CHOP Cardiology 2018
Scottsdale, AZ

KNIGHT CARDIOVASCULAR Institute
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What besides the heart influences outcomes in congenital heart disease?

Psychological & Social Factors

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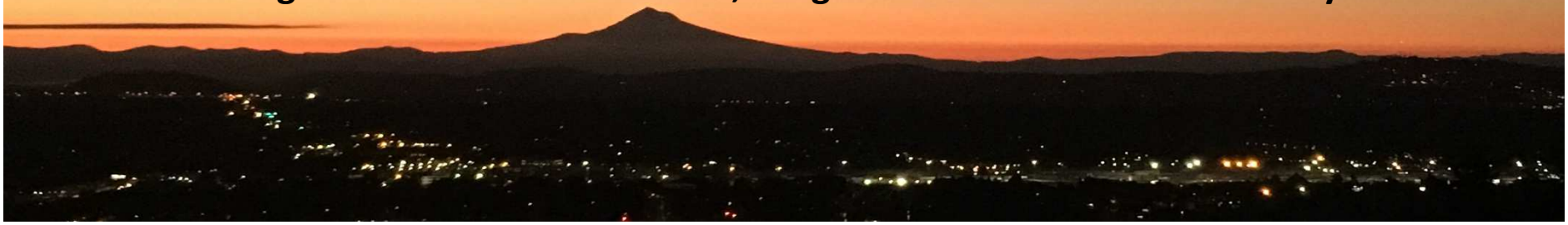
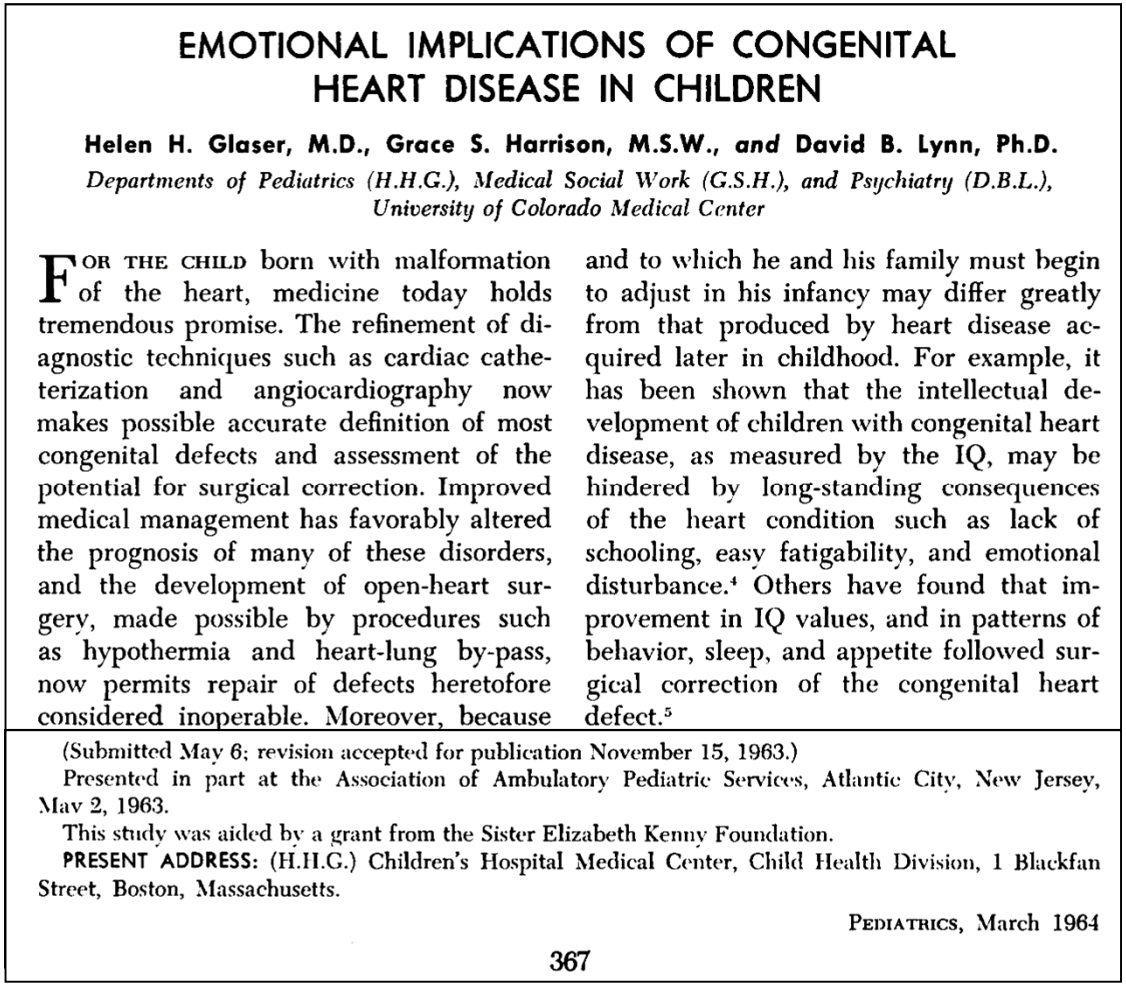


