

Long-Term Follow-Up Study

UNIVERSITY OF MINNESOTA

WOMAN'S EMOTIONAL WELL-BEING INTIMACY SURVEY

University of Minnesota
The Denver Children's Hospital
Children's Hospital of Pittsburgh
Children's Hospital at Stanford University
Dana-Farber Cancer Institute
Children's National Medical Center
U.T.M.D. Anderson Cancer Center
Memorial Sloan Kettering Cancer Center
Texas Children's Hospital
University of California at San Francisco
Seattle Children's Hospital & Medical Center
Toronto Hospital for Sick Children
St. Jude Children's Research Hospital
Children's Hospital of Columbus
Roswell Park Cancer Institute
Mayo Clinic
Children's Health Care - Minneapolis
Children's Hospital of Philadelphia
St. Louis Children's Hospital
Children's Hospital of Los Angeles
UCLA Medical Center
Miller Children's Hospital
Children's Hospital of Orange County
Riley Hospital for Children - Indiana University
UAB/The Children's Hospital of Alabama
University of Michigan - Mott Children's Hospital
Children's Medical Center of Dallas

As part of the Long-Term Follow-up Study, we are asking for your help to better understand the impact of cancer or similar diseases and their treatment on emotional well-being and sexual functioning. In a survey we sent you previously, you agreed to consider participating in a study about this subject matter. Participation in this aspect of the study involves answering a series of questions that will take approximately 30 minutes to complete.

Previous research studies suggest that some women cope well after treatment for cancer or similar illnesses during childhood and adolescence, while others experience difficulties in their psychosexual adjustment. We hope to be able to more accurately describe the issues adult females face. This information will help us better understand the needs of individuals previously treated for cancer or similar illnesses, as well as future patients with these diseases.

Some of the information requested in the questionnaire is of a personal nature. You are free to leave blank any question you are uncomfortable answering. As with all other aspects of your participation in the Long-Term Follow Up Study, information will be kept strictly confidential.

Your help in this very important project is greatly appreciated. If you have any questions or concerns, please call the Long-Term Follow-up Study office at the University of Minnesota at 1-800-775-2167

Our mailing address is:

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Toll-free phone number:

1-800-775-2167

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ccss@epi.umn.edu

Today's date: _____
(Month/day/year)

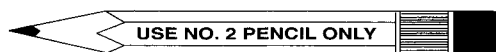


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DO NOT WRITE IN THIS AREA

Please follow these rules in completing this questionnaire. If you have any questions about completing this questionnaire, please call 1-800-775-2167.

1. Use the *No. 2 pencil enclosed* (Please do *not* use pen).
2. Completely darken your answers, that is, fill in the full circle.



CORRECT A B C INCORRECT

3. Make no stray marks of any kind. Other than your responses, please keep the form as clean as possible. Erase cleanly any answer you wish to change. Do not use "white-out".

Instructions: The first section of questions asks about your views of your current health and overall well-being. This information will help us to better understand how you feel and how well you are able to do your usual activities. Answer each question by marking the response that most closely fits your situation. Please read the instructions and items carefully. If you are unsure about how to answer a question, please give the best answer you can.

A.1 In general, would you say your health is: (Mark one)

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

A.2 Compared to one year ago, how would you rate your health in general now? (Mark one)

- 1 Much better now than one year ago
- 2 Somewhat better now than one year ago
- 3 About the same as one year ago
- 4 Somewhat worse now than one year ago
- 5 Much worse now than one year ago

A.3 The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? (Mark one number on each line)

No, Not Limited At All
 Yes, Limited A Little
 Yes, Limited A Lot

ACTIVITIES

- a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports 1 2 3
- b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf 1 2 3
- c. Lifting or carrying groceries 1 2 3
- d. Climbing several flights of stairs 1 2 3
- e. Climbing one flight of stairs 1 2 3
- f. Bending, kneeling, or stooping 1 2 3
- g. Walking more than a mile 1 2 3
- h. Walking several blocks 1 2 3
- i. Walking one block 1 2 3
- j. Bathing or dressing yourself 1 2 3

