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Original article

The subjective experience of subjects diagnosed with celiac disease in adulthood

L'expérience subjective de la maladie cœliaque des patients diagnostiqués à l'âge adulte

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ARTICLE INFO

Article history:

Received 13 May 2015

Received in revised form 15 June 2017

Accepted 21 November 2017

Keywords:

Celiac disease

Gluten-free diet

Subjective experience

Qualitative study

Interpretive phenomenological analysis

Adulthood

Mots clés :

Maladie cœliaque

Régime sans gluten

Expérience subjective

Étude qualitative

Adulte

ABSTRACT

Introduction. – Celiac disease is estimated to affect between 1 in 100 and 1 in 300 Caucasian subjects. Many quantitative studies have explored the issues encountered by these subjects; however, few studies have addressed the subjective and experiential dimensions of celiac disease.

Objective. – The objective of this qualitative exploratory study is to expand current knowledge concerning the subjective experience of celiac disease and of a gluten-free diet in subjects diagnosed with celiac disease in adulthood.

Method. – Data was collected through non-directive interviews with 14 subjects aged between 28 and 53 ($M = 41.7$, $SD = 7.48$).

Results. – An interpretive phenomenological analysis identified various themes related to the experience of illness: (1) history of the disease, (2) symptoms, (3) nutrition, (4) perception of medical experiences, (5) relationships with family and friends, (6) psychological implications, and (7) consequences for daily living.

Conclusion. – The results show the importance of developing a “mythology” (concerning the disease’s origin) to enable the inclusion of the condition in the individual’s on-going personal story.

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R É S U M É

Introduction. – La prévalence de la maladie cœliaque serait de 1/100 à 1/300 auprès des sujets de type caucasien. Si de nombreuses études quantitatives se sont intéressées aux difficultés rencontrées par les patients, peu de recherches ont questionné l’expérience subjective et le vécu de la maladie cœliaque.

Objectif. – L’objectif de cette étude exploratoire qualitative est d’améliorer la connaissance de l’expérience subjective de la maladie cœliaque et du régime sans gluten des sujets diagnostiqués à l’âge adulte.

Méthode. – Quatorze entretiens non-directifs ont été réalisés auprès de sujets âgés de 28 à 53 ans ($m = 41.7$, $SD = 7.48$).

Résultats. – Une analyse phénoménologique interprétative a permis d’identifier différents thèmes recouvrant l’expérience de la maladie : (1) l’histoire de la maladie, (2) les symptômes, (3) l’alimentation, (4) la perception de l’expérience médicale, (5) la relation avec le cercle familial et les amis, (6) les implications psychologiques, et (7) les conséquences dans la vie quotidienne.

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Conclusion. – Les résultats montrent l'importance de l'élaboration d'une « mythologie » (concernant l'origine de la maladie) pour permettre à la personne d'inclure la maladie dans le prolongement de son histoire personnelle.

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1. Introduction

Celiac disease, also known as gluten-sensitive enteropathy, is an immune-mediated disease triggered by dietary gluten in genetically predisposed individuals. It is characterized by villous atrophy of the small intestine and an increased number of intraepithelial lymphocytes, leading to the malabsorption of nutrients (Green & Cellier, 2007). Clinical presentation is thought to be typical and the main clinical manifestations include diarrhea, weight loss, and abdominal pain. However, celiac disease may in fact more commonly present various atypical extra-intestinal manifestations (of dermatological, haematological, rheumatological, or reproductive nature) or may be even completely latent or unnoticeable (although increasingly detected by serological testing). These atypical presentations of celiac disease are commonly associated with a delayed diagnosis (Green & Cellier, 2007). Symptomatic celiac disease is estimated to affect between 1 in 100 and 1 in 300 Caucasian subjects (Fasano et al., 2003; Ivarsson et al., 2013; Mäki et al., 2003; Malamat & Cellier, 2010; Utiyama et al., 2010; Zarkadas et al., 2012). It is difficult to give a precise estimate of how frequently silent celiac disease occurs; however, it is assumed that two thirds of celiac subjects live with an undiagnosed disease (West, Logan, & Hill, 2003).

The only rational treatment for celiac disease is the elimination of gluten (present in wheat, rye, and barley) from the patient's diet. Furthermore, because gluten can trigger an autoimmune response even when absorbed in small quantities, patients are also advised to eliminate products that may contain even trace amounts of gluten, such as ready meals, cooking ingredients or excipients found in drugs.

2. Background

A gluten-free diet is heavily restrictive, leading subjects to modify their dietary habits as well as their lifestyles. This is why many quantitative research studies have examined various dimensions that may reflect the issues experienced by subjects diagnosed with celiac disease.

