

GASTROINTESTINAL DISORDERS

Facilitators and barriers to adherence to gluten-free diet among adults with celiac disease: a systematic review

N. Abu-Janb*  & M. Jaana 

Health Systems Management, Telfer School of Management, University of Ottawa, Ottawa, Ontario, Canada

Keywords

barriers, coeliac, diet, facilitators, gluten, systematic review.

Correspondence

M. Jaana, Health Systems Management, Telfer School of Management, University of Ottawa, 55 Laurier Avenue East, Ottawa, ON K1N 6N5, Canada.

Tel.: (613) 562-5800 (Ext. 3400)

E-mail: jaana@telfer.uottawa.ca

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*Affiliation at the time of completion of this research.

Abstract

Background: Coeliac disease (CD) is a chronic, autoimmune disease that prevents individuals from processing gluten, leading to adverse health effects. People with CD should adhere to a gluten-free diet (GFD); however, adherence rates are well below optimal in adults with CD, ranging between 42% and 91%. To date, limited evidence is available on the nature and magnitude of factors that affect adherence to GFD. The present study aimed to develop a systematic review that critically appraises and synthesises evidence on facilitators and barriers that affect adherence to GFD among adults with CD.

Methods: Four databases were searched (Ovid Medline, CINAHL, PsychInfo and Embase) using variant keywords to identify empirical studies meeting the inclusion/exclusion criteria. A coding scheme was developed to extract relevant information from each article.

Results: Forty articles were included. Grounded in the bioecological theory of development, we synthesised the facilitators and barriers in the literature into a social ecological model with multiple levels: system, community, organisational, interpersonal and individual. The studies varied by design and level of evidence; only one randomised trial was identified. The most significant facilitators include (% of studies): increased education (22.5%); increased knowledge of a GFD (20%); increased intention/self-regulatory efficacy (17.5%); and coeliac association membership (12.5%). The most significant barriers include: lower knowledge of CD (35%); restaurant/super-market shopping (30%); poor patient education from practitioner (17.5%); and low intention/motivation to adhere to a GFD (17.5%).

Conclusions: Improving knowledge of a GFD, becoming a member of a coeliac association, and improving practitioners' abilities to educate patients on CD will create opportunities for improved adherence to GFD among adults with CD.

Introduction

Coeliac disease (CD) is a chronic, autoimmune disease that negatively impacts an individual's digestive system. Approximately 1% of the population worldwide live with CD ⁽¹⁾. For individuals who have CD, there is an environmental trigger that leads to adverse health outcomes, known as gluten. Gluten is a storage protein found in many grains, including wheat, barley, rye, oats and triticale ⁽²⁾. When an individual is exposed to gluten, the

gluten will customarily transfer through the individual's digestive system until it reaches the small intestine. At this point, the gluten particles are recognised as foreign invaders, leading to the release of immune cells that attempt to destroy the gluten particles ⁽³⁾. As a result, the lining of the small intestine also gets damaged, causing possible villous atrophy responsible for many complications, including significant levels of nutrient malabsorption, leading to comorbidities ⁽⁴⁾. Although the majority of individuals living with CD will display classic

symptoms, such as diarrhoea, malabsorption and abdomen discomfort, some individuals can show atypical symptoms or even no symptoms at all ⁽⁵⁾.

Because there is no known cure for CD, stringent adherence to a gluten-free diet (GFD) is necessary to prevent adverse health effects ^(6,7). Despite this, prior research has shown that the adherence to a proper diet is not always maintained, with dietary compliance ranging from 42% to 91% ^(8,9). The low adherence rates may compromise the health and well-being of individuals living with CD, leading to comorbidities such as anemia, severe malabsorption and various forms of malignancies ⁽¹⁰⁾. Hence, it is important to obtain a better understanding of the factors that can influence the ability of a person with CD to adhere to a GFD.

To date, although some studies have investigated various factors that may enhance, and/or limit an individual's ability to adhere to a GFD, limited knowledge is available on the existing evidence in this area, which may inform future research, practice and policy changes. Grounded in the Bio-Ecological Theory of Development (BETD) and the Social Ecological Model (SEM), the present study contributes to this area and reports the results of a systematic review of the literature that identifies, critically appraises and synthesises existing evidence on the facilitators and barriers to adherence to GFD among adults living with CD.

Bio-ecological theory of development/social ecological model

The BETD originated from Urie Bronfenbrenner ⁽¹¹⁾, progressing from his original ecological systems theory. The theory's main underpinnings dictate that, to understand human development and decision-making, one needs to explore the entire ecological system that encompasses their life.

Derived from the BETD is the SEM, which incorporates the different components of the former into a visual that describes the development of individuals as they go through their lives, faced with both facilitators and

barriers at the different ecological layers that encompass their lives. In the context of this systematic review, the SEM is used to help explain the factors that are present in peoples' lives, which impact their adherence to a GFD. Several facilitators and barriers impact their ability to cope with their diagnosis. These facilitators and barriers are expected to exist at various ecological levels. The relationship among these categories will help portray the experience of an adult with CD attempting to adhere to a GFD.

Materials and methods

Following the PRISMA guidelines ⁽¹²⁾, a systematic review was conducted that synthesises existing evidence on the facilitators and barriers for adherence to GFD among adults with CD. Four major databases were searched (November 2017): Ovid Medline (<http://ovidsp.ovid.com>), CINAHL (<http://www.ebscohost.com/nursing/products/cinahl-databases/the-cinahl-database>), PsychInfo (<https://www.apa.org/pubs/databases/psycinfo>) and Embase (<https://www.embase.com/>) (for a detailed search example, see Appendix A). These databases were used to identify empirical studies that met the inclusion/exclusion criteria (Table 1), which allowed a wide range of potential studies to be identified, helping guarantee a saturated search. The search strategy keywords included: coeliac, adherence, gluten-free, gluten, treatment, coeliac, maintenance, compliance, barrier(s), facilitator(s), factor(s) and impacts. Reference lists of the retrieved articles were further hand-searched.

Search strategy

Figure 1 presents the steps used in the search and screening process of articles. A coding scheme was developed to extract relevant information from the included empirical studies, including:

- Country of origin
- Age range and mean of participants
- Population sample including subsequent groups

Table 1 Inclusion/exclusion criteria

Term	Inclusion criteria	Exclusion criteria
Date of articles	Published until 15 November 2017	–
Age of participants	Adult population	Children studies
Study design and reporting	Empirical studies that report on facilitators and barriers	Non-empirical studies (e.g. opinion papers, policy papers, review)
Participant population Condition	Studies that solely focus on patients with CD	Studies where comorbid disorders are present that influences adherence to a GFD
Language	English studies	Non-English studies

- Design of the study
- Barriers identified
- Facilitators identified
- Barriers influencing adherence to GFD
- Facilitators influencing adherence to GFD
- Summary of results
- Potential types of bias presented

Data extraction and analysis

The facilitators and barriers reported in each study were classified according to the SEM. Hence, the facilitators/barriers are presented according to the nature of each factor: Individual factors, Interpersonal factors, organisational factors, community factors and system-level factors.

For all of the included articles, a critical appraisal was conducted to assess the strength and rigour of the study. Depending on the design of the study, a specific checklist was used to assess the quality of each particular study. Based on these validated checklists, the quality of evidence and degree of recommendation of the article was evaluated⁽¹³⁾. The investigator was responsible for coding

all of the included articles. To ensure reliability, five were randomly selected and also coded by another investigator. The coding between the two researchers has high inter-rater reliability, with 85% agreement.

Following recommended guidelines⁽¹⁴⁾, a systematic narrative synthesis was conducted; the results and specific characteristics are reported and summarised for each of the included studies. As per the PRISMA guidelines⁽¹⁵⁾, all of the information was compared across each of the included studies, as well as within each study. The reported facilitators/barriers were placed into different ecological layers. These ecological layers are described in the sections below.

