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# Experiential Fallibilism and Decision-Making Process: A Perspective from a Patient with Chronic Kidney Disease

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**Abstract**

Patient choice in healthcare follows a process in which references to evidence and experience are intertwined. From the perspective of a patient with chronic kidney disease, I propose experiential fallibilism as the use of uncertain evidence and experience, along with knowledge gained in new contexts, situations, and experiences, to attain truth and promote shared decision-making. Thus, because of their uncertain nature, both the patient's experience and the doctor's focus on evidence should be integrated into a decision-making process through a co-learning perspective so that they can mutually enrich each other and prevent inappropriate actions and decisions in other clinical contexts. The risks perceived by both the patient and the doctor should be valued equally to encourage an honest discussion of the benefits and drawbacks of the proposed treatments after considering the patient's social, economic, and medical situation. Further, experience measurement tools, both quantitative and qualitative, should be used or developed to test their transferability and effectiveness in contexts involving healthcare decisions between doctors and patients.

**Keywords**

patient perspectives/narratives, clinician-patient relationship, communication, medical decision making, relationships in healthcare

## Introduction to the Issue

Although evidence-based medicine (EBM) is proposed as the optimum approach for providing patients with the best treatments, it struggles to quantify the steps and motivations that can help orient patients toward treatments and involve their families in their care.[1] Moreover, using EBM can lead to the avoidance of applying evidence guidelines to every patient because medical decisions are based on uncertain evidence and every patient is unique in their lifestyle and experience.[2] Thus, to promote shared decision-making in kidney care, I propose the concept of experiential fallibilism, based on my own experience as a patient with chronic kidney disease. The concept of experiential fallibilism is inspired by Charles Sanders Peirce's doctrine of fallibilism, which refers to knowledge, which is not absolute, uncertain, and indeterminate as part of a search for truth through an inquiry that fosters growth.[3] According to Peirce, to attain truth, one needs to engage in an inquiry that reduces uncertainty by observing phenomena or experiments that challenge an erroneous hypothesis or idea. However, this truth is an ideal. It is relative. It is not permanent.[3]

I define experiential fallibilism as the use of uncertain evidence and experience, along with knowledge gained in new contexts, situations, and experiences, to attain truth and promote shared decision-making. In this sense, experiential fallibilism is promoted through a co-learning process, enabling the doctor and the patient to have the information they require to make decisions together. From this perspective, experiential fallibilism is an approach that enriches shared decision-making. Shared decision-making is defined as a collaborative approach in which the patient, in partnership with their doctor, chooses the option that best meets their preferences after weighing the advantages and disadvantages of each option.[4] Indeed, experiences are neither absolute nor certain. Experiential fallibilism does not oppose EBM but implies that doctors should value a patient's experience in the decision-making process. Similarly, experiential fallibilism does not place experience above EBM; rather, it advocates complementarity between the patient's experience and the EBM to which the doctor refers.

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## Key Factors for Consideration

This plea for experiential fallibilism comes from my experience as a patient with chronic kidney disease, along with that of my family during the time I had to undergo dialysis. My doctor had chosen peritoneal dialysis as the treatment option for me, and one of the eligibility criteria was that I was young as well as a student. This decision was understandable given that peritoneal dialysis is considered the most suitable dialysis modality for young individuals.[5] Nevertheless, I was worried about performing peritoneal dialysis alone, a hundred kilometers from the capital, which had the only peritoneal dialysis center at the time. After the nurses explained how to use the peritoneal dialysis machine, which hygienic measures were to be taken, the risks that could occur, and how to recognize them, I decided to follow my doctor's suggestion and chose peritoneal dialysis. These general recommendations, which were given to every patient referred for peritoneal dialysis during the individual consultation, did not always apply to me because of my lived experience as a patient who lived with a large family in a small space in a country where poor access to electricity meant frequent power cuts.[6] For instance, although the nurse wanted my parents to provide me with a single room to avoid infections, I was not always entitled to one because of the lack of space. At the university, however, I got a single room thanks to the university doctor. The university doctor was aware of the risks of peritoneal dialysis, but my parents lacked experience in managing chronic kidney disease, especially peritoneal dialysis. Thus, the decision regarding my treatment, which was made based on the understanding that peritoneal dialysis is the best dialysis method and provides a better quality of life for patients with kidney disease than hemodialysis, was, nevertheless, made without the involvement of some of the actors such as my parents, who were not aware of the full implications of the treatment. Consequently, the peritoneal dialysis treatment did not yield the expected results because my parents did not assess the risks of infection. During the treatment, I would sleep with my brother, who was occasionally present when the peritoneal dialysis catheter implanted in my abdomen was connected or disconnected from the machine. In addition, power cuts made the automated peritoneal dialysis treatment I performed at night using the machine less effective. My doctor did not know that I was living with my brother when I was performing peritoneal dialysis at home. Hence, experiential fallibilism could enable medical practitioners to consider the experiences of all the relevant stakeholders whose actions can impact the decisions and their outcomes. By integrating the doctor's evidence with the patient's and their family's experiences into the decision-making process in a manner that changes the doctor's, patient's, and the family's initial knowledge, experiential fallibilism can help reach informed decisions that impact both the quality of care and the quality of life of the patient and produce more scientific recommendations.[3]

