Speaking of Death: Representations of Death in Hospice Care

We need the power of modern critical theories of how meanings and bodies get made, not in order to deny meanings and bodies, but in order to live in meanings and bodies that have a chance for a future.
-Donna Haraway (1991, p.187)

In his short story the *Death of Ivan Illych*, Tolstoy (1886/1960) identified a major cultural transformation. Ivan, a pathetic Russian bureaucrat, lies at home sick and in pain. His wife, friends, and physician are courteous but detached, more preoccupied by the state of his organs than anything else. This polite charade continues until Ivan suddenly realizes that his condition has nothing to do with his kidneys. It is not about his liver. He is not sick. He is in fact dying. With this realization, Ivan lets out a ghastly shriek at the horror of his predicament. In this brief narrative, Tolstoy vividly captured an important conceptual shift, occurring over a century ago, in which the language of death was slowly being displaced by a language of disease (Ariès, 1981).

It is common today to conceptualize death through the stories provided by modern medicine. The language and metaphors by which death was traditionally spoken of – as a challenge, as life's last great act, or as a transition to another world – have given way to the materialist metaphors of modern science. One speaks about terminal illnesses, about dying of cancer, dying of AIDS, dying of heart disease. And one relates to mortality through these concepts. Distance from death can be 'gauged' through T-Cell counts, cholesterol levels, blood pressure measurements, and, undoubtedly sooner than we think, through genetic tests of various kinds.

The medicalization of death has clearly afforded numerous benefits. However, since the late 1960's there has been a growing criticism of medical rationality and, in particular, of its narrow focus on the body and its tendency transform each instance of death into an 'emergency'. Ivan Illich (1976), for instance, claimed that in medicalizing death, the medical community had removed it from the cultural/personal realm and had transformed it into a technical ordeal. He scathingly accused physicians of robbing individuals of their capacity to accept death as a meaningful aspect of life. The dying, he noted, had become passive "spectators of their own decaying selves" (154).

There have been a number of responses to the desperate conditions of high-tech dying, such as the development of legal wills, the growth of patient advocacy, and the vocal critique of 'right to die' movements that have lead to the institutionalization of voluntary euthanasia in the Netherlands, the State of Oregon, and for a time, in the Northern Territory of Australia. Without a doubt, the most successful challenge to the medicalization of death has come from the hospice and palliative care movement.[1] Over the past thirty years in North America, hospice has grown to offer an important institutional alternative to the depersonalized experience of high-tech dying. Rather than focusing on curative interventions, hospice attempts to provide relief from

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[1] The term "palliative care" is often used synonymously with "hospice care." Where differences are distinguished, "palliative care" is used to refer to hospital based institutions and "hospice" refers to freestanding institutions, often, though not always, run by religious organizations. For the sake of simplicity, in this paper, I shall employ the term "hospice" to refer to both hospice and palliative care programs.

suffering and other distressing symptoms. Furthermore, the hospice model rejects biomedicine's physiological reductionism and offers both a holistic and multidisciplinary approach to care (Doyle, Hanks, & MacDonald, 1998). The aim of hospice, as one of the founders explains, is "not only to help you die peacefully, but to live until you die" (Saunders, n.d.).

An aspect of the hospice movement that is often overlooked, in favour of its achievements in pain and symptom reduction, are the stories it tells of the dying process. Indeed, in this paper I shall argue that one of the reasons that hospice has been so successful is that it offers uplifting and inspirational stories with which to make sense of death. The context of legal wills offer little by way of narrative. And euthanasia advocates make their case for the right to die by telling horrendous stories of atrocious deaths that could have been avoided if only euthanasia were legalized. These are far from inspiring. Hospice, however, tells us heroic tales of individuals who have lived through suffering to gain spiritual illumination and forge ever precious bonds with their family. Not only do these stories inspire but they guide. They are moral tales, encouraging individuals to move through the dying process rather than fight it at all costs. Certainly to speak of dying as a personal "journey," as is frequently the case in hospice narratives, rather than a "pathological" process suggests a different normative orientation towards the end of life. It also reflects a different understanding of who, ultimately, ought to be in control of the dying process—the "adventurer" rather than the "therapist," for instance. Such representations work to trouble, at least in a limited manner, the medical appropriation of death.

