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

PLEASE CITE THE PUBLISHED VERSION

<https://doi.org/10.1016/j.socscimed.2017.09.022>

PUBLISHER

© Elsevier

VERSION

AM (Accepted Manuscript)

PUBLISHER STATEMENT

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Malcolm, Dominic, Mark W. Orme, Mike Morgan, and Lauren Sherar. 2017. "Chronic Obstructive Pulmonary Disease (COPD), Illness Narratives and Elias's Sociology of Knowledge". Loughborough University.
<https://hdl.handle.net/2134/26790>.

Chronic Obstructive Pulmonary Disease (COPD), Illness narratives and Elias's sociology of knowledge

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 accelerometer 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 varyingly 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.

Keywords

UK; Illness narratives; COPD; Elias; Emotions; Bio-psycho-social approach

24 **Introduction**

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

31 Primary physical symptoms include breathlessness (dyspnoea), chronic cough and
32 sputum production (Williams et al. 2011). Common measures of breathlessness and other
33 symptoms include the modified Medical Research Council (mMRC) dyspnoea scale (Bestall
34 1988) and the COPD Assessment Test (CAT) (Jones 2009) questionnaire. Additionally,
35 physical measures such as lung function tests (e.g. spirometry), field walking assessments
36 (e.g. incremental shuttle walk test (ISWT)) and more recently physical activity (e.g. using an
37 accelerometer to measure bodily movement) are used to provide a more complete picture of
38 the heterogeneity of the impact of the disease.

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

Qualitative studies of COPD illness experiences focus on 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 Halberg 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 1993), 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 co-morbidities 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.

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 Halberg 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 depicted as positivistic, treating ‘illness narratives as social facts to be interpreted’ (Thomas 2010: 655). Thomas concludes that one’s position in this debate derives from a number of fundamental

sociological questions: the relationship between micro- and macro-sociology, subjective vs objective epistemologies, the role of values in sociological research and how to demonstrate social scientific methodological rigour. Thomas comes to an essentially post-dualist position which reconceptualises these questions from an either/or into consideration of the potential balance of the two extremes of each respective spectrum. While Thomas' position is neither explicitly nor implicitly informed by Eliasian sociology, it is essentially compatible with key aspects of the approach outlined below.

Illness Narratives and Eliasian Sociology

Elias's central theory, *The Civilizing Process* (2000), undertakes an 'analysis of the historical development of emotions and psychological life ... in relation to the connections ... with larger scale processes such as state formation, urbanisation and economic development' (van Krieken 1998: 353). Fundamental to this project, therefore, is an attempt to explain micro-sociological changes in relation to macro-, social structural developments (and vice-versa). Indeed, *The Civilizing Process* centrally explores the interrelationship between particular social conditions and habitual ways of thinking and acting. Identities are thus dynamic but their rate of change varies according to broader social structural influences. Elias (1987b) further depicts humans (in their physical, existential, cognitive, and affective dimensions) as inherently situated in a recursive relationship between the biological and the social, illustrating a commitment to engage directly with the radical interdependence of embodied experiences and social processes.

Elias's *sociology of knowledge* is similarly informed by post-dualist principles. Specifically, Elias rejected the dichotomy of 'truth' and social construction/falsehood by emphasising that knowledge cannot be divorced from its social and processual character.

Consequently Elias focussed on the historical and contextual specificity of the blend of involvement (self-interest, emotion, etc.) and detachment (distanciation, reflexivity, etc.) which characterises all human knowledge. For example, the shift from an oral to written transmission of knowledge enables the development and dissemination of more complex concepts. While this relationship is not a ‘zero-sum’ game where, e.g., detachment necessarily increases as involvement decreases (Kilminster 2004), generally speaking, contemporary western modes of thought are marked by the re-/displacement of ‘magical-mythical’ or ‘fantasy-laden’ thinking which is ‘highly influenced by immediate interests and strong emotions’ (Wilterdink 2003: 303), with relatively detached, rational, reflexive forms of scientific knowledge (Elias 1987a). The co-existence of traditional medicine and biomedicalisation in the treatment of elite sport injury is an apposite example (Faulkner et al. 2017). For Elias, detachment not only entails thinking about oneself as a social being rather than an individual with biological urges, but may entail thinking about the process of producing knowledge, e.g. while being interviewed (Kilminster 2004). Conditions of relative physical and social insecurity (during times of war, but equally when one becomes ill) fuel more involved thought processes. Crucially, however, the primary determinate of what survives as ‘knowledge’ is social; namely, those concepts and ideas which survive ‘reality testing ... in the crucible of experience’ (Elias 1987a: 56). For Elias, part of that reality testing is the emotional impact of holding particular ideas. Accordingly, rejecting smoking as the cause of COPD may be emotionally comforting and thus held to be ‘true’.

