



Health educators as assistants for disabled people in universal teaching institutions in Poland

Edukator zdrowotny jako asystent osoby niepełnosprawnej w placówkach nauczania powszechnego w Polsce

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Abstract

Education dedicated to the health needs of pupils disabled because of chronic diseases in Poland remains an empty term, a chair without a backrest. In this article, suggestions of changes in the educational system are presented. These suggestions, thanks to support from interested therapeutic teams, have a chance to fulfil the educational gap in the area of chronic diseases and proceeding with disabled pupils at universal teaching institutions in Poland due to the introduction of health educators.

A health educator is a person suffering from type 1 diabetes, educated during specialised postgraduate studies conducted at the Medical University of Lodz. The aim of this article is to show the importance of the health educator's role in the education process of children and youths disabled because of chronic diseases, at educational institutions of the Polish system of universal education.

Key words:

health educator, type 1 diabetes, disabled person assistant, educational institutions of universal teaching, education, school Health Educator as disabled person assistant at universal teaching institutions in Poland.

Streszczenie

Edukacja ukierunkowana na potrzeby zdrowotne uczniów niepełnosprawnych w wyniku choroby przewlekłej w Polsce pozostaje pustym wyrażeniem, krzesłem bez oparcia. Niniejszy artykuł zawiera propozycję zmian w szkolnictwie, które dzięki poparciu zainteresowanych zespołów terapeutycznych mają szansę wypełnić lukę edukacyjną w zakresie chorób przewlekłych i postępowania z uczniem niepełnosprawnym w placówkach nauczania powszechnego w Polsce poprzez wprowadzenie funkcji edukatora zdrowotnego. Edukator zdrowotny to osoba chorująca na cukrzycę typu 1, wykształcona podczas specjalistycznych studiów podyplomowych prowadzonych na Wydziale Promocji Zdrowia Uniwersytetu Medycznego w Łodzi. Celem artykułu jest wykazanie, jak ważną rolę odgrywa edukator zdrowotny w procesie edukacyjnym dzieci i młodzieży niepełnosprawnych w wyniku chorób przewlekłych w placówkach oświatowych polskiego systemu edukacji powszechnej.

Słowa kluczowe:

edukator zdrowotny, cukrzyca typu 1, asystent osoby niepełnosprawnej, placówki oświatowe nauczania powszechnego, edukacja, szkoła.

Introduction

School health education in Poland focuses on two main areas: physical education and sport, and the popularisation of knowledge and habits related to leading a healthy lifestyle [1-5]. Both the program guidelines and specific programs implemented indicate that this education is addressed to healthy people of different school ages. School education focused on the needs of children and adolescents disabled because of chronic diseases does not exist, leading to the marginalisation of the health needs of this group of young people. Exclusion from the system of general education and social isolation of chronically ill young people is becoming a more common phenomenon, resulting from the systemic negligence and ignorance that prevails among teachers and peer groups. At the same time, every illness (not only chronic, although this type in particular) is one of the most unwanted and undesirable phenomena for every member of society. Acceptance of the disease is an extremely difficult process, both for the sick person and for the members of the family and the individual social groups to which the person belongs. Undoubtedly, the acceptance of the disease and reconciliation with the state of health, deviating from the accepted social norms in modern society, is most difficult for a person of developmental age – a child diagnosed with a chronic illness [6]. Although this problem concerns all chronic diseases, it is particularly prominent in children with diabetes [7]. Early symptoms of diabetes are usually unrecognisable, because they include fatigue, drowsiness, and excessive thirst. These symptoms, especially in children, are difficult to associate with diabetes. Therefore, a specific diagnosis of diabetes is always a surprise for the child and for the parents of a child who did not seem sick: suddenly a dangerous chronic disease is recognised, which will have to be endured not only by the child but also by the whole family. Such a diagnosis causes shock, often enhanced by the stigmatisation of people with diabetes, as well as by media chaos and by popular myths that are the cause of social rejection. In addition, diabetes causes a sense of insecurity associated with the necessity of introducing a series of changes in the current family lifestyle. This is a source of many difficult situations, because it affects the way the child functions on various levels of everyday life [8].

