Clinical Encounters and Treatment Initiation for Chronic Hepatitis C Patients: Applications of Adaptive Leadership Framework for Chronic Illness

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Abstract

Chronic Hepatitis C (CHC) is the most common blood-borne infection in the U. S. Patients with CHC undergoing treatment face many challenges including adherence to medications and management of symptoms; health care practitioners are well positioned to facilitate patients' ability to address these challenges. We used the Adaptive Leadership for Chronic Illness Framework to investigate the difficulties inherent in affecting behavior change in patients undergoing treatment. We enrolled 11 patient participants and 10 provider participants. We used data from the first clinical encounter between patients and providers during which treatment was discussed. We found examples of adaptive leadership and categorized these behaviors into three themes: support for medication, coping with family/ home life, and strategizing to manage employment. We also saw examples of what we termed missed opportunities for adaptive leadership. This study illustrates the contributions of adaptive leadership behaviors by healthcare providers and the potential risk to patients in their absence.

Chronic Hepatitis C (CHC) is the most common blood-borne infection in the U. S. affecting an estimated 2.7–3.9 million people and while cure is now possible, the number of new cases of disease has nearly tripled and is now at a 15 year high (Centers for Disease Control and Prevention, 2017). Patients with CHC who are undergoing curative treatment face many challenges including adherence to medications and management of symptoms such as pain and fatigue (Z. Younossi & Henry, 2015; Z. M. Younossi et al., 2016). While treatment regimens continue to evolve, these patients experience difficulties in self-management

similar to those of patients in treatment for other chronic conditions. How patients and families interpret and respond to the symptoms and its treatment protocols has a profound impact on how well the patient copes with the treatment regimen and moves towards a cure. Health care practitioners are well positioned to facilitate patients' ability to master the challenges they face in a collaborative effort to achieve a cure. However, not all health care practitioners are skilled in facilitating this sort of exchange during a clinical encounter.

When health care practitioners place more emphasis on disease management than on the person with the disease, patients are less satisfied with their care and have more difficulty making the behavior changes necessary for adequate treatment or cure (Dwamena et al., 2012). When patients do not change their behaviors, they are often labeled as "noncompliant" or "non-adherent," but the problem is often the result of poor communication between providers and patients, which leads to a misunderstanding of treatment goals and a failure to follow the prescribed treatment (Bezreh, Laws, Taubin, Rifkin, & Wilson, 2012; Dwamena et al., 2012; Fusfeld et al., 2013; Laws et al., 2013).

Consequently, numerous interventions have focused on improving provider communication skills (Dwamena et al., 2012; Harrington, Noble, & Newman, 2004; King & Hoppe, 2013). Communication-focused interventions, however, do not consistently yield positive results. For example, a recent meta-analysis reported that fewer than half of communication interventions focused primarily on providers had a positive impact on chronically-ill patients' health behaviors and health status measures (Dwamena et al., 2012). This raises the question, why?

In the rhetoric of patient-centered care, most discussions do not include the idea of working with patients after treatment decisions are made. While Berwick (2009) considers helping patients adapt to difficult disease-related challenges and develop new behaviors needed to manage their illnesses "bold" and necessary, this kind of help is seldom given. A key feature of patient-centered care is giving patients a voice in care decisions shaped by their values or their caregiver's preferences (Clancy & Collins, 2010; Epstein & Street, 2011; Garber, 2011). Providers find it difficult to achieve patient-centered care partly because they lack a framework to guide them in a assessing patients' response to his or her health conditions, which would enable them to better understand how to fully engage the patient as a partner in management of the health care issue at hand.

This study investigated the difficulties inherent in affecting behavior change in patients undergoing curative treatment for Chronic Hepatitis C (CHC). Patients were treated with Telaprevir and ribavirin taken by mouth and PEGylated interferon given by injection (referred to as "triple therapy").

