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Dammeyer, J., Lehane, C. M. and Chapman, M.

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Sexuality Among Adults with Congenital Deafblindness:

A Cross-Sectional Survey Study Among Primary Carers

ACCEPTED DRAFT

Abstract

Research investigating the sexuality of individuals with physical or intellectual disabilities is increasing. However, little is known about the sexuality of people with congenital deafblindness (CDB). The aim of the current study was to create a profile of the sexuality of adults with CDB in Denmark. Data was collected from the primary carers of 95 adults with CDB by use of a survey with questions about sexual behavior, the object of sexual behavior, level of sexual frustration, and pedagogical support for sexual satisfaction. The data were analysed with regard to gender, age, severity of deafblindness, communication, activities of daily living (ADL), cognitive abilities, and carer characteristics. The results revealed that approximately half the number of participants showed sexual behavior while the other half did not. In the majority of cases, sexual behavior was self-stimulation, while, for the rest, sexual behavior was directed towards other people and/or objects. Around one out of ten participants was provided with pedagogical support to help satisfy their sexual needs. Sexual behavior was significantly associated with high scores for communication skills, ADL, and cognitive abilities. Further, high ADL and cognitive abilities were associated with the provision of pedagogical support for sexual satisfaction. Around one out of ten participants, all of whom were men, experienced sexual frustrations. The findings of the current study—the first quantitative study on sexuality among individuals with CDB—are comparable to the findings of studies among individuals with developmental disorders and underline the need for sexuality-related support for individuals with disabilities including those with CDB.

Keywords: Sexuality, deafblindness, disability, gender, Denmark

Introduction

Congenital deafblindness (CDB) is a rare combination of hearing and vision disorders affecting approximately 1 in 10,000 new-borns [1,2]. Consequences of CDB include significant difficulties with communication, mobility, and mental health. In adulthood, many communicate at a pre-verbal level, cognitive impairment or low function is common, and most are in need of support and care 24 hours a day [3]. Recently, Dammeyer [3] reported that 74 % of a population of adults with CDB have a mental or behavioral disorder of which intellectual impairment (reported among 34%) and psychosis (reported among 13%) were the most common. Although little is known about individuals with CDB in general, there is almost no research-based knowledge regarding how CDB may affect sexual development, an aspect of adult life that is strongly connected to auditory and visual perception. Consequently, information on the sexual behavior of individuals with CDB is warranted in order to enhance support for individuals with CDB and their primary caregivers [4].

Sensory disabilities such as CDB that involve the loss of both hearing and vision from birth are likely to have a profound impact on the development of sexuality. However, the few practice reports that have been published are based solely on case reports. Further, they have focused on two issues: (1) how sexuality-related challenging behaviors pose difficulties for carers and, (2) how the sexual needs and interests of adults with CDB can be supported by social carers [4,5]. Although such reports may be of value to the carers of individuals with CDB, existing research has not provided an overview of sexual behaviors among individuals with CDB and their connection to other factors such as communication and cognitive abilities.

In recent years, disability-related research and practice have become concerned not only with the prevention of sexual abuse and unwanted pregnancies, but also with the rights of people with disabilities to a safe and satisfying sex life [6-8]. Individuals with disabilities typically experience the

same range of sexual needs and desires as other people, however, if adequate support is not provided, their ability to meet these needs may be impeded. Kef and Bos report that blind individuals can have difficulties initiating an intimate relationship and experimenting with sexual behavior [9]. By virtue of their lack of access to the visual and auditory world, and thereby to social sexual norms, individuals with CDB may show very different levels and kinds of sexual behavior when compared to the sighted and hearing population. For instance, Kef and Bos suggested that sexuality development may be different among individuals with blindness because they are less likely to access norms such as non-verbal cues of sexual interest and socio-cultural representations of sexual attractiveness [9]. Robinson also suggested that, unlike their hearing counterparts, individuals who are deaf cannot access auditory-related cues such as the timbre of voice, which relates to socio-cultural norms of attractiveness, and emotional intonation [10]. Existing research therefore suggests that sexuality is experienced and constructed differently among the deaf and blind communities, partly because of divergent access to social norms and cues. Consequently, research on the sexuality of adults with CDB is required to explore how sexuality is experienced and develops in this distinct group.

