Integration of Emotions and Feelings of Patients to Improve their Care - the Case of Healthcare Interface Organizations (HIO) in France

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Abstract— **In all the developed countries, Healthcare Systems are in crisis with the central question of costs. They therefore face the key issue of performance. Everywhere (United Kingdom, USA, Spain, France, etc.) solutions are sought in new uses of information and involvement of patients or empowerment. The French Healthcare System has strong characteristics (particularly divisions between primary care and hospitals) that determine its evolution that we will analyze after explaining our research position. Better integrating patients' and in particular their emotions and feelings to improve their involvement in a coproduction of services perspective is one of the main goals of New Healthcare Interface Organizations (HIO) developed recently between primary care and hospital sector. We analyze how in this perspective they may play a key role to improve the French Healthcare System.**

Keywords - Healthcare; Interface Organizations; France; emotions; feelings; services.

I. INTRODUCTION

Healthcare Systems are in crisis with the central question of costs, accentuated during the last years in all the developed countries with key issues of efficiency and performance. Solutions are sought in new uses of information and involvement of patients or empowerment. The case of France is specific: the French Healthcare System has strong characteristics that determine its evolution (Section III). We will analyze these specificities as strong constraints after explaining our research position (Section II).

We will then show the key role of new Interface Organizations (HIO) to promote coordination and traceability and a cooperative process between primary care and hospital sector (Section IV) [1] [2] [3] [4]. Then we will examine the new role that could be given to patients by including their emotions and feelings to improve their involvement in a new coproduction of services perspective (Section V) [5].

II. RESEARCH POSITION

Our research position corresponds to French Academic discipline of Information and Communication Sciences, as proposed by F. Bernard [6] at the convergence of four problems: that of link (relationships, interactions), that of meaning, that of knowledge and that of action. We choose an approach of complexity (global and systemic) and of Action Research: produce usable knowledge for action, validated by all the stakeholders [7].

We refer to the "situational and interactionist semiotic method", in French, "sémiotique situationnelle et interactionniste" (A. Mucchielli [8]). This method tries to access meanings by understanding what things mean for an actor in a specific situation. Its key concept is the contextualization. Different levels of background are built by actor interpretation and define a situation, split into different frameworks: the intentions and issues of the actors, their cultural background, their positions in relation to other actors, the quality of relations, historical and temporal framework. All the meanings for all the actors build a "global sense" of the studied phenomenon.

We propose an extension of this method to integrate the experiences of actors including the emotions and the feelings of patients in a dynamic approach, considering the patient care pathway as a process in quality management. Always in a constructivist approach, we also consider the Activity Theory of Y. Engeström [9].

Our work in progress is based on cooperation established in France (particularly around students' works for Masters' degrees: observation, participation in meetings, interviews of key actors, etc.), but also with comparisons with other countries such as the Spanish Basque Country.

III. THE SPECIFICITIES OF THE FRENCH HEALTHCARE SYSTEM

The French Healthcare System can be regarded as "out of breath" that is at the end of its possibilities (Isaac, [10]) if we consider the results in comparison with the costs around 12 % of GNP. It is strongly affected by divisions (walls) [11], particularly between the primary care and the hospital sector (very dominant: this is called "hospital-centrism"), between physicians (cure) and nurses (care), between medical and social jobs, etc.

In the 1920s, physicians practicing in primary care (outside hospitals) refused the role of Health Insurance Companies (German model) to impose fees directly paid to them by patients who are subsequently reimbursed by Health Insurance Companies. So primary care physicians deny any link with Insurance Companies. For H. Isaac, ICT (Information and Communication Technologies) can afford

to develop another model, promoting prevention and cost savings. These prospects meet issues of "augmented human" or "quantified self " with all the new uses of Open Data or above all of Big Data with the risk of abuses, particularly on privacy, highlighted by the CNIL – National Commission for Informatics and Freedom (in French, Commission Nationale de l'Informatique et des Libertés) [12], and also another risk around ultra-connection and ultra-transparency.

Patient involvement is essential, in reference to the Anglo-Saxon concept of empowerment. In France, we prefer to talk about "responsibility". In this perspective, the law of March 2002 on "The Rights of Sick People and the Quality of the Healthcare System" (in French, Loi relative aux Droits des malades et à la qualité du système de santé) was a major step by proposing the concept of "health democracy" (démocratie sanitaire) and valuing Healthcare Networks (Réseaux de santé). HIV-AIDS networks have played a key role for a new approach of patient role. The law of July 2009 ("Hospital, Patients, Health, Territories", in French : HPST - Hôpital, Patients, Santé, Territoires) proposed a new regionalization of Health management with the creation of ARS (Health Regional Agencies, in French, Agences Régionales de Santé) and two agencies to improve information systems (Agency for Shared Information Systems in Health (in French, Agence pour les Systèmes d'Information Partagés en Santé) and performance in the health and social sector (ANAP: Agence Nationale d'Amélioration de la Performance), particularly in the medico-social sector, also confirming the role of the High Authority for Health (HAS, Haute Autorité de Santé). As an extension of the Companion - Ghali report (2014) [13], a new law voted by Parliament inl 2015 wants to give a new impetus to the concept of "health democracy". It also insists on a better use of information with the repositioning of the Electronic Health Record or DMP (in French, Dossier Médical Personnel), whose management since 2004 is largely a failure. It is now redefined not as personal belonging to the patients (first perspective) but as shared by all the medical actors.

