Cardiology in the Young

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Self-reported quality of life before, during, and after pregnancy in women with CHD

Frida Wedlund[1,2] and Joanna Hlebowicz[2,3]

[1]Department of Cardiology, Skåne University Hospital, Lund University, Malmö, Sweden; [2]Clinical sciences, Lund University, Lund, Sweden and [3]Department of Cardiology, Skåne University Hospital, Lund University, Lund, Sweden

Original Article

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Author for correspondence:
Frida Wedlund, Skåne University Hospital, Lund University, Malmö, Sweden.
E-mail: frida.wedlund@med.lu.se

Abstract

Background: Adults with CHD are a growing patient group and childbirth is a relatively new phenomenon. EQ-5D is commonly used to measure health-related quality of life. We sought to investigate EQ-5D status before, during, and after pregnancy in women with CHD. *Methods:* We identified 128 pregnancies in 86 CHD women giving birth in Skåne County during 2009–2021. Repeated measures ANOVA was performed to test for differences between the five EQ-5D domains, EQ-VAS, and EQ-index over time points before, the second trimester, the third trimester, and after pregnancy. *Results:* Mean age at estimated childbirth was 30.3 (± 4.7) years; 56.25% of births were vaginal deliveries and 43.75% were Caesarean sections. The cohort consisted of patients with double outlet right ventricle (4.7%), transposition (Mustard/Senning 2.3%, arterial switch 4.7%), aortic anomalies (19.5%), Fallot's anomaly (16.4%), single ventricle (3.9%), shunt lesions (11.7%), cardiomyopathies (4.7%), coronary anomalies (1.6%), arrythmias (0.8%), and valve lesions: aortic (19.5%), mitral (5.5%), and pulmonary (4.7%). The women reported significantly worse mobility ($p = 0.007$) and higher pain/discomfort ($p = 0.049$) at trimester 3 compared to before pregnancy. The women had lower EQ-5D index during trimester 3 compared to after pregnancy ($p = 0.004$). We saw worse mobility during Tri 2 comparing multiparity with primiparity ($p = 0.046$). Looking at delivery mode, we noted significantly higher anxiety/depression before pregnancy ($p = 0.023$) in women that had a Caesarean section. *Conclusions:* In this study, women with CHD reported worse mobility and a higher pain level during Tri 3, although the overall health-related quality of life is acceptably high.

Every year in Sweden, 1000 children are born with CHDs. As a result of advancements in paediatric cardiology and cardiac surgery, the number of adults affected by adult CHD has increased steadily. Currently, it is estimated that approximately 40,000 adults in Sweden are affected by this chronic disease. Many CHD patients did not previously survive into adulthood, and childbearing is a relatively new phenomenon in this patient group with which we have little experience.[1] This is an important research field since currently the main cause of maternal deaths is cardiovascular disease, both including CHD and acquired cardiovascular diseases.[2]

Women with CHD going through pregnancy and delivery have an increased risk of complications, although severe complications are rare.[3] During pregnancy, there is an increased oxygen demand and, consequently, stroke volume, end-diastolic volume, and heart rate increase. One complication that might occur during pregnancy is arrhythmias, and of all women with cardiovascular disease, either acquired or CHD, the prevalence of sustained arrhythmias ante-, peri-, and postpartum is 7–9%.[4]

A standardised instrument to describe health status and health-related quality of life was developed by the EuroQol Group.[5] In patients with CHD, lower health-related quality of life correlates with female gender, lower education level, advanced age, number of hospitalisations in the preceding year, and prevalence of cardiac comorbidities.[6] Moreover, healthy pregnant women report lower health-related quality of life later in pregnancy, especially between months 4 and 8. Furthermore, women with pregnancies in which clinical problems occur report even worse health-related quality of life.[7] Delivery mode might have an effect on perceived health status: women delivering by Caesarean section are more likely to report a lower health-related quality of life than those who have a vaginal birth without forceps or vacuum-assisted delivery.[8]

According to the European Society of Cardiology, it is recommended to classify risk in CHD women with the modified World Health Organization (mWHO) risk classification score before conception. According to this classification, patients can be divided into groups I–IV, ranging from no or mildly increased risk to an extremely high risk of maternal mortality and morbidity. For instance, at one side of the spectrum, mWHO class I includes heart defects such as minor valve defects and mWHO class IV includes heart defects such as Fontan operation with any complication or severe valve defects such as severe symptomatic aortic stenosis.[9]

In this study, we sought to investigate health status in women with CHD going through pregnancy and childbirth. To the best of our knowledge, there are no previous studies that have

assessed perceived health-related quality of life by EQ-5D status before, during, and after pregnancy in women with CHD.

