

# Care Management: Perspectives from Managers, Professionals and Users of a Specialized Service Facility Focused on Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome

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Received date: September 28, 2016; Accepted date: October 19, 2016; Published date: October 27, 2016

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## Abstract

**Background:** Complex practices used for care management are developed to include the perspectives of professionals, healthcare organizations and patients. Therefore, to implement strategies to provide quality care, identifying gaps in these practices is crucial. This study seeks to gain a better understanding of the management of health care for people living with Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome by considering the perspective of health professionals, managers and patients of a specialized service facility in South Brazil that focuses on contagious diseases.

**Methods:** This qualitative, dialogic, reflexive and interpretative study involved 16 participants. The data were derived from semi-structured interviews conducted during 2013 and 2014. Ethnograph<sup>®</sup> software was used to provide a descriptive and interpretative data analysis.

**Results:** The results show that care management multidimensionality requires continuous attention to the way professionals think as well as reorganization of labor processes and the network of services provided. Thus emerged three categories: interdisciplinarity in care management; continuous training in care management; and strengthening of health care networks.

**Conclusion:** From the perspective of individuals involved in managing and promoting the care and health of people living with Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome, changes are needed to improve the care of people living with Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome in terms of the three dimensions of care management.

**Keywords:** Care management; HIV; Nursing; Health administration; Infectious diseases

**Abbreviations** AIDS: Acquired Immune Deficiency Syndrome; HIV: Human Immunodeficiency Virus; ART: Antiretroviral Therapy; PLWHA: People Living with HIV/AIDS; CNS: National Health Council; CESP/UFSC: Human Research Ethics Committee of the Federal University of Santa Catarina; UNAIDS: Joint United Nations Programme on HIV/AIDS

## Background

In the more than three decades since Acquired Immune Deficiency Syndrome (AIDS) emerged and grew into a global epidemic, numerous scientific advances have been made to treat AIDS, including identification of Human Immunodeficiency Virus (HIV) disease mechanisms and the introduction of Antiretroviral Therapy (ART). These scientific discoveries resulted in better care and increased the longevity of infected people. Moreover, government and non-government agencies, health professionals and people living with HIV/AIDS (PLWHA) have joined forces to establish a qualified health care model [1].

In terms of care management of PLWHA, HIV infection is no longer considered to be an acute illness, but rather a chronic condition [2]. This re-categorization presents new challenges for health managers and professionals who provide care to PLWHA.

Thus, a new self-management model is needed wherein PLWHA take an active and informed role in decisions about health care practices. This new model requires changes in behavior and social relations, because managing chronic health conditions involves life changes in the biopsychosocial dimension and the adoption of therapeutic treatments [3,4].

Care management can be categorized into three dimensions: professional, organizational and systemic. Professional care management is observed within a professional responsibility, i.e., in establishing a professional-patient relationship that includes ethical, technical-scientific and relational (personal ties) elements. In the organizational dimension, health practices undergo institutionalization, where technical and social issues concerning the division of labor emerge that result in management responsibility and a dynamic conformation of the team and relationships between team members. Finally, the systemic dimension is configured by a set of health care services that have different functions and levels of technological incorporation, as well as various integrations between

services that establish a network to offer comprehensive care to patients [4].

Health practices involve complex care that includes dialogue, understanding of human behavior, qualified listening, respect, knowledge, organization of health services and social policy [5]. Therefore, care management of PLWHA becomes relevant and prominent, because effective case management promotes understanding of multidimensional processes and actions with which PLWHA live and also their experience of being ill and feeling healthy.

By investigating the perspectives of managers, health professionals and patients, it is possible to identify gaps in care processes delivered to PLWHA and implement strategies to strengthen actions that enhance care quality.

Thus, the objective of this study was to understand health care management for PLWHA from the perspective of patients and health care professionals at a specialized service facility in southern Brazil that focuses on infectious diseases.

Complex thinking was the theoretical framework for this research that considers the dynamics of reality and is more appropriate for recognizing the multiple facets and diversity of issues related to health and its management.

## Method

### Design

The research presented here adopted qualitative, dialogical, reflective and interpretative approaches. The study was conducted in the southern Brazilian state of Santa Catarina at a hospital that specializes in treating infectious diseases. According to the classification of the Ministry of Health, this facility provides conventional hospitalization services, day hospital services and a Specialized Care Service for HIV/AIDS.

### Procedures

The data from this study were collected through semi-structured interviews conducted by five collectors, all female.

Interviewers number 1 (PhD in nursing and health researcher) and number 2 (master of nursing) work as nursing professors having extensive experience in research and qualitative data collection. This experience is similar to interviewer number 3 (professor in nursing) who work as a clinical nurse. Interviewers number 3 and 4 (nursing students), in turn, were trained to conduct the meetings and the approach of the participants.

