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“Riding It Out”: Living with Uncertainty of HIV-Related Fever at Home

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Abstract

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Study Background & Significance. Fever is a common symptom for persons living with HIV-infection (PLWH). Some of the detrimental effects of fever can be reduced if treated early and appropriately. In a recent study of home follow-up after a fever-related hospitalization, PLWH were not inclined to monitor and/or treat fevers according to the study protocol. In an effort to clarify possible factors from the patient’s perspective, the investigator analyzed extensive notes from patient telephone conversations to explore the meanings associated with fever for PLWH managing their illness at home.

Methods. A qualitative content analysis methodology was used to analyze written transcriptions of telephone conversations that occurred over a 24- month period. **Findings.** Participants described three types of fevers that were rated according to a level of perceived threat. “Typical” fevers, associated with minimal perceived threat, were attributed to “normal,” non-HIV related causes, and were monitored by assessing symptoms. “Worrisome” fevers were associated with greater threat and were attributed to HIV causes. PLWH took action against a worrisome fever in an attempt to “ride it out.” “Danger zone” fevers were perceived as scary or terrifying because they indicate, “your body is not responding,” and could result in death, “brain damage,” or pain. They meant that PLWH were “sick.” Being sick was associated

with diminishing options and capacity to carry out the work of living. **Conclusions.** PLWH worked hard to monitor and manage fevers at home if they perceived them as harmful. Less severe fevers represent an uncertainty that is more comfortable to live with than being sick; therefore monitoring and management strategies used by PLWH were quite different from the strategies used by nurses.

Key words: HIV/AIDS, Self Care, Fever, Uncertainty; Qualitative Research, Illness work, Chronic illness, Trajectory

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Introduction

The discovery of new drug combinations and improved understanding of prognostic indicators and pathophysiologic progression of the viral infection has changed the illness trajectory for persons infected with the human immunodeficiency virus (HIV). Persons living with HIV (PLWH) or acquired immunodeficiency syndrome (AIDS) are living longer and managing their illness independently at home.¹⁻³ HIV disease is considered a chronic, rather than an acute, illness and the threat of death is less imminent.^{4,5} However, longer survival and improved health are consequences of new treatments with their complex medication regimens that require PLWH to adhere to the HIV treatment plan and to learn new self-care strategies. These include measures to avoid onset of AIDS-related complications and prevent transmission of the HIV virus.⁶ Fever is a common symptom and, to the PLWH, may be the fearsome harbinger of advancing HIV disease. Although some of the detrimental effects of fever can be reduced if treated early and appropriately in the clinical setting,⁷ little is known about how PLWH deal with this particular aspect of living with HIV disease at home. The purpose of the study was to describe the meaning of fever and its impact on illness management skills for PLWH managing fever in the home environment.

¹Holtzclaw, B. J. (1998). Managing fever in HIV disease. *Journal of the Association of Nurses in AIDS Care*, 9 (4), 97-101.

²Ferrando, S. (1998). Behavioral research on AIDS – protease inhibitors and the new millennium: Comment on Kelly, Otto-Salaj, Sikkema, Pinkerton, and Bloom (1998). *Health Psychology*, 17(4), 307–309.

³Miles, S.A. (1997). HIV infection and AIDS: New biology, therapeutic advances, and clinical implications. Introduction. *Journal of Acquired Immune Deficiency Syndromes*, 16(suppl1), s1–2.

⁴Ferrando, 1998.

⁵Kirk, S., & Glendenning, C. (1998). Trends in community care and patient participation: Implications for the roles of informal carers and community nurses in the United Kingdom. *Journal of Advanced Nursing*, 28(2), 370–381.

⁶Stall, R., Hoff, C., Coates, T.J., Paul, J., Phillips, K.A., Ekstrand, M., Kegeles, S., Catania, J., Daigle, D., & Diaz, R. (1996). Decisions to get HIV tested and to accept antiretroviral therapies among gay/bisexual men: implications for secondary prevention efforts. *Journal of Acquired Immune Deficiency Syndromes*, 11(2), 151–160.

⁷Holtzclaw, 1998.

Relevant Literature

Management skills to deal with complicated combination anti-retroviral therapy regimens, side effects, and factors that interfere with self care strategies for PLWH are becoming more important to long-term survival. One issue addressed by health care providers is that PLWH

⁸Crespo-Fierro, M. (1997). Compliance/adherence and care management in HIV disease. *Journal of the Association of Nurses in AIDS Care*, 8(4), 43-54.

