

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

3 **Abstract**

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

21 **Keywords**

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

23

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).

47 Qualitative studies of COPD illness experiences focus on perceptions of aetiology,
48 and patients' everyday experiences. While psychological studies foreground smoking in
49 patients' accounts of causation and the consequent guilt of having a 'self-inflicted disease'
50 (Lindqvist and Halberg 2010: 460), sociological research explores patients' multi-causal
51 models combining smoking with industrial/environmental factors and family histories
52 (Hansen et al. 2007; Bailey et al. 2009). By explaining causation according to factors beyond
53 their control, COPD patients mitigate the moral implications of appearing to have a lifestyle-
54 induced illness. Second, the everyday experiences of COPD patients have been depicted as
55 entailing five managing strategies: *making sense of existence*; *adjusting to bodily restrictions*;
56 *making excuses for smoking related cause*; *surrendering to fate*; and *creating compliance*
57 *with daily medication* (Lindqvist and Hallberg 2010: 462). Others have highlighted patients'
58 lowered self-esteem and depressive tendencies (Nicholson and Anderson 2003; Williams
59 1993), and condition-specific features such as the relationship between anxiety and acute
60 exacerbations (Bailey 2001).

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

69 Consequently this paper advances understanding by presenting a typology of COPD
70 patient experiences that explicitly relates to broader analyses of illness narratives. It
71 subsequently provides a critical reading of illness narratives through the exploration of their

72 interdependence with both biographical contingencies (e.g. age, wealth) and embodied
73 condition (e.g. co-morbidities, lung function). Finally it seeks to explain these relationships
74 by considering the role of agency in the process of socially constructing knowledge. The
75 outcome is a more systematic, comparative and, to a degree, bio-psycho-social analysis than
76 has hitherto been produced. In pursuing our central research question – how do social,
77 physical and interactional factors influence the illness narratives patients present? - we first
78 consider debates regarding illness narratives and the premises of Elias’s sociology of
79 knowledge.

80

81 **Illness narratives**

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

94 Bury identifies three subthemes within illness narratives. *Contingent narratives*
95 contain ‘beliefs and knowledge about factors that influence the onset of disorder, its emerging

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

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

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

140 Reviewing debates over the use of illness narrative, Thomas (2010) highlights the
141 clash of poststructural and ‘traditional sociological’ methodologies. The former emphasises
142 reflexivity, emotion, empathy and ethical/political action, while the latter is depicted as
143 positivistic, treating ‘illness narratives as social facts to be interpreted’ (Thomas 2010: 655).
144 Thomas concludes that one’s position in this debate derives from a number of fundamental

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

152

153 **Illness Narratives and Eliasian Sociology**

154 Elias's central theory, *The Civilizing Process* (2000), undertakes an 'analysis of the
155 historical development of emotions and psychological life ... in relation to the connections ...
156 with larger scale processes such as state formation, urbanisation and economic development'
157 (van Krieken 1998: 353). Fundamental to this project, therefore, is an attempt to explain
158 micro-sociological changes in relation to macro-, social structural developments (and vice-
159 versa). Indeed, *The Civilizing Process* centrally explores the interrelationship between
160 particular social conditions and habitual ways of thinking and acting. Identities are thus
161 dynamic but their rate of change varies according to broader social structural influences. Elias
162 (1987b) further depicts humans (in their physical, existential, cognitive, and affective
163 dimensions) as inherently situated in a recursive relationship between the biological and the
164 social, illustrating a commitment to engage directly with the radical interdependence of
165 embodied experiences and social processes.

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

169 Consequently Elias focussed on the historical and contextual specificity of the blend of
170 involvement (self-interest, emotion, etc.) and detachment (distanciation, reflexivity, etc.)
171 which characterises all human knowledge. For example, the shift from an oral to written
172 transmission of knowledge enables the development and dissemination of more complex
173 concepts. While this relationship is not a ‘zero-sum’ game where, e.g., detachment
174 necessarily increases as involvement decreases (Kilminster 2004), generally speaking,
175 contemporary western modes of thought are marked by the re-/displacement of ‘magical-
176 mythical’ or ‘fantasy-laden’ thinking which is ‘highly influenced by immediate interests and
177 strong emotions’ (Wilterdink 2003: 303), with relatively detached, rational, reflexive forms
178 of scientific knowledge (Elias 1987a). The co-existence of traditional medicine and
179 biomedicalisation in the treatment of elite sport injury is an apposite example (Faulkner et al.
180 2017). For Elias, detachment not only entails thinking about oneself as a social being rather
181 than an individual with biological urges, but may entail thinking about the process of
182 producing knowledge, e.g. while being interviewed (Kilminster 2004). Conditions of relative
183 physical and social insecurity (during times of war, but equally when one becomes ill) fuel
184 more involved thought processes. Crucially, however, the primary determinate of what
185 survives as ‘knowledge’ is social; namely, those concepts and ideas which survive ‘reality
186 testing ... in the crucible of experience’ (Elias 1987a: 56). For Elias, part of that reality
187 testing is the emotional impact of holding particular ideas. Accordingly, rejecting smoking as
188 the cause of COPD may be emotionally comforting and thus held to be ‘true’.

