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Managing chronic disease in elderly patients in Algeria: the social interpretation of "illness"

تسيير المرض المزمن لدى الاشخاص المسنين في الجزائر: التفسير الاجتماعي للأعراض

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ABSTRACT:

Chronic disease is first and foremost a social event. It cannot be seen as a purely organic disorder. In fact, it is characterized by its disorganizing impact on all spheres of the patient's social life. Faced with the disease's various limiting disorders, the patient acquires a meaningful understanding of the symptoms, which are far from being extra-social data.

The purpose of our work is to take an inside look at the manner in which patients interpret and define the symptoms accompanying the illness.

The experience of pain is an important dimension in the management of chronic disease. It highlights the complexity of the different forms of logic developed by patients in their relationship with care. These can play a key role in the patient care process (therapeutic process, treatment, choice of medicine, etc...). They also highlight the many ways a patient can deal with illness.

Keywords: Social interpretation of symptoms, the elderly, chronic disease.

الملخص:

المرض المزمن هو حدث اجتماعي بالدرجة الاولى. لا يمكن اعتباره اضطرابًا عضويًا بحتًا. في الواقع، فهو يؤثر على جميع مجالات الحياة الاجتماعية للمريض، حيث يتميز بقدرته على اعادة تنظيم الحياة الاجتماعية للمرضى. في مواجهته لمختلف الاضطرابات والالام الملازمة للمرض، يقوم المريض بإنتاج تفسيرات مختلفة للأعراض والاضطرابات المرافقة للمرض. تعرف هذه الاخيرة في بعدها الاجتماعي بالدرجة الاولى.

تهدف هذه الدراسة الى محولة تحليل من الداخل طريقة تفسير المرضى للأعراض المرافقة للمرض المزمن.

تعتبر تجربة المرض والالم بعدا مهما في عملية تسيير الامراض المزمنة، حيث يمكنها الكشف عن درجة التعقيد التي تميز علاقة المريض بالرعاية الصحية. فهذه التفسيرات الاجتماعية للأعراض يمكن ان تكون محددة وحاسمة في عملية الرعاية الصحية (العملية العلاجية، العلاج، اختيار الطبيب، إلخ) كما يمكنها ان تمكننا من الكشف عن مختلف الطرق المختلفة لتصرف المريض في مواجهة المرض.

كلمات مفتاحية: التفسير الاجتماعي للأعراض، الشخص المسن، المرض المزمن.

1- Introduction:

This article is based on the results of a study carried out as part of the preparation of a Magister in the Sociology of Health, dealing with the theme of "the Construction of the Doctor's Reputation among Elderly People with a Chronic Disease in Algeria".

Contrary to the medical conception of chronic disease as a purely organic disorder, the patient has his/her own conception of illness. It is defined as a major social event. Patients tend

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to interpret the various signs of their own pathology in a meaningful way. In fact, the symptoms are named and identified according to their impact on the whole sphere of social life, not just on the organic space.

Indeed, pain management is a limiting factor of illness management in elderly patients. The experience of pain is understood here as a social construct.

It is crucial to highlight the importance of the different meanings given to pain during the perception of physical sensations and symptoms of chronic diseases. which are far from being extra-social data.

Elderly patients do not experience in the same way the various physical manifestations (fatigue, pain, etc...) that constitute the subjective symptoms of the illness. However, pain is far from being defined as purely organic phenomenon. It is understood in its social dimension.

The social interpretation of the illness highlights the different ways elderly patients cope with their illnesses. They are designed with the idea of resisting the effect of advancing age and illness.

The complexity of the process of interpreting illness shows that the patient is led to deploy his/her own logic, which is not that of the doctor, with the goal of defining, evaluating, and managing his/her illness.

However, the elderly patient is not passive, but an active agent in the management of his/her illness. Every day, he/she deploys resistance strategies against constraints imposed by his/her pathology.

We follow the perspective of interactionism (Strauss, A. 1992). Indeed, this research vision stresses the importance of patients' creativity as social actors, and their adaptability to the uncertainties of their illness. The patient is seen as a key player in medical work.

This research position interests us because we see patients as active creatures who model their environments and futures, and face constraints that impact action (Strauss, A. 1992).

We prefer the qualitative approach, based on in-depth, repeated interviews and detailed observations of the spaces involved.

This methodological approach is relevant for gaining access to the actors' ways of saying and doing. The field survey was carried out in two locations: the functional reeducation service at CHU, Oran, and at the homes of the respondents. The survey population consisted of people aged between 62 and 82, having chronic diseases (hemiplegia, heart disease).

