NZRC Conference
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Chronic respiratory illness: a risk to children's psychological health

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THE UNIVERSITY OF AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

MEDICAL AND HEALTH SCIENCES

What we will cover

1. What is chronic illness?
2. What psychological problems are associated with chronic illness, especially respiratory illness?
3. How do we identify psychological problems early?
4. What can we do about them?
5. What is the role of the respiratory team in addressing psychological problems?

Chronic Illness

Physical, psychological or cognitive problems lasting more than three months, which impair functioning (Van der Lee 2007)

Chronic physical illness now termed long-term physical conditions (LTPC)

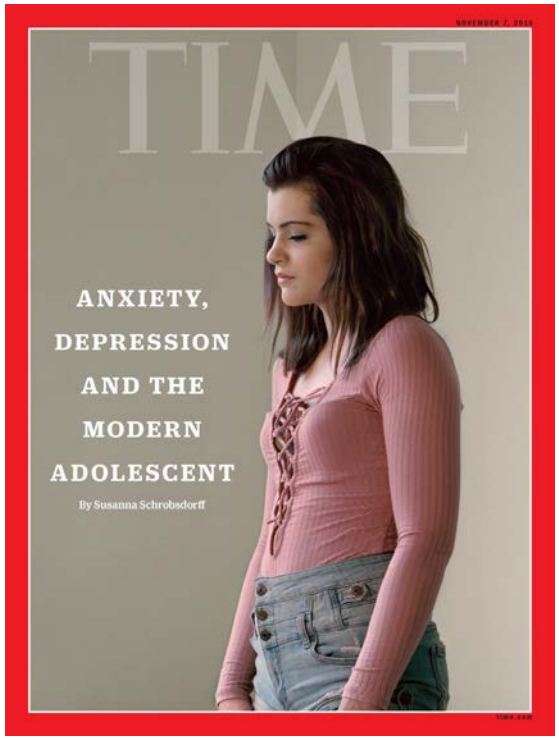
10-12% children worldwide: most commonly asthma, diabetes, CF, and epilepsy (Eiser 1997, Burkart 2000) – unless you count obesity!

Psychological problems

Risk of psychological difficulties, particularly anxiety and depression, is substantially increased in children and adolescents with LTPC (Weiland 1992, Newacheck 1991, Gortmaker 1990, Cadman 1987, Pless 1971)

Up to 40% develop depression

- Younger children, girls and those with some types of LTPC appear at greater risk of developing anxiety
- Developmentally and temperamentally-related risk
- Environmental (parenting/abuse/divorce/ poverty) too



Psychological problems associated with respiratory LTPC

Asthma

- Depression in 45% adolescents (Zadeh 2017)
- 2.5 OR anxiety (Vuillerman 2010)

CF

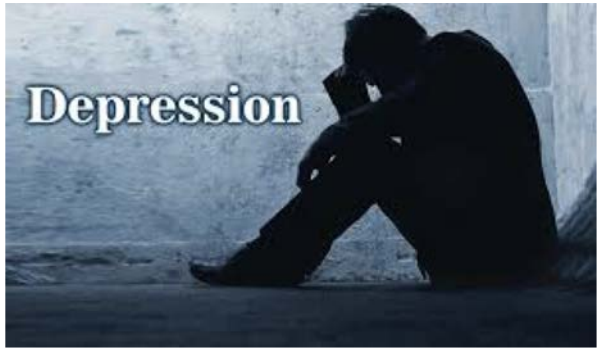
- Depression in 10% adolescents (Quittner 2015)
- Anxiety in 22% adolescents (Quittner 2015)

Bronchiectasis

- Depression in 22% all ages (Olveira 2013)
- Anxiety in 36% all ages (Olveira 2013)

Why?

- Being confronted by dangerous stimuli (such as threatening symptoms of illness or distressing procedures and unpredictable events)
- Experiencing fear of death in life-threatening diseases, having a reduced sense of control over one's circumstances
- Interference of illness and treatment routines with daily life (Suris 2004)
- Dealing with peer rejection (Sandstrom and Schanberg 2004)
- Parental overprotection (Holmbeck 2012)
- Experiencing illness-specific symptoms such as shortness of breath in asthma
- Readjusting to normal life following treatment



Is it the same in NZ?

