The Meaning of Suffering or the Meaning of Life Despite Suffering

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Relieving suffering is for all of us our primary duty, but denying that it can have meaning falls under the failure to provide assistance to a person in danger.

Cecile L. (volunteer on palliative care).

Healthcare staff, who are close to those who suffer, face all the dimensions of health as defined by the World Health Organisation as early as 1946, in the preamble of its Constitution: ‘*Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity*’.

In 2002, a law was passed in Belgium decriminalising euthanasia, under certain conditions, for people who are suffering from an incurable disease with symptoms that are difficult to control, and if all available means to relieve their suffering have been exhausted. In this framework, one thinks in the first instance of refractory pain, asphyxia, or terminal anguish. But other supporters of the law prioritise the total autonomy of the person and feel that people should be allowed to choose their time of death, if and when their life no longer has any meaning to them. From this perspective, euthanasia becomes a matter of the patient’s rights.

Everyday practice of oncology brings us to deal with symptoms and physical suffering in the terminal stage, which we are generally able to control with supportive care. Sometimes however the symptoms are refractory and palliative sedation

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proves to be necessary.¹ On the other hand, psychological suffering in the face of incurable disease, fatigue of lengthy treatments, loneliness, lack of family support, experiencing dependency, and the inability to go on with one's normal life are some of the many consequences of serious chronic illness which cannot be treated with medication. This is a matter of mental suffering that can take the form of depression, but also of existential, spiritual, or metaphysical distress. Psychological and social circumstances can give the underlying physical suffering a very different dimension. For instance, muscle pain one feels after running a marathon can be physically identical to those induced by a car accident, but they will be devoid of psychological suffering.

Thus, in the current practice of medical oncology, we observe that many requests for euthanasia from people suffering severe physical illness are motivated by psychological reasons. The patients feel that their life no longer has meaning. They fear having to suffer in the future. They are disheartened at not being able to manage their life as they previously did. And they do not want to depend on others. On the other hand, for the same reasons, requests for euthanasia can be made by people who, in the absence of any significant physical illness, consider that it is time to draw their life to a close. Autonomy, which has become a main concern, has replaced life as the fundamental value to be respected. Death, administered by the healthcare professional and offered as a solution, little by little replaces solidarity and creativity.

People who work in palliative care know that a request for euthanasia is very often a cry for help. One always has to start by listening to the pain and emotions behind the question and analysing the underlying reasons for the request. In most cases, when the suffering is taken seriously and solutions are offered, the request for euthanasia disappears.

The complaints of the people who are ill need to be heard. Minimising them or brushing them away does not help. Consequently, healthcare staff must be able to respond to physical suffering with scientific skill and knowledge (by administering pain killers in a professional way), but they must also be able to address psychological and existential suffering by drawing on their own humanity. Acknowledging that a person finds themselves in a humanly difficult situation—'What is happening to you is really hard'—is essential to avoid driving them further into distress! It is the only true help because when the person feels they are being understood, they can see themselves from the outside and come out of their despair.

But where can we find the necessary resources to respond to psychological and existential suffering? The theories of Viktor Frankl seem to be a good starting point since this psychiatrist devoted his entire career to empirical research on the meaning of life.

¹Palliative sedation lowers the state of consciousness of the dying with the help of medication, in order to relieve their pain, their (feeling of) choking, and/or their anguish. If it may be necessary to maintain sedation until the patient's death, in no way does sedation seek to hasten death. According to a study conducted in Leuven University Hospitals and published in the *Journal of Pain and Symptom Management* in January 2011, under the title '*Palliative sedation, not slow euthanasia: a prospective longitudinal study of sedation in Flemish palliative care units*,' 8% of the patients admitted to the palliative care unit needed palliative sedation at the end of life.

7.1 Viktor Frankl: The Question of Meaning at the Heart of Medicine

Viktor Frankl was born in 1905 in Vienna. Doctor in Medicine and in Philosophy, he is the founder of logotherapy, the third Viennese school of psychotherapy, along with Freud and Adler. Deported to Auschwitz in 1942, his psychiatric career was brutally interrupted by 3 years in the concentration camps. Furthermore, a manuscript which contained the essence of the thinking he had been developing since the 30s was lost. But this painful episode did not turn Frankl's life into a failure. On the contrary, it became the bedrock of his work, validating his theories that life can have meaning even in the most degrading of circumstances.