A.4 During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? (Mark one number on each line)

No
 Yes

- a. Cut down on the amount of time you spent on work or other activities 1 2
- b. Accomplished less than you would like 1 2
- c. Were limited in the kind of work or other activities 1 2
- d. Had difficulty performing the work or other activities (for example, it took extra effort) 1 2

A.5 During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (Mark one number on each line)

No
 Yes

- a. Cut down on the amount of time you spent on work or other activities 1 2
- b. Accomplished less than you would like 1 2
- c. Didn't do work or other activities as carefully as usual 1 2

A.6 During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (Mark one)

- 1 Not at all
- 2 Slightly
- 3 Moderately
- 4 Quite a bit
- 5 Extremely

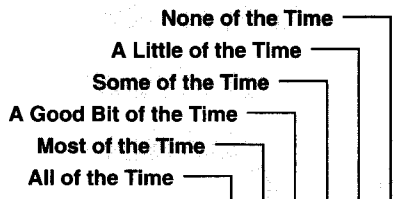
A.7 How much bodily pain have you had during the past 4 weeks? (Mark one)

- ① None
- ② Very mild
- ③ Mild
- ④ Moderate
- ⑤ Severe
- ⑥ Very severe

A.8 During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? (Mark one)

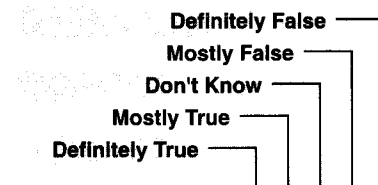
- ① Not at all
- ② A little bit
- ③ Moderately
- ④ Quite a bit
- ⑤ Extremely

A.9 These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks - (Mark one number on each line)



- a. Did you feel full of pep? ① ② ③ ④ ⑤ ⑥
- b. Have you felt very nervous? ① ② ③ ④ ⑤ ⑥
- c. Have you felt so down in the dumps that nothing could cheer you up? .. ① ② ③ ④ ⑤ ⑥
- d. Have you felt calm and peaceful? .. ① ② ③ ④ ⑤ ⑥
- e. Did you have a lot of energy? ① ② ③ ④ ⑤ ⑥
- f. Have you felt downhearted and blue?..... ① ② ③ ④ ⑤ ⑥
- g. Did you feel worn out? ① ② ③ ④ ⑤ ⑥
- h. Have you been happy?..... ① ② ③ ④ ⑤ ⑥
- i. Did you feel tired? ① ② ③ ④ ⑤ ⑥

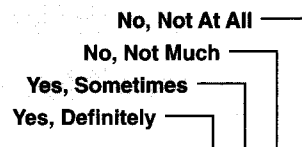
A.10 How TRUE or FALSE is each of the following statements for you? (Mark one number on each line)



- a. I seem to get sick a little easier than other people ① ② ③ ④ ⑤
- b. I am as healthy as anybody I know ... ① ② ③ ④ ⑤
- c. I expect my health to get worse ① ② ③ ④ ⑤
- d. My health is excellent ① ② ③ ④ ⑤

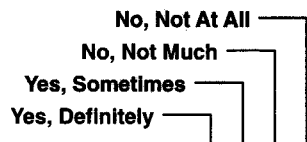
Instructions: In this next section, we will ask you to focus on some physical symptoms that some cancer survivors may experience. Because we are surveying a broad range of individuals who received a variety of medical treatments, some of the issues may apply to you whereas others will not.

We are interested in knowing the extent to which you have been bothered by any of the following problems **DURING THE PAST FOUR WEEKS**. For each physical symptom listed below, please mark the appropriate number on each line, using the scale below.



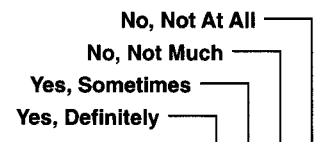
During the past four weeks ...

