


# Chronic noncommunicable diseases and dilemmas of care: the theory of negotiated order revisited

## Doenças crônicas não transmissíveis e os dilemas do cuidado: a teoria da ordem negociada revisitada

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### Abstract

In Brazil, chronic noncommunicable diseases (NCDs) have high mortality rates. From a socio-anthropological perspective, NCD realistically depict patients' experience in all dimensions of their lives, either regarding their symbolic and socioeconomic aspects or their interaction with health professionals. The negotiated order theory, created by Isabelle Baszanger and grounded on the interactionist approach, deals with physician-patient relationship in chronic diseases, which establishes a permanent negotiation between both parties. Opposed to the idea of the patient as a merely passive subject, the theory postulates patients' protagonism in scenarios that will require the physician to negotiate. This construction occurs in all spheres of social life: work, family, and health settings, where patients seek to maintain their social integration. For patients, the negotiated order theory represents first and foremost a means to manage their identity, whereby they may adopt techniques for controlling symptoms and treatment, aiming to maintain or restore a normal life. This study seeks to revisit this theory by interacting with different authors and reflections offered by previous ethnographic research.

**Keywords:** Chronic Disease; Physician-Patient Relation; Diagnosis; Treatment.

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## Resumo

As doenças crônicas não transmissíveis são responsáveis por um alto índice de mortalidade no Brasil. Do ponto de vista socioantropológico, elas são exemplares na ilustração da experiência do mundo do doente em todas as dimensões da sua vida, tanto nos aspectos simbólicos como socioeconômicos e na sua interação com os profissionais da saúde. A teoria da ordem negociada, de Isabelle Baszanger, inspirada na perspectiva interacionista, trata da relação médico-paciente diante da doença crônica em que se estabelece uma condição de negociação permanente entre os dois polos. Contrariando a ideia do doente como um agente meramente passivo, a teoria mostra o seu protagonismo onde o médico precisará participar dessa negociação. Essa construção se desenvolve em todas as esferas da vida social: trabalho, família, serviços e profissionais de saúde, nos quais o doente procura a manutenção de sua inserção social. Assim, para o doente, trata-se, antes de tudo, da gestão de sua identidade, em que ele se apropriará de técnicas de controle de sintomas e do tratamento, a fim de manter ou restabelecer uma vida “normal”. Esse ensaio busca revisitar essa teoria dialogando com outros autores e através de reflexões advindas pesquisas etnográficas anteriores.

**Palavras-chave:** Doença Crônica; Relação Médico-Doente; Diagnóstico; Tratamento.

In Brazil, chronic noncommunicable diseases (NCD), or “long-term diseases,” are responsible for a high mortality rate, especially among low-income individuals, for being more exposed to risk factors and facing greater barriers in accessing care (Malta, 2014). Thus, NCD constitute a highly relevant public health problem whose breadth provokes questioning of measures targeting disease prevention, health promotion, and epidemiological surveillance, as well as of public policies investment (Minayo; Gualhano, 2015). From a socio-anthropological perspective, NCD realistically depict patients’ experience and their interaction with health professionals. They embrace all dimensions of patients’ life, both in its symbolic and socioeconomic aspects.

This article aims to revisit Isabelle Baszanger’s negotiated order theory (1986), discussed in the article entitled “*Les maladies chroniques et leur ordre negocié*” (Chronic diseases and their negotiated order). Although written in 1986, the article offers important elements to the current debate on NCD, enabling a discussion about their peculiarities and repercussions within care and relationships intersubjectivity. For illustrating these aspects, I will employ reflections offered by previous ethnographic experiences in Brazil and France and other authors.

Among others, the negotiated order theory is grounded on Anselm Strauss’ interactionist approach and addresses physician-patient relationship in chronic diseases, which establishes a permanent negotiation between both parties. It involves events and contexts surrounding the disease and all social actors besides patient and physician: family, friends, co-workers, and other health professionals (nurses, physiotherapists, occupational therapists).

Opposed to the idea of the patient as a merely passive subject, the theory postulates not only patients’ protagonism, but also how physicians must conform to certain conditions imposed by their patients to manage the disease.

