

“He’s a normal kid now”: an ethnographic study of challenges and possibilities in a new era of haemophilia care

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Background: Recent treatment option advances in haemophilia care have contributed to a discourse of ‘normality’ around the condition, in which people with haemophilia (PwH) are increasingly expected to live ‘normal’ lives unburdened by their condition.

Aim: The aim of this article is to explore notions of ‘normality’ in the experience of haemophilia across generations. This is one of the main themes identified in a large-scale ethnographic study of the everyday life of PwH, a broad qualitative investigation of beliefs and experiences related to condition, treatment, and personal ways of managing the condition. **Methods:** The study used ethnographic research methods. Five



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While advances in treatment mean that young people with haemophilia can now expect to lead a much more ‘normal’ life than previous generations, it is essential that the discourse around ‘normality’ in haemophilia does not obscure the remaining and new challenges they experience in their everyday lives.

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haemophilia experts helped frame the research design by contributing historical and disease area context prior to the initiation of field research. PwH were recruited through patient organisations in five European countries (Italy, Germany, Spain, UK and Ireland). During field research, study researchers collected data through 8–12 hours of participant observation, semi-structured interviews, written exercises, facilitated group dialogues, and on-site observations of PwH interactions with friends, family, and health care professionals (HCPs). They also conducted on-site observation at haemophilia treatment centres (HTCs) and HCP interviews. The study employed a multi-tiered grounded theory approach and combined data were analysed using techniques

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such as inductive and deductive analysis, cross-case analysis, challenges mapping, and clustering exercises. This article explores findings related to the discourse of 'normality' and is thus focused on a subset of the data from the study. **Results:** Fifty-one PwH, aged 1.5 to 82 years, were interviewed and followed in their daily lives. Six treatment centres were visited, and 18 HCPs were interviewed. The study found that a discourse of present day 'normality', as compared to a difficult past, is ingrained in the haemophilia community. As a result, unlike most older PwH (40+), younger PwH (under 18) are not always taught to acknowledge the severity of their condition or how to sense bleeds (disease-related embodied knowledge), and risk unknowingly doing long-term damage to their bodies. Twenty-seven per cent (n=7/26) of younger PwH (children, teenagers) in the study were observed or described as engaging in high-risk behaviours in the short term indicating a lack of understanding of long-term consequences. **Conclusions:** These findings suggest that the discourse of 'normality' presents a number of challenges that need to be addressed, namely the potential for younger PwH to be unaware of bleeds and the general underreporting of haemophilia-related complications and limitations. One way forward in realising the full potential of advanced treatment could be to teach young PwH, through evidence-based initiatives, how to develop an embodied sense of their bleeds. Furthermore, if the current state of life with haemophilia is accepted as finally 'normal', then progress in further improving care may be stalled. It is important that remaining and new challenges are recognised in order for them to be acted upon.

Keywords: haemophilia, community, embodied knowledge, embodied sense of the disease, normality, chronic illness, new era of care

Haemophilia care has entered a new treatment era for many according to recent research^[1,2]. After the treatment advances of the early 1990s in Europe and North America, notably including the advent of prophylaxis, recombinant factor, and blood screening, many people with haemophilia (PwH) have experienced a drastically improved quality of life^[1,2]. These advances have resulted in improved life expectancy^[3-5], lower annual bleed rates^[6,7], better joint health^[8,9], more successful inhibitor treatment^[1], and a generally less restricted life for many people living with haemophilia^[1,2]. This shift has fundamentally changed the circumstances of many PwH^[10], and it can be

expected that younger PwH (under 18 years of age) experience living with haemophilia in a different way than older generations (over 40 years of age).

The aim of this article is to explore the impact of the significant treatment improvements in the past decades on the discourse around the condition in the haemophilia community, based on qualitative research with PwH in five European countries. The term 'discourse' is used here in the sociological sense and can be defined as "any practice (found in a wide range of forms) by which individuals imbue reality with meaning"^[11]. The study thus includes a comparison of perspectives on personal possibilities, limitations, an embodied sense of the condition, and the role of care for both the current generation of PwH and the older generation who experienced haemophilia before this shift. The findings in this article come from a large-scale ethnographic study exploring the everyday life of PwH, including their beliefs and experiences related to their condition, their treatment, and their personal ways of managing the condition. The overall results are previously published^[12].

