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Coeliac Disease in Later Life: An Interpretive Phenomenological Analysis

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Abstract Coeliac Disease (CD) is a chronic autoimmune condition characterized by heightened immunological response to the digestion of gluten in genetically susceptible individuals. Previous research suggests that being diagnosed with a chronic health condition may present psychosocial challenges. We aimed to investigate the lived experience related to a diagnosis of CD later in life, and to better understand issues that may be specific to older individuals. Semi-structured interviews were carried out with five people diagnosed with CD after the age of 60 (*mean age*: 68 years; *mean age at diagnosis*: 66 years; 60% sample female; 40% male). Interviews were transcribed verbatim and then analyzed qualitatively using Interpretative Phenomenological Analysis (IPA). A psychosocial model was constructed from the findings, which encompasses shared experiences considered to be older adult specific. This model comprises several insights associated with the diagnostic process, perceived severity of, and perceived agency in controlling, the condition. Participants reflected upon issues that were considered to relate specifically to a diagnosis later in life, although issues comparable with younger individuals were also expressed. Tentative recommendations for clinical practice are made with a focus on improving the diagnostic experience, disease management and psychosocial wellbeing of older adults diagnosed with CD.

Keywords: *Coeliac Disease, diagnosis, older adults, Interpretative Phenomenological Analysis, qualitative research*

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1. Introduction

Coeliac Disease (CD) is an autoimmune condition characterised by a heightened immunological response to the digestion of gluten, in genetically susceptible individuals [1]. Exposure to gluten, the name given to the proteins present in wheat (gliadin), barley (hordein), and rye (secalin), causes chronic nutritional malabsorption, resulting from progressive atrophy of the finger-like projections (villi) that line the wall of the small-intestine [2]. CD can be diagnosed at any age, following the introduction of gluten containing foods, and is typically identified by a screening blood test followed by an endoscopic examination of the small-intestine. Population based studies estimate that 1 in 100 people are affected by CD [3,4,5], and the incidence is likely to increase over time [6]. Nevertheless, older people have, until recently, been considered 'low-risk', overlooked for serological screening and, thus, have often experienced significant diagnostic delay [7].

Historically, CD was considered to be a paediatric condition, but today, it is recognised as a lifelong disease that may present at any age. Despite improved understanding, CD continues to be underdiagnosed in individuals over 50 [7-9]. Indeed, Gasbarrini et al. [10] demonstrated that, despite presenting with typical symptoms indicative of CD, the diagnosis was made in only a small proportion (4.4%) of subjects aged over 65 years; with an average delay of 17 years (range 0 to 58 years). The typical clinical presentation of CD includes malabsorption symptoms, such as diarrhoea, abdominal pain, vomiting and distension, which often result in dehydration and malnutrition. Those diagnosed later in life often experience atypical or 'extraintestinal' symptoms including weight loss, dyspepsia and cognitive impairment [11], which may, at least in part, explain the tendency towards delayed diagnosis in older individuals [12].

Once identified, the management of CD involves adherence to a therapeutic gluten free diet (GFD). The GFD omits all products derived from, or containing, gluten, including some medicines [13,14]. Adhering to a GFD facilitates villous regeneration, improved nutrient absorption and amelioration of the physical symptoms [15]. Despite these improvements, initiating a life-long gluten-free diet, for some, is restrictive, difficult to adapt to and challenging to maintain; particularly in older people whose dietary habits are well-established and potentially hard to disrupt [15]. Research suggests that working age adults with CD experience various difficulties relating to dietary self-management, including a lack of knowledge, increased cost and difficulties sourcing high quality gluten-free produce [16,17,18]. Older adults may be at

higher risk, as they often struggle with limited financial (e.g., pension) and social resources (e.g., depletion of social networks), decreased mobility, impaired vision, cognitive decline and poor nutritional planning/intake. Despite these age-dependant complications, older age at diagnosis has been associated with higher levels (i.e. greater agency) of dietary adherence [15].

Although older people have been shown to adapt following the receipt of a CD diagnosis, research has indicated that this group are at increased the risk of malignant, clinical and pathological complications, which may relate to the significant duration of untreated CD [12,13]. Autoimmune disorders, including type 1 diabetes, thyroid disease, dermatitis herpetiformis and Addison's disease regularly co-occur alongside CD in older people [19, 20]. Additionally, older people with CD have an increased risk of developing non-Hodgkin's lymphoma, compared to 18 to 64 year olds [21] and prolonged nutritional malabsorption may increase the incidence of osteoporosis [22,23]. Vasquez et al. [24] suggest that 75% of people with CD have a bone mass density below their age-expected average, with an increased rate of osteoporotic fractures resulting from minimal to moderate trauma (see [25] for a review). Older people with CD may be at even higher risk, given their already established age-related susceptibility (e.g. hip fracture; see [26]).

Furthermore, prolonged symptom experience may have negative psychosocial consequences for older people with CD. Ford and colleagues [27] demonstrated reduced quality of life in adults with CD, which has been shown to negatively impact sustained dietary self-management [28]. These individuals often report clinically significant symptoms of depression and anxiety, disordered eating and associated sequelae [29,30], despite broadly adhering to their recommended GFD [31] These findings in younger adults suggest that continued exposure to gluten in older people, with unrecognised or untreated CD, may be at increased the risk of experiencing mental health difficulties. However, Gray and Papanicolas [32] have shown that older people experience higher levels of quality of life, relative to their younger counterparts, prior to receiving a diagnosis of CD. This may serve as a protective factor for people who eventually receive a diagnosis later in life.

