

COMMENTARY

Nurse-led research offers unique insights into patients' psychosocial concerns

Vicky Vidler

As human beings we are all complex, diverse and unique; we are all influenced and honed by many different factors; our childhood and up-bringing, our life experiences; both positive and perhaps more significantly, negative experiences. Of course, for an individual with a life-long health problem this is an additional and very significant strand to their personality and psyche.

Two nursing papers published in this first edition of *The Journal of Haemophilia Practice* add to our understanding and awareness of two aspects that are fundamental to the care and support that we, as healthcare professionals, offer to children and young people with haemophilia and their families.

Anica Phillott has sought to consider how boys with haemophilia and inhibitors and their parents view their quality of life and the impact that the added complication of having an inhibitor places on them [1]. Using a qualitative research methodology, semi-structured interviews and a careful process of analysis and consideration of common themes we are given an insight into the uncertainties and limitations of treatment that inhibitors place on families and the stress and distress this causes.

The responses from all of the parents involved were positive and appreciative of the care and management provided by specialist haemophilia healthcare professionals. Conversely, they expressed some concern and frustration at the lack of knowledge and awareness demonstrated by non-specialist healthcare professionals. It is suggested that out-of-hours care is an area that could be reviewed and alternative care pathways considered.

Kate Khair and colleagues have taken us into a different sphere of childhood and have considered those from whom children with haemophilia seek support [2]. Perhaps, not surprisingly, at least in the early years, support primarily comes from their parents. However, as a child grows they start to seek emotional support from their

siblings and friends. This paper also emphasizes the contribution that other affected family members can make. Sometimes this contribution can be less than helpful because of the past treatment problems and the fact that modern day treatment is very different from even that of just a few decades ago. Nevertheless, generally, an affinity across the generations because of a shared experience of haemophilia is seen as empowering and valuable.

Considerable thought and effort has been put into ensuring that the methods used to obtain information from the three different age-banded groups were appropriate and robust. As well as interviews with the child or young person with haemophilia the thoughts and feelings of their parents and siblings were also explored.

Both papers open an intimate window into family life and dynamics that we may not be able to access and appreciate in our routine clinical contact with families. As well as the important insights and understanding these two papers give us; they also emphasize the unique position nurses have in the multidisciplinary team. We are ideally placed in between families and other healthcare professionals and this enables us to consider many of the psychosocial issues that concern people with haemophilia and their families. This privilege and opportunity does much to enhance our understanding and ability to support and to act as advocates. Furthermore, by becoming more engaged and involved with the research process in its wide variety of applications we can ensure that our nursing contribution is valid, reliable and well supported by evidence.

Vicky Vidler, Nurse Consultant at Sheffield Children's NHS Foundation Trust

References

- 1 Phillott A. Boys and parents' perceptions of living with haemophilia and an inhibitor. *J Haem Pract* 2014; 1(1): 17-22.
- 2 Khair K, Gibson F, Meerabeau L, 'I can always rely on them': The importance of social support for boys with haemophilia. *J Haem Pract* 2014; 1(1): 10-16.