



IPOS 2023
WORLD CONGRESS



Health and disease in the people who care

“A constant black cloud” The emotional
impact of informal caregiving for
someone with a lower-grade glioma

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Lower-grade gliomas (LGG) are a subgroup of malignant brain tumours that are rarely cured. They almost always progress to a high-grade glioma, limiting life expectancy to around 5-15 years.

- Commonly diagnosed in young adults (30s and 40s).
- People with LGGs experience a range of symptoms and impairments that often impact quality of life and everyday functioning
 - *General cancer-related* symptoms (e.g. fatigue and pain)
 - *Tumour-specific* symptoms and impairments (e.g. seizures, cognitive, and communication impairments)

Partners, family-members, and friends often assume the role of ‘informal caregiver’ to support the person living with a LGG.

- Due to caregiving responsibilities, carers can experience wide-ranging physical, psychological, relationship, and economic burden.
- Typically, carers’ most prominent support needs are emotional and psychological related.
- Little is known about the emotional impact of being a carer for someone with a lower-grade glioma.

Aim: To explore the emotional impact of being an informal caregiver for someone living with a lower-grade glioma diagnosis

Recruitment



Eligibility:

- Aged ≥ 18 years
- Lived in the United Kingdom
- Currently, or had in the past five years, informally cared for someone with a LGG
 - Specifically, grade 2 astrocytoma, or grade 2 or 3 oligodendroglioma diagnosis

Data collection:

- Remote semi-structured interviews, from August 2020 to March 2022

Data analysis:

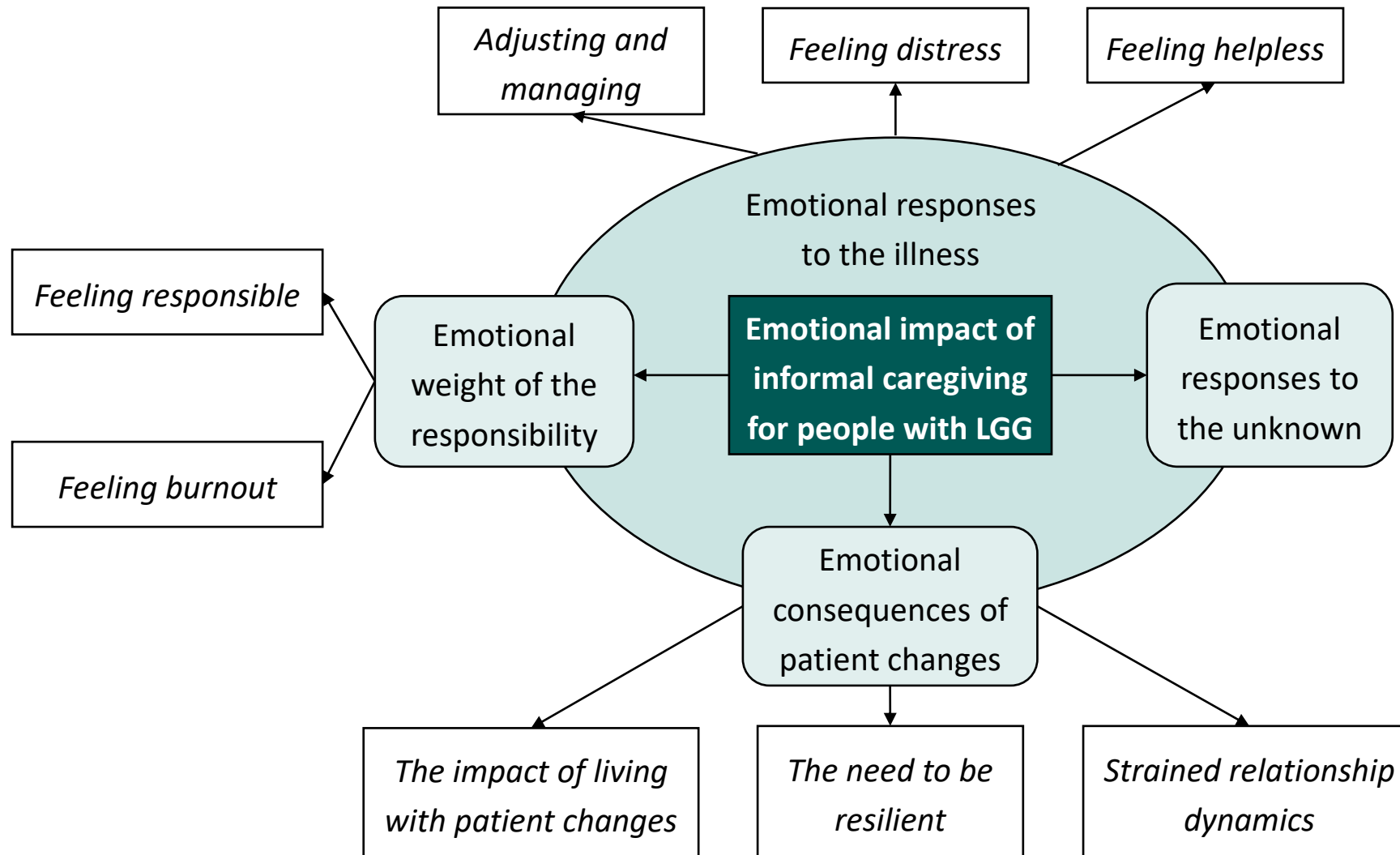
- Inductive thematic analysis

19 carers of people living with a LGG

Interview length (minutes): mean 85 (range 54-110)

