THE DEVELOPMENT AND PROOF-OF-CONCEPT STUDY OF A PSYCHOEDUCATIONAL INTERVENTION FOR ADULTS LIVING WITH COELIAC DISEASE

by

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Abstract

This thesis describes the development and initial proof-of-concept testing of a psychoeducational intervention designed to support people with CD to manage the psychosocial impacts of the condition. Chapter 2 presents a qualitative evidence synthesis of research on the psychosocial impacts of CD for adults. Chapter Three presents a small qualitative study (N=13) in which adults living with CD unanimously supported the idea that the proposed intervention would be useful and provide support. Results also found that adults often experienced both positive and negative psychosocial impacts following diagnosis. Chapter 4 described the development and preliminary validation of the LWWCD-27 measure, designed to assess adults' psychosocial adaptation to CD. In Chapter Five, the development of a psychoeducational intervention, *Living well with Coeliac Disease,* is described. Chapter Six reports longitudinal quantitative results from a proof-of-concept study of the intervention. Significantly improved levels of anxiety, stress and psychosocial adaptation to CD found at the end of the intervention did not all sustain over time. Chapter Seven presents a qualitative analysis describing participants' experience of the intervention. Overall, this thesis establishes proof-of-concept for *Living well with Coeliac Disease.* This work has implications for the management of CD in adults post-diagnosis.

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LIST OF ABBREVIATIONS

AAQ-II	Acceptance and Action Questionnaire (version II)
ACT	Acceptance and Commitment Therapy
ASES	Adult Self-Efficacy Scale
BFNES	Brief Fear of Negative Evaluation Scale
BIPQ	Brief Illness Perception Questionnaire
CASP	Critical Skills Appraisal Programme
CD	Coeliac Disease (Celiac Disease)
CDAQ	Coeliac Disease Assessment Questionnaire
CDAT	Celiac Disease Adherence Test
CD-FAB	Coeliac Disease Food Attitudes and Behaviours Scale
CDQ	Coeliac Disease Questionnaire
CDQoL	Coeliac Disease Quality of Life
CERQual	Confidence in Evidence from Reviews of Qualitative Research
CFT	Compassion-Focused Therapy
COREQ	Consolidate Criteria for Reporting Qualitative Research
DASS-21	Depression, Anxiety, Stress Scales (21 items)
DDS	Diabetes Distress Scale
DH	Dermatitis herpetiformis
ETQS	Evaluation Tool for Qualitative Studies
GF	Gluten-Free
GFD	Gluten-Free Diet
GHQ	General Health Questionnaire
HAI	Health Anxiety Inventory
HRQoL	Health-related Quality of Life
IPA	Interpretative Phenomenological Analysis
IPQ	Illness Perception Questionnaire
IPQ-R	Illness Perception Questionnaire Revised
JBI	Joanna Briggs Institute
LWWCD	Living Well with Coeliac Disease
NCGS	Non-Celiac Gluten Sensitivity
NICE	National Institute for Health and Care Excellence
NPC	New Philanthropy Capital
PCA	Principal Component Analysis
PGWB	Psychological Wellbeing Index
PP	Positive Psychology
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QES	Qualitative Evidence Synthesis
QoL	Quality of Life
RCI	Reliable Change Index
RETREAT	Review question, Epistemology, Time, Resources, Expertise, Audience, Type
RFD	Refractory Coeliac Disease
SF-36	Short-Form 36
SHAI	Short Health Anxiety Inventory
SMART	Specific, Measurable, Achievable, Realistic, Timely

SPIDER	Sample, Phenomena of Interest, Design, Evaluation, Research Type
SRQR	Standards for Reporting Qualitative Research
TA	Template Analysis
ToC	Theory of Change
WBSI	White Bear Suppression Inventory

ETHICAL APPROVAL

The design and data collection of all studies in this thesis adhered to guidelines for ethical research put forward by the British Psychological Society. Ethical approval from the Science, Technology, Engineering and Mathematics Ethical Review Committee at the University of Birmingham was granted for Study One (Chapter Three), Study Two (Chapter Four), and Study Three (Chapters Six and Seven), and is presented in Appendix A.

STATEMENT OF AUTHORSHIP

The authorship of each chapter of this work is the product of collaborative work. My supervisors, Dr Ruth Howard (RH) and Dr Gary Law (GL), aided in the design, planning, and editing of all written work and provided supervision throughout all phases of the project. In Studies One and Two, I designed the studies, undertook all data collection and analysis, wrote up the studies, and was supported in interpreting the results by RH and GL. In Study Three, I undertook the study design; Lucy Jenkins undertook data collection; Sianna Banks (SB) undertook data collection and assisted with data analysis. I wrote up the study, and was assisted in the interpretation of the results by RH and GL.

CHAPTER ONE: OVERVIEW OF COELIAC DISEASE AND DEVELOPMENT OF THE CURRENT PROJECT

1.1 Introduction

Chapter One begins with a detailed overview of Coeliac Disease (CD) and its management before considering the current role of psychology in CD management. The researcher then presents the aims, objectives and research design of the current project and an outline of the thesis structure.

1.2. Coeliac Disease

CD is a chronic condition characterised by an autoimmune reaction in the small intestine triggered by dietary ingestion of gluten (Tye-Din, Galipeau, & Agardh, 2018). Although CD is incurable, strict adherence to a gluten-free diet (GFD) can effectively manage symptoms (Caio et al., 2019).

The autoimmune response in CD is triggered by the consumption of three proteins found in the ‘gluten grains’: gliadin (in wheat), hordein (in barley) and secalin (in rye) (Beaudoin & Willoughby, 2014). Finger-like protrusions called villi line the small intestine and aid digestion of nutrients by increasing the intestinal surface area and releasing digestive enzymes (Beaudoin & Willoughby, 2014). CD-specific antibodies and helper T-cells attack the gluten proteins during the autoimmune response, creating inflammation and destruction of the villi (villous atrophy) within the small intestine (Mendoza, 2005).

1.3. Clinical presentations

CD is a long-term, complex condition associated with a diverse range of symptoms that range from mild to severe (Caio et al., 2019). Symptom patterns are categorised as ‘classical’, ‘non-classical or ‘asymptomatic’. ***Classical CD*** presents symptoms of malabsorption, such as diarrhoea, weight loss, vitamin deficiencies, and often lactose intolerance (Walker, Ludvigsson, & Sanders, 2017). ***non-classical CD*** presents no malabsorption symptoms, though gastrointestinal pain and extraintestinal symptoms can occur. Extraintestinal symptoms of CD include arthritis, depression, reduced bone density, eczema and reproductive problems (Leffler et al., 2015; Ludvigsson et al., 2013; Walker et al., 2017). Clinical screening for CD is recommended when a person has a first-degree relative with CD or has an associated condition, and this may lead to the diagnosis of ***asymptomatic CD*** (Ludvigsson et al., 2013). A blistering, itchy skin rash characterises **Dermatitis Herpetiformis (DH),** a rare CD variant likely to develop into CD over time (Jakes, Bradley, & Donlevy., 2014). All symptom patterns are associated with villous atrophy and require management through a GFD (Ludvigsson et al., 2013). **Refractory CD** (RFD) is unresponsive to the GFD and affects ≤ 4% of people with CD. RFD can be life-threatening and requires specialist management and medication (Penny, Baggus, Rej, Snowden, & Sanders., 2020).

1.4. Associated conditions

CD is associated with many autoimmune and non-autoimmune conditions, increasing the health challenges faced by people living with CD. Associated conditions include Type 1 diabetes, autoimmune thyroid disease, autoimmune liver disease, rheumatoid arthritis, Sjogren’s syndrome and lupus (Assa, Frenkel-Nir, Tzur, Katz, & Shamir., 2017; Caio et al., 2019). Overall, cancer risk is not increased in CD, though a small increased risk for non-Hodgkin’s lymphoma and small-intestinal cancer is well-evidenced (Card, West, & Holmes., 2004; Ilus, Kaukinen, Virta, Pukkala, & Collin., 2014).

1.5. Diagnosis of CD

CD can develop at any age, though is most often diagnosed in very young children and adults aged 20-40 years old (Caio et al., 2019). Diagnosis of CD is a multistage process, with positive blood tests followed by a small intestinal biopsy to confirm the diagnosis (Aziz et al., 2017). Blood tests for CD identify coeliac antibodies, so people undergoing testing are advised to eat gluten daily in two or more meals for six weeks (National Institute for Health and Care Excellence, 2015). A biopsy is needed to confirm the diagnosis of CD through assessment of the level of villous atrophy using the modified Marsh-Oberhuber Classification system (0-4) (Dickson, Streutker, & Chetty., 2006). A Marsh grade ≥ 3a indicates some level of villous atrophy and enlarged indentations between villi (called crypt hyperplasia) which indicates CD (Lebwohl et al., 2018). Children and pregnant women are generally exempt from the biopsy, and in these cases family history, genetic screening, and positive response to the GFD support the CD diagnosis (NICE, 2015). However, some people who exclude gluten from their diet before their diagnosis are reluctant to consume gluten for the time required to undertake the diagnostic tests. In these cases, people can remain undiagnosed and not receive the medical support they need (NICE, 2015).

1.6. Prevalence

The worldwide prevalence of CD is increasing: seroprevalence is estimated at 1.4%, and biopsy-confirmed prevalence is estimated at 0.7% (Singh et al., 2018). CD occurs most frequently in European countries, Australia and New Zealand, and least in Southern Africa (Singh et al., 2018). Underdiagnosis of CD is a global problem (Singh et al., 2018) and the UK diagnosis rate is just 24% (Urwin, Wright, Twigg, & McGough., 2016). Asymptomatic or mild CD is often undiagnosed. CD is also commonly misdiagnosed as irritable bowel syndrome (IBS), anxiety or the effects of ageing. Negative diagnostic blood tests can also result when people reduce or exclude gluten from their diet before completing diagnostic tests.

1.7. Causes of CD

The heritability of CD is high, and current UK guidelines recommend that first-degree relatives be screened (NICE, 2015). Some 25-35% of the general population carry the predisposing genes[1], though only around 3% of these people will develop CD during their lives. This means that other factors must interact with genes to lead to the development of CD in a subset of people (Caio et al., 2019). Dietary gluten consumption is essential for the development of CD. Significant positive correlations between predisposing genetic profiles and high dietary wheat consumption occur in those countries with the highest prevalence of CD (Lionetti, Pulvirenti, and Catassi., 2015). Gluten-grains are partly indigestible and stress people's digestive system with and without CD (Caio et al., 2019). Some authors suggest that agricultural development of grains which increased the gluten-content of modern wheat may be contributing to the rise of gluten-related disorders, though these theories are unproven (Caio et al., 2019). Infant feeding practice has also been suggested as a possible factor in the

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[1] the HLA-DQ2 or HLA-DQ8 genes

development of CD. However, a recent meta-analysis reported a lack of conclusive evidence that the development of CD is associated with either *age* of gluten introduction or the amount of gluten introduced into infants' diets (Tye-Din et al., 2018). Evidence from child and adult studies suggest that gastrointestinal infections may be a factor in the development of CD (Bouziat et al., 2017; Tye-Din et al., 2018). There is a strong association between certain medications[2] taken to reduce stomach acid in conditions like acid reflux or stomach ulcers and increased CD risk (Lebwohl et al., 2014). Several other studies have found associations between altered gut microbiota and CD, though further research is needed to confirm these associations (Caio et al., 2019; Tye-Din et al., 2018). Despite ongoing research, at the present time many people who are diagnosed with CD have no idea why they have suddenly developed the condition.

1.8. Self-management of CD

The GFD: The only current treatment available for CD is a strict, lifelong GFD, which is a diet containing no trace of wheat, barley, rye or derivative grains (Welstead, 2015). There is a lack of high-quality evidence that the protein found in oats (avenin) triggers CD. However, some people with CD experience symptoms after consuming even certified gluten-free (GF) oats, and so also exclude oats from their GFD (Pinto-Sánchez et al., 2017). The GFD effectively reverses villous atrophy and improves or eradicates clinical symptoms. Recovery can be rapid though it may take a year or longer. Attempted self-management rates are high, though around 30% of people with CD experience

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[2] Proton Pump Inhibitors

persistent symptoms despite believing they strictly follow a GFD (Penny et al., 2020). The most common cause of persistent symptoms is accidental gluten consumption (Penny et al., 2020).

Challenges of self-managing a GFD: Achieving strict dietary self-management can be difficult for practical, emotional and social reasons. Preservatives, flavourings and sauces often contain gluten. Labelling alerts consumers about unsafe foods, with EU and USA standards stipulating that foods labelled GF contain gluten levels ≤ 20 parts per million (Codex Alimentarius: International Food Standards., 2015). The UK Food Standards Agency (FSA) includes gluten-containing cereals as one of 14 allergens manufacturers must inform consumers of on food labels (Food Standards Agency, 2020). Despite this, cross-contamination during processing and food preparation regularly occurs, along with product mislabelling and unreported changes of ingredients or suppliers. One study reported that 32% of GF foods were mislabelled (Penny et al., 2020). Some people with CD are super-sensitive and affected by even trace levels of gluten, meaning that all processed foods are a potential risk, and the GFD is particularly arduous for those individuals (Penny et al., 2020).

GF recipes often recreate the palatable textures of standard foods by increasing the amounts of fat, sugar or salt, leading to a GFD potentially becoming unhealthy. Clinical guidelines recommend dietetic counselling to support those diagnosed with CD in maintaining a healthy GFD (NICE, 2015). Though potentially healthier, home-cooking may become burdensome (Sverker, Ostlund, Hallert, & Hensing., 2009). GF foods are consistently more expensive than standard items and are often unavailable in small stores, placing an economic burden on families with low-average incomes (Hopkins & Soon, 2019; Lambert & Ficken, 2016; Lee et al., 2019).

Increasing numbers of people follow a GFD for non-medical purposes, leading to widespread dismissal of the GFD as a ‘fad’ diet (King, Kaplan, & Godley, 2019). People with CD experience stigma, especially in social settings (King et al., 2019; Rose & Howard, 2014; Schroeder & Mowen, 2014). Research has found that a ‘GFD stereotype’ exists in which people with CD are judged to be high-maintenance and demanding, and this stereotype appears to be applied more frequently to men with CD than women (Aloni, Geers, Coleman, & Milano., 2019). Dietary self-management can impact diverse areas of life and can even include exclusion from religious practices (Leffler et al., 2008; Offices of the Congregation for Divine Worship and the Discipline of the Sacraments, 2017; Zarkadas et al., 2013). Around 40% of people with CD feel dissatisfied with their GFD, and studies have found that the GFD is associated with increased perceived disease burden and lowered quality of life (Caio et al., 2019). As the above overview demonstrates, CD is a complex long-term condition that can be challenging to manage practically, socially and psychologically.

1.9. Psychological intervention in long-term conditions

Complex long-term conditions are perhaps best understood through the lens of the biopsychosocial model of illness, first proposed by Engel as an extension of the biomedical model (Engel, 1980). Biopsychosocial models are systems theories in which disease occurs as part of an interaction between biological, psychological and social systems. Recent extensions of Engel's model emphasise the dynamic nature of the component systems and include the influence of temporal and wider environmental systems within the model (Lehman, David & Gruber., 2017; Wade & Halligan, 2017). Biopsychosocial theory marked a paradigm shift in thinking around the management of long-term conditions, highlighting the utility of interventions that address influencing factors in peoples' psychological, social and physiological systems (Wade & Halligan, 2017). Interventions underpinned by this model have been developed to support the self-management of long-term conditions, including chronic pain, diabetes, and multiple sclerosis (Esbitt, Batchelder, Tanenbaum, Shreck, & Gonzalez., 2015; Gignac, 2001; McCracken, Sato, & Taylor., 2013; Mo'tamedi, Rezaiemaram, & Tavallaie., 2012; Wendebourg et al., 2016). These interventions are psychoeducational, as they educate people about the biophysiological nature and management of their condition, as well as teaching psychological strategies which improve motivation, self-management, mood, quality of life, communication and social interaction.

1.10. Psychological intervention in CD

The previous sections of this chapter illustrate that CD is a complex long-term autoimmune condition. CD can be difficult to recognise, and diagnosis can be lengthy and involves multiple stages, including an intestinal biopsy. Though generally an effective treatment, the GFD is highly restrictive, and difficult to self-manage, as it requires avoiding several common staple ingredients and avoiding the cross-contamination easily created in food-processing and food-preparation. This overview shows how CD potentially affects the psychological well-being of people diagnosed with the condition, who must adjust to the reality of a lifelong autoimmune condition and to considerable changes in their everyday diet and lifestyle. Despite this, at the time of writing, just two psychological interventions to support people with CD are reported in the research literature. These are described briefly below:

- **'Coeliac School'** (Ring Jacobsson, Friedrichsen, Goransson, & Hallert., 2012): This was a psychoeducational face-to-face group run in Sweden and designed for women ≥ 20 years old with a confirmed CD diagnosis. The decision to target Coeliac School on women was based on research evidence that women face particular challenges in managing their GFD, often related to their generally increased caregiving, food-preparation and social activities (Ring Jacobsson et al., 2012; Jacobsson, Hallert, Milberg, & Friedrichsen 2012; Sverker, Ostlund, Hallert, & Hensing, 2009). Participants, recruited from hospital records, attended ten two-hour sessions of Coeliac School. Participants engaged in problem-based learning activities that aimed to help them find solutions to CD-related difficulties in their everyday lives. Topics covered included psychological attitudes towards CD, coping strategies, and knowledge of the GFD. A total of seven Coeliac School groups ran (N=54), with 7-9 women attending each group. Psychological wellbeing was measured at baseline, week 10 (final session) and six months follow-up. A control group received standard written information about CD[3]. Participants

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[3] Control group members were offered the opportunity to attend Coeliac School after their waitlist data had been collected.

showed a significant improvement in psychological wellbeing compared to controls immediately following the intervention, though most improvements had not sustained at six-month follow-up.

- **Bread n' Butter…Gluten-Free, of Course!** (Sainsbury, Mullan, & Sharp., 2013) This online intervention was open to adults > 16 years with confirmed CD recruited through the Coeliac Society of New South Wales, Australia. The intervention consisted of six modules, and the primary aim of the intervention was to improve self-management and knowledge of the GFD. Content was based on Cognitive Behaviour Therapy (CBT) and information about the GFD. Topics covered included label-reading, problem-solving, communication, and managing difficult thoughts and feelings about the GFD. A total of 101 participants completed the intervention and were compared against waitlist controls (n=88). Outcomes collected at baseline, post-intervention and three-month follow-up assessed GFD self-management, quality of life and psychological symptoms. The intervention group showed improved GFD self-management and GFD knowledge, and improvements were sustained at three-months. No improvements were found at any timepoint on psychological measures, though baseline levels of psychological distress fell within the average to normal ranges. This intervention experienced a high attrition rate (50%), though this level of attrition is typical of online psychological interventions (Forbes, Gutierrez &, Johnson., 2018).

Based on the substantial changes to health status, diet and lifestyle imposed by a diagnosis of CD, it is feasible that psychological support would be helpful to many people living with the condition. The low baseline levels of psychological distress in the intervention by Sainsbury et al. (2013) may challenge the assertion that people with CD are at increased risk of psychological distress. However, Sainsbury et al. (2013) suggest the distress specifically related to CD may have remained undetected by the generic psychological outcome measures used in the study. The primary target of both interventions described above was GFD self-management, rather than psychological distress or adjustment. Therefore, the intervention developed by Sainsbury et al. (2013) may have primarily appealed to those who felt they needed GFD knowledge and self-management skills, rather than psychological support adjusting to CD.

The discussion presented throughout this chapter suggests a need for a novel psychological intervention for people living with CD in the UK, which focuses on supporting people with psychological and social adjustment to their condition. This thesis explores this need further and presents the development and testing of a new psychological intervention designed to support people living with CD.

1.11. Aims and objectives of the current project

The primary aim of this project was to directly address the lack of psychological support available for people living with CD post-diagnosis through the design of a new psychological intervention. This aim was met through three objectives:

Objective 1: To evidence the need for a psychological intervention for people living with CD.

Objective 2: To design an original psychological intervention package targeted specifically at people living with CD. This intervention consisted of appropriate educational materials and established psychological intervention techniques.

Objective 3: To undertake a proof-of-concept study to ascertain the novel intervention's feasibility and acceptability.

1.12. Structure of the thesis

The project took a systematic, evidence-based, mixed-methods approach to the development of the new psychological intervention. Completion of the project involved background research and evidence synthesis, systematic intervention development, and three primary studies. The project outline and sequence of chapters are listed below.

1.12.1. Project outline

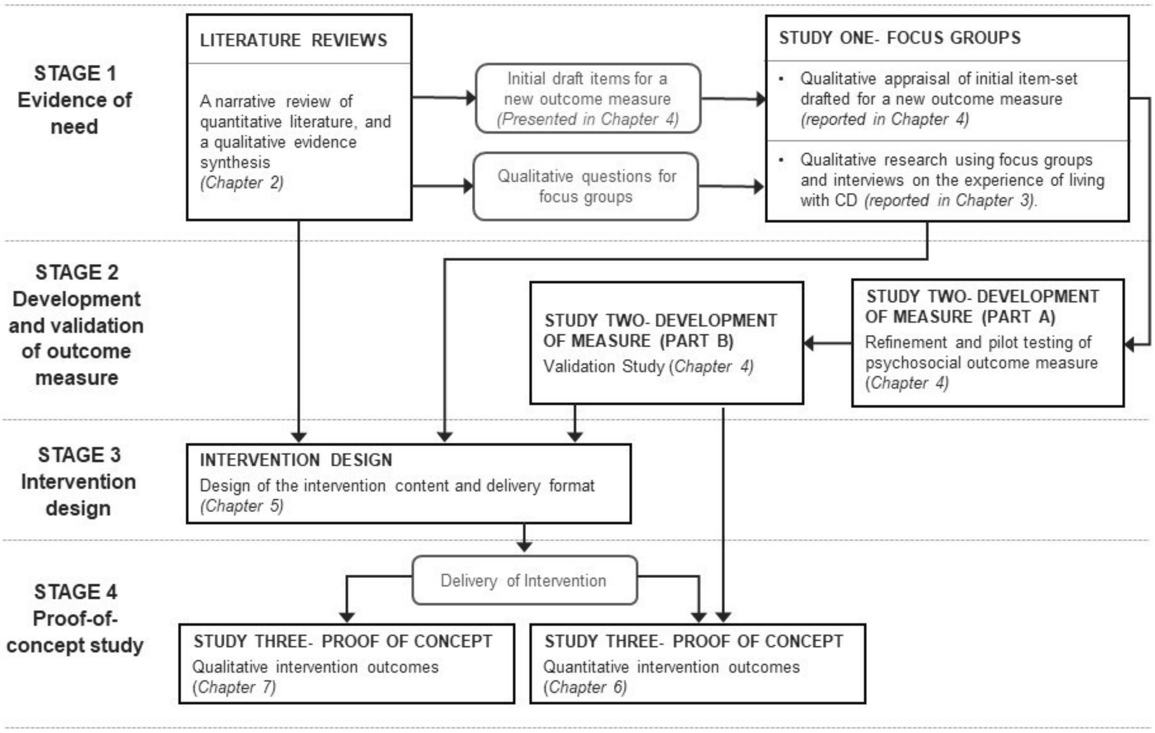
The project had four distinct stages. Figure 1 (p.13) shows the research components within each stage, the inter-relationships between components, and the thesis chapter(s) in which each component is presented.

Stage One: Evidence of need (Chapters Two, Three and Four)**.** This stage of the project explores whether the proposed intervention is needed to support people living with CD, by:

- Reviewing the research literature on the psychosocial impacts of CD;
- Undertaking primary research with adults living with CD in the UK.

Stage Two: Development and validation of outcome measure (Chapter 4) This stage of the project details the development and validation of a new psychosocial outcome measure assessing psychological and social adaptation to CD and the gluten-free diet.

Figure 1. The inter-relationships of the research components within the current thesis



Arrows show how the findings from a component inform (flow into) other components within the thesis.

Stage Three: Intervention Design (Chapter Five)**.** In this stage, systematic, evidence-based development of the new intervention was undertaken through:

- Use of an established intervention development process;
- Background research on intervention models in clinical health psychology;
- Expert consultation.

Stage Four: Proof-of-concept study (Chapters Six and Seven)**.** In the final stage of the project, a pilot proof-of-concept study tested the feasibility and acceptability of the new intervention, through:

- Analysis of longitudinal data on a range of short and long-term psychological outcomes;
- Analysis of longitudinal qualitative data exploring participants' experiences of attending the intervention, and of impacts and changes experienced.

1.12.2. Sequence of Chapters

Chapter One: This chapter has provided an overview of CD, followed by a brief discussion of the application of psychological intervention to CD. The final part of the chapter has presented the aims, objectives and structure of the current research project.

Chapter Two: This chapter presents a thematic synthesis of the qualitative evidence of the psychological and social impacts of living with CD.

Chapter Three: This chapter details Study One, a qualitative study undertaken with people who have been living with CD ≥ one year. The research aimed to gain a nuanced understanding of people's psychological and social challenges when living with CD post-diagnosis. This work also sought to gauge people's thoughts on the relevance and usefulness of a psychological intervention to support people in living with CD.

Chapter Four: This chapter presents Study Two, the development and psychometric validation of the Living Well with CD measure (LWWCD-27), which served as an outcome measure for Study Three (Chapters Six and Seven).

Chapter Five: This chapter presents the systematic development of the model, structure and content of the new psychological intervention designed for adults living with CD.

Chapter Six: This chapter presents the longitudinal quantitative results of Study Three, a pilot proof-of-concept study of the new *Living Well with Coeliac Disease Toolbox* intervention.

Chapter Seven: This chapter presents the longitudinal qualitative results from Study Three, which explores participant's experiences of attending the *Living Well with Coeliac Disease Toolbox* intervention.

Chapter Eight: The thesis closes with a discussion of the feasibility and acceptability of the *Living Well with Coeliac Disease Toolbox* intervention, piloted in Study Three. The strengths and limitations of the proof-of-concept study are outlined, and possibilities for future development of the intervention are discussed.

CHAPTER TWO: THE PSYCHOLOGICAL AND SOCIAL IMPACTS OF CD: A QUALITATIVE EVIDENCE SYNTHESIS (QES)

2.1. Introduction

As described in Chapter One, the objective of this thesis project was to design a psychoeducational intervention to support adults living with CD. The researcher developed the intervention following the systematic intervention development model by New Philanthropy Capital (NPC) (Harries, Hodgson, & Noble., 2014; NPC, 2021). The NPC (2021) model, discussed in detail in Chapter Five, begins with an initial analysis of the problem and situation. This initial step is a necessary grounding for intervention design because it is essential to ascertain substantial evidence of the need for the proposed intervention within the target group. It is also important to understand the exact nature of the problem(s) that the intervention will target.

2.1.1. Aims and Objectives

The research presented in the current chapter aimed to explore whether existing evidence suggests that a psychosocial intervention is needed to support adults diagnosed and living with CD. The second aim of this research was to describe and understand the problem(s) which are the target of the proposed intervention. These aims were addressed through three research objectives:

Objective 1: To undertake a brief narrative summary of the current evidence-base for quantitative research relating to psychological and social impacts of CD post-diagnosis, focussing on findings from recent meta-analyses and systematic reviews.

Objective 2: To contribute to this knowledge base by conducting an original qualitative evidence synthesis (QES) on the psychological and social impacts of CD post-diagnosis.

Objective 3: To answer the following research questions:

- Is there evidence of a need for a psychological intervention for people living with CD post-diagnosis?
- What problem(s) should be the target(s) for such an intervention?

2.1.2. Background research: existing quantitative evidence from systematic reviews and meta-analyses

2.1.2.1. Risk of psychological disorders

Strong evidence from a recent meta-analysis demonstrates that people living with CD have significantly higher odds of developing anxiety or depression compared to healthy controls (both $p<0.001$) (Clappison, Hadjivassiliou, & Zis., 2020). Clappison et al.'s (2020) findings are supported by results from an earlier systematic review (Zingone et al., 2015) which reported mainly consistent findings across 15 studies that rates of anxiety and depression are higher in people living with CD compared to healthy controls. Systematic reviews have reported mixed associations between the GFD and mood disorders (depression, anxiety). Some studies reported improved outcomes, others reported worsening psychological impact, and others found no association (Clappison et al., 2020; Zingone et al., 2015). Clappison et al. (2020) suggest that a series of methodological issues contribute to these mixed results across studies. These include self-reported mood and GFD adherence measures and uncontrolled confounding variables such as co-morbid conditions, symptom severity, and socioeconomic factors affecting dietary management. Further, studies often include follow-up data collected <1-year post-diagnosis, which may fail to detect the improvements in health, including mood, which can result from gains in nutritional status, intestinal healing and reduced symptoms over longer periods (Clappison et al., 2020).

Two recent meta-analyses reported an increased risk of developing an eating disorder among people with CD compared to healthy controls (Clappison et al., 2020; Nikniaz, Beheshti, Farhangi, & Nikniaz., 2021). Both reviews noted methodological limitations across studies, such as small samples (<150 participants) and the use of only self-reported outcome measures to assess psychological impacts and risk of eating disorders. Despite these limitations, the consistency of findings across studies support the reviewers' conclusions that those living with CD face an increased risk of eating disorders.

A recent meta-analysis of 16 studies reported that health-related quality of life (HRQoL) is significantly lower for those living with CD than healthy controls (Burger et al., 2017). The same authors conducted a meta-analysis on a subgroup of eight prospective studies and found that GFD treatment significantly improved HRQoL after one year ($p<.05$). The authors concluded that there is strong evidence that HRQoL, though significantly improved by the GFD, remains lower in people living with CD than healthy controls. They hypothesise that the enduring emotional and social burden of the GFD somewhat reduces the health improvements created by intestinal healing, resulting in residual negative impacts on HRQoL.

Fatigue is a common problem in CD observed at diagnosis (Skjellerudsveen, Omdal, & Grimstad., 2019; Zingone et al., 2015). However, fatigue is rarely investigated as the primary focus of studies, is often measured with unvalidated, visual or dichotomous tools, and is seldom measured over time (Skjellerudsveen et al., 2019; Zingone et al., 2015). These methodological limitations inhibit researchers' ability to understand to what extent GFD self-management alleviates the fatigue presented at diagnosis. However, a recent systematic review concludes that the weight of the limited evidence available suggests that the GFD does reduce fatigue levels in CD (Skjellerudsveen et al., 2019).

2.1.2.2. Increased risk of psychological morbidity in demographic subgroups

There is limited evidence that some groups are at greater risk of negative psychological impacts post-diagnosis than others. Zingone et al. (2015) found little evidence that women living with CD are at greater risk of depression, anxiety, social anxiety, illness burden and reduced HRQoL than men. Those living with comorbid conditions face an increased risk of anxiety and depression (Zingone et al., 2015) and reduced HRQoL (Möller et al., 2021; Zingone et al., 2015). Limited evidence has been found that those with persistent CD symptoms face an increased likelihood of lower HRQoL than those whose symptoms subside with treatment (Zingone et al., 2015). Burger et al. (2017) found that HRQoL was significantly lower in symptom-detected than screen-detected people after one year of treatment and reports that this difference in outcome may result from persistent CD symptoms.

2.1.2.3. Associations between coping strategies and the psychosocial impacts of CD

Evidence has found that the way people cope with CD post-diagnosis affects their psychological health and HRQoL. A systematic review by Möller et al. (2021) found evidence from a small number of studies that illness perceptions, psychological coping strategies (specifically emotion-focussed coping and catastrophising), and high food-related concerns were associated with reduced HRQoL. One study also reported an association between compassion-focussed coping strategies and better HRQoL (Möller et al., 2021). A meta-analysis of eight cross-sectional studies by Sainsbury and Marques (2018) reported a moderate association of poor GFD adherence with depressive symptoms. Similarly, a systematic review reported that HRQoL was significantly higher for those with better self-reported adherence to the GFD (Möller et al., 2021).

2.1.2.4. Implications of the existing quantitative evidence for the current project

The research presented above provides strong evidence that people living with CD face increased risk of experiencing anxiety, depression, reduced HRQoL, or an eating disorder following their CD diagnosis. Though GFD adherence is likely to reduce the risks of psychological morbidity, evidence across studies shows that the GFD is not a panacea and that even those with good dietary self-management may experience psychological distress and lowered HRQoL. Self-management of the GFD requires permanent changes in behaviour, considerable dietary restriction and burden. A proportion of people following the GFD will continue to experience CD symptoms which may counteract the benefits gained from self-management. Intestinal health and nutritional status may take considerable time to restore following the GFD, which may create distress and residual poor health. The behavioural restrictions and burdens of the GFD and changed health status may also contribute to the increased risk of eating disorders identified by recent meta-analyses (Clappison et al., 2020; Nikniaz et al., 2021) and the increased risk of developing patterns of disordered eating behaviour identified by (Satherley, Higgs, & Howard., 2017; Satherley, Howard, & Higgs., 2016). Psychological interventions help people cope with the psychological distress associated with long-term conditions, and can support people who need to change their eating behaviours and maintain a healthy relationship with food. Given the time needed for many people living with CD to feel their health and well-being have been improved by the GFD, psychological intervention is likely to be needed well beyond diagnosis.

2.1.2.5. The need for a qualitative evidence synthesis on the psychosocial impacts of CD

Qualitative research may effectively explore the barriers and facilitators to psychological wellbeing and HRQoL experienced by people living with CD. The exploratory and open nature of qualitative research allows variables to be identified which are not covered or adequately described by the quantitative measures pre-selected by researchers. Many qualitative studies have been published in the last decade which explore participants' experiences of living with CD. Qualitative findings will support the development of the proposed intervention by increasing understanding of the psychological and social impacts of CD and of those factors which support wellbeing. However, at the time of writing, the results of qualitative studies on the experience of living with CD had not been systematically collated and interpreted in a qualitative evidence synthesis (QES). The current study addresses this gap in research by conducting a QES on the psychological and social impacts of CD.

2.2. Methods

2.2.1. Design

The current study was a QES undertaken to investigate and synthesise qualitative data providing evidence to answer the following research question: *what are the psychological and social impacts of living with CD, following diagnosis*.

2.2.2. Eligibility criteria

The QES included studies meeting the following criteria:

Types of studies included: Studies reporting evidence of the psychological or social impacts of living with CD post-diagnosis, where data is collected from multiple participants using any qualitative design.

Types of participants: Adults with a medical diagnosis of CD. Diagnosis may be self-reported or reported by health professionals or patient records. Medical diagnosis is via any or all of the following: serological tests, gut-biopsy tests, or genetic screening.

Excluded: Studies that did not primarily investigate either psychological or social impacts of CD post-diagnosis. Studies focussed on neurological impacts (e.g. epilepsy, gluten-ataxia), developmental conditions (e.g. ADHD, ASD), or severe psychiatric disorders (e.g. bipolar disorder, psychosis, schizophrenia, suicidal behaviours). Studies with child, adolescent, or mixed adult-child samples. Single case studies; auto-ethnographies, reviews, letters, conference proceedings, opinion pieces and theoretical papers. Articles published in languages other than English where no full English-language translation is available.

2.2.3. Search strategy

Electronic database searches: A comprehensive literature search was undertaken to answer the research question. A comprehensive approach to the literature search was considered appropriate to the purpose of the review, which aimed to identify the range of psychological and social impacts of CD and establish the strength of qualitative evidence for these impacts (Booth, 2016). The comprehensive search was restricted to studies published in the last 15 years (2005 – 2020/21) within peer-reviewed academic journals. Setting these parameters ensured that findings would be relevant to people living with CD today, and originated from high-quality evidence. The 15-year span reflects the researcher’s prior knowledge that qualitative research on the psychological impact of CD was sparse in previous decades (Rose & Howard, 2014). The range and availability of GF foods have also increased considerably in the last 5-10 years, impacting the everyday experiences of people following a GFD (Aloni et al., 2019; Hopkins & Soon, 2019; King et al., 2019).

Consultation with a subject-specialist academic librarian was undertaken to inform the search strategy. The keyword search strategy followed guidance from the SPIDER search strategy tool, developed specifically for qualitative research projects by Cooke, Smith and Booth (2012). Following SPIDER, the researcher variously combined relevant search terms that represented the ***s****ample*, ***p****henomenon of* ***i****nterest*, ***d****esign*, ***e****valuation*, and ***r****esearch type*. Given the breadth of the research questions, searches relating to ‘psychological impacts’ and ‘social impacts’ were conducted separately. The following academic databases were searched using a combination of keywords and relevant index terms (Tables 1 and 2): CINAHL (OvidSP); EMBASE (OvidSP); MEDLINE (OvidSP); PsychINFO (OvidSP); SCOPUS; and, Web of Science.

Additional searches: Following retrieval of 15 full-text papers selected from the database search results, the researcher conducted a backwards search of the reference lists of these papers. The final search conducted was a forwards (citation) search using the Web of Science database.

2.2.4. Study selection

A PRISMA Flow Diagram (Figure 2, p.27) presents the study selection process. Records retrieved from the initial electronic database search were imported directly into the Zotero reference management software. Duplicate items were removed. The remaining articles were screened in two stages:

Stage 1: article titles and abstracts were screened to assess if they met the eligibility criteria (section 2.2.2). At this stage, many records were excluded based on screening of the title alone as they related to technical medical papers.

Stage 2: full-text articles meeting the inclusion criteria were retrieved and assessed for eligibility, again guided by the SPIDER criteria (Table I, Appendix B).

Table 1. SPIDER search strategy for psychological impacts of CD

SPIDER [a]	*Search Terms*
S: Sample [b]	“Coeliac” OR “Celiac”
PI: Phenomenon of Interest	“psychological” OR “depression” OR “fatigue” OR “eating behavio*” OR “eating disorder” OR “disordered eating” OR “anorexi*” OR “bullimi*” OR “feelings” OR “emotion*” OR “mood” OR “quality of life” OR “quality-of-life” OR “psychiatri*” OR “life*”
D: Design	“interview*” OR “focus groups” OR “case series” OR “narrative*” OR “thematic analysis” OR “grounded theory” OR “IPA” OR “interpretative phenomenological” OR “experiential studies” OR “narratives” OR “case series” OR “ethnography”
E: Evaluation	“view*” OR “perception*” OR “*experience*” OR “attitude*” OR “impact*”
R: Research type	“qualitative” OR “mixed methods” OR “mixed-methods”

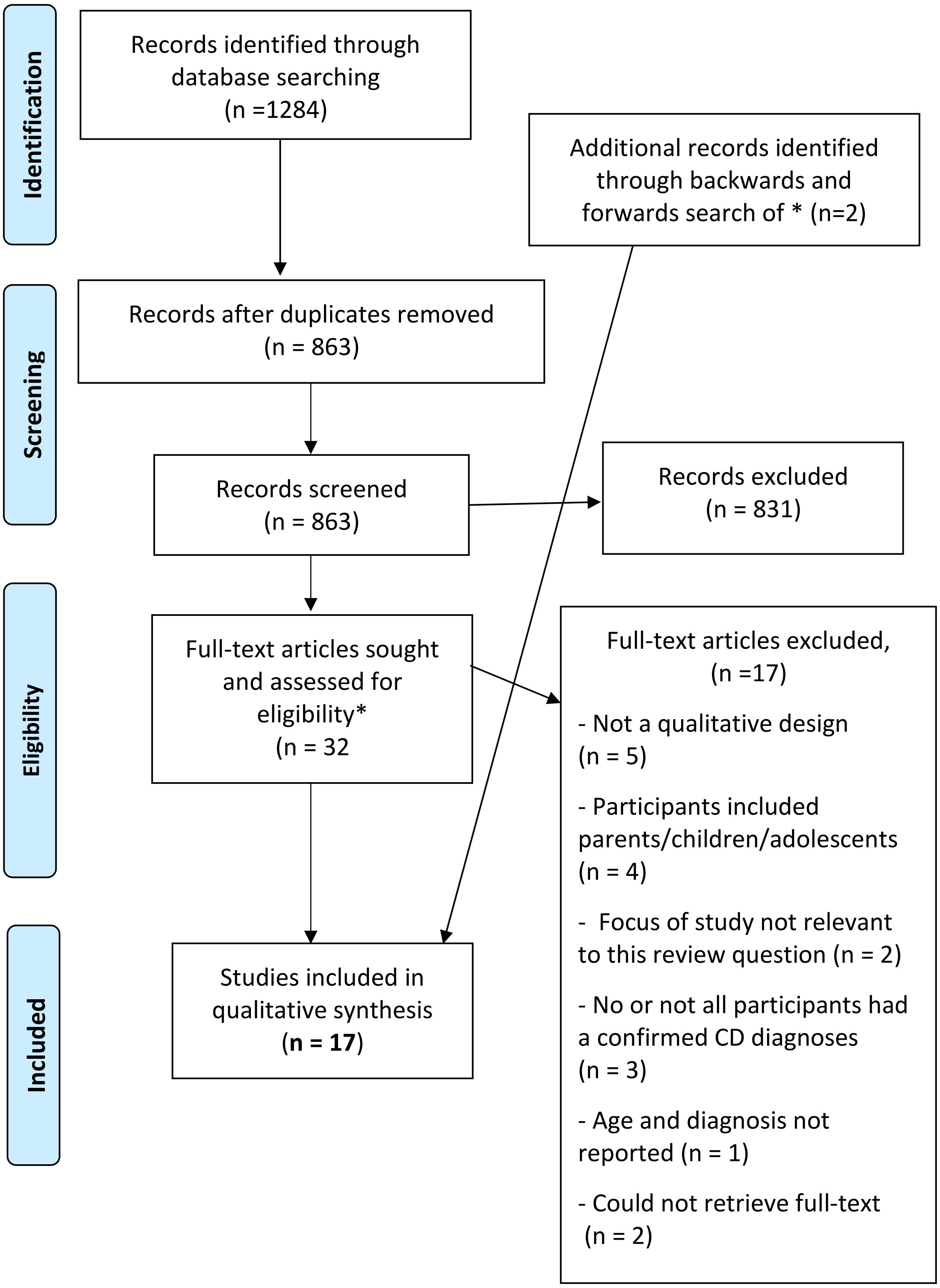
a [S AND PI] AND [(D OR E) AND R]; [b] *Database limits set to “adult population” and “2005 – present.”;* ** indicates truncation.*

Table 2. SPIDER search strategy for social impacts of CD

SPIDER [a]	*Search Terms*
S: Sample	“Coeliac” OR “Celiac”
PI: Phenomenon of Interest	“social” OR “social*” OR “identity” OR “*identity” OR “*anxiety” OR “*esteem” OR “*worth” OR “stigma*” OR “*stigma” OR “*dining” OR “dining*” OR “eating*”
D: Design	“interview*” OR “focus groups” OR “case series” OR “narrative*” OR “thematic analysis” OR “grounded theory” OR “IPA” OR “interpretative phenomenological” OR “experiential studies” OR “narratives” OR “case series” OR “ethnography”
E: Evaluation	“view*” OR “perception*” OR “experience*” OR “attitude*” OR “impact*”
R: Research type	“qualitative” OR “mixed methods” OR “mixed-methods”

*a [S AND PI] AND [(D OR E) AND R]; b Database limits set to “adult population” and “2005 – present.”; * indicates truncation.*

Figure 2. PRISMA Flow Diagram[4]



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[4] PRISMA Flow Diagram uses an open-source template adapted from Moher, Liberati, Tetzlaff, Altman & The PRISMA Group (2009). Available from: www.prisma-statement.org

2.2.5. Quality appraisal

Many quality appraisal tools have been published and are suitable for different types of qualitative study, and authors may combine tools to produce an appraisal tool ideal for their specific project (Majid & Vanstone, 2018). The researcher used a set of criteria developed by Majid & Vanstone (2018) to select a quality appraisal tool suitable for the current study (Table II, Appendix B). The 21-item Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014) was selected, a tool developed in medical research and designed for QES appraisal, and applicable across all types of qualitative research. The SRQR criteria items are relatively brief and therefore easy to use by a single researcher. The tool has been recently used in health-related QES and systematic reviews (Spyreli, McKinley, & Dean., 2021; Sugiura, Pertega, & Holmberg., 2020; Unger et al., 2019).

2.2.6. Data Extraction

The following characteristics were extracted from included studies: authors, date of publication, country of origin, methodology, participant characteristics (gender, age, time since diagnosis), phenomena of interest[5]. The findings (results) sections and all supporting data from tables, figures and supplementary documents were extracted and analysed as part of this QES.

2.2.7. Data Synthesis

Many methods can be used for QES depending on the overall purpose of the synthesis, the design of the primary studies, the reviewers' philosophical position, and the level of data transformation the QES aims to achieve. The

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[5] Psychological and social impacts of CD

current researcher used the RETREAT guidance (Booth et al., 2018) to inform her choice of QES method, which considers seven elements: *review question*; *epistemology*; *timescale*; *resources*; *expertise*; *audience and purpose*; and *type of data*. Consideration of the RETREAT criteria (Appendix B) resulted in using thematic evidence synthesis (Thomas & Harden, 2008) as the QES method. Thematic evidence synthesis is appropriate across a range of qualitative methodologies and heterogeneous studies with varying degrees of data 'thickness' (Booth et al., 2018; Thomas & Harden, 2008). Thematic evidence synthesis allows researchers to summarise existing research and move beyond this to create a novel interpretation of primary data (Thomas & Harden, 2008). Booth et al. (2018) suggest that realist, or critical or limited realist approaches such as thematic synthesis are more suitable for intervention and policy design than constructivist approaches (e.g. meta-ethnography). This is because findings remain closely anchored to the primary data, and the analysis is transparent and straightforward to explain to stakeholders.

The researcher imported data from all primary studies included in the QES into NVivo 12 software (QSR International) which facilitated and documented the analytic process. The current researcher undertook line-by-line free-coding of all primary data (abstract, findings, quotes, data tables) of all included studies. Free codes were organised into data-driven descriptive themes, which remained highly representative of the primary studies. Themes were then developed into analytical themes, which interpreted findings across studies relative to the research question. This process created a set of themes addressing the research question that both reflect and move beyond the findings of the primary studies.

NVivo was used to code and organise the data and record the researcher's ideas throughout the analytic process, creating an electronic audit trail. The current researcher undertook all of the analysis alone due to time and resource limitations, though they discussed the research process and findings with their academic supervisors.

2.2.8. Assessment of confidence in the review findings

The researcher assessed their confidence in the findings of the current QES using the Confidence in Evidence from Reviews of Qualitative Research tool (GRADE-CERQual). This tool has been developed by the Grading of Recommendations for Assessment, Development and Evaluation (GRADE) Working Group (Lewin et al., 2018). Using GRADE-CERQual, researchers assess their findings across four components: *methodological limitations, coherence, adequacy*, and *relevance*. Where broad themes are identified, these are broken down into subthemes. The body of studies contributing to each theme is analysed collectively to determine an assessment for each review finding. Review findings are rated as high at the start of the assessment and downgraded in areas where the researcher feels the levels of concern across the four GRADE-CERQual components are substantial enough to reduce overall confidence in the findings. Levels of concern range from very minor concerns unlikely to impact confidence in the findings to serious concerns likely to reduce confidence in findings (Lewin et al., 2018). Assessments are essentially subjective judgements made against the GRADE-CERQual components, and Lewin et al. (2018) recommend multiple assessors are used to resolve disagreements through considered discussion. The current researcher undertook GRADE-CERQual assessment alone due to limited resources.

2.2.9. Reflexivity

Reflexivity is an essential component of qualitative research as the researcher's views, experiences, and intentions may influence the research design, the analysis process, and the interpretation of the findings. The current researcher has researched CD since 2009. They also have experience working as an assistant psychologist in other areas of physical health and for around nine years as an independent researcher, frequently working with health-related charities and public sector services. Through her previous work, the researcher’s experience of the psychological and social impacts of long-term illness may impact her awareness of and interpretation of these phenomena within research data. The current researcher and her dissertation supervisor also authored one of the papers reviewed in the current QES (Rose & Howard, 2014), and her research supervisor is the co-author for an additional three included papers (Price & Howard, 2017; Satherley et al., 2017; Satherley et al., 2018). Despite utilising externally developed quality appraisal checklists and systematic coding throughout the research process, it is important to acknowledge the potential for bias introduced by the researcher’s proximity to those specific studies. The researcher discussed progress with this project at monthly meetings of an online interest group for postgraduate researchers undertaking QES studies at the University of Birmingham. This enabled the researcher to reflect on the methodological approaches chosen and their decision-making processes.

2.3. Findings

2.3.1. Characteristics of included studies

Table 3 presents the characteristics of the included studies. The QES included 17 articles drawn from 15 studies and included 436 participants. Studies were published between 2005 and 2021, with 70% published in the last six years (2015 onwards). Most studies were from Europe, mainly Scandinavia (six studies) or the UK (five studies). Of the remaining studies, two were from North America and two from Australia. Three studies had a 100% female sample, and six studies had a participant sample over two-thirds female. The age range across studies was wide (17 – 85 years)[6], although the average age reported was 44.8 years. The majority of studies included only or mostly participants diagnosed ≥ one year.

2.3.2. Quality appraisal of included studies

Table 4 presents the quality appraisal of all included studies. Overall, the included studies had few methodological limitations and reported fully on most of the SRQR components. However, some notable methodological limitations were present, contributing to the potential for bias or lack of transparency in findings. The majority of studies did not report on reflexivity (researcher characteristics). Most studies gave only a very brief indication of the physical

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[6] All participants were aged ≥ 18 years except for a single participant in Rodriguez Almagro et al. (2017) who was 17 years old.

research context and did not reflect on the potential impact of context on data collection or findings. Though all studies described their qualitative analysis method to some extent, most did not describe their research paradigm and the potential influence of this position on the study.

Table 3. Characteristics of the included studies

Author	*Country*	*Methodology and data type*	*Participant characteristics (gender, age, diagnosedł)*	*Phenomena of Interest*
Lee et al. (2021)	Australia	Qualitative study; Thematic analysis; interview data.	6 participants (50% female) Age 38 – 77 (M=63) Diagnosed <1 - 10 years	Access to dietetic services and experience of self-management of CD in rural areas.
Garnweidner-Holme et al. (2020)	Norway	Qualitative study; IPA; interview data	12 participants (67% female) Age 19 – 58* Diagnosed 1 - 23 years	Self-management of CD in a changing GF landscape.
Peters et al. (2020)	UK	Mixed-methods study; Thematic analysis; interview data	24 participants (54% female) Age 18 – 85 (M = 59) Diagnosed <1 - >20 years	The impact of the ending of GF food prescriptions on adults living with CD.
Ring Jacobsson et al. (2020)	Sweden	Qualitative study; qualitative content analysis; interview data	22 participants (50% female) Age 32 – 64 (M = 53) Diagnosed 5 – 42 years	Illness beliefs among people living with CD who are following a GFD.
King, Kaplan & Godley (2019)	Canada	Qualitative study; IPA; interview data	17 participants (76% female) Age unreported (adults) Diagnosed <1 - >10 years	How the changing GF landscape has affected the experience of living with CD including relationships and social life.
Satherley, Howard & Higgs (2018)	UK	Mixed methods; Thematic analysis; online focus group data	12 participants (83% female) Age 19 – 47 (M = 29) Diagnosed 1 – 14 years	People with CD's attitudes towards and everyday interactions with food. *(Study part of the development and validation of the CD-FAB scale).*
Houbre et al. (2018)	France	Qualitative study; IPA; interview data	14 participants (78% female) Age 28 – 52 (M = 42) Diagnosed 3 – 5 years	To understand the subjective experience of CD and the GFD in those diagnosed in adulthood.
Jacobsson et al. (2017)	Sweden	*As in Ring Jacobsson et al. (2020) because both articles are part of the same study.*		To explore the experience and management of residual symptoms in adults following GFD treatment for CD.

Leffler et al. (2017)	USA	Mixed-methods study; Thematic analysis; interview data	21 participants (71% female) Age 18 – 95 (M = 42)	To develop an understanding of the experience of living with CD and its impact on health-related quality of life.
Price & Howard (2017)	UK	Qualitative study; IPA; interview data	5 participants (60% female) Age 61 – 77 (M = 68) Diagnosed average 2 years	To explore the experience of receiving a diagnosis of CD and managing the GFD in later life.
Satherley, Higgs & Howard (2017)	UK	Qualitative study; Framework Analysis; interview data	21 participants (76% female) Age 19 – 59 (M = 39) Diagnosed 2 – 19 years	To understand the experience of both typical and disordered eating behaviour in adults with CD.
Rodriguez Almagro et al. (2016)	Spain	Qualitative study; Directed content analysis; interview data	19 participants (100% female) Age 17 – 47 (M = 33) Diagnosed 9 – 17 years	To explore the impact of CD on quality of life in women with CD living in Spain.
Rose & Howard (2014)	UK	Qualitative study; Grounded Theory; written narratives	130 participants (67% female) Age 19 – 78 (M = 53) Diagnosed average 10.2 years	To explore the lived-experience of CD and managing a GFD in the UK.
Taylor, Dickson-Swift & Anderson (2013)	Australia	Qualitative study; Thematic analysis; interview data	10 participants (100% female) Age 31 – 60 (M = 49) Diagnosed 2 – 26 years	To explore the experience of diagnosis and everyday management of CD.
Jacobsson et al. (2012)	Sweden	Qualitative study; IPA; interview data	15 participants (100% female) Age 30 – 75 (Median = 67) Diagnosed 5 – 67 years	To explore the lived-experience of being a woman with CD in Sweden.
Sverker et al (2009)	Sweden	Mixed methods; Critical Incident Technique; interview data	43 adults with CD** (74% female) 20 – 39 years Diagnosed: period 1991 – 98	To explore the consequences of dilemmas experienced in everyday life by people with CD and their close relatives.
Sverker, Hensing & Hallert (2005)	Sweden	Qualitative study; Critical Incident Technique; interview data	*As Sverker et al (2009) because both articles are part of the same study.*	To explore the dilemmas experienced in everyday life by people with CD.

*Mean age could not be calculated from available data; ** Accompanied by a close relative during interviews. Relatives views are also included in the data.

[†] *Length of time since the participant was diagnosed with CD.*

Table 4. Quality appraisal of the included studies using the SRQR tool.

Article	***1***	***2***	***3***	***4***	***5***	***6***	***7***	***8***	***9***	***10***	***11***	***12***	***13***	***14***	***15***	***16***	***17***	***18***	***19***	***20***	***21***
Price & Howard (2017)	*	*	*	*	*	*	P	*	*	*	*	*	*	*	*	*	*	*	*	*	?
Rodriguez-Almagro *et al.* (2016)	*	*	*	*	*	?	?	*	*	*	*	*	*	*	*	*	*	*	*	*	*
Jacobsson *et al.* (2012)	P	*	*	*	*	*	P	*	*	*	*	*	P	*	*	*	*	*	*	*	*
Lee *et al.* (2021)	*	*	*	*	P	P	P	*	*	*	*	*	*	*	*	*	*	*	*	*	*
Rose & Howard (2014)	*	*	*	*	P	?	P	*	*	*	*	*	*	*	*	*	*	*	*	*	*
Houbre *et al.* (2018)	P	*	*	*	*	?	P	*	*	*	*	*	*	*	*	*	*	*	*	*	?
King, Kaplan & Godley (2019)	P	*	*	*	*	*	P	P	*	*	P	*	*	*	*	*	*	*	*	*	*
Peters *et al.* (2020)	*	*	*	*	P	?	P	*	*	*	*	*	P	*	*	*	*	*	*	*	*
Garnweidner-Holme *et al.* (2020)	*	*	*	*	P	P	P	*	*	*	*	*	P	*	?	*	*	*	*	*	*
Jacobsson *et al.* (2017)	P	*	*	*	P	?	P	*	*	*	*	*	*	*	*	*	*	*	*	*	?
Ring Jacobsson *et al.* (2020)	P	*	*	*	P	?	P	*	*	*	*	*	P	*	*	*	*	*	*	*	*
Satherley, Higgs & Howard (2017)	*	*	*	*	P	?	P	*	*	*	P	*	P	*	*	*	*	*	*	*	*
Sverker, Hensing & Hallert (2005)	P	*	*	*	*	?	P	*	*	*	*	*	P	*	*	*	*	*	?	?	*
Sverker et al (2009)	P	*	*	*	P	?	P	P	*	*	*	*	P	*	*	*	*	*	*	?	*
Taylor et al. (2013)	*	*	*	*	P	?	P	*	*	*	P	*	P	*	P	*	*	*	?	*	*
Leffler et al. (2017)	P	*	*	*	P	?	P	*	?	P	P	*	?	*	*	*	*	*	*	*	*
Satherley, Howard & Higgs (2018)	*	*	*	*	P	?	P	*	*	P	P	*	?	*	P	*	*	P	P	P	?

* fully meets criterion; P=partially meets criterion; ?=unreported/unclear.

SRQR items: 1) Title; 2) Abstract; 3) Problem formulation; 4) Purpose / research question; 5) Qualitative approach and research paradigm; 6) Researcher characteristics and reflexivity; 7) Context; 8) Sampling strategy; 9) Ethical issues; 10) Data collection methods; 11) Data collection instruments and technologies; 12) Units of study; 13) Data processing; 14) Data analysis; 15) Techniques to enhance trustworthiness; 16) Synthesis and interpretation; 17) Links to empirical data; 18) Integration with prior work, implications; transferability, contribution to the field; 19) Limitations; 20) Conflicts of Interest; 21) Funding.

2.3.3. Themes

The QES identified five overarching themes: impact of CD on mood; the impact of CD on identity; the impact of CD on food-related attitudes and behaviours; perceived illness burden of CD; living well with CD. Each theme, including subthemes that comprise the theme, is described below and presented in no order of importance. Table 5 lists the five themes and associated subthemes. Though all the primary themes are discrete, impacts in the area of one theme can contribute to the impacts in another.

Table 5. Five themes identified in the QES of the psychosocial impacts of CD

The impact of CD on mood	• Health-related anxieties • Social anxieties • Low moods • Anger, irritability and resentment
The impact of CD on identity	• Personal identity • Social identity
The impact of CD on food-related attitudes and behaviours	• Strict self-management of the GFD • Preoccupation with food • Fears related to food • Loss of interest in food • 'Feast or Famine' behaviour
The perceived illness burden of CD	• Practical (task-related) burden • Economic burden • Social burden • Psychological burden
Living well with CD	• Confidence in the GFD treatment • Confidence in self-management • Acceptance of CD and the GFD

2.3.3.1. Impact of CD on Mood

All studies reported that CD impacted people's mood following diagnosis, including increased anxiety and low mood. Less commonly, authors described impacts of anger, irritability or resentment. Anxieties often centred around health concerns and social activities, yet some studies described anxiety as pervasive (*"Being constantly anxious was described as an anxiety that infiltrated the whole of daily life*" *Sverker et al., 2009)*

Health anxieties: CD created an increase in anxieties related to health. Participants feared accidentally ingesting gluten but also developed a heightened awareness of their physiological state. Jacobsson et al. (2017) describes how this awareness develops as an anxious attempt to identify sources of accidental gluten consumption or ongoing health problems: *"It was considered important to be observant of bodily signals, 'trying to feel what it is that makes you ill'."* Ring Jacobsson (et al., 2020) describes the common illness belief that CD had created irreparable physiological damage and vulnerability:

> *"There was a belief among the participants that, 'the gut never completely heals and thus the uptake of nutrients becomes impaired'. This was considered to cause residual problems of various kinds, 'sore intestines are not good at all. It obviously affects all the other organs and you are, like, I am bleeding inside'. It was also believed to contribute to generally poorer health."*

People often became worried about the negative impact of the GFD on their overall nutrition. Garnweidner-Holme et al. (2020) reports that participants' believed *"it was more difficult to have a healthy GF diet. They thought that a GF diet contained too little fibre and too much sugar, salt and starch".* Other worries related to fears of developing associated comorbid conditions and the genetic risk CD posed to descendants. Though some participants felt supported by health professionals, a common finding was the mistrust of health professionals due to issues such as misdiagnosis, delayed diagnosis, and little information or counselling being provided. Studies described health professionals as displaying little empathy or interest in the problems people experienced post-diagnosis. For many people living with CD, these experiences lead to reluctance to seek medical support for their health concerns and, without advice or reassurance, anxieties sometimes increased.

