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Cross-infection in cystic fibrosis: The knowledge and behaviour of adult patients

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Abstract

Introduction: The knowledge and behaviour of adult patients with cystic fibrosis (CF) regarding cross-infection are ill understood.
Methods: A questionnaire was designed to investigate this at the West Midlands Adult CF Centre.
Results: 94 patients completed the questionnaire. 54%, 36% and 46% had "no idea" of the lifetime risk of contracting *Burkholderia cepacia* complex, epidemic strains of *Pseudomonas aeruginosa*, and MRSA, respectively. 25–33% did not know the consequences of infection with these bacteria. 35% mixed with other people with CF, 6.5% during physiotherapy or nebulizer use. Most respondents did not think quality of life was significantly linked with segregation from other patients with CF.
Conclusions: Adults with CF, at least in the West Midlands, have poor knowledge of the risk and consequences of cross-infection. A significant proportion ignored advice not to mix with other patients, although segregation was not thought to impact upon quality of life. This suggests that more education about the risks of cross-infection would be beneficial.

Keywords: Cross-infection; Cystic fibrosis; Knowledge; Questionnaire

1. Introduction

The majority of morbidity and mortality in cystic fibrosis is due to disease of the respiratory system [1], which is characterized by progressive bronchiectasis and airflow obstruction. One of the main contributing factors to the progressive lung damage is chronic bacterial infection. During childhood *Staphylococcus aureus* and *Haemophilus influenzae* are the main respiratory pathogens [2,3]. In contrast, 80% of patients reaching adulthood are colonized with *Pseudomonas aeruginosa*, which is associated with increased lung function decline and a higher mortality rate [3,4].

More recently, some centres have identified epidemic colonization with *Burkholderia cepacia* complex or certain strains of *P. aeruginosa* [3,5–10]. There is evidence that these bacteria are both more pathogenic [11–14] and more transmissible [15,16] than other strains, so most centres now keep patients separate in clinic and advise patients not to mix with other patients who have CF.

The majority of patients and carers in a paediatric setting welcomed these infection control measures as a necessary measure to reduce the risk of cross-infection and consequent altered health status, but some reported a negative emotional impact of not socializing with other patients and feelings of alienation created by segregation [11]. There has been considerable concern in the medical fraternity about the potential negative impact of segregation on patients [17], however the knowledge and attitudes of adult patients have not been assessed. Furthermore, it has been demonstrated in other areas that CF professionals are not necessarily able to predict accurately the knowledge of their patients [18,19] and that patients may have issues they would like to discuss, but would prefer health professionals to raise them [20, 21].

We designed a descriptive questionnaire to investigate adult patients' knowledge about cross-infection risk and their related behaviour.

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2. Methods

All patients attending a clinic appointment at the West Midlands Adult CF Centre during June and July 2005 were offered a questionnaire to complete. Questionnaires were also offered to in-patients who were due to attend the clinic during the same period. Questionnaires were posted to 8 patients colonized with the *B. cepacia* complex, who attended a separate clinic. After 10 patients had completed a pilot questionnaire, the results were examined and the questionnaire updated. Local ethical committee approval was given.

Data were collected from the questionnaires and the following information was gathered from patients' hospital notes: age, sex, height, weight, best spirometry within the last 3 months, complications of CF (diabetes, liver disease, renal impairment, transplantation, others), antibiotic prophylaxis, number of courses of intravenous antibiotics over the previous 12 months, and microbiology of sputum samples over the previous 12 months.

3. Results

3.1. Patient demographics

Of the 184 patients who attended clinic or were posted a questionnaire, 94 (51.1%) completed the questionnaire. Demographic data were available for 90: 58.9% were male, mean age (SD) was 27.2 (8.5) years, mean BMI (SD) was 22.2 (3.4), mean FEV_1 (SD) 62.1 (26.9) % predicted, mean number of courses (SD) of intravenous antibiotics in the previous year was 2.8 (2.6). 87.8%, 32.2%, 12.2% and 2.2% had at least one isolation in the previous year of *P. aeruginosa*, *S. aureus*, MRSA, and *B. cepacia* complex, respectively. Mean (SD) number of sputum samples sent in the previous year was 10.7 (7.9). 34.4% had diabetes mellitus, 23.3% had CF related liver disease and 3.3% had chronic renal impairment.

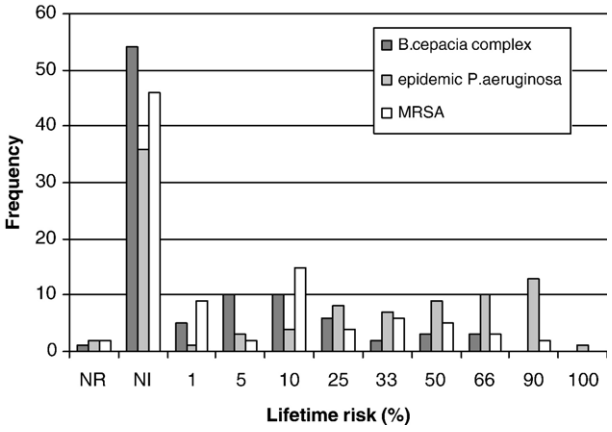

Fig. 1. Patients' estimates of lifetime risk of infection. NR = no response. NI = "no idea".

