Received: 7 November 2017 | Revised: 5 December 2017 | Accepted: 12 December 2017

DOI: 10.1002/pbc.26958

SPECIAL REPORT

WILEY Pediatric Blood & Cancer

SIOP INTERNATIONAL SOCIETY OF PAEDIATRIC ONCOLOGY

aspho The American Society of Pediatric Hematology/Oncology

Proper use of social media by health operators in the pediatric oncohematological setting: Consensus statement from the Italian Pediatric Hematology and Oncology Association (AIEOP)

Carlo Alfredo Clerici[1,2] | Paola Quarello[3] | Anna Bergadano[3] | Laura Veneroni[1] | Marina Bertolotti[4] | Paola Guadagna[5] | Angelo Ricci[6] | Andrea Galdi[7] | Franca Fagioli[3] | Andrea Ferrari[1]

[1]Pediatric Oncology Unit, Fondazione IRCCS Istituto Nazionale Tumori, Milan, Italy

[2]Department of Oncology and Hemato-Oncology, University of Milan, Milan, Italy

[3]Pediatric Onco-Hematology, Stem Cell Transplantation and Cellular Therapy Division, Regina Margherita Children's Hospital, Turin, Italy

[4]Psycho-Oncology Service, Pediatric Onco-Hematology, Stem Cell Transplantation and Cellular Therapy Division, Regina Margherita Children's Hospital, Turin, Italy

[5]Pediatric Hemato-Oncology Unit, Arnas Civico, ASLTI Liberi di crescere Onlus, Palermo, Italy

[6]Federazione Italiana Associazioni Genitori Oncoematologia Pediatrica (FIAGOP), Modena, Italy

[7]La Repubblica Newspaper, Milan, Italy

Correspondence
Andrea Ferrari, Pediatric Oncology Unit, Fondazione IRCCS Istituto Nazionale Tumori, Via G. Venezian, 1-20133 Milan, Italy.
Email: andrea.ferrari@istitutotumori.mi.it

Abstract

Social media are powerful means of communication that can also have an important role in the healthcare sector. They are sometimes seen with diffidence in the healthcare setting, partly because they risk blurring professional boundaries. This issue is particularly relevant to relations between caregivers and adolescent patients. The Italian Pediatric Hematology and Oncology Association created a multidisciplinary working group to develop some shared recommendations on this issue. After reviewing the literature, the working group prepared a consensus statement in an effort to suggest an analytical approach rather than restrictive rules.

KEYWORDS

adolescents, communication, pediatric oncology, professional boundaries, recommendations, social media

1 | INTRODUCTION

The so-called Web 2.0 is a powerful means of communication because of its intrinsic user participation features and the opportunity it offers to produce and rapidly share content on various types of social media, including blogs and microblogs (e.g., Twitter and Ask), social networking sites (Facebook), video sharing sites (YouTube or Vimeo), instant messaging applications (WhatsApp or Messenger), image sharing sites (Snapchat or Instagram), and so on.[1,2]

The web is used by patients as a source of health-related information. In recent years, social media have become very important in helping patients understand disease, and in orienting their decisions regarding their health. They have also been adopted as a new relational tool for exchanges between patients and healthcare operators, particularly with adolescent patients. This is partly because this age group generally knows how to exploit the technologies to access the web from virtually anywhere and at any time. Anybody caring for adolescents knows that learning to use these new languages and forms of communication can make it easier to really engage with their world.[3]

In recent years, there has been a growing awareness of the risks that these technologies pose. Adults often view the use of social media by adolescents with concern (partly because adults have less expertise with these tools). In the healthcare setting, social media sometimes trigger a degree of diffidence. Social media may challenge the boundaries between physicians and patients, and between physicians' professional and private lives. This can induce clinicians to be cautious about using social media. There has also been limited

Abbreviations: AIEOP, Associazione Italiana Ematologia e Oncologia Pediatrica; AMA, American Medical Association; INT, Istituto Nazionale Tumori

 © 2018 Wiley Periodicals, Inc.

attention to the opportunities that social media may offer in health communication.

Now health professionals are faced with the challenge of establishing some rules for their professional behavior on social media, both in their clinical activities and in their private usage. The Italian Pediatric Hematology and Oncology Association (Associazione Italiana Ematologia e Oncologia Pediatrica [AIEOP]) joined forces with the Federation of Parents' Associations focusing on pediatric hematology/oncology (Federazione Italiana Associazioni Genitori Oncoematologia Pediatrica) and created a specific working group to develop some shared recommendations on this issue.

