







HEALTH CONTROL FOR CELIAC PATIENTS: AN ANALYSIS ACCORDING TO THE PENDER HEALTH PROMOTION MODEL

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ABSTRACT

Objectives: to describe the health control habits that influence the daily life of celiac patients and to analyze the practice of actions related to health control and its determinants, from the perspective of the first component of the Pender Health Promotion Model.

Method: a cross-sectional study conducted through interviews with instrument with 83 individuals from Ceará and diagnosed with celiac disease. Data was analyzed using the characteristics and individual experiences component of Pender's theoretical model.

Results: of the celiac patients, 96.4% did not follow the gluten-free diet; 80.7% had inappropriate behaviors to reduce risk factors; 72.3% made ineffective choices in daily life to achieve health goals and; and 25.3% could not keep the gluten free diet in their daily life.

Conclusion: according to the theoretical model, celiac patients did not adhere to the proper diet and presented factors inherent to daily life and social issues, characterized as barriers to an effective health control.

DESCRIPTORS: Promoting health. Celiac disease. Chronic disease. Patient's cooperation. Gluten free diet.

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CONTROLE DE SAÚDE DE CELÍACOS: ANÁLISE SEGUNDO O MODELO DE PROMOÇÃO DA SAÚDE DE PENDER

RESUMO

Objetivos: descrever os hábitos de controle de saúde que influenciam no cotidiano dos celíacos e analisar a prática de ações relacionadas ao controle da saúde e seus determinantes, sob o prisma do primeiro componente do Modelo de Promoção da Saúde de Pender.

Método: estudo transversal, realizado com 83 indivíduos com diagnóstico de doença celíaca, do Estado do Ceará, através de entrevistas com instrumento. Os dados foram analisados mediante o componente características e experiências individuais do modelo teórico de Pender.

Resultados: dos celíacos, 96,4% não seguiam a dieta isenta de glúten; 80,7% possuíam comportamentos inadequados para reduzir fatores de risco; 72,3% faziam escolhas na vida diária ineficazes para atingir as metas de saúde; e 25,3% não conseguiam manter a dieta isenta de glúten na sua vida diária.

Conclusão: de acordo com o modelo teórico, os celíacos não aderiam à dieta adequada e apresentaram fatores inerentes ao cotidiano e às questões sociais, caracterizados como barreiras para o controle eficaz da saúde.

DESCRITORES: Promoção da saúde. Doença celíaca. Doença crônica. Cooperação do paciente. Dieta livre de glúten.

CONTROL DE LA SALUD EN CELÍACOS: UN ANÁLISIS SEGÚN EL MODELO DE PROMOCIÓN DE LA SALUD DE PENDER

RESUMEN

Objetivos: describir los hábitos de control de la salud que influyen sobre la vida diaria de los celíacos y analizar la práctica de acciones relacionados con el control de la salud y sus factores determinantes, bajo la óptica del primer componente del Modelo de Promoción de la Salud de Pender.

Método: estudio transversal realizado a través de entrevistas con instrumento con 83 individuos del estado de Ceará diagnosticados con la enfermedad celíaca. Los datos se analizaron mediante el componente de características y experiencias individuales del modelo teórico de Pender.

Resultados: de los celíacos, el 96,4% no seguía la dieta sin gluten; el 80,7% presentaba comportamiento inadecuados para reducir factores de riesgo; el 72,3% realizaba elecciones ineficaces en la vida diaria para alcanzar las metas de salud y el 25,3% no lograba mantener la dieta sin gluten en su vida diaria.

Conclusión: de acuerdo con el modelo teórico, los celíacos no respetaban la dieta adecuada y presentaron factores inherentes a la vida diaria y a las cuestiones sociales, caracterizados como obstáculos para un control eficaz de la salud.

DESCRIPTORES: Promoción de la salud. Enfermedad celíaca. Enfermedad crónica. Cooperación del paciente. Dieta libre de gluten.