NZ evidence suggests **anxiety** is the key issue for children at Starship (Thabrew 2016):

- Fear of not knowing
- Fear from provided information
- Fear of hospital and procedures
- Fear about leaving hospital

Thabrew, H., Stasiak, K., Garcia-Hoyos, V., & Merry, S. N. (2016). Game for health: How eHealth approaches might address the psychological needs of children and young people with long-term physical conditions. Journal of paediatrics and child health, 52(11), 1012-1018

So what?

Psychiatric symptoms have considerable consequences for a child's quality of life, their behavioural, emotional, educational and social functioning (Fergusson 2002)

- Also, increased risk of suicide

Mental ill health has, in turn, been shown to impact upon management and medical consequences of the physical illness (Levine 2001, de Araujo 2013, Fergusson 2015)

- Up to 50% increase in cost of healthcare

How good are we at identifying psychological problems in these children?

Children minimise symptoms (Walker 1987)

Parents who are stressed/depressed may miss them (Mulhern 1992)

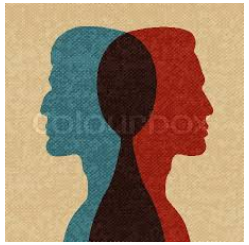
Symptoms overlap with those of medical issues (Cavaunagh 1983)

Some evidence these psychological issues are under-recognised by physicians (Bernal 2000)

Ways to identify psychological problems

Face to face assessment

- HEEADSSS assessment (adolescents)



- HEARTS assessment (younger children)

HEEADSSS assessment

Home: relationships, communication, anyone new?
Education/Employment: ask for actual marks, hours, responsibilities
Eating: body image, weight changes, dieting, exercise
Activities: with peers, with family
Drugs: tobacco, alcohol, other drugs – use by friends, family, self
Sexuality: sexual identity, relationships, coercion, contraception, pregnancy,
sexually transmitted infections (STIs)
Suicide and depression: sadness, boredom, sleep patterns, anhedonia
Safety: injury, seatbelt use, violence, rape, bullying, weapons

Issues of ethnic identity may also be critical domains, particularly among adolescents/rangatahi from minority cultures

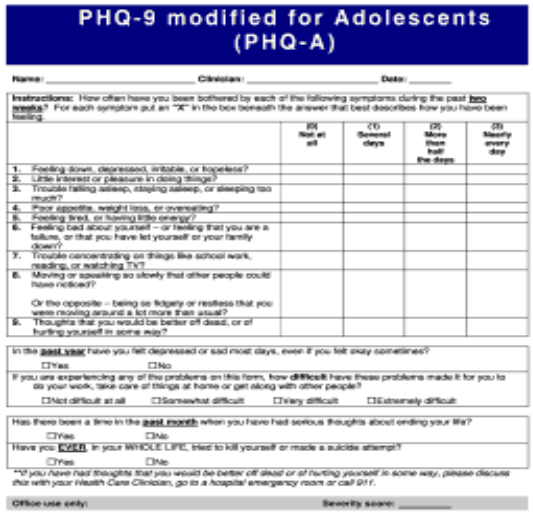
HEARTS assessment

- **Home: conduct, general behaviour, 'manageability'**
- **Education: any concerns about behaviour/progress**
- **Activities: attention span, ability to finish tasks, friendships**
- **Relationships with peers/parents: any big changes in the family, any bullying**
- **Temper: mood**
- **Size: weight gain, appetite**

Ways to identify psychological problems

Paper-based questionnaires

- The Patient Health Questionnaire – Adolescent version (PHQ-A):
  - A free, quick, self-report, validated questionnaire for identifying depression in adolescents aged 11-17 years
- The Generalized Anxiety Disorder – 7 item (GAD-7) scale:
  - A free, quick, self-report, validated questionnaire for identifying anxiety in children and adolescents aged 8-18 years
- The Substances and Choices Scale (SACS):
  - A free, quick, self-report, validated questionnaire for identifying substance use problems in adolescents aged 13-18 year



PHQ-9 modified for Adolescents (PHQ-A)

Name: _____ Clinician: _____ Date: _____

Instructions: How often have you been bothered by each of the following symptoms during the past **two weeks**? For each symptom put an "X" in the box beneath the answer that best describes how you have been feeling.

