ORIGINAL

Health service clinical information system after kidney transplantation, from the perspective of users and professionals

Sistema de informações clínicas nos serviços de saúde pós-transplante renal na perspectiva de seus atores El Sistema de información clínica después de trasplantes renales, desde la perspectiva de sus actores

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ABSTRACT

Objective: to analyze the organization, registration, and storage of patients' clinical data after kidney transplantation in health services. **Methods:** qualitative study conducted between the first and the second semester of 2016, with kidney transplant patients, professionals, and managers, totaling 30 participants. The data were collected through individual interviews recorded in audio, transcribed, and organized in the software Etnography. Then, they were analyzed in a guided content analysis. **Results:** the participants explained the existing types of medical records, that after the kidney transplantation are filed by the nephrology service where the person underwent dialysis. However, in cases of return to dialysis due to the failure of the transplanted organ, participants referred to the organization of the service for the recording of information about care. At the transplant center, the participants mentioned how the complications of health conditions, the results of laboratory tests, and the instructions transmitted are recorded. **Conclusion:** the use of tools and instruments in the organization, recording, and storage of clinical data during assistance helps health professionals in making decisions about the care to be provided and facilitates the exchange of information, providing quality of care.

Descriptors: Renal Insufficiency. Chronic. Kidney Transplantation. Information Systems. **RESUMO**

Objetivo: analisar a organização, o registro e o armazenamento dos dados clínicos das pessoas após o transplante renal nos serviços de saúde. **Métodos:** estudo qualitativo realizado entre o primeiro e o segundo semestre de 2016, com transplantados renais, profissionais e gestores, totalizando 30 participantes. Os dados coletados foram entrevistas individuais gravadas em áudio, transcritas em meio digital e organizados no software Etnography, para serem analisadas a partir de uma análise de conteúdo dirigida. **Resultados:** os participantes explicaram os tipos existentes de prontuários, que depois da realização do transplante renal são arquivados pelo serviço de nefrologia onde a pessoa realizava o tratamento dialítico. Porém, em casos de retorno à diálise pela falência do órgão transplantado, participantes referiram a organização do serviço para o registro de informações sobre o atendimento. Já no centro transplantador, os participantes mencionaram como ocorrem os registros das intercorrências no estado de saúde, dos resultados de exames laboratoriais e das orientações transmitidas. **Conclusão:** a utilização de ferramentas e de instrumentos na organização, no registro e no armazenamento dos dados clínicos, durante a assistência à pessoa, auxilia os profissionais da saúde na tomada de decisão sobre o cuidado a ser prestado e facilita a troca de informações, proporcionando qualidade no atendimento.

Descritores: Insuficiência Renal Crônica. Transplante de Rim. Sistemas de Informação. RESUMEN

Objetivo: analizar la organización, el registro, y el almacenamiento de los datos clínicos de personas después de trasplantes renales en servicios de salud. **Métodos:** estudio cualitativo realizado entre el primero y el segundo semestre de 2016, con trasplantados renales, profesionales, y gestores, totalizando 30 participantes. Se colectó entrevistas individuales, gravadas en audio, trascritas en medio digital y organizadas en el *software Etnography*, para análisis de contenido direccionada. **Resultado:** participantes explicaron los tipos de expediente, que, después del trasplante renal, son archivados por el servicio de nefrología, en que la persona hace el tratamiento dialítico. En casos en que el paciente retorna a la diálisis debido a la insuficiencia del órgano trasplantado, pacientes hablaran de la organización del servicio para registrar informaciones sobre ese atendimiento. En el centro de trasplantes, participantes mencionaron como ocurren registros de complicaciones en el estado de salud, en los resultados de exámenes laboratoriales, y en las orientaciones trasmitidas. **Conclusión:** el uso de herramientas e instrumentos en la organización, registro, y almacenamiento de datos clínicos en la asistencia a la persona auxilia profesionales de la salud en su tomada de decisión sobre el cuidado a ser ofrecido, haciendo más fácil el cambio de informaciones y proporcionando cualidad en la atención.

Descriptores: Insuficiencia Renal Crónica. Trasplante de Riñón. Sistemas de Información.

