Understanding the Role of the General Practitioner in Caring for Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in the Community.

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Objectives

- Establish a general understanding of the current awareness and knowledge of ME/CFS based on recent scientific research and publications.
- Recognise the importance of the patient voice in ME/CFS management via qualitative and quantitative information gathered from patient volunteers in the community including information obtained by telephone interviews and an online questionnaire.
- Identify factors that patients view as important to their management in primary care.
- Attend a ME/CFS clinic to observe how patients are managed in secondary care

Introduction

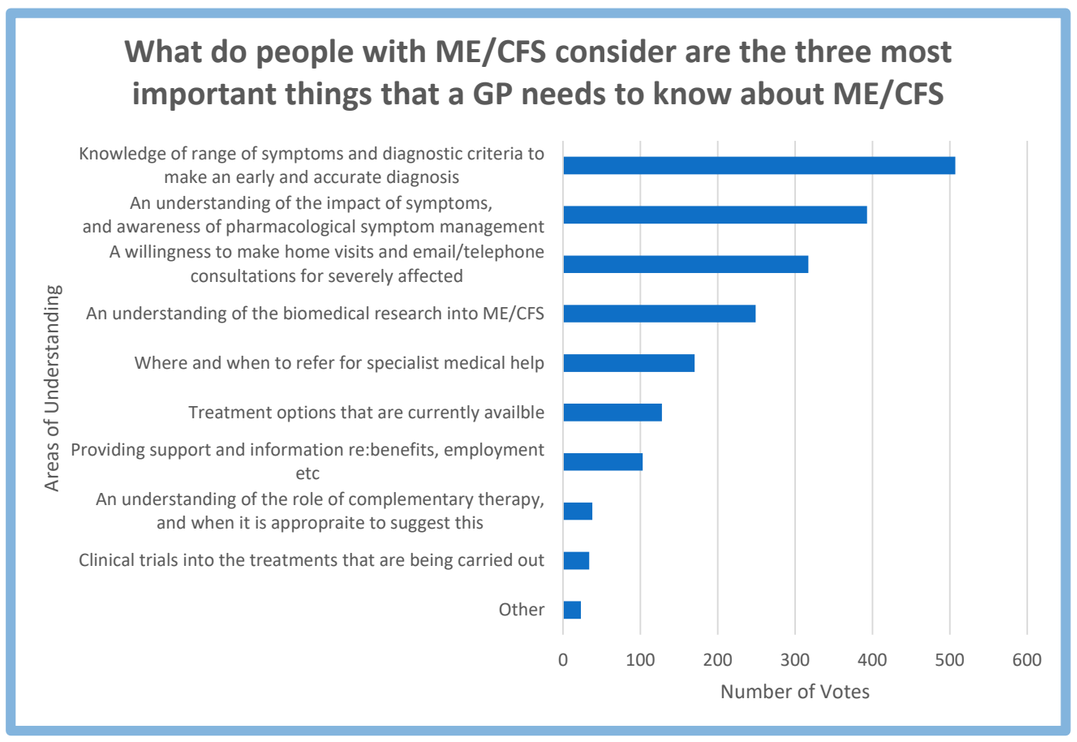
Myalgic encephalomyelitis, or Chronic Fatigue Syndrome (ME/CFS), has an estimated prevalence in the UK of 0.4% (1) which correlates to 260,000 people. Patients can be affected mildly to severely with symptoms including pathological fatigue, post-exertional malaise, neurological and cognitive dysfunction and myalgia (2). Patients rely on their GP for a diagnosis and early management, appropriate referral and holistic support (3).

There has been increasing recognition of the importance of the patient voice and using patient focus groups to aid development of guidelines. The 2002 CMO Working Group report into ME/CFS also highlighted the need to listen to the patient voice (4).

