

# An Autoethnography of a Patient with Kidney Renal Failure – How Experiences and Social Ties Promote Therapeutic Mobility

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## ABSTRACT

*This paper deals with the determinants that encourage therapeutic mobility from Senegal to France. I am both a patient and a researcher and my thesis focused on how health professionals make decisions to refer patients to a dialysis method. I also underlined how patients with kidney failure construct their choice of dialysis method. As a patient in Senegal, a low income country, I experienced some difficulties due to insufficient human resources in the health sector, the little number of dialysis centers, medical pluralism and low performance of the health system.. Choosing a dialysis method depended on many factors such as doctors' opinions, my family's approach and my student status at that time, among other things. That situation resulted in the involvement of health professionals, of my family, who both talked me into going to France in order to get a kidney transplant. Therefore, I will analyse therapeutic mobility as the outcome of social factors and personal experience beyond social bifurcations. Then, I propose here, from my experience, how to move from low performance health system (Senegal) to a high performance one (France) through an autoethnography analysis.*

**Keywords:** *autoethnography, reflexivity, social bifurcation, therapeutic mobility, chronic kidney disease.*

## Introduction

Health choices are perceived as constructed and resulting from processes<sup>1</sup>. These health choices (such as decisions) are shape through the trajectories of patients<sup>2</sup>. The latter are placed in social or medical relations which influence the nature of their care. Patients are involved in a logic of participation in health decisions whose autonomous choice is built through a dependence on various actors<sup>3</sup>.

Health democracy in France along the law of March 4, 2002 and the promotion of shared decision-making in Anglo-Saxon countries by some researchers<sup>4</sup> both advocate an increased participation of patients in decisions by reducing medical paternalism which subjected them to the doctors' authority<sup>5</sup>. An interprofessional form of shared decision making<sup>6</sup> as well as research undertaken in Africa, have demonstrated the major part played by the family and relatives in both decisions and care<sup>7,8</sup>.

Besides, the health status of the patients and the quality of care are related to the performance of the local healthcare system and to the economic problems faced by

the populations who are being treated. In some African countries, there are economic determinants that do not allow patients to benefit from good care<sup>9</sup>. In addition, socio-cultural contexts define how patients are cared for. These shortcomings and the search for better quality of care cause some patients to emigrate<sup>10</sup>.

This article deals with my care path analyzed through social bifurcations and autoethnography. This approach will make it possible to understand the reasons for my therapeutic mobility in France in order to benefit from a renal transplantation. It outlines the determinants of choice of a dialysis method (hemodialysis, peritoneal dialysis) and finally the choice of renal transplantation concretized by my emigration to France.

## Material and methods

### *Autoethnography*

In the Anglo-Saxon literature, the term »autoethnography« is used by a number of researchers<sup>11–13</sup>. It is also known as »autobiographical sociology«<sup>14</sup>. For the latter,

self-analysis makes it possible to highlight what makes the person both similar and different from others. According to Ellis and Bochner<sup>15</sup>, autoethnography is: »...an autobiographical genre of writing that displays multiple layers of consciousness, connecting the personal to the cultural«. Having a narrative approach with a reflexive attitude does not mean writing an autobiography<sup>16,17</sup> because I narrate events so as to provide a sociological explanation for my health choices. Confronting the social phenomena related to the theories and those defended mainly by sociologists and anthropologists requires some distance from my object of study as well as from myself. From the sociological point of view and in consideration of the research that I carry out on decision-making, this autoethnography focuses on the way in which the health professionals (doctors, nurses ...), my relatives and I were involved in decisions regarding the choice of a dialysis method. Consequently, I will analyse the weight of socio-cultural and economic realities in the construction of patient choices and the decisions of doctors in Senegal. My aim is also to highlight the role of social networks as well as the strategies implemented to make effective choices such as going to France in order to have the opportunity to benefit from a renal transplant.

However, this autoethnography approach has raised criticisms about its scientific validity, as Walford<sup>18</sup> who perceives autoethnography as a fiction. Other criticisms concern, among other things, the fact that self-centeredness is too centered on the self of the narrator, which can lead the narrator to be self-indulgent, narcissistic or introspective and individualistic<sup>13,19,20</sup>. One limitation I would like to outline is that I am not able to remember some past events as Strasser<sup>21</sup> noted when discussing the limits of autobiographical writing. This limitation may be noticed in my autoethnography. That is why, before the beginning of the narrative, I'd rather acknowledge my inability to remember precisely those previous situations that marked my care path. In order to overcome this shortcoming, I have decided to collect other people's viewpoint (doctors, parents...) to reconstruct their roles in the decision-making process.

