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Published in:
American Journal of Men's Health

DOI:
[10.1177/1557988319872626](https://doi.org/10.1177/1557988319872626)

Publication date:
2019

Document Version
Publisher's PDF, also known as Version of record

Citation for published version (APA):
Reinicke, K., Søgaard, I. S., & Mentzler, S. (2019). Masculinity Challenges for Men with Severe Hemophilia. *American Journal of Men's Health*, 13(4), 1-11. <https://doi.org/10.1177/1557988319872626>

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Masculinity Challenges for Men With Severe Hemophilia

American Journal of Men's Health
July-August 2019: 1–11
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sagepub.com/journals-permissions
DOI: 10.1177/1557988319872626
journals.sagepub.com/home/jmh

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Abstract

Hemophilia is a congenital bleeding disorder that mainly affects men. Men with severe hemophilia experience stigma because they are unable to live up to various ideals of masculinity. This study involves a qualitative analysis of how nine Danish men aged 40–54 years with severe hemophilia manage life as functionally impaired relative to their masculine identity. The analytical focus is on how the men manage on a daily basis, how they construct their identity as a result of the disorder, and the body's importance in these identity negotiations. The source of their biggest defeat is that the disorder often prevents them from living up to social expectations about men as fathers. This results in a variety of management strategies that they apply to neutralize the stigma, allowing them to (a) distance themselves from the disorder in various practical and verbal ways and to (b) assume primary responsibility for managing the disorder, including internalizing being experts on the disorder. The results identify that men with severe hemophilia are frustrated by the lack of advice provided by the health sector. The article proposes initiatives that can be taken to address the lack of knowledge and to create a broader network of peers for men with hemophilia across varying age groups.

Keywords

hemophilia, men's health, masculinity, qualitative methods, dialogue workshop, adolescent men

Received April 21, 2019; revised July 12, 2019; accepted July 31, 2019

The manner in which masculinity affects men's way of managing health and illness has considerable social consequences and remains an inadequately studied research field. Several studies report that gender, or rather the socially constructed *practices* related to the perception of gender, is one of the most decisive factors for issues concerning health (Charmaz, 1994; Coston & Kimmel, 2012; Courtenay, 2000, 2002; Evans, Frank, Oliffe, & Gregory, 2011; Gerschick & Miller, 1995; Madsen, 2014; Reinicke, 2013; Sabo, 2000).

Regardless of socioeconomic status, men generally have poorer health than women and are less likely to seek medical help for mental or physical illness. Men have a lower life expectancy, often dying prematurely (before the age of 65 years) and have an excessive mortality in terms of all major diseases (Evans et al., 2011). It is estimated that only half of men suffering from depression are diagnosed and in treatment, just as men are twice as likely to commit suicide than women and suffer twice as frequently from addiction, such as alcohol abuse (Madsen, 2014). Despite these research results and the considerable

associated social consequences, masculinity and the male gender are inadequately studied as a field in health research and gender research in general (Evans et al., 2011; Madsen, 2014; Sabo, 2000; Sabo & Gordon, 1995).

Little knowledge exists about the correlation between masculinity and hemophilia. Park (2000) was the first to discuss that masculinity played a significant role in men's experience and management of hemophilia. Other research has emphasized that men's masculinity can be compromised by the reduced ability to participate in sports and other risk-taking activities (Diesen & Grut, 2017; Kalmar, 2014; Kalmar, Oliffe, Currie, Jackson, & Gue, 2016). Likewise, studies reveal that men with severe

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hemophilia often value and protect their personal independence and are ambivalent toward support from society, because they, so to speak, have too much masculinity to lose by being patients (Forman, Sogaard, & Mentzler, 2018; Rolstad, 2015).

Hemophilia is a congenital bleeding disorder that predominantly affects men. Most of these patients suffer from severe hemophilia. Hemophilia patients have a blood clotting factor deficiency, either factor VIII (hemophilia A patients) or factor IX (hemophilia B patients), which makes it difficult for the blood to clot and thus hard to stop bleeding (Regioner, 2016). Healthy people usually have a blood factor level of about 100%, while hemophiliacs are divided into degrees of severity from 40% and downward. In 2018, approximately 289 men in Denmark had severe hemophilia, which means that their blood clotting factor is between 0% and 1%. Before the introduction of synthetic clotting factor concentrates, the life expectancy of people with hemophilia was very low, but this changed in the early 1970s, when a new prophylactic drug, that quickly stops bleeding when injected, entered the market (Danish Haemophilia Society, 2013). This innovation meant that a new generation of people with hemophilia would be able to grow up in the hope of a relatively normal life. Despite the new life opportunities the introduction of the new drug created, Danish Haemophilia Society studies (2012) identify that men aged 30–50 years suffer from severe joint damage, severe pain, and reduced quality of life. Due to microbleeding and/or neglecting treatment during adolescence, some men suffer from severe joint damage and pain, many of them functionally impaired to the point that it affects their family and working life. These symptoms cause their quality of life to deteriorate and they experience difficulty meeting the expectations they encounter at this important stage of their lives from the 30s to the 50s. A 2012 quantitative study of quality of life among people with hemophilia (Danish Haemophilia Society, 2013) described that some men become disabled and suffer from restricted mobility due to joint damage and pain. Furthermore, the study illustrated that they experience symptoms already in their 30s, such as stiff joints and a level of pain, which means they have difficulty playing with their children, walking, running, riding a bike, and working.

