

Online Supplementary Material

Hudson SV, Miller S, Hemler J, et al. "Not what I want, but maybe what I need": adult cancer survivors discuss follow-up in primary care. *Ann Fam Med*. 2012;10(5):418-427.

<http://www.annfammed.org/content/10/5/418/suppl/DC1>

Supplemental Appendix: Depth Interview Guide Demographic Questions

SCRIPT:

Before we get into the more open-ended part of the interview, I would like to ask you a few basic questions about yourself.

1. What is your age?_____
2. What race or ethnicity do you consider yourself to be?
 - White or Caucasian
 - Black and/or African American
 - Latino/a and/or Hispanic
 - Asian or Pacific Islander
 - Other: _____
 - Refused
3. What is your current marital status?
 - Single
 - Divorced
 - Married
 - Widowed
4. What was your marital status at the start of your treatment?
 - Single
 - Divorced
 - Married
 - Widowed
 - Don't know
5. What is the highest grade of school or year of college you completed?

[INTERVIEWER: If respondent says 2, 3, 4, OR 5 years of high school or college, probe: "Did you receive a degree?" DO NOT READ LIST]

 - No school/some grade school (1-6)
 - Eighth grade/Junior high school (7-8)
 - Some high school (9-12; No diploma or GED)
 - Graduated high school or GED
 - 1 to 2 years of college, no degree yet
 - 3 or more years of college, no degree yet
 - Graduated from 2-year school, vocational college, associate's degree
 - Graduated from a 4- or 5-year college, bachelor's degree
 - Some graduate school
 - Master's degree
 - PH.D., ED.D., MD, DDS, LLB, LLD, JD, or other professional degree
 - Refused
 - Don't know

6. Are you currently employed part- or full-time?
 Full-time Part-time Not employed Refused
 Don't know

7. Were you employed part- or full-time at the start of your treatment?
 Full-time Part-time Not employed Refused
 Don't know

8. Do you currently have medical insurance?
 Yes No Refused Don't know

9. Did you have medical insurance at the time of your diagnosis?
 Yes No Refused Don't know

10. What was your household income last year, approximately, before taxes?

[INTERVIEWER: DO NOT read list off to respondent initially. Probe for approximate amount. If respondent says, "Don't know," probe gently with categories: "Would you say your household income is..." If respondent still cannot answer, then check Don't know.

"Household" includes all income that contributes to household expenses.]

less than \$20,000 \$20,000 – \$39,000 \$40,000 – \$59,000
 \$60,000 – \$79,000 \$80,000 – \$99,999 over \$100,000
 Don't know Refused

11. What was your household income at the start of your treatment?

[INTERVIEWER: DO NOT read list off to respondent initially. Probe for approximate amount. If respondent says, "Don't know," probe gently with categories: "Would you say your household income is..." If respondent still cannot answer, then check Don't know.

"Household" includes all income that contributes to household expenses.]

less than \$20,000 \$20,000 – \$39,000 \$40,000 – \$59,000
 \$60,000 – \$79,000 \$80,000 – \$99,999 over \$100,000
 Don't know Refused

12. How many years has it been since your last chemotherapy or radiation treatment?

[INTERVIEWER: If "Don't know," ask to estimate. If still cannot answer, use Don't know.]

Less than two Two to five Six to ten Over ten
 Don't know

13. In general, how would you rate your physical health? Would you say it is: [READ LIST]

Poor Fair Good Very Good or Excellent?
 Don't know (Do not read this option)

[INTERVIEWER: If respondent says, "I don't know, I'm not a doctor," PROBE "What do YOU think?"]

GRAND TOUR QUESTIONS AND PROBE SCRIPTS:

I know that this may have been quite some time ago. But, I'm going to ask you to think back to when you finished your active treatment for [breast/prostate] cancer. By "active treatment," I mean chemotherapy or radiation treatment, not any medications you may have continued to take after this treatment [as for breast cancer, aromatase inhibitors or tamoxifen]. I understand that your last active treatment was [2-5; 6-10; more than 10; if Don't know, "some"] years ago.

P
R
O
B
E
S

1. When you completed your cancer therapy, or in the first visit after completing therapy, did you talk to anyone about cancer follow-up care?

