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Experiences of living with varicose veins: a systematic review of qualitative research

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Abstract

Introduction: Varicose veins are common in the UK and though relatively few people develop serious complications they are a chronic condition with implications for quality of life. Treatment is predominantly conservative and, in this context, understanding patient's experience of living with varicose veins and their effect on quality of life is important to inform the provision of clinical care. One method of understanding the issues faced by these patients is through the use of patient-reported outcome measures (PROMs) which should be validated and relevant to the experience of the patient group. The identification and synthesis of existing qualitative research describing the impact of varicose veins can also be used to ensure the relevance of new and existing PROMs.

Aim: The primary aim of this qualitative evidence synthesis was to examine the symptoms and quality of life domains that are important from the perspective of patients with varicose veins.

Methods: Multiple electronic databases were searched including MEDLINE and CINAHL to identify reports of qualitative research of the experience of adults with varicose veins. Following study selection, data extraction and quality assessment a thematic analysis was conducted based on initial themes identified from PROMs used in this population. An inductive approach was used and emergent themes were identified. The final stage in the thematic analysis involved the development of new interpretations.

Results: Three studies met the inclusion criteria for the review; the quality of the studies was high. The range and intensity of reported symptoms and participant's experiences of living with varicose veins were varied. Five overarching themes were identified; physical impact of varicose veins, psychological impact, social impact, adapting to VV and reasons for seeking treatment. Within these main themes further sub-themes were identified. The key theme to emerge was adaptation, as there was evidence that patients attempted to adapt to the physical, psychological and social impact of varicose veins.

Conclusion: The use of PROMS to gather information about HRQoL and symptoms is well established, but PROMs currently used with patients with VV may not capture the full extent of the impact of VV on patient's QoL. The findings of this review can be used in the development of new PROMs and also in facilitating the interpretation of the results of existing PROMs in current clinical practice and future research.

Keywords: Varicose veins, systematic review, qualitative, Patient reported outcomes, quality of life, symptoms

Acknowledgements: Irene Mabbott

Introduction

Varicose veins (VV) are a relatively common vascular condition affecting at least a third (Evans et al) and up to 40% of the UK population (Robertson et al). An estimated 30% of people with VV will develop skin changes associated with chronic venous disease (Lee et al), in addition between 3 and 6% of people with VV will progress to developing venous leg ulcers (VLU) (National Institute for Clinical Excellence 2013 (NICE)). Approximately 2% of NHS resources are spent on managing venous disease (Shingler et al), with 35,659 varicose vein procedures carried out in the NHS in 2009/10 alone (NICE).

Varicose veins can be treated conservatively, through the use of compression hosiery and lifestyle advice. However compliance can be an issue and the evidence base for the effectiveness of these approaches is limited (Shingler et al). Alternatively invasive treatments, such as endothermal ablation, foam sclerotherapy and surgery, may be required to reduce symptoms and slow disease progression. Decisions on how and when to treat VV are subject to variation across the UK, and are based on local interpretation of referral guidelines (Lim et al and Marsden et al). Quality of life (QoL) issues may be deciding factors in treatment decisions; therefore understanding the effect that VVs have on QoL is important.

One method of collecting data about quality of life is the use of patient-reported outcome measures (PROMS). PROMs provide information about the impact of a disease, or its associated treatment, from a patients' perspective. PROMS can be used by health organisations to collect routine data to inform policy decisions, and by individual clinicians to gather patient information in order to guide clinical and shared decision making (Black 2013).

Currently NICE VV guidance suggests that 'Quality-of-life measures are unlikely to reflect severity of disease because of variations in perception of symptoms' (NICE 2013); therefore it is necessary to assess whether these existing PROMs are fit for purpose and to ensure that the development of future PROMs are evidence based. Whether used in clinical practice or as a research tool PROMs need to be relevant and appropriate to the population they are used with and qualitative research methods can be used to ensure the validity of such instruments.

As recent systematic review was conducted to identify appropriate PROMs for use with patients with VV and assess their psychometric properties (Aber et al 2016 unpublished). Three disease specific (AVVQ, VVSymQ, SQOR-V) and one generic (SF-36) were identified; the review concluded the AVVQ was the most appropriate disease specific instrument, and the SF-36 was the most suitable generic PROM for use with patients with VV.

This qualitative evidence synthesis is related to the identification and evaluation of existing condition specific or generic PROMs that have been validated for use in populations with vascular conditions. The synthesis is also an integral part of the development of a new PROM, specifically an electronic patient questionnaire (ePAQ-VAS) for use in this population. The review complements a series of other projects undertaken as part of a NIHR Research Programme Grant (Vascular Programme Grant (VPG) Project ID: RP-PG-1210-12009) which has the aim of valuating vascular services and making recommendations regarding patient-focused care. VPG work-streams include:

- Similar reviews of qualitative evidence of four other vascular conditions, (abdominal aortic aneurysm (AAA), carotid artery disease (CAD), peripheral arterial disease (PAD) and venous leg ulcers (VLU))
- Five systematic reviews identifying and evaluating PROMs used by patients with five vascular conditions (AAA, CAD, PAD, VLU and VV)
- Primary qualitative research into the experience of living with these five vascular conditions.

Aim

1. The primary aim of this qualitative evidence synthesis was to examine the symptoms and quality of life domains that are important from the perspective of patients with varicose veins.
2. A secondary aim was to compare the themes identified in the synthesis to items in PROMs currently used with VV patients.