We used the Adaptive Leadership for Chronic Illness Framework (Anderson et al., 2015) to analyze the transcripts of recorded clinical encounters between CHC patients and their providers as well as related interviews with both parties following the clinical encounters. This framework has the potential to guide providers in attending to the symptoms, their side effects, and the inherent challenges of CHC patients undergoing treatment and their families. From this analysis, we propose strategies that might provide new insight for providers in

expanding their assessment of patient and family responses to the symptoms and side effects of CHC treatment.

Adaptive Leadership Framework

The Adaptive Leadership Framework developed by Heifetz and colleagues (Heifetz, Grashow, & Linsky, 2009) in the field of organizational management provides a useful way to study patient-provider relationships and patient self-management. Heifetz et al. described problem situations as having a combination of challenges, some of which are technical and some of which are adaptive in nature. A technical challenge is clearly definable by an expert, and once diagnosed, the problem can be resolved with a technical solution. Exercising the technical solution is called technical work and is usually done by the expert. In the context of this study, the need for drug therapy to treat CHC is a technical challenge, and the provider exercises a technical solution by prescribing the medication.

Adaptive challenges in contrast, require learning and behavior change by the person facing the challenge; thus the person facing the challenge is the only one who can address this by doing the related adaptive work. An example of an adaptive challenge is the requirement for a patient to fit a strict medication schedule into their daily lives. This requires organizing reminders and daily activities so that medications are taken every eight hours. Heifetz and colleagues describe adaptive leadership as the ability to mobilize resources to appropriately address technical and adaptive challenges such as supporting persons with adaptive challenges in accepting loss, learning and gaining new skills, and adopting new behaviors (Heifetz et al., 2009).

Anderson and colleagues (Anderson et al., 2015) recently expanded Heifetz's model to the Adaptive Leadership Framework for Chronic Illness by adding the concept of collaborative work between the patient and his or her family and provider. Collaborative work requires developing effective relationships among care team members to facilitate the exchange of information in ways that engage all members and create a shared understanding of treatment concerns. Without such collaborative work, a provider might assume, for example, that a patient's challenge is coping with the inconvenience of a symptom such as fatigue. The provider might then treat fatigue as a technical problem by offering medication. However, in a collaborative environment, the provider would learn that the fatigue is the result of a patient's response to the loss of his or her role as the family's provider; this is an adaptive challenge that will not be resolved by a technical solution alone. Thus, collaborative work involves more than monitoring symptoms; it involves assessing the patient's interpretations of and responses to symptoms and related adaptive challenges that arise for the patients and their families, which then forms the basis for effective care planning and management.

In a fast-paced health care system focused on offering immediate solutions, conversations during clinical encounters are often one-sided, with providers telling patients what to do, without consideration for patients' individual situations or their emotional and psychological responses to treatment. Most patients rely on self-management strategies, which are forms of adaptive work, as they undergo treatment and its side effects (Haeusler, 2010). If providers focused on supporting the adaptive work of patients, this might have a great impact on health

outcomes. However, the amount of technical work required of them often overshadows patients' adaptive challenges and potentially limits providers' use of adaptive leadership (Thygeson, Morrissey, & Ulstad, 2010).

Material and Methods

Overview

This study used data from the first clinical encounter between patients and providers during which CHC treatment was initially discussed. The first encounter between patient and provider is important because it is the point at which their relationship is established, and it sets the tone for subsequent visits. We audio recorded the first encounter as well as interviews conducted individually with the patient and provider immediately following the first encounter. Medical records were reviewed at baseline to capture the provider's written reflections on the visit. These baseline data were part of a larger longitudinal descriptive mixed- methods case study designed to describe patients' and providers' explanations of how and why they engage in technical and adaptive work, and adaptive leadership and how these strategies promote or pose barriers to patients' self-management in the context of triple therapy treatment (Bailey et al., 2012; J.W. Creswell, 2009; John W. Creswell & Plano Clark, 2011).

Ethics

This study was reviewed and approved by the university's Institutional Review Board. Informed consent was obtained from all patients and providers prior to data collection.

