

Cystic Fibrosis Research News

Title:

ADHERENCE TO INFECTION PREVENTION AND CONTROL GUIDELINES: A VIGNETTE-BASED STUDY OF DECISION-MAKING AND RISK-TAKING IN YOUNG ADULTS WITH CYSTIC FIBROSIS.

Authors:

Grace Bowmer^{1,2}, Gary Latchford³, Alistair Duff^{2,3,4}, Miles Denton⁵, Louise Dye¹, Clare Lawton¹, Tim Lee⁴

Affiliations:

¹School of Psychology, University of Leeds, Leeds, UK

²Department of Clinical and Health Psychology, Leeds Teaching Hospitals NHS Trust, Leeds, UK

³Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

⁴Regional Paediatric Cystic Fibrosis Unit, Leeds Teaching Hospitals NHS Trust, Leeds, UK

⁵Department of Microbiology, Leeds Teaching Hospitals NHS Trust, Leeds, UK.

What was your research question?

Do young adults with CF choose to engage in activities that might present a risk of infection, and what might influence their decision-making in these scenarios?

Why is this important?

Guidelines recommend that people with CF avoid situations that may pose an infection risk, such as mixing with other patients and using hot tubs. However, existing research shows that people often engage in these situations regardless of the risk. Young adults in particular may struggle to balance reducing the risk of infection with taking part in enjoyable activities. It is important that we better understand the priorities and beliefs of young adults with CF. This will allow us to develop more effective strategies to discourage risk-taking, and provide more helpful information about infection risk.

What did you do?

We developed an online questionnaire that was advertised by the UK CF Trust on social media. This presented four realistic social scenarios that posed a possible infection risk, such as using a hot tub. We asked participants whether they would engage in the activity and, optionally, to explain why/why not. We also asked participants to rate how risky they thought each situation was. Finally, participants rated seven possible infection prevention



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and control information sources (such as the Internet, or their CF team) based on how much these sources influence the participant's own knowledge. We received 87 valid responses.

What did you find?

In general, young adults could distinguish between high-risk and low risk situations. Participants were less willing to take part in activities that posed a high infection risk. In particular, most said that they would not meet another person with CF; however, almost all people were willing to engage in activities that posed some risk. We found significant gaps in infection risk knowledge, especially of environmental risk. Some participants used 'strategies' to allow them to participate in certain activities, though these were often not based on solid knowledge. Reasons for risk-taking included social influences and a wish to maintain a quality of life.

What does this mean and reasons for caution?

Young adults find it difficult to balance the needs of their CF with the desire to live a normal life. While it is important to address gaps in knowledge of infection risk, this alone is not sufficient. Intervention requires honest conversations between patients and the healthcare team to address harmful misconceptions, perhaps prior to transition to adult care. However, our sample size (i.e. number of people who responded) was small and the results may be biased. People who opt into studies are generally more likely to be active in seeking information and managing their care; therefore, the findings might underestimate risk-taking.

What's next?

Infection prevention and control information may differ between CF centres. An important next step would be to standardise this information and to develop useful patient resources. As transition to adult care requires greater independence surrounding healthcare decisions is expected; therefore, it may be best to provide information on infection risk prior to transition.

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cfresearchnews@gmail.com