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# **I Can't Eat That! Sticking to a Gluten-Free Diet**

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Additional information is available at the end of the chapter

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## **Abstract**

Despite the benefits of a gluten-free diet (GFD), rates for strict adherence range from 42% to 91%. Studies have established the maximum tolerable daily dose at 50 mg/day and led the European Union to restrict labelling 'gluten-free' products to those with less than 20 mg/kg. Qualitative studies have determined that patients experience social problems in five areas: eating in the workplace, shopping, travelling, eating out and eating at home with others. These situations may lead to negative emotions and affect relationships. Therefore, further research into investigating the underlying factors behind effective adherence is essential, as is the need for a theoretical framework to design programmes to improve adherence and quality of life in coeliac patients. Albert Bandura's Social Cognitive Theory can provide a better understanding of adherence and, moreover, a theoretical framework to design self-management programmes. Within this framework, the Health Action Process Approach (HAPA) model could provide a theoretical mechanism to better understand GFD adherence. The main aim of this paper is to review the factors related to GFD adherence and to present the HAPA model as a useful framework for the design of interventions to improve perceived self-efficacy, adherence to the diet and, thus, enhance quality of life in coeliac patients.

**Keywords:** coeliac disease, gluten-free diet, self efficacy expectation, adherence, quality of life

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## **1. Introduction: the GFD challenge**

The only treatment to date for coeliac disease (CD) is a strict lifelong gluten-free diet (GFD). However, let's analyse this sentence carefully and think about what we are conveying to coeliac patients with this recommendation.

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When we refer to '*only treatment*', we are saying that there is no other option, take it or leave it, but there is currently no alternative treatment for CD.

What do we mean by '*strict*'? How much gluten can a coeliac patient consume? In fact, we only have a few studies that focus on this issue. Carlo Catassi, in a now classic study [1], shows that a 50 mg/day intake of gluten over a period of 90 days may cause intestinal damage in coeliac patients. In other words, we are telling these patients that they cannot consume above 10 mg of gluten in each of their five daily meals. How can we ensure this? Gluten-free-labelled products have to contain less than 20 ppm (20 mg/kg). At home, it seems difficult but attainable but how can you ensure you do not surpass these levels when eating out, at work or when travelling? Logically, this strict diet is far more important in the case of CD or wheat allergy than in a non-coeliac gluten sensitivity (NCGS).

'*Lifelong*', with this word we convey the message to our patients that they must learn to deal with a chronic disease, that, the patient can no longer consume those appetizing products he or she sees on TV and enjoyed as a kid, not so long ago, or that tempting aroma of freshly baked bread or cookies.

These two paragraphs above refer to two well-differentiated issues: the first one to whether the patient will be able to follow the GFD, while the second refers to whether the patient considers giving up all those things he or she once loved and that are now banned for life, worthwhile. This distinction between confidence and motivation is what we are going to deal with in this chapter. Among people suffering from CD or wheat allergy, this confidence plays a more important role than in those suffering from NCGS, as the latter can regulate their GFD according to their tolerance to the adverse symptomatology without having to face other medical complications.

On the other hand, human beings like to celebrate events with food and drink. Frequently, coeliac patients feel obliged to choose between their physical health and their social integration— —“Which do you prefer: to follow your GFD or participate in your community?” —“Both”. Wrong! Too often this is not possible and they have to make a choice.

Despite the benefits of a strict GFD, we know that only 42–91% of coeliac patients show a correct adherence, depending on what we consider *strict* and how we measure it [2]. But why is it some coeliac patients really do stick to a GFD and others do not? These underlying principles have received scant attention so far, and we propose here an explanatory model.

## 2. Consequences of adherence and non-adherence

It seems obvious that physical and social consequences of adherence and non-adherence may be the most powerful motivators to initiate a GFD in coeliac patients. Non-adherence has well-known physical consequences as we know that small intake of gluten can lead to a varied gastrointestinal symptomatology such as abdominal pain, diarrhoea, bloating, constipation or more serious consequences such as osteoporosis, sterility in men and women or some types of tumours.

Researchers have paid less attention to the consequences of adherence to a GFD, in other words, the social costs that the correct adherence to a strict GFD has for coeliac patients. These costs are more social than nutritional. In an interesting qualitative study, Sverker [3] interviewed 43 coeliac patients and found five areas where they had problems: shopping, eating out, meals at home with others, when travelling and at work. At an emotional level, these problems led to feelings of isolation, shame, fear of being contaminated with gluten or bothering others. Because of this, coeliac patients often restrict their participation in social activities, especially in those with food, as they think that their participation may condition others' choices and they, therefore, prefer not to be a bother. Adhering to a GFD may also affect relationships as coeliac patients have unwanted visibility at social events, fear of being rejected or forgotten and, when they do participate, they must always identify themselves as coeliac patients and give detailed explanations, or if not, they must take important risks that could jeopardize their strict GFD.

