



REVISED

CARING FOR THE DYING

by

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Caring For The Dying

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The process of dying and the event of death has changed in the past decade. Medical science and medical technology have pursued the illusive goal of irradicating disease through curative and preventive treatments . Rather than solely achieving its curative intent, science has made a secondary gain in that it has succeeded in prolonging life beyond its natural limits. Terminally ill persons, who once died from the acute onset of an illness, are now living with chronic conditions. Persons living with a life threatening illness, who perhaps only a decade ago would have died from their disease, are now living months to years , if not a lifetime, with a terminal illness. They must also live with the residual effects of their curative or life extending treatment. For the first time , people are living longer with terminal illnesses than any previous generation in human history. In living longer, their living can be a complex and compound matrix of suffering.

Longer lives with illness, longer lives with progressive debilitation, longer lives with unmanaged pain and symptomatology, longer lives with dementia, longer lives with loss of both social role and function can lead to physical , emotional, social and spiritual unwellness. It can be a time of oppressive victimization, compounded by a multitude of losses associated with the changes brought about by illness and its treatment. Combine this with the complexity of a health system which is disease rather than human centered, which values the positive outcome of cure rather than chronicity and the accompanying pain, suffering and debilitation, and you will have a prescription for intense loss, suffering and trauma.

With medical science's life extending measures, dying has become a complex life process. After a protracted continuum of dying, that can take place over months and years, death takes place. Death is a moment in time which can only be loosely predicted once someone is diagnosed with a terminal illness. Predictability primarily

depends on the diagnosis, the stage of the illness, the extent of treatment and the investment of an individual's will to live or will to die. In preparation for death patients, families and professional care givers can, if they chose and if the resources are available, influence if not determine, "how" one will die.

Living with a life threatening illness over the course of months to years, patients develop an extensive knowledge base of illness and its related symptomatology. They can become indoctrinated into medicine's pursuits. Over the course of the illness, patients learn to control or master a life focused on distressing symptoms. As a person nears closer to death, symptoms may increase. This may or may not be manageable, again depending on the disease's etiology and how it was treated. After months to years of curative pursuits, that initially or eventually became unrealistic goals, patients, families and health care providers may not know what else to do but to continue their pursuit of life saving treatment. When it is realized that cure is an illusory pursuit, the patient, family and professional caregivers may feel quite helpless. In their search for some measure of autonomy, euthanasia is often considered the primary means to regain mastery and control. In other words, after being associated with interventionist models that use science and technology to control disease, and when it is clear "that a person will die", "how they will die" may continue to be determined by similar interventionist techniques, values and beliefs. Either through continued aggressive treatment, where one eventually dies from the treatment rather than a direct result of the disease, or through an act of euthanasia, science may continue to be used to conquer illness, suffering and death even in a clearly palliative situation. Indoctrinated into a value system that values cure, independence, productivity, function and purposefulness, what value can the dying find within themselves if they failure to measure up to what science values? What value do they have to offer their families, to the health care system and to society as a whole?

In health sciences, the dying are those who have failed to achieve a cure. Yet, despite little or no promise of a curative outcome, the dying often continue to receive aggressive treatment. As medicine extends life unnaturally by either curative or palliative treatment, it is increasing longevity. Medicine would say that longevity helps medicine study how a specific disease performs over a longer period of time than nature intended. By monitoring the diseases development and behavior, science has pursued longevity for the knowledge it will impart. Perhaps one day this knowledge will lead to cure and immortality. With this possibility as an outcome, dying persons undergoing treatment can be viewed as experimental fields. Their own personal gain is more time. Science gains more knowledge. However as medicine extends life, the more complex pain and symptom management can become. The more complex the symptoms the more difficult it is to achieve successful clinical outcomes in palliative care. In an attempt to manage the complexities of life extending treatment, the dying utilize resources that could be more appropriately distributed to those who have a curative potential.

The dying are a costly population to society. Faced with continued and additional expenses in order to live, a compromised ability to make an income, reduced functioning and increased dependency on others, as well as an increasingly complex symptom profile which may not be manageable, the dying can not help but be perceived as a drain on families, the health care system and society as a whole. The pleasure of having a loved one alive can last for so long before the caregivers find that they are having to relinquish a great deal of life to sustain the dying member. Emotional and financial resources are the two primary demands placed on the family caregiving system. Separately or in unison, the patient and the family may come to the realization that no greater good will come from the continuance of the dying person's life and that all must prepare, if not participate in, the ushering of death.

What has changed dramatically in deathing is that patients and families often find themselves participating in end of life decision making that will influence the final days, hours and minutes of the dying. Where once physicians made these decisions in isolation or in consultation with other physicians, the relatively recent move to consumer's rights has brought about significant changes in how decisions get made. Consumers have demanded that the physician driven , hierarchical model be replaced by a flattened hierarchical or participatory model where patient, family and health care professionals work in partnership trying to achieve consensus about how the dying will die. This model relies heavily on a psycho-educative model which seeks to convey the necessary information to patient and family so that they may make an informed decision. Unfortunately, the discipline most responsible for conveying this information is the physician trained in curative medicine. It is unlikely that after a brief exposure to dying from a theoretical perspective in undergraduate studies that physicians will be continuously exposed to end of life research, end of life ethics associated with decision making and to current palliative care interventions. The medical model is primarily interested in having a decision made by the most responsible family member. It does not often consider the consequentialism imposed on the dying , on each family member, friend or significant other associated with the dying patient.

Even with a very effective psycho-educative process and outcome, a patient and a family participating in a consumer driven model find themselves in a maze of decision making and familial consequentialism that can have ramifications for the remainder of the surviving family member's lives. The burden of responsibility to family members, particularly in end of life decision making can leave a family feeling helpless, hopeless and second guessing their decisions for decades to come. End of life decision making

which can include “Do Not Resuscitate (DNR) ” orders, the cessation of feeding and fluids, and the removal of life support systems are dramatic realities for families to live with. They are often left to wonder what would have happened if they had decided otherwise. Without full medical knowledge they often feel that they prematurely aborted a family member’s life rather than their finally allowing nature to take its course.

