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The Use of Social Media in Pediatric Urology—Forging New Paths or Crossing Boundaries?

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Abstract

Purpose of Review There has been a remarkable change in how people connect, access, and share professional and medical information over social media. This perspective article describes opportunities, potential pitfalls, and guidelines for social media use by pediatric urology providers.

Recent Findings Pediatric urologists have effectively used social media to connect and share expertise, augment scientific conference participation, promote themselves and their research, disseminate guidelines and best practices, participate in virtual journal clubs, and engage with patients and their families. Information shared over social media is not protected by copyright law, not confidential, not regulated, permanent, and subjected to public domain and scrutiny. Despite these potential pitfalls, social media is a useful tool if best practices are observed and online communication adheres to professional guidelines and organizational policy.

Summary Social media use in healthcare is here to stay and pediatric urologists have online visibility whether or not they choose to actively participate. Despite new legal, ethical, and professional considerations that social media introduces, a well-executed social media presence provides pediatric urologists a wealth of new opportunities for networking, research, and disseminating high-quality medical information online.

Keywords Social media · Pediatric urology · Digital media · Professionalism

Introduction

Social media—sometimes abbreviated "SoMe" or simply "Social"—are internet websites and applications that allow users to interact with one another and both generate and share content. Spanning social networking sites like Facebook, Twitter, and Instagram to professional networking sites like Doximity, Linkedin, and ResearchGate to media sharing on Youtube, social media has become the backbone of how many Americans connect with each other, engage in news content, and share information. The spread of social media use in healthcare has been a bottom-up, consumer-driven phenomenon that is changing demand for and access to health information. Patients and families are increasingly turning to online resources for health information, ranging from 72% of general internet users to 96% of parents bringing children to a pediatric urology clinic [1].

As patients and families look online for their health information, physicians have also adapted their professional communication to meet the expectations and needs of their medical community and patients. Urologists have been at the forefront of adopting social media for academic and professional purposes, and pediatric urologists are no exception. Surveys have found that 74% of urologists use social media for purposes that range from networking (98%), to disseminating information (96%), research (71%), career development (71%), advocacy (66%), and physician-patient communication (52%) [2, 3].

Pediatric urologists have the opportunity, and perhaps the professional obligation, to use social media to share and create health information and credible research. This article provides

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a broad review of the emergence of social media in pediatric urology and proposes opportunities, potential pitfalls, and guidelines for social media use by pediatric urology providers.

Social Media Opportunities for the Pediatric Urologist

New Venues for Professional Networking

One of the great innovations of social media is the ability to connect users across large geographic distances. This is especially beneficial for pediatric urologists given the small number of specialists worldwide. Two of the most popular services are Twitter, a microblogging platform that allows for 240 character communications, and Doximity, a professional networking site for medical professionals.

Twitter was created in 2006 and currently reports 126 million daily active users. Conversations on Twitter and other social media platforms are centered around hashtags, which are searchable terms that collect communication about a single topic. The Urology Tag Ontology project collected and formalized urologic hashtags in 2016 with an update in 2019 in conjunction with the Symplur Healthcare Hashtag Project [4, 5]. The formal hashtag for pediatric urology is #peduro, and use on Twitter has increased steadily with time (Fig. 1) [6]. Conversations under this hashtag include dissemination of research and guidelines and discussion of clinical practices including tips and tricks.

Doximity was launched in 2011 and claims that 70% of US physicians are members. This platform is not open to international providers and attempts to verify physician identity to limit members. The networking site is also known due to its partnership with the US News and World Report, which bases its hospital reputation scores in part on Doximity surveys of board-certified specialists. More recently it launched the Residency Navigator, which ranks residency programs in part based on survey data from current and former residents [7]. While a Doximity membership is not the only way to participate in the above surveys, the site has become a hub for professional networking and communication.

"Marketing" Yourself and Your Research

Self-promotion is an important aspect of social media, with hospitals, healthcare systems, medical practices, and healthcare professionals all generating professional social media accounts used for marketing their practices, patient communication, and recruitment for clinical trials [8]. In the field of Urology, departments are using social media accounts to promote faculty and residents, and to reach out to patients. This effort appears to pay off, as Ciprut et al. found a positive correlation between urology department social media presence and US News and World Report reputation scores [4].