Methods

This systematic review was conducted according to a pre-published protocol (Duncan et al) on understanding the experience and impact of living with a vascular condition from the patients perspective, and is reported according to the ENTREQ statement (Tong et al)

Study Identification and selection

Studies were included if they were primary, qualitative research studies including populations of adults with varicose veins and published in English. We included mixed methods studies where details of data collection, analyses and results of the qualitative portion of the study were reported separately.

Searches were conducted in Cinahl, Embase, Medline, PsycINFO, Science Citation Index and the Social Science Citation Index, and ProQuest dissertations and theses; no language or date restrictions were applied. Additionally reference lists of included studies and related reviews were scrutinised and citation searches were conducted (see appendix 1 for full details of the search strategy strategy).

Two reviewers (EL, PP) independently sifted the title and abstract of all studies identified by the searches and read all potential full text papers, discussion was used to resolve any difference of opinion, with a third researcher (AA) available for consultation if consensus could not be reached.

Data Extraction and Quality Assessment

Data extraction was conducted using a study specific data extraction form, details of author; date; country; research design; method of analysis; aims and objectives; sample, including age and gender; diagnosis and eligibility criteria were collected. Quality assessment was conducted independently by two researchers (EL, PP) and any discrepancies were resolved through discussion. The Critical Appraisal Skills Programme (CASP) qualitative research checklist was employed to assess the methodological quality of the included papers including its trustworthiness and relevance (CASP 1998). The checklist comprises of ten questions about the qualitative methodology and are answered either 'yes', 'no' or 'unclear';

Data Analysis

Each full text paper was uploaded electronically into NVIVO 10 (QSR International, Burlington, USA), the reviewers read through each of the papers to familiarise themselves with the study and results,

the results sections were then analysed using thematic synthesis (Thomas and Harden). Initial coding of the text was conducted independently line by line with relevant sections and quotations highlighted and assigned to the specific nodes of the provisional thematic framework which was developed based on the domains used in the validated PROMs identified in the earlier review.

An inductive approach to analysis was employed with new themes added to the framework as they emerged. Inter-observer agreement of coding was checked and consensus was high; showing substantial, almost perfect or perfect agreement with kappa coefficient rating commonly between 0.61-1 (Viera and Garrett 2005).

Comparisons were made across the three included studies matching emergent themes to those already established in the framework. Where new concepts were identified additional themes were created and previously coded papers were re-visited to establish if any aspects of their findings matched the newly created theme. The classification of text according to existing and emergent themes is comparable to the development of descriptive themes in thematic analysis (Thomas and Harden) where themes remain 'close to the primary study'. In contrast the development of analytic themes, the final stage in thematic analysis, involves the development of new interpretive constructs, explanations or hypothesis which are described in more detail in the results section below.

Results

A total of 1804 references were identified, following the removal of duplicates 1318 citations were screened, of these 56 full text articles were retrieved and screened for eligibility of these 53 were excluded. Reasons for exclusion were: the paper was not available in English, the study was of a mixed population or not VV, or the study was not qualitative research or did not detail data collection or analysis methods. Study selection is detailed in The PRISMA Flow Diagram (Figure 1, Appendix 2)

Three independent studies that met the inclusion criteria were identified (Table 1). The studies were published between 2004 and 2016 and were conducted Sweden (n=1), and the UK (n=2).

Quality assessment

The overall quality of the included studies was high with positive responses for most items on the CASP checklist (see table two). Positive responses indicate that the paper has met the relevant CASP criteria for credibility and rigour. However, two of the three studies did not fully consider the

relationship between the researcher and study participants potentially introducing bias into the research process. Studies were not excluded or weighted based on quality.

Limitations

This paper is subject to limitations due to the small number of studies included; it is therefore difficult to conclude that the findings are truly generalizable of the wider population of VV patients. In addition there is a lack of information provided by the included papers to describe the demographics of their participant populations. All papers provide the percentage of male to female participants, and the age mean and range. However, neither Palfreyman et al, or Franz and Wann-Hansson offer any descriptors, such as age or gender, about the quotes from participants. Hudson et al for one quote inform the reader of the gender of the participant, and for another quote they describe the period of time the participant had had their symptoms for. This lack of information makes it difficult to appreciate whether specific themes are more or less likely to be relevant to certain groups of participants, for example men or women, or if they occur due to the length of time symptoms have been experienced for.

Table One: Table of Included Studies

Author and Year	Country	Research Design	Method of Analysis	Aims and Objectives	Sample	Diagnosis of Participants	Eligibility Criteria	Main Findings
Franz and Wann-Hansson (2015)	Sweden	Exploratory qualitative study with phenomenological approach	Phenomenological Reduction	To describe the experience of living with VV classified according to CEAP as C4 and management of the disease in daily life.	12 (Purposive sample) Age 56 (mean) (range 32-72) Gender (42%male) (5/12)	VV (CEAP class 4)	Patients with VV C4, not previously treated surgically >18 years Who spoke and understood Swedish. Excluded pregnant women and patients with recent DVT.	The essence meant adapting to a life with VV, relieving discomfort from legs with an unfavourable appearance. Coping with discomfort involved dealing with the disease emotionally and finding strategies that helped to relieve symptoms; however, living with 'repulsive' legs was seen as embarrassing, and many found the need to hide their condition.
Hudson et al (2015)	UK	Qualitative semi-structured interviews (qualitative section of a mixed methods study including an RCT)	Thematic Analysis	To gain insight into the experience of living with VV undergoing minimally invasive surgery.	20 (4 from each arm of the wider RCT) Age (mean) 50.8 years Gender (30%male) (6/20)	Patients with VV undergoing minimally invasive treatment under local anaesthesia.	Inclusion: Patients aged 18–80, receiving endovenous thermal ablation (EVLA), TransLuminal Occlusion of Perforators (TRLOP) and/or phlebectomy for the treatment of VV. A good understanding of written/ spoken English. Exclusion: leg ulcers or were receiving micro sclerotherapy or foam sclerotherapy.	Four themes captured (1) negative emotions associated with symptoms, (2) unpreparedness for the surgical process, (3) feeling cared for and (4) improvements in well-being. An overarching theme of relationships was identified. VV had a detrimental impact on QoL prior to surgery. Post-surgery QoL improved.
Palfreyman et al (2004)	UK	Qualitative using semi structured interviews.	Framework Analysis	To explore patients' expectations and reasons for seeking treatment for VV. The exploration of symptoms associated with VV and impact on QoL.	16 (purposive sample) Age (mean) 51 years (range 20-75) Gender (19%male) (3/16)	VV patients referred to vascular surgeons from GP's.	Inclusion: Those with VV who did not have serious complications (e.g. ulcers or bleeding) or significant risk factors (e.g. DVT or fractures). No age restriction.	Participants attributed a wide range of symptoms to their VV, and were actively seeking treatment with the expectation that they would gain symptom relief. The symptoms attributed to VV had a significant negative impact on QoL and lifestyle. Improving the cosmetic appearance of their legs was seen as a secondary benefit.