Site Selection and Sample

We recruited from two clinics—a liver clinic that is part of a university medical center serving North Carolina, USA, and a private, multi-specialty health care practice serving rural eastern North Carolina. Providers were included if they saw CHC patients and prescribed the triple therapy protocol. All providers within each clinic who met the criteria for inclusion were invited to participate. Patient inclusion criteria were: able to speak English, ages 18 or older, a diagnosis of CHC, treated with triple therapy for their disease, received care from one of the two recruitment sites, and had access to a telephone. Patients were excluded if they had a history of severe mental illness (bipolar disease, psychosis) because these illnesses might compromise the relationships we wanted to observe.

Procedures

During 18 months of recruitment, a study coordinator at the university medical center reviewed the patient browser and a trained staff assistant at the rural clinic reviewed medical records to identify eligible patients. Study staff sent a letter on clinic letterhead to invite eligible patients to participate. Eligible patients could opt out of being contacted by calling a toll-free number. The study coordinator called each eligible patient about one week after sending the letter. If the patient agreed to participate, the study coordinator met with the patient in person at the clinic, prior to an appointment, to obtain consent. A trained staff assistant at the clinic discussed the study with eligible patients during a scheduled visit. The

names of those who expressed interest were forwarded to the study coordinator, who then contacted them with additional questions to ascertain eligibility and to obtain consent.

To recruit providers, the principle investigator (PI) and study coordinator met with providers individually at both sites outside of clinic hours to explain the study, determine willingness to participate, and have them sign the informed consent.

At the initial clinic visit, the study coordinator placed two recorders (one as a back-up) in the examination room to record the encounter. Following the encounter, the study coordinator took the patient to a private room and conducted the baseline interview. The study coordinator interviewed the provider at the end of the clinic day, or the next day if requested.

Data Collection

The interviews were developed by research team members (DEB, RAA, JAA, and HW). To train the data collector to conduct the interview per protocol, we had several mock interviews for practice. The team listened to the first two interviews and coached the data collector on technique and protocol adherence. Data coders (DEB and RAA) continued to coach the data collector throughout the study as needed.

The in-depth patient interview (Appendix 1) was designed to elicit patients' thoughts and concerns about beginning treatment and the challenges they anticipated. For each concern or side effect raised by a patient, the interviewer asked a series of questions to explore how the patient and provider interacted regarding the treatment concern, how the patient thought the issue might interfere with daily life, and how the patient thought he/she might manage the issue.

The semi-structured provider interview (Appendix 2) elicited providers' descriptions of the clinical encounter, including their goals for the encounter and approaches used to meet these goals. The interviewer probed to assess the extent to which the provider believed the patient understood the information conveyed in the encounter and how the provider determined the level of patient understanding. We asked the providers to estimate each patient's likelihood of completing the treatment.

Medical records from these clinical encounters were obtained and added to the database. We used ATLAS.ti (Silver & Lewins, 2009) to organize and manage all qualitative data. Procedures used to ensure rigor (Lincoln & Guba, 1985; Miles, Huberman, & Saldana, 2014) of the study processes, data collection, analysis, and interpretations are defined in Table 1. We address confirmability, dependability, credibility, and transferability.

Analysis

The first clinical encounter was the unit of analysis. The analysis team (DEB and RAA) held weekly intensive analysis sessions. In the first stage of analysis, text data were analyzed using directed coding with *a priori* codes, drawn from the Adaptive Leadership for Chronic Illness Framework and emergent coding, to tag text that was not captured by the *a priori* codes (Hsieh & Shannon, 2005). *A priori* codes included technical challenge, adaptive challenge, technical work, adaptive work, and adaptive leadership, using preliminary

definitions from the literature (Adams, Bailey, Anderson, & Galanos, 2013; Thygeson et al., 2010) (Table 2). Coding continued until all text was coded. The emergent code was "Missed Opportunity," defined as instances when the patient described an adaptive challenge but the provider addressed it with a technical solution, suggested that the issue be addressed by another provider, or overlooked the concern. In the second stage of analysis, we examined the coded data and synthesized these data into themes.

