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THE HEALTHCARE NETWORK FOR PEOPLE WITH AMPUTATION: NURSING ACTION IN THE VIEW OF BIOETHICS

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ABSTRACT

Objective: to analyze the referral and counter-referral process in the health care of people with amputations, in the perspective of nurses, in the view of bioethics.

Method: a descriptive, exploratory-analytical study with a qualitative approach, performed with semi-structured interviews with 21 nurses who provide care to people with amputations in the health care network of Florianópolis (Santa Catarina/ Brazil). The data were organized using Atlas ti 7.5.6 software and analyzed based on thematic content analysis.

Results: two thematic categories emerged: The nurse's role in the referral and counter-referral process and Advances and challenges of a process under construction. It was evidenced that without legal backing, most referrals are made based on interpersonal relationships and informality. Therefore, shared responsibility and the exchange of knowledge allows actions based on the intrinsic needs and complexities in the health care of this population.

Conclusion: the analysis in the view of bioethics allowed to conclude that not only the person with the amputation but also the nurse occupies a vulnerable position. They have shown the commitment to offer a comprehensive service. The ethical commitment, professional creativity, specialist orientation and consultation-liaison were highlighted as potentialities. The weaknesses were the lack of protocols, ineffective communication between levels of care, restricted access to information and slow referral time.

DESCRIPTORS: Amputation. Nursing. Integrality in health. Bioethics. Health care.

ATENÇÃO EM REDE ÀS PESSOAS COM AMPUTAÇÃO: A AÇÃO DA ENFERMAGEM SOB O OLHAR DA BIOÉTICA

RESUMO

Objetivo: analisar o processo de referência e contrarreferência na assistência à saúde das pessoas com amputação, na perspectiva dos enfermeiros, sob o olhar da bioética.

Método: estudo descritivo, exploratório-analítico com abordagem qualitativa, realizado por entrevista semiestruturada com 21 enfermeiros que prestam assistência à pessoa com amputação alocada na rede de atenção à saúde de Florianópolis. Os dados foram organizados com auxílio do *software* Atlas ti 7.5.6 e analisados com base na análise de conteúdo temática.

Resultados: emergiram duas categorias temáticas: O fazer do enfermeiro no processo de referência e contrarreferência e Avanços e desafios de um processo em construção. Evidenciou-se que sem o respaldo legal, a maioria dos encaminhamentos são realizados com base nas relações interpessoais e na informalidade. Logo, a responsabilização compartilhada e a troca de saberes possibilitam ações fundamentadas nas necessidades e complexidades intrínsecas na assistência à saúde dessa população.

Conclusão: a análise sob o olhar da bioética permitiu concluir que, não só a pessoa com amputação como também o enfermeiro, ocupam posição de vulnerabilidade. Estes mostraram o empenho para oferecer um atendimento integral. O comprometimento ético, a criatividade profissional, o matriciamento e a interconsulta foram pontuadas como potencialidades. As fragilidades foram a inexistência de protocolos, a comunicação ineficaz entre os níveis de atenção, o acesso restrito à informação e a lentidão nos referenciamentos.

DESCRITORES: Amputação. Enfermagem. Integralidade em saúde. Bioética. Assistência à saúde.

ATENCIÓN EN RED PARA LAS PERSONAS CON AMPUTACIONES: LA ACCIÓN DE LA ENFERMERÍA BAJO LA MIRADA DE LA BIOÉTICA

RESUMEN

Objetivo: analizar el proceso de referencia y contra referencia en la asistencia para la salud de las personas con amputaciones, en la perspectiva de los enfermeros y bajo la mirada de la bioética.

Método: estudio descriptivo, exploratorio-analítico y con abordaje cualitativo realizado por entrevistas semiestructuradas con 21 enfermeros que dan asistencia a personas con amputaciones asignadas por la red de atención a la salud de Florianópolis. Los datos fueron organizados con el auxilio del *software* Atlas ti 7.5.6 y analizados en base al análisis del contenido temático.

Resultados: aparecieron dos categorías temáticas: El hacer del enfermero en el proceso de referencia y contra referencia y Los avances y desafíos de un proceso en construcción. Quedó evidente que sin el respaldo legal, la mayoría de los encaminamientos son realizados en base a las relaciones interpersonales y la informalidad. Así, la responsabilidad compartida y el intercambio de saberes posibilitan acciones fundamentadas en las necesidades y complejidades intrínsecas en la asistencia de la salud de esa población.

