

Everyday issues in women with bleeding disorders

Naja Skouw-Rasmussen, Debra Pollard

Men and women with bleeding disorders have similar symptoms but their experiences are different. It has been shown that women with a bleeding disorder rate their quality of life on a par with that of men with haemophilia who have HIV. Many factors determine quality of life, ranging from delay in diagnosis, to access to treatment and support from family and friends. Women should ask themselves what is important to them and recognise the barriers that determine whether they can achieve their aims in life. Quality of life instruments do not measure the impact of these disorders in a way that is specific to women. Psychosocial health – i.e. the mental, emotional, social, and spiritual aspects of what it means to be healthy – can have a major impact on quality of life. Women with bleeding disorders face a number of challenges to their psychosocial health. They struggle to be believed, they live with guilt, and they may have to fight for the best care for their children. They face obstacles to building relationships and their experiences can leave them isolated. Perhaps because of this, women with bleeding disorders are strong – but they also need to be encouraged to make time for themselves and look after their mental health.

NAJA SKOUW-RASMUSSEN

Member of the Steering Committee and Chair of the of the Women and Bleeding Disorders Committee, European Haemophilia Consortium, Denmark

DEBRA POLLARD

Lead Nurse, Katharine Dormandy Haemophilia and Thrombosis Centre, Royal Free Hospital, London, UK

PROCEEDINGS OF THE THE FIRST EUROPEAN CONFERENCE ON WOMEN AND BLEEDING DISORDERS

Keywords: *Women with bleeding disorders, quality of life, psychosocial health, support*

IMPACT OF BLEEDING DISORDERS ON QUALITY OF LIFE

Quality of life is a concept familiar to everyone. Scientifically, the term means measuring clearly defined outcomes in a way that is meaningful and repeatable, so that interventions can be evaluated and compared using consistent methodology. Many instruments have been developed to achieve this: examples include the 36-Item Short Form Health Survey (SF-36) and EQ-5D instruments developed by the EuroQol Group, which produce a composite score from measurements of different aspects of life (domains) including physical health, reproductive health and social life^[1,2]. These instruments have been extensively used to evaluate quality of life. However, they are not necessarily the best way to capture the experience of woman with bleeding disorders as they do not measure the impact of these disorders in a way that is specific to women. They are designed for use in research settings rather than to identify how an individual is coping with a disorder.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License (<https://creativecommons.org/licenses/by-nc-nd/3.0/>) which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial, and no modifications or adaptations are made. Copyright is retained by the authors.

Factors influencing quality of life for an individual

Men and women with bleeding disorders share some symptoms, but others are unique to women and their experiences are different. The impact of bleeding on menstruation, pregnancy, delivery and the menopause can be profound. It has been shown that women with a bleeding disorder rate their quality of life on a par with that of men with haemophilia who have HIV^[3]. This may be due to the uncertainty associated with bleeds and the struggles they impose on daily life.

Quality of life is also influenced by whether treatment is available, how effective it is and what happens when it is not effective. A good understanding of a bleeding disorder and its management is associated with better quality of life, but is partly determined by level of education, which is not equal for all.

Effective coping depends on support from family and friends, who also need to understand the impact of living with a bleeding disorder. Support from other people with a bleeding disorder, through participation in a national member organisation (NMO) for example, comes from common understanding and shared experiences. This community of people, who do not need to hear explanations or justification, provides a special kind of support. However, women can find themselves isolated within their own community if the challenges they face are not acknowledged. Health professionals should listen to and take account of what their patients say about their experiences of living with a bleeding disorder, help them to understand their disorder, define what they want from treatment, and help them explore the best options to achieve their personal goals.

