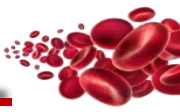




Improving quality of life in Willebrand disease

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Quality of Life (QoL) is a broad concept

Key factors affecting QoL:

Physical health

Mental well-being

Social relationships

Economic stability

Environmental quality

Education and personal growth





Health-Related Quality of Life (HRQoL)

Physical functioning

Mental and emotional well-being

Social functioning

Pain and discomfort

General health perception





Measuring HRQoL

HRQoL is assessed using various standardized tools.

- General (generic) HRQoL instruments
- Specific HRQoL instruments.



- SF-36 (Short Form Health Survey) – Measures physical and mental health aspects of quality of life.
- EQ-5D – Evaluates mobility, self-care, pain, anxiety, and daily activities.



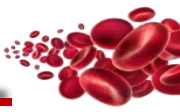


VWD and HRQoL

- The impact of VWD on patients' HRQoL is an area of growing research interest.
- Symptoms can lead to limitations in daily activities. ¹
- Bleeding episodes can significantly affect overall HRQoL.
- Adults with VWD may encounter challenges related to employment.
- Women with VWD, report a higher burden due to heavy menstrual bleeding and complications related to pregnancy and childbirth. ²

¹ Kempers et al. 2022 ² Committee on Practice Bulletins Gynecology 2012





Joint bleeds and HRQoL in VWD

Joint bleeds reduce HRQoL.¹

Patients with joint bleeds and arthropathy reported less social participation compared to patients without arthropathy.²

There are a reductions of joint bleeds after the start of prophylaxis.³

Secondary prophylaxis help reduce the burden of joint disease and arthropathy.⁴

¹Miesbach et al. 2021, van Galen et al. 2015 ²Kempers et al. 2022 ³Holm et al. 2015

⁴Castaman et al. 2023





Heavy menstruation bleeding (HMB)

In clinical practice, HMB is defined as menstrual bleeding that negatively impacts a woman's HRQoL.¹

In terms of blood loss, HMB is defined as menstrual bleeding exceeding 80 ml per cycle.²

HMB is a significant factor contributing to lower HRQoL scores in females with VWD.

¹ Committee on Practice Bulletins Gynecology 2012, ² Hallberg et al., 1966, ³ Zia et al., 2022





Iron deficiency

Women with VWD and HMB are at an increased risk of developing iron deficiency and iron deficiency anaemia.

Iron deficiency anaemia are linked to morbidity that can impair cognitive and physical health, including the ability to participate fully in school and work.¹

¹ Zia et al., 2022

Oral health

For patients with VWD, regular dental check-ups and preventive care are important to avoid complications.

- Dentists' lack of awareness about managing bleeding disorders
- Failure to consult coagulation center before performing procedures
- Concerns about excessive bleeding during or after dental interventions



