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Transition of adolescents with CHD for adult services – what they want and what healthcare professionals do

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Introduction - Adolescents with congenital heart disease transition from pediatric cardiology to adult services should be an intentional and planned process according to their medical, psychosocial and educational needs. The main goal is to promote adolescents independence and autonomy equipping them with skills for decision-making, self-care and self-management of their condition. The objective of this study is to compare adolescent expectations, about the transition process, with the practice of healthcare professionals of reference centres of pediatric cardiology in Portugal.

Methods – A quantitative, cross-sectional study was conducted. Data was collected in five hospitals, with a questionnaire "Transition of the Adolescent with Congenital Heart Disease for Adult Health Care", "Adolescents" and "Health Professionals" versions, developed for this study. The sample consisted of 93 adolescents and 39 healthcare providers.

Results - Transference to adult services occurred predominantly (61.53%) between 16 and 17 years and 43.01% of adolescents agree with this age group. However, 30.76% of the adolescents would prefer to be transferred only when they are independent. The predominant reason evoked by health professional (79.48%) for this transfer is age. Health care providers were split about involving the adolescent and the parents in the decision to transfer: 41.02% agree and 30.76% disagree, asserting that the decision is exclusively of the healthcare providers. About 23% of adolescents would not involve the parents in this decision. Healthcare professionals (61.53%) informed that the adolescent meets the adult health team in the first consultation after the transfer, but 23.65% of the adolescents would like to meet the new team at the pediatric cardiology service, previous to transfer.

Conclusions - Results of this study describe practices of transfer, not transition, to adult health care. When the adolescents reach the pediatric age limit, they are transferred to adult service, according to bureaucratic procedures defined by the institution. Adolescents expectations are not fulfilled in the transition to adult cardiology services.