CHD Psychosocial Outcomes 101

- Individuals with CHD of all ages are at increased risk of neurodevelopmental deficits and disabilities
- Children and adolescents with CHD are at increased risk of psychosocial and behavioral difficulties
- Adults with CHD are at increased risk of clinically significant depression, anxiety, and PTSD (and a minority receive mental health treatment)
- Compared to healthy peers, individuals with CHD face **additional unique** challenges pertaining to social interactions, family dynamics, education, employment, family planning, etc.

"Despite benefits derived from these remarkable therapeutic gains, children with congenital heart disease face many difficulties in their efforts toward social and emotional adjustment..."



EMOTIONAL IMPLICATIONS OF CONGENITAL HEART DISEASE IN CHILDREN

Helen H. Glaser, M.D., Grace S. Harrison, M.S.W., *and* David B. Lynn, Ph.D.

Departments of Pediatrics (H.H.G.), Medical Social Work (G.S.H.), and Psychiatry (D.B.L.), University of Colorado Medical Center

FOR THE CHILD born with malformation of the heart, medicine today holds tremendous promise. The refinement of diagnostic techniques such as cardiac catheterization and angiocardiography now makes possible accurate definition of most congenital defects and assessment of the potential for surgical correction. Improved medical management has favorably altered the prognosis of many of these disorders, and the development of open-heart surgery, made possible by procedures such as hypothermia and heart-lung by-pass, now permits repair of defects heretofore considered inoperable. Moreover, because and to which he and his family must begin to adjust in his infancy may differ greatly from that produced by heart disease acquired later in childhood. For example, it has been shown that the intellectual development of children with congenital heart disease, as measured by the IQ, may be hindered by long-standing consequences of the heart condition such as lack of schooling, easy fatigability, and emotional disturbance.[4] Others have found that improvement in IQ values, and in patterns of behavior, sleep, and appetite followed surgical correction of the congenital heart defect.[5]

(Submitted May 6; revision accepted for publication November 15, 1963.)

Presented in part at the Association of Ambulatory Pediatric Services, Atlantic City, New Jersey, May 2, 1963.

This study was aided by a grant from the Sister Elizabeth Kenny Foundation.

