THE CONTINUITY OF CARE FROM THE PERSPECTIVE OF THE BEING CARED FOR*

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ABSTRACT: This study aims to understand the continuity of the care from the perspective of companions, and service users with chronic non-communicable diseases. The research is qualitative and descriptive, and was undertaken in 2012 in an Emergency Department of the municipality of Betim in the Brazilian state of Minas Gerais, with seven participants. The information was collected through semistructured interviews. Three categories emerged from the analysis undertaken: Informational continuity and the impasses to achieving continuity of care; Managerial continuity: weaknesses which affect the continuity of the care; Meanings of the continuity, for the being cared for: positive aspects which permeate the routine actions. Weaknesses were observed in the continuity of the care for the patients with chronic complaints, caused by failures in communication, inadequate interaction between the services of the care network, and inadequate managing of the service. It is considered essential to outline strategies which aim to overcome limitations so as to ensure comprehensive and resolutive care.
DESCRIPTORS: Continuity of the care for the patient; Chronic illness; Management in health.

A CONTINUIDADE DO CUIDADO NA PERSPECTIVA DO SER CUIDADO

RESUMO: O objetivo deste estudo foi compreender a continuidade do cuidado na percepção de acompanhantes e usuários portadores de doença crônica não transmissível. A pesquisa é qualitativa, descritiva, realizada em 2012, em uma Unidade de Atendimento Imediato do município de Betim em Minas Gerais, com sete participantes. As informações foram coletadas por meio de entrevista semiestruturada. Procedeu-se à análise e emergiram três categorias: A continuidade informacional e os impasses para o alcance da continuidade do cuidado; Continuidade Gerencial: fragilidades que afetam a continuidade do cuidado; Significados da continuidade para o ser cuidado: aspectos positivos que permeiam as ações cotidianas. Observaram-se fragilidades na continuidade do cuidado aos pacientes com queixas crônicas, provocadas por falhas na comunicação, interação deficitária entre os serviços da rede de atenção, gerenciamento inadequado do serviço. Considera-se essencial delinear estratégias que visem superar limitações para a garantia de assistência íntegra e resolutiva.
DESCRITORES: Continuidade da assistência ao paciente; Doença crônica; Gestão em saúde.

LA CONTINUIDAD DEL CUIDADO EN LA PERSPECTIVA DEL SER CUIDADO

RESUMEN: El objetivo de este estudio fue comprender la continuidad del cuidado en la percepción de acompañantes y usuarios con enfermedad crónica no transmisible. Es una investigación cualitativa, descriptiva, realizada en 2012, en una Unidad de Atendimiento Inmediato del municipio de Betim en Minas Gerais, con siete participantes. Las informaciones fueron obtenidas por medio de entrevista semiestructurada. Del análisis resultaron tres categorías: La continuidad informacional y los problemas para el alcance de la continuidad del cuidado; Continuidad Gerencial: fragilidades que afectan la continuidad del cuidado; Significados de la continuidad para el ser cuidado: aspectos positivos que permean las acciones cotidianas. Fueron observadas fragilidades en la continuidad del cuidado a los pacientes con quejas crónicas, causadas por fallas en la comunicación, interacción deficitaria entre los servicios de la red de atención, administración inadecuada del servicio. Se considera esencial promover estrategias para superar limitaciones a fin de garantizar la asistencia íntegra y resolutiva.
DESCRIPTORES: Continuidad de la asistencia al paciente; Enfermedad crónica; Gestión en salud.

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INTRODUCTION

Article 196 of the Brazilian Constitution, promulgated in 1988, emphasizes health as a social and citizenship right, resulting from the population's living conditions[1]. This historic landmark in the transformation of Brazil's health model was regulated by Law N. 8,080, of 1990, which specifies conditions for the promotion, protection and recovery of health, and the organizing and functioning of the services[2].

In spite of the victories conquered by Brazil's current health system, the implantation of its principles and guidelines has still not been fully put into effect. In this perspective, emphasis is placed on the principle of the comprehensiveness of the care,

> understood as an articulated and continuous set of individual and collective preventive and curative actions and services, required for each case at all the levels of complexity of the system[2:3].

Among the attributes responsible for ensuring the comprehensiveness of the care, there is continuity of care. The key concept for this attribute, in this study, refers to the resolution of a specific health problem in an uninterrupted succession of events[3]. A search in the literature evidences the existence of varying types of continuity, among which emphasis is placed on informational continuity, managerial continuity and relational continuity[3-5].