Painful as the cessation of treatment decisions are, it is perhaps even more traumatic for families who pursue the unnatural and medically unrecommended pursuit of longevity. These are often families who are not given sufficient psycho-education about the consequences of their treatment choices. They may also be families who because of their own history of loss and harm, support the principle of “ life at all costs”. This is particularly true of people with a history of either genocide or previous traumatic loss . With this background, the unrecommended or illusory pursuit of life extending measures often presents families with memories that can be graphic and horrifying. In these cases, when families insist on continued aggressive interventionalist strategies, dying is often more complex because the treatment leads to multiple systems failing ie cardiovascular, gastrointestinal, neurological etc. For example, overly-extended treatment can result in dramatic episodes of bleeding from every orifice of the dying persons body, it can result in broken ribs and bruising from resuscitation, increased pain from trying to find an uncollapsed vein and the gross swelling of the dying person’s body as his or her system is flushed with fluids and pharmaceuticals. Those who most desperately try to avoid death through exaggerated life extending measures may in fact induce the most malicious of deaths . The impact of these memories must be traumatic for families although little if any research is being conducted into the co-relation between the impact to survivors and how the dying have died.

We know from the trauma literature that violent acts viewed by an audience has a traumatic impact on the viewer. We also know that clinicians in the field are increasingly reporting “complex bereavement” profiles in their families. The much renowned psychologist, Dr. Theresa Rando, whose area of expertise is family grief and bereavement collaborated with Dr. Charles Figley, a traumatologist, whose work stemmed from the United States veterans returning from war in Vietnam. Figley identified that many of these veterans returned home to discover that their trauma was only beginning as they suffered from Post Traumatic Stress Disorder.

The results of Rando’s and Figley’s collaboration is significant. Rando suggests that clinicians may be seeing an increase in Post Traumatic Stress Disorder after a death has taken place because of how people are dying in today’s health care settings either after an illness or an accident. Rando’s and Figley’s work implies that traumatic experiences associated with death can leave surviving family members compromised both at an individual and an inter-generational level. This means that “how one dies” can influence the health and well being of the survivors. Left undealt with, survivors of a traumatic death may begin to develop their own health related issues associated with the repression, avoidance or denial of what has taken place through the death. They may also remain susceptible to continued traumatization through their own memory of events, flashbacks or triggering from outside events such as the media or simply by hearing of other deaths within their community. It is likely that Post Traumatic Stress Disorder is associated with violent and traumatic memories of how someone known to the survivor died. Excluding acts of suicide and homicide, it is likely the violence or trauma associated with the dying may be a result of acute interventionalist strategies that produce a dramatic episode of unmanaged symptoms such as bleeding or seizures. It is also possible that trauma could result from the untreated process of

dying .

What are the consequences to the individual, the family , the caregivers and to society when aggressive interventionalist care is administered? The memories for the survivors of how their family member died are potentially traumatic. If families knew how their decisions for treatment were taking them into potentially harmful and hurtful areas, would they choose other interventions? Acute interventionalists would argue that patients receiving this type of aggressive care are fully informed about treatment decisions. Life prolonging treatment can extend a life, inducing more complex symptomatology and therefore a more difficult death. This only reinforces a family's fear of death. After the death, these same families often express their lack of trust in medicine for its history of creating illusory expectations of possible cure or a quality of longevity. Health scientists often view this breach of trust as a grief reaction related to the death itself rather than understanding that it may be a result of compound mourning or grief precipitated by a physician's information sharing regarding diagnosis and prognosis. Families can feel that there was an unrealistic emphasis, false hope, unfair expectations that led the prognostic discussions and ultimately determined the quality of a family's life over the course of the illness. In hindsight , a family who trusted the physician's judgment, but discovered later that the physician's judgment was biased or misleading, may feel that death was unexpected , a mistake, a happenstance, or a misadventure. In a palliative population any form of intervention carries certain consequences or risks that can be hurtful and harmful. The line between benefit and harm on this population is not so clear once intervention starts and once life is extended. Establishing a palliative philosophy and outcome of care helps establish a patient and family's expectations. Too often, the medical model avoids establishing this framework either because it feels it could distract from the benefit of treatment, that it causes psychological distress that might precipitate or

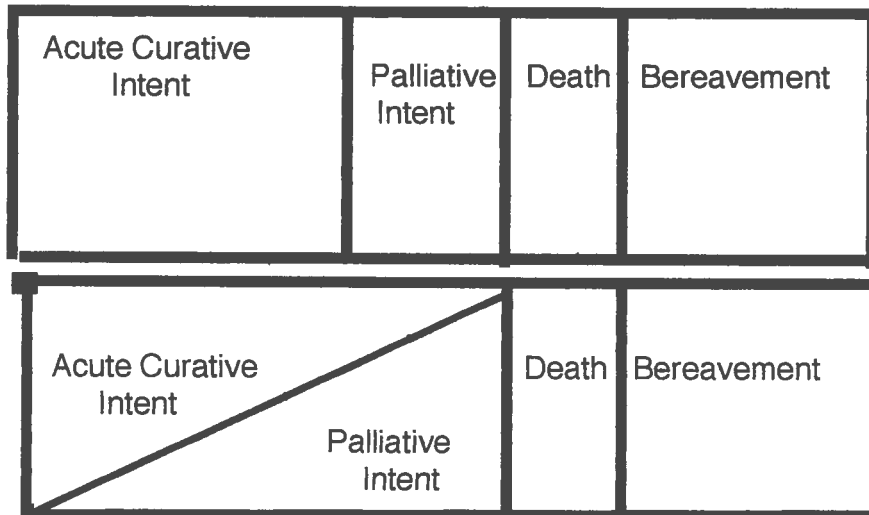
encourage more unwellness or perhaps because it is easier to avoid or deny the palliative reality. In this all too familiar scenario, it is evident that suffering from a life threatening illness can be enhanced by an organization, a team, a profession or an individual caregiver's approach to illness, death and dying.