Research Question

The overall research question concerns how men experience and manage possible challenges caused by both the physiological restriction of mobility and chronic pain—and how those challenges relate to the fact that they are men. The objective is to gain insight into how men live with severe hemophilia, what daily challenges they experience, how this affects their identity as men, and how masculinity

affects their management of the disorder. More specifically, the study is guided by the following questions.

1. How do men with severe hemophilia manage restrictions of mobility and chronic pain on a daily basis?
2. How do men with severe hemophilia negotiate their masculine identity in the context of their mobility restrictions and chronic pain?
3. For men with severe hemophilia, what role does the body play in their identity negotiations?

Masculinity, Physical Disability, and a Chronic Disorder

The theoretical framework of the study is based on Connell's (1995) conceptualization of hegemonic masculinity. This basic theory in masculinity research builds on the fundamental idea that gender and the abilities and practices associated with gender are not biologically embedded but rather part of a social practice. Connell considers hegemonic masculinity as being culturally promoted and as stabilizing a structure of dominance and suppression. This dominance is clearly seen in the unequal power relations between men and women but also among men as part of a hierarchy of historically specific masculinities. Connell points out that there is more than one type of masculinity; in fact, there is a complete structure of various masculinities. In continuation of hegemonic masculinity, Connell discusses complicit masculinities, which are commonly sustained by or characteristic of men who support the ideals pursued by the hegemonic man but are unable to comply with the ideals in the same way. The concept of complicit masculinities is important, since even though most men cannot live up to the exemplary masculinities, they still passively support and honor the pursuit of such masculinities. Connell operates with the concept of subordinate masculinities, which often relates to homosexual men or men with feminine traits. The last concept in Connell's (1995) terminology is marginalized masculinities, which refers to, for example, unemployed men, poor men, and men of a different race or skin color.

Hegemonic masculinity is often associated with physical strength, stoicism, self-reliance, and autonomy, whereas disability and chronic illness are often linked with dependence and helplessness.

In continuation of Connell's general conceptualization of hegemonic masculinity, Gerschick and Miller (1995) point out that when functionally impaired and/or disabled men need to cope with being unable to live up to hegemonic masculinity ideals, three primary strategies or mechanisms come into play, namely, the three Rs: reformulation, reliance, and rejection.

Reformulation means that the man in question redefines the prevailing hegemonic masculinity ideals to match his performed masculinity. In a way, this involves trimming and shaping the understanding of masculinity to match the person's situation, strengths, and abilities. The person may choose to emphasize personality and will-power over physical strength and appearance. *Reliance* means being sensitive to what is perceived as the prevailing hegemonic understandings of masculinity. Reliance is an emotionally tough strategy since it largely internalizes hegemonic understandings of masculinity. Consequently, these men are constantly aware that they do not live up to the ideals and they continually try to prove that they are more and greater than their disability. One example of reliance is the internalization of a masculine ideal of independence resulting in men rarely or never asking for help. One possible form of reliance is what Coston and Kimmel (2012) call hypermasculinity or overcompensation, which may also contribute to risk-taking behavior among these men. *Rejection* means rejecting or not recognizing the dominant hegemonic understandings of masculinity. An example of rejection is the denial of the importance of virility and sexual prowess. Men who apply this management strategy have in common that they consider prevailing understandings of what it means to be a "real" man as wrong, which is why they try to create new understandings and values that they associate with being a man. Notably, however, few men completely follow any one of these frameworks in defining their sense of self.

Charmaz (1994) pointed out that the identity dilemmas men with chronic illnesses face are created and exacerbated in line with the progression of their illness and symptoms as the illness starts to affect who they are and what they become. As a result, they are generally affected by an increasing threat to their masculine identity. Charmaz underlines that many people who are chronically ill are often preoccupied by a sense of uncertainty about the future. Men often handle this uncertainty by simply ignoring and minimizing it—a phenomenon Charmaz calls bracketing, which is a way of forgetting or unconsciously hiding what causes the uncertainty, for example, increasing functional impairment. Shuttleworth, Wedgwood, and Wilson (2012) point out that it is important to avoid applying a perception of the relationship between disability, chronic illness, and masculinity that is too static; this despite the fact that being severely functionally impaired can feel like a loss of masculinity and create identity dilemmas in men.

