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## That which constitutes true care! Broadening our vision of care

My aim, with these few words shared with you, is not to offer you a brilliant and definitive oration, but rather to evoke certain situations and certain ideas, to stimulate discussion in the three days which follow. A sort of overture or aperitif.

### 1. Introduction

Eliane has been hospitalised because of advanced gastro-intestinal cancer; she is in a hospice. Thanks to the morphine she has little pain. When I enter her room, she is sat on her bed, drawing. 'I colour in mandalas every day and it does me a lot of good.' We talk about the benefits of this activity to her both as a means of expression, artistically and spiritually. At the end, she tells me: 'You know, colouring in mandalas does me as much good as the morphine...if not more!'

#### **a. Medicine has become biomedicine**

This is a phrase with the potential to shock when used about the efficacy of medical treatment and pharmacological treatment, shown to be effective and above all validated. And yet, it is statements like this which cause us to change our emphasis, or even better, institute a real change in paradigm. If we really wish to take such statements seriously, we will realise that they will completely change our usual biomedical and scientific approach.

Our Western world lives nowadays in a rational and scientific paradigm, and this is obviously a good thing when we think of the fantastic progress made in medicine. But with treatments becoming more and more specialised (thankfully!), are we not at risk of losing other dimensions of care? As for medicine which has become 'biomedicine' and 'evidence-based medicine', it is not without certain negative effects.

So, as said by the psycho-analyst Roland Gori:

'The medical *subject* has progressively metamorphosed into an example of a species within a system of classification of diseases which techno scientific medicine isolates, lists, homogenizes and treats according to statistical norms, both when it comes to diagnosis and when it concerns therapeutic

protocols. [.....] We end up by believing in statistics and in science in the same way as other civilisations have believed in spirits.’<sup>1</sup>

And it is thus that medicine can make life hard...for patients who don't understand certain very invasive treatments, or who feel pressured to always accept new treatments. It is these patients who tell us that they don't feel their deepest aspirations are being listened to.

## **b. Broadening our range of vision, opening our eyes.**

Today, it is this very range of vision that I would like to invite you to broaden. Far be it for me to think that no-one has ever considered this before, and even more so given the context of your thoughts around medicine of the person. But, what I propose, is that it is well worth considering our patients from an ever-broader perspective, more integrative, more vast, even extending beyond the person to include elements which, sometimes, are found beyond the rational.

In every caring act, I can ask myself at the same time: what am I really looking at when I look at my patient? Care is basically a question of attention. And we overlook a whole dimension of care if we only look at illness at the somatic level. Our patients tell us this very firmly, when they refuse a treatment or when they tell us about what is really important to them. They don't want to be medical miracles, but they want their life to still have meaning. As the pastor Philippe Zeissig said, referring to his own experience of illness: 'What is the point of being a medical miracle on the operating table, if, once out of the operating theatre, no-one is interested in us anymore?' Sometimes also, their bodies can't cope any more with what we want to inflict on them, even if it is most certainly for their good! It is a question therefore of taking the true path of humility, which means we take into account our limited vision of the world and of our way of caring, and allow ourselves to see the illness, the role of the doctor and the healing process in a different way.

This is also the thesis of the anthropologist Anne Véga: 'The aim is no longer to consider as 'marginal' the irrational elements which inevitably accompany care – all the more so as they remain under-estimated because of the universal presence of the dominant model of expertise and scientific neutrality.'<sup>2</sup>

This is why we need first to look towards the whole person in our patient, in all their dimensions, and particularly in their spiritual dimension. For spirituality is an integral part of care, as you know well. Let us be clear, spirituality is understood here as a fundamental dimension in every human being, independent of their religious faith or their secular or atheist beliefs! In palliative care, for example, we talk of the 'bio-psycho-socio-spiritual' model of mankind, so that we can include all possible aspects of the person.

This spirituality will take us still further beyond just the person of the patient, for it also includes the space in which they and we are, the space of the room, the hospital, that space which contains us. And beyond that immediate space, we look towards the natural environment surrounding us, the Earth and, why not, the cosmos....and God, who is also one of those 'envelopes' which contain us! All of that forms part of care, and under that umbrella, it is necessary for us to take account of it when we find ourselves at the patient's bedside.

