

Experiences of people with stoma in the workplace

Vivências de pessoas com estomia no mundo do trabalho

Vivencias de personas con estoma en el mundo del trabajo

Gilcemara Barbosa¹, Heloisa Campos Paschoalin¹, Rosângela Maria Greco², Sonia Maria Dias¹

ORCID IDs

Barbosa G  <https://orcid.org/0000-0003-0291-8555>

Paschoalin HC  <https://orcid.org/0000-0001-9765-1288>

Greco RM  <https://orcid.org/0000-0003-1147-276X>

Dias SM  <https://orcid.org/0003-0003-0365-9540>

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ABSTRACT

Objectives: “To understand how the insertion in the work occurs after the intestinal stoma” and “to describe the difficulties and facilities found by people with stoma in the work environment”. **Method:** Descriptive study, of a qualitative nature, performed with seven participants with definitive intestinal stoma. Data collection was realized in the Ostomy Patients Health Care Services of a municipality in Zona da Mata Mineira, in August 2014, using a semi-structured interview. In the analysis appeared three categories: the return to the workplace; the work and the person with stoma; difficulties and facilities in the work environment. Difficulties identified: lack of adaptation of the environment to its new condition, embarrassment, physical weakness, fear of receptivity and insecurity regarding the condition of the person with stoma. Facilities mentioned: adaptation of toilets by some companies, reception of the employer and co-workers, company support and type of profession. **Result:** It has been demonstrated that the work for these individuals has important representativeness. They continued to feel useful and able to overcome the difficulties imposed by the new reality. **Conclusion:** It is concluded that work is of paramount importance for the social reintegration of the person with stoma, and that nursing has a fundamental role in its adaptation and rehabilitation in the workplace.

DESCRIPTORS: Worker health; Stoma; Occupational nursing; Stomatherapy

¹Universidade Federal de Juiz de Fora – Faculdade de Enfermagem – Departamento de Enfermagem Aplicada – Juiz de Fora/MG – Brazil.

²Universidade Federal de Juiz de Fora – Faculdade de Enfermagem – Departamento de Enfermagem Básica – Juiz de Fora/MG – Brazil.

Corresponding author: Gilcemara Barbosa | Universidade Federal de Juiz de Fora – Faculdade de Enfermagem | Rua José Nunes Leal, 442/02 – Santa Luzia | ZIP Code: 36030-230 – Juiz de Fora/MG – Brazil | E-mail: gilbarbosa.mb@hotmail.com

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RESUMO

Objetivos: “Compreender como ocorre a inserção no trabalho após a estomia intestinal” e “descrever as dificuldades e facilidades encontradas por pessoas com estomia no ambiente de trabalho”. **Método:** Estudo descritivo, de natureza qualitativa, realizado com sete participantes com estomia intestinal definitiva. A coleta de dados foi realizada no Serviço de Atenção à Saúde da Pessoa com Estomia de um município da Zona da Mata Mineira, em agosto de 2014, utilizando-se entrevista semiestruturada. Na análise surgiram três categorias: O retorno ao mundo do trabalho; O trabalho e a pessoa com estomia; Dificuldades e facilidades no ambiente de trabalho. Dificuldades identificadas: falta de adaptação do ambiente à sua nova condição, constrangimento, debilidade física, medo da receptividade e insegurança frente à condição de pessoa com estomia. Facilidades citadas: adaptação de banheiros por algumas empresas, acolhimento do empregador e colegas de trabalho, apoio da empresa e tipo de profissão. **Resultado:** Foi demonstrado que o trabalho para esses indivíduos tem importante representatividade. Eles continuaram a se sentir úteis e capazes de superar as dificuldades impostas pela nova realidade. **Conclusão:** Conclui-se que o trabalho é de suma importância para a reintegração social da pessoa com estomia e que a enfermagem tem papel fundamental na sua adaptação e reabilitação no mundo do trabalho.

DESCRITORES: Saúde do trabalhador; Estomia; Enfermagem do trabalho; Estomaterapia.

