Bristol Heart Institute

South Wales and South West Congenital Heart Disease Network

ACHD Psychology Service

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(slides by Dr Mustard & Dr O'Keeffe)

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GIG CYMRU NHS WALES

NHS

Presentation Outline

- A developmental, lifespan approach
- Biopsychosocial model
- Mental health and ACHD
- The ACHD Psychology Service
- Acceptance and Commitment Therapy
- Case example
- Non-clinical work
- Questions

Domains	Mid Adolescence 14-16	Late Adolescence 16-19	Young adulthood 19-35	Mid adulthood Mid 30's+
Physical	• Body image- scars • Physical functioning limitations		• Health decline (abrupt/gradual) • Complications/other illnesses	
Medical	• Responsibility • Learning HB's • Hospitalization	• Transition • Knowledge	• Responsibility • CHD complications • Medical procedures • Hospitalizations	
Health Behaviour	• Avoiding risky behavior • Weight • Exercise • Oral hygiene	• Regular medical follow ups • Maintaining health promoting behaviours • Avoiding risky behaviours: tattoos, piercings		

Domains	Mid Adolescence 14-16	Late Adolescence 16-19	Young adulthood 19-35	Mid adulthood Mid 30's+
Social and Family Relations	• Peer acceptance • Stigma • Lack social/CHD support • 'Sick role' in family	• Dating/sex • Independence • Lack social support CHD • Different to peers • Hopes for future e.g. children	• Life partner • Reproduction • Loss	• (Possible) Premature death impact on family
Education and Work	• Coping with ID or learning difficulties • Missing school	• Selecting goals appropriate to current/future abilities	• Employment discrimination • Medical crises • Financial concerns	• Maintaining/ changing work/goals with declining health

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Domains	Mid Adolescence 14-16	Late Adolescence 16-19	Young adulthood 19-35	Mid adulthood Mid 30's+
Emotional	• Medical procedure anxiety • Maintaining emotional adjustment during critical transitions • Low self-esteem/anxiety re scars/physical fx		• Medical procedure anxiety • Avoiding arrhythmia related anxiety • Managing MH; anx, dep, PTSD, phobia's related to CHD	
Personality and Identity	• Integrating CHD into self-image • Accepting being different + unique • Wanting to be achieve	• Lack of control over health outcomes • Increasing independence	• Balancing independence + interdependence with family/friends	• Resolving loss - typical life achievements • Facing prospect of premature death

