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RIVISTA DELLA SOCIETÀ ITALIANA DI ANTROPOLOGIA MEDICA
FONDATA DA TULLIO SEPPILLI

Fondazione Alessandro e Tullio Seppilli (già Fondazione Angelo Celli per una cultura della salute) - Perugia

In copertina

1961: Ernesto de Martino (1908-1965) alla presentazione del suo libro *La terra del rimorso. Contributo a una storia religiosa del Sud*, Il Saggiatore, Milano 1961.

Il logo della Società italiana di antropologia medica, qui riprodotto, costituisce la elaborazione grafica di un ideogramma cinese molto antico che ha via via assunto il significato di "longevità", risultato di una vita consapevolmente condotta lungo una ininterrotta via di armonia e di equilibrio.

AM

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Editoriale

AM 54 e il ritorno della sezione monografica

Giovanni Pizza
Università di Perugia
[giovanni.pizza@unipg.it]

Care Lettrici e Cari Lettori,

con questo numero 54 di AM torniamo alle sezioni monografiche. Per la cura di Roberto Beneduce e mia ne produciamo una che celebra l'anno 1961.

Si vuole così ricordare un periodo importante che, a cavallo tra gli anni Cinquanta e i Sessanta del secolo scorso, ha visto il declino del colonialismo e l'avvio, fin da subito intenso, del fenomeno postcoloniale e decoloniale.

Il discorso "postcoloniale" ci sembra fondamentale anche per l'antropologia medica. Esso cerca di andare ben oltre la Grande Separazione della salute, quel *Great Divide* tra l'Occidente e gli Altri che a lungo aveva caratterizzato anche tale branca di studi (che, per esempio, in precedenza non teneva conto delle ineguaglianze). Si cominciano a decostruire tematiche e relazioni importanti, tra le quali malessere, potere, identità. In antropologia medica è il tema del corpo e della follia ad essere esplorato attraverso lo studio di altre culture e/o di dislivelli interni alla cultura occidentale nel tempo e nello spazio, cioè sia nella profondità storica sia nel comparativismo geografico.

In tale quadro generale, abbiamo chiesto una riflessione a studiosi e ricercatori esperti, italiani e no, per rievocare quel periodo e le sue promesse. Tutti lo hanno interrogato alla luce del presente.

AM, però, non finisce qui.

Vi è una sezione non monografica con due saggi, di cui uno complementare a uno scritto che apparirà nel numero successivo, tre ricerche, due

note (una sul nostro fondatore e il suo amore per le questioni della salute mentale e un'altra sull'antropologia della pandemia da Covid-19) e infine cinque recensioni.

Questo è quanto siamo riusciti a fare per questo numero 54.

A Voi un caro saluto e un duplice augurio di buona lettura e di sereno giudizio.

AM
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"Why is it that, more often than not, docs and nurses haven't even heard of us?"
Women and Bleeding Disorders in Italy

Daniela Crocetti
University of Huddersfield, UK; University of Bologna
[d.crocetti.ac@gmail.com]

Laura Palareti
University of Bologna
[laura.palareti2@unibo.it]

Riassunto

"Perché, il più delle volte, i medici e gli infermieri non hanno nemmeno sentito parlare di noi?". Donne e malattie emorragiche in Italia.

Molte hanno sentito parlare delle malattie emorragiche (ME) nonostante siano malattie rare, a causa degli scandali del sangue infetto degli anni '90. Come per molte malattie che hanno attirato l'attenzione dei media, la comprensione del pubblico è limitata. Medici non-specializzati possono ancora credere che le ME siano esclusivamente legate al sesso maschile. Le donne con ME quindi hanno un terreno difficile da percorrere. Situazioniamo il nostro studio qualitativo sulle donne con ME del nord Italia tra gli studi sociali sul pregiudizio di genere nell'assistenza sanitaria, le malattie croniche e le disabilità invisibili.

Parole chiave: malattie emorragiche, emofilia, von Willebrand, donne, mestruazioni

Introduction

Many may have heard of Bleeding Disorders (or at least Hemophilia), despite the fact that they are rare diseases, because they have surfaced in public discourse. Hemophilia is often used as an example of hereditary disease when one is taught about Mendel, genes and heredity in secondary school as its transmission is both monogenetic and dominant (Mertens 1990). North Americans who lived through the late 1980s will remember

how the story of the young white hemophiliac Ryan White contributed to shifting public discourse and perception of Hiv and Aids (Alali 1994). As for many diseases that have caught media attention, however, little is known about the lived experience beyond the specific issue that created the media attention in the first place. In general, few know that there are other Bleeding Disorders (BDs) beyond Hemophilia and, particularly, that women can have BDs.

Lay medical practitioners may still believe that women cannot have BDs, and that Hemophilia is exclusively sex chromosome linked. A 2004 Cdc study indicated an average 16-year lag between bleeding symptoms and diagnosis (Kirtava *et al.* 2004) for women, while males are generally diagnosed within 1-2 years. People with XX chromosomes can be symptomatic carriers of Hemophilia (A or B) or can have other BDs that include Hemophilia C (factor XI deficiency), Von Willebrand's disease, Glanzmann's disease, VII deficiency, and factor XIII deficiency. Worldwide, women continue to be a hidden category in this rare disease. For the purposes of our study and the article, the social category of "woman" was self-defined, yet all the participants had XX chromosomes. While none of our participants were women with XY chromosomes, we acknowledge the compound difficulty that may occur in medical settings for Intersex and Trans women (Crocetti *et al.* 2020) with BDs or other health issues.

We situate our qualitative study of north Italian women with BDs between the social studies of gender bias in healthcare (Hamberg 2008), chronic disease and invisible disabilities (Sturge-Jacobs 2002; Davis 2005). Mid to late twentieth century medical therapies for BDs evolved from blood transfusions to clotting factor replacements and coagulation-factor stimulants, shifting BDs away from life-threatening diseases to chronic illnesses with associated invisible disabilities (see Brigati, Crocetti 2016). However, due to long diagnostic lags, many women with BDs may not have even had access to these therapies, complicating their experiences of chronic illness and associated invisible disabilities, as well as greatly limiting their capacity to access support networks and Health Social Movements (Hsms; Brown *et al.* 2004).

In the following we first provide background on the understudied area of BD experience in general, including the framing presented by anglophone patient associations that include women. We briefly outline the Italian national context and its historic Hemophilia associations. While social studies of medicine have a growing history of addressing patient mobiliza-

tion and social health movements (Shms), little attention has been paid to contexts in which Shms are neither local nor accessible in the language of the individuals involved. Despite of the lack of dedicated Hsms, but perhaps not surprisingly, our interviews revealed that the issues highlighted by our Italian participants greatly reflected those publicly outlined by anglophone groups.

The following discussion of our interview data focuses on the three primary categories that were addressed by our participants: diagnostic time-lag; menstruation and reproductive issues; and negotiating the sick-role. Gender-bias in healthcare clearly trickles down into this specific chronic disease experience regarding diagnostic time-lag, but also regarding the additional complications that MEs present in the context of the female reproductive system. The individual negotiation of the sick role offers reflection on the variegated terrain of chronic disease and invisible disabilities, where one may choose to creatively divulge a medical condition due to fear of stigma or simply desire not to be identified with a disease. In this manner we intend to contribute to investigations of female BD experience, but also emerging discussions on gender-bias in healthcare and invisible disabilities associated with chronic disease experiences.

