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Adolescents' Attitude Towards Carrier Testing for Cystic Fibrosis

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We read with much interest the paper by Welkenhuysen et al. [1] published in a previous issue of this journal on the adolescents' attitude towards cystic fibrosis (CF) carrier screening. We would like to briefly report a similar study we conducted in 1991–1992 on 142 adolescents (71 males, 71 females) between 17 and 20 years old (mean age = 18.5 years), attending a pre-university college in Chicoutimi (Saguenay Lac-Saint-Jean), to show the similarities between both studies [2, 3]. This region, located in the northeastern part of the province of Quebec (Canada), has a high incidence and/or prevalence of several hereditary disorders [4, 5], including CF. Its incidence is estimated at 1 in 902 live borns, with a carrier rate of 1 in 15 inhabitants [6, 7].

All 142 students, distributed into five cohorts, were randomly selected and well informed on hereditary disorders. They had attended a 12- to 14-hours human genetics session within a course of philosophy sanctioned by an academic examination about 2 months before answering the questionnaire. Furthermore, as in the Leuven study, the questionnaire included an informative text on CF and its genetics. It consisted in 27 closed-ended, multiple-choice questions regarding willingness to participate in a future CF carrier screening programme and attitudes towards screening; demographic data were also collected. Answering the questionnaire was on a voluntary basis and anonymous.

Twenty-six percent of the 142 students had a family member affected with a hereditary disorder, 52% knew someone outside their family with a hereditary disorder and 23% knew someone with CF.

Ninety-five of the 142 respondents (67%) answered that they would like to know whether they were CF carriers. Among them, 84% gave reasons relating to reproduction (desire of having children, presence of a hereditary disorder in the family, etc.) as the main reason for knowing; curiosity was the main reason for the others. Forty-two (30%) did not want to know their carrier status, 19 (45%) of them because of anxiety (including 5% fearing for their job and/or insurances and another 5% fearing of having a genetic file). Only 3% (4/142) of the students were undecided.

We also asked them what might be their reactions should they know they were CF carriers, whether or not they initially wanted to know their genetic status. Thirty-six (25%) of the 142 students thought that it was an advantage to know it, while 37% would be worried, 6% would panick and another 13% would need help. Forty-two percent (62/142) would alter their plans for a family should they be carriers, while 30% were undecided. Finally, 61% (86/142) thought that carrier screening could promote discrimination in the society, and 23% did not think so.

Several results in the present study are similar to those obtained by Welkenhuysen et al. [1]. Although in their study, only 37% of the adolescents wanted initially to know their carrier status, 68% would have participated in a screening programme offered by the Medical School Health Service in the near future; this is close to the 67% observed in our population. Actually, this 67% figure may be inflated since several studies showed that the uptake in screening programmes was lower than that found in hypothetical studies on attitudes [8–10]. Worry was one of the conclusions of the Leuven study; it amounted to 56% of the concerns in our study. Making more informed reproductive decisions was the main reason for knowing one's carrier status in both studies (51 versus 56%).

As pointed out by Welkenhuysen et al. [1], screening in high school has some advantages, but many disadvantages. Teenagers and young adults (20 years old and less) are already confronted with problems related to adolescence and social insertion, psychological problems of self-identity, not to mention problems of self-image and sexuality. Knowing that they are CF carriers could add a burden which they may have difficulties in coping with. Furthermore, screening in a close-captioned population could lead to pressure to be tested at an age at which individual decisions are often guided by the group's attitude ('I do not know to be different nor to act differently'). Follow-up may be necessary to prevent psychosocial damages and stigmatization. Finally, the time elapsed between testing and using the information obtained by screening could be very long; we do not know how many screened individuals would remember their carrier status when they will decide to have children.

Although the populations studied are different in that one can be considered as a CF

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low-risk population in a European sociocultural setting (Leuven), the other as a CF high-risk population in a North American sociocultural environment (Saguenay Lac-Saint-Jean), perceptions and attitudes among adolescents are almost the same. Therefore, given the risks involved, we think that if CF carrier screening is to be developed in some regions or countries, it should not target adolescents nor, of course, younger individuals. CF carrier screening should be directed almost exclusively at adults at risk who are considering having children in the near future [11, 12]. Information and education programmes on a large scale should be developed, taking into account that there are gaps between theoretical knowledge and practice and that the information is retained differently among individuals. Information should be repeated and circulated in various ways before any CF screening programme is started and counselling and follow-up provided to carriers.

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