



## ACADEMIC EXPERIENCES IN AN EDUCATIONAL PROGRAM IN THE NETWORK OF CARE FOR DISABLED PERSONS

*Vivências acadêmicas em programa de educação na rede de atenção a pessoas com deficiência*

*Vivencias académicas en programa de educación de la red de atención a personas con discapacidad*

**Luana Escobar dos Santos**

Federal University of Santa Maria (*Universidade Federal de Santa Maria - UFSM*) - Palmeira das Missões (RS) - Brazil

**Fabiéli Vargas Muniz Schneider**

Federal University of Santa Maria (*Universidade Federal de Santa Maria - UFSM*) - Palmeira das Missões (RS) - Brazil

**Vera Lucia Freitag**

Federal University of Rio Grande do Sul (*Universidade Federal do Rio Grande do Sul - UFRGS*) - Porto Alegre (RS) - Brazil

**Isabel Cristina dos Santos Colomé**

Federal University of Santa Maria (*Universidade Federal de Santa Maria - UFSM*) - Palmeira das Missões (RS) - Brazil

### ABSTRACT

**Objective:** To report experiences in the academic training of nurses in undergraduate schools through extension activities addressing the care of the disabled person. **Data Synthesis:** Tutors, preceptors and students carried out activities at the Association of Parents and Friends of the Exceptional Children (Associação de Pais e Amigos dos Excepcionais – APAE) in the municipality of Palmeira das Missões, Rio Grande do Sul, Brazil, during the period from 2013 to 2015. Activities included lectures and educational activities addressing different subjects targeted at regularly enrolled students and parents and/or guardians followed by discussions with different health professionals. **Conclusion:** The program contributed significantly to the training of those involved and allowed them to recognize the difficulties faced by people with special needs and know the system and the proposals targeted at this public, thus contributing to the health service.

**Descriptors:** Traineeships; Disabled Persons; Education, Nursing.

### RESUMO

**Objetivo:** Relatar experiências vivenciadas na formação acadêmica de enfermeiros em curso de graduação por meio de atividades de extensão abordando o cuidado à pessoa com deficiência. **Síntese dos Dados:** Realizaram-se atividades por tutores, preceptores e acadêmicos na Associação de Pais e Amigos dos Excepcionais (APAE) do município de Palmeira das Missões, Rio Grande do Sul, Brasil, durante o período de 2013 a 2015, por meio de palestras e atividades educacionais sobre diferentes assuntos voltadas aos alunos devidamente matriculados e também pais e/ou responsáveis, proporcionando discussões com diferentes profissionais da área da saúde. **Conclusão:** O programa contribuiu significativamente para a formação dos envolvidos, permitindo reconhecer as dificuldades enfrentadas pelas pessoas com necessidades especiais e conhecer o sistema e propostas voltadas a esse público, assim contribuindo com o serviço de saúde.

**Descritores:** Estágios; Pessoas com Deficiência; Educação em Enfermagem.

### RESUMEN

**Objetivo:** Relatar las experiencias vividas durante la formación académica de enfermeros de curso de grado a través de actividades de extensión sobre el cuidado de la persona con discapacidad. **Síntesis de los datos:** Se realizaron actividades con tutores, preceptores y académicos de la Asociación de Padres y Amigos de los Excepcionales (APAE) del municipio de Palmeira de las Missões, Rio Grande do Sul, Brasil, durante el período entre 2013 y 2015 con ponencias y actividades educacionales sobre distintos asuntos dirigidas a los alumnos matriculados y también a los padres y/o responsables generando discusiones con distintos profesionales sanitarios. **Conclusión:** El programa ha contribuido significativamente para la formación de los involucrados permitiéndoles reconocer las dificultades afrontadas por las personas con necesidades especiales y conocer el sistema y las propuestas dirigidas a ellos así como contribuye para el servicio de salud.

**Descritores:** Pasantías; Personas con Discapacidad; Educación en Enfermería.



## INTRODUCTION

People with disabilities are – first and foremost – people. They are people like any other people, with protagonisms, peculiarities, contradictions and singularities. People who fight for their rights, who value respect for dignity, individual autonomy, full and effective participation and inclusion in society, and equal opportunities, which shows, therefore, that disability is just another characteristic of the human condition<sup>(1)</sup>.

This subject is important nowadays and it involves a complex set of elements related to health, education, rights and social inclusion. Measuring the magnitude of disability in Brazil, both in quantitative and qualitative terms, is challenging due to the lack of scientific production related to these situations in the national scenario. The data obtained by the 2010 Census are far behind when compared with the realities observed worldwide. According to the IBGE<sup>(2)</sup>, 34% of the population living in a municipality located in Northern Rio Grande do Sul have some kind of disability, such as visual, hearing, motor or mental disabilities. Most of these disabilities have been acquired throughout life, which demonstrates the need for continuous health actions and the importance of discussing and building care networks focused on disease prevention, health promotion and recovery, and, subsequently, cure and rehabilitation.

