

FEMALE CAREGIVERS ACCOMPANYING CHILDREN WITH CANCER IN THE HOSPITAL SETTING^a

Wiliam WEGNER^b, Eva Neri Rubim PEDRO^c

ABSTRACT

The possibility of having a companion is a constitutional right guaranteed to children, elderly and parturients. Independently of their stage in the life cycle, having a companion is a situation socially and culturally determined in Brazil. This is a qualitative, descriptive-exploratory and interventionist study that aims to describe and discuss the perceptions of female caregivers of children with cancer while accompanying them at the hospital. Data were collected through a focal group with nine women, between March and May, 2007 at a teaching hospital in Porto Alegre, Rio Grande do Sul, Brazil. The thematic analyses shows the participants' passive and kind behavior in the face of daily adversities, reflection of the power and authority conditions of the institutional objectives, so common in health scenarios in the Brazilian reality. Emancipation could be reached through educative strategies, characterized by information and dissemination of users' rights as well as critical and demanding attitudes from the user when confronted.

Descriptors: Caregivers. Patient escort service. Child, hospitalized. Neoplasms. Health education.

RESUMO

A possibilidade de ter um acompanhante na internação hospitalar é um direito constitucional garantido para crianças, idosos e parturientes. Independente da etapa do ciclo vital, ter um acompanhante é uma situação socialmente e culturalmente determinada no Brasil. Trata-se de uma pesquisa qualitativa descritiva-exploratória e intervencionista que descreveu e discutiu as percepções das cuidadoras de crianças com câncer, enquanto acompanhantes no hospital. Os dados foram coletados mediante grupo focal com nove mulheres entre março e maio de 2007 em um hospital-escola na cidade de Porto Alegre, Rio Grande do Sul, Brasil. A análise temática das informações mostrou a conduta passiva e dócil das acompanhantes frente as adversidades cotidianas, reflexo das próprias condições de poder e autoridade dos objetivos institucionais, tão comuns nos cenários que desenvolvem ações de saúde na realidade brasileira. A emancipação poderia ser alcançada por meio de estratégias educativas caracterizadas pela informação e divulgação dos direitos do usuário e posturas críticas e reivindicatórias quando confrontados.

Descritores: Cuidadores. Acompanhantes de pacientes. Criança hospitalizada. Neoplasias. Educação em saúde.

Título: As mulheres cuidadoras-leigas acompanhantes de crianças com câncer no contexto hospitalar.

RESUMEN

La posibilidad de tener un acompañante es un derecho constitucional garantizado a los niños, ancianos y mujeres embarazadas. Independientemente de la etapa del ciclo de vida, tener un acompañante es una situación social y culturalmente determinado en el Brasil. Es un estudio cualitativo descriptivo y exploratorio y de la intervención que tuvo como objetivo describir y analizar las percepciones de las mujeres cuidadoras de niños con cáncer, como acompañantes en el hospital. Los datos fueron colectados a través de grupos focales con nueve mujeres, entre marzo y mayo de 2007 en un hospital de enseñanza en Porto Alegre, Rio Grande do Sul, Brasil. El análisis de la información mostró que el comportamiento de los acompañantes es pasivo y dócil ante la adversidad cotidiana lo que refleja las condiciones reales de poder y autoridad de los objetivos institucionales, tan común en los escenarios donde se desarrollan las acciones de salud en la realidad brasileña. La emancipación se podría lograr a través de estrategias de educación se caracteriza por la información y la divulgación de los derechos de usuario y las posiciones de crítica y exigente cuando se enfrenta.

Descriptores: Cuidadores. Acompañantes de pacientes. Niño hospitalizado. Neoplasias. Educación en salud.

Título: Mujeres cuidadoras, no profesionales, acompañantes de niños con cáncer en el contexto hospitalario.

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^b RN, Master in Nursing, Doctoral Student at PPGENF/UFRGS, Full Professor in Nursing Graduate at *Centro Universitário Metodista IPA*, Porto Alegre, Rio Grande do Sul, Brazil.

^c RN, Ph.D. in Education, Associate Professor at *Escola de Enfermagem* of UFRGS, Porto Alegre, Rio Grande do Sul, Brazil.

