

SURVEY ON SEXUALITY AND BODY AWARENESS OF PEOPLE WITH SPINA BIFIDA AND HYDROCEPHALUS

- First general descriptive analysis -

Introduction

The International Federation for Spina Bifida and Hydrocephalus (IF) launched a survey on sexuality and body awareness of people with spina bifida and hydrocephalus (SBH) on January 9, 2019. The questionnaire was created during the second semester of 2018 by a group of young people with SBH and coordinated by IF. The original aim of the questionnaire was to create a solid basis of evidence on what is important for young people about their sexuality and body awareness, breaking taboos and to continue working on the topic. However, given the large number of responses from people with SBH over 35 years of age, the results of the survey take into account what is important to adults with SBH too, actually expanding the scope of the survey.

The questionnaire consisted of 45 questions, the majority of which were multiple choice and others were rating scales. The questionnaire was divided into five sections:

- Introduction
- Self confidence and body awareness
- Sexual life and education
- Medical information
- Final questions

The survey gathered 399 responses. The survey was translated into 7 different languages: English, Italian, Dutch, French, Montenegrin, Turkish and Spanish. Google Modules (an app offered by Google) has been used to develop the survey.

General overview of the survey

In order to understand the results of the survey, it is important to have an overview of the participants. The survey was specifically directed to people with SBH both minors¹ and adults from the age of 18.

IF intended to address young people with SBH from any country, a reason why the choice of sharing the survey through online channels has been highly appropriate for the purpose.

Geographically:

- 78% of respondents come from different parts of Europe (the majority from Italy, Turkey, Ireland, Belgium, Spain, France and Norway)

¹ No minors with SBH have been reached successfully. In order to protect data coming from minors there was a specific box in the survey to insert an email address of a parent and get their consent.



- 3% from Africa (specifically from Algeria, Egypt, Kenya, Nigeria, Tanzania and Zimbabwe)
- 5% from Oceania
- 13% from North and South America (USA, Canada, Chile, Argentina and Panama)
- 1% from the Middle East.

Regarding the **gender**:

- the majority of respondents are females (58%) and fewer males (42%)
- two respondents are gender-fluid
- 4 respondents did not answer the question.

Concerning the **age** of the participants:

- 40% are people over 35 years old
- 37% are people from 26 to 35
- 23% are people from 18 to 25

The majority of respondents from 18 to 25 y/o live with their family (85%) but the percentage is also high for people from 26 to 35 y/o (62%). For people over 35, we can see how 38% live within the family, 26% with their partner and 24% alone.

The rate of **unemployment** is 8% more women unemployed and half of the participants from 26 years old and beyond are self-employed. It is important to take into account that 14% of respondents who are over 35 consider themselves as 'unable to work'.



Gender and age

Within the SBH community:

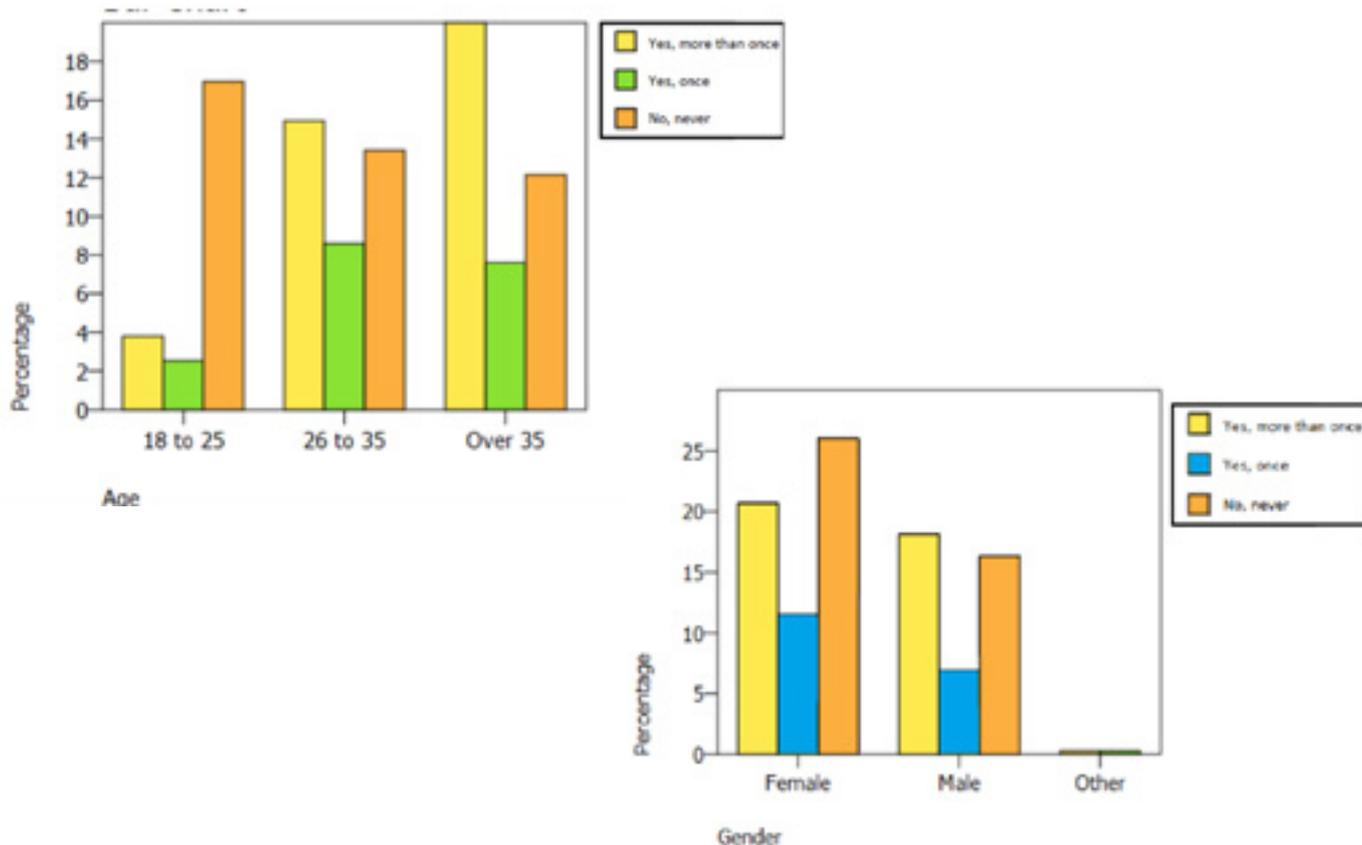
- 62% of women and 52% of men do not have a partner
- fewer women (38%) are in a romantic/sexual relationship than men (48%)
- of those latter respondents, 87% would like to be in a romantic/sexual relationship.

See Table 1: Distribution of values of people who have a romantic/sexual relationship related to gender (percentage values).

| ROMANTIC/SEXUAL RELATIONSHIP % | GENDER | |
|--------------------------------|-----------|-----------|
| | Female | Male |
| Yes | 38 | 48 |
| No | 62 | 52 |
| Total | 100 (229) | 100 (164) |
| Missing values: 4 | | |

People who had sex “more than once” are for the majority over 35 (20%) followed by people from 26 to 35 (15%). Within that group, they are mostly females (32%) and fewer males (25%). People who have never had sex are young people from 18 to 25 (17%).

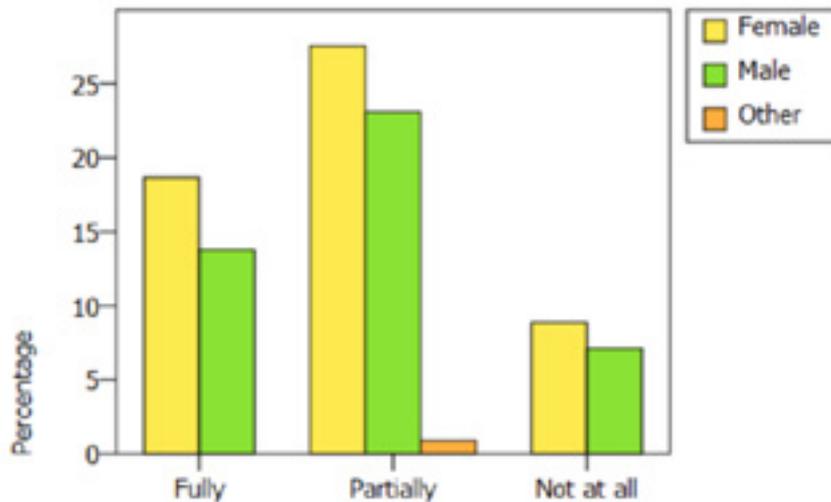
See Graph 1 Distribution of values of people sexually active related to age and gender (percentage values).