The goal of this paper is to examine a number of key representations used to conceptualize death within palliative care and to explore the way they might re-orient individuals facing their mortality. In doing so, it is hoped that an interpretive perspective will shed light on the contributions of hospice—not only as offering compassionate end of life care or dignified spaces in which to die—but also operating on a cultural level, as an interpretive intervention. However, I do not intend this paper to be a celebration of hospice. Hospice care has gone a long way to ameliorating the care of the dying. Yet, it offers only *one* alternative to dealing with dying and a limited set of interpretations to help people through this process. Guided by Donna Haraway's (1991) work on situated knowledges, it is important for critical scholarship to hold knowledge accountable for both its promises and its monsters. This paper thus concludes with a consideration of some of the limitations of hospice care's vision of death and, in particular, a reflection on the disconcerting ways in which they are deployed to shut down options such as euthanasia and assisted suicide.

Representing death

Death is conceptualized through a variety of methods: narratives, metaphors, tables, charts, films, photographic images, paintings, etc. In this paper, I employ the term "representation" to refer to these diverse forms of interpretation. The concept of representation is useful as it emphasizes the social processes through which meaning is made (Hartley, 1994). Further, by acknowledging that there are different ways of representing reality, the concept opens up ontological questions to do with what aspects of reality are brought to light and normative questions to do with how these might influence behaviour. For instance, Hans Holbein's (1538/1974) depiction of death as unruly skeleton striking its victims in the midst of life is a well known representation of death. While death does not 'exist' as a skeleton walking among us, this artistic representation draws attention to death's unpredictable nature and succeeds in conveying a certain truth: that for many, regardless of age, death often comes as a surprise. This representation also suggests a specific normative orientation towards mortality. Indeed, by pointing to the always present possibility of death, Holbein intended his work to serve a didactic purpose, encouraging people not to take life for granted (Kidder, 1998).

Representations of death are not confined solely to the arts. To date, some of the most compelling explorations of the various modes of representing death are to be found in the analyses of medical knowledge. Scholars within medical anthropology, sociology, communications and cultural studies have noted that scientific medicine is not only a technical endeavour but a cultural one as well (Byron, 1994; Lock & Gordon, 1988; Seale, 1998; Stacey, 1997). Medical knowledge provides a number of models and metaphors for the interpretation of death and, stemming from these, a set of strategies for managing mortality. The concepts of "pathology" and "risk" are among the most significant in shaping the contemporary understanding of death. Thinking about mortality through the framework of pathology, for instance, structures death in a number important ways. Sociologist Lindsay Prior (1984, 1989, 1992) notes that the concept of pathology serves to shatter the ubiquity of death by fragmenting it along causal lines into a multitude of individual occurrences of "disease." Indeed, it could be argued that the pervasiveness of the disease metaphor has lead to the frequent – and mistaken – belief that we live in a death "denying" culture (e.g. Becker, 1973). It would be more accurate to say that the pathological interpretation of death has transformed dominant responses to mortality. Far from resulting in denial, it has legitimated the expenditure of considerable time, energy, and capital in the effort to identify and avoid causes of death (Bauman, 1992, 1993).

When death is represented in terms of pathology, a further transformation occurs. Death becomes an object of medicine; it is medicalized. One of the key features of medicalization is the transfer of authority from previously non-medical domains to the medical community (Conrad, 1992). Rather than the clergy or the dying person presiding over her or his death, knowledge of death and determinations of appropriate courses of action come to be seen as falling largely under the jurisdiction of the medical profession. Recent intensification of this medical/materialist paradigm has enabled physicians to technically determine the exact 'moment' of death. No longer is death a figure with whom we dance throughout life, but a temporally bounded and physically contained micro-event in the brain. This manner of representation has had profound normative implications, not least permitting the legal harvesting of organs from warm, 'breathing' bodies and encouraging the development of transplantation as a strategy of life-extension (Lock, 2002).