Background

Much of the socio-historical treatment of Bleeding Disorders has focused on the establishment of the diagnostic category, and the contaminated blood scandals of the 1980s and 90s (e.g. Davidson 1999; Pemberton 2011; Resnik 1999). There is very little social research that addresses subjective experience of this rare disease, let alone the hidden female experience (for a literature review on BDs in general see Brigati, Crocetti 2016). While primarily addressing Hemophilia and male patients with XY chromosomes, all of the above texts mention that symptomatic women fall in an invisible category for a number of reasons. Hemophilia (A and B) was the first Bleeding Disorder to be medically described (in the late 19th century) and is sex-linked recessive (if an individual only has one X chromosome they will necessarily express the disease); yet women who are categorized as symptomatic carriers of Hemophilia can have severe episodes. Von Willebrand's disease (actually more common than Hemophilia) was first described in the 1926 (later associated with a clotting factor in the 1950s), yet often presents itself in milder forms than classical Hemophilia, yet ironi-

cally becomes more serious in relation to female reproductive issues such as menstruation and childbirth. In addition, as Pemberton indicates in the US context:

> Despite such awareness that hemophilia and its kin were a danger to females as well as males, neither the experts nor hemophilia management advocates demonstrated much commitment to inclusiveness. Throughout the 1950s, publicity by the National Hemophilia Foundation and other hemophilia associations continued to cast hemophilia as a male problem. In fact, […] popular presentations of the 1950s suggest that most experts and advocates were aggressively committed to framing hemophilia as a male affliction (Pemberton 2011: 94).

In Italy (and globally), Hemophilia patient associations have historically dedicated most of their energy to male patients[1]. Within the last 15 years subgroups or campaigns that address affected women have appeared within anglophone Hemophilia associations[2], and there is one dedicated anglophone group[3]. For many years a significant part of Italian Hemophilia association's energy was invested in pressing for justice regarding the national health system's secret yet intentional decision (on the part of high-level NHS administrators and hidden from the medical practitioners) to give BD patients infected blood transfusions during the late 1980s. As treatment has evolved and even the most severe forms of BDs are transformed into manageable chronic illnesses, associations and the medical teams they collaborated with have shifted attention to psychosocial care of the disease and quality of life issues. Italy evidences a similar level of high-quality treatment centers, and ignorance among non-specialists, as other wealthy nations, and has active regional hemophilia support groups. However, Italian women with BDs have no dedicated peer-resources.

As BDs are composite objects that can present associated invisible disabilities, we reflect on our interviews through the lenses of gender bias in healthcare, chronic disease and invisible disabilities within the larger issues posed by medical anthropology of how health and well-being are social constituted. As Ann Davis points out (2005), describing an experience as an invisible disability exposes the norm-based assumptions (as well as temporal assumptions) that underlie concepts of physical and mental disabilities. Those with invisible disabilities may not be subject to daily socially normative stigmas, yet must «meet the burden of proof» (Davis 2005: 154) of their needs. In her ethnography of chronic pain suffers, Jean Jackson argues that invisible illnesses present an ambiguous liminality that can provoke stigmatizing reactions because they «confound the codes of morality surrounding sick-

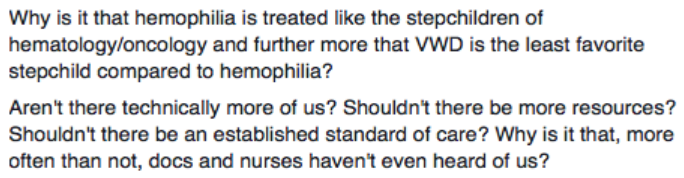
ness and health» (Jackson 2005: 332). While discussing their negotiation of the sick role, our participants exhibited caution about being perceived as social pollutants, or matter out of place (Douglas 1970), due to the issue of blood outside of the body (bleeding episodes) as well as the liminal nature of embodying invisible risk.

Apart from actual bleeding episodes which might be mitigated by prophylactic therapies (once diagnosed), the illness experience of BDs is formed of secondary consequences and issues (diseases acquired from infected blood; pain or impairment as a long-term result of internal bleeding; fear or anxiety regarding the unpredictability of episodes). BDs are chronic illnesses that are significantly marked by temporality, in which one is not chronically unwell, but rather at chronic risk. Individuals may no longer experience symptoms if their therapy regimen is effective, shifting the marker of the disease experience itself. This distinction is particularly relevant for the hidden category of women, because risks can only be managed and prevented if they are known, i.e. if there has been a diagnosis. In the 1990s sociologist DK Wysocki wrote on women and BDs:

> It didn't take long to discover that much of the literature about hemophilia is: (1) from the medical community; (2) about treatment and diagnosis; (3) about other diseases, such as Hiv and hepatitis; and (4) about the needs of men. Women have been virtually left out. (Wysocki 1997; last viewed 5 October 2022).

Since Wysocki's observations patient associations specifically addressing women and BDs have grown in the anglophone context and some shifts have been made in nomenclature. The European medical association is now called the "European Association for Haemophilia *and Allied Disorders*". The International and influential "World Federation of Hemophilia", founder of the Wiley journal *Hemophilia* encourages presentations on women's issues in BDs and has sponsored special issues on women and BDs. Yet it still appears that, on the level of scientific organization, articles and research on women and BDs must fit themselves into the Hemophilia umbrella, while the common medical description is still that women can't have Hemophilia A or B.

In our preliminary literature analysis while preparing our interviews, we found that female BD groups recurrently addressed diagnosis lag and general medical ignorance of female forms of BDs. Medical articles instead tended to address techniques. Social media group discussions included the voicing of frustration that some health professions still don't seem aware that women can have BDs.



Screen shot of closed FaceBook discussion group taken 24/06/2016.

A general search on pubmed using the key words "Hemophilia And Women" reveled 581 articles (which included VW and other BDs, as well as 30% unrelated articles) with the following topics in descending order of frequency: Birth management and/or complications (postpartum hemorrhage); carriers (genotype-phenotype correlations); Antiretroviral drugs (for prevention of Hiv transmission); heavy menstruation; preparation for surgery. Using "Women And Von Willebrand" we found 808 medical articles (at least 50% of which did not specifically address VW) with the following topics in descending order of frequency: Birth management and/or complications (postpartum hemorrhage); heavy menstruation; medicinal therapy and management; preparation for surgery; diagnosis.

Anglophone patient association production (websites; conference presentation videos) instead overwhelming focused on diagnosis lag and constant struggle with the general medical perspective that women can't have bleeding disorders (obviously these two issues are related). Some women's groups that were tied to Hemophilia associations (often made up of carers and genetic-carriers) addressed genetic transmission and reproductive choices. Menstrual and childbirth hemorrhaging were the most common symptomatic issues addressed, yet other psychosocial and quality of life issues appeared that had not been represented in the medical articles. For instance, the prohibition against Fans pain medicine (since they may contribute to bleeding episodes), and the inefficiency of other painkillers in treating pain was often referenced. The fear and anxiety around unpredictable episodes for those not using prophylactic therapy (the majority) was also quite present.

While not engaged in online discussions or peer-support groups, our Italian interview participants mirrored the publicly expressed anglophone concerns. All of our participants expressed concerns regarding the lack of knowledge around women and BDs in the general medical population. Many had also experienced issues regarding specific BD complications that

arise for people with female reproductive systems. Temporal issues such as negotiating concerns, anxiety and risk, as well as negotiating the sick role were also very present in the interviews.