METHODS

As an initial step, historical and disease area context was provided prior to the initiation of interviews by five haemophilia experts to help frame the research design. The experts included a specialist nurse at a paediatric haemophilia treatment centre (co-author NM), a practicing psychologist for people with haemophilia (co-author ATO), a physiotherapist, an anthropologist, and a medical psychologist working within the area of haemophilia. In order to gather and analyse data on the experience of everyday life with haemophilia, researchers used qualitative methods. The study employed a multi-tiered grounded theory approach and gathered data through semi-structured interviews (with PwH, their family members, health care professionals (HCPs), and experts), facilitated group dialogues, written exercises, and on-site observations of the interactions of PwH with friends, family, and HCPs. Study researchers observed consultations with HCPs when agreed upon in advance with both parties. The study researchers used audio recording, video, photography, and extensive field notes to capture rich and detailed qualitative data, which was analysed in combination using various approaches (e.g. inductive and deductive analysis, challenges mapping, and clustering exercises). The in-depth nature of the interviews and observations (researchers spent one to two days with each participant) allowed identification of the underlying needs and challenges faced by PwH,

and the drivers behind current treatment approaches, as well as unearthing 'softer' experiential metrics, such as aspirations, fears, doubts, and attitudinal shifts. All statistics in this article are based on analysis of self-reported participant information. Further detail on the methods and sample of this ethnographic study can be found in first publication of its results^[12].

Recruitment

PwH were recruited for this study in Italy, Germany, Spain, UK, and Ireland through patient organisations. The recruitment criteria aimed for a representative sample of PwH, screening candidates by haemophilia type, disease severity, treatment regimen, presence of inhibitors, and age range (under 12, 13–18, 19–49, 50+). HCPs were recruited for a mix of experience levels as well as representation of larger and smaller clinics.

Ethical considerations

PwH and HCPs participating in the study signed a GDPR-compliant consent form, which informed them of the terms of participation and the way their personal data would be managed. The study was conducted following the ethical standards outlined by the ICC/ESOMAR International Code on Market and Social Research^[13], which sets out global standards for self-regulation for researchers and data analysts, as well as relevant national standards for participating countries^[14–17].

Given the highly personal nature of the data collected in this study, participants' privacy and anonymity were of high priority. Personal data was handled with the utmost care. In order to identify the different participants, while preserving confidentiality, each participant in the study was assigned a unique number. Quotes and cases are labelled with the participant's age range (e.g. teenager). All other potentially identifying information about participants has been omitted.

RESULTS

A team of researchers conducted 51 in depth semi-structured interviews with PwH A (n=42) and PwH B (n=9) aged 1.5 to 82 years of age and receiving a range of treatments. The majority (94%, n=48) had severe haemophilia, while 6% (n=3) had mild or moderate haemophilia. The interviews and on-site observations often included the wider social ecology of the individual PwH, i.e. friends, family, and caregivers. In addition, 18 HCPs from seven haemophilia treatment centres (HTCs) were interviewed. On-site observation was conducted at six of these HTCs, with and without patients.

The study findings around PwH's perception of the current era of care in haemophilia compared to the past are grouped into four themes: discourse of 'normality', 'normality' across generations, embodied sense of haemophilia, and 'normality' of burdens.

1. Discourse of 'normality'

The study findings indicate that people in the haemophilia community (PwH, carers, HCPs, patient organisations, and pharmaceutical companies) share a strong collective memory of a difficult and recent past with poor quality of life, characterised by the contaminated blood scandal, inferior treatment options, and profoundly restricted lifestyles. In light of this difficult past, many people in the haemophilia community seem to view the present era as a time when life with haemophilia is finally 'normal'. Here the term 'normal' is not used to refer to a prescriptive definition of what constitutes a normatively correct way of living, but rather a life relatively unburdened by the disease. Researchers encountered this characterisation of life as 'normal', i.e. burden free, despite apparent persisting burdens in PwH's daily lives. In the interviews with PwH, 48% (n=24/50) of PwH's families described life with haemophilia as 'normal'. Many HCPs also described patients' present day life with haemophilia as now 'normal', and this characterisation appeared repeatedly in the collected haemophilia-related materials (medical pamphlets, pharmaceutical advertisements, and information from patient organisations) received by respondents.

