‘I Sort of Never Felt Like I *Should* be Worried About it or That I *Could* be Worried About it’: An Interpretative Phenomenological Analysis of Perceived Barriers to Disclosure by Young People with Coeliac Disease

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Data availability statement: Raw data, beyond those displayed in this article, are not shared.

Acknowledgements: The authors would like to express sincere gratitude to the participants who gave their time to participate in this research and to Coeliac UK who kindly shared the study advert. This research was conducted as part of a University of Oxford Clinical Psychology Doctoral Health Education England funded programme.

Draft version 1.0, 30.07.21. This article has not yet been peer reviewed. Please do not copy or cite without authors’ permission.

Abstract

Objectives: There has been little research in the UK regarding young people's experiences of disclosure of psychological difficulties relating to coeliac disease (CD) to others, particularly healthcare professionals. This study sought to address this systematically with a focus on the lived experiences of young people with CD. This study aimed to gain insight into how paediatric gastroenterology services could improve patient experience for those with CD and support identification of patients who may benefit from further psychological support.

Design: This study used interpretive phenomenological analysis (IPA) of patient accounts.

Methods: Seven young people with CD (aged 11-16 years) were recruited from a UK hospital paediatric gastroenterology service. Semi-structured interviews were carried out and verbatim transcripts were analysed using IPA to explore young people's experiences of CD and why they might feel able or unable to disclose psychological difficulties associated with their condition to clinicians.

Results: Three superordinate themes emerged from the data. The first encapsulated experiences of adjusting to the diagnosis within a developmental context, including the role of adults in information provision and the importance of peer support. The second outlined experiences of managing perceived or actual stigma regarding others' perceptions of the condition and themselves. The third incorporated perceived barriers to disclosure relating to power, safety, and beliefs about the role of medical professionals.

Conclusions: Findings highlight the importance of clinicians continually providing developmentally appropriate information to young people and actively breaking down barriers to disclosure through body language and use of clear questions regarding emotional experiences.

Keywords: Interpretative phenomenological analysis; paediatrics, coeliac disease, stigma, disclosure, psychological difficulties

Coeliac disease (CD) is a genetic lifelong autoimmune condition whereby ingesting gluten leads to a range of idiosyncratic symptoms including diarrhoea, abdominal pain, and chronic fatigue (Barratt et al., 2013; Green & Jabri, 2003, 2006). Treatment for CD requires the individual to maintain a strict gluten free diet (GFD), whereby they must exclude foods containing wheat, barley and rye (NICE, 2015). Long term non-adherence to the GFD is problematic and can result in complications such as osteoporosis, lymphoma, and small bowel cancer (Green & Jabri, 2003; Rubio-Tapia & Murray, 2010).

Research indicates that being diagnosed with CD as a young person, of secondary school age, poses particular challenges when adapting to the new diet and lifestyle (NICE, 2015). Developmentally, this age-range involves increasing autonomy from parents, growing responsibility for one's own wellbeing and food-related activities, and increasing peer-pressure to conform (Ludvigsson et al., 2016). Difficulties adapting to a diagnosis of CD at this developmental stage can lead to non-adherence, poor health-related quality of life, and psychological difficulties (Mayer et al., 1991; Mazzone et al., 2011; Schroeder & Mowen, 2014). A recent systematic review suggests that there is an increased prevalence of anxiety, depression, and somatic complaints in young people with CD, emphasising the importance of identifying young people who may benefit from psychological support (Coburn et al., 2019).

Identification poses a challenge to services, as young people can experience difficulties disclosing psychological difficulties, exacerbated by the process of adjusting to a chronic condition (Rickwood et al., 2007; Rutter, 1995). For instance, research exploring disclosure and support-seeking in young people with heart disease and inflammatory bowel disease (IBD) suggests that only 60% and 62.5% of individuals shared concerns related to their wellbeing during routine consultations, respectively (Ashton et al., 2016; Vatne et al., 2012). Moreover, Vatne et al. (2012) found that young people were more likely to express subtle negative emotional cues during routine consultations, as opposed to clear

verbalisations of distress. A systematic review by Gulliver et al. (2010) suggests that the characteristics of the treating clinician, including credibility, unhelpful responses, and being perceived as ‘too busy’ pose possible perceived barriers to help-seeking in 11-25 year olds.

Identification of young people who are experiencing clinically significant psychological symptoms related to their CD may be further compromised by a lack of integration of psychological support and consultation within multidisciplinary teams (MDT's; Coburn et al., 2020; Crocker et al., 2020). In line with this, Coeliac UK (2018) have identified ‘finding the best post-diagnosis support’ as a ‘top 10 research priority’ following consultation with people with CD, their families and healthcare professionals. A US study reported that 49% of young people attending a paediatric CD clinic displayed clinically significant psychological symptoms, including anxiety, depression, behaviour problems, attention and concentration difficulties, and/or disordered eating or feeding problems (Coburn et al., 2020). Moreover, 68.1% of all families identified mental health consultation as one of their top two priorities when attending medical appointments (Coburn et al., 2020). However, research in a sample of 800 adults with CD across the UK suggests that emotional well-being was rarely assessed (17.6% cases) by clinicians during follow-up appointments (Crocker et al., 2020). This raises the question of whether young people with CD perceive that they have had the opportunity to disclose distress associated with CD during routine consultations, or whether they too perceived barriers to disclosure (Gulliver et al., 2010).

