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ORIGINAL PAPER

Relationships and Sexuality: How is a Young Adult with an Intellectual Disability Supposed to Navigate?

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Abstract Individuals with intellectual and developmental disabilities have historically not had access to sexual education curriculums. Furthermore, while parents are often hesitant to provide instruction themselves, all stakeholders acknowledge that this population is at a high risk for sexual abuse. This population does have sexual feelings and the desire to have relationships with others. Therefore a need for accurate information on this topic to stay safe and healthy is imperative. This study focused on evaluating a curriculum over 3 years, with a total of 53 participants with a mean age of 20.68 years old. The curriculum included topics on relationships and boundaries, anatomy, sexual intercourse, sexual transmitted infections, and abuse red flags. The results include statistically significance for pre and posttest for the intervention groups, with no significance for the control group. Interviews with participants reveal socially validity of the topics. The discussion section highlights the importance of this subject for the participants and underscores the demand for additional replication. Future research should consider assessments and maintenance of skills learned.

Keywords Intellectual disability · Inclusive postsecondary education · Sex education · Relationships · United States

Introduction

Embracing sexuality is an organic and gratifying part of life. The Sexuality Information and Education Council of the United States (SIECUS) defines sexuality "as multifaceted, having biological, social, psychological, spiritual, ethical, and cultural dimensions" [7, 17]. Individuals with intellectual and developmental disabilities (IDD) are human beings who

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have generally been deprived of the ability to express their sexuality or participate in sexual relationships. Comprehensive sexuality education empowers individuals with IDD to enjoy personal sexual fulfillment and protect themselves from abuse, unplanned pregnancies, and sexually transmitted infections [6, 13].

This population typically does not have access to sex education [14, 15]. Some reasons for the lack of exposure include the social misconceptions/myths that portray individuals with disabilities as incapable of being sexually active, as unable to understand the intricacies of sexuality, or even refute the existence of sexuality as a part of their lives [13]. Another explanation for these fallacies may be the assumption "that adolescents with moderate disabilities could not participate in education to attain the skills that would lead to any acceptable form of quality of life" [9, p. 18]. Unfortunately, these myths often deny individuals with intellectual disabilities equal access to sexuality education that could help this population to lead a fully independent and fulfilling life inclusive of their sexuality [18]. Bernet and Ogletree [1] discredits such myths. This study found participants revealed a minimal awareness of self-determination in their sexual behavior. However, the overall negative perceptions fueled by fear of intercourse and/or intimacy caused self-imposed abstinence and adverse perceptions of sexual development. Furthermore, central to the participants' sex education expansion was needed to improve self-efficacy perceptions and implementation of safer sex practices to avert negative sexual consequence.

Literature Review

Historically, as noted in a literature review of twelve sex education curriculums, Blanchett and Wolfe [2] found that sexuality education was rooted in having teachers integrate sexuality education into existing curriculums. In other words, the curriculums were part of independent living lessons. In fact, qualitative interviews from a study by Lofgren-Martenson [10] found that sexuality is a subjective vehicle, culturally created to discuss bodily function versus the romantic relationship and safety for individuals with IDD. Clearly more research needs to be conducted to elicit effective interventions and determine best practices.

Both information and types of educational strategies (as noted below such as modeling and role-playing) may be needed to have a successful intervention for the IDD population. Sinclair et al. [18] conducted a literature review on barriers to sexuality for individuals with IDD. One theme they noted was the lack of sexuality knowledge. Schaafsma et al. [16] identified effective methods for teaching sex education to individuals with IDD. Their review of 20 articles that discussed the effectiveness of sex education programs for this population shows a lack of description of the teaching methods used in these curriculums. However, they were able to identify modeling, role-play, rehearsal, and practice of skills as to be the most beneficial types of teaching techniques. Therefore, teaching the skills in isolation is just as important as practicing the skills in a variety of formats.

In addition to the need for specific teaching methods and providing content, there are findings that strongly suggest published curricula currently in use, have little empirical support for teaching sexuality to people with significant disabilities [19]. Due to the sensitive nature of the topic, the vulnerability of the population, and students aging out of K-12, more time and larger sample sizes to conclude reliability and replicability in the research studies is often difficult to ascertain. Therefore a need for evidence based empirical research methods that include pre-post designs, single subject design, and social

validity via interviews will provide data to determine broad based efficacy of the curriculums [5, 8, 16].