From *Graph 2 Distribution of values of satisfaction of sexual life related to gender (percentage values)* it is possible to see that:

- the majority of respondents (both females and males) are “partially” satisfied with their sexual life (28% for women and 23% for men)
- out of that percentage, 19% of women and 14% of men are ‘fully’ satisfied.

See *Graph 2*:



Self-confidence and body awareness

Analysing *Graph 3 Agreement with statements I*, according to the claim “when I have questions about sex, I talk to doctors/friends/parents or look for answers on the Internet”:

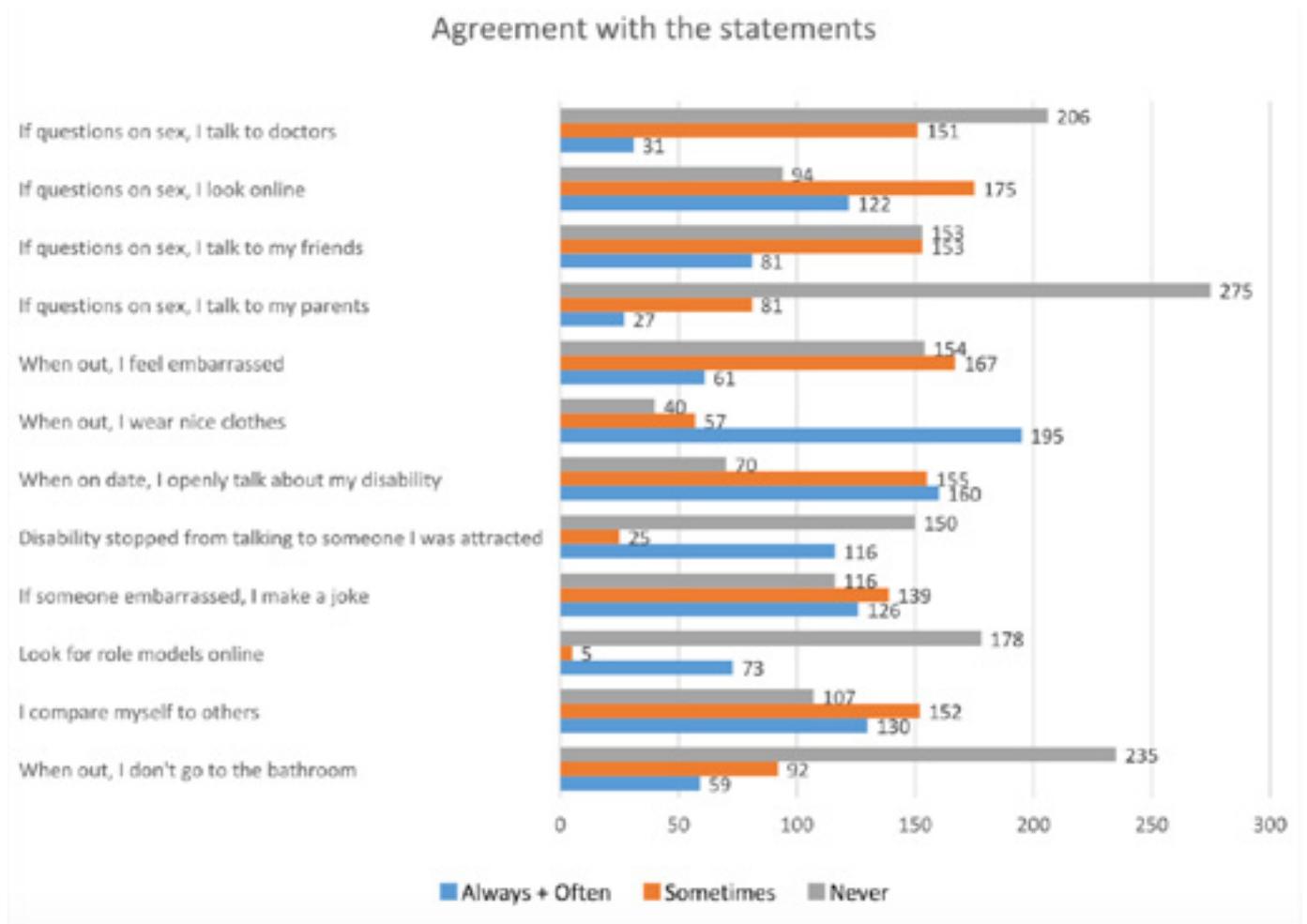
- 275 respondents said they never talk to parents
- 206 never talk to doctors