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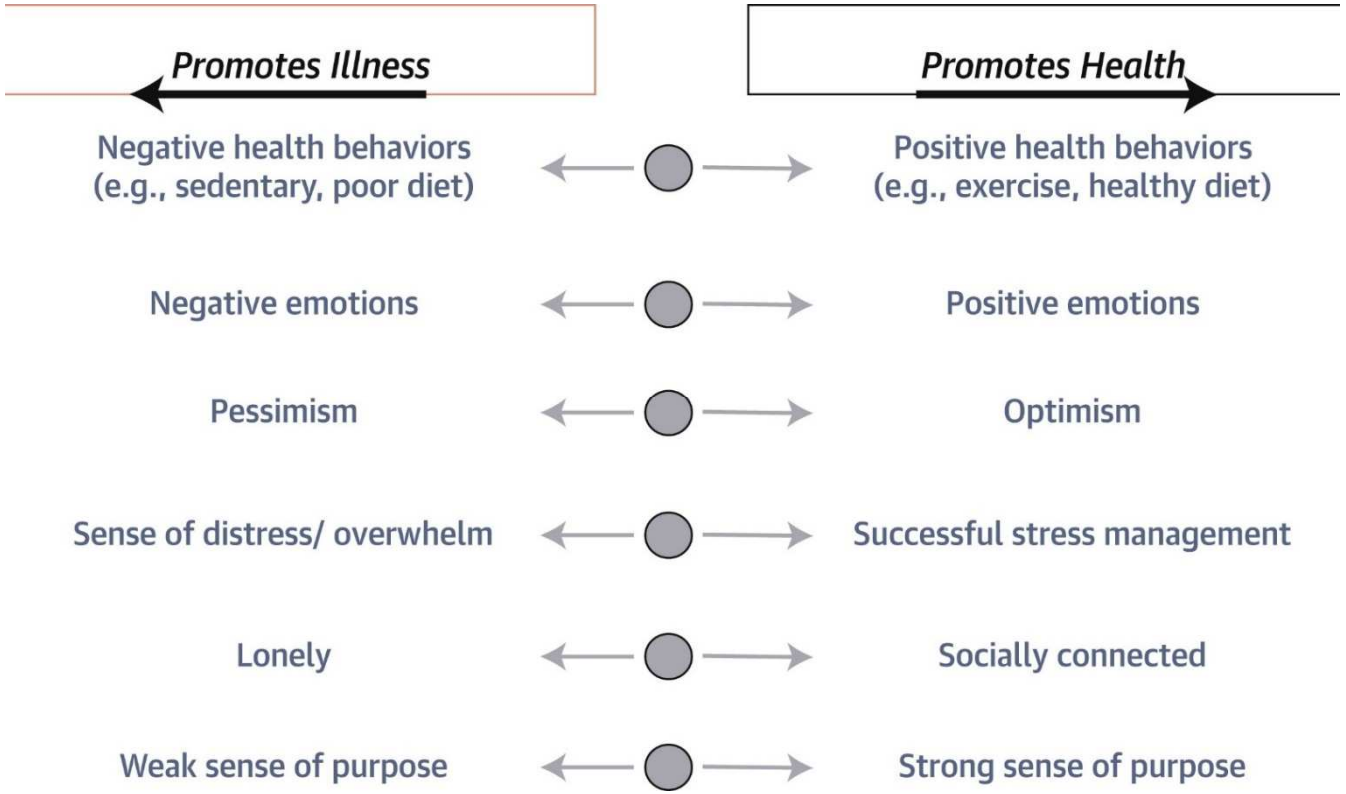
How Psychosocial Factors Impact **Medical Outcomes**

Lessons Learned from Acquired Heart Disease



Rozanski, JACC, 2014

Prognostic Value of Depressive Symptoms

60 adolescents & adults with CHD completed Beck Depression Inventory & Zung Self-Rating Depression Scale; followed for ~5 yrs

- Mean age = 29 ± 11 years, 53% male
- Mean BDI score = 9 (cut-off score = 10)
- Mean Zung score = 34 (cut-off score = 40)
- Elevated BDI + Zung in 17 pts (28%)
- MACE (death/cardiac hospitalization) = 22 pts (37%)