During weekly coding meetings, the team looked for areas of agreement and disagreement, reconciled the data, and updated the codebook. Codebook definitions were visible within ATLAS.ti (Silver & Lewins, 2009) to facilitate constant comparison of meaning as codes were used. Other members of the research team (HW and MC) reviewed and discussed the codes and codebook definitions, and reviewed the coding structures (MT). We used matrices to organize and synthesize the codes and themes, adding details from memos that coders wrote during coding. Memos included the coders' impressions about the text quotes and how these data linked to other codes or parts of the encounter or interview. Memos also included the coder's rationale for use of the code.

Results

Eleven of 13 eligible patients agreed to participate. Participants included seven men and four women who identified themselves as Caucasian (45%) or African-American (55%). Participant ages ranged from 42–65 years. (Mean=55.6); years of education ranged from 9–18 years (M=14.5). Four participants reported working full-time while seven participants reported not working. Providers included five medical doctors (MDs), three physician assistants (PAs) and two nurse practitioners (NPs). One eligible provider declined to participate.

In the initial clinical encounter between provider and patient, the provider spent approximately one hour with each patient. The provider discussed medication management and potential treatment side effects, focusing primarily on the technical aspects of care. Patients and their families often shared their adaptive challenges with the providers.

Adaptive challenges described by patients and/or family members were usually related to medication side effects and had the potential to jeopardize the patient's ability to adhere to, or to complete, treatment. At times providers addressed adaptive challenges by using adaptive leadership techniques; at other times providers responded to adaptive challenges by offering technical solutions or overlooking them. Accordingly, we present our findings into the following sections: adaptive challenges and adaptive leadership strategies, and missed opportunities to provide adaptive leadership.

I. Adaptive Challenges and Leadership Strategies

We found examples of adaptive leadership in which providers worked with patients and family members to address adaptive challenges. We categorized these behaviors into three themes: support for medication, coping with family/ home life, and strategizing to manage employment.

Support for medication challenges—Because the timing of medication is critical to treatment success, scheduling medications is often a challenge. These oral medications must be taken every 8 hours with at least 20 grams of fat, even if the patient must be awakened from sleep. In this example of support for medication challenges, the provider suggested several ways to manage the schedule with reminders such as a calendar, sticky notes, and text messages.

> Provider: …some people find it helpful, [to] use a calendar that they can put stickers on when they need medication refills …. it is helpful because you can look at things longitudinally and see what they are doing. Have you looked at the boxes of these [medications]?

> Patient: No.

> Provider: These are helpful because each box is one week. And then, within it are seven strips, one for each day of the week.

In another interview the provider recommended using a smart phone app to track medications.

> Provider: Some people have smart phone apps and they can sign up [for] … a service to send a text message to remind you every eight hours, to take your medication….That information is available in this booklet.

In this interview the provider discussed the best times for taking the injection, worked with the patient to determine how he planned to administer the injection, and then praised him for his strategy.

> Provider: … [The shot is] going to give you a fever within four hours [so] I tell people to do it at home in the evening after work.

> Patient: The way that I did it last time was 10:00 Friday night. I took two Tylenols pm. …do the shot go lay down.

> Provider: I think I might adopt that one to my practice, the two Tylenol pm. That's a great idea…

In an interview with the provider, the interviewer sought to understand how the provider determined whether the patient understood potential medication side effects and the providers concerns about the under-reporting of symptoms.

> Interviewer: What about the interaction let you know that [the patient understood]? Provider: I asked her specifically "Do you understand? Do you have questions?" She said, "Yes I understand. No I don't have any more questions," You know we spent a lot of time looking at her list of questions that she came in [with]…She had a bunch of questions.

> Interviewer: So, you talked about each one of them?Provider: About side effectsInterviewer: What concerns do you have about her following the treatment plan?Provider: I'm concerned that she's more likely to underreport her side effects because she feels like she should just tough it up and keep going.

