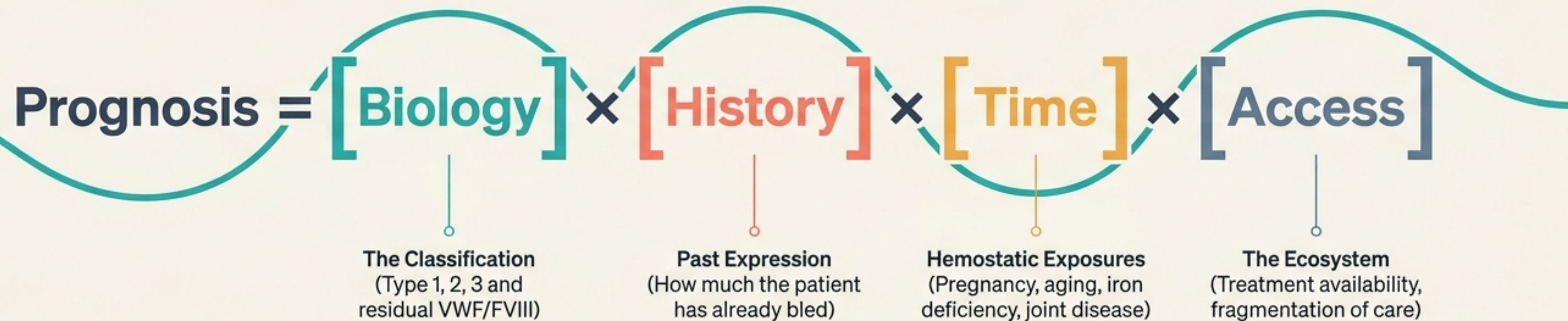


A decorative teal wavy line graphic that starts on the left, loops around the text, and extends across the bottom of the slide.

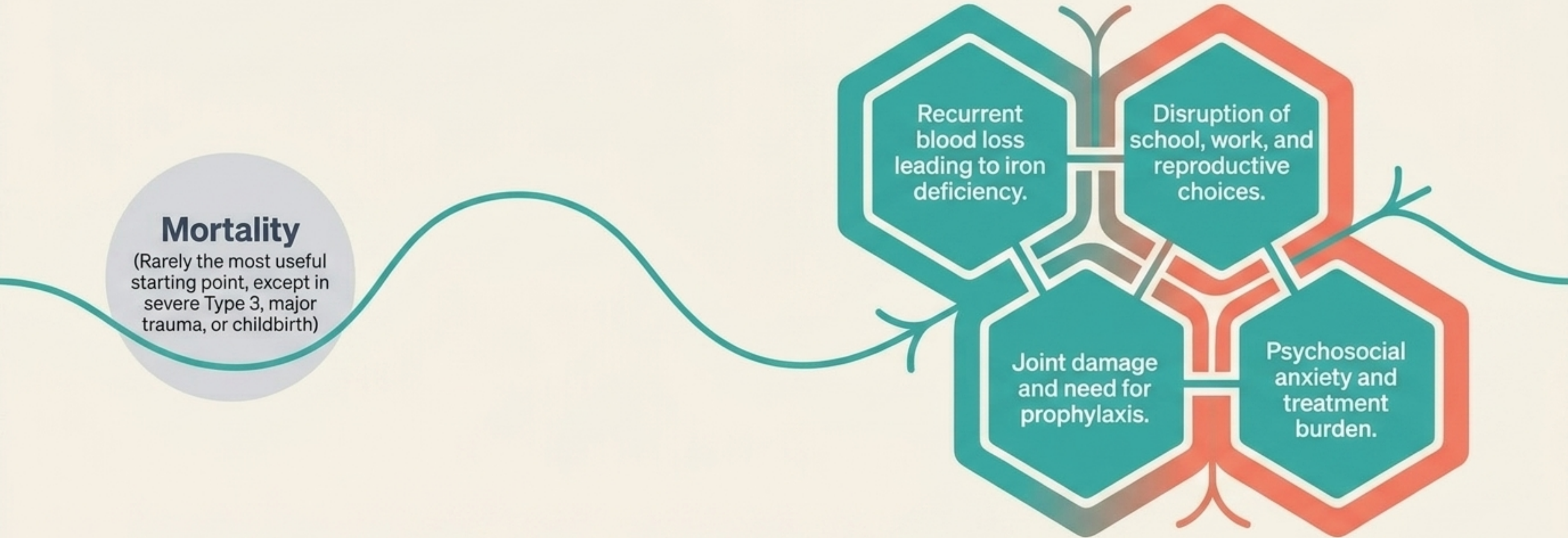
**“What does this mean
for my future?”**

