Parental reactions, distress, and sense of coherence after prenatal versus postnatal diagnosis of complex congenital heart disease

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Abstract

Introduction: A diagnosis of congenital heart disease (CHD) in offspring triggers psychological distress in parents. Results of previous studies have been inconsistent regarding the psychological impact of a prenatal versus a postnatal diagnosis. The aim of this study was to evaluate the influence of the time of diagnosis on levels of parental distress. *Methods:* Pregnant women and their partners with a fetus diagnosed with complex CHD, parents of children with postnatally diagnosed CHD, and pregnant women and their partners with uncomplicated pregnancies were invited to participate. Data were collected during pregnancy and 2–6 months after delivery using the Hospital Anxiety and Depression Scale, sense of coherence, life satisfaction, and Dyadic Adjustment Scale. *Results:* During pregnancy, the prenatal group scored lower sense of coherence compared to controls (p=0.044). Postnatally the prenatal group scored lower on sense of coherence compared to the postnatal group and controls (p=0.001; p=0.001). Postnatally, the prenatal and postnatal groups had higher levels of anxiety compared to controls (p=0.025; p=0.0003). Life satisfaction was lower in the prenatal group compared to that in the postnatal group and in controls (p=0.000; p=0.0004). *Conclusion:* Parents with a prenatal diagnosis of CHD in offspring report a low sense of coherence already during pregnancy which decreased further at follow-up. The same group reported a lower satisfaction with life compared to parents of a child with postnatal diagnosis of CHD and parents of a healthy child. This motivates further efforts to improve counselling and support during pregnancy and for parents after a prenatal diagnosis.

A prenatal diagnosis of congenital heart disease (CHD) triggers psychological distress in parents.[1–3] Maternal depression, anxiety, and stress during pregnancy may negatively affect neonatal outcome.[4,5] Postpartum distress in parents can contribute to cognitive and socio-emotional disturbances in neonates and may be associated with poor infant development.[6]

If we could identify those at increased risk of these side effects of prenatal screening, we would be able to optimise care and maybe improve outcome. Furthermore, an increased awareness and understanding of possible protective psychosocial factors of importance such as coping mechanisms,[3] social support, ability to comprehend a stressful situation, and the capacity to use the healthcare resources available could contribute to improved support during these stressful situations.[7] A possible protective factor is sense of coherence which concentrates on an individual´s resources and abilities to maintain well-being. It can explain how individuals, regardless of distressing circumstances and hardship, remain well.[8]

Studies on the impact of prenatal versus postnatal diagnosis have shown conflicting results regarding psychological distress in parents of children with CHD,[3,9–12] and sense of coherence has not been extensively studied in this context.

The purpose of this study was to estimate sense of coherence, degree of anxiety, depression, life satisfaction, and satisfaction with partner relationship in three groups of parents: those with a prenatal diagnosis of CHD in offspring, those with a postnatal diagnosis, and a group with uncomplicated pregnancies and deliveries.

Material and methods

Setting and patients

Study patients were recruited from three different hospitals in the Västra Götaland Region in Sweden during 2013–2016. To be eligible, patients had to understand and speak the Swedish

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Table 1. Cardiac diagnoses and duration of hospital stay during the first admission after birth in the pre- and postnatally diagnosed groups matched for the postnatal assessment at Time 2

	Prenatal group	Postnatal group	p
Diagnoses	n=8	n=22	
VSD		2	
CoA ± VSD		3	
AS ± CoA		2	
ToF	1	1	
TGA ± VSD	1	8	
Truncus arteriosus	1	1	
AVSD, DORV		1	
PA, VSD, MAPCA		1	
DORV		1	
Aortic atresia, VSD		1	
HLHS	2		
DILV, AoA hypoplasia	1	1	
Double discordance	1		
PA, IVS	1		
Duration of hospital stay after birth (median and range)	36 (1–262)	24.5 (1–332)	0.565

Abbreviations: VSD=ventricular septal defect; CoA=coarctation of the aorta; AS=aortic stenosis; ToF=tetralogy of Fallot; TGA=transposition of the great arteries; AVSD=complete atrioventricular septal defect; DORV=double outlet right ventricle; HLHS=hypoplastic left heart syndrome; DILV=double inlet left ventricle; AoA=aortic arch hypoplasia; PA=pulmonary atresia; IVS=intact ventricular septum.

language. After obtaining informed consent, the patients were asked to complete a questionnaire.

