Faith vs. Disease: The Burden of Chronic Illness in the Life of AW

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ABSTRACT

AW is a 26 year old man who has spent the entirety of his life dealing with autoimmune disease, specifically polyarteritis nodosa (PAN) and Evan's Syndrome. This case report examines the medical and psychosocial aspects of a man and his family's experience with chronic illness and the ongoing struggles that come with it. It highlights the strengths that patients with chronic disease possess and provides an example of where they may find it, which in this case was a man's faith.

INTRODUCTION

By 7 years old, AW and his family had already been dealing with unanswered questions about the young boy's health concerns when his situation became much more serious. In that year, he had lost nearly the entirety of the platelets in his bloodstream, had his spleen removed and dropped to the floor with a subarachnoid haemorrhage from a ruptured brain aneurysm. It was at this time that two diagnoses were given to the child and his family, meaning that for the rest of his life he would have to deal with the two uncommon conditions known as polyarteritis nodosa and Evan's Syndrome.

Polyarteritis nodosa

Polyarteritis nodosa is a rare, idiopathic vasculitis that causes necrotizing inflammation of the small and medium sized arteries affecting roughly 2-33 individuals per million annually. Though it is thought to be an immune related condition, there is no known cause of this disease but it is often associated with viral infections such as Human Immunodeficiency Virus (HIV) and Hepatitis B Virus (HBV) as well as other autoimmune conditions such as Systemic Lupus Erythematosus (SLE) and Rheumatoid Arthritis (RA). It can present clinically with many different symptoms including chest pain, weakness, arthralgias, shortness of breath, stroke-like symptoms or organ related symptoms, plus many more. Signs include livedo reticularis, skin ulcerations, arrhythmias, hepatomegaly, muscle weakness or focal neurologic signs. Diagnosis requires documentation of systemic inflammation (eg. raised erythrocyte sedimentation rate (ESR)) and assessment of organ involvement, most commonly the renal arteries and kidneys.[1,2] This must satisfy three of the following 1990 criteria created by the American College of Rheumatology[1]:

- Weight loss above 4 kg
- Livedo reticularis
- Testicular pain or tenderness
- Myalgias, weakness, or leg tenderness
- Mononeuropathy or polyneuropathy
- Diastolic blood pressure above 90 mmHg
- Elevated blood urea nitrogen or creatinine
- Presence of HBV antibody or surface antigen in serum
- Arteriographic abnormality demonstrating aneurysms or occlusions of visceral arteries due to non-inflammatory disorders
- Biopsy of a small or medium artery containing histologic evidence of vasculitis

Biopsy is the preferred method for diagnosis though angiography also can used to confirm PAN if aneurysms or tapering of small and medium vessels are seen. Auto-antibodies are rarely present and the absence of anti-neutrophil cytoplasmic antibodies (ANCA) is also key in the diagnosis of PAN versus other vasculitides. The first line treatment is prednisone for at least one year though often a low-dose regimen is needed for life and it can be combined with cyclophosphamide or azathioprine. If untreated, PAN results in progressive destruction of vital organs with a 5-year survival rate of 10-13%. Death often occurs due to myocardial infarction, complications from bowel ischemia, aneurysm rupture and stroke, though 80% of patients have a good response to treatment.[1,2]

Evan's syndrome

Evan's syndrome is described as a disorder of immune thrombocytopenic purpura (ITP) and autoimmune haemolytic anemia (AIHA) in the absence of underlying pathology. The exact pathophysiology is unknown but there is an immune mechanism that leads to the production of autoantibodies that target the red blood cells (RBCs) and

