Occupational roles of individuals with sickle cell anemia

ORIGINAL ARTICLE

Papéis ocupacionais de indivíduos com anemia falciforme

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ABSTRACT: Sickle cell anemia (SCA) can affect the performance of occupational roles of individuals due to painful vaso-occlusive crisis and frequent hospitalizations. This study aimed to verify which occupational roles are less performed nowadays and why; and to identify the degree of importance of these roles for the life of people with sickle cell anemia, attended in the Blood Bank of Uberaba/Hemominas Foundation. Thirty (30) individuals with sickle cell anemia participated in this research. Data were collected through the form of the instrument Role Checklist and, focus group methodology was used to better understand these data,. The results showed that the least performed roles were: religious, student, worker, volunteer, and participant in organizations. As for the most important roles, they were: student, caregiver, worker, volunteer, and hobbyist/amateur. We concluded that the occupations of the individuals interviewed are affected due to the clinical conditions imposed by sickle cell anemia, such as the roles of student and worker, since most of them were young adults.

KEYWORDS: Anemia, sickle cell; Role playing; Occupational therapy; Role.

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RESUMO: A anemia falciforme pode afetar o desempenho dos papéis ocupacionais do indivíduo devido à crise vaso-oclusiva dolorosa e internações frequentes. O objetivo deste estudo foi verificar quais papéis ocupacionais estão sendo menos desempenhados no presente; o porquê estão sendo menos desempenhados; e identificar o grau de importância de cada papel ocupacional com menor desempenho para a vida de pessoas com anemia falciforme, que são atendidas no Hemocentro de Uberaba/Fundação Hemominas. Nesta pesquisa participaram 30 pessoas com anemia falciforme. Os dados foram coletados por meio do formulário do instrumento Lista de Identificação de Papéis Ocupacionais e, para maior compreensão desses dados obtidos pelo mesmo, utilizou-se a metodologia do grupo focal. Os resultados demonstraram que os papéis menos desempenhados no presente foram os de religioso, estudante, trabalhador, voluntário e participante em organizações. Já os papéis mais importantes no presente foram: estudante, cuidador, trabalhador, voluntário e passatempo/amador. Conclui-se que as ocupações do tempo presente dos indivíduos entrevistados estão bastante afetadas em função das condições clínicas impostas pela anemia falciforme, tais como os papéis de estudante e de trabalhador, já que a maioria eram adultos jovens.

DESCRITORES: Anemia falciforme; Desempenho de papéis; Terapia ocupacional; Papel (Figurativo).

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INTRODUCTION

Health is supported and maintained when people are able to engage in occupations and activities they want or need to do. These activities reflect standards that are established during this process, such as habits, routines, and roles.[1,2] According to AOTA[1], "*roles are sets of behaviors expected by society, modeled by the culture, and may be highly regarded and defined by the individual*" (p. 8). These roles organize the behavior, contributing to the personal identity of individuals, leading social expectations to an achievement, organizing the use of time and involving them in the social structure.[3]

People with chronic diseases are prone to suffer interruptions or changes in the performance of their occupational roles.[2,3] Among these, the sickle cell disease outstands. It is a genetic alteration characterized by a type of mutant hemoglobin called Hemoglobin S (or HB S) that causes the distortion of cells, making them take the form of a "sickle" or of a "half-moon." It presents high morbidity and mortality and is characterized by acute clinical manifestations (vaso-occlusive crisis, splenic sequestration, and acute chest syndrome), leading the person to seek emergency services with frequency, and also for chronic clinical manifestations (it affects organs and systems).[4.5]

Among sickle cell diseases, the sickle cell anemia has the highest medical significance, and is prevalent among African-descendants and mixed-raced people.

A person with sickle cell anemia may encounter difficulties in the execution of tasks, and the problems that common situations of daily life may present extend the fragility of their health conditions, affecting their level of participation and involvement in activities in different contexts.[6]

Thus, this study aimed to verify which occupational roles are less performed nowadays and why; and to identify the degree of importance of these roles for the life of people with sickle cell anemia, attended in the Blood Bank of Uberaba/Hemominas Foundation.

METHODS

This is a cross-sectional, exploratory/descriptive/prospective study with a quanti-qualitative approach.[7,8]

This study was conducted in the Regional Blood Bank of Uberaba/Hemominas Foundation, which attends the 27 cities of the Triângulo do Sul macroregion, in the State of Minas Gerais, Brazil.

