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## **Gluten-free living in China: The characteristics, food choices and difficulties in following a gluten-free diet – an online survey**

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Keywords: non-celiac wheat sensitivity; celiac disease; gluten-free diet; China; online survey

## 1 **1. Introduction**

2 Celiac disease (CD) is a chronic autoimmune enteropathy triggered by abnormal reactions to gluten  
3 in genetically susceptible individuals (Lebwohl & Sanders, 2017). The prevalence of this condition  
4 is estimated to be 1% in general population. Historically, CD has been considered to be absent in  
5 Far East (including China), and only in recent years epidemiological studies were conducted to  
6 screen for CD in high-risk Chinese patients (Wu et al., 2010). However, the exact prevalence of CD  
7 in China was not known until recently, due to a lack of large-scale epidemiological investigation of  
8 this disease. Up to now, more than 50 cases of CD have been reported in China, with a vast age  
9 distribution of the patients (Geng, Qiao, Ji, Wang, & Yang, 2016; LI & YU, 2015; Wang et al.,  
10 2015; Yuan et al., 2013). A few small-scale studies in China have shown that the positive rate of  
11 CD-specific serology ranges from 1.77–12%, which is similar to that in western countries (Wang et  
12 al., 2011, 2015). A recent study, in which 19,778 Chinese adolescents and young adults were  
13 recruited, shed light on the epidemic of CD in China (Yuan et al., 2017). This study suggested a  
14 prevalence corresponding with global prevalence, though largely under-diagnosed.

15 Wheat allergy is another condition in which sufferers need to exclude gluten-containing foods from  
16 their diet (moreover, any foods containing gluten-free wheat starch are not being tolerated either)  
17 (Sapone et al., 2012). In a retrospective study of 1,952 cases of severe allergic reaction, wheat was  
18 found to be the most common food that caused anaphylactic shock in the Chinese population, with  
19 20% in teenagers and 42% in adults (Jiang, Yi, Wen, & Li, 2016).

20 Non-celiac wheat sensitivity (NCWS) is an emerging syndrome evoked by wheat in patients whom  
21 both CD and wheat allergy have been excluded. NCWS relates closely to irritable bowel syndrome  
22 (IBS) (Mansueto, D'Alcamo, Seidita, & Carroccio, 2015; Schuppan, Pickert, Ashfaq-Khan, &  
23 Zevallos, 2015). NCWS is thought to be more frequent than CD, with a wide range of self-reported  
24 prevalence (Aziz, Lewis, et al., 2014; Carroccio et al., 2017; DiGiacomo, Tennyson, & Demmer,  
25 2013; Ontiveros, López-Gallardo, Vergara-Jiménez, & Cabrera-Chávez, 2015). So far there is no  
26 data available regarding NCWS prevalence in China. Since there is a considerable IBS prevalence  
27 (4.4–11.8%), together with wheat being the second most popular staple food, the incidence of  
28 NCWS may not be rare (Li et al., 2014; Long et al., 2017; Zhang et al., 2014).

29 A gluten-free diet (GFD) is of vital importance for gluten-related disorders, such as NCWS, but  
30 especially for CD (Valenti, Corica, Ricciardi, & Romano, 2017). Patients with CD can suffer from  
31 various symptoms with multisystem affected (Lebwohl et al., 2017). A life-long strict GFD is the  
32 only available effective treatment for CD, while untreated CD is associated with severe  
33 complications, mortality included (Lebwohl et al., 2017). It has also been reported that compliance

