



Common problems in adolescents and sexuality in adolescents and adults

Prof. Stephan Eliez
Virginie Pouillard
Lucie Chambeyron



**UNIVERSITÉ
DE GENÈVE**
FACULTÉ DE MÉDECINE

22q11 - Europe . Dublin
07.10.2017



FONDS NATIONAL SUISSE
SCHWEIZERISCHER NATIONALFONDS
FONDO NAZIONALE SVIZZERO
SWISS NATIONAL SCIENCE FOUNDATION

Introduction

- ❖ Psychotic symptoms are a common feature of the 22q11DS *see presentation of D Gothelf*
- ❖ Various psychic difficulties as ADHD, anxiety as depressive symptoms are also frequently observed in the syndrome
- ❖ In the context of the 22q11DS, some problems that might not be immediately as noticeable can represent an important issue:
 - ❖ Socialization difficulties and specific related cognitive impairment
 - ❖ Excessive video gaming or youtubing
 - ❖ Sexuality

Sex, denial and video-games

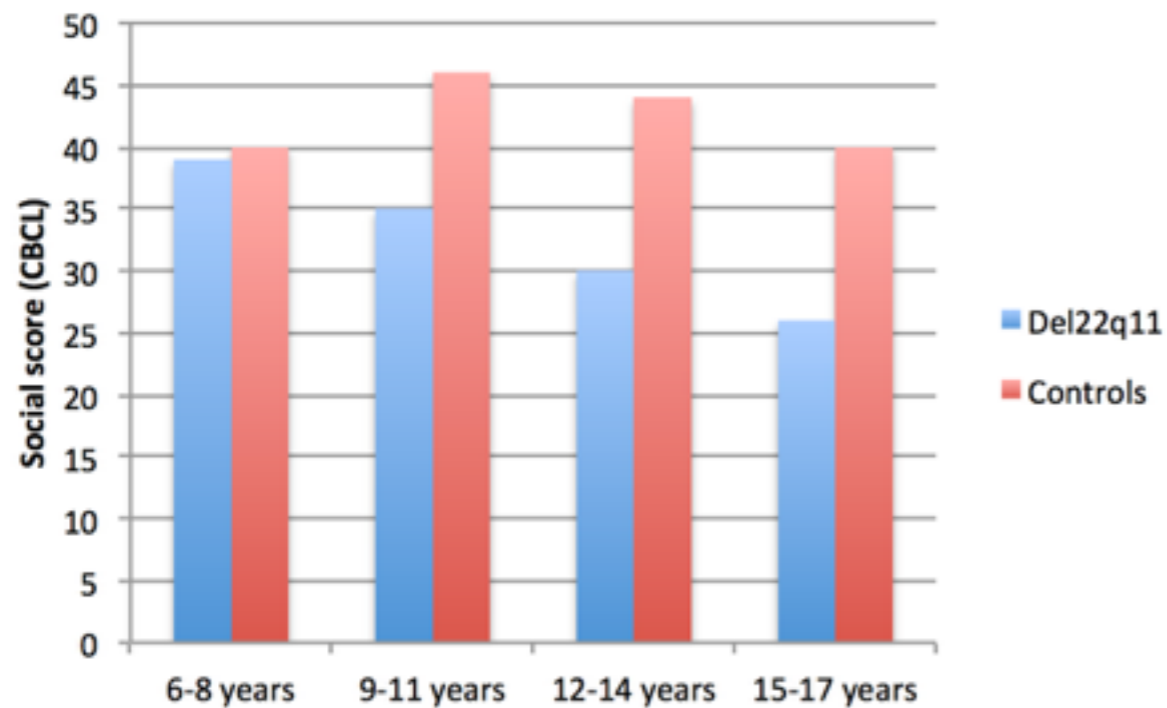
Socialization

Social Difficulties in Childhood and Adolescence

- ❖ Generally, individuals with social difficulties in childhood are at greater risk of lower self-esteem, academic failure or substance use later in life
- ❖ These difficulties often tend to be minimized by the environment of the young (Greco and Morris, 2001)
- ❖ Children affected by del22q11 have lower social skills than youth in the general population (Shashi et al., 2012)
- ❖ The level of shyness discriminates young people with a del22q11 compared to young people affected by a Williams syndrome (WS) or young people of the general population (Schonherz et al., 2014)

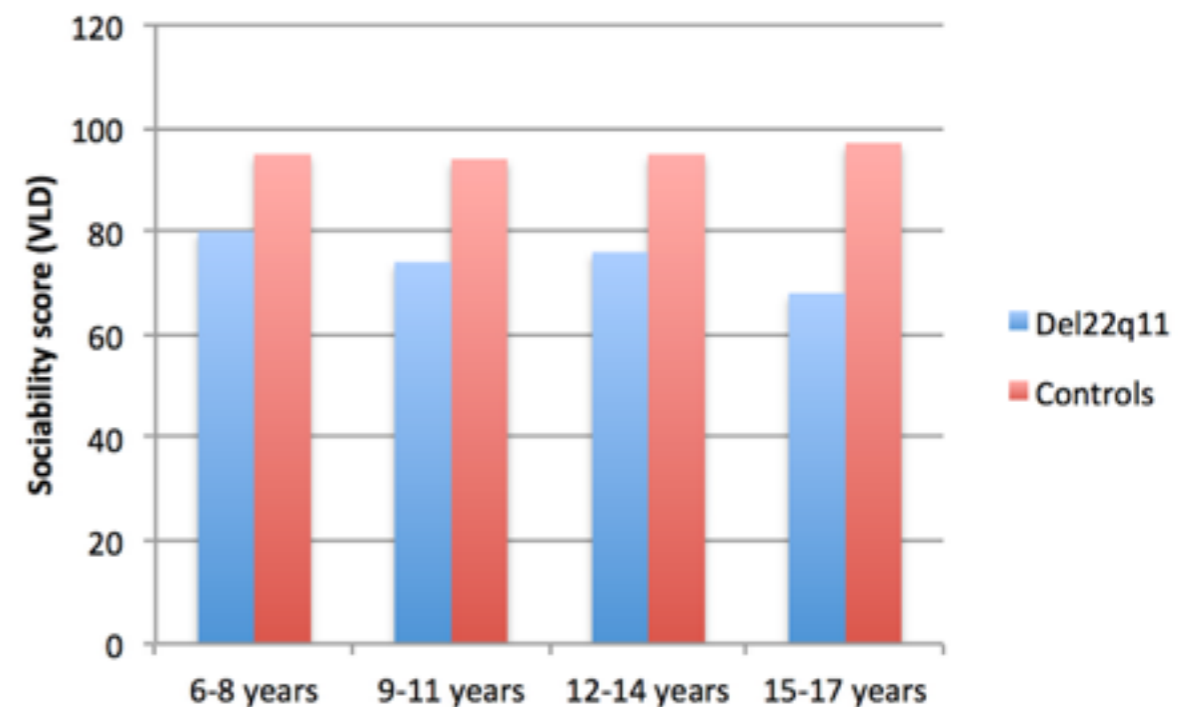


Social Difficulties in 22q11DS



- ❖ CBCL Questionnaire - Basic Evaluation of socialization (reported by parents)

- ❖ Entretien Vineland - échelle de socialisation (entretien structuré avec les parents)



Videogames and youtubing

- ❖ A lot of individuals with 22q11DS spent time playing video games and hours on youtube
- ❖ Could reinforce social withdrawn and social functioning deficit



- ❖ Understand the role played by online activities for your child
 - ❖ helps self esteem butrisk factor at the same time
 - ❖ Gives a sense of success and pseudo socialization
- ❖ Number of hours spent, “night shift”
- ❖ Risky behaviors (porn, inappropriate online exposure of oneself, etc.) and emotional desensitization
- ❖ What to do:
 - ❖ limit time, and set the hours of the day (parental control **software**)
 - ❖ avoid isolation
 - ❖ talk about it (time AND content)

The question of sexuality in adolescents and young adults

Why study sexuality in the del22q11?

- ❖ Sexuality is a major concern among parents of young people with microdeletion 22q11
- ❖ No published studies on sexuality in adolescents and young adults with a del22q11
- ❖ Our objective is to provide some avenues of reflection that could be useful in accompanying families

"We have already intercepted SMS messages and Facebook conversations, setting appointments for unknown people after classes to have sex in public toilets or in the person. We talked about it with our son, and he assured us that it did not happen. However, he remains obsessed with this idea. Does his lack of discernment have anything to do with his illness? How can he avoid doing stupid things without infringing on his intimacy? "

p. 206-207



Studies on Sexuality

- ❖ **No published studies on sexuality among adolescents and young adults with a del22q11 (one in progress: Palmer et al., University Health Network, Toronto, CA)**
- ❖ Studies on children, adolescents and adults with intellectual disabilities or cognitive difficulties suggest:
 - ❖ a high risk of physical, emotional and sexual abuse (Jones et al., 2012; McCabe, Cummins & Reid, 1994)
 - ❖ a lack of knowledge and skills related to sexual abuse situations: 36% think that someone else decides whether or not they have sex (McCabe, Cummins & Reid, 1994)
- ❖ more difficulties in recognizing sexual abuse -> implications for the ability to consent in sexual relationships (Murphy & Callaghan, 2004)
- ❖ girls and women have more difficulties to build a positive gender identity (Fitzgerald & Withers, 2011)

Studies on Sexuality

- ❖ Studies in individuals with mild intellectual retardation (McCabe & Cummins, 1996, McCabe, 1999):
 - ❖ Lower level of knowledge across several areas of sexuality
 - ❖ Tendency to have fewer sexual experiences but more at risk of contracting an STD or having a pregnancy
 - ❖ Tendency to have less romantic relationships either because of lack of opportunity or because of lack of social skills
 - ❖ More negative feelings about their sexual relationships

Our Study

- ❖ SEXKEN-ID Questionnaire (McCabe, Cummins, & Deeks, 1999)
 - ❖ Topics: friendships, romantic meetings, sex education and sexual relations, sexual activities, contraception and masturbation
 - ❖ 4 areas assessed: knowledge, needs, feelings and experiences
 - ❖ Open questions: score of 0, 1 or 2 depending on the quality of the response
 - ❖ Multiple choice questions

