

Impact of an SRH education programme on cystic fibrosis patients in Poland

Since patients with cystic fibrosis (CF) are living longer, it is important that sexual health is discussed in early adolescence. We have designed an education programme and evaluated its impact on the knowledge of sexual and reproductive health (SRH) issues in adolescents with CF and their parents. Prior to this programme most information was obtained from the internet, popular publications and other patients. Only 23% of adolescents discussed sexual health issues with their parents.

Our programme was for 12 months and consisted of group meetings and individual sessions (16 meetings; 114.5 hours). Patients aged over 14 years and their parents were tested on their CF-related sexual health knowledge before and after the programme by

means of anonymous questionnaires. A total of 46 families (87% of those attending our centre) participated in the programme; 17 patients (12 female, 5 male) and 43 parents responded to the questionnaires. The effect of the intervention was assessed using a Z-test for proportions adjusted for multiple comparisons using Bonferroni correction. A p value <0.05 was considered significant.

Before the programme, almost 50% of participants thought that CF females should use contraception to avoid an unexpected pregnancy, and up to 35% thought that CF males had no reasons to use any form of contraception. Afterwards, 65% of respondents realised the necessity of using contraception because of the risk of sexually transmitted infections, and all sexually active adolescents stated they used some form of contraception. Following the programme the number of patients and parents who understood the problems with female and male fertility increased significantly. In particular there was an increase in awareness of the risk of CF in a baby and the possibility of prenatal diagnosis. Most (82%) of the patients said they were planning to have children in the future. Before the programme 41% of them were afraid of the risk of having a child with CF, but no one considered termination of pregnancy (TOP) in the case of a CF prenatal diagnosis. Only 2/12 females and none of the males knew about the possibility of a significant health deterioration during pregnancy. After the programme 23% of patients were afraid of the risk of having a child with CF, the number of respondents who would consider TOP in the case of a CF prenatal diagnosis significantly increased (23%, $p=0.043$) and so did the number of respondents who were aware of the possibility of a significant health deterioration during pregnancy (53%). The proportion of adolescents discussing sexual health with their parents increased to 71%.

SRH issues have become an integral part of CF management and have a major influence on patients and their families.¹ We believe that family education, and improving communication between patients and their parents, is of key importance in addressing the health needs of adolescents with CF. Health professionals should actively initiate discussion with their patients. We are aware that in the UK group

meetings are discouraged because of the risk of infection; however, health professionals can still discuss SRH issues with patients on an individual basis.

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