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Dignity in Care: Time to Take Action

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Abstract
Patient care and caring about patients *should go hand in hand. Caring implicates our fundamental attitude towards patients, and the ability to convey kindness, compassion and respect. Yet all too often, patients and families experience healthcare as impersonal, mechanical; and quickly discover that patienthood trumps personhood. The consequences of a medical system organized around care rather than caring are considerable. Despite technical competence, patients and families are dissatisfied with medical encounters when caring is less than evident. Lack of empathy and emotional disengagement often accompanies health care provider burnout.* Caring is the gateway to disclosure; *without it, patients are less likely to say what is bothering them, leading to missed diagnoses, medical errors and compromised patient safety. There are also liability issues, with most complaints levied against healthcare professionals stemming from failures in care tenor. Formal education for healthcare providers lacks a continued focus on achieving a culture of caring. If caring really matters, healthcare systems can insist on certain behaviors and impose certain obligations to improve care tenor, empathy, and effective communication. Caregivers need to be engaged in looking at their own attitudes towards patients, their own vulnerability, their own fears and whatever else it is that shapes their tone of care. Healthcare professionals must set aside some time, supported by their institutions, to advance a culture of caring—now is the time to take action.* J Pain Symptom Manage 2013;■:■–■. *© 2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

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Care, caring, dignity, patienthood, personhood

"The secret of the care of the patient is in caring for the patient." Those words ring as true today as when they were first delivered by Dr. Frances Peabody in his famous address to Harvard medical students in the fall of 1925. With simple elegance, he reminds us that providing *care* for patients and *caring* about patients should go hand in hand. Although the former refers to evidence-based practices that are applied almost exclusively according to disease-specific considerations, the latter is about our covenantal relationship with patients, allowing them to trust us to always hold their interests first and to be unwavering in our loyalty to what is best for them. The only way to know what is best for patients is to listen to them, to know them, and to begin to understand what matters most to them (D. Meier, personal communication, August 1,

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2013). Caring implicates our fundamental attitude toward patients, and our ability to convey kindness, compassion, and respect. Although the world has changed a great deal since 1925, contemporary health care continues to struggle with how to marry care with caring. Modern medicine has expanded its capacity to diagnose, treat, and even cure various ailments that afflict humankind, but all too often patients and families experience health care as impersonal, mechanical, and quickly discover that patienthood trumps personhood. And despite sincere Peabody-esque declarations, which punctuate hospital mission statements, preface annual reports, or feature prominently in materials meant for public consumption, *caring* remains *care's* distant poor cousin.

How ironic that *caring* struggles to maintain a foothold in the caring professions. As medicine has made spectacular gains over the past century, the humanities of care have taken a back seat to things that are seemingly more compelling, like the illusory promise that "all diseases [are] things to be conquered … that medical advances are essentially unlimited … that none of the major lethal diseases is in theory incurable; and that progress is economically affordable if well managed."[1] If only it were the case. That said, the evolution of health care systems built to deliver *promissory* medicine have become, by necessity, more complex, more impersonal, and more technology focused; although they have immense capacity to process patients, and procedures to administer care, *caring*, it would appear, has not been as well thought out.

The consequences of a medical system organized around *care* rather than *caring* are considerable. Despite technical competence, patients and families are less satisfied with medical encounters when caring is lacking. In our own studies, *care tenor*—the tone of care—was an important predictor of whether patients felt that their dignity was upheld toward the end of life.[2] The organization of health care also has implications and consequences for those who work within it. When care is unable to stave off frailty, disability, illness, and death, people trained to protect their patients from these inevitabilities may feel that they have failed, and the emotional price of shouldering that failure can be considerable. Some medical practitioners deal with this by immersing themselves in the technical and skill-based dimensions of their work; or learn to develop an emotional armor that protects them from the sadness, the anxiety, and the grief that invariably accompanies patients and families confronting life-limiting conditions. Lack of feeling empathy or the inability to emotionally engage with patients is a cardinal symptom of health care provider burnout; perhaps, the more we run away from caring and the emotional dimensions of looking after patients, the more we spend our careers feeling chased, hassled and in too many instances, professionally exhausted and ineffectual. There are also patient safety issues related to a paucity of caring. *Caring is the gateway to disclosure.* Patients who do not feel the appropriate care tenor are less likely to say what is really bothering them, leading to missed diagnoses, more medical errors, and squandered opportunities for meaningful and effective clinical encounters. Finally, not being attentive to care tenor can have liability consequences for health care professionals. Studies consistently show that most complaints levied against health care professionals derive, not from medical misadventure, but from a failure to communicate and the absence of caring.[3]

How much attention is paid to achieving a culture of caring? If one looks at requirements for continuing education, it would seem that caring receives no attention whatsoever. Physicians, for example, are required to register a certain number of Continuing Medical Education credits each year to maintain competency; for Canadian medical specialists, this is no less than 40 hours annually with no fewer than 400 hours within a five year cycle. There is no stipulation, however, that so much as a single hour address something within the realm of caring. I suspect the situation is no different across any of the health care disciplines. One leaves training—having perhaps attended a mandatory lecture or two on communication skills or professional etiquette—with care-specific knowledge and skills, and absolutely no expectation or obligation whatsoever to revisit the issue of caring ever again. There is an assumption that so long as people working in health care have good intentions, are motivated to do good work, and have the ability to trust their gut, caring will simply follow in due course.

