Dignity and Psychotherapeutic Considerations in End-of-Life Care

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Abstract / The basic tenets of palliative care are frequently subsumed under the goal of helping patients to die with dignity. Our research group has studied the issue of dignity, with dying patients serving as the primary informants. This paper reviews some of our findings, including an overview of the Dignity Model that derives from our empirical work. Furthermore, this paper summarizes various psychotherapeutic approaches which have been considered for this vulnerable patient population. Finally, we provide the rationale based on the Dignity Model for a psychotherapeutic intervention we have coined Dignity Therapy. This brief, individualized therapeutic approach has been informed by our dignity work, and specifically designed for application in patients nearing death.

Résumé / Les grands principes fondamentaux des soins palliatifs sont souvent englobés sous l'objectif principal : aider les patients à mourir dans la dignité. Notre groupe de recherche s'est penché sur la question de la dignité et ce sont les mourants qui ont été pour nous la source première de nos informations. Cet article résume les résultats de nos travaux et, plus particulièrement, donne une vue d'ensemble du « Modèle de la dignité » lequel dérive de nos recherches empiriques. En plus, dans cet article on fait un résumé des différentes approches thérapeutiques appropriées chez une population de patients vulnérables. Enfin, nous exposons le raisonnement qui sous-tend notre « Modèle de la dignité » et l'intervention thérapeutique qui en découle et que nous avons choisi d'appeler « Thérapie de la dignité ». Cette approche thérapeutique de courte durée est fondée sur la dignité et a été conçue spécifiquement pour les patients qui sont à l'approche de la mort.

INTRODUCTION

The basic tenets of palliative care, including symptom control, psychological and spiritual well-being, and care of the family, are frequently subsumed under the goal of helping patients to die with dignity (1,2). Considerations of dignity are often invoked as justification for various, even diametrically opposite approaches to the care of dying patients, whether in reference to hydration

and nutrition, terminal sedation, or even basic symptom management (3–10). Some studies suggest that "loss of dignity" is one of the most common reasons physicians cite when asked why they agreed to their patients' request for euthanasia or some form of assisted suicide (8,9,11). In spite of this, very little research addressing the issue of dignity, using dying patients as the primary informants, has been conducted.

Dignity is defined as "the quality or state of being worthy, honoured, or esteemed" (12). Despite its politicization by the physician-assistedsuicide and euthanasia movements, dignity does not relate exclusively to considerations of assisted dying (5,7,8). Rather, dignity appears to provide a broad framework to guide physicians, patients, and families in defining the objectives and therapeutic considerations fundamental to end-of-life care (13). Systematically broaching these issues within end-of-life care discussions could allow patients to make more informed choices, achieve better palliation of symptoms, and have more opportunity to work on issues of life closure. When care targeting dignity becomes the model of palliation, care options may expand beyond a symptom management paradigm, and encompass the physical, psychological, social, spiritual, and existential aspects of the patient's terminal experience. The notion of dignity may also provide a unique framework, informing optimal psychological or psychotherapeutic support to patients nearing the end of life.

DEFINING A GOOD DEATH

While few studies have directly examined the issue of dignity in the terminally ill, several have examined the ingredients of a "good death." Stewart and colleagues, for example, developed a conceptual framework, based on a review of the literature, which outlines various domains of influence on the quality of life of dying persons in

the context of health care (14). This framework was meant to guide the development of a comprehensive set of outcome measures, and to evaluate the quality of life of dying persons and the care they require. Others have identified important domains of quality end-of-life care, listing both physical and psychosocial sources of influence (15-17). The latter domains are variably described as "support of function and autonomy" and "patient and family satisfaction" (15); "overall quality of life" and "psychological well-being and functioning" (16); and "achieving a sense of control" and "strengthening relationships" (17). Identification of these domains is an important step toward improving end-of-life care. More work is needed, however, to delineate what each of these means to the dying patient. Until these domains are operationalized, the intervention strategies needed to address these sources of distress will remain elusive, and optimal palliation beyond reach.

