

NURSE FOCUS

Living, Caring, Learning – Trust and teamwork in patient care

Marcela Ganzella Sisdelli

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Marcela, a nurse specialist in Brazil, reflects on the importance of trust in the therapeutic relationship in achieving the best patient outcomes. She describes her experience with a patient with severe haemophilia A and an inhibitor. The patient was non-adherent to his treatment regimen and immune tolerance induction (ITI) failed. At a time when he was experiencing increasing joint problems and pain due to bleeding, the treatment centre was approached regarding a clinical trial of a novel non-factor replacement therapy. Following discussion among members of the care team and with the patient, a decision was made to put him forward for the trial, despite concerns about his ability to adhere to the trial treatment regimen. The patient completed the trial, his quality of life improved and he continues to have prophylaxis with emicizumab. Marcela goes on to reflect on the role this new treatment likely played when the patient was involved in a serious accident and the surgeries that followed. She highlights the importance of not giving up on patients who present a challenge and working closely together with treatment centre colleagues to achieve the best care for individual patients.

Keywords: *Haemophilia A; Inhibitors; Treatment adherence and compliance; Therapeutic relationship; Nurses; Professional practice*



Working with bleeding disorders has become my passion – I don't know if I chose them, or they chose me. In 2009, I was working in the ER at the Ribeirão Preto hospital when I was invited to join the Blood Center. It is one of the largest hemotherapy and haematology centres in Brazil and cares for about 500 patients with bleeding disorders. Our team has 14 nurses and about 20 other support nurses, who provide care for patients with haemoglobinopathies, blood cancers and bleeding disorders, as well as blood donors. I am one of four specialist nurses who treat bleeding disorders, along with four doctors. I really like

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working with my patients and their families – not just with treatment but educating them about their bleeding disorder. Sometimes mums who carry the haemophilia gene feel guilty that they have passed on the condition to their children, and I help them understand that it is not their fault.

I have Masters and PhD degrees from the University of São Paulo, and I participate in research projects to benefit patients. I am also a member of the World Federation of Hemophilia Nurses Committee. I strongly believe in the importance of integrating nurses within the multidisciplinary teams (MDT) that care for people with haemophilia and other bleeding disorders around the world ^[1].

PUTTING TRUST IN A CHALLENGING PATIENT

I would like to tell you about Francisco (a pseudonym), a young man with severe haemophilia A. He was 14 when I first met him and has taught me so much about engaging with patients and working with colleagues.

Francisco found it hard to stick to his factor VIII (FVIII) treatment regimen. He developed an inhibitor and we wanted to try immune tolerance induction (ITI) but, given what we knew of him, we were not sure he would be adherent to the treatment. We talked to him a lot about his haemophilia, the complications of having an inhibitor and the importance of adherence for ITI to work. He understood what we said, but he sadly he did not follow the treatment regimen and ITI failed. It was really disappointing for the team, but Francisco didn't seem to mind and he went back to his previous treatment. However, his joints got worse because of all the bleeds he was having, and he had a lot of pain in his shoulder and knee. He started coming to the centre almost every day for medication to ease the pain. It was a hard time for all of us – we wanted to help him but we didn't know what more we could do.

A few years later, when Francisco was 25 years old, the centre was approached about taking part in a trial of a new medication, a monoclonal antibody ^[2,3], in patients with severe haemophilia A with inhibitors. We could only put two patients forward for the trial, and my colleague, Dr Luciana Oliveira, suggested Francisco. It was a really hard decision because if he did not adhere to treatment his place in the trial would be wasted and someone else would have lost their opportunity. We thought about it a lot and, in the end, we put Francisco forward because he had suffered so much. If this new medication worked for him, it could really help him.

We called Francisco in, together with his parents, and explained the importance of the trial and the need to take responsibility for adhering to treatment. We just could not fail this time. He said he really wanted the opportunity and he did not let us down. He completed the trial and the medication worked really well for him – his joints stopped bleeding and his life became so much better.

Some years later, Francisco was in a bad accident. He had multiple fractures requiring surgery and our team advised the hospital about the infusion of bypassing agents (FVIIr) he needed ^[4,5]. The surgeries were successful and he was discharged from hospital. However, he came to us some days later looking very pale and with pain in his right arm where he had had surgery. His haemoglobin was extremely low and he was bleeding. He had to have further surgery, again with us advising on infusions. Thankfully, it was successful. Francisco came into the centre later to thank us for all we had done. He continues to do well but if he had not been using his medication at the time of the accident, I am not sure he would have survived. I think prophylaxis with this novel treatment made all the difference for him in an accident of this severity, and also during surgeries with such a high bleeding risk.

NEVER GIVE UP!

As you may have guessed, the main lesson I took from this experience was 'never give up on your patients'. With the clinical trial, we might have decided not to take the risk that Francisco would not adhere to the treatment regimen, but we took the time to explain the importance of the study to him. We trusted him to do as we asked and he did not let us down. He benefited so much from that decision and continues to be treated well with this medication today.

In Brazil, we have almost 14,000 patients with haemophilia, 11,000 with haemophilia A. The government provides very good, free haemophilia care, including factor concentrates. However, this particular treatment is only available for people with haemophilia A who have an inhibitor and have tried ITI.

WORKING TOGETHER

At the Blood Centre, we are an MDT and work closely together to make decisions about the care of our patients. We listen to each other and learn from each other's experience because we cannot all know every patient and what is best for them. We each have our own role but we work together with a common goal to focus on the patient and their family. We talk whenever

we need to align in our response to a specific challenge and we certainly talked a lot together about Francisco before putting him forward for the trial.

My experience with Francisco taught me the importance of such an approach and the value of taking time with families so they understand what we are proposing and why their full commitment can make such a difference. On a personal level, it was very rewarding to see Francisco take responsibility for adhering to his medication so well during the trial and, as a result, how much he has benefited.

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MARCELA'S RECOMMENDATIONS FOR OTHER HEALTH CARE PROFESSIONALS

- Don't give up on your patients even when they are very challenging. Always try again!
- Be ready to catch any opportunities you are offered for your patients, e.g. clinical trials
- Respect everyone's skills and opinions within the MDT – there is always something to learn from each other

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