



Chronic obstructive pulmonary disease (COPD), illness narratives and Elias's sociology of knowledge



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ABSTRACT

This paper draws on Elias's sociology of knowledge to provide a critical assessment of illness narratives. Focusing on a cohort of chronic obstructive pulmonary disease (COPD) patients ($n = 26$), the paper employs a comparative analysis of mixed method data derived from qualitative interviews, quantitative questionnaires, and physiological and accelerometric testing. The article firstly compares four narratives conveyed in interviews with the broader paradigmatic approach to illness narratives and existing COPD-specific studies. It then explores the relationship between these 'stories' and COPD patients' biographical contingencies (e.g. age, wealth, context of diagnosis) and embodied condition (e.g. co-morbidities, lung function), demonstrating how illness narratives are shaped by both broader social structural factors and embodied experience. Invoking Elias we further find that different narrative subthemes are varying affected by patients' emotional engagement and ontological security and thus that people are differently enabled or constrained to present illness narratives that are consistent with their broader social and physical condition. Consequently, while narratives, social structure and embodied experience are interdependent, our reading of 'truth' must be sensitive to the social positioning of the 'teller' and the specific content being relayed. The paper therefore presents a more systematic, comparative, bio-psycho-social analysis than has hitherto been produced.

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1. Introduction

Chronic obstructive pulmonary disease (COPD) is characterised by airflow obstruction which is progressive and cannot be fully reversed. Diagnosis normally occurs post-40 years of age, and is therefore also often associated with multiple co-morbidities. Frequently caused by tobacco inhalation, COPD disproportionately affects males from lower socio-economic groups (Hansen et al., 2007), but is predicted to be the fourth leading cause of global mortality, morbidity and disability by 2030 (Boeckxstaens et al., 2012).

Primary physical symptoms include breathlessness (dyspnoea), chronic cough and sputum production (Williams et al., 2011). Common measures of breathlessness and other symptoms include the modified Medical Research Council (mMRC) dyspnoea scale

(Bestall et al., 1999) and the COPD Assessment Test (CAT) (Jones et al., 2009) questionnaire. Additionally, physical measures such as lung function tests (e.g. spirometry), field walking assessments (e.g. incremental shuttle walk test (ISWT)) and more recently physical activity (e.g. using an accelerometer to measure bodily movement) are used to provide a more complete picture of the heterogeneity of the impact of the disease.

Treatment for COPD focuses on smoking cessation, inhaler medication and pulmonary rehabilitation (Hansen et al., 2007). The health benefits of physical exercise for COPD patients include reduced breathlessness, improved muscle strength, and improved management of exacerbation, which potentially lead to extended life expectancy, enhanced life quality and reduced healthcare usage (Williams, 2011). However, the symptoms of COPD tend to create a double-bind situation (Elias, 1987a) in which such sedentary lifestyles lead to deconditioning, muscle weakness, further reductions in physical activity, and therefore more severe symptoms (Polkey and Moxham, 2006).

Qualitative studies of COPD illness experiences focus on

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perceptions of aetiology, and patients' everyday experiences. While psychological studies foreground smoking in patients' accounts of causation and the consequent guilt of having a 'self-inflicted disease' (Lindqvist and Hallberg, 2010: 460), sociological research explores patients' multi-causal models combining smoking with industrial/environmental factors and family histories (Hansen et al., 2007; Bailey et al., 2009). By explaining causation according to factors beyond their control, COPD patients mitigate the moral implications of appearing to have a lifestyle-induced illness. Second, the everyday experiences of COPD patients have been depicted as entailing five managing strategies: *making sense of existence*; *adjusting to bodily restrictions*; *making excuses for smoking related cause*; *surrendering to fate*; and *creating compliance with daily medication* (Lindqvist and Hallberg, 2010: 462). Others have highlighted patients' lowered self-esteem and depressive tendencies (Nicholson and Anderson, 2003; Williams et al., 2007), and condition-specific features such as the relationship between anxiety and acute exacerbations (Bailey, 2001).

As useful as these studies are, they exhibit four particular limitations. First, while most employ a variant of narrative analysis, the frequent reliance on grounded theory means that few studies locate their findings relative to a broader corpus of illness narrative work. Second, many studies explicitly exclude participants with comorbidities or at least disregard other physical ailments and thus present de-contextualised or disembodied accounts of illness. Third, this work largely ignores the influence of broader social structural factors. Fourth, the emphasis on smoking militates against the consideration of other aspects of treatments, and in particular the imperatives of remaining physically active.

