

ficou-se a categoria “sobrecarga do cuidador” com cinco declarações, descrevendo-se outras cinco subcategorias a partir desta. Com isso, verificou-se a necessidade de uma maior atenção ao manejo no domicílio como forma de apoio ao cuidador a fim de que venha a aderir efetivamente à intervenção prescrita, o que pode ser realizado com programas de orientação e educação.

AS ORIENTAÇÕES FONOAUDIOLÓGICAS AOS CUIDADORES DE PACIENTES COM LESÃO NEUROLÓGICA: A EFETIVIDADE DO CUIDADO NO DOMICÍLIO

SIMONE AUGUSTA FINARD; LETÍCIA NUNES NASCIMENTO; PALOMA LETELIER CAMPILLAY; MARISA GASPARIN; ALBERTO AUGUSTO ALVES ROSA

A deficiência é uma condição que exige longos períodos de supervisão e cuidado. A pessoa portadora de deficiência, frequentemente, necessita que membros da família prestem cuidados, normalmente em longo prazo. Além disso, dependendo da doença, o grau de recuperação pode estar associado ao apoio que a família consegue dedicar a este paciente (Bocchi e Ângelo, 2005), e essa dedicação pode exigir muito de quem cuida. O objetivo deste trabalho foi verificar a adesão dos cuidadores à intervenção, orientada pelo fonoaudiólogo, a pacientes adultos dependentes, o que incluiu a identificação das motivações e das possíveis dificuldades descritas pelos mesmos. O estudo foi desenvolvido no ambulatório de Fonoaudiologia do Serviço de Fisioterapia e Reabilitação do Hospital de Clínicas de Porto Alegre. A amostra foi composta de cuidadores que acompanhavam os pacientes adultos portadores de doenças do sistema neuro-músculo-esquelético. Os cuidadores responderam a uma entrevista semi-aberta cujas questões estavam direcionadas à descrição de particularidades para prestar o auxílio na realização das prescrições fonoaudiológicas pelo paciente. Os questionários foram entregues a 15 familiares, sendo devolvidos 10. O tema “efetivação do cuidado fonoaudiológico” emergiu das respostas, identificando-se a categoria “facilidade de manter o cuidado” e, dentro dessa, outras três subcategorias. A partir das respostas, verificou-se que, quando pacientes e cuidadores aceitam a condição de dependência, as orientações fonoaudiológicas realizadas pela pessoa que presta o cuidado são mais eficazes.

RELATION BETWEEN THE LENGTH OF USE OF THE BABY BOTTLE AND THE PACIFIER AND SPEECH CHANGES IN PATIENTS WITH MPS

GIOVANA SASSO TURRA; LÍLIA REFOSCO; IDA VANESSA DOEDERLEIN SCHWARTZ

INTRODUCTION: The mucopolysaccharidoses (MPSs) are a group of disorders caused by a deficiency of enzymes that degrade glycosaminoglycans (GAGs); as a result, GAGs are accumulated within lysosomes,

and patients present several clinical manifestations. There is not much data in the literature on the use of the baby bottle and the pacifier and its influence on the speech of MPS patients. **OBJECTIVE:** To estimate changes in speech and to relate them to the length of use of the baby bottle and the pacifier in patients with MPS. **METHODOLOGY:** Seventy-eight MPS patients were examined through anamnesis conducted with either the patient or his or her caretaker in the MPS Clinics at the Medical Genetics Service at HCPA. Of these patients, 62 were also evaluated on speech; the remaining of the patients did not cooperate with the evaluation. The following were considered abnormal: omission and/or exchanges of phonemes in speech (according to age) and the occurrence of tongue protrusion. **RESULTS:** Fifty-six patients (71.8%) were male. Mean age at evaluation was 11.5 years (2-38). Speech changes occurred in 42/62 patients (67.7%) Tongue protrusion was present in 40/42 (95.2%); phonemic changes, in 17/42 (40.4%), and phoneme omission, in 9/42 (21.4%). Patients with or without changes in speech were compared in relation to mean age and the length of use of baby bottle and pacifier, and no significant statistical difference was found between them. **CONCLUSION:** Changes in speech are frequent in patients with MPS, and their source is probably multifactorial. Although the length of use of the baby bottle and the pacifier is long in these patients, such factors do not seem to be the main determinant of the changes found in speech.

PREVALENCE OF BREASTFEEDING IN BRAZILIAN PATIENTS WITH MUCOPOLYSACCHARIDOSIS

GIOVANA SASSO TURRA; LÍLIA REFOSCO; IDA VANESSA DOEDERLEIN SCHWARTZ

INTRODUCTION: Mucopolysaccharidoses (MPS) are heterogeneous lysosomal diseases caused by intracellular accumulation of glycosaminoglycans (GAGs). There is little data in the literature regarding breastfeeding in MPS patients. **OBJECTIVE:** To characterize the breastfeeding period in patients with MPS. **METHODOLOGY:** From 2005 to 2007, 65 patients (11 MPS I, 28 MPS II, 2 MPS III-B, 4 MPS IV-A, and 20 MPS VI) regularly seen at the MPS Clinics of the Medical Genetics Service at HCPA were interviewed. Patients and/or their caretakers answered specific questions regarding their breastfeeding period. **RESULTS:** Forty-seven patients (72.3%) were male. The mean age at the interview was 11.03 years (2-30). Twenty-nine patients (44.6%) were born through vaginal delivery. Fifty-two (80%) patients were breastfed (mean time: 12.7 months – median 8 months); of these, 25 (47.2%) were exclusively breastfed (mean time: 4.5 months – median 4 months). The baby bottle was used by 58 patients (89.2%) (mean time: 42.4 months – median 36 months); 27/58 patients (41.5%) initiated the use of the baby bottle in their first month of life. No