

The best experts: The narratives of those who have a genetic condition

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Abstract

In recent years, there have been growing expectations about the future benefits deriving from the uptake of genetics knowledge in healthcare. At the same time, there have been increasing calls to make greater use of patient expertise in treatment. However, relatively little is known about the experiences, needs and expertise of those who currently have a genetic condition. Drawing on the findings from an Australian study involving 21 semi-structured interviews with members of support groups which represent those with various genetic conditions (cystic fibrosis, haemochromatosis, haemophilia, and thalassaemia) this article discusses how individuals learn about, live with and manage their condition, and assesses the extent to which their experiences differ from those with other chronic illness conditions. It argues that while the experiences of individuals who have a genetic condition would appear to be similar in many respects to those with other chronic illnesses, they tend to encounter particular challenges in managing their condition due to its inheritable nature.

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Introduction

Recent developments in human genetics have led to growing expectations about the medical benefits deriving from the uptake of genetic knowledge in healthcare. In the UK, the publication of the Genetics White Paper, *Our Inheritance, Our Future: Realising the Potential of Genetics in the NHS* (Department of Health, 2003), is indicative of these expectations. This foresees such innovations as new tests for gene disorders, improved preventive and monitoring services for those at risk of developing disease and the development of new drugs and novel therapies (Department of Health, 2003, pp. 12–19). Along with growing expectations of new applica-

tions of genetic knowledge in healthcare, there have been increasing calls to make better use of patient knowledge in treatment. It has come to be recognised that patients are an untapped resource of expertise in that they often know more about their particular condition and its management than their doctors and that this knowledge may assist treatment. A publication of the UK's Department of Health, *The Expert Patient: A New Approach for Chronic Disease Management for the 21st Century*, for instance, notes that 'today's patients' can become 'key decision-makers in the treatment process'. By developing knowledge of their condition they can become 'empowered to take some responsibility for its management' and by 'work[ing] in partnership with their health and social care providers', they 'can be given greater control over

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their lives.’ (Department of Health, 2001; see also Donaldson, 2003) In the UK, an Expert Patients Programme was piloted in 300 Primary Care Trusts in England between 2002 and 2004 and there are plans to ‘mainstream’ it into NHS activity locally (NHS, 2005). In recent years, many ‘lay led self-management courses’ have been conducted, and more are planned in the future (NHS, 2005, p. 1).

Given this current emphasis in healthcare philosophy and policy, it is imperative that healthcare workers gain a better understanding of the experiences of those who have been diagnosed with a genetic condition, including the kinds of expertise they currently possess. An appreciation of how people who have a genetic condition respond to learning about their condition and manage any resulting disruption and threats to identity would seem to be crucial if healthcare workers are to know what kinds of information and support people are likely to need after a diagnosis has been made. The literature on illness narratives highlights some common aspects of the experiences of the chronically ill that may pertain to people who have a genetic condition. These include ‘biographical disruption’ and a sense of uncertainty, frequently accompanied by efforts to reconstruct the self and gain control over one’s situation (see, e.g. Bury, 1982, 1988, 1991, 2001; Charmaz, 1987, 2000; Robinson, 1988). As this literature emphasises, illness is an inescapably *social* experience. It is one dominated by technical expertise, including associated regimes of treatment (Frank, 1995). Modernist medicine claims control over ‘the body of its patient as its territory’, at least during the period of treatment (Frank, 1995, pp. 5–10). This ‘medical colonization’ entails the redefinition of the identity of the ill (from citizen to patient) and, while for some who are cured it is a temporary indignity, it may serve to permanently exclude the chronically ill (1995, p. 11). In many contemporary societies, the ‘healthy’ body is a key signifier of one’s moral worth and a mark of distinction, separating those who deserve to succeed from those who will fail (Crawford, 1994, p. 1354). Given the strong connection between ‘health’ and ‘responsibility’ in modern societies (see, e.g. Beck & Beck-Gernsheim, 2002, Chapter 10), an inability to achieve or restore optimum health is very often seen as a weakness of the person and a failure to fulfil one’s obligations as a citizen. In light of this, it is not surprising that chronically ill people tend to reject identities based on invalidism and actively seek to re-establish a

sense of legitimacy and self outside the stigmatised meanings of illness (Charmaz, 1987, pp. 286–287; Charmaz, 2000, pp. 285–286). In their effort to ‘re-colonise’ their health, the ill may claim responsibility to turn their illness into a good story, to discover and tell the ‘narrative truth’ in it (Frank, 1995, pp. 4–7, p. 62). Narratives perform an important function in allowing their authors to ‘develop creative ways of interpreting disruption and to draw together disparate aspects of the disruption into a cohesive whole’ (Becker, 1997, p. 26). They are not simply stories about actually occurring events or experiences, but are *re-presentations*, or creations that occur against, and in relation to, particular traditions and audiences. Story telling offers the means by which the ill seek to regain agency and autonomy, by showing that one can be (as Frank puts it) ‘successfully ill’ (Frank, 1995, p. 62, pp. 137–167).

Different illness conditions obviously vary in their severity, disruption, and stigmatisation, presenting different challenges for those seeking to reconstruct their identity. With some conditions, like HIV/AIDS and mental illness, sufferers may face enormous hurdles in seeking to present a valued conception of self and in achieving adequate care and social support (e.g. Carricaburu & Pierret, 1995). A range of other conditions, which include a number of genetic conditions, have few visible symptoms or episodic symptoms or are ‘asymptomatic’, and are only potentially stigmatising, and thus present a threat to identity only at particular times or under specific circumstances. The question of whether or not genetic information is qualitatively different from other medical information, and that therefore genetic tests justify special consideration with regards to informed consent, privacy and provision of healthcare (i.e. ‘genetic exceptionalism’), is a subject of some debate in the literature (see, e.g. Green & Butkin, 2003; Suter, 2001). Because they are inherited and others in the family may be affected, learning that one’s condition is ‘genetic’ would seem to present particular challenges for affected individuals and their families. However, the question of whether these are limited to those relating to disclosure, privacy and the individual’s ‘right to know’ or ‘right not to know’ (Chadwick, Levitt, & Shickle, 1997), or include other considerations and impacts, has been relatively little explored to date.

In order to gain some insight into the experiences of those who have a genetic condition, a study

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