

Potentialities and weaknesses in the care network of people with HIV/AIDS

Potencialidades e fragilidades da rede de cuidado da pessoa com HIV/aids
Potencialidades y fragilidades de la red de cuidado de las personas con VIH/SIDA

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ABSTRACT

Objective: to understand the strengths and weaknesses in the care network of people with HIV/AIDS in a referral center in the state of Santa Catarina-SC. **Method:** participants were eight subjects and their care network, totaling 18 participants. Data were collected through interviews and examined by content analysis, theoretically supported by symbolic interaction. **Results:** the analysis resulted in the following categories: The network offering care to people with acquired immunodeficiency syndrome, and Facing Barriers in care, which reflect the strengths and weaknesses in the care network. The first depicts the provision of emotional and humanized care, and the second a restricted network formed by health professionals and a family member. **Conclusion:** the professional care network is important, despite the increased number of assistances in a physical structure and amount of professionals who no longer meet the growing demand.

Keywords: Nursing; HIV; Acquired Immunodeficiency Syndrome; Patient Care.

RESUMO

Objetivo: compreender as potencialidades e fragilidades da rede de cuidado da pessoa com HIV/Aids em um serviço de referência do Estado de Santa Catarina-SC. **Método:** participaram oito sujeitos e sua rede de cuidado, totalizando 18 participantes. Os dados foram coletados através de entrevistas e examinados por análise de conteúdo, sustentados teoricamente pelo interacionismo simbólico. **Resultado:** a análise resultou nas categorias: A rede ofertando o cuidado à pessoa com síndrome da imunodeficiência adquirida e Enfrentando Barreiras no cuidar, que refletem as potencialidades e fragilidades, na rede de cuidado. A primeira retrata a oferta de cuidado afetivo e humanizado e a segunda, uma rede pouco ampliada, constituída por profissionais de saúde e algum membro familiar. **Conclusão:** a rede de cuidado profissional é importante, mesmo diante do aumento dos atendimentos numa estrutura física e número de profissionais que já não comportam a crescente demanda.

Descritores: Enfermagem; HIV; Síndrome de Imunodeficiência Adquirida; Assistência ao Paciente.

RESUMEN

Objetivo: comprender las fortalezas y debilidades de la red de atención de la persona con VIH/SIDA en un centro de referencia en el estado de Santa Catarina-SC. **Método:** ocho participantes sujetos y su red de atención, por un total de 18 participantes. Los datos fueron recolectados a través de entrevistas y se examinaron mediante análisis de contenido, en teoría, con el apoyo de la interacción simbólica. **Resultados:** el análisis resultó en las siguientes categorías: La red de ofrecer atención a las personas con síndrome de inmunodeficiencia adquirida y tropezando con obstáculos a la atención, que reflejan las fortalezas y debilidades en la red de atención. El primero representa la prestación de atención emocional y humano y la segunda un poco más amplia, incluyendo la red de profesionales de la salud y un miembro de la familia. **Conclusión:** la red de atención profesional es importante, a pesar del aumento de las llamadas en una estructura física y el número de profesionales que ya no se comportan de la creciente demanda.

Palabras clave: Enfermería; VIH; Síndrome de Inmuno Deficiencia Adquirida; Asistencia al Paciente.

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INTRODUCTION

The acquired immunodeficiency syndrome (AIDS) is a disease that has brought concerns worldwide given the great assistance responsibilities and specific care, requiring attention from affected people and those directly involved with care over time, since its onset, especially for people who need care in the health services⁽¹⁻²⁾. People with HIV/AIDS need to restructure their life routine in face of the new context. Such a situation makes human beings rethink the confrontations of their life and death process that has chronic evolution, and requires changes in their living standards to live better every day⁽³⁾. However, it gives opportunities for these people seeking the best care strategy for their lives. It is necessary to reformulate the health care structure as a whole to enable people affected by AIDS and those involved with their care to reach the best way to live healthfully⁽³⁻⁴⁾.

