

Whispering in the Shadows: A Hospice Social Worker Learns to Ask About NDEs

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Claire is giving me the look. I've seen it before. It's the look I sometimes get after asking hospice patients if they've ever experienced anything strange, anything for which they had no conventional explanation, during the course of their terminal illness. It's that look that says, "Well, actually, yes. Why are you asking?"

"There was one thing," she says tentatively, looking for signs that it's safe to continue.

"Would you be willing to tell me what happened?"

"I never told anyone about it, except for my husband."

"It's entirely up to you. There's no pressure," I assure her. "If you're comfortable sharing it, I'd love to hear about it."

On the surface the interaction is casual, but underneath, messages are being sent – this is important; something to be taken seriously. Her eyes are testing me – can I trust you? Are you going to judge or try to explain away something that's meaningful to me? Will you think I'm crazy?

When I first began asking patients about such things it surprised me how often they responded with a story. I guess it shouldn't have been a surprise, given what many had gone through prior to coming to hospice service. Over the course of multiple hospitalizations and visits to the emergency room, not to mention invasive, potentially dangerous medical interventions, a fertile ground had usually been laid for such experiences.

I heard about Near-Death and Out-Of-Body Experiences, visitations from deceased loved ones, the appearance of guides and spiritual beings, unexplainable synchronicities, transformative dreams, unusual animal behavior and occurrences in the natural world that seemed to deliver personal or transpersonal messages.

Though these stories no longer surprise me, I continue to be mystified that patients are not typically asked about such things by medical professionals. And I am saddened by how regularly it seems that those patients who choose to share such experiences with their medical teams have them dismissed as meaningless anomalies caused by physiological, pharmacological or psychiatric factors.

It's no wonder many people do not disclose such events to medical staff. When professionals are not receptive – by ignoring conversational cues or dismissing reports offhandedly – we are missing an opportunity to more fully explore

the nature and prevalence of such experiences. And we are missing a chance to engage patients in potentially important conversations as they navigate their final weeks and days.

Why don't more healthcare professionals, particularly those in end of life settings, ask about such things? I can't speak for others, but I can reflect on my own challenges in this area. As a hospice social worker, I was in a better position than most to ask about such things, but it was many years before I recognized the extent to which these events were occurring, started taking them seriously, and mustered the nerve to begin asking about them.

Although many in palliative care view NDEs and other end of life experiences as a normal part of the experiential continuum at life's end, there is a pronounced lack of training when it comes to such phenomena. When I was orienting as a new hospice social worker, combing through articles and talking with other professionals, I came across little about such experiences. Those references I did see equated NDEs and OBEs with disease physiology indicative of a dying brain. In over twenty years working in hospice care, I was never offered any formal training in recognizing or processing with patients and families these kinds of experiences. Such an omission not only fails to alert professionals to the prevalence and potential importance of these events, it implies that they are beyond the range of normal concerns – interesting perhaps, but of little or no importance.

In a study by Fenwick, Lovelace and Brame, palliative care professionals were interviewed to gauge their knowledge and assess their beliefs about a range of unusual end of life experiences (ELEs). Over 90% of those interviewed expressed concern about their lack of education in this area. Most thought the subject should be a standard part of staff orientation and ongoing training (Fenwick et. al., "Comfort for the dying: five year retrospective and one year prospective studies of end of life experiences." *Archives of Gerontology and Geriatrics*. 2009).

With no training, I was unprepared when I initially heard patients talk about such things. Though I tried to listen compassionately, inwardly I dismissed such reports as the wishful thinking of frightened individuals looking for consolation. By then, I knew there was a collection of sophisticated sounding explanations aimed at reducing these

experiences to little more than imagination or the impact of disease states. I assumed one or more of these purported causes had already been proven. You know the list – anoxia, hypercarbia, delirium, endogenous opioids or DMT, disease-related alterations in cognition, neuro-electrical activity, morphine, wish-fulfillment, waking dream states, dissociation, depersonalization, genetic programming, reactive stress responses — and the list goes on.

Two things changed my understanding. The first is beyond the scope of this paper. It has to do with the way working with people who were dying led me to question some of my assumptions about the nature of “reality.” The other reason was a patient who had been stung by the lash of these sophisticated-sounding explanations.

Joe had a classic near-death experience while on the operating room table – consciousness left his body, traveled to another realm in which he met his deceased parents, and he experienced a sense of being loved unconditionally. He returned with a new sense of peace about life and death.

“That’s when I made the mistake of telling my doctor,” he recalled. “He basically told me I was crazy when I tried to explain what I saw. He said it was lack of oxygen or chemicals in my brain and wouldn’t listen to another word I said.”

What struck me about Joe’s story was not only the genuineness with which he spoke, but the lingering feeling of hurt at what he perceived as his doctor’s “harsh” dismissal. It got me thinking about the dangers we in healthcare tread when we presume to understand the nature and meaning of a person’s experience better than they do. Such assumptions and judgments, particularly when made about experiences with a deep personal meaning to our patients, can wound in ways we do not intend.

I realized that even though I wasn’t contradicting patients when they raised the topic, in my mind I was grafting onto their experiences my own story about what was happening rather than accepting their right to decide for themselves what they had seen and what lessons and messages they had received.

This realization changed the way I listened. Thereafter, whenever the subject arose, I practiced suspending the voice in my head with its silent doubts and focused on understanding NDEs from the point of view of those who had had them.

I wish I could say that this was the point at which I began asking patients directly about whether they had had such experiences, but it was not. I just wasn’t comfortable with

such conversations and, frankly, it seemed easier to avoid them. I assumed these phenomena were very rare, and worried that if I started asking about them people would think I was nuts. I was even concerned that asking about such things might undermine my professional credibility with patients and families, not to mention my colleagues.

