

Barriers and facilitators to self-management in people living with a low-grade glioma

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



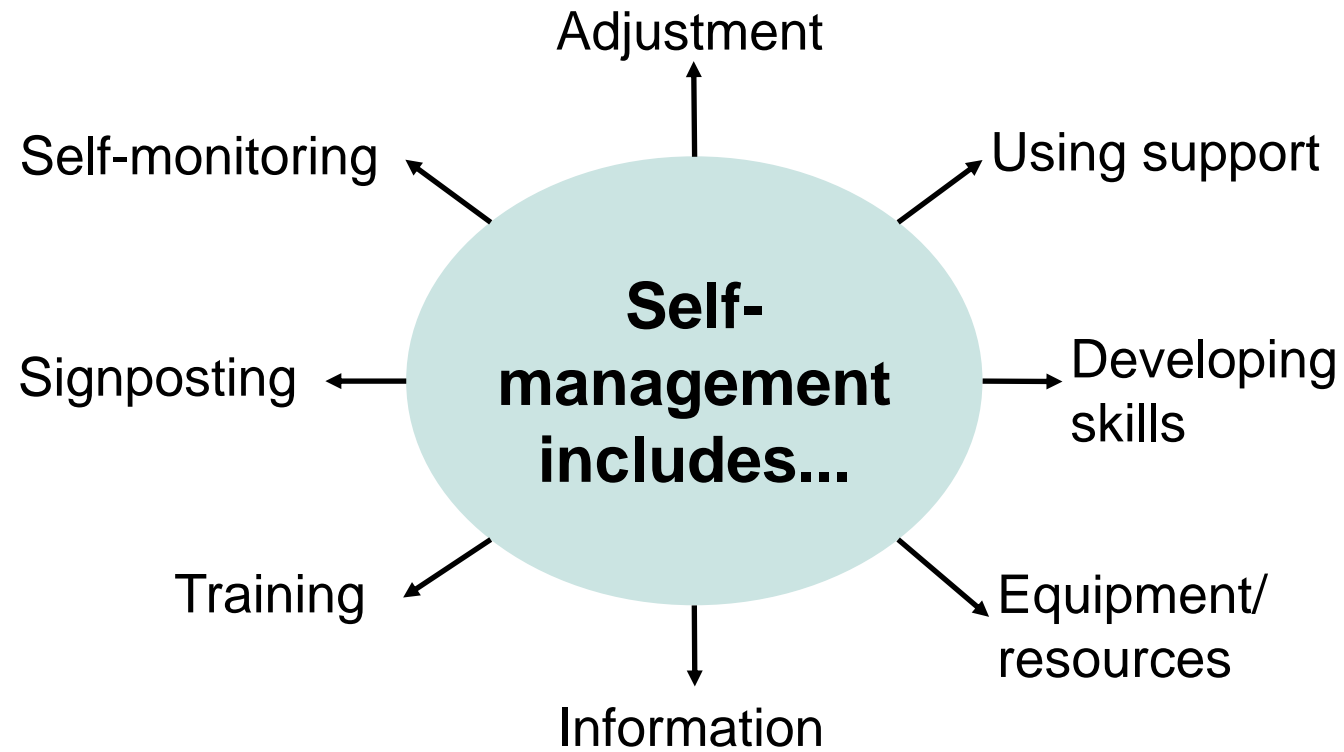
Low-grade gliomas (LGG) are rarely cured and almost always progress to a high-grade glioma, limiting life expectancy to around 5-15 years^{1,2}.

- Commonly diagnosed in young adults (30s and 40s).
- LGGs experience a range of symptoms that could impact quality of life
 - *General cancer* symptoms (e.g. fatigue and pain)
 - *Tumour specific* symptoms (e.g. seizures, cognitive, and communication impairments)
- Living for extended periods with a terminal condition can impact people's ability to recuperate and resume everyday activities, i.e. work.

Self-management is an “individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition”¹.

- To self-manage, patients need a set of skills (e.g. problem solving, action planning), which interventions seek to equip them with.
- Self-management is not – and should not be – the sole responsibility of the patient².
- Patients require support from a network of health professionals, family and friends, and fellow patients.

Examples of self-management



- In people living with a chronic illness, five categories of factors that may influence engagement in self-management have been identified¹.
- Extensive supportive evidence across chronic illness, cancer, and other neurological populations (e.g. multiple sclerosis).
- LGG patients may face specific challenges that nuance how they are influenced by these factors.
- One brain tumour study available²; included all primary brain tumours and focused on access to support services.