Arising in the 1980s, the Antiretroviral Therapy (ART) prevents virus replication, and it has been distributed for free in Brazil since 1996 through the law number 9313/96 for all people in need of such drugs, as a part of care for improving the quality of life of those affected by HIV/AIDS, together with other care strategies such as multi-monitoring, healthy eating and exercise⁽⁵⁾.

Associated with these strategies and aiming to serve people affected by HIV/AIDS better, the health care actions constitute the necessary support for people living with the disease and their families in the search for solutions that may arise from their experiences in network⁽⁶⁾.

Thus, health care networks with their professional teams are also members of care. They focus on disease management and the perspective that each affected person visualizes the care received, and the demands emerging from this process, in this sense, the user-professional interface⁽⁷⁾.

Given the above, when people with HIV/AIDS discover the disease, great difficulties and sufferings emerge due to changes and transformations caused by a physical condition visibly committed for most of them, such as impaired self-image or an unfavorable psychological condition, with prejudice and stigma still strongly present in society. Such prejudices and discrimination against the disease, even nowadays, are unfortunately part of this whole socially constructed process, since the disease onset⁽⁷⁻⁸⁾ and currently still strongly present in society.

Regarding the care network, situations of weaknesses or difficulties can be addressed by the care network, which can be the family care network, the institutional-professional network or the own person living with HIV/AIDS. Paying attention to the weaknesses and strengths of this network can lead to the discovery of better or new practices during contact with people affected by the disease. This can also be instrumental, emotional and attention support when meeting their needs.

This study aimed to understand the potentialities and weaknesses in the care network of people with HIV/AIDS treated at a referral center in the state of Santa Catarina (SC).

METHOD

This study used the theoretical framework of symbolic interaction, which considers the importance of interactions

between people in their life relations⁽⁹⁾ by understanding that these are part of their daily experiences.

This exploratory study of qualitative approach took place at a referral service in infectious and parasitic diseases in the State of Santa Catarina. Eight people with HIV/AIDS and their care network participated, totaling eighteen participants through data saturation. Among the members of the family care network were: mother, sister, brother and wife. Members of the institutional-health professional care network were represented by doctors, the nursing staff and a psychologist.

As inclusion criteria for participation, people with HIV/AIDS should have knowledge about their disease for at least an year; have cognitive acuity to answer questions during the interview and be older than 18 years.

The members of care networks mentioned by patients should be aware of the seropositivity, reside in Greater Florianópolis and have cognitive acuity to answer the interview questions. The care networks were selected during the time of the interview with those affected by HIV/AIDS in previously scheduled date and location. Thus, people who did not fit the preceding requirements would be excluded from the study. Some family members of the care network (father, aunt, friends and children) were not interviewed for not residing in the Florianópolis area or not knowing the HIV status of the person with HIV/AIDS. These were exclusion criteria.

The data collection period was from January to May 2011 through semi-structured interviews. These interviews with people with HIV/AIDS took place in the clinic (referral service) in days of medical consultation or exams; the interviews with people in the care network happened in place and time scheduled by phone in mutual agreement between the researcher and participants. The contact information (telephone number) was previously made available by people with HIV/AIDS. The interviews took place in locations such as home (for most of them), at a school where one studies, in the workplace and also in the ambulatory when they were accompanying the person with HIV/AIDS for consultations.

The interviews lasted an average of 50 minutes with a pleasant atmosphere and researcher and participants interacting, establishing the dialogue in a simple and clear language to collect information contemplated in the proposed research objectives. The guiding questions were: How does the care network contribute to the treatment of people living with HIV/AIDS? What are the weaknesses of the care network of people with HIV/AIDS?

For data analysis, we used the content analysis of Bardin⁽¹⁰⁾, thematic modality, in the following phases: pre-analysis, material exploration and processing, inference and interpretation of data.

The research ethical aspects were respected in all its phases, in accordance with Resolution number 196/96, updated by Resolution number 466/12 of the National Health Council (CNS – Conselho Nacional de Saúde)⁽¹¹⁾, which regulates research involving human subjects. The project was submitted to the Ethics Committee of the Universidade Federal de Santa Catarina under number 1157. All participants signed the informed consent form (IC).

