

The Celiac Disease Impact Towards The Adults' Life Quality

Repercussões da Doença Celíaca na Qualidade de Vida de Sujeitos Adultos

Repercusiones de La Enfermedad Celíaca en La Calidad de Vida de Sujetos Adultos

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ABSTRACT

Objective: The study's purpose has been to further understand the repercussions that Celiac Disease has on the adults' life quality. **Methods:** It is an integrative literature review, which has used the following databases for the selection of articles published between 2006 and 2017: LILACS, VHL, SciELO, MEDLINE, CINHAI and CAPES periodic portal. **Results:** Twenty articles were fully scrutinized. Based on the content analysis stages, the following three categories appeared: Eating practices of adults bearing the Celiac Disease; Quality of life of the Celiac Disease bearing adult; Importance of the patient care team in the diagnosis and follow-up of adults bearing the Celiac Disease. **Conclusion:** It is expected that science finds other means of treatment, in addition to the restrictive diet and/or the fact that the industry may adapt to the needs of adult subjects, by offering quality products and low cost, for inclusive and sociable access, then reducing the suffering generated by the disease.

Descriptors: Celiac Disease, Gluten, Adult, Quality of Life, Patient Care Team.

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RESUMO

Objetivo: Compreender as repercussões que a Doença Celíaca acarreta na qualidade de vida do sujeito adulto, por meio de uma revisão integrativa.

Método: Revisão integrativa, com buscas nas bases de dados LILACS, BVS, SciELO, MEDLINE, CINHAL e portal de periódicos CAPES, com seleção de artigos publicados entre 2006 e 2017. **Resultados:** Foram analisados 20 artigos ao final na íntegra. Pautada nas etapas de análise de conteúdo, três categorias emergiram: Práticas alimentares do adulto com Doença Celíaca; Qualidade de vida do adulto com Doença Celíaca; Importância da equipe multiprofissional de saúde no diagnóstico e acompanhamento do adulto com Doença Celíaca. **Conclusão:** A perspectiva de que a ciência encontre outros meios de tratamento, além da dieta restritiva e/ou a indústria se adequa às necessidades dos sujeitos adultos, por meio da oferta de produtos de qualidade e baixo custo, para o acesso inclusivo e sociável, diminuindo o sofrimento gerado pela doença.

Descritores: Doença Celíaca, Glúten, Adulto, Qualidade de Vida, Equipe Multiprofissional.

RESUMEN

Objetivo: Comprender las repercusiones que la Enfermedad Celíaca acarrea en la calidad de vida del sujeto adulto, por medio de una revisión integrativa.

Método: La revisión integrativa, con búsquedas en las bases de datos LILACS, BVS, SciELO, MEDLINE, CINHAL y portal de revistas CAPES, con selección de artículos publicados entre 2006 y 2017. **Resultados:** Se analizaron 20 artículos al final en su totalidad. En las etapas de análisis de contenido, tres categorías emergieron: Prácticas alimentarias del adulto con enfermedad celíaca; Calidad de vida del adulto con enfermedad celíaca; Importancia del equipo multiprofesional de salud en el diagnóstico y acompañamiento del adulto con enfermedad celíaca. **Conclusión:** La perspectiva de que la ciencia encuentre otros medios de tratamiento, además de la dieta restrictiva y / o la industria se adecue a las necesidades de los sujetos adultos, a través de la oferta de productos de calidad y bajo costo, para el acceso inclusivo y sociable, disminuyendo el sufrimiento generado por la enfermedad.

Descriptor: Enfermedad Celíaca, Gluten, Adultos, Calidad de Vida, Grupo de Atención al Paciente.