Even though it is likely that a discussion may be held as to the intentions of treatment, it is unlikely that a discussion will be held as to how certain treatment decisions would influence "how" the patient would die. A psycho-educative approach conducted with the patient or the family to discuss how treatment lends itself to a certain profile of dying and death would help everyone anticipate the harm that may lay ahead of them. If decisions to treat were driven not by the principle of extending life but of preserving the integrity of that life, patients and families would experience death differently.

Acute interventionists and medical traditionalists would argue that the graphic depiction of how one might hypothetically die could be traumatizing to the patient and family. They might also argue that dying and death are not predictable so that aggressive life extending intervention is worth the risk to all involved. Saving a patient who is terminally ill so that he or she might extend their life span is a temptation few could deny. However, extending one's life so that he or she can experience future traumas and crisis in the illness trajectory is often what makes up the course of life extending treatments. More specifically, life extending measures are too often death extending measures. It is often not until the patient and family decide that they have had enough and that no further intervention should be attempted that medical science changes in its willingness to pursue aggressive treatment.

As dying has changed, the demarcation between life and death is not such a distinct line. Diagnostic technology can predict death from a disease process months to years

before it happens. Life extending and life saving interventions can retrieve people from the edge of life numerous times. Where once the distinction between life and death was a vertical line drawn in the sand, today it is a broken line from diagnosis until death.



(Diagram from Canadian Palliative Care Association Standards "Towards A Consensus of Standards" , 1995.)

In an attempt to manage the new reality of dying, society has moved toward models of decision making and legalism. Legislation aimed at end of life decision making and living wills promotes patient autonomy and determinism. The intention is to avoid treatment that the patient would find compromising and perhaps assaultive. The process of thinking through one's own personal concept of harm and benefit as it pertains to life ending treatment decisions can be a useful and purposeful endeavor for the individual . It helps set expectations for patients, families and caregivers about what will be. However, to think that generalized decisions made before the commencement of one's dying will be relevant to an anticipated but situationally specific circumstance may be unrealistic.

The move towards legalism is a start in terms of consumer's thinking about "how" they want to die. It is a move towards patient autonomy and participatory decision making. However, the legalism can not and does not support the moral decisions confronting the patient, family and professional care givers. Nor does the legalism protect family members from the sense of trauma and harm experienced by them as they try to have their family members' wishes honored by medicine.

Historically, and predating this trend in legalism, psychological models of care were used as the primary intervention strategy for care of the dying and their family members. The popularization of psychology made it a tool available to lay and professionals alike. Traditional models of grief and bereavement counseling are largely post-mortem models which look at separation, adjustment and adaptation to loss. From the earliest clinicians such as Freud and Lindemann, psychiatry has been observing and monitoring the visible signs of grief and bereavement. These observable signs were then recorded as symptoms associated with loss. Every clinical theory had a different phenomenology of symptoms such as sleep deprivation, the loss of appetite, searching for the lost object, the loss of social and occupational functioning, to mention only a few. In the last century clinicians have only continued to build on this symptom based paradigm of grief and bereavement. It became prescriptive treatment, standardized and quantified.

In their attempts to know and quantify grief and bereavement reactions, science pathologized the process of loss associated with death. Death from an illness has an underlying pathology. Grief associated with death became associated with the same paradigms of thinking. To a great extent grief and bereavement became a disease in and of itself rather than it being a normal human process to be lived through and

experienced as an inherent aspect of life. This, combined with medical science's commitment to eradicating disease, pathologized the physical, psychological and spiritual experiences of dying and death. As a result, disease no longer stands alone as the sole enemy for science to conquer. Dying, death, grief and bereavement are similarly demonized.

A system with these views has assumed certain beliefs, values, behaviors and practices. Rather than being a natural and inherent part of life, dying and death become unnatural events which take place as a result of medical science's failure to retrieve an organism from a threat to its survivorship. Death, even in the most predictable of circumstances can be seen as a failure, a happenstance rather than a natural event. Whether it be legalistic or psychological paradigms, neither are humanly adequate frameworks from which to provide care of the dying.

From the moment of human conception there is only one guarantee life offers and that is everything must die. As Shakespeare's Prince Hal tells Falstaff, we all owe death a life. To deny and avoid this predictable reality is to pretend that life is other than it is. Confronted by what is in essence the only predictable outcome of all life, human and otherwise, and indoctrinated by medical science's values and beliefs, patients, families, professional care givers and society as a whole can support the denial and avoidance of death's imminence. This is often done at the expense of maintaining the humanity, integrity and dignity of the dying patient.

The dehumanization, medicalization and pathologizing of death is never so evident as in the predominant thanatological theory of the last 30 years of terminal care, that being the work of Dr Elisabeth Kubler-Ross. Kubler-Ross proposed a staging paradigm based on a constellation of behavioral symptoms experienced by the dying,

their family and their professional care givers. Staging is a technological metaphor for what is done by rocket ships, and on assembly lines. It is also a medical phenomenology associated with disease processes. In this, Kubler-Ross drew from her profession's conceptual framework for assessing disease pathology. Staging is not a human paradigm which promotes compassion and addresses the complex needs and expectations of palliative populations. Research suggests that Kubler-Ross' theory was drawn from the rehabilitation literature of people who survived cancer not those who were dying. If this is so, health sciences has promoted a false theory in its use of Kubler-Ross' work to care for the dying. The theory was taken verbatim with few ever looked at the underlying research. In a healthy, non-terminal population, using an ungrounded and unresearched practice protocol would be akin to malpractice.

