

Commentary of Social Media Displays in Young People with Chronic Conditions

Erin Kelleher^{1*}, Philip F. Giampietro²

¹Department of Pediatrics, Chicago Medical School, Rosalind Franklin University of Medicine and Science, North Chicago, USA;

²Department of Pediatrics, Division of Pediatric Genetics, University of Illinois-Chicago Medical School, Chicago, USA

ABSTRACT

A majority of today's adolescents and young adults are constant social media users. Social media allows individuals to express themselves, communicate with peers and meet new people. Peer support is crucial for adolescent development and disease management. Young people with chronic conditions may not know someone in their offline life with a similar condition. A majority of young people with chronic conditions are interested in finding peers with similar conditions through social media. There is a gap in the literature regarding how young people with chronic conditions use their social media in relation to their condition. The purpose of this commentary is to discuss social media use in adolescents and young adults with connective tissue disorders (CTDs) and to explore future avenues for social media research in this population.

Keywords: Connective tissue disorders; Social media; Adolescents; Young adults; Marfan syndrome; Ehlers danlos syndrome; Beals congenital; Contractural arachnodactyly; Alport's hereditary nephritis

INTRODUCTION

Adolescents and young adults are constantly on social media and use it for communication with peers, self-expression, and to gather information. Users have the ability to control the type of content shown to specific recipients. There are groups and hashtags dedicated to specific chronic illnesses on social media platforms such as Facebook, Twitter, Reddit and Instagram. Social media provides a free and easy tool for young people to use to connect with their peers without geographical or time barriers. Finding peers with similar conditions helps young people cope with their condition and improves physical and mental health outcomes. Some of the chronic conditions studied on social media include diabetes mellitus, cystic fibrosis and heart conditions.

Connective tissue disorders (CTDs) are genetic conditions that not often included in social media research. CTDs are a group of heterogeneous conditions that are associated with defects in the extracellular matrix. Individuals may have alterations in the development of bone, skin, vasculature, and other related organs. Several CTDs are associated with life threatening

aneurysms such as Marfan syndrome, Loeys-Dietz syndrome and vascular Ehlers Danlos syndrome. Some CTDs are associated with restriction in competitive sports activities.

These restrictions are difficult to accept for many as athletics comprises a major part of the extracurricular lives of some of the youth of our society. As health care providers we want to ensure that our patients have an outlet to express their concerns about their condition. Social media research is continuing to grow and is used for participant recruitment and interventions in teens and young adults. The purpose of this commentary is to discuss social media use in adolescents and young adults with CTDs and to explore future avenues for social media research in this population.

CHRONIC CONDITIONS ON SOCIAL MEDIA

There is conflicting data whether adolescents and young adults use their social media platform to publicly talk about their chronic health conditions. Some young people with chronic conditions use their social media platforms to openly discuss

Correspondence to: Dr. Erin Kelleher, Department of Pediatrics, Chicago Medical School, Rosalind Franklin University of Medicine and Science, North Chicago, 1712 W Altgeld St. Unit A, Chicago, IL 60614, USA, E-mail: erin.kelleher6@gmail.com

Received: May 05, 2021; **Accepted:** May 19, 2021; **Published:** May 26, 2021

Citation: Kelleher E, Giampietro PF (2021) Commentary of Social Media Displays in Young People with Chronic Conditions. Clinics Mother Child Health. 18:383

Copyright: © 2021 Kelleher E, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

their experiences with their condition and to connect with peers with similar chronic illness experiences. Social media allows individuals with chronic conditions to meet peers they would not meet in an offline setting. A majority of adolescents and young adults have used social media to search for peers with similar illnesses. In fact, one study found that 94.3% of youth said they never felt alone because of the Facebook chat function [1]. Social media users receive positive feedback and support from their peers when posting about their condition. Young people with chronic conditions also use social media to educate their non-chronically ill peers about their condition and their experiences. Some youth find a sense of control by choosing the information they share on their profile.

Not all adolescents and young adults share their experiences about their condition on social media. They want to fit in with their peers and are selective with the information they share online. Some do not want their social media profiles to reflect their illness because they want to appear “normal”. However, a majority of young people that do not share their experiences regarding their condition publicly are interested in finding peers with similar conditions [2,3]. Therefore, it is feasible to encourage the youth with chronic conditions to connect with peers with similar conditions. However, there may be a barrier to finding peers on social media if a majority of youth do not publicly post about their condition. Young people may need guidance to find social media groups specific to their condition.

Further research should aim to explore the differences in social media transparency between different medical conditions. There could be differences in the amount of information shared depending on the disease visibility or severity. Individuals with chronic conditions may not know someone with a similar condition online and therefore haven’t seen their condition posted on social media making it appear not to be logistically feasible to discuss their condition. Young people may be more willing to post about their condition on social media if they see evidence of their peers posting about their own conditions.

Adolescents and young adults with chronic illnesses such as diabetes mellitus type 1, inflammatory bowel disease or cystic fibrosis spend a significant more time on social media during disease episodes of pain, flare up of chronic condition or hospitalizations [1]. They report that reaching out to peers with similar experiences during a flare up helps them cope with their condition. However, since a majority do not know someone with a similar condition, many young people may feel isolated in relation to their condition. One recent example is the COVID-19 pandemic, which restricted group gatherings, contributing to the feeling of isolation among teens and young adults. Youth with chronic conditions have higher rates of depression and low self-esteem compared to their healthier peers. Peer support is important for disease management and compliance and adolescent development. As an alternative to face to face in-person contact, social media provides a safe, contact-free environment for youth to talk to peers.

