Sample Focus Group Write Up

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Hepatitis C Health-Related Quality of Life Focus Group

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This memo ("Amfg0314") documents a focus group conducted to explore health-related quality of life issues in people with hepatitis C. The first five pages summarize the result of the focus groups recruitment letter, Attachment A* the script for the initial call with potential focus group participants, Attachment B the confirmation letter, Attachment C the informed consent form, Attachment D the focus group protocol, and Attachment E the focus group background questionnaire.

Characteristics of Participants

Seven Individuals (Candy, Fred, Samantha, Jenny, Cybil, Tammy, Manny) with Hepatitis C participated in the focus group conducted at the UCLA Medical Center on Saturday, March 14th, from 10:00am until 12:00 noon. The group included five females and two males. Ages were 32, 3, 38, 47, and three individuals were 49. Six of the participants were white and 1 person was Hispanic or Latino. Four were married two were single, one was divorced. Two-individuals had more than a 4-year college degree, 1 other a 4-year college degree, 3 had some college or a 2-year degree, and 1 person did not graduate from high school. Four persons were now living with a spouse, lover or partner, and three were not. Five were working full-time, one was working part-time, and one was a homemaker. Five reported having prepaid health insurance, one fee-for-service insurance and the other was unsure.

Six of the seven were first diagnosed with Hepatitis C 2 to 5 years ago, and there was a great deal of uncertainty about how long they'd had the condition. Two people did not know, and the pothers reported 4-30 years, 10 years, 18+ years, 20-25 years, and 25 years. Two individuals indicated that the cause of them getting hepatitis C was blood transfusion, two believed it was by pneumatic "shot-gun" vaccines given by the military (one of these two indicated that he dated a lot and lived in Spain for 3 years while in the Air Force; the other also worked in the laundry room in the service hospital and received several cuts from used surgical equipment), two due to IV drug use, and one that did not know. The latter person indicated that they had had dental surgery that may have had something to do with it.

On a five-point self-reported severity of symptoms during the past 4 weeks question (no symptoms, mild symptoms, moderate symptoms, severe symptoms, extremely severs symptoms), one person reported mild symptoms, four moderate symptoms, and two sever symptoms.

Focus Group Protocol

The focus group covered *daily activities, effects of hepatitis C and its treatment, utilization of health care, and impact of hepatitis C on relationships with others.*

Participants and their Daily Activities

Candy has a full-time job (fixing earthquake damage) and "needs the rest of the day to be able to do that." She engages in heavy work, but it takes her several hours to recover from it.

Fred is married. He never knew he had hepatitis C until he took a Red Cross blood test. Geberally speaking his liver is in good shape.

Samantha is married with 5-year old twins that wear her out. Lack of energy is the biggest problems from her. When her kids were born, she thought "I just can't do this" because she was so tired. When people would come to visit her. She would hand them the kids to take the load off her. She get's depressed when she "can't keep it up."

Samantha gets up at 4:30 am, has coffee, and then gets her kids ready for school. By that time she is exhausted and tries to get some rest before the kids come home for lunch. Then she makes sure they do their homework and helps them practice karate a little bit. By the time her husband gets home, she has started dinner. Samantha then tries to take a nap and he helps out around the house.

Jenny oversees medical clinics (two hospices) as part of an AIDS foundation. She leaves her house at 7:30am and returns home at 7:30 pm for her job. She said she is real tired and real cranky. Sometimes she has to call in and tell the people that she is working with that "she just can't come in right away today."

Before *Jenny* was diagnosed with hepatitis C, she felt like her "lights were going out." She was so tired all the time and didn't know why. They tested her for HIV and chronic fatigue syndrome before testing for hepatitis C.

Jenny gets up about 6:30 am. She drives to Hollywood to work. Now she is working on an anti-retroviral adherence project (setting up programs). Because she is in charge of clinics, people are "hocking" her all the time. As a result of hepatitis C, she has had to have real good "boundaries" with people (because they will take advantage of people who like to so a real good job). She has had to close her office door (which she has never done before) and say "no" sometimes. Jenny said she has had to figure out how much energy she has to "get to the finishing line." "If I don't have enough energy to get to the finishing line, it means I won't be able for everyone else." *Jenny* also screens her calls now so she can be more selective about who she talks with. She is much more selective, for example, in speaking with some of her "needy" friends. For the first time in her life, she has had ro put herself first. She has now has to pay attention to her health.

She now tells friends that "I can only do the best I can" with respect to socializing with them. For example, she was once too tired to make it to the start of a movie so she showed up in the middle of it. Her friends were worried about having to pay for a movie that she didn't get to see, but she was content to see a part of it and spend time with the afterwards.

Cybil is single and works at a major law firm at night (paralegal). She was diagnosed through a Red Cross blood test in 1995. She is looking forward to the biopsy report to see how her liver is doing.

Cybil usually gets 7-8 hours of sleep a night. She gets up late in the morning because she doesn't get home from work until about 2:00 am. She works out regularly including jogging, but has cut down the intensity of her workout considerably in the last year and a half. She naps during the day quite a bit. *Cybil* spends her afternoons writing. She works 4 nights a week (30 hours).

Tammy is married with no children. She took a year off work during the time she was involved in an interferon study, but now she is back. When she was going through the treatment, *Tammy* told her friends that she might have to cancel social activities at the last minutes to prepare them for the possibility. She has more energy than before as a result of the treatment.

Manny is married with three children. Manny has been very physically active in his life, having been a professional surfer, snowboard, and doing 100 push-ups a day previously. He was diagnosed with hepatitis 4-5 years ago when he applied for a life insurance policy.

