

Codebook

1995

"V" series

VID CODE

Write your 4 or 5 digit ID number here

# MIDLIFE WOMEN'S HEALTH SURVEY SPRING 1995

Please complete and return in enclosed envelope. Be sure you have written your ID on the survey (the number is on the upper left of your address label).

### Menstrual and Menopausal Status

V1  
(1)

1. Some of us are experiencing changes in our menstrual cycles, others are finished menstruating, and still others are cycling as usual. Please circle the ONE statement that best describes your current menstrual status. (Read all the choices first.)

- 1 I AM MENSTRUATING IN MY REGULAR PATTERN
- 2 MY PERIODS ARE CHANGING OR HAVE CHANGED (AMOUNT, LENGTH, SPACING, ETC) FROM MY REGULAR PATTERN
- 3 I AM NOT SURE I'M STILL MENSTRUATING BECAUSE I HAVEN'T HAD A PERIOD FOR AT LEAST 3 MONTHS

V1-3A (4) 4 A. When was your last period? (month and year) \_\_\_\_\_  
4 I HAVEN'T MENSTRUATED FOR ONE FULL YEAR ("POSTMENOPAUSAL")

V1-4A (4) A. When was your last period? (month and year) \_\_\_\_\_

V1-4B (2) B. How old were you when your periods stopped naturally? \_\_\_\_\_

5 I STARTED HORMONE THERAPY WHILE I WAS STILL HAVING MENSTRUAL PERIODS, AND NOW GET HORMONE-RELATED PERIODS.

6 I HAD A HYSTERECTOMY

V1-6A (4) A. When? (month and year) \_\_\_\_\_

V1-6B (2) B. How old were you? \_\_\_\_\_

- V1-6C (1) C. For what reason?
- 1 FIBROID TUMORS
  - 2 HEAVY BLEEDING
  - 3 CANCER
  - 4 PROLAPSE OF BLADDER, RECTUM, ETC.
  - 5 OTHER \_\_\_\_\_

6=1 & 2

V1-6D (1) D. Were your ovaries also removed?  
1 YES  
0 NO

Changes. Once again, we are interested in any changes you may have experienced in the last year.

2. Have you noticed any of the following changes in your periods in the last year? (Circle "9" if you no longer have periods)

V2a (1)

	<u>YES</u>	<u>NO</u>	<u>N.A.</u>	
1	0	9	1	a. They are further apart.
1	0	9	2	b. They are closer together.
1	0	9	3	c. They last longer.
1	0	9	4	d. They last fewer days.
1	0	9	5	e. You bleed more heavily, on some or all days.
1	0	9	6	f. You bleed more lightly, on some or all days.
1	0	9	7	g. You pass clots.
1	0	9	8	h. You find the texture, color, or odor of the blood is different.

V2h (1)

3. Have you noticed any of the following changes in your emotional state in the last year?

	YES	NO	
V3a (1)	1	0	a. You are less irritable now.
	1	0	b. You are more irritable now.
	1	0	c. You are more sad or depressed now.
	1	0	d. You are less sad or depressed now.
	1	0	e. You are more energetic and productive now.
	1	0	f. You are less energetic and productive now.
	1	0	g. You feel more upset in general now.
V3h (1)	1	0	h. You feel less upset in general now.

4. Have you begun to notice symptoms usually associated with PMS in the last year?

V4 (1) 1 YES 0 NO

5. Have you noticed any of the following changes in your body in the past year?

	YES	NO	
V5a (1)	1	0	1 a. Your vagina is drier (less lubrication).
	1	0	2 b. You are putting on weight.
	1	0	3 c. Your breasts have changed in size.
	1	0	4 d. Your skin texture has changed (e.g. wrinkles, saggy, dry)
	1	0	7 e. You feel tired more of the time.
	1	0	8 f. You are more energetic than you used to be.
	1	0	9 g. You are more sensitive to touch.
	1	0	10 h. You experience more stiffness or joint pain.
V5i (1)	1	0	11 i. Your muscle tone has decreased.