The label describes the disorder. It does not, by itself, predict the life.
Prognosis in von Willebrand Disease requires looking beyond the subtype.



Prognosis is an estimation of anticipated interaction, not a deterministic prediction.

Morbidity & Quality of Life

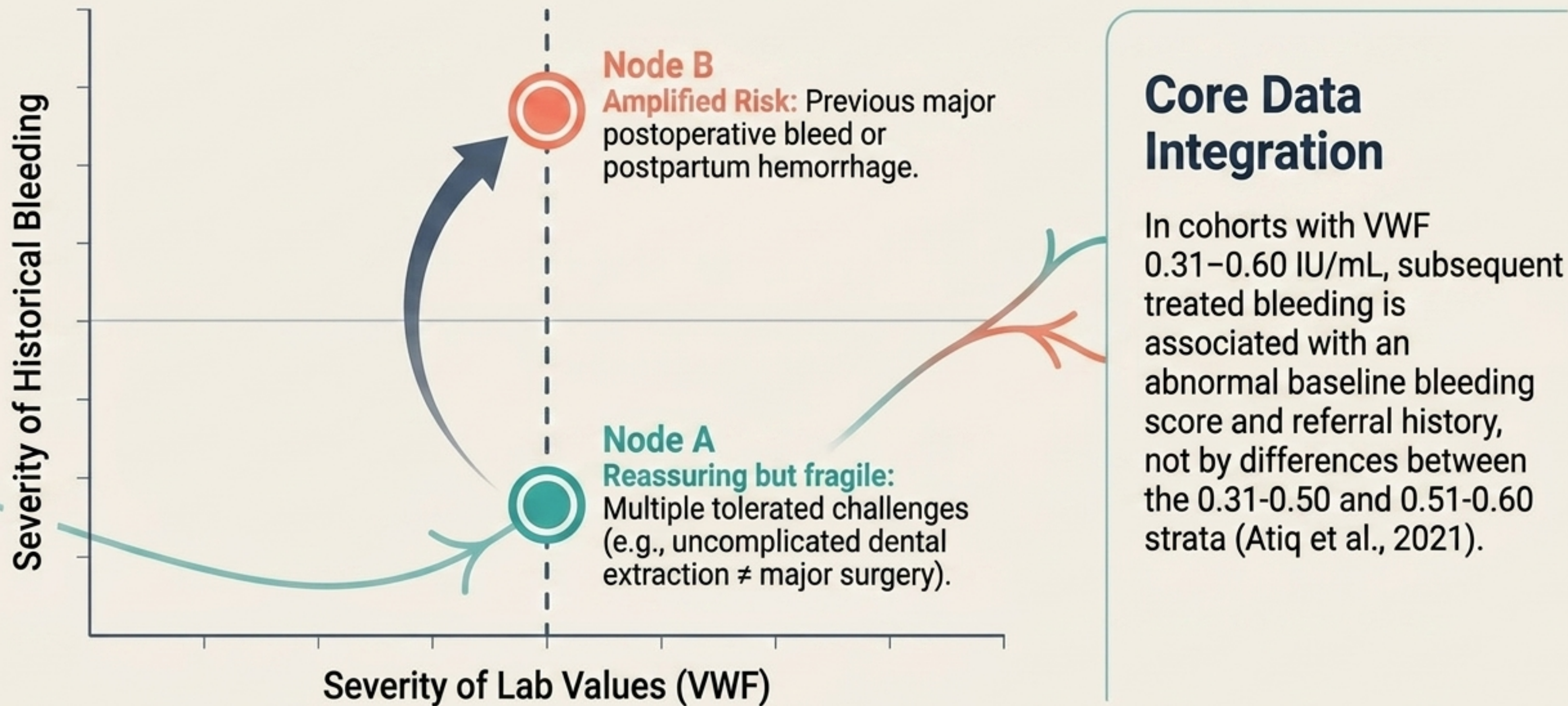


In VWD, prognosis is measured in cumulative burden, not survival.

