

“SECRETS AND LIES”: (NOT) TELLING BAD NEWS IN ITALIAN ONCOLOGY

Marco MARZANO¹

Abstract: *The problem that I treat in this paper is about the fact that people who are about to die in hospital are not usually informed about the fate awaiting them. In Italy, this attitude has remained intact over time despite the extraordinary changes which have taken place in clinical techniques and therapies, and despite the spread of hospices and palliative care wards. In this paper I shall describe the strategies adopted by Italian oncologists to prevent the dying from knowing their fate, the exceptions to this rule, and some of the structural and organizational factors which make changing the situation difficult. The discussion conducted in this paper is based on an ethnographical research carried out by the author in a large hospital in northern Italy.*

Key words: *imminent death, conspiracy of silence, “no tell” policy, communicative strategy.*

In Italy, as probably happens in other countries of the world (Seale et al. 1997; Elwyn et al. 1998; Seale 1998; Field and Copp 1999), people who are about to die in hospital are not usually informed about the fate awaiting them. To use Glaser and Strauss’s expression, a context of “closed awareness” prevails. In Italy, this attitude has remained intact over time despite the extraordinary changes which have taken place in clinical techniques and therapies, and despite the spread of hospices and palliative care wards. The policy of ‘not telling’ has been adjusted to the new circumstances.

In this paper I shall describe the strategies adopted by Italian oncologists to prevent the dying from knowing their fate, the exceptions to this rule, and some of the structural and organizational factors which make changing the situation difficult.

The discussion conducted in this paper is based on a year of ethnographic

observation of social interactions at an oncological ward of a large hospital in northern Italy and on dozens of interviews carried out by the author in the same place in the same period.

For the good of the patient: the truth concealed by Italian oncologists.

When faced by a patient afflicted with an incurable tumour, Italian oncologists generally choose to lie about the prognosis (but not always about the diagnosis). This, of course, is a ‘morally legitimate’ lie, in the sense that according to the oncologists it is an untruth intended to protect patients, to insulate them against the terrible truth of their imminent death [Gordon 1990; Surbone 1992; Gordon and Paci 1997, Campione 2004]. This behaviour is justified by the so-called benevolence principle, according to which doctors have some sort of mandate deriving from the fact that patients have placed their trust in them [Pellegrino 1992; Pellegrino,

¹ University of Bergamo.

Mazzarella and Corsi 1992; Beauchamp and Childress 1994; Engelhardt 1996]. This principle purportedly requires doctors to work for what they believe is the good of patients, or indeed in consideration of health and life itself (or of their duration) as *goods in themselves* not freely and immediately available to persons. The patient thus enters the state which Glaser and Strauss [1965] called ‘closed awareness’.

The strategy of concealing the truth from patients is made feasible because many people do not recognize (or they remove) the signs of their imminent death, or they simply do not feel authorized to talk about them with a doctor. Whatever the case may be, for the strategy to be successful, secrecy must be strictly maintained, and a so-called “conspiracy of silence” must be activated [Ariès 1991].

For this reason, all available forces must be immediately enlisted. The first actors to be involved in the conspiracy are relatives and friends: in short, those people closest to the patient and who are able to filter and control the flow of information about the illness. Unlike the patient, these people are rapidly and expressly informed of the diagnosis and the prognosis. In many cases, it is they who activate the conspiracy by beseeching the doctor not to reveal the dramatic nature of the prognosis to their loved one.

In this regard, also an ability to lie – or, better, to “pay lip service” – may prove useful. An oncology intern told me how useful he had found his experience as a waiter in Brussels, where he had learned how to communicate with people and give them “that feeling of warmth and affection which allows a human relationship to be established”, greeting them by looking them in the eye, inviting them to sit down, then asking about their jobs, and finally joking and laughing with them.

The decision not to reveal the truth holds firm even when patients explicitly ask for information. In these cases, the replies are evasive, or they concentrate on aspects and particular details of the therapy, or on secondary symptoms. This induces the patient to think that if the doctor is concentrating on these relatively minor problems, the situation cannot be so serious [McIntosh 1977]. The same function is performed by the witticisms of doctors (in these cases, patient tell themselves, “if the doctor dares to make jokes, it must mean that I am not so badly off”). Doctors often respond to more specific requests for information – for instance, whether the illness will have disabling consequences – with probabilistic paradoxes of the type “there’s more chance of me dying of a heart attack in two years’ time than of you becoming a paraplegic”.

