NURSE FOCUS

Living, Caring, Learning – Addressing challenges in the transition to adult care

Greta Mulders

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Greta, a specialist nurse at one of the largest haemophilia treatment centres in the Netherlands, reflects on the role one particular patient played in helping to reshape her centre's approach to the process of transition from paediatric to adult care. The patient, a young man with severe haemophilia B and an inhibitor, experienced frequent bleeds and venepuncture was sometimes difficult. He continued to be reliant on his mother to administer injections and order his treatment. Greta considers the importance of ensuring young people transitioning to adult care have the knowledge and skills they need to manage their haemophilia while balancing this with the reality of an individual's circumstances, often including the ongoing role of parents in their lives as supporters and caregivers. She suggests that transition is best approached as a gradual process rather than an event, reflecting on how this helps to build trust between the new health care team and both the patient and their parents. She also points to the importance of supporting parents through the transition process as needed. Greta is clear that an approach to care that seeks to understand individuals and acknowledges the feelings of everyone involved can make a difference in enabling successful transition to adult care and in patient care more generally.

Keywords: *Haemophilia; Transition to adult care; Therapeutic relationship; Nurses; Professional practice*

I became involved in bleeding disorders in 2003 when I was working in oncology and haematology at Erasmus University Medical Centre. I was asked to support the haemophilia nurse for three days a week at the haemophilia treatment centre, and this soon became full time. It is one of the largest centres in the Netherlands and we have over 1000 adult and paediatric patients with haemophilia and allied bleeding disorders. I work with adult patients and found the work very interesting and enjoyable from the start. In 2008 I started a Master's Degree in Advanced Nursing Practice, specialising in bleeding disorders. My thesis became my first publication [1] – it is important to write down and share our investigations and our findings.

It was after completing my Master's that nursing research really got my attention – so, at a relatively late stage in my career. I became more involved in research and clinical trials, as well as becoming much more aware of the need for improvements in care. This led me to start a PhD investigating potential improvements in haemophilia nursing care in the Netherlands. I started last year and try to work one day a week on it. It is very challenging to fit it around my clinical work, as patient care always takes priority! Clinical practice leads to questions – and that's what nursing research is all about. For example, when there was no consensus on how to treat patients with haematuria, I started a search and found a urologist to establish a guideline [2]. When we saw bleeds after dental surgery (with prophylactic treatment), I initiated a project focused on the dental health of people with haemophilia treated at the Erasmus Haemophilia Centre [3]. Our results showed that they had good dental and oral health status but, of course, in healthcare there's always room for improvement.

A PATIENT PREPARING FOR TRANSITION

When we take the time to listen to and understand them, the patients we care for as haemophilia nurses can contribute a lot to how we adapt and improve our clinical practices. There is one boy in particular who I will never forget, and who had a lasting impact on the way I support young people who are making the transition from paediatric to adult care.

Joris (a pseudonym) was almost 18 when I met him, but he looked much older. He had severe haemophilia B with an inhibitor, which is quite rare. He was very direct, and his humour and sense of irony appealed to me. The first time I saw him for a regular appointment at the adult hospital we briefly discussed the management of haemophilia but he much preferred to talk about football, school and his mates. In contrast, his mum wanted to know everything about his care, his laboratory results, and changes in treatment or support now that he was under adult care – how to order clotting factors, who she could call in acute situations and all the names of the new haemophilia team.

Transition is not just about the patient and care team getting to know each other, families are very involved too. Joris's mum continued to order his medication, made repeat appointments, collected his medication, did his home treatment and wrote the administration neatly in his logbook. Joris had a lot of bleeds, and venepuncture was sometimes difficult.

Just before the school holidays Joris came on an organised sailing weekend with a group of patients of the same age and a few medical staff members from the centre – I was one of them. In no time at all, those very different young men with haemophilia were a team and Joris set the pace – telling jokes and handing out sweets! The weekend was fun, the sun was shining, and Joris appreciated and understood all the boys who were there.

During the weekend, when it was time for prophylactic treatment, I assisted Joris with the injections. I noticed he was embarrassed that he didn't do it himself. We invented a ruse to explain why I was doing his injections for him, and he agreed to follow a training course when he got home. He told me: "My mother does it mostly, I try it sometimes but I often get it wrong, I want to learn it again, because I want to go to Spain with my friends."

In his injection bag he kept a silver charm in the form of a guardian angel – his mother had given it to him to keep him safe. On the outside he was such a big guy, but underneath that he was an insecure boy.

MAKING TRANSITION INCLUSIVE

Transition from paediatric to adult care can be more complex for some patients than others. They all deal with it in different ways, including the parents – many mothers may seem over-protective [4]. I have known patients in their forties who live with their parents, and the mothers still order their medication. Is that overly protective or, if both mother and son are happy with the arrangement, who are we to say they should do things differently? Having said that, we need to make sure our patients are equipped with all the knowledge and skills they need to look after themselves on their own and manage their haemophilia in a way that is individualised and safe [4,5].

At the centre, we see transition as a process, not a stage. We start preparing children for transition when they are 12 years old, and find the 'Ready, Steady, Go' programme of checklists and questionnaires useful tools during the transition years [6]. Every second year, we organise a Transition Day, where paediatric and adult patients aged 14-23 years come together, along with their health care teams, so that everyone gets to know each other in an informal way. We also hold activity days during the transition period, with exciting things to do, such as car racing and fencing, as well as educational sessions about haemophilia and latest treatments.

LETTING GO IS NEVER EASY

As a mother, I know how hard it is to let go. It's not surprising that some parents of children with a bleeding disorder find it so difficult. We can tell them that everything will be fine and encourage them to trust the new team caring for their children. But time to gain this trust is the most important thing – they need to experience their children growing up, being independent and doing well. When adolescent children reach the stage of transitioning to adult care, we invite parents to come to appointments, and also have parent-only focus group discussions where we talk about ‘letting go’ with our social worker and discuss the issues that concern them the most.

We used to slightly ignore parents when their children started coming to adult clinics, asking them to stay in the waiting room and not to be in the consultations. These days, we invite parents to come in, as long as the young adult patients give their permission – it’s their decision. Some parents just come to the first adult appointment while others continue for some time. My experience with Joris– understanding his feelings, the difficulties he experienced, and the importance of his mother’s support – contributed to this change. Tremendously sadly, an accident that left Joris with fatal injuries meant that I never did teach him to treat himself and see him become more independent. But his legacy helps all of us at the centre to support young people in successfully making the transition from children, dependent on parents to help them live with a bleeding disorder, to independent adults ready to look after themselves.

Joris’s mother came back months later to deliver his remaining medication. She said that during the last days of his life I’d been a haven for them, thanked me for this and gave me his guardian angel charm. This gesture comforted me and it became clear to me again that, in nursing, we can make all the difference.

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GRETA’S RECOMMENDATIONS FOR OTHER HEALTH CARE PROFESSIONALS

- Don’t lose sight of caregivers – include parents in the transition process
- Try not to immediately say ‘no’ to young people with bleeding disorders – ask them if what they are proposing is a good idea and be prepared to support them with factor cover while they discover boundaries for themselves
- Keep barriers between you and your patients as low as possible, and take time to find the right words to answer questions, especially those about sex, drugs and alcohol in the adolescent stage of life

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