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NURSE FOCUS

Living, Caring, Learning – The power of qualitative research in bleeding disorders care: One voice, from soloist to choir

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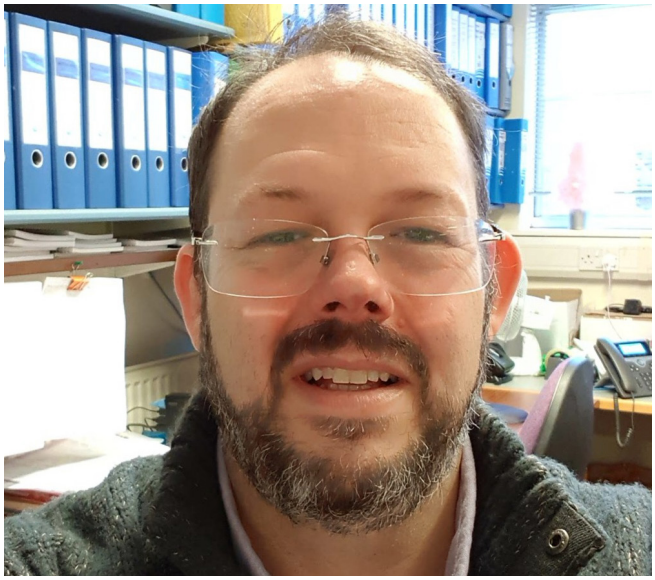
SIMON FLETCHER is Principal Researcher at Haemnet and was a clinical research nurse at the Oxford Haemophilia and Thrombosis Centre, Oxford University Hospitals NHS Foundation Trust. He is undertaking a PhD exploring the impact and lived experience of gene therapy for haemophilia.

With over three decades of nursing experience, Simon reflects on his experience as a research nurse at the Oxford Haemophilia and Thrombosis Centre at a time of huge change for haemophilia care and treatment. He recalls the impact of conversations with people with haemophilia about gene therapy, how these challenged his assumptions about living with haemophilia, and how this prompted him to pursue a PhD. Highlighting the importance of listening to individual patient stories, Simon discusses how qualitative research contributes to a deeper understanding of what it is to live with a bleeding disorder. He considers the role of nurses in research and the importance of collaboration between research and clinical nursing teams as new treatments for haemophilia and other bleeding disorders emerge.

Keywords: *Haemophilia, Gene therapy, Nurses, Professional practice, Qualitative research*



I have been a nurse for 36 years. As I look back over that time, I am filled with a sense of awe as I realise how I have been touched by and, in turn, touched the lives of others. Growing up, I never wanted to be anything other than a nurse. Having been in and out of hospital as a child, undergoing multiple orthopaedic surgeries, I saw the difference nurses made to the lives of patients, and I knew that I wanted to be able to do the same for others.

I am, by temperament, a planner. So, having made the decision to be a nurse, I ensured that I knew what the job really involved, what qualifications I would need, and where I might go to train. Working in bleeding disorders care, however, was something that I never considered as an option. I think few people ever really decide that they want to go into bleeding disorders care – it is more something you fall into, and something that never quite lets you go once you have. I had been working in intensive care and was studying for a master's degree in Medical Ethics and Law. During that time, I became interested in identity and autonomy (concepts I had explored in my Bachelor's degree [1]), and research ethics, so much so that I began to look into what jobs were available for nurses who wanted to work in research. I applied for several research posts, including one at the Haemophilia and Thrombosis Centre in Oxford. I knew a little bit about bleeding disorders through my experience in intensive care but thought, "I know It's a complete change of speciality, but it's something that interests me – let's go for it."

The haemophilia centre at Oxford was very much on the periphery of the hospital. Geographically, it was tucked behind several other buildings, hidden away – as was much of the work it did. Never at the front, the centre acted as a support team, helping patients live the lives they wanted, and providing advice and support to facilitate procedures and surgeries when required. Joining the centre as a research nurse, I found that my role was incredibly diverse and immensely rewarding. For patients, the decision to be part of a clinical trial is not always an easy one; it can be a step into the unknown, so the research nurse acts not just as a facilitator of the clinical studies but also as their advocate, teacher, guide, and 'travelling companion'.

In my previous nursing roles, I had not often seen people with bleeding disorders, and my knowledge was limited – I would not have felt confident in caring for someone who had one, and I doubt many of my colleagues would have either. I knew a little about haemophilia, von Willebrand disease and trauma-induced coagulation disorders, but rare bleeding disorders were a complete mystery. Trying to improve my own and other people's understanding of bleeding disorders and what they mean to those who live with them is now a big part of what keeps me working in the field.

INSIGHTS ON ASPECTS OF GENE THERAPY

At the time I became a research nurse, haemophilia care was going through a time of huge change. After many years of only standard factor treatment, clinical trials had shown extended half-life factors were effective and reduced treatment burden [2]. Early research into factor VIII mimetics for people with haemophilia (PwH) and inhibitors had begun and would also soon be available [3,4]. Trials were also beginning for gene therapy, and this became a personal interest for me.