Aim: To identify and explore the barriers and facilitators to self-management in people living with a low-grade glioma

Recruitment



Eligibility:

- Aged ≥ 18 years at diagnosis
- In remission following completion of primary treatment, or stable under observation
- Grade II astrocytoma, or Grade II or III oligodendroglioma diagnosis

Data collection:

- Remote semi-structured interviews

Data analysis:

- Initial inductive, open coding, then mapped to an existing framework of factors influencing self-management².

Diverse group of 28 LGG patients
Interview length (minutes): 54-167, mean 102

General characteristics

- **Sex:** Male (n=16), Female (n=12)
- **Age (years):** 22-69, mean 50.4
- **Employment:** Full time (n=8), Part time (n=4), Retired (n=4), Retired (medical) (n=6), Unable to work (n=6)
- **Education (years):** 11-20, mean 15.8
- **Relationship status:** Married (n=21), In a relationship (n=3), Single (n=2), Widowed (n=2)

Tumour characteristics

- **Tumour type:** Grade II oligodendroglioma (n=9), Grade III oligodendroglioma (n=10), Grade II astrocytoma (n=9)
- **Tumour location:** Frontal (n=18), Parietal (n=3), Temporal (n=3), Overlapping regions (n=3), Not known (n=1)
- **Hemisphere:** Right (n=13), Left (n=15)
- **Surgery:** Yes (n=28)
- **Radiotherapy:** Yes (n=22), No (n=6)
- **Chemotherapy:** Yes (n=17), No (n=11)
- **Time since diagnosis (years):** mean 8.7, range 1-18

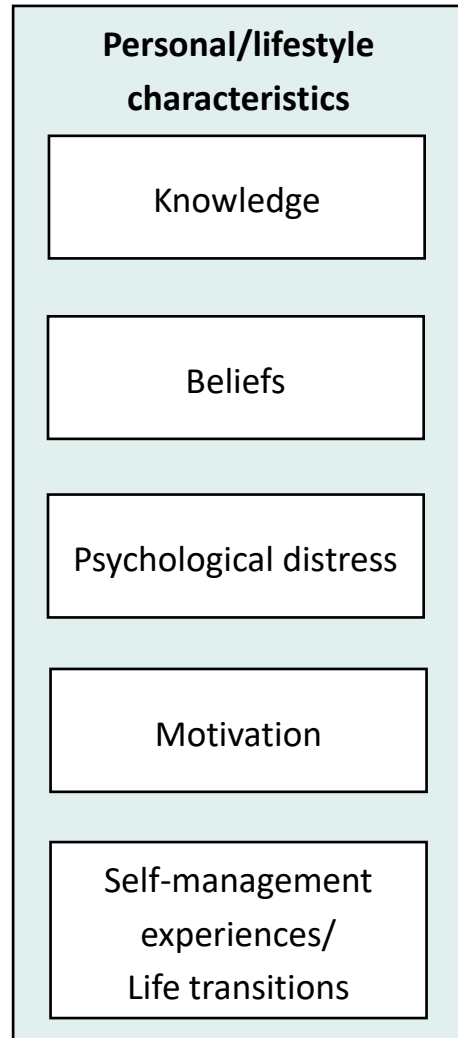
Support needs:

- Management of cognitive and functional impairments
- Cancer-related fatigue
- Seizure management
- Psychological needs (e.g. anxiety about tumour progression)
- Negotiating a return to work
 - Incapacity to work has emotional, financial, and social implications

Support needs vary greatly and depend largely on the extent of tumour- or treatment-related limitations

Self-management strategies:

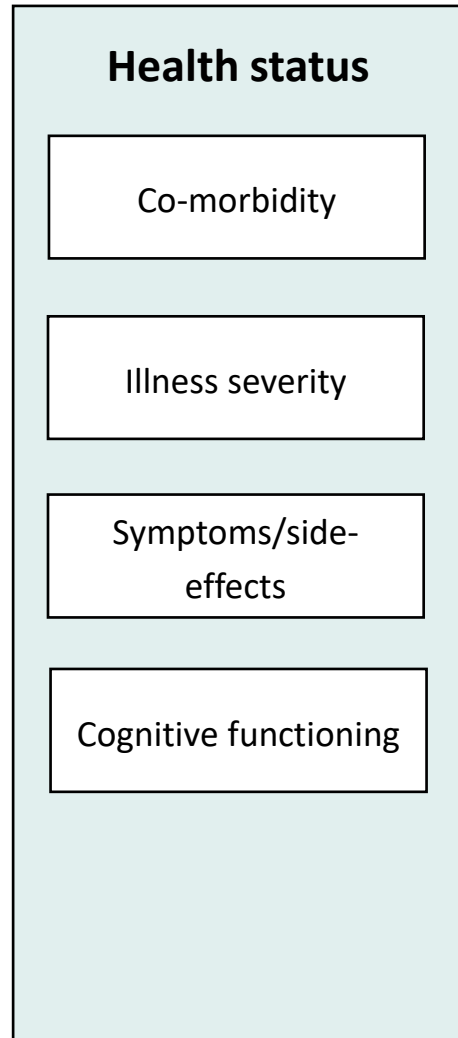
- Using support (e.g. from family and friends)
- Creating a healthy environment (e.g. acquiring equipment or information)
- Meaning making (e.g. appreciation for life)
- Self-monitoring (e.g. monitoring emotions)
- Accepting the tumour and its consequences
- Re-interpreting negative consequences



“I’m still not convinced I’ve fully accepted my diagnosis because some days I’m just, “I don’t have a brain tumour. I’m sure I don’t have a brain tumour.” I know I do but sometimes it’s hard to be forced into living a different life.” *Female, aged 42*

“Emotionally, I try and look at things just as positively as I can. I have two small kids. I’ve got my wife. I can’t just go on moping about stuff so I just try and stay positive emotionally.” *Male, aged 45*

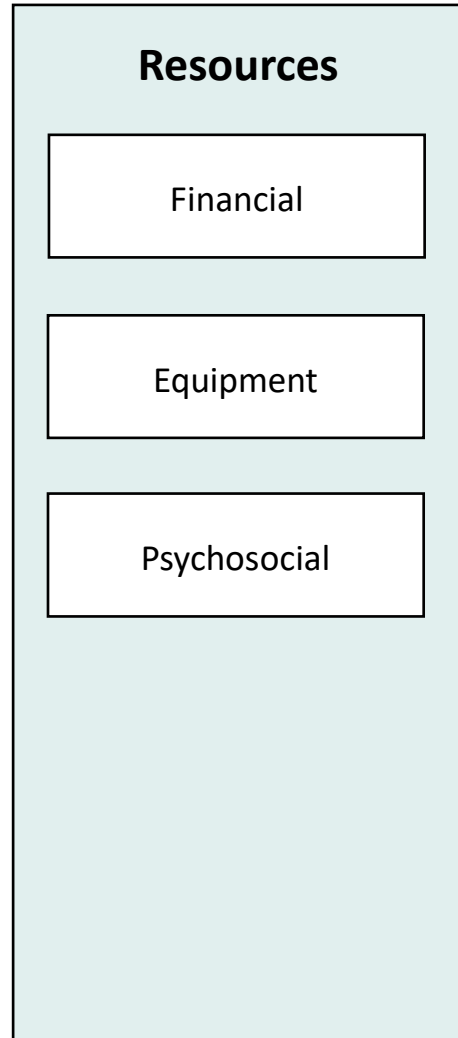
“You wouldn’t be comfortable planning anything beyond three months down the line or whenever the next scan is and that obviously longer term, you just don’t know what it’s going to look like.” *Female, aged 31*



“[Medication] goes in the medicine pot and it sits on the kitchen bench so I can see it all the time because if I didn’t see it, I would probably forget to take it.” *Female, aged 66*

“Each day is completely different. Like today, I had a good night’s sleep it’s like, yeah, crack on. Yesterday I was like, “Ugh...” It’s just pretty variable.” *Male, aged 55*

