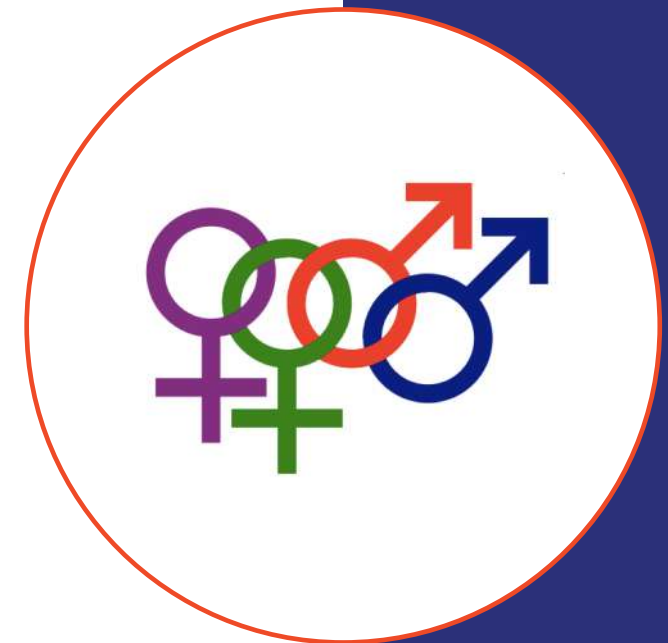


The question of sexuality in adolescents and young adults

Eva Micol

Why study sexuality in the del22q11?

- Sexuality is a major concern among parents of young people with microdeletion 22q11
- No published studies on sexuality among adolescents and young adults with a del22q11 (one in progress : Palmer et al., University Health Network, Toronto, CA)
- Our objective is to provide some reflection points that could be useful for families and professionals



Studies on Sexuality

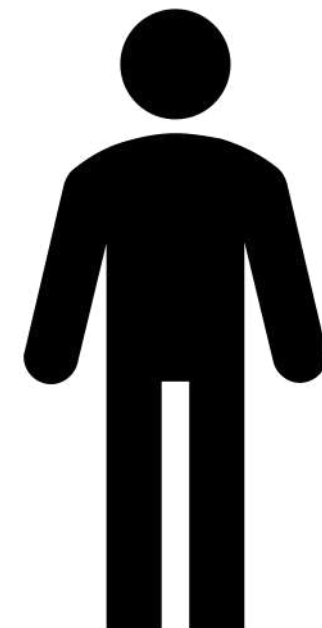
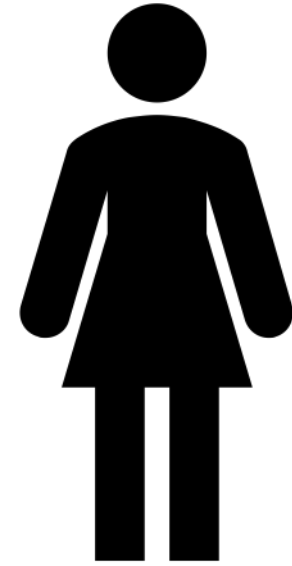
Studies on children, adolescents and adults with intellectual disabilities or cognitive difficulties suggest :

- 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)
- Tendency to have less romantic relationships either because of lack of opportunity or because of lack of social skills (McCabe & Cummins, 1996, McCabe, 1999)
- Tendency to have fewer sexual experiences but more at risk of contracting an STD or having a pregnancy (McCabe & Cummins, 1996, McCabe, 1999)

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**
- Answers
 - Open questions : score of 0, 1 or 2
 - Multiple choice questions



Characteristics of participants

Table 1. *Age*

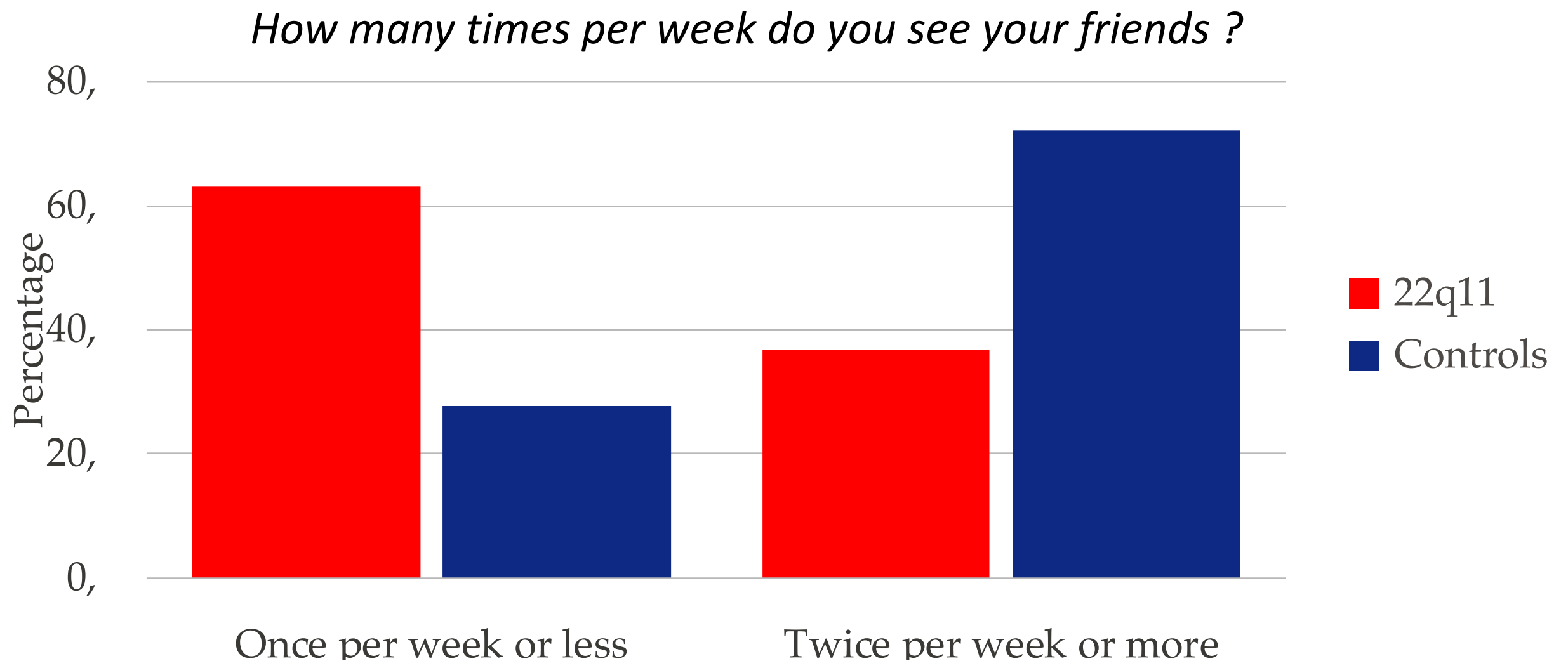
Diagnosis	Gender	N	Minimum Age	Maximum Age	Mean Age
22q11	Girls	21	15.67	31.63	22 ± 3.9
	Boys	24	12.58	27.93	19.67 ± 3.74
Controls	Girls	15	14.66	30.97	45 ± 4.59
	Boys	21	14.35	25.18	18.13 ± 2.99