We aimed to address these issues systematically by providing a theoretically integrative account of young people’s experiences of disclosing or not disclosing psychological difficulties to clinicians. Research objectives were:

1. To understand what it is like for young people to have coeliac disease.

2. To explore young people's experiences of disclosing and not disclosing psychological difficulties associated with CD to clinicians in a UK paediatric gastroenterology service.
3. To explore young people's perspectives regarding any specific changes that could be made to services to promote disclosure and improve access to psychological services, if it is felt that this would be helpful for this population.

Subsequently, this study aimed to make recommendations to services based on findings, as necessary.

Methods

Design

This study employed an interpretive phenomenological analysis (IPA) methodology in line with its focus on lived experience, with special consideration of the interpersonal and socio-developmental context (Smith et al., 2009).

Research Team

The research team comprised the lead researcher, a trainee clinical psychologist (MW), who co-designed and carried out most aspects of the study. MW was supervised by three clinical psychologists (AD, with clinical and research experience in this area, JK, with clinical experience in paediatrics, and MK, who is experienced with IPA). The positioning of researchers is included as supporting information.

Participants

Purposive sampling was used to recruit participants from a single UK hospital tertiary paediatric gastroenterology service. Participants were aged between 11-16 years old and attending secondary school, to limit sample heterogeneity. Participants were required to have a medical diagnosis of CD, to have been under the care of the service for at least 3 months and have had at least one follow-up appointment. Participants were excluded if they had a co-

morbid diagnosed gastrointestinal condition and/or if they were currently receiving psychological support from any psychological service.

Young people attending CD consultations in the service were screened for eligibility and, if eligible, their parent/guardian was sent a letter by post inviting the young person to participate in an interview. Sixteen-year-olds were sent the invitation letter directly. A further invitation letter was sent three weeks later if they had not responded. Recruitment initially commenced in March 2020 but was paused in mid-March 2020 due to the global pandemic. Recruitment resumed in September 2020 and ended in October 2020, with 25% uptake (28 invited). Interested young people or their parents contacted the primary researcher and were subsequently screened and sent an information sheet. All participants were required to give consent to take part, and parental consent was required for those under the age of 16. All participants completed a demographic questionnaire.

The sample consisted of seven white British participants, five females and two males, aged 11-16 ($M = 14$ years, 2 months; $SD = 1$ year, 8 months). All participants had a medical diagnosis of CD, whereby the mean age of diagnosis was 7 years, 5 months ($SD = 4$ years, 6 months; range 1 year, 6 months – 13 years, 5 months). All participants had at least one family member with CD. One participant had co-morbid ADHD and had previously received psychological input from the service. Remaining participants had no co-morbid diagnoses and were not under the care of other services for their CD. Additional sample characteristics are provided in Table 2.

Procedure

A semi-structured interview schedule was developed with reference to relevant CD and lifespan research literature, consultation with a young person with CD, and discussions with a clinical psychologist (see supporting information). This was piloted on two young people who met inclusion criteria and consented to take part, to check for question

comprehension and to ensure that the questions elicited in-depth conversations about disclosure of psychological difficulties. Pilot interviews were used in the final analysis as no significant changes were made to the research procedure and interview schedule.

Interviews were either carried by the lead researcher in person at the participants' home, or remotely via video-call software. Interviews were audio recorded and lasted between 48 and 85 minutes. Interviews were transcribed verbatim and anonymised. Participants received £5.00 (in cash) as compensation for their time.

Ethics

This research was approved by the Health Research Authority and Health and Care Research Wales approval Research Ethics Committee (REC reference: 19/WA/0323), in addition to Oxford University Hospitals Research and Development team. The study was pre-registered on ClinicalTrials.gov following ethical approval (Identifier: NCT04240340).

Participants were aware of the research prior to consenting and time was given to consider whether they would like to take part and raise any questions or concerns. A written debrief was provided to participants in a follow-up email with the contact details of the research team.

Analysis

Analysis comprised five fluid stages, following guidance from Smith et al. (2009; see Table 1 for further details).

Credibility Checks

Several validity checks were carried out throughout the research process. Secondary researchers individually reviewed a sample of the transcripts to support the primary researcher in reflecting on the development of themes, and to ensure that they could follow theme development from an idiographic to collective level. Reflexivity was used to identify the influences of personal and professional experiences on the study process (Smith et al.,

2009). Peer supervision was employed to facilitate a bracketing interview prior to data collection to elicit preconceptions held by the researcher which may influence the nature of questions asked and the interpretation of data analysis. A reflective journal was kept throughout the development of the research, and following each interview, to keep a record of personal and professional influences and assumptions.

Results and Discussion

In line with the flexibility provided by IPA, a decision was made to merge the results and discussion sections by relating superordinate themes to the extant literature (Smith et al., 2009). This enabled the researchers to adequately describe and provide evidence for each superordinate theme within the scope of this paper.