Results

Table 2 presents a general overview of the studies included in this review. Nineteen studies were conducted in Europe, 15 in North America, five in Australia and one in Asia. The studies were conducted from 1992 to 2017. The strength of evidence of each study is based on the JBI levels of evidence (LOE) tool, which assesses the quality of the study based on its design⁽¹⁵⁾. It includes

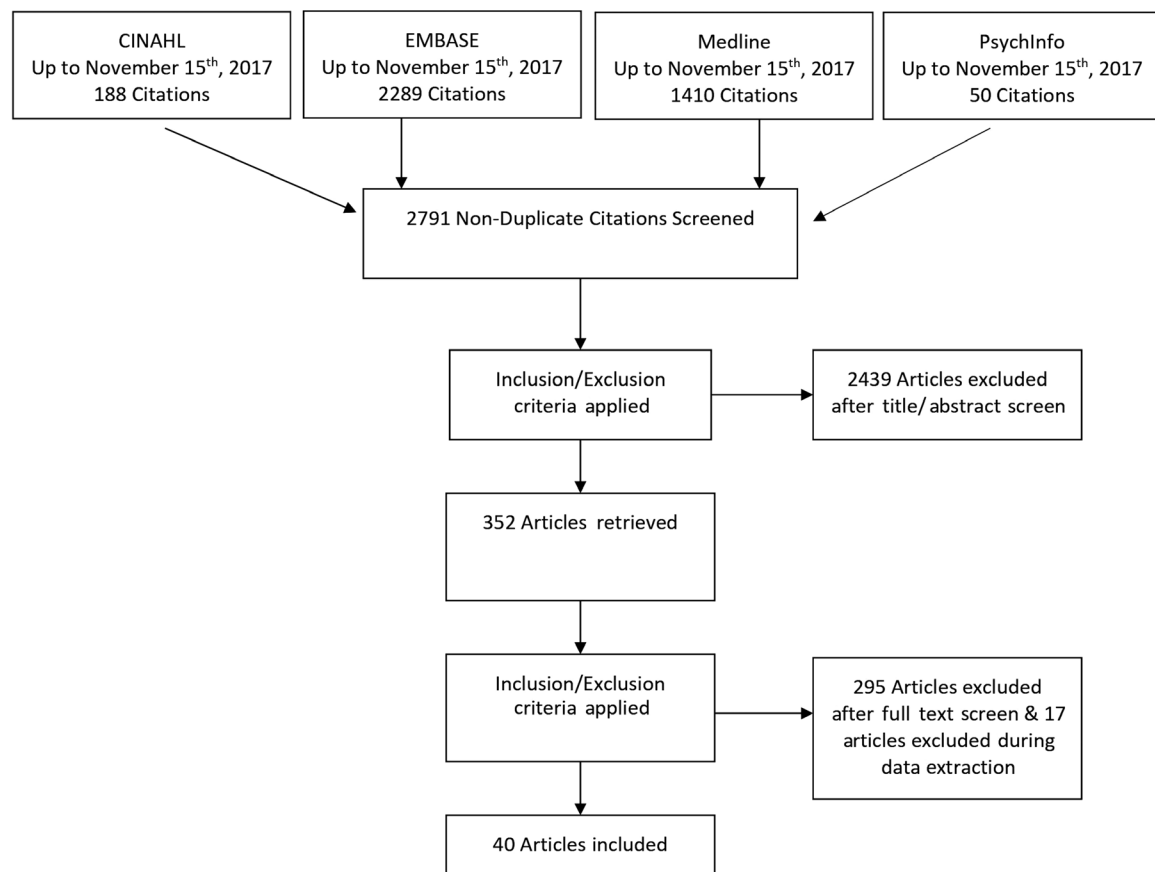


Figure 1 Search and selection of articles.

five levels, with multiple sublevels, including 1.a [systematic review (SR) of Randomised controlled trials (RCT)], 1.b (SR of RCT and lower studies), 1.c (RCT), 1.d (Pseudo RCT), 2.a (SR of quasi-experimental studies), 2.b (SR of quasi-experimental and lower studies), 2.c (quasi-experimental prospectively controlled study), 2.d (pre-test/post-test control group), 3.a (SR of cohort studies), 3.b (SR of cohort and lower studies), 3.c (cohort with control group), 3.d (case-controlled), 3.e (observational study without control), 4.a (SR of descriptive studies), 4.b (cross-sectional), 4.c (case series), 4.d (case study), 5.a (SR of expert opinion), 5.b (expert consensus) and 5.c (single expert opinion). The LOE of the studies included in this systematic review ranged from 1.c to 4.c, with 1.c–3.d referring to a high level of evidence compared to 3.e–4.c. The majority of the studies had observational/analytic designs, including case–control, cohort, and analytical cross-sectional studies. Only one randomised controlled trial was found and included in the review; 10 studies had nonrandomised control groups and six studies were descriptive in nature. The sample sizes ranged from 30 participants to 5912 participants. As a result of the nature of CD, purposive sampling was used in the majority of the studies.

Synthesis of facilitators and barriers

Tables 3 and 4 summarise the studies that reported evidence on each facilitator and barrier that impacted GFD adherence in adults with CD. Taking into consideration the magnitude of the significance, the LOE, and the quality of each study, which takes into consideration participant selection, data collection/analysis and study biases, the facilitators and barriers with the most supporting evidence at each ecological layer were identified.

The *individual layer* represents factors that influence dietary adherence based on personal characteristics, irrespective of individuals' surrounding relationships and environment. The *interpersonal layer* represents factors that influence dietary adherence based on individuals' direct relationships in their lives. The *organisational layer* includes rules, regulations and influences from one's surrounding environment on adherence to a GFD. The *community layer* refers to factors that are based on individuals' influences by their relationships with their surrounding society and social institutions. It also includes any cultural influence on dietary adherence. This layer also includes environmental boundaries. Last, the *system's layer* represents factors that impact dietary adherence that originate from a macro, policy level⁽¹⁶⁾.

Figure 2 synthesises and illustrates the results of this systematic review using a social ecological model that organises the various facilitators and barriers into

ecological layers and displays relationships that exist across many layers in an individual's life, and specifically within the health system⁽¹⁷⁾. When an individual is diagnosed with CD, they are faced with many facilitators and barriers that impact their ability to adhere to a GFD. This model reports what area of one's life each facilitator and barrier fits into, highlighting where improvements can be made to make positive changes. Beyond the individual layer, the interpersonal layer includes factors that correspond to the relationships that exist in an adult's everyday life. As we move externally, the organisational structure includes the interactions adults make in their environment and how those end up influencing GFD adherence. The community layer is past the organisational level, and relates to society's impact on an adult with CD; it includes geographical variables and cultural differences. Last, the final layer, which is most distant from the individual, is the systems layer. This layer encompasses laws and policies that may impact an adult with CD. Although this layer is the most distant, it also has the most substantial impact because the structure of this layer has an impact on every other layer of an individual's life⁽¹⁰⁾.

Individual facilitators/barriers

At the individual layer, four main factors were reported in the literature that related to adherence to a GFD by adults with CD: Education level/income, health status, knowledge, and intention/motivation. The LOE of these studies ranged from 1.c to 4.b.

First, individuals with a high level of education/income were significantly associated with having higher GFD adherence levels^(18,19). These individuals were more aware of the negative health impacts of non-adherence and were less likely to be impacted by the high costs associated with GF foods.

Second, an adult's overall health and their adherence levels to a GFD were shown to be correlated^(18,20,21). Adults' perspectives on their health influenced their adherence level to a GFD. This emphasises the importance of facilitating constant patient-practitioner communication to ensure patients are knowledgeable about their health status.

Third, understanding how the consumption of gluten can have adverse health risks to someone with CD was linked to a higher ability to adhere to a GFD⁽²²⁾. If the severity of CD is not known, someone may not be willing to put in the effort to follow a GFD^(23–28). Being educated on an illness allows individuals to be able to make a more informed decision on how seriously they take their treatment protocol.

