Patients' experiences of lung cancer during COVID-19

Insights from Brazil

GLOBAL LUNG CANCER COALITION

Introduction

The COVID-19 pandemic has had a profound impact on patients, including those living with lung cancer, and healthcare systems around the world.

The Global Lung Cancer Coalition (GLCC), an alliance of 42 patient organisations from 30 countries across the world, wanted to understand if COVID-19 is still impacting the care patients receive, and to compare the experiences of patients in different countries.

In December 2021, the GLCC shared a **global online patient experience survey**.

The survey ran for eight weeks and received **555 responses** from patients across **21 countries**.

Key findings from Brazil

Demographics

18 lung cancer patients or their carers responded

94% of respondents identified as female, **6%** identified as male

83% were diagnosed in the last **five years**

89% have non-small cell lung cancer

Treatment

83% of responding patients are currently **having treatment**. **11%** had **finished treatment**, and **6%** had **just been diagnosed**

Involvement in decisions

94% said they **felt involved** in decisions about their treatment and care to some extent. **6%** said they **were not** involved but their caregiver was

Accessing information

88% of patients said they got the information they needed **at the right time**. But two patients said they had to look for more information on their own

Screening

83% of patients said they **would attend** a screening appointment if invited

One patient said they would not attend, and two patients were not sure

Emotional impact

69% of patients said that **getting the diagnosis** had the biggest emotional impact on them, followed by having the **first treatment session** (44%) and **waiting to find out test results** or **if treatment is working** (31%)

75% said they are **fearful of relapse. 38%** said they feel **anxious about treatment and side effects**, while **31%** are **worried about the financial impact** of their cancer on them or their family

75% of patients said they found speaking with **family and friends** the most helpful in dealing with their emotions. **63%** said that speaking to their **treatment team** helped

Impact of COVID-19

94% of responding patients said they have been vaccinated against COVID-19.

56% of patients said there was **no difference** in how easy it has been to contact their treatment team during the pandemic. **63%** said their **treatment has continued** as normal. **31%** had seen their face-to-face appointments **swapped to video or telephone**

The **majority of patients prefer face-to-face appointments in most situations**, particularly at diagnosis (88%) for the first consultation and for regular check ups (100%), and if there is a change to treatment (94%). 31% of patients would like to use video or telephone if they are worried about something

Call to action

The members of the GLCC are calling for the implementation of the rights outlined in its Patient Charter, namely ensuring that all lung cancer patients have access to quality healthcare; informed self-determination, which includes involvement in decision-making; and physical and mental integrity.

More information

The GLCC's member in Brazil is **Oncoguia Institute**: http://www.oncoguia.org.br

For more information about this survey and the work of the GLCC, please visit our website: https://www.lungcancercoalition.org

You can email our secretariat at: glcc@roycastle.org