Total : 81 participants

1. Friendship

Individuals with del22q11 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

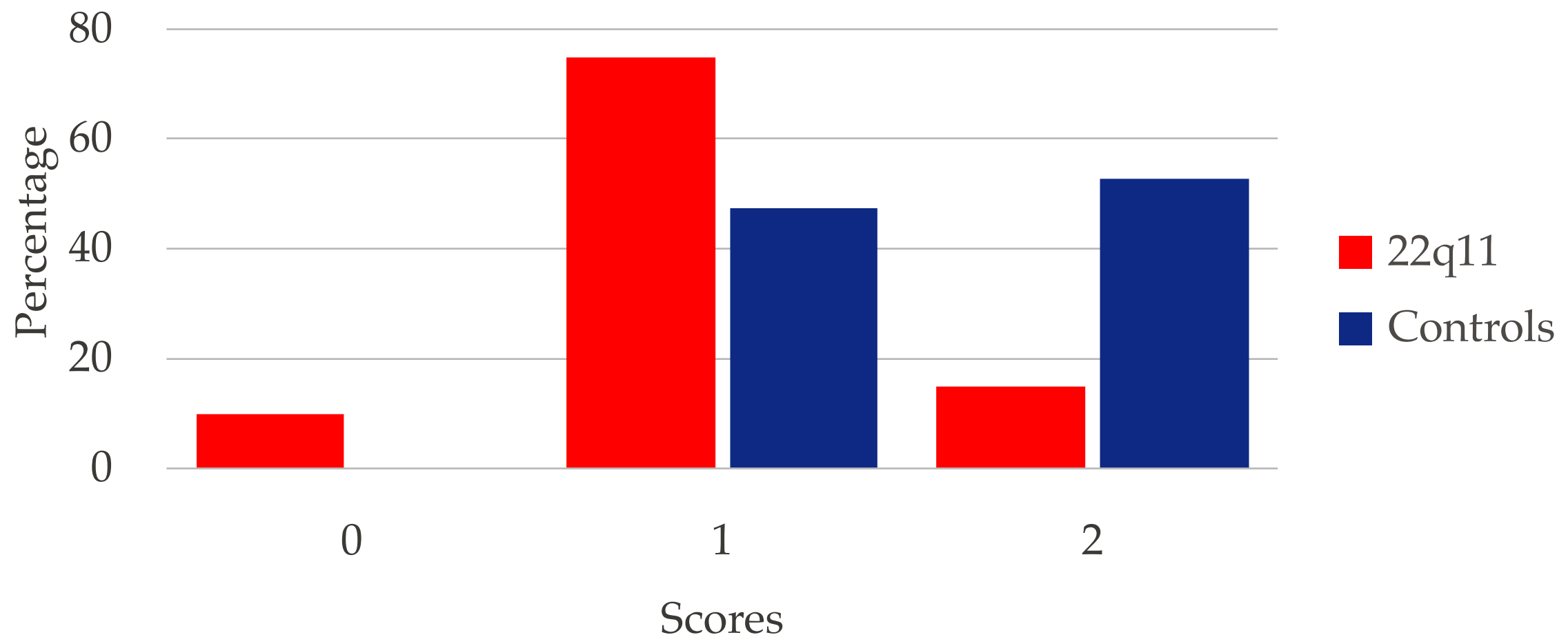
When we know everything of each other

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”?

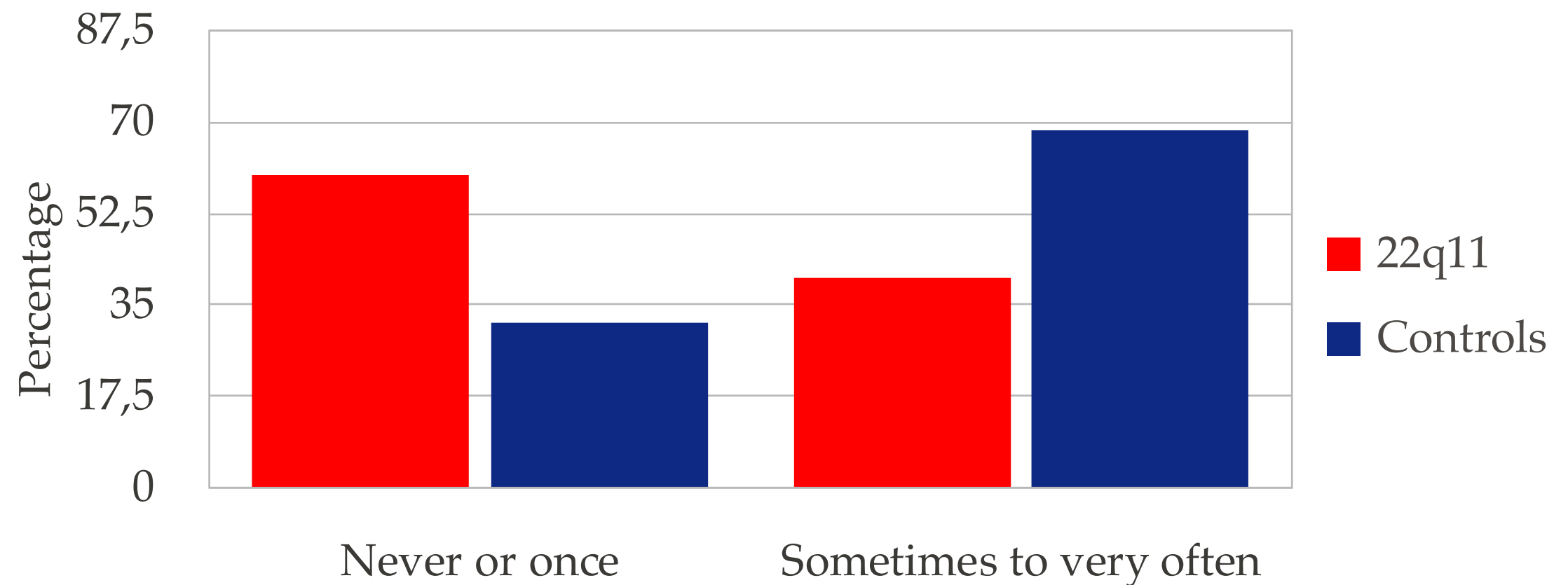
Young people with del22q11 have less knowledge on dates and intimacy



