

Challenges of the Social Workers in the Field of Discharge Planning and Promotion of Patients' Right to Self-Determination - a Case Report

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Abstract - The aim of this paper was to show the challenges of the social worker in the Clinical Hospital Centre Rijeka in the process of planned discharge and at the same time promoting the right to self-determination of an elderly patient with impaired functioning who has no close family members. The paper presents the tasks of a social worker in the process of planned discharge, which range from targeted and short analyzes of specific needs, to comprehensive psychosocial assessments and risk assessments of a whole range of social and psychological needs, strengths and stressors. The challenges that were imposed and ultimately overcome were the patient's lack of social support, different perceptions of the problem and insufficiently transparent communication between stakeholders, the patient's weakened social capital and physical disability. Therefore, the presentation of the case shows the importance of direct mutual communication of all the mentioned stakeholders, timely exchange and transparency of information. Although, the primary and most important thing is to respect the voice of the patient and enable him to shape the vision of his future life, in accordance with the resources available to him.

Key words: social workers; patient discharge; patient rights; personal autonomy

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Introduction

According to world data social work in health care is the third most common field of work of social workers that has a tendency to grow, especially in transition countries including the Republic of Croatia [1]. Therefore, the social work profession is increasingly viewed as an important component of a multidisciplinary approach in health care [2]. One of the main factors that distinguishes social workers in health care from social workers in other ar-

reas is the accelerated pace of work that is in line with health care requirements, which requires social workers in health care to get in touch with the patient, build trust, identify patient's needs, attitudes and feelings, assess the situation, provide appropriate information, advise the patient, and plan actions in a short period of time, which can be quite challenging [2]. The basic task of social work in health care is to professionally help people who are in psychosocial distress due to health problems in terms of preserving, restoring and developing their potential to create an active and equal role for the purpose of integration into social life [3]. Therefore, Department of Social Work at the Clinical Hospital Center Rijeka is guided by model "Patient in the center"

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(“patient-centeredness, patient-focused care, patient-oriented care”), which means that the patient and his family are and should be actively involved in decision-making process towards patient’s health and life, through close collaboration with professionals. The model “patient at the center” originated 30 years ago as a philosophical and unrealistic idea [4]. Although today the patient’s experience and (dis)satisfaction is considered a unique and authentic contribution to the treatment process, unfortunately, in most health care institutions around the world, the basics of patient care are still unclear [5].

Researchers from Harvard Medical School, on behalf of Picker Institute and The Commonwealth Fund, defined eight primary dimensions of patient-centered care: 1. Respect for patients’ values, preferences and expressed needs; 2. Coordination and integration of care; 3. Information and education; 4. Physical comfort; 5. Emotional support and alleviation of fear and anxiety; 6. Involvement of family and friends; 7. Continuity and transition and 8. Access to care. Recommendations of the Picker Institute in Boston and its sister organizations in Europe can be useful but each institution can have its own specific approach in establishing the model [6].

Therefore, from a social work holistic perspective this model is seen as a good practice based on an individualized approach to each patient by the team, in accordance with the patient’s specifics in terms of health and functioning, but also other psychosocial, socioeconomic and cultural determinants and often in cooperation with a narrow patient support network. Among other things, this model is recognized as significant in discharge planning. Discharge planning is the process of transitioning a patient from one level of care to the next. Ideally, discharge plans are individualized instructions provided to the patient as they move from the hospital to home or instructions provided to subsequent healthcare providers as they move to a longer-term care facility [7]. During this process social worker’s tasks are: 1. Conduction of assessment for

high risk patients; 2. Determination of need for post hospital care; 3. Engaging the patient and/or families for the development of the plan and 4. Coordination with outside resources for arranging the services.

Looking at these guidelines, we can construct the challenges that arise in almost every one of them. Thus, social workers are faced with the speed within which they make initial contact and patient assessments. Then, they come across different views of a certain situation from different stakeholders, they balance between two areas - the area of social care and health care area, which can often become the cause of conflict within the clinical multidisciplinary team, which often misses the perspective of social care from the situation. Furthermore, the role of social workers during this process also is advocating patients’ rights, because social workers are perceived as a “patients’ voice” and a communication facilitator that represents a “bridge” between patients and medical staff [8,9]. That position brings more challenges for social workers because it can become a cause of misunderstanding with the patient, when patients’ decisions about his/her own life are absolutely contrary to objective professional assessment of patients’ welfare. In such situations, social workers struggle between several ethical dilemmas, primarily between respecting the patient’s right to self-determination and/or protecting the rights and interests of the elderly and infirm.

