

Pain management in patients with AIDS: analysis of the management structure of a reference hospital*

MANEJO DA DOR DE PACIENTES COM AIDS: ANÁLISE DA ESTRUTURA GERENCIAL EM HOSPITAL DE REFERÊNCIA

MANEJO DEL DOLOR EN PACIENTES CON SIDA: ANÁLISIS DE LA ESTRUCTURA ADMINISTRATIVA EN HOSPITAL DE REFERENCIA

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ABSTRACT

The objective of this study was to analyze the structure for the management of pain in patients with AIDS in a reference hospital in Fortaleza, Brazil. This is a descriptive study with a qualitative approach, developed in 2010. Twenty interviews were performed with health care professionals (physicians and nurses), and analyzed according to the methodology of content analysis. Data were organized into categories: favorable and unfavorable structural conditions. A prevalence of unfavorable conditions was found in the discourse of the interviewees, such as an emphasis on pharmacologic treatment, absence of specific care strategies for pain, lack of experienced professionals in handling pain, and a high demand and failure in the referral and counter-referral system. It is suggested that a new management care model be instituted for patients with AIDS, emphasizing an interdisciplinary approach to pain, training of health care professionals and improvement of chart records for use in evaluating pain relief methods and more effective treatments.

DESCRIPTORS

Acquired immunodeficiency syndrome
HIV
Pain
Nursing care
Patient care management

RESUMO

O objetivo deste estudo foi analisar a estrutura gerencial para o manejo da dor em pacientes com aids em um hospital de referência de Fortaleza, CE, Brasil. Pesquisa descritiva com enfoque qualitativo, desenvolvida no ano de 2010. Foram realizadas 20 entrevistas com profissionais de saúde (médicos e enfermeiros), analisadas segundo o referencial da análise de conteúdo. Os dados foram organizados em categorias: condições estruturais favoráveis e desfavoráveis. Constatou-se prevalência de condições desfavoráveis no discurso dos entrevistados, como ênfase no tratamento farmacológico, inexistência de atendimento específico para dor, insuficiência de profissionais experientes no manejo da dor, demanda elevada e falhas no sistema de referência e contrarreferência. Sugere-se instituir novo modelo gerencial de cuidado aos pacientes com aids, enfatizando atendimento interdisciplinar à dor, treinamento de profissionais e aprimoramento de registros em prontuários para utilização de métodos de avaliação e tratamentos mais eficazes.

DESCRITORES

Síndrome de imunodeficiência adquirida
HIV
Dor
Cuidados de enfermagem
Administração dos cuidados ao paciente

RESUMEN

El estudio objetivó analizar la estructura administrativa para el manejo del dolor en pacientes con SIDA en un hospital de referencia de Fortaleza-CE, Brasil. Investigación descriptiva, con enfoque cualitativo, desarrollada en 2010. Fueron realizadas 20 entrevistas con profesionales de salud (médicos y enfermeros), analizadas según referencial de análisis de contenido. Los datos se organizaron en las categorías: Condiciones estructurales favorables y desfavorables. Se constató prevalencia de condiciones desfavorables en el discurso de los entrevistados, con énfasis en el tratamiento farmacológico, inexistencia de atención específica del dolor, insuficiencia de profesionales expertos en manejo del dolor, demanda elevada y fallas en el sistema de referencia y contra-referencia. Se sugiere instituir un nuevo modelo administrativo de cuidado al paciente con SIDA, enfatizando atención interdisciplinaria del dolor, capacitación de profesionales y mejora de historias clínicas para utilizar métodos de evaluación y tratamientos más eficaces.

DESCRIPTORES

Síndrome de inmunodeficiencia adquirida
VIH
Dolor
Atención de enfermería
Manejo de atención al paciente

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INTRODUCTION

In Brazil, pain has become one of the main causes of attendance in emergency situations and for ambulatories in several medical specialties and other health professions. In patients with acquired immunodeficiency syndrome (AIDS), pain manifests as a common symptom occurring in all stages of the disease with a different form for each. The more the disease progresses, higher the incidence and intensity of the pain⁽¹⁾.

