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The impact of lack of disease awareness on the experience of primary varicose veins

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Symptoms are often one of the main reasons for patients with chronic diseases to seek medical care. However, the symptoms experienced by patients with primary varicose veins are not serious until late in the course, hence rarely drawing enough attention. A deep understanding of disease awareness and experiences of patients is particularly important in disease management. The aim of this study was to describe the awareness and experience of patients with primary varicose veins. This study used a descriptive design with a qualitative approach. Semistructured interviews were conducted with 12 patients with primary varicose veins at a general central county hospital in China. Colaizzi's 7-step analysis was used to analyze the interview text. Participants reported their lack knowledge of the disease, including etiology, symptoms, and complications. Three themes emerged concerning the experiences: "preoperative emotional responses," "lack of confidence in disease management," and "the need for family and social support." The findings suggested that the health care system in China needed to increase the awareness about the disease and pay more attention to the needs of patients, give better health education, and provide effective social support, so as to improve self-management among patients. (J Vasc Nurs 2019;37:257-263)

INTRODUCTION

Primary varicose veins (PVVs) are chronic venous diseases (CVDs) caused by the loss of venous wall homeostasis; of these, the great saphenous veins account for 70%.[1] The etiology and pathogenesis of PVVs are still not fully understood. Valvular incompetence causing venous reflux is frequently observed and has long been postulated as the primary cause of venous wall weakness and dilatation.[2] Accumulating evidence shows that heredity plays a prominent role in the etiology of varicose veins.[3] In addition, age, sex, obesity, family history, and ethnicity were also considered the risk factors for the disease.[4]

The epidemiological statistics indicate that about 25% of adults worldwide have PVVs, and women have a higher prevalence compared with men.[1] The prevalence reported in China is 8.9%, with more than 100 million people affected.[5] High incidence of the disease and symptomatology also varies. For patients with mild varicose veins, the main manifestation is worm-like shallow veins in the lower extremities. As the lesion progresses, the superficial veins become tortuous with protruding skin. The lesion is more prominent while standing and may disappear in a recumbent position. Failure to timely and effectively prevent and control the disease can lead to complications such as pigmentation, lipodermatosclerosis, thrombosis, varicose vein rupture, and venous leg ulceration (VLU).[6] VLU is recognized as the most severe complication of advanced disease and contributes to a significant decrease in the quality of life, loss of labor force, and health care resource burden.[7-10] Prevention of VLUs is beneficial to both health care system and individuals.[11]

Given the scarcity of recent data, it is difficult to determine the pace of disease progression. However, some evidence indicates a higher risk of varicose veins progressing to an advanced stage of the Clinical Etiology Anatomy Pathophysiology (CEAP) classification system.[12] The CEAP classification system can reflect the clinical severity of venous diseases, and the clinical grade of the CEAP classification system is mainly divided into 0–6 grades from light to heavy.[13]

At present, the treatment of varicose veins is classified as invasive and noninvasive. Noninvasive treatment includes venoactive drugs and compression therapy. Invasive treatment includes classical surgical and minimally invasive treatment. Unfortunately, a clear system to determine which types of patients benefit the most from specific surgical interventions is lacking, and disease management varies greatly from region to region.[14] Expert consensus suggests that the treatment of PVVs should be based on the CEAP scoring system in China.[15] For patients with symptoms and no obvious venous signs (c0–c1), lifestyle changes should be adopted, and early treatment can eliminate symptoms; for patients with obvious symptoms and signs (c2–c6), surgery combined with compression or drug therapy should be adopted. The purpose of the treatment is to reduce CEAP grading; long-term compression therapy, along with drug therapy, is a mainstay of venous disease management that maximizes the postoperative efficacy.[15]

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However, the minimal adverse physiological experience in the early stage of the disease often fails to trigger the attention of patients to their condition.[16] Most of the patients with uncomplicated varicose veins are not treated at all.[17] Part of patients who come to the hospital have severe varicose veins (c3–c6).[5] One of the prerequisites of health-seeking behavior is thought to be the knowledge of the disease and its symptoms.[18] The qualitative studies on the disease awareness of patients with PVVs are limited.