The study of sexuality development among individuals with CDB involves a number of challenges. One challenge relates to cognitive functioning. Individuals with CDB are often diagnosed with intellectual disabilities [3], which presents difficulties for research and data-gathering that are similar to those involved in the study of sexuality among other groups of individuals with developmental disorders. A further challenge of studying sexuality among adults with CDB concerns language and communication, as individuals with CDB often communicate via touch (i.e. tactile sign language).

These challenges have implications for research methods but they also draw attention to the issues that likely impact sexual development. For instance, tactile communication has possible

implications for sexuality development because touch ignites physiological changes in the human body associated with stress reduction, social bonding and, often, sexual arousal [11,12]. Sensory difficulties that result in differences in terms of environmental awareness and social understandings are also likely to impact sexuality development and may result in sexual behavior that is experienced as challenging by carers and family members. In her review of research on autism spectrum disorder (ASD) and sexuality, Kellaher discussed studies that have explored atypical sexual behaviors, such as object fetishism, among those with ASD and observed that these may be linked to “sensory oddities” and/or “from a lack of sexual knowledge and experience and from poor social skills” [13, p. 25]. Other studies report similar findings. For example, Van Bourgondien, Reichle, and Palmer investigated the sexual behavior of 89 adults with autism in the USA and reported that the majority of participants engaged predominantly in self-stimulating sexual behaviors [14]. The study also found that higher levels of verbal language significantly increased the likelihood that the individuals would show person-oriented sexual behavior.

To summarize, next to a few case reports, research on sexuality among individuals with CDB is limited. Existing research on adults with developmental disorders or single sensory impairment suggests that adults with CDB are likely to develop an atypical sexual profile predominantly involving self-orientated sexual behavior. Further, it may be surmized that individuals with CDB likely experience significant sexual frustration due to isolation from others and perhaps also because of the sensory nature of tactile-based communication.

Methods

Participants

Through The National Knowledge Center for Congenital Deafblindness, questionnaires were sent out to the carers of all known adults (above 18 years of age) with CDB in Denmark. Adults were

identified as having CDB by use of a standardized assessment procedure [15] that followed the Nordic functional 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*” [16]. In total, 123 individuals with CDB were invited to participate. Six individuals did not take part in 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. Thus, 95 adults with CDB were included in the current study. The questionnaire was filled out by the primary carer of the individual with CDB. In the majority of cases (86 %), this was a staff member at the institution where the individual lived. In a few other cases, this was a parent/relative (9%) or other (5%). The person who completed the survey was encouraged to gather information from case records, other carers, and the individual with CDB if possible. This was done in order to ensure the validity of the data. Prior to participation, the individual with CDB or their legal guardian signed a form giving written informed consent.

Measures

Information about sexuality. The first question concerning sexuality was: “Does NN show sexual behavior?”, with response categories ‘Yes’ and ‘No’. If answered yes, the next question was: “Who or what is the object of the sexual behavior?” Response categories were ‘himself/herself’, ‘other people’, ‘objects’. It was possible to respond yes to more than one category. The following question was: “How has NN’s sexual activity changed since young adulthood?”. Response categories were ‘stable’, ‘increased’, ‘decreased’. The next question was: “Does NN experience sexual frustration?”. Response categories were ‘Yes’ and ‘No’. If the response was yes, an additional question asked if the frustration was experienced ‘always’ or ‘periodically’. The final question was: “Is pedagogical support provided so he/she can satisfy his/her sexual needs?”, with response categories ‘Yes’ and ‘No’.

Deafblindness severity. Next to gender and age, information was collected about degree of vision loss in both eyes and hearing loss in both ears. Vision loss was categorized as (1) mild $6/6 > 6/18$, (2) moderate $6/18 > 6/60$, (3) severe $6/60 > 1/60$, and (4) blind $< 1/60$). Hearing loss was categorized as (1) mild < 40 dB, (2) moderate $40 < 70$ dB, (3) severe $70 < 90$ dB, and (4) profound > 90 dB. A total score ranging from 4-16 was calculated indicating severity of deafblindness.