⁹Ferrando, 1998.

¹⁰Miles, 1997.

¹¹Corbin, J. M., & Strauss, A. (1988). *Managing chronic illness at home*. San Francisco: Jossey-Bass Publishers.

should be able and willing to do the work associated with self-care or management of these regimens.^{8,9} Research in the area of HIV self-care has not addressed all of the potential work-related issues involved.¹⁰

Corbin and Strauss¹¹ employed the phrase “illness work” to define self-care work involved in managing illness, and the long-term consequences of having a disease. Illness work refers to work done to manage an illness that is in addition to, or in conjunction with, the work of managing everyday life. It includes, but is not limited to, the work of managing complex medical regimens, eliciting assistance, self monitoring, and avoiding or managing potential crises. The patient’s condition and the particular influences of the illness dictate the specific illness work. Illness work affects all aspects of life, especially the way that time is ordered and used. Illness work may be highly involved and perceptible to others, or considered invisible work, such as the work of revising one’s biography in the face of the illness, or making sense of the illness experience.

Self Management of Fever

Fever is a physiologic defense that has both detrimental and beneficial effects,¹² particularly in persons with HIV infection. In HIV disease, fever often signals the onset of an opportunistic infection, a condition that is considered a crisis. Therefore, monitoring for fever as a sign of infection is crisis management: an important aspect of the person’s illness trajectory. Fever and its inflammatory mediators contribute to progression of muscle wasting and malnourishment, both of which contribute to the downward illness trajectories in HIV disease.¹³ The metabolic expenditure of fever also promotes fatigue. Therefore, fever symptom management is important to maintaining a stable illness trajectory.

¹²Jones, J. G. (1998). Nursing practice for HIV: A descriptive study. *Journal of the Association of Nurses in AIDS Care*, 9 (5), 53-60.

¹³Holtzclaw, 1998.

¹⁴Ibid.

¹⁵Jones, 1998.

While fever management in HIV/AIDS has been studied in the hospital environment,^{14,15} the way patients manage this symptom in the home environment has not been addressed in the

¹⁶Murphy, K., Liebman, M. (1995). Fever care: Does nursing instruction make a difference? *Journal of Emergency Nursing*, 21(5), 461-463.

¹⁷Morse, J.M. (1997). Responding to threats to integrity of self. *Advances in Nursing Science*, 19(4), 21-36.

literature. In a study of how parents perceive and manage children's fevers,¹⁶ the fear of rising body temperature was the driving force for parental fever management strategies. Little is known about how patients and their families, regardless of disease context, manage fever in the home environment, or what fever means to them. According to Morse, the meaning of an illness event is important to illness management because attributing meaning to the situation permits individuals to endure illness work.¹⁷ Such information is particularly valuable to caregivers, who may misinterpret behaviors by PLWH regarding fever as nonadherent or irresponsible.

Methods

This study was initiated as analysis of anecdotal data obtained for reporting purposes during a quasi-experimental study assessing the effectiveness of a hospital-based nurse-administered fever protocol and a home-based patient-administered protocol designed to prevent febrile shaking chills ([Table 1](#)). Participants were PLWH discharged from the hospital following an acute febrile infection. All were participants in a hospital-based fever management study who agreed to participate in the home fever management portion of the study. Consent was obtained following an Institutional Review Board approved protocol. As participants in the hospital study neared time for discharge, the nurse investigator gave them instructions for monitoring their body temperature in the home setting. Study design was based on an assumption that every participant would experience fever at home.

Thirty-eight PLWH served as participants in the home study and agreed to follow a fever management protocol that included assessment for fever and fever treatment strategies. They also agreed to allow the nurse investigator to call them regularly and to make periodic home visits. Participants were asked to monitor body temperature several times per day, keep a diary of temperature readings and other signs or symptoms of fever, and record any measures taken to manage fever. Participants were

instructed to call the nurse investigator on a “fever hot line” if they had an oral temperature higher than 100 degrees Fahrenheit. When participants called the fever hot line for the first time, a coin toss determined their random assignment to either an experimental or control group. The experimental group received instruction regarding implementing the fever study protocol similar to that they received in the hospital ([Table 2](#)). The control group received instructions to do those things that usually made them feel more comfortable during a fever. Once entered into a group, each participant was asked to treat fevers in the same manner each time there was a fever.

