

# Individuals and humanity: Sharing the experience of serious illness<sup>1</sup>

Yannis Papadaniel, Nicole Brzak and Marc-Antoine Berthod, PhD

University of Applied Sciences and Arts Western Switzerland, Lausanne

**Abstract.** When illness strikes, not only the sick person and her relationship to the world may change: the relatives may go through a similar process. They have to revisit their modes of reaching a balance between their private and their professional lives in order to articulate work, family, and care to be given to the sick person. This article is based upon an anthropological study conducted in Switzerland over a period of more than three years. It involved patients and other family members as well as colleagues, managers and health care professionals; its aim was to analyse the impacts of changes brought about by an individual illness on the relatives' employment situation as well as on family dynamics. We have observed that many of the interviewees still vividly remember the small gestures and words of a nurse or a physician perceived as "very human". These short narratives show how close relatives of very ill patients may develop a sudden attachment to people who have behaved as if they had truly, immediately understood their ordeal. Humanity is thus the keyword of this article, in which we will analyse its ambiguous meaning through the lens of individual's everyday experiences. Our hypothesis is that the notion of humanity serves as a «bridge» to a collective universe, providing a connection for individuals who have become strangers to their own world and are experiencing a specific form of loneliness.

[*Humanity, end of life, individuals, disease, illness, biopower, biosociality, loneliness, experience*]

*«For part of the way we are surrounded by  
others, but for some parts of it we are still  
all alone».*

Denise, whose spouse has a degenerative illness

## “Who is human?”

When people become ill, their relationship to the world may change. Simultaneously their relatives may experience a similar process. Dealing with medical institutions and requiring care reduces the control that patients and their families exert over their lives. Medical anthropology has shown how the dynamics of this situation modifies their relation to the world. Our article aims to investigate this statement by extending it to the close family of severely ill patients.

---

<sup>1</sup> We would like to thank Elisabeth Hirsch Durrett for the English revision of the text, and the reviewers for their constructive suggestions.

According to the results of an on-going study of family caregivers in Switzerland<sup>2</sup>, we have observed that many of them still vividly remember the small gestures and words of a nurse or a physician perceived as “very human”. These short narratives show how close relatives of very ill patients may develop an attachment to people who have behaved as if they had truly, immediately understood their ordeal. Few words, few actions were needed for this feeling to arise. How shall we consider this reference to the notion of “humanity”? What exactly does the use of the words “human” or “humanity” mean and imply in everyday life? Are the notions of “human” or “humanity” ambiguous? Indeed, they refer on the one hand to the universal nature of belonging and of shared behavioural traits, and on the other to particular attitudes that may or may not be exhibited in specific situations (such as the context of terminal illness). How are these notions used daily by laypersons who are not referring to either Aristotle or to the philosophers of the Enlightenment (Rees 2014)?

*Humanity* is thus the keyword of this article, in which we will analyse its ambiguous meaning through the lens of individual’s everyday experiences. Our hypothesis is that the notion of humanity serves as a «bridge» to a collective universe, providing a connection for individuals who have become strangers to their own world and are experiencing a specific form of loneliness that we shall examine here.

First we shall review some theoretical issues about the notion of “humanity” as social scientists and anthropologists have addressed and defined it. Secondly we will show how the notion of humanity comes up within the context of the end of life. And lastly we shall highlight the paradoxical status of this notion that brings to light the loneliness as well as the active role of individuals. The status granted to the «individual» is undeniably influenced by the way in which the health care system (and, in broader terms, the social welfare system) shapes this entity in the industrialised world (Dozon 2001). Yet we wish to show that the singularity of the experience of severe illness, whether experienced directly or shared, takes its shape independently of any kind of social isolation or failure of solidarity.

## Humanity: a given?

On the one hand, the notion of “humanity” refers to a common and universal membership to the “human race” that is self-evident (“we are all human, all part of mankind”, at least from a biological point of view). On the other, it defines some specific abilities and draws up a boundary between people able to demonstrate that they have these abilities and those who do not (whether not at all, or not yet). As such, humanity

---

<sup>2</sup> A three and a half year research entitled “Supporting a dying relative: between working and end-of-life care” (September 2012-February 2016; no 139246) and granted by the National Research Programme (NRP) 67 “End-of-Life” from the Swiss National Science Foundation.

seems to be a critical argument capable of legitimizing – or of weakening – a definition of a community. As Kantorowicz (1951), Anderson [2006(1983)] and Elias [Elias 1997 (1939)] have shown, the concept of every collective social body (of any kind: churches, believers, states) refers to a history of ideas. But, while a community depends on a theoretical and moral construct, the latter has to be tested and confirmed by actions or words (Boltanski and Thévenot 1991; Boltanski 2004)<sup>3</sup>.

Claude Levi-Strauss would have rejected all these approaches, since his definition of the human being was founded on the idea of “animality” (1952). There is no reason, in his perspective, to draw strict boundaries between animals and human beings, as both are determined by their biological condition as living beings. The main difference lies in their respective cognitive capacities. Furthermore the tendency of the ancient Greeks to consider as barbarian any non-Greek was seen as absurd by the anthropologist, who viewed it as the origin of ethnocentrism, racism, and rejection of others. Levi-Strauss’ perspective can then be understood on two different levels, ethical and epistemological.

