Examining the relevance of PROMs to patients: A systematic review of qualitative research capturing which QoL domains are important to patients.

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Background

- Part of NIHR Programme Grant (RP-PG-1210-12009).
- Relates to other work including the identification and evaluation of existing PROMs for vascular conditions.
- A primary qualitative research study examining QoL issues.
- Integral part of the development of a new PROM, an electronic patient questionnaire for vascular patients (ePAQ-VAS).
Patient Reported Outcome Measures (PROMs)

❖ PROMs should include domains that are relevant to patients.
❖ FDA (2009) advises that measures show evidence that their items have been generated through taking into account the experiences and perspective of the patient group.
❖ The use of qualitative research is the best way of examining patients.
Qualitative Research
Aim of Evidence Synthesis

❖ Primary aim of this qualitative evidence synthesis was to examine the symptoms and QoL domains that are important from the perspective of a patient with varicose veins (VV).

❖ Secondary aim was to compare the findings to existing PROMs domains that are currently used with VV patients.
Varicose Veins (VV)

- Relatively common affecting at least a third of the UK population.
- Wide range of reported symptoms, and severity can differ.
- Treatment can vary from compression hosiery through to invasive surgical procedures.
PROMs data collection in the NHS

❖ Since 2009 NHS providers have collected PROM data for four surgical procedures, including VV treatments.
❖ PROM completion rates for VV patients are much lower than the other procedures.
❖ 2013/14 VV completion rate was 40.5% compared to 86% and 94% for hip and knee surgeries respectively.
VV PROMs used in the NHS

- Patients complete the condition specific Aberdeen Varicose Vein Questionnaire (AVVQ).

- Also complete two generic measures – the EQ-5D Index and the EQ- Visual Analogue Scale (EQ VAS).

- A separate systematic review concluded the most appropriate PROMs were the AVVQ and the SF-36 based on psychometric analysis.
VV Qualitative Review

- Eight electronic databases were searched.
- 1804 citations were identified; after screening only three studies met the inclusion criteria.
Findings of the Review

Five overarching themes were identified; physical impact, psychological impact, social impact, adapting to VV and reasons for seeking treatment.
Physical Impact

❖ No definitive list of symptoms.

❖ Not all symptoms affect people in the same way.

❖ Generic PROMs won’t capture specific symptoms, such as swelling.

“The last few days I literally crawled through the door and had to sit down with my feet up high to get the blood and swelling down.”

“I’m elevating my legs at least 10 minutes a day to prevent varicose veins!”
Psychological Impact

❖ Identified a strong psychological impact.

❖ Cosmetic appearance was a significant finding.

❖ Generic measures don’t capture ‘body-image’ concerns.

“I was just very aware that my legs shouldn’t be like this and that if they were more normal and less ugly and swollen, then I would feel a bit happier.”

Patient 2 – Hudson et al
Social Impact

❖ All papers identified an impact on social function – often led to social isolation.
❖ Link to psychological impact as social isolation led to low mood.
❖ Social activities are included in most PROMs.

“I don’t feel comfortable I feel like a lot of people stare at them or feel repulsed by them.”
(Participant 11 – Palfreyman et al 2004)
Reasons for Seeking Treatment

❖ Symptom relief rather than cosmetic appearance was the primary reason.
❖ Improvement in symptoms may be an unmet expectation.
❖ Patients may be unaware of risk of failure.
❖ No PROM would capture why patients seek treatment.

“More than anything is that it won’t be as it is now, so that the pain factor, the heaviness, everything that goes with it hopefully will have gone.” (Participant 14 – Palfreyman et al 2004)
Adaptation

Adaptations

A change in the way of life that allows people to survive in a particular environment.
Construction of PROMs

“I know nothing about the subject, but I’m happy to give you my expert opinion.”
Conclusion

“HRQoL, patient-assessed symptoms (including pain, discomfort, body-image concerns, swelling, aching and heaviness), and progression......were considered to be the most important outcomes to identify who would benefit from a referral to a vascular service”
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