Improved infection control resulting from new effective drug protocols introduced at this time may have played a role in the low participation rate that followed. Only 11 of the 38 participants who entered the home fever study ever called the fever “hot line” to report fever. Some took their temperatures and maintained their diaries at least sporadically, but none followed the protocol as instructed. The investigative team considered it crucial to explore the situation in a more naturalistic way to learn more about the fever experience at home.

During the 24-month duration of the home fever study, the nurse investigator called each of the 38 participants monthly inquiring about their experiences and recording the notes that were the source of data for the study reported here. Most fever episodes were reported during these telephone calls, rather than through the mechanisms planned for the home fever study: the fever hot line or fever diaries. The conversations that occurred between study participants and the nurse investigator were recorded in notes that were maintained as data. During each telephone conversation, the nurse investigator inquired about fever episodes, participant’s general health experiences and their perceptions of fevers. The conversations were recorded in near verbatim notes as they unfolded with participants.

Following the conclusion of the home fever study, analysis of the notes recorded by the nurse investigator was undertaken as a means to answer the question, what does it mean to experience a temperature elevation or fever when managing HIV at home? The qualitative content analysis study reported here was undertaken as a means to describe fever from the perspective of those participating in the home fever management portion of the study. The notes were analyzed to answer the specific research question: What is the meaning of fever and how do PLWH make decisions about managing fever in the home?

Sample

All 38 study participants who entered the home study and provided data for this study were diagnosed with AIDS. All but two were males. The mean age was 39 and each subject had at least one HIV-related hospitalization.

Data Collection

Telephone conversations began in 1996 when the first participant was released from the hospital. The nurse investigator called each participant at least monthly. The number of calls to each participant ranged from one, made near the end of the study, to 29. The length of the call depended upon what was happening with the participant at the time of the call or since the last conversation. When no fevers or other issues were reported, the note consisted of just a sentence or two reporting this information. The conversation was lengthier when there was a fever-related event.

Each telephone interview was documented, as it occurred, in the form of an anecdotal note using quotations as much as possible. Data included notes about conversations with participants and their families, and the nurse's perceptions of the conversations. If not recorded during the conversation, the information was recorded as soon as the conversation ended.

If participants had experienced a fever, the investigator asked about the fever experience and

treatment strategies participants used. The investigator also asked about the daily fever diaries. Since participants were not using the diaries on a regular basis, if at all, the investigator asked questions about temperature-taking activities and how participants felt about those activities.

Data Analysis

A qualitative content analysis methodology¹⁸⁻²⁰ was used to analyze written transcriptions of the telephone conversations. Data were coded into major descriptive themes and sorted into categories during data reduction. Major themes and categories were recorded on note pages and sorted into more specific categories for each theme. Categories were analyzed searching for classifications of the meaning of fever and instances when the meaning changed until patterns and relationships became evident. Theme and category note pages, coding notes, and memos were maintained for an audit trail.

As themes emerged, analysis lead to hypotheses related to the meaning of fever and subsequent fever-related activities. At that point, the nurse investigator and the researcher analyzing the data visited two participants. They were asked to describe fever and temperature elevation experiences as a means to validate themes and hypothesized relationships thus assuring data saturation/redundancy.²¹ These validation participants were selected in part because they were available and because each had experienced at least one fever during the period of the home fever study. The descriptions derived from data analysis were shared with these participants. They were asked if the description fit with their view of fever and fever management. Both agreed with the analysis as presented.

Results

Data reduction revealed two major themes: 1) Participants described their fever experiences in terms of a comparison between an experience of being “sick” which included having “fever” and 2) a less ominous experience of having a

¹⁸Krippendorff, K. (1980). *Content Analysis: An introduction to its methodology*. Newbury Park, Ca.: Sage Publications.

¹⁹Szabo, V., Strang, V.R. (1997). Secondary analysis of qualitative data.

Advances in Nursing Science, 20(2), 66 – 74.

²⁰Knaffl, K.A., Webster, D.C. (1988). Managing and analyzing qualitative data: a description of tasks, techniques, and materials. *Western Journal of Nursing Research*, 10 (2), 195–210.