INTRODUCTION

The possibility of having a companion is a constitutional right guaranteed to children, elderly and parturients, when they present changes in their well-being and balance conditions. Independently of their stage in the life cycle, having a companion is a situation socially and culturally determined in Brazil. When talking about children, the companion also represents the main informal caregiver, that is, the mother figure.

The invisibility of the female caregiver presents two meanings: the first is reproduced by herself, who puts the child first; the second by health professionals, who frequently see the companion as a present body only. The work of informal caregivers is neither perceived nor socially acknowledged. This invisibility can be due to the female and domestic character attributed to the care, that is, it is considered women's work, naturally and socially expected⁽¹⁾.

This article is part of a qualitative research carried out during a Nursing Master's Program in Porto Alegre, Rio Grande do Sul, Brazil⁽²⁾. The authors, along their academic and professional trajectories, observed that female caregivers apparently abandon, partially or completely, care for their own health in order to only and exclusively dedicate themselves to the hospitalized child. Caregivers are people who take care of sick people, whether in hospital or at home, but perform their activities without any remuneration or formal education to exercise this function⁽³⁾.

The importance of the caregiver is very relevant, especially in cases of cancer. In societies where parents learn to participate in their children's care process, children live more. This participation includes seeking information about the disease, symptoms and support therapies⁽⁴⁾.

Historically, the hospital-centered model, typical in Brazil, is not concerned with the companion, so this discussion is recent. This institutionalized and fragmented care has been reproducing an unequal and unfair care model, typical of capitalism⁽⁵⁾.

Female caregivers admit that hospital norms are rigid and one-directional because professionals strictly follow imposed routines and demand their compliance. However, they remind that the de-institutionalization and movements in favor of care humanization allow for the reversal of actions and

practices that decharacterize integral care to patient and family. The hospital-centered model still persists in health institutions and reproduces practices that decharacterize the user, who is seen as a mere object of professional practices, and the family is often considered as a demand and co-participant in the process.

This gave rise to many questions: What are these women's conceptions of health? How were their lives before the child's disease? Do they take care of themselves? How do they take care of themselves? What are the health needs of female caregivers who stay by the sick child's side? Another question is related to these female caregivers' options to perform their own care. Are there alternatives to perform it?

When taking care of her hospitalized child, the mother abandons all activities and dedicates herself exclusively to the sick child, which causes intra and extra family difficulties. However, support actions are scarce and interventions need to be implemented in order to solve this situation⁽⁶⁾. Female caregivers report their desire to cooperate in care for the hospitalized child, but expect an analogous opportunity for themselves, especially when they verbalize their difficulties and need for support and help. It was observed in the discussions that professionals undervalue the complaints of companions, which evidences the model of care focused on the child and has showed itself incompatible with the guidelines of family care integrality.

The relevance of this study consists in providing health professionals, directly involved with health promotion, with knowledge regarding health conceptions of female caregivers of children in oncological treatment; in offering strategies to professionals on their specific care needs, for the teaching of nursing and other professions in health, education and human areas.

This study aimed to describe and discuss perceptions of female caregivers of children with cancer as companions in the hospital setting.

METHODOLOGY

It's a qualitative study with a descriptive-exploratory and interventionist design⁽⁷⁾. The choice of the study type was determined by the need to primarily describe the phenomenon in all its aspects of scientific relevance and then explore

its complexity. However, the descriptive-exploratory research could not offer support to intervene in emergent problems and would not propose alternatives for change. There is an interventionist character in the focus group. At the same time as discussion and reflection on the theme are promoted, subjects tend to develop strategies to solve their problems through alternatives that can modify or improve the reality studied.

The participants of this study were nine female caregivers of children in oncological treatment who were accompanying the child at the moment of selection of subjects in the Pediatric Oncological Unit. The selection of participants was intentional through the indication of a key informant (nurse at work). The inclusion criteria were: older than 18 years, accompanying the child at the moment of selection, availability to participate in the study and having full knowledge of the disease diagnosis for more than six months.