Experiential fallibilism exists when open-mindedness allows us to value or learn from each other's experiences. When I was in a coma, the doctor told my parents to let me die based on his understanding that because they could not take care of me, I was going to live in suffering. It can be argued that his experience with patients in similar situations would have made the doctor reconsider his medical judgment due to the potential existence of new information that could change the situation.[7] After learning that the university could pay for my care and that my parents wanted me to live, the doctor updated the experiences mobilized during his previous interactions with my parents over the decision regarding letting me die. There was uncertainty accompanying the doctor's initial judgment, and after receiving the correct information about my benefits as a student through an inquiry, the doctor updated his judgment. Similarly, my parents, who were still hopeful, confirmed that they wished for to me live and undergo dialysis, thanks to the new information they received from the university doctor. In this situation, without the information that the university could pay for my treatments, the doctor would have made the decision based solely on his experiences. Thus, the doctor's attitude was one of bounded rationality because he found it difficult to make a rational decision when he did not have all the information he needed.[8]

The lack of experiential fallibilism may be reflected in the patients' attitude to transferring previous positive treatment experiences to other disease contexts. I had this experience when I was using traditional medicine while on dialysis in the hopes of feeling better. Although medicinal plants can be toxic to the kidney, they are perceived to improve the quality of life of dialysis patients.[9] Similarly, experiential fallibilism on the patient's side must translate into trust in the doctor who informs them that, for instance, chronic kidney disease cannot be cured. I remember that I used to take treatments prescribed by traditional healers because the use of traditional medicine had had positive results on my other medical conditions in the past, such as malaria and flu. A traditional healer assured me that my kidneys would become intact and functional again by saying, "Your kidneys will be unclogged as soon as you eat these foods." I relied on the opinions of these traditional healers and my positive experience with traditional medicine by closing my mind to the idea that chronic kidney disease could not be cured.[10] By acting on my preferences to be treated by the methods of the traditional healer over that of the doctor based on EBM, I was demonstrating a closed-minded attitude by not recognizing the fallibility of my experience. This was because I was satisfied with my limited knowledge due to a lack of inquiry that was not integrated with medical knowledge. In other words, by placing my experience above EBM, I was suggesting to the doctor that I knew better than him about what was the best decision to make to treat my kidney disease. This closed-mindedness made me decide to use plant medicines considered toxic by medical professionals. Thus, by ignoring the advice of my doctor to act on a false hope, I took the risk of using forbidden plant medicines.

Experiential fallibilism demands that we question our experiences when it is necessary to make decisions that favor quality of life. Even in this situation, a process of inquiry is undertaken to gain access to the knowledge needed to assess the situation and decide whether to integrate experiences or practices that may be harmful.[2] When the doctor and the patient interact, they put on the table preferences based on uncertain evidence or experience. The context and impact of social life on patient health may favor evidence over experience. When I was offered a kidney transplant by the doctor, he informed me about the risk associated with the surgery and that only 1% of patients who had undergone surgery died due to resultant complications. The doctor then said to me, "You are young. You have your future ahead of you, and I would advise you to undergo a kidney transplant." Before that meeting with my doctor, I was confused about having a kidney transplant. On the one hand, I had had a negative experience with dialysis, often had cramps, and the dietary restrictions were very difficult to endure. These negative experiences encouraged me to opt for a kidney transplant. On the other hand, a soothsayer I had consulted in Senegal assured me that I should not undergo the operation because I would be risking my life. The caveat was this soothsayer did not specify the type of surgery. However, despite my hesitation, I decided to undergo kidney transplantation after all. An inquiry that enabled me to acquire knowledge in my interaction with the doctor helped me ignore certain past experiences that had not improved my quality of life. I made my decision based on what previous traditional healers had told me, which turned out to be false. Besides, making that major decision to get a kidney transplant was influenced by many factors. I had undergone several life-threatening surgeries, and the doctors and nurses had assured me that the transplant would allow me to stop the dialysis, return to a normal life, continue my studies properly, and regain my normal weight. Thus, in this situation, the exchange of experiences and preferences between the doctor and the patient resulted in a shared decision-making process that resulted in a better quality of life for the patient.[4]

