

P-012 - PARENTAL PERCEPTION OF THE USEFULNESS OF EDUCATIONAL ACTIVITIES TO ENCOURAGE ADHERENCE TO PROTEIN/AMINOACID- RESTRICTED DIETS FOR PATIENTS WITH INBORN METABOLIC DISEASE AND THEIR FAMILIES

Vinuesa MV¹, Lavorgna SL², Levy L², Blasi SN²

(1) Fundación Garrahan; (2) Hospital de Pediatría Juan P. Garrahan. Buenos Aires-Argentina.

i. Inborn Metabolic Disease(IMD) patient's relatives require a high level of understanding and special training for the preparation and comply of these strict diets. Since 2011 educational and culinary workshops were planned to anticipate difficulties to encourage adherence. After 7 years of performing these activities an evaluation was made to verify the usefulness. ii. To describe parental perception of the utility of educational workshops for IMD patients and their families. lii. Metabolic dietitians designed a questioner orientated to relatives of children treated with protein/amino-acids restricted diets followed at our hospital from 2011-2018. Inclusion criteria: relatives attending +3 workshops and at least one during 2017-2018. The survey consisted of 15 questions based on possible changes and knowledge acquired about: cooking skills, nutritional habits (variety of menus /planning of daily menus and for special occasions, etc.), difficulties in attending and useful overview of these activities. iv. 71 families participated at least at one of the 54 workshops performed during these 7 years. During 2017-2018, 9 workshops were realized and 28 families attended 1 or more. 20 families met with the inclusion criteria, and answer the survey 85%(17). All participants made learned recipes more than once, referring satisfaction with the final product(94%).The explanation and demonstration of the step-by-step of the recipes and the elaboration with their own hands during the workshops made it easy to replicate them at home. More than 80% of the participants reported having learned new concepts about the low protein / amino-acid diet during the workshops and that had facilitated compliance, helping them to elaborate a greater variety of menus and handling special occasions. The most frequent difficulty to attend workshops is distance to the hospital(40%) being 50% the families that have been invited and didn't concur. Meeting other parents and children with similar diets(100%), considering their experience useful for others(35%) and being enthusiastic with new recipes(35%) make them feel encourage. v. The answers on the questionnaires showed positive relatives perception of the usefulness of the program. Involvement of parents in the treatment is crucial to improve adherence. Metabolic team should be able to empower parents in participating actively on their children treatment.