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.

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Keywords:
Apallic syndrome
Health services
Social services
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Multidisciplinary team

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 environ-
ment.

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 unsystemat-
ically 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, anaesthesiological-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].

Bartos 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 environ-
ment. 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
ever 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 recom-
endations 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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