Current social situation of an adult with repaired « tet »

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Quality of life

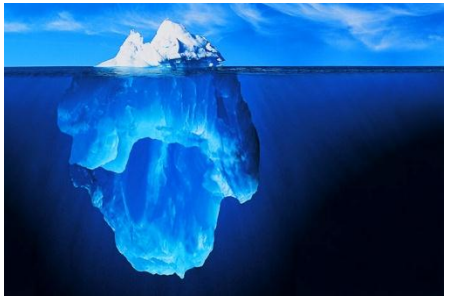
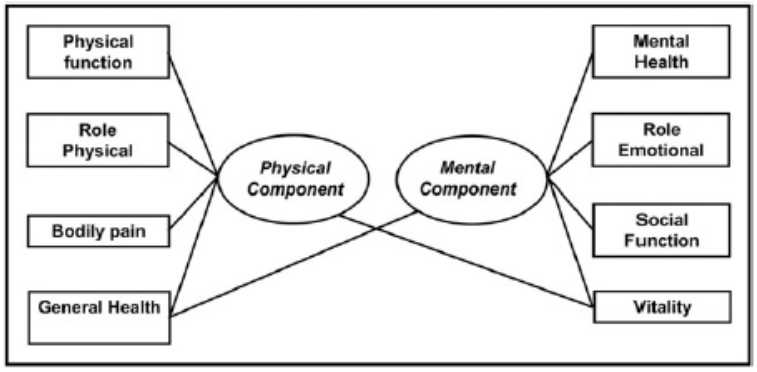


Table 4
Short Form-36 functional health z scores (n = 396)

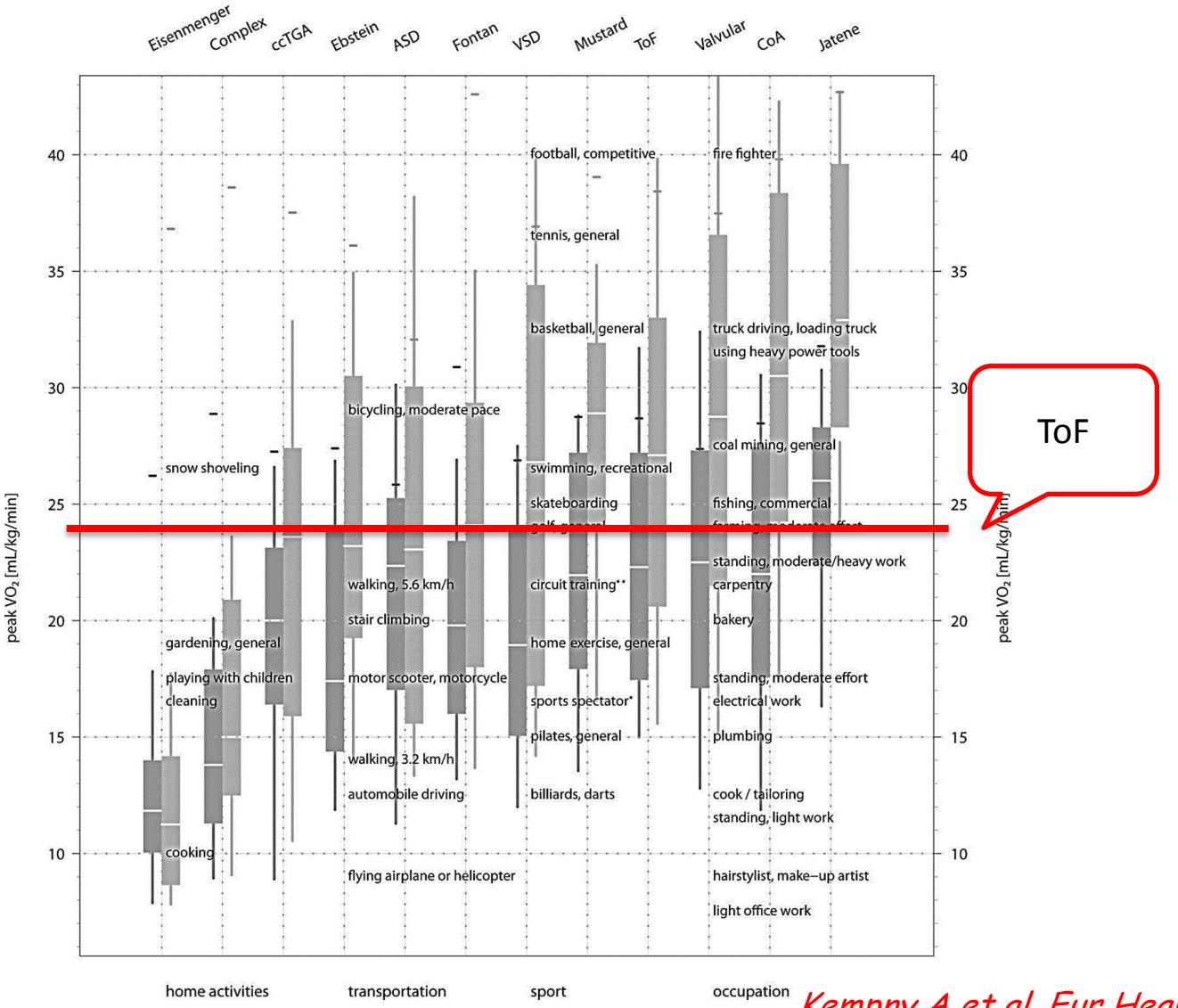
Domain	Scale	Mean	Minimum	Maximum	p Value
Physical function	physical	−0.58	−6.14	0.98	<0.0001
Role physical	physical	−0.15	−3.41	0.55	0.004
Body pain	physical	+0.20	−2.97	1.16	<0.0001
General health	physical/mental	−0.83	−5.02	1.42	<0.0001
Vitality	physical/mental	−0.25	−4.02	1.91	<0.0001
Social functioning	mental	−0.06	−5.22	0.84	0.27
Role emotion	mental	−0.01	−4.01	1.91	0.86
Mental health	mental	−0.10	−4.40	1.58	0.09



