Oncology nursing care from the perspective of family caregivers in the hospital context*

Cuidado de enfermagem oncológico na ótica do cuidador familiar no contexto hospitalar

Cuidado de enfermería oncológico en la óptica del cuidador familiar en el contexto hospitalario

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ABSTRACT

Objective: To understand the experiences and expectations of a hospital companion of cancer patients about the nursing care received. **Methods:** A qualitative, descriptive, exploratory study, conducted in an inpatient oncology unit of a medium-sized hospital. Study participants were ten family caregivers, in the months of May and June of 2010. Data were collected by means of structured interviews guided by two questions. **Results:** The results demonstrated that the care of family members who accompanied their sick family who had no possibility of cure, not only had restricted nursing actions, but also involved administrative measures and especially the infrastructure in the hospital environment. **Conclusion:** It appears that in many instances, one needs to carefully analyze each lived experience, as the basic tendency of the nurse is to open up to the standards established and to close off the humanization of care. To reflect upon this foundation possibly will open new horizons to our own authenticity and history as the ones who care.

Keywords: Nursing care; Oncologic nursing; Palliative care; Oncology; Caregivers; Hospitals

RESUMO

Objetivo: Desvelar as vivências e expectativas do acompanhante hospitalar, de paciente oncológico, sobre a assistência de enfermagem recebida. **Métodos:** Estudo de abordagem qualitativa, descritivo, exploratório, realizado na unidade de internação oncológica de um hospital de médio porte. Participaram do estudo dez familiares cuidadores, nos meses de maio e junho de 2010. Os dados foram coletados por meio da entrevista aberta norteada por duas questões. **Resultados:** Os resultados demonstraram que o cuidado com os familiares que acompanham seus doentes sem possibilidade de cura, não se restringe apenas às ações da enfermagem, mas envolvem também medidas administrativas e, sobretudo de infraestrutura no ambiente hospitalar. **Conclusão:** Depreende-se que, em muitos momentos, é preciso analisar atentamente cada situação vivida, pois a tendência básica do enfermeiro é abrir-se às normas estabelecidas e fechar-se à humanização do cuidado. Refletir sobre esse fundamento possivelmente abrirá novos horizontes a nossa própria autenticidade e historicidade como seres do cuidar.

Descritores: Cuidados de enfermagem; Enfermagem oncológica; Cuidados paliativos; Oncologia; Cuidadores; Hospitais

RESUMEN

Objetivo: Develar las vivencias y expectativas del acompañante hospitalario, de paciente oncológico, sobre la asistencia de enfermería recibida. **Métodos:** Estudio de abordaje cualitativo, descriptivo, exploratorio, realizado en la unidad de internamiento oncológica de un hospital de medio porte. Participaron en el estudio diez familiares cuidadores, en los meses de mayo y junio de 2010. Los datos fueron recolectados por medio de una entrevista abierta norteada por dos preguntas. **Resultados:** Los resultados demostraron que el cuidado con los familiares que acompañan a sus enfermos sin posibilidad de cura, no se restringe solo a las acciones de la enfermería, sino que involucra también medidas administrativas y, sobre todo de infraestructura en el ambiente hospitalario. **Conclusión:** Se desprende que, en muchos momentos, es preciso analizar atentamente cada situación vivida, pues la tendencia básica del enfermero es abrirse a las normas establecidas y cerrarse a la humanización del cuidado. Reflexionar sobre ese fundamento posiblemente abrirá nuevos horizontes a nuestra propia autenticidad e historicidad como seres del cuidar.

Descriptores: Atención de enfermería; Enfermería oncológica; Cuidados paliativos; Oncología; Cuidadores; Hospitales

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INTRODUCTION

Nowadays, cancer is proving to be a major cause of mortality worldwide and it deserves special attention by health professionals in order to lessen the suffering and despite of having cure for many cases the mortality rate is very high. It is a disease that can be cured, failing that, it is possible to establish targets to reduce the suffering of patients and their families grounded in the philosophy of palliative care[1]. Hence, palliative care conceptualized by the World Health Organization[2:3] as "[...] an approach that promotes the quality of life of patients and their families in the face of diseases that threaten the continuity of life through the prevention and relief of suffering. It requires early identification, impeccable assessment and treatment of pain and other problems of physical, psychosocial and spiritual.