The value of drawing on Elias’s sociological approach, therefore, is that it sensitises us to an analysis of illness narratives that focuses on the way accounts relate to both agency and structure, the embodied and social experience. Our aim is not, primarily, to assess the authenticity of narrative accounts but to illustrate the contingencies upon which more or less ‘reality congruent’ accounts prevail including, for instance, consideration of both the social

and emotional consequences of expressing particular illness narratives. We find that people are differently enabled or constrained to present illness narratives that are consistent with their broader social and physical condition, and different narrative subthemes are more-or-less affected by patients' emotional engagement.

Method

COPD patients were recruited as part of the Physical Activity and Respiratory Health (PhARaoH) Study which was granted ethical approval by National Health Service Research Ethics Committee East Midlands–Nottingham 2 (see Orme et al. 2016 for further details). General Practitioners (GPs) identified eligible participants from patient records (those with a diagnosis of COPD, and aged 40 to 75 years to be in line with comparable studies, e.g. Vestbo et al. 2008), and sent them study information and enrolment materials. One hundred and thirty-nine COPD patients plus a control group (recruited using various media, n=297) subsequently participated in the clinically-based quantitative phase of the research, consisting of: providing informed consent, responding to questionnaires covering demographics, smoking history, perceptions of health; participating in physical measurements (blood pressure, spirometry, skeletal muscle strength, ISWT) and a 7-day accelerometer measurement of physical activity.

The qualitative phase of the study used a maximum variation sampling technique to generate a sub-sample representative of the illness spectrum (using CAT and mMRC scores). Thirty-four of the 139 COPD patients were initially contacted, supplied with a participant information sheet for this second study phase and given at least 24 hours to consider their inclusion. Eight did not respond or did not consent to being interviewed. In total 26 interviews were conducted, comprising 18 males and 8 females. All participants self-

identified as 'white' (British or Irish). Socio-demographic characteristics of the sample appear in Table 1.

Interviews lasting 30-55 minutes took place in participants' homes, hospital and university facilities, or other convenient places (e.g. cafes). Main themes included biography (as a COPD patient), current impact on daily living and physical activity, and barriers and enablers to being physically active. Data saturation was thought to have been achieved after 23 interviews and confirmed after three further, already scheduled, interviews were conducted. Each was digitally recorded and professionally transcribed as soon as possible after the interview concluded. Interviews were conducted by the (male) lead qualitative researcher (n=19) and a (female) research nurse (n=7) trained in qualitative research methods and inducted into the study by the lead qualitative researcher.

Thematic analysis was an iterative process which began in discussions between the two interviewers as transcripts were returned. Analysis became more intensive once all interviews had been completed. Specifically, the lead qualitative researcher repeatedly read the transcripts and coded data based on existing literature and the repetition of particular types of phrases and narrative themes. This initial coding was subject to a systematic comparative approach, identifying differences and commonalities across the transcripts, and developing overarching themes. To preserve anonymity identifier codes used in the broader study (MP and FP signify male and female participant respectively, while the number represents sequential enrolment) are used to report transcript excerpts. As the four core narratives presented here crystallised - *Chaos*, *Challenge*, *Contrary* and *Coping* - a secondary phase of analysis began, exploring patients' narratives in relation to quantitatively recorded material factors (e.g. demographics, education, income), physiological measures (e.g.

strength, lung function, physical activity) and behavioural perceptions (expressed via questionnaire).

A fundamental issue with this mixed-method approach is the relative evaluation of the qualitative and quantitative data. Following Elias, we interpret neither as operating a monopoly over ‘truth’. Following Atkinson (2009) we do not seek to valorise the interview. Rather both must be reflexively considered with higher levels of detachment (Elias 1987a), or ‘managed prejudice’ (Thomas 2010), to produce the most ‘reality-congruent’ understanding. The order in which the findings are presented relates more to the analytic journey undertaken than it does to a view that the former should be ‘checked’ according to the latter. While cognisant of the view that qualitative data are predicated on the belief that what is important is the ‘meaning of what is said rather than the generalizability to make comparisons’ (Nicholson and Anderson 2003: 255), the post-dualist, bio-psycho-social, Eliasian position commends an exploration of the interdependence of the different forms of data.

