Getting Youth with Disabilities to Talk and Learn About Healthy Sexual Development: the Utility of a Canadian version of “SeCZ TaLK”

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Background

In line with the UN Convention on the Rights of the Child, all children and youth should have access to education and guidance about their sexual health. Unfortunately, review of the available literature suggests that this basic human right is not being met consistently. While young people with disabilities are similar to those without disabilities in terms of their desire for intimacy, and may not lag far behind their typically developing peers in terms of sexual experiences; youth with disabilities do not get as much information about this important aspect of their health. “Protecting” youth with childhood-onset disabilities or ongoing (chronic) health conditions from educational opportunities has been shown to actually lead to higher rates of sexual abuse.

Sexual health education interventions are seen as an appropriate strategy for promoting healthy sexual development in adolescents but unfortunately, many professionals have reservations in discussing sexual health with patients. Furthermore, sexual health is rarely addressed during medical consultations with adolescents who have disabilities or ongoing (chronic) health conditions.

The Dutch board game called SeCZ TaLK created in 2009 is a promising and attractive educational tool from both adolescent and professional perspectives. (SeCZ is a Dutch acronym for Sexuality and Chronic Conditions).

Purpose

The purpose of this pilot study was to translate “SeCZ TaLK” into English, and to validate the game’s use across cultures, and to evaluate its use among youth with disabilities in Canada.

Project Stages

Phase I – Translation of the board game from Dutch to English
Phase II – Expert meeting held with research team members from the Netherlands and Canada to review the translation and revise to assist with cross culture validation
Phase III – Train facilitators with new pilot version of game
Phase IV – Pilot game with facilitators and youth with chronic illness and disability to evaluate feasibility, use and utility.

Methods

• Youth with developmental disabilities and/or mental health diagnoses and clinicians with expertise in sex education were targeted.
• Youth were recruited through outpatient clinical services in Hamilton, ON. Research team clinicians were trained on the use of the game as facilitators.
• A mixed methods approach through surveys and semi-structured interviews were utilized.

Who played?

• 14 youth and 5 facilitators participated in playing the game on 3 separate occasions (game 1: 5 players, game 2: 3 players and game 3: 10 players (only 6 participated in the research). Youth ranged in age from 13-17, 5 were male and 9 were female.
• Professionals who participated as game facilitators included 2 Nurses, a Pediatrician, Occupational Therapist and Social Worker.
• Games were played on average for 1-1.5 hours in a hospital setting (n = 2) and one in the community

What did players think of the game?

Quantitative results

Survey scores were based on a 1 (strongly disagree) to 5 (strongly agree) scale.
• Youth: Eleven youth thought the game was appropriate for them to play (mean score 3.9) and thought that it helped them to talk about sex and relationships (mean score 4.1). Many also learned or heard something new from the game (mean score 4.1).
• Facilitators: Overall facilitators found the game useful and appropriate for their population (mean score 4.2) and work setting (mean score 4.3). Most facilitators agreed they could facilitate the game without any additional training (1 neutral & 1 somewhat disagree). Five facilitators said they would play it again and recommend it to their colleagues.

Qualitative results

• Youth enjoyed playing the game and thought using it made it easier to talk about things that are often hard to talk about
• ‘Normally people wouldn’t get to talk about questions like that or like what they … would do if they were on certain medications and stuff and how it would affect different things’ spoken by a 13 yr old female
• ‘Because it’s a hard thing to talk about with other people like parents and other grownups so I felt that it was a good game to bring it up with’ spoken by a 17 yr old female

• They found it educational in a good way and learned something
• ‘It’s a great way to get people talking. It’s fun but educational, unlike school’ spoken by a 16 yr old boy
• ‘I loved it, I learned so much’ spoken by a 17 yr old boy

• Enjoying playing the game was supported by a small group size of same age, familiar peers.
• ‘I liked how you can just have fun during the game that you can talk about it and then you’re only small groups so you’re not like, like at school when you have to do the health program with the entire class’ spoken by a 13 yr old girl

• Barriers to enjoying & playing the game include Age, Attitudes and Comprehension
• Interviewer: “Any reason you would not want to play?” ‘I think if people didn’t take it seriously’ spoken by a 16 yr old boy
• ‘Some of the questions, I didn’t understand what they meant’ spoken by a 15 yr old boy
• ‘I think the game was pretty good like it did get a little awkward at some points cause I was kinda the youngest one there’ spoken by a 13 yr old girl

Conclusion

• Overall, both youth and facilitators see utility in playing a Canadian version of the Dutch board game “SeCZ TaLK” and would play/facilitate it again.
• Youth had fun talking & learning about sex, relationships, their body and their future with their peers
• Further exploration is needed to determine how much training is required to facilitate the game and whether all questions are appropriate for all ages
• The next step will be to research this game more thoroughly as an innovative way for youth with chronic disabilities and/or mental health diagnoses to talk & learn about healthy sexual development.

References

Slegte, HA van der, Brou Al van, Hilberink S, Visser A. Using the new board game “SeCZ TaLK” to stimulate the communication on sexual health for adolescents with chronic conditions. Patient Education and Counseling 2010; 81: 324-331.


Acknowledgements

This study was generously supported by the Pollock Foundation. The study team would like to thank all the youth and staff that volunteered their time to participate.