RESUMEN

Objetivos: “Comprender cómo ocurre la inserción en el trabajo después del estoma intestinal” y “describir las dificultades y facilidades encontradas por personas con estoma en el ambiente de trabajo”. **Método:** Estudio descriptivo, de naturaleza cualitativa, realizado con siete participantes con estoma intestinal definitivo. La recolección de datos fue realizada en el Servicio de Atención a la Salud de la Persona con Estomía de un municipio de la Zona de la Mata Mineira, en agosto de 2014, usando entrevista semiestruturada. En el análisis surgieron tres categorías: El retorno al mundo del trabajo; El trabajo y la persona con estoma; Dificultades y facilidades en el ambiente de trabajo. Dificultades identificadas: falta de adaptación del ambiente a su nueva condición, vergüenza, debilidad física, miedo de la receptividad e inseguridad frente a la condición de persona con estoma. Facilidades citadas: adaptación de baños por parte de algunas empresas, recepción del empleador y colegas de trabajo, apoyo de la empresa y tipo de profesión. **Resultado:** Fue demostrado que el trabajo representa algo muy importante para ellos. De esta forma continuaron sintiéndose útiles y capaces de superar las dificultades impuestas por la nueva realidad. **Conclusión:** Se concluye que el trabajo es de suma importancia para la reintegración social de la persona con estoma y que la enfermería tiene un papel fundamental en su adaptación y rehabilitación en el mundo del trabajo.

DESCRIPTORES: Salud del trabajador; Estoma; Enfermería laboral; Estomaterapia.

INTRODUCTION

The stoma is a surgical procedure that consists in the exteriorization of a part of the human body, resulting in the opening of an external orifice, called stoma. In the case of intestinal stomization, its purpose is to divert feces to the outside¹.

Due to the assistance to the person with the stoma is also included in the scope of social rehabilitation, one must worry about their return to work activities as a way to promote the continuity of the work performed by the person before the surgery that resulted in stoma.

It should be clarified that the existence of the stoma brings to the individual changes in personal and social life due to his new condition². The person with the intestinal stoma is considered different because it distances itself from the standards considered normal by society, becoming stigmatized³.

There are those who socially restrict themselves or hide their physical condition from friends and colleagues for fear

of prejudice¹. The maintenance of work, in turn, becomes worrying for a large portion of these people, because the presence of a stoma may be able to profoundly change their professional life⁴.

Often, individuals in the middle of active life are faced with an illness for which they need to subject to a surgery that will definitely change their daily activity. Frequently, they are people who are responsible for keeping their homes and who now feel limited in their activities.

The difficulties associated with work and social interaction are related to the use of collector equipment, which can cause discomfort, insecurity due to flatulence, leaks and odors from the fecal content⁵.

The health policy of the worker guarantees the person with stoma the entitlement to practice their work activities; however these must be in accordance with their physical capacity and provide them with the entitlement to enjoy the employment quotas resulting from the National Policy for the Integration of the Person Carrier of Disability⁴.

The rehabilitation for the practice of the profession must go beyond the activities realized by the Social Security, since it is a dynamic process, a global assistance to the worker, which should also encourage companies to adopt the culture of the process of prevention, treatment, rehabilitation, readaptation and inclusion at work⁶. However, many companies have unprepared professionals to recognize the limitations of these individuals, ignoring their needs.

Scientific investigations, therefore, may provide subsidies so that the employer institution, co-workers and family members can assist the person with stoma to face with the difficulties originating from stomization, encouraging them to include themselves socially and offering them a better quality of life.

It should also be emphasized that work becomes important in socialization, in the achievement of self-realization and self-esteem of any individual, occupying a relevant role in people's lives. It is through work that people build their identity and achieve their social and financial status. The work, therefore, determines the quality of life and the survival of the individuals, becoming of increasing importance in the life of the population⁷.

When it falls ill, the worker is limited in its daily activities and is susceptible to permanently or temporarily withdrawing from its functions. These conditions may represent certain frustrations, such as suffering, reduction of the social role and reduction of autonomy⁸. In this way, the return to work can have a positive meaning in the life of the individual, restoring their social value.

In this sense, the insight of the experiences of people with stoma in the workplace may contribute to the acquisition of knowledge, since it is a subject that has not yet been studied, and also an important contribution to the academic degree of future health professionals.

OBJECTIVES

Considering the relevance of this topic, this research has the following objectives: to understand how reinsertion occurs in the work after the intestinal stoma and to describe the difficulties and facilities found by the person with the stoma in the work environment.

METHODS

A descriptive study of a qualitative nature was realized. Data were collected through a semi-structured interview in the Ostomy Patients Health Care Services, in a municipality of Zona da Mata Mineira, in August 2014.

