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“Good Deaths”: The Role of Healthcare Professionals in Facilitating Peace in the Last Stage of Life

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I have spent most of my 25 years as emergency physician, caring for people in crisis. In recent years, I have found my true calling as a physician devoted to caring for and supporting people with complex and terminal illnesses in their own homes. Over the years I have witnessed “good deaths” and “bad deaths.”

In the course of my work, and through my discussions with patients and family members, I have identified five primary needs that are universal among people at the end of their life. In my experience, when these needs are adequately met, the final chapter of life can be a meaningful, healing time, both for the person whose life is ending and the loved ones they leave behind. This kind of death could well be considered a “good death.” A “bad death” results when one or more of these needs goes unmet, and the opportunity for a peaceful, healing, transformative end of life experience is lost. “Bad deaths” can be challenging for everyone involved, often leaving lingering regrets among surviving loved ones. Once a loved one dies, there is no way of unmaking the decisions we made or undoing the things that were done while they were still alive.

I believe that it is possible to facilitate “good deaths”; This is why I choose to write and speak about dying, and a large part of why I developed my current medical practice. My goal is to ensure that we get it right while we can, so people have the best possible experience as their illness progresses and their life comes to a close, and those left behind can feel that they did everything they could to create that experience.

For the caregivers of a person with a complex or terminal illness, it can be very difficult to accept that there are no remaining cures and that death is imminent. Knowing how to make their loved ones' days more peaceful is empowering. As a professional, my goal is to help loved ones understand the following needs of the ill and dying: (1) Dignity; (2) Understanding; (3) Choice/Autonomy; (4) Planning; (5) Comfort, In my opinion, if these needs are fulfilled, death can be a peaceful experience for everyone involved.

Dignity : We are cared for with awe and reverence at the beginning of our lives, cuddled and sung to, admired and loved. Should we not receive just as much reverence and awe as our life comes to a close? Dignity is critical for a successful and transformative end-of-life experience.

At the end of our life, if we are treated with love and appreciation, we will feel dignified. It

shouldn't require any more explanation than that. People who are loved will not be allowed to remain in urine-soaked clothing; they won't be left in isolation or allowed to be in unremitting pain. People who are loved and appreciated—treated with dignity—will receive adequate attention to make sure their needs are being met.

Understanding: People need to know what is happening to them and be told the truth. Well intentioned medical professionals, and certainly, family members and friends often withhold information from a person who is dying in order to offer some sort of hope, or to keep them from feeling upset or sad. Ironically, in these situations, the person who is dying is usually aware that the end is near, and they they are not being told the whole truth. There is a sense of mistrust or betrayal that permeates the relationships in these settings, and the atmosphere becomes more stressful and less healing. Lack of understanding breeds fear.

Dying takes courage. People have a greater ability to handle “bad news” than most people think they do, especially when it relates to themselves and their mortality. We have greater difficulty accepting and dealing with bad news about others than we do about ourselves, which is a major reason why these honest conversations may not take place. It is less often that the individual can't deal with it, and more likely that the family members just aren't comfortable confronting the truth head on.

Creating an atmosphere of truth, honesty and open sharing is one of the pillars of a healing and transformative end of life journey. It can be difficult to make the leap, especially for families who have historically been emotionally reserved and distant. Families may need some guidance and support to start more open conversations, which can then lead to positive emotional changes among all involved.

It is also imperative that the medical professionals actively facilitate honest communication and ensure understanding among patients and family members. They often allow the patients and family members to lead these discussions and only reveal as much information as they are asked to, relieved to say less when allowed. But patients and families will frequently need more information down the line, when it is not readily available from a trusted source, so they will seek that information from less reliable sources. It is our responsibility as health professionals caring for people nearing the end of their lives to make sure they have all the information they need to make the best possible decisions and avoid the typical traps that befall those who are ignorant of this information.

Choice: People want autonomy, i.e., the ability to choose what happens to them for as long as possible. Even in the situation where someone is told their illness has no cure, choices exist. Despite our best intentions, making a choice for someone else robs them of dignity, which can have a devastating impact on a person going through the final stages of their life.