The prenatal group comprised pregnant women and their partners, with a diagnosis of CHD in the fetus. Patients meeting this inclusion criterion were consecutively offered participation in the study at their first visit to the fetal cardiology clinic if this appointment took place after 22 completed weeks, otherwise (and most commonly) in conjunction with the first follow-up examination after 22 completed weeks. The underlying reason was that the upper gestational age limit for termination of pregnancy in Sweden is 22 completed weeks, and we wished to avoid any interference in their decision process whether to continue the pregnancy or not.

The postnatal group were parents of children with postnatally diagnosed CHD who were consecutively recruited after delivery.

The control group included pregnant women with a normal screening ultrasound examination at 18–20 weeks' gestation. They were all consecutively recruited during 3 weeks in the spring of 2014 by midwives performing the routine screening ultrasound.

Data collection

Data were collected through a questionnaire during pregnancy within 1 month after inclusion (prenatal group and controls, Time 1) and at 2–6 months after delivery (all three groups, Time 2). Before the follow-up questionnaire was sent, the medical file was checked to confirm that the baby was alive and medically stable (not hospitalised or in intensive care). Number of eligible women/partners in each group is shown in Figure 1 as well as the numbers included at Time 1 and Time 2 (after matching).

Cardiac defects and matching of groups for postnatal comparisons

All three groups were matched for mothers' and fathers' age, sex, and parity; for the prenatal and postnatal groups; and also for complexity of CHD. The prenatal group comprised 15 fetuses and all had complex cardiac defects defined as defects requiring surgery before 12 months of age. All were included at Time 1 resulting in 28 patients at this time (13 couples, 1 pregnant woman, and 1 partner). Of the 15 fetuses/neonates, 7 did not survive to be included at Time 2. The 15 parents of the remaining 8 infants were matched with 30 parents of 22 infants in the postnatal group. After matching, it was found that all 22 infants in the postnatal group also had complex cardiac defects (Table 1).

Measures

Depression and anxiety

The Swedish version of Hospital Anxiety and Depression Scale was used to estimate depression and anxiety.[13] The scale was developed to screen for depression and anxiety among patients in non-psychiatric hospital clinics. The Hospital Anxiety and Depression Scale includes 14 items, 7 measuring anxiety and 7 measuring depression. Each item is rated on a four-point scale (3–0) from "Yes definitely" to "No, not at all." A cut-off of 7/21 for anxiety and the same for depression has been identified. The Hospital Anxiety and Depression Scale is a valid instrument with a Cronbach's α 0.83 for anxiety and 0.82 for depression.[13]

Sense of coherence

Sense of coherence is a key concept of the salutogenic model developed by Aaron Antonovsky[8] and consists of three dimensions: 1) comprehensibility, which refers to how a person perceives the stimuli that one encounters as consistent, structured, and clear; 2) manageability, which is the extent to which one perceives that the available resources are sufficient to meet life's demands; and 3) meaningfulness, which refers to the extent to which one feels that life makes sense emotionally.[7,8] The Swedish version of the short sense of coherence scale (13 items) was used. Items are rated on a seven-point Likert scale. The sense of coherence scale has been shown in previous studies to have good psychometric properties, test–retest reliability (R 0.52–0.97), and excellent internal consistency, Cronbach's α (0.74–0.91).[7,8,15]

Life satisfaction

Life satisfaction was measured by a questionnaire including 11 items which target important life domains such as vocational, financial, leisure situations, contacts with friends, sexual life, self-care management, family life, partner relationships, and physical and psychological health.[16] Each item was scored on a six-point scale from 1 (very dissatisfied) to 6 (very satisfied). The life satisfaction scale is a valid and frequently used questionnaire, Cronbach's α 0.85.[17]

Satisfaction with the relationship

To measure satisfaction with the relationship, the Dyadic Adjustment Scale was used. It reflects levels of agreement within

