Emergency Preparedness: Considerations in Chronic Fatigue Syndrome

Moderator: Loretta Jackson-Brown

Presenters: James F. Jones, MD; Roumiana S. Boneva, MD, PhD; Charles Raison, MD

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Loretta Jackson Brown

Thank you, Diane. Good afternoon. I am Loretta Jackson Brown, and I am representing the Clinician Outreach and Communication Activity, COCA, with the Emergency Risk Communications branch at the Centers for Disease Control and Prevention.

I am delighted to welcome you to today's COCA webinar, "Emergency Preparedness: Considerations in Chronic Fatigue Syndrome". We are pleased to have three subject matter experts with us today to review clinical guidance for evaluating, treating, and managing Chronic Fatigue Syndrome. You may participate in today's presentation by audio only, via webinar, or you may download the slides if you are unable to access the webinar. The PowerPoint slide set and the webinar link can be found on our COCA webpage at emergency.CDC.gov/COCA. Click on COCA calls. The webinar link and slide set can be found under additional call information. (00:01:19)

Here to provide an introduction to navigating today's webinar is Miss Callie Campbell.

Callie Campbell

Thank you. My name is Callie and I am going to walk everybody through the tools available. This webinar should last approximately an hour. If you have a question for one of the presenters you may use the Q&A button located at the top left portion of your screen. Type in your question and then hit enter to send the question to the presenters. If you are addressing a specific presenter, please state that in your question. Selected questions will be read out loud to the group. At the top right hand side of your screen you will see a Feedback tool with a colored square next to it. Select the drop down arrow next to the Feedback, you can alert me if you have trouble hearing or if you need help. This meeting is being recorded. If you have technical difficulties at any time during this presentation, you may call our technical support line at 1-877-283-7062. Thank you all for coming. Loretta Jackson Brown is your host and she will be taking over the presentation from here. (00:02:15)

Loretta Jackson Brown

Thank you Callie.

At the conclusion of today's session the participant will be able to:

- State the 1994 International Case Definition for chronic fatigue syndrome
- Describe the diagnostic process and care management approaches for chronic fatigue syndrome
- Discuss the impact of a public health emergency on persons with chronic fatigue syndrome

- Identify emergency preparedness and response clinical considerations for persons with chronic fatigue syndrome (00:02:51)

In compliance with continuing education requirements, all presenters must disclose any financial or other associations with the manufacturers of commercial products, suppliers of commercial services, or commercial supporters as well as any use of unlabeled product or products under investigational use. CDC, our planners, and the presenters for this presentation do not have financial or other associations with the manufacturers of commercial products, suppliers of commercial services, or commercial supporters. This presentation does not involve the unlabeled use of a product or products under investigational use. There was no commercial support for this activity. (00:03:26)

Our first presenter today is Dr. Roumiana Boneva. Dr. Boneva is a medical epidemiologist in the Chronic Viral Disease branch at CDC. In this role, she provides expertise in planning and implementing epidemiological studies on Chronic Fatigue Syndrome, to include the Georgia CFS surveillance studies, the clinical neural endocrine CFS study with Emory University, and the collaborative CFS study with Mayo Clinic. Dr. Boneva has authored and co-authored 39 peer reviewed scientific papers, reports, and has delivered numerous presentations at national and international conferences. (00:04:11)

The second presenter today is Dr. James Jones. Dr. Jones is a Research Medical Officer in the Chronic Viral Disease branch, CDC. He has 30 years of clinical practice in clinical and laboratory research and Chronic Fatigue Syndrome. In 2003, Dr. Jones joined CDC to devote his efforts full-time to the study of CFS. His current research centers on the clinical and laboratory evaluations of patients with CFS and applications of the definition of the syndrome. He has over 50 published papers on CFS. (00:04:47)

Our final presenter today is Dr. Charles Raison. Dr. Raison, an associate professor is Clinical Director of the Mind/Body Program and Director of Behavioral Immunology Program in the Department of Psychiatry and Behavioral Sciences at Emory University School of Medicine. Dr. Rasion received research funding from the National Institute of Mental Health and CDC. His research focuses on bidirectional relationships between stress and immune systems, especially as these pertain to depression and the medically ill. Dr. Rasion is sought after as a resource for both broadcast and print media. He served as a member of Dr. Sanjay Gupta's medical team, answering consumer questions weekly on CNN.com about mental health. (00:05:40)

Again, the PowerPoint slide set and webinar link are available from our COCA webpage at emergency.CDC.gov/COCA. At this time, please welcome Dr. Boneva.

Dr. Boneva

Good afternoon. It is my pleasure to be here today. I will talk about some epidemiological aspects of Chronic Fatigue Syndrome. (00:06:07)

In these hectic times, we all get fatigued. But for an estimated at least one million Americans, feeling exhausted--coupled with other symptoms--is attributable to Chronic Fatigue Syndrome, or CFS for short. Also, sometimes called Myalgic Encephalomyelitis. (00:06:30)

CFS is a complex and serious disorder that is characterized by chronic debilitating fatigue that is not substantially improved by rest and is worsened by physical or mental activity. The fatigue and other symptoms hinder participation in normal activities of daily life. CFS is a syndrome that is a combination of core symptoms that appear together. Syndromes may have multiple causes. For example, heart failure is a syndrome that can be caused by various underlying conditions and can have different biological mechanisms. Similarly, CFS patients may have various reasons for their symptoms. (00:07:29)

As clinicians know, fatigue is a common symptom in clinical practice. Various studies find its prevalence in primary care visits to vary from 10 to more than 40%, as shown on this figure. In a study of 200

patients with fatigue, after detailed clinical evaluation, 21% of fatigue remained medically unexplained. A portion of such patients may have CFS, however, Chronic Fatigue Syndrome is not just fatigue. (00:08:06)

In 1994, an international panel of experts, convened by the CDC, proposed a framework and guidelines for the clinical evaluation of fatigued persons in formal investigation. The experts agreed on a case definition of Chronic Fatigue Syndrome, which is now known as the 1994 International Case Definition of Chronic Fatigue Syndrome. There are other case definitions, but this one has been the most widely used. (00:08:43)

The international case definition includes three major requirements for making the diagnosis and all of them must be met.