INTRODUCTION

Celiac Disease (CD) is a chronic autoimmune small bowel enteropathy, triggered by exposure to gluten, the main protein fraction present in wheat and rye, in oats and barley, in genetically predisposed subjects. Exposure to this substance causes inflammation, with atrophy of intestinal villi and other problems, ranging from malabsorption, different clinical manifestations, lactose intolerance, and intestinal cancer.¹⁻⁴

The gluten-free diet (GFD) is the only effective treatment for CD, because it prevents the pathophysiological changes of the small intestine, promotes the efficient return of nutrient absorption and promotes the nutritional rehabilitation of the individual, with the significant improvement of his quality of life.^{3,5}

Adults bearing CD often transgress the diet due to financial difficulty, absence or lack of clarification regarding illness and food preparation, food habits with products containing wheat in the composition, lack of ability to

prepare traditional meals and difficulty in acquiring economically accessible gluten-free industrialized products.⁶

The lack of information about CD is an obstacle to be overcome, especially because of the proximity of symptoms to other diseases, which causes late diagnosis, often, inattentiveness of health professionals to the factors that could facilitate this recognition. Therefore, in order to diagnose CD, certain criteria should be considered: previous habits, transitions required by the disease and repercussions for individual and collective quality of life.^{4,5} Due to this condition, the treatment opportunities of CD are under-reporting of the disease, contributing to a greater number of neglected and/or untreated cases.^{1,4}

Adapting to the condition of food selectivity, adapting old habits to their new condition can lead to various conflicts and psychic suffering, so the individual who develops with CD goes through severe dietary changes, such as how to behave in personal and social life.⁴ Therefore, we need to consider the biopsychosocial aspects of the context, by the direct relation to subjective issues of life, such as eating habits, cultural customs, and health perception.^{1,4,5}

Hence, in order to consider the difficulties that the adult individual has in relation to the diagnosis of CD and its evolution to the dimensions of life, this work aimed to understand the consequences of CD in the quality of life of adults, through an integrative literature review.

METHODS

It is an integrative literature review, which allows us to combine data from the empirical and theoretical literature that can guide the definition of concepts, identification of gaps in study areas, review of theories and methodological analysis of studies on a theme.⁷

The scientific steps of the study included: definition of the guiding question; search and selection of literature in electronic databases, based on inclusion and exclusion criteria; analysis of the data to extract the information of the selected articles; critical opinion of the selected articles, through the interpretation of the data; and presentation of the results evidenced in the review.⁸

The study was guided by the following question: What are the repercussions for the quality of life of the adult subject who experiences Celiac Disease?

The search for the production took place electronically, during the months of July/2017 and September/2017, through the consultation of articles published in scientific journals indexed in the following databases: *Literatura Latino-Americana e do Caribe em Ciências da Saúde* (LILACS) [Latin American and Caribbean Literature in Health Sciences], Virtual Health Library (VHL), Scientific Electronic Library Online (SciELO), Literature and Retrieval System on Line (MEDLINE) Medical Literature Analysis and Retrieval System Online (MEDLINE), Cumulative Index to Nursing & Allied Health Literature (CINAHL), and the

periodic portal named Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES).

The inclusion criteria established for this review were: original articles published in full between January 2006 and September 2017; in Portuguese (Brazil) Spanish and English, available for online consultation; letters to the editor; articles of opinion, reflection and systematic and/or integrative review; and case studies and articles that did not meet the methodology steps were part of the exclusion criteria of the study.

The choice of words was based on the selection of terms included in the descriptors in Health Sciences (DeCS): “Celiac disease”, “Gluten”, “Quality of life” and “Adults”, therefore, to search the databases of English terms were used, corresponding to the DeCS: “Celiac Disease”, “Gluten”, “Quality life”, and “Adults”. It was also necessary to add the keyword in English “Gluten-induced enteropathy”, to allow the greater capture of articles; the Boolean “and” was used in the LILACS database and the “and” in the English language bases.

In CINAHL an article with the descriptor “celiac disease” was found, however, it was not possible to access it. In the attempt to cross between the other descriptors “gluten”, “adults” and “quality life”, no other production was found.