An analysis of materials distributed by HCPs and patient organisations and documented by researchers in clinics and PwHs' homes, revealed many instances of how PwH are told that they can now live 'normal' lives. However it is important to note that these messages often also come with a caveat that PwH can live a normal life now, as long as they restrict certain activities. For example, the typical patient brochures found in people's homes have photos of children engaging in physical activities with their friends and include descriptions about how important activities are to stay healthy, thus giving parents an impression of the importance and possibility for their child with haemophilia to engage in regular physical activity, while also detailing examples of activities they should not do. While these materials give an overall impression that PwH can live a normal life, the text also introduces a tension that suggests haemophilia care has not reached the point where PwH are living lives free of haemophilia-related limitations. For example, one boy's (child) mother described the booklets about haemophilia in her home:

"It is the kind of stuff you will get at all kinds of different events, but they all say the same [...] They reassure you that it is possible to lead a normal life with haemophilia, but does not offer any real advice about anything."

This discourse of normality seems to be strengthened by an observed common desire among young PwH (children, teenagers) to 'fit in' and be perceived as 'normal'. Many young PwH in the study appeared to wrestle with their sense of belonging as PwH. One incident illustrating how the expectation of 'normality' on young PwH can play out in everyday life occurred during a walk with a young adult participant (20s) and his friend. On the way home, the participant's friend remembered something that he had to pick up close by (approximately 200 metres away). His friend suggested over and over again, "Let's just walk there?!" and eventually the participant reluctantly told him that he would not be able to do that because of his condition. His friend apologised for forgetting, but the participant was clearly embarrassed by not being able to perform this 'normal' trivial activity. This and other incidents seem to indicate this participant's preference to keep his disease in the background.

2. 'Normality' across generations

Researchers observed how stories of haemophilia's past are communicated in families from generation to generation. A common narrative in families and the haemophilia community is that the hard times with the condition are now over. Many of the PwH in the study who had experienced the difficult past described the current era of haemophilia care as providing the opportunity for PwH, particularly the youth, to finally live 'normal' lives, free from disease-related limitations. Young PwH described how they are frequently told by family members and their HCPs that their life is 'normal' compared to previous generations. For instance, one boy's (child) mother explained:

"When my father was [my sons]'s age, there was no treatment. Since then it's been revolution after revolution."

This sentiment was echoed by a teenage participant's father, who told a researcher:

"It's all fine now. I used to worry, but now I don't. The really hard days are over."

Statements such as, "He lives a normal life. He's a normal kid," from another boy's (child) father were also common.

Many young PwH themselves compared their experience of the condition with older PwH in their families and described their own lives as much more normal, and the difference in quality of life is in stark contrast to previous generations. One teenage participant described the difference between his life and that of his uncle who also had haemophilia:

"I was just a kid when he died [...] he could never do the sort of normal stuff that I did (...) he could barely walk at the end."

Another teenage participant's father also described being grateful for this "new world" of care:

"He can actually go and play with the other kids now."

For the older generation of PwH in the study, the trauma of the past was often described as still very present. Their experience of the 'difficult years' deeply informs their current lives. For example, an older participant (40+) told a researcher about how he and his patient organisation are still devoted to 'seeking justice' for the contamination crisis of the 1980s:

"I went down to this protest and people went around painted red, and dressed as death with a scythe and tombstones (...) 2000 had died [due to infections]."

Many of the HCPs described how they see life with haemophilia for young people now as 'normal'. In the words of one HCP:

"The young people don't really have any struggles at all – they can live a completely normal life."

PwH also described how HCPs have told them that they are in a new era of treatment. For example, one boy's (child) mother described how an HCP told her to "delete everything you know from your hard drive, it is all different now" when she raised concerns based on her two uncles with haemophilia who had both died at a young age from brain haemorrhages.



Engaging in physical activity is one way in which PwH are living more 'normal' lives, and is important for joint health and wellness. Paradoxically, advances in haemophilia care mean that younger PwH may be less aware of their condition, lacking embodied awareness and intuitive understanding of their limitations.

3. Embodied sense of haemophilia

As a result of years of experience with less effective treatment options, it appears that most older PwH (40s, 50+) in the study have developed an embodied sense of their condition and bleeds, allowing them to distinguish a major bleed from a minor one and guide them in their treatment regimen and activity choices. For example, one man (50s) described how he senses bleeds:

"I have a register of pain. I can compare minor pain to the more severe kinds, and with serious bleeds the pain kicks in earlier. That is how I know that it's a major bleed."

Another man (50s) described how it had been impossible to ignore his condition when he was young, in comparison to young PwH in the current era of care:

"It would be hard to hide, because I was out of school for days at a time [...] Today's boys raised on prophylaxis don't know – they don't show in any part of their body. Which gives rise to another problem, in that they tend not to know what's wrong."

