

## Awareness and Knowledge of Celiac Disease Among the General Population in Saudi Arabia

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### Abstract

Celiac disease (CD) is an immune-mediated systemic disorder affecting nutrient absorption triggered by both environmental (gluten) and genetic factors. This study aimed to determine the level of awareness and knowledge of CD among the general population of Saudi Arabia. A community-based online cross-sectional study was conducted between August and October 2022 to examine the awareness regarding signs, symptoms, complications, and treatment of celiac disease. Data were collected and analyzed from 1,675 participants distributed across the five regions in Saudi Arabia. Analysis shows that 65.1% of the participants were familiar with the symptoms of celiac disease, and 49.6% confirmed that symptoms, blood tests, and endoscopy are the best way to diagnose celiac disease. The mean awareness score for the study participants was 71.8 (SD 13.9), with 5.2% of the participants needed a better level of awareness. Having a family history of celiac disease was an important predictor of having a higher level of awareness of celiac disease ( $p < 0.001$ ). The general public in Saudi Arabia demonstrates a moderate to high level of awareness of CD, emphasizing the need for extensive efforts to maintain high awareness of CD among the general public.

**Keywords:** Awareness, celiac disease, general population, gluten sensitivity, Saudi Arabia

### Introduction

Celiac disease (CD) is a systemic immune-mediated disease that impacts the small intestine and results in mucosal destruction, primarily affecting individuals with a hereditary predisposition. This disease is triggered by gluten, a protein obtained from wheat, barley, and rye.<sup>1</sup> Currently, the sole therapeutic approach entails the lifelong avoidance of gluten consumption. As a chronic condition, if untreated, it has the potential to result in increased rates of morbidity and mortality.<sup>2</sup> Based on recent statistical data, it can be observed that CD, or celiac disease, is a prevalent ailment that impacts around 1 in 100 individuals globally. The prevalence of CD is commonly observed among individuals from Europe, the Middle East, South

Asia, Africa, and South America. Nevertheless, the CD is infrequent among individuals of East and Southeast Asian descent, African Americans, and sub-Saharan Africans who lack the HLA-DR3-DQ2 haplotype, which has been linked to a heightened susceptibility.<sup>3</sup>

While there have been reports on the frequency of CD in Saudi Arabia, the precise total prevalence remains unknown. The study aims to investigate the frequency of CD in several regions of Saudi Arabia by a modest descriptive study. In a study conducted by Aljebreen et al.,<sup>4</sup> a cohort of healthy teenage students from three distinct districts in Saudi Arabia was included. The authors reported the prevalence of CD in each region, with Madinah having a prevalence of 1.8%, Aseer having a prevalence of 2.1%, and Al-Qaseem having a prevalence of 3.2%. According to a recent study, the prevalence of CD among school-aged children in Riyadh, Saudi Arabia, was found to be 1.5%.<sup>4</sup>

Previous research has proposed a higher likelihood of experiencing CD outbreaks in nations

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characterized by dietary patterns abundant in gluten, such as Saudi Arabia.<sup>5</sup> According to a study, 17.5% and 51.6% of the participants knew CD and gluten sensitivity. Approximately 17.5% of the restaurants in the study offer gluten-free meal alternatives. Additionally, 14.7% of these establishments have established protocols to prepare gluten-free food. Furthermore, a small proportion of 7.1% prominently display signs or notifications indicating the availability of gluten-free items. Lastly, a significant majority of 50.8% of the surveyed restaurants expressed their intention to incorporate gluten-free options into their menus in the foreseeable future. Furthermore, a study revealed that most gluten-free alternatives, precisely 82.5%, had a higher price point.<sup>6</sup>

The Kingdom of Saudi Arabia has an inadequate level of public awareness of gluten-related health concerns and CD. Hence, the primary aim of this research was to assess the level of awareness and information about CD within the general population of Saudi Arabia. The primary objective of this study was to investigate the level of awareness among the general population of Saudi Arabia regarding the signs, symptoms, and consequences associated with celiac disease. Additionally, this study sought to assess the knowledge about treating CD and adopting a gluten-free diet. Furthermore, we aimed to identify the sources of information that individuals in Saudi Arabia rely on for their understanding of CD.

