The systemic right ventricle

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Sexuality in adult patients with congenital heart disease and their partners

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ABSTRACT
Data on relational and sexuality issues in adult patients with congenital heart disease (CHD) are scarce. The current study aimed to evaluate relational and sexual behavior, satisfaction, and functioning in a representative sample of patients with CHD and their partners. In addition, we aimed to evaluate the relation between sexuality parameters and quality of life. Relational and sexuality issues were assessed using a Sexuality Questionnaire in 133 patients (52% male, 37±13 years) with CHD (43 coarctation of the aorta, 42 transposition of the great arteries, 36 Marfan syndrome, and 12 Eisenmenger syndrome), and 74 partners. Quality of life was assessed using the SF-36. Data were compared to an age- and sex-matched control group (n=3642). Seventy one percent of patients with CHD was involved in a relationship, which is significantly less compared to controls (79%, p<0.05). Nonetheless, patients perceived their relationship as more satisfactory compared to controls (p<0.05). Overall, sexual satisfaction was equal in patients compared to controls, although they perceived lower body esteem (p<0.001), decreased sexual esteem (p<0.05), and more distress during sex (p<0.001). Patients reported no more erectile and lubrication problems compared to partners, and controls. We found significant associations between most relational, and sexual parameters and quality of life. In conclusion, many aspects of sexuality are affected in adult patients with CHD, whereas their partners remain relatively unaffected. Moreover, sexuality is an important aspect of quality of life in these patients. We advise physicians to be receptive to discuss sexuality issues, and provide patients with adequate therapy.
INTRODUCTION

Sexuality is considered an important aspect of quality of life in patients with acquired heart disease, and is receiving increased attention.\(^1\)\(^-\)\(^3\) It is known that patients with acquired heart failure suffer from loss in sexual interest, decreased sexual frequency, decline of sexual satisfaction, and increased incidence of sexual dysfunction.\(^1\)\(^,\)\(^2\) Although changes in patients’ sexuality seem to have no negative influence on marital relationships, partners are known to suffer from distress during sexual contact, and from a decrease in frequency of sexual contact.\(^1\)\(^,\)\(^3\) Sexuality in patients with congenital heart disease (CHD) could well be equally affected, as their physical condition is often diminished, complications are numerous and the use of medication is high.\(^4\)\(^-\)\(^6\) Nonetheless, knowledge on sexuality in adult patients with CHD remains sparse. Only few studies have been performed on the subject, focusing primarily on young, male patients or on reproductive issues in female patients with CHD.\(^7\)\(^-\)\(^11\) To overcome this hiatus in current knowledge, the present study aimed to evaluate both relational as well as sexual behavior and satisfaction, and sexual functioning in a representative sample of adult patients with CHD, and their partners. Additionally, we evaluated the influence of relational and sexuality issues on these patients’ quality of life.

METHODS

Adult patients with CHD were derived from the CONCOR registry, the Dutch national registry of adult patients with CHD.\(^12\) Two-hundred thirty-one patients (70 patients with Marfan syndrome, 69 patients with coarctation of the aorta, 67 patients with transposition of the great arteries, and 25 patients with Eisenmenger syndrome) were eligible to participate in the study, and were contacted by telephone (from November 2008 till May 2009) to request their participation. Patients with partners were asked to request their current partner’s participation. An age- and sex-matched control group (\(n = 3642\)) was used to compare patients and their partners with the Dutch population. The control group was recruited by the Rutgers Nisso Group, the Dutch Expert Center on Sexuality, using the internet
panel Euroclix (>200,000 members). Recruitment was performed from November 2005 till February 2006. The first 2,000 subjects were randomly recruited from this panel, after which specific groups of subjects were requested to participate in the study to obtain a representative sample form the Dutch population.\textsuperscript{13}

The study complies with the Declaration of Helsinki, and has been approved the ethics committees of all participating tertiary referral centers.

