Psychological Determinants of Treatment Adherence in Adults with Cystic Fibrosis

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Abstract

This dissertation demonstrates that adherence to treatment in adults with Cystic Fibrosis (CF) varies significantly between treatments, and is influenced by the beliefs and perceptions that patients hold about both their disease and its treatment.

CF is a genetically inherited, chronic and life-shortening disease, with a complex and demanding daily treatment regimen. Research has demonstrated that many adults with the disease adhere poorly to at least some components of home care and yet the full extent of and theoretical underpinning for poor adherence remain unclear. Difficulties of measurement and definition have hampered research efforts.

In the studies described here, multiple methods of measurement, including electronic monitoring, were used to examine treatment adherence in a group of adults with CF. A new questionnaire measure, the Cystic Fibrosis Perceptions Inventory (CFPI) was developed and used to explore the beliefs and perceptions that adults with CF hold about their disease and its treatment, and the Self-Regulatory Model (SRM; Leventhal, Diefenbach & Leventhal, 1992) was applied to the issue of adherence in this population.

Self-report and electronic monitoring confirmed that some CF treatments that are both complex and time-consuming are managed better than more simple treatments in terms of adherence. Perceptions about the value of treatments and whether the costs of adherence to treatment outweighed the benefits, were significantly associated with self-reported and electronically monitored adherence to several CF treatments. Adherence to less complex treatments was associated with concerns about CF, and heightened attention to the disease and treatment process. The SRM provided a coherent framework for understanding these findings.

Preliminary psychometric data showed the CFPI to be a valid and reliable measure
of health related beliefs and perception about CF, both for adults and a small sample of adolescents with the disease.

These findings contribute to knowledge about the psychological determinants of adherence in adults with CF, and have significant clinical and research implications for the management of CF and other chronic illnesses.
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