

Sexuality and Well-Being Among Couples Living with Acquired Deafblindness

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Abstract Sexuality among couples living with acquired deafblindness (ADB) is an untouched research area, although recent research has reported an association between couples' sexual activity and vision and hearing loss, respectively. The aim of the current study was to investigate sexuality among couples living with ADB in Denmark and its association with psychological well-being. Deafblind individuals and their partners ($n = 45$) were recruited from the national institute providing services for the deafblind in Denmark. Partners were asked about sexual activity, reductions in sexual desire and sexual satisfaction over the past year. Both individuals and their partners completed the WHO-5 measure of psychological well-being. Further, information about degree of hearing and vision loss and use of hearing aids was also obtained. Compared to other population based studies, level of sexual activity was low and more participants reported poor psychological well-being. Sexual activity significantly predicted psychological well-being among partners but not individuals with deafblindness. Gender differences were found indicating that sexual activity was important for male partner's well-being but satisfaction with sex life was important for female partner's well-being. Degree of hearing loss and use of hearing aids were also associated with sexual activity and desire among couples where the deafblind individual-partner gender distribution was male–female.

Keywords Sexuality · Well-being · Sensory loss · Deafblindness · Couples · Denmark

Introduction

Despite global increases in the aging population, little is known about sexuality among older adults [1]. Sexuality, as defined by the WHO [2], is a central aspect of being human and incorporates sexual activity, desire, satisfaction, beliefs and functioning. Closely

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connected to subjective well-being, sexuality is thought to be a good indicator of older individuals' physical, mental and emotional health [3].

Aging and Sexuality

Although limited data on the sex lives of older couples exists, a Danish population based study showed that approximately 63.7% of adults aged 58–88 years of age were sexually active [4]. The study further found that 10.3% of women and 7% of men in this age group reported sexual problems in the form of reduced sexual desire. This indicates that older couples may report reductions in desire or functional difficulties which can impede sexual activity overtime. Level of satisfaction with sex life was also investigated [4]. It was found that 68% of women and 56.9% of men were satisfied with their sex lives, and that both satisfaction with sex life and sexual activity were significantly associated with quality of life ratings for men and women. However, a more recent study on the sexuality of older Northern Europeans has reported different figures. Laumann and colleagues found that 12.5% of men aged 40–80 years of age reported reductions in sexual desire, and this figure increased to 25.6% among women in the same age range [5]. The researchers also found that amongst those experiencing reductions in sexual desire, one or both partners are often in poor health. Age and poor health are associated with many aspects of sexuality such as sexual activity, desire and satisfaction [5, 6]. While research on elderly sexuality is limited, research on the sexuality of couples living with specific age-related disabilities is even scarcer [3, 7].

Aging, Sexuality and Disability

Disability acquired in later life can have an impact on the sexuality of older couples [8]. Previous patterns of sexual activity may be disrupted, preferred sexual positions may no longer be possible, role changes may occur redefining the relationship in terms of patient and caregiver as opposed to equal sexual partners [8]. Further, the experience of becoming disabled and the need for assistive devices may also disrupt the individual's sense of personal integrity and harm their sexual sense of self [3, 8]. Understanding sexuality and the sexual implications of specific disabilities for both patients and their partners is important when evaluating the health support needs of older couples [3]. For instance, a study on the sexuality of older Danish patients with diabetes showed that 57.5% of women and 32.2% of men reported reductions in sexual desire [9]. This is a much higher prevalence compared to the population figures reported by Ventegodt [4]. The study further showed that 18.2% of women and 28.7% of men were dissatisfied with their sex lives [9].

Research on sexuality and disability among older couples has tended to focus on disorders with demonstrated sexual implications such as Parkinson's Disease, dementia and diabetes. Overall, these studies have found that the development of a serious health condition has negative consequences for older couples' sex lives [10–12]. To date there have been no studies on the sexuality of older couples living with acquired deafblindness (ADB), a disability which is highly associated with age and whose communication related consequences, next to the hearing and vision loss itself, may affect the core of a couple's intimate relationship [13].