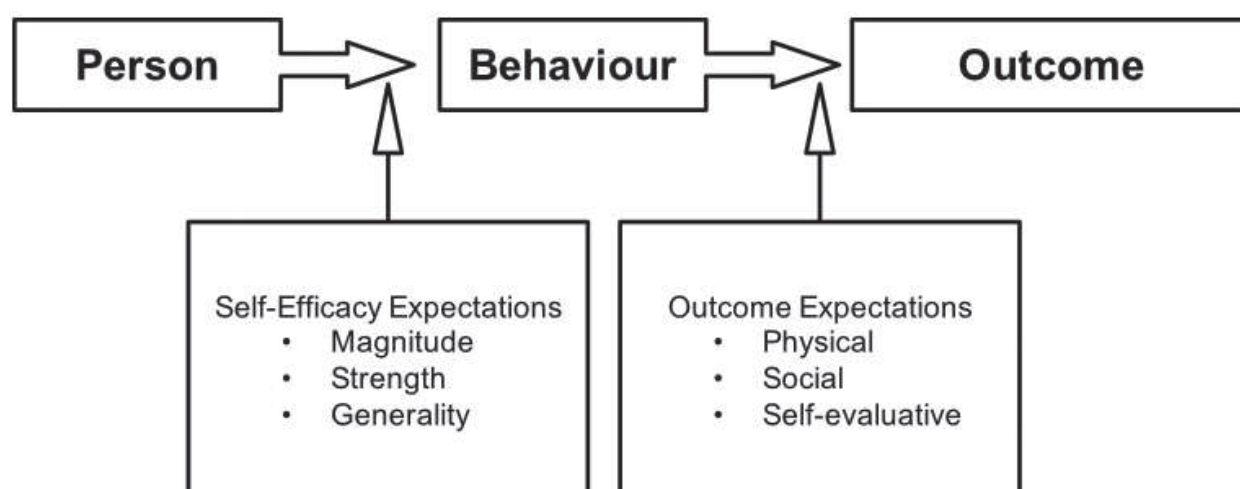
In their daily lives, they perceive restricted product choice when shopping or eating out, double work and that they have to be constantly on alert to keep up with their GFD. Often, they have to go to several shops and supermarkets to buy the goods they need for their GFD or cook different meals for each family member. In addition, they must be constantly on call while cooking to avoid cross-contamination.

Moreover, GFD adherence is expensive. Some studies estimate that the increase in the cost of shopping per affected family member reaches 1.200€/year [4, 5]. If we take into consideration that CD is genetically mediated, these differences could easily be twice or three times this amount. Therefore, some families could probably not afford a GFD.

### 3. Social Cognitive Theory, self-efficacy and gluten-free diet

The concept of self-efficacy has been widely studied in Psychology [6]. Albert Bandura proposed the self-efficacy expectation in 1977 in the article 'Self efficacy: towards a unifying theory of behavioural change' [7] where he defines self-efficacy '*as the conviction that one can successfully execute the behaviour required to produce the outcomes*' (page 193). From this first moment, Bandura distinguishes between outcomes and self-efficacy expectations stating: '*outcomes and self-efficacy expectations are distinguished because individuals can believe that a particular course of action will produce certain outcomes, but if they entertain serious doubts about they can perform the necessary activities such information does not influence their behaviour*'. Later, in 1985, he defined self-efficacy as '*one self-evaluation of one's capabilities to organize and execute the required courses of action to achieve certain outcomes. Then, it is not about the skills one has but rather about the assessment one makes on his or her own abilities*' [8].

To sum up, therefore, according to Bandura, '*self-efficacy refers to one's believes in own capabilities to organize and execute the necessary courses of action to produce certain outcomes*' [6] while outcome expectation refers to the belief regarding the most likely results of the action (**Figure 1**). Concerning a GFD adherence, one thing is the belief in being able to take the necessary steps to follow a strict GFD and something very different are the expected outcomes of strictly adhering, or not, to the diet. The first belief is what we know as self-efficacy expectation, whereas the latter is what we call outcome expectation.



**Figure 1.** Self-efficacy and outcome expectations [7].

The Social Cognitive Theory suggests three types of outcome expectations: physical, social and self-evaluative and they can all be either positive or negative. While positive consequences will increase willingness towards the GFD adherence, negative ones will decrease it. Physical consequences refer to physiological sensations such as nerves, anxiety or well-being associated with the correct adherence, while social consequences are others' understanding or rejection as well as the cost arising from the diet. The third kind of outcome expectations is self-evaluative expectations, positive and negative, derived from suffering CD and being bound to follow a strict lifelong GFD. These may come together with feelings of pride, belonging or self-assertion or, on the contrary, negative feelings of self-devaluation or depression.

On the other hand, as **Figure 1** shows, self-efficacy expectation has three dimensions: magnitude, strength and generality. The strength refers to the level of the expectation, in other words, the higher the expectation the higher the confidence in one's own ability to stick to a GFD and the associated tasks such as rejecting a dish or talking to a cook to ensure a gluten-free meal. Self-efficacy strength refers to one's resistance to failure. Finally, generality refers to the range of similar behaviours to which one can apply that given expectation.