The sample that participated in this research was by convenience and not probabilistic.[7,9] The inclusion criteria was composed of patients with sickle cell anemia over 18 years, supervised at the Regional Blood Bank of Uberaba/Hemominas Foundation, and that declared free and informed consent by signing the term to participate in the research. Other diagnoses were excluded, therefore, 30 patients with sickle cell anemia participated in this study.

Data collection occurred in two stages from April 2015 to November 2015, according to the schedule provided by the Blood Bank of the medical consultations of patients with sickle cell anemia. All the participants who have agreed to participate in this research were informed and enlightened about its objectives and that it would be carried out in two stages. These stages were explained and described in the Informed Consent Form (ICF), which was signed by the participants.

During the first stage (April 2015 to October 2015), data were collected using the Role Checklist form, which is divided into two parts. The first part assesses the occupational roles that constitute the participant's daily life in the past, in the present (up to seven days before the interview), and in the future (any date after the day of the interview); and in the second part, the form identifies the importance attributed by the participant to each role.[3]

Ten occupational roles and also the category "Other" are presented and defined in the form, so that participants can add unlisted roles. The participant may choose more than one occupational role in each part, according to his performance in his daily life. The Role Checklist requires approximately 15 minutes to be applied.

In this stage, the form was individually answered in an appropriate room of the Blood Bank. After applying the Role Checklist, each interviewed patient with sickle cell anemia was informed again, as described in the ICF, that the research would have a second stage and the importance of the of all the patients' participation in the research. Data from the Role Checklist form were categorized and analyzed through descriptive statistics in the software Microsoft Excel 2010 version.

In the second stage (November 2015), the 30 patients with sickle cell anemia who participated in the first stage were contacted by telephone to participate in this second stage. The focus group methodology was used,[10] corroborating the clinical use of the Role Checklist, which recommends the discussion between therapist and patient after filling the instrument to explore the details and generate a deeper understanding of the facts that influenced the performance of occupational roles throughout time.[11]

For this stage, a room properly set at Casa da Residência Multiprofissional of the Federal University of Triângulo Mineiro (UFTM) was made available. Because of the clinical manifestations of sickle cell anemia (painful vaso-occlusive crisis) and because some individuals live in other cities far from Uberaba, MG, Brazil, only eight patients with sickle cell anemia participated in the focus group.

An interview was carried out in the focus group through a semi-structured script, elaborated in the software Microsoft Word 2010 based on the answers that were obtained in the first stage of data collection for the Role Checklist, in order to better understand the least performed roles in the present moment and to identify the degree of importance of these roles for the life of patients with sickle cell anemia. This interview was recorded with their permissions, fully transcribed, and checked twice by two researchers to ensure the accuracy of the transcript. Data were analyzed using Thematic Content Analysis (TCA), following the phases of pre-analysis; exploration of the material; treatment and interpretation of the results obtained.[8]

In pre-analysis, the interview content of the focus group participants was read to check the understanding of the aspects that have been raised in the questions of the semi-structured script: 1– “The results showed that the least performed roles were: religious, student, worker, volunteer, and participant in organizations. Why do you think this happens?”; 2– “The most important occupational roles obtained from the Role Checklist were: student, caregiver, family member, employee, volunteer, and hobbyist/amateur. Why are they important to you?”.

In the stage of material exploration, a table containing all the answers of the patients with sickle cell anemia of the focus group was created concerning the abovementioned questions to reach the meaning core of their reports.

In the stage for treatment of the results obtained and their interpretations, a second table was created containing the answers of these participants and the interpretation of the similarities among the answers presented. Thus, it was possible to aggregate the data by specifying the meaning cores.

To ensure the anonymity of the participants, they were designated by names of stars and constellations when presenting the results. As it is an investigation involving human beings, the research project was submitted to the Research Ethics Committee of the Federal University of Triângulo Mineiro (CEP/UFTM), being approved under the opinion no. 1.032.485 of 2015, as recommended by the 466/12 Resolution of the National Council of Health (CNS).

RESULTS

Regarding sociodemographic data, 22 (73%) participants are women and 8 (27%) are men, among them 70% are single and 30% are married.

The average age of these participants is 30.1 (± 9.9) years, varying from 18 to 50 years. From the participants evaluated, 10% are between 18 and 19 years; 40% between 20 and 27 years; 33.33% between 30 and 38 years; 13.33% between 41 and 48 years, and 3.33% are 50 years old.

As for the occupation, 23 (77%) of the participants are inactive, i.e., are not currently working; and 7 (23%) are active, with a signed employment contract.