Whilst empirical research has improved our understanding of the aetiology, treatment and developmental trajectory of the condition in older people, there appears to be a paucity of experiential research in this area. An appropriate starting point, therefore, would be to employ qualitative methods. Until now, qualitative research in individuals with CD has focused on understanding the experiences of younger people [33-38]. Indeed, a broad literature search indicated that there are, to our knowledge, no published studies applying a qualitative method to better understand CD in older adults. Interpretative Phenomenological Analysis (IPA) is a useful qualitative approach, which aims to "explore in detail how participants are making sense of their personal and social world" [[39]; p 51]. As IPA is committed to the examination of how people make sense of major life experiences [40], we considered it to be an appropriate method for this study. Equally, IPA has been applied to other health-related questions [41,42].

1.1. Aims

We aimed to develop a better understanding of CD in later life by exploring the question: "What does it mean to receive a diagnosis of CD after the age of sixty?"

2. Methods and Materials

Being diagnosed with a chronic health condition can be viewed as a "significant life event". In this regard, IPA was selected as an appropriate approach. This method embraces both phenomenology and social constructionism, in that it is concerned with personal experience, but also involves interpretation that is sensitive to context (e.g., senescence). This is important as our sample comprised of people who received a diagnosis after the age of sixty. IPA does not aim to make generalisations about larger populations, but pursues more careful conclusions that represent individual experience. In the absence of larger quantitative studies investigating psychosocial factor related to a CD diagnosis later in life, we considered this a useful place to start – as Warnock said "delving deeper into the particular also takes us closer to the universal" (cited in reference [43], p. 42).

2.1. Ethics

We sought ethical approval for this undergraduate research project, at the University of Birmingham. These procedures complied with the BPS Code of Human Research Ethics [44]. Participants were given a small financial incentive for their participation, but no other expenses (e.g. travel) were reimbursed.

2.2. Recruitment

Coeliac UK has over 80 Local Groups across the UK. We recruited participants from groups located in the West Midlands, using an email advertisement sent to group leaders. Potential participants were made aware of the project by group leaders, but were not approached by the researchers until they had expressed their interest in participating. On making contact, each person was sent an information sheet and asked whether they required any further information. Participants were then afforded two weeks to consider their involvement. All participants provided written informed consent prior to arranging an interview. The participant's regular engagement with their local support group, and their ability to independently organise and attend the appointment, suggested that they were not experiencing significant cognitive impairment. This was confirmed by a brief conversation with the participant's spouse.

2.3. Sample

We employed a cross sectional design. In line with IPA recommendations, we recruited a small purposive sample [39,40]. Participants needed to have received their diagnosis of CD at 60 years or older. While our operational definition of older age is somewhat arbitrary, we were guided by the World Health Organisation's

'World Report on Ageing and Health' [45] and the UN agreed criterion of '60+ years' for referring to the 'older population' [46], as well as quantitative literature exploring CD in people aged between 50 and 85 years.

Following the recruitment process, 2 males and 3 females were included in the study (*see* Table 1 for an overview of the sample characteristics). Participants' ages ranged from 61 to 77 years (M = 68.4; SD = 6.1). The mean age at diagnosis (AAD) was 66.4 years (SD = 5.7) with an average time since diagnosis of 2 years (SD = 0.7). All five participants were native English speakers and had capacity to provide consent.

Table 1. Participant Characteristics And Demographic Information

Participant[1]	Gender	Age	AAD	Marital Status	Ethnicity
Harry	Male	65	63	Married	White British
Rachel	Female	68	66	Married	White British
Penelope	Female	77	75	Married	White British
Jeannette	Female	61	60	Married	White British
Robert	Male	71	68	Married	White British

[1]Pseudonyms were allocated to maintain participant anonymity.

2.4. Interview Procedure

A semi-structured interview schedule was developed incorporating possible areas of relevance to CD in later life, which were identified in the extant literature. The questions were flexible and open-ended with a view to encouraging a free-narrative. The interview addressed various aspects of the lived experience of CD including diagnosis, symptom experience, dietary self-management, and the management of comorbid physical health conditions (Appendix A). Example questions are included in Table 2.

Table 2. Example Questions Included In The Interview Schedule

Feature	Example Question
Diagnosis	What "place" your diagnosis has in your life?
Diet	What changes has the GFD made to eating out?
Comorbidity	To what extent does the management of your [Insert] affect your dietary self-management?
Agency	Do you consider yourself to be in control of your CD?

