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## Development of a Conceptual Etiological Model of Treatment Regimen Fatigue among Patients Engaged in HIV Care: A Qualitative Study

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### Abstract

Treatment regimen fatigue (TRF) is a decreased desire and motivation to maintain vigilance in adhering to treatment, and little is known about TRF in people living with HIV. We aimed to develop a conceptual framework of TRF. Five focus groups were conducted in 2014. Eligible participants were (a) HIV-infected, (b) at least 18 years of age, (c) prescribed antiretroviral therapy, and (d) fluent in English. Data were analyzed using thematic analysis. Analyses revealed these themes: patient experiences of TRF; etiological factors at the systems, provider, and patient levels; strategies to manage TRF; consequences of TRF; and protective factors that prevent the occurrence of TRF. The results provided a conceptual framework for future investigations to build on in an effort to improve adherence and retention in HIV care. Study results indicate avenues for intervention at multiple levels (systems, provider, and patient) to reduce treatment burden and improve patient resources and capacity.

### Keywords

adherence; HIV; qualitative methods; retention; treatment fatigue

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Adhering to lifelong HIV treatment is challenging as it requires strict adherence, continuous engagement in health care, multiple lifestyle changes, and adaptive coping skills. Maintaining optimal adherence and viral suppression allows patients to live longer, healthier lives and reduces transmission of HIV (Cohen et al., 2011; Quinn, 2008). Significant advances in the pharmacological properties of antiretroviral therapy (ART) have resulted in decreased side effects and once-daily pill-taking options, significantly reducing treatment burden. Despite these improvements, treatment adherence and retention remain a chronic problem for some people living with HIV (PLWH; Beer et al., 2012; Castro, Santiago, Jiménez, Dávila-Vargas, & Rosal, 2015).

Many PLWH develop comorbid medical and psychiatric complications over the course of their lifetimes that further complicate HIV disease management. On average, PLWH have higher rates of psychiatric and substance use disorders (Bing et al., 2001; Galvan, Burnam, & Bing, 2003; Mey et al., 2017) and may have fewer resources (e.g., social support, cognitive function, finances, and knowledge), collectively affecting ART adherence (Small, Milloy, McNeil, Maher, & Kerr, 2016). For example, there is a positive relationship between increased depression and ART nonadherence (Sauceda, Johnson, & Saberi, 2016). Multiple diagnoses and treatment protocols increase treatment burden on the patient. These factors may contribute to the onset and severity of treatment regimen fatigue (TRF).

TRF is a “decreased desire and motivation to maintain vigilance in adhering to a treatment regimen as prescribed by a provider” (Claborn, Meier, Miller, & Leffingwell, 2015, p. 261). TRF has been observed in PLWH and other chronic illness patients, including those with diabetes and multiple sclerosis (Claborn, Miller, & Meier, 2015; Crawford, Jewell, Mara, McCatty, & Pelfrey, 2014; Pyatak, Florindez, & Weigensberg, 2013). Empirical and anecdotal data have identified TRF as a common experience related to non-adherence (Castro et al., 2015); however, there is a dearth of research examining how it affects those living with HIV.

A systematic review identified several potential sources and consequences of TRF (Claborn, Meier et al., 2015). While requirements of a treatment regimen (e.g., number of pills, health care visits, and dosing restrictions) may increase risk for TRF, other patient characteristics (e.g., social support, quality of life, and cultural beliefs) may serve as protective factors. A recent qualitative study of 39 PLWH who used drugs in Vancouver, Canada underscored the importance of social and structural factors that may underlie the onset of TRF and result in ART treatment interruptions (McNeil et al., 2017). Specifically, prior negative experiences with early and complex ART regimens (e.g., side effects, development of drug resistance) emerged as a perceived factor associated with TRF. Participants also indicated that social isolation and discontinuity of HIV care (e.g., incarceration) contributed to TRF and ART interruptions.