He argues first against the practical and political consequences of the “grand partage”, with the explicit goal of addressing all cultures, “modern” or “traditional”, as equal. Yet at the same time, his conception of humanity as a whole is a way to strengthen *structural* premises: no matter how individuals think about their relationships to others or about themselves, when they view themselves as superior to animals or to others – they are wrong. The key point of anthropology lies, however, elsewhere: in the necessity to understand the invariable, structural and structural elements of *human* life.

The structural definition of humanity considers the social struggles about what humanity is or should be as secondary issues: it just ignores them, as if humanity *were* a matter of fact, even though its definition can be the subject of arguments or even wars. The capacity of individuals to consider themselves as human – a specifically human capacity – is simply not addressed in this context.

«Humanity» seems therefore to be an *impossible issue* as Piette (1996) used the term to define “God” in his study about religion. Piette shows the ambiguity of this object addressed either as an illusion to be exposed by the social sciences or as an entity whose existence has to be established by theology. In a sense, humanity may appear as the *god* of anthropology, simultaneously real and virtual, present and absent, obvious and undefinable.

As a theoretical but objective premise or as an object of conflict, the notion of humanity refers to a common affiliation that can be experienced by individuals in various ways and to varying degrees. Claiming for instance that France, or Greece, are the

---

<sup>3</sup> Both approaches derive from August Comte’s perspective, even if they break with his positivist attitude. Their definition of humanity is linked to the idea of solidarity. See Cingolani (1992). Boltanski (2004), by addressing the example of abortion, shows of the notion of humanity has to do also with a project and above all the words used to define that project.

cradle of humanity does not inevitably lead all Greek or French citizens to constantly present themselves as spokespersons for humanity. Humanity therefore has to be seen as a reality implying several degrees and layers: it simultaneously involves biological features and prescriptive, moral, even performative assumptions. As such, humanity includes, in a field of tension, two dimensions that Giorgio Agamben (1997) identified as distinct in the Aristotelian tradition: the categories of *bios* (βίος) and *zoé* (ζοή) respectively: humans as political (and thus also social, cultural and historical) and humans as living beings, in their nudity, seen – so to speak – as belonging to the zoological<sup>4</sup>.

Within this perspective, the notion of humanity thus stands at a point of contradiction. It can be defined as a reality that transcends individual and social differences, but it could just as easily be denounced as an illusory, or even a meaningless concept. This is the issue that Katia Genel (2004) brings to light in an article about biopower, based on the critical approach of Hannah Arendt on the issue of the emergence of human rights<sup>5</sup>. Genel underlines the «vacuity of the notion of humanity» (ibid.: § 34). From the range of positions recounted above, we may draw the conclusion that humanity is hardly a given. As a notion, it is derived from a form of assignation steeped in its social and political context. This may even contradict its supposed universal character.

At the level of individuals, humanity has the specificity of appearing self-evident in some daily situations, whilst referring to a «bare life» that cannot be truly grasped. As such, it must constantly be contextualized and redefined: how and when? These are the questions that should be at the core of any anthropological reflections addressing the notion of humanity. This is the goal we pursue in the present article. We shall attempt to shed light on the following three questions: how can the occurrence of a potentially fatal illness lead some individuals to view their life and their trajectory as though they were «stripped bare» of any kind of sociality? How does it lead these same individuals to experience a form of loneliness that seems independent of the forms of support they are receiving? And, last but not least, how does this experience of loneliness lead these individuals to resort to the notion of humanity?

---

<sup>4</sup> It would be wrong to think that the *zoé* refers to a static feature of humans. As many studies in the field of medical and technical anthropology have shown, even this supposed primal nudity can be re-worked and transformed. A recent book by Jürgen Habermas provides a clear illustration of this point (Habermas 2015).

<sup>5</sup> Arendt writes: «the conception of human rights, based upon the assumed existence of a human being as such, broke down at the very moment when those who professed to believe in it were for the first time confronted with people who had indeed lost all other qualities and specific relationships – except that they were still human. The world found nothing sacred in the abstract nakedness of being human. And in view of objective political conditions, it is hard to say how the concepts of man upon which human rights are based – that he is created in the image of God (in the American formula), or that he is the representative of mankind, or that he harbours within himself the sacred demands of natural law (in the French Formula) – could have helped to find a solution to the problem» (Arendt 1967:179–180).

## An ordeal

Disease involves a loss of control for patients and their families. It entails dealings with people, rules and institutions that require constant negotiations (Glaser and Strauss 1966, 1968; Augé 1984; Baszanger 1986; Aiach and al. 1989). Bataille's definition of the notion of "ordeal" fully encompasses this situation: "the idea of an ordeal helps one understand the situation of patients suffering from a severe illness. However, in our research the ordeal is considered as an event far more global than any biographical disruption. Nor is it a process of adaptation to a socially and culturally changing environment in order to internalise a new identity. The term ordeal designates a hardship that severely restricts the individual freedom of the player." (2003:261, our translation)<sup>6</sup>.

