

Psychosocial effects of cystic fibrosis on patients and their carers



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Consider the literature regarding the psychosocial effects of Cystic fibrosis on patients and their carers . How might these findings promote holistic physiotherapy patient management?

Cystic fibrosis is a life-threatening disease that can affect not only the patients that are suffering from the disease, but it can also affect the people caring for them in many ways such as mentally, socially, emotionally and even spiritually (Quittner et al, 1992). This assignment aims to explore how physiotherapists can promote and help manage patients with cystic fibrosis using a holistic approach. When physiotherapists take this approach, not only the disease is focused upon and treated, but the patient is comprehensively treated i. e. the treatment of the mind, body and soul.

Cystic fibrosis is a recessive disease considered fatal if not treated properly. The disease manifests itself in several parts of the body, particularly the lungs. Cystic fibrosis can also affect the pancreas, the integumentary system, and the urogenital system (Taber, 2009). The disease can present a variety of signs and symptoms such as but not limited to frequent coughing, an increase in phlegm/sputum production, reduced exercise tolerance, coughing up of blood, frequent lung infections, pancreatitis, male infertility, malabsorption, and clubbed fingers and toes. Patients who suffer from cystic fibrosis may go on to develop diseases such as bronchiectasis, bronchitis, emphysema, atelectasis, and some patients may even develop respiratory failure (Taber, 2009; McPhee, 2010). These symptoms and associated diseases can have a detrimental effect on the patient's physical health and can also affect the patient mentally and psychosocially (Foster et al., 2001).

The physiotherapists role in providing treatment to cystic fibrosis patients is to improve their breathing, prevent declining and deteriorating pulmonary function, and to aim for the patient to live life as comfortably as possible. Due to the complexity of the disease and the vast amount of daily medications needed, patients normally require an extensive and personalised approach to treatment (Daniels, 2010). According to Hodson, Geddes, and Bush (2007), management of patients with cystic fibrosis should be comprehensive i. e. holistic and address each patients' individual needs. The purpose of holistic physiotherapy patient management for cystic fibrosis patients is to reduce or prevent any further inflammatory changes in the respiratory system, increase life expectancy, improve or maintain exercise tolerance and provide positive patient outcomes and quality of life.

According to Harrop (2007) and Foster et al (2001), persistent coughing and the accompanying removal of sputum/phlegm from the throat during conversations or social interactions can lead to embarrassment for the patient and may cause negative reactions with friends. Patients with cystic fibrosis are usually taken care of by their close family members who may even take the professional role as carers to support and treat their symptoms. But as the disease is progressive, it can in some severe cases lead to an early death. Therefore, it can be challenging to manage and can become very stressful for the carers due to the complexity and amounts of time spent treating the patient. This can leave the carers physically and mentally exhausted (Goldbeck et al., 2014). Hence, patients with cystic fibrosis and their family members who care for them often seek help in managing the disease by acquiring guidance and knowledge that can help

with psychosocial, mental and physical issues. It is for these reasons' physiotherapists and other members of the multidisciplinary team specially trained to deal with cystic fibrosis are available to provide help and guidance when needed (National Institute for Health and Care Excellence, 2017).

One of the major factors that are disregarded during the treatment of cystic fibrosis are the patient's psychosocial issues such as family dynamics, career issues, relationships issues, depression, anxiety, social support, and loneliness (Upton 2013). From amongst the members of the multidisciplinary team, physiotherapists are the ones that spend quite a large portion of time with cystic fibrosis patients. So, they are the ones that have the best opportunity to address the patients' psychosocial issues. This requires the need for promoting holistic physiotherapy patient management so that these issues can be acknowledged and addressed when treating the patient. The above-mentioned issues can affect the progress of the patient's treatment and overall quality of life(Quittner, Modi and Roux, 2004).

A holistic approach as defined by Hyerman (2005, p. 31) is " caring for the whole person in the context of the person's values, their family beliefs, their family system, their culture, the socio-ecological situation in the larger community, and considering a range of therapies based on the evidence of their benefits and cost". Vender (2008) mentions that this approach requires physiotherapists as well as the multidisciplinary team to acknowledge that people suffering from cystic fibrosis can be complex, meaning that their lives can carry a vast amount of complexities that can affect normal day to day activities. Each aspect of their illness has the potential to affect the mental wellbeing of the affected individual. Knowing that patients with cystic fibrosis <https://assignbuster.com/psychosocial-effects-of-cystic-fibrosis-on-patients-and-their-carers/>

have a variety of factors that concern them, provides a good reason for physiotherapists as well as carers and other health care workers to promote holistic patient management. As treating the body as a whole (i. e. holistically) and not just focusing on the disease itself will have a better impact on the patient's wellbeing (Vender, 2008).

According to Paterson (2001), patients that are suffering from cystic fibrosis mentally, socially, or psychologically (i. e. the disease is having a negative impact on the patients' state of mind) are more engaging in a successful manner with practitioners and therapists who undertake a holistic approach to managing their disease. Therefore, it is significant that physiotherapists take a holistic approach to managing and treating their patients. This is to ensure that the patient's, social, emotional and physical needs are taken care of (Beck, Rawlins and Williams, 1993). Dossey, Keegan, and Guzzetta (2004) suggest that a holistic approach to patient management encourages positive outcomes between patients and the people looking after them. It also enables the therapist and patient to give full attention to one another and provides the therapist with a deeper understanding of the behaviour of patients' and meanings that they attribute to their disease.