Emanuel and Emanuel also described a detailed framework for a good death (18). While not empirically validated, it does synthesize the dying experience as a process with four critical components, including the fixed patient characteristics, the modifiable elements of the patients' experience, the various interventions that are available, and the overall outcome. Steinhauser and colleagues took an empirical approach in which they invited patients and caregivers to cite factors that they consider most important at the end of life (19). Although not presented as a comprehensive model, these factors include pain and symptom management, preparation for death, decisions about treatment preferences, and being treated as a "whole person." These were not further explicated, however, nor were clinical intervention strategies provided.

Cohen et al. have addressed the importance of existential issues within the broader construct of quality of life. As part of their work with the McGill Quality of Life Questionnaire, they have shown that existential subscales are at least as important as any other subscale in measuring overall quality of life, particularly in patients with local or metastatic disease compared to patients with no evidence of disease (20). Using this psychometric approach, they have demonstrated that, in addition to psychological and physical symptoms, significant improvements in existential well-being can be achieved as a result of hospice and palliative care (21).

In reporting patient perceptions of a good death, Payne and colleagues indicated that "dignity" was often cited as important (22). Without being further clarified, however, the term remains vague and implications for therapeutic

responses ambiguous. One study attempted to retrospectively (within 24 hours of the patient's death) have health care providers rate the deceased's level of dignity during their last three days of life (23). A list of investigator and health-care-staff-generated factors were used as criteria against which to make dignity score ratings. The authors concluded that they were unable to shed light on the deeper meaning and personal relevance of patient dignity, describing it as "an elusive concept" that needed to be studied from the vantage point of patients themselves.

MOVING BEYOND SYMPTOM MANAGE-MENT

As the field of palliative medicine develops, it is becoming clear that adequate palliation must be comprised of more than good pain and physical symptom management, and must include attention to psychiatric, psychosocial, existential, and spiritual domains of distress. Evidence is beginning to mount indicating that, while pain and physical symptoms are of great concern to patients, psychosocial and existential concerns appear to be even more prevalent (24). Addressing this diverse range of concerns has been identified as a priority both by professional organizations as well as by patients themselves. In a recent Institute of Medicine (IOM) report titled "Approaching Death: Improving care at the end of life", the IOM identified several domains of quality end-of-life care including: 1) overall quality of life; 2) physical well-being and functioning; 3) achieving a sense of spiritual peace; 4) spiritual well-being; 5) patient perception of care; and 6) family well-being and functioning (16).

Singer et al. conducted an extensive qualitative study of cancer patients' perspectives on what domains of end-of-life care were most-important to them (17). From the patients' perspective, these included: 1) receiving adequate pain and symptom management; 2) avoiding inappropriate prolongation of dying; 3) achieving a sense of spiritual peace; 4) relieving burden; and 5) strengthening relationships with loved ones. These domains begin to point to therapeutic considerations that might be of assistance to the dying patient and his or her family. Moadel et al. surveyed 248 cancer patients and asked what their most important needs were (25). Fifty-one percent needed help overcoming fears, 41% needed help finding hope, 40% needed help finding meaning in life, 43% needed help finding peace of mind, and 39% needed help finding spiritual resources. In a sample of 162 Japanese hospice inpatients, psychological distress was related to meaninglessness in 37%, hopelessness

in 37%, and loss of social role and feeling irrelevant in 28% (26). Meier et al. found, in a national survey, that among the reasons cited by physicians for patient requests for assisted suicide, pain and symptom distress accounted for 52%, while "loss of meaning" accounted for 47% (11). Wilson et al. found that the majority of dying patients who would choose a hastened death option, if it were available, would be motivated to do so because of a desire for death, a sense of hopelessness, and feeling a burden to others (27). Clearly, from the vantage point of patients, palliative interventions must extend beyond the realm of pain and symptom management if they are to be fully responsive to a broad and complex range of expressed needs.