Pain is estimated to occur in 90% of people with human immunodeficiency virus (HIV)⁽²⁾. Specifically, this pain occurs for three main reasons: as a symptom or side effect of HIV, another disease or opportunistic infection, or Antiretroviral Therapy (ARVT)⁽¹⁾.

Spreading the main principles of pain management to health professionals who care for people living with HIV/AIDS involves describing the prevalence and types of pain found in patients with AIDS, analyzing the psychological and functional impact of this pain, and discussing the barriers to appropriately treating pain in this group and those with diseases related to AIDS. Moreover, pain control in AIDS patients with a history of substance abuse should be emphasized beyond including oncologists as active participants in the AIDS care⁽³⁾.

Furthermore, there is a pressing need to analyze the care management systems implemented by institutions because of the importance of the interdisciplinary team taking increasingly individualized actions and participating in the conception of a multidimensional model for pain care in patients.

When analyzing care management, it is essential to know the structures the institution uses to affect processes related to patient care, applied resources, the physical structure, and the availability of treatments among others.

For the last 30 years, clinic research has produced therapeutic improvements for patients infected with AIDS; however, problems involving the management and control of pain in these patients have only recently begun being studied⁽¹⁻⁴⁾. Therefore, this research aimed to analyze the structures for managing pain in people with AIDS at a reference hospital for infectious diseases.

Studying the management of pain in hospitalized patients with AIDS is relevant because it addresses the perspective of health professionals on the available tools for effectively managing this symptom at the institution where they work. It is believed that such an understanding is important for planning solutions in this context.

METHOD

This is a descriptive study that uses a qualitative approach developed in a reference hospital for the treat-

ment of infectious diseases in the State of Ceará, Brazil. The physical structure of this hospital includes admission units, intensive care, day hospital care, and specialized ambulatory services for patients with AIDS with daily attendance by professionals who form a multidisciplinary team.

The studied subjects were health professionals and are listed by convenience. Of the health professionals at the institution, only doctors and nurses were selected because doctors established the therapeutic regime and nurses managed daily care, assisted patients in their biological and psychological needs, interacted with the patients and conducted the exams and procedures required for the patients' recovery.

The following inclusion criteria were considered: active at the institution for at least one year and assists AIDS patients in the hospital, emergency, day hospital or intensive therapy units. In the end, the study included 20 participants, eight doctors and twelve nurses, which was the theoretical saturation limit for data collected by the survey.

We used a semi-structured interview technique to collect data on the identification, professional background and pain management practices of the subjects, which was considered relevant to management and care; the existence of formal or informal pain evaluation protocols; descriptions of the pain management processes performed by the professional; the inpatient care activities specifically for controlling pain; and a list of the difficulties with and facilities for attending to pain at the hospital. The interviews of the professionals were conducted throughout the working day and recorded, which allowed for more accurate data collection.

A content analysis of a set of organizational and informational techniques was used for the data analysis⁽⁵⁾ and was considered a procedure for analyzing the qualitative data to find emergent issues, topics, concepts or knowledge. This analysis was composed of distinct and complementary phases: previous analysis, material preparation, material storage, categorization, and the explanation and interpretation of the obtained results.

The core of this study consisted of 20 interviews defined the phrase as the Record Unit (RU). In turn, the number of RUs was distributed across the themes from the in-depth interviews, which contained common characteristics regarding the service structures considered favorable (Category 1) or unfavorable (Category 2) to effective pain management.

To ensure the anonymity of the respondents, doctors were codified with the letter *D* and nurses with the letter *N* followed by an Arabic numeral corresponding to the order in which they were interviewed.

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With regards to ethical issues, this study was approved by the Research Ethics Committee of the institution in accordance to protocol nº 063/2009. The professionals signed an informed consent form about the study, which followed Resolution 196/96 of the Brazilian Health Ministry on studies involving humans⁽⁶⁾.

