



EXPERIENCE REPORT


Home care guidelines for family members and caregivers of patients in palliative care

Orientações de cuidados em domicílio aos familiares e cuidadores de pacientes em cuidados paliativos
Pautas de atención domiciliar para familiares y cuidadores de pacientes en cuidados paliativos


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ABSTRACT

Objetivo: relatar a experiência de dois graduandos de enfermagem no oferecimento de orientações a familiares de pacientes internados sob cuidados paliativos no período que antecede a alta hospitalar, por meio de uma cartilha educativa. **Método:** estudo descritivo, do tipo relato de experiência, de um projeto de extensão que previa as orientações de cuidados domiciliares a familiares de pacientes internados sob cuidados paliativos após a alta hospitalar. **Resultados:** Dúvidas acerca dos cuidados, medo e ansiedade foram sentimentos constantes manifestados pelos familiares e cuidadores, permitindo aos alunos, mais do que oferecer orientações, interagir com compaixão, humanidade e zelo, fazendo com que a proposta do projeto extrapolasse os aspectos técnicos. **Conclusão:** O desenvolvimento do projeto resultou em ganhos para os pacientes e seus familiares e aos alunos envolvidos. Os alunos puderam aprimorar seu conhecimento na área dos cuidados paliativos, além de desenvolver habilidades de observação sistematizada e comunicação. A universidade deve investir em atividades de extensão capazes de contribuir com a comunidade e, ao mesmo tempo, garantir o engajamento do aluno e aprimoramento de seus conhecimentos, habilidades e atitudes frente ao cuidar em enfermagem.

Descritores: Enfermagem. Cuidados Paliativos. Serviços de Assistência Domiciliar. Alta do Paciente. Educação em Saúde.

RESUMO

Objetivo: identificar as percepções e as práticas sobre a violência entre parceiros íntimos adolescentes dos profissionais que compõem os diferentes níveis de coordenação da Rede de Proteção à Criança e ao Adolescente em Situação de Risco para Violência. **Método:** estudo qualitativo ancorado na Teoria da Intervenção Prática da Enfermagem em Saúde Coletiva. Coleta de dados através de entrevistas realizadas entre dezembro de 2020 a julho de 2021. Realizou-se análise de conteúdo temática. **Resultados:** participaram sete profissionais da rede de Proteção de Curitiba, Paraná. Emergiram três categorias empíricas que versam sobre: percepções sobre a violência entre parceiros íntimos adolescentes; dificuldades e facilidades da rede para seu enfrentamento e a potencialidade da Rede de Proteção para construção de intervenções. **Conclusão:** a rede mostrou-se estratégia potente para intervir nessa forma de violência. Todavia, o enfrentamento em rede ainda é escasso, o que denota a necessidade da sua inserção na agenda das políticas públicas.

Descritores: Violência Entre parceiro íntimo. Adolescente. Rede de Atenção à Saúde.

RESUMÉN

Objetivo: relatar la experiencia de dos estudiantes de enfermería en ofrecer orientación a familiares de pacientes internados en cuidados paliativos en el período previo al alta hospitalaria, a través de una libreta educativa. **Método:** estudio descriptivo, del tipo relato de experiencia, de un proyecto de extensión que brindó orientaciones para el cuidado domiciliario a familiares de pacientes internados en cuidados paliativos después del alta hospitalaria. **Resultados:** Las dudas sobre el cuidado, el miedo y la ansiedad fueron sentimientos constantes expresados por familiares y cuidadores, lo que permitió a los estudiantes, más que orientar, interactuar con compasión, humanidad y celo, haciendo que la propuesta de proyecto extrapolara los aspectos técnicos. **Conclusión:** El desarrollo del proyecto resultó en ganancias para los pacientes y sus familias y los estudiantes involucrados. Los estudiantes pudieron mejorar sus conocimientos en el campo de los cuidados paliativos, además de desarrollar habilidades sistemáticas de observación y comunicación. La universidad debe invertir en actividades de extensión capaces de contribuir a la comunidad y, al mismo tiempo, garantizar el compromiso de los estudiantes y mejorar sus conocimientos, habilidades y actitudes hacia el cuidado de enfermería.

Descriptor: Enfermería. Cuidados Paliativos. Servicios de Atención de Salud a Domicilio. Alta del Paciente. Educación en Salud.

INTRODUCTION

Palliative Care (PC) is active holistic care, offered to people of all ages who are in intense suffering related to their health, caused by serious illnesses, especially those who are at the end of life. The objective of PC is, therefore, to improve the quality of life of patients, their families and their caregivers.⁽¹⁾

Patients in palliative care have different levels of dependence for activities of daily living and demand individualized care, which requires the training of a family member and/or caregiver to follow the treatment in a safe and qualified way in the home environment.