- B.1 I wake early then sleep badly for the rest of the night ① ② ③ ④
- B.2 I get very frightened or panic feelings for apparently no reason at all ① ② ③ ④
- B.3 I feel miserable and sad ① ② ③ ④
- B.4 I feel anxious when I go out of the house on my own ① ② ③ ④
- B.5 I have lost interest in things ① ② ③ ④
- B.6 I get palpitations or a sensation of "butterflies" in my stomach or chest ① ② ③ ④
- B.7 I still enjoy the things I used to ① ② ③ ④
- B.8 I feel life is not worth living ① ② ③ ④
- B.9 I feel tense or "wound up"..... ① ② ③ ④
- B.10 I have a good appetite ① ② ③ ④
- B.11 I am restless and can't keep still ① ② ③ ④



During the past four weeks ...

- B.12 I am more irritable than usual ① ② ③ ④
- B.13 I worry about growing old ① ② ③ ④
- B.14 I have headaches ① ② ③ ④
- B.15 I feel more tired than usual ① ② ③ ④
- B.16 I have dizzy spells ① ② ③ ④
- B.17 My breasts feel tender or uncomfortable ① ② ③ ④
- B.18 I suffer from backache or pains in my limbs ① ② ③ ④
- B.19 I have hot flashes ① ② ③ ④
- B.20 I am more clumsy than usual ① ② ③ ④
- B.21 I feel rather lively and excitable ① ② ③ ④
- B.22 I have abdominal cramps or discomfort ① ② ③ ④
- B.23 I feel sick or nauseated ① ② ③ ④
- B.24 I have lost interest in sexual activity ① ② ③ ④
- B.25 I have feelings of well-being ① ② ③ ④
- B.26 I have heavy periods ① ② ③ ④
- B.27 I suffer from night sweats ① ② ③ ④
- B.28 My stomach feels bloated ① ② ③ ④
- B.29 I have difficulty in getting off to sleep ① ② ③ ④
- B.30 I often notice pins and needles in my hands and feet ① ② ③ ④
- B.31 I am satisfied with my current sexual relationship (please omit if not sexually active) ① ② ③ ④
- B.32 I feel physically attractive ① ② ③ ④
- B.33 I have difficulty concentrating ① ② ③ ④
- B.34 As a result of vaginal dryness, sexual intercourse has become uncomfortable (please omit if not sexually active) ① ② ③ ④



During the past four weeks ...

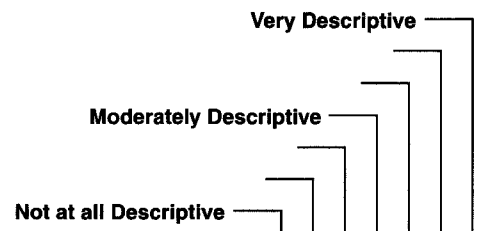
- B.35 I need to pass urine/water more frequently than usual ① ② ③ ④
- B.36 My memory is poor ① ② ③ ④

B.37 Is it very difficult for you to cope with any of the above symptoms?

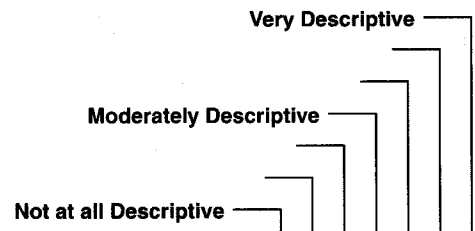
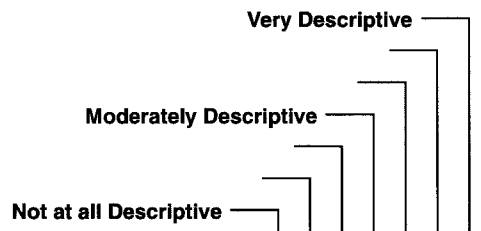
- ① Yes (If so, which ones? Please specify below.)
- ② No

Instructions: In the next section of this survey, we have provided a list of adjectives. For each word, consider whether or not the term describes you. Each adjective is to be rated on a scale ranging from 0 - **not at all descriptive of me** to 6 - **very much descriptive of me**. Choose a number for each adjective to indicate how accurately the adjective describes you. There are no right or wrong answers. Please be thoughtful and honest. Do not spend too much time on any one statement but give the answer that seems to best describe you.