> *"Well, we have talked about this (residual symptoms) a few times me and my doctor[…]but I do feel that she does not really believe me actually. I feel that she is of the opinion that if you just take care of your diet, all the symptoms will disappear."* (Rose & Howard, 2014)

Despite strong evidence that a CD diagnosis increases health-related anxieties for many people, others found diagnosis relieved their health concerns. Diagnosis validated their experiences of ill-health and they could engage with appropriate treatment to mitigate the most serious risks, as reported by Rodriguez Almagro et al. (2017):

> *"When they tell you, at first, you're surprised[…]He told us of the risks and told my mother that I could die, and that's not easy[…] but that's unlikely if you're aware of the illness, thank God[…]I have felt much more reassured since then".*

Social anxieties: These anxieties related to worries that other people would disbelieve their diagnosis or would be offended by their refusal to eat gluten:

> *"Social anxiety is evident as sufferers worry about violating social rules of politeness and about negative perception by others of their nonconformist behaviour, such as when they have to 'be rude and turn down food' (or) 'make people go out of their way'. Narrators worried about being disbelieved or being identified as a 'picky' type of person: 'Because you can't see the effects of the disease people think it's in your head'."* (Rose & Howard, 2014)

Social anxiety also relates to the fear of contamination in social situations where other people were preparing food, and people felt they could never truly trust other people's reassurances. As Jacobsson et al. (2012) report *"[t]he problems started, according to the informants, at the moment they walked out of their door".* Some studies reported people's anxieties about losing control over their food due to health problems or ageing (e.g. hospitalisation, nursing-home care, deteriorating eyesight) (Jacobsson et al., 2012; Price & Howard, 2017). People living with CD undertook many behaviours to retain control of their food in social situations and reduce their worries, including venue research, questioning staff, and taking along their food. However, preparation could not eliminate all risks, and the residual anxiety felt was described by Jacobsson et al., (2012): "*if I get the same sort of food as the others then I get almost suspicious. Is this food really also for me?"*.

Low moods: Low moods in people living with CD were reported across studies, and Houbre et al. (2018) describe this as *"[t]he impact on mood, such as a loss of drive or joie de vivre"* and *"depressive episodes".* Low moods are related to several things, including feelings of loss and grief for favourite foods, lost time, depleted vitality, and lost spontaneity around food. Unmet expectations that the GFD would be effective led to disappointment and lost hope:

> *"The message from healthcare was that if one only followed the diet, everything would be fine. Informants felt a deep disappointment when they experienced that they did not become symptom-free..."* (Jacobsson et al., 2017)

Anger, irritability and resentment: Some studies reported that people living with CD felt a sense of anger about having developed CD and about the restrictions of the GFD. Some authors reported this as an impact felt soon after diagnosis, as in Rodriguez Almagro et al. (2017): *“[It’s] a mixture of anger at what I had and at the lack of information they gave me at the time, and that I could no longer live a normal life because of food.”* Others reported anger as ongoing and related to a sense of injustice that the needs of people living with CD are unmet in comparison with other groups: *“People who are Vegetarian, a choice they have made, always get their meals’* (Rose & Howard, 2014). Persistent symptoms could also impact mood, creating irritability, frustration, fatigue.

2.3.3.2. Impact of CD on identity

Personal identity: Mild or asymptomatic CD could challenge a person’s previously held identity of being healthy. Some adopted a new illness identity, now seeing themselves as having a “*bodily imbalance*” (Ring Jacobsson et al., 2020) or being diseased or damaged by CD. Others rejected adopting an illness identity and instead chose to view CD as a relatively neutral element within their broader identity. For some people, *“[t]he term ‘disease’ is disliked, and these narrators were keen to emphasise the normality of their lives”* (Rose & Howard, 2014).

Qualitative studies provided a vehicle through which people with CD could tell the story of living with CD. Participants often reconstructed their personal histories from the point of diagnosis onwards, finding that CD explained many life experiences. Rumination on the cause of CD demonstrated the desire to fill in explanatory gaps within their life narrative. Other people narrated the negative impact CD had made on personal identities, such as having perceived themselves as an "*outsider"* since childhood (Jacobsson et al., 2012).

> *"The participants believed that living with CD for years had affected them deeply and made them into the people they had become."* (Ring Jacobsson et al., 2020)

Social Identity: CD impacted the social identities of people living with the condition with diagnosis giving them minority group status. Having a little-known condition, consuming different foods, pre-planning all social dining, and checking ingredients and food preparation procedures created visibility which was often uncomfortable for people with CD. A number of studies described CD as a stigmatising condition, which was widely misunderstood or trivialised as a 'gluten-free fad'. Self-stigma was evident as people with CD described themselves as difficult, demanding, and feeling shame about disclosure. A participant in a study by Lee, Crowley, Baines, Heaney, & Brown., (2021) describes feeling "*like the biggest pain in the neck"* and *"like a burden all the time and that sort of gets you down."* Similarly, a participant in Garnweidner-Holme et al. (2020) describes themselves as *"like a problem-child."* Stigma drove potentially damaging behaviours (e.g. risk-taking, deliberate non-adherence, non-disclosure, social withdrawal).

2.3.3.3. Impact of CD on food-related attitudes and behaviours

Following the GFD entailed a dramatic change in food-related behaviour. Most studies described participants' serious intent to follow the GFD (*"Gluten poisons me, why would you risk being poisoned?"* Satherley et al., 2017). Adhering to the GFD created an attitude of daily preoccupation with food. Participants' attitudes towards food often changed, and they saw food as problematic, even dangerous, and this could extend to non-GF foods. Potentially negative behaviours towards food were engaged in, such as unnecessary restriction, reducing calorie intake, avoiding eating outside of their own home, and fear of new foods. Attitudes of boredom, disinterest and anhedonia were described in relation to eating:

> *"Some reported that their enjoyment of food had changed since being diagnosed. 'It's rare for me to really enjoy food. It's just a matter of continually reminding myself that in the big picture food is not that important"* (Taylor, Dickson-Swift, & Anderson, 2013)

Some studies described 'feast or famine' behaviours in response to feelings of deprivation, which included sporadic over-indulgence, binge-eating and the hoarding of tasty GF foods. Despite the increasing availability of GF foods, people with CD still faced far fewer options and could perceive this as deprivation. Others managed their sense of deprivation by occasional transgressions from their GFD as a reward for their good behaviour, or to cope with situations where no GF food was available. Guilt sometimes followed transgressions with symptoms interpreted guiltily as "*a heavy punishment'* (Houbre et al., 2018). Others minimise the importance of strict dietary self-management to justify transgressions, stating that *"[a] tiny amount of gluten every so often won't have adverse effects on your long term health; it just might make you feel sick"* (Satherley et al., 2017). It is important to note that some studies reported that for some people *"the introduction of a gluten-free diet did not systematically lead to a change in the patient's relationship to food"* (Houbre et al., 2018). Difficulties in adjusting their attitudes and behaviours towards foods appeared easier for those who were confident and regular home-cooks, or for those who had previously eaten a simple, unvaried diet.

2.3.3.4. Perceived illness burden of CD

Managing CD was described as a relentless burden as people were required to plan each meal, shop for provisions, and strategize about managing all social interactions that involved food. Lack of GF convenience meals and take-away options and the limited GF products in individual stores increased this practical burden. The burden is also psychological, like a "*constant responsibility [that] is really hard to take"* (Rose & Howard, 2014)*.*

The generally higher costs of GF foods contributed to the perceived illness burden. Studies raised concerns that higher costs of GF food disproportionately affected those in rural areas or on lower incomes. Hidden costs included increased travel for shopping, mandatory bulk purchases, and higher restaurant costs for GF options. Peters et al. (2020) reported the anger and concern of people living with CD regarding the UK government's recent withdrawal of food prescriptions. People with CD felt penalised by high costs for their illness and that they deserved government (*"It should not be economically up to the people with CD to stay healthy'."* Garnweidner-Holme et al., 2020)

Educating other people was also described as a repetitive and tedious activity. Managing other people's reactions to the information was also burdensome and included managing actual or potential conflict, answering unwanted questions, correcting misinformation and monitoring others' behaviours. Symptoms created additional burdens (e.g. physical discomfort, inconvenience, cognitive impairment). Several studies reported participants sense of shouldering their illness burdens alone, feeling abandoned by health professionals and others around them.

> *"Participants describe the constant task of educating others, often found boring, irritating or embarrassing. Other people's reactions to being informed about CD ranged from acceptance to total dismissal."* (Rose & Howard, 2014)

Despite the widely reported difficulties, some studies described the beneficial impacts of social support on people living with CD. This included a sense of being accepted, of being included, of being enabled to have 'normal' everyday experiences, and of having practical burdens (e.g. planning, cooking) removed from their shoulders by supportive social circles. Family, particularly spouses, were often very helpful in alleviating burden by creating a 'teamworking' system for managing the GFD. However, Price & Howard (2017) raise the issue of over-reliance on spousal support, especially in ageing couples ("'*What happens if you're left on your own?' Honestly, I don't know. That could be a big problem".).*

2.3.3.5. Living well with CD

Many studies found that adults could live well with CD and many participants expressed positive attitudes towards the condition. Often, they expressed confidence in the efficacy of the GFD treatment coupled with self-efficacy regarding their ability to manage their restrictions. Self-management of the GFD was consistently described as a skill that needed to be learnt and was initially difficult to master but eventually rewarding. Confidently explaining their dietary needs was also integral to self-management, and many of those who felt they were living well with CD believed their assertive communication would be effective in improving social situations for both themselves and others.

> *"Persistent activism and education is a strategy some adopt to combat the widespread ignorance encountered: 'No-one will ever learn about the condition and how to cope with it if we just shut ourselves away.'"* (Rose & Howard, 2014)

Acceptance appeared in studies as a helpful and positive attitude that enabled people to live well with the condition while accepting their lives had permanently changed. Acceptance was often described as being reached at the end of an inevitable period of negative feelings, learning and difficulties. People reported facilitating acceptance of CD in many ways, such as directing their attention to positive aspects of their diagnosis (e.g. *"you discover really good food that you've never tasted"* Houbre, 2018). Some made downward comparisons with other health conditions, accepted that others would make mistakes sometimes, accepted some residual risk, and described focussing on their positive hopes for the future.

> *"[A]cceptance developed in different ways and at different times in their post-diagnosis journey, although participants ultimately recognised that in order to adequately deal with this condition and the gluten-free diet, they had to acknowledge its genuine reality." (King et al., 2019)*

2.3.4. Confidence in the findings

Confidence in the findings of this QES is based on the GRADE-CERQual assessment and ranges from moderate-high (Table 6). Generally, studies were methodologically strong and well designed, and no substantial concerns were raised about coherence or relevance. Lack of reflexivity and no discussion of the impact of context on the findings were the key problems in most studies. Where these issues were coupled with substantial concerns about adequacy, usually about the relative thinness of the supporting dataset, confidence in the findings was lowered. A supplementary table (Table IV, Appendix B) presents the CERQual assessment by component.

Two pairs of papers included in this QES report data from the same primary studies: Sverker, Hensing & Hallert (2005) and Sverker et al. (2009); and, Jacobsson et al. (2017) and Ring Jacobsson et al. (2020). The researcher decided to include all four papers as the authors had applied different research questions and theoretical focus in each. The researcher explicitly acknowledged the overlapping datasets (Table 3, pp. 34-35) and took care to ensure these studies were not disproportionately applied to particular themes, and so did not unduly influence the findings of the QES. The CERQual assessment (Table 6, pp. 48-51) shows the relative contribution of studies to each QES finding (subtheme) and demonstrates that the overlapping studies do not dominate any area of the results. Further, Table 6 shows that the overlapping studies sometimes contributed to different findings due to their different foci.

Table 6. CERQual Summary of Qualitative Findings

Objective: *To synthesise qualitative evidence on the psychological and social impacts of living with CD post-diagnosis.*

Perspective: *Experiences, attitudes and behaviours of people living with CD post-diagnosis related to the condition and GFD treatment.*

Findings (overarching themes*)	Studies[a] contributing to QES finding	CERQual assessment of confidence	Explanation of CERQual assessment
1. Anxieties and worries about health. (1)	11 studies (1,2,3,4,7,9,10,11, 12, 15,17).	High confidence	No concerns about coherence or relevance, and no or minor concerns about adequacy. Moderate methodological concerns in the majority of studies about lack of reflexivity. Overall, a fairly large body of evidence (11 studies) offers a moderately rich dataset supporting the QES finding
2. Distrust of or disappointment in health professionals. (1)	Six studies 2,4,10, 6,9,12	Moderate confidence	Moderate concerns about adequacy (fairly thin data) in half (3 studies) of a relatively small overall body of evidence. Moderate methodological limitations (reflexivity) in four studies. Overall, these limitations reduce confidence in the findings.
3. Social fears (1)	Five studies (1,3,4,12,15).	Moderate confidence	Moderate concerns about adequacy (fairly thin data) in three studies, and moderate methodological limitations (reflexivity) in four studies. One study had serious methodological limitations (trustworthiness). These limitations reduced confidence in a relatively small body of evidence (five studies).
4. Fears of contamination (1)	13 studies (1,2,3,6,9,10, 11,12, 13,14, 15, 16,17).	High confidence	No concerns about relevance or coherence, very minor concerns about adequacy. Moderate methodological limitations in seven studies regarding reflexivity. Overall, the body of evidence is methodologically strong and combined 13 primary studies provide substantial support for the finding.

5. Low moods (1)	10 studies (2,3,4, 6, 9, 10, 12, 15, 16,17).	High confidence	No concerns about relevance or coherence, minor concerns about adequacy. Moderate methodological limitations in seven studies regarding reflexivity. Overall, the body of evidence is methodologically strong and combined the primary studies provide substantial support for the finding.
6. Anger and irritability (1)	Seven studies (4, 11, 12, 14, 15, 16, 17).	Moderate confidence	Moderate concerns about adequacy (data fairly thin, references to finding relatively disparate) in four studies, of a relatively small overall body of evidence. Moderate methodological limitations (reflexivity) in all studies. These limitations reduce confidence in the findings.
7. Personal identity (2)	Six studies (2,3,9, 10, 12,17).	Moderate confidence	Moderate concerns about adequacy (data fairly thin) and moderate methodological limitations (reflexivity) in four of five studies. These limitations in a small body of evidence reduce confidence in the findings.
8. Social identity (2)	13 studies (1,2,3,4,5,6, 7 8,,11,12, 15, 16, 17).	High confidence	No concerns about relevance, very minor concern about adequacy. Very minor concern about coherence in one study (fit between data from primary study and review finding). Moderate methodological limitations in nine studies (reflexivity) and a serious methodological concern in one study (trustworthiness). However, overall the body of evidence is methodologically strong and combined the 13 primary studies provide substantial support for the finding.
9. Changed attitudes and behaviours related to GFD (3)	10 studies (1,2,4,6, 12,13, 14,15, 16,17).	High confidence	No concerns about relevance or coherence. Very minor concern about adequacy. Moderate methodological limitations in eight studies (reflexivity) and a serious methodological concern in one study (trustworthiness). Overall the body of evidence is methodologically strong and combined the 10 primary studies provide substantial support for the finding.
10. Cheating and risk-taking as a coping strategy. (3)	Five studies (2,12,14, 15,16).	High confidence	No concerns about relevance or coherence. Very minor concern about adequacy. Moderate methodological limitations in all studies regarding reflexivity. Despite this, overall the combined body of evidence (5 studies) provides substantial support for the finding.

11. Practical illness burden. (4)	Eight studies (1,2,3,6, 7,12, 15, 16).	High confidence	No concerns about relevance or coherence. Very minor concern about adequacy. Moderate methodological limitations in five studies (reflexivity) and a serious methodological concern in one study (trustworthiness). Overall, the body of evidence is methodologically strong and combined the eight primary studies provide substantial support for the finding.
12. Economic burden (4)	Six studies (1,2,6,8,15,16).	High confidence	No concerns about relevance. Very minor concern about coherence in one study (fit between data from only one primary study and review finding). Minor concern about adequacy (thin data in two studies). Moderate methodological limitations in four studies (reflexivity) and a serious methodological concern in one study (trustworthiness). Despite these limitations, overall, the body of evidence is methodologically strong and combined the primary studies provide substantial support for the finding.
13. Educating others and maintaining vigilance over their actions. (4)	Four studies (3,5,12 15).	Moderate confidence	No concerns about relevance or coherence. Moderate concerns about adequacy (relatively thin data in two studies). Moderate methodological limitations regarding reflexivity (two studies) and sampling (one study). As the body of evidence is relatively small (four studies), confidence is reduced due to these limitations.
14. Managing co-morbid conditions and CD symptoms. (4)	Four studies (4, 7, 12, 15).	Moderate confidence	No concerns about relevance or coherence. Moderate concerns about adequacy (relatively thin data in 3 studies). Moderate methodological limitations in all. As the body of evidence is small (4 studies), confidence is reduced due to these limitations.
15. Shouldering the burden alone. (4)	Six studies (1,2,3,4, 11,12).	Moderate confidence	No concerns about relevance or coherence. Moderate concerns about adequacy (relatively thin data in two studies). Moderate methodological limitations regarding reflexivity (four studies). Serious methodological limitations in one study (trustworthiness). As the overall body of evidence is relatively small (six studies), confidence is reduced due to these limitations.

16. Positive impact of social and professional support network. (4)	Six studies (1, 2, 3, 6, 7, 17).	Moderate confidence	No concerns about relevance or coherence. Moderate concerns about adequacy (relatively thin data in three studies). Moderate methodological limitations regarding reflexivity (three studies). Serious methodological limitations in one study (trustworthiness). As the overall body of evidence is relatively small (six studies), confidence is reduced due to these limitations.
17. Confidence and self-efficacy. (5)	10 studies (1,2,3,4, 6,9, 11,12, 14, 17).	High confidence.	No concerns about relevance or coherence. Minor concern about adequacy (relatively thin data in five studies). Moderate methodological limitations in six studies (reflexivity) and a serious methodological concern in one study (trustworthiness). Despite these limitations, overall, the body of evidence is methodologically strong and substantial and combined the 10 primary studies provide strong support for findings.
18: Acceptance of CD. (5)	Nine studies (2,3,4,5,6,9,12,14,17).	High confidence.	No concerns about relevance or coherence. Minor concern about adequacy (relatively thin data in five studies). Moderate methodological limitations in six studies (reflexivity). Overall, the body of evidence is methodologically strong and substantial and combined the 9 primary studies provide strong support for the findings.

Overarching themes: 1) Impact of CD on mood; 2) Impact of CD on identity; 3) Impact of CD on food-related attitudes and behaviours; 4) Perceived illness burden; 5) Living well with CD

[a] Studies: 1) Garnweidner-Holme et al., 2020; 2) Houbre et al., 2018; 3) Jacobsson et al., 2012; 4) Jacobsson et al., 2017; 5) King et al., 2019; 6) Lee et al., 2021; 7) Leffler et al., 2017; 8) Peters et al., 2020; 9) Price & Howard, 2017; 10) Ring Jacobsson et al., 2020; 11) Rodriguez Almagro et al., 2017; 12) Rose & Howard, 2014; 13) Satherley et al., 2018; 14) Satherley et al., 2017; 15) Sverker et al., 2009; 16) Sverker et al., 2005; 17) Taylor et al. 2013.

2.4. Discussion

2.4.1. Implications for the development of the proposed intervention

QES findings support results from recent quantitative meta-analyses reported in section 2.1.2.1, which have found that CD increases the risk of mood disorders (anxiety, depression) and risk of developing an eating disorder. Though some people find their mood improves after diagnosis, often due to relief and the reduction or elimination of symptoms, the negative impact on mood is substantial for many people living with CD. The impact of CD on mood appears related to a range of personal and social factors which are often interconnected and include a changed sense of identity, inter-personal difficulties, illness burden, health concerns, anger and resentment. The QES provides evidence of the need for an intervention to provide emotional support to people living with CD. Psychoeducation about emotional states and self-regulation of mood, and straightforward, flexible intervention models focussed on developing coping strategies (e.g. CBT) may be useful intervention components.

Evidence from the QES found that people living with CD often changed their attitudes and behaviours towards food in negative ways, and this concurs with recent meta-analyses reporting that those with CD faced an increased risk of eating disorders (Clappison et al., 2020; Nikniaz et al., 2021). The current QES findings describe attitudes and behaviours which may contribute to the risk of developing eating disorders, such as unnecessary restriction, avoidance, food-related fear, binging and hoarding. Satherley et al. (2017) categorised participants with CD into disordered or typical eaters using a validated measure of disordered eating and found changed food-related attitudes and behaviours in both groups that were greater in the group of disordered eaters. Satherley et al.’s (2017) findings suggest that a wide range of people with CD are at risk of negative food-related attitudes and behaviours. This evidence suggests that food-related attitudes and behaviours would be an important target for intervention, supporting those living with CD to develop a healthy relationship to food and learn to identify and challenge unrealistic worries about food. Strategies to build a GFD diet that fits personal tastes and remains interesting and enjoyable would be helpful and support quality of life.

Qualitative research allowed participants to reflect on the broader personal and social impacts of CD in their lives, rather than being restricted to the narrow focus of quantitative measures. Personal and social identity was a theme identified across studies. Strong and complex reactions were evidenced, including a sense of stigma and potentially negative coping strategies such as social withdrawal, disclosure avoidance, dietary transgression and guilt. Intervention could provide people with the opportunity to explore difficult feelings and dilemmas related to their sense of changed identity.

The QES highlighted the importance of social support, both in supporting a positive identity and helping people to manage the burden created by the GFD. Intervention should support the development of practical strategies to reduce the burden of daily GFD management, and support the development of communication strategies that would enable people to assert their needs in social situations. Group formats provide an opportunity to obtain peer support and lessen the sense of isolation experienced by many people living with CD reported in the current QES. Finally, the QES found that accepting CD and the changes created by diagnosis was important in adaptation to the condition. Therefore, an intervention model supporting the development of acceptance, such as Acceptance and Commitment Therapy (ACT) (Hayes, Luoma, Bond, Masuda, & Lillis., 2006), may be appropriate to help people living with CD.

2.4.2. Implications for future research

The QES findings revealed several areas of impact which further research might explore, including the ‘dark emotions’ of anger and resentment revealed in several studies. These feelings have not been a focus of any previous research on CD, but their presence is likely to impact mood, quality of life, and relationships (Mujcic & Oswald, 2018; Sugaya et al. 2015; Yi et al, 2008). Participants are likely to be reluctant to express their dark emotions in an open interview, as they are emotions widely considered to be socially undesirable (Fernandez et al. 2019). Targeted qualitative questioning or online questionnaire items that directly and confidentially discuss feelings like anger, envy or resentment may provide useful data to understand these impacts and their duration over time.

Further research might also explore the impact of CD on personal and social identity, which is important as our sense of identity affects our emotional responses (Jahnen et al., 2021; Marcussen, Gary & Serpe, 2021), behaviour (Shahid et al., 2021; Carfora, Caso & Connor, 2006), relationships, social roles, personal values and life choices (Richards, 2019; Maxwell et al., 2022). Research on adolescents diagnosed with CD by Kautto et al. (2016 and 2017) found that their diagnosis of CD had implications related to gender norms and social status. Given the increased risk of several associated conditions (e.g.

diabetes, type 1 and type 2) faced by those living with CD, further research would also be useful to explore how people manage CD alongside comorbid conditions and residual symptoms to improve health outcomes and quality of life. The current findings revealed some difficulties in managing comorbid conditions and that CD is sometimes ‘downplayed’ against conditions perceived as being more serious.

QES findings found that other people, especially family members, have an important role in supporting people to maintain their GFD and reduce isolation. Despite this, other people create barriers to self-management for people with CD, triggering negative emotions like resentment or guilt and increasing perceived burden. Further research might explore the impact of an adult person’s CD on other family members, family activities, and the food-related behaviours of the whole family. This research might help professionals support and advise families when an adult family member needs to eat differently and so disrupts familiar family patterns.

QES findings have shown the importance of adequate disclosure in ensuring that people with CD can access the support and information they need to manage their condition. Social pressures (e.g. stigma, social expectations and norms) and cultural pressures (e.g. the gluten-free trend, traditions) can create barriers to disclosure. Further research on factors associated with disclosure and disclosure-avoidance may provide knowledge helpful in supporting people living with CD and developing informative public messaging about the condition.

2.4.3. Strengths and limitations

The amount of qualitative research on CD has rapidly increased in the last five years, with most of the studies (70%) included in the current QES published between 2016 and 2021. The QES presented in the current chapter provides an up-to-date and coherent synthesis of the knowledge base regarding the psychological and social impacts of CD. Overall, the included studies were of good quality and constituted a moderate-strong body of evidence supporting the key findings. It is also notable that, though all studies described the context of their research, no authors discussed the impact of context on findings, and most did not reflect on the impact of the researcher's personal characteristics on the research. These methodological limitations introduce a risk of bias which is mostly unaddressed by authors. Confidence in the QES findings may also be affected by the fact that the majority of this research was undertaken by the current researcher alone due to resource constraints.

2.5. Conclusion

The QES presented in this chapter has produced original and comprehensive insight into the psychological and social impacts faced by those living with CD. These findings provide compelling evidence of the need for the proposed psychoeducational intervention to support people living with CD with the psychological and social challenges encountered in everyday life. The findings suggest several target areas for intervention: mood, food-related attitudes and behaviours, personal and social identity, management of illness burden, development of communication strategies, and acceptance. The following chapters document further steps of the intervention development and design.

CHAPTER THREE: STUDY ONE. QUALITATIVE APPRAISAL OF THE RELEVANCE AND USEFULNESS OF A PSYCHOLOGICAL INTERVENTION FOR PEOPLE LIVING WITH CD

3.1. Introduction

Current research has found strong evidence that adults living with CD face an increased risk of negative psychological and social impacts following their diagnosis (Chapter Two). Literature reviews can inform intervention design by identifying evidence of need, expanding knowledge of the problem to be targeted, and informing content design (Croot et al., 2019). Despite these strengths, literature reviews are a secondary source of knowledge influenced by their authors' interpretations of meaning and relevance (Moreira, 2007). The researcher decided to incorporate primary research with adults living with CD into the intervention development to address this limitation and extend their understanding of how CD manifests within people's lives. Further, the researcher anticipated primary research would provide insight from the target population into the potential usefulness and acceptability of the proposed intervention.

3.1.1. Aims and Objectives

The current study has three aims:

Aim 1: To increase the researcher's existing knowledge of CD's psychological and social impacts for adults living in the UK post-diagnosis.

Aim 2: To explore whether intervention would be acceptable and helpful to adults living with CD in the UK.

Aim 3: To inform the intervention design.

The objective of the study is to answer the following research question:

- How could a psychoeducational intervention be beneficial to adults living with CD in the UK?

3.2. Methods

3.2.1. Ethical approval

Granted by the STEM Ethical Review Committee, University of Birmingham (Appendix A).

3.2.2. Design and materials

The study was a qualitative investigation. Both face-to-face focus groups and individual telephone interviews were used as data collection methods to maximise recruitment and be inclusive for those in employment, those with caring responsibilities, or who faced travel barriers. The researcher followed a semi-structured interview guide (Appendix C) for all interviews and focus groups. Interview questions focused on key areas of impact identified by the literature review (Chapter Two), and these areas were: *social interaction, feelings about health, feelings about losing gluten, illness-burden* and the *positives of diagnosis.* The researcher also invited participants to share their views regarding the perceived need for the proposed intervention. The interview guide was discussed and refined during several meetings with the researcher's project supervisors, who are both experts on the psychological impact of CD.

The interviews and focus groups in study one also served as a preliminary step in validating a psychometric questionnaire; the first three questions on the interview guide (Appendix C) asked participants to review this draft questionnaire. Chapter Four presents this validation study. The remainder of the interview (questions four to ten) engaged participants in reflective discussions about the psychological and social impacts of CD, and the current chapter presents a qualitative analysis of responses to these questions. Figure 1 (p.13) shows how the qualitative data collected in Study One was utilised in both the design of the intervention and in the validation of the psychometric questionnaire

3.2.3. Recruitment

Participants were recruited using purposive sampling and were eligible for the study if they met the following criteria: aged ≥ 16 years; medically diagnosed CD; diagnosed ≥ one year ago. The volunteering coordinator for Coeliac UK, a national charity for CD, issued a call for participants and circulated this message to support group members[7]. Coeliac UK currently has approximately 65,000 members nationally[8]. Interested participants contacted the researcher by telephone or email, then received an information sheet about the study, by post or email, as requested. After reading the information, people interested in participating indicated their availability and preference for an interview or focus group. Participants completed a written consent form and returned this to the researcher before data collection began. Participants were offered a £10 shopping voucher following data collection as compensation for their time.

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[7] At the time of the study, Coeliac UK's procedure for all research study recruitment was to issue calls for participants through their own volunteering co-ordinators.

[8] England, Wales, Scotland, Northern Ireland.

3.2.4. Procedure

Group interviews took place in a private room at the University. The researcher conducted telephone interviews from a private home office at a pre-arranged time. They facilitated all sessions alone following the same semi-structured interview guide and digitally recorded each session, starting at the first question and ending at the last response. The researcher transcribed each recorded interview completely at a verbatim (word-for-word) level, without correcting grammatical errors, word-choice or completing incomplete sentences. Transcriptions provided only moderate detail of conversational rhythms, such as clear pauses and vocalisations like laughter, exclamations, heavy sighs, (e.g. ‘oh goodness! [laughing]’), and included prompts of encouragement from the researcher or other group members (e.g. ‘yeah?’, ‘OK’). This level of detail was considered appropriate for a content-focused analysis (Clark, Birkhead, Fernandez, & Egger, 2017). Pseudo-initials and pseudonyms allocated to all participants and numbers referencing each specific session were the only identifying features entered onto transcriptions and related documents. Before transcribing the audio-files, the researcher listened to all recordings once to re-acquaint herself with the conversations. The researcher verified the accuracy and completeness of the transcripts by comparing these against the recordings and correcting inaccuracies. They asked participants if they would like a copy of the transcription to check for accuracy, but no one requested this.

3.2.5. Analysis

3.2.5.1. Hybrid thematic analysis (Swain, 2019)

Thematic analysis is a group of methods used to identify patterns of meaning across a qualitative dataset relevant to specific research questions. Different thematic analysis methods vary in how researchers organise and code data, and how the results are applied and reported to answer the research question(s) (Ciesielska & Jemielniak, 2018; Swain, 2018). It is a flexible method, and coding may be inductive (data-driven), deductive (driven by *a priori* frameworks or a theory), or combined into a hybrid deductive-inductive thematic analysis (Swain, 2019). The current study uses hybrid thematic analysis, as developed by Swain (2018, 2019) and used by Farrelly (2020). Deductive approaches in qualitative analysis are *a priori*, top-down methods, in which researchers apply a pre-determined theory or coding framework to the dataset. Deductive approaches enable researchers to test whether data supports a pre-determined theory or can allow researchers to structure their dataset in a pre-defined way (Bingham & Witkowsky, 2022). In contrast, inductive approaches are ‘bottom-up’, allowing researchers to interpret meanings and patterns and develop theory from their interpretative reading of the dataset (Bingham & Witkowsky, 2022). Combining both analytical approaches can strengthen qualitative research by enabling researchers to organise their analysis around their existing knowledge while remaining open to new ideas and understandings of the subject of their research (Bingham & Witkowsky, 2022; Swain, 2018).

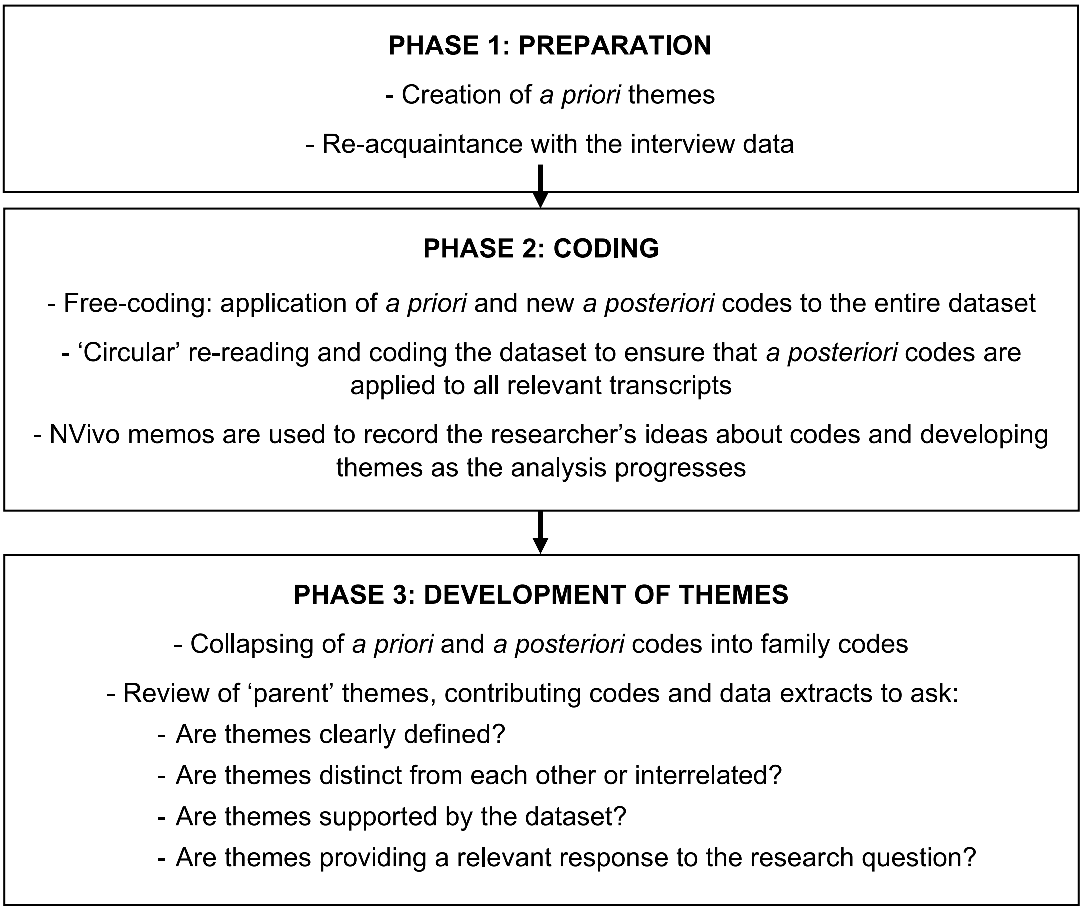
In hybrid thematic analysis, data is coded both against a set of *a priori* themes and coded inductively to develop new *a posteriori* themes. Using hybrid thematic analysis, researchers combine different philosophical perspectives on how the data relates to the phenomena of interest, as deductive methods relate closer to realist epistemologies and inductive methods lean towards more interpretivist views (Swain, 2018). Therefore, reflection and reflexivity are needed in hybrid thematic analysis to ensure that researchers make clear how their assumptions and experiences influence their coding decisions and analysis (Swain, 2018). Hybrid thematic analysis fits the philosophical position of limited realism the researcher has taken in this study (section 3.2.5.3). The method is well-suited to projects like the current study, where the researcher has a strong understanding of the phenomena of interest drawn from the existing literature (Swain, 2018).

Various descriptions of the difference between codes and themes exist across the literature. Swain (2018) considers the difference between codes and themes is relatively unimportant and fluid, as all codes are *'units of meaning'* that the researcher subsequently organises into groups or patterns, some of which develop into overarching themes. In hybrid thematic analysis, transcripts are initially free-coded. During free-coding, the researcher attaches codes (words or short phrases) to all 'units of meaning' relevant to the research question (Swain, 2018). Free-codes are subsequently sorted or clustered, with *a priori* themes serving as guiding themes. New *a posteriori* themes may develop from codes that do not relate to an *a priori* theme but reveal relevant insight.

3.2.5.2. Analytic process

The current researcher adapted the three-phase process developed by Swain (2018) (Figure 3, p.63). Swain uses a system of tables rather than computerised qualitative analysis software. The current researcher used NVivo 12 to organise and code data throughout the process and adapted Swain's method to reflect this (Figure 3, p.63). The researcher followed the three phases sequentially, though steps within phases 2 and 3 were concurrent (Swain, 2018). The researcher began the analytic process by coding data against the five *a priori* themes developed from the QES findings (Chapter Two), and around which the interview questions were based (section 3.2.2). These five *a priori* themes are: *social interaction, feelings about health, feelings about losing gluten, illness-burden* and the *positives of diagnosis.*

Figure 3. Hybrid Thematic Analysis process followed in the current study[9].



PHASE 1: PREPARATION

- Creation of *a priori* themes
- Re-acquaintance with the interview data

PHASE 2: CODING

- Free-coding: application of *a priori* and new *a posteriori* codes to the entire dataset
- 'Circular' re-reading and coding the dataset to ensure that *a posteriori* codes are applied to all relevant transcripts
- NVivo memos are used to record the researcher's ideas about codes and developing themes as the analysis progresses

PHASE 3: DEVELOPMENT OF THEMES

- Collapsing of *a priori* and *a posteriori* codes into family codes
- Review of 'parent' themes, contributing codes and data extracts to ask:
  - Are themes clearly defined?
  - Are themes distinct from each other or interrelated?
  - Are themes supported by the dataset?
  - Are themes providing a relevant response to the research question?

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[9] This process broadly follows Swain's (2018) three-stage method, but has been adapted to the computer-assisted coding techniques undertaken by the current researcher.

3.2.5.3. Theoretical position

Researchers need to clarify their theoretical position, which inevitably influences their analysis (Braun and Clarke, 2020). The current researcher takes a limited realist position that acknowledges objective reality and combines this with an awareness that truth is also partially constructed (King & Brooks, 2017). This position is compatible with hybrid thematic analysis which combines deductive and inductive methods.

3.2.5.4. Reflexivity

When thematic analysis uses inductive methods, reflexivity, rather than inter-rater reliability correlations, is the most appropriate way to assess the integrity of the analysis and interpret the interplay between participants' and researchers' perceptions (King & Brooks, 2017; Swain, 2018). The researcher began the analysis assuming that most participants would have direct experiences of the first four discussion topics (*social interaction; feelings about health; everyday burden; feelings about losing gluten*). The final topic, *positive impacts,* appears less often in the literature. The researcher assumed this topic would be experienced less often by participants and so would be somewhat 'controversial', creating disagreement about the extent to which diagnosis of CD makes any positive impacts. This assumption created a risk that the researcher may inadvertently bias data collection through interviewing style (e.g. body language). Similarly, the interviews sought to elicit participants' views about the acceptability of the proposed intervention, and these views may be affected by their knowledge that developing the intervention was part of their interviewer's PhD project.

In recognition of these potential risks, the researcher sought to convey her openness to different ideas, including disagreement and negative views about the proposed intervention. The researcher followed consistent data collection and analysis processes and discussed them with their research supervisors at monthly supervision sessions.

3.2.5.5. Trustworthiness

The use of a semi-structured interview schedule ensured the trustworthiness of the data collection. Verbatim transcripts were verified against audio recordings, ensuring the dataset remained very close to the original discussions. An audit trail was maintained documenting data collection and analysis processes and meetings between the researcher and her project supervisors.

3.3. Findings

3.3.1. Participants

In response to the call for participants, 27 people expressed interest in the study. Of these, eight people received no further information because: they had been diagnosed <1 year ago (three people), were unavailable during the study period[10] (three people), were aged <16 years (one person), or were disinterested (one person). Of 19 people who received further information, six failed to return consent forms. A total of 13 people provided written consent and participated in the study (Table 7). Nine participants self-identified as female. Variables of age and time since diagnosis were non-normally distributed with a skew towards older participants (median age 63) and those diagnosed ≤ 10

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years (median 9.5 years). Eight people participated in a focus group, and five undertook a one-to-one telephone interview. Focus groups were small, comprised of between two and five attendees, and ran for a mean of 86 minutes. Interviews ran for a mean of 53 minutes.

Table 7. Participants' characteristics (Study One)

Variable	
Age years (range)	63* (28 – 68)
Gender (self-identified)	
Male	4 (31%)
Female	9 (69%)
Time since diagnosis in months (range)	9.5 (2 – 44)
Employment	
Full-time employment	5 (38%)
Full-time parent	1 (8%)
Retired	7 (54%)
Data collection method	
Focus group	8 (62%)
Telephone interview	5 (38%)

*Median

3.3.2. Themes

Qualitative analysis identified five themes, all developments of the original *a priori* themes. Though anchored in the initial *a priori* themes, new theme titles reflect how analysis further developed these topics. Table 8 outlines the themes and provides a bullet-point summary of their relevance to the proposed intervention. The remainder of this section gives a complete description of themes, presented alongside illustrative extracts from the data. Themes have no order of importance.

Table 8. Themes identified in the current study and their implications for the proposed intervention

Theme	*Description*	*Potential elements within, or implications for, intervention*
Social division [developed from the *a priori* theme *social interaction*]	This theme describes how eating differently from those around them creates a sense of social division for people living with CD. This division can create interpersonal conflict, isolation, disclosure or, conversely, disclosure-avoidance, social anxiety, and social withdrawal. People with CD feel safe and understood among others living with the condition.	• Strategies to manage interpersonal communication and conflict. • Strategies to manage anxieties experienced in social situations. • Opportunities to meet others living with CD to reduce isolation and to share experiences and strategies. • The inclusion of those living with CD in the intervention design and delivery may increase acceptance of the programme by the Coeliac community.
Heightened awareness and anxiety about health [developed from the *a priori* theme *feelings about health*]	Diagnosis increases people living with CD's awareness of their health and vulnerability to cross-contamination and health conditions associated with CD. Increased health awareness raises anxiety but often motivates self-management and adoption of healthier lifestyle behaviours.	• Basic information about CD, the GFD and associated conditions. • Signposting to further health and dietetic information and support. • Strategies to identify the information and support needed. • Strategies to manage health-related anxiety. • Strategies to engage positively with health professionals.

Constant threats and demands [developed from the *a priori* theme *everyday illness-burdens*]	Living with CD demands constant vigilance, planning and preparation to avoid the continual threat of gluten created by processed foods and the actions of others. The GFD also creates extra demands including: locating and purchasing non-mainstream food products, storing bulk purchases, preparing GF meals, avoiding cross-contamination, checking eating venues and managing increased financial costs.	• Strategies to manage stress resulting from self-management. • Strategies to support goal-setting and task-planning.
Loss of everyday foods and experiences [developed from the *a priori* theme *feelings about losing gluten*]	Losing gluten involves losing many everyday experiences, including favourite foods, spontaneous meals, sharing foods, many convenience foods, takeaways, restaurant options and some travel options. Lost options can reduce participants' enjoyment of everyday experiences. Fatigue experienced both before and after diagnosis can also result in lost experiences. Lost every day experiences can be a source of longing, sadness and regret.	• Strategies to manage feelings of loss and grief.
Positive impacts [developed from the *a priori* theme *positives of diagnosis*]	All participants felt the benefits of diagnosis outweighed the costs of following the GFD to some extent. Benefits included relief, self-empowerment, improved overall diet and a healthier lifestyle. Some people balanced acceptance of losses with an appreciation of those options still available. Others reduced the negatives of CD by assimilating the condition into a more comprehensive, holistic concept of their identity.	• Strategies supporting acceptance of CD.

3.3.2.1. Social division.

Participants discussed the impact of CD on *social interaction* and emphasised the division created by the GFD in social settings. They described how others saw their behaviour as problematic, inconvenient and *"awkward"*. Some described the negative self-perception that they were *"always the awkward one*[11]*"*. The division food-related differences created between people with and without CD sometimes led to direct or indirect interpersonal conflicts. People living with CD described the sense of social division as pervasive (*"you always feel shut out in some ways"* Nat). Actions that "*shut out*" those with CD could be genuinely unintentional but were often perceived as ambiguous or as deliberate acts of exclusion:

> *"They give you the roast dinner, and they take the roast potatoes away[...] And then they take the flipping Yorkshire pudding away, but they don't give you an alternative. No! You're left with a meal without any gluten on it. You're left with half the meal you're paying for! [short laugh] Most of it's gone because they can't be [huffs angrily], can't be bothered to do an alternative!"* Toni

Although actual incidents of conflict frequently occurred, the fear of potential conflict also worried participants who often took pre-emptive action. A common pre-emptive action was disclosing their CD to justify their different behaviour around food. However, participants sometimes felt pressure to disclose when they would prefer not to, such as in the workplace or with people they did not know. Avoidance and risk-taking were other strategies used to prevent both conflicts and any need for disclosure:

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[11] Participant Louise

> *"You have to go past everybody when they're queueing for the buffet to make sure you get your plate of gluten-free food, and then you do feel bad! [laughing][…]Then you do feel that you've got to explain a bit."* Louise

Families sometimes attempted to reduce social division by eating gluten-free together or removing gluten entirely from their homes. By doing this, families created a home environment that became *"your castle and your safe place"* (Kennedy). For others, family members *"just didn't get it* (Toni)" and conflicts continued at home. Some participants concluded that living with anyone who did not have CD made it impossible to avoid conflicts. Participants described other people's embarrassment or guilt when they caused cross-contamination or failed to provide GF alternatives. Alex described how *"the tables have somehow been turned"* as support moves away from the person with CD who is shut out towards the discomfort felt by those who failed to make provision. Participants felt ambiguous in these situations. As Louise explains, "*you always feel like you've got to be nice to <u>them</u> because <u>they</u> feel guilty."* Alex displays both an understanding of how these situations occur and anger "*because they <u>should</u> think about it. They <u>shouldn't</u> <u>assume</u>."*. Participants were eager to share the personal coping strategies they had developed, which reduced the need for them to behave differently in social situations. Phillipa described these strategies as *"your get out clause":*

> *"Say, if they've got you some cakes or some biscuits and they've put them on the plate next to stuff that wasn't gluten-free, then you feel like you don't want to not have it because they've gone to the effort clearly of trying for you. You can always say something like, well, `I'm not hungry now but could you put them in a bag for me and I'll take them home?' You could do that, as kind of your `get-out clause.' "* Phillipa

In contrast, others respond to being *"the awkward one"* by directly, even aggressively, challenging the barriers created by other people. Despite generally negative outcomes, those engaging in these conflicts felt this approach was needed to reduce widespread ignorance about CD. After repeatedly being *"shut out"*, participants used their status as *"the awkward one"* to be heard and included:

> *"All you're doing is educating them really. I'm waiting to be challenged so I can say something. I do wait for it. [laughs]"* Sam

In contrast to the social division encountered around people who did not have CD, participants described the ease and safety they felt among those who also had the condition. Shared needs and knowledge of CD removed division and provided reassurance (*"I don't have to explain. You know that they know it."* Alex). Several participants felt the intervention should include a speaker who, unlike most health professionals, lived with CD themselves, and two even volunteered to take on such a role[12]. Participants felt this person would serve as a real-life role model and trustworthy information source:

> *"Somebody who's not been through something that you've been through, if they're sitting there telling you to be positive and everything, you're just thinking, well, now you're not dealing with this, so that's all a load of, excuse my language now, bullshit. But if you've got somebody that is dealing with it, and they're the ones who've decided to come at it from that angle, well, they can see for themselves then."* Phillipa

The desire to meet others with CD had motivated many participants to attend the group interviews. Though some had contacted support groups, and a few

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[12] Charlie and Phillipa

had relatives with the condition, all felt that meeting peers with CD was helpful but difficult to manage in everyday life. Toni described resorting to commenting on other shoppers' free-from selections in the supermarket "*just as a way of starting up a conversation and then finding out how they're managing.*"

3.3.2.2. Heightened awareness and anxiety about health.

An *a priori* topic for discussion was how people felt about their health post-diagnosis. Participants described how the diagnosis had generated a new level of health-related anxiety, which was increased further for those with comorbid conditions. Participant Alex explained how health concerns created a constant *"background"* of worries:

> *"Type 1 diabetes was completely out of the blue. And then, three years later, I got Coeliac. And then, three years after that, there was a suggestion I'd got lactose. And I was starting, thinking, every three years, I'm getting something else. Some other, like, autoimmune thing. And so, you know, I don't think you can ever say you don't worry about your health, not if you've got these conditions. I think you, you, just, that's it now. I feel like it's always something that's going to be in the background. So, you know, I don't know whether anyone would say you can stay healthy with it."* Alex

Heightened awareness of physical vulnerability motivated maintenance of a GFD *("If you don't go on a strict Coeliac diet there is a possibility of developing bowel cancer, and there is a possibility also of death.*" Jaimie). Focus on self-management shifted attention away from often unanswerable questions, such as why CD had developed, towards GFD self-management. Several participants described now prioritising maintenance of their overall physical health through activities like exercise (Charlie), supplements (Kennedy, Alex, Kim) and weight management (Sarah).

> *"I've got Coeliac Disease. I don't know how I got it. I don't know why I got it. But I've got it. So get on with it [the GFD]* Charlie

Unanimously, participants felt they had received little support post-diagnosis from health professionals (*"I found the health professionals totally useless actually and I had to sort it all out myself. Everything!"* Nat). Some felt the advice they did receive was too generic to be helpful. For example, Toni, who had several comorbid conditions and additional dietary restrictions, complained that health professionals *"don't really listen[…]You've got to look at my diet and find out what could be included in my diet."* Some participants displayed apparent gaps in their knowledge about CD, which may have arisen due to lack of medical support (*"Just talking to you all now has made me realise there's so much more that I don't know about it."* Nat). Despite embracing self-management, participants desired professional follow-up for reassurance that they were correctly managing their health (*"these are all things you've never had to think about before"* Nat). Without follow-up, people living with CD are left alone with heightened awareness and concern about their health:

> *"In a way, she [dietician] doesn't need to see me anymore, but I think it would be quite beneficial to continue to have DEXA scans because I have got bone problems."* Jaimie

3.3.2.3. Constant threats and demands.

Participants discussed the idea that CD is an everyday burden as an *a priori* topic. Participants unanimously described the burden of maintaining constant vigilance to avoid the threat of gluten. The need for vigilance is an ongoing demand because, due to ever-changing recipes and variations between different manufacturers, ‘safe’ foods must be frequently re-checked. Participants also described the burden of maintaining constant vigilance of other people’s actions around food, as others were often ignorant or careless. Phillipa describes their continued *“watching”* of a food server and the cognitive efforts needed to assess risk and plan how to protect themselves:

> *“I watched her as she was serving the people before me, I watched how she was doing things […] and then she did actually use the same tongs and the same knife to do the jacket potatoes as she did the baguettes. So I kind of knew that as soon as she got to me, I was going to have to ask her to use a clean pair of tongs and a clean knife.”* Phillipa

Participants felt adjustment to these everyday demands was a gradual *“learning curve”* (Phillipa). Sam, diagnosed for several decades, describes this learning as a never-ending “*cyclical process”*. Similarly, Sarah explains how practice helps but does not remove this burden (*“[t]he rucksack gets smaller, but you’re still carrying it.”*). Cultural phenomena and personal life stages change, requiring further learning and adaptation. For example, participants described the challenges created by the recent ‘gluten-free fad’, a double-edged sword that has simultaneously increased availability of GF foods and trivialised the GFD:

> *“I think the worst thing that’s ever happened to us, people with Coeliacs, is the idea that a gluten-free diet is a fad[…] so you, therefore, get classed as having a fad diet rather than a medical need.”* Toni

Shopping safely involved multiple demands that went beyond having to *“examine every single packet”* (Toni). Participants needed to monitor at-home food stocks since small neighbourhood shops were expensive with few GF products. Online shopping required research, ordering and receiving deliveries, and extra storage (*"you have to run another freezer"* Kennedy). GF-prescriptions entailed extra journeys to and from the pharmacy. Participants described the expense of GF products and the hidden costs (e.g. mandatory bulk purchase, travel and delivery costs, new kitchen equipment). Shopping was *"not shopping like an ordinary person* (Nat)*"* and emphasised difference and inconvenience. Despite diligently *"doing your homework*[13]*"*, situations could change unexpectedly and expected GF options could be off-menu or out-of-stock. For example, Phillipa describes becoming overwhelmed by hunger during a day-long shopping trip when the gluten-free options they expected were unavailable:

> *"You'll think, oh my God! Now I haven't got anything to eat! And I haven't even got any energy left to put up a fight about it. You still have those kinds of days."* Phillipa

Participants felt burdened by guilt that their needs inconvenienced others, such as Nat's guilt at troubling their GP: (*"They're doctors, aren't they? Not grocers. They don't want to be worrying about it."*) Alex noted that their spouse relieved them of the demands of GF cooking and shopping (*"I don't actually do much of the cooking. I come home most nights and my meal is there."*). Widowed participants described the *"the hassle"* of cooking so much just for themselves and the increased financial demands on their reduced incomes.

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[13] Participant Phillipa

3.3.2.4. Loss of everyday foods and experiences

However long since diagnosis, all participants described longings for everyday foods *("all the normal things"* Alex). The normality of gluten-containing foods seemed to intensify the sense of loss, as Gillian describes: *"sometimes it's just something ordinary. Just being able to have an ordinary piece of toast with some butter on it."* Longing is evident in Gillian's decision to *"eat vicariously"*, as are their ambiguous feelings towards others who still eat freely, and longing impacts their enjoyment of restaurant experiences:

> *"You know when you go somewhere, and you have the menu, and the dessert menu is hopeless? And all you get is the fruit salad or something, and there's this lovely long list of puddings.[…]You know, you almost have to enjoy watching others eating things vicariously [laughing]. Which is impossible that!"* Gillian

Along with losing everyday foods, those with CD live with reduced options for convenience and unplanned meals (*"You couldn't just go out of an evening, just like, be spontaneous and just go!*.' Gillian). Attempts to recreate everyday spontaneous experiences, such as collecting takeaway, now, ironically, require substantial effort and planning (*"There's a chip shop we drive half an hour to."* Alex)

Some participants feel CD has negatively impacted their travel experiences ("*We went to Reykjavik and there was nothing! Nothing!"* Kennedy). Gillian describes delaying confirmation of their diagnosis until after a holiday in France to fully enjoy French foods, which they felt were an essential part of that experience. Louise describes their reduced travel options:

> *"I can't just say, 'let's have a cheap break in Prague'. Because will they understand? It's always about planning ahead.[…]But that probably does mean that we do more self-catering, go to those sorts of places, you know?."* Louise

Some participants were optimistic about travel and accepted they could always "*revert to the basics. Rice, vegetables, grilled meats.* Alex". Some described using tools and strategies like apps and translation cards, yet others actively avoided travel. Mags explains how they are *"carefully trying to avoid"* work-related travel ("*There are some places you might have to go to where you just can't have the conversation. It just won't mean anything."* Mags). Similarly, Toni describes trepidation about booking holidays:

> *"I haven't actually been on holiday since I was first diagnosed as gluten-free[…]There are places that are literally just gluten-free hotels, everything in their kitchen and everything they serve is gluten-free.[…] [B]ut you don't get a midday or evening meal, so you've got to go out and find those."* Toni

Many people living with CD suffered from fatigue during a lengthy pre-diagnosis period. Louise describes how fatigue prevented her from fully participating in family activities which she feels has created lasting self-doubt regarding her physical strength. Similarly, Kennedy describes the impact of fatigue on their social life as a young adult ("[*F]or years I complained to the GP. I'm tired all the time, I ache all over. I'm falling asleep in the early evening, and I can't stay awake, and I'm young!").* Both express regret and sadness about lost experiences:

> *"I look back sometimes and I think if only I'd been diagnosed earlier, perhaps I'd have done more? […]I just think that if I'd have been diagnosed in my 30s, I would've felt, I might've had just that*

> *bit more energy for them, for doing those sorts of things with the children when they were small."* Louise

Some people experience fatigue as a residual symptom even while maintaining a GFD. Alex and Toni, who both have comorbid conditions, described the negative impact of fatigue on everyday activities, particularly the ability to exercise.

3.3.2.5. Positive impacts

Participants reflected on the *a priori* theme of whether there were *positive*s to their CD diagnosis. All participants felt the benefits of receiving their diagnosis outweighed the costs. Most experienced relief and, although the "*initial euphoria*[14]*"* decreased over time, some relief remained when people reflected on the extent of their symptoms pre-diagnosis. Most found self-management a positive option:

> *"It felt almost like a miracle cure. So, to me, there was never any question of not following it [the diet] because what I was giving up seemed so little in return for what I was getting."* Sarah

Almost all participants enjoyed eating, and this appeared to be important to their sense of living well with CD. Alex enjoys *"fresh home-cooked food that's healthy, and I feel better for it."* Jaimie describes taking more care over food as "*really quite a positive[…][I]t's when people don't think about what they're eating, you know? That you end up eating so unhealthily."* Only Toni felt that having CD had drastically reduced the pleasure they drew from eating and described changing from *"living to eat, to eating to live".* Interestingly, Toni did

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[14] Sarah

become animated when describing a few good GF venues they had visited, suggesting they still enjoyed eating if former freedoms could be recreated so that eating became *“like you would do normally”*:

As the researcher expected, participants sometimes expressed surprise at being asked to reflect on the positives of diagnosis. Problems dominate both research literature (Chapter Two) and the discussions in the current study. Nevertheless, this theme shows that some reflection on the positives of the experience is both realistic and potentially helpful in coping with challenges. Phillipa describes lifting their mood post-diagnosis by focussing on the variety of food still available: *“For every one thing that I thought ‘Oh, I can’t have this now!’ I’d then think of three more that I could still have.”*

Some people consciously combined focus on the positives of diagnosis with acceptance of the inevitable difficulties and felt this balanced approach enabled them to enjoy life. For example, Nat describes accepting the increased challenges while continuing to travel: *“I’ve been everywhere[…]And there are countries where, as I said, it’s been difficult.”* Phillipa now takes on the additional burden of organising social activities only because this gives them control of the catering. Similarly, Alex enjoys eating out within reduced parameters of venue choice:

> *“I still look forward to going out. We tend to only go to places that we know now, that we’ve been to, but, I think I do still enjoy a nice meal.”* Alex

A few participants minimised the negative presence of CD by assimilating it into their broader personal identity. Phillipa sighs as they explain deciding to adopt this approach, suggesting ambiguous feelings about CD remain. Yet, when viewed as a part of a person's broader identity, CD loses its dominance in people's lives because many other activities and features balance it:

> *"[Sighing] It becomes a part of who, it becomes a part of who you are[…]Otherwise, you just can't live for the rest of your life hating it, hating everything about having it."* Phillipa

3.3.3. How the discussion related to the idea of a psychoeducational intervention

All participants thought the proposed intervention would be a good idea for others, even if not needed for themselves. Several felt the intervention would benefit those recently diagnosed or struggling to come to terms emotionally with the necessary lifestyle changes. Their responses fit with the themes identified within the rest of the discussion. The theme of *Social Division* relates to the idea that people benefit from meeting others who manage the condition and can *"point them in the right direction"* [Kim] and reduce their sense of isolation. Louise thought existing support is primarily focused on dietary information and does not address CD's psychological and social impacts, which the intervention could usefully tackle.

> *"It'd just be nice to meet other people who've got Coeliacs[…]You wouldn't feel like the odd one out anymore." Toni*

> *"I think a lot of the focus is on this is what you can eat, this is what we'll do, and once you're doing that, we'll check you a few times, and you'll be fine! [laughs]." Louise*

3.4. Discussion

3.4.1. Implications of the themes for psychological intervention

The current study found that participants were positive about the idea of developing an intervention (section 3.3.3.). However, the research may have attracted those interested in psychology or in meeting peers, who would likely be positively predisposed to the idea. The researcher found support for the concept of intervention across the five themes, all of which extended the original *a priori* topics. As anticipated, CD did appear to impact people's social interactions and their feelings about health. Participants described the impact of the GFD as creating social division and conflict, which participants reacted to in various ways, including increased social anxiety, disclosure or disclosure avoidance, social withdrawal, and sometimes direct conflict. An interesting finding was the extent to which CD disrupted family relationships. This issue is less often reported in the research literature, though living alone with CD has been associated with reduced risk of an anxiety disorder (Hauser, Janke, Klump, Gregor, & Hinz., 2010) and fewer gastrointestinal worries (Marchese et al., 2013). Psychological intervention may support participants to manage interpersonal conflict and social anxieties. Sainsbury, Mullan & Sharpe's (2013) CBT-based online intervention included strategies to improve communication about CD.

Similarly, the current study found evidence that CD changed the way people felt about their health, as the researcher expected. These changes are mainly related to having health-related anxieties and a generally heightened awareness of their health status. A systematic review by Lebel et al. (2020)

reported high levels of health-related fear across populations with different chronic illnesses, supporting the finding of health-related anxiety in the current study. Yet, it is important to note that increased focus on real symptoms, fear of the exacerbation of an existing condition, and heightened awareness of the need to maintain overall physical health are normal, non-pathological reactions to long-term conditions (American Psychiatric Association, 2013; Lebel et al., 2020). Nevertheless, support in managing health-related anxieties and communicating effectively with health care providers would be a helpful aim for the proposed intervention.

The theme "*Constant threats and demands"* demonstrated that CD created an ongoing and multifaceted burden across daily life that was practical, emotional and cognitive and, for those on lower incomes, economic. An interesting finding in the current study was that disease-related burden endured post-diagnosis, rather than dissipating with time, practice or knowledge. Psychological coping and stress-management strategies may be a valuable component within the planned intervention to support self-management. The online intervention developed by Sainsbury et al. (2013) included problem-solving, goal-setting, and pleasant activity scheduling.

