The Patient: Patient-Centered Outcomes Research

Physical, Social, and Psychological Consequences of Treatment for Hepatitis C

A Community-Based Evaluation of Patient-Reported Outcomes

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Electronic Supplementary Material

PATH-C STUDY

Note: Confirm that you are speaking with the participant. Do not reveal any study details to anyone other than the named participant. If someone else answers the phone and asks who is calling and why, say no more than that you are calling from Kaiser Permanente and ask when would be a good time to call back.

(When leaving a message on an answering machine, say you are calling from Kaiser Permanente, give your phone number, and ask the potential participant to call you back.)

"Hello, may I speak with <<name of participant>>?"

If available, continue. If not available, ask when you can call back. Do not leave specific information about the study with anyone but the participant.

Telephone Script

You are being invited to participate in a study that is being conducted by researchers from the Kaiser Permanente Medical Care Program. The purpose of this study is to understand how we can improve treatment plans for patients with hepatitis C by talking with patients after the therapy has ended.

First, let me confirm that you ended interferon/ribavirin therapy and are no longer taking the drugs.

__yes ___no ► If no, thank for their time and conclude

Participation in this study is completely voluntary. Your decision will not change your treatment for any liver problems or anything else about your medical care or membership at Kaiser Permanente. If you decide to participate, you are free to change your mind and discontinue participation at any time.

If you agree, we will interview you for about 30 minutes so that we can hear about your experiences, understand your opinions, and listen to any suggestions you have about HCV antiviral therapy. You will also receive a $20.00 gift card as a token of our appreciation.

(If scheduling interview, note date and time here: _____).

Repeat above paragraphs, on interview date.

Information about you obtained for this study will be kept confidential and will be stored on paper or computers in a locked facility with limited access. All identifiable information will be protected to the full extent of the law. Your name will not be stored with your interview information. Your name will not be revealed to anyone outside the research team at Kaiser Permanente. Only group results will be reported; your identity will not be revealed in any release of results.

If you have further questions or problems you may call Rose Murphy, the Study Coordinator or Dr. Michele Manos, the study investigator at Kaiser Permanente Division of Research at 510-891-3492.

For questions about your rights as a research participant, comments, or complaints about the study, you may contact: The Kaiser Permanente Northern California Institutional Review Board, toll free at (800) 241-0690. You may also contact me at any time to learn how to reach the Review Board.

Do you have any questions? Do you agree to participate in the study by completing this interview? I am recording your response.

Record results here: Patient AGREES REFUSES (circle one)

Signature of interviewer _____ Date: _____

Printed name of interviewer: _____

PATH-C Study

AFFIX ID LABEL HERE

A1. RESPONDENT ID:

A2. FORM VERSION: V4.1

A3. DATE FORM COMPLETED (mm/dd/yyyy) ___ ___ / ___ ___ / ___ ___ ___ ___

A4. INTERVIEWER'S INITIALS: ___ ___ ___

Final screening to confirm treatment course of interest

B1. Most recent treatment course ___[*autofill treatment course of interest: date ending*]_____

B2. Has patient had treatment prior to treatment course of interest __yes ___no

B3. Clinical trial participation __yes ___no

Thank you for taking the time to complete our survey. Your responses will be very helpful to us to better understand how we can better serve the needs of the Hepatitis C community. Please remember that all information collected on this survey is for research purposes only and will be kept confidential. You may decline to answer any of the questions.

I. DEMOGRAPHICS

In this section, we'd like to understand more about you.

1. In what year were you born? _____

2. Which of the following best describes how you define your racial/ethnic background? *[choose all that apply]*

1 ☐ White, non-Hispanic
2 ☐ African-American, Black
3 ☐ Hispanic
5 ☐ Native American
6 ☐ Other *[specify]:* _____
4 ☐ Asian, PI

a ☐	Cambodian	g ☐	Malaysian
b ☐	Chinese	h ☐	Filipino
c ☐	Japanese	i ☐	Thai
d ☐	Korean	j ☐	Vietnamese
e ☐	Indian	k ☐	Pakistani
f ☐	Other *[specify]:*		

Next I'm going to ask you some questions about your life at the start of your hepatitis treatment.

