

ORIGINAL ARTICLE

**Caring for the chronically ill patient: understanding how fear leads to activity avoidance in individuals with chronic respiratory disease.**

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ABSTRACT

The likelihood of taking preventative health actions, such as engagement in physical activity, is affected by individual motivation along with the perceived threat of existing disease. Chronic respiratory disease enhances perceived threat of activity-induced dyspnoea and alters the perception of barriers to preventative action. This leads to decreased likelihood of taking the recommended positive health action and engaging in physical activity. Resulting behaviour instead is focused on avoidance of disease exacerbation in the form of activity avoidance.

**Keywords:** Activity avoidance; chronic respiratory disease.

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## **Physical Activity in Chronic Respiratory Disease**

Chronic respiratory diseases, such as chronic obstructive pulmonary disease (COPD) and asthma, are the third leading cause of death in America (CDC, 2010), and combined cost the nation approximately \$100 billion in health care cost, direct and indirect expenditures (Barnett and Nurmagambetov, 2011; US Department of Health & Human Services, 2009). Worldwide, COPD alone affects 10% of the population over 40 years (Buist, McBurnie, Vollmer, et al., 2007). Chronic respiratory disease limits quality of life (QOL) by preventing every day activities such as working, normal physical exertion, household chores, and participation in family activities (ALA, 2011). Impact on QOL can be attributed to the frequent sensations of difficulty breathing, or dyspnoea. Health-related quality of life (HRQoL) refers to the more subjective experience of the impact of the disease on the quality of life (Ketelaars et al, 1997). Asthmatics and COPD rate dyspnoea as one of the most significant HRQoL contributors on rating scales (Nishimura et al, 2008). Programs of regular exercise have been well documented to improve physical health in the amount of walking distance and the overall well-being of patients with COPD in the absence of significant lung function changes (Emery, Leatherman, Burker, MacIntyre, 1991; McGavin, Gupta, Loyd, McHardy, 1977; Cox, 1990; Cockroft 1981; Niederman et al; 1991).

Few traditional guidelines for COPD encourage increased exercise, a recommendation that so far is not evidence-based (COPD BTS, 1997; Garcia-Aymerich, Lange, Benet, Schnohr, & Antó, 2007). However, a 2011 international report recommended increasing engagement in active lifestyle and rehabilitation (Abdool-Gaffar et al, 2011). Physical activity is preventative to the development and the progression of chronic obstructive pulmonary disease (Garcia-Aymerich, Lange, Benet, Schnohr, & Antó, 2007). Regular activity improves respiratory peripheral muscle function (ATS, 1999), can reduce symptoms via decreased lactate production in the skeletal muscles (Casaburi, Porszasz, Burns, et al. 1997) and important anti-inflammatory and anti-oxidant effects have been reported in patients in rehabilitation programs (Rabinovich, Figueras & Ardite, 2003; Rabinovich, Ardite, Troosters, et al., 2001). Although lung function is not directly improved following a standardized physi-

cal training regimen, respiratory muscles can rapidly degrade following physical inactivity. Physical training may reduce breathlessness and asthma symptoms by strengthening respiratory muscles and by decreasing ventilation rate during exercise. Training programs in asthma have not, however, improved lung function in controlled trials (Shoemaker, Hurt, & Arndt, 2008).

## **Activity Avoidance**

Activity-related dyspnoea is one of the first and most negatively processed symptoms of respiratory disease, and it eventually progresses to incapacitating levels (Ofir, Laveneziana, Webb, et al., 2008). Patients with chronic obstructive pulmonary disease are progressively limited in their ability to participate in normal activities due to dyspnoea and peripheral muscle weakness (Thomas, Decramer, O'Donnell, 2013). Physical activity and the resulting dyspnoea leads to a vicious cycle of activity avoidance, physical deconditioning, and reduced quality of life (Thomas, Decramer, O'Donnell, 2013). Furthering the perceived disease severity is the increase in disease-related fear and depression, leading to social isolation (Zockler, Rief, Köhl, Kenn, 2012). Activity limitations often enhance feelings of social isolation and psychological problems and reduce a patient's perceived quality of life, which is further reduced by the subsequent inactivity and physical deconditioning (Jones, 2007). While most individuals with asthma have exercise-induced episodes, physical activity is not hazardous to asthmatics (Bundgaard, 1985). Systematic literature reviews very low incidence of physical activity related adverse events in individuals with chronic respiratory diseases (Eves & Davidson, 2011). However, asthmatics are frequently more anxious prior to exercise than non-asthmatics (Weston, Mcfarlane, and Hopkins, 1989), and nearly half of all asthmatics report that their health interferes with their ability to participate in physical activity (Parsons et al, 2011). This is an example of individual perception contributing to the perceived barrier to action (Becker, 1988).

