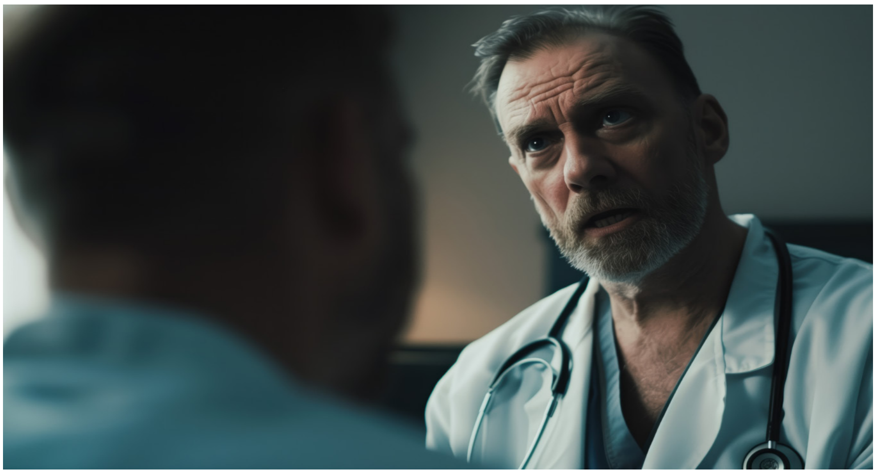
Treatment regret in head and neck cancer – trading function for survival

BY CAMILLA DAWSON, MARY QUINN AND PAUL PRACY

Treatment for H&N cancer can be extremely tough for patients. How do we explain the likely impact as they try to make decisions? And what happens when they regret their choice?

Treatment regret is a is a form of decision regret, involving multifaceted emotions related to the outcomes of clinical interventions. It is ubiquitous and complex. Recent publications have acknowledged issues grounded in individual perceptions of quality of life and functional outcomes following head and neck cancer (HNC) treatment [1]. Regret may result from a combination of factors including action or inaction regret [2], 'good' or 'bad' decisions [3], practicalities around intensity and effects of treatment, the long-term impact of oncological and surgical interventions and managing unknown outcomes. These feelings and perspectives may be static or fluctuate and they may reduce or increase over time. Regret isn't consistently proportionate to, or linear with, morbidity. We can't reduce or quantify physical and psychological burden to create explanations to substantiate or understand experiences and or capabilities. These issues are person, circumstance and context-specific; whilst parallels may be drawn between individuals, treatment interventions and progressive changes, the reality and lived experience is unique. We discuss and reflect on the practicalities of these perspectives as they are more frequently identified in research, and offer considerations for clinical teams to help manage these issues from our experience. We present the benefits of an ontological model in clinical care, where it is important to recognise that multiple realities and interpretations of reality and experience may co-exist.



Simply being alive doesn't reconcile treatment burden; this fundamental issue is key for clinicians to consider and accept. Similarly, function is an abstract notion until lost. Breathing, swallowing and communication are concepts grounded in self, interaction and autonomy. They rarely exist as a definable entity until they are compromised. As clinicians, we can quantify these capabilities with scales, scores and binary descriptors. As humans, these functions allow us to be with people, to present ourselves to the world and to make choices. It is therefore incredibly challenging to ask or expect an individual to imagine, predict or prioritise these functions. Thus, until (if ever) we are able to deliberately and consistently identify who and how people will experience burden, quantify its impact on all elements of human existence including, but not limited to, sexual function, returning to work and communicating with loved ones, we will not be able to adequately prepare people for the realities of treatment. Our own research told us that people could never truly be prepared for the impact of head and neck surgery [4]. Therefore, we must find ways to work with what we know, to help support people as they traverse the reality of treatment, while recognising that the relative importance they put on function and survival may be different pre- and post-treatment.

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Adapting and developing the cornerstones of our diagnostic and pre-treatment counselling skills may be a pertinent starting point. An ontological perspective suggests that multiple realities and perspectives can co-exist, moving beyond a positivist paradigm where there is only one reality which can be objectively measured. The introduction of trade-offs and currency are therefore useful concepts when working with people with head and neck cancer. Addressing the trade of function for survival, recognition of the potential challenge to long-term outcomes and the need for compromise as a currency in all aspects of life from the outset supports this dialogue. This is particularly pertinent when the individual is appropriately focused on their 'one shot at life' following diagnosis. A willingness to feel uncomfortable, to be with the individual in an authentic way and to have discussions about treatment decisions including trade-offs and what people may be prepared to transact for survival are fundamental. Perhaps 'being alongside' people rather than 'doing to' them is a useful way to couch this approach.

A tension can exist for the individual in discussing treatment regret with clinical teams. A sense of being grateful and indebted, along with the practicality of remaining under the care of the clinical team who have saved one's life, can create barriers in discussing regret. If we as clinical teams can feel able to explore and acknowledge what this reality may feel like, we can go some way in supporting the individual to live alongside these difficult experiences which frequently emerge following treatment. We don't need to fix these issues; it's unlikely that they can be fixed. We can seek them out, be with them and support the individual to be heard and seen – feeling grateful and regretful, elated and sad, relieved and fearful. This liminal space, the place between opposites, is a tacit part of head and neck cancer treatment [5]. Perhaps if we can recognise and normalise regret as part of the recovery and rehabilitation process, we may support people in moving forwards as their altered ('new normal') selves, in ways which acknowledge the complexities of treatment.

We are not describing a new or additional psychological intervention. We work in clinical practice and we recognise inherent time and capacity limitations. It is exactly for these reasons that we suggest an alternative perspective and / or approach to an intractable and frequently taboo concept. We all have experiences with people with head and neck cancer or their families where moments are punctuated by a look, an interaction or an insight into a reality which remains uncovered. Significant benefit and therapeutic potential can be found in seeking these opportunities to recognise, be with and capably hold a space with the individual, with language and insight that moves beyond survival.

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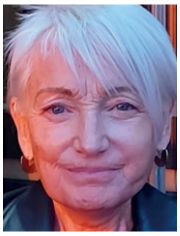

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