²¹Szabo & Strong, 1997.

temperature elevation while not being “sick” or particularly “worried” about the experience. (Table 3) Both issues, fever and temperature elevation, were discussed within the context of each participant’s personal perceptions of health at the time of the fever or temperature elevation episode. Although no specific descriptive data were available describing each participant’s experience with HIV disease, each spoke about an isolated “fever” or temperature experience within a context of living with HIV disease and the experiences of having had AIDS fevers.

Participants rated their fevers on a hierarchy of perceived seriousness. This was based on their perception of being at risk of becoming ill: interpreting fever experiences in light of overall health. “Fever” meant something more than a reading on a thermometer or a disease state. “Fever,” for the participants in this study, was a subjectively significant elevation in temperature accompanied by “worrisome” symptoms and was viewed as a harbinger of being “sick.” Being “sick” meant that the individual had entered a “danger zone” where there was certainty of living with disability or narrowing options associated with AIDS, or death. Therefore, fevers were rated according to a perception that the fever did or did not pose a threat. Less threatening temperature elevations, were called either “worrisome” or “typical.” These temperature elevations were associated with less subjectively significant symptoms similar to those experienced by persons who do not have HIV disease, thus the term typical. These fevers were associated with feeling well and were not associated with being “sick” or in the “danger zone.”

Participants described three classes of fevers/temperature elevations and associated threat categories. “Typical” fevers were associated with minimal perceived threat attributed to “normal,” non-AIDS related causes, according to one participant. These usually caused no concern or special treatment, other than monitoring symptoms. The second class, “worrisome” fevers, were associated with greater threat and attributed to AIDS causes.

Participants monitored symptoms and instituted home remedies, such as going to bed and covering up. They called these activities “riding it out” as one would ride out a storm waiting for the calm. The third and most threatening, class of fever was a “sick” or “danger zone” fever. These fevers were perceived as “scary” or “terrifying.” They denoted “your body is not responding” and could result in death, “brain damage,” or pain. “Danger zone” fevers were discussed in relationship with being “sick.”

The three classes of fevers fell within two illness categories, being “sick” and “feeling well.” Being “sick” was linked with “danger zone” fevers. It meant having diminishing options or capacity to manage the work of living. “Typical” and “worrisome” fevers happened in a context of “feeling well.” “Feeling well” was associated with health or vigor, and a wider array of options for living. PLWH preferred to maintain hope associated with “feeling well” and therefore, preferred to live with some uncertainty when they were experiencing “typical” or “worrisome” fevers. Participants talked about preferring not to validate sensations such as chills, or sweating by taking a temperature reading if the symptoms were perceived as “typical.” Strategies, including avoidance behaviors such as not taking temperatures, were used to elude having to face the threat associated with being sick.

One participant described a typical fever in this way:

“Well, I sometimes feel warm, sorta flushed in my face and head, so I check my temperature. The most it has gone to is 99.8, but it goes away by the time I go to bed. I don’t write it down cause... well, I guess I just don’t want to mess with it...I guess it’s just something, I think, that its O.K., so don’t jinx anything... You know, it’s not just the fever I don’t want to think about. I guess I know that if I get fever, I can expect to get sick again like before.”

Being “Sick”

Being “sick” meant that horizons or options related to living were contracting. Participants felt that they had fewer options for living with AIDS. They were less able, both physically and emotionally, to manage the work of living with AIDS. PLWH talked about being unable to “see a way out.” One commented: “Everything seems worse.” In general, comments were related to narrowing options such as the following: “Your body is falling apart. You have to learn to live with that. Don’t get expectations beyond that.” Participants had to focus on their diagnosis and managing their illness as opposed to imagining a future. There was “a lot of work” associated with being “sick.”

Participants who described being “sick” and “danger zone” fevers commented that they did not have the energy for any type of work. They said that they experienced mental distress resulting from attention to their diagnosis and unknowns. “You feel drained and exhausted, never knowing what they will tell you.” One participant talked about the “reality of AIDS” and others defined this issue in terms of “fear” or “terror.” “Fear” was about a variety of possibilities both physical and existential, things like “brain damage,” “extreme pain,” and “death.” They discussed their lives only in terms of the illness. Whatever a participant’s specific concern, they viewed being “sick” as being in the “danger zone.”

Feeling Well and Temperature Elevations

Most participants were not living in the “danger zone.” The study was being conducted during the time when new drug regimens were being introduced. Study participants were experiencing improved health and they chose to focus on being or feeling well rather than taking temperatures. Many of their conversations with the nurse investigator were about activities associated with daily living rather than what Corbin and Strauss called “illness work.”²² They said that they were not experiencing fever, night sweats, chills, or other signs and symptoms of “the disease.”

