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Stigmatization, Physical Illness and Mental Health in Primary Ciliary Dyskinesia

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Abstract

Primary ciliary dyskinesia (PCD) causes chronic cough, sinusitis and bronchiectasis, and half of patients also show *situs inversus*. The genetic basis and visible and concealed chronic symptoms provide potential for stigmatization. We describe a structural equation model linking a questionnaire measure of stigmatization to sex, age, personality (Big Five), symptoms (St George's Respiratory Questionnaire), health status (SF-36) and stress (GHQ-12). Stigma did not relate to physical symptoms or health, or to *situs*, but correlated with mental health and the social impact of symptoms. Neuroticism, extroversion, openness to experience, age, age at diagnosis and being female indirectly affected stigmatization via mental health.

Keywords

- *bronchiectasis*
- *chronic respiratory illness*
- *primary ciliary dyskinesia*
- *stigma*
- *structural equation modelling*

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I met this girl with a righthand heart . . .
And though I know there's nothing dangerous in it
I'm feeling queasy, getting worse by the minute
Wondering how to escape this nightmare . . .

(Momus, *Righthand heart*, from the album,
Tender pervert, 1988)[1]

The term 'stigma' derives from the Greek word term for a bodily sign or mark that was made to indicate that a person was 'a slave, a criminal, or a traitor—a blemished person, ritually polluted, to be avoided, especially in public places' (Goffman, 1963/1990, p. 11). Nowadays, as Goffman said, 'the term is widely used in the original literal sense, but is applied more to the disgrace itself than to the bodily evidence of it' (1963/1990, p. 11). Although the work of Goffman is central to the modern renaissance of interest in stigma and its understanding (with *Stigma* reprinted at least 30 times, and translated into a dozen languages; Burns, 1992), there is still much confusion about the definition of the term (Page, 1984), such that Titmuss said the concept 'is as elusive and complex as other key concepts [in social policy] like class, alienation, participation, democracy, poverty, and so forth' (1974, p. 44).

The work of Goffman

Many things can be stigmatizing—and as Burns says, Goffman casts his net extremely wide, so that:

> the catch he counts through at the beginning of the book includes the blind, the deaf, the crippled, the maimed, deformed, disfigured, diseased, prostitutes, and the mentally ill; also blacks, Jews, 'ethnics', lower class persons, homosexuals, illiterates, on to people with colostomies, mastectomies, to diabetics, stutterers, etc., and winding up with the old, along with ex-convicts and ex-mental patients. (1992, pp. 218–219)

Illness in particular can be stigmatizing, where there is potentially not only disgrace (literally, dis-grace—the falling from grace, the apparent perfection of the body being denied) but there also can also be bodily evidence of disease, the 'mark'. In some cases, such as a rash on the face, a limp or sensory impairments such as blindness,

the evidence is visible to all, whereas in other conditions—a colostomy, the risk of an epileptic attack, diabetes—the evidence is concealed or concealable. Sociologically, Goffman's conception of stigma can be seen as an extension of both his earlier work (Goffman, 1962) and his later work (Goffman, 1971), considering assaults on the self, and the ways in which they are defended, and the social processes by which society establishes what is ordinary and natural for its members (Burns, 1992).

Central to the psychological problem of stigma, particularly with conditions which are concealable and non-obtrusive, are Goffman's concepts of 'information control' and 'stigma management': 'To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where' (Goffman, 1963/1990, p. 57). Intimate relationships in particular, whatever the degree of closeness, require the exchange of personal information, as a demonstration of trust and commitment. Concealment puts that trust at risk, whereas revelation runs the converse risk of disclosure and alienation. The informed may themselves in part then become bearers of the stigma.

If the person with a hidden or discreditable stigma has the problem of managing information, the person with a visible stigma, who is already in Goffman's sense 'discredited', has to manage tension, thereby reducing the anxieties and concerns of him/herself and others during social interactions, in order to minimize the obtrusiveness of a stigma.

Although there is a large sociological and social psychological literature on stigma (Heatherton, Kleck, Hebl, & Hull, 2000), it is also the case, as Jones et al. (1984) comment, that most empirical work in the past seems to have considered so-called 'enacted stigma', the stigmatiz*ing* behaviour of 'normal' individuals (the term is used with care, since Goffman emphasizes that everyone is stigmatized in some sense), rather than the responses by those individuals with marks to being stigmatiz*ed* (what Page, 1984 calls 'felt stigma'), although that is changing in recent years (Crocker & Quinn, 2000; Miller & Major, 2000; Smart & Wegner, 2000). There is also a growing literature that uses qualitative methods to assess aspects of stigma, although none of these to our

knowledge has been used to create a generic questionnaire (Heatherton et al., 2000).