SOCIAL MEDIA PLATFORMS OVERTIME

Social media content and platforms are constantly changing. Current social media norms are not the same as five years ago. One reason for the differences in social media use is due to the widespread availability of smart phones. Roughly 95% of teens today have access to a smart phone compared to 75% in 2015 [4,5]. Almost half (45%) of teenagers today are considered near-constant online users compared to 24% in 2015 [4,5]. Social media platforms such as Facebook, Instagram and Snapchat added a feature called a story where content disappears after 24 hours. Current teenagers are also less likely to post selfies compared to when millennials were teenagers [6]. Therefore, it is important to understand the social media norms at the time the study was conducted.

HEALTHCARE PROVIDERS ON SOCIAL MEDIA

There is also discrepancy within the literature regarding whether adolescents and young adults want to communicate with their healthcare providers *via* social media. Some youth feel as though they would not fully express themselves if their healthcare providers were on social media. They felt as though their posts would be misconstrued and their healthcare provider would judge them [1]. However, some young people expressed interest in communicating with their healthcare provider through social media. They feel as though clinicians can learn about the experiences of their patients through social media. Young people often times feel more comfortable sharing their experiences online rather than in the clinic. One explanation for the differing of opinions could be age. Older adolescents may have content they do not wish their healthcare providers to see. Future studies should analyze social media use and goals expressed among age groups.

FUTURE OF SOCIAL MEDIA RESEARCH

It is important to encourage teens and young adults to find the type of online communities that will support them. Not all individuals with chronic illnesses use social media the same way and may have different goals in regards to what they want to achieve on social media. Therefore, it is important to find a community that will fit their needs. Future studies should separately investigate different chronic illnesses in order to understand how adolescents and young adults with different chronic illnesses use social media. A majority of the current literature has focused on Facebook which is less preferable by youth as compared to more recent social media platforms such as Instagram, Snapchat, Youtube or Tiktok [5,7]. Future studies could also focus on how the youth use social media both publicly and privately to discuss their condition. A majority of the current literature focuses on public displays of information and does not focus on private conversations between peers.

Not only is social media used to analyze content, but it can also be used for recruitment of participants and educational social media interventions. Researchers found recruiting through social media was cost effective and allowed for racially, ethnically and geographically diverse samples. The current literature suggests that a majority of young people support the use of social media as a means for recruitment and intervention.

Social media has successfully educated teens and young adults on their chronic conditions such as human immunodeficiency virus or systemic lupus erythematosus and improved medication compliance [8,9]. Young people found that social media interventions were easy to use and can be accessed at any time. They also felt connected to their peers and felt safer expressing themselves online rather than in person. Adolescents and young adults are aware of misleading information on social media and the internet. A majority of youth that learned about reproductive health on Facebook trusted the information shared on social media because they knew they were getting their information from licensed healthcare providers [10]. Of note, young people's biggest concerns with social media research is maintaining their privacy.

Some CTDs are rare making it difficult to recruit a larger and diverse population from one hospital organization. Social media could be used for recruitment and as an intervention platform for individuals with these rare conditions. Therefore, understanding the way adolescents and young adults with CTDs use social media is crucial for future studies.

CONCLUSION

Social media is a free platform that transcends geographical barriers and connects users around the world. Teens and young adults use social media to document their lives, express themselves and find peers with similar hobbies. Some

individuals with chronic conditions use social media to find a community and connect with others in order to decrease feelings of isolation. There is a gap in the literature regarding how young people with chronic conditions use their social media in relation to their condition. As social media is a commonly used vehicle for youth to express ideas and communicate, future research investigations could be expanded to target the use of social media amongst youth with CTDs.

REFERENCES

1. De Nardi L, Trombetta A, Ghirardo S, Genovese MRL, Barbi E, Taucar V. Adolescents with chronic disease and social media: a cross-sectional study. *Arch Dis Child*. 2020;105(8):744-748.
2. Kelleher EF, Giampietro PF, Moreno MA. Social media use among young adults with connective tissue disorders: Cross-sectional pilot study. *JMIR Pediatr Parent*. 2020;3(2):e16367.
3. Kaushansky D, Cox J, Dodson C, McNeeley M, Kumar S, Iverson E. Living a secret: Disclosure among adolescents and young adults with chronic illnesses. *Chronic Illn*. 2017;13(1):49-61.
4. Lenhart A, Page D. Teen, Social Media & Technology Overview 2015. PEW Research Center. United States. 2015.
5. Pew Research Center. Teens, Social Media & Technology . 2018.
6. Pew Research Center. Teens' Social Media Habits and Experiences. 2018.
7. Pew Research Center. Social Media Use in 2021. 2021.
8. Kelleher E, Moreno MA. Hot Topics in Social Media and Reproductive Health. *J Pediatr Adolesc Gynecol*. 2020;33(6):619-22.
9. Scalzi LV, Hollenbeak CS, Mascuilli E, Olsen N. Improvement of medication adherence in adolescents and young adults with SLE using web-based education with and without a social media intervention, a pilot study. *Pediatr Rheumatol Online J*. 2018;16(1):18.
10. Araújo JMN, Gubert FDA, Torres RAM, Silva ASRD, Vieira NFC. The use of Facebook in health education: perceptions of adolescent students. *Rev Bras Enferm*. 2018;71(2):265-271.