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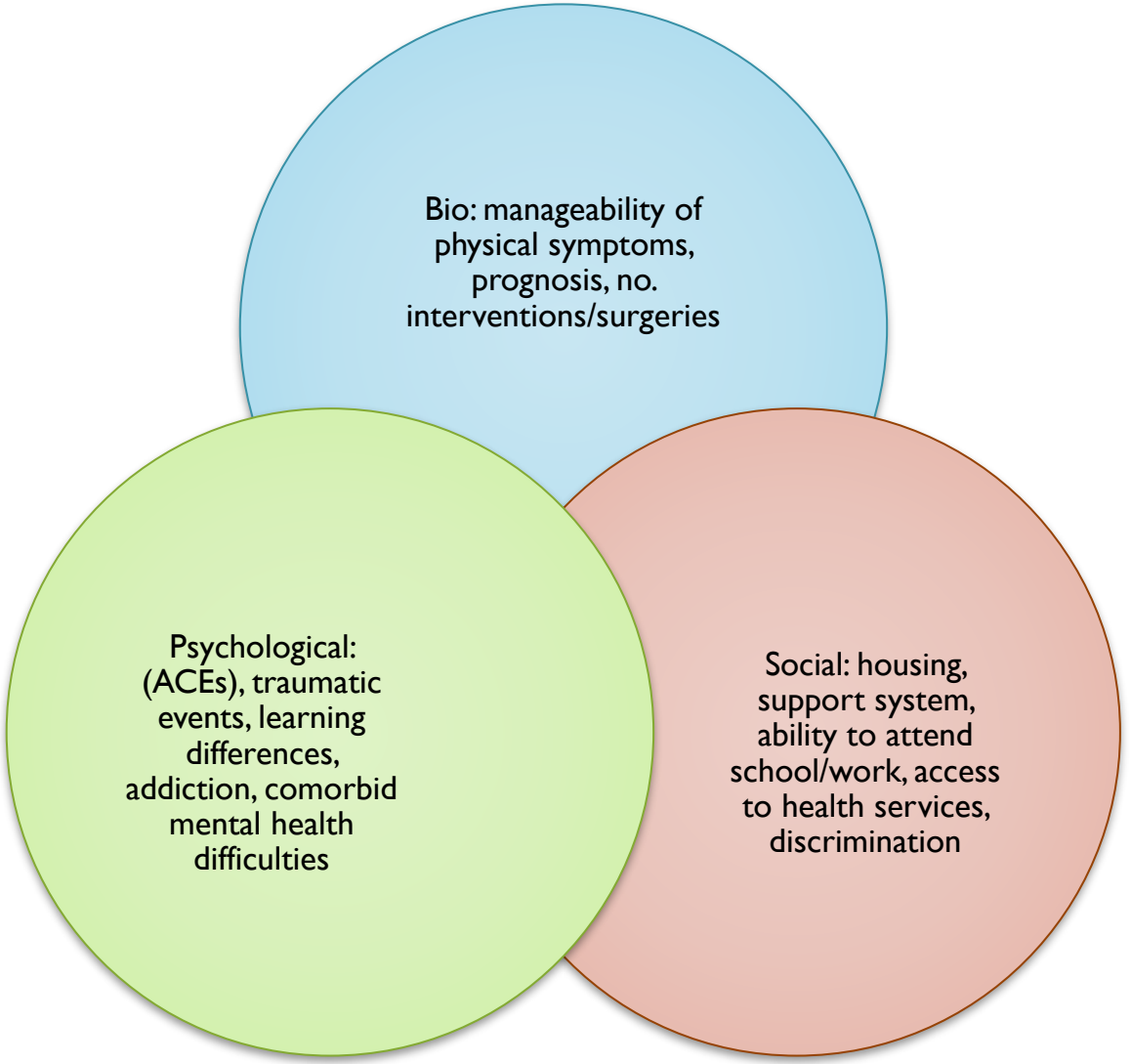
Developmental, Biopsychosocial Model of Complexity



Complex Cases in LTHCs

Kings Fund Paper (2012)

- Many people with long-term physical health conditions have mental health difficulties. These can lead to significantly poorer health outcomes and reduced quality of life.
- Care for people with long-term conditions could be improved by better integrating mental health support… with closer working between mental health specialists and other professionals.
- Clinical commissioning groups should prioritise integrating mental and physical health care.

Depression and Anxiety in CHD

- 3 North American studies (2000-2009), 1 study in Czech Republic and 1 study in Greece found that approximately 1/3 adults with CHD experience clinically significant depression and/or anxiety.
- UK study (2014) found that 17% CHD patients struggled with anxiety and depression
- German study (2016) found that people with CHD were more likely than gen popn to experience low mood and anxiety (48% vs 37.5%) with the greatest difference found with low mood (30.7% vs 10.7%)

1. Horner et al., 2000; Bromberg et al., 2003; Kovaks et al., 2009; Popelova, 2001, 2. Chung et al., 2014, 3. Westhoff-Bleck et al., 2016).

Role of the Psychologist

Psychology Clinics

NHS Congenital standards/trust requirements for psychology treatment prioritization:

- Urgent: Within two working days for inpatients
- High priority: Within 10 working days for adjustment, adherence or decision-making difficulties that interfere with medical care
- Routine: Within six weeks for all other referrals

Primarily outpatient work and inpatient work as required. Inpatient work very variable.

