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Demographic data, referral patterns and interventions used for children and adolescents with tinnitus and hyperacusis in Denmark

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Objectives: To investigate whether children and adolescents with tinnitus and/or hyperacusis are seen in Ear-Nose-Throat (ENT) clinics and to report the clinical data, treatment and referral patterns of these children. To describe the population of children and adolescents with tinnitus and/or hyperacusis found in Educational- Psychological Advisory services (EPAs) and Centres for special Education for Adults (CEAs) and to identify the referral patterns and interventions used for the children in each of these settings.

Methods: A prospective study within 15 ENT clinics was conducted from June 2014 to February 2015. All children with a primary complaint of tinnitus and/or hyperacusis was reported. No changes in daily practice regarding diagnostics, treatment or referral were made. A retrospective case review was undertaken during a five-year period from 01/01/2009 to 31/12/2013 in each Danish municipality and region.

Results: In the prospective ENT study, 12 children were identified and in the retrospective CEA/EPA study 69 children were identified. The 12 children seen by ENT (8 females and 4 male) had an age range from 5.7 to 14 years. The majority of the 69 children seen by CEA/EPA (n = 50, 72.5%) had been diagnosed with tinnitus as a primary complaint. Hyperacusis was the primary complaint in 9 cases (12.8%), and both tinnitus and hyperacusis were reported in 11 cases (15.7%). The findings of this study indicate that a majority of children with tinnitus and/or hyperacusis are seen in settings designed for adult audiological rehabilitation. Counselling, including explanations and discussion of coping strategies was the most commonly reported intervention. Intervention methods corresponding with guidelines for tinnitus management in adults were used in 11 cases (15.9%).

Conclusion: Overall only a small number of children with tinnitus and/or hyperacusis were identified in this systems, suggesting that either the children are seen at general practitioner level or not being referred at all. It may also be the case that the incidence of troublesome tinnitus in childhood is lower than the epidemiological data proposes. Referral pathways indicate a general uncertainty about which services provide acquire sufficient intervention. This study indicates that clinicians working at tinnitus services for adults (CEAs) collectively have the skills to help older children, and that a service development focus should be on the younger children as this point.

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1. Introduction

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Tinnitus is a symptom defined as a whistling or buzzing sound in the head or ears not related to any external source [1].

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Hyperacusis is the experience of reduced tolerance of sound of moderate or low intensity [2] and is often present in association with tinnitus, but also without. Tinnitus and/or hyperacusis can be experienced in both adults and children, and there has been an increase in studies on tinnitus in children and adolescents over the last 20 years.

The prevalence of tinnitus perception in adults is 10–15%, but the prevalence of troublesome tinnitus in adults is lower (0.5-2%)[1]. The prevalence of childhood tinnitus is broadly equivalent to that in adults, although differences in tinnitus definitions, the tinnitus question used to establish prevalence and whether or not it has been tested if the child understands the question make it difficult to compare across studies [3]. Childhood tinnitus prevalence estimates of tinnitus vary between 4.7% [4] to 54.7% [5] in normally hearing or population-based samples, and from 23.5% [6] to 62.2% [7] of the population of children with hearing loss. Reports of the prevalence of hyperacusis in young people vary from 3.2% [8] to 17.1% [9]. Humphriss et al. [10] found that 28.1% of 7092 11-yearold children had any spontaneous tinnitus (not associated with noise exposure). The prevalence of clinically significant tinnitus (defined as lasting minutes or hours and being bothersome), was reported to be 3.1%. Results of hyperacusis from the same study reported by Hall et al. [11] found that 3.7% of the 11-year-old children reported hyperacusis.

The prevalence of troublesome tinnitus in children ranges from 0.6% [12] to 49.2% [13], with different words used for research question [3], but it is unknown how many children need help coping with it. Only a few children are seen in established tinnitus clinics [14]. Studies have found that children rarely complain of tinnitus spontaneously [15–17], and when they do, there is probably a significant pathological cause [17]. Kentish [18] found that the child developed coping strategies to deal with tinnitus sound itself. Parents and general practitioners (GPs) may think that nothing can be accomplished by seeking clinical support [14]. Furthermore, a survey on UK GPs regarding their practice in adults with tinnitus showed that GPs with an interest in or expiries of ENT were less likely to refer patients onwards [19]. In Denmark, treatment of children with tinnitus and/or hyperacusis can be provided in both medical and non-medical settings. Medical based settings for assessment and treatment of childhood tinnitus and/or hyperacusis include ENT, located in clinics or hospitals. Non-medical settings includes Centres for special Education for Adults (CEA), who provide intervention and support for adults with speech, hearing, reading and sight disorders, or Educational-Psychological Advisory services (EPA) for children.

