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Prioritizing self care: essential experiences for caregivers of children with disabilities

ABSTRACT

RELATO DE EXPERIÊNCIA

MARIA EDUARDA GOULART TORRES¹ ,
GABRIELA RODRIGUES MORAIS¹ ,
JOÃO GABRIEL BRANDÃO DA COSTA
LIMA¹ , LORENA RODRIGUES
DE CARVALHO¹ , CARLA DE
PAULA SILVEIRA¹ , ISABELA MIE
TAKESHITA¹ 

¹ DISCENTES DA FACULDADE CIÊNCIAS MÉDICAS DE MINAS GERAIS. BELO HORIZONTE, MINAS GERAIS, BRASIL.

² DOCENTE DA FACULDADE CIÊNCIAS MÉDICAS DE MINAS GERAIS, BELO HORIZONTE, MG. ALAMEDA EZEQUIEL DIAS, 275, BELO HORIZONTE/MG - BRASIL. EMAIL: CARLA.SILVEIRA@CIENCIASMEDICASMG.EDU.BR

³ DOCENTE DA FACULDADE CIÊNCIAS MÉDICAS DE MINAS GERAIS, BELO HORIZONTE, MG. ALAMEDA EZEQUIEL DIAS, 275, BELO HORIZONTE/MG - BRASIL. EMAIL: ISABELA.TAKESHITA@CIENCIASMEDICASMG.EDU.BR

Introduction: The diagnosis of a child's disability significantly affects family dynamics, especially for those responsible for caregiving, which is most often the mothers. In this perspective, the new caregiving demand can lead to overload, stress symptoms, and difficulty in interpersonal relationships. Furthermore, self-care is constantly neglected by this audience, despite the fact that the quality of life of children is directly influenced by the health of the family members who take on this role. **Objective:** To report the experience of Medical, Physiotherapy, and Psychology students participating in a university extension program aimed at caregivers of children with disabilities, focusing on self-care. **Experience Report:** Ten meetings were held with this audience at a nonprofit institution with the goal of promoting self-care, as well as addressing other related topics. **Final Considerations:** The caregiving role assumed by the family member may lead to negative impacts on their physical and mental health. Therefore, it is necessary to balance childcare, with self-care being fundamental to promoting resilience and reducing caregiver stress. Intervention programs focused on self-care should be implemented, also considering the improvement of care provided to children with disabilities.

Keywords: Self Care; Disabled Children; Caregivers; Health.

INTRODUCTION

Dreaming about your child begins before birth and involves different emotional, social and contextual aspects. In this perspective, a child's diagnosis of disability will significantly affect the entire family dynamic, generating social, psychological, educational, financial and emotional challenges with the child's care¹. In this context, mothers primarily bear the responsibility for caring for children. From this perspective, based on a study carried out with mothers of children diagnosed with various disabilities, the main effects of this context include increased levels of anxiety, depression and, consequently, a reduction in the quality of life of these mothers. The main factors for these effects are the fact that, accompanied by the diagnosis, there is an increase in demand for continuous and specific care, promoting overload on the family member responsible for the care and the impact on their occupational activities, social relationships and emotional conditions².

Therefore, while mothers or family caregivers in charge invest in the child's care, they neglect self-care, and are consumed by the feeling that, by promoting some activity for themselves, they would be taking away the time allocated to their children's needs³.

It is extremely necessary, especially in the context of disability, to reflect on self-care, since the levels of depression and esteem of these mothers are health-protective variables⁴. In parallel to this, the quality of life of mothers is a factor that influences the upbringing of their children, which emphasizes the importance of interventions in this scenario⁵.

In this context, it is necessary to develop interventions aimed at preventing and promoting the health of caregivers, most of whom are mothers of children with disabilities, to improve the quality of life of the family as a whole.

University extension provides an important dialogue between the higher education institution and different sectors of society, enabling the exchange of knowledge and the promotion of institutional and social changes, among other impacts⁶. Therefore, university extension is an opportunity to develop these interventions.

This article aims to report the experience lived by Medicine, Psychology and Physiotherapy students in the "Take Care of Yourself" extension project performed in the first semester of 2023, in partnership with a private higher education institution and a philanthropic institution from Belo Horizonte. The extension program aimed to support informal caregivers of children with disabilities. It brought the theme of self-care, aiming to raise awareness and value the topic.

