Leg Pains, Headaches and a Single Ventricle Heart

Dr Louise Coats

Adult Congenital Cardiologist, Freeman Hospital, Newcastle upon Tyne, UK

Honorary Senior Clinical Lecturer, Newcastle University, UK





Complications of SV/Fontan

LUNG

Restrictive lung disease Pulmonary hypertension Pulmonary hemonhage Plastic bronchitts

LIVER

Congestive hepatopathy Cardiac cirrhosis Fontan associated liver disease

IMMUNOLOGY/ INFECTIOUS DISEASE

Protein-losing enteropathy Infective endocarditis Pneumonia Brain abscess

HEMATOLOGY

Secondary erythrocytosis/iron deficiency/Hyperuricemia (Cyanotic CHD) Thromboembolism Anemia

ONCOLOGY

Low-dose ionizing radiation and malignancy Hepatocellular carcinoma Age-appropriate cancer screening

PSYCHOSOCIAL

Depression Anxiety Neurodevelopment deficits

ENDOCRINE

Thyroid Calcium hemostasis/Bone health Obesity/Metabolic syndrome Diabetes Dyslipidemia

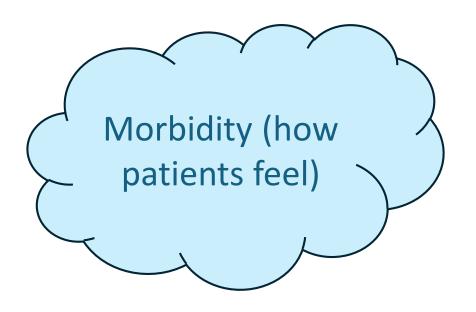
RENAL

Chronic kidney disease Cardiorenal syndrome

VASCULAR

Cerebrovascular disease
Peripheral venous/arterial disease
Aortopathy
Endothelial dysfunction
Hypertension

'My 17-year old son has been complaining of leg pain for years. Just last month, we spoke to his cardiologist who couldn't identify with it from a heart perspective.'



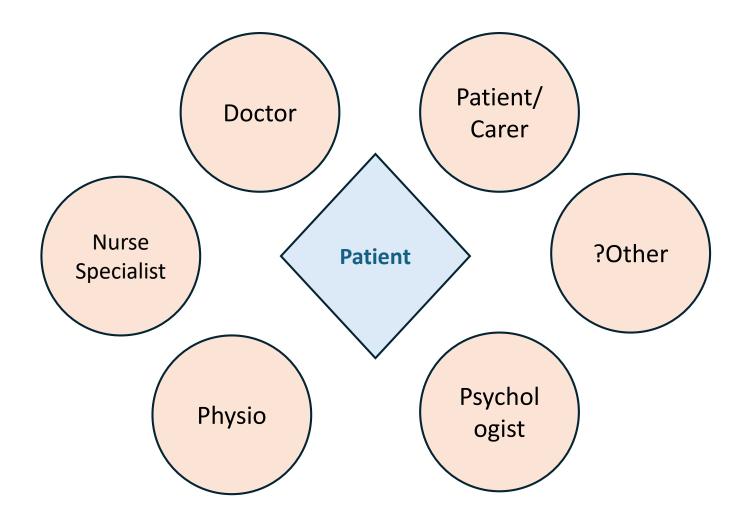
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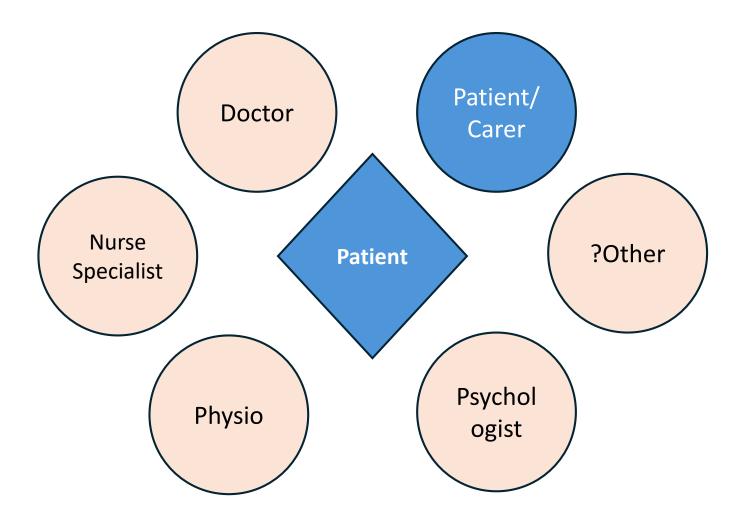
Changes clinician relationship





