

Alberta Doctors' Digest

OpenNotes

I was recently diagnosed with invasive cancer and was admitted to hospital on two occasions in the last few months – once due to complications related to the diagnosis and the second time for treatment. This experience allowed me to observe and experience our current health care environment directly, from the point of view of a patient.

Along the way, I met and observed several competent, efficient and caring health care workers, who provided the care that allowed for my discharge, with my condition improved and once again able to tackle the challenges of life. However, I was disappointed to see that our current system is far from having the patient at the center of care. In fact, I am concerned that, despite the genuine concern and high quality of health care providers, the general culture of our system may at times exclude the patient entirely from the decision-making process.

Most of my providers did not share with me what tests were being done, why they were being done, what the results were and how those results would influence my care. I was repeatedly asked the same questions with change of shift, many of which were not pertinent to the concern for which I was admitted. No expectations were set as to when I would see the physician in charge of my case. I note particularly one competent and hard-working resident physician who seemed to spend more time on the computer than he took with me. On discharge, I was presented with a summary which, while factual, was incomplete as it did not include some very important information for my future care, which I could have easily provided had I been asked. Luckily, I have an excellent family physician who provided me with a trial version of a patient portal and who quickly shared all results and notes with me as they arrived, which helped me significantly on this difficult path.

Does the problem lie with culture or technology? I believe the answer to this query is “yes” for both. The idea to make health care more transparent to the patient is not new and was proposed by Drs. Shenkin and Warner in a [New England Journal of Medicine](#) article more than 45 years ago, in 1973. American hospitals adopted a Patients Bill of Rights at about the same time. In 1991, we saw the first electronic health records, after which standards for electronic health care mandated that patients have the right to inspect, review and receive copies of their medical records.

The first patient portals were available in 1998, allowing unprecedented access for some patients to some – but not all – personal health information. The Salzburg Global Seminar in 2001 brought together health care professionals, patient advocates, artists, reporters and social scientists from many nations. They created [“People Power,”](#) a fictional country where patients and health care professionals contribute and share medical records and notes. The work done at that conference became a foundation for [OpenNotes](#), which began in 2010 with 105 primary care doctors from Boston, rural

Pennsylvania and Seattle inviting 20,000 of their patients to read their notes via secure online portals.

OpenNotes now includes more than 33 million patients in the US and Canada, with adoption of this fundamental change accelerating rapidly. Their website includes the following mission statement: “OpenNotes is an international movement advocating fundamental change in the way visit notes are managed. We’re committed to spreading the availability of open visit notes and studying the effects. We believe that providing ready access to notes can empower patients, families, and caregivers to feel more in control of their health care decisions, and improve the quality and safety of care.”

According to the OpenNotes website, the experience for both doctors and patients has been very positive, and evidence supporting sharing notes is building in the following areas:

- Accuracy and safety
 - 25% of patients who contact their doctor as a result of reading their note report a possible error.
 - Patients are reminded of important next steps.
 - Inclusivity and transparency decrease litigation.
- Adherence
 - In 2012, 78% of patients reported that open notes helped them take their medication as prescribed.
 - Patients are more likely to fill prescriptions.
- Stronger relationships, better engagement
 - Doctors felt that sharing notes led to improved patient satisfaction and trust.
 - Patients reported that reviewing notes made them feel better about their doctor.
 - One study showed that 77%-87% of patients felt more in control of their health care.
- Chronic disease management
 - OpenNotes enhance recall and understanding.
 - They allow for review of complex data including multiple medication and treatment changes.
 - Patients can share up-to-date information with their physicians.
- Support for caregivers
 - Caregivers are able to review notes and better manage the health needs of the people in their care.
 - A recent study showed care partners reported similar benefits as patients.
 - OpenNotes can serve as a bridge for patients with limited English-speaking skills or low literacy, or those without computers or Internet access.
- Addressing mental health and illness
 - OpenNotes can build trust and allow patients to feel more understood by social workers, psychiatrists and other mental health workers.
 - Formal studies are underway to analyze the use of OpenNotes as an integral component of therapy.
- New opportunities for efficiency
 - Fewer than 5% of doctors spent additional time addressing patient concerns outside of visits.
 - Most doctors reported not changing the way they write notes. Those who did adjust their note writing felt they improved their notes.
 - Patients who read their notes are more engaged and arrive more prepared at their next visit, allowing for more efficiency for both patient and doctor.

The next evolution in health care will require not simply informing our patients, but instead offering them an intimate view of the status of their own health and allowing them to play an integral role in the decision-making process. The OpenNotes movement provides tools that address both the culture and the technology required to help address this significant gap in our current system. The informative, easily navigated OpenNotes website provides tools and information to allow interested practitioners to begin the journey of inviting patients to be central players in their own health care journeys. I think this will make all of us winners in the long term.