First of all, allow me to thank-you for the opportunity to share my experiences and reflections with you today[1].

Experiencing suffering and death

In June of 2008, on Father's Day, my sister called to tell me that my Dad had been diagnosed with stage 4 cancer. What his family doctor had thought to be an inflamed sciatic nerve had been a cancerous tumour which, because of a misdiagnosis, was allowed to develop for years such that, within the span of one month, it had radically transformed my Father's life. A few weeks after his diagnosis, the anaesthesiologist confirmed my Mother's worst fears: the cancer was far too advanced to be treated – nothing could be done: the amount of chemotherapy it would take to kill the cancerous cells would kill my Dad as well.

Thankfully, my Mother is a fighter and a realist – a fighter because she decided she would do everything she could day-by-day to help my Dad survive the cancer and a realist because she is well aware of the fact that human beings – even doctors – can make mistakes. She trusted the anaesthesiologist's prognosis but she did not think it was the last word: he might conclude that my Dad had no chance but why should he be right? My Dad was still alive and that meant there was hope, that he still had a chance[2].

My Father's life was turned up-side down: in May, despite the pain from his supposedly inflamed sciatic nerve, my Dad was working, driving, gardening, etc. I had spent the weekend of May 16 – 18 with him – and I saw how his lower back was in pain making even the simplest movement laborious. Aside from that, however, he was leading a normal life. In June, he was bedridden, unable to walk on his own and in need of help to carry out the most basic functions, including going to the bathroom.

Last month, he spontaneously told me that at the worst moment of his illness, when he was completely unsure how things would develop, he wanted to die; he wanted his life to end even if that meant ending it himself. His reason? It wasn't the pain – though still not entirely controlled and, at times, it was unbearable, he felt he was able to cope with the pain; it was not the sudden drop in his quality of life – he was adaptable and felt he

[1] Despite comments from the press, the pro-euthanasia and pro-assisted suicide questions in your survey (For example, question 9 of the Questionnaire reads: If Euthanasia or assisted suicide had to be legalized, which would you chose: a) Euthanasia; b) Assisted Suicide; c) Undecided), I am trust that you are aware of your responsibility for the public good and that you are truly open to what I have to say and thank you for your attention.

[2] Of course, she could also have been swayed but the growing trend of "compassion" that seeks to eliminate suffering by ending the life of the sufferer.

would find ways to make the best of his (our) new situation: his reason for wanting to end his life was the **fear of being a burden**. Despite the limitless support of my Mother and the readiness of each of his four children to see him through this illness, my Dad was scared of making **other people suffer** and this became his greatest weight – the realization that he was becoming a "burden for others"

Our culture places a high value on independence & autonomy – and this can be very positive. Each person has a right to their opinions, to their choices, to their preferences. Independence is certainly a good thing as is autonomy: both indicate our capacity to assimilate information, reflect upon it and make our own decisions which can develop into opinions, convictions and actions. However, it is interesting to note that independence and autonomy go hand in hand with a culture also characterized for its individualism, materialism and consumerism – and misled compassion.

My Father did not kill himself nor did he ask to be killed. Why not? He deliberated a little more: if I kill myself, he thought, where am I leaving my wife and children? What message am I sending them? He recognized that while he had the right to make his own decisions, to exercise his autonomy, his autonomy was not the only value at stake: it was not absolute[3]. His choices would have direct consequences on other people – consequences that would make their sufferings easier (because they would be faced together) or more difficult to bear (because my Father could have opted out and left them to deal with loss on their own).

Advocates of Euthanasia and assisted suicide present three main reasons for their stance: the patient's inability to cope, threatened quality of life and autonomy or freedom of choice. In their eyes, all three are indexes of dignity. The first two reasons are very personal and subjective thereby warranting a case by case approach[4]. In addition, both the capacity to cope and quality of life are "dynamic" measures. They are not fixed points: rather, they change with our personal situations, our resources and the creativity with which we and our support network meet challenges. A little reflection on our part quickly reveal that this is true for everyone: at times, we are ready to take on the world, we feel able to handle and even stimulated by greater levels of stresses and pressures while, at other times (sometimes within the same week), we feel incredibly

[3] Choice is subordinate to the subject making the choice – this suggests that the subject who chooses to destroy herself is misusing "choice".

