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Short Communication

# Content of widely viewed YouTube videos about celiac disease

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ABSTRACT

*Objective:* To describe the most widely viewed English language videos related to celiac disease on YouTube.
*Study design:* This is a cross-sectional study.
*Methods:* Videos sorted by number of views yielded the 100 most widely viewed. Number of views, source (consumer, professional, or news agency), and inclusion of specific content were recorded.
*Results:* Collectively, the 100 videos were viewed nearly 7 million times. Between 2007 and 2010, 28% were uploaded, while more than 70% were uploaded after 2010. Professionals uploaded almost half (48%), consumers posted 32%, and news sources posted the remaining 20%. While gluten-containing foods/drinks were presented in 57% of the videos, these videos garnered almost 78% of cumulative views. Comparatively few videos provided substantive information related to age at diagnosis, who is at risk for the disease, hereditary nature, or that the disease can inhibit growth and development among children. Most videos (56%) did not cover how celiac disease is diagnosed, and only 14% mentioned family members of diagnosed individuals should be screened for the disease (garnering only 9% of cumulative views).
*Conclusion:* Given the popularity and potential reach of YouTube, medical professionals have an opportunity to use this medium to reach a large audience in providing accurate and useful information to the public about celiac disease.


## Introduction

Celiac disease is an autoimmune disorder trigged by gluten consumption in wheat and proteins similar to gluten in rye and barley.[1] In the United States, prevalence is estimated at 0.71%.[2] Symptoms vary from asymptomatic to digestive issues and nutritional deficiencies due to malabsorption of nutrients.[3] Treatment includes maintaining a gluten-free diet.[3]

The Internet is increasingly used by the general public to learn health information.[4] YouTube is a popular video-sharing site on which many consumers and professionals post videos related to health content.[5] The purpose of this study was,

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therefore, to describe the most widely viewed English language videos on YouTube related to celiac disease.

## Methods

In October 2017, using a cleared browser, the key words 'celiac disease' were searched. Videos sorted by number of views yielded the 100 most widely viewed. Number of views, source (consumer, professional, or news agency), and inclusion of specific content were recorded. Content categories were based on the National Institute of Diabetes and Digestive and Kidney Diseases.[3] One coder watched and coded all videos, and a second coder coded a 10% random sample, which yielded high consistency (Cohen's kappa = 0.90). Frequencies and percentages were calculated for dichotomous variables means, standard errors, and medians for continuous variables. Chi-squared tests assessed associations between source and content using an alpha level of $P < 0.01$. All analyses were performed using IBM SPSS Statistics software, version 24. The Institutional Review Board at the William Paterson University does not review studies that do not involve human subjects. The Institutional Review Board at Teachers College Columbia University approved this study.

