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RESEARCH ARTICLE

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Symptoms during pregnancy in primiparous women with congenital heart disease

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ABSTRACT

Background: As more women with congenital heart disease (CHD) are reaching childbearing age, it becomes more common for their symptoms to be evaluated during pregnancy. However, pregnancy-related symptoms are similar to those caused by heart disease. This study investigated the prevalence of factors associated with symptoms during pregnancy in women with CHD. *Methods:* The national birth register was searched for primiparous women with CHD who were registered in the national quality register for patients with CHD. *Results:* Symptoms during the third trimester were reported in 104 of 465 evaluated women. The most common symptom was palpitations followed by dyspnea. Factors associated with symptoms were tested in a univariable model; higher NYHA classification (>1) (OR 11.3, 95%CI 5.5–23.2), low physical activity (≤3 h/week) (OR 2.1 95%CI 1.3–3.6) and educational level ≤ 12 years (OR 1.9 95%CI 1.2–3.0) were associated with having symptoms. In multivariable analysis, low physical activity level (OR 2.4 95%CI 1.2–5.0) and higher NYHA class (OR 11.3 95%CI 5.0–25.6) remained associated with symptoms during pregnancy. There were no cases with new onset of impaired systemic ventricular function during pregnancy. *Conclusion:* Symptoms during pregnancy are common in women with CHD but are often already present before pregnancy. Because ordinary symptoms during pregnancy often overlap with symptoms of heart disease, it is important to know if symptoms were present before pregnancy and if they became worse during pregnancy. These results should be included in pre-pregnancy counselling and considered in the monitoring during pregnancy.

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Congenital heart disease; reproductive health; pregnancy; pregnancy symptoms

Introduction

As the population of adults with congenital heart disease (CHD) grows, more women with CHD are reaching childbearing age [1,2]. In the Western world, heart disease is now the leading cause of maternal mortality, whereas bleeding and infections are declining. Among all persons with heart disease during pregnancy, women with CHD are the largest group [3].

According to the European Registry of Pregnancy and Cardiac Disease (ROPAC), the mortality rate for pregnant women with CHD is approximately 1%, which is more than 100 times higher than among women without heart disease [4]. Women with CHD, especially those with severe complexity of heart disease, are thus considered a high-risk group with increased risk of miscarriage, premature birth, and other complications for both the mother and the child [3,5,6]. However, with early contact, regular follow-ups, monitoring of the progress of the pregnancy and cardiac function that includes symptoms and signs, and individual planning, most women with CHD can still go through pregnancy and childbirth [3–5].

Cardiac complications depend on the severity of the heart defect, ventricular function, current functional class, and the presence of cyanosis [3]. Heart failure [7] and arrhythmias [8] are the most common complications during pregnancy [9,10]. Classic heart failure symptoms and signs such as shortness of breath, palpitations, edema, dyspnea, and fatigue of varying degrees [11] may easily be confused with common and normal symptoms during pregnancy.

This aim of the present study was to investigate the prevalence of symptoms and the factors associated with these symptoms during pregnancy in primiparous women with CHD.

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Methods

Data for this register-based observational study were drawn from the linking of two national quality registers. The Register of Congenital Heart Disease (SWEDCON) is a register for patients with CHD from before birth throughout their entire lifespan [12,13]. Data from SWEDCON consisted of the following variables: social and demographic variables (*e.g.* age, marital status, housing, highest education, and employment status), a self-reported questionnaire measuring health-related quality of life, and the EuroQoL-5 Dimension Questionnaire (EQ5D). EQ5D is a short easy to use, validated and non-disease-specific questionnaire that measures quality of life [14]; also it is an integrated part of the SWEDCON. Moreover, the register consists of medical data (*e.g.* diagnosis, medication, catheterization or catheter interventions, type of surgery, and need for pacemaker), physiological data (*e.g.* electrocardiogram [ECG], and echocardiogram including systemic ventricular function with ejection fraction [EF] categorized as normal [EF >50%], mildly impaired [EF 40–50%], moderately impaired [EF 30–40%], or severely impaired [EF <30%]), general symptoms (*e.g.* edema, dyspnea, fatigue, chest pain, syncope and palpitations), and physical function scored by a cardiologist according to the New York Heart Association (NYHA) classification system.