The palliative care confronts the traditional cancer treatment such as chemotherapy, surgery and radiotherapy, which often become ineffective to cure, despite major medical and technological advances. In this situation, many patients are in need of cares that aim beyond the control of pain and other symptoms, to interfere in the psychological, social and spiritual, in order to invest in improving their quality of life[3,4].

From this perspective, for several times staying in the hospital during therapeutic measures is necessary. At this moments, it is very important the presence of a loved one because it provides a feeling of security to the patient and it helps in their recovery. Hospitalization is an opportunity for the family to learn or improve the performance of basic care for their ill relative and minimize their own difficulties related to illness and treatment[1,4]. The nursing staff and other members of the interdisciplinary team may or may not act as facilitators of this process[5].

In this context the importance of an accompanying present in cancer patients during their hospital stay has been highlighted in the literature[1,6,7], but in practice what is observed is the distance between the family and members of the nursing team . Moreover, the family caregiver when present during the admission process is often not understood by members of the nursing team as facilitator of the process of care, they end up being excluded, disrespected and unrecognized by these professionals, like social element and participant co-responsible in the treatment process[7].

In this way, on many occasions the offered care in the hospital context is deficient by the lack of relationship between nurses and family, who often become formal and bureaucratic and particularly depersonalized. They might even avoided by the health workers in the hospital environment[4], generating a stress increase in the family which befalls directly on the patient[6-8].

Given our concerns about the needs of family caregivers in the hospital context, the aim of this study was to reveal the experiences and expectations of the hospital accompanying and of cancer patients on nursing care received. Thus, this research may contribute to the health professionals and institutions to enhance understanding about the care provided to these patients.

METHODS

This is a descriptive research with a qualitative approach. Qualitative research seeks to understand and explain the dynamics of social relationships, relationships that are depositories of beliefs, values, attitudes and habits. This type of research works with the living, with experience, with the everyday life and also with the understanding of the structures and institutions, as a result of human actions targeted. Thus, the reality trimmed by its constant transformation, is richer than the look of the researcher can grasp[9].

The survey was conducted in inpatient oncology unit of a medium-sized hospital, located in a city located in the Midwest Region of the State of Paraná. The study subjects were the main caregivers accompanying patients diagnosed with malignancy, hospitalized for 3 or more days during the month of June 2010. During this period, 53 patients were admitted, however, only 22 were with companions, and these, ten were hospitalized for less than three days and two refused to participate in the study, so this study was conducted with only eight deponents.

Nevertheless, it was clarified to the readers that the steps to select the subjects did not seek to quantify them, as in the interest of qualitative research the aim is looking up for the foundations of the situations experienced through the understanding of human reality-generating meanings. Thus, in this approach, the number of people interviewed is not relevant, but rather the experience of these in respect to the phenomenon investigated.

To obtain the testimony, it was used the technique of open interview, recorded, based on a semi-structured, containing sociodemographic and profissiononal characterizations and two guiding questions "How is it for you the nursing care offered in the hospital environment?" and "How you would like the assistance at this hospital to be?" Subsequently, the interviews were fully transcribed by the researchers.

Following, all data obtained in fieldwork were gathered and recorded and the interviews were transcribed and read exhaustively and repeatedly, in order to establish the important issues and to build the empirical categories of the study. Finally, it was performed the final analysis which related the data to the theoretical references of the research[9].

With regard to ethical issues and the human subjects involvement, the project was submitted and approved by the Ethics Committee of the Integrated Faculty of Campo Mourao under Opinion No 58,865. The request for participation in the study subjects was done in person and was accompanied by two copies of the Statement of Consent signed by all participants. At the time, it was assured to them the separation between research and the care provided by the health service, as well as the anonymity of the information given.

RESULTS

The family caregivers presented ages between 29 and 88 years, nine females (five daughters and four wives) and a male caregiver (son). The predominant religion was Catholic (nine) and evangelical (one). As for schooling, four respondents had incomplete primary education, five had completed high school and one had higher education. Their activities ranged from professional homemaker (four), self-employed (two), and farmer, cashier, manicure and secretary (one from each profession). Most subjects (six) lived in cities of the region and four resided in the county where the study was conducted.