BDI determined to have better prognostic value for MACE

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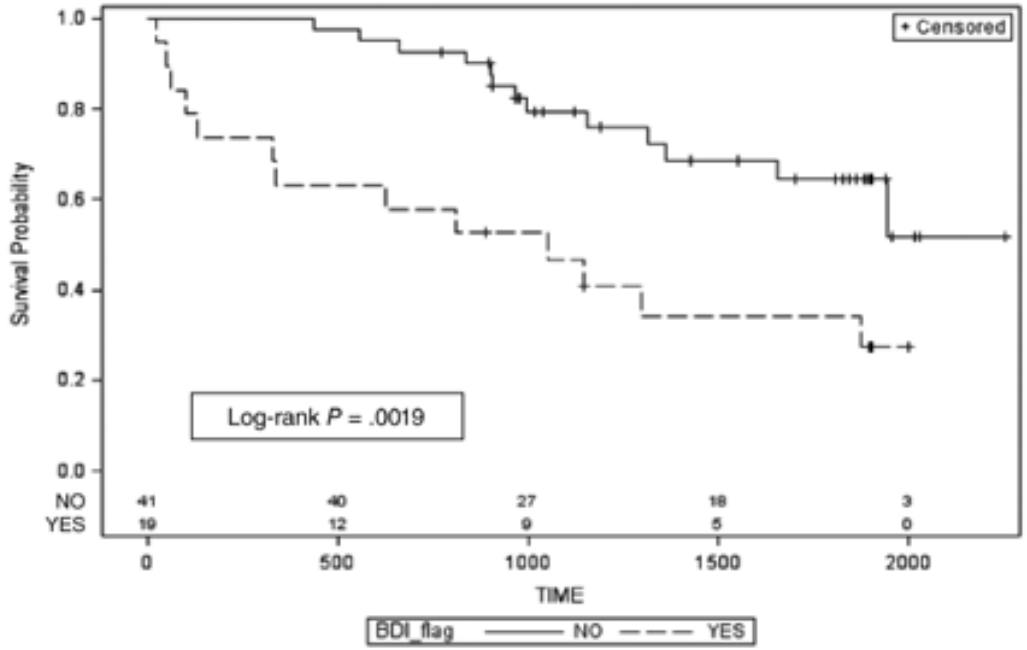
Kourkoveli et al, Congenit Heart Dis, 2015



Mean event-free survival for patients with BDI scores ≥ 10 was 986 ± 179 days (vs. 1624 ± 83 days) for patients without elevated BDI scores

No difference between patients with vs. without elevated symptoms in age, gender, functional status, NYHA class, presence of cyanosis or severity of defect

