



CASUISTIC PAPER

Sabina Krupa  (ABDFG)

Care and nurture patient with Multiple Sclerosis, mechanically ventilated at home – a case report

St. Jadwiga Regional Clinical Hospital No. 2 in Rzeszów,
Clinical Cardiac Surgery Ward Sub-Unit of Intensive Therapy

ABSTRACT

Mechanical ventilation at home is one of the methods of treatment of respiratory failure, but it is not yet widespread in Poland. Domestic ventilation can increase quality of life of patients who can remain at home under the care of a therapeutic team. Multiple sclerosis is one of the diseases that require mechanical ventilation. This disease, leads in many cases to respiratory failure. Here, we describe a case of the patient who has suffered from multiple sclerosis for 23 years and is now mechanically ventilated at home. The paper presents the current state of the patient, problems that affected her and her family, and what changes have occurred since the time of her diagnosis with MS.

Keywords. case report, mechanical ventilation at home, respiratory failure, multiple sclerosis

Introduction

Home mechanical ventilation is a way of long-term care, which in recent years has been widely recognized and used in Poland.¹⁻³ It is a system that has become extremely important for people with respiratory failure in the course of various diseases. Thanks to home ventilation, the patient has the ability to stay in his or her environment, which increases his or her mental comfort and avoids the complications associated with hospital infections.^{1,4,5} The task of medical staff, in addition to physical care, is also to motivate the patient to make an effort to maintain mental fitness.

In addition, training is provided for the families of patients, increasing the number of people taking care of home ventilated patients.^{1,6,7} The number of young

people affected by multiple sclerosis (MS) is increasing worldwide.⁸⁻¹¹ It is estimated that in Poland there are about 50-60 thousand patients with MS.¹² Authors of the study attempted to analyze the problems of MS with mechanically ventilated patients in home conditions using the individual case method.

A case report

Twenty-three years ago, the patient was diagnosed with multiple sclerosis, but initially it was unknown whether SM was a cause for growing health problems. According to the interview, two months after the birth of her daughter in 1990, the patient began to suffer from hypopituitarism, which she described as “leg confusion”. Due to the fact that the patient experienced a difficult child-

Corresponding author: Sabina Krupa, e-mail: sabinakrupa@o2.pl

Participation of co-authors: A – Author of the concept and objectives of paper; B – collection of data; C – implementation of research; D – elaborate, analysis and interpretation of data; E – statistical analysis; F – preparation of a manuscript; G – working out the literature; H – obtaining funds

Received: 06.02.2017 | Accepted: 03.08.2017

Publication date: September 2017

birth, the doctor considered that this was a symptom of postpartum fatigue.

However, a neurological consultation was commissioned. Despite the suspicion that this may be the beginning of multiple sclerosis, the diagnosis of the disease was concealed. The patient was started on hormone treatment, however, she was not informed what side effects the drugs may have for her and her child.

The patient again became pregnant. The doctor considered that the only solution to this situation was abortion, because hormone therapy can damage the fetus and its abstinence can lead to more severe symptoms. The patient refused the abortion and stopped taking hormones for the care of the baby. Despite treatment at the beginning of pregnancy, the patient gave birth to a healthy son. A year after this, a lumbar puncture was performed and she was finally diagnosed with MS. The patient accepted the diagnosis from the beginning. Unfortunately, neither doctors nor nurses taking care of her at the hospital provided information on what multiple sclerosis is and how the life of the patient and her family can change. She inquired about MS from hospitalized patients who had been suffering from the disease for a long time. In April 2011, mechanical ventilation was started for the patient because of exacerbations of respiratory failure. Neither the patient nor her family were able to determine how often hospitalization was necessary. The last hospitalization took place about a year ago due to the need to replace her tracheostomy tube. However, it is important to mention that her anesthesiologist visited her home every week and he checked that the respirator was operating properly. Currently, according to the recommendations of the doctor, the patient should be ventilated 30-40 hours per week. For the patient, the most comfortable ventilation time is at night. Currently, the patient is taking the following drugs: Furosemide (due to recurrent urinary tract infections associated with the catheter), Dexamethasone (due to muscle spasms), and Clexane (low molecular weight heparin due to continuous immobilization of the patient and thromboembolic disease diagnosed in the past). The most severe respiratory problems occur during respiratory tract infections, but this does not happen frequently. One year ago, the patient had had a respiratory viral infection with persistent wheezing. The patient has breathing problems on a daily basis. Due to surgery in the past (pulmonary thrombotic thrombosis due to pulmonary embolism in 2010), during which a sternotomy was necessary, the patient has a feeling of tightness in the chest. The major problem is mucus build up in the patient's airways. Sometimes the patient's husband has to aspirate her every 5 minutes, however, there are days when aspirating is needed less than 3 hours. The patient feels the presence of respiratory secretions, but because of tracheotomy, she can not cough. Common respirato-