**Table 1 – Characteristics of celiac disease (CD) YouTube™ videos [n (%)][a].**

| Item | Total (n = 100) | Consumer (n = 32) | Professional (n = 48) | News (n = 20) |
|---|---|---|---|---|
| **Video characteristics** | | | | |
| Year uploaded | | | | 0.43 |
| 2007–2010 | 28 (28.0) | 7 (21.9) | 17 (35.4) | 4 (20.0) |
| 2011–2013 | 29 (29.0) | 8 (25.0) | 15 (31.3) | 6 (30.0) |
| 2014–2015 | 27 (27.0) | 10 (31.3) | 9 (18.8) | 8 (40.0) |
| 2016–2017 | 16 (16.0) | 7 (21.9) | 7 (14.6) | 2 (10.0) |
| Gender of person in video | | | | 0.004 |
| No persons | 6 (6.0) | 4 (12.5) | 2 (4.2) | 0 (0.0) |
| Male | 33 (33.0) | 7 (21.9) | 24 (50.0) | 2 (10.0) |
| Female | 38 (38.0) | 14 (43.8) | 14 (29.2) | 10 (50.0) |
| Both male and female | 23 (23.0) | 7 (21.9) | 8 (16.7) | 8 (40.0) |
| Number of views | | | | 0.34 |
| Total | 6,983,233 | 4,563,490 | 1,611,187 | 808,556 |
| Mean (SE) | 69,832 (34,013) | 142,609 (105,843) | 33,566 (5669) | 40,427 (6815) |
| Median | 19,880 | 17,450 | 21,823 | 28,743 |
| Range | 8165–3,393,681 | 8165–3,393,681 | 8207–207,802 | 10,879–102,084 |
| 95% CI | 2342-137,322 | 0-358,478 | 22,161-44,971 | 26,164-54,691 |
| Video length (minutes) | | | | 0.07 |
| Mean (SE) | 8.9 (1.3) | 7.4 (0.7) | 11.8 (2.5) | 4.4 (0.8) |
| Median | 5.4 | 7.2 | 5.2 | 4.4 |
| Range | 0.5–88.18 | 0.6–14.3 | 0.5–88.18 | 0.5–14.0 |
| 95% CI | 6.4–11.4 | 6.0–8.8 | 6.7–16.9 | 2.7–6.1 |
| Thumbs up | | | | 0.29 |
| Mean (SE) | 793 (5787) | 2129 (1804) | 163 (32) | 162 (52.8) |
| Range | 0-58,000 | 0.4–58,000 | 0–1000 | 4–987 |
| 95% CI | 0–1941 | 0–5808 | 101–230 | 52–272 |
| Thumbs down | | | | 0.08 |
| Mean (SE) | 25 (115) | 62 (35) | 6.7 (1.4) | 8.5 (4.1) |
| Range | 0-1000 | 0–1000 | 0–42 | 0–78 |
| 95% CI | 2–48 | 0–134 | 4–10 | 0–17 |
| **Video content** | | | | |
| Provision of information | | | | 0.013 |
| Yes | 89 (89.0) | 24 (75.0) | 46 (95.8) | 19 (95.0) |
| No | 11 (11.0) | 8 (25.0) | 2 (4.2) | 1 (5.0) |
| Information about a personal experience | | | | 0.005 |
| Yes | 18 (18.0) | 11 (34.4) | 3 (6.3) | 4 (20.0) |
| No | 82 (82.0) | 21 (65.6) | 45 (93.8) | 16 (80.0) |
| **About the disease** | | | | |
| Mentions how many are afflicted | | | | 0.007 |
| Yes | 35 (35.0) | 8 (25.0) | 14 (29.2) | 13 (65.0) |
| No | 65 (65.0) | 24 (75.0) | 34 (70.8) | 7 (35.0) |
| Mentions who is at risk | | | | 0.45 |
| Yes | 20 (20.0) | 5 (15.6) | 9 (18.8) | 6 (30.0) |
| No | 80 (80.0) | 27 (84.4) | 39 (81.3) | 14 (70.0) |
| Mentions celiac disease is an autoimmune disorder | | | | 0.47 |
| Yes | 52 (52.0) | 17 (53.1) | 27 (56.3) | 8 (40.0) |
| No | 48 (48.0) | 15 (46.9) | 21 (43.8) | 12 (60.0) |