Methods

From the fall of 2015 to spring 2016 we conducted 32 semi-structured interviews in northern Italy that were distributed fairly evenly between healthy and affected carriers of BDs. Twenty of our participants were symptomatic. We interviewed 6 healthy carriers of Hemophilia A, 5 healthy carriers of Hemophilia B, 3 mothers of children with VW (one which had Hemophilia C), one mother of a child with factor XIII deficiency, 4 symptomatic carriers of Hemophilia A, 7 women with Von Willebrand's disease (VW), 2 women with Hemophilia C (factor XI deficiency; one who was also had a child with VW), one woman with Glanzmann's disease, one woman with factor VII deficiency, and one woman with factor XIII deficiency. The interviews, which lasted between 45 and 90 minutes, covered diagnosis and communication, personal experience with BDs, heredity and reproductive themes. Participants were recruited through a snowball method including patient association contacts. The participants were informed about the scope and focus of the project both in writing and in person before they agreed to participate. Informed consent was then obtained from participants, and pseudonyms were used throughout to maintain their anonymity.

Our interview questions were informed by anglophone BD associations and online platforms that address symptomatic women, including closed FB groups. Closed groups were presented with a description of the project as part of the process of requesting admission to observe, and the one quote pulled out was approved by the anonymous participant. Material from social (scarce) and medical sciences was also drawn on. Our perspective was also informed by consultation with a multi-disciplinary team (Psychology, Philosophy, Hematology, Social Studies of Medicine, Patient Association members) that has an over ten-year collaboration regarding BD experience and treatment (see Brigati, Emiliani 2013).

The transcribed interviews were analyzed through a situated analysis (Clarke 2005) that intended to reproductive framing with regards to BD experience. The analysis was supported by a social studies of science perspective that draws on various considerations of the limited social research on BDs (Brigati, Emiliani 2013; Davidson 1999; Pemberton 2011;

Resnik 1999; Wysocki 1998), genes and hereditary (Billings, Rothstein, Lippman 1992; Clayton 2003; Nelkin, Lindee 1995), as well as biomedicalization and biosociality (Clarke *et al.* 2003; Rabinow 1999). As the sample size is not exhaustive as BDs are rare, we do not pretend that this sample represents all women or people with XX chromosomes with these experiences.

Diagnostic time-lag. "Why is it that, more often than not, docs and nurses haven't even heard of us?"

Women with BDs can experience a long time-lag between initial symptoms and diagnosis. While literature on gender bias in healthcare highlights a general tendency to underestimate and underdiagnosis female suffering (Hamburg 2008), here the problem lies deeper in the gendered understanding of diagnostic categories. Diagnosis marks the experiential break between negotiating mild or severe unpredictable symptoms and having a care regimen that can erase the symptomatic impact of the disease. Even after diagnosis women may occasionally encounter non-specialist medical professionals who do not take their diagnosis seriously or continue to deny the possibility that women can have BDs. While the experiences related by our older participants seem to indicate that this was the standard experience with newly encountered medical professionals (even with some experience with BDs) up through the 1980s, this kind of experience was related by younger participants as a negative exception.

There is no one single path to diagnosis, which also highlights a lack of protocol and awareness around female BDs. Eight of our participants were diagnosed within a year of their first symptoms (40%), four within 3 years (20%), while the remaining eight waited 5 or more years (40%). Sometimes episodes were severe enough to draw the necessary attention to the issue right away, yet in other cases even severe symptoms were overlooked.

Of those who received the diagnosis within a year, all but one were directly following a significant episode, all of different nature. Four had severe childhood symptoms, from epistaxis to internal bleeds. Three of these women received their diagnosis before 1970 when BDs were still seen as untreatable. As one participant indicated: «When I heard them talking about it, with my mother and my father, (they said) that I unfortunately would not be able to survive my period and that in a nutshell I would die» (#18; Symptomatic carrier Hemo A, age 67).

Younger patients will not be met with the same unrealistic negative prognosis, yet the pathways to diagnosis can still be complicated. In one case the initial blood exams did not indicate a BD despite the internal hemorrhaging, but luckily the GP insisted on further testing.

> The hematologist of Hospital X told me that my daughter was healthy and had absolutely no problem of that kind. Evidently our GP suspected something, without knowing the type of disease because it is still very rare, and had the insight to make us take further exams, and in fact it was the right thing[4]. (#10; VW, age 27)

In one particularly dramatic case a girl started to hemorrhage during a nose operation, but fortunately the surgeon had some experience with BDs and was able to control the bleeding and put the family in contact with the local BD treatment center. Of the two other participants who were diagnosed relatively quickly, one woman discovered her BD after a menstrual hemorrhaging, and one received the diagnosis through blood exams for the contraceptive pill.

For the four women who received their diagnosis within three years of the first symptoms, the lag was due to a combination of not recognizing symptoms, and non-specialists not suggesting testing for BDs.

> I was diagnosed because in Puglia newborn babies' ears are pierced to highlight femininity […] it wouldn't heal, and continued to bleed. My parents gave up then, but three years later tried to pierce my ears again and there was the same problem, so I took blood tests and the pediatrician directed us to Bari[5]. (#24; factor XI deficiency; age 40)

One family saw several different types of medical figures before a BD test was suggested.

> At about six months she had started to have small specks on her skin, which seemed small moles […] The journey started there […] From the dermatology to allergology […] a clotting problem emerged, and from there we went to the center of angiology, where we investigated further, and the von Willebrand factor soon emerged […] only around three, three and a half years old, we arrived at a definitive diagnosis[6]. (#19; Hemo C, age 40)

Two of our participants were eventually diagnosed only after their sons had been diagnosed (within three years of age), yet both had had significant post-partum complications. In such cases, the diagnosis becomes an explanatory tool that reconstructs past difficulties.

> Then I had a cesarean and I saw patients in the room with me that after three or four days began to walk quietly around the room, breast-feeding… but it took me at least two or three days to get out of bed, I couldn't breast-

> feed, because even placing the baby on my belly hurt me, I was hurting all over. But the doctors said that it was normal because I had surgery and they were already giving me painkillers […] A nurse didn't want to give me (other painkillers) at all […] she humiliated me saying: "I have never seen a person feel so bad after a cesarean". I, in hindsight, discovering that I have this blood problem, coagulation, it probably took me a lot longer to recover, regarding both pain and healing[7]. (#26; Symptomatic Carrier VW type I, age 37)

One our participants didn't connect her post-partum hemorrhaging to the disease despite a significant family history with the disease because even she was unaware that women could have symptoms.

> When I was young, I didn't have anything special, until I got pregnant and I gave birth to M and had a post-partum hemorrhage that no one could understand […] I went to the emergency room three times and they sent me home, and I was bleeding, then I went to a private doctor and he gave me an admission card, otherwise they would not have admitted me and I would have been dead in a few words […].
>
> Because it was not clear that we could be carriers, it was clear that my brother had it, that we knew before […] We didn't have even the slightest idea we were, it was not in our minds, because if we think about it now, Mom was a carrier, all three of us could be actually[8]. (#33; Symptomatic carrier Hemo A, age 58)

Despite the post-partum hemorrhaging, her family history with BDs didn't become relevant to her GP until her son started having symptoms.

> Instead M, when he was a little child, you know kids, they began to fall, and from there the pediatrician told me that we would have to take a test … because I have always said that we have this thing in the family. We should have already taken the test, but I always said, "I don't believe it, its not possible". Instead then we took the test and it turned out that he is also a carrier of this disease, and from there my anxiety as a mother began[9]. (#33; Symptomatic carrier Hemo A, age 58)

The idea that BDs are a male disease can obscure not only the medical interpretation of BD symptoms, but also the individuals' perception of their own symptoms. While the majority of our participants had heard of Hemophilia in school, none had known about VW or that women could have BDs until they experienced it themselves (excluding those who had been diagnosed very young). One of our participants who had to wait more than 5 years for a diagnosis indicated that the problem involved doctors specifically not following through on coagulation tests because they were female.

