

Identity and social challenges for persons with bleeding disorders: a gender and sex comparative approach

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ABSTRACT

Bleeding disorders are genetic conditions which involve impaired blood clotting. This may lead to disability. The predominant symptoms usually differ depending on biological sex, which implicates that the disabling mechanisms of bleeding disorders are gendered. Here we review sex-specific symptoms from bleeding disorders and how they can disable gender identities. We found that men's masculinity can be compromised by sickness, economic dependency and reduced ability to participate in sports and other risk-taking activities. Women's femininity, on the other hand, can be compromised by challenges related to their fertility and cultural misconceptions concerning menstrual hygiene. Both men and women with bleeding disorders experience a general lack of understanding in society at large regarding their unique problems. Women in particular are subject to late diagnosis and disbelief, due to a common misperception that bleeding disorders exclusively affect men. Theories on hegemonic masculinity and femininity provide a framework for understanding the sex-specific consequences of bleeding disorders in a disability perspective, and suggest that lack of hegemonic masculine or feminine properties may advantageously be compensated for in life areas that remain unaffected by the bleeding disorder.

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Introduction and background

The term 'bleeding disorder' refers to a wide range of congenital medical conditions that result in problems with the body's blood clotting system (MedlinePlus 2013).

A common misconception regarding bleeding disorders is that they affect only men. Women are often thought to 'just' carry the altered gene, and as carriers they may pass on the condition to their sons. However, women can experience severe symptoms (Di Michele et al. 2014; World Federation of Hemophilia 2012; Wysocki 1998). The aim of this article is to review and discuss the literature on lived experiences of sex-specific symptoms in various bleeding disorders in a disability and gender identity context.

Bleeding disorders are rare congenital disorders, the most commonly known being haemophilia, which mainly affects men who inherit it from their mother. Other conditions, such as von Willebrand's disease and several other clotting factor deficiencies and inherited platelet disorders, affect both men and women (Centre for Rare Disorders 2008). A disorder is defined as rare when the population prevalence is less than 1/1250 in the USA or 1/2000 in the European Union (Schieppati et al. 2008). In Norway, a rare diagnosis is one that affects no more than 1/10,000 (The Norwegian Directorate of Health 2011).

Bleeding disorders usually manifest at birth or early in life and are as such a premise for a person's development of self and social life. The various symptoms depend on the type of bleeding disorder and its severity. Symptoms vary between excessive bruising and bleeding, spontaneous nosebleeds, heavy blood loss during menstruation, to internal bleeds in joints and muscles. A bleeding may be caused by a physical trauma, but very often it happens spontaneously without any obvious cause. Furthermore, persons with bleeding disorders are at high risk of serious surgical complications if no specific precautions are taken in order to control the bleeding (MedlinePlus 2013).

Bleeding disorders cannot be cured, but with medical follow-up and treatment children of today can expect to have a normal life span. Since the mid-twentieth century, the introduction of clotting factor replacement and prophylactic treatment has radically improved life expectancy and quality of life (QoL) for people with bleeding disorders (Schramm 2014). In Sweden, for example, life expectancy for a person with haemophilia has dramatically increased from median 10–15 years one hundred years ago to more or less normal for a newborn today (Lövdahl et al. 2013). However, despite advances in medical treatment and follow-up, people with severe bleeding disorders still experience recurring bleeding. Excessive bleeding is significantly painful, and may eventually lead to physical harm and impairment associated with the symptoms of their disorder (Elander 2014; Elander et al. 2009; Riley et al. 2011). Bleeding disorders are, however, not only affecting the biology of the body in an undesirable manner, but they can also be experienced as potentially disabling conditions, by restricting the person's possibilities in existential matters such as building identity and having a satisfactory social life.

Disability as a concept has been widely debated. Advocates of the strong social model of disability argue that society is creating disability by causing unnecessary barriers, discrimination and exclusion towards people with bodies and capabilities that diverge from socially acceptable normality (Oliver 1990). Regarding the purpose of the present article, however, we advocate bridging between the social model and the medical model, and in terms of Tom Shakespeare's subsequent theorizing, we understand disability as the result of an interplay between the impaired body and society; between individual and contextual factors (Shakespeare 2006). Furthermore, we understand disability and gender as 'interlocking categories of experience that affect all aspects of human existence as they simultaneously structure people's lives' (Traustadóttir 2006).

