

More than one in 10 patients with lung cancer do not know what type they have

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More than one in 10 patients with lung cancer do not know what type of tumor they have, according to data from a 17-country study carried out by the Global Lung Cancer Coalition (GLCC) to be presented at the

European Lung Cancer Conference (ELCC). Nearly one in five patients surveyed did not feel involved in decisions about their treatment and care, and a similar proportion felt that they had never or only sometimes been treated with dignity and respect by those treating them.

"I was shocked that some people didn't know what type of [lung cancer](#) they had because, if they didn't have that information, how could they understand their treatment options for making decisions about their care?" said Vanessa Beattie from the GLCC. "Receiving a diagnosis of [lung cancer](#) is devastating and it's crucial that [patients](#) receive good quality information from the start so they are empowered to make informed decisions about their treatment. At diagnosis, they should be offered information—written or in another form—about their type and stage of cancer and a potential treatment plan which they can discuss with their cancer team and their family."

Of 907 patients with lung cancer who responded to the survey carried out in January 2020, 574 (63%) were from Europe. Of European respondents, 11% did not know what type of lung cancer they had (13% globally), 19% did not feel involved in decisions about their treatment and care (18% globally), and 11% felt they had 'never' or only 'sometimes' been treated with dignity and respect by their treatment team (9% globally).

Beattie suggested that, while cancers services may vary across Europe and globally, clinicians need to keep challenging themselves to drive improvements in lung cancer care and engage with patients to address their individual needs.

"There is still a stigma attached to lung cancer because of its links with smoking, but every patient should be treated with dignity and respect at all times and have a positive experience of care wherever they are treated, including opportunities to talk about their concerns," said

Beattie.

Language differences and the increasing complexity of treatments for lung cancer can make it difficult for patients to communicate with their medical team and this may jeopardize not only their care but also recent progress in patient empowerment.

A second study to be presented at ELCC highlights the significant need for interpreters at cancer clinics. Between November 2017 and December 2020, 242 referrals for interpreters speaking a total of 24 languages were arranged at a major hospital in Ireland. The majority were for patients from Central and Eastern Europe and the number of interpreter requests ranged from 0-18 per patient. The significant number of referrals reflect the fact that one in six people resident in Ireland were born abroad, and three quarters of these speak their primary language at home, with 20% of those aged 65 and over having little or no English.

"A lack of patient understanding of their disease is a major issue especially for those with lung cancer as there have been a lot of recent advances in targeted therapies which patients take at home rather than in hospital. If there is a [language barrier](#), patients may miss appointments or take their medicines incorrectly which can affect their prognosis and quality of life," said lead investigator, Dr. Tianna Martin, from Beaumont Hospital, Dublin, Ireland.

She pointed out how easily misunderstandings can occur and stressed the importance of asking patients their preferred language especially when they come from countries where multiple languages are spoken.

"It's really heart-breaking to see a patient who appeared to understand their diagnosis and treatment become deeply distressed weeks or months later when they finally realize they have cancer," she said.

Martin suggested that records of patients with language needs should be flagged 'at risk' so that clinicians check carefully to ensure that appropriate translation services are in place. She also proposed that, given the growing complexity of lung cancer treatments, specialized training should be given to interpreters at cancer clinics.

"It is important that interpreters can accurately explain the diagnosis and treatment options at all stages of the disease so that patients can make really informed decisions and, with the rise in virtual consultations as a result of COVID-19, we need to work out the best approach for overcoming language barriers in that setting too," she concluded.

Commenting on the findings of the two studies, Professor Sanjay Popat, from the Royal Marsden NHS Foundation Trust, London, UK, said that the results should be a wake-up call to all healthcare professionals involved in the care of patients with lung and other cancers to get processes in place to ensure effective communication.

"The statistics from the GLCC survey paint a bleak picture and at least 11% of patients not knowing their type of lung cancer is a very damning statistic. We want patients to be empowered to make decisions about how and where they want to be treated and that can only happen if we have good communication at all stages, with shared aims and goals," he said.

"If we can't get the basics right, it will be very difficult to ensure that patients understand the increasingly complex issues about their treatment options and possible side-effects, particularly the 'red flag' side-effects they need to tell us about immediately," he added.

Popat pointed out that the Dublin research underlines the need for experienced medical translators in an increasingly cosmopolitan society and the importance of 24/7 professional services, especially for patients

being treated in hospital.

"The key thing is for everyone to know these translation services exist and to make use of them. Relying on family members to translate is not good practice. We need translators who know how to talk about difficult subjects such as prognosis and end of life care, and can help us understand cultural sensitivities so that we give information in an appropriate way," said Popat.

For patients with lung cancer facing communication or language barriers he highlighted the growing range of patient support groups specializing in providing information and support for specific types of the disease, such as ALK+ and EGFR mutation-positive non-small cell lung cancers.

"In many countries these specialist groups are becoming established to provide a lot of background information about these specific types of lung cancer and the kind of questions patients need to ask and what they should be expecting as part of their care. It all helps to ensure that communication about complex issues is as good as it can be in what is likely to be a very stressful situation for patients," Popat concluded.

More information: Abstract 209P_PR 'Understanding patient experience in Europe: the first Global Lung Cancer Coalition Patient Experience Survey' will be available as e-poster from 24 March at 12:00 CET. *Journal of Thoracic Oncology*, Volume 16, Number 4S, Supplement, April 2021

Abstract 212P_PR 'Language and Understanding: the complexity of insight in cancer care' will be available as e-poster from 24 March at 12:00 CET. *Journal of Thoracic Oncology*, Volume 16, Number 4S, Supplement, April 2021

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