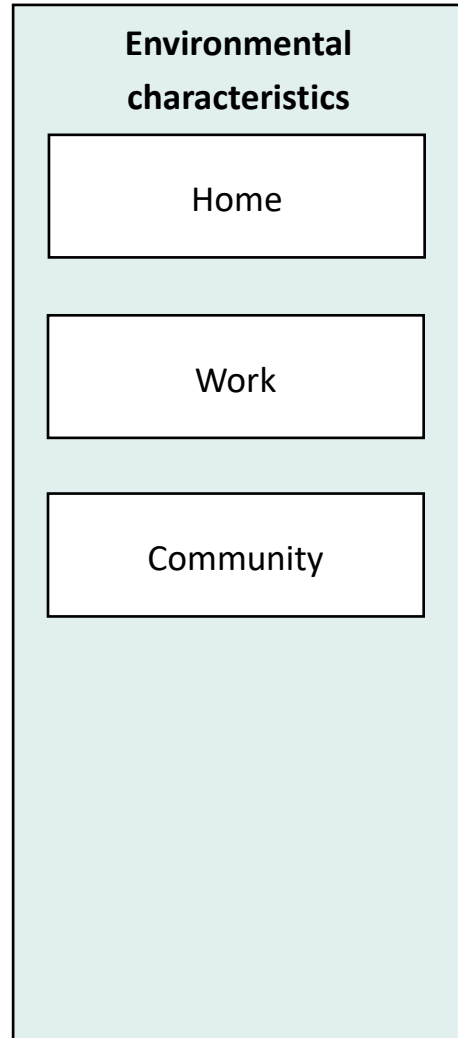
“Seizures. I’m not allowed to go swimming, and I used to be an avid swimmer. I used to love it. So, that’s something else that I can’t do now.” *Male, aged 22*



“I knew I needed to get the mortgage away to give me a chance to survive on half a wage. We sorted that so we don’t have a mortgage now and that’s a big help.” *Male, aged 61*

“I have to travel to work, and it was just lucky I had friends around me that would give me a lift to work and giving me a lift back and stuff.” *Male, aged 53*

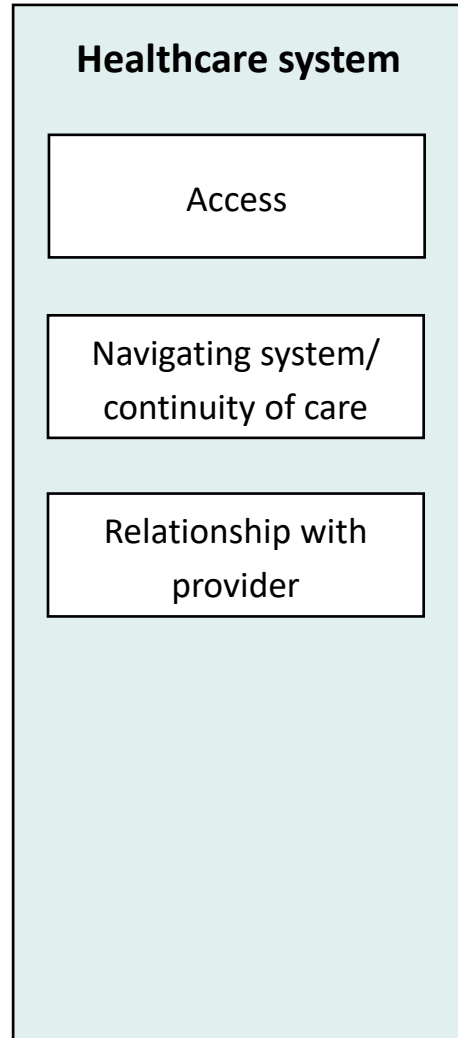
This shoulder bracelet I’ve got on makes me walk straighter, and if I can get my shoulder right, I’ll probably get my elbow right, and then my wrist right. If I get my wrist right, I stand a chance of getting my fingers back.” *Male, aged 52*



“They said they’ll never push me to, “When will you go full time?” At some point they probably will but at the minute, no, they [employers] have been more than supportive.” *Female, aged 55*

“We were in a larger house before, so we downsized a bit. As we moved in, we worked out that walk-in showers were essential, so we got a walk-in shower.” *Male, aged 52*

“I’m on this information group, a lot of people go to meet-ups and things, and there is nothing round here. The last time I looked, the closest one to me was on the other side of [place], and I can’t travel very well.” *Female, aged 47*