Heckman, Mathew, and Carpenter, (2015) identified a modified workload-capacity model for the degree of TRF in patients with chronic illnesses. Within the model, workload comprised general daily life demands and treatment burden (e.g., the demands of disease management), while capacity comprised general life resources (e.g., social support, knowledge) and illness burden (e.g., disease symptoms). Heckman et al. (2015) proposed

that TRF increased when workload surpassed capacity, essentially, when the demands of daily life and disease management outweighed one's general resources and ability to manage symptoms. This is particularly relevant to many PLWH considering the higher rates of poverty, homelessness, drug use, and mental health issues associated with this population (Centers for Disease Control and Prevention [CDC], 2015; Mey et al., 2016). Reducing treatment burden while increasing capacity to effectively manage health behaviors may decrease TRF and lead to better disease management throughout the life course (Heckman et al., 2015).

The model proposed by Heckman et al. (2015) was developed based on systematic reviews of treatment burden and treatment fatigue in patients with chronic illnesses; however, most of the studies reviewed were within the diabetes and stroke literature. It is likely that a range of chronic illnesses share overlapping etiological features of TRF; however, there may also be disease-specific etiological factors. We aimed to expand the workload-capacity model in an effort to better understand HIV-specific mechanisms that fit within this model. Thus, we conducted a qualitative study in an adult population of PLWH currently engaged in care, to examine the experience of TRF, perceived etiological and protective factors, and perceived consequences related to TRF. Results from our study will facilitate an understanding of patients' experiences and provide pathways toward better understanding mechanisms leading to TRF and the development of evidence-based prevention and intervention strategies specifically for PLWH.

## Method

### Target Population

Patients with HIV infection enrolled in treatment were recruited from an academic immunology center in the Midwest United States. Eligible participants were (a) infected with HIV, (b) more than 18 years of age, (c) currently prescribed ART, and (d) fluent in English. Adults who were unable to provide consent and current clinic employees were not eligible to participate. Recruitment occurred between November 2013 and May 2014. The study was conducted in accordance with procedures approved by Oklahoma State University's Institutional Review Board, and informed consent was obtained from each participant.

### Procedure

Patients were contacted during scheduled clinic appointments and screened for eligibility. Patients were approached in the waiting room and led by a trained research assistant to a private area, where the research assistant provided information about the study, assessed eligibility, and scheduled eligible participants for one of the five focus groups.

Five focus groups ( $N = 24$ ) were conducted after hours in a private conference room at the immunology clinic. Upon arrival at the conference room, participants individually reviewed study risks, benefits, and procedures with research staff and provided written consent prior to initiation of focus group discussions. Focus group discussions lasted approximately 90 minutes, with an additional 30 minutes allocated for completion of questionnaires assessing

demographics and HIV treatment characteristics. A trained research assistant took notes during the groups to ensure the integrity of transcription. A semi-structured interview discussion guide was used to steer focus group discussions. Items used in analyses for this study explored the following factors: (a) patient experiences and how they defined TRF, (b) perceived causes of TRF, (c) risk and protective factors, and (d) methods to prevent and manage TRF. Each participant was offered transportation assistance and received a \$20 (USD) gift card, in addition to pizza and refreshments, for participating in a focus group.

### Coding and Data Analysis

Focus group discussions were audio recorded, transcribed verbatim, and cleaned by trained research assistants. Data were coded and analyzed using thematic analysis. Data analysis was iterative, using standard analysis techniques, including open coding, marginal remarks, and memo-writing (Guest, MacQueen, & Namey, 2012). Three coders independently reviewed and coded all transcripts. A preliminary coding structure was derived deductively from the interview agenda and modified as themes emerged. A master codebook was finalized and included both the *a priori* and emergent themes. All transcripts were coded using these master codes. The coders met to review code assignments in all transcripts, and any discrepancies were discussed and reconciled. After consensus was reached, the final set of master codes for each transcript was entered into NVivo 10 (QSR International, 2002). Themes related to the *a priori* research questions were extracted. Three of the authors discussed and analyzed themes to determine implications of the data. Analyses revealed the following themes: (a) patient experiences of TRF; (b) etiological factors at the systems, provider, and patient levels; (c) strategies to manage TRF; (d) consequences of TRF; and (e) protective factors that prevented the occurrence of TRF.