This interaction demonstrated collaborative work between patients and providers to verify shared understanding and assure correct and timely administration of medications. The provider also identified a potential for an adaptive challenge of underreporting side effects.

Addressing family/home life challenges—Several patients raised family and home life challenges such as parenting during treatment. From provider-patient encounters, we identified examples of adaptive leadership used by providers to address these challenges. In this example the provider explored the home situation and addressed safety concerns relevant to having children in the home.

> Provider: Do you have children at home?Patient: Yes.
>
> Provider: [Ribavirin] cannot be anywhere near children. They have to be told – so [keep] way, way out of their reach OK? You know that the needles can't go into the garbage? The needles have to go in this [Sharps] container and this goes on top of the refrigerator.

In another interview the provider asked a patient about parenting and home life to assess the challenges that the patient might face.

> Provider: … Are you parenting children actively right now or have they flown from the nest?
>
> Patient: No they are still in high school.
>
> Provider: Ok, high school kids. So, other than being a husband and a father. Your other job right now will be Hep C medicines. …that's a full time job.

These interviews demonstrate provider awareness of the challenges patients face related to home life. Providers demonstrated adaptive leadership behavior by seeking to understand the home environment and to help patients plan to follow treatment protocols and keep other family members safe.

Strategizing to manage employment challenges—Adaptive challenges related to employment were common among patients who were still working. Using adaptive leadership, some providers supported patient's plans to manage or reduce work responsibilities while on treatment. In this interview a patient reflected on how he felt the last time he was treated and described his plans for work during his upcoming treatment.

> Patient: …the last time that I was on this. … I got pretty sick …I've already hired a guy to do my job and for the first time in my life I'm going to take a backseat and try to let the medicines work and me not work so hard…
>
> Provider: …. that's a good idea., …you have a resource that makes it easier to say 'no this is too much for me.
>
> Patient: Right and I can still go out to the jobs I won't have to swing hammers.
>
> Provider: Right… …I think you have some great plans in place so let's use them!

In another interview with a provider, the interviewer sought to understand the kinds of concerns the provider had about the patient starting treatment. The provider shared the

patient's concerns about employment and then encouraged her to limit her work responsibilities at the daycare center.

> Provider: …she helps out with her sister's daycare. And for the first few weeks, I asked her [to wait] until she has a better understanding of how these medicines will affect her. …I could only say that I knew she would have some degree of fatigue. ..I wanted her to stay out of the preschool setting.

> Interviewer: OK. And how did she respond to that?Provider: She actually wanted that because she had already told her sister that she wouldn't be there for the next several weeks.

II. Missed Opportunities to Provide Adaptive Leadership

We saw examples of what we termed missed opportunities for adaptive leadership. These were defined as instances in which the patient described an adaptive challenge, but the provider dismissed it, gave it only cursory attention, or addressed it with a technical solution. We synthesized codes about missed opportunities into four themes: affective symptom challenges, physical symptom challenges, healthy behavior challenges, and family concerns.

Affective symptom challenges—Affective symptoms commonly encountered by patients in this study were depression and anxiety. These symptoms created challenges when they interfered with other aspects of a patient's life.

One patient shared his apprehension about starting therapy. *"I haven't really slept since last Thursday. Just anticipating, yeah just being nervous."* The provider responded by discussing sleeping medications rather than exploring the cause of his sleeplessness or anxiety even though the provider knew that there was more to be explored, based on his/her comments in the follow-up interview.

> "My concern is that ….actively following the treatment plan might be problematic for him [because of his anxiety interfering with his comprehension]. You know when you are so anxious sometimes you can't focus on what's being said to you - I'm more worried about making sure he hears the treatment plan I guess"

We viewed this as a missed opportunity to address an adaptive challenge. Both the sleeplessness and anxiety posed potential challenges to the patient's ability to follow his treatment regimen. While a sleep medication might be part of a regimen, the provider ignored this adaptive challenge and lost an opportunity to address his patient's anxiety. Using adaptive leadership in response to these concerns, the provider might have asked about the patient's worries and then helped him to identify ways to reduce the anxiety and facilitate sleep using behavioral and environmental changes instead of medication.

