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Quality of Life, Health Status, and Depression:

Comparison Between Adolescents and Adults After the Fontan Procedure With Healthy Counterparts

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Abstract

Background—Quality of life (QOL) in adolescents and adults who have undergone the Fontan procedure and are living with only 1 ventricle is presumed to be diminished.

Objectives—This study aimed to compare QOL, health status, and prevalence of depression in adolescents/adults after the Fontan procedure with healthy counterparts and to identify predictors of QOL in the Fontan group.

Methods—Using a comparative, cross-sectional design, 54 adolescents and adults with single ventricle congenital heart disease who have undergone the Fontan procedure were compared with 66 age-matched healthy counterparts. Quality of life, health status, depression, and social support were measured using the Satisfaction With Life Scale, Short Form Survey Version 2, Patient Health Questionnaire Depression Module, and Multidimensional Scale of Perceived Social Support. Clinical variables were abstracted from medical records. Predictors of QOL were determined using multiple linear regression.

Results—Adolescents and adults in the Fontan group reported lower physical health status (mean [SD] = 46.5 [9.3] vs mean [SD] = 55.9 [5.1], $P < .001$) and were more depressed (mean [SD] = 7.3 [5.9] vs mean [SD] = 4.5 [4.3], $P < .004$) than their healthy counterparts. There were no differences in QOL, mental health status, or social support between the 2 groups. Functional status (New York Heart Association class), depression, and social support accounted for 55% of the variance in QOL in the Fontan group.

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Conclusions—Despite lower levels of physical health, the QOL of Fontan patients was comparable with that of their healthy counterparts; this finding contradicts previous proxy reports, self-reports, and assumptions that QOL is lower in patients with complex single ventricle congenital heart disease. However, because Fontan patients were more depressed than their healthy counterparts, the need for early screening and detection is warranted.

Keywords

depression; Fontan; health status; quality of life; single ventricle congenital heart disease

Advances in treatment of congenital heart disease (CHD) have enabled nearly 1.3 million children in the United States with significant heart defects to survive into adulthood.[1] At present, adult survivors of CHD are equal in number to children with this disease.[2,3] Single ventricle congenital heart disease (SVCHD) is considered 1 of the most severe forms of CHD and requires multiple surgical procedures in most cases.[4] Although the Fontan procedure provides satisfactory surgical palliation,[5] it leaves the patient with a single right or left ventricle and increased risk of late cardiac failure, exercise intolerance, and arrhythmias.[5,6]

Along with the medical residua of CHD, there is the potential for psychosocial difficulties.[7–13] Depressive symptoms, anxiety, and behavioral and social adjustment issues have been identified in the general CHD population.[7–14] However, conflicting reports exist regarding the level of psychological distress in CHD when compared with healthy peers. To our knowledge, there are no reports evaluating depression in adolescents or adults who have undergone the Fontan procedure.

Few studies have addressed health status[14–16] and QOL[17–19] in adolescents or adults who have undergone the Fontan procedure. Unfortunately, many of these studies had small sample sizes, included young children, and used a variety of health status instruments to evaluate QOL.[17–19] The meaning ascribed to QOL is subjective and differs among individuals, thus making it difficult to compare or contrast the literature on QOL when different conceptualizations and measurements are used.

As SVCHD mortality declines related to surgical palliation, the focus of clinical care and surgical modifications has turned to morbidity and QOL outcomes.[14] However, studies have shown inconsistencies in parent proxy reports with both overestimations and underestimations of QOL, health status, and functional abilities.[20–24] The current adolescent and adult Fontan survivors are from a previous surgical era. They have now reached an appropriate age to contribute meaningful self-report data on this phenomenon. This information is imperative for future comparisons of QOL, health status, and psychosocial issues in the current surgical era of single ventricle palliation.

The purpose of this study was to compare QOL, health status, and prevalence of depression in adolescents and adults with SVCHD who have undergone the Fontan procedure with those of age-matched, healthy control group and identify predictors of QOL in the Fontan group.

Methods

This study is a comparative, cross-sectional design with retrospective medical record reviews performed for clinical data.

