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Challenges and Praxis in Assessment of Congenital Deafblindness

Jesper Dammeyer

Abstract

The different practices and challenges of assessment of congenital deafblindness have been discussed in the research literature and are reflected in different medical and functional approaches across the world. The aim of this study is to provide an overview of the use of both medical and functional assessment practices in a Danish sample of 95 adults with congenital deafblindness. Of the participants in this study, 54% reported regular medical assessment of vision loss, 36% reported regular medical assessment of hearing loss, and 43% reported regular functional assessment by use of video-analysis/observation. Variability in assessment frequency was found, ranging from several times per year to less than once per year. Further, gender, age, ADL abilities, deafblind severity and counselling service were each found to be associated with differences in assessment practice. Findings are discussed and compared with assessment guidelines and recommendations from the research literature.

Introduction

There are two main approaches to identification and assessment of congenital deafblindness. The first is a medical approach where objective measurement of hearing (dB hearing loss) and vision (visual acuity) is used. The second is functional, which involves observations of an individual's functional abilities of hearing and vision in communication and everyday activities (Dammeyer, 2012; Andersen & Rødbroe, 2000). These two approaches are reflected in divergent definitions of deafblindness and embody different models of disability (Ask Larsen & Damen, 2014). Where the medical approach draws on a bio-medical disability model (disability is understood as caused by the degree of physical impairment and defined thereby), the functional approach draws on the social model of disability (disability is understood as emerging through barriers to participation in society, comprising systemic barriers, negative attitudes and social exclusion) (Bøttcher & Dammeyer, 2016). One of the often-used functional definitions of deafblindness is the Nordic definition: "*Deafblindness is a combined vision and hearing disability. It limits the 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).

Vervloed and Damen (2016) highlight three functional assessment approaches in the field of congenital deafblindness. The first is the Communication Matrix (Rowland, 2011) which assesses the functional use of communication in the social context through use of a questionnaire form. The form is organized in a matrix comprising four reasons to communicate, seven levels of communication and nine categories of communicative behavior. The second functional assessment approach is provided by the van Dijk Framework for Assessment of Children and Youth with Multiple Disabilities and Deafblindness (Nelson, van Dijk, McDonnell, & Thompson, 2002; Nelson, van Dijk, Oster, & McDonnald, 2009). The van Dijk Assessment is a child-guided developmental assessment approach that examines the processes children use as they learn and internalize information and is based on theories about sensory deprivation, attachment, social learning, imitation, and neurobiology (Varvloed & Damen, 2016). The Deafblind International Communication Network has developed Van Dijk's approach into a third approach placing emphasis on the dyadic interaction between the individual with deafblindness and the communicative partner (Janssen & Rødbroe, 2007). In this approach, there is a strong focus on the use of video observation/analysis (Damen, Janssen, Huisman, Ruijssenaars, & Schuengel, 2014; Janssen, Riksen-Walraven, & van Dijk, 2003, 2006, Janssen, Riksen-Walraven, Van Dijk, Ruijssenaars, & Vlaskamp, 2007; Dammeyer, 2009). In Denmark, Andersen and Rødbroe's (2000) elaboration of this approach using video observation/analysis has become part of the standard assessment toolbox (Dammeyer, 2012).

The functional assessment approaches are often inspired by the dynamic assessment tradition whereby assessment and instruction/teaching are combined to identify learning and developmental potentials (Boers et al., 2013). Thus, functional assessment programs are often combined with educational intervention programs (Vervloed & Damen, 2016) and entail recommendations for regular assessment. Other approaches, such as the one used in Denmark, combine medical and functional assessment (Andersen & Rødbroe, 2012; Dammeyer, 2012). Regular assessments are recommended because the medical degree of vision and hearing loss is often not stable (for example, due to a progressive eye disease); and because the functional degree of deafblindness also fluctuates over time and across contexts (for example, if and when an individual with congenital deafblindness moves to a new institution or their primary carer is substituted) (Andersen & Rødbroe, 2000; Dammeyer, 2012). Even though regular assessment is recommended in the literature, no uniform guidelines exist. This is of particular concern because the praxis of assessment might vary across the population due to factors such as gender, age, functional abilities, severity of deafblindness and the kind of support provided.

Even though both medical and functional assessment procedures are described in the literature, there are few studies providing a clear overview of what is used in practice. The aim of this study is to provide an overview of the medical and functional assessment of vision and hearing loss in a national Danish sample of adults with congenital deafblindness.

