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Social Media and the Adolescent Transplant Recipient

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ABSTRACT

Introduction: Social media is interwoven into adolescents' daily lives. Many adolescents utilize digital technology in their healthcare journeys, as do their caregivers. Health systems increasingly seek ways to leverage these new tools toward supporting and caring for patients. These approaches may be of particular importance of adolescents, as well as healthcare systems, in providing care for chronic and serious illness including transplant patients.

Methods: This review article will begin with an overview of adolescent social media use. We will then consider ways in which social media may impact adolescents' healthcare experience including identity development and adherence.

Results: Caregivers may leverage social media for information seeking. Families may use social media to seek social support, as well as potential donors. For healthcare systems, social media may enhance research efforts as well as information delivery.

Discussion: Future directions include studies examining how social media can support adolescent transplant patients. incorporation of youth voice into these studies may enhance application of findings to clinical practice.

1 | Introduction

Social media is nearly ubiquitous and ever-present in adolescents' lives as smartphones, tablets, and personal computers have proliferated in homes and schools. Today's adolescents are “digital natives” who have grown up with access to computers, smartphones, and the internet from an early age [1]. Over 90% of teens go online daily, and 95% of teens report having a smartphone or access to one [2, 3].

Many adolescents leverage digital technology for health, including seeking health information, receiving health information such as daily step counts from smartwatches, or sharing their own health experiences online [4–6]. As technology is increasingly available to manage health and well-being, there is potential for using these platforms to extend healthcare delivery and advance patient engagement and education [7–12]. This review article will focus on social media use. We will begin with key definitions and trends around adolescent social media use. We will then consider how social media offers opportunities within transplant medicine, including social media use by adolescent patients and caregivers, and from the healthcare system perspective. As the evidence base focused on adolescent transplant patients and social media is lean, we have drawn from broader literature around adolescent clinical care and social media as appropriate. We hope this article will inspire future work in this area of research, and we will end with some ideas for future research.

2 | Social Media: Definition and Use Rates

Defining social media typically begins by placing it in the evolution of the worldwide web. The first iteration of the web was

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Abbreviation: COVID-19, Coronavirus disease.

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known as Web 1.0. Its purpose was to provide information to consumers, mainly via static web pages. Technological advancements led to Internet 2.0, a new web that both provided information to consumers and empowered users to view, create, and share multimedia data with peers and the public. Web 2.0 led to what has been called social media, also called immersive or interactive media. Social media represents a set of Web 2.0 tools that are centered on interaction and sharing of content with others. Key features of social media include building or utilizing a profile within a network, and interactive communication capacity both privately and publicly. Thus, applications focused on exclusively messaging, or gaming, without that network or profile component, would not qualify as social media. While users may also consume content passively, social media provides a novel medium for adolescent users, as they can be in the role of both a consumer of media and a creator of content to share publicly.

The majority of adolescents and young adults report ownership of at least one social media account, or profile [3]. The landscape of social media is ever-changing, particularly among adolescents who are early adopters in this space. At present, popular platforms for adolescents include TikTok, used by 67% of teens, and Instagram and Snapchat, both of which are used by around 60% of teens. The most popular social media among adolescents is YouTube, as over 90% of teens report using this video-based platform [13].

Adolescents use social media in a variety of ways, sometimes categorized as active or passive use. Active use represents activities such as content creation and posting, commenting on or otherwise engaging with (i.e., sharing, liking) others' posts, and conversing in direct messages or group chats. All of these activities may happen on an adolescent's personal profile, on a profile of a friend, or on an organization's platform. Passive use includes scrolling through or viewing other users' content or news without responding or contributing [14]. Most adolescents' use of social media combines active and passive use.

Adolescents are not alone in their frequent use of social media. In addition to adolescents, many of their adult caregivers are active social media users. A secondary analysis of data obtained in the Pew Research Center's January 2021 Core Trends Survey found that the majority of US parents used social media [15]. Like adolescents, the most used social media among US parents was YouTube, with 88% of parents using the platform [15]. However, in contrast to adolescents, among US parents the second most used platform was Facebook (79%), followed by Instagram (47%) [15].

3 | Social Media in Healthcare for Adolescents and Their Caregivers

There are several ways in which social media may provide benefit to adolescents and their families as they navigate the transplant journey. These functionalities and opportunities within social media offer novel opportunities as well as challenges to adolescents, caregivers, or both.

3.1 | Social Media and the Adolescent Transplant Patient

There are multiple ways in which social media can intersect with the adolescent transplant patient, often in ways that align with adolescent's developmental stages. The first area is around identity development, a normal and crucial part of adolescence [16]. Social media provides opportunities to share aspects of a teen's identity through multimedia including text, photos, and videos. For some adolescents, social media can be a venue to share information about their ongoing illness and integrate that experience into their identity. A previous study of patients with diabetes found that adolescents curated online personas that allowed them to selectively include their health information while managing the potential negative emotional and social implications such as stigma [17]. Further, a recent case report illustrated how teens may use social media to communicate with peers about their diagnosis and experiences [18]. The report argues that these digital tools may provide a way to cope and enhance relationship building for adolescents with serious illness. As most adolescents use multiple platforms, they can make choices about where and when to share this type of information.