No difference in well being scores for patients and siblings despite a lower proportion of patients who perceive their general health as good (54% vs 66%)

Knowles, Ann Thorac Surg 2012
Hickey Am J Cardiol 2012

Social consequences of a lower exercise capacity



Kempny A et al. Eur Heart J 2012

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Education

- Lower school performance

School results	Insufficient: 5.6% Weak: 16.7% Average: 61.1% Good: 16.7%	Insufficient: 0% Weak: 12.5% Average: 31.3% Good: 56.3%	Insufficient: 0% Weak: 0% Average: 27.8% Good: 72.2%	.001‡
Special education	Yes: 5.6% No: 94.4%	Yes: 0% No: 100%	Yes: 0% No: 100%	.268
Repeating a school year	Yes: 16.7% No: 83.3%	Yes: 18.8% No: 81.3%	Yes: 5.6% No: 94.4%	.022†
School problems	Yes: 66.7% No: 33.3%	Yes: 56.3% No: 43.8%	Yes: 22.2% No: 77.8%	<.001‡

Miatton, JTCS, 2007

- Lower scores on academic skills
  - Reading
  - Spelling
  - Arithmetic

Wright, Arch Dis Child, 1994

Intelectual and neuropsychlogical performances in children with ToF

Variables	ToF (n=18)	Control group (n=18)	P value
Intellectual performance Estimated Full Scale IQ (100±15)	94.6±14.1	106.2±15	0.0141
Neuropsychological performances (100±15)			
Attention	112.0±13.5	117.8.5±8.5	0.7
Memory	99.4±13.1	103.0±9.5	0.232
Language	101.1±12.8	115.7±14.8	<0.001
Visuospatial skills	110.6±17.3	124.2±11.6	0.058
Sensiromotor Functionning	90.9±10.6	100.9±10.7	<0.001

Proportions with special education higher : 33%

Miatton, JTCS, 2007
Van Rijen, Eur Heart J » 2002

employment

- Lower employment rate:
  - Unemployement:8%-11.3% (2005-2012)
  - Higher social security benefits : 12%, disablement pension: 3%
  - Labor institution and activity centre for mentally handicapped: 5%,
- Works conditions

Table 3 Summary of main variables concerning occupational status for different cardiac diagnostic groups

	ASD		VSD		ToF		TGA		PS	
	%	M	%	M	%	M	%	M	%	M
Occupational level (SBC 1992)[a] (N=236)[b]										
Elementary	5		6		2		0		7	
Lower	31		35		47		28		19	
Average	42		30		34		48		55	
Higher	18		22		13		19		19	
Scientific	4		7		4		5		0	
Duration of employment (N=295)										
Full-time (≥36 h a week)	68		68		71		75		68	
Part-time	32		32		29		25		32	
Income (gross salary divided by 1000 Euros) (N=220)		27.5		25.0		24.4		21.5		32.9
Sick leave (from previous year) (N=297)[c]										
Mean sick-leave Percentage[d]		6.3		8.5		10.7		10.1		2.6