The family needs to receive support from the team to learn how to care at home and also how to deal with their conflicts and fears. When hospital discharge is imminent, ambiguous feelings are perceived, such as happiness for the relative's recovery and bitterness regarding the issue of becoming the family caregiver. Thus, a well-oriented family regarding the health-disease process becomes more balanced to collaborate in the recovery, as well as to face the imposed limitations.⁽²⁾

In this way, the discharge plan is a tool that guarantees uninterrupted care after hospitalization, through an educational process. This plan should include guidelines for the patient and family about what they need to know and understand, preventing patients from leaving the hospital insecure about the continuity of treatment.^(3,4)

In order for care to be performed by family members, they need to be supported by health professionals, since it is a great responsibility and challenge. Thus, the family needs to be well-prepared to provide care, otherwise, it may have difficulties in assisting the sick person.⁽²⁾

In the patient education process, verbal and written information are important and complementary. The writing effectively supports the verbal, which can still be misunderstood, forgotten or rejected. They also function as a resource readily available for consultation, when faced with doubts in the development of care. Thus, through pamphlets and educational booklets, patients and family members are able to understand the health-disease process and its relationship with the clinical condition experienced in the course of the disease, as well as the main care needs, and also clarify doubts, contributing to the reduction of fears, anxieties and unfamiliarity.⁽⁵⁾

The contribution of university extension is essential to strengthen the interaction between the university and society, allowing students to develop skills and competencies for human interaction, which go beyond the walls of the faculty.

Thus, the present report intends to elucidate an activity developed by nursing students in a secondary hospital in the interior of São Paulo, where they participated in the planning of hospital discharge of patients in palliative care, advising family members and caregivers about the main home care, with the

delivery of an educational booklet developed for this purpose.

METHOD

Descriptive study, of the experience report type, of a project called "I care, we care - Guidelines for family members and caregivers of patients in Palliative Care".

This is an extension project developed by undergraduate nursing students between October 2019 and September 2020. Family members and caregivers of patients hospitalized under palliative care, at the time before hospital discharge, were approached by two students for guidance related to the main home care for such patients, allowing continuity in their care, and the delivery of an educational booklet.

The project was developed in a university hospital, of secondary level, located in the interior of São Paulo. It has 50 inpatient beds, 10 of which are exclusive for palliative care patients.

For the organization of activities, two nursing undergraduates were selected, responsible for approaching family members and caregivers, in four periods of the week. The teacher responsible for the project carried out the training of the students, the control of the guided families and of the number of booklets delivered. The service's palliative care team contributed to the identification of patients who were planning to be discharged.

Initially, the project pictured two stages with different activities: the first stage, fully carried out by the students, corresponded to approaching family members and caregivers, carrying out the guidelines and delivering the booklets. The second stage predicted the holding of workshops for the practical demonstration of the most common home care for family members and caregivers, such as patient mobility in bed and body hygiene, using a simulator.

The beginning of the second stage was scheduled to take place six months after the beginning of the project, considering that after this period, the undergraduates would have greater mastery and security regarding the general guidelines of care. With the support of the nursing team of the service in question, all the necessary material was already available for the start of the workshops, however, with the outbreak of the SARS-CoV-2 pandemic and the consequent suspension of face-to-face activities by the university, the workshops were temporarily suspended.

Thus, the activities developed were reorganized through the elaboration of demonstrative videos about the nursing care covered in the educational booklet that were passed on to family members and caregivers with the help of the nursing team of that service, using a tablet.

RESULTS

With the development of the extension project, significant results were achieved. In all, 103 booklets were distributed to family members/caregivers of

patients in palliative care who were scheduled for hospital discharge. Once the proposal was successful with hospitalized patients, with scheduled hospital discharge, the project was extended to the municipality's Home Care Service and the booklets were distributed to family members of patients under palliative care assisted by this service. Furthermore, the project achieved greater visibility and notoriety when an interview given to *Jornal da Universidade de São Paulo* was published, reporting on the work developed.

Experiences of student 1

By offering guidance to family members and caregivers, the student was able to observe the importance of listening. Caregivers reported fear of death of a loved one, physical and emotional fatigue caused by the illness process and by the forsaking of other family members, which caused overload on the main caregiver.

Thus, the student started to carry out the guidelines in a different way, offering emotional support to these family members through attentive listening and, with this, he was able to observe excellent results related to the guidelines carried out, because at the end of each conversation the caregivers reported feelings of relief and gratitude.

The student also encountered emotionally well-structured family members, with a good division in the role of caregivers and acceptance of the patient's death process, however, they were insecure about carrying out the procedures that were necessary for the care of the palliative patient at home. And by offering technical support and guidance and delivering the educational booklet to these family members, their empowerment was observed to perform care safely, easing their anxieties.

During this period, the student was also able to learn, understand and teach about the importance of home care for palliative patients. At the beginning of the activities, he was constantly faced with family members who were afraid of the hospital discharge process, because they thought that care would be better performed by the hospital team, rejecting home care for their family member and, in a way, he agreed with that thought. However, during the activities and doing bibliographic searches, the student was able to recognize the importance of home palliative care for the patient, the benefits of living the active process of death within a family environment, far from a hospital routine. With that, he was able to pass this knowledge on to the family members.