ADB and Sexuality

For those who are diagnosed with both vision and hearing impairments, interpersonal communication and partner relationships can be affected [14–17]. Due in part to the

individual's reduced ability to access information through sight, such as the face of their partner, or sound, such as their partner's voice, deafblind individuals and their partners may encounter relationship and sexual problems that differ from that of other disability groups [18]. The ability to see and hear are inherently related to the way that human sexuality works [19]. For instance, it is often the combination of reciprocal visual and verbal stimulation that incites sexual arousal among couples, the loss of which results in a reduced ability to admire the physical attractiveness of a sexual partner or whisper sweet nothings to one another [18, 20]. The absence or decline of visual and verbal stimulation may pose a challenge for many couples, partners may need to rely more on tactile or olfactory stimulation such as perfume or massage. However, more challenging still may be a couple's need to adapt to these sexual needs, particularly if the previously more active partner becomes deafblind [18].

In addition to a lack of stimulation, hearing and vision loss may indirectly influence both partner's sexual activity and desire as a result of the effort that is needed to communicate effectively on a daily basis. Previous research has shown that both individuals diagnosed with ADB and their communication partners perceive communication as effortful and tiresome [21], which can negatively influence sexual desire and in turn level of sexual activity [22, 23]. Similar to other disability groups, individuals living with ADB are also provided with a number of assistive devices to improve their access to information, communication ability and subsequent quality of life [21]. Yet, the degree to which these devices are relationship enhancing or relationship compromising is unclear. For instance, one study has reported that the use of hearing aids can improve the quality of a couple's relationship [24]. However, a later study found that some partners perceive hearing aids as unattractive and stigmatizing, potentially rendering the targeted relational benefits obsolete [25].

As a group, couples living with hearing and vision impairments may experience significant challenges in their relationship, particularly in the realm of sexuality. Nevertheless, gender specific differences may also exist. For instance, in a study on correlates of sexual activity among older couples, it was identified that the association between sexual activity and vision impairment was uniform across gender; yet, a new finding in the literature showed that hearing loss was only associated with sexual inactivity among men [3]. The authors suggested that hearing loss may affect the communication between hearing impaired males and their female partners, an aspect of the relationship which has been argued to be especially important for female sexuality [3, 26].

Healthcare, ADB and Sexuality

In recent years, physicians and allied health professionals are becoming increasingly aware of the sexual needs of older adults. Regardless, many still perceive sexuality as an attribute of younger relationships and tend to focus more on the medical and functional consequences of disability when presented with older couples [27–29]. For instance, in a study on sexual help seeking behavior among older Northern Europeans, only 6.9% of men and 9.1% of women reported that a doctor had asked them about potential sexual problems in their relationship [30]. Given the associations between subjective well-being, sexuality and sensory impairments in older age, more information regarding sexual activity, desire, sexual satisfaction and their association with both partner's subjective well-being is needed in order to provide healthcare professionals with information to confidently address the topic of sexuality among this distinct population group [8].

The Current Study

In order to address the knowledge gap on elderly sexuality amongst those living with ADB, the aim of the current study was to describe level of sexual activity amongst couples living with ADB and to investigate its association with psychological well-being. Furthermore, continuing from previous literature, the current study also examined associations between sexuality and degree of vision loss, hearing loss and hearing aid use. Gender differences were also examined.

Methods

Participants

Couples whose spouses/partners were at least 50 years of age and had been assessed for ADB according to the Nordic definition [31] were recruited for the current study as a sub-project of a larger study on ADB amongst the elderly in Denmark. In addition, couples were required to be together at least one year and only one partner could be diagnosed with ADB. Participants were recruited through the national service provider for ADB in Denmark (www.CFD.dk). The data collection began in March 2015 at which point there were 513 individuals aged 50 years and above who had a diagnosis of ADB. During data collection, 14 individuals died and 43 individuals were excluded due to severe health conditions such as terminal dementia or somatic illness without consciousness. This formed a target group of 456 individuals with ADB. It was unknown how many were in a relationship, thus all individuals were sent both the ADB and partner postal surveys. In total, 302 completed and returned the ADB survey, of which 67 reported that they were in a relationship. Of those who were in a relationship and replied, two were excluded as they were both diagnosed with ADB. This left a target group of 65 couples. Of these 65 couples, two partners denied to participate, one partner was unable to complete the survey due to illness, and 17 did not reply. In total, 45 (69%) of the couples who met the inclusion criteria returned both partner surveys.