## Results

### Sample Characteristics

Twenty-four PLWH (20 male, 4 female;  $M_{\text{age}} = 47$  years,  $SD = 12.98$ ) participated in five separate focus groups ( $n = 4-8$  participants per group). They reported an average of 68 months ( $SD = 69.95$ ) on HIV medication. Twelve participants identified as gay/lesbian, followed by heterosexual ( $n = 5$ ), bisexual ( $n = 4$ ), and undecided ( $n = 1$ ). Represented racial groups included White ( $n = 12$ ), African American ( $n = 8$ ), American Indian ( $n = 3$ ), and Hispanic/Latino ( $n = 1$ ). Twelve participants were receiving disability, with seven participants reporting full-time employment, one reporting part-time employment, and four reporting unemployment (Table 1).

### Patient Experiences of TRF

Samples of participant quotes that guided study themes are presented in Table 2. Participants characterized TRF as a sense of feeling overwhelmed by treatment, unmotivated to adhere to treatment, and, in some cases, skeptical of the utility of treatment. In terms of feeling overwhelmed, they suggested that lifestyle and behavior modifications (e.g., taking pills, attending treatment appointments) and having to navigate the health care and insurance systems contributed to feelings of TRF. They stated that the continuous need for medical care decreased their motivation to deal with insurance companies, physician offices, and diet

modifications. As a result, some participants reported becoming lackadaisical in taking their medications, in part because they did not experience negative consequences upon missing a dose and in part because they believed that the stress associated with placing too much emphasis on adherence decreased medication effectiveness. They reported that it was common, at some point, to think, “What’s the use?”

## Etiological Factors

Participants identified events at the systemic, provider, and patient level that contributed to the onset, maintenance, and exacerbation of TRF throughout the life course (Figure 1 and Table 2).

**Systems level**—Participants identified several systemic factors that contributed to the onset of TRF. Financial support and insurance challenges were near the top of the list; participants described repeatedly going to the physician and making efforts to get prescriptions filled, only to find their insurance coverage had been discontinued again. In contrast, some participants were prescribed medications that were not covered by the HIV Drug Assistance Program (HDAP) or insurance. Several participants also reported difficulty obtaining their medications on time because they were dealing with “run-around from the system;” for example, needing to call every month to refill prescriptions that they needed every month for the rest of their lives. Frustration with this process seemed to be exacerbated by the paperwork involved, complications with insurance and HDAP, lapses in coverage, and navigating multiple health care systems because of comorbid diagnoses and treatments.

**Provider level**—Participants also identified provider issues such as high caseloads, insufficient education about HIV disease and communication skills, poor care coordination, lack of empathy or respect, and interactions primarily with trainees as contributors to TRF. Several participants stated that their providers’ caseloads were simply too high, preventing the provider from having the time and energy to be personal and understand their situations and individual concerns. In other cases, they reported feeling as if providers did not listen to them, respect them, or take their views seriously, particularly when they identified physician mistakes. They stated that some providers were medical students who were still learning, in which case patients perceived themselves as more knowledgeable about the disease than their physicians. This caused some patients to feel responsible for being medically literate and managing their own health care in a holistic manner. Not surprisingly, then, participants attributed part of their experiences with TRF to a lack of care coordination between multiple providers and health care systems.

**Patient level**—Emergent themes at the patient level included psychological factors, personal relationships, and treatment-related factors. In terms of psychological factors, participants associated response to HIV diagnosis with TRF but stated that this might be dependent on the individual’s emotional and cognitive responses. Specifically, the perception that HIV diagnosis required a lifestyle adjustment and dedication to medication adherence might serve protective functions, mentally preparing individuals for treatment and buffering the impact of unexpected stressors. For some people, however, an HIV diagnosis was accompanied by the belief that, “You have a problem.” In this case, hopeless and

anxious thoughts (e.g., of never feeling better or giving HIV to someone else) contributed to negative mood, which might be compounded by stress and comorbid mental health or medical conditions, leading to increased TRF. They stated that, with disease progression, memory impairment also increased treatment burden. Moreover, some participants indicated a mistrust of the medical and scientific community, in that they believed the scientific community was not telling them what was going on, were using them as “guinea pigs,” and might be withholding a cure for HIV or certain treatments from financially disadvantaged patients. These beliefs made it difficult to engage in care and/or reach out for social support.

