

HEALTH CONCEPTIONS UNDER THE PERSPECTIVE OF LAY CAREGIVER WOMEN ACCOMPANYING HOSPITALIZED CHILDREN

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This study aims to present and discuss part of the findings of a research carried out at a teaching hospital. It is a qualitative descriptive-exploratory and interventionist study with nine lay caregiver women accompanying hospitalized children with cancer. Data were collected through the focal group technique, organized in the QSR Nvivo software and analyzed through thematic analysis. Results originated during the discussion on participants' health conceptions indicate the need to (re)think the rights of patients' companions and provide instruments to several social, political and institutional stakeholders in order to (re)plan health actions that can be developed during professionals' education and qualification in the context of health care, which can be the focus of discussion within diverse contexts of society.

DESCRIPTORS: caregivers; health education; health promotion; patient escort service; health public policy; nursing; health; child hospitalized

CONCEPCIONES DE SALUD SEGÚN MUJERES CUIDADORAS, NO PROFESIONALES, ACOMPAÑANTES DE NIÑOS HOSPITALIZADOS

El objetivo es presentar y discutir una parte de los resultados de una investigación realizada en un hospital escuela. Se trata de un estudio cualitativo, descriptivo exploratorio e intervencionista realizado en nueve mujeres cuidadoras, no profesionales, acompañantes de niños hospitalizados con cáncer. Los datos fueron recolectados por medio de la técnica de grupo focal, organizados por el software QSR Nvivo y analizados mediante análisis temático. Los resultados provenientes de la problematización de las concepciones de salud de las participantes, apuntaron para la necesidad de repensar los derechos del acompañante y la instrumentalización de los diversos segmentos sociales, políticos e institucionales para replantear las acciones en salud que pueden ser desarrolladas en la formación y calificación de los profesionales, dentro del contexto de la atención a la salud, así como ser foco de discusión en diferentes contextos de la sociedad.

DESCRIPTORES: cuidadores; educación en salud; promoción de la salud; acompañantes de pacientes; políticas públicas de salud; enfermería; salud; niño hospitalizado

CONCEPÇÕES DE SAÚDE SOB A ÓTICA DE MULHERES CUIDADORAS-LEIGAS, ACOMPANHANTES DE CRIANÇAS HOSPITALIZADAS

Objetiva-se apresentar e discutir uma parte dos achados de investigação realizada em um hospital escola. É um estudo qualitativo descritivo-exploratório e intervencionista junto a nove mulheres cuidadoras-leigas, acompanhantes de crianças com câncer, hospitalizadas. Os dados foram coletados por meio da técnica de grupo focal, organizados pelo software QSR Nvivo e analisados mediante análise temática. Os resultados, provenientes da problematização das concepções de saúde das participantes, apontaram para a necessidade de um (re)pensar os direitos do acompanhante e a instrumentalização dos diversos segmentos sociais, políticos e institucionais no (re)planejamento das ações em saúde, que podem ser desenvolvidas desde a formação e qualificação dos profissionais, nos contextos de atenção à saúde, assim como, também, podem ser foco de discussão em diferentes contextos da sociedade.

DESCRIPTORES: cuidadores; educação em saúde; promoção da saúde; acompanhantes de pacientes; políticas públicas de saúde; enfermagem; saúde; criança hospitalizada

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INTRODUCTION

Nurses and college professors, working in the child and family care area, have experienced, on a daily basis, certain situations in the context where they develop their professional activities. It has been perceived that, apparently, female lay caregivers, companions of hospitalized children, partially or completely abandon self-care to exclusively dedicate themselves to the sick child. Lay caregivers are people who deliver care to the sick, whether in hospital or at home, but perform their activities without specialized education or remuneration for such work⁽¹⁾. Caregivers face difficulties because the health system does not provide care to companions, i.e. people who participate in the care of relatives, and health policies do not even give them any alternative. Some institutions' rigidity and lack of flexibility is frequently observed in care delivery to companions of hospitalized children, when the caregiver presents signs of disease or searches for information and referrals. Health professionals, in turn, neither present nor even discuss strategies to facilitate these companions' access to services. On the other hand, it seems difficult to discuss the implementation of companions in health programs if public health policies including them in care planning are not available. This observation oftentimes makes health professionals feel powerless in the face of the reality presented in their daily routine.