platelets causing the haemolytic anemia and thrombocytopenia, though there may also be a component of autoimmune neutropenia or pancytopenia as well. The exact prevalence is unknown but it does account for up to 75% of cases of pediatric AIHA. The syndrome is chronic with a course of frequent relapses and remissions. Patients with this disorder often present with signs and symptoms of haemolytic anemia (eg. jaundice, lethargy) and thrombocytopenia (eg. petechiae, mucocutaneous bleeding) with, or without, neutropenia (eg. fever) and on examination may have hepatosplenomegaly. A complete blood count will reveal cytopenias and a blood smear to look for spherocytosis should be done. These findings, along with a reticulocytosis, positive direct anti-globulin test (Coombs) and elevated unconjugated bilirubin levels are consistent with a diagnosis of AIHA. Despite this, Evan's syndrome is a diagnosis of exclusion and thus other underlying disorders (eg. autoimmune disease, immunodeficiencies) must be ruled out. There are no guidelines on management of Evan's syndrome as little research has been done on the topic. In most cases, RBC transfusion is required prior to therapy initiation, which is often corticosteroids with or without intravenous immunoglobulin (IVIG). Rituximab is an effective second-line therapy in those who have relapses while on first line treatment. Other therapies include splenectomy, cyclosporine, vincristine, danazol, alemtuzumab and hematopoietic stem cell transplant when the disease is refractory to other treatments.[3] Uncontrollable haemorrhage from the thrombocytopenia and sepsis from infection due to the neutropenia or asplenia are the most common causes of mortality in these patients.[4]

Psychosocial burden of chronic disease

An issue that is rarely addressed in case reports is the psychological and social burdens that chronic disease places on patients. Chronic diseases persist, often have a progressive or relapsing course, cause disability and pain, require long-term commitment to treatments and often are a hindrance on the quality of life that an individual wishes to achieve. One of the biggest challenges for a patient that is newly diagnosed with a chronic disease is dealing with the adjustments they will need to make in their life if they want to control and manage their disease. Most patients will achieve a good state of psychological health but for some, the adjustment is slow and prolonged and sometimes unachievable. Children who have chronic disease also experience a lower amount of self-esteem than those without and often struggle with understanding why they are different than their peers.[5] In inflammatory conditions, cytokine activity may actually be a contributor to a constellation of symptoms called sickness behaviour that is highlighted by weakness, malaise, depressed mood, lethargy and anhedonia.[6] This adjustment requirement is placed not only on the patient but also on the family of a child with a chronic illness who suffer an enormous amount of stress, financial burden and overall caregiver burden as well. Parents of these children often feel they are inadequately trained and can feel as much of a psychological burden, or more, than their child.[7]

The purpose of this case report is not only to describe the details of this patient's medical journey through his diagnosis and management, but also to highlight and explore the psychosocial burden that these diseases bring with them on himself and his family.

CASE

AW was born at 36 weeks in Winnipeg in 1991. His delivery was unusual as his mother had placenta previa and he should have been delivered by Caesarean section but the physician could not make it in to perform it due to the weather and thus he was delivered face first by spontaneous vaginal delivery. To add to this, AW had a short umbilical cord and came out with a hematoma on the top of his head that was later cleared by neurology.

At 3 months old, he became lethargic and his mother had trouble waking him so he was taken into the hospital and found to have low oxygen saturation due to impaired breathing from significant hepatosplenomegaly. Following this, he was in and out of hospital regularly for breathing concerns including allergies and asthma. His first surgery was at 18 months old and was an exploratory laparotomy to investigate his large liver and spleen. When he was 4 years old, his alkaline phosphatase (ALP) count was extremely

elevated which prompted a trip to Toronto for further investigation into the liver enlargement, elevated liver enzyme count and high copper levels. Bone marrow biopsy and liver biopsy ruled out Wilson's disease but gave no concrete diagnosis.

The majority of AW's problems began at 6 years old when his platelet count began to drop. After some investigations, it was determined that he was anemic and had a positive Coombs test. One day in the spring, he came from school with petechiae on his body and that night began to vomit blood. He was rushed to Health Sciences Centre Children's Emergency with uncontrollable epistaxis and an upper gastrointestinal bleed (UGIB). Over the next 24 hours he had 54 units of blood transfused into him and was treated with IVIG, vincristine and pulse steroids, which did not improve his status. Eventually, the health care team decided his spleen needed to be removed emergently. He entered the operating room with a platelet count of 6 x 10^9/L, barely survived the procedure and still had a pronounced thrombocytopenia and hepatomegaly so he was transferred to the Intensive Care Unit (ICU). After a period in the ICU, his platelet count began to rise towards normal.

