Considerations and Challenges in Information and Communication Technology

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Case Presentation

Addie is an 86-year-old woman who, accompanied by her daugher Melanie, comes for a new geriatrics visit with Dr. Smith. Addie was previously living independently out of state but, after a series of falls and some increased forgetfulness, Melanie convinced her mother to move into senior housing nearby in her town. Melanie, who is the mother of two teenagers, is an executive at a local nonprofit organization with full working days of her own. Addie prefers to be responsible for managing her affairs, but she is agreeable to having Melanie participate.

Melanie, dealing with her own very busy life, is looking for easier ways to communicate with clinicians about her mother. She is particularly interested in communication through texting, if possible, and to find a way to easily obtain information from visits that she can't personally attend because of work. She often lives in social media as part of her work and has naturally turned to this for information about caregiving. For the most part, Addie does not use computers, but she does have a tablet computer that she uses for video chatting and Facebook® to connect with her grandchildren.

Addie wishes to be in charge of her medical care, but, acknowledging her new forgetfulness, she is agreeable to Melanie helping out as long as she doesn't "take over." Though Addie is now closer, Melanie is still nervous about her mother living by herself and is interested in seeing what technology can be used to give her a "heads-up" if Addie has a problem. The geriatrician, whose practice does have a portal for patients to communicate with their clinicians and read their records, meets with both Addie and Melanie and begins the conversation.

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Introduction

The case above is becoming a common scenario in the offices of many geriatricians and primary care clinicians. While family members assisting their aging parents are not new, the information and communication technology landscape is rapidly changing and offering new and creative ways to enhance communication among families and their clinicians. As commonly occurs in real life, Melanie is busy with her own responsibilities and would like to apply the technology she uses everyday to help her in the coordination of care for her mother. Within the case, we see foreshadows of conflict regarding autonomy of the elderly woman and the helpful intentions of her daughter. We can also envision challenges for the geriatrician that include decisions about methods of communication between the patient and family, decisions around competency, challenges of information access, and assistance in the implementation of monitoring technology to alert caregivers about problems, such as falls and missed medication doses.

Technology and Healthcare

In the information age, people increasingly have several "always-on" communication and information channels, such as voice, text messaging, e-mail, and social media that are supported by fast mobile and home Internet connection [1]. The proportion of older people with these devices and capabilities is also increasing. In 2013, 68 % of individuals between 70 and 74 years of age and 47 % of those 75–79 years of age were online [2]. Baby boomers, the generation born between 1946 and 1964, are now caring for aging parents. This generation is accustomed to using the Internet, with 72 % of caregivers spending time online gathering health information [3, 4]. Over time, and with people living longer, the curve of older people using technology will continue to rise.

Technology has helped to break down many barriers and democratize information. Partly due to the widespread use of technology, the information asymmetry between patients and clinicians is shrinking. Patients and, by proxy, their families increasingly have access to their own medical data and records including clinician notes [5]. In addition, websites, ranging from the National Library of Medicine to Wikipedia, are offering helpful information and educational resources to patients and caregivers. Motivated patients can also access professional content. Patient-focused communities and message boards bring together people with similar conditions, struggles, and needs. Increasingly, we will see patients, especially those with more rare or nuanced conditions, be more informed than clinicians about their medical conditions.

Developing technology also brings new challenges, both to families and to healthcare professionals. Challenges can be separated into ethical ("Should I perform an action?"), technical ("Can I perform an action?"), and social/legal ("Is it acceptable to perform an action?"). Additionally, information and communication technology opens new risks, such as loss or theft of information, and this may be particularly relevant to older people online. When considering the increasing use of

technology in healthcare and the challenges that geriatricians are likely to encounter in their clinics, it is helpful to apply existing ethical frameworks when possible. It is important to realize, however, that these frameworks are not exclusive to technology but can be applied to many of the interactions that occur between patients, their families, and their healthcare providers.

Principles, Concepts, and Tools

The rapid pace of change in technology that we use for communication, as well as the diversity in circumstances for its use, precludes hard and fast rules about its acceptable use in clinical care. Rather, geriatricians should become familiar with principles and tools to help resolve any ethical dilemmas. The "Georgetown Mantra" of Bioethics lists the principles of beneficence (in the interest of helping the elderly person), non-malfeasance (do no harm), autonomy (respect the individual), and justice or farness for all. Not infrequently, ethical principles may appear to be at odds with one another, and as we shall see, it is important to understand the decision-making capacity of the elderly person, to weigh risks and benefits, and to ensure that goals and perspectives are aligned with the patient's interests (Tables 13.1 and 13.2).