34 with a GFD is crucial to maintaining optimal quality of life, and noncompliant patients are faced  
35 with a higher burden of illness, more family problems, and more problems in leisure time (Wagner  
36 et al., 2008). However, many obstacles exist, such as poor special dietary food availability, no  
37 access to GFD education, and a lack of social support, especially in rural areas where awareness of  
38 gluten-induced disorders is low (Aziz, Karajeh, et al., 2014). Gluten is ubiquitous in the Chinese  
39 diet, particularly found in staples such as wheat noodles and soy sauce. Furthermore, inherently  
40 gluten-free grains, as well as some fruits and vegetables, are likely to be contaminated by gluten  
41 during the production or preparation process, which most patients with CD or NCWS may not be  
42 aware of (Hollon, Cureton, Martin, Puppa, & Fasano, 2013). China Food and Drug Administration  
43 (CFDA) issued the standard for gluten-free foods for the first time in 2017, but the availability of  
44 gluten-free food products are still scarce (CFDA, 2017). Obstacles to GFD adherence may also  
45 come from a lack of education around the GFD. Many patients found it difficult to follow a GFD  
46 due to a lack of education. The successful adaptation to the gluten-free lifestyle often requires  
47 proper nutrition assessment, diet education and meal planning instructed by a qualified dietitian  
48 expertized in the GFD (Case, 2005). Even nowadays gluten-related disorders were considered rare  
49 conditions in China, with most physicians and dietitians having received minimal education about  
50 gluten-related disorders and the GFD. When there is a lack of awareness among healthcare  
51 providers, it could be even more difficult for patients to obtain sufficient knowledge to comply with  
52 this diet. In addition, the GFD can be economically burdensome to follow (Singh & Whelan, 2011).  
53 Patients with celiac disease often report high treatment burden, especially those from a lower  
54 socioeconomic status (Shah et al., 2014). A higher perceived burden is associated with poor  
55 adherence and consequently unfavorable prognosis, which necessitates a system to support these  
56 patients (Lebwohl, Murray, Rubio-Tapia, Green, & Ludvigsson, 2014).

57 So far, there have been no studies that look into the characteristics and behaviors of a GFD  
58 population in mainland China, even though there already are individuals who have adopted a GFD  
59 for various reasons. The primary objectives of this study were to assess the characteristics of  
60 Chinese individuals who followed a GFD and to analyze factors that influence their diet adherence  
61 difficulty. Identifying their characteristics, reasons for GFD, and difficulty factors in following a  
62 GFD could offer insights for food suppliers to provide gluten-free foods adapted to the local market,  
63 food policy researchers to formulate related food policies, and healthcare providers to help patients  
64 affected by gluten in China. It would also be helpful for the development of psychosocial and  
65 educational strategies to support those with CD or NCWS, as well as the growing group of people  
66 who follow a GFD for other reasons. The Internet and popularity of mobile devices facilitated our  
67 online survey and made the national wide distribution of the questionnaire possible.

## 68 2. Materials and methods

### 69 2.1 Study Population

70 The questionnaire was open for seven weeks in May and June 2017 and based on an online platform  
71 (Tencent Wenjuan; Tencent Inc., CN, URL: <https://wj.qq.com/s/1252506/c758>). Individuals who  
72 followed a GFD and lived in China were invited to participate through a social-media channel  
73 specializing in the GFD and an online celiac support group. To avoid data multiplication, social-  
74 media account identification was used before individuals were allowed to complete the survey.  
75 Participants were aware that they were participating in a research study and completed the  
76 questionnaire anonymously. Inclusion criteria were as follows: subjects who were residences in  
77 China and were able to complete the questionnaire by themselves or by a family member delegated  
78 to do so. Exclusion criteria included subjects not living in China or subjects unable to read and  
79 answer the questionnaire by themselves or a family member. This study was approved by the Ethics  
80 Committee of Tongji Medical College of HUST.

81

### 82 2.2 Questionnaire

83 This survey covered items with respect to demographics, reasons for following a GFD, advice on  
84 starting a GFD, medical history, food choices, gluten-free product preferences and ways of diet  
85 management (see Appendix, An online survey form). Information on nature of medical diagnosis of  
86 respondent was obtained by self-reporting.

87

#### 88 2.2.1 Reasons for following a GFD

89 Respondents were asked to indicate their reasons for following a GFD. Individuals who reported  
90 adhering to a GFD after a clinical diagnosis of CD (both biopsy diagnosed and serum-only  
91 diagnosed) were classified into the 'CD' group, while those who followed a GFD for weight loss or  
92 healthy lifestyle choice were classified into the 'healthy lifestyle' group. Those who adopted a GFD  
93 for gluten or wheat sensitivity and other health issues were classified into the non-celiac wheat  
94 sensitivity ('NCWS') group.

95

#### 96 2.2.2 Advice on starting GFD

97 Participants in 'CD' group and 'NCWS' group (see 2.2.1) were required to self-report on how they  
98 obtained their diagnosis or were advised on starting a GFD. (Participants in 'healthy lifestyle' group  
99 were required to skip related questions.) They had three options to choose from: diagnosis and GFD

100 information obtained from medical advice in China, medical advice outside of China or by self-  
101 evaluation. For comparison purposes, individuals who had self-diagnosed for gluten intolerance and  
102 in consequence followed GFD were categorized as the ‘self-evaluation’ group.

