

Extending Head and Neck Cancer Supportive Resources to Survivors and Caregivers in Rural Kansas

Topic Area: Head and Neck Cancer Prevention Community Services

Goals: Increase Survivors' and Caregivers' Access to Support and Information; Offer Additional Support Group Meetings; Increase Participation of Rural Residents in Support and Education

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Introduction: Head and neck cancer survivors are at high risk for depression¹ and those who live in rural areas may be at higher risk for suicide than survivors in urban and metropolitan areas.² Access to social support and education about side effects and coping methods or treatment could mitigate survivors' risk for depression or suicide and might improve quality of life.³ This is especially important for head and neck cancer survivors and caregivers, many of whom have never met anyone else with similar experiences.

The University of Kansas Cancer Center offers monthly head and neck cancer support group meetings via secure online video conferencing. Meetings are facilitated by a radiation oncology social worker, who is also a head and neck cancer survivor. Participants include longtime survivors as well as newly diagnosed people and caregivers. The cancer center is in a metropolitan area, but the catchment area for the cancer center extends into many rural communities. Most support group participants live nearby and only a few live in rural areas in southern Kansas, Oklahoma and Missouri. Despite being open to rural participants, the group does not have purposeful recruiting or messaging for rural patients and caregivers. Most members learn about the group when they are in care in Kansas City.

Methods: This project's goal is to extend access to supportive resources by increasing participation by rural head and neck survivors and caregivers. Specifically, we will double the number of online support group meetings and formalize relationships with rural social workers to raise awareness among survivors and caregivers. Specific target areas in Kansas include Salina, Coffeyville and Hays. These cancer centers are members of the Masonic Cancer Alliance (MCA), an outreach network for the KU Cancer Center. The group will work with the alliance's psychosocial services director to develop resources and recruiting tools specifically for this population. Resources will include items to facilitate referrals to the support group from the oncology social workers in rural sites.

The project will start in summer 2022 with mailings and phone calls to rural social workers to provide education and invite participation. The KU Cancer Center social worker will work with The University of Kansas Health System's otolaryngology fellow, MCA social worker, and hospital social workers to schedule, promote and facilitate meetings. Hospital and MCA member cancer center social workers will make referrals to the support group facilitator for recruitment in person or via phone. Survivors and caregivers will be invited to twice-monthly support group meetings on Zoom online video conferencing platform. Meetings will be facilitated by a master's level social worker who is also a survivor.

One meeting per month will generally consist of about 30 minutes of open discussion among group members followed by an expert's presentation on a topic that is of particular interest to this population. Previous guests include dentists who specialize in treating survivors with oral cancer, oncology dietitians, speech language pathologists, occupational therapists who specialize in lymphedema therapy, oncology

social workers, otolaryngology physician assistants, radiation oncologists, palliative care nurses and head and neck cancer researchers. There will also be time for questions and answers with guests. Participants are encouraged to have both video and audio access to these meetings, although phone participants are also welcomed.

The second monthly meeting will be facilitated by the social worker, but the format will be open discussion among survivors and caregivers. Participants will be encouraged to have video access to facilitate building relationships, but the facilitator will ensure that chat and phone members are equal participants.

After each guest's presentation, the facilitating social worker will summarize presentations and distribute those via email or mail to any interested survivors and caregivers. Summaries will include contact information and will encourage rural participants to call or email guests or the facilitator for additional information and support.

In addition to group meetings and summaries, individualized telephone and email peer support will be offered to survivors and caregivers. Interested participants will be matched with survivors or caregivers who have experienced similar diagnoses and treatments. The group's social worker will facilitate contacts and will assist with additional support as needed. Personalized peer support is especially important to survivors who prefer not to interact in groups and to those who have side effects that are different from most other group members.

Outcomes: Expected outcomes are increased and sustained participation in support group and peer mentoring. Project leaders will create a measure based on participants' goals and expectations, then use it to assess outcomes and to plan future meetings and recruitment. It is also expected that rural care providers will increase their knowledge of available support for this population, and that survivors and caregivers will gain new understanding about side effects, coping methods and treatments.

Budget: This project proposes to use the \$1,000 award to fund targeted marketing and educational materials, other communication materials and postage, and to provide gift cards to group and mentoring participants. The project will receive additional funding through The University of Kansas Health System's, MCA's and rural hospital's support for salaries and access to secure online video conferencing. These entities also support access to expert guests and educational and research materials.

References:

1. Chen, AM, Daly, ME, Vazquez, E, Courquin, J, Luu, Q, Donald, PJ, Farwell, DG. Depression among long-term survivors of head and neck cancer treated with radiation therapy. *JAMA Otolaryngo Head Neck Surg.* 2013;139(9), 885-889.
2. Osazuwa-Peters, N, Barnes, JM, Okafor, SI, Taylor, DB, Hussaini, AS, Boakye, EA, Simpson, MC, Graboyes, EM, Lee, WT Incidence and risk of suicide among survivors with head and neck cancer in rural, urban, and metropolitan areas. *JAMA Otolaryngo Head Neck Surg.* 2021;147(12), 1045-1052.
3. Institute of Medicine (US) Committee on Psychosocial Services to Cancer Survivors/Families in a Community Setting. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs.* Adler NE, Page AEK, editors. Washington (DC): National Academies Press (US); 2008. PMID: 20669419.