The newly revised international guidelines recommend endovenous laser ablation or radiofrequency ablation for patients with CVDs having[4] symptomatic and venous reflux. However, the traditional high ligation and vein[5] stripping (HL/S) is still the mainstay of CVDs treatment in China. It can remove the superficial varicose vein and prevent its regurgitation, thus eliminating venous hypertension and improving patients' symptoms and quality of life, which is also considered as the gold standard of surgical treatment.[19] The perception of surgical treatment and the experience of postoperative disease management in patients who meet surgical criteria have not been studied.

Therefore, this qualitative study was conducted to investigate the disease awareness and experience of patients with PVVs so as to understand individual needs and provide recommendations for the implementation of more targeted health services.

METHOD

Design

The descriptive qualitative research design was adopted in this study. Qualitative research serves as a bridge between scientific research theory and clinical practice and can obtain in-depth, rich, and authentic information.[20] All participants were interviewed using a semistructured interview guide. Data were collected between October 2018 and March 2019 using purposive sampling in the department of vascular surgery of a tertiary public hospital in China. The inclusion criteria were as follows: 1) color Doppler ultrasound of lower limbs or deep venography of lower limbs confirming definite diagnosis of PVVs and clinical grading (C grading) according to CEAP standard as C2 $\sim$ C4; 2) >18 years old; and 3) high ligation of great saphenous vein combined with venous extraction. The exclusion criteria were as follows: 1) severe heart, lung, liver, and kidney dysfunction; 2) history of venous ulcer; 3) superficial venous thrombosis, peripheral artery disease, nonvenous symptoms; 4) history of lower limb varicose vein surgical treatment; 5) pregnant and lactating women; and 6) patients with cognitive, visual, or hearing impairment.

Data collection

The original interview guide was formulated based on the research aim and a literature review, and the opinions of several vascular surgery experts with rich experience. The first author worked as a primary nurse in the setting. Before the formal interview, 2 pilot interviews were conducted, the process was reviewed, and the interview guide was revised. All the interviews were conducted face-to-face in Chinese (Mandarin) by the first author in the chief nurse's office. The interview did not need to be confined to the outline but could be flexible according to the situation.

Before each interview, the researcher explained the content, purpose, and privacy of the study to the participants. After collecting sociodemographic data (age, marital status, the highest record of formal schooling, and the occupation) of patients, the interview was conducted.

To enrich the study and obtain more comprehensive information, the participants were selected with different ages, occupations, levels of education, disease stages, and treatments. All the interviews were audiotaped (range: 24–42 minutes, mean: 33 minutes), and the participants' nonverbal behaviors, such as facial expressions and body language, were recorded in field notes. The interviews were transcribed verbatim, and data analysis was carried out simultaneously with data collection to identify the initial themes. Data saturation was achieved at interview 10, but the researchers continued on data collection by conducting 2 more interviews to ensure data saturation.

Therefore, a total of 12 individuals participated in this study.

Data analysis

Recorded interviews and observation materials were transcribed within 24 hours of the interview; all audiotapes were transcribed verbatim (using anonymous participant identifiers). The data were analyzed by Giorgi's phenomenological analysis method: 1) the interview records were repeatedly read; 2) significant statements were extracted; 3) the recurring point of view was coded; 4) the views of the code were collected, forming a theme; 5) a detailed and exhaustive description was written; 6) similar points of view were summarized; and 7) the recorded information was verified with participants. The researchers' own experience was avoided in the analysis, and the exemplars in the data were constantly sought and used.

Rigor

Interviews were conducted by professionally trained personnel. The interviewers checked with the participants to make sure that they correctly understood the questions during the interviews. They also repeated back to the participants their understanding of the answers. After the interview, the interviewer transcribed the responses into text, translated them with the help of an English teacher, and imported them into NVivo (a qualitative data analysis computer software package). The results were independently coded by the interviewer and a psychological consultant, and interpreted. The final results were agreed on by the research team.

Ethical considerations

The ethics committee from the hospital approved the study. All participants were fully informed about the study. The voluntary and confidential nature of the study was stressed, and the interviewers had the right to withdraw from the study at anytime. In addition, the fact refusal or withdrawal from the study would not influence the care the patients received was also emphasized. Verbal and written consent forms were obtained before the interviews.

RESULTS

A total of 12 participants were included in this study. They were all married. The participant's age varied from 29 to 72 years, with an average of 51.2 years. Varicose symptoms lasted from 2–3 years to more than 30 years.