Patients’ and their partners’ relational and sexual behavior, satisfaction, and functioning were evaluated using a 169-item sexuality questionnaire, which was developed for this study in collaboration with the Rutgers Nisso Group.\textsuperscript{13} The questionnaire consisted of 5 domains. Appendix 1. In summary, ‘subjective health perception’ focused on patients’ current health perception. ‘Relational satisfaction’ contained questions on marital status and satisfaction with current relationship,\textsuperscript{14} whereas ‘sexual satisfaction’ contained questions on sexual behavior and sexual perception.\textsuperscript{15} ‘Sexual functioning’ included gender-specific sexual dysfunction,\textsuperscript{16} and ‘sexuality and cardiac condition’ focused on heart disease related emotional and physical problems in relation to sexuality.\textsuperscript{17} For the latter domain, data were not obtained from the general population. All subjective sexuality scores range from 1 to 5, except sexual distress, which was scored 1 to 4, with higher scores representing a more positive sexual attitude. Additionally, patients were asked whether they were interested to receive additional information on sexuality and their disease.

Health related quality of life was assessed by means of the Dutch translation of the Medical Outcomes Study Short Form 36 item health survey (SF-36),\textsuperscript{18} which comprises of 36 questions on 8 domains (physical functioning, role functioning physical, bodily pain, general health perception, vitality, social functioning, role functioning emotional, and mental health). Scores range from 0 to 100, with higher scores representing better quality of life. The 8 domains were combined into 2 higher-ordered clusters; the Physical Component Summary (PCS) and the Mental Component Summary (MCS). Patients’ SF-36 scores were
compared with published age- and gender-matched norms from a Dutch reference population.

For statistical analyses SPSS 16.0 (SPSS INC., Chicago, Illinois) for Windows was used. Statistical significance was set at $p < 0.05$. Descriptive data are presented as mean with standard deviation if normally distributed or as median with range as appropriate. The 8 dimensions of the SF-36 scores were converted to standard scores on the basis of the scores of an age- and gender-matched representative reference sample of the Dutch population. A standard score indicates how many standard deviations the observed SF-36 score falls below or above the score from the reference population. Consequently the score of the reference population is set at 0. Linear regression analysis were used to identify and estimate risk factors for decreased relational and sexual parameters. Comparison of discrete variables was performed using the Chi-square or Fisher's exact test. Comparison of continuous variables between 2 groups was performed using an unpaired Student’s T-tests, or the Mann-Whitney test if data were not normally distributed, and comparison of continuous variables among 3 or more groups was performed using the ANOVA or Kruskal-Wallis test and post hoc tests with a Bonferroni correction.

