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Original Article

Factors that hinder of integrality in dialysis care[1]

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This study analyzes the factors, which from the perspective of the health team and users, hinder the implementation of integrality in care provided by a dialysis facility. This qualitative study collected data through semi-structured interviews held with 16 health professionals and eight users from a university hospital in Rio Grande do Sul, Brazil. Data were analyzed through thematic content analysis. Among the factors that hinder the implementation of integrality in hemodialysis care, the following were highlighted: a deficient service network, delay in accessing diagnostic exams and consultations with specialists, and a reduced number of professionals in the support team. The conclusion is that the health services network needs to be expanded and an effective interface between such networks and dialysis services needs to be established in order to overcome the reported difficulties and contribute to the implementation of integrality in dialysis care.

Descriptors: Dialysis Units, Hospital; Health Services Needs and Demand; Comprehensive Health Care.

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Fatores que dificultam a integralidade no cuidado em hemodiálise

Este artigo teve como objetivo analisar, sob a ótica da equipe de saúde e dos usuários, os fatores que podem dificultar a prática da integralidade do cuidado em uma unidade de hemodiálise. Trata-se de pesquisa qualitativa, cujos dados foram coletados por meio de entrevista semiestruturada, com dezesseis profissionais de saúde e oito usuários de um hospital de ensino do Rio Grande do Sul, tendo sido, posteriormente, feita a análise de conteúdo temática. Essa análise sugeriu que, dentre os fatores que dificultam a prática da integralidade no cuidado em hemodiálise, se destacaram deficiências na rede de serviços, demora no acesso a exames diagnósticos e a consultas com médicos especialistas e reduzido número de profissionais nas equipes de apoio. Concluiu-se, então, que a ampliação na rede de serviços de saúde e o estabelecimento de interface efetiva entre os serviços de hemodiálise e essa rede poderão representar a superação das dificuldades apontadas, e, assim, contribuir para a integralidade no cuidado em hemodiálise.

Descritores: Unidades Hospitalares de Hemodiálise; Necessidades e Demandas de Serviços de Saúde; Assistência Integral à Saúde.

Factores que dificultan la integralidad del cuidado en hemodiálisis

Este artículo tuvo como objetivo analizar, bajo la óptica del equipo de salud y de los usuarios, los factores que pueden dificultar la práctica de la integralidad del cuidado en una unidad de hemodiálisis. Se trata de investigación cualitativa, cuyos datos fueron recolectados, por medio de entrevista semiestructurada, con dieciséis profesionales de salud y ocho usuarios de un hospital de enseñanza de Rio Grande del Sur, habiendo sido, posteriormente, hecho el análisis de contenido temático. Ese análisis sugiere que, entre los factores que dificultan la práctica de la integralidad en el cuidado en hemodiálisis, se destacaron deficiencias en la red de servicios, demora en el acceso a exámenes de diagnóstico y a consultas con médicos especialistas, y reducido número de profesionales en los equipos de apoyo. Se concluye, entonces, que la ampliación en la red de servicios de salud y el establecimiento de una conexión efectiva entre los servicios de hemodiálisis y esa red podrán representar la superación de las dificultades apuntadas, y, así, contribuir para la integralidad del cuidado en hemodiálisis.

Descriptores: Unidades de Hemodiálisis en Hospital; Necesidades y Demandas de Servicios de Salud; Atención Integral de Salud.

Introduction

Terminal Chronic Kidney Failure (CKF) is recognized worldwide among chronic diseases as a public health problem[1] and is one the pathologies that most impacts the lifestyle of individuals affected by it[2]. The individual diagnosed with CKF is generally, rather abruptly, informed of the need to undergo Kidney Replacement Therapy (KRT). It forces patients and families to reorganize their lives in economic, social and professional terms, among other aspects[3]. It is estimated there are 77,589 individuals in Brazil undergoing KRT, of which 89.6% in hemodyalisis[4].

A dialysis facility is the health service that regularly cares for individuals who need hemodialytic treatment over the course of their lives or until they receive a kidney transplant. They generally receive three weekly sessions of hemodyalisis, lasting four hours each. This procedure

aims to partially replace the kidney's functions, therefore ensuring the maintenance of life[3].

Even though care provided in health services recognizes the importance of maintaining one's life and the fact that its users live with a chronic condition, such services need to increase investments in survival to maintain, at the same level or as much as possible, the quality of life of these individuals[3]. In this context, advancing the expansion of hemodyalisis care, viewing health in its broader meaning, that is, not as absence of disease but as a resource for life in which social, cultural, economic and environmental factors are included and are part of the routines of people, is an essential goal in the field of nephrology.

