

A Look Back Before Looking Ahead: Quality of Life (QoL) in Women Affected by Complex Vascular Anomalies. Lessons Learned to Improve their Health and Well Being

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1. Abstract

1.1. Background: Patients with disabling complex vascular anomalies (VA) have decreased quality of life (QoL).

1.2. Objectives: To assess QoL of women with complex VA with the help of the global Well-Being Scale (QWBSA).

1.3. Method: Female adult patients from the vascular anomaly clinic of a single tertiary care center in Canada have been recruited by retrospective chart reviews, and administered the QWBSA by phone interviews.

1.4. Results: Of the 16 patients recruited (mean age 32 years old), 14 had visible physical deformation and 50% had a history of recurrent pain, NSAID drug intake, mood disorders symptoms, and antidepressant drug use. The majority led an active life but one was permanently disabled and one woman was discriminated against at work because of her VA.

1.5. Conclusion: Though interdisciplinary partnership complex VA management and individualized care should include assessment of QoL in adult women living with these conditions. It will help them navigate their life trajectory.

2. Introduction

An aging population affected by life-long disabling conditions challenges healthcare systems. Although rare vascular anomalies

concern up to 4% of the population female adult patients with complex vascular anomalies (VA) represent a challenge for physicians and caregivers [1]. Quality of life concept (QoL) first appeared at the World Health Organization (WHO) in 1946 to assess the functional, emotional, and social well being of a person with periodical updates [2]. QoL studies are now pivotal in the management of complex diseases. Data on QoL adult patients living with complex vascular anomalies are scarce. Our study aimed to evaluate QoL global health parameters in women with complex VA to improve care and management of these chronic diseases, offering advice to provide support at any age.

3. Method

Our long spend study over several decades uses the revised ISSVA classification of 2018 [3]. Complex VA patients were selected by retrospective chart review of the VA clinic at the CHU Sainte-Justine Hospital (CHUSJ) (an academic tertiary center) from 1990 to 2020. Our VA clinic is the referring center, serving the population of eastern Canada. Female adult patients with complex VA, 18 years of age and older at the time of the study were included. VA needing repeated multimodal treatments including sclerotherapy, endovascular embolization, laser therapy and/or surgical resection were defined complex. Pediatric patients and VA not needing aforementioned treatments were excluded. Patients who were successfully recontacted by phone from a RN of the clinic completed

the standardized well-being scale (QWBSA) [4] survey evaluating three main domains: physical health and functioning, emotional health, and socioeconomic parameters. Descriptive statistics were used. Verbal consent to participate was first obtained by phone, and then a written informed consent was sent by mail. The CHUSJ ethic board committee approved the study and an IRB was obtained.

4. Results

Eighteen female adult patients with a complex VA were identified by retrospective chart study. Two patients were unreachable and 16 patients were included. Characteristics of patients are found in

(Table 1). Mean age of patients was 32 years old. Thirteen women were married and 11 suffered from Klippel Trenaunay syndrome (KTS) with a classical triad of capillary and venous malformation and limb hypertrophy. QWBSA survey (Table 2) showed that the majority of the women had a cosmetically visible VA (14), had recurrent pain episodes (9), had used NSAID drugs regularly (8) albeit wearing compressive stockings (7). Half of them reported mood disorder symptoms and had a history of antidepressant drugs intake. Socioeconomic parameters showed that the women worked full time (11 at work, 4 at home). One patient was disabled due to mood disorders and another felt discriminated at work because of her VA.

Table 1: Baseline characteristics of the female patients who completed the QWBSA questionnaire n=16 (100%)

Age (years)	32,8 (23-45)
Marital status (married)	13 (81)
Vascular anomalies types:	
Klippel-Trenaunay syndrome	11 (69)
Arteriovenous	3 (19)
Venous	1 (<1)
Lymphatic	1 (<1)
Localization:	
Lower extremity	11 (69)
Trunk	5 (31)
Head / neck	3 (18)
Upper extremity	2 (12)

Table 2: QWBSA results exploring physical, emotional and socio-economic parameters

	All patients n=16 (100%)	KTS patients n=11(100%)
1- Physical health and functioning		
Visible physical deformation	14 (87)	10 (90)
Fatigue	6 (37)	5 (45)
Pain	9 (56)	8 (73)
NSAID drug use	8 (50)	6 (55)
Compressive stockings	7 (43)	7 (64)
Walking stick	1 (6)	1 (9)
Heel pad	1 (6)	1 (9)
2- Emotional health		
Sleep disturbances	8 (50)	4 (36)
Mood disorder symptoms	9 (56)	5 (45)
Antidepressant drugs use	5 (31)	3 (27)
Suicide attempt	1 (6)	1 (9)
Eating disorder	1 (6)	1 (9)
3- Socio-economic involvement		
Full time work	2 (12)	9 (82)
Stay at home	3 (18)	1 (9)
Disabled	1 (6)	1 (9)

5. Discussion

This study reinstates that vascular anomalies weigh on the physical and mental health of adult women patients living with complex VA. VA may lead to a chronic disability affecting all spheres of life (physical, emotional and functional), resulting in significant consequences on patient's psycho-social perspectives. Even if our patients were leading active lives, day-to-day functioning was often complicated by limiting pain and dealing with the emotional stress of living with a perceptible VA for the public eye to scrutinize. Chronic diseases are a risk factor for mood disorders development and complex VA are certainly not spared even with optimal multi-modal therapies. Socioeconomically our patients fared well and the majority had a full time job. However one of them was disabled and another discriminated against her VA at work. Moreover we cannot ascertain that the employed women are not impaired in their work trajectories by their VA or if the stay-at-home moms chose freely to care for their families or if they had real or perceived limitations related to their disease. In our series KTS patients had a greater negative QoL impact from their VA than the women with a more localized VA. We hypothesize that KTS being segmental on the lower limbs is often accompanied by pain, intravascular coagulation disorders, limb hypertrophy, gravity dependant venous insufficiency, and worsening with aging, thus contributing negatively on QoL and possible stigmatization. We are well aware that our study has limitations: number of patients, heterogeneity of the VA phenotypes, selection bias from a tertiary care center and retrospective bias. Nonetheless, this series offers insights on care and management issues related to QoL of a pediatric-diagnosed female patients group now into adulthood living with complex VA: a population that should not be overlooked.

Due to the diversity of vascular anomalies, individualized care arrangements are essential to optimize quality of life and patient outcomes in an at risk population. Prior to adulthood affected adolescents must be prepared to smooth out the transition, especially female patients who will be confronted to questioning their sexuality and gynecological health. A personalized planning must be developed to ensure various and coordinated patient support. Multidisciplinary team on a micro level network [5] is key at long term to optimal management of chronic problem.

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