Measurement of stigmatization

Stigma, and particularly stigmatization, is a problem in many conditions. The *measurement* of stigmatization is still however a problem, with ad hoc solutions across a range of conditions, some of which are briefly reviewed here. Leprosy, perhaps in many ways one of the defining conditions for understanding stigma, with its biblical, classical and mediaeval roots, might seem to be ideal for measurement. However a recent review could only conclude that, 'no standard instrument has been developed' (van Brakel, 2003, p. 247), although attempts have been made (Anandaraj, 1995), with a questionnaire involving four aspects of stigma—family relations, vocational condition, social interaction and self-esteem. Stigmatization also occurs in psoriasis, another visibly stigmatizing condition, and specific questionnaires have been used to assess five aspects of stigmatization— retreat, self-esteem, rejection, concealment and composure (Schmid-Ott, Jaeger, Ott, & Lamprecht, 2005), with the experience of stigmatization mediating the effects of severity of disease upon quality of life (Vardy et al., 2002). Of particular note in this study is that the five factors are all highly correlated, suggesting a single underlying dimension (Vardy et al., 2002). Irritable bowel syndrome (IBS) is a condition that can be concealed but can be embarrassing in its symptoms, and hence those suffering from it often report stigma. A recent study assessed stigmatization using an 11-item scale, written specially for the study in the absence of a generic instrument, which included items such as 'Some people have avoided me since I became ill with IBS' (Dancey, Hutton-Young, Moye, & Devins, 2002), and found that stigmatization was negatively correlated with quality of life. Perhaps the largest, and most comprehensive study measuring stigmatization in a specific condition, is in HIV (human immunodeficiency virus) infection (Berger, Ferrans, & Lashley, 2001). The final HIV stigma scale, reduced from an initial pool of 184 items, had 40 items, which factor analysis suggested could be reduced to four factors, reified as personalized stigma, disclosure concerns, negative self-image and concern with public attitudes, and which were themselves strongly inter-correlated with a single higher-order factor which the authors say, 'represent a single construct' (Berger et al., 2001, p. 525). Overviewing the different scales that have been adopted, it is clear that most scales have several dimensions which are highly correlated, and that there is usually a single over-riding factor which can be assessed reliably.

Variation in stigmatization

A realization in recent work is that stigmatization is by no means uniform, so that 'there is considerable individual variation within stigmatized groups, just as there is within nonstigmatized groups' (Dovido, Major, & Crocker, 2000, p. 2). Certainly the studies described earlier in patients with leprosy, psoriasis, irritable bowel syndrome and HIV infection all attest to the truth of that statement. However what is striking about the literature on stigmatization is that there is almost no reference to the relationships between individual differences in personality and differences in stigmatization. As a result one can find hardly a single reference to personality in a major book on stigma (Heatherton et al., 2000), there is no assessment of personality in any of the work on leprosy, psoriasis, irritable bowel syndrome, HIV infection or any other work that we can find and there is merely a rejection of the idea that stigma 'inevitably results in deep-seated, negative, and even pathological consequences for the personality of a stigmatized individual' (Dovido et al., 2000, p. 3). Despite there being a growing recognition that stigmatizing illnesses are life-events that individuals cope with, and cope with in different ways, and with differing degrees of success (Miller & Major, 2000), there is little assessment of the major predictor of different ways of coping, which is personality (Brebner, 2001; Penley & Tomaka, 2002). There is also a growing realization among personality researchers that far from personality being determined by life-events, it is personality itself which is surprisingly stable across the lifespan, and personality therefore which determines the impact of life-events (Matthews, Deary, & Whiteman, 2003; McCrae & Costa, 2003).

In this article we will consider stigmatization, and its variation, in a large group of individuals

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with primary ciliary dyskinesia (PCD), a chronic illness with a number of features that potentially might make individuals feel stigmatized.

Primary ciliary dyskinesia

The rare condition known as primary ciliary dyskinesia (PCD), originally described by Kartagener (1933) and Siewert (1904), occurs in about 1 in 10,000 people, primarily manifesting as a chronic and sometimes severe respiratory illness (Bush et al., 1998). The normal bronchial tree and upper respiratory tract contain cilia, small cytoplasmic extrusions from the cell body, which beat in a co-ordinated fashion to remove detritus from the lungs and sinuses. In PCD the cilia either do not beat, or beat in an un-coordinated and dysfunctional way. As a consequence there are recurrent infections, which result in sinusitis and bronchiectasis, the latter resulting in a chronic cough and other respiratory tract symptoms, including the production of large amounts of purulent sputum. Physiotherapy and prophylactic antibiotics can to some extent help in alleviating symptoms (Ellerman & Bisgaard, 1997). Although sometimes diagnosed soon after birth (Coren, Meeks, Morrison, Buchdahl, & Bush, 2003), PCD can also be diagnosed surprisingly late in life (McManus, Mitchison, Chung, Stubbings, & Martin, 2003; Parraudeau et al., 1994). A crucial breakthrough in understanding and diagnosing the condition was the discovery by Afzelius (1976) that the cilia are lacking a key motor protein known as dynein.

From the perspective of stigma, PCD has four separate components of interest. First, a chronic productive cough is visible and is somewhat disabling, particularly if accompanied by dyspnoea on exercise, when it can prevent a range of daily activities; excuses and explanations need to be made, and opportunities need to be found, for various therapies, particularly physical therapies. Second, the syndrome is inherited, usually although not always being an autosomal recessive (Narayan et al., 1994; Rott, 1983), and so there are all of the associated anxieties concerned with a genetic condition. Third, for men with PCD there is the additional problem that many are sub-fertile, due to the dynein also being responsible for the beating of the tail of spermatozoa. Such infertility can now be treated

by means of ICSI (intra-cytoplasmic sperm injection). Female patients also seem to have reduced fertility. Finally, about a half of all individuals with PCD have the condition known as *situs inversus totalis*, or complete reversal of the normal left–right asymmetry of the organs of the body, so that instead of the normal condition (*situs solitus*), in *situs inversus* the heart is on the right, the lobes of the lungs are reversed, the liver and appendix are on the left, the spleen and stomach on the right and so on. In passing it should also be noted that, intriguingly, *the situs inversus* in PCD is not associated with a raised likelihood of left-handedness (McManus, Martin, Stubbings, Chung, & Mitchison, 2004). Although not immediately apparent externally, *situs inversus* is soon revealed by a stethoscope or chest X-ray, and it is medically important that patients are aware of it (in case of abdominal surgery, for instance). The origin of the reversal is complex, but in essence normal left–right development depends on the beating of cilia in the nodal region, early in the development of the embryo. The cilia are probably inactive in PCD, with the result that *situs* is random, half the cases having the organs in their normal arrangement, and half showing complete reversal (Brueckner, 2002; McManus, 2002). Although undoubtedly 'concealed', *situs inversus* has the potential for being a stigmatizing condition which may either be perceived as a mere curiosity, or its difference may be seen as sufficiently unusual that an individual might not want to reveal it to others because of the questions that would be raised, the explanations that would be necessary and so on. An example from popular culture of the potential for stigmatization, comes from the song by the band Momus, used in the epigraph above: 'I met this girl with a righthand heart . . ./And though I know there's nothing dangerous in it/I'm feeling queasy, getting worse by the minute/Wondering how to escape this nightmare . . .'