The family is the main institution delivering care to a sick family member and can reduce disorders caused by hospitalization and minimize harm of frequent hospitalizations, like in the case of children with cancer. For this reason, nurses consider family care as a resource to enlarge their level of health care⁽²⁾. When one talks about family care, the mother is the most mentioned figure, especially when the patient is a child. Thus, it is the health team's role to deliver care to this facilitator of children's care⁽³⁾.

In this scenario, many questions emerged: What are these women's health conceptions? How were their lives before their child's disease? What about now, what has changed? Do they take care of themselves? What are the health needs of lay-caregiver women who stay beside the sick child? What did they do and what are they currently doing to take care of themselves? What actions would be important to change this situation? We question if they "left their health care aside" and what are the factors that affect their life style. It is known that women are capable of abdicating

of their health in favor of a child under their care, but is the child's disease the only factor associated to this limitation? Another question is related to these women's options to develop their own care. Are there alternatives to perform it? It suggests this is an ample problem, related to the structural context of the current health system and to the technical care model. Analyzing women's social role and health as a value related to culture, we seek to investigate these issues that directly reflect on the social and structural context of our society. Health promotion is considered a viable alternative to change part of this behavior and solve some adversities faced by the health team when care is delivered to the dyad caregiver women/child with cancer. Health education could be the main strategy to improve participants' care.

One strategy is the model called radical health education, which prepares individuals to acquire critical awareness, so as to review values and concepts. It also proposes, through problemization, alternative strategies for lay caregivers and people towards a better life⁽¹⁾.

It is known that nurses, when delivering care to sick children, should extend it to their companions, who are co-participants in the hospitalization and oftentimes present behaviors susceptible to potential harm, similar to those of children but invisible to health care policies. Thus, if one thinks in terms of integrality, companions need to be taken into account and included in health care because the companion is part of the context of life and health of the hospitalized patient.

This study aims to present and discuss part of a research carried out at a large teaching hospital in Porto Alegre, RS, Brazil. The research project, result of a master's thesis, is entitled: *Women caregivers' health conceptions: strategies for health promotion*. The study objectives were: to know the health conceptions of women caregivers of children with cancer; to explore the conceptions of women lay caregivers of children with cancer, promoting a reflection on the real and idealized situations; to reflect and propose health education strategies based on aspects identified during the research.

METHOD

This is a descriptive-exploratory and interventionist study with a qualitative approach. It was developed at the Pediatric Cancer Unit (PCU -

3rd East) at Hospital das Clínicas in Porto Alegre (HCPA), between March and April 2007. Nine female lay caregivers with some degree of kinship with the child (eight mothers and one sister) participated in the study according to the following inclusion criteria: older than 18 years, more than six months of diagnosis, companion of the child at the moment of participant selection and availability to participate in the study.

Data collection was carried out through the focus group technique and identification form. The focus group technique is a kind of group interview. Its content is related to information that originates in discussions and reflections carried out through group interaction on a specific topic proposed by the researcher⁽⁴⁾. The identification form contains socio-demographic data and a profile of participants and their respective children. The objectives of the focus group technique are to reach the participants' collective thought, observe the emergence of contradictions and how they are resolved, and reproduce processes of group interaction that occur outside encounters⁽⁵⁾. Six encounters of variable duration were held according to the Focus Group Schedule, which put into operation data collection in the focus group technique.

Encounters were carried out at the hospital in an appropriate room reserved for group activity with the participants. In the first encounter, the researcher re-introduced the research project and clarified doubts regarding participation, discussed the participation contract and asked them to sign the free and informed consent term. Pre-established themes to orient the researcher during encounters were generated as from the second encounter. The themes of each encounter were: women's social role as caregivers in society (focus group 2); health as a value related to culture (focus group 3); the health of female lay caregivers: "before and after the child's disease" (focus group 4); self-care and repercussions in the attendance of basic needs of female lay caregivers (focus group 5); issues that interfere in female lay caregivers' self-care and proposals to achieve this care (focus group 6). An activity to stimulate debate and reflection was always presented, after which data collection was carried out based on collective discussion among participants on the proposed theme, that is, the discussion regarding topics generated by the activity was recorded. Stimulating activity is any action that mobilizes the group to consider and reflect

on a pre-established topic, which is then presented and discussed among the group participants and researcher. Group discussions were recorded and transcribed for analysis. Subjective information and that related to group interaction were apprehended by a research assistant previously trained to observe and facilitate the development of encounters, especially to control time and assure achievement of pre-established topics for debate.

