

Dignity, Respect for Dignity, and Dignity Conserving in Palliative Care

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One of the central concepts of modern hospice movement and palliative care is dignity. Palliative care retains the Asklepiian tradition of Western medicine which stresses healing, relief of suffering, spirituality, holistic care and dignity, for those with incurable diseases.

Autonomy, Dignity, and Respect

Kant referred autonomy or autonomy of the will is the ability for rational self-governing. Dignity means one is able to make his/her own autonomous decisions. Kant also referred respect as an attitude of deference or reverence directed at persons not just for their gifts or status, but for their dignity as autonomous creatures. There are recent narrowing and distortion of these concepts in health care ethics. Autonomy was narrowed to mean simply the ability of people to choose whatever they want. Kant's autonomy originally means to be able to stand back from one's immediate interests or desires, and to express moral values, or to be self-governing in being able to act in terms of rules which should be valid for all.

Dignity & Self-determination

The question becomes that if the patient wishes some treatments, does respect for the patient's dignity requires that they should be provided, even if these are not in their best interests according to professional judgments? Or are we only respecting the patient's self-determination? Are they different moral concepts? It is because Kant's respect originally means that this attitude is to be directed towards all persons equally.

In recent health care ethics, the object of respect has become the patient's self determination or his/her desires or choices, and to respect such decision seems to be simply to do what the patient wants, regardless of whether it is in their best interests or of its impact on resources of other patients.

Dignity / Respect for Dignity

Dignity is defined as the quality or state of being worthy, honored, or esteemed. It is a two-pronged professional value: respect for the dignity of others - other-regarding value and respect for one's own dignity - self-directed value.

Dignity taken subjectively has broad individual differences and idiosyncrasies. Dignity taken objectively is the basis of human rights. Dignity appears as a duty or a right in professional codes and human rights framework. UK Nursing and Midwifery Council code of professional conduct states that you are personally accountable for ensuring that you promote the interests and dignity of patients and clients.¹ Article 1 of the Universal Declaration of Human Rights states that all human beings are born free and equal in dignity and rights.²

Spiegelberg distinguished between dignity in general, which is a matter of degree, and is subjected to change. Human dignity refers to the minimum dignity which belongs to every human (basic human dignity). It does not admit of degree. It is equal for all humans. It cannot be gained or lost (objective view). Intrinsic dignity referred to inner self-assessment of own worth (subjective). Extrinsic dignity referred to responses bestowed by others. The subjective nature of personal dignity means that it can only be measured by knowing what these terms mean to the patient.³

Mairis suggested that dignity exists when an individual is capable of exerting control over his or her behavior, surroundings and the way in which he or she is treated by others.⁴ Haddock stated that: dignity is the ability to feel important and valuable in relation to others, communicate this to others, and be treated as such by others, in contexts which are perceived as threatening.⁵

Dignity in relation to oneself

Szawarski stated that a human being's dignity is based on respecting or preserving his or her own moral identity....my sense of self-respect will

be hampered when somebody or something forces me to act against my ideal self and thereby lose my self-respect.⁶ Shotton et al stated that dignity involves a match between circumstances and competencies. We lack dignity when we are in situations where we feel foolish, incompetent, inadequate or unusually vulnerable, or not in control of their behavior or circumstances. These definitions suggest that people should have a reasonable degree of autonomy.⁷

Pullman's ethic of dignity stated the danger to assume that people who lack the capacity for autonomy also lack human dignity, e.g. severe dementia. People still have basic dignity regardless of their levels of competence, consciousness or autonomy because they are human. It rests on basic human nature. Thus dignity is a concept with a much wider area of applicability than autonomy. Dignity is a normative term suggesting how human beings should or should not be treated in a given social or individual context. Pullman's concept of personal dignity is subjective or peculiar to that individual and is largely culturally determined. Respecting dignity requires certain basic forms of behaviors which we can all understand because we are all human (basic dignity). In addition, there are certain cultural or personal beliefs which the patients may have, about how to treat them in a dignified way (personal dignity).⁸

Dignity and Nursing Practice⁹

Dignity has two values: other-regarding by respecting the dignity of others and self-regarding by respecting one's own dignity, which requires an appraisal and recognition of one's own value and worth, both as a human and as a professional. American Nurses Association code of ethics states that the nurse owes the same duties to self as to others, including the responsibility to preserve integrity and safety, to promote competence, and to continue personal and professional growth. Moral respect accords moral worth and dignity to all human beings. Moral self-respect extends the respect to oneself: the same duties we owe to others we owe to ourselves, including personal growth, maintenance of competence, preservation of wholeness of character, and integrity. If we give our patients dignity, we need a little as well. When the dignity of nurses is not respected in tangible ways, then their own self-respect may be

compromised and their ability to respect the dignity of patients, families and colleagues is reduced.