PSYCHOTHERAPEUTIC OPTIONS IN END-OF-LIFE CARE

Very little work or empirical research on psychotherapeutic interventions for dying patients has been done. There does, however, appear to be some data suggesting the critical underpinnings for such a therapeutic approach. For example, Breitbart et al. demonstrated that spiritual well-being and meaning serve as a buffer against depression, hopelessness, and desire for hastened death among terminally ill cancer patients (28). The association between depression and hopelessness with heightening suicidal ideation and desire for death has been well established (28-32). Kissane and Kelly have described "Demoralization Syndrome" in the terminally ill, consisting of a triad of hopelessness, loss of meaning, and desire for death (33). Clearly, data such as this suggests that psychotherapeutic interventions targeting dying patients must attempt to bolster meaning and purpose, thereby lessening desire for death and overall suffering for this vulnerable group of patients.

In considering psychotherapeutic ways of supporting dying patients, it is important to review various approaches that have been applied to patients with life-threatening or life-limiting disorders.

Supportive therapy is the mainstay of psychological support for patients who are terminally ill. It is used to shore up or bolster established adaptive coping mechanisms, minimize maladaptive ones, and decrease adverse psychological reactions such as anxiety or fear (34). It is comprised of a consistent, reliable, and empathic relationship with a health care practitioner, and provides patients a way to understand their experience. While it can be combined

with expressive therapies, it tends to focus on symptomatic relief and maintaining psychological equilibrium (34).

Insight-oriented therapy has had limited application in dying patients. Traditional insight-oriented psychotherapy is based on the development of a trusting relationship between the psychotherapist and the patient, and an exploration of various unconscious conflicts and issues (34). Resolution of conflicts, through a process involving interpretation, catharsis, and enhanced insight, requires time, energy, and a commitment to an arduous psychological process that is usually too cumbersome for patients nearing death.

Interpersonal therapy has been used to enhance coping for patients facing HIV-related disorders, with some favourable results. In a research study by Markowitz et al., interpersonal psychotherapy was useful in resolving depression in HIV-positive patients (35). Patients participated in 16 weekly sessions where maladaptive patterns of behaviour related to symptoms of their depression were identified and reframed into realistic interpersonal problems that could be solved. Aspects of the interpersonal therapy that were helpful to these patients included: education about the symptoms of depression, placement of the depression in the context of present problems and solutions, a focus on stressors in their interpersonal relationships that may contribute to the depression, exploration of options for actively changing dysfunctional behaviour patterns, and identification of interpersonal problem areas (grief, role transition, interpersonal disputes, and interpersonal deficits). Given the time frame of this intervention, the limitations for patients imminently approaching death are self-evident.

Group supportive psychotherapy, including self-help groups, provides a setting for patients with similar illnesses to share information. The goal of group intervention is to reinforce active coping strategies and decrease isolation and/or stigma (34). In part based on concepts drawn from Viktor Frankl and logotherapy, Greenstein and Breitbart have developed "meaning-centred" group psychotherapy for men and women with advanced cancer. Over an eight-week period, this group focuses on meaning in their lives, developing an ability to reframe their experience from that of dying to that of living, and reviewing the historical context of their lives (36). This group intervention is intended for cancer patients who have not, as yet, entered the final palliative phase of their illness (that is, they must be sufficiently robust to participate in

a two-month structured intervention), and is currently undergoing formal evaluative testing.

Existential supportivelexpressive group psychotherapy was developed by Yalom and adapted by Spiegel for women with metastatic breast cancer. This group focused on problems of their terminal illness; on improving relationships with their family, friends, and physicians; and on living as fully as possible. Emphasis was on group cohesion, support, sharing of mutual fears, self-disclosure, and interaction between patients outside the weekly meeting (37). This group intervention decreased patients' distress and anxiety, but required a one-year commitment to treatment (38), limiting its feasibly in a palliative care setting.

Cognitive behavioural therapy is another intervention used in cancer populations to enhance quality of life. Cognitive behavioural therapy facilitates correcting cognitive distortions, emphasizing past strengths, improving coping strategies, and mobilizing inner resources (39,40). A cognitive intervention was used by Kissane and colleagues for a group of women with early stage breast cancer. They met over a six-month period to focus on working through grief, coping skills, cognitive reframing, and reordering of priorities (41). However, this type of intervention is most useful for patients where prolonged survival (i.e., several months) affords the opportunity for this kind of intensive treatment.