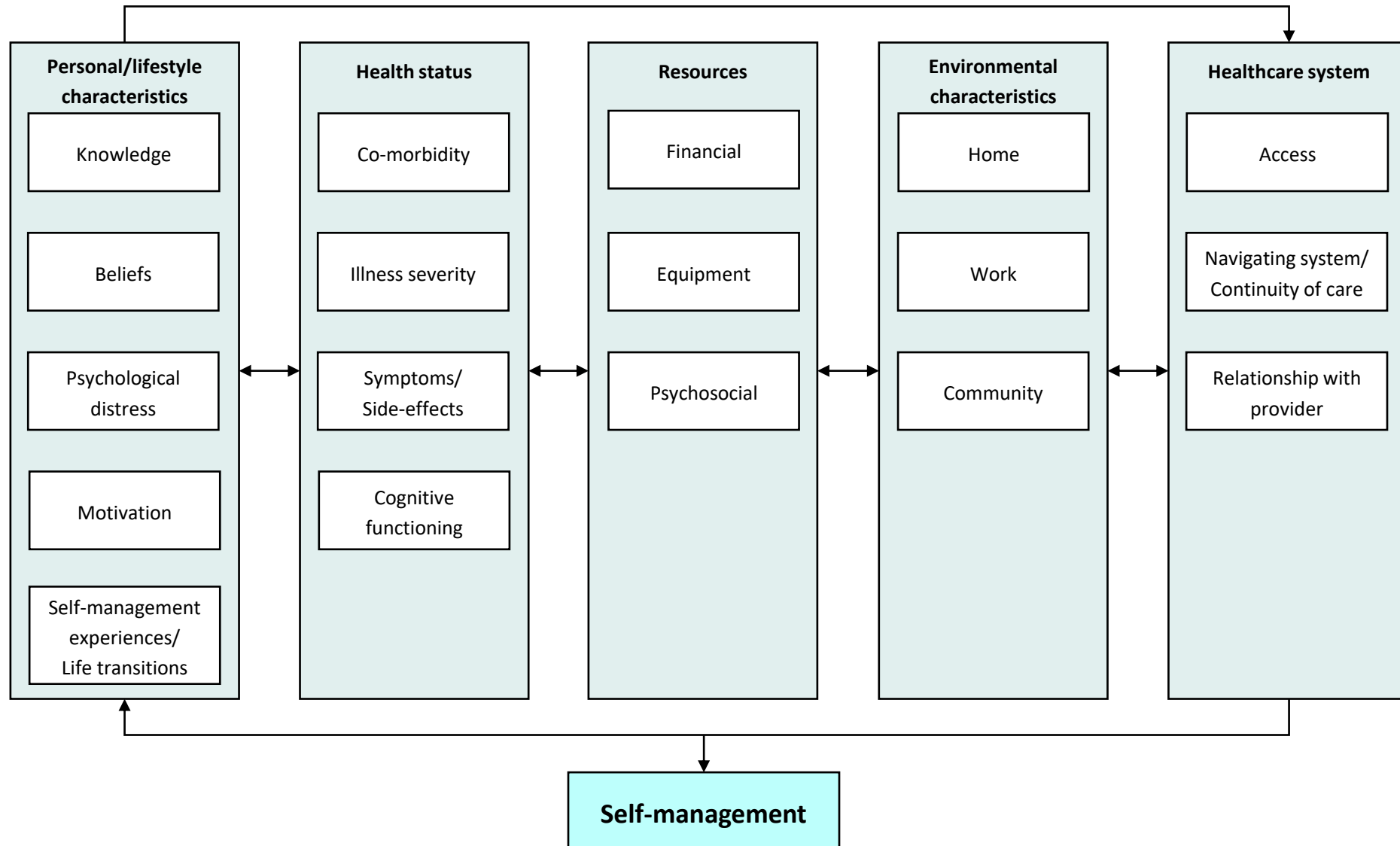


“I see a psychiatrist who’s in the cancer centre. And he’s absolutely fantastic, he’s always really good at being able to give me advice about what I can do if I’ve got a problem.”
Male, aged 45

