

Is the oncology patient a participant actor?: Designing psychosocial profiles

Maria do Rosário Dias

Egas Moniz Multidisciplinary Research Center in Health Psychology, Caparica, Portugal

Corresponding author. E-mail: mariadorosario.dias@gmail.com

Oncologic disease should be considered one of modern society's dominant pathologies because of its chronicity. Estimates of a patient's adaptation to chronicity shapes the information given to the patient, which is a powerful strategy for changing the patient's social representation from a mere clinical case to a psychosocial being. In this article, the patient's persona, when captured in the social processes and relations involved in therapeutic acts, is conceptualized as the main actor on the stages and sets of hospitals. The informative act, in which information is given to a patient in a hospital, allows identification of the psychosocial profile inherent in the patient's role; this profile describes some relevant categories, among which the "informed patient" and the "uninformed patient" stand out.

Keywords: oncology patients, psychosocial profiles, informed patient, uninformed patient

Introduction

In this article, I analyze the information given to patients with breast cancer throughout a processual medical chain in a health-care institution; this study covered patients from their first contact with the institution to the execution of a therapeutic strategy. The negotiations among the different actors involved in the interactions are also identified.

The empirical results analyzed are based on an investigation carried out during 18 months. The methodological strategy was field research through participant and continued observation of the selected unit. Content analysis of structured interviews with doctors, nurses, social workers, and patients who agreed to be interviewed was carried out as a complementary information-gathering technique.

From medical paternalism to patient autonomy

Relaying a diagnosis to any patient presents an ethical dilemma to doctors. If, on the one hand, patients have the right to know the truth about their disease, doctors, on the other hand, have the duty to inform patients, trying at the same time to

keep their hopes and spirits up and striving for the recovery of their autonomy. Is the performance of this task possible in the case of oncology patients? Although the questions related to giving out information to patients are not specific to oncology patients, in this particular situation they seem to become more dramatic as well as deserving of more attention (Goldberg, 1984).

The controversy around informing or not informing oncology patients about their condition goes back to ancient Greece (Reiser, 1980) and has lasted throughout the history of medicine. Increased emphasis on this controversy has been promoted mostly by changes in the traditional roles of doctors and patients and the increasing life expectancy of oncology patients and by concern for the quality of their survival, which is made possible by improvements both in diagnosis and in the strategies adopted for cancer treatment.

The radical change in mortality rates through the conquest of epidemic disease led to the outbreak of chronic diseases at all age levels, most of them being sequels to infectious diseases whose mortal power has been successfully controlled (Coe, 1984). What seems to remain are the most chronic conditions, which now are the dominant pathologies in our societies (Baszanger, 1986) and for which there are no effective methods for disease remission. Adaptation to the disease—more than its cure—becomes the goal to achieve, and providing information is one of the most effective strategies for doing so.

However, social values, the meaning of the disease, and the role of the doctor have developed radically from the time of patriarchal societies to our own day. From a historical point of view, the doctor/patient relationship has been dominated by the traditional Parsonian model, in which the doctor solves problems by giving out orders that are passively followed by “good patients” (Parsons, 1951), to the extent that the “active-doctor-responsible-for-passive-patient” is still the predominant model in most cases (Sharf, 1988).

The traditional concept of the doctor/patient relationship places patients in a passive, dependent role that involves cooperating with doctors to effect a cure (Brody, 1980). Doctors set the priorities, take the initiative in evaluating patients’ health conditions, and control the process through their autonomy and professional dominance, thanks to the corpus of knowledge they possess.

Szasz and Hollander (1956) suggested the active involvement of patients in the decision-making process as an alternative to the passive-patient role defended by Parsons (1951). Observers with a progressive focus countered the Parsonian model of the paternalist doctor, seen as a one-sided authority for decisions concerning health care, with a new pattern for doctor/patient relationships that included individualism and shared responsibility without, however, a loss of recognition of doctors’ knowledge, capability, opinions, and experience (Boné, 1992; Goldfield & Rothman, 1987; Mackillop, Stewart, Ginsburg, & Stewart, 1988; Schain, 1980).

