Shining a light on rare cancers: the role of continuing medical education

A rare cancer is defined as one diagnosed in fewer than six out of 100,000 people annually — accounting for roughly 24% of all cancer diagnoses in Europe. Managing and diagnosing rare cancers presents unique challenges, often leading to delays in treatment.

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global survey conducted by Medscape among 117 oncologists revealed that the biggest barrier to staying updated on rare cancers is time constraints; most oncologists prioritise learning about more common cancers. This educational gap directly contributes to delays in diagnosis and treatment.²

Rare cancer: educational and management challenges

Beyond time limitations, oncologists face additional hurdles when managing rare cancers, including limited research, scarce clinical guidelines, difficulty accessing specialised expertise and restricted availability of clinical trials.³ The same survey highlighted that oncologists struggle with inadequate evidence for treatment decisions and a lack of resources to help inform patients about their conditions.²

The scarcity of specific treatment options and

Dr Wei-Sen Lam, MBBS, Medical Oncologist and steering committee member of Medscape Education's Rare Disease Learning Center explains: "The scarcity of specific treatment options and guidelines for rare cancers often leads to suboptimal outcomes." diagnostic algorithms to maximise the impact of continuing medical education (CME).

Importance of improving awareness of rare cancers

Dr Lam says: "With the growing role of the internet in patient education, some patients are more informed about their conditions than their healthcare teams. This shift underscores the importance of clinicians being able to interpret and validate patient-found information. Educational initiatives, along with support from nurse navigators and oncology specialists, are more crucial than ever in delivering optimal care."

Patients with rare cancers often struggle to find and understand accurate information due to the rarity of their condition. Healthcare professionals should be educated and trained, so they can clearly communicate this information, empower patients and foster trust.⁴

The broader need for rare disease education is also recognised in the draft World Health Assembly's Resolution on Rare Diseases, which calls for increased awareness and training among healthcare providers, policymakers and the public.

Tackling the unmet educational needs in rare cancers

Addressing this gap requires increased research and educational efforts. To help bridge this divide, Medscape has incorporated rare cancers into its Rare Disease Initiative, aiming to keep oncologists informed on the latest developments in rare cancer diagnosis and management.

Surveyed oncologists emphasised the value of expertled education on rare cancers and expressed the need for downloadable PDFs, concise recommendations and

References:

- Gatta G, et al. Burden and centralised treatment in Europe of rare tumours: results of RARECAREnet-a population-based study. Lancet Oncol. 2017;18:1022-1039.
 Medscape Survey on Rare Cancers. Feb 2025.
- 3. Christyani G, et al. An overview of advances in rare cancer diagnosis and treatment. Int J Mol Sci. 2024;25:1201.
- 4. Farrugia T, et al. Addressing cancer survivors' information needs and satisfaction: a systematic review of potential intervention components for survivors with a rare cancer type. Orphanet J Rare Dis. 2024;19:387.



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