The measurement of the reality of people with disabilities reinforces the importance of the subject as a priority area of investments in the different fields, especially in the health field, thus favoring the formulation of policies that envisage the production of citizenship for this public. In addition, the construction of the Network for the Care of the Person with Disabilities communicates with the 2016/2019 National Health Plan<sup>(3)</sup> to tackle the challenges of improving SUS so that the population can have access to quality services based on equity and commitments agreed in the health care network, especially with the articulation of the services integrated into this proposal and their intersectoral articulation.

The Education through Work for Health Program (*Programa de Educação pelo Trabalho para a Saúde – PET/Saúde*) - Health Care Networks, in the line of Care for People with Disabilities, is associated with the development and expansion of the groups, constructed based on curricular components, of extension and research projects, thus contributing to the investments by the Unified Health System (*Sistema Único de Saúde – SUS*) in the region to produce and strengthen primary health care. In addition, the program seeks to interfere in the training of health workers, both university teachers and students and regional network workers. The points of the network which integrate the implementation of the proposal of the “Education through Work for Health Program – PET/Health Care Networks in the Line of Care for People with Disabilities”, comprised six Family Health Strategy (*Estratégia Saúde da Família – ESF*) centers which cover 60% of the municipality of Palmeira das Missões, Rio Grande do Sul; the Primary Health Care Centers (*Unidades Básicas de Saúde – UBS*); the Center for Planning and Women’s Health Care (*Centro de Planejamento e Atenção à Saúde da Mulher – CEPAM*); the Palmeira das Missões Charity Hospital (*Hospital de Caridade de Palmeira das Missões – HCPM*); the Urgent Medical Aid Service (*Serviço de Atendimento Médico de Urgência – SAMU*), which consists of two life support units – one basic support unit and one advanced support unit; and the Association of Parents and Friends of the Exceptional Children (*Associação de Pais e Amigos dos Excepcionais – APAE*). In this process, more emphasis was placed on regionalization<sup>(4)</sup>, with actions intended to implement the 15<sup>th</sup> Regional Health Coordination Office (*Coordenadoria Regional de Saúde – CRS*) of the state of Rio Grande do Sul<sup>(5)</sup>.

The design of the care networks emphasized the development of the territorial network of the regions of the 15<sup>th</sup> and 19<sup>th</sup> CRS, with research on equipment, network points, installed capacity in primary health care, health work, and management. This work provided support for decisions regarding the services required for the region and indicated the weaknesses of the network. The project presented herein sought to strengthen primary health care. Thus, the activities developed by tutors, preceptors and students were based on the strengthening of care networks and sought to strengthen them and set them as spaces for extended clinical services, permanent education, problematization, social participation, professional education and shared management centered on the user.

Activities common to all lines of care included: Flowcharts to analyze services and lines of care; therapeutic project for different priority networks; participation in meetings of the Regional Health Coordination Office of the 15<sup>th</sup> region of the state of Rio Grande do Sul; support to teams from the different production centers that make up the network; articulation with the academic community and social movements; meetings with teams and members of the networks; talking circles to address types of care and management; experimentation in networking and co-management processes.

With regard to the alteration of the care and management model, it is agreed that there is an urgent need to create conditions for overcoming the characteristics of what is known as the “model focused on the expectation of cure of acute patients” towards a model focused on the expectation of care and monitoring of chronic situations capable of tackling the complex problems that the Brazilian society has presented to SUS<sup>(6)</sup>.

This network resulted from a proposal that sought to promote articulation with the ESF; specialized care actions, represented by the Association of Parents and Friends of the Exceptional Children; and hospital care in the Palmeira das Missões Charity Hospital and in the 15<sup>th</sup> Health Region. Given that, this paper aims to report the experiences lived in the academic training of undergraduate nurses through extension activities addressing the care of people with disabilities.

## DATA SYNTHESIS

The Education through Work for Health program – PET Health/Health Care Networks was developed by interconnecting the Federal University of Santa Maria (*Universidade Federal de Santa Maria – UFSM*) – Palmeira das Missões Campus, the Palmeira das Missões (PM) Municipal Health Secretariat (*Secretaria Municipal de Saúde – SMS*) and the State Health Secretariat through the 15<sup>th</sup> and the 19<sup>th</sup> CRS (15<sup>th</sup> Health Region). It consists of several proposals, actions and thematic axes which cover these areas and are focused on disease prevention and health promotion. Its main objective is to strengthen health care networks by implementing priority care lines, enhancing primary care as a coordinator of care and improving the quality of health care at various points in the network.

