

Building the Social Link Between Patients With Renal Insufficiency and Their Family and Friends in the Samu-Abidjan Hemodialysis Service

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Abstract: On the basis of a qualitative survey (semi-directive interview and life story of the actors) this study analyses the mechanisms of construction of social links of patients with renal insufficiency with their family and friends in the SAMU-ABIDJAN. It is based on the theory of social constructivism and leads to the result that the extension of the life span of renal impaired individuals in their terminal phase is a function of biographical breaks in the self-interpretation of actors' relationship to the disease, as new behavioural codes, which must be integrated and can be supported and contained in their daily lives. However, this prospect of the patient's social reintegration into normal working life following a kidney transplant process from a compatible donor on hold must be consolidated by the socio-emotional links of assistance and support for the patient in a social context of family solidarity.

Keywords: kidney failure, biographical rupture, kidney transplant, Samu-Abidjan, socio-emotional links

Introduction

Chronic kidney disease (CKD) is on the rise worldwide. It results in an irreversible decrease in renal function as evidenced by the measurement of glomerular filtration rate (GFR) or, failing that, by blood urea and creatinine (Pouteil-Noble V., 2001).

In Côte d'Ivoire, CRI is increasingly present in hospitalization services, reflecting the high prevalence of kidney risk diseases and posing management problems. CRI, which is an ultimate term for the evolution of any kidney disease, is formidable and remains a common cause of death. 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 has more than 500 patients treated by hemodialysis, more than half of them in the three public centres (SAMU, University Hospital Centres of Treichville and Yopougon) (Health Store N°0007-April 2015).

In this respect, patient care integrates the psychology of the patient and is no longer focused solely on his symptoms but tries to help the patient to

live his illness and to manage the consequences on his personal, family, social and professional life. Thus, with reference to Act No. 62-248 of 31 July 1962 establishing a Code of Medical Ethics in articles 28 and 29: "The doctor must always draw up his diagnosis with the greatest care, without counting the time it costs him to do so, and, if necessary, by seeking help or assistance, as far as possible, from the most informed advisors and the most appropriate scientific methods... to the maximum extent compatible with the quality and effectiveness of care and without neglecting his duty of moral assistance towards his patient...".

While the code of ethics indicates that the medical profession as a whole can collaborate as long as it is driven by the same desire to improve the situation of patients through close assistance, there are practical disparities. First, the number of nephrology specialists is in deficit in relation to the number of patients undergoing dialysis. For example, 300 specialists are currently in practice for 5000 patients with renal insufficiency, i.e. 6%, and yet the hemodialysis centres have only 177 machines (APA, April 2017). Thus, SAMU-ABIDJAN has 4 centres and 40 dialysis stations. In addition, it is noticeable that not all health professionals intervene, and in all circumstances in the interest of the patient (in this case nurses and room girls prioritize daily exchanges on

social networks via mobile phones and small chats to the detriment of the patient), while on the other hand patients with kidney failure need psychosocial assistance and medical follow-up individual.

Moreover, they are forced to restrict their daily activities and social practices due to the disease, in order to be able to devote part of their time to dialysis treatments. Consequently, the restriction of social activities and practices tends to lead to a change in social roles. Indeed, patients are obviously forced to be less present in the education of children, in the sharing of activities related to the maintenance of the household of the household, they adopt for this purpose a particular diet. On the professional level, he cannot work full-time, so he is no longer economically profitable. In this health respect, two (2) dialysis sessions are scheduled per week for at least four (4) hours under the machine.

On the basis of the above, i.e. the relationship between patients and health professionals, on the one hand, and the relationship between patients and their social environment, on the other hand, how is the social link between patients with renal insufficiency and their family and friends in the hemodialysis service constructed?

A state of knowledge on the subject, provides scientific explanations on the links between patients and their entourage in a context of medical follow-up and permanent assistance. Among other things, we can note the work of (Thomas P. (2007), Ziegler 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), who approach the situation experienced by patients' relatives as a major problem that can articulate how to respond to patients' disorders and symptoms than to overcome the difficulties of assistance in organizing themselves, insisting on their lack of availability, while at the same time, the population of carers is itself subject to high demographic tension: fewer doctors in practice, a feminization of the profession, a lesser interest in liberal medicine. These demographic perspectives reveal the risk of a social divide between the need for assistance and the potential supply of informal assistance.