In the first, information is described as a connection between the care given by the professionals in the events which permeate the subject's needs[4]. This connection can be achieved through the coordination of the care given. For this, it is fundamental for mechanisms to be established for transferring information relating to the service user's needs and the conducts adopted for resolving problems[3].

In relation to managerial continuity, it is especially important in the diseases with complex clinical conditions, and in chronic diseases which require management by many professionals who can potentially work with interlinked proposals. Relational continuity, on the other hand, establishes – in the process of care for the service user – a relationship between the present, the past and the future[4].

It is fundamental to guarantee the continuity of the care at all points of the healthcare network. In this perspective, emphasis is placed on the emergency services, which constitute important gateways to the health system and for those with chronic noncommunicable diseases, as these can present situations of exacerbation[6]. Technological apparatus and geographical and organizational accessibility are aspects which contribute to the demand for attendance in these locales[7].

Considering the growing scale of the morbidity and mortality, and of the economic implications of these diseases, this article's objective is to understand the continuity of the care in the perception of service users with chronic noncommunicable diseases, attended in an Emergency Department, and their companions.

METHOD

This is descriptive, qualitative research[8], undertaken in an Emergency Department located in the municipality of Betim, in Minas Gerais. In accordance with the current legislation, these units correspond to Emergency Attendance Units, and are considered nonhospital emergency services[9].

The study sample was made up of seven participants, namely: three service users with chronic noncommunicable diseases, and four companions of service users with chronic noncommunicable diseases, who could not participate in the interview due to factors associated with the health condition. The participants were therefore identified as: U2, U3, U4 (service users) and UC1 (service user's companion 1 – caregiver), UC5 (service user's companion 5 – sister), UC6 (service user's companion 6 – daughter), and UC7 (service user's companion 7 – daughter). The inclusion of the service users was guided by the following criteria: to be over 18 years old, have one or more chronic noncommunicable diseases, and to present a complaint related to chronic disease. The inclusion of the service users' companions was guided by the following criteria: for the service user not to be able to participate in the interview due to his or her current health condition, for the user to have one or more chronic noncommunicable diseases, and for the companion to be aged 18 years old or over.

Data collection was undertaken during September 2012, being finalized through criteria of repetition and relevance. A semistructured interview script was used, with identification data, and questions referring to the issue presented. The study's guiding question was: How does the continuity of care occur for those with chronic noncommunicable diseases in an Emergency Department?

The participants' accounts were recorded and transcribed in full, ensuring the reliability of the data. Following that, the data were treated using the technique of content analysis proposed by Bardin. The organization of this analysis requires the application of three chronological poles were respected in this study: (1) pre-analysis; (2) exploration of the material; (3) treatment of the results, inference, and interpretation[10].

The rules of the National Health Council for research involving human beings were observed and applied in all phases. The study was approved by the Research Ethics Committee of the Federal University of Minas Gerais (COEP/UFMG - Opinion 0057.0.410.203-10) and by the Municipal Health Department of Betim(11). The participants signed the terms of consent after being informed about the guarantee of anonymity, privacy, and the use of the results only for scientific ends.

RESULTS

The service users' profile demonstrated that age varied from 29 to 78 years old, with a mean of 57 years old. It was observed that, of the seven service users, six had more than one chronic noncommunicable disease.

The analysis of the results allowed the elaboration of three thematic categories: Informational continuity and the impasses to achieving continuity of the care; Managerial continuity: weaknesses which affect the continuity of the care; and Meanings of the continuity for the being cared for: positive aspects which permeate the routine actions.

Informational continuity in the context of the

Emergency Department and the relationships with the other services emerged in the accounts of the service users and their companions. In this regard, some factors were observed which interfered in the essential actions for ensuring this continuity, such as: communication failures among the professionals and professionals-users, poor interaction between the services, incipient referral and counter-referral, and inefficacious planning of discharge from hospital.

The communication among professionals, in relation to direct care for the patient, demonstrated weakness in relation to the transmission of conducts established. Between professionals and service users, the shortcomings in communication occurred at the time of the undertaking of the care actions. The account below refers to the fragmentation of the care, which fails to consider the integrality of the subject and hinders clear and resolutive communication.

What I think is this, girl, very wrong, just like I'm here, the doctor told me to take heparin didn't he? The other doctor turns up and tells them to take down the heparin. Who is right, the first doctor or the second? The one who attended me yesterday, or the one who attended me today? I don't know who is right or who is wrong, it had to be one or the other [...]. (U3)

In the aspect of poor interaction between the services, problems were identified relating to the communication centered on the continuity of the care given. This finding impacts on the continuous and comprehensive care to the being cared for. Furthermore, the lack of communication between the services characterizes them as island-units, as shown in UC7's account.