To organize, codify material and facilitate the grouping of collected data, QSR Nvivo software version 2.0 was used. The use of the software does not compromise the qualitative research rigor, on the contrary, its use reinforces it, providing more details and clarity to the analysis process⁽⁶⁾. Qualitative data analysis was carried out through thematic analysis⁽⁷⁾, which was performed solely by the researcher. The software is used only to check information that can generate doubts during this stage. Bioethical issues were considered and employed according to the guidelines and standards for research involving human beings, based on Resolution 196/96, National Health Council⁽⁸⁾. The research was approved by the institution's Research Ethics Committee (N. 6-135) and all participants signed the free and informed consent term. In order to preserve participants' anonymity, the letter G added by a number representing the group encounters and P to represent participants were used.

RESULTS

Data collected from the identification form revealed that the female lay caregivers' age varied from 24 and 42 years; four of them had eight years of education (complete primary school) and five had less than seven years of education (incomplete primary school). Five came from the Metropolitan region of Porto Alegre, RS, Brazil and four from the interior of the State. Seven reported being unemployed and two were housewives; six lived with their partners and three had no partner. The frequency they went back home varied. Four reported going home monthly, three reported weekly, one every two weeks and one every two months. Regarding the number of children, five had more than three children, three women less than four children, and one of them, the one who is the sister of the hospitalized child, had one son. Family income ranged between 100 and 800 Reais (Brazilian currency).

The diverse roles assumed by mothers and exclusive dedication to the child/brother are valued and highlighted. According to participants, abandoning activities that are part of their life is secondary but care delivery is not transferred or shared. These issues were discussed during the focus group encounters, specially the search for alternatives that would allow these female lay caregivers to share the care delivered to the child with their family. According to the report: *there're women who abandon their job to take care, abandon everything to be there with them* (G1P3).

A participant summarized the health conception that would be shared along subsequent encounters, which was approved by the group and guided discussions: *the thing of happiness! If we aren't happy, we aren't healthy, you know* (G2P6).

All participants mentioned that the concern is focused on the child, especially because the team is specialized in the child's care, which they see as important and necessary. Some believe that, oftentimes, some of the professionals' conducts are inconsiderate. They believe these professionals do not perceive them as humans, citizens, according to the following report: *we're there taking care and we're also human beings, we also feel pain, get sick* (G1P6).

The participants listed some desired activities as health promotion strategies that would allow them to promote health and quality of life. Reports listed some activities: *to have some time just for us. Be able to talk, laugh, not just talk about the disease! Like, one who has some ability could teach the others [...] to have some people to take care of us! To have the hair dyed, have a manicure; cheer up our self-esteem* (G5P3).

DISCUSSION

The highlighted characteristics contextualized problems discussed and confirmed in literature, that is, all were women (mothers/sister), with limited educational level, unemployed and with insufficient financial resources. Their stage of development also caught our attention because all of them could be classified as young adults. Based on this information, we stress the social vulnerability these lay caregivers are exposed to. This vulnerability makes them susceptible to disarrangements under different perspectives, besides unequal coping in the face of crescent difficulties after the hospitalization of a child/

brother. It is essential to keep in mind that these female lay caregivers are poor and experience a severe disease in their family context. Perhaps it reaffirms their importance in the care environment and justifies their concern based on their culture, which appoints mothers as the main caregivers. We question whether issues related to citizenship, people's and communities' human rights and even humanization policies originated in government programs focused on equity, integrality, and ethics, among so many other concepts, should not be present in the professional routine of all agents involved in health care delivered to the population. It is believed that lay caregivers, patients' companions, also have demands and need to be included as users in the current health system.

The social determinism imposed by the Brazilian capitalist system shows the female figure linked to subaltern productive processes in comparison to the male figure, especially linked to the proletariat, in which women assume the role of caring for sick children and household chores, regardless of having a paid job⁽⁹⁾. Participants are poor women who face difficulties in getting inserted in the job market. This reality is experienced in diverse scenarios and contexts. Some studies⁽¹⁰⁻¹¹⁾ investigating the life of mothers who accompany and care for children with cancer report that they present drastic changes in their lives, for example, leaving their jobs, abandoning all daily activities, exclusively dedicating themselves to the child's care in addition to changes in family dynamics, among others. It contributes to these women's conception of health and, perhaps, it links the health concept to that of happiness, so desired by participants.