Fourth, adults who had positive intentions when starting out with a GFD were shown to have an increased

Table 2 Overview of the studies included in the systematic review

Study	Year	Country	Study design	Participants/sample Size	Age of participants	Level of evidence
Twist & Hackett ⁽⁴⁶⁾	1992	UK	Case-control	Group 1: 46 Group 2: 46	14-40	3.d
Lamontagne <i>et al.</i> ⁽³⁷⁾	2001	Canada	Analytical, cross-sectional	230	Mean = 49.6	3.e
Ciacci, Iavarone, Siniscalchi, Romano & Rosa ⁽²³⁾	2002	Italy	Case-control	Group 1: 25 Group 2: 114	Mean = 29.62	3.d
Ciacci <i>et al.</i> ⁽⁵¹⁾	2003	Italy	Analytical, cross-sectional	581	Mean = 31.47	3.e
Hogberg, Grodzinsky & Stenhammar ⁽⁵²⁾	2003	Sweden	Case-control	Group 1: 15 Group 2: 14	Mean = 26	3.d
Butterworth <i>et al.</i> ⁽⁴⁵⁾	2004	UK	Prospective, cohort	Group 1: 66 Group 2: 21	Mean Group 1: 46.3 Mean Group 2: 28.95	3.c
Zarkadas <i>et al.</i> ⁽⁴¹⁾	2006	UK	Descriptive, cross-sectional	2681	Mean = 56	4.b
Hauser, Stallmach, Caspary & Stein ⁽²⁰⁾	2007	Germany	Analytical, cross-sectional	522	Mean = 46.3	3.e
Hopman, Koopman, Wit & Mearin ⁽⁵³⁾	2009	Netherlands	Case-control	Group 1: 33 Group 2: 8 Group 3: 12	Mean Group 1: 57 Mean Group 2: 26 Mean Group 3: 30	3.d
Smith ⁽⁴²⁾	2009	USA	Descriptive, cross-sectional	156	Mean = 51.5	4.b
Barratt, Leeds & Sanders ⁽¹⁸⁾	2011	UK	Case-control	Group 1: 348 Group 2: 225	18+	3.d
Black & Orfila ⁽²⁴⁾	2011	UK	Descriptive, cross-sectional	146	18-70	4.b
Sainsbury & Mullan ⁽³⁸⁾	2011	Australia	Analytical, cross-sectional	265	Mean = 45.1	3.e
Biagi <i>et al.</i> ⁽³⁶⁾	2012	Italy	Retrospective, cohort	141	Mean = 34	3.c
Casella <i>et al.</i> ⁽⁵⁴⁾	2012	Italy	Prospective, cohort	Group 1: 1166 Group 2: 59	Group 1: 18-64 Group 2: 65+	3.c
Ford, Howard & Oyebode ⁽²²⁾	2012	UK	Analytical, cross-sectional	274	19-85	3.e
Lee, Ng, Diamond, Ciaccio & Green ⁽⁴³⁾	2012	USA	Case-control	Group 1: 1179 Group 2: 1743	18+	3.d
Ukkola <i>et al.</i> ⁽²⁵⁾	2012	Finland	Prospective, cohort	698	Median = 50	3.c
Hall, Rubin & Charnock ⁽¹⁹⁾	2013	UK	Analytical, cross-sectional	287	Mean = 56.17	3.e
Mahadev <i>et al.</i> ⁽⁵⁵⁾	2013	USA	Analytical, cross-sectional	413	18+	3.e
Sainsbury, Mullan & Sharpe ⁽⁵⁶⁾	2013	Australia	Analytical, cross-sectional	390	Mean = 44.2	3.e
Sainsbury, Mullan & Sharpe ⁽²⁹⁾	2013	Australia	Randomised Control Trial	Experimental: 101 Control: 88	Mean = 46.5	1.c
Verrill, Zhang & Kane ⁽³⁹⁾	2013	USA	Analytical, cross-sectional	1583	18-98	3.e
Zarkadas <i>et al.</i> ⁽⁴⁹⁾	2013	Canada	Analytical, cross-sectional	5912	18+	3.e
Dowd <i>et al.</i> ⁽³⁴⁾	2014	Canada	Descriptive, cross-sectional	203	Mean = 42.13	4.b
Rose & Howard ⁽⁴⁴⁾	2014	UK	Descriptive, grounded theory	130	Mean = 52.7	4.c
Shah <i>et al.</i> ⁽³⁵⁾	2014	USA	Analytical, cross-sectional	341	Mean = 51.14	3.e

Table 2 Continued

Study	Year	Country	Study design	Participants/sample Size	Age of participants	Level of evidence
Casellas <i>et al.</i> ⁽²¹⁾	2015	Spain	Analytical, cross-sectional	366	Mean = 40	3.e
Ferster, Obuchowicz, Jarecka, Pietrzak & Karczewska ⁽⁴⁷⁾	2015	Poland	Descriptive, cross-sectional	30	19–71	4.b
Kothe, Sainsbury, Smith & Mullan ⁽³⁰⁾	2015	Australia	Analytical, cross-sectional	228	Mean: 45.2	3.e
Rajpoot <i>et al.</i> ⁽²⁶⁾	2015	India	Prospective, cohort	Group 1: 54 Group 2: 92	Mean = 28.9	3.c
Sainsbury, Mullan & Sharpe ⁽⁵⁷⁾	2015	Australia	Case-control	Group 1: 88 Group 2: 101	Mean = 46.5	3.d
Villafuerte-Galvez <i>et al.</i> ⁽³¹⁾	2015	USA	Analytical, cross-sectional	355	Mean = 53.6	3.e
Dowd, Jung, Chen & Beauchamp ⁽³²⁾	2016	Canada	Prospective, cohort	212	Mean = 42.08	3.c
Silvester, Weiten, Graff, Walker & Duerksen ⁽²⁷⁾	2016	Canada	Analytical, cross-sectional	82	18+	3.e
Silvester, Weiten, Graff, Walker & Duerksen ⁽⁴⁰⁾	2016	Canada	Analytical, cross-sectional	222	18+	3.e
Ramirez-Cervantes, Romero-Lopez, Nunez-Alvarez & Uscanga-Dominguez ⁽²⁸⁾	2016	Mexico	Analytical, cross-sectional	56	Mean = 59.4	3.e
Dowd & Jung ⁽³³⁾	2017	Canada	Prospective, cohort	200	Mean = 44.02	3.c
Hughey <i>et al.</i> ⁽⁵⁰⁾	2017	USA	Analytical, cross-sectional	1832	19–65	3.e
Muhammad, Reeves, Ishaq, Mayberry & Jeanes ⁽⁴⁸⁾	2017	UK	Analytical, cross-sectional	375	Mean = 48	3.e

likelihood in following a GFD correctly ^(22,29–33). Studies also showed that those who had poor intention/ a poor level of self-efficacy were also found to have a lower likelihood of following a GFD ^(19,22,28). The belief an individual had, as to whether a GFD would improve their CD outcomes impacted adherence levels. Individuals considered that a GFD will improve CD outcomes correlated to an increase in GFD adherence ⁽³¹⁾ and individuals considering that a GFD will not improve CD outcomes correlated to them being less likely to follow a GFD ^(19,23,34,35). Individuals who were less careful with maintaining precautions, such as informing their cooks about their allergies, were less likely to adhere to a GFD ⁽³⁶⁾.

Interpersonal facilitators/barriers

At the interpersonal layer, four main factors were related to adherence to a GFD by adults with CD: social fear, confidence in practitioner, social activities and embarrassment. The LOE of these studies ranged from 3.c to 4.c.

It is human nature to act differently when in the presence of others. It is common for people with CD to engage in behaviour that can influence their adherence to a GFD. Studies included in this review highlighted a

significant correlation between low levels of adherence to a GFD and the social fear of having CD ^(18,23).

Confidence in the practitioner impacted GFD adherence. If an individual was not confident in their treatment advice provided by their specialist, they were less likely to adhere to a GFD ⁽³⁷⁾. In addition, individuals with CD reported that it is easier to follow a GFD when they had a high level of support from family and friends ^(38–40). Having increased support from surrounding relationships lowers the risk of isolation and allows individuals to adhere to their health needs without feeling alienated.

Last, several studies discussed that participating in social activities played a negative role in relation to diet adherence. Specifically, people reported that participating in social activities, including dining outside of the home and spending time with friends had a negative impact on their ability to maintain a GFD ^(24,41–43). Reasons included overly trusting others with food preparation ⁽³⁸⁾ and the overall ignorance of others in understanding the severity of CD ⁽⁴⁴⁾. It is common for an individual with CD to feel isolated and different from those around them. The need for inclusivity causes individuals to neglect their illness and risk adverse health outcomes.

