Original Article

Social media usage pattern and its influencing factors among celiac patients and their families

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Abstract

Background/Aim: The aim of this study was to investigate social media usage patterns among celiac patients and explore the potential factors that may influence the frequency of its usage.

Patients and Methods: A cross-sectional survey was conducted, in which an online questionnaire was sent to celiac patients registered in the Saudi celiac patients' support group through email and its related social media accounts. Eligible participants included all patients with biopsy-confirmed celiac disease or their parents.

Results: In total, 221 participants completed the survey. The majority (96%, $n = 212/221$) reported using social media networks for their disease management. We included only those participants in the analysis. The median age was 36 years (range; 18–60 years). The majority of respondents (59.4%) were female. Most participants (65.6%) were patients with celiac disease and 34.4% were parents of celiac patients. The median duration of the disease was three years (range; 1 month–26 years). The three most frequently visited social media platforms were WhatsApp by 175 (82.5%) participants, Instagram by 132 (62.3%), and Twitter by 124 (58.5%) participants. The median time spent on social media was 60 min per day (range; 10–720 min). Multivariate logistic regression showed that celiac disease patients used social media two times more than the parents of celiac patients (OR 2.37, 95% CI: 1.19 - 4.72; $P = 0.014$).

Conclusions: Celiac patients are highly involved in social media activities for purposes related to their disease. We encourage healthcare providers to be available online to provide trustable and high-quality educational materials.

Keywords: Celiac disease, gluten-free diet, social media

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INTRODUCTION

Celiac disease (CD) is a chronic autoimmune disorder that leads to intolerance to dietary gluten. The disease arises from a genetic predisposition that is highly prevalent in the Saudi population.[1] The only existing treatment for CD is lifelong adherence to a strict gluten-free diet (GFD). This can be challenging considering that food is not just a physiological need but also a social activity that involves gathering with family and friends.

Given the significance of non-adherence to GFD in celiac patients, the development of interventions to improve GFD adherence is a major objective. Social media (SM) networking is emerging as a promising tool that could be utilized to help achieve this objective.

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SM is defined as any online venue (website or smartphone application) that allows users to network and share information.[2] SM networks include various platforms such as WhatsApp, Facebook, Twitter, Snapchat, Instagram, and YouTube.

Nowadays, patients with chronic illnesses such as CD, both adults and adolescents, are using different SM platforms to obtain and exchange information about their disease and its management.[2-5] SM has the advantage of providing such patients with easy and quick access to health information. In addition, it encourages communication between these patients with the advantage of retaining anonymity. Furthermore, it provides patients with a venue in which to express and share their experiences, opinions, and concerns about their health issues. The online CD community is one of the largest and most active networks for exchanging information and experiences between patients.[6]

Previous studies showed that the majority of patients with a chronic illness are interested in incorporating social networks in some of their care, such as sharing health information, prescription notifications, and answering general questions.[7,8]

Few online behavioral interventions were examined in patients with CD to explore their effect on adherence to GFD and quality of life (QOL). In a randomized controlled trial (RCT), Sainsbury *et al.* showed that an online intervention (educational module) was effective in improving adherence to GFD.[9] In another RCT, Hass *et al.* found that an interactive text messaging tool was an effective behavioral intervention among patients with CD to improve their activation and QOL. However, the study did not detect a statistically significant change in celiac serology markers.[10]

The aim of the present study was to investigate the pattern of SM usage among celiac patients and explore potential factors that may influence the frequency of SM usage.

PATIENTS AND METHODS

We designed and conducted a cross-sectional survey and invited all celiac patients registered in the Saudi Celiac Patients Support Group (SCPSG) to participate. Eligible participants included all patients with biopsy-confirmed celiac disease or their parents (for children <18 years of age). An online link for the questionnaire was sent to all members between May and June 2019 through the email list of the SCPSG and their active SM accounts. A reminder follow-up email/message was sent 2 weeks after the initial invitation.