According to this perspective, patients are not passive spectators of disease. On the contrary, they contribute psychological and social aspects to the doctor/patient relationship, thus participating in the process of cure.

In the future the doctor/patient relationship must be conceptualized as an intervention based on real and genuine mutual respect. Medical authority should be replaced by a collaborative approach, and the wisdom of bio-medical and social

sciences should be applied to the preservation of that delicate balance we call health (Roter and Hall, 1992).

The trend toward specialization, although leading to fragmentary medical assistance, has promoted, in an unquestionable way, the technical levels of this same assistance. The path forward lies not in confrontation but in a continued search for compatibility between the best qualities of the house doctor and the technical virtues of the specialist (Coe, 1984).

The emergence of movements for increased patient participation in medical decisions has resulted in a higher level of information being given to patients so they can participate in an adequate and informed way in their own healing. Such participation can be achieved only if patients are prepared to play an active role in the medical dialogue in order to become acquainted with the different therapeutics available. If alternatives are proposed, they will be able to choose those that are most congruent with their values. Sometimes therapeutics do not make much difference for physical survival but make a significant difference for quality of life. Thus, information has become a mechanism through which the patient acquires the status of a person capable of making decisions in the field of doctor/patient relationships.

Another factor that has awakened the growing interest in doctor/patient communication and information and that also flows from greater life expectancy is the fact that cancer can be increasingly framed within the category of chronic diseases. This change implies periodic and prolonged contact between doctor and patient and naturally hampers health professionals' practice of hiding information. For their part, patients should participate in an increased way in the making of therapeutic decisions, so that they can have a more or less deep knowledge of their diseases, of the available treatments, and of the respective consequences, whether physiological or psychosocial.

In the hospital context, beyond the multidisciplinary that causes differentiated health professionals to intervene, the role of the patient as an "expert informant" emerges (Roth, 1963). Former patients build their status as privileged informers, whether to those who are admitted to the hospital for the first time or to those who find themselves in similar clinical situations, for they themselves have observed the way they have been treated in previous hospitalizations. From this development, Carapinheiro (1993) created the double-sided "professional-patient" category. Through successive hospitalizations, patients acquire the know-how to increase their control of their disease; and they also acquire a specialized sophistication in dealing with hospitalizations. In this way, patients assume the role of protagonists, playing the role of teaching agents in the informing act. In this performance, they make use of common wisdom and nontechnical speech that, although not erudite, becomes understandable when one realizes that these patients are "secondary messengers" of given information.

On another plane, in line with the increased level of public education and with a change of peoples' attitude toward the disease, since the 1940s there has been a proliferation of associations of treated patients: people who have had mastectomies, laryngectomies, or other ostomies (Conde, 1992). In particular, the volunteer associations for those with mastectomies constitute a trusted source of information based on their experience: they are naturally closer to the patients than

are medical personnel. By playing a “veteran-patient” role, they become natural consultants, assistants in the formal care provided by any institution; they help crumble the “wall of silence” that usually arises between oncology patients and health professionals.

Medical care has become increasingly socialized and institutionalized; medical work develops nowadays in a complex context with high specialization levels. The hospital, the main component of the institutionalization process, is the stage for complex interactions that have significant effects on individual and collective experiences of living and working with the disease (Carapineiro, 1993).

Despite the visibility of the spectacular steps forward in technologies and therapies, one must not forget that health care is based on a less modern but not less important human activity: the dialogue (Larsson, 1989). This dialogue takes place in an institutional environment where the patient sometimes finds it difficult to be heard. When in a context where communication is institutionalized and framed according to different social “choreographies,” both patients and health professionals, particularly doctors, mutually adjust their proximities and distances (Aronson & Larsson, 1987).

The interaction patterns in the medical setting can be conceptualized as institutionalized communication needs, which can be perceived and understood only through eye contact, not only by the interlocutor but mainly by a large spectrum of people; these needs induce constraint at the interactional level.

Barnes (1973) believes that, in a hospital context, the doctor personifies the “hospital mission” to the patient. However, the social representation of the doctor is of a “guardian” of the health-care system; the doctor’s signature is frequently the only means for accessing medication and hospital services. The nature of a health problem is defined by the medical profession, which also defines the appropriate interventions and provides access to the required resources. The patient is left with little influence and becomes the subject of professional dominance when placed in the field of medical practice and its institutions (Freidson, 1970).

