

The effect of self-efficacy expectations in the adherence to a gluten free diet in celiac disease

Objective: To analyse the effect of general and specific self-efficacy on the adherence to a gluten free diet (GFD) in patients with celiac disease along with the effect of other relevant variables.

Design: 271 patients with celiac disease participated in this transversal descriptive study and completed a series of questionnaires regarding adherence (CDAT), general self-efficacy (GSES) and specific self-efficacy (Celiac-SE) and CD-Qol, among others.

Main outcome measures: Dependent variable was adherence to the Gluten Free Diet (GFD). Main independent variables were general self-efficacy, specific self-efficacy and quality of life. Model tests were conducted using regression analysis.

Results: 71.9% of patients show an excellent or good adherence to the diet. Higher levels of adherence are positively associated to a high expectancy of specific self-efficacy, to the perceived adoption of recommended behaviours, risk perception and better quality of life (these variables accounted for 36.4 % of the variance in the adherence to a GFD, $p<.001$).

Conclusions: Specific self-efficacy rather than general has a predictive value in adherence to a GFD. Therefore, we need to develop and transculturally adapt new instruments to assess specific self-efficacy. Celiac-SE has proved to be a useful scale for this objective.

Keywords: celiac disease; self-efficacy; adherence to GFD; perceived life quality.

1. Introduction

Celiac disease (CD) is a chronic small intestinal immune-mediated enteropathy precipitated by exposure to dietary gluten in genetically predisposed people (Ludvigsson et al., 2013) which hinders correct nutrient absorption. CD is one of the most common chronic intestinal diseases (Fasano et al., 2003). Many studies report a prevalence of between 1:67 and 1:250, for the USA and Europe (Leffler et al., 2008), while 1% prevalence is widely accepted (Catassi et al., 2007). Although there are no studies in Spain for any sizeable populations, prevalence is estimated between 0.26% and 0.85% (Arranz & Garrote, 2011). However, the variety of related clinical symptoms which this illness can present makes it difficult to diagnose, with a ratio 1:7 of diagnosed: undiagnosed cases (Farrell & Kelly, 2001). Studies indicate a female: male ratio of 2:1 (Gujral, 2012). The only known treatment to date is to keep to a strict gluten-free diet (GFD) for life.

Hall, in a systematic review (Hall, Rubin, & Charnock, 2009) highlighted the wide range (42-91%) of GFD adherence, depending on the definition of 'strict diet' and on its method of assessment. Within these wide margins, an adherence of 87% has been reported in the UK (Ford, Howard, & Oyebode, 2012), 50.2% in Holland (van Hees, Van der Does, & Giltay, 2013) and 88% in Finland (Kurppa, 2012). With regards to Spain, Casellas reported 82.7% (Casellas, Vivancos, & Malagelada, 2006) and (Casellas et al., 2008) 73%. Even those studies using the same method, the Celiac Dietary Test (CDAT), differ in their adherence from 47.5% to 60.5% in Australia and New Zealand (Sainsbury, Halmos, Knowles, Mullan, & Tye-Din, 2018; Sainsbury, Mullan, & Sharpe, 2013a; Sainsbury & Mullan, 2011) or 75.5% in United States (Villafuerte-Galvez et al., 2015). These differences show the need to unify criteria and improve the methods of estimation to advance towards determining the variables implied in adherence to the GFD.

Within Social Cognitive Theory, self-efficacy refers to the belief in one's capability to succeed in planning and executing specific tasks (Bandura, 1997). This expectation has been widely studied in many areas such as physical activity, tobacco addiction, multiple sclerosis, or patients with arthritis (Chiu, et al., 2011; Lorig et al., 2014; Schwarzer et al., 2008). However, it is only in the last years that self-efficacy has been studied in the case of CD (Ford et al., 2012). Recent studies associated self-efficacy and control beliefs with a better adherence (Sainsbury & Mullan, 2011; Sainsbury et al., 2018, 2013a; Sainsbury, Mullan, & Sharpe, 2015). More specifically, self-regulatory efficacy (one's confidence in managing GFD) and concurrent efficacy (one's confidence in managing the life goals while strictly adhering to a GFD) have been revealed as important factors within the 'self-compassion model' (Dowd & Jung, 2017). Furthermore, self-regulatory efficacy has proved to be a predictor of accidental (Dowd et al., 2016) or intentional gluten consumption (Hall, Rubin, & Charnock, 2013). Many times, these efficacy-related constructs differ in their definition (self-regulation or control beliefs do not always match self-efficacy beliefs) and on their methods of assessment (frequently appraised through questions designed ad hoc but not by validated questionnaires).

Although self-efficacy was initially described as a specific construct (Bandura, 1977), in more recent years some attempts have been made to address this belief in a general way (Luszczynska, Gutiérrez-Doña, & Schwarzer, 2005; Luszczynska, Scholz, & Schwarzer, 2005). In this context, general self-efficacy is defined as individual perception of his/her ability to perform successfully across a variety of different demands and circumstances (Judge, Erez, & Bono, 1998). This general approach has raised some criticism (Bandura, 2006) mainly related to its limited explanatory and predictive value as the items are written in a general way which may seem irrelevant for the patient. However, researchers have begun to face this criticism by the development of more

rigorous psychometric studies (Scherbaum, Cohen-Charash, & Kern, 2006; Scholz et al. 2002). These and other studies have increased the soundness of this construct and make worth the effort of taking into consideration general self-efficacy in research.

As it is easier to use general self-efficacy instruments than to develop new instruments ad hoc, it is often general rather than specific self-efficacy that it is assessed, ignoring the fact that patients can have a high general self-efficacy expectation when dealing with their lives in general, but lack confidence when dealing with their GFD. Additionally, being so short, these instruments often leave out some important aspects in dealing with GFD, hindering intervention, as self-efficacy is very much influenced by situational conditions. Moreover, a patient can have strong self-efficacy beliefs while managing his or her GFD at home or when shopping, but they might be much lower when traveling. All this emphasizes, again, the need to assess self-efficacy in a specific way. Despite this undoubted advantage of using general self-efficacy instruments, we still believe that specific self-efficacy, rather than general self-efficacy, plays an important role in managing GFD. Therefore, it is necessary the development of specific self-efficacy instruments for patients with CD that take into consideration the situational circumstances of adhering to GFD.