	(0) Not at all	(1) Several days	(2) More than half the days	(3) Nearly every day
1. Feeling down, depressed, irritable, or hopeless?				
2. Little interest or pleasure in doing things?				
3. Trouble falling asleep, staying asleep, or sleeping too much?				
4. Poor appetite, weight loss, or overeating?				
5. Feeling tired, or having little energy?				
6. Feeling bad about yourself – or feeling that you are a failure, or that you have let yourself or your family down?				
7. Trouble concentrating on things like school work, reading, or watching TV?				
8. Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you were moving around a lot more than usual?				
9. Thoughts that you would be better off dead, or of hurting yourself in some way?				

In the **past year** have you felt depressed or sad most days, even if you felt okay sometimes?
☐Yes ☐No

If you are experiencing any of the problems on this form, how **difficult** have these problems made it for you to do your work, take care of things at home or get along with other people?
☐Not difficult at all ☐Somewhat difficult ☐Very difficult ☐Extremely difficult

Has there been a time in the **past month** when you have had serious thoughts about ending your life?
☐Yes ☐No

Have you **EVER**, in your WHOLE LIFE, tried to kill yourself or made a suicide attempt?
☐Yes ☐No

**If you have had thoughts that you would be better off dead or of hurting yourself in some way, please discuss this with your Health Care Clinician, go to a hospital emergency room or call 911.*

Office use only: Severity score: _____

GAD-7 score	Level of anxiety
0–4	minimal
5–9	mild
10–14	moderate
15–21	severe

Scales designed for use with the general population may lead to over or under-estimation of true rates of problems in the LTPC clinical population (Stocking 2014)

Recent systematic review of screening instruments for identifying psychological problems in children and adolescents with chronic illness (Thabrew 2017)

- 44 psychometric instruments reviewed
- None found to meet 'gold standard' criteria for use with this population
- A few found recommended for use in a targeted, not universal manner

Thabrew, H., McDowell, H., Given, K., & Murrell, K. (2017). Systematic Review of Screening Instruments for Psychosocial Problems in Children and Adolescents With Long-Term Physical Conditions. Global pediatric health, 4, 2333794X17690314.

Screening for patients with respiratory illness

Cystic Fibrosis: Recommendation for routine screening for anxiety and depression using GAD-7 and PHQ-9

https://www.cff.org/

*Quittner AL, Abbott J, Georgiopoulos AM the International Committee on Mental Health, et al, International Committee on Mental Health in Cystic Fibrosis: Cystic Fibrosis Foundation and European Cystic Fibrosis Society consensus statements for screening and treating depression and anxiety. Thorax 2016;**71:**26-34*

Ways to identify psychological problems

Electronic screening: YouthCHAT

- Ten domains, matching HEEADSSS assessment
- Includes validated screeners for depression (PHQ-A), anxiety (GAD-7) and substance use disorders (SACS)
- RCT to validate YouthCHAT against HEEADSSS assessment with 129 Year 9 students at local high school 2017/8
  - Time taken
  - Effectiveness
  - Acceptability to students, school nurses
- Acceptabilty studies with young people with LTPC 2017/8
  - Mixed LTPC
  - Diabetes
  - Chronic cardiac conditions