Promoting an individual's research on social media can help disseminate information to the scientific community to increase one's academic standing while sharing up-to-date research with the public. But it is unclear whether social media promotion effects eventual citations. While a retrospective study of the urologic publications showed a twofold increase in eventual citations of papers that had been publicized via Twitter, a recent randomized controlled trial by a medical journal found no increase in 2-year citations for articles promoted on social media despite an increase in median downloads [5, 6]. It is possible that initial interest on Twitter is higher for high-quality publications that will eventually be more commonly cited.

Augmented Scientific Conference Participation

Much has been written about the expanding and integral roles of social media at scientific events, including real-time and virtual discussion, sharing and promoting relevant scientific and social programs, and professional networking [7, 9–12]. Statistics from the AUA annual meeting in 2014 and 2015 demonstrated that the number of social media users increased drastically from 1746 to 2760 participants, generating a sharp

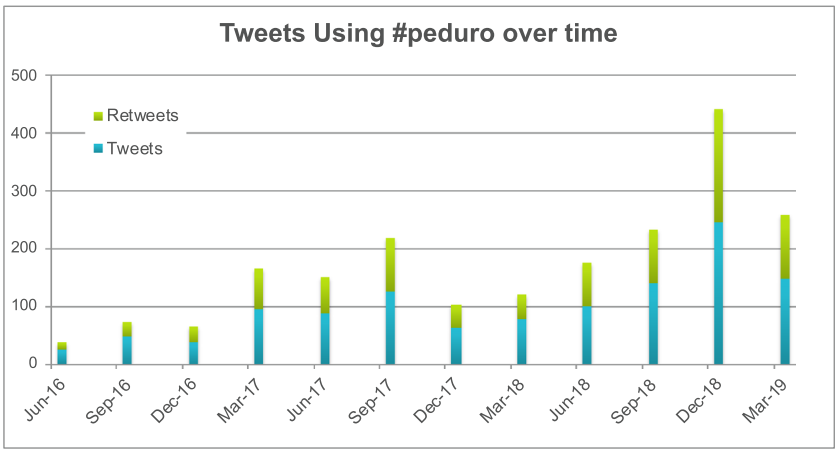

Fig. 1 Tweets and retweets per quarter using the hashtag #peduro from June 1, 2016 to May 31, 2019. Data collected from Twitter through a third-party software, TrackMyHashtag.com

rise from 13,895 tweets in 2014 to 20,202 tweets in 2015 [12]. Likewise, between 2012 and 2014, the number of Twitter participants at the EAU Annual Congress increased almost 10-fold, leading to an increase in the number of tweets from 347 to almost 6000 tweets [13].

Social media engagement at conferences has increased for pediatric urologists as well. For the 2019 Annual Spring Meeting of the Society for Pediatric Urology, one specific hashtag was identified by the organizers and an official "twitter team" was designated to live-tweet the meeting. That year, there was an increase in the percent of tweets using a pediatric-specific hashtag at the annual urology meetings to 2.1% of overall tweets about the meeting (daily range 0.4–3.5%) vs. 0.2% the year before (daily range 0–0.6%; Fig. 2) [14].

Journal Club and Research Discussions in the Era of Social Media

The *Journal of Pediatric Urology* (JPU) launched a 48-h Twitter-based journal club in February 2017 [15]. A dedicated Twitter account @pedurojc organizes the discussion using the hashtag #pedurojc. Articles featured from the *JPU* are made open access before and during discussion period to allow for broad international participation. Authors of the selected articles are often available during the 48-hour web-based journal club to enrich discussion and answer questions. This novel online journal club, following the model proposed by Thangasamy et al. in 2014 [16], is the first of its kind in pediatric urology to foster a forum for a wider global participation and international collaboration. There have been 195 total unique Twitter accounts using the #peduro hashtag as of June 2019, with an average of 12 tweets per contributor and steady participation for each journal club (Fig. 3) [14].

