Clinicians’ Prescribing of Physical Activity for Adolescents with Cystic Fibrosis: A Qualitative Study

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Cystic Fibrosis

• The most common life-limiting genetic condition in the UK
• The gene affected by CF controls the movement of salt and water in and out of cells
• Mutations of the CFTR lead to a build up of thick sticky mucus – primarily in the lungs and digestive system
• Median age of death is 31 years
Mucus in the lungs

- Reduced lung function
- Coughing and difficulty breathing
- Increased susceptibility to chronic infections
- Finally respiratory failure
In the digestive system

- Insufficient secretion of digestive enzymes
- Malabsorption of nutrients
- Decreased fat stores
- Malnutrition and muscle wastage
Treatment

- Medication
- Physiotherapy
- Controlled diet
- Physical activity
- Patients can spend three hours or more on their daily care
Physical Activity

- Improves tolerance to exercise and physical fitness
- Can improve or slow down rate of decline in prognostic factors such as lung function and aerobic fitness
- Helps with mucus clearance
- Improves quality of life
Adolescence

• Delayed puberty (up to 2 years later than peers)
• Transition to adult services and increased responsibility for self-management
• Increased time pressure at school / work
• Increased rate of depression
• Importance of peer identification increases
• PA substantially declines – particularly in girls
• Decline in PA has lasting effects well into adulthood
Attitudes of health care providers

• Large survey of exercise testing and training in UK CF clinics
• Importance of exercise testing 4 (out of 5)
• Importance of exercise training 4 (out of 5)
• Only 26% provide training programs
Aims of the current study

• To qualitatively explore:
  • Views of multi-disciplinary CF teams on PA
  • Strategies used to promote PA
  • Challenges inherent in promoting PA
Methods

• In-depth qualitative interviews
• Opportunity sample of fifteen participants
  • Eleven physiotherapists
  • Two consultants
  • Two dieticians
• Analysis
  • Thematic analysis
Results

- Three main themes emerged:
  - Perceived benefits of physical activity
  - Influences of motivation
  - Approaches to change behavior
Perceived benefits of physical activity

All participants considered physical activity to be crucial for both physical and mental wellbeing:

“If there’s one thing that seems to make the most difference to how well they become as they get older, then I think exercise is probably the most key thing”

“From experience, having done this job for quite a few years I know that the patients that do regular exercise are the patients that keep well the longest and have the slowest decline in disease”
Influences of Motivation

- Benefits of physical activity
- Anticipated positive emotional reaction
- Significant others
- Self-consciousness
- Fear of illness progression
Benefits of physical activity

Participants thought some patients were motivated by the health benefits associated with physical activity:

“One chap who used to be a physical trainer and he does say that the reason he enjoyed his exercise is that it made him healthy and kept his numbers good”
Positive emotional reaction

Enjoyment of physical activity was considered to be the most important factor:

“So even though we’re drilling it into them that it’s really important to exercise and it’s going to keep you well, it’s going to keep you better, the fitter you are the better you’re going to be - if they don’t enjoy it they’re not going to do it”

“I think [the biggest motivator] is just enjoyment. People get different physical feedback from exercise and people get really good endorphins and they want to be part of a team and they want to play as part of a team and want to socialise with friends in that way and some don’t”
Significant others

Significant others could either encourage or discourage physical activity:

“It’s got to come from the parents and you can’t expect a child to do loads and loads of exercise if the rest of the family is sitting doing nothing

“When you get friendship groups doing it, I think that helps, so they’re just joining what their friends are doing instead of going, you know, to some hospital team saying why don’t you do exercise?”
Self-consciousness

Participants were aware that some patients did not feel comfortable training in public places:

“with girls it’s being embarrassed, it’s thinking that they’re getting sweaty and hot, and putting different clothes on that they might not want to wear”

“people often won’t want to go out to public places and exercise because they don’t want to be coughing, if they’ve got a feeding tube, if they’re really, really skinny...”
Fear of illness progression

Fear of making their condition worse, and fear of what there is to come:

“For some, it’s not enjoying the feeling of getting out of breath - feeling that it’s doing them some harm rather than some good”

“Some of them don’t like it because it reminds them they have CF... if he can’t run as far now, or as far as before, he knows his lung function isn’t as good”

“We’ve got a gym and gym pods and they overlook each other and they don’t want someone to see them ill - but they also don’t want to see anyone else who is more ill because they think ‘that’s where I’m going to end up’”
Approaches to change behaviour

• Education / information
• Social support (Family / friends / MDT)
• Promote routine / habit development
• Rewards and incentives
• Provide opportunities
• Role models
Next steps

• Interviews with adolescents
• Identification of “optimal” recommendations for improving lung function
• Co-creation of an intervention to support physical activity among adolescents with CF
Conclusions

- Participants valued physical activity for physical and psychological wellbeing
- Factors influencing motivation for activity were highlighted
- Strategies to support physical activity were centered around making activity fun and normal.
- Future research is concerned with exploring patients perspectives