[4] Cases showing quality of life as rated higher by the patient than by their spouse of 40 yrs – please see Annex 1 for some charts. Ciaran O'Boyle, ABC's of Stress Management, Conference sponsored the Council on Palliative Care, Oct. 5th, McGill University.

vulnerable. Quality of life also varies when we discover that what was apparently essential to our happiness no longer is so important. Even one month before falling ill, for my Father the mere thought of not being able to lift himself our of bed or turn over on his own – let alone walk around the house or even go to the bathroom himself – would have been unbearable. Once this was his reality, he was able to find strength and tenderness he did not know he had before both within himself and in his relationships. In fact, he (we) discovered how much his relationships were worth.

The "right to autonomy" – being more theoretical – is more objective and therefore more apt to debate. It is this "reason" that I would like to discuss now.

While my Father was struggling to adapt physically, emotionally, psychologically, financially and socially to his (our) new circumstances, across the Atlantic, in a small town nestled in the Apennine Mountains, his mother was living her final days. At home, in her bedroom, accompanied by her husband, her son and the care of her two daughters (who washed her, nourished her, and attended to her person and her home) she died. She died with pain, yes; she died in absolute dependence on her caregivers; she died in peace surrounded by those she love and, most importantly, she died with dignity: without apologizing for needing help, without the slightest fear of being a burden because the thought of being one never even crossed neither her mind nor those of her family members.

My grandmother had given them everything she had so it was a natural response for them, in turn, to tend to her every need when she was no longer able to care for herself. She saw no shame in that: it was what was due to her as a person and as a wife, mother and grandmother. When I spoke with my aunts to thank them for all they had done for my grandmother, they were surprised – why should I be thanking them when, in their eyes, they only did what had to be done and they were happy to have been able to do it. They were simply thankful for the full life my grandmother had lived. In fact, I even think my gratitude made them wonder if I was taking adequate care of their brother – my Father.

Reflections: Autonomy is a value but it is not an absolute

Reflecting upon my family's experience, it became clear to me that autonomy is a human value that most people would recognize while its exaggerated exaltation is a more recent cultural phenomenon. What was almost entirely a non-issue, a mere fact of life, for my Grandmother was an obstacle, a threat to life for my Father.

What is meant by autonomy? Autonomy is independence, freedom of choice, being able to undertake activities without seeking permission from a controlling body. It means

making the choices you want to make. But autonomy is not the person nor is it as important as the person: you need to exist (among other things) in order to be autonomous. Autonomy is just one quality, among others, of a living human being.

Autonomy has an important place in the medical **ethics**. The commonly accepted principles of health care ethics include:

1. the principle of respect for autonomy[5],
2. the principle of nonmaleficence, (no harm)
3. the principle of beneficence, and (doing good)
4. the principle of justice.

We should note, then, that we are no longer simply on a strictly medical terrain but one that is intrinsically **ethical**. Autonomy, then, can not be appealed to as a principle for medical treatment but rather being treated with medical ethics.

It is arguable that autonomy has become the supreme value of our culture in Quebec. By way of anecdote, I was a bit surprised – and, to be honest, a little disappointed – when a friend, who had just had her first baby three months earlier, told me she was trying to train her new born daughter to be independent. Somehow, over the course of the past decades, autonomy has been directly linked to dignity such that loss of autonomy is understood to be a loss of dignity – and this, with very serious consequences, especially for the weaker members of our society[6].

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[5] The University of Washington, School of Medicine asserts that "Any notion of moral decision making assumes that rational agents are involved in making informed and voluntary decisions. In health care decisions, our respect for the autonomy of the patient would, in common parlance, mean that the patient has the capacity to act intentionally, with understanding, and without controlling influences that would mitigate against a free and voluntary act. This principle is the basis for the practice of "informed consent" in the physician/patient transaction regarding health care."

[6] Depression is recognized as the cause for suicide ideation yet the Annual Report on Oregon's Death with Dignity Act (Oregon Department of Human Services) states that not one assisted suicide patient was referred for psychiatric exam in 2007, only two were referred in 2008, and none were referred in 2009. (http://www.oregon.gov/DHS/ph/pas/ar-index.shtml). Furthermore, "Of the 73 physicians who were willing to write a lethal prescription and who had received a request from a patient, 20 (27%) were not confident they could determine when a patient had less than 6 months to live." PETER RASMUSSEN, HOUSE OF LORDS SELECT COMMITTEE ON THE ASSISTED DYING FOR THE TERMINALLY ILL BILL, ASSISTED DYING FOR THE TERMINALLY ILL BILL, VOLUMEII: EVIDENCE. 4/4/05, P. 312, QUESTION 842. (EMPHASIS ADDED.)
"Admittedly, we are inaccurate in prognosticating the time of death under those circumstances. We can easily be 100 percent off, but I do not think that is a problem. If we say a patient has six months to live and we are off by 100 percent and it is really three months or even twelve months, I do not think the patient is harmed in any way…" http://jama.ama-assn.org/cgi/content/full/285/18/2363

Upon what basis can we claim that needing other human beings implies a loss of dignity? Every child, from birth until adolescence, is physically, financially, emotionally, and socially dependent; do they lack dignity? At all times, we human beings are dependent at least emotionally, socially and psychologically – isolated and absolutely alone, can any human being be fulfilled and well-balanced[7]? Isn't the capacity to cultivate enduring relationships much more a sign of dignity than mere independence or individualism?