3. What was your marital status when you began treatment? *[choose one]*

1 ☐ Married, domestic partner, living like married
2 ☐ Widowed
3 ☐ Divorced/ separated
5 ☐ Single
6 ☐ Other (specify) _____
99 ☐ Refuse

4. How many people, other than yourself, lived in your household when you began treatment?
[insert numbers for all that apply]

1____None 2____Spouse/Domestic partner 3____Children 4____Roommate(s)

5____Friend(s) 6____Other relative (s)

5. What was the highest level of schooling you had completed when you began treatment?

1 ☐ Less than high school
2 ☐ Some high school
3 ☐ HS grad/GED
4 ☐ Some college (AA)
5 ☐ Vocational/ tech
6 ☐ College grad (bachelor's degree)
7 ☐ Grad school (doctorate, master's degree)
8 ☐ Professional school (MD, JD, DDS, MBA)
99 ☐ Refuse

6. Were you attending school, college or graduate school when you began treatment?

1 ☐ No 2 ☐ Yes, full-time 3 ☐ Yes, part-time 99 ☐ REFUSED

7. How would you best describe your employment status when you began treatment?

1 ☐ Working full-time
2 ☐ Working part-time
3 ☐ On a leave of absence, or modified hours, from full or part time work
4 ☐ Unemployed
5 ☐ Unemployed, but looking for work
6 ☐ Keeping house or raising children full- time
7 ☐ Student
8 ☐ Retired
9 ☐ Disabled

7a. What was your total combined family income when you began treatment? This should include income (before taxes) from all sources: wages, veteran's benefits, help from relatives, rent from properties and so on.

01 ☐ less than $25,000
02 ☐ $25,000 - $49,000
03 ☐ $50,000 - $74,000
04 ☐ $75,000 - $99,000
05 ☐ $100,00 - $149,000
06 ☐ $150,000 -199,000
07 ☐ $200,000 or more
98 ☐ DON'T KNOW
99 ☐ REFUSE

7b. What type of job did you have when you began treatment: _____

[interviewer later categorize job using scale below]

1.	☐ Level I	self-employed professionals, employed professionals, high-level management, semi-professionals
2.	☐ Level II	supervisors, technicians, middle management, forepersons, skilled clerical, skilled crafts and trades, farmers/ vintners
3.	☐ Level III	semi-skilled clerical (sales/services), semi-skilled manual
4.	☐ Level IV	unskilled clerical (sales/service), unskilled manual, farm laborers, day laborers

7c. How much physical activity was involved in this job?

1 ☐ none – very little, mostly sitting/standing in one place
2 ☐ combination of sitting and moving around
3 ☐ manual labor (janitorial, nursing assistant, etc)
4 ☐ physical labor (construction, farm labor)

7d. How much autonomy or freedom did your job allow? (i.e. freedom in the job where you can control your tasks, method of work, pace of work, and work goals)

1 ☐ none, or virtually none
2 ☐ a limited amount
3 ☐ quite a bit
4 ☐ total, or almost total

II. PROVIDERS

Now I would like to ask you some questions about your KP treatment providers.

8. At what facility did you receive the majority of your HCV treatment? ____ ____ ____
[using cover sheet, can prompt: FAC where began Rx. Insert 3 letter facility code]

9. Which health care provider(s) influenced your decision to be treated? _____
[using cover sheet, can prompt whether primary care doc was involved]

10. Which provider did you see most regularly for your Hepatitis C treatment and associated care? (or, which provider was most involved with your HCV care)

Name of treating provider: _____
[THIS BECOMES TREATING PROVIDER for further questions]

III. PRE-TREATMENT Details

11. Did you do any of the following therapies or changes in lifestyle specifically to prepare yourself for treatment?

[read all choices in Column A]

