Paroxysmal Nocturnal Hemoglobinuria Patients in New Brunswick

Need Medicare Drug Coverage to Survive

Denise Cyr LaPlante

University of New Brunswick
Abstract

New Brunswick remains the only province within Canada to implement a catastrophic drug policy. Patients with rare diseases and rare forms of cancer who live in New Brunswick remain at a disadvantage compared to other Canadians when it comes to drug access and ultimately health outcomes. In Canada, drug coverage depends on where one lives. It is unethical for the New Brunswick government to deny lifesaving, Health Canada approved treatment coverage for rare diseases and cancers that Canadians living in other provinces are granted. Canada may boast a universal healthcare system but in reality, coverage to essential lifesaving drugs in Canada is not universal. Nurses, physicians and other healthcare professionals along with patients, families and all Canadians need to advocate for equitable healthcare coverage to ensure all Canadians receive needed therapy. This is not a battle an ill or dying Canadian should have to fight.

*Keywords:* catastrophic drugs, Paroxysmal Nocturnal Hemoglobinuria, rare diseases, universal health care.
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Paroxysmal Nocturnal Hemoglobinuria Patients in New Brunswick Need Drug Coverage

New Brunswick’s Paroxysmal Nocturnal Haemoglobinuria (PNH) patients need Medicare drug coverage to survive. It is unethical for New Brunswick’s PNH patients to be denied life saving treatment in a country with universal healthcare coverage. The Canadian Cancer Society (2013) confirms that in May 2013 Prince Edward Island unveiled a catastrophic drug plan leaving New Brunswick the only remaining Canadian province without a catastrophic drug policy. The Canadian Organization of Rare Disorders (CORD, 2013) defines a rare disease, also now known as an orphan disease, as one that affects less than one person in every 2,000 people. In total, there are approximately 7,000 known rare diseases globally. PNH, one of these rare diseases, is a life threatening illness that has only one Health Canada approved disease modifying treatment option, the drug Eculizumab. New Brunswick continues to deny patients in the province coverage. It is unethical to withhold the only life saving treatment for these patients. McKeage (2011) describes Eculizumab as the only safe and effective treatment for PNH.

Canadians are citizens of a country that boasts universal healthcare coverage for basic care. It is appalling to realize that where one lives in Canada will determine their treatment options and survival. The ultimate question is how much is a life worth and who has the right to make this determination?

Woolhead, Deepak, Patel and Vaidiyanathan (2008) explain that PNH is an acquired rare clonal stem cell disease that results in hemolysis and life threatening thrombosis. Patients can suffer from splenic thrombosis and bone marrow hypoplasia which may result in severe infections or thrombosis (Woolhead, Deepak, Patel & Vaidiyanathan). They elaborate that in PNH patients certain proteins are unable to bind to the erythrocyte membrane due to an absent receptor therefore causing lysis. This disease is quite frequently misdiagnosed as leukemia as
patients often present with hemolytic anemia, thrombosis and pancytopenia (Woolhead, Deepak, Patel & Vaidyanathan). The mean age at diagnosis is 40 however patients have been diagnosed as young as 2 years old. Patients, if left untreated, can suffer from thrombosis particularity of the liver and spleen, renal failure and sepsis. Röth and Dührsen (2011) write that PNH is a life threatening and debilitating disease causing morbidity and mortality. Hall, Richards and Hillmen (2002) confirm PNH patients’ 10 year risk a life threatening thrombic event is at 44%.

It is unfair that PNH patients in New Brunswick do not receive coverage for the drug Eculizumab as it is needed for survival and productive living. Jecker (2008) defines bioethics or justice in healthcare as being the due respect every individual deserves in accessing healthcare and resource distribution. The Merriam-Webster Dictionary (2013) defines ethics as the behavior that governs a group’s moral duty and obligation. Canadians deserve equal and fair healthcare regardless of where they live. Canada has a moral obligation as the keeper of our universal healthcare system to ensure that our healthcare is indeed universal. The notion of a “postal code lottery” for healthcare coverage, defined as the differences in social services depending on the policies of the area in which you live (Kerr & Scott, 2009), is not only unethical but shameful. Patients in New Brunswick are being denied lifesaving treatment while their counter-parts in other provinces are granted access, in essence based on the policies of the area in which they live. Canadian healthcare has become fragmented and inequitable which is contrary to the intent of our universal healthcare model.

