PATIENTS EXPERIENCE ASSISTED BY A HOME CARE SERVICE (HCS) ¹

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ABSTRACT. This paper presents the results of a doctoral research in Psychology, which sought to understand, through the phenomenological method, the experience of patients assisted by a Home Care Service – HCS (Known in Brazil as Serviço de Atenção Domiciliar – SAD), that is part of the Unified Health System- UHS (Known in Brazil as Sistema Único de Saúde – SUS), in a city in the State of São Paulo-Brazil. Dialogical meetings took place, mediated by guiding questions, with seven adults, patients of both sexes. Then, based on the authors' perceptions, comprehensive narratives were written on each participant's experience. Excerpts of these narratives will be presented here as well as the essential elements of the experience of being in a care home. It was concluded that the experience of home care favors the autonomy of the patient, enabling the coexistence with family members and the maintenance of identity elements present in the housing. As a contribution of this study, it is pointed out that the home space, as a context of health care, favors positive interpersonal relationships among the team of health professionals, patients and family members, making it potentially more humanizing.

Keywords: Experiences; home assistance; Unified Health System.

A EXPERIÊNCIA DE PACIENTES ASSISTIDOS POR UM SERVIÇO DE ATENÇÃO DOMICILIAR (SAD)

RESUMO. Apresentam-se os resultados de uma pesquisa de doutorado em psicologia, que buscou compreender, fenomenologicamente, a experiência de pacientes assistidos por um Serviço de Atenção Domiciliar (SAD), vinculado ao Sistema Único de Saúde (SUS), num município do Estado de São Paulo. A pesquisadora realizou encontros dialógicos individuais, mediados por uma questão norteadora, com sete pacientes adultos de ambos os sexos e a partir de suas impressões, escreveu narrativas compreensivas sobre a experiência de cada participante. Excertos dessas narrativas serão aqui apresentados, assim como os elementos essenciais da experiência de ser cuidado em casa. Concluiu-se que a vivência do cuidado em domicílio favorece a autonomia do paciente, possibilitando o convívio com os familiares e a manutenção de elementos identitários presentes na moradia. Como contribuição deste estudo, aponta-se que o espaço da casa, enquanto contexto de cuidado em saúde favorece relações interpessoais positivas entre a equipe de profissionais de saúde, pacientes e familiares, tornando-o potencialmente mais humanizador.

Palavras-chave: Experiências; assistência domiciliar; Sistema Único de Saúde.

¹ Support and funding: Agradecemos à PUC-Campinas, pela bolsa de estudos concedida à doutoranda na condição de capacitação docente.
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LA EXPERIENCIA DE PACIENTES ASISTIDOS POR UN SERVICIO DE ATENCIÓN DOMICILIARIA (SAD)

RESUMEN. Presenta los resultados de una investigación doctoral en psicología, que intentó comprender, por intermedio del método fenomenológico, la experiencia de pacientes asistidos por un Servicio de Atención Domiciliaria (SAD) vinculado al Sistema Unificado de Salud (SUS), en una Ciudad en el estado de São Paulo-Brasil. Encuentros dialógicos individuales ocurrió, mediada por la pregunta orientadora, con 7 pacientes adultos de ambos sexos. A partir de sus impresiones, escribió narrativas comprensivas sobre la experiencia de cada participante. Los extractos de estas narrativas se presentarán aquí, así como los elementos esenciales de la experiencia de ser cuidado en el hogar. Se concluyó que la vivencia del cuidado en domicilio favorece la autonomía del paciente, posibilitando la convivencia con los familiares y el mantenimiento de elementos identitarios presentes en la vivienda. Como contribución de este estudio, se señala que el espacio de la casa, en cuanto contexto de cuidado en salud, favorece relaciones interpersonales positivas entre el equipo de profesionales de salud, pacientes y familiares, haciéndolo potencialmente más humanizador.

Palabras clave: Experiencias; ayuda a domicilio; Sistema Único de Salud.

Introduction

Although health care at home has followed men since antiquity, home care (HC) is currently a trend on the world scenario, for some reasons including reduced hospitalization costs and the risk of common infections in hospitals; promotion of a more humanized care that guarantees greater autonomy to patients; de hospitalization of patients who still need some health support that can be performed safely at home; ensuring continuity of care for patients with mobility difficulties; among others (Aoun, Breen, & Howting, 2014; Barbosa, 2017; Home Care in Canada, 2015; Marcucci & Cabrera, 2015; Silva, Büscher, Moreira, & Duarte, 2015; Simão & Mioto, 2016). In addition to the reasons for the development of HC, we still have to consider the impact that the health area has suffered, in terms of increased demand, due to recent social changes, such as demographic transition (aging population with lower birth rate and increased life expectancy); epidemiological transition (reduction of acute and infectious conditions and increase in chronic disease rates); technological development in the health area (people are kept for many years in chronic conditions of illness); changes in family structures (reduction in the number of children and, consequently, in the number of family members available to care for their elderly) (Aoun et al., 2014; Marcucci & Cabrera, 2015; Simão & Mioto, 2016). Given this and following a trend already underway in countries as France, the United Kingdom, the United States and Canada, the Brazilian Health Ministry implemented, in 2001, within the Unified Health System – UHS (known in Brazil as Sistema Único de Saúde – SUS), the Better being at Home Program (Known in Brazil as Programa Melhorem Casa) aimed at “[...] to provide to patients a contextualized care related to their culture, routine and familiar dynamic, avoiding unnecessary hospitalizations and reducing the risk of the infection” (Brasil, 2016, p. 4).
Although there are historical records of HC in Brazil since the 1960s, the first ministerial ordinance dedicated to the regulation of the practice is from 2006 (nº 2529), being subsequently replaced by Decrees nº 963 and 1208/2013. In addition to these specific laws and ordinances, HC is still mentioned as a priority in the care of the elderly, people with HIV / AIDS, physical disabilities and by National Humanization Policy (Lei nº 10.741, 2003; Lei nº 13.146, 2015; Brasil, 2004, 2007). Besides the fact that HC is already provided in Public Health Policies in our country, in supplementary care (private) it is also in the process of expansion, being named in this sector as Home Care (it is used the English term) and justified basically by the significant cost reduction concerning hospitalization (Brasil, 2012).

Thus, recognizing HC as a model of health care in expansion in Brazil, considered as more humanized and attuned to the needs and ways of patients' lives, it would be worth investigating how those involved (patients, family caregivers and health professionals) have lived this experience of caring and being cared for at home, which differs greatly from what is experienced during hospitalizations. Other studies have already dedicated themselves to investigating the perceptions of family caregivers about HC, revealing the state of intense physical, psychological and social overload to which they are exposed when they are 'elected' by the family group to care for a relative who has fallen ill (Gomes, Calanzani, Gysels, Hall & Higginson, 2013; Oliveira, Quintana, Budó, Kruse, & Beuter, 2012). Barbosa, 2017 and Davies et al., on the other side, investigated the health professional perceptions who perform in HC and concluded that they also recognized this developed assistance work as more humanized, having regarding the service, a more idealized view.

Few researchers, however, have turned their attention to the perceptions of the patients themselves who are assisted at home. Although they have not dedicated themselves to specifically investigating the subjective experiences of patients assisted at home, but rather their socio-demographic profile and their assessments about the service, the authors consider that patients are satisfied with the assistance received at home, reveal their preference for home care over the hospital care and praise the quality of the bond established with the professionals who care for them (Aoun et al., 2014; Gomes et al., 2013; Hornigold, 2015; Wakiuchi, Salimena, & Sales, 2015).

These were some of the motivations for conducting a study aimed to understand the experience of the patients themselves about the fact that they are experiencing the condition of illness and a caring relationship in their own housings. Psychology, as a field of work and research in the area of mental health, can greatly contribute to broadening the understanding of professionals from other areas of health who work in HC about the psychological peculiarities involved in the context of home care.

**Method**

The research was developed through the phenomenological method in which the researcher proposes to go to the field in search of an opportunity to understand the phenomenon of interest, as it occurs in the concrete reality, developing itself in a process that begins by the meanings of a given experience for people and continues with the researcher's interpretations about the elements that constitute the phenomenon complexity (Ales Bello, 2004; Brisola & Cury, 2016). The study aimed to understand the patients' experience who are assisted by an HCS linked to UHS in a city in the State of São Paulo. The researcher followed for 14 months the visits and assistance made by the professionals who make up the HCS team.
The service mentioned above, opened in 2004, serves a population of around 200 thousand inhabitants, which is characterized as disadvantaged in socioeconomic terms. The multi-professional team is divided into shifts. They are conducted to the patients’ homes by two vans (car model) and carried out around 70 visits/day. Most assisted patients are between 60 and 90 years old, but children and adolescents are also assisted. The most frequent diagnoses are several neoplasms, stroke sequelae, respiratory diseases, dementia syndromes, spinal trauma (CST), neuropathies (in children) and traumatic brain injury (TBI).

Seven patients attended by the HCS became participants in this research, whose characteristics are shown in Table 1.

Table 1. Summary of the profile of the research participants

<table>
<thead>
<tr>
<th>Name*</th>
<th>Age</th>
<th>Diagnosis</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caio</td>
<td>41</td>
<td>Tetraplegia due to spinal cord trauma after an attempted suicide.</td>
<td>Parents.</td>
</tr>
<tr>
<td>Helena</td>
<td>67</td>
<td>Breast cancer with bone and lung metastasis.</td>
<td>The patient herself with help from neighbors.</td>
</tr>
<tr>
<td>Carol</td>
<td>30</td>
<td>Paraplegia due to polytrauma after a car accident.</td>
<td>Husband's grandmother.</td>
</tr>
<tr>
<td>Willian</td>
<td>41</td>
<td>Tetraplegia due to spinal cord trauma after taking a dip in the sea.</td>
<td>Wife.</td>
</tr>
<tr>
<td>Neuza</td>
<td>48</td>
<td>Paraplegia due to spinal cord trauma after a car accident.</td>
<td>Husband.</td>
</tr>
<tr>
<td>Alana</td>
<td>30</td>
<td>End-stage uterine cancer.</td>
<td>Parents.</td>
</tr>
<tr>
<td>Ana Maria</td>
<td>40</td>
<td>Peritoneum cancer.</td>
<td>Mother in law.</td>
</tr>
</tbody>
</table>

Source: The authors.  
*All names are fictitious.

Inclusion criteria were patients older than 18 years old, of both sexes, who, regardless of the diagnosis, were aware, oriented and showed a willingness to talk to the researcher. The dialogic meetings started with the following guiding question “I am interested in understanding how the experience of being cared for at home is. Could you tell me what it has been like for you?”. The participant was invited to talk openly about his/her experience with the researcher. The meetings were not recorded or recorded in full, in order to keep the research design faithful to the phenomenological method.
After each individual meeting, the researcher wrote a comprehensive first-person narrative, which sought to reveal the essence of what the participant told about his experience, based on his own perceptions. After completing all comprehensive narratives (a term we have adopted to refer to individual narratives about each of the meetings), the researcher immersed herself in a more comprehensive analysis process, deepening her impressions on the set of narratives, in order to compose an overview interpretative.

It is worth clarifying that the University's Human Research Ethics Committee (under opinion nº 1,359,802) previously approved this research project. All participants or their legal representatives (in the case of tetraplegic participants) agreed to participate and signed the Informed Consent Form.

Results and discussion

Narrative Overview

The research results are presented as follows: initially, excerpts from each of the seven comprehensive narratives were included, in the order in which the dialogical meetings took place. The chosen excerpts enable the reader to identify the essential elements of each meeting. Passages appear in quotation marks and in italics, which approximate the participant's speech, considering that, as mentioned, as this is a phenomenological study, the meetings were not recorded, but rather described by the researcher in narrative form. In the sequence, the experiential elements apprehended from the set of comprehensive narratives are listed.

Caio: the other and me

Caio was 41 years old when I met him and was interested in participating in the research. He developed tetraplegia 12 years ago after a suicide attempt. At the time, he was a drug addict, was married and had a 5-year-old daughter. After the tragic event, he was abandoned by his wife and currently resides with his parents. Although he maintains a highly dependent relationship with the mother, his primary caregiver, I realize that he struggles to preserve his autonomy. He travels around the city with a motorized wheelchair and maintains previous habits such as going out with friends and having 'a beer'.

Regarding his experience of being assisted at home, Caio told a series of difficult situations that he went through before being inserted in the HCS. He established comparisons between the comfort he feels when being served by the HCS team and the troubles he faced in the past. He feels safe and more independent, as he knows he can count on the service. Knowing that he has someone to turn to in case of an emergency brings to Caio the certainty that, finally, he is free from the tiring itineraries he has already taken in health services in the search for care.

Caio feels that the HCS support also means comfort for his parents, who no longer need to travel with him around the city to get assistance. This gives him relief, as he realizes that he no longer gives them as much work as in the past. "Just me to be well is not enough, right? There is not only me in this world. I don't want to feel like I'm ending their lives and the support of HCS helps me with that too".
Helena: I do not know if I deserve all this

Helena is a divorced woman, 67 years old, strong, lucid and communicative. She worked as a nursing technician, but for six years, she has been ‘out of her way’ due to breast cancer that has already given her some metastases and a series of limitations. She struggles to remain independent; however, she is ‘tired of so many impossibilities’.

She was extremely grateful to the HCS team and would like to make this gratitude in a public way, considering that HCS’s service exceeds expectations, mainly because it is a service linked to UHC. For Helena, being assisted at home represents ‘a luxury’, an unparalleled opportunity in terms of comfort and the ‘differentiated and humanized attention’, she says she receives from professionals. She established a series of comparisons between the assistance received from the HCS and the moments when she had to make use of hospital services, concluding that, unlike the situations in which she had felt ‘a nothing person’, she now feels ‘treated as a human being’, because the professionals from HCS can see her beyond the disease.

Carol: nostalgic of my life

The story of Carol's illness is tragic. She is a young woman, 30, newly married, who literally had her life crossed by a runaway car driven by a person who deliberately caused the accident because he intended to commit suicide. The boy who caused the accident died instantly, the other people present had minor injuries, and Carol suffered a multiple trauma that left her paraplegic.

When we first met, it had been a short time since the accident and Carol was still in the mourning process. She expressed all his sadness and indignation at what had happened, regretting all that she had lost from the life she had chosen to live. Her condition revealed the intense anguish and impotence triggered by the loss of freedom and the possibility of making choices.

Her husband's grandmother cares for her, but she has not been very collaborative with the treatment, being charged by the health team and family members, in order to adopt an attitude of greater involvement. The HCS presence in her life at this moment ends up representing for her another imposition with which she cannot avoid. She is not always willing to receive the visit of professionals at the exact moment they arrive at her home, but recognizing that there is no other option Carol is once again resigned. Despite the complaint about the loss of privacy, Carol acknowledges help from the HCS and her dependence on the care they provide. She praises the service for the provision of materials and the support offered to her caregiver.

Willian: the life that has already been lived

Willian is 41 years old, married and has an 18-year-old daughter. He worked as a cabinetmaker and had a very active life, about which he likes to share details and achievements, of which he is very proud. Five years ago, he suffered spinal trauma while taking a dip in the sea and became tetraplegic.

After spending several months in the hospital and although he still had an infection and needed a tube to feed himself, he convinced the doctors to release him, as he realized that in the hospital, he would not get better. Since then, the HCS team, whose professionals he already considers ‘family members’, has assisted him at home.
Despite his physical limitations, Willian remains autonomous, well adapted and likes to make plans to improve his condition. Regarding the fact of being cared for at home, he recognizes that there may be other patients who need HCS even more than he does. However, deep in mind, Willian thinks it is great and prefers to continue receiving visits from the team, as he considers the assistance agile and effective. Although Willian knows that he currently does not need such frequent visits from the HCS, he considers this type of assistance a ‘practicality’ for people in a situation similar to his and feels safe, as he feels that the team will not abandon him. In addition, he considers that he has a comprehensive treatment and praises the support offered to her caregiver.

Neuza: my life from now on

Neuza's life course was also altered after a car accident. She is 48 years old, comes from the northeast of the country, is married, has three children and worked as a domestic worker. Since moving to the State of São Paulo 22 years ago, she has not returned to visit her mother. In 2015, she finally saved the money for the trip and managed to see her mother. On his return, she was in a car accident with two nephews and their youngest son. Only she was seriously injured and became paraplegic because of her injuries.

She spent almost four months in another state until she was finally discharged and was able to return to her home, on a long ambulance trip. While she was hospitalized, Neuza only thought about leaving. She worried about her children and felt that things would only return to the normal way when she was home. She only realized the difficulties she would face when she finally got home and was faced with the new reality of being in a wheelchair. She lives in a region of occupation, still without urbanization infrastructure. If it were not for the care provided by the HCS, she does not know how she would manage with everything, including her. She considers the care she receives at home, more than 100%. “I feel protected, cared for, and safe with them taking care of me here at home. I fear that one day they will discharge me and stop coming”.

For Neuza, the HCS fulfills its role of care for in a good way, in addition to providing her with materials, teaching her husband to take care of her and for keeping some of her social relationships preserved. She has not yet adapted to the condition of a wheelchair and feels ashamed of being seen in public. Thus, the visit of professionals is also perceived as a way to be distracted and receive attention.

Alana: the townhouse with wooden stairs

Alana is 32 years old, single, has two children and lives with her parents in a precarious wooden shack. When we were at his house for the first time, we were startled by the precariousness of the housing conditions. This situation, however, did not prove to be a problem for Alana and her family at that time.

She discovered uterine cancer, a year before she started to be assisted by HCS. Since then, she had faced surgery, hospitalizations, cancer treatments and a month before we met for the first time; she was discharged from the hospital with the news that medicine had nothing more to do in her case. Alana felt abandoned and helpless in the face of the way she was treated by the doctors at the hospital.

When Alana realized that she would be assisted by the HCS, she suspected that the service would not be good either, but she was surprised and feels safe with the care offered to her by the HCS. She is an intelligent, critical and well-informed person. She is aware of
the seriousness of her condition and knows that she is dying, but she holds onto faith as a resource to face the situation.

Alana also established comparisons between hospital and home care. She complained about the cold and disrespectful way she felt treated at the hospital and was delighted to recognize that she is now well looked after. She believes that professionals ‘need to have a profile’ to work in this service, as Alana perceives them as more capable of caring than the professionals she has already met at the hospital.

For her, having the opportunity to be close to her children and eat the food prepared by her mother, are situations that make her feel good. The meeting with Alana helped us to understand that even with all the difficulties, the home can be perceived by the patient as the best place where he could be to experience the condition of fragility that was imposed by the disease.

Ana Maria: here at home it is just my illness

Ana Maria is 40 years old; she has had peritoneum cancer for more than a decade. She has gone through several moments along this journey: hospitalizations, relapses, surgeries, a coma period in the ICU, chemo and radiotherapy and outpatient monitoring. Currently, the HCS, being considered a patient in the process of palliative care (with no possibility of cure), assists her. Ana is married and has a couple of children. Her mother has passed away and was also a patient of the same HCS. As the family comes from the northeast region and there were no other relatives available to take care of Ana, her mother-in-law came to be with her and help with the housework, at this stage when the disease is more advanced.

Although small, the family has a harmonious relationship, and Ana fears that her mother-in-law needs to leave, as she does not know how things will be without her help. Speaking of her experience of being assisted by HCS, Ana showed deep gratitude for the care she receives from the team and mentioned the convenience of not having to go to the hospital anymore.

Interestingly, unlike other participants, Ana never felt badly treated in the hospital. Her complaints about the care received at that institution involve two issues: concern for her children during the periods she was hospitalized; and the suffering in having to live with situations of pain and death on a daily routine. Ana concluded that being cared for at home, for her, is the best option, because there, she feels that it is just her illness and that her treatment is also more personalized and not a ‘series’ care as usually happens in the hospital. Ana considers that witnessing the suffering of others in the hospital ‘discourages the person from fighting’ for his recovery.

Summary of experiential elements

1. The experience of being cared for at home is limited by the characteristics of the illness condition.
2. The feeling of helplessness is triggered by illness, which is accompanied by the condition of dependence on other people. Such experiences lead to the struggle for the preservation of personal autonomy.
3. There is recognition for the care received at home, which is perceived as being effective, agile and humanized.
4. Patients express confidence, admiration and gratitude for HCS professionals, feelings that translate into an affectionate and friendly relationship. A bond develops between professionals and patients, understood by them as a differential of this type of assistance.

5. Comparisons between the care already experienced in hospital contexts and that provided by the HCS team are inevitable. Patients consider that HC provides them with greater comfort, safety and tranquility compared to the care received in health institutions. Such elements contribute to the preservation of autonomy and freedom to make choices and maintain habits.

6. Patients refer to the care received from the HCS as something that exceeded their expectations, by also providing some relief from the provision of materials and the attention paid to caregivers; because they feel treated in a comprehensive and humanized way and because they find in HCS professionals, a way to keep social contact minimally preserved.

7. As a result, some participants expressed a certain dependency concerning home care and rejection of other types of health care.

8. The own home has revealed itself as a powerful health care space capable of guaranteeing the necessary elements for truly humanized assistance.

Discussion

Given the various elements that emerged to our understanding from the meetings with the participants and the interpretation of their experiences about home care, we will specifically address on the issue that refers to this type of assistance being more humane compared to other models. Several researchers have already dedicated themselves to investigating the experiences of patients during hospitalizations. There seems to be an agreement on the fact that being hospitalized is an experience that implies a series of biopsychosocial impacts with potentially negative consequences for the person, which go far beyond the suffering already triggered by illness (Braga, Ferreira, Takeshita, & Delavia, 2013; Oliveira et al., 2012).

In addition, the interactions established between health professionals and patients in the context of the hospital are guided by attitudes that arise mainly from subordination to hierarchy, norms, and roles, which inevitably lead patients to a passive condition, which is opposed to the recommended promotion of autonomy necessary for the restoration of health. According to Oliveira and Kruse (2016) this eminent protocol assistance that takes place in hospitals, if on the one hand, guarantees the safety and standardization of procedures, on the other hand, it plagues professionals in a bureaucratic process, which often becomes responsible for the distance in the interpersonal relationships that happen in that context.

Regarding the impressions of patients assisted at home, Horngold (2015) and Orueta Sanchez et al. (2012) concluded that they usually recognize that this type of assistance promotes more autonomy, convenience, a feeling of being treated in a comprehensive and humanized way, confidence and admiration by professionals. Besides, these patients trust that they will not be abandoned, and that, for being in a known environment, they can maintain habits, privacy and relationships with family members. Orueta Sanchez et al. (2012) state that in the context of the patient's home, there is respect from the professionals for his space, unlike what happens in the hospital, and this favors that the actions are truly geared to the patient's needs. That is, in the home context, the team needs to be flexible to be able to tailor care to the patient's needs and reality and not the contrary as it happens in
Home care patients experience hospitals. Thus, professionals deprive themselves from the place of authority they are led to assume in the hospital and may have more freedom and autonomy to accept patients' creative manifestations as part of their recovery process.

Because of these results, it is worth asking: after all, what is meant by the humanization of health care? Moreover, which characteristic elements of home care can be considered as facilitators for these conditions of humanization? To discuss humanization of health care, one can adopt from the normative reference, recommended in the guidelines of Public Health Policies to more critical positions, which consider humanization beyond a set of guidelines adopted to guide the work of health professionals (Agreli, Peduzzi, & Silva, 2016; Martins & Luzio, 2017). The fact is that the ‘humanization’ term is marked by polysemy, which ends up causing a certain hollowing out of its meaning due to the multiple possibilities of interpretation.

In addition to the breadth of the term, it is understood that the proposals for the humanization of health care must be based on the valuation of the subjective and social dimensions of people, creating opportunities for the recognition of the other to be legitimate in his uniqueness (Brasil, 2009; Todres, Galvin, & Dahlberg, 2014).

The process of assistance humanization involves personal attitudes, skills and competencies that are not deliberately put into practice just because they are a guideline of the public health system. Courses, training, manuals and rules are developed for this purpose, but the patient remains unheard and is not encouraged in his autonomy. The foundation of humanization seems to have been submerged by a set of guidelines and protocols with little impact on the attitudes of professionals when relating to patients.

Agreli et al. (2016) include empathy, respect, solidarity, listening, sensitivity, affection, dialogue, trust and bonding as attitudes that would guarantee the rescue of the human condition in the professional-patient relationship. What the participants of this research showed us is that in HC, they feel that professionals treat them with these attitudes, but in the other contexts in which they were assisted, these attitudes were not always revealed.

Putting health care practices ongoing, genuinely aimed at the sick person, involved in his development process as a comprehensive person, is not an easy task. Being willing to undress from the technical ‘arsenal’ in which health professionals rely on health institutions, in order to really listen to others and understand them in their motives and desires. It challenges not only the professionals involved in the assistance but also the trainers of these professionals, the managers of the health services and even the people involved in the elaboration of Public Policies.

If the participants in this study revealed that they felt ‘treated as human being’ and recognized the professionals who care for them at home as ‘family members’, expressing their gratitude for the care they receive and admiration for the professionals, then it is concluded that something happens in this caring relationship, which goes beyond the normative dimension of humanization proposals. There is a possibility of a professional-patient encounter based on a new, creative way of being with the other, which seems to favor care that is more comprehensive, centered on the patient’s personal, and above all, with the potential to promote the autonomy of those involved.

As the term ‘humanization’, the proposal for ‘patient-centered care’ has been gaining ground in the scientific literature in the health field. It is a broader perspective of health care, considered from a holistic and comprehensive view, oriented to the patient’s real health needs; the participation of patients in care, valuing autonomy, self-care, experience, citizenship, freedom and respect for the subjectivity of those involved; of a professional-patient relationship based on a more human, empathic and affective contact (Agreli et al.,
2016; Home Care in Canada, 2015). Although the authors do not explicitly establish the approximations with the principles of the Person-Centered Approach (PCA), developed by the North American psychologist Carl R. Rogers in the early 1960s, end up suggesting a resumption of fundamental values and attitudes for a genuine care relationship.

In view of the proximity between the current health care proposals and the PCA principles, already discussed by Bacellar, Rocha and Flôr (2012), we consider pertinent to rescue some of these principles in order to support our understanding of the reasons why home care is better able to achieve these goals. Bacellar et al. (2012) discuss, for example, the approximations between the concepts of actualizing tendency, facilitation and empathy, originating from the PCA, and the principles of autonomy, protagonism, interdisciplinarity and humanization of care, which support the current care proposals in UHC. The authors consider that the PCA's emphasis on intersubjective relationships and the bond established between professionals and patients can be taken as a principle for the realization of the humanization proposal in order to enable the professionals involved to effectively position themselves based on attitudes of valuing the other as a human being since humanization is not a technique. Greater involvement in interpersonal relationships, based on empathic understanding, acceptance and genuine interest by the person of the other as such, would be conducive to developing everyone involved in the process.

Resuming these concepts, as proposed by Carl Rogers (1983), it is essential to consider the actualizing trend that consists of an underlying flow of movement present in all people towards the constructive realization of the possibilities that are potentially inherent to them. Furthermore, it is this organismic tendency that impels people to become more complex and mature, in a development process based on the recognition of their potential for self-understanding and psychological growth.

In another work, Rogers (1997) proposes some hypotheses about the facilitation of personal growth and affirms that the latent tendency of individuals towards growth seems to be released in the presence of an adequate psychological climate or of a certain type of interpersonal relationship, which can occur in different types of meetings between professionals and their patients, among people in general and not just in the psychotherapeutic relationship. Individuals who can experience facilitating relationships are more socially oriented, less defensive and frustrated, more adaptive and more able to face difficult situations creatively. They find ways to face life in a more constructive, satisfying and socialized way. They become more integrated, authentic, self-confident and flexible human beings in social interactions.

Regarding what is meant by a facilitating climate; Rogers and Rosenberg (1977) summarize some of its characteristics: an atmosphere of authenticity, consideration for the other and understanding interest. This climate is not guaranteed by the family, by the school, nor by any person or specific context, but by the quality of interpersonal relationships that are established in the different life situations of people throughout their lives. For Rogers and Rosenberg (1977, p. 86), “[...] the fact of being empathically understood by another person enables the individual to become a more efficient facilitator of his growth, a more efficient therapist of himself”.

In the face of such concepts, we are left with the impression of stating that HC can be more humanized than hospital care, just because of the comfort afforded to patients who have some difficulty in moving, which would become a superficial justification. There is no doubt that it is more than that. We found people living chronically with the disease, pain, limitations, fears, proximity to death. We witnessed situations of great economic precariousness, different operational difficulties, and a shortage of caregivers. Despite this,
the participants in this study showed themselves to be people with motivation and creativity in their daily struggles to survive and coexist with the limitations imposed by the illness conditions.

Thus, the home can be understood as providing a facilitating climate, as proposed by Rogers, capable of favoring, enabling or at least not preventing the patient from finding his own resources to continue his growth process, despite the disruptions that were imposed on him by the disease and by the treatment itself. The more he can feel himself, exercising his autonomy, making his choices and seeking to live the way he chooses to live, the less he needs to submit to merely protocol rules and conditions of care, the more humane the treatment offered to him.

Thus, we understand that the interpersonal contact that is established between professionals and patients in HC seems to be so close to what is foreseen in the classic principles of UHC, Bioethics, the National Humanization Policy (Brasil, 2004), the Biopsychosocial model, of the proposal about the Amplified Clinic, as well as the fundamental concepts of PCA and what is currently being called ‘patient-centered attention’. We understand that the possibility of establishing a less hierarchical relationship with such characteristics has the potential to favor the growth and autonomy of both characters: patients and professionals.

Todres et al. (2014) argue that the humanization of care is facilitated when promoting greater involvement of the person in his recovery process. These British researchers emphasize the importance, therefore, of the patient being able (or be allowed) to maintain characteristics of his identity, since the maintenance of this sense of personal uniqueness is fundamental to well-being. For this, it is necessary that care practices, regardless of the context in which they occur, consider the patient's subjective referential.

What the meetings with the participants of this research revealed to us is that the quality of the relationships established between the patients and the professionals who care for them in the home environment promotes well-being, preserves autonomy and, consequently, the patients' innate tendency towards development. Thus, it is concluded that the house reveals itself as a powerful space of health care, favoring a way of interpersonal relationship between patients and health professionals different from that experienced in institutional contexts in the area due to their own nature.

Final considerations

Before the potentialities revealed in the HC, it is suggested that training courses for health professionals recognize home care, not only from the assistance point of view but also as a pedagogical resource because it has the potential to put students in contact directly with the social reality and the subjective demands of the people who will be assisted by them in the future. Besides, due to the unpredictability nature and the need to consider the habits and cultural aspects of each family, the home context of health care has the potential to make the relationships between health professionals in training and their future patients more flexible.

On the other hand, the practice of students in HC can help to minimize the technical bias that the academic trajectory is often not able to avoid in the profile of health professionals in training.
References


Psicol. estud., v. 25, e44108, 2020


Received: Aug. 13, 2018
Approved: Apr. 23, 2020

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