

Coping with Lung Cancer

Understanding how a lung cancer diagnosis can affect patients emotionally – findings from a Global Lung Cancer Coalition survey

Introduction

We know that patients feel a range of emotions when they receive a lung cancer diagnosis and then throughout their treatment and care journey. To find better ways to help patients cope and get through treatment with less stress and anxiety, the Global Lung Cancer Coalition (GLCC) wanted to understand the emotions that patients feel at key moments.

We recognise that for many people, family and friends are the main source of emotional support during this time. However, some also seek support from professionals – such as oncology social workers, cancer/oncology nurse specialists, psychologists, chaplains, psychiatrists, patient navigators, charities/patient organisations, and others – to help them deal with new and sometimes scary things about lung cancer.

To understand more about the emotional support patients received, the GLCC ran a short survey to gather experiences and insights. Specifically, we wanted to learn if and when patients received professional support during their lung cancer journey; the topics they found helpful to discuss; and whether they would recommend seeking emotional support to a newly diagnosed patient.

The survey ran for two weeks across eight countries – Australia, Bulgaria, Peru, South Africa, Sweden, Taiwan, UK, and USA – and received 554 responses from people with, or who have had, lung cancer. Responding participants were verified and enrolled to Censuswide's network via direct recruitment, with their participation hinging on whether they have had, or are currently living with, lung cancer.

This briefing highlights the main global findings from the surveys. The GLCC would like to thank Censuswide, a market research company, for their support in refining the questions and for leading data collection and collation; and the members in the selected countries for their input.

Global findings

Demographics and treatment status

- 7 in 10 respondents (70%, 387/554) identified as male, and 3 in 10 (29%, 163/554) identified as female. Four respondents (4/554) identified as gender neutral
- Just under a third (32%, 175/554) of respondents were aged 55 and above, the highest of any age group. The 35-44 age group was the next largest group (27%, 148/554), and smallest age group was 16-24, with 1 in 20 respondents (6%, 32/554) of this age
- Almost a third of total respondents stated they are currently in treatment (32%, 179/554), with just slightly less having finished treatment (31%, 170/554)
- 17% of respondents (92/554) stated they are newly diagnosed and haven't started treatment yet; and just over a tenth (11%, 60/554) said they had chosen not to have treatment

Opportunities to receive emotional support

- 6 in 10 respondents (59%, 325/554) said they had previously, or are currently receiving, emotional support

- However, over a third (35%, 193/554) stated they had not received, or were not receiving, support, either because they: didn't know where to get it (13%, 70/554); weren't offered any (11%, 63/554); or didn't want to receive it (11%, 60/554)
- A small proportion preferred not to say (1%, 6/554) or stated that they have just been diagnosed and have not yet started treatment (3%, 15/554)

Between 44% to 57% of respondents said that they did not receive emotional support (Bulgaria: 57%, Sweden: 48%, Taiwan: 40%, the UK: 44%) to talk about how their diagnosis has impacted their thoughts, feeling, and mood. This compares to approximately 2 in 3 respondents in Australia, Peru, South Africa, and the USA (64%, 69%, 65%, 73% respectively).

Providers of emotional support

- Cancer/oncology nurse specialists were the most commonly reported sources of support (43%, 139/325). Over a third (35%, 115/325) spoke to a psychologist
- Just over 1 in 4 respondents (27%, 88/325) spoke to patient organisations/charities/not-for-profit organisations. The same number of respondents (27%, 88/325) had spoken to a general practitioner/primary care physician

In Peru, Sweden and Taiwan, the highest proportion of patients said they spoke to a psychologist (46%, 38%, 71% respectively) about the emotional impact of their lung cancer. In Bulgaria, the highest proportion spoke to their general practitioner or primary care physician (47%). In Australia, South Africa, the UK, and USA, cancer/oncology nurse specialists were noted to be the common source of emotional support (25%, 48%, 52%, 66% respectively).

Opportunities to discuss the emotional impact of lung cancer

- Of those who hadn't received emotional support, almost 2 in 3 (62%, 141/229) stated that they would have liked to have had the opportunity to talk to someone about the emotional impact of lung cancer following diagnosis or during treatment. However, almost a third (32%, 73/229) stated they would not have liked to receive emotional support. Just over 1 in 20 (7%, 15/229) said they weren't sure if they would have liked to have received emotional support

A high proportion of respondents who hadn't, or are not currently, receiving emotional support stated that they would have liked to receive support (ranged from 59% in Taiwan to 83% in Sweden).

Interestingly, a higher proportion of respondents in the UK and USA expressed that they didn't want to speak to someone about the emotional impact of their lung cancer diagnosis or during treatment (53% and 56% respectively).

Emotional support during the lung cancer journey

- 20% of respondents (66/325) who had received, or were receiving, emotional support stated they received the most emotional support as they were being diagnosed. When asked, almost 3 in 10 (28%, 92/325) said they would have liked to have received the most support at this stage
- Almost a third (31%, 101/325) stated they had received the most support right after they were first diagnosed – when 20% (64/325) said they would have liked to receive the most support

Respondents from Peru, Sweden, the UK, and USA noted that they received the most emotional support right after they were first diagnosed with lung cancer (49%, 38%, 30%, 41% respectively), whilst members from Australia, Bulgaria, and Taiwan were split, with the highest proportions noting



that they received the most support right after they were first diagnosed or as they were being diagnosed (20%, 29%, 29% respectively).

