



## Explanatory Model of Renal Failure in the Lobi Group (Côte d’Ivoire)

Adjoumani Kobenan<sup>1\*</sup>

<sup>1</sup>Assistant Professor, Department of Sociology-Université Félix Houphouët-Boigny

<p><b>ABSTRACT:</b> On the basis of a qualitative and quantitative survey (Semi-directive interview and life story of the actors and a questionnaire) this study analyses the perceptions and the mechanisms of construction of the social links of renal failure patients with their entourage. Indeed, the extension of the life span of the actors with kidney failure is a function of the biographical ruptures of reinterpretation of the actors' self-relationship to the disease, as new behavioural codes, which must be integrated and can be supported and contained in their daily life.</p>	<p><b>RESEARCH PAPER</b></p>
	<p><b>*Corresponding Author:</b>  <i>Adjoumani Kobenan</i>          Assistant Professor,          Department of Sociology-          Université Félix Houphouët-          Boigny</p>
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### INTRODUCTION

Chronic kidney disease (CKD) is on the increase worldwide. It is characterised by an irreversible decline in renal function as evidenced by the measurement of glomerular filtration rate (GFR) or, failing that, by blood urea and creatinine levels (Pouteil-Noble V., 2001). Renal failure is a major public health problem. It has already been the subject of numerous studies and is currently the subject of a great deal of mobilisation on the part of governments and, above all, the population to work towards a good health conscience. The reflection that this phenomenon of renal failure inspires today appears to be of great epistemological interest in the sense that it is the common object of several scientific disciplines, notably legal sciences, economics, psychology and sociology.

According to hospital data, the prevalence of renal failure varies between 39 and 52% with a mortality rate of 39% in the nephrology department of the Yopougon University Hospital alone. Indeed, most patients arrive in nephrology in emergency and at the terminal stage of the disease, requiring immediate dialysis so that at present, our country records more than 500 patients treated by haemodialysis, more than half of which in the three public centres (SAMU,

University Hospital Centres of Treichville and Yopougon) (Magazine santé N°0007-April 2015).

In relation to this, patient care integrates the psychology of the patient and is no longer focused solely on his or her symptoms but tries to help the patient to live with his or her illness and to manage the consequences on his or her personal, family, social and professional life. People with kidney failure need psychosocial assistance and special medical care. Moreover, they have to restrict their daily activities and social practices because of the disease, in order to devote part of their time to the treatment of the disease. Consequently, the restriction of activities and social practices tends to lead to a change in social roles and to a bifurcation of identity. Indeed, people with kidney failure are clearly forced to be less involved in raising their children and in sharing activities related to the upkeep of the household, and they adopt a particular diet for this purpose.

On the basis of the above, i.e. the relationship between people with kidney failure and their social environment how is the social link between people with kidney failure and their cultural environment constructed?

A state of knowledge on the issue provides scientific explanations on the links between patients and their entourage in a context of medical follow-up and permanent assistance. Among others, we can note the works of (ThomasP. (2007), Ziegle M. (2007), Paraponaris A. (2006), Plouin P. (2007), Bontout O. (2002), Colin C. (2002), Kerjosse R.(2002) Davin (B.), Verger P. (2004), Colin C. (2003), Guralnik (J.M.) *et al.* (1989) These authors approach the situation experienced by the patient's entourage as a major problem that can articulate the way to respond to the patient's disorders and symptoms as well as to overcome the difficulties of the assistance in organising itself insisting on its lack of availability. At the same time, the population of carers is itself subject to strong demographic pressure: fewer practising doctors, feminisation of the profession, less interest in private practice. These demographic prospects reveal the risk of a social divide, between the need for help and the potential supply of informal help.

## I-THEORETICAL AND METHODOLOGICAL APPROACH

The understanding of the mechanisms of construction of the social links of patients with kidney failure to their social environment suggests a theoretical model for the present study. For Lemieux Cyril (2007) and Stephen Pfohl (1993), the constructivist approach focuses on the historical and social processes of meaning making and their feedback effects on "social reality". In relation to this, the constructivist approach, as a theoretical model of analysis, seems appropriate for understanding, in specific socio-historical contexts (here, that of the patient in a family care situation), how the distinction of the disease is posed by the actors, what meaning it takes on and what consequence it

seems to have on the social experience and family care of the kidney failure patient.