In addition to journal clubs moving online, research is being adapted for social media distribution. The "visual abstract" format consists of a graphic representation of the main methods and findings of a publication. The format is specifically crafted to catch a reader's attention in the high-volume, low-text environment of social media sites such as Twitter, similar to how a movie

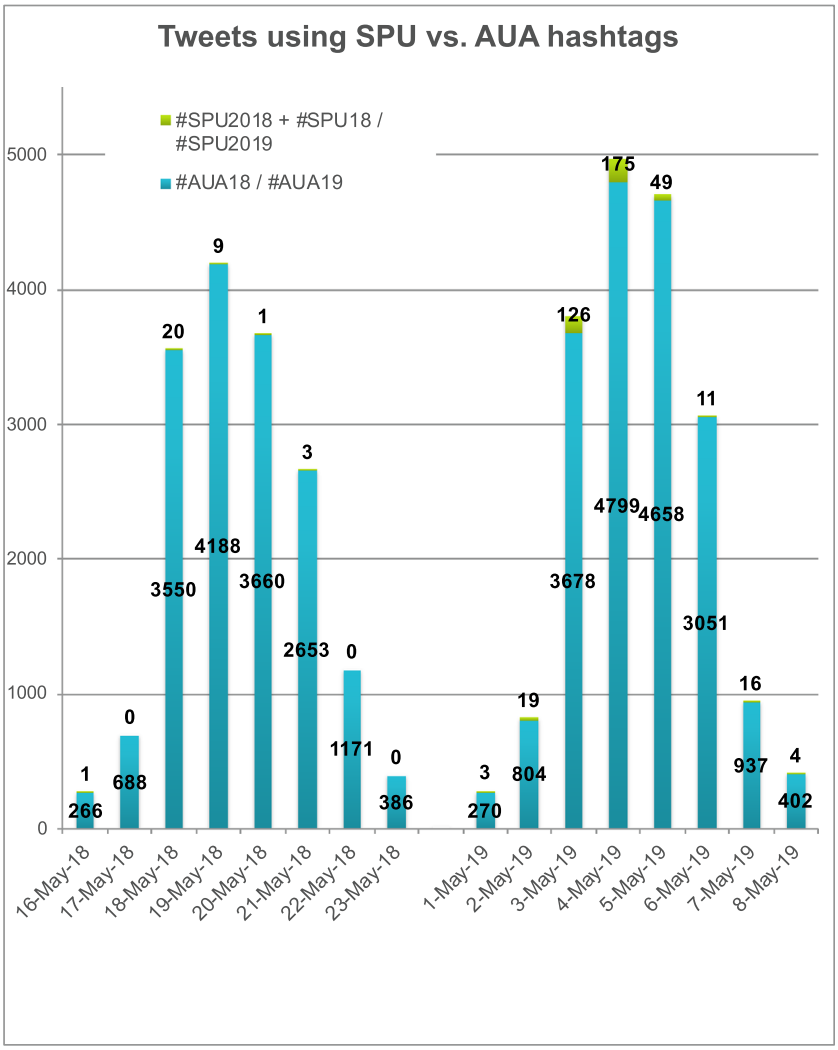

Fig. 2 Increase in percent of tweets using pediatric-specific hashtags at the annual American Urological Association Meeting from 2018 to 2019. Due to lack of designated hashtag for the 2018 meeting, both #SPU2018 and #SPU18 were recorded. Data collected from Twitter through a third-party software, TrackMyHashtag.com

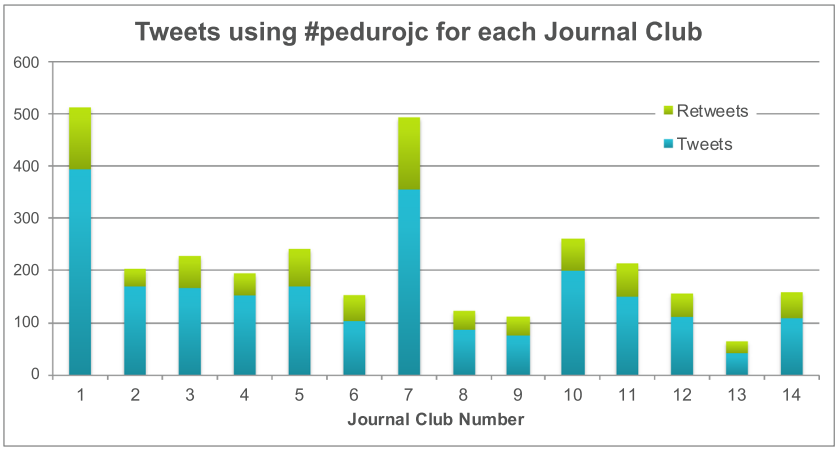

Fig. 3 Tweet and retweet participation for #pedurojc as of May 31, 2019. Data collected from Twitter through a third-party software, TrackMyHashtag.com