A door may be left open to justify future deterioration in the patient with expressions like “We’re working as hard as we can to get the best results, but you know ... it’s very difficult. Let’s hope we succeed”, or by pointing out the dangers of not taking therapeutic action (“Of course, if you stopped the chemotherapy, the consequences would be unpredictable”).

In any case, the strength of the ‘no tell’ policy – Glaser and Strauss (1965) again point out – resides in the large-scale deployment of resources (those of the doctors, nurses, family, etc.) against one man – the patient – or in the fact that the medical staff and family join together as a team against a single individual weakened by disease. The weakness of policy resides in the instability of the structural conditions i.e. in the difficulty of maintaining it unchanged over time.

The main advantage gained by the hospital from restricting the patient’s decision-making capacity is control over a potential source of environmental

turbulence which might disrupt the organization's routine. The greatest costs are aggression by patients made anxious by the uncertainty of their fates, and the amount of resources that must be deployed to keep patients ignorant. Maintaining patients in a psychological state of 'closed awareness' inevitably involves construction for them of a 'fictitious' future where, upon conclusion of the treatment, they will resume their normal lives. In the meantime, however, there arise events and circumstances which contradict that scenario. The first is the persistence of (indeed, in many cases, an increase in) the painful symptoms signalling the disease's progress. The second is hospitalization. Once in the hospital ward, the patient makes the terrible discovery that he is surrounded by others subject to devastating cycles of high-dose therapy or awaiting the death that often occurs in hospital. Dreadful questions now begin to preoccupy the patient: "Am I also one of these dead men walking? One of these temporary survivors?". Whence derives the necessity for the doctors to dispel these 'harmful imaginings' with constant and increasingly difficult creative effort.

Doctors justify the choice of this communicative strategy by saying that they do not want to inflict, with gratuitous cruelty, further suffering which would make the life left to the patient unbearable. Or, more rarely, they cite one or two cases where disclosure of the diagnosis has had tragic consequences (primarily the patient's suicide). Some doctors, indeed, deny the cognitive importance of communicating a grim prognosis. When I asked a female oncologist how she communicated bad news, she told me "What's the point of telling someone they're going to die? Don't we all have to die? Why tell him and not someone else?". In other cases, I was told that it is

impossible to make accurate forecasts in oncology. And yet such forecasts are formulated with precision and immediately communicated to the patient's relatives.

Doctors very often maintain that patients "know". The fact that patients do not ask for explicit confirmation of their conjectures is interpreted as signalling a desire not to discuss their condition, to maintain reserve and silence about it. The problem is that, as we shall see, this situation comes about at a rather advanced stage of the disease when communication has ceased: that is, at a stage when it is unlikely that the patient's imminent death will be a topic of conversation with those around him or her.

1. For Love or Money: when the Truth Can Be Told

Saying that Italian doctors generally lie to their patients by not disclosing their prognoses is not, of course, to imply that such behaviour is universal – that is, adopted without exceptions in all circumstances. Of importance, in fact, is the choice by the patient of a particular communicative strategy and the presence of specific conditions.

In regard to the latter, among the conditions justifying the truthful disclosure of the prognosis, doctors regularly cite the presence of large economic assets or a business, and the presence of children.

In other words, the truth can be disclosed more easily when the patients show that it has some 'practical importance' in that it concerns a realistic and socially approved project, such as managing a business or caring for children. As an oncologist told me: "You're always asked for the truth by people who somehow want to plan their lives. A person who doesn't have affairs to set in order is less interested in knowing the truth".

My impression on this point is that at least two other factors favour communication of the truth:

- 1) the first concerns maintenance of the social order within the healthcare organization. If the doctor receives from the patient 'good reasons' for telling the truth, s/he somehow obtains a guarantee that the patient will make good use of the information and will not, for instance, use it to commit suicide or engage in alienated behaviour or reject treatment;
- 2) frankness in a doctor's communication with a patient may be facilitated if the latter belongs to the same social class [The 2002 1], or by some other form of identification (for example, being of the same age, having children of the same age, etc).

These conditions enable the doctor to establish an otherwise difficult intimacy with the patient and be sincere with him about the prognosis.

2. Truths, Half Truths, Lies: how Much Information?

Whilst doctors generally try not to reveal to patients the gravity of their situations, it is also obvious that they cannot abstain from giving them at least some information about the diagnosis or the therapy. *The 'line' of doctors on this point is to disclose only the information deemed essential for implementation of the therapeutic decisions taken by the medical team.*

In accordance with the benevolence principle, patients are never abandoned by the healthcare organization even after the worst of prognoses. Instead, the decision is often taken to give them radiotherapy or chemotherapy intended to prolong their lives (for some weeks or months at most) or for palliative purposes, that is, to reduce pain pharmacologically.