Life stages

Living with a bleeding disorder is not a single fixed event, and age at diagnosis is a significant determinant in how it affects quality of life. A US study in 2004 showed that women with von Willebrand disease waited an average of 16 years after the first symptoms, and up to 39 years, for a diagnosis^[4]. The EHC survey showed that the median age at diagnosis of a bleeding disorder was 16, and later for women with a 'mild' bleeding disorder^[5]. An early diagnosis means growing up with the knowledge that a bleeding disorder is part of your life. A late diagnosis that explains years of symptoms might bring relief or shock; either way, a woman must adjust to a new outlook on life. People of different ages respond to news differently: a person's needs change with age, and they have different support mechanisms and



© Shutterstock

The needs, support mechanisms and daily demands on women with bleeding disorders change throughout their lives. It is important that they are supported to find ways to live with the challenges they experience as a result of their condition at all life stages.

different demands on their lives. Symptoms that are important in some years may be less so in others; treatments that worked well for a while may later be problematic. People with a bleeding disorder are likely to outlive some members of their healthcare team, over their lifetime, and this requires adjustment in their relationships. It is imperative that women with a bleeding disorder find – and are supported in finding – a way in which to live with the challenges and changes their condition raises at different life stages.

Barriers

Barriers to a good quality of life while living with a bleeding disorder can be self-imposed or external. Being clear about barriers helps to identify something specific that can be changed.

Personal limitations can be subtle. Reluctance to travel, whether because the dryness of air conditioning provokes nose bleeds or access to treatment is uncertain, can, once recognised, be tackled by planning and support from family and friends. Some limitations are more profound. The decision whether to have children depends on fully understanding a bleeding disorder and being honest with oneself about its impact. A well informed health care team should be available to educate and support women and their partners through this decision-making; however, these facilities are not universally accessible.

Barriers imposed by others are pervasive, ranging from teachers telling children they cannot join in a sport because of their fear of a bleeding disorder, to a family reluctant to let go and allow a child to take responsibility for their actions. For adults, lack of

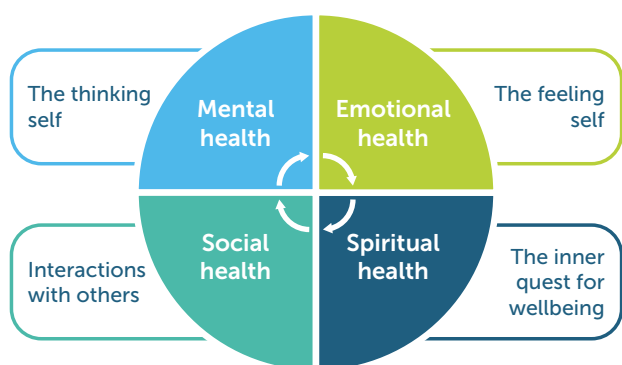


Figure 1. Elements of psychosocial health

support from their medical team can make it difficult to participate in events or develop new interests. Open dialogue is essential; children often find it difficult to be assertive with adults, and they need support in challenging the barriers they face.

Quality of life can be measured in many ways, but these should be relevant to the person living with a bleeding disorder. Women should ask themselves what is important to them and recognise the factors that determine whether they can achieve their aims in life.

PSYCHOSOCIAL ISSUES IN WOMEN WITH BLEEDING DISORDERS

The psychosocial issues that are important in people's lives are varied, highly individual and change over time. How a mother plays with her baby who has a bleeding disorder is affected by whether she has a bleeding disorder herself: she will be aware that bruises can be misinterpreted as signs of abuse. As girls develop body image awareness, their bruises are evidence of their bleeding disorder, revealed when they go swimming or when wearing summer clothes. There is growing interest in the impact of older age in the bleeding disorders community, but little attention is paid to the psychosocial effects of ageing in women with bleeding disorders. Osteoporosis is a feature of ageing in menopausal women, but may be compounded in those with severe bleeding disorders who have sustained a lifetime of joint bleeds.

Health, wellness and psychosocial health are familiar terms, the importance of which can be underestimated. Health is a state of complete physical, mental and social wellbeing, not only the absence of disease. Wellness means having optimal health and wellbeing, and includes not only physical health but emotional, mental, spiritual, interpersonal/social and environmental aspects. Psychosocial health describes the mental, emotional,

Table 1. Qualities of psychosocially healthy people

Feeling good about yourself
Feeling comfortable with other people
In control of tension and anxiety
Able to meet the demands of life
Curbing guilt and hate
Maintaining a positive outlook
Valuing diversity
Appreciating and respecting nature
Enriching the lives of others

social, and spiritual aspects of what it means to be healthy (Figure 1). A psychosocially healthy person is therefore someone who has many qualities we aspire to (Table 1).