Characteristics of participants

Table 1 : Age

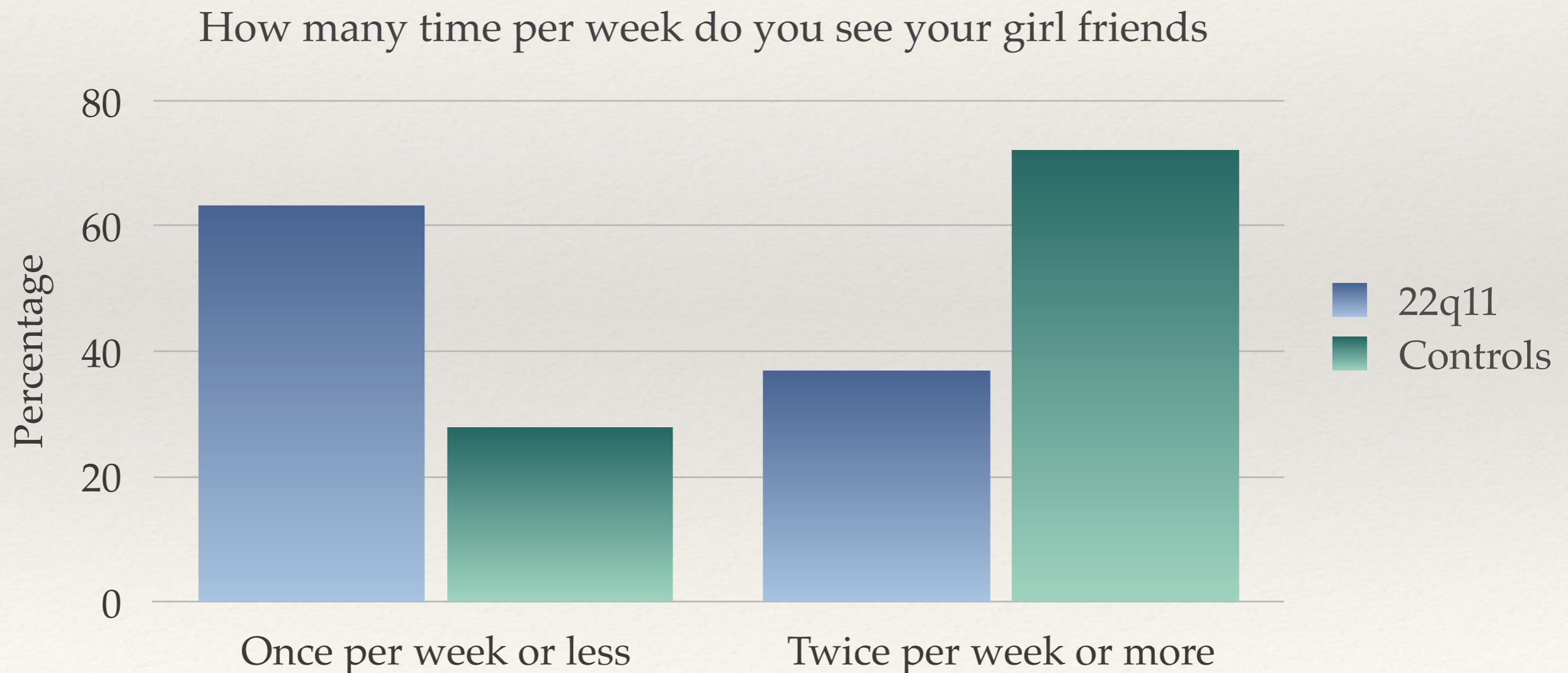
Diagnosis	Gender	N	Mean Age
22q11	Girls	18	24.77 ± 6.20
	Boys	15	19.05 ± 4.43
		33	21.91 ± 5.32
Controls	Girls	13	19.86 ± 4.72
	Boys	11	18.57 ± 3.15
		24	19.22 ± 3.94

Overall Results

- ❖ In general, participants with del22q11 have less knowledge about sexuality (M = 40.8) than control participants (M = 55.7)
- ❖ In terms of experience, feelings and needs, our results do not reveal a difference, potentially due to a lack of statistical power (n = 57)

1. Friendship

Individuals with 22q11 have less experience in friendship (e.g. frequency of their friend meetings)

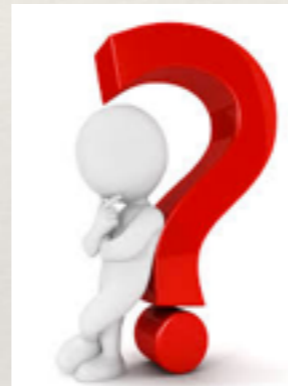


2. Date

What does it mean to “feel close to someone”?

Do a lot of things together

Love him/her

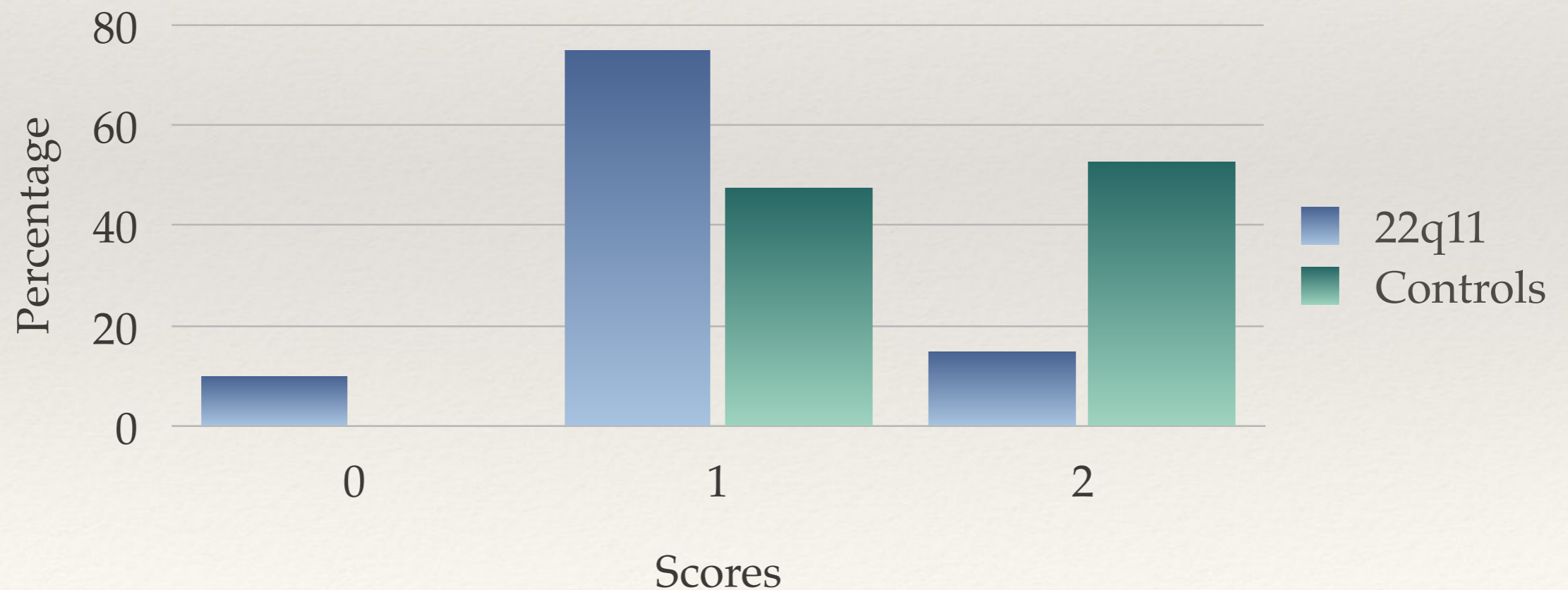


When we know everything of each other

Someone to whom to confide, we can trust. A very close friend, tell him/her everything without taboo

What does it mean to “feel close to someone”?