Following discharge from hospital, AW developed small nodules on his skin that were tender to touch and a pattern of discoloration of his skin later known to be livedo reticularis. Exactly 2 months after his surgery, AW collapsed and was rushed to hospital again. It was determined that he was suffering from a subarachnoid haemorrhage and he was taken in for surgery once again. Shortly after, he started developing more nodules, losing weight and spiking fevers so an arterial biopsy and angiography were performed and showed that AW had experienced a ruptured brain aneurysm from a vascular malformation due to PAN. This event resulted in AW having seizures for the next few years for which he was treated with anticonvulsants. He was followed by Pediatric Rheumatology and treated with a combination of prednisone, methotrexate and cyclosporine. During this time, he would experience typical symptoms of PAN including the cutaneous nodules, livedo reticularis, severe gastrointestinal pain and episcleritis. Before a stable combination of medication was determined, AW had an episode where he had a reaction to Immuran

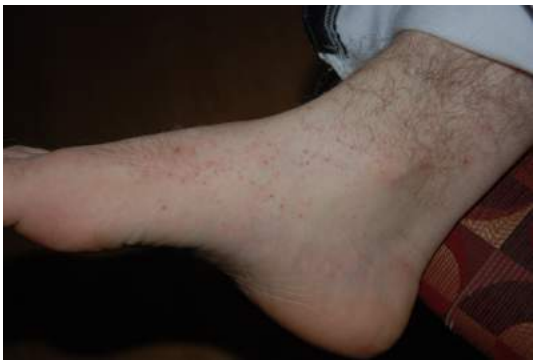

Fig. 1 Petechiae from Evan's Syndrome

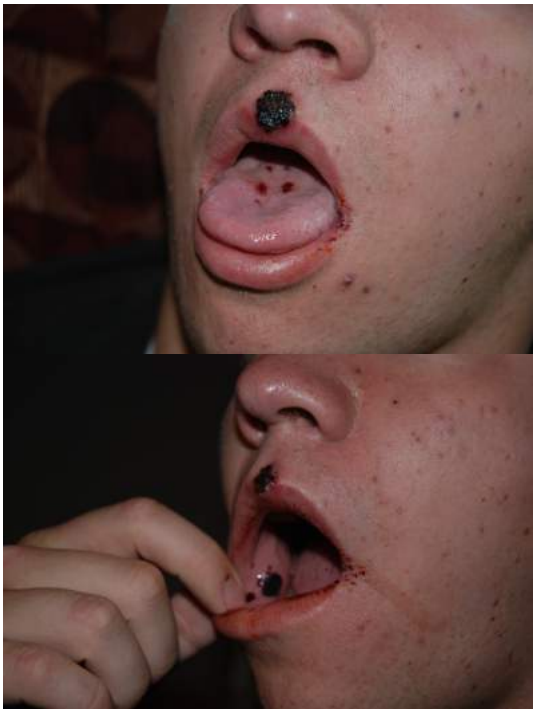

Fig. 2 Oral blisters from Evan's Syndrome in 2011. When patient reached the emergency room his platelet count was 1 x 10^9/L

(azathioprine) that led to jaundice from cholestasis, vomiting and a rise in cholestatic liver enzymes up to 1000 IU/L before he was admitted and treated, barely in time to save his life once again. Eventually, his PAN was in remission with minor flare-ups treated with low dose prednisone.

