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AIDS, FAMILY AND CARE: EFFECTS ON THE TREATMENT OF INDIVIDUALS INFECTED BY THE HIV VIRUS

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ABSTRACT

This manuscript is a literature review of the effects of treating patients hospitalized with HIV and cared for by their relatives. The therapeutics that takes into account the presence of the family of the patient with AIDS, has had positive effects on the evolution of the health of these individuals. Such results have led public health officials in several countries to include the method among the possibilities of aiding the treatment of HIV patients. This bibliographic study aims to discuss issues related to the presence of the family in the treatment of people with AIDS virus, as well as the benefits of this intervention for patients and the family in general. The theoretical reference is tributary of the areas of nursing, psychiatry, psychology and collective health. It is concluded that the insertion of the family in the treatment of people with AIDS presents satisfactory results, mainly with respect to the improvement of the clinical evolution of these patients. This improvement is due to the presence of non-quantifiable categories during hospitalization, such as affection; companionship, friendship, among others, but which are of undeniable relevance in the recovery of the patients during the time of hospitalization.

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INTRODUCTION

In the last decades several authors have discussed the importance of family participation in patient care, and they point out the need to add it during hospitalization, supported by the health team, based on a care model that entails physical benefits and emotional for both (BARBOSA; BALIEIRO; PETTENGILL, 2012; KUO *et al.* 2012). According to Wright and Leahey (2012), the family has an impact on the health and well-being of its members, and there is also ethical and moral obligation on nurses to involve families in care. In 1969, the term family-centered care was proposed, with the purpose of defining the quality of care provided in hospitals, according to the patients 'and their families' view, and of discussing the patient's autonomy in face of their health needs.

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In this case the term patient-centered medicine is used, which evolves to the term care centered in the patient, with the finding that it did not describe the intended approach, therefore the term family was included in 1990, and family (CCPF) (INSTITUTE FOR FAMILY-CENTERED CARE, 2008). The present model of health in Brazil is characterized by the "hospitalocentric" practice, individualism and excessive use of the available technological resources and with low resolution (SOUZA, 2000), being the professionals who work in this context attracted by this "hard" technology, and the (LEE *et al*., 2014). In order to reduce this practice and offer health and integrality to the communities, the Ministry of Health (MS) in 1991, started the implementation of the Program of Agents Community Health Program (PACS) as a transitional to the format of the Family Health Program (PSF) in 1994, which strategically aimed at reorienting the Brazilian healthcare model (SOUSA, 2000; TEIXEIRA *et al.,* 2000). With the community service, the PSF guaranteed that people had access

to basic health services for health promotion, basic care and prevention. It also increased the number of family-focused studies in its most varied contexts, changing the perspective of care However, analyzing the textbooks of this strategy, we observe that they address the health of children, adults, women and the elderly individually, without, however, addressing the family unit and the interaction among its members (MINISTÉRIO DA SAÚDE, 2001). The sense of the work process of the PSF is the family as a unit of care for the achievement of goals, not the definition of family in the context of health and illness, or consider that the family system is influenced by changes with its members, relationships, cultural, environmental and community changes in which they live, or even the interaction of health professionals with this family (Pinto *et al*., 2010). In Brazil, the PSF was the closest goal to the principles of the CCPF, which initially practiced the family-centered approach in the pediatric context, later incorporating and expanding care for adults and older people, and their family in other contexts (INSTITUTE FOR FAMILY CENTERED CARE, 2008). The CCPF Model has been proposed as an innovative approach to health planning, delivery, and evaluation that is mutually governed by the partnership between health care providers, patients, and families. It can be applied to patients of all ages and practiced at any health facility (Lee *et al*., 2014). The CCPF is an approach that recognizes the importance of the family as a care client, ensures the participation of everyone in caregiving, action planning, and decision making. It is remarked as a new way of caring that offers the opportunity for the family to define their problems, and jointly elaborate the action plan, where responsibility is also assumed by the team and family (BARBOSA; BALIEIRO; PETTENGIL, 2012). In this way health professionals should act as facilitators, identifying deficiencies, sharing knowledge, enabling this care of the family without delegating functions. This interaction between the professional and the patient / family should facilitate care by the professionals and reduce the anxiety and traumas that could be generated by the hospitalization to the patient and your family (GOMES *et al.*, 2015). This interaction allows the family to feel that it is exercising its role in care and aims to establish trust through safe care, as a channel of communication in which the family can check if it understands all the information and knows the procedures that are being performed (Rosenberg *et al*., 2016). However, there are still difficulties in the relationship between the health team and the family, as it is not clear to the health team and the families of the hospitalized patient what new roles should be taken by them during this period (BARBOSA; PETTENGIL, 2012). In fact, if there is no clear definition, the family may feel pressured to take on more functions than they would like, they may perceive that there is some overload or reduced number of professionals, or lack of proper care of the patient (COYNE, 2013).

There are also difficulties in identifying the family, because there are several definitions, depending on the reference used, be it biology, economics, sociology, psychology, etc. According to Wright and Leahey (2012), the family is what a person considers as such, which can guide nursing care, there are still, family theories that describe family units and how these respond to adverse events. The theory of family systems considers the constant interactions between family members and those with the environment. If there is a change with one of the family members, the interactions are changed, and the changes expand for the whole family. (HOCKENBERRY; WILSON, 2014). The Family Assessment and Intervention Model, created by Wrigth and Leahey (2012), has its theoretical foundation in Von Bertalanffy's system theory, and aggregates cybernetics, communication, the biology of cognition, and change. She further mentions that systems exist as part of other larger systems, that each individual is seen as a system, which is part of others, the family in which it is inserted and in several others such as school, work and community. This system is always in search of stability. The term "cybernetics" created by the mathematician Norbert Weiner contributes to the concept of self-regulation ability, where after an event, each member transmits feedback, generating new behaviors, or even a new pattern of behavior in the whole family, since these feedbacks occur at various levels of family systems. Pragmatics of Human Communication, Watzlawick, Beavin and Jackson (1967) deals with the theory of communication between individuals, where for an effective evaluation one must consider verbal and non-verbal communication within a context of the spoken message or behavioral. This work also deals with concepts of complementary relationships that are those with unequal status, mother and child example, and symmetrical that have equal status, having as husband and wife, both are healthy and necessary, or generate conflicts depending on the situation. The nature of family relationships can be demonstrated through the mode of communication, tone of voice and body posture, which can differentiate a loving relationship from a conflicting one. Maturana and Varela (1986) developed the theory of the biology of cognition, which states that humans use biology and physiology to create their visions of the world, that is, each person sees their own world according to their own experiences, each person has their truths about the world, and all of them are valid. The authors Watzlawick, Weakland and Fisch (1975), Bateson (1979), discussed the theory of change, which brings important concepts for understanding family systems, stating that the existence of two possible levels of change, where the first order occurs when there is a change in the members of a system, but the system itself remains unchanged, and the system of the second order, in which the whole system changes; At this level, a person only perceives this change when it is noticed by others.

Changes in a family system are determined by the structures of the system itself, not by those of others one. The important thing for a behavior modification is not the understanding of "why" a situation occurs, but "what" is the situation, since the problems are between people, not within them. The changes do not occur in the same way in all members, as they depend on the adjustment of the biopsychosocial-spiritual structures of each person to the interventions (MARCHETI; MANDETTA, 2016). In this theoretical perspective, the focus of assistance is always the family and its interactions, not just one of its members. The challenge of the nurses who work according to this theory is to know the limits of each family and to gain their trust, so that new ideas, opportunities are accepted and it is feasible to plan intervention strategies (HOCKENBERRY; WILSON, 2014), acting as a facilitator of the context to change, since it can occur spontaneously even when there is no intervention (WRIGTH; LEAHEY, 2012). The Calgary Family Assessment Model created by Wrigth and Leahey (2012), is a multidimensional structure that considers the family under three aspects: 1) structural, 2) development and 3) functional, and can be used to directly evaluate a family, or a clinical framework to help families solve problems or issues. This model is based on family strengths and resilience, focusing on

promoting, improving and sustaining effective family functioning in cognitive, affective and behavioral domains. More profound and continuous changes in the family are observed with interventions directed to the cognitive domain (family beliefs). One factor that interferes in the relationship between the team and the family is the lack of time of the nursing team, Wrigth and Leahey (2012) proposed a 15-minute interview to be used as an alternative intervention to the family that takes into account the greater nurses' complaint, lack of time to work with families. This method has 5 key ingredients: 1) therapeutic conversation, 2) good manners, 3) genogram, and 4) family etiquette, 5) therapeutic questions and praise for strengths of the family and its members. The researchers RUEDELL *et al*. (2010) and Martinez *et al*. (2007) carried out a study in a pediatric hospital, inserting a 15-minute interview on the patient's admission, and evaluating the nurses' perception before and after this insertion evaluation was that there were benefits with this practice, and that the interview should be incorporated into the routine of patient admission. Other authors emphasize that it is necessary to consider that the family should participate in care planning, and not only be an information provider, since each family knows its limits in caring for the hospital environment. To this end, the assistance negotiation process requires the channel of open, continuous and impartial communication between staff and family. (BARBOSA *et al.,* 2012). The strengths and potential of each family must be recognized and evidenced, as well as the support, because sharing experiences and feelings facilitates the re-dimensioning and reorganization of family dynamics (BARBOSA *et al.,* 2012). In order for the family approach to be effectively implemented, teaching actions, studies, policies and programs are needed to support efforts to consider the family as a system of care. It is necessary to ensure an accessible health system at all levels of care, including the training of professionals sensitive to the needs of families (American academy of pediatrics, 2003). In our reality, what is still found are mainly isolated initiatives of professionals sensitive to the realities of families (CRUZ and ANGELO, 2011). Angelo (1999) mentioned three challenges to approaching nursing care in families: 1) teaching family thinking, 2) stimulating advanced family practice, and 3) building knowledge about family nursing.

The PSF as described above is today the public policy that seeks to contemplate the problems of the family, and to seek the solutions itself. However, the challenges mentioned are still present, as we still find gaps in the training of professionals in relation to family care. These challenges are not just local because Bell (2013) mentions that despite nearly half a century of building knowledge on family nursing and CCPF, it is still common for patients and families to assess their relationship with caregivers as disinterested, difficult, and intimidating. Bell (2013) also mentions that family-based nursing interventions that use therapeutic conversation are easy to learn and teach, and several studies have shown that they make a difference in the support offered to families. However, there are few nurses in practice who know and value this intervention. In this social context and health care we highlight the HIV patients, that it is a big problem of global public health, which has claimed over 35 million lives in 2016, a million people died from causes related to HIV globally (WHO, 2017). By the end of 2016, there were approximately 36.7 million people living with HIV, with 1.8 million people becoming infected the same year around the world, and between 2000 and 2016 new HIV infections reduced by 39 %, and deaths fell by one-third, with 13.1 million lives being saved due to the use of antiretroviral therapy (OMS, 2017). It is shown that the health of family members of people living with HIV / AIDS is affected, as there are reports of patients experiencing feelings of inferiority, anxiety about disclosure of the diagnosis, and social rejection, causing the family to experience these feelings as well (WRIGHT and BELL, 2009).Members of the family of people living with HIV / AIDS experience sleep deprivation, anxiety, stress, feelings of inferiority, hopelessness, restricted freedom and rejection of people in the workplace, and financial problems by increasing expenses with the sick family member (WACHARASIN, 2007). Given the above, it was verified that the CCPF approach can contribute to a change in the culture of professionals, evidenced by a more positive perception of the family and health professionals, regarding the central elements of this care model and if it contributes to the reduction of anxiety and depression (Barbosa *et al.,* 2012).

Final considerations

It is undeniable that the presence of the family in the care process of patients affected by HIV is a positive factor in the dynamics of the treatment of these people. However, as observed in the literature review presented here, a lot still has to be done to make this process part of the therapeutic measures of health institutions, especially in Brazil.One of the problems to be faced by the teams responsible for the care of HIV patients concerns the recognition of the limits placed by the patients' own condition on the family caregivers, since it is necessary that they have the psychological conditions to be able to act positively in the treatment. Therefore, this care should be initially instructed and followed up later, so that the people involved are fully aware of their role in the improvement process of their families. For all this to become reality in the country, it is necessary that there be political will and awareness of the people for the importance of the family in dealing directly with HIV patients and other diseases. The implementation of the CCPF, within the scope of any hospital service, requires professionals to modify their attitudes, beliefs and values that restrict family access and participation in this environment, recognizing the vulnerability and suffering of the family, as well as their central and permanent role in the patient's life.

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