NURSE FOCUS

Living, Caring, Learning – Listening to patients with bleeding disorders and not being afraid to advocate

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MICHELLE WITKOP recently retired as Vice President, Research Strategy, National Hemophilia Foundation, and was previously Lead Clinician-Nurse Practitioner at the Northern Regional Michigan Bleeding Disorders Center, USA

Michelle brought experience of working with people with chronic pain to her role as a bleeding disorders nurse, before going on to develop a research department at the National Hemophilia Foundation (now the National Bleeding Disorders Foundation). Reflecting on the pain experienced by various individuals she cared for, she highlights the importance of listening carefully to what patients have to say and the value of patient-reported information. Michelle explains how understanding this led her into patient advocacy, and how nurses acting as advocates for their patients supports their care and thereby enable people with bleeding disorders to live the best life they can.

Keywords: *Bleeding disorders, Chronic pain, Patient advocacy, Nurses, Professional practice*

In the early 2000s, I was working in chronic pain and palliative care. A colleague caring for patients with bleeding disorders told me she saw a lot of chronic pain in her clinics and asked if I could help. As I was already doing the same for patients with HIV, I agreed. I spent the next year learning about bleeding disorders and helping patients with their pain and, when my colleague left, I was asked to take over her role.

It was a small haemophilia treatment centre and we had access to a physiotherapist, nutritionist and social worker. When the physician support ended, I became lead clinician. I felt it was really important to keep the

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centre open because some patients already had to drive four hours to get to us – if we closed, it would be another four hours to reach the next centre. With the support of a haemophilia specialist from a distant centre, we organised jointly-run clinics and treatment planning, and I also held telehealth consultations to get input from specialists in other parts of the state. By the time I left, 16 years later, we'd gone from 50 patients to nearly 200.

During that time, I became increasingly involved in research, starting with a study showing that people with haemophilia were consistently and inappropriately using factor to manage their chronic pain [1]. In 2017, I was asked to develop a research department at the National Hemophilia Foundation (NHF; now the National Bleeding Disorders Foundation (NBDF)). I was initially reluctant to leave clinical practice, but the opportunity to affect multidisciplinary practice and patients at national level seemed too good to pass – and I was right. I am so proud of what the NHF has achieved, including a community-generated national blueprint for future research in inherited bleeding disorders [2,3]. It's been a wonderful journey and, though I've retired from the NHF, I have had the opportunity to see the blueprint papers through to publication and help to develop a strategy for local priorities and implementation. I hope that others will find research as engaging and valuable in their working lives as I have.

THE IMPORTANCE OF LISTENING

I am not going to reflect on one particular patient with a bleeding disorder who has influenced my practice, but the many, many patients who have taught me the importance of listening to them. There was the woman with chronic pain who had a bad reaction when we changed her medication, which would not have happened if we had listened to her. There were the 50- and 60-year-old patients who used marijuana for their chronic pain before cannabis oil was legalised. We told them to stop but, after they had tried, they said they would prefer to stop their opiates. I came to realise the benefits of medical marijuana.

Perhaps the patient who influenced me most was a middle-aged man who had a huge retroperitoneal bleed which kept him in hospital for three weeks. He had an inhibitor but we were unable to tolerise him. At 20, he had been told he would die young, so he had decided to live life the way he wanted. When he started coming to me, I gave him a treatment plan but he decided what he would or would not do. He had terrible joint damage and he would come to see me on crutches. However, he would say that his pain was only a 2 or 3 on a scale of 1 to 10. I told him my pain levels were a 7 or 8 just watching him – I thought he could not possibly be in so little pain.

I started to realise that I was filtering out a lot of what my patients told me instead of really listening to them. I was looking at them through my eyes and with my expectations and perspective. As a result, I was missing key information that could affect their care – and the care of other patients. Some of what my patients told me was not evidence-based, but I began to realise the value of patient-reported information.

Through NHF, we developed a patient registry called Community Voices in Research which collects information from people directly affected by bleeding disorders [4]. Some providers have questioned the validity of this information because it comes directly from the patient and is not validated by a provider. But who are any of us to say that something our patients tell us is not valid? We really need to hear patient voices directly, without filtering what they say. That realisation probably impacted my practice more than anything else.

PATIENTS FILTER TOO

Of course, the filtering happens in both directions. Our patients treat themselves at home and we have to assume they are doing what we have advised them to do. When they come to see us in clinic, though, they often say what they think we want to hear.

One patient I cared for lived alone, and I arranged for their factor treatment to be regularly delivered to their home. I had to assume they were taking it and I made sure their supply would be enough to cover their treatment. However, one day, they were cleaning out their refrigerator and returned bags full of unused product, most of it expired. They had no idea of the cost so I sat them down and explained. They were pretty shocked and we agreed that, in future, I would give them two doses at a time. If they needed more, I would send it to them.

BLEEDING DISORDER NURSES AS ADVOCATES

My growing understanding of the importance of really listening to the patients I cared for took me into advocacy. Few of us like confrontation but we should not be afraid to stand up for patients with colleagues when we feel they are not being heard.

I remember one patient with von Willebrand disease who managed her disorder very well and rarely needed help until she broke her arm in an accident.

MICHELLE’S RECOMMENDATIONS FOR OTHER HEALTH CARE PROFESSIONALS

- Listen to your patients without filters, advocate for them when needed and be prepared for difficult conversations
- Feel comfortable in your skin and recognise that not everything will go smoothly
- We often learn best from difficult times; we should not look at them as mistakes or failures but as opportunities to learn

Her physician told her what action to take but the more insistent he was, the less she wanted to take his advice. I had been attending leadership classes as part of my doctorate and felt that I should step in on the patient’s behalf. It was not easy and I needed to walk a fine line, but as nurses we are not just conduits between our patients and their physicians. We should be able to advocate on their behalf so that their views are respected and, where necessary, compromises are reached.

Part of nursing is being a detective – looking around corners and behind doors, and really understanding what makes our patients tick and why they do the things they do. It is not our job to be friends to the physicians we work with; it is our job to understand the patients we care for and advocate for them so they can live the best life they can.

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