What connotes malpractice in care of the dying? Is it over treatment at the hands of the interventionalists? Or is it under treatment at the hands of clinicians who do not have palliative training or palliative skills? Given the inadequate standards of palliative medicine taught in health science courses and the increasing recognition that palliative care is a health science specialization, malpractice with the dying may be the norm. If this is the case, then patients and families are widely experiencing the mistreatment of the dying. If this is so who is to distinguish between the process of dying and the process of being mistreated for dying?

The average consumer knows more about euthanasia than palliative care. The consumer literature on euthanasia is now sold publicly whereas a few years ago such information was more difficult to access. Self help groups, Death with Dignity and Hemlock Societies abound. Driven by consumer demands for euthanasia, clinicians quite frequently find themselves being asked to participate in a physician assisted suicide or acts of euthanasia. Legally or illegally, actively or passively, euthanasia is

now a significant consideration in care of the dying. What is the need that drives such open requests to end one's life? Perhaps the underlying request is based on a fear of suffering, a fear that the dying will be taken to a place by science where he or she is no longer human, no longer recognizable as the person he or she was throughout life. Perhaps it is the last act of control in a health care system dedicated to conquering disease and having control over death.

The issues associated with death and dying have come to the forefront in the last few decades as the dying became a distinctly identifiable population with special needs. There are very few courses that teach comprehensive care of the dying. Most courses train people in some aspect of the field of thanatology. Pain and symptom management courses are offered through faculties of medicine and nursing. Few clinical thanatologists exist. If the training in care of the dying is in its earliest developments, care of those dying patients who request euthanasia are even more rare. Demands for euthanasia have so infiltrated the popular consciousness that few if any health care professionals have received training in a therapeutic response to these requests. For the most part, clinical responses to requests for euthanasia are dealt with from a moral or legalistic stance by health scientists, rather than exploring the underlying fears, suffering, and meaning.

Is legalism and moralism a humanly adequate response to suffering? With the move towards legalism to deal with issues related to death and dying, health care professionals are increasingly being held accountable to codes of ethics, their professional colleges and in the court systems through legal suits. When a dying person asks for an act of euthanasia, the health care professional, no matter what their occupational discipline, is placed in a dilemma. What can the response be in a world that becomes increasingly legalistic and moralistic in dealing with death and dying.

For most health care professionals , driven by professional accountability , the response must be “Don’t talk like that-there is a lot to live for!” , or “I’m sorry, I can not speak to you about that , killing yourself is illegal”, “Think of your family and what it would do to them” , “ If I speak to you about how to do that then I am guilty of helping you kill yourself ”. Are these professionally accountable responses, humanly responsive to the dying person at the level of their suffering? Whose needs are being met in these statements, the patient’s or the system that determines care ? In these limited and limiting responses the caregiver and the system are avoiding the legal risk of entering into a discussion about a person’s wish and will to die. The issues of how suicide is different than an act of euthanasia or assisted suicide can not be covered in this paper. However, the will to live and the will to die is the essential struggle of the terminally ill . Clinical paradigms have not as yet integrated this reality into care of the dying. Perhaps this is because the majority of paradigms are psychologically based . The tension created by the will to live or the will to die is largely a spiritual crisis which is not always well served by psychology. It is also within this crisis that the essence of an individual’s spirituality, as he or she is dying, becomes evident.

When health care codes of ethics were being written and when professional colleges were developing, dying people were often diagnosed with a terminal illness and died within days, weeks or months. If dying has changed, then our responses to it , our ways of managing it, the values and beliefs associated with it should also change. However, too often the gap between what the average health care consumer expects to be possible and what is possible in terms of cure and longevity is neither identified nor dealt with. If we are the first generation in human history to be able to live years if not a lifetime with a terminal illness, why is it that we are not more realistic in our expectations of what this will look like, how it will be experienced? Living a lifetime with a terminal illness can be a blessing or a curse. It largely depends on one’s will to

live and one's will to die. How one invests one's will often depends on a variety of factors that influence the quality of one's life. If there are few clinicians who specialize in clinical thanatology, then how can the dying expect the optimum in their quality of life?

In a health care system which values success as cure, the dying tend to become marginalized in the system, unless they continue to take curative treatment. Even if the goals are palliative in nature, the same curative tools of chemotherapy, surgery, radiation and rehabilitation are used to keep a person alive. It is easy to forget that one is dying in such a system. It is also easy to enter into the hope that despite the clinical evidence pointing to death there is a false expectation that cure might take place.

In a society that values productivity and frowns upon dependency as something which drains families and society of its much needed drive towards purposeful activity rewarded by income, can the dying find their worth? While science has extended the average lifespan of someone living with a life threatening illness, few have thought out what one does with this time and changed ability. Most of the world's social programs have not kept up with the medical realities. In the working world, companies rely upon their employees to be producers. If the sick and dying are busy with the business of trying to stay alive, it is unlikely that they can be producers for their employers, even at a part time level. One of the primary symptoms in any form of life threatening illness is fatigue. The only treatment of this is rest, balanced with nutrition and ambulation.

With the dying being kept alive for so long, their family members must take time away from work to attend medical appointments, as well as begin to take on the tasks of the dying's activities of daily living such as cooking, cleaning, shopping, laundry, bill paying and recreation. While benefits may exist in industrialized countries for maternity

and paternity leaves, few exist for caregiver leave in order to tend to the dying. Unsupported socially and financially, divided between what must be done to support their life and the life of their dying family member, the survivors often embrace the task of caring for their loved one. Over the course of weeks, months and years this continued commitment takes its toll. Families become depleted, exhausted and in their fragility they ask "when will this be over".

The dying are only dying, they lose their bodies but not necessarily their awareness. They are seldom without an understanding of their family member's wish. The dying often voice their concerns that they are draining the family of its life force and that an act of euthanasia would remedy this. Confronted by this sacrifice the family members often begin to argue that the dying are mistaken, that caring for them is not depleting. In this single interaction, the dying invest their will in dying, the survivors feel remorse and guilt because perhaps in their fatigue they have wished it to be so. The dying can feel abandoned and selfish for having lived too long. The survivors wonder about their own lack of fortitude and self centredness. This can lead to complex mourning with unresolved grief. Unless addressed, this dynamic can lead to a bad death for all. With the patient dead, family grief and guilt may become all the more complex to resolve.