The following identification was used to ensure the confidentiality of participants: for people with HIV/AIDS the letter P followed by the cardinal number in ascending order, from P1 to P8. People of the family care network were identified with the letters RF and the institutional- health professional network was identified with the letters RI. During the whole study period none of the participants quit the research.

RESULTS

We consider relevant to present the participating members of the care network of people with HIV/AIDS to describe the results.

Box 1 shows that people with HIV/AIDS, have basically professionals and their first-degree relatives (mother, sister, brother, wife) as representative of their care network. This is an unfortunate situation, because the needs demand specific care, much attention and dedication. Members of the institutional-health professional care network are represented by doctors, nurses and nursing staff, and psychologist, the latter not linked to the studied referral service.

The following categories and subcategories emerged from the data analysis: Category 1- The network offering care to people with acquired immunodeficiency syndrome, covering the subcategories: Providing care and meeting the needs; Having satisfaction in caring; Listening as a demonstration of concern for the care, and Instrumental and emotional care in everyday life. Category 2- Facing barriers in care for HIV/AIDS, divided into subcategories, namely: Experiencing suffering and prejudice; A restricted family care network, and Experiencing limitations in the performance of institutional health care.

Category 1 – The network offering care to people with acquired immunodeficiency syndrome

In this category, the care provided by the family and institutional- health professional networks concerns the demands of the illness throughout its course. The results of the subcategories emerging from this category are:

Subcategory 1- Providing care and meeting the needs

The care network of the person with HIV/AIDS, both the family and institutional- health professional, provide care focused on meeting the disease daily demands, as noted in the lines:

We need to address the situations experienced by each patient. I try to learn the medications she is taking to help her (RI3)

I try to adapt ... to organize the flow of his needs ..., I do everything so the patient leaves consultation with everything sorted ... (RI1)

What I can do is continue to accompany him to the doctor, so much so that I'm here today... (RF1- P4)

Box 1 - Identification of the people who constituted the care networks of people with HIV/AIDS

CARE NETWORK OF PEOPLE WITH HIV/AIDS		
Person with HIV/AIDS	Care network Family	Care network Institutional-Health professional
P1		RI1 (doctor)
P2	RF1 (mother)	RI1 (doctor) RI2 (nurse)
P3	RF1 (wife)	RI1 (doctor)
P4	RF1 (wife) (father, mother and aunt)*	RI1 (doctor) RI2 (nurse)
P5	RF1 (brother)	RI1 (doctor)
P6	RF (sister) (friend 1 and friend 2)*	RI1 (doctor)
P7	RF1 (wife)	RI1 (doctor) RI3 (psychologist)
P8	RF1 (wife) (children)*	RI1 (doctor) RI2 (nurse)

**Members of the network who were not interviewed due to not residing in the greater Florianópolis, or not knowing the positive HIV status.*

The mutual collaboration of the multidisciplinary team in meeting the care needs of people with HIV/AIDS is also present:

I try to work with the pharmacist, with the nurse. We have a psychologist and sometimes we ask for help. The nutritionist also collaborates; all this to try to serve the patient as a whole. Having a nurse near me is fundamental, I cannot live without them! (RI1)

The guidance provided by the institutional-health professional network in the practice of care to people with HIV/AIDS is part of the care range focused on attention and explanations about the disease:

They always offer the guidance and assistance we need to care for him. (RF1-P3)

The patient says, "nice talking to you!" And I feel much better. I talk about the disease, even to see if she's understanding the process and the treatment itself, I try to show the importance of all this. (RI2)

The support in everyday actions, the guidance related to the care offered by the family network of people with HIV/AIDS and the team work with interdisciplinary approach are an important potentiality of the care network in promoting the health of people with HIV/AIDS.