COPD Patients’ Illness Narratives

Six interviewees presented a primary narrative of *Chaos*. This theme contained strong similarities with the managing strategy Lindqvist and Hallberg (2010) called *Surrendering to fate*. The ‘chaos’ reported could be directly (e.g. difficulty breathing, cessation of work, weight gain) or indirectly (e.g. caring for others, co-morbidities) linked to COPD. These essentially tragic core narratives (Bury 2001) detailed how COPD had a major impact on daily living with interviewees describing themselves as ‘destroyed’ (MP392), lower than ‘a second class citizen’ (MP019), or being ‘stuck in a vicious circle’ (FP018). The inability to control or manage their condition included following recommendations to stop smoking which one interviewee described as ‘the worst thing I’ve done because I kept putting on

weight' (FP147). Of all four groups, those presenting a chaos narrative found the initial diagnosis of COPD particularly biographically disruptive. One interviewee described how on visiting his GP he was sent directly to hospital, directed to stop work, and subsequently experienced panic attacks and depression (MP019). However, in contrast to feelings of guilt through perceived self-infliction (Lindqvist and Hallberg 2010) and/or of being socially burdensome, the central moral narrative focussed on beliefs that having COPD was in some sense unfair or undeserved; '[it] makes me so angry ... I've never been overweight, always had a good diet, always been physically active' (FP023). Many expressed a lack of social support, little empathy from those who treated them 'like a child' (MP019), and being socially isolated because 'I don't go out much' (MP462). Episodes of severe breathlessness (defined by the respondents' depiction of panic and/or subsequent hospitalisation) were not particularly common in this cohort, but in being very conscious that 'it's an untreatable disease' (FP147), a sense of regression was. All believed that increased physical activity would have health benefits, but none saw themselves as able to adopt routine structured exercise. Paralleling Frank's (1995) chaos narrative category, most reported conflict with healthcare professionals; 'They don't call you in, they don't do anything ... I've got plenty of counterarguments for what they're saying ... I've got no faith in them [GPs]' (MP462).

Five expressed the desire to counter or *Challenge* their condition through lifestyle modification. Reminiscent of Lindqvist and Hallberg's (2010) *Making sense of existence*, they described their initial COPD diagnosis as only mildly biographically disruptive - a 'shock to me ... but to be honest I wasn't worried' (MP304) - sufficient to induce lifestyle change but controllably. Contingent narratives illustrated significant impact on daily living, yet individuals frequently used terms such as 'in control' (MP483), 'mind over matter' (FP382) or '[I] learned to deal with it ... you adapt' (MP192), to characterise their ability to self-manage. The cohort reported supportive social networks. None reported their condition

to be significantly worsening. All described being positively disposed towards physical activity, citing cycling, dancing, football, gym and gardening as they strove to retain a normal life; ‘I looked at it and thought, well you’ve got two ways to go. You can feel sorry for yourself and give in or you keep carrying on, which is what I’ve done’ (FP382). Individuals rarely foregrounded the role of medicine or medical personnel despite reporting some of the more severe experiences of breathlessness and episodes of hospitalisation. By implication, therefore, this group portrayed a sense that *they* had overcome their problems through active and judicious self-management, refusing ‘to take a back seat push[ing] my body as far as it will go’ (MP304). The heroism in this epic narrative appeared as interviewees contrasted themselves with those ‘people my age [who] look 92 because they sit down and they give up don’t they’ (FP050). Aligned with elements of progression, purpose and impetus for change, the *Challenge* group closely aligns with Frank’s (1995) quest narrative.

The final two groups were labelled *Contrary* and *Coping*. While the former exhibited elements of Lindqvist and Hallberg’s (2010) *Making excuses for smoking-related cause*, the latter resembled the managing strategy of *Adjusting to bodily restriction*. Both essentially represented what Frank (1995) described as a restitution narrative. While condition-specific factors - guilt of self-infliction, knowledge that ‘recovery’ COPD was impossible - combined to limit the degree of restitution anticipated, the moral narratives of the contrary and coping groups centrally positioned the teller as fulfilling the social expectations of resolving their condition. Frank (1995) suggests the restitution narrative tends to be dominant and, together, these two groups constituted almost 60% (n=15) of the sample.

