ABSTRACT

In this chapter the author describes the challenges of engaging and communicating with patients and how technology can improve communication, elicit honest patient disclosure, and create more productive conversation and help patients engage and partner in their care. The author will also discuss how research with multimedia programs reveals it can help reduce anxiety, improve knowledge, help low health literacy audiences, and contribute to improved outcomes. This chapter will also examine how multimedia decision aid programs can help patients understand their options and complex risk information, while helping them consider their values and preferences so they can truly engage in shared decision making.

INTRODUCTION

Each of us becomes a patient when we interact with the healthcare system. We all want to avoid pain and suffering, feel better, and have a good quality of life. Beyond that, we also want to avoid adverse events, infections, procedures, and unnecessary costly treatments that drive up the cost of care for everyone. And people definitely do not want to accrue medical bills that put them or their family in serious financial jeopardy (Himmelstein, Warren, Thorne, & Woolhandler, 2005).

Yet, despite the high stakes and their own wellbeing, “patients are the most underutilized resource” in healthcare (Safran, 2004). Why is this?
Unfortunately, even in the best circumstances, patient-provider relationships are beset with challenges. Over the course of a year, clinicians only have the opportunity to spend mere minutes interacting with patients and family caregivers. The challenges are compounded by the patient-clinician power dynamic, health literacy and literacy challenges, as well as, social, economic, emotional and physical stress, not to mention any pain, fatigue, or challenges caused by an illness.

Many people end up at the mercy of poor health, feeling anything but competent and in control. Illness and disease often robs us of our autonomy and diminishes our volition. The process of seeking treatment or getting diagnosed can also be unnerving. For example, if you have chest pain, are you over-reacting or under-reacting if you go to the emergency department? We often lack the knowledge to evaluate the situation and act. In the face of a diagnosis or procedure we want to feel in control and capable of dealing with our circumstances. Instead, even physicians report feeling carried along by a system that makes it harder instead of easier to act or question events.

As kidney cancer patient and Society of Participatory Medicine board member Peggy Zuckerman explains, “Patients would be more likely to communicate with their doctors, whether electronically or otherwise, if there was real encouragement in communication. Right now, much of it is one-way, physician-to-patient, with the physician setting the rules and the agenda. In most other personal encounters, there is a bit of time to create a tone of collaboration. In a medical setting, the time constraints, the culture of paternalism, and the complexity of information to be dispersed and/or shared makes communication more difficult” (personal communication, April 30, 2015).

Yet, each day patients need to take medications, make challenging lifestyle and behavior changes, remember how to do their physical therapy exercises, and show up for important but intimidating procedures, like colonoscopies.

This chapter will explore how poor communication, knowledge gaps and incomplete understanding (the realm of health literacy) and communication affects the ability, interest and motivation of patients to engage in self-care, even at the most basic level.

Then it will look at how technology such as web-based multimedia programs and interactive voice response (IVR) calls, can empower patients to participate and partner in their care and become owners of their health and wellbeing. These tools create an easy, low effort, and less stressful way for patients and families to understand their health conditions and procedures, ask honest and even embarrassing questions, and create the competency and understanding they need to participate in shared decision making. It will also describe research showing these programs can reduce anxiety and improve knowledge as well as clinical outcomes.

BACKGROUND

The term “patient” stems from Old French pacient or “patience” meaning: “quality of being willing to bear adversities, calm endurance of misfortune, suffering, etc.” To be “patient” is to “endure without complaint” (Harper, 2001). This is a historical definition, but it connotes deference, powerlessness, and passivity as well as a need to be firm and unyielding, as if to say: do as caregivers say, but do not give in to pain or despair. Only fairly recently do patients no longer see themselves as passive recipients of care or those who are acted upon, but as motivated partners, or even as advocates who must intervene in their care.