

SHORT REPORT

Female sexual health care in cystic fibrosis

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Fifty five teenage girls with cystic fibrosis and their mothers were interviewed to assess the provision of sexual health information. Parents were the most common source of information for adolescents. The cystic fibrosis doctor was identified as the key resource for parents. Yet few parents had spoken to their doctor about these issues, and 96% requested more information. This information was wanted before puberty by mothers, and from puberty onwards by girls.

As young people reach adolescence, the impact of cystic fibrosis (CF) changes. Young people with CF can obtain sexual health information from a number of sources. We aimed to determine whether young women with CF and their parents had received sufficient CF specific sexual health information.

METHODS

Females with CF aged 12 years or over who attend the specialist CF clinic at the Royal Children's Hospital, Melbourne, were eligible. Ethical approval was obtained as part of a larger study.¹ An interviewer administered questionnaire for adolescents was administered at a routine outpatient visit in 2001 and included seven questions about the provision of information on seven female sexual health issues (menstruation, thrush, fertility, contraception, safe sex, sexually transmitted diseases, and osteoporosis). A parent completed a similar self administered questionnaire separately. Parametric tests were employed where data were normally distributed; otherwise non-parametric tests were applied. Student's *t* test was used to compare means between groups.

RESULTS

Fifty five of 57 eligible female adolescents (96%) and 52 parents (95%, all mothers) took part. Two pairs of sisters participated: mothers' responses were treated separately as responses differed for each daughter. The median age of adolescents was 15 years (range 12–19). They were generally in good health, with a mean best FEV₁ in the previous six months of 80% predicted (SD 21%). Thirty nine (71%) adolescents were post-menarchal, with the mean age of menarche being 13.3 (SD 1.2) years. All were nulliparous.

Table 1 shows the main sources of information about female sexual health issues. The CF doctor or other clinic member was identified as an important source of information; however, 87% of adolescents and 78% of parents said that they had never discussed any of these issues with their CF doctor. Both girls and mothers were more likely to talk to the CF team than their general practitioner about these issues.

A third (37%) of participants felt they were sufficiently comfortable to ask questions about these topics of their CF doctor. A further third (35%) said they would be interested to learn more as long as a CF team member raised the subject, and 19% reported being too embarrassed to discuss the issues with anyone in the clinic.

Table 1 Main sources of information about sexual health issues for female adolescents and their parents (more than one response could be chosen)

Source	Adolescents, no. (%) n=55	Parents, no. (%) n=52
Parents	33 (60%)	–
CF doctor	13 (24%)	22 (42%)
Other CF team member	8 (15%)	12 (23%)
General practitioner	5 (9%)	11 (21%)
School/teachers	24 (44%)	7 (13%)
Friends with CF*	3 (5%)	6 (12%)
Other friends	15 (27%)	4 (8%)
Books/magazines	21 (38%)	20 (38%)
Internet	5 (9%)	2 (4%)
Other (n)	Sister (2)	CF association (1) Nursing or teacher training (2) Own mother (2) General paediatrician (1) Pharmacist (1)

*Or other parents of children with CF.

Adolescents felt that sexual health discussions should begin at a mean age of 13.2 (SD 1.8) years. Parents suggested a mean age of 12.2 (SD 2.3) years, with 92% wanting discussions with their daughters to start before 14 years. Mothers believed that discussions with parents should begin significantly earlier (mean 9.4 years, $p < 0.001$).

Fifty mothers (96%) requested further information on some or all of the issues raised. Requests for more information from adolescents was related to age; 34% of girls less than 16 years and 57% of girls over 16 requested information.

DISCUSSION

As the prognosis improves for those with CF, it is increasingly important that specialty CF clinics understand their role in providing CF specific sexual health information to young people and their parents. Young people with chronic disease frequently regard their subspecialist as their primary physician, but many do not speak to that physician about health needs that are thought to be unrelated to their primary disease.^{2,3} In our CF clinic, girls turned to their mothers for information on sexual health issues. However, this study highlights the fact that mothers are not necessarily sufficiently informed to provide appropriate information. Although they reported relying on the CF clinic for information, few mothers had ever discussed these issues with their daughter's CF doctor, and the overwhelming majority wanted more CF specific information. This is not surprising given that the other sources of sexual health information would not provide information specific to CF.

CF specific sexual health information is important. While women with CF are as likely to be sexually active as other young women, they are less likely to use contraception.⁴ Many have erroneous beliefs about infertility and others are unaware of the risks of pregnancy.⁴ Various aspects of CF and its treatment have relevance to contraceptive choices. For

example, higher dose oral contraception may be indicated, and the pill may not be the best contraceptive choice for those with chronic liver disease or permanent central venous access. In our experience, adolescents with CF who seek contraception may do so from a general practitioner not routinely involved in their care, who may be less aware of CF related issues. For these reasons, as well as for the sake of comprehensive health care, specialty CF clinics have a significant role in the provision of sexual health information.

When should these issues be discussed? Teenage girls wanted discussion by the age of 12–13 years, just prior to the average age of menarche in our CF population. Mothers wanted to know about these issues earlier, presumably so that they could be better prepared for discussions with their daughters. The discomfort and embarrassment reported by young people suggests the discussions should be initiated by clinic staff.

This study suggests that teenage girls and their mothers have unmet needs in relation to sexual health information. The same issues are known to affect both teenage and adolescent males with CF.⁵ Provision of developmentally appropriate information as part of ongoing health care will assist young people with CF (and their parents) to make informed sexual health choices, reduce misunderstandings about the effects of CF, and hopefully, improve both health and life outcomes.⁵

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