NURSE FOCUS

Living, Caring, Learning – Setting boundaries for the wellbeing of everyone in bleeding disorders care

Cathy Harrison

CATHY HARRISON is an Advanced Nurse Practitioner in Haemophilia & Associated Haemostasis Disorders at Sheffield Haemophilia & Thrombosis Centre, UK. She was Vice Chair of the World Federation of Hemophilia (WFH) Nurses Committee and became Chair following the WFH 2024 World Congress.

Cathy, a haemophilia nurse specialist in the UK, reflects on a challenging patient with a rare inherited platelet disorder. The patient did not attend regular clinic appointments, and when presenting at clinic due to severe bleeding or feeling unwell was often aggressive and abusive towards staff. The care team were concerned that he was putting his health at risk and followed protocols for vulnerable adults to try and ensure he was accessing the care he needed. This involved bringing in expertise outside of the multidisciplinary team (MDT), including non-medical services. Steps were also taken to ensure staff safety and wellbeing through in-house psychological support and the agreement of strategies for dealing with difficult behaviour. Ultimately, it was necessary to find an alternative care pathway for the patient. While acknowledging her disappointment in this outcome, Cathy reflects on how the processes followed have reinforced the development of individualised care plans for all patients with complex needs, and the importance of access to specialist services beyond the MDT. She also highlights considerations around the safety and wellbeing of the care team, the role of discussion and 'debriefing', and the value of staff access to psychological support.

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I have specialised in caring for people with haemophilia and other bleeding disorders for more than 20 years – having worked in haematology, including in the haemophilia centre, with an amazing team after I completed my Advanced Diploma in Nursing Studies in 2002. As a specialist, I love the variation in my role and responsibilities, and the geek in me loves the science. I enjoy working as part of a wider multidisciplinary team (MDT) and being involved in education and research. We walk hand in hand with our patients with long-term conditions, from birth to death and all that goes between, and I am particularly interested in the management of patients' comorbidities alongside their bleeding disorders. As a former Chair of the UK Haemophilia Nurses Association, it was incredibly rewarding to help support nurses across the UK to work collaboratively with the wider community and to ensure their voice was heard, and I continue to advocate on behalf of our profession – and our patients – through the World Federation of Hemophilia Nurses Committee.

A CHALLENGING PATIENT WITH A PLATELET DISORDER

A patient who has had a big impact on my practice is Sam (a pseudonym). Sam had a rare inherited platelet disorder and we knew him at the centre from being a teenager transitioning from paediatric services. The outcome was not as we would have wished but we learned so much during the time he was in our care, and we continue to apply that knowledge for the benefit of all our patients.

No one else in Sam's family had a bleeding disorder. He did not attend bleeding disorder clinic appointments regularly, either during childhood or when he came to adult services. We saw him when he had severe bleeds or felt very unwell, but we rarely persuaded him to come to regular reviews. This meant we could not assess him for iron transfusions or other interventions aimed at preventing bleeds. Sam was angry with the world, and often aggressive and abusive with the care team. We were concerned that he was putting his health at risk but also about the impact his behaviour had on the nurses and other health care professionals who were providing care for him.

REACHING OUT AND SETTING BOUNDARIES

To try and help Sam, we followed protocols for vulnerable adults. This meant we could reach out beyond the MDT and bring in other expertise to help us gain insights and safely manage his care. These included primary care and dental services, psychology and ambulance services, as well extending to non-medical services such as housing and benefits agencies, the local council and the police, if needed. Being able to find out more about Sam's background helped us better understand his behaviour, although it remained a challenge.

We also needed to consider the impact of an ongoing situation with a difficult patient on the care team. We were able to access in-house psychological support for debriefing and discussion, and we used the Boundary Seesaw Model [1] to identify where our boundaries for dealing with challenging behaviour were too rigid or too relaxed. We agreed an 'escalating' series of responses with explicit limits that we could all adhere to. At the most basic level, this involved strategies such as giving a warning for abuse on the phone and hanging up if the abuse continued. Unfortunately, as Sam's behaviour worsened, we ultimately had to find an alternative care pathway for him.

LEARNING POINTS

Having to discharge a patient from routine care was disappointing, but staff wellbeing and safety should never be undervalued. Being able to access psychological support was immensely helpful. Initiating vulnerable adult procedures was important and enabled additional support for both the care team and for Sam.

Having clear care plans in place is essential in ensuring that everyone understands their responsibilities and how to respond to challenging situations. The processes and procedures we followed in Sam's case have reinforced the way we develop care plans for all patients with complex needs, tailored to their individual requirements. It is important that patients understand who to contact in different situations, whether they have a headache, cough or cold, or a major bleed – and whether that is via a standard or a non-standard care pathway. Our ageing bleeding disorders population means that we are seeing increasingly complex patients, so we need to be aware of all the specialist services they may need to access [2,3].

At a personal level, I feel a big responsibility to support staff. I spent time following up episodes of abuse or threats, listening to concerns and taking steps to protect people, especially specialists working on their own, separately from the MDT. However, I came to realise that I could not be everywhere and do everything. There was a temptation to think that what was happening to staff was my fault and I had to realise this was not the case. I have learned – and am starting to get better at – how to say 'no' when things are getting too much.

CATHY'S RECOMMENDATIONS FOR OTHER HEALTHCARE PROFESSIONALS

- Ensure that everyone is 'on the same page' – nurses, consultants, psychologists, physiotherapists, social workers and junior doctors
- Check that all appropriate safeguarding procedures are in place
- Develop and implement individualised care plans tailored to the needs of specific patients – not just to their bleeding disorder
- After any incident of abusive patient behaviour, make sure there is an opportunity for a full debrief with psychological support and time to reflect on what has happened and what could be done if there is a 'next time'
- Understand and implement vulnerable adult procedures as needed

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