Each chronic disease has its particularities, hampering a generalized discussion about them. For example, kidney failure threatens individuals’ life; rheumatic disease their physical autonomy; and arterial hypertension takes longer to compromise their everyday life and is easier to control. Yet, all these diseases are similar regarding fluctuating

symptoms, cure uncertainty, duration (often the individual entire life) and, consequently, the required commitment to care. According to Michael Bury (2011), chronic illnesses may be defined as “biographical disruption.” The author states that long-term impairments induce a crisis in everyday life, making individuals reorganize the meanings and senses of their existence. However, such crisis becomes naturalized, and the patient embeds biomedical rationality through the contact with the physician.

In NCD, chronicity replaces the logical symptom-diagnosis-treatment-cure/death sequence, a dated historical construction that employs a therapy-oriented medical model (Freidson, 2009). In the Middle Ages, incurable chronic diseases were closely associated with healthcare settings, such as the *hôtels-dieu* and asylums. These insoluble situations arouse the compassion of health professionals and volunteers, defining tenuous boundaries between biomedicine and Christian charity. It was only by the eighteenth century that the hospital gradually became an institution of care and, above all, of medical education, hosting more and more patients in acute and chronic conditions. In this scenario, secular professionals were increasingly numerous over the religious ones (Foucault, 1980).

Anti-infective therapies disseminated throughout Europe after the Second World War, culminating in the cure of these diseases. The significant improvement in cancer treatment and resuscitation techniques lengthened life expectancy, painting medicine as a total healing power (Canguilhem, 1966; Pinell, 1992). With this logic, death and non-healing became poorly received by the Western medical culture. The legitimacy of medical practice within the hospital came to reside in the therapeutic mission of cure; in turn, the accountability for the follow-up of chronic diseases and contact with death rested with other health professionals, considered hierarchically inferior (Ferreira, 2005). The advent of palliative care itself still relegates surprise to physicians dedicated to this practice (Quintana Arantes, 2016).

Regarding the outpatient context, the treatment of chronic diseases depends not only on access conditions and professionals and materials availability, but also on patient engagement and the possibility of follow-up. However, it does not mean

to say that patients are “cooperative,” given that their viewpoint differ from that of the physician, whose concern is to control the disease.

From a medical perspective, Byron Good (1993) evaluates the story that patients tell professionals, questioning to what extent they depict “real” events or acquiesce a cultural pattern that will incorporate their disease trajectory. Employing a Geertian view, the author reinterprets medical education as a set of cultural models and classifying systems used to construct its objects. He advocates the use of semantic networks to understand the different factors building “medical realities.” Thus, all medical practice is eminently interpretative, implying a continuous work of translation, decoding, and negotiation between different semantic systems.

This physician-patient interaction presupposes constant negotiations, depending on the patient’s insertions within different contexts. Together, these aspects refer to the theory of negotiated order, which postulates a “negotiated social construction of chronic illness in which the patient is an indispensable actor” (Baszanger, 1986, p.14). This construction occurs in all spheres of social life: work, family, and health settings, where patients seek to maintain their social integration through negotiations, being the parameter for them to situate themselves in this new condition. For patients, the negotiated order theory represents first and foremost a means to manage their identity, whereby they may adopt techniques for controlling symptoms and treatment, aiming to maintain or restore a “normal” life.

Sick individuals manage chronic diseases according to their interpretation of it, their daily experiences, and their social relationships. Ana Canesqui (2013) observed how the working class often attributes “high blood pressure” to everyday crises, including “irritability,” feeding, heredity, and aging, for example. When symptoms appear, individuals manage them according to these “interpretations, common sense, and daily life conveniences” (Barsaglini, 2011, p.149). In turn, Reni A. Barsaglini (2008), when studying social representations of diabetic patients, found sick people to interpret the disease according to a gender perspective. Due to their more public life, men were found to accept and strictly follow prescribed

medical recommendations more difficultly than women, as well as follow restrictions imposed by the disease and treatment - such as the decrease in alcohol consumption and erectile dysfunction caused by medications. Mário Sareta (2014) reports how psychiatric patients manage their daily lives by seeking escape routes from a pathological identity, be it by medicine or artistic expressions.

