

The Lived Experience of Anemia Without a Cause

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KEYWORDS

- Anemia • Pernicious anemia • Anemia without bleeding • Autoimmune disease
- Vitamin B12 therapy • Iron therapy • Sadness

KEY POINTS

- Anemia symptom burden is significant outside and inside the intensive care unit.
- Diagnosis of anemia without bleeding is complex.
- Pernicious anemia has an insidious onset with slow progress and affects the hematologic, gastrointestinal, and neurologic systems.
- Failure to recognize and treat pernicious anemia can result in permanent cognitive and/or motor impairments.

AUTHOR'S NOTE TO THE READER

Evidence has become the mantra for twenty-first century health care. Nurses practice in a sea of evidence in every setting, every day. Evidence has become the final metric for nearly all aspects of nursing care: practice, patient outcomes, evaluation, and education. Often it seems that the most valuable evidence comes only from clinical trials, publications, or well-powered statistical findings.

Evidence describing the suffering associated with anemia from a patient experience is slim. This article is an attempt to integrate *the evidence* and *the experience* of anemia of one patient. Before each section of this review are the words of the patient living with anemia while trying to find a diagnosis. Not every cause of anemia is explored in this article. This patient's experience described here is not every patient's experience.

However, this author hopes that *the integration of experience and evidence in this case* may provide the clinician a broader perspective when caring for persons with anemia. May the anemic patient under your care find understanding, compassion, and hope in the darkness and fatigue.

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*A feeling of sadness and longing
That is not akin to pain,
And resembles sorrow only
As the mist resembles the rain.¹*

Darkness is my closest friend.

—Psalm 88:18 NIV

DECEMBER

Subjective: In the midst of celebrations, strangely sad. There are no reasons to be so deeply sad. I feel guilty for feeling sad. Guilt doesn't make the sadness less. Sad never goes away. Sad is dark. Sad is scary. Maybe sad is holiday stress.

Objective: Family physician evaluation.

Assessment: Negative examination. Negative laboratory tests.

Plan: Sad will pass. Take some time off.

Evidence

In a survey of 889 patients registered with a pernicious anemia (PA) support group, one-third of patients reported symptoms for 1 year before diagnosis. Fourteen percent reported waiting more than 10 years before receiving a correct diagnosis and treatment. Patients reported memory loss (78%), poor concentration (79%), emotional lability (86%), and suicidal ideation (22%) before treatment.² Because a PA diagnosis is a complex process, detection is often missed. As a result, prevalence is probably underestimated.³ Not all patients with PA display macrocytic red blood cell (RBC) indices. Usually the masking of macrocytosis is the result of a coexistent cause of microcytosis, such as iron deficiency or thalassemia trait. PA has an insidious onset with slow progress and affects the hematologic, gastrointestinal (GI), and neurologic systems.⁴

MARCH

Subjective: Winter goes on and on. Sad has brought fatigue along to stay. No energy. Less and less attention to details. No focus. Just getting the work done on the endless checklist is incredible labor. I used to love my work. Why are statistics so hard all of a sudden? I barely get through the day. I forget a lot! Something is really wrong... I have nothing ready for the holiday. So many lists of things to do. I can't keep track of everything anymore. I need more sleep. I wake up tired....all the time. Almost fell yesterday.

Objective: Thyroid tests for annual monitoring of autoimmune thyroid disease.

Assessment: Laboratory tests normal. Probably seasonal affective disorder and stress. Aging takes work!

Plan: Increase activity. Increase Vitamin D. More light. Take a vacation.

Evidence

The most frequent diagnoses before final diagnosis of PA include anxiety, depression, followed by chronic fatigue syndrome, irritable bowel syndrome, hypothyroidism, multiple sclerosis, hypochondria, fibromyalgia, celiac disease, menopause, and diabetes. In a sample of 889 patients, 98% reported a range of neurologic symptoms, including

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