Overview of Themes

Three superordinate themes emerged from the analysis. These were entitled: 1) “As soon as food started going away it was like oh *ok* this is what it is”: Adjusting to the diagnosis within a developmental context, 2) “It can either be a huge deal or not a deal at all”: How others respond to my condition matters to me, and 3) “I mean I wouldn’t just speak to the random guy or girl”: Who is my doctor to me? These encompassed a range of subordinate themes, as listed in Table 3. Superordinate themes will be discussed in turn using direct quotations to illustrate them (*italics* indicate participant emphasis).

1. “As soon as food started going away it was like oh *ok* this is what it is”: Adjusting to the diagnosis within a developmental context

This theme encapsulated accounts of participants’ journeys in adjusting to their diagnosis. Participants who were diagnosed in early childhood described an easier intrapersonal integration of CD, “It’s what I’ve always known because I was so little I don’t- it doesn’t really changed how I feel” (Finley, p.9). In contrast, those who were diagnosed from early adolescence described a more complex process of intrapersonal adjustment and

acceptance, influenced by feelings of loss, “If I went shopping I’d see like these coco pop bars that I usually love and I’ll think oh they used to be my *favourite*” (Billy, p.12). This is in line with existing research which suggests that adjusting to CD compounds the psychosocial challenges associated with the latter stage of development, impacting social relationships with peers and the formation of the young person’s identity (Högberg et al., 2003; Olsson et al., 2008; Wagner et al., 2008).

However, the benefits of early diagnosis were challenged by the need for all young people to be provided with developmentally appropriate explanations on an ongoing basis, as they grow with the condition. Participants described a reliance on adults to scaffold their understanding of CD and how to disclose it to others as they age:

I knew I couldn’t have. I couldn’t have a certain *piece* of food but... I didn’t know what it was so I could say to people that I was gluten free but I couldn’t explain to people...what I *actually* had. (Sam, p.9)

As participants developed, they described seeking new information about CD and using this to inform how they managed it e.g., GFD adherence, “I did a whole load of research into it and saw how bad it was and so I was like *I’m not going to do that anymore*” (Sarah, p.8). Provision of developmentally appropriate information relating to the importance of the GFD and its implications has been evidenced to increase diet adherence in young people (Guandalini & Young, 2014). In particular, young people seek information that is relevant to their daily activities at each stage of their development (Dovey-Pearce et al., 2005).

In line with their growing desire for autonomy, participants described the need for clinicians to adjust their language during appointments so that they could understand and respond to clinicians’ questions:

It's hard for the questions they do ask me. I *understand*, but I don't *get* what they are asking me...when it's passed on to my mum and dad they start the question and they start explaining it and then I'm like, oh I get the question now. (Maya, p.44)

Participants often had limited understanding of their condition, their diet, or the purpose of medical interventions (such as the antibody blood test) because this information had not been updated in accordance with their developmental stage, "there's just blood tests when I go basically...I actually have *no* idea (laughs) like I don't know what they are (laughs)...yeah" (Anna, p.31) and, "[it's] to check how much blood they can get from you without me going pale" (Eve, p.33). This lack of knowledge led to psychological dissonance for some older participants regarding their role in managing their condition. They described feeling both responsible for disclosing and managing their condition, whilst simultaneously feeling unskilled or, in one case, embarrassed about their lack of understanding and ability to describe the condition to others or understand what their medical consultation entailed. As young people developmentally progress through paediatric services, they need to be supported by clinicians to acquire developmentally appropriate skills, knowledge, and motivation to become well informed and committed partners in their healthcare (Dovey-Pearce et al., 2005). Participants who had experienced this reported feeling better able to explain their diagnosis to others, "They told me...my stomach is like an un-blown-up balloon and then when I eat gluten, the balloon blows up...and that's probably the simplest way, I say the exact same thing every time" (Maya, p.17).

The importance of having an informed understanding of the condition was reinforced by the need for young people to build up a peer-based network of 'supporters', who helped them navigate social situations involving food, playing a key role in their acceptance and adjustment to the condition, "If I'm going to a sleep-over I'm not just there with like a bowl of milk or something...it makes me feel quite good" (Finley, p.21-22), and "I feel like having

that person which you just really talk about it...to have conversations like “how’s your gluten free” y’know “what’s going on” and erm about everything else, more of like (pause) yeah. A supporter” (Sarah, p.23). Absence of this understanding led to difficulties correcting others’ misunderstandings, which created difficulties in cultivating support. For example, by leading to peers diminishing the importance of the GFD, “They’re like “oh can’t you try just a little bit just to see what it tastes like” and it’s always. It’s *no*. because it’s not...It’s not that simple” (Sam, p.19). Evidence suggests young people who are able to share appropriate knowledge about CD and the GFD with their peers experience reduced stigma around the condition and, in particular, the GFD (Olsson et al., 2009). Hosting group spaces for young people with CD to share information and coping strategies with each other is also associated with better psychosocial adjustment and reduced feelings of alienation and perceived stigmatization (Shani et al., 2020).