The Swedish Medical Birth Register (MBR) is an administrative database that includes 98% of all pregnancies in Sweden that have led to birth after 22 + 0 weeks of gestation. The register includes information from the first antenatal visit that covers self-reported obstetric history, infertility, use of medication, socio-demographic data, self-reported height, and measured weight. It also contains information on pregnancies, birth, and neonatal data such as mode of delivery, pain relief during childbirth, singleton or multiple births, data on the new-born child, and maternal and infant diagnostic codes [15,16]. The present project included data from 1990 to 2017.

Study population

Women with CHD registered in SWEDCON between 1990 and 2017 and who were also registered in the MBR were included in the study. The inclusion criteria were as follows: (i) having a diagnosis of CHD, defined as a structural abnormality of the heart or intra-thoracic great vessels that was present at birth and was actually or potentially functionally significant, (ii) being 18 years of age or older, and (iii) having information on symptoms in SWEDCON. After removing patients with diagnoses not considered to be CHD (*e.g.* cardiomyopathies and primary arrhythmias, persistent ductus arteriosus ($n = 170$) with intervention on early in life, and women with persistent foramen ovale ($n = 445$) evaluated for and treatment of cryptogenic stroke) there remained 5266 pregnancies in women with CHD. In the next step, parous women ($n = 2750$) were excluded. Of the first-time pregnant women, 1007 had information about symptoms in SWEDCON; however, only 684 of these women visited their heart clinic during pregnancy and 465 visited the clinic during the third trimester (Figure 1).

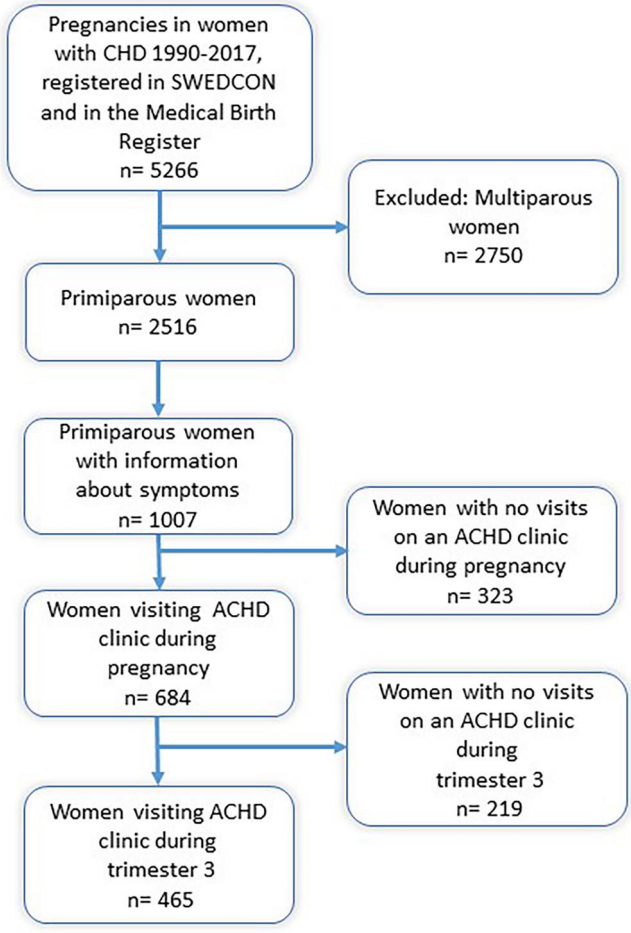

Figure 1. Overview of participants.

The women were categorized into three groups based on the complexity of CHD – mild, moderate, and severe, according to The European Society of Cardiology (ESC) guidelines [17], and these were then dichotomized into two groups – mild and moderate/severe.

This study was approved by the Swedish Ethical Review Authority (Ref nr 2020-00701).

Statistics

All calculations were performed using version 28 of SPSS (IBM, Armonk, NY, USA). The data were assessed for normality. Differences in means were tested with Student's *t*-test, and ANOVAs and ratios were tested with a chi^2-test. A multivariable model was constructed that including variables with a *p*-value = <0.15 at the univariable level; age had a *p*-value higher than 0.15 but was included in the model due to its assumed biological importance and to correct the model for age. Multivariable testing was performed in a manual backward manner. Collinearity was assessed during the analysis. A p-value < 0.05 was considered significant.

