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EXPERIENCE REPORTS

Advanced practice nursing in palliative care within the compassionate favela community: an experience report

Práticas avançadas de enfermagem em cuidados paliativos na comunidade compassiva de favela: relato de experiência

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ABSTRACT

Objective: to describe the advanced practice of nurses in palliative care who work with the Interdisciplinary team in a university extension project in the favelas of Rocinha and Vidigal in Rio de Janeiro, Brazil. **Method:** This descriptive research shows an experience report on the applicability of advanced practice nursing in palliative care in vulnerable communities, Rocinha and Vidigal, 2019 and 2020. **Results:** Through micropolitics, leading nurses seek to relieve human suffering by controlling physical, psychosocial, and spiritual signs and symptoms through clinical reasoning, problem-solving skills in nursing appointments, and articulation with the interdisciplinary team. **Conclusion**: From the perspective of the compassionate community project, the palliative care approach has shown a strong practice of nurse autonomy, provided visibility for social vulnerability, and strengthened the advanced practice of nurses in Brazil.

Descriptors: Advanced Practice Nursing; Health Care Models; Palliative Care; Social Vulnerability; Poverty Areas.

RESUMO

Objetivo: descrever a prática avançada do enfermeiro em cuidados paliativos que atua com a equipe Interdisciplinar em um projeto de extensão universitária nas favelas da Rocinha e Vidigal no Rio de Janeiro, Brasil. **Método:** Trata-se de um estudo descritivo do tipo relato de experiência, sobre a aplicabilidade de práticas avançadas de enfermagem, no contexto de cuidados paliativos em comunidades vulneráveis, Rocinha e Vidigal, 2019 e 2020. **Resultados:** Enfermeiros líderes, por meio da micropolítica, buscam o alívio do sofrimento humano, mediante o controle de sinais e sintomas físicos, psicossociais e espirituais, através de raciocínio clínico, habilidade de resolução de problemas por intermédio da consulta de enfermagem e articulação junto a equipe interdisciplinar. **Conclusão**: A abordagem de cuidados paliativos sob a ótica do projeto de comunidade compassiva tem mostrado uma forte prática da autonomia do enfermeiro, assim como proporciona visibilidade para a vulnerabilidade social e fortalecimento da prática avançada do enfermeiro no Brasil.

Descritores: Prática Avançada de Enfermagem; Modelos de Assistência à Saúde; Cuidados Paliativos; Vulnerabilidade Social; Áreas de Pobreza.

INTRODUCTION

According to estimates, there are 28 million nurses, 59% of the health workforce worldwide, and 90% provide primary healthcare services. Studies show that nurses are the only professionals in most countries who provide health care to the population. Despite this, nursing is still a neglected resource in several countries, but it can be used to expand access to palliative care and create programs that meet the diverse demands of the population in this area[1].

To meet the complex care needs of people with life-threatening diseases, new approaches and models of care are needed, such as individual-centered care and evidence-based practice, which are indispensable for the clinical practice of advanced practice nursing (APNs)[2].

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Faced with social inequalities, vulnerable populations face greater vulnerability to risks and compromised access to fundamental human rights, such as health and the preservation of their autonomy[3].

In addition, it is possible to notice a series of barriers to accessing palliative care assistance in different parts of the globe, attributed to the scarcity of programs with this approach and the lack of clear policies and educational programs that guide the philosophy[4]. This scenario is particularly relevant in developing countries, where there is a small production of government initiatives to provide palliative care to the population[5].

People who have severe diseases and are in the final stages of life tend to prefer to stay in their own homes and communities. Out-of-hospital patient care activities focus on providing palliative care through pre-established home care, hospice systems and collaborative partnerships with service agencies and individual physicians. The purpose is to maintain an individual in their home or community by improving their quality of life, optimizing function, and offering care that supports their goals and preferences[6].

In this context, Advanced Practice Nursing (APN) plays a central role in promoting the implementation of palliative care during the disease. APN requires analytical skills, problem-solving skills, adaptive attitudes, and rapid adjustments to changing clinical scenarios[2].