Sociologists talking about themselves live in particular social situations, which situations can also be similar to those experienced by other people. This perception of the autoethnography different from the autobiography has led me to adopt a type of writing that will allow me, as the anthropologist Murphy<sup>16</sup> who was paralyzed did, to trace how the disease has upset my social relations by using a socio-anthropological analysis of my care path.

### ***Bifurcations as analysis model***

Understanding the way the events led me (or my parents) to choose a replacement therapy for chronic kidney disease or to emigrate to France, brought me to use the bifurcation theory similar to the notion of turning point defined by Abbott<sup>22</sup> as being »more consequential than trajectories because they give rise to changes in overall direction or regime, and do so in determining fashions«. The work on the bifurcations carried out by French soci-

ologists<sup>23–26</sup> emphasize the unpredictability of events contrary to turning points.

In my care path, I experienced three replacement treatments for chronic kidney disease: the hemodialysis, peritoneal dialysis and renal transplantation. Transitions from one treatment to another were favoured by medical decisions and some choices my parents made for me. The experience of the disease and its treatment methods can be analysed as the occurrence of uncontrolled events underpinned by sudden changes, as a biographical disruption<sup>27</sup>, or as the unpredictability and irreversibility of events<sup>23–25</sup>. In addition, individual representations of illness vary according the social groups they belong to which may define the therapeutic itineraries they take<sup>28</sup>.

The autoethnographic approach will focus on identifying bifurcation points, paying particular attention to their consequences in terms of my social relations and the decisions they have helped me to make. In addition to the unpredictable and irreversible nature of their foundations, social bifurcations are fuelled by »ingredients«<sup>23</sup>. Indeed, I relied on those ingredients to make some changes both in my care path and in my life as a whole.

### **Results and Discussion – Bifurcations and their relational and decisional consequences**

The first bifurcation was the beginning of the dialysis. This first dialysis session caused a biographical disruption<sup>27</sup> in my life. While I was 22 years old and at university, I was diagnosed with kidney failure. I continued my studies and carried on sharing the activities of my university. This first dialysis session therefore put an end to my studies. My university was five hundred kilometres from the capital, where the only public dialysis center was located at that time. In addition to this medical diagnosis and treatment, I was taken to the traditional healer by my parents. This diagnosis suggested that my kidney failure resulted from a spell cast by a college fellow. A treatment was suggested by the traditional healer who gave me amulets to wear and potions to cure this renal insufficiency which he considered to be of supernatural cause. This medical pluralism in the treatment of my kidney failure reflected my parents' approach who thought that a mix of traditional and modern medicine would increase my chances of recovery<sup>29</sup>.

One of the consequences of the hemodialysis was a change in the position I held in my family and resulted in some kind infantilization. Murphy<sup>16</sup> had also experienced such a change with his wife who acted as a mother to her child.

A few months after my hemodialysis, doctors suggested a peritoneal dialysis. This choice for a peritoneal dialysis was apparently due to a lack of space in the hemodialysis center. The other reason was that I was a student and peritoneal dialysis would allow me to go back to university. My parents were reluctant, but they finally agreed to let me go back to university without providing amulets to protect me. Besides the medical equipment provided by

the dialysis center in Dakar, my parents had made me produce the amulets as a supernatural »material«. Such seemed to be the condition for my return to university. Then, the choice of peritoneal dialysis seemed to be designed on the influence of multiple people as Rapley<sup>30</sup> emphasized it in his study when he considers distributed the decisions.

Besides, this new change was akin to what H elardot<sup>24</sup> considers as a resistance to the disease. Indeed, I resumed my studies. With the treatment of peritoneal dialysis that I did at night, I was more autonomous during the day. Renal insufficiency no longer prevented me from carrying out certain activities and I was able to defend my master's thesis in sociology of work and organizations at the Gaston Berger University in Saint-Louis in 2008.