3. Sexual relationships

Del22q11 : a lower level of experience

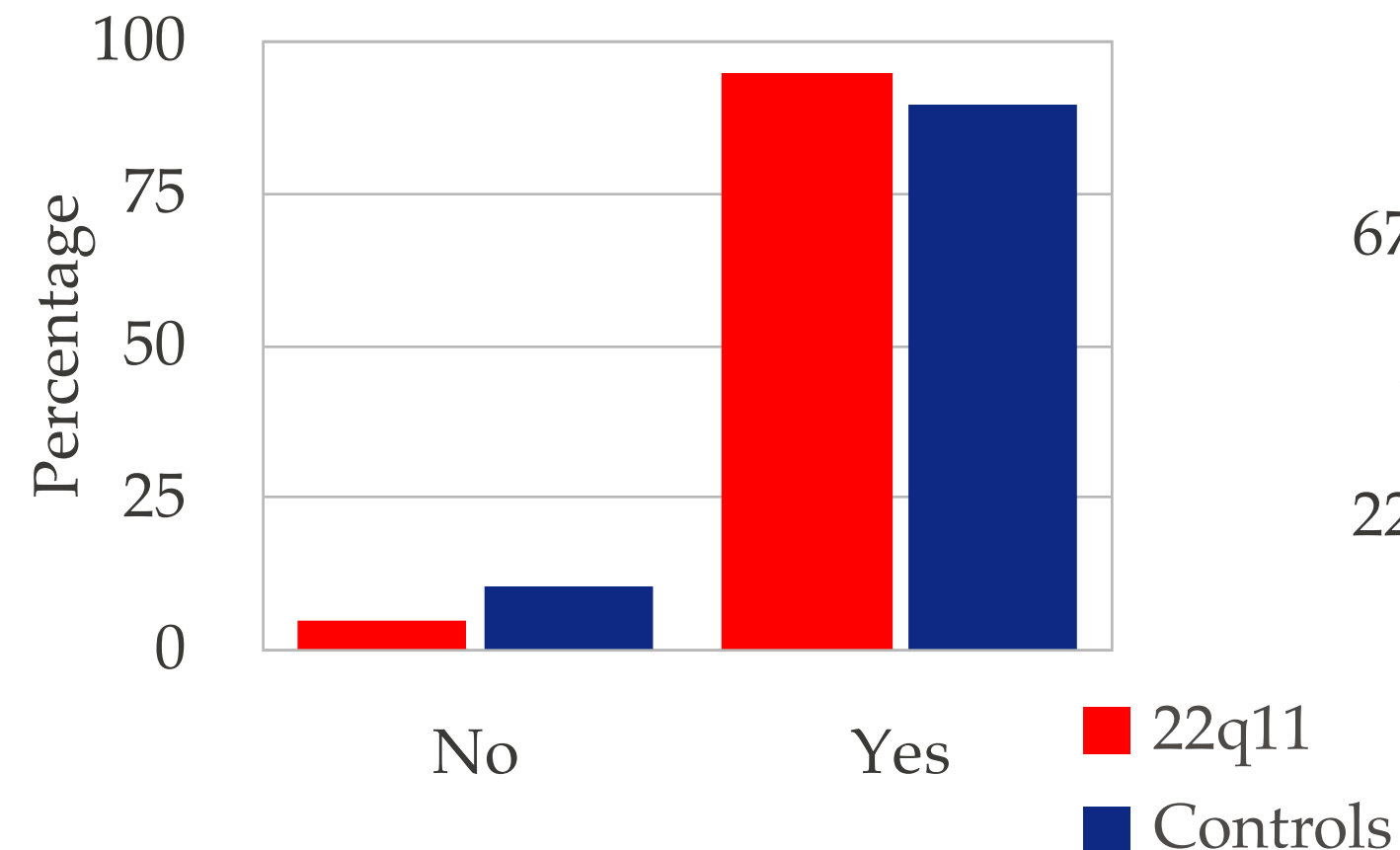
At which frequency do you talk about sexual intercourse with your friends?



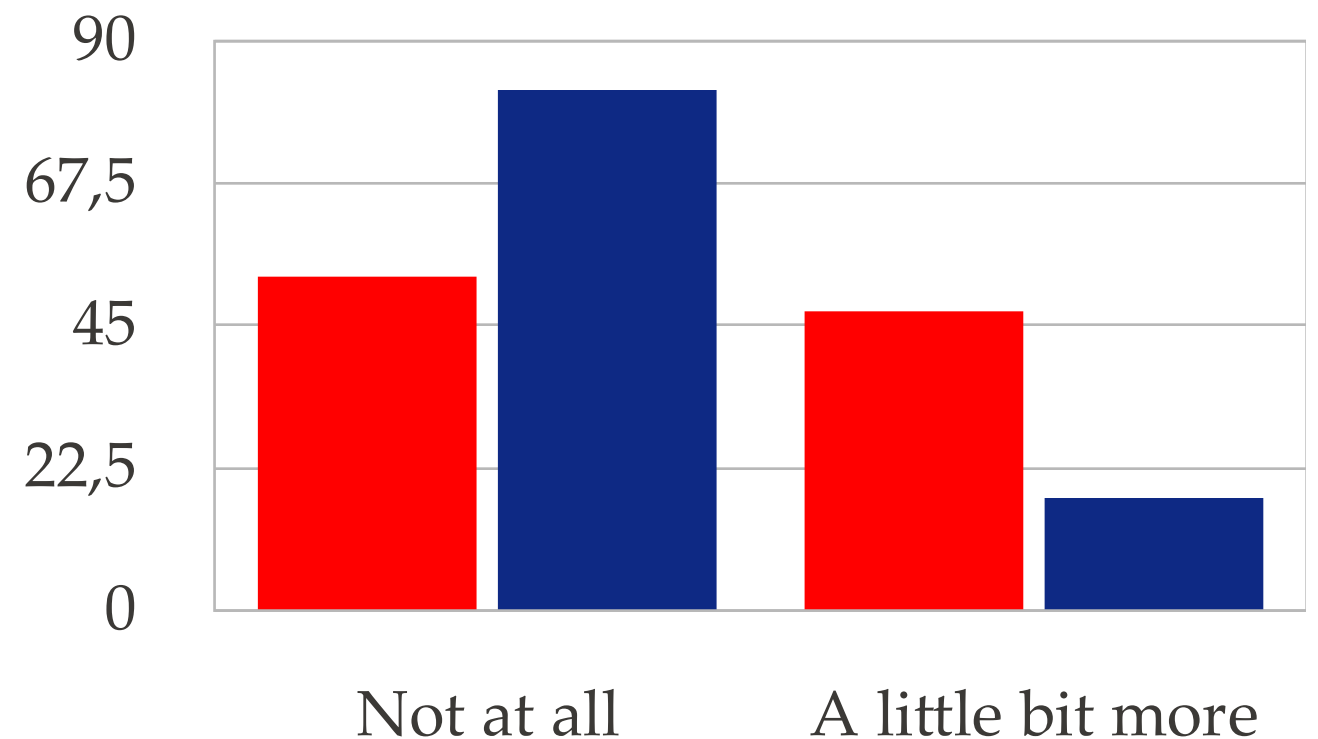
4. Sexual education

No statistical difference found between groups → del22q11 interested to be more informed

Did you ever have a sexual education ?