The interview encouraged each participant to communicate their story, speaking freely and reflectively, at a depth appropriate for IPA [40]. Discussions varied between participants and progressed through broad accounts to detailed, retrospective explanations of specific thoughts and feelings pertaining to the diagnostic process. Although the interview style was consistent across interviews, the content of each interview was dependent upon each participant's readiness to disclose. We acknowledged variability in the depth and richness of the collected data, and have attempted to demonstrate this in the extracts presented. Following the completion of the interview, respondents were invited to add any additional comments to ensure their experience had been communicated fully. Interviews were conducted in either the participant's own home or a private room at the University of Birmingham. These interactions were audiotaped and transcribed verbatim by [First Author]. The average interview length was approximately 1 hour. Following the completion of the interview, participants were afforded an opportunity to be 'debriefed'.

2.5. Analysis

Each transcript was subjected to IPA [39,40]. First there was a close reading of the text and notes written. The second stage involved re-reading the transcripts several times in an attempt to transform the initial notes into themes. The third stage, involved clustering and organising the emergent themes. This process was repeated iteratively until a level of conceptualisation of the data could be achieved, which best captured the core themes derived across the transcripts. Each stage of analysis was discussed with the second author, who acted as an ''independent audit'' [39]. Although regular consultations were held between the TP and RH, to discuss the data conceptually, the original analysis was written by TP, in partial fulfilment of his bachelor's degree. Subsequently, the original analysis was refined by both authors in preparation for publication.

2.5.1. Quality

For the purpose of "context", we have presented descriptive information about each participant in Table 1. During the data collection and analysis phase, [First Author] followed a self-directed audit framework for qualitative research, developing a chain of evidence from initial documentation to final report [47]. This promoted rigor and replicability within the study, with a particular focus on semantic commonality and validation between the transcripts. The methodology and procedures used in the study are transparently described to enable replication. We sought to ensure that each superordinate theme encompasses and communicates a "shared experience" between each participant, by only including themes that were expressed across the narratives (e.g. commonality). Only themes considered to be specific to receiving a diagnosis later in life were included.

2.5.2. Reflexivity

Qualitative research is a subjective practice and the experiences of the researcher invariably influence the analysis and conclusions. To promote best practice [48], the researcher's perspective relative to the subject, the participants and IPA, is presented to promote transparency and support the reader's interpretation of the analysis. This study was the first qualitative investigation of CD in older people completed by the researchers, though RH has conducted qualitative research in working aged adults with CD [38]. The exploratory nature of the study may have influenced the interpretative framework applied throughout. TP had to develop a thorough understanding of CD, its pathophysiology, symptomatology, management and trajectory, as well as relevant psychosocial literature. The principle researcher was a 20 year-old student, completing the project as part fulfilment of an undergraduate degree in Psychology. Differences between the researcher and participants in terms or age, and direct experience of CD, may have presented challenges in terms

of building rapport and attempting to make sense of the other person's perspective as part of a double hermeneutic [40]. We recognise that the interpretation presented in this article is ultimately influenced by the researcher's perspective and approach during analysis.

3. Results

Three superordinate themes were identified, which related to: (1) diagnostic process; (2) perceived severity and (3) perceived control. These themes, and associated subthemes, are presented in order to provide insights into psychosocial issues considered to be specific to older people. Themes like those reported by younger individuals also arose [33-38], but are not reported.

3.1. Theme 1: Diagnostic Process

This theme addresses participant experiences surrounding the diagnostic process (Figure 1). Themes relating to the possibility of cancer, misdiagnosis and eventual relief were discussed.

3.1.1. Possibility of Cancer

More than two thirds of gastrointestinal cancers occur in people 65 years of age or older [49], and fear relating to the possibility of receiving such a diagnosis was apparent. Confusion pertaining to symptoms of CD that overlap with more life threatening alternatives often underpinned these concerns.

Penelope: *I suppose there was some anxiety at that point as I'd lost all this weight…I thought I might have got cancer, that's obviously the big thing that you worry about at my age if you lose a lot of weight*

Participants reflected on a lack of knowledge about CD, or an absent illness representation. They reported that "not knowing" about CD as a viable alternative to cancer potentiated their anxieties, and that of healthcare professionals working to support them in primary care.

Robert: *Coeliac disease didn't even cross my mind at the start…it wasn't on the table…the doctor seemed to be concerned about me developing cancer.*