Identifies new areas for QIP/research



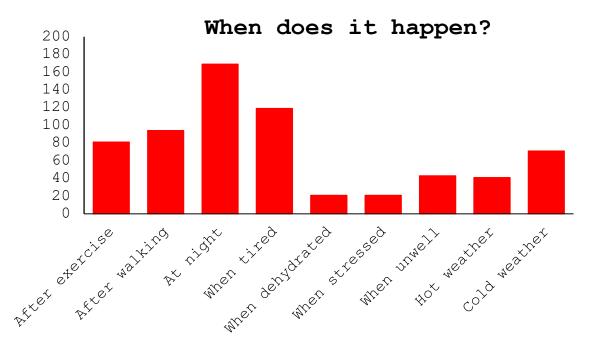




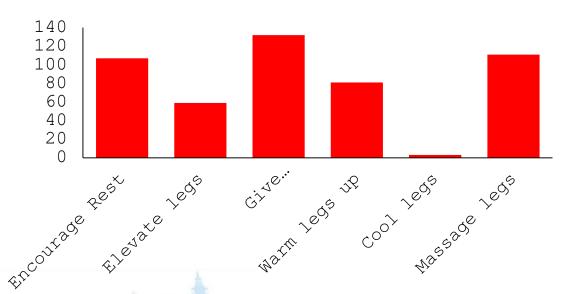
Survey sent out by LHM

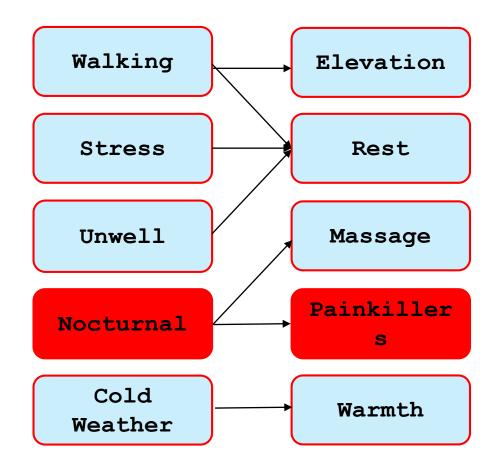
220 respondents

57% male, age 8.3 years [0.2-29], 69.5% SV
93% reported leg pains (likely selection bias)
3 times more frequent than healthy siblings

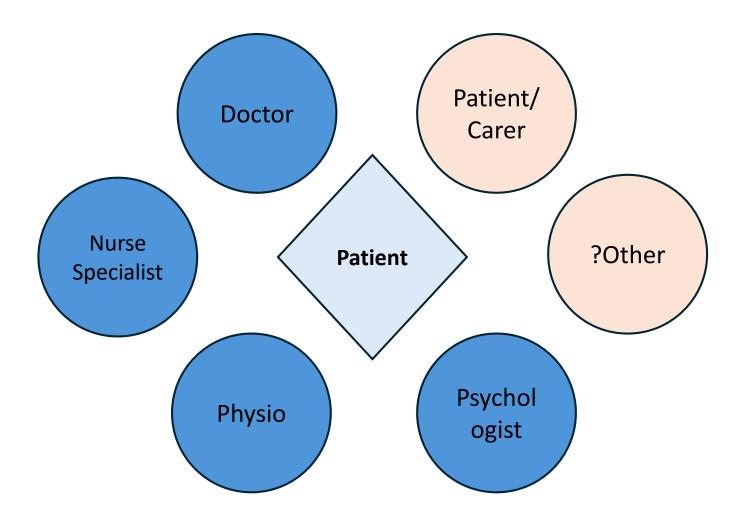


What makes it better?





- Not influenced by gender
- Associated with stress in older respondents
- Significant association with aspirin (p=0.01)
- Universal in those who were hypermobile (n=12)