Factors influencing stigma

Goffman talks of the 'moral career' of the stigmatized, the trajectory of which depends on the age at which the condition becomes apparent. If a condition is present at birth then a child may be protected by its parents from the societal consequences, at least until the school years.

Nevertheless the child will always have known a life in which the condition is present. In contrast stigma can also develop later in life, 'at a stroke' as Goffman (1963/1990, p. 48) put it, with the advent of illness or the diagnosis of illness. PCD is diagnosed at different stages during life, and therefore the age of the patient and the age of the diagnosis can potentially alter the patient's response to the condition.

Stigmata vary in potency, with a range of studies suggesting the influence of a half-dozen or more factors (Crandall & Moriarty, 1995), although there is not universal agreement on classification Dovido et al. (2000). Jones et al. (1984) suggested the importance of *concealability*, *course*, *disruptiveness*, *aesthetic qualities*, *origin* and *peril*, with factors such as course being additionally influenced by being progressively deforming or crippling, non-fatal and chronic, and appearing incurable, and origin being influenced by a condition being congenital or acquired, and by the responsibility of the bearer for it. Many of these factors might influence the potential of individuals with PCD to be stigmatized, with differing effects for the respiratory problems (non-concealable, progressively disabling, disrupting and potential peril), and *situs inversus* (concealable and congenital). Although it might seem that a visible stigma is more problematic than one which is concealed, several authors have argued that may not actually be the case, the concealed mark inevitably and inexorably influencing what Goffman called, 'the secret life of the stigmatized individual' (1963/1990, p. 41), with the continual decisions as to whether to reveal or not. Concealable stigma carries a hidden cost (Smart & Wegner, 2000).

In this article we describe a questionnaire study of a large group of individuals with PCD, some of whom have *situs inversus*, and others of whom do not. We follow other researchers in developing our own scale for the assessment of stigma appropriate for individuals with this condition. We then assess the influence of demographic factors, respiratory symptoms, physical and mental health status and stress upon the stigma experienced by these patients, and their relationship to the Big Five measures of personality. Finally we explore a possible structural equation model for the data, which helps to clarify some of the possible relationships between the various measures.

Method

A postal questionnaire was sent in January 2003 to all individuals on the mailing list of the UK's Primary Ciliary Dyskinesia Family Support Group. A reminder was sent to non-respondents after four weeks.

The questionnaire consisted of 16 pages of A4, and covered a wide range of topics, not all of which are relevant to the present study, since a study was also being carried out of lateralization (McManus et al., 2004). More detailed medical results from the present study are available in McManus et al. (2003). Separate versions of the questionnaire were provided for adults and children (under 16 years of age). The principle difference was in the consent forms (see later), and in addition there were minor changes of wording between the two forms, principally to do with work/school, and with occasional simplification of wording in the child version. The child version also did not contain questions about smoking.

Respiratory symptoms

Respiratory symptoms were assessed by the St George's Respiratory Questionnaire (SGRQ) (Barr et al., 2002; Jones, Quirk, & Baveystock, 1991; Jones, Quirk, Baveystock, & Littlejohns, 1992; Wilson, Jones, O'Leary, Cole, & Wilson, 1997), which provides three separate scales, Symptoms, Activity and Impacts. The scores are scaled in the range 0–100, where a score of 100 indicates optimal functioning within the context of respiratory illness.

Health status

Health status overall was assessed by version 2 of the SF-36 questionnaire, which is a widely used generic instrument for assessing mental and physical functioning (Brazier et al., 1992), for which UK population norms are also available (Jenkinson, Stewart-Brown, Petersen, & Paice, 1999). Although the questionnaire has eight sub-scales (Physical Functioning, Role Physical, Bodily Pain, General Health, Energy/vitality, Social functioning, Role Emotional and Mental Health), factor analysis has shown that there are two broad groups of sub-scale, physical and mental (Jenkinson et al., 1999). For the present study therefore the published weights were used to derive the Physical Component Summary

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(PCS) and the Mental Component Summary (MCS) (Jenkinson et al., 1999).

Stress

Stress levels were assessed using the 12-item version of the General Health Questionnaire (GHQ), which has good validity in general medical patients for detecting minor psychiatric illness (Furukawa & Goldberg, 1999; Goldberg, 1972; Goldberg et al., 1997). The GHQ can be scored in several ways, but for the present purpose we used 0–1–2–3 scoring. Each item is on a 4-point scale and the 4 levels on each question are given scores of 0, 1, 2 or 3, with 3 being the most serious. This scale has a range of 0 to 36, and is approximately normally distributed in the population.

Personality

The 'Big Five' personality dimensions of the Five-Factor Theory (McCrae & Costa, 2003) were assessed using a modified adjective check-list based on the work of Goldberg (1992, 2001) and Hofstee, Kiers, de Raad, Golberg and Ostendorf (1997).

Stigma

We were unable to find a generic measure in the literature that assessed stigma, and therefore we wrote questions of our own (see results section). When we designed this project the only study we could find on MedLine that included the terms 'stigma' and 'questionnaire' or 'inventory' described the PDQ-39, which is used to assess quality of life in Parkinson's disease (Bushnell & Martin, 1999; Peto, Jenkinson, & Fitzpatrick, 1998). We therefore used the stigma sub-scale of the PDQ-39 as a model on which to base and develop our own questions. In order not to make the questions too conspicuous they were integrated into the questions forming the SGRQ and the SF-36, and therefore do not all have the same number of response categories. Since carrying out the study and with better search facilities we have discovered several other studies assessing stigmatization (see Introduction).