2 | METHOD

The working group established by the AIEOP initially consisted of pediatric oncologists, psychologists, nurses, members of parents' associations, and a journalist expert in communication, for a total of 10 members.

A literature search was conducted for scientific publications relating to the use of social media in the healthcare setting, in the field of pediatric oncology, in particular. The literature search used PubMed with the following keywords: social media, social network, guidelines, recommendation, professionalism, pediatric oncology and adolescents oncology. Generic search engines, the websites of public health and government agencies, and printed books and journals were searched. The relevant scientific literature was circulated among working group members with the aid of a file sharing system.

The documentation was discussed by means of an online forum, telephone conferences, and face-to-face meetings. A first draft of comments and recommendations was developed based largely on literature or the working group members' observations and experience. It is worth adding that the literature available on the topic is generally based on empirical evidence and researchers' opinions. This first draft was discussed with groups of adolescent patients involved in the Youth Project at the Istituto Nazionale Tumori (INT) in Milan,[4] and others at the Pediatric Onco-Hematology Department of the Regina Margherita Children's Hospital in Turin. These adolescents were involved for several reasons: they are stakeholders capable of giving an opinion on the topic from a different perspective from that of a clinician, they may have had "unmet needs," especially regarding communication issues being of the generation of "digital natives," and their approach to social media is generally more evolved than that of older people. The draft recommendations were shared with the adolescents in a focus group, and then sent to them individually so that they could comment on them and make suggestions. There were a total of 10 adolescents involved.

The final document was then prepared and submitted to the AIEOP board members for approval.

3 | RESULTS

The scientific literature review revealed no specific guidelines applicable to the pediatric oncology setting, despite numerous studies and some advice circulated by international medical societies. The working group found 73 articles, four books or book chapters, and 16 documents published on websites that were judged to be of some relevance. A systematic analysis of the single documents is beyond the scope of this paper, but the approach to the use of social media that emerged can be brought down to two basic viewpoints. Some (like the Canadian Medical Association)[5,6] favor a prudent use of these novel means of communication; others (like the British Medical Association) tend to reject their use for medical communication purposes.[7] Some publications proposed guidelines, like those of the American Medical Association (AMA).[8] The AMA urges users to ensure compliance with privacy legislation to protect patients and health operators alike. The AMA underscores the need to respect the rules of professional ethics in the doctor–patient relationship. It suggests that personal content be kept clearly separate from professional content on the web. It also warns health operators to bear in mind that their online activity can negatively affect their reputation. The document issued by the American Nurses Association again emphasizes the potential ethical problems relating to confidentiality and the need to preserve professional boundaries.[9]

Most of the literature expressed concern that social media can pose a risk of violating ethical rules (even accidentally), though the potential problems were variously interpreted. It is intriguing, for instance, to find positive comments on the value of a Twitter-based general medical consultation service operating in the Netherlands, called Tweetspreekuur,[10] while this might be judged negatively by professional bodies discouraging any use of social media for interaction between doctor and patient.

The some studies sought to provide guidance on the type of behavior to avoid (e.g., do not share confidential patient information; do not share negative reactions; do not believe everything you read; do not consider social media as a substitute for scientific publications), and also on potentially appropriate behavior (e.g., be selective in deciding who you acknowledge as "friends" on your profile; promote your work with other professionals, colleagues and friends; double-check all content before sharing it; share content without any hidden agenda).[11,12]

Other studies tried to identify the possible risks and benefits of various types of behavior related to social media use. For instance, using these channels to communicate with patients can ensure a rapid response, but cannot replace a face-to-face exchange (or even a phone call) because it is open to misunderstandings. Using online information resources can favor patients' empowerment through a process of self-education, but there is a risk of their finding uncontrolled and erroneous information. Using online tools to communicate with colleagues about patients' clinical details can facilitate a quick and easy exchange of information, but poses confidentiality problems, so technological solutions are needed to ensure the safe sharing of such information. Posting personal information on social media can make it easier to develop relationships, but can also confuse the boundaries between an individual's professional and personal life.[13]

In addition to reviewing and discussing the scientific literature, the AIEOP working group drew on the experience of several of its members, who had previously conducted experiments and published articles on the use of social media in the world of adolescent oncology (one instance of this was the creation of a closed Facebook