Providing medical care is a social-control process. The provider/patient relationship can be seen as an attempt by a powerful and independent expert to change the behavior and attitudes of an ignorant receptor of the communication, who is not allowed to be an actor in the system (Friedman & DiMatteo, 1979). The health professional, owner of superior knowledge and a technical, specialized language, usually retains the right to make decisions in the name of patients and considers them the subject of a professional service (Roth, 1963). This reality, independently of how professional dominance expresses technical skills, does not however legitimate each and every asymmetry in the doctor/patient relationship, which tends to make the health professional a single leading player and systematically deprives the patient of a participant-actor role.

On the interactional level, the patients, subjects of an inexorable relational asymmetry, are therefore assigned a passive role. Their participation in the work carried out around them is denied because their knowledge is of a nontechnical nature and is depreciated by the health organization; in this way patients are incapable of penetrating the hegemonic model of central knowledge, which is medical knowledge. The only possibility of patient expression at the healing level is in rela-

tions with those in the professional execution categories, nurses and other hospital medical staff, to whom a primary role in the humanization of care is normally attributed (Carapinheiro, 1993).

Approached by the doctor as a subject of research, carrier of a disease perceived by health professionals as a topic of the health-care system, and perceived by the organization as a consumer of services, the patient is dehumanized by the structure of the system (Wiener, Fagerhaugh, Strauss, & Suczek, 1980). Therefore, patients are normally deprived of the possibility of participating in decisions about or even giving opinions about the interventions concerning their bodies.

The doctor sees the patient as a clinical case (Friedman & Di Matteo, 1979), a scientific subject (Chauvenet, 1973) because the dominant focus in the institutional context is the treatment of disease and the management of clinical cases; the ill person is left behind (Benoist & Cataebras, 1993; Chauvenet, 1973).

As a “body,” the patient, individually considered, is unknown to the different health-care providers; each patient becomes “known” to a group of actors with diversified competencies who perform on the patient a multiplicity of professional acts in an interactive environment. Therefore, the social construction of the patient’s status is composed of a variety of separate and incoherent identities, a matrix of signs and symptoms configured as an administrative unit.

Freidson (1970) refers to the existence of a conflict of perspectives between the patient and the health professional, especially the doctor, which reinforces the structurally asymmetric position of each of the parties involved in the relationship. As a matter of fact, doctors usually seek a biomedical definition for a disease using a symptom lexis through which they place a patient’s individual condition in standardized categories necessary for the application of their professional competencies. Patients, however, are much more concerned with the personal experience of the disease and, as a result, make possible on the relational level the intervention of values and expectations significantly different from those of the doctors (Cassel, 1976; Hundt, 1994).

Underlying the patients’ and the health-care providers’ standpoints are different experiences and conceptions of values. For health-care professionals, knowledge comes from a specific framing of scientific, standardized practice, which defines and regulates the activity of the hospital as an institution. For the patients, perspectives emerge from their laypersons’ knowledge, from their familiarity with scientific models and popular beliefs about the disease, as well as from previous personal experiences in health-care-providing contexts.

The conflict may therefore be located between two incomplete perspectives. While the biomedical insight points to “fighting to kill the disease” and lacks references to patients’ life contexts, in the patients’ experience scientific insight is missing as well as knowledge of the potential value of medical intervention (Roter & Hall, 1992). Even though the importance of the psychosocial dimension in the care given to oncology patients is increasingly recognized, doctors often underestimate patients’ needs in this area (Fallowfield, 1991).

In fact, hospitals are professional organizations that in several respects assume themselves to be worlds of their own, with multiple configurations unknown to most of the people who seek care. Patient psychosocial dimensions are somehow invisible to the health-care professionals in the hospital context.

