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Stress in adults with congenital heart disease – preliminary results on anxiety, life events, coping and socioeconomic factors (RCD code: IV)

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Abstract

We performed pilot analysis of the anxiety level, frequency of life events and their interactions among adults with congenital heart disease (CHD), and evaluated their coping strategies and socioeconomic functioning. In a cross-sectional questionnaire study on 30 consecutive ambulatory patients with CHD we addressed these issues by a custom-designed tool incorporating state-anxiety scale of the State-Trait Anxiety Inventory, the brief-COPE questionnaire (Polish versions) and 10 selected life events. We found that state-anxiety level adjusted for sex, age and life events differed by CHD defect category (R2 = 0,51; p<0,001). Other factors are characterized and briefly discussed. JRCD 2014; 1 (6): 10–14

Key words: congenital heart disease, emotional stress, anxiety, life events, coping

Background

Adults with congenital heart disease (CHD) is a population of patients growing in size, due to the progress in pediatric heart surgery and the following clinical care[1]. A significant number of cases, however, can still be regarded as rare cardiovascular diseases, especially when we consider the characteristics of each individual initial and residual defects and complications. These patients require tailored care in highly specialized centers, that incorporate various medical specialties to ensure the comprehensiveness of high quality treatment[2]. The socioeconomic status and mental health issues in this group has been largely neglected in this complexity of medical care, and only a few reports exist that address the anxiety and other determinants of stress among grown-ups with CHD[3]–[5]. Some of the reports suggest increased anxiety levels[3], while others claim no difference with controls[4].

Aims

In this paper we present preliminary results from a study aimed to evaluate the anxiety level in Polish population of adults with CHD, and its relation to disease severity, socioeconomic factors, life events and coping strategies.

Methods

Measures

Data were collected during ambulatory visits using a specially constructed questionnaire for self-completion. The tool incorporated Polish versions of Spielberger's *State-Trait Anxiety Inventory (STAI)* to assess state-anxiety, and Carver's *brief-COPE questionnaire* to characterize coping strategies. *Life events in the preceding six months* were evaluated using 10 custom-designed items with yes-no answers and a field to indicate which event had the greatest impact on the well-being of the individual (Table 2). Additional items included basic socioeconomic and demographic data as well as fields to count the number of physicians currently providing

Conflict of interest: none declared.

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Table 1. Basic demographic and socioeconomic data in the study subgroups

	Simple valve or vessel		Simple septal		Tetralogy of Fallot		Other Complex		Whole group	
N	6	20%	6	20%	9	30%	9	30%	30	100%
Women	1	16.7%	1	16.7%	5	55.6%	5	55.6%	12	40%
Median age (Q1-Q3)	22.5	(21–33)	22	(21–27)	29	(22–33)	24	(20–34)	23.5	(21–33)
Education										
Elementary and basic practical	0	0%	2	40%	2	40%	1	20%	5	16.7%
Secondary or technical	1	7.7%	3	23.1%	5	38.5%	4	30.8%	13	43.3%
Higher or student	4	40%	1	10%	2	20%	3	30%	10	33.3%
Not specified	1	50%	0	0%	0	0%	1	50%	2	6.67%
Occupationally active or studying	5	83.3%	4	66.7%	4	44.4%	3	33.3%	16	53.3%
Financial difficulties	2	33.3%	1	16.7%	4	44.4%	2	22.2%	9	30%
Life partner	3	50%	2	33.3%	4	44.4%	5	62.5%	14	48.3%
Children	1	16.7%	1	16.7%	1	11.1%	3	33.3%	6	20%
Support from family or friends	6	100%	6	100%	9	100%	9	100%	30	100%
Median attending physicians (Q1-Q3)	3	(2–4)	1	(1–1)	1	(1–2)	2	(2–3)	2	(1–3)
Median of visits in the last six months (Q1-Q3)	5	(2.5–8.5)	2	(2–3)	3	(0–6)	3.5	(3–5)	3	(2–5)

No significant differences were found, however, when grouped into Simple and Complex CHD classes differences at the border of statistical significance were noted for occupational activity and gender distribution.

care and visits, defined as every hospitalization, transfer to another hospital and ambulatory appointment in the preceding six months (Table 1).

Subjects and data handling

30 consecutive participants were divided into four subgroups of CHD defect category as shown in Table 1. *Simple valve or vessel* group comprised two bicuspid aortic valves, two pulmonary stenoses, one aortic coarctation and one clipped patent ductus arteriosus. *Simple septal* category consisted of four isolated ventricular and one atrial septal defect, as well as one case of corrected triatrial heart. Patients with *tetralogy of Fallot* formed the third group, while every other subject with complex CHD fell into the fourth *Other complex* category. To enhance statistical power in certain analyses, the former and the latter two were merged into *Simple defect* and *Complex defect* classes respectively.