Here, we will discuss ethical principles related to the use of technology in healthcare: protection of autonomy and respect for the individual, issues of consent and assent, beneficence, and principles of privacy and security [6].

Table 13.1 Ethical principles applied to technology

Principle	Definition
Autonomy and respect for the individual	A person's ability to preserve decision-making and exert independence
Consent and assent	A person's ability to give permission while understanding the trade-offs of a particular decision. Assent refers to the ability of a person, who is deemed unable to consent, to voice willingness to adhere to a particular decision
Beneficence	A principle to act to benefit others
Privacy and security	The protection of personal information from public accessibility

Table 13.2 Practical pearls for navigating technology

When possible, use communication channels dedicated for patient care and available to all patients
Be aware that unintended consequences of sharing health information, including disclosure of information previously kept private, may occur with proxy access to portals or records
Encourage patients to discuss information stewardship and management in the context of advance care planning
Periodically enquire about online activities
Discuss limitations of using technology with patients and families when appropriate

Autonomy and Respect for the Individual

Autonomy, perhaps one of the most central tenets in ethics related to aging, refers to the older person's ability to preserve decision-making rather than to relinquish it to another person. In the context of technology, autonomy may relate to a person's ability to have control over information flow and communication. The use of social and communication/information technologies creates needs for decisions about access and privacy. For example, can a family member read the elder's chart? Also, with whom should the doctor communicate – only with the patient or also with family members and, if so, which family members in particular?

Teachings from Immanuel Kant and other philosophers have taught us to think about respect for people and their autonomy as a process [7]. Put another way, the ends may not justify the means if the elderly person's preferences are not being honored. One example that we will come back to is the use of technology to monitor elderly people in their homes. While these signals may be helpful for early detection of problems, such as falls, they may not be acceptable if they result in loss of privacy for the elder. Data from focus groups of elderly people and caregivers provide rich food for thought. As one older gentleman noted, "we want technology to rescue us, not spy on us" [8].

For elderly people, autonomy is likely to diminish as cognition declines. Making prearranged plans for information control and sharing may be helpful for preserving and honoring peoples' wishes, even when they are unable to make decisions for themselves.

Consent and Assent

Consent refers to a person's ability to give permission while understanding the trade-offs of a particular decision. Assent refers to the ability of a person who is deemed unable to consent, often due to cognitive impairment, to voice willingness to adhere to a particular decision [9]. In the context of information and communication technologies, consent and assent may be most frequently applied when using patient portals or communicating with electronic tools, including the delegation of family as proxy users, or when using technology to monitor elderly people at home. If a patient with some level of cognitive impairment dissents with sound reason to the use of a technology, such as a home-monitoring device, this should be incorporated into the decision-making. Patients with cognitive impairments may have difficulty understanding some of the discussions regarding consent for online services, such as risks to privacy, but even when patients have some cognitive impairment, their wishes and preferences about how communication occurs should be respected.

In our case of Melanie and Addie, Addie has some form of forgetfulness that could represent mild cognitive impairment. At this time, however, she appears to have the ability to represent her interests and preferences for communication flow. She acknowledges that she wishes Melanie to be involved. Our geriatrician may go on to ask if it is okay for Melanie to have access to Addie's records and under what circumstances, if any, it would be acceptable to be in touch with Melanie directly.

Beneficence

Another vector in ethical frameworks is that of beneficence or benefit. We assume that patients, families, and clinicians are using technology to help improve or optimize health on the older person's behalf. In some cases, however, beneficence from the perspective of the family members or clinician may be at odds with the perspective of the patient when it interferes with the patient's autonomy. Put another way, what benefits one person may not benefit the other, and therefore beneficence depends on values, goals, and perspectives [10, 11]. Let's return to the example of home monitoring. Melanie may suggest that a home-monitoring device be used by Addie that would provide warnings for falls or untaken medications (putative benefit for the health and well-being of Addie). Addie may find, however, that such a device is not acceptable because it is too intrusive (autonomy – she has the right to decide). In such a scenario, beneficence and autonomy are potentially at odds. In these circumstances, determining the goals of the intervention is important; what is beneficial to Melanie (peace of mind) may not provide any benefit to Addie. In these cases, it can be challenging for all parties involved to navigate what should happen, and intra-family negotiations are often required. Ultimately, centering discussions around the goals of the patient will likely bring some clarity to the conversation.