The Danish Guidelines on Assessment and Treatment of tinnitus specifically aimed for medical staff, particular ENTs, recommend that adult patients with tinnitus should be referred to services that specialize in tinnitus management. These include Audiology Departments or CEA [20]. These guidelines state that there is currently no specific knowledge about tinnitus prevalence or annoyance in children. A Good Practice Guideline on Assessment of Tinnitus and Hyperacusis in adults, developed for hearing therapists [21], recommend that tinnitus assessment and intervention should be based on the neurophysiological model of tinnitus [22] and that the Danish version of Tinnitus Handicap Inventory, THI-DK, be used in assessment and as an outcome measure [21,23]. The UK British Society of Audiology (BSA) Guidelines for Good Practice in Childhood Tinnitus recommend that health care professionals involved should have appropriate paediatric skills, and knowledge of care pathways and law-making relevant to the paediatric population instead of being an add-on to tinnitus clinics for adults [24,25].

Currently no similar clinical guidelines exist for managing childhood tinnitus in Denmark or other northern European countries. Currently only one study [26] has looked specifically at a simplified version of Tinnitus Retraining Therapy [22] outcomes for children with tinnitus. Outcome after six months of treatment were reported to be significant improvement in 81.4% of the cases (n = 48), defined as the decrease of at least three of the measured parameters by and minimum of 20%.

As a way of exploring the discrepancy between high tinnitus prevalence numbers and low clinical referral numbers, an eightmonth prospective study has been carried out in fifteen Danish ENTs and any cases seen at EPAs or CEAs within a five-year period has been collected retrospectively. The objectives of the study were as follows:

- To investigate whether children and adolescents with tinnitus and/or hyperacusis are seen in ENT clinics and to report the clinical data, treatment and referral patterns of these children.
- To describe the population of children and adolescents with tinnitus and/or hyperacusis found in EPAs and CEAs and to identify the referral patterns and interventions used for the children in each of these settings.

2. Methods

2.1. Organizational structure of the Danish health system

The Danish health system is a tax-based, decentralized health system where hospital care, GP services and public health services are largely free of charge at the point of service [27]. Five regions main responsibility is to deliver hospital care and agree service level with medical doctors through primary healthcare contracts (including GP and ENT specialists in private practice) and 98 municipalities are responsible for providing services such as rehabilitation, public health, school health services and some aspects of prevention. Both regions and municipalities play a critical role in planning and providing public services [28].

In Denmark, patients can self-refer to GPs and directly to ENTs (primary care). Access to hospital care (secondary care) is free, provided there is a referral from a GP [27] or an ENT. These services are paid by the regions. Primary care also includes non-medical services provided and paid by the municipality polity [29]. Each municipality has an EPA service, that covers special needs education for children between the age of 0–18 years within the education system. The commissioning for these is covered by the local municipality according to its internal political and financial structure.

Primary care non-medical services are also provided in CEA, run by the region, but paid by the municipalities. CEAs provide services for. All cost of assessment and treatment in CEAs is covered by the municipal system and *not* the regional system. Within the structure of the Danish health care system, GPs and ENTs cannot refer a child to a CEA without approval from the local EPA.

As stated by the previously mentioned guidelines for medical doctors [20], adult patients with tinnitus should be referred to CEAs for treatment. Since no such guidelines have been established for children, it could be assumed that similar referral pathways would be used for children with tinnitus. This would mean that children with tinnitus and/or hyperacusis found in the medical-setting system (Hospitals or ENTs) would be referred to CEAs for treatment, without first recurring a commissioning approval from the municipal system.

Ethical committee approval was obtained before the start of the project; ID S20140043 and registration in the Danish Data Protection Agency was made, as stipulated by the law J.nr. 2008-58-0035.

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