INTRODUCTION

Chronic renal failure (CRF) is a highly prevalent disease in Brazil. It is characterized by an accumulation of toxins, with symptoms that become progressively worse. As a way to decrease the symptoms of uremic syndrome, control blood pressure, decrease blood toxicity and its side effects, dialysis is necessary, aiming at body homeostasis and thus reducing mortality. However, although fundamental, dialysis has an influence on people's nutritional, biochemical and psychological behaviors. (1-2)

Still, among the types of treatments for CRF, kidney transplantation has been considered the most effective option, in which the person receives a healthy kidney from a living or deceased donor. This treatment, thus, does not mean the end of the treatment, because it is necessary to periodically made a clinical follow-up. In this context, the Brazilian Organ Transplant Association (ABTO) pointed out that post-kidney transplant treatments require care such as: continuous use of immunosuppressive medication, dietary guidelines, and continuous physical activity according to the guidelines of the multidisciplinary health team. ⁽³⁾

For the success of the kidney transplantation, the person will need continuous care, being accompanied not only by the team responsible for the transplantation process, but also by the professionals of the nephrology service, when performing the dialysis treatment. Thus, it is important to offer quality health care, since people need coordinated assistance from the team responsible for the surgery, from the preoperative period to the numerous posttransplant review consultations.

Considering this, health services have invested financial resources in order to improve monitoring by clinical information systems. Clinical information is any information produced or used by health professionals to diagnose, evaluate, treat, or recover the health conditions of people who seek assistance. It needs to be clear, objective, effective, safe, and have quality, as it can aggravate the person's health conditions when it is not reliable. ⁽⁴⁾

Changes in the clinical information system aim to organize people's data to make the care more efficient and effective. This can be achieved through the provision of alerts, reminders, and feedbacks for health professionals and patients; the identification of subpopulations, depending on risks, for proactive and integrated health care; the development of an individual care plan for each person; the sharing of clinical information between health professionals and patients to enable coordination of health care; and the monitoring of the performance of the health team and the health care system. ⁽⁵⁾

In this context, the implementation of an information system improves the clinical practice, adapting health care and increasing the efficiency and effectiveness of health organizations. ⁽⁶⁾ It also encourages the organization of the information of patients who use the service, considering the continuity of a more efficient and effective care, in order to facilitate planning, the identification of special needs and the coordination of comprehensive

Health service clinical information system.. clinical care. ⁽⁷⁾ Considering this context, the objective of this study was to analyze the organization, the recording, and the storage of patients' clinical data after kidney transplantations in health services.

METHODOLOGY

This is a qualitative study, following the steps of the Consolidated Criteria For Reporting Qualitative Researches (COREQ) ⁽⁸⁾, being an excerpt from a Thesis, whose research took place in three cities in the southern half of Rio Grande do Sul: Pelotas, Rio Grande, and São Lourenço do Sul. The choice of these municipalities was based on their proximity, since they contain nephrology services and belong to the 3rd Regional Health Coordination of the State of Rio Grande do Sul.

People working in the nephrology services, who underwent kidney transplantations, professionals linked to the nephrology services, and managers who worked in instances associated with the Municipal and State Health Departments were invited to participate in the study. The estimated number of participants considered an intentional sample.

Thus, the total sample was composed of 30 participants, including 15 people with kidney transplants, 11 professionals from the renal replacement therapy services, and 04 managers, who fit the following inclusion criteria: for people with kidney transplantation, they had to be 18 years or older, have had at least six months of kidney transplantation, and have undergone hemodialysis or peritoneal dialysis before kidney transplantation; for professionals in the renal replacement therapy services, they had to have a degree, and must have worked for at least a year at the service; for managers, they had to occupy the position of superintendent of the sector responsible for the transplants, and must have worked in this position for at least a year.

Regarding the exclusion criteria for the selection of participants, the study excluded those who: among people with kidney transplantation, lived in the countryside, due to the difficulty of access and available means of transport; among professionals, those who were on leave from their work, for any reason (vacation, health, maternity, etc.); and for managers, those who did not perform activities aimed at caring for chronic diseases.

Since the research involved the participation of human beings in all stages, the principles of Resolution 466/2012 of the National Health Council of the Ministry of Health were followed. ⁽⁹⁾ The study was approved by the research ethics committee under protocol No. 1,548. 228 and CAAE 55712616.3.0000.5337.

Each participant was identified by a code: people with kidney transplants were specified by the letters PKT (Person with Kidney Transplant), followed by a number referring to the sequence of the interviews, plus the participant's age (for example: PKT1, 29 years old); professionals from the nephrology services were mentioned by the letters PNS (Professional from the Nephrology Service), followed by the number, followed by a number referring to the sequence of

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the interviews, plus the participant's age (for example: PNS1, 34 years old); and the managers were referred to using the letters HDM (Health Department Manager), followed by a number referring to the sequence of the interviews, plus the participant's age (for example: HDM1, 42 years old).