103

### 104 2.2.3 Food choices

105 Food choices of the respondents were determined by self-reported description (by listing foods) of  
106 their usual breakfast, lunch and supper. According to their food choices at lunch and supper, we  
107 divided the participants into four groups, namely ‘mainly gluten-free grains’, ‘mainly non-grain  
108 carbohydrate-based food’ (choosing starchy roots and tubers as the staple), ‘mainly meat or eggs’,  
109 ‘intake food that may contain gluten’ (of which the first three groups were regarded as being gluten-  
110 free). Those respondents who avoided breakfast, or only consumed soup or coffee for breakfast,  
111 were categorized into ‘No breakfast or only soup or coffee’ group.

112

### 113 2.2.4 Assessing difficulty in following a gluten-free diet.

114 The difficulty in following a gluten-free diet was assessed by a question “How do you find it to stay  
115 gluten-free?” (see Appendix: An online survey form). There were five answering options, from “No  
116 difficulties to stay gluten-free” to “It is too difficult, impossible to eat gluten-free”. The distribution  
117 of answers from the lowest to the highest difficulty was 19, 37, 83, 41 and 29. We combined the  
118 first three groups (n=139) and last two groups (n=70) separately to make it a binary variable. We  
119 then used the binary variable as the dependent variable to explore factors associated with “difficulty  
120 in following a gluten-free diet.”

121

## 122 2.3 Statistical analysis

123 Number and percentage of each subgroup were calculated to present categorical descriptive  
124 variables. Univariate logistic regressions were initially used to measure the unadjusted effects of  
125 different influencing factors on feeling difficult about managing a GFD. After that, the multivariate  
126 logistic regression with stepwise variable selection method was used to measure the effect after  
127 controlling confounders. The odds ratios (OR), 95% confidence intervals (CI) and the p-value of  
128 variables in models were reported. All analysis were considered as statistically significant when  
129  $P < 0.05$ . Statistical analysis was performed using R 3.4.1.

130

131 **3. Results**

132 In total, 209 individuals from mainland China participated in the survey (Table 1). Over seventy  
 133 percent (70.8%) of the participants aged from 19 to 35, and more than half of the total respondents  
 134 were single, well-educated females. Nearly one third (33.5%) of the participants admitted that they  
 135 found it difficult to follow a gluten-free diet. The main reason for GFD was non-celiac wheat  
 136 sensitivity (74.6%), followed by healthy lifestyle (23.0%). The majority of the respondents started a  
 137 GFD through self-evaluation (91.4%) instead of obtaining advice from medical establishment  
 138 (8.6%). On food choices, respondents preferred to selected meat and eggs as staple breakfast foods,  
 139 with gluten-free grains chosen at lunch and supper. However, a few respondents admitted that they  
 140 may ingest gluten on a daily basis. Nearly half of the respondents (41.2%) cooked themselves. The  
 141 most popular gluten-free condiment was a GF condiment or oil, and both online and physical stores  
 142 were the main choices for the respondents to buy GF groceries.

