



Mental and behavioral disorders among people with congenital deafblindness

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ABSTRACT

The population of people with congenital deafblindness faces challenges concerning communication and mobility. Due to the significance of the sensory loss it is difficult to diagnose mental and behavioral disorders. This article investigates the prevalence of mental and behavioral disorders among 95 congenitally deafblind adults. Seventy-four percent were found to have a mental and/or behavioral diagnosis. Mental retardation was found among 34%, psychosis among 13%. Mental and behavioral disorders, especially with symptoms of psychosis and mental retardation, are common among people with congenital deafblindness. Clinical experience is needed, as well as cross-disciplinary cooperation and specialized diagnostic methods together with a observation and intervention period in order to be able to assess and differentiate mental and behavioral symptoms from sensory deprivation in people with congenital deafblindness.

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1. Introduction

People with congenital deafblindness either are born deaf and blind or become deaf and blind early in life before the development of language (pre-lingual deafblindness). Post-lingual deafblindness refers to people who become deaf and blind after the development of language (acquired deafblindness).

The prevalence of congenital deafblindness has been reported to be extremely rare, with about one in 27,000 newborn babies affected (Dammeyer, 2010b). The prevalence of congenitally deafblind people is around 1/5 of the total population of deafblind people (congenitally and acquired) (Rødbroe & Janssen, 2008).

There is a wide range of causes for congenital deafblindness. Among the more common are CHARGE syndrome, prematurity, meningitis, cytomegalovirus and, formerly, Rubella syndrome (Dammeyer, 2010b). There are also many causes for acquired deafblindness. The most common is Usher syndrome which accounts for approximately half of the people with acquired deafblindness (Møller, 2003).

Evaluation of mental and behavioral disorders (ICD-10, Block F) among people who are congenitally deafblind has not been reported. One reason is that the group of people who are congenitally deafblind is small and heterogeneous, another that only little attention had been paid to this group in existing research. But among people with syndromes associated to deafblindness, few studies had reported mental and behavioral disorders. Among individuals with Usher syndrome psychosis has been reported in case studies (Hess-Röver, Crichton, Byrne, & Holland, 1999; Jumaian & Fergusson, 2003; Mangotich & Misiaszek, 1983; McDonald, Kenna, & Larkin, 1998; Rijavec & Grubic, 2009), but a higher prevalence in general was not found (Grøndahl & Mjøen, 1986; Mangotich & Misiaszek, 1983). Different mental and behavioral disorders had been discussed among people with Rubella syndrome from case studies (Sever, South, & Shaver, 1985), but no overall

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characteristics or prevalence has been reported. Finally, behavioral features of autism among individuals with CHARGE syndrome has been reported (Graham, Rosner, Dykens, & Visootsak, 2005; Hartshorne & Cypher, 2004; Smith, Nichols, Issekutz, & Blake, 2005), but the evaluated behavior were found to be associated to the dual sensory impairment (Graham et al., 2005; Vervloed, Hoevenaars-van den Boom, Knoors, van Ravenswaaij, & Admiraal, 2006).

Next to prevalence, the etiology of mental and behavioral symptoms among people with deafblindness is an important issue of concern. To what degree does dual sensory loss cause mental and behavioral symptoms? Some argue that the appearance of mental and behavioral symptoms can be caused by the loss of hearing and vision, e.g. psychosis among people with Usher syndrome (Mangotich & Misiaszek, 1983). In another study McDonnell (2009) found that communication and social support were important to avoid the experience of depression among people with acquired deafblindness, i.e. the communicative difficulties caused by the dual sensory loss, increase the risk of depression.

Cognitive decline among people with acquired deafblindness may illustrate some of the interaction between dual sensory loss and mental and behavioral disorders. Laforge, Spector, and Sternberg (1992) found, after adjusting for age, sex and cognitive status, that persons who had vision impairment or both vision and hearing impairments were 2.5 and 3.5 times more likely to experience functional decline than were unimpaired older adults, respectively. In a large study of 6112 women aged 69 and older, Lin et al. (2004) found similar odds for reduced cognitive function (2.19) for women with combined visual and hearing impairment as compared to women without impairments.