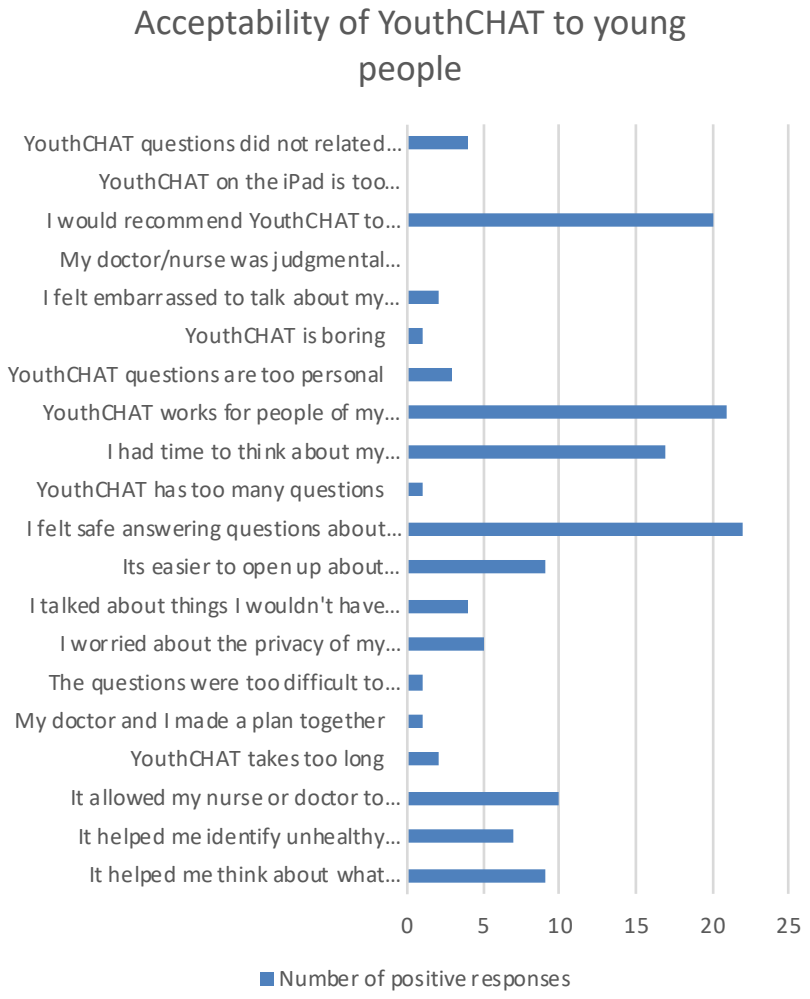
YouthCHAT results

YouthCHAT quick to complete:

- Mean 6.35 minutes (range 3.1 - 16 minutes)

Positive feedback from young people:

- 6.8 (range 5-9) on a 10 point scale from "lame" to "awesome"



YouthCHAT results

Positive feedback from paediatric clinicians:

- "Allows them to decide which issues they want to discuss and flag them to us as the clinician. I think it also might allow them to be more forthcoming with concerns/issues that they might have difficulty/not know how to raise with a clinician"

- "I used YouthCHAT twice on two very different patients. The first had nil disclosures and it was a quick way for me to screen for risk taking behaviours. The second patient turned out to have a number of high risk behaviours and concerns that had not previously been raised. YouthCHAT allowed me to quickly identify these, raise the concerns with the patient and help get them the support they needed"

Treatment of psychological problems

How?

- Medication
- Psychological interventions
- E-health interventions

Medication

Usually reserved for situations when other approaches have not been successful

Reasons: Children more prone to side-effects, dosing issues, limited research, parental preference

Exceptions: ADHD, psychosis

Psychological interventions

Psychological interventions = any psychotherapeutic treatment (talking therapy) specifically designed to change cognition or behaviour, or both, with the intention of improving outcomes (Eccleston 2012)

Limited evidence regarding interventions for psychological problems in children with LTPC (Thabrew 2018)

Majority of interventions focus on compliance with medical treatment, education about their medical condition and improving aspects of medical care

Thabrew H, Stasiak K, Hetrick SE, Wong S, Huss JH, Merry SN. Psychological therapies for anxiety and depression in children and adolescents with long-term physical conditions. Cochrane Database of Systematic Reviews 2017, Issue 1. Art. No.: CD012488. DOI: 10.1002/14651858.CD012488

Psychological interventions

Few psychological interventions have been designed specifically for use in the context of chronic illness

Primary and Secondary Control Enhancement Training – Physical Illness (PASCET – PI) (Szigethy 2008)

Co-morbid psychological issues such as anxiety and depression are usually addressed using standard treatment (*if* young people present for treatment)

Psychological interventions can be very resource intensive and the current health care system struggles to meet the demand

Therapist-assisted interventions

- Cognitive Behaviour Therapy (CBT) – anxiety/depression
- Supportive therapy - most common, limited evidence base
- Problem-solving therapy - focussed
- Motivational therapy - substance use, adherence
- Other therapy - e.g. acceptance and commitment therapy (ACT), mindfulness therapy and education

Services

- Child and adolescent mental health services
- NGOs and charitable institutions
- Private services
- Consult liaison teams
- School-based health services