Dignity in Practice

Aristotle's doctrine of the mean claimed that in relation to moral virtues, we can go wrong in either ways: too much or too little. Inappropriate amount of respect for the dignity of others can occur, including deficiency causing disrespect for dignity, and excess causing excessive deference/sycophancy. Respect for the dignity of others has to be balanced with respect for our own personal and professional dignity and with our self-respect. If respect is deficient, it results in subservience / servility; and if in excess, results in arrogance.

Our view of our own dignity or worth can be compromised by an over-concern with the views of others, which stems from status anxiety-a worry that we are in danger in failing to conform to the ideals of success laid down by our society. A proper response to develop dignity is to develop the ability to reflect critically and objectively on ourselves and on our actions so that we need to rely less on the views of others, and to consider our own measure of success and to consider more who we are, and why we need ethical concepts such as dignity.

Human nature and ethic of aspiration¹⁰

People are vulnerable physically, psychologically, emotionally, particularly in relation to dignity. People are fallible for they have limited sympathies, rationality and resources. Ethics is needed to overcome the limitations of the human predicament/condition. Warnock¹¹ writes: people are often not rational, either in the management of their own affairs or in the adjustment of their own affairs in relation to others. They are vulnerable to others, dependent on others, and yet inevitably often in competition with others. Human sympathies are limited and they may often neither get nor give help that is needed, may not manage to co-operate for common ends and may be constantly liable to frustration or positive injury from directly hostile interference by other persons. There is an infinite potential for human being to degrade, devalue and humiliate and also to be degraded, devalued and humiliated. This related not only to other people but also to ourselves.

Ethic of aspiration (Carr) as opposed to ethic of obligation reminds us to acknowledge vulnerability, fallibility and potential for dignity violations in humans, to aspire to do and be better, to pay attention to subtleties and nuances of everyday practice and demonstrate a willingness to learn.

Categories of Dignity Violations¹²

This includes not being seen—a person feels that he or she has not been recognized or sufficiently recognized and people are ignored, not spoken to, talked over or eye contact avoided, or being seen, but only as a member of a group and the individual character is denied, violations of personal space which may be culturally related. Mann pointed out that with permission, personal space can be entered without any loss of dignity, as in loving physical intimacy or in the context of professional medical or psychiatric care. Humiliation relates to being singled out for criticisms and separated from the group, and it leads to shame which is a profound and potentially wounding emotion.

Promoting Dignity in Practice

Professional practice can be highly complex and uncertain. We have to strive to understand more of the experiences of others and of ourselves humbly. People, including health professionals, are vulnerable and fallible. It is often assumed that when professionals know what to do they will naturally do it in the realm of ethics. Actually, ethical competence in practice is more complicated and requires more components of competence than knowing and doing, e.g. prudence, courage, compassion. It needs seeing and striving to see and perceive justly and compassionately— a just and loving gaze directed upon an individual reality which is the mark of an active moral agent.

It also needs reflecting to scrutinize self and other seriously with a commitment to betterment. It needs knowing the theoretical context of dignity in relation to human rights, and views of human nature. It needs doing and being in which the professionals demonstrate a commitment to acting and being better. The environment also has the potential to make people feel valued or devalued, worthwhile or worthless. Processes can be either dignity promoting or dignity diminishing, e.g. admission procedures, nursing procedures, handover.

Dignity in the terminally ill¹³

Latime (1991) argued that palliative care must be rooted philosophically in an acknowledgement of the inherent dignity of individual. Geyman (1983) listed dignity as one of the five basic requirements that must be satisfied in caring for dying patients. There is a lack of precision or consensus about the term dignity. The goal of this study is to explain the meaning of dignity for palliative cancer patients and to develop a conceptual framework that describes dignity from the perspective of individuals living with advanced cancer. This is an empirical research on how the term dignity has been used by terminally ill patients.