Data were collected through Focus Groups which is an investigation technique that collects information through group interaction on a topic pre-determined by the researcher⁽⁸⁾. This technique was chosen to collect information because of the researcher's need to understand the phenomenon in a broader way from group discussions and (re) formulation of conceptions through reflection in the group space. The meetings were held at the Hospital das Clínicas of Porto Alegre, Rio Grande do Sul, Brazil, in a room designated and authorized by the hospital management. Six group meetings were held according to the researcher's previous planning, which met the study objectives. The average duration of each meeting varied between one hour and one hour and a half. The meetings were recorded in order to apprehend the whole phenomenon. The researcher himself conducted the meetings. The theme developed in each focus group were: the woman's social role as caregiver, health as a value related to culture, health of women before and after the children's disease, the care of oneself and its relation in meeting basic needs and proposals to reach care. Afterwards, the information was transcribed and documented literally as the participants reported.

For the organization and coding of the material, QSR Nvivo version 2.0 software was used as a facilitating tool in the grouping of collected data. The focus groups were coded by the letter G and the numerical algorithms corresponding to

the number of the meeting. Thus, G1 represents Focus Group 1 and so on. The participants are indicated by the letter P and the numbers serve only to identify and differentiate them. After concluding the organization and data coding stage, the researcher initiated the analysis and interpretation of categories that emerged by means of thematic analysis⁽⁹⁾.

Bioethical guidelines were respected, according to Resolution 196/96 by the National Health Council – Guidelines for Research Involving Human Beings⁽¹⁰⁾. Data collection started after the project had been approved by the Graduate Research Group at the Porto Alegre Hospital das Clínicas, number 06-135. The researcher invited participants to take part in the study, informed and explained its justification, objectives and the way they would participate. It was also clarified that their participation would be voluntary and that they would be able to quit at any of the stages proposed, without any negative effect for themselves or the child in treatment at the hospital. All participants signed the Free and Informed Consent.

FINDINGS AND DISCUSSION

The data analysis evidenced five categories and subcategories. One category will be presented in this article: The Companion and Perceptions in the Hospital setting and its Subcategories: Perceptions on the Companion's Situation; Expectations for the Future; Female Caregivers Religiosity.

Perception on the Companion's situation

The participants report several situations in which they believe immediate action is necessary, so as to regain their happiness projects and live, in a less traumatic way, with the child's hospitalization. All of them mention that the concern during the hospitalization is directed at the child, especially because the team is specialized in the child's care, which they indicate as important and necessary.

In cultural terms, the mother's figure is frequently related to tremendous strength, a tireless warrior, maybe even unaffected by suffering, or at least well structured in the face of society. Then, when a child gets ill, even without

showing signs of tiredness because of the child's care, similar behavior is expected. However, it is known that all human beings have limits, needs and sensitiveness. The reports confirm that:

It's only that with the mothers they [professionals] don't worry much, I think that there should be more concern in relation to the mothers (G1P7).

We are there, taking care and we are also human beings, we also have pain, we also get sick (G1P6).

The daily routine of the children's companions at the hospital is a factor that makes them vulnerable to the development of problems in terms of physical and emotional health, especially because of the lack of activities to fill part of their time. Some activity would prevent them from staying with the child full-time and thinking continuously about the child's disease and family problems. These aspects are mentioned as possible triggers of changes in the participants' well-being and equilibrium of the participants, who admit the possibility of getting sick. The difficulties experienced by the mothers mean they feel the need to be taken care of, as a consequence of their involvement in care for the hospitalized child, which turns them into patients^(4,11,12).

However, the participants are afraid of getting ill and are concerned with this possibility because they know that care, compatible to their needs, will hardly be provided, and also because of their exclusive dedication to the hospitalized child, who needs maternal care. This ambivalence affects the psychological well-being of female caregivers, who do not allow themselves to exhaust their capacity of caring for the child and deny themselves as human beings, whose immediate needs have to be attended to (rest, food, comfort, listening, analgesia, access to health services, leisure, among others).

In some situations, the participants complained of the scarce opportunities they were offered in the hospital setting. They mentioned that the professionals supposed to attend them did not meet their needs for care and attention. The programs and care delivered (programs of support to families, psychological care, evaluation by the social service, among others) should be structured in the professionals and in what they believe is important for the companions. This

practice can be common for some nurses and part of their daily work, but there is huge resistance by others to include parents in their care planning as possible patients.