In the MEDLINE database, with the descriptor “celiac disease”, 24,060 articles were found. By adding the descriptor “gluten”, we obtained 8,689, “adults” 3,570 and when excluding “adults” and include “quality life”, 257 articles found. With the cross-referencing of all the descriptors, there were 169 articles and only 39 had some relation to the inclusion criteria. After reading their summaries, eight were selected because they fit the study, one in Spanish and seven in English.

In the SciELO database with the descriptor “celiac disease”, 400 articles were found, while the descriptor “gluten” was changed to 185 and “adults” was reduced to 16 articles. Of these, five were related to the inclusion criteria. After reading the abstracts, two were selected because they fit the study, both in English. By adding the descriptor “quality life” and excluding “adults”, 16 articles were found. Of these, 13 were related to the inclusion criteria, but after reading the abstracts only eight were selected because they fit the study, five in English and three in Portuguese. At the intersection of all the descriptors together there were no findings.

In the LILACS with the descriptor “celiac disease” were found 23,225 articles, including the descriptor “gluten”, reduced to 17,366 and “adults” to 987. Excluding “adults” and including “quality life” found 306 articles. Crossing all the descriptors, 47 articles were identified, of which 16 were related to the inclusion criteria. After reading the abstracts, 10 were excluded because they did not fit the study objectives and the other six were duplicates.

In the VHL applying the descriptor “celiac disease”, 22,888 identified articles. By including the descriptor “gluten” there was a reduction to 17,207. Including “adults” the number was 975 articles. By adding “quality life” and excluding “adults”, 295 articles were identified. Already at the intersection of all the descriptors, 47 were found, of which 24 were related to the inclusion criteria. After reading their abstracts, only two articles were selected, because they fit the purpose of the study, both in English.

In CAPES, with the descriptor “celiac disease”, 123 articles were found; with the descriptors “celiac disease” and “gluten”, 64 articles and “celiac disease” and “adults” 18 articles. All of them were related to the inclusion criteria, however, after reading the abstracts, only three were selected, because they fit the study but were not available in full online. When searching for the descriptors “celiac disease” and “quality of life”, 10 articles were found and all were related to the inclusion criteria. After reading the abstracts, only nine were adequate to the objectives of the study, but not available in full.

For the critical interpretation of the data, the method chosen was content analysis; an agglomeration of constantly improved methodological tools that apply to excessively diversified discourses.⁹

It must be highlighted that the search and presentation of the information contained in the study come from the public domain and accessed on the Internet, not dealing with data that require ethical secrecy and release of Ethics and Research Committee.

RESULTS AND DISCUSSION

Herein, 20 articles were analyzed. According to the results, eight (40%) articles were found in the MEDLINE database, 10 (50%) in the SciELO and two (10%) in the VHL.

The productions cover different journals, linked to the nursing areas with one article (5%), nutrition with six articles (20%), gastroenterology 13 articles (75%).

Observing the publication year, there was a balance in the number of productions in the period foreseen for this review, with absence of production only between January 2016 and the first production found in 2008, and also in 2017.

Concerning the selected productions, the very predominant language was English, totaling 16 articles (80%), whereas the remaining three were in Portuguese (15%) and one in Spanish (5%).

In **Figure 1**, the identification characteristics of the publications with regards to the journal, year, CAPES Qualis and Impact Factor (IF) are shown below.

Figure 1 - Identification of publications with regards to the journals, year, Qualis, and impact factor (n=20). Santo Antônio de Jesus city, Bahia State, 2017.

Note: All the journals' names were kept in their original language.