It is essential to ensure the cooperation of the patient, who must agree to the

therapy, keep his/her appointments at the day hospital (and often wait many hours for the first phlebotomy), undergo all the examinations required, or agree to hospitalization and accept the harsh discipline of hospital. Consequently, a completely false diagnosis (a liver tumour passed off as an ulcer) is usually only given to patients for whom therapy is foreseen.

For the same reason, the truth may be disclosed 'for therapeutic purposes': as in the case of a 70-year-old woman, of low education, with a metastatic tumour of the oesophagus, for whom a 'first line' of palliative chemotherapy was decided. Her relatives implored the attending doctor not to reveal anything about the prognosis to the woman. As almost always happens in these cases, the doctor complied and prescribed chemotherapy for the woman, without informing her about the diagnosis. The woman's body reacted well enough to the treatment, with few undesirable side-effects (nausea, vomiting, asthenia, etc.). However, after the first chemotherapy sessions, the woman began to waver and then resisted continuation of the therapy, because she could not understand why such drastic treatment had to be inflicted on her to deal with a minor problem (a cyst, so she had been told). Whereupon the doctor decided to tell her truth and informed her that without the chemotherapy she would soon be dead, because she had a tumour and not a cyst. The lady thanked the doctor and decided to continue the therapy.

In general, full or partial disclosure of the diagnosis serves three main purposes: a) to get patients to accept that, at least for a certain period, they will not be able to lead their usual lives; b) to get them to cooperate; c) to give them the impression that the organization is doing something for them.

To achieve these purposes, doctors very often engage in sophisticated language games where the semantic ambiguity of the terms ‘control’, ‘containment’, ‘recovery’ is skilfully used to induce a certain reaction in the patient. This is what happens when a doctor says to a patient that s/he cannot fully recover, but in compensation the doctor can help him/her contain the disease and indeed make it retreat. This is not an outright lie. Rather, it is a half truth, because being kept hidden is the fact that the former expression refers to the prognosis, the latter to the tumour. The doctor sometimes also provides a concrete measure of this action, for instance by saying that “Your tumour has got smaller by two centimetres, diminishing from 5.8 to 3.8 centimetres”, without specifying, however, that a decrease in the size of the cancerous mass does not signify that the patient has a chance of surviving even a single day longer. Likewise, the language used by doctors in communication with patients is devoid of reference to the most dreadful consequences of the disease. The words *cancer*, *metastasis* and *malignant* are never used (Herzlich and Pierret 1994), being replaced with more reassuring expressions like ‘cells gone mad’, ‘anomalous activity’, ‘suspicious formation’, ‘problem’ [2]. The use of dubitative expressions [Mc Intosh 1977] indicates to the patient, together with the presence of a real danger that often justifies violent and invasive therapy, an uncertainty which induces hope: the patient thinks that «if the situation was really so bad the doctor would not have any doubts and would expressly talk of ‘tumour’ or ‘cancer’».

The expressions ‘failed recovery’ on the one hand, and ‘containment of the disease’ and ‘remission’ on the other, belong to two different semantic codes, to two different “chains of signification” [Barley 1983] with different implications for social

action.[3] The former refers to constant cohabitation with the disease and evokes, together with irreversible changes in lifestyle and expectations, the need for constant medical tests, more or less intensive therapies, a regime of strict clinical control. The latter instead promotes the idea of peaceful cohabitation with the illness, and indeed its *slow* (because this is a remission, not a victory) disappearance. Their simultaneous and ambiguous presence in the discourse favours the transmission of two messages which though contradictory are equally crucial for the medical discourse: that of discipline and control on the one hand, and that of hope on the other [Del Vecchio Good et al. 1990; Perakyla 1991; Nuland 1993]. The implicit objective is to persuade patients of the gravity of their condition while simultaneously convincing them that final victory is possible, and therefore of the need to cooperate and meekly accept the specialists’ instructions.

Continuation of the therapy is one of the conditions essential for patients to be kept in a state of unawareness, the principal means with which they are distracted from inquiring about their prognoses, and so that they suppress their worst forebodings [The 2002]. For many patients, suspension of the treatment means that nothing more can be done to save them, and that the organization has declared its defeat by the disease.