In order to study the response of the Lobi, their perceptions of renal failure and the construction of resilience in the face of renal failure, we opted for a qualitative approach using appropriate survey tools, in this case documentary analysis and semi-structured interviews. The data collected from the above-mentioned actors was analysed under the prisms of Karl Popper's (1956) dialectical method and methodological individualism. The combination of the dialectical method and Popper's theory made it possible to understand the issues at stake in the different positions of the actors in their interdependent relationships linked to the care of their relatives suffering from renal failure, but above all in the search for therapeutic solutions.

## II-RESULTS

Renal failure and the representations attached to it, as well as the relationship between the patient and his or her relatives during the illness are changing and complex. The family is confronted with the chronic illness of their loved one suffering from renal failure, and this helps to decipher what is at stake in their relationship with the patient.

### 1-Social characteristics of respondents

The analysis of the social characteristics of the respondents is important because. The analysis of the social characteristics of the respondents is important because of the use of these results in the explanation of renal failure. The present study concerns age, sex, level of education, professional status, marital status and religion.

Summary table of respondents' social characteristics				
Age	( Under 15 years old)	(15 years - 30 years)	(30 years - 45 years)	(45 years and over)
	0	7	20	33
Gender	Male		Woman	
	40		20	
Level of education	Primary	Secondary	University	Not in school
	6	26	3	25
Marital status	Married / Single		Widowed/Divorced	
	10 M / 40 C		2 V / 8 D	
Religion	Christian		Muslim	
	45		15	
Employment status	Cultivator	Employee	Unemployed	Other
	9	11	36	4

Source: (Our field, 2022)

We note that 33 out of 60, or 55% of our respondents are aged 45 and over. Indeed, we realise that from this age onwards, people are mature enough to take care of a relative suffering from a chronic illness, but above all to give their experiences of building resilience to chronic illness. This is unequivocally the reason why A.M, a traditional carer, says: "The older the parents are, the easier it is to understand the disease and to follow it up" (Testimony of A.M, traditional carer).

However, out of the sample of 60 respondents, 66.66% of men and 33.33% of women participated in the study. We interviewed both sexes because perceptions of the explanation of the causes and improvement of care could vary between men and women.

### Y. S said

"We women always support our relatives suffering from chronic diseases. Women do not abandon their sick relatives. For me, the causes of kidney failure are the cumulative pain of hard work. It is the weight of the pain that destroys the kidney."

Nevertheless, it should be noted that, apart from women, for men the etiology of kidney failure is linked to the consumption of alcoholic products, but above all to hard work requiring a lot of physical and intellectual effort. Legal marital status refers to a person's marital status under the law: single, married, widowed, divorced. In the case of this study, our target population is heterogeneous as it is composed of men and mainly women. It is made up of two statuses: married and single. This analysis shows, not surprisingly, that single people represent 66.66% of the respondents, as opposed to 16.66% of married respondents.

With regard to the level of education, we find that 43.33% of the respondents in our study population have at least secondary education and 41.66% have no schooling. This situation favours knowledge of the disease and its implications. However, the fact of having such a high rate of non-educated people could constitute a handicap for a good follow-up and treatment of people suffering from renal failure in a family care situation.

Religious beliefs also play a considerable role in the daily lives of patients and their ability to build resilience. Of the 60 people surveyed, 75% were Christians and 25% were Muslims. We understand that each of these religions influences the choice of the therapeutic itinerary but reinforces the capacity of resilience of individuals in the face of the disease of renal failure. This argument illustrates:

"I am a Christian. Everything that happens to us is God's will. For me, kidney failure would be God's punishment for the wicked." Furthermore, in the

professional category, 60% of the respondents are unemployed.

### 2-Social representation of the renal failure patient: a perception seen from the patient's own perspective

The results show that for patients with chronic renal failure, debilitation, fatigue, incapacity and body changes are associated with treatments. Mainly to treatments of patients in dialysis situation. For this reason, treatments are perceived in a negative way: "When I was informed about my illness, I was very depressed. At that moment, I thought I had lost everything. Testimony of J.V., 38 years old and suffering from kidney failure. "I told myself that this disease could only affect rich people and people of advanced age. Today I am one of the people affected". Testimony of A.K. 33 years old "I used to love the show and life and I had several projects, and now everything has collapsed in one day" Testimony of Y.A. 42 years old with kidney failure.

