

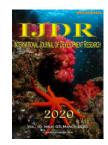
ISSN: 2230-9926

RESEARCH ARTICLE

Available online at http://www.journalijdr.com



International Journal of Development Research Vol. 10, Issue, 03, pp. 34312-34317, March, 2020



OPEN ACCESS

EXPERIENCES, MEANINGS AND PERSPECTIVES OF PEOPLE WITH CHRONIC RENAL FAILURE AFTER KIDNEY TRANSPLANTATION

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ARTICLE INFO

Article History: Received 19th December, 2019 Received in revised form 21st January, 2020 Accepted 19th February, 2020 Published online 30th March, 2020

Key Words: Kidney Transplantation. Quality of Life. Emotions. Renal Insufficiency, Chronic.

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ABSTRACT

Objective: To investigate the meaning, experiences and perspectives of people undergoing kidney transplantation, registered with the Association of Chronic and Transplanted Renals of the State of Pará, Brazil. **Method:** descriptive, exploratory qualitative research using an interview script as a tool and semi-structured interview as a collection technique. Participated in the research 10 people submitted to kidney transplant, registered in the Association of Support to Chronic and Transplanted Kidneys of the State of Pará. Research carried out in April 2019 and, for the construction of the data, the content analysis technique proposed by Bardin was used. **Results:** the participants consider that the transplant gave them a new life, recognizing that it allowed them to resume their quality of life and conditions prior to the disease. **Conclusion:** kidney transplantation has a meaning of blessing and represents the expectation of being able to return to your life and continue where you left off; it represents hope for a better life and to be able to envision a healthier future, which may require the collaboration of family members and health professionals, and personal care peculiar to the new condition of life.

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Citation: *Maicon de Araujo Nogueira et al.* 2020. "Experiences, meanings and perspectives of people with chronic renal failure after kidney transplantation", *International Journal of Development Research*, 10, (03), 34312-34317.

INTRODUCTION

The kidneys are organs located in the posterior abdomen wall, outside the retroperitoneal cavity. They perform several important functions for body homeostasis, such as excretion of metabolites and foreign chemicals; regulation of the osmolarity balance, water and electrolytes in the body; regulation of systemic blood pressure; acid-base balance; regulation of red blood cell production, among other functions. To perform such functions, the organ has the nephron as a functional unit, where each kidney contains 800,000 to 1 million nephrons, exercising the function of blood filtration. The kidney does not have the capacity to regenerate its nephrons; therefore, any kidney damage, aging and other comorbidities have the potential to decrease the amount of nephrons, with the impossibility of tissue recovery (Rodrigues, 2019). Chronic renal failure (CRF) is a disease that causes structural or functional damage to the kidneys. Slowly, insidiously and irreversibly, it causes a decline in the quantity and function of nephrons. Such pathology can be caused by other underlying etiological factors, such as: genetic abnormalities, systemic arterial hypertension (SAH), obesity, smoking, autoimmune diseases, glomerulonephritis and other diseases (Jesus, 2019). Due to the progressive loss of renal tissue, several organic and psychosocial changes are beginning to appear, and this directly interferes in the quality of life (QOL) of people affected by CRF. Urine color, pain or burning when urinating, urination several times a day and at night, SAH, nausea and vomiting, loss of libido, tiredness and muscle atony are common symptoms of CRF. The uremic crisis, the consequence and the most serious clinical condition of CRF, occurs because the blood ends up not being properly filtered and, thus, several metabolites remain in the bloodstream, triggering a cascade reaction at the systemic level (Marçal, 2019). Currently, this disease is a public health problem and worldwide. This statement is due to the fact that the rate of morbidity and mortality is high, in addition to the negative impact on people's QOL. Over the years, the number of patients undergoing dialysis, one of the therapeutic strategies in the management of CRF, has been gradually increasing, causing direct and indirect impacts on public coffers, patients and families. It is estimated that, worldwide, kidney and urinary tract diseases are responsible for approximately 850 million deaths annually, and CRF increases by around 8% per year. In Brazil, about 12 million people have some degree of Renal Insufficiency (RI) and approximately 95 thousand chronic kidneys depend on dialysis to survive (Silva, 2016 and Brito, 2019). There are three different types of treatment for CRF, which are: hemodialysis (HD), peritoneal dialysis (PD) and kidney transplantation (TxR). HD consists of the filtration of blood through a machine, which performs kidney function. PD is the process in which kidney function is replaced by a filter that uses the force of gravity to do this work inside the patient's body through a cavity between the organs (peritoneal cavity). TxR is a surgical option, where a kidney is removed, in a living or deceased person, and its implant in the recipient. The TxR is the most complete treatment alternative, in this sense, it is essential to understand that the patient has the right to choose or refuse the surgical alternative (Fernandes, 2015).