The chronic disease scope enable us to approach how both patients and physicians have elaborated interpretations and strategies. Although many studies addressed patients' perspective, studies approaching medical strategies in the management of long-term diseases are still scarce. Considering that, I would like to expatiate on this aspect, reporting my ethnographic experiences in Brazil and France.

First, I propose a reflection from an ethnographic research of a French humanitarian health center from the *Médecins du Monde* (MDM) (Ferreira, 2004), which relied on the voluntary work of health professionals and social workers. The health center attended mostly homeless people and undocumented immigrants. The case reported herein concerns management challenges faced by physicians towards the homeless - mostly people with alcohol use disorder, called *habitués* for attending the center daily.

## The healing mourning

In a conversation with the medical coordinator of the center, she drew my attention to the care provided to homeless people and people with alcohol use disorder (AUD). According to her, physicians should employ the "healing mourning" in those cases; that is, they should accept the condition of "doing nothing." However, as aforementioned, the instrumental goal of healing underlies all medical practice. How should professionals exercise medical skills when these are denied to them?

From a medical perspective, diagnosing AUD traverses its classification in the morbidity category, particularly psychiatric (Pessanha, 2004). The center psychiatrists claimed the follow-up of these patients and resented that many cases were attended by nurses and physicians without being referred to a specialized consultation: "alcohol use

disorder among *habitués* is completely banal and culturally embedded, so that it is not systematically diagnosed, and *habitués* themselves seek no care for it." (Ferreira, 2004, p. 181). In fact, physicians showed a certain denial and tolerance to this group, which was observed in the large number of patients attended in medical consultation during episodes of drunkenness, who were aggressive and violent in the waiting room. These episodes were handled by volunteers, and the police was called only as a last resort. Under any circumstance those homeless people were prevented from returning to the center - an unusual permissiveness in other health care sites. Alcohol and street life were so intertwined that this institution of humanitarian care trivialized them, neglecting these patients' social precariousness.

Some authors stress the impossibility of establishing a cause-effect relationship between AUD and precariousness, given its complexity (Souza; Menandro; Menandro, 2015). Medical practices for approaching AUD are highly heterogeneous, as observed among physicians of the MDM center. This analysis is not concerned with professionals' technical skills for treating this syndrome, but rather in observing how AUD is completely clouded by patients' social situation - that is, their condition as a street dweller. The humanitarian care ideal made the center a "context likely to drink" (Nahoum-Grappe, 1991), as explicitly stated by one of these homeless people: "I beg a little here and there, and then I go to the MDM. Certainly, there the fellows will have drink" (Ferreira, 2004, p.181). Drinking is a social act that implies prescriptions and prohibitions. In this sense, it is more pertinent to refer to the ways of drinking that implicate values, attitudes, and different relationships in time and space (Castelain, 1989). In a classical ethnography with people with alcohol use disorder, Sylvie Fainzang (1996) recalls how the relationship with the Other reflects the way these people behave towards the disease, whereby different roles and risk assessments are regarded and put into practice. The fact that drinking is paradoxically permissible and homeless people's drinking problem is trivialized by physicians of this humanitarian Health Center evinces that the disease management is constantly built and negotiated in the daily life of medical practices.

I referred to this (not trivial) example to show how care circumvents medical protocols in some contexts, requiring professional skills to be redefined and “doing nothing” to be acceptable for chronic conditions considered incurable.

Now, I will focus on two basic actions that substantiate the medical practice for chronic diseases: diagnosis and treatment. As previously stated, the basic premise for physicians to be successful is that they accurately diagnose and cure patients. Chronicity challenges this premise. However, as Elliot Freidson (2009) precisely suggests, feelings of uncertainty and vulnerability usually accompany medical practice. These aspects are integral parts of the *métier*, and how they are incorporated and interfere with the physician-patient interaction are pertinent questions to this debate.

## Diagnosis: trust and effectiveness

The diagnosis is a key action for reflecting the disease chronicity, given that it is milestone of the individual new condition - of a chronic patient being introduced to the conceptual bases of medical knowledge. Thus, the diagnosis is important for individuals to redefine their identities. Institutionally, it authorizes work permits, imposes different forms of social interaction, such as self-help groups, and even changes social relations.