Table Two: Quality Appraisal using CASP checklist

Paper	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was data collected in a way that addressed the research issue?	6. Relationship between researcher and participants considered?	7. Have ethical issues been taken into consideration?	8. Rigorous data analysis?	9. Clear statement of findings?	10. How valuable is the research?
Franz & Wann-Hansson 2015 Journal of Clinical Nursing	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Of value
Hudson et al 2015 Journal of Clinical Nursing	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Of value
Palfreyman et al 2004 Journal of Clinical Nursing	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Of value

Themes

Five overarching themes were identified; physical impact of varicose veins, psychological impact, social impact, adapting to VV and reasons for seeking treatment. Within these main themes further sub-themes were identified (Table three).

Table Three: Themes identified from included papers

	Palfreyman et al 2004	Hudson et al 2015	Franz & Wann-Hansson 2015
1. Physical impact	✓	✓	✓
Symptoms	✓	✓	✓
Heaviness	✓	✓	✓
Itching	✓	✓	✓
Pain	✓	✓	✓
Swelling	X	✓	✓
Other Symptoms (phlebitis, tiredness)	✓	✓	✓
Sleep	✓	X	✓
Management of symptoms	✓	✓	✓
Coping Strategies	✓	✓	✓
Compression	✓	X	✓
Analgesia	✓	X	X
Elevation	✓	✓	✓
Physical Function	✓	✓	✓
Limitations	✓	✓	✓
Work	✓	X	✓
2. Psychological Impact	✓	✓	✓
Worry/Anxiety	✓	✓	✓
Future Health Problems	✓	✓	✓
Deterioration	✓	✓	✓
Appearance	✓	✓	✓
Personal Feelings (embarrassment, self-conscious, disgust)	✓	✓	✓
Reactions of Others	✓	✓	✓
Self-Image/Self-esteem	X	✓	X
3. Impact on social functioning	✓	✓	✓
Restrictions	✓	✓	✓
Relationships	✓	✓	✓
4. Reasons for Seeking Treatment	✓	✓	X
5. Adapting to VV	✓	✓	✓
Life Adaptations	✓	✓	✓
Clothing Adaptations	✓	✓	✓

Physical Impact

The physical impact of varicose veins was evident across all three included papers, as were the sub themes of symptoms, management of symptoms and physical function.

Symptoms

Descriptions of pain, heaviness and itching are common to participants in all three studies with swelling reported in two papers. Cramps, tingling and numbness are also reported as troublesome symptoms (Franz and Wann-Hansson 2015) reflecting the broad range of physical symptoms described across the three papers. The symptoms often had an impact on other aspects of life such as sleep, resulting in participants feeling tired. The distress associated with symptoms is clearly described by some study participants:

“They drive me mad, absolutely mad with the itching. I’ll scratch them and scratch them that much that I make them like, you know scratch marks, I make them bleed with the scratch marks.”

Participant 13 – Palfreyman et al

“It used to affect everything I would do, every day.....it was really awful....my legs were so sore and uncomfortable.” Patient 14 – Hudson et al

While for others the symptoms appear to be less troubling.

“They weren’t painful exactly, but erm at the end of the day I would be conscious of them, like they were achy, you know, not painful” Patient 9 – Hudson et al

Management of Symptoms

All three papers offered descriptions of how participants adopted different strategies to manage the impact of their symptoms. The main coping strategies employed were elevation of legs and the use of creams, ointments and compression hosiery but where these were ineffective or inappropriate individuals called upon their own internal resources.

“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.” Patient 14 – Hudson et al

“I put cream on, you know soothing cream like calamine and stuff like that and that volterol gel, that’s quite good.” Participant 5 – Palfreyman et al

'Strategies for relief were not only instrumental measures, such as the use of compression stockings, ointments, elevation of the leg and proper shoes....but also were inherent in the power of thoughts, as was described in learning to live with discomfort and acceptance of the disease.' - Franz and

Wann-Hansson

The use of compression hosiery was viewed differently in the two studies that comment; Franz and Wann Hansen while acknowledging the difficulties involved in wearing compression hosiery report benefits in reducing swelling and suggest, that for some individuals, the use of stockings is crucial to getting everyday work done.

"I feel that the leg becomes a little more swollen when I don't have the stockings on, especially down here where the socks end it may be more pronounced if I don't have the compression stockings on." -

Informant 4 Franz and Wann-Hansson

In contrast Palfreyman et al report a widespread dissatisfaction with the use of compression hosiery by patients which to some extent seems to be shared by clinicians.