Harry: *I guess at that stage nobody knew what the problem was.*

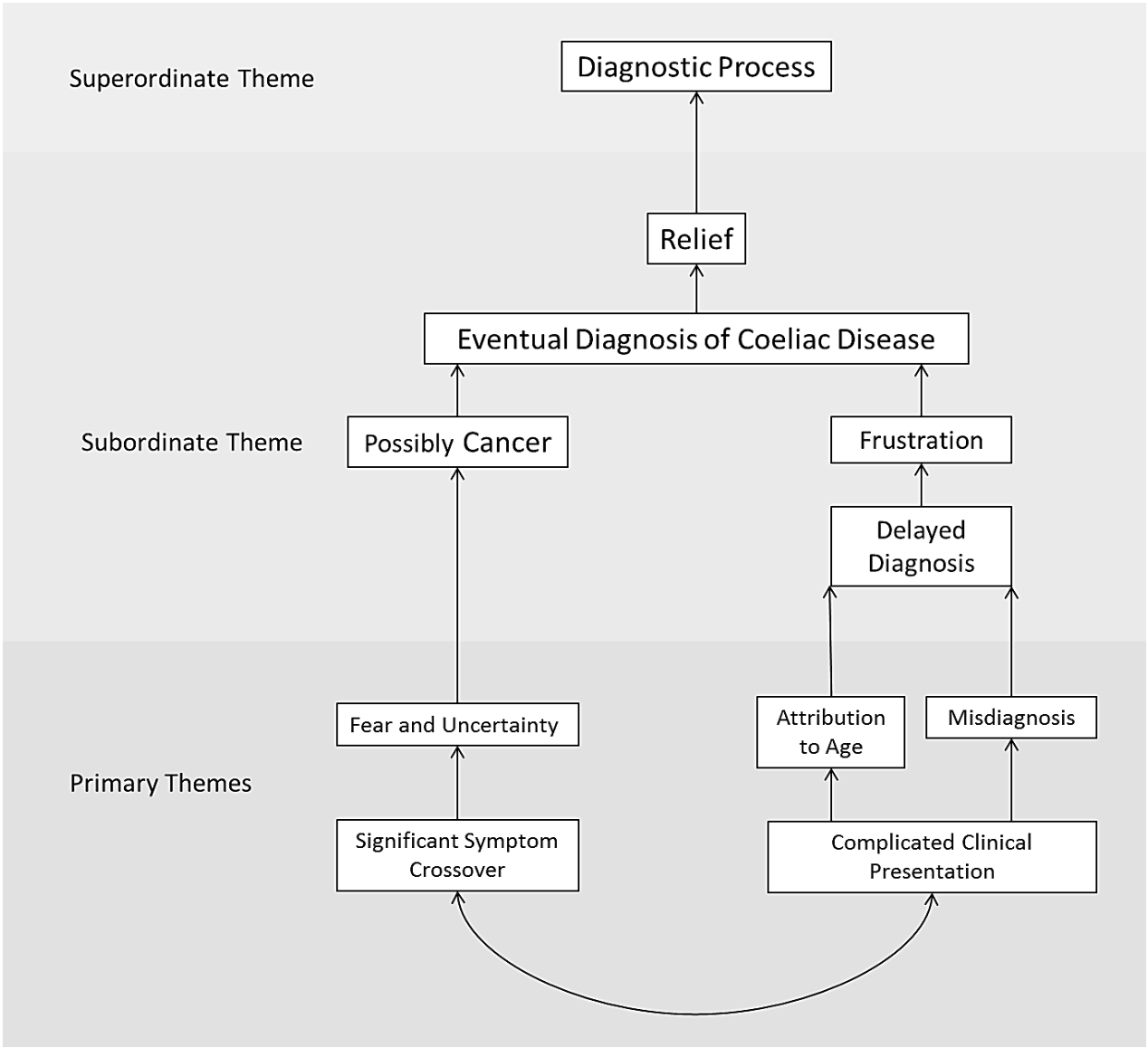

Figure 1. Model detailing participant experiences surrounding the diagnostic process

3.1.2. Diagnostic Delay

Discussions relating to misdiagnosis and diagnostic delay were commonly accompanied by feelings of frustration. These frustrations seemed to surface following a confirmed diagnosis, once concerns about cancer had subsided.

Robert appeared angry in response to questions concerning misdiagnosis. He felt that CD 'should' have been considered earlier as he frequented his general practitioner (GP) with abdominal pain and stomach problems 'for years' prior to diagnosis. Although Robert was pleased not to have developed cancer, he questioned the competency of his GP.

Robert: *I am annoyed...I remember having a lot of stomach problems. Really a lot. At times, it was like a red-hot needle was being plunged into my stomach, it hurt... I'm angry because it should've been found sooner… I wouldn't want my life to depend on that doctor [laughter].*

Others spoke about misdiagnosis in relation to delayed help seeking. Some participants discussed simply "overlooking" CD symptoms - attributing them to older age or external events. Each individual described deteriorations in health, likely the result of autoimmune responses to gluten, which were not identified as potentially treatable manifestations. Participants spoke about attributing CD symptoms to the aging process, or as consequences of events commonly experienced later in life (e.g., bereavement). All interviewees noted that these considerations may have contributed to the diagnostic delay experienced.

Harry: *I thought maybe it was just because I was getting older…I wasn't as energetic as I was and I just put that down to my age.*

Jeannette: *I started to lose weight quite quickly. I started to feel very tired and lethargic, but I let it drift on because initially I thought was the grieving process.*

Some discussed the delayed diagnosis more positively. Penelope suggested that, although the delayed diagnosis may have impacted her health negatively, the quality of her past life experiences were enriched by not following a GFD. She drew upon the idea that following a GFD now has been made easier by recent commercial developments, and that living "gluten-free in the past" may not have been as achievable as it is now.