Structural equation modelling

Structural equation modelling was carried out using LISREL 8.52, and the correlation matrix was fitted using the maximum likelihood method (Jöreskog & Sörbom, 1993). Sixteen variables were modelled using structural equation modelling. The variables were grouped into six sets in terms of their a priori causal ordering (Davis, 1985). At the extreme right was 'Stigma', since it was the primary variable of interest in the study. The other variables were distributed according to the time-scale over which they are likely to vary. The GHQ measure of stress is essentially measuring relatively short-term variation, and therefore it immediately precedes the stigma measure. Prior to that are the two SF-36 summary measures of health status, one for physical health and the other for mental health. Physical symptoms, as assessed by the SGRQ are assumed to reflect relatively long-term disease processes and therefore they are prior to the measures of perceived health status. Prior to the SGRQ measures are the trait measures of personality, as assessed on the Big Five measures, and at the extreme left are the exogenous variables of age, age at diagnosis, sex and the presence of *situs inversus*, all of which are fixed for an individual. The LISREL model was fitted such that within a 'vertical' set of variables (e.g. the personality measures or the SGRQ measures), all possible correlations were fitted within the Psi matrix, and all remained in the model throughout the fitting process. Model fitting began with a saturated model in which the Beta matrix contained all possible links from left-to-right, from variables in one set to subsequent variables in other sets. The initial, saturated model therefore completely accounted for the correlation matrix, the number of parameters equalling the number of off-diagonal elements in the correlation matrix. Subsequent model fitting took place sequentially, first by removing all Beta paths for which the z-score was less than one. At each remaining step the least significant Beta path was removed, and the Beta modification indices checked that no variables had subsequently become significant. Model fitting ceased when all Beta paths in the model were significant with $p < .1$. The relatively liberal criterion was used in order that any potentially theoretically interesting paths would not inadvertently be omitted from the model. Paths with $p < .1$ (which are indicated), should be treated with care. Because the measures are all on different scales, and the model is fitted to the correlation matrix, the path

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coefficients shown in Fig. 1 are Beta (standardized) regression coefficients.

The study was approved by the joint UCL/ UCLH Committees on the Ethics of Human Research. The mailing also included a letter from the secretary of the Support Group, which endorsed the study. In order to protect patient confidentiality, the names of members of the Support Group were not known to the researchers, address labels being applied to envelopes by the Support Group. Respondents were given the opportunity to provide contact details for further research, and a majority did so. The questionnaire contained a consent form as an integral part of its construction, and this was signed either by the patient, or, where appropriate, by the patient and their parent or guardian.

Results

Response rate

The initial mailing was to 160 addresses. Responses were received from 93 individuals, and a further 15 envelopes were returned by the Post Office as undeliverable for one reason or another. The overall response rate was therefore $93/(160–15) = 66$ per cent. No information is available at all on non-respondents. Further clinical information on respondents is provided elsewhere McManus et al. (2003).

Age

Parents of children were encouraged to respond to the questionnaire, irrespective of how young the child was, and to complete only those questions which it was possible to answer for the
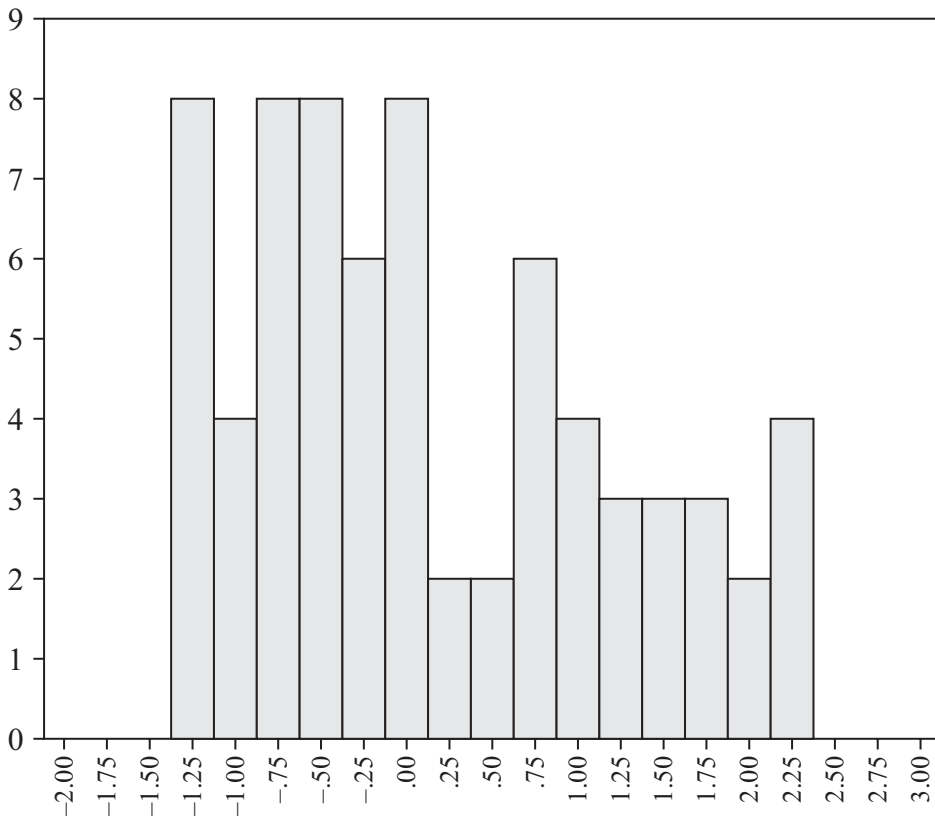

Figure 1. Distribution of stigma scores. High scores indicate greater stigmatization.