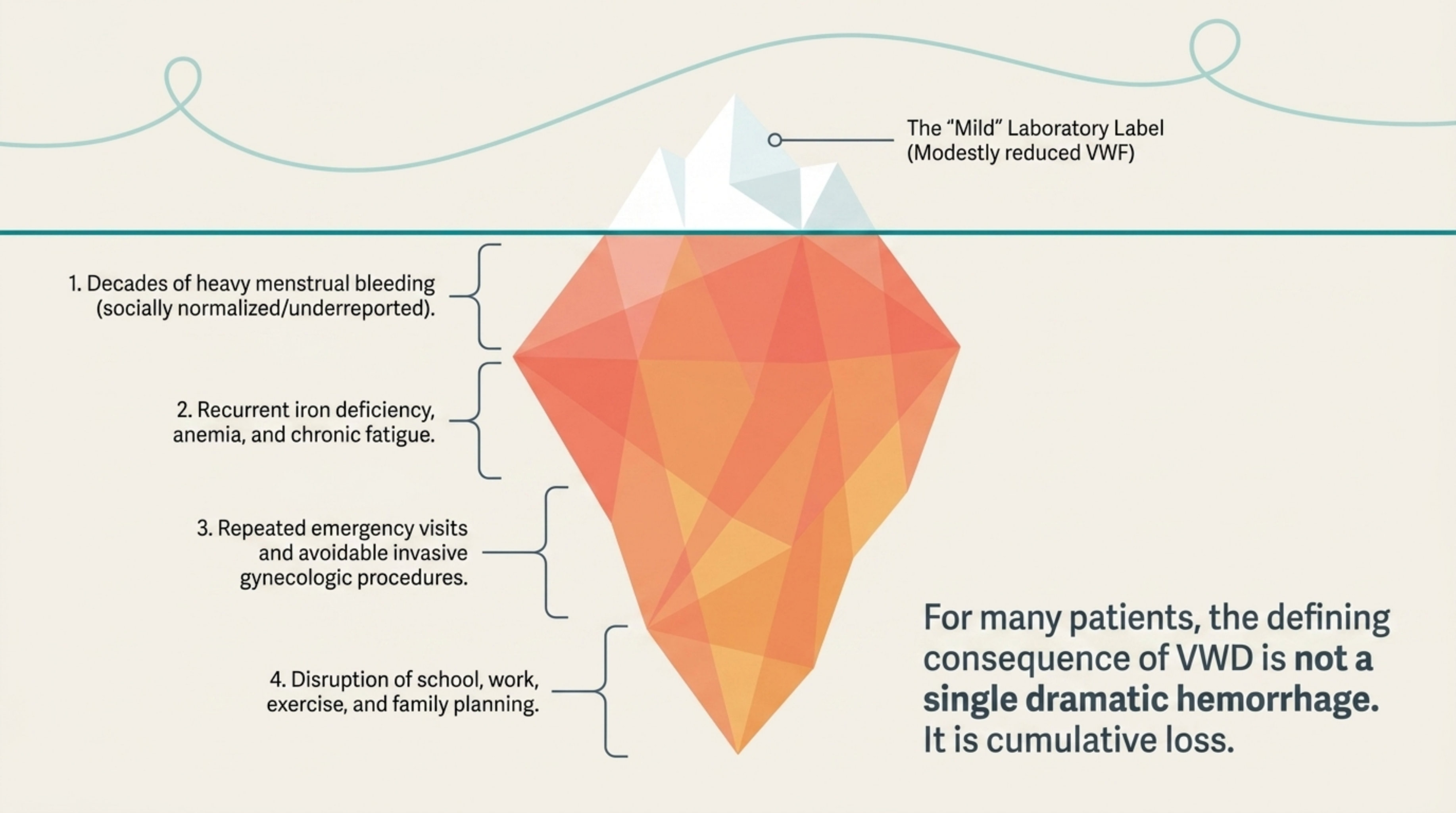
Subtype Matrix

Subtype & Severity	Biology & Expected Bleeding Patterns	Potential Long-Term Complications
Type 3 & Severe Phenotypes	Virtual absence of VWF/low FVIII. Recurrent mucosal, soft tissue, GI bleeding, hemarthrosis.	Chronic joint damage, repeated factor exposure, long-term prophylaxis.
Type 2 (Qualitative)	Loss of HMW multimers, impaired platelet activity. Distinctive risks shaped by qualitative defects or thrombocytopenia.	Altered treatment response profiles, specialized management.
Mild Quantitative (Type 1)	Modest reductions in VWF. Intermittent, often mucosal or provoked bleeding.	Cumulative burdens (heavy menstruation, iron deficiency).

Classification establishes the biological context and the expected range of bleeding. It does not fully determine the individual burden.



The level matters. The history tells us what the level has actually meant.

An iceberg diagram illustrating the clinical spectrum of von Willebrand Disease (VWD). The tip of the iceberg, which is above the water line, is labeled 'The "Mild" Laboratory Label (Modestly reduced VWF)'. The much larger part of the iceberg, which is submerged below the water line, is divided into four