Young people with 22q11 have less knowledge on dates and intimacy

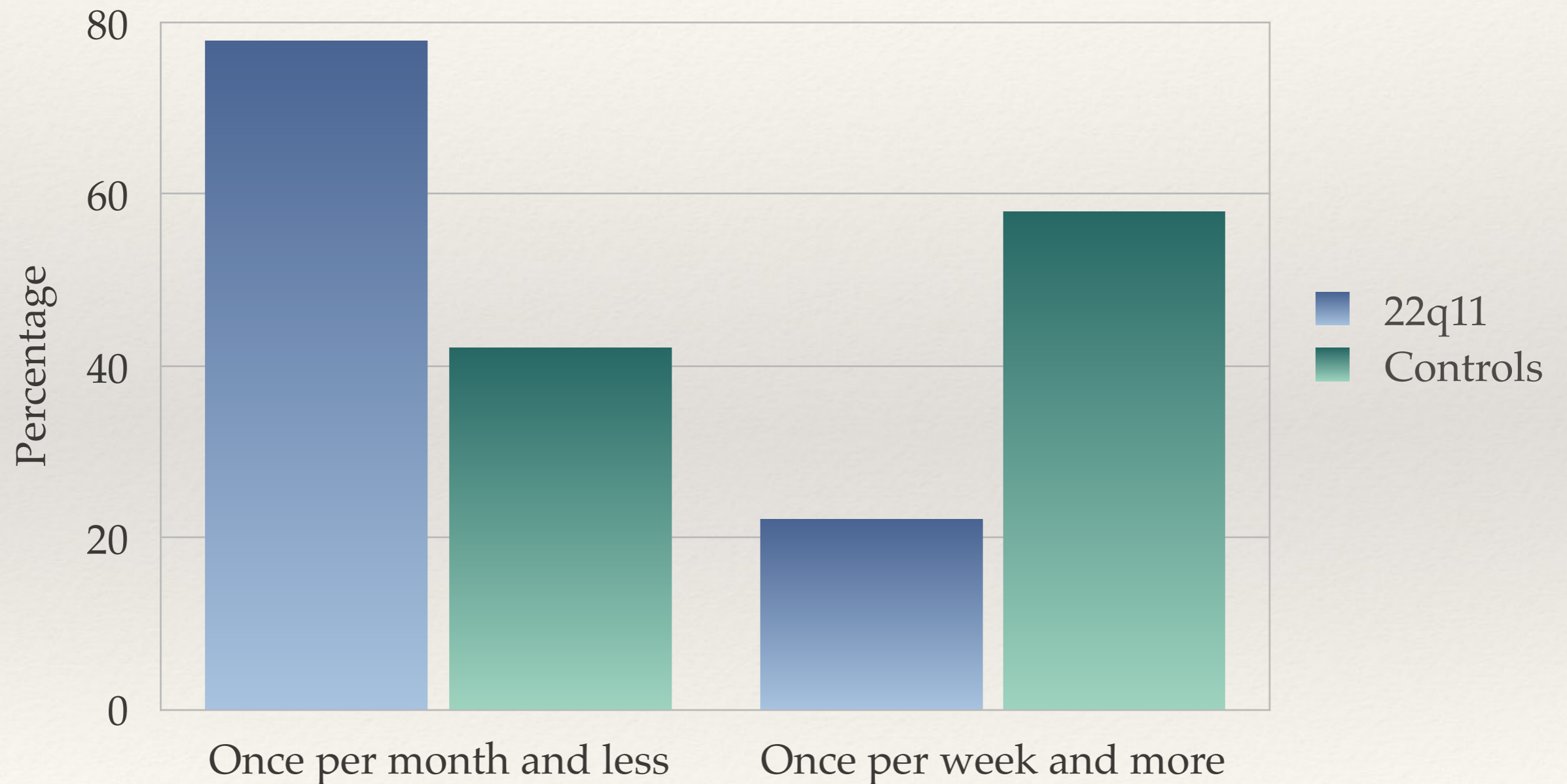


Sexual relationships

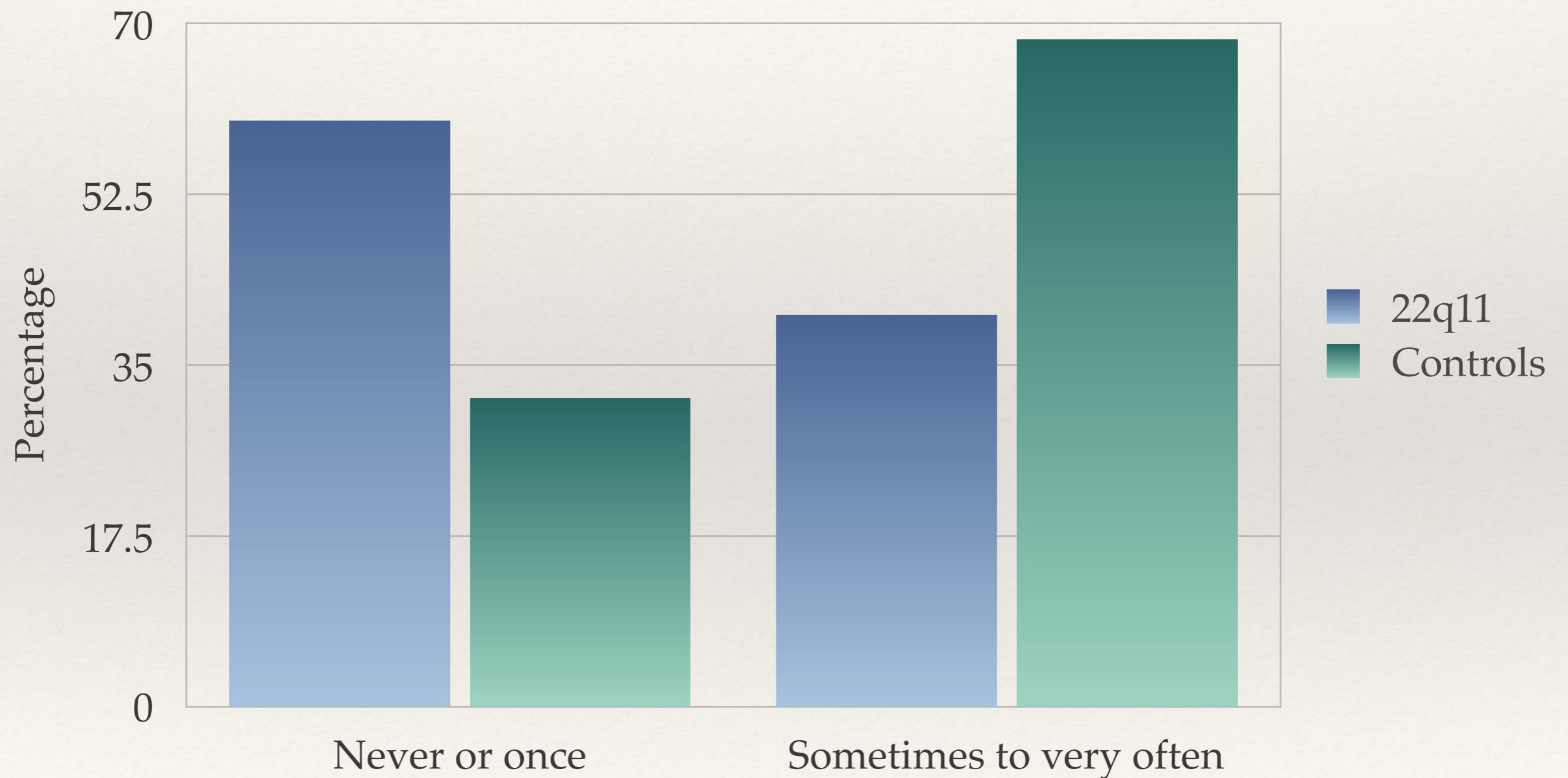
The level of experience on the subject of sexual relations is generally lower among the participants with the del22q11 compared to the controls

- ❖ Talk less about sex to friends
- ❖ Would like to have sex less often
- ❖ Talk about sexual relations to their family (little!)
- ❖ No difference in the frequency of sexual intercourse
- ❖ Think as much about sex

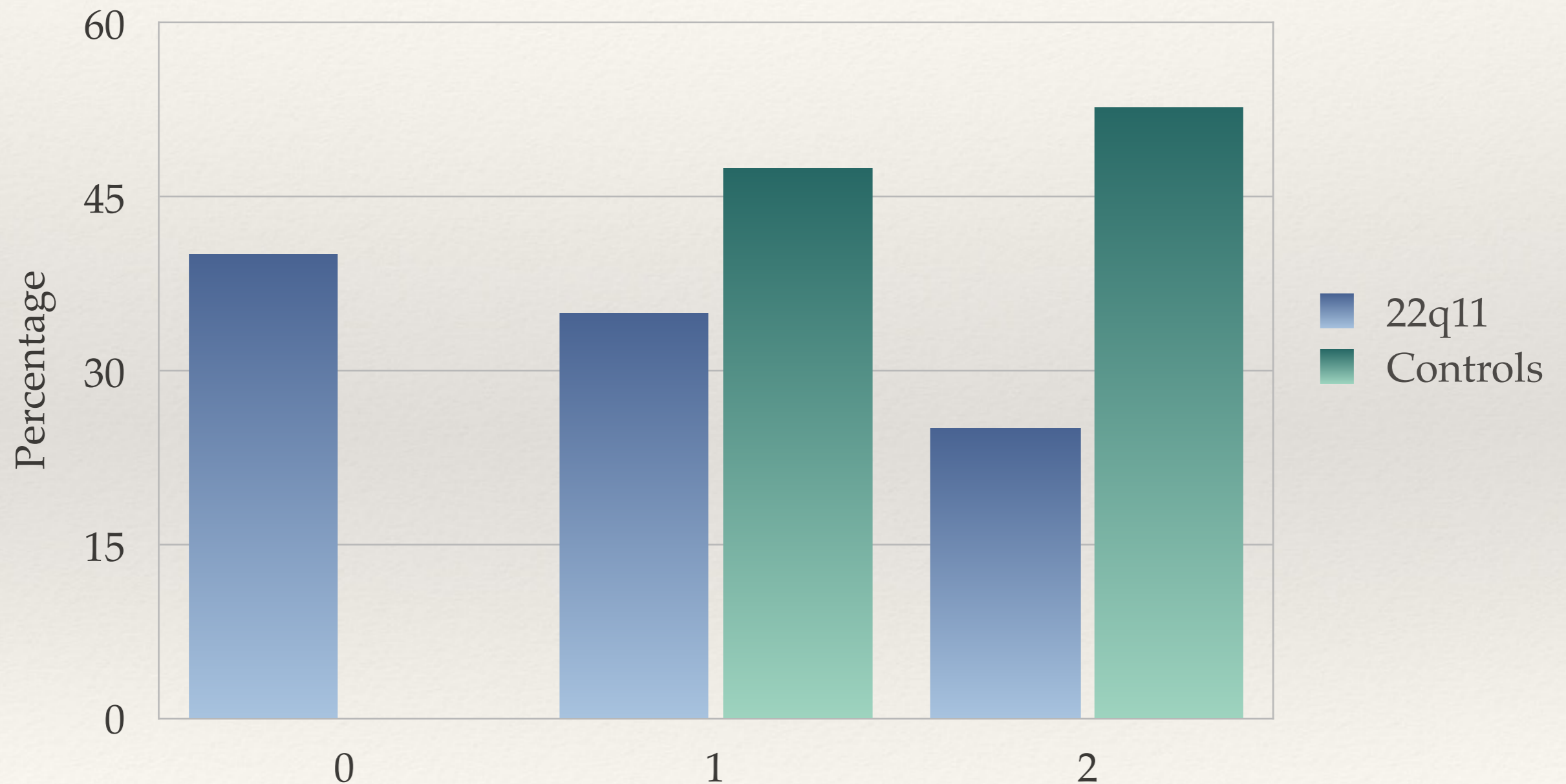
“At which frequency would you like to have sexual intercourse?”



“At which frequency do you talk about sexual intercourse with your friends?”



