In a recent British Medical Journal editorial, Ruth Macklin pronounced that dignity is “a useless concept in medical ethics and can be eliminated without any loss of content” (Macklin, 2003). The published responses offered a unanimous, firm rebuttal, arguing that dignity is somehow foundational to all we do, or ought to be doing, within the practice of medicine or medical research. Whereas Macklin argued that dignity lacked definitional specificity, the words of U.S. Supreme Court Justice Brennan were invoked by respondent Jayson Rapoport: “I can’t define dignity, but I know it when I see it” (Rapoport, 2003). Whether dignity has no place or a pivotal place within the medical lexicon, what seems clear is that discussions pertaining to dignity leave little room for indifference.

Our palliative care research group was first drawn to the notion of dignity by its regular citings in the euthanasia and assisted suicide literature. According to some sources, loss of dignity was one of the most frequently stated reasons physicians offered when explaining why their patients sought out a hastened death (van der Mass et al., 1991; Meier et al., 1998). Like Macklin, we too were troubled by an apparent lack of definitional specificity; we were also concerned that the source of these dignity findings were often removed from the most obvious primary informant, the patient himself or herself. As for empirical findings regarding how patients viewed the notion of dignity, the literature appeared silent. Be that as it may, our research group concluded that if dignity was worth dying for, it was certainly worth studying.

It is several years into our studies and what have we learned? First, the majority of dying patients report that their sense of dignity remains intact, in spite of the various end-of-life challenges they may be facing (Chochinov et al., 2002a). This is not to say that dignity is unimportant (nearly half of the patients we studied indicated they had experienced at least some or occasional dignity-related concerns). However, dignity may be resilient, intrinsically held, and perhaps less influenced by various factors that can impose themselves on someone close to death. On the other hand, it could be that people who are being well looked after toward the end of life are less likely to report dignity-related concerns. We have also found that a sense of dignity seems to correlate significantly with a variety of important variables, including psychological distress, such as depression, hopelessness, desire for death, and anxiety; physical discomforts, such as pain and difficulties related to bowel functioning; and dependency issues, including needing assistance with bathing, dressing, and toileting. Appearance, or perhaps more accurately the perception of how one is seen, emerged as an important correlate of preserved dignity (Chochinov et al., 2002a). No one wants to be viewed merely as the embodiment of an illness; rather, most of us would like to feel that our essence or personhood is somehow acknowledged and respected, in spite of the encumbrances of our illness. As stated by Sir William Osler, “It is more important to know what patient has a disease, than what disease the patient has” (Osler, 1919).

Through our studies, we have also developed an empirically based model of dignity, pointing to the various domains of concern that may influence a dying patient’s sense of dignity (Chochinov, 2002; Chochinov et al., 2002b). These influences will vary from individual to individual, and although they are inclusive of autonomy and respect—concepts that Macklin suggest conceptually usurp dignity—they extend beyond these. For some patients, the model suggests, dignity resides in achieving physical comfort or psychological quietude; for others, dignity is intertwined with spiritual comfort, or being able to maintain ones senses of essence or personhood. Others describe dying with dignity in terms of generativity—that is, knowing that something of who they are or were will transcend death itself. Perhaps most instructive to health care providers, many patients pointed to the transactional
aspects of dignity, underscoring the way in which others can support or undermine their sense of dignity. This aspect of the Dignity Model, Care Tenor (or the tone of care), suggests that everything we do as care providers is open to interpretation by patients as reflecting on their sense of worth; as an aside, the dictionary defines dignity as “the quality or state of being worthy, honored, or esteemed” (Merriam-Webster Dictionary). As such, the reflection that patients see of themselves in the eye of the care provider should be one that is affirming of their sense of dignity (Chochinov, 2004).

It could be argued that the empirical dignity data and the model itself do little to dispel confusion around dignity’s lack of definitional specificity. What every facet of the model has in common, however, is that each of these issues or domains of concern have been raised by dying patients as having a bearing on their sense of dignity. Care guided by this model, or Dignity Conserving Care (Chochinov, 2002), would thus subsume those various therapeutic actions, attitudes, or interpersonal sensitivities that would help support each individual’s sense of dignity. Rather than debating its utility, clinicians need to bring the notion of dignity back to the bedside, where it can provide an overarching approach and guide a humane response to patients and families entrusted to our care.

REFERENCES


HARVEY MAX CHOCCHINOV, M.D., PH.D., FRCP Co-Editor