horizontal sections, each representing a different clinical consequence of the disease. These sections are labeled with numbers 1 through 4, and each is connected to a descriptive text block by a bracket. The iceberg is colored with a gradient from light blue at the top to dark orange at the bottom. A wavy line at the top of the image represents the surface of the water.

The "Mild" Laboratory Label
(Modestly reduced VWF)

1. Decades of heavy menstrual bleeding
(socially normalized/underreported).

2. Recurrent iron deficiency,
anemia, and chronic fatigue.

3. Repeated emergency visits
and avoidable invasive
gynecologic procedures.

4. Disruption of school, work,
exercise, and family planning.

For many patients, the defining
consequence of VWD is **not a
single dramatic hemorrhage.**
It is cumulative loss.

Early recognition changes the trajectory via anticipatory planning. Prognosis is shaped not only by what happens, but by what is prevented.

Daily Disruption

Recurrent epistaxis causing school absences.

The Transition

Menarche, onset of heavy menstrual bleeding, and the shift to adult hematology.

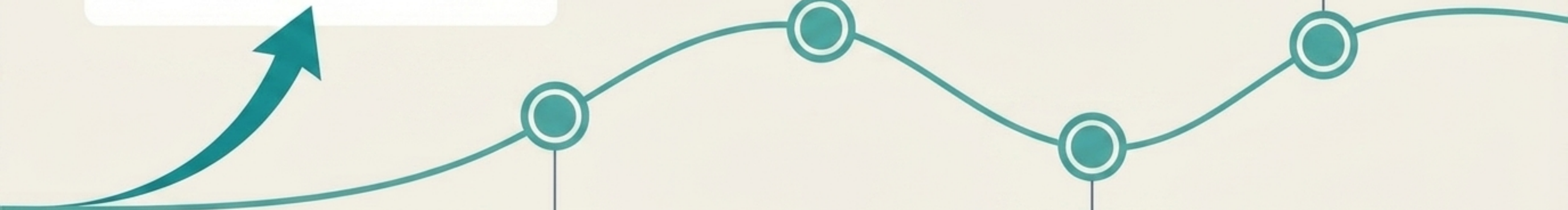
Physical Restrictions

Bruising that limits sports participation.

