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Review article

Quality of life evaluation in peripartum cardiomyopathy patients: a focus on women's heart

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Abstract

Introduction. There is limited information available regarding the quality of life (QoL) in patients with Peripartum Cardiomyopathy (PPCM). We assessed how the disease impacted the day-to-day functioning of respondents, who were concerned about their QoL in the two weeks preceding the survey.
Methods. The study involved 24 subjects treated at the Institute for Cardiovascular Diseases of Vojvodina from January 2006 to December 2019. The Kansas City Cardiomyopathy Questionnaire (KCCQ) was used to assess their quality of life. The collected data were statistically processed.
Results. The mean age of the subjects was 37 ± 6.4 years, with an average time since initial diagnosis of 5.9 ± 3.4 years. Out of 24, thirteen participants completed the questionnaire, and a majority of respondents (53.8%) reported feeling sad or discouraged due to the effects of heart failure on their lives. Only 30.8% of respondents expressed complete satisfaction with the idea of living at their current level due to heart failure. Fatigue and weakness were reported by 76.9% of female participants. The initial left ventricle ejection fraction (EFLV) was predominantly severely impaired, while the currently measured EFLV averaged 55±10%. At follow-up, 38.4% showed no symptoms of heart failure. A majority (76.9%) were unable to engage in high-intensity physical activities.
Conclusion. Although most patients experience cardiac muscle recovery after the acute phase of PPCM, the disease continues to have long-term effects on their quality of life and mental well-being.

Kew words peripartum cardiomyopathy; QoL; KCCQ; quality of life evaluation

Introduction

Cardiovascular diseases (CVDs) are a significant cause of morbidity and mortality in pregnancy, in which peripartum cardiomyopathy (PPCM), as a specific entity, is being increasingly recognized. In general, cardiomyopathy is defined as a myocardial disorder in which the heart muscle is structurally and functionally abnormal, in the absence of coronary artery disease (CAD), hypertension, valvular disease, and congenital heart disease (CHD) sufficient to cause the observed myocardial abnormality[1]. Therefore, PPCM is defined as an idiopathic form of heart failure (HF) that is developed during late pregnancy or after childbirth, in previously healthy, young women[2]. Globally, the incidence of PPCM varies, with reported rates ranging from 1 in 1421 to 1 in 9861 births[3].

The precise etiology of PPCM has not yet been established. However, various factors including inflammatory, immunological, hormonal, environmental, as well as genetic factors have been recognized to play a pivotal role in the progression of this disease. Additionally, some commonly known risk factors, such as age, obesity, smoking, alcohol abuse, diabetes mellitus, and chronic hypertension, alongside multiparity, and hypertensive disorders in pregnancy, have also been described to contribute to PPCM development[4-6]. Despite the exact pathophysiological mechanism of PPCM being understudied, one potential theory for the occurrence of this condition could be excessive exhaustion of the heart muscle during the adaptive period[7].

The disease presents itself with widely recognized symptoms of heart failure such as dyspnea, lack of stamina, cough, and orthopnea, which can sometimes be accompanied by abdominal discomfort, chest pain, and palpitations, as non-specific symptoms. Most of the patients, based on the New York Heart Association (NYHA) functional status, are classified as NYHA 3 and 4, but the class itself did not show a predictive value[8,9].

The diagnostic criteria for PPCM entail the onset of HF within the last month of pregnancy or up to five months post-delivery, with no prior diagnosis of heart disease until the final month of pregnancy. Additionally, there should be no other identifiable cause of HF present. Suspecting PPCM based on clinical evaluation alone can be challenging due to the overlapping of symptoms of normal pregnancy and HF[10,11]. In addition to the previously mentioned clinical criteria, an echocardiographic assessment is necessary to confirm the diagnosis, since PPCM can be described as left ventricular systolic dys-

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function with ejection fraction (EF) values below 45%, with an impaired fractional shortening of the left ventricle[12]. Since PPCM is present as HF, a therapeutic approach includes standard HF treatment[2].
The most commonly described outcome is a spontaneous recovery of cardiac function. However, in a smaller percentage of patients, HF may persist, or it can lead to death. Although the course of PPCM can vary, a complete recovery of the left ventricle systolic function can be expected in 6 to 12 months after the diagnosis[13]. Compared to other cardiomyopathies with reduced systolic function, PPCM objectively shows a more favorable prognosis[14]. Regardless of the most favorable outcome, the disease itself leaves a psychological and emotional burden, in the form of depressed moods, along with feelings of fear and hopelessness[15,16].
The aim of this research was to assess the impact of PPCM on the patient's quality of life, as well as their mental status.

