Mental and physical symptoms associated with lower social support for patients with hepatitis C

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Abstract

AIM: To systematically examine the impact of the hepatitis C virus (HCV) diagnosis on patients' level of social support in a large-scale study.

METHODS: Patients evaluated and treated for HCV in a tertiary referral center were enrolled in a cross-sectional study. Demographic data, functional and emotional status as measured by the Hospital Anxiety and Depression Scale (HAD) and the Sickness Impact Profile (SIP), severity of liver disease, mode of acquisition, and physical and psychiatric comorbidities were collected from patients or abstracted from the medical record. All participants completed a semi-structured interview, addressing questions of social support.

RESULTS: A total of 342 patients (mean age 45.2 years; 37% women) were enrolled. Ninety-two (27%) patients described lower levels of support by family and friends. Nearly half of the participants (45%) noted the loss of at least one relationship due to the disease. Fears related to transmitting the disease (25%) were common and often associated with ignorance or even discrimination by others (19%). Nearly one fifth of the patients did not share information about their disease with others to avoid being stigmatized. Lower levels of social support were significantly associated with living alone, being unemployed, being excluded from antiviral therapy, having psychiatric comorbidities, contracting HCV through intravenous drug use, having high levels of anxiety and depression as measured by the HAD and negative mood state as measured by the SIP. Patients reporting lower levels of social support also noted more physical symptoms as measured by the SIP.

CONCLUSION: Patients with hepatitis C often face significant social problems, ranging from social isolation to familial stress. The most common concerns reflect a limited insight of patients and their relatives and friends about the disease, the risk factors for its spread, and about potential consequences. Our data suggest that educational interventions targeting support persons and the stressors identified in our findings may lessen or alleviate the social strains patients with hepatitis C experience.

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INTRODUCTION

Hepatitis C virus (HCV) infection, a common and slowly progressing liver disease, negatively affects quality of life. Most studies addressing the important impact of HCV focus on patients undergoing antiviral therapy[1-6]. However, even HCV-infected individuals outside of treatment have lower quality of life scores compared to uninfected controls[7-9]. Negative social interactions may play a unique role as a determinant of quality of life in patients with HCV, as they often face stigmatization in their professional and private environment[10-12]. Patients living with AIDS and stigmatizing diseases such as tuberculosis and leprosy

experience a deterioration or even complete collapse of their social support network[13-15]. Despite recent evidence of negative stereotyping in patients with HCV, few studies have focused on the effect of the disease on the patients' interactions with family, friends or other important groups[16]. Relatively little is known about possible correlations between social support and demographic and psychosocial or physical characteristics, or of the specific difficulties that patients experience in their lives[17]. In this analysis we hypothesize that poor social support is associated with emotional and physical difficulties in patients with HCV both in and outside of treatment. Using mixed quantitative and qualitative methods, we propose to characterize the nature and the causes of social problems as an important first step in alerting healthcare providers of the major stressors these patients face.

MATERIALS AND METHODS

Patients

The schedules of all hepatologists practicing at a large Midwestern teaching hospital were reviewed daily between October 1998 and May 2003 for patients meeting the study inclusion criteria. Patients younger than 18 years of age, prisoners, those unable to communicate verbally, or provide informed consent were excluded from the study. No exclusions for concurrent liver disease (hepatitis A or B) or HIV status were made. Patients with a confirmed diagnosis of HCV were invited to participate on the day of their clinic visit.

Data collection

Once informed consent was obtained, participants were asked to provide demographic information, to undergo an extensive interview addressing psychosocial and health-orientated questions (see Appendix), and to complete health status and psychosocial survey measures. The interview was designed to range in length from 30 min to two hours. Each interview was recorded with a hand-held tape recorder and transcribed verbatim. After the interview, patients provided demographic information (age, gender, race, marital status, education, population of home town), and completed the Hospital Anxiety and Depression Scale (HAD), a self-assessment scale for mood disturbances in a non-psychiatric patient population[18], and the Sickness Impact Profile (SIP), a behaviorally based health status measure including sub-scales for physical symptoms (Body Care and Movement, Ambulation, Mobility), psychosocial difficulties (Emotional Balance, Social Interaction, Alertness Behavior, physical ability to Communicate), as well as physical and psychosocial summary scores[19].