Sample and Setting

After institutional review board approval was obtained, a convenience sample of 54 adolescent and adult Fontan patients, aged 15 to 50 years, were recruited from the Ahmanson–University of California, Los Angeles Adult Congenital Heart Disease clinic; the Children's Hospital Los Angeles Cardiology Clinic; and private cardiology practices and CHD support groups. Eligible adolescents and adults who have undergone the Fontan procedure were identified and referred by the patient's cardiologist and nurse practitioner or directly responded to study advertisements. In addition, participants entered the study in response to physician referral letters, clinic fliers, and support group newsletter advertisements. Additional recruitment was sought through local CHD support group meetings. Eligibility was assessed by the investigator either over the telephone or in person. The inclusion criteria were as follows: (1) aged 15 years and older, (2) English literacy, (3) single ventricle diagnosis, and (4) previous Fontan completion. Exclusion criteria were (1) severe visual, cognitive, or psychiatric problems precluding informed consent and self-administered questionnaire completion and (2) recent hospitalization or surgery (<3 months). Most patients return to baseline physical activity or better within 3 months after surgical procedure or hospitalization.

Sixty-six healthy adolescents and adults were recruited from local high schools, colleges, libraries, and malls. The healthy control group was matched for age (within 2 years), gender, ethnicity, marital status, educational level, and geographic region. Exclusion criteria for healthy controls included (1) cognitive or psychiatric problems precluding informed consent, (2) non-English literacy or visual impairment precluding completion of self-administered questionnaire packet, and (3) presence of any chronic illnesses or disabilities. Demographic characteristics of the healthy group did not differ from those of the Fontan group, indicating that it was a representative sample.

Procedures

Once eligibility was determined, consent was obtained for patients 18 years and older. For patients younger than 18 years, the parents and adolescents were approached together with parental consent and adolescent assent was required for participation. Once written informed consent/assent is obtained, the participant's clinical information was collected via medical record review by the investigator.

The questionnaire packet and a demographic intake form were completed by participants during a clinic visit or were given a self-addressed, stamped envelop to return the completed questionnaire. Monetary compensation of $20 was provided for the participant's time and inconvenience.

Measurements

Demographic information and clinical data were obtained through a standardized data collection form. A detailed medical record review was performed to obtain data on cardiac anatomy, single ventricle type, Fontan characteristics (type, fenestration, revisions), left ventricular ejection fractions (only on patients with single left ventricle), New York Heart Association (NYHA) classification, oxygen saturation level, history of arrhythmias, need for pacemaker, and current medications.

Quality of Life—Quality of life was defined as "the degree of overall life satisfaction that is positively or negatively influenced by the individual's perception of life domains important to them, including matters both related and unrelated to health."[25,26] This definition argues the notion that health status, health-related QOL, or functional status cannot be substituted for QOL. Therefore, the Satisfaction With Life Scale (SWLS)[27] was

used as a direct indicator of QOL. The SWLS consisted of 5 statements referring to general life satisfaction. Responses were scored on a 7-point Likert scale, ranging from 1 (strongly disagree) to 7 (strongly agree). The overall score was computed by summing the individual items scored, with minimum and maximum scores of 5 and 35, respectively. The sum of the scores was classified according to 7 levels of extreme satisfaction (31–35) to extreme dissatisfaction (5–9). The instrument has been extensively used in various healthy and nonhealthy populations, and its reliability and validity have been supported for measuring general life satisfaction.[28] In the current study, the Cronbach's α was measured at .84.

Health Status—Health status was defined as an individual's perceived impact of disease on daily function and well-being in physical, mental, and social domains of health.[29] Health status was measured using the Short-Form-36 Health Survey Version 2 (SF-36v2). The SF-36v2 is a widely used generic health survey instrument and has well-established psychometric properties with evidence supporting its reliability and validity data in both the United States and Europe.[30] The SF-36v2 is based on 35 items divided into 8 health domains: physical function (10 items), role limitations caused by physical health functioning (4 items), role limitations caused by emotional problems (3 items), social functioning (2 items), emotional well-being (5 items), energy (4 items), pain (2 items), and general health perception (5 items). Two summary scores were calculated from the 8 domain scores, which include a physical component summary (PCS) and mental component summary (MCS). Item number 36 is a general question on health transition and is not calculated in the summary scores. Scores ranged from 0 to 100, with higher scores indicating better health status. Correlations between the SF-36 and 15 other health measures ranged from 0.51 to 0.82 in mental health and 0.52 to 0.85 in physical health.[30] In this current study, the Cronbach's α was .83 and .81 for the PCS and MCS scores, respectively.