143

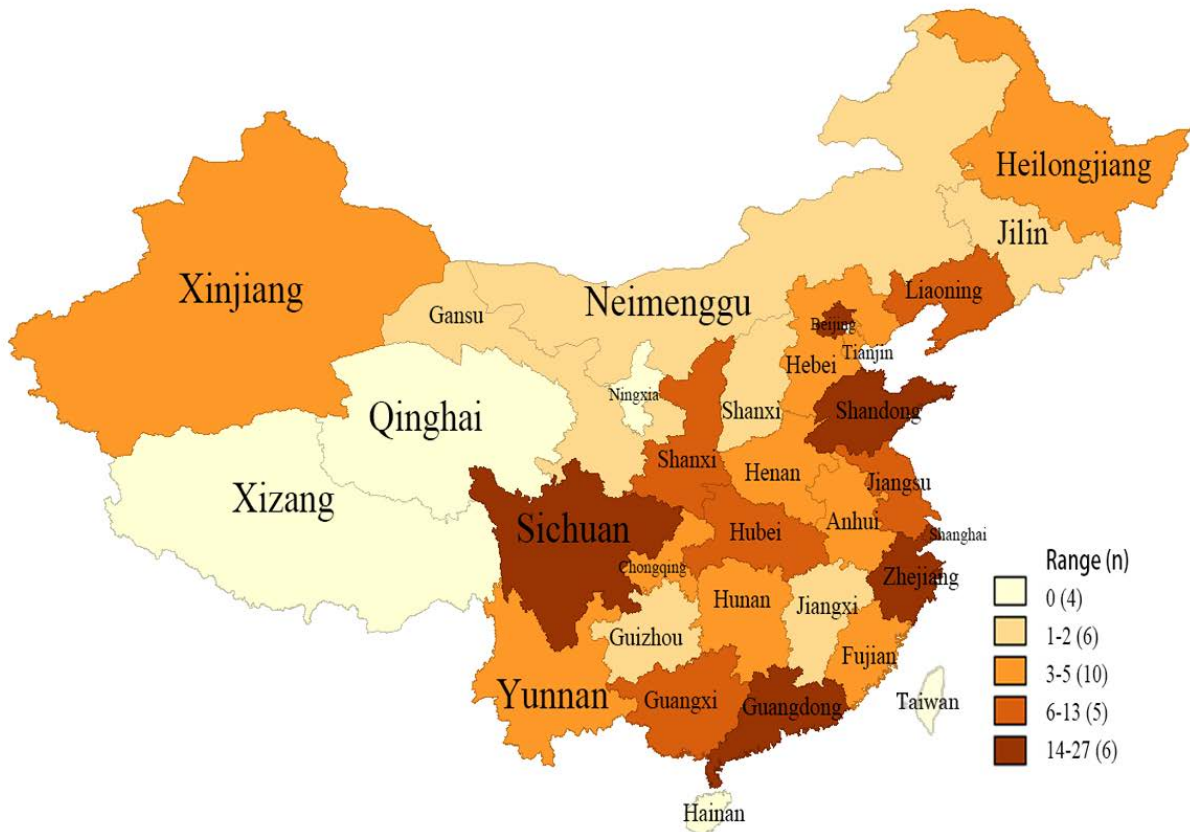
144 **Table 1.** Demographic characteristics of all participants

Characteristics		Total no. of respondents (%) (n=209)	No. of finding GFD difficult (%)
Age (years)	≤18	18(8.6)	6(33.3)
	19–35	148(70.8)	51(34.5)
	>35	43(20.6)	13(30.2)
Sex	Male	50(23.9)	13(26.0)
	Female	159(76.1)	57(35.9)
Marital status	Single	106(50.7)	36(34.0)
	In a relationship, having children	43(20.6)	15(34.9)
	In a relationship, no children	60(28.7)	19(31.7)
Education level (highest degree)	Lower than Bachelor’s degree	64(30.6)	20(31.3)
	Bachelor’s degree and undergraduate	101(48.3)	35(34.7)
	Above Bachelor’s degree	44(21.0)	15(34.1)
Main reason to follow a GFD	Celiac disease	5(2.4)	1(20.0)
	Non-celiac wheat sensitivity	156(74.6)	56(35.9)
	Healthy lifestyle	48(23.0)	13(27.1)
Advice on starting a GFD	Medical advice in China	14(6.7)	8(57.1)

	Medical advice outside of China	4(1.9)	2(50.0)
	Self-evaluation	191(91.4)	60(31.4)
Duration of symptoms before finding out intolerance to gluten (years)	<1	34(16.3)	19(55.9)
	1–2	31(14.8)	20(64.5)
	3–10	27(12.9)	18(66.7)
	>10	32(15.3)	16(50.0)
	No symptoms or uncertain	85(40.7)	66(77.7)
	No visits or uncertain	102(48.8)	26(25.5)
Food preference at breakfast	Mainly GF grains	62(29.7)	18(29.0)
	Mainly non-grain carbohydrate-based food	22(10.5)	6(27.3)
	Mainly meat or eggs	83(39.7)	26(31.3)
	No breakfast or only soup or coffee	31(14.8)	10(32.3)
	Food possibly containing gluten	11(5.3)	10(90.9)
Food preference at lunch and supper	Mainly GF grains	76(36.4)	33(43.4)
	Mainly non-grain carbohydrate-based food	16(7.7)	5(31.3)
	Mainly meat or eggs	6(2.9)	5(83.3)
	Food possibly containing gluten	111(53.1)	27(24.3)
Ways of GFD management	Cooking by himself/herself	86(41.2)	12(14.0)
	Cooking by family	21(10.1)	3(14.3)
	Eating out (restaurant)	29(13.9)	7(24.1)
	Ingest gluten occasionally	73(34.9)	48(65.8)
Main necessary GF pantry products	Substitutes of wheat / wheat flour	39(18.7)	14(35.9)
	Other GF foods	8(3.8)	4(50.0)
	Gluten-free condiments	67(32.1)	14(20.9)
	No specific requirements	95(45.5)	38(40.0)
Shopping channel for GF products	Online store/purchasing agents	96(45.9)	36(37.5)
	Physical store	81(38.8)	30(37.0)
	Both	32(15.3)	4(12.5)



