

## *Happenings*

# **Rural Head and Neck Cancer Patients: New Clinical Perspectives**

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While continual progress is being made in the development of new cancer therapies, there is considerable evidence indicating that currently available treatments are not accessible to all patients who might benefit from them. In the case of head and neck cancer (HNC), rural patients reveal disparate prevalence, incidence, and mortality (Ragin, Modugno, & Gollin, 2007). We are lacking in evidence-based practice to address the care needs and treatment choices of this rural population. Many health-care policies and programs are based on policies that have been developed for urban populations. Research-based evidence that is specific to the needs of rural patients will help to ensure that care decisions are based on rural beliefs and values.

The Appalachian region of the United States, like many rural and isolated areas in Canada, is characterized by high HNC mortality and prevalence rates, a dearth of resources to prevent HNC, and dire shortages of health-care facilities, especially for the treatment of HNC (Huang, Gal, Valentino, & Wyatt, 2007; Lengerich et al., 2005). Appalachian populations show historically persistent high rates of tobacco and alcohol use, extreme poverty, and gaps in health insurance and coverage (Behringer & Friedell, 2006; Rowles & Johansson, 1993), and they often reflect the health disparities of Aboriginal populations in Canada. Furthermore, epidemiologists have suggested that HNC will increase within the general population as a result of sociocultural changes and increased life expectancy (Marur & Forastiere, 2008).

### **Emergent Insights and Recommendations for Practice**

The health practices of rural residents often reflect their perceptions of health and illness (Bales, Winters, & Lee, 2006). By learning about the rural perceptions of HNC, clinicians may be able to better understand the specific health practices of this client group, which could translate into earlier intervention and more effective treatment outcomes. A recent

qualitative study explored and described the treatment decision-making processes of rural patients in Appalachian Kentucky newly diagnosed with head and neck squamous cell carcinomas (HNSCC).

The study documented the natural history of the HNSCC illness experience and gained rich insights into how, when, and why this specific group of rural patients act with regard to treatment selection and follow-through. Interviews were carried out with 31 rural HNSCC patients at the time of diagnosis and shortly after completion of treatment. The interviews provide rich insight and knowledge about how factors such as socio-economics, multiple health conditions, substance use, geography, culture, behaviour, and perceptions of time contribute to the timeliness and satisfaction of help-seeking and treatment decision-making among rural patients. This approach serves to capture both a range of unexplored and complex grounded perspectives and statistically validated associations. Such efforts are fundamental to improving health outcomes and reducing health disparities by producing formative data with which to develop innovative and culturally acceptable interventions (Green & Kreuter, 1999).

The study gave rise to several themes that are relevant to the care of rural HNSCC patients throughout their illness experience. These were useful in the development of three clinical recommendations.

### **Recommendation 1**

Ensure that clinicians acknowledge the rural context and social dimensions of HNC in their understanding of help-seeking, goal-setting, and treatment decision-making within this population.

**Rationale.** The timing of and reasons given for help-seeking among rural HNC patients are often influenced by the misidentification of disease symptoms as side effects of tobacco use. Such symptoms include hoarseness, dry mouth, coughing, and mouth sores. A tendency for patients and, often, providers to dismiss such symptoms leads to a delay in help-seeking and diagnosis. Furthermore, rural HNC patients often delay help-seeking until symptoms become obtrusive or negatively affect their daily functioning and/or work responsibilities.

These characteristics are salient to goal-setting and treatment decision-making in that rural HNC patients may perceive the value of treatment options from a functional rather than a curative perspective. For example, a patient may opt for a less aggressive treatment based on the goal of preserving voice function as opposed to prolonging life without voice. In-depth and focused assessment of patients' goals and perspectives throughout the cancer experience allows for less stressful and more satisfying patient decision-making and strengthens the provider's ability to work collaboratively in the overall support of the patient.

***Steps to take***

- During each clinical consultation, include ongoing discussion of patient perceptions of health and treatment as well as goals.
- Assess clinical HNC symptoms as well as impact on family and occupational roles within the rural setting.
- Provide appropriate screening and health education related to HNC cancer risk among rural tobacco users.

***Recommendation 2***

Include clinical acknowledgement and acceptance of “doing nothing” as an appropriate treatment option.

***Rationale.*** Many HNC patients expressed a desire to go home and let their cancer “take its course” in a comfortable and familiar environment with family and friends. They felt that the distinctive and considerable social, emotional, physical, and economic consequences of HNC medical treatment would greatly diminish their ability to enjoy an attenuated post-treatment life. Rural patients value the opportunity to die in the comfort of home, in a place (i.e., geographic setting) where they have many attachments and a strong sense of belonging. Patients felt they were unable to discuss “no treatment” with their provider as an appropriate option. Those patients who did discuss it, or simply elected to not engage in medical treatment, reported that they felt unsupported by their physician and less empowered to make personal health decisions. From a clinical perspective, recognizing and acknowledging “doing nothing” as a treatment choice may serve the patient-provider relationship by facilitating communication, rapport, and trust.

***Steps to take***

- Develop appropriate information for rural patients on all aspects of the array of treatment options available to them.
- Provide ongoing opportunities to discuss perceived treatment outcomes, including the option of no treatment.
- Discuss treatment options and their outcomes with patients in the context of their treatment goals.

***Recommendation 3***

Develop and implement clinically based addiction cessation and counselling services for rural HNC patients as they move through treatment and into recovery.

***Rationale.*** Services for HNC patients should include a formal means of identifying, addressing, and supporting those who have a concurrent addiction to tobacco, alcohol, and/or other substances. This is particularly important for rural patients, who often lack access to such services. The

dearth of such programs in rural areas undermines clinical management of disease and leaves patients unsupported throughout their therapy. Patients with HNC frequently present with late-stage disease and have a history of tobacco and alcohol use, substance addiction, and mental health problems such as depression, which may negatively impact treatment compliance and efficacy. The development and implementation of clinically based cessation and addiction services would greatly facilitate the management of addiction-related health problems. Furthermore, such clinical programs could provide much-needed counselling and social networks to support patients and their families during recovery.

### ***Steps to take***

- Establish rural-based clinical guidelines for assessing substance use as part of the HNC patient consultation.
- Establish rural-based clinical protocols for providing access to substance cessation programs that complement the HNC treatment protocol.
- Establish a means for ongoing mental health counselling, cessation support, and addiction education for post-treatment rural patients.

### **Moving Forward**

Appalachian people and other traditionally underserved rural populations in the United States and Canada represent a more pernicious version of the respective nation's health problems: poor health status, multiple morbidities, and increased cancer incidence and mortality (Lengerich et al., 2004; Wingo et al., 2008). Research should focus on this critical issue in order to improve our understanding of these problems and stimulate prevention and management efforts through innovative interventions. The present study generated information on previously unexplored issues in treatment decision-making and on health management interventions that facilitate the involvement of rural patients while respecting the unique needs of older rural patients and their treatment choices. Hofer, Zemencuk, and Hayward (2004) state the case well:

We need to understand, and in some cases modify, the priorities that providers (and patients) bring to clinical encounters so as to ensure that the most important interventions are not lost amid the blizzard of demands on patients' and providers' time and energy. (p. 646)

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