In this paper, I am clearly not approaching the language through which death is represented with the now (hopefully) antiquated presumption of 'objectivity'— as a 'pure' or

culturally and morally neutral form of denotation. There is no way, as far as I can see, of representing death in a manner does not miss certain dimensions of its reality, that does not reflect interests or incline one's attention and action in certain ways. None of this is to suggest, however, that the effects of particular forms of representation operate in a deterministic manner. It is possible to speak of terminal illness and still accept death and wonder at its mysteries. It is also possible to see dying as an opportunity for learning, yet wish to avoid death. It might be useful to borrow from Raymond Williams (1980, p. 32) and suggest that while particular modes of representation are not deterministic they set "limits" and exert "pressures" around on what is possible to think and what constitutes rational action.

Method

This paper is derived from an ethnographic study of hospice care undertaken between January 1999 and April 2000 in British Columbia, Canada. The study involved participant observation in both a community hospice and hospital based hospice care unit, a review of lay and professional literature, attendance at two Canadian hospice/palliative care conferences, as well as interviews with hospice and palliative care workers (nurses, physicians, members of the clergy, and volunteers). As a participant observer, I was trained and worked as a volunteer in hospice care. The work of a volunteer is ideal for research as one is assigned no specific task other than to wander about the unit and engage in conversation with those who are dying, offer assistance to them and their family (at times this would involve anything from consoling individuals to cooking meals), and helping or chatting with the staff.

The interviews that this paper draws upon were conducted with hospice care workers during the same time period. While consent was obtained to interview the staff, it was not obtained to interview the dying nor their families (and those discussions are therefore not reported). Staff interviews were open-ended, informal conversations organized around a discussion of dominant approaches to death and the advantages/limitations of hospice care. In total, 24 care providers were interviewed. Half of these interviews were recorded; half required the taking of notes immediately following the interview due to the nature of the interview context (e.g. the conversation took place while following staff on their rounds or after a variety of difficult incidents).

These conversations were analysed following Moustakas' (1990) principles of heuristic research with the intention of identifying recurring representations of death and dying. This involved an intense review of the interview transcripts and field notes so that they were thoroughly familiar. Through this process, core themes were developed and elaborated. They were then presented to staff members for feedback and validation. As part of the process of validation, my findings were also reported at the 2001 Canadian Hospice/Palliative Care Association Annual Conference. The conference participants provided many useful suggestions, which further informed my analysis. The conference itself served as an additional site of research.

In what follows, several of the more thematic representations will be examined in light of both their normative implications and the way they challenge medicalized representations of mortality. Names have been eliminated to ensure confidentiality.

Themes

The natural death

The discourse of hospice care is characterized by frequent reference to the ideal of a "natural" death, a gradual passing away unmarred by fear, denial, or technological encumbrances. As Jane Seymour (1999) points out, the representation of the "natural" death owes much to the historical work of Philippe Ariès (1976,1981), who provided a compelling narrative of the passing of a time when death was familiar and accepted. The period of the "tame" death, as he termed it, was replaced by one in which death appeared "wild" and dangerous, needing to be contained by medical intervention. Further bolstering the idea that the bad death was the modern medico-technical death were numerous "atrocity stories" supplied by researchers studying hospitalized dying (Seale, 1998, p. 102).

Not surprisingly the ideal of a lost but potentially recoverable "natural" death is often used within hospice to legitimate its critique of medicalized dying and to assert the moral superiority of its approach (Clark, 2002). Central to the rhetoric of a "natural" death, as Seymour observes, is the minimization or absence of technology. Indeed, hospice imagery is characterized by the absence of high tech devices and dominated instead by images of people, homes, and flowers (Froggatt & Walter, 1995).

My own research suggests that there is more to the notion of the "natural" with in hospice than simply a scepticism of technological intervention. My discussions with hospice workers indicate that an important difference between modern medicine and the culture of hospice lies in the way *nature* is conceptualized.