Question: To what extent does the term _____ describe me?



- C.1 Generous ① ② ③ ④ ⑤ ⑥
- C.2 Uninhibited ① ② ③ ④ ⑤ ⑥
- C.3 Cautious ① ② ③ ④ ⑤ ⑥
- C.4 Helpful ① ② ③ ④ ⑤ ⑥
- C.5 Loving ① ② ③ ④ ⑤ ⑥
- C.6 Open-minded ① ② ③ ④ ⑤ ⑥
- C.7 Shallow ① ② ③ ④ ⑤ ⑥



- C.8 Timid (0) (1) (2) (3) (4) (5) (6)
- C.9 Frank (0) (1) (2) (3) (4) (5) (6)
- C.10 Clean-cut (0) (1) (2) (3) (4) (5) (6)
- C.11 Stimulating (0) (1) (2) (3) (4) (5) (6)
- C.12 Unpleasant (0) (1) (2) (3) (4) (5) (6)
- C.13 Experienced (0) (1) (2) (3) (4) (5) (6)
- C.14 Short-tempered (0) (1) (2) (3) (4) (5) (6)
- C.15 Irresponsible (0) (1) (2) (3) (4) (5) (6)
- C.16 Direct (0) (1) (2) (3) (4) (5) (6)
- C.17 Logical (0) (1) (2) (3) (4) (5) (6)
- C.18 Broad-minded (0) (1) (2) (3) (4) (5) (6)
- C.19 Kind (0) (1) (2) (3) (4) (5) (6)
- C.20 Arousable (0) (1) (2) (3) (4) (5) (6)
- C.21 Practical (0) (1) (2) (3) (4) (5) (6)
- C.22 Self-conscious (0) (1) (2) (3) (4) (5) (6)
- C.23 Dull (0) (1) (2) (3) (4) (5) (6)
- C.24 Straight forward (0) (1) (2) (3) (4) (5) (6)
- C.25 Casual (0) (1) (2) (3) (4) (5) (6)
- C.26 Disagreeable (0) (1) (2) (3) (4) (5) (6)
- C.27 Serious (0) (1) (2) (3) (4) (5) (6)
- C.28 Prudent (0) (1) (2) (3) (4) (5) (6)
- C.29 Humorous (0) (1) (2) (3) (4) (5) (6)
- C.30 Sensible (0) (1) (2) (3) (4) (5) (6)
- C.31 Embarrassed (0) (1) (2) (3) (4) (5) (6)
- C.32 Outspoken (0) (1) (2) (3) (4) (5) (6)
- C.33 Level-headed (0) (1) (2) (3) (4) (5) (6)
- C.34 Responsible (0) (1) (2) (3) (4) (5) (6)

- C.35 Romantic (0) (1) (2) (3) (4) (5) (6)
- C.36 Polite (0) (1) (2) (3) (4) (5) (6)
- C.37 Sympathetic (0) (1) (2) (3) (4) (5) (6)
- C.38 Conservative (0) (1) (2) (3) (4) (5) (6)
- C.39 Passionate (0) (1) (2) (3) (4) (5) (6)
- C.40 Wise (0) (1) (2) (3) (4) (5) (6)
- C.41 Inexperienced (0) (1) (2) (3) (4) (5) (6)
- C.42 Stingy (0) (1) (2) (3) (4) (5) (6)
- C.43 Superficial (0) (1) (2) (3) (4) (5) (6)
- C.44 Warm (0) (1) (2) (3) (4) (5) (6)
- C.45 Unromantic (0) (1) (2) (3) (4) (5) (6)
- C.46 Good-natured (0) (1) (2) (3) (4) (5) (6)
- C.47 Rude (0) (1) (2) (3) (4) (5) (6)
- C.48 Revealing (0) (1) (2) (3) (4) (5) (6)
- C.49 Bossy (0) (1) (2) (3) (4) (5) (6)
- C.50 Feeling (0) (1) (2) (3) (4) (5) (6)