146 Figure 1 shows the geographic distribution of the participants of this survey. Generally speaking,  
 147 GF diet followers were more common in developed municipalities and provinces, such as  
 148 Guangdong (12.9%), Beijing (12.0%) and Shanghai (10.1%). Most other regions had lower but  
 149 varying numbers of people following this diet. There were no participants from regions of Xizang,  
 150 Qinghai, Hainan, and Ningxia.



151  
 152 Figure 1. Geography distribution of study participants (not including Taiwan, Hong Kong, and Macau).

153 Table 2 Shows univariate and multivariate logistics regression results of the survey data. From the  
 154 results of multivariate regression, subjective difficulty in following a GFD is associated with seven  
 155 different factors. These associated factors are age, education level, the main reason to follow a  
 156 GFD, advice on starting a GFD, duration of symptoms before finding out intolerance to gluten, food  
 157 choices for breakfast and ways of GFD management. Compared with respondents younger than 18  
 158 years old, older respondents were about 9.1-14.3 times *less* likely to feel it difficult to follow a  
 159 GFD. As for education level, respondents with higher education were 2.6-3.4 times more likely to  
 160 feel it difficult than their counterparts whose education level were lower than bachelor's degree. In  
 161 respect of advice on starting a GFD, individuals who adopted a GFD with advice obtained from  
 162 medical establishments outside China and self-evaluation were 6.3-12.5 times *less* likely to feel it  
 163 difficult than those with advice from local medical establishments. Individuals who spent over three

164 years to find out that their symptoms were gluten-related were around 1.7-2.0 times more likely to  
 165 feel it difficult in following a GFD, compared to those who spent less than 1 years.

166 Regarding food choices for breakfast, those who chose mainly gluten-free grains as their breakfast  
 167 felt GFD management easier than those who chose other types of foods. Those of whose food  
 168 possibly contained gluten experienced the highest difficulty (OR=52.48). As regards to ways of  
 169 GFD management, individuals cooking by themselves felt GFD compliance easier when compared  
 170 to other diet management methods. The most difficulty was experienced by those who were aware  
 171 that they ingested gluten occasionally (OR=40.54).

172 Table 2. Univariate and multivariate analysis of risk factors in following a gluten-free diet (GFD).

Characteristics	Univariate analysis			Multivariate analysis			
	OR	95%CI	P	OR	95%CI	P	
Age (years)	≤18	Ref.	–	–	–	–	
	19-35	1.05	0.38-3.17	0.92	0.11	0.02-0.83	0.03
	>35	0.87	0.27-2.94	0.81	0.07	0.01-0.69	0.02
Sex	Male	Ref.	–	–	–	–	
	Female	1.59	0.80-3.33	0.20	–	–	–
Marital status	Single	Ref.	–	–	–	–	
	In a relationship, having children	1.04	0.49-2.18	0.91	–	–	–
	In a relationship, no children	0.9	0.45-1.76	0.76	–	–	–
Education level (highest degree)	Lower than bachelor's degree	Ref.	–	–	Ref.	–	–
	Bachelor's degree and undergraduate	1.17	0.60-2.3	0.65	3.44	1.10-11.84	0.04
	Above bachelor's degree	1.14	0.50-2.57	0.76	2.58	0.68-10.55	0.17
Main reason to follow a GFD	Celiac disease	Ref.	–	–	–	–	
	Non-celiac wheat sensitivity	2.24	0.32-44.39	0.48	–	–	–
	Healthy lifestyle	1.49	0.20-30.50	0.73	–	–	–
Advice on starting a GFD	Medical advice in China	Ref.	–	–	Ref.	–	–
	Medical advice outside of China	0.75	0.07-7.79	0.80	0.16	0.01-2.59	0.19
	Self-evaluation	0.34	0.11-1.03	0.06	0.08	0.01-0.41	<0.001