Materials and method

Study population

The study population consisted of all pregnant women who were referred from southern Sweden to the CHD reception at Lund University Hospital, Sweden. In Sweden, the cases of all pregnant women with CHD are discussed at a multidisciplinary conference and the childbirth is planned accordingly. We have protocols for these conferences, and we identified women whose cases were discussed at multidisciplinary conferences between March, 2009 and May, 2021. The Swedish Registry of Congenital Heart Disease, SWEDCON, is a national registrar of CHD patients which started in the 1990s. From 2009, it also includes children with CHDs and cardiac surgeries.

Inclusion and exclusion criteria

We included women whose cases were discussed at a multidisciplinary conference at the CHD reception at Lund University Hospital, were registered in SWEDCON, and had data regarding doctors' appointments before, during, or after childbirth. We only included data on pregnancies in which the woman gave birth at hospitals in Skåne County, Sweden due to the lack of access to medical records outside Skåne County. Only women going through a pregnancy that resulted in a live birth were included in our study. Three women (2.3%) were excluded from analysis due to missing EQ-5D data before, during, and after pregnancy. All of these women were in mWHO classes I or II, ≤ 35 years, and gave birth vaginally.

Data collection

We collected data from the SWEDCON Register, together with details from the patient's medical records (Melior and Obstetrix). Data from SWEDCON consisted of diagnoses, operations and dates, occupation and occupation rate, housing, education level, smoking, physical exercise, weight, and height. In addition, electrocardiogram results and data from doctors' appointments and telephone appointments were collected. When applicable, we also included data from nurses' appointments or from telephone appointments by a doctor or a nurse. Dates of doctors' appointments and self-reported health status according to EQ-5D were collected. Before the doctor's appointment, the patients fill out an EQ-5D questionnaire. From medical records, we collected data about delivery mode and delivery hospital, number of previous births, and valve function at echocardiography during pregnancy. We defined the start of pregnancy as the estimated delivery date minus 39 weeks and 6 days.

EQ-5D

The EuroQol Group developed a standardised instrument to describe health status and health-related quality of life. This instrument measures five domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The scale for these five domains is in three steps: no problems, some problems, and extreme problems. In addition, the respondent fills out a visual analog scale (VAS) score, EQ-VAS, where the health status is rated as a number from 0 (worst) to 100 (best).[5] This standardised instrument is commonly referred to as EQ-5D. The EQ-5D user guide describes how to use the EQ-5D index. In this index, the five domains are collated, and the five domains are described as 1 = no problems, 2 = some problems, and 3 = extreme problems. For instance, "11111" describes the EQ-5D index if the patient scores the best possible score for every domain. Thereafter, different value sets are used to obtain the EQ-5D index value by a separate calculator.[10] Since there is no available EQ-5D index value set in Sweden, we used the Danish value set.[11] Sweden and Denmark are of similar socio-economic status, and there are cultural similarities between the two countries.

Data processing and statistical analysis

We divided all data into before and after childbirth and trimesters. We used the worst reported EQ-5D value from all appointments in trimesters; "Tri 1" = the first trimester, "Tri 2" = the second trimester, and "Tri 3" = the third trimester.

The continuous variables BMI, time duration before childbirth and the doctor's appointment and time duration after childbirth and the doctor's appointment, EQ-VAS, EQ-5D index, number of doctors' appointments, and age were tested for normal distribution with the Shapiro–Wilk test. The distribution of BMI, number of doctor's appointments, EQ-VAS, EQ-5D-index, time duration before childbirth and the doctor's appointment and time duration after childbirth and the doctor's appointment were found to be skewed. Normally distributed continuous variables are presented as mean ± SD or proportions. Non-normally distributed variables are presented as median and interquartile range.

Repeated measures ANOVA was performed to test for differences between the five EQ-5D domains, EQ-VAS, and EQ-index over time points before, Tri2, Tri3, and after pregnancy. Posthoc tests were conducted using the Sidak method for multiple comparisons. Due to few doctors' appointments in trimester one, we did not include this data in the repeated measurements analysis.