For the next 12 years, AW had fewer hospital visits and no major life threatening events. He developed some persistent cervical lymphadenopathy that was worked up by Cancer Care and PET scans have determined to be non-cancerous, but rather a

reactive lymphadenopathy. In the summer of 2011, AW had a relapse of his refractory ITP and was admitted with a platelet count of 2 x 10^9/L. Soon after he developed hematuria, uncontrollable epistaxis, GI bleeding and oral blood blisters that were again treated with IVIG, vincristine, solu-medrol and a platelet

Fig. 3 Episcleritis in 2010

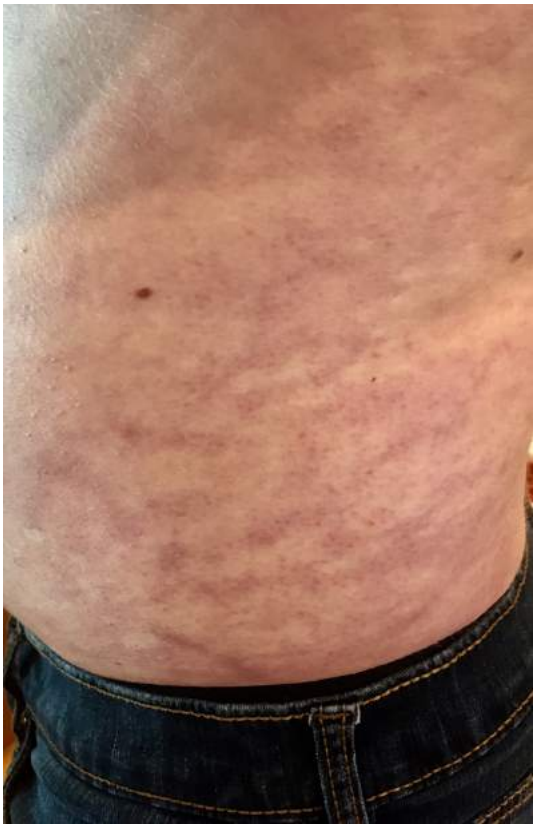

Fig. 4 Livedo reticularis on trunk from PAN

transfusion with little effect. He underwent another bone marrow biopsy and aspirate with insignificant results. It was determined he would be given a thrombopoietin analog, romiplastin, and be put on a schedule to receive doses of rituximab long-term. He stabilized on this treatment but only two months later was back in the emergency room with extreme chest pain; a CT scan of his chest revealed several pulmonary emboli. He was immediately treated with low-molecular weight heparin bridging onto warfarin.

Since then, AW has made several trips to the ER with severe chest pain, has had multiple radiological studies done and no recurrence of emboli has been found. The remainder of 2011 was difficult for AW as he struggled with anemia, episodes of numbness and tingling in his legs, flares up of his PAN with increased prednisone use and severe joint pains. Along with the chest pain, AW has also had many occurrences of palpitations, which started following his blood transfusions when he was young. Several EKGs and Holter studies have shown a sinus arrhythmia with occasional premature ventricular complexes but otherwise are always normal, yet this required him to be started on the antiarrhythmic medications metoprolol and diltiazem for rhythm and rate control. With continued trips to the ER, echocardiography and exercise MIBI studies have also been done to examine his heart function but other than mild right ventricular hypertrophy have returned no concerning results. In the summer of 2016, he was plagued with a left lower lobe pneumonia and the development of a pilonidal sinus that required surgical intervention. On top of all the disease-associated medical concerns that burden AW, he is also allergic to many different medications including sulfa drugs, cephalo-sporins, biaxin, rubbing alcohol, latex, aspirin and most recently, CT dye. As well, AW describes an allergic reaction to DDAVP (desmopressin), given to help improve his platelet count in the past, where he ran a high fever and couldn't breathe and was later told by a specialist that he was one of only a few reported cases of an allergic reaction to this medication in the world.

Treating all of the medical problems that AW has faced in his life has not come without a price. Side effects from long term immuno-suppression to treat his PAN and antibiotic prophylaxis of penicillin V since his splenectomy have always been a problem in AW's life. The largest burden comes from the extreme fatigue he feels on a daily basis as the prednisone makes him feel jittery and unable

to sleep and the rituximab drains all of his energy for weeks after a treatment. The prednisone has also caused him to have gastro-oesophageal reflux, weight gain despite appropriate exercise and diet, acne and has contributed to several bone fractures. Antibiotic prophylaxis and immuno-suppression have also likely contributed to episodes of diarrhea and he has had *Blastocystis hominis* cultured from his stool. The combination of immunosuppressant medications have made AW more susceptible to infections which have included bouts of impetigo, bronchitis, pneumonia, sinusitis as well as chronic upper respiratory infections that AW feels he deals with symptoms of every single day.

