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Try Abiding Instead of Hiding: An Approach to End-of-Life Care

As a certified geriatric, hospice, and palliative care nurse practitioner, I'm required to do quality-of-life (QOL) gatherings and palliative care rounds. These gatherings and rounds focus on palliation, palliative care education, and symptom management. I also collaborate with the hospice staff and patients and their families. In the performance of these duties, I have learned that *abiding* is a key palliative care concept.

We are the advocate for the patient, and sometimes we must make difficult decisions and get involved in family issues. Many of us have a tendency to avoid and hide from these difficult cases, making excuses, such as we are too busy or someone else can do it.

This article focuses on true "abiding" and my personal journey in learning and teaching others about abiding, including the lessons that must be learned when delivering palliative care. I show that with care and intentional abiding, the delivery of important palliative care modalities can be effective, profound, and positive.

AN OUNCE OF PREVENTION

Remember the adage, "An ounce of prevention is worth a pound of cure"? Often, this proves to be true. One of my nursing teachers once asked us, "Why is it we always run away from those things that can truly free us?" It's human nature to take the easy way out; however, the irony of doing so is that the easy way can potentially cause problems and create more work later. This challenge also occurs for a hospice team in educating other providers to "abide."

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Many times, family members come to us expressing their anger, feeling as though they are being shut out. Everyone on the team wants to avoid these families, and they are labeled "difficult" or "unreasonable." We schedule a QOL gathering with them, and afterward a metamorphosis occurs. Often these very same families become the most loving, easygoing, and memorable ones we have ever had. They are grateful that we recognized their pain, hurt, and anger. When we make the effort to practice abiding, deeper, powerful relationships develop, and everyone is happier, more content, and more fulfilled.

ABIDING VS HIDING

Abiding

Abiding is a complex word in many ways and one we don't often hear. When I was new to the hospice and palliative care practice, the director of our hospice program urged me to learn more about its meaning. She instructed me to make "abiding rounds." At first, I was puzzled and looked up *abide* in *Merriam-Webster's Collegiate Dictionary*[1] to get a clearer understanding of what she wanted of me. I found several definitions:

> Verb (1) to wait for: AWAIT; (2) a: to endure without yielding: WITHSTAND; b: to bear patiently: TOLERATE; (3) to accept without objection; intransitive verb (1) to remain stable or fixed in a state; (2) to continue in place. The synonym directed me to see *stay, continue, bear*; and the meaning of *abide by* was to conform to or to acquiesce in. Further, the definition of abiding included *enduring* and *continuing*.[1]

Now that I understood the definition of the word, my challenge was to put it into practice. Our director asked me to take notes and reflect on how I abided each day.

Our director, Deborah Grassman, a well-known national speaker and teacher of hospice and palliative care, realized the importance and value of end-of-life care. Her book, *Peace at Last: Stories of Hope and Healing for Veterans and Their Families*, includes an in-depth discussion on abiding, reckoning, and beholding and entire chapters that stress the importance of these end-of-life concepts.[2]

The concept of abiding is the cornerstone of hospice and palliative care.

Abiding is mentioned in the Bible and throughout history.[3] Abiding is part of servant leadership as well.

When I think about *abiding*, I normally think about abiding by rules and laws. I don't normally think about abiding by others needs, wants, and wishes. I also relate abiding to compassion or empathy, but in a different way: Before my research into abiding and my abiding experiences, I didn't consider abiding an important, integral part of the human condition. I also didn't appreciate the impact that abiding would have on my practice or in my personal life. I discovered that abiding is an abstract concept and less literal, albeit very important.

Palliative care teams need to practice abiding in all their interactions: with their patients and their families, with other staff members, and most of all in QOL gatherings. However, abiding takes thought, effort, and abstract thinking, and spiritual and philosophical consideration. Literal thinkers must learn new ways to become aware of abstract and metaphoric behaviors and occurrences they may encounter, as these are significant and fulfilling.

Teaching Abiding

National initiatives are under way to increase palliative care and hospice services throughout the country. However, a clear-cut teaching plan that makes palliative and hospice care meaningful and successful is necessary. The challenge is to teach the staff right from the start that abiding is an approach worthy of their consideration.

Hiding

I have no doubt that hiding hinders abiding. In various ways, many of us have mastered hiding. We hide behind our laboratory coats, education, beliefs, experiences, and administrative positions, to name a few. We hide because we know some subjects may be uncomfortable to address and talk about. Often, we do not want to take the time needed to address the difficult problems that arise with patients and their families. We may feel, "Oh, that's someone else's job." We also hide because we have pain from our own past injustices, death of a loved one, or other issues. We hide because it's easier than confronting a deep, complex issue.

We hide from confrontations because avoidance is easier than facing the problem.

We are sometimes taught hiding techniques as we go through life. We model our parents, our peers, and our superiors. We hide from our parents, bosses, children, and others. Hiding is widely accepted, and many of us might not even know we are hiding, because it has different labels, such as "time management" and "remaining professional." We hide from confrontations because avoidance is easier than facing the problem. Whatever we label it, we're still hiding.