Data collection took place between the first and the second semester of 2016, through individual interviews conducted at the home of people with kidney transplantation and at the place of service of professionals and managers. The instruments that were used comprised scripts with questions adapted from the Assessment for Chronic Illness Care (ACIC) and Patient Assessment of Chronic Illness Care (PACIC) scales ⁽¹⁰⁾, such as: "The guidance received, the complications and the results of exams are registered in any system in the health services ?"; and "In the nephrology service, what type of clinical information exists to generate the record on the health status of people with kidney transplantation, in addition to preparing and monitoring the care?"

The data were recorded in audio and then transcribed digitally. For the management and organization of the information obtained, the software Etnography was used to help the analysis. For the generation of codes in order to proceed with the guided content analysis ⁽¹¹⁾, the data were read in full, at first, and, on the following stage, a line-by-line reading was performed, allowing for the definition of the codes to be established before and during data analysis.

RESULTS

First, it is important to know the actors who participated in the construction of these results. Thus, among the 15 participants, 10 were patients with kidney transplants, whose age ranged between 26 and 63 years, the majority being male.

As for the time of CRF of people with kidney transplantation, the minimum was one year and the maximum was sixteen years. The duration of the current renal transplant was from eight months to thirteen years, all of which were carried out in the capital Porto Alegre / RS. The main source of the transplanted organ was deceased donors.

The age of the professionals of the nephrology services ranged from 31 to 64 years old, with a prevalence of females. Regarding the professional category, five were nursing technicians and one was a nurse, responsible for the service. As for academic training, specialization in Nephrology predominated, and the working experience of the professionals participating ranged from one to forty years.

The mean age of the four managers who participated in this study was 27 to 40 years old and all were female. The participants had higher education, one of them having a master's degree.

The Health Departments where the managers exercised their functions belonged to the State and the Municipality. Regarding their profession, nursing stood out. Their sector in the health departments ranged from Pharmaceutical Assistance, Primary Care Management, Control and Evaluation, and Social Work for Services Outside the Home. The managers Health service clinical information system.. had been working in their current position for two to eight years.

The data presented in this study were related to the investigation of the organization, registration, and storage of people's clinical information after kidney transplants, in nephrology services and transplant centers. First, the participants explained the existing types of records, in paper and / or digital form.

> "[...] They have our clinical history. [...] In both [paper and digital], because he [medical professional] is there seeing the results of the exam and they're also there on the computer and he's also marking the dots there, writing. And he knows everything about us" (PKT3, 39 years).

> "In both [paper and digital]. [...] In the electronic one you only mark that he is transplanted, but remains active" (PNS6, 48 years).

> "[...] It's paper and digital" (PNS8, 31 years).

"Digital and paper. We at the clinic have both" (PNS9, 46 years).

Even though it was indicated that some of the nephrology services surveyed have both types of medical records, as the participants confirmed, there were also statements according to which there was a single registration system:

"Only paper" (PNS2, 55 years).

"Digital. [...] At first it was manual, but today the service is all in digital format, [...] he [medical professional] sees my whole life there" (PKT4, 61 years).

"Everything is on the computer. I don't even have my exams at home. It is all there. I didn't even ask where my exams are. [...] It's all in there" (PKT7, 61 years).

"Everything is on paper. It's all paper" (PNS7, 54 years).

Another situation found in this study was when the participants were asked how the registration and storage of clinical information about the person's health occurs after kidney transplantation. Some pointed out that every patient has their medical record in paper and electronic form, but after the transplant, records are filed by the nephrology service where the person underwent the dialysis treatment.

> "This is how it's like, there are several sheets that we fill out, but the one for the transplant patient is like this, each day a sheet is filled, then there is another that is for the entire month, and another that is according to the use of material. So, there are several things that are filed separately, but the patient's file, where their exams are, all

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> "We have a nephrology outpatient chart. So we usually use the medical records of the nephrology clinic. But the records of all assistance are in Porto Alegre. We only help with the protocol" (PNS7, 54 years).

> "[...] Usually, for whoever transplants, the records end. They end" (PNS8, 31 years).

"It is filed. It is a dead file" (PNS9, 46 years).

"It is filed. [...] To note things down, now, we only use it when they return to hemodialysis (PNS11, 36 years).

It stays on paper, filed up. Everything is in the file, on paper and on the computer I think. My file is all there in the archive" (PKT11, 62 years).