TABLE 1 Examples of critical issues in the use of social media

A patient's Facebook page is used by his brother to announce the patient's death. Many of the friends the patient made in hospital, and other patients on the ward were linked to his profile, and consequently immediately received the news—but some of them might have preferred not to know.
An adolescent whose cancer was progressing rapidly, and proving refractory to any treatment, posts a daily update on his increasingly severe clinical conditions. His Facebook page is read by various other patients of the same age suffering from similar diseases.
The news of a patient's death is shared among various adolescents with cancer who had become friends during their hospital stay. One male openly criticizes the physicians who were his "friends" on Facebook for their indifference because they did not express their sorrow by posting a message of condolences on the patient's Facebook page.
On the closed Facebook page of the Youth Project (dedicated to adolescent cancer patients) where adolescents exchange proposals and comments concerning their shared creative and artistic activities, the problem is raised of whether or not to remove the name of a patient who has died from the list of "friends." Some of the operators who manage the page felt this was necessary, while others were concerned that it might be seen as disrespectful of the memory of the patient who died.
A parent uses the closed Facebook group (intended for discussing organized support activities) and their son's "friendship" to send private messages via Facebook to his son's pediatric oncologist, asking questions and requesting clinical assessments.
A female being treated and followed up by the psychologist on the ward seeks to gain the latter's attention by writing her private messages on Facebook at all hours of the day and night, demanding rapid answers and the immediate satisfaction of her needs.

group for adolescents taking part in the Youth Project at the INT in Milan).[14,15] Clinical observation and personal experience proved fundamentally important in preparing the recommendations. Some examples of critical issues encountered in clinical practice are given in Table 1.

In preparing its recommendations, the AIEOP working group focused on (1) whether it was feasible and/or advisable to produce recommendations to be shared by physicians, nurses, other healthcare operators, and other professionals working in the area of pediatric oncology (e.g., administrative personnel, teachers, voluntary workers); (2) whether to remind these professionals about issues already governed by their code of ethics, hospital regulations, or civil and penal law; and (3) whether it would be more helpful to suggest an analytical approach rather than restrictive rules.

The recommendations prepared by the working group, and subsequently approved by the AIEOP, are listed in Table 2.

4 | DISCUSSION

The use of modern communication technologies in the world of pediatric oncology is a complex issue and a new challenge. It can affect how we interpret professional roles and boundaries. The potential of these new communication tools makes it essential for healthcare personnel to learn how to use these media effectively. Merely framing the use of social media in a restrictive sense would risk inappropriately limiting a clinician's freedom of expression.

A particularly important aspect of this topic concerns adolescent patients, who see social media as an important resource.[16,17] For a start, these tools offer them a lifeline that keeps them connected with their own home environment. Up until recently, cancer treatments for adolescents severely restricted their chances of continuing to attend school and their social life with their peers, often leaving them isolated from their normal world. Nowadays, patients can stay in touch with schoolmates and friends, let them know about their state of health, and be informed about life outside the hospital. They can also use social media to receive notes on school lessons they miss, which has the beneficial effect of reinforcing their sense of belonging to the class, as well as, helping them to keep abreast of their schoolwork during their absences.

Social media also have a role in building and reinforcing patients' relationships (after their discharge) with other adolescents who have cancer and conditions similar to their own, who they met in hospital. This is important because it enables them to provide emotional support for each other, among peers. The opportunity to use social media for a structured aggregation is interesting—as in the case of the Youth Project at the INT in Milan.[14] It can facilitate the organization of groups and activities, as well as, becoming a channel for providing psychosocial support.

Such relational networks also risk serving as a channel—not necessarily desirable, but not easy to control—for exchanging information about the unfavorable course of a patient's disease or announcing someone's death. Even death, like so many other aspects and moments of life, has been transformed by the advent of social media from a private fact into a public event. For young people who are severely ill and their "virtual" friends, bad news circulating via social media may reach some patients who would justifiably prefer not to know about the unfavorable outcomes of other patients' treatments. They risk losing hope and expecting the same sad destiny for themselves ("I shall be next"). It is essential to bear these issues in mind, especially when planning projects to provide support or facilitate relations between young people with cancer.

Another extremely delicate problem concerns adolescent patients becoming "friends" on social media with their doctors or nurses. Firsthand experience has shown that patients are often very keen on this type of relationship, and refusing an invitation to be their "friends" can prove difficult. But agreeing to be a patient's "friend" on Facebook[18] clearly means that health professionals may be opening a window on their own private lives, accessible not only to their patients, but also to all of their other "friends." This changes the nature of the relationship, with effects that are sometimes positive, but can sometimes difficult to manage. It can generate a misleading sense of confidentiality and may give rise to confusion about the patient's and the health operator's respective roles. While it is difficult to suggest rules to cover all possible situations, the AIEOP recommends caution: operators should always bear the potential risks of such "friendships" in mind.