trailer captures attention and encourages the viewer to watch the full movie [17].

Dissemination of Guidelines and Best Practices

One novel use of social media in the professional healthcare setting includes using Twitter as a platform to systematically disseminate guidelines and evaluate adherence to specific recommendations and best practices. The EAU guideline panels and Social Media Committee converted the key points from their clinical guidelines into 140 character tweets using hashtag #EAUguidelines and a direct link to the corresponding full EAU guidelines. They subsequently conducted Twitter polls to access urologists' adherence to their guidelines [18]. The study increased traffic to the full EAU guidelines website, generating 3215 URL clicks and 5665 page views from the guideline tweets. This proof-of-principle study demonstrates the benefit of social media in disseminating new guidelines and directing web traffic to relevant websites. A similar approach may be taken to raise awareness about clinical trials and recruit potential participants [19].

Online Recruitment for Patient Outcomes Research

Social media has been validated and utilized as an important tool in patient-centered outcomes research in pediatric urology. It has been used to survey parental perception of pediatric catheterization and adherence to proper UTI evaluation, validate health-related quality of life assessment for patients with spina bifida, and understand patient-centered outcomes for rare conditions such as hypospadias and bladder exstrophy [20–28].

There are several advantages of conducting social media–based patient-reported outcome surveys. Online questionnaires reduce social desirability distortion and elicit more honest responses when the subjects involve sensitive personal topics such as sexual function and orientation [25, 29]. With Facebook claiming 1.52 billion daily active users, recruitment online allows for greater reach of eligible participants, requiring less recruiting time and cost [20, 30]. Online recruitment also facilitates identification of and outreach to difficult to reach populations or those with rare anomalies, allowing research that would otherwise be difficult to perform [31].

There are limitations of web-based outcome research, including selection bias, generalizability of study findings, participants' health literacy, and inability to link outcomes to clinical data. Social media participation is more common in younger generations, potentially skewing response data. It is also conceivable that patients with more severe symptoms or adverse experience are more likely to participate in online surveys. In addition, there is a risk that patients may attribute their outcomes to the studied conditions, such as incorrectly self-reporting a urologic anomaly because they are dissatisfied with their genital appearance and erectile functions [26, 27]. There are also ethical concerns with social media recruitment for research. Internet users have been conditioned to "agree" without reading the fine print, limiting the effectiveness of informed consent when it moves out of an in-person discussion and onto a web form [32]. Researchers and readers of social media studies should design research carefully to avoid ethical pitfalls and look critically for potential selection bias that hampers the generalizability of social media–based study findings to broader patient populations.

Engagement with Patients and Families

Parents of pediatric patients are increasingly utilizing the internet for health information. A survey of parents of pediatric surgical patients revealed that 38.3% had searched the internet regarding their children's surgical issues; 26.5% of these parents had done online research prior to their initial visits [33]. A study on web-based information on pediatric hydrocele showed that 56.7% of parents accessed the internet for information on hydrocele and 43% felt that web-based information influenced subsequent healthcare-related decisions [34].

While social media offers the opportunity for pediatric urologists to communicate directly to the public, many pediatric urologists have been appropriately hesitant to cross professional boundaries and offer medical advice directly to patients via social media. Exceptions to this include educational seminars and videos coordinated by hospitals or patient advocate groups, such as the webinars featuring pediatric urologists from a number of different institutions hosted by the Association for the Bladder Exstrophy Community (https://www.bladderexstrophy.com/webinars/). A 2017 survey of parents visiting a pediatric urology clinic did show that families are receptive to interacting with their physicians online, with 87% reporting they would access their physician's webpage or Twitter feed [1]. This survey may have anticipated a slow shift in online health information access, as a review of surveyed social media trends over time showed a decrease in the number of adults sharing health information with each other in tandem with an increase in adults exchanging information directly with a health professional [35]. It is possible that Americans are becoming more discerning regarding the source of their online information. Alternatively, this trend may reflect increasing access to health professionals online.