In this context, the development of new Interface Organizations for facilitating cooperations between primary care and hospital sector, using ICT and involving more patients, is a key issue. The Godet - Durance - Mousli report (2010) [14] emphasized the role of the Health field as essential for innovation, focusing in particular on the experience of Healthcare Networks.

IV. HEALTHCARE INTERFACE ORGANIZATIONS (HIO) AS A CHANGE LEVER

New Healthcare Interface Organizations (HIO) developed to overpass divisions between primary care and hospital sector may be considered as spaces for innovation, experimentation and development of trust (Bourret, [2] [3]), both for the human actors (individuals or belonging to organizations) and also in digital tools (digital trust), also with the recognition of different roles: that of doctors, nurses, social workers, patients and their families, etc.

Healthcare Networks (in French, Réseaux de santé) appeared in the 1980s, especially with the AIDS epidemic and the need for coordination between general practitioners (primary care) and hospital sector and between the medical and the social sector. Their role has been enshrined in the Law of March 2002. They were developed for different diseases (diabetes, cardiology, etc.), or for specific situations (perinatal care, addictions, obesity, geriatrics, oncology, etc.) and in some cases their role would be better defined with HAD (Hospitalization at Home, in French, Hospitalisation à Domicile) organizations, with whom they are often in strong competition on the same areas.

First Healthcare Networks are coordination structures of professional activities engaged in different spaces, often with just a phone center to receive patients' calls (Healthcare Network Bronchiolitis in Paris, Gérontopastel Network for old people in Toulouse, etc.).

Their rivals, Multi Medical Homes (in French, Maisons de Santé Pluriprofessions) gather different practitioners on the same site, as it is, for example in Spain for ambulatorios. In the recent years, the authorities seem to prefer them and encourage their development, focusing also on grouping and coordinating activities. Thus the Healthcare Network on Diabetes in Eastern Ile-de-France (Revesdiab) became the main actor in the new structure of GCS (Health Cooperation Group, in French, Groupement de Coopération Sanitaire) Diapason (in southern Seine-et-Marne department, which represents half of the area of the Ile-de-France Region). The GCS is a new key tool to develop cooperations between public and private sector, but also between the primary care and the hospital sector. It connects public and private health institutions, health centers, nursing homes, medical professionals and the actors of medical-social sector, acting individually or collectively.

Other modalities of cooperation have also emerged in recent years as the PAERPA experiments (Elderly People at Risk of Loss of Autonomy, in French, Personnes Agées en Risque de Perte d'Autonomie) that particularly highlight PPS (Personalized Care Plans – in French, Plans Personnalisés de Soins) (Bloch – Hénaut [4]) which, eventually focus on monitoring of individually sustain of patients' care pathway, set up by the Healthcare Networks, applying in this case to in elderly patients. So GCS Diapason applies a PPS to diabetic patients.

MAIA (Houses for Autonomy and Integration of Alzheimer Patients, in French, Maisons pour l'Autonomie et l'Intégration des Malades d'Alzheimer) were mainly intended to be the devoted entry for patients with this disease and their families. They were put in place by the new CNSA (National Solidarity Fund for Autonomy, in French, Caisse Nationale de Solidarité pour l'Autonomie). They have often considered the PAERPA as unfair and unnecessary competition.

These interface organizations are an attempt to answer the central problem of the divisions or walls [11] of the French Healthcare System. But their proliferation, often without real coherence or overall vision, according to local initiatives of different Health Insurance or Social Security

funds or territory collectivities (departments, municipalities, etc.) can lead to new divisions and a loss of efficiency.

V. A NEW PATIENT'S APPROACH INTEGRATING THEIR EMOTIONS AND ENCOURAGING THEIR INVOLVEMENT

Patients gradually asserted their role, particularly in the applications of the 2002 Law (for example the hospitalized patient's charter in 2006) with the key role of associations such as the CISS (Interassociative Collective on Health, in French, Collectif Interassociatif Sur la Santé) and with the "judicialization" of health from the perspective of "perfect health" described by L. Sfez [15]: obligation of results and not only of means.

Next, we will describe our point of view regarding experiments we are associated with.