Awareness of PVVs

Theme: Lack of knowledge. This theme was reflected mainly in the following 3 aspects: etiology, symptoms, and complications.

Etiology—Among the 12 participants, about one-half of the participants (50%; 6/12) had no knowledge about the etiology of the disease, whereas some had a vague understanding of the etiology based on their environment and experience. One of the participants even classified it as a common disease of the elderly.

> "I worked as an electric welder for 10 years when I was young, and I had to squat there for a long time, which I felt was the reason." (case 5)

> "It seems that all the old people there have this disease. The blood vessels have been used for a long time, which always causes some problems (laughter)." (case 1)

Participants also reported possible associations of the varicose vein with childhood habits.

> "May be related to my childhood, when the summer was very hot, I washed my legs with well water, and then I often had cramps at night." (Case 10)

A quarter of the participants (25%; 3/12) were able to approximate that the disease might be related to prolonged standing, sitting (n = 2) (cases 8 and 12), obesity (n = 1) (case 8), pregnancy (n = 1) (case 12), and heredity (n = 1) (case 9).

Symptoms—The most representative clinical symptom of varicose veins is the worm-like tortuous venous masses on the lower extremity surface, which can be recognized even by people without medical background knowledge. The CEAP at c2–c3 participants reported mild symptoms, with little impact on life, which has not received much attention. However, participants with a higher reoccurrence of symptoms (CEAP at c4) failed to attribute some symptoms to vascular problems.

> "So far, my symptoms are not serious. The doctor said that I have some itching now and need to be hospitalized. I always think it's because I've had a shower in the winter and my skin is dry and I don't have moisturizers." (case 7)

Surprisingly, some participants even thought that these symptoms were merely manifestations of skin diseases.

> "My right leg was really itchy some time ago. I went to the hospital to see the dermatologist. The doctor prescribed some topical drugs and told me not to eat pungent food such as chili, fish, and shrimp. But then the symptoms got worse and I now don't think it was caused by eczema." (case 3)

Complications—Lack of awareness of varicose vein complications was common among participants.

> "Complications with varicose veins?… I don't know about this. I know there are many complications from diabetes." (case 6)

As the disease was attributable to vascular problems, one of the participants took it for granted that :

> "It may be that the long duration of varicose veins leads to vascular erosion, affects large blood vessels, and leads to hypertension and heart problems." (case 1)

Only 2 participants were able to describe it vaguely based on the same symptoms reported in friends and neighbors, although they did not refer specifically to the terms VLUs or superficial thrombophlebitis.

> "…and then his lower limbs started turning black; development of ulcers was noted with watery fluid often oozing out of them. The wounds needed to be covered with a cloth in summer; otherwise, flies would sit on them. I don't know if it's a complication" (case 2)

> "My colleague was suffering from varicose veins before, and then the place where the veins protruded turned red, became hard, and the blood vessels were blocked. … Maybe this disease should be treated earlier, or I wouldn't come to the hospital this time." (case 4)

Experience of PVVs

Theme: Preoperative emotional response. Varicose veins were widely recognized as "probably not a serious problem," but the patients were aware that years of illness could be a concern, which might have contributed to their seeking help at the hospital. When told by the doctor that surgical treatment was needed, these participants showed different emotional reactions.

Surprise and fear—Part of the participants believed that the disease did not reach the level that required surgery. Surprise was observed in most participants.

> "…not completely like normal people, do what things always feel there is something restricting you, the disease may be a hidden danger, I want to come to the hospital to solve this danger as soon as possible, but I think it should not be necessary to do surgery!" (case 6).

The participants had fear and unpredictability of impending and inevitable surgery.

> "I heard that the surgery would remove all the protruding veins on my legs. I must feel very painful, and I would walk like a cripple without blood vessels in my lower limbs." (case 7)

Entanglement and worry—A certain risk of recurrence exists after varicose vein surgery. The lack of information and awareness of the participants, coupled with the poor communication

between doctors and patients, led to different degrees of suspicion about the operation effect. The participants had a postoperative recurrence of varicose veins as a factor of entanglement and worry.