A decade ago it wasn't unusual to hear palliative clinicians claim that people could die pain free. This has changed. Today, few palliative clinicians would make such claims. If they do so they are likely quoting from a theoretic knowledge rather than from a practice knowledge. It is not so much that palliative care is ineffective but that medicine has increasingly developed a more sophisticated arsenal to attack disease. Palliative care has not had similar funding to invest in complimentary research and education. Disease and health are a profitable business. Pharmaceutical companies want to find medicines that cure. Research funds are given to physicians who have

impressive curative statistics. Billions of dollars are invested yearly into curative medicine without necessarily curative outcomes. Palliative Care simply does not have such resources. If it did, perhaps progressively more sophisticated palliative interventions could be developed and utilized.

Why is it that more of medical sciences and the pharmaceutical monies are not invested in palliative strategies? Perhaps it has to do with the role of the dying in society. As medicine increasingly adopts a business ethic in order to meet the demands for research based practice, medicine is asked to examine what it produces. Ideally its most valued product is healthy productive individuals who despite a history of being unwell, are able to be fully employed occupationally and be valuable members of society.

The dying, as they are dying, are purposeful to medical science as long as they continue to take aggressive treatment. By discovering how long one can extend life, how many times medicine can retrieve life from its edge, the dying remain productive and purposeful in society for they are fields of research. Outside of this function, the dying are not producers for society. Some would argue that the dying not only fail to produce anything valuable but they also tend to deplete a family and society of resources that might be used by the living. In this the dying consume much needed resources that could be used to promote and enhance the quality of life for the living. The dying know this of themselves although it often remains unspoken by them. It must then be said that their suffering can be enhanced by the scientific and social value placed on them.

As science pursues cure, what will be enough cure for surely death is inevitable for all that lives. If science pursues longevity how much longevity will be enough? Day to

day, medicine's momentum is to extend life just a little bit more . Taken to its natural end medical science is perhaps not really searching for cure and longevity but rather immortality. Should it succeed, immortality could be enormously costly unless those who are preserved are producers and consumers of goods. Deciding who has a right to live and a right to die, who must die and what criteria must be met to grant immortality would be decisions to be made. Who would make these decisions ? What criteria would be used to make these decisions? Likely these decisions will look back on the palliative literature to help in its decision making.

Given this history of thought, how will our generation influence the future decisions on life and death? Dying has changed and the average individual , as well as society as a whole, seldom recognizes this until they are in the midst of the experience. Burdened with the multiple decisions and tasks associated with care of the dying, the end of one's life is no time to begin to gather the much needed expertise to die. Driven by the imagination of medical science, we lack our own imagination about what is possible in dying. To speak about helping someone die often means an act of euthanasia when in fact there are so many more choices.

Who but palliative care clinicians, well versed in all aspects of dying, including acts of euthanasia, can do this education? It is not enough to know how the dying die. We must also become experts on how the dying live, for ultimately this will effect how the dying die and how the survivors survive. Unfortunately, because of the legalisms that guide health science, palliative clinicians are often reluctant to enter into a full discussion about the choices of living and dying particularly as it pertains to euthanasia. Whether it be acute interventionalists, palliative care clinicians or euthanasiasts , the Death Awareness Movement is comprised of factional components each defining their own concept of what is a "good death". Partisanship must give way

to partnership for the sake of the dying and their survivors if end of life care is to be championed.

Is it naive or unrealistic to conceive of a care system tolerating a variety of models of dying? Can we bear the aggressive interventionalists who, driven by the principle of “ where there is life there is hope” , see life extending measures as the only moral response to dying? Can the interventionists accept that their pursuit of longevity is often the reason people are afraid to die? Can palliative care , which once stood in antithesis to the interventionalists, adopt a mediating role and help make a more gentle transition from aggressive intervention to palliative treatment? Can palliative care develop more effective clinical paradigms which not only standardizes clinical outcomes as a norm to be achieved but also begins to provide the leadership in speaking about dying in an open, clear and direct manner? Can partnerships develop so that patients, families and caregivers can help influence the process of dying? To speak about death is not only to speak about pain, grief or suffering . It is not only to write a living will. It is to enter into a dialogue early on in the diagnosis, if not from the moment of diagnosis, to determine how one wants to live and die, to determine what would be an unacceptable condition to find oneself in while undergoing treatment. End of life care requires that this dialogue is held repeatedly so that all participants are accountable to the changes that develop. It is in these discussions that the dying patient and family come to tolerate or despair in the wake of their suffering. It is in this wake that the caregivers begin their deeper work with the dying.

Without these discussions the acute interventionalists may be responsible for many bad and traumatic deaths. Science must look at what it is doing to death in its attempts to conquer disease. Palliative Care must admit to the limits of its abilities given that dying has changed. Palliative Care must confess that it can not manage all pain and

symptoms and that some clients may therefore choose euthanasia. The euthanasiasts must not work exclusively on the ending of a physical state but also develop family models of psycho-education and after care which deal with a family's sense of grief associated with an act of euthanasia or assisted suicide.

