

FANTASIES ABOUT PREGNANCY AND MOTHERHOOD REPORTED BY FERTILE ADULT WOMEN UNDER HEMODIALYSIS IN THE BRAZILIAN SOUTHEAST: A CLINICAL-QUALITATIVE STUDY¹

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This article discusses hemodialysis experiences in terms of meanings women attribute to several associated phenomena. Renal insufficiency may present a progressive reduction in renal function, in which the kidneys are affected and become unable to remove metabolic material from the blood. Living with hemodialysis is associated to important psychosocial adaptation mechanisms. This clinical-qualitative study was performed in two general hospitals' nephrology service. The method included purposive sample of nine women in hemodialysis and a semi-directed interview with open-ended questions was applied. After categorizing interviewees' discourse, psychodynamic approaches were used for interpretation. It was concluded that the subjects experienced different degrees of desire to get pregnant and become mothers, now challenged by a limiting illness. Considering the adoption matter, besides symbolizing a generosity act, it would represent a solution to a deep individual demand. Fantasize about adoption, even if it does not become reality, may enhance these women's self-esteem.

DESCRIPTORS: kidney failure; renal dialysis; fantasy; nursing research; qualitative research

FANTASÍAS SOBRE EMBARAZO Y MATERNIDAD RELATADAS POR MUJERES ADULTAS FÉRTILES EN HEMODIÁLISIS, SUDESTE DE BRASIL: UN ESTUDIO CLÍNICO-CUALITATIVO

Este artículo discute experiencias con hemodiálisis a través de significados que pacientes dieron a fenómenos asociados. Insuficiencia renal crónica presenta reducción progresiva en la función renal. Cuando ambos riñones están afectados, hay incapacidad de remover los metabólicos de la sangre. Vivencias de hemodiálisis se asocian a importantes mecanismos de adaptación psicosocial. Este trabajo fue realizado en dos hospitales generales y adoptó un diseño clínico-cualitativo. La muestra fue intencional, con nueve mujeres en hemodiálisis, y fue utilizada entrevista semidirigida. Después de la categorización de discursos, la interpretación fue realizada de acuerdo con el marco psicodinámico. Las mujeres observadas presentaban diversos grados de deseos de embarazarse y ser madre, ahora desafiados por una enfermedad limitante. Considerando el problema de adopción, además de simbolizar un acto de generosidad, representaría solución de una demanda individual profunda. La fantasía de adopción en sí misma, aunque sin posibilidades de convertirse en realidad, aumentaría la autoestima de esas mujeres.

DESCRIPTORES: fallo renal; diálisis renal; fantasía; investigación en enfermería; investigación cualitativa

FANTASIAS SOBRE GRAVIDEZ E MATERNIDADE RELATADAS POR MULHERES ADULTAS FÉRTEIS EM HEMODIÁLISE, SUDESTE DO BRASIL: UM ESTUDO CLÍNICO-QUALITATIVO

Este artigo discute experiências com hemodiálise em termos dos significados que mulheres trouxeram aos diversos fenômenos associados. A insuficiência renal pode apresentar uma redução progressiva da função dos rins, na qual ambos ficaram afetados e tornaram-se incapazes de remover metabólitos do sangue. A vivência da hemodiálise está associada a importantes mecanismos psicossociais da adaptação. Este trabalho adotou um desenho clínico-qualitativo, realizado em serviços de nefrologia de dois hospitais gerais. O método incluiu amostra proposital de nove mulheres em hemodiálise, aplicando entrevistas semidirigidas de perguntas abertas. Após categorização das falas das entrevistadas, a interpretação utilizou abordagens psicodinâmicas. Concluiu-se que as mulheres observadas vivenciaram graus diferentes de desejos de gravidez e de tornarem-se mãe, agora desafiadas por doença limitante. Considerando o problema da adoção, além de simbolizar ato de generosidade, representaria solução para profunda demanda individual. A própria fantasia de adoção, embora pudesse não se tornar realidade, aumentaria a auto-estima destas mulheres.