Gene therapy, offering the possibility of a functional cure for haemophilia, had been a much-promised 'silver bullet' for many years, but had remained the stuff of science fiction rather than something for the here and now. I had always thought having gene therapy for haemophilia was an obvious choice – a 'no brainer', if you will. Why wouldn't anyone want to be relieved of the burden of having to treat yourself every other day or every third day? Why wouldn't anyone want relief from the risk of bleeds and the attendant pain and mobility problems?

I was surprised, then, when an individual with severe haemophilia told me that, though it would be good not to have the bleeds or the need for prophylaxis, he did not want to have gene therapy because it would change his perception of who he was. To him, haemophilia was a part of his identity and he was reluctant to lose that in some way. Since then, I have heard this from other PwH, and come to understand that gene therapy might not be the answer for everybody [5]. For some, their current treatment allows them to live the life they want and they are happy – they have grown up with haemophilia, it is part of who they are, they are proud of who they are, and they see no reason to change things.

Another individual with haemophilia highlighted a different aspect of gene therapy that I had not considered. He was excluded from a clinical trial, and the loss of the opportunity to have gene therapy and not have to worry about his haemophilia was devastating. He became depressed and stopped taking his treatment for a while [6]. The sense of loss was felt by his whole family, too. Haemophilia affects not just the person who has it – it is a family thing, impacting who they are and who they might be as a unit. Every time I think about this, I am reminded of the poem 'No man is an Island' by John Donne:

> No man is an island,
> Entire of itself,
> Every man is a piece of the continent,
> A part of the main.
>
> (Meditations 17) [7]

It also made me think about the hopes and expectations of the haemophilia community around gene therapy, and how they may be different from reality [8]. Making sure that PwH and their families were fully prepared for all the eventualities became an important element of care for me, and also that systems are in place to support them if things perhaps do not go as hoped.

NEW TREATMENTS AND QUALITATIVE RESEARCH

Together, these conversations made me think more deeply about how haemophilia impacts an individual's identity and the importance of gene therapy to the haemophilia community. They were the spark for me to take being a research nurse a step further and start my PhD, examining the impact and experience of gene therapy for haemophilia [9].

For my PhD, I interviewed many PwH to learn more about what gene therapy means for both themselves and the wider haemophilia community [3,4,10]. I have always felt that listening to what people have to say and hearing their stories is an important part of my nurse role. Understanding who people are, what they understand about their condition and helping them cope with it has been important to me. The stories I have heard have made me think differently, challenged my assumptions, and prompted me to make changes in the care I have given. The work I now do with Haemnet as principal researcher is, I feel, a logical extension of this and a way of helping improve the care of a larger group of people.

In qualitative research, you use the stories you hear to form a web of ideas and concepts. One person might talk about loneliness and isolation; another may tell a very different story but also talk about loneliness and isolation – and when you find a third, fourth or fifth person mentioning this in their stories too, you know that there is an issue that can be extrapolated more widely. These stories might be within an individual qualitative study or between different studies using meta-analytical processes [11,12].

Qualitative research also helps in understanding the nuances of living with a bleeding disorder. It is always important to understand the clinical and quantitative data, whether a treatment works or not, but it is also important to understand what the treatment might mean to the person who has to have it. Someone might tell you, for example, that a new treatment stopped them from bleeding so frequently, but that it did not improve their mobility or their experience of pain in the way they had hoped. Understanding this can help in focusing care and support. Qualitative research highlights those experiences which cannot be quantified. It can show how 'works' and 'doesn't work' is a continuum rather than a binary concept. Ultimately, we can only really understand what works or does not work for an individual if we ask.

SIMON'S RECOMMENDATIONS FOR OTHER HEALTH CARE PROFESSIONALS

- **Listen to yourself and be willing to take a leap of faith** – If that voice inside tells you it is right, it may well be.
- **Embrace new ideas** – Never be afraid to use transferable skills or knowledge from other areas; the wheel may already have been invented.
- **Listen to what people say** – Hearing their stories will prompt a greater understanding of their situation and enable you to adapt for their benefit.
- **Collaborate** – Building relationships with clinical teams and other specialities benefits you, the other teams and most importantly, the patients you care for.

COLLABORATING FOR PATIENT BENEFIT

First and foremost, I am a nurse and would never want to lose that – but I am also a researcher, and I have come to realise that I can be both simultaneously.

Many bleeding disorders specialist nurses are involved in research within their centres, but many feel that clinical care is, and should be, the focus of what they do. As a research nurse, while the primary focus is the clinical trials process, patient wellbeing remains just as important.

When I worked at the Oxford Haemophilia Centre, there was a lot of interconnectedness between me as the research nurse and the clinical nurses – it was a collaborative relationship. In this way, we were able to have frequent regular contact, meaning that I knew what was going on with the patients they were caring for and, therefore, who might be eligible or ineligible for clinical trials, and they knew what was happening with anyone in any of the trials. This sharing of information also meant that when a new treatment became licensed and available, my clinical colleagues had some knowledge about it. Having clinical trials, research, and a research nurse embedded within the haemophilia centre enables that, and I think this will continue to be important as even more new treatments are developed.

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Beyond local changes, I have been fortunate to see the papers I have written for my PhD have a wider impact, and been invited to speak at conferences for both patients and healthcare professionals. Never did I think, even in my wildest dreams when I started nursing 36 years ago, that this would have been my career trajectory.

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