Depression—The Patient Health Questionnaire Depression Module (PHQ-9) is a self-administered instrument used to identify depression severity. The PHQ-9 scores of each of the 9 *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* criteria is 0 (not at all) to 3 (nearly every day).[31] The scores range from 0 to 27, with the sum of the scores greater than 20 (severe depression) to 0 (no depression). The PHQ-9 is a reliable and valid measure of depression severity,[31,32] with a Cronbach's α range of .86 to .89. For this study, Cronbach's α was measured at .88.

Social Support—Social support was measured using the Multidimensional Scale of Perceived Social Support, which has 12 items assessing 3 subscales of social support: family (4 items), friends (4 items), and significant other (4 items).[33] Responses to the questions were rated on a 7-point scale ranging from 1 (very strongly disagree) to 7 (very strongly agree). An overall score was summed and divided by 12. In addition, the scores on the 4 items that comprise each subscale were also summed and divided by 4. The average scores ranged from 1 to 7, with higher scores indicating increased levels of perceived social support. The Multidimensional Scale of Perceived Social Support is a reliable and valid measure of perceived social support with a Cronbach's α of .93, and the 3 subscales of family, friends, and significant others were .91, .89, and .91, respectively.[34] In this study, Cronbach's α was .92 for all 12 items and .71, .92, and .95 for the 3 subscales, respectively.

Data Analysis

Data were analyzed using SPSS for Windows (version 13.0, SPSS Inc, Chicago, Illinois). Descriptive statistics were used to present demographic and clinical data. Analysis of variance was used to determine the difference in QOL, health status, depression, and social support between groups. Hierarchical multiple linear regression using forced variable entry was used to determine the predictors of QOL among the Fontan group. Variables that

achieved univariate significance of less than .10 or variables that were considered theoretically important were included in multivariate analyses in a hierarchical fashion. Demographic characteristics (age, gender, and education) were included as covariates and were entered first. Next, to depict the impact of clinical variables on QOL NYHA classification, single ventricle type, and type of Fontan was entered as a second step. Satisfaction with life, physical and mental health status, depression, and social support were added as the third and final step in the model. Criteria for entry and removal of variables were based on the likelihood ratio test with entry and removal limits set at $P \leq .05$ and $P \leq .100$, respectively.

Results

Sample Characteristics

A total of 57 adolescents and adults in the Fontan group consented to participate; 54 completed the questionnaires (95% response rate). One participant was excluded because of severe developmental delay. Demographic and clinical characteristics of the study sample are listed in Table 1. The mean (SD) ages of the Fontan and healthy participants were 26 (9) and 25 (9) years, respectively. The demographic characteristics identified an even distribution of males and females; most were white (63%), single (73%), and employed or full-time students (93%) and have health insurance (94%). The clinical characteristics of adolescents and adults in the Fontan group are presented in Table 2.

Comparison of Quality of Life, Health Status, and Depression to Healthy Counterparts

The QOL, health status, and depression scores of adolescent and adults in the Fontan group and in the reference group are presented in Table 3. Adolescents and adults in the Fontan group reported significantly lower physical health status (mean [SD] = 46.5 [9.3] vs mean [SD] = 55.9 [5.1], $P < .001$) and were more depressed (mean [SD] = 7.3 [5.9] vs mean [SD] = 4.5 [4.3], $P < .004$) than their healthy counterparts. In the Fontan group, 32% showed moderate to severe depression (scores, >10) and 28%, mild depression (scores, 5–9) compared with 12% who showed moderate depression and 24%, mild depression in the healthy group. There were no differences in QOL, SF-36v2 mental health status, or social support between the 2 groups.

