

## Suffering of gravely ill patients

### *An important area of intervention for family physicians*

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Upon your return from vacation, you see a patient named Jacqueline, a 40-year-old businesswoman whom you have been treating for years. As soon as she enters your office, she breaks down, just as you are reading a note from one of your colleagues. When an x-ray investigation for back pain revealed a mass in her lung, she was referred to a pneumologist. Jacqueline tells you that they discovered she has inoperable lung cancer and that she will be starting palliative chemotherapy in the next few days. While her physical pain is being managed adequately with opioids, the patient standing in front of you is suffering. She tells you that she is “going through hell.” How do you react? Do you have a role as her family physician?

### **Nature of the suffering**

Unfortunately, this situation is not unusual. One in 4.3 Canadian women and one in 3.6 Canadian men will die of cancer.<sup>1</sup> Other fatal diseases can cause patients to suffer during short or long periods of palliative care. In addition to having multiple symptoms, many patients experience intense suffering<sup>2</sup> for which they might not get relief within our current health care system. There are several reasons for this. In order to relieve our patients' suffering, we must first understand it.

From a medical point of view, Cassell<sup>3</sup> was among the first to try to define suffering. He believed that suffering occurs when a person's integrity is either destroyed or threatened. Cassell thought that suffering could be caused by loss of control over serious illness and by a sense of being overwhelmed by the physical or psychological symptoms of the illness. In this sense, while they are closely linked, pain and suffering are two distinct phenomena. Pain is the result

of nociceptive messages transmitted to and then modulated by the brain; suffering is an emotional response to pain or to depression, isolation, anxiety, or fear.

This is precisely what Jacqueline is experiencing. Despite the fact that her physical pain is adequately managed, she feels assaulted and overwhelmed by her illness. She senses that her physical and psychological integrity has broken down. She now faces an uncertain future with apprehension. This is why she says that she is “going through hell.”

### **Role of medicine with respect to suffering**

Just as preventing and curing diseases has always been an integral part of medical care, so too has alleviation of suffering. Clinicians and researchers are aware that suffering has obvious clinical significance in the experience of serious illness; however, many confirm that this subject is not well covered in health care professionals' education and is not necessarily integrated into their daily practice.<sup>4,5</sup> According to Stollerman,<sup>6</sup> in recent decades, medicine has focused on diagnosing and curing patients to the detriment of alleviating suffering. Compartmentalization of medicine has taken away the time and energy physicians need to investigate their patients' suffering and attempt to respond to it. Other than training received in palliative care, family physicians have not been prepared to recognize and alleviate suffering caused by grave illness.

### **Areas for intervention by family physicians**

When treating patients diagnosed with terminal illnesses, it is important for family physicians to

understand that their patients are struggling with the chaos the illness has brought into their lives. Care providers must also let go of the idea that suffering is just another symptom that can be “managed.”<sup>7</sup> If we treat suffering as a pathologic entity rather than a psychological, existential, cultural, and social experience, we and our patients will fail in alleviating it. After repeated failures, care providers sometimes distance themselves from their patients and so increase their suffering.<sup>8</sup>

Since suffering is strongly associated with not understanding the experience of the illness, care providers can help their patients to make sense of their experience.<sup>9</sup> For example, explanations family physicians provide of the underlying mechanisms of physical symptoms might help patients in their search for meaning.<sup>10</sup> Where non-physical aspects of suffering are concerned, the search for meaning requires something different from family physicians. Since physicians have often known patients for many years, they have an opportunity to accompany them in this search.<sup>11</sup> As Saunders<sup>12</sup> reminds us, our role as care providers is not to fix the suffering of others, but simply to witness it and honour it, since much of it needs to be experienced and worked through by patients themselves.

Our very presence can help break the isolation that the illness creates, and we can share a sense of solidarity with our patients because we are all mortal.<sup>13</sup> It is important to communicate to patients and their families that, despite the illness and the harsh changes it brings, patients and patients' lives still have value. Since Jacqueline had to leave her job, her physician explored with her what might give her life meaning during the time she had left. Her hobby was making jewelry, so her physician did everything possible to control her pain while maintaining the fine motor skills that she would need to remain creative despite being terminally ill.

Family physicians must not abandon their patients. As less and less time is taken up with prescribing medications or ordering tests, the time between visits can be shortened. This is because, as Cassell<sup>3</sup> states, the relationship with the patient is the vehicle for alleviating suffering. Some<sup>11,14</sup> say that the search for meaning and finding true solidarity with others could enable

patients who are suffering to discover a new sense of integrity and to gradually move toward a simplification of self. In certain cases, these people achieve a sense of completion and satisfaction and even a certain sense of mastery and control in preparation for a “good death” or maybe even a “good life before death.”

We know that people who are suffering experience relief when their environment reflects what they want.<sup>15</sup> As care providers, we can help make an environment in which patients' values and dignity are respected.<sup>16</sup> The best environment is one chosen by a patient that also meets his or her needs. In our current health care system, the only place these needs can be met 24 hours a day is a hospital. But we also know that most terminally ill patients want to stay at home as long as possible.<sup>17</sup> Optimal delivery of home care services through private clinics and local community service centres, and creation of on-call networks providing patients with nursing or medical assistance 24 hours a day, can help patients continue living at home and encourage their family physicians to continue caring for them. Initiatives such as family practice groups can make it easier to care for these patients and contribute to their overall sense of well-being.

Jacqueline was able to get this type of care. Her family physician remained actively involved with the support of a multidisciplinary team and colleagues, who took turns providing round-the-clock medical care. Adjustments in analgesia were required to manage her pain. Her legitimate anger also forced her physician to experience a sense of helplessness, which he shared with her. Jacqueline had difficult relationships with her family. Her family physician met with them and answered their questions. This resulted in greater harmony in her home, where she remained until she died.

An in-depth understanding of the phenomenon of suffering led to a better understanding of what this patient was going through and to comprehensive responses adapted to her situation. This is one of the fundamental roles of a family physician. ❁

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