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child. The age distribution was somewhat skewed, the mean being 22.7 years (SD 16.8), with the median being 16.5 (quartiles 10.8 and 31.3), and the 10th and 90th percentiles being 5.4 and 53.7). For the present study, individuals were only included if they were 10 years or older, in order that they could respond properly to the entire range of questions (albeit sometimes with the help of an adult). The mean age of this group of 71 individuals was 27.7 years (SD 16.2), with the median being 20.1 (quartiles 15.6 and 38.7), and the 10th and 90th percentiles being 13.1 and 56.6). Forty-eight (67.6%) subjects were female and 23 (32.4%) were male.

Situs inversus

In the survey overall, 48 respondents said that their heart was on the right, and 44 that their heart was on the left (one respondent did not answer this question). There is therefore no evidence of a response bias in favour of those with their heart on the right ($\chi^2 = 0.17$, 1 d.f., NS). In the sample of those aged 10 or over, 36 had *situs inversus* and 35 had *situs solitus*. All of the respondents who said that their heart was on the right said that this had been confirmed by X-ray.

Stigma

Stigma was assessed by the response to the 11 questions shown in Table 1. The scree-slope in factor analysis suggested there was a single underlying factor, the first 5 eigen-values being 5.771, 1.154, 1.108, 0.721 and 0.590. Occasional missing values or responses of 'not applicable' were replaced by means, and a single factor score was extracted (Fig. 1). Factor loadings are shown in the right-hand column of Table 1, and it can be seen that all measures load on the single factor. Cronbach's alpha for the scale was 0.880. High scores are indicative of greater stigma. There is a suggestion of bimodality, with subjects tending to be either stigmatized or not stigmatized, with a majority being in the latter group.

Simple correlations with stigma

Stigma scores showed no association with age ($r = .141$, $p = .241$) or with age at diagnosis ($r = .241$, $p = .115$). Stigma did however correlate significantly with the SGRQ Symptom score ($r = -.297$, $p = .012$) and the SQRQ Impact of

Illness score ($r = -.454$, $p < .001$), although not with the Activity score ($r = -.204$, $p = .088$). Stigma also showed a significant correlation with the GHQ stress score ($r = .523$, $p < .001$) and with the Mental Summary score of the SF-36 ($r = -.572$, $p < .001$), although not with the Physical Summary Score of the SF-36 ($r = -.163$, $p = .174$). The stigma score correlated significantly with the neuroticism measure ($r = .360$, $p = .002$), although not with the measures of extroversion ($r = -.181$, $p = .130$), conscientiousness ($r = -.110$, $p = .363$), agreeableness ($r = -.147$, $p = .223$) or openness to experience ($r = -.142$, $p = .237$). Student's *t*-test showed that the stigma score did not differ significantly between males and females ($t = -.518$, 69 d.f., $p = .606$), or between those with *situs inversus* and those with *situs solitus* ($t = .145$, 69 d.f., $p = .885$). The interrelations between the various measures, and their relationship to stigma were explored using structural equation modelling (path analysis).

Structural equation modelling

Sixteen variables were fitted (see method section for a description of the approach). The correlation matrix, means and standard deviations are shown in the Appendix. Twenty-four paths were significant at the $p < .1$ level (see Fig. 2), of which three reached only the $p < .1$ level; of the remainder, 5 were significant with $.01 < p < .05$, 5 were significant with $.001 < p < .01$ and 11 were significant with $p < .001$.

The overall goodness of fit of the model in Fig. 2 was excellent, with $\chi^2 = 53.97$, 76 d.f., $p = .974$. The root-mean-square residual was 0.062, and the largest standardized residuals were –1.714 and 1.839. The goodness of fit index was 0.923, and the adjusted goodness-of-fit index was 0.862. The largest three modification indices for Beta were 2.46, 2.08 and 2.06. Allowing these variables to enter the model did not produce an overall significant improvement in fit ($\chi^2 = 6.73$, 3 d.f., NS), and none achieved individual significance (z = 1.62, 1.48 and 1.47).

A striking difference between the simple correlations with stigma and the structural equation model is that there is a highly significant simple correlation between stress levels and stigma, and yet there is no direct link in the structural model. Two explanations are possible —either the simple correlation is artefactual, resulting entirely from stress and stigma sharing

Table 1. The questions used to assess stigma, which were embedded among other questions on respiratory problems and health in general

These are questions about other effects that *breathing or respiratory problems* **may have**. If you do not have a particular problem then please tick 'Not applicable'.	*Definitely agree*	*Agree somewhat*	*Disagree somewhat*	*Definitely disagree*	*N/A*	*Factor loading*
My coughing or breathing is embarrassing in public	**37.3%** (25/67)	**37.3%** (25/67)	**13.4%** (9/67)	**11.9%** (8/67)	*N* = 4	.530
My breathing problem is a nuisance to my family, friends or neighbours	**15.6%** (10/64)	**17.2%** (11/64)	**18.8%** (12/64)	**48.4%** (31/64)	*N* = 7	.478
I have sometimes felt I had to hide from other people the fact that I had PCD	**25.4%** (17/67)	**19.4%** (13/67)	**10.4%** (7/67)	**44.8%** (30/67)	*N* = 4	.880
I have sometimes felt embarrassed in public because of having PCD	**21.2%** (14/66)	**28.8%** (19/66)	**12.1%** (8/66)	**37.9%** (25/66)	*N* = 5	.818
I have sometimes avoided situations where people might find out that I had PCD	**23.1%** (15/65)	**13.8%** (9/65)	**6.2%** (4/65)	**56.9%** (37/65)	*N* = 6	.863
I have sometimes felt worried about other people's reaction to PCD	**21.2%** (14/66)	**24.2%** (16/66)	**13.6%** (9/66)	**40.9%** (27/66)	*N* = 5	.866

