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Title: Mental health problems in deaf and severely hard of hearing children and adolescents : findings on prevalence, pathogenesis and clinical complexities, and implications for prevention, diagnosis and intervention

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Chapter **1**

Introduction

Introduction

The target population of specialist mental health services for deaf and hard of hearing children and adolescents consists of those hearing impaired young people whose mental health needs can not be sufficiently met in regular mental health services. The reason that these young people are the target group for specialised mental health services is that they share the need for visual or otherwise adapted communication and special facilities which make communication and social interaction accessible and effective. A medical description of hearing impairment focuses primarily on the severity of hearing loss, quantified as the unaided pure-tone decibel (dB) hearing threshold level for noise in the better ear. Degrees of hearing impairment are generally categorised as mild, moderate, severe and profound but agreed threshold levels may vary across reports within and across countries. For instance, the classification of hearing impairment used by the World Health Organization (WHO: mild <30 dB; moderate 31-60 dB; severe 61-80 dB; profound \geq 81 dB loss) differs from others, such as common classifications used in the Netherlands (e.g., mild 20-40 dB; moderate 41-60 dB; severe 61-90 dB; profound \geq 91 dB) or the UK (mild: 20-40 dB; moderate 41-70 dB; severe 71-95 dB; profound \geq 96 dB). Conversational speech is approximately 50-70 dB. From a functional perspective, young people with a severe to profound hearing loss cannot hear normal conversational speech without additional facilities. Advanced hearing devices such as hearing aids or cochlear implants can give many, though not all of them, some degree of hearing. In this introduction we shall refer to this population simply as “deaf”. In Chapters 2 to 4 of this thesis the aforementioned British classification of hearing impairment was used because of the British background of the handbook (Chapter 2) and the journal (Chapter 3 and 4) in which they were originally published. Chapter 5 of this thesis is based on the same school sample as described in Chapters 3 and 4, and was described in a comparable manner in an American journal. In Chapter 6, based on the study of a Dutch clinical sample, terminology was used according to Dutch criteria for hearing impairment. Please note that the terms “deaf and hard of hearing” or “hearing impaired” are also used throughout the text to indicate a broader

group, for instance to include children or adolescents with a moderate hearing impairment for whom a hearing aid may be recommended.

The population of deaf people

The population of deaf people constitutes a small, very heterogeneous minority in a hearing world. Reported prevalence rates of deafness vary along with the included criteria used for hearing impairment. As indicated above a *medical definition of hearing impairments* primarily focuses on the severity of hearing loss. Taking into account the age of the population studied and the method of measurement, adjusted prevalence rates may vary from 0.74 (De Graaf, Knippers & Bijl, 1997) to 0.85 per 1000 live births (Fortnum, Summerfield, Marshall, Davis & Bamford, 2001). A rise with age to at least 1.65 per 1000 live births in prevalence rate among children 9 years of age and older may be explained by postnatally acquired impairments in 4-9% of overall prevalence (De Graaf et al., 1997; Fortnum et al., 2001), delayed confirmation of congenital cases, and postnatal manifestations of some inherited causes (Fortnum et al., 2001).

A socio-cultural perspective on deafness focuses on at least three characteristics of Deaf culture (with a capital D): a primarily visual experience of the world, the use of sign language, and the identification with a unique culture with its own language, historical traditions, art forms and values (e.g., see Maxwell-McCaw & Zea; Meadow-Orlans & Erting, 2000). Membership in that culture does not require a certain level of hearing loss, but some degree of hearing loss is often necessary to be fully accepted into the culture (Maxwell-McCaw et al, 2011). In fact, to varying degrees deaf people are effectively bilingual and bicultural (Padden, 1996) or still differently culturally oriented as the experience of interaction with both hearing, deaf and hard of hearing people around them may result in a large variation of acculturative styles, either more deaf oriented, bicultural, more hearing oriented or marginal, i.e without a distinct positive preference (Hintermair, 2007).

The heterogeneity of the population of deaf people also appears from considerable diversities in many other domains. Most deaf children are born deaf or become deaf shortly thereafter, and only a minority has had more functional experience with spoken language as they become deaf after the first years of life.