## **Perception of Disease Threat**

The likelihood of taking preventative health actions, such as engagement in physical activity, is affected by individual motivation along with the perceived threat of existing disease. Understanding the behaviour motivation driving individuals with chronic respiratory disease allows care providers to predict the

likelihood of the individual to engage in self-induced activity restriction (activity avoidance). Strategies to encourage action and increase adherence to physical activity can be challenging to healthcare providers. Behavioural theories are used to better understand decisions that drive behaviour change and improve adherence. The Health Belief Model (Becker, 1974) is a theoretical framework to further the understanding of health-related behaviours and individual response to cues to preventative health action. Individual beliefs, including the perceived benefit of the action or behaviour minus the perceived barriers to the behaviour, significantly impact the degree to which an individual will choose to engage in the physical activity. Individuals vary in perceptions of their illness threats, how susceptible they feel they are to an illness consequence, and how they process barriers to initiating or continuing a positive health behaviour. One perceptual variation of concern for individuals suffering from chronic respiratory disease is heightened perception of threat of activity due to fear of exacerbating their respiratory disease. When the perceived threat, which is a modifying factor (Janz and Becker, 1984), is incorrectly processed, the likelihood of taking a recommended preventative health action (physical activity) is decreased.

Modifying factors proposed by Becker (1974; 1988) include the individuals perceived threat of disease, demographic variables, and cues to action. Among these variables, the centralized and affected factor of perceived disease threat is most heightened. Sociopsychological variables are altered as well with the emotional domain effects of chronic respiratory disease (increased depression and anxiety) and the adjustment of psychosocial losses of productive work (Ketelaars et al, 1997). This in turn makes the individual less responsive to cues to action.

### **Biological Processing of Respiration**

To fully examine the behavioural effects of the threat of dyspnoea, it is first necessary to understand the biological processing of negative (aversive) respiratory sensations. During an asthma attack or COPD exacerbation, the respiratory system is presented with a “load” that it must overcome. This can be examined in a controlled experimental setting by application of an inspiratory or expiratory resistive load. Load perception studies with inspiratory loading have historically offered a related measure of the sensitivity of the subject to the applied respiratory stimulus testing primarily the discriminative component of load perception (Davenport and

Vovk, 2009; Burki, Davenport, Safdar & Zechman 1983; Tiller, Pain & Biddle, 1987; Killia, Mahutte, Howell & Campbell 1980; Wiley & Zechman, 1986).

There are two primary cognitive components to the perception of increased respiratory loads. These two stages are the discriminative and affective (Davenport and Vovk, 2009). During the initial discriminative component, the brain discriminates the respiratory sensation, or load. This dimension includes the awareness of the spatial, temporal and intensity of the respiratory disruption by interaction between multiple respiratory afferent groups and brainstem respiratory motor drive. This is the somatosensory event related to cognitive awareness of breathing disruption.

The sensory discrimination is followed by the affective evaluation of the load, when the individual decides how it feels qualitatively. This involves determining if the respiratory sensation is pleasant or unpleasant. Subjects seldom report unpleasant evaluations of short or single breath loads, but discrimination changes as the sensation (dyspnoea) remains (Alexander-Miller & Davenport, 2010). Very large resistive loads have been shown to induce fear of suffocation and increased discomfort (Pappens, Smets, Van den Bergh, and Van Diest, 2012).

Self-reported “fear of suffocation” increases discomfort from respiratory sensations such as dyspnoea (Pappen et al., 2012). Individuals who have fear of suffocation can place greater strain on respiratory muscles by increasing ventilatory response to loads, which results in a mutual reinforcement of fear and maladaptive breathing (Pappens et. al, 2012). Some individuals react with extreme fear to respiratory stimulation such as increased CO<sub>2</sub>. This has been suggested to be a trigger of a hypersensitive fear network (Nardi, Freire & Zin, 2009; Sinha, Papp & Gorman, 2000).

### **Enhanced Threat of Dyspnoea**

Activity-related dyspnoea can influence and increase the individual perceived threat of their disease, impacting their likelihood of action (Figure 1). This perceived disease threat is enhanced by interoceptive fear. Interoceptive fear, or fear of the sensations within the body, is an important component in many diseases (Bouton et al., 2001 and McNally, 2002). Bodily sensations can trigger anxiety responses in healthy individuals (Walker and Furer, 2008) and individuals with panic disorder have reported fear of sensations of faster