Patients were retrospectively classified according to the mWHO classification.[9] We divided the mWHO risk classes into two groups: group one: classes I and II, and group two: classes II–III, III, and IV. We divided the age into age groups: group 1: ≤ 35 years, group 2: 35–40 years, and group 3: ≥ 40 years. A previous study by Furenas et al. showed that age might be of some importance for cardiac complications in CHD women, and their definition was age above or below 35.[3]

Comparison in the five EQ-5D domains, EQ-VAS, and EQ-index between age groups were analysed using the Kruskal–Wallis H-test. To investigate differences in EQ-5D status and delivery mode (Caesarean birth versus vaginal delivery), parity (primiparity versus multiparity), and mWHO (group 1 versus group 2), we performed a Mann–Whitney *U*-test.

P-values < 0.05 were considered statistically significant. For statistical calculations, IBM Corp. Released 2020, IBM SPSS Statistics for Windows, Version 27.0 (Armonk, NY: IBM Corp.) was used.

Ethics

The Ethics Committee for Human Research approved this study and our study protocol conforms to the ethical guidelines of the 1975 Declaration of Helsinki. The reference number was 2021-01636.

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Results

Demography and cohort characteristics

We analysed 128 pregnancies in 86 women. Out of the 56 Caesarean sections, nine indications (16.1 %) were missing and six were due to non-medical reasons such as maternal request for psychological reasons (10.7%). Mean age at estimated childbirth was 30.3 (± 4.7) years and median body mass index before pregnancy was 23.3 (21.2–25.4) kg/m^2 (47 pregnancies had missing data regarding BMI). Median duration between the doctor's appointment (in person or by telephone) before pregnancy and becoming pregnant was 9.3 (4.5–16.9) months and Table 1 displays the demographics at this appointment. Table 2 displays characteristics of pregnancy and childbirth.

Table 1 displays diagnoses included in the study cohort.

Out of the pregnant patients with aortopathies, 17 patients had coarctation, 5 had Marfan's syndrome, and 3 had a bicuspid aortic valve with aortic dilatation. One of the pregnant patients with Marfan's syndrome had a mechanical aortic valve. Out of the pregnant patients with coronary anomalies, one had truncus type II together with a mechanical aortic valve, aortic vessel graft, and a pulmonary homograft, and the other one had anomalous left coronary artery from the pulmonary artery. Out of the shunt lesions, four pregnant patients had persistent ductus arteriosus, two had an atrial septal defect, five had a ventricular septal defect, two had atrioventricular septal defect, and two had Scimitar's syndrome with dextrocardia.

Regarding the aortic valve lesions, 16 patients were diagnosed with aortic stenosis (one mild, 10 moderate, one moderate-severe, 4 severe) and nine with aortic insufficiency.

Out of the patients with mitral valve lesions, four had mitral valve insufficiency and three were stenotic (one mild, one moderate, one moderate-to severe). None had a mechanical valve at the time of pregnancy. Out of the six patients with pulmonary valve lesions, two had mild pulmonary stenosis, two had severe pulmonary stenosis, and two had no remaining pulmonary stenosis after surgery.

Appointments

Of all pregnancies, 98 out of 128 (76.6%) of patients had a doctor's appointment or telephone appointment before pregnancy; in 38 pregnancies (29.7%) the patient had an appointment during Tri 1, 94 (73.4%) during Tri 2, 85 (66.4%) during Tri 3, and 104 (81.3%) after pregnancy. During Tri 1, the median number of doctors' or telephone appointments was 1 (1–2) and median number of doctors' appointments during Tri 2 was 1 (1–2). During Tri 3, the median number of appointments was 1 (1–2). Median duration after delivery and an in-person or telephone appointment was 8.2 (3.4–15.0) months.

EQ-5D status, EQ-5D index and EQ-VAS

The women reported significantly worse mobility ($p = 0.007$) and pain/discomfort ($p = 0.049$) at Tri 3 compared to before pregnancy. The women had lower EQ-5D index during Tri 3 compared to after pregnancy ($p = 0.004$) (Table 3). We did not find any difference in EQ-VAS before, during Tri 2, Tri 3, and after pregnancy.

