

Palliative Care: Communication and the Patient Experience

Case Example: The Patient Experience

Daughter:
You need, anything, Dad?

Father:
No, I'm fine - thanks, honey.

Daughter:
Okay.

Father:
I'd like to take some time with the doctor.

Daughter:
Okay. I'll see you in a few minutes.

Father:
Okay. Thanks.

Daughter:
Bye.

Father:
Bye.

Father:
She goes home tomorrow. That's life.

Doctor:
Mmm hmm.

Father:
I sit here day after day. Can't get up. Can't relieve myself. And some stranger has to come in and wipe my ass.

Doctor:
Are you experiencing any pain?

Father:

The pills work; they don't work. But the team has been good. But you and I know what's coming next.

Doctor:

If there's anything that we can do...

Father:

Doc. You seem like a take-charge kind of guy.

Doctor:

Jerry, I'll bet you were always a take-charge kind of guy yourself.

Father:

Take that away, and what have you got. Think about it. Would you like to live like this?

I think I have to take charge again.

I'm going to take control once and for all. I've got a question for you: if I do that, take charge, you know, pills, can you help me?

Daughter:

Oh. I can't believe I forgot.

Father:

For this, I'm going to need some help. You know what we're talking about, don't you. [He wants the doctor to help him end his life.]

Host:

Let's talk about dying. Death and dying is a hidden topic in our society, shrouded in fear and ignorance. Attitudes toward death are highly personal and can be affected by cultural taboos and religious beliefs, or witnessing a bad death of a relative or friend. There is no one-size-fits-all when talking to a terminally ill patient. They are dying, and this is a uniquely personal experience.

A palliative patient has no previous experience of being terminally ill. On the other hand, palliative staff have insight into the clinical realities that patients may face. Preparing and supporting patients through these difficult physical and emotional challenges, are keys to good palliative care. It should start as soon as a terminal prognosis is known. Palliative care professionals need to employ a wide array of skills to uncover patient anxieties, needs, and fears. This requires both verbal and non-verbal communication. Trained as a nurse,

Nicky Barton provides one-on-one advocacy and palliative care support to patients, both in the community and the hospital setting.

Nicky Barton:

It was while supporting a friend through her three year journey with liver cancer that I truly understood the impact of poor communication on end-of-life care. Although nursing taught me good clinical care, providing this informal support allowed me to see how simpler human needs were critical to a quality of life. Whether reducing her anxiety by bridging misunderstandings between her and the palliative team; mediating complex family issues; clarifying medical jargon; or simply ensuring she had warm bed socks for her cold feet, the issues were varied and unique to her. Seeing patients as individuals is absolutely critical.

By using the same observational and listening skills we use in our clinical care, we can begin to understand our patients' deeper needs, and thereby build a level of trust. As their illness progresses, I believe this trust is the most precious aspect of good care. Despite the growing demands our palliative teams face, in my experience time taken to rectify errors caused by poor communication far outweigh the time needed to adopt effective communication skills at the start. There's no question that pain- and symptom-management are the primary goals of palliative care. However, the message from many patients reflect their need to be heard; to be spoken to honestly in words they can understand; and to be given at least some autonomy over their daily lives. The following quotes and reflections are drawn from observing, listening to, advocating for, but more importantly learning from patients and friends as they live their final days. I'm humbled by their generosity in trusting me enough to voice their feelings honestly, and am grateful for the lessons learned; not only about dying but about living those final days with dignity.

Host:

Getting to know the patient is the first step: if you don't know the person, you cannot hope to meet their unique needs. We will explore how good communication can encourage patients to be part of their treatment; support a patient with their emotional stress; provide a sense of normalcy; and build trust. And we don't always get it right.

Voiceover:

"As soon as everyone knew I was dying it was as if they spoke to me through a filter. There was a barrier between us, as if I was a different species. I just longed for people to be real with me."

"Our family knew my sister was very ill. The doctors tried to explain what was going on but they used long words to explain her diagnosis. No-one talked about her dying. We were confused; we didn't know how to process the information we were given. It was such a terrible shock when she died two days later."

Host:

Poor communication between patient and healthcare professionals exacts an emotional and physical toll on both patients and their families. Healthcare is a partnership between practitioners and the patients receiving care. Usually the aim of the team is to restore health. In palliative care the focus changes to optimizing the quality of life for a dying patient. Each patient has different needs over and above the universal requirement for pain- and symptom-management. In order to understand and meet these needs, clear communication is crucial. Words such as 'dignity', 'respect', and 'support' are found in most palliative care mission statements. The depth of understanding needed to implement these aims successfully requires clinical skills and the art of connecting on a profoundly human level. If we as professionals attune ourselves to the signals our patients give us, and use these to build a trusting relationship, we quickly learn that the palliative patient is crying out to connect in a meaningful way. We may not change clinical outcomes, but we can bear witness to and honour the dying process that is unique to each patient.

The goals of palliative care are to: provide patient-centred care that supports the best quality of life; relieve pain and suffering through pain and symptom control; and encourage patients to be part of their care. Good quality of life can only be determined by the individual facing the end of their life. It's a complex issue that includes physical and emotional care; family burden and burnout; social isolation; diminished independence; and financial concerns.