What was "natural" or "obvious" before the diagnosis is now uncertain for the patients: their future of course, is clouded. New questions arise about work, family or plans that have to be delayed or simply cancelled. When a patient enters a medical institution, he or she faces social actors whose language and attitudes are new, unexpected and compelling. The first part of the challenge consists in getting used to (or familiar with) the medical approach, its organisation, and of attempting to limit its possible influence. Bataille, among others, has shown how long-term cancer patients may attain greater autonomy: the longer their treatments last, the more likely they are to question or even refuse the physician's suggestions. However this familiarity (that may to some extent be associated to Rabinow's *biosociality*, 1996; see also Rose and Novas 2005) with the medical world is only a part of the ordeal.

As Fassin and al. (2004) have stated, suffering is contagious. In turn, close family members are likely to feel the consequences of the diagnosis right after the patient has received it. The same type of questions arises for them, as a result of the uncertainty that now characterises their everyday life.

Yet the burden is not only directly related to the illness: a new economy of social relations emerges, in which patients and their close relatives are perceived through the various threats posed by the disease process. "People change". We heard this statement

---

<sup>6</sup> Isabelle Baszanger writes: «(...) *l'univers médical n'est lui-même pour les malades qu'un sous-ensemble (a sub-world) du monde de la maladie chronique: dans leur travail de gestion, les malades doivent aller au-delà d'un travail de soins médicalement défini. Il leur faut aussi gérer les conséquences de la maladie sur leur organisation de vie, leurs rapports avec les autres et, jusqu'à un certain point, leur rapport avec eux-mêmes*» Pierre Aiach and al. add. (1986:22). «*L'incertitude, que doivent gérer l'ensemble des acteurs impliqués, contient à la fois une condamnation, celle prononcée par la maladie et une possibilité de survie, de guérison sans laquelle tout serait perdu et sans espoir; incertitude donc qui est difficile à vivre lorsqu'elle concerne la nature précise de la maladie ou le pronostic, mais qui parce que toute chance de survie et de «s'en sortir» n'est pas nulle, permet le déploiement de tout un jeu probabiliste où chaque joueur, selon sa place dans le jeu et l'importance des enjeux liés à cette place, peut formuler certaines anticipations, voire élaborer certaines stratégies*» (1989:22).

several times during interviews with patients and informal carers. The social environment does not know how to react; it may be supportive at the very beginning, but then become distant or even absent after a while. Both the support and the absence are at stake. Issues are not only related to the alleged denial that society imposes on disease and death: the nature of the support offered by the social environment could also do some harm, when it is perceived as inappropriate by patients or by their close relatives.

In such a context, patients and their immediate families find themselves seeking a balance between closer ties and more distanced relationships. An examination of this reality reveals individuals experiencing doubts and finding themselves feeling estranged from their social environment; some of them cling to it by calling upon the notion of humanity. This contradiction between a process of becoming more singular – though in an involuntary way – and the expressed reference to one of the most global common denominators possible might help us shed light on the question of the individual as an entity, and the status that should be granted to it in our analysis.

In order to conduct this part of our reflection, we shall make use of a case encountered in our field study. This situation involves a constellation of individuals. They revolve around two sisters who have developed the same illness. Within the context of our research, we conducted around sixty in-depth interviews with persons who were salaried employees and were working at least four days a week. In numerous cases, we met with several family members who were involved with the care of the same ill relative. When appropriate and with their explicit approval, we met with some of their colleagues, their supervisors and, in some cases, with members of management teams as well as human resources managers; around twenty additional interviews were conducted with these other persons.

Cross-referencing various points of view enabled us to compensate, to some extent, for the absence of direct observations. Moreover, our access to the professional world provided us with an opportunity to highlight the multiple and frequently contradictory adjustments that have to be made by the relatives of a severely ill person. Professional activity, in our view, allowed these elements to come to the fore: it provided an external – or even a social – reference point that enabled us to avoid the trap of *psychologism*, especially in a study focused on individuals, such as the one we were conducting.

## Marc, Florence and the others

We met Marc Testud<sup>7</sup> in April 2013 through a regional palliative care team. Marc is a teacher in a vocational high school. Six months earlier, he had lost his wife Katherine from uterine cancer; she had been diagnosed roughly two years before her death.

---

<sup>7</sup> All names used in this article are pseudonyms.

Katherine and Marc have a son named Pierre. Katherine had been a homemaker. Throughout his wife's illness, Marc continued his professional activities; as he benefited from a fixed but relatively light work schedule, he was able to be actively involved with his wife's care and took over some of the household chores. It is with a certain pride that he tells us that he knows how to carry out household tasks and that he can cook. Marc however is not alone: his sister and a friend of his wife's take turns at her bedside and help out with some of the lighter tasks. His sister, for instance, irons his shirts – a task for which Marc says he would like to pay her.

Marc and his wife have done their utmost to protect their son. They encouraged him to go to Canada for a year to pursue his engineering studies. Marc's sister, Marianne, tells us how Katherine kept her doubts hidden from her son, fearing she may not see him again. At the time of Pierre's departure she was still under curative treatments; thanks to the Internet she remained in contact with him, reassuring him most of the time. During the interview Pierre admits that he had not understood the seriousness of the situation and it was only much later that he realized that his mother was going to die.

According to Marc and his sister Marianne, the oncologist took into account the fact that Pierre was abroad in his choice of treatments. In the early summer of 2012 the doctor announced that curative treatments would be stopped because they were no longer effective; this did coincide with Pierre's return. Marc, with hindsight: "I don't know whether the oncologist waited for Pierre's return to break the news that there was nothing more to be done. He is also a father. I remember the date; it was the 2<sup>nd</sup> of July. My wife asked 'how long?' and the doctor said 'several months or weeks'. But always tactfully, don't misunderstand me, that doctor was really extraordinary."