The theme *Loss of everyday foods and experiences* highlights the impact on mood and lifestyle of removing gluten, a dietary staple. This theme also reports the harmful effects of fatigue on participants' quality of life. Several participants described the lasting effect on mood and self-confidence of extensive pre-diagnosis periods of fatigue. Similarly, several quantitative studies report an association between extended periods of undiagnosed CD with decreased wellbeing and lower quality of life, which persist post-diagnosis (Fuchs et al., 2018; Zingone et al., 2021). Psychological intervention may help participants process the losses they have endured, including losses resulting from periods of illness pre-diagnosis.

Qualitative research provided evidence that a CD diagnosis can positively impact people's lives (Chapter Two), and the current study supports these findings. Some participants combined an appreciation of the positives of diagnosis with acceptance of the limitations created by CD. King et al. (2019) reported similar behaviours in people living with CD which they termed '*psychological perseverance'.* Strategies to develop psychological acceptance may support people living with CD, and is a focus of the Acceptance and Commitment Therapy (ACT) model, which has been used successfully in physical health interventions (Chapter Five). Finally, despite the existence of a national network of support groups (Coeliac UK, 2021), participants reported struggling to connect with peers and expressed interest in finding others who shared their experiences and could provide both emotional support and trustworthy advice. The acceptability of the intervention relies on the CD community feeling the programme is both trustworthy and useful. Based on the current study, the involvement of people living with CD in the interventions' development and delivery would increase acceptability among the target group. This desire for interaction with peers also suggests that a group intervention format would be particularly attractive to many people living with CD who feel isolated with the condition.

3.4.2. Strengths and limitations

This study had a small sample size with a bias towards older adults. The study sample was majority female (69%), which is comparable to other qualitative studies in CD. For example, of the 15 studies included in the QES (Chapter 2), 13 had majority female samples. This gender imbalance reflects the higher prevalence of CD in women, who are diagnosed 1.5 times more frequently than men (Singh et al. 2018). The lack of male participants in both the current study and in the wider psychosocial literature may limit the researcher’s awareness of the specific impacts CD has for men. This limitation could affect the researcher’s ability to design an intervention which supports men living with CD as effectively as women.

The researcher used *a priori* themes to ensure the discussion covered topics identified through research as CD's core psychological and social impacts. This focus was helpful given the limitations of the sample in the current study. The use of hybrid thematic analysis allowed consideration of new ideas not anticipated by the researcher. New *a posteriori* themes were not identified, though additional aspects of the *a priori* themes were discovered. The findings extended the researcher’s understanding of the *a priori* themes, which provided helpful insight applicable to the intervention design. The researcher’s use of a hybrid thematic analysis technique enabled exploration of the topic *Positives of diagnosis,* which may not naturally have arisen in the discussions. Finally, a significant limitation is that the researcher undertook all data collection and analysis alone due to limited resources. Despite using systematic and consistent methods, their proximity to the research may have created a source of bias in either the data collection or analysis phases.

3.5. Conclusion

The current study provided strong support for the proposed intervention. Findings confirmed that CD impacts people’s lives in many ways and includes losses beyond the loss of gluten itself, such as lost experiences and increased everyday demands. The study also confirmed that diagnosis could result in positive impacts. Acknowledgement of these positives may support acceptance of CD, and management of the negative effects. Participants felt that interaction with other people living with CD was helpful and desirable. These findings informed the development of a new intervention to support people living with CD, which is described in Chapter 5.

CHAPTER FOUR: STUDY TWO: PSYCHOMETRIC VALIDATION OF THE LIVING WELL WITH COELIAC DISEASE MEASURE

4.1. Introduction

4.1.1. Chapter structure

The following chapter describes Study Two of the current thesis, in which the researcher developed and validated a new assessment and outcome measure called Living well with Coeliac Disease (LWWCD-27). This chapter describes:

Study Two (part a): This component of Study 2 used qualitative research to assess and develop the face validity of the initial LWWCD draft. This part of the study was undertaken with the participants recruited in Study One. Sections 4.2 to 4.4 present this part of the study.

Study Two (part b): This part of the study was the preliminary testing of the validity and reliability of the LWWCD through a series of psychometric tests undertaken with a large sample of UK adults living with CD. Section 4.5 presents this part of the study.

The chapter concludes by presenting the final LWWCD measure and discussing its potential usefulness in research and clinical practice.

4.1.2. Psychosocial outcomes in long-term conditions

De Oliveira et al. (2013, p. 103) defined a psychosocial outcome as *"the effect caused by environmental and/ or biological factors on individual's social and/ or psychological aspects".* Psychosocial outcomes in long-term conditions vary between conditions and demographic groups and include changes in mood, cognitive function, self-management, identity, illness perceptions, education, work, family life, social engagement and stigma.

Studies report psychosocial outcomes experienced by people living with a wide range of long-term conditions, including diabetes (Types One and Two) (Liu et al., 2017), irritable bowel syndrome (IBS) (Ballou, Bedell, & Keefer., 2015), dermatitis (Birdi, Cooke, & Knibb., 2020), and polycystic ovary syndrome (PCOS) (Moghadam, Fereidooni, Saffari, & Montazeri., 2018). The current researcher found strong evidence that people living with CD experience many psychosocial outcomes (Chapter Two).

Some psychosocial outcomes experienced by those with long-term conditions may be positive, as has been reported in studies of both life-threatening conditions (Hefferon, Grealy, & Mutrie., 2009) and non-life-threatening conditions (Gomersall, Smith, Blewett, & Astell., 2017; Hefferon et al., 2009; Schipper et al., 2014). For example, Schipper et al., (2014) found that people living with renal disease experienced feelings of gratefulness, trust and freedom post-transplant, as well as negative outcomes like guilt and fear. Participants in Schipper et al.'s (2014) study also developed coping strategies based on positive outcomes, such as positive refocussing and positive reappraisal (e.g. acknowledging that they were comparatively less fatigued post-transplant than before). Despite this, the weight of social science research in health is on negative psychosocial outcomes.

4.1.3. Psychological intervention in long-term conditions

Improvement in condition-related psychosocial outcomes is usually a key reason behind the implementation of psychological intervention in long-term conditions (Shaohua & Shorey, 2021; Whitehead & Hearn, 2015). These interventions take several formats (e.g. face-to-face, online, telephone) and work with individuals, families and groups (Shaohua & Shorey, 2021). Non-pharmaceutical techniques are used within these interventions, such as cognitive-behavioural therapy, counselling, and health education (Shaohua & Shorey, 2021). Ghosh and Deb (2017) describe the near-exclusive focus of psychoeducational interventions on alleviating psychological symptoms and unhelpful behaviours as a deficit approach to long-term conditions.

4.1.4. Evaluating the outcomes of psychological interventions

Evaluation of psychoeducational interventions requires the use of robust outcome measures which can capture change. Such measures need to have undergone psychometric testing to ensure they are valid, reliable and suitable for use with intervention populations (Du et al., 2021; Churruca et al., 2021). These measures are generally questionnaire-format patient-reported outcome measures (Ostevik et al., 2021). Studies typically use multiple measures to assess multiple outcomes. For example, one review of rheumatology interventions reported an average of 6.5 measures assessing 4.7 outcomes (Dissanayake & Bertouch, 2010). Generic measures allow results from different interventions to be aggregated or compared. However, condition-specific measures have benefits as they identify distress related to the presence of a specific condition and may be more sensitive to change and more valid on target populations (Churruca et al., 2021; D'Amico, Haase, & Ziemssen., 2019). Studies often combine generic and condition-specific outcome measures, such as the intervention evaluation by Merwin et al., (2021), which used the PROMIS Depression Scale and the Diabetes Distress Scale (DDS). Combining generic and condition-specific outcome measures can allow comparisons between groups living with a specific long-term condition and the general population (Szentes et al., 2018).

4.1.5. CD-specific psychosocial outcome measures

The researcher sought to identify a CD-specific psychosocial outcome measure to use alongside generic measures in the evaluation of the psychological intervention (Study Three - Chapters Six and Seven). The researcher identified measures through: **1)** reviewing the literature on the psychosocial impacts of CD (Chapter Two); and, **2)** a brief scoping review of existing CD-specific psychosocial measures, which is outlined in the current section.

The researcher conducted an electronic database search combining terms for CD with terms describing outcome measures and psychosocial outcomes (Table 9).

Table 9: Database search strategy (Study Two)

Condition	*"Coeliac"; "Celiac"*
Outcome measures	"questionnaire"; "measure"; "tool"; "survey"; "validation."
Psychosocial outcomes	"depression"; "anxiety"; "stress"; "quality of life"; "experience*"; "living"; "social"; "family"; "eating"; "food."
Databases	Web of Science; Pubmed; Scopus.
Criteria for selection of a measure	- validated on a sample of adults medically diagnosed with CD. - measuring psychosocial outcomes related to CD. - not focusing on the measurement of items assessing physical symptoms, co-morbid conditions, or GFD adherence.

The researcher's searches identified only four CD-specific psychosocial measures meeting the criteria listed in Table 9. Other published questionnaires were unvalidated surveys designed for paediatrics, solely or primarily assessing dietary self-management or CD-related symptoms (e.g. the Celiac Dietary Adherence Test (CDAT) developed by Leffler et al., 2009). The four measures selected were developed through research with adults living with CD and consultation with experts[15] (range 387 – 488 participants) and demonstrated strong psychometric properties. Two measures originated outside of the UK, in the USA (the Coeliac Disease Quality of Life (CDQoL) scale developed by Dorn et al., 2010) and Germany (the Celiac Disease Questionnaire (CDQ) developed by Häuser, Gold, Stallmach, Caspary, & Stein., 2007). Two measures designed in the UK were published after Study Three was completed, but the researcher has listed these to provide the reader with up-to-date reference material (Table 10).

Quality of life is a broad construct correlating highly with measures of well-being, life satisfaction, happiness and positive affect (Medvedev & Landhuis, 2018). Three existing psychosocial measures identified assessed CD-related quality of life, and all three contained items or subscales relating to eating socially, feelings relating to CD, and the burden of the GFD (Crocker, Jenkinson, & Peters, 2018; Dorn et al., 2010; Häuser et al., 2007). Both the CDAQ (Crocker et al., 2018) and CDQ (Häuser et al., 2007) contained subscales assessing CD-related physiological symptoms. The CD-QoL (Dorn et

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[15] Samples >300 are considered substantial. If < 300, samples should have 5 participants per item to be considered suitable for factor analysis/ principal components analysis. (Pallant, 2020)

al., 2010) contained items addressing health concerns (e.g. cancer fears). The CD-FAB (Satherley et al., 2018) was a quite different unidimensional scale with a narrow focus on attitudes and beliefs towards food and eating.

Table 10. Existing Coeliac Disease-related psychosocial measures

Measure, Authors, Country of origin	Subject	Items; Scales; internal reliability	Interpretation
Coeliac Disease Questionnaire (CDQ). Hauser et al. (2007), Germany.	CD HR-QoL	28 items. 4 Scales: *Emotion; Social; Worries; Gastrointestinal* α = 0.80 – 0.91.	Higher scores indicate better CD health-related quality of life.
Coeliac Disease Quality of Life Scale (CD-QoL). Dorn et al. (2010), USA.	CD HR-QoL	20 items. 4 scales: *Limitations; Dysphoria*; *Health Concerns*; *Inadequate treatment.* α = 0.80 – 0.91	Lower scores indicate better CD health-related quality of life.
† *Coeliac Disease Food Attitudes and Behaviours scale (CD-FAB)* Satherley, Howard & Higgs, (2018), UK.	Food attitudes and behaviours related to CD.	11 items. Single dimension. α >0.7	Higher scores indicate greater CD-related food concerns and compensatory behaviours.
† *Coeliac Disease Assessment Questionnaire (CDAQ)* Crocker, Jenkinson & Peters (2018), UK.	CD HR-QoL	32 items. Four scales: *Stigma; Dietary burden*; *Symptoms; Social isolation.* α >0.7	Higher scores indicate better CD health-related quality of life.

HRQoL–Health-related quality of life; *All Likert-type scales † *Published after completion of the current study.*

All existing measures were negatively worded and focussed on CD-related difficulties and negative impacts (e.g. CDAQ item 5: *“Have you felt guilty about the impact of your coeliac disease on your friends and family*”). No measures assessed general feelings of pleasure towards food. However, the CDAQ

(Crocker et al., 2018) has one item about *“cravings”* for gluten-containing foods, and the CDQ (Häuser et al., 2007) has one item about being unable to have “*special foods”.* The CD-FAB (Satherley et al., 2018) has one item asking if respondents still enjoy restaurant meals.

4.1.6. Development of a new CD-related psychosocial outcome measure

The current researcher sought to identify a suitable measure to assess the intervention developed as part of the current project. This measure needed to assess CD-related psychological and social outcomes and people’s ability to adapt to their diagnosis and live well with CD. Existing CD-related measures appeared unsuitable for these purposes because they were: **1)** not designed to assess positive psychosocial changes, satisfaction or the ability to ‘live well’ following diagnosis; **2)** negatively worded and problem-focused; **3)** often included scales or multiple items addressing physical symptoms; **4)** were developed and validated outside of the UK[16], which may be problematic as eating practices, dietary staples, awareness of CD, and the cost and availability of GF foods, vary internationally.

The researcher decided to develop a new measure which would: **1)** Provide assessment of both negative and positive psychological and social changes associated with living with CD; **2)** Focus exclusively on psychological and social aspects of living with CD; **3)** Would not assess physiological symptoms, knowledge about CD or the GFD, or the level of dietary self-management; **4)** Be validated on a UK adult population living with CD.

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[16] This was the case at the time of the current study. Two UK measures were subsequently published in 2018 (Table 10).

Study Two is a two-part study. In Part A, a small group (N-13) of participants reviewed an initial set of items for the LWWCD measure supporting content refinement and face validity testing. In Part B, the refined measure underwent preliminary validation testing. Study 2 (Part A) is presented first, followed by Part B.

4.2. Methods: Study Two (Part A):

4.2.1. Ethical Approval

Ethical approval for Study Two was granted by the STEM Ethical Review Committee, University of Birmingham (Appendix A).

4.2.2. Design

Qualitative and quantitative data was gathered from participants in **1)** focus groups and interviews (Part A); and, **2)** an online questionnaire study (Part B) (See Figure 1, p.13).

4.2.3. Aims

Establishing the face validity of a measure is essential in ensuring the tool is relevant and appears reasonable to respondents (Connell et al., 2018). Content validity assesses *“the extent to which the set of items comprehensively covers the different components to be measured”* (Connell et al., 2018). Study Two (Part A) had three objectives:

Objective 1) To establish the face and content validity of the initial LWWCD item-set. Review of the item-set considered both the topic areas and each of the items in the set;

Objective 2): To adapt, change or exclude problematic items;

Objective 3): To generate any additional items needed.

4.2.4. Participants

The thirteen participants in Study Two had been recruited for Study One, as described in Chapter Three. Table 7 (Chapter 3) presents participants' characteristics.

4.2.5. Initial item-set

The current researcher constructed an initial set of 45 items that covered five areas of psychosocial outcomes affecting those living with CD. These areas were: *social interaction* (12 items); *worries about health* (nine items); *losses and changes* (seven items); the *burden of managing CD* (seven items); *the positives of being diagnosed with CD* (10 items) (Appendix D). The researcher generated these items based on the findings from the QES (Chapter Two).

4.2.6. Online pilot of the draft measure

Through qualitative research data gathered from people living with CD in a series of focus groups and interviews (Study One, Chapter Three), the researcher developed a revised 41-item version of the draft measure from the initial 45-item set (see Figure 1, p.13). This revised version of the measure was hosted online for pilot testing using a secure platform (LimeSurvey™). Participants rated items on a six-point Likert-type scale anchored from '*completely disagree'* to '*completely agree'*. Six-point scales reduce non-committal mid-point responses and provide a reasonable degree of response variability (Taherdoost, 2019). Even-numbered scaling has been found acceptable to research participants and does not reduce the reliability or validity of a scale (Taherdoost, 2019). Taherdoost (2019) recommends using six-point or seven-point scales, which demonstrate improved reliability, validity and acceptability. A recall period of one month (4 weeks), as selected by Crocker et al. (2018) was chosen. A one-month recall period allowed participants to have experienced a range of situations and fluctuations in health, but is short enough to remember. The online questionnaire included space for qualitative feedback regarding the measure's face validity and ease of completion.

4.2.7. Procedure

4.2.7.1. Review of the initial item set

In Study One, which is described in full in Chapter Three, participants read through the initial set of 45 items (Appendix D) during a series of focus group and interview sessions. They identified items they felt were irrelevant or difficult to understand, suggested rewording or replacement items, and suggested where new items would be relevant. The current researcher facilitated the session using pre-written semi-structured interview questions (Appendix C).

4.2.7.2. Online pilot testing

All participants from Study One (Chapter Three) received an invitation to complete an online version of the measure, with items now revised following analysis of the qualitative data from Study One (see Figure 1, p.13). Online pilot testing of the revised measures served three purposes: **1)** a review the final set of draft items; **2)** to check the six-point scaling made sense to participants; **3)** to check the suitability of the LimeSurvey™ platform.

4.3. Results

4.3.1. Face and content validity of the initial item set (45 items)

Participants in Study One (Chapter Three) unanimously felt the five proposed topics covered by the item set were relevant to living with CD. The researcher expected these results, as the topics originated from the QES (Chapter Two). The researcher made substantial changes to the individual items within the set in response to Study One participants' qualitative feedback on these items provided during the focus group and interview sessions. Making these changes was not unexpected, as the researcher knew that respondents living with CD had not previously reviewed these items. Of the original 45 items, the researcher retained seven items in their original form, slightly reworded 12 items, and removed 26 items. Supplementary tables summarise these decisions (Appendix D). The researcher developed 22 new items in response to participants' suggestions (Table 11). This work resulted in a revised set of 41 items categorised under the original five topic areas (Table 12). Of the 13 participants in Study 2 (Part A), 12 completed the online pilot test of the revised 41 items. All participants answered every item and made no suggestions for further changes.

Table 11. New items generated in Study 2 (Part A)

New Question	*Reason for the new question*
I avoid eating outside of my own home.	Participants felt this was a very common coping strategy that could have negative consequences.
I can judge whether or not people really do understand my dietary needs.	Participants felt they had to become skilled at judging the extent to which those around them understood their dietary needs.
I find it difficult to trust that restaurant staff will prepare food safely for me.	Suggested as a problem, even with staff who were confident or said they had undergone training.
I feel bad about restricting the food or restaurant choices of my family or friends.	Added to reflect the sense of guilt participants described.
The people I live with do things that may risk contaminating my food with gluten.	A struggle for those with children, housemates, or partners or spouses who were careless or forgetful.
My diet is difficult to manage when eating at work or attending work-related events.	An issue participants felt was missing from the original question set.
If I suspect that food prepared for me by a relative or friend contains gluten, I always refuse to eat it.	An issue participants felt was missing from the original question set.
I am concerned that my body weight has changed (increased or decreased) since I started my gluten-free diet.	An issue participants felt was missing from the original question set.
My diet restricts my choice of holidays.	An issue participants felt was missing from the original question set.
My lifestyle has changed in positive ways since my diagnosis.	Participants felt diagnosis brought positive lifestyle changes: e.g. savings from less dining out and takeaways, improved health, more energy, better sleep, less worry about symptoms, healthier lifestyle.
Planning what I will eat ahead is difficult for me.	An issue participants felt was missing from the original question set.
I worry about the financial costs of eating a gluten-free diet.	An issue participants felt was missing from the original question set.
I miss convenience foods like ready-meals, cooking sauces, burgers and take-aways.	An issue participants felt was missing from the original question set.
Sometimes I take risks with food that may contain gluten because I am tired or busy.	Participants felt this was a key cause of risk-taking.

I trust certain members of my family or certain friends to prepare food safely for me.	Participants described having a very small list of specific people they trusted understood the GFD and could safely prepare GF food.
Even after I've explained about Coeliac Disease, I feel that most people dismiss my diet as a fad.	Participants felt the current gluten-free fad was a key social problem for people with CD.
I take some risks by eating food that may contain gluten to avoid awkward social situations.	Participants felt this was an important cause of risk-taking.
I feel separated from those around me in social situations because of my diet.	Participants felt social isolation was an important issue for people with CD.
I need more medical checks to make sure that my Coeliac Disease is controlled and/ or that my gluten-free diet is well-balanced.	Participants felt they could only be sure their CD was well-controlled by having appropriate medical checks at regular intervals.
I have all the information and support I need to obtain food on prescription if I want to do that	Participants described needing up-to-date information about foods available and prescription systems (e.g. prepaid prescriptions).
Managing my gluten-free diet is time-consuming	Participants described the impact on their time of managing the GFD.
I feel that my health has improved now that I follow a gluten-free diet.	Participants felt this was an important outcome of the GFD.

Table 12. The revised set of 41 items, by topic area

Social Interaction (13)	Item 1: I am confident to explain my dietary needs when eating outside of my own home.
	Item 2: I avoid eating outside of my own home.
	Item 3: If I suspect that my food has been contaminated with gluten, I will raise this with the restaurant staff.
	Item 4: I can judge whether or not people really do understand my dietary needs.
	Item 5: I find it difficult to trust that restaurant staff will prepare food safely for me.
	Item 6: I trust certain members of my family or certain friends to prepare food safely for me.
	Item 7: Even after I've explained about CD, I feel that most people dismiss my diet as a fad.
	Item 8: I take some risks by eating food that may contain gluten to avoid awkward social situations.
	Item 9: I feel bad about restricting the food or restaurant choices of my family or friends.
	Item 10: The people I live with do things that may risk contaminating my food with gluten.
	Item 11: I feel separated from those around me in social situations because of my diet.
	Item 12: I worry that people think I'm boring or irritating because I follow a gluten-free diet.
	Item 14: If I suspect that food prepared for me by a relative or friend contains gluten, I always refuse to eat it.
Worries about your health (9)	Item 15: I minimise the impact of CD on my health by following a gluten-free diet
	Item 16: Health professionals have given me all the information I want to have about CD.
	Item 17: I worry that CD increases my risk of health problems.
	Item 18: I am confident that my gluten-free diet provides me with all the nutrition and energy I need.
	Item 19: I am concerned that my body weight has changed (increased or decreased) since I started my gluten-free diet.
	Item 20: I need more medical checks to make sure that my CD is controlled and/ or that my gluten-free diet is well-balanced.
	Item 21: I feel stressed thinking about the fact that I have CD.
	Item 33: I have all the information and support I need to obtain food on prescription if I want to do that.
	Item 37: I prefer having a diet-based treatment to having to take medication.

Losses / Changes (5)	Item 22: Since being diagnosed with CD, I feel like just the same person as I was before. Item 23: I rarely crave gluten-containing foods Item 25: Eating is just as enjoyable on the gluten-free diet as it was before. Item 26: There are certain foods that I do really miss. Item 29: I miss convenience foods like ready-meals, cooking sauces, burgers and take-aways.
The burden of managing CD (8)	Item 24: My diet restricts my choice of holidays. Item 28: Managing my gluten-free diet is time-consuming. Item 30: Food, cooking and eating seem to be always on my mind. Item 31: Planning what I will eat ahead is difficult for me. Item 32: I don’t mind having to explain my diet to people more than once if they forget or get confused. Item 34: I worry about the financial costs of eating a gluten-free diet. Item 35: Sometimes, I take risks with food that may contain gluten because I am tired or busy. Item 13: My diet is difficult to manage when eating at work or attending work-related events.
Positive Changes (6)	Item 27: My lifestyle has changed in positive ways since my diagnosis. Item 36: In some ways, the diagnosis of CD was a relief. Item 38: Since changing to a gluten-free diet, I feel that the food I eat now is generally healthier than it was before. Item 39: Since being diagnosed, I am more in control of my health. Item 40: I feel that my health has improved now that I follow a gluten-free diet. Item 41: I am proud of myself for coping with CD and the gluten-free diet so well.

4.4. Discussion of findings (Part A)

Study 2 (Part A) utilised qualitative data gathered during Study One (Chapter 3) and this resulted in substantial amendments to the original items resulting in a reduced 41 item set. The researcher felt that a thorough response to participants’ feedback was important to ensure the items had face validity and could be answered coherently by people living with CD. The revisions were mainly related to participants’ concerns that items were vague or too broad, making them difficult to answer. Participants explained that different contexts changed their feelings and behaviours related to CD and the GFD. For example, Item 3 (*People understand that I'm not just fussing about my food)* was criticised as vague since ‘fussing’ could mean worries about many different things (e.g. hygiene, menu, presentation of food). Participants described some items as unrealistic, such as Item 5 (*When I explain my diet, it is quite easy for people to cook for me*). They explained that gluten-free cooking is always difficult (even if you have CD), especially in a kitchen filled with gluten. The researcher introduced more context-focussed and specific items; for example, *I trust certain members of my family or certain friends to prepare food safely for me*. Participants in the online pilot who tested the revised 41 items completed all questions and did not suggest further changes.

4.5. Study Two (Part B)

4.5.1 Aims

Study 2 (Part B) aimed to test the validity and reliability of the draft LWWCD measure (Table 12).

4.5.2. Methods

4.5.2.1. Design

The following psychometric tests assessed the validity and reliability of the LWWCD:

- **Preliminary item analysis:** scrutiny of responses to evaluate ceiling effects and inter-item correlations.
- **Principal components analysis (PCA):** assessing the internal structure.

- **Convergent validity** tests: assessing the correlation of the new LWWCD with measures of related constructs.
- **Divergent validity** tests: assessing the LWWCD's ability to detect likely differences in scores between groups that differ in the measured constructs.
- **Test-retest reliability:** assessing the reliability of the measure across two-week and six-week retest intervals.

4.5.2.2. Participants

Calls for participants were circulated by Coeliac UK; through the Coeliac Psychology research participant list[17]; other universities; and through the researcher's contacts and social media accounts. Multiple recruitment channels increased the diversity of the sample, including people who were not members of Coeliac UK. Potential participants read an online consent pack and checked a consent box at the end of the information to confirm that they wished to participate, met the eligibility criteria, and had understood the participant information provided. The researcher included their email in the participant information to enable participants to ask further questions.

4.5.2.3. Materials

This section provides details of the materials and psychometric tests used in Study 2 (Part B).

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[17] The University of Birmingham Coeliac Psychology Research Group hold a list of approximately 150 members of the public who have volunteered themselves as potential research participants. These people were recruited in previous University of Birmingham studies, at events, or contacted the University via the Coeliac Psychology research page. https://www.birmingham.ac.uk/research/perspective/coeliac-disease.aspx

4.5.2.3.1. Online questionnaire

Participants completed an online questionnaire battery hosted online using LimeSurvey™. The questionnaire battery consisted of the 41-item LWWCD (Table 12), a demographic questionnaire, and five questionnaires used in convergent validity tests (Table 13). Participants accessed the study using an online link. Questionnaire responses provided the data used in the psychometric tests described below.

4.5.2.3.2. Preliminary item analysis

Data screening before application of the PCA analysis assessed the distribution of the dataset and item responses. Weak items are likely to affect the overall performance of a scale and so may be removed before PCA. Items were considered weak if they had a ceiling effect >60% (so greater than 60% of respondents chose the maximum score) as this would reduce the ability of the measure to gauge behaviour change as participants would be unable to show improvement for the item (Dorn et al., 2010). Inter-item correlations were scrutinised, with those <.0.2 or >.0.8 considered for removal, as they may, respectively, demonstrate a very weak relationship to the rest of the scale items or be redundant with other scale items (Field, 2010). Finally, the researcher reviewed items to consider their conceptual relevance to the measure.

4.5.2.3.3. Analysis of the internal structure of the LWWCD

Exploratory principal components analysis (PCA) using SPSS 26 assessed the LWWCD's internal structure. The researcher ran the PCA with an oblique rotation (direct oblimin), as substantial correlation between components was expected (Field, 2010). Low loadings <.3[18] were suppressed, as suggested by Field (2010) and Ratislavová, Kalvas, & Beran (2015). Delta was set at 0, as recommended by Field (2010). Components with eigenvalues >1 were extracted, following Kaiser's (1960) convention (Dorn et al., 2010; Field, 2010). Cronbach's α assessed the internal reliability of the subscales.

4.5.2.3.4. Convergent validity

A measure demonstrates convergent validity when scales significantly correlate with other psychometric measures assessing similar constructs. The researcher predicted that the LWWCD would correlate with measures of social anxiety, health anxiety, illness perceptions (Consequences and Personal Control), and CD-related quality of life (Table 13). The convergent measures selected in Study Two had all demonstrated strong psychometric properties in other samples with long-term conditions and were relatively short to prevent participant fatigue and maximise completion rates. Selected measures were: the Health Anxiety Inventory (HAI) (Salkovskis, Rimes, Warwick, & Clark., 2002); the Brief Fear of Negative Evaluation scale (BFNES) (Rodebaugh et al., 2004); the Revised Illness Perception Questionnaire (IPQ-R) (subscales *Consequences* and *Personal Control* only) (Moss-Morris et al., 2002); the Celiac Disease Quality of Life Survey (CDQoL) (Dorn et al., 2010).

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[18] The researcher chose to set the threshold slightly lower than Field's (2010) recommendation of suppressing loadings <.4, to avoid prematurely excluding items before reviewing the initial solution.

Table 13. Measures of convergent validity used in Study Two (Part B)

Measure	Authors	Construct assessed	Expected correlations with LWWCD
Brief Fear of Negative Evaluation Scale (BFNES-S)	Rodebaugh et al., 2004	Social Anxiety (8 items)	Inverse correlation with *Concerns and Losses; Risk Management; Positive Changes; Total.*
Short Health Anxiety Inventory (SHAI)	Salkovskis et al., 2002.	Health Anxiety (14 items)	Inverse correlation with *Concerns and Losses; Positive changes; Total.* Positive correlation with *Risk management.*
Revised Illness Perception Questionnaire (IPQ-R)	Moss-Morris et al., 2002.	Illness Perceptions *Consequences* (6 items)	Inverse correlation with *Concerns and Losses; Positive changes; Total.*
As above	As above	*Personal Control* (6 items)	Positive correlation with *Concerns and Losses*, *Positive changes, Risk management, Total*.
Coeliac Disease Quality of Life Survey (CDQol)	Dorn et al., 2010.	*Limitations*	Positive correlation with all CDQoL subscales.
As above	As above	*Dysphoria*	Positive correlation with all CDQoL subscales
As above	As above	*Health Concerns*	Positive correlation with all CDQoL subscales
As above	As above	*Inadequate Treatment*	Positive correlation with all CDQoL subscales

4.5.2.3.5. Divergent validity

Divergent validity was assessed by comparing LWWCD scores across three known groups. These groups were women, those newly diagnosed with CD, and younger people. Women are reported to face an increased risk of reduced CD-related quality of life and increased rates of anxiety (Zingone et al., 2015). Those newly diagnosed are likely to face difficulties with dietary self-management in the early years post-diagnosis due to the considerable amount of learning and behaviour-change required (Chapter Two, QES findings). Younger people are likely to face increased difficulties with self-management, increased social anxiety and reduced CD-related quality of life due to their generally greater social interaction with new people and the reported negative impact of the GFD on behaviours such as social events and dating (Aloni et al., 2019; King et al., 2019; Schroeder & Mowen, 2014). Scores on all LWWCD scales were predicted to differ between groups as follows:

- Participants newly diagnosed with CD (≤ 2 years ago) would have lower scores than those diagnosed > 10 years ago.
- Younger people (≤ 30 years) would have lower scores than those in older age groups (31-49 years and ≥ 50 years).

The researcher also predicted that on the LWWCD *Concerns and Losses* subscale and the *Total* scale:

- females would have lower scores than males.

4.5.2.3.6. Test-retest reliability

Test-retest reliability was assessed at two retest intervals (two and six weeks). Two weeks is a commonly chosen short-term interval, long enough to prevent participants from attempting to match their original response (Polit, 2014). The researcher anticipated that feelings about CD would be, without intervention, relatively stable, and so also applied a somewhat longer retest interval of six weeks. Participants indicated if they would be willing to participate in the retests in the original study information pack. Those who consented to test-retest received an emailed link to the retest version of the questionnaire at the appropriate dates. Scores were linked using the unique identification code participants entered onto all tests.

4.5.3. Results

4.5.3.1. Participants

The online questionnaire received 351 completed responses. Ages ranged from 17–89 years. However, as in other UK research on CD, respondents were majority female (81.7%), middle-aged (63.2% > 40 years), married, University-educated, and members of Coeliac UK. The majority of respondents (71%) had been diagnosed with CD for ≥ 3 years (Table 14).

Table 14: Characteristics of the validation study participants (n=351)

Characteristic	*N*	%[a]
Age (years)	46.60 (16.79)[b]	-
Range	17 – 89	-
16-25	50	14.2
26-39	79	22.5
40-59	130	37.0
60-75	85	24.2
>75	7	2.0%
Gender		
Male	64	18.3
Female	285	81.7
Other	0	0
No response	2	-
Education		
No formal qualifications	11	3.2
GCSEs / equivalent	38	11
A-levels/ AS-levels or equivalent	59	17.1
Vocational qualifications/ apprenticeship	28	8.1
University degree(s)	210	60.7
No response	*5*	-

Employment status		
Full-time employment	139	40.9
Part-time employment	70	20.6
Homemaker	10	2.9
Full-time education	30	8.8
Jobseeker	2	<1
Retired	73	21.5
Not working due to ill health	16	4.7
Prefer not to say / no response	11	-
UK region		
England	305	86.9%
West Midlands	76	21.8
East Midlands	23	6.6
South West	37	10.6
South East	60	17.2
North West	21	6.0
North East	14	4.0
London	27	7.8
East of England	24	6.9
Wales	15	4.3
Scotland	27	12.4
Northern Ireland	1	<1
Who do you live with		
I live alone	56	16.2
Spouse/ Partner	135	39.1
Spouse/ Partner, and children	97	28.1
Alone, with children	12	3.5
Parents or carers	25	7.2
Housemates / other adults	20	5.8
No response	*12*	-
Does anyone else in your home have CD or DH[c]?		
No	289	83.8
Yes	56	16.2
No response	6	-

Time since diagnosis (years)		
< 1	31	10.3
1 -2	57	18.9
3 – 5	66	21.9
6 – 10	55	18.2
> 10	93	30.8
No response	49	-
Membership of Coeliac UK		
Current member	259	74.6
No membership	88	25.1
No response	*4*	-

[a] *of those who responded to question,* [b] *Mean (SD),* [c] Dermatitis Herpetiformis (an autoimmune condition which is a skin manifestation of CD).

4.5.3.2. Preliminary item analysis

Following preliminary item analyses, just three items were removed (Table 15), resulting in 38 items retained for PCA analysis. Data distribution was non-parametric, with the majority of the items displaying varying degrees of negative skew. The researcher attempted data transformation using both a reflected Log10 transformation, and then a reflected square-root transformation. However, attempts at transformation proved unsuccessful, with widely varying degrees of skew remaining across the item set. PCA is an exploratory technique suitable for use on both normal and non-normally distributed data (Jolliffe & Cadima, 2016), so the researcher applied PCA to the untransformed scores.

Table 15: Items removed following preliminary item analyses

Items removed	*Statistical and conceptual reasons for removing items*
I have all the information and support I need to obtain food on prescription if I want to do that.	• Low inter-item correlations; • Many people choose not to claim prescriptions or have set up repeat prescriptions. • GF prescriptions in the UK were under review at the time of the study.
My diet is difficult to manage when eating at work or attending work-related events.	• Missing data >5% • Likely to substantially affect only a minority of people..
I minimise the impact of Coeliac Disease on my health by following a gluten-free diet.	• Ceiling effect (88.6% maximum score). • Likely to relate to the high self-management reported.

4.5.3.3. Principal components analysis

The Keiser-Meyer Olkin (KMO) value of 0.904 confirmed that sampling adequacy was excellent (Field, 2010). Bartlett's test for sphericity was highly significant (*p*<.000), indicating that inter-item correlations were sufficient for PCA (Field, 2010). The PCA with oblique rotation (Direct Oblimin) was applied as described above (section 4.5.2.3.3). The initial solution yielded eight factors, four of which explained <4% of the variance. Unreflective reliance on Kaiser's eigenvalues >1 criterion can lead to retention of too many factors, making the solution difficult to interpret (Pallant, 2020). The scree plot indicated that it would be useful to retain components with eigenvalues >2. The PCA was rerun, retaining only components with eigenvalues >2, resulting in a solution of four components explaining 44% variance. Appendix D (supplementary Table VII) presents the pattern matrix showing loadings for all 38 items. Four items[19] failed to load sufficiently (>.4) onto any component, so they were excluded from further analysis. Of 34 retained items, 31 items were loaded onto only one of the four components. The four components were named: *Concerns and Losses* (component one); *Positive changes* (component two); *Risk management* (component three); and, *Communicating about Coeliac Disease* (component four). Three items that loaded across two components were retained for subsequent analysis. Items were attributed to the component onto which they loaded most highly. The item *Eating is just as enjoyable on the gluten-free diet as it was before* cross-loaded equally but was attributed to component two (*Positive changes*) as a better conceptual fit. Table 16 shows the four components resulting from the initial PCA analysis.

Table 16: Four components following the initial PCA analysis[20]

Component	*Item*
1. Concerns and Losses *(18 items)*	- Managing my GFD is time-consuming. - I worry that CD increases my risk of health problems. - Food, cooking and eating seem to be always on my mind. - I feel stressed thinking about the fact that I have Coeliac Disease. - Planning what I will eat ahead is difficult for me. - I feel separated from those around me in social situations because of my diet. - I worry that people think I'm boring or irritating because I follow a GFD. - Since being diagnosed with CD, I feel like just the same person I was before. - I worry about the financial costs of eating a gluten-free diet. - I need more medical checks to make sure that my CD is controlled and/ or that my GFD is well balanced. - I feel bad about restricting the food or restaurant choices of my family or friends.

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[19] Items removed: *I trust certain members of my family to prepare food safely for me*; *I prefer having a diet-based treatment to having to take medication, I rarely crave gluten-containing foods*, and, *Health professionals have given me all the information I want to have about Coeliac Disease*.

[20] 34 items remain in this solution.

	- I miss convenience foods like ready-meals, cooing sauces, burgers and take-aways. - I am concerned that my body-weight has changed (increased or decreased) since I started my gluten-free diet. - I find it difficult to trust that the restaurant staff will prepare food safely for me. - My diet restricts my choice of holidays. - I am confident that my gluten-free diet provides me with all the nutrition and energy I need. - There are certain foods that I do really miss. - Even after I've explained about CD, I feel that most people dismiss my diet as a fad.
2. Positive changes *(7 items)*	- Eating is just as enjoyable on the GFD as it was before. - Since being diagnosed, I am more in control of my health. - My lifestyle has changed in positive ways since my diagnosis. - Since changing to a gluten-free diet, I feel that the food I eat now is generally healthier than it was before. - I feel that my health has improved now that I follow a gluten-free diet. - In some ways, the diagnosis of CD was a relief. - I am proud of myself for coping with CD and the gluten-free diet so well
3. Risk management *(5 items)*	- I take some risks by eating food that may contain gluten to avoid awkward social situations. - Sometimes, I take risks with food that may contain gluten because I am tired or busy. - If I suspect that food prepared for me by a relative or friend contains gluten, I always refuse to eat it. - If I suspect my food has been contaminated with gluten, I will raise this with the restaurant staff. - The people I live with do things that may risk contaminating my food with gluten.
4. Communication *(4 items)*	- I am confident to explain my dietary needs when eating outside of my own home. - I don't mind having to explain my diet to people more than once if they forget or get confused. - I can judge whether or not people really do understand my dietary needs. - I avoid eating outside of my own home.

4.5.3.4. Internal consistency

4.5.3.4.1. Removal of weak items

Cronbach's α was computed for each component and, for three components, indicated acceptable or strong internal consistency: *Social interaction* (α =

.898), *Positive changes* (α = .807), *Risk management* (α = .760). *Social interaction* was a long scale (18 items), and its internal consistency did not reduce when two items were removed: *There are some foods that I do really miss,* and *I am concerned that my body-weight has changed (increased or decreased) since I started my gluten-free diet.* The researcher reflected on the usefulness and relevance of these items, and decided to delete them from the scale. The internal consistency of the *Risk management* scale improved by deletion of the item: *The people I live with do things that may risk contaminating my food with gluten,* reaching α = .779. The *Communication* scale demonstrated unacceptable internal consistency (α = .579), which the removal of any items could not improve. Therefore, component four was removed.

In summary, PCA and internal reliability analysis (Cronbach's α) resulted in a 27-item LWWCD measure with three subscales: *Concerns and Losses*, *Positive changes*, and *Risk management*. This solution was confirmed by a subsequent PCA run on the remaining 27 items (supplementary table VIII, Appendix D). The solution explained 48% of the variance (Table 17), which is a level of variance described as respectable by Pallant (2020, p206). Table 18. presents the LWWCD-27 items by subscale. Table 19 defines the constructs measured by the LWWCD total scale and subscales.

Table 17. Total Variance Explained by the LWWCD-27 measure

Component	*% of variance*	*Cumulative % of variance*
Concerns and Losses *(16 items)*	29.194	29.194
Positive Changes *(7 items)*	9.606	38.800
Risk management *(4 items)*	8.367	47.166 (total)

Table 18: Final solution for the LWWCD-27 measure

Concerns and Losses *(16 items)*	- Managing my gluten-free diet is time-consuming. - I worry that Coeliac Disease increases my risk of health problems. - Food cooking and eating seem to be always on my mind. - I feel stressed thinking about the fact that I have Coeliac Disease. - Planning what I will eat ahead is difficult for me. - I feel separated from those around me in social situations because of my diet. - I worry that people think I'm boring or irritating because I follow a gluten-free diet. - Since being diagnosed with Coeliac Disease, I feel like just the same person as I was before. - I worry about the financial costs of eating a gluten-free diet. - I need more medical checks to make sure that my Coeliac Disease is controlled and/ or that my gluten-free diet is well-balanced. - I feel bad about restricting the food or restaurant choices of my family or friends. - I miss convenience foods like ready-meals, cooking sauces and take-aways. - I find it difficult to trust that restaurant staff will prepare food safely for me. - My diet restricts my choice of holidays. - I am confident that my gluten-free diet provides me with all the nutrition and energy I need. - Even after I've explained about Coeliac Disease, I feel that most people dismiss my diet as a fad.
Positive Changes *(7 items)*	- Eating is just as enjoyable on the gluten-free diet as it was before. - Since being diagnosed, I am more in control of my health. - My lifestyle has changed in positive ways since my diagnosis. - Since changing to a gluten-free diet, I feel that the food I eat now is generally healthier than it was before. - I feel that my health has improved now that I follow a gluten-free diet. - In some ways, the diagnosis of Coeliac Disease was a relief.

	- I am proud of myself for coping with Coeliac Disease and the gluten-free diet so well.
Risk management *(4 items)*	- I take some risks by eating food that may contain gluten to avoid awkward social situations. - Sometimes, I take risks with food that may contain gluten because I am tired or busy. - If I suspect that food prepared for me by a relative or friend contains gluten, I always refuse to eat it. - I suspect my food has been contaminated with gluten, I will raise this with the restaurant staff.

Table 19: Constructs measured by the LWWCD-27 measure

Scale	*Construct Measured*
Total scale *(27 items)*	Overall psychological and social adaptation to the CD diagnosis and to GFD self-management. Higher scores on this scale indicate better overall psychosocial adaptation to CD.
Concerns and Losses *(16 items)*	Worries, perceived losses and restrictions related to CD. Higher scores on this subscale indicate lower levels of concern and sense of loss related to CD (so indicate positive adaptation to CD).
Positive changes *(7 items)*	Experiences of positive psychosocial changes related to CD. . Higher scores on this subscale indicate greater perception of positive changes related to CD.
Risk management *(4 items)*	Impacts of negative psychosocial factors on risk-taking while self-managing the GFD. Higher scores on this subscale indicate greater levels of constructive and adaptive risk-management of the GFD.

4.5.3.5. Construct validity testing

4.5.3.5.1. Convergent validity

The LWWCD-27 was correlated with measures of similar constructs (Table 13). The resulting Spearman's correlations are presented in Table 20 and are interpreted as weak (r = <0.35), moderate (r = 0.36-0.67), or strong (r = >0.68) (Doubova et al., 2020).

All LWWCD-27 subscales yielded significant correlations, as predicted, with the health anxiety measure (HAI). However, the association with the LWWCD-27

Positive Changes subscale was weak (-.265, *p*<.01), and the association with the *Risk management* subscale was very weak (.092, *p*<.05). The measure of Social Anxiety (BFNES) demonstrated significant correlations, as predicted, with all LWWCD-27 scales, though again, associations with the *Positive Changes* and *Risk management* subscales were weak. The LWWCD-27 correlated as predicted with the measure of *perceived illness consequences* (IPQ-R Consequences). Similarly, All LWWCD-27 scales showed the predicted associations with perceived *personal control* (IPQ-R), though these associations were weak. All scales measuring quality of life (CDQoL subscales) were associated with all LWWCD-27 scales, as predicted. Associations between the LWWCD-27 *Concerns and Losses* scale and three CDQoL scales (*Dysphoria, Limitations* and *Health Concerns*) were strong. Similarly, the LWWCD *Total* scale showed strong associations with the CDQoL *Dysphoria* and *Limitations* subscales. All LWWCD-27 subscales showed moderate-strong positive correlations to the LWWCD-27 total scale score, as expected. All LWWCD-27 subscales were associated with each other, though associations with the *Risk management* subscale were relatively weak.

Overall, the LWWCD-27 measure demonstrated the expected associations with measures of similar constructs, particularly with the measure of CD-related quality of life. Notably, the associations of convergent measures with the LWWCD-27 *Risk management* subscale were weak, suggesting that this subscale measures a quite distinct construct (namely, psychosocial influences on risk management).

Table 20: Results of tests of convergent validity

	M	SD`	LWWCD (*Positive*)	LWWCD (*Concerns*)	LWWCD (*Risk*)	LWWCD (*Total*)
Health Anxiety Inventory (HAI)	13.6	7.06	-.265**	-.508**	.092*	-.465**
Brief Fear of Negative Evaluation Scale (BFNES)	20.7	9.8	-.261**	-.449**	-.311**	-.449**
Illness Perception Questionnaire (*Consequences*)	21.7	4.4	-.338**	-.676 **[a]	*-.073*	-.613**
Illness Perception Questionnaire (*Personal Control*)	25.5	3.9	.269**	.211**	.220**	.282**
Celiac Disease Quality of Life Scale (CDQoL) (Limitations)	57.1	24.9	.484**	.853**	.155**	.805**
CDQoL (Dysphoria)	83.2	19.8	.416**	.701**[b]	.241**	.683** [a]
CDQoL (*Health Concerns*)	55.0	26.3	.262**	.695**	.147**	.606**
CDQoL (*Inadequate Treatment*)	74.6	28.0	.365**	.493**	.207**	.539**
LWWCD-27 (*Positive Changes*)	29.2	6.9	*1.00*	.475**	.243**	.709**
LWWCD-27 (*Concerns and Losses*)	51.7	15.8	.475**	*1.00*	.255*	.927**
LWWCD-27 (*Risk management*)	19.3	4.7	.243**	.255**	*1.00*	.447**
LWWCD-27 (Total scale)	100.2	21.9	.709**	.927**	.447*	*1.00*

Table 20 presents correlations using Spearman's *r* * significant at <.05; significant at <.001;
Correlation strengths (Doubova et al., 2020): (r = <0.35), moderate (r = 0.36-0.67), or strong (r = >0.68);
[a] upper threshold of *moderate* association; [b] close to the lower threshold of a *strong* association

4.5.3.5.2. Divergent validity

The divergent validity of the LWWCD-27 was tested by comparing the scores of participant groups predicted as likely to significantly differ in psychosocial adaptation to CD. Table 21 presents the comparison of the LWWCD-27 scores by age group. As predicted, younger people scored lower across the measure than older people. This was confirmed by a Kruskall-Wallis H test showing statistically significant differences by age group on the *Total* scale (H=44.72, *p*<.001), the *Concerns and Losses* subscale (*H*= 42.790, *p*<.001*),* and the *Risk management* subscale (H = 56.988, *p*<.001*)*. Mean scores on the *Positive changes* subscales varied less between age groups, though the Kruskall-Wallis H test confirmed that these differences approached statistical significance (*H* = 5.903*, p*=*.052*).

Table 21: Comparison of LWWCD-27 scale scores by age group

LWWCD-27 scales	*Ages groups (years)*			
	≤ 30 (n=83) mean (SD)	31 – 49 (n=99) mean (SD)	≥ 50 (n=169) mean (SD)	
Total scale (27 items)	88.29 (21.28)	96.88 (20.16)	108.00 (20.07)	*p*<.001
Concerns and Losses	43.87 (14.66)	49.33 (14.40)	57.01 (15.30)	*p*<.001
Positive changes	28.45 (7.11)	28.32 (6.69)	30.11 (6.90)	n.s
Risk Management	15.98 (5.25)	19.22 (4.38)	20.88 (3.62)	*p<.001*

Tests of difference between scores: Kruskall-Wallis H test.

The researcher predicted that women would score lower than men on the LWWCD-27 *Concerns and Losses* and *Total* scale. A Mann-Whitney *U* test confirmed that, as predicted, women scored significantly worse than men on both the *Total* scale (*U* = 64778.5, *p*<.001) and the *Concerns and Losses* subscale (*U* = 6459.0, *p*<.001). The researcher predicted there would be no difference between the scores of men and women on the *Risk management* or *Positives changes* subscale. Accordingly, no significant difference was found on the *Risk management* subscale. However, women scored significantly worse on the *Positive changes* subscale (*U* = 7598.50, *p*<.05), suggesting that women perceive significantly less positive change than men following their CD diagnosis (Table 22).

Table 22: Comparisons of the LWWCD-27 scores by gender groups, and by time since diagnosis.

LWWCD-27 scales	*Gender*			*Time since diagnosis (years)*		
	Male (n=64) mean (SD)	Female (n=285) mean (SD)	*p*	≤ 2 (n=88) mean (SD)	*> 10 (n=93)* mean (SD)	*p*
Total	109.47 (21.62)	98.10 (21.36)	*p<.001*	93.66 (20.35)	109.58 (20.83)	*p<.001*
Concerns and Losses	58.52 (16.63)	50.21 (15.21)	*p*<.001	46.99 (15.01)	58.25 (15.47)	*p<.001*
Positive changes	30.89 (6.46)	28.80 (6.96)	*p*<.05	28.81 (6.88)	31.11 (6.35)	*p<.05*
Risk Management	20.06 (4.20)	19.09 (4.78)	n.s.	17.86 (4.83)	20.23 (4.28)	p<.001

Comparisons used a Mann-Whitney *U* test.

Finally, the researcher predicted that people diagnosed ≤ two years ago would have significantly lower scores on all LWWCD-27 scales than those diagnosed for a substantially longer period (> 10 years ago). Mann Whitney *U* tests confirmed these predicted differences: *total* scale (*U* = 2394.00, *p<.001*), *Concerns and Losses* subscale (*U* = 2427, *p<.001*), *Positive changes* (*U* =

3347.00, *p*<.05), and *Risk management* (*U = 2815.00, p<.001*) (Table 22). Overall, the LWWCD-27 demonstrated strong divergent validity by detecting the predicted differences between known groups.

4.5.3.5.3. Test-retest reliability

Over one-third of the sample completed a retest at two weeks and one quarter at six weeks. Statistical tests confirmed no significant differences in the demographic profile of the group that completed retests at either interval compared to the group at baseline[21].

Calculation of the intraclass correlation coefficient (ICC) assessed the relationship between baseline and retest scores (Table 23). This method is widely used in test-retest analyses (Koo & Li, 2016) and is suitable with non-parametric datasets (Mehta et al., 2018). All LWWCD-27 scales yielded correlations >.90 at both retest intervals indicating excellent test-retest reliability (Koo & Li, 2016)[22].

Table 23. Test-retest reliability of the LWWCD-27

Scale	*M (SD) Baseline N = 352*	*M (SD) Two weeks n=122*	*M (SD) Six weeks n=86*	*Two weeks*	*Six weeks*
Concerns and Losses	51.80 (15.86)	54.7 (16.3)	55.58 (17.5)	.939*	.950*
Positive Changes	29.15 (7.02)	29.4 (6.9)	31.0 (7.1)	.938*	.923*
Risk management	19.25 (4.68)	19.04 (5.15)	19.71 (5.3)	.950*	.943*
Total score	100.21 (21.87)	103.21 (23.21)	106.26 (25.0)	.955*	.956

*p<.001

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[21] Chi-square tests for binary categorical variables; Mann-Whitney test for the continuous variable (‘age’).

[22] Strength of ICC correlation (Koo & Li, 2016): <0.5 *poor* reliability; 0.5-0.75 *moderate* reliability; 0.75-0.9 *good* reliability; >0.90 *excellent* reliability

4.5.4. Discussion

4.5.4.1. Strengths and utility of the new LWWCD-27 measure

The LWWCD-27 demonstrates sufficient psychometric strength to be used, as intended, as an outcome measure in the researcher's intervention feasibility study (Study Three, Chapter Six). The measure may also be useful to practitioners assessing a person's adaptation to the psychological and social challenges related to CD. The strong correlation of the LWWCD-27 with established CD-related quality of life, health anxiety and social anxiety measures suggests that the LWWCD-27 could indicate where supportive patient counselling is needed to support people in adapting to CD. Unlike the CD-QoL and CDAQ, the LWWCD-27 only focuses on psychosocial items and includes no items relating to physical symptoms, comorbidities, fatigue, or treatment adherence. This increases the focus of both participants and those interpreting the results on psychosocial aspects of adaptation to CD and can support appropriately tailored intervention. Finally, at 27-items, the measure is comparatively short, and this, combined with a mix of positive and negative wording, may increase the likelihood that respondents will complete the measure. The relative brevity of the LWWCD-27 also makes it appropriate for busy practitioners (e.g. GPs, nurses, dieticians) who need to make a quick needs assessment.

Those living with CD are particularly affected by worries and difficulties relating to health and social interaction. The LWWCD-27 correlates strongly with measures of both social anxiety and health anxiety, and so it is likely to be sensitive enough to detect elevated psychological distress in people living with

CD, perhaps more so than generic measures (e.g. HADS). However, further research is be needed to confirm this hypothesis, comparing the performance of the CD-specific LWWCD-27 against a generic measure of mood.

At the outset of Study Two, the researcher conceptualised psychosocial distress in CD in four discrete areas: *social concerns, health concerns, losses,* and *illness burden.* PCA analysis merged items from these categories into a single dimension, which the researcher conceptualised as *Concerns and Losses.* This analysis suggests that CD-related psychosocial distress is a broader dimension than originally conceived, represented by the *Concerns and Losses* subscale.

A number of studies report positive responses to long-term illness and positive thoughts about a long-term condition may enhance people's coping strategies and increase their engagement with valued activities (section 4.1.2). Therefore, a scale including both positive and negative outcomes provides a realistic appraisal of psychosocial adaptation to CD. No existing CD-related psychosocial measure offers this balance, suggesting that the LWWCD-27 is a novel and useful addition to the increasing bank of existing CD-related psychosocial measures.

4.5.4.2. Limitations

Study Two provided a preliminary validation of the LWWCD-27. The measure now requires further analysis, including a Confirmatory Factor Analysis (CFA) on a new sample of adults living with CD to confirm the internal structure and construct validity of the measure. This was beyond the time available for the current study.

A limitation of the current study was the relatively small number of male participants. This gender disparity is frequently found in research in CD, and may reflect the fact that women are diagnosed with CD 1.5 times more frequently than men (Singh et al. 2018). Women may also be more likely to engaging in help-seeking behaviours than men (Juvrud & Rennels, 2017), and so may have been more likely than men to engage with the channels supporting people living with CD (e.g. Coeliac UK, support groups, social media group) used to recruit in this study. Ethnicity data was not collected in Study 2 which was a further limitation to this study. These limitations may reduce the ability of the LWWCD to assess psychosocial adaptation to CD in males and in non-White British groups, and further development of the LWWCD should utilise more diverse participant samples.

4.5.5. Conclusion

Strong psychometric properties combined with its relative brevity support the use of the LWWCD-27 as an outcome measure for assessing psychosocial adaptation to CD in the intervention proof-of-concept study (Study Three, Chapter Six). Study Two has provided a thorough preliminary validation of the new measure, which can form the basis for future research confirming the performance and utility of the LWWCD-27.

CHAPTER FIVE: INTERVENTION DEVELOPMENT

5.1. Introduction

Chapters Two, Three and Four have presented evidence that CD and its management can lead to negative and enduring psychosocial impacts for a substantial number of people diagnosed with the condition and that post-diagnostic support is limited. Psychological intervention to support people living with a long-term condition self-manage their treatment and cope with the psychosocial impact are important areas of applied health psychology (Barley & Lawson, 2016). Therefore, the current researcher will apply health psychology research and other relevant information to develop a psychological intervention designed to support adults to live well with CD.

5.1.1. Aims and objectives

The current chapter aims to describe the development of a psychological intervention for people living with CD. The chapter has three objectives:

Objective 1) To present the research and rationale informing the development of the intervention.

Objective 2) To describe the intervention model.

Objective 3) To describe the development of the intervention content and delivery format.

5.2. Methods

5.2.1. Synthesis of existing research

Synthesis of the primary and secondary research conducted in the preceding chapters was undertaken to inform the intervention, specifically:

- to provide evidence of the need for intervention;
- to identify target areas for intervention;
- to define intervention outcomes and impacts.

5.2.2. Background research on suitable models

The researcher has previously undertaken introductory training and supervised the delivery of CBT in a physical health setting and so decided to investigate the use of CBT within the proposed intervention. The researcher reviewed the research literature and CBT textbooks to understand how CBT might be applied to support people living with CD, specifically considering:

- Would the CBT model be appropriate for this intervention?
- What content would be relevant to participants?
- What delivery format would be effective?

5.2.3. Expert consultation

Expert consultation is frequently undertaken in intervention design to ensure the fidelity and appropriateness of the chosen model and components (Hurley et al., 2016; Sainsbury, 2013; Spector et al., 2012; Walsh, 2018). The current study included expert consultation with the following objectives:

- To obtain constructive feedback on the appropriateness and relevance of the proposed intervention for the target group.

- To gather suggestions for suitable activities or approaches for inclusion in the programme.

The researcher undertook consultation with the following experts, who were professional and personal contacts of members of the research group:

- a nutritionist who has expertise in CD;
- a clinical psychologist with expertise in second and third-wave CBT;
- two experienced clinical psychologists with expertise in clinical health psychology and CD;
- one adult living with CD for >10 years with experience of providing support to others living with the condition;
- one adult living with CD >3 years.

All those consulted reviewed the draft intervention design and content. The current researcher conducted a private one-to-one interview with each expert and took contemporaneous notes on the discussions. She then reviewed the intervention design with her research supervisors, clinical psychologists with expertise in physical health interventions, to further refine the intervention content and materials. Results from the expert consultation are presented later in this chapter (Table 28).

5.2.4. Development of a Theory of Change (ToC)

The researcher constructed a conceptual intervention model using the ten-step Theory of Change (ToC) development guidance produced by New Philanthropy Capital (NPC) (Harries, Hodgson, & Noble, 2014), which was recently updated (NPC, 2021). The NPC ToC model is a generic programme planning methodology developed from theory-based evaluation practice (Ringhofer & Kohlweg, 2019). A ToC is a structured, sequential model in which an intervention is defined and systematically modelled in terms of its *inputs*, *targets*, *activities*, *change mechanisms* and *outcomes* (NPC 2021). ToC usefully separates short-term *outcomes* at the end of intervention from longer-term outcomes (or *impacts*) that result from sustained changes. Use of ToC encourages programme developers to outline the proposed direction of change through a logical sequence of components which move from input to activity to outcome (short term) to longer term impact. The NCP ToC extends the basic logic model by emphasising the importance of developing a programme from an initial *situation analysis*, as well as through involvement of *stakeholders* in the programme design. The model also encourages developers to consider the impact of their assumptions on the model, and to outline both the elements that will facilitate the programme, and any real or potential barriers.

As a general programme planning model, ToC is not specific to health psychology but has been used by organisations to develop mental health and well-being interventions in the public sector and not-for-profit programmes aimed at community empowerment. Examples where the NPC model has been used include in the development and piloting of interventions for people living with complex mental illness (Collom et al., 2019; Lloyd-Evans et al., 2017). Kooth Plc also developed a ToC to articulate the processes, change mechanisms and outcomes underpinning their web-based mental health services (Hanley, Sefi, Grauberg, Prescott, & Etchebarne 2021; XenZone & The University of Manchester, 2019). As well as facilitating development and evaluation, a ToC serves as a useful learning tool and is iteratively developed as programmes are tested and refined (Ringhofer & Kohlweg, 2019).