The large majority of parents of deaf children is hearing. So, only a minority of deaf children grows up as early native signers, with a naturally adapted visual communication pattern between parents and their newborn deaf child. Hearing parents have to adapt their communication to the needs, strengths and weaknesses of their deaf child to find a communicative balance to guarantee satisfying interaction in the family. This may require much emotional and interactional investment of all family members, as well as environmental support, of other parents of deaf children as well as professionals. Later in life it will become clear whether deaf people either prefer sign language, spoken language, or a combination of both depending on their conversation partners. Still others, such as individuals who have become deaf later in life, will make more use of sign supported spoken language. Another subpopulation may communicate by home signs, gestures, or a combination of signs, gestures and behaviour. Four hand signing may be used by deaf blind people. Differences in language and literacy skills, language modality, unaided or aided functional hearing capacity, variable early social interactions and educational background, may not only contribute to differences in cognitive functioning between deaf and hearing individuals but they are also likely to be related to in-group differences in cognitive functioning, problem solving, academic achievement and meta-cognition, including Theory of Mind (e.g., see Marschark & Wauters, 2011). In addition, particularly acquired or syndromal aetiologies of deafness may be related to underlying CNS disorders, concomitant cognitive impairment, or physical disorders in other organ systems which all may greatly affect physical and psychological development of deaf children, adolescents and adults. Finally, diversity in race/gender, socioeconomic status or educational placements may contribute to heterogeneity of the deaf population (Maller & Braden, 2011).

History of mental health care for deaf people

Systematic clinical and scientific interest in mental health problems with deaf and hard of hearing people originated in the 50s and the early 60s. However, the first study on deaf individuals with mental illness was probably a study on 36 deaf adult patients in regular psychiatric hospitals in Norway by the deaf psychiatrist Hansen

in 1929 (Remvig, 1972; Vernon & Daigle-King, 1999). Hansen reported that deaf adults were overrepresented in these psychiatric hospitals, and that the average duration of stay in hospital was significantly longer than that of hearing adults. Many patients were undiagnosed, reflecting the issue of performing adequate assessments with deaf people by hearing psychiatrists and psychologists without sufficient communication skills with deaf patients (Vernon et al., 1999). In fact, it was common practice worldwide that deaf people were assessed and treated in regular outpatient and inpatient mental health services without trained staff and proper facilities to receive deaf people and communicate with them effectively. In 1955 the first specialist mental health clinic for deaf and severely hard of hearing people opened in the U.S, their inpatient and outpatient services and patients being described in the early 60s (Rainer & Altshuler, 1966; Rainer, Altschuler & Kallman, 1963; Rainer & Altschuler, 1971). In 1963 Robinson established another inpatient program. In the same year Schlesinger & Meadow opened the first ambulatory treatment services for deaf children in the U.S. (Vernon, 1980). In 1972 Schlesinger and Meadow published a survey on 516 students at a state residential school for the deaf with teachers and school counsellors as informants. Nearly 12% of the students were found to have a severe emotional or behavioural disturbance, and nearly 20% showed a mild disturbance. Comparing results from a similar mental health survey with the much larger general population of hearing children in the region, Meadow & Schlesinger (1972) found a five times increased rate for severe disturbances and a three times increased rate for mild disturbances with deaf school children. In line with this finding others found a three to six times increased rate for emotional and behavioural problems for deaf children as compared to hearing children (Greenberg, 1986; Meadow & Trybus, 1979). Meadow and Schlesinger emphasized that such data indicates how much deaf children are in need of special mental health services, special training for teachers working with deaf children, early intervention programs and effective psychiatric consultation to contribute to a decrease in the high incidence of mental health problems. In the same time period that these services were set up and these early major research projects were conducted in the U.S. (e.g., Rainer, Altschuler, & Kallman, 1963; Grinker, 1969; Schlesinger & Meadow, 1972), interest in research

as well as setting up special services started to increase in Northern European countries and especially in Great Britain (e.g., Denmark & Warren, 1972; Mahapatra, 1974; Williams, 1970), Scandinavia (Basilier, 1964) and Denmark (Remvig, 1969; 1972). From that time on there has been a great number of studies on the prevalence of psychopathology and characteristics of deaf individuals with mental health problems. Although prevalence studies have varied considerably in the criteria used to indicate psychopathology, the samples in study, the informants and the measures in use, most comprehensive studies have demonstrated that the rate of psychopathology is increased in deaf and hard-of-hearing children and young people compared to hearing peers from the general population (Willis & Vernon, 2002; Hindley & Van Gent, 2002).

In The Netherlands, during the major part of the 20th century a small number of schools for the deaf, three of which had residential facilities, were the only institutions that organized special education for deaf children and young people. A minority of children attended schools for hard of hearing children and children with speech and language difficulties, and very few attended mainstream schools. The large institutions for the deaf were also the only organizations to deliver orthopedagogical care, i.e. support for social and educational learning difficulties, social work and welfare services, but until the 1980s there were no specialized mental health services for deaf people available.