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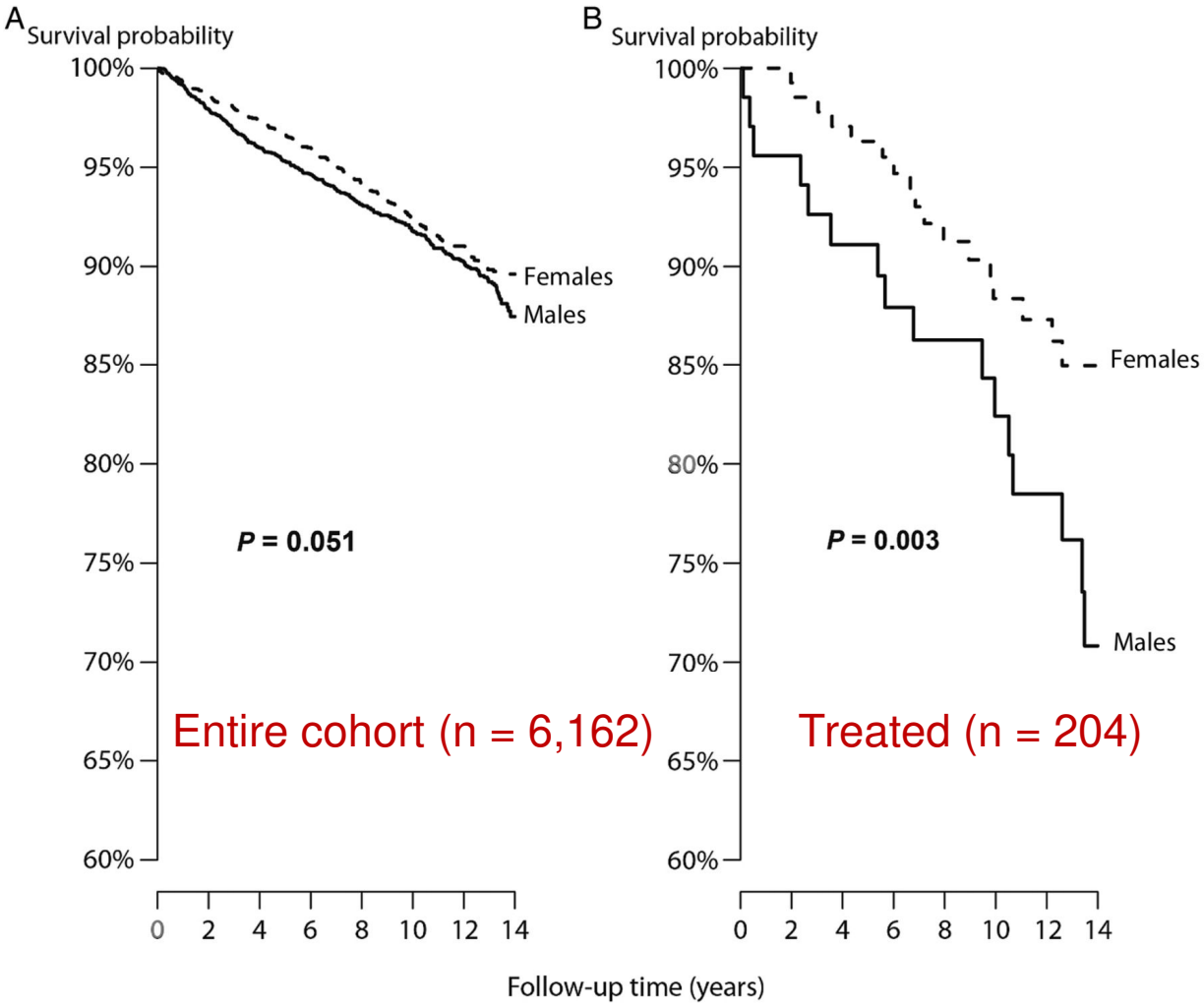
Antidepressant Medication in ACHD: Prevalence, Risk Factors & Prognosis

Of 6,162 patients of the Royal Brompton Hospital, 204 (3.3%) were on anti-depressant drug therapy

- 4.4% of females vs 2.2% of males ($p < 0.0001$)
- Treated patients were more likely to be symptomatic (57% vs. 31%) & have complex CHD (32% vs. 20%)
- Treated patients were older (36 vs. 30 years)
- Males taking anti-depressant medication were more likely to miss follow-up appts than untreated males (no difference for females)

Diller et al, Eur Heart J, 2015


A
Survival probability
100%
95%
90%
85%
80%
75%
70%
65%
60%
Females
Males
P = 0.051
Entire cohort (n = 6,162)
B
Survival probability
100%
95%
90%
85%
80%
75%
70%
65%
60%
Females
Males
P = 0.003
Treated (n = 204)
0 2 4 6 8 10 12 14
0 2 4 6 8 10 12 14
Follow-up time (years)

Resource Use for ACHD Surgery Admissions in Pediatric Hospitals

ACHD surgical admissions (>3,000) from 42 pediatric hospitals from 2000-2008

- High resource use (HRU) admissions defined as > 90th percentile for hospital charges
- HRU admissions accounted for 10% of admissions and 34% of charges
- Mortality rate was higher for HRU admissions (16% vs. 0.7%, $p < 0.001$)

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Kim et al, Circ Cardiovasc Qual Outcomes, 2011

Table 2. Multivariable Analysis of Risk Factors for High Resource Utilization

	Odds Ratio	95% Confidence Interval	*P* Value
DiGeorge syndrome	4.2	(1.5, 11.6)	0.006
Depression	3.1	(1.7, 5.5)	<0.001
RACHS-1 risk category			
1	1.0	. . .	. . .
2	3.6	(1.2, 11.2)	0.02
3	13.7	(4.1, 45.6)	<0.001
4+	30.7	(10.6, 88.9)	<0.001
Unassigned	18.2	(5.8, 56.7)	<0.001
Government payer status	2.0	(1.5, 2.8)	<0.001
Weekend admission	2.6	(1.6, 4.1)	<0.001

RACHS-1 indicates Risk Adjustment for Congenital Heart Surgery.
c Statistic=0.731.

