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Caregiver Perceptions and Implications for Sex Education for Individuals with Intellectual and Developmental Disabilities

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Abstract Caregivers are important to the educational experiences of individuals with intellectual and developmental disabilities. Sexuality is an area of concern for many caregivers and parents. This study explores the relationship of caregiver perception of sexuality of individuals with intellectual and developmental disabilities, the caregiver perception of agency support for sex education, and their perception of their ability to participate in a sex education program designed specifically for individuals with intellectual and developmental disabilities.

Keywords Caregiver · Intellectual disability · Developmental disability · Sex education · Agency support

Introduction

Experience is often the basis of decisions, including decisions about how to act on one's sexuality. According to Lunsky and Konstantareas [1] feelings of sexuality are important to the physical, mental, and social health of the individual. Sexuality defines how individuals interact with others, what relationships are developed, how love and affection are demonstrated, and how individuals feel about their bodies. Unfortunately, sexuality for the individual with an intellectual disability (ID) is often shaped by inaccurate information and unpleasant experiences. The message from the most important persons in an ID individual's life, the parent or caregiver, implies that sex is bad. This message is internalized by the individual with ID [2].

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Studies conducted by Shepperdson [3] and Halstead [4] identified the importance of the caregiver beliefs toward sexual experiences and marriage of individuals with ID and the influence that these beliefs exert toward the developmental of sexual identity. Caregivers agreed that experience was important to the development of social skills, but individuals with ID were rarely left alone and had limited exposure to situations that might lead to a friendship or sexual relationship outside of their immediate environment. In this climate, decision-making skills regarding good and bad social relationships cannot develop.

McCabe [5] and McConkey and Ryan [6] identified that education strengthens the resources of individuals with ID, providing them with the tools needed to integrate into their community successfully. Caregivers are important to this integration, aiding the development of appropriate personal space and the recognition of appropriate and inappropriate behaviors that cross the personal space boundary of individuals with ID and others.

Sexual misinformation, deliberate or not, has led to denying this segment of the population the opportunity to achieve their full potential as sexual and social members of society. By denying individuals with ID the opportunity to learn about their sexuality and develop social relationships with others, society has denied them the right to self-fulfillment [7].

Wolfensberger [8] wrote that the individual with profound ID had a reduced sex drive. Reid [9] later wrote that sex drive in the profound ID was not uncommon. The ID population is vulnerable to abuse and exploitation due to their inability or lack of experience to make good social choices. The societal view of this vulnerability for abuse has been to deny its existence. The individual with ID has been denied their right to sexual feelings and has been pictured as a perpetual child who is protected. Society holds to the myth that the individual with ID has not developed an interest in their own sexuality or the sexuality of others.

As a result of this denial and lack of attention to develop sexual skills in the individual with ID there has been the increased risk of harm placed upon the ID population. Society tolerates this abuse risk. As individuals with ID are exposed to sexual experiences their reactions to those experiences create the pattern for future relationships. Women with ID who experience sexual abuse often do not recognize the abuse. If they do recognize the abuse they are discouraged from reporting.

Studies suggest that 39–60% females with ID and 16–30% of males with ID are more likely to be victims of sexual abuse by age 18 years when compared to the “normal” population [10–13]. Ward et al. [14] found that males who had experienced sexual aggression may begin to then hurt others. This study reports that 10–40% of these individuals may be involved in sexual offenses, but not charged with a crime nor convicted due to inability to help with own defense.

Education is the mechanism to promote the ability to make of good choices and empower the individual with ID. Decision making skills will enhance the individual’s ability to make choices based on knowledge and then reinforce the decision to act for the good of one’s health and well-being. Education will not only contribute to reducing vulnerability but also contribute to the reduction of inappropriate sexual expression [15–19].

The belief held by the ID community is that individuals with ID can, with support and practice, learn to make decisions and build relationships based on a common language to relay these decisions. Individuals with ID need to be allowed to participate in the decision related to their lives. Parents, professional service providers, and healthcare professionals have identified the need for sex education. Education does improve knowledge and impact decision-making skills and sexual behaviors. Current sex education courses do not utilize

information identified by individuals with ID as helpful in the development of sex education programs. Current courses, designed for the general population, are made to fit the ID population. Individuals with ID have limited sexual knowledge and limited formal or informal resources to gain this knowledge [20].

Little research has been conducted related to the influence of caregiver on positive sexual outcomes for individuals with ID. Historically the literature portrays the individual with ID in a negative position related to sexuality by using such terms as vulnerable, victims, and perpetual child. The literature does support high levels of sexual abuse.