The adaptation of oncology patients to their disease is strongly influenced by the psychosocial support they are given. Adaptation comes from the network of interactions among the patient, health-care professionals, and other patients. Providing oncology patients with information benefits their psychosocial adjustment and is obviously relevant to the quality of their health care because it reduces their feelings of vulnerability in regard to the disease. Various research projects show patients' preference for being informed about their diagnosis and all other aspects of their disease (Cassileth, Zupkis, Sutton-Smith, & March, 1980; Durà, 1990; Reynolds, Swanson-Fisher, Poole, Harker, & Byrne, 1981; Spencer, 1981).

Not all patients, however, wish to assume an active role in the health-care services they are given. Although many prefer to receive the most information possible, others want to know the least possible, placing all the responsibility for decision-making in the doctors' hands (Schain, 1980). Although a great number of patients strive to be highly informed through communication transmitted with sympathy and support, others create obstacles to communication, perhaps as a way to avoid the stress of making decisions. The role of the information given to oncology patients has, therefore, to be conceptualized according to individual preferences, for they modulate how adaptive or nonadaptive the information is.

Oncologic disease is a stressor, and information is a mechanism for coping with it (Ibañez, 1988). In the same way, individual differences in preferences for the level of information provided can be conceived as coping styles or idiosyncratic adaptation strategies.

The strategic negotiations

Talking about the responsibility of patients in the health-care process may seem strange (Entralgo, 1982; Siegler, 1981; Smith & Newton, 1984). Therefore, it is not surprising that empirical data on patients' participation in medical decisions are few (Love, Wolter, & Hoopes, 1985; Silverman, 1987). Besides, some studies have shown in a consistent way that the power of the health-care consumer is limited when dealing with the medical profession (Maurin, 1980).

The progressive socialization and institutionalization of medicine have broadened the range of the medical act in a decisive way. The patient is usually faced with a highly technological order of intervention along with a predominantly technical perspective; in this environment the trend is to establish a net of depersonalizing relationships that distort patients' experiences in their daily social relations. Thus, the doctor/patient relationship in the institutional context is far from having the deliberately personal character of a dialogue between doctor and patient, which can be experienced as a "singular colloquy."

Facing the dominant position of medicine within the health-care system, the patient perceives the doctor as a "guardian" of the care system (Freidson, 1970). The surgeon, however, as opposed to the doctor, embodies a superhuman dimension (Barnes, 1973) and is capable of being a symbolic vision of deification; this configuration elicits an attitude of passivity and true devotion from the patient because of the charismatic surgeon's magical authority.

Patients' blind confidence in surgeons is partly supported by the patients' view of their disease. Once limited to having a layperson's knowledge of their condition, patients consider the disease to be a phenomenon that requires professional knowledge and thus place their care in the hands of the "good trades," of professionals legitimately certified to exercise the healing art.

Denied their active participation in decision-making, patients withdraw, a move unconditionally supported by the technical quality of the given medical assistance. They consider themselves partners in the therapeutic dialogue, but their decisional incompetence is legitimated by their secular knowledge as expressed in terms of "benefits" and "ignorance advantages" (Dias, 1996). The category of "compliance and collaboration ideology," developed by Carapinheiro (1989), fits this analysis because it assists in the emergence of social control of patients' behaviors by doctors with social and scientific authority who consider patients subjects of medical knowledge.

Incapable of producing a phenomenological disease knowledge system, patients retreat from the negotiation process inherent in participant decision-making and take shelter in their role as passive actors inevitably sentenced to acquiescence and collaboration before the authority emanating from the doctor:

I didn't ask any questions. ... I really didn't ask any questions. ... I resigned myself. ... And then, when we come here, we see so much. ... And we conform ourselves. ... I didn't ask any questions. [ED g3 4]

The growing complexity of hospitals leads inevitably to increasingly difficult communication among the different members of the organization. The division of work shatters and hardens relations between doctors and patients.

The patients in the study imagined a "conspiracy of silence" (Barnes, 1968) on the doctors' part; this conspiracy translated into a deliberate refusal, at certain moments, to give information concerning therapeutic decisions:

You doctors don't like telling us things. ... You eat too much ... that's why you are so fat. [n.t.c]*.