DESCRIPTORES: falência renal; diálise renal; fantasia; pesquisa em enfermagem; pesquisa qualitativa

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INTRODUCTORY QUESTIONS

Chronic kidney failure requires hemodialysis, surgery and even kidney transplantation. It is a disease defined as an irreversible and progressive reduction in renal function in which both kidneys have been damaged and they became unable to remove the metabolic products from the blood and regulate the body's electrolyte composition and acid-base balance⁽¹⁾. According to the American Society of Nephrology (ASN), almost half a million of Americans suffered from End-Stage Renal Disease (ESRD), being about 80% on dialysis or requiring a kidney transplant. It is estimated that sixty thousand ESRD patients die each year in USA, consisting the ninth among the ten-top causes of death. More than 50% patients with ESRD received dialysis, being diabetes and hypertension the two main causes of renal disease.

ASN emphasizes that dialysis is not a cure for this disease, as well as its blood-filtering process is laborious, expensive and it requires both a strict dietary and lifestyle limitations. In epidemiological terms, ESRD occurs more commonly in African-Americans, followed by Native Americans, Asian Americans and, finally, Caucasians. To better understand the people's life experience on hemodialysis is obligatory to consider that this process represents to be connected in a machine, removing and filtering his/her blood, for three or four hours a day, at least three times a week, spending many years of life⁽²⁾.

According to the American Nephrology Nurses' Association (ANNA), the role of nephrology nursing is both to assess all kind of reactions of renal disease on individuals and to diagnose/treat their respective responses. From this perspective, it is necessary to assist and help each individual to achieve an optimum level of functioning, through preventing renal disease or rehabilitating the patient. To reach these aims, practitioners should seek high standards of patient care that are continually updated. For ANNA, research is essential for the advancement of nursing sciences and so new concepts must be developed and tested to sustain the continued growth and improvement of nephrology nursing. Finally, they concluded that both the team's approach toward patient care and to embrace interdisciplinary communication are essential to the achievement of the highest attainable level of cost-effective and quality patient care⁽³⁾. Accordingly, a Brazilian study aimed to contribute to the knowledge of the nurse's educative

activity with chronic renal patients undergoing an hemodialytic treatment, providing an improvement in the patient's quality of life and using a model called "awareness education".⁽⁴⁾.

It is supposed that there are about 35,000 patients with Chronic Kidney Failure nowadays in Brazil, who are kept in dialysis programs, being the great majority of them females in fertile age. The dialytic and medicamentous treatment for these patients presented a spectacular enhancement in the last two decades, extending considerable their life expectancy and improving their quality of life. Successful pregnancy became possible for the female group kept in chronic dialytic therapy. The frequent clinical-obstetric complications mean low-risk for mothers but high-risk for babies, even though fetal death is rare⁽⁵⁾.

In spite of the treatment progress, uremic women present low reproductive capacity, when compared with normal ones. This difference elapses mainly from the presence of common abnormalities in these patients, such as: hormonal alterations, menstrual and ovulation disorders, diminished sexual function and reduced fertility. All these factors are added to the risks after conception, including increase of blood pressure, anemia, and immunologic alterations. These conditions culminate in a non-indication of pregnancy, the so-known "restriction to the motherhood", therefore a pregnancy is considered a very important maternal-fetal risk for prognostic of nephropathic patients.

The restriction to become pregnant may be understood in several ways by nephropathic patients in fertile age who are under hemodialysis treatment. Frequently, it is observed that, despite of both orientations regarding the contraception and risks, which a pregnancy brings for these women, many of them become pregnant. Therefore, it suggests an interference of emotional factors but the awareness on risks, which can threaten their lives. However, the counseling on the use of contraceptive methods for these patients seems insufficient or inadequate, it results in many cases of pregnancy during the hemodialysis treatment, according to the literature⁽⁶⁾.

The motherhood becomes then an ambivalent question - consciously and unconsciously - in these fertile women's life under dialytic treatment. For them, thinking on this matter brings up feelings which, often, antagonize desires and imposed medical restrictions between themselves, reaching deeply the maternal role or instinct - placed by the nature and/or by the

culture - and being present in greater or minor intensity in each woman.

In spite of pregnancy risks on dialysis, it must not be forgotten that there are women determined to have children because of their fervent religious beliefs that make them believe the divinity protects both themselves and their babies from damage. It is calculated that, each year, one in 200 women of childbearing age conceive while on dialysis. Almost half of them result in a surviving baby, considering those pregnancies not optionally interrupted. Obviously, this situation should not generate an ethical quarrel with members of the health care team, mainly within those who have opinion that a pregnancy would be harmful⁽⁷⁾.