Individuals with intellectual disability identify interest in sexuality and confirm the importance of parent and caregiver involvement in education programs. Caregivers are important to the development of positive sexuality for individuals with ID. Caregivers hold ambivalent feelings toward sexuality. Caregivers acknowledge the sexual needs of ID individuals, yet maintain a protective perpetual child stance. The theory of reasoned action and planned behavior assumes that individuals are rational and can make use of information available to them. Behavior is influenced by attitude. Behavior and attitude change can occur though influences of knowledge and implications of actions [21]. The normalization theory acts as an underlying guide to frame this study to future research projects. The manner in which people are perceived and treated will in turn, affect the way they perceive themselves and the way they behave in response to their societal environment [22].

Research Questions

The research questions explored in this study were:

1. What is the relationship between the caregivers' attitude of sexual behaviors and their perception that the agency will support a sex education program?
2. What is the relationship between the caregiver's attitude of sexual behaviors and their perception that they can participate in a sex education program?
3. What is the relationship between the caregiver's attitude of their ability to participate in a sex education program and their perception of agency support for a sex education program?

Methods

The research design for this study is a descriptive survey. The setting was the city of Anchorage, Alaska, a diverse community with a mix of numerous ethnic groups, ages, religions, and abilities and disabilities. The sample for the study was drawn from three agencies that provide services to the ID community. Inclusion criteria included caregivers who provide direct services to individuals with ID. Exclusion criteria were staff at participating agencies that did not provide direct services to individuals with ID.

Sampling Plan

The sampling plan was a purposive convenience sample. A power analysis revealed the need for 84 participants for a medium effect. The survey was administered to 160 participants. Eighty-seven were returned with 85 being complete.

Instrument

Two tools were utilized for this survey. The Perception of Sexuality Scale (POS) developed by Scotti et al. [23], was used to measure perception of sexual behaviors. This instrument has been used in several studies [24–30]. The instrument consists of a Likert scale with 28 items measuring perception of appropriateness of sexual behaviors. A score of one denotes behavior is absolutely inappropriate and a score of 5 denotes absolute appropriate behavior. The instrument also measure seven areas of sexual behavior: private display of affection, public display of affection, safer sex, same sex partners, prolonged public kissing, different gender partners, and risky sex. A test–retest reliability done before the study indicated at reliability score of 0.95. The Cronbach's alpha score for this study was 0.905.

The second tool was a demographic questionnaire. Two additional questions were included on the demographic tool to gather data on two of the variables of interest. The first question was used to gather data regarding participants' perception of their ability to participate in a sex education program, while the second question was used to measure their perception of agency support of such a program. The investigator conducted an evaluation of the reliability of the two questions using the test–retest method. The reliability measure is 0.92 for question one and 1.00 for question two. The demographic instrument was pretested with a small sample of caregivers to ensure clarity and readability. Needed changes identified in the pilot study were integrated into the final instrument.

Procedure for the study included approval from the University of Alaska Anchorage and the Walden University IRB. The survey was distributed to the three local agencies that serve the ID population. The surveys were placed in the staff mailbox for those staff that provided direct client services. To avoid presentation bias the distribution was such that every other survey distribute asked the participate to first rate their perception of their own or peers sexual behaviors then the behaviors of the ID population, the other survey format asked for the rating of the ID population first then self or peer behavior. Return of a completed survey implied consent.

Results

The purpose of this study was to determine the correlation between perception of sexuality and perception of ability to participate in sex education classes aimed at the ID/DD population. It is a follow up report of a study conducted by Swango-Wilson [31] regarding caregiver perception of sexuality of the ID/DD population.

Research question 1: What is the relationship between the caregivers' attitude of sexual behaviors and their perception that the agency will support a sex education program? A Spearman rho correlation was computed to analyze the relationship between perception of agency support for sex education and POS of the ID population. The answer was determined by comparing the POS scores for the individual with ID to the caregiver's perception of agency support for sex education (Swango-Wilson). No significant relationship was found ($r = .182$; $p = .05$) for agency support of sex education and perception of sexual behaviors for the ID population. A weak ($r^2 < .25$) positive correlation was identified between perception of sexuality of the ID population and agency support of sex education. Three percent of the variance in perception of agency support for sex education ($r^2 = .033$) was related to the perception of sexuality of the ID population. To avoid a

Type I error related to multiple dependent variables on the independent variable a MANOVA calculation was done. A one-way MANOVA was calculated to evaluate the effect of the seven sexual behavior areas for the individual with ID and caregiver perceived agency support for sex education. No significant effect was found (Lambda(28,261) = .636, $p > .05$). None of the seven sexual behavior areas significantly influenced perceived agency support for sex education. The relationship between perceived agency support and same sex partner found in the Spearmen rho calculation is rejected.

Research question 2: What is the relationship between the caregiver's attitude of sexual behaviors and their perception that they can participate in a sex education program? To test the theoretical concept of perceived control the POS scores for the sexuality of the ID population were examined in relation to the data related to the participant's perception of the caregiver's ability to participant in a sex education program. A Spearman rho correlation was calculated to determine the existence of relationship of these two variables.