Instructions: The next section covers material that is sensitive and personal. These questions are very important in understanding how medical treatment affects one's body and sexuality. If you are unable or do not wish to answer any question, you may leave it blank and go on to the next. Some questions ask about your experience, thoughts and feelings, while others ask about how treatment has affected your intimate relationships. Please answer each question honestly and accurately. Be assured that your responses will be kept completely confidential. Answer the following questions by choosing the most appropriate response for the past month.

- D.1 Do you currently have a sex partner?**
 - (1) Yes
 - (2) No
- D.2 Have you been sexually active during the past month?**
 - (1) Yes (Go to Question D.4)
 - (2) No (Go to Question D.3)



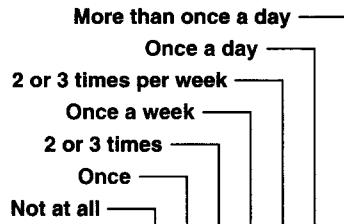
D.3 I am not sexually active because: (Mark all that apply)

- 0 I have never been sexually active.
- 1 I am too tired.
- 2 I am not interested.
- 3 I have a physical problem that makes sexual relations difficult or uncomfortable.
- 4 My partner is not interested.
- 5 My partner is too tired.
- 6 My partner has a physical problem that makes sexual relations difficult or uncomfortable
- 7 I do not have a partner as this time.
- 8 Other (please describe) _____

D.4 During the past month, how frequently have you had sexual thoughts, fantasies, or erotic dreams? (Please mark the most appropriate response.)

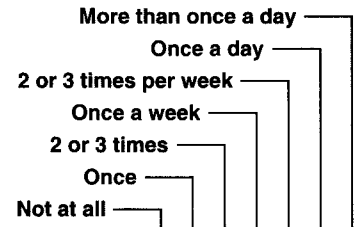
- 0 Not at all
- 1 Once
- 2 2 or 3 times
- 3 Once a week
- 4 2 or 3 times per week
- 5 Once a day
- 6 More than once a day

D.5 Using the scale below, indicate how frequently you have felt an interest or desire to engage in the following specific activities in the past month. (This question is about your thoughts, desires or wishes, not about how you feel during sexual activity.) (For each item, please mark one number that is closest to your experience):



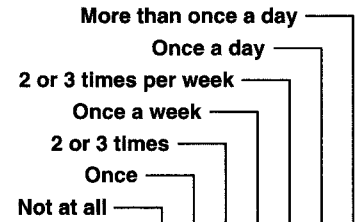
- a. Dreams or fantasy 0 1 2 3 4 5 6
- b. Masturbation 0 1 2 3 4 5 6
- c. Touching, hugging, holding, kissing 0 1 2 3 4 5 6
- d. Petting and foreplay 0 1 2 3 4 5 6
- e. Vaginal intercourse 0 1 2 3 4 5 6
- f. Other sexual activity 0 1 2 3 4 5 6
(please specify below):

D.6 Using the scale below, indicate how frequently you have become aroused by the following sexual activity in the past month. (By arousal, we mean the physical and emotional responses in your body and mind that tell you that you are feeling sexually excited):



- a. Dreams or fantasy 0 1 2 3 4 5 6
- b. Masturbation 0 1 2 3 4 5 6
- c. Touching, hugging, holding, kissing 0 1 2 3 4 5 6
- d. Petting and foreplay 0 1 2 3 4 5 6
- e. Vaginal intercourse 0 1 2 3 4 5 6
- f. Other sexual activity 0 1 2 3 4 5 6
(please specify below):

D.7 Using the scale below, indicate how frequently have you engaged in the following sexual activity in the past month.