A physician abstracted from the electronic medical record patients' psychiatric diagnoses, Charlson Comorbidity Index[20], Child-Pugh score, dates of treatment for HCV infection (before, during, after interview), substance abuse, mode of transmission (drug use, blood transfusion/needle stick, tattoo/other/ unknown), and response to treatment (durable responder, nonresponder/disease recurrence, naïve). Patients who were naïve either self-excluded from treatment or were excluded based on physical comorbidities, psychiatric disease, or substance use. Based on clinical records from the attending hepatologist, no patient was determined to remain naïve based on a lack of social support.

Coding

For the construction of our codebook[10,21] we used the quasi-statistical method as outlined by Miller and Crabtree[22]. We also employed the qualitative computer software program Atlas.ti (version 4.2, Berlin, Germany) to aid in the management and analysis of data. Twenty trained interviewers, each with over one year of experience in interviewing, read 50 out of 150 randomly selected interviews and ranked the top ten themes in terms of overall frequency and importance. The primary investigator and two trained coders then synthesized this list to create the master codebook which included the central themes related to social support, stigmatization, and quality of life. Using this codebook, each transcript was then coded by two independent coders, one who had undergone a minimum of three weeks formal training and a master coder with at least one-year experience. The initial coding sheets of each coder were converted into a spreadsheet to determine a final kappa score that assessed the agreement between the evaluators. The coders then met and processed the codes for each case until 100% agreement was achieved between them. From this a master code databank was developed which was then used for the statistical calculations.

For this analysis, the chief code was for social support, noting where patients described a dominantly negative environment (coded as 'unsupportive') versus all others (coded as 'supportive'). We defined social support as involving sexual partners, family members, and friends. An 'unsupportive' social environment was defined as dominantly negative (e.g., 'They have basically excluded me; so I'm all alone now,' 'Relations with my husband are just not good any more.') Conversely, a 'supportive' social environment was defined as either positive or mixed (e.g., 'They are always there for me,' 'My in-laws won't have me in the house, but my wife and kids are okay with it.') When the interview was too conflicted or when too few details were provided, the code of 'cannot judge social situation' was used. These interviews were then excluded from the final analysis. The ordinal code of social support had an inter-coder reliability kappa score of 0.72, or what Landis and Kock label as a 'substantial' agreement between coders[23].

Two coders then conducted a close textual analysis of each discussion of social support present in the interviews. For the purpose of this analysis we concentrated on two main domains: (1) the negative impact of HCV on social support, and (2) the reasons for this negative impact.

Statistical analysis

All analyses were performed using SPSS version 12.0 (SPSS, Inc. Chicago, Illinois, USA). We first summarized the demographics and clinical characteristics of the patient sample, excluding anyone with missing data on social support. We then examined demographic, psychosocial,

and clinical characteristics of the patient sample, both overall and by level of social support, treating the level of social support as binary ('supportive' versus 'unsupportive'). We tested for differences between groups using ANOVA for the means of continuous variables (age, Child-Pugh score, HAD, SIP) and Chi-Square and Fisher's Exact for categorical variables, where appropriate. We then examined factors associated with social support. $P < 0.05$ was considered statistically significant.

RESULTS

Patient characteristics

A total of 499 patients were approached, with 96 declining to participate, largely due to time constraints. Of the 403 patients successfully entered into the study, 61 were excluded due to either a technological failure in recording the interview ($n = 12$) or an inability to judge the social support code ($n = 49$). This left 342 patients in the total sample with a code for social support. This sample was (Table 1) predominantly male, white, and had acquired the disease mostly through intravenous drug use. Two hundred and fifty patients (73%) were categorized as having a 'supportive' and 92 (27%) as having an 'unsupportive' environment. Of all the patients in the study only 4 (3 with hepatitis B and 1 with HIV) had another chronic, sexually transmittable disease.

Bivariate analysis

Considering the cross-sectional design, participants were interviewed at different points during the evaluation of and/or treatment for HCV (pretreatment, treatment, post-treatment, naïve). Naïve patients (typically excluded from treatment due to psychiatric illness or substance use) reported more negative social experiences compared to patients in the pretreatment, treatment, and post-treatment groups (Table 2). Marital status (living without partner) and employment status (unemployed) were significantly associated with level of social support, while all other demographic and disease-related variables did not correlate. Psychiatric comorbidity and prior substance abuse as the mode of acquisition for HCV were associated with lower levels of support. The category of unsupportive social support also correlated with greater physical symptoms as measured by the physical summary scores of the SIP and all physical sub-scales (Body Care and Movement, Mobility, Ambulation). Similarly, lower support was associated with the psychosocial summary scores and all psychosocial sub-scales of the SIP (Emotional Balance, Social Interaction, Alertness, Communication), as well as higher scores for the depression and anxiety scales of the HAD (Table 2).