Diagnosis of diabetes or other chronic disease puts the young person in a difficult situation, which is disturbing, and sometimes makes it impossible to implement goals, tasks, plans, and needs. Frequent stays in hospital, isolation from the family environment, as well as the need to adhere strictly to the rigors of treatment, cause fatigue symptoms increase over time. Children suffering from diabetes for many years show a greater severity of fatigue symptoms in comparison to children with newly diagnosed illness. A characteristic feature of teenage diabetics is also the feeling of this fatigue in the whole body; young people in this group often complain about various physical ailments of pain in the back, legs, joints, and muscles. They have periods of drowsiness during the day, at the same time complaining about difficulties in falling asleep. Long-term

patients, often lacking patience and energy, lose interest in their previous activities. They often become tense, irritable, quarrelsome, and tearful. In addition, they have rather low self-esteem and lack of self-confidence.

Teens suffering from diabetes live in a state of chronic mental stress caused by the need for constant and active involvement in treatment. This leads to a sense of constant danger, guilt, low self-esteem, and, unfortunately, depression. Awareness of the incurability of the disease and the fear of possible complications are factors that additionally burden the psyche of teenagers, which in turn may lead to the emergence and then exacerbation of the main illness symptoms.

The extent to which diabetes prevents a child from functioning in society depends not only on the illness itself and its causes, but also on the way in which the patient accepts the difficulties associated with the disease. A disease such as diabetes can be treated by the child as a weakness, a defect, and even a punishment. In this way, diabetes becomes an enemy, and the fight with it becomes the child's life goal, which negatively affects his/her further, normal development and the perception of the disease itself as "impossible to manage". The long-term psychological burden associated with the disease and its treatment can lead to a change in the self-image and the way of valuing personal needs in a young person suffering from diabetes.

Such perception contradicts the technological progress of the last three decades that has been made in diabetes treatment. Currently, thanks to the use of modern glucose monitoring systems and technical solutions (e.g. mobile applications), diabetes is not only a "manageable" disease, but, when properly conducted, it is not an obstacle to any activities, including sports appropriate for children, adolescents, and adults. It is possible to make friends with diabetes and lead a normal lifestyle while being aware of it. In order to build such awareness in a young person diagnosed with diabetes, it is necessary to cooperate with an experienced person – a health educator, who will take a supporting role in the educational process: a proactive role, not only reactive in crisis situations. This educator knows and can recognise the symptoms of various disease states in diabetes and provide first aid. At the same time, the educator, recognising the states of malaise and reduced intellectual efficiency of the child caused by fluctuations in the blood sugar level, knows how to include them in the everyday learning process (from the child's side) and teaching (from the teacher's side).

Health educator – education and role in the school education system

Chronic diseases, their monitoring, management, and holistic treatment process are the greatest challenge for any health care and education system. A special educational emphasis related to the daily monitoring of young people suffering from a chronic illness should be put on educational institutions of universal teaching. Supervision of children and adolescents

with disabilities resulting from chronic illness in an educational institution requires not only basic and current knowledge about first premedical actions in cases of problematic situations, but above all also skills in educating and consolidating good health habits. Educational institutions where children and young people function are not prepared to help either sick students or teachers and healthy students to take appropriate actions to develop methods conducive to co-existence in one school social group. The project of the health educator profession created in 2011 is to meet these needs defined over the years [9]. The aim of the project is to combine all aspects of health education: prevention, educational pathways of health, and personal assistance for people with chronic diseases, which require the help of a third party (mainly for children with type 1 diabetes) for a specific educational and preventive action, which is the health educator's role in modern educational institutions of universal teaching.

Preparation of a person to pursue the profession of a health educator must be based on an integrated model of further education. Therefore, along with the idea of the profession itself, in the "Diabeciaki" Foundation a special program was developed for *Postgraduate Studies for Health Educators in the field of health promotion, health education, and diabetes prevention and related chronic diseases in children and adolescents*. Diabetes, asthma, allergies, celiac disease, and cardiovascular disease are increasingly common among children and adolescents. Therefore, there is a great need for educational institutions to be well prepared and to provide strong support for parents and doctors, as well as for teachers themselves. The goal of these postgraduate studies is to broaden knowledge about chronic diseases through the use of new forms of teaching, combining theoretical knowledge with the experience of the sick, based on specific expectations expressed by the charges of foundations like "Diabeciaki", analysed by specialists in the field of diabetology cooperating with the Foundation and implemented in postgraduate education. The knowledge gained during these postgraduate studies is a perfect complement to previously acquired qualifications in such fields as nursing, pharmacy, biology with didactics, pedagogy, sociology, psychology, and many others.

Postgraduate studies for Health Educators allows the acquisition of knowledge and skills necessary to conduct health education, consolidate good eating habits and good psychophysical condition, support families and patients with chronic diseases in the school / professional environment, and support general practitioner / diabetologist / paediatrician in this area.