Mom has come here many times with phlebitis, and I have to request more material due to the secretions, these things which come out more, and the girls at the health clinic go, like, "hey, was she in hospital?" The staff at the clinic themselves didn't know. And they don't try to find out. (UC7)

As it is an emergency center, the service users consider that the Emergency Department does not undertake referral and counter-referral, which reinforces the model of attendance based on the complaint-conduct relationship, contributing to the lack of continuity of the care.

No, there wasn't any referral. That doesn't happen here. What happens here is first aid. That doesn't happen here. (U4)

Another factor which interferes in ensuring continuity of care is the discharge, which, when not planned, is identified as a problem for coordinating the care to be provided by the family and by the specialist service, as shown in the account of UC5.

The hospital didn't say anything, they discharged him [the patient], *the ambulance was already arriving with him at home, I didn't even know he had been discharged, and there they were already turning up* [..] (UC5)

Managerial continuity: weaknesses which affect the continuity of the care

In the participants' accounts, the managerial continuity was mentioned as a type of continuity (managerial continuity), and also due to managerial aspects related to the Emergency Department.

In relation to the continuity of care directed towards the chronic conditions, it was evident that – in the Emergency Department – protocols or guidelines for managing and operationalizing the care for the users of the Healthcare Network either did not exist or were not being used.

Here there is the inhaler, there is micro-nebulization. It's no use, you have to come to ED. That [Emergency Department] *is where my problem is resolved.* (UC2)

Bearing in mind the scale of the chronic noncommunicable diseases, the managing of the chronic conditions was shown to be deficient, as it did not ensure integrated care, as established by public policies[1-2,9]. UC7's account depicts this context, which impairs the service users' quality of life.

No, it's not very continuous, because she, for example, sometimes depends on certain specialties, there is a certain difficulty, so it ends up with us having to chase things up, otherwise the delay is very big, we know that in the SUS everything is slow because of the demand, but there are certain things which really do take too long. (UC7)

In relation to the aspects related to the management, the participants point to the characteristics of the care offered in the Emergency Department which contribute to service users seeking this service. This demand may be explained by the concentration of hard technology, explained in the accounts of U2 and U4 as those which do in fact resolve their needs.

I think the E.D is very good, because it attends us faster, it does x-rays, it does everything, you know? That's why I like the E.D. (U2)

We prefer here [the Emergency Department] *because of the tests. You leave here all tidy.* (U4)

This characteristic of the Emergency Department causes the service user to consider the service to be resolutive, and to return there whenever she needs attendance, as can be observed in the account of UC6.

We have always come here, whenever we needed them [Emergency Department]. *I don't even go to another, so as not to cause problems for the attendance* [...]. (UC6)

U6's companion makes it clear that the service user has various chronic diseases, receives medical treatment in a specialized center in Belo Horizonte, and that, when her clinical situation worsens, she seeks attendance in the Emergency Department.

This account demonstrates the importance of the service user understanding the characteristics of each service in the care network, such that she can attend the appropriate one for her health needs.

Also in relation to the managerial aspects, the discussion regarding the management of material resources emerged in the accounts of those participants who pointed to failings and difficulty in obtaining medication. The absence of support inherent to the service users' treatment directly interferes in the continuity of the care.

I brought the [medication] for high blood pressure which I take it home. [...] *What I am taking was bought*. (U4)

Meanings of the continuity for the being cared for: positive aspects which permeate the routine actions

In spite of the weaknesses presented above, the study also made it possible to capture experiences which confirmed the presence of actions allowing the resolution of the health problems presented by the service users. One action which contributes to the continuity of the care, made clear in UC7's account, refers to the provision of medications at the time of discharge.

At the time of discharge, they give you the prescription, because normally he came here because of shortness of breath or pneumonia, so he takes medication here. When he needs to continue the treatment orally, she [the doctor] gives the medication and he continues the treatment at home, and he gets better, and everything is okay. (UC6)

[...] *She leaves with a specific medication at that time* [...] *She is treated in the clinic, for high blood pressure, diabetes, these things, so she already gets her medication there. The E.D doctor assesses the prescription, has always assessed this prescription that she brings from the health clinic* [...] *Maybe she stops this or increases that, but she always contacts the primary healthcare center straightaway, so mom has continuity.* (UC7)

The study made it possible to identify that the continuity of care is partially experienced by the service users through the care actions. This fact demonstrates that, in spite of the limitations identified, this continuity exists and that it integrates the care given in the Emergency Department.