Inadequacy of job for educational level: 29% are unskilled workers

- Risk factors:
  - Lower academic level: 52%
  - Lower exercise capacity

Van Rijen, Eur Heart J, 2003 (ToF subgroup)
Bygstad , cardiol Yoing, 2012
Zomer, Am J Cardiol, 2012
Daliento, heart 2005
Kamphuis M et al. Arch Pediatr Adolesc Med 2002

Work difficulties

Table 2. Patient Characteristics*

Characteristic	Congenital Heart Disease	
	Complex (n = 76)	Mild (n = 80)
Age, mean, median (range), y	24.3, 24.5 (18-32)	24.6, 25 (17-32)
Male sex	43 (57)	30 (38)
Medical care >1 y ago	6 (8)	67 (84)
Education level		
Primary	32 (42)	21 (26)
Higher	44 (58)	59 (74)
Daily life		
Employed >12 h/wk	43 (57)	61 (76)
Employed + disability benefit, partial	2 (3)	. . .
Student	11 (15)	13 (16)
Student + disability benefits, full	4 (5)	. . .
Disability benefits, no activities	10 (13)	. . .
Other (housewife, unemployed, or sick leave)	5 (7)	3 (4)
Other + disability benefits, full	1 (1)	2 (3)†
Other + disability benefits, partial	. . .	1 (1)†

Difficulties reported:

- Feeling restrictive in the choice of a job
- Being excluded from a job
- Being excluded from a job after a medical examination
- Not being promoted

Main causes of difficulties reported:

- Physical disabilities
- Tiredness
- Emotional problems

Kamphuis, Arch Pediatr Adolesc Med 2002

Psychological and cognitive outcomes

- Normal IQ in 2/3 (Raven's progressive matrices)
- Low percentage of patients had a deficit learning and attenton function
- Deficit in tasks, that involves executive function, problem solving, and planning strategies (53% altered in the Tower of London test)

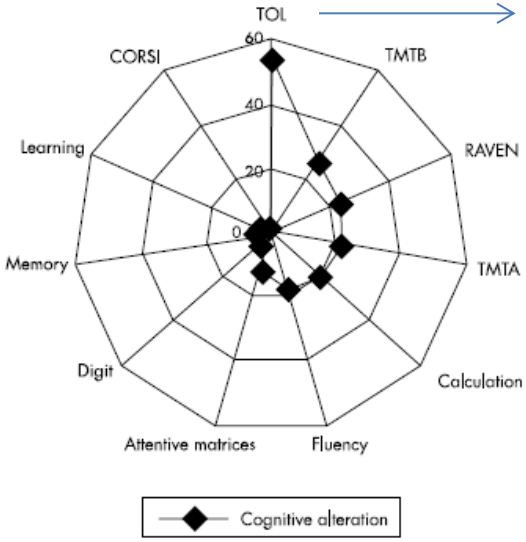

Figure 3 Scheme of neuropsychological impairment. CORSI, Corsi blocks test; RAVEN, Raven test; TMB, trial making test B; TMTA, trial making test A; TOL, Tower of London.

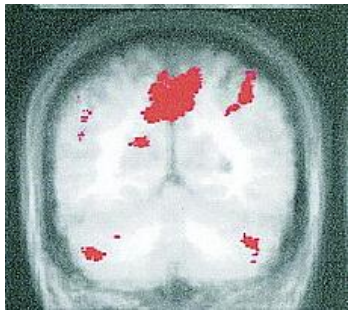

Table 1 Summary of the neuropsychological tests and description of the cognitive domains evaluated

Test	Cognitive domains
Tower of London	Planning, executive functions
Trial making test B	Attention shifting, psychomotor speed, response inhibition
Raven	Problem solving ability, IQ
Trial making test A	Attention shifting, psychomotor speed, response inhibition
Calculation	Arithmetical abilities
Verbal fluency	Linguistic abilities, lexical access
Attentive matrices	Selective and sustained attention
Digit span (forward)	Short term memory
Logical story	Long term memory
Corsi blocks	Spatial memory, visual attention
Paired associate word learning	Learning and memory

IQ, intelligence quotient.