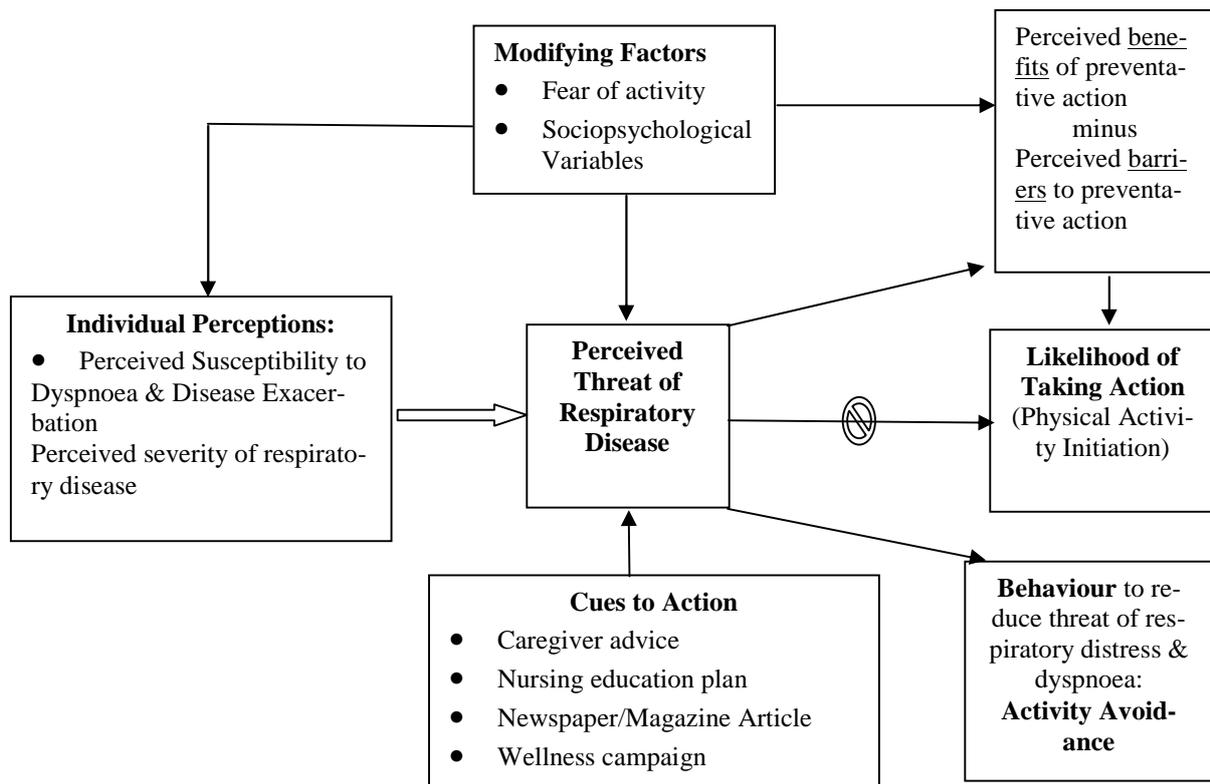


Figure 1. Conceptual application of the Health Belief Model to Respiratory Related Activity Avoidance

breathing or elevated heart rate (Schmidt et al., 1997).

Chronic respiratory disease leads to increased fear of dyspnoea, enhancing the perceived threat of the disease itself in a positive feedback mechanism. Disruption to breathing can be truly distressful. Breathing sensitivity creates a classic feed-forward loop resulting in further hyperventilation and anxiety symptoms that in turn become anxiety-provoking (Holman and Lorig, 2000). This creates a fear of repeating the precipitating incident (engagement in physical activity). Aversive respiratory stimuli (such as an asthma attack or dyspnoea) may increase introspective, apprehensive, negativistic and perceptual/attentional focus to the body which may lower the perceptual threshold for somatic sensation (Van de Bergh et. al., 1995). This means that the negative feelings associated with respiratory disruptions leads to an increased sensitivity, attention and focus on the negative sensation of dyspnoea.

To optimize quality of life, individuals with chronic respiratory disease learn to fear disease exacerbations and specifically dyspnoea. This fear is self-potentiating and eventually becomes limiting as individuals avoid activities that they fear will induce their dysp-

noea or heighten their disease manifestations. This vicious cycle becomes more limiting as perceived barriers outweigh perceived benefits of engaging in physical activity.

In summary, when the perceived threat of activity-induced dyspnoea is enhanced in chronic respiratory disease, this will increase the perceived barriers to preventative action, further decreasing the likelihood of taking the recommended positive health action (physical activity). Resulting behaviour instead is focused on avoidance of disease exacerbation in the form of activity avoidance. Supportive care interventions should reduce the perception of the threat and enhance the perceived benefits of physical activity, including a thorough patient education program to decrease knowledge deficits, cultivate motivation to change behaviour, and provide quality of life enhancement. Further work is needed to evaluate specific interventions to reduce the heightened disease threat in this chronic illness population.

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