The Perils of Social Media in Pediatric Urology

Professionalism Issues

Medical professionals are held to high standards of professionalism outside of work and social media is no exception. A defining characteristic of digital communication is its ability to be replicated which means that even communications that are meant to be private can be duplicated and widely shared. Offensive comments using her personal Facebook account led to the resignation of a Denver anesthesiologist in 2016, while a Cleveland resident was fired for offensive Twitter posts she had made 6 years earlier [36, 37].

Despite the risk of consequences from unprofessional behavior, physicians continue to engage in questionable activities online. A review performed in 2016 showed that 43% of urologists who had recently completed residency and had a publicly accessible Facebook profiles had posted unprofessional content ranging from profanity and public intoxication to illicit substances [38].

While the above examples are clear cut in their lack of professionalism, a survey published in 2013 showed that there are many gray areas for what state medical boards consider unprofessional behavior on social media. The fictional vignettes presented ranged from examples of behavior with a high consensus for medical board investigation such as websites with misleading clinical information and patient images used without consent, to behaviors with a low consensus such as alcohol use without evidence of intoxication and clinical narratives without violation of confidentiality.

Pediatric urologists should also be aware of the increased engagement in social media in medical circles. Many public communications and interactions now have the potential to be shared online, from photographs at medical graduations and visiting professor events to slides from hospital lectures or scientific meetings. Physicians should take care that their online actions and public interactions maintain the highest level of professionalism and respect for patient privacy given the possibility that they may end up on social media and therefore in the public view.

Patient Privacy Concerns

The informal nature of social media has occasionally led to HIPPA violations when medical professionals described a case in enough detail online that the patient could be identified. A Rhode Island emergency room physician was one of the first fired by her institution in 2011 for posting enough clinical information on a Facebook post that a patient could have been identified [39]. These social media HIPPA violations continue, with a Texas nurse fired in 2018 for posting about a measles case at her hospital on a Facebook group [40].

Even when there is no concern for direct HIPAA violation, social media comments that include references to patients risk being seen as insensitive. A New York nurse who shared an Instagram photograph of an emergency room after a trauma with a comment about the mechanism of injury was fired not for a HIPAA violation but for the insensitive nature of her comment [41]. Anticipating public reaction on social media is difficult and therefore erring on the side of caution is wise.

Misinformation or Poor Information on Health Topics

While social media has been a powerful tool for communication, it has also encouraged the spread of false or misleading health information given its unregulated and unvalidated nature. Nowhere have the negative consequences of this been more clear than the ability for misinformation about vaccinations to be spread through social media channels [42]. Forty-one percent of top Google search pages and 74.3% of top YouTube videos are anti-vaccine, and there is evidence that increased reliance on social media for health information is associated with acceptance of vaccine conspiracy theories [42, 43].

Pediatric urology has not been immune to the trend of inadequate or inaccurate online health information. Cisu et al. evaluated the quality and accuracy of information available on the internet about hypospadias. Only 2 of 46 sites reviewed were written at the 6th–7th grade reading level recommended by the American Medical Association and the

National Institute of Health, and only 3 were considered 100% accurate by a pediatric urologist reviewer [44].

There are services that guide Internet users toward trustworthy online health information, including the Health on the Net (HON) foundation and validated DISCERN quality criteria. The HON foundation is a non-profit and non-governmental organization found in 1995 from a collaboration of the World Health Organization (WHO) and leading experts on telemedicine (https://www.hon.ch/Global/). The HON foundation guides both lay users and medical experts to reliable source of health information on the cyberspace. DISCERN is a standardized and validated set of criteria to guide the public and health professionals appraise information and outline the standards for information publication online [45].