Measures

Sexuality

For the purpose of this study we used sexual activity, reductions in sexual desire and satisfaction with sex life to define our participant's sexuality. Sexuality related items were only asked in the partner's questionnaire. This was decided as individuals with ADB were assisted by their partner when completing the survey which may have increased the risk for discomfort or social desirability. In addition, previous studies on sexuality and disability among couples have reported a high level of agreement between spouses' reports of sexual activity [32]. In order to use items already validated for an elderly Danish population, we used the items used both by the national health survey and Ventegodt's population based study [4, 33]. A couple's sexual activity was measured using a yes/no response to the item "Are you currently sexually active with your partner?". Sexual activity was not specifically defined to allow for differing sexual orientations and perceptions of sex. Satisfaction with sex life was measured using a 1 (very unsatisfied) to 5 (very satisfied) scaled response

to the item “How satisfied have you been with your sex life in the past year?”. Reduced sexual desire was measured from 1 (yes, all the time) to 5 (no, never) according to the item “In the last year, have you experienced a decrease in your sexual desire?”.

Psychological Well-Being

The WHO-5 [34] measures current psychological well-being. It contains five items referring to positive well-being such as how often over the past two weeks an individual has “felt cheerful and in good spirits”. Answer categories range from 5 (all of the time) to 0 (at no time). Higher scores indicate better psychological well-being. The scale cut-off point is 13. Scores lower than 13 indicate poor well-being and the need to assess for depression. The WHO-5 has been validated for use with middle aged and older populations, and in the Danish context [35, 36]. The WHO was completed by both partners.

Statistical Analysis

Chi square tests were used to test associations between sexual activity and degree of hearing loss, vision loss and use of hearing aids amongst the couples. Associations between sexual activity, reductions in sexual desire and sexual satisfaction were also investigated using Chi square tests. Secondly, hierarchical linear regression analyses were used to test whether sexual activity was associated with the psychological well-being of individuals with ADB and their partners, respectively. Age and severity of vision and hearing loss were added as covariates in both models. Finally, gender effects were investigated by running Spearman Rank order correlations separately for male and female individuals and partners. Statistical significance was set to $p < .05$. Analyses were performed using SPSS for Windows version 22.0.

Respondents versus Non-respondents

Respondents did not differ from non-respondents with respect to age, psychological well-being or severity of vision loss. Severity of hearing loss was the only factor in which the groups differed, that is, couples wherein both partners participated were more likely to have worse hearing than couples wherein only the individual with ADB participated $X^2(3) = 10.71, p < .05$.

Results

Associations Between Sexuality and Vision Loss, Hearing Loss and Hearing Aid Use

Sample characteristics are presented in Table 1. In total, 51.1% of the partners reported that they were not currently sexually active with their partner, 42.2% were sexually active and 6.7% did not provide an answer. A total of 55.6% of partners reported at least some reduction in sexual desire, 8.9% reported no reduction in sexual desire and 35.6% did not provide an answer. With regard to satisfaction with sex life, 22.2% reported some level of dissatisfaction with their sex life, 20% were neither satisfied nor dissatisfied, 42.2% reported being satisfied with their sex life, and 15.6% did not provide an answer.

Amongst the couples, sexual activity was not found to be associated with degree of vision loss $X^2(3, 42) = 5.27, p = .15$, hearing loss $X^2(2, 42) = 2.08, p = .35$, or use of hearing aids $X^2(2, 40) = .19, p = .91$. A Chi square test indicated that sexual activity was associated with both reductions in partners' sexual desire and sexual satisfaction, in that, partners who were sexually inactive were more likely to report reductions in sexual desire and sexual satisfaction, $X^2(4, 28) = 10.76, p = .03$, and $X^2(4, 36) = 10.2, p = .04$, respectively.

With regard to psychological well-being, 27% of partners and 24% of ADB individuals scored below the WHO cut-off point indicating poor psychological well-being. Transforming the WHO-5 scores into percentage scores, two single sample t-tests were conducted to determine whether the mean psychological well-being scores of ADB individuals and their partners were significantly lower than that of the Danish population mean [37]. The psychological well-being of ADB individuals ($M = 63.18, SD = 22.75$) was significantly lower than the mean population WHO-5 score ($M = 70$); $t(44) = -2.26, p < 0.05$. Similarly, the psychological well-being of partners ($M = 64.71, SD = 20.95$) was also significantly lower than the population mean $t(44) = -1.69, p < 0.05$.

Sexual Activity and Psychological Well-Being

The first hierarchical linear regression model was generated to test whether sexual activity was associated with ADB individual psychological well-being while controlling for the potential effects of age and severity of vision and hearing loss. In the first block, results showed that neither age nor severity of vision and hearing loss $F(3, 37) = .099, p = .96$ were associated with psychological well-being. In the second block, sexual activity $F(4, 36) = .304, p = .87$ was also not associated with psychological well-being.