Logotherapy, a type of existential psychotherapy developed by Viktor Frankl, explores ways in which suffering can be experienced from a more positive perspective. The primary tenet of logotherapy is that one always has control over one's attitude or outlook, no matter how daunting the problem. The goal is for patients to decrease suffering and to live life to the full by engaging in activities that bring the greatest amount of meaning and purpose (42). The focus is on goals to achieve, tasks to fulfill, and responsibilities towards others. Rather than covering up patients' distress, logotherapy acknowledges and fully explores patients' suffering (43). Zuehlke and Watkins explored the use of logotherapy with six dying patients, and reported them to have a greater sense of freedom to change their attitudes, and to see themselves and their lives as meaningful and worthwhile (44). Logotherapy was not originally designed for patients with advanced cancer or patients who were imminently dying.

Grief therapy is usually considered within the realm of bereavement interventions. However, anticipating and processing loss is ubiquitous to the psychological

adjustment of patients nearing death. This includes loss of sense of self, sense of well-being, future life possibilities, and relationships. Therapists doing grief work provide patients with the opportunity to explore these issues, acting as a witness to the experience (34). Therapists must be extremely sensitive to the patients wish to variably approach or withdraw from this work, monitoring the intensity of the affect so that it remains within a tolerable range. As the illness progresses, some patients may move into a state of detachment, in which they feel too numb or sick to access their feelings. While grief therapy may help some to resolve their feelings, disease progression and fluctuating levels of consciousness may interfere with such resolution (34).

Life review provides patients with the opportunity to identify and re-examine past experiences and achievements in order to find meaning, to resolve old conflicts, and to make amends with friends and family, or resolve unfinished business (45-48). The process of life review can be achieved through written or taped autobiographies, by reminiscing through storytelling of past experiences, or discussion of the patient's career or life work, and by creating family trees (49). Various other life review activities include: going on pilgrimages, doing arts and crafts (creating a collage or drawings, poetry), and by journal writing (45). Life review has traditionally been used in the elderly as a means of conflict resolution and facilitating an acceptance of death (50). For cancer patients, stories have a special meaning. In negotiating their way through regimens of treatment, changing bodies, and disrupted lives, the telling of one's own story takes on a renewed urgency. This approach has not, however, been widely used in palliative care settings.

Life narrative places the meaning of the physical illness in the context of the patient's life trajectory. It is designed to create a new perspective of dealing with the illness, to emphasize past strengths, to increase self-esteem, and to support effective past coping strategies. The therapist emphatically summarizes the patient's life history and the patient's response to the illness to convey a sense that the therapist understands and knows the patient over time (51,52). Life narrative can bolster patients' psychological and physical well-being. One study by Pennebaker and Seagal demonstrated that, when patients wrote about important personal experiences in an emotional way for 15 minutes over three days, improvements in mental and physical health occurred (53). In another study, participants who wrote about their previously suppressed emotional thoughts had an increased blood level of circulating total

lymphocytes and CD4 (helper) T lymphocytes (54). Rather than in palliative care settings, life narrative has traditionally been used for treating depressed patients whose depression is a response to physical illness.

Aside from supportive therapy, other psychotherapeutic traditions have not been widely embraced in palliative medicine and are rarely invoked as approaches for patients suffering at the end of life. This is largely due to lack of feasibility and a paucity of efficacy studies supporting their application in this population. Given these limitations, our research group has been exploring the psychotherapeutic implications of dignity at the end of life