Misrepresentation of Research

Beside false or misleading health information on social media, genuine scientific research can be misrepresented. Conclusions are often overly simplified due to character restrictions on platforms such as Twitter and there is a fine line between presenting an enticing overview of a study that encourages others to read it in full and inadvertently misleading casual readers about the limitations and conclusions of a research publication. Social media posts do not undergo peer review process and are subjected to bias and cherry-picking of citations. Abstracts and preliminary findings are routinely publicized on social media by both authors and conference attendees, yet a Cochrane review found that only 37% of abstracts complete the peer review process to become full publications [46]. One benefit to increased social media participation in pediatric urology and other specialties has been the opportunity for authors to comment directly on their own work and for senior physicians to weigh in with the perspective of experience when new research is being discussed.

Loss of Control over Copyright or Private Information

Urologists also need to be aware of the risks of presenting unpublished data and protecting their intellectual properties, as the prevalence of social media use will mean that any data shared at scientific conferences will essentially enter the public domain. An example that brought this issue to the limelight was the controversy surrounding liraglutide, a novel medication for patients with type 2 diabetes. At the American Diabetes Association (ADA) conference 2016, the lead author presented the modest effect of liraglutide (Victoza) in reducing cardiovascular death in adults with type 2 diabetes compared to placebo prior to its publication in the *New England Journal of Medicine* (NEJM) and official release to the public and the markets [47]. Despite explicit requests not to post presentation slides on social media, conference participants posted embargoed data within minutes of presentation on Twitter. The magnitude of liraglutide's effects was much less than anticipated by investors, leading to a one-day drop of $7.77 billion decline in market value. As the ADA conference controversy demonstrated, data presented at scientific conference cannot be protected from copyright infringement and may have great academic and financial consequences.

Social Media Guidelines and Best Practices

All physicians have online visibility regardless of whether they choose to actively participate in social media. In addition to the inadvertent social medial participation described above, this includes digital identities on social media created by the physician, their institution or posted by third-party sources such as physician-rating sites. Given the ubiquity of these digital identities, it is important for pediatric urologists to be aware of their own online footprint and how best to manage it.

The AUA, EAU, and BJUI have all published best practice guidelines for social media use [48–50]. Recommendations are similar—most importantly be professional, respect patient confidentiality, and remember that social media is both public and permanent.

The EUA guidelines advise starting as a passive consumer to understand social media before becoming an active participant. The American College of Surgeons and the AMA also recommend physicians remain aware of their publically accessible digital profile by periodically searching for themselves online [51, 52]. If pediatric urologists choose to become more engaged with social media, the EAU recommends they establish a transparent online identity that also complies with any social media policies set out by their employer. A number of guidelines recommend a "pause before posting" approach to ensure professionalism with every communication. A general rule of thumb is to only post what would be appropriate to say in a crowded elevator filled with strangers.

Most pediatric urologic organizations have a social media presence, including the Twitter accounts for the *Journal of Pediatric Urology* (@jpurology), the Societies of Pediatric Urology (@SPU_Urology), the European Society for Paediatric Urology (@ESPUorg), the AAP Section on Urology (@SectionOnPedUro), the Pediatric Urologic Oncology Working Group (@PedsUroOnc), and the Pediatric Urology Nurses and Specialists (@PUNSUrology). Both adult urology and medical groups and other pediatric subspecialties also maintain social media accounts. Joining this network as well as participating the pediatric urology journal club would be a good start for a pediatric urologist interested in getting more involved.

Readers who are interested in harnessing social media for research would find the review article by Gelinas et al. helpful for understanding potential ethical and privacy pitfalls when

designing their research [53]. Meanwhile, those interested in pursuing Twitter metric research can investigate the website Symplur (www.symplur.com), which provides detailed data about all Twitter related activities around user-uploaded healthcare-related hashtags.

Conclusion

As physicians in the twenty-first century, pediatric urologists need to take control of their online presence and curate their professional identity. They have the professional obligation to create and disseminate well-vetted high-quality medical and research information and refute inaccurate online health information as a service to their professional community and patients. In return, social media savvy physicians will find a wealth of opportunities for networking, research, and professional growth.

Compliance with Ethical Standards

Conflict of Interest Hong Truong, Andrew Salib, and Courtney Rowe each declare no potential conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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