As with his praise for the oncologist, Marc freely expresses compliments about those he believes deserve them. He also evaluates how he thinks he himself handled things. "That's all one can do. One has the easy part (...). How could I say, in comparison, that I am a poor devil because my wife has cancer. One must forget oneself a bit because psychologically it's tough (...) One is involved but one's own life isn't at stake".

Retrospectively however, Marc settles several scores with people he sees as not having behaved adequately: "There are people I won't see again, because they didn't do what they should have done when my wife was ill (...) They didn't hold out a hand to her as they should have (...) I don't want to be told 'you know, I don't know what to do'". From then on his wife's illness has an impact on his friendships. New friendships are formed, others are lost: "The case of a friend who lost his wife, we stood by him without expecting anything in return, he was there for me, he is a good person, he is a friend, he became a friend".

Marc therefore did pay attention to whether his friends were present or absent: "When friends are not there, it hits even harder". In his workplace, he is less focused on his colleagues' behaviour, and his expectations are less direct, though still present. When his wife first became ill, Marc had a headmaster he thought professionally com-

petent but personally distant: “I am a bit resentful, he wasn’t able to ask me ‘how is your wife?’” A few months later a new headmaster takes over and he feels the difference: “A headmaster who was more skilled than the other in human relations”. Jean-Jacques (the headmaster) was all the more understanding of Marc because he was simultaneously going through a similar experience. His mother was critically ill and was attending the same hospital unit as Katherine. Marc and Jean-Jacques ran into each other one evening by chance at the palliative care unit. Each was coming out of their sick relative’s room. They then started sharing their hopes and their despair. Jean-Jacques – who sees himself as the initiator of a project he himself describes as humanistic for the school he runs – admits that with this coincidence “there was a change; as a headmaster who is going through it, one sees things differently”.

They rarely talk about their shared experiences at the hospital and seldom run into each other there (Jean-Jacques does however have a coffee with Katherine, whom he had met at a school meeting). They make no appointments to discuss the subject but talk about it informally when they meet up at school or attend a professional meeting together; “when the opportunity arose”, Jean-Jacques specifies. They speak of their “hopes and their despair as they await “an answer from medicine, that never comes. It is not an exact science”. This common experience is thus shared on a daily basis albeit in diluted form.

Marc acts in the same way with his colleagues. At the end of a formal meeting he tells some of his colleagues about his wife’s illness. One day, he considers speaking up at a general conference but in the end he changes his mind, relying on word of mouth and on a form of spontaneity: “I don’t know how word got round”. Later Marc specifies: “I hesitated about addressing a plenary session (...) but in the end, you know, colleagues, there were those who wanted to know, those who knew but were uncomfortable and those who didn’t want to know (...) That’s life! (...) Some people are awkward in human relations”.

As for his pupils, Marc did not tell them anything, preferring to protect them. The news however did get around the school informally, without anyone knowing exactly which pupils knew (or how they had come across the information). Marc remembers vividly a note a pupil of his wrote at the end of the year, thanking him and mentioning knowing “what he had been through”. The mere recollection of this event brings tears to his eyes.

His emotion is also tangible when, for the second time in two of our encounters, he mentions the words of a colleague with whom he previously only had occasional contacts: “He came up to me and said ‘Marc’, he was very embarrassed, ‘I never ask how your wife is doing but I do think of you’ (...) “It’s not easy to do that but it’s enough. That’s about it. Because there are people who just can’t ask how somebody is doing. They can’t. And especially where cancer’s involved. With some other people it all happens naturally”.

On a daily basis, Jean-Jacques gives Marc the leeway to adapt his timetable so that he can be at his wife’s bedside. This flexibility is based on trust; Jean-Jacques knows

Marc will only take time off when he has to teach if he absolutely needs to. More generally he relies on Marc's work ethic and on the inherent requirements of the teaching profession: "There are times when one just cannot not be there. It's like the theatre".

It is precisely in this way that the employer's flexibility meets up with the doctor's receptiveness: "I made a point not to miss too much school. Here too, thank you to the doctor, because Doctor Barbot, after two or three bad experiences with my wife, I made all the doctor's appointments with her. I find that it is necessary, essential to be together to hear the bad news (...) Because my wife and I have certainly been punched in the face. Also to be able to emphasize the (good) news and minimize the bad. It's easier. I think the doctors like it when someone is there. It gives some breathing room. Because at first she had a different oncologist but there was no chemistry there, which is paradoxical because my wife was easy to get on with. Very, very good-natured. For there to be no chemistry, one really had to try hard. And it happened with that one doctor".

Marianne – Marc's sister – gives more details on the changing facets of the relationship between her brother, his wife and the doctors. If the final part of the medical care they received was "extraordinary", a word used unanimously, the beginning was more difficult, particularly with the physician Katherine had consulted at first. "She had to be told. He did things that just weren't fair. Error is human, no question about it, but he had a dreadful attitude towards her. Really, really, really (...) And humanly he was cold, as if shrugging his shoulders. As if everything was already over".

