Adolescents with chronic disease and social media: a cross-sectional study

Laura De Nardi ^(D), ¹ Andrea Trombetta ^(D), ¹ Sergio Ghirardo, ¹ Maria Rita Lucia Genovese, ¹ Egidio Barbi, ^{1,2} Valentina Taucar²

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¹Department of Medicine, Surgery and Health Sciences, Department of Pediatrics, University of Trieste, Trieste, Italy ²Institute for Maternal and Child Health IRCCS 'Burlo Garofolo', Trieste, Italy

Correspondence to

Dr Andrea Trombetta, IRCSS Burlo Garofolo, Universita degli Studi di Trieste, 34137 Trieste, Italy; andreamer91@live.it

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ABSTRACT

Objective This study aims to explore the attitude of adolescents with chronic diseases toward social media exposure, focusing in particular on Facebook. **Design** Cross-sectional study.

Setting An anonymous semistructured survey was distributed to an Italian hospital-based cohort of adolescents with chronic disease to explore the role of Facebook in their daily life.

Patients We recruited 212 adolescents (aged between 13 and 24 years) with a diagnosis of inflammatory bowel disease, coeliac disease, diabetes mellitus type 1 and cystic fibrosis.

Results Two hundred and seven of the 212 (97.6%) expressed the need of sharing their illness experience with friends, 201 out of 212 (94.8%) usually searched information on the internet to find new therapies and to discover their prognosis. One hundred and forty-nine out of 212 adolescents (70.3%) perceived dependence on their parents as the most negative aspect of having a chronic disease, and 200 out of 212 (94.3%) were looking for friends with the same disease on Facebook. Two hundred and ten out of 212 (99.1%) did not want their doctors or nurse on their social media platforms. During the active disease periods, the time spent with social media increased from an average of 5 to 11 hours. Conclusions This descriptive analysis focused on the Facebook impact on chronic disease perception among affected adolescents. It showed that they used to spend an increased amount of time on this platform during disease flare-up and highlighted their wish of keeping doctors and nurses away from their social dimension.

INTRODUCTION

Chronic diseases, defined as chronic medical conditions lasting longer than 6 months, currently affect up to 20%–30% of teenagers. About 10%–13% of them reported such conditions as compromising their health-related quality of life,¹ which not only depends on disease activity but also is strongly affected by anxiety, depression, disease cognition and a sense of loneliness.²

There is increasing evidence to suggest that young people who experience periods of longterm illness have a greater emotional, psychological and behavioural vulnerability, along with distinct health needs than other groups.³ A healthy psychological development, based on strengthening selfawareness, promoting positive coping strategies, providing a functional peer group and minimising catastrophism,^{2 3} plays a crucial role in the severity and disability of patients reporting symptoms, as

What is already known on this topic?

- Social media have a key role for adolescents to fulfil their need for sociability.
- Studies investigating the role of Facebook in supporting adolescents with a chronic disease showed controversial results with half of them suggesting a positive role.
- Doctor and nurses-patient relationships on social media platforms have not been studied before in this population.

What this study adds?

- This study shows that the self-perceived social needs that young people feel are met by using Facebook.
- This study shows that adolescents and young people with chronic disease do not want healthcare professionals on their social media platforms.

shown in some studies focusing on the intestinal bowel diseases. $^{\rm 4-6}$

These factors influence the way adolescents perceive their chronic disease and, in turn, are modulated by the use of social media.^{7 8} With this term, we usually define web-based platforms that allow people to create their personal profile and build a network of connections with other users, becoming part of a global phenomenon.⁷

Studies addressing the effects of social media on adolescents' well-being showed heterogeneity of findings, describing these extraordinarily popular tools as a double-edged sword. On the one hand, they seemed capable of acting as a protective factor against avoidant behaviours, alienation and depression, providing a higher level of social connectedness, promoting more positive mental health outcomes, and decreasing feelings of anxiety, distress and loneliness.⁸