Suicide Risk in Adolescents with Chronic Conditions

IN THE LAST 12 MONTHS	FEMALES		MALES	
	Without chronic condition	With chronic condition	Without chronic condition	With chronic condition
Had times when wanted to kill themselves	20.8%	**29.7%**	12.6%	**22.0%**
Attempted suicide	3.4%	**7.7%**	2.0%	**4.9%**

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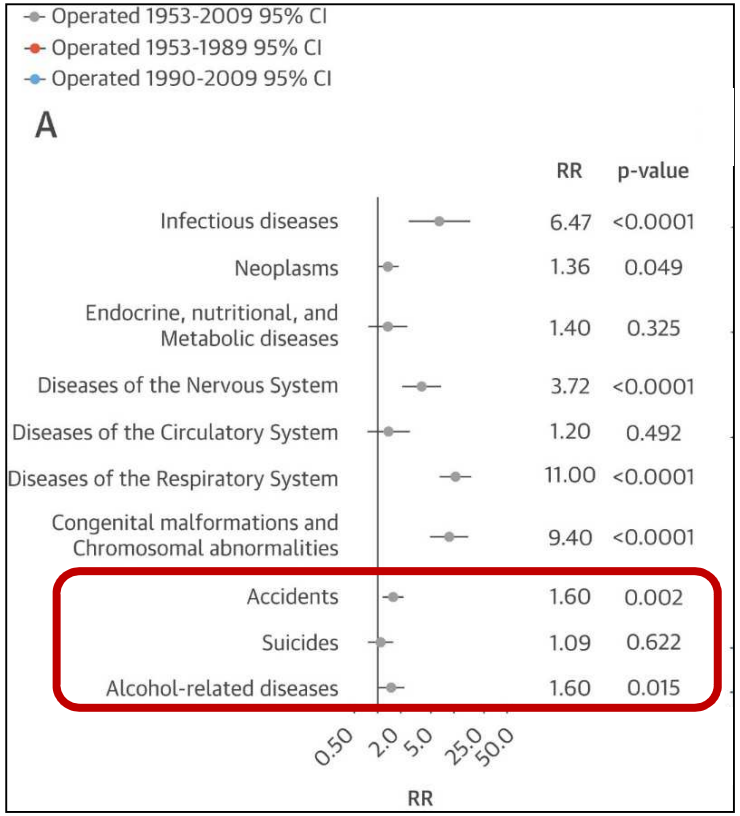
Miauton et al, Eur J Pediatr, 2003

Late Causes of Death after Pediatric Cardiac Surgery



Suicide rate determined to be similar between study patients and general population

Of 879 patients with late mortality and operated on between 1953 – 1989, 37 (4%) died by suicide (almost 10% of non-CHD related deaths)

Raissadati et al, J Am Coll Cardiol, 2016

Causes of 29 Late Deaths in Patients with Repaired TOF

Cause of Death	No. (%)
Cardiovascular origin	15 (51.7)
Heart failure or pulmonary hypertension	7 (24.1)
Sudden cardiac death	5 (17.2)
Arrhythmia	3 (10.3)
Accident or suicide	8 (27.6)
Suicide (falling several floors, drug intoxication, gas intoxication)	3 (10.3)
Accident	5 (17.2)
Hepatic or gastrointestinal cause	3 (10.3)
Infection	2 (6.9)
Stroke	1 (3.4)

Chiu et al, Circ Cardiovasc Qual Outcomes, 2012

Therefore

If we wish to improve long-term medical outcomes, we cannot ignore psychological factors.