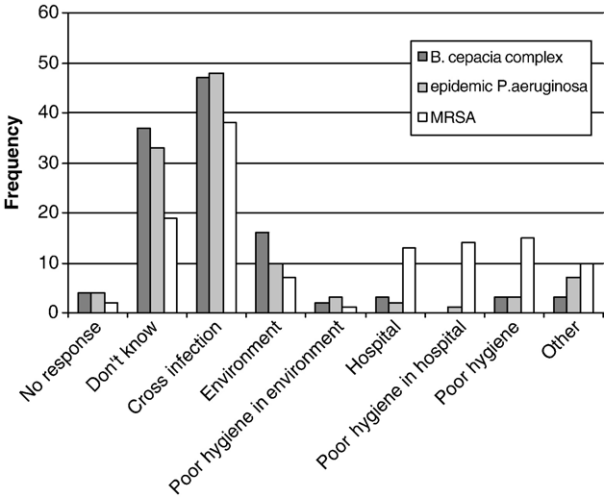

Fig. 2. Patients' beliefs about method of acquisition of infection.

3.2. Knowledge

60 respondents (63.8%) said they had been advised not to mix with other patients who had CF, 33 respondents (35.1%) said they had not received any advice and 1 (1.1%) did not respond to the question.

Figs. 1–3 are frequency charts showing (1) respondents' estimates of lifetime risk of infection with each bacterium, (2) respondents' beliefs about how each bacterium is acquired, and (3) respondents' beliefs about the consequences of infection with each bacterium. Table 1 shows the levels of concern patients expressed about each bacterium.

3.3. Behaviour

Table 2 shows the proportion of patients who mixed with other people with CF. Of the 20 patients who did mix with others, 16 (80.0%) reported that they had been advised against this activity. Of the 48 who deliberately avoided

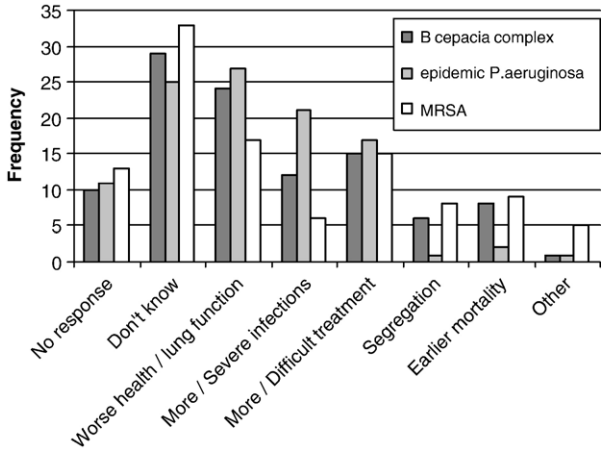

Fig. 3. Patients' beliefs about the consequences of infection.

Table 1
Levels of concern about a bacterium

Bacterium	Not at all concerned	Extremely concerned
Epidemic *P. aeruginosa*	29 (31%)	9 (10%)
B. cepacia complex	33 (35%)	14 (15%)
MRSA	21 (22%)	18 (19%)

contact, 30 (62.5%) said that their quality of life did not suffer as a result. Of the 43 who did not avoid contact, 10 (23.3%) said that their quality of life would suffer a 'significant amount' or 'a great deal' if they were to begin avoiding others.

4. Discussion

4.1. Knowledge

The majority of respondents had been advised not to mix with other people who had CF. Despite this advice, knowledge about the risk of cross-infection was very poor. Most had no idea of the risk of becoming infected with the three important pathogens asked about in the questionnaire, and the remainder estimated risks across a broad spectrum from 1% to 90%. In general, estimates of lifetime risk are 3 to 8%, with occasional epidemics of 30%, for *B. cepacia* complex [7,22,23], 20 to 30% for epidemic strains of *P. aeruginosa* [9,10,24], and 3% for MRSA [19]. Our centre does not differ significantly from these figures.

Similarly, a significant proportion did not know how these infections were acquired. The most common method of acquisition for all 3 bacteria was thought to be cross-infection from other patients, followed by acquisition from the environment. As far as the *B. cepacia* complex and *P. aeruginosa* are concerned, these views are broadly consistent with the evidence that most patients harbour unique strains which are presumably environmentally acquired, and other have epidemic strains which may have been acquired by cross-infection [6,7,15,25–32]. Any uncertainty on the part of patients with CF may be at least in part due to the uncertainty that exists in the scientific community [33,34]. It was interesting, in the light of recent political campaigns, to note how many mentioned "dirty" or "unclean" hospital wards (see Fig. 2) when there is very little evidence that MRSA is linked with ward cleanliness per se.

