

Survey of Sexual Concerns among Little People (Short Statured People)

Consent Form

Survey of Sexual Concerns among Little People (Short Statured People)

You are invited to participate in a brief survey of little people / short statured people (any person diagnosed with a form of dwarfism). I ask that you read this page before agreeing to be in the study.

This study is being conducted by: Brian Zamboni, Ph.D. in the Program in Human Sexuality at the University of Minnesota Medical School

Background Information:

The title of this study is Survey of Sexual Concerns among Little People (Short Statured People). The purpose of this study is to gather information about the degree to which little people / short statured people experience sexual health concerns and if sexual concerns are related to minority stress, body image, depression, or anxiety.

Procedures:

You must be a person who has been diagnosed with any type of dwarfism to participate. You are being asked to complete an online survey that includes questions about sexual concerns, body image, minority stress, depression, and anxiety. The survey takes about 10 minutes to complete.

Risks and Benefits of being in the Study

The risks to you as a participant are minimal. The only risk is that some of the questions may make you feel uncomfortable because some questions relate to human sexuality, body image, depression, and anxiety. If you find participation to be too stressful or uncomfortable, you may exit the survey at any point.

Participation in this study will not benefit you directly. Your participation may benefit others by educating health providers on the sexual health needs of little people and encouraging health care professionals to provide more services to little people / short statured people accordingly.

Confidentiality:

The results of this study may be published in scientific research journals or presented at professional conferences. I am not collecting any identifying data for this study, including names, mailing addresses, or IP addresses. The records of this study will be kept private. In any sort of report I publish, I will not include any information that will make it possible to identify a participant. Research records will be stored securely and only researchers will have access to the records.

Voluntary Nature of the Study:

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the Program in Human Sexuality or the University of Minnesota. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

Contacts and Questions:

If you have questions about this research study, you can contact Dr. Brian Zamboni at

bzamboni@umphysicians.umn.edu or 612-624-7869.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, you are encouraged to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

IRB Code Number 1611S00464

In which area of the world do you live?

- Asia
- Australia
- Canada
- Europe
- Ireland
- South America
- United Kingdom
- United States of America
- Other

If you marked Other, please specify

To which the following organizations do you belong, if any?

- Short Statured People of Australia
- Little People of America
- Other
- None of the Above

If you marked Other, please specify

How would you describe your relationship status?

- Single
- Married
- Divorced
- Separated
- Widow / Widower
- Living together, not married
- Other

If you marked Other, please specify

How do you identify?

- Male
- Female
- Transgender Male
- Transgender Female
- Gender variant
- Other

If you marked Other, please specify

Which of the following matches how you identify?

- heterosexual
- gay or lesbian
- bisexual
- asexual
- Other

If you marked Other, please specify

How old are you today in years?

- 15 or younger
- 16
- 17
- 18
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- 100
- 101 or older

How would you describe your racial-ethnic background?

- Caucasian
- African American
- Latino(a)
- Asian
- Other

If you marked Other, please specify

Which of the following diagnoses do you have?

- Achondroplasia
- Hypochondroplasia
- Pseudoachondroplasia
- Spondyloepiphyseal Dysplasia congenita (SEDC)
- Diastrophic Dysplasia
- Spondyloepimetaphyseal Dysplasia (SEMD)
- Cartilage-hair Hypoplasia
- Kniest Dysplasia
- Morquio Syndrome
- Other

If you marked other, what condition have you been diagnosed with?

If you would like to add any information about your condition or diagnosis, please feel free to make any comments here.

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at All	Several days	Over half the days	Nearly every day
Feeling nervous, anxious or on edge?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not being able to stop or control worrying?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worrying too much about different things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble relaxing?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being so restless that it is hard to sit still?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Becoming easily annoyed or irritable?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling afraid as if something awful might happen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Over the last two weeks, how often have you been bothered by any of the following problems?

	Not at All	Several days	Over half the days	Nearly every day
Little interest or pleasure in doing things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling down, depressed, or hopeless?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble falling or staying asleep, or sleeping too much?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling tired or having little energy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Poor appetite or overeating?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling bad about yourself - or that you are a failure or have let yourself or your family down?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble concentrating on things, such as reading the newspaper or watching television?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thoughts that you would be better off dead, or of hurting yourself in some way?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How frequently have people stared at you because of your physical appearance?

- Not at all
- Rarely
- Sometimes
- Frequently
- Every day

How frequently have people laughed at you because of your physical appearance?

- Not at all
- Rarely
- Sometimes
- Frequently
- Every day

How frequently have people made jokes about you because of your physical appearance?

- Not at all
- Rarely
- Sometimes
- Frequently
- Every day

How frequently have people made rude comments about you because of your physical appearance?

- Not at all
- Rarely
- Sometimes
- Frequently
- Every day

Please indicate if there are other forms of stress, bias, or discrimination you have experienced. (If there is nothing else, please write none.)

How frequently have you experienced the other forms of stress, bias, or discrimination that you noted (if applicable)?

-
- Not at all
 - Rarely
 - Sometimes
 - Frequently
 - Every day
 - Not applicable

My parents talked with me about sexual health matters.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

My religion has provided me with information about sexual health matters.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

My school provided me with education about sexual health matters.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

I have had a medical provider who has asked me about sexual health concerns.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

I have had a therapist or mental health provider who has asked me about sexual health concerns.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

I have asked a medical provider questions about sexual health concerns that I have had.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

I have asked a therapist or mental health provider about sexual health concerns that I have had.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

In this space, please feel free to comment on your experience of sex education over the years.

In this space, please feel free to comment on your experience of sexual health care over the years.

Sexual Functioning

	never	rarely	sometimes	often	every day
Compared with the most enjoyable it has ever been, how enjoyable or pleasurable is your sex life right now?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How frequently do you engage in sexual activity (sexual intercourse, masturbation, etc.) now?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you desire to engage in sexual activity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How frequently do you engage in sexual thoughts (thinking about sex, sexual fantasies) now?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you enjoy books, movies, music or artwork with sexual content?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much pleasure or enjoyment do you get from thinking about and fantasizing about sex?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you become sexually aroused?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you easily aroused?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have adequate vaginal lubrication during sexual activity (get wet)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you become aroused and then lose interest?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you experience an orgasm?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you able to have an orgasm when you want to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you have an erection related or unrelated to sexual activity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you get an erection easily?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you able to maintain an erection?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you experience painful, prolonged erections?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How often do you have an ejaculation?

Are you able to ejaculate when you want to?

How much pleasure or enjoyment do you get from your orgasms?

How often do you have painful orgasm?

I rarely think about how I look.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

I think it is more important that my clothes are comfortable than whether they look good on me.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

I think more about how my body feels than how my body looks.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

I rarely compare how I look with how other people look.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

During the day, I think about how I look many times.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

I often worry about whether the clothes I am wearing make me look good.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

I rarely worry about how I look to other people.

- Strongly Disagree
- Disagree
- Somewhat Disagree
- Neither Agree nor Disagree
- Somewhat Agree
- Agree
- Strongly Agree

I feel positively about my genitals.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

I am satisfied with the appearance of my genitals.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

I would feel comfortable letting a sexual partner look at my genitals.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

I think my genitals smell fine.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

I am satisfied with the size of my genitals.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

I think my genitals work the way they are supposed to work.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

I feel comfortable letting a healthcare provider examine my genitals.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

I am not embarrassed about my genitals.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

What topics did this survey neglect to cover?

Please feel free to make any comments about this survey or the topic, if you wish.