The most frequent options have been:

- “looking for answers online”: 175 replied ‘sometimes’ and 122 replied ‘always/often’
- “talking to friends”: 153 replied ‘sometimes’ and 81 replied ‘always/often’.



See Graph 3:



It is interesting to better analyse this information since it seems that there are some **differences between people with or without disability**. A longitudinal study (Bleakley et al, 2009) on youth aged 14-16 identifies the sources of information from which adolescents learn about sex. This study also considers the extent to which these sources influence their sexual beliefs and behaviour. The most frequent sources of information mentioned here were friends, followed by teachers, mothers, the media and doctors.

As we observe in both cases (our survey and the longitudinal study) the **mass media** is recognized as an important contributor to sexual knowledge. Some sources may be more influential than others and may emphasise different aspects of sexuality. For example, parents (specifically mothers) might discuss sexual transmittable diseases and the human immunodeficiency virus and try to impart moral views, while adolescents may be learning sexual norms from their peers.

What differs is that our survey shows that for people with SBH, parents and doctors are not identified as the most frequent sources of information. This could probably be related to the overprotective behaviour towards the son/daughter with disabilities and medical providers not always being prepared to provide practical answers when requested.



For instance, parents often accompany their son/daughter with disability to healthcare visits at later ages than their peers without disabilities, inhibiting open conversations about sexual health. This should serve as a reminder that health professionals should make themselves a reliable and safe source for sexual health information by maintaining confidentiality with their (young) adult patients when they address the issue of sexuality and romantic relationships (Berlan & Bravender, 2009).

Another study on youth shows how certain participants made it very clear that they did not want their parents to know about their sexual or romantic life (Akre et al, 2015) and how there is an important gap between information desired by people with SBH and what health professionals are providing (Alexander et al. 2014).

Although the issue of sexual health can be more complex and patient-specific for people living with disabilities, it is imperative that their sexuality be acknowledged and supported with adequate and appropriate information and open discussion by their healthcare providers. Indeed, it seems that standardised sex education in school and/or by parents (Verhoef et al. 2005) is typically insufficient for those living with physical impairments.

Considering the following statements on:

- embarrassment of physical appearance: 167 respondents sometimes feel embarrassed while 61 always/often. Body changes as a result of physical impairments have been linked to anguish over changes in appearance and body image, resulting in individuals withdrawing from social contact (Karlen, 2002), reducing personal well-being. The construction of sexual identity is prevented by the limited perception of the own body, the stereotyped models of perfect bodies in society and relationships that are often based on care (i.e. overprotective parents and partners who tend to be mostly caregivers).
- wearing nice clothes when going out: 195 did this always/often
- not going to the bathroom when being out: 235 said this never happens when being out with friends
- openly talk about disability when on date: 160 did this always/often, 155 only sometimes