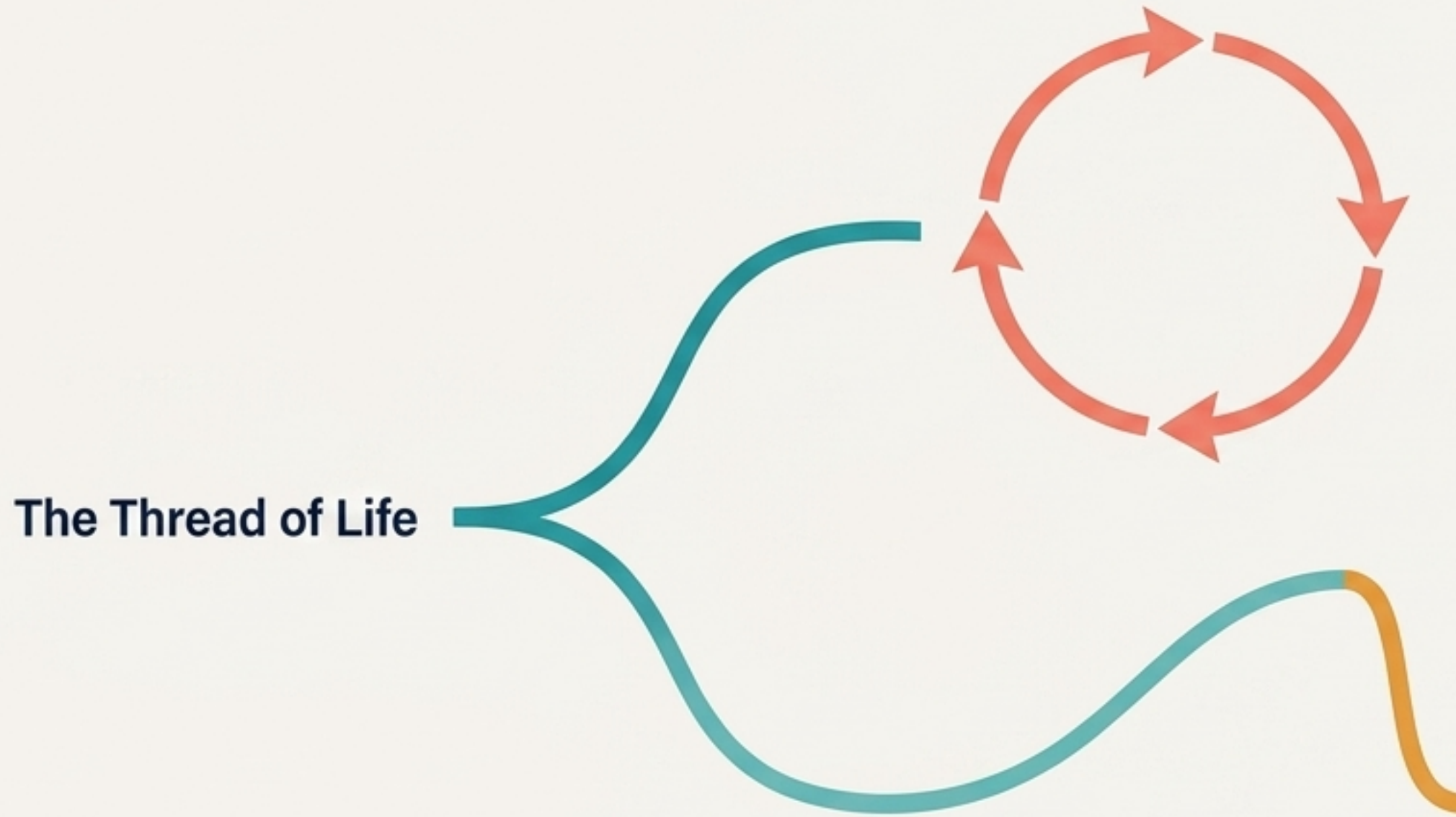
Psychosocial Impact

Delayed recognition leading to anxiety among children and caregivers.