Since the advent of palliative medicine and hospice care, there has been an assumption that how one dies is more than a physiological event. That dying can be a profound human experience that witnesses to the growth of all those associated with the dying, that as the body diminishes something else can be given birth to. Traditions drawn from a variety of spiritual traditions such as the Tibetan Buddhism and Native American spiritualities suggest this also. However, because medical science has viewed death as the failure of an organism to thrive, it has viewed dying and death as a physiological state. Science views the body as parts that are functional and dysfunctional. Dysfunctional parts have to be removed or replaced so as to enhance function. This functionalist model does not take account of what, besides function, makes up a human being. Indoctrinated into functionalist values the dying do not know what else to do but function. Socialized by such a system, the dying can not help but feel the essence of oneself is lost when functioning is diminished or lost. Few clinicians sit at the bedside of the sick and dying and speak about the values inherent in science and society today. Few clinicians deconstruct the value and belief systems associated with illness and disability, challenging their principles. Few clinicians then reconstruct a value and belief system for which the dying can live and die in. Few clinicians prevent the dying from prematurely abandoning their familial role, few re-role the dying into a new position in the family as someone who has a potential to avoid more harm for the family, as someone who can heal some of the hurt endured, as someone who will leave a legacy of human courage, of someone who at death was more than their disease.

Throughout time and cultures the dying and the dead have had a role to play in the sustaining of society. When death came upon us quicker, perhaps this role was more significantly a part of the survivor's consciousness than the dying themselves.

However, now that the dying are living longer, there is a very real opportunity and need for the dying to develop a new role and function in the family. The dying can determine a sense of what they can do to promote family health and well being as well as familial survivorship, for this is the purpose of a family to help its individual members to grow and survive. The dying can assume this role, if they are allowed to give value to their diminishing lives.

With time to be conscious of death, with an environment and clinicians to support the exploration of this consciousness, the dying can become more than an experimental field for research. For some this time can be an opportunity for personal growth, a time to reflect and explore the meaning and experience of a life lived and suffering endured. It can be a time to formulate and propose a philosophy of one's life which family and friends can inherit. It can be a time to construct the tapestry of one's life. To bring closure on relationships in a ritualistic manner, to celebrate life lived and love experienced. It can be a time for confessions, admissions and forgiving. It can also be a time for a long awaited conflict to come to culmination. This time in life can create a spirit for the next generation to abide by or distinguish itself from. It can be the remnant that fortifies the survivor's life. It can be the legacy that the dying leave to be remembered by. In itself, it can be a person's sense that the integrity of his or her consciousness will survive bodily death, preserved in the consciousness of others or elsewhere, depending on how they view life after their death. The work of the dying, if they are allowed to step outside of the traditional values attached to dying, can be deeply spiritual in thought, word and deed.

We know from family theory that one generation effects the next generation in terms of values, beliefs, habits, behaviors and coping strategies. Dying in a contemporary western health care system at least affords us time . How we use that time to construct the end of our life may be the most significant act of our lives . The legacy we leave to our family, friends, and community of caregivers can bring comfort to the bereaved. No matter which venue of dying is chosen, there is a great deal to accomplish in the tasks of dying.

How can clinicians step out of the legalisms and the psychological paradigms to begin developing methodologies for working differently with the dying? Explorations by science into what is consciousness and mindfulness began sometime ago by researchers but few clinicians feel comfortable integrating this research into practice so that the dying can feel free to speak about the experiences of dying, their dreams, their nightmares, their near-death and out-of-body experiences. All of these experiences lend themselves to a dialogue about consciousness, and the nature of death itself.

When science assumed the responsibility of the dying from religious orders , it was because religions tended to pay insufficient attention to the physiology of illness and dying. For religion so much that mattered was the soul or the spirit of the individual. In assuming responsibility, medical science become similarly myopic for they only tended to dysfunctional parts, rather than care of the whole person.

Clinicians steeped in theory of "how" one will die can influence the dying process. Based on an astute physiological description of how one will die, which largely comes from medicine and nursing, other disciplines can begin to optimize the patient's quality

of life and do some of the preparation so that forearmed about death is forewarned. When death is demythologized for patients and families, when the Hollywood scenes of both a peaceful death and an act of euthanasia are also demythologized, patients and families can usually bear up under the weight of what lies before them.

The success of these interventions depends on clinicians who are risk takers, who do not accept the legalistic stance and who are prepared to reform the systems that care for the dying. The success of these outcomes depends on thanatology viewing itself as a specialization. Clinical paradigms must draw from the history of care and then propose new models of care that are pre-mortem rather than post-mortem.

Thanatology must work pro-actively not reactively with the trauma associated with dying and thereby begin to work from a preventative model of practice that helps dying people die with their self-identity intact, a self that may have changed, grown or perhaps been diminished, but nevertheless a self that draws a conclusion to this life and simultaneously speculates on what, if anything, makes up the next.

Life after death has historically been viewed as a matter for religion. However, again the consumer model and the populist literature have the dying reading about out-of-body, near death experiences and then speculating about a life after death. Normative medicine and psychiatry have traditionally viewed these as delirium states induced by drug reactions, disease and grief. Based on this perspective, the dying often die feeling deluded, mistaken and crazed. Like other allied health professionals, chaplaincy's comments about the nature and meaning of the dying's experience are not always welcome data on a medical chart which values data about the provable and quantifiable. Furthermore because of chaplaincy's history both within health care settings and its own traditions, it may inherit much of the dying's spiritual experiences in private. How much of these spiritual experiences are conveyed either verbally or

written in the medical chart is unknown because historically there has been a fear that such notations would instigate a psychiatric response to a spiritual confession.

Clinicians versed in the literature about the nature of human consciousness, altered states of mind and a variety of afterlife phenomenologies could change this. To a great extent, the experiences of the dying go unrecorded. The inner life of the dying is often observed as a physiological and psychological state. This is not enough, for there is so much more that is often experienced but unexpressed .

Dying in today's health care systems often resembles a ride on a roller coaster going backwards. The patient, the family and to some extent the professional care givers can only hold on and hope they endure the ride. Our destination is clear but we can not see how many ups and downs there will be or how many times we will go around before the ride stops. Patients and families enter into the roller coaster with only the best of intentions and hopes. Health care professionals who have been trained to see disease as their mortal enemy also enter into the care of the dying with the best of intentions and hopes. However, health care professionals can not help but know more than the average consumer does about the ride being rougher than they can anticipate. Health care professionals are caught in this dilemma. In not wanting to frighten the consumer with too much information too soon, in wanting to attend to the need for hope knowing that a patient's attitude can play a significant role in longevity if not cure, yet feeling compelled by the need to begin somewhere and somehow to prepare the dying to die and the survivors to survive.