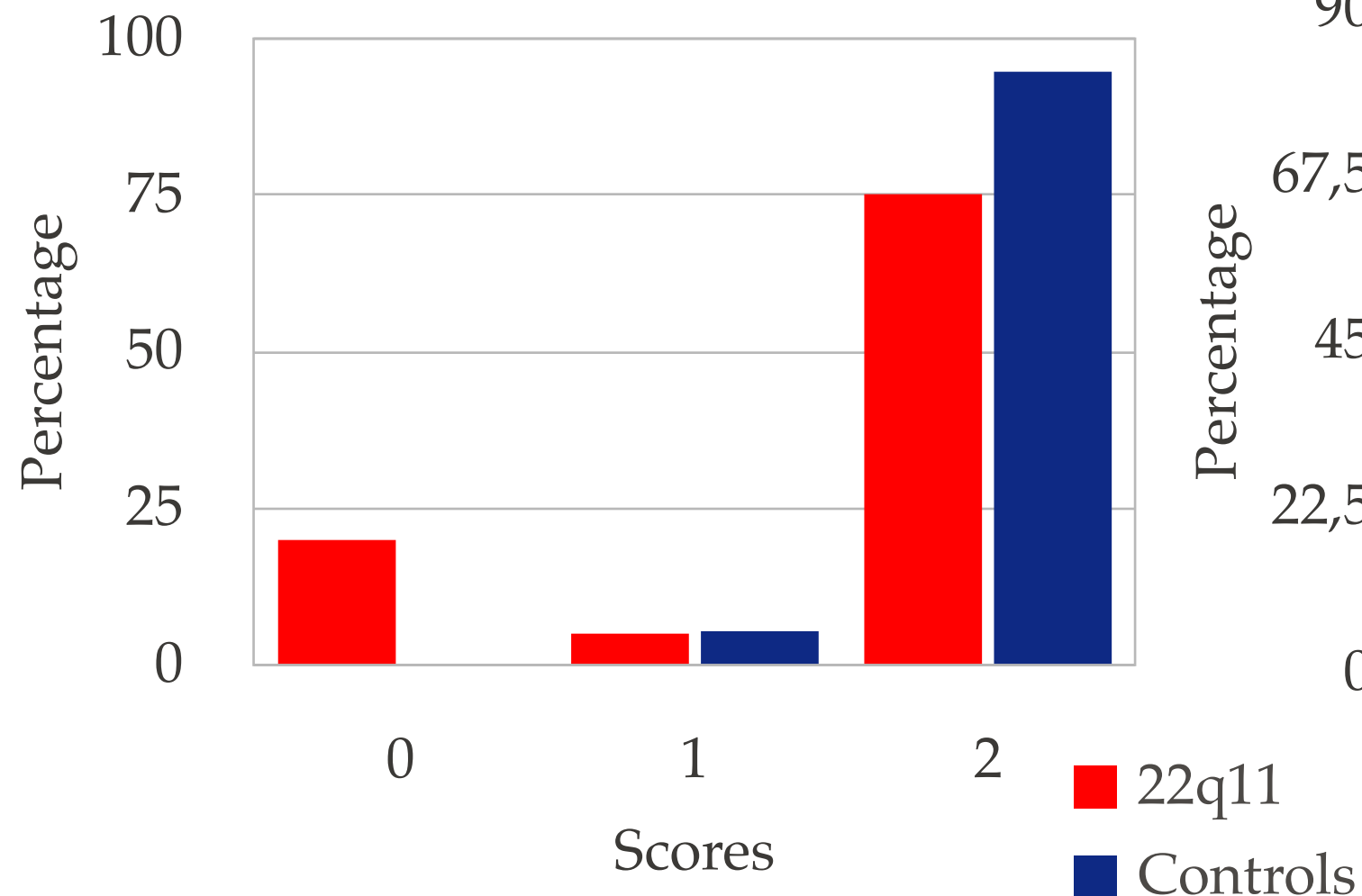
Would you like to learn more about sexual education ?