Penelope: *I am quite glad I wasn't diagnosed earlier. We lived in Jakarta, Australia, Canada, and I think now about how it would've been because the food, the free from food is much easier now, I think I would've found it particularly difficult if I had been diagnosed earlier…but at the same time I can see, from a common-sense point of view that if I had been diagnosed earlier I might have been healthier.*

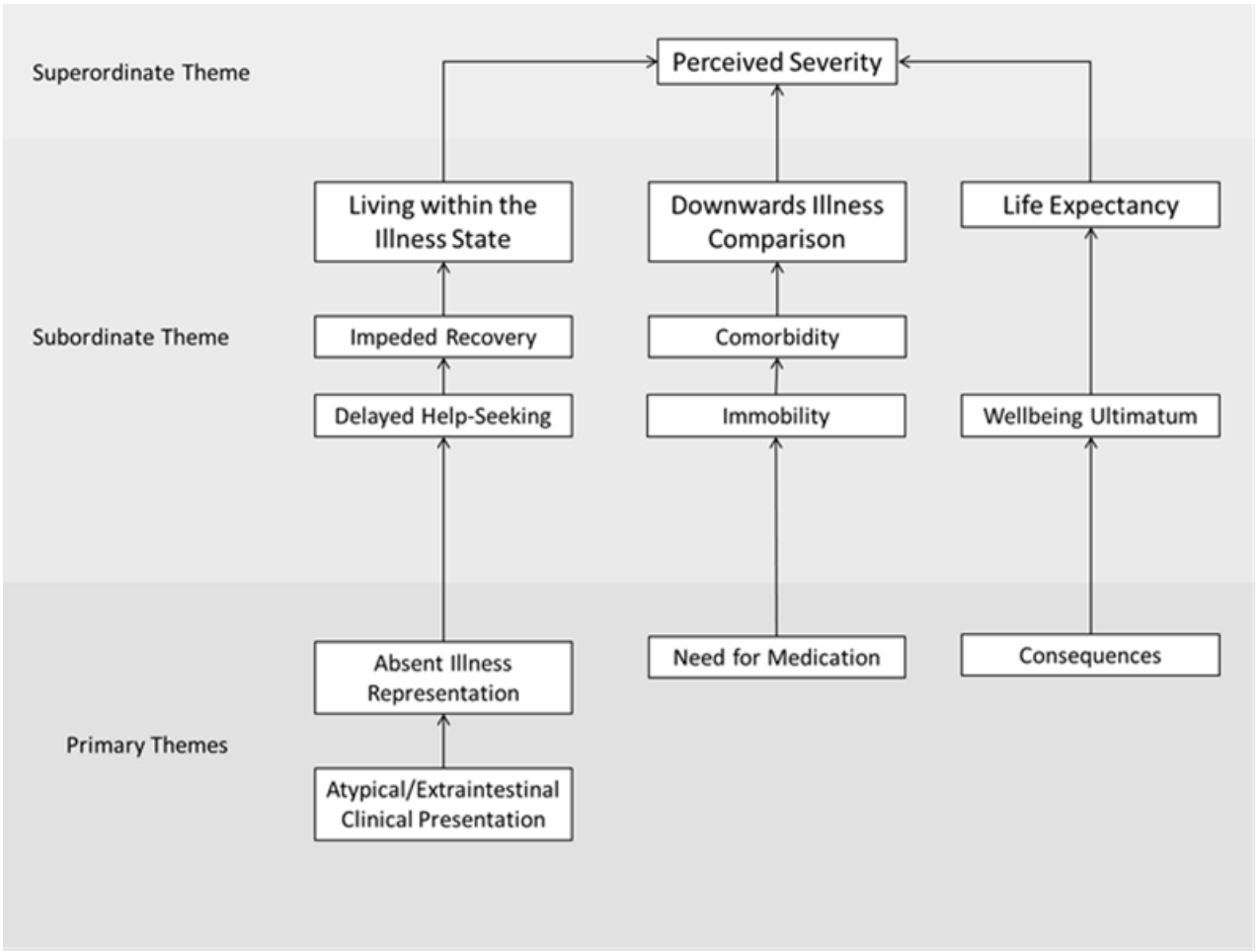

Figure 2. Model detailing participant experiences surrounding the perceived severity of the condition

3.2. Theme 2: Perceived Severity

This theme relates to participants' perception of the severity of CD (Figure 2). Downward illness comparisons, concerns relating to life expectancy and the internalisation of CD symptoms into a perceived normality prior to diagnosis, emerged as important features.

3.2.1. Living within the Illness State

Most participants discussed being asymptomatic or experiencing extraintestinal symptoms (e.g. cognitive decline), which were not identified as clinical indicators of CD for many years prior to diagnosis. They spoke about stumbling upon CD by "accident", in the absence of information about the condition. This suggests that CD symptoms had been internalised into a perceived normality, or a sense that "this is how everyone must feel". Without the insight afforded to them by diagnosis and subsequent support, the lines between typical experience and ill health were distorted.

Penelope: *I used to think that everyone felt bloated after a meal. I thought it was quite normal.*

Robert: *…I don't know what life is like without stomach problems.*

Penelope: *You don't notice the difference from one day to the next…you're just never well, you never feel very good.*

Discussions around 'living within the illness state' indicate that there was a distinct absence of an illness representation, prior to diagnosis. Diagnosis, therefore, increased participants' understanding about CD, which facilitated retrospection. Looking back, many participants raised concerns about delayed help-seeking. Some reported attempting to isolate certain foods (e.g., bread) from their diet in the past, which may have resulted in periods of improved health that could not be sustained without following a strict GFD. Attempts to manage these unspecified symptoms independently, through trial and error, may have contributed to the idea that "this is how I am" and "there is nothing I can do to change it".