The core of modern medical practice lies in the Cartesian belief that nature, and hence the human body, can be treated as if it were a machine (Leder, 1992). As Carolyn Merchant (1980) has noted, viewing nature as dead matter operating along mechanical lines has significant normative consequences. It justifies, not least, relentless efforts at domination through technical intervention. The machine metaphor also shapes the understanding of human mortality. Within the mechanical paradigm, death comes to be represented as a "breakdown" of the body-machine, and dying is perceived to begin at that point where nature's disorder outstrips the technical capacity for intervention (Illich, 1976). Individual deaths are, therefore, often spoken of as if they were the result of a physiological "failure" (Sexton, 1997).

In contrast, organic notions of the body frequently underlie the interpretation of death within hospice culture. Organic modes of representation characterize nature as a living, interconnected and intentional organism (Merchant, 1980). Thus, the human body is represented as an organism imbued with agency and purpose. To say that dying is "natural," in this context, gives it an entirely different normative valence than to represent it as the result of a breakdown. To say that it is natural is to mean that death is *supposed* to occur. It is a process that the body intends, is prepared for and is capable of achieving. The following description conveys this representation of the dying body as an intelligent and purposeful organism:

> Your body is so wonderful, for anyone who is going through a gentle dying process. The body chemistry changes, just as it does at birth. The person who is dying usually starts to lose interest in food, then not only foods but liquids. They no longer feel thirst. As the body becomes dehydrated the endorphins—like you get in a runner's high—start to be released in the body so it creates a calming effect, a sort of euphoria. (hospice nurse 4)

In the above statement, the body is not only depicted as an intelligent body—wilfully undergoing the process of dying and changing in preparation for death—but it is also a compassionate body, releasing "endorphins" to relieve discomfort. To be sure, the mention of

"euphoria" and the analogy to a "runner's high" place this representation at a distance from that of a "failure" or "breakdown." More importantly, one senses a profound trust in the body's capacity to die and to die peacefully in the majority of cases. Such faith in nature enables hospice workers to question the wisdom of technical intervention. As one hospice physician humorously observed:

> There're people who talk about the "perfect Harvard death." So basically you have someone who is in the middle of the dying process and they'll keep medicalizing and drawing blood work everyday and saying "Oh, your potassium's all little bit out of whack, we'll give you some" or "Your magnesium a little low, we'll give you more." And the joke is that people will say that "I'm sorry that your parent died, but you know, they were in perfect health when they did."

While such statements are clearly a critique of the hubris that 'medicine knows better', it would be a mistake to view them as representing an anti-technological worldview. Rather they would be better seen as indicating the existence of a different norm guiding the use of technology. Flowing from a respect for the organic body, and nature more generally, good health care practice within hospice means *working* with, rather than attempting to correct, nature's will. Or as one interviewee bluntly put it:

> When we start messing around with people who are just slipping away, you start to muck with nature. (Community Hospice Director)

Birth

Many of the professional caregivers interviewed commented on the emotionally challenging nature of their work. They also noted that it was immensely rewarding. The possibility of accompanying someone through the end of life, perhaps holding their hand as they took their last breath, was frequently described as a "privilege." A common dilemma noted by many hospice workers, however, was conveying the power of this experience to those with little or no knowledge of dying. Analogies to "birth" and the "miracle of life entering the world" were often employed to give some sense of what it might be to witness life leaving. The concept of "birth" thus served as a conceptual bridge, providing a common ground for shared meaning to be constructed.

The concept of "birth" shapes the understanding of death in a number of ways. On the one hand, the act of giving birth is the archetypal "natural" act. The use of the concept thus furthers the representation of the body as an organism with an innate capacity to die (e.g. "The body chemistry changes [in death], just as it does at birth," hospice nurse 4). On the other hand, the birth of a child is easily understood as an awe-inspiring experience. The analogy to birth thus encourages one to consider the mysterious and beautiful dimensions of dying:

> I've found death to be actually, in many cases, to be very beautiful, and I don't say that lightly.... But rather just like birth is beautiful—it's a rite of passage—so death is beautiful. (Director of pastoral care 1)

