

What is the psychosocial impact of living with Vascular Ehlers Danlos Syndrome?



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Participants

A research project conducted by Leanne Barrett, investigating the psychosocial impact of living with Vascular Ehlers Danlos Syndrome (vEDS).

18: women

3: men

Age range: 19 to 61 years old

There is limited research focusing on the psychological and social implications associated with living with vEDS. This project was the first to explore this topic with UK based vEDS individuals. The interviews produced large volumes of data which were analysed and discussed.

Literature review points

Research into the psychosocial impact of living with vEDS is minimal. Analysing the impact of living with similar conditions such as Marfan Syndrome, Loeys Dietz syndrome, Hypertrophic Cardiomyopathy and Long QT syndrome provided an insight into the possible challenges vEDS patients may face. The table below displays the common issues seen in these patient groups:

Grief and loss	Physical functioning
Pain and fatigue	Limited social life
Pregnancy and worries about future children	Anxiety and worry (mental health complications)
Fear of the unknown	Frustration with healthcare professionals
Family life	Lifestyle choices

Methods

Initial phone call

Discuss the study and answer any questions, arrange interview

Interview

Semi-structured telephone interview, lasting between 45mins to 1 hour.

Debrief phone call

Participants discussed how they found the process and reflected on their experience.

Results summary

Six major themes were identified, with subsequent sub themes and further sub headings. These are discussed in more detail on the following page. Each interview was transcribed and analysed using thematic analysis. Quotes, graphs and in-depth exploration of the results can be found in the dissertation document.

Six key themes (in no particular order)...



Resilience and coping mechanisms

Positive attitude and outlook on life
Exercise as a coping mechanism: physical health, mental health
Thought management and diagnosis
Appreciation for life
Providing a voice to the unheard

Communication and support

Discussing diagnosis within the family unit
Discussing diagnosis amongst friends
Lack of faith in healthcare professionals
vEDS support groups; striking a balance
When to tell and how to tell
Barriers in relationships
Differences within the vEDS community

Risk perception and existential thoughts

Living cautiously
Obtaining diagnosis, fear, relief or regret?
The uncertainty of living with vEDS
The future and growing old
What if? Life without a vEDS diagnosis
Feeling different amongst others
vEDS, an invisible condition

A world of responsibility

Concern for future generations: parental guilt and relief, parental protection
Personal health and management: support and care, ownership of the condition
Career progression
Financial uncertainty
Raising awareness: companionship, raising awareness

Physical limitations to daily life

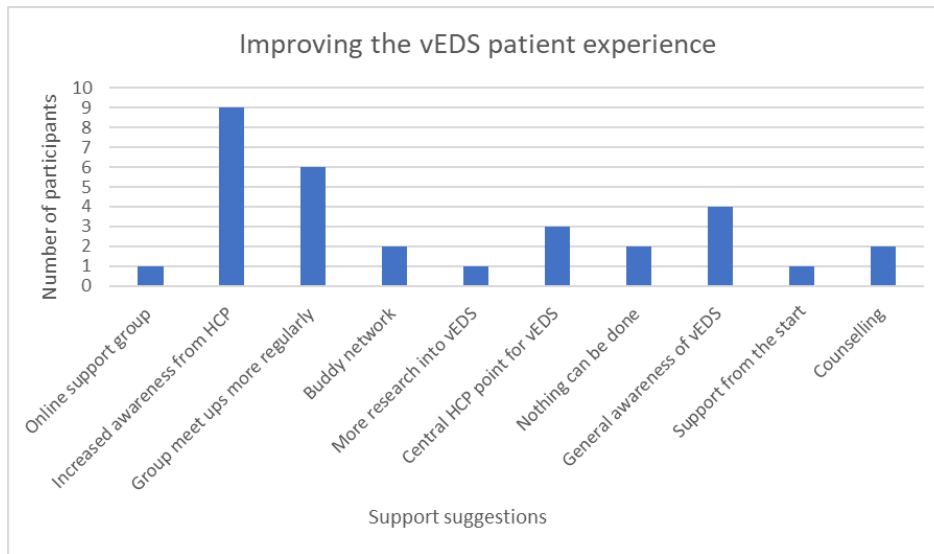
Fatigue and pain
Time and energy management
Engaging in social activities
Inability to carry out activities and tasks
Intimacy
Achievements and accomplishments

Loss

Identity
Social freedom and independence: independence, desire to socialize
Choices around pregnancy & having a family: anticipated loss, retrospective thoughts
The lasting impact of losing a family member to vEDS

Discussion of results...

This project found similar results to those in the other studies discussed in the literature review. This study also uncovered several other factors that effect individuals psychological and social lives.



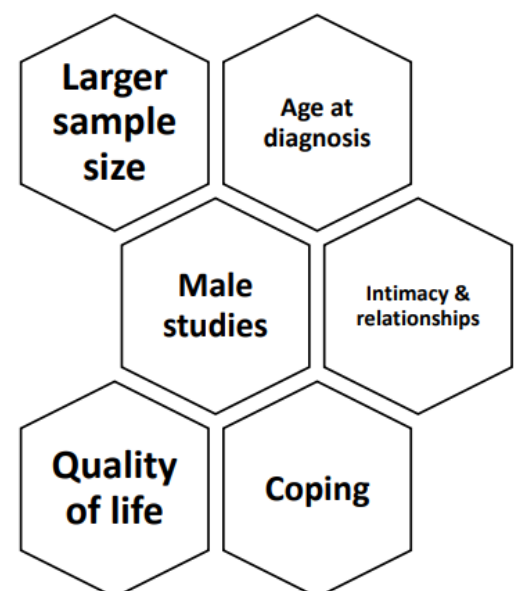
Noticeably, increased awareness from healthcare professionals was the most common response to how the vEDS patient experience could be improved.

Main discussion points...

- **Day to day living:** fatigue and managing personal, social and medical factors of the condition.
- The **uncertainty vEDS** placed on individuals lives.
- How vEDS affects **decision making**, in relationships and reproductive options.
- **Family life:** concern for children, partners and future generations.
- **Grief and loss:** anticipating loss due to vEDS, grieving for a child with vEDS, losing a family member to vEDS.
- **Age at diagnosis:** it became clear that the age in which individuals were diagnosed impacted their outlook.
- **Inner strength and mental health:** over half of the participants had experienced mental health issues as a result of living with vEDS. But, in the face of all these challenges, participants remained strong in their day to day lives.

Future research projects

Literature surrounding the psychosocial aspects of vEDS is still in its infancy. This project revealed various areas for future research to take place, including:



Clinical implications

It is clear that vEDS patients face an abundance of psychosocial issues. This study highlights the need for change within clinical practice in order to support vEDS patients effectively, by addressing their psychosocial health and needs.

Thank you!

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