When choosing to treat CKD using TxR, patients have a tendency to believe that their lives will return to pre-diagnosis. However, this therapeutic modality requires several restrictions (dietary, physical, and pharmacological - through

immunosuppressants). Upon learning of these facts, various feelings, such as guilt, remorse and hopelessness, come to the fore, mobilizing in the individual, a feeling of loss of autonomy, QOL, fragility and mourning (Fernandes, 2015). In addition to the difficulties inherent to TxR, individuals are challenged to live with a range of negative factors, such as side effects and changes in drug dosages, psychosocial pressure to return to their autonomy and difficulties in professional adaptation (Brito, 2019). In this context, conditions that impact on QOL emerge, understood as the human notion about the degree of satisfaction in their family, loving, socioenvironmental life and the existential aesthetic. The set of these factors is what society considers a standardization of comfort and well-being, impacted by a chronic disease such as RI (Santos, 2018). Given the above, this work aims to investigate the meaning, the experiences and perspectives of people undergoing kidney transplantation, registered at the Association of Chronic and Transplanted Renals of the State of Pará, Brazil.

MATERIALS AND METHODS

Descriptive, exploratory study with a qualitative approach, carried out in a Support Association for Chronic and Transplanted Kidney People in the State of Pará, Brazil, in the period of April 2019. Ten patients participated in this research, which were identified by means of alpha numeric codes, with the following name: "P1, P2 ... where the" P "means participant and the number in the order in which they were addressed in the interview. An interview script was used as an instrument for data collection, and the semi-structured interview was used as a technique, where the interviewees' speeches were recorded, for transcription, analysis and interpretation. The sampling was carried out for convenience, through the snowball process, where the interviewees and / or service professionals indicated individuals to participate in the research. The sample closure was due to saturation around the thematic axes. Minayo (2017), describes that in this type of research, the researcher closes the group when after the information collected with a certain number of individuals, new interviews start to present a few repetitions in their content (Minayo, 2017). The inclusion criteria were: people who underwent kidney transplantation, of both genders, aged between 18 and 60 years old, with the ability to talk, registered with the Association of Chronic Kidney Transplants of the State. The exclusion criteria were: people who were not submitted to a kidney transplant procedure, those who were not in full mental faculties or had speech limitations.

The content of the interviews was transcribed in an original way, preserving the expressions used by the participants. However, to use them as a unit of analysis, orthographic corrections were made, excluding language vices, exchange or absence of letters, but maintaining the linguistic vices that have meaning in the context of speech. From the collection of information, it proceeded to the construction of the data, from the methodological framework of content analysis proposed by Bardin (Bardin, 2016). The study corpus made it possible to organize the content into empirical categories, grouped according to the theme extracted from the responses. The results allowed the construction of four empirical categories, namely: Understanding life before transplantation, Knowledge and meanings about kidney transplantation, Understanding transplant recipients about the changes that occurred after the procedure and the main difficulties encountered and Changes

and improvement in the quality of life after transplantation (Bardin, 2016). This research was submitted to the Research Ethics Committee (REC) of Instituto Campinense de Ensino Superior LTDA, Universidade da Amazônia (UNAMA), CAAE: 06943219.8.0000.5173, with approved opinion, number 3.211.767, in 20/03/2019. All participants signed the Free and Informed Consent Form (ICF) and the Voice Recording Authorization Form before participating in the study. The research was carried out following the norms that regulate research involving human beings contained in the resolutions nº 466/12, 510/16 e 580/18 National Health Council (CNS) / National Research Ethics Commission (CONEP).