Q11. Preparation for treatment	Q11b. Did while on treatment	11c. Did this help? How did this help?
Column A	**Column B**	**Column C**
1. ☐ Acupuncture/ Herbal medicine/ homeopathy/ other alternative or complementary therapies	☐	
2. ☐ Decreased or stopped smoking	☐	
3. ☐ Decreased or stopped drinking alcohol	☐	
4. ☐ Stress reduction activities (eg, yoga, meditation)	☐	
5. ☐ Began exercise program	☐	
6. ☐ Changed to a healthier diet	☐	
7. ☐ Gained or lost weight	☐	
8. ☐ Attended individual or group counseling or therapy	☐	
9. ☐ Kaiser Hepatitis C Class	☐	
10. ☐ Gathered information from internet	☐	
11. ☐ Participated in support group for liver problems (in-person or web-based)	☐	
12. ☐ Other	☐	
13. ☐ Other	☐	
14. ☐ Other	☐	

III. TREATMENT Details

12. What viral genotype(s) did you have when you started treatment? *[choose all that apply]*

1 ☐ GT 1 2 ☐ GT 2 3 ☐ GT 3 4 ☐ Other 98 ☐ Don't know

13. At this point, what do you know about your treatment response? *[choose one]*

1 ☐ I have SVR (sustained viral response, no virus 6 mo after end of Rx) ► **SKIP to Q15**
2 ☐ Successful, but don't know yet about SVR
3 ☐ Not successful (no SVR or no viral clearance) ► **SKIP TO Q15**
98 ☐ Don't know

14. Although you do not yet know your treatment response, how would you rate your chance of a sustained viral response; that is virus undetectable at 6 months after your last dose? *[choose one]*

1 ☐ Very Poor chance 2 ☐ Somewhat Poor chance 3 ☐ Neutral
4 ☐ Somewhat Good chance 5 ☐ Very Good chance

15. Did your treatment provider lower your doses of either IFN or ribavirin during your treatment? *[choose all that apply]*

1 ☐ Ribavirin lowered 2 ☐ IFN lowered 3 ☐ Neither

16. Were you ever unable or unwilling to take your required daily dose of ribavirin?

1 ☐ Yes 2 ☐ No ► **SKIP to Q18**

17. How often did this happen?

1 ☐ a few days during my treatment (1-3 days) 2 ☐ more than a few times

18. Were you ever unable or unwilling to inject your full required weekly dose of interferon?

1 ☐ Yes 2 ☐ No ► **SKIP to Q20**

19. How many times did this happen?

1 ☐ a few weeks during my treatment (1-3 weeks) 2 ☐ more often than a few weeks

20. Were you given any of these supplemental treatments during treatment?

a. EPO (Procrit) [low red blood cell] 1 ☐ Yes 2 ☐ No

b. G-CSF (Neupogen, Filgrastin) [for low white blood cell) 1 ☐ Yes 2 ☐ No

c. Anti-depressants 1 ☐ Yes 2 ☐ No

d. Medication for sleep 1 ☐ Yes 2 ☐ No

21. How long did you stay on treatment?

1 ☐ Full course (about 24 wk)

2 ☐ Full course (about 48 wk)

3 ☐ Stopped because treatment not working - not responding (no viral load decrease)

4 ☐ Stopped due to side effects or personal reasons

22. Did you experience any physical or mental side effects, even if minor, while on treatment?

1 ☐ Yes 2 ☐ No side effects ► **SKIP to Q24**

IV. DIFFICULTIES

A. PHYSICAL OR MENTAL SIDE EFFECTS

[If necessary, prompt: ***Did you have difficulties with physical or mental side effects during treatment?***]
[Fill in Col. B and Col. C for each side effect checked in Col. A]