2. "It can either be a huge deal or not a deal at all": How others respond to my condition matters to me

This theme also stems from a consideration of developmental context, in that it captures the importance young people place on how others, particularly peers, respond to their condition. When it comes to disclosing the condition, participants hoped to strike a balance between others taking it seriously and providing safe foods, without drawing unwanted attention from others, which they perceived as highlighting difference:

Cus I mean you can be like at two ends of the scale like sometimes when people completely overreact like, “OH MY GOD SOMEONE’S GLUTEN FREE LETS ALL DO THIS BIG THING FOR THEM” and then the other side there’s like I’m in *this situation* and there’s *nothing* gluten free and *no one* cares at all. (Sarah, p.10)

In striking this balance, participants described facing a conundrum with regards to the label they used to disclose their condition. The label ‘disease’ often drew unwanted attention and

could lead to perceived or actual stigma from peers, “If I say coeliac disease they’re like “OHMYGOD you’ve got a DISEASE” (Sarah, p.21) and, “coeliac disease sounds a lot worse than gluten free...because it’s *disease*...It makes it sound as though like, you’re gunna *die* from it when really you’re not” (Eve, p.27). Participants’ choice of label could result in others misunderstanding the condition and co-creating the their identity in a way that felt problematic, “A few people responded in like “*oh that’s so rubbish*” or “that’s *terrible*”...then I have in my mind always, you know in the back of my mind that it is gunna be *rubbish*” (Billy, p.4), and:

If my friends say “Oh Anna is gluten free” I (laughs) *often* correct them like no I’m actually *coeliac* because it’s like not a *choice* and I feel like places like restaurants or pubs they kind of don’t *get* that that much. (Anna, p.7)

This challenge speaks to their developmental context, whereby young people are both yearning to carve out their personal identity whilst also consolidating their social identity based on their membership of certain social groups (Arnone & Fitzsimons, 2012). This poses the challenge of trying to navigate the complexities of disclosure to avoid taking on an unwanted identity and the perceived or actual stigma resulting from real or imagined differences (Erikson, 1950; Schroeder & Mowen, 2014).

Participants often anticipated stigma through disclosure to peers, in line with the developmental need to ‘fit in’ and avoid difference, “I just felt like I was just like the odd one out like the *one* friend who couldn’t have that specific thing” (Sam, p.36), and “obviously in primary school everyone wants to be the same...So it’s like are they gunna think I’m *weird*” (Maya, p.21). This was sometimes based on experiences of others’ stigmatising reactions to disclosure in situations involving food, “He still finds it *shocking*. That I can’t eat KFC” (Sam, p.12) and “they’ll be like oh Maya with her gluten free, she can’t eat anything” (Maya, p.32). CD and the GFD are not always well understood by others, suggesting young people

with CD may be more likely to internalise others' views about their condition being undesirable, abnormal, and something that should be concealed through avoidance (Copelton & Valle, 2009; Schroeder & Mowen, 2014), a coping strategy utilised by some young people in this study, "I didn't tell my friends for ages and I can *remember* that. Like not telling them" (Sarah, p.11) and, "on the rare occasions when I have been asked to go out to places to eat I just say no...I'm like very *careful* about it" (Anna, p.5).

Alternative coping strategies included reframing the condition as something that others were missing out on, "when I was younger, like when people asked me why I couldn't eat things I'd say because I'm *special*" (Eve, p.9) and, "I sort of say quite a lot of gluten free food is *better* than food with gluten in it" (Billy, p.17). By reframing the condition and the GFD as a strength or assert, it reduces the likelihood that others will perceive these as weaknesses (Kaushansky et al., 2017). Alternative strategies used to incorporate CD into their identity in a stigma-reducing way included educating their friends and family about the condition to 'bring others onto their side' and curate self-acceptance, "They're like oh that's fine and, accepting that I can't eat it and, it's not personal" (Maya, p.4), and:

They may have heard the term gluten-free but I don't think they've ever like *asked* like what it *actually* was. So they just never really *learn*...they're just like "oh *what's* that?" and then they *understand* and then they take it seriously. (Sam, p.21)

This is similar to the 'neutralising motive' set out by Sharp (2009), whereby disclosure of and education about a condition was found to minimise the effects of stigma. This approach has been evidenced to help young people maintain a positive social identity and can result in greater understanding and solidarity in their social groups (Schroeder & Mowen, 2014).

3. "I mean I wouldn't just speak to the random guy or girl": Who is my doctor to me?