Table 3 Facilitators to gluten-free diet (GFD) adherence

Study	Individual facilitators	Interpersonal facilitators	Organisational facilitators	Community facilitators	Systems facilitators
Twist & Hackett ⁽⁴⁶⁾	–	–	–	–	–
Lamontagne <i>et al.</i> ⁽³⁷⁾	Older age increased a person's ability to maintain a GFD ($P < 0.05$)	Having a high level confidence in gastroenterologists and dieticians was correlated with a higher adherence to a GFD ($P < 0.005$)	Having a high level of satisfaction with GF products was correlated with improved GFD scores ($P < 0.01$)	–	Having improved communication with specialists was correlated with a higher adherence to a GFD ($P < 0.005$)
Ciacci, Iavarone, Siniscalchi, Romano & Rosa (2002) ⁽²³⁾	A longer time on a GFD was correlated with a higher adherence level to a GFD ($P = 0.0025$)	–	–	–	A longer time on a GFD was correlated with a higher adherence level to a GFD ($P = 0.0025$)
Ciacci <i>et al.</i> (2003) ⁽⁵¹⁾	A higher education level was associated with an increase GFD adherence ($P = 0.0001$) If an individual was diagnosed later in life (after 20), there was a correlation with a higher level of GFD adherence ($P = 0.0001$) Women were statistically more likely to be adherent to a GFD ($P = 0.0025$)	–	–	–	–
Hogberg, Grodzinsky & Stenhammar ⁽⁵²⁾	A significant relationship found between being diagnosed before the age of 4 years and having improved GFD adherence ($P = 0.021$)	–	–	–	–
Butterworth <i>et al.</i> ⁽⁴⁵⁾	–	–	Membership in a coeliac society was correlated with an increase in GFD adherence. OR (95% CI) 2.94 (1.72–5.26) for Caucasians Having a better understanding of food labelling was correlated with an increase in GFD adherence [OR (95% CI) 2.13 (1.08–4.17)]. Affordability of GF products was correlated with an increase in GFD adherence OR (95% CI) [Caucasian: 1.82 (1.12–2.86)]	–	Obtaining GF products by prescription was correlated to increased adherence to a GFD OR (95% CI): Caucasian: 2.0 (1.04–3.85) A GFD was shown to improve as more GF products were prescribed. OR (95% CI): Caucasian: 1.89 (1.08–3.33) Detailed explanation post-diagnosis was correlated with better adherence to a GFD OR (95% CI) 2.04 (1.16–3.57) Regular follow-up with a practitioner or dietician showed a correlation with increased dietary adherence OR (95% CI): Caucasian: 2.22 (1.12–4.35)

Table 3 Continued

Study	Individual facilitators	Interpersonal facilitators	Organisational facilitators	Community facilitators	Systems facilitators
Zarkadas <i>et al.</i> (2006) ⁽⁴¹⁾	Descriptive data highlighted that individuals were better able to adhere to a GFD if they were diagnosed earlier in life	–	Individuals in this study stated that having better access to GF foods in supermarkets, as well as restaurants, and understanding food labels increase their ability to maintain dietary adherence	–	Individuals in this study shared what would improve their ability to adhere to a GFD. Factors included: Early diagnosis, better food labelling, and increased follow-up for dietary counselling
Hauser, Stallmach, Caspary & Stein ⁽²⁰⁾	–	–	–	–	–
Hopman, Koopman, Wit & Mearin ⁽⁵³⁾	–	–	–	–	–
Smith ⁽⁴²⁾	–	–	–	–	–
Barratt, Leeds & Sanders ⁽¹⁸⁾	Individuals who were from an Affluent background had better adherence to a GFD [$P = 0.0077$; OR = 0.33 95% CI (0.15–0.75)]	–	–	–	–
Black & Orfila ⁽²⁴⁾	–	–	–	–	–
Sainsbury & Mullan (2011) ⁽³⁸⁾	Through a qualitative process, participants shared factors that increased their ability adhere to a GFD. These factors included: Increased knowledge of ingredients/ label reading, being prepared and organised, the desire to minimise CD symptoms and feel physically better	Participants shared factors that increased their ability to maintain a GFD including: Support from friends and the confidence to ask food-handlers questions about contamination	Support from coeliac associations was mentioned through interviews as a facilitator to adhering to a GFD. Clear labelling of foods was a common response by participants as a facilitator to adhering to a GFD	–	Clear labelling of foods was a common response by participants as a facilitator to adhering to a GFD
Biagi <i>et al.</i> ⁽³⁶⁾	–	–	–	–	–
Casella <i>et al.</i> ⁽⁵⁴⁾	–	–	–	–	–
Ford, Howard & Oyeboode ⁽²²⁾	A higher rating of self-efficacy was correlated with increased adherence to a GFD ($P = 0.04$); There was a correlation between Older age and increased adherence to a GFD ($P = 0.002$); If an individual viewed the consequences of Ingesting gluten as more severe, there was a correlation with increased adherence to a GFD ($P = 0.009$); The belief in the cyclical nature of CD was correlated with an increase in GFD adherence ($P = 0.02$)	–	–	–	–
Lee, Ng, Diamond, Ciaccio & Green ⁽⁴³⁾	–	–	–	–	–
Ukkola <i>et al.</i> ⁽²⁵⁾	–	–	–	–	–

Table 3 Continued

Study	Individual facilitators	Interpersonal facilitators	Organisational facilitators	Community facilitators	Systems facilitators
Hall, Rubin & Charnock ⁽¹⁹⁾	<p>If an individual was diagnosed as an adult, there was a correlation with an increased level of GFD adherence ($P < 0.05$)</p> <p>There was a correlation between having a higher education and an increased adherence level ($P = 0.047$)</p> <p>If an individual was older they were more likely to have a higher level of GFD adherence ($P < 0.001$)</p>	–	Being a member of a coeliac society was correlated with an increase in GFD adherence ($P < 0.001$)	–	<p>Regular follow-up with practitioner was shown to be correlated with an increase in GFD adherence ($P < 0.01$)</p> <p>A correlation was shown with time of diagnosis. A longer time since diagnosis was correlated with an increase in GFD adherence ($P = 0.019$)</p> <p>A correlation also showed a relationship with being diagnosed as an adult and increased GFD adherence ($P < 0.05$)</p> <p>A correlation was present between receiving prescription GF foods and better adhering to a GFD ($P < 0.01$)</p>
Mahadev <i>et al.</i> ⁽⁵⁵⁾	–	–	–	–	–
Sainsbury, Mullan & Sharpe (2013) ⁽⁵⁶⁾	<p>Having higher intention to maintain a GFD was correlated with an increased likelihood of maintaining a GFD ($P < 0.01$)</p> <p>Having an increased level of knowledge on CD and a GFD was correlated with an increased level of adherence to a GFD ($P < 0.01$)</p> <p>If an individual had a high Perceived behavioural control level, they were more likely to also be following a GFD at a higher level of adherence ($P < 0.001$)</p> <p>This study also highlighted that being female was linked to better adherence to a GFD ($P < 0.05$)</p>	–	–	–	–

Table 3 Continued

Study	Individual facilitators	Interpersonal facilitators	Organisational facilitators	Community facilitators	Systems facilitators
Sainsbury, Mullan & Sharpe (2013) ⁽²⁹⁾	<p>This RCT concluded that Completing the Intervention was linked with an improvement in following a GFD ($P < 0.001$)</p> <p>For those specifically who had low GFD adherence levels prior to the intervention, they were more likely to follow a GFD following the intervention ($P = 0.014$)</p>	–	–	–	<p>This RCT concluded that Completing the Intervention linked to improvement in following a GFD ($P < 0.001$)</p> <p>For those specifically who had low GFD adherence levels prior to the intervention, they were more likely to follow a GFD after the intervention ($P = 0.014$)</p>
Verrill, Zhang & Kane ⁽³⁹⁾	<p>This study also found a correlation between being Female and having an improved level of GFD adherence ($P = 0.013$)</p> <p>High self-rated health was also linked to an improved level of GFD adherence ($P < 0.0001$)</p>	<p>This study found that having Support from family and friends was correlated to improved adherence levels to a GFD ($P < 0.0001$)</p>	–	–	–
Zarkadas <i>et al.</i> (2013) ⁽⁴⁹⁾	<p>If an individual was following a GFD for longer period of time, they were less likely to make a mistake ($P < 0.001$)</p> <p>If an individual had a high level of strategy to maintain a GFD, they were correlated with better following a GFD ($P < 0.001$)</p> <p>Participants noted other reasons that lead them to being extremely careful with following a GFD: Preventing long-term complications; Immediate reactions; knowledge of GFD.</p>	–	–	–	<p>A correlation was shown between being on a GFD for longer period and better being able to adhere to that GFD ($P < 0.001$)</p> <p>Participants shared that having a higher knowledge level on CD and a GFD post-diagnosis increased their ability to maintain a GFD</p>
Dowd <i>et al.</i> (2014) ⁽³⁴⁾	<p>A recent diagnosis decreased likelihood of purposeful gluten consumption ($P = 0.002$), and having a diagnosis further in the past decreased accidental gluten consumption ($P = 0.001$)</p> <p>Participants listed the following as facilitators: Pain as a result of CD, Hitting rock bottom, and the need to gain or lose weight</p>	–	–	–	–