The most recent and most concerning iatrogenic problem for AW has been the development of recurrent, refractory warts. Since he was in his teenage years, AW has had warts removed from his feet, hands and face with no concerns. In recent years, these warts have grown back and all treatments thus far have proved futile. He has made numerous trips to see his family physician, dermatologists, a plastic surgeon and most recently an infectious disease doctor who specializes in viruses.

Fig. 5 Refractory warts on AW's hands

Family History

AW comes from a Mennonite family with both Paraguayan and Canadian roots. His father was a Canadian who moved to Paraguay for 2 years to do mission work where he met AW's mother, a woman from Paraguay who's grandparents had immigrated from Prussia. As previously mentioned, AW was born in Canada and has one older brother. Details of the medical status of AW's distant family are vague and incomplete, although what is reported is quite intriguing. Medically, his father's side of the family is mostly unremarkable though AW's paternal grandfather passed away from a ruptured brain aneurysm. The maternal side of the family is where things become interesting as a total of eleven family members have had their spleens removed back in Paraguay because they were "losing blood." The only specific details given are with the maternal grandmother's sister who had seven children, five of whom were affected by this problem and three of whom died thereafter. To make things more interesting, AW's only brother has an extra spleen-like organ as well as an irregularly shaped spleen.

In regards to AW's vasculitis, his maternal grandmother has also suffered from arthritis since she was a young girl. In 2013, AW's mother collapsed and was flown to Calgary for an emergency stent as she had a ruptured para-opthalmic artery aneurysm causing a subarachnoid hemorrhage. Three years later, she began to have daily tonic-clonic seizures. She has also been followed by rheumatology for many years for constant arthritic pains and other connective tissue disorder-like symptoms although a diagnosis of PAN has not been confirmed. At 50 years old, AW's mother also had to go to the emergency room for severe stomach pain and was found to have an acute appendicitis, a rare occurrence for an individual at her age.[8]

Psychosocial History

AW claims that he struggled with identity as a child, as he always questioned why he wasn't like other kids he knew, why he had to spend lots of time in a hospital bed while other kids were out playing and having fun. This created turmoil in his social life and he felt that he didn't have a lot of good relationships with peers, but rather was bullied a lot and had difficulty engaging well with others. Throughout most of his life, AW has not had a lot of control over what happens to him so as a child, his mother always wanted to give him as much control as she could. She would constantly ask how he was feeling about what was happening to him, when he wanted procedures done, meals or medications to be given or what he thought a new symptom might mean. Despite always wondering what else could go wrong with him