Perceived self-efficacy has been applied to many different domains such as self-regulated behaviour, and patients with arthritis [9], physical activity [10], multiple sclerosis [11] or addictive behaviours [12] but it has received scant attention in relation to CD.

Although Bandura [6] proposes a specific self-efficacy expectation narrowly linked to each situation, some authors [13, 14] work with the hypothesis of a more general self-efficacy belief that accounts for behaviour in different domains in life.

Higher levels of general self-efficacy correlate with positive feelings, higher achievements, better quality of life and the perception of potentially stressful situations as challenges rather than as potential threats [6]. Self-efficacy, therefore, is linked to a wide number of psychological constructs and affects not only coping behavior, but human functioning in general.



According to Bandura, levels of general self-efficacy are related to the perception of well-being and healthy behaviours, while he finds negative correlations with negative feelings. According to this author, a high sense of general self-efficacy also correlates with lower levels of depression in patients with heart problems, less pain and low levels of anxiety in individuals with gastrointestinal problems. There is also evidence of greater adherence to physical exercise and healthy eating in those with high general self-efficacy. In the same way, Luszczynska finds that gastrointestinal patients use less passive coping techniques and more active techniques of pain management [13]. This author, together with Scholz, has carried out several studies to search for evidence to consider self-efficacy a universal construct [14]. Because of all this, we think self-efficacy beliefs may play a major role in the adherence to a GFD and this relation has only just begun to be studied in recent years.

#### **4. How do we increase self-efficacy to improve adherence to a GFD?**

According to Bandura [6], there are four sources of self-efficacy: performance accomplishments, vicarious experience through model observation, verbal persuasion on own capabilities and, lastly, the evaluation of emotional arousal during performance. Any change in the level of self-efficacy expectation is going to take place through one of these sources or a combination of any of them.

##### **4.1. Performance accomplishments**

According to Bandura's Social Cognitive Theory, performance accomplishments are the strongest source of self-efficacy as is the real evidence that a person can perform a task successfully. Generally speaking, success events help to build a high level of self-efficacy while failures tend to lower it. Although this is the general rule, this does not always work this way as success and failure need to be cognitively processed. After this analysis, and depending on, for instance, attribution mechanisms, a higher or lower belief of self-efficacy will be instilled. Other factors such as skills assessment, perceived task difficulty, the effort made, the situation or former successes or failures will also condition the sense of self-efficacy. Failure is especially negative in early stages before a strong belief of personal efficacy has been developed. On the other hand, if success comes too soon, the self-efficacy belief instilled could be high, but weak and vulnerable to failure. It is success after overcoming difficulties and setbacks that builds high and strong self-efficacy beliefs, in other words, resilient to future adversities. This source of self-efficacy also builds up an expectation easier to apply to new situations than those obtained through the other three sources. In adhering to a GFD, the successful management of the diet at home, when travelling or eating out may lead to a high and strong sense of self-efficacy while conflicts in those areas, the failure in lowering serological markers or symptomatology may reduce self-efficacy beliefs.

##### **4.2. Vicarious experience**

Vicarious learning has been widely studied during the 1960s in the last century and the underlying mechanisms have been well established. People do not learn only by direct experience but also by

imitation or vicarious observation. So, self-efficacy expectations are also affected by individual's exposition to models that execute, successfully or not, a certain task. The higher the similarity to the model, the higher the effect in the observer's self-efficacy beliefs. If the model is too different from the observer, the expectation may not be altered significantly as the observer may consider himself or herself to be incomparable. There are a number of circumstances in which this source is especially effective: the greater similarity in sex, age and race between the model and the observer, the greater the influence conveyed. On the other hand, models facing self-doubts and difficulties but controlling masterfully them seem to be more effective than those who perform perfectly. This source is especially useful with people who have not executed the task before and have not faced failure or success yet. But a competent model not only conveys a sense of self-efficacy but also the knowledge and skills of how a task should be executed. The model not only transmits that the goal is achievable but also shows how the task needs to be performed. Those who appear to be confident and persevere in the task help to develop stronger beliefs of self-efficacy in the observer. Vicarious experience emphasizes predictability and controllability. Through observation, the observer anticipates what is going to happen at the same time that he or she learns to control and manage difficulties, reducing stress and increasing self-efficacy beliefs.

In adhering to a GFD, this source of self-efficacy is especially useful, developing efficacy beliefs among siblings, friends or class or workmates who have been diagnosed at the same time. Support groups promoted by patients' associations illustrate clearly how this source can be useful in real settings. This source of self-efficacy must be taken into account, therefore, when designing self-managed health programmes where new members can observe the required behaviour and strategies put into practice by veterans or by recently diagnosed patients.