Next, the second hierarchical linear regression model was conducted, and similar to the first model, the results showed that in the first block neither age nor severity of vision and hearing loss $F(3, 36) = .116, p = .95$ were associated with partner psychological well-being. However, in block two, both age and sexual activity $F(4, 35) = 5.41, p < .05$ were associated with psychological well-being. Sexual activity ($\beta = .822, t(39) = 4.59, p = .000$) had a strong association with psychological well-being and so had age ($\beta = .546, t(39) = 3, p = .005$). The addition of sexual activity in block two accounted for 31.1% of the variance in psychological well-being.

Gender Differences

Male Individuals: Female Partners

A Spearman's rank-order correlation was run to determine the associations between sexual activity, severity of hearing loss, severity of vision loss, hearing aid use and psychological well-being among couples where the individual with ADB was male and partner was female. A negative correlation was found between sexual activity and severity of hearing loss $r_s = -.549, p < .05$, indicating that male individuals who were not sexually active were more likely to have severe hearing loss. Reductions in the partner's sexual desire was positively associated with hearing aid use $r_s = .651, p < .05$, indicating that female partners were less likely to report decreases in sexual desire if their partner wore hearing aids. Partner rated satisfaction with sex life was positively associated with partner psychological well-being $r_s = .568, p < .05$, indicating that female partners who were more

Table 1 Sample characteristics (n = 45)

	Partner	ADB individual
Gender (%)		
Male	44.4	55.6
Female	55.6	44.4
Age		
Mean (SD)	69.21 (12.02)	71.71 (11.74)
Length of relationship (years)		
Mean (SD)	41.25 (17.46)	–
Time since ADB diagnosis (years)		
Mean (SD)	–	20.29 (16.23)
Severity of hearing loss (%)		
Profoundly deaf	–	6.7
Severe hearing loss	–	64.4
Moderate hearing loss	–	28.9
Slight hearing loss	–	0
Severity of vision loss (%)		
Blind	–	8.9
Severe vision loss	–	64.4
Moderate vision loss	–	22.2
Slight vision loss	–	4.4
Hearing aids (%)		
Use hearing aids	–	86.7
Do not use hearing aids	–	13.3
Sexual activity with partner (%)		
Sexually active	42.2	–
Sexually inactive	51.1	–
No response	6.7	–
Psychological well-being		
Mean (SD)	16.18 (5.24)	15.8 (5.69)
Possible range	0–25	0–25
Actual range	2–25	3–25
Alpha	.89	.87

satisfied with their sex lives also scored higher on psychological well-being. No other significant associations were found.

Female Individuals: Male Partners

Similarly, Spearman's rank-order correlations were completed where the individual with ADB was female and the partner male. A positive correlation was found between sexual activity and partner psychological well-being $r_s = .569$, $p < .05$, indicating that male partners who were sexually active had higher well-being scores. Sexual activity was also positively correlated with reductions in partner's sexual desire $r_s = .644$, $p < .05$, indicating that male partners who were sexually active were less likely to report reductions in sexual desire. No other significant associations were found.

Discussion

Despite the preliminary nature of the current study, we found that, in comparison to the general population [4], there is a much larger percent of sexual inactivity among older couples living with ADB. Moreover, sexual activity was found to be associated with partners' reports of reductions in sexual desire and satisfaction with sex life. Among those who replied, partner satisfaction with sex life and reductions in sexual desire also significantly differed from the figures in the general population [4, 5]. While Ventegodt and Laumann stated that 8.7 and 19.1% of their participants reported reductions in sexual desire, respectively; the current study found that 55.6% of partners had experienced at least some reduction in sexual desire in the past year. Further, compared to the figures reported by Pedersen and colleagues [9] regarding reductions in sexual desire among diabetes patients, the current sample of partners still reported more problems with sexual desire. Level of satisfaction with sex life was also significantly lower than previously reported figures, with 42.2% of this study's partners reporting some degree of satisfaction with their sex life compared to 62.5% among Ventegodt's sample [4]. These findings indicate that older couples living with ADB experience sexuality related issues.