You will have noticed that I am speaking here of care (singular) and not of treatments (plural); for the diverse treatments which we give are only a part of what I call care. Care, on the relational level, is more than the sum of individual treatments. For as we care for the 'biological' dimension, we also touch on the other dimensions: there are much vaster harmonics which vibrate when we take care of a wound or of a cancer: resonances which are psychological, social and spiritual appear.... which form an integral part of care.

We will now look at those things which can provide care, outside our usual biomedical scenarios. And we will remain very concrete, in other words true to the things which patients I have met have been able to tell me.

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<sup>1</sup> **GORI Roland**, 2006. The over medicalisation of our existence is a disavowal of 'self interest'. *Champ psychosomatique*, 2006/2;42:55-83

<sup>2</sup> **VEGA Anne**, 'Nursing care: added value from anthropology' in: Vonarx, Bujolk, Hamelin-Brabant, 'Social sciences in the field of health and nursing care. Volume 1. Experiences of health, care-giving and learned scholars'. Québec, Les Presses de l'Université Laval, 2010:252

For it is they, who challenge me and oblige me to open myself always more. And that will allow us to see 'which are the treatments which we need, want and can give to the patient under our care', as in the theme of this conference. I have often been surprised, for these various types of 'treatments' are sometimes astonishing.

## 2. That which provides care despite everything...

As we enter a room, we have got in the habit of focussing on the individual patient themselves. But if our gaze widens its focus, we see that we always see the patients themselves AND at the same time everything around them: there is the space of their room, always furnished in a unique way, there are living spaces in the hospital; but equally there is the environment within which the hospital sits; and all these elements play their role as well in the care we give the patient.

### a. Atypical care

Here are a few examples experienced with patients:

- **Philippe** is in a room which looks out on a curtain of trees. 'Since I was a child, I have always wanted to live in a forest; I was never able to fulfil that dream; and now I have achieved it. I feel so much better.'
- **Christine** tells me to contemplate the scenery she can see through her window; it nourishes her, gives her a purpose to her day, and she realises that this contemplation is a real source of healing for her. Can scenery be a form of treatment?
- **Edmond** sees three friends in the hospital living room several times a week: the four of them play cards together; this time is an integral part of his treatment.
- **France** has started to paint again, for she used to be a painter. She paints thirty or so little paintings on the theme of divine light. She has them framed, and with the help of her relatives she is able to organize a painting exhibition in the hospital. On the first day of the exhibition she sells the lot. Painting as treatment?
- **Robert**, a mountain farmer admitted to hospital under us is being visited by three friends; the doctor arrives to do his rounds. Looking at his watch, he says to the four friends; 'Isn't it time for a drink?' – 'Yes'. So, he goes to the kitchen and prepares glasses, wine and little snacks, and brings the drinks tray. The doctor, amply fulfilling his role of care-giver?

Simple stories? But each time, the patient confirmed to me that they really felt cared for on that day. So, we see that drinks with friends can provide treatment? Trees provide care? Painting a form of healing? Countryside a therapy? I absolutely believe so. We could add that music or essential aromatic oils act as therapy, just as does the presence of a relative or a kind gesture. Besides major treatment and taking numerous medications, other forms of care can be just as beneficial. And the reason is simple; these are things which firstly give back purpose to life lived in the present and on the other hand link in to the deepest desires of our patients. Obviously, this isn't always the case, but it very often is. And so, something starts to vibrate, the patient feels supported, encouraged, their inner life awakened, their spiritual life revived. And that allows them not only to live better, perhaps with their illness, but also to be better able to tolerate the onerous treatment, with its accompanying procession of side effects.

How do we draw all of this together? The thing in common, is relationship; relationship with oneself, with others, with one's environment, with nature, with creation and with God.

### b. It is relationship which provides treatment

In the end, I think it, is always relationship which provides treatment.

And it is particularly the case in the relationship between therapist and patient, this relationship based on trust which builds over time. I need to say a few words about this. For the model of 'therapeutic relationship'

has changed considerably; we know nowadays that it is first necessary to give back to the patient their experience, their expertise, their feelings, their ideas about what good care looks like for them. This immediately places the doctor in a new role, called to co-operate ever more with the patient.

So, what is the minimum requirement for a relationship to prove therapeutic? The foundation needed to obtain healing, is *'to be placed in a healing context' recognised as such*. The professor of medical ethics, Howard Brody affirms that this 'healing environment' comprises at least three conditions:<sup>3</sup>

- 1) The patient receives an *explanation* of their illness consistent with their pre-existing view of the world.
- 2) A group of individuals with *socially recognised care roles* are available to provide emotional support for the patient.
- 3) The healing intervention (treatment or ritual) allows the patient to gain a feeling of personal *mastery and control* over their illness.