23. Difficulty experienced as a result of treatment. *[**DO NOT READ OPTIONS**. Check ✓all that apply; fill-in col. B & C for those checked]*	23b. Did this side effect impact your ability to take treatment as prescribed?	23c. Did this side effect cause you to stop completion of treatment?	23d.
Column A	**Column B**	**Column C**	**NOTE**
1. Flu-like symptoms			
a. ☐ fatigue/ weakness	a ☐ 1	a ☐ 2	
b. ☐ dehydration	b ☐ 1	b ☐ 2	
c. ☐ fever/ chills/ muscle ache	c ☐ 1	c ☐ 2	
2. Gastrointestinal			
a. ☐ nausea/vomiting	a ☐ 1	a ☐ 2	
b. ☐ diarrhea	b ☐ 1	b ☐ 2	
c. ☐ abdominal pain	c ☐ 1	c ☐ 2	
d. ☐ taste changes	d ☐ 1	d ☐ 2	
e. ☐ weight loss	e ☐ 1	e ☐ 2	
f. ☐ loss of appetite	f ☐ 1	f ☐ 2	
3. Hematologic			
a. ☐ anemia	a ☐ 1	a ☐ 2	
b. ☐ neutropenia (low white blood ct)	b ☐ 1	b ☐ 2	
c. ☐ thrombocytopenia	c ☐ 1	c ☐ 2	
4. Musculoskeletal			
a. ☐ muscle/joint pain	a ☐ 1	a ☐ 2	
b. ☐ back pain	b ☐ 1	b ☐ 2	
5. Neurologic			
a. ☐ Headache/migraines	a ☐ 1	b ☐ 2	
6. Psychiatric			
a. ☐ Irritable /anxious /nervous	a ☐ 1	a ☐ 2	
b. ☐ Insomnia	b ☐ 1	b ☐ 2	
c. ☐ depression	c ☐ 1	c ☐ 2	
d. ☐ impaired concentration (brain fog)	d ☐ 1	d ☐ 2	
e. ☐ mood alteration	e ☐ 1	e ☐ 2	
f. ☐ suicidal ideation	f ☐ 1	f ☐ 2	
g. ☐ homicidal ideation	g ☐ 1	g ☐ 2	
h. ☐ urge to resort to harmful habits	h ☐ 1	h ☐ 2	

23. Difficulty experienced as a result of treatment. *[**DO NOT READ OPTIONS**. Check ✓all that apply; fill-in col. B & C for those checked]*	23b. Did this side effect impact your ability to take treatment as prescribed?	23c. Did this side effect cause you to stop completion of treatment?	23d.
Column A	**Column B**	**Column C**	**NOTE**
7. Respiratory			
a. ☐ short of breath (dyspnea)	a ☐ 1	a ☐ 2	
b. ☐ cough	b ☐ 1	b ☐ 2	
c. ☐ out of breath with exercise	c ☐ 1	c ☐ 2	
8. Skin			
a. ☐ hair loss (alopecia)	a ☐ 1	a ☐ 2	
b. ☐ rash (dermatitis)	b ☐ 1	b ☐ 2	
c. ☐ dry skin	c ☐ 1	c ☐ 2	
d. ☐ eczema	d ☐ 1	d ☐ 2	
e. ☐ sweating increased	e ☐ 1	e ☐ 2	
f. ☐ injection site reaction	f ☐ 1	f ☐ 2	
9. Visual			
a. ☐ vision blurred	a ☐ 1	b ☐ 2	
10. ☐ Other, write in:	☐ 1	☐ 2	
11. ☐ Other, write in:	☐ 1	☐ 2	

[**IMPORTANT NOTE**: If participant is still experiencing physical or mental side effects, instruct participant to contact their provider]

B. DEVELOPMENT OF ANY NEW MEDICAL CONDITION(S)

[If necessary, prompt: ***Did any new medical conditions develop during treatment?***]

[Fill in Col. B and Col. C for each side effect checked in Col. A]

