

Chapter 25

Healthcare Narratives and Self–Care Stories: Developing a User–Driven Taxonomy for Adults with Cystic Fibrosis

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ABSTRACT

The aim of this chapter is to explore how a group of adults with cystic fibrosis (N=40) manage and account for self-care. By focussing on the development of character and plot, narrative analysis will illustrate how distinct patient identities may be constructed and performed as participants defend and justify their preferred self-care practices. These stories do not, however, always fit with the prevailing master narratives on which healthcare is often premised. Drawing on exemplars of 5 distinct types of storytelling an alternative user-driven taxonomy will be suggested which not only recognizes a range of self-care practices but also affirms their legitimacy beyond the horizons of mainstream biomedicine¹.

INTRODUCTION

Cystic Fibrosis (CF) is the UK's most common inherited genetic disorder. It is a multi-organ disease affecting the lungs and digestive system by clogging them with thick sticky mucus resulting

in infections and inflammation that make it hard to breathe and digest food (CF Trust, 2006). Until recently the majority of people with CF were not expected to reach adulthood but improvements in diagnosis and treatment mean that there are in fact now more adults than children living with the condition in developed countries. With adulthood

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however, self-care becomes increasingly complex and costly as patients seek to manage the (often) competing demands of body and society.

According to Best Practice Guidance in the UK, ‘self-care is all about individuals taking responsibility for their own health and well-being. This includes: staying fit and healthy, both physically and mentally; taking action to prevent illness and accidents; the better use of medicines; treatment of minor ailments and better care of long term conditions’ (Department of Health, 2006). Self-care is not just the responsibility of the ‘ill’, therefore, but incorporates maintaining health and managing risks more generally. While *everybody* is expected to conform to these ‘universal self-care requisites’ (Orem 2001) however, if people with CF were to do so it would most likely have serious consequences. That is, because of the high energy demands of their bodies and the malabsorption of nutrients, most people with CF need to eat copious high calorie foods, which, along with regular intensive physical activity, is in fact the opposite of what is normally recommended or expected for most other adults, especially females (Willis, Miller & Wyn, 2001; Stark, Jelalian, McGrath, & Mackner, 2001; CF Trust 2006). For people with CF therefore, ‘universal self care requisites’ are complicated as diet and physical activity can in fact deviate significantly from healthy norms. Orem’s (2001) ‘health deviation self care’ by way of contrast refers to disease specific activity which, for people with CF, typically includes both medical and behavioural treatments such as daily chest physiotherapy, continuous antibiotics, enzymes and inhaled bronchodilators. These together with regular intensive interventions needed to manage exacerbations make for an unusually demanding self-care regimen.

Given the extensive and often contradictory requirements to both comply to medical prescriptions and conform to societal expectations it is unsurprising that few people with CF do all of their treatment all of the time (Kettler, 2002). There

are many well documented reasons for this and the most significant appears to be forgetfulness (Pfeffer, Pfeffer, & Hodson, 2003; Arias Llorente, Garcia, & Diaz Martin, 2008). The unpleasantness of the treatment, degree of infringement on their lives and embarrassment are also significant factors (Abbot, Dodd, Bilton, & Webb, 1994; Conway, Pond, Hamnet, & Watson, 1996; Gotz & Gotz, 2000; D’Angelo & Lask, 2001; Arias Llorente *et al.*, 2008). These observations, of course, require more systematic consideration and this chapter will demonstrate how a narrative approach can help both challenge the existing order and construct an alternative pluralistic framework of understanding. The self-care stories presented here may or may not fit with the master narratives of healthcare, but we must at least start to recognise their legitimacy if patients are to be respected and a truly user-driven approach is to succeed.

BACKGROUND

This research grew out of a concern that prevailing healthcare models tend to draw from a limited range of experiential evidence and, as a result, silence patient voices that do not fit within mainstream discourses of health and illness. This is perhaps most clearly seen in the research, practice and conceptualisation of compliance which is not only one-dimensional but, at its very heart, also contains the assumption that ‘doctor knows best’. Consequently, non-compliance to prescribed regimens has often been regarded as irrational, maladaptive and morally reprehensible as researchers, practitioners and even patients themselves talk about ‘failing’ to comply (Broom & Whittaker, 2004). The corrective concept of concordance (RPSGB, 1997; DH, 2001) goes some way to addressing this imbalance suggesting, rather, that self-care regimens should be based on a negotiation between equal partners. Caution needs to be exercised, however, as even

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