The Patient’s Role in Patient Safety: Starting Early Patients who are involved in their own care get the best outcomes

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Articles and studies have reported this for years. But how do we make this happen and what does it mean? People don’t usually plan to become patients just as they don’t plan on getting into a car accident. Still we buckle up in case someone causes an accident, not because they are bad drivers but because accidents and mistakes can happen. We teach young people to “stop, drop and roll” in case they catch on fire. But how often does that happen? We teach people how to do CPR or Cardiopulmonary Resuscitation before they witness someone having a heart attack, not as it’s happening.

Currently, it is not uncommon for preparation to become a patient to happen after someone has entered the healthcare system either because they are visiting their clinician for a well check-up or have been injured or are not feeling well. By then, the healthcare team is charged with learning someone’s medical history as well as making a diagnosis and then “fixing” the problem — too often the patient sits on the sideline and allows others to take responsibility of their entire medical care. This can be because they are unfamiliar with what their role is or may just be feeling vulnerable, confused or have never been told they can speak up.

This is dangerous, costly and unfair to all the others who are in need of medical care and who have to wait behind those who have left it completely up to the medical professional to get it right – hopefully 100% of the time. This is not about eating right and exercising, or even about “health”. This is about the process leading up to restoration of good health: health care.

Most people are not taught to be well-prepared patients. At the age of 18 children are legally adults, and parents have no legal rights to make medical decisions for their adult children should those children not be able to make such decisions themselves. A missing piece of that transition to adulthood is learning how to be a well-informed patient. Young people could learn this in their high school health classes. That would be a start in changing the current situation: medical errors being the third leading cause of death in the United States [1].

High school health classes can teach young people about advance directives — the process of choosing the person who will speak for you if you can’t make your own medical decisions. They can learn about Karen Ann Quinlan, the twenty-two-year-old woman who was left in a permanent vegetative state after lack of oxygen caused irreversible brain damage. This well-known case, which introduced the concept of the “right to die”, could become part of a high school history lesson while encouraging young people to become better prepared as patients [2].

Young people can also learn about medication safety. According to the National Association of the Boards of Pharmacy the risk of a 15–19-year-old experiencing medication poisoning is six times greater than that for a 1–4-year-old. The Association recommends that teens be taught to read drug labels and to understand the importance of taking the correct dose of medication [3].

Another important step towards being better prepared as a patient is to make a list of questions for the doctor ahead of time. That might mean confiding in a close friend or asking a family member to assist. 80,000–160,000 people in the US suffer permanent disabilities each year as a result of misdiagnosis. Planning ahead by listing symptoms along with questions, and listing any new medications, can help reduce the risk of misdiagnosis [4].

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Having an advocate or being an advocate for others also builds on the team of people assisting in a person’s care, which can lead to a larger support system.

The role of the patient and the patient’s family plays a crucial part in care outcomes. Training — whether in school, workshops, online, or in classes such as Pulse Center for Patient Safety Education & Advocacy www.pulsecenterforpatietsafety.org has offered for almost twenty years — can help anyone be better prepared for the day they become a patient.

Pulse CPSEA is presently promoting the TakeCHARGE Campaign — 5 Steps to Safer Health Care (www.takecharge-care.org), a community-based (not hospital-based) campaign that encourages people to be more active and responsible as they transition from being healthy to using the healthcare system.

Just months ago, people were not thinking about being patients just as they were not thinking about how to exit a plane if there were an emergency landing. Still, when we board a plane, we are taught what to do in an emergency. How to work our seatbelt, the oxygen, where the exits are, and even the life jackets that we all probably know by now are under the seats. Yet, how often is that information used? Being a patient and experiencing injury from mistakes in health care are much more common than a plane crash, but there is no preparation for those as there is for air safety.

People who are not well informed and prepared are taking away important time and resources from our healthcare system and the economy. The extra time a doctor needs to spend with an unprepared patient is taking time away from another patient. One study reports that the cost of medical errors can be as high as $617 million in excess insurance claims [5].

A recent post about causes of death in the United States lists heart disease as the number one cause and COVID–19 as the second–greatest cause of death, moving cancer to number three with no mention of medical errors on the list. Medical errors, which are not listed on the death certificate, may be left off some reports but the reporting is there, done by researchers, not by the news, patients or attorneys. We need to be taking medical errors more seriously and starting education earlier [6].

References

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