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Original research article

Integrated care for people with Apallic syndrome in homes for people with disabilities in the Czech Republic

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ABSTRACT

Long-term care for Apallic clients in residential social institutions in the Czech Republic faces the problem of insufficient definition in present legislation. The trend in the provision of services to clients in a coma is an integrated attitude from a multidisciplinary team providing health and social services. The aim of the text is to analyze the conditions of integrated care for people with Apallic syndrome in homes for people with disabilities and, in a comprehensive manner, to describe the functioning of a registered residential social service for apallic people. The goal was achieved through qualitative research, making use of semi-structured interviews and knowledge gained by the means of studying available relevant sources. The results proved that the issue of provision of integrated quality care to persons in a coma is resolvable. In the residential social service, it is possible to provide high-quality health care, nursing care and social care under specific conditions which are based on the individual needs of clients.

Introduction

Over the last few decades, significant progress has been made in the world and the Czech Republic in the field of science, modern technologies, health care and management of healthcare. As a result, the number of people surviving brain damage by entering a vegetative state (hereinafter referred to as VS) or Apallic syndrome (hereinafter referred to as AS) has been increasing. A remarkable improvement in pre-hospital care, acute diagnostic and treatment options in hospital, and a high level of resuscitation and intensive therapy can serve as a good example [1]. Wild et al. [2] attribute the increasing number of surviving people mainly to advanced rescue services, emergency reception, and intensive care after the acute brain damage, and the activation of high-quality nursing care. In professional literature, the prevalence of new cases is stated somewhere between 0.2 and 6.1 patients per 100,000

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inhabitants per year [3]. One-third is made up of traumatic and two-thirds of non-traumatic cases [2]. AS is relatively common in young people. It may take several days or even years. It may be a temporary as well as a final state. Unfortunately, hand in hand with the length, the chances of recovery and restoration to full consciousness decrease. According to Milotová and Bendík [4], 15% of patients move closer to the standard; in favourable cases, more than 50% of patients are able to reintegrate into society, even if only in a sheltered environment.

The issue of provision of integrated health and social care to people with Apallic syndrome in residential social services has not been professionally treated in a sufficient manner; nor has it been grounded in publications or defined in present legislation. The problem is a mismatch between the health and social care systems that provide the care. Contemporary management, including the financial security, is unsystematically distributed among the departments of the Ministry of Health of the Czech Republic (hereinafter referred to as MH CR) and the Ministry of Labour and Social Affairs of the Czech Republic (hereinafter referred to as MLSA CR), which causes practical problems with the implementation of both health and social services to clients in a coma. There are also problems in the absence of trained professional staff which would focus on this target group [5]. In accordance with the permeation of health and social care, the terminology used to denote people with Apallic syndrome differs, too. While healthcare makes use of the term ''patient'', social services use the term ''client''.

At present, clients/patients with Apallic syndrome are usually placed into institutions of a hospital type. These are intensive care units, anesthesiological-resuscitation units, follow-up intensive care units (FIC), long-term intensive care units (LTIC), and long-term care hospital beds (LTCH). All these departments provide health services for a limited period of time. As quality inspections point out, optimum conditions cannot be seen in social services either. The controls focus mainly on administrative tasks, while the practical care for clients is of peripheral importance.

Theoretical background

In clinical terms, we meet the terms Apallic syndrome, coma vigil, persistent vegetative state or vegetative state. The term Apallic syndrome is not considered to be apt enough in the Anglo-Saxon literature and is used mainly in Central European countries (Austria, Germany, the Czech Republic, Slovakia); the Anglo-Saxon literature considers the term 'vegetative state' to be apt [1].

Bartoš et al. [6, p. 200] describe the Apallic syndrome as the state of ''*extinct cerebral cortex functions with a relatively well-preserved function of the brain stem*''; Erp et al. [3, p. 1361] call it a ''*non-responding wake syndrome*''. According to Dolce and Sannita [7], the vegetative state is characterized by the absence of consciousness of both the self and the environment. The quality of life of apallic people is closely related to the humanistic approach of the nursing staff even in moments when their lives reach their end.

Clients with Apallic syndrome can achieve certain progress in terms of eating and communication, but they need and will always need long-term care and assistance. Despite advanced medicine and considerable improvements in nursing care, these people can no longer return to full health. This disease is related to the collaboration of all persons involved in long-term care [8]. Management of the care for people with Apallic syndrome focuses on social reintegration of patients or must guarantee follow-up humane care if the treatment fails. The outcome depends on the cause and duration of AS/VS as well as on the patient's age [2]. Subsequent supportive care includes mainly aggressive prevention of health complications related to mechanical ventilation and prolonged immobility [9].

A long-term or incurable disease breaks one's way of life and forces him and his environs to adapt to unusual, sometimes strange and unexpected conditions. The hierarchy of values is completely changed and the severely ill lose their original meaning of life. In this life situation, ''social support'' enters the life of the seriously ill in the form of help provided by others to someone who is in a situation he is unable to face [10].

Long-term care is defined as ''*a set of services needed by people with limited functional capacity, physical or mental, who are permanently dependent on assistance in their basic daily activities*'' [11, p. 152].

The entire system of long-term care is organized and secured in terms of ensuring control, quality, financing, efficiency, and effectiveness. The basic aims and principles of the long-term care are:

- fair access to all health and social services;
- protection of human dignity and provision of individual care;
- ensuring the optimum method of long-term care;
- assessment of the client's needs and providing him with benefits, services or aids [12].

The concept of the MLSA CR [13], which contains a discussion paper on the long-term care in the Czech Republic, includes – besides others things – an analysis and recommendations for changes in this area. The necessity of the long-term care for people who can no longer stay at home and need a long-term or permanent institutional residence to treat their unfavourable situation is discussed here.

According to the experts of the Expert Panel of the MLSA CR, the strength of the implementation of long-term care in the Czech Republic is the interconnection of social health services and their accessibility, and the establishment of a specialized field of medicine, i.e. ''*long-term care medicine,*'' which will bring better understanding and treatment of long-term health challenged persons. Nowadays, the state supports the care of both professional carers and family members, so-called informal carers [14], so that the ill can stay in their natural environment. It also supports the constitution of field services and of new medico-social services [12].

The aim of our research was to analyze the conditions of integrated care for people with Apallic syndrome in homes for people with disabilities from the viewpoint of a social worker as a researcher. From the point of view of the non-systemic approach of the relevant ministries, there is no clear boundary of responsibility in the long-term care for this specific group of clients, both from the health and social point of view. In the research, we asked: (1) How is the integrated care for people with Apallic syndrome in residential social care facilities

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