As a result , a gulf exists between what is known and what can be conveyed. The struggle begins between measuring the harm and benefit of information shared and treatment given. The struggle continues, driven by the fear that something might kill the

patient before he or she is able to die. Both health care consumers and health care professionals resist death, making it an enemy. So pervasive are these values that it is difficult to imagine death in any other way.

From birth, death is a companion that follows all that is living. How you enter into a relationship with death is to a great extent how you live life, for death can come in many forms, in many measured ways throughout life. How you live with death to a great extent determines "how you will die". Trapped within a system that views death as an evil to be overcome, as an opponent or as an unnatural part of life, only the very brave or the very foolish are willing to entertain any other imagination about death. But imagine we must for the future of our dying and our living depends upon it.

Case Examples

Case 1

Heather Cluff was a 16 year old girl, living in Northern Canada with her family. She was a scholarship student in 11th grade. Her mother Nancy was an intensive care nurse, her father Jim an occupational health coordinator who inspected working conditions and tried to prevent accidents. Heather had a younger brother Brian , age 14 and a sister Sarah, age 8. Heather also had a dog named Lucky. Her grandparents lived in Florida. Her uncle in Paris, France. She had long red hair, ice blue eyes, freckles and a beautiful smile.

At age 16 she was diagnosed with a life threatening gastric sarcoma. Surgical intervention proved unsuccessful as once her abdomen was opened it was clear that the cancer was so entwined with her gastric system that surgery was not going to be possible. She underwent chemotherapy, losing her long red hair . She also lost

considerable weight and looked anorexic. She became too weak to walk and so remained in bed or in a reclining chair. She could not sit up as her abdomen was so swollen with the tumor she looked to be 9 months pregnant .

Her mother Nancy lived at the hospital for 6 months sometimes staying at a local nursing residence. She had to take a leave of absence from her job thus limiting the family to one income at a time that their expenses from living in two cities and meeting their children's every need increased. Heather's father, Jim cared for the other children as well as taking on the responsibilities of the household such as shopping, cooking and cleaning. He and his children acknowledged he did less well than his wife at these tasks. Both parents felt that somehow the healthy children were being neglected.

I met Heather 10 days before she died on the night her final surgery was canceled. I was paged by staff as I left the hospital because Heather knew what the cancellation of surgery meant . I approached Heather's mother and asked if I might speak to her daughter about her dying. Naturally after 6 months of acute treatment avoiding any mention of dying, Mrs Cluff denied me access to her daughter. I pursued this request, quietly insisting we had little to lose and that Heather could ask me to leave the room if she was offended by my words. Heather was known as a "dragon" for her fiery temper and for the number of clinicians she had asked to leave her room, never to return in the course of her six months of treatment in our hospital.

Finally in surrender, not knowing what else to do , Heather's mother consented to my request . I entered the room with my colleague an occupational therapist in Palliative Care. As Heather lay in her reclining chair, I sat on a stool , lower than Heather's eye level, so as to enforce a sense of equity with her , rather than my hovering over her. I

asked if she might listen to me. If she agreed she could nod. If she disagreed she could motion for me to stop. Listening took much less energy than speaking or writing. I knew she would be successful at this our first intervention. I began to search for Heather's value as a dying person, a value that I believe is inherent in the sick, disabled and dying. I took her out of her role as submissive, helpless dying patient and offered her the opportunity to develop a new role, a very important role.

I told Heather that over these many months I thought she had protected all of us, her family and care givers from the knowledge that she was dying. That while she took treatment and endured pain knowing she must try, she never let on that at times she knew it would not work. I said in this she was brave for she had offered us hope. At this point Heather's hand which rested on the arm of her reclining chair moved over and took my hand. She nodded in the affirmative. Given Heather's history of throwing people out of her room, this was a significant gesture. Heather's mother began to weep quietly at the courage of her young daughters admission. It hardly seemed likely in one so young, known so well by a mother who had lived with her these many months.

I did not go into the sorrow of the failed treatment. I did not explore her grief that night for it was already a day full of loss. Instead, I asked Heather to do some homework for me. I said that the next day I would return and we would begin to do what we must to help continue the healing she had started so many months ago with those around her. I asked her to think of the last 5 minutes of her life and what would be important to her, what would be essential so she had few if any regrets about how she was leaving others behind. I asked her to imagine how she would maintain her relationships with those she loved so she would be remembered for her life force rather than her illness. On the night Heather went to bed knowing she would die soon, Heather was

dreaming of something else to do besides dying.

It is impossible to do justice to what came to pass . In the course of the next 10 days, Heather had a celebration of life party at the hospital for 20 of her school mates who bused in from the north to celebrate her friendship. After their arrival, I had a 20 minute psycho-educational session with them to teach them about what to expect from Heather-how she looked, what she would feel, how she would fatigue easily, how it would be difficult to speak about what was happening. I asked her friends to think of a way to greet Heather that would fill in the space created by the silence following their greeting of her. I then left the students to plan this drama. When I brought Heather into the room, pushed in a chair by her mother, a staff nurse and myself, attached to intravenous and pumps-her friends sang a song "Cluff the magic dragon"-taken from a 1960's song by Peter, Paul and Mary, "Puff the magic dragon". They sat on the floor, knees bent under them, shoes removed from their feet and attached to their knee caps. They looked like midgets. They did this so they could be at eye level with Heather in her chair. One spokesperson, also 16, approached Heather and said they had traveled through a snow storm to come celebrate their friendship. They laughed and told stories and when Heather tired we took her back to her room. One by one her friends came to her, sat beside her on the same stool I had sat upon that first night and from there she asked each of them to do something for her. Some she asked to walk her dog Lucky, some to play with Sarah, some to watch over Brian at school, some to have Saturday tea with Heather's parents once in a while. She gave each of them a gift, bestowing on them a piece of jewelry that she had purchased through funds raised . Each piece of jewelry was engraved with "friends for life". When her friends left the hospital , the palliative care team had another session in the school bus before the students returned to North Bay. They wept and I reminded them of their courage to come and face their friend's suffering, of their gift to Heather which confirmed that

their shared friendship and love surpassed the time and distance between them.