We owe it to the work of Viktor Frankl that the question of meaning, a fundamental philosophical theme, *entered the world of Medicine* and became the basis of a new school of psychotherapy: logotherapy. In a survey involving thousands of students, Frankl established that for most participants finding meaning in life was their highest priority. Being human always points, and is directed, to something, or someone, other than oneself—be it meaning to fulfil, dedication to a cause or another human being to encounter. Humans are not pure instinct, neither is their behaviour entirely determined. They need purpose, direction and motivation, without which they risk experiencing 'existential frustration' with widespread consequences such as alcoholism, substance abuse, suicide, depression, and fear of ageing.

Existential frustration leads to 'noögenic neurosis' which has its roots in the 'noös' or the spirit of the person, and arises from meaninglessness. Sometimes, man's search for meaning can induce tension instead of inner balance, but this tension is vital to mental health. People with a purpose in life are more likely to withstand adversity. Frankl quotes Nietzsche: '*He who has a why to live can bear almost any how*' [1] and points out that missing accomplishment can bring about minor psychological disorders in the young unemployed.

During therapy, Frankl's primary focus with patients is to awaken transcendence, i.e. the capacity to rise above adversity using their inner resources of mind and spirit. In order to do so, he conducts an existential analysis of what gives purpose and meaning but, unlike other European existentialists, Frankl is neither pessimistic nor anti-religious. He endeavours to draw together the fragile threads of a broken life and to reveal the pattern of meaning and responsibility they are displaying.

During consultation Frankl often asked patients with symptoms of depression why, all things considered, they would not commit suicide. The range of answers he gathered in conversations with thousands of people allowed him to 'empirically' ascertain a collection of motivations in life which can be grouped into three categories: finding meaning in accomplishment, in love, and in suffering. Accomplishment is achieved through creating a work or doing a good deed; love is about experiencing something in-depth such as goodness, truth, and beauty which can be found in nature or culture, or—better still—getting to know the uniqueness of another human being through love. Thus, Frankl recounts how, despite the dullness of the camp barracks, some prisoners stood in awe of the beauty of a sunset. As to the meaning of suffering, Frankl was struck by how many people in the camp were able to find

meaning in spite of suffering and, for a number of them, even because of their suffering. Suffering, of course, is to be avoided as much as possible, but faced with unavoidable suffering, one needs to develop a way of bearing it. Frankl believes that this is possible. In Auschwitz, he has seen people 'shoulder' their situation like heroes. He liked to quote Dostoyevsky *'There is only one thing I dread: not to be worthy of my sufferings.'* One needs to uplift suffering, make the most of each situation, adapt, and learn. If suffering cannot be avoided, one needs to learn how to suffer.

Let me give an example of existential analysis into what gives purpose and meaning to life. A man suffering from depression came to see Frankl because he could not overcome the loss of his wife with whom he had shared 50 years of marriage. Frankl confronted him with the question 'What would have happened, if you had died first, and your wife would have had to survive without you?' 'Oh,' the man said, 'for my wife this would have been terrible; she would have died of grief!' and felt much better after Frankl told him that he had spared his wife this suffering by surviving and mourning her.

In the camps, amidst indescribable suffering, Frankl encountered many opportunities that gave his life meaning. To name but one example, he chose to care for people with infectious disease rather than working on the night shift, thinking: *'if I die, I'd rather it be caring for the sick than doing useless work.'* Another drive for him was to carry on developing his theories. Frankl knew that that desire kept him going. In any case, he was one of the few survivors, even though on his arrival at the camp, the SS officer hesitated a long while before considering him suitable for work instead of sending him straight to the gas chamber.

According to Frankl, we need to look outside ourselves to find meaning. Through self-actualisation and transcendence, we can turn our talents into achievements. Reaching out, we can find meaning in self-effacing love, or in service to relieve another's suffering. *'For success, like happiness, cannot be pursued; it must ensue, and it only does so as the unintended side effect of one's personal dedication to a cause greater than oneself or as the by-product of one's surrender to a person other than oneself.'*

Similarly, when 'one expects nothing more of life' is not the time to put an end to it, Frankl says. Instead, it is the time to ask oneself 'what does life expect from me?' This is particularly true for people with a life-threatening illness. He remembers a patient who had been paralysed from his neck down since an accident which rendered him a quadriplegic, aged 17. This young man learned to live with his condition and even managed to take courses at College via a special telephone. In a letter to Frankl he wrote: *'I view my life has being abundant with meaning and purpose. The attitude that I adopted on that fateful day has become my personal credo for life: I broke my neck, it didn't break me. I believe that my handicap will only enhance my ability to help others. I know that without the suffering, the growth that I have achieved would have been impossible'*. [2].