**Table 1 – (*continued*)**

| Item | Total (n = 100) | Consumer (n = 32) | Professional (n = 48) | News (n = 20) |
|---|---|---|---|---|
| Mentions celiac disease is hereditary | | | | 0.78 |
| Yes | 31 (31.0) | 11 (34.4) | 15 (31.3) | 5 (25.0) |
| No | 69 (69.0) | 21 (65.6) | 33 (68.8) | 15 (75.0) |
| Mentions how celiac disease affects the body | | | | 0.38 |
| Yes | 74 (74.0) | 24 (75.0) | 33 (68.8) | 17 (85.0) |
| No | 26 (26.0) | 8 (25.0) | 15 (31.3) | 3 (15.0) |
| Mentions damage of villi in small intestine | | | | 0.13 |
| Yes | 55 (55.0) | 19 (59.4) | 29 (60.4) | 7 (35.0) |
| No | 45 (45.0) | 13 (40.6) | 19 (39.6) | 13 (65.0) |
| Mentions gluten as primary cause | | | | 0.47 |
| Yes | 81 (81.0) | 28 (87.5) | 38 (79.2) | 15 (75.0) |
| No | 19 (19.0) | 4 (12.5) | 10 (20.8) | 5 (25.0) |
| Mentions age when celiac disease can develop | | | | 0.16 |
| Yes | 14 (14.0) | 2 (6.3) | 7 (14.6) | 5 (25.0) |
| No | 86 (86.0) | 30 (93.8) | 41 (85.4) | 15 (75.0) |
| Mentions risk for other chronic health conditions | | | | 0.50 |
| Yes | 44 (44.0) | 12 (37.5) | 24 (50.0) | 8 (40.0) |
| No | 56 (56.0) | 20 (62.5) | 24 (50.0) | 12 (50.0) |
| Mentions inhibited growth/development in children | | | | 0.46 |
| Yes | 26 (26.0) | 6 (18.8) | 15 (31.3) | 5 (25.0) |
| No | 74 (74.0) | 26 (81.3) | 33 (68.8) | 15 (15.0) |
| **Symptoms** | | | | |
| Mentions food and drink that contains gluten | | | | 0.62 |
| Yes | 57 (57.0) | 20 (62.5) | 25 (52.1) | 12 (60.0) |
| No | 43 (43.0) | 12 (37.5) | 23 (47.9) | 8 (40.0) |
| Mentions bloating | | | | 0.44 |
| Yes | 29 (29.0) | 11 (34.4) | 11 (22.9) | 7 (35.0) |
| No | 71 (71.0) | 21 (65.6) | 37 (77.1) | 13 (65.0) |
| Mentions chronic diarrhea | | | | 0.30 |
| Yes | 46 (46.0) | 15 (46.9) | 19 (39.6) | 12 (60.0) |
| No | 54 (54.0) | 17 (53.1) | 29 (60.4) | 8 (40.0) |
| Mentions constipation | | | | 0.63 |
| Yes | 14 (14.0) | 6 (18.8) | 6 (12.5) | 2 (10.0) |
| No | 86 (86.0) | 26 (81.3) | 42 (87.5) | 18 (90.0) |
| Mentions nausea | | | | 0.15 |
| Yes | 10 (10.0) | 6 (18.8) | 3 (6.3) | 1 (5.0) |
| No | 90 (90.0) | 26 (81.3) | 45 (93.8) | 19 (95.0) |
| Mentions stomach pain | | | | 0.09 |
| Yes | 36 (36.0) | 12 (37.5) | 13 (27.1) | 11 (55.0) |
| No | 64 (64.0) | 20 (62.5) | 35 (72.9) | 9 (45.0) |
| Mentions vomiting | | | | 0.46 |
| Yes | 12 (12.0) | 5 (15.6) | 6 (12.5) | 1 (5.0) |
| No | 88 (88.0) | 37 (84.4) | 42 (87.5) | 19 (95.0) |
| Mentions ulcers/sores in stomach or lining | | | | 0.30 |
| Yes | 8 (8.0) | 3 (9.4) | 2 (4.2) | 3 (15.0) |
| No | 92 (92.0) | 29 (90.6) | 46 (95.8) | 17 (85.0) |
| Mentions dermatitis herpetiformis | | | | 0.74 |
| Yes | 20 (20.0) | 6 (18.8) | 11 (22.9) | 3 (15.0) |
| No | 80 (80.0) | 26 (81.3) | 37 (77.1) | 17 (85.0) |
| Mentions why symptoms vary between individuals | | | | 0.82 |
| Yes | 11 (11.0) | 3 (9.4) | 5 (10.4) | 3 (15.0) |
| No | 89 (89.0) | 29 (90.6) | 43 (89.6) | 17 (85.0) |
| Mentions symptoms in children | | | | 0.78 |
| Yes | 28 (28.0) | 8 (25.0) | 15 (31.3) | 5 (25.0) |
| No | 72 (72.0) | 24 (75.0) | 33 (68.8) | 15 (75.0) |
| **Diagnosis** | | | | |
| Mentions how diagnosed | | | | 0.21 |
| Yes | 44 (44.0) | 10 (31.3) | 25 (50.0) | 10 (50.0) |
| No | 56 (56.0) | 22 (68.8) | 24 (50.0) | 10 (50.0) |
| Mentions blood tests to diagnose | | | | 0.50 |
| Yes | 41 (41.0) | 14 (43.8) | 17 (35.4) | 10 (50.0) |
| No | 59 (59.0) | 18 (56.3) | 31 (64.6) | 10 (50.0) |

(*continued on next page*)