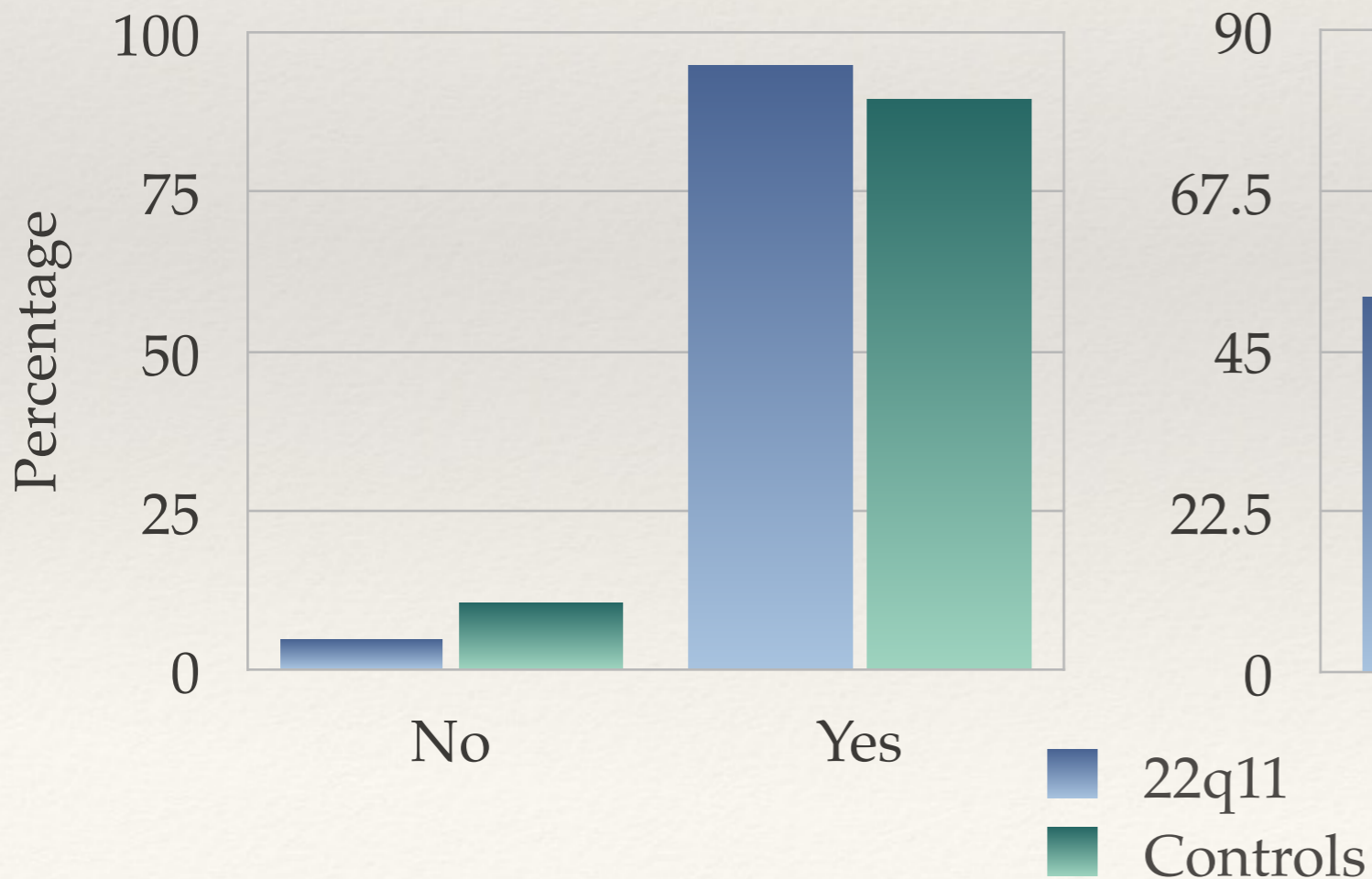
Knowledge: «What is meant by having sex ? »



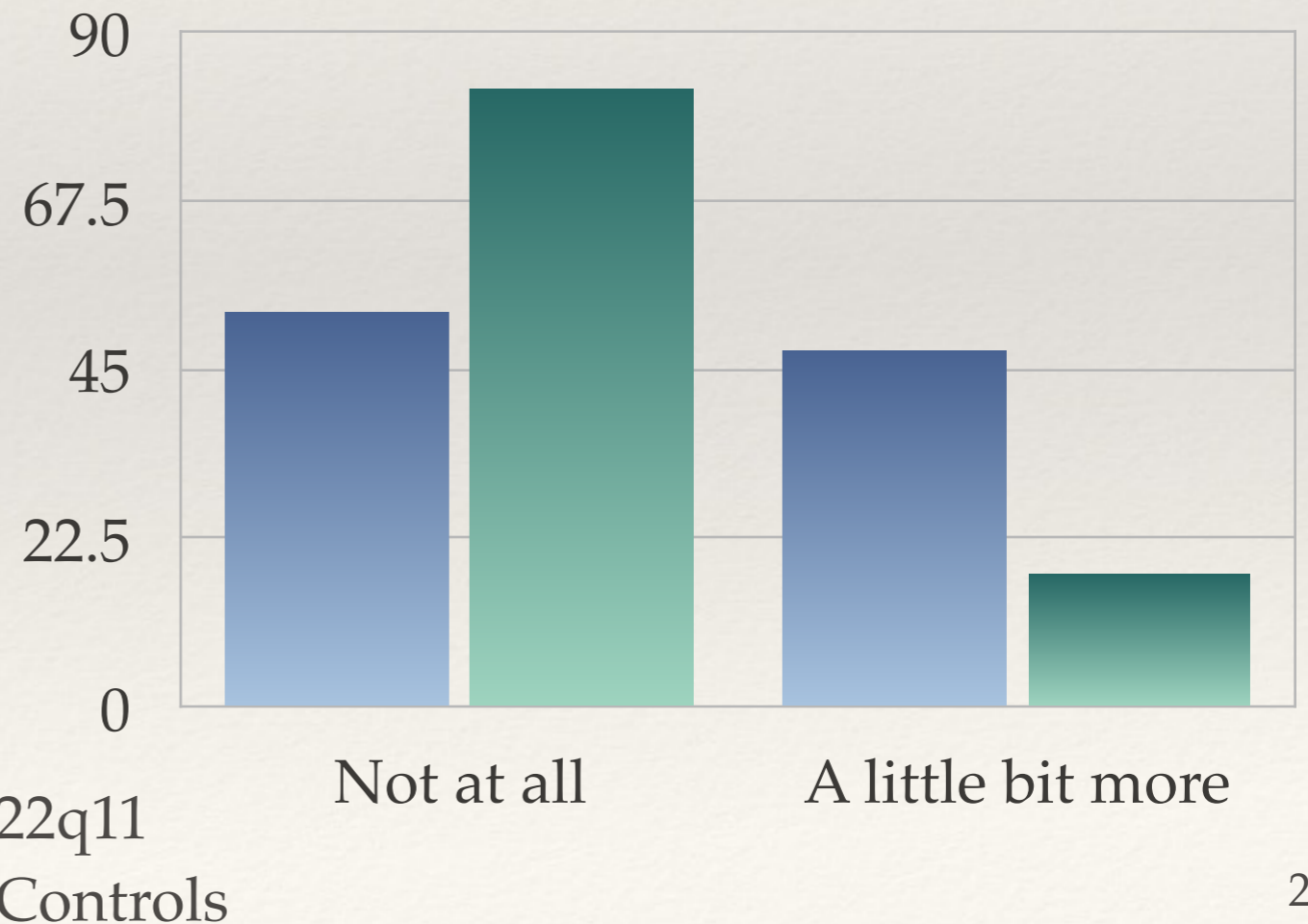
Sexual education

Concerning the section sexual education: no statistical difference found between groups but slightly more interested to be more informed

Did you ever have a sexual education?



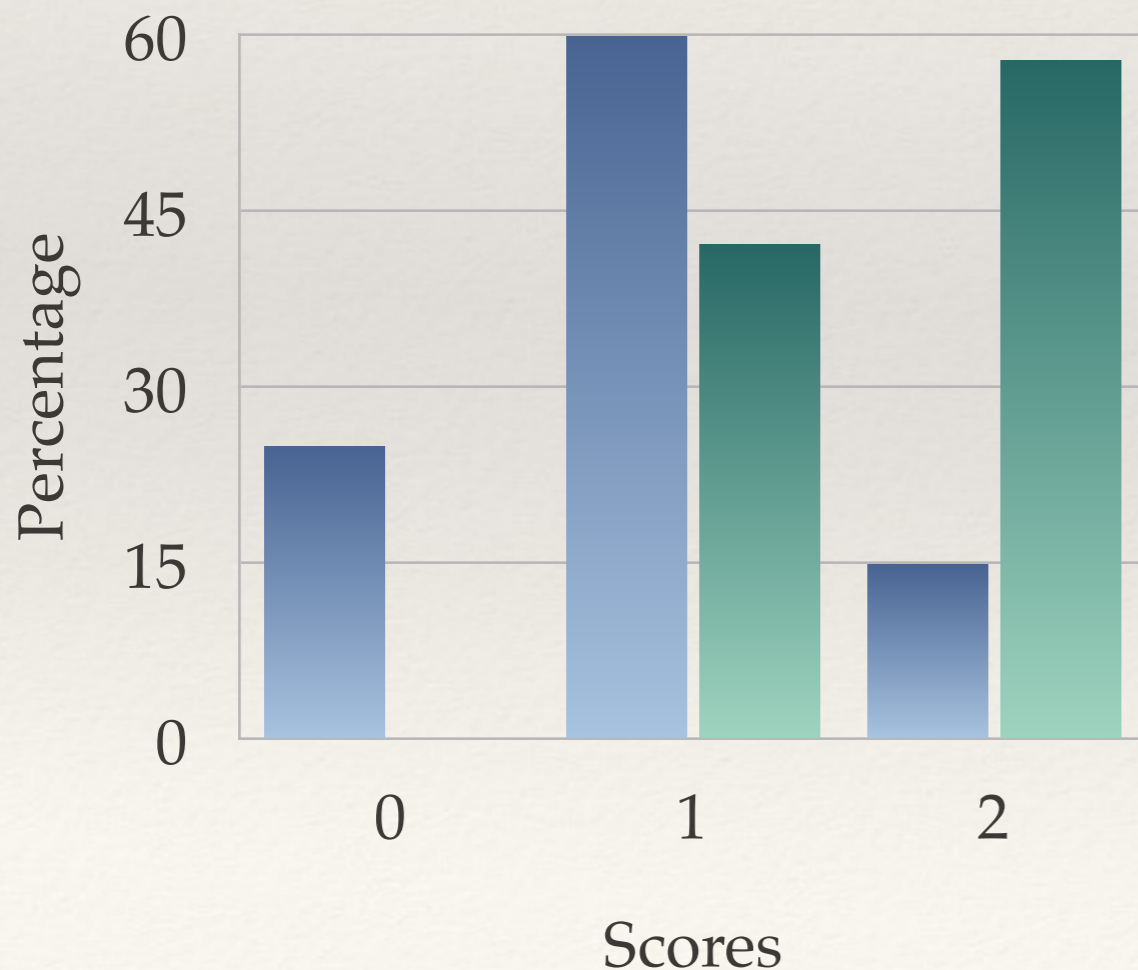
Would you like to learn more about sexual education ?