E-health interventions

Information & Support

- For children
- For families

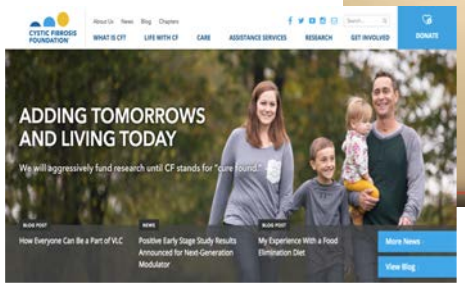
Treatment

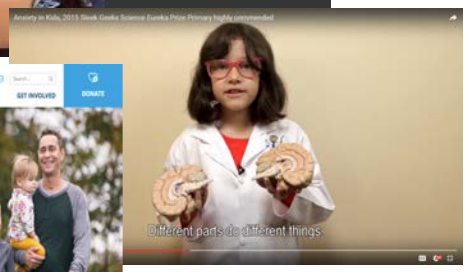
- Interactive therapies, including serious health games

Information and support

Information about psychological problems such as anxiety/depression

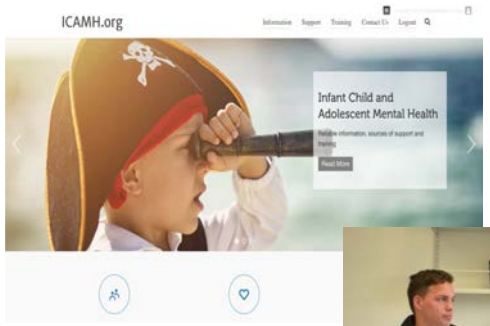
- Lowdown (NZ)
- CFF.orf (USA)
- Youtube (International)





Information about mental health services

- Werry centre (NZ)
- ICAMH.org (NZ)



Interactive e-therapies

Many different types:

- Health apps
- VR systems
- Relaxation training
- Biofeedback Serious health games – most CBT based
  - SPARX (depression)
  - BRAVE (anxiety)
  - Cool Kids (anxiety)

Serious health games

Increasing evidence:

- Psychological (and physical) serious health games result in improvements in illness-related knowledge, information-seeking behaviour and physical or psychological symptoms (Beale 2007, March 2008, Merry 2012)
- Computerised CBT endorsed by NICE as 1st line treatment for mild-moderate anxiety and depression
- Review of 15 studies suggested that children with chronic health conditions may be less likely to drop out from computerised interventions than from face-to-face interventions (Dunn 2011)
- Cochrane review of e-health interventions for children with LTPC suggests preliminary evidence of their efficacy (Thabrew 2018)


Cochrane Library
Cochrane Database of Systematic Reviews

E-Health interventions for anxiety and depression in children and adolescents with long-term physical conditions (Review)

Thabrew H, Stasiak K, Hetrick SE, Wong S, Huss JH, Merry SN

www.cochranelibrary.com

WILEY

Thabrew H, Stasiak K, Hetrick SE, Wong S, Huss JH, Merry SN. E-Health interventions for anxiety and depression in children and adolescents with long-term physical conditions. Cochrane Database of Systematic Reviews 2018, Issue 8. Art. No.: CD012489. DOI: 10.1002/14651858.CD012489.pub2

What's on the horizon?

Starship Rescue:

- CBT and biofeedback-based computer game to treat anxiety in children with LTPC
- Co-designed with young people from Starship Hospital
- Open trial underway

What's on the horizon?

The Patience Project:

- VR technology to link hospitalised children and adolescents with their schools and homes
- Open trial to commence 2019

So what does all this mean for respiratory clinicians?

- Be aware that psychological problems, especially anxiety and depression, are more common in patients with chronic illness
- Consider targeted screening using validated instruments when you suspect psychological problems
- Offer initial support and liaison to access further care via supports in familiar environment (e.g. school/GP)
- If that doesn't work or there are more acute concerns (e.g. suicidal ideation, self-harm, significant adherence issues), refer for CAMHS, consult liaison and online treatment

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Acknowledgments

- Game for Health project research
  - Treatment of anxiety in kids with LTPC

Starship Foundation

- HABITS project
  - Platform for research and delivery of eHealth interventions for NZ children
  - Emotional health apps, AOD app, Play Kindly, more to come…

cure kids

A BETTER START | National SCIENCE Challenges

- YouthCHAT research
  - Screening for psychological problems in kids with LTPC

Starship Foundation

- Patience Project research
  - VR technology to improve wellbeing and reduce social isolation in hospital

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Thank you

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