International Journal of Advanced Engineering Research and Science (IJAERS) *[Vol-7, Issue-6, Jun- 2020]*
https://dx.doi.org/10.22161/ijaers.76.12 *ISSN: 2349-6495(P) | 2456-1908(O)*

Impacts of Celiac Disease on quality of life: Integrative Literature Review

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***Abstract*— *Objective: to understand the repercussions that Celiac Disease has on quality of life, through an integrative review. Method: integrative literature review, with searches in the LILACS, SciELO and Web Of Sciece databases, with a selection of articles published between 2014 and 2019. The articles were selected by searching with the following Health Sciences Descriptors: Celiac Disease, Glutens, Adult, Quality of Life, Patient Care Team and Gluten Free Diet, using the Boolean operators AND and OR as a tool for crossing them, enabling the location of 111 articles. Results: Six articles were analyzed in full from the application of the inclusion and exclusion criteria, with the production of data guided by the content analysis steps proposed by Bardin, enabling the construction of two empirical categories, namely: dietary practices and Quality of life of the person with Celiac Disease and importance of the multidisciplinary team in the diagnosis and monitoring of the person with Celiac Disease. Conclusion: it is essential to continue in the search for knowledge in the perspective that science finds other means of treatment, in addition to the restrictive diet, and the industry adapts itself to the needs of individuals, through the offer of quality and low cost products, for inclusive access, reducing the suffering and impacts generated by the disease on the quality of life of people with Celiac Disease.*

***Keywords*— Celiac Disease. Quality of life. Patient Assistance Team. Gluten Free Diet.**

I. INTRODUCTION

Celiac disease (CD) is recognized as a chronic enteropathy, genetic pathogenesis, characterized by partial or total atrophy of the microvilli of the small intestine mucosa, crypt hyperplasia and an increase in the number of intraepithelial lymphocytes, which affects the small intestine in nature autoimmune, triggered by exposure to the protein complex called gluten and derivatives, the main protein fraction found in wheat and rye, oats and barley, in genetically predisposed people. Exposure to this substance causes intestinal inflammation, with atrophy of intestinal microvilli, among other problems, which cause everything from malabsorption, bringing different clinical manifestations, lactose intolerance to intestinal cancers(1,2).

It is characterized by intolerance to gluten intake, and is associated with several other important diseases and complications, which makes early diagnosis a fundamental factor in the management of the disease. The diagnosis is admittedly difficult, considering that the majority of patients have an oligo-asymptomatic or asymptomatic form(3). In the management of the disease, the gluten-free diet is the only treatment known to be effective for CD, as it corroborates and prevents the pathophysiological changes of the small intestine, promoting the efficient return of nutrient absorption and providing the individual's nutritional rehabilitation, with improvement of your quality of life(2).

This disease can manifest at any age and presents itself in two forms: atypical, non-classical or subclinical forms, characterized by a varied clinical picture, or even with the absence of gastrointestinal symptoms, and classic or typical form, which presents specific positive serology and biopsy compatible with classic signs and symptoms, such as malabsorption, chronic diarrhea, anorexia, abdominal distension, loss of muscle mass, flat buttocks, steatorrhea, hypoalbuminemia edema, flatulence, weakness, irritability(4).

Since the association between gluten intake and CD described by Dicke, during World War II, the knowledge about the pathophysiology of this gluten-sensitive enteropathy has increased dramatically, especially with the resources of molecular diagnostic investigation. However, it is clear that gluten intake causes enteropathy and extraintestinal disease in genetically susceptible individuals, lacking knowledge about the additional factors associated with the triggering and prevention mechanisms of the disease(5).

Historically, CD has been considered rare and predominantly pediatric. Currently, this scenario has changed, especially due to the development of more sensitive and specific serological tests, which, in addition to making early diagnosis possible, allow the performance of several screening surveys in asymptomatic individuals, whose results indicate that the true prevalence of CD may be greater than 1% in different locations. Currently, CD has been diagnosed mainly at a later stage of life, with the highest prevalence found in female adults(6).