Another area in which social media may enhance the adolescent transplant patient's healthcare experience is supporting adherence. For adolescent patients with complex treatment regimens, there are many factors that can compromise adherence to therapy. Studies of adolescent patients, not focused on transplant patients, have found that issues with adherence have been observed more frequently in adolescents who struggle with psychosocial factors such as low self-esteem, depression, and lack of adult support [19]. Identifying strategies to support adherence aligned with adolescent's developmental phase is a critical priority [20, 21].

Several studies have incorporated technology to support adherence and engagement in adolescent patients. Adolescents who incorporated a motivational texting component for Type I diabetes reported improved self-efficacy and adherence [22]. This type of messaging could be adapted to be direct messaging (DM) on social media. Further, another study incorporated social media into an ongoing intervention and found enhanced motivation for ongoing adherence and engagement within the intervention itself, suggesting that social media could be incorporated into intervention design to support adherence [23].

As adolescents engage in identity development and potentially share health-related information, protecting their privacy is crucial [24–26]. Millions of digital health users have experienced un-permissioned/inappropriate access to their health data [27–30]. Adolescent patients may be particularly vulnerable as they connect most often to these platforms on mobile devices [31]. Wireless signals and sensors rely on broadcasting, which is a risk for eavesdropping, information extraction and tampering [31]. Another challenge on social media is not knowing or not caring about privacy settings. Adolescents often do not change their privacy settings from the default platform setting, which is often public availability [32]. Even when adolescents utilize their privacy settings, they tend to doubt their effectiveness and believe "urban myths" about privacy [33]. Previous studies have found that adolescents tend to consider privacy for social reasons (e.g., maintaining an image) instead of for security reasons [33].

As adolescent patients seek health information online and through social media, they will encounter information with varying degrees of accuracy [34]. Previous studies have shown that adolescents often trust health information found online and are less likely to assess the credibility of online sources compared to adults [35, 36]. One previous study found that adolescents with low health literacy tended to evaluate online health resources based on search position, celebrity endorsement, and picture quality [37]. Further, health posts on social media with misinformation can attain higher levels of popularity (e.g., more likes and shares) than posts disseminating accurate information on the same topic [38–40]. Fortunately, some studies suggest that adolescents have grown more skeptical of online health information. One study found fewer than a quarter of teens believed that social media provided them with helpful information about health [41].

3.2 | Social Media Use by Caregivers of Adolescent Transplant Patients

Many caregivers of pediatric transplant patients report using social media to acquire health information. A qualitative study involving caregivers of children with sickle cell disease found that one way caregivers learned of curative options (including hematopoietic cell transplantation) was through social media [42]. Another study of parents of children who had received liver transplants found that over 40% of those surveyed reported regularly receiving information about COVID-19 through social media [43].

3.3 | Social Media Potential for Both Patients and Caregivers

One area in which social media can impact both patients and caregivers is via providing enhanced social support. By its very nature, social media incorporates social connection, information sharing, and means of providing feedback and response to that information. Studies have found that social media can enable a sense of belonging and social support [44, 45]. This support may include keeping friends and family updated on the health status of the adolescent patient. This support may also include connecting teens or their parents to online communities of other families facing a similar health situation. Studies have shown that this social support may reduce stress or physical illness and improve psychological and physical well-being [46, 47]. Social support may sustain teens or their caregivers during a prolonged illness, the waiting period for a transplant, or the acute posttransplant time period. Social media can also provide opportunities for sharing knowledge and experiences, which may encourage positive health behaviors [48], and increase health-related self-efficacy [49]. One observational study in Lebanon found that several caregivers of and/or adolescent kidney transplant patients had used Facebook to communicate with other kidney disease patients [50].

Another novel area in which social media may impact the field of pediatric transplant medicine is through information sharing to reach or influence potential donors to increase the donor base. A previous study conducted in Saudi Arabia tested a social media approach to enhance organ donation awareness. The team provided information from social media and evaluated whether this information impacted whether participants would act as organ donors. Findings supported that most participants indicated that they would act as organ donors based on that information [51]. Similarly, a school-based study focused on engaging adolescents in creating educational materials about being an organ donor [52]. Intervention participants were asked to create a short video to share on YouTube about organ transplantation. The study found increased positive attitudes toward organ transplantation among youth in the intervention. Further, the YouTube channel received over 100 k views. A grassroots organ donation advocacy group in New York has presented their experience using various social media platforms to promote awareness around organ donation to local college students, and tracked an increase in visitors to the group's website, engagement in Twitter account, Facebook page, and views on YouTube [53].

Social media could also help facilitate conversations for patients who are candidates to receive organs from living donors. Studies have found that candidates for living donor organ transplantation find it difficult to discuss living donation with people in their social network, and there is a lack of interventions to train them. A previous study tested a Kidney Coach Program to engage possible donors and found it increased possible donors [54]. This may be another route to use social media.