Many participants in the 50+ age range described frequent bleeds and hospitalisations in their childhood and adolescence. Most of the older PwH have now developed a sense of their condition, but most also described having to push through pain in their everyday lives as a result of the damage these frequent bleeds have caused to their joints.

In contrast, most young PwH in the study appeared less attuned to the possibility and severity of bleeds

compared to the older PwH. For many of the younger PwH, this potential lack of embodied sense could result in bleeds going unnoticed for long periods of time, only to be realised in later doctor's appointments. HCPs described several stories similar to the following quote from a nurse:

"We had a patient recently, 19 years old, who just got his first bleed ever. He didn't do anything about it at first; he had no idea what it was."

This lack of embodied awareness appeared to impact many young PwH's intuitive understanding of what their limits are in relation to their condition. Researchers observed that many (27%; n=7/26) younger PwH in the study are relatively inclined to engage in high-risk behaviour in the short term; behaviour which could have long-term consequences. Young PwH in the study also appeared to generally have a difficult time both in sensing when they are experiencing a bleed and knowing what action to take to counter it. Both of these observations are exemplified in the case of a teenage participant, who was the first in his family to have haemophilia and has grown up being on prophylactic treatment. While he has always had a strong care network, with his mother and sister being particularly attentive to his treatment regimen and care, he nevertheless decided not to wear a helmet while performing risky bike tricks in his teenage years. Despite experiencing joint bleeds in both ankles, his shoulder, and his hip, he still plans on not always taking injections in the future. He said that he wants to live a 'normal' life and extreme sports are his passion. Although these activities have caused bleeds, instead of reacting and administering treatment to stop the bleed, he rather prefers to continue with the activities for as long as possible. His mother described an injury that he ignored that turned out to be a severe bleed:

"He was helping his dad [...] when he fell on his shoulder [...] He only told me it was hurting the next day, and it turned out it was a severe bleed!"

4. 'Normality' of burdens

The major challenges PwH face in their daily lives that were observed in this study are significant: 34 out of 51 (67%) experienced bleeds in the past year, only eight of whom had inhibitors at the time. Forty out of 51 (78%) in the study actively limit their activities due to concerns around protection, and many described frequent pain and severe limitations. Furthermore, in

spite of adherence to current treatment models, PwH developed unexpected injuries, either spontaneously or because their treatment regimen is not aligned with their activity level. For example, in spite of being adherent to his treatment one young man (20s) still experienced regular bleeds, with the latest incident hospitalising him for a week. Another example was described by a participant in his 20s who has severe haemophilia A. His recent trip to the cinema was cut short when he unexpectedly developed an ankle bleed while walking up the stairs to his seat:

"We went to the cinema and I got an ankle bleed from walking up the stairs – I wasn't prepared for it. That was a bad one."

He described not feeling prepared for the bleed because he had been diligently following his prophylaxis treatment, but he was still having bleeds nearly every week.

Despite many such observable and patient-reported burdens, the majority of both young and older PwH in our study appeared hesitant to acknowledge them and described their current treatment as satisfactory. Many expressed that PwH have little to 'complain' about after the paradigm shift in care. As one older participant (50+) put it:

"Kids [with haemophilia] today live a life of luxury [...] We complain out of addiction. We're privileged. We have good doctors, good healthcare, good treatment that is free. What more do we want?"

For the older PwH, the limitations they experience today were toned down, viewed in the context of what they witnessed when they were young. In light of this progress in care, many older PwH tended to accept their current situation as 'normal' and could not contemplate asking for more, especially when they are often aware of what one respondent called the 'cost on society' of public health systems supplying the latest medicine. As one man (40s) stated:

"We can't afford for everyone to get it, so the new [treatment] should go to the youngsters."

DISCUSSION

The current research indicates that PwH are often told by their families and health care providers that, in light of major treatment advances and haemophilia's difficult past, they are finally able to live a 'normal' life. The history of haemophilia treatment's evolution is deeply linked with

many families' own personal histories and this familial perspective of the past is an important part of a general discourse of life with haemophilia finally being 'normal'. The history of treatment was relatively well known among study participants and, in fact, intimately linked to how many perceive their present-day experience of the condition, as the improvements in care have been observed, felt, and described throughout generations for many families with haemophilia. In this sense, PwH in the study were often viscerally aware of how they are closer than ever to a 'normal life' where they could potentially live completely free of disease burden. However, the perspective that things are finally normal neglects the fact that PwH today still face many limitations and burdens.

