

## Creating meaning in fibromyalgia syndrome

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### Abstract

Gaining a diagnosis is considered to legitimate a person's illness, to both the self and the wider social world, while also giving hope that treatments, and possibly a cure, will be found. A further function of diagnosis from the patient's perspective is to give meaning to the illness experience, which is often uncertain and confusing. To do so, a diagnosis must itself have meaning. This paper explores the creation of meaning in a medically unexplained disorder, fibromyalgia syndrome (FMS). Semi-structured interviews, in which the diagnostic process was explored, were conducted with 17 people diagnosed with FMS in the United Kingdom, selected from a hospital database (16 women, 1 man). Documentary analysis was also undertaken on information available from support groups and health professionals. Although initially an acceptable diagnosis to sufferers, FMS was viewed as a mysterious label, which provided no meaning at the time of diagnosis. The sought information was accessed in an attempt to resolve its meaninglessness, but this proved problematic due to the ambiguous definition of FMS within the medical and support group literature, the invisible nature of the illness, and the lack of an environment where these uncertainties could be openly discussed. Informants varied in the degree of longer-term acceptance of a diagnosis of FMS, in relation to the concordance they achieved between the diagnosis and their experience of illness.

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### Introduction

Diagnosis is often a taken-for-granted process within modern medical practice (Brown, 1995; Mishler, 1981). Although not explicitly discussed by Parsons within the sick role, the obligation of the sick person to seek technically competent help and for the doctor to use such skills to aid recovery is a key premise within this model of illness (Williams,

2005); recovery, it may be argued, can only be achieved once a diagnosis has been made, thereby providing a logical and hopefully effective range of treatments (Mishler, 1981). By the 1960s, new theories examining the role of diagnosis emerged within symbolic interactionism, where attention turned to the actor's viewpoint and his or her social world. Initially, labelling theory emerged, with a focus upon society's reaction to deviant behaviour, which in the case of illness was when the sick person no longer performed expected social roles (Smith, 1980). However, in the 1970s labelling theory lost favour due to its apparent view that individuals are passive products of social interactions. The act,

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rather than the symptoms, is why a person is labelled ill (Meile, 1986); hence it is the diagnosis applied by society which forces the negative change in an individual's identity.

Labelling theory was superseded by the negotiated order, following work by Stewart and Sullivan (1982) exploring diagnostic experiences of people with multiple sclerosis. Gerhardt's (1989) interpretation of the negotiated order claims that a key function of the health care system is to provide a diagnostic label to legitimate a claim to be sick. Without such validation, an individual is in a socially invidious position—claiming to be ill but not socially defined as such. Hence, a person may be considered by doctors, significant others or employers to be malingering for secondary gains (Arksey & Sloper, 1999; Glenton, 2003; Telles & Pollack, 1981; Woodward, Broom, & Legge, 1995). If achieved, however, such validation offers a social explanation for illness (Cooper, 1997; Lewis, 1995), with increased support from health professionals and significant others (Stewart & Sullivan, 1982). However, the label must be acceptable vis-à-vis the individual's beliefs, or else it may be rejected (Stewart & Sullivan, 1982). The individual can only adapt to maintain normal social status if he or she has validated the diagnostic label offered by the doctor (Gerhardt, 1989). Reflecting more traditional views of symbolic interactionism, the theoretical foundations of negotiated order, a person is characterized by an ability constantly to adapt, thus being able to maintain or return to previous social roles, despite a chronic illness having been diagnosed. The negotiated order rejected the view of a passive individual, and acquiring a diagnosis is viewed as a negotiable, open exchange between the individual and the practitioner, even though power relations may remain in favour of the medical profession (Gerhardt, 1989).

Whilst Parsons' sick role theory, along with labelling theory and negotiated order, offer some insights into the role of diagnosis, further research into chronic illness has argued that a crucial function of a diagnosis from the patient's perspective is to give meaning to the illness experience, which may hitherto be vague and uncertain (Draucker, 1991; Garro, 1994; Kralik, Brown, & Koch, 2001; O'Flynn & Britten, 2000). This is achieved by providing an explanation for symptoms, which in turn allows the individual to impose order upon and regain control over the illness experience (Adams Pill, & Jones, 1997; Broom &

Woodward, 1996; Draucker, 1991). Such resolution of illness uncertainty enables the individual to adapt and cope (Peters, Stanley, Rose, & Salmon, 1998). However, for a sense of mastery to develop over the meaning of the illness, reinterpretation needs to be undertaken, in which any diagnosis must fit and reflect the illness experience (Adams et al., 1997; Charmaz, 1995; Lewis, 1995). Only when such a 'fit' is established will the diagnosis be accepted. In this sense, the meaning of diagnosis may be conceptually separate from the meaning of the illness (Bülow & Hydén, 2003; Lewis, 1995). If this reinterpretation does not occur, a diagnosis may not be deemed compatible with the individual's identity (Adams et al., 1997; Kralik et al., 2001), and may not be accepted (Adams et al., 1997).

For reinterpretation to occur, individuals must develop a degree of knowledge and meaning surrounding the diagnosis. This is particularly important as a diagnosis may also be confusing and increase uncertainty (Lewis, 1995). Often, people feel that their knowledge of a diagnosis is incomplete and that they require further information (Kralik et al., 2001). Hence, individuals search for information, to develop and refine the meaning of a diagnosis and ultimately reduce the uncertainty experienced (Brashers et al., 2000; Molleman et al., 1984). It is argued, therefore, that the meaning of the diagnosis needs to be discovered and developed (Kralik et al., 2001). Receiving a diagnosis is thus not a one-off event but rather a process of discovery, which unfolds over time and is never complete (Adamson, 1997).

Although reinterpretation of a diagnosis in relation to the illness experience is generally acknowledged as part of accepting a diagnosis, little attention has been given to how the meaning of a diagnosis is created and how this influences its acceptability. The aim of this paper, therefore, is to examine how patients diagnosed with fibromyalgia syndrome (FMS) construct meaning in the diagnosis and interpret this in relation to their illness experience. FMS may be regarded as an unorthodox and contested illness. In many ways it is similar to conditions such as chronic fatigue syndrome, irritable bowel syndrome, and some categories of repetitive strain injury, such that the existence of the syndrome is questioned by the medical profession; some argue that FMS is not a valid diagnostic label and should not be used. Such scepticism may derive from doubts as to FMS being a distinct disease entity (Cohen & Quintner, 1993; Ehrlich, 2003), but

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