

Spirituality should not be overlooked

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During my medical school days in the British Isles, palliative care “training” was just a one-week affair amidst a long and arduous training package, buried somewhere between intense surgical and medical attachments. My hurried hospice visits and team “discussions” were akin to listening rather than participating. Most palliative patients did not have an advanced care directive, and we often fulfilled demands from family members and health professionals to resuscitate, without considering whether the patients would have really wanted it. My main objectives in those patients included inserting an intravenous canula, minimizing exhaustion during chest compressions, remembering the 4Hs (hypoxia, hypokalemia/hyperkalemia, hypothermia/hyperthermia, hypovolemia) and 4Ts (tension pneumothorax, tamponade, thrombosis, toxins) in advanced life support, obtaining timely blood samples, and looking for opportunities to do pericardiocentesis, chest drains, etc.

As my medical training progressed, my personal convictions evolved. I began to think about palliative patients as individuals with souls rather than human subjects to practice my skills on. I started to systematically check for advanced care directives during patient admission. If unavailable, I commenced recording the patient’s wishes pertaining to resuscitation, ventilation, intubation, etc. I started to integrate holistic palliative patient care by factoring in physical, mental and spiritual care (1).

Although there were chaplains on call in Somerset, UK, none of the patient-chaplain interactions seemed to include Judeo-Christian, or even spiritual topics. When a clinician discussed this topic with a palliative patient, let alone any patient, it was promptly frowned upon.

There was an unsubstantiated and unhealthy skepticism apropos spirituality or Christianity that ran rife through clinicians, regardless of how literate the clinicians were or how “evidence-based” they claimed to be. Nevertheless, I consistently noted that chaplaincy services brought peace, comfort, and hope to patients and their families, even in situations of great grief and stress. Time and time again, I saw patients in distress display an intense, but unrequited yearning for spiritual support. I have referred several patients to palliative care after having quality conversations with them regarding their wishes, hopes, fears, disappointments, regrets, physical requirements, and spiritual needs.

I present the story of one such palliative care patient here. Bryan was a 23-year-old well-built, healthy young university student. One day, as he was going to work, he lost his balance and fell. Although he was brought to our emergency department for a “closer look”, he was promptly discharged after his condition was assessed as a “minor fall”. However, over the next couple of weeks, he progressively got weaker and frequently found it difficult to get up after sitting down. He also had frequent falls but did not divulge these issues to his widowed mother, for fear of making her upset.

Bryan’s mother raised him in a civil war zone, and subsequently brought him out of the conflict areas. She managed to extricate herself and her son from the chaos and successfully translocated themselves into a developed country. Bryan’s mother was widowed and had raised Bryan single-handedly. Out of loving concern for his mother’s state of mind, Bryan did not divulge the extent of his maladies. However, Bryan soon developed noticeably

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significant neurological deficits in both his lower limbs, for which he was brought back to the hospital.

Computerized tomography and magnetic resonance imaging revealed a lower thoracic tumour that was compressing the spinal cord and causing his neurological weakness. Biopsies revealed that Bryan had a rare aggressive glioblastoma. The available management options of surgery, radiotherapy, and chemotherapy were discussed with him and his family who chose surgery, despite the aggressiveness of the tumour and potential complications of the surgery (2,3). As predicted, Bryan lost some neurological function of his right lower limb after the surgery but was still able to sit up. I happened to be visiting my friend who was admitted with cranial osteomyelitis to the same ward where Bryan was admitted. I was looking around for my friend's mother Celine, whom I found not next to her son, but next to Bryan and his mother. Although this puzzled me, I understood she was supporting Bryan and his mother, although they had only met for the first time in that ward. I also found out that Celine kept in contact with Bryan and his mother to support them even after they were discharged.

Unfortunately, Bryan's symptoms returned within 5 months. Subsequent imaging displayed tumour recurrence, and Bryan was offered palliative chemotherapy and radiotherapy. Despite this devastating news, Bryan did not make his grief explicit in front of his mother, as he did not want to upset his mother. Out of gratitude for all his mother had done for him, and out of deep concern for her well-being, Bryan did not want to add insult to injury by expressing his anguish.

Celine spent a lot of caring for Bryan and his mother, praying with them, shopping for them, and doing chores around their home. She also served as their spiritual mentor and counsellor. Most of the time, Celine was just there for them. Her presence meant a lot to Bryan and his mother as evident by the peace and hope they displayed when she was around. Bryan, a complete stranger 5 months ago, was now another son to Celine.

Bryan was soon admitted to a hospice for palliative care. One day, I received a call from Celine requesting me to arrange a haircut for Bryan, as she was concerned Bryan's hair had grown too much, obscuring his good looks. I was not sure how I would go about this. The last thing on my mind was how to cut hair in a patient who was expected to die soon. For a short while, I had forgotten that he was still living, and deserved all the "aesthetic privileges" that we take for granted. I contacted a local hairdresser who went to the hospice to do the needful at no cost, despite my protest!

One day, I had a call from Celine. She asked me if I could come and baptize Bryan before his health deteriorates further at the hospice. Although I thought I was not "qualified" to do this, Celine and Bryan were adamant that I support them spiritually in this way. Celine was well-prepared with the necessary Biblical requirements, and Bryan was immersed into Jesus after confessing his sins and repenting. There was an inexplicable newfound peace and joy that Bryan displayed from then on. Death was at his doorstep, but there was no anger or questioning as to "why me?".

Bryan passed away four days after his baptism. Celine and I also found our peace regarding this. It was as though Bryan's supernatural peace had also engulfed us somehow. We bid Bryan farewell at his funereal and supported his devastated mother emotionally and spiritually.

I believe that a human being is a soul with a body, and all palliative patients should be considered for holistic care, including care covering the emotional, mental, and spiritual aspects of life (1). Bryan's story impressed upon me that palliation is not just about dying, but also about supporting patients to live with sound body, mind, and spirit.

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