The main contingent narrative of the *Contrary* group was that they could ‘plod along as I’ve always done’ (MP041) because of the limited impact on daily living. Of all the groups, those presenting a contrary narrative expressed the least biographical disruption in relation to

314 initial diagnosis, and many continued to exhibit denial, attributing symptoms to ‘the ageing
315 process’ (MP176), suggesting that ‘it was perhaps a misdiagnosis ... I don’t believe it’
316 (FP275), or revealing that ‘I almost feel a bit of a fraud’ (MP437). They thus suggested that
317 COPD did not directly define their identity or significantly structure their lives, typically
318 stating that ‘I don’t worry about it’ because compared to others ‘I think [to myself] “Oh God,
319 you’ve got nothing”’ (FP166). Another claimed ‘I don’t care, I was told I’d be dead by 21’
320 (MP160). All defined their respiratory health as stable or improving, portrayed an ability to
321 exert considerable control over their condition – ‘it’s an attitude isn’t it’ (MP176) - and
322 expressed little concern about future deterioration. While the degree of socially supportive
323 relations varied, none portrayed a sense of isolation. Although two currently exercised
324 explicitly to enhance health, most viewed physical activity as the *Making excuses* cohort
325 viewed smoking; acknowledging the potential benefits but expressing rationales ranging from
326 control - ‘I’m going to do what I can do’ (MP160) – to indifference – ‘I can’t be bothered’
327 (MP437). Most downplayed the significance of healthcare, either expressing ‘hope’ that
328 medication worked (MP187) or the belief that an ‘inhaler helps a litte bit but not that much’
329 (MP160). None recalled experiencing severe episodes of dyspnea or conflicts with healthcare
330 professionals.

331 The seven interviewees who expressed a *Coping* narrative represented a moderated
332 form of the contrary groups’ heroic narrative. While both groups expressed limited
333 biographical disruption on initial diagnosis, and satisfaction at their control of the condition,
334 the central distinction was that the contingent narrative of the coping cohort depicted greater
335 limitations in daily living. Within the *Coping* cohort, interviewees recalled being ‘out of
336 breadth and [I] couldn’t cope with the job I was doing’ (MP009), struggling with routine
337 domestic work, such as cleaning (MP302) and carrying grandchildren (MP465), and relying
338 on family or paid domestic help (MP345, FP476). While some were conscious that their

condition was deteriorating, the decline was perceived to be manageable, one interviewee stating, ‘I know that progression is going to be that I will virtually become inactive physically. I know that and I’m prepared for that, but at the moment I’m just managing to cope’ (MP345). Respondents mainly reported good social networks and supportive partners. Most reported a strong history of physical activity participation although motivation for their continued exercising ranged from the pleasurable - ‘it hurts when I do it [play golf] but I really enjoy it’ (MP125) - to the instrumental - ‘it’s not about enjoyment, it’s about keeping fit’ (FP476). However, akin to Lindqvist and Hallberg’s (2010) *Adjusting to bodily restriction* interviewees who emphasised saving energy, not hurrying, and being responsive to bodily sensations, a particularly notable feature was how many specifically used the term ‘own pace’ to describe attitudes to physical activity (MP009, MP125, MP345, MP465). None spoke of their relations with healthcare providers, although four of the seven had experienced severe episodes of dyspnoea.

Interviewees, therefore, expressed illness narratives which largely resonated with the broader paradigmatic approach (Frank 1995), and Lindqvist and Hallberg’s (2010) earlier study of COPD patients (see Supplementary Files for extracts from interviews with individuals in each narrative group). But as behoven by a more bio-psycho-social, Eliasian approach, we subsequently assessed the resonance between narratives and: a) broader social structural factors; and b) embodied conditions. Through this we were able to consider interviewees’ accounts within a broader context of their lived reality and thus begin to reflect on how particular illness narratives emerge.

Illness narratives and quantitative measures

Demographics

The relationship between narrative, gender and age mirrored Hansen et al.'s (2007) findings. The chaos narrative, in which multiple conditions and complications merged into pronounced biographical disruption, was most commonly presented by female interviewees, while the coping and contrary narratives downplaying or refuting the condition was most frequently expressed by male respondents (see Table 1). Similarly more extreme biographical disruption was commonly expressed by younger and more recently diagnosed interviewees. While mean ages were not particularly different, the chaos cohort contained the largest proportion of people in their 50s while the coping cohort contained the largest proportion of people in their 70s.

