

# *Bulletin de la Dialyse à Domicile*

## *Home Dialysis Bulletin (BDD)*

*International bilingual journal for the exchange of knowledge and experience in home dialysis*

*(English edition) (version française disponible à la même adresse)*

### **The patient as “number one” partner in the CKD (Chronic Kidney Disease) process. Time-tested evidence**

(Le patient comme 1er partenaire du parcours MRC (Maladie Rénale Chronique). Une évidence à l'épreuve du temps)

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To cite: Letrecher S. The patient as “number one” partner in the CKD (Chronic Kidney Disease) process. Time-tested evidence. Bull Dial Domic [Internet]. [cited 2025 May 4];8(2). Available from: : <https://doi.org/10.25796/bdd.v8i2.87079>

#### Summary

The CKD pathway is punctuated by multiple comings and goings, whether from the pediatric ward to the adult ward, to entry into dialysis, from one dialysis technique to another, from home to the institution, sometimes right up to the end of dialysis cessation and death. Allilaire (2002) speaks of «a process of continual adjustment, the modalities of which vary according to the mode of entry into chronic illness». Adjustment, however, is not only a matter for the patient, but also for the professionals working with him or her. This is why we propose to enrich our thinking on this journey through the concepts of transference, transition and transitionality.

#### Résumé

Le parcours MRC est ponctué d'allers-retours multiples que ce soit du service de pédiatrie vers le service adulte, vers l'entrée en suppléance, d'une technique de suppléance à l'autre, du domicile à l'institution, parfois jusqu'à la fin l'arrêt de dialyse jusqu'au décès. Allilaire (2002) parle «d'un processus d'ajustement continu dont les modalités varient selon le mode d'entrée dans la maladie chronique». Mais l'ajustement, s'il est à entendre du côté du patient, est également à penser du côté des professionnels qui l'accompagnent. Raisons pour laquelle nous nous proposons d'enrichir la réflexion autour de ce parcours au travers des concepts de transfert, de transition et de transitionnalité.

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**Keywords :** dialysis, chronic kidney disease, transition, transfer, clinical psychology.

**Mots-clés :** dialyse, maladie rénale chronique, transition, transfert, psychologie clinique.



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## Introduction

The CKD pathway is punctuated by multiple comings and goings, whether from the pediatric ward to the adult ward, to entry into dialysis, from one dialysis technique to another, from home to the institution, sometimes right up to the end of dialysis cessation and death [1]. Allilaire (2002) speaks of «a process of continual adjustment, the modalities of which vary according to the mode of entry into chronic illness» [2]. Adjustment, however, is not only a matter for the patient, but also for the professionals working with him or her. This is why we propose to enrich our thinking on this journey through the concepts of transference, transition and transitionality.

### Transfer and transition in nephrology

Transfer is defined as «movement, transport (of people or things) from one place to another according to precise modalities»[1]. The spatial dimension is emphasized here. In nephrology, for example, we can think of the transfer from a hospital to a follow-up care and rehabilitation department for patients requiring rehabilitation following lower-limb amputation.

As for transition, while it does not exclude spatiality, it introduces a temporal variable. It is defined as «the gradual transition from one state to another»[2]. Thus, the transfer of young patients from the pediatric ward to the adult ward is rarely aligned with the legal age of majority. Rather, it is a process that unfolds over several years, involving both departments in order to best support adolescents at this pivotal moment. The aim is to avoid a breakdown in care [3].

Meleis [4] develops a nursing theory of transition as a passage from one stage of life, one state, one status to another. Transitions are understood here as the process and outcome of complex interactions between the individual and his or her environment. They are developmental (stages in the life cycle), situational (new roles), organizational (new policies, practices) and articulate passages from health to illness.

Four elements are interrelated: the nature of the above-mentioned transitions; facilitating and constraining conditions; response indicators; nursing interventions.

### Transitionality: a concept from pediatrics

Anglo-Saxon psychoanalysis has focused on the role of the environment in the psychic development of the subject. We will therefore borrow the concept of transitionality (1945) [5] from one of its representatives, the pediatrician Donald W. Winnicott, to enrich our thinking on the role of the environment in the CKD trajectory.