Interviewers and participants of this study did not have any direct relationship prior to the survey, however, some managers and health professionals who composed the study sample had references about the curriculum and professional features of number 1 interviewer, because she is a prominent researcher in the HIV/AIDS area.

### Research participants

Study participants included managers, health professionals and patients who would enable a comprehensive understanding of care management related to HIV/AIDS, forming a intentional sample

Patients enrolled in the study were >18 years old, were diagnosed with HIV one or more years earlier and were registered and regularly

attending service for treatment and/or monitoring. Professionals and managers in the study must have been directly caring for PLWHA for more than one year. These criteria ensured that the collected data reflected accumulated participant experiences.

The research participants were personally addressed in a hospital that specializes in treating infectious diseases. Of the total addressed people, two refused to participate in the study citing fear of break of confidentiality.

In this qualitative approach, there was no preset number of participants, and the priority was on the theoretical deepening of approaches so that data collection was independent of the number of participants. The study included a total of 8 health professionals, including 2 doctors, 3 nurses, 1 administrator and 2 nursing technicians. Of these, three held management positions. In addition, 8 PLWHA who were patients of the specialized service facility were selected to complete the 16 study enrollees.

The number of participants was determined by theoretical saturation or when the data collection reached a point where no new elements were presented to support the desired theorization [6].

The data collection involved semi-structured interviews composed of questions regarding the professional and organizational dimensions of care management that was created by the authors. The one-to-one meetings were previously scheduled and addressed values, attitudes, beliefs and individual experiences that were relevant to the research.

The meetings occurred in a private room of the hospital, where they were present only an interviewer and the participant. These individual interviews were conducted in only one meeting during on average 30 min and were audio recorded and later transcribed in full without use of field notes. The data collection period was divided into two phases. The first phase was carried out between March and December 2013 and the second phase was done in August 2014. The second phase was included because during collection, transcription and coding of the data for the first phase, the need arose for further exploration of the data in terms of the perspective of PLWHA towards care management.

The interviews were transcribed by hand by all the authors of this study, concomitantly data collection, being in possession of the same until the end of the survey, without returning to the participants.

### Data analysis

Qualitative content analysis of the transcripts of interviews was performed by the authors this article using the interactive software *Ethnograph*<sup>®</sup>, which assists qualitative researchers in gathering, organizing and analyzing qualitative data [7]. For data analysis, a descriptive and interpretive strategy was adopted.

In structuring analysis and interpretation processes, the first step was an initial and comprehensive reading of the entire text of the interview transcripts, followed by the deconstruction and unitization of the corpus. The aim with this fragmentation or corpus deconstruction, was to highlight the meanings of the text to the limits of its details, with the understanding that this limit is never fully achieved [8].

After rereading and deconstructing, the content relevant and pertinent to the research – termed meaning units – was selected. The second step of the analysis was the categorization of units of analysis where was delimited three main categories. Categorization is a process of constant comparison between the units defined in the initial analysis

process, leading to group similar elements. The sets of similar elements form the categories [8].

The research participants were not contacted in order to do that feedback from the search results.

### Ethical aspects

To comply with ethical standards, the recommendations of Resolution no. 196/96 of the National Health Council (CNS) of Brazil and its complementary recommendations updated by resolution 466/12, CNS were followed [9]. After receiving authorization from the hosting institution, the assent of the Human Research Ethics Committee of the Federal University of Santa Catarina (CESPH/UFSC) was obtained under Opinion no. 167 681 on December 10, 2012.

The participants were informed of the study objectives and research methods, and were assured of their rights regarding access to data, preservation of anonymity and the possibility to withdraw from the study at any point. All patients signed an Informed Consent Form.

In order to maintain the confidentiality of the research participants, their testimonials were identified with a letter that refers to the sequential sample group followed by a number according to the interview sequence: managers (G1, G2, G3), health professionals (PR1, PR2, ...) and people with HIV/AIDS (PA1, PA2, ...).

### Results

The management research participants were all female with a mean age of 41.66 years and average time performance of 16.5 years. Health professionals, in turn, were characterized mostly by women (80%) with operating time in service an average of 14.8 years, and mean age of 39.8 years. Already the PLWHA were mostly male (75%), single (62.5%) and white (87.5%) with mean age of 40.87 years, with a mean time of diagnosis of 11.5 years.

The results of the data analysis process revealed three categories: interdisciplinarity as interface in care management; continuous training in the context of care management; and strengthening of healthcare networks.