RESULTS

Table 1 shows the results of the thematic content analysis, which used two categories and six subcategories for a total of 51 units.

Table 1 - Distribution of the thematic categories, sub-categories and respective frequencies for the pain management structure for people with AIDS. Fortaleza, CE, Brazil. May/September, 2010

CATEGORIES (CODIFICATION)	f (%)	SUBCATEGORIeS (CODIFICATION)	f (%)
1. FAVORABLE STRUCTURAL CONDITIONS (FEC)	13 (25.5)	1.1. Availability of human, material and organizational resources (FECAHMOR)	10 (19.6)
		1.2. Reference hospital (FECRH)	3 (5.9)
2. UNFAVORABLE STRUCTURAL CONDITIONS (UFEC)	38 (74.5)	2.1. Lack of specific attendee for pain (UFECLSAP)	19 (37.2)
		2.2. Shortage of professionals with experience in the pain clinic(UFECSPEPC)	9 (17.7)
		2.3. Elevated demand (UFECED)	7 (13.7)
		2.4. Failure of the references and counter-refers (UFECFRCR)	3 (5.9)

Note: N=51

The aspects of pain management discussed by the professionals for patients with AIDS are described by the following categories:

Category 1: Favorable structural conditions

This category included 13 RU and addressed the professionals' perception on hospital conditions considered favorable to pain management.

Availability of human, material and organizational resources

When asked about the ease of proper pain management at the institution, the professionals noted the frequent availability of medicines in 10 RU.

The hospital really has all medications! (N8).

We have no lack of medicine; the doctors are considerate and leave everything as prescribed (N9).

The easiest part is that, as soon as the diagnosis is made, the medication is available! (N1).

There is no inter-disciplinary pain treatment; however, we have medicines and professionals for prescription and management (N12).

Other topics, such as convenient organizational structures for exams and monitoring patient's response to their hospitalization and treatment, were mentioned as relevant to characterizing the service structure as adequate. Such aspects are detailed in the following quotations:

Facilities (we have found) are to conduct an XR exam, medicate, and refer a specific service... (N2).

We have medication on hand, there is the capability with hospitalization where you may pass medication to the in-patient and monitor the response (D4).

The nurses noted their concern and the professionals' disposition for assuring the comfort, safety and relief from pain of the patients with the effective management of this symptom considered favorable.

Whenever he/she mentions pain, we are ready to assist (N7).

When the patient is not feeling very well or feels pain, we put him in an armchair and try to give him some comfort! (N4).

Reference hospital

The surveyed professionals also considered the service structures adequate for pain management considering that the institution is a reference for the treatment of HIV/AIDS.

Everything is at our disposal, for this is a reference hospital (N9).

As a reference service, we receive many patients and assist them! (D1)

There is simplicity because this is a reference hospital... there are medicines, many employees and physiotherapists, except there is no speech therapy specialist! (D2)

Category 2: Unfavorable structural conditions

This category deserves emphasis based on the quantity of RUs, 38. Half of these address the non-existence of specific attendees for pain at the institution and the remaining were divided between problems relating to the shortage of experienced professionals, elevated demand from patients at the institution and faults in the reference and counter-refers amongst the health units that attended to the AIDS patients.

Lack of specific attendee for pain

Various protocols and measurements have been developed and implemented to help professionals better address pain relief in various health care settings. In this regard, 19 RU detailed concern for professionals in the absence of evaluation protocols for pain at the institution despite it being a reference hospital. The professionals felt the absence of a specific attendee made promoting directed and individualized care more difficult for patients with pain.

Because there is no protocol for dealing with this pain, we do the basics: analgesics and the recommendation of physiotherapy (D3).

Difficulties exist because of the lack of a protocol (N6)

A systematic protocol would be ideal, but we still do not have it (N10).

Shortage of professionals with experience in the pain clinic

The surveyed professionals reported a failure in the processes relating to the inter-disciplinary management of pain as detailed in nine RU.