A suffering person can find great solace in knowing that they are a unique person. Each one of us is unique and irreplaceable and nobody can suffer in a patient's place. They alone can face up to their situation and accept it with courage and

strength. With dignity too. And crying can be dignifying. There is no need to be ashamed of tears, for tears bear witness to the greatest of courage, to suffer and accept the struggle ‘in spite of the despites’. Suffering makes us stronger. Nietzsche said it even more clearly: ‘*Was mich nicht umbringt, macht mich starker*’ (‘What doesn’t kill me, makes me stronger’) [3].

No one knows what the future holds. Even though prisoners in the camp had little chance of surviving, they could not exclude the hope that they might find happiness again be it in a family, a job, or in freedom. Also, the past could be a comfort for a prisoner, without making him nostalgic, because that which we have experienced or done well, cannot be taken away from us. Our experiences, the deeds we have done, our positive thoughts, all our suffering—no one can take them away. Even committed to the past, they are not lost because we have experienced them. In times of trial, the past is as contemporary as the present day, if not more so.

Death, which is inevitable, must spur us to live in a responsible way. In life there are many opportunities for self-actualisation, and bringing to fruition the talents we have. If we seize these opportunities, we will be able at the end of life to look back with contentment on all we have been able to experience and achieve.

Such an attitude towards suffering can be achieved thanks to an inner freedom we can maintain, whatever the circumstances. Our capacity to choose our attitude and stick to it, whatever the circumstances, is the ultimate—and probably the only real—human freedom. Human beings can uphold this ultimate freedom in adversity, although Freud claimed the opposite. Frankl holds that, within certain limits, human beings can choose their destiny and pleads for allowing more space and importance to human freedom and responsibility in the practice of psychiatry. ‘*A human being is not one thing among others; things determine each other, but man is ultimately self-determining. What he becomes—within the limits of endowment and environment—he has made out of himself. In the concentration camps, for example, in this living laboratory and on this testing ground, we watched and witnessed some of our comrades behave like swines while others behaved like saints. Man has both potentialities within himself; which one is actualised depends on decisions but not on conditions.*’ [4] For Frankl, freedom without responsibility was an oxymoron. That is why he suggested that the Statue of Liberty in New York Harbor be supplemented by a ‘Statue of Responsibility’ somewhere along the West Coast.

7.2 How Can We Apply Viktor Frankl’s Theories to Helping Patients?

Now that we know something about Frankl’s theories, we can try and apply them to the situation ill people find themselves in. How do patients find meaning despite suffering and illness? Why do some experience meaningfulness and are keen to keep alive despite the hardship? Why are others disheartened and feel their life is not worth living?

7.2.1 First Pathway: Accomplishment Through Love

A number of patients hang on, hoping to be at a family event such as the wedding of a child or the birth of a grandchild. Others want to stick around as long as possible so as not to leave their partner behind or in order to watch their children grow.

A 72-year old patient with prostate cancer had already received many treatments, including chemotherapy, when he suffered a relapse in October. By that time, he had become frailer due to his advancing disease and prior treatments. We discussed the possibility of another course of chemotherapy. The patient was undecided because of his overall condition but, as his daughter was getting married the next year on July 26th, he wondered about his chances to be around for the wedding. We told him that life-expectancy can be difficult to gauge, but a new line of chemotherapy might help him make it, which seemed unlikely without any more treatment. He decided to have the treatment, knowing that he could stop it at any time if he wanted. He had four courses of chemotherapy until February, when he asked for a pause due to fatigue. In April he had two more courses before asking for another pause. He was at his daughter's wedding and the following day was admitted to hospital, where he died on July 28th. This man's motivation to live was undoubtedly boosted by the will to be at his daughter's wedding.

Illness can be *an opportunity to deepen a relationship*. We have seen couples who, having had a difficult relationship, found peace and a revived love when one fell ill and the other could—finally—start looking after them. A patient wondered whether his wife could still love him in the circumstances, to which she replied ‘now it is getting interesting!’

Many patients fear becoming a burden, although being cared for by someone can be very beneficial, both for the patient and for the carer. Here follows a conversation with a patient in the presence of her daughter:

‘Doctor, I don't want to be a burden to my children.’—‘Have you ever cared for someone who was ill?’—‘Oh, yes, I looked after my mother for three years and my father for six months before they died.’—‘Did that worry you?’—‘Not at all, I did it with great pleasure.’ Before I could tell her that maybe it was her turn now, her daughter took her mother's feet and, in tears, asked if she would let her care for her.