Also, in the frame of scientific medicine, medical knowledge and wisdom are discerned as control mechanisms that make an active and effective intervention viable for controlling the natural processes of the disease. Within a paradigm in which diseases are considered uniform entities, which is the opposite of the holistic approach, the oncologic disease presents a threat to the basic assumptions of the model because it presents itself as a scientific challenge, without any apparent consistent patterns that are either etiological or that arise from response to treatment (McIntosh, 1976).

On the margins of uncertainty and indetermination, which in the case of oncologic diseases assume a special relevance, the image doctors have of themselves and the medicine they practice survives devaluation of medical authority and challenges to their professional prestige and status. This fact assumes particular relevance in doctors' reports of their role in giving information to oncology patients. Concealing information from patients or abstaining from directly com-

* Fieldwork notes from the researcher.

municating the truth seems to reveal all the contradictions embodied in doctors' charismatic power.

The doctors in the study who never, or almost never, disclosed diagnoses to their patients justified their choice by claiming that they did not have the ability to face them. Some doctors referred to this justification as "moral cowardice," while others reported that the halo of uncertainty involving this kind of pathology forces them to be defensive. A "biomedical conflict" then arises from the contradiction between the power of medical knowledge and the scientific impotence lying underneath this knowledge-power; this impotence defies the scientific authority of the physician, which is therefore susceptible to being threatened.

It's cowardice ... surely it is. ... It's facing someone who knows what she's suffering from and not being able to give her anything; ... so there come the lies ... and the false hopes. I feel really bad. I think I've been studying all these years for nothing. ... I mean, when you graduate in medicine you're supposed to keep people alive, not help them die. ... The doctor should help his patients die but that is not what we learned. ... We are all defensive. ... No one, not even the ones who claim they say every single thing to the patient, really says anything, no! This kind of pathology allows [us] to be defensive, sure! [EM 12]

In the social relations involved in the medical act, obstructive traces of patients' protagonist role arise, and they are "religiously" placed in a passive-outcast role, in the condition of being merely a "silent care receptacle" (Carapineiro, 1993).

Information, which is a power-raising dimension of patients' participation in medical decision-making, is warded off and undisclosed by medical authority; in this way conditions are created for subordination and uncritical acceptance by the patient of the health care provided:

Because I get orders from the doctors. I don't make questions, right? I get them and I do what I'm told to do. Get orders and obey. What he tells me to do I'll do. I have placed myself in their hands, I haven't asked anything. [ED g2 3]

In the presence of strategies for blocking patients' participation as active and conscious agents and also before the barrenness symbolized by their nontechnical knowledge, patients become advocates for medical authority. They have no choice but to submit to that "untouchable symbol" of all the work produced around them.

In fact, in regard to information confined to the clinical dimension in the study, the fundamental piece that determined the information flow between doctor and patient was whether the patient questioned the doctor (Dias, 1994). The physicians, in their role as privileged informers, seemed to suppose and expect that if patients wished for information, they would look for it and ask questions during their medical appointments:

If the patient asks what's wrong with her and wants to know. . . and how it is going to be, obviously we talk. But if they're the silent type and don't even want to know anything, one has not much time to be there. ... Maybe those are the ones who don't understand things because they really don't want to know. [EM 17]

In this same sense, the following statement by a patient seems to reaffirm the gratuitous character of the informative act, which doctors considered a waste of time for patients who did not exhibit the will to be informed:

I also feel that, when it comes to them, it's really a bit like wasting time. ... Talking or being quiet would be the same thing. ... What I consider here is this: If people ask they will be informed. Some people ask and they are given explanations. The ones who don't ask ... well ... they are not informed; it's no use. [ED g3 7]

The criteria usually mentioned for giving or holding back information are often related to structural and institutional variables. The physicians claim time unavailability when faced with increasing demands from the patients' side. However, giving patients an opportunity to ask questions subverts the avoidance technique, for it may bind patients, making them dependent on the source of medical information. In a more deprecating way, the physician as an "interrogatory" recognizes the inquisitive attitude of the patient but describes the information given as a "cold shower," as can be observed in the following interview sample:

'Cause they don't have time. ... 'Cause many times the person tells the patient the truth and he thinks he's going to tell the truth then he talks for 5 minutes and the patient leaves; ... it has happened to me several times and I spend an hour there with a patient who expected 10 minutes. 'Cause after you give a person a cold shower, you can't also ... leave and slam the door. I have to accept any questions the patient wants to ask me and digest it all 'cause despite all it's a burden placed on us people. [EM 17].