We conducted 18 in-depth (repeated) interviews lasting an average of two hours with patients from a wide range of social backgrounds. The interviews were audio-recorded, transcribed and translated for final analysis.

By focusing on the elderly, we went beyond the quantitative aspects and tried to understand their history and experience of their illness. Far from being viewed in a reductive way as a burden on society, the elderly are also the bearers of invisible and little-recognized social and health skills. They embody authority, wisdom, and knowledge.

In addition, it should be pointed out that aging is a hidden phenomenon in Algeria. However, a notable increase in the number of elderly people has been noted in recent years. The National Office of Statistics (ONS) confirms that the number of people aged over 60, estimated at 2.2 million in 2002, will reach 6.7 million by 2030. These are the findings of ONS population projections for the period 2000-2030. (L'Office National des Statistiques ONS, 2004). These factors indicate the beginning of a gradual aging of the Algerian population. On the basis of these data, it is important to understand the category of elderly people with chronic diseases, in all its complexity, by focusing on the experience of symptoms in the management of their pathologies.

This study highlights two key aspects. The first element is to understand the importance of the work of interpretation and identification carried out by the elderly patient in relation to his/her illness. In order to find an explanation for his/her various disorders. The elderly patient refers to his or her social experience of illness, as well as to the problems of daily life.

The second is to highlight the different socialization strategies developed by elderly patients in the process of managing their illness. The latter are understood here as forms of resistance to the advancing age and illness. They highlight the active involvement of elderly patients in the management of their own illness.

2- Giving meaning to illnesses:

The arrival of the illness is characterized by an undeniable quest for meaning. It is by no means a set of organic afflictions that can lead to a visit to the doctor.

For the patient, it is an unfortunate event insofar as it not only imposes changes in the concrete organization of life, but also calls into question the meaning of existence. However, it leads to the formulation of questions regarding the very meaning of the event (Adam P, Herzlich C. 1994).

In this quest for meaning, a number of questions arise: "...why has this sickness chosen me in particular...", "...why has this catastrophe affected me personally and not another person...". These are the types of questions that recur in patients' conversations.

In the perception of the organic symptoms and pains, the patient equally searches for a meaning to ascribe to these manifestations and, depending on how he/she interprets it, tries to make them disappear or lessen them (Aiach P, Cébe D. 1999).

We see chronic disease as a social experience. Its distinguishing feature is that it assesses and interprets the patient's various ailments on a daily basis.

This social interpretation is defined as the set of judgements, beliefs, and knowledge developed concerning health, illness, and medicine (Mebtoul M, 2001).

Indeed, chronic disease is characterized by an "interpersonal crisis" that affects both the individual and those around him/her. An interpersonal crisis is a situation in which attention is focused on symptoms, prompting the individual to take an interest in them. (Aich P, Cébe D, 1999). This situation is defined as one of the factors that trigger the decision to seek care. It is

perceived, by the elderly patient, as a moment that marks the transition from "normal" to "pathological", making it the initial phase that triggers the decision-making process.

Fatiha, former cleaning lady (retired), is a 70 years old widow. She has been hemiplegic for 5 years following a stroke, and has also suffered from hypertension for 12 years. She aptly describes the moment of her stroke attack, as a "biographical upheaval" (Bury M, 1982), causing a break with with her previous health status, which she describes as "normal":

> *" ..... I had nothing before, my daughter! I wasn't suffering from anything. I was well. I had all my health "كنت انقز" I had the health of a galloping horse". It was after a violent dispute with my work colleagues that I had this illness [...]. The director was furious with me. He was very upset with us, and I came home that day feeling very dizzy. My eyes...It was like sparks in my eyes, and my ears began to ring. I was very upset. They [her colleagues] are the ones who caused my illness. I've never had its signs before, so when it happened to me "la dherba" (the blow) it was as if ... I felt as if there was someone hitting me with a hammer on the head. Then, I fell ... Since then, I haven't regained my health... I don't leave the doctor's office...."*

Accustomed to the various ailments of hypertension, Fatiha considers her new-found affliction (stroke) indicative of a real health problem. "Experienced" in other chronic diseases, usually hypertension and heart disease, "their crises" become routinized (Baszanger I, 1986) becoming known and less worrisome. The new illness is perceived as the most worrying. It encourages the elderly patient to engage in a different care process.

Fatiha's comments also highlight the importance of identifying and interpreting the symptoms experienced by elderly patients. She does not hesitate to prioritize her various symptoms, forcing her to seek medical attention. "The big illness" appears to be sufficiently inconvenient to force elderly patients to break with their previous habits. "I don't walk like I used to" and "I can't get around on my own anymore" are recurring expressions said by elderly patients.

