



Original article

Experiences and own management regarding residual symptoms among people with coeliac disease



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ABSTRACT

Context: Between 7% and 30% of people with treated coeliac disease suffer from residual symptoms, and there is a knowledge gap about their own management of these symptoms.

Aim: To explore experiences and management concerning residual symptoms despite a gluten-free diet in people with coeliac disease.

Methods: A qualitative explorative design with semi-structured interviews with 22 adults with coeliac disease in Sweden. Data were analysed using qualitative content analysis.

Results: The informants had, at diagnosis, thought that their symptoms would disappear if they followed a gluten-free diet, but the disease was continuing to have a substantial impact on their lives, despite several years of treatment. They experienced cognitive, somatic as well as mental symptoms, including impact on personality (e.g. having a "shorter fuse", being more miserable or tired). However, only a few informants had sought medical care for persistent symptoms. Instead they tried to manage these by themselves, e.g. abstaining from food during periods of more intense symptom, or using distraction. The management of persistent symptoms resembled thorough detective work. To prevent problems related to residual symptoms the informants used withdrawal of social contact as well as acceptance of their situation.

Conclusion: People with treated coeliac disease may experience residual symptoms of both a physical and psychological nature, causing major negative impacts on their lives in different ways. In the light of this, healthcare staff should change their practices regarding the follow-up of these people, and in addition to medical care should provide guidance on management strategies to facilitate the daily life. Furthermore, information to newly diagnosed persons should make them aware of the possibility to experience continued symptoms, despite treatment.

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1. Introduction

People with chronic diseases such as coeliac disease (CD) may not always respond to ordinary treatment, but may still suffer from residual symptoms despite long-term treatment (Dewar et al., 2012; Kaukinen, 2014; Paarlahti et al., 2013). Adherence to a lifelong gluten-free diet (GFD) is the only treatment in CD. This diet is considered very successful in managing the symptoms of CD (Kelly, Bai, Liu, & Leffler, 2015), and in the majority of cases will restore the intestinal damage (Rubio-Tapia & Murray, 2010), resulting in a significant improvement of symptoms within a few months (Garcia-Manzanares & Lucendo, 2011). Evidence shows that between 7% and 30% of people with CD suffer from residual

symptoms (O'Mahony, Howdle, & Losowsky, 1996; Wong et al., 2003), despite long-term treatment (Dewar et al., 2012; Kaukinen, 2014; O'Mahony et al., 1996; Paarlahti et al., 2013; Wong et al., 2003). Gastrointestinal (GI) symptoms have been reported (Paarlahti et al., 2013; Sainsbury, Sanders, & Ford, 2013) but also extra-intestinal symptoms such as fatigue (Hauser, Gold, Stein, Caspary, & Stallmach, 2006; Siniscalchi et al., 2005), musculoskeletal pain (Hauser et al., 2006), reduced health-related quality of life (HRQoL) (Ford, Howard, & Oyeboode, 2012; Hauser et al., 2006) and reduced psychological well-being (Ford et al., 2012; Hauser et al., 2006; van Hees, Van, & Giltay, 2013; Zingone et al., 2010). There is still some uncertainty about experiences of residual symptoms in people with treated CD and how they deal with these symptoms.

Living with CD and a GFD might be psychosocially complex as the disease influences daily life in different ways (Jacobsson Ring, Hallert, Milberg, & Friedrichsen, 2012). A measurable degree of social

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impairment has been found in this group (Silvester, Weiten, Graff, Walker, & Duerksen, 2016), and feelings of being different from others, and of environmental neglect of dietary needs are common (Olsson, Lyon, Hörnell, Ivarsson, & Sydner, 2009), as is a reduced pleasure in eating, and doing enjoyable things less often due to the diet (Whitaker, West, Holmes, & Logan, 2009). Frustration and isolation have been highlighted as the most negative emotions related to the disease (Zarkadas et al., 2013).

Caring is intended to promote well-being (Meleis, 2011), and in order to support people with CD who are suffering despite treatment, it is important to investigate residual symptoms from these peoples' own perspective and deepen the knowledge about their own management of these symptoms. By getting this knowledge, support can be modified in the manner that is most beneficial to this group. The aim of this study was therefore to explore experiences and management concerning residual symptoms despite a gluten-free diet in people with coeliac disease. No previous study has, to our knowledge, investigated this before.