PREMISES AND OBJECTIVES

The present scientific project belongs to a Research Line entitled "Clinical-Qualitative Studies in Health Field", that raises problems related to health-disease process, such as experienced by patients, relatives or health professionals. Inside this line, the hemodialysis issue offered a prior study that discussed the relationship between health professional teams and renal patients. The paper extracted from this first project concluded that patients wished that the health care team could listen to their concerns more carefully, which go beyond physical aspects, considering that the provided clinical care had focused on both patients' biological aspects and mechanical procedures⁽⁸⁾.

Therefore, the *specific goal* of this sequent investigation was both knowing and discussing *fantasies*, which adult women in fertile age, under dialytic treatment, have about an eventual pregnancy, as well as identifying and interpreting psychological conflicts relative to the desire and a real possibility of playing the maternal role. Fantasy is here understood as an imaginary construction in which the subject is present and that would represent, in a way partially deformed due to defensive processes, the fulfillment of a wish. The authors started departed from a presupposed idea that the women experience, above all when marked by the biological phenomena of being in fertile age, desires and expectations of pregnancy - consciously or not - manifest in different degrees. Toward this affective-existential condition, when understood as universal, being under a drastic medical treatment would mean, for the patients, having

fantasies more present in mind and very probably accompanied by a special, but not abnormal anguish.

METHODOLOGICAL RESOURCES

If one wants to explain scientifically the phenomena related to disorders of urinary tract, this is a matter for researchers in clinical nephrology, human physiology or renal histopathology. But if one wants to understand what kidney disease means for the daily life of an renal patient, then it becomes an issue for qualitative researchers, who can be psychologists, psychoanalysts or other human scientists⁽⁹⁾. However, it is much appropriated that health professionals adopt qualitative methods themselves. Nurses, for instance, bring the great advantage of having, due to their practice, an inherent clinical and existential attitude, which will lead them to collect data richly and to derivate new knowledge with high competence.

On the one hand, knowing what the ill people imagine about their illness conducts to a harmonious nurse-patient relationship. On the other hand, it is always highly indispensable to know what things, in general, mean for people, because *symbolic meanings* have a crucial *structuring function* in the individuals' life. Around of what the things mean for ones, they organize their lives, including the healthcares of themselves. Besides, it was taken into account that the core property of the meanings is its always-present polysemy.

From these principles, in order to achieve the proposed goals, this research elected the so-called clinical-qualitative method, which definition is found to be delimited at the health sciences' methodology literature⁽¹⁰⁾. This method is understood as a particularization and a refinement from the generic qualitative ones, as developed into the human sciences and it has been proved as being adequate for qualitative researches performed in health field.

Its methodological construction comprehends *"the theoretical study - and its corresponding use in investigation - of a set of scientific methods, techniques and procedures, adequate to both describe and interpret the senses and meanings given to the phenomena and related to the individual's life, these being patients or any other person participant of the healthcare setting (relatives, members of both the professional team and the community)"*⁽¹¹⁾. The data collection tool was the *semidirected interview of open-*

ended questions, which seeks to get a strong-willed depth for the questions under investigation. For this sample, it was looked intentionally for women, which had both information on the focused matter and characteristics of good verbal expressiveness, in order to bring data, at least, for the intended reformulation, deflection, complementation and/or clarification of the initial hypotheses⁽¹²⁾.

The following inclusion criteria for patient selection had been established: (a) women in fertile age under hemodialysis treatment; (b) medical, emotional and intellectual conditions to be submitted to a clinical-psychological research interview; (c) participation agreement according to the Term of Free and Informed Consent approved by the Ethics Committee of the institution. Finally, some criteria were considered non-excluding ones, such as: gender, age, origin, conjugal status, family composition, educational level, socioeconomic status, and beliefs/religion. However, to deal properly with eventual bias, the variations of these data were taken at the discussion section.

The study sample consisted of nine women in hemodialysis, which was closed by *saturation criterion*. The set of the transcribing interviews, forming the *corpus*, was submitted to the *qualitative content analysis*: free-floating readings were made by the authors in order to well acquaint all the informative material. Once the *categorization procedure* was performed and the topics were discussed, the researchers chose two categories to present in this paper.

It is known that the qualitative analysis of a set of interviews does not allow defining its categories from frequencies of certain citations neither any type of information (or from other mathematization resources). The questions, which gain the category status, were those that reply consistently to the initial objective or another one assumed during the fieldwork. After the rereadings, aiming this writing, the categories defined were the following: (1) quality of life in hemodialysis, normality/normativity, stigma and pregnancy and (2) ideas of adoption as a possibility of playing the motherhood role.