The ability of the birth metaphor to powerfully represents death as a magical experience—one that is essential to life—was also useful for hospice nurses who sometimes struggled to find adequate words to convey the privilege of their role as care providers. Increasingly, the term "midwife" was encountered as a manner of characterizing the work of hospice nurses:

> People say to me now "How on earth can you work with dying people?" And they can't believe that I feel fulfilled and that I absolutely love my job. I think that some of the terminology that's being coined would maybe give the feeling of this. They are classing nurses working in hospice now as "midwives" to the dying. And I think if you take that whole concept of "birth" and "rebirth," giving as I say individual interpretation, I think that the concept of "midwifes to the dying" as "midwifes to birth" works really quite well to express the gentleness and the celebration of life even in death. (hospice nurse 3)

The cycle of life

Morris Berman (1981) contends that the scientific revolution, and the coterminous move from a purposeful to a mechanical conception of nature, occasioned a radical transformation in the type of questions asked about the world. Questions to do with "why" things occurred were displaced by questions that asked "how" things happened. This transformation is reflected in the contemporary belief that understanding death means knowing "how we die" (e.g. Nuland, 1994). Dominant explanations for death in such narratives are causal, pointing to the effects of pathologies, risks, and accidents.

While the interpretation of mortality through the metaphors of "pathology" or "risk" may be a necessary logic for a system of thought geared towards the avoidance of death, it likely impedes the care of the dying. Not least, hospice workers have noted that the connection between death and disease heightens anxiety:

> Death doesn't need to be sombre. It doesn't need to be scary. It doesn't need to be fearful. But we've created all this....It's all cancer and heart disease. It's all fear and worry. (Hospice nurse 2)

Further, thinking of mortality through the metaphors of "disease" and "risk" frames each individual death as somehow "abnormal," "unnecessary" or "premature." Within this perspective, the ethical—or healthy—response to mortality is to engage in the rituals of avoidance that curative medicine offers.

The hospice workers interviewed did not deny the legitimacy of understanding death as the result of disease. However, they also spoke of death more broadly, locating it within a larger "cycle" of life or nature. The interpretation of death as part of a cycle is important for it draws attention away from questions to do with how people die. It suggests, instead, an answer to the question of why they die. From this perspective, people die because it is through the ongoing cycle of birth and death that the human species reproduces itself. Locating death within a cycle of life provides a rationale—a justification—for dying. As part of a cycle, mortality becomes meaningful and death purposeful:

> The trouble is that we are so caught up in our human emotions of the loss of an individual and, you know, probably never seeing them again, that it becomes a tragedy sort of thing. But I think in actual fact that it probably is a gift. Imagine life as it stands now, if it didn't have a cycle and we were all plonked here and X amount of us were maintained. (Hospice nurse 3)

The idea that death may be thought of as a "gift," as in the above quote, radically opposes the more common negative interpretations of death. That such a positive vision is possible when one situates death as part of a natural cycle may well explain the predominance of circles and natural imagery such as flowers in hospice logos and promotional material (Froggatt & Walter, 1995).

Thinking of death in terms of a cycle further encourages the transcendence of the self. It enables the perception that one's death is part of something greater than the end of an individual life. The importance of transcendence has been observed to be fundamentally important in coping with existential suffering (e.g. Frankl, 1992; Stanton, Shuy & Byock, 2001; Yalom, 1980). Thus the representation of death as part of a cycle may serve as a source of healing in itself. The following story, told by a director of pastoral care, illustrates the healing that may be afforded when death is interpreted as part of the cycle of life:

> The situation involved a lady who had no religion who was basically agnostic.... I came in and for the next few weeks I visited with her. She told me about her life, and about her husband. Anyway, it was during the spring time and she had told me how much she loved daffodils and just at that time at the place where I was living I had a little garden and, of course, daffodils were coming in. And so I cut her some daffodils and brought them in. I put them in a vase and brought them in for her. She was just delighted. And then she talked to me about how beautiful the flowers were but that they would fade and then they would die—you know they were cut—but even flowers in the ground would fade and die through the seasons. It was nature. And that she accepted this, and she accepted the fact that she was going to die and that she was fine about it, because she had known love, she had know her husband, she had known other people who were significant in her life. And then she said, "and for what it's worth I've seen something in nature, which if you want to call it God it might be God, I knew it was something greater than just myself." And she said "whatever it is, I'm at peace."