Identification	Year	Qualis	IF
1: Revista da Escola de Enfermagem da USP - Os impactos psicossociais gerados pelo diagnóstico e tratamento da doença celíaca. ⁹	2016	A2	0.455
2: Revista Española de Enfermedades Digestivas - Transcultural adaptation and validation of the Celiac Dietary Adherence Test. A simple questionnaire to measure adherence to a gluten-free diet. ¹¹		B2	1.455
3: Revista Española de Enfermedades Digestivas - Health-related quality of life and determinant factors in celiac disease: a population-based analysis of adult patients in Spain. ¹²	2015	-	-
4: Revista Española de Enfermedades Digestivas - Benefit on health-related quality of life of adherence to gluten-free diet in adult patients with celiac disease. ¹³		B3	-
5: Revista Española de Nutrición Humana y Dietética - Protocol development for a scale to assess self-efficacy in adherence to a gluten free diet: Self-Efficacy and Celiac Disease Scale. ¹⁴	2014	B1	0.2012
6: Arquivos de Gastroenterologia - Quality of life evaluation in celiac patients from Southern Brazil. ¹⁵		B4	-
7: GE Jornal Português de Gastroenterologia - Percepção do estado de saúde e da qualidade de vida numa amostra de celíacos portugueses. ¹⁶	2013	B4	-
8: DEMETRA: Alimentação, Nutrição & Saúde - Fragilidades da atenção à saúde de pessoas celíacas no SUS: a perspectiva do usuário. ¹⁷		A2	4.411
9: PLoS ONE - Validation of a French version of the Quality of Life "Celiac Disease Questionnaire". ¹⁸	2012	A1	18.187
10: Gastroenterology - Benefits of a gluten-free diet for asymptomatic patients with serologic markers of celiac disease. ¹⁹		A1	14.921
11: Gut - Diagnosis and management of adult celiac disease: guidelines from the British Society of Gastroenterology. ²⁰	2011	B1	2.468
12: BMC Gastroenterology - Predictors of persistent symptoms and reduced quality of life in treated celiac disease patients: a large cross-sectional study. ²¹		B2	1.455
13: Revista Española de Enfermedades Digestivas - Transcultural adaptation and validation of the Celiac Disease Quality of Life (CD-QOL) Survey, a specific questionnaire to measure quality of life in patients with celiac disease. ²²	2010	-	-
14: Canadian Journal of Gastroenterology and Hepatology - Clinical features and symptom recovery on a gluten-free diet in Canadian adults with celiac disease. ²³		C	-
15: Nutrición Hospitalaria - Calidad de vida y proceso diagnóstico em celíacos adultos de la comunidad Valenciana. ²⁴	2009	B1	1.497
16: Journal Gastrointestinal and Liver Diseases - Quality of Life in Coeliac Disease is Determined by Perceived Degree of Difficulty Adhering to a Gluten-Free Diet, not the Level of Dietary Adherence Ultimately Achieved. ²⁵		A2	1.891
17: Alimentary Pharmacology & Therapeutics - The development and validation of a new celiac disease quality of life survey (CD-QOL). ²⁶	2008	A1	6.32
18: Alimentary Pharmacology & Therapeutics - The quality of sleep in patients with celiac disease. ²⁷		-	-
19: Arquivos de Gastroenterologia - Celiac disease in Brazilian patients: associations, complications and causes of death. Forty years of clinical experience. ³	2007	B1	0.2012
20: World Journal of Gastroenterol - Factors that impact health-related quality of life in adults with celiac disease: A multicenter study. ²⁸		B1	2.787

Eating practices of adults bearing the Celiac Disease

When diagnosed with CD, the adults' life changes completely. Eating properly becomes a health issue, and this simple, commonplace, and fundamental act can turn into a disorder for those who experience CD. The symptoms associated with gluten intake, or the difficulty to follow a GFD due to several factors, affect the perception of the health status and quality of life of these subjects, demonstrating that eating can be negative due to the dilemma of eating properly, or to be led by difficulties in the production and consumption of gluten-free foods.^{3,15}