"The doctor [at the outpatient clinic] asked if I used stockings. I said there a waste of time. He says 'You think so? I'm inclined to agree with that'. I says 'They're useless. They don't stop up, you want a blummin' suspender belt or som'at to hold 'em up. Absolutely useless'. So I tried them up to knee, like pop socks, and when you had them on for a bit, well they give you some right pain, you know where the veins swell? When you've had 'em on a bit, they're so tight stockings, your glad to get home and get 'em off." – Participant 1 Palfreyman et al

Palfreyman et al also noted the use of analgesia to manage pain and discomfort, with one participant describing the use of a range of non-steroidal anti-inflammatories (NSAIDs) with varying effects and another participant using paracetamol/ codeine combinations.

The management of symptoms theme is directly linked to the 'Adapting to VV' theme as all three papers report how participants make life adaptations, as well as practical ones to relieve symptoms, in an effort to cope with a life with VV.

Physical Function

None of the papers identified that VV had an impact on specific activities of daily living such as personal care or housework; however they clearly showed that participants were subject to limitations in their lives, for instance being able to participate in leisure activities, walking distances or exercise. These restrictions sometimes resulted from a physical inability to undertake activities but some individuals, while physically able, accepted limitations to their activities due to the

appearance of the VV. The consequences of the impact of VV on physical function were best described as 'not being able to live life fully' (Franz and Wann-Hansson).

"I found that they (my legs) get very tired and heavy if I am on my feet for too long, or I have to walk too far, so it was always at the back of my mind, that my legs were too sore if I did too much...."

Patient 20 – Hudson et al

Two papers (Palfreyman et al, Franz and Wann-Hansson) identified that VV could affect the work lives of participants. Franz and Wann-Hansson found both those that were still working, and those that were now retired, spoke of the struggle of coping with symptoms and trying to find relief at work. Palfreyman reported employment was affected for a female participant due to her concerns about the appearance of her VV and associated clothing restrictions.

'She felt that any job that did not allow her to wear trousers meant that she would be unable to take up any job offer.' – Palfreyman et al

The theme of adaptation is again relevant to discussions about work as people tried to make adaptations in order to work.

"Well I have been thinking about the work situation...if it's possible to perhaps change the length of the period and the length of working hours during the day and if you can do something about it."

Informant 9 - Franz and Wann-Hansson

Psychological Impact

Psychological impact encompassed sub-themes of worry/anxiety and appearance. In all studies participants expressed worries about deterioration of VV and the risk of future problems such as venous leg ulcers or deep vein thrombosis. This anxiety was sometimes rooted in experiences of family or friends.

'There was also a feeling amongst the participants that if they had surgical treatment it would prevent any further deterioration....' – Palfreyman et al

"Well, then the thoughts came that it could be something like that (ulcers) which is starting"

Informant 4 - Franz and Wann-Hansson

"I noticed a scratch and I was very worried about opening some skin or something, you know, and possibly getting an ulcer." Patient - 10 Hudson et al

The psychological effect of VV was also related to appearance; this was reported in all three papers and included personal feelings of embarrassment, disgust and feeling self-conscious.

“I think that that’s the thing that bothers me the most that I don’t like the look of them at all. I think that the symptoms aren’t really drastic, but I think that it’s the look that I dislike most.” Participant 4

– Palfreyman et al

“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

There was also the impact of the reactions of others, or the worry about a potential negative reaction.

“...because I don’t like being stared at and laughed at for something that I can’t particularly help. And they’ve upset me many a time when I was younger. They called me a freak and things for having them. And a lot of people would stare at them and make noises at me.” Participant 11 – Palfreyman

et al

“It’s more psychological that I think people are staring at my knees” Informant 12 – Franz and Wann-Hansson

“I was very conscious of them and wouldn’t wear shorts or skirts for a long time....I guess they weren’t that obvious to other people, but to me they were disgusting and I just felt more comfortable in trousers...or at least thick tights.” Patient 2 – Hudson et al

These issues contributed to negative self-image and self-esteem for participants, both male and female. Again there is a link to the theme of adaptation as the cosmetic impact of VV led to people adapting clothing to ensure they covered their VV; in addition they also altered the activities they took part in, such as sports and swimming.

“You do not want to walk among people....and show your legs” Informant 3 – Franz and Wann-Hansson

Social Impact

Impact on social functioning consisted of the sub-themes of restrictions and relationships. All papers highlighted that participants had faced restrictions in their social lives. For some this had led to a degree of social isolation due to being unable, or unwilling, to participate in leisure activities or exercise.

“But everyone I meet says, ‘Can you come and exercise with us? It’s more fun when we are more people.’ But I can’t. I’ve tried twice. I have several friends who exercise twice a week.” Informant 2 –

Franz and Wann-Hansson

‘If any activity meant that they (participants) would have to expose their legs to public view they would cease to be involved.’ – Palfreyman et al

The social impact of VV is further illustrated by Hudson et al who describe study participants reporting the positive effects of surgery in terms of the removal of restrictions, allowing full engagement once more with life and others around them.

There was also discussion of the impact on relationships. All papers reported that the negative emotions participants had experienced due to the appearance of their VV directly influenced how they perceived and interacted with others both within a wider social context.

“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

Hudson et al also noted an impact on close personal relationships.

‘One participant reported that her symptoms influenced her interactions with her husband, leading to tensions in their relationship.’ Hudson et al

Reasons for Seeking Treatment

This theme was common to two papers (Palfreyman et al, Hudson et al), it should be noted that in one paper (Palfreyman et al) exploring reasons people seek treatment was a specific objective of the study. Both papers identified that a primary reason for seeking treatment was symptoms relief or to prevent worsening of their VV and the possibility of other complications.