On the other hand, some researches indicated precisely the opposite, attributing to the use of social media the risk of feelings of anxiety and isolation, as they can cause addiction, alienate adolescents from family, real-life and spread the risk of emulative behaviours (ie, alcohol consumption, smoking, bullying, self-harm, etc).⁸ An excessive social media usage has also been associated with poor sleep, low self-esteem, negative image of their own body and

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consequent increased risk of anorexia nervosa, along with higher depressive symptom scores.⁹

The existing literature on social media use in chronic diseases currently addresses two different lines of research. The first one is their possible use as platforms where patients and caregivers can communicate in real time to facilitate disease self-management.¹⁰⁻¹⁷

The second one, analysed in this work, concerns the possible role of social media in reducing suffering, anxiety, sense of lone-liness and disease burden, responding to the need for peer relationships.^{10 12 15 18-24}

Although some studies suggested that discussion forums and collaborative projects can be promising resources for the management of chronic diseases,²⁵ there is still no global consensus on strategies tailored to guide health professionals in assisting patients with such conditions.¹²

The reported impact of social media use on people with longterm conditions is controversial: the main systematic review, including 42 works on the topic¹⁰ reported benefits for almost half (48%) of the analysed studies, whereas 45% were neutral or undefined and only 7% suggested harms. Sixteen of these studies explored the social media 'supporting' role, 3 of them referred to Facebook and they were all set among an adult population (>18 years of age).

Few studies addressed social media use among young people with long-term conditions, showing that social media provide social, emotional or experiential support, with Facebook and blogs, being the most likely to improve patients' quality of life.¹⁰¹¹

This study aimed to investigate the impact of social media on a cohort of adolescents with long-term conditions, exploring how and how much they use them, how social media use can modify patients' disease perception and how they perceive the presence of healthcare professionals on these platforms. We focused on Facebook, in particular, considering if and how it could modulate the following topics mentioned in literature: disease communication to other users, sharing illness with other affected adolescents, sense of loneliness/isolation and inadequacy toward other peers.

METHODS

This cross-sectional observational study was conducted from 1 October 2018 to 28 October 2018 at the Institute for Maternal and Child Helath—IRCCS 'Burlo Garofolo' in Italy.

It is a tertiary referral university teaching hospital, serving an area of 2 50 000 people with patients coming from outside the region too. Eligible participants were young people aged between 13 and 24 years with a diagnosis of chronic disease limited to cystic fibrosis, inflammatory bowel disease (IBD), diabetes mellitus type 1 and coeliac disease.

We arbitrarily decided to include patients with these specific pathologies for pragmatic convenience criteria based on the number of patients regularly followed up at the Institute services.

The inclusion criteria encompassed to have an open Facebook profile and at least one admittance at the hospital as an inpatient or outpatient.

Exclusion criteria were considered the inability to understand Italian, diagnosis of the disease within the last 3 months and having another chronic pathology not included in the list above.

Study enrolment was offered to 243 adolescents meeting the inclusion criteria, and 31 out of 243 have declined to enter the study. The involved patients or their parents (if they were minors) signed the informed consent to take part in the study.

We collected data from a semistructured survey (see online supplementary file 1) based on other questionnaires¹²¹⁸ addressing the following main domains found in literature: 'disease information searching on the internet', 'privacy and disease communication to other users', 'need to share illness with peers', 'sense of loneliness/isolation', 'disturbing psychological effects of the disease' and 'pattern and time of internet utilization'. We added a further domain 'adolescent desire of having doctors or nurses on their social platforms'.

The survey had previously been administered to a pilot group (not included in the final analysis) of 72 people to understand the degree of perceived demand and provide any adjustments.

The final questionnaire including 18 questions with binary answers (yes/no), multiple choices, open-answers was distributed through Facebook instant messaging service, email and it was anonymous. For each enrolled patient, we collected the following demographic variables: age, gender and diagnosis.