In addition to this, the chronicity of the disease addressed by the latest authors also calls for new forms of intervention, for which families can be solicited, but not necessarily prepared. This is particularly the case for home hospitalization (HAH), which is part of alternative care structures to full hospitalization. It involves a coordination of professional workers and a role of supervision and participation in everyday life, which underpin the economic interest of the formula,

through a transfer of charges, from collective solidarity to the family. Thus, the relative, in a society under demographic and epidemiological pressure, is emerging as an actor in the making. Finally, Darmon M.'s (2003) book on anorexia goes much further in taking into account the role of the patient. He is one of the few to present the career of an acting patient, doing real work on his body and implementing socially situated perceptions. However fruitful it may be, this perspective remains closely linked to the fact that the pathology in question is essentially characterized by practices: the individual construction dimension highlighted is therefore not necessarily generalizable to other diseases.

This grid, which is herewith elaborated, attempts to highlight the issues of care and permanent assistance for patients in chronic situations. However, it does not address in a singular way the way in which social links are built between patients, their carers and their relatives, who seem to be essential actors in such close relationships. In this perspective, by adopting a constructivist approach from Lemieux Cyril (2009) and Pfohl Stephen (2008), the general objective of this study is to understand the social mechanisms of construction and deconstruction of the social link between patients with renal insufficiency and their families and friends in the hemodialysis service of SAMU-ABIDJAN. Specifically, this study consists of: i) identifying the ideological references that structure the nature of the relationship between patients and patients ii) describing the relationship between patients and parents, i.e. anyone who accompanies their patient for care iii) explaining the relationship between patients and parents, i.e. behaviour after dialysis at home.

1. Theoretical foundations: social constructivism

The understanding of the mechanisms for constructing the social links of patients with renal insufficiency to their social environment suggests a theoretical model for this study. For Lemieux Cyril (2007) and Stephen Pfohl (1993), the constructivist approach focuses on the historical and social processes of meaning production and their effects in turn on "social reality". Relatively speaking, the constructivist approach, as a theoretical model of analysis, seems appropriate to understand in specific socio-historical contexts (here, that of the patient in dialysis), how the distinction of the disease is made by the actors, what meaning it takes and what consequence it seems to have on the social experience and the care of the renal insufficiency patient.

2. Methodology and methodology

This study was conducted in Abidjan. It was essentially qualitative and consisted of life stories and semi-structured interviews with: 11 patients on dialysis, 8 parents of patients and 9 attendants (doctors, nurses,

ward girl). It took place from 26 September to 15 October 2018. The choice of the actors interviewed was made systematically at SAMU-ABIDJAN. This was a selection that was made with the attending physicians. The approach was to use the attending nephrologist to clarify the purpose of the study. He then took on the task of informing and explaining our instructions to patients according to the objective of the study. In addition, each patient under medical recommendation referred us to the parent in charge of assisting the patient.

3. Results

3-1. Social representations of renal failure and the construction of links between care providers and patients

Chronic kidney failure and the representations attached to it, as well as the relationship between the patient and his or her family and friends in the disease, are changing and complex. The attending physician is confronted with the chronic disease of the patient suffering from renal insufficiency, allows to decipher what is at stake in the relationship between the patient and each of his relatives, while maintaining the patient in his central place in the medical relationship

3.1.1.1. Social representations of the renal insufficiency patient: a perception seen from the perspective of the treating person

The actors' speeches reflect the idea that respect for the dignity and privacy of the individual is at the heart of the medical profession's ethical charter. Thus, all health personnel must pay the utmost consideration and attention to everyone, regardless of their physical or mental condition, culture, social origin, political opinions and age. Indeed, hemodialysis is considered as one of the treatments for end-stage renal disease (ESRD) that allows patients to survive this pathology, which is perceived as fatal.