3. “The First Move is the One that Counts”: the Imprinting of Communication

The communicative decisions taken in the early stage of disease heavily condition all subsequent events through an ‘imprinting’ effect whereby “it is first move that counts”. This effect stems from the action of trust mechanisms and is therefore related to the “context of expectations with positive value for the

social actor and formulated in conditions of uncertainty". Studies on the matter have identified two main dimensions of trust: the systemic or impersonal one where the recipient of the expectations is the natural and social organization as a whole, or in its single institutional and collective components; and the personal dimension, where the recipients are other social actors (Mutti 1996). The object of former type of trust is the production and stability of the social order, whilst that of the latter consists in interpersonal relations, and in particular the expectation that the communication will not be altered or manipulated and that the behaviour of the actors will be sincere. In social interactions whose object is truth about life and death, and which involve complex organizations like modern hospital structures, personal trust and systemic trust interweave and fuel each other [Giddens 1990]. Consequently, if doctors are to get patients to obey their instructions, and in order not to lose 'face' [Goffman 1967], they must offer sufficient guarantees that the personal communication will not be manipulated and that they will not resort to concealment, or indeed to lies, fraud, or deception. But they must simultaneously acknowledge the goodness of all the decisions taken in the past by their colleagues. They must, that is, support the patient's 'systemic trust' in the healthcare system, the hospital, the medical community, and therefore in all the 'abstract systems' for whose safeguarding they are jointly responsible [Giddens 1990]. If this does not happen, for instance if a doctor gainsays a diagnosis made by a colleague, the risk is that patients will start to doubt the sincerity of their interlocutors, imagine themselves as victims of a conspiracy, and in the worst cases become angry at the thought of everything that they have had to suffer without being informed. What the maintenance of a high level of

systemic trust serves to protect, therefore, is the social reputation of the 'care system', whose representatives are recognized as being equally competent and skilled, and whose superiority is guaranteed by possession of a consolidated stock of technical-scientific knowledge. To be prevented, by contrast, are conflicts which would confirm the discretionary nature of therapeutic decisions and would culturally disclose the cognitive limitations of bio-medical culture and the culturally connoted nature of modern medicine.

It is for this reason that the first information given to the patient is so important. This information delimits the level of legitimate expectations to which the patient's hopes of recovery can aspire. Consider the effects that denial of the original diagnosis would have on the patient, not so much on cognition as on his or her trust in the care system. The many doctors who will examine the patient in the weeks and the months following the first tests, and who are convinced that the patient's greater awareness is advisable, will ask themselves a question which runs as follows: "How do I tell this person, who for weeks or months has been subject to often devastating therapies, that he is terminally ill and that the treatment which he has suffered has only been palliative?". It is precisely for this reason that many interactions between doctors and new patients start with the question "What do you know about this illness?". The reply immediately marks out the boundaries of the doctor's responsibility, establishing the cognitive limit which he or she cannot go beyond.

The main perverse effect of this interweaving between systemic trust and personal trust is therefore the fact that errors cannot be corrected. In order to maintain trust in the 'system' of which they are members, doctors are forced to keep on lying to patients even when they

are aware of the numerous harmful consequences of that communicative strategy on the mental health of the sick.

Another factor that explains the onset of this effect is the particular *organizational structuring of the care system*. Oncological care is organized in Italy like any other specialist branch of medicine. Indeed, the exceptional complexity and dangerousness of cancer have increased the specialist fragmentation of care services and heightened the likelihood of the 'imprinting effect'. From the beginning of the disease, a patient comes into contact with, and receives information on his/her illness from, a medley of doctors, from the general practitioner to the surgeon, to the oncologist, and finally to the specialist in pain therapy and palliative care. Furthermore, in every operational unit, despite the constant efforts by patients and family members to construct a privileged relationship, the doctors constantly 'rotate', and patients can never be sure that the next doctor to examine them will be same doctor that examined them previously. In other words, patients with advanced-stage tumours are very likely, and often in the same hospital, to come into contact with (and be informed by) dozens of different doctors (some belonging to the same unit, others to different ones), none of whom is able fully to assume the task of following the patient's case at first hand. Hence, patients are deprived of single referent within the organization, and they are forced by these communicative difficulties to concentrate more on collecting and selecting reliable clinical information than on managing the disease as a whole.