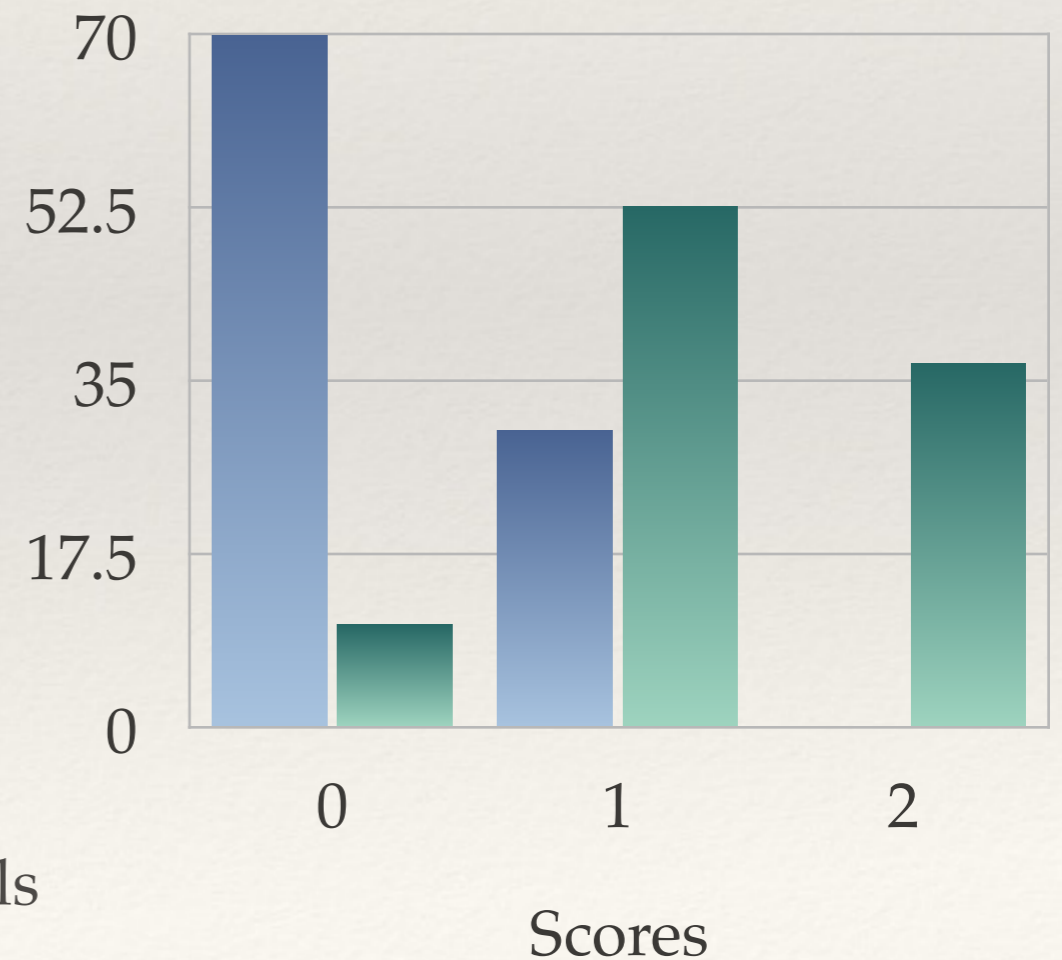
Sexual intercourses

Individuals with 22q11 have less knowledge on sexual intercourse

What is a sexual intercourse



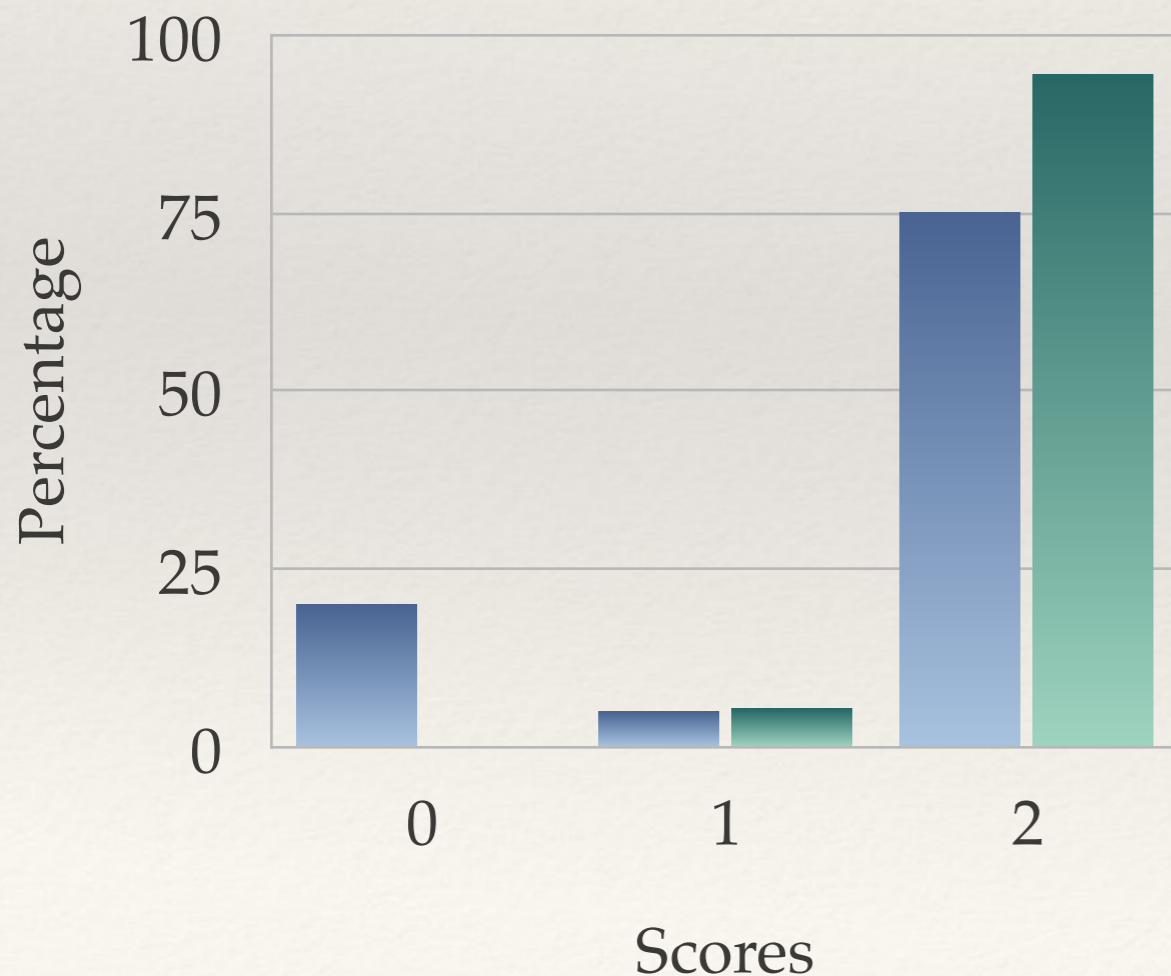
What does it mean to have an orgasm or to come?



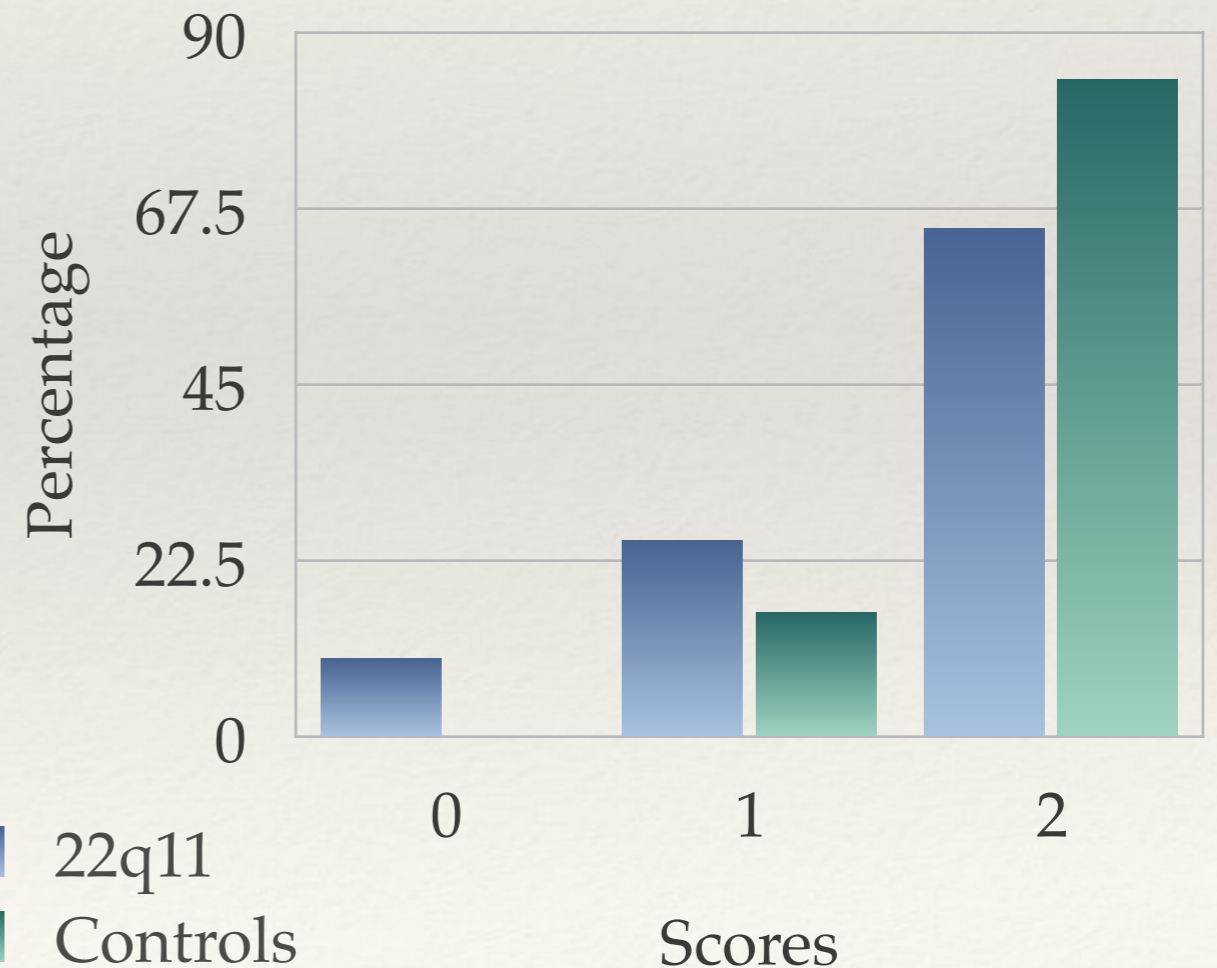
The consent

About a third of individuals with 22q11 did not know how to react in front of a sexual abuse threat, and would not know how to deal adequately with a threat of sexual abuse

What would you do if someone would like to have a sexual intercourse with you while you do not want it ?



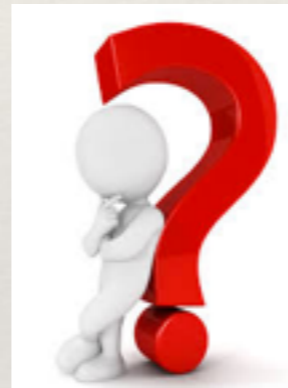
How say "No" ?