Manny is a self-employed builder who has owned his business for 25 years. Manny goes to bed about 9:00 and gets up about 5:30am. He wakes up several times during the night. He has changed from participating actively on the job site with his employees to only setting up the job and supervision.

Effects of Hepatitis C and Its Treatment

The day after getting her first interferon shot *Jenny* felt like she was hit by a bus. She said it was awful and she couldn't imagine doing that to herself again. Her finger-tips became dry, started to itch and then she got "full on" pain in them. Hair loss is another side effect of interferon Jenny reported.

Cybil indicated that she recently went through an 11-month interferon protocol and that this put her into an anxiety/depression spell. She is doing ok now, but she is moderating her activities more than before. *Cybil* reported having muscle aches in her shoulder.

Tammy was in a 6-month interferon study, and took a year off work during this time. She went back to work in November to work and feels great except from the muscle aches in her neck and arm. "I feel like pulling out my hair" she said. (*Fred* indicated that he took calcium citrate for his muscle aches and it cured it.) *Tammy* said now she has energy she never had (raring to go), but she is sore.

Since he went off interferon, *Manny* has had a lot of muscle fatigue. His legs cramp when he surfs, he can't wrestle his 12-year son, etc. Forcing himself to do even 10 pushups now is difficult. *Manny* also indicated that he gets a stomach ache daily somewhere between noon and 2pm whether or not he has eaten. "All of a sudden I feel nauseous." *Manny* has also been getting little pimples on his legs ("cryo globulins") due to inadequate blood circulation. When taking interferon, *Manny* said he tended to get angry and yell and scream at his wife.

Candy stated that she doubles over several times during the day and sometimes vomits. *Fred* indicated that drinking a lot of water helped him with similar symptoms.

When *Fred* is on interferon, he feels a little down. When he is off it has more energy and a more positive outlook on life. He has had three rounds of interferon therapy and considers it a "real pain."

Other symptoms mentioned in the group included joint pain, night sweats insomnia, and arthritis. Participants had some uncertainty about whether the problems they were experiencing were due to hepatitis

C or to the treatment, but when they believed it was due to treatment this attribution was generally based on temporal proximity of the treatment and effects.

Utilization of Health Care

The focus group participants were infrequent users of general health care aside from their participation in clinical trials. Manny said he goes to the doctor "as little as possible," *Tammy* about every 3 months, *Cybil* "infrequently," *Jenny* every 6 months, *Samantha* about every 3 months, *Fred* every few months, and *Candy* only for lab tests. Most visits were tied to the protocol of lab tests and checkups that they happen to be on at the time.

Impact on Relationships with Others

Tammy lost her best friend as a result of hepatitis C, because the friend didn't like her last minute cancellations caused by her disease. However, it has brought her very close together to her spouse–he is very supportive and even "babies" her now. For the most part, hepatitis C has had a positive impact.

Samantha has had a lot of guilt because other people don't understand how sick she is (you don't look sick, so why are you lying around?). She had one friend who is a "germ freak" who was afraid of her for a while. Her husband fought the idea of using a condom for a long time. *Samantha* and her husband avoid sex around the time of her menstrual cycle.

Cybil has been in the same relationship since the time she was diagnosed and he has been wonderful and supportive. When she was on the interferon and was hostile and alienated from others, he was her only contact with reality. She is cautious and selective now in relationships with other and feels libido because of the fatigue associated with the disease.

Jenny is feeling a lot more now than she did before. She was a functioning person before, but now she feels psychological more pressure and a need to attend to her feelings. She has allowed people to help her more now. One thing that has bothered her is her relationship with her mother. She has had to be very mindful of what she tells her because her mother worries about losing her daughter. She doesn't kiss anyone on the mouth anymore. She is very mindful of transmission of hepatitis C.

Fred only recently told other people that he had hepatitis C (apart from his wife). He told a few people and recommended they get checked for it themselves. He is more comfortable telling people now because he has more information about the disease and he can explain what is happening and answer their questions. Fred has had friends who joke around with him by feigning nonverbal rejections, and this bothers him a little bit. Fred and his wife avoid sex around the time of his wife's menstrual cycle.

Candy said that people tend to forget because she doesn't look sick. For example, her boss will push her until she can't take it anymore and them back off when he realizes that she is at her limit. Her daughter from out-of-state calls 2-3 times a week. Her son is dependent on her and will have the most adjusting to do when she is gone. She says that her family frequently asks how she is feeling and that gets annoying. “If there is anything new, I’ll tell you.” She is very cautious in sexual practices including no open-mouth kissing.

Manny’s wife is a VA nurse and is very supportive. His oldest daughter has been affected because he was unable to be there for her sometimes because of his own health problems. His mom checks on him quite a bit, but his dad never says a word. Both of them have medical problems and they try to talk about more positive things (how are the kids doing?). *Manny* is not with his crew at work as often because he just can’t do it. He and his wife want another child and this they are trying. His wife’s attitude is that “if you are going, I’m going with you”.

Adhoc Issues Raised During Focus Group Discussion

Information about Hepatitis C Participants expressed concern about inadequate writeen information about hepatitis C, especially for the recently diagnosed. One person recommended Amgen’s pamphlet and noted it to be very useful. Other people talked about the internet as being a good resource for information.

Delay in Getting Results of Viral Load Test. Fred and others expressed strong concerns about the delay from the time of testing for the virus and getting the results back about the status of the virus (has it relapsed?) when he goes off of drug. The long delay creates a lot of anxiety.