Conclusión: el análisis bajo la mirada de la bioética permitió concluir que no solo la persona con amputación sino también el enfermero ocupan una posición de vulnerabilidad. Los mismos demostraron empeño para ofrecer un atendimiento integral. El comprometimiento ético, la creatividad profesional, el apoyo matricial y la interconsulta fueron considerados como potencialidades. Las fragilidades fueron la inexistencia de protocolos, la comunicación ineficaz entre los niveles de atención, el acceso restringido a la información y la lentitud en la referenciación.

DESCRIPTORES: Amputación. Enfermería. Integralidad en salud. Bioética. Asistencia para la salud.

INTRODUCTION

The term amputation is defined as the total or partial removal of a limb, which is considered a treatment method for several diseases. Amputation is not the treatment in its entirety, but part of its general context, whose objective is to provide a better quality of life for the user.[1] Currently, the global outlook on the causes of amputations revolves around chronic diseases such as Diabetes *Mellitus* (DM) and Systemic Arterial Hypertension (SAH) and traumatic amputations.[2-3] Despite the controversies regarding the number of amputations worldwide, several studies indicate an incidence of approximately 46.1 / 10,000 per inhabitant / year.[4]

All persons with disabilities are legally insured in Brazil. In the area of health, the Unified Health System (SUS) brings together policies, programs and actions in the areas of health promotion, protection and recovery / rehabilitation. Among the duties of health professionals is the search for solutions that reduce the inequalities and inequities confronted almost daily by people with disabilities. Thus, it is argued that integrality in health care is directly related to the implementation of an organizational process of the health system called referral and counter-referral.

The referral and counter-referral system is an administrative arrangement that aims to guarantee universal access to all health services according to the needs of the user. The referral occurs from a service of low complexity to high complexity / specialization services. The counter- referral corresponds to the return of this user to his original unit for the continuity of care. In further detail, high complexity and technological density services should be referred through the entry points in the Health Care Networks (RAS), which are: primary healthcare, emergency care, psychosocial care and special open access.[5]

This process goes beyond simply referring. Referrals and counter-referrals are mechanisms of connection, communication and follow-up between the different health professionals and care services that make up the network and guarantee solvability, integrality and continuity in health care.

However, the consolidation of the referral and counter-referral system faces challenges which are typical of a process of change, from the biomedical care model to the integral model. The organization of healthcare and management in SUS still faces fragmentation in services, programs, actions and clinical practices, with a strong inconsistency between service provision and health care needs.[6]

The complexity of the current actions and demands of the healthcare area imposes specific theoretical and practical knowledge as well as a need to build a body of ethical / bioethical knowledge regarding the issues involved in the daily services. Teaching bioethics for the construction of moral conscience is considered fundamental in order to search for new approaches that favor the training of professionals who are capable of reflecting on professional conduct with commitment, responsibility and competence.[7]

One relevant aspect to this theme is Social Bioethics and its developments in the Bioethics of Protection and Intervention. Social Bioethics refers to the theoretical production in the field of bioethics carried out by authors who consider a social content in their discourses covering topics relevant to

the quality of human life.[8] Bioethics of Protection reflects on the functioning of the public health system structure , in which the State is responsible for managing resources, social control and for qualified human resources, and to provide / develop techniques that minimize disabilities by achieving quality assistance.[9-10] Finally, Bioethics of Intervention arose in order to provide more appropriate ethical responses to macro problems and collective conflicts; it mirrors the matrix of contemporary human rights and incorporates the discourse whose rights are beyond the guarantees provided by the State.[10] It addresses the right of each person to equality and equity as a citizen, understanding that each human being has different ways of acting , with physical and mental dimensions, which act in an integrated way in their relationships with society.[11]

Health professionals are routinely faced with ethical problems such as inequalities in living conditions, user access to services, and the lack of preparation / qualification of human resources in health care, leading us to the emerging reflections of bioethics of protection and intervention, as they are present in the effectiveness of public policies.[9]

This context articulates integral assistance to the health of the person with an amputation, the referral and counter-referral system as an organizational mechanism and bioethics as a reference for reflection. This allows analyzing the referral and counter-referral process in the health care provided to people with amputations, from the perspective of nurses, in the view of bioethics. Thus, the objective of this study is to analyze the referral and counter-referral process in the health care of people with amputations, from the perspective of nurses, in the view of bioethics.

METHOD

A descriptive, analytical exploratory study with a qualitative approach developed in healthcare services in the greater area of Florianópolis (Santa Catarina/Brazil), covering the levels of primary, secondary and tertiary complexity. Data collection occurred in: a surgical ward and an outpatient unit of a teaching hospital in the greater area of Florianópolis; the reference center in rehabilitation in Santa Catarina; a polyclinic with several specialties and five Primary Healthcare Units in Florianópolis.

