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Paving the Way to Evidence-Based Clinical Practice: Establishing Effective Caregiver and Family Support

Interventions

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MAIN TEXT

Over the past decade, there has been significant progress in the field of neuro-oncology family caregiving research¹. Following a brain tumor diagnosis, families commonly face altered priorities in their daily life and struggle to find appropriate coping strategies for managing the physical, emotional, and logistic challenges that arise². Research indicates that family caregivers' wellbeing is associated with patient outcomes – specifically, the level of mastery experienced by family caregivers can serve as a predictive factor for survival of patients with glioblastoma³. This underscores the importance of focusing not only on the individual patient but also on the family network to optimize patient outcomes. As our understanding of this life-threatening condition and its impact on families continues to expand⁴, we see a growing recognition of the crucial role family caregivers play in providing valuable support and empathetic care for those affected.

Researchers, healthcare professionals, and support organizations⁵ are actively collaborating to address the specific needs of caregivers, aiming to improve their wellbeing and equip them with the information, tools and encouragement to provide optimal care of the patient and themselves⁶. In doing so, we should strive for caregiver support to be evidence-based – paralleling the standards set for patient care.

The physical, practical and emotional demands of providing care, coupled with often inadequate support, and lack of prior knowledge and skills⁷, contribute to a profound burden in neuro-oncology caregivers². This issue of Neuro-Oncology Practice recognizes these challenges, with the pilot study: Exploratory Multi-Methods Evaluation of an Online Intervention for Carers of People with High-Grade Glioma from an Australian research group⁸. Based on a nurse-led program (Care-IS), which demonstrated improved caregiver preparedness following intervention versus usual care in a randomized controlled trial of 188 caregivers,⁹ Dr Haydon *et al.* performed a pilot study of a standalone online extension called 'Caring for the Carer'. Ten caregivers of people with high-grade glioma evaluated a six-module, online interactive psychoeducational program designed to prepare them to undertake caregiving responsibilities. Although not designed or powered to establish changes in caregiver outcomes, the pilot program showed potential for improving caregivers' mood, unmet needs, and validation of experiences. With the intervention's high levels of usability and acceptability the study contributes to the growing field of eHealth interventions¹⁰ aimed at effectively addressing the unmet needs of neuro-oncology caregivers. Based on qualitative findings, the authors address the notion of self-doubt among caregivers as well as the interplay between

confidence, feeling validated, and caregiver preparedness. An interesting perspective that in our view highlights the importance of improved signposting to any support or information locally available to caregivers, which will differ from region to region, country to country. Whether it be counseling, peer support groups, education on symptom management and caregiving strategies, or anything else; many existing options may allow caregivers to feel validated and recognized for their vital role in the care team whilst we work to build the evidence-base for caregiver support.

Assessing the effectiveness of caregiver interventions poses significant challenges. Apart from difficulties with recruitment and retention, as well as other methodological challenges that are not specific to neuro-oncology caregiving research, the field still lacks agreed definitions of key constructs and suffers from inconsistency in their assessment, with the same construct rarely being evaluated using the same outcome measure across studies¹¹. To enhance comparability of studies, facilitate meta-analyses, and expedite scientific progress, we find it imperative to develop consensus or guidance regarding definition and assessment of these constructs.

We strongly advocate for rigorous research to assess the impact and cost-effectiveness of caregiver interventions within respective resource-constrained healthcare systems. Also, we suggest longitudinal mixed methods approaches and the active inclusion of a diverse range of neuro-oncology caregivers when developing and testing interventions. With the field gaining momentum, we envisage that within the next five to ten years, we will be able to identify the most critical and impactful caregiving interventions. Collaboration with caregivers, healthcare providers, researchers, community organizations, charities, and policymakers could raise awareness of the importance of supporting caregivers and its potential long-term benefits, while ensuring that any newly developed or tested intervention meets the needs and requirements of all stakeholder groups. To help expand the reach of caregiver support and overcome resource limitations, innovative solutions such as telehealth, mobile applications, and digital platforms including the integration of Artificial Intelligence technologies need to be embraced. This multifaceted approach will help meet the challenge of (cost-)effective and scalable intervention implementation.

Developing an international collaborative strategy for neuro-oncology caregiver research is paramount. In light of this, we emphasize the need for further research in this field and extend an invitation to interested readers to contact us for research collaborations, and to join the International Neuro-oncology Caregiver Consortium. This consortium will support the development of targeted interventions, policies, and support systems that address the unique needs of neuro-oncology caregivers, promoting wellbeing in this challenging and important role.

1. Leeper HE. Survivorship and Caregiver Issues in Neuro-oncology. *Curr Treat Options Oncol* 2019;20(11):80. doi: 10.1007/s11864-019-0681-y [published Online First: 20191113]
2. Piil K, Jakobsen J, Christensen KB, et al. Needs and preferences among patients with high-grade glioma and their caregivers - A longitudinal mixed methods study. *European Journal of Cancer Care (Engl)* 2018;27(2):e12806. doi: 10.1111/ecc.12806 [published Online First: 2018/01/10]
3. Boele FW, Given CW, Given BA, et al. Family caregivers' level of mastery predicts survival of patients with glioblastoma: a preliminary report. *Cancer* 2017;123(5):832-40. doi: 10.1002/cncr.30428 [published Online First: 2016/10/28]
4. Piil K, Laegaard Skovhus S, Tolver A, et al. Neuro-Oncological Symptoms: A Longitudinal Quantitative Study of Family Function, Perceived Support, and Caregiver Burden. *Journal of Family Nursing* 2022;28(1):43-56. doi: 10.1177/10748407211029986
5. Lawler M, Oliver K, Gijssels S, et al. The European Code of Cancer Practice. *J Cancer Policy* 2021;28:100282. doi: 10.1016/j.jcpo.2021.100282 [published Online First: 20210419]
6. Pointon L, Grant R, Peoples S, et al. Unmet needs and wish for support of family caregivers of primary brain tumor patients. *Neurooncol Pract* 2023;10(3):271-80. doi: 10.1093/nop/npac099 [published Online First: 20230104]
7. Sherwood PR, Price TJ, Weimer J, et al. Neuro-oncology family caregivers are at risk for systemic inflammation. *J Neurooncol* 2016;128(1):109-18. doi: 10.1007/s11060-016-2083-3
8. Haydon HM, Blackler A, Nowak AK, et al. Exploratory Multi-Methods Evaluation of an Online Intervention for Carers of People with High Grade Glioma. *Neuro-Oncology Practice* 2023 doi: 10.1093/nop/npad032
9. Halkett GKB, Lobb EA, Phillips JL, et al. Carer preparedness improved by providing a supportive educational intervention for carers of patients with high-grade glioma: RCT results. *J Neurooncol* 2023;161(3):501-13. doi: 10.1007/s11060-023-04239-0 [published Online First: 20230119]
10. Halkett GKB, Berg MN, Daudu D, et al. Supportive care of patients diagnosed with high grade glioma and their carers in Australia. *Journal of Neuro-Oncology* 2022;157(3):475-85. doi: 10.1007/s11060-022-03991-z
11. Boele F, Hertler C, Dirven L, et al. Family caregiver constructs and outcome measures in neuro-oncology: A systematic review. *Neurooncol Pract* 2022;9(6):465-74. doi: 10.1093/nop/npac058 [published Online First: 20220720]