Regarding interdisciplinarity, the results showed that both managers and users recognize that interdisciplinarity is required in delivering health services for PLWHA, especially for a perspective that focuses on the quality of care.

The interdisciplinary perspective points to the relevance of comprehensive care to the individual's needs. The quotes below illustrate that fragmenting the work of a multi-professional team complicates the systematization of interdisciplinary and intersectorial relationships as well as interaction practices:

*"The team works the multi-professional dimension but do not work the interdisciplinary, you know? Many professionals such as psychiatrists, pharmacists, nurses, doctors, nutritionists [...] they do not exchange experiences [...] people have to get over it and come back to talk about this issue." (G3)*

*"But when there are health professionals working together with you, understanding your situation, assessing the best options available... this gives you direction... this is important...you have more desire to really come back, to follow the treatment better" (PA4)*

However, the perceptions of participants and everyday working practices reinforce a fragmented type of work, where each professional

individually fulfills their function, and the interrelationship between them that is so critical for interdisciplinarity gradually disappears. This loss of interdisciplinarity is reflected in a fragmented perception of the patient and the health-disease process instead of a comprehensive view, and may be a consequence of the current model of care management applied in practice.

From the perspective of PLWHA, joint efforts of professionals expand recognition of their care needs and promote more effective participation and commitment. For interdisciplinarity to occur, different disciplines must engage in a dialogue, which may be affected by professional barriers that managers must recognize.

*What is needed to ensure long-term and comprehensive care is highlighted by the following participant:*

*"There is a limitation of each profession, that is why I say they are multiprofessional but do not work the interdisciplinary dimension" (G3)*

Thus, continuous training in the context of care management could improve relationships between professionals, and especially between professionals and patients.

This research also identified the need to understand the patient as a person who has complex needs that arise from various determinants of life and health conditions, particularly the challenges of living with HIV/AIDS. This need for a better understanding of the patient as a person is mirrored in the need for professional training to conduct and manage these situations every day as evidenced by this statement:

*"I think that continuous training is beyond the technical part. I think it should have something different. There is a human being behind all this. The person arrives here and they have a background, prejudices." (PR4)*

However, in the context of this study it was impossible to identify aspects that involve other dimensions of care beyond the technical-scientific, such as interpersonal and institutional relations or conflicts between values and principles.

In addition, on several occasions the interviews highlighted issues such as the importance of continuous training as a tool to enhance the user-professional-user relationship as well as the relationship between professionals. Such training tools should emphasize communicative practices and relational activities that characterize a humanized and welcoming care environment:

*"We are discussing some things on continuous training, to make a survey of what the training needs are thinking of the care provided to the patient profile that we meet here. Now my concern is how to bring, how to reformulate a continuous training service thinking of a new model for people to feel responsible for a process of change as well." (G1)*

*"In daily life I think that the personal relationships are enhanced with continuous training. I think they are two parallel things: fighting with managers to make things work and training, because training is everything! To enhance this I think training is fundamental." (PR4)*

In this sense, care could be improved through training processes that include planning and coordination of interactions between knowledge bases and between various professionals.

Finally, the strength of health care networks highlights the need to reorganize network services to provide comprehensive care to PLWHA with the intention of improving care management.

In the testimonials from the professionals participating in this study, difficulties in conducting long-term care are evident and shared among various health facilities:

*"There is a lack of an organization of the service as a whole. I think there should be more communication between administrations."* (PR1)

Also in terms of care management and creating stronger care networks, interviewees discussed their experiences with overcoming weaknesses of this process. These experiences directly affect the quality of services and satisfaction of professionals and users, as shown by these statements:

*"There is a lot of negligence, nobody takes responsibility. I am not satisfied."* (PA5)

*"One sends the patient from one place to another and the person gets confused. There comes a time that the person is tired! [...] Many drop out of treatment because of that."* (PR1)

Thus, the interviews explicitly show dissatisfaction of professionals and users with the lack of coordination between health care services, absence of care lines and no clearly defined referral and counter referral system.

The above statement by PA5, shows that the user perceives negligence by professionals and establishments, i.e., low accountability for the provision of healthcare service.

Another aspect that was highlighted as being important for care management was the decentralization of health services that is intended to facilitate user access and improve the effectiveness in referral processes:

*"I think if it was more decentralized, not all patients should come here. Because the biggest problem is the patient who travels a long way to come here."* (PR1)

*"Because the person goes to the Center (Healthcare Center), then the Center refers them to the specialist. By the time they get an appointment, the person is dead."* (PR3)

The professionals are aware of the proposal by the Ministry of Health in Brazil, which intends to decentralize care throughout the health care network, and demonstrates the need to manage the reorganization of services.