Table 3 Continued

Study	Individual facilitators	Interpersonal facilitators	Organisational facilitators	Community facilitators	Systems facilitators
Rose & Howard ⁽⁴⁴⁾	–	–	–	Through narratives given by individual's with CD, having access to the Coeliac Community improved their ability to adhere to a GFD	–
Shah <i>et al.</i> ⁽³⁵⁾	–	–	–	–	–
Casellas <i>et al.</i> ⁽²¹⁾	This study showed that there is a correlation between an increased Quality of Life score based on a validated questionnaire and an increase in GFD adherence ($P < 0.05$)	This study showed that there is a correlation between an increased Quality of Life score based on a validated questionnaire and an increase in GFD adherence ($P < 0.05$)	This study showed that there is a correlation between an increased Quality of Life score based on a validated questionnaire and an increase in GFD adherence ($P < 0.05$)	There is a correlation between an increased Quality of Life score based on a validated questionnaire and an increase in GFD adherence ($P < 0.05$)	This study showed that there is a correlation between an increased Quality of Life score based on a validated questionnaire and an increase in GFD adherence ($P < 0.05$)
Ferster, Obuchowicz, Jarecka, Pietrzak & Karczewska ⁽⁴⁷⁾	–	–	–	–	–
Kothe, Sainsbury, Smith & Mullan ⁽³⁰⁾	Having an improved attitude towards a GFD was correlated with higher adherence ($P = 0.029$) Having a higher Perceived behavioural control level was also correlated to higher adherence to a GFD ($P < 0.001$) Higher intention to maintain a GFD (when Perceived behavioural control is low and habit is high) was a third factor that was correlated to maintaining a GFD ($P < 0.001$)	–	–	–	–
Rajpoot <i>et al.</i> ⁽²⁶⁾	–	Having a Counselling relationship improved an individual's ability to maintain a GFD ($P = 0.014$)	–	–	–
Sainsbury, Mullan & Sharpe (2015) ⁽⁵⁷⁾	This study (follow-up to RCT) showed that if individuals rated a portion of the intervention as interesting, it was more likely to improve the adherence level to a GFD ($P < 0.05$)	–	–	–	–

Table 3 Continued

Study	Individual facilitators	Interpersonal facilitators	Organisational facilitators	Community facilitators	Systems facilitators
Villafuerte-Galvez <i>et al.</i> ⁽³¹⁾	<p>If an individual Perceived the effectiveness of GFD as high, there was a correlation with a higher GFD adherence ($P < 0.0001$)</p> <p>If an individual had a high level of Knowledge of GFD and CD, there was a correlation to being better able to follow a GFD ($P < 0.0001$)</p> <p>If individuals had a high Self-effectiveness score at following GFD, they were correlated to better follow a GFD ($P < 0.0001$)</p>	–	–	–	If an individual had a high level of Knowledge of GFD and CD, there was a correlation to being better able to follow a GFD ($P < 0.0001$)
Dowd, Jung, Chen & Beauchamp (2016) ⁽³²⁾	<p>This study highlighted that having greater symptom severity increased GFD adherence ($P < 0.05$)</p> <p>If an individual viewed CD as having a lower perceived cost, GFD adherence was increased ($P < 0.05$)</p> <p>If an individual had a High self-regulatory efficacy level based on a validated questionnaire, GFD adherence was shown to be higher ($P < 0.001$)</p> <p>If an individual had increased plans to eat GFD, their adherence was higher ($P < 0.001$)</p> <p>If an individual had Greater knowledge of CD and a GFD, their adherence rates were higher ($P < 0.001$)</p> <p>If individuals had Positive intentions with their GFD, their adherence was higher ($P < 0.001$)</p>	–	–	–	If an individual had Greater knowledge of CD and a GFD, their adherence rates were higher ($P < 0.001$)
Silvester, Weiten, Graff, Walker & Duerksen (2016) ⁽²⁷⁾	–	–	–	This study found a correlation between having a Patient-advocacy group and better adhering to a GFD ($P < 0.005$)	–

Table 3 Continued

Study	Individual facilitators	Interpersonal facilitators	Organisational facilitators	Community facilitators	Systems facilitators
Silvester, Weiten, Graff, Walker & Duerksen (2016) ⁽⁴⁰⁾	Participants shared that having access to Internet-based advice on CD and a GFD, as well as Magazines, increased their ability to maintain a GFD.	Participants shared that knowing another person on GFD increased their ability to follow a GFD.	It was stated that being a member of the Canadian Celiac Association allowed adherence to be improved; This was also mentioned for local CD groups.	Participants shared that having access to complementary medicine professionals such as naturopaths increased their ability to adhere to their GFD	Participants clearly articulated the importance of having access to practitioners when help was needed. This includes: Access to Family doctor/specialist, Dieticians and Complementary medicine professionals. Having this open communication was stated to improve the participant's ability to maintain a GFD.
Ramirez-Cervantes, Romero-Lopez, Nunez-Alvarez & Uscanga-Dominguez ⁽²⁸⁾	–	–	–	–	–
Dowd & Jung (2017) ⁽³³⁾	If an individual had a higher level of Self-compassion based on a validated questionnaire, their adherence levels were higher ($P < 0.01$ GFD) If an individual had a higher level of self-regulatory efficacy based on a validated questionnaire, their adherence levels were higher ($P < 0.001$)	–	–	–	–
Hughey <i>et al.</i> ⁽⁵⁰⁾	–	–	–	–	Visiting a health care practitioner in the last 5 years was correlated with an increase in an individual's ability to maintain a GFD ($P = 3.6 * 10^{-4}$)
Muhammad, Reeves, Ishaq, Mayberry & Jeanes ⁽⁴⁸⁾	This study found that being of an older age increased the ability to adhere to a GFD, slightly ($P = 0.03$)	–	This study found that being a member of the UK Celiac Society was correlated with an increase in GFD adherence ($P < 0.001$)	–	This study found a correlation between a General practitioner prescribing GF foods and an individual's ability to maintain a GFD ($P < 0.001$)

Organisational facilitators/barriers

At the organisational layer, four main factors related to adherence to a GFD by an adult with CD: Membership in a coeliac association, availability of GF foods in restaurants/supermarkets, clear labelling, and affordability. The LOE of these studies ranged from 3.c to 4.c.

Membership in a coeliac association was considered as a facilitator to adherence to GFD in several studies. Membership allowed for exposure to others with CD, improved the lives of many people with CD, and as a result, improved GFD adherence^(19,27,38,45).

Furthermore, the presence of GF foods in restaurants/supermarkets play an important role in enabling access to GF products. Studies showed correlations between the inability to find GF products in stores and restaurants to a lower likelihood of following a GFD^(23–26,34,42–44,46). Even in situations where there are GF options, participants shared that the poor taste of the items impacted adherence levels to a GFD^(36,43). Without access to sufficient food items, consumption of products containing gluten is more likely to occur. Availability of GF foods is linked to societies' awareness of CD. In societies where CD is not prevalent or well known, availability of products will unlikely be sufficient. Many individuals in multiple studies reported that dining establishments were unable to provide a safe experience for them correctly and, as a result, they made a mistake on their GFD⁽¹⁸⁾. These mistakes include the risk of cross-contamination^(34,47). Overall, lack of patient education can translate to the individual's ability to follow a GFD when choosing food in restaurants and supermarkets. Using available tools to get others to understand the severity of CD and to find suitable food options can impact their ability to properly follow a GFD. It is also important to note that the studies that highlighted the lack of availability of gluten-free food are older, and therefore not as relevant in today's context.

Gluten is found in multiple, hidden ingredients. Hence, clear food labelling can act as an important facilitator to GFD adherence^(38,45). Although gluten and its derivatives must be disclosed on packaged labels in North America, clear food labelling is not a requirement in all countries/regions. If allergens are explicitly listed, individuals will know to avoid certain products. Individuals with CD can instantly identify a product as being safe to consume if there is a GF claim on the product.