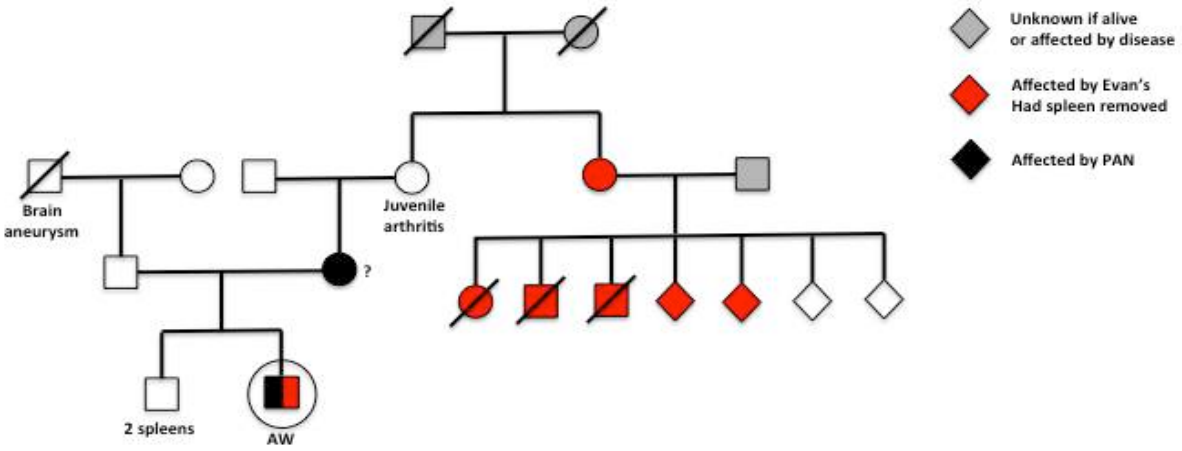

Fig. 6 Pedigree created for AW

and feeling frustrated about what was happening, he remained patient and eventually medication regimes, regular appointments and experiencing symptoms and side effects became things he was at peace with.

A large part of his problem dealing with identity stemmed from the adversity he and his family faced in dealing with his school administration. When AW returned from hospital after his subarachnoid haemorrhage, his school administration stated that he needed to have an educational assistant and the only one they had at the time was also working with a child who had violent outbursts. This was concerning for his well-being so the school required a signed letter from a physician or parent that said they had permission to place him with this other child or they would not let AW back to school. For three months, the school would neither hire another assistant to help AW nor allow him to return to school without a signed letter, which both the doctor and AW's parents refused to sign. AW's mother resorted to attempting to contact the Minister of Education to speak about their problem and this was extremely hard on her and the family. Finally, AW was allowed back to school but was told he had to wear a helmet to attend gym class and shoulder pads around school for protection. Rather than help AW, this tactic only contributed to the bullying he experienced as he now had something else that made him different than other kids and some would enjoy "testing out" his shoulder pads for fun. This continued for a few years before AW's family decided to remove AW and his brother from school and hired a retired teacher to teach the two of them at home. This continued for the remainder of AW's elementary and high school education. Despite feeling like he was always part of the "unpopular crowd," being bullied and struggling to fit in, AW came out of his school years with some good friends. Considering AW's situation, it would be reasonable to think that he would rely on these friends for advice and comfort. Instead, AW says that he is often the person that his friends will seek out for counsel, the person they rely on to listen and help them through their troubles.

On the contrary to way things were at school, at home AW was encouraged to participate in as many activities as he wanted. In regards for safety considering his medical conditions, he was allowed to push the envelope to a certain extent though AW always felt he was restrained more than other kids. His brother was engaged in Motocross racing with dirt bikes, so his parents bought AW a bike as well. He did not enjoy the activity like his brother, but he did participate in a lot of youth activities with the church group. Most activities didn't interest him, but AW found his real passion in Tae Kwan Do, a sport that his mother competed in competitively and his brother engaged in as well. For years his doctors told him the sport was too physical for him, but the day he was finally told he could try it out there was no

going back. He has continued with Tae Kwan Do despite injuries and trips to the ER to this day and now volunteers as the head instructor for the town as a double black belt. His desire for physical exercise poured over into weightlifting as well which he started as a teenager and continues doing to this day, despite physical limitations due to his chronic conditions.

In 2011, AW filed for long-term disability and income assistance based on the impairments from his chronic medical conditions, which made it nearly impossible for him to work a full-time, or part-time job. Previously, he had worked jobs in construction, landscaping and barn washing but each job was frustrating for him and his employer due to his medical restrictions, physical restrictions and constantly having to take off time for doctor's appointments. In the past five and a half years, AW has had approximately one hundred and twenty-six visits to either a doctor or primary care nurse. Eventually, he made the decision to focus more on volunteering and only doing what he was able to when he could. The long-term disability income assistance does not provide AW with much for disposable income, but it covers the majority of his medication expenses. Before 2012 when his income assistance was activated, AW's parents were responsible for the majority of the expenses of his multiple medications. Though some such as rituximab, which was around $5000 a treatment, were covered through Cancer Care Manitoba, others such as cyclosporine, prednisone and methotrexate were paid for by his parents who had no private insurance and would often have a bill of $450 a month or more. This was not the only expense to AW's parents for his care as time off work to transport him to appointments or when he was in hospital, the cost of transportation alone and the cost of hiring a private tutor for home schooling were all factors at play for the family's finances.