Methods

Patients were recruited from an urban extended care hospital with a specialized palliative care unit, comprising in-patient services and community based services. A consecutive sample of consenting cancer patients was recruited over a 15 months period. Fifty patients agreed for the study and their medium length of survival from the time of study entry to death being 82 days. A semi-structured interview was conducted to explore how patients cope with their cancer and detail their perception of dignity. The questions covered the following issues:

- In terms of your illness experience, how do you define the term dignity?
- What supports your sense of dignity?
- What undermines your sense of dignity?
- Specific experiences recalled in which dignity is compromised? Or supported?
- What would have to happen in your life for you to feel that you no longer had a sense of dignity?
- How do you feel about it- life without dignity is a life no longer worth living?
- Do you believe that dignity is something you hold within you, or /and is it something that can be given or taken away by others?

Each interview lasted about 60 minutes, taken either in palliative care units or in the home setting.

Analysis

Qualitative analysis

Latent content analysis and constant comparison methods were used. Categories, themes and sub-themes of dignity were

identified. A model of dignity that reflects associations between these resulted.

Results

Three major categories emerged from the analysis, which capture the experiences, events and feelings at where dignity or lack of dignity becomes a salient concern, the Illness related concerns, Dignity conserving repertoire, Social dignity inventory.

A) *Illness-related concerns that influence dignity*

There are two themes, and the sub-themes are specific to patients' illness experiences:

- 1) Level of Independence - the degree of reliance an individual has on others, and the sub-themes are cognitive acuity/thinking ability and functional capacity which is the ability to perform tasks associated with activities of daily living.
- 2) Symptom distress - the experience of discomfort or anguish related to progression of one's disease, and the sub-themes are: physical symptom distress, psychological distress - mental anguish related to the progressing illness, which includes medical uncertainty- not knowing, or being aware of aspects of one's health status or treatment; death anxiety - worry or fear associated with the process of anticipation of death and dying.

B) *Dignity Conserving Repertoire*

It includes the dignity conserving perspectives - a way of looking at one's situation that helps to promote dignity, and dignity conserving practices- personal actions that can reinforce one's sense of dignity. Dignity Conserving Perspectives include internally held qualities based on long standing personal characteristics, attributes, or an acquired world view and consist of eight sub-themes:

- 1) Continuity of self: the sense that the essence of who one is continues to remain intact, e.g. still viewing herself as someone worthy of respect;
- 2) Role preservation: patient's ability to function in usual roles and is in congruence with prior views of self;
- 3) Generativity / legacy: patient finding solace and comfort in knowing that following their death, they would leave behind something lasting and transcendent of death, or finding a

sense in their lives when they identify their accomplishments, contributions, connections to life (e.g. children, good works);

- 4) Maintenance of pride- patient may lose their dignity when they are unable to maintain their independence, positive sense of self-regard or self-respect;
- 5) Hopefulness- associated with an ability to see life as enduring, or having sustained meaning or purpose, e.g. having something to look forward to;
- 6) Autonomy / control - having a sense of control over their life circumstances and referring to the degree of autonomy the patient subjectively feels, despite of what he can or cannot do;
- 7) Acceptance - an internal process of resigning oneself to changing life circumstances;
- 8) Resilience or fighting spirit- the mental determination that patients exercise to overcome their illness-related concerns or to optimize their quality of life e.g. not giving up.

These perspectives reflect the unique characteristics of patients and may buffer against diminishing dignity as a result of advanced illness. Not every perspective will be held or exercised by all patients. The extent to which patients invoke these perspectives depend on individual and his or her particular style. These perspectives are not hierarchical - no one perspective appears to be more potent than the others.

Dignity Conserving Practices include personal approaches or techniques that patients use to maintain their sense of dignity. The sub-themes are:

- 1) Living in the moment - focusing on immediate issues in the service of not worrying about the future, e.g. to live everyday and be considerably happy;
- 2) Maintaining normalcy - carrying on usual routines and schedules while coping with the physical and emotional challenges of being ill;
- 3) Seeking spiritual comfort - turning toward or finding solace within one's religious or spiritual belief system.