Daliento, Heart, 2005

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Socioeconomic profile

Table 1
Sociodemographic characteristics in adult patients with congenital heart disease (n = 1,496) versus reference group (n = 6,810)

Sociodemographic Characteristics	CHD			Total Patients* (n = 1,496)	Reference Group (n = 6,810)	p Value†
	Mild (n = 682, 45.6%)	Moderate (n = 656, 43.9%)	Severe (n = 157, 10.5%)			
Age (years), median (interquartile range)	44 (31–56)	38 (28–48)	30 (25–37)	39 (29–51)	35 (30–45)	0.006
Male gender	50.90%	51.10%	56.10%	51.50%	44.80%	<0.001
Educational attainment						
No education	2.80%	2.30%	4.50%	2.70%	3.40%	
Lower	31.40%	26.60%	26.10%	28.80%	26.90%	<0.001
Average	34.90%	38.40%	47.10%	37.80%	30.10%	
Higher	30.80%	32.60%	22.30%	30.70%	39.70%	
Daily life						
Employed						
Paid job ≥12 hours	59.80%	67.60%	65.60%	63.80%	77.70%	<0.001
Hours of work/week, median (interquartile range)	37.5 (28–40)	37 (30–40)	36 (27–40)	36 (28–40)	38 (32–40)	
Paid job <12 hours	2.10%	2.90%	0%	2.20%	0.80%	
Unpaid volunteer work	0.90%	0.90%	0.60%	0.90%	0%	
Unemployed						
Household	7.80%	5.60%	7.00%	6.80%	8.00%	
Job seeking/disabled	9.70%	11.30%	17.20%	11.20%	6.80%	
Retired	14.40%	5.00%	0%	8.80%	5.40%	
Student	5.4	6.6	9.6	6.4	1.4	
Annual income‡						
<€20,000	37.60%	36.50%	54.50%	38.90%	28.90%	
€20,000–€30,000	24.40%	22.80%	24.50%	23.70%	16.90%	<0.001
€30,000–€40,000	17.80%	20.70%	14.50%	18.80%	25.80%	
>€40,000	20.20%	19.90%	6.40%	18.70%	28.40%	

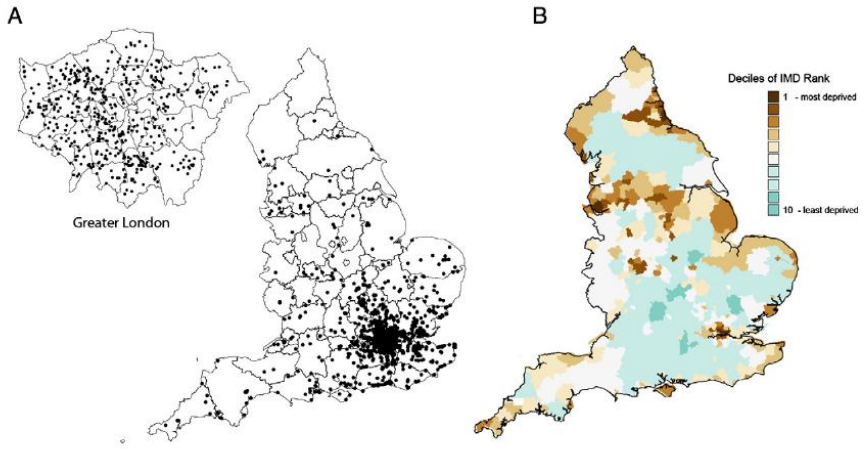
ConCor

Zomer AC et al. Am J Cardiol 2012

Socioeconomic profile (english experience)

Table 2
Relationship between epidemiologic parameters and peak oxygen consumption on rank correlation analysis.

Variable	Spearman's rho correlation coefficients (95% confidence intervals)	*P*-value
Parameters of socioeconomic status		
Income score	−0.0863 (−0.141 to −0.0314)	**0.002**
Employment score	−0.0761 (−0.131 to −0.0212)	**0.007**
Education score	−0.0655 (−0.120 to −0.0105)	**0.02**
Health	−0.0646 (−0.119 to −0.00954)	**0.02**
Barriers to housing	−0.0437 (−0.0985 to 0.0114)	0.12
Living environment	−0.0506 (−0.105 to 0.00442)	0.07
Crime	−0.0435 (−0.0983 to 0.0116)	0.12
Total score	**−0.0865 (−0.141 to −0.0316)**	**0.002**
Rural–urban dwelling/access to physical activity resources		
Rural–urban score	0.0411 (−0.0139 to 0.0960)	0.63
Percentage green space	0.0373 (0.0179 to 0.0922)	0.19
Distance closest gym/fitness club	0.0601 (0.00507 to 0.115)	**0.03**
Air pollution		
Particulate matter (<10 μm) score	−0.0523 (−0.108 to 0.00359)	0.07
Nitrogen dioxide (NO_2) score	−0.0383 (−0.0939 to 0.0176)	0.18
Sulfur dioxide (SO_2) score	−0.0491 (0.105 to 0.00679)	0.09



Diller GP et al. Int J Cardiol 2011

Insurance
How mortality ratio is calculated?