This treatment is a real substitution for kidney function. Indeed, the patient is attached to a machine that aims to pump blood, filter it in order to restore it, remove toxic substances and excess fluid that clogs the body. To do this, as one attending physician testifies: "The patient will have to comply with this purification which takes place twice a week for four hours notes that the patient's weight can increase the duration of time under the machine "About K.M. attending physician.

In view of this, there is unanimous agreement among treatment providers that CRI is a fatal disease. However, thanks to medical advances, patients' life expectancy can be extended. They can even recover their recovery definitively. However, these actors must be able to comply with the injunctions of regular treatment under a hemodialysis machine, and better benefit from a kidney transplant.

Moreover, even if the care of the patient is intended to be close to the principle of deontology, it is nevertheless devoid of a fundamental principle as expressed in the Charter: that of respect for human dignity. The following verbatim comes to corroborate this state of affairs: "Here the attending physicians are insufficient in number, but the little that is assigned to our centre is not regular and our care leaves much to be desired; it disturbs us a lot"

3.1.1.2. Social representation of the renal insufficiency patient: a perception seen from the perspective of the patient himself

The results show that for patients with chronic renal failure, debilitation, fatigue, disability and body changes are associated with treatment. Mainly to the treatment of patients in dialysis situations. For this reason, treatments are perceived in a negative light: "When I was informed of the illness I was suffering from, I was very depressed. At that moment, I thought I had lost everything. Testimony of J.V. 38 years old with kidney failure. "I thought that this disease could only affect the rich and the elderly. Today I am one of the people affected " Testimony of A.K. 33 years old " I who loved the show and life I had several projects here that everything collapsed in a single day " Testimony of Y.A. 42 years old renal failure.

In view of this, the announcement of the disease in the patient is perceived as serious, chronic or a disability and remains engraved as terrible news, which may mark the end of a life in which living with the disease was absent or even unthinkable. Indeed, the announcement of the disease affects the patient and his relatives a priori and causes psychological trauma, the extent and characteristics of which depend on the personality of each individual, his or her history, the period of life he or she is going through and above all on family ties and balances.

In addition, at the end of treatment, patients have difficulty adapting to treatment, 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 affects the ability to perform the various daily activities. Finally, dialysis treatments are often represented as a waiting period and a transition to transplantation.

3.1.2. Caregivers' perceptions of relatives and their patients

The discourse of the entire medical profession, which constitutes one of the first circles of family members' entourage, has a favourable opinion of their

patients' relatives. Indeed, for medical professionals, the role of the family and friends in the care of sick people is likely to develop and consider that the family and friends are more visible and interactive with them. The potentially beneficial role of the family and friends in the care of the sick person is clearly affirmed and can prove to be a true partner in care. As such, they recognize its beneficial role in terms of health economics. As one discussant stated: "The contribution of the family and friends could help to reduce health care costs. ». That said, while the presence of the family and friends is considered beneficial for the patient as a whole, it is not without its difficulties. Among the ones that professionals most often report witnessing are: the exhaustion of the environment and its intrusiveness towards the patient.

3.2. Relationships between patients and parents, i.e. anyone who accompanies their patient for care

Close relatives are involved in the history of the disease. This disrupts family balance and power relations. Thus, the disease inflicts a deep wound on the patient, but it also represents a psychological trauma for the loved ones, depending on the bond that unites them to the patient (spouse, children, brothers, cousins, etc.), their personalities, their history and the moment of life they are going through.

3.2.1. Biographical break-up of the renal insufficiency patient: reinterpretation of social roles

Michael Bury's concept of biographical rupture develops the idea that a person with a chronic disease goes through a process of rupture that then allows them to rebuild themselves. First, there is a rupture in self-evident behaviour. Then, there is a breakdown in the system of self-explanation, which will require the person to review his or her biography and definition of himself or herself.

Chronic kidney disease is perceived as an unexpected event that disrupts patients' perceptions and all aspects of their lives.