Predictors of Quality of Life in Adolescent/Adult Fontan Patients

The univariate relationship among QOL and demographic and clinical variables was examined in the Fontan group. The best model associated with QOL was NYHA class, depression, and social support accounting for 55% of the variance (Table 4). No demographic variables were associated with QOL in this cohort.

Discussion

Our findings demonstrate that QOL does not differ in patients with complex SVCHD and their healthy counterparts. Two previous studies in Fontan survivors support the findings of normal or satisfactory QOL,[18,19] which contradicts previous assumptions, parental proxy reports, or self-reports of decreased QOL.[14,17,22,23] However, major conceptual and methodological issues still remain in CHD QOL research,[26] making it difficult to compare previous studies because of different assessment instruments, conceptualization, and use of comparative normative data. This study provides operational definitions of QOL and health status; instruments congruent with these definitions; and utilization of an age-matched, reference group of healthy adolescents and adults.

Moons and colleagues[25] identified better QOL in a large European study of all types of CHD patients compared with a healthy control group and used similar conceptualization and measurement of QOL. Our findings provide similar outcomes in a group of Fontan survivors in the United States. Furthermore, Moons et al[25] describe possible explanations for better QOL as the disability paradox,[35] a sense of coherence,[36] and response shift.[37,38] Another potential explanation for our finding is that individuals born with CHD lack the ability to differentiate their state of wellness from "normal" because they have never experienced normal health as most people know it. Their only reference of wellness is imbedded in chronic disease. In individuals with acquired disease, the concept of wellness is derived in reference to a lack of chronic illness, a situation unknown to our population of interest. In adults who have heart failure, their reports of QOL are made implicitly in reference to their former healthy state and are compared with healthy controls or normative data.[39,40] This situation may yield more dramatic transitions in cognitive recall than that experienced by adolescents and adults born with CHD. The adolescent's or adult's previous experience with an inherently altered health-illness continuum may affect his/her rating of health status or perception of QOL at any given time.

This study also identified deficits in physical health, which is consistent with previous studies in children, adolescents, and/or adults with complex CHD.[14–17] New York Heart Association classification is often used as an objective measure of functional status. The results of our study identified NYHA classification as a negative predictor of QOL, with more than 50% of the Fontan group identified as NYHA classification II and III. However, in the present study, QOL was comparable to healthy counterparts despite physical health and functional status deficits. This finding supports the belief that physical functioning deficits may not be perceived as a "true" disability or limitation, such as paralysis or a missing limb, but more as a limitation that is adapted to in daily life.[16]

Depression was also identified as a negative predictor of QOL. However, the MCS score on the SF-36v2 was not significantly different in group comparison. This may reflect the sensitivity of a disease-specific instrument to detect more subtle changes. Research has shown that some generic measures of health or health-related quality of life were considered sensitive to identify depression but, when compared with PHQ-9 scores, the utility of the measure declined as the severity of depression increased.[41] Another plausible explanation for the lack of difference in group comparison could be the reflection of undiagnosed depression in the general population presumed to be "healthy" by self-report. A large study of 9282 adults revealed a 12-month prevalence of *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* mood disorders in the general US population to be 10%.[42] However, most people who are depressed may not realize it and do not seek treatment. Thirty-six percent of the healthy control group had moderate to mild depression. This could explain the lack of significance in the MCS scores of the SF-36v2 in group comparisons.

Previously, studies have measured and identified depression or depressive symptoms using a variety of disease-specific instruments in the general CHD population.[7–11] Varying levels of psychological distress in CHD have been contributed to methodological differences, heterogeneity of cardiac defects, and small sample sizes.[10] Our findings in the first study on the assessment of depression in a homogeneous sample of Fontan survivors showed that depression and NYHA status were negative predictors of QOL. Other studies support similar findings of depression associated with worse NYHA classification.[9,12,13] Despite the significance between groups in depression, the mean scores for both the Fontan and healthy group were below 10, which is the cutoff for moderate to severe clinical depression. Nonetheless, 32% of the Fontan group had moderate to severe depression and 28% had mild depression.