Projects of happiness involve the subject's body/mind and/or material/spirit and experiences, which are unique to each person⁽¹²⁾. Happiness is the person's goal in diverse existential projects, but its concept is unique and variable. Health is considered in the participants' projects, that is, positively valued experiences are identified as means to achieve happiness. The child's recovery and resuming their routine previous to the child's hospitalization is an ideal to expect. It is believed that health conceptions incorporate personal values of each participant and permit the understanding of essential aspects for care integrality, conceptual (re)formulations and policies focusing on the caregiver.

The work of informal caregivers is not perceived or socially acknowledged. This invisibility can be a result of the female character, which is attributed to care, that is, naturally and socially expected⁽¹³⁾ female work. Thus, it is perceived that they need a more attentive consideration, more evident care with themselves, more opportunities for dialog so that they can feel involved in their children's treatment process and not mere coadjuvants. Care integrality implies changing our health concept, enlarging the focus to the context and family. Integrality presupposes innovative practices in all health care scenarios, in different environments and analysis of the individual and collective contexts, based on the principles of the Brazilian Single Health System (SUS) and focused on people's social and health needs⁽¹⁴⁾.

Health promotion is a theoretical-practical-political area that presupposes the sanitary reform movement and is defined as policy that should include a set of actions and health projects that present all levels of management and health care system complexity⁽¹⁵⁾. Radical health education could be a strategy to promote health in communities through reflection and development of critique in people. The nurses' role should be in agreement with the lay caregiver, both in the hospital and household environment. Even though their role is first focused on the prevention of diseases and other injuries, nurses should, in a second instance, focus their actions on caregivers' emancipation⁽¹⁾. For instance, measures to sensitize professionals involved in the child's care to extend their care to the female lay caregivers, to understand the importance of support, solidarity and empathy with the mother/companion of the hospitalized child, discussion groups to share experiences, partnerships with other segments to teach handworks, among other possibilities of care are essential to women assure their human rights and citizenship. The formation of support groups is a positive strategy for family companions/caregivers, but political and institutional mobilization is necessary, in addition to agents responsible for care for the development of this kind of work.

In this perspective, health promotion strategies characterize female lay caregivers' health conception and provide social, educative and political segments of society with a reflection on essential transformations necessary for health practice and equitable political reformulations.

Reflection on health conceptions: educative and emancipatory proposals for health promotion

Literature presents little evidence related to care delivered by a companion. Studies discussing this issue indicate concern with supporting the companion (mother) caring for the hospitalized child or providing coping/adapting strategies for the way family members experience the disease and the child's treatment. Other studies discuss issues related to companions of hospitalized adults and/or elderly and show the difficulties they experience and the initiatives of the nursing team with a view to care delivery⁽¹⁶⁻¹⁸⁾. The contribution of this study, on the other hand, is to bring a perspective focused on the companions' context of life in the hospital environment, pointing out their life and health needs. It also stresses that freeing these companions and giving them a voice as health services users is an urgent intervention, so that professionals understand the complexity of integrated health care.

Being so close to these women, companions of children with cancer, certainly aroused many feelings, among them solidarity, compassion, understanding and especially the importance of being "with the other" in vulnerable and lonely situations. The study permitted the understanding of some questions existent before the research and confirmed assumptions regarding lay caregivers in the context where activities were developed. The invisibility of companions of hospitalized children, the lack of public health policies focused on lay caregivers, in addition to institutions' rigidity and norms, are some examples of the researcher's questioning and disagreement, which defined the study object and helped to clarify the research problem. On the other hand, the women lay caregivers' abandonment and lack of information were discussed under a new perspective of health conceptions, well being and quality of life presented by the participants.

The participants complained of restrictions the healthcare institution imposed on the companion, lack of options and lack of concern with their situation. Perhaps integral care is really a utopia in this context, in which exaggerated relations of power and domination prevail over human beings. Is it possible to discuss integrality in a biologicistic and normative environment? What are potential strategies for collective construction of ethical-social equity? These questions potentiate a consideration that has been posed long

ago, that is, switching the flexnerian technical care model, so as to problemize a "new public health".

Considering radical health education as a mechanism to emancipate and educate the population can strengthen the expansion of health promotion to vulnerable communities and problemize user-professional-government of public health policies towards integrality. Further research in the area is

suggested so that, hopefully, those who concentrate power and opinion formers are awakened to new forms of discussing interests based on demands. Finally, it is believed that new paths appoint to changes in practices and policies that depend on the will of governors, lawmakers, managers, faculty members, professionals and users, that is, political will of important segments of society and people.

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