The prevalence of “risky behaviour” in adults with cystic fibrosis

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Abstract

Background: The prevalence of “risky-behaviour” including alcohol and illicit drug use, smoking and unprotected sexual intercourse, of adults with cystic fibrosis (CF) is unknown. We conducted this prospective questionnaire-based study to further explore this issue.

Methods: An anonymous 71-point questionnaire was sent to all adult patients aged ≥18 years attending the Royal Brompton CF Unit. Results were compared to national (non-CF) data.

Results: 83% (n=151) drink alcohol and 13% (n=23) drink more than recommended by national guidelines. 46% (n=84) have tried smoking and 3% (n =5) continue to smoke regularly. 35% (n=64) have tried illicit drugs and 3% (n =6) continue to use them. 86% (n=154) are sexually active; 60% use contraception (males 46%, females 62%). Compared with the general (non-CF) UK population, less CF patients drink heavily (13 vs. 23%; p <0.001), smoke (3 vs. 21%; p <0.001), have tried illicit drugs (35 vs. 37%; p <0.001) and are sexually active (86 vs. 97%; p <0.001). The same proportion use contraception (60 vs. 61%; p=0.8).

Conclusion: Participation in risky behaviour was modest. With improved life expectancy this may increase. Awareness of this is important so that health promotion measures can be introduced early.

Keywords: Cystic fibrosis; Smoking; Illicit drugs; Pregnancy

1. Introduction

“Risky behaviour” describes participation in activities which pose a risk to the individual or individuals involved, e.g. excessive alcohol, smoking, illicit drug use and unprotected sexual intercourse. These behaviours pose a particular risk to those suffering from a chronic illness such as cystic fibrosis (CF).

The harmful effects of smoking on “healthy” adults are well documented [1]. In CF exposure to smoke irritates mucosal linings which increases coughing and sputum production. This can increase the risk of bacterial infections, worsen symptoms and increase admissions to hospital [2, 3]. Smoking may also directly affect the function of CFTR (cystic fibrosis transmembrane conductance regulator), accelerating pulmonary function decline [4]. Furthermore, the appetite-suppressing effects of tobacco may complicate the nutritional challenges of CF [5]. Respiratory complications are also associated with long-term cannabis use, resulting in severe emphysematous change [6]. Inhalation of other illicit drugs, such as cocaine and heroin, are also known to have detrimental effects on the lung [7].

The adverse health effects of excessive alcohol consumption are well documented and include direct toxicity to organs, especially the liver [8]. Up to 25% of patients with CF will develop liver disease and up to 3% progress to liver decompensation as a result of abnormal CFTR [9].

Unprotected sexual intercourse risks both unwanted pregnancy and sexually transmitted infections. Pregnancy is more risky for CF patients due to decreased physiological reserve and should be carefully planned [10].

Earlier and more aggressive treatment of patients with CF has dramatically improved their prognosis [11]. Individuals with CF are therefore coping with the burden of disease for longer. There are many positive strategies used by CF patients to cope with their disease but partaking in risky behaviour may be a negative one. Alternatively, they may be partaking as they have more of...
an opportunity to live a ‘normal’ life and therefore, like their peers, are tempted by such opportunities. The prevalence of risky behaviour has been studied in adolescents with CF but not in adults [12]. The present study explores this area and compares it to the general (non-CF) population.

2. Methods

A prospective postal survey using a 71-point anonymous questionnaire of all adults (aged ≥18 years; n=599) attending the RBH Adult Cystic Fibrosis Unit was performed. A self-addressed (pre paid) envelope was included. Due to incompletely answered questionnaires, the results reflect individual question responses. UK governmental guidelines were used for describing alcohol consumption. Less than the recommended limit=women who drink ≤14 units per week (u/w) and men ≤21u/w, more than the recommended limit=women who drink 15–34u/w and men who drink 22–49u/w, and significantly more than the recommended limit=women who drink >34u/w or men >49u/w. The study was approved by the Royal Brompton Hospital Ethics Committee. Differences between the study population and national data were tested using the chi-square test.

3. Results

182 questionnaires were returned and analysed (response rate 30%). Females (55%, n=100) were higher responders than males. The highest response was from patients aged ≥40 years (27%, n=50); the lowest response was from patients aged 18–20 years (9%, n=16); the remainder were 21–25 years (20%, n=36), 26–30 years (18%, n=33), 31–35 years (14%, n=26) and 35–40 years (12%, n=21).