The Service is composed of a multidisciplinary team, being represented by a stomatherapist nurse, a social worker, a psychologist, a medical coloproctologist, a nutritionist and an administrative agent. The study included seven people with definite intestinal stoma who returned to work after recovering from surgery, without any impediment to their work activities and who agreed to voluntarily participate in the study.

The interviews were recorded, with the authorization of the participants, in order to maintain the trustworthiness of the answers, being transcribed in totality. These interviews were coded by the letter E followed by a numbering (E1, E2, E ...), according to the order of each one. They were held in a quiet place, at a pre-scheduled time, according to the availability of each participant.

Data analysis was performed according to the Content Analysis, following the steps of pre-analysis, material exploration and treatment of results and interpretation of the data⁹.

The project was appreciated and approved by the Research Ethics Committee of the Federal University of Juiz de Fora under opinion n° 715.330.

RESULTS AND DISCUSSION

Among the participants, five were men and two were women. Age ranged from 50 to 75 years, four of them aged between 50 and 57 years, two between 63 and 67 years and one with 75 years. As for marital status, six were married, the majority of which had a partner, which could be a support for the person with the stoma, facilitating the adaptation and confrontation with the new condition of life.

The presence of a partner makes the individual feel more secure during the rehabilitation process, in addition to offering financial support, and the spouses can share the expenses⁴. Such support can also positively influence in the return to activities, including return to work.

As for schooling, two had completed elementary school, one had incomplete elementary school and four had college education.

Stoma time ranged from 5 to 27 years, with 5 to 7 years in four participants, 16 to 18 years in two and 27 years in one participant.

Working time ranged from 25 to 60 years, with 25 to 33 years in three, 40 to 45 years in two and 50 to 60 years in two. It is noticed that all participants worked for many years, which allows us to infer that this fact has an important meaning for these individuals, whether for the matter of survival or for other issues related to self-esteem and personal and social valuation.

When discussing the meaning of work in people's lives, it should be considered that it is through it that the man is able to transform nature, acquire new knowledge and gain new spaces in society, improving himself as a human being¹⁰.

Upon returning to the work environment after the stoma, only two of the participants remained performing in the same activities as before, while the others changed function due to their own desire or changes made within the company.

The period of return to the labor activities ranged from 1 month and a half to 9 years. It is perceptible that some took a longer time than others to return, due to the type of disease that each presented and/or complications as a result of the stoma.

After the systematic reading of the interviewees' speeches, three categories appeared: return to the workplace; the work and the person with the stoma; difficulties and facilities in the work environment, being described and discussed below.

The return to the workplace

Returning to social and professional life after the stoma surgery can represent a difficult time for the individual. It may experience a number of feelings such as fear, insecurity and anxiety about its new condition of life. The presence of a stoma requires specific cares with the device, with the peristoma skin and with the food, in addition to making social interaction difficult and favoring distance and isolation¹¹.

The confrontation of the new situation generated, in the interviewees, fear and insecurity. These feelings were related to the possibility of rejection by superiors and co-workers. They experienced the expectation of how they would be seen by their companions after performing the stoma. The demand for new needs and cares also made these people feel insecure and fearful about their work day:

I was afraid, not how I would face my activities, but how my superior would receive me, how I would face the new challenges in terms of working day. (E5)

Returning to work from then on represented to the worker a new and unknown situation, for which it still had no experience, thus generating anxiety and insecurity:

I was anxiously waiting for this because I always been used to work since I was fourteen and somehow, I was insecure. (E3)

For these people to insert themselves in the work scenario can become difficult due to the interaction with the fears and physical, social and psychological changes that can interfere in their return to the work activity⁴. Performing surgery to make the stoma, the adaptation to the collector equipment, and changing lifestyle can bring on symptoms of depression, anxiety, and feelings of fear and uncertainty about the future¹¹.

On the other hand, the desire to return to the routine of life and daily activities is also present and the person with stoma as soon as it is able to perform its daily activities manifests the desire to return to work. Going back to being a worker, realizes your previous tasks, and being able to ensure your living, becomes the individual stronger in front of potential problems.

At this stage, the effective participation of family and co-workers is important so that the person with the stoma feels welcomed and respected and can adapt more easily to their work environment. The challenges and difficulties to be earned overcome the physical issues, since the presence of a stoma can also interfere with emotional balance.