> "Some people in our factory also had varicose vein surgery in the local small hospital, but after a few years, the vein bulged again, and I felt that the surgical effect was not very good, the doctor told me to have an operation, but I did not know whether it was necessary (tangled)."(case 10)

The participants with weak financial status experienced certain financial burden because of the cost of surgical treatment.

> "We are all farmers. How much money can we have? One leg surgery costs nearly 10,000 yuan." (case 3)

Varicose veins have long been considered a cosmetic problem. Therefore, they were more concerned about the cosmetic effect of surgical treatment.

> "I'm afraid I've had surgery on my back legs and it might look worse than my legs right now." (case 12)

Expectation

In the interview, only one participant showed his expectation according to the successful cases of other people's surgical treatment.

> "My neighbor … did the same surgery in this hospital last month. His leg symptoms are worse than mine, and now he is recovering well." (case 2).

Theme: Lack of confidence in disease management. Chronic diseases require long-term disease management. The most common postoperative management for patients with PVVs was elastic stockings and lifestyle changes. For the most common disorders in disease management, the patients wore elastic stockings for a long time and were not optimistic about the effect, weather, and physical and psychological symptoms.

> "Finish an operation to wear elastic stockings at least half a year even, wear these stockings really useful? and I can still wear them in winter. It's so hot in summer, I may not be able to hold on. Besides, it's a shame for a man to wear them." (case 4)

Some of the participants were middle-aged and had been engaged in a work that required standing for a long time. Faced with the financial burden, they lacked confidence in long-term lifestyle changes after surgery (especially avoiding standing for long periods of time).

> "What we work in the factory is that we need to stand for a long time. Now our son is not married (frowning), and the family needs money. If not, well, let's just take it 1 step at a time." (case 9)

Theme: Need family and social support. Family supervision and help—Participants were asked to determine how they could improve their disease management skills; most often they described it with the help from family members. One participant believed that long-term family supervision and support were required to make them pay more attention to behavioral changes.

> "This disease has something to do with my daily lifestyle. If someone reminds me to wear elastic stockings every day and rest more, I will certainly pay attention to it."(case 8)

For patients, especially older patients, donning and doffing had some difficulties. Such patients said that wearing was more dependent on the help of family members.

> "This sock is very tight, I can't pull it up by myself, and I may need some family friends to help me wear it." (case 11)

Professional guidance—In the interview, the participants described different ways to acquire knowledge. They all had little access to information, could not judge the authenticity of the information, and even had some superstitions. Almost all participants were eager to seek professional help.

> "Many people in the countryside suffer from this kind of disease, and it can't be cured well. It feels like a knotty problem. We are illiterate. A lot of that information comes from neighbors, occasionally watching TV or listening to the radio. I think this disease should be publicized on TV, and medical staff should have more time to tell us about the prevention and treatment of this disease." (case 1)

> "I read medical books, but I didn't see the disease. There are many opinions on the Internet. I don't know which one is right. Is there any reliable website or WeChat platform that can be recommended to us? In this way, we can learn by ourselves and more people can learn about this disease." (case 12)

DISCUSSION

This study offered novel insights into the awareness and experiences of patients with PVVs in China. The findings showed that participants generally lacked relevant knowledge, which was similar to the research results reported by Wellborn et al.[21] It might be related to 3 aspects: 1) Vascular surgery started relatively late in China, and a few medical professionals in this field were available.[22] 2) The medical staff did not have enough knowledge of the severity of the disease, ignored the seriousness of the problem, and failed to provide timely, effective, and comprehensive supportive education to patients. 3) Compared with chronic diseases such as hypertension and diabetes, the awareness of patients with PVVs is low, and the prevention and management system has lagged behind.

The government, media, and relevant departments should pay more attention to PVVs and disseminate more knowledge about disease risk factors, clinical symptoms, and impact on health. For one thing, the high-risk groups who stand for a long time should

improve their awareness of prevention and reduce physical labor intensity, avoid long-term standing, and wear elastic stockings at work. For another, patients with symptoms should seek medical advice as soon as possible. Considering the characteristics of this population, part of the participants in this study were farmers and workers with a low education level. A low education level can interfere with the assimilation of the content transmitted by health care professionals.[23] Therefore, science popularization skills need to be improved.