RESULTS

Among the ten participants, six were male and four were female. Age ranged from 35 to 56 years, mean 48.6, median 49.2 years, with a standard deviation of 6.4.Half of them were single (50%), 30% had high school and higher education, respectively. The predominant religion is Catholicism with 70% and the transplantation time varied between 1 to 14 years. Participants were characterized according to marital status, gender, age, education, religion and time of transplantation (Table 1).

traveling! I couldn't travel. I had no life. I was a prisoner of that machine" (P2).

"[...] Difficult, very difficult" (P10).

Knowledge and meanings about kidney transplantation: This category analyzes people's knowledge about kidney transplantation, the meanings attributed to this therapy and how it intertwines and impacts in different ways on the continuity of life. The speeches allowed the understanding that the interviewees had no knowledge about the disease before the diagnosis, as observed in the following reports:

"[...] Nothing, I didn't know anything! Today I know a lot more, and I will be more careful" (P1).

"[...] No, I never knew (pause) anything. I found out when I got sick, what happened to me. I had a lot of hope to perform the transplant, it was a lot of suffering to wait for the kidney, a lot of anguish" (P2).

"[...] I was ignorant in that part. I had never heard of a kidney problem, or hemodialysis, or anything. What I do know is that it was extremely distressing to wait for the transplant" (P8).

"[...]Before I knew almost nothing, I confess" (P9).

"[...]I even attended some lectures. I asked my doctor at the clinic a lot, but I was always very limited in this matter" (P10).

 Table 1.Characteristics of the study participants, according to marital status, gender, age, education, religion, Belém, Pará, Brazil, 2019

Interviewee identification	Gender	Age	Marital Status	Education	Religion	Transplant time
P1	Female	35	Separated	incomplete elementary school	Catholic	7 years
P2	Male	49	Married	incomplete elementary school	Catholic	7 years and 6 months
Р3	Female	49	Single	complete high school	Catholic	7 years and 10months
P4	Female	50	Married	complete primary education	Catholic	14 years
P5	Male	56	Single	incomplete high school	Catholic	1 year and 8 months
P6	Male	52	Single	higher education	Catholic	5 years and 3 months
P7	Male	56	Married	higher education	spiritist	2 years and 6 months
P8	Female	41	Single	complete high school	Catholic	6 years and 4 months
Р9	Male	47	Single	complete high school	Evangelical	3 years and 4 months
P10	Male	51	Married	higher education	Evangelical	11 months and 20 days

Source: Field Research, Belém, Pará, Brazil, 2019.

The results indicate aspects related to the experiences, senses and meanings attributed to the important and significant changes occurred in the lives of people undergoing kidney transplantation, thus defining the following categories resulting from the research.

Understanding life before transplantation: This first category describes the meanings attributed by the participants to the experiences before the transplant, highlighting issues related to CRF and the treatment of renal replacement therapy, especially hemodialysis, considering that this is a process that causes discomfort and impacts on several aspects in life of people. Thus, the speeches made it possible to understand that this therapy seems to be understood as a form of "imprisonment" that leaves a mark on people's lives even after undergoing kidney transplants, considering that the interviewees mention the treatment of hemodialysis as a difficult and arduous, as can be seen in the following reports:

- "[...] The life of patients on hemodialysis is not easy" (P3).
- "[...]I say I was hostage to a machine" (P3).

"[...] I have freedom now. I feel like doing something, I go there and do it" (P5).

"[...] You need to undergo hemodialysis all the time, you have the problem of not drinking water, the problem of

In this study, participants highlighted kidney transplantation as significant, especially for those on hemodialysis. The expectations of a transplant are related to the hope of a new life, of improving his biopsychosocial and spiritual condition.

It is emphasized that the transplant has a meaning of hope and faith, providing the person with the opportunity to gather conditions to free themselves from dependence on hemodialysis, resume their autonomy of life and continue their daily routines. And among the highlighted aspects that most contribute to such reframing, the time and feelings they experienced during the hemodialysis process and the changes that occurred after the transplant stand out. Discourses were identified that allow to understand the meaning attributed to the kidney transplantation procedure, and how it is related to the improvement in QOL after the procedure. People relate the idea of kidney transplantation as something that freed them, as evidenced in the statements:

"[...] I was reborn. Today I know a lot more, and I will be more careful" (P1).

"[...] For me, a better life. I started to know things that I didn't know, even taking certain precautions in my diet, in my way of acting" (P2).