DIGNITY RESEARCH

Over the last five years, our research team has completed some of the first empirical studies on the issue of dignity among the dying (13,55,56). We have examined the extent to which patients near the end of life are able to maintain their sense of dignity, and have determined how various demographic and disease-specific variables are related to the issue of dignity in the terminally ill. In one study, we asked 213 terminal cancer patients to rate their sense of dignity (56). The main outcome measures included a 7-point Sense of Dignity Item (24), the Symptom Distress Scale (57); the McGill Pain Questionnaire (MPQ) (58); the Index of Independence in Activities of Daily Living (59); a quality of life scale (60); and a brief battery of self-report measures, including screening for desire for death (61), anxiety, hopelessness, will to live (62), burden to others, and social support. Of 213 patients, 99 (47%) indicated at least some degree of lost sense of dignity. Sixteen patients (7.5%) indicated that

loss of dignity was a significant concern. These patients were much more likely to endorse increased pain, decreased quality of life, difficulty with bowel functioning, heightened dependency needs (such as bathing, dressing, incontinence), loss of will to live, increased desire for death, depression, hopelessness, and anxiety.

A factor analysis of the dignity data set yielded six primary factors, including: 1) pain; 2) intimate dependency; 3) hopelessness/depression; 4) informal support network; 5) formal support network; and 6) quality of life. When a regression analysis of modifiable factors was completed, a two-factor model included hopelessness/depression and intimate dependency, underscoring the importance of providing endof-life care that includes addressing depression, fostering hope (i.e., meaning and purpose), and facilitating functional independence (63).

Our research on the issue of dying with dignity has also included qualitative studies, yielding an empirically based model of dignity in the terminally ill (13,55). This model provides caregivers a "therapeutic map," incorporating a broad range of physical, psychological, social, and spiritual/existential issues that may affect individual perceptions of dignity. This may point those who care for the dying toward a standard in palliative care we have called "dignity-conserving care" (55). Because the empirical dignity model forms the theoretical basis for a dignity-based psychotherapy, a more detailed explanation about the model is necessary.

The Dignity Model

This model is based on a qualitative study which examined the dignity perceptions and concerns of 50 dying patients. While further studies on the issue of dignity in this population are warranted,

Figure 1 / DIGNITY IN THE TERMINALLY ILL: A DEVELOPING EMPIRICAL MODEL MAJOR DIGNITY CATEGORIES, THEMES, AND SUBTHEMES Illness-Related Concerns Dignity Conserving Repertoire Social Dignity Inventory Level of Independence (Dignity Conserving Perspectives) **Privacy Boundaries** · continuity of self Cognitive Acuity Social Support · role preservation generativity/legacy **Functional Capacity** · maintenance of pride Care Tenor · hopefulness · autonomy/control **Burden to Others** Symptom Distress acceptance · resilience/fighting spirit **Aftermath Concerns Physical Distress Dignity Conserving Practices Psychological Distress** · living "in the moment" · medical uncertainty · maintaining normalcy · death anxiety · seeking spiritual comfort

our initial findings provide a context from which further investigations might be pursued. Three major categories emerged from our qualitative analysis of dignity, including: 1) Illness-Related Issues; 2) Dignity-Conserving Repertoire; and 3) Social Dignity Inventory. These categories refer to a broad range of issues, identified by patients, which determine how they experience their sense of dignity in the course of approaching death. Each of these categories contains several carefully defined themes and subthemes, serving as the foundation for a model for understanding dignity in the dying (see Figure 1).

Illness-Related Issues: These issues derive from the illness itself, and threaten to, or actually do impinge on the patients' sense of dignity. They are illness-mediated, with the associated themes and subthemes relating specifically to the patient's illness experience. The two broad themes within this category are "level of independence," (determined by one's ability to maintain cognitive acuity and functional capacity, referring to the ability to perform daily living tasks) and symptom distress. Symptom distress is further divided into the subthemes of physical distress and psychological distress. Psychological distress includes the subthemes: uncertainty, that is, the distress associated with the uncertainties of one's health status; and death anxiety, that is, worry or fear specifically associated with the process or anticipation of death and dying.