#### **4.3. Verbal persuasion**

Verbal persuasion is the third most effective source of self-efficacy when trying to install a healthy habit. It is easier to develop a sense of self-efficacy when others believe in your capabilities. Its effects may be limited when trying to generate high and long-lasting levels of self-efficacy but it is effective if kept within a realistic contest. On the other hand, people seem more motivated when avoiding the negative costs of a certain habit than for the gains that the adoption of a new habit may bring. Meyerowitz and Chaiken [15] reported that emphasis in potential losses of not adhering to a healthy habit is more effective and builds a stronger sense of self-efficacy than the emphasis on the advantages of adhering. It seems that the efficacy of a message based on gains and losses depends on the pre-existing efficacy beliefs. So, emphasis on losses is more effective for those high in self-efficacy while those with a lower pre-existing sense of self-efficacy have their effort undermined. This leads us to think about the need to adapt the message depending on the pre-existing levels of self-efficacy in the coeliac patient. If he or she is confident in being able to follow a GFD strictly we must emphasise the costs of non-adherence while we must moderate the message for those with lower self-efficacy beliefs.

#### **4.4. Self-evaluation of emotions and feelings**

According to Bandura, self-appraisal of affective and physiological states is the fourth source of self-efficacy beliefs. When patients evaluate their capabilities, they often integrate information

from their physiological response. People differ in the amount of attention they pay to their emotions and feelings: the less immersed they are in their activities the more likely they are to concentrate on inner sensations and physiological reactions to difficulties. Diseases and physical deficiencies may focus their attention on their own limitations.

A coeliac patient excessively focussed on the internal sensations and anxiety may develop a lower and weaker self-efficacy expectation due to the anxiety generated by the activities required when following a GFD menu, such as talking to waiters, cooks, rejecting food, and so on. This also happens if he or she pays much attention to associated symptomatology.

## **5. Self-efficacy expectation and health management**

Since Bandura published the theory of self-efficacy in the 1970s, it has been applied to many areas such as adherence to medical treatments, rehabilitation, sexual risk behaviour, physical exercise, nutrition and weight control, breast and prostate examinations or drug addiction [6].

The World Health Organization (WHO) defines health not only as a lack of illness but as a complete feeling of biological, psychological and social well-being. It is not only about being healthy but also about perceiving a good health status and a good quality of life.

Since the end of the twentieth century, western countries adopted this biopsychosocial model in which health and disease are consequences of the interaction of biological and psychological factors. Healthy habits have a beneficial effect on the organism while the absence of them may have an accumulative impact that leads to the development of chronic diseases; this is why it is necessary to develop self-managed health programmes as the most effective medicine nowadays. Fuchs [16] reported that medical expenditure has only a moderate influence on life expectancy and that, apart from genetics, it is their lifestyle and environmental conditions that are the most important factors in determining patient's health. People suffer from physical problems and die prematurely because of pernicious habits and from preventable causes.

These are the main reasons why we think that self-efficacy expectation and the Social Cognitive Theory offer a suitable framework for intervention in CD. The self-efficacy expectation seems to play a major role at two different levels and both have been widely investigated in the last decades. The former refers to the effects of perceived self-efficacy in neurophysiological systems in coping situations and an extensive summary can be found in Bandura's 'Self-efficacy: The exercise of control'. This first level is of great importance if we link it to the recent research about the role of self-immune mechanisms and intestinal microbiota in the etiopathogenesis of coeliac disease [17–20]. A second level, and more relevant for the adherence to a GFD, is the role of self-efficacy expectation in the instillation of healthy habits and the elimination of risky behaviours. The Social Cognitive Theory offers, therefore, the necessary knowledge to develop effective health promotion programmes. In this case, how to improve GFD adherence in coeliac patients in order to enhance quality of life is shown.

The Social Cognitive Theory studies three basic change processes: the adoption of new habits, their maintenance through time, and their generalization to new situations. In other words,



how self-efficacy affects the establishment of a strict GFD, its persistence in time, recovery after transgressions and the generalization of those strategies to correctly maintain the diet in different areas such as at home, when travelling, at work or eating out.

### **5.1. Initiating a gluten-free diet**

People's beliefs about their own ability to motivate themselves and organize their behaviour play a central role when giving up unhealthy habits and adopting medical treatments as the GFD in coeliac patients. If they hold discouraging beliefs, they will not be able to do what is needed to go on a GFD, they will simply not begin. According to the Social Cognitive Theory, those with high pre-existing self-efficacy expectations will succeed better in definitively adhering to a GFD than those with self-doubts and frequent voluntary or involuntary transgressions. Even those who realize that their current habit is not healthy will not go on a GFD while they lack the self-efficacy required to resist temptations and cope with mood alterations. Di Clemente studied the changes in self-efficacy expectations along different stages of habit change and concluded that patients with weak self-efficacy beliefs give up preventive behaviour faster than those with stronger beliefs [12, 21].

According to Bandura, patients need to have sufficient knowledge about the disease and risk behaviours without being frightened by the message. What patients need are clues about how to behave and the strong conviction of being able to change their concerns about their health into preventive behaviour. That is, as we explain below, the intention-action gap is bridged with planning. So, those patients lacking enough self-efficacy to adhere to a GFD must enrol in self-managed programmes that provide them with gradual experiences that will increase their competence and self-efficacy levels while those fostering high beliefs can start a GFD with the medical recommendation alone. The problem is that today these programmes neither exist nor are scientifically based.