Thematic analysis

Two domains emerged as patients discussed their problems. First, they described the negative impact of the infection on their social support; second, they gave potential reasons for negative changes.

Negative impact of HCV on social support

Deterioration of relationships: One hundred and fifty-

Table 1 Demographic and clinical characteristics of the study population

Patient characteristics	*n* (%) of total study population
Demographic characteristics	
Mean age in years (SD)	45.2 (9.2)
Women	128 (37.4)
Racial/ethnic background	
White	310 (90.6)
Black	19 (5.6)
Other[1]	13 (3.8)
Marital status	
Living with partner	212 (62.0)
Living alone	130 (38.0)
Education	
K-12	137 (40.1)
College	205 (59.5)
Employment prior to diagnosis	
Employed	296 (90.0)
Unemployed	33 (10.0)
Current employment	
Employed	217 (65.0)
Unemployed	117 (35.0)
Population of hometown	
Rural	220 (64.3)
Urban	122 (35.7)
Interview to treatment status	
Before	32 (9.4)
During	93 (27.2)
After	94 (27.5)
Naïve	123 (36.0)
Clinical characteristics	
Current substance use	
Yes	24 (7.0)
Total psychiatric diagnosis	
0	251 (73.6)
1	74 (21.7)
2	14 (4.1)
3-5	2 (0.6)
Advanced liver disease (cirrhosis)	81 (23.8)
HCV due to IV drugs	177 (62.3)
HCV due to other methods of transmission	107 (37.7)
Mean Child-Pugh score (SD)	5.46 (1.2)

SD: Standard Deviation; HCV: Hepatitis C virus; IV: Intravenous. [1]Other ethnicity includes Hispanic, Native American, Asian and Pacific Islander.

five patients (45% of the total sample) noted that having HCV had resulted in the breakdown or loss of at least one relationship. The deterioration of their social network affected sexual relationships (59 patients, 17% of the total sample) and interactions with family members (56 participants, 16% of the total sample): "I am estranged from my family. My wife and I divorced a year and a half ago. I didn't understand what was going on with me. One element of this disease is depression and an inability to think coherently sometimes. Being irrational, it's hard on relationships." Forty individuals (12% of the total sample) noted that they had experienced the loss of at least one friend.

Twenty-nine patients (8% of the total sample) mentioned multiple sources of loss: "Basically I do not have any good relationships with anyone." For these patients, the HCV diagnosis led to what they described

Table 2 Characteristics of groups categorized by social support

	Social support group		P value
	Supportive environment (n = 250)	Unsupportive environment (n = 92)	
Demographic characteristics			
Mean age in years (SD)	45.33 (9.82)	44.88 (7.52)	0.49
Women	91 (71.1)	37 (29.0)	0.52
Racial/ethnic background			0.09
White	229 (73.9)	81 (26.1)	
Black	15 (79.0)	4 (21.0)	
Other†	6 (46.2)	7 (53.8)	
Marital status			< 0.001[1]
Living with partner	171 (80.7)	41 (19.3)	
Living alone	79 (60.8)	51 (39.2)	
Education			0.59
K-12	98 (71.5)	39 (28.5)	
College	152 (74.1)	53 (26.0)	
Employment prior to diagnosis			0.63
Employed	218 (73.6)	78 (26.4)	
Unemployed	23 (70.0)	10 (30.0)	
Current employment			0.01[1]
Employed	169 (78.0)	48 (22.0)	
Unemployed	75 (64.1)	42 (36.0)	
Population of hometown			0.29
Rural	165 (75.0)	55 (25.0)	
Urban	85 (70.0)	37 (30.0)	
Interview to treatment status			0.03[1]
Before	23 (72.0)	9 (28.0)	
During	72 (77.4)	21 (23.0)	
After	76 (81.0)	18 (19.1)	
Naïve	79 (64.2)	44 (36.0)[1]	
Clinical characteristics			
Current substance use			0.8
Yes	17 (71.0)	7 (29.0)	
Total psychiatric diagnosis			< 0.001[1]
0	197 (78.5)	54 (22.0)	
1	42 (57.0)	32 (43.2)	
2	10 (71.4)	4 (29.0)	
3-5	0 (0.0)	2 (100.0)	
Advanced liver disease (cirrhosis)	63 (78.0)	18 (22.0)	0.27
HCV due to IV drugs	117 (66.0)	60 (34.0)	0.002[1]
HCV due to other methods of transmission	89 (83.2)	18 (17.0)	
Mean Child-Pugh score (SD)			0.68
Normal	234 (69.0)	85 (25.0)	
Elevated	15 (4.4)	7 (2.1)	
Mean HAD summary scores (SD)			
Depression score	4.04 (3.47)	6.95 (4.48)	< 0.001[1]
Anxiety score	6.57 (3.86)	8.95 (4.40)	< 0.001[1]
Mean SIP summary scores (SD)			
Physical score	4.64 (7.03)	10.4 (12.17)	< 0.001[1]
Psychosocial score	10.81 (13.67)	22.9 (18.82)	< 0.001[1]
Mean SIP subscale scores (SD)			
Social interaction	18.86 (25.40)	34.17 (27.72)	< 0.001[1]
Emotional balance	8.76 (12.06)	19.3 (16.30)	< 0.001[1]
Alertness	5.15 (8.69)	9.79 (11.24)	< 0.001[1]
Body care and movement	7.06 (12.56)	16.09 (23.73)	0.002[1]
Ambulation	9.60 (16.53)	22.38 (24.48)	< 0.001[1]
Mobility	4.34 (7.67)	11.19 (13.36)	< 0.001[1]
Communication	2.32 (6.41)	7.91 (12.63)	0.001[1]