On the other hand, the harmful effects on patients notwithstanding, it is difficult not to recognize the benefits of this organizational structure for the hospital system. These benefits consist mainly in:

1. the reduced risks of burnout to which the doctors would be exposed if they were required to accompany patients until death. The death of a patient is, as we shall see, not only a professional 'defeat' for the doctor but also an emotionally painful event if proximity with the patient has been close and prolonged;
2. the decreased likelihood that a single doctor will be held liable for therapeutic choices and possible errors of assessment, responsibility for which is shared by all members of the team;
3. avoidance of conflicts over the amount of information to give to the patient [McIntosh 1977];
4. the homogeneity of the criteria applied when decisions are taken, without explicit socialization, by newcomers, the reduced complexity of decision-making, a reliable routine, and simplification of the doctors' cognitive work when dealing with patients.

This last point should be expanded further. The fact that doctors know that they do not have to inform patients about prognoses relieves them from having to decide from case to case. This concerns a routine useful and important for the taking of critical decisions [Taylor 1988]. Let us see why. Doctors maintain that they apply different strategies according to the 'real desires' of patients. But these desires are very difficult to identify with certainty. For example it is highly plausible to argue, as do many doctors, that patients who ask for information about their state of health really want only reassurance, not accurate information; that is, they want to receive only positive news from their doctors. In this case, lying can be considered a legitimate action by the doctor. The point is that the doctor knows too little about the patient, his/her personality, his/her possible reactions, his/her relationship with the disease and death, to be able to decide

from case to case according to individual exigencies. And how could it be otherwise if the interaction between the two lasts no longer than the half hour of an out-patient examination?

The only alternative is therefore to choose between two "policies of communication": telling the truth to all patients or not telling it to any of them [Mc Intosh 1977]. The intermediate solutions are either too costly (they might, for example, require the regular intervention of a psychologist and careful evaluation of the patient's clinical history) or too risky, both to the team's social cohesion and to its legal and moral responsibility, which thus remains collective.

Individualization, or treatment differentiated case by case, is therefore mainly a rhetorical strategy used in interaction with patients [Schou 1993] in order to:

- (a) prevent them from learning of their fates through comparison of their condition with that of other patients. I frequently heard doctors making statements of the kind "Don't look at what's happening to the person in the next bed, Mrs Brown. Every case is different. Your neighbour has a different disease from yours. Concentrate on your own case". In this way, the doctor sought to reassure the patient and convince her that what she saw in her room-mate did not anticipate her own demise;
- (b) indicate the *body* of the patient, of that specific patient, as the source of the disease and the resistance to the care therapies and the healing actions of the medical team. The fact that the disease does not have an external manifestation, that it is not immediately visible, and must be diagnosed by complicated and precise tests, convinces many patients that they are ignorant of their bodies and the dangers that lie within them [Lupton 1998]. The message is that

chemotherapy must be beneficial because it fights the treacherous disease that lurks in that body.

It is by now quite clear that the decision not to inform patients and the principle of collective responsibility interweave and sustain each other. The lie becomes anonymous; it does not assume the features of a specific face and it does not involve single responsibility or a real choice. It becomes practicable without the system being required to bear excessively high human and organizational costs.

From the more general point of view, what the Italian oncological care system does not recognize is the exceptionality and the force of cancer as a disease, the extreme difficulty of medicine in fighting and defeating it, and its contiguity with the end of life. Tumours are instead equated with diseases of other kinds, to which the principles of specialization and collective responsibility are less problematically applicable. In the case of curable diseases, in fact, it is simpler to justify the concentration of the medical team's efforts on the organs to repair or the functions to restore, without too much concern for the persona of the patient as a whole. In these cases, in fact, the patient's condition is provisional, just as his/her absence from everyday life is temporary.

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Notes

1. Also according to The (2002), better-educated and better-off patients often ask for more precise and detailed information; they possess modes of

- communication that facilitate dialogue with doctors; and they want to participate more closely in decisions on therapies.
2. Schou and Hewison [1999] have observed the same behaviour among English doctors, who seek to 'to minimize' and to conceal the gravity of the disease by speaking of a 'growth' rather than a 'cancer', resorting to humour to conceal the seriousness of the news to be announced, delaying disclosure of the diagnosis as long as possible, reducing to the minimum the time devoted to interaction with the patient, or again, leaving the task of giving bad news to junior doctors, and failing to mention that further treatment will be necessary after surgery.
 3. The [2002] has signalled the ambiguity that also surrounds the terms 'to treat,' 'treatment', 'treatable' so often used in communication about tumours.