“One of my friends’ mothers had a lot of problems with her veins, I think she had an ulcer and I remember all the trouble that caused. I didn’t want something like that happened to me, so that spurred me on to get treated.” Patient 12 – Hudson et al

“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

It was noted that expectations for the effectiveness of treatment were often unrealistic (Palfreyman et al). Ameliorating the cosmetic appearance was a secondary consideration despite this being commonly reported across the papers as having a distressing psychological and social impact.

Adaptation

Adaptation was a common theme across all papers with many different kinds of adaptations noted. Overwhelmingly these were life adaptations such as changing activities due to the impact on physical function or coping strategies to deal with symptoms and adapting work situations.

“Well, I have been thinking about the work situation...if it is possible to perhaps change the length of the period and the length of working hours during the day...” Informant 9 – Franz and Wann-Hansson

Adaptations can be broadly classified as negative, for instance when an activity was given up due to the difficulties associated with it, or more positively

‘When it came to interests involving physical activity and exercise, the informants tried to find alternative activities that they could do despite their leg problems.’ – Franz and Wann-Hansson

In addition it also appears in relation to the theme of psychological adaptation as in all papers there was mention of participants adapting what clothing they wore to disguise the appearance of having VV and the subsequent negative emotions this caused.

'Many participants reported shame regarding their legs and took measures to avoid exposing them in public, often at cost to their comfort.' – Hudson et al

'Those who had been living with VV symptoms for a long time had different methods to conceal their unattractive legs. For example, covering the legs with long pants or a sarong in the summer was one way of hiding them.' – Franz and Wann-Hansson

'In addition to the impact on their activities, the cosmetic appearance of their legs also influenced the type of clothing worn by participants.' – Palfreyman et al

Discussion and synthesis of emergent themes:

The findings of the review have been discussed with reference to the domains used in PROMS that have undergone some form of validation in populations with VV. This approach was taken as PROMS are regularly used to support clinical decision making but there is perhaps an over-reliance on using instruments such as PROMS and a lack of qualitative research examining the experiences of patients with VV. In our synthesis we identify physical, psychological and social impact alongside reasons for seeking treatment and adaptations as the five key themes that should be addressed in the design of future PROMs and in the provision of care to patients with varicose veins.

Physical Impact

The range of physical symptoms reported across the three papers is varied, for example swelling is not mentioned by Palfreyman yet appears strongly in the other two included papers; in addition swelling is also a domain in both of the VV specific PROMs (AVVQ and VVSymQ).

The degree to which people were bothered by symptoms of VV such as pain also varied widely both within and across the papers. For some the symptoms appeared to make the participants 'aware' of their VV whilst for others the pain could be debilitating resulting in restrictions to their lives and requiring the need for active management.

The diversity and impact of the symptoms reported across the three papers demonstrated that there is no definitive list of VV symptoms, and that not all symptoms affect everyone in the same way.

The subjective nature of symptom experience has implications for the use of PROMS as specific symptoms may not be included in the PROM, for example worries about the appearance of VV, or there may symptoms, such as itching, that are included that are not typical to all patients. There are also implications for clinical decision-making due to the difficulty in measuring symptoms of VV, as NICE guidance for the management of VV states; QoL measures are unlikely to reflect severity of disease because of variations in perception of symptoms.

The variety of descriptions of practical day-to-day symptom management across the papers highlighted the variety of methods that VV patients employed. This may demonstrate a deficit of information available to patients about the most effective means of symptoms control, and the importance of adherence to recommended management options.

Compression hosiery is widely used as first-line treatment for VV symptomatic management (NICE) yet NICE VV guidelines acknowledge that the current evidence of any benefit, in terms of symptom

relief, QoL improvement or preventing disease progression, is weak and that there are many issues around compliance. A Cochrane review (Shingler et al 2013) also cited insufficient and poor quality evidence for the effectiveness of compression hosiery though reporting subjective symptomatic improvement where assessed. The result of this is that the guidance about the use of compression hosiery is ambiguous.

Inconsistency in the use of compression hosiery is demonstrated in this review as the two papers that covered it offered contradictory points. The patients in Franz and Wann-Hansson appeared to have more positive experiences of the use of compression than those of Palfreyman. What is not clear is whether this differentiation could be due to lack of compliance, lack of understanding of the benefits of compression or using incorrectly fitted compression hosiery.

Low adherence to the wearing of compression hosiery, and potential complications, has been studied (Palfreyman and Michaels 2009); with discomfort appearing to be the main reason for lack of compliance.

It would appear that health care professionals need to be properly trained in the fitting of compression hosiery, and for them to discuss the potential benefits for symptomatic relief with patients, in order for patients to potentially receive benefit from them.

Physical function was not reported to be noticeably affected by VV in any of the papers, however limitations were discussed. The lack of clear physical impact may be a contributing factor in the reluctance of NHS trusts to fund VV surgery if the assumption is that lack of measurable restriction does not merit costly, and not necessarily fully effective, intervention.

The generic PROM (SF-36) used in the VV population, and one of the VV specific instruments (AVVQ), both have 'physical function' domains; however the findings in this review would appear to show that this may not be a particularly relevant domain to patients. The SF-36 does include a domain for physical limitations which based on the findings reported in the included studies with regard to the physical impact of VV is perhaps more applicable.