Among the primary healthcare units, the criterion for the choice of places considered the area which served the largest population of elderly people (65 years old or older), due to the close relationship wioth the theme and the most common chronic diseases in this population group and main cause of elective amputations.[12] It was decided to investigate the issue from the point of view of professional nurses since they have the important role of care manager and they must act with the principle of responsibility, one of their commitments being the promotion of integral health of the human being.

Twenty-one nurses participated in the study, who were from distributed from the three levels of healthcare in Florianópolis. Inclusion criteria were: to be permanently allocated in one of the study sites for a minimum of three months and to provide direct or indirect health care to people with amputations. Nurses who were on vacation or sick leave during the data collection period were excluded from the study.

Research participants signed the Informed Consent Term. The data collection occurred in the months of April and May in 2015 through the application of a semi-structured individual recorded interview, which had an average duration of 40 minutes. The interviews were performed by two assistant researchers and three scripts were used, previously validated by experts, one for each level of complexity of care due to the specificities in the type of assistance. After transcription of the interviews, content validation was requested for each of the participants.

The Atlas.ti 7.5.6 (Qualitative Research and Solutions) software was used to assist in the treatment and analysis of the data. Readings were performed, followed by codification, which was accomplished through the creation of codes. In these codes, quotations from the interviews that supported each one were grouped together. This categorization supported the exposure and discussion of the results. The data analysis occurred through the analysis of thematic content, using the following steps: pre-analysis, categorization, inference, description and interpretation.[13]

In this perspective, it is emphasized that the pre-analysis was characterized by the transcription of the interviews, the insertion and organization of the interviews in the software Atlas ti software. The categorization took place at the time of the creation of the codes according to the quotations, which corresponded to the research objectives. Inference occurred by grouping and organizing the codes in order to create the categories that resulted from the search. The description and interpretation of the data arose after the use of the software. It should be emphasized that the use of the software serves to assist the organization of the data resulting from the conducted interviews.

The ethical principles addressed in Resolution No. 466/12 of the National Health Council dealing with the Guidelines and Standards Regulating Research involving Human Beings were respected. The research project was approved by the Research Ethics Committee under opinion No. 970.902 of 02/24/2015, CAAE: 41274615.1.0000.0112. The confidentiality of the participants was maintained, participants were mentioned in the text by the use of the letter E followed by numbers 1 to 21 (E1, E2, E3 ... E21). The distribution of the numbers was done randomly

RESULTS

Two thematic categories related to the objective of the study emerged in the data analysis: The role of the nurse in the referral and counter-referral process and Advances and challenges of a process under construction.

The nurse's role in the referral and counter-referral process

All the nurses indicated that they are not aware of any protocol, document or form that guides their practices in the care of the person with an amputation regardless of the level of complexity of the services where they work.

If there was a protocol it would help a lot in the day-to-day work! I'm not aware of any documents! When the patient comes in here and you are with the situation at the front, then you will find a way. Call the secretary, for elderly health, for adult health, and find out! (E4)

In the care of the person with an amputation, these professionals show ethical commitment and dedication to provide comprehensive care. Focused on the multiple needs, nurses make use of the entire network of professionals at their disposal, each one playing its specific role.

When he came he was in a very critical situation, he went to a hospital and had the amputation. We went to the social worker to see if he could get a pension for him. We scheduled a visit with the physical education staff, then the physiotherapist directed him to the Rehabilitation Center. We got a walker and the evaluation for the prosthesis. [...] *He had to go through several specialists and there was no one to bring him, the family had difficulties. The driver and the health agent went with him* (E7).

Participants reported nursing confidence and autonomy in the referral and counter-referral process. In some cases, they require the intervention of other professionals to carry out referrals and this collaborative work guarantees integral care.

If you need any other level of attention, you have full autonomy. If we have to send the patient to the specialist in similar situation, a medical referral is necessary, unfortunately our city does not have protocols that allow us to do an automatic referral directed to specialists, we require the assistance of our team for direction (E3).

I think we have all the autonomy to refer the patients, but here in the hospital, if we had the time, we would have better treatment continuity and effectiveness (E19).

In relation to effective referrals, the fragility of the counter-referral was evidenced. It is not common that these professionals receive the return of their referrals. Practitioners do not have access to information regarding the therapist's adopted practices at other levels of care, which brings innumerable disadvantages to the continuity of care.