Additionally, the chaos cohort was the most recently diagnosed. Moreover, the three members of this group who had been diagnosed ≥ 10 years ago all reported co-morbidities (arthritis, hypertension, diverticulitis) during interview, while all three who had been diagnosed ≤ 3 years ago did not. In contrast, the other cohorts were relatively similar in terms of mean time since COPD diagnosis, with the longest diagnosed group (contrary) most likely to 'explain' their condition during interview relative to the aging process. While to some extent these findings diverge from Frank's (1995) suggestion that the restitution narrative is more frequently expressed by those for whom illness is more recently diagnosed, the known lack of a 'cure', the tendency for COPD diagnosis to occur at a relatively advanced age, and the frequently gradual and imperceptible progression of the disease may help explain this pattern. In part they speak to Yoshida's (1993) pendulum model of identity re-construction. While not predictive, age and gender certainly seemed to contour the narratives people provided.

Further distinctions were identified in the relationships between narrative presented and education, occupation and affluence. First, the coping and contrary groups had, on average, left continuous education a year later than the chaos and challenge groups. However,

a notable distinction *between* the latter two was that everyone in the chaos cohort had subsequently studied for additional qualifications, including undergraduate and postgraduate degrees. Second, in line with the above, the chaos group were least likely to (have) work(ed) in manual occupations. Reflecting their sense of transience, the chaos group was most likely to describe themselves as currently unable to work, a manifestation perhaps of how tangibly illness had affected them. Despite their relative ages, but consistent with their narratives, the coping and contrary cohorts were most likely currently to be in paid employment. The challenge cohort was most likely to be retired. Third, while the highest household incomes were, unsurprisingly, reported by the working cohorts (although, tellingly, two of the chaos group were unable to estimate their income), in a more holistic assessment of relative deprivation indicators (income, housing, employment, education, etc.) the chaos group came from the most ‘well off’ neighbourhoods. The coping group lived in the most deprived areas. Although no cohort was particularly wealthy, data partly support Williams’ (2000) hypothesis that biographical disruption may be most severe amongst the higher socio-economic classes due in part to their higher expectations for life and the less frequent prior experience of adversity.

However, these data suggest that *trajectory* (Yoshida 1993) rather than relative deprivation is particularly important. Specifically, data for the challenge group depicted fairly linear life trajectories, having left school relatively early, worked in manual occupations, and retired with relatively little accumulation of wealth. Conversely the chaos group, whilst having left education relatively early acquired subsequent qualifications, experienced occupational mobility (in the sense of moving to non-manual occupations) and relative economic security (hence reporting the least deprivation). It was against this background that the disruption of illness was experienced as particularly acute and that the most ‘hard working’ illness narratives were produced (Jordens et al. 2001: 1235).

413

414 *Physical and behavioural measures*

415 Patterns linking patient narratives, physical and behavioural measures and thus
416 aspects of the embodied experience were similarly observable. The chaos group had the
417 lowest leg strength and hand grip scores but the least severe airflow obstruction. While most
418 had relatively minor and simplistic COPD-related medication regimes (i.e. mainly reliant on
419 inhalers) half reported co-morbidities.

420 The coping group, whose measures placed them somewhere near the middle of the
421 spectrum of upper body and lower body strength test results, had worse walking performance
422 (ISWT), participated in the lowest light to vigorous physical activity and lowest time
423 sedentary (assessed via an accelerometer over 7 days), which perhaps reflected the
424 philosophy of being active at their ‘own pace’. They also had the poorest lung function, were
425 the most likely to report co-morbidities, and reported the most extensive COPD-related
426 medication regimes. While the contrary group also tended to be in the middle range of
427 physical measures (physical function and respiratory health) they returned the highest light to
428 vigorous activity scores, and the lowest total time sedentary.

429 Finally, the challenge cohort had the highest leg strength scores and the second best
430 grip strength, but presented a diverse pattern of lung function scores, scoring highest in two
431 categories and second in two others. They were least likely to report co-morbidities. This
432 cohort performed best in the ISWT (an indication of exercise capacity) yet they were also
433 most likely to self-report walking to be ‘hard’ (evaluated through questionnaire data). This
434 perception of difficulty was partly reflected in the accelerometer-assessed physical activity
435 where they ranked second in terms of moderate to vigorous activity, and third in time spent

436 undertaking light physical activity. They ranked second of the four groups in terms of daily
437 sedentary time.

