

REFLECTIVE ARTICLE

CARE BEYOND HEALTH: MAPPING BONDING, AUTONOMY AND EMOTIONAL TERRITORY IN FAMILY HEALTH

O CUIDADO ALÉM DA SAÚDE: CARTOGRAFIA DO VÍNCULO, AUTONOMIA E TERRITÓRIO AFETIVO NA SAÚDE DA FAMÍLIA

LA ATENCIÓN MÁS ALLÁ DE LA SALUD: CARTOGRAFÍA DEL VÍNCULO, AUTONOMÍA Y TERRITORIO AFECTIVO EN LA SALUD DE LA FAMILIA

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Submitted on: 2014/05/14

Approved on: 2014/11/27

ABSTRACT

This reflection aims to discuss health care and the concepts of bonding, autonomy and territory as a structuring of care practices, from the perspective of the subjectivity of patients requiring care at the Family Health Strategy. It starts from an experience when a team witnessed a patient with a diagnosis of breast cancer; at first, care turned to the need for care of a wound. However, the patient's physical pain was lower than that related to the pain due to the absence of her family. By deciding to discontinue drug treatment, she highlighted her unique demands of care that fell outside the scope of technologies offered by the health care service. Facing this demand, professionals experienced a process of redefining concepts, knowledge and care practices. New linkages were established in a territory that was not only physical and institutional, but also affective. Respecting the patient's autonomy involved creating new forces of care, beyond technical and scientific knowledge. Based on this experience, it was realized that care itself goes beyond the offer of actions and health services. If considered from the perspective that, during health care, we deal with subjects, their lives and individually produced care perspectives, health care cannot be subjugated to procedures, routines and care protocols. The Family Health Strategy constitutes a privileged locus of care experiences that go beyond health itself.

Keywords: Patient-Centered Care; Family Health; Primary Health Care; Family Relations.

RESUMO

Esta reflexão propõe-se a discutir o cuidado em saúde e os conceitos de vínculo, autonomia e território como estruturantes das práticas assistenciais, a partir da perspectiva da subjetividade dos pacientes que demandam o cuidado junto à Estratégia de Saúde da Família. Parte-se de uma vivência em que uma equipe assistiu uma paciente com diagnóstico de câncer de mama. A princípio, essa assistência voltou-se para a necessidade de cuidados com uma ferida operatória. Mas a dor física da paciente era menor do que a proporcionada pela ausência da família. Ao decidir descontinuar o tratamento medicamentoso, ela colocou em evidência suas demandas singulares de cuidado que não se enquadravam no escopo de tecnologias ofertadas pelo serviço de saúde até então. Diante dessa demanda os profissionais vivenciaram um processo de ressignificar conceitos, saberes e práticas assistenciais. Novos vínculos foram estabelecidos em um território que não era apenas físico e institucional, mas também afetivo. Respeitar a autonomia da paciente implicou elaborar novas formas de cuidar, além do saber técnico e científico. Com base nessa vivência, percebeu-se que o cuidado em si ultrapassa a oferta de ações e de serviços de saúde. Se considerado na perspectiva de que na atenção à saúde lidamos com sujeitos, com suas vidas e suas perspectivas de cuidado produzidas singularmente, o cuidado em saúde não pode ser subjugado aos procedimentos, às rotinas e protocolos assistenciais. A Estratégia de Saúde da Família se constitui em um locus privilegiado de vivências do cuidado além da própria saúde.

Palavras-chave: Assistência Centrada no Paciente; Saúde da Família; Atenção Primária à Saúde; Relações Familiares.