The messages, therefore, must be tailored to suit the chronic patient. Some authors have designed programmes of this type to individualize messages for each patient in tobacco addiction, healthy eating or preventive behaviour in cancer but we have not found any for CD and we think that programmes like these may be useful in clinical settings [22].

### **5.2. Sticking to the gluten-free diet**

In order to stick to a GFD, intention alone will not suffice to develop the intention, patients will need self-regulatory skills. They must learn to design the menu, to set short- and long-term goals to focus the effort, such as travelling, eating out or in different places and to be able to anticipate positive and negative consequences of adherence. Once empowered with these skills and with strong self-efficacy beliefs, patients are ready to adopt the necessary behaviours and habits for following a strict GFD.

Over the past decades, the authors have found strong evidence that adherence to healthy habits are mediated by strong expectations of self-efficacy [6]. The higher this expectation is, the more likely the patient is to adhere to treatment and the more intense will be their efforts

made to keep up with the new habit. This relationship has been found in different health topics such as obstructive lung disease, heart function recovery, pain reduction in patients with arthritis, chronic pain, stress reduction, weight loss, control of bulimic behaviour, cholesterol reduction through diet, adherence to physical exercise and many others. Bandura makes a systematic review of this extensive research [6] but this link with CD has scarcely been studied.

GFD has few positive consequences unless it is strict and maintained for a long time. Patients not only have to be able to start the diet but also be able to cope with potentially conflictive situations such as temptations or voluntary and involuntary transgressions. The development of these self-regulatory skills requires a resilient sense of self-efficacy to resist temptations and return to the GFD after transgressions.

### **5.3. The generalization of GFD to different settings**

The easiest setting to install a GFD is, logically, at home and with naturally gluten exempt food as fish, meat or vegetables but we are social animals and we need to generalize those self-efficacy beliefs developed at home to other settings like restaurants, when we are at work or travelling. This generalization process is not easy, and it is important not only to control the disease but, more specifically, to achieve an adequate quality of life. Coeliac patients must force themselves to conquer new settings and gain confidence without putting themselves at risk. They have to overcome their feelings of 'being forgotten', 'being a bother' or their fear of 'be contaminated by gluten' and to fully participate in the activities of their communities. We are, therefore, speaking about the third of Bandura's dimensions: magnitude, strength and *generality*. This is about applying the specific self-efficacy from one setting to others until reaching full social integration.

## **6. An explanatory mechanism for adherence: the HAPA model**

It might be easy to go on a GFD, but sticking to it is a very different thing. Traditional explanatory models of change fail to explain the gap between intention and action. The HAPA model [23] tries to address this question and we think it fits very well with the GFD. This model was suggested by Schwarzer in 1988 and deeply reviewed recently by the author as an attempt to integrate the Heckhausen and Gollwitzer's [24] action phases model with Bandura's Social Cognitive Theory [8]. Five principles help to define the model:

### **6.1. Principle 1: motivation and volition**

The model distinguishes between preintentional motivational process and postintentional volitive processes that lead to healthy habits. Therefore, HAPA is a two-phase model: It is in the initial motivational phase, when the individual still has to develop the intention to acquire a healthy habit, which in this case is adherence to a GFD. In this phase, risks are assessed as

threatening but unlikely, especially by asymptomatic patients, and not important enough to build an intention but they motivate the patient towards a contemplation stage and an evaluation of the capabilities needed to take up a GFD (social skills, facing temptations, etc.) and the consequences (giving up to certain foods, identifying oneself as coeliac, changing habits or extra work associated with the diet). Analogously, positive consequences are important at this motivational phase (e.g. a healthier diet or symptomatology improvement). In addition, in this time, high self-efficacy beliefs, together with positive outcome expectations, play a major role and both are necessary to develop an intention.

But the development of an intention is not the end of the road. Once developed, this has to be turned into action and, ultimately, into a strict adherence for which self-regulation skills and strategies are required. In this postintentional moment, volitional phase, planning and the self-efficacy beliefs to face transgression (recovery self-efficacy) play a central role.

This distinction is important because, while action self-efficacy predicts intention, maintenance and recovery self-efficacy beliefs are better predictors of adherence. So, individuals that go back to a GFD after a transgression need different self-efficacy beliefs than those that keep their adherence. As the saying goes, it is better to fall and rise again than never have fallen at all.

6.2. Principle 2: two volitive phases

Once the intention has been developed and the patient enters the volitive phase, we can distinguish between those with the intention to go on a GFD (intenders) and those who have already adhered to the new diet (actors) (Figure 2).