SD: Standard Deviation; HCV: Hepatitis C virus; IV: Intravenous; HAD: Hospital Anxiety and Depression Scale; SIP: Sickness Impact Profile. † Other ethnicity includes Hispanic, Native American, Asian and Pacific Islander. [1]Denotes statistically significant P value.

as widespread social isolation. This feeling negatively impacted nearly all aspects of their social lives: "Well, it has affected my family, like even my parents and stuff. My mother's afraid to kiss me; she thinks it's like AIDS, you know. It caused a divorce." In 25 additional cases (7% of the total sample), it was the patients themselves who chose to withdraw from families or friends: "When I first found out that I had something wrong with my liver I was very upset and didn't want anyone around me and tried to keep people from me…Right at the moment I have spent a lot of time away from my family. I'm not really wanting to go around them until I find out for sure what's going on."

Underlying reasons for a loss of social support: Three dominant themes emerged when patients explained why their social support had been lessened because of their HCV infection. (1) Transmission of the virus: First, concerns about possible transmission of the virus were described as a major stressor by 84 patients (25% of the total sample). Most of these concerns, voiced by 69 patients (20% of the total sample), focused on sexual partners and family members: "I live with a woman who's deathly afraid of contracting HCV from me, so there's friction there." A smaller number of patients (n = 36; 11% of the total sample) were afraid that they might infect friends. Because of fears related to maternal-fetal transmission, 2% of the total sample mentioned concerns about having children, which included the decision to forgo having a family: "(I feel) like I am cootied- like I have cooties. I feel like even if I wanted to have children, I couldn't." However, these often excessive concerns also led to some appropriate precautions. Forty participants (12% of the total sample) stated that they had started using various precautions, including barrier methods for contraception as well as keeping all wounds bandaged, utensils clean, and/or warning others of potential infection risks. (2) Ignorance surrounding the disease: Ignorance, sometimes leading to frank discrimination, was described by 66 participants (19% of the total sample) as directly disrupting relations with family and/or friends. One young man stated: "I lost probably half my friends as they don't know what the disease is. They just automatically put up a front. I just don't see them anymore-fear of what may happen. So ignorance is how I like to put it." In

conjunction with these feelings, 61 patients (18% of the total sample) had decided that they would not tell others of their disease to decrease the chance of experiencing a negative reaction: "I don't tell anybody 'cause…people are stupid about this disease. Just like they're stupid about AIDS." A small group of patients (*n* = 11; 3% of the total sample) did not experience discrimination, but rather sensed that those around them simply did not understand that HCV was a serious disease that could affect physical and emotional functioning: "Family members still don't understand because you don't look sick, so therefore, you should still be able to do everything." (3) Stress caused by the disease: Eighty-three participants (24% of the total sample) experienced problems in their social environment, which they attributed to disease related stress. Such HCV related stress took several forms. One was the unpredictability of the infection's outcome, which left family members and/or friends worrying about the patient: "It's sort of depressing for my family members, because they're all really concerned. I've got daughters and they're worried that I'm going to die." For some patients, a major stressor of living with HCV was their own personal concerns for family and/or friends: "I've got to make sure that my family is provided for, 'cause I don't know if I'm going to croak here anytime."