Positive choices is a program designed to teach skills and increase judgment about healthy relationships, sexuality, and safe boundaries for secondary students with IDD [6]. Positive choices was created with guidance from an advisory board of self-advocates, parents, educators, clinicians, and administrators. By becoming informed about sex education curriculum and program design, stakeholders (teachers and administrators) in education can make more knowledgeable decisions on how to teach sexuality to young adults with ID/DD concerning sexuality, intimate social situations, and sexual relationships. The purpose of the current study was to evaluate the effectiveness of positive choices. Specific research questions are:

1. Will there be a significant difference between pretest and post-test for the experimental group in knowledge gained in the area of sex education?
2. What thoughts will the participants of the intervention group have regarding the usefulness of this curriculum and topic on their personal lives?

Methods

Setting

This study was conducted at an inclusive postsecondary program for students with IDD at an urban east coast university over the course of 3 years. The program includes 55 students ages 18–27. The program is a comprehensive transition program that focuses on functional academics, employment, residential/independent living skills, and auditing university classes.

Participants

Participants for the first intervention group included all first year students taking the human growth and development (HGD) class. For the control group, 2nd, 3rd, and 4th year students who had taken the class as first year students, but were taught with a different curriculum, were recruited. Participants for the second and third intervention groups included all first year students. There was no control for the second and third year intervention groups. All participants were recruited by the researchers inviting them to participate, and they signed a consent form written in simplified English, that was read aloud to them.

The first phase control group had 12 participants with a mean age of 22.1 (SD 21.9) years old. The group was comprised of 33.3% males and 66.6% females and included intellectual disabilities (ID) (83.3%) and other (16.7%) disabilities. Control group participants ranged in years of the program with 41.7% being 2nd year students, 33.3% being 3rd year students, and 25% being 4th year students. The intervention group in the first phase had 13 participants with a mean age of 20.7 (SD 1.44) years old. The group comprised of 46.2% males and 53.8% females and included ID (76.9%) and autism spectrum disorder (ASD) (23.1%) disabilities.

The intervention group in the second phase had 12 participants with a mean age of 20.8 (SD 1.66) years old. The group comprised of 66% males and 33% females and included ID (50%) and ASD (50%) disabilities. The intervention group in the third phase had 16 participants with a mean age of 19.33 (SD 4.61) years old. The group comprised of 43% males and 56% females and included ID (71%) and ASD (29%) disabilities. When

combining the three intervention groups from all phases, there were a total of 41 participants with a mean age of 20.20 (SD 3.14) years old. The group comprised of 51% males and 48% females, and included ID (71%) and ASD (29%) disabilities.

Instructors

Instructors for the first intervention group included a Ph.D. student who was a licensed special education teacher as well as a BCBA with 15 years' experience, and a master's student who was a licensed special education teacher with 5 years' experience and a master's student who was also a BCaBA with 5 years' experience. Instructors for the second intervention group included three master's students, one with 7 years of classroom experience, and two with 3 years of classroom experience. Instructors for the third intervention group included three masters' students, one with a teaching license and all with 3 years of classroom experience.

Materials

Positive choices (PC), created by the Oak Hill Center for Relationship and Sexuality Education (CRSE) from Hartford, CT, was taught to the intervention groups as the curriculum for the HGD class. This curriculum focuses on teaching students components of healthy relationships, particularly for this age group and population. The curriculum includes a teacher workbook with outlined objectives and goals, assessment evidence, a lesson plan, and suggested extension activities. The student workbook contained educational material in simplified English with colorful and contemporary pictures. The workbook contained fill-in-the-blank sections for notes during the lesson, as well as homework and activity sheets. PC contains five chapters: (1) relationships and self-awareness, (2) maturation, (3) the life cycle, (4) sexual health, and (5) being strong, staying safe. Included in the units are a variety of activities including decision making and role playing activities. Due to time constraints, the chapter 3 (which focused on pregnancy and birth) was not taught to any intervention groups. Although PC has end of the chapter unit tests, because they were open-ended questions with no grading rubrics provided, the researchers chose to create chapter assessments to be used as pre and posttests. These assessments (see "Appendix A" in Supplementary material) included matching and fill in the blank questions. Researcher also developed a questionnaire (see "Appendix B" in Supplementary material) to measure participant's thoughts regarding their usefulness of each topic in the curriculum.

The second and third intervention groups were also supplemented by teacher created differentiated guided notes (see "Appendix C" for a sample in Supplementary material) to complete during lessons. This was to allow for greater participation among students whose reading level was below that of the curriculum student workbook. The readability as noted by the Flesch–Kincaid is sixth grade level (http://www.readabilityformulas.com/flesch-grade-level-readability-formula.php).