- Who?
- Do you remember what topics they talked to you about?
- Did [person specified above or team] create and hand you a printed copy of a cancer follow-up treatment plan to follow?
 - IF NO: Did [person specified above or team] say you should do anything *specific* for cancer follow-up care?
 - Did they tell you how often you should be screened or monitored and for what?

Definition:

Treatment team = any health care clinician who handled your care during active or follow-up treatment (eg, oncologist, treatment nurse, primary care physician).

P
R
O
B
E
S

2. Who do you see now for cancer follow-up care?

- Do you still see the oncologist you had while under treatment for cancer?
 - IF YES:
 - How often?
 - [] Whenever I have problems
 - [] Once a year [] Every 6 months
 - [] Other: _____
 - IF NO:
 - Did your oncologist discharge you? If so, to whom?
 - Did your oncologist/treatment team recommend you follow-up for cancer care with a primary care or other kind of doctor?
 - Did they recommend you receive cancer follow-up care through a hospital or cancer center, community clinic, or private practice?

If not answered above:

- Do you currently see a doctor for cancer follow-up care?
 - Is this person a specialist?

P
R
O
B
E
S

If respondent does not see a doctor for cancer follow-up care:

- Do you see anyone for general health care problems (like illnesses or injuries)?
- Do you have any ailments in particular that you see [this person or doctor] for?
 - Can you tell me what kind?
- Does [person or doctor specified] also attend to your cancer follow-up care needs?
 - What proportion of visits would you say were related to cancer follow-up care versus other problems?
[All, ¾, ½, 1/3, ¼. None]

P
R
O
B
E
S

3. What do you currently do for your cancer follow-up care?

- What tests does your physician recommend for your cancer follow-up care?
 - How often do you have these tests done?
 - Who does those tests?
 - Where do you go to have the tests done?
- Is there any other monitoring or follow-up care you do?
 - How often?
- Do you see a physician for this? Who?

SCRIPT:

The next set of questions addresses your feelings and evaluations of any cancer follow-up care you have received. Remember, your doctors will not have access to any of the information you tell me today. The first question I want to ask is:

P
R
O
B
E
S

4. How do you feel about the quality of the cancer follow-up care – the actual care and the treatments – you have received so far?

- Have you had any problems with your cancer follow-up care?
 - Can you tell me about them and how you deal with them?
- Is there anything you like about your cancer follow-up care that you'd like to point out?

5. How do you feel about the quality of the cancer follow-up care you have received specifically from your doctor(s)? If you have had or still have several doctors, let's address each one separately.

Let's start with your current or main doctor.

P
R
O
B
E
S

- What kind of doctor is this?
- Are you satisfied with the quality of cancer follow-up care you receive(d) from this doctor?
 - Would you say:
[] A lot [] Somewhat [] A little [] or Not at all?
- How would you rate the quality of general care with this doctor?
 - Would you say:
[] Excellent [] Very good [] Good [] Fair
[] or Poor?
- Did or do you have any problems with this doctor? What kind?

Now, your other or previous doctor:

P
R
O
B
E
S

- What kind of doctor is this?
- Are you satisfied with the quality of cancer follow-up care you receive(d) from this doctor?
 - Would you say:
[] A lot [] Somewhat [] A little [] or Not at all?
- How would you rate the quality of general care with this doctor?
 - Would you say:
[] Excellent [] Very good [] Good [] Fair
[] or Poor?
- Did or do you have any problems with this doctor? What kind?

Do you have any other doctors who provided or currently provide you with cancer follow-up care?

P
R
O
B
E
S

- What kind of doctor is this?
- Are you satisfied with the quality of cancer follow-up care you receive(d) from this doctor?
 - Would you say:
[] A lot [] Somewhat [] A little [] or Not at all?
- How would you rate the quality of general care with this doctor?
 - Would you say:
[] Excellent [] Very good [] Good [] Fair
[] or Poor?
- Did or do you have any problems with this doctor? What kind?