ry ailments common are felt when the patient lies on her side, so usually she sleeps on the back. The probe is changed on average every 1.5 months. Currently, the patient is trying to take a small amount of fluids orally and she is fed 3 or 4 servings a day by Nutrison (750 ml). The patient believes that she is well nourished and has recently gained weight. Despite the probe in the stomach, the patient has not forgotten the taste of some dishes. Her favorite food is pizza and she hopes to taste it again in the future. Due to the progressive form of the disease, many actions can not be carried out by herself, such as bathing, feeding by the probe, dressing, preparing medicines, etc. If weather allows, the patient is happy to spend time outside on the terrace. The patient is not able to use the toilet herself. She could not care for her children in the past because she needed care herself. The patient sometimes feels pain from the tracheotomy tube. This pain depends on the position of the tube and the oppression of neighboring structures. Pain occurs at different times and passes when the tube itself "sets itself up" in a convenient position. The patient does not feel pain in her bones or joints and does not require to use of painkillers. One of the symptoms that accompanies the patient is constipation which is probably due to limited physical activity. Our patient does not complain about bloating, and she does not have diarrhea. The patient also does not feel any cardiovascular discomfort. One main problem is periodic swelling of her lower limbs. However, the patient has nystagmus which prevents her from reading. Nystagmus appeared in the past before the thrombarterectomy operation in 2010. The patient lies down to sleep around 23:00 and sleeps up to 5:00 hours, but later stays in bed after waking up. Her husband prepares breakfast and helps her with going to the toilet at around 10:00 hours. During the day, the patient does not sleep. For a half a year in the past, she had to stay in bed when rehabilitation was taking place. For the past eight years, she has been using a wheelchair. In the past, she moved with two orthopedic balls. At present, she is unable to move independently, and thanks to her family, she can spend several hours a day on the terrace in front of her house. The patient is not able to stand up or to stand alone. She can not sit on a bed or in a trolley. The patient uses a diaper pad and she has Foley's catheter inserted into the bladder. Since the patient is completely immobilized, home and financial affairs are dealt with by the patient's husband. During the interview the patient communicated verbally without any problems. She can also talk on the phone, provided she has a superimposed "plug" on the tracheotomy tube. Sometimes the patient has to take longer breaks in the conversation. During the interview, the patient admitted that physical fatigue is felt with changing aura. In the past (October 2010), she was found to have a bedsore on the bone. During hospitalization, the bedsore reached

IV^o in the Torrance scale. After the patient was discharged home, the only drug that did not cause an allergic reaction was Solcoseryl. Currently she has a bedsore on the right buttock I Torrance's scale. Other sores do not occur. As mentioned earlier, the patient has accepted the disease. There is no problem with expressing emotions, but she does not need to talk about the disease because she thinks she is healthy enough not to have to think about it. According to the interview, the patient now gets angry faster, which is not comfortable for her, because she knows that she hurts her family the most. The patient tries not to think about "what could have been," and lives from day to day. She does not want to hold on to bad thoughts and hopes that she will always remain positive in the fight against her illness. Health is the most important value for the patient, and she feels no emptiness in her life because she is surrounded by a loving family. At home she feels safe. The patient does not compare herself to her peers, and the only thing she wants is to have good care and a normal life as far as possible allowing for the disease. Despite the great care that the family provides, the patient feels limited socially. Holidays, birthdays and name days are spent at home with family rather than visiting family and friends due to her condition. She has a son and a daughter who are already adults and despite the illness she does not feel like a bad parent. She believes that her children have witnessed her illness from the beginning and remember their mother as always sick. Not only work, but also daily life has changed since the onset of the illness. The biggest support for her is her family. In the past, the patient was a member of the MS Society. Due to the severe financial situation, she was unable to pay contributions to the association and she was discharged. Before the onset of MS, one of her favorite activities was to knit and read books. Because of the disease, she can no longer enjoy these hobbies. The patient does not have any pets and enjoys relaxing on the terrace with her family. She is interested in nature (she likes to watch nature films), she also likes to listen to music. At the beginning stages of the disease, the patient was able to handle official affairs by telephone. The disease did not affect her religious practices. Prior to the onset of symptoms, the patient attended church regularly. Both in the past, and currently, the patient does not use the Internet. She does not like to read and listen about her illness from others. She also does not read information from the "forums" dedicated to people with MS. Currently, the patient is very happy with the treatment and care by medical staff. She does not feel that her condition has improved, but she does not think she is getting worse either. Sometimes she feels like her breathing is getting worse. Treatment continues as directed by her doctor. It was very helpful for her to have rehabilitation, thanks to which the patient does not have con-