Although APN is not yet regulated in Brazil, it is one of the Latin American countries with the greatest potential for APN development and training in APN, which can thus contribute to the progress of the population's positive health outcomes[7]. An example of this practice is the Compassionate Communities in Brazilian Favelas project, which arose from the concerns of the nurse and professor Alexandre Ernesto Silva, from the Federal University of São João del-Rei (UFSJ). Silva experienced care challenges and potentialities in these areas. With the voluntary support of residents, a compassionate network was developed.

Until 2019, these actions were structured with university extension support. Two nurses and professors from the Federal University of Rio de Janeiro (UFRJ), Maria Gefé da Rosa Mesquita and Liana Amorim Corrêa Trotte developed the extension project in the university in line with the Compassionate Community project, demonstrating the leadership of nursing in this perspective.

It is worth noting that, in this project, health care benefits from voluntary contributions from various health professionals. Together, they bring palliative care to this context, a strong example of social entrepreneurship led by Brazilian nursing in palliative care. In this place, nurses exercise autonomy based on scientific evidence and clinical reasoning.

Therefore, this study aims to describe the advanced practice of nurses in palliative care who work with the Interdisciplinary team in a university extension project in the favelas of Rocinha and Vidigal in Rio de Janeiro, Brazil.

METHOD

This descriptive research shows an experience report on the applicability of advanced practice nursing in the context of palliative care in vulnerable communities, based on the experiences of nurses working in the university extension project entitled "Compassionate Community: a proposal for social engagement to strengthen palliative care", carried out in two favelas in Rio de Janeiro, RJ, Brazil.

This professional experience report was developed in the subnormal agglomerations - favelas - of Rocinha and Vidigal, in the southern zone of Rio de Janeiro, RJ, between 2019 and 2023. According to the Brazilian Institute of Geography and Statistics (IBGE)[8], these locations have at least 51 housing units, including shacks, huts, houses, and other types of housing that usually have a deteriorated physical structure.

In addition, these spaces are usually built through the illegal occupation of land in the public or private sphere, which leads to the lack of essential public services, such as health, education, social assistance, basic sanitation, and urban accessibility. Thus, subjects who present life-threatening conditions experience pronounced human suffering[9], which highlights the need to institute actions to expand access to palliative care in these territories.

APN actions in the context of palliative care in scenarios of vulnerable populations of favelas will be reported by mapping the care provided, namely: the premises of the development of compassionate communities led by nurses; nursing appointments in palliative care as a guiding instrument for autonomy and professional decision-making; navigation activities; articulation of the assistance developed with the project's health team, and other instruments of the Health Care Networks (RAS) of the municipality; telehealth actions to expand palliative care

assistance in scenarios of difficult urban access; and health education practices carried out with the residents of these territories, for the development of basic palliative care at home.

This study reflects the authors' impressions on the experiences of applying APN in palliative care. As this study did not require data collection, it was not necessary to be assessed by the research ethics committee.

EXPERIENCE REPORT

Beginning/implementation of the compassionate community by nurses

The initiative for developing Compassionate Favela Communities in Brazil is based on strengthening community ties with the participation of community residents and health professionals from various specialty areas. Thus, the nurses leading the project, through the micropolitics of living work in health, seek to relieve human suffering, controlling signs and symptoms that may be related to physical, psychological, social, and spiritual problems by using clinical reasoning, the ability to solve problems and the articulation with professionals from different areas of the health team, in addition to the instruments of the Heath Care Network.

In the project, nurses have strategic coordination and development roles, as they stand out as protagonists in the planning and execution of this action. In addition, nurses are the professionals closest to the person under palliative care, their family members/caregivers, the compassionate agent (as the resident and volunteer are called), and the support networks established in these communities. Thus, through their care management activities, nurses decentralize and improve actions to manage signs and symptoms arising from different life-threatening conditions, in addition to prevention and health promotion actions.

This model of care, idealized by nurses for people eligible for palliative care, brings together social control, university extension, volunteering, and civil society, seeking integration with the local Unified Health System (SUS), that is, with the health care units of the territory. Furthermore, as a strategy for delivering this type of care, nurses use their skills as health educators to shape and strengthen the various types of knowledge found in these territories, linking them to evidence-based practice. For example, health training activities are carried out with local volunteers to provide them with the knowledge of basic approaches to palliative care in daily life as compassionate agents. What makes this initiative unique is the participation of residents. It is rewarding to see them gain knowledge, empowerment, and confidence and use these resources to care for each other.

