Patient engagement: Reality or annoyance?

By Lori Hartwell

The primary goal of the health care community is to improve the health of their patients by addressing physical ailments, mental health, and overall quality of life. Data have consistently shown that patients who are engaged as active participants in their own care typically have better morbidity and mortality outcomes, as well as a better quality of life. The importance of the patient's opinion in evaluating the latter component of care has been highlighted by the movement toward patient-reported outcomes as the standard for evaluating how a therapeutic course is affecting the patient's quality of life.

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While the health care literature consistently heralds the importance of patient empowerment, patients who try to express their opinion can sometimes receive verbal and nonverbal messages from health care professionals that discourage involvement in care plan decisions. The following provides a series of examples that illustrate how patients with chronic kidney disease may deal with day-to-day issues that are important to them, and how health care professionals may respond to help encourage patient empowerment.

Patient emotional stages

Patients with a chronic disease often pass through an emotional spectrum that typically progresses through the stages of denial, depression, anger, and acceptance. Health care professionals should be aware of these emotional stages and the fact that a patient's acceptance of educational materials may only occur once a patient has internalized and accepted the need for change. When health care professionals don't acknowledge the emotional roller coaster that patients experience, that can exasperate patient anger. Health care professionals may have to demonstrate extra patience and compassion during this stage of the patient's evolution—maybe by just lending a heart-

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felt sympathetic ear. This also represents a prime opportunity to encourage patient empowerment. Remember that anger typically arises from the patient's feeling that they are losing control of their life.

Limiting lifestyle benefits

Disallowing simple conveniences of daily life during a patient's time on dialysis can be very disturbing for patients and diminish their feeling of self-control. One example is the policy that cell phones are not allowed during treatment. One would suspect that it could be annoying and distracting to health care professionals and other patients when cell phones are ringing during treatments. From another view, dialysis facilities should offer a dialysis experience that encourages patients to stay empowered. The patient on the cell phone could be attempting to conduct business, deal with family matters, or otherwise stay actively involved in his or her life. To ensure that cell phone calls are not inconveniencing their neighbors (or the staff), a compromised approach requiring that patients keep their cell phones on vibrate and limit their calls to brief conversations could be considered.

Care with cannulation

Patients have a choice of where they dialyze and are often particular about who cares for them. A patient may come in and request that a particular dialysis technician/nurse stick them. Understandably, the dialysis facility may have a protocol that sees this kind of request as being impractical from a staffing perspective. But dialysis facilities should also strive to understand the patient's perspective. Patients realize that the vascular access is their lifeline, and many have had unpleasant and potentially life-threatening experiences when problems arose related to their access. Empowered patients are therefore protective of their access.

While a dialysis facility's policy not to give in to patient requests for a specific staff member for cannulation may be understandable, requests for a particular staff member should not be routinely dismissed. Such a response may diminish patient confidence in the dialysis staff, while hindering empowerment and patient adherence.

As an alternative to requesting a familiar technician, the facility could also offer to teach patients to self-cannulate to help them overcome their fears.

Time (what time?) on dialysis

Understandably, it's hard to accommodate a patient's scheduling request. But instead of responding with an apologetic negative response, the dialysis facility can provide other alternatives. Examples could include educating patients about home treatments or providing a bulletin board where notices can be posted to see if another patient would be willing to switch their schedule. Such an approach could be especially important to accommodate patients who are still able to work.

'It's cold in here.'

Patients need to be made aware up front that they will often feel cold during dialysis. Most dialysis facilities no longer provide blankets, but staff members can encourage patients to bring their own blankets, warm socks, or scarves.

Be consistent on patient information

It is important that all members of the health care professional team deliver the same information. For instance, a patient may hear from their dietitian that it is okay to eat high potassium foods in moderation, while their doctor may tell them to avoid all potassium foods. Meanwhile, the technician may tell the patient what foods are high in potassium in a way that conflicts with information from other team members. Dialysis facilities need to develop policies and procedures that provide cohesive educational information with consistent messages from all staff members.

By acknowledging the importance of patient feedback, dialysis facilities can help empower patients by providing them with a sense of their own importance. In contrast, I suspect that if the patient perceives that their treatment has gone poorly several times in a row, they'll have a higher likelihood of not showing up for dialysis. This is the ultimate disengagement.

Patient engagement may be a bit more time consuming, but the rewards are unparalleled. There are five simple steps to remember that will help you to engage your patients: Listen, smile, respond, thoughtfully, encourage, and provide hope. Learn by example, and people who have kidney disease can learn to be engaged when they see fellow patients who are actively involved in their own care. And engagement is even more likely if patients see and know that their health care team is encouraging and fostering patient involvement and empowerment.

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