This theme encapsulates the barriers that young people identified to disclosing psychological difficulties to clinicians. Identified barriers were in line with previous research,

suggesting that they are not specific to young people with CD (Beresford & Sloper, 2003; Gulliver et al., 2010; Radez et al., 2020). Some young people held stereotypical beliefs about doctors as serious and strict, “They may think that if they tell them like they may be angry about it because they don’t have that like gentle face, they have a very serious face” (Sam, p.34). Some ascribed doctors with a high status and positioned them as ‘knowing everything’. This contrasted with a sense of their own inferiority, which could generate feelings of anxiety:

I definitely myself get nervous...if I’m talking to doctors...it’s very intimidating when someone’s sitting there and asking you is *this* wrong with you...you’re sitting there talking to an adult who knows everything, and you don’t know anything yourself. That’s the scariest part of it. (Maya, p.43-52)

Many held beliefs about what doctors are and are not interested in hearing about and this often led them to anticipate that medical consultations would not be an appropriate place to disclose emotional difficulties:

These people are here to help me for medical reasons... if someone was struggling I don’t think they’d even *think* about a doctor like being an outlet to explain their emotional like problems with it. (Anna, p.44)

There is evidence that young people who have established and trusted relationships with clinicians are more likely to seek help in the future (Gulliver et al., 2010; Rickwood et al., 2007). Thus, there is a need for clinicians to actively break down barriers. For example, by adapting their body language to communicate safety and time:

They don’t just ask you a question and then do something else but they’ll pay attention to it...they usually like turn around on their chair and push out from their computer and that just shows that they’re not gunna be doing anything on the computer. (Billy, p.27)

Young people were often aware of the stress on the wider hospital system and either felt that the way they were feeling was not important enough to take up the clinician's time or that they would be seen by the clinician as a timewaster, "I didn't want people to think I'm – not weak, but I didn't want people to think I was like *struggling* with something which is supposedly y'know outlook and seen as so just *easy*" (Sarah, p.36) and, "They're like doctors and they just wanna like- they've got a lot of people to see they just wanna do the session and move on" (Anna, p.36).

In line with existing research, few participants recalled being explicitly asked about their emotional adjustment during consultations and suggested that it would be helpful for clinicians to provide clear permission to disclose psychological difficulties, so that they could recognise and respond to this accordingly (Crocker et al., 2020; Radez et al., 2020):

I feel like when the doctors are *speaking* maybe there should be like an extra question like "how are you feeling?"...every time I think they say "how are you going with it?" I always assume they're asking me like how am I finding alternatives...I don't actually think they're asking me like *emotionally* like "how do you feel?". (Anna, p.42)

Young people reported an assumption that if they were not explicitly asked about their emotional wellbeing, then this must be because they should not be experiencing difficult feelings, clinicians are not interested in this, or that their appointment is not the place to disclose this, "I haven't really spoken about how I feel about being gluten free...I don't really feel it's necessary...I mean it's not something they really *need* to know" (Finley, p.27-28), and:

[the doctor] has always just sort of been like so "how's your stomach feeling?"...it's never been like "how are *you* feeling?" so like I didn't feel like it was the right *place*

for me to talk about my feelings to them. Um or that I *should* be feeling those feelings about something so (pause) *small*. (Sarah, p.37)

Existing literature suggests that young people hold beliefs that they should be able to manage their own emotional difficulties, and may perceive help-seeking as a sign of weakness (Radez et al., 2020; Rickwood et al., 2007). Thus, permission-giving is equally important when young people are doing well with adhering to the diet, to normalise that they may still experience difficult emotions relating to the condition and that this is not a reflection of them not managing well and can be discussed.

Recommendations for Services

Recommendations were generated based on findings to support young people's understanding of CD and the GFD, provide them with the language to disclose and explain this to others, and break down perceived barriers to the disclosure of psychological difficulties to clinicians. Feedback on these recommendations was gathered through discussion with members of the medical team in the present service and is incorporated into this discussion.

Recommendations Regarding the Provision of Developmentally Appropriate Information

Young people described the need for information to be updated and repeated at each appointment in accordance with their developmental stage. Findings suggest that a proactive and sensitive approach to providing updated information during appointments is required as young people can feel embarrassed or lack confidence in asking for this information themselves. Providing information in a leaflet that goes out to patients ahead of appointments explaining what the appointment and blood test is for in accordance with their developmental stage may enable this information to be shared. This method acknowledges the time-constraints of routine consultations, which may make it difficult for clinicians to provide this updated information themselves. Notwithstanding this, findings suggest that during the

appointment it may also be helpful for clinicians to normalise forgetting and provide key information again, for example by stating, “Often people forget what the blood test results mean, so here is the information again”.

Young people described how the lack of an age-appropriate understanding of their condition could lead to avoidance of disclosure to peers and adults and, occasionally, non-adherence to the GFD. Through checking that young people have the language to explain their condition, diet, and medical intervention to peers and adults during consultations, it may mitigate these risks.

An additional way of sharing this information could be through the service facilitating education days, to equip young people with the knowledge and language to share this information with their peers. In line with findings, education days could take place at different developmental stages such as during years five or six, ahead of transitioning to secondary school, and again in years nine or ten, as young people develop greater autonomy over their diet. As an alternative to this, one young person suggested developing an educational video, or resources for teaching about the condition in schools as a way of making it easier for young people to talk about how the condition makes them feel.