EXPERIENCE REPORT

The university tripod consists of teaching, research and extension. Extension has the role of articulating teaching and research with the community, translating university knowledge to society to democratize learning processes and make research relevant to the population⁷.

A private higher education institution located in Belo Horizonte, Minas Gerais, has been developing the extension project "Take Care to Care" since 2021, which

has its main goal the theme of self-care for informal caregivers, who are, mostly mothers of children with disabilities. During the months from March to July 2023, continuing the project, the actions were developed in a philanthropic institution located in the city of Belo Horizonte.

The profile of caregivers at that institution is predominantly women with different age groups. The entity serves approximately five thousand children with various types of disabilities and is maintained through the collaboration of people, companies and civil society entities. The institution aims to promote improvements in quality of life, ensure the physical integrity of people with disabilities in terms of neuropsychomotor rehabilitation, support and advise their families.

Participation in the extension project took place through an online selection process, where candidates answer questions that would be evaluated blindly by the project supervisor, such as; availability of time, student interest, knowledge about extension activities and their impact on the student's academic and personal development. Each answer was evaluated and scored and the candidates who secured the highest scores were approved.

The extracurricular extension project happens every six months and each semester the Research and Extension Sector of the Higher Education Institution provides a new notice for the selection of academics to continue and be linked to the "Take Care of Yourself" project.

The respective extension project covers students from undergraduate courses in physiotherapy, medicine, nursing and psychology. The four students from each area approved to carry out extension activities were divided into two pairs in which each week one of them performed the actions, alternately. Initially, the first meeting was held, led by the supervisors, online on the "Google Meet" videoconferencing platform, with the aim of presenting a comprehensive perspective of the project, in addition to presenting all approved members.

Subsequently, three meetings that are more weekly were held, synchronously, to discuss the methodology that would be used in each of the institutions, since each two pairs of academics were responsible for a different entity, in addition to presenting the intervention proposals that they were going to be used in the first meeting with mothers of children with disabilities. Furthermore, students were encouraged to structure a critical and reflective view of the main objective of the activity, through the provision of articles on the themes.

After the third meeting, meetings were held biweekly to align and plan the activities to be carried out, discuss the themes and better understand the topics to be presented to the public at the meetings. The importance of these moments is highlighted to promote a better understanding of the themes before meetings with mothers, along with guidelines for preparing the materials used and ideas for dynamics capable of facilitating interaction.

Face-to-face meetings with mothers of children with disabilities were held on Fridays at 1 pm and each pair,

weekly and alternately, performed the activity at the clinic, totaling 10 meetings during the execution of the project. The methodology used in each meeting was in the conversation circle format, where the parents were encouraged to participate in the theme that would be worked on through a dialogued exhibition, in addition to the use of dynamics to encourage greater interaction between them.

It is noteworthy that the participation of mothers was optional, creating a democratic space for speaking and listening. Each meeting lasted an average of 60 minutes and was attended by approximately 5 mothers. The topics covered in the conversation circles were: presentation and objectives of the “Take Care of Yourself” project, rights related to children with disabilities, self-esteem and self-care, support network-



PHOTO OF ONE OF THE MEETINGS' END

ks, challenges related to discrimination and prejudice, stress, anxiety and overload in the face of the routine.

It is necessary to highlight that the topics covered were chosen based on the interest and desire of the participants, since the focus was to create a space led

by these mothers, highlighting their needs and promoting a horizontal dialogue. From this perspective, the academics, in addition to providing information, were able to position themselves as mediators of the exchange of experiences between mothers, promoting a more interactive and reflective environment.



STUDENT OF THE PROJECT HELPING TO FILL OUT THE SELF-CARE CHECKLIST WITH ONE OF THE CAREGIVERS

Associated with the interventions carried out, folders were handed out with contacts for Government Institutions and support NGOs, pamphlets with a self-care checklist, as well as methods to relieve stress and anxiety, such as breathing techniques. Such activities aimed to promote self-care and health promotion.

At the end of each meeting, the academics encouraged joint analysis with the mothers on how the topic discussed influenced or had an effect on promoting these women's self-care. Moreover, they sought to hear suggestions or criticisms to improve future dialogues. In this way, the impact of the interventions and the effectiveness of the work carried out were analyzed, in order to make possible changes to achieve the extension objective.