Finally, GF foods are often more expensive than non-GF foods. Studies showed that the inability to afford GF foods was linked to lower adherence to a GFD^(34,42,43,45).

Community facilitators/barriers

At the community layer, two main factors were related to adherence to a GFD by adults with CD: general society

awareness and culture. The LOE of these studies ranged from 3.c to 4.c.

General society awareness was discussed in some studies, which showed a significant correlation between society's general knowledge of what gluten and CD are, as well as an adult's ability to maintain a GFD^(19,32). In more CD-friendly communities, individuals were able to find better options on foods to eat and to communicate their dietary restrictions. Improved society awareness translates to improved knowledge of employees at restaurants and other food establishments. There is also an increased chance that peers will be more knowledgeable about CD as a result of them being a part of a CD-friendly society. This translates to better support from peers to those with CD^(19,32).

Another important discussed factor was culture, with individuals reporting that cultural factors lowered their likelihood to follow a GFD^(26,28,46). Being of South-Asian background was shown to significantly be correlated to a lower likelihood of following a GFD^(45,48). Individuals also reported relatives forcing them to eat foods containing gluten, not understanding how harmful they can be⁽⁴⁶⁾.

System facilitators/barriers

At the system layer, three main factors were related to adherence to a GFD by adults with CD: physician–patient knowledge, poor communication post-diagnosis and finances. The LOE of these studies ranged from 1.c to 4.b.

Physician–patient knowledge communication/follow-up was considered as an important barrier in multiple studies in the literature, and was significantly correlated with lower adherence to a GFD^(25–27,35,43). The most prominent system-level barrier found in the systematic review was the lack of knowledge that individuals recently diagnosed with CD had with their disease and the composition of a GFD. Although this is also an individual barrier, this is rather a systematic issue. At a system level, this lack of knowledge stems from patient-practitioner communication, which may inadequately equip individuals with CD with the educational tools and resources. Several studies showed that providing recently diagnosed patients with detailed descriptions of what CD was and what a GFD entailed, correlated to them being more likely to be able to accurately follow a GFD^(31,34,37,45,49). These studies' findings emphasise that there need to be proper communication channels open with a patient once they are diagnosed, to ensure that they entirely are aware of the extent of their disease and that they know how to handle their diet correctly.

Table 4 Barriers to gluten-free diet (GFD) adherence

Study	Individual barriers	Interpersonal barriers	Organisational barriers	Community barriers	Systems barriers
Twist & Hackett ⁽⁴⁶⁾	–	Participants shared that forcing foods limited their ability to adhere to a GFD	Participants shared that the lack of availability of GF products lowered their ability to adhere to a GFD	Participants shared that relatives forcing foods limited their ability to adhere to a GFD (cultural impact)	Participants shared that their dietary adherence was lowered as a result of doctors being unwilling to prescribe GF products, as well as having problems with the large chemist responsible for prescriptions
Lamontagne <i>et al.</i> ⁽³⁷⁾	This study shows a correlation between worrying over planning and cooking GF meals and a lower ability to follow a GFD ($P < 0.005$)	–	–	This study showed a correlation between living in a large region of residence and having a lower ability to adhere to a GFD ($P < 0.02$)	–
Ciaci, Iavarone, Siniscalchi, Romano & Rosa (2002) ⁽²³⁾	A correlation was shown between a patient with CD reporting being angry and them having a lower ability to follow a GFD ($P = 0.0005$)	–	–	–	–
Ciaci <i>et al.</i> (2003) ⁽⁵¹⁾	Individuals reported that having anger towards CD, not wanting to be different than others and believing the occasional consumption of gluten was okay lowered their ability to adhere to a GFD	Embarrassment of CD was shown to have a strong correlation to being unable to adhere to a GFD ($P = 0.0001$)	Participants showed that dining at restaurants lowered their adherence levels to a GFD	–	–
Hogberg, Grodzinsky & Stenhammar ⁽⁵²⁾	–	–	–	–	This study presented showed a significant relationship between being diagnosed after the age of 4 and having lower GFD adherence levels ($P = 0.021$)
Butterworth <i>et al.</i> ⁽⁴⁵⁾	–	–	–	The study highlighted that being of a South Asian background, lowered the ability to follow a GFD ($P = 0.04$)	–
Zarkadas <i>et al.</i> (2006) ⁽⁴¹⁾	–	This study highlights that participants find that dining outside home limited their ability to maintain a GFD	This study highlights that participants find that dining outside home limited their ability to maintain a GFD	–	This study highlights that patients find Hospital stays lower their GFD adherence

Table 4 Continued

Study	Individual barriers	Interpersonal barriers	Organisational barriers	Community barriers	Systems barriers
Hauser, Stallmach, Caspany & Stein ⁽²⁰⁾	This study showed a correlation between a Reduced Health related quality of life score and having a lower likelihood to follow a GFD ($P = 0.01$)	This study showed a correlation between a Reduced Health related quality of life score and having a lower likelihood to follow a GFD ($P = 0.01$)	This study showed a correlation between a Reduced Health related quality of life score and having a lower likelihood to follow a GFD ($P = 0.01$)	This study showed a correlation between a Reduced Health related quality of life score and having a lower likelihood to follow a GFD ($P = 0.01$)	This study showed a correlation between a Reduced Health related quality of life score and having a lower likelihood to follow a GFD ($P = 0.01$)
Hopman, Koopman, Wit & Mearin ⁽⁵³⁾	This study reported that individuals were less likely to follow a GFD when they had no symptoms when ingesting gluten, as well as if they were diagnosed with CD at a younger age	–	–	–	This study reported that GFD adherence was negatively impacted by poor medical advice (statements that CD was cured)
Smith ⁽⁴²⁾	Participants shared reasons as to why they did not adhere to a GFD. This included the dislike of the taste of GF foods	Participants found that problems outside the home, including social events/potluck dinners contributed to non-adherence to a GFD	Participants in this study shared that dining at restaurants and the high cost of GF foods impacted their ability to adhere to a GFD	Participants shared that whenever they traveled, their ability to adhere to a GFD was lowered.	–
Barratt, Leeds & Sanders ⁽¹⁸⁾	Reductions in QOL paired with risk of anxiety and depression were correlated with a lower level of GFD adherence ($p < 0.001$)	Individuals reported that eating out, personal relationships, home environment, and socialising lowered their ability to adhere to a GFD	Individuals reported that eating out and an individual's workplace environment lowered their ability to adhere to a GFD	Individuals reported that traveling lowered their ability to adhere to a GFD	–
Black & Orfila ⁽²⁴⁾	Individuals reported that a lack of care, as well as lacking knowledge of GF options lowered their ability to follow a GFD;	Individuals reported that dining of outside home lowered their ability to adhere to a GFD	Individuals reported that specifically, dining at restaurants lowered their ability to adhere to a GFD	–	–
Sainsbury & Mullan ^{(2011) (38)}	Participants shared that overly trusting non-coeliac individuals with their food preparation lowered an individual's ability to follow a GFD	–	–	–	–

Table 4 Continued

Study	Individual barriers	Interpersonal barriers	Organisational barriers	Community barriers	Systems barriers
Biagi <i>et al.</i> ⁽³⁶⁾	A questionnaire that asked specific questions about an individual with CD was linked to not adhering to a GFD. The questions included: 1. Not informing cook about allergy, 2. Not checking labels. 3. Eat packaged food not certified by Celiac Association, 4. Desire to taste gluten-containing food. ($P = 0.001$)	–	–	–	–
Casella <i>et al.</i> ⁽⁵⁴⁾ Ford, Howard & Oyebo ⁽²²⁾	This study reported a correlation between having a Low self-efficacy rating and lower adherence to a GFD ($P = 0.04$)	–	–	–	–
Lee, Ng, Diamond, Ciaccio & Green ⁽⁴³⁾	Individuals in the study stated that finding a GFD Difficult to follow, and finding GF foods Tasteless lowered their adherence to a GFD	Several interpersonal factors limited participant's ability to maintain a GFD. These included: Social activities, spending time with friends, and being uncomfortable in social settings	Dining at Restaurants and finding a GFD too expensive were highlighted as barriers to a GFD. A correlation was also shown between finding a GFD too restrictive and low adherence to a GFD ($P = 0.01$)	–	Participants in this study reported that their dietary adherence was lowered as a result of not learning about CD from physicians
Ukkola <i>et al.</i> ⁽²⁵⁾	Lack of knowledge on GF foods was highlighted by participants that lowered their likelihood of following a GFD	–	Participants helped highlight that the poor labelling of GF products and difficulties in identifying GF food when dining out lowered their ability to adhere to a GFD	–	At a systems level, Lack of knowledge of CD and a GFD, as well as poor labelling of GF products decrease the ability to adhere to a GFD