Results

Of the 5266 pregnancies that were identified, 465 women met the inclusion criteria and were included in the study

(Figure 1). The characteristics of the study population are presented in Table 1, and an overview of the womens' CHD diagnoses is presented in Table 2. In the population, 104 had symptoms during the third trimester that were most commonly palpitations ($n = 42$) followed by dyspnea ($n = 40$), fatigue ($n = 35$), edema ($n = 9$), chest pain ($n = 3$), and syncope ($n = 2$). Some patients experienced more than one symptom (Table 3). Women who experienced symptoms during the third trimester were more likely to have a higher NYHA functional class (>I) (66% *vs.* 15%, $p < 0.001$), lower educational level (27% *vs.* 17%, $p = 0.01$), and a less physically active lifestyle (≤3 h physical activity/week) (29% *vs.* 16%, $p = 0.01$).

Of the 104 women with symptoms in their third trimester, 68 (65%) had already had symptoms when visiting their ACHD clinic before becoming pregnant. Again, the most common symptoms were palpitations ($n = 24$), followed by dyspnea ($n = 21$), and fatigue ($n = 14$) (Table 3). Notably, only one person who experienced palpitations had atrial fibrillation.

Variables possibly associated with experiencing symptoms during the third trimester were tested in univariable mode as shown in Table 4. Results of the multivariable model are presented in Table 5. In this model, NYHA class > I and being physically active less than 3h/week remained associated with experiencing symptoms.

Of the women who experienced symptoms during the third trimester ($n = 104$), 9 had impaired systemic ventricular function before pregnancy. This number of cases with impaired systemic ventricular function did not increase during the third trimester of pregnancy.

Forty women reported symptoms when they visited their ACHD clinic for the first time after pregnancy. The timing of the follow-up visits varied with a median of 18 months (minimum 5, maximum 82 months) after delivery. At this point, fatigue was the most common symptom (Table 3).

When estimating NYHA class during the third trimester, 41 patients were in NYHA class II-III with 27 of these known before pregnancy. A worsening of functional class was mainly seen in the group with aortic valve disease but was not associated with impaired systemic ventricular function.

Discussion

This register-based study of pregnant women with CHD showed that most did not experience any heart-related symptoms during pregnancy, which indicates that pregnancy is well tolerated by most women with CHD. In addition, those who experienced symptoms during pregnancy were usually those who already had symptoms before becoming pregnant. In our CHD population, palpitations and dyspnea were the most reported symptoms; such symptoms are also common in healthy pregnant women due to changes in the cardiovascular system during pregnancy [18]. Fatigue was the most common symptom after pregnancy, however, it is known that the CHD population experiences a relatively high prevalence of fatigue [19].

Many of the symptoms during pregnancy may be expected due to the physiological changes that come with being pregnant, but they also may be a sign of worsening

Table 1. Overview of patient characteristics.

	Total $n = 465$	Symptoms $n = 104$	No symptoms $n = 361$	*p-value*
Age in years, *mean (±SD)*	28.6 (5.1)	28.2 (5.0)	28.7 (5.1)	0.33
Family situation *n (%)*				0.70[a]
Living alone	10	3 (30)	7 (70)	
Living together	408	91 (23)	317 (78)	
Educational level *n (%)*				0.01
≤12 years	223	61 (27)	162 (73)	
>12 years	188	32 (17)	156 (83)	
BMI, (kg/m^2) *mean (±SD)*	23.6 (4.1)	23.2 (3.5)	23.7 (4.3)	0.26
Physical activity, *n (%)*				0.004
≤3 h/week	247	71 (29)	176 (71)	
>3 h/week	144	23 (16)	121 (84)	
NYHA functional class *n (%)*				<0.001
I	316	46 (15)	270 (85)	
II-III	41	27 (66)	14 (34)	
Systemic ventricular function, *n (%)*				0.25
Impaired	29	9 (31)	20 (69)	
Normal	413	88 (21)	325 (79)	
CV medications during pregnancy, *n (%)*				0.26
Yes	65	18 (28)	47 (72)	
No	392	84 (21)	308 (79)	
EQ5D, *mean (±SD)*	81.1 (16.2)	68.7 (17.7)	84.6 (14.0)	<0.001
Complexity of the heart disease, *n (%)*				0.50
Simple lesions	164	37 (23)	127 (77)	
Moderate lesions	244	51 (21)	193 (79)	
Severe lesions	57	16 (28)	41 (72)	

BMI: body mass index ; NYHA: New York Heart Association; CV: cardiovascular; EQ5D: EuroQol-5 dimension questionnaire; SD: standard deviation.
[a]Fischer's Exact Test.