We categorised recurrent open answers and compared the results of this descriptive analysis with current literature findings.

STATISTICAL ANALYSIS

Using a separate Excel spreadsheet, data were anonymised according to the European Union directive 2016/679 and then evaluated for statistical analysis, performed using R commander version 1.9-5. We reported the binomial data as numbers and percentages. The Shapiro-Wilk test was applied to identify if continuous variables presented normal distribution. Normal data were reported as mean±SD while non-normal data were reported using mean, range, first and third quartile. We compared the time spent on social media during disease activity with healthy periods using the Wilcoxon signed-rank test and considered statistically significant p<0.05.

RESULTS

A register was created based on a questionnaire answered by 212 patients. Demographic data are displayed in table 1.

Purposes of internet usage and searching disease information on the internet

Nine patients (4.2%) used social media other than Facebook (ie, Instagram or Twitter), and all the participants used the internet also for purposes other than social media. The most common answers were 'to search information in general', 'to send emails', 'to watch TV/movies', 'to do shopping online', 'to read the news', 'to book holidays' and 'to do school papers'. When asked

Table 1 Demographic data	
How old are you?	
13–17 years	146 (68.9%)
18 years or more	66 (31.1%)
Which is your gender?	
Male	104 (49.1%)
Female	108 (50.9%)
Which is your disease?	
Coeliac disease	34 (16%)
DMT1	36 (17%)
Cystic fibrosis	88 (41.5%)
Inflammatory bowel disease	47 (22.2%)
Coeliac disease and DMT1	7 (3.3%)

All the results are shown in online supplementary file 2. DMT1, diabetes mellitus type 1.

if they were usually looking for specific information about their disease on the internet, 201 out of 212 (94.8%) answered yes. They did it to find out news about the most recent therapies (90 out of 212, 42.5%), latest scientific researches (88 out of 212, 41.5%), information on their near future perspectives (89 out of 212, 42%) and long-term prognosis (95 out of 212, 44.8%).

Privacy and disease communication

Two hundred and seven out of 212 (96.4%) said that "their friends need to know about their disease." They clearly expressed the willingness to share their sickness: 65 out of 212 (30.7%) considered their condition 'not worthy of being hidden', 63 out of 212 (29.7%) preferred avoiding rumours, by informing friends in advance to 'not to be judged'. Forty-three out of 212 (20.3%) wanted people to be aware of the disease 'to be able to help them in case of problems'. Five out of 212 (2.4%) concealed their condition to friends, two due to their parents' wishes (0.9%), and three (1.4%) due to other unaware relatives. Two hundred and one out of 212 (94.8%) used their real name on Facebook, and 205 out of 212 (96.7%) wanted their friends on Facebook to know about their condition. Eighty out of 212 adolescents (37.7%) thought they could contribute to the medical research by getting in touch with as many people as possible, and 66 out of 212 (31.1%) would like people not to be afraid of their condition. For some patients, making people aware of these conditions is essential to develop a more positive awareness (72 out of 212, 34%) and reduce the isolation (80 out of 212, 37.7%).

Pattern and time of internet utilization

Patients spent an average of 5 hours a day on Facebook during their healthy periods, and this time increased to an average of 11 hours during periods of flare-up or hospitalisation for those with cystic fibrosis and IBD (see figure 1). The time spent on Facebook out of the disease activity presented a non-normal distribution (W 0.98) median 5 hours, range 0.5-9.5 hours, first quartile 8.75 hours, third quartile 6.5 hours. The time spent on this social media during disease relapses presented a non-normal distribution (W 0.89) median 12.5 hours, range 0.5-16.5 hours, first quartile 9 hours, third quartile 14 hours and was statistically significant (p<0.0001).