Growth

In order to illustrate the benefits of the hospice approach, those interviewed frequently told stories that described the dying process as offering a number of opportunities, such as the chance to strengthen family bonds, to put one's life in perspective and to deepen spiritual awareness. Similar narratives were also encountered in popular and professional hospice literature (e.g. Byock, 1997; Kübler-Ross, 1975; Living Lessons, n.d.) as well as by other researchers (e.g. Seale, 1998; Hockey, 1990). These narratives illustrate a most important re-interpretation within hospice, whereby death is symbolically transformed from a time of physical "decay" to an opportunity for "growth."

In narratives of growth, dying is represented as a "challenge." It is a time punctuated by various threats, hazards, and difficulties, which—if courageously faced and successfully overcome—offers the possibility to learn valuable lessons and to grow as a person. Growth is represented as occurring along a number of lines—personal, interpersonal, spiritual, existential, emotional—and for a number of people as well:

> [the end of life] is a time of growth for the individual who is experiencing the actual process of dying, it is a time of growth for his family, friends, support system, significant other, and, indeed, the entire community which is the context for the person (Director of pastoral care 2).

The importance of the metaphor of "growth" as a way of thinking about death is hard to overstate. Growth opposes the conception of death as a "problem." Instead, stories of growth draw attention to the positive dimensions of dying. This is not without significant normative implications. The possibility of growth suggests that one ought to try and overcome difficulties rather than avoid them. It inspires hope and implies that suffering may not be pointless.

The metaphor of growth also removes death from the confines of the body. Dying is no longer represented as a "disease process" that transpires, mechanically deep within human flesh nor is it accessible only to medical professionals through specialized diagnostic technologies. Instead, the metaphor of growth represents dying as a process that is "lived." It is a process that lay people participate in and may shape. In a reversal of notions of failure, the hospice vision portrays dying as a positive act of transformation. Indeed, in narratives of growth, the dying person and his or her family are often represented as having a moral obligation to act and to make the most of this "last chance for living:"

> [Dying] will only be an opportunity for growth if all these various people engage it as such. If they disengage or they try and deny it then it is not going to happen....Somewhere down the line the fact that the dying person accept that as a reality and rather than tries to fight it does everything possible to make it a positive experience: utilize the time to do those things that they need to do, reaffirm the family ties, maybe put closure on unfinished business, tidy up financial affairs or legal affairs, maybe even plan their own funeral or memorial, or whatever is to happen to them. And then just enjoy the time with friends or their relatives, etc. Perhaps make peace with their God. To revisit what it is they exactly believe about God or about life. (Director of pastoral care 2)

Journeys

Within hospice the dying process is frequently spoken of as a "journey." This reflects not only the belief that the end of life is an open field of possibilities but the belief that the dying person is an active participant in the process. The connection between death and journeying is an old one. It dates back at least to ancient Greek civilization—where the dead were believed to journey across the river Styx to Hades, their final resting place. The metaphor also parallels the Christian vision of dying as a "passage" to an otherworldly existence in either heaven or hell. However, those interviewed generally situated the journey within life rather than after death. While this secular use lends the metaphor a certain versatility, it does not necessarily foreclose the possibility of an afterlife. On occasion it was used to suggest a transition to another "plane of existence" (hospice nurse 15).