In spite of the strain that medical problems have put on AW's family, they have remained patient, supportive of each other and as close-knit as anyone could hope for. AW's father has perhaps felt the most drastic emotional load and has struggled at times watching his son and wife deal with near-death experiences. He feels as a husband and a father that his job is to fix things and look after his family and when he is not able to do that, it weighs on him heavily. Indeed, the entire family has felt the emotional burden as AW's mother has also struggled with some depression in the past. Following her episodes of seizures, AW's mother had her driver's license revoked and required AW to drive her around for an entire year. The loss of freedom coupled with side effects of the anticonvulsant medication made AW's mother slightly short-tempered, but the appreciation she gained for her son's patience only made them closer. The purest example of the strength in their family was exhibited when AW's mother had her aneurysm and was air lifted to Calgary. Her family never left her side, and as she lay unconscious in her hospital bed, AW laid on the floor beside her with his Bible. When the nurses asked if he wanted to go to the lounge for a while to be more comfortable, his response was "I don't mean to be disrespectful but may I please stay here beside my mom?" The love and support that AW showed for his mother was so impressive to the nurse that she took a photo to show his mother when she awoke.

Although his family has always been there for him, the biggest problem in AW's life is loneliness. Throughout his lifetime, AW has been single, and until recently was afraid to ask any girl out on a date. With the physical manifestations of his disease including the warts, blisters and cutaneous nodules affecting his appearance, he has never had the courage to pursue a romantic relationship. Recently, he decided he was ready to settle down and began the search to find a partner, but every girl who he asked either cancelled or did not show up for their date. He feels that there isn't a girl who wants to be with a man who could be gone at any time, who cannot provide for a family or stand on his own in the world. This problem has lowered his self-esteem the most and has made him feel like he is dealing with problems that he shouldn't be at his age, like his life is on pause. His journey of dealing with medical and social problems has made him feel angry, frustrated, sad and empty but has also made him patient, wise and unafraid of death. He finds comfort in his religion and in the Bible, and him and his family continue to pray for the right woman to come and find him. His battle with staving off death has made him realize that he wants to take time to find the person who will

be there for him like his family has, who won't run if things become difficult or he falls ill again, someone he can talk to about how he is feeling about everything in his life. Despite his troubles, he has not reached out to speak to a professional about how he is feeling about his life and persistently feels like he wouldn't trade his life for anyone else's.

AW has always found comfort and security in his faith. Every time he has been given unfavourable odds of coming through, he has kept his faith and made it through. When he was seven years old and lying in a hospital bed, his grandfather told him to have faith, to which AW responded:

"Grandpa, it's amazing how much faith you can have, when faith is all you have left."

In a life where identity has been hard to find for him, AW seems to find his identity in volunteering through his church, giving back to the community as much as he possibly can. He volunteers in programs that work with youth in the community, at a drop-in centre, puts on lunches, but he especially enjoys working in the prison ministry. AW journeys to the prisons to give sermons and sing hymns with inmates before taking time to speak with them about their lives and faith. He has realized that the people he works with remind him of himself; people judge them for what they see but when the time is taken to get to know them, you can be surprised at the person underneath. AW also does street ministry work where he will walk through the streets of Winnipeg with food, Bibles and clothing for homeless individuals and speak to them about how they can be helped through faith. The food is bought on AW's small amount of income and prepared by him prior to his trip to the city. Although one would not think so, he describes his volunteer work as a selfish act because he feels it is also a way that he can be social and show people that he is more than a bunch of medical problems. His mother describes him as the type of guy who doesn't just lie down and quit when life throws adversity at him, but rather fights it as much as he can and inspires people doing it. In her words, she said:

"AW gives back more than he takes. He gives until his very last ounce, even though he has a good reason to not."

