Intensive Care Med (2019) 45:1119–1122
https://doi.org/10.1007/s00134-019-05629-7

WHAT'S NEW IN INTENSIVE CARE

Dealing with internet-based information obtained by families of critically ill patients

Yên-Lan Nguyen*

You are probably relieved when families deny having questions about their loved ones' care. Well, take comfort in the fact that they do not mean to deceive you. They simply do not want to embarrass themselves by appearing naive, and instead plan to consult that higher authority "Dr. Google."

1. Be mindful of frequent health-related internet use

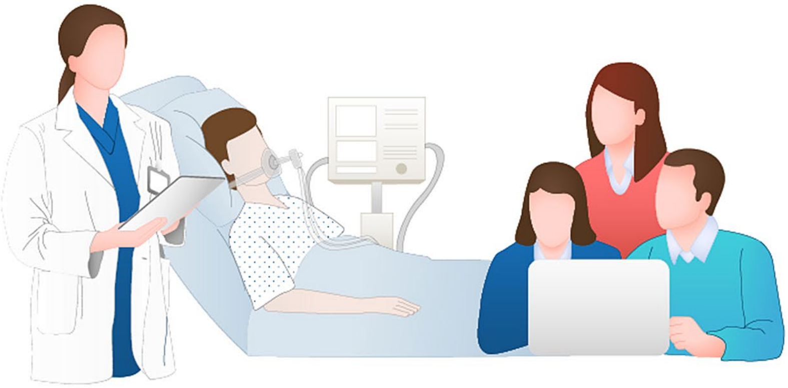
The majority of families of critically ill patients you have talked to or will talk to in the upcoming days are going to search for additional information online about their loved ones' condition. A recent survey suggests that six out of ten Europeans have used the internet for this purpose, particularly those who are younger, have greater educational achievements, or have a good quality of health themselves [1]. This does not indicate mistrust or dissatisfaction with healthcare providers. Instead, they seek to better understand the situation (information on symptoms of a specific illness, treatments, medical tests) [1, 1]. As in domains (e.g., pediatrics, oncology), those using the internet to research critical illness do not restrict themselves to data [1, 3, 4]. It is likely that the feeling of loneliness, the fear of losing a loved one, or the hope of healing also lead them to search for testimonials of other families experiencing similar situations; the web provides a readily accessible source. In a multicenter French study, we found that methods to enhance communication with families, such as provision of an informational leaflet or developing a procedure on how to standardize delivery of information, were not associated with internet use [2]. Additionally, satisfaction with global ICU care or medical information delivery or the presence of anxiety/depression symptoms were independent of internet searches. Bouju et al. highlight the positive impact of internet use on improving medical information comprehension and on facilitating the communication, without impacting the trust in care providers [5].

The most common sources include search engines, dedicated websites/blogs/forums, websites run by healthcare organizations, newspapers or magazines, social networking sites, or specific apps [1]. The majority of people are satisfied with information that they find, describing it as useful, easy to find, and easy to understand. However, digital literacy influences the acquisition and interpretation of this data, because of its unpredictable reliability.

Unmoderated online forums in particular (those sites run without input from healthcare professionals) have both strengths and weaknesses. On the one hand, input on personalized health networks like PatientsLikeMe may offer emotional support and tips on how best to make medical decisions [6]. Moreover, peer review by contributors (acknowledging lay status and promoting semi-expertise or providing medical advice) helps to minimize the risk of false or misleading information available on these sites [7–9]. On the other hand, the presence of forum moderators does not guarantee the reliability of the information. Some articles or videos popularized on social media have contributed to the spread of medical misinformation, driving propaganda on esoteric or unscientifically founded health practices. Too often, the videos with inaccurate information have the largest number of views (in comparison to those from government organizations and professional associations), making it difficult for users to find reliable information [10–12]. Unfortunately, current algorithms used by search engines do not promote dissemination of trustworthy and valid information sources.

---

*Correspondence: yen-lan.nguyen@aphp.fr
Department of Anaesthesia and Intensive Care Medicine, AP-HP, Cochin Academic Hospital, 27 rue du Faubourg Saint-Jacques, F-75679 Paris, France



Critical care societies' web sites

English

http://www.ics.ac.uk/ICS/Education
https://www.scottishintensivecare.org.uk/patients-families
https://www.sccm.org/MyICUCare
https://canadiancriticalcare.org/Patients-&-Families

French

https://sfar.org/pour-le-grand-public/
https://www.sgi-ssmi.ch/fr/patients-en-etat-critique.html

German

https://www.dgai.de/aktuelles-2/489-broschuere-die-intensivstation-2016/file.html

Italian

http://www.intensiva.it/

Spanish

http://www.semicyuc.org/ciudadanos

Dutch

https://nvic.nl/patiënten

Other web sites dedicated to families

English

https://icusteps.org
https://healthunlocked.com/icusteps
https://icuunwrapped.co.uk
http://www.criticalcarerecovery.com/x37/families_page
www.healthtalkonline.org/Intensive_care
https://www.worldsepsisday.org
https://www.startinghearts.org
http://www.lifeaftersca.org
www.icudelirium.org
https://www.cruse.org.uk

German

www.eric-projekt.de

Portuguese

http://www.utivisitas.com.br

Dutch

https://www.fcic.nl/
https://icconnect.nl/

Fig. 1 List of websites that may be helpful for patients' families

2. Be open towards families' health internet searches

Intensivists should interpret the search for additional information as a willingness to become a well-informed surrogate, more apt to be engaged in the shared decision-making process. Unfortunately, too often, families fail to disclose their search for additional information: in our study, only one-third of families shared with intensivists what they had found [2]. Major barriers that prevent the discussion of health-related findings with physicians are resistance, discouragement, and skepticism on the part of physicians or the fear of embarrassment of patients and their families [2]. Strategies for using or revealing online findings are asking additional questions or making suggestions based on their findings [2].