Table 2. Overview of congenital heart disease diagnoses.

Diagnosis, *n* /%)	Total $n = 465$	Symptom $n = 104$	No symptoms $n = 361$
Atrial septal defect	51	15 (29)	36 (71)
Ventricular septal defect	66	12 (18)	54 (82)
Aortic valve disease	88	19 (22)	69 (78)
Pulmonary valve disease	13	0 (0)	13 (100)
Marfan syndrome	27	3 (11)	24 (89)
Tetralogy of Fallot	25	4 (16)	21 (84)
Coarctation of the aorta	60	10 (17)	50 (83)
Atrioventricular septal defect	13	3 (23)	10 (77)
Ebstein anomaly	8	3 (38)	5 (62)
cc-TGA	4	1 (25)	3 (75)
TGA (arterial switch)	4	1 (25)	3 (75)
TGA (atrial switch)	25	6 (24)	19 (76)
TGA (Rastelli)	1	0	1 (100)
Pulmonary atresia with intact ventricular septum	3	1 (25)	2 (75)
Pulmonary atresia with ventricular septal defect	10	4 (40)	6 (60)
Double outlet right ventricle	5	1 (25)	4 (75)
Fontan/TCPC	5	2 (40)	3 (60)
Truncus arteriosus	1	0	1 (100)
Miscellaneous	31	9 (29)	22 (71)

cc-TGA: congenitally corrected transposition of the great arteries; TCPC: total cavopulmonary connection; TGA: transposition of the great arteries.

Table 3. Distribution of symptoms, divided into groups based on the complexity of the heart disease.

Distribution of symptoms at the visits before pregnancy			
	Simple lesions ($n = 28$)	Moderate lesions ($n = 33$)	Severe lesions ($n = 7$)
Edema	0	1	0
Dyspnea	9	10	2
Fatigue	8	6	0
Chest pain	4	1	0
Syncope	1	6	0
Palpitations	12	10	2
Total symptoms	34	34	4
Distribution of symptoms at the visits during the third trimester			
	Simple lesions ($n = 37$)	Moderate lesions ($n = 51$)	Severe lesions ($n = 16$)
Edema	4	3	2
Dyspnea	13	17	10
Fatigue	14	14	7
Chest pain	3	0	0
Syncope	0	2	0
Palpitations	16	22	4
Total symptoms	50	58	23
Distribution of symptoms after pregnancy			
	Simple lesions ($n = 15$)	Moderate lesions ($n = 18$)	Severe lesions ($n = 7$)
Edema	2	1	0
Dyspnea	3	7	2
Fatigue	6	7	4
Chest pain	3	0	0
Syncope	0	1	0
Palpitations	7	5	4
Total symptoms	21	21	10

Note that a patient could have more than one symptom.

Table 4. Univariable logistic regression analysis with perceived symptoms as dependent variable.

	Wald	OR	95 % CI	*p*-value
Age in years	0.9	1.0	0.9–1.0	0.34
BMI (kg/m^2)	1.0	1.0	0.9–1.0	0.31
Educational level $\leq$12 years	6.5	1.9	1.2–3.0	0.01
Physical activity $\leq$3 h/week	7.9	2.1	1.3–3.6	0.005
Complexity, *moderate/severe lesions*	0.0	1.0	0.6–1.6	0.99
NYHA > I	43.9	11.3	5.5–23.2	<0.001
Cardiovascular medication, *yes*	1.7	1.5	0.8–2.7	0.19
Impaired systemic function[a]	2.3	1.8	0.8–4.1	0.13

OR: odds ratio; CI: confidence interval; BMI: body mass index; NYHA: New York Heart Association; $p < 0.05$.
[a]Not included in multivariable analysis due to small numbers.

of the heart disease. Some of the pregnant women who experienced symptoms had impaired ventricular function. Of these, the majority were patients with transposition of the great arteries with a previous atrial switch operation. Despite this, only 44% of those who had impaired systemic ventricular function and had undergone atrial switch experienced symptoms. However, most of the patients with atrial switch remained asymptomatic during pregnancy, irrespective of ventricular function. These findings are in line with a previous study that showed that women who had undergone atrial switch often remained asymptomatic during pregnancy [20].

Table 5. Multivariable model with variables associated with perceived symptoms.