24. Difficulty experienced as a result of treatment. *[**DO NOT READ OPTIONS**. Check ✓all that apply; fill-in col. B & C for those checked]*	24b. Did the difficulty impact your ability to take treatment as prescribed?	24c. Did the difficulty cause you to stop completion of treatment?	24d.
Column A	**Column B**	**Column C**	**NOTE**
1. Hepatic			
a. ☐ liver failure	a ☐ 1	a ☐ 2	
b. ☐ worsening of liver function	b ☐ 1	b ☐ 2	
2. ☐ Pancreatitis	☐ 1	☐ 2	
3. ☐ Diabetes	☐ 1	☐ 2	
4. Cardiovascular condition			
a. ☐ Hypertension	a ☐ 1	a ☐ 2	
b. ☐ Chest pain	b ☐ 1	b ☐ 2	
c. ☐ MI	c ☐ 1	c ☐ 2	
5. ☐ Cerebrovascular	☐ 1	☐ 2	
6. Autoimmune			
a. ☐ psoriasis	☐ 1	☐ 2	
7. Endocrine			
a. ☐ Hyperthyroidism	a ☐ 1	a ☐ 2	
b. ☐ Hypothyroidism	b ☐ 1	b ☐ 2	
8. ☐ Renal	☐ 1	☐ 2	
9. Ophthalmologic			
a. ☐ retinopathy	a ☐ 1	a ☐ 2	
b. ☐ macular degeneration	b ☐ 1	b ☐ 2	
10. Pulmonary			
a. ☐ pneumonia	a ☐ 1	a ☐ 2	
b. ☐ sarcoidosis	b ☐ 1	b ☐ 2	
11. ☐ Other, write in:	☐ 1	☐ 2	
12. ☐ Other, write in:	☐ 1	☐ 2	
13. ☐ No significant issues			

[**IMPORTANT NOTE**: If participant is still experiencing effects of medical conditions, instruct participant to contact their provider]

Besides physical side effects, we would like to know what additional difficulties you encountered while on treatment.

C. MEDICATION

[If necessary, prompt: ***Did you have difficulties with taking/injecting or otherwise managing your prescribed medication during treatment?***]

[Fill in Column B and Column C for each side effect checked in Column A]

25. Difficulty experienced as a result of treatment. *[**DO NOT READ OPTIONS**. Check ✓all that apply; fill-in col. B & C for those checked]*	25b. Did the difficulty impact your ability to take treatment as prescribed?	25c. Did the difficulty cause you to stop completion of treatment?	25d.
	Column B	**Column C**	**NOTE**
1. Storing medication a. ☐ IFN b. ☐ Supplemental drugs	 a ☐ 1 b ☐ 1	 a ☐ 2 b ☐ 2	
2. Using the syringe a. ☐ IFN b. ☐ Supplemental drugs	 a ☐ 1 b ☐ 1	 a ☐ 2 b ☐ 2	
3. Maintaining schedule a. ☐ daily RIBA b. ☐ IFN c. ☐ Supplemental	 a ☐ 1 b ☐ 1 c ☐ 1	 a ☐ 2 b ☐ 2 c ☐ 2	
4. ☐ Traveling with medications	☐ 1	☐ 2	
5. ☐ Other, write in:	☐ 1	☐ 2	
6. ☐ Other, write in:	☐ 1	☐ 2	
7. ☐ No significant issues			

D. FAMILY

[If necessary, prompt: ***Did you have family related challenges during treatment?***]

[Fill in Column B and Column C for each side effect checked in Column A]

26. Difficulty experienced as a result of treatment. *[**DO NOT READ OPTIONS**. Check ✓all that apply; fill-in col. B & C for those checked]*	26b. Did the difficulty impact your ability to take treatment as prescribed?	26c. Did the difficulty cause you to stop completion of treatment?	26d.
Column A	**Column B**	**Column C**	**NOTE**
1. Meeting daily obligations to			
a. ☐ Spouse/ partner	a ☐ 1	a ☐ 2	
b. ☐ Children	b ☐ 1	b ☐ 2	
c. ☐ Parents	c ☐ 1	c ☐ 2	
d. ☐ Other relatives	d ☐ 1	d ☐ 2	
2. Family member(s) not supportive			
a. ☐ Spouse/ partner	a ☐ 1	a ☐ 2	
b. ☐ Children	b ☐ 1	b ☐ 2	
c. ☐ Parents	c ☐ 1	c ☐ 2	
d. ☐ Other relatives	d ☐ 1	d ☐ 2	
3. Family member(s) encouraged me to quit			
a. ☐ Spouse/ partner	a ☐ 1	a ☐ 2	
b. ☐ Children	b ☐ 1	b ☐ 2	
c. ☐ Parents	c ☐ 1	c ☐ 2	
d. ☐ Other relatives	d ☐ 1	d ☐ 2	
4. Hid illness and/or treatment from family member(s)			
a. ☐ Spouse/ partner	a ☐ 1	a ☐ 2	
b. ☐ Children	b ☐ 1	b ☐ 2	
c. ☐ Parents	c ☐ 1	c ☐ 2	
d. ☐ Other relatives	d ☐ 1	d ☐ 2	
5. ☐ Other, write in:	☐ 1	☐ 2	
6. ☐ Other, write in:	☐ 1	☐ 2	
7. ☐ No significant issues			