Pervasive developmental disabilities are also of interest with regard to people who are deafblind and the etiology of mental and behavioral disorders. Autism or autism-related conditions are common among blind children (Cass, 1998). Similarly though, to a lesser degree, there have been found more occurrences of autism within the group of children with hearing loss (Carvill, 2001; Jure, Rapin, & Tuchman, 1991). With regard to children with deafblindness, there are no accounts of the occurrence, but one must assume that the occurrence of autism-related symptoms is at least the same. Similarities of communicative, social and cognitive symptoms of autism may be similar to symptoms of dual sensory loss (Hoevenaars-van den Boom, Antonissen, Knoors, & Vervloed, 2009).

Mental retardation may also be a common occurrence among individuals who are deafblind due to common underlying etiology, such as genetically based syndromes, prenatal infections etc. No report on prevalence could be found. It is difficult to differentiate between behavioral symptoms of deafblindness and mental retardation. Deafblindness among people with mental retardation has been reported to be undiagnosed (Fellinger, Holzinger, Dirmhirn, van Dijk, & Goldberg, 2009; Meuwese-Jongejeugd et al., 2008).

The complexities of mental and behavioral issues associated with people who are deafblind do often complicate and limit the foundation for appropriate clinical treatment. More knowledge of the prevalence and etiology of mental and behavioral disorders among people who are congenitally deafblind are needed. The aim of this study is to explore the prevalence and etiology of mental and behavioral symptoms among people with congenital deafblindness.

2. Method

2.1. Participants

All people in Denmark above the age of 18 known to be congenitally deafblind were included in the study. This amounted to 123 individuals. The Scandinavian definition of deafblindness was used: "Deafblindness is a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to a degree which requires that society compensates by means of specific services, environmental alterations and/or technology." (Nordisk Lederforum, 2007). The people included were recruited from an updated national survey study from 2004 (Dammeyer, 2010b; The Danish Resource Centre on Congenital Deafblindness, 2004). The protocol was approved by The National Board of Social Services and The Danish Resource Centre on Congenital Deafblindness.

Questionnaires were distributed to all 123 individuals by mail. Six persons were omitted from the study because they (or their guardian/committee) did not want to participate. Twenty two of the remaining 117 individuals had not returned the questionnaire after a third reminder by mail and phone. Thus, 95 individuals were included in the study.

2.2. Method and procedure

The questionnaire contained information about gender, age, etiology and place of residence (institution for deaf, blind, deafblind or intellectual disabilities in general), vision, hearing, current mental and behavioral diagnoses and patient's age by diagnosis.

Informed consent was obtained from all participants or their legal guardians. The questionnaires were completed by staff together with a deafblind consultant at the institution where the person with congenital deafblindness resided. It was possible to call staff at The Danish Resource Centre on Congenital Deafblindness if any difficulties were encountered in filling out the questionnaires. All medical information (mental and behavioral diagnoses, etiology, vision and hearing etc.) were collected from the medical case record. All mental and behavioral diagnoses, tests of etiology, vision and hearing was checked to be made by a medical specialist.

Analysis was conducted using descriptive and non-parametric tests (Pearson's chi-square test or Fisher's exact test). Analysis was made in SPSS 17.0.

Table 1

Number of mental and behavioral disorders and etiology among 95 individuals with congenital deafblindness. Only main diagnose is listed.

	<i>n</i> (%)	Aetiologies (<i>n</i>)
Mental retardation	32 (34)	Chromosomal or genetic (11), prenatal infection (7), unknown/other (14)
Pervasive developmental disorders (Autism)	2 (2)	Unknown/other (2)
Psychosis	12 (13)	Chromosomal or genetic (4), prenatal infection (6), unknown/other (2)
Mood (affective) disorders	10 (11)	Chromosomal or genetic (3), prenatal infection (5), unknown/other (2)
Obsessive-compulsive disorder (OCD)	5 (5)	Chromosomal or genetic (1), prenatal infection (3), unknown/other (1)
Anxiety	4 (4)	Chromosomal or genetic (3), unknown/other (1)
Behavioral disorders (hyperkinetic and/or conduct disorders)	5 (5)	Chromosomal or genetic (1), prenatal infection (1), unknown/other (3)
No mental or behavioral disorders	25 (26)	
Total	95 (100)	

3. Results

3.1. Population

Fifty-nine percent ($n = 56$) were men and mean age for both men and women were 41 years ($SD = 12.6$). Etiology distributed to 27% ($n = 26$) with Rubella syndrome, 8% ($n = 8$) Downs syndrome, 6% ($n = 6$) prematurity, 4% ($n = 4$) CHARGE syndrome, 4% ($n = 4$) CMV. For 22% ($n = 21$), etiology was unknown, and among the rest 27% ($n = 26$), etiology was rare, with 3 or less individuals of each syndrome.