A significant proportion had poor knowledge of the consequences of infection with these bacteria. Although it is possible for patients to remain stable after colonization with *B. cepacia* complex or epidemic strains of *P. aeruginosa*, there is evidence that both may increase morbidity and mortality [11–13,23,30,35]. In contrast there is much less evidence that MRSA contributes to morbidity or mortality [19,36,37], yet a significant number of patients thought that it did. Levels of concern also reflected a bias towards higher anxiety about MRSA than *B. cepacia* complex or epidemic *P. aeruginosa*. This may reflect the recent increase in media coverage of MRSA. One respondent (a teacher) commented that they had been banned from work until they had 3 clear screens, another respondent commented that there was "a lot of hype about [MRSA] in the press" and another sited a party political election campaign as the source of their knowledge. It was interesting to note that 2 patients mentioned refusal for transplantation as a result of MRSA infection, whereas nobody mentioned this with regard to *B. cepacia* complex infection.

4.2. Behaviour

Only the minority (21.3%) said they mixed with other people who had CF, yet more (35.1%) said they did mix with other patients with CF whilst in hospital. It is interesting to note that patients didn't necessarily consider this in-patient contact as mixing with other patients. More worrying still, 6.4% said they were present while other patients were performing physiotherapy or using a nebulizer; activities which are known to increase the airborne bacterial load and risk of cross-infection [38].

Of those who mixed with others, a significant proportion (51.1%) said their quality of life would not suffer at all if they avoided others with CF, with only 23.3% saying their quality of life would be significantly or greatly affected. Therefore the behaviour of these patients as a group does not seem to reflect their need for contact with other people with CF. This may reflect a lack of consideration of the risk of cross-infection or a belief that the risk is low.

The proportion of patients who mixed with others despite receiving advice against such activity is worrying. Most of the advice was received from members of the CF team (data not shown) and would have been given during clinic or in-patient discussions. Only a few patients mentioned having written advice. It is possible that written formal information would be a more potent influence on behaviour.

Most respondents who avoided other patients did so to avoid cross-infection. Interestingly, more were trying to avoid *B. cepacia* complex and epidemic *P. aeruginosa* than MRSA, even though worries about MRSA were greater. This

Table 2
Proportion of patients who mix with other people with CF

Question	Yes	No	No response
Do you mix with anyone else with CF?	20 (21.3%)	70 (74.5%)	4 (4.3%)
Do you mix while in hospital?	33 (35.1%)	59 (62.8%)	2 (2.1%)
Do you mix during physio or nebulizer therapy?	6 (6.4%)	82 (87.2%)	6 (6.4%)
Do you deliberately avoid contact?	48 (51.1%)	43 (45.7%)	3 (3.2%)
To avoid infections in general?	46 (95.8%)	2 (4.2%)	0 (0.0%)
To avoid *B. cepacia* complex in particular?	29 (60.4%)	18 (37.5%)	1 (2.1%)
To avoid epidemic *P. aeruginosa*?	32 (66.7%)	15 (21.2%)	1 (2.1%)
To avoid MRSA?	22 (45.8%)	25 (52.1%)	1 (2.1%)

indicates that worries about cross-infection do not necessarily determine behaviour.

It is important to note that these data pertain to patients treated at the West Midlands Adult CF Unit. Though the findings may be different at other centres, these data highlight the importance of not making assumptions about patients' knowledge and behaviour. Additionally, only 51.1% of patients attending the clinic completed the questionnaire. We are unable to retrospectively ascertain why the other patients did not fill in the questionnaire, but response rates of this order are not unexpected [39,40].

5. Conclusions

In this questionnaire-based descriptional study of adult patients with CF we found that, despite a high proportion having received advice not to mix with other people who have CF, respondents had a poor idea of the lifetime risk and the clinical consequences of acquiring infection with *B. cepacia* complex, epidemic strains of *P. aeruginosa*, or MRSA. There was a bias towards overestimating the impact of MRSA and underestimating that of the *B. cepacia* complex and epidemic strains of *P. aeruginosa*. Levels of worry about the different bacteria reflected this bias (see Table 1).

In practice, 20–35% of patients mixed with other people with CF, and a small number (6.5%) spent time in the same room during physiotherapy or nebulized therapy, although the majority (51.1%) reported that their quality of life would not suffer by avoiding other people with CF. Of those who did avoid other people with CF, the majority (62.5%) did so to avoid cross-infection and most reported that their quality of life did not suffer as a result.

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