“What would you do if someone wanted to kiss you when you did not want him / her to do it?”

I don't know, I would not do it

I don't know



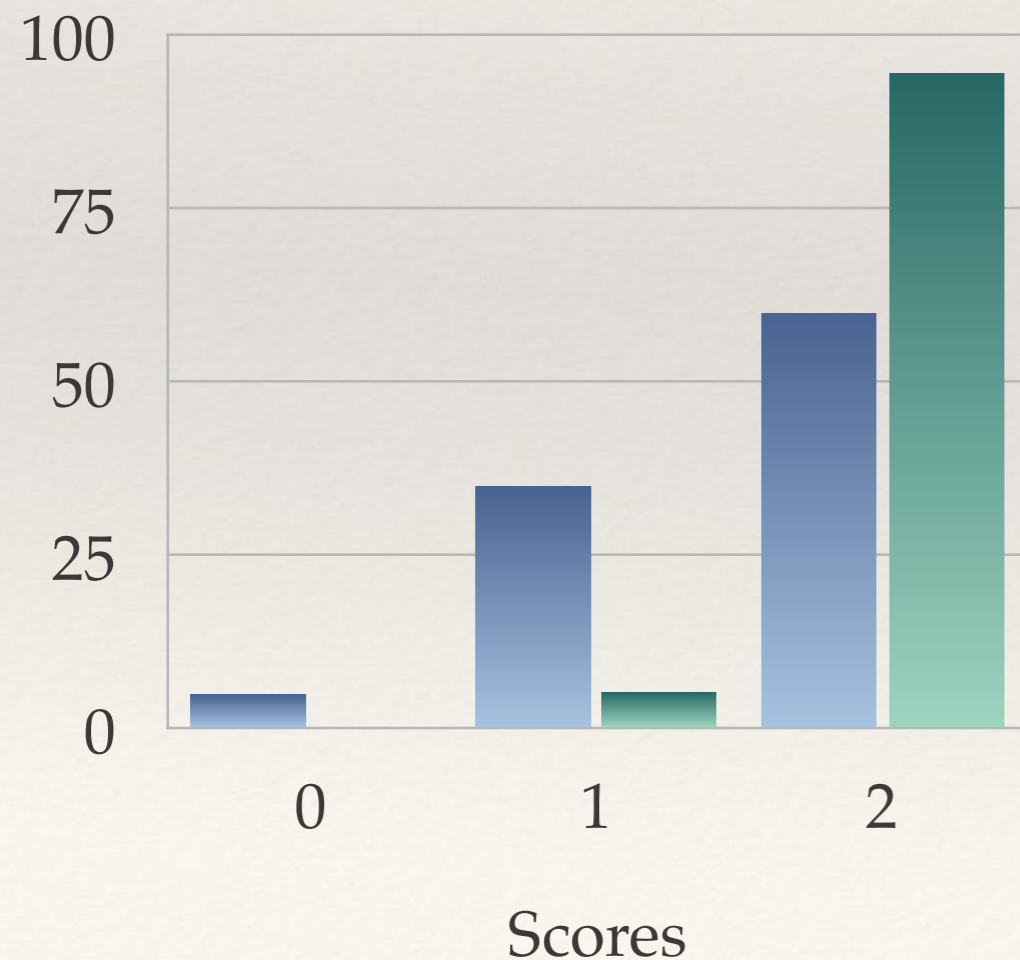
I turn my head

I would say no. If he doesn't understand I push it

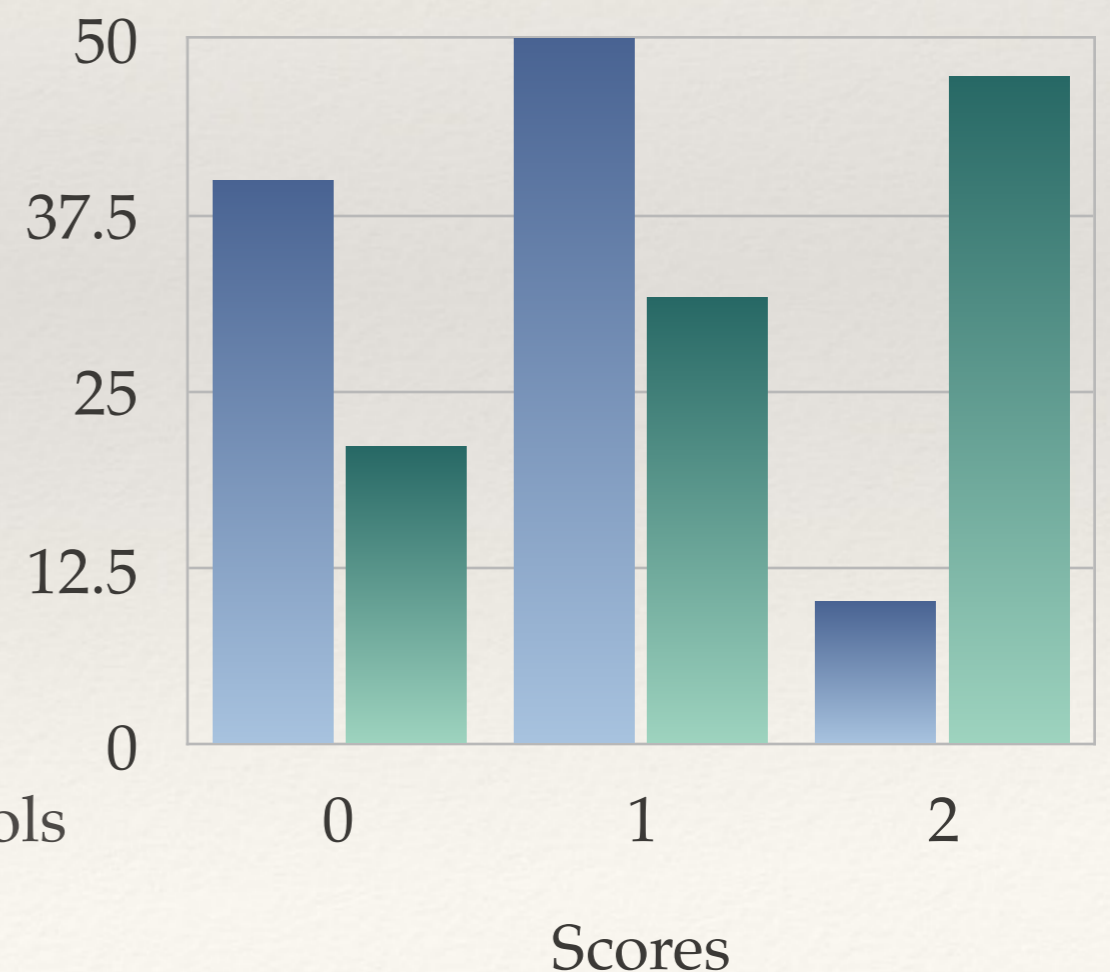
The contraception

People with 22q11 have less knowledge on contraception methods

What is a condom ?