Mental health describes the 'thinking, rational self' that responds to challenges constructively. It follows that irrational thinking may be a sign of poor mental health. Emotional health concerns the 'feeling self', the subjective side of psychosocial health that includes emotional reactions to life – that is, the complex patterns of feelings as varied as love, hate, frustration, anxiety and joy. Social health is a person's ability to use social support and adapt to different situations; it is critical to good mental and emotional health. Spiritual health means different things to different people. It can be a sense of peace, place or purpose; a feeling of connection or belonging to something, whether that is nature or a higher power.

Women with bleeding disorders face a number of challenges to their psychosocial health. They have to fight to be believed that their experience is not normal. They live with the guilt of passing on a bleeding disorder. They may have to fight to get the best care for their children. Their bleeding disorder gets in the way of building and maintaining relationships and it affects their children's relationships with their peer groups. Prolonged bleeding has a marked impact on sexual relationships for women and adolescents and has an impact on their partners. Their fears for their present and future health are well-founded. Their symptoms isolate them from their friends and work colleagues.

Strong women

Despite the challenges their conditions bring, it is clear from the life stories of many women with bleeding disorders that they are strong – but psychosocial support from family, friends and healthcare professionals is important in underpinning this.

Stronger Together



© Shutterstock

Case 1

Juliette has severe Type 2N von Willebrand disease (VWD). She is the only daughter in her family, all of whom are affected. The treatment centre team did everything it could to prepare her for menarche well in advance, but her periods started on her first day at high school – a devastating experience in which she recounts she “flooded the chair”. Her medical team had given her the impression that having VWD meant she could not have children. However, she was fortunate in having a strong family to support her, and is now a happy mother with two (unaffected) boys.

Case 2

Molly has severe Type 1 VWD. She divorced in her late twenties and found a new partner with whom she tried, without success, to have children. She has heavy menstrual bleeding and has lost one ovary. Now in her thirties, she is sad and angry, but she has faced her challenges and found strength – not with the help of health professionals, but through her partner and friends.

Case 3

Seema experienced extremely heavy menstrual bleeding that impacted on every aspect of her life, and had to have hormone therapy to stop her periods completely. She took control of the management of her bleeding disorder and asked health professionals to support her. She is Muslim and had expected to have an arranged marriage with her first cousin, but was counselled against this because of the risk of transmitting the bleeding disorder. She has a loving family, which

has played a crucial role in helping Seema handle the challenges she faces, and her brothers have been particularly kind.

Stronger together

Support for the health and wellbeing of women with bleeding disorders can come from different sources. Family, friends and partners can be key in this, but the role of haemophilia treatment centres and NMOs is also essential in supporting their psychosocial health. The voices of many women with bleeding disorders may not have been heard before, and it is important for treatment centres and NMOs to listen, provide a caring response, and not think of their wellbeing solely in terms of treatment. Education is empowering, but should be based on establishing realistic expectations: women with bleeding disorders must not be set up to fail.

Women should be helped to find a support group and to make time for themselves. They should be physically active, take exercise and ensure that they give themselves the time to get enough sleep. They should be able to assess the problems they face, seek help if they need it, and recognise that it is important to look after their mental health too. In supporting women to achieve and maintain health and wellbeing, NMOs need to share and reiterate the following key messages:

- If you are tired, rest
- If you are upset, give yourself compassion
- Be kind to yourself
- If you are emotional, use it
- Counselling comes from many sources – don't suffer alone or in silence, reach out.

The cyclist Lance Armstrong, infamous for his involvement in the biggest doping scandal in cycling history, has been wrong about some important things.

KEY LEARNING POINTS

- Quality of life should be measured in a way that is meaningful to women with bleeding disorders
- The experiences of women with bleeding disorders are different from those of men
- Women face internal and external barriers to achieving a good quality of life
- The psychosocial issues that are important in people's lives are varied, highly individual and change over time
- Treatment centres and NMOs should listen to women's voices, provide a caring response, and not think of their wellbeing solely in terms of medical treatment
- Women with bleeding disorders are stronger when they stand together

However, he was right when he said: "Knowledge is power, community is strength and a positive attitude is everything." There is strength in community, and women with bleeding disorders are stronger when they stand together.

