



## Editorial

## The challenge of rare cancers in nursing care

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Rare cancers account for about 24% of all new cancer diagnoses, including all paediatric cancers. Cancer is considered rare when its incidence rate is less than 6 cases per 100,000 people per year (Gatta et al., 2017; Rare Cancers Europe, 2016). There are nearly 200 different types of rare cancer, such as mesothelioma, malignant thymoma, retinoblastoma, and acute myeloid leukaemia; the whole list can be found online (Orphanet, 2022; RARECARENet, 2021). People living with rare cancer face specific challenges along their cancer continuum, including delayed diagnosis, limited access to genomic tests, understudied effective therapies, poor availability of orphan drugs, and other unmet clinical needs (Levedahl et al., 2022; Tambuyzer et al., 2020). The result is a lack of progress in survival (de Heus et al., 2022; Kasper, 2021) as well as impaired quality of life when compared to the general population of patients with cancer (Bergerot et al., 2018). Furthermore, they struggle to access specialised oncology consultations, as they have to travel as long as necessary to a reference centre (de Heus et al., 2021), and to receive tailored psycho-social support and information, as the rarity of their condition leads them to endure isolation (Bergerot et al., 2018). Despite various attempts for collective research, epidemiologic estimates, and shared databases across countries (Botta et al., 2016; Gatta et al., 2017), national registries are still suboptimally implemented.

Reflecting on the challenges posed by rare cancers on health professionals in an effort to deliver a high level of quality multi-disciplinary and multi-professional care, there are a few things to be considered. For example, specialised oncologists face challenges in decision-making, since the level of evidence-based treatment guidelines to rely on is quite limited. Also, the treatment might not be an established protocol, but perhaps a clinical trial, and along the way, they will hardly find other patients with the same type of cancer to enrol. Primary care practitioners often lack adequate knowledge and relevant expertise for ensuring continuity of care for patients with rare cancers. Although nurses play a key role in promoting quality and equal care (Houlihan, 2015), they may have never encountered a patient with that specific diagnosis before, having to accommodate several unknowns in the care

they need to deliver. One could argue that oncology nurses can easily adopt a comprehensive approach to ensure the best quality of life for every patient with cancer, regardless of the disease incidence. However, the patient-nurse relationship can be significantly challenged by the lack of information on what it means to live with that specific rare cancer (Ejegi-Memeh et al., 2022). Other challenges to nursing care for patients with rare cancers include dealing with complex needs, administering off-label medications, and providing compassionate, honest and supportive care. Additional challenges are encountered by nurses caring for paediatric patients with rarer cancers since specific and advanced competencies are required to ensure high-quality care across the cancer continuum (Woodman and Spencer, 2022). Therefore, it is essential to strengthen and further specialise health care professionals' competencies in managing patients with rare cancers while fostering advanced practice in specific oncology areas, such as paediatric cancer care.

There are ways to help us understand how nurses can better tackle inequalities in rare cancer care. First, nurses are uniquely positioned to help patients with rare cancers engage in self-care activities, including treatment adherence and symptom monitoring, and maintain supportive family relationships (Beghean and Coffey, 2021). As advocates, nurses can facilitate their inclusion into informed patient networks, as well as promote patient education to increase disease knowledge and recognition. Nurses can support informal carers by addressing their specific needs, improving decision-making, and reinforcing their health literacy. Also, nurses can lead campaigns to increase public awareness of rare cancers and decrease stigma.

In particular, the nursing values can be disseminated through the European Oncology Nursing Society (EONS), which plays an important role in influencing policy at the European level. For example, EONS advocates towards investing in early diagnosis, novel therapeutic approaches, clinical research aimed at improving not only survival but also the quality of life, and establishing certified reference centres providing multidisciplinary care. Moreover, care coordinating nurses are recommended in all specialised centres with an added value in the rare cancer context (Blay et al., 2021). Partnering with other organisations active in

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the Rare Cancer policy agenda provides the opportunity for a stronger voice on this challenging topic. For example, such collaborations have been established with *Rare Cancers Europe (RCE) (2021)*, which represents a partnership of cooperating stakeholders with the scope to place the issue of rare cancers firmly on the European policy agenda, to identify and promote appropriate solutions, and exchange best practice. It also advocates towards the involvement of patients and patient advocates in establishing research priorities, in all areas of rare cancers research, in order to ensure the relevance of the research produced. Another such partnership has been established together with *EURACAN (2022)*, a European Reference Network (ERN) that consists of virtual patient-centred networks involving healthcare providers and patient representatives across Europe. Working together, relevant stakeholders aim to tackle complex or rare diseases and conditions that require highly specialised care and concentrated knowledge and resources.

Ultimately, the healthcare research agenda in this field can shed light on the unmet clinical needs of patients with rare cancers, who are affected by a lack of adequate funding and interest in research and clinical trials. For example, in the new EU research & innovation framework programme for 2021-2027, cancer research will be conducted under the Horizon Europe's Cancer Mission placing more focus on rare cancers. In this way, it will be possible to increase our understanding of rare cancers and their manifestations in people's lives and, at the same time, provide the knowledge to fill some of the existing gaps in cancer nursing interventions for patients with rare cancers (*Charalambous et al., 2018*).

Rare cancer challenges in Europe can only be tackled when a collective approach is introduced at the EU level and embraced by the member states. *The Special Committee on Beating Cancer (2021)* released a 'Background note on paediatric and rare cancer' re-emphasising this pathway of recommended action and drawing on the EU *Joint Action on Rare Cancers (2019)* recommendations for the Rare Cancer Agenda 2030. The Agenda includes 10 specific recommendations related to research, policy, education, regulation, and policy strategies. In conclusion, the evidence warrants further attention to this population, rare individually but not collectively, which will ultimately lead to reducing inequalities in cancer care. Europe's Beating Cancer Plan and Cancer Mission present a unique opportunity for high-level policy decision-making (National and European) that impacts the context of rare cancers in Europe. Already towards the end of the second year of the Plan's implementation roadmap, relevant organisations and networks in the field should capitalise on the positive conditions that have been created for introducing changes that can shape the future of Rare Cancers.

## Declaration of competing interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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