Robert: *Here I am now with a ticking time bomb inside of me [an abdominal aortic aneurysm]…I'm more concerned about the ticking time bomb than I am the Coeliac Disease.*

3.2.2. Downward Illness Comparisons

The seriousness of CD was experientially downplayed in comparison to "alternatives" (*see* the possibility of cancer). This included other conditions commonly diagnosed in older adults, which were deemed "more threatening". We interpreted these discussions as severity trade-offs, with CD constituting the "lesser of two evils".

Robert: *I was starting to feel better, I was managing the Coeliac Disease and then they say "Oh incidentally you have this, too…" I was devastated.*

Physical comorbidity and CD was discussed as cumulatively contributing to feelings of helplessness and hopelessness. This may pose a significant risk to the mental health and wellbeing of older people diagnosed with CD, who are attempting to manage both chronic and acute health problems.

Jeanette: *I think my coeliac caused the osteoporosis … so I'm not happy with it because of that… my body was calling for nutrients that it wasn't getting from food and unfortunately it did leech quite a lot of calcium out of the bones…It's a bit like carrying a parasite isn't it?*

Jeanette discussed the severity of CD in relation to the development of osteoporosis, a likely consequence of prolonged malabsorption and malnutrition. There was a sense that Jeanette blamed the CD for her current physical condition, referring to it as a selfish parasitic entity.

Jeanette: *It was quite severe…my hip count is -2.8, which is unnerving because I love walking.*

She went on to discuss the sadness that arose in relation to reduced mobility because of osteoporotic joints. She spoke about the potential loss of meaningful activities for which she, at least in part, blamed untreated CD.

3.2.3. Life-expectancy

For some, concerns about life-expectancy influenced their decision making around adherence to the GFD. We understood these concerns as stemming from the perceived severity of the condition. The consequences of CD were viewed as potentially dangerous and, therefore, the decision to adopt a GFD to promote wellbeing was, as Harry stated, "a no-brainer".

Harry: *I've got the choice…I can either carry on doing myself no good at all or I can look after myself and hopefully be around a little longer…I definitely want to be around… "If I stop eating gluten, I'll be okay?" It's a no-brainer.*

3.2.4. Medication

Medication in the context of perceived disease severity featured across the transcripts. It is interesting to note that participants felt that a condition, which requires adherence to medication, is more severe than CD – a condition that 'only' necessitates dietary changes (i.e. no medication).

Jeannette: *It's a condition that I have to live with and monitor and I can monitor it, really easily…I've just got to eat the right stuff. It's not like diabetes where I would need an injection every day.*

Harry: *Unfortunately, I've got many friends and colleagues that have illnesses that they have to take medication for, which helps with their illness but at what cost?...they have all these side effects…I suppose it was a relief that it [coeliac disease] was something that I didn't have to take medication for…just be on a diet, it was the best outcome really.*

3.3. Theme 3: Perceived Control

This theme encompasses experiences relating to the participants' perception of 'how much control they have over their CD' (Figure 3).