A significant relationship, between the variables ability to participate in a sex education program and perception of sexual behaviors for the ID population was found ($r = .326$; $p < .01$). There was a weak ($r^2 < .25$), positive correlation between perception of sexuality and ability to participate in a sex education program. Ten percent of variance of perception related to ability to participate in sex education class ($r^2 = .106$) is related to perception of sexuality of the ID population. Spearman rho correlation was conducted to determine if there was a relationship between perceived ability of the caregiver to participate in sex education for the intellectually disabled and a sexual behavior of the individual with ID. Table 1 summaries this data.

The data indicates that there is a significant relationship $p < .001$ for the behaviors of safe sex and same sex partner. A significance of $p < .05$ was identified for anal sex and prolonged public kissing. All correlations were weak in a positive direction. The data indicated that 6.9% of variance in perceived ability to participate in sex education is related to safe sex; 13.9% of variance is related to same sex partner; 4.5% variance related to anal sex; and 6.3% related to prolonged public kissing.

To avoid a Type I error related to multiple dependent variables on the independent variable a MANOVA calculation was done. A one-way MANOVA was calculated to evaluate the effect of the seven sexual behavior areas for the individual with ID and caregiver perceived ability to participate in sex education. A significant effect was found (Lambda(28, 296) = .572, $p < .05$). A univariant ANOVA identified that the variables: anal sex ($F(4, 77) = 1.57, p > .05$); risky sex ($F(4, 77) = .36, p > .05$); public display of affection ($F(4, 77) = .43, p > .05$); private display of affection ($F(4, 77) = 1.27, p > .05$); and prolonged public kissing ($F(4,77) = 1.41$, $p > .05$), did not significantly influence caregiver perceived ability to participate in sex education classes. Variables found that did significantly influence perceived ability to participate in sex education classes were: safe

Table 1 Correlation between perceived ability of caregiver to participate in sex education and perceived appropriateness of sexual behaviors of individuals with ID

Ability	r	r^2	p
Safe sex	.263	.069	.008
Anal sex	.212	.045	.028
Risky sex	.094	.009	.200
Same sex partner	.374	.139	.000
Public display of affection	−.044	.002	.346
Private display of affection	.067	.004	.275
Prolonged public kissing	.251	.063	.012

For all categories $N = 82$; $r^2 < .25$

sex ($F(4, 77) = 3.09$, $p < .05$) and same sex partner ($F(4, 77) = 4.92$, $p < .01$). This disproves the correlation significance found for anal sex and prolonged public kissing causing the rejection of this relationship. The significance of influence of the variables safe sex and same sex partner is confirmed.

Research question 3: What is the relationship between the caregiver's attitude of their ability to participate in a sex education program and their perception of agency support for a sex education program? A Spearman rho correlation was used to examine the data in a manner that would answer this question. The answer was determined by subjecting the scores for perceived ability to participate in a sex education program for the individual with ID and the participant's perception of agency support for a sex education program. A significant relationship was found, between the variables perceived ability to participate in sex education and perceived agency support ($r = .493$; $p < .01$). There was a weak ($r^2 < .25$) positive correlation between perceived ability to participate in sex education and agency support for sex education. Twenty-four percent of variance found in perceived ability to participate in sex education class ($r^2 = .243$) is related to perception of agency support for sex education.

Discussion

Eighty-seven participants completed surveys for this study representing a return rate of 55.4%. The ages of the participants ranged from 18 to 59 years. Their experience with the ID community ranged from less then a year to more then 5 years. The majority of the participants identified their relationship as caregivers ($n = 81$), parent ($n = 3$), both parent and caregiver ($n = 2$), and unknown ($n = 1$). There were 21 males and 66 females completing the survey.

The data indicates a significant relationship between attitude of sexual behavior of the ID population and perceived ability of caregiver to participate in a sex education program. A significant relationship was identified for the specific behaviors of safe sex and same sex partner. The nature of this relationship appears to contradict the theory of planned action. A lower perception of sexuality does not relate to a lower perception of ability to participate. This data does support the dissonance found in studies by Lofgren-Martenson [32] and Cuskelly and Bryde [24].

There was a significant difference found between perception of caregiver's ability to participant in sex education and perception of agency support of sex education. A weak positive correlation was identified between the two variables. This does support the concept of social norm, as social support is evident and ability and intention to perform is affected in the positive direction. Caregivers perceive that they are able to participate in sex education classes but rank the perceived appropriateness of sexually behaviors of individuals with ID as uncertain. This dissonance can influence the quality of interaction caregivers have with the ID community.

Support for caregivers as they introduce the individual with ID into full community membership is implicated. Caregivers need support to increase their understanding and perception of the sexual nature of the ID population. Caregivers need support in their efforts to fully integrate individuals with ID into the social communities as fully contributing members.

The findings from this study support the need to provide information and support to caregivers as they attempt to participate in sex education programs designed for people with ID. Specific areas of sensitivity toward caregiver needs are safe sex and same sex

partner issues. Further research is needed to determine how attitudes on these two variables influence caregiver action.

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