Based on my understanding, for shared decision-making to become a reality, we must go beyond the need to know what caused the illness and have the patience and humility to acquire knowledge about the factors that led to the formation of the patient's and doctor's decision-making rationale. This requires closeness to the patient that is built over time, as well as trust that favors a patient sharing sensitive or intimate experiences with their doctor, which can enlighten and enrich the decision-making process. Shared decision-making is regularly evaluated at all stages of the process using experience measurements tools. The process outlined in Figure 1 begins with initial medical judgments and patient experiences, and moves to the attainment of truth after inquiry, through an initial discussion on treatment options where the contribution of new contexts, situations, and experiences enriches the uncertainty of the doctor's evidence and the patient's experience. An acquisition and updating of knowledge emerge from the complementarity between uncertainty and new sources of knowledge that allow the doctor and the patient to update their knowledge. The doctor's and patient's preferences resulting from this updated knowledge promote truth seeking and acceptance of the patient's choice of treatment. This promotes shared decision-making and the patient's quality of care and life. Because truth is fallible[3] due to the existence of new contexts, situations, and settings that perpetuate the uncertainty of evidence and experience,

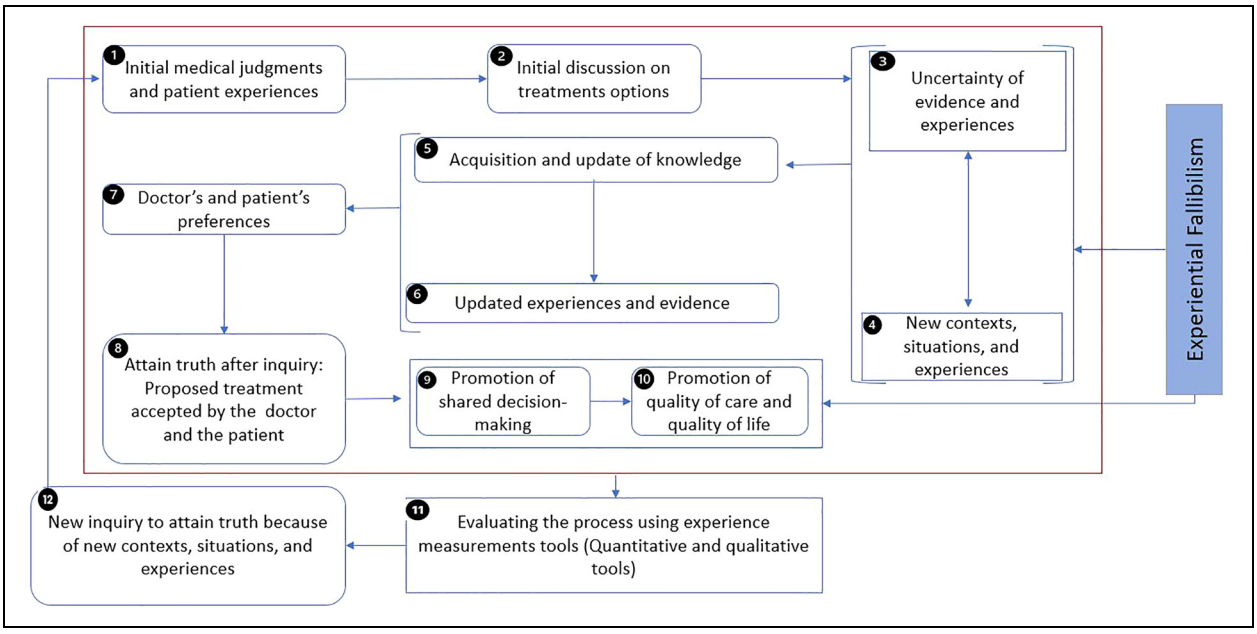


**Figure 1.** The experiential fallibilism process.

experience measurements tools can suggest a new inquiry and a need to attain truth.

## Recommendations

Based on the concept of experiential fallibilism applied to my experience as a patient with chronic kidney disease, I propose the following recommendations:

1. For the decision-making process to lead to shared decision-making, both the doctor and the patient must be open to mutually enriching each other and building their preferences based on information that helps to attain truth.
2. The patient's experience and the doctor's focus on evidence should not be systematically incorporated into a decision-making process without first updating one's knowledge with new contextual, situational, and experiential information to avoid inappropriate actions and decisions in other clinical contexts.
3. The risks perceived by both the patient and the doctor should be valued equally to encourage a clear and honest discussion of the benefits and drawbacks of the proposed treatments, after considering the patient's social, economic, and medical situation.
4. Experience measurement tools, both quantitative and qualitative tools (eg, focus groups, questionnaires, and interviews), should be developed to test their transferability and effectiveness in other contexts involving healthcare decisions between doctors and patients. Because of the fallibility of truth, these tools should be used to evaluate the process of experiential fallibilism and to initiate a new inquiry.

## Conclusion

In this article, experiential fallibilism unfolds through socioculturally satisfying experiences that are continually tested and updated based on new contexts and through inquiry into kidney care. However, there are also challenges associated with the use of experiential fallibilism, such as a greater emphasis on experience at the expense of scientific evidence and the risk of making healthcare decisions based on experience. Therefore, we must ensure that scientific evidence and experience are in constant dialogue to avoid their unbalanced use and promote change.

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