In the meantime, the team carried out home visits to the people mentioned by the compassionate agents, selecting first those with life-threatening conditions to be followed up on the project. Then, through networking, health professionals from different areas were invited to participate in the project through volunteering and joined the initial team, which allowed them to expand the services. In addition, considering the completeness of the health needs observed, social demands have arisen to be worked on, which has been possible thanks to a network of supporters.

Finally, the people treated are part of a single health system, which follows universality, integrality, and equity as doctrinal principles. Therefore, they are inserted in the broad context of a health care network, which may not function properly for several reasons. However, as SUS nurses, we believe in and work in this system and aim for its success. Therefore, the compassionate community is proposing a care model in palliative care to support the SUS, given the absence of a current public policy that rules palliative care in the country.

Home nurse clinical practice

With the strategic planning established, the operational dimension of the project was designed based on: monthly home visits of a health team; periodic visits of the compassionate agent establishing a bond and co-responsibility; telemonitoring to manage signs and symptoms; guidance and decision-making between monthly appointments; contact with the primary health care team responsible for the person with a life-threatening condition to inform about the visit and alignment of conduct; activation of some point of health care in the secondary or tertiary care network where the person is being served at the specialty level, in a "navigation" action by the type of care in which they are inserted in order to reduce barriers and optimize access; and mobilization of the network of supporters in case of identification of the need for social support that collaborates for the health of the person/family being served in the project.

The home visits are made in person through collective mobilizations once a month in the pro-

ject. Seven interdisciplinary teams composed of at least four people, including the volunteer resident, are involved in it. Each individual's main complaint, discussed in a previous meeting, is approached at each visit. As part of the team, the nurses use the nursing appointment as a script to identify human responses. Thus, they can list the main problems and prioritize them to systematize the essential conducts of the synchronous care plan with the interdisciplinary team.

Nursing appointment

To assess the clinical status of the individual during the nursing appointment, the professional uses three instruments: the Palliative Performance Scale (PPS), which evaluates the patient's functional activity and ranges from 0 to 100%, from death to complete level of consciousness, and the Edmonton Symptom Assessment Scale (ESAS-br), which measures 9 signs and symptoms (pain, tiredness, drowsiness, nausea, lack of appetite, shortness of breath, depression, anxiety, and well-being) that ranges from 0 to 10, where 0 is the absence of symptoms, and 10 is the worst possible. There is also the visual analog scale of pain to measure pain intensity, with a score from 0 to 10, where 0 is the absence of the symptom and 10 is the worst possible. The instruments mentioned assist nurses in identifying the signs and symptoms of clinical deterioration in the end-of-life process of the individual in a life-threatening condition and contribute to nurses' decision-making.

During the nursing appointment, the nurse inquires and observes the entire context in which the individual is inserted, performing the nursing diagnoses and prescribing interventions pertinent to the reality and daily routine of the individual and support network/family. For example, a person who needs pain control usually makes use of opioids every 4 hours. However, suppose the individual does not have a support network/family and depends on the care of the local compassionate agent and neighbors. In that case, they cannot be offered the drug every 4 hours. In this case, the dose increases, and a new time interval of administration (every 6 hours) is discussed with the prescribing physician to achieve an adequate level of analgesia even with a simple change.

The autonomy of the nurse in optimizing the schedule of the administration of the prescribed medication offers agility in care and, most importantly, pain control, which, when not controlled, can often trigger other types of (emotional, social) pain and even worsen symptoms such as dyspnea, fatigue, nausea, etc.

Furthermore, the leading nurse in the compassionate community project is responsible for breaking bad news using the SPIKEs technique. It is a six-step mnemonic protocol for breaking bad news that helps professionals and patients maintain clear and open communication.

Assistance is provided continuously once a month and in person. Between the visits, the patient is followed up through telehealth. In most cases, the nurse is the leader of the interdisciplinary group and is responsible for the referrals.