438 Thus patterns were evident between physiological measures and narrative expressed.
439 Supporting the development of aforementioned measures of health status (CAT) and
440 breathlessness (mMRC), lung function did not closely align with illness narratives. Physical
441 strength was, to some extent, better aligned to patients' rejection or acceptance of identifying
442 as ill, with the most physically strong (challenge) expressing the intention to live with and
443 seek to abate the progression of COPD through physical activity, and the physically weakest
444 (coping) exhibiting resignation. Those who expressed the strongest sense of agency
445 (challenge and contrary) were, in turn, the most physically active while those who effectively
446 accepted an identity of illness (coping and chaos) were the least active. Additionally,
447 however, the existence of co-morbidities (plus, for the chaos cohort, other complicating
448 factors) promoted patients' acceptance of the medical categorisation of illness (i.e. chaos and
449 coping cohorts), whereas the most medically resistant narratives (i.e. the contrary and
450 challenge cohorts who did not perceive themselves to be ill or explicitly sought to combat
451 illness) were given by those who had a more 'one-dimensional' illness experience.

452 It is, of course, impossible to specify causation – whether activity levels were a cause
453 or consequence of attitudinal and behavioural responses to COPD diagnosis – but combining
454 the challenge cohort's ISWT scores with perceptions of 'ease of walking', for example,
455 suggests an agreement between perception and physical test results. Indeed, it is reasonable to
456 suggest that the findings are influenced by a degree of double-bind (Elias 1987a) or indeed
457 'virtuous circle'; that is to say, multiple comorbidities align with poor lung function and
458 particular attitudes towards illness, and those with relatively good physical strength are able
459 to keep active, maintain strength, resist the onset of other conditions and vocalise a
460 concordant outlook. While the *severity* of disease (as medically assessed) did not determine

social life, a ‘dialectic interaction’ existed between the biological and social (Timmermans and Haas 2008: 661).

What we can say with more certainty is that, while the chaos cohort was particularly strongly affected by social structural factors, the other three groups (expressing what Frank (1995) calls quest and restitution narratives) were seemingly more heavily influenced by physiological factors and thus embodied condition. The stronger influence of external factors on the chaos narrative is, moreover, logically consistent with the expression of a lack of control. Indeed, underpinning the presentation of the chaos narrative are demographic/life trajectory factors experienced as so overwhelming that they appear to disrupt the connections with embodied condition. For example, the incongruence between respiratory capacity and relative physical strength amongst this group suggests that while they did not ‘feel’ it, physically they had a relatively high capacity (i.e. lung function) to exert control over illness and everyday life. In contrast, narratives characterised by a greater sense of agency or control, are more strongly influenced by embodied or ‘internal’ factors. Specifically, the physical performance of the challenge cohort was largely commensurate with the philosophies depicted in their quest narratives (including participating in more physical activity). Of the two groups presenting a variant of the restitution narrative, the coping cohort offered less contestation (either in terms of their diagnosis or restorative actions), had worse lung function, more extensive medical regimes, more frequently had co-morbidities, and were less active. Conversely, the contrary group resisted the label of ‘being ill’, stated that they did not perceive themselves to be restricted in daily living and demonstrated that such attitudes matched behaviour assessed through empirical measures. Thus for these three cohorts, activity measures and perceptions of illness aligned.

485 **Accounting for illness narratives: Elias's sociology of knowledge**

486 While the above suggests that illness narratives are not free-floating but shaped by
487 both broader social structural factors and embodied experience, Elias's (1987a; 1987b)
488 approach alerts us to the idea that the 'reality congruence' of what people seek to portray
489 (indeed 'believe') in the 'special situation' of interview (Atkinson 2009), relates to the blend
490 of involvement and detachment within an individual's thought processes which, in turn, is
491 influenced by elements of physical and social (in-)security. Consequently it is unsurprising
492 that the apparent compatibility between narrative and physical measures is greater amongst
493 those expressing a quest or restitution narrative than for the chaos cohort. Specifically, social
494 structural factors are particularly influential for the latter because, by definition, such
495 'external' factors are less amenable to individual agency and control. In other words,
496 ontologically insecure patients produce the 'most involved' accounts of illness. While
497 described in the literature as 'chaotic' (Frank 1995), or possessing a greater complexity in
498 combining multiple narrative genres (Jordens et al. 2001), placed in historical and cultural
499 context, we can understand them as effectively defying the kind of rationality and reflexivity
500 that characterises more detached forms of thinking dominant in contemporary western
501 societies.