"[...]100%, improved. I feel reborn ... Because that machine over there (pause), that there is no life there! Of

course, we live because we are obliged. I feel reborn, another life" (P4).

"[...] Improved. No need to go to the hospital, things like that! It's not in a machine. Regarding health changed, I'm no longer hostage to that machine" (P8).

"[...] It's like I said ... the fact that I could do those things that were prevented from doing again, right, reborn. Renewed Faith"(P10).

Understanding of transplant recipients about the changes that occurred after the procedure and the main difficulties encountered: In this category, speeches were identified that allow inferring that the transplant allowed significant changes in people's daily lives, as well as the main difficulties experienced by the participants. Data emerged that associate well-being and emotional growth with transplantation, and consequently positive changes in QOL.A highlight was given to changes related to food, travel, leisure, returning to family life, and independence from the hemodialysis machine, as can be seen in the speeches:

"[...]Improved in relation to food and water intake, liquids in general" (P1), (P5).

"[...] The first change was that I was able to return to my home. live with my family again (pause), because I lived here, and the husband had to stay! Many good things, I will tell you like this, the first thing I know is this (pause) being able to go home again"(P4).

"[...] Major life changes. Now I can do what I did before. Whenever I can I still go with my friends to "ball"" (P7).

"[...] Life-changing. Look for a job. (P6).

"[...]I left the hemodialysis machine" (P8).

Changes and improvement in quality of life after transplantation: The results show that the participants attribute a new meaning to this new life that begins with kidney transplantation. Lifestyle changes, mainly related to hemodialysis treatment, emerged as something that profoundly affects the daily lives of these individuals in family, professional and social relationships, which end up changing habits and lifestyle. The return to day-to-day routines stood out, as they no longer needed the hemodialysis machine. From the findings, it appears that QOL was restored and reframed, with the return of their autonomies, which allowed them to perform activities that were previously prevented due to the limitations imposed by the disease. The revealed speeches show that people give a new meaning to life, mentioned here as "new life", as they report:

"[...]I started to know things that I didn't know, even taking certain precautions in my diet, in my way of acting! New life" (P2).

"[...] Yes, it's almost normal. Can I drink water! I take medication, but now everything is reduced. I took 3, I took 2, I take 1" (P6).

"[...]Improved. You don't have to go to the hospital and stuff, it's not in a machine. In relation to health it changed, I am no longer hostage to that machine, new life!" (P8).

"[...]It didn't improve, it was excellent". I started to eat better, quality of life improved, I go out more, I can take a trip, I feel reborn" (P3).

DISCUSSION

Understanding life before transplantation: Feelings of uncertainty, sadness and frustration were reflected in the

speeches, allowing to understand the difficulties faced by the patients in this study, with regard to the limitations and clinical manifestations underlying the chronic disease and its hemodialysis treatment, and these findings are in line with other studies (Santos, 2016 and Galvão, 2019). The statements highlight feelings of "imprisonment" or "dependence on the machine" during hemodialysis treatment sessions, and reports of hope and freedom were associated with TxR. A world full of rules and treatment routines that surrounds the patient, has emerged as a major nuisance and that deeply impacts the QOL of chronic kidney patients. Hemodialysis sessions take place from three to four hours, on average three times a week, and this has a significant impact on the daily routines of the participants in this study (Riegel, 2018). In this perspective, corroborating the findings, Santos et al. (2016) states that kidney transplantation is a treatment that considerably improves the QOL of people with CRF. The freedom gained after the transplant is comforting to them, as they feel free to do things that they could not do before. However, the person and the family are presented with various precautions that a person must receive when having a new kidney, as the transplant does not exclude the chronic character of kidney disease (Santos, 2016).