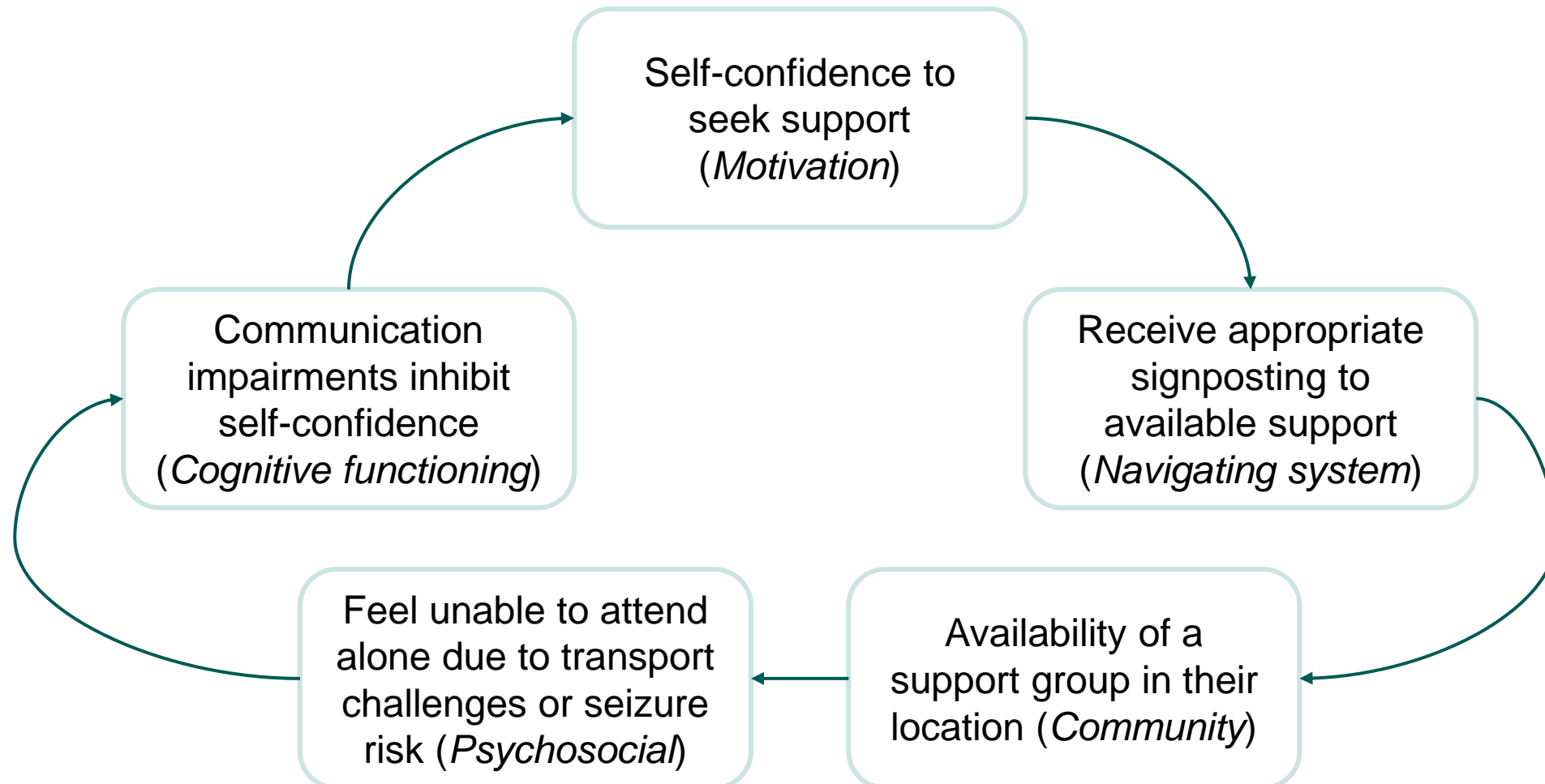
“I’ve had to seek it out. There’s nothing upfront that says, “This is what you’ve been diagnosed with. This is what you can expect. This is what we can do for you.” I’ve had to go and look for it.” *Female, aged 47*