Expanding the focus of care on hemodyalisis services in this direction means to align care practices with the principles of the Brazilian Unified Health System (SUS). The context of hemodyalisis care, a setting where a diversity of daily and unique experiences of suffering flow together, requires investments to bring care practices in line with the principle of integrality. Basing care that is provided to individuals under hemodyalisis on this principle means to align care with the projects of these individuals' lives, going beyond the disease's signs and symptoms and broadening the perspective of care so as to seek the solutions for patients' health needs in other services' networks.

Integrality in this study is seen as a way to increase the understanding of individuals' health needs, which brings to technical knowledge a perspective that is beneficial in looking at the socio-cultural dimensions into which individuals are inserted. This principle is based on the contextualization of these individuals' lives and on a dialogical relationship between the health team and users[5].

The notion of integrality is increasingly being addressed by researchers, especially in the field of collective health[6-8]. Integrality is highlighted in many of these approaches because it fills in a gap in health care, when one realizes that technological advancements, equipment and specialized care *per se* do not themselves contemplate the health needs of people[8]. From this perspective, one needs to acknowledge that the health of an individual with CKF does not depend only on the success of the hemodyalitic treatment, enabled by the dialysis machine, but also depends on responses the health care network can provide to the set of his/her health needs that may originate from the kidney condition or elsewhere.

Integrality, among the SUS principles and guidelines, is the least visible element in the system's development and practices. Changes within SUS related to decentralization and social participation are more explicit, however, because changes concerning integrality do not achieve visibility and the desired generalization. They have not been very evident[5].

In this context, experiences and research related to integrality and its scope are important for analyzing the factors that influence the implementation of these principles in the routine practice of health services and health teams[5].

Despite this principle's growing importance in the current debate in the context of primary care, research that addresses the notion of integrality in analysis and reflections related to care provided in the hospital context is still incipient. Specifically related to nephrology and nursing in nephrology, there are few studies that bring together collective health and the notion of integrality in care, which indicates there is a gap of knowledge in this field. This shows the relevance of studies that explore the care provided to individuals undergoing hemodyalisis from such a perspective.

A study was developed in the context of a Master's program entitled "Challenges of integrality in care provided in hemodyalisis: views from the health team and users" [3], which was designed to analyze the possibilities of integrality in care provided in a dialysis facility from the perspective of the health team and users. Identifying the health needs of individuals undergoing hemodyalisis, verifying to what extent health care actions have met such needs from the perspective of integrality and unveil the aspects that hinder or facilitate integrality in hemodyalisis care were all questions that guided this study. This study fills in a gap in knowledge through a study of a dialysis unit as the setting, from a university hospital located in Rio Grande do Sul, Brazil. The knowledge produced can encourage reflections concerning health care provided to individuals undergoing hemodyalisis and potential transformations in the logic that grounds such care and, consequently, enlarge its limits.

This paper is part of the larger study previously mentioned and analyzes, from the perspective of the health team and patients, the factors that hinder integrality of care.

Method

This qualitative study with a descriptive exploratory approach was carried out in a dialysis facility of a university hospital located in Rio Grande do Sul, Brazil.

This health service is contracted with SUS and provides care as a supplementary sector to adults with chronic kidney disease or acute kidney failure who require dialysis therapy.

The study's participants included 24 individuals: 16 professionals from the health team who worked in the studied facility (four nurses, six nursing technicians, one nutritionist, one psychologist, one social worker, three physicians) and eight patients from the dialysis unit. The users and nursing technicians were chosen to meet the study's objectives[9]. In qualitative research, the sample size is determined according to the need for information. Thus, there is no concern with generalizations since the proposal is to acquire deep knowledge concerning the phenomenon of interest[9]. It was possible in this study given the sample that met the study's objectives.

Data collection was carried out between April and July 2008 through individual semi-structured interviews previously scheduled according to the participants' convenience in a previously reserved room in the dialysis unit. The content of the interviews was digitally recorded and later transcribed for analysis.

A flexible script was defined prior to the interviews to enable the interviewees to construct the narratives of their experiences concerning the studied phenomenon. The interview's questions were based on conceptions of the integrality of care and health needs[10-12].

A software program was used to organize, encode and store data in specific categories[13], enabling the maintenance of a qualitative database both easy to use and access.

Data were analyzed through thematic content analysis[14] based on the study's theoretical framework, from which two categories emerged: 'perceptions of health needs that guide care provided in hemodialysis' and 'similarities and differences of integrality in care provided in hemodialysis'.

