

# How to build an “active” patient? The work of AIDS associations in France

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## Abstract

“What is an “active” patient?” is a question that arises in most medicine and illness-related social science research. This article examines the normative work carried out by AIDS associations in France to define an “active” patient in healthcare and research. While the fight against AIDS is often presented as being homogenous, we look at the diversity of opinion between different associations (Aides, Act Up-Paris, Actions Traitements and Positifs). We find four different cases: the patient as *manager of his illness*, the *empowerment* of patients, the *science-wise* patient and the *experimenter*. Systematic comparison of these cases shows that these perceptions of the “active” patient, in terms of the same pathology, are based upon different ways of seeing: the nature of the relationships between the different types of knowledge of the illness (scientific knowledge, clinical knowledge, experience of the illness) and the distribution of roles and powers among the various actors in the healthcare system (the government, pharmaceutical companies, the medical profession, the patients). This article highlights the historical dynamics which allow us to have a better understanding of these differences, especially the major distinction between two generations of associations, which adopted different positions with regard to their public identity.

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## Introduction

The evolution in relationships between patients and the medical profession is both a central item of social science work on medicine and illness, and an especially important question within public debate. The way in which patients approach their relations with their doctors and the new demands developed by their groups and associations with regard to the organization of care and medical research are at the hub of lively debate between a wide variety of actors (doctors, public authorities, patient associations). While they welcome

greater patient involvement in the field of healthcare, actors do not necessarily agree on the nature and boundaries of this new involvement. On the one hand, we see increasing acceptance of the perception of the “active” patient, a patient who is more “tuned in” to the medical world, with skills and the wherewithal to act. Yet on the other hand, despite this acceptance, opinions differ when it comes to defining the limits to patients’ newfound skills, the nature of their scientific and medical knowledge, the validity of their actions and the scope and legitimacy of their powers. The purpose of this article is to examine how patient associations approach these questions.

One set of social science research on medical practices shows the way in which, historically speaking, the boundaries have moved between what are considered

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to be patient skills and initiatives and what remains the responsibility of the doctor. The issue was raised already back in the 1950s, when Talcott Parsons attributed very few scientific or medical skills to patients, judging their reactions to be emotional and therefore irrational. A patient was nevertheless expected to “cooperate” with the therapy in order to facilitate reintegration into the society from which the patient had been temporarily excluded (Parsons, 1951, 1964). The matter was studied from a variety of different perspectives. In the 1960s research based upon institutional monographs examined the condition of persons immersed in hospital environments. Studies of a functionalist nature highlighted the way in which patients who were cut off from their usual world “socialized themselves” to suit the operation of the medical institution, with the help of staff and longer-standing patients (Coser, 1962; Fox, 1959). Patients had to become more “active” in order to acquire the cognitive and moral references of their medical environment, and thereby usefully participate in their own therapy. In contrast, studies of an interactionist nature looked at situations in which patients used the knowledge they felt they had acquired of their illnesses to question the legitimacy of medical decisions (Goffman, 1961; Roth, 1963). A new perspective was born: that of a patient who was actively involved in “negotiating” therapy by using his or her own knowledge and resources. Following the line of research by Anselm Strauss, studies went on to explore this new dimension of patient activity within the framework of chronic illnesses (Anderson & Bury, 1988; Baszanger, 1986; Charmaz, 1999; Conrad, 1987; Herzlich & Pierret, 1987; Strauss et al., 1984). Such research was important in demonstrating how patients learn to “manage their illnesses” over the long term, to interpret the symptoms and anticipate crises. They show that by carrying out an increasing number of technical acts, patients take an active part in the allocation of the medical work. Because they live in different “social worlds” (the medical world, but also the world of work, family, etc.), patients construct a point of view of their illness which cannot be reduced to just that of the world of medicine. They are therefore obliged to act in order for their doctors to recognize the legitimacy of this point of view.

Parallel to this social science research which highlights the historical roots of the various “active patient” models within medical practice, another set of studies demonstrates how associations created to fight illnesses have themselves worked on the models. In France, the philanthropic leagues created at the dawn of the 20th century paint a picture of patients who are seen on the one hand as “objects of solicitude” and on the other hand as “subject to moralization.” For example, when it was first created, the league against cancer—mainly composed of society women and of key medical and political personalities—organized fund-raising events

and then delegated the task of defining the orientations of care and research to the specialists (Pinell, 1992). Patients could do no more than express—as in the Parsonian model—their confidence in the doctors and researchers upon whom their “hope of being cured” depended. The numerous studies on associations created to help chronic illnesses show that major changes were to follow. These associations were far more involved with the patients and their families, and gave new room to the experience of illness. Self-help groups sprang up in Anglo-Saxon countries to allow patients to share experiences (Morgan, Calnan, & Manning, 1985). In France in the 1950s, hemophilia and diabetes led to the first associations being created to lobby doctors and public authorities in order to improve everyday conditions for patients (Carricaburu, 2000). More often than not, these associations feel that skills should be divided between the specialists (doctors and researchers) who hold both the medical knowledge and the initiative regarding care and research, and the patients and their associative entourage who deal with the “psychosocial” aspects of the illness. This distribution of roles was criticized at the beginning of the 1980s. Several social science studies showed that patient associations have joined established actors in the production of medical and scientific knowledge. This is particularly the case of those involved in rare illnesses (Rabeharisoa, 2003; Rabeharisoa & Callon, 1999) and in AIDS (Barbot, 1998; Dodier, 2003; Epstein, 1995, 1996).

Within this new form of collective involvement regarding care and research, how have associations remodelled the perception of the active patient? Taking the example of AIDS, this article attempts to answer that question. In many countries the fight against AIDS constitutes a paradigmatic example of transformations in patients’ individual and collective relationships with the medical world. This paper argues that it would nevertheless be a mistake to interpret this as the arrival of an “active” patient model that is both radically new and unique (Barbot, 2002; Barbot & Dodier, 2002). On the contrary, with regard to the same pathology we can see that different associative perceptions of the active patient coexist. In its own way, each association establishes a hierarchy and distributes the different types of knowledge of the illness among the actors. Some of these different perceptions of the active patient prove to be very similar to those which have been developed by associations in France since the 1950s, with regard to chronic illnesses; others are more original (for example, we find models that were imported from the US).

## Methods

From among the many AIDS associations, we chose to study those which have publicly stated their interest in

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