THEORETICAL REFLECTIONS

For the first meeting, the academics defined a time to present the project and its members, whose main objective was to enable the creation of a bond between mothers, caregivers and students, enabling the most diverse topics to be worked on. At this meeting, participants received a pamphlet with information about the project, the students responsible, as well as the dates and times when the meetings would take place.

The second meeting addressed the topic related to the rights present in the 1988 Federal Constitution regarding people with disabilities. In this conversation, we sought to identify programs offered free of charge that facilitate transportation to health services, in addition to promoting a space for exchanging experiences. The students created a folder with the contact details of ins-

titutions capable of helping these mothers obtain information about benefits offered to people with disabilities in relation to orthotics, prostheses and wheelchairs. The mothers present at this meeting did not have children who use these devices, however, the theme was maintained so that these mothers could share the information with other mothers, thus disseminating information and knowledge to those who need it.

In 2012, the National Urban Mobility System was created, a body that aims to organize modes of transport and infrastructure with the aim of ensuring that all Brazilians can move around the national territory, taking into account the guaranteed right to come and go all citizens by the Declaration of Human Rights and the Federal Constitution. Even nowadays, we see people with disabilities who have great difficulties accessing this fundamental right⁸.

For meetings three and four, students researched and talked about mothers' self-care and self-esteem. When analyzing the profile of the participants, it is noted that most mothers leave the job market after the birth of a child with a disability and begin to neglect self-care, ceasing to carry out activities that were previously enjoyable to them or even not seeking medical care for herself⁹. During the conversation circles, the mothers reported that they had begun to organize their lives around the needs and routines of their children. They avoided activities and places they used to frequent, as it was impractical to take the child with them. Additionally, they often lacked anyone to leave the child with. As a way to encourage mothers to return to the activities they liked, the students developed a "self-care checklist", the idea consists of a list

filled out by the mothers themselves with activities that they would like to carry out or return to carrying out. As they manage to include such activities in their daily lives, they can “cut” the item from the list or add a new item, creating and stipulating goals that they can apply in their daily lives with the aim of rescuing this look of care for themselves. In the end, the mothers reported that there were indeed activities that they would like to do again, however, they still had difficulty fitting them into their routine, along their effort and attempt to make the changes was clear.

At the request of the participants themselves, in the fifth and sixth meetings the topic of the conversation was about support networks and their importance for mothers and children. Many participants reported that their support network was made up of just one person, either their partner or an older child, however, there were reports of mothers who did not have any support network, as the child’s parent was not present on a daily basis -day and the family did not accept the child’s clinical condition.

The absence of support networks is a very common reality among these women, a fact that affects the quality of life not only of the caregivers, but also of the children. Because of this lack of support, physical and mental exhaustion arises, generating a state of stress and chronic fatigue that can be reflected in the child. Another point is reports of social isolation, which can have various causes. These include the specific needs of the child, society’s prejudice against those who are different, and a lack of accessibility to the city’s various spaces, among other factors, which always end with a feeling of loneliness for these women^{10 11}.

At the seventh meeting, topics related to stress and anxiety were addressed. There are multiple stressors for these women; anxiety about the future and development of children, lack of support networks, financial issues and others¹². These mothers dedicate themselves to caring for their children, other activities related to daily tasks, and most of the time are not socially recognized, presenting high levels of stress and low quality of life.