Identity is a concept that may be approached as a biographical chain of events, and the core of a person's identity lies in that person's capacity to continue a particular narrative (Giddens 1991). Gender is one of several key features of identity. While sex refers to the biological differences, gender refers to the culturally appropriate and expected behaviour of men and women (Bury 2005). This dichotomy between sex and gender has been significantly debated during the last decades. The two concepts imply different meanings to different theorists. Strong, feminist voices convincingly argue that the dichotomy between sex and gender falsely assumes that all women belong to a restricted group, where membership is somehow fixed, and experiences are falsely expected to be shared and pre-defined (Butler 1999). For the purpose of the present article, however, we find it necessary to include the dichotomy, due to the biology of bleeding disorders. Men simply do not menstruate, and women are generally affected by their condition in a less impairing way. That being said, gender is seen as fluid, yet hierarchically ranked in hegemonic, subordinate and marginalized masculinities and femininities (Connell 1995; Schippers 2007; Shuttleworth, Wedgwood, and Wilson 2012). Both gender and ability are part of our symbolic capital, which consists of individually possessed properties that are unevenly distributed and socially valuable to have (Bourdieu 1986), and can be traded on and negotiated in various contexts (Connell 2012).

Data and method

Literature searches were performed using the PubMed database, the Springer Link database and the Haemophilia Journal online library. The following keywords were used: 'haemophilia/hemophilia'; 'bleeding disorder(s)'; 'von Willebrand's disease/vWD' plus 'stigma'; 'lived experience'; 'identity';

'women'; 'girls'; 'femininity'; 'men'; 'boys'; 'masculinity'; 'gender'; 'social' and 'sport'. The majority of the articles found dealt with diagnostics and medical treatment. For the purpose of this article, they were excluded, except for those included for explanatory reasons.

Articles with sole focus on the HIV epidemic were excluded, as were articles on being a genetic carrier with no symptoms. Publications prior to 1995 were excluded, because of changes in society, diagnostics and treatments from the mid-1990s.

As the primary focus of the study was to identify social implications of living with a bleeding disorder on gender identity, the qualitative articles on lived experiences from bleeding disorders were thoroughly read. In questionnaire-based articles about QoL for persons with bleeding disorders, abstracts were the main focus.

The first overview of the literature showed that most studies were sex specific, due to the biology of bleeding disorders. The articles included in this study were therefore systematically separated into two categories, one concerning men and the other concerning women. The articles were then analysed and discussed in light of gender theory and medical sociology.

Bleeding disorders and QoL

One review covering 24 studies concerning psychosocial stressors for persons with haemophilia, a condition that mainly affects men, showed reduced QoL (Cassis et al. 2012). The reduced QoL showed a possible negative impact on education and employment for men with haemophilia, especially when effective treatment was unavailable.

All studies identified in the present study, dealing with women with bleeding disorders and their QoL, focus particularly on menstruation. For women with abnormally heavy and prolonged menstrual periods (diagnosed with menorrhagia) the QoL was significantly lower than that for women in the control population (Kadir, Edlund, and Von Mackensen 2010; Kadir et al. 1998; Kulkarni et al. 2006; Von Mackensen 2011). Several of the articles show that both men and women with bleeding disorders experienced a general lack of understanding among the public. A common experience was to be met with ignorance in the public health system (Barlow, Stapley, and Ellard 2007; Barlow et al. 2007; Khair, Holland, and Pollard 2013; Wysocki 1998). Research on other rare disorders supports this finding. When a diagnosis is rare and thus unknown to professionals, underestimation of risks and symptoms, and unwillingness to get involved occur, despite a clear diagnosis (Berglund, Mattiasson, and Randers 2010; Grut and Kvam 2012).

Masculinity and bleeding disorders

Men with bleeding disorders who experience disability may face a number of challenges in respect to fulfilling and maintaining social expectations of masculinity. Financial independence and the ability to provide for one's family is traditionally a high-ranked aspect of masculinity. A significant group of men with bleeding disorders suffer from severely damaged joints, co-morbidities such as arthritis, and co-diagnosis such as HIV and hepatitis from blood transfusions, all having negative impacts on the men's health and functional ability (Barlow, Stapley, and Ellard 2007; Cassis et al. 2012; Elander et al. 2009). When a bleeding disorder becomes disabling, it may be difficult to complete education, and full-time work is no longer an option for many of the affected individuals. A high prevalence of depression among adult men with haemophilia has been shown to have a significant association with unemployment and lack of social support (Iannone et al. 2012), and persistent pain and joint impairment (Kim et al. 2013).