DISCUSSION

Facing everyday issues as a woman with a bleeding disorder can be challenging, and coping mechanisms are important. The question was raised as to whether there are examples of humour being used as a coping mechanism in the bleeding disorders community. People with bleeding disorders can have a morbid sense of humour – it is one way in which people with a shared problem can bond or deal with a stressful event – and there are examples of clowns being brought into paediatric wards. However, humour must be used carefully, not least because what one person finds amusing could be upsetting to another, and consideration must be given to cultural differences and sensitivities. For health professionals considering bringing humour into their interactions with patients, the best option is to take the cue from the person in the clinic. As the relationship between patient and health professional grows over time, it will become clear what will and will not be funny.

The discussion around humour prompted a joke from one of the delegates:

Question: "How many haemophiliacs does it take to change a light bulb?"

Answer: "None. Their mother will do it!"

The challenge for women with bleeding disorders, and the people who provide their care, is their tendency to prioritise the interests of their children and family, sacrificing their own needs in the process. This is a difficult behaviour to change, but there are different approaches that can help. For example, a woman with a bleeding disorder should be encouraged to

share her tasks and daily demands with her partner or family. Joining a parent group or taking part in a "mothers' weekend" can help provide women with a new perspective on their lives, through discovering how other women cope and how investing time and effort in themselves can help them build resilience. Thinking about self-care is not an indulgence, and tiredness is a particularly difficult challenge for women with bleeding disorders that is overlooked in research studies.

Women who struggle with guilt about passing on a bleeding disorder should be encouraged to remember that the fault is not theirs: genetic inheritance is not a choice. The experience of member organisations is that people with bleeding disorders, by and large, do not blame their parents. This is something that would be valuable for parents to hear more widely.

Discussions about mental health – and good mental health – should be approached in the same way as talking about dental health or cardiovascular health: it must be destigmatised. Psychology services have an essential role to play in supporting good mental health; however, in many countries there are problems around access to or reimbursement for psychology services for people with bleeding disorders. Latvia is an exception: the national healthcare policy includes ten psychology sessions per year for people with a rare disorder. Sadly, those responsible for funding healthcare, whether through an insurance-based system or otherwise, often do not recognise that psychological health is as important as physical health. While expensive treatments may address the physical symptoms of a bleeding disorder, ultimately individuals who live with the disorder will not feel "better" until they also have good psychosocial health.

ACKNOWLEDGEMENTS

Writing support was provided by Steve Chaplin, Haemnet.

The authors have advised no interests that might be perceived as posing a conflict or bias.

This article does not contain any studies involving human participants or animals performed by any of the authors.

ORCID

Debra Pollard  <https://orcid.org/0000-0002-7797-3500>

REFERENCES

1. Rand Health Care. 36-Item Short Forum Survey (SF-36). Available from https://www.rand.org/health-care/surveys_tools/mos/36-item-short-form.html (accessed 28 June 2019).
2. EuroQol. EQ-5D instruments. Available from <https://euroqol.org/eq-5d-instruments/> (accessed 28 June 2019).
3. Barr RD, Sek J, Horsman J, et al. Health status and health-related quality of life associated with von Willebrand disease. *Am J Hematol* 2003; 73: 108-14. doi: 10.1002/ajh.10237.
4. Kirtava A, Crudder S, Dilley A, Lally C, Evatt B. Trends in clinical management of women with von Willebrand disease: a survey of 75 women enrolled in haemophilia treatment centres in the United States. *Haemophilia* 2004; 10: 158-61.
5. Noone D, Skouw-Rasmussen N, Lavin M, et al. Barriers and challenges faced by women with congenital bleeding disorders in Europe: results of a patient survey conducted by the European Haemophilia Consortium. *Haemophilia* 2019; 25: 468-74. doi: 10.1111/hae.13722.

HOW TO CITE THIS ARTICLE

Skouw-Rasmussen N, Pollard D. Everyday issues in women with bleeding disorders. Proceedings of the First European Conference on Women and Bleeding Disorders. *J Haem Pract* 2019; 6(2): 44-49. <https://doi.org/10.17225/jhp00144>.



The Journal of Haemophilia Practice

An open-access journal for sharing
experience in the care of people
with bleeding disorders