²²Corbin & Strauss, 1988.

Although they knew that they were “not cured,” they reported that they were feeling well. They reported feeling well even though they were continuing to manage complicated medical regimens and might possibly be experiencing side effects from medications.

Well participants told the nurse investigator that they were able to participate in normal activities associated with living in spite of having to take medications and follow up with physicians. Participants talked about being able to “think about having a future to make plans.” They talked about engaging health promotion activities, such as taking part in physical activities like water aerobics or body building programs. They also ate nutritious diets and did things to improve their mental outlook and to reduce stress. Some returned to work.

They acknowledged the potential for becoming sick. One commented: “I have to take care of myself. If I don’t, there’s going to be hell to pay... the virus will take over and I’ll get sick again, or die, one or the other.” Another talked about seeing the potential of a “real future... I’m beginning to believe that I have a reason to actively pursue goals... I’ve started eating right, quit smoking, drinking. I exercise. I’ve given up all my vices.” They engaged in monitoring, testing out theories about signs and symptoms, and developing hypotheses about individual reactions and their relationship to sickness, but did not want to measure a temperature. Each participant had become expert in interpreting individual signs and symptoms that included interpreting and managing those associated with fever or an elevated temperature.

Strategies to evaluate and manage temperatures, when they did occur, were aimed at maintaining the status of “feeling well.” Having a temperature, validating fever with a thermometer, was perceived as a harbinger of being “sick.” Participants who felt well did not take their temperatures on a daily basis as requested for the study. Often they did not take a temperature even when they were experiencing symptoms indicative of fever. They did not want

to take their temperature because the action itself was a reminder of the “worries” associated with being “sick.” When feeling well they did not want to do anything that would threaten this precarious position, either returning them to the “danger zone” or causing them to think about being there. One person said:

“I don’t want to be continuously thinking about having AIDS. I know I’m not cured. I have to take prescriptions, see the Doctor, all that, but checking the temperature is a negative for me. When I have a fever I know that I’m sick and everything seems worse.”

Participants did have a means of assessing symptoms they might be experiencing to ascertain whether they had a temperature. They employed rather intricate self -assessment schemes that included evaluating activities and potential causes for symptoms as well as the potential threat posed by symptoms. Harbingers of a temperature elevation, “typical” or “worrisome” fever, were noted before the actual event. The signs were individual. However, most participants perceived a difference in their normal pattern of feeling well. They might feel “tired,” or “chilled.” These chills were different from the chills associated with a sick or “danger zone” fever event. “I get chills, especially in my face and neck, then they start moving to my arms and legs.” Some experienced a feeling of being warm. Whatever pattern, participants were each able to provide the nurse investigator with a detailed description of the particular signs that they identified as harbingers of fever.

Participants utilized this diagnostic process as the means to determine if the sensations were associated with an activity as opposed to being an indication that they were indeed becoming “sick.” One participant described the different processes and interpretations. He explained his interpretation of a “typical” fever by telling of a non-typical, “sick” or “worrisome” fever. He awoke from a nap with a “worrisome” fever, “my shirt drenched and having pain, being

exhausted.” He took his temperature. When he had a “typical” fever he said: “I feel really warm, but I wasn’t tired, having sweats, or any other symptoms I used to have.”

“Typical” Fevers

“Typical” fevers were not perceived as a threat. They were “little fevers” and were attributed to causes other than AIDS. They were similar to those that typically happen to anyone. They may have resulted from overexertion or exposure to the elements. These fevers required less treatment. Some resolved spontaneously and others only required an antipyretic medication, rest, and/or fluid replacement. The actual temperature range (up to 101.6° F) when participants did take a reading was lower than that of “worrisome” or “sick” fevers. These fevers were not reported to the nurse investigator when they happened, but were described during a routine call.

One participant related the following experience with a “typical” fever. He had a temperature of “101.2° F elevation at the coast after being on the beach all day. Took two aspirin, the fever went away with no chills or sweating. Drank lots of fluids ‘cause I was dehydrated.” This participant reported another similar “typical” fever episode in which he felt hot and feverish after a long day. “I just relaxed, drank a soda, and it was normal in an hour.”