Method

A qualitative study outlined how nine Danish men, aged 30–54 years, with severe hemophilia managed life as functionally impaired relative to their masculine identity. Specifically, this involved semistructured interviews with

three men and a dialog workshop with six men (see Table 1). The two methods were intended to complement each other, with the semistructured interview providing in-depth insight into each individual's life experience and attitudes, and the dialog workshop, with its interpersonal and interactionist design, offering a different dimension by supplying access to the negotiations and opinion formation created among the participants (Onyx & Small, 2001). The semistructured interview with open-ended questions ensured a certain level of consistency across interviews while allowing participants to speak freely as well. The dialogue workshop, as a kind of participatory research, aimed at constructing knowledge, which was meaningful and significant for men with severe hemophilia.

The dialogue workshop was designed so that participants had to contribute information about their own experience with the disorder and also propose new measures to help the next generation manage life with hemophilia. Although gaining insight into their experiences and hearing their ideas for new measures was of interest, the main purpose of the study method was to gain access to the narratives, opinion formations, and negotiations the men created together during the workshop.

The theoretical reflections on the workshop also apply Haug's (1999) conceptualization of memory work, which is a methodology approach to collectively studying methods that focus on activating the subjects' experiences and memories. Haug stated that when a group sits together and shares memories in a given area, individual stories will stimulate and inspire others to recollect old memories that they might not have thought of, had their memory not been jogged by the other participants' stories. This method is particularly useful for studying experiences that are not immediately present to the participant. For example, if one participant talked about a challenge, someone else in the group would often say, "I've experienced something similar" and proceed to tell a new story. In that way, the stories served to expose forgotten or unconscious experiences that the men might not have revealed had they taken part in one-on-one interviews.

Data Analysis

The first step in processing the empirical data from the interviews and dialogue workshop involved transcribing the material verbatim (Kvale & Brinkmann, 2009). The next step entailed coding the material (Charmaz, 2006) while maintaining the aim of adhering closely to the raw information to better understand the various types of reasoning and experiences. Grounded theory has, as a practical iterative framework, enabled the findings to develop and unfold in a reflexive interpretive way throughout the research process. Grounded theory has been useful in the coding process to review and refine the material and to

Table 1. Overview of Study Participants.

Qualitative interviews.

Participant	Age	Type of hemophilia
1.	48	Severe hemophilia A
2.	40	Severe hemophilia A
3.	43	Severe hemophilia A + HIV

Dialogue workshop.

Participant	Age	Type of hemophilia
4.	51	Severe hemophilia A
5.	46	Severe hemophilia A + HIV
6.	48	Severe hemophilia A + HIV
7.	47	Severe hemophilia A
8.	50	Severe hemophilia A
9.	54	Severe hemophilia A

discover new themes in the narratives that had not explicitly been searched for, but which turned out to be significant for the design of the main themes in the result section. The data was initially read and decoded into various concepts or words describing what was being talked about in a given section of the transcription. This made it easier to create an overall picture of the collected material. The coding process was nevertheless also inspired by the theoretical framework focusing on hegemonic masculinity and men and chronic disorders. Then the various codes were reviewed into overall categories summarizing the concepts or words defined in the first step: loss of masculinity, quality of life, the fight against the body, an identity as having hemophilia, and being restricted by pain. As a result, the data analysis involved a combination of a bottom-up and top-down analysis and theory-led reading, where the uptake of information, to a certain extent, was guided by the authors' prior knowledge and expectations.

Results

Life as a Hemophiliac

Childhood. Hemophilia is a chronic congenital disorder, which means that the men have had to relate to living with hemophilia from a very young age. Still, the men had different experiences in terms of how the disorder affected their lives. In examining the challenges the men encountered during childhood, many of the men clearly remember having to wear a helmet as a child. The men saw this as traumatizing because they simply wanted to be normal boys. This is consistent with Breakey, Blanchette, and Bolton-Maggs (2010) who highlight that it can be difficult for young people to cope with the impact of hemophilia on

lifestyle. The men mentioned that it was hard to pass as normal children when everyone could see that they were wearing a helmet. A 43-year-old talked about how the disorder was a major issue for him when he was young:

From a very early age, until I turned 14, it was a major issue and I needed a special needs assistant at school and had to wear a blue helmet and foam rubber in my sleeves and stuff like that.

A 48-year-old discussed how he had had to reevaluate his life and adapt to his disorder his entire life, which was tough because he had to negotiate with himself every day about how to get the best out of life. He compared himself to ordinary people who do not have to reevaluate their lives on a daily basis, indicating that he saw himself as being different compared to people without a chronic disorder:

You do it all the time, constantly. Day after day. It's tough. It's tough because ordinary people don't have to go through the same things.

In addition, doctors and parents told some of the men that they should not expect to get particularly old when they were young. A 54-year-old man explained that the adults around him had doubts about whether he needed to go to school at all since his future was so uncertain:

Sometimes you just wanted to say, to hell with it. I won't get that old anyway.