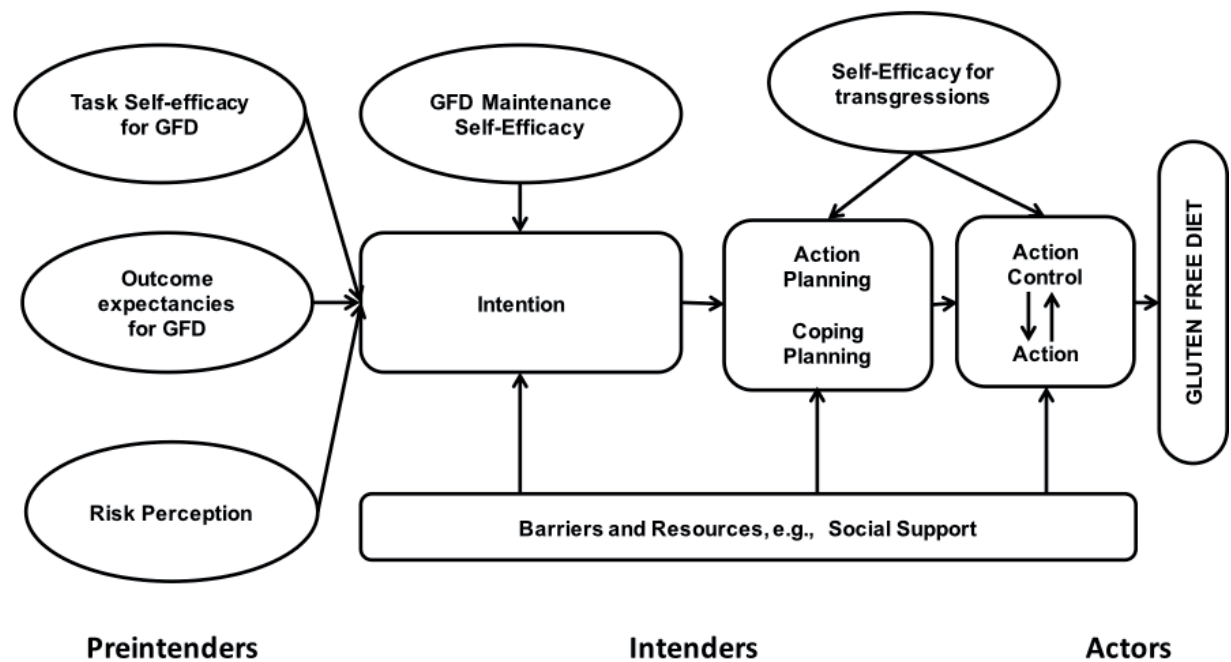


Figure 2. The HAPA model [23] (adapted).

### 6.3. Principle 3: postintentional planning

To adhere to a habit, intentions need to be transformed into actions through detailed planning, for which people need to imagine themselves in different settings and the different strategies that they can deploy to get a GFD.

### 6.4. Principle 4: two types of planning

Schwarzer distinguishes between action planning and maintenance planning. *Action planning* goes beyond intention because it obliges patients to specify when, where and especially how to stick to a GFD. Leventhal [25] suggests that aversive communications in health promotion are only effective if they come with the correct action plan with instructions about when, how and where to execute the proper tasks that lead to establishing a high *maintenance self-efficacy*. Patients are less likely to forget their intentions when these have been expressed in terms of when, where and how they are going to maintain their diet. *Maintenance planning* is about foreseen barriers, difficulties and alternative behaviours to overcome them. This second type of planning is more important as it implies action planning, designing contingency plans and coping strategies before difficulties may arise.

### 6.5. Principle 5: specific self-efficacy for each phase

Self-efficacy expectation is necessary along all this adherence processes to a GFD but this expectation is slightly different depending on each phase. Marlatt et al. distinguish between initial, maintenance and recovery self-efficacy.

*Initial self-efficacy* (or action self-efficacy) refers to the motivational moment in which the coeliac patient does not go into action yet but has the confidence to begin a GFD. At this moment, individuals with high self-efficacy foresee the success, and outcomes and are more likely to start the diet. Those with a low self-efficacy expectation imagine themselves failing, are vulnerable to self-doubts and prone to procrastination. The other two types of self-efficacy take place during the volitive phase. *Maintenance self-efficacy* refers to the belief that one is going to be able to cope with the difficulties of guaranteeing a gluten-free meal; recovery self-efficacy deals with the belief that a person holds that he or she is going to be able to go back to a GFD after a transgression. In this context, Marlatt defines the abstinence violation effect (AVE) when an individual makes a stable, internal and global attribution of his or her relapse or abandons the healthy habit. Patients with high *recovery self-efficacy* beliefs avoid this effect as they attribute their relapse to external or controllable causes that allow them to rekindle their hopes of following with the diet. Therefore, people with high self-efficacy trust their capabilities to reinstall their abandoned diet after a transgression and to reduce its negative consequences.

The HAPA model points out the necessary constructs to work on each phase in a self-management health programme. Patients and professionals need to work on the following variables for the motivational phase: action self-efficacy, risk perception, outcome expectations and goal setting while the constructs to work on the volitive phase are action planning, coping planning, social support, maintenance self-efficacy, recovery self-efficacy and action control.

In addition, McLean [26], following a systematic review about adherence to treatments, concludes that this is higher when (1) this follows a cognitive, motivational and behavioural approach, (2) it helps patients to overcome barriers and face relapses and (3) it takes into account the conditions that come from health organizations.

To conclude, we must say that we think that the HAPA model can provide a valid framework for the design and implementation of programmes to improve adherence to a GFD in primary-care settings.