Another physician pointed out the uncomfortable "risks" of patient dependence:

A patient to whom you talk too much is a patient who is going to hold on to you immediately, that way giving you more work, seeking us more than the others. [EM 13]

Information is seen not as a patient's right to receive but as a physician's privilege to give; "good patients" are those who follow medical prescriptions without questioning them, those who remain silent about the routines and rhythms of hospital activities:

I was operated on, had very good doctors and nurses. But if you want them to be good to you, you have to collaborate with them, don't you think? That's why I am a very quiet person and I'm not rude or have ever been and I accepted everything they told me to do. [ED g3 1]

Such patients, described as "dissimulated actors," turn to cunning mechanisms in order to subtly control the gathering of information:

Patients understand the information when they want to understand it. I think the patient is a lot smarter than we think. Sometimes they act as if they don't understand the information [and] then act foolish. [EM 12]

While going through the medical chain, the patient proceeds to gather detailed information from the diversity of institutional agents in order to test the coherence of the information given by them. “Inquisitive patients” attempting to have information disclosed are “stage actors” whose entrance into the social set of the hospital is made difficult by the avoidance strategies used by health-care workers. They then have no choice but to act as “good patients” as a conciliating strategy:

Some patients ask only [in order] to confront [us] with other opinions. They go inside and ask the assistant, then the nurse, then me, then my colleague. So, they go asking around to see whether the information matches or not. There are many patients like this. I think [they do this] exactly for that [reason], to see if someone ... if the doctor isn't telling the truth or if he knows something else she hasn't been told. [EM 17]

Here enter the “fortune-teller patients,” who make their own diagnoses and prognoses based on scrutiny of the therapies prescribed as well as on the possible outcomes they symbolically run through the institution:

We're not all that silly, because if I had a surgery and I was sent to have radiotherapy, it couldn't be good. [ED g3 11]

Patients complain about doctors who seem more interested in fighting technical-scientific battles with the body and the disease, privileging medical-clinical information, than in providing information about the social management of the disease:

Yes, they are quite busy and it's very hard to interrupt a doctor when he is on duty. I thought that, when we are operated on and discharged, ... even after or during treatments, ... there would be a date for us to get an appointment [to discuss] some doubt we might have or something we want to ask or some problem ... so we can be informed and alert to other problems that may come. [ED g3 22]

This dissonance seems to be consistent with the dissatisfaction many patients reported about the information they got from physicians, whom they accused of withholding and manipulating the information they really needed.

By becoming part of the organizational structure of the hospital as nonprofessionals among those with medical power-knowledge, patients negotiate some privileges that allow them to create “survival strategies in an institution not designed for patients to live in ... but only to physically survive” (Carapineiro, 1993). Patients also develop powerful mechanisms for seeking information about their disease; these strategies allow them to increase their negotiating power as actors in the healing process:

I mean, sometimes I don't understand the medical information that well. But I haven't had any problems because I've been getting information from patients who are already informed at their own expense. That's why self-experience also says a lot and that is why I haven't paid much mind when they don't pass on information. [ED g2 6]

“Informed patients” break the barriers and limitations of a formally instituted process; they overcome their position as passive spectators of the disease, unfailingly carrying out the doctors’ orders. Thus, the “professional-patient” category, devised by Carapinheiro, includes several kinds of patients: “inquisitive patients,” who desperately uncover information; “dissimulated actors,” who resort to sinuous mechanisms to gather the information they need; “fortune-teller patients,” who scrutinize diagnoses and prognoses according to the possible outcomes they symbolically run through the institution. Even patients who “specialize” in medical curricula can be inscribed in the “professional-patient” category.

Oncology patients, involved in the chronicity of their diseases, are forced to learn so much that they gain a “specialization” based on their knowledge of their condition. That was how one of the patients in the study, in a humorous mood, illustrated the setbacks of spending too much time waiting in hospitals:

Since I came to this hospital, I became a doctor too. ... I majored in waiting.