With regard to the adaptation of the interviewees, this occurred in a varied way. Some reported that this process was quieter and they had no difficulty in reintegrate in the work environment. This facility was related to the good relationship with the members of the work team, which caused greater security:

It was not difficult to return, I already knew everyone, the company staff. It was quiet, no problem. I felt calm because, as I said before, everyone was already my acquaintances; everyone always treated me with affection, treated me well, and was also quiet. (E1)

The person with the stoma is in a delicate moment and may feel more fragile, need for host, patience and attention. All these positions can positively influence their improvement and each individual has its own rhythm to overcome its losses and find the strength to accept and work his possibilities after the stomization².

When the person feels really accepted in its work environment it is able to have more security and better face the difficulties, making the process of adaptation easier. Overcoming fear and anxiety can be easier when one receives the affection and support of co-workers.

Other participants mentioned that they had some challenges to face, and new habits were necessary. One of the issues addressed was in relation to clothing:

My relationship with work and with my boss, at first generated in people a little surprise. They said, "You had a recent surgery, you're an ostomized." Because I used to wear the shirt to the inside of my pants, today I wear the shirt as it is here, to the outside. (E2)

The person with the stoma changes the way they dress in an attempt to hide the collector equipment. In this sense, it leads the individual to a personal transformation, in addition to resulting in a surgery that leads to a mutilation. The patient keeps its new condition covered under its clothes and starts to feel different from the others⁷. Changes in habits and even in clothing can arouse the curiosity of other people, since the presence of the stoma and the collector equipment has been, over time, stigmatized by society.

Another situation that required modification in the worker's life was related to food:

An adaptation I had to make with the schedule to feed better because of the flatulence. All this I had to adapt, to make a new diet plan to be able to exercise my profession with more tranquility. (E4)

Often as a result of the stoma, the individual feels the need to adapt their eating habits to their new lifestyle, because there are certain foods that cause an increase in intestinal discomforts, even though the stomization itself causes the lack of control. The uncontrolled sphincter may lead the individual to certain constraints, such as flatulence, odor,

altered effluent volume and diarrhea, which make it difficult to return to work⁴. The lack of control of flatulence and feces is the most frightening; making the person does not feel able to lead a normal life. Nowadays, with the advancement of technology, we have new equipment that offers greater safety and protection, and can minimize the interurrences related to extravasation of feces and odors, thus improving the quality of life of the person with intestinal stoma¹².

Shortening the workday also became a significant change in the life of the person with the stoma:

I worked as freelance, working fewer hours and having a flexible schedule. Doing something with fewer hours of work is less tiring. Being able to have the flexibility of when I needed to go to my house, use the toilet in my house. (E6)

It is notorious that flexibility is needed in the work environment, especially when it comes to their continuous necessity to use a toilet, since the loss of sphincter control and the use of the collector system bring discomfort and insecurity, which can lead to leaks and embarrassment⁴. The hygiene itself may represent a need and also a difficulty in the work environment, generating the fear of the social rejection and the prejudice on the part of the employers.

Thus, the planning of care and return to the work environment should be based on the identified self-care demands so that it can, in fact, contribute positively to the readaptation of the worker. The return to work requires the effort and participation of the whole society, including health professionals who through education, guidance and follow-up can favor the rehabilitation of the person with the stomach.

The job and the person with stoma

Several studies approach work as important in people's lives, being able to favour social interaction and the construction of identity, skills and competencies, as well as being responsible for the survival and subsistence of the human being^{7,9}.

The work has a very important role in our lives, influencing physical and mental health. Therefore, it can be seen as an activity that transforms man and makes it an integral part of society¹³.