RESULTS

Of the 231 eligible patients, 223 (97%) could be reached telephonically, of whom 209 (90%) agreed to participate. A total of 133 patients returned their questionnaires, as did 73 partners. Figure 1. There were no statistically significant differences in cardiac condition, sex, or age between patients who did, and who did not return the questionnaire, nor between patients and their partners. Table 1. The control group was age- and sex-matched and consisted of 3642 subjects (50% male, 40 ± 12 years).
Table 1. Baseline characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Patients (n=133)</th>
<th>Partners (n=73)</th>
<th>Controls (n=364)</th>
<th>CoA (n=43)</th>
<th>TGA (n=42)</th>
<th>MS (n=36)</th>
<th>ES (n=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>69 (52%)</td>
<td>30 (41%)</td>
<td>1821 (50%)</td>
<td>26 (60%)</td>
<td>25 (60%)</td>
<td>14 (39%)</td>
<td>4 (33%)</td>
</tr>
<tr>
<td>NYHA class I</td>
<td>102 (77%)</td>
<td>-</td>
<td>-</td>
<td>39 (91%)</td>
<td>31 (74%)</td>
<td>32 (89%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>NYHA class II-IV</td>
<td>31 (23%)</td>
<td>-</td>
<td>-</td>
<td>4 (9%)</td>
<td>11 (26%)</td>
<td>4 (11%)</td>
<td>12 (100%)</td>
</tr>
<tr>
<td>Medication B-blocker</td>
<td>42 (32%)</td>
<td>-</td>
<td>-</td>
<td>7 (16%)</td>
<td>7 (17%)</td>
<td>27 (75%)</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>Medication ACE/ATII</td>
<td>54 (41%)</td>
<td>-</td>
<td>-</td>
<td>13 (30%)</td>
<td>21 (50%)</td>
<td>16 (44%)</td>
<td>4 (33%)</td>
</tr>
<tr>
<td>Medication Diuretics</td>
<td>8 (6%)</td>
<td>-</td>
<td>-</td>
<td>3 (7%)</td>
<td>3 (7%)</td>
<td>0 (0%)</td>
<td>2 (17%)</td>
</tr>
<tr>
<td>Medication Other medication</td>
<td>61 (46%)</td>
<td>-</td>
<td>-</td>
<td>26 (61%)</td>
<td>9 (21%)</td>
<td>15 (42%)</td>
<td>12 (100%)</td>
</tr>
<tr>
<td>Medication No medication</td>
<td>47 (35%)</td>
<td>-</td>
<td>-</td>
<td>13 (33%)</td>
<td>29 (69%)</td>
<td>4 (11%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

* Data are years [range]; number of patients (percentage). ACE = angiotensin converting enzyme inhibitor; ATII = angiotensin II receptor antagonist; CoA = coarctation of the aorta; ES = Eisenmenger syndrome; MS = Marfan syndrome; NYHA = New York Heart Association; TGA = transposition of the great arteries.

Figure 1. Inclusion of patients with CHD and their partners.
In the sexuality questionnaire, patients report their subjective health perception to be similar compared to their partners and the Dutch population (patients 2.2±0.7; partners 2.1±0.7; population 1.9±0.7). Patients’ SF-36 scores were significantly lower on the PCS, but equal on the MCS compared to the general population (-0.2±0.9 vs. 0; and 0.1±1.0 vs. 0). Physical quality of life was particularly diminished in patients with Marfan Syndrome and the Eisenmenger Syndrome, with no differences in mental quality of life among groups. Figure 2.

Patients with CHD were less likely to be involved in a relationship compared to the general Dutch population (71% vs. 79%; p<0.05), although those patients who were involved in a relationship perceived their relationship as more satisfactory, as did their partners (patients 4.3±0.5; partners 4.3±0.4; population 4.1±0.6; p<0.01). Relational satisfaction was positively associated with both the PCS, and the MCS (r=0.2; p<0.05 and r=0.4; p<0.001, respectively).

The total number of sexual partners in their lifetime was significantly lower in patients, and their partners, compared to the general population (patients 5.4±7.6; partners 3.4±2.9; population 7.5±9.2; p<0.001). The average frequency of sexual contact in current relationship was equal between patients and the population, with lower figures only for patients with Eisenmenger syndrome (patients with Eisenmenger syndrome: <1 time/month; all other groups: >1 time/month; p<0.05). Although sexual satisfaction was equal among patients, partners, and the population (patients 1.5±0.7; partners 1.3±0.5; population 1.5±0.8), sexual contact caused distress in both patients and their partners, as compared to the control group (patients 1.0±1.1; partners 1.1±1.1; population 0.6±0.6). Figure 3. Both sexual behavior and sexual satisfaction were important factors of quality of life, as the frequency of having sexual contact was positively associated with the PCS (r=0.2; p<0.05) and sexual satisfaction was related to both PCS, and MCS (r=0.3; p<0.01, and r=0.3; p<0.01, respectively). The number of sexual partners, and the level of distress during sexual contact were not related to quality of life.
Figure 2. Quality of Life in adult patients with CHD.

