

Andrew James Murrell¹, **Ben Rimmer**¹, Lizzie Dutton¹, Joanne Lewis², Richéal Burns³, Pamela Gallagher⁴, Sophie Williams², Vera Araújo-Soares^{1,5}, Tracy Finch⁶, Linda Sharp¹

¹Newcastle University, ²Newcastle upon Tyne Hospitals NHS Foundation Trust, ³Atlantic Technological University, ⁴Dublin City University, ⁵Heidelberg University, ⁶Northumbria University

✉ Ben.rimmer@newcastle.ac.uk

🌐 <https://research.ncl.ac.uk/waysahead/>

Background

- People living with a low-grade glioma (a subgroup of malignant brain tumours) have a limited life expectancy of 5-15 years. They may require support from partners, family-members, and friends to manage their symptom burden (e.g. fatigue, seizures, cognitive deficits).
- Caregiving demands and the incurable nature of the condition can impact the wellbeing of those who provide support, meaning they themselves may require support.
- Informal networks are a common avenue of support, but the nature and quality of support provided has not been well investigated.

Methods

- We recruited caregivers of people with a low-grade glioma (i.e. family-members or friends who identified as supporting or having supported in the last five years) from across the United Kingdom.
- We conducted remote semi-structured interviews from August 2020 to March 2022
- We analysed the data using thematic analysis, before deductively mapping our findings to House (1981)'s dimensions of social support¹.

Results

- **19 informal caregivers** were interviewed (mean age 54.6 years; 5 males, 14 females; 15 spouses (husband or wife) of person with LGG; 13 were employed; 6 had children).
- Participants received multiple forms of support from their informal networks, including emotional, instrumental, information, and appraisal support (Figure 1).
- Informal networks were perceived to help protect participant wellbeing.
- The most valuable networks comprised strong/familiar (e.g. close friends) and weaker/unfamiliar ties (e.g. other informal caregivers).
- Poor understanding and unsolicited advice were perceived to weaken the quality of support.

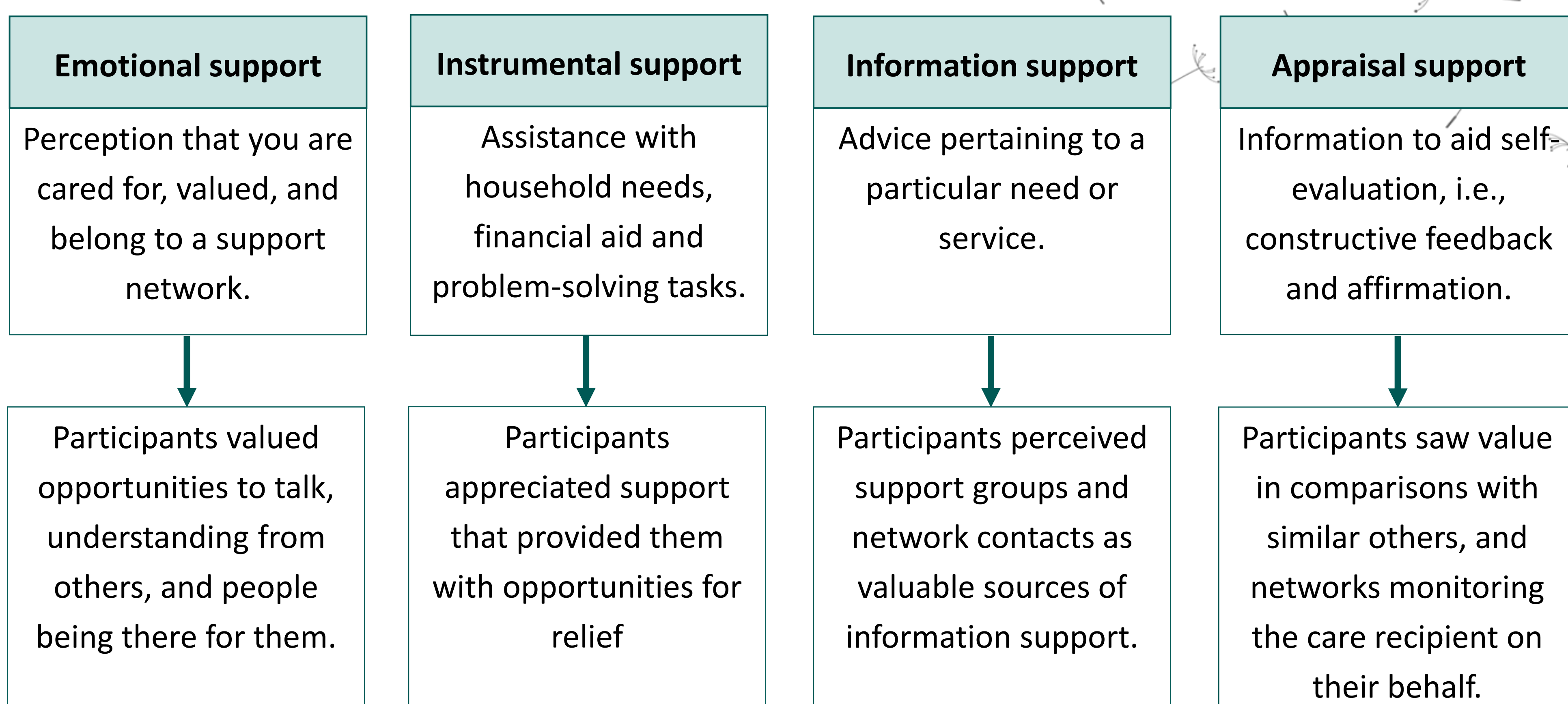


Figure 1. Overview of themes and sub-themes and how they link to House (1981)'s dimensions of social support

Aim: To explore the nature and quality of support from informal networks for informal caregivers of people with low-grade gliomas.

"I'm sure it helped to have friends and neighbours to talk to and just go over things with. . .that allowed me to be calmer and more supportive." – IC13 (aged 51, husband)

"My work were texting me all the time, "How are things? Are you okay? Do you want somebody there with you?" just that caring." – IC2 (aged 55, wife)

"We met at the Maggie's [cancer support centre]. We were both doing the stress group on how to relieve your stress. . .there was about six of us in the group and we've all stayed in touch." – IC19 (aged 54, wife)

"My dad is often here helping to look after him, pretending he's doing a bit of work in the house but he's really keeping an eye on him for me if I'm at work." – IC14 (aged 37, wife)

"Various friends have offered, "Look, if you ever need somebody to sit with [patient] and you go out for the afternoon, just pick up the phone," which is lovely." – IC24 (aged 67, husband)

Conclusions

- Informal networks can provide wide-ranging support for informal caregivers of people with a low-grade glioma.
- Different supports may be sought or provided from different contacts, highlighting the importance and value of extended networks.
- Our findings highlight the importance to caregivers of being able to talk; healthcare services might usefully explore how they could facilitate this.



SCAN ME

Published in European Journal of Cancer Care



The Ways Ahead study was funded by...

¹House, J. S. (1981). *Work Stress and Social Support* Addison. Wesley Publishing Company.