

'SO MANY LIMITS': LIVING WITH SUBGLOTTIC STENOSIS AS A RESULT OF VASCULITIS

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RATIONALE

Systemic vasculitis

- Is a group of rare, serious and complex autoimmune diseases
- Causes inflammation of blood vessels and organ damage
- Needs powerful medication and sometimes surgery
- Is not curable and can flare or attack new areas of the body
- Needs long-term coordinated multi-professional support

Systemic vasculitis and its consequences can affect communication and / or swallowing. A rare effect is subglottic stenosis.

RESEARCH QUESTION

What are people's experiences of systemic vasculitis and healthcare?

METHODS

- 32 in-depth qualitative video (or audio) interviews (UK wide)
- Maximum variation sample
- Narrative interview style and thematic analysis

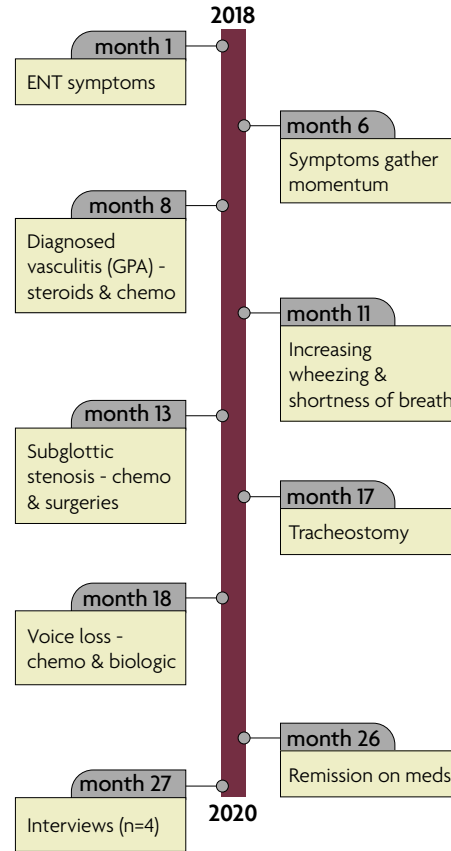
RESULTS

Some people talked about communication or swallowing problems, but only three of them mentioned speech and language therapy support.

Systemic vasculitis is heterogeneous and unpredictable. An individual and their family's need for speech and language therapy intervention is likely to fluctuate and change over time, and may be underestimated.

We illustrate this with excerpts from Charlie's experiences.

CHARLIE'S VASCULITIS TIMELINE



CHARLIE

[The speech and language therapists] had no experience of it. So they were starting from day zero, really, with me trying to explain the condition, explain my needs, explain kind of how it looks for me, and then them trying to adapt their procedures for that.

...the main thing that I felt with illness was the loss of independence, really, and I think the increased reliance on others, either with my body not being able to function in certain ways or be very unpredictable or being reliant on others for communication, for hearing, for speaking

I think anyone with this type of device, I think, would have to significantly adjust the way that they prepare and consume food in order to kind of maintain safety.

...there is a lot of awareness around people who are deaf and awareness of the things like Makaton and of different sign language, but the key part of that is that no one else knows it. [smiles] So you go to the shop, you go on the bus, you go to other places and nobody has any idea and cannot interact with those.

...we've even tried to do things like increasing doing videos with my daughter or increasing different recordings, or just things for our own family, of saving the voice. Just in case, within a few years I lose it permanently, and my daughter never knows the sound of my voice when she's older.

...for those people that have completely lost their voice and got to the point where you cannot make any sound, there really aren't many options out there.

...the voice tends to get very tired and doesn't seem to be able to sustain like it used to be, but also I struggle using different tones and different pitches that I used to be able to, because of the damage.