Knowledge and meanings about kidney transplantation: Regarding knowledge, it was found that before the transplant was carried out, the participants had low levels of knowledge about the subject. From these findings, it appears that the topic was little discussed during the treatment trajectory of the respondents, corroborating the development of taboos, myths and mistaken beliefs. For Santos et al. (2018) every treatment performed through transplantation causes several hesitations, ambiguities, and uncertainty in patients. In the face of such complexity, education and awareness-raising policies about kidney transplantation are needed, aimed at professionals, health students and the population in general (Santos, 2018).Regarding the meanings attributed by the participants, the findings allow to interpret the transplant awareness as a new beginning, a new chance to live. Feelings and expectations of hope emerge around the transplant, and these feelings that permeate patients' experiences are supported by the desire to have a new life, significant change in QOL and the desire to start over. In the meantime, the possibility of transplantation appears as a reality since when people are notified about the need and possibilities of treatment, and consequently the inclusion of this in the transplant "queue"; and this possibility starts to be understood as the only resource and way to return to the conditions of life before the disease, a real possibility of cure and return to life called "normal" (Brito, 2019).

Understanding of transplant recipients about the changes that occurred after the procedure and the main difficulties encountered: The speeches made it possible to infer that the transplant made it possible to reestablish itself in the biopsychosocial and spiritual state, making it possible to carry out activities of daily living, previously prevented by the disease and treatment routine. Based on the findings, it is considered that the transplant provided a new existential sense to patients. The search for new ways and means of living under the conditions after the transplant is highlighted, taking into account that the patient still experiences the constant risk of organ rejection, making it necessary the daily use of immunosuppressive drugs, and the adaptation to a new lifestyle. Silva (2015) states that the expectation that comes

through the transplant procedure is related to the feeling of freedom that comes from not depending on hemodialysis machines and the obligation of weekly treatment sessions (Silva, 2015). In the reports it was noticeable that the feeling of hope was renewed after the transplant and that there were beneficial changes, which allowed to express feelings of joy, reestablishment of dreams and perception of freedom. The change in physical conditioning and health was another point reported. On this subject, Navarrete and Slomka (2014) corroborate the evidence of new horizons and hope after kidney transplantation, linked to the desire to have a new life and a significant change in QOL (Navarrete, 2014). This statement was ratified by Brito et al. (2015), referring that the meaning of the transplant goes through an expectation in the increase of the QOL and hope of a better life, mainly for the belief of the liberation and independence of the hemodialysis machine (Brito, 2019).

Changes and improvement in quality of life after transplantation: Despite the different meanings attributed by patients to the performance of kidney transplantation, the posttransplant experience led to a feeling of expectation for a better life. It should be noted that the expectation attributed to kidney transplantation encompasses the socio-cultural dimensions existing in the life of everyone submitted to it. Although kidney transplantation improves the patient's life in several aspects, it is necessary to understand that this procedure does not exclude the chronic nature of the disease, since the person will still have some limitations and dependencies on care, medications, professional monitoring and institutions of health. It is understood that the person needs to reinvent himself in the way he will live, looking for other ways to deal with his limitations and at the same time being able to be more autonomous than he was before the transplant. For this reason, it is essential to monitor health professionals, especially nurses, to assist in this quest to improve QOL (Brito, 2019). Kidney transplantation allows the patient to eat a less strict diet, compared to before the transplant, and thus can drink water normally. Water is a vital element for human beings. One of the factors that increase QOL is the possibility of the person being able to ingest this liquid without worries, since during dialysis treatment, they remained with restrictions in the amount of liquid ingested in a certain period (Santos, 2017).

This study showed that after kidney transplantation, people had a significant improvement in QOL. Discourses emerged with reports of return to activities of daily living which were impossible before the transplant. Participants consider that their autonomies have been restored almost completely, which also contributed to the improvement in QOL. Corroborating these findings, Brito et al. (2018) describe that kidney transplantation, in addition to allowing the rehabilitation of the patient to a normal lifestyle, also enables significant savings for the health system. It is worth mentioning that, although transplantation has been considered the most cost-effective treatment, one must consider the setback of organ procurement and the need for a well-equipped transplant center and a defined and competent multidisciplinary team (Brito, 2019). Thus, the disease process caused by pathologies, in this case, kidneys, gives individuals the possibility to reflect on their lives and values, since they were between life and death, and now, they are receiving new opportunities conquered after the transplant. The transplanted ones, in most cases, believe that they have been provided with a reunion with life, a time when the values previously learned are rethought; understand and recognize the real meaning of being alive, making a personal commitment to value life (Santos, 2018). Regardless of the several positive and negative characteristics that the transplant produces in patients with CRF, it is evident that the performance of this procedure allows a new meaning of their lives, which were marked by the realization of dialysis sessions for a long period (Brito et al. 2018). QOL is directly related to hope and spirituality, the greater the tranquility and happiness of a person, the greater the chance that they will have a high QOL, which is believed that in the context of the life of chronic kidney people it is a quite dimension affected by the strenuous treatment routine and the limitations imposed by the disease (Brito, 2019 and Malaguti, 2015).