RESULTS AND DISCUSSION

In terms of research procedures in field, the first stage consisted of the contact with the direction

of the Integrated Center of Nephrology from the UNICAMP, which acquiesced in the project development in this service. Due to methodological needs of new information collections, the sample was extended to another city hospital, a partner of the public health service, until the data had reached the saturation point. The interviews were made on the routine dialysis session days, having occurred before or during the sessions. The same space of the hemodialysis wards was used as a setting to the psychological interviews. It was aimed, with the help of the nursing team, a strategy that guaranteed the interviewee's privacy, forming an empathic and confidential relationship between subject-patient and researcher-interviewer.

Quality of life in hemodialysis, normality/normativity, stigma and pregnancy

The interviewees brought generically several conceptions, which reflected relevant worries with both alterations and aggravation of their health conditions. The central concern seemed to be their quality of life. It is very well known that to receive a diagnosis of a serious illness is a disturber event able to change life course in many aspects. Thus, a complicated life due to hemodialysis, in principle, is an "external" factor that would control the desires linked to the body, for instance, to become pregnant. Desire was understood as a strong feeling that used to move to the attainment of something that is within the reach in reality or imagination. It may also conduct to rupture feelings of individual welfare, now carried by revolt and fear for a nameless something.

"Ah, for me it was the worst of the world. I had no idea what hemodialysis was. It was despair for me... Then, I noted that it was not like this... In the beginning, I did not want to accept it, and after I had to see that I did not have more... The kidney had already stopped!" (Patient 01)

On its turn, the emotional adaptation occurs in a slow and gradual form facing limitations imposed by the illness, sometimes reaching resignation, another times having passed by indignation.

"Ah... Now, I have my home, and I have my things to take care. I have my son, thanks god, who I got. It was my goal. Every woman has the will of being a mother. So, for me, having to do hemodialysis is difficult to incase in my life. People become incapable of doing many things, neither they can take a trip, nor they can eat whatever they like, nor to think of drinking liquids." (Patient 07)

Despite the objective worsening these women's quality of life, it is imposed a discussion on the *normality versus normativity* question, since the interviewees, contradictorily, believed they had a normal life. Therefore, health professionals must consider the conceptual differences between such conditions forth certain diseases. From a Canguilhemian vision, disease is a medical abnormality, but it can express a normativity that does not consider the nosological entity as something incompatible with normal functioning of quotidian life. In the light of medicine's epistemology, *health is more than normality; in simple terms, it is normativity*⁽¹³⁾.

For health professionals' team, chronic renal failure is an abnormality from the medical-scientific viewpoint, but there is a psychosocial vital force that resists to the disease, according to an established normativity. The restrictions imposed by treatment were perceived as being multiple by the subjects under this study, however these women considered that, although experienced the limits of their familiar and social activities, their lives were practically normal.

"My life is good, I do the housekeeping and I take care of my children... On the days when I do not feel encouraged, I do nothing. But on those days when I (fell animated) am livened up, I work hard in my things... Hemodialysis can make me physically bad, you know, but I am not lazy..." (Patient 05).

Paradoxically, a treatment full of both life restrictions and impositions to obtain positive outcomes or, considering better, to allow greater survival (continuance of life under so adverse conditions) for these patients, leads us to reflect about certain *stigma*, as a meaningful sociological event, for who submit themselves to such procedures. Being sick is to forge a new personal identity. In the social dimension, there are illnesses that become an indelible mark. Since the Ancient Greek Culture, which had apparently many visual aids, there has been the term *stigma* to allude to *bodily signs designed to expose something unusual and bad about the moral status of the signifier*⁽¹⁴⁾.

The signs were inflicted on the body and served to advertise that the bearer was a slave, a criminal, or a traitor: a stained person in order to be avoided, especially in public places. During the Christian times, however, two levels of metaphor were attached to the initial meaning: one was referred to bodily signs of holy grace that took the form of eruptive flowers on the skin; another one was a medical mention to this religious reference, considered

as bodily signs of physical disorder. Nowadays, many students believed that this word is employed in something like the original literal sense, but it is utilized more to the disgrace itself than to its bodily evidence. Besides, changes have occurred in the disgrace types that cause concern. In spite of that, sociology recognizes that there is still little effort to characterize the structural preconditions of stigma, or even to provide a satisfactory definition of it.

