THE PSYCHOLOGY OF COELIAC DISEASE AND GFD ADHERENCE

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Outline

■ Psychology: what and why?
■ The building blocks of behaviour change
■ Explaining the ‘intention-behaviour gap’
■ Initiation vs. maintenance
■ What can you do?
■ Children and adolescents
What is psychology?

- The science of thoughts, emotions, and behaviour
- Health psychology
  - Adjustment to illness
  - Adherence to treatment/medical recommendations
  - Health behaviour change
  - Attitudes, beliefs, behaviour
- Clinical psychology
  - Mental illness
  - Symptoms
  - Treatment and prevention
  - Emotions, distress, wellbeing
Why psychology?

- Rates of strict adherence are inadequate
- Knowledge-behaviour gap
- Patient behaviour is the single most important factor that determines clinical outcome/remission in CD
- Need to understand the *modifiable* patient factors associated with poor adherence → design interventions (formal and/or clinical practice) to improve adherence
Building blocks of behaviour change

Environment/context

Knowledge

Motivation

Action/planning

Coping with barriers
Building blocks of behaviour change
Theory

- Blue print for intervention efforts
- Why did/didn’t it work?
The intention-behaviour gap

- Why do some people with coeliac disease fail to adhere strictly to a GFD despite having positive intentions to do so?

- Depressive symptoms
- Coping strategies
- Emotion regulation
- Confidence

Sainsbury et al. (2013). Gluten free diet adherence in coeliac disease: The role of psychological symptoms in bridging the intention-behaviour gap.
Depressive symptoms

- Depressive symptoms are more common in coeliac disease than healthy controls (= other chronic illnesses)
- Depressive symptoms explained some of the intention-behaviour gap
  - Positive intentions: inadequate adherence > strict GFD
- Higher depressive symptoms associated with poorer GFD adherence (medium effect size: r = .40)

Smith & Gerdes (2012). Meta-analysis on anxiety and depression in adult celiac disease.
↑ Depression/depressive symptoms

Barrier to behaviours needed for good adherence

↓ GFD adherence

Physiological mechanism (tryptophan, B12), reaction to restrictions
Coping strategies & emotion regulation

- Better GFD adherence associated with:
  - ↑ task-oriented coping (e.g., problem solving)
  - ↑ acceptance, reappraisal (i.e., thinking differently)
  - ↓ emotion-oriented coping (e.g., getting upset/frustrated)
  - ↓ maladaptive coping (e.g., distraction, self-blame, suppression)

- Only the maladaptive strategies differentiated intenders with good vs. inadequate adherence

- Coping related to depressive symptoms

Sainsbury, Mullan, & Sharpe (2013). Reduced quality of life in coeliac disease is more strongly associated with depression than gastrointestinal symptoms.
Confidence

Better GFD adherence associated with:
- General confidence for adherence
- Confidence for the specific behaviours
- Confidence to balance adherence with other goals/priorities
- Perceptions of behavioural control (vs. actual behavioural control)
- Perceptions of difficulty

Dowd et al. (2016). Prediction of adherence to a gluten-free diet using protection motivation theory among adults with coeliac disease.
Hall et al. (2013). Intentional and inadvertent non-adherence in adult coeliac disease: A cross-sectional survey.
An intervention to improve GFD adherence

- Motivation
- Confidence
- Beliefs/attitudes
- Knowledge
- Coping:
  - problem solving, communication, reframing, achieving balance between GFD and other areas of life

Sainsbury et al. (2013). Randomized controlled trial of an online theory-based intervention to improve gluten free diet adherence in coeliac disease.
Initiation vs. maintenance

Strength vs. type of motivation

Self-regulation

GFD adherence

- Reading labels
- Avoiding contamination at home
- Telling other people about CD/need for GFD
- Asking questions (food prep, contamination)
- Planning in advance
- Carrying GF food in case of low availability
- Planning for if/when unexpected things get in the way

Initiation vs. maintenance

Strength vs. type of motivation → Self-regulation → Habit → GFD adherence

Self-regulation → Social/environmental support

Self-regulation → Reduced self-control and resources

Habit → Goal priority and conflict

The role of the ‘maintenance constructs’ in GFD adherence

- Cross-sectional survey in Australia and New Zealand
- N = 5573
- Measures:
  - GFD adherence (coeliac dietary adherence test)
  - Psychological distress
  - Intention, perceived behavioural control
  - Maintenance constructs

Results

- ✔ Type of motivation
- ✔ Resources
- ✔ Self-regulation
- ✔ Habit
- ✔ Goal priority and conflict
- ✔ Support
- ✔ Intention
- ✔ Perceived control
- ✔ Distress
Results: type of motivation

- Enjoyment of behaviour
- Consistency with values
- Part of who I am
- Increased energy
- To feel emotionally well

- Avoid pre-diagnosis symptoms
- Avoid symptoms post-diagnosis with gluten
- To feel physically well

- To avoid long-term health problems

- Other people expect me to
- My GP/health professional told me to
- I would feel guilty if I didn't
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Results: psychological resources

- Temptation: 68-81% never felt tempted
- Intentional gluten consumption: 88-94% never
- Less careful → potential unintentional gluten consumption: 70-89% never

- Busy/limited time
- Break from usual routine
- Stressed
- Upset/down
- Emotionally exhausted

- Feeling physically unwell
- Unable to see any positive effect of the GFD
- Bored
- Tired
- Low energy
- Unmotivated
Results: predicting GFD adherence

- ↑ social and environmental support
- ↑ perceived behavioural control
- ↓ temptation
- ↓ unintentional gluten consumption

↑ GFD adherence

- ↓ psychological distress
- ↑ self-regulation
- ↓ intentional gluten consumption
- ↑ social and environmental support
- ↑ perceived behavioural control

↑ GFD adherence
What can you do?
What can you do?

- Encourage development of future-focused, internal motivations for adherence
- Prompt patient to identify risky situations when self-control and resources are likely to be low (different routine, busy, stressed) → plan
- Enlist and/or mobilise social support
- Normalise/validate difficulties and need for effort at start → easier with time (habit)
- Identify any conflicting priorities and plan/problem solve ways to integrate GFD
- Identify depressive symptoms → referral to psychologist
Children and adolescents

- Mood and behavioural changes may be suggestive of CD prior to diagnosis
- Children with CD had 1.4 x greater risk of **psychiatric disorder** than healthy controls (mood, anxiety, eating, and behavioural disorders, ADHD, autism spectrum disorders, intellectual disability). Non-affected siblings of CD patients were at no greater risk
- Adolescents with good GFD adherence displayed more **adaptive coping**: used more planning, flexibility, and acceptance
- Adolescents with poor adherence were more likely to get frustrated at CD and refuse to accept the medical need for a GFD
- **Caregivers** (parents, spouses) of patients with CD were at heightened risk of depression and anxiety

References


References