Subcategory 2 – Having satisfaction in caring

The satisfaction expressed by people in the network when providing care to people with HIV/AIDS demonstrates their pleasure in caring, gratification, happiness, and sense of mission accomplished by doing it:

Taking care of her... for me it's a pleasure ... (RF1- P7)

It's quite rewarding! I'm very happy! (RI2)

Helping them gives me a sense of accomplishment. (RI2)

A form of satisfaction and gratification is seeing that some things have changed for better, of being able to change some behavior that compromised the health of people with HIV/AIDS:

Taking care of him is a matter of honor for me, just for the fact that he managed to get out of the life he used to lead ... (RF1-P3)

Thus, from the perspective of people in the care network, taking care of people with HIV/AIDS brings satisfaction, is rewarding, pleasurable and causes a feeling of happiness to see them well. Moreover, providing care brings the feeling of mission accomplished. Thus, people from the network have the potential to satisfy people with HIV/AIDS.

Subcategory 3 - Listening as a demonstration of concern for the care

The practice of listening by people from the care network of people with HIV/AIDS was identified as a potentiality because in moments of orientation and conversation, the feelings of anxiety, doubts and outbursts are minimized.

Listening and guiding! It's important to listen to the patient for providing proper guidance! (RI1)

The contribution is like that: it's feeling, realizing, listening, talking and even not talking! When you give the diagnosis. Sometimes the most important thing is to let the patient talk, let them express themselves, you know? (RI2)

... I listen to what he has to say, especially when he's distressed, I think it's important to listen, it's an outburst for him ... (RF1-P8)

The potentiality and the importance of listening to patients, give them voice, allow them to express their feelings contributes to the exercise of specific care that the person with HIV/AIDS needs.

Subcategory 4 - Instrumental and emotional care in everyday life

The instrumental care provided by the family network includes daily care actions that facilitate the routine of people with HIV/AIDS.

I do whatever is in my reach. I take care of the house to leave everything clean, take care of food, clothes ... (RF1-P2)

I help him in the firm as well. Sometimes, when I can, I get the medicines for him, I help like that. (RF1-P5)

The available care seeks to achieve all the life aspects of these people, which are focused on the needs of guidance and support. Thus, is perceived the importance of continuity of

care, in which emotional balance is achieved by experiencing daily confrontations:

When receiving these guidelines, the patient naturally feels more relaxed, and this also includes the emotional issue. With guidance, I see a great emotional evolution. (RI2)

In short, the instrumental care consists of important elements for the life of people with HIV/AIDS, providing benefits in their daily needs, affective and emotional support, and strengthening their self-esteem.

Category 2 - Facing barriers in care for HIV/AIDS

This category covers the subcategories depicting the barriers in the process of caring for HIV/AIDS: Experiencing suffering and prejudice; A restricted family care network; Experiencing limitations in the performance of institutional health care.

Subcategory 1 - Experiencing suffering and prejudice

The prejudice situations experienced daily not always allow expanding the care network of people with HIV/AIDS.

There is still a lot of prejudice because of this disease, one doesn't know very well what's it like to live with the disease or live with someone who has the disease. (RF1-P3)

Nobody helped at the time she most needed, she had only me, no one else, because of prejudice. That made me really angry. (RF1-P6)

The person does not tell for fear of losing the job, fear of losing the family, the husband. (RI2)

On the other hand, the actions of people in the network with guidance and conversations occurring at times of consultation between professionals and patients, help to visualize solutions to minimize anxiety in living with HIV/AIDS.

The patient develops ways to deal with suffering, it's being able to see it in another way and realize that it will affect in a less painful way. (RI2)

Suffering and prejudice hinder the expansion of the network and can bring other damage to relationships and social life. These situations faced by people with HIV/AIDS on a regular basis can be minimized through humanized actions like emotional and professional support.

Subcategory 2 - A restricted family care network

The family care network of people with HIV/AIDS is restricted, normally represented by only a member or two.