In this sense, qualitative research shows that patients with CD have to cope with problems mainly in five areas when dealing with their GFD (Sverker, Hensing, & Hallert, 2005). These are: eating in the workplace, shopping, traveling, eating out and eating at home with others. These hardships can lead to negative feelings and affect relationships, which means that patients with low self-efficacy may find eating and drinking situations potentially stressful. Hence, some of them are not able to keep to their GFD under such circumstances or, if they are able to, they show a worse quality of life (Leffler et al., 2008). As self-efficacy is much more affected by the situation, we believe that an

assessment of specific self-efficacy in CD should consider these areas.

In this context, the aim of this study was to investigate the role of general and specific self-efficacy and their relationship with other psychosocial variables that can affect adherence to a GFD in patients with CD. Namely, quality of life, perceived adherence to recommended behaviours, risk perception, intensity of symptomatology, perceived consequences of abandoning the diet, age, age at diagnosis, and time since diagnosis. More specifically, it was hypothesized that both general and specific self-efficacy would play an important role in adhering to a GFD and that specific self-efficacy would be a better predictor of adherence than general self-efficacy. Finally, we expected to find differences in specific self-efficacy and adherence to GFD in those patients who have been dealing with a firm diagnosis for a longer period.

2. Materials and Methods

The study population was made up of individuals with CD from the only patients' association in the region of Aragon (Spain). The inclusion criteria were to be 18 years or over, to have a firm diagnosis of CD and to have been prescribed a strict GFD for life. These criteria were established by responding affirmatively to three self-reported questions.

A test battery was designed to analyse the relationship between adherence to a GFD, self-efficacy expectation, quality of life, the perceived adoption of recommended behaviours and risk perception in patients with CD, along with other sociodemographic variables. The questionnaires were distributed online and on paper to 1,882 members of the main patients' association in the region. After receiving written information about the study, the patients completed an informed consent document. The SPSS v.21 program was used for the statistical analysis. Descriptive analysis was conducted and t- Student

and Chi squared tests were calculated in order to examine the differences in adherence to a GFD. Various linear regression analyses were performed to analyse GFD adherence. Statistically significant differences were set at $p < 0.05$.

This research was approved by the Ethics Committee of Research of Aragon (CEICA) registered under number PI 14/0011.

2.1 Adherence to a GFD

GFD adherence was estimated through the CDAT questionnaire (D. Leffler et al., 2009). The questionnaire is made up of seven questions. It is easy to apply and has good psychometric properties. According to the author's studies, it also offers the advantage of correlating with serological and histological variables, as well as with interviews with dieticians. The questionnaire was translated into Spanish for the purposes of this study and this version again presents good psychometric properties (Fueyo et al., 2016). Patients are asked to answer the seven items on a 5-point Likert scale. Scores are additive (7-35), with higher scores indicating lower adherence. Following the author's recommendations, scores below 13 are deemed to represent excellent or very good adherence, 13-17 moderate adherence, whereas scores greater than 17 show fair to poor adherence (Leffler et al., 2009).

2.2 General and specific self-efficacy

General self-efficacy was evaluated using a Spanish adaptation of the GSE scale (Baessler & Schwarzer, 1996). The scale comprises ten questions in which the patient is asked to answer items of the type, "I can solve difficult problems if I make enough effort" on a 4-point Likert scale (not at all true, hardly true, moderately true, exactly true). Scores are accumulative and range between 10 and 40, with higher scores indicating greater self-

efficacy.

Specific self-efficacy was evaluated using the Celiac-SE scale, which was developed and validated as part of this research (Fueyo-Díaz et al., 2018) to measure the degree of adherence to a GFD in patients aged 12 years and over in different situations, such as shopping, eating at home with others, traveling, eating out or eating in the workplace or at school. A 20-question scale was used in which patients rated items from 0 (I could definitely not do this) to 10 (I am completely certain I could do this). The questionnaire gives a mean overall score for the whole scale and for each of the areas explored. Scores above seven are indicative of high specific self-efficacy. The Cronbach's alpha for the scale was 0.81 and between 0.64 and 0.91 for each factor.

2.3 Quality of life

Quality of life of patients with CD was evaluated using the Celiac Disease Quality of life (CD-QoL) survey (Dorn et al., 2010) in its adapted Spanish version (Casellas et al., 2013a). This questionnaire contains 20 questions that are answered on a 5-point Likert type scale. Scores are additive from 10 to 100 points, with higher scores reflecting a higher quality of life. Scores of 70 and above are considered to be indicative of a high quality of life (Casellas et al., 2013b). The questions are grouped into four sections: limitations, dysphoria, health problems and inappropriate treatment.

2.4 Risk perception, perceived adoption of recommended behaviours, time since diagnosis and others

Simultaneously, we evaluated risk perception and perceived adherence to behaviours recommended by patient associations (FACE, 2015). Fifteen questions were scored from zero to 10 according to the risk perceived and from zero to 10 depending on whether the

recommended behaviour was adopted or not. Scores were additive for each category with higher scores indicating a more perceived serious risk and a closer perceived adherence to recommended behaviours. Examples of these items were: 'I consider being a risk consuming processed products without a gluten free label', 'consuming products without checking the label' or 'not eliminating bulk products from diet'. The same item was evaluated as a risk (not risky- very risky) and as an adopted behaviour (I avoid this behaviour- I do not avoid this behaviour. Other issues studied include experience with the disease (time since diagnosis), and self-reported questions about perceived consequences for abandoning the diet or transgressing (1: No consequences - 5: very severe consequences) or the presence of digestive or non-digestive symptoms before diagnosis or associated diseases.

