



# How patients with rare cancers are getting 'doubly hit'

Rare cancers (RC) are a heterogeneous group of conditions that can be associated with psychological and physical impairments.

The incidence of RC is less than six cases per 100,000 people/year<sup>1</sup> but altogether, **RC diseases account for approximately 24% of all cancer cases diagnosed, higher than any single common cancer**<sup>2-4</sup>.

Despite advances in treatments and more long-term survivors living with cancer as a chronic illness<sup>5</sup>, **five-year relative survival rates are still lower for patients with RCs than common cancers (47% vs. 65%)**<sup>3</sup>



It has been well documented that impairment of **Health-quality of life (HRQoL) and psychosocial outcomes tend to be poorer for patients with rare cancers**<sup>6,7</sup>. Like other cancers, psychological factors and processes influence emotional distress, driving and maintaining symptoms of anxiety and depression among RC patients (Curran et al., 2017).

The challenges and psychological stressors facing people with RCs along their care continuum are unique, and although RC is life threatening like more common cancers, in rare cancer, this threat is further exacerbated, and patients are **“DOUBLY HIT”**.

Despite this, scant attention has been paid to the experience of survival in the longer term<sup>8</sup> and **research regarding the psychosocial impact of RC's as well as the factors driving poorer psychosocial outcomes have not been well studied**. For example, throughout patient and caregiver experiences with living with the illness and care continuum, there is greater uncertainty and loss of control compounded by unmet clinical needs and other factors.

- **First**, there is a general lack of public awareness and information, as well as stigma (especially in rare Gynaecological and Genitourinary cancers)<sup>9,10</sup> which may deepen a sense of isolation.
- **Second**, a common standardised presentation for RCs often does not exist, access to genomic tests is limited and diagnostic intervals tend to be extended resulting in late referrals to specialists with the right expertise to treat.
- **Third**, availability/ access to orphan drugs are limited, physicians may have inadequate experience in treating and available therapies may be ineffective<sup>11,12</sup>.
- **Last**, patients with RC and their caregiver have needs that are complex requiring effortful adjustments to everyday life, and resulting emotional, psychological and social factors that resonate with RC patients and caregivers are unique<sup>13</sup>.

Altogether, **patients and caregivers must therefore endure tremendous ongoing uncertainties and loss of control as they try to cope with living with the cancer**. Consequently, researchers need to examine the link between these factors to truly understand their relationship with disease-related variables and QOL to design high quality care and psychosocial support across the care continuum for patients and their caregivers.

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