## Methods

A community-based online cross-sectional study was conducted between August and October 2022 to examine the awareness regarding signs, symptoms, complications, and treatment of celiac disease. Saudi adults aged 18 years and older formed the study population. This study excluded those below 18 years of age, incomplete questionnaires, and non-Saudis.

A convenient sampling technique was applied in this study. The questionnaire link was distributed to the general public in Saudi Arabia via a Google Forms link through social media platforms (Facebook, Twitter, Snapchat, and Instagram), along with a cover letter attached to a consent form. Participation was voluntary, with the option to withdraw at any time. All responses were anonymous, with no tracking of e-mail addresses or any identifying information.

The questionnaire was developed based on an

extensive literature review to conduct this study. The socio-demographic variables in the survey questionnaire for the present analysis included gender, age, region of residence, education level, marital status, occupational status, family history of celiac disease, and how the participants rate their knowledge of celiac disease. The second part was about participants' awareness of celiac disease. Participants' awareness was examined regarding signs, symptoms, and complications of celiac disease and knowledge regarding celiac treatment and gluten-free diet.

The awareness of the general population toward celiac disease has been assessed using a 29-item questionnaire. The questionnaire has two patterns; item 1 to 8 was assessed by identifying the correct answers and marked as 1, and the incorrect answers were as 0; items 9 to 29 were a 5-point Likert scale type of questionnaire ranging from "strongly disagree" coded with 1 to "strongly agree" coded with 5. The total awareness score has been calculated by adding all 29 items. A possible score ranging from 21 to 113 points has been generated; a higher score indicates a higher awareness of celiac disease. By using 50% and 75% as the cut-off points to determine the level of awareness, participants were categorized as having poor awareness if the score was below 50%, 50% to 75% were categorized as moderate awareness, and above 75% were categorized as good awareness levels. In addition, the participants were asked about celiac disease treatment methods and their information sources.

During the first piloting phase, the questionnaire was randomly distributed to different regions of Saudi Arabia among 40 participants to measure the internal consistency of the study. These participants did not contribute to the findings of the main study. Based on the pilot study, the questionnaire was modified according to our research objectives and revised to overcome all obstacles faced during this pilot study. The reliability of the study questionnaire was measured using a 21-item questionnaire with 5-point Likert scale categories ranging from "strongly agree," coded as 1, to "strongly disagree," coded as 5. The overall reliability analysis of the 21-item questionnaires has a Cronbach Alpha of 0.889 indicating a very good internal consistency.

The required sample size from each study population was 385 participants, based on a confidence interval of 95%, a standard deviation of 0.5, and a margin of error of 5%.

The ethical approval for this study was

obtained from the ethical research committee of the Institutional Review Board (IRB) of Imam Mohammed Ibn Saud Islamic University (IMSIU), Riyadh, Saudi Arabia, wherein they reviewed and approved this project (HAPO-01-R-0011; Project No.273/2022).

Data were analyzed using Statistical Package for Social Science Software (SPSS), version 28. Categorical variables were shown as numbers and percentages (%), while continuous variables were presented as mean and standard deviation. The normality test was carried out using the Shapiro-Wilk test and Kolmogorov-Smirnov test. The differences in the awareness score about the socio-demographic characteristics and the perceived knowledge rating about CD were examined using the student-t test and ANOVA as appropriate. Binary logistic regression analysis was applied to identify predictors of higher awareness. The dummy variable for the binary logistic regression analysis was identified using the mean awareness score for the study sample as the cut-off point. The statistical significance level was assigned as 5.0%.

## Results

The data was collected and analyzed from 1675 participants distributed across the five regions in Saudi Arabia. Around half of the participants (52.1%) were aged 18-25 years. More than half of the participants (64.5%) were females. Around 29.0% of the participants were from the Western region. More than half of the participants (74.6%) reported holding bachelor's degrees and were single (59.8%). Around 40.7% of the participants were university students. Around 8.9% of the participants reported that they have a family history of celiac disease. Around 45.6% of the participants confirmed that they were not aware of celiac disease. For further details on the socio-demographic characteristics of the study participants, refer to Table 1.