Sometimes we just medicate patients and do not have a culture of physiotherapy working together (D3).

In some patients (with pain), there is no prescribed pain medication (N6).

The experience of these professionals was questioned once the following comment had been analyzed:

For specific pain management, related to nursing care... there is nothing I consider specific here! (N4).

One professional confirmed the existence of barriers to attendees of patients in chronic pain.

Health professionals do not like attending patients who complain about chronic pain (D7).

Elevated demand

In the professionals' comments about managing the difficulties found, seven RU emphasized elevated demand from patients at the institution.

There is a very large demand here at the hospital, and we do not have time enough for the patient (D4).

We have many patients, and there is no means to focus a specific treatment in this way, only for pain! (D2)

When he arrives with pain and his doctor is not present, we must refer him to the doctor's office, and we know he is going to wait in a queue... (E4)

Failures in the reference and counter-refers

In the interviews, three RU emphasized the failures in the reference and counter-reference system, which were experienced daily.

When it is a headache, you want to refer the patient to a neurologist, and there are none available at the moment! (D7)

References leave much to be desired! (N2)

Suspecting pain, I have to send for another service, and I will only know whether the patient has improved after the appointment, which will be in four months... (D6)

DISCUSSION

The availability of medicines to investigating professionals represents a favorable condition for pain management. Access to essential raw materials for controlling pain is discussed as a transversal factor for quality assurance, both from a management-budgeting and technical-scientific standpoint, which is consistent with several programs, actions and strategies of the Single Health System (SHS) in Brazil⁽⁷⁾.

However, therapeutic intervention should not necessarily aim at removing causal factors and pain treatments involving pharmacological, physical, anesthetic, psychiatric, and functional neurosurgeries. A guided rehabilitation to treat disabilities should be provided by specialized professionals who should be capable of clarifying conditions and changing incorrect beliefs⁽⁸⁾.

In this context, the ability to manage pain management was verified and indicated that the participation of the professionals and presence of a common work project are essential conditions to that truly integrating tasks to relieve inpatient suffering. This calls for a unified multidisciplinary activity linked to the composition, involvement and responsibilities of each professional on the working staff.

However, we noticed a belief that the institution, as a reference for the care of HIV/AIDS, had favorable conditions for meeting the various symptoms experienced by these patients including pain. Reference institutions usually contain professionals, materials, equipment and medications that overcrowd hospital and decrease its effectiveness. However, the surveyed professionals indicated that the hospital can meet the demand because of the prescription and availability of medications for pain treatments.

These procedures seemed insufficient for meet the user demand in the face of the symptomatology, which required new strategies to improve the quality of care and thus the patient's life and health condition.

When discussing unfavorable pain management conditions, the lack of a specific attendee for pain at this institution was emphasized. This finding corroborates the results of a recent survey conducted at a university hospital in Goiás-Brazil, which revealed the absence of a routine for the systematic pain evaluation of patients by nursing teams and was considered a worrying result⁽⁹⁾. The researchers inferred that the nurses who directly con-

tact patients can more easily analyze the intensity of both their pain and response to pain therapy.

Another study at a private hospital in Fortaleza-Ceará-Brazil demonstrated that nurses had only incipient knowledge about the systematization of proper pain management despite the constant distribution of several instruments and procedures for their evaluation⁽¹⁰⁾.

Multidimensional tools for pain measurements are applied in clinics, where a physician has more time and can better understand the chronic pain patient. For these patients, physiological, behaviorist, contextual, and self-recorded scales are used to assess the various existing dimensions of pain, which are sensory, affective, and evaluative⁽¹¹⁾. In a hospital setting, unidimensional scales are used to measure pain because and only measure the intensity.

Despite the large amount of data reported in the literature, few Brazilians institutions have implemented routine pain assessments as a fifth vital sign, which indicates the need to better integrate medical and nursing staff to raise awareness on the importance of studying the pathology, physiology and treatment of pain and to seek both the patient's evolution and the humanization of hospital treatments⁽⁹⁾.