## Discussion

Given the analysis and results, a limitation of this research is the fact that it was conducted in a specialized service facility, which may affect the data because the participating managers, professionals and PLWHA at the site have better preparation and more experience. However, the data may not reflect the reality of most care services for PLWHA, to whom the multidimensionality of care management does not have as much relevance as it does in a specialized facility.

The interdisciplinarity that is seen as a perspective for care management of PLWHA requires its own team that goes beyond a multi-professional team with fragmented practices. Thus, interdisciplinarity demands a reconnecting of knowledge, since the complexity of life involves both interrelation and interaction between life issues [10].

To achieve interdisciplinarity, efforts must be made to break the hegemony of knowledge in health care and reconnect disciplinary knowledge. Knowledge and experiences of professionals need to be

shared so that there is no dominance of one discipline over others or of one professional over others. In doing so, it becomes possible to provide expanded care according to the needs of users, while respecting and accepting the singularities both among health workers and between them and patients [11].

Of note is that continuous training in the context of healthcare management is built from the practice of the teams. Thus, demands for training cannot be solely defined or updated according to a list of needs for individual professionals or by guidelines issued by central management.

The constant professional education that is required in health care guarantees that the professional has knowledge of the best and most effective practices of nursing and medicine. Such attentive, serious and competent care that results from knowledge of best practices can alleviate suffering and even prevent unnecessary deaths. Moreover, professionals must understand that the patient is entitled to accurate diagnosis as well as effective treatment and communication, among other services. Furthermore, they should never be offered care as a favor, but rather as a quality service [12].

The core of continuous training is aimed at reconstructing professional identities and coordinating different areas of knowledge and practices. The training also provides a proactive role for professionals, wherein they are empowered to identify their own strengths and weaknesses, as well as transform the reality, of which they are part, that begins by making a commitment to quality patient care [12].

Another important point highlighted from the perspective of care management for PLWHA refers to the strengthening of healthcare networks, with defined care lines that work to implement a new model of health. Notably, the implementation of health programs that focus on chronic conditions is one of the mandates of the Joint United Nations Program on HIV/AIDS to ensure universal access for PLWHA to programs that prevent and treat their disease as well as provide care and support [13,14].

Maintaining fragmentary healthcare models may be directly related to the failure to achieve goals that are related to controlling chronic disease and the complications that accompany these diseases. Thus, the obsolescence and inadequacy of this compartmentalized organization clearly indicates the need for a new model of care that addresses the needs of people living with a chronic condition [15].

This new model should develop a consolidated, organizational approach to health care that addresses fragmented views of health-disease processes and of the individual patient. In this respect, organization of services in care networks has proven to be a more efficient and effective alternative for professionals, users and managers of health systems [15]. The need for decentralization in HIV/AIDS programs worldwide is reaffirmed by UNAIDS and calls for improved mechanisms through which the population can access services. These mechanisms should include primary care as a protagonist of disease treatment programs [13,14,16].

Although governments and institutions working in the area recognize the importance of committing to reorganized services, this practice is still new to Brazil. In early 2014 the Brazilian government proposed reform measures to consolidate the network of service and technical support to primary healthcare institutions to incorporate the therapeutic management of citizens infected with HIV/AIDS [17].

This reorganization is justified primarily by the promising results reported in the literature for PLWHA who are monitored in a primary care setting [18] and by evidence that centralization of HIV/AIDS services and minimizing the distance between the homes of PLWHA and health facilities are factors that affect the likelihood that PLWHA will follow treatment protocols [19-21].

## Conclusion

From the perspective of individuals involved in managing and promoting the care and health of PLWHA, changes are needed to improve the care of PLWHA in terms of the three dimensions of care management (interface interdisciplinarity, training and network strength). Implementing these changes will require continual efforts to address the way in which professionals regard health care and organize their labor in various areas, as well as how services such as continuous training programs and care networks can be re-organized to promote effective patient care.

The research presented in this paper aims to contribute to reflections on the care management practices in nursing and highlight perspectives that can be used for improving activities and services provided to PLWHA at all levels of care.

The various participants involved in this study, whether they were people with HIV/AIDS, or managers and/or professionals, point out the importance of comprehension in health care, and the need to minimize prejudices about uniqueness and diversity. A horizontal perspective of the actions and services is also highlighted, and considers the importance of relationships and interactions that take place around the complex issue of what it means to live with a chronic condition as well as the need for connection and continuous care.

Because this reorganization of services is a process that is still under construction, there will be new long-term challenges to be faced by health professionals and managers who care for PLWHA. Due to the multi-dimensional nature of chronic diseases such as HIV/AIDS, interdisciplinarity, continuous training and the strengthening of health care networks are among the top considerations for care management of PLWHA.

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