Throughout their careers as chronic patients, they personify the “professional patient” par excellence. Because of prolonged stays in institutions, time spent running from one department to another, patients assemble and connect knowledge and can negotiate with health professionals the exchange of professional knowledge for lay knowledge; they can then proclaim themselves patients “enrolled” in the institution:

And he said: I can’t find anything now. So tell me. And I did this in my breast [reproduces the gesture]. It’s here! ... And the poor fellow went and palpated it, and said: “Indeed!” He palpated my whole body—he’s a really good doctor—from head to toe. But it was so small, only I could feel it. I myself became aware of it; I’m already enrolled. [ED g3 5]

In this tumultuous strategic convergence of these demanding and nondemanding movements by patients as protagonists before the information is given to them, the profiles of “informed patient” and “uninformed patient” rise; they are configured by delimiting pole ranges that are formally and informally established (Dias, 1996).

In the negotiation between actors in their assistance networks and their adopted strategies, typical behaviors of “informed patients” and “uninformed patients” are revealed; these behaviors indicate the existence of patients with differences of an individual nature when they are faced with the information that is given to them.

Thus, it is possible to regard “informed patients” as those who assume a protagonist role throughout the course of their chronic-patient career; they automatically establish a monopoly on information strategies, whether in informal ways or in formally institutionalized ones. Resorting to assistance from a multiplicity of privileged informers, whether institutionally legitimated or not, or even from other patients with whom they establish a relationship based on equality among peers, these same patients turn themselves into active and vigilant agents through their assistance networks. They acquire specialization degrees on their disease, while a

bio-psycho-social entity allows them to shape their knowledge-power role as “professional patients” and “expert informants.”

In the daily experience of their condition as patients in hospitals, they assume their role as information-seeking agents, converting the information obtained through the use of psychosocial adjustment strategies to their status as ill people. Patients who fit the “informed patient” category are great opponents of the “conspiracy of silence,” which subverts the informative process. They consider informative bankruptcy as a threat to their survival, for it does not allow them to build up “protections” and adopt a preventive attitude:

I want to know the truth. ... Never hide anything from me. I think that if they hide something from me I can become suspicious and then I get annoyed, which is not good at all. ... If I know everything, I can warn my organism about a particular situation. ... If they hide it from me, ... I can't protect myself; ... and this way I can. So then ... when I go for an exam and I don't understand, I want him to explain everything and where the nodules are. They show me everything in the exams. I think that is great for a patient. ... I wouldn't want anyone hiding anything from me because I think it's a protection, since the beginning. I think that's the only way I can create my own defenses, by being told the truth and receiving information. [ED g3 16]

In the dialectical reading of the features of patients' profiles, a certain patient did not fit the “uninformed-patient” category but did assume a passive attitude, submitting to the physician's authority, withdrawing from any and every process of informed and shared decision-making. When confronted with strategically placed patients in waiting rooms, this patient adopted avoidance and deliberate-escape techniques so as not to face uncertainty and doubt; she took shelter in the ignorance “advantages”:

I'm like this. Look, there's an old Chinese saying ... that the fool is happier than the wise [person]. So I ... well, I let it pass. I'm here ... they know best, I don't ask or talk to [other] patients. [ED g3 2]

And another patient adds:

I didn't try to know anything. I was better off like this, in uncertainty, in doubt, and I keep running away. ... When I was undergoing radiotherapy I would sometimes run off, because there were patients I would pretend to. ... I would come in and I wouldn't talk. ... I'd go sit at the back and when I looked, they'd go sit next to me. [ED g3 10]

The group of patients who identify themselves as “uninformed patients” is the group that resorts to information-denial techniques, rarely formulates questions about their clinical condition and instead chooses the subliminal resort of using euphemistic language as an expression of defensive avoidance.