Psychological Impact

The psychological impact of living with VV appears strongly in this review, with all three papers demonstrating a significant impact. Fears of further deterioration and future problems such as developing venous leg ulcers (VLU) or deep veined thrombosis (DVT) were common in many patients across all papers; this common anxiety has been described as an 'exaggerated sense of risk from VV' by NICE (2013). There appears to be little reliable evidence about the proportion of VV that progress

to VLU with perhaps only an estimated 3-6% of people with VV affected (Nelzen 2008). Ensuring patients are well informed about their VV condition and about the risk of other complications may go some way to mitigating unnecessary worry and anxiety.

Neither of the VV specific PROMS include domains that would enable VV patients to report relevant psychological, emotional or mental impacts, relevant to the anxiety and worry reported in this review. The SF-36 however does include domains that capture both emotional and mental health.

The significance of the cosmetic appearance of VV has perhaps historically been trivialised in comparison to the impact of symptoms, however this review has found that appearance was a significant psychological issue for patients. All three papers highlighted feelings of distress and embarrassment felt by patients due to the look of their VV. This was both due to their personal perception and the reactions of others.

In the NICE vascular referral guidelines 'body –image concerns' is included as an important measurable outcome of patient-assessed symptoms and 'appearance' is included as a domain in the AVVQ; however it would not be specifically captured by either the VVSymQ or the SF-36.

Social Impact

Social function was clearly found to be affected in all papers, often leading to varying degrees of social isolation. The impact of some VV symptoms resulted in some participants being unable to undertake usual leisure activities and hobbies. For others it was down to avoidance due to a reluctance to expose their VV.

In both cases the outcome of social isolation prevented people from living their lives fully, and often had implication for personal relationships with partners, friends and family. It would appear that there is potentially a close link between social and psychological impact, with social isolation contributing to feelings of low mood. Impact of VV on social activities is measured by both the SF-36 and the AVVQ.

Reasons for Seeking Treatment

Symptom relief rather than the cosmetic appearance was the primary reason for seeking treatment in the two papers that explored this theme.

Existing literature demonstrates that improvement in symptoms is a common, yet potentially unrealistic, expectation. Dillon et al (2005) reported that 75% of participants expected VV treatment

to improve their symptoms, whilst Darvall et al (2009) found that 100% of their participants had expected some improvement following treatment yet 20% had unmet expectations.

If patients feel that their treatment has not met their expectations this is likely to have an impact on their QoL. Clinicians need to ensure that all patients are fully informed about potential benefits and risks of treatment, including the fact that they might need more than one treatment, they may have a reoccurrence, and they may develop new VV in the future.

Adaptation

Participants adopted a wide range of adaptations in order to continue to live their lives as fully as possible. This was seen in all aspects regarding the impact of VV on QoL physically, psychologically and socially.

Some adaptations may be characterised as passive, for instance when an individual stops doing something because of pain or appearance, whereas other adaptations are positive – rather than stopping exercise because of appearance or discomfort a new form of exercise is adopted.

The ability of VV patients to positively adapt to their condition and make the adjustments necessary to continue working and otherwise safeguard their health and wellbeing is one suggested reason for the perception of VV as a cosmetic condition (Franz and Wann-Hansson).

An expectation of successful treatment may be that there would no longer be a need to adopt these adaptations thus leading to a resumption of 'normal' life.

No available PROM, validated for VV populations, currently exists that would capture how patients adapt their lives to their condition. It is only by using qualitative methods that capture the true subjective experience of patients that we can see that this overwhelming aspect of their lives.

Conclusion

Health-related quality of life, patient-assessed symptoms (including pain, discomfort, body image concerns, swelling, aching, and heaviness), and progression have been cited as the most important outcomes to identify which people would benefit from a referral to a vascular service (NICE 2013).

The use of PROMS to gather such information is well established but as this review has shown those PROMs currently validated for use with patients with VV, both generic and condition specific, may not capture the full extent of the impact of VV on patient's QoL.

Clinicians involved in the care of patients with VV, and those involved in planning vascular service provision, need to be as familiar as possible with the lived experience of such individuals in order to provide a patient centred service.

Familiarity with qualitative research methods and findings would allow clinicians and commissioners of care to have a more in-depth understanding of the range and severity of symptoms experienced by patients, and to interpret the results of PROMs in the wider context of the lived experience of people with VV.