How Psychosocial Factors Impact **Quality of Life Outcomes**

Even if psychosocial distress has no impact on medical outcomes…

The negative impact on quality of life warrants intervention

Factors associated with QOL in children, adolescents & adults

- Physical limitations & NYHA class
- Parental support
- Socioeconomic status
- Sense of coherence
- Anxiety and depression
- Substance use disorders (alcohol and/or nicotine dependency)

Drakouli et al, Cardiol Young, 2015
Westhoff-Bleck et al, J Aff Dis, 2016

Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart Disease – International Study

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Quality of Life of Adults With Congenital Heart Disease in 15 Countries

Evaluating Country-Specific Characteristics

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Study Rationale

Study Rationale

- ***In general***: When defined by physical functioning, adults with CHD have poorer outcomes than healthy peers
- ***In general:*** When defined by broader criteria (eg, satisfaction with life), many studies show similar or better QOL in patients
- ***Inconsistent results:*** Vary by study methodology (particularly assessment of QOL) and country of study

Fteropoulli et al, Cardiol Young, 2013;
Apers et al, Curr Cardiol Rep, 2013

Global Participation

Enrollment: n = 4,028
Survey completion: n = 3,952
53% female; mean age = 32 yrs

Argentina (178)
Australia (132)
Belgium (276)
Canada (508)
France (96)
India (200)
Italy (66)
Japan (257)
Malta (119)
the Netherlands (256)
Norway (174)
Sweden (471)
Switzerland (278)
Taiwan (250)
US (752)

Patient Surveys

PRIMARY VARIABLES

- Physical health status (SF-12, EQ-5D)
- Psychosocial functioning (Hospital Anxiety and Depression Scale; HADS)
- Health behaviors
- Quality of life (**Linear Analogue Scale** & Satisfaction with Life Scale)

POTENTIAL EXPLANATORY VARIABLES

- Sense of coherence (SOC-13)
- Illness perceptions (Brief IPC)
- Sociodemographic variables
- Medical variables

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Results: QOL Linear Analogue Scale

100 = best imaginable QOL

What number reflects YOUR quality of life?

0 = worst imaginable QOL

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Results: QOL Linear Analogue Scale

100 = best imaginable QOL

80

Median ACHD patient quality of life

0 = worst imaginable QOL

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Results: QOL Linear Analogue Scale

- **Inter-country variation was relatively minor compared to intra-country variation**
- **Multivariable general linear mixed models (GLMM)**
  - Lower QOL associated with older age, job seeking, no marriage history and worse NYHA functional class
  - QOL was not associated with sex, educational level, defect complexity
  - Model predicted 21.5% of variation in QOL

