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Rights and duties of the Unified Health System users: experience report*

Direitos e deveres dos usuários do Sistema Único de Saúde: relato de experiência

Derechos y deberes de los usuarios del Sistema Único de Salud: relato de experiencia

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This article aims to report the experience of the group *Programa de Educação Tutorial* (Program of Tutorial Education) regarding the university extension project "Rights and Duties of the SUS users". Said project took place from October to December 2016, in the general surgery and orthopedics wards of a teaching hospital. Ten students and six professors of the nursing graduation course participated. The study used the knowledge developed from a dialogic perspective in the approach of the Charter of Health Users Rigths. The project aimed at contributing to empower the patients regarding their rights and duties as SUS users, so that they have autonomy to demand for them. When rights and duties of SUS users are articulated and strong in the health services, this can lead to an increased quality, equity, and a greater capacity to deal with problems, generating a more dignified, just, and equal assistance.

Descriptors: Social participation; Health education; Knowledge; Unified Health System

Este artigo tem como objetivo relatar a experiência do grupo Programa de Educação Tutorial de Enfermagem na realização do projeto de extensão universitária “Direitos e Deveres dos Usuários do SUS”. A atividade ocorreu entre outubro e dezembro de 2016, nos setores de clínica cirúrgica e ortopedia de um hospital de ensino, com participação de 10 alunos e 6 docentes do curso de graduação em enfermagem. Utilizou-se do conhecimento desenvolvido na perspectiva dialógica para abordagem da Carta dos Direitos dos Usuários da Saúde. O projeto buscou contribuir para o empoderamento dos pacientes sobre seus direitos e deveres enquanto usuários do SUS, para que os mesmos disponham de autonomia para reivindicá-los. Quando direitos e deveres dos usuários do SUS são articulados e estão fortalecidos nos serviços de saúde, isto pode conduzir à maior qualidade, equidade e resolutividade, proporcionando uma assistência mais digna, justa e equânime.

Descritores: Participação social; Educação em saúde; Conhecimento; Sistema Único de Saúde.

Este artículo tiene como objetivo relatar la experiencia del grupo Programa de Educación Tutorial de Enfermería en la realización del proyecto de extensión universitaria “Derechos y Deberes de los Usuarios del SUS”. La actividad ocurrió entre octubre a diciembre de 2016, en los sectores de clínica quirúrgica y ortopedia de un hospital de enseñanza, con participación de 10 alumnos y 6 docentes de la carrera de graduación en enfermería. Se utilizó el conocimiento desenvuelto en la perspectiva dialógica para abordaje de la Carta de los Derechos de los Usuarios de la Salud. El proyecto buscó contribuir para el empoderamiento de los pacientes sobre sus derechos y deberes como usuarios del SUS para que los mismos dispongan autonomía para reivindicarlos. Cuando derechos y deberes de los usuarios del SUS son articulados y están fortalecidos en los servicios de salud, esto puede conducir a una mayor calidad, equidad y resolutividad, proporcionando asistencia más digna, justa y ecuánime.

Descriptores: Participación social; Educación en Salud; Conocimiento; Sistema Único de Salud.

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INTRODUCTION

The 1988 Federal Constitution highlights a broad concept of health and the universality principle, according to which health is a right of all individuals, and the State must safeguard this right, diminishing the chances for diseases and other health problems.

The Unified Health System (SUS) emerged from fights for democracy. It is constituted on the principles of: universality, safeguarding healthcare for all, with no distinctions; equity, according to which all citizens are equal to SUS, despite having their particularities; and integrality, which indicates an integral assistance that respects the rights of each citizen[1]. Considering this, the population's access to health services must public and integral[2,3].

To actualize the propositions of SUS, the Charter of SUS User Rights, which is based on six principles, which are: every citizen has the right to have an orderly and organized access to health systems; to an effective treatment adequate to their problem; to humanized treatment, that protects them from discrimination, and to respectful treatment. The charter also highlights that the citizen is co-responsible for the service to be carried out adequately, while the managers must care for the effective compliance of the service to all those principles[4].

Despite being instituted for more than 20 years, the SUS still has challenges to overcome, especially those that involve social mobilization for the defense of quality universal health.

The fragile social mobilization is believed to result from the lack of knowledge of the population regarding their rights and duties in the context of SUS. The lack of knowledge of the users regarding this may be a result of a lack of educational actions. The professionals may have knowledge on the subject[5], but that is not enough to raise the awareness in the community. That is because the population has little knowledge on their rights and lack the means and abilities to claim for them[6].