A close-knit circle of people gathered around Katherine. However this group had its failings and its conflicts. Florence – Marc's sister in law – was thus "reprimanded" by Marc the day he found her in tears in the hospital room. Florence says: "I couldn't let something out that I felt (...) Something was taken from me then". Not being allowed to express her sorrow did not cause an argument after Katherine's death, but it did leave its mark on Florence.

It would seem that the cause of Katherine's disease was genetic. It is at any rate the assumption of her friends and family; indeed her sister Florence has the same disease. She was by Katherine's side until her death. Their parallel experiences were of course difficult for Florence. The two sisters remained very close, sharing their fears and their suffering. Two years earlier, she had been diagnosed with a primary tumour of the uterus that was treated successfully. Six months later it recurred and required chemotherapy, which was unsuccessful. Florence and her husband Sébastien were initially resigned to the oncologists' pessimism: "You know, with all you have already had. There are no miracles", is how Florence sums up the coldness of the last conversations.

However during a visit to her general practitioner, Florence finds out about cyber-knife laser treatment; it is meant to desiccate the tumour and its ramifications without harming the surrounding tissue. This treatment is available in the medical centre of another town than the one where Florence is being treated. In the hope of being referred, Florence goes to see her oncologist. But the latter still seems completely resigned: this

treatment is not appropriate for her kind of cancer, he argues. Encouraged by her general practitioner, Florence perseveres and contacts the cyber-knife team directly. It will take her six months to get an appointment and get access to the treatment. At the time of our meeting, she is waiting for the results of the treatment. The six-month waiting period was not without consequences: a new lymph node has “lit up”.

Sébastien summarises the situation at the last medical meeting: “The way we were received was hardly adequate. The consulting room was tiny, without a window. Obviously you can’t have windows everywhere but (...) The doctor, he came in saying ‘there is little chance, there is nothing to be done, but it depends on how you want to fight it’. It sent a shudder down my back and I thought to myself “now there is no solution””. Florence was upset at her oncologist: “You’re the doctor, not me”; on the contrary she was quite enthusiastic about her interactions with the radiologist who met with her: “I was greeted by a super nice doctor, very human, who explained things to me”.

## Loneliness

From Marc to Florence, formally, we see no loneliness: they each have their place in a network of solidarities, despite the upheavals induced by the illness. The approach we used in our study, the way in which we were able to meet the “chain” of people involved and to have access to the narrative of their individual experiences, actually reveals multiple solidarities and shows that connections are maintained. Formally, the individuals we met are clearly not alone.

Yet the experience of serious illness in the family modifies relationships to others. At the same time, everyone stays in place and most changes are subterranean or silent. Marc only expresses his disappointment in some of his friends in their absence, never explicitly in front of them. He does not see them anymore, and they do not try to get in touch either. Besides, Marc gives great importance to an event that is particularly fleeting: he remembers the colleague who, when passing by, expressed his support. This colleague did not become a friend and he never played an active part in the situation, yet Marc gives him a central place in his recollections.

The new economy of relationships resulting from an illness gives way to new balancing acts. Friendships are tested, patterns of gift giving and returning are revived and, the illness can become a way of settling one’s debts, of marking one’s attachment or of highlighting friendships. Yet distance, consciously or unwittingly kept, is also a point of focus: illness, for the person who experiences it directly but also for close relatives and friends, can lead to unexpected closeness. Thus illness does not necessarily interrupt relationships; it can also provide opportunities for bonding and sharing. As such, the advent of an illness may represent the beginning of a testing period that may lead, or indeed compel, individuals to examine the different capitals at their disposal, to use a bourdieusian metaphor; on this point, we refer to the work of Jack Katz, who

analyses the use made by social actors of various type of symbolic capital in times of crisis (Katz 2011).

Sharing is thus neither always wanted, nor possible at all times. Marc is careful when communicating about his wife's illness with his colleagues. This is a frequently observed attitude in the professional realm where social relationships are, at least partly, constrained. As a result, all that relates to the private or even to the intimate sphere – as illness does – is only shared with parsimony and/or with carefully selected people (this statement may be viewed as specifically relevant to Northern countries and to contexts involving a potentially fatal illness). However this attempt at control is not completely effective: repeated absences, worries, concentration problems, all require understanding from colleagues (as in the headmaster's example).

Either too much or not enough; no appropriate measure of norm of reference seems to exist. Sébastien finds himself in a troublesome professional situation a few months after his wife's diagnosis. A series of misunderstandings, worsened by his own awkwardness in professional dealings, will lead people in the workplace to have doubts about his place as a company employee. His job and his legitimacy are clearly threatened. While conflicts with his hierarchy have nothing to do with his wife's illness, the level of attention she requires and absences – although sporadic – from work will not help either. They will aggravate tensions. All in all, he is present and available neither at work nor at home, always risking being in the wrong place.

No social arrangements exist to specifically take into account and alleviate this type of difficulty. All existing offers are targeted on the sick patient. For relatives to be taken into consideration, they must be viewed, in turn, as patients themselves (at least in Switzerland, but also in many other European countries). Depression in the face of insurmountable tasks and symptoms of burn-out are the only motives for a medical certificate that could justify a leave of absence from work and give rise to possible compensatory measures.