We designed a questionnaire comprising three sections. The first section contained questions about respondents' demographic data including age, gender, level of education, duration of disease, and the participant's relationship degree to the child. The second section looked at the details of the disease diagnosis and the third section focused on exploring the patterns, opinions, and barriers of SM usage among celiac patients. We used a five-point Likert scale to assess the opinion of participants regarding the usefulness of SM ranging from 1-"strongly agree" to 5-"strongly disagree."

A pilot pretest of the survey was conducted on 20 celiac patients to validate the instrument and ensure its readability and comprehensiveness.

We divided the participants into three age groups: the young-age group (18–30 years), middle-age group (31–45 years), and older-age group (more than 45 years). We hypothesized that the pattern of SM usage differs between these three groups and that they have different opinions regarding the usefulness of SM.

Statistical analysis

The mean, median, and standard deviation were calculated for the continuous variables and frequency and proportions for categorical variables. We used a Chi-square test (or its alternative Fisher Exact test, if any cell count was less than five) for categorical variables to assess the differences between the different age groups.

A binary logistic regression analysis was conducted to study the potential predictor factors associated with SM usage (age, gender, education level, duration of the disease, and degree of engagement in SM activities). Adjusted odds ratios (OR) and corresponding 95% confidence intervals (CI) were calculated. A P value of <0.05 was considered significant. All data analyses were performed using SPSS (version 21, Chicago, IL, USA).

Ethical considerations

The study protocol was approved by the Institutional Review Board at King Khalid University Hospital, King Saud University (KSU). The completion and return of the questionnaire were regarded as consent to proceed with the study. All responses were anonymous.

RESULTS

Participants' characteristics

In total, 221 participants completed the survey. Of the participants, 96% (212/221) reported using SM networks for their disease management. Only these participants

Table 1: Baseline Characteristics of Participants

Characteristic	All cases (*n*=212)
Age (years)	36
Disease duration (years)	3
Gender	
Female	126 (59.4)
Male	86 (40.6)
Participant type	
Patient	139 (65.6)
Parent of a patient	73 (34.4)
Education level	
High school	61 (28.8)
College	128 (60.4)
Postgraduate (Masters and PhD)	23 (10.8)
Compliance to GFD	
Strictly compliant	164 (77.4)
Partially compliant	46 (21.7)
Poor compliant	2 (0.9)

Values are presented as median or number (%)

were included in the subsequent analysis. The median age was 36 years (range; 18–60 years). The majority of respondents (59.4%) were female. Most participants (65.6%) were patients with celiac disease and 34.4% were the parents of celiac patients. The median duration of the disease was three years (range; 1 month–26 years). Table 1 summarizes the participants' characteristics.

SM usage patterns

The three most frequently visited SM platforms were WhatsApp by 175 (82.5%) participants, Instagram by 132 (62.3%), and Twitter by 124 (58.5%) participants. Figure 1 displays the percentage of the preferred SM platforms (participants were allowed to choose more than one SM platform).

Two-thirds of participants (*n* = 162, 76.4%) reported visiting SM platforms daily. The median time spent on visiting SM was 60 min per day (range; 10–720 min).

The three most frequently cited reasons for using SM were searching for GFD stores by 50 (23.6%) participants, searching for information about GFD by 45 (21.2%), and searching for information about celiac disease by 44 (20.8%) participants. Figure 2 displays the percentage of all cited reasons for using SM.

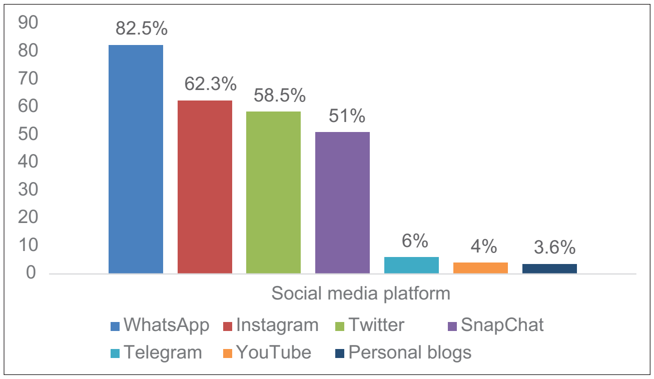

Figure 1: Preferred Social Media Platforms. Participants were allowed to choose more than one option

The majority of participants (87%) reported that the quality of the posted information about CD/GFD in SM platforms was either very good (*n* = 112, 53%) or acceptable (*n* = 73, 34.4%). Almost 66% of participants stated that no barrier interfered with their SM usage while 21% believed that poor credibility of the posted information was the greatest barrier regarding their usage of SM platforms.