Experiencing authentic care by nursing staff

Nursing care is not restricted to the therapeutic patient care, but it extends to their families, through actions that aim to encourage them to stay with the patient during treatment and so receiving information about using medication and care to be dispensed. Therefore, on the analysis of the statements of witnesses regarding to the care given by the nursing staff, it was noted that they felt satisfied with the care provided to their family and themselves.

They are very good people, and since we got here we have been treated very well, you have to see. They arrange the bed, clean up and provide medications [...] (S-02).

They are very helpful, whenever I need them, they come. (S-01).

[...] the treatment is great, in all nursing shifts, I can't complai. If he (the patient) has to be left alone because we cannot stay, he says that the treatment is outstanding, they are all the time asking if everything is fine [...]. (S-07).

What they do me is everything, these things they do for us is God working, it's a great blessing. (S-04).

When referring satisfaction service they received, the witnesses also highlighted that authentic care must address, not only the biopsychosocial and spiritual patient needs, but it is also needed effective communication between nursing staff and patients / families, especially with regard to truthfulness of the information provided by the professional.

Any medication I ask what it is and what it is for, I am not unaware [...]. When I have doubts, I go after the nursing [...]. All the medicines offered they explain what each is for, whether it is for vomiting, malaise [...] (S-05).

[...] When they do something they explain it, when they will do it, I ask how it is and they explain very calmly and clear . They aren't rough. They know how to treat people with education they treat you well in the morning and it isn't different in the afternoon (S-09).

When we need to ask something they call the doctor and provide feedback on the spot. (S-07).

My father is very curious and when they come to give the medicine he asks what it is for and they always explain everything and then everything they will give, they promptly explain why, if it is for pain [...] (S-01).

Besides the establishment and proper communication, the team needs to be vigilant to perceive the needs not only of the patient but also the family members accompanying the ill relative during his or her stay in the hospital, because once meeting the familiar physical, psychological and social needs aspects, it is avoided that they may later come to the patient.

The second time I stayed here with him, there wasn't anyone to stay with him, and I had to stay 15 days I cried, I had to take medicine and they came and talked to me then I felt better. I was a trouble for them and I think that's why they are really nice (S-08).

So, I was over there and I saw and can say who are the best ones, those who care most and those who look closer, right? (S-10).

These statements show the appreciation that the caregiver gives to the nursing staff by hearing his afflictions and feelings generated towards the situation they experience. It also shows the perception of these family members about the care given and observes those who demonstrate more attention at the time of caring for the patient as well as for the family.

Living with disregard in the hospital context

When you discover the hospitals world the cancer patient and family are living in a reality in which the possibility of death is revealed in a concrete and inevitable, in a way that they do not aspire only care but they also yearn for expressions of solicitude that include their loved one and themselves in the hospital environment.

In this way, when it comes to their emotional needs the care they get from the professionals is important

but it must also contemplate the physical aspect through appropriate accommodations so they can develop themselves in the lived spatiality.

The chairs of the companions are pretty bad, it could be a more comfortable, I know we come only to be around, looking after the patient, it's not for sleeping but... (S-01).

The chair that I sit on is uncomfortable [..]. It could be something cozier, right? Few more blankets, maybe (S-06).

[...] I dont think this chair is very comfortable, I think all should be the same like those that have black leather place to put your feet, to rest well at night, because with this one here is very difficult to spend the night (S-03).

Based on the statements of the family it is possible to understand that in order to offer a decent and humane care, improvements must be made in the hospital infrastructure[1] which should provide the patient and family more privacy and comfort during their stay in the institution. Another aspect mentioned by the family refers to limiting the number of visits during hospitalization, since we know that visitation has as main objective, to support the patient emotionally, assisting him in his recovery. Notwithstanding, in the speeches is possible to verify that these expressions of concern are not provided to patients and families.

I would like that more visits were possible… because, sometimes, someone wants to visit and they can't because only two per visit are allowed to go in. In their condition, they should have the privilege of more visits (S-03).

I'd like that more people could come in [...] (S-06).

Only two visits per time are allowed, three sons came from Sao Paulo and they had to go back without seeing him [...] we asked the chief nurse for the section but no one permitted to go in. I think it should have some exceptions, at least for those visitors that come from outside the city and patients that are very bad (S-01).