Quality of life is one of the most frequently studied outcomes. However, results are contradictory: although quality of life appears to deteriorate rapidly following the implementation of a gluten-free diet (Fera, Cascio, Angelini, Martini, & Guidetti, 2003; Hallert et al., 1998; Hauser, Musial, Caspary, Stein, & Stallmach, 2007; Sainsbury & Mullan, 2011; Siniscalchi et al., 2005; Usai et al., 2002; Usai, Manca, Cuomo, Lai, & Boi, 2007), several studies show no significant difference between celiac subjects and the general population (Casellas, Lopez, & Malagelada, 2005; Hallert et al., 1998; Lorenzo et al., 2012; Skjærning et al., 2014; Van Koppen et al., 2009; Viljamaa et al., 2005). Mustalahti et al. (2002) and O'Leary et al. (2004) even show that celiac subjects may experience a better quality of life than others.

Other dimensions, such as depression and anxiety, have also been explored. Compared to the general population, celiac subjects are found to be more prone to experience anxiety (Addolorato, 2001; Addolorato et al., 2004; Ciacci et al., 2003; Fera, Cascio, Angelini, Martini, & Guidetti, 2003) and depression (Addolorato, 2001; Addolorato et al., 1996, 2004; Ciacci, Iavarone, Mazzacca, & De Rosa, 1998; Ciacci, Iavarone, Siniscalchi, Romano, & De Rosa,

2002; Fera et al., 2003; Hallert et al., 1998; Stone, Storey, & Hugues, 2012; Van Hees, Van der Does, & Giltay, 2013). The debate on the meaning of the relationship between celiac disease and such psychological dimensions remains nonetheless. Indeed, although dietary constraints may cause mood variations, several authors claim that such variations may be explained by metabolic effects linked to malabsorption (Addolorato et al., 1996; Ciacci, Iavarone, Mazzacca, & De Rosa, 1998; Hallert et al., 1998).

Celiac disease may also lead subjects to experience various other emotions. They may have a sense of injustice (Cinquetti, Micelli, & Zoppi, 1997) and feel anger in relation to the disease (Ciacci et al., 2003; Rashid et al., 2005). Children and adolescents also experience a feeling of shame towards their peers (Cinquetti, Micelli, & Zoppi, 1997; Schroeder & Mowen, 2014). In adults, the diagnosis often follows a long series of misdiagnoses or even a failure to recognize the existence of an actual condition, accompanied by digestive problems that are often debilitating, while remaining unexplained. Understandably, when the diagnosis is finally reached, the predominant feeling is often one of relief (Hallert & Derefeldt, 1982). In addition, a close correlation seems to exist over time between the expression of sadness and anger, and the fear of ingesting gluten (Ciacci et al., 2002).

Researchers have also examined the possible effects of celiac disease on subjects' personalities (De Rosa, Troncone, Vacca, & Ciacci, 2004). Following their findings, these authors suggest that a "profile" may be defined for the celiac subject. This profile would include increased irritability (because of the anxious vigilance and the psychophysiological reactivity due to fatigue), but also a tendency towards more conventional choices. This last trait might be explained by the marked presence of a behavioural and affective inhibition related to dietary constraints. The profile described by the authors would only be observed in subjects diagnosed in adulthood.

Multiple studies have analyzed the difficulties experienced by adult celiac subjects by using quantitative methods. Only four studies (Dowd et al., 2013; Rose & Howard, 2013; Sverker, Hensing, & Hallert, 2005; Sverker, Östlung, Hallert, & Hening, 2009) focused on experiential aspects by inviting subjects to express themselves freely regarding their experience of celiac disease and the associated gluten-free diet. More precisely, research has focused on situations that hinder or motivate the individual to adhere strictly to dietary constraints. One study (Rose & Howard, 2013) explores the nature and development of psychosocial issues related to living with celiac disease.

Sverker, Hensing, and Hallert (2005) found five situations that give rise to problems pertaining to diet and celiac disease: meals at work, purchasing food products, eating while traveling, preparing meals at home, and meals outside the home. Feelings experienced during these situations are related to various aspects identified by Sverker et al., 2009: emotions (solitude, shame, the fear of being contaminated), relationships (hiding one's disease, taking risks, appearing different from others), and daily diet (limited choice of products, time devoted to preparing meals, being constantly vigilant). More recently, an analysis was performed using autobiographical literature that addressed various suggested topics (daily life experiences, changes in relationships, etc.) written by 130 adult members of Coeliac UK, enabling researchers to build a psychosocial model of living with celiac disease (Rose &

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