This paper addresses the content of the second category of analysis. Given the emphasis conferred by the study's participants on the limits that are imposed on them in the practice of integrality in care provided to hemodialysis, we opted to specifically focus on the hindering factors that emerged from the study, which are: 'delay in accessing diagnostic exams and consultations with specialists', 'deficient network service' and 'reduced number of professionals in the support staff'.

Ethical principles were complied with during the entire study, in accordance with the recommendations of Resolution 196/96, National Council of Health, which regulates research involving human subjects. The project was approved by the Research Ethics Committee at the hospital (Process No. 08071).

The study's participants were invited and informed of the study's objective. Free and informed consent forms were read and signed by those who consented to participate in the study. In order to maintain the participants' confidentiality, 'HT' followed by the number of the interview was used to designate participants from the health team and 'HU' to designate the health service's users.

Results

Considering the perspective of the health team working in the studied dialysis facility and that of the service's users, the factors that hinder the implementation of the principle of integrality in this health care context are mainly related to problems in the organization and functioning of the health system. There is a perception on the part of the study's participants that difficulties are limited to structural problems in this system. In other words, the problem arises, initially, in the micro-context of care. The perceptions of users and professionals reveal how biomedical issues (exams, consultations, medication) fill in the care practices in a specialized facility.

The results related to the difficulties indicated by the study's participants are presented.

Delay in accessing diagnostic exams and consultations with specialists

The interviewees report that one of the factors that hinders integrality of care provided in hemodialysis is related to the delay in gaining access to other medical specialties within the health system. Another element they highlighted is related to access to diagnostic exams, as shown in the following excerpt:

The doctor came and gave me a paper to schedule a X-ray of the blood vessels. I went upstairs to schedule it and they told me there wasn't any more slots and that I couldn't try to schedule it because I wouldn't be able to have the exam that year (HU 01).

Sometimes it takes awhile, especially when you need people from the vascular unit (surgery). You have to wait a lot there and it's not easy to talk to them. You stay there the entire morning to knock on the door, they only tell you that for you to be able to schedule it, you have to attend a consultation. I guess that hemodialysis patients should have more and faster access, because we depend on the dialysis fistula, it's a matter of life or death, so we should have priority (HU 08).

It is very difficult to access some specialties, it takes a lot, for instance, in vascular surgery, urology, proctology, orthopedics, especially in the surgical unit, it's very complicated and takes a lot of time. Not that in the clinical field it is easier, but it is a bit easier. We end up referring and scheduling a return visit, but it takes a lot in any field, you have to be patient, this is something that could certainly be improved (HT 16).

The problem here (hospital) is the delay, sometimes a consultation take two years on average, one year to be cared for in another specialty. The problem is the delay, not only for consultations, but also for taking exams (HU 02).

The reports reveal the obstacles found both by users and professionals. A concern with delay in receiving care and the need to have vascular access to undergo hemodialytic treatment and its potential repercussions is evident in the testimony of HU 08.

Terminal chronic renal disease triggers other co-morbidities related to the course of the disease and such a situation requires these individuals to have regular access to health services or other specialists. The trajectory of the individual is monitored by the health team from the dialysis facility, thus the difficulties faced by the patients are shared with the team.

Deficient network service

Data indicate another difficulty found by the study's participants in the implementation of integrality in hemodyalisis care related to the network of services available: heeding the health needs of CRF patients, as the following excerpts show.

(...) we go seek alternatives with the Health Department, see what it can offer. We also have certain difficulties, so that these [help requests], so that they have an answer (HT 13).

Specifically related to the transportation issue, it is a situation in which we've intervened several times, but no solution was reached. There are various patients who could not use the free ticket or bus in this case, because of a clinical situation that impedes this patient from leaving home and going to a bus stop, having access to this bus, climbing its stairs. There were various situations in which you really can't access social transportation. So, suddenly, you see yourself tied up, you can't solve the problem (HT 11).

(...) in relation to medication, they use a lot and don't have money for everything, we end up providing two copies of prescriptions so they go to the health department, to SUS pharmacies (…) it depends on the city health department, the city where the patient lives, there are some that are very well structured and manage to provide at least the basic medications, while others don't, there is no acetaminophen, pain relievers, but most go here and there and end up getting what they need. (HT 15)

The continuity of hemodialysis care depends, among other factors, on heeding the health needs of individuals in other services as the testimonies report. According to the reports of professionals HT 13 and HT 15, the health departments are places where they look for solutions to care demands and that cannot be heeded by the dialysis facility. It is evident in the report of HT 15 that hemodialysis patients often have to go from service to service to get medication.