At first, symptoms are unclear to physicians, so that they may delay the diagnosis until being sure. This is the case of rheumatic diseases, often syndromic and inaccurate in their diagnosis. According to Isabelle Baszanger (1986), delaying the communication of the diagnosis to the patient may have yet another reason: to postpone the “bad news” for as long as possible. This is particularly true for stigmatizing disorders, such as mental illnesses.

Undiagnosed diseases are increasingly rare, reflecting rationality and scientific progress. Advanced technologies, medical imaging, and *pet-scanner* denote body virtuality, altering our conception of self, disease, and time. Bodies mediated by technologies, promises, and expectations are intrinsically associated with the ideal of transparency, which significantly increases the spectrum of perfection, modifiability, malleability,

and control over human physiology. The great paradox is: such technology generates conventional images and numerical and abstract data; that is, the “transparent body is its absence” (Tucherman; Saint-Clair, 2008, p.15). Thus, normality, abnormality, and the chronic condition also involve conventions and imply constant negotiation between social actors (Camargo Jr., 2005). The structural and organizational context of the medical work, as well as its interactions, should consider these conditions, increasingly evidencing medical knowledge as historically and socially constructed.

In turn, hardly ever do patients attribute their cure to the physician, but to diagnostic and treatment technologies. Ana Maria Canesqui (2013) approached how diagnostic tests and X-rays may provide concreteness to unexplained symptoms, enabling physical and moral disorders to be solved. The MDM center, for example, attended many Africans in condition of clandestinity who quite often mistrusted physicians and queries about their social situation. The fear of being reported to immigration authorities did not prevent them from attending the center, but made them control the information provided and even lie about certain facts of their social life (Ferreira, 2004). In such cases, we may ask ourselves: How did the symbolic effectiveness of healing operate in the sense attributed by Claude Lévi-Strauss (1996)? In his famous text “The Effectiveness of Symbols,” the author emphasizes that, being part of a believing society, patients attribute their healing to the person or instrument that provided them treatment and holds the trust of the society. In other words, trust is the basic premise for an accurate diagnosis and treatment. In the case reported, trust was not attributed to the physician, but to French medicine resources, which did not exist in Africa. As stated by a Senegalese patient: “We believe in French medicine” (Ferreira, 2004).

Patients often fail in recognizing the first signs and symptoms as part of an ongoing chronic disease. For them, it is a moment of uncertainty where physician’s *expertise* is continually called into question: the diagnosis is unsatisfactory, does not account for the symptoms; the proposed treatment makes no sense in their daily lives. They return

several times; ask for new exams. They also seek various professionals, ask, and position themselves, doubting the legitimacy of medical pretension. They often seek a personalized diagnosis, which interferes with biomedical rationality.

In turn, patients quickly gather information and knowledge provided by the Other: they search for all the information. Some studies discuss how online-available knowledge interferes with physician-patient relationship (Pereira Neto et al., 2015). Patients articulate their arguments to negotiate with the physician, provoking a conflict, since diagnosing is the physician's role.

Thus, diagnoses are constantly negotiated and each of the two poles may perceive them differently, as is the case with systemic arterial hypertension or "high blood pressure." Hypertension is a common chronic disease that, along with diabetes, is the leading cause of hospitalization in the Brazilian Public Health System. It may entail cardiovascular, coronary, renal, encephalic, and peripheral vascular complications, among which 40% (stroke, acute myocardial infarction) are estimated to be easily preventable with drug therapy (Brasil, 2001). Patients claiming that they are not sick but need drugs for treating "high blood pressure" are encountered quite often in everyday medical practice. This disease is commonly trivialized by those affected by it (perhaps for not interfering in the daily life in the short- and medium-term), leading us to believe that they seek to deny their condition as a patient, especially of a chronic disease. Abandoning treatment once symptoms and blood pressure levels stabilize for a long period (due to treatment) is yet another sign of such premise. The following reports are rather common: "I only take medicine when the pressure is very high," "I do not have high blood pressure, I have uncontrolled pressure." According to Soraya Fleischer (2012, p.154), hypertension symptoms identified as "being sick" are not attributed to the disease at first, and only after that do patients take the drugs - "the difference between diagnosed and undiagnosed patients is that the former are more experienced in 'reading' the 'being sick'."