6. Have you noticed any changes in your sexuality in the last year? Use this scale to describe the way each of the following has changed. (If you have experienced no change, circle "4." If an item does not apply to you, circle "9.")

1	GREATLY REDUCED	5	SLIGHTLY INCREASED
2	MODERATELY REDUCED	6	MODERATELY INCREASED
3	SLIGHTLY REDUCED	7	GREATLY INCREASED
4	UNCHANGED	9	NOT APPLICABLE

(Circle one for each item)

V6a (1)	a. Desire for nongenital sexual activity with a partner (hugging, cuddling, kissing, etc.)	1 2 3 4 5 6 7 9
	b. Becoming aroused (turned-on) through nongenital sexual activity with a partner	1 2 3 4 5 6 7 9
	c. Enjoyment of nongenital sexual activity with a partner	1 2 3 4 5 6 7 9
	d. Ease of orgasm through nongenital sexual activity with a partner	1 2 3 4 5 6 7 9
	e. Desire for genital sexual activity with a partner	1 2 3 4 5 6 7 9
	f. Becoming aroused (turned-on) through genital sexual activity with a partner	1 2 3 4 5 6 7 9
	g. Enjoyment of genital sexual activity with a partner	1 2 3 4 5 6 7 9
	h. Ease of orgasm through genital sexual activity with a partner	1 2 3 4 5 6 7 9
	i. Desire for self-stimulation (masturbation)	1 2 3 4 5 6 7 9
	j. Becoming aroused (turned-on) through self-stimulation	1 2 3 4 5 6 7 9
	k. Enjoyment of self-stimulation	1 2 3 4 5 6 7 9
	l. Ease of orgasm through self-stimulation	1 2 3 4 5 6 7 9
	m. Pain during genital sex	1 2 3 4 5 6 7 9
V6n (1)	n. Other (Please explain _____)	1 2 3 4 5 6 7 9

7. As you move/moved through the menopausal transition, who or what was most helpful or supportive to you? Was it your family, or your mother, or friends, or your health care provider, or a particular book or magazine, or even being in this study? And, was anyone/anything a disappointment to you? Please explain.

V7a1 (2)  
 V7a2 (2)  
 V7a3 (2) } Part A (supportive). Code up to 3 2-digit items  
 V7b (1) } Part B (disappointing). Code one 1-digit item

8. How would you describe your level of sexual desire at the present time?

- V8(1)
- |   |          |   |        |
|---|----------|---|--------|
| 1 | STRONG   | 3 | WEAK   |
| 2 | MODERATE | 4 | ABSENT |

**Health and Well-Being**

9. By telling us which of the following conditions you have experienced in the last year or so, you will help us gain a better understanding of midlife women's health issues. Indicate how often you have experienced each item by circling 1, 2, 3 or 4 for each item.

V9a(1)

	VERY OFTEN	OCCASIONALLY	RARELY	NEVER OR HARDLY EVER
a. Hot flashes 1	1	2	3	4
b. High energy 3	1	2	3	4
c. Headaches/migraines 5	1	2	3	4
d. Insomnia 6	1	2	3	4
<hr/>				
e. Weight gain 7	1	2	3	4
f. Feeling calm (focused) 8	1	2	3	4
g. Food cravings 9	1	2	3	4
h. Irritability/anger 10	1	2	3	4
<hr/>				
i. Feeling unattractive 11	1	2	3	4
j. Heart palpitations 12	1	2	3	4
k. Urinary tract infections 13	1	2	3	4
l. Diarrhea 14	1	2	3	4
<hr/>				
m. Joint pain 15	1	2	3	4
n. Anxiety 16	1	2	3	4
o. Fatigue 17	1	2	3	4
p. Depression/sadness 18	1	2	3	4
<hr/>				
q. Vaginal dryness 19	1	2	3	4
r. Incontinence 20	1	2	3	4
s. Facial hair growth 21	1	2	3	4
t. Memory loss 22	1	2	3	4
<hr/>				
u. Fibroids 23	1	2	3	4
v. Endometriosis 24	1	2	3	4
w. Other 25	1	2	3	4