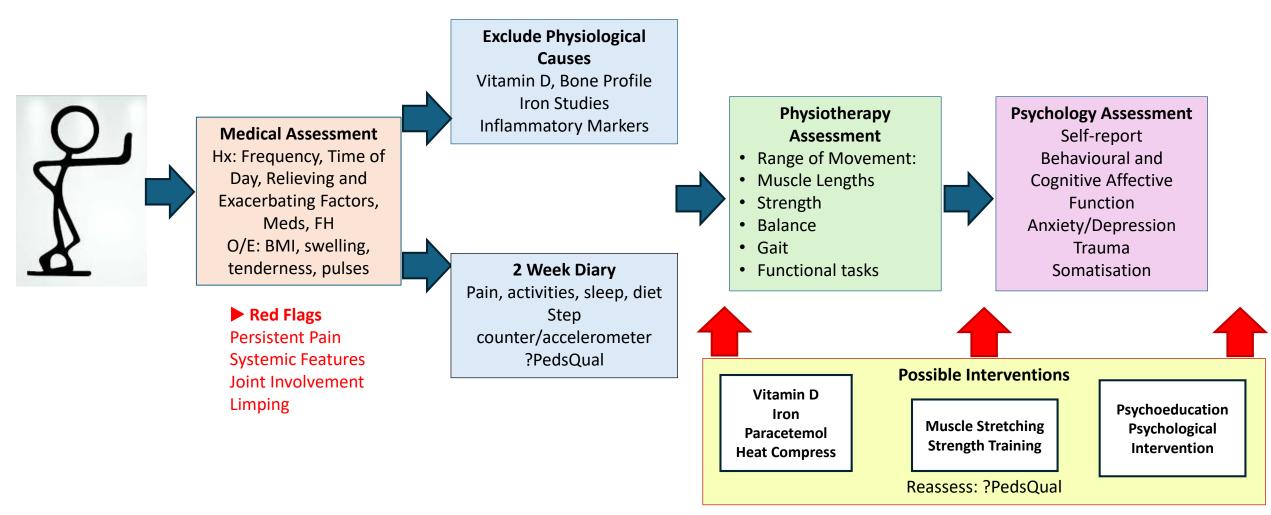


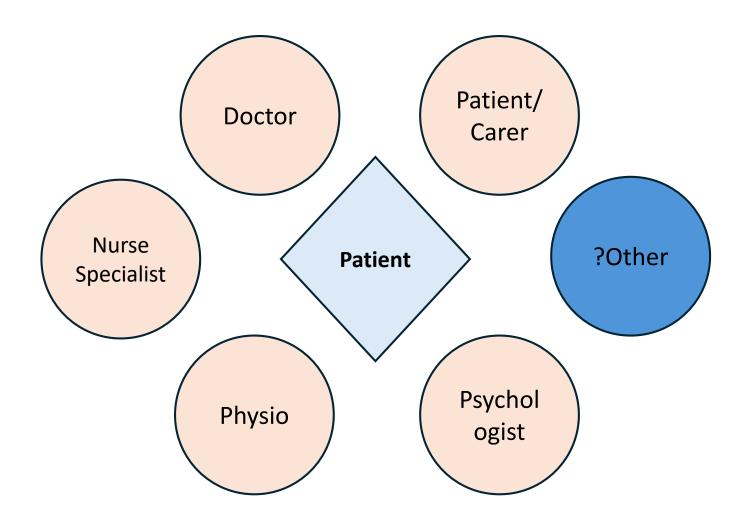
The key finding for these children tends to be muscle weakness particularly around the gluts and, hips and core which then alters the biomechanics of the lower limb which can then cause pain. The pain tends to be worse at night due to little distraction and the tired muscles at the end of the day.

Strengthening programme and some targeted exercises has been shown to improved symptoms.

Clinical Specialist Paediatric Cardiothoracic Physiotherapist, Newcastle

Clinical Pathway Development



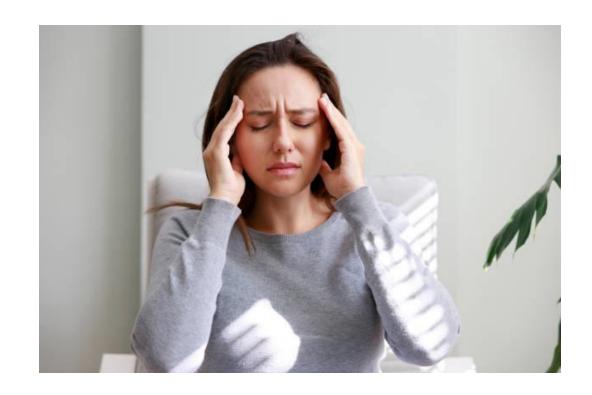


Headaches

? 50% Fontan patients [Pike et al. 2011]

? Elevated dural venous sinus pressure

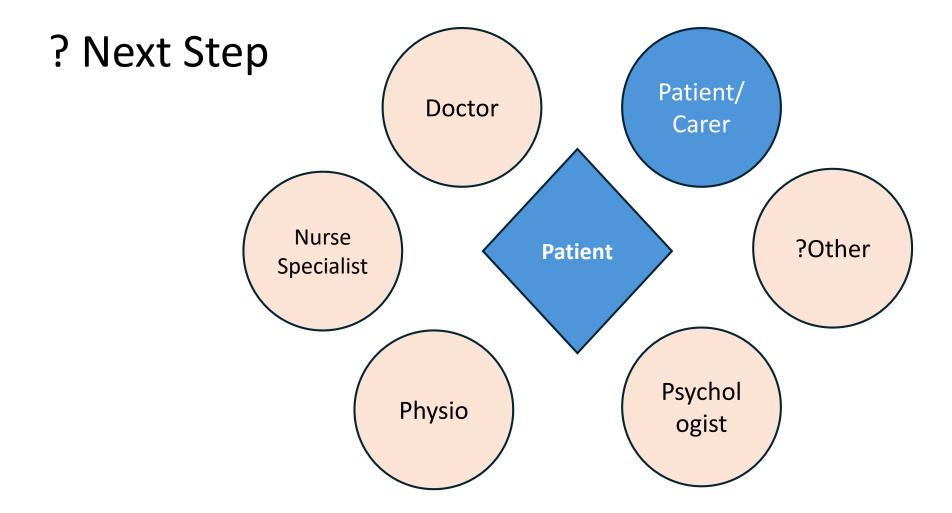
? Infection/abscess



? Medication

? Right to Left Shunt, like PFO

? Shunt closure/Aspirin



To Conclude

- Social media facilitates important evidence for what matters
- Patient groups & organizations can help delve deeper
- The MDT perspective can shape a pathway forwards
- Regular audit and evidence review will refine the approach