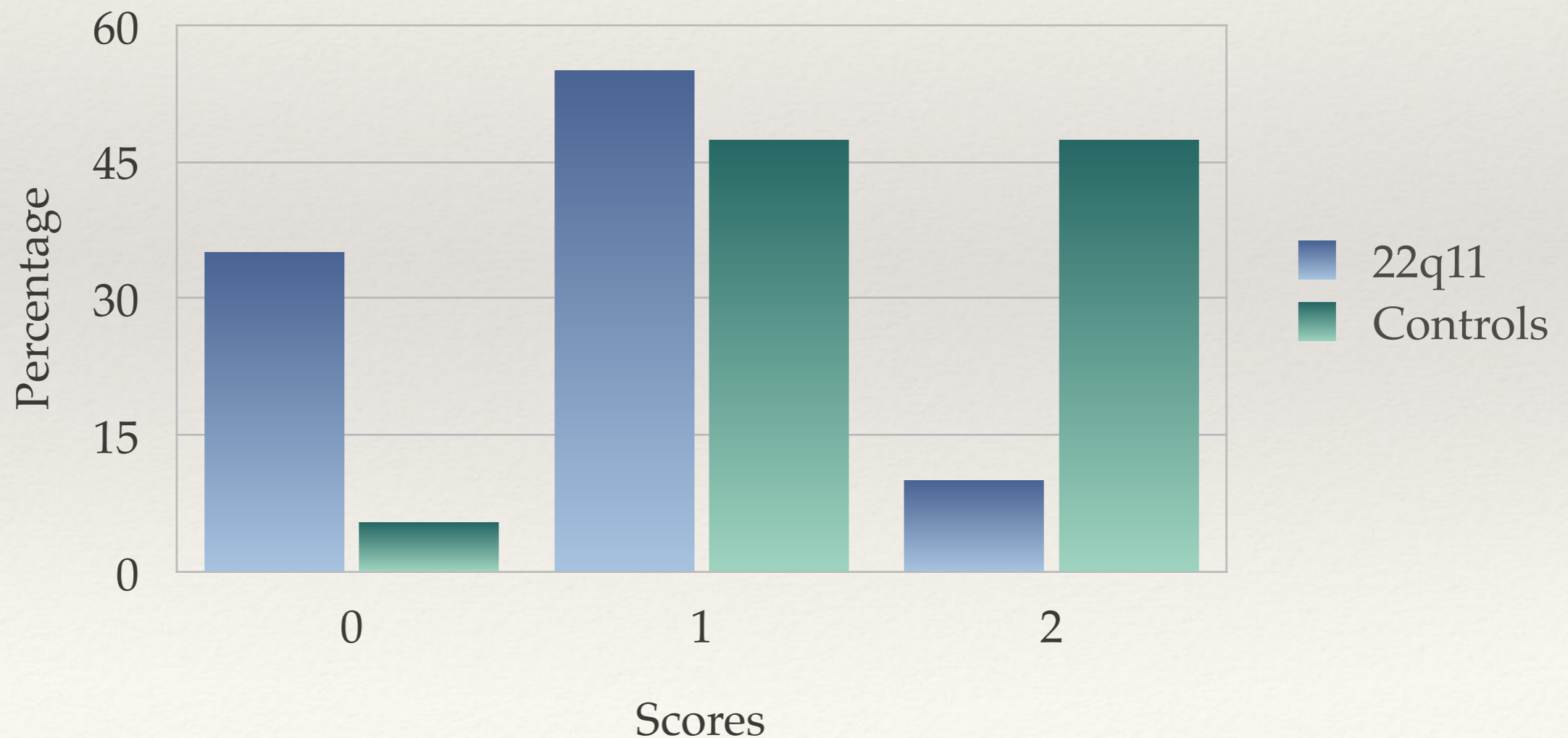
Explain me how to put a condom



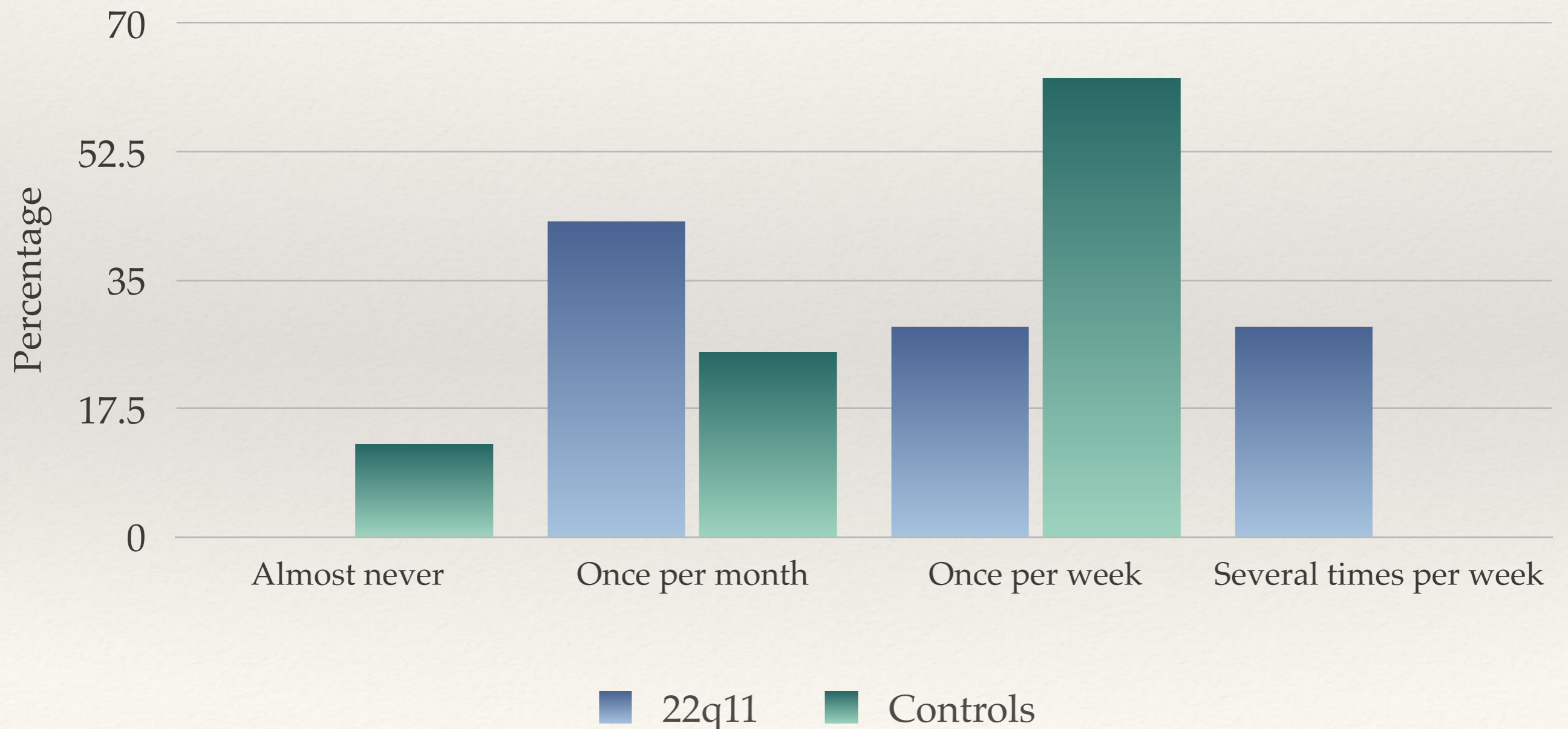
The masturbation

Individuals with 22q11 have less knowledge on masturbation

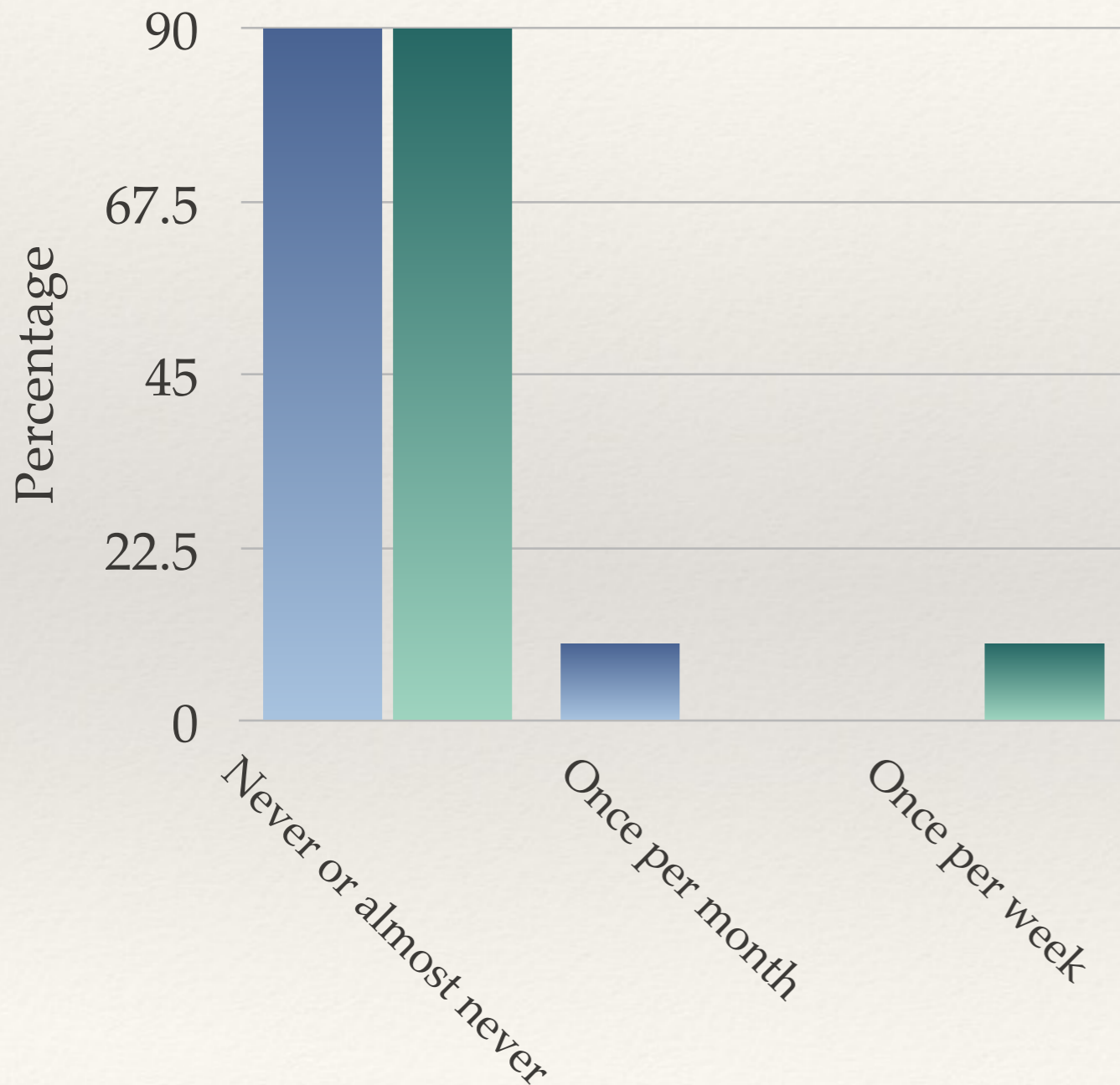
What is masturbation ?



Masturbation frequency of boys



Masturbation frequency of girls



- The majority of girls say they never or almost never masturbate what represents a bias in our study.
- In the general population, 48% of women aged 18-39 masturbate regularly (Hebernck et al., 2010)

■ 22q11
■ Controls

Conclusions

- ❖ In almost all fields and in general, the level of knowledge is lower among participants with the del22q11.
- ❖ Despite this gap, they say they do not (or barely) feel the need to know more.
- ❖ This lack of knowledge puts these adolescents and adults at risk of contracting STDs, having unplanned pregnancies, being confronted with abuse and responding to inappropriate behavior

Appropriate sex education

- ❖ Provide sex education that is individualized and appropriate to their developmental age and intellectual functioning
- ❖ The importance of visual and realistic aids as well as a practical dimension of teaching
- ❖ Role of parents