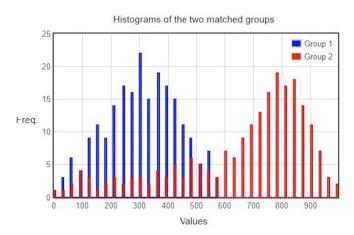


Figure 1 Distribution of hours spent on Facebook during periods of well-being (blue histograms) and relapses (red histograms). The number of hours spent on Facebook is reported on the x axis and the number of patients reporting this specific number of hours is reported on the y axis.

Need to share illness with peers

Two hundred out of 212 (94.3%) usually searched for friends with the same disease on Facebook. Most of them (188 out of 212, 88.7%) did this to find a shared community or, as they said, "to find somebody who can understand their feelings." They looked for peers to compare and 'share similar experiences' (101 out of 212, 47.6%), 'not to be pitied' (112 out of 212, 52.8%) and to be 'comforted by others' worse experiences' (73 out of 212, 34.4%). Other patients searched friends on Facebook 'to have general information on the disease' (98 out of 212, 46.2%), 'to be up to date with the latest medical devices' (82 out of 212, 38.7%) and 'with the latest home supplies' (78 out of 212, 36.8%).

Sense of loneliness/isolation and feeling different

When asked whether they felt different from their friends, 31 (14.6%) out of 212 answered 'often' and 8 (3.8%) 'always'. The prevalent answer was 'never' (84 patients out of 212, 39.6%), 52 out of 212 (24.5%) said 'sometimes' and 37 out of 212 (17.5%) said 'seldom'. This sense of 'feeling different' seems to diminish when the same question is posed, referring to friends on Facebook. Indeed, 21 (9.9%) and 6 (2.8%) out of 212 answered 'often' and 'always', respectively. Eighty-nine of the 212 (42%) patients answered 'never', 64 of the 212 (30.2%) said 'seldom' and 32 (15.1%) 'sometimes'. Four patients of the 212 (1.9%) complained about the disease-related sense of loneliness, while 200 out of 212 (94.3%) referred that 'they are never alone thanks to Facebook and its instant chat service'.

Psychological disturbing effects of the disease

The 70.3% of adolescents perceived dependence on parents or other people as the most disadvantageous part of having a chronic disease (149 out of 212). Out of the 212, 25 (11.8%) complained about recurrent medical examinations and hospitalisations, 20 (9.4%) about dietary restrictions and 18 (8.5%) about side effects of drugs.

Adolescent opinions on having doctors or nurses on their social platforms

When asked about creating a specific social media platform on which to discuss their disease with healthcare professionals, 2 out of 212 patients (0.9%) considered this acceptable or useful, while the other 210 out of 212 patients (99.1%) did not want their caregivers on these platforms. Almost the entire population believed that a platform like this would compromise their freedom, mainly because they considered doctors and nurses as inspectors. They reported perceiving Facebook and social media as a world where parents, adults and controllers in general were not welcomed as they could misunderstand some posts or considerations judging them on what should or should not be done.

DISCUSSION

This observational study highlighted Facebook impact on the chronic disease perception of affected adolescents, suggesting a possible role of social media in influencing their perceived quality of life.

The preferred platforms for young people are well known, as shown by Underwood, although it is difficult to achieve a real standardisation due to the very rapid change in preferences and regional prevalence worldwide.²⁶ Over 20 million minors globally use Facebook, 7.5 millions of whom are under the age of 13. Adolescents are moving to Twitter in large numbers; Instagram is at the time, the preferred social media platform for 76% of the adolescents.²⁶ Adolescents' preferences among young people with chronic diseases have been well described by Hausmann *et al* which asserted that Facebook and Instagram are the most used platforms (58.1% and 31.4%, respectively), followed by Twitter (26.7%), blogs (11.4%%) and Pinterest (3.8%).⁹

Eight studies in literature focused on adolescents using social media to help endure their long-term conditions,^{11 12 21-24 27 28} while three included both adolescents and adults.¹⁴⁻¹⁶ Among these, four evaluated Facebook,^{11 12 15 23} while the majority explored less known platforms, such as Starbright,²¹ Zora²² and Web 2.0,^{14 16 17} created ad hoc for exchanging disease information between patients and doctors. The mentioned studies agreed in saying that building social media strategies tailored to specific diseases and adolescent preferences may improve their clinical care in terms of outcomes.^{15 21 22}

A similar study, including 218 adults with chronic pain,¹⁵ ¹⁸ ²⁰ examined patients' reported health outcomes and therapeutic affordances of social media. According to the findings of our study, they observed increased use of social media during pain flares up.