Consequently, some of the men with hemophilia felt that they had not been given a fair chance in life, which is why they would rather prioritize living life while they were still able to. This was especially due to the lack of prospects for a long life and the reduced work opportunities.

Current restrictions. Several of the men said that it was a major challenge and restriction in their daily lives that they could no longer walk very far anymore. A 40-year-old talked about how he was no longer able to go for an evening walk with his wife but had to bicycle instead. He explained that the disorder caused frustration because it restricted the activities he could do with his wife. This is in line with Diesen and Grut (2015) who emphasized that the masculinity of men with hemophilia can be compromised by the inability to participate in physical activities. A 48-year-old concurred about the drawback of not being able to walk very far but described it as a fact of life that he had to accept.

In that regard, several of the men talked about how important it had been for them to pass as healthy and normal, which is why they tried not to identify with the disorder or as hemophiliacs. A 40-year-old explained that he did not consider being chronically ill as a major challenge, stating:

I've managed to live a fairly normal life and still do. I have to say no to minor things. So, I might as well suffer from something else.

As this quote indicates, the men with severe hemophilia deal with how the disorder affects their life in different ways—also depending on how many challenges and restrictions they have experienced due to the disorder. Despite the 40-year-old's feeling of living a normal life with a chronic disorder, forgetting to take his medication remained an issue:

If I forget to take it in the morning, I'm sure to feel it in the evening.

A 46-year-old was also challenged in terms of working on his house and in the garden, explaining:

I'm unable to do things like gardening during the week because I'm completely exhausted when I get home from work. This means that any work on the house and stuff like that has to wait until the weekend. That's a real challenge, if you ask me.

During their youth, the men with severe hemophilia have had to weigh the pros and cons, make choices in terms of what they should do and participate in—often at the expense of their health. For some, the price to be paid came quickly while others had to pay later in life, when their bodies began showing signs of aging. One 40-year-old talked about the time he was with his childhood girlfriend and had forgotten to take his medicine and woke up the next morning in terrible pain, a bleeding ankle making it impossible to walk.

Since physical actions having consequences is a daily reality for the men, they continuously make decisions about the level of physical activity they can engage in. They engage in a cost–benefit analysis concerning activities that may have consequences. One 48-year-old put it very clearly:

"I'll always, i.e., no matter what you ask me to do, I'll always be able to do it; I'll even be able to run from here to there. Only I will know that it comes at a price, so I do this constant calculation, 24/7: Do I want to pay that price?"

Impact on the role of being a father. In their daily lives, the men experienced challenges due to their disorder that might affect their family life. Many of the men have children, and they particularly experienced challenges in terms of engaging in physical activities with their children. They were no longer able to run around and play with their children. Almost all the men mentioned their relationship with their sons in particular as an area where they were unable to live up to the

hegemonic understanding of masculinity related to fatherhood. Several mentioned ball games, especially soccer, as an important activity in relation to their children. This indicates that playing soccer with their sons was perhaps one of the best possible ways to exercise a masculinity marker as a man and a father. That is why it is mentioned so often—as an action that is both a desire, and a source of defeat. Similarly, in a New Zealand context, Park (2000), in an article with the very telling title "The Worst Hassle Is You Can't Play Rugby," described how men with hemophilia experienced distress because they were unable to play typical masculine sports like rugby.

One 47-year-old described this when he explained how extremely excruciating it was when he had to give up playing soccer with his son already in his 20s. A 48-year-old also stated:

It's extremely tough having a 10-year-old son who wants to play soccer or dig a hole in the ground or something else, and you just can't take part. You just can't. And then sometimes you do it anyway, and then you have to be all smiles and say 'Oh, this is so much fun' and all you can think about is how much you just need to lie down on the couch.

Together with many other statements made by the men, this father's experience indicates that some of the men experienced challenges created by their disorder that made it difficult to engage in the activities their children were interested in. Many of the men still chose to do activities that were challenging, but this came with a price in the form of pain, swelling, and possible bleeding—both during and after the activity.

One 47-year-old father expressed his frustration about not being able to function as a regular dad. Thus, he expresses a hegemonic understanding of masculinity as being able to live out the good father role only to realize that he is failing in this role when he experiences functional restrictions. The internalized hegemonic masculinity and the failure to live up to it engender a reliance strategy in which the individual who deviates from it absorbs guilt and frustration for not being able to live up to the social ideals of a good father. A 48-year-old father expressed the same sense of frustration for his perceived failure in his role as a father, which led him into a depression.

Two of the men talked about having to go to the emergency room due to their disorder after having played with their children. A 51-year-old said that he once suffered major bleeding while playing soccer with his son. He had to go to the hospital and was unable to play all summer due to pain.

Work and career obstacles. Work appears as a central aspect for many men's masculinity (Reinicke, 2013).