M.G. 33 years old, tries to adapt and accept the escapades of this disease that has been eating him for more than 1 year 6 months: "Before the disease, I was like young people of my age, today I became aware of the seriousness of the situation I am experiencing I know that it is for life the treatment under machine, I accepted this and I deal with it until one day I do the transplant".

The disease experience is analyzed as a process that is composed. Indeed, 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 lives, adopt new habits at all levels.

3.2.2. Reconstruction of the links between parents and patients between psychological trauma and the feelings of relatives around renal failure.

Renal insufficiency disease is accepted a priori by the patient's parents as serious information that conveys an omnipresent fear of death and can introduce discomfort into the family. Even if death is never announced before the terminal phase. Despite the desire to restore ritualization around death and to accompany terminally ill patients with humanity to their "final resting place", it must be noted that addressing death, its context and the questions about it is still taboo in our society this extract from S C. Mother of a patient: "My first daughter contracted the disease at the age of 42. When she learned of the evil that was distressing her, she immediately preferred death, she no longer found it useful to live, because what we had learned from this disease was terrifying. We were all afraid for her to live or not until we were reassured by the doctor that she could even live with the disease for a long time until she had the opportunity to receive a kidney transplant. Thus hope is reborn. »

Parents are already facing a double trauma: the trauma of the death of a loved one and the trauma of the death of a child that goes against the usual order of things (parents die before the child). The death of the child is in itself a paradox that upsets our very conception of death, which should logically only occur at an advanced age (Brognon, 1998). As soon as the diagnosis is made, parents are confronted with questions and concerns related to their wishes and projections about the child. "Life is unfair these days 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 parents start burying their child it is a failure" says H. L parents of patient

These remarks concern the difficulty of continuing to invest a being who may not respond to their desire for perpetuation and who may abandon them, thus confronting them with their powerlessness. However, family solidarity strengthens the family bond in order to give the patient a hope of life.

3.3 Social behaviour after dialysis at home: a social recomposition of the relationship between patients and parents

The period of return home after hospitalization radically disrupts the established order, with new role distributions. The people around them are then called upon to take important decisions, sometimes in a hurry and most often without any prior preparation. Insidiously, the long-term evolution of the renal insufficiency patient will increasingly strain the family

and friends to the point of leading to a constraining and often repetitive workload.

3.3.1. The role of the family member in assisting the patient as a prerequisite for the patient's social rebirth

The figures closest to the patient about parents take into account, alongside the traditional cell (father-mother-sister etc.), those of separated or reconstituted families (sometimes with differences in perception), even unrelated persons: a friend, a neighbour, a doctor or a family assistant who has also become a confidant.

Indeed, the importance of relatives is essentially measured for three main reasons: first, because the relatives have a knowledge of the situation and an experience of the experience that makes them allies of the caregiver; second, because they generally remain in contact with the patient and are expected to facilitate his or her reintegration into his or her living environment; and third, because they themselves suffer from the situation and may therefore require care. "We cannot reject our blood because of illness. That's why we live with him. So we are taking care of him because of his diet. We have hope by the grace of God that he will heal. But we don't know when?". In the light of the above, emotional support predominates over relationships, gives hope and helps to strengthen the bonds around the patient.

3.3.2. Degrees of family involvement: an assistance partnership not seen 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 patients, and therefore also in the degree of involvement of families. It is always a 'tailor-made' collaboration, the intensity of which may vary according to the family.

Indeed, the family context seems complex and relationships with the patient are sometimes tense and degraded.

3.3.2.1. At work, restriction of daily activities due to illness

Renal failure affects individuals in their ability to engage in everyday activities and they have a significant potential to influence the demand for health services. It increases dependence on others and reduces quality of life, particularly through access to opportunities for social and economic participation and a sense of exclusion.

"I was working in a local company I did more than three months without working at the beginning of the illness my boss was paying me something today nothing more because physically I am not working. It

affects me enormously I feel isolated I am a workload without work". In such cases, the renal failure patient is associated with an increased risk of depression and institutionalization so the patient may die of premature mortality.