The NPC (2021) model maps closely onto the first stage of the four-stage Medical Research Council (MRC) Framework for Developing Complex Interventions (Craig et al., 2008). This is the MRC *Development* phase, in which intervention developers identify the evidence base (ideally through systematic review), develop or identify an underpinning theory, and model process and outcomes before undertaking a full evaluation to refine the design of both intervention and evaluation processes (Craig et al., 2008). The initial stage(s) of the MRC Framework has been used in the development of psychological interventions by authors including Walsh (2018) who developed an online positive psychological intervention for depression, and Wu (et al., 2017) in the development of an intervention for post-stroke fatigue. In the current study, I used the comparatively simple ToC, rather than adapting the MRC Framework, for several reasons. The current project aimed to design a community-based psychological intervention developed and delivered outside of clinical services and recruiting from the community rather than through healthcare staff. Therefore, using a model which has been designed to develop a wide range of interventions across settings seemed appropriate. Secondly, identifying assumptions, facilitators, and barriers is emphasised in the development of a ToC. This is important when considering the feasibility of rolling out an intervention that will be community-based and does not draw on clinical referral routes or similar resources. It has to work in a community setting and relies on the support of stakeholders. For example, the intervention must be acceptable to the Coeliac community and promoted through community-owned channels like Facebook groups and organisations like Coeliac UK. Thirdly, a ToC is relatively simple and pragmatic to develop, so is very easy to communicate to stakeholders and the public, but it still includes sufficient detail to ensure it is useful and identifies all the important model components (hence it maps onto the first stage of the MRC development framework). Finally, the complexity of the model can be developed iteratively, as the initial programme is tested for acceptability and feasibility. In the initial design phases and early testing, it is easy to review and refine a ToC. If the intervention was developed further and a comprehensive trial was feasible (e.g. an RCT), it may be useful to switch to a more complex programme development model designed for larger scale evaluations (e.g. the full MRC Framework).

The current chapter details how a complete ToC for the intervention was developed through this project. Table 24 maps the thesis project against the NPC's (2021) ToC guidance. The former guidance (Harries et al., 2014) was reconfigured in 2021 and is now usefully presented as a 10-step process (NPC, 2021).

Table 24: Development of the new intervention (current project) mapped against the NCP (2021) Theory of Change (ToC) process

NCP (2021) ToC process	*Objectives (current thesis)*	*Section of the current thesis*
Step 1: Situation analysis	Objective 1	QES findings (Chapter Two); Study One
Step 2: Target groups	Objective 1	QES findings (Chapter Two); Study One
Step 3: Impact	Objective 1-2	Table 26, Table 30
Step 4: Outcomes	Objectives 2-3	Table 26, Table 30, Figure 5 (p.158)
Step 5: Activities	Objectives 2-3	Table 30, Figure 5 (p.158)
Step 6: Change mechanisms	Objectives 2	Table 30.
Step 7: Sequencing	Objectives 2-3	Figure 4. (p.149)
Step 8: Theory of change diagram	Objectives 1-3	Figure 5 (p.158)
Step 9: Stakeholders, enabling factors	Objective 3	QES findings (Chapter Two); Study One, Tables 28-29
Step 10: Assumptions	Objective 3	Figure 5 (p.158)

5.3. Results

5.3.1. Identification of intervention targets, outcomes and impacts

Synthesis of research findings from Chapters Two and Three formed the *Situation Analysis.* This is the first step of the NPC ToC process in which intervention designers develop a thorough understanding of the issue they want to address, how the target group are affected, and what change is needed. The summaries below outline the implications of this work for the intervention design (Table 25).

Table 25. Synthesis of primary and secondary research and implications for intervention design

Aim (NPC guidance step)	*Method*	*Results*	*Implications for intervention content and format*
Situation analysis (1): *evidence of the problem, and potential solution.*	A qualitative meta-synthesis and interview study (Chapters Two and Three)	Identification of enduring negative psychosocial impacts spanning four key areas: social interaction, health concerns, illness-related burden, and loss.	Evidence of need for psychoeducational intervention post-diagnosis. Justification for intervention to focus on supporting people living with CD in areas of social interaction, health concerns, illness-related burden, and adjusting to loss and change.
Situation analysis (1): *evidence of the problem and potential solution*	A qualitative meta-synthesis and interview study (Chapters Two and Three)	Evidence of positive impacts resulting from diagnosis, including relief, empowerment through self-management, healthier lifestyle, enjoyment of new activities, and appreciation of social support. Evidence that positive changes support adjustment to CD.	The potential usefulness of some intervention focus on reflecting on positive changes post-diagnosis, and on developing engagement with positive activities.
Situation analysis (1): *evidence of the problem and potential solution*	A qualitative meta-synthesis and interview study (Chapters Two and Three)	Strong support from participants in Study One for the proposed intervention concept. Participants also expressed a desire for a face-to-face format enabling direct connection with peers. Peers were considered a useful, authoritative source of support. Low faith in the support provided by health professionals.	Evidence of need for intervention. Evidence that many people with CD would find a group format particularly supportive. Potential challenge for a facilitator without CD to gain trust and engagement in a group setting.

Identification of the target group (1, 2).	A qualitative meta-synthesis and interview study (Chapters Two and Three)	Evidence of sustained psychosocial impact that endures post-diagnosis. Evidence that there may be a heightened sense of relief post-diagnosis, and that awareness of the level of impact may be more strongly experienced once some time has passed.	Intervention may be particularly suitable for those diagnosed > 1 year. This allows time for confirmatory tests, dietetic counselling, basic dietary adjustment and experience of managing CD throughout the calendar of social events.
Other stakeholders and enabling factors (9)	A qualitative meta-synthesis and interview study (Chapters Two and Three)	The level of support and information received post-diagnosis varied. Though reported strict GFD maintenance is high, knowledge gaps about CD and GFD were evident, and participants received varying levels of support from people around them. Coeliac UK is a key source of information post-diagnosis. Evidence of the impact of family and the wider social circle on adaptation to CD. Evidence that living with others may increase interpersonal conflicts about food and increase the risk of contamination. Living alone may increase the financial and practical burden.	Intervention may require some refreshment of key information regarding CD and the GFD. Signposting to relevant services and sources of information may be appropriate. Intervention may focus on developing adaptive behaviours around social interaction, communication strategies and strategies to manage everyday tasks (e.g. shopping, cooking) which can become a source of stress for people with CD.

Situational analysis identified six target areas for intervention: *knowledge*, *anxiety*, *illness burden*, *adjustment*, *communication* and *isolation*. This situational analysis consisted of the evidence synthesis (Chapter Two) and primary research with people living with CD (Chapters Three and Four). Each intervention target is described below:

- *Knowledge:* Despite both secondary and primary research reporting high GFD maintenance rates, qualitative data (Chapter Three) found a subset of participants experiencing difficulty accessing reliable information about CD and demonstrated gaps in their knowledge about the GFD, CD and co-morbid conditions. Primary and secondary research found that people with CD often experience a lack of information and guidance from health professionals post-diagnosis. This issue is coupled with a sense of burden at undertaking copious research about the GFD and CD alone. Therefore, an intervention target was set to address residual gaps in essential knowledge about CD and the GFD and support people to access reliable and up-to-date information.
- *Anxiety:* Primary and secondary research (Chapters Two, Three and Four) identified that many people living with CD experience considerable anxiety relating to the condition. Anxiety often arises from social situations involving food and health-related anxieties about contamination and the impact of CD on health (e.g. nutritional deficits, fatigue, heightened risk of developing or managing co-morbid conditions). Therefore, an intervention target was set to enable people

living with CD to manage anxieties about the condition, particularly those relating to social and health concerns.

- *Illness burden:* Primary and secondary research (Chapters Two, Three and Four) identified that many people living with CD struggled to manage the sense of illness burden that everyday coping entailed. The research found that burden was linked to stress caused by increased demands on people living with CD. An intervention target was set to support people living with CD to manage the stress related to the practical and psychological burden experienced when managing CD and the GFD.
- *Adjustment:* Primary and secondary research (Chapters Two and Three) identified that people struggled with psychological adjustment to the diagnosis of CD. Problems with adjustment centred around the sense of changed identity following diagnosis (e.g. becoming a person with a long-term condition), altered lifestyles (e.g. accommodation of the GFD) and coping with loss (e.g. loss of certain foods and tastes, lost ability to eat spontaneously and without restriction). An intervention target was set to support people living with CD to manage difficulties in adjusting to changes in identity and lifestyle and to cope with loss.
- *Communication:* Primary and secondary research (Chapters Two, Three and Four) identified high rates of social anxiety and the increased difficulties faced by people living with CD in communicating their needs and having these needs accepted and accommodated by other people. Social difficulties permeated the full range of social interactions, from strangers and acquaintances to colleagues, friends and family. An

intervention target was set to support people living with CD to better manage communication difficulties.

- *Isolation:* Qualitative research found that participants felt a key strength of the intervention would be to enable people living with CD to interact with others managing the same condition, as they often feel isolated (Chapter Three). An intervention target was set to reduce participants' sense of CD-related isolation.

Table 26. Intervention targets, outcomes and impacts

Target	*Outcomes*	*Impact*
Knowledge: - gaps in essential knowledge about CD and the GFD. - failure to access reliable sources of information about CD.	1) essential knowledge about CD and the GFD. 2) ability to access information needed from reliable sources.	- increased knowledge about self-management of the GF, and sources of support.
Anxiety: - feelings of anxiety related to CD and the GFD.	3) awareness of how anxiety develops and is maintained. 4) self-management strategies to cope with anxiety in difficult situations.	- increased ability to manage anxiety related to CD. - decreased feelings of anxiety related to living with CD.
Illness burden: - high levels of stress related to the everyday burden of CD and the GFD.	5) awareness of how stress levels are escalated by external and internal demands. 6) psychological strategies to reduce levels of everyday stress.	- increased ability to manage CD-related stress. - decreased feelings of stress related to living with CD.

Adjustment: - difficulties with emotional adjustment to the CD diagnosis, and to associated losses and lifestyle changes.	7) validation of the range of emotional reactions experienced in response to CD. 8) understanding adjustment as a temporal process. 9) psychological strategies to support adjustment to change and loss.	- understanding of and ability to manage the emotional adjustment process related to CD.
Communication: - difficulties communicating with others about CD and the GFD.	10) understanding individual, social and cultural factors involved in difficult communication about CD. 11) development of flexible strategies for effective communication about CD.	- ability to effectively communicate about CD and the GFD. - decreased feelings of social anxiety related to living with CD.
Isolation: - experience of social and emotional isolation as a person living with CD.	12) direct connections with other people living with CD. 13) validation of everyday challenges in living with CD.	- social support through connection with the CD community.

Following the ToC guidance (NCP 2021), each intervention target was linked with relevant post-intervention *outcomes.* Achievement of these outcomes is linked with longer-term outcomes (*impacts*), enabling participants to live well with CD through an increased ability to self-manage the psychosocial impacts of their condition. Table 26 details the intervention targets and all related outcomes and impacts.

5.3.2. Choice of psychological intervention model(s)

5.3.2.1. First-wave and second-wave cognitive behavioural therapy (CBT):

CBT has developed in three consecutive and distinct ‘waves’ (Wills, 2014). First-wave CBT emerged in the 1950s and countered the dominant therapeutic model of psychoanalysis. CBT shifted psychologists’ focus away from historical and internal processes towards external behaviour and the influences of the environment. Behavioural psychologists including Watson, Pavlov and Skinner developed empirical methods of behavioural modification (Hayes, 2004; Pilgrim, 2011). Behavioural interventions had clear hypotheses, outcomes and mechanisms of change and interventions, like desensitisation through exposure, could be easily explained, taught, and their outcomes experimentally tested. Despite these benefits, first-wave interventions had limited clinical application and neglected the internal, cognitive processes which appeared important influencers of mood and behaviour (Beck, 1979; Pilgrim, 2011).

Beck developed the second-wave CBT therapy that emerged in the 1970s (Beck, 1979). CBT considered that psychological problems arose from internal cognitive behaviours applied inappropriately in certain situations (Beck, 1979). In CBT, individuals learn to recognise connections between thinking, emotions, and behaviour in different situations. When distressed, people learn to reassess and replace unhelpful thoughts and behaviours with adaptive substitutes, breaking unhelpful cognitive-behavioural cycles. Beck asserted that CBT could provide rapid, straightforward alleviation of psychological distress in many cases as individuals can “[…]*regard [themselves] as prone to learning erroneous, self-defeating notions and capable of unlearning or correcting them* *as well."* (Beck, 1979, p. 10). The CBT model is essentially non-pathologizing as psychological distress arises from natural, useful processes applied inappropriately, and recovery happens when the individual re-applies the same processes differently. The unhelpful thinking styles identified in therapy are universally experienced, and CBT therapists commonly position themselves as working with the client in a collaborative partnership where they discover cognitive distortions and alternative replacement thoughts together (Wills, 2014).

5.3.2.2. Use of second-wave CBT in mental and physical health interventions

CBT became a dominant therapeutic paradigm and is widely used in individual, group, telephone-based and online formats (Wills, 2014). The CBT model has crossed into other disciplines, including social work and coaching (Pilgrim, 2011; Wills, 2014; Neenan, 2011). Empirical evaluation of CBT outcomes is the focus of the majority of current research on psychological treatment efficacy (Fordham et al., 2021). A meta-analysis of second-wave CBT across mental and physical health conditions reported strong evidence that CBT achieves consistent modest-level improvements in anxiety, pain, HRQoL and, less consistently, in depression (Fordham et al., 2021).

5.3.2.3. Development of third-wave CBT

Since 2000, several new CBT therapies have developed, which Wills (2014) terms the *'mindfulness and acceptance wave'*. Third-wave therapies are characterised by the different approaches they take towards unhelpful thinking patterns. Rather than seeking to change thoughts, third-wave interventions focus on *acceptance, compassion* or *mindful awareness* of thoughts. Third-wave therapies include acceptance and commitment therapy (ACT), compassion-focussed therapy (CFT), and mindfulness-based cognitive therapy (MBCT). ACT, developed by Hayes (Hayes, 2004; Hayes, Stroshal, & Wilson., 1999), has become particularly influential. The ACT model developed from a language-based theory of learning (Relational Frame Theory) and the philosophical position of functional contextualism (Hayes, 2004). The centrality of language to learning leads people to over-identify with the reality of their thoughts, and this behaviour develops into the patterns of psychological inflexibility, which Hayes regards as the root of psychological distress (Hayes, 2004). ACT seeks to increase psychological flexibility through six processes – acceptance, defusion, present-focus, self-as-context, values and committed action. The first four processes relate broadly to *acceptance* and the latter two to *action* (Hayes, Levin, Plumb-Vilardaga, Vilatte, & Pistorello, 2013). By accepting internal thoughts and feelings, individuals reduce the need to maintain the behaviours (internal and external) developed to avoid these phenomena, such as behavioural avoidance, over-compliance, substance misuse, distraction, and inappropriate safety behaviours. Through committed, values-driven action, people are encouraged to re-focus their attention towards the rewarding behaviours that ultimately improve their quality of life (Hayes, 2004; Hayes et al., 2013). ACT is also essentially contextual, emphasising that psychological behaviour is idiosyncratic and arises in response to an individual’s context, including present and past experiences. Hayes criticises second-wave approaches for neglecting context and producing an abstract, mechanical view of human psychology that does not relate to individuals' complexity and holistic nature (Hayes, 2004).

5.3.2.4. Use of ACT in mental and physical health interventions

The utilization of ACT as an intervention in both mental health and physical health has risen rapidly in the last decade. Positive outcomes are reported for ACT interventions across many conditions, including chronic pain (Feliu-Soler et al., 2018), cardiovascular disease (Rashidi et al., 2021), diabetes (Rashidi et al., 2021), insomnia (Salari et al., 2020), and substance-misuse (Osaji, Ojimba, & Ahmed, 2020). Meta-analyses report ACT as significantly more effective than no treatment or treatment as usual in improving outcomes in depression (Bai, Luo, Zhang, Wu, & Chi, 2020; Coto-Lesmes, Fernandez-Rodriguez, & Gonzalez-Fernandez., 2020) and anxiety (Coto-Lesmes et al., 2020). Meta-analysis suggests that ACT is effective for those with mild, but not moderate-severe, levels of depression (Bai et al., 2020), and effects across conditions often decrease in size over time (Bai et al., 2020; Coto-Lesmes et al., 2020). Studies comparing ACT's efficacy against controls utilising CBT report that outcomes for the two interventions are generally equivalent (Collard, 2019; Coto-Lesmes et al., 2020). Methodological issues such as small samples, missing outcomes data and poorly reported sampling practices reduce the quality of many ACT intervention studies (Bai et al., 2020). Additional meta-analyses are needed to ascertain the effectiveness of ACT with specific populations, conditions and levels of distress.

5.3.2.5. Hybrid CBT-ACT interventions

CBT and ACT have different philosophical and theoretical roots, these being realism and behaviourism (CBT), and functional contextualism, and relational frame theory (ACT) (Beck, 1979; Collard, 2019; Hallis, Cameli, Dionne, & Knauper., 2016; Hayes, 2004). Collard (2019) criticised Hayes for his reductionist presentation of CBT and neglect of the complexity of advanced CBT formulations to create a schism between the methods and position ACT as a distinct and more versatile intervention. However, later writings by Hayes (Hayes et al., 2013) and CBT trainers (Wills 2014) describe the third-wave as a development of second-wave CBT, which usefully advances and broadens, but does not reject, CBT methods. The approaches are united in pursuit of the end goal of reducing psychological distress by developing self-supporting, rather than self-defeating, behaviour.

Both CBT and ACT develop psychological flexibility (Collard, 2019), and studies comparing the two models generally report equivalent outcomes on measures of psychological flexibility, which show mixed effectiveness across studies (Barrett & Stewart, 2021; Coto-Lesmes et al., 2020). In both methods, individuals learn to respond flexibly to their thoughts and change their habitual response to internal phenomena. However, the two models certainly promote different responses – acceptance (ACT) or change or challenge (CBT). Collard (2019) writes that the different terminology used by CBT and ACT can obscure the similarities between models. For example, acceptance of thoughts once considered dangerous or unacceptable can be described as ‘cognitive restructuring’, albeit ACT takes the indirect approach of acceptance compared to the direct thought-challenges of CBT. Similarly, both ACT and CBT position experiential avoidance as central to the development of psychological distress, and use different means to reduce this, namely, using behavioural exposure and thought-challenges (CBT), or mindfulness (contact with the present) and acceptance (ACT) (Collard, 2019). In summary, despite clear differences, both models overlap in their end-goals and underpinning aim of restructuring cognitive responses to develop flexibility and usefulness.

Despite the overlaps between ACT and CBT, interventions usually use a single model. Combining the approaches may risk conveying mixed messages about how people should approach their unhelpful thoughts (Harrison, McCracken, Jones, Norton, & Moss-Morris, 2017), yet some hybrid CBT-ACT interventions have been developed (Table 27). Hybrid CBT-ACT interventions report good outcomes for participants suffering a range of health problems, including pain (Lunde & Nordhus, 2009; Margolies, 2020), rheumatoid disease and generalised osteoarthritis (Vriezekolk et al., 2013), and life-limiting conditions (Ramos, Hastings, Bosworth, & Fulton., 2018). Hybrid CBT-ACT approaches have achieved generally positive outcomes across a range of psychological measures (Table 27). However, a brief scoping review by the researcher found that existing studies published as full research papers are few, and the researcher only identified seven (Table 27). Further, these studies are heterogeneous in intervention and research design and frequently have small samples, making drawing strong conclusions about their format and outcomes difficult.

Authors have suggested that hybrid CBT-ACT models may have distinct benefits for those living with long-term conditions. Vriezekolk et al. (2013) suggest hybrid CBT-ACT interventions correspond with Brandtstädter's (2009) ‘dual process’ model in which dual-processes of tenacious goal pursuit and realistic goal adjustment are combined in response to ageing or health-related decline. This would suggest that hybrid interventions promoting both direct challenge and goal pursuit alongside the acceptance of limitations are a realistic approach to health challenges, correlating well with Brandtstädter's coping model. Harrison et al. (2017) suggest that delivering both CBT and ACT methods allow people freedom of choice in terms of the techniques they adopt. This is reasonable given the two approaches frequently achieve equivalent clinical outcomes. Vriezekolk et al., (2013) suggested that post-intervention decline may be reduced by increasing people’s repertoire of coping strategies and found outcomes from their hybrid CBT-ACT intervention were sustained at 12-month follow-up. The different clinical exercises and metaphors used in ACT, visual and experiential, and the structured diagrammatic formulations of CBT, may appeal to different personalities (Collard, 2019). Taking a different approach could also be an option for people who have experienced limited success with standard treatments, including standard CBT (Hallis et al., 2016). Third-wave approaches may be less stigmatizing, as they focus on awareness and acceptance of challenges rather than identifying ‘maladaptive’ thoughts (Marino, DePasquale, & Sirey., 2015). This final point is important, as mental health stigma has been found to reduce individuals’ willingness to accept mental health support (Schnyder, Panczak, Groth, & Schultze-Lutter, 2017).

Table 27. Hybrid CBT-ACT interventions identified from a brief scoping review

Authors	*Condition*	*Components*	*Sessions*	*Format*	*Outcomes (improved)*
Ramos *et al.* (2018)[1]	Palliative care	- Personal values; - Mindfulness; - Psychological flexibility	6-8	Weekly groups of 4-8 participants	- depression$^{\Delta}$ - anxiety$^{\Delta}$ - stress$^{\Delta}$ - psychological inflexibility$^{\Delta}$
Margolies (2020)	Insomnia and chronic pain	- sleep education - stimulus control - sleep restriction - cognitive defusion - self-as-context - present moment awareness - mindfulness - values-guided behavioural activation	6	Weekly group of 4 participants	- anxiety* - insomnia symptoms* - sleep efficiency* - pain catastrophizing* - pain acceptance* - beliefs about the relationship between pain and sleep*
Harrison et al. (2017)	Multiple sclerosis pain	- psychoeducation (pain models) - vicious cycles - rest and activity scheduling - values-based goals - Unhelpful thoughts - thought challenges - Cognitive defusion (distancing) - Contacting the present-moment - commitment to values-based goals (long-term)	8 chapters self-study manual; 3 hours telephone support	7 participants (home and telephone support)	3 out of 7 participants $^{\Delta}$ A battery of pain outcomes measures

Vriezekolk et al. (2013)	Rheumatic disease or generalised osteoarthritis.	- unspecified combination of CBT and ACT therapeutic content	19.5 hours over 16 weeks (embedded within multimodal programme)	Weekly groups	- Psychological distress* - illness acceptance** - role physical (SF-36)* - vitality (SF-36)** - mental health (SF-36)** *Effects sustained at 12-month follow-up*
Lunde & Nordhus (2009)	Chronic headache	- psychoeducation (pain) - values and goal-setting - Experiential avoidance and acceptance - Behavioural activation (physical exercise regime) - negative automatic thoughts (awareness) - cognitive defusion - Behaviour experiments/exposure - Mindfulness (contact with the present moment)	8 x 1.5 hour weekly sessions	1 (case study, individual therapy)	- **Pain quality**$^{\Delta}$ - Sleep outcomes$^{\Delta}$ - Willingness to engage in physical activities despite pain$^{\Delta}$ **Bold text –** improvement maintained at six-month follow-up
Marino et al. (2015)	An older adult with declining physical health and mobility.	- Psychoeducation - CBT model - CBT strategies (cognitive reframing, relaxation, distraction, social activation, pleasant activity scheduling) - mindfulness and acceptance	12 x 50 mins weekly sessions	1 (case study, individual therapy)	- depression$^{\Delta}$ - quality of life$^{\Delta}$ *Effects sustained at 3-month follow-up*

Strandskov et al. (2017)	Eating disorders	- psychoeducation - control - experiential avoidance - mindfulness - cognitive defusion - acceptance - behavioural activation - emotional regulation - values-work	8 weeks, internet-delivered. 8 modules. Weekly therapist assessment (approx. 15 mins). Brief contact as needed by internet chat or phone.	46 intervention 46 waitlist controls	- eating disorder symptoms (global score) *** - body dissatisfaction* Drop-out rates: 32.6% (intervention) vs. 8.7% (controls).

$^{\Delta}$ clinically significant improvement; *p<.05 ** p<.01 *** p<.001 [1] abstract only available

5.3.3. Choice of intervention format and delivery model.

Through discussion with research supervisors, both experienced clinical psychologists (RH and GL), the researcher decided to develop a hybrid CBT-ACT intervention for people living with CD. The researcher anticipated that the combination of approaches would enable participants to challenge unhelpful automatic thoughts and engage in self-management behaviours while also supporting them in accepting the inevitable and permanent changes and losses incurred by CD. This is in line with Brandtstädter's (2009) 'dual process' model, as discussed above (section 5.3.2.5).

A small group intervention format was chosen, partly in response to findings from research in which people living with CD desired supportive contact with peers (Tables 25-26). Small groups (≤10 participants) are the dominant intervention format in published research on both single-model and hybrid ACT interventions (Table 27; Bai et al., 2020; Coto-Lesmes et al., 2020). The number of sessions within a group intervention varies across studies, though between six and eight weekly sessions appear common (Table 27), with typical group sessions lasting between one and two hours. The current researcher designed a six-session course of weekly 2.5 hour sessions, including a refreshment break allowing participants to socialise (Figure 4, p.149). The intervention was designed with a modular structure to enable the researcher to separate components by topic and intervention method, avoiding potential confusion between models and allowing participants to process and learn the different approaches separately. Modular structures are common in protocols for ACT, CBT and hybrid CBT-ACT interventions (Brassington et al., 2016; Harrison et al., 2017; Sainsbury, 2013).

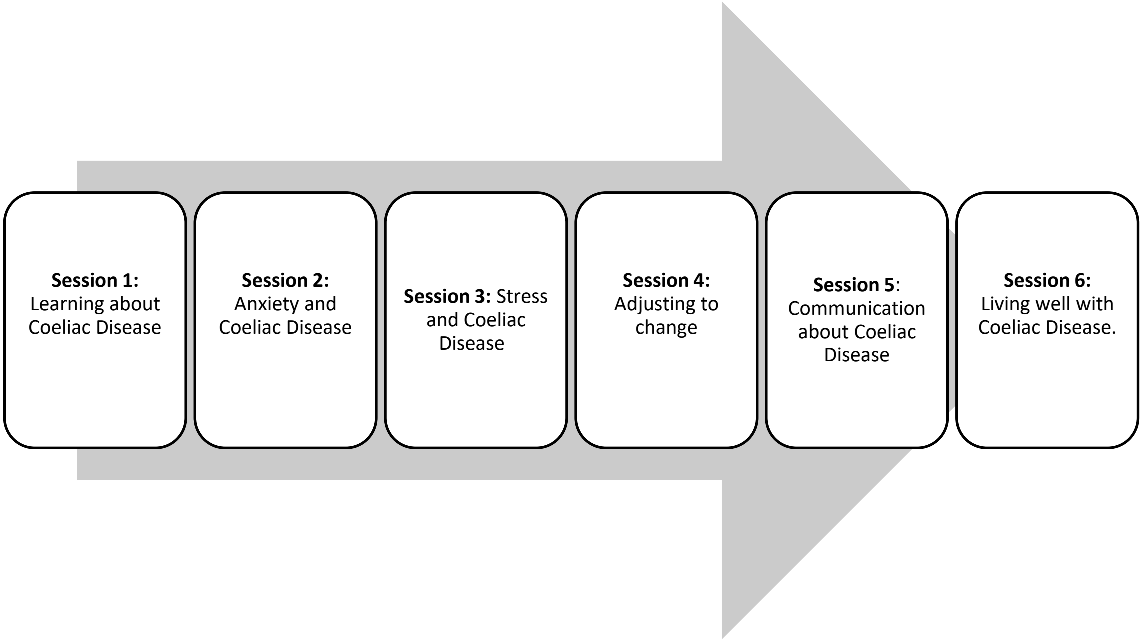

Figure 4. Six-session modular intervention format.

5.3.4. Expert consultation

Selected intervention activities fit into the six module themes detailed in Figure 4 (p.149). When combined, the modules addressed all six intervention targets and linked outcomes (Table 26). Activities were short (≤ 45 mins) and suitable for people with no previous experience of psychology. CBT and ACT activities were selected from key texts and published intervention protocols and chosen to fit with the aims of the intervention. The mix of activities aimed to provide opportunities for group interaction and individual reflection, appealing to different thinking and learning styles and maintaining engagement with the course materials. As well as drawing on the expertise of supervisors, the researcher attended training sessions on ACT and workshop teaching, hosted by the University of Birmingham, to develop her understanding and development of the sessions.

After drafting a set of materials and session plans, the current researcher conducted consultation sessions with relevant experts in CD (described above, section 5.2.3.). Table 28 and Table 29 outline key learning from the expert consultation and application of this to the intervention design.

5.3.5. Final intervention design

Figure 1 (p.13) illustrates how each research component in the project contributed to the final intervention design. This process ensured that the design was grounded in evidence of need drawn from both primary and secondary research with people living with CD. Following the expert consultation and review of the draft materials described above (section 5.3.4.), the researcher finalised the content and structure of the intervention. Appendix E (supplementary Table IX) lists the final set of activities and the worksheets and handout materials given to participants by each of the six modules (intervention sessions). Appendix F contains the facilitator's slides which were used to guide each session. The sessions followed this structure of content and materials, which ensured fidelity to the intervention model for each repeat of the intervention[23]. Table 30 specifies the specific change mechanisms and the psychological model relating to intervention activities.

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[23] The intervention ran twice during Study Three.

Table 28. Expert consultation on content relating to knowledge about CD and the GFD.

Findings from expert consultation	*Implication for intervention*
All experts: Knowledge levels will vary. Pre-course information and supplementary material will allow people to take what they need. Disagreement between *People with CD:* and the *Nutritionist* about the level of information required. *People with CD* wanted comprehensive information about CD and links to other conditions. The *Nutritionist* felt only information necessary for self-management was needed.	• Supplementary material on CD and GFD to be provided to participants in a folder, with a brief overview of what that contains given by the facilitator.
Nutritionist: All information on CD should come directly from Coeliac UK, currently a comprehensive and reliable source. *All experts:* The Coeliac UK website is full of information but can be hard to navigate and some people get bored and tired by looking through it.	• All information about CD and the GFD from the course is publicly available information from the Coeliac UK website.
Nutritionist: People with CD: may find the legal requirements for food labelling available from Food Standards Agency useful. Eatwell Plate is a good guide to ensuring diet remains balanced.	• Included both these resources in the participants' information folder.
All experts: The Internet is confusing and potentially distressing. Guidance and strategies for online information searching are needed.	• Short presentation on managing online information-seeking included in the intervention.
All experts:: There is a great variation in symptoms and response to the GFD, which can confuse people. Comparison of own symptoms with others can be unhelpful.	• An introductory presentation that emphasises the difference in symptom presentation in CD and that CD is incurable whatever symptom presentation occurs.
People with CD: Self-management is a learning process that takes time, patience and perseverance. *Top Tips* exercise useful and positive.	• The first session emphasises the 'learning curve' of CD and retains the *Top Tips* exercise.
Nutritionist: Those living with CD need to develop a GFD that suits their pre-existing tastes, cooking skills and lifestyle. Comparison with others (e.g. social media) can be unhelpful.	• Worksheet exercise (session one) emphasises the need to develop a GFD that suits personal needs.

Table 29. Expert consultation on the psychoeducational content of the intervention

Findings from expert consultation	*Implication for intervention*
People with CD: Anxiety and stress have been issues for both, and occasionally still are. *People with CD:* Both feel the CBT approach will be relevant and helpful. Feel it is important to take an experimental problem-solving approach to living with CD. *People with CD:* Hassle and stress are inevitable, so learning to accept and manage this is essential.	• Retaining emphasis on managing anxiety and stress relating to CD (two full sessions).
ClinPsy: If CBT is only covered in a few sessions, keep simple and focus on the link between thoughts, feelings and behaviours and the impact that challenging a negative thought can have.	• Retaining the simple problem-solving focussed introduction to CBT.
ClinPsy: Hybridised CBT-ACT: Important to acknowledge the philosophical differences between the two approaches but overlaps of techniques and direction. Hybrid intervention can be presented to clients in a way that is compatible and useful. Both are relevant to the idea of 'living well' – struggling less, doing more, feeling better.	• CBT and ACT content was kept to separate sessions and presented as alternative ways to approach thoughts. • CBT and ACT models were presented in simple language, using simple models and images (e.g. 'criss—cross model'; ACT metaphors) rather than more complex models (e.g. ACT Hexaflex, complex CBT formulations).
People with CD: Values, positive activities and goals are useful to remind people they are more than their CD. *People with CD:* Found the idea of values a motivating focus that could help people to bear the hassles they experience and move forwards.	• Retaining content on positive activities, values and committed actions to help people balance the challenges of CD with the rest of their lives.

ClinPsy: Values work: Take a 'light touch' as this can get quite emotional where people feel they have lost touch with important values. The compass metaphor is useful. *ClinPsy:* Values-driven actions that are small and frequent can have a greater impact than occasional leaps. Can provide great motivation to act. *ClinPsy:* Values: no rules about at what point in an intervention these are introduced, and can work as an initial practice or later on.	• Used a 'light touch' and focussed on the simple compass metaphor. Avoided 'life review' exercises, focussing instead on the idea of choosing one new values-driven action to work towards.
ClinPsy: Mindfulness can be a useful tool. Simple exercises include *Dropping anchor* and *Leaves on a stream*.	• Used the *Leaves on a stream* meditation. Deliberately avoided term 'mindfulness or meditation' presenting this exercise as a way of practising defusing from thoughts ('not getting tied up with them), as recommended by Harris (2019).
ClinPsy: Self-education resources are useful, as the intervention is brief, and encourage ongoing practice. Recommended books: *Happiness Trap* (Russ Harris, 2009), *ACTivate your Life* (Morris, Oliver, Hill), *Mind over Mood* (Padesky). Many good, free videos on *YouTube*.	• Included some of these resources as further reading (slideset, appendix F). Linked to relevant Youtube recording of the *Leaves on a stream meditation* (Inner Melbourne Clinical Psychology, 2016).
People with CD: Both volunteered to help (e.g. share stories, tips) if needed. A clinical psychologist was concerned that introducing a 'patient story' section would be time-consuming and distracting in a pilot intervention	• Decided not to include a 'patient story' section, but spent some time in each session allowing participants to share experiences and thoughts on living with CD. Also included are some reflections on the experiences of PLCD reported in the research literature, used to stimulate discussion.

ClinPsy = Clinical Psychologists

Table 30. Intervention model: activities, outcomes and change mechanisms

Activity	*Outcome*	*Change mechanism*	*Model*
- Review of relevant information about CD and the GFD.	- improved understanding of CD and GFD. Improved knowledge to support management of CD.	- Shaping knowledge through information and instruction	- Health Psychology behaviour change technique (Michie et al., 2008, 2011)
- Sign-posting to reputable information and support sources.	- access to further information and support. Improved knowledge to support self-management.	- Shaping knowledge through information and instruction	- Health Psychology behaviour change technique (Michie et al., 2008, 2011)
- Identification of personal learning needs and goal-setting exercise.	- Focus for self-management of the condition.	- Shaping knowledge through information and instruction - SMART goal-setting.	- Health Psychology behaviour change technique (Michie et al., 2008, 2011)
- Learning a CBT model of anxiety and negative automatic thoughts (NATs)	- awareness of how anxiety develops and is maintained.	- Psychoeducation	- CBT
- Challenging NATS	- self-management strategy to cope with anxiety in difficult situations.	- Cognitive-restructuring	- CBT
- Learning a psychological model of stress	- awareness of what stress is, and how levels are escalated by external and internal demands	- Psychoeducation	- CBT
- Diaphragmatic breathing exercise.	- psychological strategy to reduce levels of everyday stress.	- Physiological (behavioural) change	- CBT
- Pleasant activity scheduling	- psychological strategies to reduce levels of everyday stress.	- Behavioural change	- CBT

- Learning model of experiential acceptance	- awareness that a person can accept their thoughts and feelings without judgement	- Psychological flexibility (experiential acceptance)	- ACT
- Cognitive defusion exercises	- psychological strategies to reduce levels of everyday stress.	- Psychological flexibility (cognitive defusion)	- ACT
- Presentation and group discussion: application of the five stages of grief model (Kübler-Ross, 1970) to the CD diagnosis.	- validation of the range of emotional reactions experienced in response to CD. - understanding adjustment as a temporal process.	- Psychoeducation	- Health Psychology research (Rose & Howard, 2014)
- Values identification exercise	- understanding the role of values-driven action in adjustment to change.	- Psychological flexibility (values)	- ACT
- Commitment to values action exercise	- strategy to live well with CD through values-driven action	- Psychological flexibility (values)	- ACT
- Presentation and group discussion: communication with others about Coeliac Disease	- understanding individual, social and wider cultural factors in difficult communication about CD. - development of personal strategies for effective communication about CD.	- psychoeducation	- Health Psychology research (Rose & Howard, 2014, current thesis)
- Reviewing communication scenarios	- developing strategies for effective communication about CD.	- cognitive restructuring - cognitive empathy - helpful behaviours	- CBT
- Group work and group discussion on living with CD.	- connections with other people living with CD. - validation of everyday challenges in living with CD.	- peer support	- Health Psychology research (Rose & Howard, 2014, current thesis)

5.3.6. ToC diagram

A ToC diagram was developed for the intervention following NPC guidelines (2021) (Figure 5, p.158). The ToC provides a logic model showing the progression from *inputs* and core *activities* to *outcomes (short-term)* and *impacts* (longer-term outcomes). *Inputs* include the research detailed in previous chapters, participant recruitment processes, and materials for the course activities outlined in Table 30. The ToC also details *risks* and *assumptions* underpinning the intervention. ***Key risks*** identified included poor recruitment and drop-out rates, participants’ lack of understanding or disengagement from the course content, poor attendance and unwillingness to undertake ‘catch-up’ sessions or self-study if sessions were missed. The researcher aimed to mitigate these risks through a multisource recruitment strategy, undertaken over several months. Multiple course dates were set to maximise attendance. The researcher assessed participants suitability for the course before their enrolment through a pre-screening telephone interview (Appendix G contains the Pro-forma for the pre-screening interview). The course content was designed to be varied, simple and engaging with visual material and a mix of experiential and written exercises. Module one focused on developing knowledge about CD and the GFD and ensuring that participants understood the hypothetical relevance of psychology to CD before moving on to the core psychoeducational content. Throughout the modules, many generic activities and examples were tailored specifically to daily life with CD (e.g. drawing of cognitive-behavioural models in session two), and group discussions were focused on participants' everyday experiences with CD, again to underline potential relevance to CD.

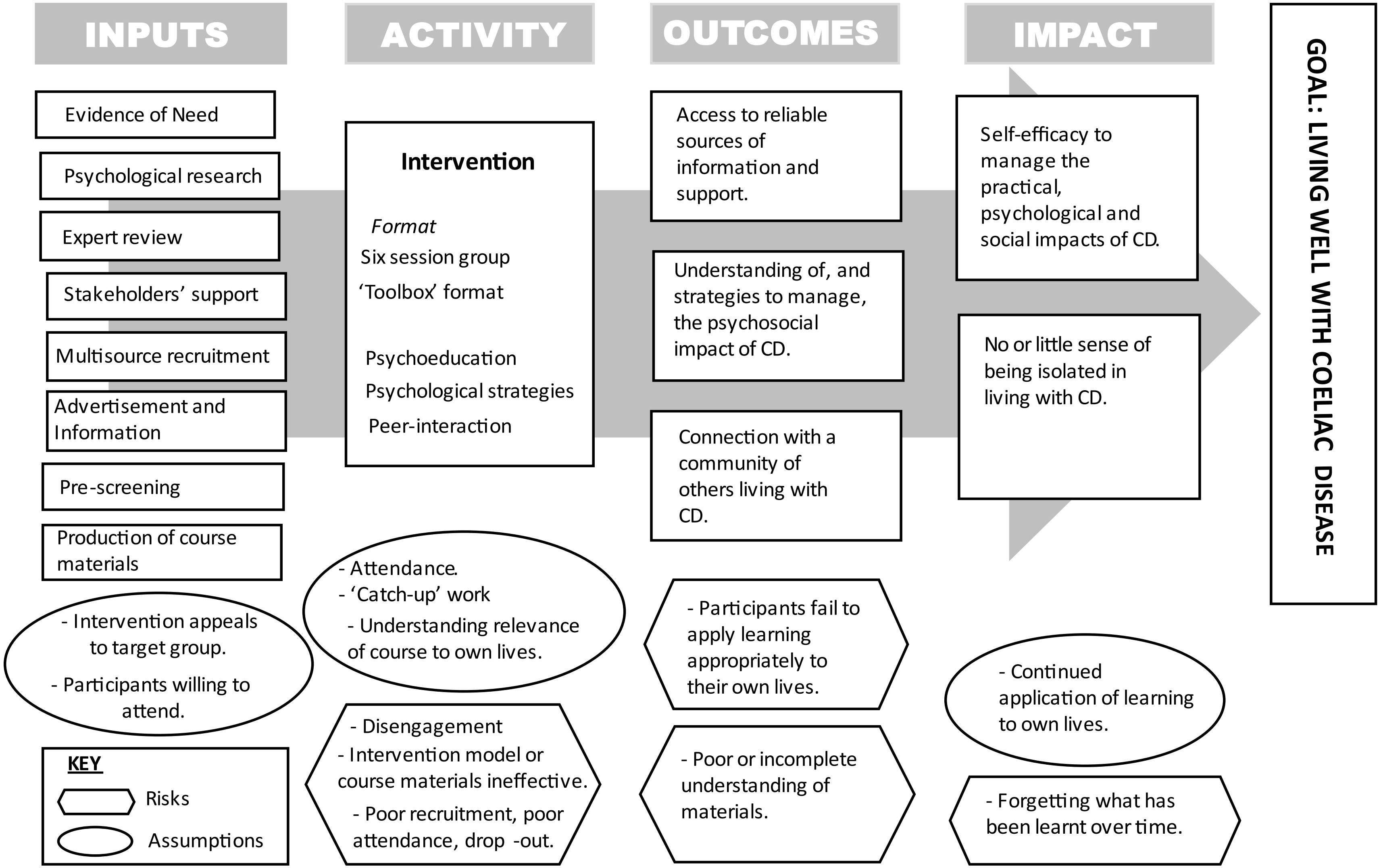
Key assumptions threatening longer-term impacts were the expectation that participants would continue applying learning from the course within their own lives and recall the course content sufficiently. The researcher attempted to mitigate this by producing a written folder of materials to act as a reminder of the modules.

5.4. Discussion

5.4.1. Impact of the design process on the intervention

The current chapter reports both the process through which the Living well with Coeliac Disease intervention model was designed and the structure and content of the final intervention. By following the ToC development model (Harries et al., 2014; NPC, 2021), the intervention was based on comprehensive situation analysis and evidence-gathering, which combined primary and secondary research on the psychosocial impacts of living with CD. The intervention model identified six clear targets: *knowledge*, *anxiety*, *illness burden*, *adjustment*, *communication* and *isolation*. The process of building the ToC ensured that each intervention target linked to specific activities, outcomes and impacts. The ToC also specified the hypothesised change mechanisms connecting activities to outcomes. The final ToC acknowledges the assumptions and risks implicit within the model, allowing the researcher, where possible, to mitigate these risks and assumptions within the intervention design.

Figure 5. Intervention Theory of Change (ToC)



5.4.2. Strengths and limitations

The ToC development process will support the evaluation of the efficacy of the intervention, as short and longer-term outcomes are clearly identified and are explicitly related to the six intervention targets. The process also ensured that the intervention is grounded in clearly evidenced needs within adults living with CD ≥ 1-year post-diagnosis. This grounding is important when applying generic psychological interventions to a population, as the specific factors contributing to psychological distress in one condition may be quite different to another. For example, discrete groups of individuals suffering from chronic headache, life-limiting conditions, and CD may all experience anxiety, but the causes may be very different (e.g. recurring pain, fear of decline or death, fear of dietary contamination). Understanding the target problems enables activities to be tailored specifically to real-life concerns and barriers. The ToC model encouraged consideration of the required inputs and the assumptions and risks implicit within the intervention design, enabling steps to ensure these factors do not undermine the successful implementation of the intervention. The ToC has broadly specified the change mechanisms by which activities lead to achieving the proposed outcomes. However, a limitation of the ToC model is the logical structure of discrete components which does not convey the likely overlap between elements of the model, though it is likely that, in reality, overlap exists between the six intervention targets, change mechanisms, and intervention outcomes. Similarly, the eclectic nature of the intervention increases the model's potential complexity, which is not conveyed in the current ToC. Despite this limitation, the current ToC conveys the intervention's core elements and key connections between its elements and outcomes. This creates a useful development tool and guide to evaluating outcomes of the proof-of-concept study (Study Three). Finally, a limitation of the design process that should be noted is that only two people living with CD were included in the expert consultation exercise, though professionals working with the Coeliac community were part of this process. This limited the researcher’s ability to review the acceptability and relevance of the planned intervention to the target population before this was tested on participants in the pilot intervention.

5.5. Conclusion

The current chapter has detailed the systematic and comprehensive conceptual development of an evidence-based hybrid intervention designed to support adults in living well with CD post-diagnosis. The ToC provides a logical model of the link between intervention activities and outcomes, which will be used to test the acceptability and feasibility of the intervention in the proof-of-concept study (Study Three) reported in Chapters Six and Seven of the thesis.

CHAPTER SIX: STUDY THREE. PROOF-OF-CONCEPT STUDY OF THE *LIVING WELL WITH COELIAC DISEASE* (LWWCD) INTERVENTION: QUANTITATIVE OUTCOMES

6.1. Introduction

Chapter Five described the development of the LWWCD Toolbox intervention. This was a community-based psychological intervention for people living with CD that ran twice in 2019 as a proof-of-concept pilot study. Chapter Six presents an analysis of quantitative outcome measures completed by participants who attended the intervention.

6.1.1. Aims and objectives

Key objectives of this chapter will be:

- To present participants' baseline demographic, health and psychological characteristics.
- To quantify end-of-intervention and longitudinal psychosocial outcomes by use of repeated measures.

These objectives will answer the following research questions:

- Does the LWWCD Toolbox intervention support participants' achievement of positive change?
- Are these positive changes sustained over time?

6.2. Methods

6.2.1. Design

The current study (Study Three) used a prospective, mixed-methods longitudinal design. This chapter reports on the quantitative outcomes only; Chapter Seven presents the qualitative outcomes.

6.2.2. Participant recruitment

Participants were recruited using purposive sampling and were eligible for the study if they met the criteria in Table 31. Coeliac UK forwarded a call-out for participants to its members. The researcher forwarded the call-out to people listed on the Coeliac Psychology research participant list[24]. Coeliac UK advised the researcher to issue a national call for participants. They anticipated some members would be willing to travel to participate and did not want to prevent this opportunity. The researcher also placed a short call for participants on her own social media pages (Twitter, Instagram) and an online Coeliac forum[25]. They also created a Facebook page promoting the study, the link to which was shared by approximately 40 other Facebook groups targeted either at adults living with CD (e.g. *Coeliacs on the Go* page) or at large community audiences. Advertisements on physical noticeboards and e-noticeboards were displayed around the campus.

People interested in taking part in the study were asked to express their interest by email or telephone, and the researcher provided further information about the intervention, including its purpose, eligibility criteria, and planned dates. Those still interested in taking part were asked to arrange a longer screening call with the researcher, who would further explore the suitability of the intervention for the person calling. The researcher completed a Pro-forma for

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[24] The University of Birmingham Coeliac Psychology Research Group hold a list of approximately 150 members of the public who have volunteered themselves as potential research participants. These people were recruited in previous University of Birmingham studies, at events, or contacted the University via the Coeliac Psychology research page. https://www.birmingham.ac.uk/research/perspective/coeliac-disease.aspx

[25] *The Coeliac, DH and Gluten Free Message Board* at https://members2.boardhost.com/glutenfree/

each person during this screening call (Appendix G) in order to ensure a consistent screening process and that records were maintained. Following the screening call, eligible people who felt they would like to participate were sent a link to an online information pack. At the end of this pack, readers wishing to participate completed an online consent form to confirm their eligibility for the study and confirm that they understood the participant information. Each time a consent form was completed, the researcher received an automatic email notification and sent those participants a pre-course information pack confirming session times, dates, venue and travel details. The pack also contained the researcher’s contact details, and participants were encouraged to contact them if they had any questions or concerns about the intervention before it began. Participants received no payment or gratuities for taking part, but received full reimbursement for travel costs (vehicle fuel or standard public transport fares).

6.2.3. Ethical clearance

Ethical approval was granted by the STEM Ethical Review Committee, University of Birmingham (Appendix A).

Table 31: Eligibility criteria for the LWWCD Toolbox intervention

- ≥ 18 years old;
- A self-reported medical diagnosis of CD (>1 year ago);
- Has ability in spoken and written English language such as will allow understanding of course materials;
- No serious cognitive or sensory impairment such as would prevent the ability to follow the course content or participate in activities;
- UK resident;
- Able and willing to attend face-to-face group sessions.

6.2.4. Intervention

The intervention ran for six consecutive weekly face-to-face sessions. Sessions were 2.5 hours long, including breaks with refreshments, and followed pre-written session plans. Chapter Five describes the design and development of the intervention.

6.2.5. Data collection

Quantitative data were collected using a questionnaire battery repeated at four time-points (Table 32), and the questionnaire set took around 20 minutes to complete. Pre-post questionnaires were completed on paper at the start of the first session (week 0) and the close of the final session (week 6). Participants completed the battery again online using the LimeSurvey platform at weeks 12 and 22, though they were able to complete longitudinal measures on paper if they preferred. The researcher entered an alphanumeric code onto questionnaires instead of participants' personal identification. Participants were given paper questionnaires in a personal pack with their code printed onto all papers and were emailed the code and instructed to enter this, rather than identifying information, onto online questionnaires. The researcher retained a list of codes linked to participants’ names for reference and stored this securely as a password-protected file. Quantitative data were collected at four time-points, but due to limited resources, qualitative data were only collected at two time-points (Table 32).

Table 32: Mixed-methods data collection schedule (Study Three)

Time (weeks)	**0 (baseline)**	**6 (end-of-intervention)**	**12 (Follow-up 1)**	**22 (Follow-up 2)**
Quantitative	✓	✓	✓	✓
Qualitative	-	✓	✓	-

6.2.6. Outcome measures

Quantitative outcomes data were gathered using seven self-report psychometric questionnaires (Table 33).

Table 33. Quantitative outcome measures (Study Three)

Psychometric tool	***Items***	***Attribute measured***	****Clinical cut-off point(s)***
DASS-21 (Lovibond & Lovibond, 1995)	21	Depression; Anxiety; Stress.	***Depression:*** *Mild* (10-13); *Moderate* (14-20); *Severe* (21-27); *Extremely Severe* (≥28). ***Anxiety:*** *Mild* (8-9); *Moderate* (10-14); *Severe* (15-19); *Extremely Severe* (≥20). ***Stress:*** *Mild* (15-18); *Moderate* (19-25); *Severe* (26-33); Extremely Severe (≥34). (Lovibond & Lovibond, 1995)
AAQ-II (Bond et al., 2011)	7	Psychological inflexibility	>25 (Bond et al., 2011)
AAQ-II (CD) (adapted by current researcher)	7	Psychological inflexibility (relative to CD)	None available
BIPQ (Broadbent et al., 2006)	9	Illness Representations: six cognitive representations *(consequences; timeline; identity; personal control; treatment control; coherence*) and, two emotional representations (*emotions; concerns*); and, *causal representations* (single item[26]).	None available
LWWCD-27 (current researcher)	27	Adaptive psychological and social behaviours towards CD Three subscales: - *Concerns and Losses* (16 items) - *Positive changes* (7 items) - *Risk-management* (4 items)	None available
ASES (Based on Senécal et al., 2000)	34	Self-efficacy in self-management of the GFD	None available
About your GFD (Ford et al., 2012)	6	General and situation-specific self-management of the GFD	None available

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[26] Not used in this study

6.2.6.1. Depression, Anxiety, Stress Scales (DASS-21) (Lovibond & Lovibond, 1995)

The DASS-21 consists of three subscales measuring symptoms of depression, anxiety, and stress. Items are scored on a 4-point Likert-type scale (0-3) where each item assesses a single mental or physiological symptom of psychological distress (e.g. *"I was aware of dryness of my mouth"* and *"I felt I was rather touchy").* Respondents indicated the level to which each item applied to themselves '*over the past week'*. The DASS-21 is a short version of the DASS-42 (Lovibond & Lovibond., 1995). Likert-scale scores on the DASS-21 are summed and then multiplied by 2 to enable direct comparison with scores on the DASS-42. Scores fall across five bands indicating levels of distress (*normal, mild, moderate, severe* and *extremely severe*) (Table 33), though the DASS-21 is not a diagnostic tool (Lovibond & Lovibond., 1995). Researchers have used the DASS-21 in studies of a range of mental and physical health conditions, including dermatology (Clarke, Thompson & Norman, 2020), HIV (Landstra, Ciarrochi, Deane, Hillman., 2013) and CD (Satherley et al., 2016). Henry and Crawford (2005) validated the DASS-21 on a large non-clinical general population sample in the UK (N = 1794). They found all scales demonstrated strong internal consistency (α = 0.82-0.90) and reported strong convergent and discriminant validity against the well-established Hospital Anxiety and Depression Scale[27]. Gloster, Walder, Levin, Twohig, & Kerekla (2020) validated the DASS-21 with 222 older adults (≥ 60 years) in the USA and reported strong convergent reliability against well-established measures of depression (BDI-II)

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[27] Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)

anxiety and stress (BAI)[28]. The depression and stress scales showed strong internal consistency (respectively, α = 0.87, α = 0.89). However, internal consistency was notably weaker for the anxiety subscale (α = 0.69), which the authors suggest may be due to the many somatic symptoms common in older adults. Overall, evidence suggests that the DASS-21 has strong psychometric properties and is suitable for use in many populations with physical health conditions, though the anxiety subscale should be interpreted with caution where respondents have somatic symptoms, such as those frequently reported in CD like fatigue and 'brain fog'.

6.2.6.2. Acceptance and Action Questionnaire (AAQ-II) (Bond et al., 2011)

The AAQ-II is a seven-item unidimensional measure of psychological inflexibility. Levin, Krafft, Pistorello, and Seeley (2019) define psychological inflexibility as *"the tendency to rigidly engage in behaviours based on internal experiences (e.g. avoiding unwanted thoughts or feelings, acting on urges or thoughts) at the expense of more effective or meaningful activities."* Psychological distress is associated with increased levels of psychological inflexibility. Therefore, psychological inflexibility is a key target for interventions using the ACT model (Bond et al., 2011; Levin et al., 2019). Items on the AAQ-II include *"I'm afraid of my feelings"* and *"My painful memories prevent me from having a fulfilling life."* Responses are given on a seven-point Likert-type scale on which respondents are asked to indicate the extent to which each item is '*true of you'*. No recall period is suggested, which is appropriate because 'psychological inflexibility' is considered a relatively stable behavioural pattern

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[28] Beck Depression Inventory (BDI-II); Beck Anxiety Inventory (BAI)

(Bond et al., 2013). The total scale score is derived from the summed item scores, and possible total scores range from 7 – 49, with higher scores demonstrating higher levels of psychological inflexibility. The AAQ-II is not a measure designed to diagnose mental health problems. However, Bond et al. (2011) used regression analysis to determine the AAQ-II score predictive of clinical levels of psychological distress indicated on other measures. Bond et al. (2011) reported that an AAQ-II score >25 predicted clinical levels of psychological distress on the General Health Questionnaire (GHQ) in two general public UK samples[29] and is the cut-off referenced in the current study (Table 33).

AAQ-II demonstrates strong internal reliability (α = .88) and convergent and predictive validity on measures of psychological symptoms (BDI, BAI, DASS-21) and thought suppression (WBSI[30]) (Bond et al., 2011). AAQ-II has been used in studies of long-term health conditions, including HIV (Landstra et al., 2013), multiple sclerosis (Bogosian, Hughes, Norton, Silber, & Moss-Morris., 2016) and inflammatory bowel disease (IBD) (Trindade, Ferreira, & Pinto-Gouveia., 2016).

6.2.6.3. AAQ-II-CD (Bond et al., 2011 - adapted by the current researcher).

To date, there is no measure of psychological inflexibility specific to CD, and Bond et al. (2011, 2013) suggest rewording the AAQ-II to apply to specific areas. Contextually sensitive wording is in line with ACT theory which views psychological inflexibility as relatively stable and influenced by people's changing values and demands in different contexts (Bond et al., 2013). For

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[29] Financial services workers

[30] White Bear Suppression Inventory (WBSI) Wegner and Zanakos (1994).

example, contextual factors in a group situation (e.g. an unfamiliar task, unfamiliar people) may cause a person to be overwhelmed by the thought of possible failure, and therefore anxious, in a way which they are not when at work. Validated context-specific versions of the AAQ-II include versions for students (Levin et al., 2019), Trichotillomania (hair-pulling disorder) (Houghton et al., 2014), chronic pain (Reneman et al., 2014) and cardiovascular disease (Spatola et al., 2014). A review of 28 context-specific AAQ and AAQ-II variants by Ong et al. (2019) reported that, overall, context-specific variants had greater ability to detect psychological inflexibility and intervention response. For example, Houghton et al. (2014) reported that AAQ-TTM (Trichotillomania) demonstrated stronger correlations with measures of distress related to hair-pulling severity than to measures of general anxiety (BAI) or general depression (BDI). No guidelines exist on the extent of the authors' rewording when developing AAQ-II variants, and the literature shows wide variation. For example, Reneman et al. (2014) only slightly modified generic items (e.g. *"I'm afraid of my feelings"* AAQ-II becomes *"I'm afraid of my pain"*). In contrast, Spatola et al. (2014) developed substantially original items for a variant AAQ-II (e.g. *"I eat things that are dangerous for my heart because the urge to eat them is overwhelming"*). Overall, both minimally and substantially differently worded variants have demonstrated good psychometric properties (Ong et al., 2019). Ong et al. (2019) suggest that minimal context-specific changes are most likely to succeed but concludes that further research is needed to determine this.

The current researcher created a CD-specific variant of the AAQ-II by slightly rewording all seven generic items. For example, *"It seems like most people are* *handling their lives better than I am."* was modified as *"It seems like most people with coeliac disease are handling their lives better than I am."*. This slight rewording followed the recommendation by Ong et al. (2019) and the type of rewording recommended for the BIPQ (section 6.2.6.4). Scaling and scoring remained the same as in the generic AAQ-II (section 6.2.6.2). It was beyond the scope of the current study to validate this variant before use, though the study served as an initial check of face validity and acceptability. The AAQ-CD was administered alongside the original AAQ-II to allow comparisons between results on the two measures, following recommendations by Bond et al. (2013) and Ong et al. (2019).

6.2.6.4. The Brief Illness Perception Questionnaire (BIPQ) (Broadbent, Petrie, Main, & Weinman., 2006)

The BIPQ is a measure of cognitive, emotional and causal illness perceptions. BIPQ is a short revision of the longer Illness Perception Questionnaire (IPQ-R). Eight single items assess eight types of illness perception. Six items assess cognitive illness representations (*consequences, timeline, personal control, treatment control, identity, coherence*) and two items assess emotional illness representations (*concern, emotions*). The final item is an open-ended causal question asking respondents to list in rank-order *"the three most important factors that you believe caused your illness".* Items are all similarly worded, for example *"How long do you think your illness will continue?"* (item 2, *timeline*), or *"How concerned are you about your illness?"* (item 6, *concern*). Authors of the BIPQ replaced the Likert-scale of the IPQ-R with a 0-10 point scale, as they felt this would increase the speed and ease with which the measure could be completed, particularly by those who were ill or with literacy problems

(Broadbent et al., 2006). Each scale is anchored at the 0 and 10 points with wording corresponding to each item. For example, item 7 (*How well do you understand your illness?*) is anchored at 0 with *"Don't understand at all"* and 10 with *"Understand very clearly"*. Higher scores represent increased strength in the illness perception assessed. Broadbent et al. (2006) state that, as with earlier IPQ versions, researchers may engage in minimal rewording by replacing the generic terms *illness* and *treatment* with condition-specific terms. In the current study, *'illness'* was replaced with *'Coeliac Disease',* and *'treatment'* was replaced with *'the gluten-free diet'*. For example, item 8 ("*How much does your illness affect you emotionally?"*) was reworded to *"How much does Coeliac Disease affect you emotionally?".* BIPQ shows concurrent, predictive and discriminant validity (Broadbent et al., 2006; Lochting et al., 2013) and one-week re-test reliability (Lochting et al., 2013), and a large meta-analysis, further confirmed the validity, reliability and sensitivity of the BIPQ (Broadbent et al., 2015).