Table 2 represents the participants' knowledge of and awareness of celiac disease. In general, 45.6% indicated that they were not aware of celiac disease. About 64.8% of participants knew about gluten, and 46.6% had the opinion that children and adults have a high risk of developing celiac disease. Around 65.1% were familiar with the symptoms of celiac disease. Around 49.6% of participants confirmed that symptoms, blood tests, and endoscopy are the best way to diagnose celiac disease. The majority of them were not aware

of the complications of celiac disease (70.7%). However, 53.9% believed that complications of celiac disease can be prevented.

Table 3 presents participants' awareness of celiac disease symptoms, prevention, complications, and products. A significant number of respondents strongly agreed that celiac disease symptoms include abdominal pain, diarrhea, flatulence, respectively, at 18.4%, 18.8%, and 18.0%. Furthermore, 21.3% of respondents strongly agreed that non-celiac gluten sensitivity should avoid eating gluten. The knowledge of celiac disease treatment could have been better; only 13.7% were aware that celiac disease can be cured. Only 5.4% of respondents strongly agreed that gluten-free products were available on the market, and only 10% strongly agreed that gluten-free dishes were available on restaurant menus. The mean awareness score for the study participants was 71.8 (SD 13.9). Around 5.2% of the participants showed poor level of awareness, 78.3% showed a moderate level of awareness, and 16.5% showed a good level of awareness, Table 4.

According to the participants' knowledge, a gluten-free diet was the most preferred method of treatment for celiac disease (25.6%), followed by oral medications (7.9%).

Social media was found to be the most commonly used source of celiac disease information (33.4%), followed by healthcare providers (29.3%) and family and friends (19.9%).

Table 5 presents the mean awareness score stratified by socio-demographic characteristics. Older patients, those who have a higher level of education, widowed or single participants, university students, and those having a family history of celiac disease had higher awareness scores compared to others ( $p < 0.05$ ).

Binary logistic regression analysis identified that having a family history of celiac disease was an important predictor of having a higher level of awareness of celiac disease ( $p < 0.001$ ). On the other hand, older age (36 years and over), being married, and being unemployed or employed were factors that increased the likelihood of having a lower level of awareness of celiac disease ( $p < 0.05$ ; Table 6).

## Discussion

Celiac disease is a chronic immune-mediated disease that is initiated by the use of gluten and associated prolamins. This disease impacts

**Table 1** Participants' socio-demographic characteristics

Variable	n (%)
Age group	
18–25 years	873 (52.1%)
26–35 years	417 (24.9%)
36–45 years	210 (12.5%)
>45 years	175 (10.4%)
Gender	
Male	595 (35.5%)
Female	1080 (64.5%)
Region of residence	
Central Region	432 (25.8%)
Southern Region	318 (19.0%)
Eastern Region	302 (18.0%)
Northern Region	146 (08.7%)
Western Region	477 (28.5%)
Education level	
Secondary or below	298 (17.8%)
University	1249 (74.6%)
Postgraduate	128 (07.6%)
Marital status	
Single	1002 (59.8%)
Married	616 (36.8%)
Divorced	44 (02.6%)
Widowed	13 (0.80%)
Occupational status	
Student	682 (40.7%)
Employee (governmental)	363 (21.7%)
Employee (non-governmental)	199 (11.9%)
Unemployed	373 (22.3%)
Retired	58 (03.5%)
Family history of celiac disease	
Yes	149 (08.9%)
No	1526 (91.1%)
How would you rate your knowledge of celiac disease?	
Strongly aware	183 (10.9%)
Aware	285 (17.0%)
Neutral	140 (08.4%)
Little aware	304 (18.1%)
Not aware	763 (45.6%)

**Table 2 Assessment of Participant's Awareness of Celiac Disease**

Awareness Statement	n (%)
Knowledge about gluten	
Yes *	1085 (64.8%)
No	590 (35.2%)
In your opinion, who are the people at risk of developing celiac disease	
Children only	105 (06.3%)
Adults only	73 (04.4%)
Children and adults *	780 (46.6%)
I don't know	717 (42.8%)
How many people do you think are affected by celiac disease?	
1.5-3% *	359 (21.4%)
15-35%	428 (25.6%)
45-60%	106 (06.3%)
70-80%	11 (0.70%)
I don't know	771 (46.0%)
Are you familiar with the symptoms of celiac disease?	
Yes *	585 (34.9%)
No	1090 (65.1%)
What do you think is the best way to diagnose celiac disease	
Symptoms only	66 (03.9%)
Symptoms and blood test	321 (19.2%)
Symptoms, blood test and endoscopy *	831 (49.6%)
I don't know	457 (27.3%)
Do you think that complications of celiac disease can be prevented?	
Yes *	902 (53.9%)
No	136 (8.1%)
I don't know	637 (38.0%)
Are you aware of the complications of celiac disease?	
Yes *	490 (29.3%)
No	1185 (70.7%)
Are you familiar with celiac disease treatment methods?	
Yes *	509 (30.4%)
No	1166 (69.6%)