Therefore, the aim of this paper is to present the challenges of the work of social workers in the field of discharge planning and the promotion of patients’ right to self-determination through the presentation of case studies in the Clinical Hospital Center.

Case report

Patient A (61 years old) was admitted to the Neurosurgery Clinic in May 2018 for brain malignancy surgery (diagnosis: C71.9 - Malignant neoplasm of the brain). She stayed in Clinical Hospital Center about one month. In a few weeks the patient was re-hospitalized to the Clinic in July 2018 for brain reoperation, when she was in Clinical Hospital Center about three

weeks. She was a widow for several years and in that moment lived alone in house in suburb of Rijeka. Patient was not literate, she could not neither read nor write. She was a beneficiary of a survivor's pension for her late husband. She owned the house where she lived. She had no children or close relatives. From the extended family, she mentioned an older sister and two nephews, who are living Republic of Serbia.

This case study is explanatory whose purpose is to explain how or why a state of affairs occurred or why a series of events did or did not occur. In our case, it is about social workers' challenges in the process of planned discharge and promotion of patients' right to self-determination. A case study involves multiple forms of qualitative data sources and observations.

Discussion

In May 2018, one week after successful operation the patient was stable, mobile and ready for discharge preparation. In meanwhile, the head nurse of the Clinic noticed that the patient has no family members who are able to take care for patient. Lack of contact with a family member of an elderly person who needs further care was the trigger for the intervention of a social worker. Social workers in Clinical Hospital Center have range of skills, knowledge and research in order to ensure comprehensive assessment, interventions and a holistic analysis of the patient's situation. Social work assessments range from targeted and brief specific-needs analyses, through to comprehensive psychosocial and risk-assessments of the full range of social and psychological needs, strengths and stressors. These assessments underpin needs-based and evidence-informed interventions that address the social and emotional issues that are impacting on the patient and their family/carer's health, wellbeing, adjustment and recovery [10]. In process of discharge planning social workers create individual planning for each patient. Individual planning is process of planning and creating an individual plan for changing the patient's life situation or behavior, established on the basis of a comprehensive assessment of the patients' needs, difficulties and resources, with cooperation and partnership with users and their families, the creation of which in-

cludes the activities of assessment, organization of access to rights and services, coordination with other service providers, monitoring and evaluation that should respond to patient needs [11]. In the context of the scope of work of a social worker in a Clinical Hospital Center, this case referred, first of all to assessment, than case management, service coordination and multidisciplinary work, which also included the advocacy of the patient's rights. The social worker's assessment, in this case, included the collection of socio-anamnestic data in order to assess the patient's capacity, her functioning, perceived and real social support, and the adequacy of housing and accommodation.

Social worker visited the patient at the Department to establish initial contact and supplement socio-anamnestic data. Initial contact between social worker and patient is a very important base for further relation-making. It is very common that patient become confused and frightened by the the social workers visit leeded with their own prejudices so social worker approached the patient with a lot of respect and appreciation, without imposing our role of helper (for example, "we came to help you"). Such a paternalistic attitude undermines the creation of a cooperative relationship between social worker and patient and creates a sense of "helplessness" in patients. So, instead of a paternalistic approach, we used an individualized approach to patient. In the conversation with the patient, was used a very simplified language, especially taking into account the health condition and educational status. During the conversation with the patient, she stated that she was ready for discharge, that she would take care of herself because she was able to do so, and thanked us for our visit.

The patient's opinion radically conflicted with the psychosocial report, which stated that she is an elderly person who is currently unable to live and function independently, given her health condition, and also does not have available social support in the form of family members or a trusted person who would take

care of her. The house where the patient lives is in the suburbs and isolated, which further complicates the availability of formal rounds of social support. On the one hand, these facts made the social worker feel helpless and at the same time worried about the life and health of the patient. On the other hand, this challenging moment was a space for creative action and the search for new information and alternatives. Despite the low educational status, cognitive preservation with a clear articulation of one's needs and religiosity as a mechanism for easier acceptance of one's condition were recognized as strengths, which was visible through the statements "God's will. I pray for myself, I will go to church" and the like.