Table 2. Socio-demographic characteristics of patients at Time 1 and Time 2

Variable (n and %)	Time 1		Time 2 – matched groups		
	Prenatal group (n=28)	Controls (n=152)	Prenatal group (n=15)	Postnatal group (n=30)	Controls (n=88)
Sex					
Female	14 (50%)	79 (52%)	7 (46.7%)	15 (50%)	44 (50%)
Age (mean and SD)	31.5 (4.1)	30.8 (4.7)	32.8 (3.3)	32.8 (5.2)	32.9 (4.0)
Education					
Upper secondary school	8 (28.6%)	53 (34.9%)	1 (6.7%)	10 (33.3%)	36 (40.9%)
University	19 (67.9%)	96 (63.2%)	14 (93.3%)*	20 (66.7%)	52 (59.1%)*
Occupation					
Unemployed	0 (0%)	3 (2%)	0 (0%)	0 (0%)	1 (1.1%)
Employed	27 (96.4%)	130 (85.5%)	14 (93.3%)	24 (80%)	80 (90.9%)
Self-employed	0 (0%)	7 (4.6%)	0 (0%)	2 (6.7%)	3 (3.4%)
Other	1 (3.6%)	7 (4.6%)	1 (6.7%)	4 (13.3%)	4 (4.5%)
Size of city					
>200 000	17 (60.7%)	56 (37.1%)	8 (53.3%)	6 (20%)	26 (29.5%)
50 000–200 000	0 (0%)	48 (31.8%)	0 (0%)	12 (40%)	32 (36.4%)
20 000–50 000	1 (3.6%)	14 (9.3%)	1 (6.7%)	1 (3.3%)	8 (9.1%)
Rural area (<20 000)	10 (35.7%)	33 (21.9%)	6 (40%)	11 (36.7%)	22 (25%)
Years in present relationship Mean and SD	6.55 (4.02)	6.92 (3.92)	6.73 (3.2)	6.77 (3.1)	7.63 (4.39)
Parity					
No previous children	12 (42.9%)	60 (42%)	5 (33.3%)	12 (40%)	27 (31%)
Previous children	16 (57.1%)	83 (58%)	10 (66.7%)	18 (60%)	60 (69%)

*Time 2 postnatal group versus controls p=0.011.

the couple and discriminates between well-adjusted couples, poorly adjusted couples and couples with a high likelihood of divorce (below 100). The questionnaire includes 32 items divided into four subscales: dyadic consensus (the degree to which couples agree on matters of importance to the relationship), dyadic satisfaction (the degree to which couples are satisfied with their relationship), dyadic cohesion (the degree of closeness and shared activities experienced by the couple), and affectional expression (the degree of demonstrations of affection and sexual relationships). The items are dichotomous (yes/no) or Likert scale (0–5) with a maximum score of 151 (higher scores indicate better quality of the relationship).[18] The Dyadic Adjustment Scale has been shown to be a valid instrument, Cronbach's α 0.98.[19]

Socio-demographic characteristics

Data included age, sex, educational level, occupation, size of city where they live, years in present relationship, gestational week, and parity.

Statistical analysis

The statistical software SAS was used. For categorical variables, n (%) is presented; and for continuous variables, mean (standard deviation). For comparisons between groups, Fisher's exact test was used (lowest 1-sided p value multiplied by 2) for dichotomous variables; the Mantel–Haenszel χ^2 test for ordered categorical variables, and the χ^2 test for non-ordered categorical variables. Mann–Whitney U test and Kruskal–Wallis test were used for continuous variables. For

comparisons over time, Wilcoxon Signed Rank test was used for continuous variables and Sign test for categorical variables.

Results

The response rate was 82% (n=28) in the prenatal group, 100% (n=52) in the postnatal group, and 51% (n=152) in controls (Figure 1). There was no difference in follow-up at Time 2 between the three groups (p=0.368). It was 164 days (98–210) in the prenatal group, 170 days (66–210) in the postnatal group, and 190 days (78–199) in the control group.

Background characteristics for comparison at Time 1 – prenatal

Socio-demographic characteristics of patients at Time 1 and Time 2 are shown in Table 2. Because there were no significant differences in background characteristics between the prenatal group and controls, the comparison at Time 1 was made between unmatched groups (prenatal group n=28, controls n=152). However, patients in the prenatal group completed the questionnaires at a later gestational age than those in the control group (prenatal 31.0 weeks ± 3.6, controls 24.4 weeks ±2.8, p<0.0001).