As I got better at listening with an open mind, I began hearing more and more reports. Maybe people picked up on my increased receptivity. Maybe, on some unconscious level, I stopped trying to avoid the topic or steer the conversation in other directions.

I began wondering if NDEs and other deathbed phenomena were as rare as I had surmised. I decided to take a look at some of the research, hoping to find some reliable prevalence estimates, expecting to find mountains of empirical data showing this or that physiological mechanism at work.

Though I found some studies claiming to have isolated a biological or psychological cause, these were less plentiful than I had imagined and very far from convincing. Many were so narrowly defined that, even if taken at face value, they could only explain a small part of a typical NDE – the sense of separating from one’s body, for example, or seeing a tunnel or light. Some were opting for a multifactorial explanation but the gyrations necessary to explain such events as simultaneous physiological processes occurring across multiple systems of the body (all orchestrated to create such a profound and coherent experience) seemed unlikely.

There were cases in which consciousness had been demonstrated to exist under conditions in which current brain science would have us believe consciousness is impossible. I found myself agreeing with Kelly, Greyson and Kelly, who pointed out that until those positing materialistic causes can reconcile these facts, such explanations would be little more than “ill-founded neuroscientific and psychological speculations.” (Kelly and Kelly. *Irreducible Mind: Toward a Psychology for the 21st Century*, 2007, p. 421.)

Though there were no definitive studies, I was stunned to find there was actually systematic research suggesting that these events represented phenomena which cannot be satisfactorily explained using biological or psychological models. I walked away convinced that the evidence tilted in favor of the conclusion that NDEs are objectively real events illustrating the survival of consciousness beyond death.

Again, I would love to say that this profound turning point was the moment at which I began asking patients directly about such things. It was not. But learning more about the details and patterns of NDEs, and confirming that they occurred frequently, increased my comfort level when the subject came up and enhanced my ability to explore such things with patients in a way which seemed helpful. It also emboldened me to begin asking hospice colleagues about what they were seeing. Nearly all of them had heard of such experiences from patients and families, though they rarely, if ever, asked patients directly about them. A majority believed these were objectively real events of a spiritual nature but they were reluctant to admit this among professional peers, and especially among doctors, for fear of ridicule.

It dawned on me how pervasive and intimidating the medical model of care can be with its reductive, materialistic and mechanistic approach to illness. Here I was, surrounded by professionals who suspected something was going on which defied materialistic explanations, and we were all afraid of speaking up, self-conscious, as one nurse put it, of “looking soft or loopy.” All of us were merely whispering in the shadows. If such fear existed among hospice professionals, I could only imagine what it might be like for those working in the emergency room, trauma, oncology or intensive care units.

Looking back, I see that the potential barriers to professionals creating a safe space for patients to speak openly about NDEs and deathbed phenomena are formidable: lack of knowledge about the nature of such events; little or no training in how to initiate and have such conversations; assumptions that negatively affect our ability to listen and impede our willingness to let patients decide for themselves what their experiences mean; and fear of appearing naïve or unprofessional. Add to these the hectic pace and multiple demands on one’s time, a medical culture which often has rigid assumptions about “reality,” and demands that medical staff exhibit expertise and knowledge by focusing on the physical body. It’s no wonder so few doctors, nurses and social workers seem to be asking about these mysterious, construct-shattering experiences.

Here’s the paradox: NDEs and related events can be of great importance as patients come to terms with their impending deaths, yet this is an area often ignored or regarded as off-limits to healthcare providers, unless patients bring it up first.

When I finally began asking patients about NDEs and other ELEs, it transformed my practice. No one accused me of being nuts or unprofessional, even among those for whom

such events were ajar with their worldviews. Whether they’d had such experiences or not, most appeared comfortable with the question. Approximately one third responded by sharing some kind of experience (I did not keep an exact tally, and it was not a random sample since it consisted only of those patients I chose to ask). Though some were troubled by these experiences and others dismissed them as symptoms of physiological dysfunction, a majority saw them as objectively real events which held deep personal meaning and which brought them and their loved ones great comfort.

Many had never spoken about these occurrences or had done so only sparingly, choosing silence over the risk of being dismissed or misunderstood. This included a surprising number of combat veterans who’d had NDEs and related experiences, decades earlier, during times of war. The value of openly discussing these experiences was profound. For most, the event brought a sense of peace or happiness, and reduced fear of death. Many found valuable insights in the wake of these events, and gained perspective on how they wanted to live the remainder of their lives. It was common for people to express relief at being able to talk about what had happened without being judged.

To say these explorations have transformed my practice as a social worker is only part of the story. In a larger sense, they have transformed my life. Although I’m still a big fan of research, I no longer look exclusively in that direction when it comes to making sense of NDEs and other deathbed phenomena. I’ve talked with enough patients who have glimpsed into these unseen realms that I’ve learned to trust them. I’ve seen how their lives are changed for the better. I’ve heard the genuineness in their voices and seen the look in their eyes. For some, I have borne witness to the difference in their lives before and after such experiences occurred. In some cases, I’ve been at their bedsides as visitations, visions or travels were taking place.

I don’t mean to imply I’ll no longer look at the research or that my mind is closed to new empirical data. But for me the best data has been the lives of many dozens, maybe hundreds, of men and women who have looked beyond the threshold into an unseen world. I hope one day it will be standard for professionals in healthcare, geriatrics, bereavement care and trauma counseling to receive training and education in this area. You never know what you’ll find or how your life will change when you’re no longer afraid to ask.

For more information about NDEs — www.IANDS.org