Therefore, it is necessary to share the rights and duties of the users through another fundamental right: information, which generally is mediated by health professionals[7]. Therefore, educational actions should intend to develop user co-responsibility, which makes them capable of facing the difficulties involved[5].

Concerning the information on their rights and duties, society is not well equipped, which may lead to passivity regarding their health situation resulting in little to no social participation[6].

It is necessary to empower the population regarding the rights and duties of users in the perspective of SUS, so that they understand the context, and have the abilities and attitudes to demand their rights. The empowering of a group is a result of an educational process which offers subsidies for the development of autonomy and critical thinking regarding health policies[8]. This may contribute for users who are more conscious and critical of the role they can and should have as protagonists in their own life and health choices.

The exchange of information on user rights and duties may be a responsibility of the health team. In this case, nurses can be tools to close the gap between users and the knowledge about their rights and duties, since education in health is part of their professional formation, which makes them one of the main agents in this mobilization, which aims at the integral care of the user[9].

Communicational, dialogical, and educational actions about the rights and duties of SUS users must include individuals from the many levels of healthcare, offering safety to the users, and thus strengthening their participation in the services, and collaborating with the changes that the current setting of health services require[10].

Considering the assistance levels, when one refers to the tertiary level and to hospital services, the perception of the user in the hospital regarding their rights and duties is permeated by their lack of knowledge, and many of them are afraid of retaliation from the professionals who offer them healthcare[11]. In this context, the health team, especially the nurse, must articulate to share information and re-elaborate values and organizational practices to guarantee and disseminate rights and duties, aiming at offering assistance quality and, above all, patient safety[12].

As a result, health rights are perceived to involve broader issues as opposed to being restricted to the health field, involving public administration and the law[13]. The scarcity of publications addressing the rights and duties of SUS users is clear. However, it should be highlighted that said theme is a crucial device to generate effective social participation and bring democracy to the space of health[11].

This study aims to report the experience of the group *Programa de Educação Tutorial* (Program of Tutorial Education - PET) regarding the university extension project "Rights and Duties of the SUS users".

METHOD

This is the experience report of an activity of university extension carried out with the Program of Tutorial Education of the nursing course (PET Nursing), named "Rights and Duties of SUS users", an activity that took place from October to December 2016, in the general hospital (GH) of the Federal University of Triângulo Mineiro (UFTM).

Ten students participated. They were separated into pairs, each pair being responsible for one day of the week, during weekdays only, in varied periods of the day. They were under the supervision of six professors from the Nursing graduation course of UFTM. At the end of each day, the pair would write a report about the activity. Said reports were used to make a field journal which was used for consultation during the creation of this report.

The university extension project "Rights and Duties of SUS users", register at SIGPROJ under protocol 315/2016, was carried out in the orthopedics and general surgery departments of the UFTM-GH, which, respectively, included 17 and 61 beds. The GH offers high complexity assistance to 27 cities that are part of the Amplified Health Region (RAS) called Triângulo Sul.

To start the university extension activities, the students went through a training based on the Charter of Health Users Rights, from the Ministry of Health[4], thus acquiring knowledge on the theme. The training, which lasted for nearly two hours, was carried out by a student, who received support from the professors who were responsible for the activity.

The methodological references that guided this report is based on the framework of Empowering in Health. The word Empower, which already existed in English, means "to give power" to someone, so that this person can carry out a task without needing the permission of others. In social contexts, the concept of Empowering — especially in the works of Paulo Freire — is broader than it usually is in the English language[4,14].

A person, group, or institution is the one that carries out, alone, the changes and actions they need to evolve and become stronger. Therefore, empowerment can be a social, cultural, psychological, or political process, through which individuals or social groups can express their needs and preoccupation, in addition to conceiving strategies for decision making[14].

In general, the process of Empowering a patient has four essential components: a) an understanding of their role; b) the acquisition by the patient of enough knowledge to become engaged in their own healthcare; c) their development of abilities, making it easier for them to live in the context they experience[14], and d) autonomy (Image 1).