PwH and other people with chronic conditions have likely always felt pressure to be perceived as normal due to stigma^[18,19] and pressure to pursue a 'normal' life in order to be seen as resilient^[20]. However, the relative 'invisibility' of haemophilia^[21], post-paradigm shift, allows some people to now act 'normal' with fewer immediate repercussions than ever. The prevalence of lengthy hospital stays and long absences from school before the recent paradigm shift in care are well documented in the existing literature^[2,22,23] and made the disease more visible than today. Being perceived as 'normal' is especially important for young PwH and recent research indicates that for adolescents and young adults with haemophilia 'differences' from healthy peers in a period often marked by competition can bring out emotions of anger and frustration, due to the feeling of being marginalised with regard to activities, such as sports, socialisation, self-esteem and group membership^[21]. The stigma felt around the condition in young PwH is also well documented^[24,25-27]. Peltoniemi et al. found that young PwH felt bullied due to their condition and struggled with absences from school due to hospital visits^[28]. Other studies have documented how young PwH engage in risky physical activities, like climbing trees, in an effort to be perceived as 'normal'^[24,29].

However, when PwH are told that they can lead 'normal' lives other issues arise. The findings of this study suggest that the younger generation of PwH seem to be losing the embodied sense of their condition, i.e. the ability to recognise and analyse the bodily sensation of the condition, that the older generations have. In the case of a bleed, the World Federation of Hemophilia (WFH) has described this as the feeling of a "tingling sensation or an aura" before physical manifestations arise^[30]. Due to advances in treatment, many young PwH in the study experienced fewer bleeds than previous generations

and as a consequence some were less experienced in recognising bleeds and judging their severity. This increasing lack of embodied awareness could also be related to young PwH often being told that 'everything is fine now'. Paradoxically, it seems that although young PwH are generally better cared for than ever, they now risk being less aware of their condition.

Another observed issue in the era of normality is the hesitance of PwH to fully acknowledge the remaining challenges of living with the disease. Despite significant advancements within haemophilia care, most PwH in the study live lives that are still far from 'normal', i.e. free of challenges related to haemophilia. While they experience many limitations and treatment-related issues, they tend to downplay or ignore their condition and generally accept the status quo of care. Many PwH in the study evaluated the conditions of today in comparison to the events of the past, and in light of this, many considered it to be 'too much' to ask for more in terms of care and support. This common perspective indicates that PwH may generally be more likely to hide or underreport the challenges they still face with the condition and less inclined to pursue activism in the community and campaigning for better care, thereby further reinforcing the discourse of normality around the condition. While recent treatment advances have obviously been positive for PwH, it is critical to be aware of new and existing challenges in this era of normality in order to further improve patient lives and to push treatment progress further.

Limitations of the study

The findings described in this article are representative of patterns observed across several European countries. However, the data from this study were not sufficient to produce an analysis of country-specific differences within Europe. Further investigation is needed to produce a more comprehensive analysis of patient needs at a country level. It is also important to note the potential of self-selection bias in the volunteer-based recruitment approach.

CONCLUSION

This article explores some of the key challenges that remain or have been created by a discourse of 'normality' whereby PwH today are expected more than ever to have 'normal' lives. Addressing these new and remaining challenges is essential. For example, to realise the full potential of advanced treatment for young PwH, it may be possible to support them through evidence-based initiatives on how to develop

a greater embodied sense of their bleeds. This could be through HCPs, support organisations, or other relevant organisations, creating a more structured approach aimed at education and training in the management of their disease, how to detect bleeding and assess its severity, and providing guidance on how to act. With such initiatives the discourse of normality could then shift more to a discourse of possibility, wherein PwH are more supported in more personalised ways to reach their personal goals.

Furthermore, there is a danger for PwH that if the current state of life with haemophilia is accepted as finally 'normal', then progress in further improving care may be stalled. Existing challenges faced by PwH must be recognised in order for them to be acted upon, and it must also be acknowledged that when PwH tell their HCP that everything is fine this may obscure burdens that could be addressed. Moving beyond a general discourse of normality is essential in order to one day achieve a true normality through personalised approaches to care that could make improvements more attuned to individual contexts, thereby allowing PwH to live 'normal' lives.

DISCLOSURES

This study was carried out by ReD Associates with funding from Sobi. Sobi and Sanofi reviewed the article. The authors had full editorial control of the article and provided their final approval of all content. TH, MBK, YG, AML and ABL are employees of ReD Associates. ATO is a researcher at the University of Murcia. NM is a researcher and nurse at Alder Hey Children's Hospital. JS is an employee of Sobi.

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Informed consent has been obtained from the participants in the study reported in this paper.

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