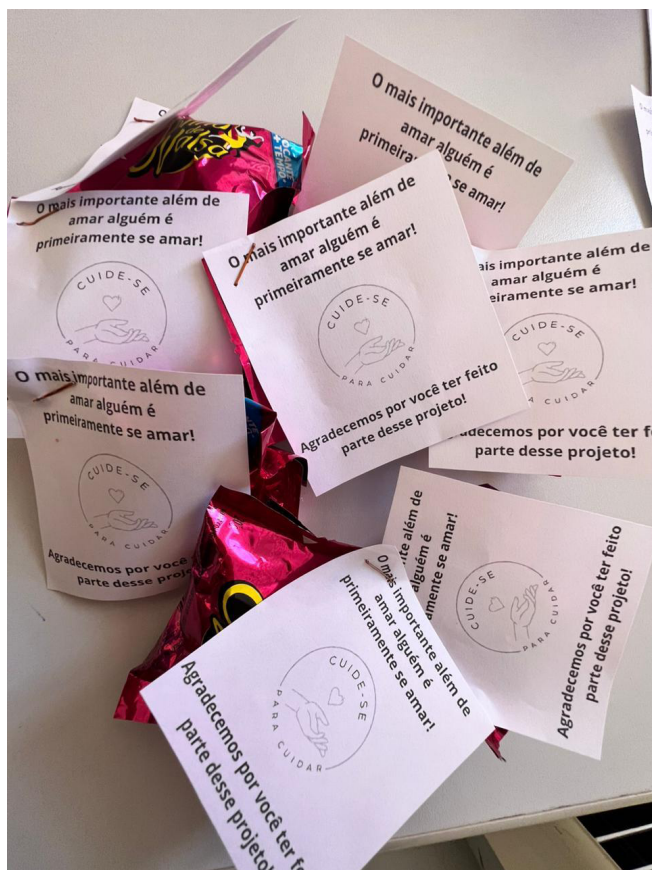
As a suggestion proposed by students to reduce stress levels, physical exercise was mentioned. The literature has already shown how practicing physical exercise can reduce symptoms of anxiety, stress and depression, in addition to increasing the feeling of pleasure¹³.

Unfortunately, the mothers were unable to participate in the eighth meeting because they were receiving feedback from the professionals caring for their children at the institution that day. The theme chosen for the ninth meeting was food selectivity faced by children with various pathologies, especially those with Autism Spectrum Disorder (ASD). Food selectivity consists of the refusal or lack of interest in certain foods, often related to a sensory sensitivity to the texture of the food, therefore, it greatly reduces the variety of these children’s diets¹⁴.

It is also worth highlighting children’s preference for ultra-processed foods. This food selectivity can culminate in nutritional deficiency and greater health risk¹⁵. During the conversation held, it was possible to observe that most of the mothers and caregivers present at the meeting go through similar and challenging situations, in addition to reports about the difficulties

they face when trying to introduce new foods into their children's diet and the adversities generated for a diet poor in nutrients. The tenth and final meeting did not have a specific theme, a get-together was held between the students and their mothers; a relaxed moment filled with thanks.

For the students, this project was of great value, allowing countless learning, possibilities to develop and train skills, such as active listening, empathetic communication and teamwork, to valuable knowledge of the caregivers' experiences.



MESSAGE ENDING THE PROJECT AND THANKING CAREGIVERS FOR THEIR PARTICIPATION

FINAL CONSIDERATIONS

Implemented more than 2 years ago, the extension project "Take Care to Care" made it possible to welcome countless caregivers, for the first time in person this semester. The target audience of the project, most of them being women and caring mothers, presented an emotional lack when it came to themselves, an aspect worked on throughout the project by the students to understand the context and guide them with a view to improving this aspect in their lives.

The continuity of self-care must be a daily practice in which participants must continue to develop in their daily lives, with "Take Care of Yourself" being just an opening for such caregivers to cultivate and acquire, such a habit continuously, always remembering to take care of others, it is essential to first take care of yourself.

Significantly, the project achieved its objective, demonstrating the importance of self-care for mothers who play the role of caregivers of disabled children, making it clear that the balance between dedicated care for the child and care for one's own well-being is essential for promoting physical and mental health.

At last, the experiences during the project highlight the need to implement support programs and targeted interventions to encourage self-care among these caregivers. By adopting these practices, they can strengthen their resilience, reduce stress levels and increase quality of life, allowing them to continue to provide care to their children. Furthermore, awareness about the importance of self-care must be disseminated.

minated among health professionals, family members and the community, in order to create a supportive environment that recognizes and values the journey of caring mothers.

In addition, this extension project served an important purpose. It created a space for discussions that built knowledge. This allowed academics to responsibly translate their work into practical activities within society. Furthermore, the project contributed to the scope of research and the social sphere, as its primary goal was to have a social impact. This aligned with the team's role and social nature. Therefore, it is seen that it had an educational, scientific character, to complement the academic and personal training of the participants, and mainly a social importance of significant proportions as it sought to solve existing problems of interest and need to society in diverse and accessible to them. Furthermore, it was an opportunity for essential inter-academic interaction in the field of health, as it created contact with students and professionals from the same and other areas to being a bridge between the faculty with its theoretical knowledge and the society together with everyday labor practice.

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