tracting muscles, and she is able to raise her hand slightly. According to the patient, the therapeutic team fully fulfills their obligations. The only problem related to the treatment are problems with the device for suctioning secretions from the bronchial tree. The problem occurs when there is a temporary lack of electrical current. At present the family is trying to organize a device for suctioning secretions from the bronchial tree that could work regardless of whether or not the current is on. The data in the information sheets show that the patient was originally diagnosed for non-infectious gastroenteritis and colitis. Also, that a concomitant pulmonary embolism was reported. The patient was admitted to the unit due to diarrhea with a fever of up to 40 °C, which lasted for a week. After the surveys, viral and bacterial etiology of diarrhea was excluded and had subsided after treatment.

During hospitalization, the results of gasometrics were as follows:

pH = 7.46; pCO₂ = 21.5 mmHg; pO₂ = 60.5 mmHg; HCO₃ = 14.6 mmol/L; BE = 6.9 mmol/L ; arterial blood saturation was 92.9%.

Computer tomography showed pulmonary embolism and after consultation, the patient was transferred to a pulmonology department. In the pulmonology department respiratory failure was reported. Oxygen therapy was applied with an oxygen mask at 6 L/min. Echocardiography showed pulmonary hypertension of about 100 mmHg with features of right heart overload. Included in the treatment was Fraxiparin at a dose of 0.8 ml/d. During hospitalization, there were problems with the intake of fluids (choking). For this reason, the supply of fluids was supplemented with intravenous infusion under controlled central venous pressure. Despite the applied treatment, no improvement was made and the patient continued to require oxygen therapy. Saturation ranged between 85-89%. The patient was transferred in stable condition to the Silesian Heart Disease Center in Zabrze. Before discharge from hospital, saturation was 94% at 5 L/min oxygen supply. Upon admission to the Silesian Center for Heart Diseases, pulmonary embolism, pulmonary hypertension, respiratory failure in pulmonary embolism deep vein thrombosis was diagnosed. The patient was consulted by a cardiologist and was qualified for the treatment of pulmonary embolism (healing doses of Fragmin). After consultation, the patient was again transferred to the Department of Pulmonology at the University Hospital in Cracow. During admission to the hospital the patient needed oxygen therapy with a flow of 4-5 L/min. The patient was treated with pulmonary thrombosis therapy for pulmonary embolism with clinical features of pulmonary hypertension with