Furthermore, 77% of surveyed participants expressed an interest in following their healthcare provider's SM account if they had one.

To explore the differences in participants' patterns of SM usage, we divided them into three groups according to age: the young-age group (18–30 years), middle-age group (31–45 years), and older-age group (more than 45 years). We found that compared to the other two groups, the middle-age group was the most engaging either fully or partially ($P = 0.004$). Furthermore, this age group tended to spend more time (min/day) on SM networking than the other two groups, although the difference was not statistically significant. No other significant differences were found for the other factors. Table 2 provides detailed information on the SM usage patterns.

Participants' opinion regarding the usefulness of SM

Participants' opinion regarding the usefulness of SM were examined in different domains. The majority (94%) either agreed or strongly agreed that SM was helpful in increasing understanding of their disease and their compliance with GFD, and 78% agreed or strongly agreed that SM was helpful in promoting community awareness about CD. Finally, 75% of participants agreed or strongly agreed that

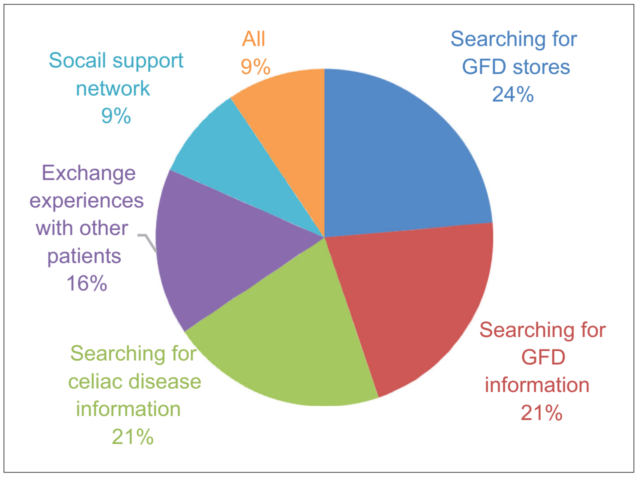

Figure 2: Reasons for Social Media Usage

Table 2: Social Media Usage Patterns

Parameter	Group-1 (18-30 years) (*n*=61)	Group-2 (31-45 years) (*n*=123)	Group-3 (>45 years) (*n*=28)	All cases (*n*=212) *n* (%)	*P*
Frequency of SM visits					
Daily	39 (63.9)	98 (79.7)	25 (89.3)	162 (76.4)	0.064
2-4 times/week	19 (31.1)	20 (16.3)	3 (10.7)	42 (19.8)	
Irregular	3 (4.9)	5 (4.1)	0 (0)	8 (3.8)	
Time spent in SM visits					
Less than 60 min/day	40 (65.6)	72 (58.5)	18 (64.3)	130 (61.3)	0.615
More than 60 min/day	21 (34.4)	51 (41.5)	10 (35.7)	82 (38.7)	
Degree of engagement in SM activities					
Actively engaged	12 (19.7)	31 (25.2)	4 (14.3)	47 (22.2)	0.004
Partially engaged	24 (39.3)	72 (58.5)	14 (50)	110 (51.9)	
Silent follower	25 (41)	20 (16.3)	10 (35.7)	55 (25.9)	
Quality of existing information on SM					
Very good	26 (42.6)	68 (55.3)	18 (64.3)	112 (52.8)	0.446
Acceptable	24 (39.3)	42 (34.1)	7 (25)	73 (34.4)	
Poor	9 (14.8)	11 (8.9)	3 (10.7)	23 (10.9)	
Not sure	2 (3.3)	2 (1.6)	0 (0)	4 (1.9)	
Barriers for SM usage					
No barriers	36 (59)	82 (66.7)	21 (75)	139 (65.6)	0.088
Poor credibility	16 (26.2)	27 (22)	2 (7.1)	45 (21.2)	
Privacy concerns	1 (1.6)	5 (4.1)	0 (0)	6 (2.8)	
Time consuming	8 (13.1)	7 (5.7)	3 (10.7)	18 (8.5)	
Inability to use SM	0 (0)	2 (1.6)	2 (7.1)	4 (1.9)	