In my opinion, I would add a fourth condition, since the context in which healing occurs is even broader in my view, since it encompasses the place where healing occurs, the natural environment and the whole of creation!

According to psychologists Bachelor and Horvath (1999)<sup>4</sup>, the role of the healer in the therapeutic contract is to establish a climate of trust, to communicate their understanding, their appreciation and their respect to the patient. In fact, *the relationship* represents already *in itself* a certain type of *therapeutic intervention*, the fact of experiencing a trustworthy and stable environment guaranteed by the therapist already induces a certain number of changes in the patient. The role which belongs to the patient, for their part, is active engagement in the therapeutic process and collaboration. According to these two authors, we come back to *'the full understanding of the purpose of our essential intersubjectivity, to the fundamental importance of relationship, and to the potential for healing of a well-managed therapeutic alliance.'* For, in addition to all the possible surrounding technical expertise surrounding it, the therapeutic relationship has at its centre *'an intensely human, personal and essentially unique encounter.'*

And that which the psychologists envisage here in the context of interpersonal relationship can be expanded to include the spiritual dimension. At that level, the relationship is equally therapeutic, as we will now see.

It is only as we think about the therapeutic relationship in a global and integrative manner that we will succeed in getting close to that *'intangible something'* which circulates between the therapist, the carer and their patient. If we take seriously all that I have talked about, if we really listen to the spiritual aspirations of our patients, we will be better able to assess those outcomes which we are seeking to obtain or to elicit through our care, and better able to understand those which emerge – sometimes quite independently of our treatment plans.

### 3. Global care, to achieve what?

#### a. Searching for equilibrium

Equilibrium is the first of the spiritual states which we always tend to strive for, and which care facilitates. As said by a Sioux medicine man *'equilibrium, equally, is important for health. If we retain equilibrium in everything, we are in harmony and at peace with ourselves. Perhaps equilibrium is the best thing in the world for combatting disease.'*<sup>5</sup>

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<sup>3</sup> Cited by Spiro, H. (1986). Doctors, patients, and placebos. New Haven/London, Yale University Press. P252.

<sup>4</sup> Bachelor, A. & Horvath, A. (1999). The therapeutic relationship. In M.A. Hubble, B.L. Duncan & S.D. Miller (Eds.). *The heart and soul of change. What works in therapy?* (pp 133-178). Washington D.C.: American Psychological Association, p.161.

<sup>5</sup> MAILS Thomas E., Fools Crow. 1994. Wisdom and power. Monaco, Editions du Rocher (Nuage Rouge): 169

Care-giving aims to restore a form of equilibrium, whereas the illness can be viewed as a breakdown in a certain number of equilibria: first of all, biological, but equally psychological, social or spiritual. Something needs to be compensated for or repaired at these different levels. Something of harmony is broken, whether on the level of the relationship with the created world, visible and/or invisible, or on the level of interpersonal relationship, social relationship in the heart of the group and of the community, and finally at the level of intrapersonal harmony, the accord one can have with oneself. The restoration of these equilibria constitutes the very purpose of care.

Illness thus implies a process, at the end of which, the sick person will have integrated into their lives new elements, and will have discovered new forms of equilibrium. 'Healing, is to give new norms to life, sometimes better than the old ones.'<sup>6</sup>

## **b. Searching for beauty**

The second spiritual experience is beauty, seen here not as something ephemeral, but as something essential. As Isabelle said, sick and approaching the end of her life; 'I want people to be able to see beauty in me, not in order to give me pleasure, but because it's true.' Do we know how to see beauty in our patients, and how to share that feeling with others in our care team? Do we know how to see beyond what first appears before our eyes; the suffering written all over a face or the body altered by disease? And if care had as its goal to draw out something of that essential beauty? This is also what Paul says in 2 Corinthians 4, v16: 'Though outwardly we are wasting away, yet inwardly we are being renewed day by day.'

In reality, for us, at the bedside of the patient, that vision of beauty confers on each act of care a purpose and a profound significance which goes beyond (while still integrating) the act of care in its most concrete reality; each injection, each dressing, each medication is a simple element which nonetheless can insert itself in a universe which is not only much greater, but still imprinted with the sacred or with beauty. Here is something which gives a bit of perspective to our technical viewpoints and our measurable and controllable actions, which are always at risk of losing their soul. For each act 'steeped in the soul' thus becomes something inhabited by something greater than it.