| How does *PCD* affect your daily life?	*True*	*False*			*N/A*	*Factor loading*
I sometimes feel it makes people reject me	**18.8%** (13/69)	**81.2%** (56/69)			*N* = 2	.586
Sometimes it makes it more difficult for me to make friends	**16.2%** (11/68)	**83.8%** (57/68)			*N* = 3	.592
It is sometimes difficult telling people about my condition	**43.5%** (30/69)	**56.5%** (39/69)			*N* = 2	.860
Sometimes I prefer not to let other people know that I have PCD	**59.4%** (41/69)	**40.6%** (28/69)			*N* = 2	.710
Sometimes it is difficult having a rare and unusual condition	**56.5%** (39/69)	**43.5%** (30/69)			*N* = 2	.622

N/A = Not Applicable
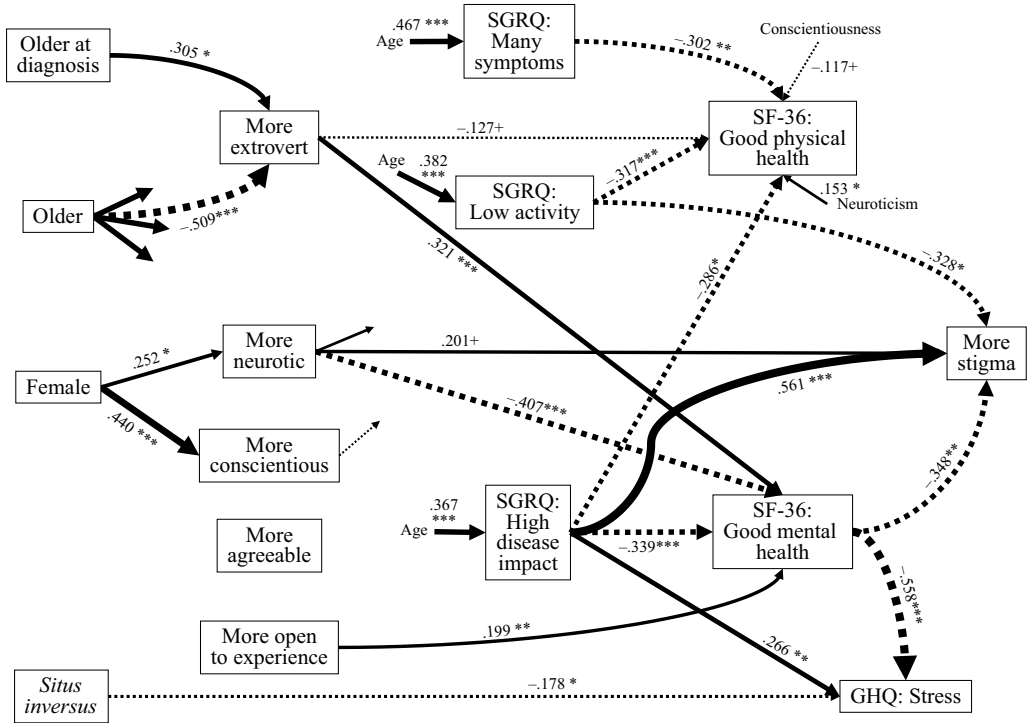
Figure 2. Path model of the relationships between stigma, health measures, measures of respiratory symptoms (SGRQ), personality and background variables. The width of arrows is proportional to the size of the path coefficient, and negative relationships are shown as dashed lines. A few lines from age and personality are interrupted to avoid the diagram being too confusing. See text for details of the model fitting process.
+p < .1; *p < .05; **p < .01; ***p < .001

antecedents, in particular the MCS of the SF-36 and the SGRQ Impact measure, or the structural model has a specification error, and stress is not prior to stigma, as fitted. The latter can be checked by comparing several models. The model as fitted, with no link between stress and stigma has χ^2 = 47.241 (73 d.f.). Allowing a causal link from stress to stigma reduces the χ^2 value to 46.671 (72 d.f., $\Delta\chi^2$ = .570, Δ d.f. = 1, NS), allowing a causal link in the reverse direction from stigma to stress reduces the χ^2 value to 45.746 (72 d.f., $\Delta\chi^2$ = 1.765, Δ d.f. = 1, NS) and allowing a non-directional correlation between stigma and stress (in effect treating them as indicators of a single factor) reduces the χ^2 value to 46.492 (72 d.f., $\Delta\chi^2$ = 0.749, Δ d.f. = 1, NS). Since none of these is a better fit than the model in Fig. 2 it has to be concluded that the model is correctly specified and the simple

correlation between stress and stigma is indeed a consequence of them both correlating with antecedent variables.

Discussion

The present study has used a quantitative methodology to identify stigma in a large group of individuals with a chronic illness, with moderately severe respiratory symptoms, which has a genetic origin, and which is sometimes associated with the unusual condition of *situs inversus*. Although stigma is much discussed in the sociological literature, there seem to be few questionnaire methods that allow it to be assessed generically in groups of individuals who potentially perceive themselves as stigmatized as a result of their condition. We have therefore developed a novel questionnaire, which parallels

those developed elsewhere for other potentially stigmatizing conditions such as leprosy, psoriasis, IBD and HIV infection. This scale suggests that about one-third or so of these individuals have responses that can be considered as typical of stigmatization. It is clear from the answers to the questions described in Table 1 that many people with PCD are embarrassed or are ashamed about their symptoms, feel they are a nuisance to friends or family and they prefer not to let other people know about their condition. There seems little doubt that such a combination of responses should be categorized as stigmatization, and they are equivalent in many ways to those reported by patients with Parkinson's disease, and the PDQ-39 instrument includes a stigma sub-scale (Peto et al., 1998).