Background characteristics for comparison at Time 2 – postnatal

Since age, parity, and educational level differed at Time 2 between the three groups (see supplemental Table 2a), they were matched
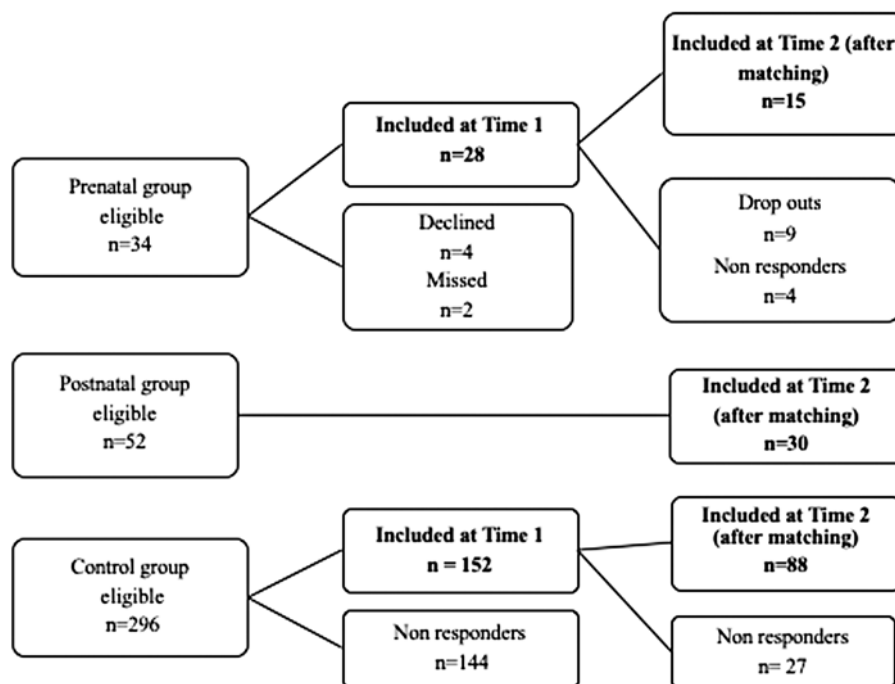
Figure 1. Eligible pregnant women/partners at Time 1= prenatal assessment, Time 2=postnatal assessment.

for age, sex, and parity and for the prenatal group and the postnatal group and also for complexity of CHD. After matching, the number of patients in the prenatal group were n=15, postnatal group n=30, and controls n=88 (Table 2 and Figure 1). There was one difference after matching: the proportion with university education (prenatal group 93%, controls 59%; p=0.011). It was not possible to match for educational level because too few patients in the postnatal group had university education. The results of matching for complexity of CHD are shown in Table 1. As can be seen, the complexity of CHD and the hospital stay after birth were similar in the two groups.

Anxiety and depression

Prenatal assessment – Time 1

The mean values of patients in the prenatal group and controls were <7 on anxiety or depression at Time 1 (7 is the cut-off value for possible need for treatment of anxiety and depression), though the prenatal group scored higher for symptoms of depression compared to controls (p=0.002), Table 3.

Postnatal assessment – Time 2

During follow-up, the mean values for parents in both the prenatal and postnatal groups were above 7 on anxiety. These scores were higher than for parents in the control group (prenatal versus controls p<0.02; postnatal versus controls p<0.0001), Table 2. There was no difference between the prenatal and postnatal groups (p=0.73). Both the prenatal and postnatal groups scored higher on symptoms of depression compared to the control group, but still below the cut-off level for depression, see Table 3.

Satisfaction with life

Prenatal assessment – Time 1

No differences were found in satisfaction with life between the prenatal group and controls (p=0.273), Table 3.

Postnatal assessment – Time 2

Life satisfaction was lower in parents in the prenatal group compared to the postnatal group (p<0.001) and controls (p<0.001). In addition, the postnatal group scored higher than controls (p=0.002), Table 3. Life satisfaction decreased in the prenatal group from Time 1 to Time 2 (p=0.01), Table 4. The mean change differed between the prenatal group and controls (p=0.006).

Sense of coherence

Prenatal assessment – Time 1

During pregnancy, expectant parents in the prenatal group had a lower sense of coherence compared to controls (p=0.044), Table 3.

Postnatal assessment – Time 2

Parents in the prenatal group scored lower on sense of coherence compared to both parents in the postnatal group (p=0.001) and controls (p=0.001), Table 3. Sense of coherence decreased in the prenatal group from Time 1 to Time 2 (p=0.05), Table 4.

Satisfaction with the relationship

Prenatal assessment – Time 1

No differences were found between parents in the prenatal groups and controls, Table 3.

Postnatal assessment – Time 2

Parents in the postnatal group scored satisfaction with the relationship significantly higher than parents in the control group (p=0.012), Table 3. No differences were found between parents in the prenatal group and controls (p=0.44). In the control group, but not in the prenatal group, the mean change from Time 1 to Time 2 was significant (p≤0.0001), Table 4.