This positive view of the work was also evidenced among the participants of the present study. Some people, after going

through the procedure of stomization, went back to work, experiencing positive feelings about their work capacity:

I found it good because I felt I could still continue to be useful. (E6)

The return to work also meant for these people to overcome the difficulties experienced with the disease and they associated the fact that they are returning to activities to the continuation of life:

I'm alive, I'm working and I do not want to stop. I am an outgoing person, I am cheerful. I am happy, as I said, I am happy to be alive and thank the Father who operated me. (E7)

The fact of being alive, reported by the participant, reveals itself as something that motivates it to continue working and work is a vital activity for the human being and defines its position in social relations and in society as a whole¹⁴. To return to work causes that the social relations are re-established, being able thus to extend the social support to this individual, which is essential for the overcoming of its difficulties:

It was very good; it was interesting because there were moments that I saw myself without realizing that I was an ordinary person. I don't have stoma! (E3)

The return to work allows the person with the stoma to feel socially active, besides favoring the coexistence with others who are not its family and friends¹⁵. Returning to work activities means overcoming and allows the individual, when feeling equal to other people, abandon the feelings of inferiority and uselessness. By rebuilding their roles and responsibilities, they regain their self-esteem and self-confidence, and gain their physical and emotional independence. When one enters the labor activities, the person recognizes its social role and its citizenship.

Difficulties and facilities in the work environment

One of the difficulties most cited by the interviewees was related to the use of toilets. As their new condition requires the emptying of the collector equipment and the more systematic

hygiene, it is necessary that the work environments provide adapted toilets. When this is not adapted, these workers find it difficult to re-enter their work environment:

As for the hygiene I use the ladies' toilet of the company. The toilet is clean, but it is a common toilet. (E1)

You need to have a toilet with a special cleaning, toilet with a bidet for you to do hygiene. So, this is the difficulty, the rest is no obstacle. (E4)

Where I worked there was not a proper toilet, so the physical environment did not provide my back for that kind of work and I was going to feel uncomfortable because it was just a toilet for all employees. (E6)

The adequate physical environment attenuates the deficiencies and is more pleasant for all, favoring the good performance of the worker¹⁴. Having to share the same toilet with the other employees was also a concern, making it a difficult time to stay at work. The emptying and cleaning of the collector equipment requires privacy and expose, in this environment, the condition of a person with stoma can create embarrassment, hindering their psychosocial well-being.

On the other hand, it was observed that some companies took this attention and adapted a toilet to the new conditions of the person with stoma, which became a facilitating factor for their reintegration into the activities:

We're going to adapt the toilet upstairs. We'll take action. And indeed they took the providence! (E2)

The factory had to pass for some changes. It even had to make a women's toilet and a men's toilet. This situation of adaptation fits for this. (E3)

According to Brazilian legislation, all citizens are guaranteed unrestricted access and it is recommended by the International Labor Organization (ILO) that the work environment has accessibility conditions for the disabled people who are in it¹⁶.

Therefore, the adaptation of the toilet becomes essential so that the worker with the stoma can feel more secure and rehabilitated. When the environment is adequate and adapted

to your needs, it becomes easier to insert, making it develop better your activities.

The physical weakness also compromised the readaptation of the worker, causing it to take a longer time to return to its work activities:

Well, my return was gradual. Because at first I had a little trouble locomotion due to a loss of muscle mass. (E2)

The individual in question has Crohn's Disease, a pathology that affects the mucosa of the gastrointestinal tract, mainly in the small intestine, and there are usually signs and effects of malabsorption of nutrients. Therefore, the nutritional status of these patients is proportionally affected according to the extension of the disease in the small intestine and the degree of inflammatory activity presented¹⁷.

Another situation that has also compromised the return of these individuals to work concerns the interference of the stoma in social life. People with stoma, in addition to facing the problems described above, also go through constraints, such as involuntary leakage and leakage of feces and excrement, which causes them to be exposed in public^{11,12}.

When I got there around nine, nine-thirty o'clock I felt like that would bother me. I had to force it, so I was afraid of it breaking, sometimes with an excess of gases it swells. So that was embarrassing. (E2)

You are inside an elevator and suddenly you blow off and then you blush because you will think the whole world is watching you including the elevator camera looking at your face if it was you. (E5)

The ostomized in general is very constricted. I even think that it is more difficult for those with disabilities to have a mobility problem because I do not know if it is because the deficiency involves fecal material, urine, something that is referred to as a childhood or something disgusting. So, this is not easy, it is difficult, it is an internal struggle and you have to fight

a struggle with yourself for self-acceptance and struggle with society. (E5)

Lack of stool elimination leads to restrictions in social interaction, mainly interfering with the return to work activity of the person with stoma^{11,12}. This has been one of the great difficulties faced in the daily life of these people, often leading to isolation, low self-esteem and distortion of the body image.