Methods

Analyzed sample

This retrospective, single-center study included 24 participants who were diagnosed with peripartum cardiomyopathy during a 14-year period (January 2006-December 2019). Clinical data were collected from the Hospital Information System of the Institute for Cardiovascular Diseases of Vojvodina (Sremska Kamenica, Serbia).

Clinical Data, Quality of Life (QoL) and Left Ventricular Ejection Fraction (EFLV) assessment

The diagnosis of PPCM was the main requirement for the inclusion in the study, and out of primarily 24 patients, quality of life (QoL) was assessed for 13, while the rest of the participants were not included due to lethal outcomes (n = 4), refusal of participation (n = 1), or other non-specified reasons (n = 6). Required data consisted of patient age, date of delivery, admission, and discharge, present comorbidities (e.g. hypertension, preeclampsia), harmful habits (e.g. smoking, alcohol consumption), performed diagnostic and therapeutic approaches, and echocardiographic findings.
The QoL was assessed using a specific Kansas City Cardiomyopathy Questionnaire (KCCQ), which was developed to provide a better insight into the quality of life of HF patients[17]. Using the questionnaire, the following clinically relevant domains were assessed: physical limitations (question 1), frequency of symptoms (questions 3, 5, 7, and 9), their severity (questions 4, 6, and 8), and fluctuation over time (question 2), level of independence and knowledge about the disease (questions 10-12), as well as quality of life (questions 13-15). We established contact with the interviewees through telephone conversations, during which they were provided access to relevant research materials. The survey questions, derived from a questionnaire, were then verbally presented to the respondents. On average, the data collection process, encompassing the entire interview, lasted approximately 15 minutes.
Measurements of the left ventricular ejection fraction (EFLV) were divided into three groups: (I) the initial value, (II) the value measured during a follow-up, and (III) a current EFLV value.

Statistical analysis

The data were analyzed using the IBM SPSS Statistics, Version 28.0 (IBM Corp, Armonk, NY, USA). Continuous variables were expressed with their mean values, along with the associated standard deviations, while categorical variables were presented as numbers (percentages). The paired T-test was used to determine whether there was statistical evidence that the analyzed groups' means were significantly different, and the statistical significance was observed at a level of $p<0.05$.

Results

Analyzed sample

The average age of diagnosis was 31±5.6 years, with the average time frame from birth to the disease onset of 35.8±47 days. More than half of the participants were multiparous (54.2%), 8.3% were twin pregnancies, and 41.7% of the pregnancies ended with a cesarean delivery. None of the participants had subsequent deliveries after the diagnosis of PPCM. Almost half of the participants (45.8%) had some other comorbidity present. Data obtained about patients' medical history, physical examination, echocardiography, therapeutic approach, as well as the frequency of death, are shown in Tables 1 and 2.

Table 1. Data of the entire sample

Variable	n=24
Age at diagnosis Mean ± SD	31 ± 5,6
Days from delivery to diagnosis Mean ± SD	35,8 ± 47
Parity (%, n) primiparous multiparous	 45,8 (11) 54,2 (13)
Multiple pregnancy (%, n) yes no	 8,3 (2) 91,7 (22)
Type of delivery: vaginal delivery cesarean section	 58,3 (14) 41,7 (10)
Arterial hypertension (%, n) yes no unknown	 20,8 (5) 75 (18) 4,2 (1)
Preeclampsia (%, n) yes no	 8,3 (2) 91,7 (22)
Tobacco use yes no	 58,3 (14) 41,7 (10)

SD - Standard Deviation

Table 2. Clinical data of the participants

Variable	n=24
EFLV initial mean value ± SD	30,5 ±6,3 (24)
NYHA class (%, n) II III IV	 12,5 (3) 62,5 (15) 25 (6)
Treatment option ACE inhibitors ARBs Beta-blockers Diuretics	 79,2 (19) 4,2 (1) 83,3 (20) 95,8 (23)
Fatal events	16,8 (4)

EFLV- left ventricle ejection fraction; NYHA class- New York Heart Association Classification; ACE inhibitors- Angiotensin-converting enzyme inhibitors; ARBs- Angiotensin II Receptor Blockers

Quality of Life (QoL) assessment

The average age was 37±6.4 years (Table 3), 92.3% were married, and 61.5% had higher education. The time that has passed from an initial diagnosis was 5.96±3.44 years. More than half of the respondents pointed out that they fully understand the necessity of compliance with the regime of secondary prevention (61.5%), and that HF did not diminish their life satisfaction in the last two weeks (53.8%). Furthermore, 38.5% of the patients are certain about the steps that should be taken in case of worsening HF symptoms, while the majority are somewhat sure. Analysis including the impact of HF on the lifestyle is shown in Table 4, while the physical limitations due to HF are present in Table 5.