In another interview, a patient expressed concerns about depression. In the interview after the visit, the patient explained his feelings to the researcher:

> "First you got to understand depression. Personally I don't understand it. I don't know what it is… What causes you to be depressed? So, I'm trying to figure this out. I mean if I become depressed, I still got the responsibility of being a father and

taking care of kids and the house. …my wife says I'm a little depressed sometimes… I don't understand, what is depression?"

During the encounter, when the provider asked this patient if he was depressed, the patient denied being depressed but said that his wife thought he was depressed. The provider responded by telling the patient that he would have to say he was depressed before the provider could prescribe an antidepressant. This was an example of a missed opportunity for the provider to explore what caused the wife to think the patient was depressed, to educate him about depression, and to use adaptive leadership strategies to explore the challenges he might experience if he was or became depressed.

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Physical challenges—Physical challenges included the perceived physical health challenges reported by the patient to the provider in their initial encounter. One patient expressed concerns about his enlarged spleen and worried that he might develop esophageal varices. After a discussion about his concerns related to esophageal varices, he finally told the provider he was scared because a friend who underwent treatment for CHC died. Rather than listening and exploring his patient's concerns, the provider simply said, "*That's not you right?*" and left to see another patient.

Patient: Since I have an enlarged spleen and [esophageal] varices could come up at any time, … do you think it could come up now…? [Provider discusses negative X-ray results]

Patient: I'm worried about that.

Provider: I can't take that away… If you had a normal endoscopy [then] there's no varices…

Although the provider was correct that the patient did not have this technical challenge of *esophageal varices,* the patient was expressing a psychological burden. An adaptive leadership approach would be to stop, listen to his concerns, and explore what these

concerns meant to him and how they might affect his self-management during treatment, and then work collaboratively to identify new strategies to address this concern.

Healthy behavior challenges—Healthy behavior challenges included alcohol consumption, known to be particularly caustic for individuals with CHC.

In one example of challenges to healthy behavior, a patient's wife revealed that her husband was consuming alcohol.

> Wife: Is he allowed to drink wine?
>
> Provider: You should not be drinking wine at all… Do you drink wine now?
>
> Patient: Uh I drink some and I may have a glass of Chardonnay once in a while.Provider: Once in a while? Is that like once a month or like once a week? Patient: Once a week.
>
> Wife: Once a day.

The provider then told the patient he should not be drinking any alcohol because his virus was already damaging his liver, and that consumption of alcohol added to that burden. The provider shared with the patient examples of other patients who wished they had not consumed alcohol because it made them feel really bad on treatment. Here, the provider had the opportunity to witness a patient in denial about the extent of his alcohol use, indicating a potential problem with substance abuse or addiction. An adaptive leadership approach to this scenario would include exploring the challenges to his abstention from alcohol and then following that with education about why he should not drink.

Family challenges—Family adaptive challenges included the burdens faced by the patient and his or her family members during the treatment period. One patient told the provider he was very concerned because he believed he could not return to his job unless he was cured. The provider did little to explore the meaning of this issue and how it would affect his patient's well-being and family. Yet afterward in an interview with a researcher, she said:

> " ..this sounds horrible. This poor guy feels like he has to get cured in order to keep working;… that sounds like an awful burden for him, but there is a lot riding on this beyond just the medical piece of it."

In a follow-up interview with a researcher, the patient's impressions of the encounter were:

> "The provider's more into the medical side of it. As far as that I didn't even want to impose that [employment concern] on the provider. I want to handle that on my own. But provider is more into the medical aspect of it getting treated.… just needed to know was it workers comp

The patient was clear in expressing his concern, and the provider recognized that the patient was facing a tremendous burden, yet the provider did not address this burden with the patient, leaving the patient to sort this out on his own. This was another missed opportunity.