The second bifurcation point occurred at that time. One week after my defense, I contracted a peritonitis which forced me to return to Dakar to be treated in the nephrology department. I experienced a series of painful episodes: first of all, the catheter, which was placed in the abdomen for the purpose of peritoneal dialysis, had to be removed in order to treat peritonitis. I had not the possibility to make a choice for another replacement therapy because I was in an emergency situation. Indeed, as Kaufman, Shim and Russ<sup>31</sup> noticed it »In some of those cases, the patient's nearemergency condition and subsequent diagnosis precluded patient choice entirely«. I was treated again by hemodialysis, which led to some complications. I had a vascular access problem, the arteriovenous fistulas did not work and the catheters placed alternately at the level of the groin and at the level of the jugulars eventually caused thromboses. I finally ended up with acute oedema of the lungs because I had spent a fortnight without dialysis. A solution was subsequently found by placing a catheter with the assistance of a computer.

In economic terms, these complications impoverished my parents because of the high cost of medicines to buy and the medical analyses to be undertaken. Although my university was supposed to cover the cost of my dialysis sessions by my university, some sessions were not paid for, so my state of health was getting worse. Diallo<sup>9</sup> refers to this reality when he points out that poor people who do not have adequate financial resources are not taken care of in health facilities.

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These stressful situations experienced during my care in Senegal are the ingredients that influenced me in my choice to emigrate to France. Two of my sisters who were already in Europe began to look for a way to make me leave Senegal. One of them who worked as an au pair for a Belgian doctor told him about my illness and both started to find ways to raise the money required for a kidney transplant in Belgium.. For my part, I started the pre-registration process via the Campus France platform. The outcome was positive and I was able to join France not only to study but also to undergo treatment as I was also registered in the option of therapeutic mobility<sup>10</sup>. At the same time, both my care and studies helped me diversify my goals, which change my approach from a form of a temporary stay or a primary objective of medical care. Indeed, I neither felt I was experiencing some kind of exile nor of medical tourism<sup>32</sup>.

The decision to emigrate was therefore based on experience but also on the mobilization of a social network capable of promoting positive changes, a bifurcation, which was the opportunity to benefit from a renal transplantation whose outcome was both irreversible and unpredictable in terms of future experiences and choices.

## Conclusion

Applying some reflexive analysis to my situation of a patient in interaction with his social environment proved necessary to distance myself from my own experience; otherwise one could fall into the trap of narcissism as noted by some researchers. The dual posture of researcher and patient has thus contributed to enrich the methods of analysis used in social sciences. Initiating the process of the autoethnography in the understanding of the trajectory of a patient with renal failure, without falling into easy generalization, has enabled me to grasp individual singularity in a given sociocultural context and diversifies the approach to chronic patients. In addition, this particular narrative process focusing on health choices can be used to explain and develop the different factors that may drive individuals to mobility. The reasons for my therapeutic mobility finally emerged from experiencing painful medical treatments and financial difficulties.

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## **AUTOETNOGRAFIJA BOLESNIKA SA ZATAJENJEM BUBREGA – KAKO ISKUSTVO I SOCIJALNE VEZE PROMIČU TERAPEUTSKU MOBILNOST**

### **SAŽETAK**

Ovaj se rad bavi odrednicama koje potiču terapeutsku mobilnost iz Senegala u Francusku. Ja sam i pacijent i istraživač, a moja je teza usmjerena na to kako zdravstveni stručnjaci donose odluke o upućivanju pacijenata na metodu dijalize. Također sam naglasio kako pacijenti s zatajenjem bubrega konstruiraju svoj izbor metode dijalize. Kao bolesnik u Senegal, zemlji s niskim prihodima, doživio sam neke poteškoće zbog nedostatka ljudskih resursa u zdravstvenom sektoru, malog broja centara za dijalizu, medicinskog pluralizma i slabih performansi zdravstvenog sustava. Odabir metode dijalize ovisi, između ostalog, o mnogim čimbenicima kao što su liječnička mišljenja, pristup moje obitelji i mog studentskoh statusa u to vrijeme. Ta je situacija rezultirala uključivanjem zdravstvenih djelatnika, moje obitelji, koji su me oboje nagovarali na odlazak u Francusku kako bi dobili transplantaciju bubrega. Stoga ću analizirati terapijsku mobilnost kao ishod socijalnih čimbenika i osobnog iskustva izvan društvenih bifurkacija. Zatim predlažem ovdje, iz mog iskustva, kako se preseliti iz zdravstvenog sustava niske učinkovitosti (Senegal) na visoko učinkovitu (Francuska) kroz autoetnografsku analizu.