Another important aspect of the dominant idea of masculinity in many societies is expectation of physical strength and fitness, for instance connected to the ability to participate in sports activities. Men with bleeding disorders face a significantly higher risk of injury and pain while engaging in sports than do other men (Park 2000). Over the last years, studies have shown how adapted physical exercise for men with bleeding disorders is beneficial to their health and physical condition (Gomis

et al. 2009; Souza et al. 2012). Yet, being severely affected by a bleeding disorder is still incompatible with playing rough sports that include physical contact and/or falls, for example football, wrestling and rugby (Heijnen 2008; Park 2000). In New Zealand, for instance, rugby is a key part of a 'normal' boyhood. The sport is played among peers, and is important for building relationships between boys, and also between fathers and sons. Park (2000) described the inability to play rugby as the chief problem facing father-son relationships. Due to the mode of inheritance, either the father or the son is affected by haemophilia, not both of them. This can create a failed sense of masculinity for men with haemophilia (Park 2000).

Some men with bleeding disorders have experienced stigmatization due to the historic relation between bleeding disorders and HIV and hepatitis. The social stigma that is attached to these diseases, along with the side effects of treating these co-morbid conditions, can lead to depression and anxiety (Barlow, Stapley, and Ellard 2007). During the 1980s, many men with haemophilia were infected with HIV and hepatitis from blood transfusions (Kirp 1999). Advertising campaigns in the media in the 1980s caused the general public to link haemophilia with HIV and hepatitis, which led to a fear of touching and sharing things with individuals with haemophilia. This misconception is argued to still exist (Barlow, Stapley, and Ellard 2007). In addition, related stigmas of homosexuality and HIV still persist among the general public, and may lead to erroneous assumptions that all men with haemophilia must be gay (238).

Men with bleeding disorders can be perceived as weak and sickly. They learn at a very early stage in life the need for caution in all activities, and they then develop a cautious movement pattern (Thorsen, Grut, and Myrvang 2011). Many of them experience recurring need for prolonged bed rest. This of course is in contrast to the ideal of a strong and vital masculinity. The men have to balance the need for caution with the cultural expectations of hegemonic masculinity, which implies strength, risk-taking behaviour and fitness. They are easily marginalized if they do not manage to compensate with less physical, but socially acceptable, activities. According to Barlow, Stapley and Ellard (2007), bed rest and sickliness can deprive men with bleeding disorders of a full social life. It can be challenging to complete an education and to have a career. Sickliness and inactivity can lead to discrimination and detachment from colleagues. Thus, it is in many ways important for men with bleeding disorders to work in a field where they can gain success and respect for their achievements, but at the same time avoid physically demanding job tasks. Achievements in the professional arena can lead to a more positive QoL for men with bleeding disorders, resulting in a satisfactory integration of his disorder in his sense of 'self' (Beeton, Neal, and Lee 2005).

Femininity and bleeding disorders

Abnormally heavy and prolonged menstrual periods (menorrhagia) is a medical condition that may be harmful to the woman's health. The condition is a major problem for women with bleeding disorders, and has been the main subject of existing research on women and bleeding disorders (Kadir, Edlund, and Von Mackensen 2010; Kadir et al. 1998; Khair, Holland, and Pollard 2013; Kulkarni et al. 2006; Von Mackensen 2011; World Federation of Hemophilia 2012; Wysocki 1998). Because women's menstruation cycles are not always predictable and standardized, some women with bleeding disorders experience being disbelieved, and they are also often misdiagnosed. This is partly because the public as well as the general health services tend to believe that women do not have bleeding disorders. Late diagnosis is therefore common in women with bleeding disorders (Di Michele et al. 2014; Khair, Holland, and Pollard 2013; World Federation of Hemophilia 2012; Wysocki 1998).

A high-ranked aspect of femininity is cleanliness; a woman should keep herself and her surroundings clean. For women with abnormally heavy and prolonged menstrual periods, bleeding through their clothing in public is at times inevitable. This can cause embarrassing episodes that lead to stigmatizing misconceptions about their ability to maintain proper hygiene. Fear of new, embarrassing bleeding episodes can keep women with such symptoms home from school or work during menstruation (Wysocki 1998).