various physiological systems and exhibits symptoms that can differ among individuals, particularly those with a genetic predisposition. A previous systematic review has demonstrated that the prevalence of CD among children in Saudi Arabia varies between 1.5% and 18.5%.<sup>7</sup> Consequently, this study aims to assess the extent of awareness and knowledge regarding CD among the general population in Saudi Arabia.

The study's findings revealed that most participants, specifically 45.6%, reported a lack of awareness regarding CD. This percentage is comparable to the results obtained from a study conducted in Saudi Arabia, where 48.4% of the participants had prior knowledge of CD.<sup>8</sup> Similar proportions of individuals who had never heard of the disease were observed in studies conducted in Turkey and the United Kingdom.<sup>9</sup> The study's

**Table 3 Participants' Awareness Of Celiac Disease Symptoms, Prevention, Complications, and Products**

Variable	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Do you think abdominal pain is a symptom of celiac disease?	2.6%	6.9%	39.5%	32.6%	18.4%
Do you think diarrhea is a symptom of celiac disease?	3.0%	7.2%	38.5%	32.5%	18.8%
Do you think flatulence is a symptom of celiac disease?	2.8%	9.3%	40.8%	29.1%	18.0%
Do you think being underweight is a symptom of celiac disease?	2.8%	9.9%	42.0%	26.1%	19.2%
Do you think iron deficiency anemia is a symptom of celiac disease?	3.4%	12.8%	48.8%	21.6%	13.4%
Do you think infertility is a symptom of celiac disease?	9.0%	27.2%	50.0%	9.1%	4.8%
Do you think miscarriage is a symptom of celiac disease?	7.6%	22.9%	52.8%	11.5%	5.1%
Do you think skin sensitivity is a symptom of celiac disease	4.5%	15.7%	45.9%	22.7%	11.2%
People with non-celiac gluten sensitivity are strictly prohibited from eating gluten.	3.0%	7.2%	37.4%	31.2%	21.3%
People with celiac disease are completely prohibited from eating gluten.	3.0%	5.3%	37.2%	26.9%	27.6%
People with wheat allergy are completely prohibited from eating gluten	3.6%	8.6%	40.8%	27.1%	19.9%
Do you think anemia is a complication of celiac disease?	3.5%	10.3%	49.7%	21.7%	14.9%
Do you think osteoporosis is a complication of celiac disease?	3.5%	12.7%	49.5%	20.5%	13.9%
Do you think malabsorption is a complication of celiac disease?	2.9%	6.4%	40.7%	28.3%	21.7%
Do you think small bowel cancer is a complication of celiac disease?	3.4%	9.8%	51.2%	23.3%	12.3%
Do you think miscarriage is a complication of celiac disease?	5.3%	17.1%	55.9%	14.6%	7.1%
Do you think infertility is a complication of celiac disease?	6.3%	19.0%	57.1%	10.9%	6.7%
Do you think nutritional, vitamin and mineral deficiencies are a complication of celiac disease?	2.9%	7.0%	40.1%	29.7%	20.2%
Celiac disease can be cured once and for all with a treatment plan	6.1%	13.0%	41.8%	25.4%	13.7%
Are gluten-free products readily available in the market?	7.4%	31.5%	32.4%	19.8%	9.0%
Are gluten-free dishes available on restaurant menus?	15.2%	36.8%	32.3%	10.3%	5.4%

findings indicate that around 64.8% of the participants knew gluten, whereas 72.4% were aware of gluten sensitivity, as reported in the study conducted in Saudi Arabia.<sup>6</sup> Furthermore, it is worth noting that a significant proportion (46.6%) of the individuals involved in the study

maintain the belief that children and adults face an increased susceptibility to the development of CD. It is essential to acknowledge that CD can manifest in genetically predisposed children at any stage from 9 months old until adulthood.<sup>10</sup> Various environmental factors contribute to the

