PATIENTS’ EXPERIENCES OF HEALTHCARE SERVICES IN COELIAC DISEASE

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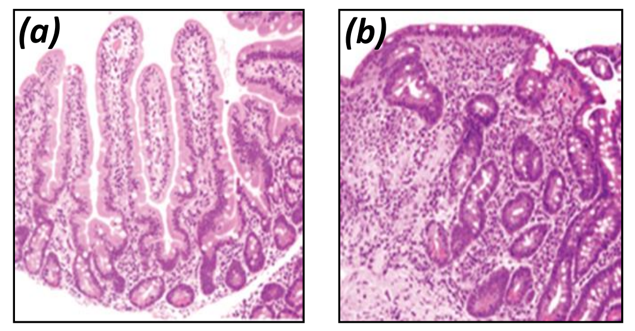
BACKGROUND

Research Objectives

The UK government has outlined in the NHS Outcomes Framework their commitment to ensuring patients have a positive experience of healthcare. As little is known about the healthcare experiences of people with coeliac disease, this research aimed to explore experiences from the perspective of people with the condition.

Coeliac Disease

- Coeliac disease is a chronic autoimmune disease in which an immune response is triggered by the consumption of gluten (wheat, barley, rye), resulting in intestinal damage.
- It affects approximately one per cent of the UK population.
- It is typically diagnosed by serological testing followed by duodenal biopsy.
- Treated with a life-long gluten-free diet.



(a) Undamaged intestinal lining

(b) Damaged intestinal lining (untreated coeliac disease)

(Volta and Villanacci, 2011)

METHODS

In-depth, semi-structured interviews were conducted with adults with coeliac disease between June and October 2012.

Recruitment

- Interview participants were recruited through Coeliac UK, a charity for people with coeliac disease, and snowball sampling.
- Participants were recruited from three geographical areas (Oxford and the surrounding area, Yeovil and the surrounding area, and Birmingham). These areas were selected to ensure that members from both rural and urban areas, and more and less socially deprived areas were included in the study.
- Variation was sought across demographic and disease characteristics, particularly gender, age, and duration since diagnosis.

Interview data was audio-recorded with consent, transcribed verbatim, and a thematic analysis conducted in NVivo 9.

RESULTS

Twenty-three adults with coeliac disease were interviewed (see Table 1).

Participant Characteristic	Summary (n)
Age Range (years):	29 – 90
Gender:	Female (15), Male (8)
Marital Status:	Single (1), Married (17), Widowed (3), Divorced (2)
Ethnic Origin:	White British (19), White Irish (3), Asian/Asian British (1)
Occupational Status:	Full-time work (4), Part-time work (6), Unemployed (1), Retired (12)
Time since diagnosis (years):	<1 – 40

Table 1: Summary of Interview Participants

Themes

Patients’ experiences of healthcare were grouped into eight themes. Variations in patients’ experiences were identified across all themes, with some patients reporting particularly negative experiences of care. In particular, considerable variation was identified in terms of the time taken to obtain a diagnosis, and the extent and type of follow-up care received.

(1) Satisfaction with healthcare

Satisfaction with healthcare varied between participants and appeared to be affected by the patients’ experiences of the following seven themes.

(2) Diagnosis

- There were considerable variations in duration between first seeking help and receiving a diagnosis of coeliac disease (from a few weeks to many years).
- An endoscopy was not conducted for all participants.
- Coeliac disease was frequently diagnosed as a result of investigations due to another illness (e.g. anaemia).
- In one instance, there was a significant delay in communicating the diagnosis to the patient.

> *“I was in and out of hospital with various problems with my stomach but no-one ever found it. I was going to specialists and what have you for a long time…it’s hard to understand why it wasn’t found before”* (CD18; 70yrs; F)

(3) Follow-up consultations

There were large variations between participants regarding whether and how they received follow-up care.

- Frequency of care varied from no care to routine annual care.
- Follow-up care took place in the GP surgery or hospital with a wide range of healthcare professionals - nurse, GP, hospital consultant, or dietitian.
- The arrangement of follow-up appointments was either self-managed or the patient would receive an invitation from their healthcare provider.

(4) Access to services

Some participants:

- faced a long wait for an endoscopy,
- had difficulty seeking advice from a healthcare professional when needed,
- felt they had to manage their own condition, for example, arranging follow-up appointments, private bowel cancer tests, and requesting DEXA scans.

> *“We looked at the NHS waiting list and it was I think 44 days to … have an endoscopy on the NHS … I couldn’t stop eating gluten until I’d had the endoscopy and I thought I can’t keep eating something for another month and a bit, when I know it’s making me ill”* (CD21; 29yrs; F)

(5) Prescriptions

Prescriptions for gluten-free food are available to people diagnosed with coeliac disease. Participants discussed:

- their uncertainty surrounding potential changes to prescribing policies,
- difficulties navigating the prescription process,
- and the cost of obtaining food on prescription – some felt it helped with the cost of buying gluten-free foods, whereas others felt prescription charges were expensive.

> *“I went for my prescription and I thought everything would be £8 and they told me to pay forty something pound and obviously I wasn’t going to pay forty pound for my list so that was a disaster”* (CD23; 32yrs; F)

(6) Integrated care and continuity of care

- Some participants rarely saw the same healthcare professional, but did not state this as a particular problem.
- Participants reported poor information sharing between private healthcare and the NHS, and primary and secondary care.
- Participants were sometimes provided with conflicting information.

(7) Relationships with healthcare professionals

- Some participants felt that their GP did not take their symptoms seriously prior to diagnosis.
- Many participants commented that their GP is supportive
- Levels of empathy and understanding varied.

(8) Information provision

- Some participants felt that the dietitian did not provide them with enough information.
- Lack of communication regarding tests and processes.
- Knowledge about coeliac disease varied between healthcare professionals.

> *“My doctor first off said this is the gastroenterologist said ‘some people get cancer’ um, lymphatic cancer if it goes untreated … but I went away feeling a little bit like, basically a little bit like I was going to die because I was going to get cancer because he said ‘oh it’s lymphatic cancer and that’s one of the cancers we can’t treat so it’s usually terminal’”* (CD21; 29yrs; F)

IMPLICATIONS

This research gives an in-depth understanding of the wide variation of patients’ experiences of healthcare in coeliac disease. Due to the nature of qualitative research, generalisability of these results is limited and therefore, the findings will form part of the development of a survey. This will produce data on a larger scale, which will help identify specific areas for service quality improvement.

This research is part of a doctoral research programme funded by the Medical Research Council.