Another information brought by a health professional who participated in this study was the way in which the nephrology service is organized to record information about the care it promotes to people after a kidney transplant or when they return to the dialysis program due to problems with the transplanted organ. The statement is from PNS5.

> "It's the same. It is the same single medical record. From the time he [patient] underwent dialysis until the moment he was transplanted and the return for any consultation, we use the same medical record" (PNS5, 64 years).

When questioning the participants about how the records refer to the complications, the results of laboratory tests and the guidelines transmitted by the professionals after the kidney transplantation, the majority showed knowledge about the process of organization and storage of clinical data in the transplant center:

"[...] There is a medical record. They have it on paper. They have a file that shows the blood creatinine, urine creatinine, potassium, phosphorus, all. All types of exams you did, he [medical professional] writes by hand there. And on the computer, he receives the exams and then he checks and puts the results there. Everything is recorded, everything documented. It is since the transplant happens" (PKT12, 51 years).

"Everything is registered, everything on the computer. [...] The exams you do. Everything! Everything goes to the computer" (PKT13, 63 years).

Also in the reports brought by the participants, some people stated that the transplant centers provide the results of laboratory tests through an electronic system. The statements presented are from PKT5 and PKT7. Health service clinical information system..

"Before, I used to bring all the exams home, but now they don't give them anymore, as there is no paper there. The exams, when you enter the room [doctor's office], are already on the doctor's computer. Everything is already on the doctor's computer. Previous and current exams and weights. Everything" (PKT5, 43 years).

"The exams, soon it's all there [electronic system] and I don't even need to bring the exams, everything is there. Before, I always had to get the exams, but now everything is online" (PKT7, 61 years).

These two statements show how easy it is, in the transplant centers that PKT5 and PKT7 attend, to access the results of laboratory tests electronically. In view of this reality, health services have sought to modernize, in order to guarantee quality care to the population served.

DISCUSSION

Before discussing the types of medical records present in nephrology services, it is essential to clarify that all the assistance provided to people in a health institution includes several professionals, such as physicians, nurses, physical therapists. occupational therapists, nutritionists, biomedical, physical educators, dentists, social workers, speech psychologists, among therapists, others. Α fundamental task of the professional is to register each service for future research and care. Information is usually registered occurs in the medical record. This is a complex document, used for numerous purposes during care, as well as for administrative activities to support clinical practice. The medical records are, in fact, documentation produced and used for the provision of care, being relevant for the management of information in health services. ⁽¹²⁾

It is part of a logistical system for the organization of the health care network, providing information on people's referral and counter-referral, promoting efficient data exchange between health services. ⁽⁵⁾ In this context, the medical record is a legal document that must always be available to professionals in health services, since it has clinical data, diagnosis and treatment records, information on scheduling returns, request, results of control tests, and surveillance of the family. ⁽¹³⁾

As noted in the statements about the existence of two types of medical records, paper and digital, it is important to highlight the positive experiences of mixed medical records found by a survey conducted in Toronto, Canada, using the electronic method of clinical records during care, without completely excluding the paper chart. ⁽¹⁴⁾ Although the paper chart is the most traditional, and the electronic one provides greater quality to care and public management, both can complement each other in the health care network.

With the existence of only one type of medical record in the nephrology service, as mentioned by

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some participants, it is relevant to highlight that paper records have not yet been entirely replaced by digital systems, which provokes reflections about the resistance of the health professionals against adhering to electronic medical records, and the unavailability of equipment in health services. This situation can be justified by the need to seek basic computer knowledge and receive adequate training in order to efficiently operate the digital system ⁽¹⁵⁾, in addition to a greater financial investment for the acquisition of computers and / or software.

In Brazil, the experiences of implanting the electronic medical record are not always positive due to the existing differences in the infrastructure of health services, the need to high investments in technology, and insufficient professional preparation for the use of digital media. Some difficulties are listed based on the experiences reported, representing weaknesses that need to be overcome, such as the improvement of the system, professional training and investments in technology that guarantee advances in the process of implanting the electronic medical record. ⁽¹⁶⁾

Regarding the process of filing medical records in services, as mentioned nephrology by the participants, in Portugal there are different legal institutions that define the terms of custody for health services. However, sometimes it is a difficult to understand the Portuguese system. Among the various Ordinances issued by the Ministry of Health of that country, there is one that defends the permanent conservation of most of the information produced by the institutions (including administrative ones), while others recommend minimum deadlines for certain documents, which leads to a lack of general / subsidiary regulation. In Brazil and Angola, despite the national legislative absence, the Federal Council of Medicine itself is responsible for regularizing and filing medical records based on Resolutions issued by the regulating body of the medical profession. (17)