Evidence shows that CD can present with variable frequency in children and adults in different geographical areas, with a variable spectrum of symptoms. In Western countries, it appears that CD affects approximately 1% of the general population. In the United States, a prevalence of 0.71% is identified, and in the European continent, the highest occurrence of CD is found in Finland (2.4 to 2.6%) and the lowest in Germany (0.3 to 0.5 %). Evidence shows that the prevalence of CD in developing countries is similar to that identified in the western world, revealing the following data: Middle East (0.5 to 1.8%), East and South Asia (0.32 to 1, 04%), North Africa (0.14 to 5.6%) and Latin America (0.15 to 2.7%). In Brazil, results of studies carried out in some regions have shown that the prevalence of CD is similar to that found in developed countries, varying from 0.15 to 1.94%(6). A study conducted in Brasília, Distrito Federal, showed a prevalence of 0.34% for CD(4).

The lack of information about CD has been considered an obstacle to be overcome, above all, due to the similarity of clinical findings with other diseases, which generates a late diagnosis, which in turn may go unnoticed by health professionals, making early diagnosis and management difficult. disease. For this condition, the opportunities for treatment of CD end up being underreported, contributing to a greater number of neglected and / or untreated cases(2).

People with celiac disease need a gluten-free diet, that is, they should avoid foods that contain gluten for life. Minimal amounts can trigger significant reactions due to the severe injury that such protein produces in the small intestine, atrophying it and resulting in malabsorption of nutrients, which can cause growth retardation, diarrhea and chronic constipation, vomiting, pain and bloating, anemia iron deficiency, osteoporosis, infertility, among other symptoms(4).

The treatment strategy for CD is completely dietary, consisting of the total removal of gluten and derivatives from the diet permanently, regardless of the clinical presentation of the disease. From the diagnosis, the person with CD goes through a process of arduous and continuous adaptation, given that, often the products offered on the market do not meet the total needs of the individual. Thus, the gluten-free diet is hampered by food monotony, since there is a low variability and availability of gluten-free foods. Therefore, nutritional guidance with creative possibilities for food recipes becomes important in the treatment of CD(1).

In this context, people with CD tend to transgress the diet due to financial difficulties, absence or little clarification in relation to the disease and the preparation of food, eating habits with products containing wheat in their composition, lack of ability to prepare artisanal meals and difficulty in purchasing economically accessible gluten-free industrialized products(2).

In this understanding, it is considered that adapting to the condition of food selectivity, adapting old habits to their new condition can cause several conflicts and psychological suffering, therefore, the individual who is diagnosed with CD undergoes severe dietary changes, including in the way of eating. behave in the face of personal and social life(4,2).

In this dynamic of difficult adaptation, despite the advance in diagnostic techniques, it is possible to infer that most cases of CD still remain undiagnosed. Results of studies indicate that the late diagnosis of CD increases the risk of complications and severity of the disease, in addition to increasing the chance of the installation of associated comorbidities. Despite the severity of CD, there are few studies in Brazil and other parts of the world on its occurrence(6).

In this sense, the study is justified by the reemerging need to know the repercussions of CD on the quality of life of individuals, aiming at a better understanding of how this event occurs and impacts people's daily lives. It is believed that, based on the production of this knowledge, different characters, patient, health professionals, managers, educational institutions, who are interested and are interested in studying and getting to know the theme more deeply, can reach more subsidies to support their reflections. and discussions on the topic, with a view to seeking qualitative and humanized assistance. Thus, the identification and discussion of the characteristics that permeate the phenomenon, become important for the proposition and validation of public policies that present feasible strategies for coping and changing care paradigms, based on current evidence.

The scarcity of comprehensive studies that allow generalizations and estimates of magnitude, the methodological limitations of investigations on the theme, the multifactorial and multidimensional character of the phenomenon, point to gaps in knowledge, and the need to expand the discussion and studies, including different views, with a view to unveiling the aspects that permeate the repercussions of CD on the quality of life of individuals. Given the above, the study aimed to understand the repercussions that Celiac Disease has on quality of life, through an integrative review.

II. METHOD

Integrative literature review, a study that offers quick access to relevant research results and evidence that underlie the conduct or decision making, providing critical knowledge, from six distinct stages(7).

The guiding question consisted of: What are scientific evidences available in the literature about the repercussions and impacts that Celiac Disease has on quality of life? The search was carried out from October to November 2019. The time frame was from 2014 to 2019, with 6 full articles listed, published between 2014 and 2017.