I have ten siblings altogether, and everyone knows about my problem, but when I got sick, she (the sister) was the only one who embraced me. (P6)

There are other people in my life. My aunt cares about me, calls me, asks how I am, but she doesn't live with me every day! (P7)

My support is my wife and my children, but they (the children) don't know that I have the disease! (P8)

The existence of a small family network reflects a condition of limited assistance and prejudiced thoughts of other network members, or even for self-protection of the person living with HIV/AIDS in face of possible reactions when revealing the disease to others. In this sense, the few family members involved in the care of people with HIV/AIDS cause overload and loneliness for those who are near, or greater need for self-care by the sick person.

I do everything alone, never sought anything, don't think it's necessary. He already knows everything he can do and what he needs to take care of, he's no longer a child! (RF1-P2)

... I have no time to go out to seek help because I work, ... when he needs something or realizes he's not very well, he goes to the hospital ... (RF1- P3)

The family care network behaves with a distance from the person with HIV/AIDS due to various situations resulting from the disease. The prejudice still present in society brings weaknesses for the care network.

Subcategory 3 - Experiencing limitations in the performance of institutional health care

The care offered by health professionals of institutional services to people with HIV/AIDS has some limitations arising from the high care demands and the scarce number of qualified professionals, making the assistance and even the systematization of care difficult.

The clinic has grown and our greatest lack is of nursing professionals, psychologists, psychiatrists. The Specialized Assistance Service leaves much to be desired by the lack of nurses. We cannot give the necessary attention to nursing consultations, adherence groups after medical appointments, etc. (R12)

Another point that makes specific care to people with HIV/AIDS more difficult is related to the great care demands of other conditions/diseases.

We must meet the demands of accidents with sharp objects, dog bites, cases of sexual violence. And the patient who comes here for a consultation, we're not able to see. (R12)

What is happening is that we are procrastinating, covering holes and putting out the fire, right? ... Because there's no time... (R12)

The physical structure has also hampered institutional care because it did not grow together with the demand. It is still small and with few areas available for professionals continuing the treatment, especially nurses.

If they send another nurse over here, then I ask you: where will he/she work? We have a problem that is not only of personnel, but physical too ... (R12)

Today we have five doctors' offices and only a nursing office. Then, there is the situation, if we have two nurses, what do we do? Because one should see chronic patients and the other acute patients ... (R12)

Caring for the health of people with HIV/AIDS is no easy task as cited by members of the institutional- health professional care network because the care demands are increasing. The same limitation occurs when providing assistance in a limited physical infrastructure and with lack of qualified professionals to work in specific care.

DISCUSSION

Through its course over the years and depending on the viral load, AIDS may affect the body of those who have it, which, requiring great skills of caregivers. From this perspective, it is important that people with the disease feel good when receiving care, to ensure an acceptable quality of life alongside the people with whom they live together daily⁽⁸⁾.

On the other hand, professional care requires interdisciplinary practices in face of the needs of a quality and satisfactory service to those seeking such care, meeting the established strategies⁽¹²⁾.

The care for people with HIV/AIDS should be provided without distinction from care to patients with other health problems, without differences between these cares and causing impediments in the delivery of assistance. Professionals of the area should offer multidisciplinary care where the ideal is provided according to the capability to meet the patients' needs⁽⁷⁾.

The experiences lived by people with HIV/AIDS and their care network are represented by affection exchange, instrumental support and above all, a convivial relationship with the disease in order to provide quality care. This experience occurs from understanding the past events in order to attribute meanings to things based on their beliefs, values and interactions⁽⁹⁾.

The family representation in care for people with HIV/AIDS affects the available support, especially when the care is related to instrumental support, in addition to affective care, an important fact in meeting patients' needs. The surveyed people with HIV/AIDS have at least a family member to assist them with daily care. However, they report that in some cases, such activity is seen as a job option like any other, bringing physical and mental strain, even greater due to being a relative, constituting a determinant of care provided. On the one hand, these situations are experienced with mixed feelings of concern, anger, pity and fears, but on the other hand, the caregivers report feeling well because providing care brings gratitude and pleasure⁽¹³⁻¹⁴⁾.