To further demonstrate the importance of sexuality among older couples living with ADB, the results of the current study showed that, even when controlling for age and impairment severity, sexual activity was significantly associated with the psychological well-being of partners. This finding is of interest given that many of the participants in the current study were found to have poor psychological well-being. Although this association was not found for the psychological well-being of individuals with ADB, the results may indicate that when faced with a disability such as ADB, maintaining sexual intimacy may be a protective factor for the partner's psychological well-being. This has also been reported among couples wherein one partner has had a stroke, in that, the partner's level of depression was found to be associated with the patient's post-stroke sexual functioning [32].

In general, the current study found that neither degree of vision loss nor degree of hearing loss were associated with couples' sexual activity. However, this association changed once the results were viewed according to the couple's individual-partner gender distribution, namely, whether the individual with ADB was male or female. From a gender perspective, the results of the current study partially support that of Bach et al. [3]. While no general association between vision loss and sexual activity was identified, in the current study, sexual activity was associated with hearing loss when the gender distribution was male–female. Thus, these results may indicate that the communication-related consequences of hearing loss may have a larger impact on the sexuality of female partner's than males [3]. This is an important finding which should be investigated in future studies.

In addition to the association between male hearing loss and female sexuality, previous studies report conflicting findings with regard to the use of hearing aids and its effect on older couples' personal lives. While Stark and Hickson reported that the use of hearing aids can benefit a couple's relationship [24], Wallhagen found that some couples find hearing aids unattractive and stigmatizing [25]. Neither study specifically examined the association between hearing aids and sexuality; however, the results of the current study are more in support of the finding by Stark and Hickson, in that, hearing aid use may buffer against reductions in sexual desire among female partners. Together these results indicate that more severe hearing loss may negatively impact the sexual relationship between men with

ADB and their female partners but that the use of hearing aids may be a potential protective factor against negative sexual consequences.

Another interesting finding in relation to gender was that sexual activity was associated with psychological well-being among male partners, but it was degree of satisfaction with sex life that was associated with psychological well-being among female partners. This partially contradicts Ventegodt [4], who reported significant associations between satisfaction with sex life, sexual activity and quality of life among both males and females. While research has yet to examine why there are gender differences among couples living with ADB, previous research argues that men and women have different levels of sexual desire and that sexual activity is more strongly associated with men's well-being [38, 39]. As such, men may feel more psychologically distressed than women if the onset of an illness further reduces their partner's sexual desire. Nevertheless, it is important to consider, particularly for health professionals, that reductions in sexual desire and level of sexual activity do not necessarily imply that individuals will be dissatisfied in their sexual relationship. Regardless of whether a couple is sexually active or not, whether they have experienced reductions in desire or not, they may still be quite satisfied with their sex life. For instance, previous studies have shown that among older couples, and particularly those living with illness, the need for sexual intimacy may not be as important for well-being as the expression of affection such as kissing and holding hands [40–42]. In the context of ADB where the individual may benefit more from tactile stimulation and touch based affection, it may be the case that level of physical affection between the partners is a stronger determinant of psychological well-being. Future studies considering the role of love and affection in addition to sex may be able to explain further the current findings in relation to gender and sexuality.

Limitations

Although this study has reported a number of interesting findings, the limitations associated with having a small sample size and using a cross-sectional design must be considered. More specifically, the cross-sectional study design cannot determine whether any of the associations are causal, for instance, the question of whether sexual activity enhances psychological well-being, or whether couples who are doing better psychologically have more sex, cannot be answered from the current data. Furthermore, this study suffers from a risk for both type one and type two errors as the small sample size may have restricted the ability to reach statistical significance, while multiple testing may have increased the likelihood of reaching significance. However, while it may not be possible to make generalizations from the current study, the results nevertheless provide a valuable indication of a connection between sexuality and psychological well-being among couples living with ADB. Larger and longitudinal designs as well as more in-depth qualitative studies are needed to determine the direction and strength of associations. Finally, many of the partners did not respond to the questions regarding satisfaction with sex life and reductions in sexual desire. This may be a reflection of the sensitive nature of this topic amongst this group, therefore, future studies aiming to further explore sexuality amongst couples living with ADB should be mindful to address this topic in a sensitive manner.

Irrespective of the recognized limitations, this is the first study to focus on sexuality among older couples living with ADB and the results indicate that the experience of ADB may have an impact on older couples sexual relationships. Thus, it can be recommended

that healthcare professionals should consider the importance of sexuality when consulting with couples living with ADB. Future studies are needed to develop a more comprehensive picture of the sexual experiences of older couples living with ADB and to provide guidelines for health care professionals on how to approach the topic of sexuality among such couples.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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. The ethical approval number for the current study is 2015/02.

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

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