Holistic treatments may incorporate alternative methods like music therapy particularly using wind instruments. These types of therapies are considered to be beneficial towards treating patients psychologically. Some studies have shown that music therapy can even improve/enhance lung function and reduce stress and anxiety levels of patients with lung diseases (Griggs-Drane, 1999; Wade, 2002).

Physiotherapists treating patients with cystic fibrosis may often sense or feel the need to understand their patients and carers concerns more deeply, especially those with psychosocial issues. So, in order to treat the patients and also to understand the concerns of their carers may require a holistic approach (Wicks, 2007). When using a holistic approach, many questions may need to be addressed such as asking about the patients' work, hobbies, what they mostly think about, and asking about their feelings. Also acknowledging the concerns of their carers, helping them with any issues and giving them support and advice can lead to better outcomes for patients (Booth 2004).

Doring (1976) mentions that physiotherapists have occasion to enquire into the ability and feeling levels of patients. For example, what kind of things is the patient is able to do now that they are suffering from the disease, what they were able to do normally, how they feel towards their pain, how the disease is affecting them in relation to friends or family, what they perceive the future holds for them and so on. These types of questions may begin to get the patient to open up and feel free to say things to get off their chest. In this way the therapist is using a holistic approach which benefits both the patient and the physiotherapist as it enables the patient to gain trust in the therapist (Doring, 1976).

Identifying and addressing the impact that emotions, depression, and anxiety can have on patients with cystic fibrosis and their carers can aid in promoting more personalised suitable treatment and management plans. This can ultimately improve the overall wellbeing of the patient (Besier, Quittner and Goldbeck, 2008). Anxiety and depression can have an effect on <https://assignbuster.com/psychosocial-effects-of-cystic-fibrosis-on-patients-and-their-carers/>

outcomes in patients, have a poorer adherence to treatment, and affect a patient's quality of life. Not only does anxiety and depression affect patients, but it can also affect their carers especially the ones close to them especially parents and children (Besier, Quittner and Goldbeck, 2008). Understanding the things that encourage the patient to adhere to treatment while identifying their strengths and weaknesses provides the physiotherapist with key information, so that they may be able to provide an optimum holistic treatment program (Bezner, 2015).

Conner and Norman (2005) stress that a holistic approach to physiotherapy is the key to encouraging and sustaining a good and healthier lifestyle. It involves the patient having a sincere intention to follow treatment plans, have belief and confidence in themselves, showing ability to prosper, creating a perception that there is a social pressure to perform, and having hope and eagerness of an outcome that would be beneficial and satisfactory to them.

The Chartered society of physiotherapy (2012) stipulates the need to care for patients as a whole and not just focus on disease, but focus on patient centred management, i. e. caring for the patient holistically. As Physiotherapists are expected to make clinical choices together and in agreement with patients while having consideration for various suitable treatment options. The importance on holistic practice in their clinical choices is emphasised along with the anticipation that other members of the multi-disciplinary team will implement holistic practice in all aspects of their care too.

Quittner, Modi and Roux, (2004) found that the benefits of managing physiotherapy holistically, enables patients to avoid unnecessary and multiple visits to the hospital which reduces costs and also is less time consuming. They also found that patients who had received some type of training to help with the symptoms of their disease were easily able to continue guided physiotherapy treatments in the comfort of their own homes - again the major benefit being not having to use scarce healthcare resources.

The median survival age for people with cystic fibrosis is anticipated to reach approximately 50 years and adults with cystic fibrosis in the United Kingdom will be more in number than children living with cystic fibrosis (Dodge et al., 2007). But surviving the disease and reaching adulthood begins presenting some of the people affected with the disease with various challenges that are completely new and can be overwhelming to them. For instance, being the main person responsible for their own care instead of their parents or other family members, trying to find suitable employment, sorting out finances, becoming independent from parents, settling down, getting married and thinking about planning a new family life (Bezner, 2015). Special cystic fibrosis clinics with the required specialist health staff, i. e. physiotherapist, doctors and nurses are in place to enable an easier transition between paediatric and adult care. One of the biggest issues and complaints that can arise from therapists in these clinics is that there is not enough time to provide the holistic care needed. This is because the professional environment a lot of the time consists of heavy workloads which

can affect therapists and other healthcare workers from providing consistent holistic care (Olive, 2003).

Holistic patient management can increase motivation in physiotherapists and other health workers alike as well as increasing their knowledge. A point to note is that the importance of professional and suitable environment is a prerequisite of holistic care (McEvoy and Duffy, 2008). One of the biggest contributing factors for disregarding holistic patient management is poor compliance and ignoring needs of the patient. Some of which may not seem that important to the therapist but are of concern to the patient (Henderson, 2002).

In conclusion, physiotherapists should be able to recognise and address the effects that are associated with patients suffering from cystic fibrosis. They should also consider the effects on their carers and how these effects can be addressed and managed in a suitable way. As mentioned, one of the best ways that these effects can be managed is through a holistic approach to care and patient management. This essay has defined what holistic care and management is, why it is important, how it should be done and the outcome that can be accomplished by both Physiotherapists and patients when using a holistic approach. (word count: 2073)

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