



Ethically Speaking...

A Publication of the Canadian Catholic Bioethics Institute
at Assumption University

Winter 2020

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provides news and information from the Canadian Catholic Bioethics Institute



at Assumption University

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Spiritual Care at the End of Life

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In October I had the good fortune to be invited to join the team at the Hospice Residential Home in Windsor as their Spiritual Care Practitioner. One of the lessons I learned early on was that many of us don't really know what 'spiritual care' means. We have a general idea, but the term is often vague and misunderstood. What exactly does a spiritual care practitioner do? And why would I want or need to see one?

Patients and families dealing with serious illness often experience spiritual distress or desire spiritual support. For many patients, spirituality helps them to find meaning in their illness. They often rely on religious practices or spiritual beliefs to guide their choices about end-of-life care. When faced with a medical crisis they *want* healthcare providers to ask about their spirituality because for many, it is what helps them cope with their mortality. Despite this knowledge patients often identify that their spiritual needs are not adequately met, and that spirituality is not discussed as openly as they wish.

The more time I spend with those in our care, the more I am convinced that providing spiritual care at the end of life is not a luxury but a necessity. Studies have shown that spiritual care is a crucial part of providing quality care to the dying and ignoring spiritual needs comes at a cost. Inattention to spiritual distress has been associated with higher end-of-life costs, including more ICU deaths and less hospice utilization.



By addressing a person's spiritual needs, not only do we provide a safe forum for them and their family to acknowledge the source of their suffering, but we also help them identify ways to cope and alleviate that distress.

Now, the term spiritual care can be interpreted in many ways. What do we mean when we talk about spirituality? Spirituality is the way individuals seek and express meaning, purpose, and connectedness with the sacred or the significant.

For those who practice an organized religion, end of life spirituality may be about following and taking comfort in the traditions and rituals of their faith. For others, it comes from family, friends, and relationships or from art, literature, and music. For many people, spirituality simply means connecting with another human being. Simply put, spirituality is what fulfills you; what gives your life meaning and purpose. Every person is unique, so how each of us expresses our spirituality is also unique.

Care That Goes Beyond Prayer

Most people mistakenly understand spiritual care to be specifically about religious beliefs, rituals, or practices, but the duties of a spiritual care practitioner go beyond this. One of the benefits of the palliative specialty is that the approach to care is truly interdisciplinary. Within many palliative care teams there is a collaborative community which consists of physicians, nurses, PSWs, social

workers, spiritual care practitioners and volunteers; together the team addresses the physical, emotional, and spiritual needs facing of those who are at the end of life and their families. The spiritual care practitioner's role is to identify those who have unmet spiritual needs or who are experiencing spiritual distress and offering them and their family support. Support is also offered to the staff members who care for the dying.

A study that examined the concerns of those nearing end of life identified the following common spiritual needs and sources of spiritual distress:

Spiritual Needs

- To finish business: such as forgiveness, reconciliation, or to review their lives for meaning.
- To be involved and have control in their care plan, medical decisions, hospital, or home environment.
- To maintain a positive outlook: by utilizing spiritual strengths and personal resources to keep an open mind and live in the present.

Sources of Spiritual Distress

- Fear: of death, the afterlife, separation from loved ones, pain, and suffering, and not leaving a legacy.
- Losses or grief: loss of independence, mobility, life, control.



Along with assessing the spiritual needs of the patient and family, the spiritual care practitioner also assesses cultural and religious factors which may be influencing care decisions. Interventions may include providing reflective listening, prayer, empathetic support, contacting the faith community, performing a life review, and assisting patients in integrating their spiritual beliefs with their medical reality.

The work of the spiritual care practitioner is interfaith. They do not represent any particular religion or denomination, rather they assist serve people from all faith traditions, backgrounds, and cultures as well as those who are unsure of their faith or follow no particular tradition. The common thread is an offering to care for the human spirit in whatever manner a person chooses to express that spirit.

It All Starts with Listening

Spiritual care is about relationships. Sometimes developing a level of trust happens quickly in other cases it happens over time. Conversations are often about anything and everything: family, work life, home life, even music or nature. Anything that fills someone's life with meaning, or truly moves them, is spiritual. The most important quality however is the ability to listen. Providing spiritual care is very much like coaching; a coach is someone who can help you identify strengths and weaknesses and overcome obstacles. It's not a coach's role to impart wisdom, but rather to facilitate the process of connecting to your own inner wisdom and making choices about your actions. Similarly, the role of spiritual care is to say what is it that you believe and what spiritual resources can you draw from to help you through this process of dying. They help identify the resources and strength to find the answers you are looking for and to reach a peaceful place in the process. On any given day I may address issues around

family dynamics; I may help families with making funeral arrangements or I may quietly sit and recite the rosary with someone who is imminently dying. I have had the privilege of writing letters to loved ones asking for forgiveness; of making videos and recordings so families have something tangible after their loved one dies.

Meeting People Where They Are:

Spiritual Care Practitioners don't pry or offer answers or advice, rather we ask open ended questions and let the story unfold. Some turn to us to share the burdens they have carried for a lifetime. They share stories of trauma, shame, and guilt. But not everyone is comfortable talking about death or somber topics. Many times, interactions are lighthearted. There have been many times when conversations turn to the funny and absurd. It is not unusual to hear laughter and giggling coming from rooms in the residence. Those lighthearted conversations are just as important as the emotionally laden ones.

Silence is as necessary as talking. Like most in healthcare, we want to help, to fix what needs fixing, but this is one instance where it is important to honour the silence. Initially I found the silence difficult, but it quickly became apparent that those moments of silence are as important as the conversations to those with whom I journey.

What unites us at the end

Like our spirituality, everyone's end of life experience will be unique, but one thing is certain: death does not discriminate based on what we own or our position in the world. All the 'things' that we accumulate and surround ourselves with are nothing but mere window dressing. In the end we are all human beings seeking comfort and compassion from others – and hopefully finding it.

At the heart of palliative care is the call to cure sometimes, treat often, and comfort always. There is no greater honour than to accompany someone on their final journey; nothing more sacred than to bear witness to someone's last breath. When cure is no longer possible, in our final days the best medicine we can offer is love. I have been blessed to work with the dying. They have taught me the value of each precious moment and for that I am eternally grateful.

If you have questions, comments or concerns, either theological or practical, regarding spiritual care at the end of life, I invite you to contact me by email or phone:

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References & Resources

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