Finally, social media has been used by individuals for specific requests for an organ donation. One previous study examined Facebook for pages seeking kidney donors for a specific individual [55]. In the 91 pages meeting inclusion criteria, the mean age of potential recipients was 37. Approximately a third of the pages reported testing of potential donors, and 10% reported receiving living donor kidney transplants. The pages with successful campaigns tended to provide more information about the transplant candidate, such as photos or stories, as well as more information about living donor transplantation in general. This study found that transplant candidates are already using social media to locate living kidney donors.

While an adolescent with chronic kidney disease may not actively try to identify a potential living donor on social media, their caregiver may try and identify a kidney donor on social media, thus reducing the time spent on dialysis and expediting a necessary transplant. In a previous study, an online questionnaire administered by a transplant team to primary caregivers of pediatric kidney and liver transplant recipients found that 32% of the caregivers who responded used social media to look for a possible liver donor for their child, and 67% of those who used social media found at least one possible living donor through this method [56].

4 | Social Media Use by the Health Care Team

There are also several ways that clinical transplant teams can thoughtfully use social media. Transplant teams can utilize social media to assist adolescent patients in the transition from pediatric to adult care, to involve them in research studies, and to quickly provide large numbers of adolescents and their caregivers with timely information.

One other way that healthcare teams can leverage social media is during transition periods. A study by Kreuzer et al. [57] which used surveys to assess European pediatric nephrology centers' adherence to well-accepted guidelines around the transition of adolescent and young adult kidney transplant patients from pediatric to adult centers concluded that using social media to bolster education and support during the transition from pediatric to adult care is a critical priority.

4.1 | Research Studies

Social media can be used by clinical and research teams to both recruit adolescent transplant patients into research studies as well as to administer surveys to their caregivers. Facebook advertisements were successfully used to recruit caregivers of children aged 7–17 years old with relapsed and/or refractory cancer into a research study [58]. Another study described using social media groups focused on pediatric liver disease to distribute surveys to caregivers of children with chronic liver disease or pediatric liver transplant to study dietary supplement use in the studied population [59]. Social media recruitment can allow studies to selectively reach and recruit target groups, thus increasing the reach beyond local recruitment efforts.

In studies that have incorporated social media platforms for health interventions, adolescents report high satisfaction and engagement with interventions that target various clinical domains, such as physical activity, weight loss, smoking cessation, and reproductive and mental health [60–63]. These studies have leveraged social media for functions such as sharing peer support messages, promoting goal achievements, and monitoring progress via shared social media posts. Publishing research protocols may also enhance the capacity of other research teams to try new approaches using social media [64].

4.2 | Information Delivery

Social media has also been used by healthcare teams to disseminate important information to the caregivers of adolescent transplant patients, especially in recent times of emergency, such as the COVID-19 pandemic. At the beginning of the COVID-19 pandemic in 2020, a kidney transplant team in India conducted a prospective study using several means of communication, one of which was Facebook, to inform their kidney transplant recipient patients and their caregivers about availability of telemedicine services [65]. The team then conducted 296 telemedicine consults via WhatsApp. However, it is notable that WhatsApp is generally considered to be more of a messaging platform, rather than fully interactive social media.

5 | Conclusion and Future Possibilities

In this review article, we have illustrated the ongoing popularity of social media use for both adolescents and caregivers. We have shown the diverse approaches by which social media can impact the field of transplant medicine, from influencing how teens navigate their own health journey, to supporting caregivers in their ongoing roles, as well as acknowledging potential pitfalls of unchecked social media use. Further, the incorporation of social media into research efforts and healthcare system delivery also represents innovations in the field. However, social media research is still in its early stages, and there remains much more to be learned in order to fully optimize the adolescent transplant patient experience using all available tools.

To move the field forward, several areas of future work are needed. These include enhanced understanding of how to educate adolescents on how their own use of social media can be optimized in the context of their healthcare journey as well as how to mitigate risks of social media use. These include studies to further explore how social media may provide improved availability and connection to potential donors. These also include further understanding of how social media can enhance ongoing research in the field. Publications focused on empirical studies and their findings will be important toward these efforts, as well as publications illustrating research protocols to enhance the work of others [64].

One novel consideration toward these goals is for clinical care and research teams to consider avenues to include the adolescent patient or caregiver voice in programs and studies. Adolescents are experts in the area of social media, having exposure to it throughout their lives and understanding how it can and cannot be used among their peers. Thus, their experiences and perspectives can be incredibly valuable when considering how these tools can be used for healthcare or research. For youth engagement, creation of a youth advisory board is one avenue to provide ongoing input from this critical target population. One paper describes experiences with youth advisory boards and best practices for establishing and maintaining respectful and beneficial relationships with these youth [66]. For caregiver input, options can also include parent advisory boards or panels to provide in person or online feedback and ideas. Engagement of these stakeholders can ensure that social media tools are leveraged to benefit patients and caregivers, and advance knowledge and practice.

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Data Availability Statement

Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

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