INTRODUCTION

Celiac disease is a gluten-related autoimmune disorder in individuals who are genetically predisposed. Gluten is present in foods containing barley, rye, wheat, Brazilian oats, malt and derivatives. In addition to the genetic factor and gluten consumption, immunological and environmental factors influence the onset of the disease. Celiac disease causes an inflammatory process in the mucosa of the small intestine, causing atrophy of the intestinal villi and thus hindering the absorption of nutrients, which triggers the appearance of various forms of clinical manifestations.¹

Celiac disease is currently considered a public health problem, in view of its chronic character, morbidity and mortality related to malignant diseases in the gastrointestinal tract and high worldwide prevalence. Thus, for the reduction and/or elimination of comorbidities, there is a need for direct participation of the celiac patient, since the treatment is based on the absence of contact with gluten.¹⁻³

Contact with gluten can have negative health impacts (diarrhea, distension and abdominal pain), changes in the psychological state (anxiety and depression) and social and family difficulties in the patients that directly affect the quality of life of celiac individuals.⁴⁻⁵

Therefore, adherence to and strict follow-up of the diet promote better quality of life.⁶ However, for a good adherence to the therapeutic plan, it is necessary to promote health among celiac patients, since the lack of information about the disease, the diet, the ability to identify gluten-free foods outside the home and the correct interpretation of food labels also interfere with the good quality of life of patients with celiac disease. In addition, the socioeconomic issues are equally relevant for adherence to the diet, because gluten free foods are expensive.⁴

Given the above scenario, the nurse has an essential role in promoting health and quality of life in celiac patients. In this sense, using models and theories from the perspective of health promotion can help nurses understand the determinants of the health problems and outline specific interventions for the population with chronic diseases.⁷

Accordingly, one way to develop nursing care in this area is to use and apply the Pender Health Promotion Model.⁸ It articulates nursing theories and behavioral theories in order to interpret the relationships between healthy lifestyles and the adoption of behaviors through the environment in which the individual is inserted, given their biopsychosocial context. In addition, the individual is the protagonist of his health, managing his behaviors. Using the Pender Model, nurses can plan, intervene and evaluate their actions.⁹

Several studies in which the Pender Health Promotion Model was used in different biopsychosocial and illness contexts are found in the scientific literature. Among these, there are studies aimed at the populations of the elderly, children, adolescents, pregnant women, adults, among others.⁹⁻¹⁴ However, research studies with the Pender model directed at the celiac is still insufficient. Therefore, conducting studies that address the model now exposed to the celiac audience is relevant due to the variety of actions and interventions that nurses can implement to contribute to and/or increase the quality of life of these patients.

Given the premise that professional nurses have direct and continuous contact with their clients and know their biopsychosocial factors, they therefore have the opportunity and responsibility to contribute to the health control of the community in which they operate.¹⁵

From this context, the objectives of the study were to describe the health control habits that influence the daily life of celiac patients and to analyze the practice of actions related to health control and its determinants, from the perspective of the first component of the Pender Health Promotion Model.

METHOD

A cross-sectional study conducted in the Celiac Association of the state of Ceará (*Associação de Celíacos do Estado do Ceará, ACELBRA-CE*), from May to September 2017, through the application of a data collection instrument, with individual, social and family variables, in addition to issues related to health control.

Non-probability and convenience sample, composed of individuals with a medical diagnosis of celiac disease, of both genders, aged ≥ 18 years old, residing in the state of Ceará, and members of ACELBRA-CE. As exclusion criterion, it was established to present some mental and/or cognitive limitation that compromised the veracity of the data during the research, this limitation being reported by the individual or the family, or detected at the time of collection. It is noteworthy that there was no exclusion of participants.

The data collection process took place via an interview directly with the celiac participant, conducted by a master student nurse and three undergraduate nursing students, who were scientific initiation scholarship holders. To this end, the day, time and place of the interview were scheduled: the home of the celiac or other setting agreed between participants and researchers.