> I wouldn't stop bleeding, I didn't know if I had cut my lip, so the doctor said it was strange that I didn't stop bleeding, and told us to go have some tests

> because I could have some problem. So they took me to hospital Z and there they told me that because I was female could not be hemophiliac and didn't investigate further[10]. (#10; VW, age 27)

It wasn't until 5 years later when she had an internal hemorrhage and was hospitalized that they finally gave her the blood tests that lead to the BD diagnosis.

For the other seven women who went many years before receiving a diagnosis, two were diagnosed after the diagnosis of their fathers and subsequent family testing, one indicated the menstrual hemorrhaging became debilitating enough to seek a specific cause/solution, one was diagnosed randomly by a medical colleague (she was nurse), one had routine blood tests and one specifically moved to Italy to find a name for her reoccurring problems.

As we have seen, menstruation and/or reproductive issues may be some of the most pronounced reoccurring problems for women with BDs experience, yet heavy menstruation alone is not always enough to push doctors or the woman herself to seek a BD diagnosis or even medical attention. As one participant indicates:

> I have always had heavy bleeding during menstruation, but it has always stopped, so I thought that was just how I was. I never questioned it, I never had hemorrhages (besides menstruation)[11]. (#6; VW, age 29)

In total four of our participants received their diagnosis after a male relative was diagnosed, two sons and two fathers. By pure coincidence, neither of the two daughters had lived in the same city with their father, and had not had a clear experience of the severity of their father's symptoms. Both had to be pressed to talk about their own symptoms, which seemed to appear in their memories as after-thoughts or normal episodes. Some participants engaged clear strategies to distance themselves from the disease identity. For instance, one when asked about symptoms only mentions the preparation needed for a tooth removal, while throughout the course of the interview a long period of frequent epistaxis and significant post-operative hemorrhage emerge.

A handful of our participants indicated that not only had they waited several years for diagnosis, but that even with a diagnosis there could still be problems. Two of our participants indicated that even in an emergency situation they prefer to go to the BD center (40km and 50km from where they live), instead of the nearby emergency room because of repeat experiences of lay medical practitioners telling them that women cannot have BDs.

Gender bias has muddled the history of diagnostic category itself, but also impacts the medical consideration of the gravity of symptomology. In the following section we describe the double complication of BDs and the female reproductive system.

Menstruation and reproductive issues

Symptomatology, or the practical experience of BDs, is not necessarily the first thing our participants referenced when addressing their own experience of BDs. Whether or not one has received a diagnosis obviously makes a huge impact on how actual episodes will develop. While women with BDs remain strangely invisible to non-specialist medical practitioners, the female reproductive cycle is ever present and creates specific symptomatology. Childbirth is a particularly risky moment for women with BDs; extremely manageable once diagnosed, potentially deadly if not. Menstruation can become a cyclical risk, for some manageable through hormonal contraception (the pill), requiring increased attention for others. For ten of our participants (50%), menstruation presented itself as a significant problem at some point in their lives.

Early anthropology addressed the social regulation of the biological event of menstruation, as well as the cultural currency of menstruation in different societies, either as taboo, pollutant, or even as a powerful spiritual entity (Buckley, Gottlieb 1988). "Modern" societies seem to maintain some level of taboo around menstruation (Spadaro, d'Elia, Mosso 2018; Thomas 2007), including implicit social rules that also influence perceptions of menstrual disorders (O'Flynn 2006). Visual art that explicitly evidences this bio-event will be censored, and menstrual product commercials are often so euphemistic as to obscure the subject of the product itself (women running in fields, etc.; see Del Saz-Rubio, Pennock-Speck 2009). The lack of formal sex education in Italy (Beaumont, Maguire, Schulze 2013) can contribute to a general lack of knowledge about expectations for menstrual quantity and frequency (Garside, Britten, Stein 2008). Fruzzetti *et al.* (2008) observed that Italian women do not regard menstruation as a comfortable topic. The social perception of menstruation is an ongoing area of investigation (see Delaney, Lupton, Toth 1988; Laws 1990; Beausang, Razor 2000).

In order to address to the lack of public dialogue surrounding menstruation, a Canadian women's BD association advocated putting notices on

menstrual products informing women that they might have a BD if their cycle was extremely heavy or prolonged. The association fears not only that most women may not know about BDs, but also that they may not talk about the length or typology of their periods in general, and therefore do not receive much feedback from their peers.

In our interviews, in contrast with research on Italian women's comfort level in discussing menstruation (Fruzzetti *et al.*, 2008), almost all of our participants had talked to several people about the length or severity of their menstrual cycle (some only with family members). Only one indicated that it was a subject not to be talked about in her household. Significantly however, the majority of our participants reported some irregularity or problems with their menstruation, yet this symptom lead to diagnosis only for two of them.

Communication with others didn't always draw out the severity of their symptoms. Participants expressed ambiguity gaging what is "normal" regarding both cycle length and heaviness. A few stated that they had very heavy cycles but that for they didn't identify it as a problem.

> I have always had heavy bleeding but it was menstruation, and it has always stopped, so I just thought that is how I was. I never even asked the question, I have never had significant bleeding problems. (#6; VW, age 29)

Most participants had cycles that require some form of treatment, yet options are limited. Hormonal contraception was effective for around half of our participants, yet the pill does not always work as expected for everyone.

> They told me that the pill is good for von Willebrand, a kind of cure. Actually I need to stop taking it because it always makes me feel bad. Now its 10 days from when it should have my period and I already have it […] I never had these irregularities. I had my very abundant cycle […] I have already switched three (types of contraceptive pills)[12]. (#6; VW, age 29)

Or can bring significant side effects:

> So I took the pill and after I was fine because it regularized my (menstrual) flow, the flow was soft, even though it ruined me in another way because these ovarian cysts formed[13]. (#35; Deficit factor VII, age 59)

Another option is regular therapy with coagulation factor, either at the clinic or through self-infusions. In any case, as the following participant explains, the most useful therapy can change over the years and knowledgeable medical support is essential.

> The problem, even now, is menstruation. I had some pretty good years, with the pill everything was under control. Now menstruation and this disease

> are one, so I've had several hemorrhages, last year was especially bad […] even with the pill, it didn't work (anymore), I kept changing the pill for 6, 7, 8 months and I continued to drip, I always had leaks, it was exhausting and frustrating. At one point I said, "enough, the pill does not work for me", and they told me I could stop, but that I could not bleed continuously and had to learn to self-infuse and take Haemate P each month […] I have come to peace with this aspect. I'll take Haemate P with me and I'll be free[14]. (#10; VW, age 27)

Before the pill or coagulation therapy the menstrual aspect of bleeding disorders was a desperate unknown, often accompanied by fears of traumatic prognosis.

> In fact, the morning I got up and had my first period, I realized I had my period, I started to cry and said I did not want to go to the hospital because I wanted to die at home […] Instead everything was resolved by going to X and having a transfusion […] My brother was nine and a half, and he came up to the room and said to me, "but you're dying?". I said, "why?", And he says, "because Mom and Dad are downstairs and crying and not speaking"[15]. (#18; Symptomatic carrier Hemo A, age 67)

Yet, even now menstruation represents one of the unpredictable aspects of BDs.