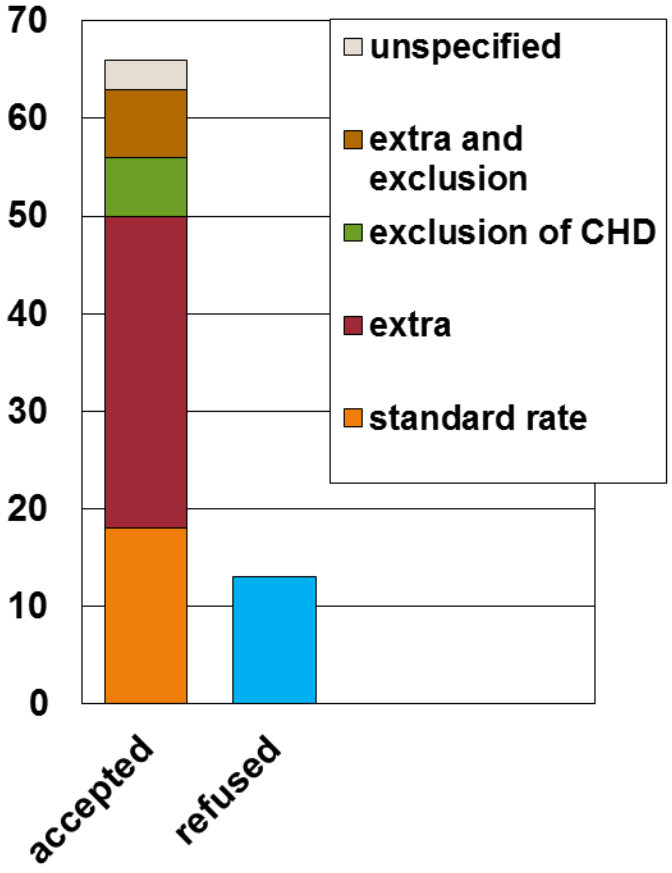
Table 2 Mortality rates for operated congenital heart lesions compared to a reference population. (Where permitted by available data, mortality in low risk subgroups within each lesion are shown)

Lesion	Reference	Duration of Follow-up (years)	Late Mortality All Patients[a] (%)	Late Mortality Low Risk Subgroup (%)	Mortality in Reference Population (%)	Mortality Ratio All Patients[b] (%)	Mortality Ratio Low Risk Subgroup[b] (%)	Mortality Ratio Insurance Underwriting Manuals[c] (%)
ASD	5	40	5[d]	N/A	7	71	N/A	100
PDA	5	45	12[d]	N/A	6	200	N/A	100
PS	10	25	10	6[e]	6[e]	167	100	100 up
VSD	7	27	20	5	3	667	167	100–200
COA	8	20	16[d]	9[d]	5[e]	320	180	100–300
AS	11	25	15[d]	8[d]	4	375	200	275–400 up
TOF	12	32	14	7	4	350	175	200–400
Senning/Mustard	15	20	24	N/A	5[f]	480	N/A	Declined
Single Ventricle	4	34	85[d]	N/A	3[e]	>2800	N/A	Declined

Vonder Muhll I et al. Eur Heart J 2003

Mortgage application in France

The only risk factor of refusal: CHD



	Standard rates	Exclusions and/or extra	Refusal
Mild (n=8)	7 (87.5%)	1 (12.5%)	0
Significant (n=40)	5 (12.5%)	26 (65%)*	9 (22.5%)*
Complex (n=28)	6 (21.4%)	18 (64.3%)*	4 (14.3%)*

*Refusal and insurance at non standard rates were more frequent in significant and complex CHD ($p<0.0001$ and $p=0.003$)

Ladouceur M et al. Arch Cardiovasc Dis 2011

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Physical activity

Reported Medications and Activity	Patients	Siblings	Ontario Residents[a]
Frequency of physical activity			
Regular, >12 times a month	49%	52%	49%
Occasional, 4 to 11 times a month	24%	27%	20%
Infrequent, 0 to 3 times a month	28%	21%	24%
Intensity of physical activity			
Inactive, 1.5 kcal/kg daily	73%	63%	56%
Moderately active, 1.5 to 2.9 kcal/kg daily	15%	21%	23%
Active, >3 kcal/kg daily	12%	16%	21%

=0.45Kcal/kg/h

- Same level of activity undertaken by patients in daily life or employment
- No difference in participation in physical activities or any leisure-time physical activity
- moderate level of exercise training improves aerobic capacity.