Concerning the presentation of the results of the Role Checklist, in Table 1 we can observe the distribution of roles over time (past, present, and future), and in Table 2, the distribution of the degree of importance of occupational roles (no importance, some importance, and much importance).

The results from Table 1 showed the most performed roles in the past were: student (97%), family member (93%), domestic service, and friend (90% each).

In the present, the most performed roles are: home service (93%), family member (90%), hobbyist/amateur (63%), caregiver, and friend (57% each). And in the future, the roles most likely to be performed are: family member (100%), caregiver (93%), domestic service, and friend (83% each).

In Table 2, the results indicate that the roles considered more important by the patients with sickle cell anemia are: student (90%), caregiver (87%), family member (87%), worker (77%), voluntary (77%), and hobbyist/amateur (77%).

The results showed that the least performed occupational roles in the present are: religious (47%), student (23%), worker (23%), voluntary (17%), and participant in organizations (17%).

Table 1 – Distribution of occupational roles over time

Occupational Roles	Past		Present		Future	
	n	%	n	%	n	%
Student	29	97%	7	23%	16	53%
Worker	18	60%	7	23%	21	70%
Volunteer	10	33%	5	17%	24	80%
Caregiver	23	77%	17	57%	28	93%
Domestic Service	27	90%	28	93%	25	83%
Friend	27	90%	17	57%	25	83%
Family member	28	93%	27	90%	30	100%
Religious	21	70%	14	47%	23	77%
Hobbyist/Amateur	23	77%	19	63%	27	90%
Participant in organizations	8	27%	5	17%	10	33%

Table 2 – Distribution of the degree of importance of occupational roles

Occupational Roles	No importance		Some importance		Much importance	
	n	%	n	%	n	%
Student	0	0%	3	10%	27	90%
Worker	3	10%	4	13%	23	77%
Volunteer	1	3%	6	20%	23	77%
Caregiver	0	0%	4	13%	26	87%
Domestic Service	5	17%	9	30%	16	53%
Friend	3	10%	7	23%	20	67%
Family member	0	0%	4	13%	26	87%
Religious	2	7%	6	20%	22	73%
Hobbyist/Amateur	1	3%	6	20%	23	77%
Participant in organizations	8	27%	9	30%	12	40%

We noted in Table 1 that the roles performed in the past, present and future do not show differences between the roles they perform and the roles they want to perform. However, when the results of the least performed roles and their level of importance to the participants are crossed, some of these occupational roles (such as worker and student) are not primarily mentioned with great future prospects. The investigation of this phenomenon seemed necessary to researchers. These data are of great importance when they show low performance and high degree of importance of such roles to a group largely composed of young adults.

Two men between 27-41 years participated in the focus group , being one married and the other single; as well as six women between 27-48 years, being two married and all the other ones single. All were inactive.

From the analysis of the similarities in the participants' answers, and based on the results obtained with the Role Checklist, two meaning cores were created: 1– The least performed occupational roles in the present: religious (47%), student (23%), worker (23%), voluntary (17%), and participant in organizations (17%); 2– The most important occupational roles: student (90%), caregivers (87%), family member (87%), worker (77%), voluntary (77%), and hobbyist/amateur (77%).

The first meaning core refers to the least performed occupational roles in the present. We can observe in the report below that the religious role is affected due to episodes of pain and because of ulcers caused by sickle cell anemia complications:

> *"For us who have sickle cell anemia, there are days we wake up well, there are days we don't [...] I have an ulcer in the leg that hurts, it hurts a lot [...] that's when the religious part is affected, but I participate anyway, I do things, but just the days I'm fine, there are days I'm not fine, and I don't get out of the house." (Centaurus)*

The second most affected role is the student, due to complications of the illness justified in pain, ulcers, followed by financial conditions, climatic conditions (cold and rain), and the need for medical care and hospitalization:

> *"When I was in college, I had no conditions to pay for it [...] If you're in pain, you can't focus on studies." (Centaurus)*

> *"You start studying, but you can't memorize anything [...] Your mind is in the pain [...] In the case of ulcer, I wasn't able to walk, I felt pain for almost 24 hours." (Adhara)*

> *"I studied until the 8th grade, and when I went to high school, I couldn't do it, a little because of the cold and the rain [...] I got caught in the rain twice and was hospitalized for 12 days [...] When you're in pain you can't get up and go to school." (Electra)*

The participants' reports below show the role of worker is also affected due to painful vaso-occlusive crisis, which prevent them from going to work:

> *"If I show you my employment record book, it has a lot of registers from companies I've worked for [...] When I felt sick I was hospitalized, and when I got back to work I was dismissed." (Centaurus)*

> *"I was three months away from work [...] I'm 38 years, it was the worst painful crisis I have ever had, and I spent 16 days in the hospital [...] When I came back, the company fired me." (Sarin)*

In this study we observed that the performance of the occupational roles "volunteer" and "participant in organizations" depends on the health condition of these participants. We noted, from the following reports, that when there is no pain or ulcers, they can perform these roles, otherwise, they have difficulties:

> *"This Voluntary role is like that, sometimes people want to call us to volunteer, but they think: I won't call her, what if she gets sick and can't help [...] I find it hard for people to call us to be volunteers [...] We are left out." (Gatria)*

> *"It all depends on how is sickle cell anemia at that time, if it's pain-free, if you're in pain, with ulcers, no way [...] Your life revolves around it." (Adhara)*

In the second meaning core that refers to the most important occupational roles, we can note the importance of the student role to the following participants, when they affirm that through the performance of this role, they could have better living conditions and a better future:

> *"In my point of view, I think that through study, I could have a better living condition today [...] I think it's important not only for me, but for anyone." (Centaurus)*

> *"I think it's important because if you study, you learn more, so you can have a better future." (Alhena)*

The second most important role, the caregiver, represents to the next participant a form of gratitude for the support that the family offers in times of difficulties and complications of sickle cell anemia:

> *"In my point of view, the caregiver role represents gratitude [...] When we're having a crisis, people closer (family) are the ones that help us [...] When I have a chance, I always want to be present and help my family." (Sarin)*

Following the family strand, we noted the importance of the role of family member in the next report:

> *"Family is the focus of everything [...] They always help me in what I need [...] It helps a lot when the family is united, [...]When I get sick, they visit me, if I need something [...] It really helps, and the family together is the focus of everything." (Alhena)*

According to the report, this role is important because of the presence of the family when support and assistance are needed, as in medical consultations and examinations and hospitalizations.

Then we have the worker role with the following observations about its importance to improve the self-esteem of these participants and make them feel productive, capable and helpful:

> *"Self-esteem [...] retirement is good because it's a certainty you know you can count on every month, but there is a side in feeling useful, productive and capable." (Sarin)*

> *"We wanna be there (work), being productive, having a chance to think about our future." (Centaurus)*

Concerning the importance of the volunteer role, from the following report we observe that the participant considers this role important because helping others gives them personal satisfaction:

> *"For me the volunteer work is like I'm on both sides [...] When I was in the hospital, there was a group of people singing, playing [...] As I was as a patient, it was very important [...] For those in the nursing home, in the hospital, anywhere, when we visit them is very important [...]To hear someone thanking you for dedicating a little time of your life it's priceless; beyond words, there is no way to translate how I feel as a volunteer." (Sarin)*

Finally, the importance of the hobbyist/amateur role in the following reports:

> *"For me, leisure is very important [...] I like going to the cinema, going to a bar and talking to friends, visiting a family member [...] It makes you forget that you have a problem, a medical routine, medical examinations [...] You feel more normal, like everybody else around you." (Adhara)*

> *"I like walking every day, going to the farm, fishing [...] I think it's very important, you get distracted, sometimes you're in pain, but when you start doing what you like, it relieves a little." (Gatria)*

For the participants, this role is important because leisure makes them forgetting about their personal and health problems; it changes the routine of consultations, examinations and divert the focus from the pain.

DISCUSSION

Because it is not a sex-linked genetic disease, there are few publications addressing gender in sickle cell anemia. In a study with 47 patients with sickle cell disease, 59.6% were women and 40.4% were men.[12] This datum from the literature is similar to the one found in this study, in which: there was a greater number of women (73%) compared with men (27%).

Regarding the least performed occupational roles in the present, the role of religious, student, worker, volunteer, and participant in organizations, presented in the first meaning core, are largely affected by episodes of pain. Sickle cell anemia can cause complications that affect almost all organs and systems; and the pain caused by this disease is a limiting factor to the performance of activities.[4,6,13]

We noted in this study the harm that pain brings to the roles of student and worker, since most of the participants are young adults, i.e., they are in the moment of searching for a job, professional training, or starting a project based on their own interests,[14] but they are inactive due to the clinical manifestations of sickle cell anemia that alter the carrier quality of life, making it more difficult to maintain the work activity[12,15]. This datum is similar to the one found in the study by Felix *et al.*[12], in which 42.5% of the participants with sickle cell disease had no income, through formal or informal sectors, due to very unstable clinical conditions.