Dignity-Conserving Repertoire. This category was divided into two major themes: Dignity-Conserving Perspectives and Dignity-Conserving Practices. Dignity-Conserving Perspectives are internally held qualities or a worldview consisting of eight subthemes: 1) continuity of self (a sense that the essence of who one is continues to remain intact, in spite of one's advancing illness); 2) role preservation (the ability to continue to function in usual roles, as a way of maintaining a sense of congruence with prior views of self); 3) generativity/legacy (the solace and comfort of knowing that something lasting of oneself will transcend death); 4) maintaining pride (the ability to maintain a positive sense of self-regard or respect); 5) maintaining hope (an ability to see life as enduring, or as having sustained meaning or purpose); 6) autonomy/control (a sense of control over one's life circumstances); 7) acceptance (the internal process of resigning one's self to changing life circumstances); and 8) resilience/fighting spirit (the mental determination to overcome illness-related concerns and optimize quality of life). Dignity-Conserving Practices refer to various personal approaches or techniques that patients used to bolster or maintain their sense of dignity. Three components of these practices were identified: living in the moment (focusing on immediate issues in the service of not worrying about the future); maintaining normalcy (continuous or routine behaviours, which help individuals manage day-to-day challenges); and seeking spiritual comfort (turning toward or finding solace in one's religious or spiritual belief system).

Social Dignity Inventory: This refers to the quality of interactions with others that enhance or detract from one's sense of dignity. This inventory refers to external sources that may influence or impinge on a patient's sense of dignity. Five primary inventory themes were identified: 1) privacy boundaries (the extent to which one's personal environment is encroached upon during the course of receiving care or support); 2) social support (the presence of an available and helpful community of friends, family, or health care providers); 3) care tenor (the attitude others demonstrate when interacting with the patient that may or may not promote dignity); 4) burden to others (the distress engendered by having to rely upon others for various aspects of one's personal care or management); and 5) aftermath concerns (the worry or fears in anticipation of the burden or challenges one's death will impose on others).

This model of dignity in the terminally ill provides an empirically derived theoretical framework, helping us understand the notion of dignity at the end of life. It offers a foundation upon which to understand how a dying patient may experience a waning of their dignity and, in turn, provides direction for how to construct dignity-enhancing interventions for pattents nearing death.

Dignity Therapy: Based on our prior dignity studies, our group has developed and piloted a brief, individualized psychotherapy specifically intended for patients near the end of life. Until further testing and refinements to the therapy are completed, it is being offered to patients expressing psychosocial or existential distress, or patients indicating a need or desire to bolster their waning sense of purpose or self-worth. For dying patients, sensing that one is a burden to others is frequently based on a feeling of lacking any particular purpose. Engaging the patient in Dignity Therapy offers a tangible, meaningful activity, which may be of benefit to them and their family.

Most of the content of Dignity Therapy is guided by the Dignity Model subthemes of

generativity, continuity of self, maintaining pride and hope, role preservation, burden to others, and aftermath concerns. As such, Dignity Therapy provides patients the opportunity to create a legacy or generativity document, addressing aspects of life of which they feel proudest, things they feel are or were most meaningful, the personal history they would most want remembered, things that need to be said or they would want to take the time to say once again. Informed by the theme "aftermath concerns," the Dignity Therapy protocol includes questions that provide patients a chance to address grief-related issues, offer comfort, or even provide instructions, in the service of helping to look after their soon to be bereft friends and/or family. All protocol questions are based on the Dignity Model, and are designed to let patients speak to issues that might reinforce their sense of personhood, and sustain a sense of meaning, purpose, and self-worth, thereby decreasing distress or bolstering their quality of life.

The Dignity Model establishes the importance of "generativity" as a significant issue. As such, Dignity Therapy sessions are taped, transcribed, edited, and the transcription quickly returned to the patient. The creation of a tangible product that will live beyond the patient acknowledges the importance of generativity as a salient dignity issue. The empathic, nonjudgmental, and respectful tone of the therapist (informed by the notion of Care Tenor), along with the immediacy of the returned transcript, is intended to bolster the patient's sense of purpose, meaning, and worth, while tangibly experiencing their thoughts and words as still being valued. These transcripts are intended to be left for family or loved ones, forming part of a personal legacy that the patient will have helped shape and create.