Left Ventricle Ejection Fraction analysis

In the majority of patients (68.5%) the initial EFLV was seriously impaired (38.5%, EFLV = 25- 30%; 30.8%, EFLV = 30-35%). The average time that has passed from an initial diagnosis to the control echocardiography was 1.3±1.8 years, and it revealed that 69.2% of participants had satisfactory EFLV (>50%), with the highest percentage of recovery in the first year. The mean value of the initial EFLV was 31.7±6.5%, while the control EFLV was 49.6±11.1% (Table 6), and a statistically significant difference was observed between the compared measurements ($p<0.05$). The mean value of current EFLV measurements was 55±9.6%, and out of thirteen, only two participants (15.4%) did not reach satisfactory values. Statistically significant differences between the first and third measurements of EFLV ($p<0.05$) were observed, but there was no statistically significant difference between the control and current EFLV values.

Table 3. Demographic data of the QoL survey participants

Variable	n=13
Age (mean value ± SD)	37±6,4
Caucasian	100% (13)
Years since initial diagnosis (mean value ± SD) 1 month to 1 year 1 to 3 years over 3 years	5,9± 3,4 7,7% (1) 23,1% (3) 69,2%(9)
Marital status married divorced	 92,3% (12) 7,7% (1)
Education primary school high school faculty	 15,4% (2) 61,5% (8) 23,1% (3)
Later pregnancy	0% (0)

SD - Standard Deviation

Table 4. Quality of life among surveyed respondents

How would you feel if you had to spend the rest of your life with the quality you currently have due to heart failure?	
unsatisfied	15,4% (2)
somewhat satisfied	23,1% (3)
mostly satisfied	30,8% (4)
completely satisfied	30,8% (4)
In the past 2 weeks, how often have you felt discouraged or sad because of the effect of heart failure on your life?	
constantly	7,7% (1)
most of the time	7,7% (1)
periodically	38,4% (5)
infrequently	23,1% (3)
never	23,1% (3)
On average, in the last 2 weeks, how much did fatigue limit you from doing what you want?	
at least 1 per day	15,4% (2)
>3 times a week	7,7% (1)
1-2 times a week	15,4% (2)
<1 per week	38,5% (5)
non even once	23,1% (3)
How much does heart failure change your lifestyle when it comes to your employment or household chores?	
quite a lot	7,7% (1)
moderately	23,1% (3)
a little bit	23,1% (3)
does not change	46,2% (6)

Discussion

Quality of life involves multiple dimensions that consist of mental and physical health, social functioning, and psychological and general well-being[18], and its assessment is of great importance. Nevertheless, QoL in women who are faced with this disease still represents an understudied research objective. Therefore, we assessed how the disease affected the daily functioning of the participants who were concerned about their quality of life in the two weeks prior to joining the survey. Our study, in alignment with previous research, affirms that PPCM is more prevalent among women over the age of 30, particularly among those who have given birth multiple times as opposed to first-time mothers[13]. Addition-

Table 5. Physical limitations of the interviewed respondents

Please indicate how short of breath or fatigue limited you in performing the following activities during the last 2 weeks.	n=13
ACTIVITIES OF MODERATE INTENSITY	
- Working in the house, yard or carrying groceries	
very much	15,4% (2)
moderately	23,1% (3)
few	38,5% (5)
no limits	23,1% (3)
- A walk lasting 30 minutes	
a little	30,8% (4)
no limits	53,8% (7)
I didn't do that	15,4% (2)
HIGH-INTENSITY ACTIVITIES	
- Climbing the stairs without stopping	
very	23,1% (3)
moderately	7,7% (1)
few	7,7% (1)
no limits	38,5% (5)
I didn't do that	23,1% (3)
- Running	
very much	7,7% (1)
moderately	7,7% (1)
no limits	7,7% (1)
I didn't do that	76,9% (10)

Table 6. Left ventricle ejection fraction analysis results

n=13	n=13	n=13	
EFLV initial mean value ± SD	EF control mean value ± SD	EF current Mean value ± SD	p-value
31,6± 6,5	49,6± 11,1	55± 9,6	*p*1<0,05 *p*2<0,05 *p*3>0,05

EFLV- ejection fraction; SD- Standard Deviation
*p*1- EF initial and control, *p*2- EF initial and current, *p*3- EF control and current

ally, it suggests a relatively swift recovery of cardiac function in this demographic. While various studies[4-6] corroborate the higher incidence of PPCM in cases of multiple gestations and in pregnant or postpartum women with preeclampsia, our study diverges in this regard, as our dataset shows a notably smaller proportion of such patients. Research indicates that women of African descent are more susceptible to developing PPCM[9,19]. The highest recorded incidence of PPCM is in Nigeria, affecting 1 in every 102 births. Similarly, elevated incidences have been observed in South Africa and Haiti[20]. In our specific demographic, the majority of the population is of white racial background, and consequently, our study did not include any respondents of African descent.