The highest proportion of respondents from South Africa noted that they received the most emotional support when the lung cancer came back (27%), contrasting the experiences of lung cancer patients from other countries.

The highest proportion of respondents said they would have liked to receive the most emotional support as they were being diagnosed (Australia: 22%, South Africa: 30%, Bulgaria: 24%, Sweden: 31%, Taiwan: 29%, USA: 38%) or right after they were first diagnosed (Peru: 26%, UK: 30%)

Finding emotional support

- 1 in 5 respondents who had received, or were receiving, emotional support (21%, 68/325) said they had asked for help in coping with their diagnosis, with a similar number (21%, 67/325) saying they were referred by a friend, family, or insurance provider. Of note, the same proportion stated that they were offered support without having to ask (21%, 67/325)

The highest proportion of respondents from Australia, Bulgaria, and Taiwan asked for helping in coping with their diagnosis (22%, 35%, 38% respectively). Respondents from Peru noted that they were offered support (26%), with a high proportion of respondents from Australia also stating this (22%).

The highest proportion of respondents from the USA noted that they were referred by a friend, family member, or insurance provider (34%), whilst the highest proportion in South Africa, Sweden, and the UK noted that they were referred by someone at their treatment centre (21%, 35%, 27% respectively).

Emotional support over time

- Approximately three quarters of respondents who had received, or were receiving, emotional support spoke to the person supporting them for up to six months (74%, 242/325). Only eight respondents (2%, 8/325) spoke to the person providing emotional support for less than a month
- When asked about the frequency of meetings, most respondents stated that they speak to their support person a few times a week – 35% (112/325) spoke to their support person 2-3 days a week, and 26% (84/325) spoke to their support person 4-6 days a week. While 15% (50/325) said they speak to their support person once a week, 12% (38/325) expressed that they speak to their support person every day

While the highest proportion of respondents in Bulgaria, the UK, and USA spoke to their emotional support person for up to three months (53%, 41%, 44% respectively), in Australia, Peru, South Africa, and Taiwan, respondents most frequently stated speaking to their support person for four to six months. The highest proportion of respondents from Sweden said they spoke to them for seven months to a year (38%).

The highest proportion of respondents in the UK noted speaking to their support person between 4-6 days a week (30%), which contrasts what more respondents from the other countries involved stated, only speaking to their support person 2-3 times a week (ranged from 27% in South Africa to 48% in Taiwan).

Topics discussed with emotional support person

- Respondents stated they most frequently spoke about coping with treatment side effects and the impact on their life (47%, 151/325), their emotions about starting treatment (43%, 139/325), coping with their diagnosis when they were first diagnosed (41%, 133/325), and dealing with the financial impact of their lung cancer on themselves and their family (40%, 131/325)
- Interestingly, only a small minority (2%, 7/325) discussed how to cope when treatment did not work. This may be because few patients speak to their treatment team about the emotional impact of their diagnosis

The highest proportion of respondents in Australia, Peru, the UK, and USA most frequently spoke to their support person about how to cope with treatment side effects and the impact on their lives (36%, 57%, 55%, 53% respectively). Respondents from South Africa and Taiwan most frequently spoke about how to talk to their treatment team, family and friends, and people at work (45%, 62% respectively). Patients in Bulgaria frequently spoke to their support person about how to deal with the financial impact of their cancer on themselves and their family members (53%), whilst respondents from Sweden frequently discussed their emotions about starting treatment (46%).

Recommending emotional support

- Interestingly, just over half of respondents (51%, 167/325) who had received, or were receiving, emotional support said they were unsure if they would suggest someone diagnosed with lung cancer seek emotional support. Positively, 49% (158/325) said they would, with no respondents saying they wouldn't

Whilst a higher proportion of respondents from Peru, Taiwan, the UK, and USA said they would suggest seeking emotional support (57%, 76%, 70%, 66% respectively), the majority of respondents from Australia, Bulgaria, South Africa, and Sweden said they weren't sure if they would suggest someone diagnosed with lung cancer seek support (87%, 53%, 73%, 62% respectively).

Respondents who said they would recommend getting emotional support frequently cited a number of reasons for their answer, including: to help deal with anxiety, stress, fear, anger, depression; to gain clarity; to cope with their lung cancer; to get more support; to help with mental health and wellbeing; to feel understood; to help deal with the stigma; to talk to someone who isn't a family member; to know what to expect; to vent; and to continue to believe.

Conclusion and next steps

It's clear from the findings that receiving emotional support from a professional – in addition to family and friends – helps patients living with lung cancer deal with the emotions they experience once diagnosed and throughout their treatment and care journey. The GLCC is committed to raising awareness of the importance of supporting patients mentally and emotionally, as well as physically; and will be exploring in the coming months what best practice in emotional care should look like, drawing on examples from around the world.

More information

Established in 2001, the GLCC is an international alliance of 42 patient organisations from 30 nations committed to promoting global understanding of lung cancer and the right of patients to effective early detection, better treatment, and supportive care, to improve disease outcomes for all. For more information about the GLCC's work, please visit our website at www.lungcancercoalition.org or email our secretariat at: glcc@roycastle.org.