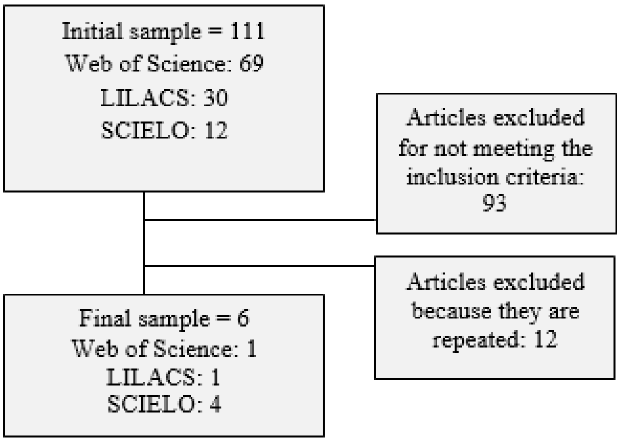

Fig.1: Flowchart of constitution of the sample.

Source: adapted from Pereira et al. 2019(8).

The search was carried out in the Scientific Electronic Library Online - SCIELO, Literature databases Latin American Health Sciences - LILACS and Web Of Science. The articles were selected by searching with the following Health Sciences Descriptors (DeCS): Celiac Disease, Glutens, Child, Adult, Child, Quality of Life, Patient Care Team and Gluten Free Diet, using operators Booleans AND and OR as a tool for their crossing, allowing the location of 111 articles, where 06 were included in the research (Figure 1). The texts are summarized in Table 1.

The inclusion criteria were: articles in Portuguese, published between 2014 and 2019, that addressed the repercussions and impacts of Celiac Disease on the Quality of Life of adults, adolescents and children, and full articles in the free version. This period was established due to the scarcity of content in the literature, related to the research topic, and because it considers that the publications of the last 5 years represent the current knowledge on the topic. Exclusion criteria were: articles in other languages, texts in Thesis, Dissertations, Monographs, Course Conclusion Papers, Letter to the editor, Annals of events, articles where only abstracts were available, articles published outside the established time frame for the present study. To systematize the articles selected in the search, an instrument validated by Ursi(7,9) was defined.

The analysis of the selected studies was carried out in a descriptive way, making it possible to observe, count, describe and classify the data, in order to gather the knowledge produced on the theme. The selected productions that were submitted to the Content Analysis technique(10) and grouped into two thematic pillars, which are presented and discussed below.

III. RESULTS AND DISCUSSION

Table 1: Summary of articles according to author, title, journal, year, and methodological procedure and research findings.

Code	Author. Title. Periodic. Year	Data base	Methodological procedure	Research findings
A1	Pimenta-Martins, Ana; Pinto, Elisabete; Gomes, Ana M.P. Percepção do estado de saúde e da qualidade de vida numa amostra de celíacos	SCIELO	Cross-Sectional Research	Survey conducted with 195 Portuguese individuals, through a structured questionnaire, self-applied and online. The perception of the state of health and quality of life of the sample of celiac patients studied seems to be better than what is seen in the general population. These results are different from what is reported in the literature, with studies that do not find differences in quality of life between CD patients and the general population and others that report that celiac patients have a worse quality of life than the general population. The self-perception of health status and quality of life in the study sample may be underestimated in