An existential dimension compounds this institutional dimension: the uncertainty linked to the illness is a powerful vector for existential questioning. However, uncertainty does not have the same impact on patients as on their close family members. Like suffering, it is lived by patients from the inside. They suffer in their bodies and face their own finitude. Family members and friends, on the other hand, envisage it from the outside while also thinking about – if they will be able to face the future – their own life after the illness. Suffering does spread, but it becomes transformed when passing from one individual to another.

Different forms of experience mean different forms of suffering and create a line of demarcation. Marc stayed at his wife's side during the two-year duration of her illness. Yet he emphasizes the difference between their experiences. The bonds between them remain, but everything that was taken for granted changes from day to day, and the course of the disease makes differences more and more patent. Marc prepares himself to be left alone while his wife gets ready to leave the world. In a way, they are both alone.

As far as we know, loneliness is seen in anthropology as deriving from some sort of lack or deprivation. Indeed, social sciences tend to view this notion as a symptom of some other condition. The loneliness of the dying (Elias 1987) is, for example, viewed as part of a more global process – social death is construed as deriving from abandonment and from of an institutional ability to “overlook” that was well documented by Sudnow (1967) as well as Glaser and Strauss (1966; 1968). Loneliness, in this perspective, is too often synonymous with isolation and the failure of a social structure to bring aid to people in difficult situations. It is analysed through the lens of its negative consequences<sup>8</sup>. In this article, loneliness is rather more of a fundamental constituent revealed by the immediate confrontation with illness and death. It does not depend on the structures of society.

From a different standpoint, Marie-Chantal Doucet (2007) underlines, without necessarily analysing all the implications of her statement, that there exists neither a psychology nor a sociology of “the lonely”, but yet that many worlds of solitudes do exist. Such an observation should allow us to broaden our focus, and to view loneliness less as a phenomenon derived from an anomaly but rather as an object with its foundations and its own social ontology.

John Dewey (1905:293) gives a specific illustration of the basis of this form of loneliness. The quote is lengthy, but it deserves to be included in its entirety: “Immediate empiricism postulates that things – anything – everything, in the ordinary or non-technical use of the term ‘thing’ – are the way they are experienced. Hence, if one wishes to faithfully describe anything, one’s task should be to describe what is being experienced. If it is a horse that must be described, or *equus* that is to be defined, then it is up to the horse-trader, or the jockey, or the timid family man who wants a ‘safe mount’, or the zoologist or the palaeontologist to tell us what horse they are experiencing. While these accounts may differ in some respect, as well as concur in others, this is no reason for assuming the content of one of them to be completely ‘real’, and that of others to be ‘phenomenal’; for each account of what is experienced will demonstrate that it is the account of the horse-dealer, or of the zoologist, etc. and hence will fulfil conditions requisite for understanding where accounts differ as well as where they concur”.

In other words, illness – as experienced by each protagonist of the situation – refers to a separate kind of experience that is, to a certain extent, singular. It is precisely the inclusion of actors in a network (a relatively tight-knit network in the case we presented, in which sociality was strong and tangible) that, by contrast, brings to light occurrences of unity as well as of disunity. Experiences can never be completely shared. There is always an aspect of reality that remains singular. When individuals experience these fault lines, they may feel a kind of existential loneliness (Piette 2009). This kind of loneliness is distinct from the type of isolation that can stem from the combination

---

<sup>8</sup> See Déchaux 1995.

of unfavorable socio-economic factors and the individualization that is characteristic of modern medical care (on this point, see for instance Lovell, 2001); rather, it is related to the singular lived experience of actors and may be felt by them as an experiential gap between «me» and «the others».

Let us sum up: work, its requirements, proximity with – or distance from – colleagues, social protection, loyalties towards a circle of family members, family expectations and responsibilities, family history, emotional involvements, all forge day-to-day experience. These elements simultaneously channelling and founding experiences, help individuals to bond, anchoring them into statuses and roles that they willy-nilly endorse, put up with, or attempt to transform. The emergence of the illness and its potentially fatal outcome create a disturbance. Those who were bound together – husband and wife; mother and child – and who looked ahead to a common destiny are now forced to contemplate rupture.

For family members, placed in second (Marc; Sébastien) or in third (Pierre) line, who are neither sick nor truly healthy, social channels of communication and social supports are liable to wither without being replaced<sup>9</sup>. Doubts may gain ground. Professional activity can be a support but may also represent a threat. The hospital, technology and science appear to be a source of hope and simultaneously of fear and disillusionment; colleagues could be supportive and also be seen as sources of trouble that should be kept at a distance. Should one mention the situation or remain silent? How should one talk about it? Who to? Without norms of guidelines, a conflict can flare up at any moment, as when Marc berates Florence for crying with Katherine in her hospital room.

Standing up for each other and standing by the sick family member do not prevent cracks from appearing in the cement of solidarity. These crevices can take the form of an increased singularity of each person involved, an absence of sharing and a multiplication of experiences that Albert Piette would associate with what he calls the minor mode<sup>10</sup>. Illness causes social actors to feel a kind of loneliness, and to dig themselves in. This loneliness can be perceived as a social symptom of the illness. Yet from an anthropological point of view, it is possible to go beyond this statement. Indeed, on the basis of this analysis and in accordance with Dewey's perspective, our hypothesis is that illness does not create this specific form of loneliness, but that it reveals it. In this sense, illness is a catalyst for this type of loneliness.