Consequently this paper advances understanding by presenting a typology of COPD patient experiences that explicitly relates to broader analyses of illness narratives. It subsequently provides a critical reading of illness narratives through the exploration of their interdependence with both biographical contingencies (e.g. age, wealth) and embodied condition (e.g. co-morbidities, lung function). Finally it seeks to explain these relationships by considering the role of agency in the process of socially constructing knowledge. The outcome is a more systematic, comparative and, to a degree, bio-psycho-social analysis than has hitherto been produced. In pursuing our central research question – how do social, physical and interactional factors influence the illness narratives patients present? – we first consider debates regarding illness narratives and the premises of Elias's sociology of knowledge.

2. Illness narratives

Concern with illness narratives is predicated on the understanding that disease entails both physiological disturbance and biographical disruption (Bury, 1982). The value of the approach is to illustrate how the practical consequences and symbolic significance of illness shape how people see themselves, how they think others see them and, ultimately, the overall experience and impact of disease. Illness narratives help to establish a sense of meaning or purpose which helps relocate the relationship between the self and world. They do not simply reflect, but create and structure symptoms/suffering, and are themselves shaped by broader social, cultural and material contingencies. Key principles of this approach are that the narrative strategies available to individuals are influenced by their life experience and social location, and that the narrative we produce effectively *becomes* the illness experience. It is important, however, to recognise the fluidity of 'identity construction [which] is a continuous, evolving dual directional process' (Yoshida, 1993: 241).

Bury identifies three subthemes within illness narratives. *Contingent narratives* contain 'beliefs and knowledge about factors

that influence the onset of disorder, its emerging symptoms, and its immediate or "proximate" effects on the body, self and others' (Bury, 2001: 268). Contingent narratives are therefore central to the focus on everyday experiences of COPD patients in relation to everyday management strategies and dealing with extreme exacerbations (Bailey, 2001; Williams et al., 2007). *Moral narratives* reveal the broader social context in which illness is experienced. They contain an evaluative dimension to the personal and social condition, potentially combining themes of culpability and exoneration and thus 'help to maintain self worth' (Bury, 2001: 275). Moral narratives are therefore central to the focus on the aetiological role of smoking prominent in qualitative studies of COPD (Nicholson and Anderson, 2003; Lindqvist and Hallberg, 2010). Finally *core narratives* may be epic or tragic, depicting the illness experience as progressive, regressive or stable. The core narrative depicted in existing COPD studies is therefore largely tragic, with portrayals of stability or slow decline (Williams et al., 2011), and analysis of acute exacerbations depicting dramatic if intermittent regression (Bailey, 2001).

Frank's (1995) widely used and highly regarded typology identifies three primary illness narratives: *chaos*, *quest* and *restitution*. A single story/interview can contain elements of all three, but it is likely that one will predominate. If the dominant narrative is *chaos*, a person will portray a sense of being out of control, struggling to understand what is happening to them, and frequently reporting unexplained symptoms and clinical and/or social rejection. In a predominantly *quest* narrative, illness is interpreted as a challenge to be confronted, an impetus for change or as having a broader purpose. Finally, *restitution* narratives are based on assumptions that, while medicine will return the body to its former self, it is behoven on the sufferer to resolve illness. The restitution narrative is both the expected and dominant illness narrative in Western cultures, particularly common amongst the recently ill who perceive themselves as temporarily in an 'unlucky' state.

Critiques of the use and value of illness narratives relate to: a) their authenticity which, by necessity, is derived from the 'special occasion' of being interviewed; and b) the lack of attention to social structure (Riessman, 2002). Atkinson (2009), for instance, argues that the illness narrative approach stems from broader socio-historical processes which valorise 'the interview' in the contemporary cultural condition. In assessing the meaning and function of including multiple narrative genres within an account of illness, Jordens et al. (2001: 1235) conclude that while 'generic complexity of the illness narratives was an index of the degree of life disruption experienced', the form of narrative is also shaped by the unfolding of interaction. Simple narratives are presented by those who have reinstated order post-diagnosis, and complex and chaotic narratives are constructed in the 'real time' of the interview. The narrative approach further entails an a priori commitment to the value of patients' experiential self-knowledge relative to clinicians' impersonal biomedical knowledge, to subjective satisfaction rather than health outcomes (Timmermans and Haas, 2008). It thus treats patient accounts uncritically, positioning them as testimony rather than perspective. In so doing, we frequently see a psychologisation and de-socialisation of the individual, not only obscuring the ways in which the illness experience is contoured by social location, but missing the 'dynamic interplay between biological health and social life' (Timmermans and Haas, 2008: 661). Responses to these issues include calls for more 'systematic, comparative analysis' (Atkinson, 2009: 2.1) and a move towards a sociology of disease (Timmermans and Haas, 2008).

Reviewing debates over the use of illness narrative, Thomas (2010) highlights the clash of poststructural and 'traditional sociological' methodologies. The former emphasises reflexivity, emotion, empathy and ethical/political action, while the latter is

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