The results were analyzed by reading and interpreting the data according to Pender's theoretical health promotion model.⁸

The Pender Health Promotion Model, developed by Nola J. Pender, contributes to the understanding of complex psychological processes that motivate people to change their behavior and instigate them towards health promotion.⁹ Moreover, in this model, health promotion is understood as actions for the development of resources, which maintain or enhance the well-being of human beings,⁸ and has been implemented in various contexts to analyze the behaviors related to health promotion.¹⁶⁻¹⁷

In Pender Health Promotion Model, its theoretical framework starts from the perspective that people have a multidimensional nature, with interpersonal and environmental interaction, which has a significant impact on health control. The Pender Model has the potential to allow nurses to develop individualized or group care, with the stages of planning, intervention and evaluation of their interventions.¹⁷

It is also noteworthy that the Pender Health Promotion Model aims to evaluate human behavior related to health promotion through three components: 1) individual characteristics and experiences (previous behaviors, personal factors); 2) specific behavior (perceives benefits for action; perceives barriers to action; perceives self-efficacy; feelings about behavior; interpersonal influences; influencing situations); 3) result of behavior (immediate demands; health promoting behavior).⁸

In this study, the variables of the first component will be analyzed, and they group the individual characteristics and experiences of the individual's previous behavior, which must be changed. In turn, the personal factors are divided into biological factors (age and body mass index); psychological (self-esteem, self-motivation); and sociocultural (education, socioeconomic status, ethnicity/skin color, marital status and religion).⁸

Regarding previous behavior, this is a unique condition to base nursing interventions, and the personal factors intervene in the behavior related to health promotion, for health control.¹⁸

The previous behavior variable directly interferes with the health promotion behavior, as well as with the other components. Therefore, this component is the starting point of the model, since it enables the elaboration of nursing interventions, besides directly impacting on the health promotion behavior.⁸

RESULTS

Personal factors

Of the 83 individuals interviewed, 73 (88%) were female, 45 (54.2%) said they were white and 42 (50.6%) denied the presence of mates. Most of the celiac patients (83.1%; n=73) were members of a gluten-free religion in their communion rituals and had over 18 years of schooling. The participants had a mean income *per capita* of R\$ 2,333.00. As for the support association for celiac patients, 52 (62.7%) respondents reported participating in this type of association. It was also identified that 23 (25.3%) celiac patients were between overweight (16) and obesity (7), according to the classification of the body mass index. When asked about the feeling of motivation to control the gluten-free diet, 16 (19.3%) respondents stated that they did not feel motivated.

Previous behaviors

Regarding the difficulty in including the daily treatment regimen, 80 (96.4%) respondents reported that, even following a gluten-free diet, within the last 30 days they had shown gastrointestinal, neurological, and/or mood, musculoskeletal signs and/or symptoms and/or dermatological. This finding corroborates in the statement that there were misconceptions in daily therapy compliance.

As for the reduction of risk factors, 67 (80.7%) celiac patients had behaviors that contributed to the failure to reduce risk factors. Therefore, the participants handled, prepared and shared meals in settings and with supplies that were contaminated with gluten, did not perform proper sanitation when using utensils that had already had contact with gluten, they did not separate household utensils in their homes, and had difficulty talking to their partner about why oral hygiene during kissing.

Regarding the choices in daily life, 60 (72.3%) celiac patients made ineffective choices to meet the established health goals. Based on this finding, it can be inferred that: the majority of the participants made a daily intake of foods containing gluten; did not check the labels of naturally gluten-free foods; were not in the habit of recognizing trustworthy establishments regarding the availability of gluten-free foods or products when there went out from home; and did not verify labels and/or the composition/ingredients when buying or using miscellaneous products.

Regarding the maintenance of the gluten-free diet, 21 (25.3%) individuals could not maintain the gluten-free diet in their daily life, which is a worrying factor, given that the treatment is based on a gluten-free diet for life.