Table 3. Comparisons between groups at Time 1=prenatal assessment and Time 2=postnatal assessment

Variable mean (SD)	Time 1			Time 2					
			p Value				p Value		
	Prenatal group n=28	Control group n=152	Prenatal group versus Control group	Prenatal group n=15	Postnatal group n=30	Control group n=88	Prenatal group versus Postnatal group	Prenatal group versus Control group	Postnatal group versus Control group
HAD									
Anxiety	6.11 (3.9)	5.11 (3.16)	0.220	7.60 (4.69)	8.18 (4.16)	5.05 (3.15)	0.73	0.025	<0.0001
Depression	3.96 (2.85)	2.38 (2.0)	0.002	5.73 (4.18)	4.37 (3.36)	2.93 (2.57)	0.27	0.002	0.049
LiSat									
Sum score	52.0 (7.0)	53.6 (5.8)	0.273	44.9 (9.9)	56.5 (5.0)	52.4 (6.2)	<0.0001	<0.0001	0.002
SOC									
Total sum	66.6 (9.6)	70.8 (9.1)	0.044	59.6 (12.6)	72.5 (7.5)	70.4 (10.6)	0.001	0.001	0.469
DAS									
Total score	116.6 (9.9)	120.0 (10.1)	0.273	115.3 (14.8)	121.8 (12.5)	115.6 (14.1)	0.10	0.443	0.012

SD=standard deviation; HAD=Hospital and Anxiety scale; LiSat=life satisfaction; SOC=sense of coherence; DAS=Dyadic Adjustment Scale.

Table 4. Mean change from Time 1=prenatal assessment to Time 2=postnatal assessment

Mean (SD)	Prenatal group Mean change from Time 1 to Time 2 n=14	p Value	Control group Mean change from Time 1 to Time 2 n=75	p Value
HAD				
Anxiety	0.714 (5.25)	p=0.69	0.197 (2.06)	p=0.43
Depression	1.14 (4.67)	p=0.57	0.35 (2.008)	p=0.23
LiSat				
Sum score	−6.29 (8.63)	p=0.013	−0.97 (4.487)	p=0.059
SOC				
Total sum	−5.63 (9.63)	p=0.048	−1.08 (7.40)	p=0.27
DAS				
Total score	−0.808 (9.64)	p=0.46	−4.19 (9.99)	p=0.0001

SD=standard deviation; HAD=Hospital and Anxiety scale; LiSat=life satisfaction; SOC=sense of coherence; DAS=Dyadic Adjustment Scale.

Discussion

There are clear medical benefits from diagnosing CHD prenatally.[20] It enables centralised delivery of infants with critical CHD, thereby optimising perinatal care to improve short- and long-term outcomes.[20–23] In Sweden, as well as in many other countries, prenatal diagnosis also gives pregnant women the option to terminate pregnancy when a cardiac defect is diagnosed. A prenatal diagnosis may, however, result in high levels of psychological distress in expecting parents,[1–3,19] which may have negative effects on fetal and neonatal outcome.[4,5] A postnatal diagnosis is also associated with parental distress and previous studies report increased, decreased, or no difference in parental psychological distress when CHD has been prenatally diagnosed as compared to a postnatal diagnosis.[3,9–12] Furthermore, there is lack of knowledge about potential indicators that could help healthcare professionals identify individuals at increased risk of developing psychological distress regardless of when the diagnosis is made.

In the present study, patients were only asked for participation when a decision to continue the pregnancy had already been made in order not to interfere with the decision process whether pregnancy should be terminated or continued. Parents of children with a pre- or postnatal diagnosis of CHD irrespective of the time of diagnosis reported higher levels of anxiety compared to parents of children without CHD at 2–6 months after delivery. The anxiety levels were on a moderate level indicating possible need for treatment of anxiety.[14] No group reported depression (>7 is the cut-off value for possible depression) at the prenatal or at the postnatal assessment. This observation could be an indication that targets for intervention should be anxiety more than depression.[11]