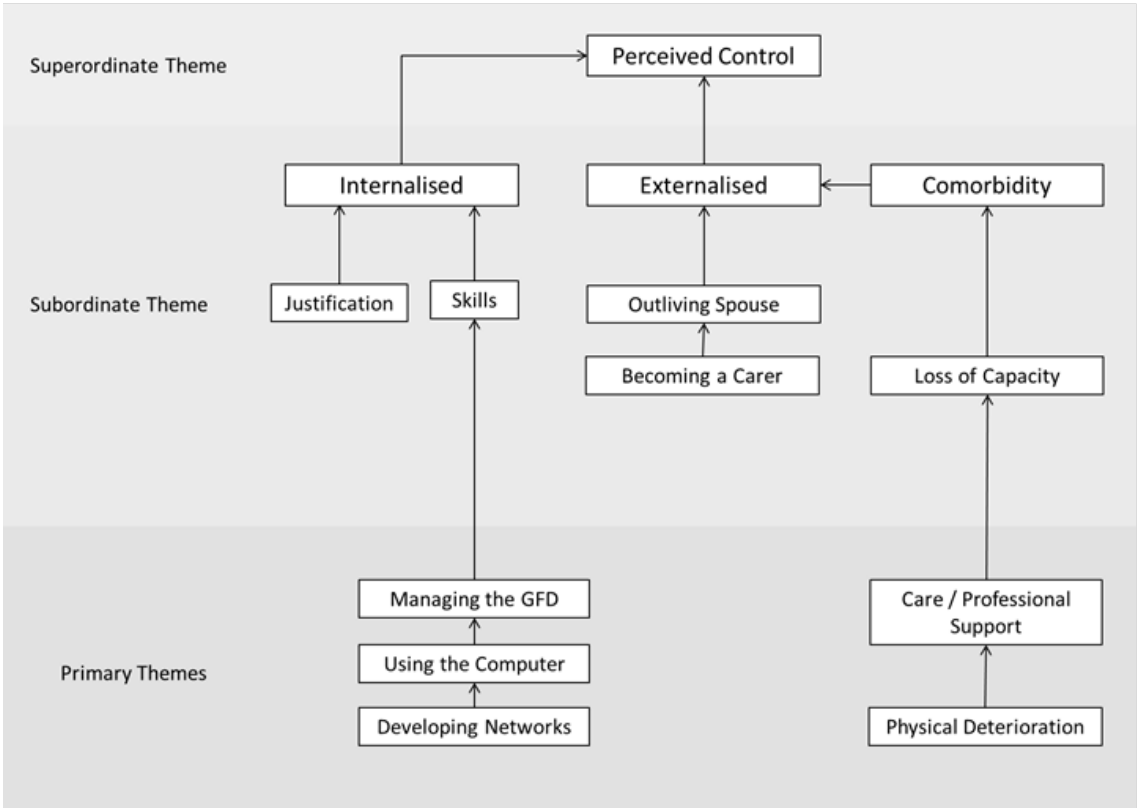

Figure 3. Model detailing participant experiences surrounding the perceived control of the condition

3.3.1. Skills

All participants reported wanting to take responsibility for the management of their CD, with most demonstrating a proclivity to try new recipes and access resources online. Penelope did, however, voice concerns relating to difficulties she has experienced when attempting to access smartphone applications, which have been developed to support people with CD.

Penelope: *I know you can download these apps to put on your phone, but my phone isn't a smartphone so I can't do that…I think if I was younger I probably would.*

3.3.2. Justification

For some, receiving the CD diagnosis enabled them to explain periods of sickness, which had caused great distress – in the absence of understanding about CD. This was discussed in relation to personal experiences, as well as giving friends and family reasons for missed activities. Receiving the diagnosis validated her need to occasionally be excused from social events.

3.3.3. Role of Spouse

Many participants discussed their own ability to take control of the CD, by adapting their diet and searching for resources online. Others spoke about relying on their martial partners to support stable dietary management. Marital interdependence was important for maintaining adherence to the GFD, particularly for the two male participants. Through working "as a team" with his wife, Harry utilised her skills, extending his ability to adhere to the new dietary requirements.

Penelope: *Now I've got an excuse, a reason for having been so poorly.*

Harry: *It was a real education for her, she had to start baking and cooking from scratch…it was a real change…it was a new start for her as it was for me and we both had to find out what I could and couldn't eat.*

Others discussed the importance of their marital partners in relation to emotional support, a theme that arose amongst all participants.

Rachel: *He's been really supportive, what I don't learn my husband learns for me.*

Marital interdependence, although broadly adaptive, provoked anxiety for Robert as he discussed the possibility of outliving his wife and the consequences that may result.

Robert: *I need to be able to do this, to look after myself…she spoils me! Someone said to me last week, "what happens if you're left on your own?" Honestly, I don't know. That could be a big problem.*

3.3.4. Comorbidity

Penelope discussed the possibility of developing dementia, or other degenerative condition causing cognitive deterioration, which may require admission to a hospital or other care facility. She was concerned about a loss of capacity and, therefore, an inability to control her diet and/or inform others of her dietary needs. Her dialogue outlined concerns about being away from those already integrated into her social/familial framework that supports the management of her CD (see *Role of Spouse*).

Penelope: *One thing that occurred to me actually, in a slightly concerning way…what if I end up in a care home? Supposing I go a bit gaga [laughter] or become immobile…*

would they be careful enough? I had this little mental picture of me sitting there and them bringing me my food and my daughter saying "excuse me, she can't eat that!" I thought, well suppose my daughter wasn't there you know.

Penelope also reflected on concerns about neglect and recent reports that she had read in the news regarding the quality of care afforded to older people in some care facilities.

Penelope: There has been an awful lot in the news recently about people in care homes and the level of care they are receiving…Gosh! What if that did happen to me?

Physical deteriorations were also discussed in the context of control and dietary self-management. Most participants discussed worsening eyesight as an issue, particularly whilst shopping for gluten free food. The size and choice of font on gluten-free product packaging may be challenging for older adults with poor eyesight.

3.3.5. Becoming a Carer

Developing other health problems may negatively impact adherence to the GFD, which may reduce community engagement, in older adults with CD. These considerations may be generalised to those individuals whose partners develop an illness requiring additional support (i.e. care). In becoming a Carer, the partner's illness may reduce an individual's ability to engage in appropriate self-care (e.g. managing their GFD) and activities with the wider community (e.g. attending CD support groups).

Rachel: I never miss a meeting with my local support group, but I don't know if I'll be able to go in the future because my husband has just been diagnosed with cancer…he had hardening of the arteries, although he is better now, he still doesn't walk a lot…that restricts me because we go everywhere together.

4. Discussion

In this paper, we have attempted to present the experience of five individuals who received a diagnosis of CD later in life. Using IPA, participants were invited to describe their lived experiences and an analysis of the data enabled us to draw themes specific to a diagnosis later in life and to issues experienced by older people specifically. Three superordinate themes emerged, each with associated subthemes and although the reported extracts only denote themes deemed relevant to a later life diagnosis, common themes to a CD diagnosis for adults in general were also identified [33-38]. Our interaction with the data suggests that the diagnosis and management of CD later in life is complicated, at least in part, by older adult specific considerations, including fears about being diagnosed with a "more serious or life threatening illness" more commonly seen in later life (e.g., cancer), delayed help seeking, poorer engagement with available support systems, and reduced confidence in maintaining adequate self-care if appropriate support were unavailable.