The respondents had expectations regarding a specific protocol to improve pain management despite the implementation of this instrument not having been proven.

Moreover, the shortage of active professionals experienced in pain management at the institution was emphasized. It is known that the inadequate management of pain worsens the health and quality of life of the patient. In addition, such pain may increase the duration a patient is admitted to the institution and cause constant hospitalization with repercussions for both the patient and health care service⁽¹²⁾.

Adequate pain management begins with a medical evaluation of the patient, which in turn involves a diagnosis that allows therapeutic strategies to be developed. Therefore, it is necessary to institute an interdisciplinary pain program with competent professionals to work in teams to provide solutions to patients in pain, who are generally searching resources without any satisfactory improvement, so that evaluations and treatments are performed effectively.

The lack of prescribed pain medications was emphasized and indicates an incipient knowledge and practice about appropriate management for doctors, which reveals neglect seeing as the patients have a right to be evaluated and adequately treated for pain⁽¹³⁾.

Another survey discussed problems with the sub-prescription of analgesics. Nursing professionals mentioned the doctor's dependence on prescriptions of this type of medicament, which reinforces the complexity of an ineffective prescription because the pain was underestimated by the health team⁽¹⁴⁾.

These results also corroborate those from a study detailing the doctors' perception about the barriers for the adequate management of pain associated with AIDS. The main difficulties reported were a lack of knowledge on pain management among these professionals, the inaccessibility of specialists on the subject and doubts related to the use and potential addition of opioid analgesics in these patients⁽¹⁵⁾.

Additionally, the lack of knowledge of the nursing professional (N4) directly responsible for care regarding the identification of nursing activities for pain management is noteworthy. Despite this result, the nurse in the professional interdisciplinary team currently maintains close contact with the patient and is a pioneer in studying and implementing programs for assessing pain in various scenarios⁽¹⁶⁾.

In addition, when guided by the biological, psychic, and social attendance of human being, nurses can evaluate, examine and implement non-pharmacological strategies for effective pain relief, which assures the life quality for patients with pain during hospitalization.

The unsatisfactory management of chronic pain in patients with AIDS was the subject of another survey⁽¹⁷⁾. This survey emphasized that, though less frequent than before anti-retroviral therapy implementation, pain management remains unsatisfactory and is significant problem that should be considered in developed countries where professionals do not always systematically evaluate the signs and symptoms of patients, and not validated instruments are used for this purpose. This situation interferes with evaluating pain and requires more research to find better alternatives and instruments.

The data are even more alarming in underdeveloped countries, where professionals ignore their role in adequate pain management and neglect to assist in pain evaluations, which make the care process fragmented, unbound and inhuman.

These issues were exploited by researchers who noted nurses found pain to be underestimated by professionals linked directly to their assistance, which demonstrates that the evaluation and relief of pain were realized as a secondary factor, while other symptoms were considered a priority to the detriment of pain management⁽¹⁴⁾.

The adequate treatment of pain has relevance to the welfare of human beings; therefore, it is legitimate to recognize and promote the treatment of pain as a fundamental human right. Such recognition will serve as the basis for the legal right to be incorporated into the laws of several countries and will be enforceable through international and regional treaties.

Therefore, the combination of educative programs and governmental rulings for service management to require professional practices that promote the adequate control and relief of pain is urgent⁽¹³⁾.

Thus, the implementation of behavioral protocols under scrutiny allow for the care, regulation, evaluation and control of pain to be improved, while the training and continued education of health staff involves, graduate and technical professionals, is necessary according to the guidelines of the Single Health System in Brazil⁽¹⁰⁾.

Elevated demand was also mentioned as one of the primary factors contributing to the ineffective management of pain at this institution. The emphasis on large numbers of attendee matches the reality of many health institutions where they use a certain way to address work that favors procedures and activities over the results and effects for the people under their responsibility. Many hospitals offer services totally inconsistent with demand and believe that the object of their work is the disease or procedure while devaluing the importance of the complexity and suffering of people⁽¹⁹⁾.