Knowles, Ann Thorac Surg 2012
Therrien, Can J Cardiol, 2003

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Psychological functioning

Table 4 Mean scores, 95% CI, standard deviations and Cohen's *D* on the DPQ[a] for patient sample and reference group and DPQ-EX.[b] group

DPQ[a]	Patient sample (*N*=351)		Reference (*N*=5686)		Cohen's *D*
	M (CI)	SD	M (CI)	SD	
Hostility	14.9(14.1–15.6)	7.2	18.2(18.0–18.4)	6.7	0.5
Self-esteem	31.0(30.5–31.6)	5.3	28.0(27.9–28.1)	5.6	0.5
Neuroticism					
Male[c]	6.5(5.6–7.4)	6.3	10.1(10.0–10.2)	7.5	0.5
Female[c]	10.3(9.2–11.5)	7.6	13.9(13.6–14.2)	8.3	0.4
DPQ-EX (*N*=307)					
Hostility	15.0(14.2–15.8)	7.2			0.5
Self-esteem	31.2(30.5–31.8)	5.4			0.6
Neuroticism					
Male[d]	6.5(5.5–7.4)	6.4			0.5
Female[d]	10.2(8.9–11.4)	7.5			0.4

- But female: less favourable self esteem, significantly more complaints on neuroticism
- No age effect

Van Rijen, Eur Heart J, 2003

Psychological functioning

- 83%: emotional difficulties at adolescence because of the presence of scarring in the thorax
- Reoperation is associated with a lower emotional role and social functioning score (SF-36)
- prevalence of depression is lower than in the general population:9.6%
- Lower rates of suicidal ideation and attempted suicide(3%)

Daliento, heart, 2005
Knowles, Ann Thorac Surg 2012
Muller, Int J Cardiol, 2012

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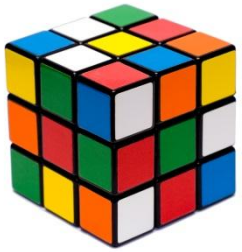
Social functionning

- Normal social support
- Higher participation in leisure-time activities

Table 5 Significant differences in leisure-time activities (proportions of participation and 95% CI) between patient sample and reference group

Item	18–24 years				25–34 years				35–44 years			
	Males		Females		Males		Females		Males		Females	
	Patient sample (*N*=50)	Reference group	Patient sample (*N*=27)	Reference group	Patient sample (*N*=100)	Reference group	Patient sample (*N*=98)	Reference group	Patient sample (*N*=43)	Reference group	Patient sample (*N*=40)	Reference group
	% (CI)	% (CI)	% (CI)	% (CI)	% (CI)	% (CI)	% (CI)	% (CI)	% (CI)	% (CI)	% (CI)	% (CI)
Movies							69 (60–79)	53 (48–58)	60 (45–76)	36 (31–41)		
Playing games									88 (78–98)	66 (61–71)	93 (84–100)	73 (68–78)
Walking/cycling			100	95 (93–97)								
Visiting clubs					49 (39–59)	32 (28–36)			53 (38–69)	24 (19–29)		
Visiting discos							43 (33–53)	25 (21–29)				
Watching TV											100	95 (93–97)
Shopping					79 (71–87)	54 (49–59)	96 (92–100)	83 (79–87)	77 (64–90)	49 (44–54)	95 (88–100)	77 (73–81)

Only significant differences were reported in the table. No significant differences were shown on the following eight items not reported in the table: watching sports, brain-teasers, making music/acting, handicrafts, odd jobs, listening to radio, doing sports, visiting bars.



Brain teasers are less performed by patients with ToF

Van Rijen, Eur Heart J, 2003
Knowles, Ann Thorac Surg 2012

Social relationship

- No difference in married or living with a partner (53%),
- Better adjusted family functioning (Mac Master Family Assessment Device)
- Less likely to have children (39% versus 51%, *p* 0.006).

Van Rijen, Eur Heart J, 2003
Knowles, Ann Thorac Surg 2012

To have children

Table 5. Comparisons between different reported series of patients with tetralogy of Fallot.