Telecare

Remote contact occurs to monitor clinical cases at home to solve problems identified in the in-person visit and follow-up throughout the month. Telecare allows a greater bond among the volunteer agent, patient, and support network/family in this illness process, mainly because they are difficult urban access areas that sometimes reverberate as mobility limitations and accessibility to health devices.

Family videoconferences are also used in cases where the support network cannot be present on the day of the visit or for conflict mediation when there are problems in direct patient care. The nurse implements communication through telephone guidance via WhatsApp, in writing, audio messages, and video calls. Thus, previously trained family members can also conduct procedures, such as dressing, managing urinary bladder catheter to relieve the bladder, tracheostomy aspiration, and administering nasogastric or gastrostomy to standardize the procedures when indicated. In addition, it contributes to better communication, education, and training of the compassionate agent in cases where it is necessary to perform any of the abovementioned procedures.

Volunteers, professionals of the interdisciplinary team, and nurses are responsible for these volunteers' training and qualification apparatus. In addition, they monitor the care they provide.

RESULTS AND DISCUSSION

In the report of this experience, it is possible to perceive that the actions developed start from the perspective of avant-garde nursing, which acts in the educational scenario and manages to inspire new actors to improve their practices even in scenarios challenging to manage. Thus, nursing leads a movement promoting noticeable changes in the lives and deaths of vulnerable

people. It has managed to bring together several fronts to develop a social enterprise that shows, in addition to obtaining better health outcomes, the actual involvement of the university with the various layers of society.

Social entrepreneurship has been increasingly relevant in several areas of knowledge and is defined as a self-organized process that stimulates new attitudes, procedures, and services, allowing the reconstruction of knowledge and professional practices and improving the living conditions of individuals and communities. Nurses have the chance to undertake, materially or immaterially, and thus enable the expansion of their vision and passion for improving health outcomes through innovative and transformative approaches[10].

The Nursing Appointment (NA) is characterized as a private action of the nurse. It comprises of systematized and interrelated actions in different contexts, such as households, schools, and community associations. Moreover, due to its flexible organization, it can occur individually or collectively[11].

Its main objective is to support quality user care based on a clinical analysis based on human, scientific, and empirical knowledge. Through NA, nurses can plan health promotion actions, immediately identify possible changes in the individual's health, and, after the diagnosis, follow the patient in the health-disease process[12].

Nurses who are palliative care specialists can offer specialized appointments in the home environment. It includes complex care coordination roles, symptom management, and end-of-life care. Examples of cases in which home palliative care can be used are: cases in which visits to the nurse's offices are challenging, require long, intensive, or more frequent visits, or in cases of patients in areas with no palliative care service available[6].

In this context, nurses use assessment tools and/or scales such as ESAS-br and PPS during nursing appointments. These are recommended instruments to identify and assess the clinical status of individuals in a life-threatening condition and allow them to make the appropriate decision to control signs and symptoms[13].

The classic symptoms of the clinical deterioration of the individual in end-of-life care are pain, fatigue, nausea, lack of appetite, and dyspnea, among others. Pain is seen as the main symptom to be treated because the estimate of pain in patients with advanced cancer, for example, is 75% to 100%. It is considered a subjective symptom encompassing several emotional, physical, social, and spiritual aspects of the end-of-life care phase. It is also responsible for triggering other symptoms such as fatigue, depression, fear of dying, shortness of breath, and suffering, which can become total pain[13,14].

Excellent pain control can be extremely complex and challenging for professionals in the interdisciplinary team working with palliative care, as it is a subjective and genuinely personal experience. This shows that the individual's perception of the symptom of pain, which surpasses the physical sensation in the body, is related to their affective and emotional experiences, which needs to be understood within the social, emotional, psychic, and spiritual spheres, according to the concept of total pain[15].

Regarding palliative care, breaking bad news is seen as a complex and delicate action in which the nursing professional plays a fundamental role in the multidisciplinary team. Studies show that nurses' dedication to the care process shows they can recognize the needs and develop strategies to minimize the suffering and restlessness of those receiving bad news[16]. In addition, the nurses' tone of voice and the adoption of a language that does not refer to abandonment are fundamental to maintaining the well-being of individuals[17].