Other limitations mentioned among the men were how the disorder limited their choice of work. During the dialogue workshop with the six men with severe hemophilia, they discussed what work dreams they were unable to realize. A 46-year-old said: "I had a dream of working on a drilling rig. That wasn't possible," while a 48-year-old backed this story, explaining how his dream had been crushed: "I'd always dreamt of becoming a carpenter. However, I was quickly told to forget all about it, as it is too strenuous." Practically all of the men participating in the workshop, and several of the others interviewed, talked about how the disorder had put a stop to their dreams in various ways. This means that the disorder limited some of the men's dreams about education and work. One of the men talked about not wanting to be the person who everyone would have to show consideration for and take care of at work, which is why he waited to tell people that he was living with hemophilia until he was almost done working there.

Regarding work and career obstacles, social class and age play a significant role because the middle class and today's youth largely pursue higher education and professions that do not require the use of muscle power or performing masculinity in a traditional way.

Social consequences for the family. Hemophilia can also affect men on a social and psychological level. Men with hemophilia often feel that they have to navigate between contradictory and internally struggling identities. This identity challenge is manifested in various way in the men. According to Charmaz (1994), men tend to make an effort to keep this identity conflict at arm's length via bracketing, and she points out that this dissociation may have consequences for their families and their surroundings. In terms of emotional and mental well-being, several of the men said that wearing their hearts on their sleeves, particularly when they are in pain, affects their social relationships. This indicates that during certain periods of their lives, the men find it hard to find peace of mind and thus have a hard time saying that their quality of life is good. The limitations the men experience in living out their role as a father also affect their mental and emotional well-being.

This dilemma is reflected in a 48-year-old's description of how, during the transition to being in chronic pain, he was grumpy and embittered, which also affected his family. A 43-year-old also articulated how chronic pain had an impact on his mood and temperament:

"Because the pains were so unbearable, that it was actually . . . One key thing was actually that my fuse was so short when it came to other people, so damn short, so everyone around me didn't like being around me at all."

An Identity as Having Hemophilia

The interviews and workshop revealed that men with hemophilia have different constituting narratives in terms of what it means to live with hemophilia—or having an identity as someone with hemophilia. This identity primarily consists of the two aspects: being tougher and being an expert in terms of having knowledge about having hemophilia.

Being tougher. Primarily, the men tend to articulate that having severe hemophilia bestows upon them special abilities, thus turning it into something positive. This can be interpreted as an example of the management strategy of reformulation, where they reformulate their condition into being one of strength in alignment with masculinity indicators, such as control and knowledge (Gerschick & Miller, 1995). As part of having an identity as someone with hemophilia, several of the men said that having hemophilia was synonymous with having a higher pain threshold and that they, as individuals with hemophilia, are tougher and more persevering than healthy people. Thus, the reformulation made having hemophilia a physical strength. To illustrate, a 48-year-old emphasized that as someone living with severe hemophilia, he had a higher pain threshold than other people. He often provided this as an example of how living with severe hemophilia had made him stronger: "For someone with hemophilia at my age, or at least for me, pain has been a fact of life, something that I've had to learn to deal with."

Several of the men describe having to learn to live with constant pain. This may indicate that they are unable to manage the pain but accept it as a condition of life and learn to live with it. Painkillers can alleviate pain for some, but they cannot control the symptoms of major bleedings, and not all the men want to take painkillers every day because they become a sign of the disorder.

Internalization of being an expert. The other aspect of how the men handle daily challenges is that they experience becoming frustrated by the lack of advice provided by the health sector, which means that they are left alone, together with others living with hemophilia, to manage their disorder and its effects. The men described that they had only little access to information that could improve their lives with the disease such as advice on stiff joint training and what kind of food is good or bad for men with severe hemophilia. Likewise, the men described that they were too late to learn about microbleeding and that they did not feel that they were being counseled or that the latest information was being made available to them when visiting the doctor. The men have lived with their disorder their entire lives, and as part of the treatment strategy, the health sector has, with the best of intentions, allowed patients to

administer their medication at home. This makes treatment more flexible, and since treatment used to be on demand, allowing home treatment was preferable to visiting a hemophilia center when they had a bleed.

From a young age, the men have had to manage their own medication and have therefore assumed responsibility for their disorder. Already from the age of 6 years, most of the men had learned to inject themselves at hemophilia camps. Thus, the men were forced to become experts on their own disorder and they feel that their expert knowledge, in some cases, is superior to medical knowledge. This commonly creates problems in the communication between doctor and patient. This expert role can be seen as a way of taking control over their situation, which is why it is a reformulation strategy many apply. In many cases, the men take pride in being good patients, many of them highlighting their in-depth knowledge about the disorder and medications. Although there are examples of reformulation as a management strategy having a negative effect on the doctor–patient relationship, there are good indications that reformulations gave the men self-confidence and had a positive effect on their daily lives and self-esteem.