However, not everyone has a talented gut; just ask any medical administrator or patient representative. Most patient and family dissatisfaction and the source of most complaints, they will tell you, can be traced back to poor care tenor and a failure to express kindness, compassion, and respect.

So what can be done? The pessimistic and nihilistic retort is "caring cannot be taught," "health care systems cannot be changed," and "no one has time to do anything any differently than they are already doing now." But if caring *really* matters—and indeed it does, given its impact on patient and family satisfaction, health care provider burnout, implications for patient safety, and risks of medical liability—these responses simply cannot be abided. Health care systems can insist on certain behaviors and impose certain obligations when they set their minds to it. (Recently, our hospital insisted that every single employee receive fire safety training. I doubt that I would have lost my job had I not attended, but the barrage of e-mail reminders made any such resistance seem futile. The whole exercise, from the time I left my office to the time I returned to my desk, took 80 minutes. I along with staff from everywhere within the organization stood in an empty parking lot, listening to the fire marshal describe the hazards of using non-hospital–issued electrical appliances, the characteristics of different kinds of flames, and a demonstration of various fire extinguishers. My name was only checked off the list when I was able to successfully extinguish a small gas flame set within a sandbox; my technique, I am proud to say, was impeccable). The point is, when the cause is deemed sufficiently important, expectations, initiatives, and compliance strategies can all be set in motion.

So what could be done in the service of trying to establish a medical culture of care and caring? If care tenor needs to be honed, than caregivers need to be engaged in looking at their own attitudes toward patients, their own vulnerability, their own fears, and whatever else it is that shapes their tone of care. If emotional detachment reduces patients to the embodiment of their ailments, emotional engagement would need to reconnect health care providers with the idea that first and foremost, patients are people with feelings that matter. There are some wonderful materials online that, in a very effective and succinct way, are designed to do just that. Take for example, *A Story About Care* (produced by the Canadian Virtual Hospice and the Canadian Association of Schools of Nursing; http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support/The+Gallery/Stories/A+Story+About+Care.aspx), an extraordinary video running just under 16 minutes, about one man's reflections on the power of caring relationships that can exist when people working in health care see the person and not just their disease. Another wonderful video, *The Human Connection to Patient Care* (developed by the Cleveland Clinic Media Production Team; https://www.youtube.com/watch?v=cDDWvj_q-o8&feature=player_embedded#at=24), invites health care providers to look at the world through the eyes of patients and their families; it runs just under five minutes. These are examples of teaching materials that might be used to challenge health care providers' sensibilities; to have them question long-held assumptions; and perhaps even briefly, set aside their protective armor to hone their capacity for caring. Collectively, I would imagine that the readership of the *Journal of Pain and Symptom Management* could identify a wealth of such material using various different media platforms and formats. Some of these may be more site specific (e.g., hospitals, outpatient clinics, personal care homes, and so on), whereas others may be more role focused (e.g., physician, nurse, health care aid, medical administrator, and so on). The two previous examples are generic and will likely resonate with anyone working in health care. Should readers wish to contact me, I would be pleased to house further recommendations and resources on dignityincare.ca. Together, we should be able to assemble a vast repository of material, suitable for health care professionals spanning a wide diversity of settings.

Finally, how much time would be reasonable to ask health care professionals of all stripes to set aside in the service of trying to establish a culture of caring? Before answering this, consider the following: the average American watches about 34 hours of television weekly, closer to 40 if one counts taped programs, plus about eight hours on the Internet. Also,

recall that fire safety training took 80 minutes; spread out over the course of a year, this would amount to 20 minutes per quarter. What if, in an attempt to create a culture of caring, all health care professionals were required to spend up to 20 minutes per quarter online (for instance, perhaps September 20th, December 20th, March 20th, and June 20th could be designated Dignity in Care days [the 20th being a reminder that materials should take no longer than 20 minutes to watch]), with viewing assignments chosen according to local needs and specifications? Although protocols for implementation would take some effort to work out, and compliance challenging to enforce (people may want to consult with the Winnipeg Fire Marshals Office; those people were relentless), is the cause—and all that hangs in the balance—not worth the effort? The nay-sayers, the pessimists, and the nihilists will say why bother; that it is too little too late, or that it will not really make any difference. I say *caring* is too important to be deterred by anyone lacking a better idea to put forward. Caring matters to patients and families; it matters to health care providers; and it matters to health care systems. About 20 minutes four times a year may not sound like much, but it is a start. "The secret of the care of the patient is in caring for the patient." Well and good. Now is the time to take action.

Other readings that may be of interest:

Chochinov HM, McClement SE, Hack TF, et al. Health care provider communication: an empirical model of therapeutic effectiveness. Cancer 2013; 119:1706–1713.

Chochinov HM. Humility and the practice of medicine: tasting humble pie. CMAJ 2010; 182:1217–1218.

Chochinov HM. Dignity and the essence of medicine: the A, B, C and D of dignity conserving care. BMJ 2007; 335:184–187.

References

1. Callahan D, Nuland SB. The quagmire. New Republic 2011. Available from http://www.newrepublic.com/article/economy/magazine/88631/american-medicine-health-care-costs#. Accessed August 1, 2013.

2. Chochinov HM. Dying, dignity, and new horizons in palliative end-of-life care. CA Cancer J Clin 2006; 56:84–103.

3. Tamblyn R. Physician scores on a national clinical skills examination as predictors of complaints to medical regulatory authorities. JAMA 2007;298: 993–1001.