Referral Criteria

- Under the care of an ACHD Cardiologist in SWSWCHD Network
- Consent for referral to be made

<u>Outpatient Referrals</u>

Mental health affected by their CHD

- CHD distress which has a negative impact on their life
- Adjustment difficulties
- Distress associated with physical issues, e.g. scars
- ICD anxiety
- Anxiety related to upcoming medical tests or procedures
- Phobias
- Trauma/PTSD associated with past medical interventions.
- Pregnancy/fertility

Referral Criteria

Inpatient Referrals

- Distress related to a long hospital admission/changing procedure dates/procedural anxiety
- Supporting patients following an acute cardiac event

Referral data (2021)

- 94 referrals between Dec 2020-Oct 2021 vs 104 referrals April 2018-March 2019
- 68% women
- Referral method: ACHD Psychology Medway Service Order and clinic letters
- Referrers: BHI and Cardiff CNS's and Cardiologists
- 90% outpatient referrals
- 52% patients opted in vs 73% opted in for treatment April 2018-March 2019

Psychological support

- 1:1 remote or f2f
- Assessment, formulation, treatment
- Assessment:
  - Current difficulties and their historical context, nature of CHD and impact, personal background, risk, mental health, support network, tx goals
- Formulation:
  - Shared understanding of the problem, the contributing factors, vicious cycles and how improvements can be made based on evidence-based practice and tx goals
- Treatment:
  - 4-16 sessions depending on need
  - CBT, MI, CF-CBT, ACT

ACT: Meaningful Lives

- https://www.youtube.com/watch?v=OV15x8LvwAQ

Case example

- AB
- Early 30s, Man
- Tetralogy of Fallot
- Reason for referral: Health Anxiety, Anxiety re: tx decision. BG: hospital trauma as child.
- Tx Goals: Have space to consider tx decision, reduce health anxiety so can engage with things enjoyed before (socialising, light exercise)

Formulation

Relevant Background:
Loving family; some overprotection from parents
Traumatic experiences in hospital as child: memories of feeling powerless and frightened
Missed out on school and social events due to poor health and surgeries

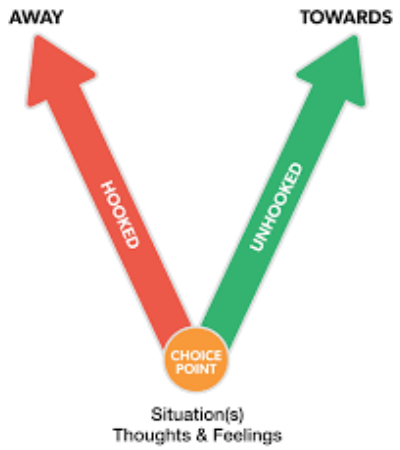
Current Situation:
Needs to make decision about tx; trauma memories from past surgeries are triggered (with associated anxiety)

Thoughts/Cognitions: Memories of childhood trauma, "I have no control, I can't trust others"
Feelings: Anxiety, shame (for feeling anxiety)
Physical sensations: Increase in heart rate
Behaviour: Avoid the decision; monitor heart rate/body for signs of danger

Formulation Continued

Impact: Low in mood, 'stuck' and helpless. Increased stress when does think about tx decision. Increase in self-criticism and shame. Social withdrawal. Increase in thoughts re: being a burden. Stops doing things enjoys. Increase in body monitoring and anxiety.

Considerations for Treatment: How does current coping move away from values/what is important now. Childhood and beliefs connected to this, inc medical. Resilience and resources. Risk. Support. Treatment plan may include MDT work with CNS's re: conversations with patient about tx decision



Stages of Psychological Therapy

Shared formulation

Establish personal values and blocks to engaging with them to lift mood

Revisiting past-trauma: how relates to current cognitions and behaviours

Motivational Interviewing re: tx decision

Compassion Focused Therapy: imagery work (“wasn’t my fault”)

Revisit treatment goals, values: progress made? Remaining blocks?

Outcomes

- Feedback from pts (who completed tx):
  - Less self-critical, less shame, improvement to mood and anxiety
  - More willing to do meaningful things, even though difficult
  - More able to make difficult decisions for self and management of healthcare; some increase in trust re: medical teams
  - Have strategies to manage anxiety/trauma memories/mow days
  - Felt listened to

Non-Clinical Work

- Supervision of Trainee Clinical Psychologists
- Group supervision to CNS's
- Consultation around patient care
- Teaching for the ACHD team
- Presenting at Network days and events

Any Questions?