Dependent Variables

The dependent variable was the knowledge acquired from the PC curriculum as measured by pre/post assessments created by the researchers. The assessment was typed in large font and included matching of vocab and definitions, as well as one word fill in the blank

statements. Accommodations were provided, such as questions read aloud when deemed necessary by the researchers or advocated by the participants.

Procedures

Before each unit, all participants took the assessment for that unit as a pretest. The intervention groups then received instruction in the PC unit. Upon completion of the unit, all participants took the assessment again as a post measure. The curriculum was delivered as suggested in the teacher manual, although the researchers at times supplemented by created PowerPoints of the material. Additionally, the second and third intervention group participants were given differentiated guided notes to better correspond with their reading levels (determined from previous testing). For role plays, the class was divided into smaller groups to allow more participation and further support from the staff. During the female and male hygiene units, the class was divided by gender for instruction. The opposite gender was offered the material and instruction from the other, if they so desired.

During the last class, participants in the first two intervention groups were given a questionnaire. This was typed in large font, simple English and visual pictures. Researchers read each item aloud. The last three questions were open ended and participants dictated their answers to the researchers.

Interrater Observational Agreement

All assessments were scored by a primary researcher. A second researcher then scored the assessment. Any disagreements were taken to a third researcher for a third opinion. The accepted score was 2 out of 3 agreements. Most common disagreements included poor handwriting, or directions of the lines between vocab words and definitions not being clear. At the end of this procedure there was 100% agreement in all assessments between 2 out of 3 researchers, for all four groups (intervention 1 group, control group, intervention 2 group, intervention 3 group).

Fidelity of Classroom Behaviors

Because the curriculum was being implemented as suggested, and due to the nature of the topic, researchers decided to create a checklist (see "Appendix D" in Supplementary material) focusing on classroom interaction and behavior to measure fidelity. Items included classroom rules being implemented, off-topic comments being redirected, sensitive topics being responded to appropriately, and positive reinforcement provided during each class session. Fidelity was 100% for all three intervention groups.

Results

A paired sample *t* test was conducted to compare sexual education knowledge for the control group and all three intervention groups (Tables 1, 2, 3, 4, 5).

These results suggest that positive choices has a statistically significant effect on acquiring sexual education knowledge for units 1 and 2, and moderately for units 4 and 5. The control group made no statistically significant gains, while the intervention group did show gains.

At the end of the course, a questionnaire was given to all participants in the first two intervention groups as a social validity measure. Due to the consistent nature of responses, this was discontinued for intervention group three. This questionnaire asked participants to rate on a picture Likert scale their thoughts on the topics as not useful, useful, and very useful. Results, in rank order of most useful, indicate that the chapters containing information on healthy relationships, information on red flags in relationships, and gender specific health care were perceived as the most useful by the participants. Participants reported that they would like more information on relationships in general, menstruation, types of abuse, health care, and taking care of a baby. Participants also disclosed that they would use the topics of types of relationships, birth control, and red flags in relationships outside of class.

Discussion

The purpose of this study was to compare results from a control and intervention groups on the effectiveness of the positive choices curriculum as well as to gather qualitative social validity from the participants themselves. Results indicate that the positive choice curriculum was effective at increasing sexual education knowledge to young adults with IDD.

One topic discussed was safe judgment in relation to dating and dating behavior. Part of the PC curriculum discusses qualities the individual desires in a dating relationship as well as rules for safe dating. Due to deficits in the ID population, social skills and judgement can be difficult [11]. Participants were motivated to learn more about this topic as some were beginning to develop crushes on their new peers. Student questions ranged from "Why does a guy cheat on you or if you're in a relationships?" to "What does it mean after a guy leaves you after having sex?" and "How does a person with a disability have sex?" Another student confided she had a crush on someone in the program, but that she was scared to talk to him and was not sure how to tell if it was mutual. She was also concerned about recognizing red flags, should they occur in the relationship, because a previous relationship she was involved in had physical and emotional abuse. Role playing scenarios provided in the curriculum were useful for practicing these skills in a safe environment with specific praise and corrective feedback. Red flags in relationships was rated the most useful topic by participants.