SM was helpful in reaching out to healthcare policymakers to express their needs. There were no significant differences between the three groups regarding their opinions. Table 3 provides more details of participants' opinions.

Factors affecting the frequency of SM usage

Multivariate logistic regression showed that patients with celiac disease spent more time using SM (two times more) than the parents of celiac patients (OR 2.37 (CI = 1.19-4.72), $P = 0.014$) when adjusting for age, gender, education level, duration of the disease, and degree of engagement in SM activities. The influences of the other factors were not statistically significant [Table 4].

DISCUSSION

To our knowledge, this study is the first to examine the patterns, barriers, and opinions of celiac patients toward SM usage. The results of the present study may contribute to filling the gap in the current knowledge in this area.

Table 3: Participants' Opinion Regarding the Usefulness of Social Media

Parameter	All cases (*n*=221) *n* (%)	Age (18-30 years) (*n*=67)	Age (31-45 years) (*n*=126)	Age (>45 years) (*n*=28)	*P*
SM helps celiac patients to understand their disease better					
Strongly agree	134 (63.2)	30 (49.2)	83 (67.5)	21 (75)	0.060
Agree	66 (31.1)	26 (42.6)	35 (28.5)	5 (17.9)	
Not sure	8 (3.8)	2 (3.3)	4 (3.3)	2 (7.1)	
Disagree	3 (1.4)	2 (3.3)	1 (0.8)	0 (0)	
Strongly disagree	1 (0.5)	1 (1.6)	0 (0)	0 (0)	
SM helps celiac patients to comply with GFD better					
Strongly agree	132 (62.3)	35 (57.4)	78 (63.4)	19 (67.9)	0.537
Agree	68 (32.1)	21 (34.4)	39 (31.7)	8 (28.6)	
Not sure	7 (3.3)	2 (3.3)	5 (4.1)	0 (0)	
Disagree	5 (2.4)	3 (4.9)	1 (0.8)	1 (3.6)	
Strongly disagree	0 (0)	0 (0)	0 (0)	0 (0)	
SM promotes community awareness about celiac disease					
Strongly agree	96 (45.3)	21 (34.4)	59 (48)	16 (57.1)	0.325
Agree	74 (34.9)	22 (36.1)	43 (35)	9 (32.1)	
Not sure	25 (11.8)	11 (18)	12 (9.8)	2 (7.1)	
Disagree	17 (8)	7 (11.5)	9 (7.3)	1 (3.6)	
Strongly disagree	0 (0)	0 (0)	0 (0)	0 (0)	
SM helps in approaching health policymakers					
Strongly agree	109 (51.4)	34 (55.7)	63 (51.2)	12 (42.9)	0.796
Agree	52 (24.5)	13 (21.3)	32 (26)	7 (25)	
Not sure	45 (21.2)	13 (21.3)	23 (18.7)	9 (32.1)	
Disagree	3 (1.4)	1 (1.6)	2 (1.6)	0 (0)	
Strongly disagree	3 (1.4)	0 (0)	3 (2.4)	0 (0)	

Table 4: Factors Associated with the Frequency of Social Media Usage

Factor	aOR (95% CI aOR)	*P*
Age	1.02 (0.98-1.05)	0.367
Duration of the disease	0.99 (0.93-1.06)	0.79
Gender		0.115
Female	1.67 (0.88-3.16)	
Male	1	
Participant type		0.014*
Patient	2.37 (1.19-4.72)	
Parents of a patient	1	
Education level		0.375
High school	0.83 (0.30-2.26)	0.712
College	0.58 (0.23-1.49)	0.257
Postgraduate (Masters and PhD)	1	
Degree of engagement in SM activities		
Actively engaged	2.18 (0.92-5.18)	0.163
Partially engaged	1.86 (0.89-3.88)	0.079
Silent follower	1	0.089

aOR=adjusted odds ratio, CI=confidence interval, *Statistically significant association