	portugueses. GE J Port Gastrenterol. 2014.			relation to what will happen to the average of Portuguese celiac patients. The characteristics of age and education lead to the hypothesis that we are facing a sample of celiac patients who are very proactive in the search for solutions that minimize the limitations imposed by the disease, namely the search for information and new food products, as well as solutions for your preparation. These skills will allow them to live better with the disease, making it less affect their quality of life.
A2	Lins, Manuela Torres Camara et al. Tradução, adaptação transcultural e validação do Celiac Disease DUX (CDDUX). 2015.	SCIELO	Methodological study of translation, cross-cultural adaptation and validation of a questionnaire to assess quality of life	Research carried out with four pediatric gastroenterologists, a professional with experience in validating instruments, three English teachers and 33 celiac patients, between eight and 18 years old, with their guardians. Quality of life scores obtained from patients were compared with those obtained from their guardians. The translation and adaptation adequately followed the proposed steps, with equivalence being achieved satisfactorily. The translated instrument proved to be valid for assessing the quality of life of children and adolescents with CD.
A3	Cieslinski, Juliana Zimerman; Kotze, Lorete Maria da Silva; Utiyama, Shirley Ramos da Rosa. Tratamento da doença celíaca: estado da arte. 2016.	LILACS	Pesquisa de revisão	Review research, which aimed to identify the therapeutic options that present the greatest advances and, therefore, has the potential to be available to celiac patients in the near future. So far, the gluten-free diet remains the only effective therapy available for Celiac Disease, although promising results have been obtained in several experiments. The gluten-free diet allows a complete restoration of the intestinal mucosa in most cases, but its disadvantages such as the high cost of food for this diet, the short shelf life and the lower sensory properties have a great impact on the lives of patients , and continue to have a low resolution perspective. The development of non-toxic wheat varieties remains a major challenge; therefore, the most promising pathway for the treatment of CD is to assist the organism in the degradation of gluten or to awaken the individual's oral tolerance, thus preventing the inflammatory response from developing. Immunogenic studies were able to prove the pathogenic model of Celiac Disease and thus programs for the discovery of new therapies emerged based on this model. However, scientific research is still deficient in several aspects when it comes to CD, such as the lack of pre-clinical models and good non-invasive markers, factors that hinder new discoveries, since clinical studies need to be encouraged and driven by encouraging pre-clinical results.
A4	Brancaglioni, Bianca de Cássia Alvarez et al. Crianças e adolescentes que convivem com diabetes e doença celíaca. Rev Gaúcha Enferm. 2016.	SCIELO	Qualitative, exploratory and descriptive study	Research carried out with 3 children and 2 adolescents, in a diabetes clinic at the Hospital das Clinicas of FMUSP or at the residence of the participants in the city of São Paulo, through semi-structured interviews. The diet appears as the focus of the participants' experience, but with different meanings. Children have difficulty following the diet, while adolescents report that social and emotional aspects are the most affected. It reinforces the importance of the nurse to seek strategies in partnership with children, adolescents and their families in order to minimize the difficulties found mainly in the management of the diet imposed

				by both diseases. The results reinforce the importance of the nurse, when planning the care of the child / adolescent with DM1 and CD, to seek strategies together with the child / adolescent and the family to minimize the stress and suffering caused by the diet and to promote adherence or maintenance of the as well as other therapeutic measures. Various resources can be used by nurses, such as: using social networks and exchanging messages through "WhatsApp" programs in order to establish and strengthen bonds and, above all, to be available for questions related to the management of DM1 and CD.
A5	Rocha, Susy; Gandolfi, Lenora; Santos, Josenaide Engracia dos. Os impactos psicossociais gerados pelo diagnóstico e tratamento da doença celíaca. Rev Esc Enferm USP. 2016.	*Web Of Science*	Qualitative study	Research carried out with 12 newly diagnosed patients with CD, between the years 2013 and 2014, at the Hospital Universitário de Brasília (HUB). The interviewed patients had negative impacts in three categories: psycho-affective, family relationships and social relationships, indicating problems of social readaptation after the start of treatment, and difficulty in maintaining a gluten-free diet. Celiac disease has substantial impacts on the psychological, family and social relationships of diagnosed patients, requiring a biopsychosocial clinical view for better adherence to treatment and the patient's quality of life. From these three points, there were changes in the emotional state of the patients interviewed, conflicts in family relationships and difficulties in social relationships due to the gluten-free diet. On the other hand, the support of family and friends proved to be an important facilitator that had a significant impact on the adaptation of patients to the diagnosis, especially with regard to aspects of relationships and social adaptations, showing that greater knowledge of biopsychosocial factors may contribute to a significant improvement in the overall health and quality of life of celiac patients.
A6	Sevinc, Eylem; Cetin, Fatih Hilmi; Coskunc, Banu Demet. Psychopathology, quality of life, and related factors in children with celiac disease. J Pediatr (Rio J). 2017.	SCIELO	Cross-sectional study	Research carried out with 52 patients previously diagnosed with CD and recruited at the Pediatric Gastroenterology Department at Emel Mehmet Tarman Children's Hospital in Kayseri, Turkey, between January and March 2016. This study showed once again that CD is associated with some symptoms / diagnoses psychiatric disorders and reduced quality of life. The low rate of adherence to the DSG can mean more exposure to gluten and thus more psychiatric symptoms / diagnoses. Another important factor is the psychosocial stress related to CD. Not being able to eat out, the difficulty in finding DSG and the inconvenience in school and social life result in isolation and stigmatization. This can generate low self-esteem and constitute risk factors for psychopathologies.