Privacy and Security

Clinicians have a duty to safeguard patient information, but the use of information technology provides some inherent risks. These risks can be managed with good information habits and by following best practices. However, we sometimes will see where security is at odds with usability, especially in the consumer space. Clinicians and supporters of elderly people, such as family members, will need to consider trade-offs of optimal usability with privacy and security and often have to balance the privacy risks to the elderly person with the benefit of the service [12]. A common example is the use of traditional e-mail, which is typically not secured or encrypted, compared with the use of a dedicated and secured patient portal for messaging. E-mail is available to nearly all – most individuals are using it already for other purposes – and many people may feel comfortable with this technology. In contrast, a portal requires additional steps to use including a distinct visit and log-in to the site using a separate username and password. Some elders, who are comfortable with traditional e-mail, may find this confusing or cumbersome.

Elderly people may be especially vulnerable to breaches in security. The Federal Trade Commission has noted that about a fifth of identity theft complaints reported to the agency were for people over the age of 60 [13]. In particular, the most common type of fraud focuses on healthcare or health insurance. Elderly people may have less facility with technology and, as such, be potentially be more trusting of nefarious e-mails and content such as phishing attacks, where an e-mail or website

purports to ask for information for legitimate purposes but instead collects and uses the information for malicious purposes. Elders may be more susceptible to scams from the phone, web, social media, and e-mail. Funds, including savings and social security payments, may be at risk.

Technologies and Communication Channels

It is important to understand how to apply the above principles to scenarios clinicians may encounter. For each medium, we will (1) review the context and frame the issues, (2) consider issues in the context of the guiding principles, and (3) provide practical suggestions for geriatricians.

Patient/Family and Clinician Messaging

Technology has facilitated the proliferation of communication channels. Clinicians now try to balance in person meetings, phone calls, and e-mails and secure patient portal messages. They may even have requests, such as in our case, to use text messaging. In the ever-changing landscape of communication media, clinicians caring for elderly patients are likely to encounter new dilemmas and challenges. Does the elderly patient provide consent or assent for proxies or other family members to communicate with the clinicians? How do clinicians balance their communication with patients and the family members? When is it appropriate for clinicians to raise concerns directly with the patient's family members?

The guiding principle of autonomy encourages clinicians to ensure that they communicate directly with the patient in so far as possible, in the manner in which he or she prefers. Acknowledging that family members may wish to communicate directly with them, clinicians should ask patients when and under what circumstances this would be acceptable or preferable. They should also clarify which family members are to be involved in the communication. In our case, Melanie, the daughter of Addie, wishes to develop communication channels directly with Dr. Smith. This makes sense for several reasons including being able to communicate concerns and questions as well as being able to alert Dr. Smith of important changes. We also see that Addie does not want Melanie to "take control." Geriatricians will often need to balance competing interests of the patient and family, but being transparent and forthright in asking the patient about preferences is an important first step in helping to prevent downstream conflict.

Where possible, clinicians will want to use communication channels that are dedicated for patient care and available to all patients. For example, communication through secure messaging in a patient portal is preferable to e-mail because of security and self-documentation in the permanent medical record [14]. Since a patient's clinician may not be readily available to receive an important message (in the middle of the night, on vacation, or during a busy clinic session), it would be particularly

helpful if the patient's messages could be directed as well to appropriate clinic members who will be available around the clock.

Health Information, Patient Portals, and Open Notes

Access to information can be a boon to family caregivers [15, 16]. Especially when they cannot attend an appointment, for them to have summary information available from the visit can help with providing care and reduce their stress [17]. Patients and families may wish to sign up for dedicated patient portals for a variety of reasons, such as communicating with clinicians, viewing lab results, accessing other test results, and facilitating medication refill requests. Increasingly, clinicians are also making their medical notes available to patients through portals [5]. These notes are referred to as "open notes," named after the large demonstration project in 2012 at three major medical centers [18]. Open notes have been linked with patients feeling more in control of their health. Recently, attention has been directed to sharing open notes with family members and other caregivers [19, 20]. Open notes provide a way for family members, such as Melanie who cannot attend clinic visits because of her working schedule, to know what was discussed and the plans that were made.