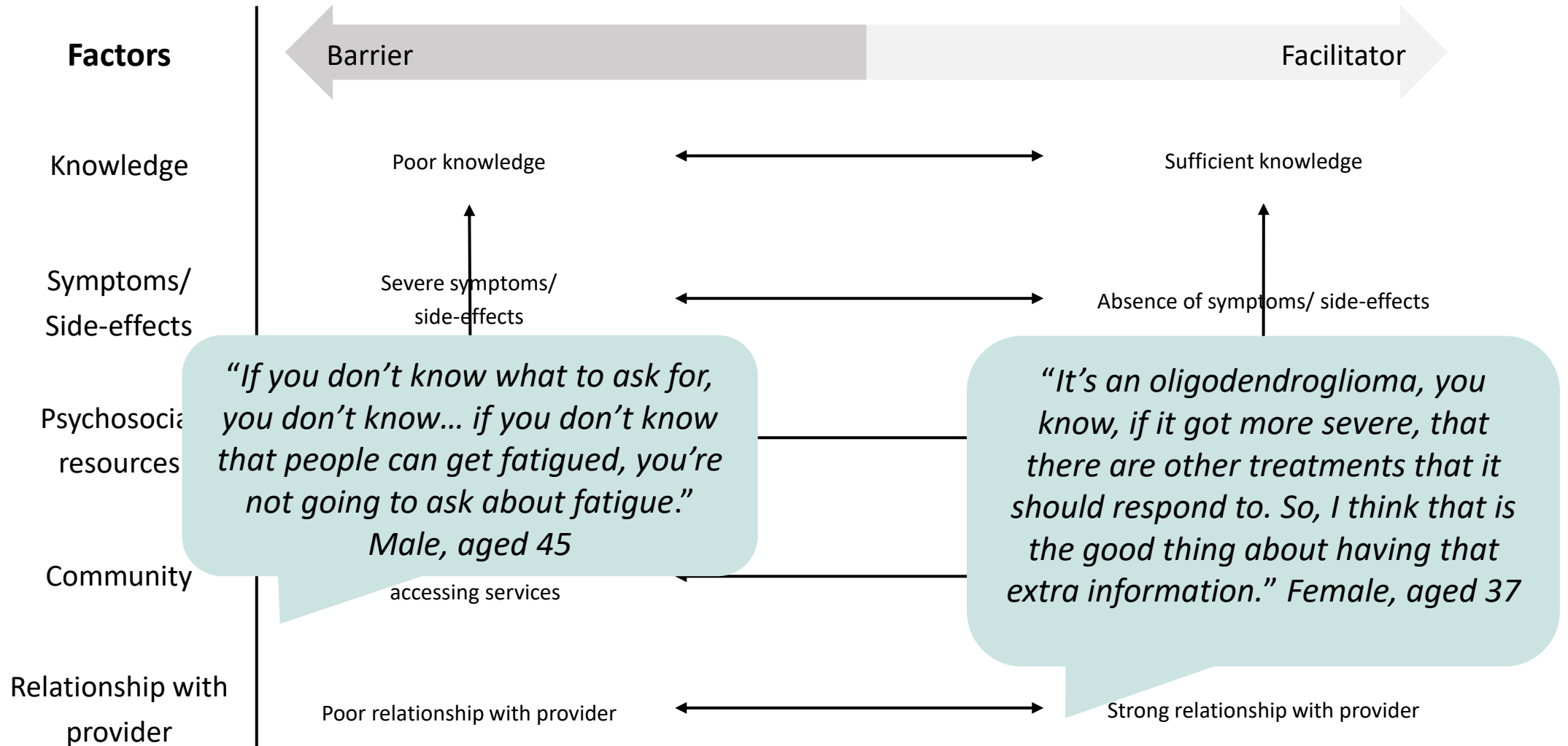
“I understand it’s the patient’s responsibility to negotiate. But they should at least be given the tools to allow them a fighting chance...I think they should point you in the right direction.” *Male, aged 22*

Factors influencing self-management



EXAMPLE: Support group attendance





1

We highlight the distinctive experiences and wide-ranging factors influencing self-management in people living with a low-grade glioma.

2

These findings will complement evidence on the self-management strategies used by people living with a low-grade glioma.

3

We highlight potential support needs and barriers to help seeking that will improve healthcare professionals' awareness of the challenges faced by this patient group.

4

We underline how each individual may be influenced differently, depending where they fall on a continuum.

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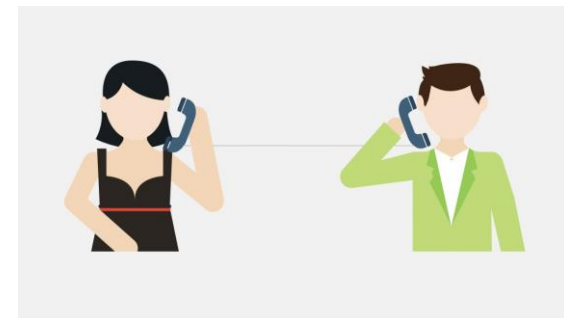
Future research should consider whether certain patient-level factors influence healthcare professionals' ability to provide support.

Strengths:

- Diverse sample (e.g. age, sex, time since diagnosis)
- Flexibility of semi-structured interviews
- Inclusion of patients with cognitive and communication impairments
- Novel contribution to the evidence-base
- Reasonable data sufficiency achieved

Weaknesses:

- Possible self-selection bias in charity recruitment, due to Covid-19
- Interview demands may have preceded interest for lower functioning patients
- Remote interviews had varied influence on participant comfort



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