CONCLUSION

It was found that the methodological resource applied allowed the understanding about the meaning, experiences and perspectives of people submitted to kidney transplantation, thus responding to the objective proposed in the present study. In the meantime, it was found that kidney transplantation aims to promote QOL and enable greater autonomy, despite the need for care following treatment after transplantation, given the chronic nature of kidney disease that does not end with the transplant. The view of transplant recipients indicated that expectations regarding kidney transplantation were achieved after the procedure was performed, with a feeling of rebirth and life change emerging. It was observed that the understanding about CRF and kidney transplantation were few, and that only after the beginning of treatment, this understanding was consolidated and increased considerably. This study provided an understanding that kidney transplantation has a blessing meaning for the person with CKD, and represents the expectation of being able to return to their healthy life and continue from where it was interrupted; represents hope for a better life and to be able to glimpse a healthier future, which in a way may require the collaboration of family members and health professionals, and personal care peculiar to the new life condition, thus characterizing the care network and support the transplanted person.

It was found that the independence of hemodialysis treatment, the fact of being able to plan life better, being considered peaceful and normal, the feeling of well-being, the adoption of health care and the absence of some restrictions in the activities to be performed, counterbalanced with factors related to changes in dreams, changes in interpersonal relationships, obligation to use immunosuppressive medication, nonperformance of work activities, the finding that the durability of the transplanted organ is not eternal, in addition to the constant search for knowledge of rights and the way people should act. It was noted in the statements that, although there were changes in the person's life, the transplantation process did not represent significant changes that would lead to suffering or despair. On the contrary, it represented a new life, which was permeated by a better QOL than when undergoing hemodialysis. Faced with what the transplantation process provided in people's lives, they highlighted the independence of hemodialysis treatment, the existence of a peaceful and normal life and the feeling of well-being. The transplant promoted changes that led to a new reality. Although important changes have occurred in the person's life, kidney transplantation did not represent significant changes that would lead to suffering. The disease experience of kidney

transplant patients integrates meanings about the disease to the meanings constructed throughout their narrated life trajectories, based on the meanings about the phase in which they experienced hemodialysis, the way the transplant was carried out and, now, as transplanted. The importance of a network of health services that offers care to people in this condition was evidenced, since they need continuous monitoring. The contribution of this study, in the voice of kidney transplant recipients, reveals their health needs, from the moment the need for the procedure is identified, until the moment when they start living as transplanted patients, in addition to highlighting that the Nursing has a primary role in building positive meanings in the lives of people with kidney transplantation. With the results of the present study, we understand that it is necessary to train new professionals in this area, so that there is greater attention to patients who will be submitted to such procedures, and thus, due awareness is given about this theme. It is also necessary to conduct further studies addressing the health professionals who help these people, in order to better understand the awareness process between professional and patient. In this sense, it is expected that this study will contribute to the construction of knowledge related to the person's life after kidney transplantation. And so that health professionals, especially nurses, have theoretical subsidies to assist in this experience, which is permeated by positive and negative consequences. It should be noted that, like all scientific studies, this research has some limitations that can be minimized in future works. One of them is the reduced number of participants, from a specific region of Brazil, making it difficult to generalize the results obtained, which, however, enabled us to achieve the proposed objective. Another limitation, despite all the precautions, concerns the possible information bias on the part of the interviewees, such as lack of attention or understanding, haste to respond, selfcensorship and fear of being identified through the statements, considering the fact of being few participants in this scenario in the State. However, these limitations did not detract from the results of the study and the conclusions we reached. The work records the meaning, the experiences and perspectives of people who have undergone kidney transplantation, and their results can serve to provoke discussions and for future comparisons, since this type of study should try to cover a larger number of institutions, federation units and people who experience CKD submitted to TxR. It is concluded that this study corroborates to reveal the vision and meaning of the experiences of kidney transplanted people about the importance and impacts of transplantation in their lives.

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