- a. Dreams or fantasy 0 1 2 3 4 5 6
- b. Masturbation 0 1 2 3 4 5 6
- c. Touching, hugging, holding, kissing 0 1 2 3 4 5 6
- d. Petting and foreplay 0 1 2 3 4 5 6
- e. Masturbation with a partner 0 1 2 3 4 5 6
- f. Vaginal intercourse 0 1 2 3 4 5 6
- g. Other sexual activity 0 1 2 3 4 5 6
(please specify below):

D.8 During the past month, who has usually initiated sexual activity? (Please mark the most appropriate response.)

- 0 I do not have a partner (Go to Question D.24)
- 1 I have not had sex with a partner during the past month
- 2 I usually have initiated activity
- 3 My partner and I have equally initiated activity
- 4 My partner usually has initiated activity

D.9 During the past month, how have you usually responded to your partner's sexual advances?
(Please mark the most appropriate response.)

- ① No sexual advances during the past month
- ② Usually refused
- ③ Sometimes refused
- ④ Accepted reluctantly
- ⑤ Accepted, but not necessarily with pleasure
- ⑥ Usually accepted with pleasure
- ⑦ Always accepted with pleasure

D.10 During the past month, have you felt pleasure from any sexual activity?

- ① I have had no sexual activity in the past month
- ② I have not felt any pleasure
- ③ Seldom, less than 25% of the time
- ④ Sometimes, about 50% of the time
- ⑤ Usually, about 75% of the time
- ⑥ Always felt pleasure

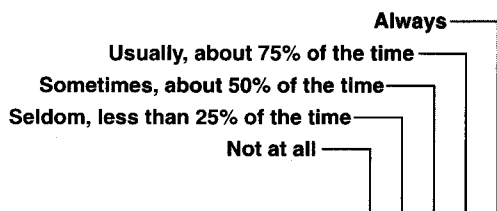
D.11 During the past month, has the frequency of your sexual activity with a partner been: (Please mark the most appropriate response.)

- ① Less than I desired
- ② As much as I desired
- ③ More than I desired

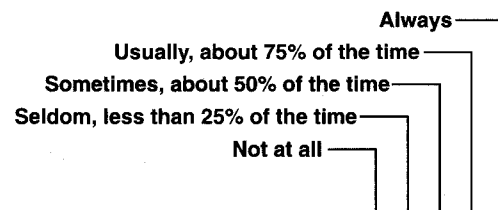
D.12 In the past month, how often have you reached orgasm (climax) during sexual activity?

- ① I have had no sexual activity in the last month.
- ② I have not experienced orgasm.
- ③ Seldom, less than 25% of the time.
- ④ Sometimes, about 50% of the time.
- ⑤ Usually, about 75% of the time.
- ⑥ I always experienced orgasm.

D.13 How frequently in the past month have you had the problems listed below?



- a. Lack of wetness in your vagina as you become sexually excited ① ② ③ ④ ⑤
- b. A long time for your vagina to become wet and slippery as you become sexually excited ① ② ③ ④ ⑤
- c. Lack of sexual desire ① ② ③ ④ ⑤
- d. Lack of sexual arousal ① ② ③ ④ ⑤
- e. Difficulty reaching orgasm ① ② ③ ④ ⑤
- f. Vaginal tightness ① ② ③ ④ ⑤
- g. Painful penetration or intercourse ① ② ③ ④ ⑤
- h. Vaginal bleeding or irritation after penetration or intercourse ① ② ③ ④ ⑤

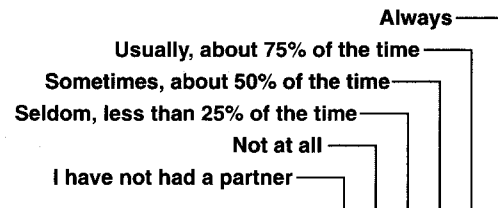


- i. Sharp pain inside or outside your vagina ① ② ③ ④ ⑤
 - j. Increased sensitivity of your skin to intimate touching ① ② ③ ④ ⑤
 - k. Other problem with sexuality ① ② ③ ④ ⑤
- (please specify below):

D.14 Do you use vaginal lubricant?