Eating practices and quality of life of people with Celiac Disease

The dietary restrictions imposed by celiac disease and the care with contamination by products that have gluten in their composition, experienced by celiac people, lead to a new social behavior that ends up modifying the individual's daily life, bringing repercussions not only on their habits as well as their social, economic and quality of life habits as a whole. When changing their diet, the person can go through a process of reconstruction and resignification of their social identity(4).

Celiac disease has substantial impacts on the psychological, family and social relationships of people, requiring a biopsychosocial view of professionals, focusing on the best therapeutic approach and quality of life. In the study (A5), there were changes in the emotional state of the interviewed patients, conflicts in family relationships and difficulties in social relationships due to the gluten-free diet. On the other hand, the support of family and friends proved to be an important facilitator, which had a significant impact on the adaptation of patients to the diagnosis, especially with regard to aspects of relationships and social adaptations, showing that greater knowledge of biopsychosocial factors can contribute to a significant improvement in the overall health and quality of life of celiac patients(4).

Research carried out with 195 Portuguese individuals (A1), showed that the state of health and quality of life of the sample of celiac patients studied seems to be better than what is verified in the general population. These results are different from what is reported in the literature, with studies that do not find such differences between people diagnosed with CD and the general population and others that report that celiac patients have a worse quality of life than the general population(11).

Regarding these impacts, a survey of 52 patients previously diagnosed with CD recruited at the Pediatric Gastroenterology Department of the Children's Hospital Emel Mehmet Tarman in Kayseri, Turkey, between January and March 2016 (A6), once again demonstrated that CD is associated some psychiatric symptoms / diagnoses and reduced quality of life. The low rate of adherence to a gluten-free diet can mean more exposure to gluten and, thus, more psychiatric symptoms / diagnoses. Another important factor is the psychosocial stress related to CD; not being able to eat out, the difficulty in finding a gluten-free diet and the inconvenience in school and social life, resulting in isolation and stigmatization. This can generate low self-esteem and constitute risk factors for psychopathologies. The statements that indicated low self-esteem in the sentence completion test in this study were: " unfortunately, I am sick ", " I wish I wasn't sick ", " I don't understand why I'm sick " and " I never forget that I'm sick"(12).

It should be noted that in the study sample a (A1), the characteristics of age and education lead to infer that it is a sample of celiac patients who are very proactive in the search for solutions that minimize the limitations imposed by the disease, notably characterized by the demand information and new food products, as well as solutions for their preparation. These skills allow them to live better with the disease, causing it to affect their quality of life to a lesser extent.

The fact that the vast majority of participants reported that, after diagnosis, the social relationship with family, friends, co-workers had not changed; that food had become healthier and even though they were satisfied that they had been diagnosed, even taking into account all the changes they had to make, are reasons that can help explain the results obtained. It is reasonable to consider that the discomfort associated with symptoms prior to diagnosis, which can take years, and the anxiety associated with not knowing the disease, make it possible for people, after diagnosis, to better control the signs and symptoms and to show better quality of life(11).

It is worth mentioning that in a survey conducted with 3 children and 2 adolescents, in a diabetes clinic at the Hospital das Clínicas of FMUSP in the city of São Paulo, through semi-structured interviews (A4), the diet appears as the focus of the participants' experience, however with different meanings. Children have difficulty following the diet, while adolescents report that social and emotional aspects are the most affected. In this context, the importance of nurses, within the multidisciplinary team, is to seek strategies in partnership with children, adolescents and their families in order to minimize the difficulties encountered mainly in managing the diet(13).

Review research (A3), which aimed to identify the therapeutic options that present the greatest advances and, therefore, has the potential to be available to celiac patients in the near future, demonstrated that until now, the gluten-free diet remains the only one effective therapy available for CD, although promising results have been obtained in several experiments. The gluten-free diet allows a complete restoration of the intestinal mucosa in most cases, but its disadvantages such as the high cost of food, the short shelf life and inferior nutritional properties have a great impact on the lives of patients(14).

Importance of the multidisciplinary team in the diagnosis and monitoring of people with Celiac Disease

Monitoring by a multidisciplinary team and periodic assessment of complications and diseases associated with CD, since childhood, regardless of age at the time of diagnosis or the duration of a gluten-free diet, are necessary measures for the life and quality of life of the celiac person which, if properly implemented, produce less financial and social impact. For this to happen, it is necessary to face the weaknesses in terms of guaranteeing the right to health and overcoming inequalities as a political and ethical commitment(15).