This study shows adolescents' need to share their medical conditions on social media. Such finding is consistent with current literature, as different results were found only among 20 hospitalised patients that showed a trend toward hiding their condition, saying that "not all my friends need to know."¹² This attitude reflects the adolescent perception of social media as a place where discussing everyday life without mention of their long-term condition. Social networks seem to answer the request of peer relationships in two ways: supplying adolescents a way out from thinking about their disease, making them feel like a normal part of society, but also allowing them to share good and bad experiences with other people affected by the same disease.

The last point addressed by the survey concerned the involvement of doctors and nurses in adolescents' social media platforms. They perceived it as absolutely not useful and harmful for their independence. To our knowledge, this issue has not previously been studied among young people with chronic disease, while it is different from what reported among adults, who seem to appreciate the involvement of healthcare professionals in social media platforms.^{18–20}

This study had some limitations. It included people aged from 13 to 24 years, a quite broad age group with possible differences in the way patients experience their life and disease. It was at the same time a strength, as adolescents and young adults both share a common vulnerability, being their health needs so much different if compared with those of younger children and older adults.

Second, it included pathologies that are different in their disease burden, as cystic fibrosis is not coeliac disease and did not analyse further differences between them. However, results suggested that adolescents' need for feeling 'normal' could prescind from the type of disease.

Third, we did not ask adolescents about the possible damage perceived by the use of social media, as spending plenty of time online could steal time from doing physical activities, physiotherapy or taking therapies. Moreover, no one has explicitly been asked if they belonged exclusively to a 'Facebook closed disease group'.

Additionally, Facebook was the only social media considered in this study, which made it difficult to generalise these findings to all the other existing platforms. It was chosen because of its widespread use in Italy, although adolescents' preferences on social platforms can be country-specific and change rapidly. Furthermore, a single questionnaire performed at a definite moment of a patient's history is subject to some selection bias and recall bias.

Finally, the authors created the administered survey, as there is not an existing validated instrument able to correlate adolescents' quality of life to social media usage. However, we compared the questionnaire to other similar surveys found in the literature, addressing the same main explored domains.^{12 18}

The study also had some points of strength. It is the first work that investigates the possible psychological role of social media involving such a high number of adolescents and young adults. Indeed, all the other similar studies included fewer patients¹² ²¹⁻²⁴ ²⁷ or addressed different aspects of social media usage, such as real-time disease management through apps and specific platforms built up for the communication with doctors.^{11 28}

Second, the questionnaire was first trialled in a large group of young people to refine questions. The overall participation of the recruited people, reaching a final number of 212, proved the essential impact of the theme among this age group.

The study suggests that social media can support adolescents in their chronic illness experience, showing that the self-perceived social needs that young people feel are met by using Facebook. Further studies are warranted to compare various platforms in different chronic diseases and to create specific social mediabased strategies for this population.

CONCLUSIONS

The interviewed adolescents said that they perceived social media as an instrument to overcome social isolation due to the disease relapses and frequent hospitalisations, offering the chance of sharing their experiences everywhere, at every time.

The main findings of this study are the increased amount of time spent on Facebook during disease flare-up and the wish of adolescents and young adults with long-term conditions not to share Facebook platforms with their doctors and nurses.

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ORCID iDs

Laura De Nardi http://orcid.org/0000-0002-8141-3389 Andrea Trombetta http://orcid.org/0000-0003-2092-3067

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Original research

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