Most of our respondents were married, had more than two children, and bore the responsibility of caring for a multi-member family. Among the reported symptoms, fatigue was the most experienced. These women, who are primarily mothers, are tasked with the care and well-being of their families. A significant portion of them expressed occasional feelings of sadness and discouragement, which can be attributed to the impact of heart failure on their lives[17]. At the moment of bringing a newborn into the world, rather than being able to attend to their child, they found themselves grappling with acute heart failure[15]. The respondents exhibit a strong awareness of the severity of this disease, especially concerning its long-term management, secondary prevention, and the reduction of relapses. It is recognized that subsequent pregnancies and childbirth can potentially represent a trigger[21], which would explain the fact that none of the patients reported subsequent pregnancies. A study assessing the quality of life may involve anywhere from one to several thousand patients[22]. In our region, epidemiological data on PPCM is limited. One of the challenges we encountered was the difficulty in identifying a larger number of women to form a representative sample, as this is a common issue faced by researchers studying rare diseases, and PPCM serves as a tangible example[16]. At the institution where the research was conducted, a total of twenty-four patients were treated over a fourteen-year period, and since only 13 of these patients were included in the survey, it is conceivable that the quality-of-life assessments could have yielded different results with a larger sample size.

According to the NYHA classification, during the initial hospitalization and the first presentation of the disease, individuals in class III and IV (representing 87.5% of cases) - signifying a severe degree of heart failure - were predominant. These findings align with the data reported by Shah T et al[9]. It has long been recognized that parameters of cardiac function, such as left ventricle ejection fraction and cardiac output, show only weak correlations with a patient's exercise capacity[23]. This observation is evident in our example, where a notable number of women with a high and stable ejection fraction are unable to engage in strenuous physical activity. Previous research has indicated that the presence of gestational hypertension, the onset of the disease after childbirth, as well as initial EFLV values above 35%, are associated with a favorable prognosis and the recovery of systolic function[24]. Conventionally, a patient is considered to have 'recovered' if the EFLV values are 50% or higher[25].

Patients with all cardiomyopathies should have access to multidisciplinary team with expertise in the management of cardiomyopathies. Recommendations for reproductive issues in patients who had PCMP are to be counseled for safe and effective contraception and pre-pregnancy risk assessment which is a class I recommendation according the Guidelines on Cardiomyopathies. It is also recommended that genetic testing and physiological support by a trained health professional should be offered to all individuals with cardiomyopathy[26].

Conclusion

By applying the KCCQ we assessed the quality of life in patients with PPCM. Even though cardiac function recovers after the acute phase of the disease, long-term

consequences on quality of life and mental status could have been observed. It's necessary to search for aiding factors that contribute to the lowering of the quality of life so that their impact can be reduced or eliminated.

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Sažetak

Procena kvaliteta života kod pacijentkinja sa peripartalnom miokardiopatijom: Fokus na žensko srce

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Uvod. Dostupne su ograničene informacije o kvalitetu života pacijentkinja sa peripartalnom kardiomiopatijom (PPCM). Cilja rada je bio da se proceni uticaj bolesti na kvalitet života u dve nedelje koje su prethodile anketi.
Metode. Studija je obuhvatila 24 ispitanice lečenih u Institutu za kardiovaskularne bolesti Vojvodina od januara 2006. do decembra 2019. Upitnik za kardiomiopatiju Kanzas Siti (KCCK) je korišćen za procenu kvaliteta njihovog života. Prikupljeni podaci su statistički obrađeni.
Rezultati. Prosečna starost ispitanica bila je 37.0 ± 6.4 godine, sa prosečnim vremenom od inicijalne dijagnoze od 5.9 ± 3.4 godine. Od 24, trinaest učesnica (53,8%) je izjavilo je da se osećaju tužno ili obeshrabreno zbog uticaja simptoma srčane insuficijencije na njihov život. Samo 30,8% ispitanica je izrazilo potpuno zadovoljstvo sa aktuenim stanjem. Umor i slabost je imalo 76,9% žena. Početna ejekciona frakcija leve komore (EFLV) bila je smanjena, dok je trenutno izmerena EFLV bila 55±10%. Tokom praćenja, 38,4% nije pokazalo simptome srčane insuficijencije. Većina (76,9%) nije bila u stanju da se bavi fizičkim aktivnostima visokog intenziteta.
Zaključak: Iako većina pacijenatkinja doživljava oporavak srčanog mišića nakon akutne faze PPCM, bolest nastavlja da ima dugoročne efekte na njihov kvalitet života i mentalno blagostanje.

Ključne reči: *peripartalna kardiomiopatija; kvalitet života; KCCK*