	Singh, 1982 UK[10]	Siu, 2001 Canada[12]	Veldtman, 2004 USA[5]	Meijer, 2005 Netherlands[6]	Khairy, 2005 USA[11]	Pedersen, 2006 Denmark
single or multicentric	single	multicenter	single	multicenter	single	single
retrospective or prospective	retrospective	prospective	retrospective	retrospective	prospective	retrospective
period of study	1958–1974	enrolment 1994–99	not informed	enrolment 2001–3	enrolment 98–2004	1972–1992
number of patients studied	52[a]	53[b]	72[a]	83[a]	15[a]	58[a]
eligible patients	100	not informed	147	not informed	not informed	58
age range	≥16y	28 ± 6y	≥18y	17–45y	12–50y	≥18y
infertility	1 (2)	not informed	not informed	5 (7)	not informed	2 (4)[d]
pregnant women	27 (52)	not informed	43 (60)	26 (31)	15	25 (43)
childless women	25 (48)	not informed	29 (40)	57 (69)	not informed	33 (57)
pregnancies	46	53	112	63	15	54
spontaneous abortions	6 (13)	0	30 (27)	12 (19)	0	8 (15)
life births	40[c]	53	82	46	15	41
premature births	not informed	not informed	1 (1)	5 (11)	not informed	6 (15)
weight at birth	3.0 kg (2.1–3.8)	not informed	3.2 kg (2.1–4.2)	3,1	not informed	3.2 kg (2.5–4.7)
small for date	6 (19)	not informed	7 (9)	8 (17)	not informed	1 (2)
undefined adverse neonatal outcome		11 (21)			not informed	
caesarean section	2 (6.5)	not informed	10 (12)	13 (28)	not informed	5 (12)
congenital cardiac disease in offspring	1 (3.2)	not informed	3 (3.6)	2 (4.3)	not informed	2 (4.8)
maternal NYHA class deterioration[e]	0	2 (4)	2 (2)	2 (4)	not informed	0
maternal cardiac complications	0	6 (11)	6 (7)	5 (11)	5	0

Mean pregancies per patient: 2.4

Mean life births by patient: 0.65 children per man/ 1.7to 1.8 children per woman

Age at first pregnancy: 26 yo

Pedersen, cardiol Young, 2008

Bygstad , cardiol Yoing, 2012

Sexual behavior

Table 1
Sexual practices among young adults (19–20 years old) with congenital heart disease (CHD) and comparison samples

	Sample			Statistical comparisons	
	Young adults with CHD	Under-graduates	NCHRBS	Under-graduates chi-square (*p*)	NCHRBS chi-square (*p*)
Sexual behavior				12.0 (.003)	5.7 (.06)
Not sexually active past 3 months	52%	26%	42%		
One sex partner	38%	61%	46%		
Two or more sex partners	10%	12%	12%		
Contraception [a]				4.5 (.11)	1.9 (.38)
No birth control	6%	0%	6%		
Withdraw or unsure	6%	0%	11%		
Pill, condom, other	88%	100%	83%		
Substance use and sex[a]					
At least sometimes have sex after drug or alcohol use[b]	21%	21%	N/A	.004 (.95)	N/A

Actually I admit I don't have a sore throat, I just wanted clarification on contraceptives

Reid, Int J Cardiol, 2008

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Risky behaviors

Table 4. Patient- and Sibling-Reported Use of Alcohol and Illicit Drugs

Alcohol and Illicit Drug Use	Patients	Siblings	Ontario Residents[a]
Alcohol consumption			
Former drinker[b]	6%	2%	—
Former at-risk drinker[c]	2%	1%	—
Other current drinker[d]	67%	71%	52%
Current occasional drinker[e]	17%	17%	21%
Never	9%	9%	—
Drug use			
Marijuana	32%	33%	—
Cocaine or crack	3%	5%	—
LSD	5%	7%	—
Amphetamines	4%	6%	—
Heroin	<1%	<1%	—
Glue, solvents, or gasoline	<1%	<1%	—

- No differences in alcohol each consumption category
- Fewer patients are cigarette smokers (16%)