Several patients indicated that the lack of social support was a primary contributor to TRF. Participants consistently reported experiencing HIV-related stigma, which sometimes resulted in rejection, isolation, and a decrease in social support. The perception of stigma could contribute to hesitation to disclose their HIV status to others, and the fight for privacy was even more draining when friends or loved ones asked questions about their behaviors and routines, such as why they were going to the clinic. In some cases, participants reported losing valued relationships after disclosing their HIV status, which left some of them feeling even more socially isolated. Yet hesitation to reach out to others was not limited to fear of rejection; there was a general theme of wanting to protect their friends and loved ones. Participants also noted challenges with intimacy in serodiscordant relationships.

**Treatment related factors**—Planning, medication organization, and medical status emerged as themes related to HIV treatment. Specific aspects of treatment that contributed to treatment fatigue included (a) complicated regimens; (b) prescription restrictions (e.g., take with food); (c) inconvenience in terms of medication transportation and planning in advance (e.g., ensuring a sufficient amount of medications prior to leaving for vacation); (d) the life-long nature of treatment; and (e) side effects (e.g., weight gain, fatigue, diarrhea, constipation). Adhering to HIV treatment required continuous preparation and appointments that often interfered with daily routines and work schedules.

Finally, medical status was identified as a potential contributor to TRF. For those with poor clinical outcomes, use of avoidance coping (e.g., denial) could lead to even greater treatment non-adherence. On the other hand, those with good clinical outcomes experienced decreased motivation to adhere to treatment if they became asymptomatic or misunderstood the mechanisms of medication action (e.g., some patients reported a discontinuation of medication adherence when viral loads became undetectable or CD4+ T cell counts were high).

### Course and Duration

Participants described TRF as being somewhat ubiquitous among PLWH, despite individual variability in its course and duration (Table 2). For some people, TRF seemed to be worse upon diagnosis and improved as a daily treatment routine was established and adjustment to medication became easier. For others, it became worse after they had been adherent to treatment for a while, motivating them to take “medication vacations,” and they had to learn about the consequences of non-adherence through experience. Several participants noted that the experience of TRF was cyclical and could be different in different generational cohorts.



### Consequences of TRF

Participants identified emotional, behavioral, and physiological consequences of TRF (Table 2). At the emotional level, they stated that TRF lead to increased stress and frustration, apathy, and depression. At the behavioral level, inadequate adherence to medications, treatment dropout or reduced care engagement, and increased substance use were identified. Some participants also knew the physiological consequences of TRF, such as disease progression.

### Protective Factors that Prevent the Occurrence of TRF

Social support and active coping were identified as protective factors against TRF. Participants stated that support (defined as respect, compassion, and willingness to listen) – not only from family and peers but also from health care providers – was integral to patient adjustment to HIV diagnosis and sustained treatment engagement. Participants also identified positive thinking, acceptance, active coping (e.g., yoga, making treatment a part of a daily routine or a habit), and a sense of accomplishment and identity that was not defined by HIV as resilience factors. They stated that autonomy and the ability to perceive medications as life-giving (rather than a death sentence) helped them stay motivated.

### Strategies to Manage TRF

Participants identified TRF coping strategies that were consistent with the risk and protective factors they discussed. Given the importance of a strong support system, they noted that support groups could be helpful. Along the same lines, they expressed concern that neither patients nor providers had the education required to treat and manage HIV disease effectively. At the patient level, education regarding the impact of HIV on physical health and daily function, skills for problem-solving and adaptive coping (e.g., yoga, mindfulness, finding purpose), and skills to improve communication with physicians and health care providers could be helpful. Participants also recommended finding ways to address fear, self-doubt, and self-hatred in patients at the beginning of treatment to prevent these issues from festering and impeding treatment progress over time. At the provider level, participants stated that some physicians simply did not know what they should about HIV, and some were not trained to listen to and respect what patients had to say. Finally, at the systems level, they stated that it was important to improve the structure of treatment so it would be less burdensome (e.g., integrated, holistic care).