Table 4 Continued

Study	Individual barriers	Interpersonal barriers	Organisational barriers	Community barriers	Systems barriers
Hall, Rubin & Charnock ⁽¹⁹⁾	This study shows a correlation between people who believe they have a Perceived tolerance to gluten and lower GFD adherence ($P < 0.001$) Another correlation was found between having a Low Self-efficacy score and having a lower adherence level to a GFD ($P < 0.01$) A third correlation was shown between an individual having low intention with following a GFD, and actively following a GFD ($P < 0.001$)	–	–	–	–
Mahadev <i>et al.</i> ⁽⁵⁵⁾	–	–	–	–	–
Sainsbury, Mullan & Sharpe (2013) ⁽⁵⁶⁾	This study showed a correlation between depression and a lower ability to adhere to a GFD ($P < 0.01$) If an individual was at-risk for an eating risk disorder, a correlation showed they were also less likely to adhere to a GFD ($P < 0.05$)	–	–	–	–
Sainsbury, Mullan & Sharpe (2013) ⁽²⁹⁾	–	–	–	–	–
Verrill, Zhang & Kane ⁽³⁹⁾	This study showed that a greater consumption of packaged, processed foods was associated with participants being less likely to adhere to a GFD	–	This study showed that a greater consumption of packaged, processed foods was associated with participants being less likely to adhere to a GFD	–	–
Zarkadas <i>et al.</i> (2013) ⁽⁴⁹⁾	–	–	–	–	–

Table 4 Continued

Study	Individual barriers	Interpersonal barriers	Organisational barriers	Community barriers	Systems barriers
Dowd <i>et al.</i> (2014) ⁽³⁴⁾	Individuals who had a belief in being less sensitive, the desire to taste gluten-containing foods, the desire to travel, and being exposed to alcohol, reported having a lower adherence level to a GFD	–	This study highlighted organisational factors that limited adherence to a GFD. These include: Dining at restaurants, GF foods being too expensive and cross-contamination risks	The study highlighted that travelling lowered individual's ability to adhere to a GFD	–
Rose & Howard ⁽⁴⁴⁾	This study shared participants views that those who did not have visible symptoms, were less likely to adhere to a GFD.	Participants found that the ignorance of others limited their ability to maintain a GFD	Participants shared that the ignorance of others and the lack of GF options impacted their ability to maintain a GFD	–	–
Shah <i>et al.</i> ⁽³⁵⁾	This study displayed several correlations that were linked with lower adherence to a GFD. These included: Having an income less than \$200,000 ($P = 0.047$), being unemployed ($P = 0.05$), having increased severity of CD symptoms ($P < 0.001$), having a lower perceived importance of treatment ($P < 0.001$) And having a greater treatment burden score ($P < 0.001$)	–	–	–	Having a lower perceived importance of treatment was correlated with a lower level of adherence to a GFD ($P < 0.001$)
Casellas <i>et al.</i> ⁽²¹⁾ Ferster, Obuchowicz, Jarecka, Pietrzak & Karczewska ⁽⁴⁷⁾	–	–	This study showed various factors that participants found limited their ability to adhere to a GFD. These include: Inadequate food labelling, and cross-contamination risks from mass catering establishments	This study highlighted that travelling (both within the country and international) were linked as factors that lowered the ability for an adult with CD to adhere to a GFD	This study highlighted that inadequate food labelling, having no governmental reimbursement plan and having limited access to nutritionist's advice lowered their ability to adhere to a GFD
Kothe, Sainsbury, Smith & Mullan ⁽³⁰⁾	–	–	–	–	–

Table 4 Continued

Study	Individual barriers	Interpersonal barriers	Organisational barriers	Community barriers	Systems barriers
Rajpoot <i>et al.</i> ⁽²⁶⁾	Individuals in this study reported that their lack of understanding of gluten and CD, and issues with their regular eating habits, lowered their ability to follow a GFD	–	Individuals in this study reported that the lack of availability of GF products and high costs of GF foods lowered their ability to adhere to a GFD	Participants stated that travelling, set eating habits, as well as social/cultural factors negatively impacted their ability to adhere to a GFD	Individuals in this study reported that their lack of understanding of gluten and CD initiating from poor communication with physicians lowered their ability to adhere to a GFD
Sainsbury, Mullan & Sharpe (2015) ⁽⁵⁷⁾	–	–	–	–	–
Villafuerte-Galvez <i>et al.</i> ⁽³¹⁾	–	–	This study showed a clear link between participants finding the Cost of a GFD being high and their likelihood of not following a GFD ($P < 0.0001$)	–	–
Dowd, Jung, Chen & Beauchamp (2016) ⁽³²⁾	–	–	–	–	–
Silvester, Weiten, Graff, Walker & Duerksen (2016) ⁽²⁷⁾	This study showed a clear link between the lack of knowledge of gluten-containing foods and not being able to adhere to a GFD. Every single participant was unaware of all gluten-containing products	–	–	–	This study showed a clear link between the lack of knowledge of gluten-containing foods and not being able to adhere to a GFD. Every single participant was unaware of all gluten-containing products
Silvester, Weiten, Graff, Walker & Duerksen (2016) ⁽⁴⁶⁾	–	–	–	–	–
Ramirez-Cervantes, Romero-Lopez, Nunez-Alvarez & Uscanga-Dominguez ⁽²⁸⁾	This study explained that participants low intention with following a strict diet and having lower knowledge on CD decreased their ability to follow a GFD	–	–	This study showed that cultural differences decreased participants' abilities to adhere to a GFD	–
Dowd & Jung (2017) ⁽³³⁾	–	–	–	–	–
Hughey <i>et al.</i> ⁽⁵⁰⁾	–	–	–	–	–

Table 4 Continued

Study	Individual barriers	Interpersonal barriers	Organisational barriers	Community barriers	Systems barriers
Muhammad, Reeves, Ishaq, Mayberry & Jeanes ⁽⁴⁸⁾	The study reported a decrease in ability to follow a GFD for south Asian patients compared to Caucasian patients. A correlation was found between an individual finding unpleasant taste when it comes to GF foods and their adherence to a GFD ($P = 0.028$)	–	This study reported that poor food labelling was correlated with a lower ability to adhere to a GFD ($P < 0.001$)	The study reported a decrease in ability to follow a GFD for south Asian patients compared to Caucasian patients.	This study reported that poor food labelling was correlated with a lower ability to adhere to a GFD ($P < 0.001$).

This systematic review found that many individuals are left to manage their disease on their own without support. This lack of communication continues post-diagnosis. Studies have shown that when adults with CD are looking for aid from a practitioner, they are not always readily available, leading to lower adherence rates to a GFD⁽⁴⁷⁾. Many studies also reported on the benefit of consistent follow-up with practitioners, post-diagnosis^(19,41,45,50). Specifically, correlations existed that showed that, when individuals had constant follow-up appointments with their physicians, they were more likely to continue adhering to a strict GFD^(19,41,45,50).

Last, finance can impact multiple layers in an adult's life. Hence, lack of financial reimbursement to support individuals with CD acts as a barrier, at the system level, to adhering to a GFD. While certain individuals had access to reimbursement plans to help offset the high costs of GF foods, it was reported that the lack of adequate reimbursement provided by the government lowered their ability to follow a GFD⁽⁴⁶⁻⁴⁷⁾. Studies reported correlations between the supply of prescription foods, and an improved ability to maintain a GFD^(19,48). Individuals who receive these subsidies do not need to worry about finding safe foods.