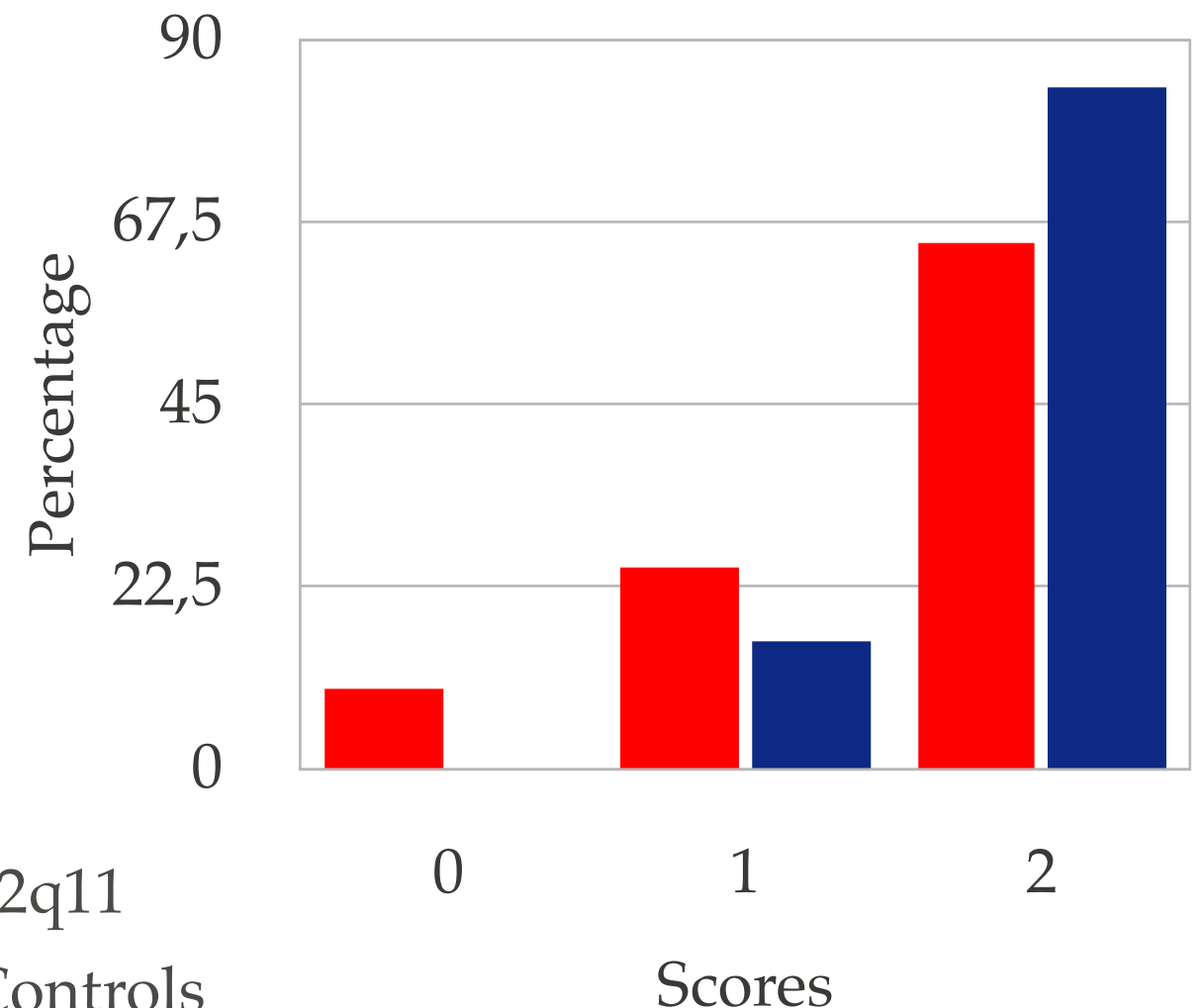
5. The consent

Del22q11 : 25 % did not know how to react in front of a sexual abuse threat

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



How to say "No" ?



Conclusions



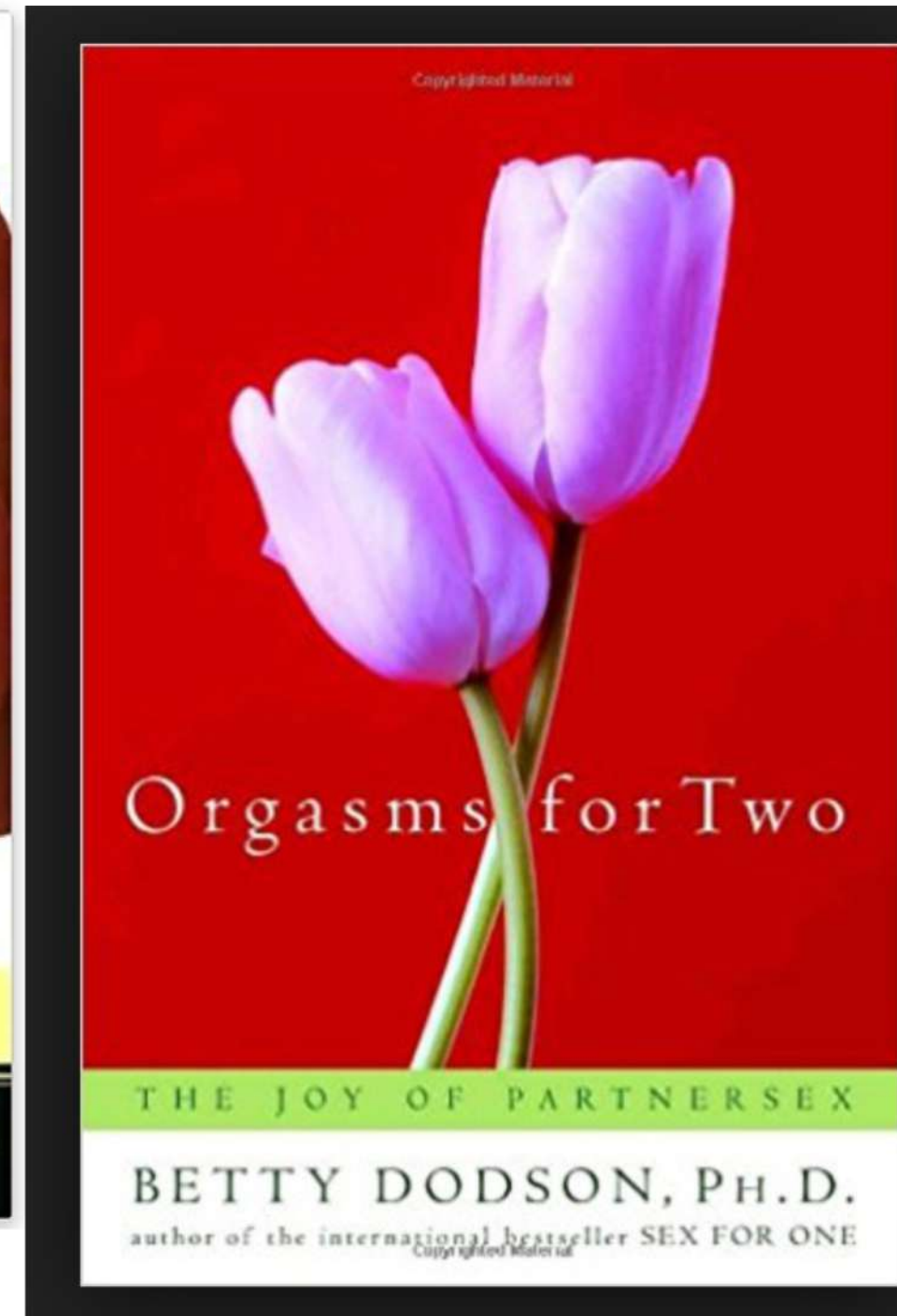
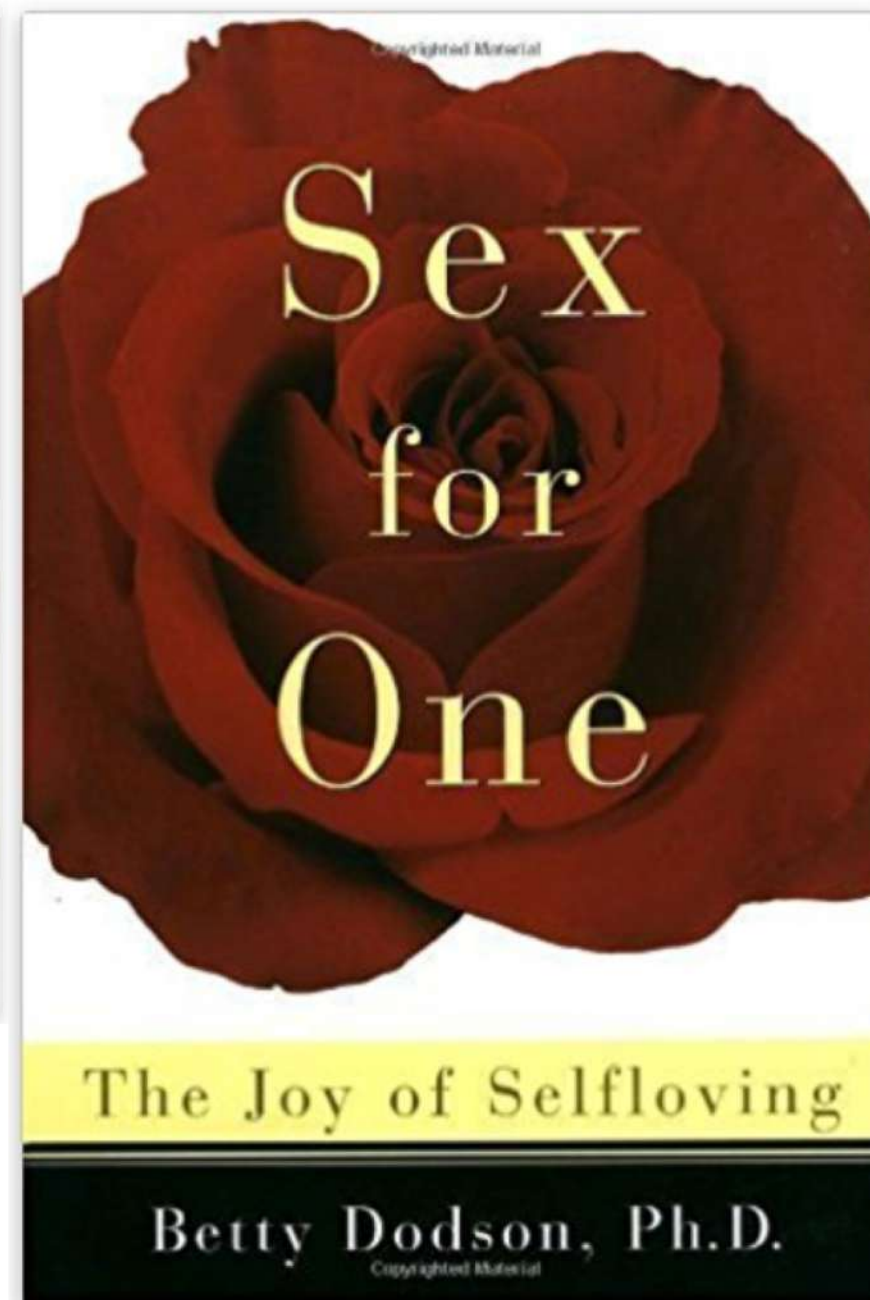
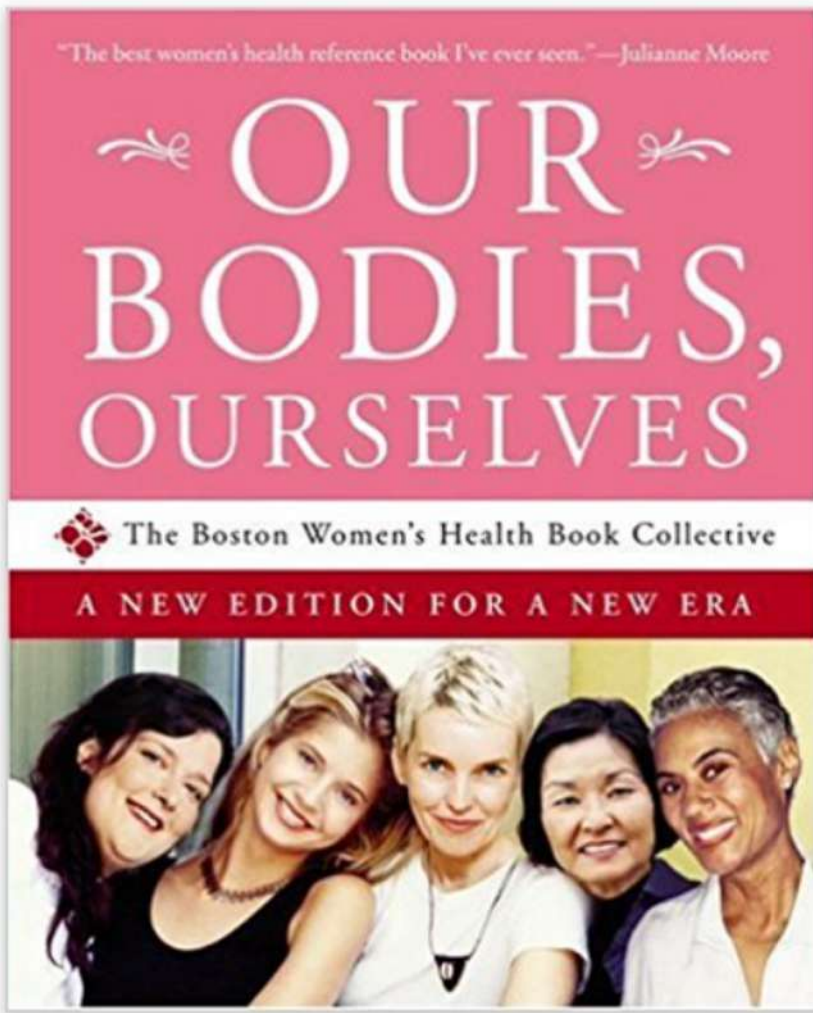
- In almost all fields the level of knowledge is lower among participants with the del22q11
- They say they do not (or barely) feel the need to know more
- Adolescents and adults at risk for STD, pregnancies, abuse and responding with inappropriate behavior
- ➔ **Appropriate sex education !**
- Role of parents
- Provide sexual education that is individualized and appropriate to their **developmental age** and **level of comprehension**
- The importance of visual and realistic aids as well as a practical dimension of teaching