V9w(1)

10. Overall, how would you rate your physical and emotional health these days? (Circle one in each list)

V10A(1) →

A. <u>Physical Health</u>	B. <u>Emotional Health</u>
1 VERY POOR	1 VERY POOR
2 POOR	2 POOR
3 FAIR	3 FAIR
4 GOOD	4 GOOD
5 VERY GOOD/EXCELLENT	5 VERY GOOD/EXCELLENT

V10B(1) →

11. Could you explain how you decided on your answers to Question 10 above? For example, did you decide on the basis of your menopausal experiences, or sick days, or what's going on in your life these days, or the results of your last physical, or how fit you feel, or other factors? Please explain.

How did you decide on your "Physical Health" rating?

V11a1(2)  
 V11a2(2)  
 V11a3(2)

} code up to 3 2-digit responses

How did you decide on your "Emotional Health" rating?

V11b1 (2)  
 V11b2 (2)  
 V11b3 (2)

Menopausal hormones. In this section, we are interested in your decisions about taking or not taking hormones.

12. First, which is true for you at this time? (Circle one.)

- V12 (1)
- 1 I AM CURRENTLY TAKING HORMONE THERAPY > Go to next question
  - 2 I AM NOT CURRENTLY TAKING HORMONES BUT DID IN PAST > Go to next question
  - 3 I HAVE NEVER TAKEN HORMONE THERAPY > Skip to question 15.

13. Some of you have reported starting on hormones and staying on them, while others of you have quit, and still others never started. Some of you have tried and quit more than once. These usage patterns have become important to clinicians and researchers who are trying to understand women's needs and experiences when using these hormones. Please describe in the box below your own hormone use history. IF YOU ARE A CURRENT USER, enter information about this use on the first line (if you've never quit, you will only enter information on this line). Then, on the following lines, describe all the previous products you've taken, starting with your earliest usage and moving on toward the present.

Use these codes to describe the hormone product you are/were using:

- 1 Estrogen pill alone
- 2 Estrogen patch alone
- 3 Estrogen cream alone
- 4 Combination estrogen/progestin pills
- 5 Combination estrogen patch/progestin pills
- 6 Combination estrogen cream/progestin pills
- 7 Natural progesterone
- 8 Other \_\_\_\_\_

Use these codes to describe why you quit:

- 1 Heavy bleeding
- 2 Unwanted menstrual periods
- 3 Migraine headaches
- 4 Increased blood pressure
- 5 Breast cancer
- 6 Other breast problems (cysts, pain)
- 7 Irritability
- 8 Tiredness
- 9 Depression
- 10 Weight gain
- 11 Increased bladder incontinence
- 12 Thrush
- 13 Worsening of diabetes
- 14 Varicose veins
- 15 Chest pains
- 16 Anxiety
- 17 Fibroids
- 18 Endometriosis
- 19 Other \_\_\_\_\_

V13 Total products used  
 (see below) (1)

	Product (enter code)	Month, year begun	Approximate Number of months on product	Reason(s) why you quit (enter code(s) from above)
a Current Product	V13a1 (1)	V13a2 (4)	V13a3 (3)	XXXXXXXXXXXX
b Earliest product used	V13b1 (1)	V13b2 (4)	V13b3 (3)	V13b4 (2) V13b1 (1)
c Next product used	_____	_____	_____	_____
d Next product used	_____	_____	_____	_____
e Next product used	_____	_____	_____	_____
f Next product used	_____	_____	_____	_____

14. If you are currently using hormones, which best describes the way you take them?

V14a (1) → Estrogen  
 1 DAYS 1-25 OF MONTH  
 2 DAYS 1-30  
 3 MONDAY-FRIDAY  
 4 EVERY DAY  
 5 OTHER \_\_\_\_\_

Progesterone/Progestin  
 1 DAYS 1-12 OF MONTH  
 2 DAYS 1-14  
 3 DAYS 16-25  
 4 MONDAY-FRIDAY  
 5 EVERY DAY  
 6 EVERY 3 MONTHS  
 7 OTHER \_\_\_\_\_