It is only what the patient reports when he returns. Even if he is followed up at the health clinic, nothing comes in writing, what was the progress, if he got worse or not. With the secondary and primary level, there is no correlation, nor with the outpatient department here inside the hospital! The only contact we have is the emergency itself, they call informing you that there is a patient who needs to go to the hospital with amputation and nothing else. Only what is described in evolution. Some patients who have already been admitted here will return without their medical records. There is no continuity in that! (E18)

Advances and challenges of a process under construction

The second category showed aspects of the referral and counter-referral process that characterizes it in relation to the advances and reveals persistent challenges for its consolidation in the health services network in the city of Florianópolis.

As a potential, it shows the engagement of professionals in the integrality of care. In the absence of a unified electronic chart or a predefined flow, the nurse was creative and obstinate in providing continuity to care.

We contact all the cases that arrive here that we are not accustomed to,[...] *to know how this referral should be done, will they go to rehabilitation? How to do the referral?* (E5) *Usually by telephone, or written referral. When my involvement finishes, I must continue treatment in primary care. I always send a type of discharge summary from the medium complexity services* [...] (E15).

Also highlighted as potential are the work process strategies such as specialist consultation and consultation-liaison in the primary health care team which allows a more detailed and assertive referral.

If we need the support from the psychologist, physical educator, nutritionist [...], *we discuss it as a team and after a consensus we will make a call* [...] *When we get a patient with an amputation, we do a* consultation-liaison *with the physiotherapist* [...] (E4)

Regarding the weaknesses, the absence of a protocol that guides the professional action, directs and defines the care flow ensuring the rights and the adequate assistance to the person with an amputation was evidenced, which very negatively impacts the nurse's behavior in the referral and counter- referral process.

There is nothing specific for amputation! There is no flowchart to follow for referrals we do not know what to do [...]. *I am not aware how the flow works* [...]. *We have to run after information when we come across each specific situation* (E5).

In this context of discussion, two tools are highlighted which are available in the municipal services and are cited as strengths to the network: the Electronic Patient Record, which allows communication and access to information among professionals, and the National Regulation System, for enabling equity in referrals and requests for consultations or examinations. However, municipal health institutions have limited access to these tools, excluding state and / or federal administration services. The limitation in communication between services are difficulties which affect the rehabilitation process of the person with an amputation.

The first contact with the hospital was fine, [...] *the counter referral, was bad! He gets discharged from hospital with nothing, with dressing guidelines for the primary healthcare unit! When you return to the unit, he is yours again, you must understand what has happened and what is the best course of action for the new condition. I think that this is a gap* (E3).

Restricted access to information leads to fragmented services and hinders the continuity of care, resulting in an inadequate rehabilitation process.

People with amputation arrive for rehab between 8 months and 1 year after amputation. The patients come here much later and without guidance, without any preparation of the stump. They could take less time in stump preparation, prosthesis fitting, if they were oriented and came earlier (E16).

DISCUSSION

There are positions of vulnerability in the referral and counter-referral process for the person with an amputation. The person with an amputation and the nurses and their reports are also vulnerable in the service network seeking effective integral attention. Anyone can be in this vulnerable condition, we are all susceptible to situations that can create risk and discomfort. From the moment that the problem occurs, we are in a condition of being violated, one that has a condition that requires more attention and readaptation in order to have well-being.[11] It is up to the professionals, who are links between public policy and those assisted by it, to minimize disparities that may arise amid present vulnerability,[14] independent from the one in need.

With legal support still in consolidation and few concrete guidelines, the nurses make use of several resources, including involvement with all the network of professionals at their disposal, the friendships and the creative initiatives such as the elaboration of their own form to help their performance.[15] All of this is driven by the ethical commitment to their profession and the exercise of their autonomy as a nurse, in order to offer better care conditions to those who need assistance. Therefore, it is evident that nursing acts in the entire process of rehabilitation of people with amputations. It can also be said that, even in situations of inadequate working conditions, professionals maintain their duty to protect the right to health of users in the face of situations of inequities and inequalities. Thus, professionals strive to guarantee access to all services and levels of health care, as well as the right to exercise their citizenship and autonomy.[16]

Before any referral or orientation occurs, the professionals strive to identify the real needs in each case. The guidelines provided reflect the short, medium and long-term recovery in the prevention of health problems associated with amputation and chronic diseases, as well as to enable an adequate rehabilitation process.[17-18]

Bioethics of Protection deals with access to health, making equity possible, given that it is the right of every citizen to have equal access to health services, according to the needs of the population.[19] Thus, the bioethics of protection and intervention as a reference for care, highlights that the skills and technical skills and experiences of these professionals enable them to identify different needs and consequently diverse treatment possibilities more easily. This fact, along with autonomous professionals with knowledge of current public policies, potentially guarantees access to all rehabilitation contexts. The professionals are one of the links between the policy prescribed and the people assisted by it. It is in this intermediary that Social Bioethics,

evidenced here by the bioethics of protection and intervention, is present.