Furthermore, findings revealed that the men who had other people with hemophilia in their network experienced more support and understanding. This support was crucial to the men's quality of life, which means the social network was a factor that helped increase their quality of life. There are indications that this sense of community and identity is a feature of life that the men created as children through social events organized by the Danish Haemophilia Society. This feature was not as pronounced in the participants who did not take part in activities offered by the Danish Haemophilia Society as children. A 54-year-old who was not among those who attended hemophilia camps did not have as distinct a relationship with hemophilia and often described how he had distanced himself from this identity of having hemophilia because he would rather live a social life that revolved around something besides his disorder.

The fight against the body. As described earlier, being disabled can create a strong sense of loss of masculinity. The body and its functions often play a fundamental role in the way in which men define themselves as it is often with the body as a tool that they are able to position themselves in relation to other men. Endurance, strength, and competition are central in positioning one's masculinity, whether it involves physical activities, alcohol tolerance, or sexual performance (Gerschick & Miller, 1995). Accordingly, the body and the masculine understanding of it are, to a large degree, involved in the social practices that create and maintain masculine identity (Reinicke, 2013). In this context, Budde (2009) explained that men,

from a very young age, use their bodies for negotiating an internal hierarchy, which means that the body plays a crucial part in marginalization and ranking practices. Budde argued that the body often becomes the starting point for a constant negotiation of masculine performativity, which creates the framework for inclusion and exclusion processes. The body is both a recipient and a player in the marginalization and hierarchical arena of masculinity.

The consciousness of deviating from the norm drives men to extremes to prove to themselves and their surroundings that they are “real” men. The data clearly show that, already at a young age, these men had exhibited highly risky behavior. Overcompensation during adolescence was a recurring theme; some of the men had played various sports at a high level and others talked about parties and alcohol. Another aspect of this overcompensation that originates in an attempt to disassociate oneself from the stigma of having a disorder is that practically all the men were careless about their medication during this period. This correlation between overcompensation and dissociation from the stigma is described by a 48-year-old who said that as a young boy he tried to push back against hemophilia and went on a 2-week holiday without his medicine, convinced that he would be able to drown out his pain with alcohol.

For some of the men, this meant that the disorder became an enemy, and since the disorder is an invisible part of the men's DNA and bodies, the body becomes an enemy of the mind and the identity. For most, this neglect and risky behavior helped define their adolescence, but stopped when they got older. For especially one interviewee, sports offered a way of escaping the identity of having a disorder, which ended with him having to stop when his joints had become too stiff and his pain had become too severe for him to continue. For a man who applied reliance as his central management strategy, this meant that the body had won the fight, a huge personal defeat that resulted in depression and a life crisis.

As a result, the body is the source of both an identity crisis and stigmatization, which is why it becomes essential to the way in which the men negotiate and live out a masculine identity. This is expressed at various levels and in various ways. The body is used as a tool to prove and exercise masculinity; it plays a decisive role in their physical appearance and becomes an enemy and player in relation to their limitations. Consequently, on many levels, the body plays a decisive role in these men's lives and masculine identity processes; it is the cause, tool, arena, and visual marker of how the men live out and perceive masculine identity.

Discussion

This study has shown that socially constructed gender roles can influence men's experience of hemophilia. Although all the men do not practice their identity in the

same way, most of them have applied reliance as a primary management strategy at some stage of their lives. This is largely due to a general risk-taking willingness among young men, but in the case of men with hemophilia, this is enhanced by a desire to be normal. Many of the men experienced being marginalized during their childhood because of the disorder, for example, by not being allowed to participate in sports activities or by having to wear a helmet. Although home treatment makes taking medication more flexible and living a life with a chronic disorder easier, it involves a pitfall since the men, to some extent, fail to manage their medication, especially during adolescence. In line with Kalmar et al. (2016), who also studied men with hemophilia from a masculinity perspective, this study shows that the fear of becoming socially marginalized among their peers during adolescence made the men overcompensate for their functional impairment by trying to live a rebellious life at times. During adolescence, they tried to rid themselves of the identity of having a disorder by, for example, drinking alcohol heavily and/or neglecting their medicine. A Scandinavian study (Lindvall et al., 2006) demonstrated that 41% of young people with hemophilia confessed that they had not followed the directions for taking their medicine. As pointed out by Breakey et al. (2010), this may be because the responsibility for taking the medicine is transferred during a critical period in which the individual undergoes other fundamental social and personal changes. For most, this behavior stops when they become older, and many of them appear to come to terms with their disorder as they become older. This indicates that many of the men with hemophilia are more likely to apply reformulation as a management strategy later in life.