Choice is closely tied to understanding. People can only make appropriate choices about their care and their life when they have a clear understanding of what they are dealing with.

Choices differ depending on the projected time left to live; a person given three weeks to live will make very different choices than one given three years. Choices also depend on one's personal values, which may be different from those of loved ones. While a loved one may focus on prolonging the patient's life, the patient himself or herself may focus on their quality of life. For example, if a course of chemotherapy will likely allow them to live for another two months, but will make them weak and nauseated and unable to do what they enjoy, they may choose not to undergo treatment to better enjoy their time in the present. Indeed, research shows that people tend to choose *quality* of life over *quantity* of life. I have found this to be consistently true in my own professional experience.

Each situation and each patient will be facing different choices, but the concept applies to every situation; giving a person as much free choice as possible near the end of their life is critical for creating the most positive, nurturing and transformative experience possible.

A Plan: In my experience, this need varies among people. There are people who do not need to have a well-developed plan as they approach their final days of life. People who did not set much store in planning, rather, did things more spontaneously, tend to approach the end of life with a similar attitude. For lifelong planners, however, this need may be an important one to fulfill. For these people, having a plan and knowing what it is factors heavily into all of the other needs—understanding, choice, comfort and dignity.

When my patients and families need a plan laid out, I take the opportunity to discuss the different paths their journey could follow, and we do some planning around each possibility. The end-of-life journey seldom follows a straight and predictable path, but we do the best we can. There are usually twists and turns, both major and minor, that need to be navigated.

Most patients and families who are forced to navigate this end of life journey have far too little guidance when it comes to planning. This promotes confusion, anxiety and fear, which as I have already discussed, can interfere with the peaceful, transformative experience we should be striving for.

Comfort: Both physical and emotional comfort are important for a person's well-being at the end of their life, and must be met as best as possible for a positive experience. When physical pain, or other distressing symptoms, such as nausea, shortness of breath, itching, etc., are poorly controlled, there is really no way for the experience to be peaceful or transformational. Similarly, when someone is feeling emotional discomfort or spiritual unrest, transformation is impossible to achieve. There will still be a transition, but without a transformation.

In Abraham Maslow's theory of the hierarchy of needs, physical security is near the base of the pyramid—it is quite literally, the basis of our other experiences. Just as in every developmental stage of life, as a person approaches death, their safety, security and physical comfort are among their most urgent needs. Until we address those, the rest of the needs can

never be adequately met.

Getting to know each individual we care for is crucial for providing adequate comfort. What is comforting for one person will differ from what is comforting for another person. It is up to the team supporting each patient, including his or her loved ones, to determine what they need for maximal comfort, and to make sure it is provided for them.

For one patient it will be relief of pain, for another patient it will be knowing that their legal affairs are in order, while for another it will be an honest discussion about past regrets or unresolved issues. For some people, massage will be comforting, or music, or watching old movies. For others, narrating a life history or spending time with friends will provide comfort. We are all comforted by different things, though as we near the end of our lives, our focus shifts, and those around us must recognize this and respond accordingly.

When the needs of those facing the imminent end of their life go unmet, it is usually because of a lack of knowledge about what is needed and what is available, and/or a lack of funds available to pay for these services. The only way to ensure that you are able to have these needs met is to be a strong advocate for yourself or your loved one, and to ask for the commitment and partnership of your health care provider. It may take a little effort to find the provider who is willing to have an open discussion with you and address your needs. Caring for sick and dying people is very much part of a medical professional's job description, but few have the necessary training and capacity to be of optimal help. Professional care managers such as nurses, social workers, and geriatric specialists with training and experience in advocating for and navigating people through the health care system may be a good option.

The goal of this article is to primarily educate other professionals, family members, and patients themselves, in order to minimize “bad death” experiences. I hope to also bring awareness about professionals such as myself, who are devoted to caring for the dying, and expanding the conversation about these important end of life issues.

Death should not be the taboo subject it is in our society. It should be recognized for what it is: a fundamental and transformational part of life.