Duration of symptoms before finding out intolerance to gluten (years)	<1	Ref.	–	–	Ref.	–	–
	1-2	0.70	0.25-1.89	0.48	0.14	0.03-0.69	0.02
	3-10	0.63	0.22-1.79	0.39	1.69	0.41-7.15	0.47
	>10	1.27	0.48-3.37	0.63	2.03	0.46-9.41	0.36
	No symptoms or uncertain	0.36	0.16-0.85	0.02	0.21	0.06-0.74	0.02
Food preference at breakfast	Mainly GF grains	Ref.	–	–	Ref.	–	–
	Mainly non-grain carbohydrate-based food	0.92	0.29-2.63	0.88	4.3	0.79-24.53	0.09
	Mainly meat or eggs	1.12	0.55-2.31	0.77	10.51	2.69-48.76	<0.001
	No breakfast or only drink soup or coffee	1.16	0.45-2.93	0.75	28.99	4.76-215.71	<0.001
	Food possibly containing gluten	24.44	4.23-465.53	<0.001	52.48	4.7-1490.45	<0.001
Food preference at lunch and supper	Mainly GF grains	Ref.	–	–	Ref.	–	–
	Mainly non-grain carbohydrate-based food	0.59	0.17-1.8	0.37	0.73	0.13-4.05	0.72
	Mainly meat or eggs	0.42	0.22-0.78	0.01	0.24	0.07-0.80	0.02
	Food possibly containing gluten	6.52	0.99-128.03	0.09	9.09	0.34-439.60	0.22
	Ways of GFD management	Cooking by himself/herself	Ref.	–	–	Ref.	–
Cooking by family		1.03	0.22-3.66	0.97	1.25	0.22-5.70	0.78
Eating out (restaurant)		1.96	0.66-5.51	0.21	3.57	0.97-13.17	0.05
Ingest gluten occasionally		11.84	5.59-26.74	<0.001	40.54	12.75-157.11	0
Main necessary GF pantry products	Substitute of wheat / wheat flour	Ref.	–	–	–	–	–
	Other GF food	1.79	0.37-8.66	0.46	–	–	–
	Gluten-free condiment	0.47	0.19-1.14	0.09	–	–	–
	No specific requirements	1.19	0.55-2.62	0.66	–	–	–
Shopping channel for GF products	Online store/purchasing agents	Ref.	–	–	–	–	–
	Physical store	0.98	0.53-1.81	0.95	–	–	–
	Both	0.24	0.07-0.67	0.01	–	–	–

174 **4. Discussion**

175 Our data suggest that a lack of knowledge on maintaining a GFD and frequent intentional gluten  
176 ingestion may be the most important factors that are associated with subjective difficulty in  
177 following a GFD in China. In addition, a delay in diagnosis of a gluten-induced disorder,  
178 undergraduate status, and a breakfast based on non-grain foods are associated with higher subjective  
179 difficulty to following a GFD.

180

181 4.1 Advice on starting a GFD

182 Individuals who started a GFD based on medical advice obtained locally in China found it more  
183 challenging to stay gluten-free than those who received medical advice overseas or those who had  
184 self-diagnosed the condition. To our knowledge, screening of CD and diagnosis of NCWS have not  
185 been routinely performed in China. Moreover, in many areas, celiac testing is not available even at  
186 private hospitals or clinics. Due to a lack of routine clinical practice, physicians and dietitians may  
187 not be experienced at giving practical dietary advice to those newly diagnosed, which may make  
188 patients confused about food choice (See, Kaukinen, Makharia, Gibson, & Murray, 2015). Standard  
189 diagnosis practice and dietary management of gluten-related disorders, especially CD, have been  
190 established in western countries (Rubio-Tapia et al., 2013; Schuppan et al., 2015). After diagnosis,  
191 patients generally have an appointment with a dietitian to learn how to eliminate gluten from their  
192 diets and understand cross-contamination risks (Case, 2005; Fok, Holland, Gil-Zaragozano, & Paul,  
193 2016). Muhammad *et al.* (Muhammad, Reeves, Ishaq, Mayberry, & Jeanes, 2017) found a high  
194 proportion of South Asian CD patients reporting difficulties in following a GFD, such as not  
195 understanding food labeling and not knowing what to eat. They also reported a significantly higher  
196 proportion of CD patients being compliant to a GFD when they receive GF foods on prescription.  
197 Insufficient guidance from medical providers may lead to a lack of knowledge on maintaining a  
198 GFD in the patients. It thus would not be surprising that those who started a GFD from overseas  
199 medical advice felt it less difficult in keeping a strict diet.

