



Understanding adolescents' adherence to their cystic fibrosis treatments

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Introduction

Available treatments for cystic fibrosis (CF) aim to minimise disease progression and require adherence for maximal benefit. A daily regime typically involves a combination of physiotherapy, oral, inhaled and nebulised medications. The essence of CF care requires a lifelong commitment. It is questionable how this impacts upon the quality of life young people as they strive for independence and self identity. The key aim of this study was to understand in more detail how adolescents manage their CF treatments.

Literature Review

Adherence in chronic illness varies from 30-80% (Meichenbaum and Turk 1987). Meyers et al (1975) report CF non-compliance is 20-30%. Abbott et al (1994) found CF adherence is treatment specific, reporting adherence rates of 53% to physiotherapy, 73% to exercise at a beneficial level, 83% to enzymes and 46% to vitamins. Whilst highlighting adherence as a significant problem in adolescents, the CF literature does not provide explanations or management strategies to address this. Specifically these studies do not explore the young adolescent's actions or care choices. In addition the majority of evidence relating to adherence in CF comes from adult studies, where medication adherence only is assessed.

Poor adherence is common, complex and challenging. CF treatment includes physiotherapy and multiple medications which are time consuming and do not always give symptomatic relief or perceived benefit. Adolescence is a turbulent time, made more difficult when living with CF. In practice, it is a time when adherence fluctuates and transition to adult care becomes reality. There is a need for greater understanding of the factors that influence adolescents' adherence with CF treatment regimes.

Study Aim: to explore the adolescent's perceptions of adhering to CF treatment

Specific Questions



- What do adolescents with CF perceive as their treatment regime?
- How do they describe their treatment adherence level and what affects this when well/unwell?
- How dependent are young people on their family?
- Which treatments are easier/more difficult to adhere to?
- How often are treatments missed?
- Do adolescents wish to know more about their treatments?

Methodology

This study used a new questionnaire the CF Treatment and Management Questionnaire (CF-TMQ) which included self-rating scales and questions. Currently available questionnaires that measure adherence to treatments in CF include the Manchester Adult CF Questionnaire (Abbott et al 1994) and the Medical Compliance Incomplete Stories Test (MCIST – Koocher et al 1987). These questionnaires were used in the development of the CF-TMQ alongside the theoretical framework of the Health Belief Model (Becker 1974). The CF-TMQ was designed to describe adherence, the level of dependence on the family and explore what factors affect adherence and which treatments are most difficult and easiest to adhere to. It has been used as a pilot tool only, as no testing for validity and reliability have been performed. Face validity was gained through the review of the questionnaire by a panel of experts from different CF centres, academic and clinical supervisors and also by inviting two adolescent CF patients to comment. Adjustments were made to the questionnaire following the initial review (e.g. the addition of family/parent support and re-wording of the categorical scaling). The questionnaire was then re-submitted to the expert panel and face validity was confirmed.

Participation was voluntary, no remuneration was offered and ethical approval was gained locally. A sample of 36 persons (12-18 years of age) was accessed via postal questionnaire. Participants were selected using non-probability sampling that was purposive in nature. Patients who were identified through the CF database at a major CF centre in London and met the inclusion criteria were requested to participate. Demographical data including age, gender, educational and employment status, and recent intravenous antibiotics.

Statistical data were analysed using Statistical Package for the Social Sciences (SPSS). As a small sample was included and data were not normally distributed descriptive and non-parametric tests were applied. Statistical significance was set at $p < 0.05$.

Results

A total of 20 (57%) patients responded to the postal questionnaire. The mean age was 15 years (SD = 1.75) and 40% were male. Five percent were in employment, the remainder in education. All participants lived with family members. Half had intravenous antibiotics within 6 months preceding questionnaire completion.

The CF-TMQ

Treatments perceived to be the CF regimen

Participants listed their CF treatments as follows;

Physiotherapy - 70%

Tablets - 70%

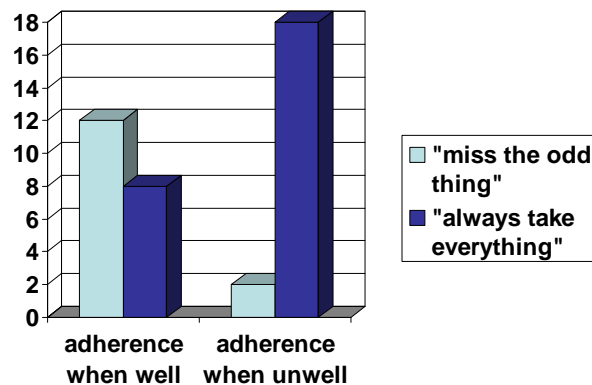
Nebulised antibiotics - 50%

Oral antibiotics - 40%,
Pancreatic enzymes - 35%
Vitamins - 25%
CF diet - 25%
Inhalers - 20%
Gut medications - 15%
Hospital and clinic attendance – 15%
Intravenous antibiotics - 10%.