Thus, it will not be surprising that patients who are isolated, with few family members around, may find it more difficult to find meaning than others who are well connected. Studies show that the survival rate in cancer patients is higher for people who enjoy personal bonds [5] and in our practice we note that euthanasia requests are more often made by people who are lonely. Long lasting family conflicts can also trigger psychological suffering. Unfortunately, these are often difficult to solve and it is not uncommon that patients request euthanasia ‘because they no longer see their children.’

7.2.2 Second Pathway: Accomplishment Through a Meaningful Life

Many people want to go on living, despite illness or treatment, because they feel they have a reasonable quality of life and they can still enjoy good times. They plan weekends and trips in between chemotherapy courses, are happy as long as they can have a cigarette or enjoy cycling in good weather. Such an attitude requires the patient to adjust and adapt. They need to avoid focussing on what they can no longer do, in favour of finding new pursuits or resuming old ones they had let go of for lack of time. Sorting pictures, for instance, can be very meaningful. In youth one looks forward, in older age or illness, there is not much to look forward to anymore, but one can enjoy looking back on a life full of wonderful moments. Memories can be cherished with thanksgiving. Some patients say *'it is not so hard to leave, because I've had a full and meaningful life'*. Nobody can take our memories away!²

Even so, not everybody can achieve this, and particularly people who suffer from depression can find this very difficult. This is where the doctor and professional carers have an important input: they can help the patient and their family find meaning. That is, if they do not shy away from the question of meaning for themselves. In order not to cause an erroneous understanding of the notion of Christian Salvation through suffering, I do not say that patients find meaning in suffering, preferring to use the expression: *patients can find meaning in life despite suffering*.

7.2.3 Third Pathway: Knowing How to Deal with Suffering

Challenging patients' fears of physical pain, decline, and the burden of treatment are important. I can think of a number of reasons why these fears seem to have increased in recent years. First, we are less confronted with death in everyday life, so we no longer see it as a natural process. Another source of fear is the practice of therapeutic obstinacy which proves ineffective and leaves the patient exhausted. Finally, there are the media who repeat again and again that *'now that we have euthanasia, we no longer have to endure horrible suffering'*, by which they generate a very negative image of suffering.

In our daily clinical practice, we notice that dispelling patients' fears bring peace. We assure them that we will not undertake therapeutic obstinacy. We explain that they may die from kidney or liver failure or a cerebral herniation,³ for instance, which usually induces coma and a peaceful death after a few days. We tell them that, if necessary, we can use palliative sedation to lower their consciousness during the last hours of life. Eight percent of the patients in our university hospital have

² Some palliative care units allow patients to meet with a biographer who can help them write their memoirs.

³ A cerebral herniation is the shift of a part of the brain structures through a reduced opening, for instance the connection between the skull and the cervical spine. This leads to compression of the brain structures and loss of function, which will lead to coma and death.

palliative sedation at the time of death; in New Delhi, India, community palliative care teams can help up to 20% of patients dying at home with palliative sedation. Being clear about these helps drive out patients' fears of not being helped in the terminal stage.

A patient suffering renal cancer with bone metastases that paralysed her was still in treatment. Yet, she needed to remind us regularly that she was determined to request euthanasia at some point in the future. When we asked why, she said that she did not want to end up 'attached to a ventilator in ICU in a vegetative state.' We told her that was unlikely because admission to ICU is not easy for patients with advanced metastatic cancer, as intensive care makes no sense when the underlying condition can no longer be treated. We also said that we would make a note in her file stating her request not to be transferred to ICU and we reminded her that we did not practise therapeutic obstinacy. On hearing this, the patient's face lit up immediately, and she told me that if this was the case, she would no longer request euthanasia. After a few months her cancer treatment, which had become ineffective, was stopped. She was transferred to a nursing home near her daughter and lived there happily for two months, enjoying several outings. She organised a party for her 70th birthday, surrounded by about a hundred friends. When her condition deteriorated again six weeks later, she was nearing the end of life. She then asked for euthanasia again, but died naturally a few days later, before her request could be fulfilled. She was in fact already dying, after having filled her last weeks of life with meaning, despite being paraplegic.