In a small study by Brosig et al,[9] higher levels of distress was found 6 months after birth in parents of children with a prenatal diagnosis of severe CHD compared to those with a postnatal diagnosis and normal controls. We did not find a similar difference but a lower satisfaction with life, and a low level of sense of coherence in the prenatal group was recorded. Surprisingly, parents of children with a postnatal CHD diagnosis reported significantly higher satisfaction with life than parents of healthy children. The same group (postnatal) also displayed a higher sense of coherence compared to parents with a prenatal diagnosis. It has been suggested that a high sense of coherence is protective against critical life events[26] and is a predictor of a better quality of life.[27] It has also been suggested that critical life events may lead to an impairment of sense of coherence.[24] This phenomenon was confirmed in the present study in which the sense of coherence decreased significantly from Time 1 to Time 2 in the group with prenatal diagnosis. However, since we did not have baseline data on sense of coherence before diagnosis, it is not known to which extent the sense of coherence in the prenatal or postnatal group was affected by the diagnosis in itself. The mean score for sense of coherence in the prenatal group was significantly lower compared to the other two groups. Furthermore, compared to the mean sense of coherence level in parents of healthy children (at 6 months of age), as shown in a previous study from Sweden[28] (sense of coherence mean 68–72), our prenatal group reported a lower sense of coherence. Sense of coherence has been described

as being associated with high education, good economy, good social support and social integration though this was not supported in a systematic review article by Eriksson et al.[25] It was evident that the group with a prenatal diagnosis had a significantly higher educational level but the lowest sense of coherence. Parents of children with postnatally diagnosed CHD reported higher sense of coherence, higher satisfaction with relationship, and a better satisfaction with life compared to parents in the prenatal group and controls.

In a study by Rychik et al,[4] partner/marital satisfaction was associated with less maternal stress, and the use of the coping mechanism denial was associated with more maternal stress, anxiety, and depression. There is probably an important link between the level of psychological distress experienced by parents and sense of coherence/satisfaction with relationship that should be explored in future research. By measuring the sense of coherence level, it might be possible to determine how parents having children with CHD find their life comprehensible, manageable, and meaningful.

The results recorded in the present study indicate that parents with a prenatally diagnosed fetus scored lower life satisfaction and sense of coherence than those with a postnatal diagnosis. One explanation could be the emotional reaction, dilemma, and distress associated with the decision whether or not to terminate the pregnancy. This could potentially be the starting point of a higher psychosocial distress, which continues throughout the pregnancy and have consequences postnatally as well. Another aspect is that a prenatal diagnosis is sometimes less precise regarding the most likely postnatal outcome because of the continued development of the heart during the rest of pregnancy. It may, for example, not always be possible to predict with certainty at 18–20 weeks of gestation whether a biventricular repair will be possible after birth or whether one will have to plan the surgical treatment along a univentricular route. Such an uncertainty in terms of both the precision of the prenatal diagnosis and the long-term prognosis may be one cause of increased psychological distress compared to when the diagnosis is made after birth.

To completely prevent distress after a prenatal diagnosis of CHD is of course impossible but healthcare professionals need to have good knowledge and understanding of the psychological reactions in parents to be able to develop strategies aiming at decreasing psychological distress. Health promotion focusing on strengthening sense of coherence may be a promising new strategy, potentially affecting levels of psychological distress. To accomplish this, it is important to develop clinically useful methods. In a previous study by Bratt et al,[29] parents emphasised the importance of support from other parents with experience from similar situations. Parental support groups have been shown to be effective in assisting expectant mothers to improve coping strategies, increasing cohesion and a sense of power and belonging, and decreasing anxiety and depression as some of the benefits.[30–32] Furthermore, health professionals need to make sure that expectant parents feel involved in the planning of the postnatal care, that they are offered sufficient information, and that they have access to emotional and instrumental support structures.[33]

Limitations

There are certain limitations to the present study that should be addressed. There was a difference in educational level between the prenatal group and controls at Time 2 that remained after matching, and this might have influenced the results. Although all cardiac defects were complex (after matching), the groups were small and there was an overrepresentation of newborns with single ventricle defects in the prenatal group. Although there was no significant difference in the duration of hospital stay between the groups, we cannot exclude that varying degrees of complexity and varying results of surgical treatment might have influenced the results. However, the duration of hospital stay after birth was not different between the groups, indicating that they were of comparable complexity. Furthermore, differences between prenatal and controls may partly depend on the difference in gestational age that surveys have taken. Finally, we cannot exclude that the different response rates in the three groups might have influenced the results. A strength of the study was the matching for age, sex, parity since these variables could potentially affect the results.

Conclusion

In conclusion, parents with a prenatal diagnosis of CHD in offspring report a low sense of coherence already during pregnancy which decreased further at follow-up. The same group reported a significantly lower satisfaction with life compared to parents of a child with postnatal diagnosis of CHD and to parents of a healthy child. Irrespective of the time of diagnosis, parents with a child with CHD reported higher levels of anxiety and depression compared to parents of healthy children. This motivates further efforts to improve counselling and support during pregnancy for parents after a prenatal diagnosis.

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