### Discussion

TRF is understudied in patients with chronic illnesses. Our qualitative study examined patient experiences of TRF in PLWH engaged in care. In the context of the study, a treatment regimen was defined as the medication regimen and any other treatment requirements, including attending clinic appointments and completing blood draws and lab work. Emergent themes at the system, provider, and patient levels highlighted the importance of reducing treatment burden and increasing patients' resources and capacity to manage HIV. TRF appeared to have a cyclical course, exacerbated at certain points throughout a patient's life.

Some participants noted the onset of TRF symptoms upon receipt of the HIV diagnosis and feeling overwhelmed with the need for multiple behavior changes and difficulties adjusting to the diagnosis itself, which may have led to delays in accessing care and receiving ART. Because TRF cannot onset prior to the initiation of a treatment regimen, it appeared that some participants may have perceived depressive symptoms as symptoms of TRF; on the other hand, the recent treatment as prevention (TasP) initiative recommended initiating ART immediately upon diagnosis of HIV infection (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2016). Therefore, participants may have perceived attending clinic appointments and reading HIV education materials as a component of treatment. Because our study consisted of focus groups, it was unclear if there was a lag in ART initiation post HIV diagnosis and the extent of depressive symptomatology experienced by participants upon diagnosis. Participants in our study discussed experiencing TRF at HIV diagnosis as a result of having to make behavior and relationship changes (e.g., disclosing HIV status, attending HIV appointments, initiating ART treatment, reading HIV pamphlets), and experiencing emotional distress such as denial and depressive symptoms as a result of the diagnosis. More research is needed to understand if TRF is a unique predictor of treatment nonadherence or if TRF is a consequence of depressive symptomatology. Of note, TRF seems to become more prominent or to re-emerge as a person ages. PLWH incur comorbid diagnoses (e.g., heart disease, cancer, diabetes) throughout their lives, which may result in additional treatment regimens and increased treatment burden, suggesting that TRF may be unique from depressive symptoms.

Interventions designed to reduce treatment burden and improve patient resources and capacity are needed to reduce TRF. Preventing or reducing the severity of TRF in PLWH may lead to improved treatment adherence and retention in care. Identification of people who are experiencing or at-risk of TRF may help to identify patients at-risk for treatment dropout and allow clinicians a means of identifying and triaging patients in need of additional support.

Results from our study indicate avenues for intervention at multiple levels (systems, provider, and patient). Some PLWH experience challenges navigating the health care system. Transportation is frequently a challenge, and participants reported difficulty attending appointments at multiple locations. Patients with comorbid diagnoses tend to be referred to multiple providers at off-site clinics, which presented challenges for our participants when coordinating care between providers. Insurance and financial assistance programs required paperwork and follow-up that participants found burdensome. Changes within the health care infrastructure that result in the integration of services for patients (e.g., one-stop shopping) or patient navigator approaches are needed to reduce burden on both patients and providers.

Participants reported that negative experiences with HIV providers increased the perception of treatment burden and TRF. Patients with inadequate social support systems may seek additional support through health care providers and view the HIV clinic as a stable source of support. It may be particularly important to train medical interns and residents in patient-provider communication and listening skills to help establish empathy and respect for patients. In regard to patient-level interventions, educating patients about the roles of the



various providers on the health care team could increase understanding. Further, education regarding the etiology, identification, and management of TRF is needed for both providers and patients. We highlighted the utility of HIV-specific support groups, increasing social support, teaching patients problem-solving strategies and communication skills, engaging patients in active coping (e.g., yoga, mindfulness), and helping patients find a purpose in life.

## Limitations

Findings from our study should be considered in light of several limitations. Consistent with the exploratory and qualitative nature of this study, the sample size was small and non-random. All participants were actively engaged in HIV care which limits the generalizability of these findings. Future studies should explore TRF in patients who are not actively engaged in care or have dropped out of treatment. We primarily addressed HIV-related factors that contributed to TRF. Future studies should investigate how HIV non-specific factors may be associated with TRF. For example, stressful life events and socioeconomic factors (e.g., housing instability, food insecurity) likely impact TRF, but our study was not designed to probe participant responses in these domains.