**Table 1 – (*continued*)**

| Item | Total (n = 100) | Consumer (n = 32) | Professional (n = 48) | News (n = 20) |
|---|---|---|---|---|
| Mentions endoscopy to diagnose | | | | 0.75 |
| Yes | 21 (21.0) | 7 (21.9) | 11 (22.9) | 3 (15.0) |
| No | 79 (79.0) | 25 (78.1) | 37 (77.1) | 17 (85.0) |
| Mentions importance of screening other family members | | | | 0.36 |
| Yes | 14 (14.0) | 5 (15.6) | 8 (16.7) | 1 (5.0) |
| No | 86 (86.0) | 27 (84.4) | 40 (83.3) | 19 (95.0) |
| **Treatment** | | | | |
| Mentions treatment | | | | 0.98 |
| Yes | 47 (47.0) | 15 (46.9) | 23 (47.9) | 9 (45.0) |
| No | 53 (53.0) | 17 (53.1) | 25 (52.1) | 11 (55.0) |
| Mentions food/drink in strict gluten-free diet | | | | 0.17 |
| Yes | 32 (32.0) | 14 (43.8) | 14 (29.2) | 4 (20.0) |
| No | 68 (68.0) | 18 (56.3) | 34 (70.8) | 16 (80.0) |
| Missing | | | | |
| Mentions gluten-free medications | | | | 1.00 |
| Yes | 100 (100.0) | 32 (100.0) | 48 (100.0) | 20 (100.0) |
| No | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| Mentions annual follow-up treatment instructions | | | | 1.00 |
| Yes | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| No | 100 (100.0) | 32 (100.0) | 48 (100.0) | 20 (100.0) |
| Mentions potential complications if treatment plan not followed | | | | 0.009 |
| Yes | 19 (19.0) | 4 (12.5) | 6 (12.5) | 9 (45.0) |
| No | 81 (81.0) | 28 (87.5) | 42 (87.5) | 11 (55.0) |

CI, confidence interval; SE, standard error.
[a] Unless stated otherwise.

## Results

Collectively, the 100 videos were viewed nearly 7 million times (range = 8165–3,393,681 times) with an average duration of 8.9 (SD = 1.3) minutes (range = 0.5–88.18 min) (Table 1). Between 2007 and 2010, 28% were uploaded, while more than 70% were uploaded after 2010. Professionals uploaded almost half (48%), consumers posted 32%, and news sources posted the remaining 20%. The mean number of views was 69,832 (standard error = 34,013), and the mean length was 8.9 min (standard error = 1.3, median = 5.4 min).

The content most covered was providing general information (89% and >97% of cumulative views) and mentioning gluten as the primary cause of the disease (81% and >92% of cumulative views), while topics least covered and garnering a comparatively small proportion of cumulative views were symptoms such as ulcers/sores in the stomach or lining (8%), nausea (10%), variation in symptoms across individuals (11%), vomiting (12%), and constipation (14%). While gluten-containing foods/drinks were presented in 57% of the videos, these videos garnered almost 78% of cumulative views. Blood tests used for diagnosis and risk for chronic conditions were covered in 41% and 44% of videos, respectively, but garnered >70% of total cumulative views. Comparatively, few videos provided substantive information related to age at diagnosis (14.0% and 6.5% of cumulative views), who is at risk for the disease (20.0% and 9.6% of cumulative views), hereditary nature (31.0% and 17.2% of cumulative views), or that the disease can inhibit growth and development among children (26.0% and 12.7% of cumulative views). Most videos (56%) did not cover how celiac disease is diagnosed (garnering only 25.6% of cumulative views), and only 14% mentioned family members of diagnosed individuals should be screened for the disease (garnering only 9% of cumulative views). There was no significant difference in content covered by source for 28 of the 31 content categories. Differences were observed for personal experience (presented in 34% of consumer videos vs 6.3% of professional and 20% of news videos), numbers affected (covered in 65% of news videos vs 25% of consumer and 29.2% of professional videos), and potential complications if treatment plan is not followed (mentioned in 45% of news videos vs 12.5% of both consumer and professional videos).

## Conclusions

We did not identify any published studies about the content of English language celiac disease videos on YouTube. Given the popularity and potential reach of YouTube, medical professionals have an opportunity to use this medium to reach a large audience in providing accurate and useful information to the public about celiac disease. With few exceptions, the most widely viewed videos uploaded by consumers, professional, or news agencies covered similar content. Most of videos did not cover symptoms, and greater attention to this issue may address the problem of under diagnosis. This study did not address the accuracy of information presented, and additional research to do so is needed.

## Author statements

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Results of this study have been described in brief as an abstract presented at Digestive Disease Week in Washington, DC.

### Ethical approval

The Institutional Review Board at Teachers College Columbia University approved this study.

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No funding was acquired for this study.

### Competing interest

None of the authors report a conflict of interest.

### Author contributions

C.H.B. and C.E.B. conceived and designed the study. P.G. was the first coder and C.H.B. the second coder. G.C.H. conducted the statistical analysis. C.H.B., G.C.H., P.G., and C.E.B. wrote and critically revised the manuscript.

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