## 7. Psycho-CD: a programme to improve adherence to GFD

Due to advances in medicine and the subsequent increase in life expectancy in western countries, chronic disease has become a prevalent type of illness and disability in the last decades. Most people with chronic illnesses receive a treatment more based on medication than on education or the development of healthy lifestyles that allow them to manage their illness in a more effective way. This medical treatment is not possible in coeliac disease as there is no other cure besides sticking to a strict GFD for life. According to the Social Cognitive Theory, problems with adherence are more related to a poor belief in the benefits of the treatment or the perceived lack of capacity to stick to it than to the difficulties directly derived from the disease.

Holman and Lorig [27–31] have designed a prototypic programme for the self-management of different chronic diseases. These programmes include the development of technical skills such as pain control, relaxation, short-term goal setting, self-reinforcement, problem solving, health changes interpretation, community resource finding, medication management and they can be promoted in primary care settings.

Different chronic diseases present very similar problems concerning how to manage symptomatology and how to overcome difficulties when adhering to the treatment or the control of emotions associated to the loss of quality of life. Programmes of this kind are, therefore, generic models that can be adapted to different chronic diseases (e.g. coeliac disease). This research team has not found any scientifically based programme for improving adherence to a GFD and because of this, we would at least like to present the outline of a proposal in this chapter.

Cunningham and Lookwood [32] found that the more the coping self-efficacy for chronic disease is improved through a programme, the higher the improvement is in terms of quality of life. These studies show the need to combine medical treatments with psychosocial interventions based on self-management programmes and we think that coeliac disease treatment would benefit from this approach.

Psycho-CD has the following objectives:

### 7.1. General objectives

The general objectives include the following:

- To improve adherence to GFD in coeliac patients.
- To develop a level of quality of life in coeliac patients to match non-sufferers.



- To develop high, strong and generalized self-efficacy expectations in different areas to reduce stress and increase the sense of competency in adhering to GFD.

## 7.2. Specific objectives

The specific objectives include the following:

- To improve knowledge about coeliac disease and adherence to a GFD.
- Develop self-efficacy in specific settings such as eating at home, at work, eating out, shopping and when travelling.
- To increase social support and referents in the self-management of the disease.
- To learn to manage emotions associated with the disease.

## 7.3. Theoretical framework

We propose to adapt Schwarzer's HAPA model (**Figure 2**) within the wider framework of Bandura's Social Cognitive Theory with three phases:

### 7.3.1. Preintentional phase

In this phase, patients will work on self-efficacy expectations to start a GFD, outcome expectations and risk perception in order to develop the intention to stick to a GFD.

### 7.3.2. Intentional phase

During this intentional phase, patients will mainly work on the maintenance of self-efficacy as well as barriers to and resources for adherence to a GFD. The objective of this phase is to work on the intention-action gap with patients through the detailed planning of the diet and how to overcome difficulties.

### 7.3.3. Action phase

During the action phase, together with barriers and resources, patients will work on planning to follow the diet correctly in the five areas identified by Sverker, as well as the social skills and coping strategies together with the development of recovery self-efficacy after transgressions.

## 7.4. Principles

### 7.4.1. Principle of motivation and volition

According to HAPA model principles, along the programme, two different stages will be distinguished depending on the patient's expectations:

- Motivational moment (sessions 1 and 2) when the patient still needs to develop his or her intention (preintender) to follow a GFD.

- Volitive moment (sessions 3–10) when some patients have already developed their intention (intender) but have not gone into action and those who already have (actors).

#### *7.4.2. Principle of empowerment*

Responsibility is transferred to the patient. Coeliac disease is a chronic disorder and the only treatment to date is a lifelong strict GFD and, therefore, once the treatment has been set up through adequate training, it is the patient who must take accountability for the adherence.

#### *7.4.3. Principle of self-efficacy*

Self-efficacy plays a central role in the programme. Professionals must evaluate specific self-efficacy to initiate, maintain and manage transgressions during the GFD.

#### *7.4.4. Principle of postintentional planning*

According to the HAPA model, the programme is based around a detailed plan to ensure adherence, in other words, professionals will help the patients to plan how to prevent relapses and avoid transgressions.

#### *7.4.5. Principle of evaluation*

Professionals will carry out several evaluations throughout the programme:

##### **1. Initial evaluation**

- a. Evaluation of the diet.
- b. Evaluation of specific self-efficacy.
- c. Evaluation of quality of life.

##### **2. Final evaluation**

- a. Evaluation of diet after intervention.
- b. Evaluation of levels of specific self-efficacy after the programme.
- c. Evaluation of quality of life after the programme.

##### **3. Evaluation of the programme as a whole**

#### **7.5. Setting**

This programme is designed to be implemented in primary care or by Patients' Associations.

## **7.6. Variables of intervention**

### *7.6.1. Motivation*

Professionals will adapt motivational intervention depending on whether the patient is in a preintentional, intentional or behavioural phase. Messages will be designed according to previous levels of self-efficacy, thus grading the level of threat and the discrepancy between current behaviour and the new demands of adherence.