## Conclusions

TRF is a pervasive experience in PLWH that impacts quality of life, treatment adherence, and retention in HIV care. We outlined a conceptual etiological framework of TRF in PLWH from which future investigations may build. Future research should seek to confirm our findings via quantitative methods in order to better understand mechanisms by which TRF interferes with HIV treatment. Educating clinical providers and patients about TRF and how to identify and intervene with at-risk patients is important. Effective interventions designed to reduce treatment burden and improve coping resources are needed.

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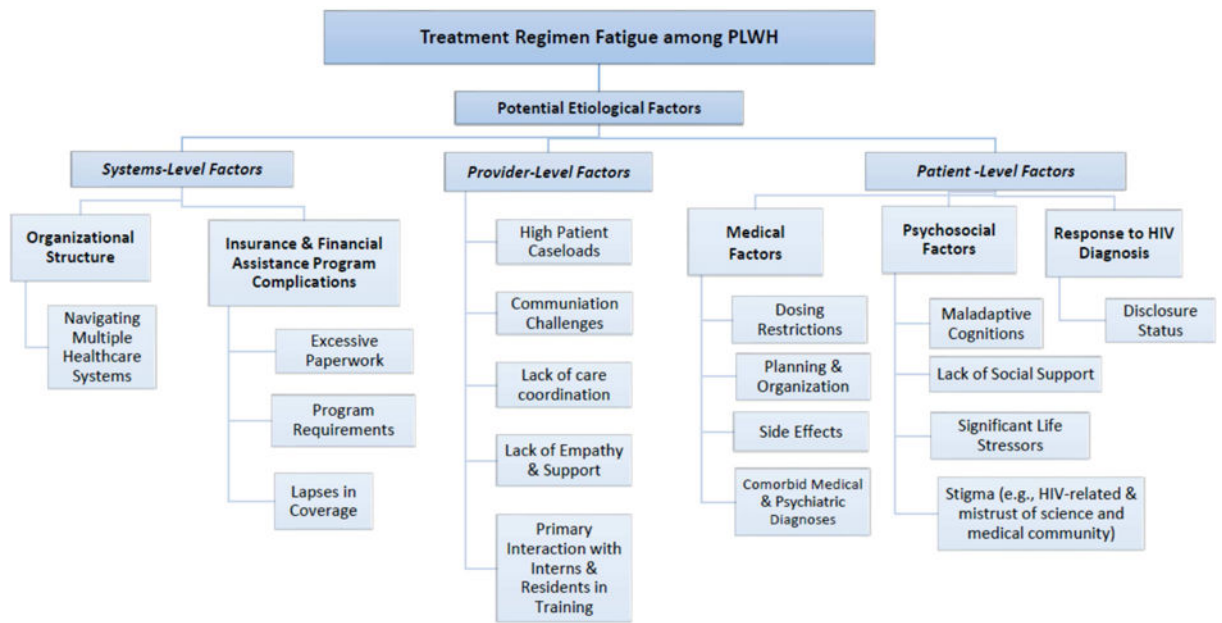
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**Key Considerations**

- Some people living with HIV experience treatment regimen fatigue, which may negatively impact treatment adherence and retention.
- Factors at the systems, provider, and patient level contribute to the onset, maintenance, and exacerbation of treatment regimen fatigue.
- Understanding the causes of treatment regimen fatigue in patients will inform avenues to intervene for patients experiencing, or at-risk for, treatment regimen fatigue.



**Figure 1. Etiological Model of Treatment Regimen Fatigue among HIV-infected patients**

*Note.* PLWH = people living with HIV infection.