DISCUSSION

There was a predominance of female participants. This finding is in line with the profile identified in another study conducted with celiac adolescents, as there was a male prevalence.¹⁹ However, at the international level, in a study conducted in Colombia, females prevailed with 88%.²⁰

Regarding the race/skin color of the interviewees, 45 (54.2%) declared themselves white. Similar results were reported in a study conducted with patients suffering from celiac disease and liver cirrhosis, as 83% of those evaluated were white.²¹ It is also noteworthy that a population survey concluded that individuals of white skin color/ethnicity are five times more likely to present celiac disease.²²

Regarding the marital status of the interviewees, 42 (50.6%) denied the presence of partners. This characteristic differs from the results of a study conducted with 195 celiac patients, since 55% of them were married or referred to a marital union.²³ Diverging data were also presented in American and Iranian surveys, as 76% and 67%, reported the presence of a mate, respectively.^{20,24}

Most of the celiac patients in this study were part of some religion in which gluten was consumed in communion rituals. Consequently, according to Brazilian census data, 86.8% of the population reported being Christians: 64.6%, Catholics and 22.2%, evangelicals.²⁵ In Christian communion rituals, the host has wheat as its main ingredient, so it should not be eaten by the celiac. However, a ritual of religious unification can represent a moment of rejection and isolation for celiacs.²⁶ Thus, celiacs may not maintain the treatment regimen because of the strong social representation associated with the religious and spiritual significance of the host.

Regarding the years of study of the respondents, 18 years of schooling meets the finding of a research conducted with 1,835 celiacs, in which more than half of the participants (55%) had at least one degree.²⁰

The *per capita* income is an important factor for adherence to the gluten free diet due to the costs of the treatment. In the present study, the participants had a monthly income of almost two and a half minimum wages. This value was higher than the mean *per capita* income in the state of Ceará, because, in 2017, the Cearenses received less than a minimum wage: R\$ 751.00. In a study which assessed the celiac patients' perceptions of their treatment costs, the respondents' incomes were higher than those with hypertension, diabetes mellitus, congestive heart failure, chronic kidney disease, gastroesophageal reflux, inflammatory bowel disease, and irritable bowel syndrome.²⁷

Given the fact that the majority of the respondents in this study participated in celiac associations is considered an essential factor in relation to social, psychological support and even to obtain information and to share experiences to promote health and improve quality of life and adherence to the gluten-free diet.²⁰

Based on the number of overweight and obese participants (25.3%), it is noteworthy that, in the production of processed gluten-free foods, there are usually more carbohydrates and lipids than their gluten-containing counterparts. This is currently relevant considering that obesity is increasing among celiac patients. As a result, these individuals are at risk for overweight and obesity, especially during the first year after starting the gluten free diet. This is probably influenced by the fact that they can eat without the presence of signs and/or symptoms prior to the gluten-free diet. If this is combined with the consumption of gluten free and high calorie foods, the patient will gain more weight than desired.¹

Regarding motivation, 16 (19.3%) celiac patients were unmotivated to control the gluten-free diet. This personal factor is a direct indicator of intentional gluten consumption.²⁸ On the other hand, the adherence to gluten-free diet is associated with better self-regulation scores, healthy habits, self-efficacy, priority setting, daily facilities and social support.²⁹

Therefore, health education is required to empower celiac patients about what to choose when following the gluten-free diet in order to improve long-term quality of life. Health promotion should begin at the time of diagnosis, emphasizing the importance of adhering to the gluten-free diet, especially in relation to the possible nutritional deficiencies and to maintaining a healthy, controlled diet in relation to weight gain.³⁰

As for the difficulty in including the daily treatment regimen due to the severity of non-adherence to the gluten-free diet for the celiac and due to the level of difficulty inherent in the implementation and maintenance of any strict eating behavior, the identification of factors associated with noncompliance with the regimen is essential to promote health and effective interventions to improve adherence to the gluten-free diet.³¹

