

Clinical Health Psychology in Paediatric Cardiology

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Clinical Health Psychology (CHP) in Paediatric Cardiology

Aims

To provide an introduction to clinical health psychology in paediatric cardiology at Alder Hey Children's Hospital:

- The role and overall structure of the department.
- The psychological impact of congenital heart disease: reasons why a referral to CHP may be appropriate.
- An overview of assessment, formulation and the implementation of interventions.
- Research





Congenital Heart Disease

- Congenital heart disease (CHD) refers to a structural cardiac defect or abnormality present at birth (NHS, 2021)
- Diagnostic and interventional procedures for CHD have significantly advanced over the last eight decades (The Lancet, 2020), and over 90% of individuals now born with CHD will survive into adulthood (Baumgartner et al 2021).
- Appropriate treatment is dependent on the specific abnormality and specialist review is frequently required throughout childhood and into adulthood (NHS, 2021).
- There is increasing recognition of the need to better understand the particular challenges relating to CHD, including the broader impact of living with CHD and its psychosocial consequences.





Congenital Heart Disease





Clinical Health Psychology (CHP)

- The purpose of our service is the provision of psychological support to patients and families experiencing chronic paediatric illness, acute medical conditions or physical trauma.
- The primary objective is to reduce the psychological impact of living with a health condition(s).
- This is achieved through the implementation of psychological assessment, consultation and psychotherapeutic intervention.
- Cardiology provides support for young people and/or their families living with congenital heart disease.





Clinical Health Psychology

Our role in paediatric cardiology

Clinical psychologists provide support to young people and their families living with congenital heart disease. The broad objectives for a clinical psychologist working within clinical health psychology (cardiology) at Alder Hey Children's Hospital include but are not exclusive to:

- Providing support for the child/young person living with CHD at an individual level.
- Working with the family unit: parents/guardians, siblings, extended family of patients with CHD.
- Systemic work: accessing support at school or hospices.
- Liaison and/or consultation with MDT: contributions to treatment care plans and accessing information about the individual's condition.
- Liaison with additional services: CAMHS, social services, school or voluntary sectors.
- Teaching/training, supervision and staff support.
- Involvement with regional and national networks.
- Consultation work.





Psychological Impact of CHD

Reasons for referral to CHP for patients

There are many reasons why a patient's experience of congenital heart disease may result in a referral to clinical health psychology. The following may be experienced in combination or isolation.

- •Adjustment to diagnosis.
- •Feelings of difference.
- •Trauma related experiences.
- •Invisible illness: absence of symptoms or visible difference.
- •Experiences of living with a heart condition whilst at school/college.
- •Perceptions of risk.
- •Perceptions of surgical scars: visible difference.
- •Concerns and uncertainty about their future.





Psychological Impact of CHD

Reasons for referral to CHP for family members

Similarly, when considering the impact on a patient's family there may be varying reasons why a referral would be appropriate for a member of the family unit:

- Mental health considerations at diagnosis and acute or long term periods.
- Adjustment to illness.
- Impact of home environment: marital/relational pressure.
- Managing illness: decision-making, providing direct care.
- Practical elements of illness: employment, travel, cost.
- Attachment
- Impact of child's emotional and behavioural challenges.











Process of Assessment

Following a referral to clinical health psychology, an initial screening assessment will be made to assess the appropriateness of the referral.

A liaison telephone call will be made to the young person or a family member to establish:

- An overview to the young person's medical history and their understanding of their heart condition.
- The current challenges they they may be experiencing and if they are in relation to their congenital heart defect.
- Previous and current coping strategies: successful and unsuccessful implementation.





Assessing Risk

During the initial screening call, it will be necessary to obtain any information relating to risk. The aim will be to establish:

- Suicidal ideation
- Deliberate self harm
- Treatment non-adherence or refusal

If concerns regarding risk have been identified:

- Appropriate advice will be provided about how to access emergency support if required.
- The young person or family member will prioritised for support where appropriate.





Assessment Appointment

During the assessment appointment, the main objective will be to acquire sufficient detail about the psychosocial implications of living with congenital heart disease.

Opening comments

- Introduction to the clinician, the department and the role of a clinical psychologist
- Confidentiality
- The purpose of the appointment and consent
- Details about the referral

Current circumstances

- Details about CHD
- Child's understanding/conceptualisation of their illness
- Self-concept/identity
- Home environment
- School
- Social environment
- Extracurricular interests
- Child's past experience of illness.

- Mental health and wellbeing
- Current challenges experienced
- Perceived and confirmed coping strategies.
- Confirming risk and safeguarding
- Social and external units of support
- Self-concept/identity
- 'Positives' of illness: post-traumatic growth
- Session goals





Framework for Assessment

Edwards & Titman, 2010

g General

• Cultural background

Social factors

• Deprivation

• Family resources

Illness related factors

Disability

Visibility

• CNS

• Burden of care

Developmental stage of chid and family

Child's internal world: understanding, beliefs and coping

Parental internal world: understanding, beliefs and coping

Family structure and function

Physical health or symptoms

Psychological distress/emotional or behavioural problems

Quality of life/wellbeing

Decision about treatment or adherence



Psychological assessment



Target for intervention outcomes



Formulation

- Formulation is the process by which an individual's experiences of congenital heart disease and any challenges are summarised.
- The summarisation of these experiences can encourage a more coherent understanding of why these challenges may occur and facilitate the appropriate application of therapeutic interventions.
- A formulation is not a static process and will be reviewed periodically, evolving throughout our work with a young person or family member living with congenital heart disease.
- Different methods can be applied when formulating:
 - Five P's (Macneil et al, 2012).
 - Cognitive Behavioural Therapy (CBT).
- Formulation integrates a broad range of biopsychosocial causal factors. It is based on personal meaning and constructed collaboratively with service users and teams.

 (The Division of Clinical Psychology Good Practice Guidelines; DCP, 2011).





Psychotherapeutic Interventions

A variety of therapeutic approaches may be implemented and will be dependant on the referral and formulation.

- Psycho-education
- "Counselling" approaches
- Facilitate (MDT / family) communication
- Mindfulness-based therapy
- Facilitate choice, control and treatment planning
- Facilitate decision-making
- Cognitive therapy / CBT
- Parenting / behaviour management
- Narrative approaches
- Solution-focused therapy
- Normalisation and validation

- Skills training
- Motivational interviewing
- Acceptance and commitment therapy
- Compassion focus therapy
- Family therapy
- Behavioural therapy
- Systemic
- Self help
- Support groups
- Play therapy





Group Interventions

Group-based interventions provide the opportunity for young people and their families with congenital heart disease to engage with the service independent of, or in addition to, individual therapy sessions.

Groups-based interventions offered by clinical health psychology at Alder Hey Children's Hospital:

- Groups for parents and siblings living with chronic illness.
- *Tree of Life:* narrative therapy group intervention in clinical health psychology.
- Start of Something New: cardiac specific day for young people transitioning from primary school to secondary school. This annual event can be attended by both young people and parents.
 - This day incorporates the narrative therapy Beads of Life.





Research

Current research addressing the psychological implications of living with congenital heart disease.

Higher prevalence of anxiety and depression among young people with congenital heart disease (Gonzalez et al, 2020).

Systematic review summarising the psychosocial well-being of children and young people with congenital heart disease. Review highlights the risk for emotional, social and behavioural development difficulties (Clancy, Jordan, de Weerth & Muscara, 2020).

Psychosocial impact of congenital heart disease in siblings: a systematic review aiming to summarise the literature about the psychosocial well-being and quality of life for siblings of children with congenital heart disease (Schamong et al, 2021).





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Thank you