Adherence level and factors influencing adherence

40% of participants reported that they “always take everything the hospital advises me to” and 60% reported they “miss the odd thing here or there” when well. When unwell, this increased to 90% stating they “always take everything” and only 10% reported they “missed the odd thing”. This increase in adherence was significantly different when comparing ‘well’ (40%) to ‘unwell’ (90%) ($p = 0.004$).

Figure 1: Patient reported adherence when well and unwell



Why do adolescents not adhere to their treatments?

When questioned what affects adherence when well/unwell adolescents cited several reasons. The predominant reason when unwell was health (75%) – wanting to avoid further medications, hospital attendance or admission. Reasons when well included time constraints and social commitments.

Dependence on family

All adolescents reported they received help by their family members to complete treatments. The predominant family member identified were mothers 55%.

Most difficult/easiest treatments and missed treatments frequency

30% stated physiotherapy was the most difficult treatment, 40% stated tablets the easiest. A further 40% did not cite any treatment as difficult. Despite tablets being “easiest” these were missed by 30%, despite participants acknowledging the consequences of not taking, for example, pancreatic enzymes which usually ensures “tummy ache” and “diarrhoea”. Other treatments missed were



nebulisers/inhalers (25%) and physiotherapy (15%), again often with side effects being acknowledged by the participants. Almost all (80%) reported they missed a treatment at least once a week, and there was a wide variability of missed treatment frequency. When examining what would make treatments easier 40% stated faster administration. Time was a recurring factor in responses relating to difficult treatments. Participants suggested “fewer treatments”, “a change in routine” and “a reminder” would help.

Participants’ knowledge

Adolescents were asked about their treatment knowledge and to list this under subheadings - “treatments I know a lot about”, “treatments I know a little about” or “treatments I would like to know more about”. Analysis showed 40% would like to know more about some of their treatments. 61 treatments (including physiotherapy, nebulised antibiotics, and pancreatic enzymes) were listed under the heading of treatments that they “know a little about”. In comparison 12 treatments (including antibiotics, tablets and medication) were listed under “know a lot about” and 10 (including new treatments, medications and CF generally) under “know more about”.

Discussion

This study provides insight into adolescents’ thoughts regarding adherence to CF treatments. Exploring patients’ level of adherence is frequently debated in the literature, though mostly in relation to medications only. Whilst this information is important to the clinician it does not account for the multi-faceted regime expected from adolescents with CF. In addition, both patient and parents can affect how regularly treatments are adhered to. Highlighting areas where adherence is an issue requires a multi-disciplinary team approach. Increasing patient knowledge is not enough to maintain a sustained improvement as a behaviour change is also required (Fielding and Duff 1999).

Interestingly, not all participants listed all of their treatments though physiotherapy and tablets were most frequently mentioned. In CF, non-adherence includes failing to keep appointments and inability to follow dietary/lifestyle changes. Only 15% of participants noted hospital clinics and admissions as treatments. For CF to be managed well, regimens aside from medications and physiotherapy include clinic attendance (for all every two months) and for many hospitalisations or home intravenous antibiotic therapies.

Adherence levels stated fitted two of the four categories on the scale – these were “take nothing”, “take very little”, “miss the odd thing here or there” or “always take everything the Hospital advises me to”. The improved adherence when unwell could be interpreted as patients regarding treatments as more important when sick. Statements regarding adherence included unintentional (“forgetfulness”) and intentional reasons (“can’t be bothered” and “too time-consuming”). Socially driven reasons (i.e. wanting to spend time with friends) are intentional decisions to opt out perhaps due to the practical limitation of juggling life and treatments to be the same as peers.

Half of the participants relied on their family for help most of the time. For some, this entailed medications being ‘put out’ by a parent to ease self-administration. In CF balancing dependence against independence and transition into adulthood requires a gradual change. Family factors positively impacting on adherence include family support, flexibility and good problem-solving skills, where as those impacting negatively include marital conflict and lone parent status. As families assume responsibility for additional treatments i.e. intravenous antibiotics, the challenge involves developing innovative ways to provide sensitive, personalised family health care (Coyne 1997).



The CF Nurse Specialist role includes guiding patients with adherence issues and both patients and family members are also expected to participate. The relationship between patient, family and professionals requires effective communication, negotiation, competence, confidence, respect and commitment to be successful (Kyngas et al 2000). Negotiation provides the adolescent with some control over their CF by improving education, awareness and self-monitoring, all of which potentially increase adolescents' independence. Sawyer (2003) discussed that parental "nagging" does not improve adherence and can paradoxically make things worse, thus strategies to help reminding the young person place the emphasis on the young person remembering treatments before being prompted and asked. In practice, parents use various methods to maximise adherence including encouragement, insistence, and persuasion and offering help. These tactics may be interpreted differently by both parent and child.