The dialog with the different types of services allowed to visualize the situation of the network of Care for the Person with Disability in the analyzed municipality. The ESF centers develop activities aimed at this public in the different stages of life. They include: preventive, educational and care actions; guarantee of the right to medical and nursing consultations; home visits; dental care; examinations; dispensation of medications provided by the unified health system; referral to the state-run facilities for orthoses and prostheses services. The APAE multidisciplinary team carries out an average of 412 procedures/month and serves both spontaneous demand and users referred by schools, the regional health coordination office, and pediatricians.

In this regard, the main objective of this proposal was to strengthen health care networks by implementing priority care lines, enhancing primary care as a coordinator of care and improving the quality of health care in the various points of the network. In addition, it also sought to develop a line of care for this group of users; ensure specialized care; ensure accessibility policies; provide early investigation of abnormalities during pregnancy; promote the social inclusion of the group; carry out health promotion and maintenance activities; create specific protocols for the care of people with disabilities; and guarantee home care for the person with disability and his/her family with a view to integrating the actions through the knowledge of the reality of the users.

Examples of actions that have already been carried out and incorporated into the project are: institutional support to the 15<sup>th</sup> CRS team; participation in updating the Municipal Health Plan of the municipality and Regional Plan for Permanent Education; matrix support to the ESF teams of the region; support to the management team of the Municipal Health Secretariat of the municipality.

The activities of the PET Networks were carried out in 2013 and in 2015 through activities carried out in APAE. This project counted on six preceptors and twelve university students/scholarship holders from two undergraduate schools: the School of Nursing and the School of Nutrition of the UFSM.

In APAE, activities were carried out with nursing students, two preceptors – nurses who worked in Family Health Care centers, one social worker and one psychologist. Generally, the activities were carried out in groups or in pairs during eight hours per week.

We proposed a schedule of eight hours a week for the development of activities such as: meeting with coordinators and tutors (conducting group); talking circle with emphasis on management and coordination with tutors and preceptors; work in the Production Centers (services to which preceptors and students are affiliated), where the activity was permanent in two shifts/week during the whole project period; and meetings with all the members of the group.

The activities were directly associated with the demand for the care of people with disabilities and were carried out through learning workshops with students using playful instruments to facilitate the understanding of the analyzed subject.

The meetings in APAE aimed to discuss and decide which theme should be addressed in the school. Then, the preceptors working in the environment and the students planned and organized the workshops. Some of the themes addressed included: lectures and activities related to personal hygiene, cineclubs with students, and discussion about sexuality with parents and/or guardians of children and adolescents.

However, such experiences were fundamental for students' learning as the practice of nursing care require the development of strategies to help children and adolescents with disabilities and their families become protagonists and makers of their own history and capable of changing their reality, thus breaking the standards of normality imposed by society and achieving beneficial results<sup>(7)</sup>.

Some the constructs that resulted from the workshops related to body hygiene carried out with students were the collection of donated materials in the city to make personal hygiene kits to be distributed to APAE students.

In this regard, body hygiene was set as a quality aspect for a healthy life. Physical hygiene routines begin in childhood, with emphasis on the importance of orderly practice. The experiments of carrying out activities that can be performed together with the children in the school space, such as hand washing and tooth brushing, have a great impact on learning<sup>(8,9)</sup>.

With regard to hygiene, one of the health professionals invited to participate was a dental surgeon who explained to the students how to brush their teeth correctly and later conducted a tooth brushing activity. After that, the students who needed intervention were scheduled to be seen at the professional's dental office and then referred to intervention.

Dental care is a standard component of comprehensive health care for children with special needs. Therefore, oral health care for these patients should be a routine and efficient practice. The most appropriate treatment would be prevention and control of

oral health because restorative treatment can often not be performed in an outpatient clinic. Furthermore, treatment performed under general anesthesia is a risk for the patient and is costly to the public authority<sup>(10,11)</sup>.

The Health Promotion School seeks to: increase information, agility and training for self-care and the prevention of risk behaviors in educational occasions; provide a critical and reflexive analysis of values, behaviors, social conditions and ways of life, thus seeking to strengthen anything that contributes to human health and development; promote the participation of all the members of the school group in decision making to rethink strategies in search of quality in care during health education actions; and contribute to the promotion of social affinities among people<sup>(12,13)</sup>.

Health actions, both educational and curative, aim to provide human groups with the highest level of health, thus allowing a better quality of life. The educational process is necessary in dentistry and it aims at behavior changes that are essential for maintenance, acquisition and promotion of care<sup>(14,15)</sup>.

There was also a discussion with the parents and/or guardians of students of the institution regarding sexuality. Such discussion was suggested by them in view of some difficulties experienced. Initially, the mothers were welcomed and after that a talking circle was held with the presence of a gynecologist to answer their questions about the subject.