We saw worse mobility during Tri 2 comparing multiparity with primiparity (p = 0.046), but not before, during Tri 3, or after. Also, we saw worse EQ-5D index during Tri 2 comparing multiparty with primiparity (p = 0.031). We did not see any other differences in the EQ-5D domains, EQ-VAS, or EQ-5D index between primiparity or multiparity. Furthermore, we did not find any difference in the EQ-5D domains, EQ-VAS, and EQ-5D index in relation to mWHO class or age groups (Table 2). Looking at delivery mode, we noted higher anxiety/depression before pregnancy ($p = 0.023$) and worse EQ-5D index during Tri 2 ($p = 0.017$) in women going through Caesarean section. However, we noted no other differences before, during Tri 2, Tri 3, and after pregnancy in the EQ-5D domains, EQ-VAS, and EQ-5D index in relation to delivery mode.

Discussion

Women with CHD are a growing patient group due to advancements in paediatric care and paediatric cardiac surgery. Our findings indicate that women with CHD have significantly worse mobility and higher pain/discomfort during Tri 3 compared to before pregnancy. We noted a significantly higher anxiety/depression before pregnancy in women that had a Caesarean section. However, the women reported an overall high health-related quality of life. Health-related quality of life is important since it reflects how the women perceive their own health. Furthermore, a previous study in French healthy women by Morin et al. showed that health-related quality of life is higher if there are no medical problems during pregnancy.[7]

Questions about family planning are common and childbirth is a relatively new phenomenon in women with CHD. To the best of our knowledge, there are no previous studies that have assessed perceived health-related quality of life through EQ-5D status during pregnancy in CHD women. Our aim was to investigate how women with CHD perceive their health status during pregnancy. We found that women report significantly lower health-related quality of life during Tri 3 compared to before pregnancy. Morin et al. in France showed that healthy women reported lower health-related quality of life during months 4–8 of pregnancy.[7] In a systematic review by Calou et al., several factors that affect health-related quality of life negatively were identified: these included presence of depression or pain, younger age, and low education level.[12] In our study, we found a significant difference in the domain of pain/discomfort while comparing before pregnancy and Tri 3. Wu et al. conducted a study in China to investigate health-related quality of life during pregnancy in healthy women.[13] They found a decrease in health-related quality of life during Tri 3 and the lowest health-related quality of life was found during late Tri 3.

We compared women's cardiovascular risk with mWHO since this is currently recommended by the European Society of Cardiology (ESC) guidelines.[14] However, in a recent study by Denayer et al., mWHO seems to overestimate the risk, and they found that the ZAHARA risk classification score could be related more closely to the maternal risk in their cohort of CHD patients.[15] When we studied whether women with an mWHO risk classification of classes I and II report any differences in their health status compared to those with classes II–III, III, and IV, we found no significant differences, even before, and after pregnancy. Berghammer et al. conducted a study at Sahlgrenska University hospital in Sweden and found that patients with CHD report significantly lower health-related quality of life if they have a more complex disease such as single ventricle.[16] We did not find any similar difference in our cohort, although we only had 60 pregnancies in our study in mWHO risk classes II–III, III, and IV and only five pregnancies in whom the patient had a single ventricle. However, according to the ESC guidelines, there is a significantly increased

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Table 1. Demographics regarding ACHD pregnancies.