When the friends arrived home some five hours later their parents awaited them in the school parking lot. The children alighted from the school bus singing "Cluff the magic dragon". It is reported by the parents that the children were full of joy as they told their parents of the day. The parents didn't know what to make of this for it didn't meet with their expectations of what grieving children should be. Each day after that the friends sent FAXED letters through to Mt Sinai to stay connected with Heather in her final hours. We posted them on the walls of Heather's room for all to see.

In the remaining days, Heather taught a class of medical students at the university who were studying palliative care. She presented them with a well thought out 10 point plan on how to care for the dying. She had wanted to be a physician and grieved over this loss of future. When this dream wasn't possible, she and her parents were pleased to think at least in her lecturing, she might influence future generations of physicians by making medicine more sensitive as a result of her own experience with suffering. She of course was too weak to read the points but members of the team helped her achieve this. One of the students fainted at the sight of Heather's suffering.

Heather bought \$70.00 worth of stickers and had her sister Sarah cut up each packet into individual stickers. She then asked that the word be spread to everyone in the hospital who had ever treated her to come for one final visit. She gave each one of us, and there were hundreds of caregivers, a sticker to symbolize who they'd been to her. With the stickers came a thank you from Heather for having tried to save her. She did not want people to feel they had failed her. The caregiver on the team closest to her, the occupational therapist, received a humming bird, for all the times she buzzed closely to Heather, reaching inside her to draw what she could from her suffering. I

received a rose with a thorn. To this day, many years later, we still wear our stickers on our name tags and our pagers to remind us of what is possible when the dying are allowed to do their work in concert with a team of people dedicated to facilitating the role of the dying as they bring closure on their life.

When Heather died, her brother Brian phoned the school and informed them his sister had died. He felt it was a way he could care for his sister by telling them "how " she had died quietly in her bed. Heather's father and mother were stunned by their son's courage. This is only a small part of the story but enough to realize some of what has been said in the body of my paper.

Case 2

Sam was a 65 year old Jewish male, married with two adult married sons. Sam was a child survivor of the holocaust. He had been in many camps and was to have been executed many times. He dug graves for his family and community before they were shot and buried. Just before Sam was to be shot, his uncle had him smuggled out of the burial ground, returning to the camp barracks to await the next execution. One Christmas eve the camp's commandant and some soldiers had been celebrating. They came to the barracks to shoot a few prisoners. As they began to select the most vulnerable, Sam, who was 10 years of age, sang a Christmas carol-the only one he knew. The commandant began to cry and then ordered his men to leave. He turned to Sam and said "Tonight your song has saved lives".

Sam survived the camps although he had no family or home to return to. He had seen many gruesome and horrific sights in the camps and at the executions. He came to Canada, married had children and was a very successful business man. He loved his family. He also spent time singing at local homes for the elderly trying to bring some

happiness into their lives.

Some fifty years after his surviving the camps he was diagnosed with a gastric cancer. Was this a result of what he had had to eat in the camps to survive? Was it a result of the stress he had endured in surviving? Was this another cruelty from a God that allowed him to survive the extinction of his family of origin only so he could not grow old with his own sons, not know his grandchildren.

Sam raged against and feared death because of what he knew of it. We spoke about his death images drawn from genocide, torture and humankind's inhumanity. We spoke about how he had escaped death so many times, it seemed unbelievable that this time he would not succeed yet again. Each time he came into hospital he became very upset. Over time, I realized why. From the time of his admission we put an identification band on his wrist with a patient number to identify him. We took down his demographic information. We took his clothes away and gave him a patient gown. We spoke about collaboration and experimental surgery. We asked him if he wanted to go to the showers . In our care, we triggered ancient memories of times gone by. Identifying this phenomena led us to develop a special care plan for holocaust survivors and to ask about people's "history of harm". Canada is a country of immigrants most of whom have fled persecution, starvation or genocide at one time or another.

Sam found little meaning in anything but bringing people happiness with his songs. I spoke about the legacy of his songs. I wondered if there would be a way for his grandchildren to know about how he saved lives with songs. He told his son of our discussions. His son contacted Stephen Spielberg's film company which was documenting "righteous people" using money from "Schindlers List". Spielberg sent a

film crew to Toronto. They filmed Sam as he told his stories. They filmed him with his family surrounding him. Sam left a copy of this to me in his will so that I might teach others that in the face of death, the only choice one has is how one faces it. Sam did not want to be remembered as a survivor of the holocaust or for his fight against death. Sam wanted to be remembered for his singing and the love he brought into the presence of death, so that others might fear less.

Summary

To help the dying live, to help hold them accountable to the time before them, to help them reflect and bring closure on time past, is to help them die. To clinically alleviate their pain and suffering so that they might accomplish the closure of their life in a meaningful and purposeful way is appropriate clinical care. To accomplish this through activities associated with the tasks of the dying rather than solely through psycho-therapeutic models that deal with grief and illness must become a part of responsible clinical practice.

Clinicians can help create the opportunities whereby the dying leave memories behind to comfort and sustain their family members. What can be left behind is a memory that, despite months of disease focused treatment, reaffirms the humanity of the dying, enhances their personhood, and creates a legacy that is not the story of their disease but is a story of their life and their courage to endure suffering. Through this process of story telling and reflection, dying and its associated suffering can become a means by which people can be transited to a spiritual world view.