3.1. Alcohol (Fig. 1)

Ninety-four percent (n=77) males and 98% (n=98) females have tried alcohol and 83% (n=151) continue to drink regularly. 79% (n=144) of all patients do not drink or drink within the recommended limit (88% men and 84% women) which is significantly more than the general adult (non-CF) population (77%; p<0.001; Fig. 3[13]). One patient (female) drinks significantly above the recommended limit (>34 units per week). The median age alcohol was first tried was 16.3 years (range 10–30). 30% (n=55) admit to binge drinking (patient’s own definition), with no frequency difference seen between males (29%) and females (31%).

3.2. Smoking (Fig. 2)

Forty-five percent (n=37) males and 47% (n=47) females have tried cigarette smoking. 6% (n=5) of those who have tried smoking still smoke now - significantly less than the general adult population (21%; p<0.001; Fig. 3[14]). The average number of cigarettes smoked per day was 6 (range 1–20). The median age patients first smoked was 15.6 years (range 7–30; no difference seen between sexes) compared to the national average of 11.

3.3. Illicit drugs

35% (n=64) have tried illicit drugs, which is less than the national average (37%, p<0.001; Fig. 3[15]). Of those, 31% (n=56) have used cannabis, 14% (n=25) cocaine, 10% (n=19) ecstasy, 6% (n=11) other hallucinogenic drugs (e.g. ‘Acid’), 2% (n=4) sniffed glue/inhaled aerosols and 0.5% (n=1) heroin (the same patient often tried more than one drug). No patient had used illegal steroids. The median age illicit drugs were first tried was 19 years (range 13–43). Sniffing glue or inhaling aerosols was tried at the earliest age (15 (13–18) years). 3% (n=6) continue to take recreational drugs, some taking more than one type of drug (cannabis, n=6; cocaine, n=4; ecstasy, n=3; other hallucinogenic drugs, n=2; and, sniff glue, n=1).

3.4. Sexual behaviour

Ninety percent (n=155) described themselves as heterosexual, 5% (n=8) homosexual and 5% (n=9) bisexual. 180 people answered questions relating to sexual intercourse. 86% (n=154) have had sexual intercourse. The median age of first sexual intercourse was 18.6 years (19.1 for men and 18.1 years for women). Of those who are sexually active, 21% (n=33) have only ever had one partner, 24% (n=37) have had ≤4 partners and 54%
(n=84) have had >4 partners. 46% males use condoms and 62% women use contraception [16]. 4% (n=3) women stated their reason for not using contraception was that they were trying to conceive.

4. Discussion

This is one of the first studies to explore the prevalence of risky behaviour in adults with cystic fibrosis. This is important because such behaviour potentially poses additional health risks in CF. The present study suggests that participation in risky behaviour at our adult CF unit was modest and currently lower than the national average. Risk-taking behaviour tended to start at a later age compared to healthy peers and was more prevalent in women.

This study provides an insight into the risk taking behaviour of the adult CF population. Given that CF life expectancy continues to rise and modern therapies improve quality of life, the adult CF population have more opportunities and may be more inclined to engage in risky behaviour than the previous generation. However, most individuals with CF have a long and intensive medical history and are therefore more aware and probably better informed about health risks compared to their peers. The current low incidence of risky behaviour in CF may reflect this as patients may be making an active decision and choosing not to partake. From our results, more women were engaging in risky behaviour. The reason for this is unclear and we can only speculate that this reflects trends seen in the general population. This study is limited by its cross-sectional design and inability to correlate risk taking behaviour to clinical disease severity due to questionnaire anonymity. The response rate was low which was probably due to the subject matter. Further detailed CF studies are required to understand the factors determining risky behaviour so that we can better understand these relationships and CF-specific education can be tailored appropriately.

In conclusion, the prevalence of risky behaviour in adult patients with CF was modest but currently less than the national average. Women may be at greater risk. We suggest that education of specific CF themes in relation to risky behaviour is integrated by the multidisciplinary team at appropriate stages into CF care.

References

[14] Drinkware.co.uk (ICM research).

Fig. 3. Prevalence of risky behaviour compared to UK national statistics. *p<0.05.