Those with a more positive perspective are also able to invoke more dignity conserving practices.

C) *Social Dignity Inventory*

Social concerns or relationship dynamics may enhance or detract from a patient's sense of dignity. There are five themes of them. They are:

- 1) Privacy boundaries - the extent that one's personal environment is being encroached upon during the course of receiving care or support;
- 2) Social support - presence of an available and helpful community of friends, families or health care providers;
- 3) Care tenor - the attitude others demonstrate when interacting with them, whether it is caring or respectful;
- 4) Burden to others - distress engendered by having to rely upon others, arising either from feeling that oneself is a burden, or from the fear of becoming a burden to care givers;
- 5) Aftermath concerns - worries or fears associated with anticipating the burdens or challenges that one's death will impose on others leaving behind.

Outpatients were more likely than inpatients to state that dignity was intrinsically held and two-thirds of patients cared in hospital expressed the belief that dignity could be taken away by others. This may be due to the greater degree of autonomy in outpatients.

Proposed model of Dignity

Burdensome illness-related concerns and taxing social dignity inventory have deleterious effect on dignity. These negative influences might be buffered by positive dignity conserving repertoire. Sense of dignity is the final outcome of these interactions. Limitations of findings are: the study group composed largely of elder patients; all patients were in an advanced stage of terminal cancer; and the study was cross-sectional, but the perceptions of dignity may change with the fluctuating course of the advancing illness.

Dignity Conserving model of Care¹⁴

This can be used to explicitly target the maintenance of dignity as a therapeutic objective and as a principle of bedside care. This model considers three broad areas of influence on individual perception of dignity, while acknowledging individual differences and personal attributes. Each individual will ascribe varying degrees of importance to each of its

components. The first thing to do is to understand how a particular patient and his or her family perceive dignity and create interventions that enhance it. This dignity model of care will cover care that includes biomedical, psychological, psychosocial, existential and spiritual issues.

To manage illness-related concerns will include attentive management of physical and psychological symptoms and medical uncertainty, providing information about treatment options or the anticipated unfolding of an illness. To tackle death anxiety, we offer information about the way in which the end stage of the illness can be managed, and to bolster independence, we treat delirium, bolster patient's sense of autonomy and their ability to function as independently as possible by giving orthotic device, physiotherapy, occupational therapy, enabling home care.

To apply Dignity Conserving Strategies, we help patients adopt or expand their perspective on the illness situation, give them opportunities to maintain autonomy by participating in decisions about their care, convey respect for patients as whole person with feelings, accomplishments and passions, enhance the specific meaning of the patient's life at a given moment by adopting a more liberal policy on visiting, reviewing lifetime photographs or stories, engage them in meaning-engendering projects (organizing photo albums, writing journals, preparing one's obituary), giving them a sense that they continue to serve a vital function. Dignity conserving practices include helping patients connecting to a spiritual or religious practice or community, or facilitating their expression of culturally held beliefs or denominationally appropriate practices.

Dignity Psychotherapy

For some patients, dignity is maintained if something of their essence will survive beyond the event of death itself (generativity / legacy sub-theme). The patients are asked to speak into tape about various aspects of life they would most want permanently recorded and ultimately remembered. The therapy includes the following steps: patients ask a series of questions, focusing on things which they feel are most important and they would most want their love ones to remember; the interviews are transcribed and edited so they read like well honed narratives; the life manuscript is returned to

patient, to be left for surviving loved ones, providing a lasting legacy for their love ones and thus enhancing their sense of dignity.

To enhance patients' Social Dignity Inventory, noting that dying patients' perceptions of support are significantly related to psychological adjustment. Mobilization of social support network has to be balanced by each individual's wish or need for maintaining privacy boundaries. Opening discussions about burden issues and reassuring that others may consider it a privilege to be able to be with them, or look after them in the little time they have left are helpful strategies. Aftermath concerns are addressed by encouraging patients to settle their affairs, write an advance directive, make a will, or be involved in funeral planning. Try to convey respect and an affirmation of the patient's continued worth in care.

Conclusion

Dignity conserving care comprises not only what one does to patient, but how one sees patients. When dying patients are seen, and know that they are seen, as being worthy of esteem by those who care for them, dignity will be maintained.

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