In view of this, the announcement of the disease to the patient is perceived as serious, chronic or as a handicap and remains engraved as terrible news, which can mark the end of a life where living the disease was absent or even unthinkable. Indeed, the announcement of the disease affects the patient as well as his relatives and causes a psychological trauma, the extent and characteristics of which depend on the personality of each individual, his history, the period of life he is going through and, above all, the family ties and balance.

Moreover, after treatment, patients find it difficult to adapt to the treatments, particularly because they are associated with significant side effects, which do not necessarily lead to recovery but which impose time restrictions due to their pace, as well as water and food restrictions. Fatigue is one of the most reported side effects. In addition, fatigue due to dialysis treatments has an effect on the ability to carry out various daily activities. Finally, dialysis treatments are often represented as a period of waiting and transition to transplantation.

### 3-Biographical rupture of the renal failure patient: reinterpretation of social roles

Michael Bury's concept of biographical rupture develops the idea that a person affected by a chronic illness goes through a process of rupture that allows him or her to reconstruct. First, there is a breakdown in the behaviours that are taken for granted. Secondly, there is a breakdown in the self-explanatory system, which will require the person to undertake a review of their biography and self-definition.

Chronic renal failure is perceived as an unexpected event that disrupts the perception of patients, as well as all spheres of their existence.

M.G., 33 years old, is trying to adapt and accept the ravages of this disease which has been eating away at him for more than 1 year and 6 months: "Before the disease, I was like young people of my age, today I have become aware of the seriousness of the situation I am living in, I know that it is for life, the treatment under machine, I have accepted this and I am making do with it until one day I have the transplant.

The experience of the disease is analysed as a process that is composed. Indeed, the actors reinterpret their relationship to themselves between survival and death in a different way. They are no longer the same; nothing is the same as before. From now on, the actors will have to adapt to their new life, adopt new habits at all levels.

#### **4-Reconstruction of the links between the parents and the patient between psychological trauma and the feelings of the relatives around the renal failure**

The illness of renal failure is accepted a priori by the patient's relatives as serious information that conveys an omnipresent fear of death and may introduce unease within the family. Even if death is never announced before the terminal phase. Despite the desire to give a place to the ritualisation of death and to accompany terminally ill patients with humanity to their "last resting place", it is clear that dealing with death, its context and questions about it are still taboo in our society. Mother of a patient: 'My first daughter contracted the disease at the age of 42. When she learned of the illness that distressed her, she immediately preferred death. She no longer found it useful to live, because what we had learned about this illness was terrifying. We were all afraid for her - would she live or not until we were reassured by the doctor that she could live even with the disease for a long time until she had the possibility of a kidney transplant. Thus hope was reborn.

Parents are now faced with a double trauma: the trauma of the death of a close relative and that of the death of a child, which goes against the usual order of things (parents die before the child). The death of a child is in itself a paradox that upsets our very conception of death, which logically should only occur at an advanced age (Brognon, 1998). As soon as the diagnosis is announced, parents are confronted with questions and concerns related to their desires and projections for the child. "Life is unfair nowadays; the child who has to bury his parents is the one who leaves before them, leaving them in terrifying anguish. It is not acceptable if the parents start to bury their child, it is a failure", said H.L., a patient's parent

These comments touch on the difficulty of continuing to invest in a being who may not respond to their desire for perpetuation and who risks abandoning them, thus confronting them with their powerlessness.

However, family solidarity strengthens the family bond in order to give the patient hope for life.

#### **5-The role of the relative in assisting the patient as a prerequisite for the patient's social rebirth**

The figures closest to the patient in terms of relatives include, in addition to the traditional family unit (father mother brother sister etc.), those of separated or blended families (sometimes with differences in perception), even non-relatives: a friend, a neighbour, a doctor or a family carer who has also become a confidante.

Indeed, the importance of relatives is essentially measured for three main reasons: firstly, because they have knowledge of the situation and experience of it, which makes them allies of the carer; secondly, because they generally remain in contact with the patient and are expected to facilitate the patient's reintegration into his or her living environment; and thirdly, but also because they themselves suffer from the situation and may therefore be in need of care. "We cannot reject our blood because of an illness. That is why we live with it. So we are caring for him because of his diet. We have hope by the grace of God that he will get well. But we don't know when". In view of the above, emotional support predominates in the relationships, gives hope and allows the consolidation of the links around the patient.