The journey metaphor is also frequently employed to describe the work of care providers, acknowledging that by accompanying the dying they too are undertaking an emotionally and spiritually challenging endeavour. As John Ralston Saul observes in the introduction to the 2001 Canadian Hospice/Palliative Care National Conference Syllabus, aptly titled, *An Odyssey: Personal and Professional Journeys in Hospice Palliative Care*:

> Experiencing the death of a loved one is one of our most difficult, complex and profound personal journeys. For those who have chosen hospice palliative care as a profession or as volunteer work, the daily journey you take with others and with yourself is a deepening experience that brings you face to face with the core of life. (p.3)

While the metaphor of a journey may be hastily dismissed as a euphemism, it is important to note how it moves the conception of death away from the negative, the frightening, and the uncontrollable. Instead, the metaphor frames the difficulties encountered as a test of personal character, courage, and will power. It further suggests that striving to surmount or to make the most of these difficulties is purposeful—a tacit assumption being that the journey has a

meaningful destination. The representation of the dying person as "an individual on a quest" thus provides an inspiring way to interpret one's position in the face of death. Indeed, it frames the dying person as the one ultimately in charge of negotiating the dying process. This perspective may therefore be viewed as contesting the authority the medical community has gained over death and, specifically, over the determination of appropriate responses to mortality.

However, the metaphor does not deny a role for medicine or hospice. By framing the end of life as a difficult and uncertain territory, an important task for hospice is to guide people through this land. In describing his motivation behind a recent collection of end of life narratives, well known hospice physician Ira Byock (1997) remarks:

> Years ago I began keeping notes on the developmental landmarks and "taskwork" as I call it, relevant to the end of life. I hope that defining the landmarks might provide some light and offer a general sense of direction within this dim, foreboding landscape, and that naming the taskwork might provide paths for a person's individual journey. (p. 15)

Task-oriented models, such as the one Byock offers, may be viewed as a "map" through the end of life, though here one is not mapping out the physiological cause-and-effect processes that take one to the grave but the personal and interpersonal "landmarks" that mark the route to growth. Since task-oriented models are less deterministic than stage theories, they leave room for the active, self-reflexive individual to act as their own navigators and thus work well with the journey metaphor. On the other hand, as Seale (1998) has observed, this vision also transforms dying into hard work.

The limits of optimism

Partial perspective can be held accountable for both
its promising and its destructive monsters.
-Donna Haraway (1991, p.190).

Donna Haraway (1991) observes that there is no such thing as a total perspective that captures all facets of reality. All knowledge is partial. As a consequence, while partial perspectives might offer powerful ways of seeing and acting in certain limited situations, they become dangerous when over-generalized, universalized or taken for granted. Given this, she argues that one of the key tasks of critical scholarship is that of holding knowledge accountable for both "its promising and its destructive monsters" (190).

Thus far, however, I have only considered the possibilities enabled by hospice care's vision of death. Its vision is both appealing and optimistic—certainly one of the reasons the movement has been so successful in recruiting staff, volunteers, and public support for its expansion. Without a doubt, in the context of a culture where death is feared or systematically avoided through life-extending practices and strategies of risk management, hospice culture offers a promising way of thinking: providing inspiring interpretations that encourage individuals to confront death and move *through* the dying process.

However, the faith in human progress that has played such an integral role in legitimating medicine's war on death is implicit in some, though certainly not all, of the optimistic interpretations encountered in hospice culture. The metaphor of "growth" is particularly problematic in this regard. While inspiring, narratives of growth and the possibility of "dying well," as Byock (1997) terms it, may also be viewed as a continuation of the hope that if one just

approaches death in the right way, with the correct knowledge, it may be mastered. In this case, death is not avoided but made meaningful.

The framework of optimism provides a limited vocabulary with which to speak of the darker side of death. To be sure, meaninglessness, suffering, and chaos are found in hospice narratives. However, all too often, they take on a *temporary* existence. Optimistic representations frame them as a “challenge” to be overcome, a “task” on the route to growth. A recent editorial by David Roy (2001) in a major hospice journal offers a case in point. Roy calls for the need to attend to the “shadow side” of death. Yet, the editorial is framed by the possibility that one can “suffer up” and move through this moment towards some deeper (though vaguely specified) connection with “living” (68). Of course, there is truth to this. In certain situations, people do learn through suffering. And hence grow. However, when over-generalized, the metaphor becomes ideological, in Stuart Hall’s sense of the word, offering a one-sided representation (Hall, 1983/1996). It thereby obscures another truth: that for some individuals dying may ultimately be a meaningless experience or growth at the end of life tiring, trivial, or too little too late.