The Physical Component Summary and the Mental Component Summary of the 36 item Short Form, among the 4 patient groups. Data are presented as mean ± 2 SD. * Significant difference with other group of p<0.01; † Significant difference with other group of p<0.001. CoA = coarctation of the aorta; ES = Eisenmenger syndrome; MS = Marfan syndrome; TGA = transposition of the great arteries.

We found that 42% of male patients experienced difficulties in either obtaining, and/or maintaining an erection during sexual contact, whereas 42% of partners, and 54% of healthy subjects experienced similar difficulties (p=N.S.). We found no relation between congenital cardiac defect, use of medication, or NYHA class and the occurrence of erectile problems. There was no relation between the presence of erectile problems and quality of life. Sixty-six percent of female patients had difficulties in obtaining, and/or maintaining sufficient vaginal lubrication for sexual contact, against 51% of partners, and 56% of healthy subjects, which was not statistically significant. Although we found no relation between lubrication difficulties and cardiac defect, or medication use, patients with lubrication difficulties had higher NYHA class (1.4±0.7 vs. 1.1±0.2; p<0.05). Female patients with difficulties in obtaining, and/or maintaining lubrication had significantly lower MCS (-0.5±1.2 vs. 0.4±0.8; p<0.05).
**Figure 3.** Sexual satisfaction and sexual distress.
Sexual satisfaction (a.), and levels of distress during sexual contact (b.) on a 1 to 5 scale among the general population, partners, and patient groups. Data are presented as mean ± 2 SD. * Significant difference with other group of p<0.05; † Significant difference with other group of p<0.01. CoA = coarctation of the aorta; ES = Eisenmenger syndrome; MS = Marfan syndrome; part. = partners; pop. = general population; TGA = transposition of the great arteries.

![Box plots for sexual satisfaction and distress](image)

**Figure 4.** Body esteem and sexual esteem.
Body esteem (a.), and sexual esteem (b.) on a 1 to 5 scale among partners, and patient groups. Data are presented as mean ± 2 SD. * Significant difference with other group of p<0.05; † significant difference with other group of p<0.01; ‡ significant difference with other group of p<0.001. CoA = coarctation of the aorta; ES = Eisenmenger syndrome; MS = Marfan syndrome; part. = partners; TGA = transposition of the great arteries.

![Box plots for body and sexual esteem](image)
Patients with the Eisenmenger Syndrome experience increased physical discomfort during sexual contact compared to partners, and other patient groups (p=0.01), whereas we found no differences among other patient groups. Overall, we found no relation between physical discomfort during sexual contact and age, or use of medication. However, increased NYHA class was related to physical discomfort during sex (r=0.4; p<0.001). Overall, physical discomfort during sexual contact was negatively associated with both PCS and MCS (r=0.42; p<0.001, and r=0.3; p<0.001, respectively). Patient’s body esteem was low in comparison to their partners (2.5 vs. 3.4; p<0.001), as was sexual esteem (3.2 vs. 3.5; p<0.05). Figure 4. Body esteem, and sexual esteem were positively associated with PCS and MCS (body esteem: r=0.3; p<0.001, and r=0.3; p<0.001; sexual esteem: r=0.5; p<0.001, and r=0.3; p<0.001).

Most patients (62.5%) stated that they felt the need to talk about sexuality issues. However, 80.6% of these patients would talk solely to their partners about these matters, whereas a mere 11.6% of patients would seek professional help.

**DISCUSSION**

Adult patients with CHD describe their relationships as highly satisfactory compared to the general population, although they are less likely to be involved in one. Overall sexual satisfaction is normal, although both patients and partners experience increased levels of distress, and patients stated more physical discomfort during sex. Patients with CHD have low body esteem and low sexual esteem, and they feel that their sex-life is negatively influenced by their cardiac defect. Moreover, sexuality is an important aspect of quality of life in these patients.