6.2.6.5. Living Well with Coeliac Disease (LWWCD-27)

The LWWCD-27 is a 27 item measure assessing overall psychosocial adaptation to CD (total score) and has three subscales: *Concerns and Losses, Positive Changes* and *Risk management*. The *Concerns and Losses* subscale assesses CD-related social and health concerns and the sense of CD-related losses and burdens (e.g. *"I feel separated from those around me in social situations because of my diet"*). The *Positive changes* subscale assesses the extent to which people feel they are living well with CD (e.g. *"My lifestyle has changed in positive ways since my diagnosis*"). The *Risk management* subscale assesses psychological and social factors relating to GFD risk-management (e.g. *"Sometimes I take risks with foods that may contain gluten because I am tired or busy.").* Items are scored on a six-point Likert-type scale ranging from *Completely disagree* to *Completely agree*. Items are summed to create scale scores, and higher scores indicate increased psychosocial adaptation to CD. Items are split between negative wording (e.g. *"I find it difficult to trust the restaurant staff to prepare food safely for me."*) and positive wording (e.g. *"I am confident that my gluten-free diet provides me with all the nutrition and energy I need"*). This mix of wording helps to maintain and check respondents' engagement with the items, and emphasise that the measure assesses positive adaptive behaviours and attitudes. Chapter Four details the development and preliminary validation of the LWWCD-27. All three subscales demonstrated strong internal reliability (Cronbach's α ranged from 0.760 – 0.899). The LWWCD-27 demonstrated convergent reliability against measures of health anxiety[31], social anxiety[32], illness perceptions (*consequences; personal control; limitations*)[33], and CD-related quality of life[34]. The LWWCD demonstrated good discriminant validity in differentiating between known groups. All scales demonstrated excellent test-retest reliability (>0.9) at two-week and six-week test-retest intervals.

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[31] Health Anxiety Inventory (HAI) Salkovskis (et al., 2002).
[32] Brief Fear of Negative Evaluation Scale (BFNES-S) Rodebaugh (et al., 2004)
[33] Revised Illness Perception Questionnaire (IPQ-R) Moss-Morris (et al., 2002)
[34] Coeliac Disease Quality of Life Survey (CDQoL) Dorn (et al., 2010)

6.2.6.6. About your Gluten-Free Diet (Ford et al., 2012)

Self-efficacy in GFD self-management when faced with contextual barriers (e.g. when at home and away from home) and level of concern about accidental gluten-ingestion were assessed using a six-item measure developed by Ford, Howard, & Oyebode (2012). Items are rated on a five-point Likert-type scale worded to correspond to each item (e.g. Item 5: *"How concerned are you about accidental gluten-ingestion"* is rated on a scale from *"Extremely concerned"* to *"Not concerned at all."*). The measure was used with samples of adults living with CD in studies by Ford et al. (2012) and Satherley et al. (2016).

6.2.6.7. Adult Self-Efficacy (for the Gluten-Free Diet) Scale (ASES) (Based on Senécal et al., 2000)

ASES measures self-efficacy in GFD self-management across a range of everyday situations. A total of 34 items cover three key types of situations: 'temptations', 'negative moods' and 'uncontrollable situations'. Respondents indicate confidence in their ability to self-manage in each situation. Items include *"when I am watching television at home"* and *"when I am feeling annoyed or angry."* Items are rated on a 0-10 scale., anchored at 0 (*"Not confident at all"*), at 5 (*"Moderately confident"*), and at 10 (*"Totally confident"*). Summed scores are converted to a percentage of the maximum score[35]. Higher percentages indicate increased dietary self-efficacy. This measure was developed at the University of Birmingham (2011-2012) and is based on the model of dietary self-management by Senécal et al. (2000). In a large study (N=1578) of UK adults living with CD (Talbot, 2018), ASES had a high

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[35] Maximim score is 340 (ASES)

completion rate and showed significant correlations with measures of depression, anxiety and stress (DASS-21) and CD-related quality of life (CDQ).

6.2.7. Analysis

6.2.7.1. Reliable Change Index (RCI)

An underpowered sample (n=9) meant inferential statistics would be unreliable. A Reliable Change Index (RCI) (Jacobson & Truax, 1991) was used instead to compare scores from baseline to each subsequent time-point (so, weeks 0-6; 0-12; and 0-22). RCI is widely used in psychotherapy intervention studies (Flink, Smeets, Bergbom, & Peters, 2015; Harleston, 2014; Megson, 2014). Some authors have modified Jacobson and Truax's (1991) original method. However, these modifications have resulted in very similar outcome data, and the original method is still recommended (Morley & Dowzer, 2014). RCI answers two questions:

> 1: ***Is the change between scores a reliable estimate of change or the product of measurement error*?**
>
> 2*:* ***Is the change between scores (improvement or deterioration) of a magnitude indicative of clinical significance?*** Reliable and clinically significant change occurs if an outcome score moves across the clinical cut-off threshold *and* is reliable (i.e. satisfies question 1, above). The direction of change (improvement or deterioration) follows the psychometric structure of each measure.

RCI results are categorised as one of five outcomes (Table 34).

Table 34: RCI outcome categories

- Reliable and clinically significant improvement
- Reliable (not clinically significant) improvement
- No reliable change
- Reliable (not clinically significant) deterioration
- Reliable and clinically significant deterioration

The RCI is calculated using published reliability statistics and clinical cut-off points for the measures used in the study (supplementary Table X, Appendix G). The current analysis aggregates data from both runs of the LWWCD intervention to create a group score (N=9).

6.3. Results

6.3.1. Participants

In response to the call for participants, 98 people expressed interest in the study. These responses came from the following sources: Coeliac UK or University of Birmingham call-outs (39 responses); Social media (Facebook - 48 responses; Instagram - 6 responses; Twitter - 4 responses; Online chat forum - one response). All those who expressed interest were given further information about the course by email or telephone. Of the people who received this further information, 83 people did not wish to participate. Of these, 33 people gave no reason for not wishing to participate. Some 27 people reported that the distance was too far to travel. It should be noted that enquiries were made from all four UK nations and two outside of the UK (France and USA), with many of these people asking if they could participate in an online course or suggesting we run such a course in a wider range of locations. Other reasons given for not participating were: did not meet eligibility criteria (diagnosed <1 year - 5 people; < 18 years old – one person; no medical diagnosis of CD – one person); unavailable during the study period (seven people); did not feel they needed this level of support (four people); could not commit to at least five sessions (four people); could only attend if they could bring their child (one person).

A total of 14 people volunteered to participate in the study and provided written consent. The researcher forwarded all these people a welcome pack confirming venue, times and dates. Of those booked onto a course, three people did not attend the first session and provided the following reasons in retrospect: the distance was too far to travel (one person); the time commitment was too great (one person); worries about working with a group (one person). Two participants withdrew from the study after three sessions: one person explained this was due to managing difficult personal circumstances, the other person gave no reason for their withdrawal.

Table 35 provides the demographics of the nine participants who completed the course (n = 9). Appendix G presents the Normal Q-Q plots of both variables, which the researcher feels indicate a non-normal distribution, and suggests skew towards those aged ≥40 and diagnosed < 30 months (2.5 years) ago. However, Shapiro-Wilk tests of normality were non-significant, suggesting that the variables of age and time since diagnosis may be normally distributed (respectively, $W(9) = 0.902$, $p = .264$; $W(9) = 0.905$, $p = .288$), though the small sample (n=9) may have led to type II error and failed to detect the non-normality in the distribution (Ogunleye, Oyejola, & Obisesan., 2018). Table 36 presents participants' health and lifestyle information.

Table 35. Participants’ demographic information (Study Three)	
Variable	
Age (mean) years; (range)	48 years (20-63 years)
Gender (self-identified)	
Male	1
Female	8
Ethnicity	
White British	8
Asian / Asian British	1
Employment	
Full-time employment	3
Part-time employment	3
Full-time student	1
Full-time carer	1
Unable to work (ill-health)	1
Education	
Current postgraduate student	1
Degree	3
Current undergraduate student	1
Vocational qualifications	3
A/ AS-levels	1
Lives with	
Spouse/ partner (with children)	2
Spouse/ partner (without children)	2
Parents	2
House or flatmates	2
Lives alone	1

Table 36. Participants’ health and lifestyle information	
Variable	
Time (mean) diagnosed with CD; (range)	29 (13-60) months
Autoimmune conditions	
Thyroid disease	3
Sjogren’s syndrome	1
None	5

Other physical health conditions	
Asthma	1
Epilepsy	1
Irritable Bowel Syndrome (IBS)	1
None	0
Mental health conditions*	
Anxiety	2
None	7
Other dietary restrictions	
Lactose and/ dairy	2
Multiple food intolerances	2
Oats intolerance	1
Following a low sugar diet	1
None	3
First-degree relative with CD	
Yes	2
No	7
Current member of Coeliac UK	
Yes	8
No	1

* Self-reported that they are currently experiencing symptoms

6.3.2. Completion and attrition

All participants (n=11) completed a full set of baseline measures. Two participants did not complete the course (attrition = 19%) and were excluded from the analysis presented in this chapter. Some 81% of participants (n=9) completed an acceptable ‘dose’ (≥ four sessions). Just one session received full attendance, and the least well-attended session was session five (Table 37). Three absences were pre-agreed with the researcher (before participants were issued a timetable) as participants were attending weddings or holidays. One participant, who travelled by foot, reported that they had decided not to attend session five because of the severe weather that afternoon.

Table 37: Intervention session attendance (%)

Session number	*Attendance*
1 Learning about Coeliac Disease	8 (89%)
2 Anxieties about Coeliac Disease	9 (100%)
3 Stress and Coeliac Disease	7 (78%)
4 Adapting to Change	8 (89%)
5 Communicating about Coeliac Disease	4 (44%)
6 Living well with Coeliac Disease	8 (89%)

6.3.3. Quantitative outcomes

6.3.3.1. Symptoms of Depression, Anxiety and Stress (DASS-21 scales)

Table 38 presents longitudinal mean scores for the group (n = 9) for the three DASS-21 subscales, DASS-21-D (Depression), DASS-21-A (Anxiety), and DASS-21-S (Stress) across time-points. The RCI and clinically significant change indicator (CSC) are also presented in Table 38.

6.3.3.1.1. Symptoms of depression (DASS-21-D scores)

At baseline, the group's mean score of 12 fell into the DASS-21-D range *Mild,* indicating the group experienced mildly elevated depressive symptoms. At all three subsequent time-points, the DASS-21-D score had decreased and fallen into the *normal* score range. Despite this apparent improvement, the RCI indicated that the changes were not statistically significant and that no reliable or clinically significant change in the group's symptoms of depression had occurred since baseline.

6.3.3.1.2. Symptoms of anxiety (DASS-21-A scores)

At baseline, the group’s mean score of 10 fell into the DASS-21-A clinical score range *Moderate,* indicating that the group experienced moderately elevated anxiety symptoms. At all three subsequent time-points, the DASS-21-A score had decreased and fallen into the *normal* clinical score range. The greatest improvement was seen at six weeks, immediately following the final intervention session. Symptoms of anxiety increased slightly between weeks 6 and 12 and increased slightly again between weeks 12 and 22. RCI indicated that the changes observed at six weeks and 12 weeks were reliable and clinically significant improvements from the baseline DASS-21-A score. However, the RCI at 22 weeks was not statistically significant, and this confirmed that at 22 weeks, the group’s anxiety had not significantly improved from baseline. Overall, the results on DASS-21-A suggest that the substantial improvement in the group’s anxiety symptoms at week six did not sustain long-term.

Table 38. Group mean scores and RCI for DASS-21 subscales

	Baseline (0 weeks)		*End of course (6 weeks)*				*Follow-up (12 weeks)*				*Longitudinal (22 weeks)*			
	M (SD)	*Cut-off*	*M (SD)*	*Cut-off*	*RCI*	*CSC*	*M (SD)*	*Cut-off*	*RCI*	*CSC*	*M (SD)*	*Cut-off*	*RCI*	*CSC*
DASS-21-D	12 (8.67)	Mild	8 (5.33)	Normal	-1.14	No	7 (5.67)	Normal	-1.43	No	9 (9.23)	Normal	-0.86	No
DASS-21-A	10 (5.27)	Moderate	3 (3.32)	Normal	**-2.73****	**Yes**	5 (6.40)	Normal	**-1.95***	**Yes**	7 (5.20)	Normal	-1.17	No
DASS-21-S	21 (4.58)	Moderate	13 (3.89)	Normal	**-2.78****	**Yes**	9 (7.15)	Normal	**-4.17*****	Yes	13 (7.42)	Normal	**-2.78****	**Yes**

*Significant at p<.05; ** Significant at p<.01; *** Significant at p<.001; All one-tailed
RCI: Reliable change index statistic from baseline to time-point; CSC: RCI: Clinically significant change from baseline to time-point

6.3.3.1.3. Symptoms of stress (DASS-21-S scores)

At baseline, the group's mean score of 21 fell into the DASS-21-S clinical score range *Moderate,* indicating that the group was experiencing *moderate* symptoms of stress. At all three subsequent time-points, the group's DASS-21-S score decreased and fell into the normal range. RCI indicated that changes observed at all time-points were reliable and clinically significant improvements from the group's baseline DASS-21-S score. However, the score at 22 weeks is equivalent to the immediate post-course score (six weeks). This suggests that the group did not continue to improve over time and risk further deterioration (i.e. increased stress symptoms) if the trajectory of slight deterioration observed between weeks 12 and 22 continues.

6.3.3.2. Psychological inflexibility: general (AAQ-II) and CD-related (AAQ-II-CD)

Table 39 presents longitudinal scores and the RCI for the AAQ-II scale, which assesses the group's level of psychological inflexibility. Scores are also presented for the subgroup (n=4) scoring >25 on the AAQ-II, which is the cut-off score indicative of clinically significant levels of psychological distress (Bond et al., 2011). Table 39 also presents the AAQII-CD results, though the RCI could not be calculated for this measure as no normative or reliability data is available.

Table 39: Group mean scores and RCI for the AAQ-II and AAQ-II-CD

	Baseline (0 weeks)	*End of course (6 weeks)*		*Follow-up (12 weeks)*		*Longitudinal (22 weeks)*	
	M (SD)	M (SD)	RCI	M (SD)	RCI	M (SD)	RCI
AAQII: Whole group (n=9)	23.56 (8.13)	19.56 (7.80)	-0.86	20.44 (7.04)	-.0.67	22.67 (7.42)	-0.19
AAQII: Subgroup scoring >25 (n=4)	30.75 (3.86)	21.75 (10.94)	***-1.94****	22.75 (8.69)	-1.73	27.5 (7.05)	0.70
AAQII-Coeliac[a] Disease (n=9)	21.50 (9.86)	16.11 (7.80)	**-**	17.22 (7.33)	-	18.67 (9.30)	-

*Bold italicised: p=.05. *All one-tailed*
RCI: baseline to time-point;
[a] No RCI could be calculated for the AAQ-II-CD as this was an unvalidated measure.

6.3.3.2.1. General psychological inflexibility (AAQ-II scores)

The score at baseline was less than half of the maximum AAQ-II score, suggesting psychological inflexibility was not problematic for the group overall. The RCI indicated that no significant change compared to baseline occurred at any subsequent time-point. The subgroup (n=4) with higher psychological inflexibility at baseline scored substantially lower when the measure was repeated at six weeks, indicating decreased psychological inflexibility. This improvement reached the threshold of reliable change (RCI -1.94, p=0.05). Follow-up at weeks 12 and 22 showed deterioration (that psychological inflexibility had increased) and showed no reliable change from the baseline score. Overall, these results suggest that the course made no impact on psychological inflexibility for the group, and baseline scores suggest that this characteristic was not generally a problem for participants at baseline. For the four participants with greater levels of psychological inflexibility at baseline, post-course scores indicate that initial improvements in psychological flexibility were not sustained in the follow-up period.

6.3.3.2.2. Psychological inflexibility related to CD (AAQ-II-CD scores)

Mean AAQ-II-CD scores across all time-points were of a similar level to those on the AAQ-II (respectively, 16.5-21.5; 19.56-23.56). This indicates little difference in the group's general psychological inflexibility compared to psychological inflexibility specifically related to their CD. Scores for the AAQ-II-CD fluctuated by only a small magnitude across time-points (≤5 points), as was the case for AAQ-II scores (≤4 points) (Table 39). This suggests the group overall experienced no significant change in their levels of CD-related psychological inflexibility during the study.

6.3.3.3. Psychosocial adaptation to CD (LWWCD-27 scores)

Table 40 presents longitudinal group mean scores and RCI for the LWWCD-27 total scale and subscales (*Concerns and Losses*; *Positive Changes*; *Risk management*). This measure has undergone preliminary validation (Chapter Four), but no cut-off points have been estimated.

Table 40: Group mean scores for the LWWCD-27

	Baseline (0 weeks)	*End of course (6 weeks)*		*Follow-up (12 weeks)*		*Longitudinal (22 weeks)*	
	M (SD)	M (SD)	RCI	M (SD)	RCI	M (SD)	RCI
Concerns and Losses subscale	38.67 (10.07)	43.22 (7.29)	0.80	48.56 (12.42)	**1.75***	47.89 (10.04)	**1.63** [a]
Positive Changes subscale	28.22 (5.87)	29.33 (3.35)	0.46	28.89 (5.44)	0.28	28.67 (3.84)	0.19
Risk management subscale	20.78 (3.90)	22.00 (2.24)	0.75	22.33 (2.60)	0.95	22.89 (1.36)	1.30
Total LWWCD score	80.78 (13.28)	94.56 (6.77)	**2.09***	99.78 (17.80)	**2.89****	99.44 (13.66)	**2.84****

*Significant at p<.05; **Significant at p<.01; [a] p = .0518 *All one-tailed*
RCI: Reliable change index statistic from baseline to time-point;

6.3.3.3.1. LWWCD-27 total scale

At baseline, the group mean score (80.78) for the total scale fell within the second-lowest quartile of the score range (range 27-162)[36], suggesting that the group experienced some difficulties with psychosocial adaptation to CD. At six weeks, RCI analysis indicated a significant and reliable improvement in the group's score (RCI 2.09, p<.05). Follow-up measures at week 12 indicated that this improvement had further increased (RCI 2.89, p<.01) and sustained at week 22 (RCI 2.84, p<.01).

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[36] Quartiles (Q) for *Total LWWCD* scale: Q1 (27 – 61), Q2 (62 – 95), Q3 (96 – 128); Q4 (129 – 162)

6.3.3.3.2. Concerns and Losses subscale

At baseline, the group mean (38.67) fell within the second-lowest quartile (16-96)[37], suggesting concerns and losses related to CD were difficulties faced by the group. Though the group mean score had risen slightly at the end of the intervention (week 6), this was not of a magnitude indicating a reliable change from baseline. Follow-up at week 12 found further improvement in the group's score, and RCI analysis indicated that this was now a significant reliable improvement from baseline (RCI 1.75, p<.05). At week 22, the score had deteriorated and improvement from baseline only reached the threshold of statistical significance (RCI 1.63, *p*=.052).

6.3.3.3.3. Positive Changes subscale

At baseline, the group mean of 28.22 was at the threshold of the second-highest quartile of the possible score range (7 – 49)[38], suggesting that the group recognised positive changes relating to their diagnosis to a considerable extent before the course began. Scores were near-equivalent across all repeated measures, and RCI analysis confirmed that no reliable change from the baseline score had occurred at any time-point.

6.3.3.3.4. Risk Management subscale

At baseline, the group mean (20.78) fell within the highest quartile of the possible score range (7 – 24)[39] . This indicated that participants had adapted to the psychological and social factors influencing dietary risk management. Scores on the *Risk management* scale were near-equivalent across all

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[37] Quartiles (Q) for *Concern and Losses* scale: Q1 (16-36); Q2 (37-56); Q3 (57-76); Q4 (77-96).

[38] Quartiles (Q) for *Positive changes* scale: Q1 (7–18); Q2 (19–28); Q3 (29–39); Q4 (40–49).

[39] Quartiles (Q) for *Risk management* scale: Q1 (7–11); Q2 (12–16); Q3 (17–20); Q4 (21–24).

repeated measures, and RCI analysis confirmed that no reliable change from the baseline score occurred at any time-point.

6.3.3.4. Illness perceptions (BIPQ scores)

Table 41 presents longitudinal scores and the RCI for the eight BIPQ items[40]. The current researcher compared group baseline scores to baseline and cross-sectional scores reported in eight samples of adults with long-term physical health conditions (Broadbent et al., 2015). These comparisons were made to understand the potential differences and similarities in illness perceptions of those living with CD compared to those living with other conditions. Appendix G (supplementary Table XI) contains these comparative scores for samples living with Type 2 diabetes, Bipolar disorder, Gastro-oesophageal reflux disease (GORD), Systemic Lupus, Chronic kidney disease (CKD)[41], and Multiple chemical sensitivities.

6.3.3.4.1. Illness perceptions at baseline

At baseline, the group had a high score on the *Consequences* item*,* similar to scores reported in comparable studies. This indicates that CD, and other long-term conditions, are perceived to substantially impact everyday life for those affected. The group attained the maximum score (*'Forever'*) for *Timeline,* indicating that all participants correctly perceived CD as incurable. The group score for *treatment control* was also high, comparable to that reported in other long-term conditions, indicating that those living with CD felt that the prescribed treatment would be beneficial. As in other conditions, the score for *personal*

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[40] No cut off points have been published for this scale.

[41] All participants were pre-dialysis, and in full or part-time employment.

control was markedly lower than for *treatment control*, indicating that people with CD felt they had only moderate control over their CD. The group had a low score for *identity,* meaning they perceived themselves as experiencing relatively few symptoms from CD. Interestingly, this score was lower than in any of the comparable conditions. However, it was close to one Type II diabetes study, and this likely reflects the efficacy of the GFD in reducing symptoms and the high self-management reported by the group. The group had a high score for the *coherence* item, higher than in any comparison studies, and this indicates that the group perceived themselves to understand CD well. Despite their confident self-management, the high score for the *concerns* item indicated the group's ongoing concerns about the condition. Of the comparison scores, only one Type II diabetes sample scored higher for *concerns*, showing that the level of concern CD creates in people's lives is substantial. The group score for *emotions* was also relatively high (7.11) and one of the highest of the comparable datasets, demonstrating the emotional impact incurred by CD.

6.3.3.4.2. Illness perceptions post-intervention and at follow-up

RCI analysis indicated no reliable change from baseline in the group mean score at any subsequent time-point.

Table 41: Group mean scores and RCI for the BIPQ

	Baseline (0 weeks)	*End of course (6 weeks)*		*Follow-up (12 weeks)*		*Longitudinal (22 weeks)*	
	M (SD)	M (SD)	RCI	M (SD)	RCI	M (SD)	RCI
Item 1: *Consequences*	7.44 (0.88)	6.33 (2.40)	-0.81	7.00 (2.00)	-0.32	6.44 (2.2)	-0.73
Item 2: *Timeline (chronic)*	10.00 (0.00)	10.00 (0.00)	0.00	10.00 (0.00)	0.00	10.00 (0.00)	0.00
Item 3: *Personal control*	5.44 (2.83)	6.67 (2.12)	0.87	8.00 (1.22)	1.82	7.67 (1.32)	1.58
Item 4: *Treatment control*	7.44 (3.32)	8.44 (2.07)	0.83	9.11 (1.45)	1.38	7.78 (2.95)	0.28
Item 5: *Identity*	3.89 (2.32)	2.89 (1.62)	0.83	4.22 (3.46)	0.27	2.33 (1.41)	-1.29
Item 6: *Concern*	7.44 (2.30)	7.44 (2.96)	0	6.44 (2.70)	-0.67	6.78 (2.17)	-0.44
Item 7: *Coherence*	8.78 (1.39)	8.78 (1.56)	0	9.22 (0.83)	0.30	8.89 (1.05)	0.07
Item 8: *Emotional*	7.11 (2.20)	5.67 (1.58)	-0.78	5.33 (3.20)	-0.96	4.67 (1.87)	-1.32

RCI: Reliable change index statistic from baseline to time-point

6.3.3.5. Self-management of treatment (About your Gluten-free Diet questionnaire)

Table 42 presents longitudinal scores and RCI for the six items on the *About your Gluten-free Diet* questionnaire. Baseline scores (items 1– 4) were at the ceiling, with participants unanimously reporting strict GFD self-management both when at home and away from home, and these scores did not change at any subsequent time-point. Similarly, ceiling baseline scores for items 5 and 6 showed that the group was unanimously concerned about the health risks of accidental ingestion of and exposure to gluten. This level of concern did not change at any subsequent time-point.

Table 42: Group mean scores on the *About your Gluten-Free Diet* measure

	Baseline (0 weeks) M (SD)	*End of course (6 weeks)* M (SD)	*Follow-up (12 weeks)* M (SD)	*Longitudinal (22 weeks)* M (SD)
Item 1	1 (0.00)	1 (0.00)	1 (0.00)	1 (0.00)
Item 2:	1 (0.00)	1 (0.00)	1.1 (0.03)	1 (0.00)
Item 3:	1 (0.00)	1 (0.00)	1.1 (0.03)	1 (0.00)
Item 4:	1.44 (1.01)	1.33 (0.50)	1.56 (1.01)	1.22 (0.44)
Item 5:	1.67 (0.71)	1.78 (0.83)	1.56 (0.53)	1.67 (0.87)
Item 6:	1.78 (0.83)	1.78 (0.83)	1.78 (0.67)	1.78 (0.97)

1: In the last two weeks, how often have you knowingly eaten foods containing gluten while at home? [Never] – 5 [All the time].
2: In the last two weeks, how often have you knowingly eaten foods containing gluten while away from home? 1 [Never] – 5 [All the time].
3: How well do you stick to your gluten-free diet when you are at home? 1 [Extremely well] – 5 [Not at all]
4: How well do you stick to your gluten-free diet when you are away from home? 1 [Never] – 5 [All the time].
5: How concerned are you about accidental gluten-ingestion? 1 [Extremely concerned] – 5 [Not concerned at all]
6: How harmful do you feel accidental gluten-exposure is to your health? 1 [Extremely concerned] – 5 [Not concerned at all]

6.3.3.6. Self-efficacy in GFD self-management (*ASES)*

Scores on ASES indicated high self-efficacy at managing the GFD at baseline, which sustained across all time-points (93-95%) (Table 43). Of note is the decrease in participants completing all items on this measure at 12 and 22 weeks. This may have been due to boredom, fatigue or the change from completing the measure on paper in a group setting to completing the measure online in their own home.

Table 43: Group mean scores on the *Adult self-efficacy (Gluten-Free Diet) scale (ASES)*

Time-point	*N**	*Mean Score (SD)*	*Percentage self-efficacy*
Baseline	8	316.63 (34.23)	93.13%
6 weeks	8	322.25 (23.30)	94.78%
12 weeks	4	323.25 (32.18)	95.07%
22 weeks	3	323.00 (27.73)	95%

** Cases with > 2 items of missing questionnaire data were excluded from the analysis.*

6.4. Discussion

6.4.1. Acceptability, feasibility and fidelity

A self-selecting, non-clinical group of adults living with CD attended the LWWCD Toolbox intervention. Attrition was low (19%), with 81% of participants completing ≥ 4 sessions. This attrition and completion rate is comparable with rates reported across similar ACT and ACT-CBT group interventions. A review of 20 CBT intervention studies reported a pooled attrition rate of 15.9% (Carlbring, Andersson, Cuijpers, Riper, & Hedman-Lagerlof., 2018). Completion rates across a sample of group interventions are comparable (72.9%-87%) (Breitbart et al., 2015; McCracken et al., 2013; Merwin et al., 2021). Despite this, only one session achieved total attendance. Every participant who missed a session completed a substantial in-person or telephone ‘catch-up’ session with the researcher (45-60 mins), closely following the session plan, meaning that everyone who completed the course received the full set of materials. Nevertheless, incomplete attendance lowers the fidelity of an intervention designed as a weekly group experience (Rixon et al., 2016). Different participants receiving a different ‘dosage’ may also have affected outcomes. The intervention format was demanding for participants in terms of time (the course was delivered over 15 hours during weekends), travelling, and the inevitable emotional demands of joining an intervention group of strangers. From a review of systematic reviews, Sekhon, Cartwright, & Francis (2017) developed a theoretical framework of the acceptability of healthcare interventions. Opportunity costs were a key component of acceptance and were found to affect participation. That most participants missed one or more sessions may have reflected the high opportunity costs involved in attending the intervention. Developing ways to reduce opportunity costs may improve participation and outcomes.

6.4.2. Self-management outcomes

Participants in the current study self-reported both high dietary self-management and self-efficacy (items 1-4, *About your GFD;* ASES), high awareness of the risks created by accidental ingestion of and exposure to gluten (items 5-6, *About your GFD*), and a strong perception of the value of the GFD in managing CD (BIPQ item 4). These results did not change across the course of the intervention and concur with recent research in CD reporting high levels of attempted GFD self-management and low rates (<5%) of deliberate transgression (Penny et al., 2020). Our measures did not assess whether participants were as successful at self-management as they reported themselves to be, and research suggests that accidental gluten consumption is typical (Penny et al., 2020). However, these results support the decision to include only a very brief review of CD and the GFD in the first intervention session since, based on research from the literature, the researcher believed knowledge about CD, the GFD, and dietary self-management behaviour would already be high. Outcomes support the researcher’s decision that CD-related knowledge and information, and dietary self-management, should not be a key focus of this intervention.

6.4.3. Outcomes on mood and disease-related attitudes and perceptions

Baseline data indicated that at the start of the intervention, participants experienced moderate symptoms of anxiety, stress (DASS-21-A; DASS-21-S), slightly elevated symptoms of depression (DASS-21-D), and substantial difficulties in adjusting to concerns and losses related to CD (LWWCD scores). Participants also experienced CD-related *concerns* (BIPQ item 6) and *emotional impact* (BIPQ item 8). This baseline data supports the need for psychological intervention for people living with CD, and these negative psychological impacts were likely a motivation for participants to attend the course.

Outcome measures for symptoms of anxiety and stress demonstrated reliable and clinically significant improvement at 6 and 12 weeks. However, as a small feasibility study without a control group, this cannot be considered causal evidence of impact. Results at 22 weeks show a trajectory of both anxiety and stress levels increasing from the improvements observed at week 12, suggesting that these positive changes will not sustain long-term. As the DASS-21 is a general rather than disease-specific measure, it is also possible that mood was affected by changes in other variables in the participants’ lives not assessed in this study.

No changes occurred for any illness perceptions were measured. This outcome suggests that the course made no difference to participants’ perceptions of CD, including their perception that the condition was concerning (item 6) and had an emotional impact on them (item 8). Scores on the *Total* LWWCD scale and the *Concerns and Losses* subscale improved and sustained at weeks 12 and 22. These outcomes support the hypothesis that the intervention could help participants' to manage the concerns and feelings of loss they experienced relating to their CD. Further, unlike outcomes on the generic measure of mood (DASS-21), changes on the CD-specific LWWCD-27 measure sustained over time. These results suggest that the intervention may have impacted disease-specific outcomes. However, as a small study, this does not provide causal evidence for the effectiveness of the intervention. Significant change did not occur on the other LWWCD subscales (*Risk management* and *Positive changes*). Items on the *Risk management* scale related to the management of psychological and social influences on dietary self-management. These results may reflect the strong dietary self-efficacy reported on other measures (ASES; *About your GFD*). The lack of change observed on the LWWCD *Positive changes* subscale may reflect that the course did not alter participants' perceptions of CD, as shown on the illness perceptions (BIPQ) measure. It may also reflect that participants already scored relatively highly on this scale at baseline, suggesting that they already had a balanced view of their condition as having positive and negative impacts on their lives.

Moods, perceptions and attitudes are distinct mental phenomena (Rolls, 2013). Therefore, it is plausible that an intervention may impact mood while having little or no impact on attitudes and illness perceptions. Some unwanted symptoms and experiences are unavoidable for those living with long-term conditions. The incorporation of ACT within the intervention aimed to support participants in accepting, rather than seeking to ignore or eliminate the perhaps inevitable negative feelings and cognitions relating to their condition. This approach has been taken in other interventions for long-term conditions, as discussed in Chapter 5. Participants in the current study maintained strict dietary adherence and awareness of the potential risks of contamination. To do this required that they maintain a continued cognitive and behavioural burden of restriction and vigilance. The LWWCD intervention may have improved participants ability to 'live well' alongside perceptions and attitudes towards CD, which, though indicating heightened concern and emotion, are useful for self-management of the GFD. Developing increased acceptance of the restrictions and effort required to adhere and simultaneously increasing engagement in values-driven action may have resulted in the outcomes of improved mood.

6.4.4. Psychological inflexibility

A core objective of ACT is the development of individuals' psychological flexibility. Despite qualitative evidence of positive, values-driven behaviour change (Chapter Seven) and improvements in mood, no significant change were observed in the group mean for psychological inflexibility (AAQ-II). At baseline, only a small subgroup (n=4) had elevated levels of psychological inflexibility compared to comparison populations (Bond et al., 2011). Improvement in this subgroup did approach statistical significance at the end of the intervention (week 6; p=<.05), but this improvement was not sustained. These results suggest that the intervention made a limited improvement on psychological inflexibility. Other ACT-based interventions are found to significantly improve psychological symptoms but not show significant change on the AAQ-II (Fowler et al., 2021; Reeve, Tickle, & Moghaddam., 2018). In the current study, overall, the group did not have high levels of psychological inflexibility at baseline. Therefore, the changes in psychological distress may have been due to other aspects of the intervention. The impact of the intervention on psychological inflexibility may also be limited by the relatively low 'dose' of ACT activities within the overall intervention programme.

6.4.5. Strengths

The call for participants attracted a great deal of initial interest from the Coeliac community. Participants were a convenience community sample who showed moderate anxiety and stress levels at baseline. Coupled with low attrition, this suggests the LWWCD Toolbox is a feasible intervention that meets the need for support experienced by many people living with CD. Positive outcomes of improved mood and psychological and social adaptation support the hypothesis that the LWWCD can help people live well with CD. However, a controlled study is needed to provide causal evidence of change. The range of outcome measures used supported the researcher's hypothesis that people with good knowledge of CD and self-management of their GFD may still experience psychological and social difficulties adapting to the condition and would benefit from support. Further, using both general and disease-specific measures allowed exploration of the impact on these different psychological factors. Longitudinal data enabled investigation of the changes observed at the end of the intervention at six weeks and four months later. The results suggest that psychological and social impacts specifically relating to CD, rather than broader moods, may have been sustained over time for the participants.

6.4.6. Limitations

The study was underpowered, and results cannot be generalised to a broader group. The small study was unable to compare the efficacy of the LWWCD intervention against controls or comparison interventions. Therefore, it is impossible to ascertain whether the current intervention is more effective than treatment-as-usual or other intervention protocols. Sample size meant it was not possible to explore subgroup differences either. Analysis on a larger sample would enable exploration of relationships between psychosocial outcomes and factors such as baseline levels of psychological inflexibility, illness perceptions and attitudes towards Coeliac Disease. The sample was somewhat homogenous, being majority white females aged >40, as found across samples in CD research (Roy et al., 2016; Singh et al., 2018). Larger trials would enable subgroup analysis assessing the relationship of demographic variables on acceptability, feasibility, and intervention outcomes. A further limitation of the study was the use of seven outcome measures. Participants invested considerable time in the study and reducing the length of the questionnaire battery in future studies would reduce this time-burden. Further, the longest measure (ASES) had low completion rates at weeks 12 and 22 during which participants completed the questionnaires alone at home rather than as a group (see Table 43, p.192). This suggests that ASES was perceived to be burdensome and should be replaced with a shorter measure in future studies. Overburdening participants may have influenced the extent to which they accurately completed any or all of the quantitative outcome measures. It is also possible that time-burden may have contributed to the decision of two participants to drop out of the course (see section 6.3.2., p. 179).

Finally, a potential limitation of the study was the researcher’s reporting of the group mean RCI scores rather than the RCI results of individual cases. Reporting the RCI group mean does not show the variability in outcomes that exists between individual participants. Future studies of the LWWCD intervention would benefit from reporting the variability between the outcomes experienced by individuals in a small intervention group, and case-by-case analyses of any factors which may have contributed to this variability.

6.5. Conclusion

The current chapter has presented a longitudinal quantitative analysis of the LWWCD Toolbox intervention. In line with the course objectives, the results support the hypothesis that the intervention resulted in positive and sustained improvements in participants levels of psychological and social adaptation to their CD. Future work with a larger sample and control group is needed to provide causal evidence of change and explore the impact of demographic differences and differences in baseline levels of wellbeing and CD-related cognitions on outcomes.

CHAPTER SEVEN: STUDY THREE: QUALITATIVE EXPLORATION OF PARTICIPANTS' EXPERIENCES OF A PROOF-OF-CONCEPT STUDY TESTING THE *LWWCD TOOLBOX* INTERVENTION

7.1. Introduction

Quantitative measures taken at the start and end of the LWWCD Toolbox intervention showed significant improvement in participants' levels of stress, anxiety and psychosocial adaptation to CD. Longitudinal follow-up found that improvements in stress levels and psychosocial adaptation to CD had sustained over time (Chapter Six). The current chapter aims to explore participants' qualitative accounts of their experience of attending the intervention.

7.1.1. Aims and objectives

This chapter aims to understand participants' experience of attending the LWWCD Toolbox intervention. The specific objectives are to explore the following questions:

- How did participants feel about the topics covered by the intervention content?
- How did participants feel about the intervention format?
- What aspects of the intervention did participants find more helpful, and less helpful?
- What goals did participants set for themselves? What were the participants' experiences of working towards these goals?
- Overall, how would participants describe their experience of the intervention?
- How did the experience impact participants' everyday life, once the intervention had ended?

7.2. Methods

7.2.1. Design

The current chapter presents the qualitative element of the mixed-methods proof-of-concept study of the LWWCD Toolbox intervention.

7.2.2. Ethical clearance

Ethical approval for this pilot study was granted by the STEM Ethical Review Committee, University of Birmingham (Appendix A).

7.2.3. Participants

All participants who completed four or more sessions of the LWWCD Toolbox intervention (n=9) participated in the current study. The preceding chapter (Chapter Six) presents the participants' demographic and lifestyle information (Tables 35 and 36).

Participants provided written and verbal consent to participate in post-intervention research interviews as part of the original recruitment and consent process (Chapter Six). At the end of session six, participants confirmed that they were willing to be contacted for an interview both verbally and in writing and completed a short form indicating dates and times when they would be available. At this stage, participants received a verbal reminder of their right to withdraw from the research project, though all participants consented to participate in the interviews.

7.2.4. Philosophical position

Study Three takes a limited realist position (King and Brooks, 2017). This philosophical position recognises an objective reality external to human perception, though our subjective perspective always limits our knowledge and experience of reality. This limiting personal perspective influences the interpretation of data. Therefore, researchers should fully acknowledge this perspective by adopting a reflexive approach to the research. Through reflexivity, researchers identify and challenge the assumptions and decisions about the data and interpretation of that dataset throughout the analytic process (King & Brooks, 2017).

7.2.5. Template Analysis (TA)

7.2.5.1. Background to TA and application to the current study

Data were analysed using TA, a generic form of thematic analysis applicable across philosophical positions (Brooks, McCluskey, Turley, & King, 2015; King & Brooks, 2017). Psychologist Nigel King popularised TA in book chapters and articles from the mid-1990s onwards (King, 1998; King et al., 2002). TA is an approach applied to healthcare and psychology research, and the approach is useful in these areas because of its fit with the realist and limited realist approaches often taken in healthcare research and service evaluation (Brooks, Bratley, Jones, & Lucock., 2021; Fadyl, Channon, Theadom, & McPherson., 2017; Stephenson, Woodhams, & Harkins., 2017). TA also provided a good approach for Study Three since a template provides an explicit visual coding structure that is modifiable as new data is collected. This approach is helpful in a study that collates data from sequential ‘runs’ of the same intervention. Further, though the analysis explores individuals’ experiences, constructing a single template draws these experiences together into coherent and structured descriptions. Overarching superordinate themes highlight significant aspects of this experience. Lower-order themes (subthemes) allow the nuances of superordinate themes to be defined.

7.2.5.2. Coding technique

TA researchers code qualitative data to identify patterns (themes). Researchers then develop their coding into a thematic hierarchy (the ‘template’). Researchers may introduce an initial template of *a priori* themes before data collection. Alternatively, researchers may generate a template entirely from the analysis of their dataset. As a study progresses, templates develop in iterations. Creation and documentation of modifications make TA particularly useful for multi-stage projects. Template versions may map how researchers’ understanding of a topic changes throughout a study (Brooks et al., 2015; King & Brooks, 2017). In longitudinal studies, researchers may develop a separate template for each timepoint. Alternatively, a single template can encompass changes over time, which is the more commonly taken approach to longitudinal TA (Brownlee, Walker, Wallace, Johansson, & Scholes., 2019; Jee, Schafheutle, & Noyce., 2017; King & Brooks, 2017). The current study followed the latter single-template method. A single template is suited to exploring participants’ overall experience rather than drawing contrasts between groups or time points. Change across time is examined through the quantitative analysis presented in Chapter Six.

7.2.5.3. Generation of *a priori* themes

The researcher developed a set of *a priori* themes for the current study based on the intervention objectives outlined in the ToC developed in Chapter Five (Figure 5, p.158). The use of *a priori* themes is appropriate to a limited realist approach to exploring participants’ experiences of a highly structured intervention with pre-defined objectives such as the LWWCD Toolbox. These *a priori* themes are presented in Table 44.

Table 44. *A priori* themes (Study Three)

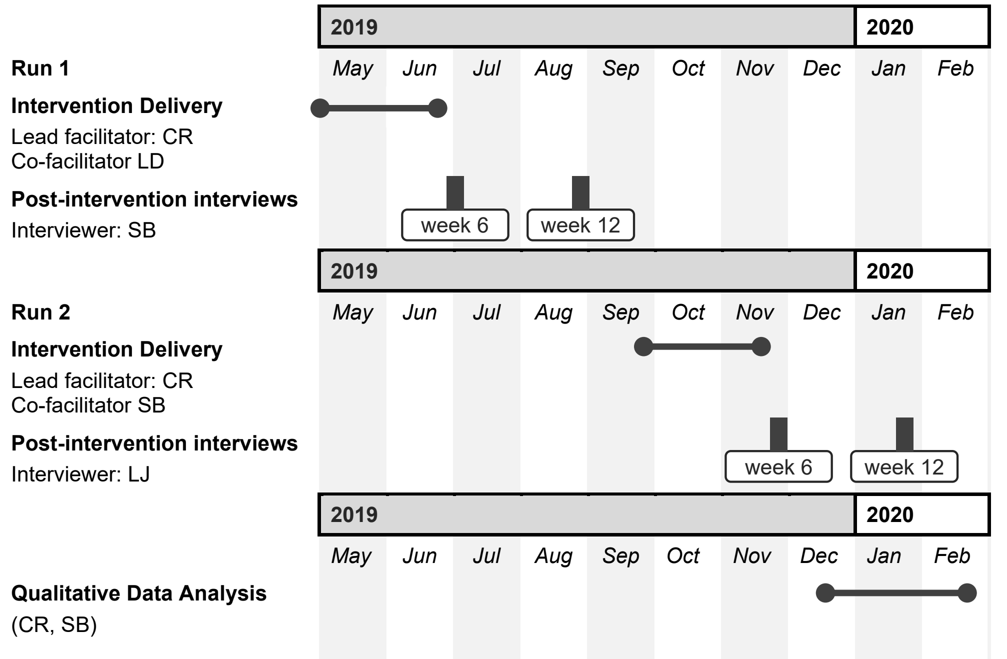
Theme One	**Connection to a Coeliac community** An aim of the intervention was to connect people living with CD to others managing the same condition.
Theme Two	**Developing a personal toolbox of coping strategies** The intervention’s structure and format provided participants with a toolbox of ideas and strategies that may help them live well with CD.
Theme Three	**Creating a pathway to change** Throughout the intervention, participants were encouraged to set goals and think about what actions they needed to undertake to live well with CD. Using tools and ideas learnt, they were encouraged to develop their own ‘stepping stones’ pathway, helping them move towards their goals.

7.2.5.4. Semi-structured interviews

Semi-structured interviews are a popular, straightforward and flexible approach to data collection (Kallio, Pietila, Johnson, & Kangasniemi., 2016). Interviewers use a pre-written interview guide, ensuring they cover key questions and topics. However, the guides remained flexible enough to allow participants and interviewers to raise relevant areas not covered by the pre-written questions (King & Brooks, 2017). Audio-recorded, transcribed semi-structured interviews provide a valid and comparable dataset (Cohen & Crabtree, 2006). The aim of Study Three was to pilot test the LWWCD Toolbox intervention. The researcher aimed to explore participants' intervention experience after completing the six modules and explore lasting impact through a follow-up six weeks later. The researcher developed separate interview guides for the post-intervention interview (week six) and follow-up (week 12) (Appendix H).

Week six interviews explored participants' immediate perceptions of attending the intervention, and questions asked participants to reflect on each of the six sessions. Follow-up questions explored what of the experience was memorable or felt particularly helpful in living well with CD and what was unhelpful. The interviewer also asked participants whether a 'refresher' session could be beneficial to them. The follow-up interview (week 12) discussed progress made towards goals and other lasting changes. The week 12 interview was much shorter than the first. The researcher did not want to overburden participants through unnecessary or repetitive questioning, given the time they had already invested in Study Three. Interviews were mainly open and probing. The current researcher developed the interview guide and also authored and delivered the intervention. The interview guide reflected the *a priori* themes (Table One). The researcher discussed and refined the questions with support from a third-year undergraduate research assistant who had no prior involvement in the project (SB). Two academic supervisors reviewed the draft interview guides for clarity and relevance before data collection began. Appendix H contains both interview guides.

Figure 6 (p.206) shows the timing of the intervention delivery and associated qualitative research, and the support roles provided by each of three students who supported the study. Two students (SB and LJ) supported data collection by undertaking all interviews with the research participants. Both students were studying psychology in the department, one was a third-year undergraduate, and the second was a final year MSci Psychology and Psychological Practice student. At the time of conducting participant interviews, neither student had attended any intervention sessions or had any previous involvement in CD research. This meant participants could talk about their experience freely with an interviewer who they had not previously met during the intervention sessions. Both student interviewers received a full briefing about the research project before commencing the interviews. Interviewers also received a folder containing all intervention materials to help them understand participants' comments during the interviews. The two student interviewers independently conducted the one-to-one interviews with participants by telephone. Post-intervention (week six) interviews lasted on average 42 minutes (range 16-58 mins). Follow-up interviews (weeks 12-18) lasted on average 14 minutes (range 5-20 mins). All discussions were audio-recorded with participants' consent. Interviewers followed the pre-written interview guides described above (Appendix H).



CR – PhD candidate (current researcher); LD – 3rd year undergraduate; LJ – 3rd year undergraduate;
SB – MSci Psychological Research and Practice student

Figure 6: Timing and facilitation of LWWCD intervention and associated qualitative research

7.2.5.5. Analytical process

The researcher transcribed all interviews word-for-word (verbatim), as King and Brooks (2017) recommended. The initial template consisting of three *a priori* themes was the starting point for the analysis (Table 44). Two researchers undertook the analysis of the data, the researcher and SB, who was the MSci. Psychology and Psychological Practice student who supported data collection (see Figure 6, p. 206). Both researchers initially read transcripts once without coding to familiarise themselves with the data. They then independently coded a subset of transcripts through an iterative reading, re-reading, and refining their coding. The three *a priori* themes (Table 44) influenced the initial coding. SB coded transcripts by hand using Word and printed copies. The researcher undertook initial coding by hand before transferring coded transcripts into NVivo to support further analysis, organisation and an audit trail. Researchers also kept notes and, in the researcher's case, NVivo memos as they read and re-read the dataset. Notes and memos referred to points of interest, patterns, and potential coding hierarchies. After coding the first set of transcripts researchers discussed their coding together and developed an initial hierarchical template of superordinate themes and sub-themes. They then independently coded the remaining dataset and repeated this process. The research team discussed progress throughout the analysis, reviewed and refined the template until a final solution was agreed. Both researchers checked the quality of the final template by reviewing its fit against the coded dataset. Figure 7 (p.208) describes the analytic process undertaken in the current study.

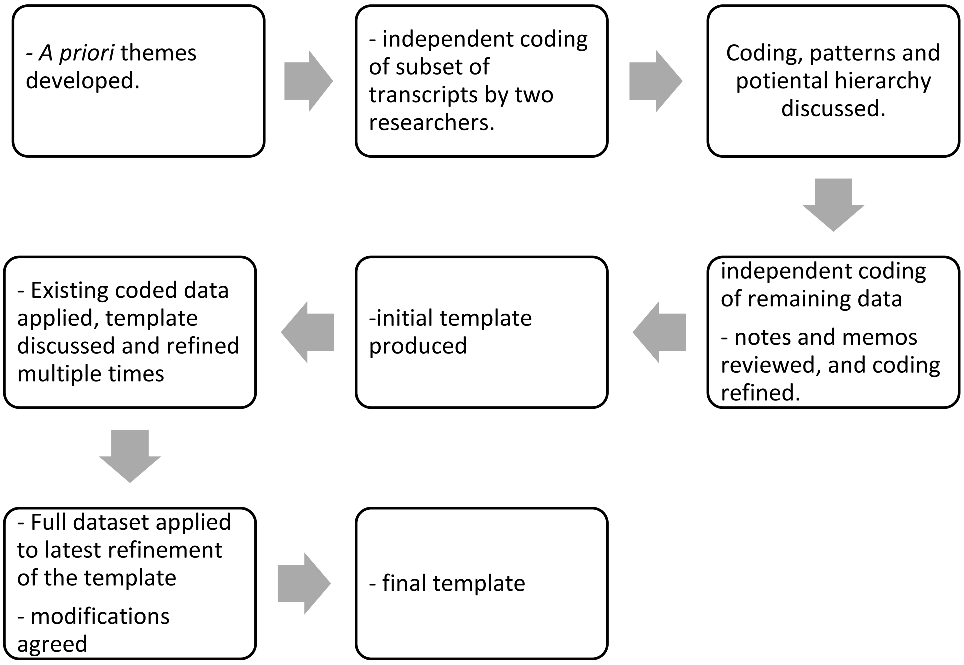


Figure 7: The Template Analysis process followed in Study Three

7.2.6. Ecological validity and Consistency

Authors disagree on the extent to which checks of measurement *reliability* apply to qualitative research. Some argue that reliability checks are concerned with quantitative measurement and rarely apply to qualitative studies (King & Brooks, 2017). Others argue that reliability remains an important criterion to ensure the quality of qualitative research, recommending that researchers employ verification techniques during data collection, analysis and *post hoc* (Morse et al., 2002). Noble and Smith (2015) recommend that concepts of reliability and validity be broadly maintained, but the terms be replaced with language closer to the nature of qualitative research. King and Brooks (2017) suggest that the concept of *ecological validity* is highly relevant to limited realist qualitative work. By ecological validity, King and Brooks (2017) mean that the data and interpretation remain congruent with the 'real-world' experiences and perspectives participants have presented. The current study adopts this understanding of validity: the ecological validity of the dataset relative to participants' original responses and perspectives.

Nobel and Smith (2015) also suggest that reliability in qualitative studies refers to the consistency of methods. Consistency means researchers are consistent in the application of methods throughout all research stages. Transparency, through the management of bias, supports reliability. Maintaining reflexivity throughout the research process also reduces bias. Audit trails documenting all research stages support transparency (King & Brooks, 2017). In the current study, multiple procedures supported both ecological validity and consistency and these procedures are listed and described in Table 45.

7.2.7. Reflexivity

The researcher had designed and delivered the intervention discussed in the interviews. This meant that they had assumptions and expectations about the participants' intervention experience and how they might use the content to live well with CD. These assumptions potentially posed a risk to ecological validity (Table 45), as the researcher may inadvertently add their assumptions to their interpretation of the data. The student research assistant SB (see Figure 6, p.206) coded transcripts independently and drafted some ideas about initial themes for the template (not yet structured into a hierarchy). The research team shared iterations of the template throughout the process of interpretation. Coders ensured the data was represented in the template by reflecting between the template and dataset. As the researchers progressed through their analysis, the researcher discussed coding and drafts of the template independently with both project supervisors (GL and RH), who challenged the researcher about decisions and assumptions made. As a result of these valuable discussions, an earlier version of the template was substantially refined and simplified. The researcher kept an audit trail of earlier versions of the template and the thinking behind revisions and continued the process of reflecting on the original data and the draft template during the write-up, as is common in a limited realist study (King & Brooks, 2017).

Table 45: Procedures undertaken to support validity and consistency in Study Three

Type of check	*Action*
Consistency	**Semi-structured interviews using a guide:** ensuring that all interviewers followed the same interview procedure (Cohen & Crabtree, 2006).
Ecological validity	**Semi-structured interviews (technique):** Clarification of responses through the interviewer's use of probes and additional questions (Barriball & While, 1994).
Ecological validity	**Audio-recording and word-for-word (verbatim) transcription:** anchoring the dataset in participants' original responses (King & Brooks, 2017).
Consistency	**Record-keeping:** Transcripts, coding, memos, discussion notes, iterations of the developing template. These documents provide an audit trail of the analysis process and ensure that procedures can be checked (King & Brooks, 2017; Noble & Smith, 2015).
Consistency	**Independent coders:** Initial independent coding. Discussion and clarification of emerging themes. Ensures dataset is analysed fully and consistently, that codes are consistent, and themes are fully described ('thick description'), consistent and relevant to the dataset and research question (King & Brooks, 2017; Noble & Smith, 2015).
Ecological validity	**Familiarity with the topic and data:** The researcher delivered the intervention and transcribed the audio-recorded interviews. The second researcher (SB) attended half of the intervention sessions and conducted ten (56%) of the participant interviews. Familiarity with the events discussed and the original interview data enables researchers to reflect on the dataset's 'real-world' context and meaning more easily (King & Brooks, 2017). However, familiarity with the topic area and data may have created some unconscious bias. Reflexivity (section 7.2.7) is important to mitigate this source of potential bias (King & Brooks, 2017; Noble & Smith, 2015).

7.3. Results

A TA of the data identified seven superordinate themes, thirteen second-order themes and one third-order theme. Table 46 presents a summary of the superordinate themes. Table 47 shows the percentage of participants in the sample whose data contributed to each theme. The narrative description of the themes contained in this section includes a selection of participant quotes[42].

Table 46: Summaries of the seven superordinate themes in the template

"I think I was really up for it"	The participants were enthusiastic and motivated to attend the intervention, which, overall, was perceived to be an interesting, novel, timely and potentially beneficial opportunity.
"You don't just generally come across these people"	The participants had little or no contact with other people living with CD. Taking part in the group intervention reduced feelings of isolation and enabled the sharing of resources and ideas. Difficult feelings and experiences related to CD were shared with and normalised by the group.
"A resting point"	The intervention provided participants with a safe space and the time to reflect on the psychosocial impacts of CD and the GFD, which they did not have the opportunity to do in their everyday lives.
"You get a little bit blasé"	Participants described becoming disengaged and bored with the effort and repetition involved in maintaining a varied and nutritious GFD. The intervention developed their motivation to experiment and re-engage with the GFD, to make meals interesting again and increase the satisfaction they gained from food.
"You have all these random thoughts"	Some participants felt that applying psychological models to their feelings, thoughts and experiences with CD normalised their reaction to the condition and provided them with the strategies and hope needed to move forward.
"Can I trust you?"	Participants were able to apply psychological strategies and concepts from the intervention to help them in difficult social situations where they needed to assert their needs, eat differently from those around them, and question other people's behaviour and understanding.
Progression	Participants used the intervention experience to live better with CD once the sessions ended, through continued action (e.g. practice, learning, experimentation).

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[42] Some words in participant quotes are underlined to show where the speaker placed a very strong verbal emphasis on particular words.

Table 47: Percentage of participants who contributed to each theme in the template.

Theme*	Participants' contribution (% of N)
"I think I was really up for it"	**78%**
Acknowledgement that CD impacts more than diet	67%
"I think it came along at just the right time"	44%
"You don't just generally come across these people"	**89%**
Shared discomforts and difficult feelings	56%
Us vs Them	67%
The influence of the group	56%
"A resting point"	**78%**
Becoming aware of the significance of food	56%
Contemplating future directions	89%
"You get a little bit blasé"	**56%**
"It gets a bit dull"	44%
Nutrition	56%
"You have all these random thoughts"	**89%**
Structured delivery enhanced the experience	67%
"Can I trust you?"	**78%**
Becoming an effective educator	78%
Progression	**100%**
"It's not like a quick fix"	67%
Acceptance of difficulties	44%
- Values provide direction	33%

* Themes are not presented in any order of importance
Second-order themes are indented; - indicates a third-order theme

7.3.1. Theme One: "I think I was really up for it"

"I think I was really up for it" was the first of the seven superordinate themes. This theme has two second-order themes (Figure 8, p.213). The description below begins with the superordinate level.

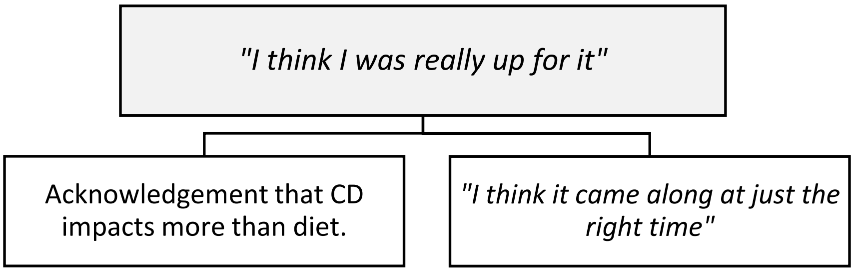

Figure 8: Theme One. *"I think I was really up for it."*: superordinate and second-order themes

Attending the intervention involved a considerable investment of time (15 taught hours, plus travel time). Some participants expressed their enthusiasm at the prospect of attending the intervention, which four participants[43] described as an "*opportunity*". Tan described feeling excited and *"really up for it"* and that "*I'm really ready to do this".* Su explained that their strong sense of needing to take up a good opportunity helped them overcome the high anxiety they felt about something unfamiliar. Tan's explanation of how they *"built my day around it"* demonstrates the effort made to attend. Some participants were motivated by the psychological focus of the intervention, which sounded interesting or novel. Having an attitude of being very open to a new experience was shown by some participants, who described feeling "*open"* or "*curious"* towards the concept, despite being unsure of what would result.

> *"I didn't really know, but I was sort of open to trying it really, to er, to see what it could offer". Oli*

Everyone who attended took part in an initial screening call with the researcher. Some felt the information received during this call increased their initial interest

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[43] Laura, Anthea, Oli and Tan

because the sound of the intervention seemed to 'fit' with their own needs (*"it just sounded perfect for me"* Su). Some participants felt it had been important to have a clear, detailed picture of what to expect before they attended and appreciated asking the researcher questions beforehand. This information supported participants' initial sense that the intervention would fit them well and clarified the practical details, which helped manage their anxieties.

> *"I wasn't worried about attending [because] I think Cate was really clear. I knew where I had to go. She sent maps and things.[…] Cate was always very kind of, erm, she was very accessible. She was very much on her emails, and we had a bit of contact, to-and-fro, beforehand. So I felt that it was all sorted and fine and I knew what I was there for". Nic*

Despite the considerable commitment required, participants appeared willing to invest in *"what it* [the intervention] *said it was offering*[44]*"*. Several reported having weighed up their decision to enrol based on the information provided. Everyone expressed an explicit expectation that they would benefit in some way from attending. Some openly expressed that they were seeking help to manage their CD better because it negatively affected them psychologically (*"I've been having problems coping with CD"* Nic*)*. Others more implicitly suggested that a need for help motivated their attendance, for example, by lightly indicating that they hoped to get some useful tips or were primarily looking for information to help a family member who had CD too.

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[44] Oli

7.3.1.1. Acknowledgement that CD impacts more than diet (second-order theme)

The intervention acknowledged CD's broader psychosocial impacts, which was central to some participants' liking the sound of the intervention and being *"really up for it."* Participants explained how this focus contrasted with other available support from healthcare services which focused exclusively on physiological and dietetic information (*"it's purely all diet-related"* Anthea).

7.3.1.2. "I think it came along at just the right time" (second-order theme)

"I think it came along at just the right time[45]*"* is a theme that describes how timing appeared to be an important factor in the participants' decisions to attend. Oli was relatively newly-diagnosed (< two years) and felt the intervention could help them progress and manage their difficulties as they adapted to CD. Other participants felt the time was right because they had reached a pivotal point in their journey with CD. For example, Su described having reached an anniversary of their diagnosis and how they had finally resolved some unexplained medical problems, so they were beginning to feel physically stronger for the first time in years. Some participants had reached key life-markers, including retirement, bereavement, or unexpected co-morbid diagnoses. These life-markers or life-changes motivated a desire to develop their ability to self-manage their CD as part of the process of moving forwards (*"turning a page"*) in their now changed life:

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[45] Participant Su

> *"This is actually why I wanted to do this course so much.[…] Coming to a change in my life, you know, turning a page[…] And it has worked as I kind of foresaw that it might do. It's given me, well, (pauses) a kind of toolbox to, erm, assist".* Tan

7.3.2. Theme Two: "You don't just generally come across these people"

The second superordinate theme is *"You don't just generally come across these people"*[46], which overarches three second-order themes (Figure 9, below).