The importance of nurses is reinforced in the study (A4), in order to plan care, seek strategies together with patients and family to minimize the stress and suffering caused by the diet and to promote adherence to the care and treatment plan, as well as other therapeutic measures. In this study, several resources were pointed out, which can be used by nurses, as an aid in the management of care for people with CD, such as: social networks and exchange of messages, through "WhatsApp" type programs, in order to establish and strengthen bonds and, above all, be available for questions; another very effective strategy pointed out in this study were educational workshops using games and games to learn skills and techniques related to the treatment of the disease(12).

In order to guarantee the quality of life of people with CD, systematic monitoring with a multidisciplinary health team, capable of meeting different needs, is necessary. Follow-up should start from suspicion, diagnosis, and remain throughout life, through joint and engaged actions, with competent professionals, whose care must involve eating habits and the control or mitigation of consequences from a biopsychosocial and spiritual perspective. Gluten-free addict is primarily responsible for the negative impact on quality of life, as it is indispensable and can directly interfere in the individual's social structure. In this perspective, support and professional guidance are the path to social reintegration and successful adaptation to the new reality of life(2).

The professional accompaniment of the person with CD aims to make him responsible for his treatment, without frustration or feeling of rejection, thus contributing to alleviate the repercussions on the quality of life and seek the reinsertion of the family and other social bonds in the process, as a way to ensure the least possible damage to everyday life(2).

In this understanding, health professionals should be informed about the symptoms, diagnosis and treatment, the most common problems and the multiple repercussions, regardless of their role in the health care system. The intervention must prioritize health promotion, teaching and learning to the patient and family, followed by confirmation of the diagnosis of CD(15,16,2).

The treatment and acceptance of the gluten-free diet are important to avoid possible more serious manifestations, such as, for example, infertility, osteoporosis, short stature, neuropsychiatric disorders, intestinal lymphoma that are problems associated with the absence of treatment. This usually happens in the classic form of the disease, which requires more attention to the diet, but asymptomatic patients should still be aware of these types of risks. In this context, maintaining discipline and accepting a gluten-free diet requires that the patient be determined and have the support of the family, since basic and daily food has several gluten-based foods(17).

In the meantime, it is believed to be extremely important that the individual is informed about the clinical manifestations and complications arising from CD, and about what foods are allowed in the diet, following a care plan built jointly with professionals from the interdisciplinary team, trained to assist , being able to instruct people about the foods that may be included and excluded from the diet, in addition to contributing to the preparation of varied recipes and gluten-free preparations, using another nutrient as a substitute. Support from family members is considered an indispensable factor for improving results, contributing to improving the acceptance of the diagnosis. People with CD should be monitored frequently, ensuring the assessment with a focus on good nutritional status, analyzing adherence to eating habits and ensuring that the patient is in good psychosocial adaptation, thus ensuring positive results for health and quality of life(17,18,19,20,21).

IV. CONCLUSION

The data revealed that so far the gluten-free diet remains the only effective therapy available for CD, although promising results have been obtained in experiments. It is confirmed that the gluten-free diet allows a complete restoration of the intestinal mucosa in most cases, but its disadvantages such as high cost, short shelf life and inferior sensory properties have a great impact on people's lives, remaining with low perspective for changes that meet the needs of people with CD.

Evidence of strategies emerged to facilitate the management of the disease, the use of resources such as the assistance of health professionals. The results reinforce the importance of the multidisciplinary team, when planning care, seeking strategies together with the patient and family to minimize the stress and suffering caused by the diet and to promote adherence to the care plan. The identification of social support is also essential for the multidisciplinary team to be able to support, help to establish and strengthen support. It is essential to continue in the search for knowledge in the perspective that science finds other means of treatment, in addition to the restrictive diet, and the industry adapts to people's needs, promoting inclusive access, reducing the suffering and impacts generated by the disease on quality. of life. This is believed to be a significant factor in reducing frustration and isolation after the diagnosis of the disease.

The construction of the data allowed us to realize that when well oriented, people tend to assume the role of coparticipants in the care process, becoming able to overcome limits, through new possibilities of coping, maintaining healthier social relationships and reframing the pursuing higher levels of quality of life. It is necessary to highlight that the small number of publications can be considered as limitations of the study. Finally, in view of the limited number of studies found, we reinforce the need for new research on the topic, with a larger number of participants, with variable methods and that evaluates the problem from other perspectives, so that understanding about diseases and its impacts on quality of life can be expanded.

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