Key topics for individualized sex education

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



Sexual education books



Thank you for your
attention !



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.

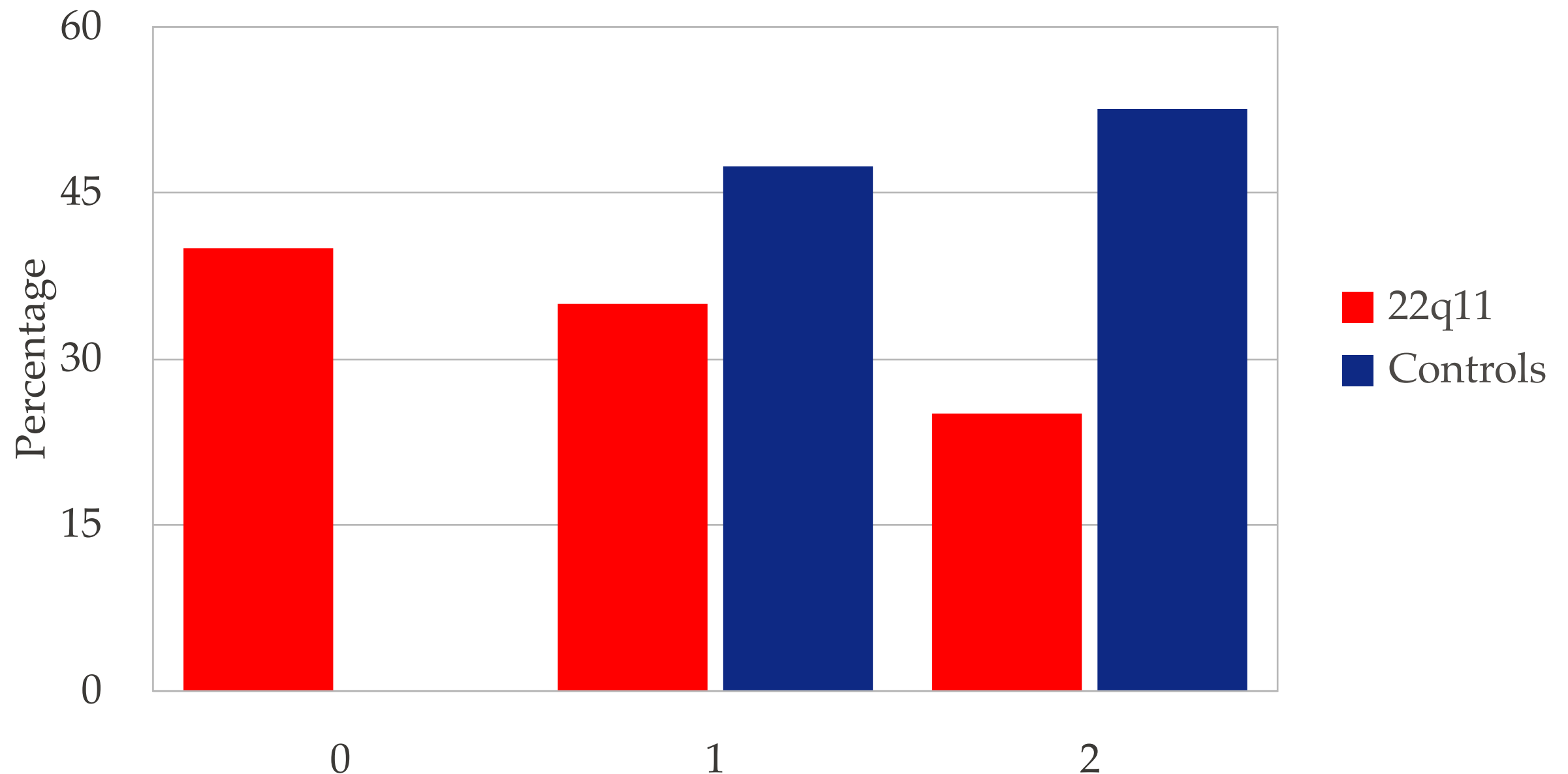
"We have already intercepted SMS messages and Facebook conversations, setting appointments for unknown people after classes to have sex in public toilets or in the person. We talked about it with our son, and he assured us that it did not happen. However, he remains obsessed with this idea. Does his lack of discernment have anything to do with his illness? How can we protect him and respect his intimacy ? "



3. Sexual relationships

Lower level of knowledge among 22q11 participants

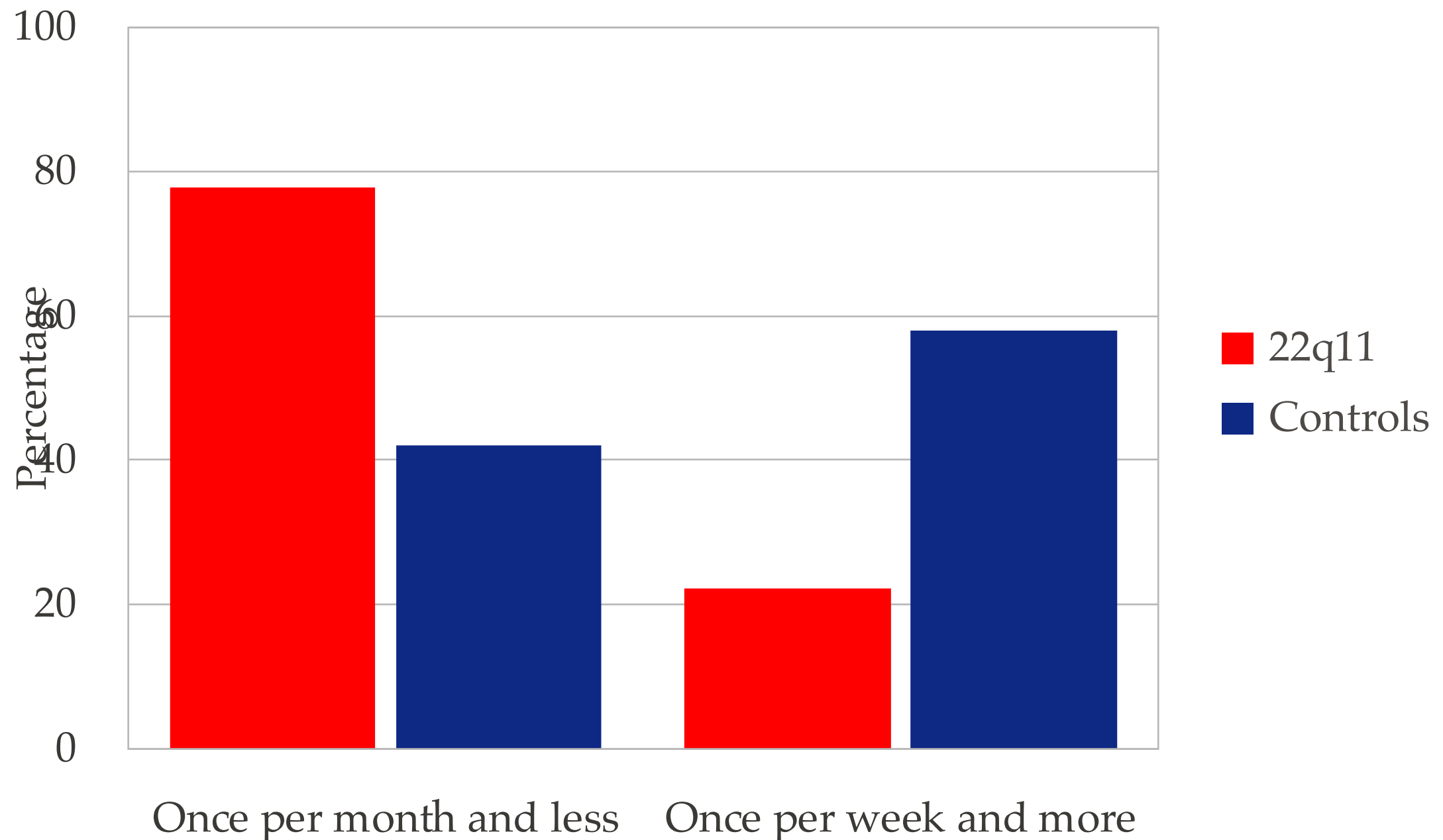
Knowledge : «What is meant by having sex ? »



3. Sexual relationships

Would like to have sex less often

At which frequency would you like to have sexual intercourse?