In the 1970s new welfare services in The Netherlands were founded through the initiative of a growing interest organization for the Deaf (“The Dovenraad”, currently “Dovenschap”) which also founded a new independent social work organization in the late 80s. In particular the FODOK (Federatie van Ouders van DOve Kinderen), the Dutch federation of parents of deaf children, undertook pioneering work in bringing together interest organizations, the responsible Ministry of Public Health, the Inspection of Health, interested service providers, and the aforementioned educational organizations for the deaf to discuss the establishment of specialist mental health services. In 1984 the FODOK published “*En niemand heeft geluisterd*” (“And No One Listened”), written by W. Frenay, the mother whose deaf son died as a consequence of not being understood in a regular mental health hospital with professionals inexperienced in working

and communicating with deaf people. The booklet gave greater publicity to the extreme distress which deaf people may suffer through the absence of adequate communication in regular mental health services for deaf people, and helped to establish the Platform Psychische Hulpverlening aan Doven (PPHD; platform for mental health for deaf people) in 1985 when the significant, aforementioned organisations started to work together to set up specialist ambulatory and clinical services in The Netherlands. In 1987 an outpatient child and adolescent mental health service started as part of Academic Centre for Child and Adolescent Psychiatry, Curium in Oegstgeest. In 1991 the national specialist in- and outpatient mental health service for adult deaf and hard of hearing patients was opened (Sleeboom-van Raaij, 1991). In 1993 the new national specialist mental health service De Vlier, department of the Academic Centre for Child and Adolescent Psychiatry, Curium, opened her doors to deliver inpatient services, outpatient services and consultation services for deaf and hard of hearing children and adolescents in The Netherlands. It was one of the first specialist inpatient mental health services for deaf children and adolescents worldwide. From the beginning both specialised mental health centres have actively promoted cooperation with the five supra-regional ambulatory mental health services, the in- and outpatient mental health service for elderly deaf and hard of hearing patients and other new services in this relatively new specialist field in the country, as well as with regular mental health services, educational institutions and other organizations abroad, such as the European Society of Mental Health and Deafness.

Mental health services for deaf children and adolescents provide highly specialized cure and care in a low incidence area. Currently, the largest educational organization in The Netherlands, Royal Dutch Kentalis, and existing specialist mental health services are in the process of exploring the joint establishment of a coordinated network of cooperating services in The Netherlands, from school based mental health programs to ambulatory, outreach, and new inpatient services, for children, young people, adult and geriatric patients. The need to join forces in mental health and deafness and to bundle knowledge, clinical expertise and organisational power is as urgent as it was in the 70s (see Meadow & Schlesinger, 1972). Specialist mental health services, experienced professionals,

training facilities, and consultation facilities to generic services are still too scarce to meet the needs of deaf people with mild or more serious mental health problems sufficiently.

Research with deaf children and adolescents

In the second edition of the Oxford Handbook of Deaf Studies, Language, and Education, Marschark & Spencer (2011) describe how an interdisciplinary variety of hearing and deaf researchers has made considerable progress over the years in a broad range of scientific areas such as language, social-emotional, (neuro-) cognitive and cultural aspects of development, as well as educational issues and academic achievement. However, the editors also highlight the areas where more extensive research is needed, among which are the provision of mental health services for deaf individuals, and understanding the challenges of deaf children with multiple handicaps. To date, research in these two related areas has been conducted by a relatively small, but steadily growing group of researchers. Methodology is complex. Firstly, as the population is small and heterogeneous, it is difficult to obtain a sufficient homogeneous sample of sufficient size to conduct research. Secondly, in epidemiologic research large variations in reported prevalence have been reported which may be explained by differences in the measurement instruments used (e.g., questionnaires versus interviews; sufficiently adapted or specially developed and standardized for the use with deaf people; interviews with all participants or only with participants screened positive), differences in the choice of informants (e.g., parents, teachers, self-reports, clinical judgements, or a multi-informant approach), differences in the methods of ascertainment of problems or disorder (e.g., differences in cut-off scores for problems or disorder; using different criteria for clinical disorder; conducting interviews or testing procedures in the preferred mode of communication of the interviewee or not; making use of a qualified sign language interpreter in agreement with the interviewee or not), and differences in the homogeneity or composition of samples (e.g., with or without additional physical handicaps, with or without varying degrees of hearing impairment, with or without cochlear implantation, with or without varying types of schooling, different communicative modalities, or considerable variations in cognitive capacities)

(e.g., see Hindley & Brown, 1994; Hindley & Van Gent, 2002; Maller & Braden, 2011). Such differences between studies hamper the comparability of results. To date, relatively little is known about specific risk factors for psychopathology in deaf children and adolescents in addition to known general risk factors such as CNS damage, low cognitive capacities, additional physical disorder, low parental SES (afkorting zonder uitleg handiger voluit), poverty, family distress and stressful life events (e.g., Friedman & Chase-Lansdale, 2002). Many deafness- and context related findings in studies with deaf samples only explain a small portion of variance in psychosocial adjustment, suggesting that other factors are important (Polat, 2003), such as intrapersonal factors or intrapersonal factors interacting with environmental factors. In addition, little is known about characteristics of deaf children and adolescents who are referred to mental health services, as well as characteristics that may distinguish deaf referrals from hearing referrals in sufficiently large samples.

