Case Study

Antiphospholipid Syndrome Related Massive Pulmonary Embolism through the Eyes of a Healthcare Professional who Survived Death: A Case Study

Kubra Incirkus, RN, PhD
Research assistant, Trakya University Faculty of Health Science, Public Health Nursing Department, Edirne, Turkey

Correspondence: Dr. Kubra Incirkus, Research Assistant, Trakya University Faculty of Health Science, Public Health Nursing Department, Balkan Campus, 22030, Edirne, Turkey E-mail: kubraincirkus@trakya.edu.tr

Abstract

Although the illnesses, which is life-threatening and requiring life-long treatment, such as antiphospholipid syndrome and pulmonary embolism, cause trauma and stress at the acute stage, in time they may be seen as an opportunity or a second change by some patients. Pulmonary embolism is an experience which requires emotional care rather than medical care in the long term, affects the feelings and behaviors severely after the first shock and change lives. However, it is observed that especially in life-threatening situations the focus is generally on the physical aspect of the disorder and the psychological effects and emotional support might be overlooked. In this study, the perspective of the person, being both patient and a healthcare professional, who encounters some communication related problems with medical staff during her antiphospholipid syndrome related massive pulmonary embolism experience, is presented. It is aimed to increase the healthcare professionals' awareness regarding supporting the patients in order to help them to cope with the illness, overcome this traumatic process and grow stronger. Thus, in addition to ensuring recovery in a shorter period and positive effects in treatment and care results; psychological problems, which might appear in the long term, can also be prevented.

Key Words: Antiphospholipid syndrome, pulmonary embolism, health psychology.

Introduction

Antiphospholipid syndrome is an autoimmune disease characterized with recurrent arterial/venous thrombosis, spontaneous abortion, preterm delivery or stillbirth, stroke, thrombocytopenia (Gezer 2003; Kawczyk-Krupta et al., 2013; Maggiorini et al., 1997). The most common pulmonary symptom of this syndrome, in which thrombophilia related antiphospholipid antibodies exist in blood, is pulmonary embolism or pulmonary hypertension after embolism (Gezer, 2003; Maggiorini et al., 1997). Pulmonary embolism, which might result in death if the diagnosis is not made in one hour after the first signs and symptoms, is categorized under three groups depending on the amount of the pulmonary vessels affected: massive (major), sub-massive and non-massive (minor). In massive pulmonary embolism which detected with more than 50% obstruction of the pulmonary vessels early period mortality rate is reported to be between 15-30% (Shaughnessy, 2007). Almost 50% of the patients having experienced venous thrombolysis before carry the risk of an embolism recurrence and in the case of a genetic or coagulation related factor, it is reported that this recurrence risk will increase. With a life-long anticoagulation treatment this risk could be reduced at the rate of 80-90%, however this treatment brings along a major bleeding risk (Bennett et al., 2016; Gezer, 2003; Kearon et al., 2003; Ozturk et al., 2004; Prandoni et al., 2014; Shaughnessy, 2007). In other words, the patient has to continue his/her life in the thin line between the risk of bleeding and coagulation (Bennett et al., 2016).

Pulmonary embolism is an experience requiring emotional care rather than physical in the long term and changing the emotions and behaviors drastically after the first shock. It is also stated that while physical complications of the disease are

well-known, very little is known about its psychological effects; and this increases the risk of failure in defining the patients' psychological needs by healthcare professionals (Bennett et al., 2016; Noble et al., 2014). Especially major pulmonary embolism puts patients through a continual emotional distress, because it is a life-threatening situation and the risk of recurrence is undetermined. For this reason, it is highly important to research the psychological effects of the disease (Bennett et al., 2016; Noble et al., 2014). In this study, the aim is to examine the effects of the antiphospholipid syndrome and this related massive pulmonary embolism from the perspective of an individual, who is both a patient and a healthcare professional. It is also aimed to increase the awareness of the healthcare professionals regarding providing the necessary psychological support that the patient and relatives need during this traumatic process and grow stronger.

Case Report

32-year-old female patient, who had no history of illness or operation, applied to the emergency service consciously with complaints of increasing shortness of breath, chest pain and transient fainting. The patient describes what she experienced at the emergency service as follows: *"I heard one of the healthcare personal at the emergency service telling my family "It must be a stress related fainting. There is nothing to worry about. Has something might bothered her happened lately?" Then I told that my complaints are increasingly continuing. I told that I am a healthcare worker either, and I am having trouble breathing. A thrombus which blocking the both of main pulmonary artery and affecting the heart was detected with the lung x-ray and the computerized thorax tomography (CT). When bilateral massive pulmonary embolism was diagnosed, one of the healthcare personal came and told "You are a healthcare professional it is okay for you to know." He told me the diagnosis, explained the severity of the situation, which I was in a risk of death, I might not recover, and I was going to be taken into intensive care immediately. For a while, I watched the people around me in a slow motion and heard their voices as if they were coming from further away and thought "Is that it? Am I dying now?" There was nothing I could do; I surrendered and started to watch the people rushing around me."*