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

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

198

199 **Method**

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

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

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

220 Interviews lasting 30-55 minutes took place in participants' homes, hospital and
221 university facilities, or other convenient places (e.g. cafes). Main themes included biography
222 (as a COPD patient), current impact on daily living and physical activity, and barriers and
223 enablers to being physically active. Data saturation was thought to have been achieved after
224 23 interviews and confirmed after three further, already scheduled, interviews were
225 conducted. Each was digitally recorded and professionally transcribed as soon as possible
226 after the interview concluded. Interviews were conducted by the (male) lead qualitative
227 researcher (n=19) and a (female) research nurse (n=7) trained in qualitative research methods
228 and inducted into the study by the lead qualitative researcher.

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

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

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

254

255 **COPD Patients’ Illness Narratives**

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

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

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

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

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

311 The main contingent narrative of the *Contrary* group was that they could ‘plod along
312 as I’ve always done’ (MP041) because of the limited impact on daily living. Of all the groups,
313 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

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

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

360

361 **Illness narratives and quantitative measures**

362 *Demographics*

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

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

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

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

404 However, these data suggest that *trajectory* (Yoshida 1993) rather than relative
405 deprivation is particularly important. Specifically, data for the challenge group depicted fairly
406 linear life trajectories, having left school relatively early, worked in manual occupations, and
407 retired with relatively little accumulation of wealth. Conversely the chaos group, whilst
408 having left education relatively early acquired subsequent qualifications, experienced
409 occupational mobility (in the sense of moving to non-manual occupations) and relative
410 economic security (hence reporting the least deprivation). It was against this background that
411 the disruption of illness was experienced as particularly acute and that the most ‘hard
412 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

461 social life, a 'dialectic interaction' existed between the biological and social (Timmermans
462 and Haas 2008: 661).

463 What we can say with more certainty is that, while the chaos cohort was particularly
464 strongly affected by social structural factors, the other three groups (expressing what Frank
465 (1995) calls quest and restitution narratives) were seemingly more heavily influenced by
466 physiological factors and thus embodied condition. The stronger influence of external factors
467 on the chaos narrative is, moreover, logically consistent with the expression of a lack of
468 control. Indeed, underpinning the presentation of the chaos narrative are demographic/life
469 trajectory factors experienced as so overwhelming that they appear to disrupt the connections
470 with embodied condition. For example, the incongruence between respiratory capacity and
471 relative physical strength amongst this group suggests that while they did not 'feel' it,
472 physically they had a relatively high capacity (i.e. lung function) to exert control over illness
473 and everyday life. In contrast, narratives characterised by a greater sense of agency or control,
474 are more strongly influenced by embodied or 'internal' factors. Specifically, the physical
475 performance of the challenge cohort was largely commensurate with the philosophies
476 depicted in their quest narratives (including participating in more physical activity). Of the
477 two groups presenting a variant of the restitution narrative, the coping cohort offered less
478 contestation (either in terms of their diagnosis or restorative actions), had worse lung function,
479 more extensive medical regimes, more frequently had co-morbidities, and were less active.
480 Conversely, the contrary group resisted the label of 'being ill', stated that they did not
481 perceive themselves to be restricted in daily living and demonstrated that such attitudes
482 matched behaviour assessed through empirical measures. Thus for these three cohorts,
483 activity measures and perceptions of illness aligned.

484

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

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

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

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

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

553

554 **Conclusion**

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

558 there are also more generic patterns in terms of contingent, moral and core subthemes (Bury
559 2001), as well as resonance with chaos, quest and restitution narratives (Frank 1995).

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

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

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

587 Fundamentally then, narratives are of considerable analytic value, both for social
588 scientists of medicine exploring the lived illness experience, but also biomedical scientists
589 and practitioners seeking to invoke lifestyle changes in patients. This paper suggests that the
590 insights of both quantitative and qualitative data can be enhanced by a critical cross-
591 referencing and thus the advantages of mixed-method and multidisciplinary working over
592 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.