> Because when she has her period, being female, when her period hemorrhages, we go often go to hospital X. She's at that age, in fact it's not regular, not very regular, and we are always on the alert: "will come it or not?". It's complicated […] there are times when we don't think about it because she leads a normal life, doesn't have her period, nothing happens. Her period has become a thing we're getting used to […] But you are always waiting for it, when it comes you know you have to be careful if there is a severe hemorrhage[16]. (#14; Mother VW Type III, age 48)

For some, menstrual hemorrhaging simply worsens with age, to be resolved either by menopause: «I went through menopause naturally […] I'm very happy, because for me my period had become a nightmare[17]» (#17; VW, age 50); or a hysterectomy. Three of our participants (who already had children) had had hysterectomies due to BD complications that the various therapies (including the pill) could no longer resolve. Most of these women were older (ages 51, 66, 67), yet not all of the hysterectomies occurred before there were modern coagulation treatments (in 1971, 1998, 2008). One participant describes her hysterectomy as a final therapy after all others had failed:

> The pill, no. I tried it, but it didn't work […] The spiral worked for a few years, now I do not remember exactly. When it was time to change it, I had a continuous flow and ended up in the hospital two or three times, and after

> I said "enough, this is the only solution, let's do it". Ah, there weren't […] they didn't propose other solutions[18]. (#32; VW, age 51)

One of our participants described the resistance of the gynecologist in granting her hysterectomy because she was young.

> The gynecologist said, "but to have an operation like that, really, you are young", I was 25 years old, "you risk losing your mind", and my doctor said, "No, she won't lose her mind, I'll explain the situation to her,". And he told me […] "listen to me, they say these things, that the woman goes crazy, but don't believe it, because it is not true. The only thing you can't do is have more children, for the rest, you can live your life normally. With a difference: you'll be better" … I already had a daughter, and it (the hysterectomy) never bothered me[19]. (#18; Symptomatic carrier Hemo A, age 67)

Hemorrhaging related to the female reproductive system remains among some of the most significant symptoms for women with BDs, creating a large area of concern that the better recognized male category does not experience. Gender bias and a historical focus on XY forms of hemophilia clearly obstacle the treatment path. What emerges from our interviews is not a communicative taboo surrounding menstruation, but rather around identifying (are heavy periods normal?) and claiming suffering. Qualitative studies of menstrual disorders indicate women «feel under pressure to conceal their symptoms» (O'Flynn 2006: 955). As we will also see in the next section, women may alternately down-play the severity of their suffering, or feel confined by the request they "prove" their suffering. These themes clearly cross both social framings of the gendered body and invisible disability.

Negotiating the sick role

Several issues arise in the description of many BDs patients experience with the disease: negotiating "sickness time" (Toombs 1990); the unpredictability of episodes; weighing risk prevention against personal freedom; and creative descriptions of their diagnosis to friends and acquaintances. Here it may appear useful to divide the group into those who have experienced severe symptoms and those for whom the diagnosis is primarily a risk factor (either because they have not had serious symptoms, they have not had surgery or given birth, or their therapy holds the symptoms at bay).

Yet, it has to be noted that the anxiety surrounding risk does not seem to be proportional to the severity of symptoms one has experienced. Some participants had severe symptoms and expressed little anxiety; while others

had practically no symptoms and a very high level of anxiety regarding risk. The disease is presented by even those who have hardly ever had symptoms as always lurking in the background waiting to strike, «risk and anxiety»[20] (#25; Symptomatic carrier Hemo A, age 45), potentially interrupting the flow of daily life, regardless of how frequent episodes may be. Beyond the anxiety surrounding risk, the unpredictability of episodes breaks the flow of everyday life, creating pockets of "sick time".

> Perhaps in daily activities, in the sense that if I'm doing X and a hemorrhage happens, I have to leave what I'm doing […] it's like a roommate: it's there, and sometimes it makes its presence felt. Let's say it doesn't have first place in my self-image[21]. (#11; VW, age 27)

The unpredictability of bleeding episodes presents itself as a symptom in its own right.

> So therefore, figuring out what is happening and understanding how to act when there is something […] it's always an unknown, because when you start to bleed you don't know how long it will last, this is what makes me a little anxious[22]. (#29; Mother VW, age 45)

As one woman observed, the uncertainty (rather than the bleeding episode itself) creates anxiety: «The worst thing about von Willebrand disease is that one is never fully aware of the seriousness of what is going to happen» (#16; Von Willebrand Type II, age 31).

For those with serious symptoms, particularly older patients, these temporal interruptions implicate further practical issues to be negotiated.

> Because I was never at school, I was always at the hospital. You can only imagine if my parents, we lived in a village near here, were going to send me cycling to town everyday with the risk […] and so school definitely (suffered) […] then I had to adapt, because with only a fifth-grade education you can't do much[23]. (#18; Symptomatic carrier Hemo A, age 67)

When discussing the impact the disease had had on their lives, the majority of our participants referenced this worry surrounding risks, but also the negotiation of decisions not to limit themselves regarding physical activity and other potentially dangerous activities.

> In reality over time, I actually tried to force myself to go back to doing everything, once I even went canyoning with my father […] And so I was a little reassured, telling myself that after all I could do anything, if I do things others don't I'm not doing that bad[24]. (#6; VW, age 29)

This negotiation of physical activity can be particularly complicated regarding children. Some parents severely limit the physical activity of their

children due to the anxiety surrounding risk (not the gravity of experienced symptoms).

> In the sense that they [her parents] relied a lot about what the doctors said, so for example sport had always been forbidden, and therefore at school, while the others were doing PE I just watched. Then growing up I saw that there were no serious problems, and I started to play sports on my own, without asking anyone advice because they would have said no, so[25]. (#24; Hemo C, age 40)

Others try to allow for their children to have an active life despite having experienced severe episodes.

> The anxiety appears, though I try not to […] even when she is hurt or is in pain, I always play it down […] But I'm not one who wouldn't let her go out because I'm afraid … she plays sports […] even though she has passed out when she has her period […] Then I think about tomorrow, when she has kids, or an emergency operation. And there, the thing worries me[26]. (#14; Mother VW type III, age 48)

Four of our participants referenced having been limited in their childhood, two with severe symptoms and two without.

> But that period was devastating for me. The school years […] Now it seems, but come on, what importance does a game have, but because now I'm big and adult. But tell a child that they can't play a game, or if they want to go on a trip […] I could not understand why I couldn't go on a trip […] but it was right that I couldn't go, if anything happened who would take responsibility[27]? (#35; Deficit factor VII, age 59)

Several other issues that our participants addressed revolved around risk and worry. One referenced the still present fear of infected blood, five talked about surgery, two addressed fears that it could get worse in the future, four referenced fears surrounding accidents and two stated that they limited their travel.

What emerges as particularly interesting is that this multifaceted aspect of risk and anxiety was presented much more frequently as the impact of the disease on their lives, as opposed to episodes themselves. For one woman in particular, the disease revealed itself as a complication in other pressing health events.

> More than anything if I hadn't had all these operations I would almost have never noticed (the BD). Apart from my period and the end of my period, that is. But these things gave me some anxiety, oh no, the hemorrhaging, the operating room […] If I had not had all these surgeries, no. I don't take any medicine, nothing, and I'm fine[28]. (#32; VW, age 51)

BDs do not represent an omnipresent issue for most, but can appear at unpredictable moments, or represent risks in determined activities. As we noted earlier, some with little experience of symptoms still feel the risk associated with BDs very strongly. Those with severe symptoms negotiate this presence of risk along with the regularity of the symptoms themselves. In the following section we discuss how our participants negotiate their symptoms with the people they interact with.