Incontinence and sexuality

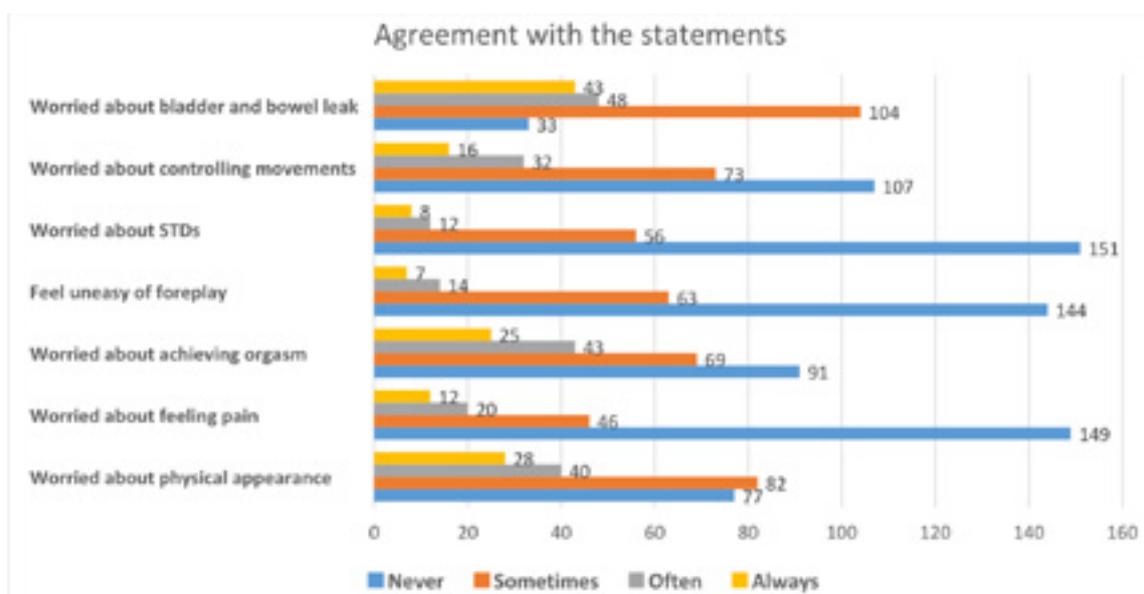
As we can observe in the *Graph 4 Agreement with statements II*, analysing the “always” and “often” answers, what worries most people with SBH are:

- leakage from bladder and bowel during sex (91 answers)
- achieving orgasm (68 answers)
- the way the other partner looks at the physical appearance of the partner with disability (68 answers).

In addition:

- 151 respondents said they have never been worried about contracting STDs during sexual relationships
- 144 respondents never felt uneasy during foreplay
- 149 are not worried of feeling pain during sex.

See *Graph 4*:



A **general concern about leakage from bladder and bowel** was also confirmed as one of the three main reasons for the people that are not sexually active. The impact of incontinence on sexual activities is poorly understood.

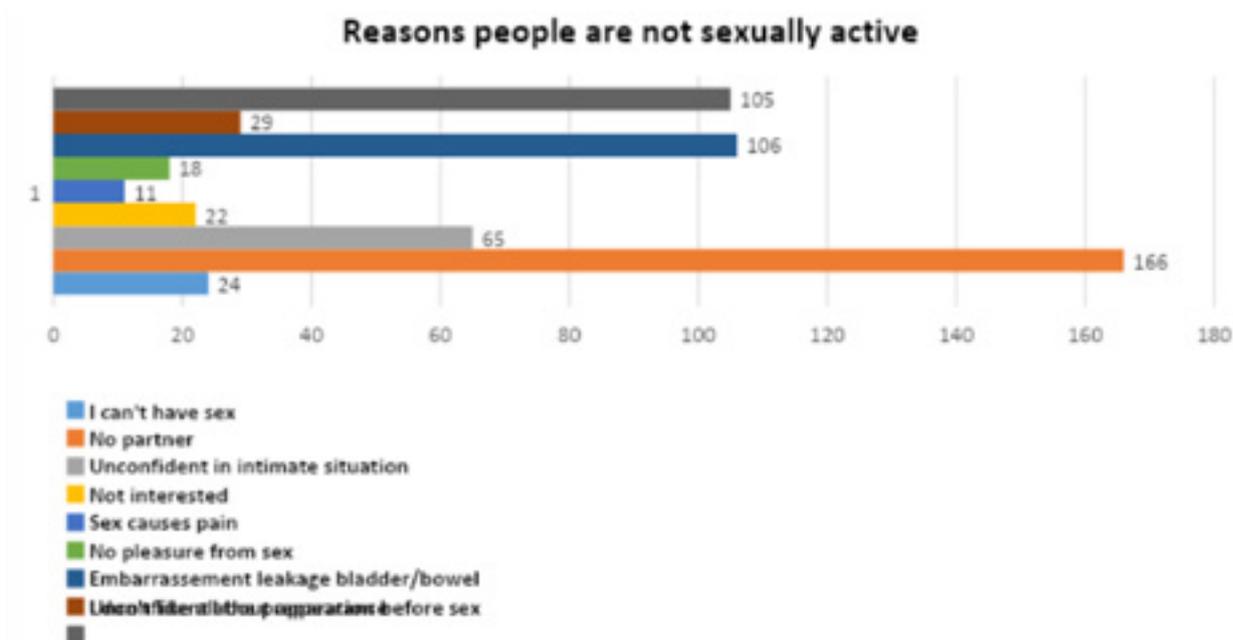
Some studies show that people who have incontinence during sexual intercourse were more likely to report low sexual desire and satisfaction, difficulties with lubrication, pain and orgasm (Laurel R. Imhoff et al., 2012). While these data show that the presence of incontinence and physical disability may discourage sexual activity, Lassmann et al. found that sexual activity was not related to the severity of incontinence.



