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Head and neck cancer: a marginalised group?

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Despite people with head and neck cancer having especially complex needs, they are a population at real risk of marginalisation as most have poor access to timely and appropriate palliative care. In this editorial, we will outline the complexities these people face and argue that:

1. The optimal way of providing high-quality, cost-effective palliative care for those with head and neck cancer needs to be developed and defined, accepting a ‘one model to fit all’ approach will be insufficient to adequately meet needs on a global basis.
2. Defining the optimum research methodologies that best engage, recruit and retain people with head and neck cancer within palliative care studies represents a particular area for focus.
3. The role of Specialist Palliative Care for head and neck cancer patients with complex holistic needs, but for whom the treatment intent is potentially cure, needs to be debated and clarified.

Internationally, head and neck cancer is the 6th most common cancer (1) with developing countries accounting for more than 60% of the global head and neck cancer burden (2). For example, in India, head and neck cancer is the most common cancer among men, with individuals often presenting at an advanced stage, and potentially having limited access to palliative care specialists.

The complexities of the illness and treatment are well established and have a profound effect on core elements of bodily function including communication, breathing, eating, expression of intimacy and sexuality, and physical appearance. Initial surgery and subsequent anti-cancer treatment can be extensive and gruelling; even more so if there is subsequent disease recurrence. People with head and neck cancer can have extensive care needs including: the management of fungating wounds; pain resistant to standard therapies; facial disfigurement; complex nutritional needs; anxiety and depression. Individuals are less well placed to advocate for themselves. There is the social stigma caused by the overt outward appearance of their illness. But more so, these individuals can literally lose their own voice due to the cancer or treatment, and so are unable to verbalise their concerns or

anxieties and are reliant on the support from others. As a result, the high level of psycho-social distress experienced by family carers involved in their care should not be underestimated.

Socio-economic factors are likely to contribute to their marginalisation. Within the United Kingdom, the most disadvantaged groups have a higher incidence of head and neck cancer and higher mortality rates (3). In terms of place of death, 44% of people with head and neck cancer from the most deprived areas of England died in hospital compared with 38% from the least deprived (4). Conversely, those from a deprived area are less likely to die in hospices suggesting geographical variations in access to specialist palliative care services. The unmet need of this population and subsequent impact is revealed with the disproportionate use of healthcare services by head and neck cancer patients. Patients are more likely to have multiple hospital visits (5) and more 'aggressive' end-of-life care such as emergency department attendance or admission to intensive care units in the last month of life (6).

Determining the best way to provide palliative care

In our pursuit to improve quality of care and access to specialist palliative care services, it is recognised that early access to palliative care may be most effective if targeted to the specific needs of individual populations (7). Within head and neck cancer, we strongly advocate for a two-pronged approach: the improvement of the general palliative care skills of the head and neck multi-disciplinary team; and the integration of a needs-driven mechanism for access to specialist palliative services. Facilitating cost-effective ways to enable direct integration between surgical, oncological and palliative care specialists is imperative to enhance joint decision-making, facilitate advance care planning and encourage 'cross-fertilisation' of knowledge. Multi-disciplinary team approaches which incorporate patient-reported outcome measures into routine clinical practice would help with timely identification of patients needing specialist palliative care input. Possible models may include the introduction of cross-boundary roles with the position of the Clinical Nurse Specialist being a pivotal one. Working across care settings would improve care continuity and also play a key role in the upskilling of generic primary healthcare providers. Consideration needs to be given about whether focused palliative care training including key components of advance care planning and end-of-life care should be incorporated into routine surgical training programmes.

Defining the optimum research methodologies

As evidence is lacking to support a particular model of care, clarification as to which methodologies best engage, recruit and retain head and neck cancer patients to evaluate palliative care interventions is needed. Flexible and innovative ways are needed that go beyond the standard

randomised controlled trial. Learning from quality improvement approaches and engagement with more participatory style techniques would seem to sit well within this remit. Action research, for example, would allow for the methodological flexibility to be culturally, organisationally, and socially acceptable whilst promoting engagement with patients, family carers, healthcare professionals and management. If verbalisation is challenging, then the use of patient diaries; information technology (IT) devices such as tablets or smartphones; direct observations; or family carers as proxy measures for care could be considered. Additionally, a focus on how best to address issues of 'health literacy' and the impact this has on consent processes and study recruitment would be important, with public and patient engagement being fundamental in directing new approaches. Interventions need to be tested that offer support to patients taking into account their social context and often limited access to resources.

Clarifying the role of Specialist Palliative Care when treatment intent is potentially cure

One of the most controversial areas surrounds whether or not Specialist Palliative Care has a role in the care of those head and neck cancer patients, for whom the treatment intent is cure, but who have ongoing complex holistic needs. Our view is that there are specific areas where our expertise and approach to care has a beneficial role to play. The model of care would be one of a partnership with other disciplines, as opposed to full ownership; where our knowledge and skills would be utilised as an additional resource to the wider multi-disciplinary team, before discharging back, where appropriate, to the primary responsible healthcare professional. Such situations would include:

- Specific advice on complex symptom control issues and contribution to the development of evidence-based symptom control guidelines relating to anti-cancer treatments, where the preservation of bodily function is as important as good symptom control.
- Contribution to complex decision-making and helping guide conversations about advance care planning and future uncertainties. This would entail appropriate patient identification where although the intent of treatment was cure, the multi-disciplinary team recognised that the patient was at 'high risk' of recurrence.

In order to adopt such approaches it is important to acknowledge a number of barriers: the desire for patients to focus on cure, in part to help them endure the arduous treatment; the prevailing misconceptions of palliative care and hospice among patients, family carers and healthcare professionals; and the potential reluctance within the palliative care speciality about treading

unfamiliar ground, in a manner that may echo the reservations previously expressed when specialist palliative care extended into the non-cancer field. We would challenge these concerns, however, and, with the focus back on complex needs and a recognition of the uncertainty of cure, propose that Specialist Palliative Care has a contributing role in the care of these patients, who often have limited options and support.

Our improved understanding needs to inform and influence clinicians and policy makers across the globe. In short, ensuring in the future that equitable access to Specialist Palliative Care is embedded in healthcare systems for those with head and neck cancer who are in greatest need is imperative, and not just available to those with the loudest voice.

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