Source data were essentially complete, a small number of omitted or doubtfully marked items in the questionnaires were replaced by the means of the corresponding subscale (e.g. in *STAI-state* separately for simply and inversely scored items). *State-anxiety score (STAI-state)* was adjusted for age and sex by assigning centiles (*STAI-centile*) according to the Polish normalization to each raw score (separately for males and females aged 18–20, 21–40, 41–54 and 55-69)[6]. We calculated a simple *sum of life events* to include them as a covariate independent variable in the analysis of anxiety. Each *coping strategy* was derived as simple mean from the two corresponding items and compared with the mean in the adult population according to the Polish normalization[7].

Statistical methods

All statistical analyses were conducted using STATISTICA 10 (StatSoft, Inc., Tulsa, OK, USA, www.statsoft.com). Quantitative variables were assessed for normality of distribution by graphic analysis and *Shappiro-Wilk test*, as well as for homogeneity of variances by *Brown-Forsythe test*, in the compared independent subgroups. Since the normality of distribution was rarely met in the studied group, we provided *medians* and upper values of the first and third quartile (Q1-Q3), and performed *Mann-Whitney U test* and *Spearman's rank correlations*, unless otherwise specified. In *ANCOVA*, due to the robustness of variance analysis for slight infringement of the normality assumption, we allowed for inclusion of non-normally distributed variables in these analyses, if the distribution was not suggestively skewed in graphic investigation, and their means and standard deviations were not correlated. *Corrected R2* was reported as the model's goodness-of-fit. *Post-hoc* analyses included *Tukey's test* for uneven groups, as well as normality of residuals and homogeneity of regression slopes testing for interactions to verify assumptions. Unless otherwise specified, all variables in a covariance model had statistically significant contribution. *Chi2 test* was used to assess differences in qualitative variables, and *Yates' correction* was applied if any subgroup counted less than 10 cases. We assumed statistical significance level at $p<0,05$ in all tests.

Table 2. **Results from psychological questionnaires**

A.	**Mean score (standard deviation) in 14 coping strategies based on brief-COPE questionnaire**			
	Simple defect (N = 12)	**Complex defect (N = 18)**	**Whole group (N = 30)**	**¥Population[1] (N = 590)**
1. Active coping	¥1.88 (0.86)	1.81 (0.69)	1.83 (0.75)	1.87 (0.79)
2. Planning	¥1.88 (0.86)	2.08 (0.55)	2.00 (0.68)	1.89 (0.79)
3. Positive revaluation	1.67 (0.75)	**2.19 (0.52)	*1.98 (0.66)	1.67 (0.77)
4. Acceptance	1.79 (0.72)	*2.25 (0.46)	*2.07 (0.61)	1.78 (0.77)
5. Humorousness	¥1.04 (0.78)	0.75 (0.49)	0.87(0.63)	0.82 (0.78)
6. Turn to religion	¥1.13 (1.03)	¥***1.72 (0.84)	¥***1.48 (0.95)	0.85 (0.85)
7. Seeking emotional support	¥2.17 (0.69)	**2.33 (0.49)	***2.27 (0.57)	1.66 (0.91)
8. Seeking instrumental support	¥2.00 (0.52)	*2.08 (0.43)	**2.05 (0.46)	1.56 (0.93)
9. Doing something unrelated	1.63 (0.83)	1.67 (0.42)	*1.65 (0.60)	1.34 (0.84)
10. Denial	¥0.83 (0.65)	¥0.94 (0.73)	*0.90 (0.69)	0.63 (0.71)
11. Expulsion	¥*1.42 (0.56)	**1.47 (0.81)	¥***1.45 (0.71)	1.01 (0.69)
12. Psychoactive substance use	0.38 (0.48)	*0.06 (0.16)	0.18 (0.36)	0.37 (0.65)
13. Cessation of actions	0.46 (0.45)	*0.94 (0.84)	0.75 (0.74)	0.58 (0.60)
14. Blaming oneself	¥1.04 (0.69)	*0.75 (0.71)	*0.87 (0.71)	1.20 (0.76)
B.	**Proportion of life events in the preceding six months**			
	Simple defect (N = 12)	**Complex defect (N = 18)**	**Whole group (N = 30)**	**Relative impact[2]**
1. Major life change (e.g. work, relationship, place of living)	17%	28%	23%	57%
2. Close person's life change	17%	39%	30%	11%
3. Loss of a close person	0%	28%	17%	80%
4. Diagnosis of a new disease	0%	6%	3%	100%
5. Aggravation requiring hospitalization	8%	17%	13%	50%
6. Unhappy accident	8%	11%	10%	33%
7. Daily hassles	8%	17%	13%	50%
8. Change of surroundings (e.g. family meeting, vacation)	25%	39%	33%	10%
9. Significant decision	50%	17%	30%	33%
10. Other event	0%	22%	13%	25%
C.	**Median (Q1-Q3) life events count and state-anxiety**			
	Simple defect (N = 12)	**Complex defect (N = 18)**	**Whole group (N = 30)**	
Life events (range: 0–10)	1.5 (0–2)	1.5 (1–4)	1.5 (0–3)	
STAI-state (range: 20–80)	38 (32,5–46)	34.5 (25–38)	36 (29–40)	
STAI-centile[3] (range: 0–100)	59.5 (27–81.5)	29 (8–46)	35 (13–64)	