Another frequently mentioned problem with detrimental effects on relationships was fatigue (*n* = 49, 14% of the total sample). Treatment or disease related fatigue limited the patient's ability to spend time with others: "Basically I am just non-functioning; cannot maintain relationship with my wife; I cannot work. I have two little boys I am not able to spend quality time with. I can spend time with them, but…I don't have the energy to go out and play baseball with them or any of that stuff."

A final source of stress, especially for families, was the financial burden that came either through a loss of work and/or through the cost of the antiviral medication (*n* = 16, 5% of the total sample). One patient explained the reaction of her husband to the treatment of her disease: "Not good, it's a lot of strain on him and stress and he's emotionally upset because of everything. And he's had to hold the whole road as far as work and we're in debt $40 000. You know, that's the big one, the debt and money 'cause we don't have insurance. How are we ever going to pay for it?"

DISCUSSION

This is the first analysis to display the frequency and to characterize the nature of the relationship challenges that patients with HCV experience. About one third of this large group of HCV infected patients described a negative impact of their disease on personal relationships. The most devastating consequences were with breakups or major stressors on sexual relations as experienced by about 17% of the participants, and the loss of relationships with family members in an additional 16% of cases. Our results are consistent with prior studies focusing on patients with HIV/AIDS or tuberculosis, who also felt rejected by relatives and friends[24,25]. While all chronic diseases can

potentially tax a social support network, a diagnosis with HCV appeared to carry with it unique challenges. Patients feared interactions with others, especially sexual partners, because of the perceived risk that they might infect them. Patients also complained that those close to them lacked information about HCV, that they harbored prejudices or simply did not consider the disease to be "real" and, therefore, serious. As a result, 7% of HCV positive patients in our study personally chose to withdraw from social contact with others.

A similar breakdown occurred outside of the home, with participants reporting that friends had shied away from them. As reported in prior studies, a substantial number of patients experienced frank stigmatization[26-29]. Changes in employment, sometimes attributed to perceived stigmatization[10], sometimes fatigue, created additional strains, as patients were facing financial problems exacerbated by the significant costs of the antiviral treatment.

Concerns about quality of life emerged with patients' estrangement from family and friends. Relationship deterioration can constitute an important stressor, which can limit a patient's ability to cope with a disease[30-32]. Several studies have previously found that a lack of social support and personal coping resources can affect mood and trigger depression[33-36].

Our bivariate analysis is consistent with the above mentioned theoretical considerations. Similar to prior reports, we noted an association between emotional problems, including depression, as measured by the HAD, and lower levels of social support[37-39]. A lower level of support was also associated with higher scores for anxiety, as measured by the HAD, more psychiatric diagnoses as listed in the medical chart, and lower psychological well-being as measured by sub-scales and summary scores of the SIP. While studies have consistently found antiviral therapy to be associated with higher levels of depression[40-45], our cross-sectional data did not show differences in the level of social support of those currently on therapy, as compared to those who were pre or post treatment. This may be surprising at first glance because of the known effects of antiviral therapy on mood. Yet our thematic analysis pointed to specific challenges-transmission risks, unpredictable outcomes, feelings of isolation and the perceived need to withdraw from others-that are not unique to patients undergoing treatment.

Interestingly, patients with lower levels of social support were also more likely to report more severe physical symptoms, as shown in higher SIP scores on Body Care and Movement, Mobility, and Ambulation. While we did not notice a relationship with the presence of cirrhosis or the Child Pugh score, a prognostic indicator for advanced liver disease, most of the patients did not have cirrhosis or had well compensated disease, thus, limiting the discriminating value of these variables. The underlying mechanisms for the relationship between poor social support and physical functioning are unclear[46-49]. One explanation, as noted by patients in our study, was that worse physical functioning limited their ability to meet expectations of family and/or friends.

This study was shaped by the belief that patients' accounts accurately reflected their lived experience of having HCV. As such, the narrative findings were limited to patient recall. However, we maintain that an open account by patients is the best way to understand the breadth and depth of the problems affecting their social support. In addition, we interviewed a very large group of patients with HCV, enabling us to see which themes appeared most dominant, thereby decreasing the anecdotal nature of most qualitative findings.