We will analyze in particular the concept of Personalized Care Plan (PPS) from the case of GPS Diapason whose mission is animation of the territory of Seine-et-Marne and testing of innovative practices involving the patient, especially diabetic, around the telemedicine project "Diabetes 2.0" (including the Healthcare Network Revesdiab). Diabetes 2.0 is a multi-year large-scale innovative project involving both the city and the hospital. It provides various tools of tele-consultation, remote monitoring, tele-expertise, as well as virtual tools of therapeutic education. 2.0 Diabetes wants to use telemedicine as a training tool for health professionals and to promote patients' compliance. The ultimate goal is to improve the management of chronic diseases (diabetes here) and associated complications, optimizing care pathways and controlling health expenditures.

We will offer broader perspectives from "situational and interactionist semiotic method" (described in section II) extended to emotions and feelings of actors (Goleman, [16]), especially for patients and their families. And also extended to a dynamic approach of change (in a process approach regarding quality management), the patient's pathway can be regarded as a process.

We will insist on the concept of emotional skills of patients, central element of emotional intelligence. The human body is the mediator from which the individual can sensitize its affects and communication support them (Martin-Juchat, [17]).

Our goal hypothesis is that managing emotions can become a collective objective of improving the quality of care. Social sharing of emotions is essential to promote the group membership (Bègue-Desrichard, [5]). This integration of emotions and feelings in the patient's personalized care can improve the quality of care, for example through better patient adherence to prescription compliance and taking medication. The notion of recognition is also essential in the discussion groups. So we will evoke the role of "mediator patients" already developed in some Healthcare Networks and that of "case manager" for coordination of care. So we will place ourselves in the perspective outlined by the High Authority of Health (HAS) (2007 [18]) in its recommendations for patient's education, asking to

recognize how to act in the patient's positioning to analyze his psychological evolution by developing techniques of patient-centered communication (active listening, empathy, encouragement, etc.).

In an Action Research perspective, we will conduct specific interviews with patients and their families both in individual and group perspectives and then we will try to improve the integration of their ideas by interactive discussions with medical and social actors. We particularly insist on the role of "mediator patients" with an idea to specific training to help to improve the implication of all the other patients. We will particularly work on the notion of "complex patient", especially elderly people with chronic diseases and social problems.

The digital dimension (ICTs) is also essential. The areas of activities of different Interface Organizations can be considered as Digital Care Territories (in French, TSN: Territoire de Soins Numérique), in the same way an individual patient is.

The prospects outlined represent a new approach of services coproduction integrating emotions and feelings of actors (Maman, [19]) applied in this case to the Healthcare sector. More generally, this crossing from the individual dimension to the collective dimension is a major challenge to found a new citizenship, particularly in the Smart Cities project (digital), as outlined by M. Zacklad [20].

With GCS Diapason we begin to study the Diabetes 2.0 Project. In isolated areas, to obtain an appointment with a specialist is very difficult with often very long delays. The main idea is to use telemedicine solutions to develop connection points on still isolated territories. Priority is given to new patients, but also patients who experience complications and elderly patients with reduced autonomy. The project is going to manage three different cohorts. A first cohort corresponds to newly diagnosed diabetic patients without known diabetes complications. A second cohort of already known and treated patients; diabetics aged 65 and older with at least one known diabetes complication. And finally, a third cohort of patients ages 65 years and older with loss of autonomy at home or in nursing homes, in diabetes care with risk of hypoglycemia. Integration of emotions of patients by discussions and use ICTs to develop their implication and their responsibility are key parts of this project.

Loneliness is a huge problem. Discussing with other people, not to be alone and sharing views on illness is the first step to improve the quality of life of these patients and for integrating their emotions and their feelings. It is also a manner of taking into account the different times of all the actors and their different goals: these of patients being very different than those of doctors, nurses or social workers. Trying to integrate patients' knowledge about their disease will be the second step.

VI. CONCLUSION

The role of patients is essential to reinvent the Welfare State and a new local citizenship, with all the importance of the integration of their emotions and feelings. Health Interface Organizations may constitute privileged spaces for

developing new approaches emphasizing emotional intelligence dimensions, building trust, from the recognition of the role of all stakeholders, not just of the medico-social, but also of patients and their families. These approaches correspond to coproduction of services perspectives and "daily innovation", according to N. Alter [21].

We have also begun to address these issues in a comparative European perspective, especially for cases of elderly patients in complex situations for example with the Carewell Project, principally coordinated by Healthcare Organizations of the Spanish Basque Country. Carewell is a project for the development of a new organizational model based on integrated care for chronic and elderly patients through ICTs [22].

The tracks we started to trace also belong to a more comprehensive approach to "sustainable development" of territories, corresponding to that of the Brundtland Report (1987) [23], which cannot be reduced solely to environmental issues but is also based on two other pillars: economic (growth) and social (education, health and respect for freedoms).

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