The feeling of being powerless and limited in something that they really want to do is clearly expressed by the men when they talk about the challenge of spending time with their children as it affects an essential part of their understanding of fatherhood. This means that in terms of their identity as a father, the body becomes a tool in the way in which the men exercise the masculinity marker and therefore also becomes a source of frustration when the disorder causes the body to fail. In that regard, an interesting finding was that the men often experienced a degree of denial in terms of the severity of their pain or how the disorder affected their lives and, in some cases, it was difficult to get them to talk openly about their challenges. However, one approach to getting the men to speak more openly about the challenges they experienced because of their disorder was to ask about how it affected their relationship with their families. Normally, when asked about whether they experienced any challenges, the answer was no and that they were doing fine. This behavior is consistent with other findings and the

literature on men's mental health (Madsen, 2014; Oliffe & Philips, 2008). However, when asked about their working life and their families, and particularly their relationship with their children, the men started to open up about their problems and challenges, since the disorder often prevented them from living up to social expectations about men as fathers. Therefore, the men were reluctant to admit to any weakness when talking about themselves, but this is overshadowed by the desire to be good fathers, which is often the source of their biggest defeat.

The empirical data illustrated that men with severe hemophilia are affected in various ways by the disorder. This can be seen in the varying degrees of engaging in activities and exercise among the men. One of the most important observations is that the men experience a conflict of interest in terms of understanding their masculine identity and an identity as someone with hemophilia. They distance themselves from the disorder—in some cases to a degree that is nearly self-destructive. In this connection, examples occur of men having distanced themselves so much that they only realize that they must live with having hemophilia when the pain and the limitations become a real, unavoidable factor in their lives.

The experience of not being able to meet hegemonic masculine ideals and its impacts is not something that only affects men with severe hemophilia; see, for example, studies on chronic illnesses such as diabetes and cystic fibrosis (Di Battista, Hart, Greco, & Gloizer, 2009; Towns & Bell, 2011). Men with hemophilia are, however, more affected than men who do not have a chronic disorder. For instance, older men who experience impaired functionality to a greater degree are able to accept it as a natural condition of life, whereas men with hemophilia experience the functional impairment at a stage of their lives where expectations concerning their abilities are different. As a result, they have a much harder time having to live up to the idea of the hegemonic masculinity ideal as they experience that they are unable to live up to the ideal of being a father. Men with hemophilia thus experience the same mechanisms and effects of deviating from the ideal—the only difference is that they experience it much earlier and much more strongly than others.

The expert role implies a reformulation of masculinity understandings and gives the men a sense of control and authority. Nonetheless, this approach might also have a disadvantage. For instance, some of the men are not open to medical knowledge, as they assume that they know what they need to know about their disorder. This is consistent with Rolstad (2015), who pointed out that men with hemophilia are often ambivalent in terms of measures intended to help them because they want their independence. In some cases, this means that the expert role has a flip side, but it is an example of a way of managing and detaching oneself from the identity as a patient, that

is, “I’m not a patient, I’m an expert.” This is also illustrated by the fact that many of the men, not only as adolescents but also as adults, have neglected to take their medicine. The men in the study simply had too much to lose by being patients. Nonetheless, they expressed a clear desire to change this, both for their own sake and for their health and their families.

The men do not feel that they get qualified help and guidance from doctors and medical professionals, which is why they look to other hemophiliacs to get advice and guidance. Characteristically, the men in the study may have difficulty asking for help as they become stigmatized and lose masculinity once the disorder is brought up. The literature regarding men and help seeking reveals that the ability and desire to ask for help is a complex and dynamic process that depends on the person in need of help, the institution providing the help, and the type of help being asked for (Galdas, Cheater & Marshall, 2005; Möller-Leimkühler, 2002). The establishment of legitimacy for the men is important in this context. Addis and Mahalik (2003) pinpointed that all potential situations where men must ask for help will create a tension between the personal gains of getting help and the risks the men expose themselves to. Simonsen (2004) reported that men will often want to limit any talk about their disorder because they refuse to be turned into patients unnecessarily and that men’s ways of managing disorders often lie somewhere between negative isolation and positive autonomy. Men’s action patterns can be positive because they want to be independent and participate in decisions concerning what the health sector should offer them. However, there are also many men who are in denial when it comes to their vulnerability and do not want to accept any advice or medical guidance.

As described by Budde (2009), men often use their bodies as a tool to measure and exercise social masculinity indicators such as competition, strength, endurance, and physical ability, and it therefore affects men’s positioning in relation to one another. Accordingly, functionally impaired or disabled men constantly live with the knowledge that they are unable to live up to or fulfill the expectations society has for their bodies and functions. Men with physical disabilities experience an internally embattled identity: a conflict between two opposing notions of what it means to be a man and what it means to be a person with a disability. On the one hand, these notions can be that men are expected to be strong, brave, aggressive, independent, and self-reliant and, on the other hand, that individuals with a disability are passive, weak, and dependent on others. Accordingly, these expectations and stigmas, coupled with the major role the body usually plays in various masculinity practices, create an internally embattled identity, and men with disabilities often

feel that they need to struggle hard to become recognized by others as masculine.