Communicative abilities. Communicative ability was evaluated by use of seven questions. For example, one question was: “Can NN communicate his/her experiences with support?” Responses were rated on a five-point Likert scale ranging from (1) cannot, to (5) can always. A sum score ranging from 7-35 was calculated. The questions were developed for this study and based on a social interaction approach to communication [17].

Activities of daily living (ADL). Four questions were asked about ADL abilities of the individual with CDB, specifically their ability to eat, dress and undress, go to the toilet and take a shower, all without support. Response categories were (1) Yes, (2) Partly, (3) No. A total score ranging from 4 to 13 was calculated.

Cognitive abilities. A modified version of the IQCODE questionnaire for evaluating cognitive decline among the elderly was used to assess cognitive abilities [18]. Questions concerning vision and hearing were omitted, resulting in a final 17 items. Examples are a question that asked about the ability to “remember things about family and friends e.g. occupations, birthdays, addresses” and a question that asked about the ability to “remember where to find things which have been put in a different place from usual”. The response categories for all the questions were (1) True, (2) Somewhat true, or (3) Not true. A total score ranging from 17-51 was calculated.

Information about carers: The questionnaire asked if all, most, some, few, or none of the carers supporting the person with CDB on a daily basis had formal qualifications for working with

people with disabilities (such as a diploma in social work) and/or formal qualifications for working with people with deafblindness (such as a postgraduate diploma in deafblind studies).

Statistical Analysis

Firstly, descriptive analyses (frequencies) of the questions concerning sexuality were generated. Secondly, pairwise Goodman and Krustal's Gamma rank correlation tests between each of the sexuality questions and gender, age, degree of deafblindness, communicative abilities, ADL abilities, and cognitive abilities, respectively, were completed. Pairwise rank correlation tests between each of the sexuality questions and level of formal education working with people with disabilities and deafblindness, respectively, among the carers was also carried out. The Goodman and Krustal's Gamma is a non-parametric test which can be used on ordinal and dichotomous variables (Yule's Q) [19, 20]. The level of significance was 0.05 and SPSS version 22.0 was used for all analyses.

Results

Of the 95 participants, 41.1 % were women ($n = 39$) and the mean age was 40.9 years ($SD = 12.6$, range 19-80 years of age). All participants except three resided at institutions, two resided with their parents and one in his/her own residence. As shown in Table 1, it was found that about half the number of adults with CDB demonstrated sexual behavior. For two-thirds of this group, the object of sexual behavior was the person themselves. For the last third, the object of sexual activity was other people, objects, or a combination of the person themselves, other people, and/or objects.

With regard to whether the sexual activity of the individual with CDB had changed since early adulthood, about two-thirds answered that it had been stable, one out of ten that it had increased, and two out of ten that it had decreased. It was reported for more than 90 percent of the participants that they did not experience any frustrations in relation to their sexuality. For around one in ten of

participants, it was reported that they had been provided with pedagogical support to satisfy their sexual needs.

[Table 1 approximately here]

Table 2 shows the results of the rank correlation analyses between sexual behavior, frustration related to sexuality, and pedagogical support for sexual life, and gender, age, severity of deafblindness, communication, ADL, and cognitive abilities. The analysis found that sexual behavior was significantly associated with having high scores for communication, ADL, and cognitive abilities. With regard to sexual frustration, the only significant difference was found with respect to gender. Men with congenital deafblindness were significantly more likely than women to experience sexual frustration (indeed, all the individuals reported to experience frustration were men). Next, high ADL and cognitive abilities were associated with being provided with sex-related pedagogical support. Finally, no significant associations were found for change in sexual behavior.

[Table 2 approximately here]

Rank correlation analyses between carer education level and the sexual behavior, sexual frustration, and pedagogical support for sexual life of adults with CDB revealed no significant findings.