Recommendations Regarding How to Actively Break Down Perceived Barriers to Disclosure

Young people reported an assumption that if they were not asked about their emotional wellbeing, then this must be because it should not be spoken about, or it was something that doctors were not interested in hearing about. Sending written information to young people in advance of their appointment to explain that the hospital is a place where they can go to talk about how they feel, to bring this into the young person’s awareness before they arrive at a hospital for their appointment may be helpful. Several young people also suggested that it would be helpful for clinicians to provide clear permission to disclose

psychological difficulties during appointments, by asking an extra question about how young people are feeling emotionally. This is in line with evidence reinforcing the need for disclosure to be scaffolded by others (Crocker et al., 2020; Radez et al., 2020). For example, clinicians could ask, “Sometimes young people tell me that they worry about eating out with their friends, is this something you worry about sometimes too?” This could be followed-up by use of a screening tool if mental health difficulties are indicated. When this feedback was discussed in the current service, clinicians shared concerns that opening-up conversations about emotions would lead to requests for referrals to psychology at a rate that could not be managed by existing psychological provision and that they therefore felt they should be prioritising access to psychology for young people with conditions such as IBD. This reflects very real limitations in service provision but may also validate participants experiences of feeling that their condition is perhaps ‘less important’ than other conditions and there is not enough resource in the system to support them. Through discussion, clinicians were made aware that most young people would likely not need psychology input but would benefit from having their feelings validated and normalised and perhaps being directed towards self-help resources. This would be in line with a stepped care design, which would consider the most efficacious use of resources in a busy paediatric hospital setting (Hamall et al., 2014; NICE, 2019).

Although some young people described experiencing a supporting and containing power dynamic during appointments by positioning the doctor as an ‘expert’, many young people disclosed experiencing a negative power-dynamic in their appointments, describing themselves as feeling inferior, or at risk of being ‘told off’. Many also had pre-existing assumptions about the role of a medical doctor which did not include talking about emotions or coping. By clearly showing the young person that the clinician has space and time for discussion, understanding, and empathy of emotions, clinicians could help redress unhelpful

power-dynamics and break down pre-existing stereotypes. One way of doing this may be to put an 'emotion poster' on display in the consultation room. The clinician could then use this to ask the young person which picture represents the way they are feeling about their condition and share the emotion that they are feeling that day too. Young people also commonly described the importance of the clinician's body language in developing their perception of how 'safe' and interested they were. Specifically, young people were often keen to please clinicians and were attuned to their facial expression, whether the clinician asked questions whilst typing notes on the computer or whilst facing the young person with their full attention, and whether the clinician was addressing questions to the young person themselves, or their parents/guardians.

Conclusions

This is the first UK study to directly explore the barriers perceived by young people with CD to disclosing psychological difficulties to clinicians during routine consultations. Findings highlight the importance of clinicians providing developmentally appropriate information to young people and actively breaking down barriers through body language and use of clear questions regarding emotional experiences. Future research could explore the impact of implementing the stated recommendations in services on overall patient experience and on the identification of patients who may benefit from psychological support.

Findings demonstrate an alignment in experience between the seven participants interviewed, suggesting reliability and generalisability. However, the sample comprised of a small number of white British participants receiving support from a single service, which may limit the cultural and geographical generalisability of findings. Several validation methods and credibility checks were used, however the analysis presented is the researchers' interpretation of the data and other interpretations are possible.

This study emphasises the value of in-depth, qualitative feedback from patients in identifying areas for service improvement. Although the provided recommendations are made based on young people's experiences of the present service, evidence suggests that the barriers identified are not specific to young people with CD. Therefore, it is hoped that findings may positively benefit patient experience and improve access to psychological support in both other paediatric gastroenterology services and other healthcare settings.

References

- Arnone, J., & Fitzsimons, V. (2012). Adolescents with celiac disease: a literature review of the impact developmental tasks have on adherence with a gluten-free diet. *Gastroenterology Nursing*, 35(4), 248-254.
<https://doi.org/10.1097/SGA.0b013e31825f990c>
- Ashton, K., Myers, S., Whitehead, E., & Sebastian, S. (2016). OC-058 Perspectives of Adolescent IBD Patients Undergoing Surgery. *Gut*, 65(Suppl 1), A34-A34.
<https://doi.org/10.1136/gutjnl-2016-312388.57>
- Barratt, S. M., Leeds, J. S., & Sanders, D. S. (2013). Factors Influencing the Type, Timing and Severity of Symptomatic Responses to Dietary Gluten in Patients with Biopsy-proven Coeliac Disease. *Journal of Gastrointestinal & Liver Diseases*, 22(4).
<http://www.jgld.ro/2013/4/6.pdf>
- Beresford, B. A., & Sloper, P. (2003). Chronically ill adolescents' experiences of communicating with doctors: a qualitative study. *Journal of Adolescent Health*, 33(3), 172-179. [https://doi.org/10.1016/S1054-139X\(03\)00047-8](https://doi.org/10.1016/S1054-139X(03)00047-8)
- Coburn, S., Puppa, E., & Blanchard, S. (2019). Psychological comorbidities in childhood celiac disease: a systematic review. *Journal of pediatric gastroenterology and nutrition*, 69(2), e25-e33. <https://doi.org/10.1097/MPG.0000000000002407>
- Coburn, S., Rose, M., Streisand, R., Sady, M., Parker, M., Suslovic, W., Weisbrod, V., Kerzner, B., & Kahn, I. (2020). Psychological needs and services in a pediatric multidisciplinary celiac disease clinic. *Journal of Clinical Psychology in Medical Settings*, 27(3), 433-443. <https://doi.org/10.1007/s10880-019-09673-9>

Coeliac UK. (2018, March 15). *Coeliac UK's Top 10 Research Priorities*.