**Facts About Yourself**

- V15a (1) 15.1  
 V15b (1)  
 V15c (1)  
 V15d (1)
- A. Are you using a birth control pill? YES 1 NO 0 If yes, which brand? \_\_\_\_\_  
 B. Are you using Norplant? YES 1 NO 0  
 C. Are you using Depo-Provera? YES 1 NO 0  
 D. Aside from birth control pills or menopausal hormone therapy, are you taking any other hormones? YES 1 NO 0 If yes, which? \_\_\_\_\_

16. Your answers to this question every year show us that midlife women do indeed experience many major life challenges. We are, therefore, asking this important question again. For each item below, if you have not experienced the event in the last year or two, circle 'O.' If you have experienced the item, circle the code that best describes how stressful that event was for you.

- 0 DID NOT EXPERIENCE  
 1 NOT AT ALL STRESSFUL  
 2 A BIT STRESSFUL  
 3 QUITE STRESSFUL  
 4 EXTREMELY STRESSFUL

Life Challenges

How Stressful?

	0	1	2	3	4
a. Personal health problem	0	1	2	3	4
b. Family or close friend's health problem	0	1	2	3	4
c. Death of spouse	0	1	2	3	4
d. Death of someone close to you (not spouse)	0	1	2	3	4
e. Moving to a new home	0	1	2	3	4
f. Family problem	0	1	2	3	4
g. Marriage/remarriage	0	1	2	3	4
h. Divorce/break up of important relationship	0	1	2	3	4
i. Work problems/loss of job	0	1	2	3	4
j. Partner's work problems/loss of job 16	0	1	2	3	4
k. Starting a new job/new position 10	0	1	2	3	4
l. Problems with children 17	0	1	2	3	4
m. Problems with parents/in-laws 18	0	1	2	3	4
n. Financial problems 19	0	1	2	3	4
o. Birth control issues 15	0	1	2	3	4
p. Relationship problem 14	0	1	2	3	4
q. Working toward graduate degree/other schooling 11	0	1	2	3	4
r. Other _____	0	1	2	3	4

17. Please select the ONE statement that best describes your current partner status (circle one):

- 1 MARRIED OR REMARRIED AND LIVE WITH YOUR SPOUSE
- 2 MARRIED OR REMARRIED BUT DO NOT LIVE WITH YOUR SPOUSE
- 3 PREVIOUSLY MARRIED (NOW DIVORCED, SEPARATED OR WIDOWED), YOU NOW LIVE WITH A ROMANTIC PARTNER
- 4 PREVIOUSLY MARRIED (NOW DIVORCED, SEPARATED OR WIDOWED), YOU NOW HAVE A ROMANTIC PARTNER YOU DO NOT LIVE WITH
- 5 PREVIOUSLY MARRIED (NOW DIVORCED, SEPARATED OR WIDOWED), YOU NOW DO NOT HAVE A ROMANTIC PARTNER
- 6 NEVER MARRIED, YOU NOW LIVE WITH A ROMANTIC PARTNER
- 7 NEVER MARRIED, YOU NOW HAVE A ROMANTIC PARTNER YOU DO NOT LIVE WITH
- 8 NEVER MARRIED, YOU NOW DO NOT HAVE A ROMANTIC PARTNER

- A. Your date of birth: mo \_\_\_\_ day \_\_\_\_ year 19\_\_
- B. Your height: \_\_\_\_ inches
- C. Your weight: \_\_\_\_ lbs.