*- p<.05, **- p<.01, ***- p<.001; ¥ – normal distribution; interpretation of these results should be extremely cautious, since the only available statistics was parametric (t-test equivalent), fragile to any violations in the normality of distribution.

[1] – Coping strategies were compared to general population of adults according to Polish normalization[7]. No significant difference was observed between subjects falling into simple or complex defect category. The following ranks are assigned within the questionnaire for each behavior: 0 – almost never, 1 – rarely, 2 – often, 3 – almost always. Results shown are the mean ranks of behaviors constituting each coping strategy scale.

[2] – Relative impact of the event is the proportion of how many times this particular event was marked as having the greatest influence on the responder's well-being to the total occurrence of this event in the studied group. This parameter was not used in the present analyses to rank the events, but might be useful in larger study groups.

[3] – Adjusted for sex and age group according to Polish normalization[6].

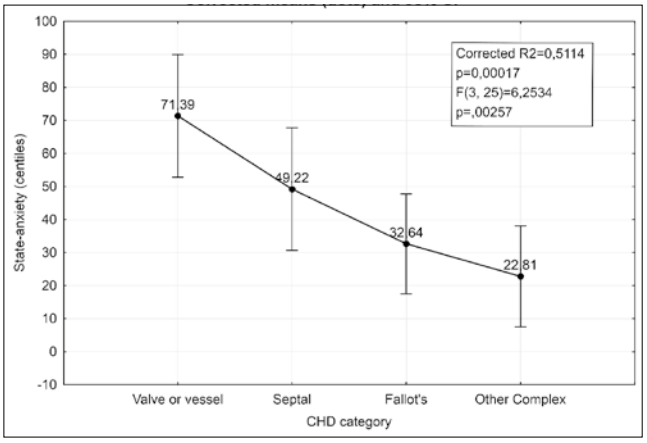

Figure 1. Covariance analysis (ANCOVA) of state-anxiety adjusted for sex, age group and sum of life events in the preceeding six months vs. defect category. Corrected means (dots) and 95% CI (brackets)

Results

Socioeconomic factors

Basic demographic and socioeconomic data of the studied group is shown in Table 1. Only 53% of participants are *occupationally active or studying*, no more than one third has *higher education or* is *studying*, and as many as 30% declared having *financial difficulties*. Less than half is in relationship with a *life partner* and only 20% possesses *offspring* (in one case adopted). It is also worth pointing out that median count of *attending physicians* (3; Q1-Q3: 2–4) and *visits in the preceding six months* (5; Q1-Q3: 2.5–8.5) was seemingly the greatest in the *Simple valve or vessel* defect category. Still, there were no significant differences between the subgroups. 100% of participants declared receiving support from family or friends when they need it.

Coping strategies

Characteristics of coping strategies is shown in Table 2A. The only proper conclusion is that adults with CHD, especially those with complex defects, declare *more frequent religious behaviors* than general population (see captions). However, one can see more tendencies, which would require confirmation in larger sample. For instance strategies of *expulsion*, *denial* and *doing something unrelated*, which together form a construct of *avoidance strategies*, tend to be higher in all patients with CHD than in general population. Similar can be noted for *seeking support*, both *instrumental* and *emotional*, while *acceptance* of difficult situation, its *positive revaluation* and *cessation of actions* seem to be more frequent only in people with complex CHD. No significant differences were noted between the subgroups.

Life events

No significant difference between the CHD classes was observed in the structure of life events as shown in Table 2B. Borderline statistical significance in the frequency of *significant decision* regarding future or treatment option and *loss of a close person* was achieved if *Yates' correction* was not applied. The median sum of life events was also no different.