In addition, the roles of student and worker are mentioned in the participants' speech, with the understanding that the first leads the second to success. However, the report about the low performance in these two roles due to pain and hospitalizations indicates personal damages both in studies, because they increase the chances of a better professional qualification and thus better projections of the economic and social point of view; and at work, because clinical instability caused by sickle cell anemia do not allow the patients to satisfy the demands of the formal sector. It is noteworthy that patients with sickle cell anemia suffer from the effects of pain crises, infections and other significant emergencies that increase the number of hospitalizations and decrease the hours spent at school.[4,16] The absences at work imposed by clinical manifestations of the disease, on the other hand, end up resulting in dismissals by their employers.

The literature shows us that despite the implementation of public policies and the growing availability of information in order to clarify the consequences that sickle cell anemia causes to their carriers, corresponding to work demands and yet due to the high number of hospitalizations, ignorance is still present in society.[13,17,18]

When the participants report on the most important occupational roles, indicating once again student (90%) and worker (77%), they reinforce how these roles are significant in their lives. The most expected role in adulthood is the worker. Work is an activity that demands greater time in adulthood and through it people can obtain social and financial recognition[19].

However, we should remember that education is the main way for people to ascend socially or take a critical stance towards their realities. Still, under-qualified people have greater difficulties of insertion in the labor market.[20,21] We emphasize that approximately 80% to 85% of patients with sickle cell anemia have low education.[14]

Participants mentioned volunteer work as a form of personal satisfaction and social participation that has been growing; it is an activity in which a person freely offers her/his time to benefit other people, group or organizations, without monetary retribution.[22]

The family member role was mentioned in the perspective of care among family members and with the carrier of sickle cell anemia. Family was considered an important occupational role as a social institution whose main task is the care and protection of its members[23] and was considered by the participants of this study as the main source of support for continuous care during periods of sickle cell anemia complications. It is important to say that this disease is a chronic condition and that individuals require care throughout their entire lives.[5] This information can be find in a study by Silva *et al.*[24], who observed that the family who experience chronic condition for sickle cell anemia is quite affected in its daily life due to the intense need for long-term care that the person affected by SCA needs.

Finally, these participants found in the role of hobbyist/amateur a way to "forget" their personal and health problems, since leisure temporarily turns them off from their duties, in addition to being an essential practice for a productive, healthy, and balanced human life[25].

CONCLUSION

A common issue that outstands in the participants' speech concerns pain and its consequences for the least performed roles. Its acute manifestation affects these individuals often disabling them for roles, such as the religious, student, worker, volunteer, and participant in organizations.

In addition, pain and constant hospitalizations prevent the establishment of certain level of commitment to the performance of these roles that tend to be practiced regularly, especially when they involve religious or volunteer activities, or in organizations that add moral values and ethical responsibility in their practices.

We also observed that student and worker roles appear in the reports both from the point of view of low performance and in the degree of importance to the participants. The fact that most participants are young adults indicates that these roles are even more significant at this point of their lives and that occupational therapy can give its powerful contribution by searching strategies aiming at the better performance of student and worker roles.

To do so, the occupational therapist should consider the periods that vary between clinical manifestations, called "stable phase," and its interruptions by acute manifestations of pain and hospitalization that mark the daily lives of these individuals. These issues make it impossible for them to "fit" in the formal labor market, but should not be an impediment for performing the worker role through working relationships with more flexible contracts, as new models that have been modifying mainly in the last decade.

The performance of the student role, also marked by episodes of pain and recurrent hospitalizations requires great attention from the occupational therapist. It is necessary to think of strategies that help these individuals to face the challenges imposed by the clinical condition from the beginning, creating possibilities of studies and professional qualifications with minimal damages on the improvement of social and economic life.

The family member role, when discussed among the participants, appears to rely on the affection and gratitude that the participants feel in being taken care of. In this perspective, the occupational therapist and the health team should consider the proximity and the family support during the treatment as a crucial factor in the daily confrontations of the disease.

The hobbyist/amateur role was also presented as fundamental for the development of public policies, programs and actions that offer recreation for this population.

Thus, we can observe the relevance of the occupational therapist to pave the way and find strategies along with the patient affected by sickle cell disease, towards a better performance and level of satisfaction for the occupational roles highlighted as important for these individuals.

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