Discussion

Systematic reviews provide the highest level of evidence on a particular topic. This systematic review critically appraised and synthesised evidence from primary studies, which investigated the facilitators and barriers that influence dietary adherence for adults with CD. Several empirical studies in the literature have analysed the factors that influence an individual's adherence to a GFD. However, limited information was available to date on the evidence on the impacts that these factors may have in relation to GFD adherence. In light of the adverse events that may result from poor adherence to GFD, and the potential social and financial impacts at the individual and system level, it is of utmost importance to understand what changes and improvements can be made to facilitate GFD adherence. Hence, the results of this review present relevant information that can inform changes at the policy and practice levels. To provide practical solutions to policymakers in the healthcare system regarding the lives of adults with CD, a clear understanding of their day-to-day lifestyle is needed. Fully understanding the lifestyle of adults with CD can potentially improve dietary adherence, and as a result, improve the health of individuals with CD.

At the individual level, *knowledge of CD/GFD* was the most significant factor identified in the literature. It was reported in eight studies as a facilitator, and 14 studies

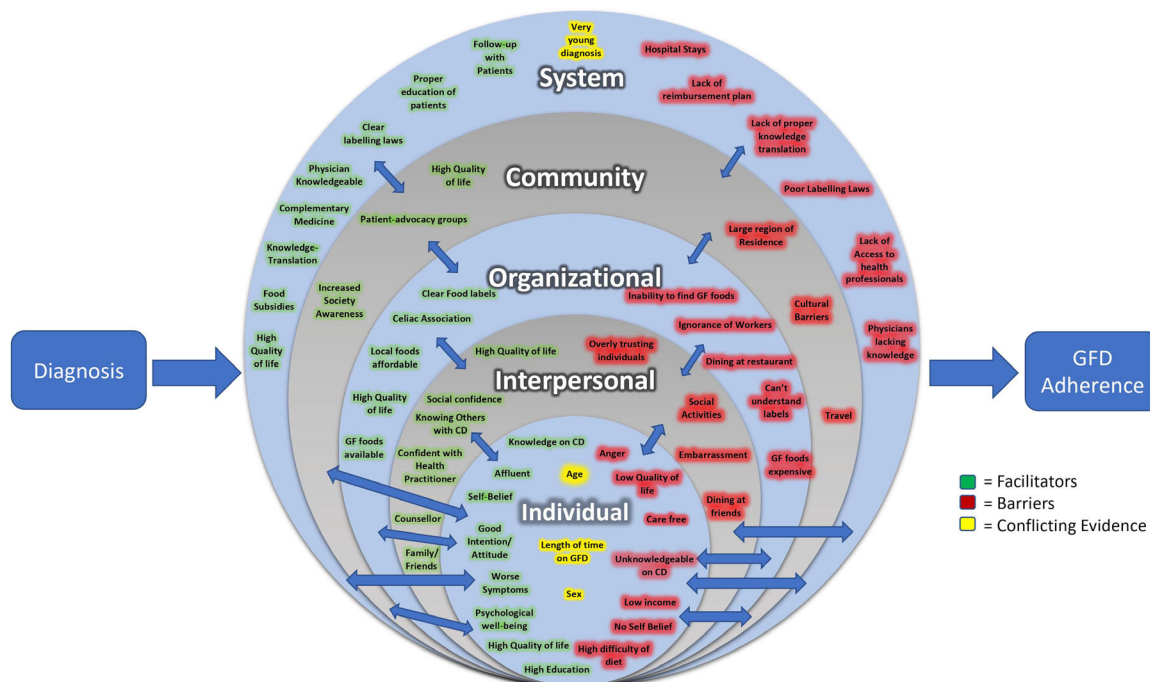


Figure 2 Social ecological model. CD, coeliac diet; GFD, gluten-free diet.

indicated lack of knowledge of CD/GFD as a barrier. The designs of the studies varied greatly; some studies had strong designs, and others presented the results of descriptive studies that employed rigorous methodologies.

At the interpersonal level, *social support* was the most significant facilitator reported in four studies. All of these studies had analytical designs. On the other hand, the most significant barrier presented at the interpersonal level was *social fear*. Although other interpersonal barriers such as *social activities* were discussed by a higher number of studies, as compared to *social fear*, the strength of the designs and methodologies that reported significant effect of social fear was higher, which is an indication of its significance.

At the organisational/environmental level, *membership in a coeliac association* was the most significant facilitator, reported by five studies, which varied in the rigor of their study designs. On the other hand, *restaurant dining and supermarket shopping* were the most significant reported barriers, with twelve studies presenting evidence on their impacts on adherence to GFD. Despite the variation in the LOE in this group of twelve studies, it is worth noting that several of these studies were conducted in Canada, and presented very rigorous methodologies.

At the community level, *high society awareness* was the most significant facilitator, which was reported in three studies, despite the limitations of their study weak designs. Cultural factors were the most significant barriers at the community level, with five studies (analytical and

descriptive) referring to them as important barriers to adhering to a GFD. From our analysis, it was clear that the study of and reporting on facilitators and barriers at the community level was very limited.

Last, at the systems level, *patient education/ physician-patient communication* was the most significant factor reported. Ten studies reported that improved patient education from physician to patient was a facilitator to GFD adherence and seven studies reported that poor patient education/lack of physician-patient communication was a barrier to GFD adherence. These studies varied in their designs and LOE, with one randomised clinical trial and remaining descriptive studies; several studies were presenting findings in the Canadian context.

Overall, the relatively low LOE in the empirical studies found in the literature calls for more carefully designed studies that employ more rigorous methodologies. It is important to also acknowledge the limitations associated with this review. In the coding and data extraction from the empirical studies, there was reliance on the information presented by the authors of the included studies, which may have not always been complete or detailed. Furthermore, we had to make an assumption that the diagnosis of CD for the individuals in the studies was conducted through a valid process; either a serological test or an upper-intestinal endoscopy.

Understanding the existing barriers to GFD adherence is the first step towards planning interventions that may provide decision-makers with knowledge on where to

target aid and future research, and practitioners with examples of how to improve adherence. In this systematic review, we organised the facilitators and barriers to GFD adherence among adults with CD into a SEM that helps portray a clear picture of what an adult with CD faces following diagnosis. Targeted, future research on specific facilitators and barriers highlighted in this systematic review is recommended to provide additional evidence and support. Examples include, amongst others, conducting an empirical study that examines the impact of implementing a program that increases patient education; evaluating healthcare providers' extent of knowledge of CD and the impact of improving the knowledge levels of CD/GFD on the GFD adherence rates among adults with CD; assessing the impact of financial compensation and label-laws at the system level. We call for system-level interventions addressing the main factors identified in this review to address the challenges faced by adults with CD, improve their health and alleviate the pressure on the health system. Facilitators and barriers presented in this systematic review also potentially impact individuals who are facing dietary restrictions as a result of other chronic illnesses in their lives. Hence, the importance and necessity of understanding these factors to support the care of individuals living with these conditions and enabling a better quality of life for them.

Transparency declaration

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being reported. The reporting of this work is compliant with PRISMA guidelines. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

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Conflict of interests, source of funding, and authorship

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All of the authors made substantial contributions to the conception and design of the study, or acquisition of data, or analysis and interpretation of data; drafting the article or revising it critically for important intellectual content; and final approval of the

version to be submitted. In particular, Nicholas Abu-Janb developed the concept for the systematic review, drafted the initial article, oversaw all data collection and analysis, developed the initial interpretation of the findings, and approved the final version submitted for publication. Mirou Jaana revised the initial article, refined the coding scheme, analysed the data and refined the interpretation, and approved the final version submitted for publication.

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Appendix A

Search Strategy

- 1 Coeliac Disease/
- 2 coeliac disease.tw,kw.
- 3 coeliac disease.tw,kw.
- 4 coeliac.tw,kw.
- 5 coeliac.tw,kw.
- 6 gluten sensitive entero*.tw,kw.
- 7 1 or 2 or 3 or 4 or 5 or 6
- 8 Patient Compliance/
- 9 patient compliance.tw,kw.
- 10 adher*.tw,kw.
- 11 nonadher*.tw,kw.
- 12 maint*.tw,kw.
- 13 compliance.tw,kw.
- 14 noncompliance.tw,kw.
- 15 coopera*.tw,kw.
- 16 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 17. Diet, Gluten-Free/
- 17 gluten free diet.tw,kw.
- 18 Diet/
- 19 treatment.tw,kw.
- 20 gluten.tw,kw.
- 21 diet*.tw,kw.
- 22 17 or 18 or 19 or 20 or 21 or 22 24. 7 and 16 and 23