



Difficult journeys

Cancer stories: on life and suffering

David M. Gregory and Cynthia K. Russell
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This is a disturbing book that took courage to write. The first chapters present an overview of cancer and the difference between the science and the humanity of cancer care. Do we really understand what people with cancer are living through, or do we let them suffer in silence? The authors challenge us as health care professionals to examine whether we attend to the suffering of our patients or hide behind science instead.

The body of the book narrates the stories of five people who were interviewed by David Gregory at weekly intervals for up to six months. All five “wanted their stories shared with others”; they “wanted their encounters with cancer to matter.” Following each narrative is a section presenting the “practical knowledge embedded in experience.” To health care professionals, these sections demonstrate that “not all suffering can be treated with a pill, a tonic, or a counselling session.” And, more universally, “the experiential knowledge uncovered in each of the narratives can prepare us to live more fully with advanced cancer, should cancer enter our lives or the lives of those we love.”

Courage is central to these testimonies. It took courage for these people to allow themselves to be accompanied on their journey, to allow themselves to be vulnerable and reveal their innermost hopes and fears. Their suffering is not glossed over, but is conveyed in such a way that the reader cannot be unmoved. I read the entire five stories in one day. As I read each one, I needed to go on. The reflection I was seeing of the health care system was a

hard one to accept. I realized that I needed to find some redemption for the health care providers depicted in these accounts. With each new story my hopes would rise, only to be disappointed. John’s story, the last of the five, left me angry and numb. John was a difficult man whose challenging personality made it especially difficult for him to live with a disease that was destroying him physically, emotionally and spiritually. Admittedly, some of the things that happened to him were the consequence of his manner of interacting with others. We all know that such a devastating journey can bring out the worst in people as they resort to whatever coping strategies they have. Instead of finding an empathetic system, one that attempted to understand him and to draw alongside him, we hear how the system abandoned him at the very time he needed help most.

In contrast to the depth of emotion and the reality of lived experience expressed in the narratives, the sections on lessons learned are very practical. They contain a combination of science and experience that attempts to set out some guideposts, suggestions that may help to make the cancer journey easier. Tellingly, many of the suggestions are about how to navigate through the health care system, so that one is heard and one’s needs are met. As soon as the science is put back in, the tone of the book shifts. No longer close and personal, it takes a step back and becomes

more objective. This made me realize why most of us would rather stay in the domain of science and leave it for others to attend to the suffering.

The authors challenge us to look at the language and images that surround cancer. Patients are given messages of coping, hope and survival, as in the slogan, “Cancer can be beaten.” They are told that it is important to take control, to look and feel good. But for those whose experience does not fit into this framework, suffering can be compounded by a sense of failure. The reality is that suffering occurs regardless of the outcome.

For the five people whose stories are told in this book, suffering occurred because of the nature of cancer itself, difficulties with intimate relationships and encounters within the health care system. Their experiences challenge us to examine how we do our work. Do we

add to the suffering of those we are attempting to care for? Are we “interested in [our] patient’s spiritual and emotional lives as well as their medical histories”? Are we “able to hear a patient’s fears about dying?” Are we willing to listen, knowing we have no answers? These things require “a high degree of spiritual maturity.”

This book achieves its goal of “giving voice” to those who have died with cancer. As a palliative care physician, I became much more aware of the extent of the suffering experienced by people living with cancer. This is a book that should be read by everyone who encounters cancer in his or her life. It is a book that takes courage to read, but it is well worth the effort.

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