The aim of the studies is to provide and systematise general knowledge about:

- pro-health behaviours in the field of diabetes and related chronic diseases in children and adolescents,
- treatment of diabetes, including insulin therapy, the principles of proper nutrition, and physiotherapy,
- anatomy, physiology, and pathophysiology of selected internal systems and organs,
- emergency medical services,
- psychology with elements of psychoanalysis,

- pedagogy with teaching methodology,
- psychoprophylaxis and interpersonal communication,
- organisation of health services for chronically ill people in general health insurance and in private product offers.

The ways of conducting classes allow the assumed learning outcomes to be achieved; these are, among others, lectures, seminars, and exercises in the form of workshops. Learning outcomes are monitored on an ongoing basis by lecturers in consultation with the study management in different ways of assessing the learning outcomes: presentations, workshops, team work, observations and assessment of practical skills, and involvement in discussions. Checking the learning outcomes in a limited time allows student's ability to organise work, and independence of thinking and communication under stressful conditions to be assessed. The graduate obtains knowledge and qualifications in the field of health promotion, health education, and prevention of diabetes and related chronic diseases in children and adolescents. The acquired skills and qualifications are confirmed by the certificate of Postgraduate Studies completion.

The postgraduate students also gain knowledge in the field of law regarding the provision of services to chronically ill patients. It allows the identification, properly and early enough, of the patient's needs in everyday life as well as in emergency situations related, for example, to changes in the treatment method. Students also learn to supervise rightly the functioning of their charges in the healthcare system, which assures the implementation of the patients' needs; the Polish health care system is difficult for every patient, and for young patients who are chronically ill and their families it is another continuous challenge.

A health educator should have psychological preparation. Diabetes from the very moment of its diagnosis is a source of stress, anxiety reactions, and depression disorders. The relationship between depression and diabetes has been recognised in medicine for over 300 years [10]. Numerous studies conducted since the 1980s indicate a positive correlation between diabetes and cognitive impairment in patients with diabetes. The threat of loss of independence due to progressive deterioration of cognitive functions and physical fitness may be the cause of greater fears and stress than the clinical progress of known diabetes complications [11]. Awareness of illness, of its incurability and of the risk of hypoglycaemia, ketoacidosis, as well as the possibility of developing late complications of the disease, may strongly affect the mood and social behaviour of children and adolescents. Individualised psychological and pedagogical support for a chronically ill student is another aspect of the proposed postgraduate studies. This type of help is an essential element of school life, which has a direct impact on the results of teaching and on the patient's position in their peer group. According to legal regulations [12-15], children with diabetes and other chronic diseases are included in the group of children with specific learning disabilities, for whom the school headmaster should organise assistance consisting of recognising and satisfying individual student's developmental and educational needs and recognising their individual psychophysical abilities. That is why the proposed postgraduate

studies can become extremely useful for employees of educational institutions.

Assuming that the health educator employed by the given institution is a person who has knowledge and personal experience in operating the electronic devices with which a child with diabetes is equipped, there is an unprecedented improvement in safety for both the sick children and their surroundings. An experienced and educated health educator is able to measure the level of sugar and knows how to deal with problematic situations, e.g. exchange of infusion set when a sick child uses an insulin pump; a health educator can also deal with situations that threaten the health and life of the charge, e.g. in the case of hypoglycaemia (a life-threatening complication of diabetes that means a drop in blood sugar below 20 mg/dl), is able to inject GlucaGen, and knows how to help the child in case of hyperglycaemia (complication associated with high blood sugar that can cause life-threatening ketoacidosis). Such complications may occur in stressful situations for the child, e.g. during examinations. According to the law, during the examinations there must be a person accompanying a child with diabetes, protecting the child and being able to recognise the risks associated with fluctuating blood sugar levels in the child and provide assistance on time. Both in the case of hypoglycaemia and hyperglycaemia, the patient must regain his/her mental balance and mental independence in order to continue the exam. The educator assists the patient throughout this time.

Educator – symbol or reality

The word “educator” in Polish is a commonly used word that does not correspond to its real meaning. According to the “Dictionary of Polish Language”, an educator is “a person who professionally deals with education – teaching, educating someone; teacher” [16]. Meanwhile, according to some observations, today the “educator” is in most cases an empty word, for which neither a person nor an idea is standing. This word finds its support only in the vision of an educator who has no human form, no personality, no intelligence, no knowledge, and no empathy. In contrast to the vision itself, a person-educator who fulfils his/her tasks, especially in the area of health, is a must; the educator becomes a response to clearly defined social needs (and thus: shortcomings) in the field of health education in educational institutions. An educator, as an assistant to a chronically ill person in schools, kindergartens, nurseries, educational institutions, and orphanages, is a person who exists in the program of the proposed postgraduate studies. In addition, the profession of health educator is also a proposal for people with disabilities.