ENHANCING QOL

At the daily QOL gatherings, the focus is on QOL issues and meeting the needs of patients and their families. The informal, relaxed gatherings last about 30 minutes. Physical, emotional, and spiritual pains are explored. We also ask patients about their most pressing needs and talk about the impact of their military history. The patient guides us, we don't guide the patient.

The gathering is not a forum for teaching but for listening. The patient can ask anyone to attend, and anyone else who wants to attend is welcome. A plan is then formulated, depending on the information gathered, then clearly documented and discussed with the hospice teams. This forum results in true abiding and a happier patient. A happier patient usually equals a happier family and staff.

LETTING GO

A key concept of true abiding includes "letting go." Letting go refers to letting go of your own issues, beliefs, experiences, and feelings. True abiding means that you put yourself in another person's place; in that person's shoes, state of mind, and spirit. You have to think and be like that person. This psychological transformation is not an easy feat and can be uncomfortable. Letting go takes effort, intention, and practice. Once you have let go, you feel different. Here's how I know.

My Epiphany

One day I realized I had finally experienced true abiding. I was feeling stressed and tense before going into a patient's QOL meeting. My jaw was clenched and my shoulders and neck were in a knot as I entered the room. All tension slipped away, however, when I looked at the dying patient. I felt the stress leave me and thought only of the patient's and the family's issues.

I sat down and thought, "Wow, now I know what this abiding thing is about." I had let go of the 3 admis-

sions that were due, the discharge that was going home, the several notes, the QOL meetings, orders, and consults I had to do after making rounds, my meeting at noon, and all the other duties I was expected to complete that day. I was astounded by that feeling and felt liberated and at peace. My mind was open and accepting. I no longer felt stressed when I thought about the long list of tasks ahead of me that day. My hands relaxed, my jaw and neck were no longer tense, and I seemed to melt into my seat. Death and abiding with it made other daily tasks seem minimal, and I almost felt guilty about fretting over these things. Nothing was more important at that time than the patient's and family's needs. It was their death experience, and I felt honored now to be a part of it. I also realized that when I let go, I helped my patients and their families to let go.

PUTTING ABIDING INTO PRACTICE

Body Language Speaks Louder Than Words

Another key element when intentionally abiding is being aware of body language. Standing with your hands on your hips does not relay a true abiding approach—neither does poor eye contact, ringing phones, multiple conversations, talking over others, loud talking, and pagers going off. These distractions undermine abiding and weaken its foundation and power.

Open Up

Once you enter the room, close the door, take a seat, shut out the world, and be open and accepting of where you are at that moment. Open your eyes, ears, mind, and most of all, your heart. Put yourself at the same eye level as the patient: Standing over someone and looking down on the person is just that. The patient may think you are an authority figure, you're not approachable, or have feelings like "You think you're better than me," or "I don't count as much as you do."

I recognize these feelings and thoughts, because I have been that person who has felt dismissed and devalued by another person. These feelings do not encourage open dialogue or effective communication. They hinder it. By opening up, you will help the patient and the family to open up.

Be Flexible, and Go With the Flow

At a QOL meeting, you have to learn to go with the flow. For instance, your voice modulation and approach are important. When someone is dying and the family in the room is quiet and somber, it is inappropriate to enter the room boisterously or laughing. The patient and family guide the interaction. Sometimes, a quiet presence is enough. Other times, the family may want a celebration of life while the person is still alive and is able to enjoy it. In this instance, the QOL gathering may be upbeat with music, storytelling, and laughter. We also have QOL gatherings that go from one extreme to the other, which is also fine. Flexibility is key.

Ensure a Comfortable Environment

As mentioned earlier, the seating arrangement is important. Often, you enter a room to find not enough chairs. Make sure everyone has a chair or bring in more, such as rolling chairs. Also, although we are taught in nursing school that we shouldn't sit on the patient's bed, in hospice and palliative care that is acceptable. Of course, in abiding fashion, we should ask the patient's permission. We also urge the family to sit on the patient's bed. This request may seem to be a simple one, but human closeness has a positive effect while abiding and should not be dismissed or minimized. Being at the same eye level as the patient is immensely powerful for both.

CONCLUSION: A VALUABLE LESSON

Abiding can be a powerful tool for hospice and palliative care professionals. Abiding builds trust, open communication, the respect of others, and self-respect. It shows that you are really listening, meeting people's needs on their terms, not yours.

At times, I still forget to practice abiding, and when I do, I do not feel the same level of peace and fulfillment. Abiding is a way to experience the human condition in a new light. When I truly abide, I know I have served my fellow man in a better way. Abiding has affected not only my hospice and palliative care practice, but also every aspect of my life. Abiding, instead of hiding, builds unforgettable experiences. ●

Author disclosures

The author reports no actual or potential conflicts of interest with regard to this article.

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