502 But equally an Eliasian sociology of knowledge enables us to make sense of
503 apparently incongruous data. Because involvement and detachment is not a zero-sum game
504 (Kilminster 2004), people's ability to 'impression manage' is as important as their ability to
505 verbalise a position that coheres with the behaviour we were able to measure. Within the
506 study 'inconsistent' findings, and thus potential indications of impression management,
507 occurred in relation to accounts of physical activity and smoking. First, in addition to the
508 incongruence between the chaos cohort's perceptions and measurements of strength and
509 respiratory health, it was notable that the coping cohort was most likely, via questionnaire, to

report themselves as being ‘sporty’ in both their youth and adulthood and provide the highest rating of ‘current sportiness’. Conversely the most active group (contrary) rarely depicted themselves as having a ‘sporty’ child- or adult-hood. Second, there were discrepancies between how individuals reported their smoking biographies in interviews and questionnaires. The greatest discrepancies between these two sets of findings occurred in relation to the chaos cohort (a greater number of whom said in interview that they *currently* smoked), and the coping and challenge cohorts (a greater number of whom said in interview that they had *never* smoked). This would appear to support Jordens et al.’s (2001: 1235) conjecture that ‘simple narratives may reflect the ... process of reinstating order by assigning meaning, whilst complex narratives reveal the process happening “on line” as it were, in discourse’.

While partly this shows that defining one’s identity or self as ‘sporty’ or ‘a smoker’ is somewhat subjective, it also suggests that what counts as ‘true’ at any one time is contextually and temporally bounded. For instance, one could argue that the coping cohort’s acknowledgement of their physical limitations (getting by, at their ‘own pace’) behove them to present a moral narrative including a history of being physically active and not smoking. Conversely the underlying illness ‘denial’ of the contrary group effectively absolved them from an obligation to maintain self-worth via a ‘virtuous’ history of physical activity or to vary their representation of smoking behaviour between interview and the relatively impersonal context of questionnaire survey. Denying the existence of illness behoves them to deny the aetiological importance of both exercise and smoking. It is also logically consistent to think the challenge group, whose meta-narrative was essentially one of *currently* undertaking morally responsible action, would gain comfort from depicting more socially acceptable smoking behaviour in interview. Finally, the chaos cohort who, as illustrated, struggled to control their condition, perhaps equally struggled to control their self-representation in the interview setting and thus presented as *less* morally virtuous compared

to their questionnaire responses. Because they did not perceive themselves as relatively physically capable, in ‘reality testing’ (Elias 1987a) of accelerometer measurement, they performed much ‘worse’ than predicted in light of their performance in the ‘special occasion’ of clinical testing.

What we see therefore is that while narratives, social structure and embodied experience interconnect, our reading of ‘truth’ must be sensitive to the social positioning of the ‘teller’ and the specific content relayed. While the previous section identified that people are not all equally capable of presenting narrative accounts which are (relatively) congruent with their embodied experience, here we see that people present narrative accounts which contain varying elements of what others would observe, what the tellers themselves ‘believe’, and what they would like others to believe about them. Because physical activity and smoking were the biographical aspects that most directly resonated with notions of blame and self-worth (Bury 2001), they were also the aspects of narrative that hold the most significant social and emotional consequences for the teller. As Elias (1987a) indicates, where knowledge is invested with the greatest degree of immediate self-interest, it is most likely to be infused with ‘fantasy laden’ or emotionally comforting thinking. Moral rather than contingent narratives are therefore most likely to be reflexively presented in the interview setting.

Conclusion

Building on previous studies (Lindqvist and Halberg 2010), this article demonstrates how COPD patients may depict their illness experience through a particular set of narratives. Moreover, while there are certain condition-specific elements to the narratives expressed,

there are also more generic patterns in terms of contingent, moral and core subthemes (Bury 2001), as well as resonance with chaos, quest and restitution narratives (Frank 1995).