E. EMPLOYMENT [If necessary, prompt: ***Did you have employment-related challenges during treatment?***]
[Fill in Column B and Column C for each side effect checked in Column A]

27. Difficulty experienced as a result of treatment. *[**DO NOT READ OPTIONS**. Check ✓all that apply; fill-in col. B & C for those checked]*	27b. Did the difficulty impact your ability to take treatment as prescribed?	27c. Did the difficulty cause you to stop completion of treatment?	27d.
Column A	**Column B**	**Column C**	**NOTE**
1. ☐ Took too much time off work	☐ 1	☐ 2	
2. ☐ Less productive at work	☐ 1	☐ 2	
3. ☐ No support from employer/ co-workers	☐ 1	☐ 2	
4. ☐ Employer was not flexible	☐ 1	☐ 2	
5. ☐ Lost or quit job	☐ 1	☐ 2	
6. ☐ Hid illness and/or treatment from employer/ co-workers	☐ 1	☐ 2	
7. ☐ Other, write in:	☐ 1	☐ 2	
8. ☐ Other, write in:	☐ 1	☐ 2	
9. ☐ Was not employed/ No significant issues			

F. FINANCIAL [If necessary, prompt: ***Did you have financial difficulties during treatment?***]
[Fill in Column B and Column C for each side effect checked in Column A]

28. Difficulty experienced as a result of treatment. *[**DO NOT READ OPTIONS**. Check ✓all that apply; fill-in col. B & C for those checked]*	28b. Did the difficulty impact your ability to take treatment as prescribed?	28c. Did the difficulty cause you to stop completion of treatment?	28d.
Column A	**Column B**	**Column C**	**NOTE**
1. ☐ Paying for medicine and bills	☐ 1	☐ 2	
2. ☐ Lost medical insurance	☐ 1	☐ 2	
3. ☐ Treatment led to less work, resulting in less income	☐ 1	☐ 2	
4. ☐ Other, write in:	☐ 1	☐ 2	
5. ☐ Other, write in:	☐ 1	☐ 2	
6. ☐ No significant issues			

G. SOCIAL [If necessary, prompt: ***Did your treatment affect your friendships or your social life?***]
[Fill in Column B and Column C for each side effect checked in Column A]

29. Difficulty experienced as a result of treatment. *[**DO NOT READ OPTIONS**. Check ✓all that apply; fill-in col. B & C for those checked]*	29b. Did the difficulty impact your ability to take treatment as prescribed?	29c. Did the difficulty cause you to stop completion of treatment?	29d.
Column A	**Column B**	**Column C**	**NOTE**
1. ☐ Maintaining personal relationships/ meeting obligations to friends	☐ 1	☐ 2	
2. ☐ Attending social functions	☐ 1	☐ 2	
3. ☐ Hid condition and/or treatment from friends	☐ 1	☐ 2	
4. ☐ Other, write in:	☐ 1	☐ 2	
5. ☐ Other, write in:	☐ 1	☐ 2	
6. ☐ No significant issues			

H. KAISER PERMANENTE FACILITY [If necessary, prompt: ***Did you have difficulties with your health care at a KP facility during treatment?***] [Fill in Column B and Column C for each side effect checked in Column A]