References

- Black N (2013) Patient reported outcome measures could help transform healthcare. *BMJ* 2013; **346**:f167. [doi:10.1136/bmj.f167](https://doi.org/10.1136/bmj.f167)
- Carroll C, Booth A. Quality assessment of qualitative evidence for systematic review and synthesis: Is it meaningful, and if so, how should it be performed? *Res Synth Methods* [Internet]. 2014;(August): Available from: <http://doi.wiley.com/10.1002/jrsm.1128>
- Critical Appraisal Skills Programme (CASP) 2014. CASP Checklists (<http://www.casp-uk.net/checklists>) Oxford. CASP
- Darvall KA, Bate GR, Sam RC, Adam DJ, Silverman SH, Bradbury AW. Patients' expectations before and satisfaction after ultrasound guided foam sclerotherapy for varicose veins. *European Journal of Vascular and Endovascular Surgery*.2009; 38(5):642-647
- Dillon MF, Carr CJ, Feeley TM, Tierney S. Impact of the informed consent process on patients' understanding of varicose veins and their treatment. *Irish Journal of Medical Science*.2005; 174(3):23-27
- Duncan, R., Booth, A., Woods, H., Essat, M., Phillips, P., Poku, E., Kaltenthaler, E., Jones, G. and Michaels, J., 2016. Understanding the experience and impact of living with a vascular condition from the patients perspective: a qualitative evidence synthesis protocol
- Evans CJ, Lee AJ, Allan PL, Ruckley CV, Fowkes FG. Incidence and risk factors for venous reflux in the general population: Edinburgh Vein Study. *European Journal of Vascular and Endovascular Surgery*. 2014 Aug 31;48(2):208-14.
- Evans CJ, Fowkes FGR, Ruckley CV, Lee AJ. Prevalence of varicose veins and chronic venous insufficiency in men and women in the general population: Edinburgh Vein Study. *J Epidemiol Community Health* 1999;53:149-53.
- Franz A, Wann-Hansson C. Patients' experiences of living with varicose veins and management of the disease in daily life. *Journal of clinical nursing*. 2015 Mar 1;25(5-6):733-41.
- Grant MJ. How does your searching grow? A survey of search preferences and the use of optimal search strategies in the identification of qualitative research. *Health Information & Libraries Journal*. 2004 Mar 1;21(1):21-32.
- Hope C, Braithwaite B.D. The Online Aberdeen Varicose Veins is an Acceptable Rationing Tool. *The Journal of One Day Surgery* 21 (1) 15-17
- Hudson BF, Ogden J, Whiteley MS. A thematic analysis of experiences of varicose veins and minimally invasive surgery under local anaesthesia. *Journal of clinical nursing*. 2015 Jun 1;24(11-12):1502-12.
- Lattimer CR, Kalodiki E, Azzam M, Geroulakos G. The Aberdeen varicose vein questionnaire may be the preferred method of rationing patients for varicose vein surgery. *Angiology*. 2014 Mar 1;65(3):205-9.

Lee AJ, Robertson LA, Boghossian SM, Allan PL, Ruckley CV, Fowkes FG, Evans CJ. Progression of varicose veins and chronic venous insufficiency in the general population in the Edinburgh Vein Study. *Journal of Vascular Surgery: Venous and Lymphatic Disorders*. 2015 Jan 31;3(1):18-26.

Lim CS, Gohel MS, Shepherd AC, Davies AH. Secondary care treatment of patients with varicose veins in National Health Service England: at least how it appeared on a National Health Service website. *Phlebology*. 2010 Aug 1;25(4):184-9.

Marsden, G., Perry, M., Kelley, K., Davies, A.H. and Guideline Development Group, 2013. Diagnosis and management of varicose veins in the legs: summary of NICE guidance. *Bmj*, 347, p.f4279.

Micheals J et al. The Design, Development, Commissioning and Evaluation of Patient Focused Vascular Services, NIHR Programme Grant. [Internet]. 2014. Available from: <http://www.nihr.ac.uk/funding/fundingdetails.htm?postid=2244>

Moher D, Liberati, A. Teetzlaff J et al (2009) Preferred Reporting Items for Systematic Reviews and Meta-Analyses. The PRISMA Statement. *Journal of Clinical Epidemiology* 62 (10) 1006-1012

National Institute for Health and Care Excellence (2013) *Varicose Veins in the Legs: the Diagnosis and Management of Varicose Veins*. London: NICE. www.nice.org.uk/CG168

Nelzen O. Prevalence of venous leg ulcer: the importance of the data collection method. *Phlebolympology*. 2008;15(4):143-50.

Palfreyman SJ, Michaels JA. A systematic review of compression hosiery for uncomplicated varicose veins. *Phlebology*. 2009 Apr 1;24(suppl 1):13-33.

Palfreyman SJ, Drewery-Carter K, Rigby K, Michaels JA, Tod AM. Varicose veins: a qualitative study to explore expectations and reasons for seeking treatment. *Journal of clinical nursing*. 2004 Mar 1;13(3):332-40.

Paty J, Turner-Bowker DM, Elash CA, Wright D. The VVSymQ® instrument: use of a new patient-reported outcome measure for assessment of varicose vein symptoms. *Phlebology*. 2015 Jul 15:0268355515595193.

Shepherd AC, Gohel MS, Lim CS, Hamish M, Davies AH. The treatment of varicose veins: an investigation of patient preferences and expectations. *Phlebology* 2010; 25(2):54-65

Shingler S, Robertson L, Boghossian S, Stewart M. Compression stockings for the initial treatment of varicose veins in patients without venous ulceration. *Cochrane Database of Systematic Reviews* 2013, Issue 12. Art. No.: CD008819. DOI: 10.1002/14651858.CD008819.pub3.

Smith, J. J., et al. "Evaluating and improving health-related quality of life in patients with varicose veins." *Journal of vascular surgery* 30.4 (1999): 710-719.

Thomas, J. and Harden, A., 2008. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology*, 8(1), p.1

Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol*. 2012;12:181.

Viera AJ, Garrett JM. Understanding interobserver agreement: the kappa statistic. *Fam Med*. 2005 May 1;37(5):360-3.

Ward A, Abisi S, Braithwaite BD. An online patient completed Aberdeen Varicose Vein Questionnaire can help to guide primary care referrals. *European Journal of Vascular and Endovascular Surgery*. 2013 Feb 28;45(2):178-82.

Ware Jr, John E., and Cathy Donald Sherbourne. "The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection." *Medical care* (1992): 473-483.