The alimentary practices of adults with a diagnosis of CD restrict them, not only by the fragile acceptance of their social environment, but by the supply and value of the foods allowed, and by the deficiency of the detailed description of the product labels. The restrictive diet has a considerable impact on family functioning, being favorable when there is support and encouragement for changes in lifestyle, or unfavorable when there are conflicts over the food restriction and the necessary care in the production mechanism, in order to avoid possible contamination and health problems.¹⁵

It is fundamental to the adaptation process of the adult bearing CD to develop strategies that facilitate their day-to-day life, family and social life. The mobilizations so that the food production industries are sensitized in the greater offer of variety and lower cost of products without gluten is

an alternative that would contribute to this adaptation of the individual and who is close.⁵

Understanding dietary restriction as a permanent condition can generate biopsychosocial repercussions on the adult bearing CD, due to the impossibility of attending to habitual places, since they are unprepared spaces for specific or restrictive food demands, being one of the main difficulties faced after the diagnosis of the disease. Consequently, a GFD can directly impact the psychological dimension of this subject and trigger anxiety, depression, mood or sleep disorders, compromising the quality of life.^{10,16,17,24,25,27}

Quality of life of the Celiac Disease bearing adult

The Quality of Life (QOL) of adults bearing CD requires mastery of their dimensions, which according to World Health Organization (WHO) is "the subject's perception of their insertion in life in the context of the culture and value systems in which he lives and in relation to the their goals, expectations, standards and concerns."^{29:403}

Starting from the concept of QOL, it is evident the need to delimit its relationship with CD, from the point of view of the subject who experiences it, so that one can have sufficient knowledge of the difficulties faced and propose strategies that facilitate everyday life.

It is essential to create specific instruments to evaluate the quality of life adults bearing CD, to identify the sensations surrounding the changes that the disease generates for life. When applying generalist instruments, a more complete evaluation of the dimensions affected by the CD does not happen, consequently leading to an analysis focused on the improvement and/or disappearance of symptoms, without evaluating the other repercussions for the QOL.^{10,12,13,24,25}

Understanding that the treatment for CD is not restricted to a strict dietary restriction only, but that nutrition is intrinsically associated with cultural, social and psychological issues, whose diagnosis brings significant changes. Therefore, the condition of new eating habits should not negatively impact the subjective life of the adult, which is a major challenge for him, the family and the health team.^{9,26}

The implications of the psycho-affective aspects occur from the diagnosis of CD, ranging from mild depression and/or discreet anxiety to the manifestation of severe emotional disorders, especially related to the lack of knowledge about the disease.⁹ Thus, the acceptance process can occur in a more relaxed way, when there is an understanding of CD and treatment, an important step to confront the diagnosis, the symptoms, and the new dietary routine. The adult bearing CD needs information and reception so that, instead of being an adjunct, he is the protagonist of his therapy, with possible harm reduction.¹⁶

Understanding the subjectivity of diagnosis and effective treatment for CD is key to improving QOL in adults. The broader understanding of the facts surrounding the disease and the disorders caused by the restrictive diet may be a

mechanism for the identification of factors that trigger the change in the quality of life of the subject and the family.²⁸

The probable limitations that the treatment of CD implies on the life of the adult and those who surround him/her can generate transgressions in the resized nutritional habits, precisely by the constant food deprivation. Such a reality can have serious consequences for the adult and his QOL, because the limitations focused on the restrictive diet, in the beginning, can, over time, reveal subjective conditions, as impacting as the physiological manifestations.⁹

Therefore, the adult's QOL is not restricted to alleviating and/or eliminating the clinical signs of CD, but to consider the different habits necessary for the maintenance of multi-factorial stability, without damage or major suffering. Considering the aforementioned, it is fundamental that there are broad instruments and parameters to evaluate the adult with a diagnosis of CD, to guarantee an integral health follow-up that is decisive and that helps in the promotion of healthy living.^{11, 13, 14, 16, 17, 18, 21, 22, 24, 28}

Importance of the patient care team in the diagnosis and follow-up of adults bearing the Celiac Disease