After the investigations carried out it was detected that the massive pulmonary embolism was developed after the deep venous thrombosis occurred in the right lower leg. Then, the patient was taken into the intensive care unit and they started thrombolytic and anticoagulant treatment. After 15 days the patient was discharged. She was diagnosed with antiphospholipid syndrome after the examinations at various hospitals for eight months. The patient stated that she experienced intense fear, pessimism and stress in the early periods and during the treatment, but after a while she gained a different perspective of life: *"I experienced psychologically damaging and hard times because of the fear of a recurrence of the embolism, possibility of living the same things, fear of death, countless tiring examinations, the uncertainty of the diagnosis and all the healthcare staff at the hospitals I applied saying that "You're back from death's door, you might have been dead now. But don't worry about that, take it easy." I was told that I have to be strong, I must know this process, I have to be more understanding and bold saying that "You are a healthcare worker." I couldn't understand why I should be more bold or strong just because I was a healthcare worker. There were moments that I felt like I was my own caregiver that was trying to support and protect the sick part of me by standing straight patiently… Even though I was a little relived after the diagnosis of antiphospholipid antibody syndrome because at least the reason behind the embolism was revealed, I experienced an intense stress and desperation when I found out that I was going to be on medication and under control for my whole life. The risk of recurrence of embolism was high because of my disease and my previous embolic episode, I had to be on the alert at all times and I should not interrupt the treatment… The disease changed my life; I realized that the traumatic experienced I had after the acute period and standing face to face with death were the triggering factors for me to realize the value of life. I started to think that what I went through was a second chance and an opportunity to improve myself. I saw how important and valuable the support of my family and relatives is. I had quite a*

time for thinking and reading. There were advantages of being a healthcare worker in terms of accessing the current medical resources. On the other hand, in that process I got the chance to evaluate myself as a healthcare worker. I saw/experienced especially how important emotional support and empathetic approach provided to the patients in life-threatening acute situations are. Even though I have not experienced visible changes; my priorities in life, the value I give to ones I love and myself, the reactions I give to the small or everyday problems have changed. Seeing that I could overcome this great crisis led me to be more confidants while solving other problems and deciding, and realize that I was much stronger than I had thought. Yes, it is a life-long, hard process but now I believe that I will overcome. Patient's warfarin treatment and follow-ups are continuing with an active INR (between 2 and 3).

Discussion

Negative life experiences such as disease bring along serious physical and psychological trauma and may change the individual's perspective of life and sense of compliance and peace (Connerty & Knott, 2013; Jim et al., 2006). Especially in life-threatening situations like pulmonary embolism, as from the first moment the diagnosis is made, the patient tries to cope with the problems such as an intense emotional distress, sense of losing oneself, the thought of not deserving the happened, withdrawal, long term fear regarding the trauma memories, making life-changing decisions, change in behaviors and worries about the future (Bennett et al., 2016; Jim et al., 2006; Noble et al., 2014). Patients always have concerns and anxieties whether or not they will have another embolism attack or when it is going to happen. On the other hand, focusing much more on the symptoms like shortness of breath and getting exhausted quickly, and limitations in daily life and exercises can be observed (Noble et al., 2014). However, individuals can respond this experience differently. While some individuals might show a fatalistic and nihilistic approach feeling that they can no longer control on their faith and they are at the mercy of following thrombosis cases; other ones see this situation as an opportunity to improve themselves, realize the value of life, reset their priorities, improve spiritually, establish meaningful relations and gain a deeper perspective. It is reported that if they can overcome their problems, individuals can go through this process with not just a fast recovery also growing stronger, and some individuals can even essential change their carriers and life styles (Connerty & Knott, 2013; Jim et al., 2006; Noble et al., 2014; Ozcetin & Hicdurmaz, 2017).

In massive pulmonary embolism, successful care results depend on two main factors: firstly, quick diagnosis and intervention in order to prevent the life-threatening situation; secondly and most importantly, patient care and emotional support including from patient's family (Bennett et al., 2016; Noble et al., 2014; Shaughnessy, 2007). In this case, even though symptoms as panic, fainting, shortness of breath and weakness were regarded as stress related, in the first one hour the diagnosis was made and they started the treatment. Along with the early diagnosis and treatment, it is vitally important that the members of the healthcare team understand the traumatic process the patients and relatives are going through, provide the physical and psychological support they need during this process, plan supporting approaches and use effective communication techniques through this process and while giving bad news (Okyayuz, 2003; Ozcetin & Hicdurmaz, 2017). In the national literature, it is stated that healthcare professionals have hard time while giving bad news, majority of them have not received adequate training about this situation and they feel incompetent. At this point the suggested approach is that the physician, who made the diagnosis, or the nurse, who plays an active role in the treatment, should give the bad news at a proper time after all the laboratory investigations are completed (Bahadir, 2009; Ucun, 2014). Especially when giving bad news or explaining the diagnosis, it should be taken into consideration what the patient knows about the situation, or if she/he wants to know at all and also patient's readiness level for the news; it is also important to offer options with short and understandable sentences, to show empathy and to support the patient in order to help her/him to express her/his feelings after the information is given (Bahadir, 2009). It is extremely important that healthcare professionals should attend vocational and post-graduate trainings in order to