Regardless of the digital literacy of patients' families, they may have had difficulties navigating the internet effectively and identifying reliable sources. Intensivists should therefore take the lead and specifically ask whether families have questions concerning online discoveries. Most of the time, they may ask about the decision process for choosing a particular treatment. They may have discovered other options and want to understand the reasons for selecting one over another. This questioning is reasonable as our decisions are not always rational and are influenced by emotional, cognitive, and social factors [13]. If the information is accurate, your role will be simple: you will have to explain the rationale behind your decision, the limitations of the "one size fits all" approach, and role of the multidisciplinary team in formulating all major decisions. If the information is inaccurate, you can take the opportunity to recommend a list of reliable websites. There are numerous trustworthy sources with readily accessible medical data and videos dedicated to patients or families (Fig. 1).

However, sometimes the situation may be more complex. For example, how do you respond to a family asking for unfamiliar medical tests or treatments? How do you interact with a family more convinced by the authority of online resources than your medical judgment? It is important to remember that these questions, regardless of their framing, only reveal a family's desire to ensure that their loved ones receive the best possible care. How can you blame them? They are in a vulnerable position, which may affect their capacity to discriminate between reliable and misleading sources of information. Furthermore, they want to trust information that offers hope of a positive outcome. Do not take these questions as a personal challenge. Instead, try your best to answer in a positive manner to avoid interpersonal conflict and the loss of trust. Acknowledge their sense of autonomy and ask them about their information sources. Do not be surprised if you do not recognize their reference, since there are more than 70,000 health-related websites [14]. If they ask about an unknown medical exam or treatment, tell them that you are going to investigate further, and discuss the matter with colleagues. If they accept your dismissal of misleading online findings, share with them other sources of information. If they remain convinced that better options exist, do not try to contradict them—it is a waste of time. Simply, offer them the opportunity to transfer their loved one to another unit of their choice. There is another tricky situation: what if you are wrong? Errors in judgment do occur. Particularly when patients have chronic diseases, their caregivers develop significant content expertise (through exposure to online educational resources and time spent in medical facilities). Dismissing their insights or excluding them from the clinical decision-making process would be a mistake. As physicians, we must acknowledge that we are not infallible and that each of our decisions reflects a risk–benefit assessment, conditional on the particular circumstances of that case.

To conclude, the increasing availability of web-based health information resources should foster intensivists to step out of their comfort zone and encourage families to discuss their online discoveries.

Acknowledgments
A sincere thank you to Dr D. Mohan for her diligent proofreading of this editorial.

Compliance with ethical standards

Conflicts of interest
The author declares no conflict of interest.

Publisher's Note

Received: 26 February 2019 Accepted: 24 April 2019
Published online: 9 May 2019

References

1. TNS Political & Social. Flash Eurobarometer 404: European Citizens' digital health literacy. Brussels: European Union; 2014
2. Nguyen Y-L, Porcher R, Argaud L, Piquilloud L, Guitton C, Tamion F et al (2017) "RéaNet", the internet utilization among surrogates of critically ill patients with sepsis. PLoS One 12(3):e0174292
3. Park E, Kim H, Steinhoff A (2016) Health-related internet use by informal caregivers of children and adolescents: an integrative literature review. J Med Internet Res 18(3):e57
4. Kinnane NA, Milne DJ (2010) The role of the internet in supporting and informing carers of people with cancer: a literature review. Support Care Cancer 18(9):1123–1136
5. Bouju P, Tadié J-M, Uhel F, Letheulle J, Fillatre P, Lavoué S et al (2014) Internet use by family members of intensive care unit patients: a pilot study. Intensive Care Med 40(8):1175–1176
6. Wicks P, Mack Thorley E, Simacek K, Curran C, Emmas C (2018) Scaling PatientsLikeMe via a "generalized platform" for members with chronic

illness: web-based survey study of benefits arising. J Med Internet Res 20(5):e175

7. Fage-Butler AM, Nisbeth Jensen M. The interpersonal dimension of online patient forums: how patients manage informational and relational aspects in response to posted questions. HERMES J Lang Commun Bus. 2017;26(51-2013);21–38.
8. Esquivel A, Meric-Bernstam F, Bernstam EV (2006) Accuracy and self correction of information received from an internet breast cancer list: content analysis. BMJ 332(7547):939–942
9. Hoffman-Goetz L, Donelle L, Thomson MD (2009) Clinical guidelines about diabetes and the accuracy of peer information in an unmoderated online health forum for retired persons. Inform Health Soc Care 34(2):91–99
10. Basch CH, Zybert P, Reeves R, Basch CE (2017) What do popular YouTube™ videos say about vaccines? Child Care Health Dev 43(4):499–503
11. Pithadia DJ, Reynolds KA, Lee EB, Wu JJ (2019) A cross-sectional study of YouTube videos as a source of patient information for topical psoriasis therapies. J Dermatol Treat 18:1–14
12. Goobie GC, Guler SA, Johannson KA, Fisher JH, Ryerson CJ. YouTube videos as a source of misinformation on idiopathic pulmonary fibrosis. Ann Am Thorac Soc. 2019. https://doi.org/10.1513/AnnalsATS.201809-644OC.
13. Mohan D, Angus DC (2010) Thought outside the box: intensive care unit freakonomics and decision making in the intensive care unit. Crit Care Med 38(10 Suppl):S637–641
14. Grandinetti DA (2000) Doctors and the Web. Help your patients surf the Net safely. Med Econ 77(5):186–188, 194–196, 201