

Park, J., Scott, K., York, D. & Carnahan, M. (2019) *Haemophilia in Aotearoa New Zealand. More than a bleeding nuisance*. Abingdon: Routledge.

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Haemophilia is a blood-clotting disorder where the clotting process takes longer than usual.

Small cuts on the skin are usually easily treated with first aid, but bleeding deeper into muscles or joints can cause major pain and permanent damage. Although superficial bruising can look dramatic, the much bigger problems are often unseen. Internal bleeding causes the most damage and can lead to complications for a person with haemophilia. Some bleeding episodes occur as a result of injury (trauma), but many occur seemingly without cause. If untreated, bleeds can be life threatening, and immediate treatment is often necessary for bleeds in the head, throat, gut, or iliopsoas (groin). Thankfully, most bleeds can now be managed and treated effectively (<http://www.haemophilia.org.nz/bleeding-disorders/haemophilia/>).

The condition varies from mild (requiring treatment following trauma) to severe (usually treated with regular injections of clotting agent). Bleeds usually follow some form of trauma, but can also occur spontaneously for no apparent reason. The origin of the condition is genetic and usually known in families, but it can also occur with no previous family history. Predominantly a male condition, a milder form of the condition can be found with small numbers of women. All up, approximately 600 New Zealand residents are currently known to have the disorder.

Not surprisingly, research about haemophilia has been dominated historically by medical sciences. When the first study of its social dimensions was undertaken starting in 1994, there was no previous research of this type in New Zealand and very little internationally. Since then, Park and a series of research colleagues (including haematology collaborators) have undertaken a comprehensive programme of participatory research about this group, who are socially disparate in every way apart from a common medical condition (a biosocial community).

The book contains seven sections: a history of the condition in New Zealand, a medical overview, gender and haemophilia, technologies of care, the impact of Hepatitis B & C and HIV, the role of the national membership association and care provision and a conclusion. The writing is predominantly based on a series of research studies led by Julie Park and a series of co-researchers over the past 25 years. Park and co-author Kathryn Scott have strong interest and experience in medical anthropology; the other two co-authors (Deon York and Mike Carnahan) both have haemophilia and have been heavily involved in the national membership body and health professional roles. While Park's influence is clearly evident throughout, it is not always clear who has co-authored the different sections. Additional researchers in the various studies are named in the chapter references, but

presumably have not been involved in writing the different chapters where the research is used.

There is always a danger with books based on completed research studies that the book can lack a distinctive character independent of the original research, but the authors have managed to avoid this pitfall and the end result is an integrated and coherent stand-alone publication that draws skilfully from the body of research they have undertaken.

The span of the research and the book's content is extensive and fortuitous in that it covers a range of significant developments in the New Zealand health sector, from the re-organisation of health service provision and funding, major health crises such as the contamination of the blood supply by hepatitis (B and C) and HIV, the development of treatment and testing innovations and the role of voluntary organisations such as the Haemophilia Foundation, which has sought to ensure equitable provision for people with haemophilia generally as well as minority groups within its membership such as women, Maori and those living in remote areas. The role of the Foundation is a real strength of the book, clearly describing and analysing the role of patient advocacy groups such as the Foundation, how they need to evolve to meet changing environments while always remaining in close contact with members. The book clearly demonstrates how the success of the national foundation was built on the skills, knowledge and commitment of a strong cadre of office-holders lobbying and influencing not only national politicians, but also health bureaucrats and specialist practitioners. This aspect of the book should be of interest to a range of other health and social service organisations who struggle to have their voices heard in the health arena.

So, what other audiences might be interested in this publication? Anyone with an interest in health reforms over the past two decades will gain an insightful view of these reforms from the perspective of a particular group's needs and perspective.

The book demonstrates the distinctive value of seeing health issues through the standpoint of the people involved; the interview narratives from the various studies add an invaluable and insightful dimension to the discussion. Furthermore, the researchers' commitment and skills in working alongside the haemophilia community is exemplary and provides an excellent example of the benefits of participatory research.

Finally, the book will provide a useful resource for many medical practitioners who, although they may only come across haemophilia a few times in their working lives, will gain a much broader understanding of the condition's biological basis and its social influences and be able to make more informed decisions about treatment and referral than a vague 'oh yes, I remember they mentioned that in fourth year.'

John Benseman has a son with haemophilia, as did his late grandfather Merv Hancock, sociologist and family counsellor.