The Thread of Life



Path A: Chronic Blood Loss (Menstruation)

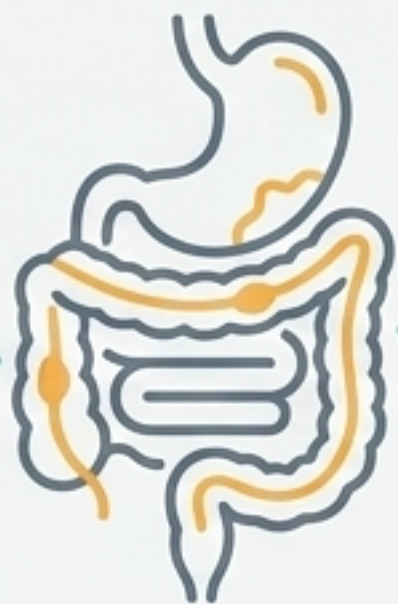


Heavy menstrual bleeding creates a chronic cycle of iron deficiency, fatigue, and impaired concentration. The iron depletion often remains an ongoing disease burden even if bleeding normalizes.

VWF/FVIII often rise and normalize by the third trimester, improving hemostatic reserve. However, postpartum hemorrhage risks remain high due to uterine atony, genital tract trauma, and the rapid postpartum decline in VWF.

Path B: The Pregnancy Paradox

Clinical Mandate: A favorable laboratory trajectory during pregnancy does not guarantee an uncomplicated clinical outcome; third-trimester delivery planning is essential.



The Gut

Focus: GI bleeding (often associated with angiodysplasia and lack of HMW multimers).

Impact: Converts an intermittent mucosal bleeding disorder into a chronic management problem dependent on iron repletion, lesion-directed treatment, and sometimes continuous prophylaxis.



The Joints

Focus: Severe VWD (Type 3 / Severe Type 1 or 2).

Impact: Recurrent hemarthrosis leading to joint damage, chronic pain, and impaired mobility—creating a quality-of-life burden analogous to (though not identical to) hemophilia.

Organ-specific manifestations change the rules of prognosis, demanding multidisciplinary management beyond simple factor replacement.

The Aging Paradox



Aging does not merely modify VWD. It changes the problem VWD is part of.