Based on the family's perceptions it was evident that the physical difficulties reported by them during their tenure as companion/family in hospital settings are related to inadequate infrastructure rigidity and inflexibility of institutional rules.

DISCUSSION

The nursing care offered to patients and families in oncology aims to "[...] provide comfort, to act and react appropriately to the situation facing death with the patient family and themselves, to promote personal growth of the patient family and oneself, to appreciate the suffering and achievements empowering others with his or her care and empower themselves for care fighting to preserve the physical, moral, emotional and spiritual integrity to connect, to link up and to help each other and themselves to find meanings in the same situations[(8)]".

To make these measures more effective the nursing staff should educate, care, promote, advocate and coordinate its carefulness. In this way, there is a need for professionals who have some skills such as attention and concern for the other as well as being understanding, kind, receptive and respectful. It is still necessary to be dedicated and being open to discussion, having personal maturity, availability to listen carefully and also technical and scientific knowledge[(1,4,8,10,11)].

In analyzing the witnesses statements regarding to the care given by the nursing staff it was also observed their satisfaction with the care provided to their family and themselves however, it is expected that the health care activities provided by the team be effective and capable of generating on the patient and family, a high degree of satisfaction, for the reason that nursing is closer to them throughout their hospital stay[(4.8)].

To provide an authentic care the same must articulate the patient and his or her family, being involved in the care and above all that they can be assisted in a humane way and receive from the team manifestations of zeal, since an effective nursing interaction with the patient's family is a key step in their recovery process.

In most of the cases, the presence of the companion configures itself in an increasingly necessity when seeking continuity of care in the hospital environment that aims at the reduction of the hospitalization length. In one hand, this stay is extremely effective with regard to emotional support and security provided to the patient since the presence of a family member is their contact with the outside world reaffirming its very existence to the patient and ensuring the link with their social network, on the other hand, the hospital is an unfamiliar environment with inflexible schedules and visit restrictions[(1)]. In this sense, the companion plays another important role of enhancing patient adherence to the treatment[(12)], since the family usually brings an explanatory model of health and illness consisting of values beliefs, knowledge and practices that guide their actions in promoting the the health of their members[(1,13,14)].

All described aspects point out the need for health professionals to engage with the family as partners as well as target that focus on patient care thus promoting an understanding of this in its uniqueness. This will enable effective communication between nurse patient and family in which each member is in a constant state of self-care and concern for each other[(1,7)]. We also emphasize that all communication has a content and a relationship and these two aspects do not only exist side by side, but they complement each other in all messages[(15)].

Given the above, the relatives expressed in their speeches referring that for the realization of quality care, it is needed an authentic communication between nursing staff and patients/families, especially with regard to the accuracy of the information provided by professional. Such effective communication is defined as the ability to exchange ideas or to discuss, to dialogue and to talk aiming to a good relationship between people. The same is part of the caring and should be developed in any sphere of service, whether it is in the hospital outpatient or at home and should be systematically developed, based on customer needs through individual or collective orientations[16].

In this sense, once this communication is applied in the hospital setting between nurses patients and families it will determine the quality of an integral care, i.e., one that aims to meet human beings in all their needs: physical, information, practical, psychological, spiritual, social and emotional[4,16].

In this way, within palliative care, the nursing should prioritize communication and use visiting hours and direct monitoring of a family during hospital stay as a strategy for its implementation among family patient and nursing. It is necessary that the nurses give guidance to the family members so as to clarify their doubts and satisfy their needs for comfort affection and attention[17].

Therefore, it is understood that in the health field, to know how to deal with people is essential because only by effective communication the professional can help the patient and their family. By interacting directly with these, nursing must be careful, being able to decode and decrypt messages sent by them and only then develop an appropriate and consistent care plan according to the biopsychosocial, spiritual, emotional, practical and information needs of each one. It is also noteworthy that, among health professionals, the nurse is the one who is the closest and is the one who patient and family look for when they need guidance and clarification on the treatment[4,18].

According to this line of thinking, the family also needs to feel cared for, since the feeling of being far away from their everyday life, home and business, make them also feel fragile and in need of care. The nursing staff must be careful to understand the care needs of the family members accompanying the patient in the hospital seeking to meet their physical, psychological spiritual and social needs.