**Table 1**

## Participant Characteristics (N = 24)

Variable	N	%
Participant gender		
Male	20	83
Female	4	17
Ethnicity		
White	12	50
African American/Black	8	33
Hispanic/Latino	1	4
American Indian	3	13
Employment Status		
Full time	7	29
Part time	1	4
Unemployed, Seeking	2	8
Unemployed, Not Seeking	2	8
Disabled	12	50
Education		
Some high school	5	21
High school/GED	7	29
Some college	6	25
College	4	17
Master's level	1	4
Sexual Orientation		
Bisexual	4	17
Gay/lesbian	12	50
Heterosexual	5	25
Undecided	1	4
Relationship Status		
Never married	10	42
Domestic Partnership	2	8
Married	6	25
Divorced or Separated	2	8
Widowed	1	4
Live with Same-sex Partner	2	8
Live with Opposite-sex Partner	1	4
	<i>M</i>	<i>SD</i>
Age	47	12.98
Months Prescribed HIV Medication	68.29	69.95

Note. GED = Graduate Equivalency Degree.

**Table 2****Emergent Themes Regarding Treatment Regimen Fatigue**

THEME	GROUP	PT	AGE	QUOTE
<b>Experience with TRF</b>				
	4	5	> 35	"Taking all those medications were a hassle, and I think the hassle was all mentally because of the diagnosis. It seemed like all of a sudden, every time I turned around, there was something wrong. I had to see a doctor for this, and I had to get examined for that, and I had to get prescribed medications. I think it was psychological..."
	4	5	> 35	"Once you're diagnosed, it's an ongoing deal...until you die! It's for life! And, at some point...some people will - will get to...the feeling that, you know, what's the use?"
	5	3	> 35	"Just the fact that this is something you have to do to, you know, sustain life."
<b>Etiological Factors</b>				
Systems level	1	2	> 35	"I can get the scripts wrote, but I can't get them filled... Every single month, they shut my insurance off - every single month."
	2	6	> 35	[Treatment fatigue comes from] "the run-around from the system... I gotta call [my medications] in every 21 days. If I don't call, I don't get it... I get a letter constantly that I have to do this, I have to do that... You get a letter in the mail, and...you gotta have all this information ready, and it's...every 3 or 4 months."
Provider level	1	2	> 35	"I have no faith in the doctors...I have learned more by reaching out for social support."
	3	1	18-35	"Sometimes the lab [results] don't make sense for what you are doing... They told me they must have gotten my labs mixed up with somebody else. How can you do that? This is my health. That just really irritated me, and I felt disrespected because they called me a liar."
	4	1	> 35	"The doctors either don't have enough knowledge or they don't care."
	4	5	> 35	"Let's face it: The doctors are interns. They are at a point to where they are learning as well as treating us for this medical condition...someone who may not know as much as they need to know about the disease that they're treating you for and has not become attained to an attitude or a form of communication that they need to create a [expletive] genuine physician-patient relationship."
	4	5	> 35	"I have five doctors. Three of them are specialists. My psychiatrist, when it comes to medication, he is mostly interested in psychotropics. I have a pain specialist. He is more interested in the medications and situations that deal with my nervous system and my pain. And my HIV doctor is concerned more on-eh, you get my point? So there is no way for all of these doctors to come to a point together, to realize exactly everything that's going on with me and how what they do will affect what someone else is doing. In other words, there's no networking."
Patient level				
<i>Psychological factors</i>	1	1	> 35	"I don't care how many times you take a pill, you stay alive."
	2	6	> 35	"That little pill is letting me know right now that, if you don't take me, you're not gonna be here."
	2	4	> 35	"My fear is that I don't want to give [HIV] to somebody else. If them babies have even the slightest possibility [of contracting HIV], then I was not going to go through with this pregnancy."
	3	4	18-35	"Well, after almost 3 years...it starts to get boring. It's just like, 'Uh, I gotta take this pill again.'"
<b>Experience with TRF</b>				
	4	5	> 35	"I am skeptical. I do not trust anyone or anything when it comes to the medical community. That's why communication between me and whoever I am dealing with - my physician or whatever - it is a must. It is a requirement."
	4	5	> 35	"If you have to take medication for something that means you have a problem."
	4	1	> 35	"This is something I'm gonna die from. It's never gonna leave, so why should I sit here and take all these pills when I'm gonna die anyways?"