### *7.6.2. Knowledge and risk behaviour*

The programme will be based on solid scientific evidence regarding coeliac disease from which professionals will define risk behaviour and make their corresponding recommendations.

### *7.6.3. Self-efficacy*

Self-efficacy expectation is a central factor in the programme. Self-efficacy expectations will be developed using Bandura's sources: previous achievements in programmed behavioural trials in which the required social skills can be put into, use of models through mates and mentors' support, verbal persuasion with the messages designed by professionals and emotional appraisal through the control of symptomatology and the anxiety associated with social interaction that can threaten adherence to a GFD.

## **7.7. Agents**

### *7.7.1. Professionals*

This programme will be managed by dietitians with specific training and experience in coeliac disease.

### *7.7.2. Patients*

Patients are responsible for the correct management of their disease, achieving access to a more normalized life through careful planning.

### *7.7.3. Doctor*

Doctors are in charge of initial diagnosis and motivation as well as the derivation to this programme of adherence improvement.

### *7.7.4. Mentor*

Patients will be assigned a mentor among more experienced coeliac patients and, preferably, who have undertaken the programme before. Mentors, according to the Social Cognitive Theory, will be similar to the patients to better help the development of empathy and self-efficacy.

The mentor will be a veteran in managing coeliac disease and will guide the patient through the programme, serving as a reference during and after, as a way of increasing his or her social support.

## 7.8. Timing

The programme is designed for 10 sessions, preferably in groups of five to eight patients, with a weekly frequency and an estimated duration of 2 h. It would be possible to offer five 4-h sessions.

### 7.8.1. Session 1: presentation, relationship creation, mentor assignment and contingency measures

In the first session, dieticians give an introduction to CD and GFD, introduce the mentor and offer a tailored GF menu for the next 15 days along with the basic recommendations for starting the diet. Mentors do not need to attend the rest of the sessions but they should be available according to the patient's needs.

### 7.8.2. Session 2: coeliac disease and gluten-free diet: developing the intention

During session 2, dieticians will give a detailed explanation of CD and GFD and will motivate patients towards adherence customizing messages based on patient's moment of change (preintention, intention or action). Dieticians will work on action self-efficacy, positive and negative outcome expectations (physical, social and self-evaluative) and risk perception.

### 7.8.3. Session 3: emotion management in coeliac disease

In this session, dieticians will review emotions associated with coeliac disease such as stress, anxiety, sadness, frustration and others as a strategy for preventing relapses and improving quality of life.

### 7.8.4. Session 4: planning for shopping

In this session, dieticians will explain concepts related to packaging and labelling as well as the acquisition of unpacked goods. Dieticians will review risk behaviours and associated recommendations.

### 7.8.5. Session 5: planning eating at home with others

Dieticians will review possible problems associated with eating at home with family and friends. Patients will act out role plays about how to correct inadequate behaviour in guests that may be a risk to their diet as well as how to reject or accept invitations.

### 7.8.6. Session 6: eating out planning

Dieticians will review risks when eating out. Patients will act out role plays associated with the social skills needed when ordering gluten-free food, rejecting an unsafe dish and other similar situations.

#### *7.8.7. Session 7: at work and at school planning*

Dieticians will review problems that arise at work, school or university, associated legislation, if there is any, and patients will plan how to get gluten-free food in those settings.

#### *7.8.8. Session 8: planning for travelling*

Dieticians will help to plan trips and patients will learn to find patients' associations in other cities and countries, as well as other valuable information for following the GFD when travelling.

#### *7.8.9. Session 9: first follow-up session*

Dieticians will carry out a follow-up interview at 6 months to assess adherence.

#### *7.8.10. Session 10: final session*

In this last session, dieticians will evaluate again self-efficacy expectations, adherence and quality of life as well as the programme as a whole.

### **7.9. Session structure**

Sessions 1–3 will combine technical expositions with presentations of patients and mentors' experiences.

Sessions 4–8 will have the following structure:

- Review of former achievements.
- Technical presentation.
- Objectives for next session: Design of behavioural trial.
- What could go wrong? Contingency plans.
- Closing summary and commitment.

Sessions 9 and 10 will combine quantitative and qualitative evaluation of adherence and quality of life together with the sharing of the benefits of the programme.

## **8. Conclusion**

This chapter presents a theoretical framework that can be useful to improve adherence to a GFD for patients affected by gluten-related disorders, in particular for coeliac patients. The difficulty for a correct adherence lies mainly on how strict the diet needs to be as we understand that it needs to be very strict in the case of CD and wheat allergy, and it could be more relaxed in the case of NCGS.



Self-efficacy expectations play a key role in adherence and quality of life of these patients and the HAPA model offers not only an explanatory mechanism but also the contents that need to be present in any programme to improve adherence.

Psycho-CD is a self-management programme designed to improve adherence and quality of life when adhering to a GFD that can be implemented in primary-care settings or from patients' associations.

As there is currently no alternative treatment for CD, programmes of this type may result not only in an improvement of the quality of life of the patient but also in a reduction of the costs associated with expensive diagnostic procedures and severe complications arising from inadequate adherence.

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