**Table 4 The Mean Awareness Score For The Study Participants**

Variable	n (%)
Total awareness score (mean ± SD)	71.8 ± 13.9
Level of awareness	
Poor	87 (5.2%)
Moderate	1312 (78.3%)
Good	276 (16.5%)

risk of CD, including infant feeding practices, early infections, gut microbiota, multiple instances of antibiotic usage during early life,

and the quantity and timing of initial gluten introduction.<sup>11</sup>

The results of the study showed that the vast majority of participants (78.3%) had a moderate level of awareness, where the mean awareness score for the study participants was 71.8 (SD 13.9), and around 5.2% of the participants showed a poor level of awareness, and 16.5% showed a good level of awareness, unlike study in Kuwait, where the vast majority of the participants showed a low level of awareness.<sup>12</sup> Also, the study results found that around 65.1% were familiar with the symptoms of celiac disease, and around 49.6% of participants

**Table 5 Awareness Score Stratified by Socio-Demographic Characteristics**

Variable	Awareness Score Mean ± SD	P-value
Age group		
18–25 years	72.9 (12.8)	0.001**
26–35 years	72.5 (14.01)	
36–45 years	70.2 (12.7)	
>45 years	69.4 (10.9)	
Gender		
Male	72.7 (13.0)	0.158
Female	71.8 (13.0)	
Educational level		
Secondary or below	70.7 (14.7)	0.020**
University	72.2 (12.5)	
Postgraduate	74.5 (13.2)	
Marital status		
Single	72.8 (12.8)	0.039*
Married	71.0 (13.0)	
Divorced	71.5 (16.1)	
Widowed	75.1 (14.0)	
Occupational status		
Student	73.4 (12.9)	<0.001***
Employee (Governmental)	73.1 (13.1)	
Employee (Non-Governmental)	69.0 (12.2)	
Unemployed	70.2 (13.3)	
Retired	72.9 (10.4)	
Family history of celiac disease		
Yes	83.6 (12.3)	<0.001***
No	71.0 (12.5)	

\* Significant p<0.05 level; \*\* Significant p<0.01 level; \*\*\* Significant p<0.001 level

**Table 6 Predictors of a Higher Level of Awareness**

Variable	Odds Ratio of Having a Higher Level of Awareness	p-value
Age group		
18–25 years (Reference group)	1.00	
26–35 years	0.93 (0.74–1.18)	0.559
36–45 years	0.63 (0.46–0.86)	0.003**
>45 years	0.58 (0.41–0.81)	0.001**
Gender		
Female (Reference group)	1.00	
Male	0.92 (0.75–1.13)	0.426
Educational level		
Secondary or below (Reference group)	1.00	
University	1.18 (0.92–1.52)	0.200
Postgraduate	1.41 (0.93–2.14)	0.102
Marital status		
Single (Reference group)	1.00	
Married	0.72 (0.59–0.88)	0.001**
Divorced	0.92 (0.51–1.69)	0.798
Widowed	1.18 (0.39–3.54)	0.767
Occupational status		
Student (Reference group)	1.00	
Employee (Governmental)	0.77 (0.60–1.00)	0.046*
Employee (non-governmental)	0.54 (0.39–0.74)	<0.001***
Unemployed	0.65 (0.50–0.84)	<0.001***
Retired	0.74 (0.43–1.26)	0.263
Family history of celiac disease		
No (Reference group)	1.00	
Yes	8.16 (5.09–13.09)	<0.001***

\* Significant p<0.05 level; \*\* Significant p<0.01 level; \*\*\* Significant p<0.001 level

confirmed that symptoms, blood tests, and endoscopy are the best way to diagnose celiac disease, indeed, as reported in various studies, celiac disease presents with a range of symptoms, which can include diarrhea, failure to gain weight, irritability, oral cavity issues, chronic abdominal pain, fatigue, headache, bloating, weight loss, anemia, skeletal pain, and neuropathy.<sup>13-15</sup> This is similar to our study findings, where a significant number of respondents strongly agreed that CD symptoms include abdominal pain, diarrhea, flatulence, being underweight, iron deficiency anemia, infertility, miscarriage, and skin sensitivity.