We are social beings

Looking at the basic facts of how we come into the world and live our lives, it is no surprise that we need others at the end of our lives as well. In Mitch Albom's best-selling and well-loved book, *Tuesdays with Morrie*, he quotes his dying Professor "In the beginning of life, when we are infants, we need others to survive, right? And at the end of life, when you get like me, you need others to survive, right? His voice dropped to a whisper. "But here's the secret: in between, we need others as well.[8]" It is much more human to need others and be needed by others than to be absolutely autonomous. How is our culture encouraging this solidarity which is a fact of life? After all, society rests on the cultivation of the human person's social dimension.

Granting the right to be killed or to assisted suicide on the basis of autonomy in one case makes it impossible to deny it in any other case. That is why in Holland, what began as a restricted palliative measure for the terminally-ill suffering *"hopeless and unbearable"* pain has become policy for those suffering from pain in all stages of life - including newborns who will not die simply from withheld treatment and so must be euthanized[9]. Most currently, a movement is underway allowing those over the age of 70 who are "simply tired of living". On that note, it should also be mentioned that the restrictions are hardly restrictive: how else do you explain the findings of the Dutch government initiated study: *The Remmelink Commission*, led by Dr P. Van der Maas of the

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[7] We only have to consider the case of Kimveer Gill, the man who entered Dawson College and opened fire upon the students, killing one young women and injuring 19 others on Sept. 13, 2006.

[8] Albom, Mitch. *Tuesdays with Morrie: an Old Man, a Young Man and Life's Greatest Lesson*, Broadway Books, New York p. 157 (all other citations from this book come from this edition)

[9] Eduard Verhagen, paediatrician at the Groningen University Medical Centre and one of the doctors who set up what is now known as the Groningen Protocol, says: "Discontinuation of care is acceptable for newborns in specific cases all over the world. In most cases children die subsequently. However there is a very small group - and this is the group that we are focusing on - that remains alive if you discontinue the care." According to a national survey this group consists of 15 to 20 of the 200,000 children born in the Netherlands per year. But even within the Groningen Protocol it remains illegal in the Netherlands to deliberately end the life of a severely ill newborn.
http://www.rnw.nl/english/article/faq-%E2%80%93-euthanasia-netherlands

Erasmus University in Rotterdam[10]. Just to cite one of them: in 1990, there were 1 000 people whose lives a doctor had deliberately ended without a clear and explicit request from the patient[11]. The "possible exceptions" to patients who had never requested euthanasia (in plain terms, they were killed against their will) are justified by claiming that this occurs in other countries as well. [12] Hardly reassuring and certainly not the model I would like my government to follow – and definitely not the kind of health I would like my Father or anyone to receive. Clearly then, the autonomy of a few individuals who clamour for the "right to die" (i.e. the right to be killed) should not be allowed to prevail over the autonomy of others or determine the cultural course of an entire nation. And such decisions do determine culture. In the questionnaire put

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[10] **Breakdown on Dutch euthanasia - voluntary, non voluntary, involuntary, infanticide; as found in the Remmelink Report - also referred to as the MDEL. (Medical Decisions Concerning End of Life)**

This article presents the first results of the Dutch nationwide study on euthanasia and other medical decisions concerning the end of life (MDEL). The study was done at the request of the Dutch government in preparation for a discussion about legislation on euthanasia. Three studies were undertaken: detailed interviews with 405 physicians, the mailing of questionnaires to the physicians of a sample of 7000 deceased persons, and the collecting of information about 2250 deaths by a prospective survey among the respondents to the interviews. The alleviation of pain and symptoms with such high dosages of opioids that the patient's life might be shortened was the most important MDEL in 17.5% of all deaths. In another 17.5% a non-treatment decision was the most important MDEL. PMID: 1715962 [PubMed - indexed for MEDLINE]

SOURCE: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=1715962

In about 40 per cent of these cases the decision to increase drug dosages and the possibility that this might hasten death had been discussed with the patient. In 73 per cent of the cases where these matters had not been discussed with the patient, the patient was incompetent.(145)

- There were 22 500 cases where death had resulted from non-treatment decisions (ie withdrawal or withholding of medical treatment), representing 17.5 per cent of all deaths.