Guidance provided by the care network, whether the family or institutional-health professional, enables people with HIV/AIDS to reflect about the disease, giving them the opportunity to share their feelings, feeling more relieved and less anxious. A study with professionals who care for these people specifically, showed the professional dialogue in the hospital environment favors the encouragement to continue treatment⁽⁷⁾, the same way it allows to solve much of the conflict,

especially those arising from tackling the stress of the illness, clarifying things better⁽⁸⁾. Demonstrations of affection, respect, care and support help to provide comfort, trust and communication between patients and professionals⁽⁴⁾, given the sensitivity manifestations. Often, people with HIV/AIDS live apart from both the family environment and society. Therefore, the unconditional acceptance of the other, and affection demonstrations bring to surface the value of these key practices for interacting with people and society. This enhances the care process because it strengthens the bond of trust and emotional support between those who care and those who are cared, minimizing conflicts experienced in the seropositivity situation^(4,14).

Listening is a potential action in caring for people with HIV/AIDS because it approximates the professional and the conflicts of patients, giving them condition to think of better strategies to minimize suffering. In this respect, communication, especially active listening, shows interest and concern to those exposing their grievances, which gives a sense of complete dedication in the professionals' act of caring⁽⁴⁾.

Structural issues of the service, especially the skilled workforce, insufficient number of specialized professionals and inadequate physical structure form the main tripod of difficulties in the assistance to the studied people with HIV/AIDS. Faced with the provision of care by services specialized in AIDS, a study aimed at evaluating the quality of services has identified that Brazil has a quite heterogeneous range of services when it comes to institutional and infrastructure characteristics. The services provided have an infectious disease doctor and other professionals forming the team, such as nurses, psychologists, social workers, pharmacists, among others, in the various health institutions⁽¹⁵⁾.

The difficulties faced to meet the expected amount of assistances in the health service researched relate both to increased demand as the insufficient number of trained professionals, mainly nurses. This was identified as a barrier in other studies, resulting in impediments to the exercise of quality care practices. Poor conditions of service are also reasons of professional dissatisfaction and bring impediments to exercise their practices with quality⁽¹⁶⁾. Another study found the lack of medical professionals was a difficulty, given the importance of specific medical information pertinent to care, leaving users unsatisfied⁽⁸⁾. All of these situations unfortunately result in

losses for both those providing care and receiving care.

Regarding the study limitations, it was observed that the care network for people with HIV/AIDS is quite restricted to family and professionals, making it impossible to do other more in-depth analysis on the topic. However, the study showed this network has an important contribution for disease control and the quality of life of these people.

FINAL CONSIDERATIONS

The care network to people with HIV/AIDS provides important care for their living. Potentialities were observed, such as affection feelings, and instrumental support in the case of help with everyday tasks, displacement to collect medication, among others. This provides greater strengthening of their relations in everyday experiences. The care guidelines regarding the disease concerns are always welcome, making people feel more firm in their daily living relations.

As for the institutional-professional network members, the potentialities are focused on active listening, demonstrating concern for the disease sufferings, and its guidelines to clarify any possible doubts. This facilitates understanding the care extent in the home environment, in this case, not only for the patient but also for people of the family care network. Therapeutic adherence is expected as a positive result of the exchanges between those involved in consultations.

Of all weaknesses pointed out by people with HIV/AIDS, prejudice is strongly suggested as a factor that hinders living with the disease because, in addition to stopping the care network expansion, it reinforces the difficulty of facing the disease alone, without support. Moreover, specifically for the institutional-professional network, the care demands and inadequate physical structure prevent the provision of a service with more attention and quality.

Given the above, we see the need to continue enhancing the care network of people with HIV/AIDS, since within a restricted network, the strengthening of care actions positively influences the lives of these people. As for the care potential provided by the institutional-health professional care network, it requires investment actions in public services that can promote the care quality, given the daily limitations such as inadequate physical infrastructure and the limited number of qualified professionals to meet the growing demand for care.

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