New Brunswickers should have health coverage for Eculizuma which is the only available treatment that improves PNH symptoms and prevents premature death. Röth and Dührsen (2011) describe this treatment as not only reducing thrombosis, haemolysis and fatigue but as the golden standard for the treatment of PNH. Eculizumab, a monoclonal antibody and the
only disease modifying treatment option for PNH patients, has been approved through Health Canada since 2009. To date, four years post Health Canada’s approval, New Brunswick continues to deny its residence living with PNH coverage for this drug. McKeage (2011) explains that this treatment not only results in a rapid and sustained positive response for patients by reducing haemolysis and decreasing lactate dehydrogenase (LDH) but it also results in a significant reduction in the need for blood transfusions, incidence of thrombosis, and repeated hospitalizations. This improved symptom management results in improved productivity, employment and quality of life. Parker (2009) acknowledges that this treatment not only affects health but also quality of life. Parker explains that although the cost of therapy is expensive, cost of the drug needs to be weighed against costs for supportive care when patients are not treated with the drug. These costs include, but are not limited to, blood infusions and care for renal disease, pain related to haemolysis, dehydration and numerous other medical treatments. He concludes that Eculizumab is not only effective but the only treatment for this disease.

New Brunswickers with PNH require coverage for Eculizumab so that they have the highest quality of health possible. PNH patients suffer from deteriorating health due to chronic high LDH levels, severe anemia and extreme fatigue. This leads to a reduced quality of life and a considerable risk of death. Brennan (2013), a New Brunswick PNH patient, describes his journey as a PNH patient (Canadian Association of PNH Patients, 2013). He describes suffering from shortness of breath, impaired kidney function and high risk of thrombosis. He also writes that without treatment the survival time for one-third of PNH patients is five years. Ueda, Hayakawa, Yamanishi, Maeda, and Fukunaga, (2013) analyzed patients post Eculizumab treatment and observed significantly improved fatigue which was caused disruption in these
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patients’ daily lives. Additionally, patients who were often unable to participate in social activities before treatment were considerably improved post treatment.

Eculizumab is a drug that should be covered because Canada boasts a universal healthcare system and all other provinces provide this financial resource for individuals with PNH. But the question is whether Canada truly operates a universal healthcare system. Phillips (2009) describes the catastrophic drug system in Canada as “patchwork coverage” (p.3). In fact Chicoine (2012) explains that Canada has 19 different publicly funded drug plans and over 1,000 private plans with no consistent coverage for all Canadians. Although the catastrophic drug initiative was put in place to help Canadians who potentially could suffer from significant financial hardship, there continues to be great variances on drug coverage from province to province. The Romanow Commission Report, 2002 recommended a national strategy to address the issue of catastrophic drugs and an insurance plan to help Canadians with the financial burden related to rising pharmaceutical costs (Grootendorst & Veall, 2005). Although the provinces agreed to develop this national plan in 2003, New Brunswick remains the only province without a plan in place 10 years later. The Canadian Health Act covers all essential physician care and pharmaceutical care within a hospital setting. However Canadians are left to their own resources for prescription coverage outside of the hospital setting. While Canadians may have a portion of their prescription drugs covered though private insurance, co-payment responsibilities could cost patients up to thousands of dollars per year. In the past, pharmaceutical coverage was not a significant issue. However, since the 1980s a consistent and significant rise in the cost of prescription drugs has created a financial burden for many Canadians (Grootendorst & Veall 2005). Copeland (1999) notes that prescription costs have increased by over 10% every year since the 1980s. With the advent of new and very expensive therapies for rare diseases and
catastrophic conditions, the differences in provincial coverage have become an even more important concern for many Canadians.

A Catastrophic drug coverage plan is needed for New Brunswick because individuals with PNH continue to suffer hardships while those in other provinces do not. The cost of Eculizumab is in the range of $500,000.00 per year. Although the cost of treatment is expensive, governments should consider the lifetime cost of medical care for a non-treated patient and the value of improved quality of life for the patient and community as a whole. The Canadian Cancer Society (2013) argues patients are placed in financial peril related to drug costs and that governments need to consider the long-term cost of withholding drug treatment. For those not on the drug, symptom management could involve multiple hospitalizations throughout their lifetime for pain management, transfusions, renal failure and infection. In contrast, when treated with Eculizumab a patient can often continue to function in their work environment, community and family unit.

Ultimately, Canadians will determine how much pressure to put on federal and provincial governments to cover these innovative but expensive treatments. As nurses, we believe that a patient’s treatment should be determined by their medical needs not by the province in which they live. As healthcare professionals, nurses need to advocate actively for these patients and their families. The unfortunate reality is that because PNH is among very rare diseases, many Canadians and health professionals are unaware of the tremendous battle these patients face. Changes in provincial policies and treatment coverage will only occur only through education and advocacy from NPH patients and all concerned New Brunswickers who realize they could be in the same situation if things do not change. All stakeholders need to act now. Patients who are ill should be able to focus on healing and not have to deal with concerns over the cost of
treatment or deal with financial burden when they pay for the best treatment available for their medical condition. It is imperative that patients know they can receive prompt, effective care and not substandard treatment due to poor Medicare coverage. One thing that I believe most Canadians would agree with is that our politicians should not have the power to determine who lives or dies.
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References


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