As can be seen in *Graph 5 Distribution of values of the reasons why people are not sexually active*, the main reasons are:

- they do not have a partner (166 answers)
- embarrassment of leakage of bladder and bowel (106 answers)
- feeling insecure with their own physical appearance (105 answers).

See *Graph 5*:



Regarding contraceptive methods, the results show that the most commonly used and known method is **condom**, however no one mentions that latex¹ allergies can compromise their use as shown by Visconti et al. in 2012. A 2014 pilot study released by the University Medical Center Hamburg-Eppendorf and Children's Hospital Altona analysed prenatal latex sensitization in patients with spina bifida by examining the levels of immunoglobulin E in umbilical cord blood and found these levels higher than the healthy individuals chosen as a control group. Therefore, this study pointed out that this correlation could be positively associated with the occurrence of a latex allergy in the future of a person with SBH. As can be seen in a 2016 SBH Scotland fact sheet, many healthcare products contain latex so people with spina bifida are exposed to it on a regular basis².

The conclusions of this report are presented as part of the output that the 399 participants' responses offer and as a first general overview and analysis of what is important for people with spina bifida and hydrocephalus regarding their sexuality and body awareness.

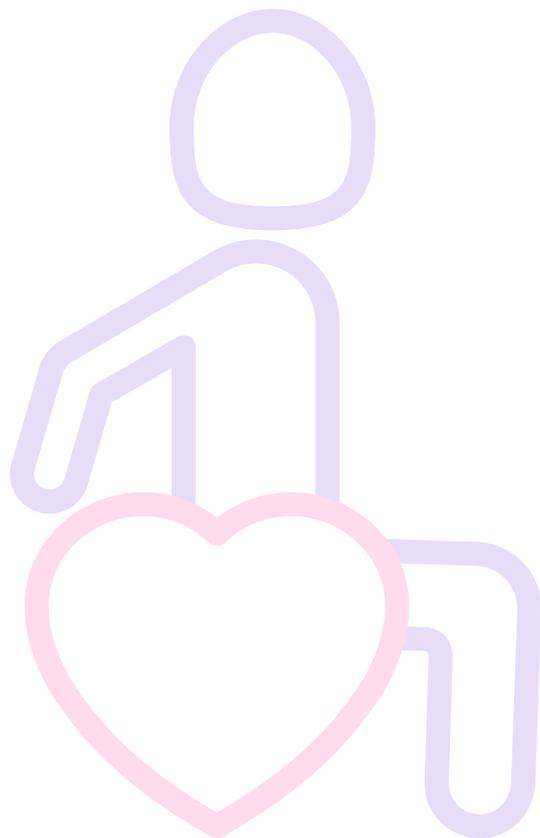
1 Latex is a cloudy white liquid which comes from a rubber tree. Once a liquid has been tapped from the tree, chemicals are added to it which provide the strength and elasticity of many common rubber products (SBH Scotland fact sheet 2016).

2 Some of these products are: household gloves, hospital gloves, condoms, wheelchair tyres, adhesive tapes, urinary catheters and enema tubing, protective sheets, balloons and rubber balls, art supplies, some dental equipment, baby bottle teats and dummies, beach toys, chewing gum



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