The disease information is conveyed directly to patients by means of illustration and text so as to improve disease awareness among patients. China needs to establish a management platform based on medical institutions and provide patients with reliable information through relevant websites and WeChat platform so that they can be more aware while encountering problems.

Four of the participants in this study were from rural areas. For those with financial constraints, social assistance should be sought. Support can be provided by increasing the reimbursement share of medical insurance or reducing part of medical expenses in hospitals so as to reduce the pressure on patients.

Improving medical technology

Varicose vein treatment has evolved rapidly. Minimally invasive therapy may become a trend of future treatment, but with a certain risk of recurrence compared with surgery.[22,24,25] The causes of recurrence are complicated. In addition to differences in surgical options,[26] postoperative living habits and wearing elastic stockings are also related to variance in long-term outcomes.[27] From another perspective, they may be related to the imperfect preoperative examination and unclear diagnosis by nonspecialized medical staff. Secondary varicose veins caused by iliac vein compression syndrome and Budd-Chiari syndrome need to be considered.[28,29] Regular and targeted training on standardized diagnosis and treatment of CVDs should be organized for nonspecialist doctors. Improving awareness of nonspecialist doctors on CVDs is essential for the early detection, diagnosis, treatment, and long-term standardized management of diseases. Vascular surgeons also need to grasp the opportunity of disease treatment through their own continuous improvement to practice, optimize the treatment program, and improve the effectiveness of treatment.

Shared decision-making

The emotional response of the participants to surgical treatment is caused by the insufficient understanding of the treatment. It may be caused by obstacles in effective communication with patients because of the limited time and the difference in patients' literacy. Involving patients in decision-making is often neglected by the current medical staff. In the model of biopsychosocial medicine, the determination of the diagnosis and treatment in humanistic medicine should consider not only the patient's disease status and the level of medical care in the medical institution but also the patient's preference.[30] It is suggested that patients should be detailed about treatment, purpose, and postoperative recovery of this surgery. Involving patients in treatment decisions can not only reduce the uncertainty of treatment for patients but also improve treatment satisfaction and compliance.[31-33]

Enhance self-management

Elastic stockings can promote blood circulation and lymph return by increasing pressure on the lower limbs and often have a certain pressure gradient. A considerable number of participants said that they could not persist in wearing elastic stockings after the surgery. Previous studies have found that despite having VLUs, the noncompliance rate for stockings is as high as 30%–65%.[34] Moffatt et al[35] reviewed the literature and reported that the physical, esthetic, and cosmetic factors, besides the lack of education, influenced compliance with elastic stockings. Medical staff should inform patients of the importance of wearing compression stocks postoperatively. Reports continue to support and encourage the strategy of continuous long-term health-related behaviors in chronic diseases,[36,37] thus creating an environment of social support, cooperation, and supervision for patients; adjusting patients' self-behavior; and strengthening their ability for self-management. Peer education can help patients with chronic diseases better manage through mutual communication and encouragement between peers with the same characteristics and experience and target groups.[38,39] Medical staff can improve the self-management ability of patients via increasing the frequency of telephonic follow-up after surgery and holding regular patient fraternity.

CONCLUSION

This study provided insights into the awareness and experiences of patients diagnosed with PVVs (c2–c4) in China. Early prevention, detection, and treatment of varicose veins may be more cost-effective than the treatment of VLUs. However, this study found that patients lacked relevant knowledge of diseases and received inadequate medical information and support. This emphasized the need for more attention to the existing problems in our future work. People should pay more attention to the popularization of knowledge about the disease in different forms so as to improve awareness among patients. Family and medical care providers should provide support and help patients and enhance their disease self-management. In the future, vascular surgery specialists also need to adhere to evidence-based research, and optimize treatment programs and individualized treatment, so as to benefit patients.

LIMITATIONS

Several limitations of this study should be mentioned. First, the sample in this study was small and from one hospital in China. However, small sample sizes are typical for qualitative research, where the focus is on the depth of data rather than representativeness. Second, participants were selected with PVVs of clinical grade c2–4 in this study. In future studies, the research objects should be expanded to comprehensively understand the real experience and needs of patients with varicose veins caused by different areas, clinical grading, and etiology. Finally, the study was performed in Chinese; although we attempted to translate close to the original Chinese meaning, it may be difficult to generalize findings in other cultures.

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