Particularly disconcerting is the way in which narratives of growth have been mobilized in public debates on euthanasia and assisted suicide as a means to reject the legitimacy of killing oneself. In such situations, ending one’s life is portrayed as either too hasty—occurring before the always deferrable moment of insight was gained—or too easy—an instance of avoiding life’s hard lessons. The use of growth to foreclose the option of suicide occurred not only in a number of conversations I had with hospice workers but was a strategy deployed during Canadian policy debates on euthanasia as well. As the Special Senate Committee report on euthanasia and assisted suicide attests (1995, p. 60): “Some witnesses felt that coming to terms with suffering and the suffering associated with dying were an important part of life, and neither could nor should be avoided by such mechanisms as assisted suicide and euthanasia.” A typical example of the use of growth as an ideological strategy can be seen in the following statement made during the Committee’s hearings:

> A month ago I sat at the bedside of a very dear friend of mine who was 39 years old and dying of cancer. Two months before she died, she asked her husband to help her commit suicide. He refused. Three days before she died she had what can only be described as an extraordinary reconciliation with her family. This would not have happened had the suicide request been granted. (p. 61).

If the above statement were only meant as encouragement to persevere, there would be merit in it. We need to hear that these sort of “extraordinary” moments exist in order to be inspired and moved to take advantage of our time—perhaps to work towards reconciliation with our own families and friends. However, this statement was not intended to inspire; instead the example of growth was offered as a reason why the option of euthanasia should not be allowed. Here the opportunity for growth becomes restrictive and disables alternative forms of dying.

My comments here should not be taken as an argument in favour of euthanasia or assisted suicide; the issue is far to complex for fair treatment in this paper. However, my discussions with hospice workers on the subject (not all of whom were against euthanasia, it should be noted) suggested that the potential for growth can sometimes be taken too literally. In other words, hospice workers believe that they have discovered a fundamental truth about dying. Consider the following statement by Byock (1997):

> I have learned from my patients and their families a surprising truth about dying: This stage of life holds remarkable possibilities. Despite the arduous nature of the

> experience, when people are relatively comfortable and know that they are not going to be abandoned, they frequently find ways to strengthen bonds with people they love and to create moments of profound meaning in their final passage. (xiv).

The claim to the discovery of a generalizable truth limits the ways in which one may legitimately think about and approach death. As an antidote to such thinking, it would help to switch metaphors from *discovery* to *interpretation*. The hospice movement has worked to ameliorate the care of the dying, in part, by operating on a cultural level, challenging the dominance of biomedical representations and offering an alternate set of interpretations. It has, in effect, broadened the range of legitimate narratives and metaphors that one may use to conceptualize death. There is little to be gained by affecting another form of closure.

The fact that hospice care's models are often not adequate to reality has not gone unnoticed by members of the community (e.g. Barnard, Towers, Boston, & Lambrinidou, 2000). However, the degree to which it is possible for a community that is primarily concerned with *improving* the care of the dying to simultaneously bear witness to meaninglessness and anguish—and to do so *outside* of a logic of meliorism—is worth questioning. If only to draw attention to the need to avoid the formation of another monopoly of knowledge and to remain continually open to other interpretations of death and other approaches to dying.

Conclusion

Representations of death have important implications for the manner in which individuals approach dying and societies manage mortality. While the hospice movement has contributed significantly to pain and symptom management and has helped raise awareness of the need for better terminal care, it has also contributed by providing alternate forms of interpreting death. The representations offered by hospice envision dying as a difficult but natural stage in which meaningful living is possible. They encourage individuals to move through the dying process and draw attention to beauty and mystery in a stage of life otherwise feared. In light of a culture that conceives of death in the negative and a medical community that represents dying as a pathological process, such inspiring interpretations are urgently required. However, to the degree that they may forgo an exploration of futility or silence other voices, the metaphors provided by hospice may simultaneously reflect a continuation of efforts to rationalize and master human mortality.

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