Methods

Participants

All adults in Denmark aged above 18 years and identified as having congenital deafblindness by use of the Nordic definition were invited to participate in this study. This amounted to 123 individuals. Six individuals were omitted from the study because they (or their legal guardian) did not want to participate. A further 22 did not return the questionnaire after a third reminder by mail and phone. Therefore, 95 adults with congenital deafblindness were included in the study. The mean age was 41 years (*SD* = 13, range 19-80), and 39 (41%) of the participants were women. The questionnaire was completed by the primary carer of the deafblind individual, which in the majority of cases was a staff member at the institution where the individual lived. In other cases, this was a parent or legal guardian.

Information about assessment

The first question in this study asked if hearing loss was assessed regularly by an otolaryngologist or similar (response categories: “yes”, “no”). If the response was affirmative, there was a further question asking how often the assessment took place

(response categories: "one per year", "once every second year", "other, please specify how often"). The same questions were asked regarding vision loss. Finally, there was a question asking how often video-analysis/observation for assessment and intervention was used (response categories: "once per week", "once per month", "once every third month", "once every year", "less than once per year, please specify").

Other information

Further to gender and age, information about whether the participant received specialized deafblind counselling services or not was included. Deafblindness severity was measured by the sum score of degree vision loss both eyes ((1) mild: 6/6>6/18, (2) moderate: 6/18>6/60, (3) severe: 6/60>1/60, (4) blind: <1/60) plus hearing loss both ears ((1) mild: <41 dB, (2) moderate: 40<71 dB, (3) severe: 70<91 dB, (4) profound: >90 dB), giving a total score ranging from 4-16. Finally, Activities of Daily Living (ADL) was measured by four questions: Are you able to eat without support; dress and undress without support; go to the toilet without support and take a shower without support? Response categories were (1) Yes, (2) Partly and (3) No. Responses were summed into a total score ranging from 4 to 13.

Analysis

Firstly, descriptive statistical analysis of vision, hearing and video assessment was completed. Secondly, Chi-Square, t-test and Kendall's tau-b statistics were used to test significant differences or correlations between, on the one side, medical vision, medical hearing and video assessment and, on the other side, gender, age, ADL score, deafblind severity and receipt of specialized deafblind counselling services.

Results

Of the 95 participants, 34 (36 %) reported that hearing loss was assessed regularly by an otolaryngologist or similar, and 50 (53 %) reported that it was not. The remaining 11 (12 %) participants did not respond. Six participants reported that hearing loss was assessed annually; 14 participants reported every second year; 4 participants reported every 3-5 years; and 3 responded "when needed". The remaining 7 participants did not provide any information.

Of the 95 participants, 51 (54 %) responded that vision loss was assessed regularly by an ophthalmologist, and 34 (36 %) responded that it was not. The last 10 (11 %) participants did not provide any response. One participant reported that assessment took place every six months; 10 participants reported every year; 13 participants reported every

second year; and 13 participants reported every 3-5 years. Five participants responded "when needed" and the remaining 9 did not provide any response.

Regarding use of video-analysis/observation for assessment and intervention, 5 (5 %) participants reported that this was used once a month; 13 (14 %) participants reported every three months; 23 (24 %) participants reported every year; and 48 (51 %) participants reported less than once a year or never. Six (6 %) participants did not respond to this question.

Table 1 shows the findings from the analysis, with regard to assessment practice, of gender, age, ADL score, deafblind severity, and receipt of specialized deafblind counselling services. Women were significantly more likely than men to receive regular medical hearing assessment. No gender differences were found with regard to medical vision or video assessment. Regarding age, participants receiving regular medical vision and hearing assessments were significantly younger than those not receiving regular assessment. No significant association was found between age and video assessment. Having better ADL abilities was significantly associated with regular medical vision assessment, but no significant associations were found between ADL score and regular medical hearing assessment or frequency of video assessment. Regular medical assessment of both hearing and vision was significantly associated with less severe deafblindness (that is, the better the vision and hearing, the more likely it is that regular assessment is carried out). No significant association was found between frequency of video assessment and deafblind severity. Finally, those participants receiving specialized deafblind counselling service were significant more likely to receive regular medical hearing assessment and frequent video assessment. However, no significant differences were found with regard to medical assessment of vision.