2.5 Socio-demographic variables

Finally, we incorporated a series of socio-demographic variables related to age, residence, gender, nationality, marital status, work situation and education.

3. Results

Three hundred and thirty-nine questionnaires (18.01%) were collected, of which 271 corresponded to patients with CD, 22 were gluten sensitive and 46 others did not fulfil the age requirements or were uncompleted.

3.1 Description of the sample

Of the 271 patients with CD (15.6% male; 84.4% female), 89.3% declared that they belonged to a patients' association and 10.7% did not. Ages ranged from 18 to 72 years ($M = 40.15$; $SD = 11.92$). Most of the participants had several years of experience with the disease ($M = 7.61$; $SD = 8.39$). Main characteristics of the sample are shown in table

1 while main results related to psychosocial factors are shown in table 2.

<Insert table 1>

3.2 Data analysis

We compared high and moderate/low adherence groups for the following variables: general self-efficacy (GSES), specific self-efficacy (Celiac-SE), quality of life (CD-QoL), recommended behaviours, risks, intensity of symptoms, consequences of abandoning, age, age at diagnosis, time since diagnosis and gender. The variables included in the linear regression were those significant from the univariate analysis. Risk perception was included although it was not significant due to the relationship it has with self-efficacy beliefs. We use a linear regression analysis to study the role of these variables in adherence to a GFD.

<Insert table 2>

3.3 Adherence to GFD

The results of the CDAT showed very good adherence ($M = 11.56$, $SD = 2.99$). 71.9% showed excellent or good adherence to the diet, with scores below 13, while 4.5% declared poor adherence, with scores above 17. Table 3 shows differences between the high adherence group (individuals with excellent or very good adherence, with score < 13) and the moderate/low adherence group (individuals with moderate, poor and fair adherence, with scores ≥ 13) with any of the psychological factors studied. No differences were found for gender or age.

<Insert table 3>

3.4 Self-efficacy

Participants showed a high general self-efficacy ($M = 31.19$; $SD = 5.31$) and we found differences between the high and moderate/low adherence groups ($p = .021$). Regarding specific self-efficacy, we found differences between the high and moderate/low adherence groups, showing those participants with better adherence to a GFD to have a higher specific self-efficacy expectation ($p < 0.001$). Generally, individuals showed high specific self-efficacy when dealing with their GFD for the total score ($M = 8.60$; $SD = 1.66$). In a more detailed analysis by areas (Table 2), we found the lowest specific self-efficacy for traveling (8.06), followed by eating out (8.48), shopping (8.49), and at work or school (8.58). Eating at home with others showed the highest self-efficacy (9.21). We found differences $p < .001$ between all of them except for shopping and eating out ($p = 0.981$), shopping and eating at work ($p = 0.279$) and eating out and at work ($p = 0.213$). We also found differences for each of these areas between high and moderate/low adherence groups (Table 4). No differences were found in either variable for gender. 12.2% show a specific self-efficacy score for shopping of 7 or below, 23% for traveling, 8.7% for eating with others at home, 17.5% for eating outside with others and 18.3% for adhering to a GFD at work.

<Insert table 4>

3.5 Quality of life

The results in CD-QoL showed a good quality of life ($M = 75.88$, $SD = 15.16$). 30.8% of patients scored below a direct score of 70. The dimensions most affected were inadequate treatment ($M = 6.90$) and health concerns ($M = 17.14$). Significant differences were found between the high and moderate/low adherence groups for the whole scale ($p < 0.001$), with those participants with a better adherence to a GFD perceiving themselves to have a

better quality of life. No differences were found for gender.

3.6 Intensity of symptoms and risk perception.

High and moderate/low adherence groups showed no differences in terms of the consequences of abandoning the diet ($p = .079$) and in relation to risk evaluation ($p = .074$) of following or not following the recommended behaviours. However, it seems clear that patients who perceive themselves to follow the recommended behaviours have a better adherence to GFD in the CDAT ($p < .001$).

3.7 Age at diagnosis and time since diagnosis

Age at diagnosis and time since diagnosis do not appear to have an important role in the degree of GFD adherence.

3.8 Relationship between the variables and GFD

Table 5 shows the results of a linear regression to determine the impact of changes in the independent variables on the adherence to a GFD. After studying the main variables, we only show those that have very clear effects: specific self-efficacy in coping with the disease, perceived adoption of recommendations of the patients' associations and quality of life, all of which are significant. We include risk perception due to the importance that risks play in self-efficacy beliefs. The model with these four variables accounted for 36.4 % of the variance in the adherence to a GFD. As far as semi-partial correlations are concerned, recommended behaviours accounts for 15.3 %, quality of life accounts for 6.7%, risk perception accounts for 3.7% whereas specific self-efficacy accounts for 1.8%. This means that the higher the specific self-efficacy beliefs, the better the quality of life, the higher risk perception and the stronger the perceived compliance with the recommended behaviours, the better the adherence to a GFD.

<Insert table 5>

The correlation matrix shows that adherence to GFD correlates with specific self-efficacy, risk perception, quality of life and the perceived adoption of recommended behaviours, all of them significant ($p < .01$). We observe a high correlation (0.630) between following the recommendations for a GFD and risk perception. It seems logical that those who perceive a more important risk in not adopting a preventive behaviour are those who believe that they adopt that recommended behaviour.

The relationship between specific self-efficacy and risk perception is high (.545) and significant (Cohen, 1988), showing that the higher perceived risk the higher self-efficacy. There is also a correlation between quality of life and specific self-efficacy ($p = .000$) showing that those with a higher specific self-efficacy have a better quality of life. There is a significant ($p < .01$) correlation between specific self-efficacy and the perceived adoption of recommended behaviours (0.361). Finally, the matrix shows no relationship between quality of life and risk perception or the perceived adoption of the recommended behaviours. The full correlation matrix has been added in text as table 6 (dependent variable has been also included in correlation table).