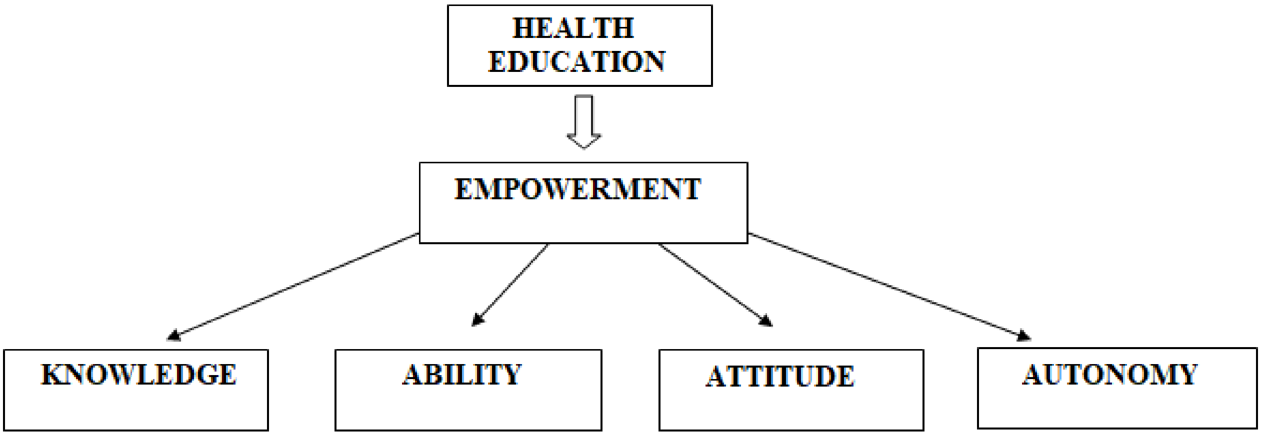

Image 1. Conceptual map about education in health and empowering.
Adapted from Cesarino e Sciarra[14].

RESULTS

Themes related to the principles presented in the Charter of Health Users Rights, guidance regarding the ways to approach the users and their families, proper posture and clothing for the undergraduate students participating in the project and general guidance were discussed during training.

Later, students were separated in pairs and each pair became responsible for a day of the week according to their availability. The group was under supervision of at least one professor who was responsible for accompanying the activity.

After the students had a previous knowledge of the users and of their experiences, there was an exchange of knowledge. The objective was to offer users abilities to make decisions, attitudes to build a critical posture, and self-knowledge to develop autonomy.

Equipped with those, the users can act as disseminators of knowledge, sharing the information in their own social contexts. This experience also allows for the student to be sensible to the real demands and needs of the users of health services.

A total of 45 meetings were developed, lasting approximately one hour each, from October to December 2016. The actions directly reached 102 patients, 52 of whom were female (50.9%) while 50 were male (49.1%). 38 were there accompanying someone, and from them, 34 were female (89.4%) and four were male (10.6%). The total number was 140 people, 86 of which were female (61.4%) and 54 male (38.6%).

The experience made it possible for the undergraduates to ponder on the situations of fragility and emotional instability of users, something they are not always being prepared to face during graduation. There are situations in which communication is the primary element, and one must listen and understand the other during the hospitalization process.

The reports elaborated contained information regarding the development of the activities in each day, such as: date, ward, number of users/companions approached, questions, involvement of users, doubt clarification and information exchange, comments from the target-population and the perception of the undergraduates regarding the activity they performed.

All these reports resulted in a field journal, aimed at centralizing the information found, so that it could serve as a parameter to inform the approach of future meetings.

During the activities, the principles the Charter contains were clarified. One principle that the users/companions often remembered was the first one, regarding orderly and organized care, that is, it is essential for healthcare to follow the order of priority/necessity.

Users and companions reported situations which indicate compliance to this principle. Despite the fact that they were waiting for attention, they did not mind the fact that people who arrived after them were attended first in other health services, since they understood that these people needed priority treatment.

Regarding the communication with the health team, users/companions stated that there are some difficulties, associated to their lack of knowledge or insufficient information regarding their health framework or even their treatment. This is the opposite of the second principle of the Charter, according to which everyone has the right to quality care. This leads to anxiety and distress, and many users feel outraged regarding the attention received.

Regarding the right to a humanized and non-discriminatory care, included in the third principle, the users and companions, when it comes to their satisfaction with the attention, reveal to perceive the professionals as not only prepared for the procedures, but also, as being humane, presenting features such as being welcoming, active listeners, and empathy, characteristics that were not observed in other health services.

Another aspect that stood out is related to the fourth principle, according to which all must have their rights as users respected. Through the experience lived through in this university extension project, it was found, based on the reports of users/companions, that in practice, the patterns follow in the opposite direction. Therefore, it was found that the solicitation from users and companions to their medical records is not respected, and the users feel fear regarding the possibility of refusing undergoing some procedure or exam.