200 In this study, the majority of subjects (74.6%) in the self-diagnosis group were suffering from self-  
201 reported NCWS. Løvik *et al.* (Løvik, Skodje, Bratlie, Brottveit, & Lundin, 2017) showed that 91%  
202 of the self-reported NCWS subjects were self-educated and seemed to cope well with a GFD. Self-  
203 education may partly explain why NCWS subjects found it less difficult to follow a GFD than  
204 domestically diagnosed patients. The lack of confirmed diagnosis and assumed higher tolerance of  
205 gluten than typical CD patients may also account for the perception of less difficulty. Moreover, it

206 is noteworthy that some of those individuals reporting themselves suffering from NCWS may  
207 actually have undiagnosed CD.

208

#### 209 4.2 Duration of symptoms before finding out intolerance to gluten

210 A considerable proportion (15.3%) of the respondents found themselves intolerant to gluten more  
211 than 10 years after the onset of their symptoms. These subjects had more difficulty in keeping a  
212 GFD than others. Fuchs *et al.* (Fuchs et al., 2014) demonstrated that a diagnostic delay in CD was  
213 common; 32% patients observed had a delay of more than 10 years. Increased diagnostic delays  
214 were associated with worse clinical outcomes (Norström, Lindholm, Sandström, Nordyke, &  
215 Ivarsson, 2011). Those long-delayed subjects may have a more compromised health status, possibly  
216 leading to numerous symptoms and/or a higher sensitivity to gluten (Norström et al., 2011). Hence,  
217 stricter dietary adherence might be needed for these people to keep symptoms under control. This  
218 could add their perceived difficulty in keeping a GFD.

219

#### 220 4.3 Education

221 Interestingly, undergraduate subjects (or subjects with a bachelor's degree) felt it more difficult in  
222 maintaining a GFD than those who had a lower or higher education level (OR 3.44, P=0.04). This  
223 may be due to a lack of gluten-free food supply in canteens as well as a lack of self-catering flats in  
224 universities and colleges in China. At the time of this writing, food allergen labeling has not been  
225 strictly regulated in China. Additionally, until the *Standard for Foods for Special Dietary Use for*  
226 *Persons Intolerant to Gluten* was issued by CFDA in March 2017, there were no criteria for gluten-  
227 free foods in this country (CFDA, 2017). Consequently, the gluten-free market in China is far from  
228 mature, and gluten-free products or meals are usually difficult to obtain.

229 This finding indicates food policymakers should promote and standardize the gluten-free market in  
230 China. Furthermore, public catering sectors (such as university administrators) may have to pay  
231 attention to gluten-related disorders – as well as special dietary needs due to other food allergies or  
232 intolerances – and take care of those who are affected.

233

#### 234 4.4 Food choices for breakfast

235 Results also revealed that food choices for breakfast played a role in subjective difficulty in  
236 following a GFD. Respondents whose breakfast was based on gluten-free grains were less likely to  
237 find a GFD challenging compared to respondents whose breakfast was based on other foods like

238 “meat or eggs” or “soup or coffee only”. Food availability may influence the adherence and thus  
239 perceived difficulty in keeping a GFD. A typical Chinese breakfast was normally based on grains  
240 (rice and wheat), such as wheat noodles, steamed buns, rice porridge and rice noodles. In addition,  
241 convenient breakfasts provided by convenient stores or bakeries are usually gluten-loaded foods  
242 like breads or sandwiches, which are inappropriate for a GFD. In this study, about half of the  
243 participants (48.8%) didn’t cook by themselves or by their family, it is possible that individuals  
244 aiming non-grain diet may find it harder to follow their diet. Then, some grains may help diversify a  
245 strict gluten-free diet, resulting in an improved quality of life. Aaltonen *et al.* (Aaltonen et al., 2017)  
246 demonstrated that gluten-free oats consumption in celiac disease patients may bring about better  
247 physical role limitations. All in all, more choices and variation in the diet, especially for breakfast,  
248 improve perceived satisfaction and thus again ease the difficulty in GFD compliance.