The right to health in the Brazilian health care context provides for comprehensive care in addition to universal access. Therefore, the movement of people with amputations to different health services should receive the attention of different areas of knowledge, contemplating interdisciplinarity.[20] In this research, the specialist orientation and consultation-liaison were evidenced as potentialities of the assistance. The involvement of a multiprofessional team acting in an interdisciplinary way allows for more detailed and assertive referrals, resulting in the most appropriate interventions. Shared accountability and knowledge exchange lead to the best choices considering the intrinsic needs and complexities in health care for this population.

Consultation-liaison and specialist practices allow an expanded view of cases assisted by health teams, as well as allowing greater assistance to the reference team, by discussing the case between different knowledge and disciplines. The interdisciplinary character of these actions promotes their existence in several fields, attending to a range of needs to promote a more integral service.[21]

A health care model with a focus on health promotion, disease prevention, continuing education and participation as a tactic in the reorganization of health services, involving all members involved in the process,[22] provides the person with an amputation with a better adaptation to their new condition.[23]

It is reaffirmed that the multidisciplinary performance which is extremely present in the findings of this study provides greater confidence in decision making, resulting in an expanded, safer and more beneficial care. However, communication and the exchange of information are essential for the implementation of interdisciplinarity through the team approach.[24] In these cases, in addition to the professionals' experience, we have all the technological apparatus available for the care strategies.[25]

The positive aspects related to the process of referral and counter-referral to the integral care of the person with an amputation are undeniable. Despite the advances highlighted in the research, weakness emerged regarding the records and access routes to information of different services. The connectivity between health units is a decisive predictor of successful care coordination. The health professionals involved must have access to the information they need in order to provide adequate care. Generalist healthcare professionals need to be sure that specialist healthcare professionals know the reasons for referrals and contain the information they need in order to carry out their duties. Likewise, specialists need to provide information that responds to the needs and expectations of generalists through the counter-referral process.[26]

Even with the professional efforts to enable the person with an amputation move through the services which they need, there are limitations in the adequate access and conditions of these services. Responses to referrals are delayed and make the rehabilitation process slower than what is recommended and desired.

Thus, the Network of Care for Persons with Disabilities establishes a financial incentive for specialized rehabilitation centers aimed at guaranteeing access to the people who need the service and to eliminate difficulties in accessing the rehabilitation services, in addition to the other services of the Network.[27] However, there is a need to evaluate the impact of the implementation of this network precisely in relation to the referral and counter-referral process.

The gap left by the absence of nursing protocols for the care of the person with an amputation also contributes to this delay in referral. The nurse is present at all points of the network and must seek information and ways of performing the referral, which demands time, something which is essential to the rehabilitation process.

The use of protocols supports autonomy of the nurse, since the standardization and the correct direction of the actions of this professional assists in decision making. In order to do this, these protocols need to be based on scientific evidence and legitimized by specialists.[28] Thus, the elaboration of a protocol could bring benefits to all stages of rehabilitation and assistance, as each step of the process would be previously defined and standardized, creating public policies and providing an integral, continuous and dignified care to this citizen.

The limitations of the study are data collection in a geographical area limited to one city, which may not reflect the realities of the referral process and counter-referral in other regions of the country.

CONCLUSION

The nurse is present in the entire rehabilitation process and works at all points of care in the healthcare services network. Therefore, it is incumbent upon them to be empowered in relation to the public healthcare policies to the person with

an amputation in order to make them aware and exercising their rights.

However, most referrals are still made based on interpersonal relationships and informality. Thus, the analysis in the view of bioethics allows us to conclude that, in this context of attention, the person with an amputation and the nurses who care for them occupy a vulnerable position.

To deal with this situation, among the professionals involved in this study, some showed a responsible behavior towards this paradox and the complexity of the assistance. Therefore, they kept the legal responsibilities of the profession in mind and made use of an interdisciplinary action enabling the referral and counter-referral process.

Thus, professional engagement and creativity, ethical commitment, and specialist orientation and / or consultation-liaison are identified as potentialities that enable more appropriate behaviors through multiprofessional involvement.

On the other hand, it is necessary to construct points of connectivity between the services in order to allow the movement of users, but also the exchange of information regarding the same. These aspects are decisive in the conduct of information and in the success of the referral and counter-referral process, as they are in line with the bioethics precepts of intervention and protection in defense of the rights of the person with an amputation.

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