There is a concern on the part of the person with stoma involving the social and some friends move away or even the individuals themselves perceive that they are being stigmatized and choose to move away from the conviviality with the others. The fact of being a person with stoma does not only involve the use of the collector equipment, but also the adaptation to the new body image, being a process that involves together the subjective, the collective/social. The confrontation of the difficulties depends on the ego of each one and the social support coming from the family, the professionals and the care offered to the person with the stoma².

Some testimonies have shown that the receptivity of significant people in their work environment has become important for the return of these individuals and for their social inclusion:

I set up a ration factory, dairy cattle ration in partnership with a friend. He already knew of this situation of ostomized, but we were treated normally, we had four employees and I realized that they knew and respected this situation. (E3)

For being very cordial, very frank, the staff understood in a good way. I had no problem with them and the boss. (E4)

My work environment was good, with the two friendships I always had. It did not have, as I have already explained that indifference to be an ostomized, the person not to be disgusted. (E7)

The company, when deciding to admit people with stoma, should first prepare to deal with prejudice and then make it overcome by adopting a healthy coexistence¹⁴. To know respect the differences and understanding the

limitations and specificities of each one helps in the inclusion and adaptation of the disabled person in the social and work environment.

One of the factors that influenced the return to work was the type of profession or function performed by the worker before the stoma:

I did not have much trouble getting back to work because of my profession. As a teacher I did not have much difficulty. (E4)

It was not in the same function that I did before because the company closed part of that area. I returned and instead of working in the operating area, I went to work in the administrative area. I had no problem adapting, it was quiet. (E1)

Workers with stoma can perform their work activities unhindered as long as their professions or occupations do not expose them to physical wear or the use of physical force. They should avoid long periods of standing or sitting and do not expose the stoma to high temperatures or excessively cold, thus being able to act skillfully in the execution of their abilities without their health being damaged⁴.

The last factor cited as a facilitator for return to work refers to the strategies adopted for rehabilitation:

God gave me something called good mood, so I'm making fun of my tragedy, my misery. (E5)

Over time, the person with stoma develops strategies to cope with the problems present in their daily life, but this depends on how each individual deals with their limitation⁷.

It is noted that humor had a fundamental contribution to this interviewee (E5), favoring the coping of adversities and the adaptation of the definitive condition as a person with stoma. Humor and laughter bring health benefits and are important for improving the quality of life and ensuring people's longevity. The smile has no financial cost and can do well to people, in addition to influencing others and around them¹⁸.

In a way, this person has inside him the feeling that this condition is definitive and that he will have to live with stoma all its life, but it continues to smile anyway, because good mood helps to conquer positive thoughts.

CONCLUSION

Through an analysis of the experiences of people with stoma in the work environment, we found that they experienced situations and feelings that had negative and positive dimensions.

When they returned to work, some encountered several difficulties, but the lack of adaptation of toilets to their new condition of life was the most significant, since the companies in which they were inserted did not make a change or adequacy, thus damaging the insertion in work activities. On the other hand, there were people who did not find problems regarding the adaptation of the environment to their necessity, once the company was committed to the new reality of its workers.

Therefore, even faced with some challenges, people with stoma did not abandon their work condition and some referred to work as a fundamental factor for their social reintegration.

It is concluded that of all the difficulties faced, the fact that most of the companies did not worry about offering these workers a favorable condition to their situation had a direct repercussion on their return to work.

In this way, we emphasize the importance of the professional nurse in the work environment of these individuals, since this can make employers aware of the necessity for receptivity and support, respecting mainly the condition of physical handicaps in which these workers are. In addition, the nurse can offer these workers psychological and emotional support, helping to overcome the existing challenges in the search for adaptation strategies within the company in which they are inserted.

AUTHOR'S CONTRIBUTION

Conceptualization, Barbosa G and Paschoalin HC; Methodology, Barbosa G and Paschoalin HC; Investigation, Barbosa G and Paschoalin HC; Writing – Original Draft, Barbosa G and Paschoalin HC; Greco RM and Dias SM; Writing – Review & Edition, Barbosa G and Paschoalin HC; Greco RM and Dias SM; Funding Acquisition, Barbosa G and Paschoalin HC; Greco RM and Dias SM; Resources, Barbosa G and Paschoalin HC; Greco RM and Dias SM; Supervision, Barbosa G and Paschoalin; Greco RM and Dias SM.

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