This type of isolation is scarcely noticeable in everyday life. The social network is constantly present: the care of dependent children, their upbringing and education, professional integration, institutional care or even solidarity itself are as many signs

---

<sup>9</sup> The medical and associative fields do provide many services to patients, but few to their relatives.

<sup>10</sup> That is to say a mode that «only really exists when a gesture, a specific detail, is not presented as a behavioural model nor as a type of involvement that can be shared with other actors of the interaction» (Piette 1996:181).

of an attachment to the collective and of societal formatting. Yet a large part of the experience of close relatives of the seriously ill rests upon uncertain, vague foundations and sometimes on the experience of failure or loss. Socially protective walls become permeable in front of death; they seem meaningless, useless or unwelcome. The “too much” or the “not enough” tend to blend (we think here about a woman we encountered during our research, who blamed her colleagues both for being overly discreet when they failed to enquire about her severely ill mother, and for being inappropriately curious when they did); adjustments are difficult to make, necessitate too much effort and are brushed aside as vain in the face of the imminent departure of a loved one.

The figure of the individual arises as a negative, appearing in a grey zone between on the one hand usual codes, normal statuses and instituted categories, and his or her individual fate on the other. Without adequate support, seized by doubt, anyone is likely to experience loneliness and to reflect upon his or her singular condition. This condition was already there – from the very beginning are we tempted to say – but it was concealed under multiple strata.

## And humanity?

Illness highlights discrepancies of all kinds: in our interviews with him, Sébastien plays down, in turn, his difficulties at work and the illness of his wife (“She is strong, I am not worried about that”). Florence herself is simultaneously worried about her husband and focused primarily on her own issues; she prefers to handle things alone, giving him breathing space to avoid unduly worrying him. Possible disagreements or differences of opinion lurk under a façade of marital unity<sup>11</sup>.

The divisions caused by the disease also set apart patients, informal carers and health professionals: every single detail may bring up doubts. A lack of understanding or of attentiveness, a dingy consulting room can trigger recurrent underlying negative feelings towards the medical care institution. Its alleged coldness, inhumanity, and general lack of consideration for patients’ feelings feed into further misunderstandings.

Yet, in their narratives, Marc, Katherine and Sébastien ceaselessly identify individuals that they associate with a common humanity: “extraordinary people”, “full of empathy”, and also “very human”. It is thus interesting to notice the gap between the collective, and even generalising, nature of a labelling process and the single, lonely experience from which it arises.

This gap is even more noticeable because the characterization of humanity is founded upon small details: a passing comment, a carefully worded cautionary remark.

---

<sup>11</sup> The Italian writer Antonio Tabucchi suggested that one of the driving forces of social life was misunderstandings.

Marc told us that the nurses advised him to set aside some time for himself outside of the hospital and not to feel he should always be present at his wife's side. Florence and later Sébastien, while they place all their trust in medical technology, appreciate the time taken by the physician to explain to them in simple terms the challenges, the limits and the potential benefits of the technique that will be used. At the same time, the oncologist who treated Katherine was incredulous when we told him that he had a reputation as being «human».

Humanity thus seems to lie in contrasts and to be found in details. Humanity is made up of opposites: having faith in medical techniques but not in the technician; trusting the hospital, but not at any price; seeking medical knowledge (even understanding physician's errors), but not medical power; being willing to accept injunctions, but not to be made to give in to them. Hence, humanity is much more than a virtual, future plan or projection (Rees 2014). As Callon and Rabeharisoa (2004, pp. 16 and following) have stated, as medicine becomes more specialized and technical, as it acquires more specific knowledge, it produces not less but more humanity as the potential for new associations and new entanglements continues to grow (Latour 1999).

Humanity is not meant to be described, but rather to be acknowledged. It stands at the crossroads of similar, but not identical experiences. It roams the halls of institutions, alters the normal order of things but does not fundamentally put social roles into question. The physician maintains his or her social status; so does the headmaster. Yet both of them take on a stature that could be described as situated either underneath, or above institutional boundaries and regulations, thus placing both the physician and the headmaster – in some way – outside of the institutional context to which they belong. As we have seen, this revelation does not stem from a mechanism of mutual adjustment but arises through the workings of an individual, subjective hypothesis of a common humanity.

The use of this notion springs up in the context of the experience of a 'bare life', that is from a feeling of existential nudity that arises alongside – and despite – strong solidarities and forms of support. Without explicitly denouncing the artificiality of social life, individuals operate using positive subjectification (Rémy 2009). In this sense, Marc, Sébastien and the others re-humanise humans. Through pointing out who – and what – is more, or less, *human* they re-examine the economy of their relations and their personal ties to institutions. Making use of the notion of humanity brings to light the attachment and detachment processes that are at work even when a troubled group is attempting to set some form of solidarity. In fine, the fact that individuals are part of a collective does not erase their solitude. The social sciences should perhaps focus more frequently on this odd angle – this very ambiguity – rather than concentrate on investigating the occurrences of 'regularities'.