Appendix 1

Qualitative Search

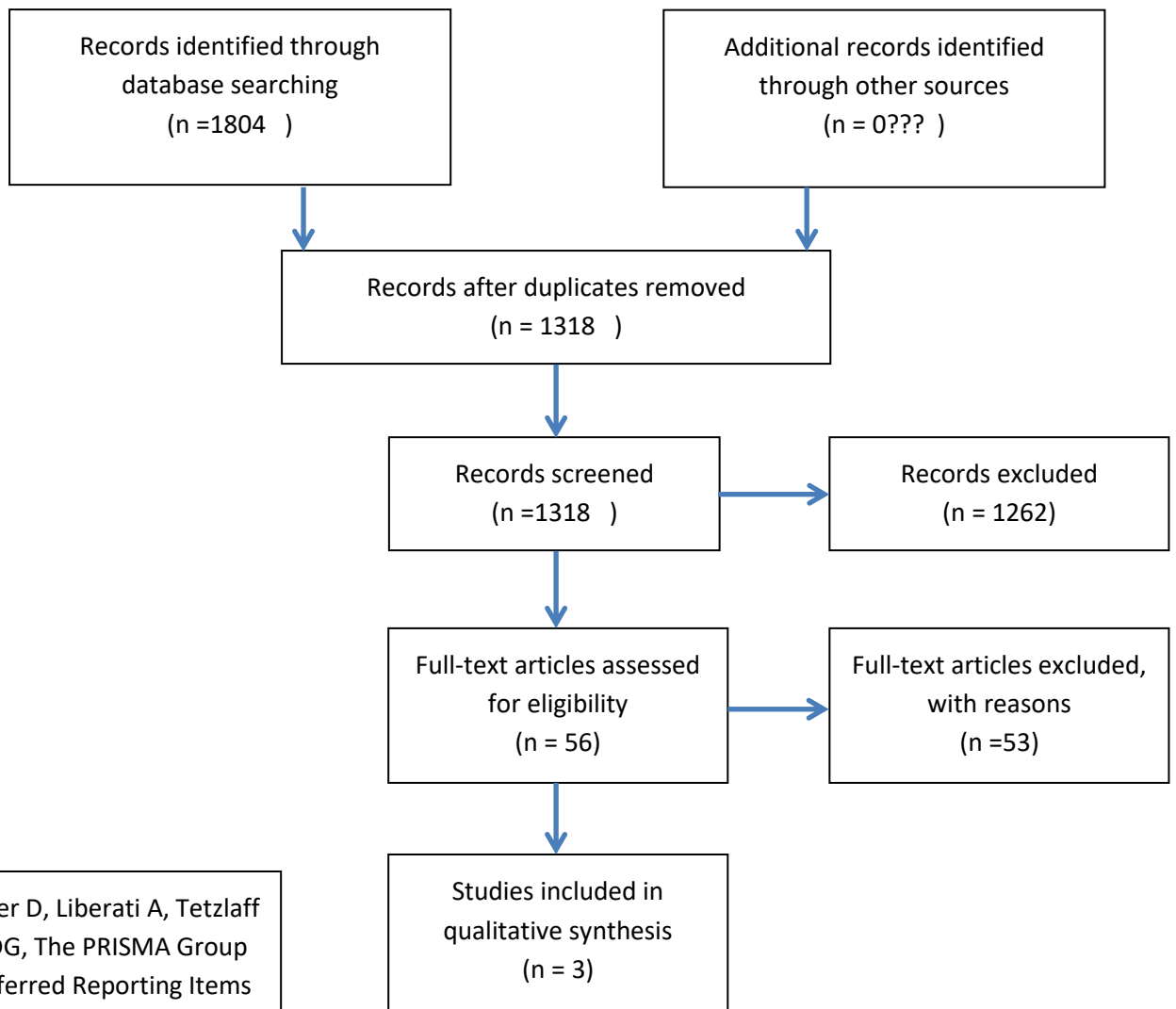
Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

-
- 1 ((Venous or vein) adj2 (disease or stasis or obstruction or incompetence or insufficiency or syndrome or thromboembolism)).tw. (25881)
 - 2 (Venous ulcer\$ or leg ulcer\$ or venous leg ulcer\$).tw. (6752)
 - 3 (Venous insufficiency or Venous incompetence or Venous thromboembolism or VTE or Venous outflow obstruction or VOO or Venous valvular incompetence or VVI).tw. (20317)
 - 4 exp Venous Insufficiency/ (6251)
 - 5 exp Varicose Veins/ (16173)
 - 6 (Venous adj2 (edema or oedema)).tw. (267)
 - 7 Venous disorder\$ of the leg\$.tw. (16)
 - 8 (Varicose vein\$ or spider vein\$ or varicosity or varices or telangiectasia\$).tw. (28766)
 - 9 Endovenous occlusion.tw. (11)
 - 10 post-thrombotic syndrome.tw. (742)
 - 11 Venous Thrombosis/ or Venous Thromboembolism/ (25218)
 - 12 or/1-11 (84718)
 - 13 *Attitude to Health/ (38618)
 - 14 *Self Care/ (13923)
 - 15 *Health Knowledge, Attitudes, Practice/ (42825)
 - 16 (patient* adj4 (feeling* or emotion* or view* or symptom* or perception* or attribute*)).ti,ab. (175843)
 - 17 ("health related quality of life" or "health related qol" or "health related ql" or hrqol or hql or "patient reported outcome*" or "patient-reported outcome*" or prom or proms or "disease reported outcome*").ti,ab. (33984)
 - 18 ("quality of life" or "qol" or "outcome measure*" or "health outcome*").ti,ab. (354573)
 - 19 *"Quality of Life"/ (60353)

- 20 *Outcome Assessment (Health Care)"/ or *Outcome and Process Assessment (Health Care)"/ (30619)
- 21 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 (632316)
- 22 (qualitative* or findings or interview*).mp. (1839410)
- 23 focus groups/ or interviews as topic/ (62635)
- 24 exp qualitative research/ (25171)
- 25 22 or 23 or 24 (1845336)
- 26 12 and 21 and 25 (714)

Appendix 2 - PRISMA Flow Diagram:



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement.