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Illness and hospitalization: reflections on family counselling as care

This article is based on research with families who accompany and provide care for their chronically ill members. It has been inspired by reflections on the family, chronic illness, care and hospitalization. Our findings stem from the analysis of data collected through semi-structured interviews with fourteen (14) families within one of the wards of a public general hospital in the city Feira de Santana, in the Brazilian state of Bahia. Interviews were conducted with families whose members were hospitalized in the ward. In some cases, we interviewed more than one family member, with the total number of eighteen respondents. We assumed that in order to understand illness and hospitalization, we need to take into account the views of people affected by these experiences, so as to facilitate reflection and identify issues related to the course of illness, support or hospital-based family counselling. Based on the collected narratives, we identified two categories discussed in the sections “Accompanying and care as mutual support” and “accompanying and care as obligation”.

Keywords: contemporary family, illness, care, counselling

This article is based on experiences of families, studied at the stage preceding home care and assisting the chronically ill family member currently suffering from cardiovascular disease. Our argument is grounded primarily in the analyses done as part of the research on interactions that emerge between family members close to the patient and health care professionals in the context of support and care at the ward for chronically ill patients. Semi-structured interviews were conducted¹ with fourteen families within one of the wards of a public general hospital in the city of

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As we have seen, most of the counselling practices by healthcare professionals are limited to preparing the family for providing homecare after the patient's discharge. However, such counselling is often provided without specific knowledge about the patient's family life. The data collected, especially based on observation, have shown that counselling offered by health care professionals does not constitute the kind of care that most families are able to provide. In view of this situation, the following questions were formulated: What happens when a family member suffers from a chronic illness? In what way does family life need to be arranged and reorganized when an illness requires a series of hospital stays and round-the-clock care?

We assumed that health care professionals need to reflect on counselling and care for hospitalized patients and families who participate in care activities. During this difficult period, patients and their families seek professional help from healthcare professionals, especially the assistance offered from a **partnership-based** perspective. While treating the patient, medical staff providing such care in a hospital also face the suffering of the Other. Drawing on their scientific and technical expertise, they try to improve their patient's health or cure them, but their work is not psychologically neutral, and involves their own tensions, fears, conflicts and feelings of helplessness, which increase their personal involvement with the patient's situation, making their work more strenuous and causing further suffering.

We need to remember that illness and hospitalization disorganize families, as they begin to experience a new dynamic, and the planning process occurs in parallel with the experience. Role changes are necessary and family members wish for their loved ones to be cured or for their health to improve. The family cares for the patient, but often is in need of care itself. According to Cecil G. Helman, disease is a social process that involves others in addition to the patient (Helman, 2009, p. 119). The narratives collected from family members in the hospital, describe an experience imbued with fear, tension, expectations, love and conflict. Activities, emotions and feelings seem to be associated with the changes imposed by the illness and hospitalization, the fear of death, and the need to learn how to deal with suffering associated with illness. This is vital, because physical presence and care offered by most families alleviate the anxiety and confusion commonly experienced by patients faced with illness and hospitalization. By offering care, family members

² Brazil's national health policy is based on the 1988 Federal Constitution, which sets out the rules and directives for the provision of health care in the country by private and public institutions through a unified health care system (SUS – Sistema Único de Saúde). The responsibility for the provision of health care lies with the government and is implemented at three levels: governmental (federal), state, and municipal. 75% of the population has access to social health services, while the remaining 25% belong to the so-called Supplementary System, which also provides health care. In 2014, there were 6706 hospitals in Brazil. More than 50% of them are located in 5 states: São Paulo, Minas Gerais, Bahia, Rio de Janeiro, and Parana. (From the editors based on Health care in Brazil – https://pl.qaz.wiki/wiki/Healthcare_in_Brazil).

directly support the efforts of healthcare professionals. Moreover, in this way they can closely follow any improvement or worsening of the patient's condition and symptoms, and thus are able to instantly and directly ask health professionals for advice and intervention. Based on our observations, for the family members such presence and care may constitute not only an act of caring and loving, but also obligation arising from kinship and relationship ties.

The patient's family

Some disciplines offer helpful interpretations of certain aspects of family life that definitely contribute to our understanding of illness and hospitalization. From this perspective family and kinship are issues pertaining to two different orders, the former being a specific social group, the latter an abstract concept – formal structure resulting from the combination of different types of basic relationships. Thus, anthropology helps us to understand the extent to which family relationships, the institution of marriage and the gendered division of labour constitute universal structures, since combinations of relationships and dependencies exist in all societies. At the same time, it enables us to conceptualize variability, de-universalize and de-naturalize the family, as well as understand what causes the breakdown of typical social relationships.

It is expected that the family, as the primary social environment of an individual, will constitute the essential context for his or her development and learning, as well as a place to experience health care. There are important and permanent tasks that are regularly carried out in the family: upbringing and socialization, and the essential transmission of cultural heritage (Bastos & Franco, 2007). Since it fulfils an important role in shaping personality, the family is considered as the most important “social institution”, having an impact on relations of its members with their environment. The family's instability gives rise to crises and conflicts. The family makes it possible for a person to survive, to shape his or her own system of values, develop a culture and experience feelings of love, friendship and attachment (Negrelli & Marcon, 2006). Social interactions depend on the family, culture and changes in daily life.

Social sciences do not exhaust our knowledge about family as a research subject. In Brazil, there are numerous studies focusing on cultural determinants, the study of which aims to provide insight into a family's identity constructed within the framework of patriarchy. Microsociology, which gives priority to the observation of families “from within”, has contributed significantly to this body of research (Costa, 2011). In this context, we wish to highlight the contribution of studies focusing on family dynamics, carried out in recent years in Portugal, analysing types of family interactions (Aboim & Wall, 2002). The results of one of these studies, focusing on Portuguese families, led to identification of six types of interactions.

The study also demonstrated that there is now a significant plurality of home and family life forms (Aboim & Wall, 2002). Other Portuguese studies revealed that relationships and identities pertaining to family life can change as a result of various events, such as the birth of a child or the illness of a family member. Family-related research focusing on satisfaction spheres and key moments in the lives of women-respondents demonstrated that such moments include childbirth, starting family life with a partner, and the illness or death of a loved one (Aboim, Cunha, & Vasconcelos, 2005).

Chronic illnesses and hospitalization

We know that chronic non-communicable diseases (NCDs) not only cause significant number of premature deaths, but also reduce the quality of lives among the survivors, impose limits on work and leisure activities, and have an economic impact on families, small communities and the society as a whole. In Brazil, these diseases are among the most common causes of hospitalization, but they also make social inequalities and poverty more acute (Ministério da Saúde, 2011).

Chronic illness, although it involves a change in the patient's way of life, creating the need for counselling, care, health monitoring and previously unimaginable restrictions and limitations, also provides an opportunity to learn and engage in new interactions. Coming to terms with chronic illness is not easy, as it poses a threat to life and well-being, but striving for acceptance and living with the disease in the best possible way can help develop new perspectives and open up new possibilities (Araújo et al., 2011). Chronic disease is in fact embedded in a context characterized by a variable complexity, where periods of relative calm alternate with periods of deteriorating clinical prognosis for the patient, which may lead to long hospitalization necessary to restore balance (Campos et al., 2011; Freitas & Mendes, 2007). Therefore, living with an illness is one of the forms of human life (Sato et al., 2012). Research with hospitalized adolescents has shown that the respondents do not always feel sick, as there are remission periods, and anyway, they may have experienced bad health from birth. Thus, chronic illness does not always mean that an individual feels sick. And even though they need to undergo treatment, endure the restrictions, they may also benefit from the opportunities that present themselves as their illness becomes a way of life (Maia Neto, 2003). Although living with an illness requires special care, because of poor health, the patient's life may also abound in ordinary pleasures and disappointments.

It is widely accepted that discussion about chronic illnesses must include the patients' point of view, because apart from the interpretative idiosyncrasies, it involves various situational and cultural factors, specific for a given social structure, including the way in which it organizes medical care, knowledge in which it is grounded, and information provided by the media, shaping the construal of

non-expert representations of disease (Canesqui, 2007). Chronic illness requires internal and external reorganization because it consists of physical and emotional transformations, and their confirmation by other people observing the person who is being ill (except for individuals in complete isolation). Suffering is experienced as a condition leading to a reduced agency of individuals (Costa, Jacquet, 2006), and confirmation of the changes that occur is usually obtained by consensus among all those involved, who are aware of what constitutes health and what signs and symptoms indicate abnormal states (Helman, 2009).

It has been noted that while seeking hospital care, the sick person is also co-opting attention – through his or her biological body, which is showing signs and symptoms of the disease, indicating the need for intervention, advice and care – of their family, which is inevitably affected and which participates in the illness, hospitalization and recovery. Also, during the period of hospitalization, the health care professionals share in the suffering, although their primary focus is to deliver necessary procedures, provide care and advice (Amin, 2001), in line with the organizational requirements of the hospital as an institution.

On the one hand, the hospital – which appears to be a place providing professional scientific and technical care – offers patients and their families some kind of relief, but on the other hand, its organization is governed by norms and procedures that are unfamiliar to the family, which causes anxiety, uncertainty and confusion. Fulfilling the purpose of attending to the physical, emotional and social needs of individuals, a hospital is an organization of great complexity, involving technical equipment, the need for personalized services and, more recently, an awareness that no sole professional group has the knowledge necessary to sufficiently respond to the patient's social and cultural needs (Alves et al., 2005). Even though the patient temporarily suspends his or her life projects during hospitalization, he or she needs guidance and assistance from the family in dealing with this new organization. A family member who accompanies the “patient” in the hospital begins to follow hospital norms and routines, is exposed to culturally alien smells and moods, which often gives rise to embarrassment and shame. Moreover, the privacy of both family members and patients is compromised during hygienic procedures performed for the loved one, combined with the pain and shame experienced during examinations, treatments, dressing changes, etc. This happens because people, whenever they are forced to abandon their old habits and customary behaviour, are always at risk of losing their self-image. In the physical space of the hospital this is more likely to occur, since such space is experienced by the patient as a kind of “non-place”, lacking identity and depriving the patient of their identity: confined, white spaces filled with equipment, beds occupied by other patients, healthcare professionals delivering care, treatment and counselling, and the family shrunk to a sole accompanying family member.

Research methods

In terms of methodology, we present an empirical exploratory study grounded in the qualitative research model, conducted in a single hospital ward. The hospital where the research took place is a public general hospital located in the city of Feira de Santana in the Brazilian state of Bahia, fully funded by the Brazilian Uniform Health Care System (SUS). Participants in the study – patients' family members – were preselected using a list of hospitalized patients drawn by a ward nurse, and then selected based on the patients' medical records. Some families were recruited through conversations initiated in the corridors and rooms of the ward, so as to supplement data derived from medical records. During the second or third meeting with the families, we invited family members to participate in the study and, if they agreed, asked them to read and sign the Voluntary and Informed Consent Form (ICF). We interviewed 14 families, in some cases the interviews involved more than one relative, giving a total of 18 interviews. For the purposes of our analysis, in this article we identified two categories emerging from the narratives of four family members: "Accompanying and care as mutual support" and "Accompanying and care as obligation".

Family members' narratives

Care activities and custody of life are the foundations of all cultures. Since the beginning of human history, people have strived for survival. It is precisely this imperative of care for life and taking the steps necessary to sustain life, that gives rise to and triggers the development of all modes of action and forms of knowledge from which views and types of social organization originate (Collière, 2003). However, the family care that the patient has experienced before hospitalization is taking on a new shape, as it is now situated within an unfamiliar environment and subject to the rules imposed by scientific expertise.

Accompanying and care as mutual support. Faced with an illness, the family must reorganize its life to be able to live with illness and its consequences (Motta, 2002, p. 158). For some family members who accompany the sick person, re-organizing life means staying in the hospital for the entire period of treatment in order to carefully observe the patient's condition and the healthcare provided by medical personnel. We should note that staying with the patient fosters a sense of well-being despite the inconveniences suffered by the accompanying family members. Such family members often report feeling physical fatigue and sleepiness. Other unpleasant symptoms include swelling of the lower limbs, blood pressure irregularities and suffering caused by witnessing the pain and death in the hospital ward. Social and economic circumstances also make it difficult for family members to stay in the hospital. On the other hand, noticing physical and emotional symptoms of the patient's

recovery increases the well-being of some accompanying family members. In such cases, being present can bring relief and comfort, even in difficult circumstances.

The narratives we have identified in this category enable us to interpret family care and the care provided by medical staff in the hospital ward in terms of mutually satisfying support. It was expressed in the following statement:

if I had a way to get here, I swear, I would be here every day and just leave for the night [...] but the thing is, I can't. I feel really bad when I'm there – at home – and not here, it's no problem, it is enough for me to be with him to feel good. Today, for example, I arrived, and I was very happy to see him, he looks completely different. When I stay at home, I feel worse, [...] I talk here, I don't enter his room, I put both chairs, one for the shower and the other one, in the bathroom, I opened the curtain, so that now I see if he's calling me [...]. (63-year-old woman).

It has been noted that sickness and imminence of death often enable family members to come together and increase their desire to be close. While they provided care for an ill family member, the respondents noticed and verbalized their sense of empowerment. Assisting others alleviates suffering and helps to cope with adversity. Being an accompanying family member enables people to bond and reduces their feeling of guilt in case of the patient's death, as they believe that they devoted attention to the sick family member and have done all that was humanly possible.

I'm at hand at all times, you know, with him, [...] by doing this, I feel good, because one day I'll know that I've done everything I can for him, so, I don't know when, but one day, when he's gone, when he dies, I'll have this feeling, for myself, I'll feel that I've done my best, that I've sacrificed everything, so it'll be easier for me, I mean with this absence [...] the feelings [...] it is something that shifts the family's life, [...] the opportunity to look after gives strength [...].] opportunity to be here, I am a person who wants to see it all, even if I can't do much, it's the contact itself, [...] my presence here helps me, gives me some comfort, so much so that when his heart fails and they take him downstairs from the ward, to the ER or the intensive care unit so that they can take better care of him, and I can't be there, I feel, I'm more worried, I'm more tense, so when I'm at the bedside, I'm calmer. (33-year-old man).

In the narrative presented below, the respondent focused on care as an activity requiring responsibility and devotion, triggering a sense of pride contributing to a specific kind of happiness.

At home I am taking good care of him, when he asks me to "cut his nails" I cut them, "trim my nose and ear hair" I go ahead and do it, it is the same in the hospital, just yesterday, I trimmed a hair in his ear. When I am taking care of my grandpa, I am happy, I am proud that I do it, he is my grandpa, you know. [...]

my grandpa, who used to take care of me, in fact, it was him who looked after me [...]. (22-year-old woman).

Accompanying and care as obligation. *Care*³, as an appropriate reaction to the weakness of another person occurs in situations where there is an interaction, and the care-provider feels responsible (Molinier, 2012, p. 32). With regard to our second category, “accompaniment and care as obligation”, our analysis of the narratives indicated that family members sometimes decide to accompany and care for the patient because of a sense of moral obligation. Other studies involving spouses caring for their partners suffering from chronic illness also demonstrated that care was understood as moral obligation (Amorim et al., 2014). For some people, however, caring for the patient is an obligation that also causes suffering and dissatisfaction.

I don't like it, I don't feel good taking care of a sick person, [...]. Neither here, nor anywhere else. I don't like it, do you understand? Yes, I do it, out of necessity, but I don't feel good about it, not at all. [...] if he were a stranger, I would look after him, but I wouldn't like it [...] he is my father. I have to look after him, because he is my father, it is my blood, [...]. I would never have forsaken him, even if somebody forced me to leave him, I wouldn't, I have to look after him (45-year-old woman).

Such attitude may stem from different reasons. Angelo Soares (2012) believes that care dimensions should be analysed in relation to the corporeality of both the care-provider and the recipient of care, as the inevitable bodily contact with another person is a typical element of care activities. Such bodily contact occurs while changing diapers, bathing, washing intimate parts of the body, etc. These activities are unpleasant. Accompanying and caring for the sick person can, therefore, cause unhappiness and suffering for those who need care, as well as for those who provide it.

Conclusions

It is assumed that a family is a social structure whose aim is to care for its members and support them from birth to death. In general, the family members are responsible for physical, emotional and personal development of their loved ones. With regard to health care, the family is present almost all the time, devoting their attention to sustaining life either by means of ordinary care that meets basic human needs: food, hygiene, rest, etc., or by seeking professional care focusing on restoring health, disease prevention and treatment.

³ The Portuguese expressions for “care, guardianship, looking after, attention” cannot fully render the meaning of the English term “care”, which resists translation due to its polysemic nature, with its definition invoking simultaneously an “attitude” and “actions” related to looking after others, caring for them, attention to and the wish to satisfy their needs, etc. (Hirata & Guimarães, 2012).

Illness is the moment when social ties within a family become stronger. Conflicts and disputes, and solidarity are two sides of the same coin – they are intertwined or crystallize, but above all, give rise to specific, sometimes alternative family relationships that either favour the healing process of the sick person or they do not. Illness usually disrupts reciprocity, undermines solidarity, and creates misery that permeates human relationships. But also, paradoxically, it mobilizes networks of support, assisting competences, feelings and experiences. The analysis of narratives focusing on the experience of illness and care reveals tensions that abound in the process of health and illness. Therefore, a dialogue between caregivers, family members and medical staff should take place on a plane of partnership and non-hierarchical relations. It is important for healthcare professionals to realize that families living with chronic illness are also at risk and need support. Medical professionals can help members of such families by counselling them about strategies that will benefit their health and reduce tension associated with the illness affecting the Other.

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