In another interview with a researcher, a provider expressed awareness that a patient was facing some challenges in his marital relationship:

> …he and his wife …. don't seem to interact in a positive manner with each other in front of me, and I don't know if that is their basic way of communicating, but he made some statements in the room about how she thinks this and she thinks that… so I worry, I wonder. What sometimes happens in those scenarios is that the wife tells me one thing, and he denies it… I think that if your wife says you are having problems [with depression], we'll have to see what you think about them…

The provider shared their impressions of the relationship between the wife and patient as it related to his possible depression. The provider's approach was to use a technical solution by writing a prescription, while admitting that he probably would not take the medication unless he believed he is depressed. The provider could have used adaptive leadership to assess how these potential depressive symptoms and the couple's relationship might influence his ability to adhere to treatment.

Discussion

The Adaptive Leadership Framework for Chronic Illness (Anderson et al., 2015) served as a useful organizing tool for our analyses of clinical encounters between providers and CHC patients and their family members. We identified examples of provider behaviors consistent with collaborative work and adaptive leadership (e.g., the ability to mobilize resources to address adaptive challenges with new skills and behaviors). These findings align with the tenants of patient-centered care in which the patient and family members' values and preferences are considered in healthcare decisions (Clancy & Collins, 2010; Epstein & Street, 2011; Garber, 2011).

We found examples of collaborative work and adaptive leadership strategies initiated by providers on behalf of their patients in the areas of medication support, family/home life, and employment. Considering family and home life challenges, we found an example of a provider using adaptive leadership behaviors to understand the home environment in relation to treatment. These efforts align with and have important implications for coordinating care for adults with complex care needs in patient-centered medical homes (Haley & Kreek, 2015). These findings are also consistent with current recommendations that providers expand their assessment of CHC patient/family responses to symptoms and side effects and offer navigation programs for these patients (Ford, Johnson, Desai, Rude, & Laraque, 2016).

We also identified provider behaviors that we described as missed opportunities for adaptive leadership. When a patient shared his challenge of future employment, the provider missed the opportunity to assess and learn more about the impact of this challenge on the family. There were times when providers did not address the patient or family member's concern or may have employed a technical solution when an adaptive strategy would have been more appropriate. This was evident when the provider acknowledged the differing views of the patient and his wife as it related to his possible depression and offered a technical solution to an adaptive challenge for this family.

Prior studies have demonstrated the positive impact of provider support and positive feedback during treatment initiation (Fusfeld et al., 2013). Our study provides a unique, in-depth analysis of missed opportunities to provide supportive strategies from both the

provider's and patient's perspectives. By not addressing affective symptom challenges such as anxiety and depression, concerns about one's physical health, alcohol and tobacco use, and the impact of treatment, patients and their family members are left without the tools to address these challenges.

By giving examples from the perspectives of the patient and provider, we have shown that both can have congruent beliefs on the challenges to treatment initiation and incongruent beliefs on how to manage those same challenges. Previous studies that addressed patient-provider communication have found it is common for patients and providers to have different perspectives on a variety of topics such as treatment goals and patient expectations, (Heisler et al., 2003; Hooper, Rona, French, Jones, & Wessely, 2005; Rao, Weinberger, & Kroenke, 2000) but that agreement between patient and healthcare provider usually results in improved outcomes such as increased patient satisfaction and adherence to treatment plans (Jackson, 2005; Rao et al., 2000; Staiger, Jarvik, Deyo, Martin, & Braddock, 2005).

Of greatest interest, however, is our finding that even when the patient and healthcare provider agreed on the challenges to treatment initiation there was no evidence of collaborative work to develop a plan. For example a patient and provider both acknowledged that his anxiety was a challenge to treatment initiation. However, the patient did not understand the impact of anxiety and the provider missed an opportunity to explore the concern. In terms of behavioral changes, a provider noted that a patient was a smoker but did not fully explore the issue with the patient. There were numerous examples in the study of instances when a patient or healthcare provider would speak about a challenge, yet take no action. Lack of action might be explained by a variety of circumstances, ranging from short appointment periods to provider uncertainty of how to address clinical issues unrelated to his or her specialty area. Future research should seek to better understand the reasons why patients do not directly raise concerns with their healthcare providers, and why healthcare providers, who acknowledge the perceived challenges to care, might not address them with their patients.