Another point that deserves to be highlighted is the time nurses dedicate to patients and their families to ensure they understand what was mentioned[18]. Nurses remain at the patient's side after breaking the bad news to clarify the terms used or provide them with support and comfort[19].

Nurses rely on Telecare to provide continuous assistance, although there is little evidence of its use. However, studies show that this resource is a tool that expands and improves access to palliative care providers, contributing to an increased sense of security and protection and establishing a close connection with patients and families[20].

Telenursing is an attribute that can assist nurses in implementing effective and quality care with a positive impact on health services[21].

In addition, in the context of telehealth-based palliative care, information science, through telecommunication and videoconference technology, allows the health provider to communicate and offer care to individuals from anywhere[20].

A study of advanced practice nursing with the approach of nurse-patient interactions corroborates the clinical praxis of nurses in Brazil. In this scenario of vulnerability, even if working for

unregulated hours, we see the central components of the philosophy of palliative care, such as communication and a multi-professional approach to offer physical, psychological, social, and spiritual comfort. Therefore, there are several challenges to decision-making and care coordination as an essential part of community care[22]. In community models, nurses can be crucial in coordinating, delivering, and supervising care at home and in the community, collaborating indirectly with lay community health professionals[6]. The literature suggests that nurses with experience in advanced practice can contribute to the innovation of the current model of access to palliative care. One study evaluated a new role for APN in a multidisciplinary palliative care service. In this study, patients under the responsibility of APN had a reduction in admissions to emergency services compared to the remainder of the service (17.0% vs. 27.2%). In addition, there was no emergency admission for patients in terminal care, and they could choose the preferred place for death (87.2% *vs*. 72.2%). In addition, the multidisciplinary team revealed, in its majority (93.3%), that the role of APN had a beneficial impact on patient care since it was comprehensive, safe, and met the needs of the patient[23].

In addition, a recent scope review conducted in Australia[24] identified several well-defined nursing roles in the provision of palliative care in primary health settings. With proper training and support, GP nurses can initiate and facilitate conversations about advanced care planning with patients. In situations where access to specialists is unfeasible, APN offers specialized care. In addition, palliative care coordinated by nurses seems to provide more integrated care, which increases the potential for collaborative primary care and may effectively reduce hospitalizations.

Limitation

The difficulty in describing this study was related to the lack of clarification and regulation of advanced practice nursing in Brazil, since there is still a great deal of confusion in the differentiation of the nomenclatures and competencies of advanced practice nurses. Despite the progress in discussions on this relevant topic for developing nursing as a discipline, science, and research, standardization is still necessary.

CONCLUSION

In the context of advanced practice nursing in Brazil, there is a growing movement, with several specialized areas of nursing standing out for their activities and scientific research. Despite the absence of formal regulation in the country, this scenario has contributed to the implementation of advanced practice nursing throughout Latin America.

The role of nurses in primary care with a palliative care approach from the perspective of the compassionate community project has shown to be a strong practice of autonomy and articulation of actions with the interdisciplinary team to provide care to ill individuals in their end-of-life phase.

It is worth mentioning that the role of nurses in Advanced Practice is not focused on transforming nurses into physicians, given the different professional responsibilities that each role entails. However, they have specialized knowledge bases, complex decision-making skills, and expanded clinical competencies, enabling them to offer more comprehensive solutions in their practice. Through appropriate regulation and legislation, Advanced practice nursing could increase the scope of decision-making by facilitating referrals to other healthcare professionals, such as specialty physicians, and prescribing pre-established medications by adhering to rigorous protocols. This could accelerate health care delivery in a country marked by vast dimensions and unequal distribution of health services and professionals.

The evolving scenario of advanced practice nursing in Brazil shows the power of specialized nursing roles and their impact on health. The involvement of nurses in palliative care through the Compassionate Community project emphasizes autonomy and collaborative capacity. Advanced practice nursing, when properly regulated, can enhance nurses' decision-making capacity, paving the way for more efficient health interventions and improving the overall health landscape.

CONFLICT OF INTERESTS

The authors have declared that there is no conflict of interests.

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