Table 1

Comparison of regularly medical assessment of vision and hearing and frequency of video assessment with gender, age, ADL abilities, deafblind severity and if the participant received specialized deafblind counselling services

	Assessment		
	Regularly medical assessment of vision (1 = yes)	Regularly medical assessment of hearing (1 = yes)	Frequency of video assessment (range 1-5, 1 = every week)
Variables			
Gender (1 = women)	NS	χ^2 (1, N = 84) = 6.30, p = .02	NS
Age	t(82) = -2.70, p = .008	t(83) = -3.53, p < .001	NS
ADL abilities (range 4-13, 4 = high abilities)	r_τ (N = 84) = .32, p < .001	NS	NS
Deafblind severity (range 4-16, 4 = low levels of vision and hearing losses)	r_τ (N = 67) = .25, p = .012	r_τ (N = 70) = .25, p = .009	NS
Receives specialized deafblind consultant counselling service (1 = yes)	NS	χ^2 (1, N = 81) = 5.81, p = .024	r_τ (N = 85) = .27, p = .003

Discussion

Only one-third of the sample reported regular medical assessment of hearing loss and only about half of the sample reported regular medical assessment of vision loss. The importance of regular medical assessment of vision and hearing has been underlined by a study by Fellinger, Holzinger, Dirmhirn, van Dijk and Goldberg (2009) among 253 individuals with intellectual disability. Before the study's systematic medical assessment of the participants' vision and hearing, deafblindness was only identified in 3.6 % of participants. After the assessment, deafblindness was identified in 21.4 %.

It is noteworthy that gender differences were found with regard to regularity of medical hearing assessment and future research should test for potential gender biases in deafblind rehabilitation. It is surprising that the younger participants were more likely to receive regular medical assessment of both vision and hearing than the older participants because high age is known to be associated with acquired vision and hearing disorders (Dammeyer, 2013). More research is needed in order to test for potential age biases in deafblind rehabilitation and to establish if the assessment needs of elderly people with deafblindness are being met. One reason why having higher ADL abilities was associated with regular vision assessment might be that vision assessment often involves cooperation of the patient. However, this is often also the case in medical hearing assessment, and the level of ADL functioning in this study did not reveal a significant difference. The finding that having more severe degrees of deafblindness was associated with regular medical vision and hearing assessment was also surprising, given that mild and moderate vision and hearing losses might be progressive and because profound deafness and blindness in some cases make medical assessment needless. However, more research is needed where specific information about medical aetiologies of vision and hearing loss are taken into consideration in order to evaluate if some groups of people with congenital deafblindness are not provided with adequate assessment. Those congenital deafblind individuals with severe vision and hearing losses have also been reported to be those with the most deviant and tactile communication and behaviour (Janssen & Rødbroe, 2007) and thus, video assessment might be a significant tool for identification and interpretation. However, this study did not found any significant association between severity of deafblindness and frequency of video assessment. Finally, the finding that those participants who received specialized deafblind counselling support were more likely to receive regular medical hearing assessment and more frequent video assessment is meaningful, because deafblind counselling services are based on the use of regular medical and functional assessment (Dammeyer, 2012). However,

and surprisingly, no association was found between specialized deafblind counselling services and regular medical assessment of vision.

A study by Dammeyer (2012) found that congenital deafblindness was identified in 76 % of a sample of adults by use of functional assessment in addition to medical examination. The study argued that functional assessments are needed because the presence of severe additional disabilities often makes medical assessment difficult to carry out. The study underlines the importance of both regular medical and functional assessment of congenital deafblindness. Regular use of systematic assessment methods by use of video-observation/analysis in educational practice with individuals with congenital deafblindness has been recommended in Denmark as well as other countries (Rødbroe & Janssen, 2006; Nafstad & Rødbroe, 1999, 2013). It is therefore noteworthy that only 41 of the 95 participants in this study reported functional assessment by use of video-observation/analysis at least once a year or more often. This finding calls for a renewed focus on the need for regular medical and functional assessment of deafblindness and how adequate programmes of assessment can be better implemented to improve treatment and educational rehabilitation for all individuals with congenital deafblindness no matter the gender, age, ADL functioning and severity of deafblindness.

More research is needed to understand which factors might be barriers for appropriate assessment for people with congenital deafblindness and how these barriers can be eliminated. Factors of interest, further to those included in this study, might be medical aetiology and staff knowledge about deafblindness and educational background. Another limitation of this study was its cross-sectional design, making it difficult to conclude on the importance of regular assessment. Future studies should investigate if and how regularly medical and functional assessment of deafblindness lead to improved communication and quality of life. More research is needed in order to conclude what works for whom in deafblind rehabilitation.

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Jesper Dammeyer, Dr. Med., *Lektor, Department of Psychology, University of Copenhagen; e-mail: <jesper.dammeyer@psy.ku.dk>.*