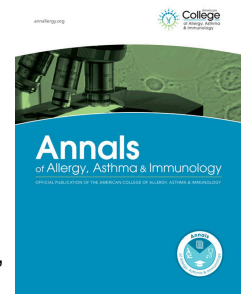


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Illness perceptions in difficult to treat asthma compared with a depressed psychosis cohort

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Beliefs about one's illness or "illness perceptions", such as severity, chronicity or degree of control over illness have been shown to be related to long term reported health status, psychological wellbeing and treatment outcomes across a range of physical health conditions (1) and to adherence in asthma (2). Difficult to treat asthma (DTA) is a broad disease describing persistent symptoms despite maximised standard treatment (3). The psychiatric morbidity in DTA is recognised (4); however, the specifics about how people relate to their illness are less well understood.

The Personal Beliefs about Illness Questionnaire – Revised (PBIQ-R) (5) is a 20 item self-report questionnaire, originally designed to explore the impact of psychosis upon people's beliefs about their social value. DTA individuals tend to display themes of loss of social function, status and role, a feeling of disconnection with others, stigma and a perceived need to conceal their asthma due to others' misconceptions and negative evaluations, and a sense of asthma controlling their lives (6). Such themes relate closely to the domains measured by the PBIQ-R.

Whilst these conditions may initially appear to be completely different, DTA is poorly understood by mainstream society, has a variable course and is associated with exacerbations which may lead to posttraumatic stress disorder (PTSD) (7). Any traumatic experience may lead to a realistic fear that similar relapse could happen in the future. Within psychosis literature a "sealing over" coping style may be adopted to maintain self-esteem in people with psychosis "believe that their psychotic episode was a singular and past event, denying

chronicity of the condition, and the need for treatment in order to stay well”. Within DTA, a similar pattern of “denial coping” can be observed, whereby people minimise the seriousness of their asthma, deny it’s chronicity, and dismiss any sense of association of being ‘asthmatic’. Therefore there may be some unexpected similarities in the experiences of living with these two very different conditions. Disease denial is associated with poor health outcomes, including increased hospitalisations and risk of near fatal asthma (3).

A sense of belonging is theorised to be fundamental to mental health (8). The PBIQ-R assesses subscales associated with perceived social value or where one sees their place in society as a result of having their illness. These subscales are: 1. social marginalisation - the extent to which the client feels relegated to the fringes of society; 2. Shame - the perceived internal characteristics that threaten how acceptable a person is to others; 3. Control over illness - the perceived level of control the person has on the management of their symptoms; 4. Loss - loss of a valued role or reduced opportunities to fulfil important roles in their life; and 5. Entrapment – perceived inability to escape or move on from an event. Higher scores of PBIQ-R indicate stronger negative beliefs.

The PBIQ-R was completed by 40 consecutive patients with DTA referred for psychological assessment across two regional UK severe asthma centres. All patients were on maximised asthma treatment at GINA step 4/5 with 15 (38%) were prescribed maintenance oral corticosteroids. The average age was 41 years (range 18-65), 29 (73%) females, 28 (70%) White, 7 (18%) Asian, 2 (5%) Black, and 3 (7%) were other. We compared the results of these participants to those reported in the PBIQ-R reliability and validity data (5) that included depressed individuals with psychosis (DP) groups, in which psychosis represented first episode of psychosis and up to 3yrs post diagnosis.

There was a trend towards higher subscale scores in DTA than the DP group, except for social marginalisation, suggesting the possibility of poorer beliefs about self due to their illness within the DTA population (table1). People with depression are inclined toward self-diminishing, negative patterns of thinking and stronger self-criticism.

Illness perceptions associated with entrapment and loss, were the most highly endorsed in the DTA group. Losses in functioning and future possibilities were prevalent in the DTA population with 35 (88%) agreed or strongly agreed with the statement “My illness stops me doing the things I want to do”, 26 (65%) reported “my illness is too brittle/delicate for me to work” and 24 (60%) reported embarrassment because of their asthma.

The comparator group from Birchwood et al (5) was of broadly similar multi-ethnic structure to our DTA population but was younger (age range 16 to 35 vs 18 to 65 years). The effect of age on these observations is uncertain. Our results are also probably skewed towards worsened illness beliefs in DTA due to pre-selection of patients with high psychological burden for psychological assessment. However, it could be argued that those in the DP group were also psychologically burdened by their depression. The psychological burden in DTA is high (4) and is probably being underestimated within severe asthma services due to lack of routine psychological assessment.

Early assessment of illness perception in DTA, may allow identification and timely referrals of suitable patients for psychological interventions to improve clinical outcomes such as adherence with medication or physiotherapy. Evidence in other disease areas such as diabetes demonstrated benefit of improved adherence and quality of life using cognitive

behavioural therapy “CBT” (9). Third Wave CBT has had a reported positive impact upon illness perceptions in DTA and intervention to alter illness perceptions have been shown to impact upon adherence in asthma. Clinical experience of the authors show that when patients feel they have no control over their asthma and they are ashamed of having it, they are much less likely to be actively engaged in self management and to believe it is possible to make positive changes to their lives. Changing these beliefs to instil a sense of hope and to feel more in control over symptoms can help people to engage more in activities such as exercise (10).

Herein we describe the impact of DTA upon the perceived social value and illness perceptions and report at least similar, if not worse scores to those with DP. We recommend assessment of illness perceptions via questionnaires such as the PBIQ-R or others such as the Brief Illness Perception Questionnaire to identify patients who may benefit from relevant psychological interventions. Further research is warranted to confirm our findings and establish whether addressing these beliefs improves treatment adherence and outcomes in DTA.

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Table 1: PBIQ scores in difficult to treat asthma compared to psychosis plus depression subjects

Subscale	<u>Difficult to treat</u> <u>asthma</u>	<u>Psychosis +</u> <u>depression</u>	Difference (95% CI)	p-value
	N=40	N=37		
<u>Mean subscale score (/16) & (SD)</u>				
Shame	10.45 (± 3.7)	9.9 (± 2.2)	0.53 (1.9 to -0.87)	0.45
Loss	11.9 (± 3.2)	10.1 (± 3)	1.8 (3.21 to 0.4)	<0.013
Entrapment	12.2 (± 3.8)	10.3 (± 2.6)	1.9 (3.4 to 0.41)	<0.013
Control over illness	11.4 (± 3.4)	10.2 (± 2.7)	1.2 (2.6 to -0.2)	<0.09
Social marginalisation	9.2 (± 2.8)	9.2 (± 2.4)	0 (1.2 to -1.2)	1.00

(Psychosis + depression comparator group was derived from Birchwood et al (9)), PBIQ=personal beliefs about illness questionnaire. Higher scores equates to poorer illness perception "stronger negative beliefs". PBIQ-R is scored on a 4 point scale from strongly disagree to strongly agree