In summary, to discern beauty, is to make the wager that behind the visible and concrete elements are hiding (or throbbing) a greatness which gives to each of our acts of care an unsuspected scope or value. As one orthodox priest puts it, 'Spirituality is that which throbs behind appearances.'

Such a vision, which acknowledges our link with the sacred has certain obvious consequences on the ethical level. Within such a perspective, the rapport with the other (just as much as with oneself) cannot but be imprinted with a profound respect, and a real sense of responsibility. In a word, sacred people move within a sacred universe. Quite a scheme of things!

## **c. Being there in a sacred space!**

A sacred space (for example a temple or a church) has two complementary characteristics which confer on it its sacred nature: it is at the same time closed and open, enclosing and without frontiers. In the same way, the room of a sick person is at the same time a container, closed, protective and at the same time open to the hospital community and the natural environment. This is a pre-condition of the space being truly curative. Place heals! 'I am going to die soon. While waiting, let us make the most of what nature has to offer us', says a patient to me. In the same way, the architectural design of the building or department, and the positioning of it within its environment possess in equal measure a spiritual function. The garden or the country-side are not there just to 'look pretty'! They participate in the overall care and are therefore part of the cure.

The patient's room can therefore become a sacred space, a temple. And if that is the case there will be consequences which are very real for the behaviour of the patient: the way we behave there will change and will be imbued with respect and with tact. One wouldn't wander about in a temple in the same way as in a

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<sup>6</sup> LAPLANTINE François, 1986. Anthropology of disease. Paris, Payot (Bibliothèque Scientifique Payot):243

big department store! That respect forms part of the ethics of care, and it also contributes to the giving of care!

And in a temple, it's all about being present there, truly present. What a gift we give our patients when we make ourselves completely present to them (and for that one must first take the time to sit oneself down!). That capacity to be there seems simple, but it isn't at all. It implies the development of a whole physical and psycho spiritual awareness of oneself, of the presence of the other and the complete presence of all which surrounds us, as well as being fully alive to the presence of God.

#### **d. Dying cured!**

It can seem paradoxical to put it in this way. In our world, if someone dies, it means, by definition that they have not been cured; and if one is cured, it is that death has been beaten back. But as Professor Bernard-Marie Dupont says, healing does not consist in finding again a state of 'unlikely pre-existing biological innocence.'<sup>7</sup> Healing is a path, a transformation; it is that way of finding a purpose to one's life; it is that way of restoring equilibrium, of finding again one's beauty and all of that despite the illness. And it can also happen as one is arriving towards the end of one's life. More often than not it doesn't happen, but I have seen many people 'die cured', in the psychological, social and spiritual sense of the term, and die while being totally themselves.

And so, I think that it is possible to 'die cured', that is to say, at one with oneself again! Perhaps the path taken by the illness can still be a path to healing, even if the illness is terminal! For, before leaving this life, one needs to have been able to give birth to oneself in the broadest sense of the term; with one's equilibria restored, and linked once more to our worlds. So here it is, true health, even on the threshold of death!

And we find ourselves back at our first point: To heal, is to find again equilibria with our self, with others, and with the world, natural and spiritual.

## **Conclusion as a form of commission**

I have tried to move away a little bit from our models and our methods of practising to give them a new inspiration, a greater scope, a new density and depth, basically, of spirituality!

The aim for those of us who are care-givers, is to keep that uplift of the heart, to stay possessed by a momentum which comes from further away and will take us further. For it is this which, in the end, provides the most profound care for those whom we are called to encounter.

As for doctors, for care-givers, it is a sort of invitation always to expand our gaze to integrate, alongside the biological or psychological evidence, the elements having to do with life and mystery running through the unique being whom they are in the process of treating.

For in the end, treating the patient, means simultaneously treating the family, the community, nature and finally the equilibrium of the world itself.

So, we could describe our doctors as those who know how to 'restore harmony' around them or as 'creators of beauty' and as 'enchanters of life'!

I conclude with this thought from an American Indian medicine man who talks of his medical practice and that art of looking; 'I use my eyes to touch with love and gentleness'....

Thank-you.

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<sup>7</sup> Being human or the essence of life, in **HIRSCH Emmanuel** (editor) 2012. End of life, ethics and society. Toulouse, Erès (Espace éthique) : 56