Characteristic	n	Characteristic	Mean (range)
Sex		Full-time education (years)	14.9 (10-18)
Female	14	Relationship to care recipient	n
Male	5	Wife	10
		Husband	5
Age		Mother	2
≤40	3	Sister	2
41-50	3		
51-60	8	Relationship status	
>60	5	Married	18
		Single	1
Employment status		Dependents	
Full-time employee	10	None	13
Part-time employee	3	One	3
Retired	4	Two	3
Caring for family	2		

Overview of themes and subthemes



Emotional response to the illness

Adjusting and managing

Feeling distress

Feeling helpless

- Participants expressed feelings of distress and helplessness in response to the diagnosis, its impact on the care recipient, and potential prognosis; emotional adjustment was required to help participants manage.

"It's been, like, in a little box that I've got locked up and put somewhere that will get dealt with when it needs to get dealt with. So, probably not dealt with it." - IC15 (aged 44, wife)

"I wasn't really prepared for the maelstrom of emotions that I experienced." - IC23 (aged 56, husband)

"I just feel like I've had any hope taken away... There's no outcome from this other than [patient] dying and [patient] dying at a young age." - IC14 (aged 37, wife)

Emotional responses to the unknown

- Participants described feelings of fear, anxiety, panic, and uncertainty about the future, related to their awareness that the tumour is/was incurable and likely to progress eventually.

“It’s still that background nervousness of knowing how things can be, will be in the future. It’s perhaps not knowing but... my time horizon for planning and the future is now six months which is so much smaller than what it used to be.” - IC2 (aged 55, wife)

“It’s a constant black cloud hanging over you all the time, it’s something that is always there, you know it’s there, you can blank it out most of the time because it’s not having a direct impact... but you know that it’s not going away.” - IC13 (aged 51, husband)

Emotional consequences of patient changes

The impact of living with patient changes

The need to be resilient

Strained relationship dynamics

- Participants detailed the emotional consequences of the care recipient's cognitive and behavioural changes, due to the tumour and its treatment. This had a profound impact on relationships, requiring carers to be resilient.

"At the back of your mind you know you always have to be prepared. You feel like you have to stay mentally strong and ready for what might happen if [patient] gets ill." - IC12 (aged 66, wife)

"The point at which I feel most down about it are the points [patient] is very down and stimulates us doing any nice stuff." - IC18 (aged 48, wife)

"As far as I am concerned, my husband died on [date]...And I have been left with a complete stranger in my house." - IC1 (aged 38, wife)

Emotional weight of the responsibility

Feeling responsible

Feeling burnout

- The pressure and demand of the associated responsibilities of being a carer for a LGG patient meant that participants often experienced emotional exhaustion.

"I was trying to manage work and manage things at home. I never really had problems with my mental health, but I was bursting out into tears for no good reason." - IC15 (aged 44, wife)

"One day last week I just felt like getting in the car and driving off and just not coming back because it just all got on top of me." - IC19 (aged 54, wife)

"I was always concerned, "What happens if I get ill?" because I've got lots of health problems myself. What was going to happen?" – IC8 (aged 68, mother)

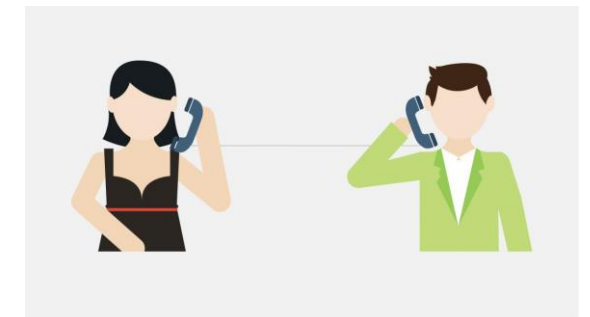
Strengths:

- Novel contribution to the evidence base
- Qualitative approach allowed exploration of *how* emotional impact is experienced
- Reasonable data sufficiency was achieved

Weaknesses:

- Possible self-selection bias in charity recruitment, due to Covid-19
- Participants were largely spousal carers, may not fully generalise to other family members
- Remote interviews had varied influence on participant comfort

- Representation of males



1

Carers of people with LGG are navigating substantial levels of fear and uncertainty due to the incurable nature of the condition.

2

Carers can be emotionally impacted by, and experience challenges with, adjustment to caregiving responsibilities, living with patient changes, and shifts in family dynamic

3

We highlight the importance of advice and signposting to ensure carers are aware of, and can access, available emotional support.

4

Carers' support needs should be monitored alongside patient need assessments to ensure they are offered the required support.

5

Carers may benefit from resources that highlight what they might expect and provides advice or active strategies that promote emotional adjustment. Care is needed to make sure anxiety is not exacerbated.

Thank you for listening.

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