We observe a significant correlation between the studied variables and adherence: the perception of following the recommended behaviours correlates with a better adherence (-.469), a better quality of life is related to a better adherence (-.387) and, a specific self-efficacy correlates with a higher adherence (-.318). Finally, regarding risk perception this correlation is low but significant (-.191).

<Insert table 6>

Age, age when diagnosed, time since diagnosis, intensity of symptoms or the belief in serious consequences of abandoning the GFD were not predictive to adherence.

4. Discussion

This research shows that elements such as self-efficacy, perceived quality of life, risk perception and the perceived adoption of recommended behaviours play an important role in adhering to GFD in patients with CD. Moreover, it is self-efficacy assessed in a specific way, rather than in a general one, which is important for predicting this adherence.

4.1 Adherence to GFD

Adherence to a GFD was high in the research, with 71.9% showing excellent or good adherence according to the criteria of Leffler (Leffler et al., 2009) and within the range of the systematic review made by Hall (N J Hall et al., 2009). The frequent high adherence found in research may be because in most cases the questions are self-informed with no physiological correlates. Furthermore, many studies are carried out through associations of patients which are made up precisely of better prepared people who are also more motivated to observe the diet (Butterworth, 2004; Hall et al., 2009; Leffler et al., 2008). In our study, this adherence to GFD is related to specific self-efficacy, quality of life, risk perception and the perceived adoption of recommendable behaviours.

We must note that general self-efficacy was significant in the univariate analysis and not in the regression analysis. According to the original definition of self-efficacy expectation (Bandura, 1997), self-efficacy has to be measured in a specific way taking into account the situation (Bandura, 2006). This fact may explain why a general measure does not predict the adherence. Perceived risks are included in the model as they play a role through self-efficacy expectations. According to Social Cognitive Theory, patients

with high self-efficacy expectations see risks as a challenges, whereas patients with lower self-efficacy expectations see them as a potential threat (Bandura, 1997), hindering their adherence and, hence, their quality of life. In contrast to other studies (Ford et al., 2012; Kurppa et al., 2012), no relationship is found with age, age when diagnosed, time since diagnosis or gender.

The definition of strict adherence and the way GFD adherence is measured varies from some studies to others (Hall et al., 2013). The difficulty of finding sensitive, specific methods has led researchers to use self-informed questions, rather than to establish objective criteria to assess adherence to a GFD. These subjective methods may be moderated by the patients' correct or erroneous knowledge of the disease and by their appropriate or inappropriate assessment of the risks. On the other hand, although it seems obvious that any tool that is developed will need to present some correlates between adherence and the objective state of health, histological and serological measures are expensive and invasive and lack sensitivity in detecting occasional transgressions from the diet (Leffler et al., 2007). Dietetic evaluations (Leffler et al., 2007; Ludvigsson et al., 2014) and immunogenic peptides (Comino et al., 2012; Moreno et al., 2017) have proved to be effective in the celiac disease follow-up. Therefore, it is necessary to develop, validate and transculturally adapt new instruments that base evaluation of adherence on patients' knowledge, expectations, risk behaviours and state of health in order to measure adherence effectively. These methods should also be properly correlated with physiological variables of adherence.

4.2 Self-efficacy

General and specific levels of self-efficacy are high in the sample with no gender differences. Indeed, the general self-efficacy levels are significantly high compared to

those published in previous studies (Scholz et al., 2002). This would support the idea put forward by other authors (Bellini et al., 2011) that patients with CD may develop a more internal locus of control than occurs in other chronic illnesses, since in CD control lies more in the hands of the patient than in those of the doctor. In other words, adherence to their treatment demands greater responsibility in the management of their disease from patients with CD than it does in other chronic diseases where doctors lead their treatment. We believe that this fact instils stronger self-efficacy beliefs in patients with CD, not only specific but also general ones. According to the results here, the expectation of specific self-efficacy plays an important role in adherence to the GFD, while general self-efficacy is not so important. This fact reinforces the arguments in favour of an evaluation of specific self-efficacy in contrast to a general one as a better predictor of future behaviour (Bandura, 1997) and more useful to design new programs to improve adherence. Regarding health behaviour, previous research on self-efficacy often assessed control beliefs in a general way (Luszczynska, Gutiérrez-Doña, et al., 2005; Luszczynska, Scholz, et al., 2005; Schwarzer et al., 2008). Concerning GFD adherence, when self-efficacy is assessed in a specific way, studies differ in its definition and method of assessment (Dowd et al., 2016; Lorig et al., 2014; Sainsbury et al., 2018; Sainsbury & Mullan, 2011) which frequently leaves out the influence of situation. We found differences not only between high and moderate/low adherence groups, but also among the different areas assessed by Celiac-SE. Therefore, it is necessary to develop new instruments to assess specific self-efficacy for different domains of life, and more specifically in dealing with GFD. Celiac-SE has proved to be a useful instrument in this context and we believe it can be very useful in clinical settings where it can help to identify patients with low self-efficacy for certain domains of GFD. Using Social Cognitive Theory as a framework for the design of interventions will allow us to increase

specific self-efficacy through well-known sources such as previous accomplishments, modelling, verbal persuasion or the self-evaluation of physiological and affective states (Bandura, 1997) increasing its operational power to increase adherence to GFD.

Finally, although we expected variables related to time, such as age, age when diagnosed, years since diagnosis, to have played a major role in developing specific self-efficacy and hence, adherence to GFD, we found no relationship. This could be explained, within the framework of Social Cognitive Theory, as it is positive experiences in coping with the disease that are responsible for the development of specific self-efficacy and not the mere passage of time.

4.3 Quality of life

The results from the CD-QoL indicate a good quality of life in patients with CD, with the issues that are most affected being health problems and the perception of unsuitable treatment, as found in other studies (Casellas et al., 2013b). Nevertheless, we need to note that an important number of individuals (30.8%) are below the recommended cut-off point of 70 which shows good quality of life (Casellas et al., 2013b).