3.3.2.2. On the dietary level, adoption of a special diet

An appropriate diet is recommended for patients with renal insufficiency to whom they will have to follow to avoid complications. Thus, with the help of medical support and therapeutic education, each patient can adopt the appropriate diet for his or her state of health. However, difficulties are noted in situations where family financial conditions cannot always meet the needs of the child: doctors have asked me to limit my drinks to 750ml / 24h and my consumption of salts (at the risk of being thirsty and increasing water consumption) we must have two menus a day and the family budget increases and because of this complaints and murmurs are heard daily".

3.3.2.3. Socio-family crisis: patients can clearly no longer fulfil their conjugal duty and are forced to be less present in the education of 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 getting an erection, while women suffer from vaginal dryness and have more difficulty in experiencing pleasure during sex. These sexual disorders are usually the result of a combination of several factors. That is, fatigue due to anaemia and sex hormone deficiency are treatable causes for both men and women. In men, erectile dysfunction can be medically caused by damage to the nervous system or impaired blood circulation in the penis. All these factors have a devastating sociological effect that can constitute an additional source of tension in an already tense intimate relationship, which can weaken socio-family ties: "I was married, mother of three children, I worked in a micro-finance institution in Abidjan until the day I received the information that I was suffering from kidney failure. I can tell you that my husband abandoned me today for another woman because of my situation. "Testimony of A.D. sick IRC.

4. Discussion of the results

This study, which aimed to understand the social mechanisms for building social cohesion between patients with renal insufficiency and their families at the SAMU-ABIDJAN hemodialysis service, produced the following results:

First, it was necessary to identify the social representations of renal failure in the construction of social ties. Then, the relationship between the patient and the accompanying parent of the patient for his or

her care was highlighted. Finally, the article helped to identify the social behaviours of recomposition relationships between patients and parents.

The study relied mainly on Lemieux Cyril's (2009) and Stephen Pfohl's (2008) theory of social constructivism to understand, in specific socio-historical contexts, how the distinction of disease is posed by actors, what meaning it takes and what consequence it seems to have on the social experience and care of the renal impaired patient. It can therefore be concluded that chronic renal failure is socially represented by medical specialists and patients with renal insufficiency, as a fatal disease. However, the extension of the life span of renally impaired actors in their terminal phase depends on biographical breaks that reinterpret the relationship to oneself and to the disease as new behavioural codes, which must be integrated and can be supported and contained by these actors. However, this prospect of the patient's social reintegration into normal working life following a kidney transplant from a compatible donor must be supported by the socio-emotional links of assistance and support for the patient in a social context of family solidarity.

On this basis, this study is close 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 can be approached, but not necessarily prepared through home hospitalization and daily assistance: from now on, the renally impaired will have to adapt to their new lives, adopt new habits at all levels. Moreover, the perception of the child's death before the biological parents is in itself a paradox that disrupts the conception of death, which should logically have occurred only in old age (Brognon Ph., 1998), but the study extends this idea by examining investment problems, articulating the desire for social reproduction and the perpetuation of achievements that can be destroyed 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 tense intimate family relationship, with complaints and murmurs on the one hand relating to the weight of the patient, often perceived as socially useless (unproductive for his or her family), and on the other hand to the weight of the patient. From this point of view, our results reinforce those of Fougeyrollas et al (1998) showing that the expectations and needs of individuals and the population as well as the management of home services within a system make it possible to give an ever more important place to the patient through concerted, collective action in favour of people with a disability to take care of themselves.

5. Conclusion

In total, this study is intended to contribute to the understanding of the mechanisms for building social bonds between patients with renal insufficiency and their families and friends. Indeed, the scientific issue of this work consists in showing that the realization of a kidney failure patient's lifestyle habits is determined by the interaction between individual and socio-environmental factors in the family. It should also be noted that lifestyle habits refer to the current activities and roles that individuals occupy in their social life context. From then on, the biographical rupture occurring immediately after the illness allows the actor to redefine himself socially. Thus, the social rebirth he demonstrates is described on a scale from patient participation to final healing through kidney donation. This is an important contribution of this study: the disability situation resulting from renal failure can be controlled and supported by the interaction between the characteristics of this individual (the renal failure patient) and the context in which he or she evolves.

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