Reduced number of professionals on the support staff

The reduced number of professionals on the support team (nutritionist, psychologist, social worker), who work in a consultation arrangement in the studied dialysis facility, was also reported as a factor that impacts continuity of care.

The difficulty for me, I guess that this support team should be more available, like, I guess they should be committed to assess, monitor these patients (HT 03)

I was cared for [by the psychologist] but it stopped. They said she [psychologist] would come back but she didn't, nobody knows why (HU 08).

I don't consider the social worker to be part of the team, this is a mistake from the perspective of integrality. The hospital has no social worker in dialysis doing systematic work (HT 12).

Follow-up from a multidisciplinary team is essential in care provided to individuals under hemodialysis, considering the set of care actions and adaptations required on a daily basis. Some professionals composing the studied team recognize the importance of gathering diverse types of knowledge for quality care.

Discussion

The difficulties experienced by the study's participants lie in the problem of access to health services, support services and dimensions of the health team. Universal and equalitarian access to actions and services to promote, protect and recover health is one of the requirements established in the Brazilian Federal Constitution (art.196), in the sense that health is a right for all. Health policies have repeatedly stressed that access provided to the services' users is a basic paradigm in national plans, as well as for regional and local projects, to extend the existing service network[15].

Even though access and integrality of health care are ensured by the Organic Health Laws, Nos. 8080/90 and 8142/90, in which the commitment to improve situations of inequality in health care provided to the

population is legitimated to guarantee universal care for all citizens[16], there are some barriers hindering the accomplishment of these principles as seen in the studied context. Among such barriers are the delay in gaining access to diagnostic exams and excessive wait time to have consultations with specialist physicians.

The difficulties related to maintaining flow within the health system and being able to count on other support services harm the practice of integrality, since the health of individuals does not only depend on the success of hemodialysis treatment but also on responses the health care network can provide to a set of needs that may originate from the kidney condition or from other sources.

Other studies[17-18] also show the need for a services network to ensure the continuity of care to patients. This network should be mobile, asymmetrical and incomplete of services that operate different health technologies, which are accessed by diverse people or groups of people[19-20].

Most importantly, working based on the notion of integrality in health care implies having a macro perspective of life and health, recognizing the interdisciplinary nature of such care and the importance of a network.

In relation to the inclusion of a support team in hemodialysis care, data indicate the need, perceived by the remaining members of the team, for a more effective and continuous participation of professionals from the fields of psychology, nutrition and social work. This observation refers to the idea that promoting integrality in hemodialysis care requires interdisciplinary teamwork in which, jointly with the user, therapeutic actions are individualized so that all can contribute their knowledge.

It was observed in the studied setting and in another study[21] that even though professionals acknowledge the importance of a multidisciplinary work, it is not always accomplished. Data permit the conclusion that this fact is due to the restricted number of professionals on the support team; they are not able to effectively participate in the planning and follow-up of care provided to individuals undergoing hemodialysis.

Final considerations

The conclusion that emerges from the studied setting is that the health services network needs to be urgently expanded in order to provide access to users from the dialysis facility and to professionals who directly provide hemodialysis care, especially at the secondary care level.

An organized network with problem-solving capacity to treat the health needs of individuals affected by a chronic disease is crucial. A better structured network would favor the access of individuals undergoing hemodialysis and meet their needs. When data are analyzed from a constitutional perspective in terms of integrality, it is possible to state that the effective transit of users through the different levels of complexity within the health system experiences resistance.

This study also shows the need perceived by the health team members for a more effective participation of professionals from the fields of psychology, social work and nutrition in hemodialysis. It reinforces the idea that integrality in care is supported by multidisciplinary care and the team from the dialysis facility understands such dimensions.

This study's findings also enable reflecting on the number of health professionals in the different professions that work in a hospital facility. Once more we observe that the investments in hospitals are based on a curative logic, which leaves aside services provided by nutritionists, social workers and psychologists. The importance of these fields of knowledge, directly intertwined with the health of individuals, needs to be acknowledged by these institutions in the same way it occurs with other professions.

This study's findings can help health teams and managers of services caring for individuals with chronic kidney diseases and other chronic diseases because important elements that should be considered when planning care for people that permanently live with a disease are discussed. Alleviating the symptoms of these individuals is not sufficient. The actors involved in the care process need to be committed to the project of the lives of those who seek care.

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