RESUMEN

Esta reflexión se propone discutir la atención de la salud y los conceptos de vínculo, autonomía y territorio como estructuración de las prácticas de cuidado, desde la perspectiva de la subjetividad de los pacientes que buscan ser atendidos en la Estrategia de Salud de la Familia. Se trata de una experiencia del personal de salud que atendió a una paciente con cáncer de mama. Al principio se le trató la herida operatoria pero el dolor físico de esta paciente no era tan grande como el que sentía por la ausencia de su familia. Cuando se le suspendió la medicación quedaron evidentes sus demandas, que no estaban incluidas en los servicios de salud que se ofrecían hasta entonces. Ante tales demandas, los enfermeros sintieron la

necesidad de reconsiderar el significado de los conceptos, conocimientos y prácticas de atención. Se establecieron otros vínculos en un territorio que, aparte de físico e institucional, era también afectivo. Respetar la autonomía de la paciente significó elaborar nuevas maneras de cuidar, además del conocimiento técnico y científico. En base a esta experiencia, se observó que la atención en sí va más allá del ofrecer acciones y servicios de salud. Si consideramos que, desde la perspectiva de atención de la salud, tratamos con personas, sus vidas y sus propias expectativas de cuidados, la atención de la salud no puede limitarse a procedimientos, rutinas y protocolos. La Estrategia de Salud de la Familia es un lugar privilegiado de experiencias de atención más allá de la propia salud.

Palabras clave: Atención Dirigida al Paciente; Salud de La Familia; Atención Primaria de Salud; Relaciones Familiares.

INTRODUCTION

Health care in contemporary society is characterized by its comprehensiveness, complexity and diversity of actions, settings and actors. These attributes can be attested to by the strategies that materialize public health care policies in a network that is structured from Primary Health Care (PHC) to medium- and high-complexity services. The right to universal, equitable and integral health care supports this organizational, technical and political setting; this organization also aims to expand health care beyond the focus on disease, by using preventive and health-promoting actions.¹

However, ontologically, care itself exceeds the offer of health care actions and services; if considered from the perspective that we deal with subjects, with their lives and their individual care perspectives in care settings, health care cannot be subjugated to the procedures, routines and care protocols. Technicizing health care results in unmet care needs that will inevitably produce implications in the lives of patients who use the care network.²

This reflection aims to discuss the production of care from the subject's perspective, by using the concepts of bonding, autonomy and affective territory as a reference. It is based on the articulation between these concepts, and introduces its redefinition from a mapping experience within the Family Health Strategy (FHS).

Bonding between professionals and people requiring health care is permeated by affects and subjectivities that deprive the places occupied in the health care area, totalitarian knowledge and interventional practices. In addition to being institutional and physical, the territory of care is emotional and produces singularities; care does not always mean acting, developing actions, performing procedures. At times, the subject requiring care needs only to exert a singular autonomy in this affective territory.

ON THE CONCEPTS AND THEIR MEANINGS BEYOND WORDS

The change of the Brazilian care model has not only occurred in the technical and political dimensions, but it was also impacted by new concepts in the discursive field of health. Among these concepts, bonding, autonomy and emotional territory stand out in this reflection.

The production of bonding between health care professionals and service users is emphasized as an inherent demand to the actions undertaken by the FHS; it consists of the link between the provision of services and demand, by bonding the user to the FHS as a priority gateway to the health care system. Another concept that arises in everyday life is the production of user autonomy as a movement of co-management, as well as sharing knowledge and practices that qualify him/her to make choices that promote his/her health. User autonomy presupposes a capacity to affirm oneself in the face of professional interventions, bringing one's knowledge and potential for care assistance.³

A redefinition of these concepts is proposed by this reflection, having as a reference the mapping experience from a meeting between professionals of the FHS team and a woman, who at first demanded care for her status as a bearer of breast cancer. From that meeting, it was considered that the concepts went beyond the words, for they constituted themselves as a multitude of significant concepts. These are not simple, single component concepts, because they are multifaceted and each of these faces can lead to another concept.⁴

The contours are irregular and its construction occurs from the various situations with which they relate, and those that they cross and by which they are crossed. In these crossings, concepts are born, coming from other pieces of concepts that used to respond to other problems, but no longer respond to what happens now; a concept is heterogeneous, namely, an ordering of its components by neighboring zones.⁴