2. Methods

2.1. Design

A qualitative exploratory study was conducted as the field had not previously been explored, and the study endeavoured to understand the reality (Patton, 2015). Semi-structured interviews were employed to collect data, and informants were encouraged to talk freely to reach a deeper understanding of the problem studied (Kvale & Brinkmann, 2009).

2.2. Participants and setting

Informants were recruited using regional care-databases in the southeast of Sweden, and they were purposefully selected (Patton, 2015) in an attempt to achieve maximum variation regarding gender, age, number of years since diagnosis and residence (Table 1). People diagnosed at a university hospital and a county hospital, and people from primary health care were included. Inclusion criteria's for the study were: (i) CD diagnosis with ICD 10-code K90.0A; (ii) living on a GFD \geq five years; (iii) any kind of residual symptoms as reported by the people themselves; (iv) able to speak and understand Swedish. An information letter was sent by the first author to people in the regional

care-databases. Approximately one week after receiving the letter, the informants were contacted by telephone by a nurse with experience of research in the area (first author). Twenty-two people (11 women and 11 men) were approached, and all consented to participate.

2.3. Data collection

Data were collected by qualitative semi-structured individual interviews from May 2014 to March 2015. A semi-structured interview guide with open-ended questions was developed by the authors (Kvale & Brinkmann, 2009). It was based on results from previous studies (Jacobsson Ring, Friedrichsen, Göransson, & Hallert, 2012a; Jacobsson Ring, Hallert, et al., 2012; Jacobsson Ring, Friedrichsen, Göransson, & Hallert, 2012b) and peer-reviewed by a gastroenterologist, who was an expert in the field of CD. The main questions were: What remaining symptoms do you still have that you believe are caused by your CD? How do you get relief from the symptoms that you are experiencing? Probing questions such as: "Can you give me an example?" or "What happened then?" were asked when the interviewer wished to search for a deeper explanation. The interviews were conducted by the first author in a secluded room at the university ($n = 18$) in any of the included cities, or alternatively in the informants' own homes ($n = 4$) if this was their preference. One pilot interview was conducted (included in the study), resulting in no changes in the way questions were asked. The interviews were audio-recorded and lasted about 50 min.

2.4. Data analysis

A qualitative content analysis was used (Krippendorff, 2013). This technique is a systematic way to achieve replicable and valid inferences from texts. Data collection and analysis proceeded simultaneously until the point at which no further information was added to the analysis (Krippendorff, 1980). The first author transcribed all interviews verbatim. The transcripts were read several times to obtain a sense of whole. Notes and headings were written in the margins about ideas that arose. In the next step the text were broken into smaller textual units relevant to the aim. Subsequently textual units were condensed i.e. reduced but with context retained. Accounts with similar core content were identified and grouped together, and then coded into preliminary subcategories. During the whole analysis, comparisons were made between the subcategories and the text as a whole. Sub-categories with similar meanings were grouped together into categories. The aim was to be open to as much variation in the material as possible and search for regularities, patterns and contradictions developing sub-categories and categories (Krippendorff, 2013).

To increase the validity of the findings (Krippendorff, 2013), the first and the last author independently coded five of the transcribed interviews and then compared the codes to clarify and discuss any discrepancies. However, the coding showed high agreement. This interactive process continued until a set of commonly agreed codes were created. Thereafter, the remaining transcribed interviews were coded in the agreed way by the first author. Validity was also established by providing quotes from the interviews as examples of explicated meanings and to further illustrate the categories (Krippendorff, 2013), and by seeking consensus between the co-authors during the procedure of analysis (Flick, 2014).

2.5. Ethical considerations

Approval was obtained from a regional ethical review board (Dnr 2014/92-31). In accordance with the Helsinki Declaration the informants were guaranteed confidentiality and assured that participation was voluntary. Written informed consent was obtained and they were guaranteed that they could end their participation at any time and

Table 1
Background data of the 22 informants included in the study.

| Variable | |
|-------------------------------------|------------|
| Age (years) ^a | 53 (32–64) |
| Duration of CD (years) ^a | 10 (5–42) |
| Gender (n) | |
| Male | 11 |
| Female | 11 |
| Work situation (n) | |
| Full time | 13 |
| Part time | 4 |
| Sick leave | 4 |
| Unemployed | 1 |
| Marital status (n) | |
| Married | 18 |
| Single | 4 |
| Domicile (n) | |
| Town | 11 |
| Village | 3 |
| Rural area | 8 |
| Education level (n) | |
| Primary | 5 |
| Secondary | 12 |
| University | 5 |

^a Values are median (range).

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