care: An Indispensable Component of Modern Oncology. *Clinical Oncology*, 32(11), 781–788. https://doi.org/10.1016/j.clon.2020.07.020
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. Qualitative Research in Sport, Exercise and Health, 11(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806
- Dagnelie, P. C., Pijls-Johannesma, M. C. G., Lambin, P., Beijer, S., De Ruysscher, D., & Kempen, G. I. J. M. (2007). Impact of fatigue on overall quality of life in lung and breast cancer patients selected for high-dose radiotherapy. *Annals of Oncology*, 18(5), 940–944. https://doi.org/10.1093/annonc/mdm057
- Jiang, C., Yabroff, K. R., Deng, L., Wang, Q., Perimbeti, S., Shapiro, C. L., & Han, X. (2022). Self-reported Transportation Barriers to Health Care Among US Cancer Survivors. *JAMA Oncology*, 8(5), 775–778. https://doi.org/10.1001/jamaoncol.2022.0143

Results

FCG Providing Transport Support: It must have been a bit of a blow when he stops driving because he loses a bit of independence... It also meant that I had then to step up to the plate and do it... all the stuff that I let him do I didn't ... I had to then do. (FCG)

Access to transport support and remote services

Costs associated with transport for LCSs: it's €30 to get a taxi, €35, into [location removed]. So, you don't do that out of €198 social welfare (LCS)

Financial Support for optimum treatment my daughter and all her friends and all his friends raised funds to get the money to send him to Germany for treatment. (FCG)

Financial and socioeconomic support

Struggling with Multiple Financial Costs: Financially you struggle, I'm all the time borrowing. Financial is an issue and heating, electric. There are always big bills... I can't afford to pay my landline and my mobile. So financially things like even going into hospital, having to buy clothes and things like that.

(LCS)

The need for FCGs to have flexibility in work: I just would take a week off and it would be okay. They knew I needed to be there so I was very lucky in that regard that I was able to do that because it's not every job that would be so understanding. (FCG)

Access to services as an important practical need for LCSs: I think one of the big barriers is probably the geographical issue that we have. Our patients, we have a massive area to cover. (HP)

If there was more regional groups or if there was little satellite groups or something it might be more helpful for them. (HP)

Low literacy among LCSs: I had a thing about the literacy, but I would say every second week I would have somebody who doesn't read and write, and I think that needs to... I suppose on the whole people with lung cancer, it's a big generalised statement and obviously not, but on a whole you're talking about the lower socioeconomic group (HP)

Literacy Needs of LCSs

Impact of literacy needs on service delivery for LCSs: There are some of my patients who don't read or write. So, group for them would not be fantastic. They'd feel very vulnerable, whereas in a one-to-one, they do great. (HP)

Support to maintain work

LCS Struggles Taking Leave: I went back to work full-time which I didn't want to do but it is an issue in our place, they don't want part-timers. I went back full-time and never talked about [receiving treatment] really. The ones I worked with, they always said they just couldn't believe that I just came back as if everything was fine. [LCS]

Conclusion

- The current research offers insights into the met and unmet practical care needs of people affected by lung cancer. The results highlight a need to develop evidence-based interventions that address the practical needs of LCSs and their FCGs, which are feasible to implement within the context of current healthcare services.
- Paraponaris, A., Teyssier, L. S., & Ventelou, B. (2010). Job tenure and self-reported workplace discrimination for cancer survivors 2 years after diagnosis: Does employment legislation matter? *Health Policy*, 98(2), 144–155. https://doi.org/10.1016/j.healthpol.2010.06.013
- Sugimura, H., & Yang, P. (2006). Long-term Survivorship in Lung Cancer: A Review. Chest, 129(4), 1088–1097. https://doi.org/10.1378/chest.129.4.1088
- Tan, J.-Y., Molassiotis, A., Lloyd-Williams, M., & Yorke, J. (2018). Burden, emotional distress and quality of life among informal caregivers of lung cancer patients: An exploratory study. *European Journal of Cancer Care*, 27(1), e12691. https://doi.org/10.1111/ecc.12691
- Utz, R. L., & Warner, E. L. (2022). Caregiver Burden Among Diverse Caregivers. Cancer, 128(10), 1904–1906. https://doi.org/10.1002/cncr.34171
- Vijayvergia, N., Shah, P. C., & Denlinger, C. S. (2015). Survivorship in Non–Small Cell Lung Cancer: Challenges Faced and Steps Forward. *Journal of the National Comprehensive Cancer Network*, 13(9), 1151–1161. https://doi.org/10.6004/jnccn.2015.0140

