Advocating for carers: A qualitative study exploring the needs of UK carers of patients with an acoustic neuroma

Katie Gilchrist and Dr Cecilia Vindrola-Padros | University College London | International Journal of Care and Caring

Aim

To identify the needs of carers of acoustic neuroma patients in relation to the diagnosis, approaching surgery and recovery stages of the condition and establish what interventions or support may be beneficial to this carer group.

Methods

We interviewed 12 carers of patients with an acoustic neuroma; patients were spread across different stages of the diagnosis to recovery pathway. Thematic analysis was carried out to develop key findings.

Findings

Life disruption Carers experienced life disruption with a lot of fear, uncertainty and prolonged waiting times. Patient survival, post-operative quality of life and side-effects of surgery were main concerns.

Support Most carers turned to family or friends for support. Some found online forums and support groups to be helpful while others found they had a negative effect. Of those who did engage with these, many did not find out about them until after surgery. Satisfaction of healthcare providers support was mixed, leaving some carers unprepared for the patients recovery.

Wellbeing Most of the carers interviewed had experienced some impact to their wellbeing or mental health. Ranging from worry and loneliness to stress, anxiety and post traumatic stress disorder. Coping strategies included drawing on own resilience as well as using emotion-focussed and problem-focussed coping methods.

Carer role Most of the carers provided both emotional and practical support to the patient and carried out tasks such as housework, meal preperation, helping with personal care and attending appointments with the patient.

Lessons learned The carers shared their advice and suggestions to help shape our recomendations.

Impact of Covid-19 Communication with HCPs was minimal, reducing the opportunity for carers to ask their own questions. Delayed tests and surgery created uncertainty and frustration.

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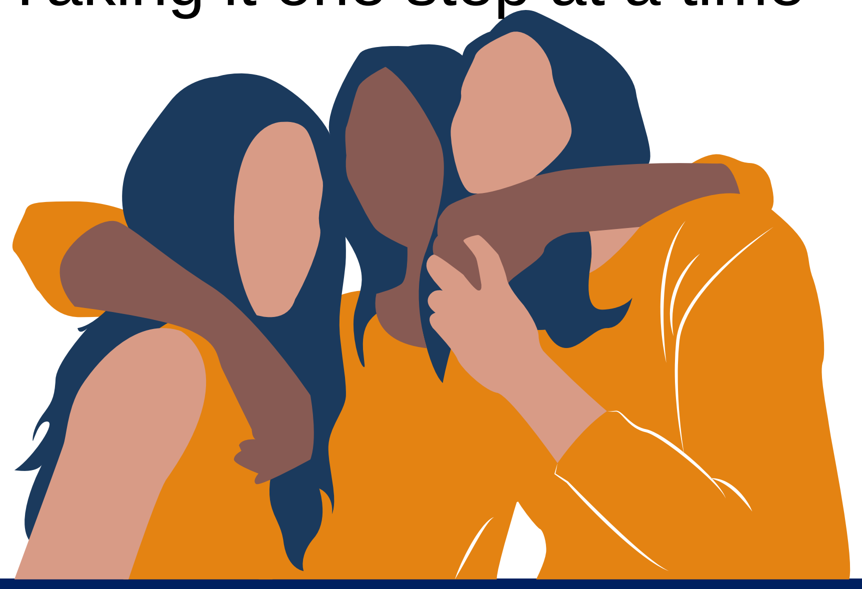
Coping strategies

- Caregiver and patient supporting each other
- Connecting with other carers/patients
- Positive reframing
- Distractions; hobbies, dog walking, family
- Focusing on life returning to normal
- Not dwelling on the negative aspects
- Acceptance of a “new normal”
- Conscious decision; AN does not rule life
- Researching the condition
- Focusing on goals and practicalities
- Maintaining your own good health
- Maintaining a routine throughout recovery
- Taking it one step at a time



Advice from carers

- Discuss what level of personal care you are both comfortable with.
- Would have asked more questions if they knew what questions to ask.
- Ensure you are fit to care for somebody and get help if you can.
- Have a trusted GP in place.
- Look after your own mental health and well-being.
- Nothing can prepare for unexpected complications.
- Talking to friends, family or charities more may have helped.
- Keep doing things you enjoy.
- Ensure you are aware of what you are facing physically and emotionally.

Recommendations

Diagnosis

- Carers to be systematically recognised and assessed as carers at diagnosis to evaluate their coping skills and resilience and potential interventions.
- Healthcare providers to practice consistent signposting to relevant auxiliary services, allowing carers to access practical information and emotional support.

Approaching surgery and recovery

- Carers to be provided with more information from healthcare providers on patient outcome for the days in hospital, following surgery, and what care the patient will need once home.
- We suggest informational materials on practical and emotional carer tips and patient recovery, as well as advice on coping techniques.

Future work

- Further studies on other non-malignant brain tumours to explore whether those populations have similar needs.
- development of models of support specifically for patients of non-malignant brain tumours.

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