30. Difficulty experienced as a result of treatment. *[**DO NOT READ OPTIONS**. Check ✓all that apply; fill-in col. B & C for those checked]*	30b. Did the difficulty impact your ability to take treatment as prescribed?	30c. Did the difficulty cause you to stop completion of treatment?	30d.
Column A	**Column B**	**Column C**	**NOTE**
1. ☐ Obtaining medication from pharmacy	☐ 1	☐ 2	
2. ☐ Getting answers to questions about side effects experienced	☐ 1	☐ 2	
3. ☐ Scheduling follow-up appointments or calls to see my treating provider	☐ 1	☐ 2	
4. ☐ Making it to all the lab tests	☐ 1	☐ 2	
5. ☐ Traveling to follow-up appointments	☐ 1	☐ 2	
6. ☐ Wanted psychiatric counseling	☐ 1	☐ 2	
7. ☐ Other, write in:	☐ 1	☐ 2	
8. ☐ Other, write in:	☐ 1	☐ 2	
9. ☐ No significant issues			

I. CONCERNS, WORRIES, FEARS

[If necessary, prompt: ***While you were on treatment, did you have any specific concerns, worries, or fears?***]

[Fill in Column B and Column C for each side effect checked in Column A]

31. Difficulty experienced as a result of treatment. *[**DO NOT READ OPTIONS**. Check ✓all that apply; fill-in col. B & C for those checked]*	31b. Did the difficulty impact your ability to take treatment as prescribed?	31c. Did the difficulty cause you to stop completion of treatment?	31d.
Column A	**Column B**	**Column C**	**NOTE**
1. Personal feelings			
a. ☐ Shame/ guilty feelings	a ☐ 1	a ☐ 2	
b. ☐ Fear that tx was hurting my body	b ☐ 1	b ☐ 2	
c. ☐ Fear that treatment was going to make me more sick	c ☐ 1	c ☐ 2	
2. Felt I would be stigmatized by			
a. ☐ Spouse/ partner	a ☐ 1	a ☐ 2	
b. ☐ Children	b ☐ 1	b ☐ 2	
c. ☐ Parents	c ☐ 1	c ☐ 2	
d. ☐ Other relatives	d ☐ 1	d ☐ 2	
e. ☐ Friends	e ☐ 1	e ☐ 2	
f. ☐ Employer	f ☐ 1	f ☐ 2	
g. ☐ Co-workers	g ☐ 1	g ☐ 2	
h. ☐ KP staff	h ☐ 1	h ☐ 2	
i. ☐ Other social groups	i ☐ 1	i ☐ 2	
3. ☐ Other, write in:			
4. ☐ Other, write in:			
5. ☐ No significant issues			

V. HELP / SUPPORTIVE

We'd like to know more about what actually did help you during treatment. Then, looking back, what you think would have been helpful while on treatment, but that you did not have available during your treatment.

A. MEDICAL/ SOCIAL *[Fill in Column B for each item checked in Column A]*

32. Help / supportive during treatment. *[**DO NOT READ OPTIONS**. Check ✓all that apply; fill-in col. B & C for those checked]*	32b. In retrospect, if I had support from this/these individuals it would have made treatment easier. ***[for those who stopped tx]*** …or, more likely help me to complete treatment.	
Column A	**Column B**	**NOTE**
1. Kaiser Permanente providers		
a. ☐ Treating physician	a ☐ 1	
b. ☐ Treating nurse	b ☐ 1	
c. ☐ Treating pharmacy	c ☐ 1	
d. ☐ Other staff involved with treatment	d ☐ 1	
2. Mental health		
a. ☐ Kaiser Permanente Psych	a ☐ 1	
b. ☐ Kaiser Permanente group	b ☐ 1	
c. ☐ Other group (AA, etc.)	c ☐ 1	
3. Family members		
a. ☐ Spouse/ partner	a ☐ 1	
b. ☐ Children	b ☐ 1	
c. ☐ Parents	c ☐ 1	
d. ☐ Other relatives	d ☐ 1	
4. ☐ Friends and Social contacts	☐ 1	
5. Employment		
a. ☐ Boss/ supervisor	a ☐ 1	
b. ☐ Co-workers	b ☐ 1	
6. ☐ Church group	☐ 1	
7. ☐ Other, write in:	☐ 1	
8. ☐ Other, write in:	☐ 1	

VI. TREATMENT PROVIDER

In this section, we'd like to understand more about the relationship you had with your treating provider. Please consider the provider you saw most regularly for evaluation and/or treatment of your Hepatitis C.