However, it is reminded that health care must be planned from the user's demands, considering the uniqueness of each person. The female caregivers seek mutual support to get comfort in moments of crisis and despair. The reports illustrate some situations:

There should be a psychological follow-up since the beginning [...] a program to follow, especially us [...] we don't have anybody to help us, one supports the other, I always get along with everybody, but there are some [women] who don't care (G1P4).

We should have a physician for whenever we need one, or when in an emergency, with a reference, we could like stop by, because the children cannot stay by themselves (G1P6).

Another important issue for them is related to the recognition of their role during hospitalization and in their housework routine, which corresponds to the mother's care for the child, which is many times shared by the health team. The caregivers' work usually is not perceived and is not socially acknowledged. There is a relation between the female and domestic character of care^(1,13).

Staying in the hospital setting seems to be the main aspect determining alterations in the participants' health, because they live daily with the expectation of losing their children and also because they are distant from their home and family. In hospitals, several mechanisms have been frequently observed to enforce disciplinary power and exert control on the clients' bodies, especially because the professionals determine rules and standards of living which the service users should passively observe⁽¹⁴⁾. When there is any complaint from a companion, negligence and lack of competence by professionals in meeting these demands are observed. The statements below evidence some situations the participants expressed:

A person with high pressure has to have someone to take care of her; they've got to take care of people who are here, because they are not sick out there, but they get sick when they get here (G2P4).

Yeah, the children's care is very good, we have nothing to complain about, excellent, they do their part very well! The team's lack of interest is with us (G2P6)!

According to the companion's point of view, the child's care was considered adequate and even received compliments. However, the lack of interest happens with the companion, who divides the responsibility for several aspects of care with the health team, usually imposed and demanded when not performed by the female caregiver. It can be inferred here that the inclusion of the companion in care practice by the professionals is yet something to be reflected on. Solutions need to be searched in the attempt to minimize situations that generate conflicts in the care environment. Obviously, both parts must be heard, so that advancement in these issues and proposals can be reached. Family companions are concerned with meeting the patients' needs, have the opportunity to follow the health team's work performed and express different feelings about the care that is delivered (fear, insecurity to assume certain procedures and pleasure and satisfaction with being able to help)^(13,15).

The health team denies clients the right to autonomy when they are kept alienated about their health condition and the procedures performed in their bodies. The professionals seem to assume authoritarian attitudes, giving orders and determining actions understood as unquestionable⁽¹⁴⁾.

In this context, it is worth mentioning the reports regarding food, for instance, when they say their opinions and desires are not considered as companions, it is perceived that they have to submit to and passively accept what is imposed. When they were at home, they had autonomy and options but, out of their context, they need to fit in. The reports confirm this:

Then, you go to the kitchen and there is something you don't like and end up eating something elsewhere, anything (G4P9).

At home, we eat what we want, what we like, what we like to eat (G4P1)!

When the participants left their community and home to accompany their sick child in a new context and situation, the strictness and regulatory power of health institutions is perceived, as

imposition is prevalent, contradicting dialogical and collective problem solving.

Female caregivers somatize many situations and present oscillations in their health status according to the child's status. When a child is hospitalized, all family members are equally affected⁽¹⁶⁾. Many times, the professionals, when informing the mothers about the possibility of unsuccessful treatment and appointing possible advances or backlashes in the disease trajectory, do not perceive how well the mothers understand or assimilate their observations. In the mother's perception, it was revealed as a discomfort, a nuisance, because in a certain period of the natural history of a severe disease, they expect care specific to the unique situation of their children, that is, individualized care. Attitudes and postures like these favor alterations in the emotional health of female caregivers. Their reports clarify this:

If the child is well, the mother is also well, and if they feel bad, so do we (G3P2)!

What bothers you is when they keep saying the same thing over and over, saying that it doesn't help, that the child will not get better (G3P9).

These women face an often long hospitalization, coming from distant places, are involved in a difficult process of acceptance, which is child cancer, and see themselves exposed to hospital norms and routines, assuming the role of caregiver/companion. Thus, a "new" demand was identified, vulnerable to a series of events that modify the whole context of life and health. On the other hand, the majority of professionals try not to get involved with these people and continue to reproduce a care based on the Cartesian and imposing model, decharacterizing care integrality.