The Federal Nursing Council, on the other hand, states that records are a form of written communication between professionals, in order to facilitate coordination and the continuity of care, through the description of procedures and actions performed. Article 36 of Resolution No. 0564 of 2017, of the Nursing Professionals Code of Ethics, establishes the duty to write in the medical records documents the and other necessary and indispensable information for the care process. The information must be clear, objective, chronological, readable, complete, and with no erasures. In this context, the nursing professional needs to record their care and planning practice as recommended, to enable the continuity of quality care. $^{\scriptscriptstyle (18)}$

The statements from the health professionals showed that there is only one medical record per transplanted patient, from the moment they started dialysis up to their follow up after transplant. Thus, records, when made carefully, bring benefits. When not, they can cause losses for all parties involved (patients and professionals). Therefore, the importance of the data in the medical records is emphasized, since they can support better care practices, and their evaluation enables the Health service clinical information system..

development of strategies and actions that aim to improve care and provide legal support for the professional.⁽¹⁹⁾

Regarding what is stored in their medical records, the transplanted participants in this study cited the results of tests, the prescribed medications, the instructions given, in addition to the history of the disease and treatment. With this statement, it has been emphasized that the person's medical record is a document that records facts that occurred during a health care consultation, being related, at that moment, to the reasoning of health professionals and the way the professional understands the healthillness process. ⁽¹²⁾

The informatization process is happening, aiming to improve people's living conditions, and the health field has received a great contribution from the advent of technology. Thus, health services have sought to become informational, reviewing work processes to ensure better care. ⁽²⁰⁾

In addition, there have been changes in the profile of the person assisted by health services, going from a passive being who only receives care to a being who makes demands and has to understand his health and illness processes. Even if the medical record belongs to the person, the responsibility is conferred on the medical professional and / or the health service to which he / she is linked, as set out in article 87, paragraph 2 of Resolution No. 1931/2009 of the Medical Code of Ethics of the Federal Council of Medicine. ⁽²¹⁾

It is important to note that the medical record needs to be filled with complete information and not have information that does not concern the person being cared for. ⁽²²⁾ Since this document includes and reports the entire clinical history, it has immeasurable value for the health service, as well as for the team of health professionals. In this context, the medical record must be well prepared and handled with care, ensuring the integrity of data, as it proves the provision of care and enables an accurate analysis of the facts that have occurred, serving as a legal instrument of defense or prosecution, given its elaboration. Therefore, the professional responsible for their safekeeping must meet the established criteria. $^{(23)}$

Furthermore, the use of medical records, regardless of whether they are paper or digital, is essential in health services. In this context, it became evident that the integration of information and quick access to it contribute to the quality of care for people who attend health services ⁽²⁰⁾, especially when considering the electronic systems.

On the digital side, interaction between health services becomes possible, so that each person can have a unique and accessible medical record in any service, that is, from primary care to the transplant unit. Such fact would contribute to the knowledge of the person's past history (life, health, and illness), in the monitoring of the adopted treatments and in the referral and counter-referral flows. Thus, health professionals would be more aware for the provision of an effective care, especially regarding the area of Nephrology.

This study is limited due to the fact that it was conducted only in public health care services, which

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do not reflect the reality of the private sector. With this observation, the contribution of this study is highlighting the importance of new researches that take a broader look at the health care network, both in the public and private sectors, with an emphasis on kidney transplantation.

CONCLUSION

The present study analyzed the organization, the way of recording and the process of storing people's clinical information after kidney transplantation, in nephrology services and transplant centers. Mainly, the existing types of medical records (paper and / or digital), the responsibility of the reference service and the non-sharing of data between the nephrology service and the transplant center were addressed.

It is noteworthy that, for the consolidation of an ideal care model, the use of digital tools and instruments in the organization, and the recording and storage of clinical data during assistance to the person, assist health professionals in making decisions about the care to be provided. Furthermore, these measures facilitate the exchange of information between professionals and health services, providing quality care.

In health services that adopt only paper medical records, difficulties are often perceived for the implementation of computerized systems. This situation can be attributed either to the lack of investment for the installation of programs, or to the resistance of professionals to the use of digital technology. In this context, the importance of available data for the multiprofessional team is emphasized, since the implementation of a feasible and efficient registration system can assist in communication and care planning.

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