When healthcare providers address these concerns, patients experience less worry. Pincus and colleagues (Pincus et al., 2013) found that when healthcare providers addressed patients' affective concerns through cognitive reassurance (explanation and education) patients experienced less worry and greater satisfaction. Our work adds value to this literature by operationalizing an approach to codifying patient and provider behavior within the context of the Adaptive Leadership Framework for Chronic Illness, identifying "missed opportunities" that serve as an assessment of the quality of the provider-patient interaction, and triggers for improving the clinical encounter. Our findings serve as a foundation for interventions designed to enhance providers' use of collaborative work strategies to engage patients and their family members involved in initiating treatment for CHC.

Our study has two main limitations. First, we recruited providers and patients within a certain geographic proximity, thereby limiting the generalizability of this study. Second, patients in this sample were treated with Telaprevir, PEGylated interferon and ribavirin (referred to as "triple therapy"), a therapy no longer used as part of the current treatment regime in the United States.

Conclusion

This study illustrates the contributions of adaptive leadership behaviors by healthcare providers and the potential risk to patients in their absence. These behaviors focus on supporting medication challenges, addressing family/ home life challenges, and strategizing to manage employment challenges. Interviews with patients and providers demonstrated the healthcare professional's ability to assess patient and family challenges and begin the important collaborative work needed to support the patient's self-management during treatment for CHC. These strategies provide new insight and guidance for more collaboration and adaptive support work between patients and providers in the effort to achieve better health outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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Table 1.

Strategies for Assuring Rigor of the Case Study Design

Confirmability—freedom from unrecognized researcher biases

- Meeting with research team members to review data collection and analysis procedures
- Review of data collection and analysis by team members to assess for study biases
- Research team member continuously ensure that rival hypotheses or conclusions are considered

Dependability—the process of the study is consistent across researchers and settings

- Case study protocols were used to ensure comparable procedures by data collectors and analyzers
- Code book used to provide for consistency across data analyzers
- Coding checks to assess level of agreement; disagreements were resolved through discussion
- An audit trail was established
- Investigators assessed connectedness of the study to the guiding conceptual framework.

Credibility—authenticity and plausibility, or truth value of the results

- Analysis triangulation between multiple forms of data to strengthen inferences
- Findings compared with current adaptive leadership literature

Transferability—usefulness beyond the individual participants in the study

- Rich detail of data to facilitate comparison of findings in other contexts
- Explicit criteria for the case selection provides for comparisons with other samples
- Rich descriptions in the data to facilitate judgments about potential transferability

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Table 2.

A Priori Codes and Definitions

Code	Definition
Adaptive Challenge	The disparity between the capabilities of familiar methods, habits or values and the demands of the present clinical circumstances. Adaptive challenges require the patient (or family member) to adjust to a new situation and to do the work of adapting, learning, and behavior change.
Adaptive Work	The specific adaptive changes (e.g, values/attitudes, skills, learning and behaviors) that providers, patients, or caregivers need to make to achieve the clinical, lifestyle, or system outcomes they desire.
Adaptive Leadership	Adaptive leadership aims to develop the capacity of the patient, family, and/or provider to address adaptive challenges. New capacities emerge when patients/families and providers gain new values/attitudes, skills, learning and behaviors which enable them to achieve the clinical, lifestyle, or system outcomes they desire. Adaptive leadership included anticipating adaptive challenges, differentiating between technical and adaptive challenges and work and collaborative work.
Collaborative Work:	The process of engaging providers, patients and families in developing shared understanding of symptoms, actors' responses to the symptoms, associated challenges and sense-making for shared meaning. These are the basis for jointly developing care plans to address technical and adaptive challenges (might be owned by patient, family members, provider). The care plan is translated into technical and/or adaptive work for patients, families and providers.