

Cystic Fibrosis Research News

Title:

Disease disclosure in individuals with cystic fibrosis: Association with psychosocial and health outcomes

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What was your research question?

This study focused on disease disclosure by adults with cystic fibrosis (CF) and our research questions were: who do people with CF tell about their CF diagnosis (i.e. disease disclosure)? How comfortable do people with CF feel talking about their disease status? Do people with CF perform treatments in front of other people? We also looked at other factors, which disclosure might be related to such as, social support.

Why is this important?

This is important because adults with CF have specified that disclosure can influence how easy or difficult it is to do daily treatments. Parents of children with CF often handle disclosure, but the transition to young adulthood passes this issue to adults with CF. Understanding disclosure in adults with CF is vital because advances in therapies for CF are leading to longer lives, and thus, more times where adults with CF face disclosure situations. In other chronic illnesses, disclosure has been linked with health, emotional well-being, and quality of life. If we learn more about factors that are affected by disclosure in CF, we could potentially change existing treatments or develop new treatments to improve outcomes.

What did you do?

This study included people with CF, who were 16 years or older. Participants completed questionnaires about their personal information (e.g. age and gender) and, stated whom they told about their CF diagnosis (disclosure). Participants also rated their social support, emotional and social functioning, depression, and how confident they feel about regularly doing their treatments. We looked at how often the participants refilled their medications

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to get an idea of treatment adherence. Furthermore, we collected health information including lung function and body mass index. This enabled us to determine if disease disclosure was related to any of the information gathered.

What did you find?

Participants were more likely to tell romantic partners and close friends about their CF diagnosis rather than casual friends, bosses, or coworkers. Participants were more comfortable talking about CF with and doing treatments in front of romantic partners and close friends than other groups of people. Feeling comfortable talking about CF and doing treatments in front of other people was linked to better social support, social functioning, and confidence in regularly doing treatments. Participants who told bosses and coworkers about their CF diagnosis had lower lung function whilst participants who told close friends about their CF diagnosis perform their treatments more often.

What does this mean and reasons for caution?

Overall, disease disclosure is linked to more positive emotional and social outcomes such as, better social support. Adults with lower lung function are more likely to tell bosses and coworkers about their CF diagnosis because their symptoms are more obvious or because they have to take time off from work. Feeling comfortable to disclose disease status to friends appears particularly important for social support, social functioning, and confidence in the ability to perform daily treatments. Feeling comfortable about disease disclosure to romantic partners and close friends is also linked with doing treatments more often. However, as our study information was collected from one point in time, interpretation of the results is limited to correlations.

What's next?

Social workers or psychologists, who are part of the CF care team, may want to discuss disease disclosure strategies with people with CF. Future research will determine if disclosure changes with age, since sources of support change over the lifespan. Future studies should also further explore the link between disclosure, treatment adherence, and how confident adults with CF are in their ability to completing treatments.

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