Three aspects are known to predominantly influence sex life of patients with acquired heart disease in a negative way; the decline in physical condition, changes in mental condition, and pharmacological therapy. Adult patients with CHD face similar challenges, as their physical condition is frequently diminished, complications are numerous, and the majority of patients being dependent on
pharmacological therapy. Notwithstanding the known impact of a cardiac condition on sexuality, only a few small studies had been performed on sexuality in adult patients with CHD, none of which included these patients’ partners. We found adult patients with CHD to be less likely to be involved in a relationship, compared to their peers. Although not confirmed by our results, this could be caused by a low self-perceived body image due to morphologic differences, smaller stature, and surgical scars. Moreover, physical manifestations of a cardiac condition could lead to fear of being rejected by a potential partner. On the other hand, those patients who are involved in a relationship judge their relationship as highly satisfactory. These findings confirm previous reports stating that the majority of patients with CHD are capable of maintaining normal marital relations.

Additionally, we found sexual behavior to differ significantly in adult patients with CHD compared to the general Dutch population. These findings are in line with those of Reid et al. and Lyon et al. who found lower rates of sexual activity in adolescents with CHD. Scars and cyanosis in adult patients with CHD increases self-consciousness and decreased body image, which could account for the decreased levels of sexual activity in these patients. Distress during sexual contact has previously been described in both patients with acquired heart disease, and their partners. Although patients with CHD are chronically affected by their condition, anxiety on possible complications could play a role in the distress. Partners are mostly confronted with their partner’s condition at a later age. The lack of thorough knowledge on the condition could well be the cause of increased anxiety.

Physical discomfort during sexual contact, as defined by exhaustion, pain, insensibility, tremor and a lack of energy during sex, was most pronounced in patients with Eisenmenger syndrome, which is not surprising, as sex equals light to moderate exercise. Jaarsma et al. described the relation between a heart failure patients’ 6-minute walk distance and level of sexual functioning, indicating that disease severity negatively influences sexuality. Besides patients with
Eisenmenger syndrome, patients with Marfan syndrome stated that their disease negatively influenced their sexuality. As the latter groups consists of a heterogeneous patient population, with an overall relatively low cardiac burden, there could be an important mental component.\textsuperscript{2, 28}

Adult patients with CHD did not suffer more from erectile or lubrication difficulties than their peers. Moreover, we found no relation between cardiac defect, or the use of cardiac medication and sexual dysfunction in these patients. These findings are in contrast with the report of Cook et al., who found patients on B-blockers and ACE-inhibitor to be more likely to experience erectile problems.\textsuperscript{29} Low patient numbers could be the cause for our negative results on the effect of cardiac medication on sexual dysfunction.

Quality of life was influenced by almost all relational and sexual components that were examined. Although we found only a minority of patients to be interested in professional help on sexuality issues, we advise physicians to be receptive to discuss this important issue. Patients who raise questions should be made aware of the fact that their cardiac condition and medication could have negative influence on their sexuality. To dispel the threshold to discuss sexuality is important, as psychological or pharmaceutical treatment of sexual problems could increase both sex life, and the overall quality of life in patients with CHD.

Currently, there are no internationally validated questionnaires to measure relational and sexual health. We feel that our questionnaire gives a representative view on relational and sexual health in this specific patient group. Our study was performed in patients with 4 different types of CHD. Nonetheless, we consider our study population to be representative for a much larger group of patients with CHD, as it comprises of patients with minor mental and physical limitations, to patients with more pronounced limitations. A substantial number of patients did not complete, or return the questionnaires. This could be due to the extent of the questionnaire, and to the private character of the questions.
The control group completed the questionnaires on the internet, whereas patients received the questionnaires at their home address, which could have caused different privacy expectations between these groups. In addition, control group information was collected 3 years prior to patient information.
12. van der Velde ET, Vriend JW, Mannens MM, Uiterwaal CS, Brand R, Mulder BJ. CONCOR, an initiative towards a national registry and DNA-bank of patients with congenital heart