5. The consent

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

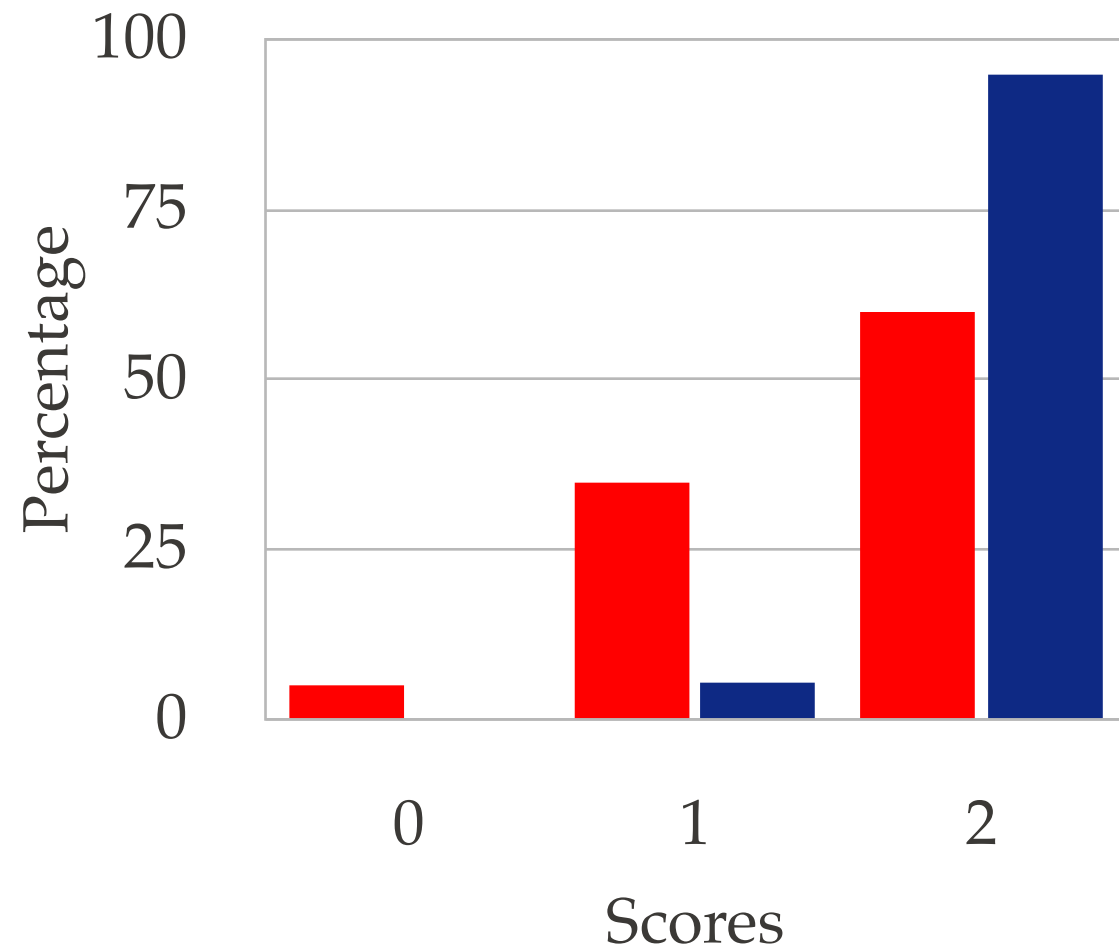
I would say no. If he doesn't understand I push him



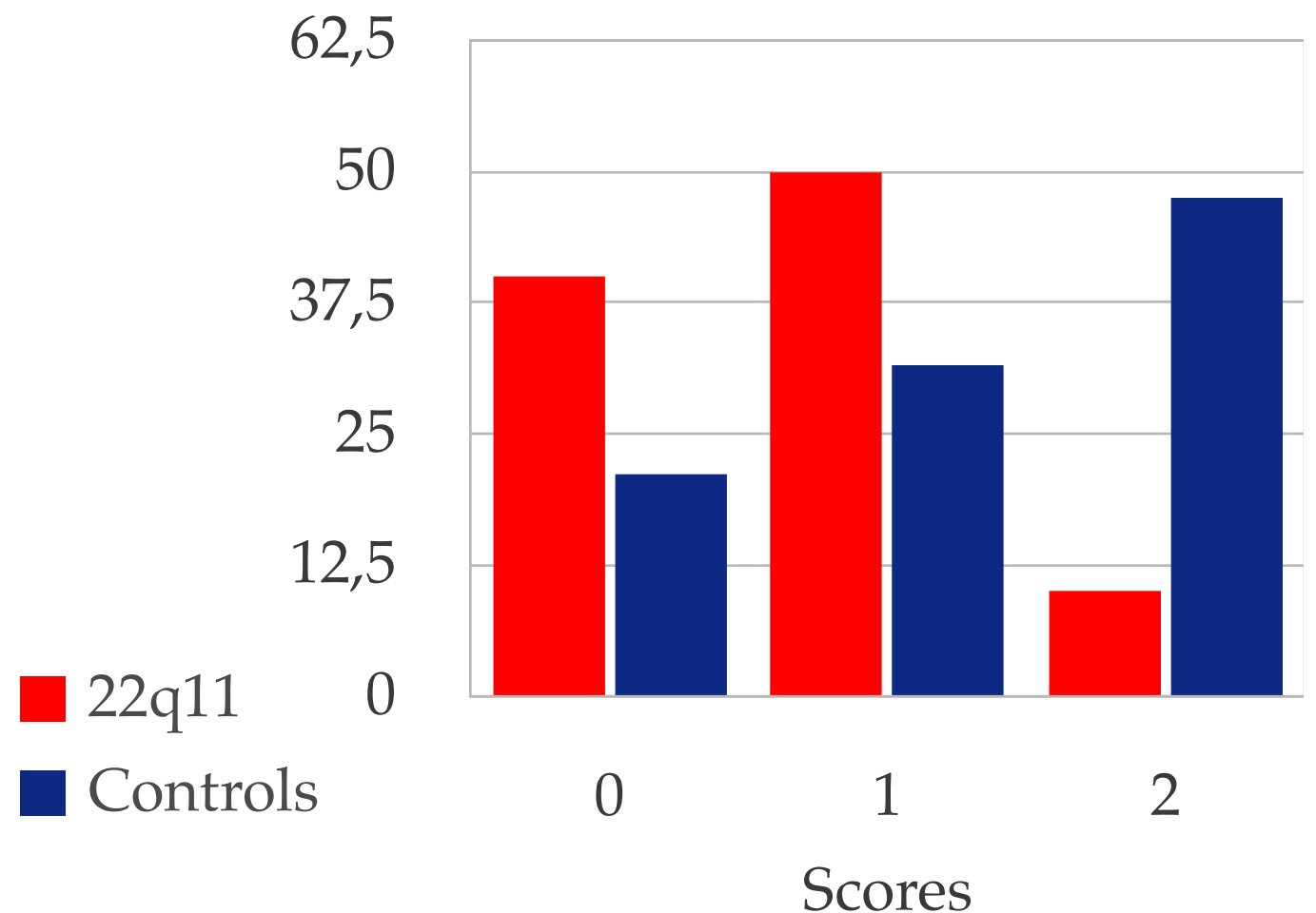
6. The contraception

People with 22q11 have less knowledge on contraception methods

What is a condom ?



Explain me how to put a condom



7. The masturbation

Individuals with 22q11 have less knowledge on masturbation

What is masturbation ?