This enable us to conclude that, more than just a set of universal physical symptoms, the disease

is a subjective and sociocultural process, and its pharmacologization is an individual decision-making process in its management.

## Treatment management

The limits of medical knowledge and ambiguous therapy outcomes denotes the stress induced by treatment. In chronic noncommunicable diseases (NCD), medical work does not aim to cure the disease, but to manage it by limiting its progression and controlling its resulting problems as effectively as possible.

The negotiated order theory postulates that the disease should be understood as a work, and the sick as actors in the division of medical labor. In that sense, the sick must provide their own care, and each step they take (as changing their lifestyle, undergoing invasive treatments such as dialysis, using continuous medication, and self-applying injectable solutions) are underlined by strategies of persuasion, correction, and rejection. Patients do not accept diets and treatments immediately; rather, they evaluate these propositions based on their consequences, discomforts, and required energy. For choosing a treatment, patients also consider symptoms discomfort, the fear of the pathology consequences, and the side effects of the therapy itself, so that treatment is often administered according to patients needs, partially or entirely modified. That is, the disease daily management mobilizes patients' participation around their social life, and its organization is more based on social than medical criteria, whereby the physician becomes a paramedic, providing prescriptions and examinations.

Health authorities raise an important issue: adherence to treatment, a major public health problem. For patients to adhere to treatment, it should interfere as little as possible in their everyday life, without shaking their identity.

Some authors indicate the possible decrease in effective disease management, increased hospitalization risk, and increased mortality as consequences of non-adherence. Differences on culture, age, gender, social class, and health status are also factors that influence adherence (Remondi;

Cabreira; Souza, 2014). Patients are commonly held responsible for non-adherence or poorly conducted therapies. However, responsibility can only be attributed to the patient once other determining causes are excluded, such as poorly designed programs or poor access to healthcare. Patients from lower classes are also unable to adhere to costly and lengthy treatments that are usually designed to privileged classes, increasing social inequalities (Castro; Savage; Kaufman, 2015).

Therapies vary considerably according to the disease. Although some diseases require advanced technologies, drug therapy is one of the main resources for many of these pathologies. As for drug therapy follow-up regarding physician-patient relationship, some studies show the decisiveness of physicians' behavior. Studies on hypertension treatment, for example, show how sociocultural discrepancy between the two poles determine a lack of communication and, consequently, patients' adherence or not to treatment. According to them, even if physicians question patients about treatment, it is done superficially, without discussing its outcomes and goals. In that way, patients obtain fragmented information about the medication even after several consultations (Duarte, 2010).

A study conducted in North America found physicians to provide greater information about antidepressants to white than Latin American patients, proving that biomedicine is embedded and underpinned by economic systems of social and political domain (Hayes-Bautista, 2003). Thus, our study aim to overcome the common sense of neutrality in Biomedical Science and of the incompatibility between low-income groups behaviors and beliefs and biomedical rationality, being less likely to adhere to drug therapies proposed (Ferreira; Engstrom; Alves, 2012).

## Final remarks

Physicians and patients often perceive disease management differently. For example, diabetic patients may opt by not injecting insulin before a walk and hypertensive patients may avoid using the diuretic if they have a long bus ride ahead, "disorganizing" the scheme prescribed by the physician. Likewise,

insulin-dependent diabetics learn the symptoms of hyper and hypoglycemia and administer insulin doses according to their own experiences and routine, regardless of medical recommendations. Patients with psychiatric diseases may periodically discontinue medications for fear of becoming dependent, often justified by the return of symptoms once medication was discontinued. This calls into question two logics: the logic of disease control as opposed to symptom control; physician and patient should learn to manage these logics over time.

Thus, NCD are an ideal object for addressing social situations, facts, rules, and roles within the disease universe. According to the negotiated order theory, patients have an active and conscious role in managing the disease, where their daily interactions and agreements, therapeutic resources, and representations of immediate situations are extremely important. There is no established and immutable order, but a fluid, constantly trading one. Such negotiations seek to restore and maintain an order shaken by changes in the routine of those affected by the NCD.

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