According to the linear analyses, quality of life is a predictor of adherence to GFD. Moreover, quality of life may affect adherence at the same time, because it seems logical that people who adhere to a GFD, with disappearance of symptoms, improve their quality of life. On the other hand, when quality of life gets worse they are prone to abandon the diet. The alterations in both mood and quality of life may lead to a GFD abandonment. That is why we think that quality of life may play an important role in adherence to a GFD as depressive symptoms and other psychiatric conditions may affect adherence and vice versa (Sainsbury, Mullan, & Sharpe, 2013b; Sainsbury et al., 2013a; van Hees et al., 2013; Zarkadas et al., 2013).

This study has several limitations: firstly, participants were recruited through a patients' association which might affect their knowledge or awareness of the disease and their adherence to a GFD. Secondly, although in order to become a member, they are interviewed by an expert dietitian, they were included in the sample after responding affirmatively to the questions related to having a firm CD diagnosis and being prescribed a GFD for life. Therefore, CD was not confirmed with concurrent histological evaluation. Finally, being a long and online survey may have affected the number of completely answered questionnaires that were returned.

Future research should focus on distinguishing specific self-efficacy expectations at different moments in adhering to a GFD. New instruments should be developed, for example, to differentiate among action, maintenance and recovery self-efficacy (Schwarzer, Lippke, & Luszczynska, 2011) as useful constructs to ensure a lifelong adherence. Additionally, it will be interesting to study the impact of these psychosocial variables on quality of life in the future. The Social Cognitive Theory offers a theoretical framework for research and to develop programs to improve adherence and quality of life of chronic patients in clinical settings (Lorig et al., 1999; Lorig, 1993, 1996). These programs can be adapted to patients with CD and can, moreover, constitute an important saving when they are addressed as a part of primary health care (Ahn et al., 2013; Bodenheimer, Lorig, Holman, & Grumbach, 2002).

5. Conclusions

Specific self-efficacy expectation, quality of life, risk perception and the perceived adoption of the behaviours recommended by patients' associations play an important role in adherence to GFD and these factors need to be addressed in clinical settings to improve adherence. Specific self-efficacy rather than general self-efficacy has a predictive value

in adherence to a GFD. Therefore, we need to develop and transculturally adapt new instruments to assess specific self-efficacy. Celiac-SE has proved to be a useful questionnaire for this objective. Identifying the factors behind high adherence to a GFD will enable the design of programs to improve adherence and, subsequently, quality of life in patients with CD.

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References

- Ahn, S., Basu, R., Smith, M. L., Jiang, L., Lorig, K., Whitelaw, N., & Ory, M. G. (2013). The impact of chronic disease self-management programs: Healthcare savings through a community-based intervention. *BMC Public Health*, 13(1), 1141.
- Arranz, E., & Garrote, J. A. (2011). *Enfermedad celíaca: Introducción al conocimiento actual de la enfermedad celíaca*. Majadahonda, Madrid: Ediciones Ergon.
- Baessler, J., & Schwarzer, R. (1996). Evaluación de la autoeficacia: Adaptación española de la Escala de Autoeficacia general. *Ansiedad y Estrés*, 2(1), 1–8.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84(2), 191–215.
- Bandura, A. (2006). Guide for constructing self-efficacy scales. In T. Urdan & F. Pajares (Eds.), *Self-Efficacy Beliefs of Adolescents*. Greenwich, Conn: Information Age Publishing.
- Bandura, Albert. (1997). *Self Efficacy: The Exercise of Control*. New York: Worth Publishers.
- Bellini, A., Zanchi, C., Martelossi, S., Leo, G. di, Not, T., & Ventura, A. (2011). Compliance with the gluten-free diet: The role of locus of control in celiac disease. *Journal of Pediatrics*, 158(3), 463–466.
- Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient Self-management of Chronic Disease in Primary Care. *JAMA: Journal of the American Medical Association*, 288(19), 2469. <https://doi.org/10.1001/jama.288.19.2469>
- Butterworth, J. (2004). Factors relating to compliance with a gluten-free diet in patients with coeliac disease: Comparison of white Caucasian and South Asian patients. *Clinical Nutrition*, 23(5), 1127–1134. <https://doi.org/10.1016/j.clnu.2004.02.009>
- Casellas, F., Rodrigo, L., Vivancos, J. L., Riestra, S., Pantiga, C., Baudet, J. S., ... Malagelada, J. R. (2008). Factors that impact health-related quality of life in adults with celiac disease: A multicenter study. *World Journal of Gastroenterology*, 14(1), 46.
- Casellas, F., Vivancos, J. L., & Malagelada, J. R. (2006). Current epidemiology and accessibility to diet compliance in adult celiac disease. *Revista Espanola De*

Enfermedades Digestivas, 98(6), 408.

- Casellas, Francesc, Rodrigo, L., Molina-Infante, J., Vivas, S., Lucendo, A. J., Rosinach, M., ... López-Vivancos, J. (2013a). Adaptación transcultural y validación del "Celiac Disease Quality of Life (CD-QOL) survey", un cuestionario específico de medida de la calidad de vida en pacientes con enfermedad celiaca. *Revista Española de Enfermedades Digestivas*, 105(10), 585–593.
- Casellas, Francesc, Rodrigo, L., Molina-Infante, J., Vivas, S., Lucendo, A. J., Rosinach, M., ... López-Vivancos, J. (2013b). 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. *Rev Esp Enferm Dig*, 105, 585–93.
- Catassi, C., Fabiani, E., Iacono, G., D'Agate, C., Francavilla, R., Biagi, F., ... Fasano, A. (2007). A prospective, double-blind, placebo-controlled trial to establish a safe gluten threshold for patients with celiac disease. *The American Journal of Clinical Nutrition*, 85(1), 160–166.
- Chiu, C.-Y., Lynch, R. T., Chan, F., & Berven, N. L. (2011). The Health Action Process Approach as a motivational model for physical activity self-management for people with multiple sclerosis: A path analysis. *Rehabilitation Psychology*, 56(3), 171–181. <https://doi.org/10.1037/a0024583>
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Lawrence Erlbaum Associates. (B. Econ. y Empr. Paraiso-Análisis Económico AEC 141-347).
- Comino, I., Real, A., Vivas, S., Síglez, M. Á., Caminero, A., Nistal, E., ... Sousa, C. (2012). Monitoring of gluten-free diet compliance in celiac patients by assessment of gliadin 33-mer equivalent epitopes in feces. *The American Journal Of Clinical Nutrition*, 95(3), 670–677. <https://doi.org/10.3945/ajcn.111.026708>
- Dorn, S. D., Hernandez, L., Minaya, M. T., Morris, C. B., Hu, Y., Leserman, J., ... Drossman, D. A. (2010). The development and validation of a new coeliac disease quality of life survey (CD-QOL). *Alimentary Pharmacology & Therapeutics*, 31(6), 666–675. <https://doi.org/10.1111/j.1365-2036.2009.04220.x>
- Dowd, A. J., Jung, M. E., Chen, M. Y., & Beauchamp, M. R. (2016). Prediction of