Therefore, the conversations with family members/caregivers went beyond guidance and delivery of the booklet, becoming a moment of relief for the caregiver, where therapeutic communication proved to be very effective, alleviating the negative anxieties caused by the hospital discharge process, making the orientation a humanized educational procedure. The extension project made it possible to identify different health care contexts and how informal care can overload the family and, above all, the main caregiver, exposing the importance of

educational actions during the hospital discharge process, taking into account the individuality of each patient and family member/caregiver, to then structure care guidelines according to the needs of each patient and individual difficulties of each of those involved.

Experiences of student 2

Active listening and therapeutic touch were important tools in contact with patients and their caregivers at the time of hospital discharge. In many moments, the student faced the difficulty of caregivers and family members in dealing with all the concerns inherent to this moment, such as the conciliation of home care and other daily personal activities, the insecurity for the management of the patient at home and the possibility of some intercurrent and, mainly, the imminent risk of death and the responsibility and decisions arising in the emotional-sentimental and bureaucratic scope in the family context.

All the families and caregivers that the student had the opportunity to accompany showed interest in continuing the care and zeal with the patient's health-disease process. At times, it became evident how conflicting it can be to deal with the end of life, when feeling great affection for the person and wishing for their recovery and, at the same time, being faced with great suffering resulting from the advancement of the disease and the desire to stop all pain and discomfort.

The management of emotions and feelings was the most challenging aspect throughout this process. No training, however complete and comprehensive, is capable of fully preparing students to deal with difficult situations and the suffering of others. The student believes that over the years of the undergraduate course, the expanded and humanized professional look could be developed in different ways, but the project brought experiences of living in close contact with death and learning how to manage emotions and personal feelings and the other.

The student also highlighted the contribution of the extension project in the development of an educational action at the time of hospital discharge, especially in improving the perception and identification of the patient's needs in each situation. The student reports the opportunity to accompany family members and caregivers who had knowledge about the patient's health condition and experience in home care with a history of several hospitalizations. She also had contact with palliative care patients who were being discharged from their first admission. In each situation, it was necessary to identify the priority aspect in the care process, effectively seeking to understand the individuality of each patient and their reality, considering physical, emotional and informational support.

DISCUSSION

Despite little preparation, caregivers and family members play an important role in providing care to patients with advanced disease.⁽⁶⁾ Thus, even during the hospitalization period, it is essential that they

receive adequate guidance in order to enable continuity of care to the patient in the home environment.⁽⁷⁾

Thus, the use of educational booklets or manuals is relevant to contribute to family members and caregivers in the provision of care, reducing their insecurities, uncertainties and unfamiliarity that can contribute to the emergence of patient health complications.⁽⁸⁾

Overload, often manifested by family members and caregivers, may be associated with levels of anxiety, depression and somatization, and such symptoms tend to increase with the decline in the patient's functional status.⁽⁶⁾

Therefore, offering assistance that goes beyond the technical aspects, addressing emotional support to family members and caregivers, is an essential role of the palliative care team.

As an emotional support strategy, communication is of paramount relevance to the practice of palliative care. And, if supported by a relationship of attitude, cooperation, feeling and sensitivity, it becomes an important instrument to boost the relationship between the nurse and the patient.⁽⁹⁾

Finally, it is identified that the university plays an essential role in the formation of a professional capable of dealing with the subjectivities inherent to the process of caring for PC patients.

However, it is observed that the curricular approach of PC is insufficient, both in content and in instigating the academic to seek more knowledge on the subject. Carrying out practical activities, such as visits to patients in PC, are a great learning experience. Such activities make it possible to refine the different types of skills necessary for the health professional who works with patients in a situation as delicate and complex as that of PC.⁽¹⁰⁾

The students' experience with PC made them realize the various aspects of the professionals' work with patients, family members and caregivers in palliative care. Such assistance implies the expanded concept of health, which includes the process of dying with dignity and with a minimum of uncomfortable symptoms for patients.

The main functions of university extension are based on professional training, production of knowledge, social development and improving the quality of life of scientific and popular society. In this way, the student has a fundamental role in this practice, which must be transformative, a mechanism that the university has as a fundamental weapon to fulfill its role of social responsibility⁽¹¹⁾.

The contribution of this article is given as it reports a successful experience, of simple execution, and that can be expanded to different health contexts, considering the profile of the patient in palliative care. The limitations refer to the fact that the activity had to be interrupted due to the pandemic, which prevented the students from embracing a more complex discussion in the present experience report.

CONCLUSION

The development of the project resulted in gains for patients and their families, in addition to the team and students involved. It allowed greater safety for patients and family members at the time of hospital discharge; culminated in the awareness of the health team for the adoption of the educational booklet as a complementary resource for the follow-up of treatment at home and support to family members/caregivers in a safe and qualified way. Furthermore, the project allowed students the opportunity to develop skills of systematic observation, verbal and non-verbal communication, interaction, empathy and dissemination of knowledge about palliative care based on scientific evidence that can be spread to our professional life and in other contexts of care.

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