Hadj Mohamed is 83 years old. He manages his hypertension, which he says he treats regularly, without much concern. The heart attack crisis of the past 9 years is known as "big illness". This "big illness" is what worries him most:

> *"... I didn't feel this illness coming on. I used to have "tension", but I was "normal". I was treating it, but one day I had "the big blow" "الضربة الكبيرة" "the big illness". My heart just stopped beating! ... My wife took me to hospital, where they referred me to the cardiologist. I've had it for over 9 years. I don't do anything like I used to. I am very careful. It took me a long time to find the 'right doctor'...".*

These comments are a good illustration of the identification of symptoms experienced by elderly patients. Illness is qualified and interpreted according to the degree of pain, its persistence, and the sensation of discomfort it may cause. Persistent pain seems worrying enough, forcing the elderly patient to seek medical attention.

Hadja Fatma is a housewife. She is 62 years old. She has suffered from rheumatic heart disease for 5 years. But what worries her most are the "new" problems of hypertension. With unstable blood pressure causing discomfort and preventing her from performing her usual activities, she decided to seek medical attention:

"..... So, I decided to go and see him (the doctor), when I saw that my blood pressure wasn't stabilizing, and I was getting worse and worse. I felt unwell from time to time. I didn't sleep like I used to. I don't do anything like I used to. The "salat of jomoa "(prayer), I stopped it for fear of falling in the mosque. Weakness wouldn't leave me. With the slightest effort, I felt so weak, I couldn't even take two steps...".

The appearance of new signs of illness prompts the elderly patient to give meaning to these afflictions. (Augé M, Herzlich C, 1984). A label signifying illness is applied. In contrast to medical logic, where illness is represented as a purely organic disorder, the elderly patient refers it to the social problems experienced on a daily basis.

Hadj Saïd is an ex-moudjahid and former employee of the prefecture. He is 82 years old and has been hypertensive for 20 years. Hadj Saïd refers to a difficult life path to interpret the various illnesses. The feeling of "injustice" he felt every day, "the ingratitude of the state", to his sacrifices are the source of all his discomfort. His retirement is seen as the trigger for his suffering:

"... Since my retirement I've fallen to the lowest level... [...]... I've only had this apartment for all the work I've done. I am in a difficult situation! The truth and I piled it up... I piled it up in my heart, until I got sick. It made me sick. This misfortune has shattered my heart " "هذا الهم قلبي فتتلي I was fine, I had nothing. It's this misfortune of the State's ingratitude towards the sacrifices I've made that has made me ill. Through amassing... [A long sigh] ... Since then, I haven't regained my health, my heart has been getting weaker and weaker. The tension... [...]...I'm very unwell, to the point where the disease has taken hold of me, the sickness keeps hitting me ..... And I walk with a cane now .... That's how far I've come, my daughter... Since then, I've only lived thanks to doctors and medication...".

The social interpretation of the symptoms experienced differs according to each patient's social situation. The origin and causes of the illness differ. It can be a family dispute. For example, Hadj Djelloul, aged 67, has been hemiplegic since 2004. In his comments, he does not hesitate to make the connection between his stroke and an argument with a member of his family:

"..... This illness came to me all of a sudden. I had normal blood pressure. I always took my blood pressure medication. But one day, I was angry, it was boiling over in my head... [A silence] ... Following a violent argument with one of my sons-in-law. He treated my daughter badly. I was angry, extremely angry. I felt as if someone had hit me on the head with a hammer, I've never had pain like it ... My eye ..., I felt that my eye "was going to come out of its socket", but I told myself at first that it was

nothing. I took a pill for the headache, but it didn't do anything. I doubled the dose but nothing happened ... So, I tried to sleep. I thought it would make me feel better. So, I slept... And that was it, when I tried to get up, I found that my hand... My whole arm and foot didn't want to move. I was shocked. I tried and tried to move them, but nothing! That's when... [A deep sigh] ... That's when I realized I was doomed! My children rushed me to hospital. Since then, I haven't regained my health, I've lost it for good...".

Illness can also be interpreted as a perverse effect of "wear and tear" and "exhaustion". The pressure and stress experienced throughout one's working life can be at the root of deteriorating health in the elderly patient.

Hadj Taher is a former state executive (former head of daïra). He is 73 years old. He has suffered from hypertension for over 20 years, diabetes for 14 years, and hemiplegia for a year. He is married. He considers the pressure and stress inherent in his work the source of his health issues:

"I lost my health a long time ago. Working for the State did it to me. The first stage was the jihad for "El blad" and then it was work for the State. I was always moving. You know, I didn't see my sons grow up. That's what made me lose my health, I worked too hard, and you know, being a senior civil servant, there's pressure all the time. I've had high blood pressure for 20 years. It's medication for life...".