In order to guarantee the QOL towards the CD bearing adult, a systematic follow-up is necessary with a well-prepared patient care team able to meet different needs. The follow-up should start from the suspicion, remain when diagnosed and throughout the life of adults bearing CD, through competent professional actions, whose care should involve the alimentary conducts and the control or mitigation of the consequences from a biopsychosocial perspective.^{16,19,22}

The GFD is the main responsible for the negative repercussion in the QOL of adults bearing CD, because it is indispensable and can interfere directly in its social functioning. From this point of view, professional support and guidance are the way to social reintegration and successful adaptation to the new reality of life.¹⁸

Therefore, professional adult follow-up with CD aims to make it responsible for its treatment, without frustration or rejection, to alleviate repercussions on QOL and seek the insertion of family and other social ties in the process, as a way of guaranteeing the lowest possible daily harm.¹⁹

Early diagnosis and frequent evaluations help to decrease the onset of associated diseases, as well as the onset of mood, sleep, and psychological disorders. When the adult with DC is closely followed, it tends to improve QOL by the motivation to follow the GFD and, therefore, to favor the elimination of clinical symptoms and histopathological changes.²⁰

It is essential for adults bearing CD to assess the degree of impairment in personal, family and social life, as well as the repercussions of treatment, since the main role of the health professional is to cooperate in the adaptation of the subject and family to their new lifestyle, through the color-responsibility of treatment.¹⁶

The emotional, family and daily frailties involved in the diagnosis of CD should be valued by health professionals, through multi-professional follow-up, periodic evaluations, and evaluation of possible problems, to maintain the picture. The right to health, overcoming inequalities and efficient care are guidelines for reducing the negative repercussions in the lives of adults with CD and family. The absence of support groups and the precariousness of the psychotherapeutic and nutritional care contribute to a restricted evolution in relation to QOL. Health professionals should be guided about the symptoms, diagnosis, and treatment of the disease in adults, the most common diseases and multiple repercussions, regardless of their role in the health care system. The intervention should prioritize health promotion, through teaching-learning to the adult and family followed by confirmation of the diagnosis of CD.^{17,30}

The articles of this review are unanimous, evidencing the importance of the support given by the health professional, to the adult bearing CD and how this will positively implicate in the adherence and permanence of the treatment. The studies further affirm the need for life-long excellence assistance, the understanding of continuing changes in habits, frustrations, and restraints that arise capable of triggering psychosocial problems and frailisation in interpersonal relationships. To that end, health professionals should be trained about CD and caring for the subjects and family, as well as health institutions, at all levels of attention, in the search for broad and re-meaning care.^{16,17,19,20}

The authors emphasize that adults bearing CD have being treated in a restricted manner, due to the lack of extended action in the care provided. Regarding the food reorganization and effective prioritized treatment, it is perceived that the limitation of health care is the main cause of the decrease in QOL for this population.^{11,16,17,22,26,27,28}

To look after those who live CD from the multidimensional point of view is to perceive the real repercussions in life, which are infinitely beyond those related to GFD, but directed at QOL. Its meaning in the face of a chronic illness, such as CD, reveals the need to expand health actions in integrality, in this sense, it is imperative to favor the sharing of decisions and to stimulate autonomy for self-care and the patient care team participation in the attention to health, bearing in mind a collective and settled approach.

CONCLUSIONS

It is expected that science finds other means of treatment, as valued as the GFD, and that the industry might be able to favor more the CD bearing adult, through products of quality and low cost, then generating more inclusive and sociable access. It would be a significant factor to reduce frustration and isolation after diagnosis of the disease.

Ultimately, this integrative literature review allowed us to understand that adults, when well oriented and assuming the role of co-participants in the process of care for their disease,

are capable of overcoming limits, through new possibilities of coping with CD, healthier social relationships and the meaning of life, with an emphasis on QOL.

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