Caution is warranted also when accessing a patient's social media pages.[19] Posting comments or clicking to "like" or sharing some of the content are actions that can have emotional and relational implications. It is important to monitor the risk of a health professional's involvement in a patient's private life being misunderstood. Every care

TABLE 2 Recommendations on the use of social media by physicians and other health operators working in the field of pediatric oncology

General aspects	Protecting the patient's privacy
Be cautious: the same deontological rules apply to online communications too[a]	It may be best to avoid accessing patients' social media profiles without their consent[a,b]
Remember that social media can make public not only a personal professional image, but also that of a whole professional category[a]	Be wary of joining discussions, commenting, or clicking to "like" content on a patient's personal page. It may have unexpected emotional and relational effects[b]
Remember to use virtual media to sustain, not to replace, real interactions[a]	Be aware that patient groups using instant messaging systems uncontrollably expose patients to the risk of receiving sad news, or erroneous or distressing information. Recipient lists are preferable (e.g., WhatsApp "broadcast lists")[b]
Think twice about inviting patients or members of their families to be your "friends" on social media[a]	
Decide how you will answer invitations to be "friends" on social media[a]	Establish procedures for how patient groups on social media react to a patient's death. Condolences can be expressed, but other patients have a right not to be informed if they wish[b]
Do not post content incompatible with professional ethics and decorum, or concerning your private life, political or religious convictions[a]	
Do not comment on patients or colleagues, even if they are not readily identifiable[a]	Beware of confidentiality issues. Providing details of other patients' clinical conditions or death is not permitted[a]
Make sure your social media settings safeguard your own privacy and that of your "friends"[a]	Supervise the use of photographs of minors. Privacy violations are punishable by law[a]
	Protecting the healthcare worker's privacy
Avoid sending or uploading information that can make a patient identifiable[a]	Distinguish between public platforms and channels for patients[b]
Follow your deontological principles, and maintain your professional boundaries[a]	Use social media pages for patient groups exclusively for their intended purpose, not for posting personal content. Check the identity of all participants to avoid intruders. Establish rules for participants, and appoint one or more moderators[b]
Be aware that patients, colleagues, institutions and employers can read your messages[a]	
Do not share or publish information or images exchanged between a health professional and a patient for non-professional purposes, or without the necessary authorization[a]	Prefer offline meetings to discuss crucial issues, and face-to-face encounters instead of virtual discussions on delicate topics[b]
Ensure that all multidisciplinary team members are aware of the need for caution when using social media. This includes nonhealthcare professionals too (e.g. administrative personnel, teachers, educators, voluntary workers), whose ethical and deontological rules may be less precisely encoded than those of clinical professionals[b]	Posting personal information on social media can facilitate relationships, but also confuse professional and personal boundaries[a,b]
	When "friends" with patients or members of their families, keep personal and professional matters separate. Make it clear that social media cannot be used to exchange clinical information[a,b]
Check whether you are obliged to report any social media content that could negatively affect a patient's (or colleague's) privacy, well-being and rights, to the competent authorities[b]	Use virtual media to sustain, not to replace, real human interactions[a]
Contribute to the development of cultural and institutional frameworks for governing online behavior[a,b]	

[a]General recommendations based on the literature.
[b]Recommendations based on the working group's observations and opinions.

must be taken to safeguard the clinical relationship against potentially sentimental and seductive dynamics (be they real or perceived).

Some hybrid applications, like WhatsApp, place users in contact with only one other party, facilitating an (at least illusory) degree of intimacy. Using this type of digital media necessarily implicates a "confidential" approach because this type of exchange relies on each party giving the other a private telephone number and, since one writes and the other answers, this can only be a consensual communication.

Turning now to a rather different issue, there are the possible scientific uses of social media. Facebook and Twitter are increasingly used by research institutions, hospitals, and professionals for work-related purposes. Their use can unquestionably pose problems for individual clinicians, whose university or specialist training may not have provided them with appropriate "user instructions." The recent example of the Christmas Carol written and sung by a group of adolescents on the Youth Project in Milan—which unexpectedly went "viral" (and was viewed more than 8 million times) because of a chain started on WhatsApp—confirms the fundamental importance of adequately managing the use of social media to ensure proper communications in the medical setting.[20]

In conclusion, the AIEOP recommendations are intended as "food for thought," an initial attempt to help clinicians working in the field of

pediatric oncology (among others) to be cautious and knowledgeable in the use of social media. Working with adolescents who have cancer has provided special opportunities to experiment with these media and gain experience of the issues involved.