Health professionals differentiate these two categories of patients. “Informed patients” participate in the medical work, although this form of collaboration may place them in the “cooperative-patient” category. They show a high level of adhesion to the prescribed therapeutics and a predisposition for shared decision-

making, where they act as intervening social partners. Patients who categorize themselves as “informed patients” also aim to take control of the informative act; they have a nonconformist attitude toward the absence of information and confront health professionals with questions about their disease in order to obtain information:

Yes, I was informed. Maybe I was more informed because I ask. ... But I was informed and I ask all the questions. So, I attend to all the information because I don't want not to know. [ED g3 20]

On the opposite side, “uninformed patients” assume a “weary” attitude and “dodge” the administered therapeutics, eventually walking out of their assistance course:

I think the informed patient who wishes to be informed is a patient much more interested in taking part in the therapeutic decisions and she cooperates with us much more easily. ... The uninformed patient is a patient who normally develops a more loose, frail relationship with us, more tenuous, and is normally a patient who skips more appointments, who misses more appointments, is capable of saying, “Yes sir, I'm having the treatment,” and then she doesn't. ... Therefore I think that, indeed, the informed patient is the best one from all points of view. I don't think of information as having a negative effect on the patient. ... Also, of the hundreds of patients with cancer I've treated, at least 90% ... are well informed about the disease they have; none has ever committed suicide. [EM 4]

There is a certain unanimity among doctors concerning the benefits of patients' collaboration with medical work; this collaboration arises from the vigilance strategies of patients as “active observers” of their career as chronic patients. The same cannot be said about the impact of the given information for patients' psychosocial adjustment. The interview sample and the following quotation illustrate different opinions about the psychological impact, positive or negative, of the information given to patients:

The badly informed patient has one advantage over the informed one. She lives more carelessly, [is] less anxious, less depressed. I mean it's holy ignorance. It's not all advantages. ... The informed patient is a more conscious one, maybe more careful, doesn't skip her follow-up, doesn't miss the exams, doesn't stop coming ... has her breast-check done every year. She's a more vigilant patient in regard to her disease. ... She can perfectly easily continue with her daily routine if she's well informed ... while the other can't. [The other] is a much more failing patient ... who may walk out, who never comes back to pick up the medication, who leaves therapeutics. [EM 5]

The patient who fits the “informed patient” category is usually feared by health professionals who take shelter, on a regular basis, in escape strategies, adopt defensive behaviors, and are evasive when dealing with patients' annoying questions, as can be gathered from the following excerpts from interviews with a doctor and a nurse:

If people have the knowledge to answer and do it, there's nothing wrong with that. If the person is not quite at ease, he's afraid of the informed patient! [EE 14]

To me, it's easier to treat a patient who doesn't know than a patient who does. If a patient knows, I'll get really afraid of her. If the patient doesn't know, I'm much more comfortable, you see? Because the patient who doesn't know, usually doesn't ask, but there's the one who asks all sorts of questions ... how's it like ... how many months. ... I'm really afraid of the patient who knows. ... To me, they are people who cause me problems at the dialogue level. [EM 12]

At the end of this analytic reflection it must still be mentioned that, from the negotiations between actors and the strategies regarded as cooperative in the information-giving process arise psychosociological profiles of patients who do not surrender their layperson's knowledge. They are holders of knowledge resources that allow them to develop strategic adjustments of confrontation and resistance to other knowledge-powers (Carapineiro, 1993).

Patient may have different degrees of information ranging from total knowledge about the disease to complete ignorance; this range includes being suspicious or having ambiguous knowledge (Dupont, 1978; ; Durà, 1990; Szmajke, Hans, & Kaiser, 1987). These different levels of information have distinct consequences for patients' psychosocial adjustment; it has been empirically proved that suspecting a cancer diagnosis has many more negative consequences than having perfect knowledge of a diagnosis.

Conclusion

The trajectory of the patient in the medical chain assigns the sick person to a dependency status in relations with the specialized medical act. The category of the paternalist doctor is embodied in the defensive institutional philosophy of hiding information; it is an expression of the traditional doctor/patient relationship model, which belittles the patients' central role in the decision-making process, basing itself instead on a relational asymmetry in which obstructionist features of the patients' protagonist role survive.

The reality of hospital practice encourages abandonment of the informative process. Nevertheless, in the stages and sets of hospitals emerge a fringe of patients who take a pro-active stand toward the lack of information by letting loose, in a systematic way, a panoply of information-disclosing strategies, whether by informal means or by the formally institutionalized ones.

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