Fluid replacement was a strategy that was often employed. Rest, whether going to bed or just curtailing daily activities, was another. Antipyretic use varied based upon the circumstances. Some participants included a psychological adjustment in their treatment regimen such as “keeping mentally straight, clear thinking keeps you from getting sick.” Others resorted to herbal teas and vitamin preparations to help promote feeling well.

“Worrisome” Fevers

When participants called the fever hot line to report a fever to the nurse investigator, they were experiencing a temperature elevation ranging from 100.9° F to 103° F. They were more

concerned about the potential threat associated with this higher fever. Typically, participants called because they were seeking advice from the nurse about managing the fever so that they could avoid becoming “sick.” This fever was associated with symptoms that were more significant and was usually associated with sweating, fatigue, and chills. These symptoms were a source of greater discomfort than when they occurred with a “typical” fever. Other physical symptoms that were more apt to be associated with infection accompanying the fever symptoms included headache, sore throat, sinus drainage, and gastrointestinal distress or general malaise. Participants talked about their fears of becoming “sick” when they talked to the nurse investigator about their “worrisome” fevers. Fever treatment strategies were aimed at maintaining “hope.” Participants wanted to manage the fever at home. They hoped that treatment strategies would effectively forestall becoming sick. They talked about the activities associated with feeling well that they were involved in and the importance of being able to continue those activities. One said:

“I have enrolled in a massage therapy class... have really enjoyed it. I only have two weeks left and I don't want to get sick and not be able to finish. I've been doing so much to begin living my life; for so long I've been afraid I'd die; then with therapy I've done so much better...Now I'm afraid to try to live 'cause if I spend time around people and still get sick...It's so ironic, you're afraid to die and you're afraid to live.”

Participants feared becoming “sick” and losing all that had been gained while feeling well. Therefore, the focus of treatment was to “ride it (the fever) out” waiting for the fever to “break.” Riding out the fever did not mean that participants did nothing about the fever. “Worrisome” fevers demanded attention. They could not be ignored and they were not. Strategies for managing “worrisome” fevers were

more elaborate. Some participants, who had called the fever “hot line” and been entered into the experimental group, had received very specific fever management instructions, which included information about dressing, resting, taking fluids, taking antipyretics, when to resume bathing, and how to maintain the environmental temperature in the home. They followed these instructions for the most part, but modifying things as necessary to accommodate special and specific needs. They all commented that they did not experience the usual debilitating effects of the fever when their temperature returned to normal. “I feel great, no fatigue and my mouth is moist,” one participant said.

Others, who did not receive fever management instructions either because they had never called the “hot line” to report a fever or because they had been assigned to the control group when they called, also implemented elaborate strategies for managing the fever episodes. Because they perceived this fever as more than just typical, they were more active in their management strategies intending to “ride out” the fever and lessen its effects. Strategies included altering their clothing to provide more warmth and comfort. They got into bed, and drank fluids of varying temperatures: from chilled drinks to warm herbal teas. In all but one case, they took antipyretic drugs when they were available. One person intentionally avoided taking antipyretics. This individual wanted to be able to evaluate what would happen without them. Participants were apt to adjust the temperature in their homes; some warmed their homes, while others used a fan to cool themselves. In addition, as soon as the fever “broke” with sweating, they changed clothes and usually bathed.

One participant’s treatment regimen was described in a nursing note. “The participant began with taking an antipyretic and if the fever did not respond to the medication he takes a luke-warm bath with the heat lamp (in ceiling) on. He usually gets strong chills – then the fever goes down. Then he gets out of the tub – gets

dressed and lays in bed with the fan on, so he won't get fever again."

"Sick" Fevers

"Sick" fevers were severe and strategies aimed at "riding them out" proved ineffective. In each case, participants with "sick" fevers were hospitalized. The nurse investigator often learned of these fevers after the fact. Participants related the experience in the form of a history that included the following: 1) events that led up to the fever, 2) hospital treatment to ascertain the cause of the fever, and 3) fear associated with such an event. In the hospital participants neither wanted to, nor were they able to, do anything. "Sick" fevers were very frightening and debilitating. They indicated that the body was not responding appropriately and were "terrifying" because the result could very likely be bad. For example, one said:

" I was in the hospital with pneumonia and PCP, one week after they released me, I was back with a collapsed lung. PCP fever, my body felt different. Felt like I was very very sick. I guess what I mean – on top of the typical fever, my body was not responding, aching more than usual. Trying to move and do things, had to be done slowly... It was different, really bad before it got better. They thought I was pretty much gone. Miserable night sweating, I had nightmares, and all that, and then it just snapped off... I thought I was gone... I couldn't take food or drink, started to lose a lot of weight. I was really really sick. Scared all of them. Well, I scared myself."

