NURSE FOCUS

Living, Caring, Learning – Reflections on the therapeutic relationship in haemophilia care

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Now nearing retirement, Regina, who was involved in establishing a haemophilia programme for children and young adults in the United States, reflects on the therapeutic relationship between haemophilia nurses and their patients. Having been involved in haemophilia nursing in the 1980s, Regina's practice has been influenced by her experience of caring for young patients who were infected with HIV/AIDS following treatment with contaminated blood products. She considers compassion and emotion in nurses' relationships with their patients and highlights the key role of contact with colleagues and peer support, particularly during difficult times. While trust is an essential part of the therapeutic relationship and is valued by both the patient and the nurse, Regina reflects on how this can result in dependence. She points to the importance of setting clear boundaries and how this ensures that the patient establishes trust with the wider team or system delivering their care, not just an individual nurse. In her roles as clinical manager, haemophilia centre director and nurse coordinator, this is now part of the advice she shares with her own team. Despite a sense of caution about new therapies as a result of her experience during the 1980s, Regina has been involved in gene therapy trials and feels that the future looks positive for people with haemophilia.

Keywords: *Haemophilia; HIV; Acquired Immunodeficiency Syndrome; Therapeutic relationship; Nurses; Professional practice*

When I started working in haemophilia care in 1973, there were no haemophilia treatment centres (HTCs) in the United States (US). I arrived at the Children's Hospital of Philadelphia to help set up a haemophilia programme and it was terribly exciting. I had so much

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to learn, much of it from the patients and their families. We started with 33 children and young adults with haemophilia; today we have 450. We've gone from spending all day infusing factor, treating bleeds, and making splints, to focusing on patient education, bleed prevention, carrier detection, treating girls with bleeding disorders, developing outreach services and, most recently, getting involved in gene therapy trials. In 1997, I became Clinical Manager of the Division of Hematology and, in 2009, Regional Director of Mid-Atlantic Region III HTCs – the first director and the first nurse to become a director. This year, I'm going full circle as I start to wind down towards retirement – handing over responsibilities to wonderful colleagues in a service that has transformed since I started, with 144 HTCs across the US.

Being in haemophilia practice in the 1980s meant my early approach to care was shaped by the needs of the growing number of children and adolescents, and their families, living with HIV/AIDS as a result of contaminated blood transfusions. Suddenly, we went from a new era of home treatment, new factor replacement products, and caring for patients expecting to lead a near-normal life, to treating many children and young people who had developed what was, at that point, a terminal disease. Having been a cheerleader for all the new possibilities for people with haemophilia, I found myself giving parents the devastating news that their child had HIV.

THERAPEUTIC RELATIONSHIPS

Unsurprisingly, these patients and their families needed a lot of support. Looking back, I have come to realise that I allowed many to develop a dependence on me that was not what we would today call a therapeutic relationship [1]. It is essential that patients and their families have easy access to a team of highly trained health care professionals (HCPs) who can respond to their different needs [2]. As individuals, we nurses understandably enjoy the trust and friendship that can develop, but there's a risk that this becomes a dependence. It's nice to feel needed, but allowing dependence to develop – either from the patient or mutually – means we minimise the ability of other team members to gain that patient's trust and help them.

During the 1980s, after being so excited about the possibilities for young people with haemophilia, the cumulative grief of seeing patients die from AIDS took a significant emotional toll on us. When we lost them, we felt as though we were losing family and friends. It's hard for any HCP to watch patients die, and essential that they have appropriate training and support. In a good therapeutic relationship, we cannot be best friend and confidante to our patients. If we do allow that to happen, it's likely to affect our own health and relationships.

At my centre, less than 20% of our children with haemophilia had HIV, partly because we switched back to cryoprecipitate as soon as we heard about the first cases of what came to be called AIDS. Even so, working in those very difficult early days, I benefited from connecting with nurses at other centres via a network set up through the National Hemophilia Foundation. I was also very fortunate to work with an amazing physician who volunteered to partner with me in caring for my young patients with HIV. We were all experiencing the tragic effects of HIV contamination of blood supplies on our patients, and it helped to be able to share the burden and to support and encourage each other.

EVOLVING APPROACHES

A turning point for me came when I was nine months pregnant. I felt a big responsibility to stay with a dying patient and attend their funeral before I was due to give birth. But I realised then that I had become too 'embedded' in the lives of my patients and started to re-evaluate my role and the importance of my own family.

We did discuss the problems of dependence within the team, and I also talked to the doctor who was my partner in caring for patients with AIDS. As a

Regina's recommendations for other health care professionals

- Remember you're not the only person who can help a person with haemophilia and their family – don't encourage a dependence on you alone
- Establish care pathways and boundaries that enable patients to get the help they need from a range of team members
- Make sure you have a good therapeutic relationship with the people you care for – and understand that letting patients have what they want isn't always in their best interests
- Share concerns and partner with other members of the care team for mutual support and encouragement
- Connect with nurses working in haemophilia at other centres for informal discussions and problem solving.

physician, she may have been better trained to deal with such painful situations. With hindsight, though, it would have been helpful for me to seek professional support. I couldn't abruptly change the compassion I felt for children who I'd known since birth, and for their families. However, as the team got bigger, I tried to involve other nurses more actively and not always be available myself. With new patients, I established appropriate boundaries; for example, parents had numbers to call during the day and at weekends, but they no longer had my home phone number. This benefitted our patients and their families as it enabled them to develop trust in the system that was caring for them, rather than individual nurses.

Nursing has evolved since those sad times. Training now includes education about the nurse-patient therapeutic relationship based on mutual trust and respect, sensitivity and support – without unhealthy co-dependence [1,3]. Today, I stress to members of my team that we want to do the best we can but have to set limits. We can't do everything our patients want: it isn't good for them or for us.

LESSONS LEARNED

I have a different role now, but I do still have twinges of regret when patients don't ask for me. We have a great team and any one of the nurses can help the children and families we care for and respond to their needs. That's how it should be, and we must all realise that we can't be everything to everybody! In general, I find that today's patients and their families understand that they are being treated by a team and everyone will do all they can to help them.

The whole experience of HIV/AIDS in the patients I cared for in the 1980s has made me cautious about new therapies. That said, we are in a different place now from where we were then and we know so much more. I was involved in some of the first gene therapy trials in the US and I believe that, in 2023, there is so much to be excited about for people with haemophilia, now and in the future.

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