<https://www.coeliac.org.uk/document-library/5081-research-priorities-brochure/?return=/research/our-approach/research-priorities/&&&type=rfst&set=true#cookie-widget>

Copelton, D. A., & Valle, G. (2009). “You don't need a prescription to go gluten-free”: The scientific self-diagnosis of celiac disease. *Social Science & Medicine*, 69(4), 623-631.

<https://doi.org/10.1016/j.socscimed.2009.05.012>

Crocker, H., Jenkinson, C., & Peters, M. (2020). Healthcare experiences and quality of life of adults with coeliac disease: a cross-sectional study. *Journal of Human Nutrition and Dietetics*.

<https://doi.org/10.1111/jhn.12757>

Dovey-Pearce, G., Hurrell, R., May, C., Walker, C., & Doherty, Y. (2005). Young adults' (16–25 years) suggestions for providing developmentally appropriate diabetes services: a qualitative study. *Health & Social Care in the Community*, 13(5), 409-419.

<https://doi.org/10.1111/j.1365-2524.2005.00577.x>

Erikson, E. H. (1950). *Childhood and Society*. W. W. Norton.

Green, P., & Jabri, B. (2003). Coeliac disease. *The Lancet*, 362(9381), 383-391.

[https://doi.org/10.1016/S0140-6736\(03\)14027-5](https://doi.org/10.1016/S0140-6736(03)14027-5)

Green, P., & Jabri, B. (2006). Celiac disease. *Annu. Rev. Med.*, 57, 207-221.

<https://doi.org/10.1146/annurev.med.57.051804.122404>

Guandalini, S., & Young, S. (2014). Special Considerations in Children and Young Adults with Celiac Disease. In *Celiac Disease* (pp. 177-192). Springer.

- Gulliver, A., Griffiths, K., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry*, 10(1), 113. <https://doi.org/10.1186/1471-244X-10-113>
- Hamall, K. M., Heard, T. R., Inder, K. J., McGill, K. M., & Kay-Lambkin, F. (2014). The Child Illness and Resilience Program (CHiRP): a study protocol of a stepped care intervention to improve the resilience and wellbeing of families living with childhood chronic illness. *BMC psychology*, 2(1), 1-10. <https://doi.org/10.1186/2050-7283-2-5>
- Högberg, L., Grodzinsky, E., & Stenhammar, L. (2003). Better dietary compliance in patients with coeliac disease diagnosed in early childhood. *Scandinavian journal of gastroenterology*, 38(7), 751-754. <https://doi.org/10.1080/00365520310003318>
- Kaushansky, D., Cox, J., Dodson, C., McNeeley, M., Kumar, S., & Iverson, E. (2017). Living a secret: disclosure among adolescents and young adults with chronic illnesses. *Chronic illness*, 13(1), 49-61. <https://doi.org/10.1177/1742395316655855>
- Ludvigsson, J., Agreus, L., Ciacci, C., Crowe, S., Geller, M., Green, P., Hill, I., Hungin, A., Koletzko, S., & Koltai, T. (2016). Transition from childhood to adulthood in coeliac disease: the Prague consensus report. *Gut*, 65(8), 1242-1251. <https://doi.org/10.1136/gutjnl-2016-311574>
- Mayer, M., Greco, L., Troncone, R., Auricchio, S., & Marsh, M. (1991). Compliance of adolescents with coeliac disease with a gluten free diet. *Gut*, 32(8), 881-885. <https://gut.bmj.com/content/gutjnl/32/8/881.full.pdf>
- Mazzone, L., Reale, L., Spina, M., Guarnera, M., Lionetti, E., Martorana, S., & Mazzone, D. (2011). Compliant gluten-free children with celiac disease: an evaluation of psychological distress. *BMC pediatrics*, 11(1), 46. <https://doi.org/10.1186/1471-2431-11-46>

- NICE. (2015). *Clinical Guidelines: Coeliac Disease Recognition, assessment and management: Methods, evidence and recommendations* (Standard No. NG20).
<https://www.nice.org.uk/guidance/ng20/evidence/full-guidance-pdf-438530077>
- NICE. (2019). *Depression in children and young people: identification and management* (NICE guideline NG134).
<https://www.nice.org.uk/guidance/ng134/chapter/Recommendations#stepped-care>
- Olsson, C., Hörnell, A., Ivarsson, A., & Sydner, Y. (2008). The everyday life of adolescent coeliacs: issues of importance for compliance with the gluten-free diet. *Journal of Human Nutrition and Dietetics*, 21(4), 359-367. <https://doi.org/10.1111/j.1365-277X.2008.00867.x>
- Olsson, C., Lyon, P., Hörnell, A., Ivarsson, A., & Sydner, Y. (2009). Food that makes you different: the stigma experienced by adolescents with celiac disease. *Qualitative Health Research*, 19(7), 976-984. <https://doi.org/10.1177/1049732309338722>
- Radez, J., Reardon, T., Creswell, C., Lawrence, P. J., Evdoka-Burton, G., & Waite, P. (2020). Why do children and adolescents (not) seek and access professional help for their mental health problems? A systematic review of quantitative and qualitative studies. *European Child & Adolescent Psychiatry*, 1-29. <https://doi.org/10.1007/s00787-019-01469-4>
- Rickwood, D., Deane, F., & Wilson, C. (2007). When and how do young people seek professional help for mental health problems? *Medical journal of Australia*, 187(S7), S35-S39. <https://doi.org/10.5694/j.1326-5377.2007.tb01334.x>
- Rubio-Tapia, A., & Murray, J. A. (2010). Classification and management of refractory coeliac disease. *Gut*, 59(4), 547-557. <https://doi.org/10.1136/gut.2009.195131>