The widespread and growing popularity of SM can be used as an important resource for celiac patients for their disease education and management. The majority of participants in this study (96%) used different SM platforms as part of their disease management. Over two-thirds of participants visited SM networks daily. This finding is consistent with the results of other surveys on different chronic medical conditions.[2-4]

The quality of the posted information on CD and GFD on SM varies greatly. The majority of participants (87%) in this study reported that the quality of the posted information (mostly in Arabic languages) was either very good or acceptable. McNally *et al.* reported that the information on many English-language websites addressing CD was not sufficiently accurate, comprehensive, or easily readable to be considered a sufficiently reliable source for patients' education.[11] Nadasan *et al.* assessed the quality of CD information among the top 100 Romanian websites, finding that while the posted information is extremely deficient, the accuracy thereof was relatively good.[12]

Interestingly, most participants (65.5%) face no significant barriers in dealing with SM platforms for their disease. However, 21% expressed their concern about the credibility of the posted information, which can be an obvious obstacle hindering SM usage. Concern about privacy and confidentiality was reported by only 2.8% of the participants. A previous study by Bosslet *et al.* showed that the majority of the surveyed physicians (79%) expressed their concerns about preserving patient confidentiality on SM, and almost half were doubtful about the potential use of SM to improve patient-doctor communication.[13]

Comparing the SM usage patterns of the three age groups, we found only one statistically significant difference, namely that the middle-age group (31–45 years) was the most actively engaged in SM activities (either fully or partially). This may be related to the fact that this age group tended to spend more time on SM networking than the other two groups, although the difference was not statistically significant.

We tried to explore potential factors that may influence the frequency of SM usage; however, we found no significant differences between users in terms of age, gender, education level, degree of engagement, or duration of the disease. The only statistically significant difference found was related to the "type of participants." Participants with celiac disease spent twice as much time on SM than parents of celiac patients. These findings need to be further explored in future studies.

Two-thirds of the participants in our study expressed an interest in following the SM accounts of their healthcare providers. Healthcare providers in the field of CD (physicians, nurses, and dietitians) should be aware of this and the fact that their patients are increasingly interested in including SM in their healthcare management.[2,7] Thus, healthcare providers should take an active role in utilizing SM to increase awareness about the disease and provide the celiac community with trustworthy educational material.

The impact of GFD on QOL has previously been studied in pediatric CD patients in Saudi Arabia.[14] Although the majority of the participants in this study agreed/strongly agreed that SM was very helpful for them in terms of gaining a better understanding of their disease and GFD, we cannot comment on the effect of SM on their QOL, because our study was not designed to assess this target. Lee *et al.* found that participation in face-to-face CD social support networks was associated with greater QOL scores compared to online social support networks. The same study found that lower QOL scores were associated with a longer duration and greater frequency of the use of online social support networks. They attributed these findings to the fact that SM may provide ongoing technical connectivity; however, they may not be able to provide patients with the real core support they are looking for.[15] Further studies are needed to explore the association between SM usage and QOL.

Our study is not without limitations. Because of the study design, the participants in the present study were limited to those registered in the SCPSG (primarily were adult patients), and this may affect the generalizability of the study. Therefore, the results may not be representative of all celiac patients in the community, especially those less than 18 years of age. Another limitation is related to the survey being self-reported, and therefore we should take this into consideration, particularly in interpreting the reported compliance to GFD.

CONCLUSIONS

Celiac patients are highly involved in SM activities for purposes related to their disease. This study demonstrated the positive impact of SM on celiac patients. We highly encourage healthcare providers to be available online to provide trustworthy and high-quality educational material. Future research is needed to assess the quality of the posted information on celiac disease and explore the impact of SM on the disease QOL.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

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