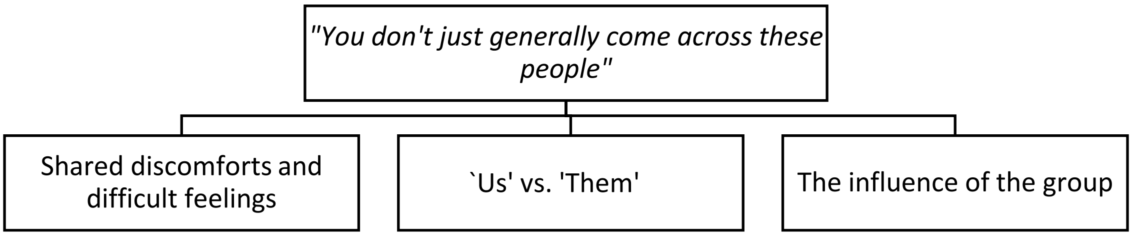

Figure 9. Theme Two. *"You don't just generally come across these people": superordinate and second-order themes*

The superordinate theme *"You don't just generally come across these people"* demonstrates how the intervention enabled participants to connect with other people living with CD. Most participants had never met another adult living with CD, and all were enthusiastic about doing so. Meeting other people living with CD was a key motivation for several participants to attend. Participants described the value of connecting with others living with CD through the intervention. Once sessions ended, a few participants tried to establish connections with community-based CD support groups. Some participants did stay in touch with each other and reported that this provided ongoing support. These behaviours show both the desire people living with CD have for peer

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[46] Participant Tan

connections and the real-world barriers that often prevent people from meeting others who share their condition in everyday life.

> *"I do have a couple of people that are Coeliac [in the workplace]. But they are, are firmly, kind of, partnered up and also sort of busy. And so we never quite meet in the kind of situations where you could sit down and say, "<u>Soooo</u>, now tell me all about this! (laughs)" Yaz*

7.3.2.1. Shared discomforts and difficult feelings about CD (second-order theme)

Most participants reported having experienced a range of difficult feelings relating to CD. Their lack of contact with peers or professionals meant they were left to process these feelings alone. Some had wondered if their reactions to CD were justified or proportionate and hearing other people's stories and experiences enabled them to normalise their feelings. Nic described how having their experiences and difficulties normalised had made them feel able to speak more freely about CD to those outside the group. Participants realised that they shared discomforts related to living with CD, particularly when in social dining situations. To maintain a strict GFD, participants needed to explain how to avoid cross-contamination to those cooking or serving food. Group members shared discomfort with terminology like 'contamination', which became the focus of lively discussions during intervention sessions. Participants described worries that others perceived them as *"neurotic"*[47] or would feel they were implying they had poor hygiene, were lying or didn't know how to do their job. Another shared

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[47] Nic

discomfort was the need to remain vigilant and ensure that others follow necessary procedures to avoid cross-contamination.

Similarly, participants shared discomfort at being the centre of attention when asserting their needs or explaining CD, or worried that constant checking made them seem boring. Understanding that others experienced their distress helped participants see these feelings as a normal consequence of self-managing their CD. Through discussions and group exercises, participants could think of ways of managing their discomfort or viewing the situation slightly differently. For example, Ingrid recognised and began to challenge the guilt they felt about asking others for support. This insight enabled Ingrid to take better care of themselves when eating socially. Participants also described a shared sense of psychological isolation as they often felt alone in managing the difficulties of living with CD. Attending the intervention alleviated this sense of isolation for a limited period. Still, once the sessions ended, the lost connections with peers felt isolating for some participants (e.g. *"You need to be able to chat about it* […] *I did feel a little bit bereft when it finished."* Tan).

> *"I realised that actually I feel guilty for having Coeliac Disease and I, ahm, I almost apologise before I ask a question, or before I like, you know. We went through some scenarios, and I realised that actually, I would be thinking, like, feeling guilty because I'd put somebody out with my Coeliac Disease [...] And I didn't think, didn't know, that I did that until I actually I wrote it down and thought it through. (laughs) So, I learnt, I learnt that I need not to feel guilty". Ingrid*

7.3.2.2. 'Us' vs 'Them'. (second-order theme)

Participants described how people living with CD were a discrete community. Yaz describes joining the group as feeling like they had met their *"tribe".* Using the word ‘tribe’ suggests a separate identity from people outside of the tribe and a sense of in-group safety and support. Together as a group (*“tribe”*), people with CD felt confident of being understood as they all lived by the same (GFD) rules. They felt reassured by advice from other group members, assuming this was accurate because the group had shared needs, experiences, and knowledge of CD. This sense of safety contrasts with the lack of understanding and safety often experienced when participants interacted socially with people who did not live with CD.

> *“I can bring things up at home, but it’s not gonna be, ah, the other person’s not got it (Sighs. Long pause) […]The group, oh, they knew where you were coming from” Tan*

Sometimes participants conveyed a sense of conflict between people living with CD and those who did not have the condition. Participants’ references to which ‘side’ has the ‘problem’ conveys this sense of two conflicting sides, (e.g. *“As coeliacs, we aren’t necessarily the people with the issues!”* Yaz). Participants felt unfairly perceived as being people who were being needlessly difficult in social dining situations. They sometimes described people who lived without CD negatively as being dismissive or insincere. However, some participants reported that intervention sessions had led them to reflect on the assumptions they often made about people who did not have CD. They considered how making assumptions about how others viewed them might affect their behaviour and, on occasions, escalate difficulties:

> *“I leant that I shouldn’t just presume that people will, you know, think that, ahm, that they’re making judgements about me because I’m Coeliac (Interviewer: Yeah?) Oh Yeah. I definitely do pre-think ah, you know, and I jump to conclusions about what*

> *people are thinking, trying to pre-empt what they're thinking, so, ahm, that was definitely something that I now know that I need not keep doing. That, that I need to give people the benefit of the doubt". Ingrid*

Interestingly, some participants noted that the intervention facilitators did not have CD themselves. The facilitators' knowledge about CD and their open acknowledgement of their 'outsider status' and desire to learn more about the condition from participants' appeared to minimise a potential 'us vs them' divide:

> *"They connected with us very well. OK, so neither of them were coeliacs, but they could empathise with us and understand our frustrations. They did very well" Charlotte*

7.3.2.3. The influence of the group (second-order theme)

Several participants described how the ideas and opinions of the group had influenced them. Yaz explains how the group effectively worked together, forming a *"hive mind" and* generating new strategies and perspectives. Group opinion appeared to have influenced some participants' behaviour considerably. Reflecting on a discussion in which group members offered advice to another participant, Yaz raised a concern that the influential `weight' of group opinion, however well-intentioned, may have felt over-powering. Though neither of the two facilitators present in the session or the participant concerned felt this way, it raises an important potential risk regarding group discussions, which can be powerful and influential. Some participants remained in contact after sessions ended and described how they encouraged each other to work towards goals and share ideas and resources. The group's influence continued after the intervention ended through this continued contact and action.

> *"I talked about it to the group who said if I don't go, I'm allowing the condition to govern my choices." Nic*

7.3.3. Theme Three: "A resting point"

"A resting point" is the third superordinate theme. This theme relates to participants' experience of sessions as a safe space dedicated to reflection on CD. Two second-order themes sit below "*A resting point*" (Figure 10, below).

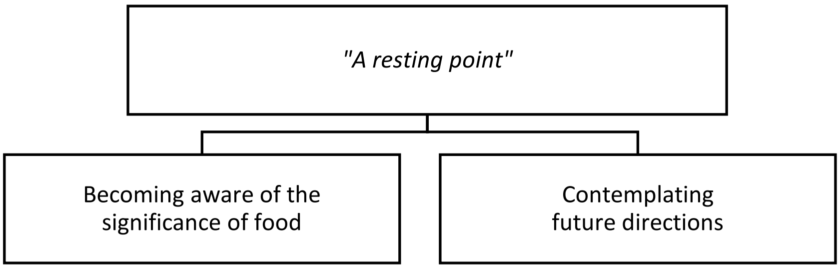

Figure 10. Theme Three. *"A resting point":* superordinate and second-order themes.

The intervention offered a safe, physical and temporal space, which Yaz described as a "*resting point*". Participants used this space to reflect on their CD and the broader psychosocial impacts the condition had made in their lives. Many felt they had not had the opportunity for this type of reflection on their CD before. They explained that in daily life work, family and the practical process of avoiding gluten take up their time and focus. Reflective exercises and discussions enabled participants to recognise the broader psychosocial impacts of CD. The experience of being in an accepting group of people also interested in the topic created this reflective space. Participants described the delivery of the intervention as supporting reflection by being *"informal"*[48] *and "comfortable"*

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[48] Participant Laura

and that they did not feel under any pressure to speak or rush through activities and discussions[49].

> *"All you're doing is concentrating on getting it [the GFD] right. So you don't think of the consequences of what it's done, and it's only when you start to breathe again that you can realise how anxious you do get about things." Charlotte*

7.3.3.1. Becoming aware of the significance of food (second-order theme)

This second-order theme describes how the intervention enabled some participants to reflect on the significance of food within their lives. Participants could not eat many favourite foods and described how this created a deep sense of loss. Some felt any sense of pleasure in eating had disappeared from their lives. Others thought they had lost elements of daily life that felt like a key part of their identity. Charlotte described how their life-long preference for "*plain and simple"* foods and their *"fuddy-duddy"* resistance to trying new foods meant that their GFD was even more restrictive than it needed to be. Su described the significance of food in bringing the family together and in cultural celebrations and described feeling *"like my identity and my culture had been ripped out".* Nic explained how they had, before diagnosis, been a keen traveller and how the GFD now made foreign travel *"a really daunting thing".* Nic and Ingrid reflected on their pre-diagnosis love of food and their realisation of how significant this was for them. Nic felt this realisation helped them to understand why they had found the GFD so challenging to handle:

> *"What I did find, and it built up later on in the course, was realising how much, how (pauses) I was always a real foodie before I got*

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[49] Participant Ingrid

> *diagnosed [...] and that was really interesting, just to get me thinking about where and why I really struggle". Nic*

7.3.3.2. Contemplating future directions (second-order theme)

Contemplating future directions is a second-order theme describing how, in follow-up interviews, participants felt their focus had pivoted away from feelings of loss towards intentions and actions that could help them manage some of the negative psychosocial impacts of CD. As they contemplated future actions, their use of '*research*'[50], '*commitment*[51]*'* and '*courage*'[52] showed that they recognised the effort needed to try new things and create lasting changes. Some goals referred to a mindset change, such as having the *"courage to look up other foods and experiment* (Charlotte)." Others planned to take practical actions, like learning to cook specific items (e.g. Indian bread, tortilla wraps) or particular types of food, (e.g. lunch options, cakes, quick main meals). Several planned to refresh their knowledge of the foods that they were allowed to eat within the GFD.

> *"I want to really research into the foods that I eat and expand what I eat. […] Because I love food. When you have a lovely meal, whether it's a lunch from a box or a meal from a restaurant, actually eating something nice with friends it, it makes you feel happy". Ingrid*

7.3.4. Theme Four: "You get a little bit blasé."

"You get a little bit blasé" is the fourth superordinate theme in the template. Two second-order themes sit below *"You get a little bit blasé"* (Figure 11, p.224).

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[50] Participants Ingrid and Laura

[51] Participant Nic

[52] Participant Charlotte

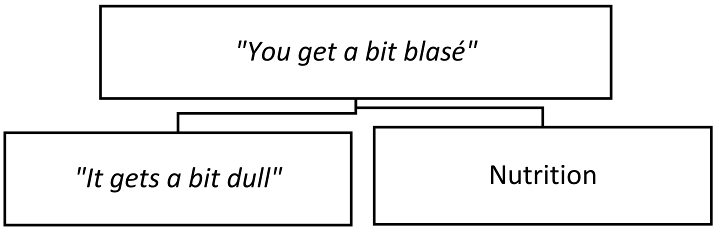

Figure 11. Theme Four. *“You get a little bit blasé”: superordinate and second-order themes.*

In this theme, blasé behaviour describes becoming disengaged with the management of the GFD. Charlotte explained how *”sometimes, because we live with the condition all the time, like everything, you get a little bit blasé’ about it.”* Blasé actions included never re-checking ingredients lists of familiar foods and making assumptions about which products contained gluten which could lead to inadvertently consuming gluten or avoiding safe products. The initial session gave participants essential information about safe and unsafe foods and checks they could make to help prevent contamination. Generally, participants felt this was a helpful way to revisit “*the basics*[53]*”.* Some participants reported feeling more relaxed about their condition and more positive about exploring new foods and recipes at follow-up. Interestingly, two participants described experiences where they had been unusually inattentive, even blasé, following the intervention. Nic reflected that they may now have become too relaxed around food and how they were striving to find a healthy balance between being ‘blasé’ and maintaining the vigilance needed to stay safe.

> *“I’ve actually let my guard down a little bit, and there have been a couple of points where I’ve thoughts ‘whoops! I shouldn’t have done that!’, as a result. So nothing serious. I haven’t actually eaten anything gluten, I haven’t made myself unwell, but putting something into a soup before I’d checked, it was quite an unusual*

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[53] Participant Charlotte

> *thing for me to do. So I took that on board as on one level, like, it was a good thing. Because, like, I'd obviously relaxed a little. On another level, obviously, it is a challenge (laughs) in that there is obviously a level of vigilance that I do need to maintain". Nic*

7.3.4.1. "It gets a bit dull" (second-order theme)

One result of becoming disengaged with the GFD is that it *"gets a bit dull*[54]*"* because participants disengage with further experimenting and learning about the GFD and eat only a limited range of safe options. Yaz describes always taking "*easy options"* with processed foods and restaurant meals, which were expensive and limited in range, but allowed them to avoid the hassle and learning involved in home-cooking. Yaz recognised that developing a more varied diet may involve more effort, described as "*restructuring my life".* However, Yaz also realised the effort may have a positive pay-off by making food *"[p]leasurable again[…]Not just simply, oh right, here's today's plate of diesel."*

7.3.4.2. Nutrition (second-order theme)

Some participants expressed concern that their repetitive, limited diet could cause nutritional deficits and mentioned problems like fatigue, weight gain, and increased risk of comorbidities. Some talked about the future actions they needed to take to improve their nutrition, such as consulting a dietician, improving their cooking skills, sourcing new recipes, or meal planning. When followed up at 12 weeks, participants' intentions to expand their GFD had delivered mixed results. Some had carried their intentions through, but others reported encountering barriers. Waiting for 'the right time' was a common

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[54] Participant Laura

reason given for not making behavioural changes. Some participants identified multiple internal and external barriers to change and seemed stuck in a stage of contemplation.

> *"It's something that I'm going to have to try, at some point, yes, at some point, that sort of thing. I suppose it's, I suppose, because the food is always so expensive I'm always dubious of buying if I'm not going to like it. So it's taking the bull by the horns and trying to, so, looking into it. But because of everything that's going on, I haven't really been looking into it. But, but consciously I know I've got to do it at some, at some point. And I do frequently find I need to get to the stage where I say to myself, enough is enough, and then I start doing it, and I've not quite got to that point yet". Charlotte*

7.3.5. Theme Five: "You feel like you've got all these random thoughts."

"You've got all these random thoughts" is the fifth superordinate theme in the template and has just one second-order theme (Figure 12, below).

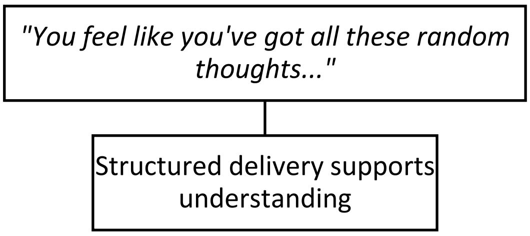

Figure 12: *"You've got all these random thoughts":* superordinate and second-order theme

The theme "*You've got all these random thoughts*[55]*"* describes some participants' sense that attending the intervention enabled them to understand better the different feelings and thoughts they experienced about CD. The intervention content and group discussions helped them to relate their seemingly random thoughts to psychological models. Participants' experiences

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[55] Participant Anthea

of living with CD were often emotional, and some described how they had judged their feelings negatively, as disproportionate, too intense, or confusing. Situating feelings within a psychological model provided reassurance that these were natural and manageable processes. Through gaining a better understanding of their internal experiences, participants were more able to accept their feelings and understand why they experienced them. For example, learning how the "Five Stages of Grief" model might relate to adaptation to CD in Session Five generated hope for some participants, like Oli and Ingrid. They said they now saw themselves differently, as moving forwards through some difficult emotional stages with the hope that they would eventually reach a place of acceptance.

> *"I could identify with that model of the different stages, you know? Particularly the stage of depression and denial, I think. So I could very much relate to that in, in terms of going towards acceptance, hopefully. And I recognise that I'm not quite there yet, but this is something that I'm hoping to, I suppose, to achieve". Oli*

7.3.5.1. Structured delivery enhanced the experience (second-order theme)

All intervention sessions had content tightly structured around one or two key topics. This structure aimed to enable participants to process several different models and ideas across the intervention without becoming confused, and feedback suggested that this was helpful. A slide set supported each session and outlined all key points, discussion topics and references. Participants found the slide-set useful to follow the content during sessions and to recall it later on. Discussions were extensively incorporated into sessions but were time-limited and focused on a specific session topic. Again, this structure aimed to prevent discussions from becoming tangential or overwhelming, and feedback suggested this approach to running the discussions had also worked as planned.

> *"I've found all of that structure really good. I wouldn't have liked it to kind of have gone the way of just doing group discussions all the time, no. It was very, very good to get the actual background as well. Because with some of these things, I'd not ever come across this before". Tan*

7.3.6. Theme Six: "Can I trust you?"

"Can I trust you?" is the sixth superordinate theme in the template and has one second-order theme sited beneath it (Figure 13, below).

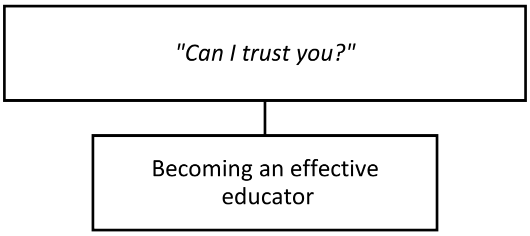

Figure 13: "*Can I trust you?*": superordinate and second-order theme.

The superordinate theme *"Can I trust you?"* describes participants' need for constant vigilance and scepticism about other people's actions. Both friendship and formal hospitality situations rely on a sense of trust and ease between guests, hosts and friends, and questioning and doubt created social dilemmas and unease. Applying learning from the intervention to these social dilemmas was important for participants, as all continued to find at least some social interactions challenging. Nic describes the group discussion about the difficulty of questioning friends

> *“I’m still trying, we’re <u>all</u> still trying, to get <u>trust</u> in that situation. Because when you’re asking someone, Is this OK? Is that OK?’ what you’re <u>really</u> saying is Can I <u>trust</u> you? And that’s a kind of really difficult thing to ask someone. Particularly if they’re friends and they say, ‘Oh look, I’ve cooked this for you, it’s gluten-free’. And what you really want to say is, Is your kitchen clean enough? Are your work surfaces <u>really</u> clean?” Nic*

Trusting others understood why they needed a GFD and what it entails was challenging for everyone who attended the intervention. Participants reflected on their experiences of people providing assurances but then not following through with appropriate actions. Post-intervention, a few participants began to feel that they needed to give people an opportunity to learn about CD and express any misunderstandings. One of the intervention exercises involved participants reading a series of fictional social stories. Through reading the different perspectives of people in the stories, the group considered how others often quite genuinely misunderstood CD and the GFD. Some participants also began to feel more optimistic that, with new strategies around their communication and planning, it might often be possible to engage in social activities with lower levels of anxiety.

> *“Looking at things from different perspectives and other people’s point of view […] I know this might make me sound really selfish, but that wasn’t something that I’d erm, ah (pauses) well, <u>considered</u>”. Oli*

7.3.6.1. Becoming an effective educator (second-order theme)

Living well with CD required participants to communicate with others about the condition. Through group discussion, participants began to frame this as a constant education process, as most people genuinely did not know what CD was or what a GFD required. Participants felt one of the challenges of communicating about CD was that it was both complex and emotive. Participants described feeling bored, frustrated and upset at having to explain CD and re-articulate their GFD requirements repeatedly. Through discussion and working through the intervention exercises, they reported having identified that they needed to find ways of remaining calm and explaining things clearly, even if they felt frustrated. Some strategies from sessions on anxiety (session two) and stress (session three) had helped with this. During session five (Communication), the group had discussed how wider society often holds mistaken beliefs about illness, such as the belief that illness is always visible. People described having begun to understand the barriers they faced in educating those who held common social and cultural beliefs and misconceptions about health and food. Again, some participants described using psychological strategies from the intervention to avoid escalating their anger or frustration and deciding not to engage anymore in feelings of guilt and anger when met with other people's inappropriate or intractable attitudes. From this perspective, participants also described having lessened their sense of being 'difficult' whenever social situations became awkward.

> *"I think what helped me was to remember to put it in its proper place and to remember that it's not all my problem. Sometimes it is the other person's problem. And all I can say is that it is getting easier because society is becoming more aware". Charlotte*

At 12 weeks, some participants reported having practised communicating their needs in social situations, some of which they had previously avoided. Strategies used included pre-planning social meals and practising how they would handle these conversations in advance. Some participants reported more effective communication about CD and positive outcomes, including restaurant visits, meals with family and friends and planning holidays.

> *"I've managed to educate them in a little way, just by a short conversation. It only has to be a short chat. And they were actually really quite understanding. I felt that the information from the course just helped me do that. Because sometimes I do get in quite a bit of a flap. Just in the sense that, erm, I might just get offended or get a bit defensive". Su*

7.3.7. Progression

Progression' is the seventh superordinate theme in the template. Two second-order themes and one third-order theme sit below 'Progression' (Figure 14, below).

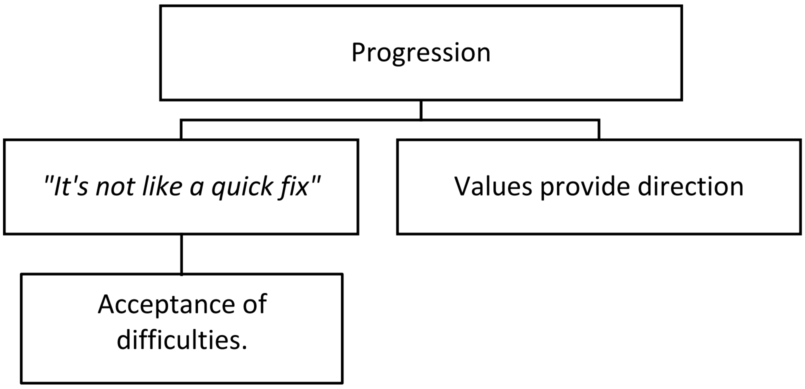

Figure 14: 'Progression' superordinate, second-order and third-order themes.

The theme 'Progression' describes how participants had taken ideas learnt on the intervention to develop a personal strategy to help them live well with CD, which was in line with intervention objectives. All participants expressed a sense of progression and hope for the future as they discussed the learning process they had just engaged in, which Su described as *"quite a journey"*. Everyone described having realised that something had changed for them related to CD following their attendance, which were psychological and (or) behavioural changes. For example, Oli felt less isolated with the condition and more able to manage their feelings of stress and social anxiety about CD using strategies from the intervention. Su used ideas from the intervention to explain CD and assert their needs to family members who had not been understanding in the past.

7.3.7.1. “It’s not like a quick fix” (second-order theme)

This theme describes participants’ understanding that the intervention was “*not like a quick fix*[56]*”*. Participants lived with CD alongside other challenges and demands (e.g. other health conditions, jobs, University courses, and caring responsibilities), which meant they were often tired and short of time. Tan observed that implementing strategies learnt during sessions was *“a little bit different”* in a *“real-life situation”*. Ingrid pointed out that family and friends were also involved in the adjustment and learning, adding a layer of complexity to the process. Some participants identified their need for further support to facilitate their progression in the future. In the follow-up interviews, they told us about ways in which they were now engaging with informal and formal sources of help. These outcomes were positive because intervention seemed to have nudged participants into organising the support they needed. Participants were asked if attending a ‘refresher session’ might be helpful to them. Some felt the intervention had been sufficient to enable them to move forwards

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[56] Participant Su

independently. However, others felt that follow-up would be beneficial, serving as a further "*nudge*[57]*"* to continue their progress.

> *"It's such a journey really and, yeah, and possibly, even if there was an initial course, and then a follow-up course for people, you know, sometime down the line, rather than just setting them off on the journey. That might be useful". Charlotte*

7.3.7.1.1. Acceptance of difficulties (third-order theme)

Participants reflected that even when implementing strategies, living well with CD involved repeated inconveniences which could become boring, tiring and frustrating. Some participants observed that developing a sense of acceptance of these inevitable struggles was part of moving forwards. Others felt they needed to accept that they would make errors of judgement themselves as they progressed. In the quote below, Tan identifies feelings of self-recrimination when they accidentally contaminated their cooking and how they used a psychological strategy to manage these feelings and continue their progress:

> *"I was really kind of almost, like, battering myself up really. Thinking, 'why've I done it?' That was a <u>stupid</u> thing to do, you know? […] So that's when, what I'd learnt, about these negative thoughts and them moving on, moving them off. Thinking, well, yes, this <u>can</u> happen. And yes, it's a <u>bit</u> of a step backwards, which <u>can</u> happen. And yeah. That helped". Tan*

7.3.7.2. Values provide direction (second-order theme)

Some participants felt that identifying their personal values had given them a sense of direction to help them live well with CD. Reflection on their core values encouraged them to look for meaningful ways to live out these values in

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[57] Participant Yaz

everyday life. For example, values about natural health encouraged several participants to persevere with home-cooking rather than relying on processed foods. Su wanted to focus on their value of ‘helping others’ and began to look for volunteering opportunities. The value of 'gratitude' encouraged several participants to focus on their life's positive but neglected areas. The value of ‘fun’ encouraged Ingrid to seek out new fun activities which did not involve food. Anthea’s value of ‘friendship’ helped her to persevere with the challenges of eating out. Su, Ingrid and Anthea all identified a value of health and wellbeing and began to engage in self-care and fitness activities. These results show how connecting with values increased participants engagement in positive activities and encouraged perseverance through some of the difficulties living up to personal values involved.

> *“The session really opened up some things for me about the way that the condition is actually compatible with some of my core values and beliefs. So some of the things that I have to sort of suffer with it are actually things that I’m sort of <u>choosing</u> to suffer with it because they’re important to me. So I mean around eating unprocessed food and home-cooked food[…]The condition actually <u>forces</u> me to live up to some of my values!”. Nic*

7.4 Discussion

Study Three aimed to explore participants' accounts of attending the LWWCD Toolbox intervention. Qualitative analysis identified several key features characterising participants' experience of the intervention.

7.4.1. Key features of participants' experience of attending *the LWWCD Toolbox intervention*

7.4.1.1. Attitudes

Participants expressed a state of enthusiasm and readiness about developing knowledge and skills to support self-management of the psychosocial impacts of CD. Prochaska and DiClemente's (1982) transtheoretical model of behavioural change may relate to these findings. Even before attending, participants all engaged in substantial maintenance behaviours as they self-managed their GFD well. The readiness to change expressed by participants may have been a causal factor in their positive engagement with the LWWCD intervention sessions and the progress most made towards their commitments once the sessions ended. Curiosity, interest, and willingness to try something new also appeared to drive some participants' attendance. The results suggest that the intervention was perceived to offer a novel opportunity and encouraged engagement with new people and with positive activities.

7.4.1.2. Engagement with a CD Community

Study Three found that engaging with a community of people living with CD was a beneficial component of the experience for participants. The opportunity to connect with others living with CD both attracted people to the intervention and proved therapeutic. Therapeutic benefits were threefold: sharing stories normalised difficult feelings about living with CD; provided cathartic release in a safe, empathic environment; and reduced participants’ sense of isolation.

The analysis also revealed the potentially divisive power of group dynamics. The current intervention took an overt patient-practitioner partnership approach, commonly used by CBT and health-behaviour change practitioners (Michie et al., 2008; Wills, 2014). This approach was intended to reduce anticipated in-group-out-group dynamics between the coeliac group and facilitators who did not have CD. Results suggest that this approach effectively reduced these potentially divisive group dynamics.

Formal and informal peer support can benefit those living with long-term conditions through building resilience and self-efficacy, reducing isolation, and increasing hope (Black, McLaughlin, & Giles., 2020; Pryce, Moutela, Bunker, & Shaw., 2019). Sharing information and knowledge with peers may also increase a sense of control and facilitate goal-setting (Black et al., 2020; Pryce et al., 2019). However, peer support in groups does carry some risks, as members can fall victim to negative in-group out-group dynamics (Pryce et al., 2019). Study Three piloted a professionally facilitated, structured group in the semi-formal setting of the University. Our findings suggest this format provided organisation, focus, and structure, enabling the group to remain supportive, reflective, and safe.

7.4.1.3. Acceptance and values-driven action

The LWWCD intervention combined acceptance and values-driven action (from ACT) with traditional behavioural strategies and psychological education. This intervention structure aimed to provide participants with a balanced ‘toolbox’ to apply to their daily life. A systematic review of 18 transdiagnostic studies by Graham, Gouick, Krahe, & Gillanders. (2016) concluded emerging evidence that ACT-based interventions often improve psychological flexibility and self-management in populations with long-term conditions. The reviewers suggest ACT may be effective in long-term conditions because ACT encourages acceptance of the often inevitable negative psychological experiences associated with long-term conditions, rather than attempting to challenge these in the style of ‘second-wave CBT’ (Graham et al., 2016). Participants did appear to broaden their thinking around the difficulties they encountered, identifying where they could manage situations differently and where they needed to accept limitations and uncertainty. Some participants integrated the idea of CD into their core values and began to engage more positively with activities related to self-management of CD and broader wellbeing (e.g. home-cooking, fitness). Acceptance appeared evident in some participants’ willingness to seek ongoing support once the intervention ended. Our analysis found that participants recognised the strategies learnt did not provide a ‘quick fix.' Still, many had developed a more flexible, holistic approach to their lives that included acceptance, challenge and positive values-driven activity that supported living well with CD.

7.4.1.4. Progression

Hope can support people in adjusting to long-term conditions (Hirsch & Sirois, 2016; Pryce et al., 2019). Follow-up found that most participants had progressed towards their goals or remained hopeful that they would soon do so. ACT theory states that linking action to core values increases engagement and meaning (Harris, 2019). Indeed, participants found the core values exercise engaging and revealing and still expressed engagement with these plans and ideas at follow-up. Harris (2019) emphasises the importance of taking action, expecting failure, and committing to continue to act in the direction of your values despite failure. The ‘Stepping Stones’ exercise (Brassington et al., 2016) undertaken in week six emphasises the need for flexibility and ‘baby steps’ but does not explicitly state that participants should expect some failures. Adding a reference to an anticipated experience of failure to the worksheet (e.g. ‘slipping off a stone’) could encourage participants to persevere, despite likely setbacks (Harris, 2019).

7.4.2. Experience of the intervention structure and materials

The structured content supported both participants’ learning and acceptance of difficult feelings relating to CD (theme “*You have all these random thoughts.*”). Visuals and metaphors were used throughout sessions, as is typical in ACT (Brassington et al., 2016; Harris, 2019). This approach helped participants to recall and relate to different ideas and models covered without confusion. They also engaged with the ‘toolbox’ metaphor, and some described how they had begun to construct and use their own ‘toolbox’ from the strategies presented. As expected, different participants engaged more strongly with other models and ideas, and the ideas participants worked with and reflected upon post-intervention varied. Participants also drew ideas from the group discussions and added these to their ‘toolbox’. Overall, the intervention structure and materials appeared relevant and facilitated learning.

7.4.3. Implications for future development of the *LWWCD Toolbox intervention*

7.4.3.1. Evidence of Need

The current study provided evidence of the need for a group-based supportive intervention aimed at people living with CD. Our participants arrived having managed psychosocial disease burden and isolation with minimal support from health professionals or other sources. They welcomed support with the broader issues related to CD and connection with a supportive group of peers. Further development and provision of the intervention would be likely to attract more participants.

7.4.3.2. Drawing further on the positive influence of the group.

Facilitators did not actively encourage participants to share aloud the goals or commitments they wrote down in sessions because the researcher wanted to allow participants control and choice in how they engaged with the intervention and keep sessions relaxed. However, interview data revealed that some participants had made multiple or rather vague commitments, despite facilitators explaining that this could make following through on a commitment more difficult. Encouraging the group to make a public commitment aloud to the group may have increased the likelihood of participants' progression. Some ACT practitioners recommend making commitments public (Harris, 2019) to increase participants' resolve and sense of direction. This outcome seems likely considering the powerful group dynamics present in this study (theme: *Influence of the group*). Sharing commitments aloud would also allow the facilitator to check that the goals set were SMART and provide guidance where needed (Harris 2019).

Facilitators did not actively encourage participants to remain in touch, though some participants did so. Others expressed regret that they had not done this. The majority felt a ‘refresher’ session would be helpful and enjoyable. In future, a closed social media group or a ‘reunion’ session could provide a ‘safe’ way for participants to remain in touch, share learning and support each other.

7.4.3.3. Focus on those recently diagnosed (1-5 years).

Participants recruited in Study Three were mostly quite recently diagnosed and, as expected, knew the basic information required about the condition and self-management. However, some participants reported finding the folder of reference material helpful as a ‘refresher’. Our findings suggest that our eligibility threshold of ≥ 1 year was suitable, as people had already learnt the essential medical information and had attended at least one dietetic interview.

7.4.3.4. Psychosocial attitudes to food

An interesting finding was that although participants did not require dietetic information, they were interested in exploring food's psychosocial significance within their lives. Some participants found that thinking about their relationship with food and how this related to their adjustment to CD and their core values was crucial in moving forward. A module exploring psychosocial attitudes to food would be a relevant addition to the intervention.

7.4.4. Strengths

The use of semi-structured interviews, TA and a limited realist perspective provided the methodological flexibility needed to evaluate a highly structured intervention. Participants had space within the research interviews to fully describe their experience in their own words and put forward their ideas. Yet, the interview guide had enough structure to ensure interviews covered all topic areas and objectives.

The collection of longitudinal data is comparatively uncommon in TA but was a strength in the current study because it allowed exploration of the behavioural and psychological outcomes of the goals and commitments participants set at the end of the intervention. Using independent student interviewers, rather than the researcher, allowed participants to freely express their thoughts about the intervention without any social concerns about upsetting the researcher who had been their LWWCD facilitator.

Finally, two supervisors and a postgraduate psychology student supported the researcher's analysis and interpretation of the data. This assistance helped to ensure consistency and ecological validity of the analysis, which was particularly important given the researcher’s proximity to the intervention itself.

7.4.5. Limitations

The researcher’s involvement in the design and delivery of the intervention is a source of potential bias in Study Three, though multiple measures were taken to reduce this impact. The study also had a relatively small participant sample. Some sessions had much greater attendance than others, which may have led to some aspects of the intervention being given greater consideration in the analysis than others.

Finally, Study Three presents data from participants who completed the intervention. Two participants dropped out in sessions three and four, and we do not have any information about their perceptions of the intervention. It may be helpful to understand what prompted participants to drop out and how to reduce drop-out in further roll-outs of the intervention.

7.5. Conclusion

In conclusion, the LWWCD Toolbox intervention achieved its primary aim of providing a community-based psychological intervention to adults living with CD. Study findings would support recommendations to offer the intervention again in the future, with some developments to the original content. Participants appeared to experience psychological benefits from the group format, which may have enhanced the overall effectiveness of the intervention. A key objective of the LWWCD Toolbox intervention was to help participants consider and manage the broader psychosocial impacts of CD. The results found that all participants felt in need of psychosocial support related to their condition. The intervention appeared effective in helping them clarify their areas of difficulty and generate useful strategies to live better with CD.

CHAPTER EIGHT: GENERAL DISCUSSION

8.1. Thesis Aim

The overall aim of this thesis was to develop an intervention to support adults' psychosocial adjustment to CD. This aim included the following objectives: 1) to develop an intervention programme and delivery format that would be acceptable and feasible to people living with CD; 2) to undertake a brief assessment of the intervention's acceptability and feasibility through an initial proof-of-concept study.

8.2. Summary of findings

8.2.1. Study One

Study One (Chapter Three) was a qualitative study with a group of adults (N=9) living with CD. Participants were unanimous that a psychoeducational intervention would be a useful source of support for people adjusting to CD. A group intervention format was felt to be particularly appropriate, as people living with CD are keen to interact with peers who share the condition. Themes highlighted that CD significantly affects people's lives by disrupting social interactions, eating behaviours, daily routines, and increasing the effort involved in everyday activities like shopping, cooking and travelling. Results revealed that CD raises people's anxiety about health, social interactions, and personal food safety. Feelings of loss, regret, and anger were evident due to both changes experienced post-diagnosis and the considerable diagnostic delays many people living with CD had experienced. Participants experienced these negative psychosocial impacts despite their overall confidence in self-managing the GFD and their generally improved health. These findings support results reported by Fuchs et al. (2018), who found that 53% of participants in a study of adults living with CD (n=611) experienced a delayed diagnosis (≥ three years). Further, Fuchs et al.'s (2018) study found that participants who had experienced diagnostic delay reported significantly elevated levels of anxiety and significantly poorer general health at one-year follow-up, despite following a GFD. These findings support the researcher’s hypothesis that many people living with CD require psychosocial support, even if they are successfully self-managing treatment. Interestingly, Study One, and the qualitative evidence synthesis (Chapter Two), also identified that many people living with CD experience positive impacts from their diagnosis and GFD lifestyle. Based on these findings, positive changes related to CD was a construct explored further in the thesis. The concept of *Positive Changes* became a subscale of the LWWCD-27 (Chapter Four), which was developed and used as an outcome measure in the intervention proof-of-concept study (Chapter Six).

8.2.2. Study Two

In Study Two (Chapter Four), a measure of psychosocial adaptation to CD (LWWCD-27) was developed and subjected to preliminary validation with a sample of 351 UK adults living with CD. This measure consists of three subscales, which are: *Concerns and Losses,* designed to assess psychological and social adjustment to CD; *Positive changes*, designed to assess positive psychosocial changes related to CD; and, *Risk management*, designed to measure the influence of psychosocial factors on GFD management. The LWWCD-27 demonstrated a reliable internal structure and good construct validity. Psychometric strength and conceptual focus meant that the LWWCD-

27 was a suitable outcome measure for use in the intervention proof-of-concept study (Study Three).

8.2.3. Study Three

In Study Three (Chapters Six and Seven), a six-session psychological intervention developed by the researcher (Chapter Five), underwent initial proof-of-concept testing. The intervention ran twice in 2019, with a period of three months between each run (see Figure 6, p. 206). Results demonstrated that the intervention was feasible and acceptable to participants, with acceptable levels of attrition and completion. Outcome measures showed that participants had moderate levels of anxiety and stress at the start of the intervention. At the end of the intervention, repeated measures showed significantly improved anxiety and stress levels, which were sustained at follow-up six weeks later. Longitudinal results found that improvements in anxiety were not maintained at 22-week follow-up, though stress levels remained significantly improved from baseline. The CD-specific measure (LWWCD-27) showed improved scores on both the *Total* scale and *Concerns and Losses* subscale that were statistically significant at weeks 12 and 22. These results suggest that participants experienced some psychosocial improvements, which were partially sustained, following the completion of the intervention.

Qualitative data from Study Three indicated that participants benefited from the group experience and from using the dedicated time and space provided by the intervention to reflect on the changes CD had brought to their lives. Participants felt learning about psychological models and how these could be applied to the experience of living with CD helped them to normalise and make sense of their feelings and behaviours. Practical exercises (e.g. values identification, goal-setting, positive-activity scheduling, reframing) enabled participants to develop strategies to manage some of the everyday difficulties they encountered.

8.3. Contribution to knowledge

The current thesis has made a significant and original contribution to knowledge by developing the LWWCD Toolbox intervention and establishing the programme's acceptability and feasibility through an initial proof-of-concept study. At the time of writing, this was the first psychological intervention designed specifically to support adults with *psychosocial adjustment* to CD and the first psychological intervention for adults with CD developed in the UK.

Before this thesis, only two psychological interventions for people with CD were reported in the literature, and both of these primarily aimed at improving self-management of the GFD. Though self-management of the GFD is critical to living with CD, the current thesis took a different approach to intervention by aiming to support people to manage difficult feelings about having received the diagnosis of CD and about the GFD. This approach was grounded in the researcher's synthesis of existing research evidence (Chapter Two) and primary research on people living with CD (Study One, Chapter Three). This work identified that many people living with CD who self-report successful GFD management struggle emotionally with the restriction and burden incurred by the diet. Further, findings from the QES (Chapter Two) and Study One identified that people living with CD often experience negative psychological impacts relating to the diagnosis itself, including diagnostic delay. CD is a serious autoimmune condition, and diagnosis can create feelings of shock, loss, health-related anxiety and impact personal identity. These results support the direction taken in developing this new intervention and challenge the near-exclusive focus on self-managing the GFD taken in other interventions and available sources of support.

8.4. Implications for clinical health psychology

8.4.1. Supporting people who already have good self-management outcomes

Clinical health psychology interventions often target behaviour change directly relating to practical aspects of self-management, such as adopting adaptive behaviour (e.g. medication management) and reducing maladaptive behaviours (e.g. sedentary lifestyle). An example is an online intervention developed by Sainsbury et al. (2013) to improve self-management in adults living with CD who deliberately or inadvertently ate gluten. Similarly, 42 psychoeducational interventions, based on the health psychology SDT model[58], were reviewed by Phillips and Guarnaccia (2020). These interventions were designed to support people with diabetes or pre-diabetes to improve diabetes control or reduce the risk of progression through changing behaviours relating to nutrition and physical activity. Practical self-management behaviours are essential to living well with a long-term condition. Still, where intervention design is focussed on behavioural self-management, support becomes targeted only to those who are not coping with self-management (e.g. failing to reduce risks or to follow necessary treatment). Yet, findings from the three studies in this thesis show that those living with CD may experience psychological distress, despite

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[58] Self Determination Theory (SDT) (Deci & Ryan, 1985)

excellent self-management of their treatment and their overall health. This is because of the continued disruption, burden and change following a GFD has on people's lifestyle, and the health implications of the diagnosis, as evidence presented throughout this thesis has demonstrated. These findings suggest that psychological interventions are needed which combine support for both the necessary self-management behaviours (e.g. GFD) and the effective processing and self-management of the psychosocial impacts of long-term conditions (e.g. health-related anxieties, impact on identity). In this way, people will be supported whose difficulties relate to self-management behaviours (e.g. diet), emotional reactions (anxiety), or both. The LWWCD Toolbox intervention contained material that would support self-management of the GFD (e.g. sources of information, communication, and CBT strategies), but maintained an emphasis on wider psychosocial adjustment.

Guidance by NICE (2015) very briefly alerts health professionals to the risk that people living with CD may experience anxiety or depression and require intervention (NICE, 2015, Guideline 1.6.4.). However, if health professionals focus intervention on those clearly exhibiting anxiety, depression and poor self-management, they may fail to offer psychosocial support to those who are outwardly coping and in good health. Further, those living with CD may not self-identify as needing support and could fail to engage in help-seeking behaviours. A qualitative study by Stewart et al. (2012) found that people living with Hepatitis C and experiencing psychosocial distress were often reluctant to seek help because they believed their problems were not sufficiently serious to justify accessing support. Stewart et al.'s (2012) study found other barriers to help-seeking, including poor awareness of the psychosocial support available, beliefs that under-resourced mental health services could not support non-urgent needs, and not understanding how talking therapies could help with problems relating to a physical health condition. Healthcare professionals need to be able to identify those with mild-moderate psychosocial distress, encourage help-seeking, and be able to signpost people to appropriate support. The LWWCD-27 is a measure that shows promise of being a brief tool that healthcare staff could use to assess where those living with CD are experiencing psychosocial difficulties. The inclusion of items focussed on positive changes means that the measure shows where respondents are adapting well, and this may increase the acceptability of the measure by making it feel less threatening or negative to complete. Responses could be used to initiate a positive conversation about how people feel they have adjusted to CD, beyond their understanding of the diet, and where they might benefit from support.

8.4.2. Community-based psychological intervention

The LWWCD Toolbox was a community-based psychological intervention targeted at those who self-identified interest in the research and, in some cases, expressed a desire for some psychosocial support. The intervention aimed to destigmatise and normalise psychological symptoms, introduce evidence-based psychological models, and utilise these to support the everyday lives of people with CD. At baseline, participants, overall, showed evidence of moderate levels of anxiety and stress, though participants whose scores fell within the normal range on all measures attended the intervention too. Qualitative results found that all those who completed the intervention perceived they had received some benefit from the intervention in terms of living with CD. Notably, follow-up interviews found that some participants had subsequently engaged in further help-seeking through formal mental health services, Coeliac UK support groups, increased self-care activities, or continued contact with other participants. These outcomes indicate that self-initiated participation in a community-based psychological intervention helped participants understand where they might benefit from formal psychological intervention or additional support and encouraged appropriate help-seeking and self-care behaviours. These outcomes correlate with a systematic review of 98 interventions promoting mental health literacy (Xu et al., 2018). Xu et al. (2018) found that mental health literacy interventions improved intentions and behaviours towards help-seeking and resulted in improved mental health literacy, reduced personal stigma, and increased formal help-seeking. Interestingly, the reviewers found that, overall, interventions did not result in increased help-seeking from informal sources (Xu et al., 2018). This suggests that informal and formal help-seeking behaviours are different and that people may need additional psychological support, whether or not they have a supportive social network of family and friends.

Even though challenging, living with a long-term condition is one that many of us will face in our lives. In England, approximately one-quarter of adults aged 30-34 have at least one long-term condition. This figure rises steadily by age to 55% of adults aged 60-64 (Office for National Statistics, 2019). One role of health psychology is to provide psychologically informed, evidence-based and safe guidance and techniques that people can access to help the process of psychological adjustment to health challenges. Psychological support can ensure that the understandable distress created by adjustment to a long-term condition is manageable and does not escalate to severe levels of distress or create sustained barriers to living well. Given the recent evidence from meta-analyses of the increased risk of psychological distress in CD (reported in Chapter Two), accessible community-based psychological intervention may reduce these risks for those adjusting to the condition.

8.4.3. ‘Living well’ as an intervention target

The LWWCD Toolbox intervention aimed to help people ‘live well’ with CD, and exercises encouraged participants to think about what ‘living well’ meant to them. Participants were encouraged to develop psychological strategies like goal-setting, identifying valued actions and positive activity scheduling. These exercises were designed to broaden everyday experiences, increase positive emotional experiences, and raise participants’ quality of life. The aim of ‘living well’ reflects the concept of ‘positive health’, introduced by Seligman (2008). Seligman (2008) defined positive health as being *“beyond the absence of physical illness”*, *“desirable in its own right”* and consisting of factors including *“positive emotion, engagement, purpose* [and] *positive relationships”.* Seligman’s work is a central part of the Positive Psychology (PP) movement, which seeks to use psychological intervention to identify the positive aspects that are *“best in us”*[59] and build on these to maintain a positive personal identity, to achieve goals, and to cope with life’s difficulties (Worth, 2020). PP interventions are increasingly developed for people living with long-term conditions. Though a small systematic review of 14 positive psychology

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[59] Worth (2020)

interventions in health found inconclusive evidence for their effectiveness, participants found them acceptable and feasible (Ghosh & Deb, 2017). The definition of living well in PP, which aims to identify and foster positive feelings (e.g. happiness and ‘flow’) and traits (e.g. `character strengths’), differs from the idea of living well defined in ACT.

In contrast to PP, ACT defines living well as having an integrated awareness and acceptance of both positive and negative mental and physical events, which are, essentially, unavoidable facets of a life lived fully (i.e. without avoidance). However, there are clear parallels between strategies used and outcomes attained in both movements. Shared strategies include exploring personal values, engaging in positive activities, of contact with the present moment, and developing a sense of personal purpose. Shared outcomes include identifying and developing positive aspects of the self, like strengths and values, and focusing on engaging in activities of personal value. The positive approach to psychosocial adjustment taken by the LWWCD Toolbox intervention can be seen to reflect this relatively recent ‘positive shift’, which is creating marked changes in both health and clinical psychology.

8.4.4. Condition-specific interventions

Transdiagnostic interventions are those which can be applied with little or no adaptation either to a group of related physical disorders (e.g. different types of cancers) or a group of very different diagnoses (e.g. both mental and physical conditions) (Brassington et al., 2016). An example is the ACT intervention for long-term conditions developed by Brassington et al. (2016). This group intervention was completed by participants living with diverse conditions (e.g.

chronic pain, diabetes, bowel conditions, and cardiac diseases) and effectively improved psychological outcomes (Brassington et al., 2016). Transdiagnostic interventions have several benefits, including cost-effectiveness, little additional development of an original protocol, little ongoing training for facilitators, and are more acceptable to commissioners than condition-specific interventions, particularly where resources are low (Martin et al., 2018). Sauer-Zavala et al. (2017) describe the suitability of psychological techniques like CBT and ACT to transdiagnostic application, as the intervention mechanisms of change and symptoms addressed are similar across conditions. However, Sauer-Zavala et al. (2017) argue that the 'one-size-fits-all' approach of transdiagnostic intervention cannot be assumed to work in all conditions. Importantly, results from Study Three identified clear benefits of the condition-specific approach for people with CD. For example, the theme *You don't just generally come across these people* described how meeting others with CD, sometimes for the first time, reduced feelings of isolation and normalised psychosocial experiences and the need for support. The subtheme *"Them vs Us"* showed how shared adversity increased group cohesion. The subtheme *Influence of the Group* found that the advice of group members was considered especially useful and authoritative to fellow participants.

Condition-specific interventions have benefits beyond the social interaction between people living with the same condition. Exercises and techniques can be tailored to the specific issues faced by people living with particular conditions. This may increase the likelihood that the technique would be considered relevant and so be utilised. An example from the LWWCD was session one, which focussed specifically on the GFD, and session five, which focussed on tailoring communication with other people about CD. It is unlikely that the specifics of the GFD would be relevant to those with other diagnoses but are necessary to ensure people are self-managing their diet and communicating their needs to others. Similarly, part of the *communication* session involved discussions of the sociocultural factors which create misunderstanding and stigma, some of which are very specific to CD (e.g. the ‘gluten-free fad’). The group spent time thinking about the different meanings others ascribe to requests for GF foods and how such requests can be communicated in different situations. Finally, condition-specific intervention may also increase acceptability and engagement from participants, as was conveyed in the findings of Study Three, in which participants felt the LWWCD facilitators were knowledgeable and empathic towards the unique dilemmas those living with CD face.

However, despite the benefits of a CD-focus in Study Three, it is important to consider the increasing incidence of other gluten-sensitive conditions, such as non-celiac gluten sensitivity (NCGS), when considering a future roll-out of the LWWCD intervention. NCGS has an estimated worldwide prevalence of up to 10% (Rej et al., 2020). NCGS differs considerably from CD because it has no biomarkers, a variable timeframe, and variable response to GFD management. Still, it means that many people who are not diagnosed with CD maintain a medically-prescribed GFD for an extended period (Rej et al., 2020). Future work could explore the suitability of the LWWCD intervention for those with NCGS and other gluten-related conditions. It would be important to explore the impact on the group experiences if participants with CD and NCGS were combined.

8.4.5. Using a multi-model ‘toolbox’ intervention

The LWWCD Toolbox intervention introduced multiple psychological models to participants, including CBT, ACT and the Five Stages of Grief. This eclectic approach allowed participants to choose the strategies and ideas they felt were most helpful. Qualitative findings from Study Three found that different participants identified different strategies and ideas from the intervention as most useful and memorable. This finding supported the researcher’s reasoning that a one-size approach would not be appropriate for a diverse group of people living with CD. This approach may have been particularly appropriate for a community-based intervention engaging a self-selecting group of participants. Self-selecting participants were not referred to the intervention by a professional (e.g. GP, dietician). They therefore had no imperative to continue to attend if they did not find the intervention useful or engaging.

Despite the benefits of a multi-model toolbox approach, there are potential drawbacks. When designing a hybrid CBT-ACT intervention for multiple sclerosis, Harrison et al. (2017) were concerned that participants may become confused about challenging or accepting unhelpful thoughts. Each discrete LWWCD module focussed on specific topics (e.g. communication, anxiety, information searching) and referred to only one or two psychological models in each session. Qualitative data suggest that participants were not confused and responded well to the sessions. Outcomes in an eclectic intervention may be reduced by the comparative shortness of each component, which means participants receive a low ‘dose’ of each strategy and do not repeat material covered in earlier sessions. Due to this limitation, participants risk leaving the course with incomplete understanding or retaining common misunderstandings about the material (e.g. that negative automatic thoughts are ‘wrong’; or that diffusion or mindfulness exercises are designed to suppress or distract from distressing thoughts). Finally, it is difficult to assess the relative impact of the various segments of an eclectic course, and it is important to include only effective, relevant material within modular interventions. Overall, practitioners need to weigh the pros and cons of mixed-model and single-model interventions with different populations. In Study Three, attrition, completion, quantitative outcome measures, and qualitative feedback suggested that the LWWCD Toolbox was acceptable, feasible and helpful to participants. Future work could assess the feasibility of individual modules through post-session feedback, using methods such as short quizzes and reflective diary entries. Similarly, future work could compare outcomes from the mixed-model version used in Study Three against a single-model variant covering the same topics in each module.

8.4.6. Supporting an individual to ‘live well’ within a stigmatising sociocultural climate

A recent systematic review of 14 studies of disabled people and their families reported that people with acquired or congenital differences face severe inequality and social exclusion, leading to reduced activities, opportunities and social interaction (Caynak et al., 2021). Similarly, a study by Kulkarni (2021) found that those with hidden disabilities experience stigmatisation and face dilemmas about disclosure, often engaging in behaviours that conceal their condition, such as avoiding certain activities and social events at work. The qualitative evidence synthesis in Chapter Two and Study One and Study Three of the current thesis found that people living with CD experience hostility and social stigma, correlating with findings reported in studies by other authors. For example, a qualitative study by Schroeder and Mowen (2014) describes both social and self-stigma related to the GFD, with participants reporting exclusions in many areas of life, including religious practice, dating and college activities. Psychologists face a considerable challenge in providing support to individuals with CD within a wider sociocultural climate of barriers, stigmatisation and exclusion. Recognition within interventions of wider sociocultural influences on behaviour is important. The current researcher attempted to address this throughout the intervention, particularly through the discussion sections within sessions, in which people discussed instances where they felt the GFD had impacted their lives in areas such as reduced opportunities, gender identity, social identity and religious participation. Participants also discussed the impact of CD on family relationships. They described tension created between spouses, between older and younger generations, and their concerns about the potential impact of their GFD on their children's food-related behaviours. It may be useful to develop interventions for CD that include information designed to support family members, which may help to reduce some of the social and environmental barriers to self-management and wellbeing people living with CD experience.

In the behaviour change wheel model (Michie et al., 2011), sociocultural policies operate at a macro-level to enable or disable an intervention's ability to impact an individual’s behaviour. According to the COM-B model, which is the central ‘hub’ of the behaviour change wheel, behaviour is enabled by an individual’s ***C****apability* (psychological and physical), ***O****pportunity* (social and physical), and ***M****otivation* (automatic and reflective). Interventions in health psychology enable behaviour change by developing an individual’s *capability*, *opportunity* and *motivation*, as needed. For example, the LWWCD intervention used psychoeducational material and education on externally available resources to increase people’s capacity to socialise and travel with CD. Macro-level factors that support this include the GF food-labelling laws, the increasing availability of GF foods and increased public knowledge about CD. However, there remain macro-level barriers that can thwart the best behavioural efforts of people living with CD. For example, participants may change their behaviour by developing a clearer explanation of their needs tailored to particular situations, pre-research venues and booking ahead. However, they are still likely to encounter situations where expected options or resources are unavailable, labelling or information is unclear, or other people attribute cultural misconceptions about ‘fad diets’ and food-related health conditions to their need to follow the GFD. In such situations, strategies from ACT are potentially useful, allowing participants to accept the inevitability of certain barriers and failures, whilst persevering to ‘change what they can’ to live well with CD.

8.4.7. Accessibility and inclusivity

Despite a high initial response to the call for participants, only nine people completed the intervention. Key barriers to recruitment were travel distance, travel costs and the time needed to participate in all six sessions. Alternative formats, such as a residential course or an online programme, would allow those living further away or with less ability to spare a regular block of time over six weeks to attend. Adults are diagnosed with CD at all ages, and, as our research found, many are working or studying full-time, have caring responsibilities or are non-drivers. These factors increase the difficulty of travelling long distances or repeatedly attending live sessions. Future research could explore adaptation of the LWWCD Toolbox into more accessible formats. Sainsbury et al. (2013) delivered an online CBT intervention for people with CD comprised of a static set of six modules that participants worked through in their own time. Online psychological interventions in health psychology have rapidly increased over the last 20 years (Simon et al., 2021), in part due to rapid advancements in technology and increased public access to the Internet. Since the start of the COVID-19 pandemic in 2020, the delivery of online psychological interventions in the UK has increased further, and modular CBT courses are one of the most frequent types of intervention delivered in this way (Simon et al., 2021). Attitudes to online participation have also changed. A qualitative stakeholder study by Simon et al. (2021) found that service managers were increasingly positive about the potential of these interventions to deliver low-intensity support and reported that some service-users preferred remote services. Technology now enables online modules to embed video tutorials with subtitles, and live sessions are easily delivered. Online group meetings, moderated closed discussion boards and closed social media groups can enable a community of participants to connect with and support each other safely without meeting face-to-face. These developments in social attitudes and technological options mean that an online format for the LWWCD would likely be acceptable to many people. Future work to develop an online version of the LWWCD Toolbox would need to explore whether remote sessions enabled similarly supportive community connections that the face-to-face intervention provided in Study Three, as this appeared to be a valuable part of the course experience (Chapter Seven).

8.5. Strengths

Systematic, evidence-based approach to development: The researcher developed the LWWCD intervention systematically, following an established Theory of Change development model (New Philanthropy Capital, 2021; Harries et al., 2014). The systematic ‘bottom-up’ intervention development process ensured that content was grounded in the needs and experiences specific to the target group, which were identified through the synthesis of existing research and a primary study with people living with CD (Study One). This systematic approach increased the acceptability and relevance of the intervention to the target group. It ensured that all included content was linked to one or more of the intended outcomes (Chapter Five). The intervention content incorporated established psychological models and theories – including CBT, ACT, health behaviour change techniques (Michie et al., 2008), and the Stages of Grief model (Kübler-Ross, 1970).

Review by people living with CD and experts on CD: The objectives, model and materials were reviewed by people living with CD and experts in CD. These consultations helped to ensure that the material was acceptable and relevant to the target group's lives. The researcher collaborated with two experienced

Clinical Psychologists (RH, GL) to develop the course and its materials, ensuring that the content was clear and manageable. A third experienced Clinical Psychologist, and expert in CBT and ACT intervention, was consulted as part of the development process to provide an external perspective on the programme. This strengthened the course content and contributed to the successful delivery of the intervention. By gathering qualitative data at two post-intervention timepoints, the researcher gained insight into participants' experience of the course, what they valued and found useful, and identified possible changes for future roll-outs.

8.6. Limitations

Study size: Study Three was a small proof-of-concept study, and therefore no causal evidence for the effectiveness of the intervention could be generated. Similarly, the lack of a control or comparison group meant that no evidence could be gathered regarding the effectiveness of the LWWCD intervention compared against treatment-as-usual.

Risk of bias: An important source of potential bias in this study is that the researcher conducted data collection and analysis alone during Study One and the qualitative evidence synthesis (Chapter Two). In Study Three, the researcher was supported in delivery of the intervention and analysis of the data by three students, and this provided the researcher with a valuable source of reflection. The students undertook all qualitative data collection in Study Three which gave participants the necessary space to reflect on their experience without the researcher's presence. In retrospect, the thesis findings would have been strengthened by research assistant support in the earlier studies.

8.7 Directions for future research

The discussion above has outlined several potential areas for future research based on the findings of this thesis. Having established initial proof-of-concept for the LWWCD Toolbox intervention, a trial is now recommended with a larger sample of participants to confirm its acceptability and feasibility. This should include a waitlist control group against which outcomes are compared. It is also important that future research explores alternative formats, especially online delivery, which would increase the accessibility and reach of the intervention. Finally, Study Three attracted participants who were already confidently self-managing CD. The researcher has argued in this thesis that such people are likely to experience psychological distress and benefit from intervention. It is also important to consider how those who struggle to manage their GFD might benefit from support through this intervention and be recruited in further trials.