- adherence to a gluten-free diet using protection motivation theory among adults with coeliac disease. *Journal of Human Nutrition and Dietetics*, 29(3), 391–398. <https://doi.org/10.1111/jhn.12321>
- Dowd, A. Justine, & Jung, M. E. (2017). Self-compassion directly and indirectly predicts dietary adherence and quality of life among adults with celiac disease. *Appetite*, 113, 293–300. <https://doi.org/10.1016/j.appet.2017.02.023>
- FACE-Federación de Asociaciones de Celíacos de España. (2015). *Lista de Alimentos aptos para celíacos, 2014-2015*. Madrid.
- Farrell, R., & Kelly, C. (2001). Diagnosis of celiac sprue. *American Journal of Gastroenterology*, 96(12), 3237–3246. [https://doi.org/10.1016/s0016-5085\(98\)70383-x](https://doi.org/10.1016/s0016-5085(98)70383-x)
- Fasano, A., Drago, S., Thorpe, M., Kryszak, D., Fornaroli, F., Horvath, K., ... Murray, J. a. (11). (2003). Prevalence of Celiac disease in at-risk and not-at-risk groups in the United States: A large multicenter study. *Archives of Internal Medicine*, 163(3), 286–292. <https://doi.org/10.1001/archinte.163.3.286>
- Ford, S., Howard, R., & Oyebode, J. (2012). Psychosocial aspects of coeliac disease: A cross-sectional survey of a UK population. *British Journal Of Health Psychology*, 17(4), 743–757. <https://doi.org/10.1111/j.2044-8287.2012.02069.x>
- Fueyo Díaz, R., Gascón Santos, S., Asensio Martínez, Á., Sánchez Calavera, M. A., & Magallón Botaya, R. (2016). Transcultural adaptation and validation of the Celiac Dietary Adherence Test. A simple questionnaire to measure adherence to a gluten-free diet. *Revista Española De Enfermedades Digestivas: Organo Oficial De La Sociedad Española De Patología Digestiva*, 108(3), 138–144. <https://doi.org/10.17235/reed.2016.4033/2015>
- Fueyo-Díaz, R., Magallón-Botaya, R., Gascón-Santos, S., Asensio-Martínez, Á., Palacios-Navarro, G., & Sebastián-Domingo, J. J. (2018). Development and Validation of a Specific Self-Efficacy Scale in Adherence to a Gluten-Free Diet. *Frontiers in Psychology*, 9. <https://doi.org/10.3389/fpsyg.2018.00342>
- Gujral, N. (2012). Celiac disease: Prevalence, diagnosis, pathogenesis and treatment. *World Journal of Gastroenterology*, 18(42), 6036. <https://doi.org/10.3748/wjg.v18.i42.6036>

- Hall, N J, Rubin, G., & Charnock, A. (2009). Systematic review: Adherence to a gluten-free diet in adult patients with coeliac disease. *Alimentary Pharmacology & Therapeutics*, 30(4), 315–330. <https://doi.org/10.1111/j.1365-2036.2009.04053.x>
- Hall, Nicola J., Rubin, G. P., & Charnock, A. (2013). Intentional and inadvertent non-adherence in adult coeliac disease. A cross-sectional survey. *Appetite*, 68, 56–62. <https://doi.org/10.1016/j.appet.2013.04.016>
- Judge, T. A., Erez, A., & Bono, J. E. (1998). The Power of Being Positive: The Relation Between Positive Self-Concept and Job Performance. *HUMAN PERFORMANCE*, (2/3), 167.
- Kurppa, K. (2012). Endomysial antibodies predict celiac disease irrespective of the titers or clinical presentation. *World Journal of Gastroenterology*, 18(20), 2511. <https://doi.org/10.3748/wjg.v18.i20.2511>
- Kurppa, K., Lauronen, O., Collin, P., Ukkola, A., Laurila, K., Huhtala, H., ... Kaukinen, K. (2012). Factors Associated with Dietary Adherence in Celiac Disease: A Nationwide Study. *Digestion*, 86(4), 309–314. <https://doi.org/10.1159/000341416>
- Leffler, D. A., Edwards George, J. B., Dennis, M., Cook, E. F., Schuppan, D., & Kelly, C. P. (2007). A prospective comparative study of five measures of gluten-free diet adherence in adults with coeliac disease: Measures of gluten-free diet adherence. *Alimentary Pharmacology & Therapeutics*, 26(9), 1227–1235. <https://doi.org/10.1111/j.1365-2036.2007.03501.x>
- Leffler, D. A., Edwards-George, J., Dennis, M., Schuppan, D., Cook, F., Franko, D. L., ... Kelly, C. P. (2008). Factors that influence adherence to a gluten-free diet in adults with celiac disease. *Digestive Diseases and Sciences*, 53(6), 1573–1581. <https://doi.org/10.1007/s10620-007-0055-3>
- Leffler, D., Dennis, M., Edwards George, J. B., Jamma, S., Magge, S., Cook, E. F., ... Kelly, C. P. (2009). A Simple Validated Gluten-Free Diet Adherence Survey for Adults With Celiac Disease. *Clinical Gastroenterology and Hepatology*, 7(5), 530-536.e2. <https://doi.org/10.1016/j.cgh.2008.12.032>
- Lorig, K., Laurent, D. D., Plant, K., Krishnan, E., & Ritter, P. L. (2014). The components of action planning and their associations with behavior and health outcomes. *Chronic Illness*, 10(1), 50–59. <https://doi.org/10.1177/1742395313495572>

- Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown Jr, B. W., Bandura, A., Ritter, P., ... Holman, H. R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Medical Care*, 37(1), 5–14.
- Lorig, Kate. (1993). Self-management of chronic illness: A model for the future. *Generations*, 17(3), 11.
- Lorig, Kate. (1996). Chronic disease self-management. *American Behavioral Scientist*, 39(6), 676.
- Ludvigsson, J. F., Bai, J. C., Biagi, F., Card, T. R., Ciacci, C., Ciclitira, P. J., ... Sanders, D. S. (2014). Diagnosis and management of adult coeliac disease: Guidelines from the British Society of Gastroenterology. *Gut*, 63(8), 1210–1228. <https://doi.org/10.1136/gutjnl-2013-306578>
- Ludvigsson, J. F., Leffler, D. A., Bai, J. C., Biagi, F., Fasano, A., Green, P. H. R., ... Ciacci, C. (2013). The Oslo definitions for coeliac disease and related terms. *Gut*, 62(1), 43–52. <https://doi.org/10.1136/gutjnl-2011-301346>
- Luszczynska, A., Gutiérrez-Doña, B., & Schwarzer, R. (2005). General self-efficacy in various domains of human functioning: Evidence from five countries. *International Journal of Psychology*, 40(2), 80–89. <https://doi.org/10.1080/00207590444000041>
- Luszczynska, A., Scholz, U., & Schwarzer, R. (2005). The General Self-Efficacy Scale: Multicultural Validation Studies. *Journal of Psychology*, 139(5), 439–457.
- Moreno, M. de L., Cebolla, Á., Muñoz-Suano, A., Carrillo-Carrion, C., Comino, I., Pizarro, Á., ... Sousa, C. (2017). Detection of gluten immunogenic peptides in the urine of patients with coeliac disease reveals transgressions in the gluten-free diet and incomplete mucosal healing. *Gut*, 66(2), 250–257. <https://doi.org/10.1136/gutjnl-2015-310148>
- Sainsbury, K., Halmos, E. P., Knowles, S., Mullan, B., & Tye-Din, J. A. (2018). Maintenance of a gluten free diet in coeliac disease: The roles of self-regulation, habit, psychological resources, motivation, support, and goal priority. *Appetite*, 125, 356–366. <https://doi.org/10.1016/j.appet.2018.02.023>
- Sainsbury, K., & Mullan, B. (2011). Measuring beliefs about gluten free diet adherence

- in adult coeliac disease using the theory of planned behaviour. *Appetite*, 56(2), 476–483. <https://doi.org/10.1016/j.appet.2011.01.026>
- Sainsbury, K., Mullan, B., & Sharpe, L. (2013a). Gluten free diet adherence in coeliac disease. The role of psychological symptoms in bridging the intention–behaviour gap. *Appetite*, 61, 52–58. <https://doi.org/10.1016/j.appet.2012.11.001>
- Sainsbury, K., Mullan, B., & Sharpe, L. (2013b). Reduced quality of life in coeliac disease is more strongly associated with depression than gastrointestinal symptoms. *Journal of Psychosomatic Research*, 75(2), 135–141. <https://doi.org/10.1016/j.jpsychores.2013.05.011>
- Sainsbury, K., Mullan, B., & Sharpe, L. (2015). Predicting intention and behaviour following participation in a theory-based intervention to improve gluten free diet adherence in coeliac disease. *Psychology & Health*, 30(9), 1063–1074.
- Scherbaum, C. A., Cohen-Charash, Y., & Kern, M. J. (2006). Measuring General Self-Efficacy: A Comparison of Three Measures Using Item Response Theory. *Educational and Psychological Measurement*, 66(6), 1047–1063. <https://doi.org/10.1177/0013164406288171>
- Scholz, U., Gutiérrez Doña, B., Sud, S., & Schwarzer, R. (2002). Is General Self-Efficacy a Universal Construct? *European Journal of Psychological Assessment*, 18(3), 242–251. <https://doi.org/10.1027//1015-5759.18.3.242>
- Schwarzer, R., Lippke, S., & Luszczynska, A. (2011). Mechanisms of health behavior change in persons with chronic illness or disability: The Health Action Process Approach (HAPA). *Rehabilitation Psychology*, 56(3), 161–170. <https://doi.org/10.1037/a0024509>
- Schwarzer, R., Luszczynska, A., Ziegelmann, J. P., Scholz, U., & Lippke, S. (2008). Social-cognitive predictors of physical exercise adherence: Three longitudinal studies in rehabilitation. *Health Psychology*, 27(1, Suppl), S54–S63. [https://doi.org/10.1037/0278-6133.27.1\(Suppl.\).S54](https://doi.org/10.1037/0278-6133.27.1(Suppl.).S54)
- Sverker, A., Hensing, G., & Hallert, C. (2005). ‘Controlled by food’—lived experiences of coeliac disease. *Journal of Human Nutrition and Dietetics*, 18(3), 171–180. <https://doi.org/10.1111/j.1365-277X.2005.00591.x>
- van Hees, N. J. M., Van der Does, W., & Giltay, E. J. (2013). Coeliac disease, diet

adherence and depressive symptoms. *Journal of Psychosomatic Research*, 74(2), 155–160. <https://doi.org/10.1016/j.jpsychores.2012.11.007>

Villafuerte-Galvez, J., Vanga, R. R., Dennis, M., Hansen, J., Leffler, D. A., Kelly, C. P., & Mukherjee, R. (2015). Factors governing long-term adherence to a gluten-free diet in adult patients with coeliac disease. *Alimentary Pharmacology & Therapeutics*, 42(6), 753.