Currently, AW lives in the country with his brother next to their parent's yard. He struggles to contribute as much as he would like to around the home as the PAN causes constant joint pains that also prevent sleep and the rituximab treatments contribute to extreme fatigue. Despite this, AW eats a balanced diet and exercises everyday including weightlifting as much as he can. He is no longer haunted by a feeling that something evil is coming for him in the form of another major flare up or incident and instead feels prepared and ready to face anything. His desire for a partner and family of his own continue to be his most precious goal in life, but in the meantime he wants to continue his ministry work, to reach out to people and make their lives better, and in his own words, "go wherever God takes me."

DISCUSSION

The case of AW highlights some very interesting points about medicine and how we approach chronic disease in children and young adults. Medically, AW has experienced multiple different events from his two rare conditions that most people won't experience a single one of. He is an individual who may be humbling for some physicians as they try to detect what could be a serious problem or more minor manifestations of his disease in his many visits to their office or emergency room. His case reminds physicians that it is important to always have a high index of suspicion, to always perform their due diligence and exclude the more serious possibilities before chalking it up as a simple concern. AW's case also reiterates the importance of listening to what the patient has to tell you, to remember that they know their own body the best and can often give the most important hints in providing the best care possible.

Through years of appointments, diagnoses and treatments, there still remain some questions about AW's diagnoses and treatment progress. With persistent relapses and additional problems continuing to arise despite treatment, AW's physicians are not satisfied with his diagnosis. Recently, his rheumatologist proposed the question of testing AW for a different genetic disorder more common in his ancestry that may mimic

his PAN, but does not describe the disease. A rare, autosomal recessive loss-of-function mutation in the *CECR1* gene location leads to a disease known as adenosine deaminase 2 (ADA2) deficiency.[9] This disease can very commonly mimic PAN in children and is also more common in those of German ancestry, as AW is.[2,10] Indeed, ADA2 deficiency can seem like PAN as it will present with fevers, livedoid rashs, childhood strokes and haemolytic anemia.[11] Another possibility to consider would be autoimmune lymphoproliferative syndrome (ALPS) which is manifested by lymphadenopathy, hepatomegaly, splenomegaly and autoimmune disease involving the blood cells.[12] Although the criteria for the disease does not completely fit AW's case, it is known to occur with the same frequency in many different ethnic groups and research has shown a large proportion of overlapping cases of ALPS and Evan's Syndrome.[3,13] This disease of abnormal lymphocyte survival can be tested for in children with Evan's by examination for double negative T-cells.[14] The importance of determining an exact diagnosis may not seem crucial in the present as most of these diseases are treated similarly with poor effectiveness, but in the future targeted therapies may be discovered and may provide hope for AW for a better quality of life.

The value that was identified in this case was based on the psychosocial burden that accompanies chronic illness. AW himself describes one of the biggest concerns in people who experience these diseases, and that is isolation. His feelings of loneliness and despair come from the fact that he has always felt different than everyone, that no one else is like him and that nobody in the world will want to enter his life romantically knowing what he deals with everyday. He describes feeling a relation to the inmates he works with because they also understand feeling isolated from others. Though one of these barriers is physical and the other emotional, the feeling is mutual between them. The battle that has raged within AW his whole life has had less to do with his physical symptoms, but rather the hindrance they place on his ability to function in modern society. The necessity for patients to feel support and love, and find something that keeps them going everyday is essential for their mental, and subsequently physical wellbeing. This once again highlights the importance of understanding patients with chronic disease as a whole, rather than the sum of their medical problems.

AW's case would be fascinating to any medical professional, but inspirational to anyone who should hear it. The patience and perseverance this young man and his entire family have had to possess to overcome and endure the enormous adversity that has been shoved their way is incredible. This case also exemplifies the strength that can be found in things such as faith for people who have problems that are far beyond their own control. That strength is absolutely essential for a patient's physical and mental wellbeing, no matter how it is found. For AW, the love he has for his family and his faith will continue to provide him with the strength he needs to reach out to people through ministry, to be patient for the partner he deserves and to hope for medical advances to find a way to improve his quality of daily life so that he may achieve the life he is most certainly worthy of.

**Photographs were sent from and used with consent of the patient and his mother*

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