

## Telling genes: the story of genetic counseling in America

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This is a comprehensive history of the development of the genetic counselling profession in America, although it must be said that it relates purely to North America, specifically the United States. The author is an historian and I found her research into the establishment of genetic counselling in the US by Sheldon Reed particularly impressive. Following an initial general history chapter, the book is organised into themes, including race, disability, prenatal diagnosis and a specific chapter on the contribution of women to the profession. The description of genetic counselling in the modern era is confined to that offered by genetic counsellors and does not include the same types of activities undertaken by medical geneticists or other health professionals.

As a genetic counsellor, I found it interesting to look back on the antecedents of the modern genetic counselling profession. While there have been many changes due to the availability of advanced technology, the wish to address human needs is still clear in the many quotes from genetic counsellors. In one section, the author cites (p167) a woman who stated in 1977 that the most difficult part of prenatal testing was ending the pregnancy; this is no less true today, as evidenced by research into patient perspectives on non-invasive prenatal diagnosis.

The book includes a discourse on the challenges involved in providing genetic services in the context of race or cultural differences, particularly as US genetic counsellors are predominantly from white middle class backgrounds. The section on the tensions experienced by genetic counsellors in relation to providing support for

those with a disability, alongside offering prenatal testing for the same conditions, is well covered. The topic of non-directiveness is also addressed, placed into the historical context of Rogerian counselling, with the changing views on the effectiveness of using a non-directive approach. However, it would have also been useful to bring Kessler's views on non-directiveness versus coercion into the discussion. As with much of the book, I felt that this area of the book was incomplete and would have benefitted from bringing the discussion into the present with more current perspectives.

There is a strong focus on particular personalities; in some cases (e.g. Sheldon Reed), this is entirely understandable. However, in other areas of the book, the reason for selectively discussing or interviewing particular individuals is not clear and the opinions of some informants are treated as factual. The book would have benefitted from a more critical appraisal of the material. For example, in one quotation, a contributor states that genetic counselling has proven its worth in getting patient-centred care into clinical medicine. There are health professionals in many settings with a long history of patient-centred care who would challenge that statement.

In the final chapter, the author does attempt to look to the future with a discussion of the emergence of direct-to-consumer genetic tests and non-invasive prenatal testing, but there is little real synthesis of the different views of the future of genetic counselling. Overall, this is an interesting historical text that will add context to the practice of genetic counselling in North America and beyond.

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