Expectations for the future

Participants show confidence regarding their child's health recovery and, consequently, expect that their health will also go back to levels of well-being and balance according to their needs. Despite experiencing extremes and instabilities, all believe in a future according to their individual projects of happiness. The return to daily routines experienced before the child's hospitalization is the main objective they devise. According to the reports:

I think everything is going back to normal! I want to work. Our routine makes us better. The school schedule, we know we have to prepare lunch, we miss it! Having a normal life! I've always been a dedicated mother, I like to take them to school, to talk, to be in touch with teachers, know whether my child is doing well, if he got a bad grade, I've always liked it (G3P7).

Hopelessness is a feeling not very present in the female caregivers. They create strategies to always believe in the improvement and cure of their child, in order to return to family life. Work is a production form the participants want upon their return to their lives after the experience of accompanying their hospitalized child. Each participant has devised her project of happiness as a strategy to return to her life and health in different senses after the group meetings, so optimism and persistence are virtues that permit their reflection.

Women are increasingly inserted in the job market very early and the active/productive life represents the foundation of their future around which there will be changes in the family dynamics. There are North-American programs that favor female caregivers, reducing their workload so they can dedicate part of their time to take care of some dependent relative and also to receive financial incentive to continue their practice⁽¹⁷⁾. In the meantime, informal caregivers in Brazil usually become invisible and discouraged to continue taking care of relatives because they do not even get attention when they ask for it.

Female caregivers' religiosity

Religion plays an important role in the human being's moral, ethical and cultural formation, providing an understanding of the reality experienced and its essential objectives. The trust parents have in God and the spiritual comfort that makes them calm is notable. It gives them tools to overcome the situation experienced through the child's hospitalization⁽¹⁶⁾. Female caregivers present religiosity and belief in God as hope for the cure of their child and also as a way of seeking strength to survive the adversities presented while accompanying the child. Faith in God and prayers are strategies participants consider as a way of taking care of themselves. Religiosity can represent a form of care for oneself proposed by these female caregivers. Their reports confirm that:

I think faith is everything! Believing in a God. We have to hold on to a God (G4P9).

Culturally, religiosity is a strategy largely observed in hospitalized patients' companions. Cure by faith is present in different cultures and there is a symbolic component with rituals that permit cure⁽¹⁸⁾.

Spirituality is also an aspect strongly identified in these caregivers. It can be understood as a set of qualities of spirit such as: love, compassion, patience, tolerance, forgiveness, joy, responsibility and harmony with oneself and with others⁽¹⁹⁾. The participants develop their spirituality in daily care for the child with cancer and in living with other female caregivers, strengthening their psychological health to face the difficulties imposed by life.

Therefore, belief needs to be reinforced in companions who use it as a strategy to get comfort and overcome the difficulties faced. Health professionals in general, more specifically in the nursing area, have the means to know or even to identify beliefs and cultural differences of each companion. The free exercise of religiosity for female caregivers can provide them well-being and equilibrium in the context they experience.

CONCLUSION

In the pediatric hospital setting, the companion reflects a right legally guaranteed to the family, though out of context or, maybe, distorted by health institutions in Brazil. It reflects a macro structural problem linked to public health policies, to institutions, and also to health professionals who reproduce the centralization of disease and usually ignore those involved. The companions are usually included in the patient's care in an impositive way, especially by nurses who delegate tasks and care which are, many times, of their competence. It is perceived that companions/caregivers accept this imposition, although they demand an opportunity to take care of themselves when they feel this need.

This study showed the passive and kind behavior of participants in the face of daily complicators, reflections of the power and authority conditions of the institution objectives, so common in the scenarios where health actions are developed. Emancipation could be reached

through educative strategies, characterized by information and dissemination of users' rights and critical and demanding postures when confronted.

Finally, it is believed that new ways point to transformations in practices and policies that depend on the will of governors, legislators, managers, faculty, professionals, that is, political will in important segments of the Brazilian society.

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Author's address / Endereço do autor / Dirección del autor:

William Wegner
Rua Jacinto Gomes, 635, ap. 202, Santana
90040-270, Porto Alegre, RS
E-mail: wiliamwegner@yahoo.com.br

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