Currently, of all chronic diseases, type 1 diabetes in children and adolescents is best equipped with electronic “gadgets” that allow much better control of the illness. These are systems of continuous glucose monitoring, often coupled with modern insulin pumps and mobile devices such as smartphones. Such systems facilitate making the right therapeutic decisions during the 24-hour functioning of the body. Despite this, diabetes in

a 3-8-year-old child attending an educational facility every day requires the presence of an attendant during the basic activities related to the disease: hygiene, assistance in measuring blood sugar, conversion of carbohydrate and protein-fat exchanges consumed by the child in a meal, and compensation for a meal with insulin given in accordance with the child’s treatment regimen. For teachers, educators, and other teaching staff, and often also for school nurses, the time that a young person suffering from diabetes spends in school and the process of dealing with such a person is a significant problem disrupting the normal educational process of both the sick child and other students.

This situation caused the appearance of a new form in Polish educational institutions: a woman with dark circles under her eyes called the Camping Out Mother. During the entire stay in school of a sick child, this person sits next to the classroom and waits. During breaks, she runs into the classroom and takes away the child’s time to rest between classes by measuring sugar and giving a sandwich or insulin if the sugar level exceeds 120 mg/dl because in this situation the child will not get food. After the bell for the next lesson, the Camping Out Mother is still waiting outside the room, until the next break, and so on, for five days a week. There is another, new character: Tolerated Mother, in the case of a child in a nursery or kindergarten, who accompanies the child all the time during the activities in order to make them “socially adapted”. The introduction of health educators to schools and kindergartens, as assistants of children with diabetes, can effectively solve the problem of Camping Out Mothers and Tolerated Mothers, which at the same time will encourage the mothers to return to work and support the process of automating children with diabetes.

Conclusions

Statistics related to the incidence of diabetes indicate that the number of people in Poland suffering from this chronic disease is increasing every year [17, 18]. This applies not only to the adult population, but also to children. Therefore, year by year, there will be children and adolescents in schools struggling with diabetes and other chronic diseases. Educational institutions of universal teaching create a teaching and education environment for children, including those with various chronic diseases. The environment is inconsistent, often discriminating against the needs of ill children, while the pedagogical staff are unable to perform simultaneously many functions: educational, caring, and supportive for children with disabilities because of a chronic illness. There is therefore a clearly defined need to supplement pedagogy and educational staff with people who have knowledge about chronic diseases, basic skills, and coaching skills, essential in leading diabetes training to patients – students with diabetes. Health educators are such people.

The idea of the *Postgraduate Studies project for Health Educators* is a way to meet the expectations of a society with poor knowledge and a thirst for education, who are eager to learn and acquire the information provided.

School, through health educators, should become the exponent of the needs of children with diabetes and other chronic diseases in every field: emotional, social, and cultural, offering them a full education in which there is no missing link. The school should combine activities of various people and institutions (school, family, diabetes centre, medical staff at school, school psychologist, associations supporting diabetics and their families) for the benefit of chronically ill students and their families, ensuring that the educational process remains consistent, non-discriminatory, and includes social inclusion, fostering the proper development of children. If possible, educational establishments should bring together education at school with the lifestyle of a child suffering from diabetes in the family and its functioning in the modern world, so that the children can implement the treatment program and experience their illness in the least traumatic way. Appropriate preparation of the educator in the field of diabetes care is necessary to ensure the

safety of the students and create a sense of security for all of their surroundings.

Through health educators, every institution of universal teaching should encourage other pupils and pedagogical staff to maintain constant contact with the child's family with diabetes and to learn about diabetes and appropriate behaviour towards a sick child, as well as initiate and support learning about diabetes in school through organising knowledge courses for staff, providing students with basic information about diabetes, and raising awareness of health and disease problems.

Children with a chronic illness, regardless of the time of its occurrence, must befriend the disease and learn to live with it to get the most out of life without harming their own health. That is what an educator will teach them. In relations between a child with diabetes and a health educator, the crucial issue is not presenting knowledge that concerns bans and orders but building relationships based on confidentiality and trust with the patient.

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