respiratory failure requiring oxygen supply through an oxygen mask of approximately 8 L/min. After surgery, the patient was intubated on controlled breath. The patient was extubated after 14 hours. In the 3rd day after surgery, during oral feeding trials, she choked on food and then began to develop respiratory failure with atelectasis. The patient was again intubated and mechanically ventilated. On the day of discharge, the patient was conscious and breathing on her own. It was decided to install a tracheotomy tube through which passive oxygen therapy was performed. During the next visit in the hospital the patient was in stable condition but required chronic oxygen therapy. On the sixth day, a general worsening condition of the patient occurred with fever and vomiting. After surgery consultation, parenteral nutrition was ordered. In addition, it was decided to implement a fluid supply through the gastric tube. Before the discharge to home, the patient was informed about the need for mechanical ventilation at home. It was recommended to use passive oxygen therapy for the tracheotomy tube with 4 L / min oxygen, periodically connected to ventilator. A stable, uncontrollable patient has been at home for many days and the family has been trained how to provide home-based care. After a month, the patient was re-admitted to the Pulmonary Clinic, where a tracheotomy tube was exchanged during the visit. The condition of the patient has improved significantly in recent months. Before discharge to home, the Foley catheter was changed to silicone. The patient was discharged in good condition to home. Both the patient and her family have been trained about respiratory system treatment and toilet use. If necessary, they can be in immediate contact with the physicians and people responsible for the mechanical ventilation of patients at home. The study was conducted with a patient aged 48 years who resides in the Małopolska area. Currently, the only source of income is a pension of about 1000 PLN. In the past, the family was additionally dependent on the salary of the patient's husband, but 2 years ago he had to resign from work to provide his wife with constant care. The patient lives with her family at home.

Discussion

Despite the many benefits of mechanical ventilation, it is associated with the risk of complications. People who have recently started home ventilation often feel anxiety and fear about their own health and well-being, as well as their dependence on respirators. Families of patients are worried about whether they will be able to handle the situation.^{4,5} The problems of mechanically ventilated patients are complex. Patients report gastrointestinal complaints (nausea, vomiting) related to, among other factors, with a swelling stomach. In many cases dysphagia occurs, which in con-

sequence involves the need to insert a probe into the stomach. In addition, tracheostomy infection may occur, so special attention is paid to the care of the tracheostomy tube. In ventilated patients, there are problems with communication because the tube interferes with speaking and causes disturbed contact with the environment. Besides, there are problems related to maintaining personal hygiene. The sick do not have the strength to go to the toilet on their own, clean their whole body or dress up in clean clothes. Over time, this disability deepens and the patient needs “permanent” care. It is not possible that the patient can go to the toilet alone, and she can not control excretion. Patients who have been diagnosed with multiple sclerosis have to get used to the “new life”. Thanks to home mechanical ventilation, patients improve their comfort of living through a more friendly environment created by family members and friends.¹³⁻¹⁵ When the disease has a progressive character, there are new problems every day. When acute respiratory failure becomes acute (passing through chronic), patients become suddenly addicted to respirator treatment. Few people have the opportunity to use home respirator treatment, so these patients are condemned to hospital treatment. This is related to the fact that the patient has to give up many things. A respirator does not give one the opportunity to leave home, meet friends or enjoy most hobbies. It must be borne in mind that patients with MS often fall into depression, which is related to dysfunction in the social and occupational roles. The problem is also the cost of care and treatment. Patients need to constantly use diapers, preparations for skin care etc. It is considered necessary to insert a catheter into the bladder, which is related to further problems, like urinary tract infection. In MS, the problem may be excess secretion from bronchi due to weakness and loss of respiratory muscles. Other problems include paresis, muscle cramps, muscle weakness and fatigue, and pain associated with it. These symptoms worsen with the progress of the disease.¹⁶⁻²⁰ It is important for a patient in the advanced stage of multiple sclerosis to prevent bedsores to which he or she is exposed as one spends the most time in bed or in a wheelchair. Despite many studies conducted by scientists, no drug was developed that could cure patients with MS.²¹ Considering the above problems, we can see that patients in the advanced phase of the disease are heavily dependent on their family and/or friends.^{4,13} Literature indicates that smoking is a major problem for people with MS, as Fijalkowski mentioned in his article.²² An important issue in these people is rehabilitation. According to Woszczak, rehabilitation should be carried out in such a way that it also covers the social and psychological problems of the sick person.²³ In patients with MS it is very important to show respect and concern to them.²⁴

Summary

Patients who suffer from Multiple Sclerosis are exposed to many of the dangers associated with the onset of the disease. Mechanical ventilation at home is an important contributor to mobilizing patients and, in addition, allows them to enjoy every day despite the progression of the disease. Patient ventilation at home has a positive effect both on the convalescence of patients and their families and the desire to care for patients with MS.

