Dietary treatment in Dutch children with PKU: an inventory of associated social issues and eating problems.

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\textit{Background:} Phenylketonuria (PKU) is caused by a deficiency in phenylalanine hydroxylase which leads to high blood phenylalanine and results, if untreated, in severe developmental delay. A phenylalanine-restricted diet is the cornerstone of treatment in PKU. Eating problems and social issues of this diet are known to exist but knowledge on both the magnitude and prevalence is limited. The aim of this study is to evaluate the social issues and eating problems PKU children and their caregivers experience.

\textit{Methods:} A web-based questionnaire, based on the Behavioral Pediatric Feeding Assessment Scale with additional PKU specific questions, was distributed via the Dutch PKU Association and filled in by parents of PKU children. The control group consisted of parents of age matched children without PKU. Data were analyzed using SPSS.

\textit{Results:} 89 responses were analyzed. Parents of PKU children (N=56) reported to have more difficulty offering a varied eating pattern, to experience more stress during dinner outside of home and during holidays and to have a more strict approach to spilling food during dinner (P<0.05) in comparison with the control group (N=33). They reported to get more frustrated and/or anxious when feeding their child and more often felt their child's eating pattern affects his/her general health (P<0.05). PKU children showed more difficulty trying new foods in comparison with the control group (P<0.005).

\textit{Conclusion:} This pilot study shows the social issues and eating problems PKU children and their caregivers experience due to dietary restrictions, and warrants more awareness on this topic.