The next day, after finished assessment, social worker started with case management which was including ensuring communication and understanding of post-hospital care among patients and family. The patient is referred to services from the health care system (extended treatment in another institution, visiting nurse, and home care) and the social welfare system (accommodation in a home for the elderly, financial benefits, help and care services at home, meal delivery...) but patient refused all services. Her wish was to go home in the hope that her sister and nephew from Serbia would visit her. Contact with extended family members was not possible, the patient was illiterate and did not have the phone numbers of family members written down. Considering that it is another country, we were unable to reach the family members by other means. Accordingly, we lacked a family perspective in order to complete a complete picture of our patient's life in her natural environment, and to complete the existing data on her capacities, functionality, needs, available social support and more. Subsequently, for the purpose of intersectoral cooperation and coordination of the case, the responsible social worker from the center for social welfare was contacted, with whom information was exchanged. Intersectoral cooperation is very important because it implies a partnership in which organizations or systems work together in a transparent

manner, using their own resources, in order to achieve common goals [12]. In this case, the general objectives were to protect the rights and interests of the elderly and infirm. From the center for social welfare was confirmed all previous knowledge and the fact that the patient had previously refused services from the social welfare system. The social worker at the center also did not have contact information for the patient's sister and nephew. In order to complete the anamnesis, the competent visiting nurse from the county health center, who occasionally visited the patient, was contacted. It is learned from the visiting nurse that she previously managed to function independently and that she was occasionally helped by the locals and the local priest. Neither did the visiting nurse have any information or contact information for the family.

In conclusion, the patient's perspective is very important when planning discharge, where the goal of social worker is to empower the patient and advocate her rights as much as possible in the realization of their efforts. However, it is important to be realistic in expectations, in accordance with the person's capacities and to take into account the professional, legislative and family perspective. Usual empowerment and advocacy are strategic processes of working with users/ patients or on their behalf, in order to achieve a more equal position in society, the right to social services or some other form of assistance that would otherwise not be available to them, which also includes advocating for a better social policy, better social legislation and social justice in society [11]. In our case, empowering and advocating the patient's rights meant respecting her decision to be discharged at her home address and ensuring the greatest possible professional support available to her. Although in this case the objective evaluations were not in accordance with the subjective evaluation of the patient, there were no legal obstacles for the discharge of the patient. According to the Law on the protection of patients' rights a patient in a healthcare facility, as part of informed consent, has the right to autonomously decide

whether to accept or reject the offered therapeutic/diagnostic procedure, which is evident in the case through the refusal to consent to prolonged treatment in other institution [13]. Also, according to Law on social welfare, in order to receive compensation and services in the social care system, the consent of the beneficiary or his legal representative is required [14]. Since the patient did not consent, we were not able to initiate any service from the social care system on her behalf.

The patient autonomously decided that she wanted to be discharged to her home address, and the patient's decision was respected. In the context of autonomy, we distinguish between „autonomy of execution” and „autonomy of decision”. Thus, we could say that the patient had „decisional autonomy”, which is defined as the ability to make decisions, for personal choices and values, regardless of the ability to independently execute decisions („executive autonomy”) [15]. Therefore, by official duty, the center for social welfare and the visiting nurse were informed about the discharge of the patient and asked for a field inspection in order to monitor the condition and functioning, as well as to ask again about consent for certain services in addition to the social welfare system. After a month, the patient was found by a neighbor lying motionless on the floor of her house (over 12 hours) so she was brought to the Clinical Hospital Center by ambulance. Conditions in the house were inadequate- she was lying in the feces, there was no edible food, things were scattered all over the house. The patient was re-admitted to the Neurosurgery Clinic where she had a brain reoperation. Postoperative, she was in a weaker condition compared to the first hospitalization. The discharge planning process by the social worker followed the same principle as before, with the fact that the patient's dependence on others was assessed to be even greater than before, and extra-institutional forms of care for the patient were assessed as insufficient. However, as before, the patient refused to give authorization for informed consent for extended treatment at another in

the health facility and refused placement in a nursing home or foster family. She exclusively wanted to stay in her house. The patient again claimed that her sister and nephew would take care of her. Although, it was clear that this would not happen because no one had even contacted the Clinic so far to ask about her and her health and no one visited her after the previous discharge from the home. This time, we asked her to sign a statement confirming that she refuses extended treatment and accommodation in the institution, and that she wants to go home on her own initiative and responsibility, regardless of the fact that she is not independent and does not have a person to take care of her. The patient refused to sign anything because, as she said, she is illiterate and distrustful of us.

During hospitalization, psychiatrists were called on two occasions to for the purpose of determining patient's clinical competence to give consent and determine whether there were certain deviations in the patient's mental state and functioning. After both examinations, the psychiatrists concluded that there were no deviations, that she was oriented in all three directions and that she consciously, in accordance with her capacities, made decisions about her life and treatment. Therefore, there were still no legal or clinical obstacles to respecting the patient's decision.