Another highlighted aspect based on their testimony is that the offered hospital care is not holistic by not considering the needs for physical comfort of the family companion when providing inadequate accommodations that do not allow them to develop themselves in the lived spatiality. This aspect, which does not meet the principles of palliation which determines that the care, should be directed to the patient and their relatives in order to educate, embrace support, advocate, relieve discomfort, control symptoms and minimize suffering. It should be noted that actions of discomfort relief are not merely palliative, but inherent to all ways of caring[8] and thus, nursing as flexor must provide adequate physical conditions to their customers.

Given the speech of the family members, it appears that to offer a comprehensive and humane care it is necessary that improvements are carried out on the hospital infrastructure. Hosting is showed in studies as an aspect that should be incorporated into the principle of hospital humanization by professionals and manager, having the ambience as one of its axes that infer comfortability focused on the user's individuality and privacy[12].

Thus, it becomes necessary to establish measures of a structural and administrative proportions that may be committed in ensuring greater welfare to the companions during their stay in the hospital aiming for a positive impact on the patient health reestablishment through the companion's presence[12,19].

Therefore, as the company of a loved one during hospitalization benefits the patient, receiving visits provides emotional support to the patient and helps them in their recovery[1,6-7]. When verifying on the interviews that only a limited visits numbers are allowed it appears that these expressions of concern are not provided to the patients and their families.

The nursing, as care executor should value the humanization taking into account cultural differences, beliefs and values seeking to adequate the necessary care to the patient welfare[20]. Therefore, it is important that they establish proper visitation standards taking into consideration the needs of the patient and their family and not only the standards established by the hospital.

In the face of messages from the relatives it is believed that humanization in the oncology hospital context should have as instrument the principles of palliative care from the National Program for the Humanization of Hospital Care[4,11,21]. On the basis of strategies it can established greater flexibility in their rules especially regarding the visits liberation, offering individualized accommodations to family caregiver and to the patient as well as respecting and preserving their intimacy and particularities aiming to help the family in managing the patient's disease (1,4,22,23) and coping with this condition.

On this perspective, the literature points out to be of "[...] great importance the need to expand actions that have the caregiver as main subject so that this activity

be recognized and invested in appropriate practices, bringing benefits for those who care and also for those who are cared for"[23].

Therefore, we emphasize the important role of health professionals and it is highlighted here the nurse's availability to find solutions with the patient and family in order to humanize the care, preparing the family caregiver and patient to find alternatives that can improve the capacity and quality of care.

CONCLUSION

The solicitous living is an existential characteristic of the human being in its being-in-the-world. Listening and paying attention become an indispensable tool for nurses to learn to understand the patients and families in their totality and singularities. Therefore, it is essential to enter the world of the other, to see things through their eyes and involvedly hear their experiences and especially in their distress towards the lived situation *per se*.

Through this study it is inferred that is necessary carefully analyze each situation experienced as the basic trend of the nurse is to open to the standards set and close to the humanization of care. A reflection on this ground possibly open new horizons to our own authenticity and historicity as care professionals.

We perceived that the given care to the family members who accompany their ill without the possibility of healing, is not restricted to nursing actions but they also involve administrative measures and, above all towards the infrastructure in the hospital environment which must be observed and discussed by nurses and administrators because these needs go beyond the biological aspect and should be added to the psychological, social practices, emotional, spiritual and information beads, thus providing patients and their families a holistic, integral, authentic and effective caring.

Hence, it is necessary to rethink these values and visions developed and ensnared throughout time in hospitals by instituting more comprehensive forms of care based on a palliative care in a humane way.

In this context, it becomes necessary to revise the administrative rules regarding hospital visiting hours and its physical restructuration, as well as the sensitivity of the professional nurse in the perception of the needs of carers and developing a care plan aimed also to caregivers and not just to the patient.

Finally, it is worth noting some study limitations that occur as a result of being qualitative and contextualized in the daily experiences of the individuals involved. Thus, the results do not allow generalizations, however it can be used in similar situations, helping to deepen knowledge and reflection on the concrete needs of family caregivers in the hospital context. In this sense, there is a need to develop further research in this line involving a larger number of families.

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