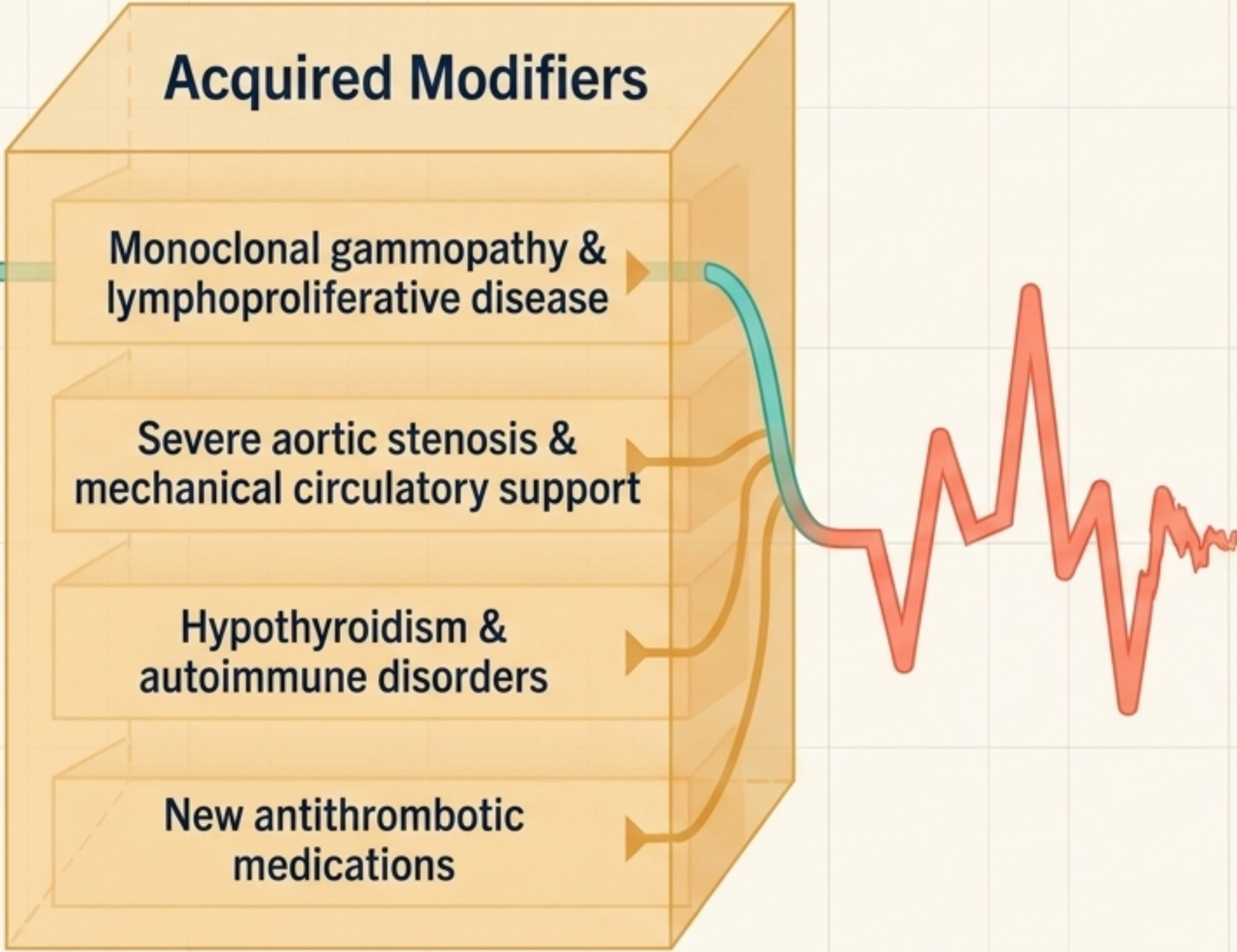
Acquired Modifiers

Monoclonal gammopathy & lymphoproliferative disease

Severe aortic stenosis & mechanical circulatory support

Hypothyroidism & autoimmune disorders

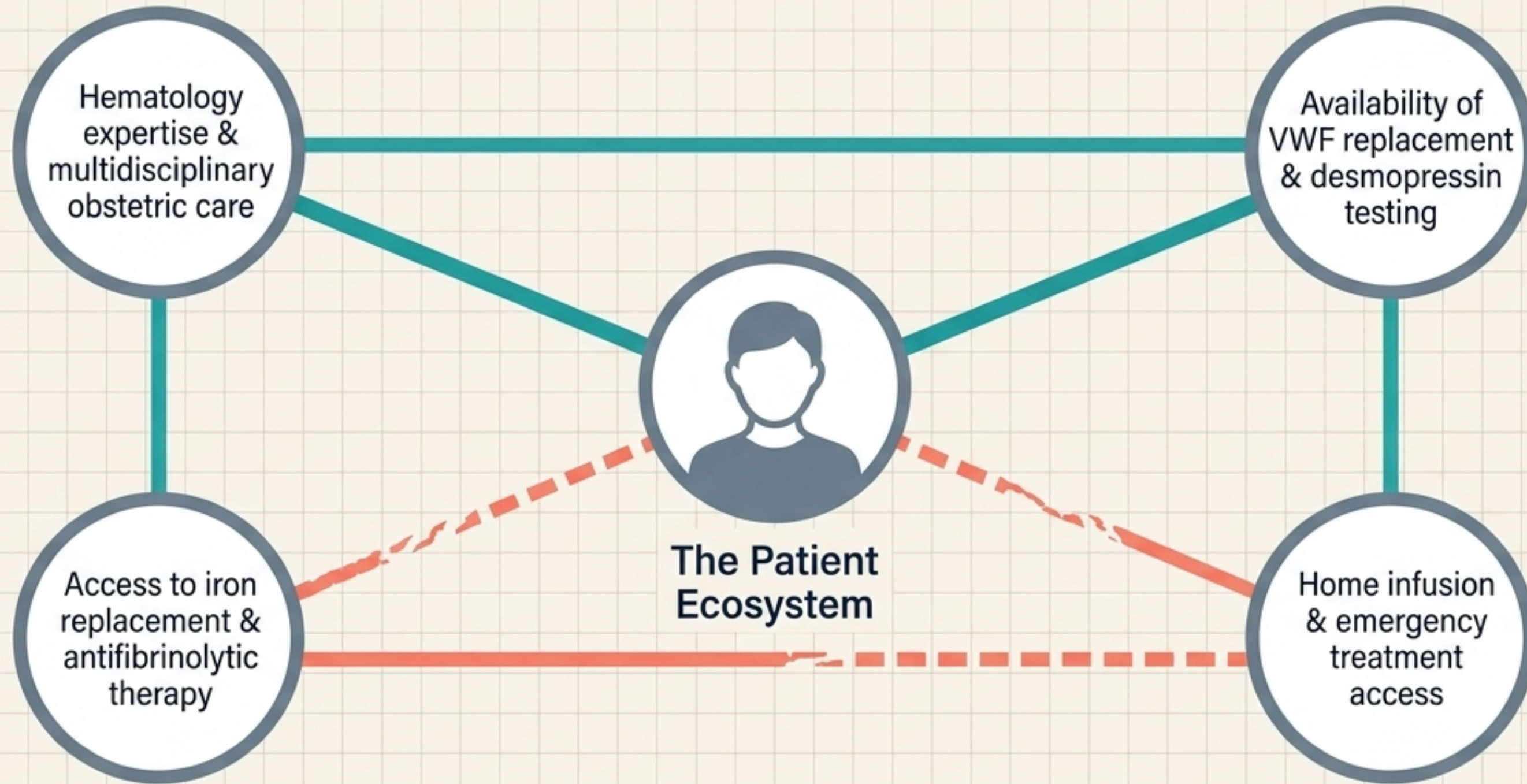
New antithrombotic medications



New or unexpectedly severe bleeding later in life should not automatically be interpreted as progression of inherited VWD.

Clinical Rule: Prognosis must be revised when the underlying mechanism changes

The Systemic Web of Care



Biology is not the only determinant of outcome. A biologically manageable disorder becomes profoundly burdensome when treatment is unavailable, delayed, or fragmented. Quality of life is how prognosis is actively experienced.

Patient 1

VWF Activity: 24 IU/dL.

History: Untreated dental extraction and appendectomy with no abnormal bleeding. Never pregnant.

Patient 2

VWF Activity: 44 IU/dL.

History: Heavy menstrual bleeding since menarche, recurrent iron deficiency, postpartum hemorrhage, repeated ER visits for epistaxis.

Who has experienced the greater burden? Clearly, Patient 2.

Who has the worse future prognosis? This requires asking two questions:

What biological defect is present? AND

What has that defect actually done in this person's life?

Counseling Spectrum



“

VWD is usually manageable, but its burden is highly individual. Its future impact depends on the phenotype already expressed, the challenges ahead, and the burdens you are already carrying.

Evidence Anchor

Atiq (2021/2024): Low-VWF cohorts show prior bleeding history/age <18 predict future bleeding better than borderline lab strata. VWF rises with age, but bleeding phenotype may persist.

Lavin (2018): Significant gynecologic morbidity (HMB, PPH, interventions) occurs despite 'modest' laboratory reductions.

Castaman (2023): VWD is strongly associated with impaired quality of life, heavy treatment burden, and joint pain.

Connell (2021): Long-term prophylaxis reduces recurrent bleeding in selected severe phenotypes.

Open Questions

- How much does age-related normalization actually reduce risk?
- How best to balance bleeding/thrombotic risks in older adults?

Uncertainties do not make prognostic counseling impossible. They make it probabilistic, individualized, and revisable.