

Abstract

Since the 1980s, prenatal detection of cleft lip with or without cleft palate (CLP) is possible with a transabdominal ultrasound. The improvement of prenatal detection has resulted in an increased demand for prenatal information and counselling. The aim of this study was to, by means of a questionnaire, evaluate how families, who received the diagnosis prenatally and postnatally, respectively, think about the prenatal and postnatal consultation. Patients referred prenatally or postnatally to the department, due to CLP, between January 2006 and September 2010 were included in the study. Thirty-six of the families (95%) answered the questionnaire concerning prenatal counselling. A total of 46 parents (82%) answered the questionnaire concerning postnatal counselling. In the prenatal group, half of the patients were first informed by the ultrasound unit, whereas 16% were initially informed by the cleft team. More of the families that were informed by the cleft team were content with the information received than the families who were informed by the ultrasound unit. The majority of the families were satisfied with the structure of the consultation. Most of the patients in the postnatal group were happy with the postnatal consultation. Most of the parents in the postnatal group would have wanted to know about the diagnosis prenatally. The great majority of the parents was happy with the consultation with the cleft team and thought that they received enough information. However, the information received at the referring units could be improved. Parents seem to want information on the cleft diagnosis and its treatment as soon as possible.