Article 25 of the Convention on the Rights of Persons with Disabilities<sup>(16)</sup> directly addresses the right of access to health care programs, including sexual and reproductive health. In the document, sexuality is defined not only as sexual instinct nor activities that depend on the functioning of the genital apparatus; instead, it has great plasticity and is related to the personal history of each individual. Each person has his/her own way of expressing his/her sexuality because his/her way of acting and feeling is something quite individual.

The principle of equal rights for all people with and without disabilities means that the needs of every individual are of equal importance and should form the basis of social planning, with employment of all the resources in order to guarantee an equal opportunity of participation to each individual. All disability policies must ensure disabled people's access to all community services, as provided for by the Brazilian legislation on persons with disabilities<sup>(17)</sup>.

Other activities included visits to the homes of users who needed follow-up, active tracing of students who were not attending classes, and cineclubs for mothers. For students, there were group activities in which movies were used as a way to address the social inclusion of people with disabilities and life lessons.

Group work is a valuable space for learning and sharing experiences, and it can be developed through different approaches focusing on the needs of the participants and in different scenarios. However, it requires qualified professionals. This model is an important factor in a person's healthy development, with benefits for the promotion of cognitive integrity and well-being. Success is directly related to the synchronism between participants' expectations and demands<sup>(18,19)</sup>.

An event was held in partnership with the preceptors in the city council to celebrate the Autism Day. Previously, society was informed of the date and everyone was invited to participate and also to put in their businesses the blue color as a symbol. During the event, there was a movie presentation and a talking circle about the subject, highlighting the importance of early diagnosis and group activities as a means of promoting health and space for discussion and learning.

The talking circles allow the conduction of dialog meetings and provide possibilities of production and redefinition of senses, knowledge and also exchanges of knowledge between the participants. The choice is based on the forms of power relations. The participants are engaged and they dialog as historical and egalitarian actors who behave critically and reflectively before a fact. The image of the master as the core of the method is broken and speech appears as a symbol of values, precepts, culture, learning and discourse<sup>(20)</sup>.

During the activities, the main action of the group included the promotion of health, both at school and in other places where work was done, seeking to improve the quality of life by applying the theory acquired in the classroom during undergraduation.

The Tutorial Education Program has been offering a training field that privileges this type of care, expanding knowledge not only for project members, i.e., future health professionals, but also for the groups that receive them, thus valuing care in its multidimensionality. This exchange movement allows the construction of knowledge, articulating the individual and collective dimensions of the educational process and favoring the empowerment of everyone involved.

The objective of the PET is in line with the development of this health education work as it includes students in these spaces. It improves professional training, which needs to be focused mainly on health promotion and disease prevention, since the program has provided a broader view of its cultural, educational and bureaucratic aspects to its participants. In addition, one of the great highlights of the project is the autonomy that the student acquires to create proposals for the improvement of both the academic environment and society in general, which is an essential characteristic for a future quality professional practice<sup>(21-23)</sup>.

The PET also allowed students' insertion in the health services, since during the nursing undergraduate program there were no courses directly related to this subject, which caused the scholarship holders to approach this public and to study about what would be addressed and what was the best way of interacting to have everyone contribute and participate. The search for knowledge about the proposed theme made it possible to share the acquired knowledge, thus reaching the proposed goals.

Another thing learned from the PET project was the possibility of interacting with different sectors and professionals in the health field (psychologists, social workers, nutritionists, physicians, and others) from the beginning of undergraduate studies,

which strengthened the group and provided a broad learning experience with exchanges of knowledge of different areas, which made the service work in a multidisciplinary way.

The project brought benefits to the students and also to APAE, where the activities took place. Some of the benefits were: improvement of students' access to health care and self-care and the completion of tasks that made them more independent. Thus, there was also social contribution through the insertion of health students and professionals in the school to carry out the most diverse activities, clarify doubts and promote health.

## CONCLUSION

Participating in the PET/Health Care Networks, line of Care for the Person with Disability, was a rewarding experience for both university students and APAE students and parents given the presentation of themes of collective interest and activities to promote the health of these families, thus favoring the exchange of knowledge.

The project contributed positively to the students by providing unique experiences during undergraduate studies through different experiences lived with this public. In addition, it brought the public and the system and the proposals targeted at them closer.

Extension programs are extremely important in the academic environment because they enable students to enter into different services and carry out practical activities, thus acquiring more knowledge about their field of study.

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**Mailing address:**

Luana Escobar dos Santos  
Av. Independência, 535  
Bairro: Centro  
CEP: 98300-000 - Palmeira das Missões - RS - Brasil  
E-mail: luana\_escobar93@hotmail.com