The first few weeks of a baby's life are marked by a magical omnipotence in which the mother figure is entirely at the baby's disposal. The test of external reality and its constraints (the mother figure will be absent), to be tolerated, must go through a gradual disillusionment orchestrated by the parent. They are based on an intermediate area experience between the «outside» (the external world) and the «inside» (internal reality), where the child can create, imagine and invent an object with which he or she has an affective relationship. It is the lack of a mother figure, the spatial gap (the mother is absent) and the temporal gap (she is slow to respond), that will motivate this creativity [6].

The transitional object (“doudou”) is the best-known illustration. It is the first thing possessed in its own right that the individual distinguishes from himself. For Winnicott, it is not so much the object as such that is important as the child’s use of it: to enable him or her to keep internal and external reality separate and linked, while coping with separation anxiety.

This transitional space survives into adulthood in the form of a «resting place» to which the subject can have recourse as soon as reality seems too painful to cope with. It enables the elaboration of difficulties encountered, a strengthening of the ability to tolerate frustrations and thus a more creative contact with reality (Aiello-Vaisberg & Lousada Machado) [7]. However, this is only possible if favorable childhood conditions have enabled the child to elaborate.

Anzieu [8] extended his thinking on transitionality by introducing «external» transitional therapeutic devices. Thanks to identification, these will enable the (re)creation of an internal transitional space in patients who lack one (borderline states, adolescents, psychosomatic pathology).

### Transitionality of the CKD route.

Some patients’ transitional deficiencies lock them into two cleaving relationship modalities: fusion/confusion between relationship partners where each is idealized, abrupt rupture as the only solution when the other becomes unsatisfactory or too intrusive [9]

The idealization associated with fusion is comfortable for the care team, but risky. The patient says yes to everything we suggest. And then suddenly (but is it so sudden?) the patient refuses everything. Rejection, while more violent and worrying, is often just the other side of the same coin. Sometimes it is one member of the team who embodies the good object, satisfying and valued, while another who is the object of negative projections. In this sense, for caregivers, distancing themselves from idealization is a way of protecting themselves from rejection.

In the hospital, transitionality can also be undermined by institutional constraints: lack of time and resources can lead professionals to rigidify their *modus operandi* along procedural lines (e.g. no longer involving the patient in toileting for lack of time).

The CKD pathway and its many to-ing and fro-ing may induce a certain passivity in the patient, a passivity reinforced by the dependence linked to disability or ageing. This passivity can go as far as passivation (Green, 1999) [10], i.e. a mode of protection against extreme internal distress manifested by a withdrawal of one’s subjectivity in favor of another caregiver perceived as all-powerful. A «ça va de soi» in which the patient’s self is increasingly absent. Yet transitionality requires the presence and collaboration of two subjectivities.

Example of a patient aged 78. With his kidney function deteriorating, it had been planned for several weeks to start home hemodialysis with the assistance of a nurse. As far as his doctor was concerned, everything was in order. However, he suddenly came back to question this harmony, evoking his wish to die. Faced with this about-turn, the nephrologist who had been treating him for several years was unsettled. He asked him to meet me.

During our first meeting, Monsieur clearly expects me to encourage him to start dialysis. When I ask him what has prompted him to consult me, he replies quite bluntly: «Dr. X. must have told you». I tell him that I’m interested in his own words. These will be difficult to formulate. Gradually, the therapeutic space helps him to recognize his request to die as a fear of dying. After a few weeks, the patient finally decides to start dialysis.

Later on, he would talk more spontaneously during our interviews about his life: a very poor childhood, success at school which gave them him access to brilliant university studies, retirement surrounded by his family, and his passion for chess. After a few months, he regained control of a situation he felt was getting out of hand. I think dialysis is now part of my life».

## Conclusion

Transitions in the CKD pathway are moments of fragility that also provide an opportunity to reshuffle the cards. Patients must be able to remain involved in the care process, i.e. play, create, tinker, and thus (re)find a transitional space in which they are co-authors. In the face of time wear and tear, the support of a multi-disciplinary team makes it possible to call on internal relays. The psychologist's mission is to ensure that the psychic dimension of the individual is recognized and respected [11]. The psychological interview can help restore an intermediate area of experience, so that the patient remains the 1st "number one" partner in the CKD process.

## Funding

The author received no funding for the writing and publication of this article.

## Ethical considerations:

Not applicable.

## Declaration of interest

The author declares that she has no conflict of interest with this article.

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