The data suggested that, for the five participants, there was a sense of relief that they had received a diagnosis of CD, rather than cancer, which many feared. This linked to the perceived seriousness of the condition (e.g. CD as less serious than potential alternatives), as something that is managed by diet rather than a need for prescription medication (i.e. relative to other problems that necessitate a long-term course of medication). Further, the possible threat to life was removed by the diagnosis, leaving participants able to engage in appropriate self-management, with practical and emotional support from their partner. Some participants felt that they had delayed help-seeking for their CD, or that CD was not a diagnostic option readily considered by their GP, or that they did not themselves have any knowledge of the condition upon which to form an illness representation. Some felt unhappy that they were left with the long-term consequences of undiagnosed CD, whilst others perceived this delay in diagnosis as almost a "blessing in disguise", given the life choices they had made in the past and the experiences that they had enjoyed (i.e. eating foods whilst traveling that would have been excluded by the GFD).

Specific challenges for older people in general were proposed as impacting on participants' ability to manage their CD. They spoke about the possibility of being in a carer role and the impact this might have on their ability to manage their GFD (e.g. attend support groups), or participate consistently in other social engagements. Others were concerned about actual or possible future ill-health and the extent to which this may impact on self-management. Most participants discussed difficulties reading labels on food packaging, although they noted that this has been improving in recent years. Overall, the five interviewees demonstrated an adaptive tendency to access CD resources (e.g. books). However, some reported difficulties when attempting to access smart-phone applications, blogs and other online resources; and, therefore, may require additional support. We propose that these issues may constitute a barrier to adaptive help seeking for some older people, which may need to be considered in clinical practice, with appropriate support offered. 'User-centred design work' (e.g. focus groups) may provide a useful avenue to support the development of health technologies better suited to older people with CD (see [50], for a useful discussion around developing a smartphone "app' to support older adults in monitoring their liquid intake).

With this, the first UK exploration of the lived experience of a CD diagnosis as an older person using IPA, we hope to have successfully conveyed "what it is like" to receive this diagnosis later in life. However, a number of limitations should be highlighted. The interviews produced rich data, some of which reinforced earlier findings about the lived experience of CD for adults in general. Therefore, the first limitation is that we only report an older adult specific portion of the data here, although this affords the paper a particular focus. The sample was a self-selecting group of older people who were regularly engaging in their local Coeliac UK support group. It is possible, therefore, that this group of individuals were resilient and had good self-efficacy for the GFD and sought support when appropriate. A broader sample of participants may have yielded additional emergent

themes, or concerns relating to cultural values – our sample was comprised entirely of people with white British heritage in heterosexual spousal relationships. In terms of data analysis, although this was discussed as part of on-going supervision, the data were analysed exclusively by TP, which may have narrowed the scope of interpretation. We acknowledge that, in absence of quantitative data, it is difficult to draw any robust generalizable conclusions. By contrast, the detailed and inductive approach of IPA, with its roots in phenomenology and hermeneutics, allows the researcher to paint a detailed picture of the subjective experience of CD as it is embedded in the narrative of later life [39,40].

The current findings offer an initial insight into some of the issues faced by older people diagnosed with CD later in life, specifically. This is important as current estimates indicate that the number of older adults will double, from approximately 901 million, to more than 2 billion by 2050 [46]. As we expect people to live longer, and we endeavour to become more knowledgeable about CD as condition that commonly effects people later in life, we will need to continue to improve our psychosocial understanding. Indeed, we would urge clinicians to consider issues specific to older age when diagnosing people over the age of 60, and assess patients' standing in terms of co-morbid health conditions, carer status, possible sensory and/or cognitive difficulties, and financial and social challenges, in addition to providing support specifically for CD. Future research, focussing on older people with CD, who were diagnosed in earlier adulthood, or who are newly diagnosed, through larger empirical studies, would support improved awareness in clinical practice and within wider support systems. Future research could also focus on the link between cognitive decline and self-management in CD, some of which has been considered in published case studies.

5. Conclusions

Our findings provide important early insight into the experiences of older people diagnosed with CD. The narratives suggest that people diagnosed with CD later in life experience psychosocial issues that are specific to their age group. In addition to these concerns, older people also report issues analogues with those described by younger people (e.g. see 33-38 for an experiential overview of CD in working age adults). Further work in this area is needed, with a particular focus on larger quantitative studies to investigate psychosocial aspects of CD in later life.

List of Abbreviations

CD – Coeliac Disease
GFD – Gluten Free Diet
IPA – Interpretative Phenomenological Analysis
WHO – World Health Organisation
UN – United Nations
UK – United Kingdom

Transparency Declaration

The lead author affirms that this manuscript is an honest, accurate, and transparent account of the study being reported. The reporting of this work is compliant with Interpretative Phenomenological Analysis (IPA) best practice guidelines and the BPS Code of Human Research. The lead author affirms that no important aspects of the study have been omitted – Indeed, the scope of the reporting has been narrowed to better reflect the specific aims of the study (i.e. themes central to the experiences of 'older adults diagnosed with CD later in life').

Conflicts of Interest

No conflicts of interest.

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