While most early portals were not designed with caregiving in mind, some allow for proxy access, meaning a family caregiver can use their own log-in credentials to access the site [21]. It may become complicated, however, if the elderly patient wishes to keep some specific information in the past medical chart private. Proxy access to health records through a patient portal may unintentionally disclose information about sensitive matters previously undisclosed, such as abortions, sexually transmitted infections, or past diagnoses. In situations where there is information patients would not want revealed, clinicians should tend toward protecting the autonomy of the individual patient. The ability of patients to manage their information, however, is dynamic and depends on the health and functional status of the patient. In cases where patients can no longer manage their health affairs on their own and the proxy is provided access to the medical record, clinicians should be aware that unintended consequences of sharing health information, including disclosure of information previously kept private, may occur. In anticipation of this issue, clinicians would be wise to discuss issues of information stewardship and management in the context of advance care planning early on with their patients. For example, should the proxy have access to all historical information or only be provided with information moving forward? Patients should be encouraged to consider such discussions and to share their preferences with their proxy.

In our case, Melanie and Addie need to discuss Melanie's access to the portal and to clinical notes. Addie may wish to have sole access to the portal in order to keep control of her information or she may wish to delegate permission for Melanie to access the portal as well. If Addie wishes to have sole access at this time, she and Melanie should be encouraged to have a discussion about those circumstances in the future when Melanie would have access to the health records in order to be an informed proxy and surrogate decision-maker.

Social Media

Patients and families are likely to use social media to connect with one another as well as to seek information from others with similar experiences in aging. Offline social integration and networks have been related to improved health [22–24]. Higher social integration leads to becoming better informed, helping with decisions, and helping to access tangible resources. Evidence is building that online networks and communities are translating into improved health and reduced caregiving burden [25–27].

If clinicians do not have a channel available for electronic communication with patients, such as a patient portal, patients may be more likely to attempt to communicate through more personal channels, such as personal e-mail, Facebook, or other social networking sites that may be retrieved through a web search [28]. Social media channels such as these should, however, be discouraged as communication channels for patient care because of concerns about security, confidentiality, ownership of content, and reliability. Additionally, patients may read blogs or information that has not been vetted or does not apply to their particular circumstances. Clinicians should periodically enquire about patients' online activities to determine if their use is helpful or a source of misinformation or stress. Learning what types of health-related information patients may be reading can help the clinician, when appropriate, recommend better sources of information. If clinicians become concerned that elderly patients have been the victim of a scam or elder abuse through online tools, they should respond appropriately as for any other form of abuse, including mandated reporting where applicable.

Melanie and Addie may use social media to connect with friends and others with similar situations to seek support. Social media is becoming an important channel to learn about new information and learn how others have responded to similar challenges. It is likely that over time they will bring questions and ideas from social media to Dr. Smith, who will play an important role in helping the family navigate this information.

Remote Monitoring

As consumer devices, appliances, and other objects gain connections to the Internet, in the so-called Internet-of-things, technology could increasingly be deployed to the home environment to help monitor for safety problems. Connected sensors are currently able to send alerts in situations where a fall occurs or medications go untaken. On the horizon are sensors and algorithms that can monitor changes, such as in gait or voice, of relevance to changes in health that could initiate alerts leading to prompt interventions that might prevent falls or the need for late-night trips to the emergency department. Studies have demonstrated that elderly people are accepting technology in the home, as long as it better helps them remain independent and preserve their autonomy [29]. Although one report has suggested that in the future the acceptability of monitoring technology may decrease with use due to false

alarms or concerns around issues of privacy, there is little evidence at this juncture to discourage the use of these types of assistive technology in the home [30, 31]. Geriatricians may be asked about the use of assistive technology by patients and families, and it is important for all parties involved to be sure they understand what problem is being addressed, who will monitor the alerts, what will be done when an alert occurs, and what contingency plans are available if the technology fails to work properly. Further, the family and healthcare team need to determine if the technology is acceptable to the particular elderly person in the home. Additionally, and also from an ethical perspective, the limitations of the technology should be fully discussed such that the technology is not being relied upon in lieu of other home safety plans, such as visits by family, nurses, or personal care attendants.

In our case, the geriatrician and team may wish to recommend some basic technology to help with Addie's independence in her home, this could include alert devices that when pressed can call family or emergency services. In the future, it will be important for patients and their families to discuss with their clinicians what other technologies could be helpful and acceptable in their homes.

Summary

Technology offers promise to make lives better, but also introduces new challenges to patients, families, and clinicians. Many of these challenges, however, are not unique to technology and ethical dilemmas about information sharing, autonomy, and privacy existed before patient portals and social media. Clinicians can apply existing ethical frameworks and approaches to most of these new challenges when conflicts arise.

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