	Initial model				Final model			
	Wald	OR	95 % CI	*p*-value	Wald	OR	95 % CI	*p*-value
Age	0.5	1.0	0.9–1.0	0.46				
Educational level ≤12 years	1.5	1.6	0.8–3.2	0.22				
Physical activity ≤3 h/week	5.6	2.4	1.2–5.0	0.02	4.4	2.0	1.1–3.9	0.04
NYHA > I	33.5	11.3	5.0–25.6	<0.001	37.12	10.30	4.9–21.8	<0.001

OR: odds ratio; CI: confidence interval; NYHA: New York Heart Association.
$p < 0.05$.

Only 22% of the patients experienced symptoms during pregnancy, which was somewhat more common among patients with severe heart lesions. However, the complexity of heart disease did not emerge as an important factor in the regression analysis. In this context, it is worthy to note that there is a selection advice given to women with CHD. If certain cardiovascular criteria are present, such as extremely complex lesions with severe cyanosis, patients are likely to be advised against pregnancy [5]. This potential exclusion of high-risk patients may thus reduce the risk of becoming symptomatic during pregnancy.

Aortic valve disease is a potential problem during pregnancy, both before and after intervention. Significant aortic stenosis may be a contraindication to pregnancy, whereas aortic regurgitation is usually well tolerated. In patients with mechanical valves, anticoagulation poses risks, including mortality, for both the mother and the fetus [21]. In the present study, we show that women with aortic valve disease, mainly aortic stenosis of various degrees, were more common among those with a worsening NYHA class during pregnancy. This worsening may be both acceptable to the patient and an acceptable medical risk that is not necessarily related to other, and potentially more severe complications. Nevertheless, the risk of worsening of NYHA class should be included in the preconception consultation for those women for whom pregnancy is still advised.

The absence of symptoms in most patients within our cohort may be a result of the well-developed healthcare in a high-income country where nearly all women with CHD are followed in tertiary centers and by specialized services. These women are followed on a regular basis before and during pregnancy, often by a multidisciplinary team according to contemporary guidelines [5,22].

Limitations

This is a register study and thus restricted to the persons within the register. However, both registers have high coverage and validity [13,16].

As in most registered studies, missing data posed a potential problem; however, the missing data were evenly distributed and had no obvious effect on selection bias. When patients with data on symptoms at any time during pregnancy were compared with those who had data only in the third trimester, there were no differences in either age or the distribution of diagnoses. Furthermore, as there was no control group comparisons with healthy women were not possible. However, here we exclusively study within group differences and associations.

Conclusions

Most of the women with CHD did not report symptoms during pregnancy. However, one-fourth of the women had symptoms during the third trimester that were most commonly palpitations. Higher NYHA class, lower educational level, and being physically active less than 3h/week were associated with symptoms during the third trimester. A majority of those with worsening NYHA class had aortic valve disease. These data should be considered in the monitoring during pregnancy and included in pre-pregnancy counseling. Since symptoms can easily be missed or confused with ordinary symptoms during pregnancy, special attention should be given to the worsening of pre-existing symptoms. One way to gain more knowledge about how women with CHD experience symptoms during pregnancy is to include interviews with this population in future research.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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References

[1] Mandalenakis Z, Giang KW, Eriksson P, et al. Survival in children with congenital heart disease: have we reached a peak at 97%? J Am Heart Assoc. 2020;9(22):e017704.

[2] Marelli AJ, Ionescu-Ittu R, Mackie AS, et al. Lifetime prevalence of congenital heart disease in the general population from 2000 to 2010. Circulation. 2014;130(9):749–756. doi: 10.1161/CIRCULATIONAHA.113.008396.

[3] Roos-Hesselink J, Baris L, Johnson M, et al. Pregnancy outcomes in women with cardiovascular disease: evolving trends over 10 years in the ESC registry of pregnancy and cardiac disease (ROPAC). Eur Heart J. 2019;40(47):3848–3855. doi: 10.1093/eurheartj/ehz136.

[4] Dawson AJ, Krastev Y, Parsonage WA, et al. Experiences of women with cardiac disease in pregnancy: a systematic review and metasynthesis. BMJ Open. 2018;8(9):e022755. doi: 10.1136/bmjopen-2018-022755.