- A. How many children live at home with you year-round? \_\_\_\_
- B. How many parents or other family members live with you? \_\_\_\_
- C. What is the total number of people living in your household, including yourself? \_\_\_\_

20. A sign of the times: More and more people are using e-mail these days, and there might be a time when it would be helpful for us to reach you that way. So, if you have an e-mail address and would be willing to share it with us, please write it here: \_\_\_\_\_

21. Finally, as the directors of this project, we admit to being touched by your continued willingness to participate in this study. We are very, very grateful to you for helping us fulfill our dream of conducting a truly woman-centered study of menopause. So, to conclude this year's survey, we would like to ask you to tell us what it has meant to you to be part of the study. Have you benefitted in some ways? What are your motivations for staying part of the study? Please comment freely.

Once again, we thank you very much for your continuing support of this research project. RETURN THIS QUESTIONNAIRE (AND YOUR COMPLETED 1994-1995 MENSTRUAL CALENDAR IF YOU HAVE ONE) IN THE ENCLOSED POSTAGE-PAID ENVELOPE. MAKE SURE YOU HAVE ENTERED YOUR ID# ON ALL MATERIALS. IF YOU HAVE LOST YOUR NUMBER, CALL OUR OFFICES AND WE CAN GIVE IT TO YOU. If you have any questions, you may call our Project Office at (814) 863-4025 (PA) or (801) 581-8272 (UT).

**THANK YOU!** - Last year one of our doctoral students asked for volunteers to participate in her menopause study using personal telephone interviews. Your response was overwhelming, and she was able to call only a portion of the women who volunteered. She (and all of us on this project) want to thank those of you who expressed interest in participating and those of you who were called and gave so generously of your time. Linda intends to provide participants with results of her study when they become available. Thank you again.

Code Scheme for Special Question on Women Without Partners - 1995

7

BEING ALONE: ...

NEGATIVE FEELINGS ABOUT BEING ALONE

- 11 LONELY/MISS COMPANY
- 12 MISS SEX
- 13 MISS INTIMACY/CLOSENESS/PHYSICAL TOUCHING (NOT "SEX")/loving
- 14 HARD WORK DOING EVERYTHING
- 15 DAUNTED BY THE RESPONSIBILITY
- 16 DOUBTS ABOUT ATTRACTIVENESS
- 17 NOT ENOUGH AVAILABLE MEN OUT THERE/WANT A PARTNER/FEEL FRUSTRATED
- 18 SCARED
- 19 OTHER

POSITIVE FEELINGS ABOUT BEING ALONE

- 21 SENSE OF FREEDOM AND EMPOWERMENT/INDEPENDENCE
- 72 22 MOST MEN NOT WORTH THE TROUBLE/ NOT LOOKING FOR PARTNER/ HAD ENOUGH OF MEN WHEN MARRIED/ GLAD NOT TO HAVE A PARTNER WHO IS CRITICAL, UNLOVING ETC.
- 23 FAMILY AND FRIENDS FULFILL NEEDS FOR INTIMACY/COMPANIONSHIP
- 24 CONTENT WITH BUSY, FULFILLING LIFE
- 43 25 NOT WILLING TO RISK AIDS, ETC. JUST FOR SEX
- 26 FIND SEXUAL SATISFACTION THROUGH MASTURBATION, FANTASY ETC
- 29 OTHER

NEUTRAL FEELINGS ABOUT BEING ALONE

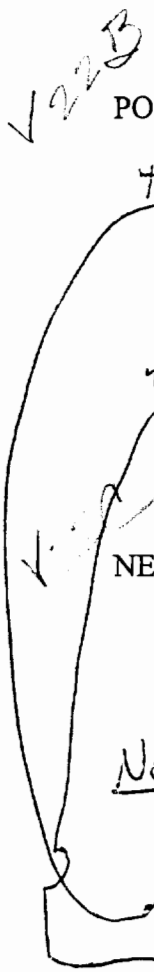
- 31 NEITHER LIBERATING NOR FRUSTRATING
- 32 I JUST CARRY ON/DON'T THINK ABOUT IT
- 33 Non-existent sex life (no value judgment attached)

Neg. Feelings about relationships

- 41 Terrified of having a relationship / of intimacy

→ 42

43



CODING FOR OPEN-ENDED QUESTIONS, MIDLIFE WOMEN'S HEALTH SURVEY Spring  
1995

QUESTION 7A: As you move/moved through the menopausal transition, who or what was most helpful or supportive to you? Was it your family, or your mother, or friends, or your health care provider, or a particular book or magazine, or even being in this study? Please explain.