## Bibliography

- Agamben, Giorgio 1997: *Homo sacer. Le pouvoir souverain et la vie nue*. Paris: Seuil.
- Aiach, Pierre; Kaufmann, Alicia; Weissman, Renée 1989: *Vivre avec une maladie grave*. Paris: Méridiens-Klincksieck.
- Anderson, Benedict 2006(1983): *Imagined communities: reflections on the origin and spread of nationalism*. London, New-York: Verso.
- Arendt, Hannah 1967: *Imperialism. Part two of the origins of Totalitarianism*. San Diego, New-York, London: Harvest Book.
- Augé, Marc 1984: Ordre biologique, ordre social: la maladie forme élémentaire de l'événement. In: M. Augé, and Cl. Herzlich (eds.), *Le sens du mal: anthropologie, histoire, sociologie de la maladie*. Paris: Editions des Archives contemporaines, pp. 35–93.
- Baszanger, Isabelle 1986: Les maladies chroniques et leur ordre négocié. *Revue française de sociologie* 27 (1): 3–27.
- Bataille Philippe 2003: *Un cancer et la vie: les malades face à la maladie*. Paris: Balland.
- Boltanski, Luc; Thevenot, Laurent 1991: *De la justification: les économies de la grandeur*. Paris: Gallimard.
- Boltanski, Luc 2004: *La condition foetale. Une sociologie de l'engendrement et de l'avortement*. Paris: Gallimard, NRF.
- Callon, Michel; Rabeharisoa, Vololona 2004: Gino's lesson on humanity: genetic, mutual entanglements and the sociologist's role. *Economy and Society* 33(1): 1–27.
- Cingolani, Patrick 1992: L'idée d'humanité chez Auguste Comte: solidarité et continuité. In: P. Chevalier (ed.), *La solidarité: un sentiment républicain*. Paris: PUF, pp. 42–54.
- Dechaux, Jean-Hugues 1995: Sur le concept de configuration: quelques failles dans la sociologie de Norbert Elias. *Cahiers internationaux de sociologie* 99:293–313.
- Dewey, John 1905: The postulate of immediate empiricism. *The journal of philosophy, psychology, and scientific methods* 15(2): 393–399.
- Doucet, Marie-Chantal 2007: *Solitude et sociétés contemporaines: une sociologie clinique de l'individu et du rapport à l'autre*. Québec: Presse de l'Université de Québec.
- Dozon, Jean-Pierre 2001: Quatre modèles de prévention. In: J.-P. Dozon, and D. Fassin (eds.), *Critique de la santé publique: une approche anthropologique*. Paris: Balland, pp. 23–46.
- Elias, Norbert 1987: *La solitude des mourants*. Paris: Christian Bourgois.
- Elias, Norbert 1997 [1939]: *La civilisation des mœurs*. Paris: Pocket.
- Fassin, Didier, Aiach Pierre 2004: *Des maux indicibles: sociologie des lieux d'écoute*. Paris: La Découverte.
- Genel, Katia 2004: Le biopouvoir chez Foucault et Agamben. *Méthodos* [Online] uploaded on 09th april 2004, consulted on 21st mai 2005. <http://methodos.revues.org/131>; DOI:10.400/methodos.131
- Glaser, Barney G.; Strauss, Anselm L. 1966: *Awareness of dying*. London: Weidenfeld & Nicolson.
- Glaser, Barney G.; Strauss, Anselm L. 1968: *Time for dying*. Chicago: Aldin.
- Habermas, Jürgen 2015: *L'avenir de la nature humaine. Vers un eugénisme libéral*. Paris: Gallimard.
- Jankelevitch, Vladimir 1977: *La mort*. Paris: Flammarion.
- Kantorowicz, Ernst H. 1984: *Mourir pour la patrie*. Paris: PUF.
- Katz, Jack 2011: Se cuisiner un statut. Des noms aux verbes dans l'étude de la stratification sociale. *ethnographiques.org* 23 consulted on 20<sup>th</sup> may 2015 <http://www.ethnographiques.org/2011/Katz>
- Levi-Strauss, Claude 1952: *Race et histoire*. Paris: UNESCO.
- Lovell, Anne 2001: Ordonner les risques: l'individu et le pharmacosociatif face à l'injection des drogues. In: J.-P. Dozon; D. Fassin (eds.), *Critique de la santé publique: une approche anthropologique*. Paris: Balland, pp. 309- 342.

- Piette, Albert 1996: *Ethnographie de l'action*. Paris: Métailié.
- Piette, Albert 1999: *La religion de près: l'activité religieuse en train de se faire*. Paris: Métailié.
- Piette, Albert 2009: *L'acte d'exister*. Marchienne-au-Pont: Socrate.
- Rabinow, Paul 1996: *Making PCR: a story of biotechnology*. Chicago: University Chicago Press.
- Rees, Tobias 2014: "Humanity/Plan; or, on the 'stateless' today (also being an anthropology of global health)". *Cultural Anthropology* 29(3): 457–478.
- Remy, Catherine 2009: *La fin des bêtes: une ethnographie de la mise à mort des animaux*. Paris: Economica.
- Rose, Nikolas; Novas Carlos 2005: Biological Citizenship. In: A. Ong; S. J. Collier (eds.), *Global Assemblages*. London: Blackwell, pp. 439–463.
- Sudnow, David 1967: *Passing on. The social organization of dying*. New Jersey: Prentice-Hall.
- Testart, Alain 1992: La question de l'évolutionnisme dans l'anthropologie sociale. *Revue française de sociologie* 33(2): 155–187.