Methods

1. **Ethical approval;** Application through SMREC
2. **Single online question;** published on the ME Association website with nine multiple choice answers which had 690 responses
3. **Written feedback;** 47 participants sent additional free text in response to the online question
4. **Semi-structured, telephone interviews;** Ten participants with a diagnosis of ME/CFS asked about their experience of GPs and how care could be improved
5. **Qualitative Analysis;** NVivo software was used for thematic analysis of the written feedback and interview transcripts and create word clouds

Word Cloud from online free text feedback



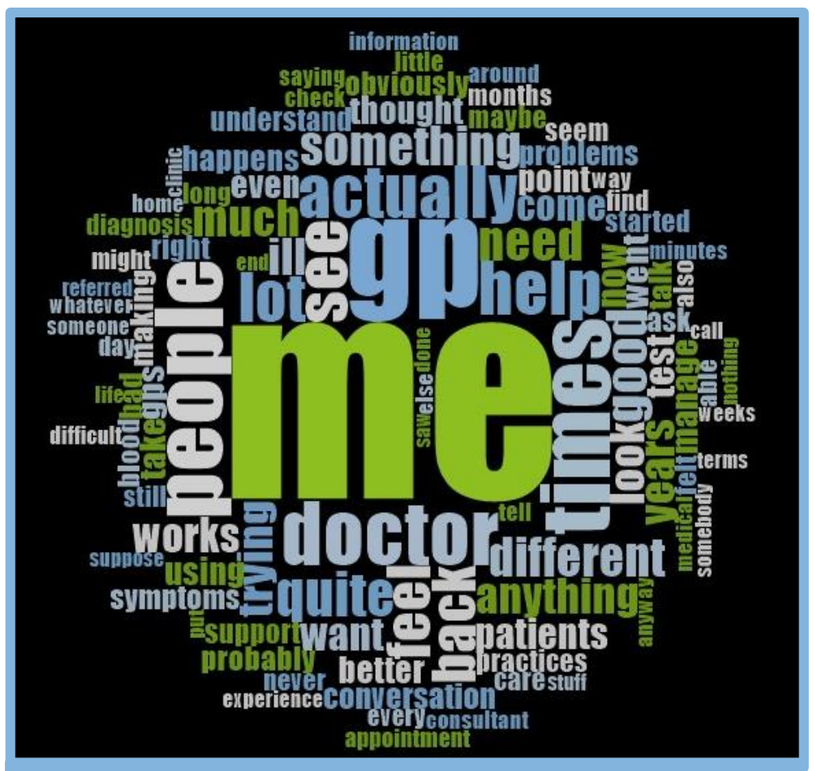
Themes identified

From written feedback;

- Knowledge about condition
- Diagnosing
- Management
- Practical support
- Communication

From interviews;

- GP understanding and resources
- Diagnosing
- Management
- Practical points
- GP attitude to ME/CFS
- Understanding the patient
- Supporting the patient
- Respecting the patient
- The broader role of the GP



Word Cloud from semi-structured interviews

Results

Both the online question and free text feedback emphasised that patients prioritised an understanding of the symptoms of ME/CFS in order to make a diagnosis and to appreciate the impact of the condition on patients.

The interviews discussed the wider aspects of the relationship between GPs and patients with ME/CFS. Participants suggested having a single healthcare practitioner to offer consistent care and develop an understanding of the patient and their history. GPs who were willing to learn more about ME/CFS and engage with the patient to better their own understanding of ME/CFS were held in high regard by participants. All but one participant had experienced feeling dismissed by a GP and some participants, who had not developed positive relationships with their GP, questioned the level of respect demonstrated by a GP.

"They just need to be honest and kind and respectful and together we'll figure out what the best way forward is."

'You hope to have a supportive GP because he will help you, even if he can't treat you, he will help you."

Conclusion

Participants described mutually beneficial relationships with GPs through working together but also instances where relationships had been less constructive or had broken down. Overall, online feedback and semi-structured interviews emphasised the perception that a supportive GP who is honest and open with patients can make a significant impact, regardless of their ability to cure the patient. In a future study, the patient perspective could be supported with parallel information gathering from GPs on their experiences to create a more thorough analysis of ME/CFS care in the community from a dual perspective.

"He's just been sympathetic to what I'm going through which is a big thing."

"And I just found it too upsetting to keep going because nothing was happening."

Acknowledgements

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References

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