#### **6-Degrees of involvement of families: a partnership of assistance not understood as a ready-made formula that could be applied everywhere and always in the same way**

The results of the study show that there are differences in the care needs of the patients, and therefore also in the degree of involvement of the families. It is always a case of 'tailor-made' collaboration and the intensity of this collaboration can vary from family to family.

Indeed, the family context seems complex and the relationship with the patient is sometimes tense and deteriorated.

#### **7-Occupational, restriction of daily activities due to the disease**

Kidney disease affects people's ability to carry out activities of daily living and has the potential to significantly influence the demand for health services. It increases dependency on others and reduces quality of life, including access to opportunities for social and economic participation and a sense of exclusion.

"I used to work in a local company, I did not work for more than three months at the beginning of the illness, my boss paid me something, but now I get nothing because physically I cannot work. This affects me enormously, I feel isolated, and I am a burden without work.



In such cases, the renal failure patient is associated with an increased risk of depression and institutionalisation and the patient may succumb to premature mortality.

### **8-Socio-familial crisis: patients are clearly no longer able to fulfil their marital duties and are forced to be less present in the education of their children**

For both men and women with kidney failure, kidney failure leads to a loss of sexual desire. Medical information shows that men have more difficulty in achieving an erection, while women suffer from vaginal dryness and have more difficulty in experiencing pleasure during sexual intercourse. These sexual disorders are usually the result of a combination of several factors. Fatigue due to anaemia and a lack of sex hormones are treatable causes in both men and women. In men, erectile dysfunction can be caused medically by damage to the nervous system or by impaired blood flow to the penis. All these factors have a devastating effect on the sociological level, and can constitute an additional source of tension in an already tense intimate relationship, which can weaken socio-familial ties: "I was married with three children and I worked in a micro finance company in Abidjan until the day I was informed that I was suffering from renal failure. I can tell you that my husband abandoned me today for another woman because of my situation. Testimony of A.D., CKD patient.

### **III-DISCUSSION OF THE RESULTS**

The study was based mainly on the theory of social constructivism by Lemieux Cyril (2009) and Stephen Pfohl (2008), in order to understand, in specific socio-historical contexts, how the distinction of the disease is posed by the actors, what meaning it takes on and what consequence it seems to have on the social experience and the management of the renal failure patient.

We can therefore conclude that chronic renal failure is socially represented as a fatal disease. However, the extension of the lifespan of actors with kidney failure is a function of biographical ruptures that reinterpret the relationship with oneself and the disease as new behavioural codes that must be integrated and can be supported and contained by the said actors. This perspective of social reintegration of the patient into normal working life must be supported by the socio-affective links of assistance and accompaniment of the patient in a social context of family solidarity. On this basis, the present study is similar to the results of Colin C. (2003), Guralnik (J.M.) *et al.* (1989) showing that the chronicity of the disease is addressed by new forms of intervention, for which families may be called upon, but not necessarily prepared, particularly through home hospitalisation and daily assistance: from now on, kidney patients will have to adapt to their new life, adopting new habits at all levels. Moreover, the

perception of the death of the child before the biological parents constitutes in itself a paradox which upsets the conception of death which logically should only occur at an advanced age (Brognon Ph., 1998), but the study extends this idea by questioning the problems of investment, articulating the desire for social reproduction and the perpetuation of achievements which may be collapsed by the disease.

Finally, the study identifies sociological implications at the professional, financial and family level that may constitute an additional source of tension in an already strained intimate family relationship, with complaints and whispers on the one hand relating to the burden of the sick person often perceived as socially useless (non-productive for his or her family). From this point of view, our results support those of Fougeyrollas *et al.* (1998) showing that the expectations and needs of individuals and the population as well as the management of home care services within a system allow for an ever more important place to be given to the patient through concerted, collective action in favour of people who are unable to look after themselves.

### **CONCLUSION**

All in all, this study aims to contribute to the understanding of the mechanisms of construction of the social links of patients with kidney failure with their entourage. Indeed, the scientific challenge of this work is to show that the realization of the life habits of a renal failure patient is determined by the interaction between the individual and socio-environmental factors of the family. Furthermore, it can be stressed that lifestyle habits refer to the current activities and roles that individuals occupy in their social life context. Therefore, the biographical break that occurs just after the illness allows the actor to redefine himself socially.

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