Several factors may explain our findings regarding social support. Our results show that perceived social support was a positive predictor of QOL. Regarding the subscales reflecting perceived support from family, the Fontan and healthy groups tended to differ, with the Fontan group reporting higher levels of perceived support from family. Other studies in the general CHD population identified better social or family support as a positive influence on QOL.[43–45] However, it is believed that parents who view their child as "vulnerable" may result in parental overprotective behavior that can limit the child's social experience,[45] making it difficult for children with CHD to adjust socially and live independently.[8,17,46] This belief is supported in our finding that more than 50% of the study participants were single and continued to live with their parents into adulthood. This phenomenon has been reported by other investigators in larger study samples.[18,24,45,46] Furthermore, studies in CHD have shown that social adjustment and perceived health status were more predictive of depression and anxiety than medical variables.[8] Such findings are consistent with our report that social support, together with depression, is associated with QOL.

Limitations

The results of this study must be viewed in light of some limitations. This population may be healthier than normal secondary to selection bias (ie, currently seeking medical follow-up and agree to participate, speak English, and meet inclusion/exclusion criteria) and may not be generalizable to the entire Fontan population. In addition, the study sample size is small. However, this limitation is mitigated by the relatively small population of Fontan recipients and by the fact that our sample size is comparable with that of previous studies.[14–19] Another limitation in this study is that the sample is primarily representative of single left ventricle Fontan patients. Most single right ventricle patients are starting to reach young adulthood and beginning the transition to adult CHD clinics, so future studies should aim to include them. In this comparative, cross-sectional design, medical history data were collected from retrospective medical record review and questionnaire data were cross-sectional.

Conclusion

Patients with SVCHD who have undergone the Fontan procedure are surviving to adulthood and facing the challenges of an uncertain future. The findings of this study show that despite lower levels of physical health and the presence of depression, the QOL of Fontan patients was comparable with that of their healthy counterparts; this finding contradicts previous proxy reports, self-reports, and assumptions that QOL is lower in patients with complex SVCHD. However, because Fontan patients were more depressed than their healthy counterparts, the need for early screening and detection is warranted.

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What's New and Important

- Quality of life (QOL) in adolescents/adults with single ventricle congenital heart disease is comparable to that of their healthy counterparts. However, deficits were identified in physical health and depression. Predictors of QOL in Fontan patients were New York Heart Association status, depression, and social support.
- Depression and social support are modifiable predictors of QOL and a potential focus for nursing interventions. To understand the psychological experiences of the Fontan patient, greater attention should be placed on early screening and detection of depression and fostering social support as these variables were more predictive of QOL.

TABLE 1

Demographic Characteristics Between the Fontan and Healthy Groups

	n (%) or Mean (SD)				
Characteristics	**Fontan (N = 54)**		**Healthy (N = 66)**		***P* Value**
Age, y	25.6 (9)		24.5 (9.2)		.505
15–17 (Late adolescents)	10	(18.6)	20	(30.3)	
18–35 (Young adults)	35	(64.5)	37	(56.6)	
36–50 (Adults)	9	(16.9)	9	(13.1)	
Gender					.340
Male	26	(48.1)	26	(39.4)	
Female	28	(51.9)	40	(60.6)	
Race					.371
White	34	(63)	41	(62)	
Hispanic	11	(20.4)	11	(16.2)	
Other	9	(16.7)	14	(21.8)	
Marital status					.210
Single, widow, divorce	40	(70.3)	52	(78.9)	
Married	10	(18.5)	10	(15.1)	
Living with partner	4	(7.4)	4	(6.0)	
Education					.555
≤High school	21	(38.9)	29	(44)	
≤College	28	(51.9)	29	(43.9)	
Beyond college	5	(9.3)	8	(12.1)	
Employment status					.446
Student (full time)	14	(25.9)	27	(40.9)	
Employed	35	(66.7)	39	(59.1)	
Unemployed/Disabled	5	(7.4)	0	(0)	
Insurance					.503
PPO	20	(37)	20	(30.3)	
HMO	14	(25.9)	21	(31.8)	
Medical/SSI/Disability	18	(31.6)	3	(4.5)	

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	n (%) or Mean (SD)				
Characteristics	**Fontan (N = 54)**		**Healthy (N = 66)**		***P* Value**
Self-pay/Uninsured	3	(5.6)	4	(6.1)	
Not sure	0	(0)	18	(27.3)	

Abbreviations: HMO, Health Maintenance Organization; PPO, Prepaid Organization; SSI, Social Security Insurance.