In a meaningful "a language of illnesses" (Olivier De Sardan JP. 1994), the elderly patient names the origin of his/her illness. He/she makes the connection between the symptoms identified and the problems of his/her daily life. Pain is not a simple organic issue. It also has a social significance (Freidson E, 1984).

Hadj Tayeb is 77 years old. He is retired (he worked as a laboratory agent at the university). He has suffered from hypertension for 10 years and heart problems. With his moudjahid pension and retirement, he feels satisfied. He lives with his 9 children (3 boys and 6 girls) in a three-room apartment. The only cause of his health problems is his daughters, whom he "hasn't been able to marry off". He describes his discomfort in metaphorical language that shows the depth of his suffering:

" ... Yes, my daughter, I have my children's problems, they are many! 6 girls you can imagine... [A deep sigh] None of them "could move from their immobility". One of them despaired, to the point of crying. That's my real concern. And she said, "No wedding, no job, what am I going to do? Imagine, in the old days, the daughter could stand in front of her father and say that! Never, impossible, but my daughter reached the point of despair. She tried to find a job but didn't get one, even though she has a degree. One day, she came to me and said: "Ebba, I can't take it anymore, I'm tired, I'm afraid you'll die and leave me alone, and what will become of me without you? So, I swear it's like she took a saw and cut me in half, really cut me. How do you expect me not to think about that? I think about it all the time and that's what's causing me all

the pain I'm having "rani mesaoues". These problems have weakened me. They can crush stones.

They pierced my whole body; how do you expect me not to get sick?

These different ways of expressing and interpreting illness reveal that the language in which we express ourselves about illness, in which causes, manifestations and consequences are interpreted, is not a language of the body, but a language of the individual's relationship to society (Adam P, Herzlich C, 1994). This social interpretation of illness is partly responsible for triggering "a care-seeking process" (Chrisman N J. 1977) constructed by the elderly patient and those around him/her.

It should be emphasized that chronic disease is first and foremost defined in the patient's social space. However, the relational space is an essential element in managing it. Indeed, this social event mobilizes a whole range of actors (the elderly patient's close circle of family, friends and neighbors). The absence of this relational network can be considered a limiting factor for the patient. The latter has his/her own way of dealing with this limitation.

3- Socialization strategies and/or forms of resistance:

Chronic disease is also a relational event. We emphasize the importance of interactions in the experience of illness. In the latter case, interactions with others can cause feelings of isolation. Thus, social support networks are seen as ambivalent support by the elderly patient. They can be a source of solicitation, support and encouragement for the latter, just as they can lead to relational confinement and marginalization.

Given the heterogeneity of elderly patients' situations, the absence of social support (help with information, emotional, material or financial support, etc.) can be a prominent characteristic in the management of an elderly patient's chronic disease. The latter is often forced to manage his/her illness alone. Social support can become a major factor in social inequality.

Hadj Saïd's illustration confirms this idea. He is a moudjahid and former employee of the prefecture. Aged 82, hypertensive for 20 years. He is married and lives with his son, a secondary school teacher. He gives us a good description of the situations of uncertainty, faced with the absence of support from those around him, especially his children:

".....It's very hard when you're all alone with your illness...It makes you even sicker...When I first got sick, I didn't have anyone by my side. Except this "khlika", but poor thing, she's as sick as I am... I had no one to guide me, advise me or inform me...You go to the hospital, they don't tell you anything, you get a consultation and that's it. I knew nothing about my illness. It's normal that I didn't know the doctors. I went through a lot to find a doctor...".

The absence of informational support, often mentioned by the patients, will become a major limitation, leading the elderly patient to situations of therapeutic wandering. The accessibility of information is a major factor in the social inequality of health. When information on the nature and quality of services is produced mainly within informal networks, patients

with social capital are best able to access the relevant information to choose their provider (Pauly M. Satterthwraite MA. 1981).

The absence and unavailability of family and friends, especially children, is very difficult for elderly patients.

Hadj Djelloul is a shopkeeper. He is 67 years old. He is married. He has suffered from hypertension and heart failure for 9 years. He has had hemiplegia since 2004. He has great difficulty dealing with the "ingratitude" of his children:

" .....When I think of the trouble I've gone through to raise my children... [A sigh followed by a moment's silence] ...Oh yes! And now I'm alone! Truly alone! Sick and alone...I gave them my whole life, and what do I get in return? Nothing! Absolutely nothing! A few visits from month to month. I raised them to find them by my side in this age, but...they're too busy!...".