Another aspect of femininity is the expectation of motherhood. Women with bleeding disorders have many concerns regarding how to plan and carry through a pregnancy. Girls and women with bleeding disorders often rely on taking oral contraceptives in order to control their abnormally heavy and prolonged menstrual periods. Because the contraceptives prevent pregnancy and the alternative is having long-lasting excessive menstrual bleedings, it can lead to concerns about fertility (Khair, Holland, and Pollard 2013). The pregnancy, the delivery and the time immediately after delivery are associated with increased risk for complications and miscarriage. Such problems require special care, diagnosis-specific treatment and close monitoring (Di Michele et al. 2014; Pacheco et al. 2010; Sharief and Kadir 2013).

Some women with bleeding disorders have become infertile due to mistreatment. In an attempt to remove the abnormally prolonged and heavy menstrual periods, some women with bleeding disorders have had a surgical removal of the uterus (hysterectomy) or operations to stretch and dilate the uterus, including the lining of the uterus being scraped off (Wysocki 1998). In terms of the participants in Wysocki's (1998) study, decisions to perform such procedures had often been made without conferring with a haematologist or testing for bleeding disorders. The procedures were associated with painful complications.

Discussion

We have systematized literature on sex-specific symptoms of bleeding disorders, and the possible consequences this can have on men's and women's social life.

Persons with bleeding disorders are faced with a number of misconceptions and implications that may compromise their gender identity and thereby function as disabling barriers in their social lives. The gendered implications from bleeding disorders need to be considered in light of structured, hegemonic expectations towards the gender categories, as well as the biologically given premises.

Connell (2000) defines a multiplicity of masculinities as male practices that are derived from social structures, such as cultural expectations, class and ethnicity. For Connell, a social structure of male dominance over female is stabilized and upheld by a hegemonic masculinity. The concept hegemonic masculinity includes a large number of characteristics, such as physical strength, courage, risk-taking behaviour, vitality and success. Many typically masculine sport activities involve rough physical contact which entails a risk of bodily injury (Mahalik, Burns, and Syzdek 2007), which can be particularly harmful for persons with a bleeding disorder. Hegemonic masculinity consists of a hierarchy of dominance over subordinate groups of masculine characteristics (Coles 2009; De Visser, Smith, and McDonnell 2009). Although a man can be both masculine and feminine, male femininity is associated with having a lower ranking in this hierarchy (De Visser, Smith, and McDonnell 2009). Subordinate or marginalized masculinities, for example being gay or disabled, are arguably negatively related to the hegemonic masculinity. Although traditional expectations of male financial self-sufficiency are changing in many societies due to women increasing their work participation, it is still difficult for some men to accept having a lower income than their spouse or partner (Lui 2013). Whether or not an individual engaged in subordinate masculine practices accepts the dominant conceptions of masculinity is a key factor that determines whether or not he feels inadequate (Shuttleworth, Wedgwood, and Wilson 2012).

Within the field of women's studies, mostly studying feminine suppression beneath the masculine, the term femininity is scarcely defined (Schippers 2007). Attention has rather been drawn to conventional gender pathways and 'what it means to be a woman' (Thomas 2006, 178) in the arenas of motherhood, partnerships and family household responsibilities, among others. Feminist writers in the field of disability have shown that disabled women face considerable disadvantages in their efforts to achieve full social inclusion, compared to men with disabilities (Thomas 2006). Motherhood is described as the woman's basic mission, profession and an inseparable part of her nature (Leskošek 2011). In this sense, expectations of motherhood characteristically belong to a hegemonic femininity. Concerns about sexuality and motherhood are culturally sensitive issues. Many women with bleeding

disorders have concerns about their fertility, and may thus feel that their femininity is being compromised. The impact of reduced fertility on femininity depends on a variety of cultural and individual factors. However, in the dominating idea of femininity and womanhood, childlessness is often seen as unnatural and unwomanly and may lead to feelings of inadequacy (Rich et al. 2011). Menstrual taboos exist in all religions and societies. In Western cultures women are expected to conceal that they are menstruating, keep clean and control the bleeding (O'Flynn 2006; Patterson 2014; Stubbs and Costos 2004). Experience with menstruation, including personal and societal attitudes towards menstruation, contribute to women's own perception of what it means to be feminine. Thus, negative experiences connected to excessive and prolonged menstruation, being unable to control a bleeding, and cultural taboos concerning menstruation may lead a woman to detach from other women (Stubbs and Costos 2004).