[5] Regitz-Zagrosek V, Roos-Hesselink JW, Bauersachs J, et al. 2018 ESC guidelines for the management of cardiovascular diseases during pregnancy: the task force for the management of cardiovascular diseases during pregnancy of the European society of cardiology (ESC). Eur Heart J. 2018;39(34):3165–3241. doi: 10.1093/eurheartj/ehy340.

[6] Drenthen W, Boersma E, Balci A, et al. Predictors of pregnancy complications in women with congenital heart disease. Eur Heart J. 2010;31(17):2124–2132. doi: 10.1093/eurheartj/ehq200.

[7] Ruys TP, Roos-Hesselink JW, Hall R, et al. Heart failure in pregnant women with cardiac disease: data from the ROPAC. Heart. 2014;100(3):231–238. doi: 10.1136/heartjnl-2013-304888.

[8] Furenäs E, Eriksson P, Wennerholm U-B, et al. Effect of maternal age and cardiac disease severity on outcome of pregnancy in women with congenital heart disease. Int J Cardiol. 2017;243:197–203. doi: 10.1016/j.ijcard.2017.04.100.

[9] Drenthen W, Pieper PG, Roos-Hesselink JW, et al. Outcome of pregnancy in women with congenital heart disease: a literature review. J Am Coll Cardiol. 2007;49(24):2303–2311. doi: 10.1016/j.jacc.2007.03.027.

[10] Haberer K, Silversides CK. Congenital heart disease and women's health across the life span: focus on reproductive issues. Can J Cardiol. 2019;35(12):1652–1663. doi: 10.1016/j.cjca.2019.10.009.

[11] McDonagh TA, Metra M, Adamo M, et al. 2021 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure: developed by the task force for the diagnosis and treatment of acute and chronic heart failure of the European society of cardiology (ESC) with the special contribution of the heart failure association (HFA) of the ESC. Eur Heart J. 2021;42(36):3599–3726. doi: 10.1093/eurheartj/ehab368.

[12] Swedish Registry of Congenital Heart Disease. 2020 https://www.ucr.uu.se/swedcon/arsrapporter/arsrapport-swedcon-2020/viewdocument/280. [cited 2021-10-01].

[13] Bodell A, Björkhem G, Thilén U, et al. National quality register of congenital heart diseases–can we trust the data? J Congenit Heart Dis. 2017;1(1):11. doi: 10.1186/s40949-017-0013-7.

[14] Rabin R, de Charro F. EQ-5D: a measure of health status from the EuroQol group. Ann Med. 2001;33(5):337–343. doi: 10.3109/07853890109002087.

[15] Swedish Medical Birth Register. https://www.socialstyrelsen.se/statistik-och-data/register/medicinska-fodelseregistret/2023. [cited 2023-04-11].

[16] Cnattingius S, Källén K, Sandström A, et al. The Swedish medical birth register during five decades: documentation of the content and quality of the register. Eur J Epidemiol. 2023;38(1):109–120. doi: 10.1007/s10654-022-00947-5.

[17] Baumgartner H, De Backer J, Babu-Narayan SV, et al. 2020 ESC guidelines for the management of adult congenital heart disease: the task force for the management of adult congenital heart disease of the European society of cardiology (ESC). Endorsed by: association for european paediatric and congenital cardiology (AEPC), international society for adult congenital heart disease (ISACHD). Eur Heart J. 2021;42(6):563–645. doi: 10.1093/eurheartj/ehaa554.

[18] Datta S, Kodali BS, Segal S. Maternal physiological changes during pregnancy, labor, and the postpartum period. In: obstetric anesthesia handbook. New York: Springer; 2010. pp. 1–14.

[19] Ternrud L, Hlebowicz J, Sandberg C, et al. Prevalence of fatigue in adults with congenital heart disease. Cardiol Young. 2022;32(9):1–8. doi: 10.1017/S1047951121004297.

[20] Pizula J, Devera J, Ng TM, et al. Outcome of pregnancy in women with d-transposition of the great arteries: a systematic review. J Am Heart Assoc. 2022;11(23):e026862.

[21] Bortnick AE, Levine LD. Valvular heart disease in pregnancy. Clin Obstet Gynecol. 2020;63(4):910–922. doi: 10.1097/GRF.0000000000000570.

[22] Lammers AE, Diller G-P, Lober R, et al. Maternal and neonatal complications in women with congenital heart disease: a nationwide analysis. Eur Heart J. 2021;42(41):4252–4260. doi: 10.1093/eurheartj/ehab571.