Rutter, M. (1995). *Psychosocial disorders in young people: Time trends and their causes*.

John Wiley & Sons Ltd.

Schroeder, R., & Mowen, T. (2014). "You Can't Eat WHAT?" Managing the Stigma of

Celiac Disease. *Deviant Behavior*, 35(6), 456-474.

<https://doi.org/10.1080/01639625.2014.855105>

Shani, M., Kraft, L., Müller, M., & Boehnke, K. (2020). The potential benefits of camps for children and adolescents with celiac disease on social support, illness acceptance, and health-related quality of life. *Journal of Health Psychology*, 1359105320968142.

<https://doi.org/10.1177/1359105320968142>

Sharp, S. (2009). Escaping symbolic entrapment, maintaining social identities. *Social*

Problems, 56(2), 267-284. <https://doi.org/10.1525/sp.2009.56.2.267>

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis:*

Theory, method and research. Sage.

Vatne, T. M., Ruland, C. M., Ørnes, K., & Finset, A. (2012). Children's expressions of

negative emotions and adults' responses during routine cardiac consultations. *Journal of pediatric psychology*, 37(2), 232-240. <https://doi.org/10.1093/jpepsy/jsr074>

Wagner, G., Berger, G., Sinnreich, U., Grylli, V., Schober, E., Huber, W.-D., & Karwautz, A.

(2008). Quality of life in adolescents with treated coeliac disease: influence of compliance and age at diagnosis. *Journal of pediatric gastroenterology and nutrition*, 47(5), 555-561. <https://doi.org/10.1097/MPG.0b013e31817fcb56>

Table 1*Stages of Analysis Based on Smith et al. (2009)*

Stage	Overview
1	Each interview transcript was repeatedly read and listened to whilst initial, unstructured notes were made denoting powerful recollections of interviews and observations about transcripts.
2	Exploratory descriptive, linguistic, and conceptual codes summarising the experiences described by participants were noted (steps 1 and 2 repeated in an iterative process).
3	Initial notes were reviewed and theme titles that emerged were recorded, considering both specific quotes and overarching narratives for each transcript.
4	Emergent themes were clustered within transcripts to identify cluster labels using methods such as subsumption, abstraction, numeration, polarization, and function. Cluster labels were then combined and reduced into master themes.
5	Patterns in master themes were identified across cases to identify superordinate and subordinate themes.

Table 2*Sample Characteristics*

	Pseudonym	Current age (y, m)	Gender	Age when diagnosed (y, m)	Family members with CD
1	Sarah	15y, 4m	F	10y, 0m	Second cousin
2	Maya	14y, 6m	F	9y, 3m	Father; Mother
3	Eve	11y, 10m	F	1y, 6m	Brother
4	Finley	14y, 8m	M	4y, 6m	Sister
5	Sam	14y, 6m	F	3y, 0m	Mother
6	Anna	16y, 4m	F	13y, 5m	Aunt
7	Billy	11y, 11m	M	10y, 9m	Uncle

Note. y = years; m = months; F = female; M = male.

Table 3*Participant Endorsement of Superordinate and Subordinate Themes*

Superordinate and Subordinate Themes	Total	Sarah	Maya	Eve	Finley	Sam	Anna	Billy
1. "As soon as food started going away it was like oh <i>ok</i> this is what it is": Adjusting to the diagnosis within a developmental context								
1.1 "Over time it just-it feels more normal": Growing with the condition	6		•	•	•	•	•	•
1.2 "Why can't I just have one?...Will it really have an effect on me?": The need for adults to scaffold my understanding over time	7	•	•	•	•	•	•	•
1.3 "My friend group is very good...they always like share what they can like sweets and stuff": the importance of others creating (a safe) space for me	7	•	•	•	•	•	•	•
2. "It can either be a huge deal or not a deal at all": How others respond to my condition matters to me								
2.1 "I don't want to make it serious": The power of labels in mitigating stigma	5	•	•	•		•	•	
2.2 "This has kind of been my life": The problem of others co-creating my identity	5	•	•			•	•	•
2.3 "I didn't want to be different and people to think of me as like this weirdo": Attempts to avoid anticipated stigma	7	•	•	•	•	•	•	•
3. "I mean I wouldn't just speak to the random guy or girl": Who is my doctor to me?	6	•	•		•	•	•	•

Note. • Indicates that the participant endorsed the theme.