249

#### 250 4.5 Gluten ingestion

251 Frequent intentional gluten ingestion was a significant predictive factor for feelings of difficulty in  
252 maintaining a GFD. Gluten ingestion could be a result of perceived difficulty and related poor  
253 adherence. As a restrictive diet, the GFD can be difficult to stick in many cases, such as gluten-free  
254 foods being unavailable. These difficulties may lead to maladaptive behaviors, including disordered  
255 eating patterns (Satherley, Howard, & Higgs, 2015). Satherley *et al.* found that disordered eating  
256 was associated with poor dietary management, which may include intentional gluten ingestion  
257 (Satherley, Higgs, & Howard, 2017). In addition, one's ability to adhere to the GFD (self-efficacy)  
258 could also play a role. Hall *et al.* found perceived difficulty is associated with low self-efficacy, and  
259 low self-efficacy is a predictive factor for intentional gluten ingestion (Hall, Rubin, & Charnock,  
260 2013).

261

#### 262 4.6 Limitations

263 The present study has several limitations. Firstly, this questionnaire was internet-based and may  
264 have selection bias. However, since gluten-induced disorders have not received enough attention in  
265 clinical practice in China, it would be challenging to obtain information of the patients in clinical  
266 settings. Hence, an online survey could be an efficient way to find and connect with those who are  
267 affected. In particular, the online nature of this study allowed respondents to be located in different  
268 regions throughout China, covering most of the provinces. Secondly, we didn't investigate effects of  
269 a GFD on either symptom responses or health-related quality of life, which could be important  
270 factors in subjective difficulty in maintaining a GFD in the first place. The influence of the

271 aforementioned outcomes of a GFD should be explored in further studies. Additionally, the limited  
272 sample size, especially in some subgroups, cause wide confident intervention in some coefficient  
273 estimations. Further observations are needed to obtain more accurate characteristics of Chinese CD  
274 and NCWS, which could be used to develop practical strategies to help affected patients.

275

#### 276 4.7 Implications

277 To our knowledge, this study is the first to show the characteristics of GFD followers in China. A  
278 large proportion of the respondents in the NCWS group were self-assessed and have not been  
279 properly tested to exclude CD. This might indicate that CD is not paid enough attention in China  
280 despite probable increasing prevalence. Among the NCWS group, many chose to follow a GFD for  
281 thyroid disease. Zhao *et al.* (Zhao et al., 2016) demonstrated that tissue transglutaminase  
282 autoantibodies positivity in Chinese patients with autoimmune thyroid disease was 22%, which was  
283 significantly higher than healthy controls (1%). These findings suggest missed diagnosis of CD  
284 might be a common problem in China, which should have implications for clinical practice.

285

### 286 5. Conclusions

287 In conclusion, there is a significant group of individuals following a GFD in China for various  
288 reasons. In this study, nearly one third of them found it difficult to follow the diet putting them at  
289 risk of co-conditions and/or lower perceived quality of life. Sufficient GF education, timely  
290 diagnosis, and GF diet recommendations adapted to Asian culture may help those who need to  
291 exclude gluten from their diet in China. Although the majority of the GFD followers were not  
292 medically diagnosed celiac patients, other studies have already shown that CD exists in China. It is  
293 well-known that the only treatment of CD is a strict life-long GF diet, which is necessary to avoid  
294 health deterioration and possibly serious co-conditions. Therefore, untreated celiac patients and  
295 those with gluten-induced disorders currently burden public health care, let alone personal  
296 suffering. In these circumstances, there is an urgent need for the Ministry of Health of China to  
297 formulate specific rules for gluten-free labelling, to ensure special dietary food availability, and to  
298 support research & development and the prescribing of gluten-free foods. We call on colleagues and  
299 authorities to work together to develop diagnostic guidelines for CD and NCWS in China as well as  
300 public education for promoting successful gluten-free living.

301

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305

306 **Conflict of interest**

307 The authors declare that they have no conflicts of interest.

308

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311

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