	Quantity	Frequency (%)	Missing (%)
Diagnoses			0
DORV	6	4.7	
Transposition - Mustard/ Senning	3	2.3	
Transposition - arterial switch	6	4.7	
Aortic anomalies	25	19.5	
Fallot's anomaly	21	16.4	
Aortic valve lesions	25	19.5	
Mitral valve lesions	7	5.5	
Pulmonary valve lesions	6	4.7	
Shunt lesions	15	11.7	
Single ventricle	5	3.9	
PSVT	1	0.8	
Cardiomyopathies	6	4.7	
Coronary anomalies	2	1.6	
Occupation			7
Employed	85	66.4	
Unemployed	5	3.9	
Student	17	13.3	
Other	10	7.8	
Retired	2	1.6	
Occupation rate (%)			28.9
50	2	1.6	
75	1	0.8	
100	88	68.8	
Housing			8.6
Living in own house	103	80.5	
Living with parents	12	9.4	
Living in institution	0	0	
Other	2	1.6	
Education level			18
Compulsory school	7	5.5	
High school	59	46.1	
Adult education college	1	0.8	
University	34	26.6	
Other	4	3.1	
Smoking			7
Active	10	7.8	
No	98	76.6	
Previous	11	8.6	
Parity			0
Parity 0	62	48.4	
Parity 1	49	38.3	
Parity 2	15	11.7	
Parity 3	2	1.6	
Delivery hospital			0
Helsingborg Hospital	7	5.4	
Central Hospital Kristianstad	4	3.1	
Skåne University Hospital, SUS Lund	96	75.0	
Skåne University Hospital, SUS, Malmö	15	11.7	
Ystad Hospital	5	3.9	
Ängelholm Hospital	1	0.8	
Mode of delivery			0
Vaginal	72	56.25	
Caesarean section	56	43.75	
ECG before			28.9
Sinus rhythm	86	67.2	
Pacemaker rhythm	3	2.3	
Bradycardia	2	1.6	
ECG during			17.2
Sinus rhythm	103	80.5	
Pacemaker rhythm	2	1.6	
Supraventricular tachychardia	1	0.8	
mWHO class			0
I, II	68	53.1	
II-III, III, IV	60	46.9	

Data are shown as numbers (quantity) or as percentage (frequency and missing). Adult education college is another alternative for studies for adults in Sweden and this education is equal to upper secondary school. Skåne University Hospital, SUS, Lund and Malmö are the biggest hospitals in Skåne County. Helsingborg Hospital, Central Hospital Kristianstad, Ystad Hospital and Ängelholm Hospital are local hospitals of different sizes.
DORV = double outlet right ventricle; mWHO class = modified World Health Organization class; PSVT = paroxysmal supraventricular tachycardia

risk of mortality and morbidity during childbirth in women with mWHO risk class III, and for women in mWHO risk class IV, the risk of morbidity and mortality is extremely high. Thus, pregnancy is contraindicated in women in mWHO risk class IV.[14] Consequently, this might reside in a difference between the two cohorts, where patients in Berghammer et al.'s cohort probably have more complex CHD disease than in our cohort.

We aimed to study if there were any differences regarding EQ-5D status according to whether the woman had a Caesarean section or a vaginal delivery, since previous studies by Kohler et al.[8] and Jansen et al.[17] report that there were significant differences. Comparingly, we did observe a significant difference in EQ-5D index while comparing data from Tri 3 and after the pregnancy. However, in our study, median occurrence of a doctor's appointment was at 8.2 months after the estimated delivery date. Kohler et al. reported that the difference was still significant 21–30 days

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Table 2. EQ-5D index according to mWHO risk class and EQ-VAS according to age.

EQ-5D index				
mWHO class	Before	Tri 2	Tri 3	After
p-value	1.000*	0.459*	0.993*	0.086*
I, II				
N	41	37	20	38
Median (IQR)	1.0 (0.92–1.0)	1.0 (0.86–1.0)	1.0 (0.78–1.0)	1.0 (0.91–1.0)
II–III, III, IV				
N	38	40	38	47
Median (IQR)	1.0 (0.91–1.0)	1.0 (0.91–1.0)	0.93 (0.79–1.0)	1.0 (1.0–1.0)
EQ-VAS				
Age at estimated birth	Before	Tri 2	Tri 3	After
p-value	0.369**	0.917**	0.124**	0.969**
>35				
N	65	65	45	65
Median (IQR)	91.0 (80.0–99.0)	87.5 (78.5–95.0)	85.0 (80.0–95.5)	90.0 (80.5–100.0)
35–40				
N	13	9	9	14
Median (IQR)	98.0 (84.5–100.0)	90.0 (80.0–94.5)	90.0 (68.8–99.0)	90.0 (85.0–100.0)
>40				
N	2	3	2	2
Median (IQR)	85	71.3	55	85

P-value according to Mann–Whitney U test* and Kruskal–Wallis H test**
IQR = interquartile range; mWHO =modified World Health Organization risk classification; N = number of women; SD = standard deviation

Table 3. Comparison of problems by EQ-5D health dimension in women with adult congenital heart disease.