In contrast to many other supportive approaches, Dignity Therapy is brief, can be done at the patient's bedside, and has the potential to favourably influence the patient as well as their loved ones. It borrows elements from various psychotherapeutic traditions, including supportive therapy and its emphasis on empathy and connectedness; logotherapy and its focus on "meaning"; existential psychotherapy and its engagement of issues such as meaning, hope, and mortality; life review; and life narrative. Unlike other psychotherapies, Dignity Therapy is grounded in an empirical model based on dying patients' self-reported notions of dignity. It also places less weight on interpretation, insight, and "working through," and more emphasis on the meaning enhancing process itself. While its application is limited to those maintaining the cognitive wherewithal to participate, it can and has been applied to very ill, highly vulnerable patients quite proximate to death.

CONCLUSION

Dignity is an important construct, particularly at the bedside where it can help to inform and guide care for dying patients and their families. Besides providing a broad framework for comprehensive palliation, it also informs the content and provides the theoretical foundation for a novel psychotherapeutic approach we have called Dignity Therapy. The phase I data of patients who have participated in the intervention are currently being analyzed. These results will form the basis for a randomized controlled trial, which will attempt to further establish the efficacy of this approach to addressing suffering, distress, or paucity of meaning and purpose in patients nearing death.

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AFTERTHOUGHTS

n spite of your impressions of Ruth Macklin, the author of a *British Medical Journal* editorial titled "Dignity is a useless concept", she is not a moral monster (1). In fact, one of the particular pleasures in attending the St. John's conference "Human Dignity, Narrative Integrity, and Ethical Decision-Making at the End of

Life: an International, Interdisciplinary Symposium on Dignity" was the opportunity to meet and get to know Professor Macklin. She bears no horns, has no witch's cackle; rather, she is a bright and articulate person who seems to have held up well under the barrage of critical correspondence her editorial unleashed. Like others who have entered into the dignity fray, she learned that the topic is not passion-neutral and, in fact, is often perceived as sacred terrain—ergo, watch your step or watch your back.

One of the primary concerns raised by Macklin's editorial is dignity's lack of definitional specificity. Attendees seemed to grapple with this problem, each presenting a take on dignity shaped by their own particular disciplinary, academic, or vocational perspective. (For some reason, the image of the Tower of Babel comes to mind; while I recall seeing lips moving, and recognizing snippets of language, meaning was sometimes hard to grasp or integrate into a collective whole). Christian, Islamic, and Tamil perspectives were offered, suggesting that, within those particular traditions, dignity has a reasonable degree of specificity or intellectual coherence. Others suggested that, particularly within social policy discourse, dignity is too vague a term to be invoked in the context of safeguarding human rights and basic freedoms.

Does this imply, however, that the notion of dying with dignity has no real meaning and the term itself no real utility when applied to bedside palliative care? Does a lack of definitional specificity automatically discount its importance in considering how to meet the needs of dying patients and their families? The notion of happiness, too, may lack definitional specificity; although we each arrive at it in slightly or even profoundly different ways, the place it brings us to has certain elements that we would all agree fall under the rubric of happiness. Similarly, while the notion of dignity subsumes considerations such as autonomy, respect, and acknowledgement of

personhood, the ways in which dying patients find this, or their health care providers engender it, are indeed multifaceted and diverse. For some dying patients, dignity is equivalent to autonomy and respect. For others, it is about achieving a quality of death devoid of pain or undue suffering; or being able to feel that their essence or influence will transcend death; or that they are able to safeguard the well-being of people they will soon leave behind; or that they will die in a fashion consistent with their internalized notion of who they are or were. Each of these ideas has been raised by individuals within the course of our program of research addressing the notion of dying with dignity (2–4).

Based on a limited sample of attendees! spoke to, it would appear that clinicians might be more comfortable with definitional ambiguity. Perhaps this speaks to the subtleties and uncertainties of clinical work, with responses to illness being as idiosyncratic as are people themselves. If dignity is viewed as a broad, overarching concept, subsuming a variety of salient issues, concerns, and corresponding therapeutic possibilities, it is one worth keeping in the service of helping patients die with dignity...however they might define that.

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