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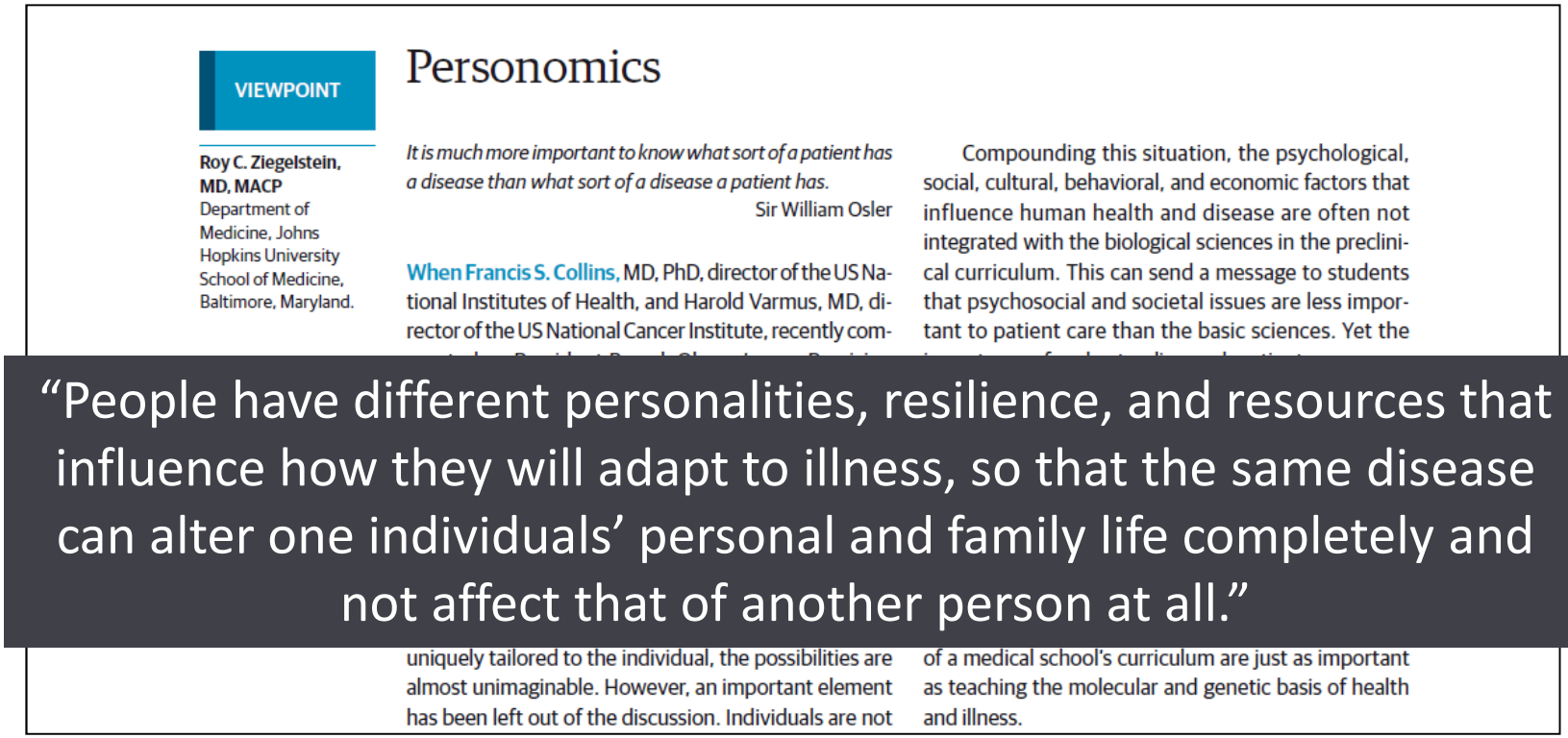
Therefore

If we wish to improve long-term quality of life outcomes, we cannot ignore psychological factors.

"Personomics"



VIEWPOINT

Roy C. Ziegelstein, MD, MACP
Department of Medicine, Johns Hopkins University School of Medicine, Baltimore, Maryland.

Personomics

It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has.
Sir William Osler

When Francis S. Collins, MD, PhD, director of the US National Institutes of Health, and Harold Varmus, MD, director of the US National Cancer Institute, recently com-

Compounding this situation, the psychological, social, cultural, behavioral, and economic factors that influence human health and disease are often not integrated with the biological sciences in the preclinical curriculum. This can send a message to students that psychosocial and societal issues are less important to patient care than the basic sciences. Yet the

uniquely tailored to the individual, the possibilities are almost unimaginable. However, an important element has been left out of the discussion. Individuals are not

of a medical school's curriculum are just as important as teaching the molecular and genetic basis of health and illness.

"People have different personalities, resilience, and resources that influence how they will adapt to illness, so that the same disease can alter one individuals' personal and family life completely and not affect that of another person at all."

Ziegelstein, JAMA Intern Med, 2015

Take Home Messages

- For > 50 years we have known of the psychosocial impact of CHD.
- Psychosocial factors affect health outcomes. There is emerging evidence that depression in CHD impacts morbidity/mortality.
- Even if psychosocial distress has no impact on medical outcomes, the negative impact on quality of life warrants attention.
- We have a collective responsibility and **opportunity** that goes beyond saving lives. We can help patients live as rich and fulfilling lives as possible.