- ① No
- ② Yes, sometimes
- ③ Yes, almost always

D.15 Using the scale below, indicate the frequency with which the following factors have influenced your level of sexual activity during the past month.



- a. My own health problems (for example, infection, illness) ① ② ③ ④ ⑤
- b. My partner's health problems ① ② ③ ④ ⑤
- c. Conflict in the relationship ① ② ③ ④ ⑤
- d. Lack of privacy ① ② ③ ④ ⑤
- e. Other (please specify below): ① ② ③ ④ ⑤

D.16 During the past month, how frequently have you been able to communicate your sexual desires or preferences to your partner? (Please mark the most appropriate response.)

- ① I have been unable to communicate my desires or preferences
- ② Seldom, about 25% of the time
- ③ Sometimes, about 50% of the time
- ④ Usually, about 75% of the time
- ⑤ I was always able to communicate my desires or preferences

D.17 Overall, how satisfied have you been with your sexual relationship with your partner? (Please mark the most appropriate response.)

- ① Very satisfied
- ② Somewhat satisfied
- ③ Neither satisfied nor dissatisfied
- ④ Somewhat dissatisfied
- ⑤ Very dissatisfied

D.18 Overall, how satisfied do you think your partner has been with your sexual relationship? (Please mark the most appropriate response.)

- ① Very satisfied
- ② Somewhat satisfied
- ③ Neither satisfied nor dissatisfied
- ④ Somewhat dissatisfied
- ⑤ Very dissatisfied

D.19 Please rate how satisfied you have been with your ability to share warmth and intimacy in the past month by marking the number from 0 - 10 (0 = not at all satisfied, 10 = extremely satisfied).

Not at all ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩ Extremely

D.20 Please rate how comfortable you have been with touching, hugging or holding your partner in the past month by marking the number from 0 - 10 (0 = not at all satisfied, 10 = extremely satisfied).

Not at all ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩ Extremely

D.21 How satisfied are you with the overall appearance of your body? (Please mark the most appropriate response.)

- ① Very satisfied
- ② Somewhat satisfied
- ③ Neither satisfied nor dissatisfied
- ④ Somewhat dissatisfied
- ⑤ Very dissatisfied

D.22 Please rate how interested you have been in sexual thoughts, feelings, or actions in the past month by marking the number from 0 - 10 (0 = not at all interested, 10 = extremely interested).

Not at all ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩ Extremely

D.23 Please rate the extent to which sexual activity has been satisfying for you in the past month by marking the number from 0 - 10 (0 = not at all satisfying, 10 = extremely satisfying).

Not at all ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩ Extremely Satisfying

D.24 Overall, how important a part of your life is your sexual activity? (Please mark the most appropriate response.)

- ① Not at all important
- ② Somewhat unimportant
- ③ Neither important nor unimportant
- ④ Somewhat important
- ⑤ Very important

D.25 Mark the number that corresponds to the statement that best describes your sexual experience.

- ① Entirely heterosexual
- ② Largely heterosexual, but some homosexual experience
- ③ Largely heterosexual, but considerable homosexual experience
- ④ Equally heterosexual and homosexual
- ⑤ Largely homosexual, but considerable heterosexual experience
- ⑥ Largely homosexual, but some heterosexual experience
- ⑦ Entirely homosexual

Thank you for completing this questionnaire. All your responses will be kept strictly confidential. If you have any comments that you would like to share with us regarding your experiences or additional responses to this questionnaire, please feel free to write them on this page or on a separate piece of paper.

Use this space for any additional comments you may have.

After completing this questionnaire, please return by using the enclosed envelope, and mail to:

Long-Term Follow-Up Study
Department of Pediatrics
University of Minnesota
420 Delaware St. SE, MMC 715
Minneapolis, MN 55455

Again, thank you for your help and your participation in this study!