The UFTM-GH Ombudsman Services were frequently discussed during the meetings in the activity, as a place to be listened and for suggestions, critics, and compliments to be made according to the experiences had during hospitalization. Concerning this information, the users/companions revealed to not know that the Ombudsman Services was also a space for compliments and that they believed it received only critics and suggestions.

Regarding the respect to the duties of the SUS users, which constitute the fifth principle, the experience allowed the undergraduate to understand that there are some situations in which the user omits or distorts some information regarding their own health to the team. That makes assistance more difficult and can lead to risks to the user's health.

The sixth and last principle regards the compliance with the aforementioned Charter of Health Users Rights by all. It may be the most difficult principle to see in action in daily experience, since it involves all previous principles. It also states that the government too, in its different levels — federal, state and municipal — is responsible for respecting these rights. However, it became clear that the users or companions seek some of these organs to have access to health services, especially to find the adequate permissions to require some surgical procedure.

The university extension project, focus of this report, aimed to contribute to empower SUS users during the meetings conducted, since they were lacking knowledge about the rights and duties they had as users of the health services.

It was also found that the users and companions were interested in the theme. They stated that the actions were relevant for the promotion of the autonomy of the users, so that they can become more active regarding health policies.

DISCUSSION

The experience was a group of potential initiatives to bring information on health to increase the autonomy of people regarding their decision-making abilities in health actions, in addition to clarifying that when patients lack knowledge, respect, and have the legitimacy of their power to choose denied, non-humane healthcare processes are favored.

Considering this, the Charter of SUS user rights and duties suggests that health professionals keep a more extensive relationship with those they assist, understanding their needs as more than physical[2,3].

The integration of the PET Nursing group of undergraduate students in this setting helped for the approaches conducted during the hospitalization of the patient not to be limited to their diseases. This made it possible, considering the general state of each hospitalized person, to raise awareness about SUS, since it is a crucial resource for promotion, prevention, care, and rehabilitation of people throughout the nation's territory[2,3,15].

The overload of activities makes it more difficult for the nurses in the hospitalization unit to carry out, in their daily work, actions such as the ones mentioned in this experience[15]. Considering this, the work conducted by PET Nursing undergraduate students showed itself as capable of performing actions of health education in a way that can improve individuals' autonomy and self-care.

In addition, the experience reported involves an initiative that measures information to empower the people cared for in a hospital unit, giving them the knowledge to question and demand, and therefore, propose improvements and changes in the care they receive.

Empowering individuals through information is crucial for their self-transformation, especially when it transforms the SUS user from passive information receptor into a participative being[7,16], who acts as a protagonist, and is co-responsible for the therapeutic plan.

Those who aim to aid human beings must, first and foremost, have a posture of respect and commitment. In the hospitalization units, traditionally, the approach is focused on the disease. Therefore, the experience reported here showed itself as an innovative possibility to articulate humanistic aspects, and aspects involving the right to health in an intervention in this specific setting[7,15,16]. That means that acting in the health field requires not only technical, but also human competence.

As to the limitations of this study, the experience reported did not aim to measure the satisfaction of users and participants in this moment. However, since this is a unique experience in which dimensions of humanized care, empowerment in health, and information on SUS come together in a setting which traditionally tends towards the repetition of disease-focused practices, it has the potential of being reproduced in similar contexts.

CONCLUSION

This study showed how fundamental humanization is in healthcare. From this perspective, the need to empower patients regarding their rights and duties as SUS users becomes clear, as it provides them with the autonomy necessary to demand said rights.

The experience in this extension project allowed the study to identify that, when rights and duties of SUS users are articulated and strong in the health services, this can lead to an increased quality, equity, and a greater capacity to deal with problems, generating a more dignified, just, and equal assistance.

The experience reveals the importance of the knowledge created from a dialogic perspective. It was possible to understand that the dissemination and exchange of knowledge collaborate with user emancipation practices. Understanding this theme contributes for the users to make their own choices, through the methodology of transformative education that can promote autonomy, thus providing means that can lead to changes in the health services.

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CONTRIBUTIONS
Bruna Carolina Sousa Castro, Letícia Gabriela de Almeida, Rafaela Costa Silva took part in the conception, bibliographical research, writing and critical review. **Bethânia Ferreira Goulart** took part in the writing and critical review.

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