Knowles, Ann Thorac Surg, 2012

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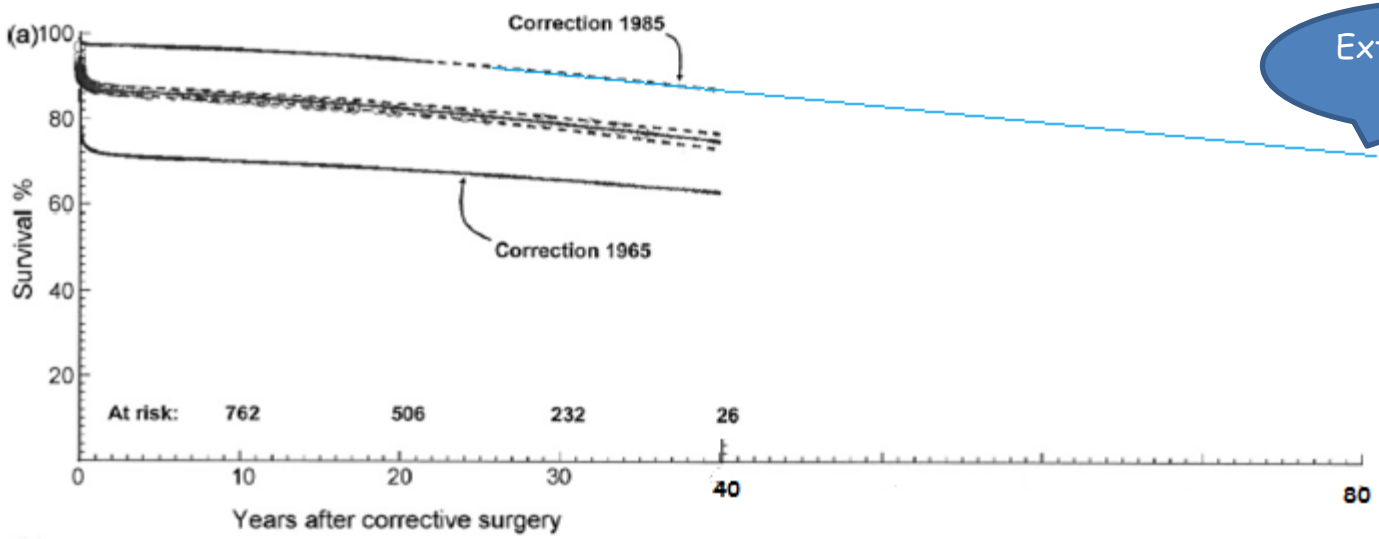
perspective



Extrapolation: 75%

Hickey, Eur J Cardio-thorac Surg, 2009

Specific issues

1. QoL
2. Socioeconomic status/insurability/ Health care
3. Physical activities
4. Relationship/ sexuality
5. Family functioning, social support/ psychological functioning
6. Risky behaviors

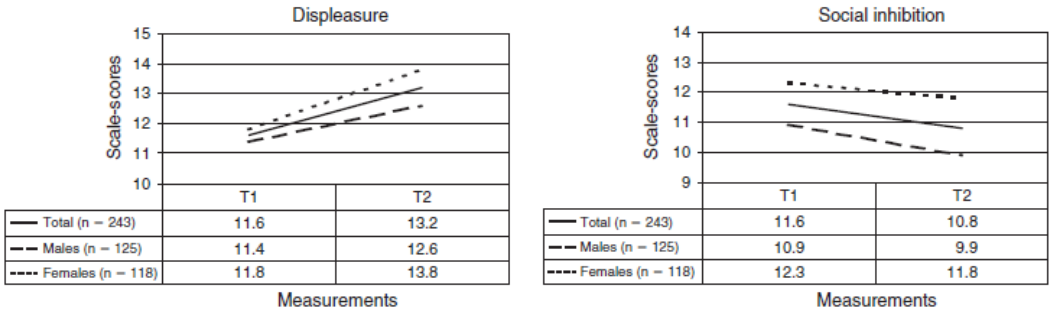
Projection (in 2040)

- Possible decrease in QoL
  - Dependency :

Forecast: 1.2M dependent elderly people in France in 2040

La dépendance des personnes âgées : une projection à long terme. Insee data, 2004

  - well being with aging : coping strategy



Van rijen, Cardiol Young, 2005

Projection (in 2040)

- Larger decrements in overall physical functioning are consistently associated with older age in ToF

Hickey, Am j Cardiol, 2012

- Impaired executive functioning has been fund to be the best predictor of functional decline in the elderly

In Anderson, Peter; Anderson, Vicki; Jacobs, Rani. Executive functions and the frontal lobes: a lifespan perspective. 2008

conclusion

- Good quality of life
  - Social functioning
  - Psychological functioning
  - Health behaviors

- Continual process of normalization : specific coping strategy

- Except employment: to improve by screening development abnormality, educational support, employment support

- Aging population: will health care meet their needs?

THANK YOU