In the case of women "marked" by hemodialysis, beyond the bodily stigmas-signs resulting from the treatment, such as arteriovenous fistula, there is mainly the psychosocial stigma due to being people limited in taking a normal familiar, professional or social life like many others. The pregnancy, in this context, may be perceived as doubly stigmatizing due to wound symbolically, in certain way, a stereotype imposed by society, of being a healthy body woman waiting for the motherhood

"When I started doing hemodialysis, my psychological conditions had been very puzzled. I wore only long sleeve blouses due to the fistula in my arm. But I started doing psychological treatment. One day, I interrupted the psychotherapy and told myself: I will live a common life." (Patient 02)

Ideas of adoption as a possibility of playing the motherhood role

Chronic renal failure, its restrictions and risks bring conflicts to nephropathic women, related to both motherhood and femininity, in special to patients who did not had children previously to of their disease diagnosis⁽¹⁵⁾. In any case, the ambiguity of feelings and thoughts seems to become a psychological rule forward so disquieting illnesses.

"I would like to have children, but at the same time I would not like it. When I was a child, I used to say I did not want to have them. So, I passed through an age that I desired to have children. But then all this happened. It became a subject about that I do not think anymore and it does not worry me." (Patient 02)

From a psychoanalytical view, motherhood responds to the human being's desire for giving continuity to life, immortalizing the existence of who had both generated life and become capable to make a history⁽¹⁶⁾. The women under hemodialysis, when inquired on the meanings of being mother, reproduced the motherhood psychocultural model in their speech.

"To be a mother must be good, right? I think it is the every woman's dream... to build a family... to feel quite ideal achieve, doesn't it? I think it is that so..." (Patient 05)

All indicates that there has being an intense sociocultural and moral pressure for a couple to bear children, establishing thus a familiar nucleus. The interviewees had found themselves facing a social pressure, unveiled by metaphors, such as "to be a tree without fruits" or a "dry tree", which are some depreciating expressions for those who, due to any reason, had not constituted a socially determined familiar group. As inserted in this context, some women had idealized the adoption as a concrete possibility of having a motherhood role in fact, but exempt from risks to both, themselves and children.

Adoption, according to the some patients' sight in dialytic treatment, had started to be a relevant question in their minds. This possibility, besides symbolizing a generosity act, would represent a solution toward a personal psychological demand.

"I have already thought that, if I got marry, I would adopt a child. But I have already given up the pregnancy itself because of a risk that I run, that the baby runs. I have dealt this subject with my family and I have already talked about it with them." (Patient 01)

It was found, in these speeches, an ambivalence of attitudes due to a strong motherhood desire, even so it does not reveal itself in a clear way. Contrary thoughts imply in a psychological conflict, in part caused by treatment real limitations. Thus, cogitating a child adoption might represent good mental health conditions. Fantasy adoption by itself, even though it does not materialize, seems to improve the women's self-esteem. Psychoanalytically, imagining is at least partially rewarding.

Finally, strengthening the motherhood idea is perhaps always an actual feeling, even to those patients who already were mothers. The true restriction to a new pregnancy seems to make them revive the desire of being mom once more

"Ah, after starting to dialyze, the doctor said that I could not... And I put in my head that I could not... although I really would not want another child, right? It occurs that my plan was to have a couple of children and I had them. My husband and I did not have plans of having children anymore. Then, it means that the hemodialysis did not affect me too much, ok?" (Patient 08).

CONCLUSIONS

The studied women experienced different degrees of desires of both pregnancy and to become mother again, clearly or not in their consciousness, now challenged by the real condition of a limiting chronic illness, such as the renal failure. This affective-existential situation may generate a special but not necessarily abnormal anguish, which must be held by health professional team. There is a recognized social pressure for women in order to assume a mother's role in our culture. Being inserted in this psychoanthropological context, some interviewees had idealized the adoption as a possibility of playing the motherhood, but exempt from clinical risks to both themselves and children. Adoption, according to the some patients' sight, under dialytic treatment, had started to be a relevant question in their thoughts. This possibility, besides symbolizing a generosity act, would represent solution toward a deep individual demand. Fantasy adoption by itself, although it does not get to perform, may enhance the women's self-esteem.

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