Although we have referred to the dimension underlying the questions in Table 1 as 'stigma' (and in so doing we followed Peto et al., 1998, as well as other researchers on other conditions), we are also aware that several of our own questions, and also other measures of the impact of specific illnesses, refer to 'embarrassment'. An example is the Cystic Fibrosis Questionnaire (and in many ways cystic fibrosis is similar to PCD, albeit being a more severe chronic lung disease), which not only contains a scale entitled 'embarrassment', but also under the 'Body image' scale contains an item, 'I am embarrassed about being thin' (Henry, Aussage, Grosskopf, & Goehrs, 2003; Wenninger, Aussage, Wahn, & Staab, 2003). A literature search on MedLine also found six recent studies in which the terms 'embarrassment' and 'stigma' were used in the same study, suggesting a conceptual relatedness (Adetunji & Meekers, 2001; Alvidrez & Azocar, 1999; Dixon-Woods et al., 2001; Maynard, 2001; Ferrario, Zotti, Baroni, Cavagnino, & Fornara, 2002; Solomon, Man, Gill, & Jackson, 2002).

Embarrassment is an emotion concerning which there is much confusion in psychology, some workers seeing it as a minor version of shame, whereas others see it as conceptually separate, with different social roles and autonomic origins (Keltner & Buswell, 1997). There seems little doubt though that, 'Embarrassment is subtle and pervasive in its constraints and pressures' (Ricks, 1974, pp. 1–2), and, as Goffman (1956) emphasized, that embarrassment forms a central part of social interaction. Individuals also differ in the extent to which they show embarrassment, and in the situations in which they find themselves embarrassed, although of particular relevance to our present study is that neuroticism was a predictor of the extent of embarrassment in all situations (Sabini, Siepmann, Stein, & Meyerowitz, 2003). The extent to which stigma, embarrassment and shame are assessing separate or linked variables clearly needs further research, with questionnaire measures that are designed to separate the concepts. However much the stigma reported by our subjects may contain a component of embarrassment, we feel that embarrassment alone cannot account for the range of phenomena reported in Table 1.

Our study has a reasonable number of background variables, which can be used to assess those factors that are linked with stigmatization, and the structural equation model provides a clear picture of those variables. The fitted model can be divided into several portions. A number of measures predict the overall stigma score. However of particular note is that neither the measure of stress, nor the measure of physical health, is predictive of stigma. The largest direct predictor of stigma is a high impact measure on the SGRQ, although good mental health on the SF-36 and Low Activity on the SQRQ are also predictive. There are also indirect influences on the stigma score, although these are somewhat difficult to see in Fig. 2. Figure 3 therefore shows the same model as Fig. 2 but including only direct and indirect paths that influence stigma. It is now clear that as well as the effect of the high disease impact measure being the largest direct effect, the measure also has large indirect effects via its influence on the SF-36 mental summary score. Among the personality variables, extroversion, neuroticism and openness to experience all have indirect effects on stigma, acting via the SF-36 measure of mental health: stable extroverts who are more open to experience have better mental health and hence lower stigma scores. There is also a suggestion of a direct link from neuroticism to stigma, although the path does not quite reach the conventional $p < .05$ level of significance ($z = 1.912, p = .0558$). In view of its theoretical interest, this result clearly requires replication.

It should be emphasized that there are a number of 'absent' paths in Fig. 3. In particular there are no effects upon stigma of any of the
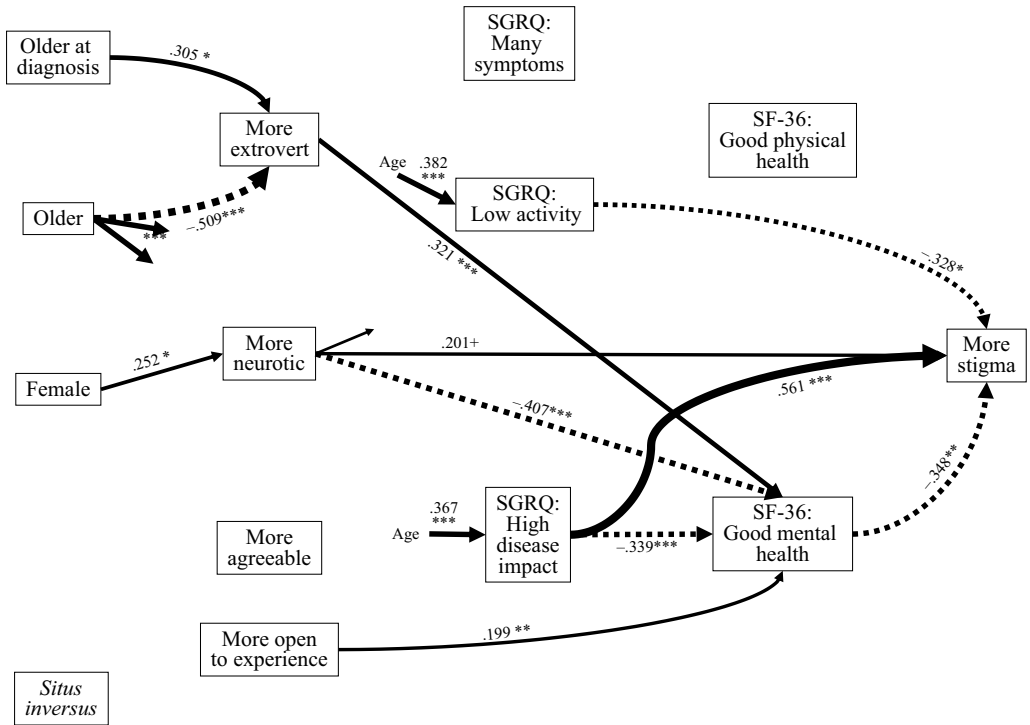
477

Figure 3. The same diagram as fig. 2 except that all paths that are not direct or indirect influences upon stigma have been removed, to clarify the relationships of the variables to stigma.

