

Supporting the Patient's Choice to Open Access Private Health Information

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ABSTRACT

The nurse practitioner (NP) was asked to videotape the surgical procedures of 2 patients so that they could post it on social media. The NP faces many challenges to ensure that patient's rights of disclosure and privacy are addressed when video recording their surgical procedure. There are both federal laws and hospital policies aimed at protecting patient confidentiality. The NP needs to support individuals in making choices that are in line with their personal values and beliefs, with awareness and freedom.

Keywords: awake craniotomy, open access, privacy, social media

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Social media is transforming health care.^{1,2} Social media improves access to information for providers and the public alike. In return, the public, health care institutions, and educational programs are recognizing and embracing social media.

Patients want to stay connected to family, friends, and loved ones during hospitalizations.³ Patients may choose to openly access private health information in order to inform and help others about a condition and/or treatment options. Social media is also controversial because it has the potential to violate patient privacy. These case studies describe patients who requested the support of a nurse practitioner (NP) to use social media to share private health information.

BACKGROUND

The use of the Internet is extensive, with more than 2 billion estimated worldwide consumers.⁴ Internet users in the United States are primarily 18- to 64-year-old, non-Hispanic white females with at least some college education, of greater socioeconomic status, and who have access to home-based Internet.⁵ Of Internet users, 72% reported using it to seek health information in the last year.⁶

Research indicates that persons who use the Internet for health information do so to be more informed, are more engaged in their health care, and more closely follow the advice of their providers.^{1,2} Health care providers and patients alike report that

seeking health information via the Internet results in a more positive relationship between the patient and provider. However, information obtained from the Internet can present challenges to providers related to the need to dispel misinformation.⁷

Although in-person advice from health care providers remains the most popular way to receive health information,⁸ computer and mobile device use is resulting in changed behaviors. One in 4 adults who use the Internet has done so to seek information from others who share their condition or to benefit from another person's health care experience.⁶ It is widely acknowledged that social media is an influential tool for communicating, influencing, and educating audiences via the Internet.⁹ Social media is an Internet-based medium that allows an individual or a group of individuals to communicate instantly with a virtual audience of potentially limitless size.

The changing landscape of Internet use has resulted in changes in health care education. Providers now need to learn how to use the technology to communicate more effectively with patients while protecting patient privacy.¹⁰ The Health Insurance Portability and Accountability Act of 1996, state law, individual facilities, and various professional organizations all explicitly protect the right to patient privacy.¹¹

Health care providers are trained in and held to standards that protect patient right of privacy. Violations of privacy are a serious offense that at minimum can lead to an individual's dismissal. Less clear is

how to handle assisting patients who choose to openly share private health information via the Internet through social media platforms. To date, there are no known studies or case reports discussing health care providers assisting patients with open access.

Theoretical Framework

Barrett's Theory of Knowing Participation in Change informs the practice of the NP within our neurosurgical practice. Barrett suggests that power is the capacity to participate knowingly in change. The dimensions of power are awareness, choice, freedom to act intentionally, and the involvement in making change.¹² Power, defined as participation in change, means the person is aware, able to choose, has the freedom to act, and is an active participant in the change.¹²

Barrett's theory is useful in guiding the NP to assess the person's awareness of the pros and cons, the personal perception of choice, and the person's sense of freedom to act intentionally. After assessing these choices, the NP has an important role in advocating for the patient so that he or she can have the freedom to actively participate in the change that is desired.

CASES

The patients are both men in their late 20s. The first is a musician, and the second is a PhD student. They each required magnetic resonance imaging after having presented post-seizure. They required a craniotomy for tumor resection. Pathological testing revealed each patient had a malignant brain tumor.

The musician was a bass player for a famous band. Social media is very important to him. He has a huge fan base that follows him on social media sites. His video updates of what is generally considered private information are viewed many times per day by thousands of people.

He wanted to videotape and share the filming of his surgery with his followers. He was aware that he would be awake in the operating room and may experience a neurologic deficit or other untoward event. However, he was pleased he would be able to communicate with his fans during the surgery. Preoperatively, the patient posted on the Internet that he was going to a Boston hospital on a specific date, that

he was going to have brain surgery, and that he was going to be awake for a portion of the surgery.

The second patient uses social media in a very different way. As a PhD student, he wanted to open source his medical record with others in the scientific world. At the end of the consultation, this patient specifically requested that the surgery be video recorded. He wanted others to have access to the knowledge about his condition, the treatment options, and the procedure he was undergoing.

The Challenge: Patient Privacy

Health care providers are keenly aware of the need to protect patient privacy, but in these cases, the patients themselves were requesting that their cases not only be videotaped but also shared on social media. The individual's rights to privacy versus their right to self-determination were 2 conflicting aspects of each case. Autonomy refers to the patient's right to compose self-governing decisions or to self-determine a course of action. Self-determination suggests the person has the right to make decisions about his or her life without interference from others. In health care, this pertains to the patient's right to make choices about his or her own life and health without undue interference from a NP, physician, or any other team member. All members of the team must respect and consider the patient's right to independent decision making. This involves resisting the urge to interpose personal feelings, values, or beliefs onto the patient. Infringement upon this right can be unethical.¹³

Advocating for the Patient's Right to Use Social Media

To address the patients' requests for video recording of their procedures, the NP arranged for the team to meet with the hospital's legal counsel to seek guidance. The legal counsel suggested that the NP assess the patients to ensure that they understood their decision, to review any potential concerns, and to obtain written consent. The legal counsel also suggested that the NP obtain verbal consent from the surgeon, which was also obtained.

The Surgical Procedure

Over the past few decades, awake craniotomies have been used more frequently for brain tumor resections. There are certain benefits from this

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