Unexpected or inappropriate ways of displaying one's gender, such as being a sickly and unemployed man or an unhygienic and infertile woman, are often met with negative attitudes in society, and places the person in a marginalized position. Disability materializes, according to Garland-Thompson (2011), when men and women with impairments fail to act according to gender-specific values in their society. Disability puts the person in an incongruent relationship with the world, while

"fitting in" allows a person to navigate the world in relative anonymity, in the sense of being suited to the circumstances and conditions of the environment, of satisfying its requirements in a way so as not to stand out, make a scene, or disrupt through countering expectations. (Garland-Thomson 2011, 596)

Individuals have to find ways of re-doing gender in order to fit in (Lui 2013). In this sense, gender can be seen as material practices as well as a form of symbolic capital, consisting of locally legitimate and individually possessed skills and knowledge, social connections and reputation (Bourdieu 1986). What makes a form of capital valuable to possess, to reproduce and to trade on, is the unequal distribution of it, and thus ways of performing one's gender are situational and culturally fluid and contradictory. Gender capital is traded on by compensating for the non-masculine or the non-feminine activities in other arenas (De Visser, Smith, and McDonnell 2009). Persons with bleeding disorders who experience forms of disability that affect their individual gender identity and social life, and who accept the hegemonic gender expectations, have to compensate for their loss of gender capital by finding ways to express themselves in arenas that are unaffected by their disability, in order to fit in. Men with bleeding disorders can compensate for their loss of physical ability by using their intellectual capacities, for example by achievement in white collar professions or other suitable work areas that are not physically demanding (Beeton, Neal, and Lee 2005). Women with bleeding disorders' opportunities to compensate for their lost femininity remain undiscovered in this sense.

The rarity of the bleeding disorder can become an extra burden to the affected individual, who is continuously met with ignorance, mistrust and disbelief. When the disorder is essentially invisible, as it may and may not be for a person with a bleeding disorder, the invisibility may add to the vulnerable situation of the affected individual, as people tend to take invisible impairments less seriously than impairments which are obvious and visible (Diesen et al. 2014; Lingsom 2008).

A need for further research

This review has shown how sex-specific symptoms from bleeding disorders can have a negative impact on the affected individual's gendered identity and social life. However, not all women with bleeding disorders have menorrhagia nor do they suffer from infertility, and not all men with bleeding disorders are disabled, sickly or economically dependent. Does this mean that they remain unaffected by their condition in their everyday lives? As we have shown in this article, both men and women with bleeding disorders generally have a lower QoL, compared with the healthy population.

Social implications from having regular sudden nosebleeds, as well as large, dark and heavy bruises on the face and body have not yet been investigated, although such symptoms affect

many people with a bleeding disorder. The excessive bruising, for example, may lead to erroneous and gender-specific prejudice. A man with heavy bruises may be seen as one who has had an accident, while a woman may be seen as a victim of domestic violence, which also places her partner under suspicion.

Bleeding disorders are rare, and both men and women with these disorders experience a lack of understanding outside specialized treatment and resource centres. Further research on the social and identity implications of having a bleeding disorder and knowledge dissemination is needed to give better understanding of the challenges they face, and to improve awareness of these disorders among people who come in contact with them.

Concluding remarks

The masculinity of men with bleeding disorders can be compromised and disabled by sickness due to repeated prolonged bed rest, continuous need for treatment and inability to participate in physically challenging activities. Furthermore, public misconceptions exist regarding the HIV epidemic among haemophiliacs caused by infected blood transfusions. Finally, men with bleeding disorders can face loss of self-sufficiency due to disability and unemployment.

The femininity of women with bleeding disorders can be compromised and disabled by challenges regarding their fertility. Women with bleeding disorders experience misconceptions regarding their ability to maintain proper hygiene during heavy menstruation. They are often not taken seriously when they recount their abnormally prolonged and heavy menstruation, and consequently they are often diagnosed late in life. Their experiences are partly due to a general misconception that bleeding disorders affect only men.

The degree to which the gender identity of men and women with bleeding disorders is challenged by disabling symptoms depends mainly on each individual's acceptance and identification with the culturally established hegemonic expectations of the masculine and the feminine. In order to maintain a congruent gender identity, persons with bleeding disorders may have to compensate by excelling in domains that remain unaffected by their disability.

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