Furthermore, the study’s findings indicate that a significant proportion of the study participants (70.7%) lacked awareness regarding the potential complications associated with CD. Additionally, approximately 53.9% of the participants believed these complications could be prevented. It is worth noting that CD has been linked to an elevated risk of autoimmune diseases and cancer.<sup>16</sup> Moreover, ingesting gluten damages the small intestine in individuals with CD.<sup>17</sup> However, early detection and diagnosis of CD can play a crucial role in preventing the development of complications<sup>18</sup>. Furthermore, adhering to a gluten-free diet has been shown to



offer protection against most complications and reduce the associated mortality<sup>16</sup>.

In addition, a gluten-free diet emerged as the predominant therapeutic approach for managing CD, with a preference rate of 25.6%. Oral drugs were also utilized but to a lesser extent (7.9%). Undoubtedly, adhering to a gluten-free diet represents the most productive and secure non-pharmacological intervention for individuals with CD.<sup>19</sup> A gluten-free diet encompasses naturally gluten-free foods such as meats, fruits, and vegetables and gluten-free alternatives to wheat, rye, and barley-based products like bread, pasta, and cereal. These alternatives typically use maize, rice, or millet flour.<sup>19</sup> However, it is important to note that an imbalanced gluten-free diet can increase the risk of metabolic issues. This underscores the significance of nutritional counseling in preventing and treating these complications.<sup>20</sup> Additionally, patients must comprehend the necessity of lifelong adherence to the gluten-free diet.<sup>21</sup> Consequently, the sole available treatment for CD is a strict exclusion of gluten from the diet.<sup>22</sup> Nevertheless, oral enzyme supplementation has been developed to expedite the breakdown of proline-rich gluten in the gastrointestinal tract.

The association between socio-demographic variables and awareness of celiac disease is intricate and has several aspects. Typically, increased education and income levels are associated with greater awareness, maybe because of improved access to information and healthcare. Youth are typically more informed, likely due to enhanced public health initiatives and educational endeavors in recent times. Women may have greater awareness than men, potentially attributed to variances in healthcare-seeking behavior. Geographic location and cultural influences contribute to differing levels of awareness seen among different regions and ethnic groups. A family history of CD has been identified as a significant predictor of increased awareness of the condition. It is known that individuals who have first-degree relatives with celiac disease are at a higher risk of developing the disease.<sup>23</sup> Additionally, the involvement of parents and children in the treatment of CD and their attitudes towards adhering to a restrictive gluten-free diet are essential factors influencing compliance with the treatment.<sup>24</sup> Notably, this involvement enhances awareness regarding CD within families with a history of the condition. In contrast, advanced age (36 years and older), marital status, and employment status were identified as factors associated with a higher

likelihood of having a lower level of awareness regarding CD. It is worth noting that celiac disease can manifest in older individuals, although with less frequent symptom presentation, resulting in delayed diagnosis. This underscores the necessity of enhancing knowledge and awareness among the elderly population regarding CD.<sup>25</sup> Furthermore, it underscores the importance of healthcare professionals being knowledgeable about CD in the elderly and the advantages of adhering to a strict gluten-free diet. Failure to recognize the onset of symptoms in adults, associated comorbidities, and the significance of serology testing may contribute to the underdiagnosis of CD.

The study's findings emphasize the importance of implementing public health awareness efforts that specifically target persons at risk, particularly those with a familial predisposition to the disease. Furthermore, it is imperative to enhance the training of healthcare professionals in the accurate diagnosis of CD, with a specific focus on older individuals. Additionally, it is crucial to emphasize the significance of adhering to a strict gluten-free diet and provide essential nutritional counseling to prevent metabolic complications. Improving awareness and facilitating access to appropriate care can enhance the quality of life for individuals with CD while simultaneously reducing the risk of complications.

This study has limitations. The cross-sectional study design restricted our ability to infer causality among the study variables and follow up with the study participants. Online survey studies are prone to generalisability bias as the study participants might not represent the study population. Therefore, this study's findings should be interpreted carefully.

In conclusion, public awareness of CD in Saudi Arabia varied from moderate to high. The study highlights the necessity for organized public educational campaigns to raise knowledge about managing CD. Consistent efforts are needed to maintain a heightened public awareness of CD.

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