8.8. Conclusion

This thesis aimed to develop an intervention to support adults to manage the psychosocial challenges of adapting to CD, enabling them to live well. Results reported in the thesis established a need for this type of intervention in the CD community. An initial proof-of-concept study demonstrated the acceptability and feasibility of the new intervention. Participants drew support from the psychoeducational content and the group delivery format. Overall, this work demonstrates that a biopsychosocial approach is needed to ensure that people live well with CD. Crucially, effective dietary self-management can have a high psychosocial cost due to the everyday disruption and burden it creates. Therefore, an important conclusion of this work is that psychosocial intervention is often needed by people who are effectively self-managing their GFD.

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APPENDIX A: Ethical Approval

Study One (Chapters Three and Four)

Re: “Design and validation of the Living Well with Coeliac Disease Measure (LWWCD)”
Application for Ethical Review ERN_15-0637

Thank you for your application for ethical review for the above project, which was reviewed by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

Study Three (Chapters Six and Seven)

Re:“Pilot delivery and study of the CBT-ACT based psychoeducational intervention Living well with coeliac disease”
Application for Ethical Review ERN_17-1232

Thank you for your application for ethical review for the above project, which was reviewed by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

Study Three (Chapters Six)

Re: “Pilot delivery and study of the CBT-ACT based psychoeducational intervention Living well with coeliac disease” Application for amendment ERN_17_1232A

Thank you for the above application for amendment, which was reviewed by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I can confirm that this amendment now has full ethical approval.

APPENDIX B. Chapter Two- Supplementary Tables

Supplementary Table I. (Chapter Two) Screening of papers informed by the SPIDER search tool.

SPIDER	Inclusion	Exclusion
S: Sample	Adults with a medical diagnosis of CD. Diagnosis self-reported or reported in patients' records. Medical diagnosis is via any or all of the following: serological tests, gut-biopsy tests, or genetic testing.	Studies with mixed child and adult samples; samples with participants < 18 years old; studies where data was collected pre-diagnosis; participants without a medical diagnosis of CD; participants following a GFD for reasons other than treatment of CD; studies where it is unclear if participants' have obtained a medical diagnosis of CD.
PI: Phenomenon of Interest	Articles in which the primary foci are the psychological or social impacts of CD. Such impacts include anxiety, depression, fatigue, eating disorders, disordered eating, feelings, emotions, mood, quality of life.	Studies where the primary foci are not the psychological or social aspects or CD. Studies where qualitative data is very thin or unclear. Studies that focus on neurological conditions (e.g. epilepsy, gluten ataxia), developmental conditions (e.g. ASD, ADHD) or severe psychiatric disorders (e.g. psychosis, schizophrenia, suicidal behaviours).
D: Design	Qualitative designs with multiple participants, including interviews, focus groups and narrative studies. Studies may cover a range of qualitative methodologies, including thematic analysis, grounded theory, IPA, experiential studies, ethnography.	Single case studies; auto-ethnography, reviews, letters, conference proceedings, essays and opinion pieces,
E: Evaluation	Data presents participants' perceptions, experiences, views, or attitudes regarding CD's psychosocial or social impacts.	Secondary research on the experience of living with CD. Quantitative outcomes.
R: Research type	Qualitative or mixed-methods studies published in peer-reviewed journals in the English language. A complete English translation of studies undertaken in another language.	Quantitative studies. Studies in non-peer-reviewed journals; unpublished theses; non-English language studies (where no translation is published).

Supplementary Table II. (Chapter Two) Selection of Quality Appraisal Tool using criteria by Majid and Vanstone (2018)

Tool	*Origin*	*Purpose*	*Criteria*	*Items*	*Structure*	*Ethics*	*Expertise*
CASP (2006)[1]	UK	- QES appraisal - reporting standards - educational tool	- Interrogative criteria	10	Short length, structured. Scoring given.	Explicit appraisal item.	Recommended for novice assessors
COREQ (2007)[2]	Australia (Healthcare/ medical)	- QES appraisal - reporting standards	- Interrogative criteria - Limited to interview and focus group studies	32	Moderate length; balances breadth and comprehensiveness. No guidance for the assessor.	No explicit check.	-
ETQS (2004)[3]	UK (Sociology)	- QES appraisal	- Interrogative criteria	38	Lengthy, comprehensive.	Reflexive questions.	-
JBI (2020)[4]	Australia (Healthcare/ medical)	- QES appraisal	- Interrogative criteria - Aimed at policymakers	10	Short, structured. Scoring given.	Explicit appraisal item.	-
SRQR (2014)[5]	USA (Healthcare/ medical)	- QES appraisal - reporting standards - manuscript review	- Declarative criteria - designed to apply across all qualitative methods	21	Moderate length; Balances breadth and comprehensiveness.	Explicit appraisal item.	Requires some experience to make a judgement.
Walsh (2006)[6]	UK (Healthcare/ medical)	- QES appraisal - rapid reviews in policymaking	- Declarative criteria	12	Short length.	Reflexive questions.	-

1. Critical Appraisal Skills Programme (CASP, 2021); 2. Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007); 3. Evaluation Tool to assess the quality of Qualitative Studies (Long & Godfrey, 2004); 4. Checklist for Qualitative Research (Joanna Briggs Institute, 2020); 5. Standards for Reporting Qualitative Research (O'Brien et al., 2014) 6. Criteria put forward by Walsh and Downe, (2006)

Supplementary Table III. (Chapter Two) Consideration of the RETREAT[1] criteria in the selection of the QES method

RETREAT criteria	*Approach to meta-synthesis used in the current chapter*
(R) Review Question	The research question provides clear anchors which keep research within parameters (e.g. target group, type of phenomena, purpose of review). However, the QES method must be flexible enough to expand the researcher's initial concepts of 'social' or psychological' impacts.
(E) Epistemology	The researcher adopted a limited realist position (King, 1998) throughout the project.
(T) Time / timescale	The review aims to synthesise a comprehensive but manageable bank of primary literature to provide an overview of the psychological and social impacts of living with CD. The review is one component within the background research section of a larger, time-limited intervention development study. The QES aims to balance breadth and depth. Data is expected to vary in degree of 'thickness', and studies will range in size and scope. Findings of primary studies will be broadly taken at 'face-value', in line with a limited realist position, rather than be submitted to extensive theoretical critique and interpretation.
(R) Resources	The research will only synthesise existing primary studies published in peer-reviewed journals. NVivo software will support line-by-line coding and sorting of codes into a thematic map. Reference management software (Zotero) will facilitate database searching. The current researcher will undertake all aspects of the review alone.
(E) Expertise	The current researcher has previously conducted primary studies using qualitative research, including thematic analysis (Braun & Clarke, 2006; Swain, 2018). A subject-specialist research librarian will support the development of the search strategy. The researcher will discuss the analytic findings at intervals throughout the review with an online interest group for QES studies and their research supervisors.
(A) Audience and Purpose	The QES will inform the design of a novel intervention by providing evidence of need and understanding the problem and potential solutions. The QES will be suitable for publication in journals in the fields of health and the allied professions.
(T) Type of Data	Research interviews, focus groups, written narratives.

1) Booth, A., Noyes, J., Flemming, K., Gerhardus, A., Wahlster, P., van der Wilt, G. J., Mozygemba, K., Refolo, P., Sacchini, D., Tummers, M. & Rehfuss, E. (2018) Structured methodology review identified seven (RETREAT) criteria for selecting qualitative evidence synthesis approaches. *Journal of Clinical Epidemiology* 99: 41-52.

Supplementary Table IV. (Chapter Two) Complete CERQual assessment of the evidence

Findings (overarching theme)*	*Studies*^{a}	*Methodological limitations*	*Coherence*	*Adequacy*	*Relevance*	*CERQual*^{b} *Assessment*
1. Anxieties and worries about health. (1)	11 studies (1, 2, 3, 4, 7, 9, 10, 11, 12, 15, 17)	Minor methodological limitations (seven studies did not discuss the research paradigm, no studies discussed the impact of research context, one study gave no rationale for chosen data collection method). Moderate methodological limitations (eight studies had no reflexivity). Serious methodological limitations (one study did not report trustworthiness).	No concerns	Minor concerns about adequacy (Body of evidence combined offers moderately rich data).	No concerns	High confidence
2. Distrust of or disappointment in health professionals. (1)	Six studies (2,4,10, 6,9, 12)	Minor methodological limitations (four studies did not discuss the research paradigm, no studies discussed the impact of research context). Moderate methodological limitations (four studies had no reflexivity).	No concerns	Moderate concerns about adequacy (three studies offering fairly thin data)	No concerns	Moderate confidence
3. Social fears. (1)	Five studies (1,3,4,12 , 15)	Minor methodological limitations (four studies did not discuss the research paradigm, no studies discussed the impact of research context). Moderate methodological limitations (four studies had no reflexivity). Serious methodological limitations (one study did not report trustworthiness).	No concerns	Minor concerns about adequacy (three studies offering relatively thin data)	No concerns	Moderate confidence

4. Fears of contamination. (1)	13 studies (1,2,3,6, 9, 10, 11,12, 13,14, 15, 16,17)	Minor methodological limitations (eight studies did not discuss research paradigm, no studies reported impact of research context). Moderate methodological limitations (nine studies did not report reflexivity, two studies gave a minimal description of instruments). Serious methodological limitations (one study did not report data processing; one study did not report on trustworthiness).	No concerns	Very minor concerns about adequacy (Body of evidence combined offers rich dataset).	No concerns	High confidence
5. Low moods. (1)	10 studies (2,3,4, 6, 9, 10, 12, 15, 16,17)	Minor methodological limitations (six studies did not discuss research paradigm, no studies reported impact of research context). Moderate methodological limitations (seven studies did not report reflexivity).	No concerns	Minor concerns about adequacy (Body of evidence combined offers rich dataset).	No concerns	High confidence
6. Anger, irritability, envy. (1)	Seven studies (4, 11, 12, 14, 15, 16, 17)	Minor methodological limitations (five studies did not discuss research paradigm, no studies reported impact of research context). Moderate methodological limitations (no studies contained reflexivity).	No concerns	Moderate concerns about adequacy (four studies offering quite thin data)	No concerns	Moderate confidence
7. Impact of CD on personal identity. (2)	Six studies (2,3,9, 10, 12, 17).	Minor methodological limitations (three studies did not discuss research paradigm, no studies reported impact of research context). Moderate methodological limitations (four studies did not report reflexivity).	No concerns	Moderate concerns about adequacy (four studies offering relatively thin data)	No concerns	Moderate confidence

8. Impact of CD on social identity. (2)	13 studies (1,2,3,4, 5, 6,7,8,,11, 12, 15, 16, 17)	Minor methodological limitations (eight studies did not discuss research paradigm, no studies reported impact of research context, one study gave no rationale for data collection methods, one study gave a minimal description of instruments). Moderate methodological limitations (nine studies did not report reflexivity). Serious methodological limitations (one study reported no details of trustworthiness).	Very minor concerns (concern regarding the fit between data from only one primary study and QES finding)	Very minor concerns about adequacy (Body of evidence combined offers rich dataset).	No concerns	High confidence
9. Changed food-related attitudes and behaviours. (3)	10 studies (1,2,4,6, 12,13, 14,15, 16,17)	Minor methodological limitations (seven studies did not discuss research paradigm, no studies reported impact of research context, one study gave no details of data processing, one study gave a minimal description of instruments). Moderate methodological limitations (eight studies did not report reflexivity). Serious methodological limitations (one study reported no details of trustworthiness).	No concerns	Very minor concerns about adequacy (Body of evidence combined offers rich dataset).	No concerns	High confidence
10. Food behaviours: Cheating and risk-taking. (3)	Five studies (2,12,14, 15,16)	Minor methodological limitations (three studies did not discuss research paradigm, no studies reported impact of research context, one study gave a minimal description of instruments). Moderate methodological limitations (no studies reported reflexivity).	No concerns	Very minor concerns about adequacy (Body of evidence combined offers rich dataset).	No concerns	High confidence

11. Practical burdens. (4)	Eight studies (1,2,3,6, 7,12, 15, 16)	Minor methodological limitations (five studies did not discuss research paradigm, no studies reported impact of research context, one study gave no rationale for data collection methods, one study gave a minimal description of instruments) Moderate methodological limitations (five studies reported no reflexivity). Serious methodological limitations (one study reported no details of trustworthiness).	No concerns	Minor concerns about adequacy (Body of evidence combined offers a moderately rich dataset).	No concerns	High confidence
12. Economic burden (4)	Six studies (1,2,6,8, 15,16)	Minor methodological limitations (four studies did not discuss research paradigm, no studies reported impact of research context). Moderate methodological limitations (four studies reported no reflexivity). Serious methodological limitations (one study reported no details of trustworthiness).	Very minor concern (concern regarding the fit between data from only one primary study and review finding)	Minor concerns about adequacy (Two studies offer thin data, one very thin data).	No concerns	High confidence
13 Educating others and maintaining vigilance over their actions. (4)	Four studies (3, 5, 12, 15)	Minor methodological limitations (two studies did not discuss research paradigm, no studies reported impact of research context, one study gave a minimal description of instruments). Moderate methodological limitations (two studies reported no reflexivity, one study gave incomplete details of sampling strategy).	No concerns	Moderate concerns about adequacy (Two studies offer relatively thin data).	No concerns	Moderate confidence

14. Managing co-morbid conditions and CD symptoms. (4)	Four studies (4, 7, 12, 15)	Minor methodological limitations (no studies discussed research paradigm, no studies reported impact of research context, one study gave no rationale for data collection methods, one study gave a minimal description of instruments). Moderate methodological limitations (no studies reported reflexivity).	No concerns	Moderate concerns about adequacy (3 studies offer relatively thin data).	No concerns	Moderate confidence
15. Shouldering the burden alone. (4)	Six studies (1,2,3,4, 11, 12)	Minor methodological limitations (three studies did not discuss research paradigm, no studies reported impact of research context). Moderate methodological limitations (four studies reported no reflexivity). Serious methodological limitations (one study reported no details of trustworthiness).	No concerns	Moderate concerns about adequacy (Two studies offer fairly thin data, two very thin data).	No concerns	Moderate confidence
16. Positive impact of social and professional support network. (4)	Six studies (1, 2, 3, 6, 7, 17)	Minor methodological limitations (four studies did not discuss research paradigm, no studies reported impact of research context, one study gave no rationale for data collection methods, one study gave a minimal description of instruments). Moderate methodological limitations (three studies reported no reflexivity). Serious methodological limitations (one study reported no details of trustworthiness).	No concerns	Moderate concerns about adequacy (Three studies offer fairly thin data, one very thin data).	No concerns	Moderate confidence

17. Living well: confidence and self efficacy. (5)	10 studies (1, 2, 3, 4, 6, 9, 11,12, 14, 17)	Minor methodological limitations (six studies did not discuss research paradigm, no studies reported impact of research context, one study gave incomplete details of sampling strategy, one study gave a minimal description of instruments). Moderate methodological limitations (six studies reported no reflexivity). Serious methodological limitations (one study reported no details of trustworthiness).	No concerns	Minor concerns about adequacy (5 studies offer relatively thin data, one very thin data).	No concerns	High confidence
18. Acceptance of CD. (5)	Nine studies (2, 3, 4, 5, 6, 9, 12, 14, 17)	Minor methodological limitations (five studies did not discuss research paradigm, no studies reported impact of research context, one study gave incomplete details of sampling strategy, two studies gave a minimal description of instruments). Moderate methodological limitations (six studies reported no reflexivity).	No concerns	Minor concerns about adequacy (Five studies offer relatively thin data, one very thin data).	No concerns	High confidence

a Studies: 1) Garnweidner-Holme et al., 2020; 2) Houbre et al., 2018; 3) Jacobsson et al., 2012; 4) Jacobsson et al., 2017; 5) King et al., 2019; 6) Lee et al., 2021; 7) Leffler et al., 2017; 8) Peters et al., 2020; 9) Price & Howard, 2017; 10) Ring Jacobsson et al., 2020; 11) Rodriguez Almagro et al., 2017; 12) Rose & Howard, 2014; 13) Satherley et al., 2018; 14) Satherley et al., 2017; 15) Sverker et al., 2009; 16) Sverker et al., 2005; 17) Taylor et al. 2013.

Overarching themes: 1) Impact of CD on mood; 2) Impact of CD on identity; 3) Impact of CD on food-related attitudes and behaviours; 4) Perceived illness burden; 5) Living well with CD

APPENDIX C: Chapter Three- Supplementary material

Semi-structured interview guide.

*The **first three** questions related to the review of the 45 draft questionnaire items, and analysis of this section of the interview is presented in Chapter Four (Study One, Part A).*

Question 1: Are there any questions which you don't understand, or which you think might be difficult for other people to understand? How could I make the question(s) easier to understand?

Question 2: Do any of these questions make people feel uncomfortable? Why do you think that might be?

Question 3: Is this questionnaire something you'd feel OK about filling in?

Analysis of this section of the interview is presented in Chapter Three (Study One).

Question 4: Do you think social interaction is an important area for our intervention to cover? Can you explain why you think that?

Question 5: Do you think looking at how people feel about their health after their diagnosis is important? Can you explain why you think that?

Question 6: Do you think it is important that we look at how people feel about losing gluten from their lives? Can you explain why you think that?

Question 7: Some research has found that people can find that Coeliac Disease is a considerable everyday burden in their lives. Do you think this idea of Coeliac Disease being a burden is something we should look at?

Question 8: We found that the research to date seems focussed on the problems people encounter post-diagnosis. Do you feel there can be positive things resulting from diagnosis too? Can you tell us more about that?

Question 9: Do you think there is a need for us to design an intervention to provide psychological support for people with Coeliac Disease? Can you tell me why you feel that?

Question 10: How do you feel about us designing our intervention around the areas we've discussed. Are there things related to living with CD that are relevant, but we haven't covered? Could you tell me about those?

APPENDIX D: Chapter Four- Supplementary Tables and materials.

Initial set of 45 questionnaire items reviewed in Study One (Chapter Four).

Social interaction (12 items)

1. I feel confident to ask people for gluten-free food when I eat outside my home.
2. I feel OK about sometimes eating differently to those around me.
3. People understand that I'm not just fussing about my food.
4. I eat gluten sometimes just to avoid being different.
5. When I explain my diet, it is quite easy for people to cook for me.
6. People still invite me eat out with them when they know I have Coeliac Disease.
7. Some people think I eat differently in order to get special attention.
8. If I think my food has gluten in it, I am confident to discuss this with the restaurant staff.
9. People take Coeliac Disease seriously when I explain it to them.
10. Some people think I'm boring or annoying because I follow a gluten-free diet.
11. I never worry about what other people think when they see me checking labels or buying special brands.
12. People are understanding when they know about my diet.

Feelings about your health (nine questions)

13. Having Coeliac Disease doesn't worry me.
14. I can minimise the impact of Coeliac Disease on my health by following the gluten-free diet.
15. Health professionals are able to give me all the information I need about Coeliac Disease.
16. I do not worry that Coeliac Disease increases my risk of health problems.
17. My gluten-free diet provides enough nutrition to keep me healthy.
18. I do not worry that Coeliac Disease damaged my body before I was diagnosed.
19. I don't worry if Coeliac Disease sometimes makes me feel tired or unwell.
20. People with Coeliac Disease can stay healthy.
21. I rarely get stressed thinking about Coeliac Disease and my health.

Losses / Changes (seven items)

22. Since being diagnosed with Coeliac Disease, I feel like just same person as I was before.
23. Avoiding gluten is not a big loss to me.
24. I rarely crave gluten-containing foods.
25. I never feel sad thinking of the foods I can't eat any longer.
26. My new diet is just as satisfying as my old diet was.
27. Eating is just as enjoyable on the gluten-free diet as it was before.
28. There are some special foods that I do really miss.

The burden of managing Coeliac Disease (seven questions)
29. Cooking and shopping for my gluten-free diet takes no longer than it did when I ate gluten.
30. I don’t find Coeliac Disease to be a burden in my life.
31. Food, eating and cooking seem to be always on my mind.
32. Keeping to a gluten-free diet is no real effort.
33. Coeliac Disease causes no hassle in my daily life.
34. I find the gluten-free diet quite interesting.
35. I don’t mind sometimes having to explain my diet to people more than once.

The positives of being diagnosed with Coeliac Disease (ten questions)
36. In some ways, my diagnosis of Coeliac Disease was a relief.
37. I much prefer having a diet-based treatment than having to take medication.
38. I am no longer worried about what might be wrong with me.
39. I enjoy trying new gluten-free foods.
40. I’ve become a much better cook since my diagnosis.
41. I feel that my new gluten-free diet is healthier than my old diet.
42. Since being diagnosed, I’m much more in control of my health.
43. I’ve been really happy at how other people in my life have supported me with my diagnosis and new diet.
44. I feel quite proud of myself for coping with Coeliac Disease so well.
45. I’ve enjoyed learning about how other people manage Coeliac Disease (e.g. through friends, support groups, online).

Supplementary Table V (Chapter Four). Items removed from the original set of 45 questions.

Item removed	*Reason removed*
Item 2. I feel OK about sometimes eating differently to those around me.	People felt this was unspecific.
Item 3. People understand that I'm not just fussing about my food.	People felt this was unspecific.
Item 4. I eat gluten sometimes just to avoid being different.	People felt risks were taken for specific practical reasons, such as there being no other option, not to avoid being 'different'.
Item 5. When I explain my diet, it is quite easy for people to cook for me.	Cooking for someone with Coeliac disease is inevitably difficult.
Item 6. People still invite me eat out with them when they know I have Coeliac Disease.	Unspecific: depends who and where. Hard to be sure why you haven't been invited.
Item 7. Some people think I eat differently in order to get special attention.	Unspecific: How do we know what others are thinking? They might disbelieve or argue, but that is different.
Item 9. People take Coeliac Disease seriously when I explain it to them.	Unspecific: Depends who the other person it. Sometimes people take it seriously but do not understand as well as they think they do.
Item 11. I never worry about what other people think when they see me checking labels or buying special brands.	No participants thought this was an issue.
Item 12. People are understanding when they know about my diet.	Depends who the other person is. Also, 'understanding' people may still misunderstand or make mistakes.
Item 13 Having Coeliac Disease doesn't worry me.	Participants felt worrying was inevitable and that some level of worry is necessary to stay safe.
Item 18. I do not worry that Coeliac Disease damaged my body before I was diagnosed.	Difficult to answer. Is this instead about having appropriate medical checks post-diagnosis?
Item 19. I don't worry if Coeliac Disease sometimes makes me feel tired or unwell.	Unspecific and difficult to answer. Lots of people have co-morbid conditions that cause fatigue or other problems.

Item 20. People with Coeliac Disease can stay healthy.	Unspecific.
Item 23. Avoiding gluten is not a big loss to me.	Feels like a duplicate of other questions
Item 25. I never feel sad thinking of the foods I can’t eat any longer.	Feels like a duplicate of other questions
Item 26. My new diet is just as satisfying as my old diet was.	Feels like a duplicate of other questions
Item 29. Cooking and shopping for my gluten-free diet takes no longer than it did when I ate gluten.	Should the question should be more about managing this, as it will inevitably take longer.
Item 30. I don’t find Coeliac Disease to be a burden in my life.	A number of participants felt the word ‘burden’ is too strong
Item 32. Keeping to a gluten-free diet is no real effort.	People feel the extra effort is necessary, the question should be more about coping.
Item 33. Coeliac Disease causes no hassle in my daily life.	People feel the extra hassle is necessary, the question should be more about coping.
Item 34. I find the gluten-free diet quite interesting	No-one found the diet ‘interesting’, but felt they just had to follow it.
Item 38. I am no longer worried about what might be wrong with me.	Vague and difficult to answer for those with co-morbid conditions.
Item 39. I enjoy trying new gluten free foods	People disliked connotations of ‘enjoy’, as they felt they had no choice.
Item 40. I’ve become a much better cook since my diagnosis.	People felt they had no choice but to cook.
Item 43. I’ve been really happy at how other people in my life have supported me with my diagnosis and new diet.	Feels like a duplicate of some questions in the social interaction scale.
Item 45. I've enjoyed learning about how other people manage Coeliac Disease (through friends, support groups, online)	No participants felt they did this.

Supplementary Table VI (Chapter Four). Original items retained or slightly reworded

Items	*Status*
Item 1. I am confident to explain my dietary needs when eating outside of my own home.	Slight rewording
Item 8. If I suspect my food has been contaminated with gluten, I will raise this with the restaurant staff.	Slight rewording
Item 10. I worry that people think I'm boring or irritating because I follow a gluten-free diet.	Slight rewording
Item 14. I minimise the impact of Coeliac Disease on my health by following a gluten-free diet.	Slight rewording
Item 15. Health professionals have given me all the information I want to have about Coeliac Disease.	Slight rewording
Item 16. I worry that Coeliac Disease increases my risk of health problems.	Slight rewording
Item 17. I am confident that my gluten-free diet provides me with all the nutrition and energy I need.	Slight rewording
Item 21. I feel stressed thinking about the fact that I have Coeliac Disease.	Slight rewording
Item 22. Since being diagnosed with Coeliac Disease, I feel like just the same person as I was before.	Original
Item 24. I rarely crave gluten-containing foods.	Original
Item 27. Eating is just as enjoyable on the gluten-free diet as it was before.	Original
Item 28. There are certain foods that I do really miss.	Slight rewording
Item 31. Food, eating and cooking seem to be always on my mind.	Original
Item 35. I don’t mind sometimes having to explain my diet to people more than once.	Slight rewording
Item 36. In some ways, the diagnosis of Coeliac Disease was a relief.	Original
Item 37. I prefer having a diet-based treatment to having to take medication.	Original
Item 41. Since changing to a gluten-free diet, I feel that the food I eat now is generally healthier than it was before.	Slight rewording
Item 42. Since being diagnosed, I am more in control of my health.	Slight rewording
Item 44. I am proud of myself for coping with Coeliac Disease and the gluten-free diet so well.	Original

Supplementary Table VII (chapter 4). PCA loadings for the LWWCD (38 items)

Item	*Item detail*	*Components*			
		1	*2*	*3*	*4*
1	Managing my gluten-free diet is time-consuming.	**.669**			
2	I worry that CD increases my risk of health problems.	**.660**			
3	Food, cooking and eating seem to be always on my mind.	**.654**			
4	I feel stressed thinking about the fact that I have Coeliac Disease.	**.650**			
5	Planning what I will eat ahead is difficult for me.	**.648**			
6	I feel separated from those around me in social situations because of my diet.	**.634**			
7	I worry that people think I'm boring or irritating because I follow a GFD.	**.594**			
8	Since being diagnosed with CD, I feel like just the same person I was before.	**.577**			
9	I worry about the financial costs of eating a gluten-free diet.	**.574**			
10	I need more medical checks to make sure that my CD is controlled and/ or that my GFD is well balanced .	**.568**			
11	I feel bad about restricting the food or restaurant choices of my family or friends.	**.565**			
12	I miss convenience foods like ready-meals, cooing sauces, burgers and take-aways.	**.555**			
13	I am concerned that my body-weight has changed (increased or decreased) since I started my gluten-free diet.	**.552**			
14	I find it difficult to trust that the restaurant staff will prepare food safely for me.	**.498**			.395
15	My diet restricts my choice of holidays.	**.491**			
16	I am confident that my gluten-free diet provides me with all the nutrition and energy I need.	**.455**			
17	There are certain foods that I do really miss.	**.442**			
18	Eating is just as enjoyable on the GFD as it was before.	.406	**406**		
19	Even after I've explained about CD, I feel that most people dismiss my diet as a fad.	**.405**			

20	I rarely crave gluten-containing foods.	*.388*			
21	Health professionals have given me all the information I want to have about CD.	*.309*			
22	I trust certain members of my family, or certain friends, to prepare foods safely for me.		No loading		
23	Since being diagnosed, I am more in control of my health.		**.781**		
24	My lifestyle has changed in positive ways since my diagnosis.		**.728**		
25	Since changing to a gluten-free diet, I feel that the food I eat now is generally healthier than it was before.		**.711**		
26	I feel that my health has improved now that I follow a gluten-free diet.		**.679**		
27	In some ways, the diagnosis of CD was a relief.		**.674.**		
28	I am proud of myself for coping with CD and the gluten-free diet so well		**.530**		
29	I prefer having a diet-based treatment to having to take medication.		*.331*		
30	I take some risks by eating food that may contain gluten to avoid awkward social situations.			**.822**	
31	Sometimes I take risks with food that may contain gluten because I am tired or busy.			**.806**	
32	If I suspect that food prepared for me by a relative or friend contains gluten, I always refuse to eat it.			**.717**	
33	If I suspect my food has been contaminated with gluten, I will raise this with the restaurant staff.			**507.**	.501
34	The people I live with do things that may risk contaminating my food with gluten.			**.428**	
35	I am confident to explain my dietary needs when eating outside of my own home.				**.666**
36	I don't' mind having to explain my diet to people more than once, if they forget or get confused.				**.567**
37	I can judge whether or not people really do understand my dietary needs.				**.485**
38	I avoid eating outside of my own home.	.410			**.461**

Supplementary Table VIII (chapter 4). PCA loadings of the LWWCD (27 items)

Item	*Item detail*	*Components*			
		1	*2*	*3*	*4*
1	Managing my gluten-free diet is time-consuming.	**.698**			
2	I worry that Coeliac Disease increases my risk of health problems.	**.618**			
3	Food cooking and eating seem to be always on my mind.	**.650**			
4	I feel stressed thinking about the fact that I have Coeliac Disease.	**.714**			
5	Planning what I will eat ahead is difficult for me.	**.666**			
6	I feel separated from those around me in social situations because of my diet.	**.746**			
7	I worry that people think I'm boring or irritating because I follow a gluten-free diet.	**.694**			
8	Since being diagnosed with Coeliac Disease, I feel like just the same person as I was before.	**.624**			
9	I worry about the financial costs of eating a gluten-free diet.	**.554**			
10	I need more medical checks to make sure that my Coeliac Disease is controlled and/ or that my gluten-free diet is well-balanced.	**.554**			
11	I feel bad about restricting the food or restaurant choices of my family or friends.	**.614**			
12	I miss convenience foods like ready-meals, cooking sauces and take-aways.	**.468**			
13	I find it difficult to trust that restaurant staff will prepare food safely for me.	**.628**			
14	My diet restricts my choice of holidays.	**.580**			
15	I am confident that my gluten-free diet provides me with all the nutrition and energy I need.	**.463**			
16	Even after I've explained about Coeliac Disease, I feel that most people dismiss my diet as a fad.	**.537**			
17	Eating is just as enjoyable on the gluten-free diet as it was before.	.487	**.378**		
18	Since being diagnosed, I am more in control of my health.		**.788**		
19	My lifestyle has changed in positive ways since my diagnosis.		**.721**		

20	Since changing to a gluten-free diet, I feel that the food I eat now is generally healthier than it was before.	**.709**	
21	I feel that my health has improved now that I follow a gluten-free diet.	**.682**	
22	In some ways, the diagnosis of Coeliac Disease was a relief.	**.661**	
23	I am proud of myself for coping with Coeliac Disease and the gluten-free diet so well.	**.556**	
24	I take some risks by eating food that may contain gluten to avoid awkward social situations.		**.835**
25	Sometimes I take risks with food that may contain gluten because I am tired or busy.		**.827**
26	If I suspect that food prepared for me by a relative or friend contains gluten, I always refuse to eat it.		**.757**
27	If I suspect my food has been contaminated with gluten, I will raise this with the restaurant staff.		**.549**

APPENDIX E: Chapter Five- Supplementary Tables

Supplementary Table IX (Chapter Five) Description of activities by intervention session

Target (session week)	*Activities*	*Description*
Knowledge (week 1)	- Sign-posting to reputable information and support sources.	- Presentation: 1) signposting to reputable information and support sources (Coeliac UK; NHS; health professionals). 2) Strategies to avoid misinformation and overload when internet browsing. - Printed information pack: participants received a pack of printed information from reputable sources about CD and the GFD. Session is focussed on information shaping to support self-management (Michie et al. 2008)
Knowledge (week 1)	- Identification of personal learning needs and goal-setting exercise.	- Worksheet activity: Participants identified one piece of information or skill they wanted to learn which would help them to live well with CD. Worksheet exercise based on SMART goal-setting, a health psychology behaviour change technique (Michie et al., 2008).
Anxiety (week 2)	- Understanding the cognitive model of anxiety. - Understanding what negative automatic thoughts (NATS) and thinking biases are. - Sharing experiences of anxiety related to living with CD.	- Presentation: Explaining the cognitive model (Padeskey & Mooney, 1990), with examples customised to CD-related anxiety. - Worksheet exercise (in pairs): drawing a cognitive model of a person’s thoughts, feelings and behaviours during a difficult situation related to CD. A hypothetical scenario is given and participants had an opportunity to repeat the exercise with personal examples if desired. - Group exercise: variation of ‘white bear’ experiment used to demonstrate how easily automatic thoughts are triggered (Wegner, 1994). The facilitator explains what negative thinking biases are, and how this can contribute to the anxiety experienced in many situations, including those related to CD. The supporting handout is adapted from Wills (2014). - Group Discussion: Anxiety related to living with CD. The researchers’ qualitative research findings were used as discussion focus material.

Illness burden; Stress (week 3)	- Understanding the psychological model of stress	- Short presentation explaining the psychological model of stress and its relationship to both large and small external demands. - Group Discussion: Stress related to living with CD. The researchers' qualitative research findings were used as discussion focus material.
Illness burden; Stress (week 3)	- Reducing stress through behavioural changes	- Group exercise: Diaphragmatic breathing. - Worksheet exercise: scheduling pleasant activities ('everyday uplifts') to balance the stress of managing CD.
Illness burden; Stress (week 3)	- Understanding the idea of psychological flexibility	- Exercise (individual): Using the Chinese finger trap game as a metaphor fo*r* experiential acceptance (Hayes et al., 1999). - Discussion of the self-as-context (observing self) using the *Sky and the Weather* metaphor (Harris, 2019). - Group exercise: Cognitive defusion exercise *Leaves on a Stream* (Harris, 2019). Participants were emailed a link to an online version of the exercise to practice at home (Inner Melbourne Clinical Psychology, 2016).
Adjustment (week 4)	- Understanding the Five Stages of Grief model (Kübler-Ross, 1970), and its relevance to CD.	- Presentation: Describing the Five Stages of Grief model, and how research has found the model can be applied to the temporal process of adjustment to long-term health conditions, including CD. - Group Discussion: Stress related to living with CD. The researcher's qualitative research findings were used as discussion focus material.
Adjustment (week 4)	- Identifying Core Values	- Presentation: Description of what core values are and the difference between values-driven and goal-driven action. - Worksheet exercise: identifying core values using a stimulus list of 42 values and options to add additional values not listed.

	- Commitment to take values-driven action	Worksheet exercise: prompt to choose an action or goal to work on within an important area of life. The goal should be in line with one of the core values identified in the previous exercise.
Communication (week 5)	- Understanding why communication with others about CD can be difficult	- Presentation: Psychological reasons (individual and sociocultural) that create difficulties when communicating about CD and the GFD. - Group discussion: Communication difficulties experienced relating to CD. What do we need to communicate, and why? What values do we try to communicate? - Exercise (in pairs) Reviewing scenarios depicting potentially difficult conversations about CD. Participants are asked to imagine what both they, and the people without CD they are communicating with, think and feel in this situation, where difficulties might occur, and how they can communicate effectively in that situation. The exercise is designed to 1) help participants develop a problem-solving approach to communication about CD; 2) better understand the feelings and dilemmas experienced by everyone in such situations; 3) develop awareness that wider sociocultural factors influence conversations about CD.
Communication (week 5)	- Understanding how experiential acceptance can support effective communication in difficult situations - Developing communication strategies	- Exercise (individual): *Pushing away the paper* metaphor (Harris, Russ, 2019) - Exercise (in pairs): Participants are given a scenario where communication about CD may become difficult. They imagine what both they and the person they are communicating with may think and feel. They are asked to identify where problems may arise and how they might communicate effectively. The exercise encourages a problem-solving approach to communication and broadens awareness of the individual, social and cultural factors which can influence communication.
Isolation (weeks 1-6)	- Group format; pair-work; group discussions on the experience of living with CD.	- all sessions were designed to create opportunities for participants to share experiences and strategies with others living with CD.

Supplementary materials (Chapter 5)

Worksheets and Handouts for the LWWCD Toolbox intervention

Worksheet One (part a). Session One

Is there something you want to learn about the gluten-free diet?

To be happy with your gluten free diet, you need to feel that it is your diet. It should suit your lifestyle and tastes.

If you struggle to manage your diet, or feel bored by food, ask yourself the questions below. The answers will show you where your diet may not fit with your own needs or lifestyle, or where more information or skills could be useful. This may be guidance on nutrition, recipes, cookery skills, places to shop, information from food companies, or tips from other people living with Coeliac Disease.

- Do I feel I am eating enough? Am I often hungry and missing meals and snacks I need? Do I feel my food is nutritious and gives me enough energy?
- Am I spending more time than I want to on food preparation?
- Am I spending more time than I want to on shopping?
- Am I spending more time than I want to researching ingredients?
- Am I confused by ingredients and labels on food packaging?
- How much do I enjoy the taste of my everyday diet? Am I finding food boring, tasteless or repetitive?
- Am I spending more money on food that I would like to?
- Do I have other dietary needs? Do I feel able to manage these within my gluten free diet?
- Am I finding anything else particularly difficult about my everyday diet?
- Is there anything I find particularly difficult with other types of eating? (e.g. eating out, parties, desserts, BBQs, food for treats, holidays).
- Is there a cooking skill I could learn that would help me to manage gluten-free cooking more easily?

Think about your answers to the questions above. Choose **one** area that you are finding difficult. Is there information that would be helpful to find? Is there a skill you would like to practice? If so, write it below.

____

If you don’t have a question relating to diet, is there something else you think it would be helpful to find out or learn about Coeliac Disease?

____

Worksheet One (part b). Session One

Finding information about Coeliac Disease

Set a goal to search for the information or practise the skill you wrote on the first page.

It might be tempting to keep going and do more. But stick to one question/ topic each time you do this..

What I want to learn about or practice is

____

____

This will help me to live well with coeliac disease because

____

____

I’m going to search in the following place(s) or ask the following people. **OR** (if practising a skill) I will practice it in the following place and have the materials I need (if not, state where you will find them).

____

____

____

I’m going to do this search or practice: [day and time]

____

My back-up plan. (Set a back-up time to do this, and a back-up source to check):

____

____

How confident do I feel that I can follow this plan? (circle)

Least confident									Most confident
1	2	3	4	5	6	7	8	9	10

Supplementary handout. Session Two.

Negative Automatic Thoughts

- Thoughts run through our minds constantly. This is our ‘stream of consciousness’.
- Most of our thoughts are **automatic**.
- Automatic thoughts are triggered by other thoughts, memories, and things around us.
- Automatic thoughts can’t really be stopped.
- The more you try to not have a thought, the more you are likely to have it.

- Try not to think of a white bear. The more you try not to think of it, the more the thought of the bear pops into your mind. (this is a famous psychology experiment that has been run hundreds of times).
- We all tend to think in certain ways called ‘thinking biases.’ One bias is towards negative thinking.
- Our negative thinking biases are completely normal, but can sometimes be quite unhelpful.
- Thinking biases happen because your brain tries to help you by:
  - Predicting problems.
  - Noticing danger.
  - Encouraging you to avoid risk.
  - Simplifying all the information around you.
  - Making sense of the world by filling in the gaps in your knowledge.

COMMON NEGATIVE THINKING BIASES	
Negative Filter	Being drawn towards negative thoughts and negative predictions about what will happen. E.g. only remembering the times things went wrong/ didn't work out.
Black or White thinking	Seeing things in simple either/or ways. *"I can never manage this." ; "She copes all the time, but I never do."*
Ignoring Positives	E.g. Most people were helpful, but you will only *really* remember the one who was not.
Generalising	*"Because X happened once…..X will always happen".* *"Because Y said this…..everyone thinks the same way as Y does."*
Mind-reading, or 'jumping to conclusions'	Making negative predictions about what will happen or what other people are thinking with little/ no real evidence. *"I know they deliberately excluded me."; "They think I'm attention-seeking."*
Catastrophic thinking	Maximising negative consequences. *"My social life is totally ruined forever."*
Making it personal	Always feeling that bad things are somehow your fault. *"That dinner felt awkward. That's because I've put a dampener on it."*
Emotional Reasoning	Thinking that what you feel is how things are in reality. *"I'm feeling like a burden, therefore I must be a burden."*
Creating Rules	Thinking about things should or ought to be. *"People shouldn't make mistakes."* *"People shouldn't need to be reminded over and over again."*
Labels	Applying a label to yourself – such as *"I'm boring"* ,

We can't help having **negative automatic thoughts** and **negative thinking biases**. Even those 'positive' people have them.

- We can be more aware of them, and of how they influence our feelings and our behaviour.
- We can also learn to ignore or challenge them if they are unhelpful.
- That isn't the same as not having the thoughts. We can't help having automatic thoughts.
- Instead, it is about deciding what we are going to *do* with the thoughts we have when they pop into our minds.
- By catching negative automatic thoughts (NATS), you can think about whether they are helpful, and decide how much you will listen to them, or whether they need to be challenged or ignored.

Worksheet Two. Session Two.

Choose one of the examples on the sheet. Then answer the questions below.

Example 1: Susanne has been diagnosed with coeliac disease for around a year. She feels very worried about it, and sometimes very downhearted and sad. She finds shopping takes a very long time because she needs to read the labels carefully to check which foods are safe. Sometimes she feels very tearful before going shopping, and she often rechecks everything she has bought once she gets home. It feels exhausting. She also still finds she gets stomach symptoms a lot, especially if she buys processed food. She is worried she is buying foods with gluten in them by mistake, or about not reading the labels properly. Susanne now tends to buy mostly fresh foods and sticks to the two or three main meals that she can make from scratch. She is often quite hungry and very bored of eating the same food. Sometimes she thinks about buying some different foods, but starts to feels anxious in case she makes a mistake. It seems safer to stick with the few foods she feels sure are safe.

Example 2: David has been invited to share a takeaway with some friends. Before he arrived, he asked if they could use a local restaurant which he trusts, and his friends agreed. When he arrives, there are some more people there who he doesn't know. They have brought discount vouchers for a different restaurant and everyone now wants to order from there. Everyone seems excited about the money they can save. David is last to arrive and everyone seems keen to order food straightaway. David is feeling like he needs to find out a lot more about this restaurant before ordering from there. But he doesn't want to have to explain about it around all these new people. They might think he is weird, or a health-fanatic, or an attention-seeker. He starts to feel quite stressed and panicky. He is starting to get a headache now too. He thinks it will be much easier if he just leaves. So he decides to pretend his sister has texted him about a family emergency and goes back home.

Question 1)

- What thoughts does this person have?
- How are they feeling – mentally and physically?
- How are they behaving?

Question 2)

- Create a criss-cross diagram to show how thoughts, feelings, physical sensations and behaviour are linked. (use the sheets).

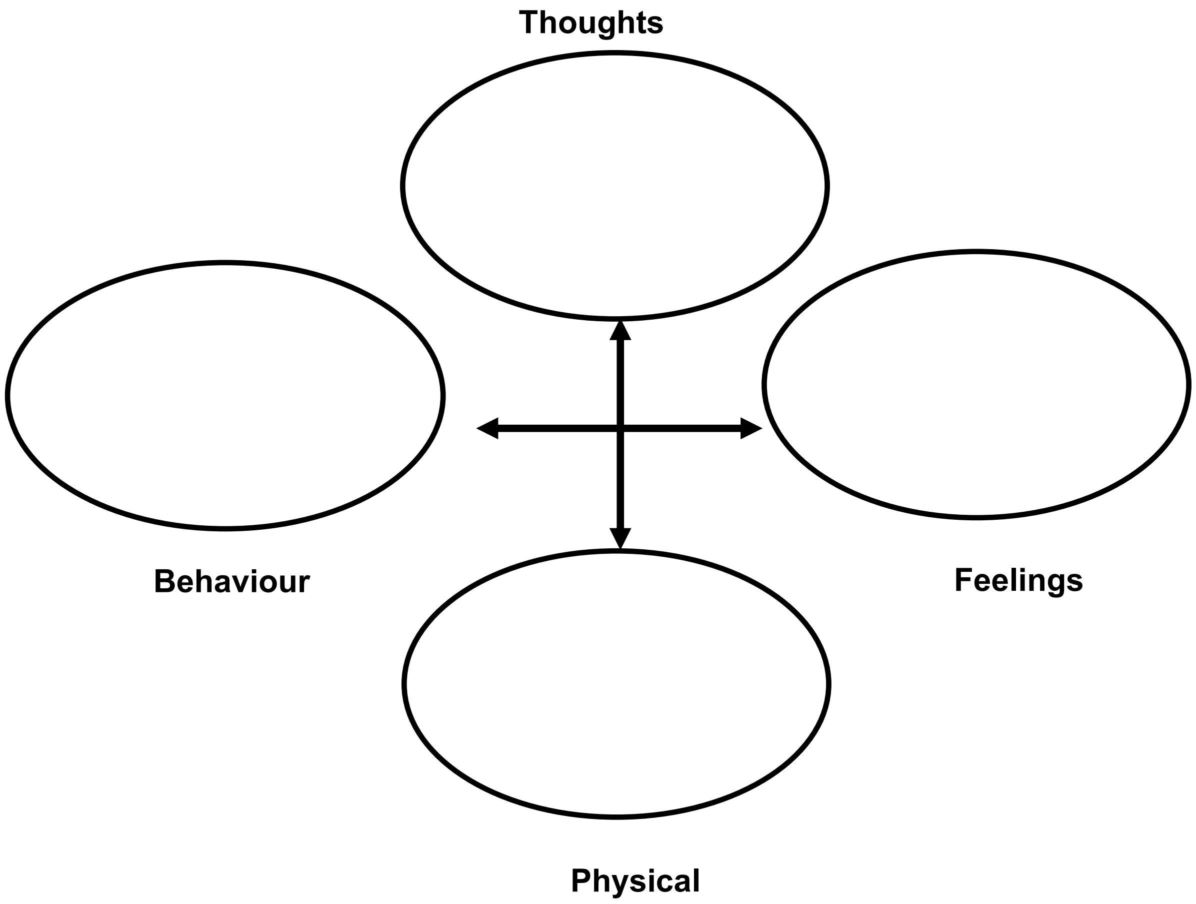
Question 3)

- What might the consequences of this behaviour be? Are these positive or negative?

Question 4)

- Do any of the thoughts they have seem very negative or unhelpful?
- Can any thought be challenged with different thoughts/ behaviours?

Supplementary Worksheet. Session Two.



Worksheet Three. Session Three.

My every day uplifts

It is easy to get overwhelmed by stressors, demands and obligations on our time.

It is important not to forget to schedule in uplifting activities. These are things that are uplifting just because they give us a sense of pleasure and enjoyment. These small everyday uplifts can decrease stress (just as small everyday hassles can build up and increase it).

Think about the everyday uplifts that you can easily do and enjoy, rather than things that cost a lot of money or take a lot of planning. Every day uplifts are the things around you, at home and in your community, which you can access easily.

Here are some ideas:

- Being ‘in nature’ – gardening, parks, walking, birdwatching, visiting areas of natural beauty.
- Sports / exercising.
- Hobbies – reading, arts and crafts, cooking, photography, playing musical instruments, collecting things, books, computer games, jigsaws.
- DIY / home-improvements / decluttering.
- Pets.
- Community activities/ volunteer work.
- Clubs.
- Board or card games.
- Socialising with friends.
- Cinema / films.
- Theatre.
- Museums / Galleries / Shows / Exhibitions.
- Visiting historical places.
- Sports (as a spectator).
- Visiting new places/ sightseeing.
- Religious activities.
- Relaxation practices.
- Concerts / Comedy.
- Dancing / clubs.
- Socialising with friends or family.
- Spending time with children.
- A relaxing bath.
- Beauty treatments.
- Listening to music.
- Learning (for fun) - visiting a library, attending a talk or class.
- Shopping (for fun).
- Driving / Motor-sports.
- Creativity.
- Getting involved in a cause/ campaign.
- Dating / romance.
- Social media.

My every day uplifts

Write down **THREE** or more uplifts in each box that you enjoy.
Make sure that at least one uplift in each box does not have to involve food.
Circle ONE or TWO uplifting activities you intend to do over the coming week.

Uplifts that are FREE	**Uplifts I can do ALONE**
Uplifts that involve OTHER PEOPLE	**Some other uplifting activities**

Supplementary handout. Session Three.

Thoughts and feelings are like the weather….

Thoughts and feelings are always there, and always changing, like the weather.

The type of thoughts and feelings we have also constantly change, like the weather.

Some of our thoughts and feelings are pleasant, others are uncomfortable and we don't like them, just like the weather.

Our pleasant thoughts and feelings are not something we can hold on to all the time because negative thoughts and uncomfortable feelings eventually crop up. This is like the weather too, neither good weather nor bad weather lasts forever. Weather constantly shifts and changes.

We spend a lot of time trying to hang onto pleasant feelings and positive thoughts, and try to avoid difficult thoughts and feelings. When we can't do this, and the weather in our minds changes for the worse again, we get angry and frustrated.

But, although our negative feelings and frustrations towards bad weather doesn't make it go away, it always clears in its own time. And this is the same with thoughts and feelings.

Acceptance

This is learning to feel our feelings, to have our thoughts, both pleasant and difficult, without trying to push them away or not experience them.

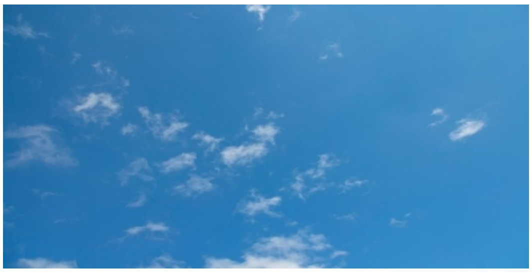
It is about allowing our thoughts and feelings to pass through our minds and bodies, without trying to escape them.

It is like watching the clouds and experiencing the change in the weather. You can accept that the experience/ feeling is very real, but also know that the feeling will eventually change of its own accord.

It is like being the sky itself, full of weather, both good and bad, but having infinite room for it. Weather is never 'too much' or 'too bad' for the sky to hold. And the sky is never damaged by any kind of weather.

When we accept our feelings, rather than spend our energy pushing them away, we can use our time and energy to get on with other things, whatever the weather is doing

Adapted from Harris, R. (2007) *Acceptance and Commitment Therapy (ACT) Introductory Workshop Handout.* https://thehappinesstrap.com/upimages/2007%20Introductory%20ACT%20Workshop%20Handout%20-%20%20Russ%20Harris.pdf



Worksheet Four. Session Four.

What really matters to you?

☐ _ Achievement/ Success
☐ _ Beauty
☐ _ Caring / Kindness / Helping
☐ _ Contribution / Service
☐ _ Community
☐ _ Co-operation / Collaboration
☐ _ Courage/ Braveness
☐ _ Creativity
☐ _ Curiosity/ Exploration
☐ _ Equality / Fairness / Justice
☐ _ Enthusiasm
☐ _ Excitement / Adventure
☐ _ Enjoyment / Fun
☐ _ Health / Fitness / Well-being
☐ _ Flexibility / Adaptability
☐ _ Generosity
☐ _ Genuineness/ naturalness
☐ _ Gratitude / Thankfulness
☐ _ Growth / Development / Challenge
☐ _ Leadership / Inspiring others
☐ _ Learning
☐ _ Humour
☐ _ Independence
☐ _ Individuality / Originality
☐ _ Intimacy / closeness to others
☐ _ Love
☐ _ Nature / Environment
☐ _ Nurturing/ Encouraging
☐ _ Persistence / Determination
☐ _ Respect
☐ _ Responsibility
☐ _ Order / Organisation
☐ _ Popularity
☐ _ Political / Social values
☐ _ Safety/ security
☐ _ Self-awareness
☐ _ Self-discipline / self-control
☐ _ Simplicity
☐ _ Spirituality
☐ _ Tradition
☐ _ Trustworthiness / Reliability
☐ _ Wealth/ Plenty/ Acquisition

Step 1. Read the list of values. In the boxes, put a tick in the box next to values that seem **Very** important to you, put a horizontal line through those that are **Quite** important to you, leave blank those that are **not or not very** important to you. Use the blank lines to add any you think we missed out.

Step 2. If you ticked more than six, RANK these to show which are most important to you.

Step 3. Write the SIX highest ranked/ most important values below. Check that these are values that:

- Are important and feel meaningful to **you**?
- Values you would like to work towards?
- Values you would like to stand for and be remembered for?

My core values are:

1.______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________
6. ______________________________

Values sheet is adapted from:

Carnegie Mellon University: https://www.cmu.edu/career/documents/my-career-path-activities/values-exercise.pdf

Russ, Harris (2010) A quick look at Your Values http://thehappinesstrap.com/wp-content/uploads/2017/06/complete_worksheets_for_The_Confidence_Gap.pdf

Worksheet Five. Session Four.

Doing what really matters worksheet

Our lives have multiple dimensions, but sometimes it can feel as if only one area is dominating our time and our thoughts. It is important to think about spreading our time and attention across a number of different areas of life, to give us a sense of balance and to ensure we engage in a range of activities. When those activities are in line with our values, they can feel very enriching and worthwhile.

Of the areas of life below, circle those that seem most important to you today. Of those you circle, choose the ones that feel most important to you to focus on. If it is difficult to choose, try ranking the areas you have circled. When you have chosen, write those that seem most important to you in the boxes below. (There are four boxes, but you do not have to choose four areas to focus on).

- Work
- Intimate relationship
- Parenting
- Education / Learning / Personal growth
- Friendships / Social life
- Health / self-care/ well-being
- Family relationships (other than partner/children)
- Spirituality
- Community life/ roles
- Recreational activities/ hobbies / creativity
- Contact with natural world

Now briefly write why these areas are important to **you**? What does this area of life bring to you? What do you want to stand for in this area of life? Which of your values do you want to express?

Area Why this area matters? Which of my core values am I or could I express here?	Area Why this area matters? Which of my core values am I or could I express here?
Area Why this area matters? Which of my core values am I or could I express here?	Area Why this area matters? Which of my core values am I or could I express here?

Valued-action plan

We hope that these worksheets have given you some insight into what values really matter you and give meaning to your actions, and the areas in your life that you most want to engage with today.

By acting according to your values in the areas of your life that matter to you, you will strengthen your sense of direction and purpose.

Looking at the lists you have made, you might feel you have been neglecting some of your values, or some areas of your life. We all do this, and feeling that is completely normal.

The final part of this exercise is to think about what activities or goals you would like to work towards, in one or more of the areas of life you listed above. Write down that goal or activity. Think about whether it is in line with the values you have listed. Remember that goals/ activities (unlike values) *can* be ticked off a list…

Thinking back to the goal setting exercises we covered earlier in the course, try to make this goal/ activity something very SPECIFIC and ACHIEVABLE….

ACTIVITY (Goal): I am going to

____

____

I feel this activity is worth doing because

____

____

VALUE: This activity represents a value that is important to me, which is

____

Doing things we value is not always easy. But we are more likely to have the motivation to work through problems if what we are trying to do is something of real value to us.

What might make doing this activity difficult?

____

____

What might you do to overcome this difficulty?

____

Worksheet inspired by Pearson, K. et a. (2015) *More to Life Group Program: Acceptance and Commitment Therapy for Chronic Health Conditions – Group Facilitator Manual*

www.contextualscience.com

Worksheet Six. Session Five.

Communication with Coeliac Disease

Please think about the thoughts and feelings both you, and the other person, might be experiencing in these social situations. How might you explain coeliac disease to this person?

Scenario 1: An elderly relative goes to make a cup of tea and comes back with a plate of sandwiches and a pork pie for you. You can’t remember if you’ve ever told them about Coeliac Disease before…

Scenario 2: A waitress in a café who comes to take your order. The menu does have a few gluten-free options, but you want to make sure that they really are gluten-free and have been prepared safely. It is very busy in this café…

Scenario 3: A friend/ relative says: “I didn’t invite you out for that meal with us all, because I know that’s not your sort of thing.”

Scenario 4: You go for a pre-booked Xmas meal with your office party. You were quite concerned about the choice of venue but the organiser said she’d ‘sort it’ and refused to look at any of the restaurants you suggested. When your meal arrives, you find you have fruit salad for starter, steamed potatoes and broccoli (no sauce) for main, and more fruit salad for dessert.

Scenario 5: *A friend suddenly arrives with a mini-birthday cake she has handmade herself for you. It obviously took ages. She is a good friend and knows you have coeliac disease, but looks very guilty and says she ‘forgot’ when you ask if it is gluten-free? She says “A bit won’t matter though, will it?”*

Scenario 6: You go for an annual check. You have quite a few questions about coeliac disease that you wanted to ask the nurse/doctor, but you can see that the clinic is very busy and everyone seems in a hurry. A nurse quickly runs through your results, which are fine, and says “Well, you’re doing great, off you go then. Same time next year.” and turns away.

Questions:

- What were they thinking?
- What were they feeling?
- What were you thinking?
- What were you feeling?
- Will you find explaining about coeliac disease in this situation easy, or difficult? Why?
- How will you explain about coeliac disease to this person?

Worksheet Seven. Session Six.

Living well with Coeliac Disease

Throughout this course we've been thinking about what it is like to carry coeliac disease around every day. We've also been thinking about how we can live well with this condition.

So, thinking over what you've experienced over this six week course, and through your experience of living with Coeliac Disease and answer this question:

What does **living well** with coeliac disease mean to you?

Now think about what barriers prevent you living well with coeliac disease. What gets in the way and blocks your path?

Barriers could be internal (like thoughts, feelings, knowledge and beliefs), or they might be external (e.g. risk, people, difficult situations).

Thinking about your life right now, what gets in the way of you living well with coeliac disease?

Worksheet Eight. Session Six.

Commitment to action / change.

In this exercise, we are going to ask you to think about how you want to live well with coeliac disease in the future.

Take some time to think about what action/ change you can take over the next few weeks and months that will help you to live well with coeliac disease, in the way that you want to.

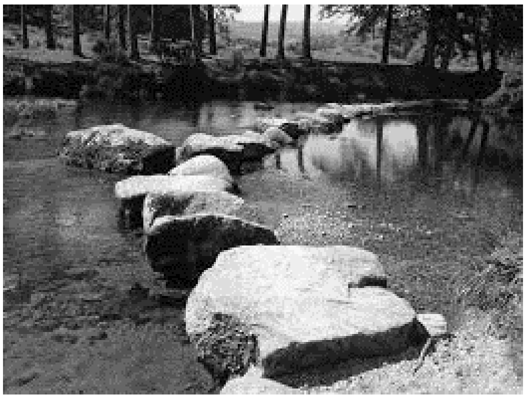
The actions you take or changes you make don't have to be big. Just as long as they are heading in the way you want to go. Think of stepping stones. Each stone gets you a little closer, but it takes time to get across the water and you might need a series of stones.

But to get across the water you need to be willing to commit to walking on those stones.

If you feel a stone is not safe or is too far to step across, think about what is worrying you about it or making it unsafe. Could you step on a nearer stone? Could you a choose different stone/ safer route?

With stepping stones, if you want to cross the water, at some point you have to commit to taking some action. You have to really start to step across.

So, with the idea of stepping stones in mind…



What one thing are you willing to commit to doing that will help you to live well with coeliac disease?

My commitment is to…

This will help me to live well with coeliac disease because…

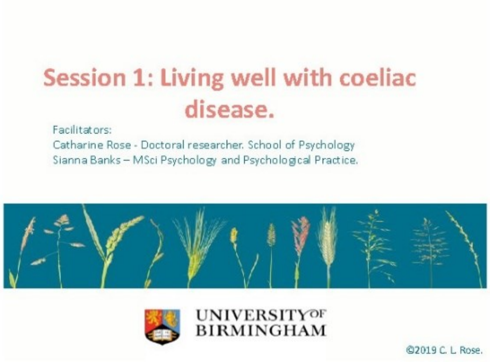
Troubleshooting

What might get in my way when I am keeping this commitment?

How will I overcome this? What tools/ resources could help me?

Reference: ‘Stepping Stones’ inspired by exercise used in intervention by Brassington, Ferreira, Yates, Fearn, Lanza, Kemp and Gillanders (2016) ‘Better Living with Illness: a transdiagnostic acceptance and commitment therapy group intervention for chronic physical illness.’ *Journal for Contextual Behavioural Science* 5 (4): 208-214.

APPENDIX F: Intervention facilitators' slide sets



Session 1: Living well with coeliac disease.

Facilitators:
Catharine Rose - Doctoral researcher. School of Psychology
Sianna Banks – MSci Psychology and Psychological Practice.