$+p < .1$; $*p < .05$; $**p < .01$; $***p < .001$

'physical' measures, be they symptoms of illness on the SGRQ, the SF-36 physical summary score or the presence of *situs inversus*. Stigma in PCD therefore seems to be the result of the impact of the illness upon social, emotional and mental life, rather than the direct outcome of physical problems per se. The absence of any relationship with *situs inversus* is a particularly forceful demonstration of this principle, since although an integral part of the syndrome, it only occurs in a random 50 per cent of individuals with PCD, and it is independent of disease or symptom severity (McManus et al., 2003). The conditions are therefore almost properly met, uniquely in a study of a disease, for a controlled study, subjects in effect being allocated at random to the *situs inversus* and *situs solitus* groups.

This study inevitably has a number of limitations. In particular it has concentrated on only some aspects of stigmatization, mainly centring

on information management. It is a quantitative analysis and as such has strengths and weaknesses. Its strengths are that absent relationships can clearly be seen (as for instance in the fact that stigma is *not related* to physical symptoms, or to stress, despite there being many reasons for presuming they would be). The quantitative approach, particularly involving structural modelling, also allows indirect relationships to be clearly identified. The strengths of the quantitative approach are of course also its weaknesses, and a qualitative methodology would allow more detailed insight into the processes and underlying reasons, as well as a more detailed description of the nature and breadth of the stigma that is felt. It is hoped to carry out such a study at a future time, perhaps using the same group of individuals that is described here.

Our study suggests that perceived or felt stigma in these patients mainly relates to measures of mental health, and to symptoms

that are related to the social impact of the respiratory problems. If correct, that finding has the important practical implication that patients who particularly suffer from feelings of being stigmatized might respond to psychotherapy or cognitive therapy to address the problem.

Note

1. See www.phespirit.info/momus/19880106.htm

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Appendix. Correlation matrix for the variables used in the structural equation model. Means and Standard Deviations are shown at the bottom

	1	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*	*11*	*12*	*13*	*14*	*15*	*16*
1 Age at diagnosis	1	0.625	0.253	–0.168	0.002	0.013	0.143	–0.003	0.051	0.378	0.336	0.389	–0.275	–0.182	0.313	0.168
2 Age	0.625	1	0.155	–0.030	–0.307	–0.056	0.246	0.037	0.036	0.467	0.382	0.367	–0.321	–0.225	0.246	0.141
3 Sex (1 = male, 2 = female)	0.253	0.155	1	–0.020	–0.010	0.193	0.454	0.152	–0.058	0.091	0.180	0.158	–0.174	–0.176	0.145	0.062
4 Heart (1 = left 2 = right)	–0.168	–0.030	–0.020	1	0.115	–0.122	0.042	0.088	–0.067	–0.112	–0.070	–0.018	0.103	0.093	–0.235	–0.017
5 Extroversion	0.002	–0.307	–0.010	0.115	1	–0.245	–0.116	0.033	0.033	–0.255	–0.303	–0.217	0.084	0.501	–0.414	–0.181
6 Neuroticism	0.013	–0.056	0.193	–0.122	–0.245	1	–0.094	–0.418	–0.130	–0.062	0.071	0.007	0.189	–0.514	0.357	0.360
7 Conscientiousness	0.143	0.246	0.454	0.042	–0.116	–0.094	1	0.244	0.200	0.140	0.088	0.069	–0.227	0.095	–0.036	–0.110
8 Agreeableness	–0.003	0.037	0.152	0.088	0.033	–0.418	0.244	1	0.011	0.108	–0.020	0.000	–0.162	0.289	–0.230	–0.147
9 Openness	0.051	0.036	–0.058	–0.067	0.033	–0.130	0.200	0.011	1	0.065	0.073	0.112	–0.134	0.229	–0.149	–0.142
10 SGRQ Symptoms	0.378	0.467	0.091	–0.112	–0.255	–0.062	0.140	0.108	0.065	1	0.652	0.767	–0.711	–0.339	0.376	0.297
11 SQRQ Low Activity*	0.336	0.382	0.180	–0.070	–0.303	0.071	0.088	–0.020	0.073	0.652	1	0.741	–0.704	–0.295	0.324	0.204
12 SQRQ Impact	0.389	0.367	0.158	–0.018	–0.217	0.007	0.069	0.000	0.112	0.767	0.741	1	–0.731	–0.389	0.486	0.454
13 SF-36 Physical	–0.275	–0.321	–0.174	0.103	0.084	0.189	–0.227	–0.162	–0.134	–0.711	–0.704	–0.731	1	0.030	–0.209	–0.163
14 SF-36 Mental	–0.182	–0.225	–0.176	0.093	0.501	–0.514	0.095	0.289	0.229	–0.339	–0.295	–0.389	0.030	1	–0.678	–0.572
15 GHQ-12 (0-1-2-3 scoring)	0.313	0.246	0.145	–0.235	–0.414	0.357	–0.036	–0.230	–0.149	0.376	0.324	0.486	–0.209	–0.678	1	0.519
16 Stigma score	0.168	0.141	0.062	–0.017	–0.181	0.360	–0.110	–0.147	–0.142	0.297	0.204	0.454	–0.163	–0.572	0.519	1
Mean	14.83	27.74	1.676	1.507	0.915	–1.155	2.423	4.479	4.408	–48.29	–76.14	–72.83	41.44	47.85	10.80	0.158
SD	15.54	16.16	0.471	0.504	2.980	2.430	2.584	2.190	2.424	23.72	23.96	18.17	13.95	10.64	5.357	1.041

* Scored so that a high value means less activity