

“It’s a delicate dance” How informal caregivers experience the role and responsibilities of supporting someone living with a low-grade glioma

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Background

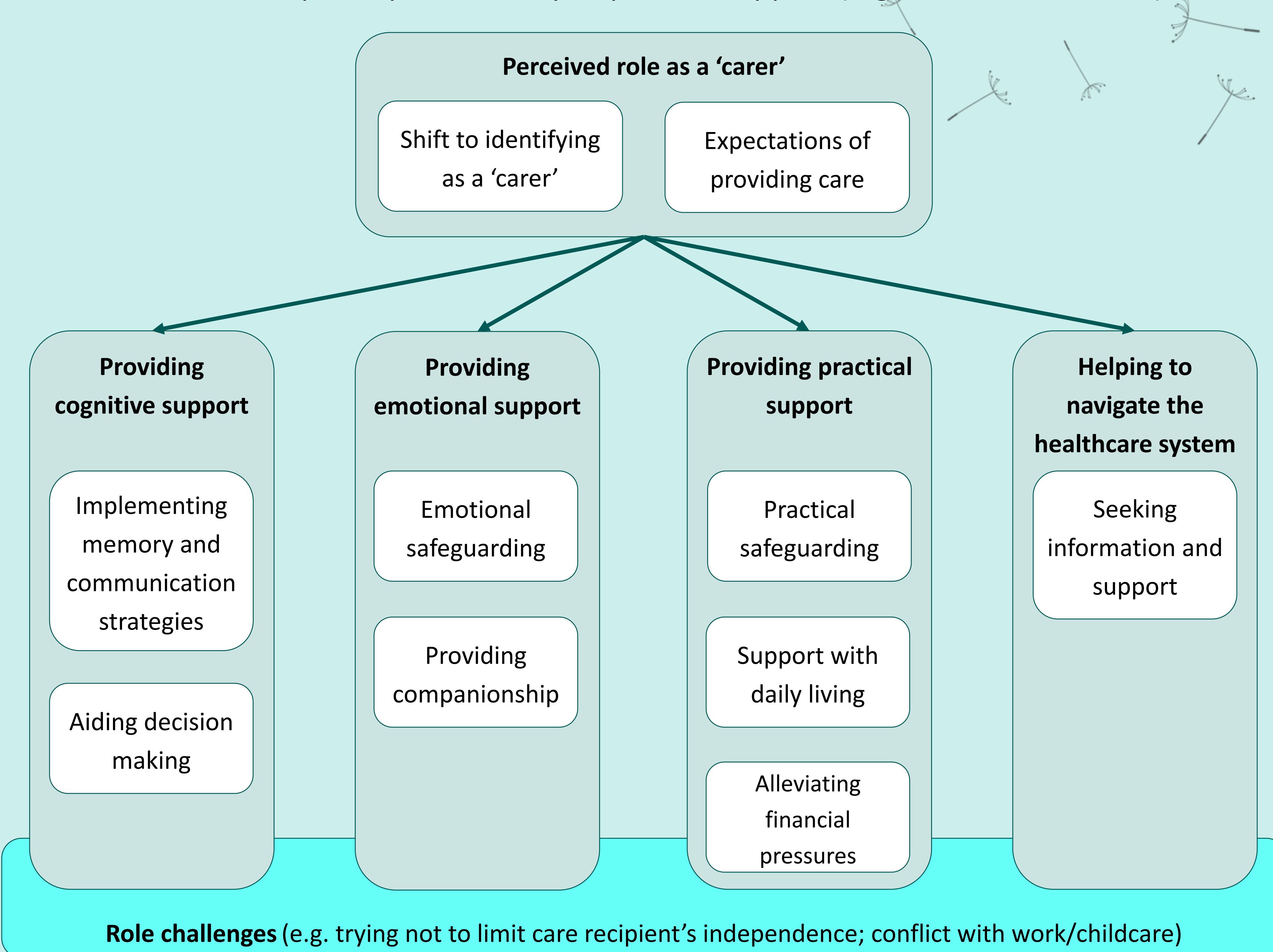
- People living with a low-grade glioma (subgroup of brain tumours) may require support to manage their symptom burden (e.g. fatigue, seizures, cognitive deficits).
- Partners, family-members and friends often assume the role of ‘informal caregiver’.
- The types of support provided by informal caregivers, and their experience of this has not been well investigated.

Methods

- We recruited family-members or friends who identified as supporting, or supported in the last five years, someone living with a low-grade glioma, from across the United Kingdom.
- We conducted remote semi-structured interviews and analysed the data using thematic analysis.

Results

- **19 informal caregivers** were interviewed (mean age 54.6 years; 5 males, 14 females; 15 spouses (husband or wife); 13 in employment; 6 had children).
- There was one overarching theme “Perceived role as a ‘carer’” and 4 additional themes (providing cognitive, emotional, and practical support, and helping to navigate the healthcare system), each with associated subthemes (Figure), underpinned by challenges that influenced participants’ ability to provide support (e.g. conflict with work).



Aim: To explore, for the first time, how informal caregivers experience the role and responsibilities of supporting someone living with a low-grade glioma.

“When I use the word ‘carer’, I don’t mean that I’m looking after his every domestic need. He’s very independent...I feel a greater weight of responsibility about how he is, where he is, is he okay.”
- IC2 (aged 55, wife)

“He’s got a diary. So, when I want him to remember things, I write in that diary. So, he looks at that diary.”
- IC4 (aged 57, sister)

“We try to put the good energy that he does have into quality time with me and the kids and doing the family stuff.”
- IC15 (aged 44, wife)

“We go to a specialist day centre for brain injury. He is really lucky, it took us a lot of working to get him into it. But when they met [patient] and listened to me, there really was no question.”
- IC1 (aged 38, wife)

“It’s a delicate dance, it’s about me not doing too much for her. It’s about communicating and saying, “I’m going to put the laundry in unless you would like to do that today?””
- IC23 (aged 56, husband)

Conclusions

- Informal caregivers can offer wide-ranging support to help manage the consequences of the illness; largely fatigue, cognitive deficits, and the emotional impact.
- Consideration of ways to help informal caregivers to manage the challenges faced could help improve experiences and outcomes of people living with a low-grade glioma.