It is considered that concepts are not only definitions, but tools used to try to solve a question or a problem. When a concept is born, the problem has already been identified and new ways of dealing with it will be needed. The importance of creating concepts is the possibility of confronting those already in place, allowing for new variations, operating vibrations, multiplying possibilities and raising new developments. Thus, what was crystallized starts to move where not only functioning objects exist, but also stimulating the production of subjectivities.⁴

One problem is always something to be illustrated by a concept, hence the uniqueness of its act of creation. A word can express its history, even understanding that it unfolds in a zigzag and irregular manner, since there is no linearity in its production. Words can secretly have numerous emphases, be-

cause they are interlocutors and foment multiple meanings. It is this secret life that throws us into a sea of possibilities when trying to define reality through words.⁴

This sea is not always quiet and often brings with it a polysemy that cannot only communicate, but also confound. Therefore, because finding the history of concepts and words will always be a limited activity, mapping them becomes necessary to link them, to describe how they constitute themselves, and what they express in a given space-time.⁵

Thereby, bonding, autonomy and the affective territory, as concepts that are included in the discourse of health integrality and in the discussion that considers the production of care as a subjective production, should be reinterpreted and polysemically institute new arrangements and ways of caring. Bonding cannot be restricted to the simple ascription of formally scheduled clientele in the organizational and operational FHS. Autonomy is not restricted to transferring responsibilities for the user to adopt the prescriptions made by the health care professionals into his/her life.⁵

The experience described below is considered mapping because, unlike the method of modern science, mapping does not isolate its object of study from its historical articulations or its connections to the world. Mapping aims to draw the network of forces to which this object is connected. Mapping is a way of producing knowledge that, among other things, refers to the act of thinking and method of intervening/acting in the world. Mapping is revealed by its permanent invention of practical action.^{3,4}

THE REPORT OF AN EXPERIENCE: SPLITTING WORDS, AND PRODUCING SENSE FROM THE GAPS

This report was produced based on the theoretical framework adopted in this reflection; histories, stories and subjects are involved. The protagonist of our reflections is highlighted: Mrs. Maresia was 86 years old, lived near the beach since birth, and lived in Icapuí-CE at the time of this meeting. The FHS professionals met her because a community health agent (CHA) requested a home visit; according to the CHA, in addition to being elderly and living alone, she had breast cancer. During the visit, the team found hyperemia of the surgical incision, indicating the breast removal; there was the need for daily dressing changes and monitoring of chemotherapy. Other visits were then conducted in an atmosphere of approach, sharing life and what was left of it; bonds were produced beyond the institutional roles held by health care professionals and patient/user.

On one of these visits, Mrs. Maresia was very weak and said something about her treatment:

Doctors, I do not want you to stop coming here, but I confess to you that this is the last pill that I will take for

this treatment. I want you to know that I am grateful and I am aware that I have lived a lot. Right now, I only miss my children.

The team went away feeling anguish because of its impossibility to act, to care according to what the academic training emphasized the most: care for the body in its biological dimension. Would it be possible to consider this decision as an exercise of autonomy? The limitations of technological devices, knowledge and care practices were evidence by a singular demand, which for Mrs. Maresia caused more suffering than her own physical pain.

The request by Mrs. Maresia provoked a dialogue among professionals about the case and about the interventions made to date. The basic health unit was closed for one afternoon, when a workshop was held to discuss the implication of each professional and family member on the patient. That moment was dynamic, with resentment, statements, and redefinition of territories by other statements that also expressed joy. Between music, poetry, tears, laughter and prescriptions formulated by all, a follow-up schedule for Mrs. Maresia's situation was designed.

It was then decided to offer actions that could provide her with some quality of life, and a death with minimal physical suffering, according to the resources available. A wise decision was to call the family, listen to them and mediate a rapprochement with Mrs. Maresia.