Thirty-three percent lived at an institution for intellectual disabilities not specialized for individuals with sensory loss, 34% at an institution for people who were congenitally deafblind and 5% lived at an institution for persons who were either deaf or blind. No one resided by parents or family. No information was given regarding the remaining 28%.

3.2. Mental and behavioral disorders

Table 1 shows the number of mental and behavioral disorders among the 95 congenitally deafblind individuals. Thirty-two individuals were found to be mentally retarded, 2 with autism, 12 to be psychotic, 10 with a mood disorder, 5 with an obsessive-compulsive disorder, 4 with anxiety disorder and 5 with a behavioral disorder (e.g. hyperactivity and/or conduct disorder). 25 individuals did not have any mental or behavioral disorder.

No associations were found between etiology and to be psychotic (Rubella syndrome versus not Rubella syndrome, chromosomal aetiologies versus not chromosomal, etc.). There were also no associations to be found for all other mental and behavioral disorders. Similarly, no associations were found between level of vision and/or hearing impairment and any of the mental or behavioral disorders.

Mean age of diagnosis of psychosis was 30 years ($SD = 13$). In all cases mental retardation was diagnosed in childhood. For other disorders information of age of diagnosis was incomplete.

4. Discussion

This study found a high prevalence of mental and behavioral disorders among individuals with congenital deafblindness, in special mental retardation and psychotic symptoms. Only one out of four did not have any mental or behavior disorder.

As introduced, etiology of mental and behavioral symptoms among people with deafblindness is an important issue to discuss to explain the high prevalence and to be able to offer appropriate intervention. To what degree does dual sensory loss cause mental and behavioral symptoms?

Dammeyer (2010a) found a strong association between communication abilities and communicative functioning among people with congenital deafblindness, indicating an interaction of dual sensory loss, cognitive function and communication. Research conducted among deaf and blind children, respectively, do find associations between sensory impairment (deafness or blindness) and symptoms of autism. Several authors have asserted that due to the behavioral similarities found in the two conditions there has been an over-diagnosis of autism in persons with sensory impairments (Andrews & Wyver, 2005; Cass, 1998; Hobson, Brown, Minter, & Lee, 1997). Symptoms like autism or mental retardation among children with sensory disabilities sometimes disappear, when visual or tactile sign language, or other forms of total communication, has been successfully developed and becomes communicatively functional for the child. In other cases the autistic symptoms remain dominant and the conclusion is co morbidity.

In this study two individuals had the diagnosis of autism. Among adults mental retardation or psychosis seems to be a more frequent given diagnosis to the behavior seen among individuals with congenital deafblindness.

All mental and behavioral disorders occur in combination with dual sensory loss. It is important to determine the main diagnosis and to determine whether the person has a congenitally inferior cognitive, social and communicative potential, or if the person has a normal potential, but low cognitive, social and communicative functioning as a result of congenital

sensory loss. In most cases it rarely is a question of either/or, but more a question of interaction of dual sensory loss and symptoms of mental and behavioral disorders.

4.1. *Cognition*

Even though a child with vision and hearing impairment has normal cognitive functioning, the sensory loss gives the child some functionally serious cognitive difficulties. This holds true for most cognitive areas, but is especially true for attention, conceptualization, language, social understanding etc. (Janssen & Rødbroe, 2007; Rødbroe & Souriau, 1999). The older the child gets, the more the child will “fall behind” as compared to a normally hearing and sighted child. The sensory impaired child demands more time, as information doesn’t reach the child all that easily. Some congenitally deafblind children exhibit normal cognitive abilities – yet, functionally, they will not function in accordance with their age.