Anxiety

The median *state-anxiety adjusted for sex and age group* (*STAI-centile*) was corresponding to the 35th centile (Q1-Q3: 13–64) of the general population. *STAI-centile* was moderately correlated with the *sum of life events* (R=0.49; p<0.01) and *blaming oneself* coping strategy (R=0.54; p<0.01). The difference in medians between *Simple* and *Complex* CHD classes was at the border of statistical significance (59.5, Q1-Q3=27–81.5 vs. 29, Q1-Q3=8–46; p=0.06). A model (ANCOVA) comprising *STAI-centile*, *sum of life events* and *four CHD categories* explained more than half of the variance in *state-anxiety* (R2=0.51; p<0.001) as shown on Figure 1. Similar results were achieved when we included only a bimodal grouping variable, dividing patients into *Simple* or *Complex* CHD class (R2=0.48, p<0.001). The addition of *blaming oneself* strategy to the model explained additional 4% of the variance (R2=0.55; p<0.001), but this was limited by a significant interaction between *life events* and this coping strategy in testing homogeneity of regression slopes (p<0.05) and by sample size. Post-hoc analyses showed that *state-anxiety* adjusted for *sex*, *age*, and *life events* differed only between *Simple valve or vessel* and *Other complex* categories of CHD (71.4; 95%CI: 52.8–89.9 vs. 22.8; 95%CI: 7.5–38.1; p<0.05) or between *Simple* and *Complex* CHD classes in bimodal analysis (60.3; 95%CI: 46.6–73.9 vs. 27.8; 95%CI: 16.6–39; p<0.05).

Discussion

State-anxiety, standardized for gender and age group, was not heightened in the studied group as a whole, according to the Polish normalization. However, after adjustment for the burden of *life events* in the covariance analysis we were able to identify a subset of patients with an elevated level of anxiety: subjects with simple CHD, and mainly those with simple valvular or vascular defects. Conversely, patients with complex CHD, especially those other than *Fallot's syndrome*, had low *state-anxiety* level. Inclusion of more variables in the model was limited by sample size and their interactions as shown above.

This is in contrast with the previous reports showing significantly higher *state-anxiety*[4] or *total anxiety* and associated symptoms in adults with CHD[3]. We identified two studies comparing anxiety between different CHD subgroups[4], [5], but only one found significant differences. In opposition to our findings, they reported the higher anxiety, the more severe the disease, as expressed by the type of undergone surgery – *curative*, *reparative* or *palliative*[5]. However, since both studies used other grouping criteria and concentrated more on the *trait-anxiety* (which is a psychological construct possibly more closely related to the aspect we would like to measure, but in our belief associated with much larger recollection error), our results are not directly comparable with earlier reports.

Additionally, it is worth noting that most *Complex defects* were already surgically corrected, whereas most *Simple defects* remained in observatory group and some of them were expecting surgery. We previously found that awaiting surgery is a potent stressor, increasing *state-anxiety*[8] and that differences in *coping patterns* may in-

fluence *negative emotionality*, including anxiety, in patients scheduled for surgery[9]. Hence, we hypothesize that being considered for heart surgery is a possible confounder, not captured in this pilot study. Study participants declared significantly more frequent *religious behaviors* than general population of Polish adults in response to stressful situation. Several other tendencies in coping strategies were noted, but inconclusive due the violation of assumptions for parametric testing. These were roughly in line with previous reports[10], but further investigation is needed in this field.

Also, none of the identified studies included *life events* as a covariate affecting anxiety level. Relatively low proportion (13%) of affirmative answers to a question whether there was any other event that influenced subject's well-being and its low *relative impact* (25%, see captions in Table 2) suggest that this short and tailored list of *life events* we propose is quite complete, and does not indicate the need to incorporate the originally published *questionnaire of life events* comprising more than 80 items[11]. Although statistically insignificant in our study group, people with *Complex defect* tend to be less occupationally active and more socially dependent, as reviewed elsewhere[2], which may also contribute to the observed outcome.

Limitations

This study is restricted mainly by sample size. Furthermore, at the present pilot stage, several factors that might potentially influence results, such as concomitant diseases, duration of the explicit CHD (e.g. time from diagnosis), severity of symptoms, intellectual functioning or antidepressants use were not evaluated. This provides an important direction for our further study in a larger patient sample. Another aspect is that all subjects came from a single tertiary care center with focus on rare and complex cardiovascular diseases, which may limit the generalization of results on all adults with CHD.

Conclusions

State-anxiety adjusted for gender, age and life events vary in different categories of CHD, tending to be inversely related with the complexity of the disease. This effect might be in part due to differences in coping strategies and socioeconomic functioning. Further evaluation of stress and associated psychological aspects in the Polish population of adults with CHD is needed.

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