In 30 per cent of these cases the non-treatment decision had been discussed with the patient. In 62 per cent of these cases it had not. In 88 per cent of all cases where the non-treatment decision had not been discussed with the patient, the patient was incompetent.(146)

- There were 1 000 cases where a doctor had deliberately ended the life of a patient without a clear and explicit request from the patient.

The information from footnotes 5 – 7 comes from: http://www.chninternational.com/breakdown_on_dutch_euthanasia.htm

[11] Ibid. In other cases, possibly with a few exceptions, the patients were near to death and clearly suffering grievously, yet verbal contact had become impossible The decision to hasten death was then nearly always taken after consultation with the family, nurses, or one or more colleagues. In most cases the amount of time by which, according to the physician, life had been shortened was a few hours or days only.

[12] Ibid. The Dutch data on medical practices which shortens life, in the cases of non-competent or of competent but not-consulted patients, are indeed a matter of concern... [but there] really is not a shred of evidence that the frequency of this sort of behaviour is higher in the Netherlands than, for example, in the United States; the only thing that is clear is that more is known about it in the Netherlands. In short,

together by the select committee, Dying with Dignity, a series of questions (qq. 1- -13) are asked regarding the role of law: should it simply mirror what society wants? I would argue that law strives to shapes what society thinks – and this is what will happen with laws passed surrounding the end of life[13]. I ask myself why my Father – who, like his mother, has done everything for his family – felt he was becoming a 'burden' and had no right to place this "burden" on his family while my grandmother would not have even been able to think in those terms[14]. The "right to die – or rather, be killed" very quickly becomes the "duty to die – rather, to be killed."

Leaving aside, for a moment, the complexity of human suffering and the compassion due to those who are suffering, the insistence on the right to choose one's death is not the right to die with dignity. Choice and dignity are not synonymous nor are autonomy and dignity. I did not choose to be born in Canada, I did choose to be Anglophone, I did not choose my temperament, I did not choose my parents, I did not choose to be born... do these "lacks of choice" somehow rob me of my dignity? The only way to safeguard dignity is to identify it with the subject – no matter what choices he or she makes.

More importantly, is my autonomy isolated from your autonomy? If I push for the right to be euthanized, am I not "obliging" you to kill me? If I insist on a legal enshrinement of my choice, am I not radically changing the justice system? If I ask the very person to whom I entrust my health to terminate my life, am I not undermining the relationship of

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there is no reason to assume ... a causal relationship between limited legalisation of euthanasia and 'lack of control' over other sorts of medical behaviour.(154)

[13] **- Do the majority of the Dutch public support the euthanasia law?**
Two years before the law was passed in 2002, the country was divided down the middle. An opinion poll two years ago showed support from 50 per cent of the population, with the remainder either opposed or undecided. By the time the law was passed, a clear majority of the population were in favour of the legislation.
What do the public think about 'tired of life' euthanasia?
A poll by Dutch research bureau Intomart GfK showed that 63 percent of the 1,000 people surveyed supported granting the right to die to the elderly, even if they were not ill, while 74 percent supported the controlled distribution of "suicide" pills to those who felt their lives were done.
From: http://www.rnw.nl/english/article/faq-%E2%80%93-euthanasia-netherlands

[14] *Tuesdays with Morrie*, p. 155: "Here's what I mean by building your own little subculture," Morrie said. "I don't mean you disregard every rule of your community. I don't go around naked, for example. I don't run through red lights. The little things, I can obey. But the big things – how we think, what we value – those you must choose yourself. You can't let anyone – or any society – determine those for you. "Take my condition. The things I am supposed to be embarrassed about now – not being able to walk, not being able to wipe my ass, waking up some mornings wanting to cry – there is nothing innately embarrassing or shaming about them.
"It's the same for women not being thin enough, or men not being rich enough. It's just what our culture would have you believe. Don't believe it."

trust that healthcare professionals worked so hard to establish? If I demand that my autonomy trump other principles and values, am I not breaking with the Western tradition of safeguarding life? And if the basis for helping someone end her life is her autonomy, her choice, when my 21 year old room mate attempts suicide twice within 24 hours (as she did two years ago), am I not left helpless before her "right to choose"?

The need for clear guidelines

Life is complex and each person is an entire universe. Our health care professionals are being asked to be experts in medicine, in ethics and in compassion – it is a challenging situation to be in.