TABLE 2

Clinical Characteristics of Fontan Group (N = 54)

Characteristics	n	%
Single ventricle diagnosis		
Tricuspid atresia	19	35
Double inlet left ventricle	13	24
Hypoplastic RV	8	15
HLHS/Variants	4	7
Double outlet right ventricle	3	6
Atrioventricular canal	2	4
Ebstein anomaly	1	2
Other complex anatomy	4	7
Ventricle type		
Left	42	78
Right	9	17
Undetermined	3	5
Fontan type		
Classic RA to PA	15	28
Bjork RA to RV	2	4
Lateral tunnel	24	44
Extracardiac Fontan	13	24
Fontan revision		
Yes	18	33
Fontan fenestration		
Yes	20	33
Number daily medications		
≥3	33	61
<3	21	39
NYHA classification		
I	26	48
II	17	32
III	11	20
LVEF%		
≤50	14	33
>50	28	67
History of arrhythmias		
Yes	41	76
Pacemaker		
Yes	22	41
Oxygen saturation		
≤90	17	31
>90	37	69

Abbreviations: HLHS, hypoplastic left ventricular heart syndrome; LVEF%, left ventricle ejection fraction; NYHA, New York Heart Association; PA, pulmonary artery; RA, right atrium; RV, right ventricle.

TABLE 3

Comparison of Quality of Life, Health Status, Depression, and Social Support Between Adolescent and Adult Fontan and Healthy Group

	Mean (SD)		
Variables	**Fontan (N = 54)**	**Healthy (N = 66)**	***P* Value**
Quality of Life			
SWLS total	24.1 (7.5)	24.9 (7.1)	.562
Health status			
SF-36v2 subscales			
Physical function	74.3 (22.4)	95 (16.3)	<.001
Role function physical	75 (24.2)	92.2 (15.4)	<.001
Bodily pain	69.5 (25.1)	78.6 (19)	.026
General health	52.4 (22.1)	76 (17.1)	<.001
Vitality	53.2 (20)	60 (18.3)	.064
Social function	76.4 (26)	79.4 (18)	.535
Role emotional	78.4 (24)	83 (21.2)	.297
Mental health	68.3 (19.2)	70.4 (18)	.535
Component scores			
PCS	46.5 (9.3)	55.9 (5.1)	<.001
MCS	46.2 (10.5)	45.5 (11.8)	.708
Depression			
PHQ-9 total	7.3 (5.9)	4.5 (4.3)	<.004
Social support			
MSPSS total	5.9 (1)	5.6 (1.3)	.237
Family	6.0 (0.9)	5.5 (1.6)	.099
Friends	5.8 (1.2)	5.6 (1.4)	.642
Significant other	5.9 (1.5)	5.7 (1.4)	.356

Abbreviations: MCS, mental component score; MSPSS, Multidimensional Scale of Perceived Social Support; PHQ-9, Patient Health Questionnaire Depression Module; PCS, physical component score; SWLS, satisfaction with life scale.

TABLE 4

Model Best Associated With Quality of Life in Adolescent and Adult Fontan Patients

Scale	Variables	β	R^2	Adjusted R^2	F	P Value
SWLS	NYHA class	−.292[a]	0.085	0.067	22.599	<.001
Total	Depression	−.641[b]	0.411	0.400		
	Social support	.323[a]	0.576	0.550		

Abbreviations: β, standardized slope coefficient; NYHA class, New York Heart Association classification; SWLS, satisfaction with life scale.

[a] $P < .05$.

[b] $P < .001$.