Perhaps, at first glance, the planning emerged as hard technology, but because of the relationships established and the affection produced, it was also configured as a device capable of establishing bonds and enhancing care.⁵ The visits were maintained, and from that moment on they became meetings in a territory that was not only physical and institutional, but affective; they were meetings between subjects moved by their affection, desires, demands and needs.

Mrs. Maresia died serenely on a full moon night, using only dipyrone to ease her physical pain, because the pain of the soul, which was her greatest care demand, was appeased by what she had always wanted: a family around her at such a unique moment. The experience of a process of death by cancer, when physical pain was the lowest reported suffering, produced questions about the immanent and necessary correlation between assistive technologies and the unique demands of care.

THE SUBJECTIVE PRODUCTION OF CARE IN THE FHS: BONDING

Bonding is often a call, and sometimes a mantra, when health care is discussed. The concept of bonding itself says nothing out of the context in which this process happens, because each care context is unique and reflects a dynam-

cally established reality. The reality emerges from intertwining lines, which can be hard, flexible and escaping, and which will shape these various arrangements of ways of acting in health care in the FHS.⁵

In the health field, these lines can be exemplified by the discourses, practices and knowledge that constitute care. The line of discourse involves discursive formations ranging from the Flexnerian model (focusing on disease and medicalization), through the natural history of the disease (focusing on the ecological triad), to the social determination model of health-disease, which arises in the 1970s in Latin America, as a way to denounce the relationship between social inequality and disease.¹

The line of practices involves the concrete way in which subjects act in their daily lives, namely, fragmented care that is not linked to the context of life or history of the subjects who require health care services, conducting vertically integrated campaigns or interventions.⁵

The line of knowledge covers both the formal and disciplinary knowledge from academic training, and knowledge mediated by experience with the various groups and their contexts: family, popular, social movements, and others.⁶

It is understood that the articulation of these three lines leads to a subjective production, or a complex network of multiple lines, which molds reality and the subjects therein at the same time. This conception highlights a constantly changing field, making it increasingly difficult to think of a single framework that sets out to meet the diversity of knowledge, discourse and practices present in everyday health care.⁷

THE SUBJECTIVE PRODUCTION OF AUTONOMY AND THE ABILITY TO TAKE CARE

Within this experience, taken as empirical reference, it is understood that this process of dispossession can be viewed when a patient, who was commonly considered to be terminal, revealed her desire and her decision to discontinue drug therapy when talking to the team. At first, this decision would be outside any health care treatment plan or prescription. However, since care takes place in existential territories, the subject's exercise of autonomy was set there.

In the current scenario of health care practices, the relevance of this concept is present by its power to question certain kinds of relationship with each other, which is encouraged by the science ideal. Modern science has been responsible for considerable progress in various areas of our lives; as it specifically relates to health, one can mention the innovations in diagnosis and therapy, with greater pharmacological refinement, encoding of the human genome, and epidemic control methods for various diseases.¹

However, all this scientific advancement, in the name of prolonging life, also has an evil face, as it proclaims a health ideal on whose behalf health interventions are performed almost universally, in a mandatory way, regardless of cost.⁸

From this "ideal of health", propagated by the media and the medical industry, any sign of pain is seen as outrageous and, therefore, it should be done away with; any difference from the ideal is seen as a greater distance and unbearable deviation of the collimated perfection and it must be "corrected".^{7:26}

In order to achieve this ideal:

The affects are mobilized and manipulated narcissistically in order to raise in the person the feeling and the fantasy that if he/she does not follow the collective ideal of optimal health, he/she will not only not reach his/her own optimal health, but will mainly be outside the current human group, a symbolic exclusion. He/she will not be part of the manners that unite the current individualities, and therefore will be below others, of those included, who arguably not only enjoy close-to-optimal health, and, when this is not the case, will have helicopters for one last and glamorous ostensive ride.^{7:26}

In this experience, it was noted that, from the decision making of Mrs. Maresia, the team was supposed to rebuild its work plan, respecting her revolutionary becoming, whose objective in that situation was to discontinue the use of medication. Addressing the professional-patient relationship, which in this case would be more of an agent and less of a patient, the bias of autonomy involved recognizing that access to the truth about oneself does not lie on the professional side view.