Clear guidelines are required precisely because extremely complex cases exist and clashes of values occur. If there is still one fixed principle that can be agreed upon internationally so as to guide our decisions in difficult circumstances it is the sacredness of human life. Isn't that the lesson learned by Captain Semrau and the entire world – the judge's statement is quite clear: it is not up to you to decide who should live and should die[15]. Are we not asking our medical staff to do just that? The point is, however, that we are agreeing that human life is disposable. And when you put a "price" on human life, the price goes down. We might argue that this is only the case in restricted circumstances, but that would be to fool ourselves.

The Dutch government concedes that patients euthanized without prior consultation (that is, patients killed against their will) is certainly a "matter of concern": should not their deaths be an incentive for us to protect the lives of vulnerable people rather than place them in the same danger. Each of us, in particular those with legislative power, are called to ask ourselves: am I willing to assume responsibility for the murder of even one patient – no matter how near I (or a doctor or a nurse or a family member) might think she is to death or how much I (or a doctor or a nurse or a family member) might think she is suffering. Is not this the exact opposite of the respect for autonomy pushing us to open up legal exceptions?

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[15] Montreal Gazette. The code of conduct clearly states we must offer assistance to wounded enemies who do not pose a threat to us," Perron (the military judge) said. "Decisions based on personal values cannot prevail over lawful commands." In deciding to shoot an unarmed insurgent, the judge said, Semrau ignored the laws that govern warfare and applied his own morality.
His actions, placed his subordinates in an "unimaginable situation," the judge noted. "They had to either support him with their silence or do their duty and report his misconduct," Perron said.

Read more:
http://www.montrealgazette.com/news/Soldier+avoids+jail+death+Afghan+insurgent/3626079/story.html#ixzz1211EIqHL

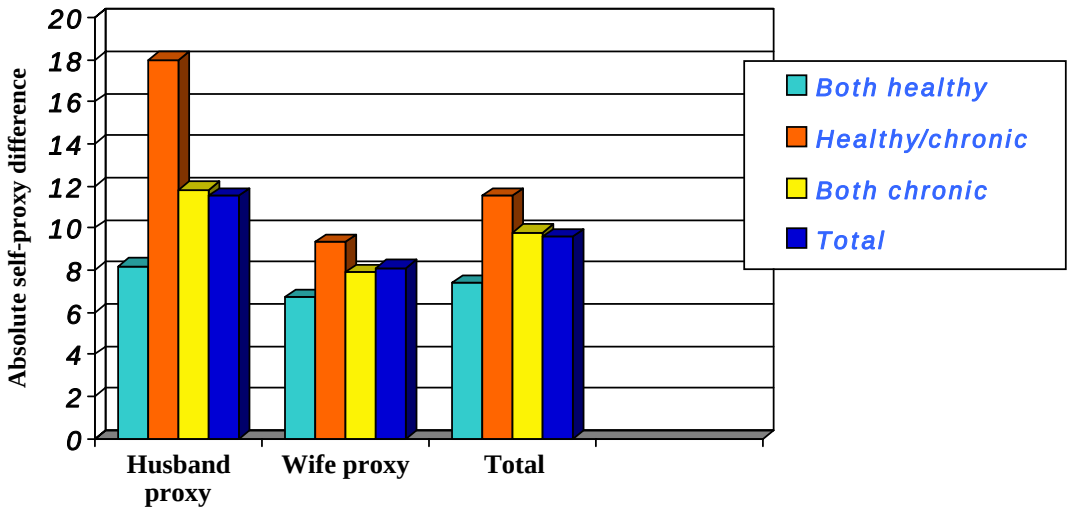
Difficult and challenging cases do exist – there is no denying that. But precisely in these complex situations, we are called to rise above a two-dimensional either-or paradigm: the dignity of a person does not always reside in respecting their choices. Some times it is about exposing him/her to other choices and alternatives. My Father was challenged to see beyond and to accept that his suffering was not only his but his family's and his society's (at base, financially). This proved to be another source of suffering for him because dependency grates on our individualist culture which all too often turns human lives into objects and means to an end rather than respecting them infallibly as subject, ENDS unto themselves. On the other hand, my grandmother had no problem because it never crossed her mind that her life, or any life, was disposable. We cannot allow a single life to be disposed of (even if it is at their request) without threatening the life of every other person[16].

Natalie Valle

Annex 1

SEIQoL index scores: absolute differences between self and proxy ratings

* P<.05 for male/female differences



[16] The powerful scene at the close of the movie, Judgement at Nuremberg, is very telling: when Dr. Ernst Janning tries to justify himself claiming that he never imagined millions of people would die, "I never knew it would come to that.", Chief Judge Dan Haywood responds saying "It came to that the first time you sentence a man to death knowing him to be innocent."