Regarding the reduction of risk factors, the participants of the present study reported aspects of cross contamination. This refers to the process by which food is in contact with foreign substances, potentially harmful to health, and incorporates them. Cross contamination in the gluten free diet means that a gluten free food has acquired it, and this process can occur from the production line to the preparation of the food.³

In this regard, when preparing gluten-free foods, care should be taken to separate dietary products and cooking utensils that are not contaminated with gluten, as well as food ingredients and/or any potential source of contamination. The risk increases when food is kept in open containers and sold in bulk at a *buffet* or in any setting where a variety of foods share nearby common spaces.¹

As for the choices in daily life, studies conducted in different countries of the world, such as Canada, Australia, and the United Kingdom, demonstrated that celiac patients have difficulty finding gluten-free foods. Thus, the difficulty in understanding and the habit of not checking food labels prevent an effective adherence and maintenance of the gluten-free diet and may lead to unintentional gluten consumption.³

In the studies cited above, celiacs stated that they avoided eating in restaurants and traveling. They also reported that the information provided by the health professionals was of low quality, although this was generally obtained from other sources, such as celiac support associations, for example. In addition, the respondents stated that early diagnosis, better food labeling, greater understanding of the choices in restaurant menus and better dietary advice would improve their quality of life.³

The maintenance of the gluten-free diet involves factors which can be difficult to accept and follow such as nutrition and dietary education, cross-contamination, nutritional follow-up, the tolerated amount of gluten, eating out and cooking, understanding food labeling and identifying gluten-free foods.³²

Moreover, the financial impact is one of the important factors for adherence to the gluten free diet. Accordingly, a study assessed the costs, access and availability of gluten-free foods and concluded that gluten-free foods are considerably higher in cost than foods containing gluten. In addition, the access to and the availability of these types of foods are still obstacles to consumption.³³

Given the above, it is considered that physical, sociocultural, psychological factors and previous behaviors, presented in the first component of the Pender Health Promotion Model, influenced the health control of people with celiac disease, in view of their impact on the adherence to the gluten-free diet. In addition, the importance of Paulo Freire's method for health education in relation to empowerment and the development of a critical awareness of celiac disease is acknowledged based on the recognition of knowledge about the disease and the factors that interfere with non-adherence to the gluten-free diet. It is emphasized that the nurse, as an educator, can adhere to Paulo Freire's conception of liberating education in order to improve adherence to the health treatments, since the active participation of the educator and the student would promote the understanding of determinants of non-adherence to the treatment.³⁴

It is noteworthy that the place where some interviews for data collection were conducted may have impacted on the attention and concentration of the celiac participants, and this aspect, therefore, is a limitation to be considered in the present study.

The authors recommend conducting studies, such as longitudinal ones, that address individuals with celiac disease, as it is necessary to verify the impact of social factors and previous behaviors on the quality and control of life of these individuals.

CONCLUSION

Adherence to the gluten-free diet is a key factor for an adequate quality of life for the celiac patient because diet is the only effective treatment. Despite this, the adherence rates to the gluten-free diet vary widely, presenting a high value in the present study.

Adherence to the gluten-free diet is influenced by several extrinsic factors in which celiac patients have difficulties in their daily lives, including inappropriate behaviors to reduce risk factors and making ineffective choices in daily life to achieve the health goals. In addition, the socioeconomic issue may aggravate the clinical condition, since gluten-free foods are expensive.

Therefore, health promotion in celiac patients is indispensable for an improved quality of life. For this, nurses can use the Pender Health Promotion Model as a theoretical framework to identify and carry out health education actions to promote health among celiac patients.

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NOTES

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Analysis and interpretation of data: Bessa CC, Silva LA, Sousa TM.

Discussion of the results: Galvão MTG, Silva LA, Sousa TM.

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ETHICS COMMITTEE IN RESEARCH

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CONFLICT OF INTEREST

There is no conflict of interest.

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