The search for this truth may lie in the perspective of taking care of oneself that does not correspond to the Western aphorism of "know thyself". Self-care is rather a principle of agitation, movement:

[...] "of permanent concern in the course of existence." It is a matter of relationships established between the subject and the truth: "the issue of the price that the subject has to pay to tell the truth and the issue of the effect on the subject arising from the fact that he/she told it, that he/she can tell it, and told the truth about his/herself."^{8:40}

From this perspective, speaking of autonomy does not imply a lack of responsibility either of the health professional or of the State, as those in charge of guaranteeing access to health, but as a guiding principle in building devices that can mobilize

the already established power relationships, so that there is a circulation of this power, with the creation of a power of action, which can be translated as power to be affected by something.⁹

EXPANDING THE TERRITORY

In addition to its geographical sense, composed of its geographical and geopolitical elements, the territory can be understood from the notion of place. A place is a portion of the space, as well as its physical dimension, which involves networks of relationships in which each individual produces a certain identification with the place. Each place is a *locus* of production, consumption, becoming ill, living and healing.⁹

Because it is a place in the territory, an intense production of the relationship emerges between the subjective and the social desire. The start of this production happens in contacts between the bodies, not only human bodies, but languages, knowledge and perceptions; and affections arise from these contacts, the desirable intensity or strengths.⁹ For:

The affections are becomings: sometimes they weaken us, when they diminish our power to act and break our relationships (sadness), sometimes they make us stronger, when they increase our power and drive us to be a more vast and superior individual (joy).^{10:73}

For the affections to be expressed, it is necessary to set up territories, even if they are temporary, because contact with other bodies generates new affections that do not fit in these territories, creating then an escape or dispossession line. However, dispossession can never be total, and the escape line should not lead to self-destruction, but rather encourage the building of new territories. This is because:

[...] Escape is not renouncing actions, there is nothing more active than an escape. It is the opposite of imaginary. It is also making an escape, not necessarily others, but making something escape, making a system escape as one makes holes on pipe. [...] Escape is drawing a line, lines, a whole mapping. Worlds are only discovered through a long, broken escape.^{10:49}

Understanding a care territory as an affective territory presupposes a dispossession, not only of the concept, but of care practices and their purposes when faced with care demands. Unlike problems or health needs, these demands emerge only when there is an emotional bond to be established in terms of uniqueness and autonomy.^{9,10}

FINAL CONSIDERATIONS

More than words, the concepts are devices capable of mediating the experience of a production of health care, far beyond its assistance perspective. Based on this reflection, it is understood that the concepts of bonding, autonomy and territory need to be rethought in the context of FHS, therefore care is a demand produced in the encounter with subjects and their concrete lives, their desires, their potentials and their needs. Bonding and autonomy must be understood beyond their formal and institutional character; it is bet on the recognition of a subjective production that takes place in an affective territory, whose *locus* can be the FHS.

Mrs. Maresia presented a demand that was, at first, outside the technological scope of the FHS. Before this demand, professionals experienced a process of redefining concepts, knowledge and care practices. New bonds were established in a territory that was not only physical and institutional, but also affective.

It was noticed that care itself goes beyond the offering of actions and health services; if considered from the perspective that, during health care, we deal with subjects, their lives and individually produced care perspectives, health care cannot be subjugated to procedures, routines and care protocols.

This reflection sought to contribute to the widening of that debate from other frameworks and to involve other actors, such as patients for whom the FHS provides care. The FHS constitutes a privileged *locus* of care experiences beyond health itself, given its inclusion in affective and unique territories. It is this place where the ways of acting are established every day. The need for professionals to be also subjects of their practice was identified, investing in what is significant: patients for whom they provide care, because the concepts are also updated, as well as the bonds and the territory itself.

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