4.2. *Social behavior and communication*

It can be difficult for an individual who are deafblind and dependent on tactile sign language, to extend social understanding beyond one to one interaction with a familiar grown-up. The person may seem uninterested in other persons; behave instrumentally in the contact with other individuals. In order to differentiate between psychosis or autism and sensory disability, it is important to examine the person’s social behavior in a familiar setting, for example, the child together with a familiar grown-up communicative partner (Janssen & Rødbroe, 2007). Communicative impairment in the case of individuals with congenital deafblindness is similar to symptoms of autism or mental retardation (Hoevenaars-van den Boom et al., 2009).

4.3. *Self-injurious or self stimulating behavior*

Self-injurious (biting and hitting) or self-stimulating behavior (rocking, looking into light etc.) often occurs in connection with dual sensory loss; also among individuals without mental retardation. This behavior can be interpreted as compensation for the lack of sensory input and/or as an expression of frustration because of the lack of language/communication skills (Hoevenaars-van den Boom et al., 2009), and is different from restricted patterns of behavior seen in people with autism, psychosis and mental retardation. The self-injurious behavior usually decreases when adequate measures are taken such as useful communication and/or vision and hearing aids, while the self-stimulating behavior may continue (Janssen & Rødbroe, 2007).

4.4. *Intervention on communicative development*

Next to pharmacological treatment and visual and hearing aids, a therapeutic treatment concerning social interaction and communication rehabilitation are found to be important (Janssen & Rødbroe, 2007; Rødbroe & Souriau, 1999) to prevent mental and behavioral disorders. The importance of communication development is also demonstrated among deaf children (Hindley, 2000, 2005; Mayberry, 2003). The emergence of communication takes place via the processes of social interaction during play activities and in natural settings using the tactile modality. The partner responds to and expands upon the person’s expressions of emotions and desires by regulation of contact, joint attention, turn-taking, and rhythm and tempo using tactile stimulation (Bjerkan, 1996; Janssen & Rødbroe, 2007; Nafstad & Rødbroe, 1996).

4.5. *Diagnostic hierarchy*

Like any other organic or somatic causes to mental and behavioral disorders, e.g. head trauma, tumour, drug abuse etc., vision and hearing impairment need to be checked and treated before any other diagnoses are considered. Even for a person who is severe mentally retarded, it is vital to compensate for the dual sensory loss by hearing and visual aids and communicative development. Treatment of mental and behavior disorders among individuals who are congenitally deafblind is, next to pharmacological medication, first of all a matter of progressing as far as possible with the development of the person’s communicative abilities to reduce negative impact of the dual sensory loss. Deafblindness must be on top in a diagnostic hierarchy of mental and behavioral disorders.

4.6. *Diagnostic procedures and tools*

Due to the person’s dual sensory loss, it is generally difficult to use traditional psychological and psychiatric tests and diagnostic tools, since these often require full sensory functioning as a prerequisite (Ronnberg & Borg, 2001). For example, it is not possible to use various diagnostic tools for autism among individuals who are deafblind (Hoevenaars-van den Boom et al., 2009). This is also the case for cognitive tests (see for example Maller, 1997 for deaf children). It is straightforward to triangulate diagnostic tools and procedures. Both structured and non-structured observation, formal and informal tests must be used. Diagnostic procedures of a patient with dual sensory loss and mental and behavioral disorders often needs to be a multiannual and cross-disciplinary task of deafblind consultants, vision consultants, speech and hearing therapists, psychologists, psychiatrists, physiotherapists, etc. with experience working with patients with dual sensory impairment and mental and behavioral disorders.

It is important to continuously monitor and analyse the communicative competencies of the person in addition to the person's vision and hearing. Observation by video is a useful tool, which specifically may add value to some of the key parameters in relation to the relevant diagnose. Nafstad and Rødbroe (1999), Rødbroe and Andersen (2000), and Dammeyer (2009) describe approaches of video observations of congenitally deafblind patients.

5. Conclusion

People who are congenital deafblind face a high risk of mental and behavioral symptoms. Mental retardation and psychosis are common conditions. In most cases there is an interaction of dual sensory loss and symptoms of mental and behavioral disorders. Focus must be on communicative development in a multiannual and cross-disciplinary approach.

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