Discussion

The current study is, to our knowledge, the first quantitative investigation of sexuality among adults with CDB. The finding that many adults with CDB express sexual behavior and engage mostly in self-stimulatory behaviors is similar to that of other studies on the sexuality of individuals with

severe developmental disorders including intellectual disabilities and autism spectrum disorder [13,14,21]. Given the level of social isolation associated with being both deaf and blind, and the prevalence of mental health difficulties, it can be argued that engaging in self-stimulatory behaviors may serve as an anxiety-reducing coping mechanism. For instance, engaging in self-stimulatory behaviors such as masturbation is likely to act as a cognitive distraction while also producing pleasurable physical sensations. For instance, prior research on the sexual behavior of anxious men found that 20.6% of the men in their sample reported greater sexual behavior when anxious. Qualitative follow-up questions confirmed that the men's sexual behavior functioned as a self-soothing or calming coping mechanism [22]. Similar research among women has reported a curvilinear relationship, that is, neither low nor high levels of distress were linked to sexual arousal, however, moderate levels of anxiety were associated with greater sexual arousal [23]. Research on the stress and coping strategies of normally functioning couples has also indicated that, for men in particular, sexual activity is an effective method to reduce stress [24]. Together, these studies indicate that under high distress conditions (which might be the case for many adults with CDB) men may be more likely than women to engage in sexual behaviors in order to alleviate or cope with their distress. This suggestion may provide one explanation for why, in the current study, only men were reported to experience sexual frustration.

Alternatively, however, this gender gap in sexual frustration may be explained by the findings of research on adults with intellectual impairments. For instance, Crocker, Mercier, Allaire, and Roy found that, compared to women, men with intellectual impairments were significantly more likely to engage in overt and aggressive sexual activities, such as genital exposure and touching others sexually [25]. Gilmore and Chambers also report that carers of adults with intellectual disabilities typically view men as having less sexual self-control than women [26]. The results of these studies suggest that two

further factors may need to be considered to explain the gender gap in sexual behavior both in the current study and in other studies on adults with intellectual impairments. First, research suggests that female sexual desire is less spontaneous and apparent than males, and is often contextual and responsive in nature [27]. As such, males may simply demonstrate more sexual behavior or more obviously recognisable sexual behavior than women. The cognitive impairment of females with CBD may diminish their demonstration of sexual behavior more than the cognitive impairment of males with CBD diminishes theirs. Second, gender-based sexual beliefs might be reflected in the carer's perception of the individual's sexual behavior. That is, carers who typically hold the belief that men are more sexual than women may be more likely to recognize and label men's behavior as sexual. In line with this, carers may also be more accepting of men engaging in sexual behavior than of women engaging in sexual behavior. Consequently, it may be useful for future research to consider the role of carers' beliefs regarding gender and sexual behavior, in particular in studies such as this where the carer is the individual completing the survey.

Interestingly, and perhaps attesting to the social nature of sexuality, high levels of both communication and ADL abilities were associated with showing sexual behavior, but not the severity of the participant's deafblindness. This result falls in line with that of a recent review suggesting that multiple social and institutional factors rather than degree of sensory loss tend to explain life outcomes [28]. Thus, it may not necessarily be the loss of one's hearing and vision that has a direct and inhibiting effect on sexuality development, but rather, the restrictions that individuals with CDB experience when attempting to access the social world. This finding may also support the suggestion of Abolfotouh who reported a possible link between social deprivation, mobility, and delayed sexual development among blind and deaf adolescents [29].

The finding that level of cognitive ability was associated with sexual behavior was not surprising given the relatively robust findings from literature that higher cognitive functioning is associated with a greater level of sexual activity and desire for intimacy among people with intellectual disabilities [21,30]. In her study on the sex lives of young people with intellectual disabilities, Löfgren-Mårtenson suggests that the connection between cognitive ability and sexuality may also be influenced by environmental factors such as the attitudes of carers regarding sexual activity and disability [30]. Specifically, Löfgren-Mårtenson suggests that family and institutional caregivers often feel responsible for the sexuality of individuals with intellectual disabilities and take a disciplinary role, potentially restricting sexual development and satisfaction. More recent research has reported that this level of restriction depends upon who the caregiver is and other factors such as the caregiver's age and level of education. The research found that institutional staff members tend to be more supportive of sexuality development. Further, younger staff members and those with higher levels of education were found to be more supportive than older staff members and those with lower levels of education [31,32].