But perhaps more significantly this paper uses Elias first to speak to key debates about the use of illness narrative, and second to effectively reconceptualise central issues. Thus we see that demographic categories such as gender and age, and timing of diagnosis may influence the illness experience, as might cultural contingencies of biographical trajectory, such as experiences of social mobility and relative affluence (relative, that is, across one's life-course). Similarly the data suggest a pattern linking the kinds of narrative expressed and physical measures of the embodied condition. Physical function, respiratory health and physical activity patterns influenced the way those diagnosed with COPD experienced this particular illness. Qualitative illness narratives appear, therefore, largely 'authentic', and correlate with the kind of quantified physiological health outcomes that form the basis of biomedical knowledge and vice versa. Illness narratives are not free-floating but shaped by both broader social structural factors and embodied experience. Calls for the development of a sociology of disease therefore seem well-founded (Timmermans and Haas 2008).

Moreover, following Elias's sociology of knowledge, the central question is not whether narratives can be treated as testimony rather than perspective, but what are the social contingencies we must consider when seeking to assess the 'reality congruence' of (particular parts of) patients' accounts. Specifically we identify the significance of both moral and core narratives, for the former holds particular resonance for the ontological security, social and emotional wellbeing of interviewees, while the latter provides an indication of the individual's capacity for relative detachment. Those who express the least 'control' of their illness are similarly likely to be least in 'control' of what they convey in interview *about* their response to illness, while those who project accounts which could be said to be more consistent with cultural expectations and dominant illness moralities, are most likely to be

able to present accounts which: a) they would like others to see as ‘true’; thus b) vary most from the lived experience; and subsequently c) a researcher is likely to believe because it is delivered with the appearance of reflexivity and rationality which humans have come to see as reliable tools for assessing the value of knowledge.

Fundamentally then, narratives are of considerable analytic value, both for social scientists of medicine exploring the lived illness experience, but also biomedical scientists and practitioners seeking to invoke lifestyle changes in patients. This paper suggests that the insights of both quantitative and qualitative data can be enhanced by a critical cross-referencing and thus the advantages of mixed-method and multidisciplinary working over epistemological isolation.

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683

Table 1: Illness Narratives and Quantitative Measures

	Narrative			
	Chaos (n=6)	Challenge (n=5)	Contrary (n=8)	Coping (n=7)
Demographics				
Gender (male : female)	3 : 3	3 : 2	6 : 2	6 : 1
Age (years)	62.1	62.6	64.5	68.5
Years since COPD diagnosis	6.8	15.8	16.3	13.8
Age left full-time education (years)	15.3	15.2	16.0	16.5
Manual occupation (n = described in interview)	3	3	6	4
IMD score	32.9	20.2	21.9	13.9
Comorbidities reported (n = reported in interview)	3	1	3	6
Respiratory health				
Interview smoking status (current : former : never)	5 : 1 : 0	1 : 1 : 3	2 : 5 : 1	0 : 4 : 3
Questionnaire smoking status (current : former : never)	2 : 4 : 0	3 : 2 : 0	1 : 6 : 1	1 : 5 : 1

FEV1 (L)	2.06	2.4	1.89	1.15
FEV1%pred	76.8	72.4	65.5	41.7
FVC (L)	3.5	3.8	3.7	3.18
FEV/FVC	58.7	53.6	52.8	37.4
Physical activity				
Sedentary time (minutes/day)	616	595	547	678
Light PA (minutes/day)	336	348	368	326
MVPA (minutes/day)	13	16.1	16.4	9.1
Sporty as a child (n = yes)	3	2	1	5
Sporty during adulthood (n = yes)	1	2	1	5
Sportiness scale (0-100)	10	34	40	51
Physical function				
Leg strength (kg)	32.7	49.8	36.1	35.8
Grip strength (kg)	33.17	39.5	39.7	37.3
ISWT (m)	308	458	395	276

684

685 Abbreviations: COPD, chronic obstructive pulmonary disease; FEV1, forced expiratory
686 volume in one second; FVC, forced vital capacity; IMD, index of multiple deprivation; ISWT;
687 incremental shuttle walk test; MVPA, moderate-to-vigorous physical activity; PA, physical
688 activity (see Singh et al. 1992; Edwards et al. 1977; Parvatikar et al. 2009; and Quanjer et al.
689 1993 for details of measurement protocols).
690 All figures refer to cohort means unless otherwise stated.