improve their awareness and knowledge on the subject (Okyayuz, 2003; Ucun, 2014). In this case it can be seen that occasional problems between the patient and the healthcare professionals regarding the explanation of the diagnosis, communication and providing psychological support affected the patient's coping process, her self-confidence and her hopes for the future negatively.

As a result, it should not be forgotten that the psychological support provided in the early period has a positive effect on the treatment and care results, as well as it reduces the symptoms of post-traumatic stress and prevents the possible psychological problems that might occur in the long term (Bennett et al., 2016; Noble et al., 2014). Especially in life-threatening or life-long treatment requiring diseases like antiphospholipid syndrome or pulmonary embolism, it should always be taken into consideration that a positive communication with the patient, psychological support and empathetic approach are just as vital as early diagnosis and treatment.

References

Bahadir G. (2009) Physician-Patient Communication in General Medicine. In: Kulaksizoglu IB, Tukel R, Ucok A, Yargic I, Yazici O. (Editors). Psychiatry. Istanbul University Printing and Publishing, Istanbul, Turkey, 16-17.

Bennett P, Patterson K, Noble S. (2016) Predicting post-traumatic stres and health anxiety following a venous thrombotic embolism. Journal of Health Psychology 21(5): 863–871.

Connerty TJ & Knott V. (2013) Promoting positive change in the face of adversity: experiences of cancer and post-traumatic growth. European Journal of Cancer Care 22: 334-344.

Gezer S. (2003) Antiphospholipid syndrome. Dis Mon 49: 691-742.

Jim HS, Richardson SA, Golden-Kreutz DM, Andersen BL. (2006) Strategies used in coping with a cancer diagnosis predict meaning in life for survivors. Health Psychol 25(6): 753-761.

Kawczyk-Krupta A, Cieslar G, Dubik K, Dubik A, Sieron A. (2013) Primary antiphospholipid syndrome-case report. Annales Academiae Medicae Silesiensis 67(1): 78-83.

Kearon C, Ginsberg JS, Kovacs MJ, Anderson DR, Wells P, Julian JA, MacKinnon B, Weitz JI, Crowther MA, Dolan S, Turpie AG, Geerts W, Solymoss S, van Nquyen P, Demers C, Kahn SR, Kassis J, Rodger M, Hambleton J, Gent M. (2003) Comparison of low-intensity warfarin therapy with conventional-intensity warfarin therapy for long-term prevention of recurrent venous thromboembolism. The New England Journal of Medicine 349: 631-639.

Klok FA, Cohn DM, Middeldorp S, Scharloo M, BUller HR, van Kralingen KW, Kaptein AA, Huisman MV. (2010) Quality of life after pulmonary embolism: validation of the PEmb-QoL Questionnaire. J Thromb Haemost 8: 523–532.

Maggiorini M, Knoblauch A, Schneider J, Russi EW. (1997) Diffuse microvascular pulmonary thrombosis associated with primary antiphospholipid antibody syndrome. Eur Respir J 10: 727-730.

Noble S, Lewis R, Whithers J, Lewis S, Bennett P. (2014) Long-term psychological consequences of symptomatic pulmonary embolism: a qualitative study. BMJ Open 4: e004561.

Okyayuz UH. (2003) To Be Diagnosed With A Malignant Disease: A Life Crisis Should The Bad News Be Broken? Crisis Journal 11(3): 29-35.

Ozcetin YSU & Hicdurmaz D. (2017) Posttraumatic Growth and Resilience in Cancer Experience. Current Approaches in Psychiatry 9(4): 388-397.

Ozturk AB, Kaya Z, Kiyan E, OkumuS G, Kucukkaya R, Ece T, Arseven O. (2004) Recurrent pulmonary thromboembolism and deep venous thrombosis in the primary antiphospholipid syndrome-Two case reports. The Journal of the Faculty of Medicine University of Istanbul 67(1): 47-51.

Prandoni P, Barbar S, Milan M, Vedovetto V, Pesavento R. (2014) The risk of recurrent thromboembolic disorders in patients with unprovoked venous thromboembolism: new scenarios and opportunities. European Journal of Internal Medicine 25(1): 25-30.

Shaughnessy K. (2007) Massive pulmonary embolism. Critical Care Nurse 27(1): 39-50.

Ucun Y. (2014) Health Care Workers Are Forced Contact Area: Breaking Bad News. Yildirim Beyazit University School of Health Sciences Nursing E-Journal 2(3): 63-71.