When looking at how the disorder and its limitations affect their sense of identity and masculinity, it is clear that the men have to negotiate their identity as individuals with hemophilia while trying to disassociate themselves from the disorder at the same time. Though hemophilia also influenced the men’s identity and self-perception, the men fought being limited by both the physical and emotional limitations the disorder placed on them because they did not want hemophilia to define them. The men’s experience was that they are unable to live up to the hegemonic understandings of masculinity due to their chronic disorder, physical limitations, and the related stigma. Because of the physical impact of the disorder, all the men were in a subordinate or marginalized masculine position. Therefore, an identity conflict arises between being a hemophiliac and being a man trying to conform to hegemonic understandings of masculinity. This makes it necessary for them to apply various management strategies to cope with their complex identity engendered by the hemophilia. Some of these are destructive but others belong to a regime of healthy masculinities.

Limitations

One limitation of this study is the low number of participants, which can make it difficult to derive any general conclusions about the correlation between masculinity and hemophilia. Nonetheless, the dialogue workshop in particular served as an excellent tool for gaining access to some of the underlying reflections that new studies can apply in guiding future research focusing on hemophilia management. Another limitation of this study is the relative limited age range of the participants and the restricted focus on men with severe hemophilia. This makes it difficult to extrapolate beyond this age group and to men less physically disabled. It should also be noted that this study was carried out in a Scandinavian welfare state context, where there is a long tradition of providing social security benefits and services to people with special needs and where most of the health sector is publicly financed via taxes. This means that health insurance schemes are not widely used and that there is no tradition for letting patients pay for the services they receive. These circumstances also affect the ways in which medical initiatives are rolled out in many areas of society. The conclusions and reflections made based on the analyses should therefore be considered with the welfare state services as a premise for the men’s understandings of being patients, having a chronic disorder, and being experts on their own disorder. Thus, the findings may not be generalizable to all societies.

Conclusion and Practical Implications

This study of men with severe hemophilia can aid in understanding how men with physical limitations handle their identity as individuals with a disorder. The men handle their loss of hegemonic masculine identity in various ways. Nevertheless, in keeping with Kalmar (2014), the present study demonstrates that overcoming their limitations and establishing their identity was a complex and delicate process that often included testing the limits of their bodies. One overall aspect of the men's management strategies is that they all subscribe to the hegemonic understandings of masculinity. In this understanding, the body becomes an arena for managing the loss of masculinity. This is evident when they, even as adults, neglect their medicine, refuse to take painkillers, focus on sports and exercise, drink, or have drowned out or ignored their disorder. The consequences of this attempt to push the disorder away occur when they again experience the constraints the disorder puts on their lives, which is why they experience it as a double defeat. For some, this defeat causes massively reduced quality of life, depression, or a life crisis. However, there is an indication that their management strategies undergo several phases and that, with time, the men might learn to have a good quality of life with their physical impairments since they may learn to redefine themselves and manage their physical abilities through their lives as the disorder progresses.

Indeed, the fear and experience of losing masculinity are the most dominant factors in explaining how the transition from suffering periodic to chronic pain affects the men's quality of life and masculine identity. As pointed out by Lane et al. (2013), hemophilia is a complex disorder to manage that requires getting the right information at the right time from the right source. It might therefore be expedient to try to create initiatives that establish inter-generational contact, where hemophiliacs of all ages can meet and learn from one another, provide good advice and inspiration, and gain access to self-management tools for their disorder.

The men are not experts in the clinical aspects of hemophilia but on how hemophilia influences their lives. Yet, Kalmar (2014) also stated, there is no doubt that men with hemophilia may benefit from education about the management of the disorder and improved support in transitioning from adolescence into adulthood. An example of a specific possible service is the establishment of a knowledge-sharing platform that people with hemophilia can use to find advice from lay and professional experts. The Danish Haemophilia Society, for instance, could provide a timeline with authentic age-specific narratives (e.g., from childhood through adolescence to young adulthood). Each age could contain a video log by people with hemophilia

who talk about life with hemophilia at a given age. The person with hemophilia can discuss what it is like to live with hemophilia at that specific time of life and reflect on the concerns that arose during the process of living with the disorder as well as provide good advice on, for example, treatment, routines, or exercise. Links to a debate forum could also be provided with videos to allow peers to share knowledge and read more about how to manage the disorder. However, since users can interact anonymously, it is crucial that the aspects of the platform directed at men navigate between being sufficiently personal so that they are able to recognize themselves and being sufficiently impersonal so that users do not experience a loss of masculinity.

Acknowledgment

The authors would like to thank the participants in the study.

Ethics Approval Obtained

This study and the collection of the different interview data was approved to be in accordance with standards for good scientific practice by the Committee for Research Ethics at Roskilde University, Denmark.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

Informed Consent Obtained

Informed consent has been obtained from all participants in the study in the following way: All the participants have received written invitations, which described and specified the purpose and terms of the study. When the participants showed up on the scheduled day for the interviews and the dialogue workshop, the conditions were repeated verbally with a specific emphasis on the measures taken to ensure confidentiality and anonymity in the report/article. This is a central focal point because only around 490 Danes currently live with hemophilia.

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