THEME	GROUP	PT	AGE	QUOTE
<i>Personal relationships</i>	2	2	> 35	"It's important to realize that you can be with somebody that is not [HIV] positive, and you can still have passion and all that in your relationship."
	3	1	18–35	"You gotta hide your pills because your friends don't know [your HIV status], and you don't want them to know...then you hide them and forget where they're at."
	4	4	> 35	"If you have HIV, the chances of finding a husband and doing that..." participant shrugged, as if to say, "Not likely."
	5	1	> 35	"It's very hard because there [have] been so many people that I thought I could trust, who would love me regardless of what you tell them. They were there for a day or two; then they just fell off the face of the earth. Well [expletive], who do I keep? Who do I trust?"
Treatment level				
<i>Planning &amp; organization</i>	1	2	> 35	"I have meds...I have to [take when I] eat. I've had meds that I'm supposed to take on an empty stomach. I've had meds that I'm supposed to take when I first get up. I have meds that I have to take when I go to bed. You know, it becomes exhausting to complete this regimen on a regular basis with the hopes of getting better."
	2	1	> 35	"When you're on meds like we are, there is a certain amount of extra planning that has to go into things...you know you're gonna go on this trip 3 weeks in advance; you need to load up on your meds and have enough to take 'em."
	3	6	18–35	"If I have to go every 2 months, and then that puts me in the lab there, and I'm out of work twice."
	5	3	> 35	"You just think about that day coming up [that you have] to go to the doctor or get your labs done – being stuck with a needle and pulling out...tubes of blood-three, four, five, six tubes. Thinking, 'Okay, am I gonna die today?' I just wanna feel like I'm not a pin-cushion."
<i>Medical status</i>	1	3	> 35	"I wouldn't take my meds because my viral load was undetectable and I had a reasonably high CD4 count; and I saw no reason to invite the devil in to dance until it was time."
	3	4	18–35	"Because there's no symptoms, you tend to forget about it."
	4	3	> 35	"When his viral load would get down to undetectable, he'd stop taking his medication."
Course and Duration				
	2	5	>35	"For me, personally, [treatment fatigue]-it just comes and goes."
	5	3	> 35	"[It's a] constant thought process of why this happened to you, what's your purpose in life now, and what it is you want to do at this point, and is any of these things worth it?"
Consequences of TRF				
	1	2	> 35	"You get tired of putting up with what it takes to get your insurance, get your doctor payments, get to the doctor, to get your drugs, to eat right, to stick to your diet."
	2	5	> 35	"I smoke weed every day. I think it helps me more as far as dealing with a lot of issues, just with my own self. You know, because when I'm doing it, I feel great; but at the same time, I know everything is still there."
	2	6	> 35	"I'm an alcoholic. I may have three, four martinis every night, and I do have them every night, just so I can relax."
	4	5	> 35	"One day I looked at that basket [of medications] and I went, 'This is ridiculous. I'm not going to die not taking 'em 1 day.' Well, that turned into 1 day, but a few days; then it would be that I would take the medication a couple weeks prior to the examination."
Managing TRF				
	2	5	> 35	"The best thing to do is – the minute someone is diagnosed with HIV – that's when there should be a support group automatically to help them along. Because when you send them out, it's like sending out a cat among dogs who hates cats. You don't do that."

THEME	GROUP	PT	AGE	QUOTE
	2	5	> 35	"I've also done karate and a lot of training as far as mental aspects. Your pain is just a matter of your mind... Sometimes meditate, spending time alone, you know maybe going for walks or whatever. Refresh your mind."
	2	6	> 35	"Yoga will help...it's just mind over matter."
	2	4	> 35	"Me and my wife, we got two granddaughters. Right there is just enough alone to stay on your routine of your medicine."
	4	3	> 35	"Have the doctors listen to what you have to say...I think some of the fatigue is maybe some of the doctors are just not listening...they're doing what they think would be done, but my body knows what needs to be done."
	4	1	> 35	"These doctors...should focus on everything that's going on with your body. Don't just focus on the HIV."
	5	1	> 35	"I don't want your response; I just want you to hear what's going on."

*Note.* TRF = treatment regimen fatigue; PT = participant number.