

Neurooncol Pract. 2024 Feb 16;11(3):296-306. doi: 10.1093/nop/npae015. eCollection 2024 Jun.

# What do carers of people with high-grade glioma perceive could improve their preparedness to care, and what additional support do they require?

James J Clarke <sup>1 2</sup>, Georgia K B Halkett <sup>1</sup>, Emma McDougall <sup>1</sup>, Haryana M Dhillon <sup>3 4</sup>, Elizabeth Lobb <sup>5</sup>, Jane L Phillips <sup>5 6</sup>, Peter Hudson <sup>7 8 9</sup>, Anna K Nowak <sup>10</sup>

Affiliations

PMID: 38737602 PMID: PMC11085844 (available on 2025-02-16) DOI: [10.1093/nop/npae015](https://doi.org/10.1093/nop/npae015)

## Abstract

**Background:** Concerning levels of stress, strain, and poorer mental health are observed in family carers of patients diagnosed with high-grade glioma (HGG). Understanding the reported unmet needs of these carers will enable future interventions to address such needs to improve their preparedness for care and well-being. In this secondary analysis, we aimed to explore: (i) *what carers of people with HGG perceive could improve their preparedness to care*; and (ii) *what needs carers reported they required additional support with*.

**Methods:** Responses from 188 carers of patients with HGG participating in a randomized controlled trial of the Care-IS intervention were analyzed to identify reported unmet needs. Of this larger sample, 92 participants answered a qualitative question seeking to identify perceived unmet needs in carer preparedness over 12 months. These responses comprised the data for the current secondary analysis. Content analysis was used to analyze the qualitative data and observe trends across participant responses.

**Results:** Five overarching themes were identified: *carer needs, providing emotional and practical care, coping with uncertainty, coping with the consequences of illness progression, and processing and supporting end-of-life care*. Notably, the content analysis identified differences in response numbers between groups in the Care-IS trial, particularly with the control group having more needs regarding illness progression and end-of-life care.

**Conclusions:** Future interventions aimed at improving the well-being and preparedness of carers of people with HGG should consider providing better support centered on carer needs, their changed circumstances, living with uncertainty, and care transition.

**Keywords:** carers; content analysis; high-grade glioma; preparedness to care.

© The Author(s) 2024. Published by Oxford University Press on behalf of the Society for Neuro-Oncology and the European Association of Neuro-Oncology. All rights reserved. For commercial re-use, please contact [reprints@oup.com](mailto:reprints@oup.com) for reprints and translation rights for reprints. All other permissions can be obtained through our RightsLink service via the Permissions link on the article page on our site—for further information please contact [journals.permissions@oup.com](mailto:journals.permissions@oup.com).

[PubMed Disclaimer](#)