Zarkadas, M., Dubois, S., MacIsaac, K., Cantin, I., Rashid, M., Roberts, K. C., ... Pulido, O. M. (2013). Living with coeliac disease and a gluten-free diet: A Canadian perspective. *Journal Of Human Nutrition And Dietetics: The Official Journal Of The British Dietetic Association*, 26(1), 10–23. <https://doi.org/10.1111/j.1365-277X.2012.01288.x>

Table 1. Sample characteristics

	N=271
Mean age ± standard deviation (years)	40.15 ± 11.92
Gender (% female)	84.4
Mean age at diagnosis ± standard deviation (years)	31.52 ± 14.09
Mean time since diagnosis ± standard deviation (years)	7.61 ± 8.39
Associated to a support group (%)	89.3
Nationality (% Spanish)	99.3
Civil status (% married/single/divorced/other)	72.7/22.9/3.40/1
Self-reported gluten-free diet adherence (% strict)	95.1
Intensity of symptoms after transgressions (%none/mild/moderate /intense/very intense)	19.8/23.6/23.6/2 2.9/10.1
Associated diseases (%)	42.8
Education (% primary/secondary/university/other)	5.6/28.4/63.5/2.5
Years with symptoms before diagnosis (% 0/<1/1-5/>5)	7/17/19.6/0.7/45
Presence of digestive symptoms before diagnosis (%)	74.5
Presence of non-digestive symptoms before diagnosis (%)	61.3

Table 2. Psychosocial factors studied

	N	Minimum	Maximum	Mean	SD
Adherence to GFD	263	7	2	11.56	2.99
General self-efficacy	261	13	40	31.19	5.31
Specific self-efficacy	239	1.66	10	8.60	1.66
Shopping	263	2.50	10	8.49	1.68
Traveling	265	0	10	8.06	2.27
Eating at home with others	258	0	10	9.21	1.80
Eating outside with others	263	0	10	8.48	1.92
At work or Studies	262	0	10	8.58	2.14
Age at diagnosis	251	0	71	31.52	14.09
Intensity of symptoms	258	1	5	2.80	1.28
Consequences of abandoning	259	1	5	1.44	.70
Time since diagnosis	251	0	42	7.61	8.39
Quality of Life (CD-QoL)	253	25	100	75.88	15.16
Limitations	254	10	45	34.45	7.92
Dysphoria	261	5	20.00	17.50	2.94
Health concerns	261	5	25.00	17.14	5.01
Inadequate treatment	263	2	10.00	6.90	1.79
Perceived adoption of recommended behaviours	233	0	150.00	132.62	21.07
Risks perception	241	32.00	150.00	129.69	21.56

Table 3. Factors associated with high or moderate/low adherence to a gluten-free diet

	Adherence	N	Mean	SD	p
General self-efficacy	Moderate/Low	113	30.86	5.72	.021*
	High	42	31.51	4.87	
Specific self-efficacy	Moderate/Low	99	8.15	1.80	.000**
	High	136	8.91	1.30	
Quality of life	Moderate/Low	105	70.78	16.25	.000**
	High	144	79.77	13.19	
Perceived adoption of recommended behaviours	Moderate/Low	115	147.70	29.69	.001**
	High	118	161.22	20.47	
Risk perception	Moderate/Low	115	148.40	28.24	.115
	High	148	154.75	28.64	
Intensity of symptoms	Moderate/Low	109	2.87	1.26	.300
	High	144	2.74	1.29	
Consequences of abandoning	Moderate/Low	109	1.55	.78	.079
	High	145	1.36	.63	
Age	Moderate/Low	115	39.10	12.23	.677
	High	148	40.28	11.49	
Age when diagnosed	Moderate/Low	106	31.58	13.60	.710
	High	139	30.91	14.35	
Time since diagnosis	Moderate/Low	106	6.45	7.45	.125
	High	139	8.51	9.11	
Gender	Moderate/Low	147	0.81	.40	.561
	High	114	0.87	.34	

* Significant at p<0.05; ** Significant at p<0.01. High adherence group with CDAT scores <13 and moderate/low adherence group with CDAT scores ≥13. A chi-square test was performed for variable gender.

Table 4. Specific self-efficacy in adherence to GFD

	Adherence	N	Mean	SD	p
Shopping	Moderate/Low	72	7.77	1.92	.000**
	High	186	8.77	1.50	
Traveling	Moderate/Low	72	6.95	2.58	.000**
	High	187	8.44	2.01	
Eating at home with others	Moderate/Low	70	8.73	2.15	.025*
	High	182	9.38	1.65	
Eating outside with others	Moderate/Low	71	7.65	2.22	.000**
	High	185	8.79	1.72	
At work or studies	Moderate/Low	72	7.74	2.57	.001**
	High	184	8.90	1.86	
Overall Scale	Moderate/Low	63	7.86	1.87	.000**
	High	172	8.85	1.51	

* Significant at p<0.05; ** Significant at p<0.01

Table 5. Linear regression analysis predicting GFD adherence.

Variable	B	β	$R^2 (\Delta)$	F
Specific Self-efficacy	-0.322	-0.171*	.364	38.13**
Recommended behaviours	-0.077	-0.512**		
Quality of life	-0.057	-0.283**		
Risk perception	0.030	0.206*		

* $p < .01$, ** $p < .001$

Table 6. Pearson's correlation matrix of regression variables.

Variable	Adherence GFD	Recommended behaviours	Quality of life	Risk perception	Specific Self- efficacy
Adherence GFD	1	-.469*	-.387*	-.191*	-.318*
Recommended behaviours	-.469*	1	.089	.630*	.361*
Quality of life	-.387*	.089	1	-.065	.263*
Risk perception	-.191*	.630*	-.065	1	.545*
Specific Self-efficacy	-.318*	.361*	.263*	.545*	1

* $p \leq .001$