In further conversations between social worker and patient the patient stated that she was very satisfied with her stay at the Clinic and that she would like to be there as long as necessary but Clinical Hospital Center Rijeka is institution for acute patient care and hospitalizations are limited. On the other hand, a neurosurgery specialist gave a recommendation for radiotherapy at the Clinic for Radiotherapy and Oncology, which was an opportunity to extend the patient's stay in the Clinical Hospital Center, which she agreed with. Hospital's rules dictate that patients should be discharged home first and wait their turn for radiotherapy. Also, for some patients, outpatient therapy is planned, while for some, hospitalization with mandatory weekend discharges is

approved. Social worker's task was to stand up for the patient and advocate for her rights to treatment, taking into account the specificity of the situation. In order to prevent certain negative consequences of discharge from the Neurosurgery Clinic to patient's home, social worker ask the head of the Radiotherapy and Oncology Clinic to admit the patient to radiotherapy directly from the Neurosurgery Clinic. The request was made orally and in writing. The joint initiative of the patient and the social worker, which finally degenerated after a long period, in the end it was not appreciated, so the patient (less mobile) was discharged home. The social care center and the visiting nurse were again informed about the discharge and they were asked to visit the patient at home in order to monitor her condition and functioning.

Eventually, three weeks after the patient came for radiotherapy, a significantly impaired condition. During this period, our request was partially granted and the patient was not discharged home on weekends. During therapy, the condition worsened, so the palliative care team intervened. The palliative team assessed that the patient was a patient in the terminal phase of the disease, which opened the possibility of accommodation in a hospice. Hospice care focuses on the care, comfort, and quality of life of a person with a serious illness who is approaching the end of life. The palliative team talked to the patient for almost a week in order to apply for hospice accommodation, but the patient did not agree, even though she was running out of energy. Finally, in the absence of ideas and opportunities to find an adequate solution, we presented the hospice accommodation from a different perspective. The hospice in Rijeka is an institution founded by the archdiocese and it nurtures Christian principles. Knowing that the patient was a believer, social worker presented her the hospice through a religious perspective, and this method proved to be successful. The patient agreed to be placed in a hospice. The patient died in a dignified environment after a month spent in a hospice.

The question remains, what could have been done differently to cope with mentioned challenges and what impact it would have had on the whole case. What was missed was a collective, immediate, multidisciplinary and multisector approach to the patient, instead of an individual approach by each expert. Also, the connection between the doctor in the Clinical Hospital Centre ospital and the patient's family medicine doctor was at an insufficient level. Subsequently, the local priest was failed to be contacted, although information was available that the patient was involved in the church. In conclusion, we certainly believe that a different decision could have been made regarding radiotherapy, in such a way that the patient was included in it immediately, and not discharged home and admitted after she entered the terminal phase of the disease, where such therapeutic procedures lose their meaning. It remains unknown whether these actions would have had an impact on the outcome of the case or whether it would have remained unchanged.

The principle of self-determination of patients has largely narrowed the paternalistic approach according to which the expert made decisions for the benefit of the patient [7]. While paternalistic approach is guided by reasons to promote health and preserve patient life, the patient's right to self-determination allows decision taking into account a very wide range of reasons: avoiding the agony of terminal illness, avoiding pain, disability, dependence on other people's help or humiliation, religious reasons, or strong philosophical beliefs, the desire to avoid the burden of family or friends, financial status, maintaining dignity and self-esteem. The presented clinical case shows how challenging tasks of social workers are in the process of the patient's planned discharge. The clinical context is particularly challenging for the work of social workers in preserving the patient's autonomy, since social workers are the link between several stakeholders (patient, family, healthcare team of the institution, external healthcare team, social service,

community...) whose perceptions and opinions are very important in the process of the patient's planned discharge, and often conflicting with each other. Therefore, from the presentation of the case, it is evident the importance of direct mutual communication of all mentioned stakeholders, timely exchange and transparency of information, for which the work of the Department for Social Work should strive even more. Although, the primary and most important thing is to hear the patient's voice and allow them to constantly shape the vision of their future life, in accordance with the resources available to them. But, in the other hand self-determination that does not recognize its limitations, does not seek additional knowledge and insights within the competences of experts, is the reason for creating wrong and incorrect beliefs about one's own state of health, diagnosis, prognosis and treatment, and becomes the opposite of a person's decision-making autonomy and self-determination.

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Conclusions

Through the described approach, the right to self-determination and autonomy in patient decision-making will continue to be nurtured with the awareness that we will continue to face diverse challenges related to this topic. Since this research has shown that the approach, skills, abilities and knowledge of social workers facilitate overcoming potential challenges, we believe that the investment in further education of social workers, but also of the entire multidisciplinary team, seems like a good way to improve professional practice.

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