DISCUSSION

In the ambit of the informational continuity, the communication between the users, companions and the professionals contributes to the undertaking of activities geared towards the continuity of the care. In the health service, the service user faces a routine and norms which control her actions; consequently, it is important for the communication process to succeed effectively, so as not to affect the treatment and the care offered[12].

Considering the continuity referred to, in relation to the interaction between the services, one study undertaken in Portugal evidenced that the exchanging of information between the same is scarce or nonexistent; this fact can hinder decision-making[13].

For the service users to receive comprehensive and continuous care, it is necessary to use various services with distinct technologies[14]. In this context, one of the competencies of the Emergency Department emerges, which consists of its articulation with the Primary Health Care services, the Ambulance Service, the hospital centers, and the other health services, constructing effective flows of referral and counter-referral[15].

The findings of this study, however, demonstrated the absence of the service users' referral to the various services. This situation can be understood as a saturation of the units' operational limits. Overcrowding commonly found in the emergency services, affects the working conditions, and negatively influences the actions which aim for the continuity of the care[16].

One of the possible suggestions for overcoming this impasse is found in the operationalization of teams with the function of recognizing and referring service users in accordance with their needs. In this regard, discharge from the health services is understood as a fundamental moment for undertaking the appropriate counter-referral and for the continuity of the care, not only bureaucratically, but through the commitment of the professional and the institution[14].

In spite of the informational continuity presenting gaps, the health care has been given. In the light of this perspective, the articulated participation of the managers, professionals and service users becomes necessary, so as to make the continuity effective[6].

In relation to the managerial continuity, the analysis of the participants' accounts demonstrated a model of care grounded in complaint-conduct, based on the biomedical model, in which the work processes remain strongly influenced by knowledges, equipment, norms and organizational structures which

emphasize biological aspects for interpreting vital phenomena[17].

It is necessary to highlight the need to reflect on this logic of the suffering which is manifested, of the complaint-conduct, and of the fragmentation of the therapeutic interventions, so as to come to work within a comprehensive perspective[14, 17-18].

Studies have shown that the continuity of the care predicts lower use of the emergency services, in particular among individuals with various comorbidities and multiple episodes of inpatient care in hospitals[19-20]. Patients with diabetes, seen by family doctors who aim for the continuity of care, had lower rates of hospitalization and lower mortality when compared with patients who did not receive this care[21].

The managerial dimensions which permeate the continuity of care influence the quality of the care given, and have complex and dynamic characteristics. Regarding the planning of the health services, it is necessary to improve the systems for the management of material resources, as well as those of infrastructure, so as to ensure continuous, quality, care; at lower cost and without risks for professionals and service users alike[22]. Furthermore, it is important that the care actions should occur holistically and in a way unique to the patient[23].

In relation to the patients' and professionals' perception regarding the continuity of the care in the care routine, it is appropriate to highlight that this is not a characteristic of the professionals or of the organizations. The continuity translates in how the individual feels the integration of the services, in the effective exchanging of information between the professionals and the service users, and in the coordination of the care[4-5, 13].

The study's results demonstrated that the continuity is not experienced to the fullest degree by the service users. In order to achieve it, effective communication between the services, and the understanding, on the part of the professionals, of the needs of the person to be cared for, are fundamental.

FINAL CONSIDERATIONS

The study evidenced breakdowns related to failures in communication; poor interaction between the services of the care network, and inadequate management of the service, all of which need to be considered in defining policies and strategies aiming for humanized, quality care.

In relation to the informational continuity, weaknesses were found which need to be overcome. A question emerges from this context: Has the service user been transformed into a technology of the "walking medical records" type, in having to ensure her referral and counter-referral?

Bearing in mind the scale of the noncommunicable chronic diseases, the management of the chronic conditions in the Emergency Department presented some weaknesses which are reflected in the service users' quality of life and which influence the health system as a whole.

In spite of the weaknesses found, in the perception of some service users, the continuity of the care occurs through the making available of resources. It is necessary, however, to consider the need to outline strategies, with the aim of providing continuous care which goes beyond the individual and subjective sphere.

This study is relevant due to having been undertaken from the perspective of the being cared for, which promotes the creation of strategies and policies which are consistent with the social needs. The undertaking of further studies will make it possible to minimize concerns referent to the issue and will make it possible to define actions viabilizing the achieving of continuity of care for all the subjects involved in the health-illness-care process.

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