Health dimension	Problem level	Before (%)*N* = 83	Tri 2 (%)*N* = 78	Tri 3 (%)*N* = 59	After (%)*N* = 85	*P*
Mobility	No problems	77 (92.8)	67 (85.9)	42 (71.2)	79 (92.9)	
	Slight problems	6 (7.2)	11 (14.1)	16 (27.1)	6 (7.1)	0.000
	Severe problems	0	0	1 (1.7)	0	
Self-care	No problems	81 (97.6)	75 (96.2)	56 (94.9)	84 (98.8)	0.026
	Slight problems	2 (2.4)	3 (3.8)	3 (5.1)	1 (1.2)	
	Severe problems	0	0	0	0	
Usual activities	No problems	75 (90.4)	63 (80.8)	41 (69.5)	80 (94.1)	0.005*
	Slight problems	7 (8.4)	12 (15.4)	16 (27.1)	5 (5.9)	
	Severe problems	1 (1.2)	3 (3.8)	2 (3.4)	0	
Pain or discomfort	No problems	63 (75.9)	56 (71.8)	33 (55.9)	68 (80.0)	0.006
	Slight problems	19 (22.9)	21 (26.9)	25 (42.4)	17 (20.0)	
	Severe problems	1 (1.2)	1 (1.3)	1 (1.7)	0	
Anxiety or depression	No problems	65 (78.3)	58 (74.4)	45 (76.3)	68 (80.0)	0.168*
	Slight problems	14 (16.9)	18 (23.1)	13 (22.0)	16 (18.8)	
	Severe problems	4 (4.8)	2 (2.6)	1 (1.7)	1 (1.2)	

P-value according to repeated measures ANOVA Sphericity Assumed without * or Greenhouse-Geisser with *

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postpartum[8] and Jansen et al. reported that women having a Caesarean section had a full physical recovery in 6 weeks for elective and > 6 weeks for emergency Caesarean section.[17] In a previous study from 1997 to 2012 at Sahlgrenska University Hospital in Gothenburg, Sweden, 19% of patients were delivered by Caesarean section.[3] In comparison, in our cohort between 2009 and 2021, in 43.8% of pregnancies, the CHD women were delivered by Caesarean section. Looking at delivery mode, we noted a significantly higher anxiety/depression before pregnancy in women that had a Caesarean section. This may explain the high rate of Caesarean section in our study. We found that 10.7% of Caesarean sections were due to non-medical reasons, such as maternal request for psychological reasons.

According to Berghammer et al. patients with CHD mostly report problems in the pain/discomfort and anxiety/depression domains.[16] In a national study in CHD patients and children with CHD in New Zealand, 71% of patients reported feelings of anxiety/worry correlating to their heart defect and, likewise, 55% reported depressive thoughts as a result of their heart defect.[18] In our study, we observed more problems with pain/discomfort in Tri 3 compared to before pregnancy. We found no differences regarding anxiety/depression in Tri 3 compared to before pregnancy.

Limitations

The small size of the study cohort, together with the retrospective study design, is an important limitation. A comparison to age-matched normal pregnancies may help discern normal pregnancy-related discomfort from changes in QoL domains due to CHD. Also, the fact that healthier women (lower mWHO class) tend to have fewer doctors' appointments and might have missing data for one of the trimesters or before/after pregnancy is another limitation. In our study, three women gave birth vaginally with no EQ-5D data before, during, and after pregnancy, and all of these women were aged under 35 years and in a low mWHO class. Another limitation is that we do not assess and adjust for potentially important confounders in the analysis. Yet another limitation is that we do not have the date for the last menstrual period to base the start of the pregnancy. A limitation of the study and likely the result for the unequivocal results is that there is universal health care in Sweden that has a high compliance rate with appointments and, therefore, likely generally better health in these women with CHD as a result. This may not be the case in many other countries.

To conclude, in this retrospective study, women with CHD reported significantly worse mobility and a higher pain level during Tri 3 compared to before pregnancy, although the overall health-related quality of life is acceptably high. We noted a significantly higher anxiety/depression before pregnancy in women that had a Caesarean section. There were no differences regarding self-reported health-related quality of life between women with mWHO risk classification classes I and II compared to those with II–III, III, and IV before, during, or after pregnancy. However, we had a relatively small number of pregnancies, and further larger, ideally prospective studies are warranted to confirm our results.

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Conflicts of Interests. None.

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