Conclusions

1. Multiple sclerosis (SM) is a serious disease that has led to respiratory failure requiring mechanical ventilation at home, which allows life in a friendly environment.
2. The patient now tolerates mechanical ventilation well and the family is able to look after her and help meet her daily needs. However, a large deficit exists in self-care due to the advanced disease.
3. Despite the progressive of the disease, the patient is in good mental condition and accepts her state of health.

References

1. Wysocka M. Domowa wentylacja dorosłych jest wciąż elitarną metodą leczenia. *Puls Med.* 2003;9(58):23–25.
2. Simonds AK. Home ventilation. *Eur Resp J.* 2003;47(22):38–46.
3. Lloyd-Owen SJ, Donaldson GC, Ambrosino N, et al. Patterns of home mechanical ventilation use in Europe: results of the Eurovent survey. *Eur Respir J.* 2005;25:1025–1031.
4. Wójcik A, Płaszewska-Żywko L. Funkcjonowanie fizyczne i psychospołeczne chorych wentylowanych mechanicznie w domu. *Pielęg XXI w.* 2007;3/4:5–6.
5. Simonds AK. Home ventilation. *Eur Resp J.* 2003;47(22):38–46.
6. Windisch W. Impact of home mechanical ventilation on health-related quality of life. *Eur Resp J.* 2008;32:1328–1336.
7. Piotrowski M. *Respir Lek.* 2006;1:16–18.
8. Kwieciński H, Kamińska AM. *Neurologia Merritta.* Tom 3. Wrocław: Elsevier Urban & Partner;2008.
9. Jaracz K, Kozubski W. *Pielęgniarsztwo neurologiczne.* Warszawa: PZWL;2008.
10. Kozubski W. *Neurologia i neurochirurgia.* Wrocław: Elsevier Urban & Partner;2006.
11. Kozubski W, Liberski PP. *Neurologia.* Warszawa: PZWL;2008.
12. Czarnecka I. *Stwardnienie rozsiane. Konsekwencje dla Ciebie i Twoich bliskich.* Warszawa, PTSR;2009.
13. Szkulmowski Z. Nieinwazyjna wentylacja mechaniczna w domu. *Pol Med Paliat.* 2004;3 (1):39–43.
14. Markstrom A, Sundell K, Lysdahl M, Andersson G, Schedin U, Klang B. Quality-of-life evaluation of patients with neuromuscular and skeletal diseases treated with noninvasive and invasive home mechanical ventilation. *Chest.* 2002;122(5):1695–1700.
15. Schonhofer B, Geibel M, Sonneborn M, Haidl P, Kohler D. Daytime mechanical ventilation in chronic respiratory insufficiency. *Eur Respir J.* 1997;10(12):2840–2846.
16. Kochański A. Choroby kręgu Charcot-Marie-Tooth – wczoraj, dziś i jutro. *Neurol Neurochir Pol.* 2006;40(4):327–335.
17. Hausamanowa-Petrusewicz I. Laminopatrie – wspólny mianownik wielu stanów chorobowych (nowy rozdział neurobiologii inie tylko). *Neurol Neurichir Pol.* 2004;38(1):1–2.
18. Bilińska ZT, Fidzińska A. Laminopatie-problem multidyscyplinarny. *Kardiol Pol.* 2008;66:335–339.
19. Lipowska M, Kwieciński H. Zespół Guillaina-Barrego. *Przew Lek.* 2006;9:59–65.
20. Fridman A. Choroby układu pozapiramidowego w praktyce lekarza podstawowej opieki zdrowotnej. *Przew Lek.* 2001;4(11):10–3.
21. Jewczak B. Postępowanie z chorym na stwardnienie rozsiane w opiece domowej- studium przypadku. *Pielęg Neurol Neurochirurg.* 2013;2(5):216–22.
22. Fijałkowski P, Kowalczyk E, Błaszczuk J, Rapacka E, Matysiak R. Palenie tytoniu a rozwój i przebieg stwardnienia rozsianego. *Żyw Człow.* 2007;34(3–4):1435–1439.
23. Woszczak M. Postępowanie rehabilitacyjne w stwardnieniu rozsianym. *Pol Prz Neurolog.* 2005;1(3):130–133.
24. Kwolek A, Podgórska J, Rykała J. Doświadczenia własne w rehabilitacji osób za stwardnieniem rozsianym. *Prz Med Uniw Rzesz.* 2010;(2):213–220.