Discussion and Conclusions

Within a context of improving health associated with new drug regimens, participants in this study interpreted the meaning of fever according to the degree of threat posed by signs and symptoms. The work that they did to manage fever was attributed to meaning of fever. Fever management "illness work" was accomplished through the process of self-evaluation with a

focus on living with uncertainty, i.e. “riding it out” in order to live with the “hope” for the future. When a temperature elevation was attributed to overexertion, or doing too much, it meant there was still hope and it was treated as non-threatening. If there was a greater temperature elevation and the fever occurred with signs and symptoms interpreted as “worrisome,” more elaborate fever management strategies were attempted to “ride it out” in an attempt to avoid the debilitating effects. “Sick” fevers were those that were interpreted as being related to AIDS. These fevers were frightening because they meant that the person might become too sick to care for him/herself. There was always the potential for even greater loss.

²³Ibid.

Corbin and Strauss²³ defined chronic illness as living with a “failed body.” The characteristic trajectory phasing as the illness evolves is that of ups, downs, quiescent periods, and changes. There are periods of stability and instability, and downward trends that can result in death. Illness work associated with managing trajectories is likened to walking a tight rope. It is an intricate balancing of illness work with the regular work of living. When participants were feeling well, they were able to manage the regular work of living, and when threatened they took action to contain the threat. When they had “danger zone” fevers and were “sick” they were unable to manage any regular work or illness work; hospitalization was necessary. When participants talked about being sick, they talked about living with a “failed body,” having no future, and being on a downward illness trajectory. In this group’s fever experience, not only was the idea of an uncooperative or failed body evident, but they also represented phases of a chronic illness trajectory. As each different type of fever occurred, the person faced the necessary illness work required to preserve self by avoiding being “sick.”

Illness work associated with managing fever in the home represents attempts to maintain balance between living with the certain knowledge that “fever” means being “sick” and maintaining regular activities associated with

²⁴Ibid.

“feeling well.” Participants in this study talked about fever in a decidedly existential context. Their conversations with the nurse investigator revolved around preserving health, vigor, and a future, and being able to contemplate eventualities. Corbin and Strauss would classify this as biography work associated with a downward trajectory.²⁴ Fevers were a reminder or a harbinger of being “sick” and participants worked hard to maintain or regain stability when they were experiencing a “worrisome fever.” According to one participant, it was like living with a body that was, “falling apart.” When they were “feeling well,” they were again able to imagine a future, to construct plans for living with all of the limitations, possibilities, and work associated with managing their HIV infection.

²⁵Weitz, R. (1989, September). Uncertainty and the lives of persons with AIDS. *Journal of Health and Social Behavior*, 30, 270-281

²⁶Ibid.

When possible, participants who were otherwise feeling well, avoided the unpleasant thoughts related to fever by attending to less ominous symptoms in ways that allowed them to avoid contemplating downward illness trajectories. They preferred to live with uncertainty about the symptoms rather than know that they are moving into a downward trajectory, into the “danger zone.” Weitz²⁵ described this phenomenon in the context of avoiding initial diagnosis of HIV/AIDS when living with uncertainty associated with ominous symptoms is preferred over knowing the diagnosis and facing the prospects, or certainty, of early death. Although informants in the Weitz²⁶ study talked about fearing disability more than fearing death, they did not address being sick directly as a limitation. Illness was rather something to be avoided. They dealt instead with uncertainty by taking an active role in managing their disease i.e. attempting to control symptoms through health promotion activities.

Participants in the study reported here employed similar strategies. They worked hard to remain in the “feeling well” trajectory phase. Therefore, they did not want to investigate symptoms, or to validate symptoms through such actions as monitoring temperature readings, until these symptoms represented a significant threat. The illness work of managing fever within a

framework of uncertainty, i.e. riding out fevers, was done to avoid the certainty of diminishing options for living, the certainty of pain or discomfort, and the very real potential that this would be the last downward spiral resulting in death.