For the 30% of the participants who found physiotherapy "most difficult", reasons for this were time, help required and the other medications required. This compares to studies by Passero et al (1981), Abbott et al (1994) and Conway et al (1996) who also found non-adherence to physiotherapy occurred in around 30% of patients, for many with no perceived benefit when performed. New techniques attempt to enhance the variety of options available, and greater emphasis is being placed on exercise for the chest and preventing osteoporosis. Exercising is also "normal activity" helping peer identification. A positive self-concept enhances confidence and self-respect in adolescents. This study highlighted that managing a normal lifestyle and not appearing "different" is critical. Abbott (2003) examined coping and CF, linking omitting treatments as an appealing option for those who wanted to escape the reality of CF. As professionals we need to balance disease management with achieving normal lifestyles, allowing for individuality, variable disease progression and therapies. During adolescent rebellion, the increase in freedom from parental control and the option to make decisions regarding self-care can increase non-adherence (Pownceby 1995).

As professionals, we cannot guarantee what level of adherence with current CF management regimes is required to maintain health and prevent disease progression. The probable outcomes of poor adherence are exacerbations, weight loss and faster disease progression, which affects time away from school and peers due to increased time spent in hospital, Czajkowski and Koocher (1987), Abbott and Gee (1998). Treatments giving immediate symptomatic relief are seen by patients as being beneficial and are more likely to enhance adherence (Czajkowski and Koocher 1987, Abbott and Gee 1998). When there are no immediate treatment benefits and it may be some time before a health change is noticed, behaviour associated with missing treatments becomes reinforced (Foster et al 2001). Factors associated with increased adherence include help, support, encouraging self-management, personal control, optimistic coping and individualised teaching (Dodd and Webb 2003). It is also important that patients understand the long term benefits of complying with these types of treatments.

Koocher et al (1990) suggests that non-adherence falls into two groups that are based on patients' knowledge and beliefs – inadequate knowledge (unintentional non-adherence), psychosocial resistance and educated non-adherence (intentional non-adherence). Responses examining patient knowledge regarding treatments showed that 40% of participants would like to know more about how some of their CF treatments work. The CF-TMQ asked participants to self report knowledge and highlighted that most have some knowledge but not examining whether this was age appropriate or at the level the team would expect. A small study by Hames et al (1991) found that adolescents preferred to obtain CF knowledge from medical staff in preference to their families. Knowledge and



understanding regarding treatments needs regular review (reinforcement and repetition) with short-term health goals agreed (Sawyer 2003).

Within multi-disciplinary consultations, discussion aims to assess and improve the patient's knowledge. However, this was not reflected in the current study whereby the majority of participants stated they "knew a little" about their treatments and it is questionable whether this is satisfactory. Additional efforts to assess patient education regarding illness and management may highlight areas to target and enhance adherence. Written and verbal education may need supplementing by computer based learning or assessed educational packages. In practice, pre-adolescence, the majority of information is aimed at parents. Health information needs repeating to ensure all parties agree to the plan to ensure positive behaviour changes are reinforced (Sawyer 2003). For education to be successful it must be targeted individually and developmentally and mindful of disease severity. The CF-TMQ did not explore adolescents' knowledge or perceptions relating to research, fertility and pregnancy, which could be a focus of further research.

When working with adolescents regarding adherence it is important to acknowledge that they may have routines for certain medicines and not for others (Sawyer 2003). Adolescents are often reminded to complete treatments, but as they try to gain independence a reminder such as a mobile text message may be more acceptable to them. Exploring new and innovative, and ideally evidence-based ways, to manage treatments may improve both adherence and patient satisfaction (Ooermann et al 2000). Offering a spectrum of options may feel less restrictive to the adolescent and them a greater sense of control and independence

Study Limitations

The main limitation of this study was the small population size. For the sample to be representative of a larger population of patients, increasing the confidence in the findings, participants would need to be recruited from other specialist CF centres. Wider recruitment would need to allow for different communication and treatment recommendations. An increased population size would also make results more generalisable to adolescents with CF as the results would have greater reproducibility and not have been influenced by one centre's practice. The response rate (55%) also questions whether patients that do adhere to their treatments would be more likely to respond to such research.

The questionnaire was used as a pilot tool to explore adherence. It was not tested for reliability and validity and requires more analysis to be further used. In future investigation of this phenomenon, the researcher would consider combining the adherence questionnaire with a tool that assesses coping behaviours. Using a self-report questionnaire as an indirect measure of adherence gives insight to some of the issues raised by both individuals and the population group as a whole. Further insight into specific issues could be further examined by interviewing participants and exploring opinions, behaviours and attitudes in relation to adherence.

Conclusion

This study highlighted adherence is an issue for adolescents with CF, and that time and ease of treatment administration are crucial. The observed improvement in adherence when adolescents were unwell reflects what is seen in practice. This highlights the importance of educating adolescents of the importance of maintaining adherence during times of relative 'wellness'. Whilst this study provides some insight into adolescents' perceptions of adherence future research targeting



a larger CF population is required. Through improving our understanding of individual patient factors, we need to remember that adherence is only one part of an individual's life amongst other needs, including personal priorities and social roles.

Suggested Reading

A suggested reading list may be provided upon request. Please email editor@cfww.org to obtain a copy.