34. Please indicate your agreement with the following statements regarding your treatment experience with

("Dr", if applicable _____). *[Select one response for each row below.]*
treatment provider name as per Q10

*[**READ ALL STATEMENTS BELOW**]*	Never	Sometimes	Usually	Always	Don't know
1. My treatment provider was knowledgeable about the disease	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
2. My treatment provider provided me the information I need to know, in a way I could understand.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3. During your treatment, how often did your treatment provider listen carefully to you?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4. During your treatment, how often did your treatment provider show respect for what you had to say?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
5. During your treatment, how often did your treatment provider spend enough time with you?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
6. During your treatment, how often did you feel that your treatment provider at Kaiser treated you poorly or made you feel inferior because of your race or ethnicity?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
7. During your treatment how often did you feel that your treatment provider at Kaiser treated you poorly or made you feel inferior because of your level of education?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

VII. DISCUSSION – In this section, we would like to ask you some questions and allow you to make suggestions…

35. What were the most challenging aspects of your HCV treatment? *[list up to 3 in order of importance]*

1.

2.

3.

35a. Did you have any challenges or problems during the first several months after treatment?

1 ☐ Yes (describe below) 2 ☐ No significant issues

35b. Describe:

36. What would have made your HCV treatment easier? *[list up to 3 in order of importance]*

1.

2.

3.

37. What would you advise someone about to begin HCV treatment? *[1- 3 pieces of advice]*

1.

2.

3.

[Skip question 38, if SVR]

38. Would you try again if your HCV treatment is not successful? 37b. What would be needed for you to try treatment again?

1 ☐ Yes 2 ☐ No 9 ☐ Not sure/ Don't know

38b.

VIII. OTHER RESOURCES

39. We would like your advice and opinion about possible resources that could be available for patients undergoing Hepatitis C treatment. How helpful would these options be to a patient being treated with Hepatitis C?

[READ ALL STATEMENTS BELOW]	Not at all helpful	Not very helpful	Somewhat helpful	Very helpful	Don't know	Check if pt stated "but, not for me"
1. An in-person support group with other patients who are undergoing treatment at the same time.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9 ☐
2. An internet chat group with other patients who are undergoing treatment at the same time.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9 ☐
3. Being connected with other patients undergoing treatment at the same time, so you can talk with each other by phone.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9 ☐
4. A support group for sobriety and/or addictions issues during treatment.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9 ☐
5. Peer support available from someone who has been treated for Hepatitis C in the past (e.g. telephone).	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9 ☐
6. Weekly in-person meetings with a nurse or other healthcare provider.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9 ☐
7. Weekly telephone check-ins with a nurse or other healthcare provider.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9 ☐
8. Email or other internet access to a nurse or other healthcare provider.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9 ☐
9. Individual, professional mental health counseling/ therapy offered every 1-2 weeks during treatment	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9 ☐
10. Professional counseling available to you with your family prior to, or during, treatment.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9 ☐
11. A nutritionist/dietician available to offer guidance for your dietary needs or dietary questions during treatment.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	9 ☐

VIII. CONCLUSION

Thank you very much. I've learned a great deal speaking with you. We appreciate the time and information you have shared to help us with this study

40. May we contact you about future Hepatitis C or other liver health studies? *[check one]*

1 ___Yes 2 ___No 9____Don't Know

Before we finish, do you have any questions about the study or anything else you would like to share? Thank you again. You'll be receiving a $20.00 gift card in the mail. *[Read available gift card choices –will be 2-3 of possible choices of Safeway, Target, and Starbucks]*

Note participant's gift card choice:_____

(verify address with participant)