An individual assesses an illness-related event to be uncertain when the individual is unable to make sense of, or define, illness-related cues such as feeling warm.^{27,28} In most cases, that feeling of uncertainty would lead to activities aimed at buffering the uncertainty, and investigating and ascertaining the cause of the cue. However, in the case of chronic illness, when uncertainty is associated with predictable negative outcomes such as death, the individual might opt to maintain uncertainty. The individual may also wish to avoid making sense of illness-related cues/symptoms because symptoms, such as fevers, may be reminders of the chronic illness and the potential outcome of the illness. Therefore, persons living with chronic illnesses accept uncertainty associated with symptoms as a way to avoid even being reminded of the certainties of living with the chronic illness.²⁹

Participants appeared to be using similar logic when they justified the strategies they employed to appraise “typical” fever symptoms in a less frightening light, or to ride out “worrisome” fevers. As fevers became more “worrisome,” they attended to them more carefully, attempting to control their effect, while still maintaining a degree of mystery by avoiding alerting health care providers, in hope that the worry was unwarranted. Mishel³⁰ suggested that individuals would select to disregard or overlook symptoms associated with uncontrollable uncertainty. Participants in this study, while in effect not disregarding or overlooking fever symptoms, chose not to know and chose to live with uncertainty by waiting and wondering. Cautiously living with uncertainty was preferred

²⁷Mishel, M.H. (1988). Uncertainty in illness. *Image: Journal of Nursing Scholarship*, 20 (4), 225-231.

²⁸Mishel, M.H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: Journal of Nursing Scholarship*, 22 (4), 256-261.

²⁹Mast, M.E. (1995). Adult uncertainty in illness: A critical review of research. *Scholarly Inquiry for Nursing Practice: An International Journal*, 9 (1), 3-23.

³⁰Mishel, 1988.

to knowing that one was entering the “danger zone.”

In view of the qualitative nature of this study, findings should be interpreted with caution. The findings represent reality for the study participants without necessarily representing reality for all PLWH experiencing fever in the home. Individualized patient care requires intimate knowledge of patients and their subjective appraisal of living with HIV disease or AIDS. Nurses in hospitals often intervene with PLWH experiencing fever to prevent or diminish the effects of fever without necessarily understanding the patient’s subjective interpretation of the fever. However, when PLWH manage their own fever in the home environment, nurses will better understand their client’s self-care behaviors if they are able to share their interpretation of fever. Nurses who understand individual interpretations of the meaning of fever can assist PLWH select strategies that both limit debilitating effects of fever and allow them to maintain their personal strategy for living with HIV/AIDS. This kind of understanding requires that nurses spend time with PLWH discussing their plans and ideas for living with HIV disease as well as their interpretations of illness events. Effective nurses will not attempt to control behavior, but will try to understand and support activities that allow PLWH to manage their illness trajectory and illness work in a manner that is most congruent with their values, beliefs, and hopes for living with this disease.

Further research should address the meaning of other events involving fever or HIV-related temperature elevations such as “night sweats” or shaking chills. The present study could be replicated using more specific qualitative methods with the intent of elaborating the process of interpreting illness events and choosing ways of living with HIV disease. The nature of HIV disease is changing to that of a chronic illness. Therefore, the human response must be elaborated more clearly as a means to direct nursing interventions.

Table 1**Recommended Hospital Protocol for Managing AIDS Fevers**

Goal	Intervention	Purpose
Initiate therapy early	Temperature q 15 minutes	Identify fever
Reduce disability	Wrapping arms and legs	Insulate sensitive regions of skin against chills to Prevent shivering
	Light clothing	Allow fever-generated heat to dissipate
	Bed rest until fever breaks	Lower metabolic requirements
	Warm liquids	Restore fluid loss without stimulating shivering

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Table 2**Home Fever Management Recommendations**

Interventions	Rationale
Dress in sweat suit and socks	Decrease chills
Change clothing under covers when wet	Avoid drafts: Prevent shivering
Bed rest	Reduce metabolic requirements
Warm liquids to drink	Prevent dehydration without stimulating shivering

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Table 3**PLWH Fever Typology and Meanings**

Context:	Feeling Well		Being Sick
Fever types	Typical	Worrisome	Danger Zone
Trajectory Phase	Stable	Unstable	Downward
AIDS associated meaning	Unrelated related	potentially	Related
	Non-threatening threatening	potentially	Scary
Meaning	Normalcy	living with HIV	Lost future
Activities	Maintain uncertainty out”	“ride it	Hospitalization

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