CODE UP TO 3 RESPONSES IN ORDER OF APPEARANCE  
CODES MAY BE REPEATED

01. husband / romantic partner
02. other family
03. friends/ colleagues/ group members
04. health care provider
05. lifestyle behaviors  
(examples: diet, exercise)
06. self support/ self reliance/ own coping skills  
(examples: own assessment; keep busy; faith)
07. literature
08. study
09. no problems/ minor problems
10. "All"
11. other
99. NA

QUESTIONS 7b: And, (through the menopausal transition) was anyone/anything a disappointment to you?

CODE ONLY 1 RESPONSE

1. physician

2. friends / family

3. husband

4. none

5. everything

6. written materials / workshops (info obtained from ...)

9. NA

7. other

QUESTION 11a: Could you explain how you decided on your answers to Question 10 above. For example, did you decide on the basis of your menopausal experiences, or sick days, or what's going on in your life these days, or the results of your last How did you decide on your "Physical Health" rating?

CODE UP TO 3 RESPONSES IN ORDER OF APPEARANCE.  
CODES MAY BE REPEATED.

01. Sick days
02. Physical exam results
03. Number of doctor visits
04. Self-assessment
05. Health has improved (including recovery from disease)
06. Health has become worse (including new disease)
07. Managing a chronic illness (I have a problem & am managing it.)
08. Engaging or not engaging in lifestyle activities to feel good/  
fit or unfit  
(Examples: physical fitness, diet, exercise)
09. Life events/ interactions  
(Examples: school, work, money problems, leisure time; good marriage, children doing well etc.)
10. Menopausal experience (menopause mentioned)
11. Appearance/ weight/ fat
12. Feedback/ base on what I am ABLE or UNABLE to do  
(Examples: I can job 5 days per week; I have lots of energy; coping)
13. Emotional state/ moods/ stress (includes work stress and that which influences physical health)
14. Other
15. NA

QUESTION 11 B: How did you decide on your emotional health rating?

CODE UP TO 3 RESPONSES IN ORDER OF APPEARANCE  
CODES MAY BE REPEATED

01. depression
02. anxiety
03. irritability
04. other moods/emotions
05. Life events/interactions  
(Examples: stress, school, work, money problems,  
family problems, leisure time)
06. own physical health (nonmenopausal)
07. health of family/friends
08. impact of menopausal experiences (if menopause mentioned)
09. signs of aging (if aging specifically mentioned)
10. ~~sense of well being / happy~~  
(Examples: centeredness/control; self assessment/  
perception) "I feel" statements, e.g. happy, unhappy, "how I feel"
11. lifestyle factors/activities (doing things)  
(Examples: physical fitness, weight, diet, exercise)
12. personal orientation and outlook  
(Examples: faith, self-reliance, sense of humor,  
positive thinking, self-esteem, self-acceptance, roll  
with punches) "looking for — to be centered"  
(more active than 10)
13. other
99. NA

QUESTION 21: .... So to conclude this year's survey, we would like to ask you to tell us what it has meant to you to be part of the study. Have you benefitted in some ways? What are your motivations for staying part of the study. Please comment freely.

CODE UP TO 4 RESPONSES IN THE ORDER OF APPEARANCE

(Code 3 may be entered twice for the same entry: once for mail information & once for the study itself as the answer)

1. altruism: to be of help to other women; other generations
2. history/ connectedness / commitment  
(Examples: length of time with study; number of generations with study; general sense of community with other women in study)
3. menopause information gained from being part of the study, either through mailed information or answering the study.
4. benefits of keeping personal charts and records
5. other
9. NA