This thesis: Aims & Structure

The first aim of this thesis is to contribute to filling the gap in knowledge in the area of psychopathology, its correlates, intrapersonal risk factors, and characteristics in the population of deaf children and adolescents with psychiatric disorders. The second aim is to identify factors which may help to focus more specifically on prevention and early recognition of a psychiatric disorder. The third aim is to identify more specific focuses for the improvement of specialist mental health care for deaf children and adolescents and the planning of service provision for this population with special needs.

Chapter 2 is a recent and extensive update of a subchapter on mental health and deafness, which -in its first version- was written in *Child and Adolescent Psychiatry, fourth edition* (eds. M. Rutter and E. Taylor, 2002). The revised version provides an introduction in currently significant aspects of mental health in deaf children and adolescents. In Part I epidemiology, aetiology, cultural, linguistic, interactional, and developmental aspects of deafness are discussed. In Part II important aspects of psychopathology are highlighted. The main focus of the chapter is on severely and profoundly deaf children and adolescents, but the effects of otitis media, mental

health challenges for children with a multisensory impairment, i.e. deafblindness, for hearing children of deaf parents, and for children with a cochlear implantation are also discussed, as well as adult outcome of deafness.

This thesis contains five articles (chapters 2-6). Three chapters (chapters 3-5) concern research with the same population deaf adolescents. As all chapters are self-contained manuscripts, some overlap between them is inevitable.

Chapter 3 is a study on the prevalence and correlates of psychopathology in this population. It fills a number of gaps in the existing literature on prevalence and correlates of psychopathology in deaf children and adolescents. It is the first study to make use of a diagnostic interview with all of the participating adolescents in order to assess psychopathology in this type of study with deaf children and adolescents. Also novel in this field is the use of consensus expert rating of psychiatric caseness and DSM IV classification, bringing together information from parents, teachers, adolescents' self-reports clinical judgements and medical files, as is the comparison between the multi-informant expert ratings with the single ratings of problems and disorder by the separate informants. The significance of early recognition, of the contribution of a single- and multi-informant approach to the assessment of problems and disorders, and of the identification of specific correlates of psychopathology -which may be related to increased risk of psychopathology in deaf children and adolescents- are discussed in the light of these findings.

Chapter 4 concerns a study on possible moderating effects of putative chronic stressful conditions in the lives of deaf adolescents (e.g., peer problems, living in a mainly hearing world) on the associations between aspects of the self-concept and psychopathology. Based on findings from literature, moderating effects of chronic stressful conditions on the association between global self-worth and emotional disorders and on the association between self-perceived social acceptance and behavioural disorder are examined. The importance of considering self-concept dimensions and chronic aversive conditions in subgroups of deaf adolescents when assessing and treating deaf adolescents are discussed.

Chapter 5 concerns a study of two intertwined aspects of self, i.e. self-concept and ego development, in the same representative sample of deaf adolescents of

normal intelligence. Levels of self-concept and ego development in deaf adolescents were compared with levels found in hearing norm groups, and associations of self-concept and ego development with deafness- and context related variables (e.g., cause of deafness, identification with the deaf) are examined. In addition, social self-concept profiles of deaf adolescents are identified and the associations of the profiles with global self-worth, ego development and deafness and context related variables are explored. The findings are discussed in reference to interventions aimed at the well-being of deaf adolescents.

Chapter 6 contributes to the knowledge of characteristics of children and adolescents who are referred countrywide to a national specialist mental health service for deaf and hard of hearing children and adolescents over a time period of 15 years, as well as differences between hearing impaired and hearing referrals with mental health problems. In addition, differences between subgroups of referred patients with and without multiple disabilities, and between the subgroups of (i) hearing impaired children of hearing parents, (ii) hearing impaired children of hearing impaired parents, (iii) hearing children of hearing impaired parents, and (iv) hearing children of hearing parents are examined. Implications of findings for current and future service provision are discussed.

Chapter 7 addresses the main conclusions, limitations, and recommendations for future research and clinical practice.

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