For unit 2, researchers asked females if they have had a gynecological exam. Surprisingly, 40% had not had one. Other topics that were discussed by female's participants included reasons for pain/discomfort during menstruation and uncomfortableness with a doctor seeing, and touching their private parts. Male participants stated being uncomfortable during prostate exams due to being touched in the private area, but understood once it was explained it was for medical reasons. Based on the end of the class

Table 1 Control group paired *t* test pretest to posttest

Unit	Pretest		Posttest		
	Mean	SD	Mean	SD	Significant
1	25.16	4.42	25.75	5.54	.632
2	9.83	4.19	9.83	4.15	1.00
4	4.75	3.16	5.08	2.60	.339
5	5.08	2.71	6.08	2.02	.185

Table 2 Intervention group 1 paired *t* test pretest to posttest

Unit	Pretest		Posttest		
	Mean	SD	Mean	SD	Significant
1	25.23	5.26	27.84	6.44	.029
2	8.23	6.17	12.53	6.62	.001
4	5.07	2.59	7.38	2.02	.001
5	5.23	2.52	7.76	1.69	.004

Table 3 Intervention group 2 paired *t* test pretest to posttest

Unit	Pretest		Posttest		
	Mean	SD	Mean	SD	Significant
1	22.25	8.25	26.50	7.09	.001
2	9.41	6.72	13.66	6.49	.003
4	5.45	2.62	6.45	2.38	.058
5	5.50	2.91	5.0	3.68	.381

Table 4 Intervention group 3 paired *t* test pretest to posttest

Unit	Pretest		Posttest		
	Mean	SD	Mean	SD	Significant
1	22.25	6.67	26.81	5.62	.005
2	8.06	4.63	14.13	4.96	.000
4	5.87	2.12	5.93	1.98	.882
5	5.33	2.58	6.46	3.15	.087

Table 5 All three intervention groups paired *t* test pretest to posttest

Unit	Pretest		Posttest		
	Mean	SD	Mean	SD	Significant
1	23.19	6.76	27.04	6.20	.000
2	8.52	6.20	13.47	5.89	.000
4	5.50	2.38	6.55	2.14	.002
5	5.34	2.58	6.52	3.02	.007

questionnaire, participants rated sexual health tied as the third most useful topic. Researchers who have commented on what topics should be included in sex education curriculum for individuals with ID state that sexual anatomy and hygiene should be included [4].

In unit 5, the participants were most vocal since this chapter covered sexual abuse. Sexual abuse is a concern for this population [3, 12]. One participant shared through a discussion an incident with cyber bullying that resulted in self-harm and therapeutic interventions. Another participant talked about ongoing conflicts with peers via social media, and how to navigate a healthy relationship and boundaries. Another participant shared fears of being pressured into intercourse as well as not being able to protect herself from being raped. Based on the end of the class questionnaire, participants rated abuse

prevention as the second most useful topic. They also indicated they wanted to learn more about the topics noted above.

Many of the topics in PC are intertwined. For example, part of having a healthy relationship is also being aware of red flags. Part of having a healthy sexual relationship is being able to provide consent. One of the overlaps in the curriculum was the development of friendship growing into a romantic relationship. The students were taught a critical foundation for a healthy romantic relationship stems from a healthy friendship. A friendship in which a person feels safe, respected and happy precedes romantic involvement with another person. Although the underlying theme for healthy friendships was a segway to developing romantic relationships, this knowledge is also important for interacting with roommates.

As a result of this curriculum and the quantitative and qualitative data, this inclusive postsecondary program created a follow-up class as an elective for students. In this follow-up class, topics were explored further such as social conflict, healthy relationships, and bullying. Results from this study indicated a need for a comprehensive sex education curriculum for this population. This need is based on scores from pre to posttest, as well as qualitative and anecdotal information from the participants themselves.

Limitations

One limitation involves the curriculum itself. Due to time constraint, chapter 3 was not taught. Also, the assessments do not provide a rubric for scoring. Furthermore a lower reading level for the curriculum would be helpful so the target audience's academic challenges are better meet and/or help teachers when modifications are needed. Since the control group was upper level students, their scores may have been impacted by maturation and/or regression from their exposure to when they participated in the human growth and development course in previous semesters. In addition, the fact that the instructors had various levels of classroom experience may have contributed the variability of success in units 4 and 5.

Future

Future research may want to investigate lowering the reading level for the curriculum or incorporating standardized supplemental material at a lower reading level. In addition, unit assessments should be standardized to minimize the impact of handwriting legibility. Lastly, research should investigate maintenance of skills learned, exploring self-determination, and self-advocacy of skills in the realm of sexuality. Another important topic would be exploring if sexual knowledge decreases the risk for sexual abuse and exploitation.

Compliance with Ethical Standards

Conflict of interest The first two authors, Dr. Graff and Dr. Moyher were asked to be on Oak Hill's Advisory Board to assist with revisions of some of their publications. Oak Hill is the organization that published positive choices—the curriculum evaluated in this article. We have not been asked to revise this particular curriculum. Also, we were asked to be on their Advisory Board after the completion of this study. Therefore, we do not believe this is a conflict of interest, but felt it should be stated.

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 individual participants included in the study.

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