Social studies of genetics in society have addressed a lot of attention to the relationship between a genetic diagnosis and individual identity (Taussig *et al.* 2003). For BDs the genetic aspect of the diagnosis hangs in the background, implied but not always actually tested for. The genetic aspect is relevant to reproduction, yet had not had a significant impact on the reproductive choices of the women we interviewed. All participants were in favor of the legal right to voluntary termination of pregnancy, but did not feel BDs warranted termination. Only one participant (non-symptomatic parent of a child with severe symptoms) had considered other selective reproductive technologies such as pre-implant diagnosis (only legal in Italy for those with a documented hereditary genetic disease). While we do not have the space to do justice to the complexities of identity, genetic, disease and reproductive choices, we can reflect further on how our participants distance themselves from identifying with the disease. Despite the ever-present liminal risk, the vast majority of our participants specifically stated their BD was not part of their identity, and they did not seek out others with similar experiences (such as patient groups).

The majority of our participants had told something to their friends or other people in their lives, employing different strategies of disclosure. Interestingly, those who had experienced life-long severe symptomatology were more likely to hide their symptoms, particularly from their colleagues. In some ways this aspect mirrors the inverse relationship we found between anxiety and risk (those that had severe symptoms had less anxiety surrounding potential episodes), yet also reflects the trope of "being strong" in the face of chronic physical issues.

Some of the women with severe symptoms shared their experiences with their colleagues while still preferring a certain level of independence.

> Yes, because I'm independent […] I always have Humate-P with me, so I can infuse myself. I do not have to explain anything to anyone, because interactions with other doctors outside of hospital X are always a little difficult […] I went home, I took the Humate-P and then I went back[29]. (#10; VW, age 27)

Two others instead, who are both nurses and older, reported hiding their symptoms or physical issues from their colleagues, not wanting to be treated differently or provoke special treatment. Instead of "proving" their invisible suffering, they embraced the invisibility. One woman's colleagues found out about her BD only after a significant hospital stay.

> They asked me why I had not said anything before […] I had to be hospitalized after an emergency and then they found out […] I didn't want to feel different from the others, or watched out for because I had this problem[30]. (#35; Deficit factor VII, age 59)

Another woman with fairly regular symptoms chose not to tell her colleagues anything based on their reactions regarding children bleeding at the school she works in. She creatively explained her episodes to co-workers and friends as "fragile capillaries".

> And that's why I decided not to disclose it, because I saw adults who were not able to handle it […] Yes, I stay at work, much to the chagrin of my parents […] Maybe this denial to others is wrong, sometimes I tell myself that maybe I should talk about it like any other illness, a tumor […] I also hate compassion, it is something that makes me angry […] It would really annoy me because I consider myself normal, like everyone else, so I'm convinced of my choice (not to tell anyone)[31]. (#13, Glanzmann's Disease, age 43)

Only two of the participants explicitly expressed a fear of stigmatization due to their BD, specifically regarding prejudice surrounding blood borne diseases. However, many expressed the desire to hide their sickness or be independent within their disease experiences, and therefore not be subject to pity or compassion. Fear of being stigmatized as "out of the order of things" is mitigated by embracing the invisible aspects, as well as not identifying with the disease. The relevance women with BDs give to their suffering is also tangled in the low priority medicine and society give to complications related to the female reproductive system. It will be interesting to see if bio-sociality grows around this experience in Italy as it is in the anglophone context.

Conclusions

Several people responded quickly to the FB post we cited in the introduction (in which a VW patient wonders why more doctors don't know about the disease) to voice their frustration on this hot topic. Our findings confirm that diagnostic lag is a primary issue for Italian women with BDs, even in the absence of bio-social networks in which to voice these concerns.

Medical publications may acknowledge the phenomena, but do not address the problem with the same frequency as BD suffers themselves. For women with BDs, diagnostic lag is directly correlated to gender bias in the diagnostic conception, that in turn overlaps with gender bias in medicine regarding female reproductive related suffering, and further with invisible disability experience.

BDs present many particular issues for women due to aspects of the reproductive system, which are often treatable or avoidable *if diagnosed*. The vast majority of our participants have had, or continue to experience, problems tied to their reproductive system. Menstruation and childbirth can be difficult in general, and there appears to be difficulty in assessing both clinically and subjectively when the situation might indicate a BD. Research in parallel arenas of menstrual disorders indicate that women downplay or creatively communicate menstrual or reproductive suffering.

Our participants engaged in creative communication strategies that appear to reflect fear of being stigmatized for being perceived as unwell, or out of the order of things. One participant expressed a perceived stigma around blood, but not menstruation (beyond the general social expectation to hide the event). Anxiety surrounding the unpredictability of episodes was presented as the most present aspect of BDs, while symptoms (once diagnosed) might be kept largely at bay. The majority of our participants were happy to downplay their sick role, and leave co-related disabilities invisible. Those with severe symptoms expressed a strong desire for independence and not being limited, while some specifically hid the diagnosis from others to avoid "special treatment".

All of the areas we have addressed beg further study. As indicated by patient associations, there is a need for further general and medical education specifically on women and BDs. In addition, further psychosocial research is necessary to understand how to move beyond just acknowledging the diagnosis into promoting the quality of life of women with BDs.

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Notes

(1) https://fedemo.it/chi-siamo/; The 'pink window' (finestra rosa) project that ended in 2017 was oriented to female family members, not the directly afflicted.

(2) Such as the European *Women and Bleeding Disorders Committee of the European Haemophilia Consortium* https://www.ehc.eu/women-and-bleeding-disorders-committee/ started in 2018 (after our research), or sections that address von Willebrand disease (VWD) such as in the American and UK Hemophilia associations. Recent years have also seen the expansion of campaigns such as Talking Red https://haemophilia.org.uk/support/talking-red/.

(3) https://www.fwgbd.org/about (last viewed 5 October 2022).

(4) Perché l'ematologa dell'*Ospedale X* mi ha detto che mia figlia era assolutamente sanissima e non aveva nessun problema di quel tipo. Evidentemente il medico generica aveva avuto un sospetto pur non conoscendo il tipo di malattia perché comunque è molto raro e ha avuto l'intuizione di farci fare questo ulteriore approfondimento, e in effetti era la cosa giusta.

(5) La diagnosi è avvenuta perché in Puglia si usa fare i buchi alle orecchie ai bimbi appena nati per delineare la femminilità […] non si cicatrizzava, continuava a perdere sangue. Poi i miei genitori hanno lasciato perdere, a tre anni hanno riprovato a fare i buchi e c'era sempre lo stesso problema, per cui abbiamo fatto il prelievo del sangue e il pediatra ci ha indirizzato a Bari.

(6) La bimba verso i sei mesi aveva iniziato a mostrare delle piccole macchiette sulla pelle, che potevano sembrare dei piccoli nei […] Da lì abbiamo iniziato un percorso […] Dalla dermatologia siamo passati all'allergologia […] è emerso che c'era un problema legato alla coagulazione, e da lì siamo passati al centro di angiologia, dove abbiamo approfondito la cosa, e in poco tempo è emerso del fattore von Willebrand […] solo verso i tre anni, tre anni e mezzo, siamo arrivati ad una diagnosi definitiva.