It is now clear that modern communication technologies can be put to good use for exchanging information and possibly also for supporting the patient–doctor relationship. It is very important for health operators to learn to use these media effectively, while always keeping in mind that they can only sustain, not replace real human interactions.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

ORCID

Paola Quarello http://orcid.org/0000-0002-1940-7375
Laura Veneroni http://orcid.org/0000-0003-2152-0411
Andrea Ferrari http://orcid.org/0000-0002-4724-0517

REFERENCES

1. Van De Belt TH, Engelen LJ, Berben SAA, Schoonhoven L. Definition of Health 2.0 and Medicine 2.0: a systematic review. *J Med Internet Res 2010*;12(2):e18.
2. Schreiber WE, Giustini DM. Pathology in the era of Web 2.0. *Am J Clin Pathol*. 2009;132(6):824–828.
3. Kind T. Professional guidelines for social media use: a starting point. *AMA J Ethics*. 2015;17(5):441–447.
4. Ferrari A, Clerici CA, Casanova M, et al. The Youth Project at the Istituto Nazionale Tumori in Milan. *Tumori*. 2012;98(4):399–407.
5. Canadian Medical Association. Social media and Canadian physicians–issues and rules of engagement. 2013. http://policybase.cma.ca/dbtw-wpd/Policypdf/PD12-03.pdf.
6. Canadian Medical Protective Association. Using social or professional networking websites can breach confidentiality. 2010. https://oplfrpd5.cmpa-acpm.ca/-/using-social-or-professional-networking-websites-can-breach-confidentiality.
7. British Medical Association. Using social media: practical and ethical guidance for doctors and medical students. 2011. http://bma.org.uk/-/media/Files/PDFs/Practical%20advice%20at%20work/Ethics/socialmediaguidance.pdf
8. AMA Policy. Professionalism in the use of social media American Medical Association Reports & Resolutions. 2010.
9. American Nurses Association (ANA). 2011 ANA's principles for social networking and the nurse. http://www.nursesbooks.org
10. Brandenburg BJ, Jansen E. The proof of the pudding: first results of a primary care consultation service on Twitter. Maastricht, The Netherlands: Medicine 2.0 Congress; 2010. http://www.medicine20congress.com/ocs/index.php/med/med2010/paper/view/415.
11. Ranschaert ER, van Ooijen PM, Lee S, et al. Social media for radiologists: an introduction. *Insights Imaging*. 2015;6(6):741–752.
12. Wiener L, Crum C, Grady C, Merchant M. To friend or not to friend: the use of social media in clinical oncology. *J Oncol Pract*. 2012;8(2):103–106.
13. Farnan JM, Snyder Sulmasy L, Worster BK, et al., Online medical professionalism: patient and public relationships: policy statement from the American College of Physicians and the Federation of State Medical Boards. *Ann Intern Med*. 2013;16(8):620–627.
14. Veneroni L, Ferrari A, Massimino M, Clerici CA. Facebook in oncology. *Recenti Prog Med*. 2015;106(1):46–51.
15. Clerici CA, Massimino M, Veneroni L, Ferrari A. Pros e cons of using Facebook in pediatric oncology. *J Cancer Res Ther*. 2015;11(4):1042.
16. Perales MA, Drake EK, Pemmaraju N, Wood WA. Social media and the adolescent and young adult (AYA) patient with cancer. *Curr Hematol Malig Rep*. 2016;18:449–455.
17. Magni MC, Veneroni L, Clerici CA, et al. New strategies to ensure good patient–physician communication when treating adolescents and young adults with cancer: the proposed model of the Milan Youth Project. *Clin Oncol Adolesc Young Adults*. 2015;5:63–73.
18. Langenfeld SJ, Sudbeck C, Luers T, et al. The glass houses of attending surgeons: an assessment of unprofessional behavior on Facebook among practicing surgeons. *J Surg Educ*. 2015;72(6):e280–e285.
19. Kind T, Patel PD, Lie DA. Opting in to online professionalism: social media and pediatrics. *Pediatrics*. 2013;132(5):792–795.
20. Ferrari A, Signoroni S, Silva M, et al. Viral!: the propagation of a Christmas Carol produced by adolescent cancer patients at the Istituto Nazionale Tumori in Milan, Italy. *Pediatr Blood Cancer*. 2017;64(9). https://doi.org/10.1002/pbc.26516.

How to cite this article: Clerici CA, Quarello P, Bergadano A, et al. Proper use of social media by health operators in the pediatric onco-hematological setting: Consensus statement from the Italian Pediatric Hematology and Oncology Association (AIEOP). *Pediatr Blood Cancer*. 2018;65:e26958. https://doi.org/10.1002/pbc.26958