The Importance of Regular Follow-Up

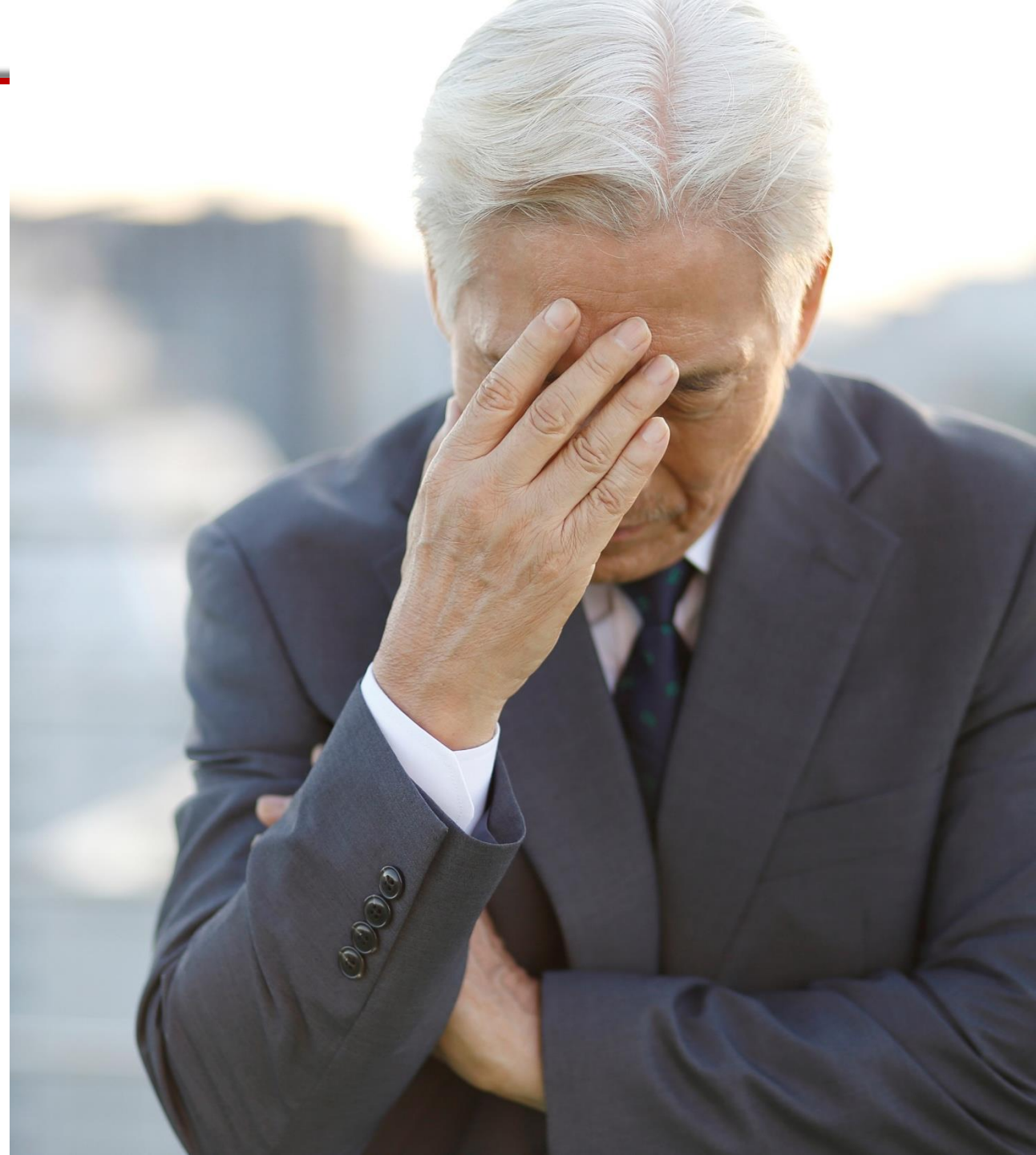
A recent study found that approximately 30% of patients were lost to follow-up.¹

Lack of follow-up increases the risk of developing iron deficiency and iron deficiency anemia.

Regular visits and frequent blood tests for ferritin and hemoglobin levels are important.

Iron deficiency can become the person's new "normal" if left unaddressed

¹Shelton et al, 2024





Parents of children with VWD

A multicenter study were conducted in the three EHCCC in Sweden.

70 parents to children with moderate or severe VWD were included.

A questionnaire developed for the study was used for the collection of psychosocial and socio-demographic data

A validated scale that assesses the burden for caregivers of children with bleeding disorders and SF-36 was used.



Significant differences were found in parental QoL based on the child's clinical status

Parents reported a significantly higher burden if:

- The child was diagnosed due to a bleed
- The child had one or more bleeds in the past 12 months
- The child had prophylactic treatment



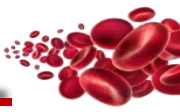


Significant differences were found in parental burden based on psychosocial aspects

Parents reported a significantly higher burden if:

- The child's VWD had an impact on what the parent allowed the child to do
- The child was absent from preschool/school ≥ 2 days in the past 12 months due to VWD
- The child's VWD affected their own lives in general
- The child's VWD had a financial impact on the family





Differences between boys and girls

The girls had on average 5.0 days absence from preschool/school in the last 12 months due to VWD and the boys had on average 1.8 days absence.

For children aged 11–17, the difference between the sexes was girls 5.2 and boys 0.5 days.

Parents of girls reported a higher frequency of absence from work due to the child's VWD than parents of boys.





Impact of child's VWD on family life

One third of the parents (38% of the fathers and 31% of the mothers) reported that the child's VWD affected their lives in general.

39% of the parents (53% of the fathers and 33% of the mothers) reported that the child's VWD had an impact on what they allowed the child to do.

10% of the parents (19% of the fathers and 6% of the mothers) reported that caring for a child with VWD had a financial impact on family life.





Conclusion

- A patient-centered approach is essential for improving the HRQoL in persons with VWD.
- By addressing the physical, emotional, and social challenges of the disease, healthcare providers can enhance patient well-being and ensure better long-term outcomes.
- Clinical follow-ups should include psychosocial aspects to identify patients that are at risk of high burden.
- The importance of regular follow-ups in patients with VWD.







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ERN-EuroBloodNet's EDUcational Youtube channel



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