(7) Dopodiché si procede con il cesareo e io vedevo le pazienti in camera con me che dopo tre o quattro giorni cominciarono a camminare tranquillamente per la stanza, allattavano […] io invece c'ho messo sicuramente almeno due o tre giorni per alzarmi dal letto, non riuscivo neanche ad allattare, perché solo il fatto di appoggiare il bambino sulla pancia mi faceva un gran male, mi faceva male dappertutto. Però i dottori dicevano che era normale perché avevo fatto l'intervento e mi stavano già dando l'antidolorifico […] Ma un'infermiera non me la voleva dare (altri dolorifici) a tutti i costi […] lei mi ha umiliata dicendomi: "non ho mai visto una persona stare così male per un cesareo". Io, col senno di poi, scoprendo che avevo questo problema al sangue, della coagulazione, e quindi molto probabilmente ci ho messo molto più tempo a recuperare, sia per il dolore sia per la guarigione.

(8) Però nella mia gioventù non ho sentito niente di particolare, finché sono rimasta incinta e ho partorito M e ho avuto delle emorragie post partum che nessuno riusciva a capire […] Sono andata al pronto soccorso tre volte e mi hanno mandato a casa, e io avevo le emorragie, allora sono andata da un professore privato e lui mi ha fatto la carta di ricovero, sennò non mi avrebbero preso e io sarei già morta in poche parole […].

Perché non era tanto chiaro che dovevamo essere delle portatrici, era chiaro che mio fratello ce l'aveva, quello lo sapevamo prima […] Non abbiamo neanche minimamente pensato che fossimo, non era nel nostro pensiero, perché se ci pensiamo adesso, mamma era portatrice, potevamo essere tutti e tre effettivamente.

(9) Invece M anche lui quando era piccolino, sai i bimbi piccoli, ha iniziato cadere, e da lì c'era il pediatra che mi ha detto che avremmo dovuto fare un esame… perché anche lì ho sempre espresso che abbiamo questa cosa nella famiglia. Però avremmo dovuto fare l'esame, e io ho sempre detto: "ma io non ci credo, non è possibile". Invece poi abbiamo fatto questo esame ed è saltato fuori che lui è un portatore di questa malattia, e da lì anche la mia ansia come madre ha iniziato.

(10) Io non smettevo di sanguinare, non so se avevo una ferita al labbro, quindi la dottoressa disse che era strano che non smettevo di sanguinare, e quindi ci disse di andare a fare qualche ricerca perché potevo avere qualche problema. Quindi mi portarono a Ospedale Z e là mi dissero che siccome ero femmina non potevo essere emofilica e non fecero ulteriori ricerchi.

(11) Io nella mia vita ho sempre avuto forti emorragie ma per le mestruazioni, che però si sono sempre fermate, e quindi pensavo fossi io predisposta. Non mi sono mai nemmeno posta la domanda, non ho mai avuto grandi problemi emorragici.

(12) Mi hanno detto che per il von Willebrand la pillola fa bene, è una sorta di cura. In realtà dovrei sospenderla perché mi porta a stare sempre male. Adesso che sono a 10 giorni da quando dovrei avere il ciclo ho già il ciclo. Quindi magari passo 15 giorni col ciclo e 15 senza […] con la pillola. Senza io non ho mai avuto questi sbalzi. Avevo il mio ciclo molto abbondante […] ne avrò già cambiate tre.

(13) Poi ho preso la pillola e dopo mi sono trovato bene, perché comunque mi ha regolarizzato il flusso, il flusso per me era soft, anche se mi ha rovinato dall'altra parte perché si sono formate queste cisti ovariche.

(14) Dopo il problema, e anche adesso lo sono, sono le mestruazioni. Ho fatto degli anni abbastanza buoni, anche con la pillola riuscivamo a tenere tutto sotto controllo. Adesso le mestruazioni e questa malattia fanno comunella, quindi mi è capitato di avere emorragie, soprattutto l'anno scorso è stato molto pesante…. anche con la pillola, che non ha funzionato, quindi ho continuato a cambiare delle pillole per 6, 7, 8 mesi e ho continuato a sgocciolare sempre, ho avuto perdite sempre, quindi è estenuante e frustrante.

A un certo punto ho detto: "basta, la pillola con me non funziona", e allora mi hanno detto che potevo stare senza, però non potevo avere emorragie continuamente e quindi dovevo imparare ad autoinfondere e a fare l'emate ogni mese […] Ho fatto un po' pace con quest'aspetto. Prenderò il mio emate p con me e sarò libera.

(15) Infatti io quella mattina che mi alzai e avevo le mestruazioni, mi accorsi di avere le mestruazioni, mi misi a piangere e dissi che non volevo andare in ospedale perché volevo morire a casa […] Poi invece si è risolto andando a X e facendo delle trasfusioni […] il mio fratello ne aveva nove e mezzo, lui venne su in camera e mi disse: "ma stai morendo?". E io: "perché?", e lui: "perché la mamma il babbo stanno giù e piangono e non parlano".

(16) Perché quando ha il ciclo, essendo femmina, quando ha il ciclo forte le vanno in emorragia e quindi siamo andate spesso giù al Sant'Orsola.

È nell'età proprio clou, infatti non sono ancora regolari, non sono regolarissime, ed allora siamo sempre allerta: "Arriveranno o non arriveranno?", è abbastanza complicata la cosa […] cioè, complicata, dipende, ci sono dei periodi che non ci pensi neanche perché proprio fa una vita normale, non ha il ciclo, non succede niente. Il ciclo adesso è diventata una cosa diciamo abituale […] Però te l'aspetti, quando arriva il ciclo sai già che devi stare attenta se arriva l'emorragia forte.

(17) Sono entrata in menopausa naturalmente […] Sono molto contenta, perché per me il ciclo mestruale era diventato un incubo.

(18) La pillola no. Ho provato ma non funzionava […] Con la spirale sono andata bene per un paio danni, adesso non mi ricordo esattamente. Poi quando è stato il momento di cambiarla avevo proprio il flusso continuo e sono finita all'ospedale due o tre volte, e dopo ho detto "basta, l'unica soluzione è questa, facciamolo". Ah, non c'era […] non mi hanno prospettato altre strade.

(19) C'era il ginecologo che diceva: "ma andare a fare un intervento del genere, insomma, è giovane", io avevo 25 anni, "si rischia che vada fuori di testa", e il mio professore diceva: "no, fuori di testa non ci va, adesso gliela spiego io com'è la storia", e lui mi disse: "ascoltami, dicono così, che la donna perde (il senno), ma tu non ci credere a questa cosa, perché non è vero. L'unica cosa che non puoi fare sono altri figli, il resto, puoi vivere la tua vita normalmente. Con una differenza: che starai meglio". Queste furono le sue parole, e aveva ragione. Io una figlia ce l'avevo già, e non l'ho vissuta così male la cosa.

(20) Rischio e l'ansia.

(21) Forse nelle attività quotidiane, nel senso che se sto facendo X e mi capita un'emorragia devo lasciare quello che sto facendo […] è come un coinquilino: è lì, ogni tanto si fa vedere. Diciamo che nell'immagine che io ho di me non è al primo posto.

(22) Quindi capire di che cosa si tratta e capire come agire quando c'è qualcosa […] È pur sempre un'incognita, perché quando incominci a sanguinare non sai quanto tempo dura, è quella la cosa che mi mette un po' in ansia.

(23) Perché io a scuola non c'andavo mai, ero sempre all'ospedale. Allora non si poteva evitare, figurati se i miei, noi abitavamo in una frazione qui vicino, mi mandavano in tutti i giorni in bicicletta in paese a fare le medie con il rischio che […] e quindi quello scolastico sicuramente […] poi dopo ho dovuto adeguarmi per forza, perché avendo una quinta elementare non è che puoi fare chissà cosa.