Although, in this study, the level of education among the carers was not related to the sexual behavior, sexual frustration, or pedagogical support for the sexual life of adults with CDB, the care-related restrictions on sexuality development reported by studies on intellectual impairment and sexuality are still likely to occur between adults with CDB and their caregivers and should be studied further in future research. Care-related restrictions could, for instance, provide one explanation for why so few participants in the current study received pedagogical support to enhance the quality of their sex lives.

Together, the findings of the current study indicate that adults with CDB have a comparable sexual profile to adults with other developmental disorders. Similar to research on the sex lives of adults with intellectual disabilities [8], this study's findings suggest that adults with CDB show a lower level of sexual behavior compared to individuals without developmental disorders, that their sexual

behavior is most often self-focused, and that gender differences in sexual frustration exist. While sexuality among adults with CDB is challenging to study and likely difficult for caregivers to support, recent normalisation movements highlighting the right for individuals with disabilities to experience satisfactory sex lives should also be applied to adults with CDB [6,30]. More research is needed to understand how to support both adults with CDB and their primary caregivers in promoting a safe and satisfying sex life when living with CDB.

Strengths and Limitations

As outlined in the introduction, CDB is a very rare condition and samples are typically small [33,34]. One of the strengths of the current study is its relatively large sample of individuals with CDB and high survey response rate. Together, this increases the validity and generalisability of the current findings to adults with CDB. On the other hand, the main limitation of this study is that data were only drawn from carer reports and, as a consequence, may be biased by carer perceptions. Future studies should aim to incorporate carer reports and participants' observations in order to create a more comprehensive overview of sexuality in the context of CDB.

Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent: Informed consent was obtained from all participants included in the study.

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Table 1

Frequency of sexual behavior, orientation, frustration and support among 95 adults with congenital deafblindness

Variable	% (n)
Does NN show sexual behavior:	
Yes	52.7 (49)
No	47.3 (42)
If yes, oriented towards:	
Himself/herself only	65.3 (32)
Other persons only	4.1 (2)
Objects only	6.1 (3)
Himself/herself and others	10.2 (5)
Himself/herself and objects	8.2 (4)
Other and objects	0.0 (0)
Himself/herself, other and objects	6.1 (3)
How has NN's sexual activity changed since early adulthood:	
Stable	69.9 (51)
Increased	9.6 (7)
Decreased	20.5 (15)
Is NN's sexuality associated with frustration:	
Yes, always	2.8 (2)
Yes, in periods	5.6 (4)
No	91.7 (66)
Is NN offered pedagogical support:	
Yes	12.0 (10)
No	88.0 (73)

Table 2

Correlations between sexual behaviour, sexuality-related frustration, and pedagogical support for sexual life on one side, and gender, age, deafblindness severity, communicative abilities, ADL abilities, and cognitive abilities on the other side

	Shows sexual behavior (yes = 1, no = 2)	Sexuality-related frustration (yes = 1, no = 2)	Pedagogical support for sex life (yes = 1, no = 2)	Change in sexual behavior (decreased = 1, stable = 2, increased = 3)
Gender (1 = female, 2 = male)	-.134	-1.000**	-.023	.087
Age (years)	.161	-.247	.162	-.227
Deafblindness severity (high scores profound deafblindness)	.162	-.170	.325	-.084
Communicative abilities (high scores high abilities)	-.364**	.069	-.282	-.044
ADL abilities (high score low abilities)	.358**	.545	.544*	-.107
Cognitive abilities (high score low abilities)	.417**	.370	.351*	-.208

Gamma rank correlation coefficients, * $p < .05$, ** $p < .01$