Old age is generally characterized not only by the restriction of the relational space of the elderly person and the loss of past relationships and connections, but also by the addition and building of new ties (Ripon A, 1992).

To cope with loneliness and isolation, the elderly patient will try to develop new, active friend networks. He/she will shape his social relationships through a series of sociability strategies (Lesmann F, Nahmiash D, 1993).

Hadj Mohamed is 83 years old. He's a former taxi driver. He is married. He suffers from hypertension and had a heart attack 9 years ago. He has 3 married daughters. He has his own way of "continuing to live socially":

"...To avoid being alone all day, I put a chair in front of the door. And I sit on it. There's always someone coming to chat with me and keep me updated. But if I stay at home, I'm sure no one will come knocking on the door to visit me...".

Sociability strategies are diverse. They are defined by the individual's ability to forge new connections with others by taking advantage of opportunities (Ripon A, 1992).

Hadja Fatiha is a former cleaning lady. She is 70 years old. She is a widow and lives with her eldest son, a mechanic. Hemiplegic for 5 years following a stroke, she has also been suffering from hypertension for 12 years.

She is "on her own". She takes advantage of opportunities to make friends and obtain information that can help her with her illness. Despite her hemiplegia, she is very active:

"...I've always known how to talk to people. I'm "kafza" (resourceful). My children are busy and I don't like to be alone! So, I go out a lot. I want to get to know people and new things. My illness demands it. I take advantage of opportunities to meet other women at the bath, at the mosque, etc....That's how I've made a lot of friends...".

Occasional meetings in certain places (mosque, bath, cafeteria, etc.) help rebuild the elderly patient's relational network.

For Hadj Tayeb, the mosque is the ideal place to forge links with people. He is a former moudjahid. He is 77 years old. He worked as a laboratory assistant at the university:

"...You know! People don't like to bother with old people. People like us! (A smile and he continues) ...So I take advantage of every opportunity.... You know, meetings and all.....For example, I always make a point of praying at the mosque, when I'm feeling well. In this place, I'm the one who starts the discussion to get to know people...".

Family get-togethers are seen as vital social spaces for elderly patients, offering them a sense of continuing social life.

Hadj Mohamed is always keen not to miss these opportunities:

"...I never miss family occasions if I'm feeling well, of course. It's where you can meet people and talk to them. It gives me great pleasure when someone invites me. It proves that I still exist for them. And that I still have value for them...".

Old age cannot be understood in the singular. The heterogeneous situations of the elderly clearly shows that there is not "an old age but many old ages" (Coudin G, 2005). We cannot consider it in this negative image alone, which is a product of society. The elderly person can also produce interpretations, reasonings and strategies that can help him/her cope with illness.

Indeed, old age is often seen as a process of irreversible decline in a person's abilities, leading to loss of autonomy. However, it is the set of possible paths determined by a multiplicity of factors and offering the possibility of preserving autonomy (Pin S, 2005).

Even in situations of dependence, the elderly patient tries to maintain his/her place in the family circle and continue to play an active role in his/her immediate environment. By fighting the disease, he defends his authority and his status as head of the family.

The presence of an impairment can relatively restrict the scope of an elderly patient's activities. It cannot prevent him/her from defending and preserving his/her autonomy.

However, the patients' own words are a reminder of the importance of social interpretations of the disease in its management. Signs of illness are always socially constructed.

4- Conclusion:

Chronic disease is a social construct. It is important to stress the importance of the "network of meanings" (Massé R, 1995) attributed by the elderly patient to the disease and the various disorders that characterize it. Symptoms are described metaphorically, enabling patients to give meaning to their pathology. They produce their own semantic field to name, interpret and evaluate the illness.

This social interpretation of the patient's illness highlights the importance of the social dimension of illness. Hence, it is important to remember that the different ways of expressing and interpreting illness reveal that the language with which we speak about illness, in which we interpret its causes, manifestations and consequences, is not a language of the body, but a language of the individual's relationship to society. (Adam P, Herzlich C, 1994).

When the elderly have to manage their illness in solitude and isolation. There is a need to forge new links in order to face the challenges. Elderly patients with chronic diseases often

engage in an active, participatory approach to social life (Ripon A, 1992). They invest in physical movement and social activities.

They will try to develop new active friend networks. However, the development of relational space appears to be a relevant form of sociability strategies developed by the patient. These different forms of resistance to the effects of illness and advancing age lead us to consider the elderly person as a key player in the management of their chronic disease.

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