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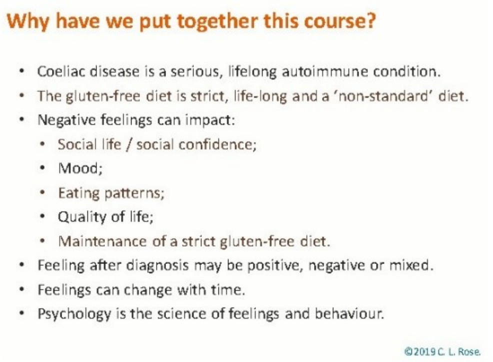

Why have we put together this course?

- Coeliac disease is a serious, lifelong autoimmune condition.
- The gluten-free diet is strict, life-long and a 'non-standard' diet.
- Negative feelings can impact:
  - Social life / social confidence;
  - Mood;
  - Eating patterns;
  - Quality of life;
  - Maintenance of a strict gluten-free diet.
- Feeling after diagnosis may be positive, negative or mixed.
- Feelings can change with time.
- Psychology is the science of feelings and behaviour.

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- No reports of a course like this having been developed specifically for people with coeliac disease in the UK.
- The course has been designed to be a toolbox.
- Topics: based on our research with people living with coeliac disease;
- Tools: commonly used by psychologists in healthcare/ related fields.

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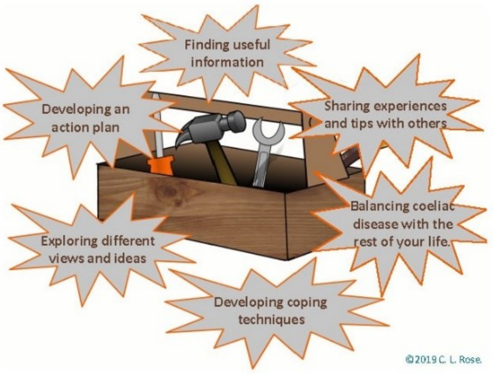

Finding useful information

Developing an action plan

Sharing experiences and tips with others

Balancing coeliac disease with the rest of your life.

Exploring different views and ideas

Developing coping techniques

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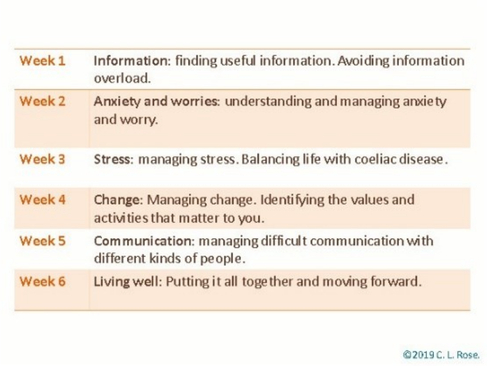

Week 1	**Information**: finding useful information. Avoiding information overload.
Week 2	**Anxiety and worries**: understanding and managing anxiety and worry.
Week 3	**Stress**: managing stress. Balancing life with coeliac disease.
Week 4	**Change**: Managing change. Identifying the values and activities that matter to you.
Week 5	**Communication**: managing difficult communication with different kinds of people.
Week 6	**Living well**: Putting it all together and moving forward.

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Group rules

Let's make sure the group feels safe for everyone:

- You do not have to say or do anything you feel uncomfortable with;
- Listen to what everyone has to say;
- Be positive and respectful;
- Don't repeat what others say outside the group;
- Let us know if you are having any difficulties – contact us between sessions if you prefer;
- Please try to attend all sessions and arrive on time;
- Help us to stick to time;
- Let us know if you can't attend;
- Mobiles: switch off or switch to vibrate/ silent;
- Anything else………………..?

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Session 1: Learning about coeliac disease.

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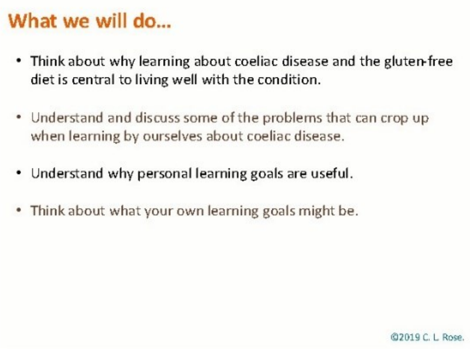

What we will do...

- Think about why learning about coeliac disease and the gluten-free diet is central to living well with the condition.
- Understand and discuss some of the problems that can crop up when learning by ourselves about coeliac disease.
- Understand why personal learning goals are useful.
- Think about what your own learning goals might be.

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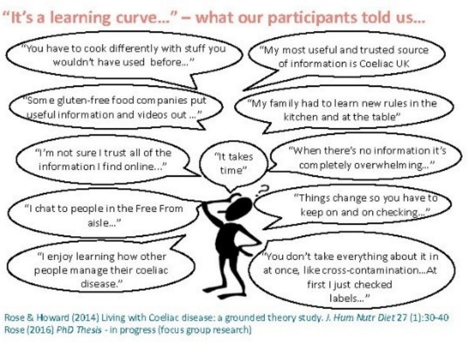


"It's a learning curve..." – what our participants told us...

"You have to cook differently with stuff you wouldn't have used before..."

"My most useful and trusted source of information is Coeliac UK

"Some gluten-free food companies put useful information and videos out ..."

"My family had to learn new rules in the kitchen and at the table"

"I'm not sure I trust all of the information I find online..."

"It takes time"

"When there's no information it's completely overwhelming..."

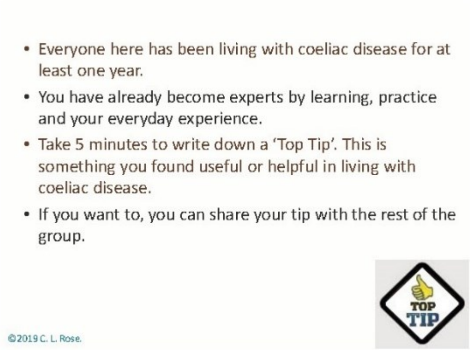
"I chat to people in the Free From aisle..."

"Things change so you have to keep on and on checking..."

"I enjoy learning how other people manage their coeliac disease."

"You don't take everything about it in at once, like cross-contamination...At first I just checked labels..."

Rose & Howard (2014) Living with Coeliac disease: a grounded theory study. *J. Hum Nutr Diet* 27 (1):30-40
Rose (2016) *PhD Thesis* - in progress (focus group research)



- Everyone here has been living with coeliac disease for at least one year.
- You have already become experts by learning, practice and your everyday experience.
- Take 5 minutes to write down a 'Top Tip'. This is something you found useful or helpful in living with coeliac disease.
- If you want to, you can share your tip with the rest of the group.

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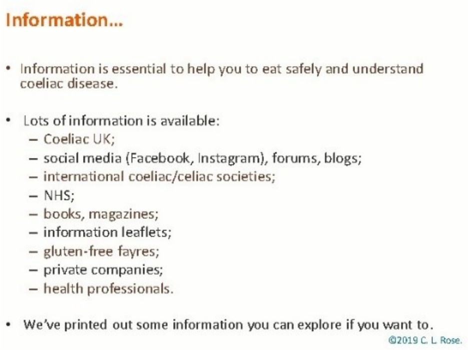

Information...

- Information is essential to help you to eat safely and understand coeliac disease.
- Lots of information is available:
  - Coeliac UK;
  - social media (Facebook, Instagram), forums, blogs;
  - international coeliac/celiac societies;
  - NHS;
  - books, magazines;
  - information leaflets;
  - gluten-free fayres;
  - private companies;
  - health professionals.
- We've printed out some information you can explore if you want to.

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Information can be...

- Helpful;
- Reassuring;
- Overwhelming or confusing;
- Worrying;
- May be untrustworthy;
- Can be difficult to find specific answers;
- Time can be wasted 'browsing'.
- Tendency to make negative social comparisons (e.g. *"they are managing this better than me?"*).

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Avoiding internet overload…

- Is my internet research distracting me from other things?
- Am I spending too much time on this?
- Am I feeling tired or drained by information?
- Does my anxiety/ worry increase during or after internet browsing?
- Am I 'going around in circles' with the same worries/ questions without finding a satisfactory answer?

Tips…

- ❖ Try finding information offline instead – e.g. library books, talking directly to health professionals, visiting a gluten-free fayre or a local support group.
- ❖ Set a time limit for browsing each day / week. Set a timer and stop as soon as it goes off.
- ❖ Temporarily disconnect from the internet. It will still be there tomorrow.
- ❖ Are you considering removing other foods from your diet or using medication or supplements based on online information? Check these ideas out with a trustworthy medical source (e.g. health professionals, or Coeliac UK's website/ advice line).

Avoid internet overload…

- ❖ Check out advice found online:
  - – Who wrote it? What qualifications or experience do they have?
  - – When was it written?
  - – Is the author/ website selling or promoting anything?
  - – Are other trustworthy sources or scientific research referenced?
  - – Does this match information from other trustworthy sources (e.g. medical professionals, NHS online, Coeliac UK)?
- ❖ Remember that **everyone** is **different**.

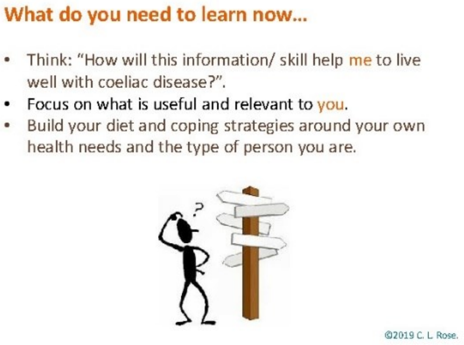
People experience coeliac disease differently.

- Some have lots of symptoms, or none.
- Some have other health conditions too.
- People respond to the gluten-free diet at different rates.
- Everyone with coeliac disease needs to avoid gluten for life.

People at all ages and stages live with coeliac disease….

Diabetic diet
Cooks for family
Low energy
Vegetarian / Vegan
Frequent traveller
Ethnic Cuisine
Lives alone
Tight-budget
Student
Rural area
Plain flavours
Love to Cook
Loves entertaining
Shares kitchen
No internet
Carer
Office worker
Sporty
Busy
Sweet-toothed
Very sociable
Pregnant
Hates cooking
Shift work
Widowed
Has never cooked
Dating
Likes a drink
Retired
Spiritual
Cyclist
Easily bored

…and have different nutritional needs and lifestyles.



What do you need to learn now…

- Think: "How will this information/ skill help me to live well with coeliac disease?".
- Focus on what is useful and relevant to you.
- Build your diet and coping strategies around your own health needs and the type of person you are.

What do you really need to know / learn now?

- **What** will help you to live better with coeliac disease?
  - Do you have question you need the answer to?
  - Do you need some specific information?
  - Do you need new ideas / inspiration?
  - Do you need to learn or practice a skill?
- **How** will learning this help you to live better with coeliac disease?

What you need to know….

- Choose a **specific** question / skill?
  - "Find more interesting food" is vague
  - "Find one new lunch item that I can take to work" is specific
- Choose something **positive**:
  - A question that can be answered;
    - "Why am I the only one in my family with coeliac disease?" – can this be answered?
    - "Do I need to take vitamin supplements?" – could be answered?
  - A skill to practice (e.g. cooking, shopping);
  - Information / skill that will help you manage coeliac disease
    - Enjoying lunches again;
    - Reducing a potential health risk

- Take one step at a time. Break up a question/ skill into several mini-steps if necessary…

Example:

"To be able to cook a nice two-course gluten-free meal for my friends. A gluten-free chicken curry and a gluten-free dessert."

Setting mini-goals/ steps:
- Finding the first recipe: curry.
- Practising the first recipe.
- Finding the second recipe: dessert.
- Practising the second recipe.
- Practice cooking them both together.
- Inviting friends over.

Start with first step only: Finding the curry recipe….

- Choose something that you are **able** to do?
  - Know where will you find the information / materials you need.
  - How confident are you (from 0 - 10) that you can do this?
  - Choose something you are reasonably confident about (7+).
  - If you are not confident, then start with something to increase your confidence…
- Set a **time limit**
  - When will you do this (be specific and realistic)?
  - How long will you spend on it?

The goal is set…

"I will search for GF chicken curry recipes on the Coeliac UK or BBC Good Food websites. (*so he knows how and where…*)

I will look for recipes that are fairly simple and use familiar ingredients. I used to cook before I was diagnosed with coeliac disease…..so I am '8'-confident that I can follow the recipes **if** they use familiar ingredients." (*he is confident*)

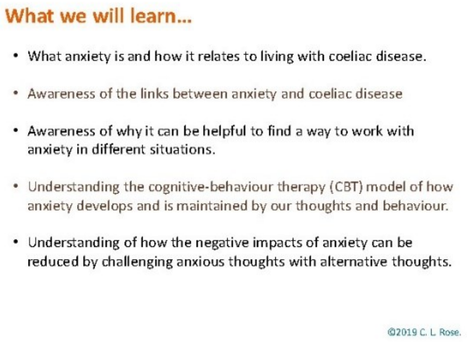
"I will spend an hour Tuesday evening, from 9 – 10pm, researching recipes. I can print out the recipes and ingredients list at work on Wednesday before I leave." (*set time limit*)

Troubleshooting….

- Make sure all effort counts - this is about learning.
- Do you need a backup plan?
- Set one step at a time only.
- Choose something interesting and/ challenging (but achievable).
- Stick to your time limit.

Anxiety, worries and coeliac disease.

Facilitators:
Catharine Rose - Doctoral researcher. School of Psychology
Lana Delic – 3rd year undergraduate. School of Psychology



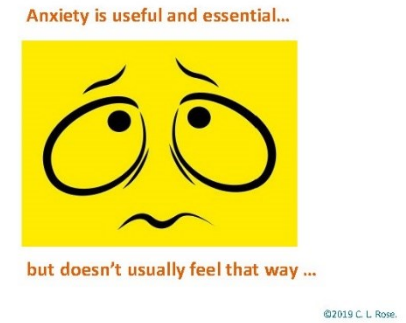
What we will learn…

- What anxiety is and how it relates to living with coeliac disease.
- Awareness of the links between anxiety and coeliac disease
- Awareness of why it can be helpful to find a way to work with anxiety in different situations.
- Understanding the cognitive-behaviour therapy (CBT) model of how anxiety develops and is maintained by our thoughts and behaviour.
- Understanding of how the negative impacts of anxiety can be reduced by challenging anxious thoughts with alternative thoughts.

Anxiety is our brain's system of preparing our mind and body to respond to a threat….

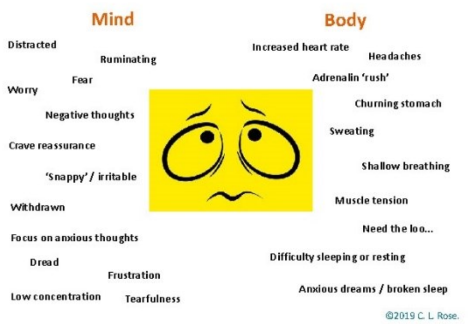
- Defensive / aggressive
- Avoid/ escape
- Delay/ disengage/ 'play dead'.

…it causes changes to our thinking and behaviour so that we can protect ourselves from perceived harm.



Anxiety is useful and essential…

but doesn't usually feel that way …



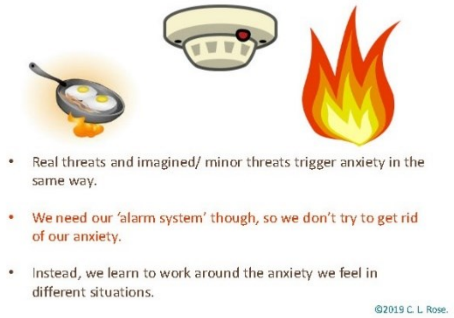
Mind

Distracted
Ruminating
Fear
Worry
Negative thoughts
Crave reassurance
'Snappy' / irritable
Withdrawn
Focus on anxious thoughts
Dread
Frustration
Low concentration
Tearfulness

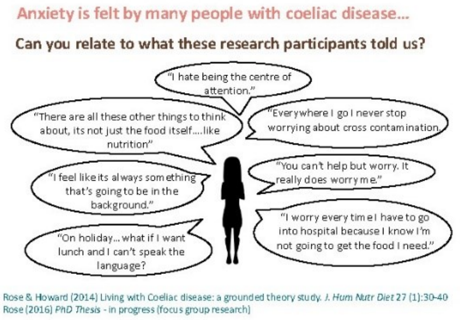
Body

Increased heart rate
Headaches
Adrenalin 'rush'
Churning stomach
Sweating
Shallow breathing
Muscle tension
Need the loo…
Difficulty sleeping or resting
Anxious dreams / broken sleep

Instinctive (automatic) response to threat…real and anticipated.



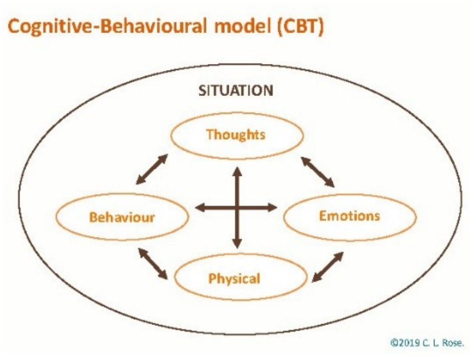
- Real threats and imagined/ minor threats trigger anxiety in the same way.
- We need our 'alarm system' though, so we don't try to get rid of our anxiety.
- Instead, we learn to work around the anxiety we feel in different situations.



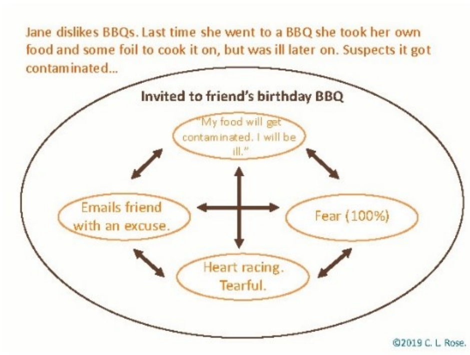
Anxiety is felt by many people with coeliac disease...

Can you relate to what these research participants told us?

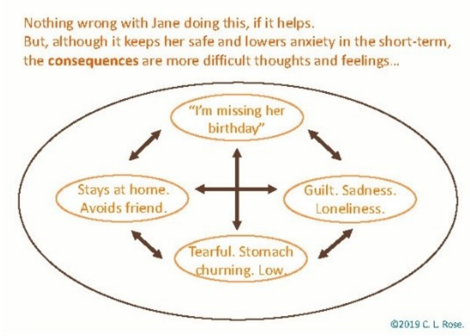
Rose & Howard (2014) Living with Coeliac disease: a grounded theory study. *J. Hum Nutr Diet* 27 (1):30-40
Rose (2016) *PhD Thesis* - in progress (focus group research)



Cognitive-Behavioural model (CBT)



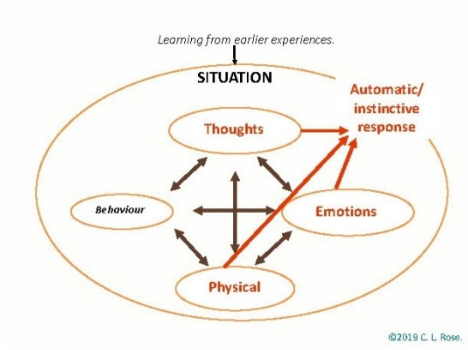
Jane dislikes BBQs. Last time she went to a BBQ she took her own food and some foil to cook it on, but was ill later on. Suspects it got contaminated...



Nothing wrong with Jane doing this, if it helps.
But, although it keeps her safe and lowers anxiety in the short-term, the **consequences** are more difficult thoughts and feelings...

Cognitive behaviour therapy - CBT

- Being more aware of the thoughts, feelings and behaviours we have in difficult situations.
- Being more aware of how our thoughts and behaviour are linked to our emotional and physical feelings.
- Experimenting with different thoughts or behaviours. How does that change how we feel?
- Finding what works. What can help us to feel better? What can help us manage difficult situations?



Learning from earlier experiences.

SITUATION

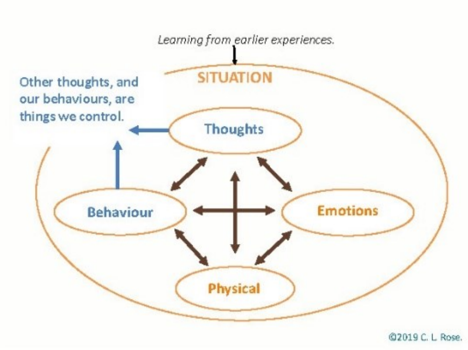
Automatic/ instinctive response

Thoughts

Behaviour

Emotions

Physical



Learning from earlier experiences.

Other thoughts, and our behaviours, are things we control.

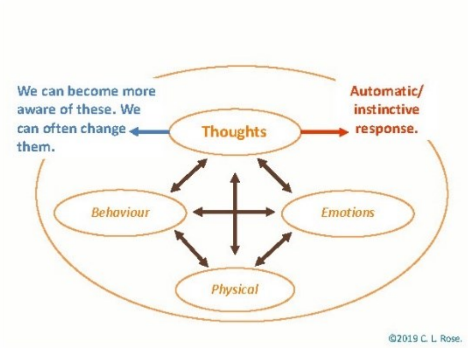
SITUATION

Thoughts

Behaviour

Emotions

Physical



We can become more aware of these. We can often change them.

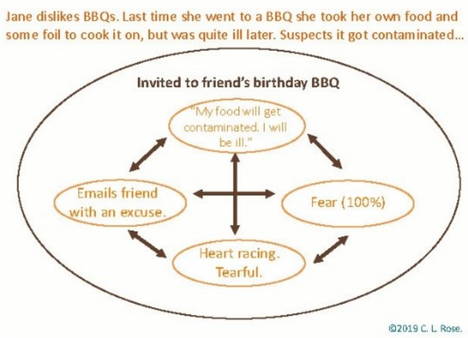
Thoughts

Automatic/ instinctive response.

Behaviour

Emotions

Physical



Jane dislikes BBQs. Last time she went to a BBQ she took her own food and some foil to cook it on, but was quite ill later. Suspects it got contaminated...

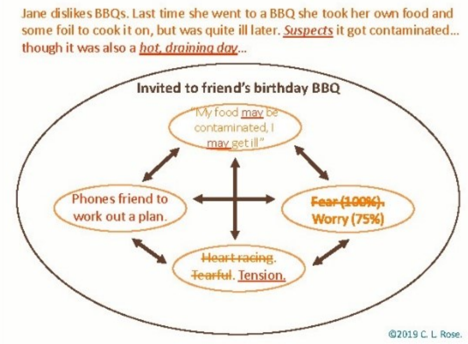
Invited to friend's birthday BBQ

"My food will get contaminated. I will be ill."

Emails friend with an excuse.

Fear (100%)

Heart racing. Tearful.



Jane dislikes BBQs. Last time she went to a BBQ she took her own food and some foil to cook it on, but was quite ill later. *Suspects* it got contaminated... though it was also a *hot, draining day*...

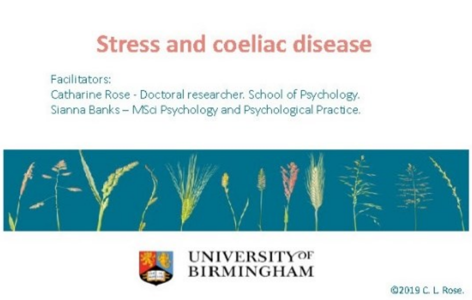
Invited to friend's birthday BBQ

"My food may be contaminated, I may get ill"

Phones friend to work out a plan.

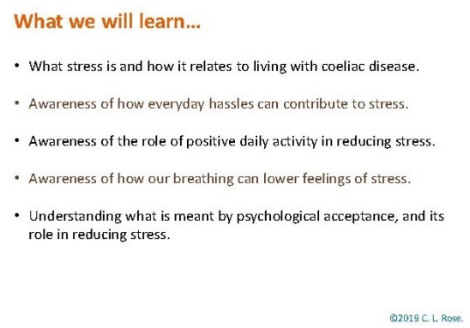
~~**Fear (100%).**~~ **Worry (75%)**

~~Heart racing~~. ~~Tearful~~. Tension.



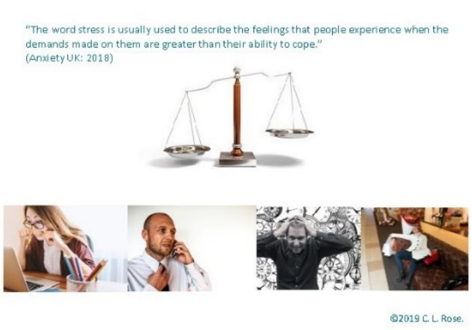
Stress and coeliac disease

Facilitators:
Catharine Rose - Doctoral researcher. School of Psychology.
Sianna Banks – MSci Psychology and Psychological Practice.

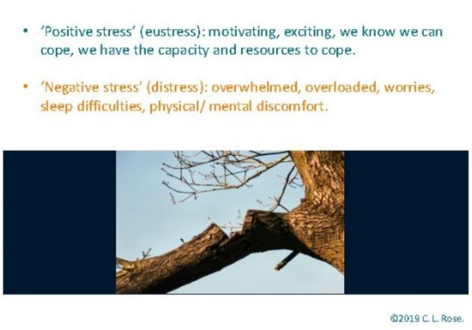


What we will learn…

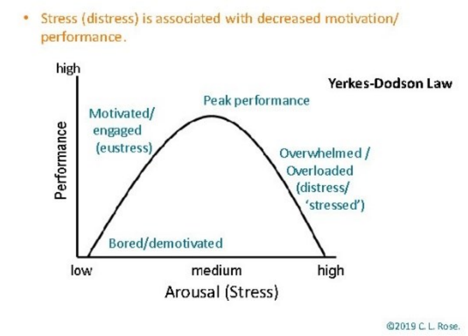
- What stress is and how it relates to living with coeliac disease.
- Awareness of how everyday hassles can contribute to stress.
- Awareness of the role of positive daily activity in reducing stress.
- Awareness of how our breathing can lower feelings of stress.
- Understanding what is meant by psychological acceptance, and its role in reducing stress.



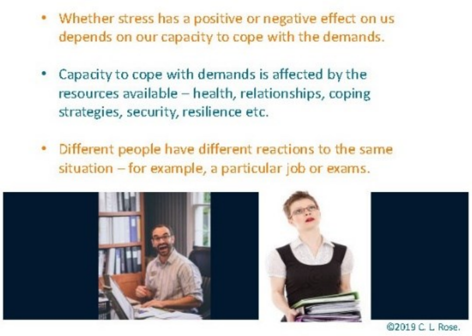
"The word stress is usually used to describe the feelings that people experience when the demands made on them are greater than their ability to cope."
(Anxiety UK: 2018)



- 'Positive stress' (eustress): motivating, exciting, we know we can cope, we have the capacity and resources to cope.
- 'Negative stress' (distress): overwhelmed, overloaded, worries, sleep difficulties, physical/ mental discomfort.



- Stress (distress) is associated with decreased motivation/ performance.



- Whether stress has a positive or negative effect on us depends on our capacity to cope with the demands.
- Capacity to cope with demands is affected by the resources available – health, relationships, coping strategies, security, resilience etc.
- Different people have different reactions to the same situation – for example, a particular job or exams.

- People often use the terms stress and anxiety/ worry interchangeably, but they are different reactions..

STRESS	ANXIETY
Overload / Overwhelm	Anticipation of threat
A direct response to a stressful activity/ event.	Felt before, during and even sometimes after a threatening situation/ activity.

- Our bodies are designed to cope with short periods of stress or anxiety.
- But stress and anxiety can become problematic if they persist without resolution over long periods.

Daily stressors / 'hassles'

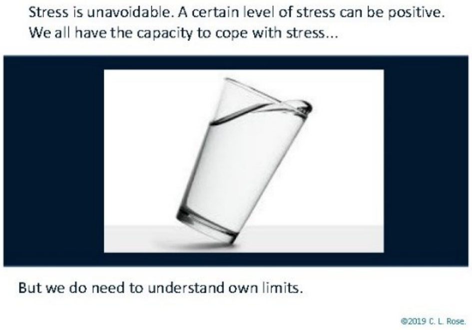
Small everyday changes and demands, but can pile up

- Commuting / driving
- Minor arguments / disagreements
- Losing things
- Caring for children or pets
- Weather
- Chores
- Delays
- Shopping
- Organising events / activities
- Changes/ difficulties in friends' lives
- Paperwork

Major life stressors

Big changes in circumstances

- Moving House
- Relationship breakup
- New family member
- Bereavement
- Serious illness or accident
- Financial difficulties
- Being a victim of crime
- Losing job
- Changing job
- Significant exams
- Financial insecurity

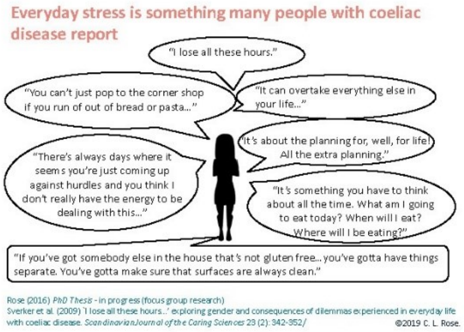


Stress is unavoidable. A certain level of stress can be positive. We all have the capacity to cope with stress...

But we do need to understand own limits.

Every day stress can build up over time...

We can use coping strategies in our daily lives to 'tip away' some of this stress as it builds, preventing our capacity (glass) overflowing.



Everyday stress is something many people with coeliac disease report

"I lose all these hours."

"You can't just pop to the corner shop if you run of out of bread or pasta..."

"It can overtake everything else in your life..."

"It's about the planning for, well, for life! All the extra planning."

"There's always days where it seems you're just coming up against hurdles and you think I don't really have the energy to be dealing with this..."

"It's something you have to think about all the time. What am I going to eat today? When will I eat? Where will I be eating?"

"If you've got somebody else in the house that's not gluten free... you've gotta have things separate. You've gotta make sure that surfaces are always clean."

Rose (2016) *PhD Thesis* - in progress (focus group research)
Sverker et al. (2009) 'I lose all these hours...' exploring gender and consequences of dilemmas experienced in everyday life with coeliac disease. *Scandinavian Journal of the Caring Sciences* 23 (2): 342-352/

Coeliac disease: adjustment to change.

Facilitators:
Catharine Rose - Doctoral researcher. School of Psychology
Sianna Banks – MSci Psychology and Psychological Practice

UNIVERSITY OF BIRMINGHAM

What we will learn…

- How adjustment to diagnosis of coeliac disease can be described as a process involving five key emotional stages.
- Awareness of how different people can experience this process differently.
- Awareness of the different strategies people have used to manage this process.
- Awareness of how values-led action can help us cope with change.
- Understanding what our personal values are, and how we can use them to move forwards as our lives change.

The living with coeliac disease project…

- 130 adult members of coeliac UK. Average age 53. 67% female.
- Average time since diagnosis approx 10 years.
- Each wrote a narrative account of their experience of living with coeliac disease. Sent to me anonymously in letters and emails.

Key findings

- Grief (sense of loss; mourning) was a key theme, and this was linked to a feeling of a changed / new identity.
- The grief experienced followed the famous '5 stages of grief' model (Kubler-Ross; 1970).

Denial
Anger
Bargaining
Depression
Acceptance

Reference: Rose, C. & Howard, R. (2014) Living with coeliac disease: a grounded theory study *J. Human Nutrition and Dietetics* 27 (1): 30-40.

- As was found in the original study (Kubler-Ross 1970), and later studies, people moved through this grief process at different rates.
- People sometimes move backwards and forwards between stages before reaching the 'acceptance' stage.
- Kubler-Ross (1970) wrote that true acceptance of a loss involves` experiencing all five stages during the grief process.
- Other research has found that people living with a range of chronic health conditions move through these five stages of grief as they adjust (Garner & Kinderknecht 1994; Carrillo-Alarcón et al, 2015).

E. Kubler-Ross, E. (1970) *On Death and Dying.* London: Tavistock Publications.
Garner & Kinderknect, 1994. Living Productively with Arthritis *J. of Women & Aging 5: 61-82*
Carrillo-Alarcón et al (2015) Level of Knowledge in Patients with Type 2 Diabetes Mellitus and its Relationship with Glycemic Levels and Stages of Grief According to Kübler-Ross. *J Diabetes Metab* 6: 495.

What participants said about denial…

"Following the initial euphoria, I came down to earth a bit."

"I left hospital with a light heart…I had no idea what it all meant."

"I didn't take it in at first."

"I was feeling so well again. So I didn't think I needed to keep so strictly to the diet. [Later] I found out I had osteoporosis"

- Denial was the minimisation of the diagnosis.
- Participants described underestimating the extent of the changes they would need to make.

What participants said about anger…

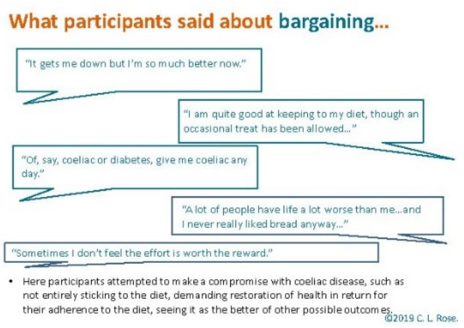
"People who are vegetarian, a choice they have made, always get their meals."

"I still feel fairly upset and resentful."

"I remember feeling very, very put out."

"I had possibly been undiagnosed for 20 years or so, if not even longer!"

- People sometimes described a sense of anger and injustice.
- Sometimes this was directed at medical professionals, such as where diagnosis had been wrong/ delayed.



What participants said about bargaining…

"It gets me down but I'm so much better now."

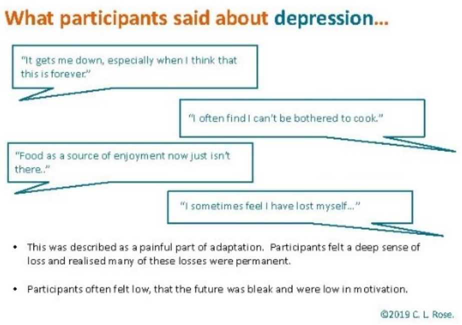
"I am quite good at keeping to my diet, though an occasional treat has been allowed…"

"Of, say, coeliac or diabetes, give me coeliac any day."

"A lot of people have life a lot worse than me…and I never really liked bread anyway…"

"Sometimes I don't feel the effort is worth the reward."

- Here participants attempted to make a compromise with coeliac disease, such as not entirely sticking to the diet, demanding restoration of health in return for their adherence to the diet, seeing it as the better of other possible outcomes.



What participants said about depression…

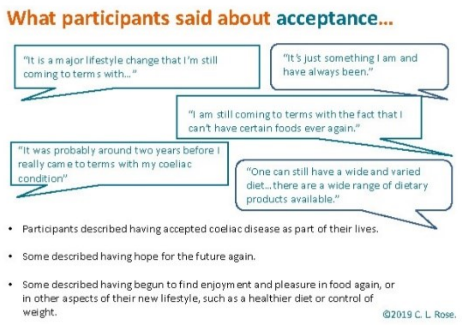
"It gets me down, especially when I think that this is forever."

"I often find I can't be bothered to cook."

"Food as a source of enjoyment now just isn't there.."

"I sometimes feel I have lost myself…"

- This was described as a painful part of adaptation. Participants felt a deep sense of loss and realised many of these losses were permanent.
- Participants often felt low, that the future was bleak and were low in motivation.



What participants said about acceptance…

"It is a major lifestyle change that I'm still coming to terms with…"

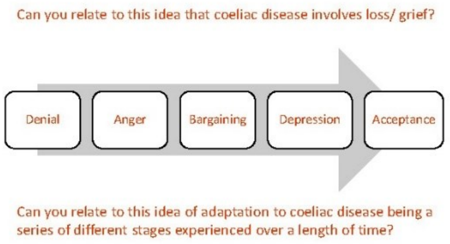
"It's just something I am and have always been."

"I am still coming to terms with the fact that I can't have certain foods ever again."

"It was probably around two years before I really came to terms with my coeliac condition"

"One can still have a wide and varied diet…there are a wide range of dietary products available."

- Participants described having accepted coeliac disease as part of their lives.
- Some described having hope for the future again.
- Some described having begun to find enjoyment and pleasure in food again, or in other aspects of their new lifestyle, such as a healthier diet or control of weight.



Can you relate to this idea that coeliac disease involves loss/ grief?

Denial

Anger

Bargaining

Depression

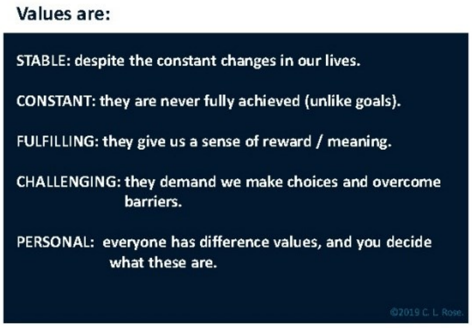
Acceptance

Can you relate to this idea of adaptation to coeliac disease being a series of different stages experienced over a length of time?

How to move forward despite the changes?

Knowing what matters

Values-led action can help us move forward.



Values are:

STABLE: despite the constant changes in our lives.

CONSTANT: they are never fully achieved (unlike goals).

FULFILLING: they give us a sense of reward / meaning.

CHALLENGING: they demand we make choices and overcome barriers.

PERSONAL: everyone has difference values, and you decide what these are.

Values-led action is acting in a way that moves you in the direction of your values.

It is the direction of travel, not a destination.

GOAL

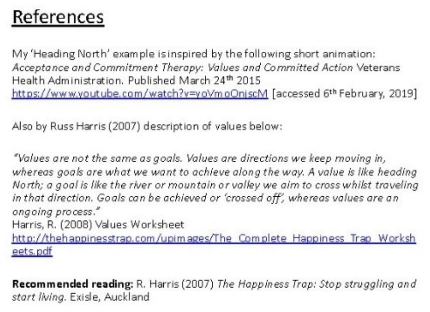
VALUE

"Going to Norway" is a goal

"Heading North" is a direction

Following your values will mean that you always have a sense of direction and purpose, regardless of your goals.

So whether or not you ever get to Norway (or what happens if you do) you can keep heading North.



References

My 'Heading North' example is inspired by the following short animation: *Acceptance and Commitment Therapy: Values and Committed Action* Veterans Health Administration. Published March 24th 2015 https://www.youtube.com/watch?v=yoVmoOniscM [accessed 6th February, 2019]

Also by Russ Harris (2007) description of values below:

"Values are not the same as goals. Values are directions we keep moving in, whereas goals are what we want to achieve along the way. A value is like heading North; a goal is like the river or mountain or valley we aim to cross whilst traveling in that direction. Goals can be achieved or 'crossed off', whereas values are an ongoing process."
Harris, R. (2008) Values Worksheet
http://thehappinesstrap.com/upimages/The_Complete_Happiness_Trap_Worksheets.pdf

Recommended reading: R. Harris (2007) *The Happiness Trap: Stop struggling and start living*. Exisle, Auckland

Talking to other people about Coeliac Disease.

Facilitators:
Catharine Rose - Doctoral researcher. School of Psychology.
Sianna Banks – MSci Psychology and Psychological Practice.

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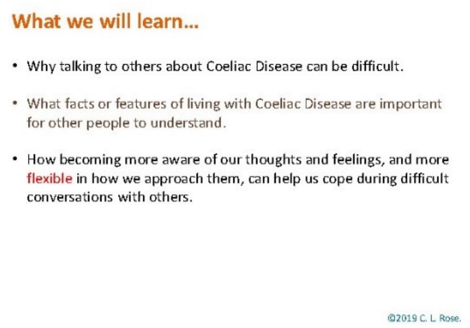
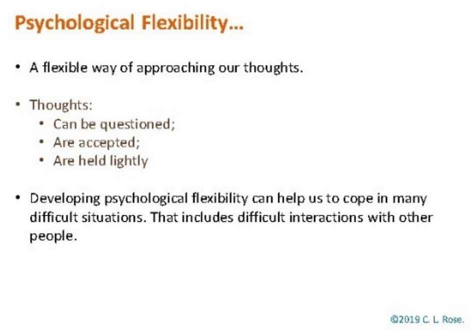


What we will learn…

- Why talking to others about Coeliac Disease can be difficult.
- What facts or features of living with Coeliac Disease are important for other people to understand.
- How becoming more aware of our thoughts and feelings, and more flexible in how we approach them, can help us cope during difficult conversations with others.



Psychological Flexibility…

- A flexible way of approaching our thoughts.
- Thoughts:
  - Can be questioned;
  - Are accepted;
  - Are held lightly
- Developing psychological flexibility can help us to cope in many difficult situations. That includes difficult interactions with other people.

Why Coeliac Disease is difficult to talk about…

Reason #1: Language

- Our understanding of terms/ words are influenced by society and culture.
- Associations are made with different words/ terms.

Reason #2: Thinking biases…

Our mind is always trying to protect us from harm, including **social rejection…**

….and it often **overestimates risk**…

Our fight/flight/freeze response can be triggered by our mind's 'alarm system' in some social situations, protecting us from actual or possible harm.

- Defensive/ aggressive / argumentative
- Avoid/ escape
- Can't explain/ express yourself

Reason #3: Social significance of food is strong

Reason #4: Internal conflict felt around food...

Communication about food, and about Coeliac Disease, can lead to strong, powerful feelings about ourselves, about our relationships with others and about our values.

The task of discussing these things can feel deep and overwhelming.

Questions:

What do we need to communicate to other people about Coeliac Disease?

Why do we need them to know these things?

What values are we trying to communicate when we talk to others about Coeliac Disease?

Session 6: Living well with coeliac disease.

Facilitators:
Catharine Rose - Doctoral researcher. School of Psychology
Sianna Banks – Msci Psychology and Psychological Practice

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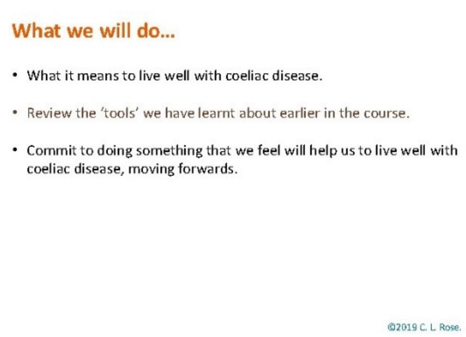
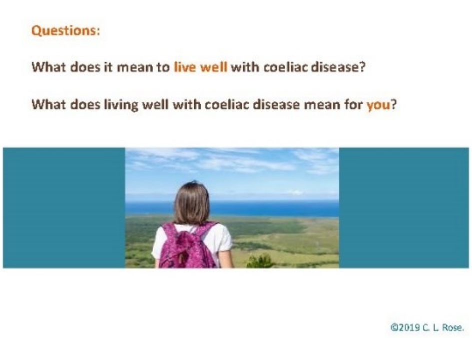


What we will do...

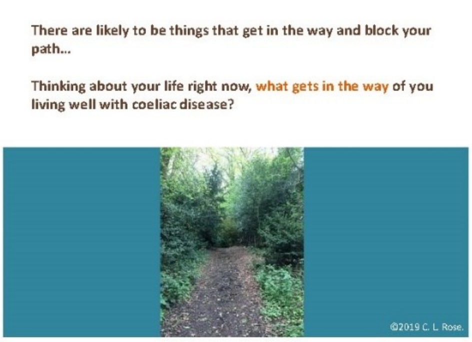
- What it means to live well with coeliac disease.
- Review the 'tools' we have learnt about earlier in the course.
- Commit to doing something that we feel will help us to live well with coeliac disease, moving forwards.



Questions:

What does it mean to live well with coeliac disease?

What does living well with coeliac disease mean for you?



There are likely to be things that get in the way and block your path...

Thinking about your life right now, what gets in the way of you living well with coeliac disease?

Information

Challenging Negative Automatic Thoughts

Skills-building

Breathing technique

Time

Values

Connecting with Others

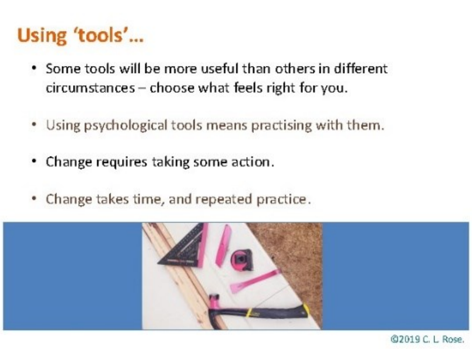
Acceptance

Observing self

Getting untangled from feelings and thoughts

Understanding others' perspectives

Planning



Using 'tools'...

- Some tools will be more useful than others in different circumstances – choose what feels right for you.
- Using psychological tools means practising with them.
- Change requires taking some action.
- Change takes time, and repeated practice.

Further reading…

- Harris, Russ. (2008) *The Happiness Trap.* London: Robinson.
- Greenberger, D. & Padesky, C. A. (2015) *Mind Over Mood* Second Edition. Guildford Publications.

Most of the exercises in this course are based on CBT and ACT. The books above are designed as self-help books for the public, and have inspired much of the content in this course.

Academic references…

Session 6 has also been inspired by the protocol produced by –
Brassington, L., Fereira, N. B., Yates, S., Fearn, J., Lanza, P., Kemp, K. & Gillanders, D. (2016) 'Better Living with Illness: A transdiagnostic acceptance and commitment therapy group intervention for chronic physical illness' *Journal for Contextual Behavioural Science* 5 (4): 208-214.; :

If you want to speak to me about the course in the future, please feel free to contact me…

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Twitter: @UoBSoPCoeliac
Website: www.coeliacpsychology.bham.ac.uk

And finally…

APPENDIX G: Chapter Six- Supplementary Tables and materials

Pro-forma for participant screening call

Name __ __ __ __ __ __ __ __

☐ Consent to complete this pro-forma and store it securely at the University of Birmingham as research data for the following periods of time:

  - Until end of PhD project – for those who do not choose to participate, as a record of the recruitment process;
  - Ten years – for those who do participate, in accordance to The University of Birmingham's policy of research data.

Tick if '*Yes'*

☐ ≥ 18 years old.

☐ Medical Diagnosis of Coeliac Disease.

☐ Spoken and written English Language.

☐ No serious sensory or cognitive impairment such as would prevent ability to follow the course content or participate in group activities.

Format of Group

☐ Willing to attend for at least five of the six x 2.5 hour sessions.

☐ To best of knowledge, able to attend on the scheduled course dates

☐ Course 2: 14th September – 19th October, 2019 (Saturdays); Time – 2:00 – 4:30pm

☐ Known date(s) can't attend.

☐ Willing and comfortable with the idea of joining a small, diverse group.

☐ Able to make own way to the group sessions.

Self-reported need

☐ Do you think that you would benefit from some support in adapting to diagnosis of Coeliac Disease and/or the gluten-free diet?

☐ Do you think you would find the course described helpful to you?

Thinking about living with Coeliac Disease and the gluten-free diet, is there any area in particular you feel you would benefit from support with? (briefly list)

____

____

____

Willingness to participate in a research project.

☐ Willing for data to be used as part of PhD research project?

☐ Willing to complete research measures at four time-points – 0 weeks, 6 weeks, 12 weeks, 22 weeks.

☐ Willing to participate in a post-course telephone interview (1 and 6 weeks after course ends)?

(circle response) Would you like to receive a copy of this pro-form by post **Y / N** or email **Y / N** ?

(circle response) Would you like to receive a paper copy of the participant information pack and consent form by post, with a pre-paid return envelope? **Y / N** or access these materials online **Y / N**

If yes, take down address (for paper version) or email address (for online version):

____
____

Any other relevant information you feel we need to discuss…?

____
____
____

Any worries, concerns or questions at this stage?...

____
____

Calculation of the Reliable Change Index

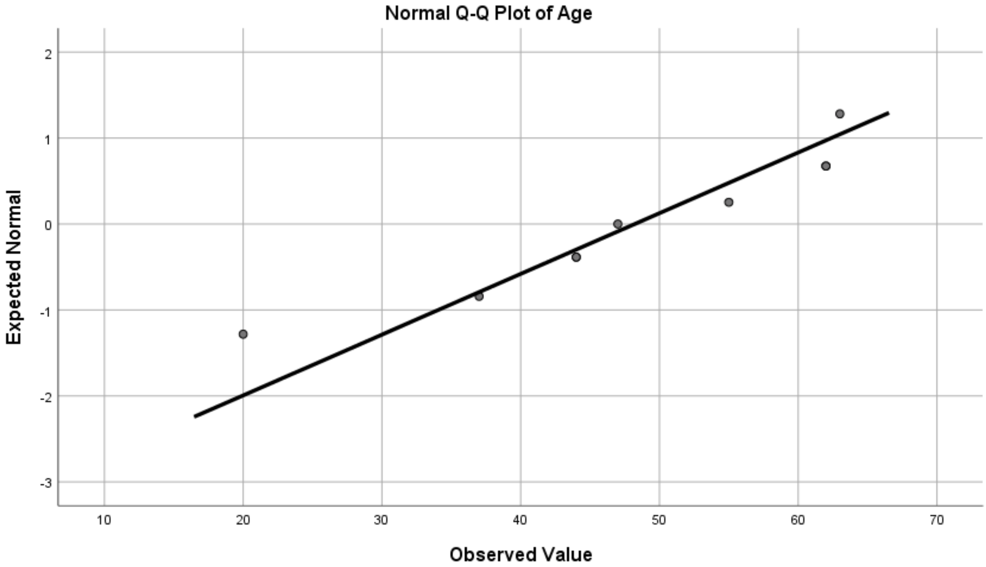
The formula below is Jacobson and Truax's (1991) method of calculating the Reliable Change Index.

$$\mathrm{RC} = \frac{x_2 - x_1}{s_{diff}}$$

Supplementary table X (Chapter Six): Reference Data used to calculate the reliable change index in the current study

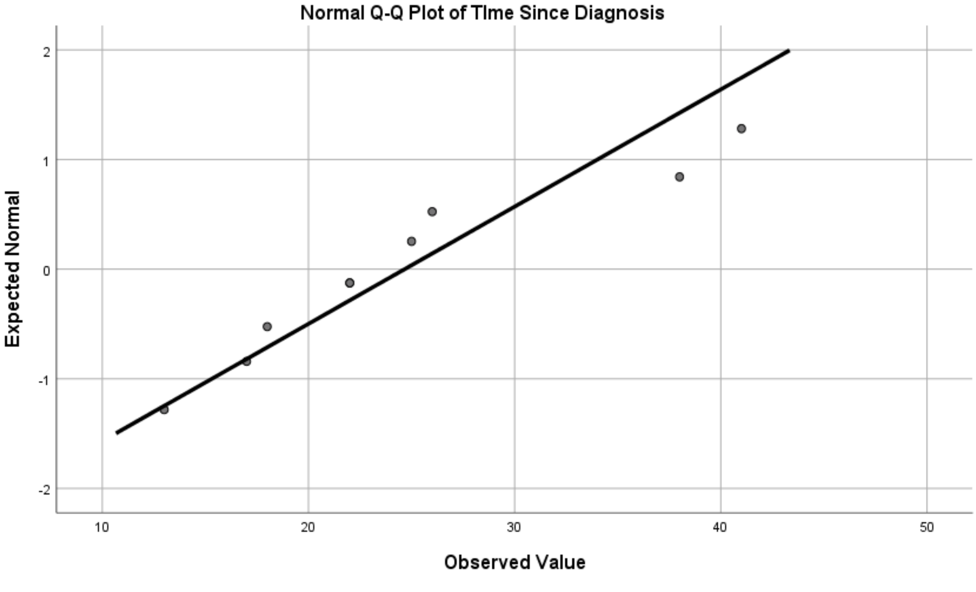
Measure	*Test- re-test reliability*	*SD (normative population)*	*Publication*
DASS-21 (depression)	*ICC = 0.71*	4.59	Asghari et al., 2008
DASS-21 (anxiety)	*ICC* = 0.79	3.95	Asghari et al., 2008
DASS-21 (stress)	*ICC* = 0.81	4.67	Asghari et al., 2008
AAQ-II	*ICC = 0.81*	7.52	Bond et al., 2011
LWWCD (total scale)	ICC = 0.96	23.27	Chapter 4, current researcher
LWWCD (concerns and losses)	ICC = 0.94	16.35	Chapter 4, current researcher
LWWCD (positive changes)	ICC = .938	6.87	Chapter 4, current researcher
LWWCD (Risk Management)	ICC = 0.95	5.14	Chapter 4, current researcher
Whole scale	ICC = 0.86	5.03	(Lochting et al., 2013)
BIPQ (Consequences)	ICC = 0.75	1.94	(Lochting et al., 2013)
BIPQ (Timeline)	ICC = 0.88	2.40	(Lochting et al., 2013)
BIPQ (Personal Control)	ICC = 0.68	1.76	(Lochting et al., 2013)
BIPQ (Treatment Control)	ICC = 0.85	2.21	(Lochting et al., 2013)
Identity	ICC = 0.79	1.87	(Lochting et al., 2013)
Concern	ICC = 0.83	2.56	(Lochting et al., 2013)
Understanding (Coherence)	ICC = 0.64	1.74	(Lochting et al., 2013)
Emotional representation	ICC = 0.77	2.72	(Lochting et al., 2013)

Normal Q-Q Plot of Age (course participants, n=9)



A Shapiro-Wilk test showed no significant departure from normality, W(9) = 0.902, p = .264

Normal Q-Q Plot of Time since diagnosis (course participants, n=9)



A Shapiro-Wilk test showed no significant departure from normality, W(9) = 0.905, p = .288

Supplementary Table XI (Chapter Six). BIPQ Item Means (SD) across a range of adult study populations reported in meta-review data (Broadbent et al., 2015)[60]

Condition	*Consequences*	*Timeline*	*Personal Control*	*Treatment Control*	*Identity*	*Concern*	*Coherence*	*Emotions*	*Authors; Country*
Type 2	3.97 (2.74)	9.14 (1.58)	6.94 (2.15)	8.46 (1.73)	3.99 (2.78)	6.33 (3.07)	7.71 (2.30)	3.72 (3.42)	Bean (2014); New Zealand
Type 2	5.45	8.55 (2.42)	4.45 (2.77)	6.80 (2.80)	4.37 (3.54)	4.95 (3.61)	5.91 (2.99)	5.09 (3.72)	Keogh et al. (2011); Ireland
Type 2	6.80 (3.50)	6.80 (3.60)	4.60 (4.30)	7.00 (2.90)	7.00 (2.80)	7.80 (2.70)	5.20 (3.90)	7.60 (1.60)	Vedhara et al. (2012); UK
Bipolar	7.38 (2.76)	7.27 (2.98)	4.69 (2.70)	7.44 (2.37)	7.01 (2.51)	7.21 (2.98)	6.71 (2.90)	7.08 (2.72)	Lobban et al. (2013); UK
GORD	5 (1.75-6.25)	10 (8-10)	6 (4.5-7.5)	8 (6-10)	5 (3-7.25)	6 (2.5-8.0)	7 (4.5-8.0)	4 (1.0-7.0)	Dibley, Norton, & Jones (2010); UK
Systemic Lupus	6.50 (2.30)	9.20 (1.80)	5.60 (2.70)	8.40 (1.60)	6.00 (2.60)	5.80 (2.70)	6.80 (1.90)	5.80 (2.70)	Daleboudt, Broadbent, Berger, & Kaptein (2011); Netherlands
CKD (employed, pre-dialysis)	6.70 (2.50)	9.30 (1.70)	4.70 (2.90)	6.80 (2.90)	5.20 (2.90)	6.90 (2.70)	7.30 (3.10)	5.00 (3.10)	Jansen, Grootendorst, et al. (2010); Netherlands
Multiple Chemical sensitivities	7.20 (2.02)	9.15 (1.69)	4.95 (2.64)	4.63 (3.02)	7.20 (1.85)	6.10 (2.08)	6.00 (3.85)	5.75 (2.55)	Skovbjerg, Hauge, Rasmussen, Winkel, & Elberling (2012): Denmark
Coeliac Disease (baseline)	7.44 (0.88)	10.00 (0.0)	5.44 (2.83)	7.44 (3.32)	3.89 (2.32)	7.44 (2.30)	8.78 (1.39)	7.11 (2.2)	Current researcher; UK

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[60] Supplementary tables accessed through online version of the article at: https://www.tandfonline.com/doi/abs/10.1080/08870446.2015.1070851?journalCode=gpsh20
Article: Broadbent, E., Wilkes, C., Koschwanez, H., Weinman, J., Norton, S. & Petrie, K. J. (2015) A systematic review and meta-analysis of the Brief Illness Perception Questionnaire. *Psychology and Health* 30 (11): 1361-1385. DOI 10.1080/08870446.2015.1070851

APPENDIX H: Chapter Seven- Supplementary materials

Interview schedule week six

Questions:

1. Thinking back, could you tell me why you decided to come to the course?

2. Thinking back to before you attended that first course session, did you have any hopes for the course?

3. Again, thinking back to before that first session, was anything worrying you about attending? [if yes] Did you feel better once you started attending sessions?

4. Overall, how would you describe the experience you had on the course?

5. Would you say that the course met all your expectations? [if not, what expectations were not met and why?].

6. How did you length of the sessions feel?

7. How did you feel about the amount of content in the sessions? (e.g. right amount of content? Wanted more/ less material covered?)

8. Overall, what did you think about the way the presenters set-up and ran the sessions?

9. Each session had a different topic, and included teaching about one or more different 'tools' to help you manage Coeliac Disease. What is your opinion on that format?

I'm going to ask you to think back to the individual sessions now – do you have the folder with you (doesn't matter if not). You might want to flick through it as we go. When you answer these questions, please think about how useful or relevant the session are to ***you personally*** *in living well with coeliac disease.*

10. Thinking about session one. In the second half, Cate focussed on learning about coeliac disease. She also gave you some printed information about the condition and the gluten-free diet to look through in your own time.

11 How did you find this session? Did you learn anything in this session that is useful to you in living with coeliac disease?

How useful did you find the printed information about CD that she gave you?

At the end of that session, Cate got you to work through an exercise to think if there was anything you needed to find out or practice that would help you to live well with coeliac disease. Did you think of anything and write that down? Would you mind telling me what that was?

12.. In the second session, Cate focussed on anxiety and coeliac disease… She explained how anxiety works, and how you might use some ideas from CBT to understand how anxious feelings and thoughts happen, and can be challenged.

How did you find this session? Did you learn anything in this session that is useful to you in living with coeliac disease?

13 In the third session, Cate talked about the stress that can be caused by Coeliac Disease, and about some different ways you can lower stress levels – like a breathing technique and scheduling uplifting activities into your week. She also talked about the idea of Acceptance, how stress can be lowered by accepting difficult thoughts and feelings, rather getting tangled up with and fighting them.

How did you find this session? Did you learn anything in this session that is useful to you in living with coeliac disease?

14 In the 4th session, Cate talked about psychological research that has found that adjusting to chronic conditions like coeliac disease can involve grieving losses. She also talked about the idea that coeliac disease can change some people's sense of their social or personal identity, and how time is generally needed to adapt to big lifestyle changes. Then in the second half she looked at values and values-driven action.

Did you learn anything in this session that is useful to you in living with coeliac disease?

15 In the 5th session, Cate focussed on the issue of why communication about coeliac disease can be difficult. There was quite a bit of discussion in this session, as well as two exercises, one looking at how distancing from thoughts might help, the other looking at communication from different perspectives.

How did you find this session? Did you learn anything in this session that is useful to you in living with coeliac disease?

16. In the last session Cate asked you to commit to doing or changing one thing to help you live better with Coeliac Disease.

Would you mind telling me what the commitment you made to yourself was?

Why did you choose that?

Now the course has ended, do you think you will really try to keep that commitment you made? Why / why not?

17. My final question is what difference, if any, has the course made to how you live with CD

Thank you so much for your time.

Interview schedule for follow-up interview (12 week post-baseline)

1a. The main objective of the course was to support people in living well with Coeliac Disease. Thinking now, six weeks on from that last session, do you feel the course achieved that objective?

1b. [*If yes*] How is it supporting you now, six weeks on? [*If no*] Why do you think it isn't supporting you now?

2. You came to a session every week for six weeks. How did you feel once those weekly sessions had ended?

3. Did you stay in touch with any other group members? [*If yes*] Is that something which you find supportive?

4. Reflecting on the experience now, six weeks on, is there just **one** session/ activity you use or particularly remember? [*if yes*] Do you feel that helps you to live better with Coeliac Disease? How does it do that? [*If no/none*] Why do you think, six weeks on, the sessions are not feeling useful or memorable?

5. When we last spoke, you said you were thinking of making a few changes… **[refer to LIST]** Have you been doing these things? *(if not, do you think you will in the future?)* Has anything got in the way? Has doing these things made a difference to you? Will you keep these changes up?

6. Finally, do you think attending a 'refresher' session would be a useful thing? [*If yes*] Why? [*If no*] why not?

7 Is there anything else you'd like to tell us about your experience of the course?

Thank you so much for participating in the course, and giving us your feedback.