For the Single Health System, some causes may be attributed to the existence of this elevated demand and the challenges accompanying it. One of these causes is the difficulty in planning and discussing the work dynamics for certain services; other reasons would be a compromise between reference and counter-refer for users, information on differing health attention levels, different team management, the sometimes approximate and sometimes conflictive representation of relationships, contradictory expectations and conflicts between both health staff and the local powers and the relationship between health services and the population when the team cannot meet demand⁽²⁰⁾.

It is therefore essential to evaluate the opening encounters between health professionals, the user and his social net as a fundamental link in health production, service reorganization, work process problematization to ensure the intervention of the multi-professional staff in charge determining and solving the user's problem, elaborate on individual and collective therapeutic projects, and promote structural changes through service management, the enlarging of democratic spaces for discussion and decision making, listening, and the exchange of collective decisions⁽¹⁹⁾.

These actions should be developed by subjects involved in assisting the patients, from managers and health professionals to the patients, their family and the community. Thus, one can envision individualized care based on the entirety of health care.

Discussions about demand generate other reflections, mainly regarding the completeness of health care, that deepen in the subcategory that talked about reference and counter-refer. These reports point out faults in the references and counter-references amongst the specialists and services that care for AIDS patients.

Attention to health in the SHS is organized in increasing degrees of complexity, with the population flowing in an organized way among primary, secondary and tertiary levels through the formal reference and counter-refer mechanisms.

In practice, this system represents a prescriptive posture attached to formal rationality that does not consider the real needs and flows of those in the health care system and therefore ends up for not coming true. Health care operates using very different logics that do not articulate among each other; a solution to the problem is not assured and the population ends up entering the system through all possible doorways⁽²¹⁾. It would be ideal for users to enter through the first level of care in the health system and be subsequently sent to the other levels according to need.

The reality shown by the interviewed professionals involves treating and monitoring patients with pain and was considerably harmed by the fragility of the reference and counter-refer system with the understanding that these cases are worse due to the urgent need for relieving the patient's pain as a primary complaint.

Despite advances, mainly relating to antiretroviral therapy, many challenges still persist with prevention and care⁽²²⁾. These people continue living and facing numerous consequences of their serum-positive condition including stigma and prejudice, which have impact their social, familiar and sexual relationships.

Investments in the forming professional processes should be made that improve the client's health recovery when living under conditions of self-care using simplified and safe procedures in addition to the results in hospitals, which are measured using documentation quality and records of nursing actions.

Therefore, an important change would be to develop effective managing practices and integrate them among those institutions that may treat people with both AIDS and pain. Such practices make the system of references and counter-references more efficient and ensure that services adequately communicate to continue providing for this patient at the original institution.

CONCLUSION

The managing structure of a specialized pain management service for hospitalized patients with AIDS was clearly identified. In this context, both the favorable and unfavorable structures in the hospital were analyzed. The availability of material, human resources and organizational resources were initially identified as favorable conditions despite the institution being a reference, which indicates the existence of trained staff to attend to the abundant complains of patients for daily attendance.

The primary factors preventing the adequate management of pain at this institution were identified as the large number of patients, absence of specific attendee or protocol for managing decisions related to pain and the frequent inter-institutional faults caused by references and counter-references.

Despite being considered a reference, this institution showed a fragile attendee where even the professionals can identify the advantages and difficulties found in the daily activities of treating pain. Yet, their assistance was informal and based on individual perceptions rather than models patterned for treating pain, such as using scales or instruments to provide a more accurate evaluation.

The current pain management system in the institution needs to be reconsidered, which implies a restructuring of the current model for managing inpatient care to improve the material, human and organizational resources. Workers should be trained to conduct routine pain evaluations, and a culture of analysis should be developed for this symptom so that therapeutics are better implemented to insure the analgesic satisfaction of the patient.

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