CONFERENCE ABSTRACT

Who cares? Uncovering social Support Needs and Resources of malignant CNS Tumor Patients and their informal Caregivers

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Background: Social relationships (i.e., interpersonal relations with individuals or groups) have been shown to have long- and short-term effects on health outcomes including reduced mortality risk and quality of life among cancer patients. Patients with tumors in the central nervous system (CNS) often suffer cognitive, neuropsychological and functional impairments, causing major support needs among this patient group and their loved ones caring for them, here referred to as informal caregivers. Informal caregiving can be a positive experience, but it may also have negative psychosocial and physical implications for the caregiver. Further, the quality of social relations among cancer patients and their informal caregivers may decrease over time as illness progresses.

The Swedish Brain Tumor Association has started an initiative whereby patients and their informal caregivers are introduced to drawing so-called caremaps, social network diagrams visualizing both their formal and informal relations. The hypothesis is that caremaps can support communication and coordination, and may even contribute to strengthening social relations.

The aim of this study is 1) to explore what type of social relations and resources are important for CNS tumor patients and their informal caregivers and 2) to explore how they reason about the potential benefits and risks of using caremaps to map and possibly share their social relations.

Methods: Setting: During the fall of 2018 and early spring 2019 patients and informal caregivers who have been introduced to Caremaps through the Swedish Brain Tumor Association will be invited to participate in focus group discussions or individual interviews to reflect on their social support needs and their impressions of the Caremaps tool. We estimate to involve approximately 10-20 participants.

Results: We expect to be able to present our preliminary findings from the workshops, interviews and focus group discussions at the ICIC 2019 conference, highlighting experienced needs and challenges, as well as first impressions of using caremaps.

Discussion: An increasing incidence and prevalence of CNS tumor patients calls for innovative solutions to secure adequate care and support for both the patients and their informal caregivers. Identifying an individual’s informal and formal care resources may provide a context in which to navigate among the existing and potential support. It may also serve to facilitate the assessment
and appreciation of patients’ dependence on informal care as well as of caregiver burden and thus caregivers’ support needs.

**Contribution:** Our findings will contribute with insights about how social relationships can be mapped and supported and how caremaps can be a tool for CNS tumor patients and their informal caregivers in self-management, which has implications for designing services to enhance patient and informal caregiver self-care and well-being.

This research project is conducted in collaboration with the Swedish brain tumor patient association, Karolinska Institutet, Karolinska University Hospital and the Regional Cancer Center Stockholm-Gotland.

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