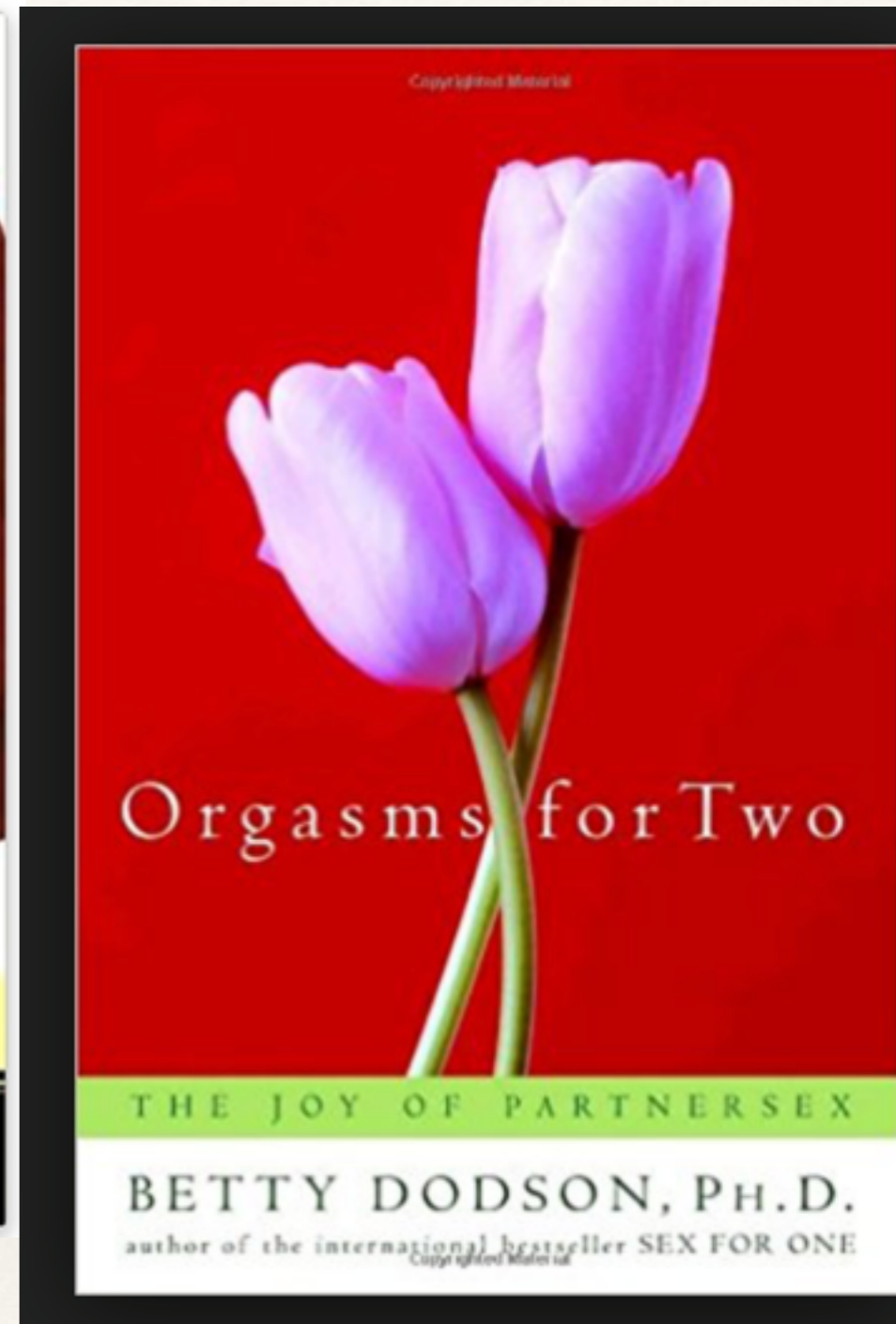
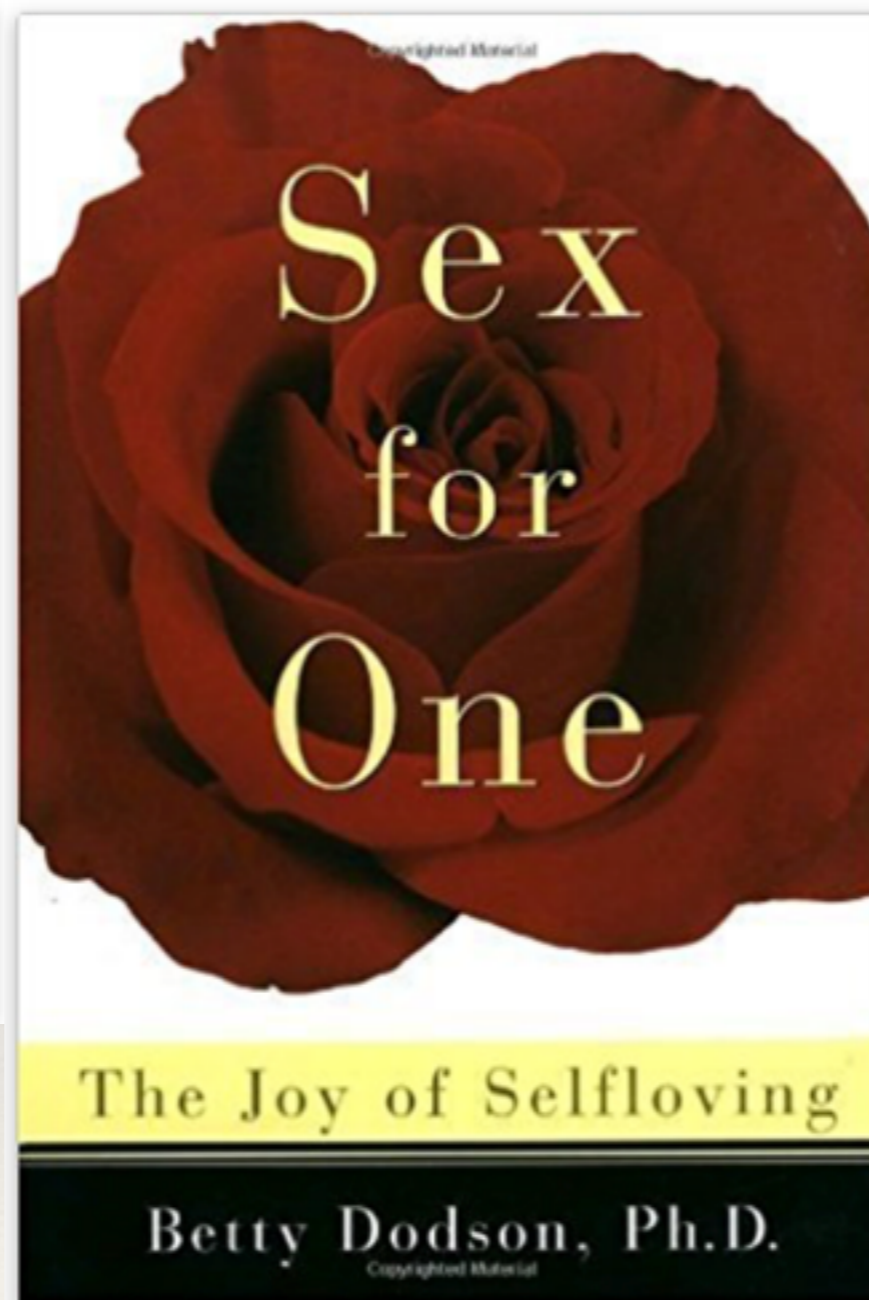
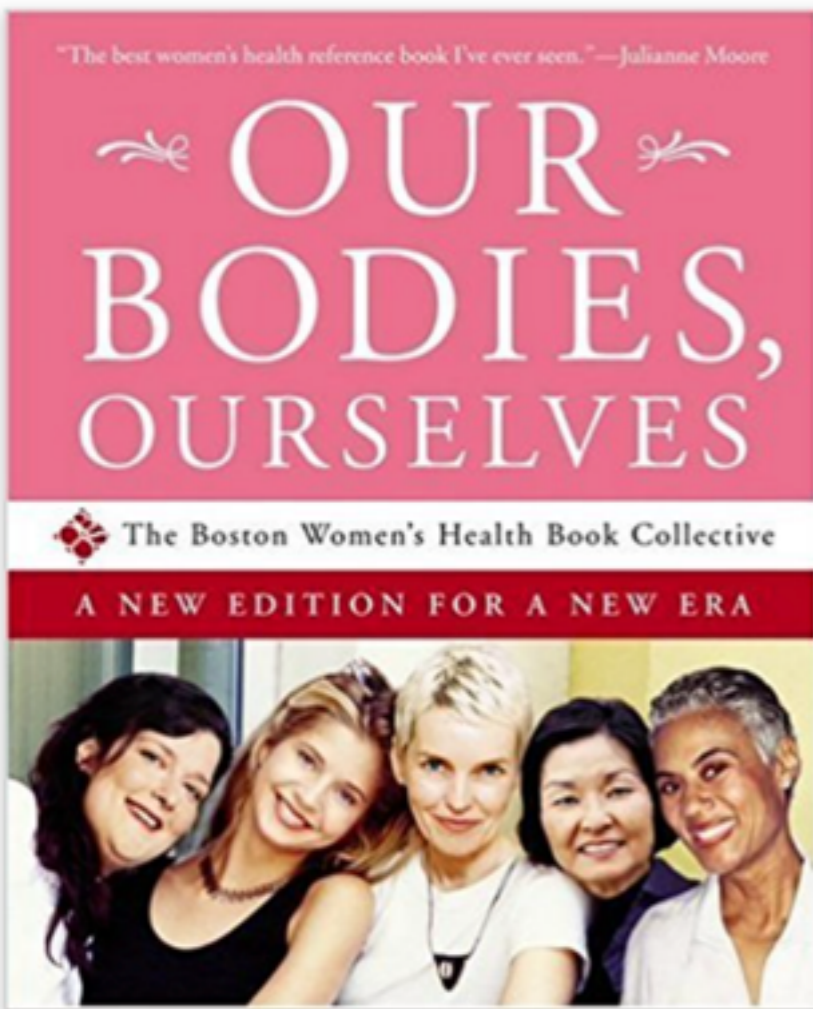
Key topics for individualized sex education

- ❖ **Social interactions:** the difference between friendship and love relationships, seduction
- ❖ **Sexual relationships:** appropriate places (public / private), definitions of the genitals, different sexual acts, orgasm
- ❖ **Contraceptive methods:** different methods, STD protection and pregnancy, how to use them
- ❖ **Consent:** recognizing non-consensual situations, the possibility to withdraw consent, how to react in a situation of threat of abuse, how to say affirmatively
- ❖ **Masturbation:** intimate but not taboo activity, education around practice (Betty Dodson method)

References

- ❖ Eliez, S. (2015). *J'élève un enfant pas comme les autres: Retard mental, autisme, polyhandicap...* Paris: Odile Jacob.
- ❖ Fitzgerald, C. & Withers, P. (2011). 'I don't know what a proper woman means': what women with intellectual disabilities think about sex, sexuality and themselves. *British Journal of Learning Disabilities*, 41, 5-12.
- ❖ Hebernich, D., Reece, M., Schick, V., Sanders, S.A., Dodge, B. & Fortenberry, D. (2010). Sexual behaviors, relationships, and perceived health status among adult women in the United States: Results from a national probability sample. *International Society for Sexual Medicine*, 7(5), 277-290.
- ❖ Jones, L., Bellis, M.A., Wood, S., Hughes, K., McCoy, E., Eckley, L., Bates, G., Mikton, C., Shakespeare, T. & Officer, A. (2012). Prevalence and risk of violence against children with disabilities: a systematic review and meta-analyses of observational studies. *Lancet*, 380, 899-907.
- ❖ McCabe, M.P. (1999). Sexual knowledge, experience and feelings among people with disability. *Sexuality and Disability*, 17(2), 157-170.
- ❖ McCabe, M.P. & Cummins, R.A. (1996). The sexual knowledge, experience, feelings and needs of people with mild intellectual disability. *Education and Training in Mental Retardation and Developmental Disabilities*, 31(1), 13-21.
- ❖ McCabe, M.P., Cummins, R.A. & Reid, S.B. (1994). An empirical study of the sexual abuse of people with intellectual disability. *Sexuality and Disability*, 12(4), 297-306.
- ❖ Murphy, G.H. & Callaghan, A. (2004). Capacity of adults with intellectual disabilities to consent to sexual relationships. *Psychological Medicine*, 34, 1347-1357.

Sexual education books



Thank you for your attention !
...and a big thank you to 22q11
Europe