Being open with the patient, describing their situation clearly and precisely brings peace. Good communication with patients about their diagnosis and prognosis is a real challenge for doctors, which we have to face up to. For many patients, not knowing is often worse than clear information, even when it is bad news. With so much to research online, patients and families will soon find out if they were not given accurate information, and they will lose trust in their doctor, while good communication based on facts can help them appraise what they might still try to achieve in life.

Illness can teach us how to live with uncertainty, in a way that is habitual for less stressful cultures. Living with uncertainty is particularly difficult in a society which keeps projecting itself into the future and seeks insurances to keep it safe from each and every hazard. When one suffers a chronic disease with an uncertain outcome, one is bound to experience living more in the moment. If patients have been given bad news of a cancer diagnosis, it does not necessarily mean that good surprises can no longer come their way. They may respond well to treatment, even better than expected, or their illness can plateau for a while, and it would be sad to throw that lease of life away with negative thinking.

Recently an ambulance was seen in front of a patient's house. She had been suffering from cancer for many years and her condition was deteriorating. Neighbours came out, worried about her, only to discover that she was fine, but that her husband, who had been in very good health, had suffered a pulmonary embolism and died...

Finally, doctors too must learn to accept death as the natural outcome of illness and of every human life. For some, death can be a relief after a long and difficult illness. Theresa of Lisieux's autobiography [6] is interesting on the subject: 'Oh!

What is agony? It feels like I am in it all the time... how will I manage to die? I will never know how to! Could it be today? If I were to die right now, how wonderful it would be! When will I choke completely? I can't stand any more...' Thus, we notice that even a Doctor of the Church like little Theresa can at the same time both long to die and fear death, but it must be said that she experienced 'agony' (during the last hours of life) in a time when palliative care was not as advanced as it is today... Although people without any religious perspective can find ways to live with suffering, we are aware that religion can mitigate patients' psychological and existential suffering. Someone who stands tall in the faith that God loves them personally, that their name is written in the palm of His hand, and that He gave His life for them may have a different outlook on death and dying. But some atheists also speak about their 'spirit', or the 'soul of the world' and discuss their 'desire for eternity'. We each hold a seed of eternity in us which drives our longing for total and sustainable happiness, and leaves us horrified at the thought that death might lead to nothingness. For those of us who have faith, death becomes a passage... to another mysterious way of life.⁴ From experience, I would say that people with faith often die more peacefully, but they too can suffer terminal anxiety, which can be something physiological.

7.3 What Happens in a Country Where Euthanasia Has Been Decriminalised?

The most important reasons why patients request euthanasia are: fear of deterioration, of becoming dependent, of being a burden, of terminal suffering and of no longer being able to do what one was used to. Very rarely do patients request euthanasia because of severe and unappeasable physical pain; it is more often about existential suffering underlying the physical pain. Let us think for instance of an elderly lady in a nursing home who suffers urinary incontinence and is becoming blind. When she asks for euthanasia, it is not because of intolerable physical pain, but because of underlying psychological suffering such as loneliness. Another person with a similar physical condition, who is well supported by family and friends, may not even think about euthanasia!

Cases of euthanasia that hit the media in Belgium are a perfect example. A transsexual man who was not satisfied with his bodily transformation is but one example of someone suffering psychologically, not physically. The writer who requests euthanasia as soon as he notices the first symptoms of Alzheimer's disease does so because he fears foreseeable deterioration, more than because of what he is currently experiencing. Twins who requested euthanasia out of fear of becoming blind still had good eyesight at the time of their euthanasia, and the Nobel prize winner with bowel cancer spoke of his loneliness in the face of illness.

⁴Thus, some compare death to a new birth. In his mother's womb, a baby does not know either what to expect after birth. Why should he leave this warm and comfortable place where he has his needs met?

Euthanasia requests are more frequent among people who are isolated or depressed. It is important to make them understand that, if we can no longer add days to their life, we can still add life to their days! The last phase of their life can still be full of meaning, for instance when they feel supported by carers, or a long-standing family conflict can be resolved. Because of this, carers and family members need to dig deep into their creative resources, day after day, to make patients' lives satisfying. The purpose of palliative care can be summed up in two Latin words: '*consolare et sedare*' to bring comfort and peace—a peace which is physical as well as psychological, spiritual, and social. Furthermore, the question of meaning which is a feature of human beings all through their lives needs to be taken seriously in their final moments. Palliative care respects the course of an illness which leads the patient to natural death, neither precipitating nor delaying it unnecessarily. Family and carers will draw on everything they can, with love and ingenuity, to make those final moments meaningful: a last opportunity for self-actualisation and growth; a final moment of humanity and love.

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