The study was also cross-sectional in nature, thereby limiting causal evidence of whether social support difficulties actually resulted in worse mental and physical health. Future studies should assess patient's social support level prior to HCV testing in order to determine whether the knowledge of having the disease results in negative interpersonal consequences or whether patients with risk factors for HCV are instead prone to having social difficulties. Finally, the study population was representative of the non-urban Midwest of America. Our age and sex distribution are similar to those reported in many of the prominent studies on HCV[50-53]. Also, our results found no significant association between social support and rural/urban living or ethnicity. However, as the majority of our participants were Caucasians, the study is not an ideal vehicle for examining the role of race or ethnicity in social support.

In conclusion, as far as we are aware, our results are the first to characterize in a large patient sample the negative consequences of carrying a diagnosis of HCV on patients' social support. Providers and case managers need to be aware of the themes expressed in this analysis, as fears of contamination, feelings of isolation or withdrawal from others may reduce the emotional willingness of patients to initiate and remain on antiviral therapy. Structured educational sessions for both the patient and their partners and families could help reduce the misunderstandings expressed here, such as the ignorance of the disease or the view that the disease is somehow not "real," which can further burden the resilience of patients with HCV to cope with their disease.

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APPENDIX

1 Can you tell me what your condition is exactly? What physical limitations do you have and when were you initially diagnosed?

2 Could you tell us a little bit about yourself: the things you've done, your roles in life, who you are? What in your life are you most proud of?

3 Can you share with us anything specific that might have caused or helped cause your illness?

4 Have any of your family members had similar health problems? Does this family history worry you?

5 What impact has your physical condition had on the quality of your life? Would you say that your quality of life as compared with 1 year ago is better, about the same, or worse?

6 As you go through this experience, have you begun to think about yourself differently?

7 What has been the hardest thing for you to cope with related to this experience? How do you go about coping with your condition?

8 How does this illness make you feel emotionally? If there was one emotion that you would use to express how you feel, what would that be?

9 Since you were diagnosed, what would you say has been your biggest regret? Would you say you feel emotionally worse since you were diagnosed, about the same as before, or emotionally better off than before?

10 Can you share what health related worries you have? Do you worry more about your health than you do other aspects of your life? Did you share these worries with your doctor or nurse?

11 How would you describe your outlook or thoughts as you look to the future?

12 What are the various things that make your life meaningful for you? What do you turn to when you are in need of strength?

13 **We are interested in the impact this illness has had on your relationships:**
    (1) If you were in a crisis, who would you turn to?
    (2) Do you have a spouse or significant other? How has that person reacted to your situation of being ill? When you think about when you were healthy, would you describe the two of you as closer, somehow further part, or just as close as you always were? (3) Can you describe the level of support you can find in your family? Can you explain why are you able or not able to rely on your family to help you through difficult times? (4) Would you say that you are close to others outside of your family? Why would you say that? What about co-workers, are they understanding and supportive?

14 **Have you encountered any negative judgments from others because of your disease? If yes, can you say who has made you feel this way and under what circumstances?**

15 How has your disease affected your sense of control in your life? What are the situations where you feel you're not in control?

16 What has been your experience with your doctors here or elsewhere? Would you describe it as positive or negative and what has made it positive or negative? What in your eyes makes a good doctor?

17 Do you feel that you can ask your doctor or nurse any question? Do you worry that you may be taking their time with your concerns?

18 Where do you get most of your medical information? Is there a source you tend to rely or believe in the most? In general, are there other things about your health condition that you would like to learn from your doctor?

19 What is the most difficult part of following the treatment the doctor recommended for you? Can you describe situations where you are unable to follow the doctor's treatment, such as taking your medicines, watching your diet, or exercising?

20 **Did you feel comfortable with your treatment decisions? Do you feel you had choices in your treatment and that they were respected? Who did you discuss your treatment decisions with; what really helped you to make up your mind?**

21 Do you use other or supplemental, herbal, or alternative medicines, and if yes, what are those?

22 If you were to describe yourself as something- it can be anything in this world--an object, an animal, anything-- before when you were healthy and now, what two things would you choose?

23 Is there anything else that you would like to add that would help us to understand your experience?

24 Finally, is there anything you would like us to share with a social worker, a pastor, or your health care team about the way you are feeling?

Interviewing Question Guideline (Bold indicates primary questions used in this analysis)