SCRIPT:

The next couple of questions deal with your expectations about cancer follow-up care: what you expect out of your care now...what your expectations were for your care in the past.... By "expectations," we want to know about how you judge the quality of your care, and also what you think cancer follow-up care should include: your attitudes about what kind of care is important or necessary. Let's start with now:

P
R
O
B
E
S

6. What do you expect now from your cancer follow-up care? What type of care do you think should you be receiving?

- Are you happy with the *frequency* of the cancer follow-up care you have?
 - Why or why not?
- Are you happy with the *content* of the cancer follow-up screening/care you get?
 - Why or why not?
- Would you do anything different in terms of how you receive cancer follow-up care, if you could?
- What do you think cancer follow-up care should be?

P
R
O
B
E
S

7. In terms of your expectations in the past...if you think back to when you finished your active cancer treatment, did you have any expectations then about what your cancer follow-up care would be like?

- For example, did you consider how often you should be monitored?
- Did you make a conscious decision about who or what kind of doctor would be your cancer follow-up care provider?
- Did you think your cancer follow-up treatment would be any different than what it turned out to be?

P
R
O
B
E
S

8. Have you noticed a shift in your expectations of what you want out of your cancer follow-up care from the past to now?

- For example, do you think cancer follow-up care is important?
 - Do you think this is still something you need to do?
 - ...or perhaps "should" do?
- What kind of cancer follow-up plan would you recommend to someone else?
 - How often do you think screening or surveillance is necessary?
- We already talked about what you do now for your cancer follow-up care, but did you have a different routine, or do different screenings or tests, previously?
 - What did you do before?
 - When was this? How long ago?
 - When did your routine change?

SCRIPT:

Now let's talk about your ideal health care scenario.

P
R
O
B
E
S

9. Given a choice, who would you like to see for cancer follow-up care and why?

- Do you feel strongly about what kind of doctor cancer survivors should see for cancer follow-up care visits?
 - Who would do your cancer monitoring? Why?
 - Are there any reasons or situations in which why you would want to see a different kind of doctor than you're seeing now for a cancer follow-up care visit?
- Ideally, where would you like to be getting your health care information?
- When, if ever, do you think it is *better* to see an oncologist than a primary care physician for cancer follow-up care?
- When, if ever, would you say it's *acceptable* to see a primary care physician instead for cancer follow-up care?
- When, if ever, is it *better* to see a primary care physician for cancer follow-up care instead of other doctors?

SCRIPT:

My last set of questions involves some of the practical aspects of arranging cancer follow-up care and finding doctors you like. Some survivors have support people or groups who help them plan and get to their treatments whereas others prefer to do this on their own. Some people are very vigilant about making and keeping appointments whereas others are more relaxed.

P
R
O
B
E
S

10. How would you characterize yourself in terms of scheduling and keeping your cancer follow-up care visits? Would you say you are more vigilant or more relaxed?

- Is there a reason you happen to be more vigilant or more relaxed?
- For instance, some people worry about their chances of recurrence. Is this something you happen to think about?
 - What do you consider your risk of cancer recurrence to be?
 - Is this something your doctor has told you or more of a gut feeling?

SCRIPT:

Let's talk a bit more about the specifics in how you organize your cancer follow-up care and get to your appointments.

P
R
O
B
E
S

11. Can you tell me about how you coordinate your cancer follow-up care?

- Do you take care of planning and getting to your cancer follow-up care visits yourself?
- Do you have someone helping you now to make sure you get your cancer follow-up care?
 - Who?
 - What do they do for you?
 - How do they help?
- When you were in active treatment—chemotherapy or radiation treatment—did anyone help you coordinate your doctors' appointments and treatments then?
 - Who?
 - What did they do for you?
 - How did they help?
 - Are they still involved?
- Were you part of a support group during your chemotherapy or radiation treatment?
 - If yes, Which one?
 - Can you tell me what that was like for you?
 - Did you find it helpful?
 - Did you like the people there?
 - Did you get good information there?

P
R
O
B
E
S

P
R
O
B
E
S

- Are you part of one now?
 - If yes, Which one?
 - Can you tell me what it is like for you?
 - Do you find it helpful?
 - Do you like the people there?
 - Do you get good information there?

- If no and previously was in a support group
 - Can you tell me why you stopped?
 - When did you stop?