(24) Poi in realtà col tempo ho cercato di forzarmi a ricominciare a fare tutto, una volta sono anche andata con mio padre a fare torrentismo… E quindi mi sono un po' rassicurata dicendomi che tutto sommato potevo fare tutto, se faccio cose che gli altri non fanno non sto poi così male.

(25) Nel senso che loro si affidavano molto a quello che dicevano i medici, per cui ad esempio la pratica sportiva era stata sempre vietata, e quindi a scuola, mentre gli altri facevano educazione fisica io ero lì che guardavo, e quindi è stato sempre un po' così.

Poi io crescendo ho visto che non c'erano problematiche gravi, e quindi ho iniziato fare sport per conto mio, senza chiedere pareri a nessuno perché tanto mi avrebbero detto di no, quindi.

(26) La preoccupazione viene fuori, però cerco sempre di non […] anche quando lei si fa male o ha dei mali, sdrammatizzo sempre […] Però non sono quella che non la lascia andare in giro perché ha paura… poi anche l'attività sportiva la fa […] anche se delle volte è capitato che quando ha il ciclo sviene […] Poi penso al domani, a quando avrà un figlio, un'operazione d'urgenza. Ecco, lì la cosa mi preoccupa.

(27) Però per quell'epoca per me è stato devastante. L'epoca della scuola […] Adesso sembra, ma dai, che cosa vuoi che sia un gioco, ma adesso è perché sono grande e adulta. Però dire a un bambino che quel gioco non può farlo oppure se vuole andare in gita […] ma non riuscivo a capire perché non potevo andare in gita […] ma perché era giusto che non andassi, se fosse successo qualcosa la responsabilità di chi sarebbe stata?

(28) Più che altro se non avessi avuto tutti questi interventi non me ne sarei quasi accorta. A parte il ciclo e la fine del ciclo, quello sì. Però per tutte queste cose qua che mettono un po' d'ansia, Oddio, l'emorragia, la sala operatoria […] Se non avessi avuto tutti questi interventi, no. Non è che prendo delle medicine, niente, e sto bene.

(29) Si, perché sono autonoma. […] l'emate p ce l'ho sempre con me, quindi lo faccio. Non devo spiegare niente a nessuno, perché il rapporto con gli altri medici fuori dal Malpighi è sempre un po' difficile […] sono andata a casa, ho fatto l'emate p e poi sono tornata.

(30) Loro mi hanno chiesto perché non gliel'avevo detto prima […] mi hanno dovuta ricoverare d'urgenza e quindi dopo lì hanno saputo […] Non mi volevo sentire diversa da un altro, oppure con un occhio di riguardo in più perché avevo questo problema.

(31) E da lì la scelta di non divulgarla, perché ho visto degli adulti che non erano capaci di sostenere […] sì, rimango al lavoro, con grande disappunto dei miei […] forse questa negazione rispetto all'esterno è sbagliata, a volte mi sono detta che forse dovrei dirlo come qualsiasi altra malattia, da un tumore […] poi odio la compassione, è una cosa che mi manda in bestia […] mi darebbe molto fastidio perché io mi considero normale, pari di tutti gli altri, quindi sono convinta della mia scelta ecco.

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Author bionote

Daniela Crocetti was born in NYC, USA on March 6th 1975. Their research has focused on the production and co-production of knowledge in medical settings, with attention to the implications of the gendered body. They are interested in social health movements (Shms) as well as individual narratives, in particular how individuals and groups mobilize to render their experiences valid medical evidence. Crocetti has primarily worked in Italy and the UK, after a childhood in the US. They obtained their master in anthropology in Bologna and went on to a doctorate on the medicalization of Variations of Sex Characteristics (Vsc). Their 2013 book *L'Invisibile Intersex: Storie di Corpi Medicalizzati* [Invisible Intersex: Histories of Medicalized Bodies], Pisa: Edizioni Ets, remains one of the main texts in Italian on medicalization of Vsc. They collaborate with

the association Intersexesiste (founded in 2016) that provides workshops and material on Vsc rights claims. Other relevant work includes: with S. Monro, and T. Yeadon-Lee, *Rhetoric of Change: intersex rights claims, rhetoric and medical practice in Italy* (Rivista Illuminazioni 55: 146-194 2021); and with R. Brigati, *A State of Flux: On Bleeding* (Journal of Literary & Cultural Disability Studies, 10(3):305-321, 2016).

Prof. Laura Palareti was born in Bologna, IT on April 11th 1970. She has been an associate Professor at the University of Bologna since 2019, in the field of social psychology. Palareti's research interests are regard the evaluation of prevention/intervention programs in the socio-educational field, residential communities for minors, chronic diseases such as Bleeding Disorders (BDs) as well as the protective function performed by routines and rituals of daily life. In particular Palareti has studied the psychosocial and relational aspects that involve families and health personnel in the management of congenital BDs. Other relevant work includes: with S. Brondi, and G. Mazzetti, *Comprehensive care for haemophilia: A literature review for improving institutional cooperation* ("International Journal Of Healthcare Management", 14, 402-411, 2021).

Abstract

"Why is it that, more often than not, docs and nurses haven't even heard of us?": Women and Bleeding Disorders in Italy.

Many have heard of Bleeding Disorders (BDs) despite the fact that they are rare diseases, because of the infected blood scandals of the 1990s. As for many diseases that have caught media attention, public understanding is limited. Lay medical practitioners may still believe that BDs are exclusively sex-linked. Women with BDs therefore have a difficult terrain to navigate. We situate our qualitative study of north Italian women with BDs between the social studies of gender bias in healthcare, chronic disease and invisible disabilities.

Keywords: bleeding disorders, hemophilia, von Willebrand, women, menstruation

Resumen

"¿Por qué, la mayoría de las veces, los médicos y las enfermeras ni siquiera han oído hablar de nosotros? ": mujeres y trastornos hemorrágicos en Italia.

Muchos han oído hablar de los Trastornos Hemorrágicos (TH) a pesar de que son enfermedades raras, debido a los escándalos de sangre infectada de la década de 1990. En cuanto a muchas enfermedades que han llamado la atención de los medios, la comprensión pública es limitada. Los médicos legos todavía pueden creer que los TH están exclusivamente ligados al sexo. Las mujeres con TH, por lo tanto, tienen un terreno difícil de navegar. Situamos nuestro estudio cualitativo de mujeres del norte de Italia con TH entre los estudios sociales del sesgo de género en la atención médica, las enfermedades crónicas y las discapacidades invisibles.

Palabras clave: trastornos hemorrágicos, hemofilia, von Willebrand, mujeres, menstruación

Résumé

"Pourquoi est-ce que, le plus souvent, les médecins et les infirmières n'ont même pas entendu parler de nous?": femmes et diathèse hémorragiques en Italie.

Beaucoup ont entendu parler des diathèse hémorragiques (DH) malgré le fait qu'il s'agissent de maladies rares, à cause des scandales du sang infecté des années 1990. Comme pour de nombreuses maladies qui ont attiré l'attention des médias, le grand public en comprend peu. Les médecins non spécialisés peuvent encore croire que les DH sont exclusivement liées au sexe. Les femmes atteintes de DH ont donc du mal a se faire soigner. Nous situons notre étude qualitative sur les femmes du nord de l'Italie atteintes de DH entre les études sociales sur les préjugés sexistes dans les soins de santé, les maladies chroniques et les handicaps invisibles.

Mots-clés: diathèse hémorragiques, hémophilie, von Willebrand, femmes, menstruation