The first one is the presence of chronic fatigue which is clinically evaluated, remains unexplained, and has been persistent or relapsing for six months or more. The second one is functional impairment that significantly affects daily activities of work. The third one is the presence of at least 4 of 8 case defining symptoms.

The chronic fatigue should be clinically evaluated, remain unexplained with other conditions and persistent or relapsing for six months or more. It is not the result of ongoing exertion and it is not substantially alleviated by rest. (00:09:49)

The second important characteristic is the presence of substantial functional impairment ,which affects the patient's previous levels of activities such as occupational, educational, social, or personal. For example, someone with Chronic Fatigue Syndrome may be able to work but then comes home and cannot take care of family responsibilities or participate in social activities.

And third, at least 4 or more of 8 case defining symptoms should be present.

These include: impaired memory and concentration--for example, the patient misplaced their wallet and then found it in the refrigerator, or a person is driving to work and suddenly realized they were not sure how to get there. Some describe this as brain fog.

Post-exertional malaise is another symptom. Activities that previously did not cause exhaustion now result in malaise or need to rest. For example, some patients describe the need to rest in bed after just taking a shower. Other patients describe feeling malaise 24 to 48 hours after exertion. (00:11:20)

Unrefreshing sleep is another characteristic. Patients describe not sleeping well or not feeling refreshed in the morning after a whole night's sleep. Muscle pain can be one of the symptoms, painful joints without redness or swelling, headaches of new onset or severity, recurring sore throat. CFS patients often say, “I got the flu and I never got better.” Tender cervical or lymph nodes are another characteristic. In addition some patients may describe increased sensitivity to light. (00:12:09)

Before making the diagnosis of Chronic Fatigue Syndrome, other conditions that could explain the fatigue and other symptoms need to be excluded. For example untreated hyperthyroidism, sleep apnea, anemia, side effects of medications, unresolved infections such as hepatitis B or C, or major depressive disorders with psychotic or melancholic features, bipolar disorder, or dementias of any type. Alcohol or substance abuse within two years before fatigue onset also needs to be excluded, or severe obesity of BMI greater than 45. Any physical or lab abnormality suggesting exclusionary conditions must be resolved before giving the diagnosis of Chronic Fatigue Syndrome. (00:13:09)

Now I am going to talk briefly about some aspects of the epidemiology of CFS such as prevalence and demographics.

Based on various studies, it is estimated that there are about 1 to 4 million people with CFS in the United States and up to 8 million may have CFS-like illness or idiopathic fatigue. However, studies show that only 16% of those meeting the criteria for CFS have been given a CFS diagnosis by a physician. (00:13:50)

Broken down by socio-economic status 29% of persons from the upper middle-class who met criteria for CFS have received a CFS diagnosis versus 8% of persons with middle income.

And finally, one quarter of those with Chronic Fatigue Syndrome are either unemployed or receiving disability. (00:14:17)

Community and population based studies give various prevalence estimates that range from 0.4% to 2.5% worldwide. Estimates for prevalence of current Chronic Fatigue Syndrome range from 0.006% to 2.6% in the general adult population for the United States. This is a burden similar to that of AIDS and multiple sclerosis.

These prevalence estimates vary depending on the population sampled and the screening methods employed. However, regardless of the differences in estimated prevalence, most, but not all, studies find that Chronic Fatigue Syndrome is 3 to 4 times more common in women than in men and that it affects mostly individuals in the 40 to 50-year-old age group. However, any age group, including adolescents, can be affected. (00:15:28)

Contrary to the initial impression that Chronic Fatigue Syndrome was an illness of white, wealthy, highly educated women, later studies both in the United States and in other countries found that persons of lower socioeconomic status are more frequently affected. Highest prevalence is found in racial and ethnic minorities. Some studies found that African-Americans and Native Americans were more frequently affected than Caucasians. Other studies found that Latinos were even more frequently affected than African Americans. (00:16:09)

In summary, fatigue is a common medical complaint, but Chronic Fatigue Syndrome is different. It is not just fatigue. CFS is a long-lasting debilitating illness with impact similar to heart disease, multiple sclerosis, or AIDS. Most Chronic Fatigue Syndrome patients have been ill for over 5 years. Only 16% have been diagnosed and treated as CFS patients. And 1 to 4 million Americans probably suffer from CFS. CFS is 3 to 4 times more common in women and it is more common in racial and ethnic minorities and in the socioeconomically disadvantaged.

CFS has significant impact on the individual, the family and society. It is estimated that in the United States, Chronic Fatigue Syndrome results in annual productivity loss of about $9 billion. Annual loss of income to each family with CFS is estimated at around $20,000. (00:17:25)

For the individual struggling with Chronic Fatigue Syndrome, coping with the illness symptoms leads to stress. Often these are individuals who have been highly productive and it is difficult for them to accept their current limitation and that their condition is often not taken seriously because they do not look ill all the time. Patients feel stigmatized because of lack of illness recognition.

When a member of a family has a disabling condition, this affects the dynamics of the whole family. One or more family members become caregivers. Healthcare providers need to be alert to the associated family problems. (00:18:14)

In the workplace, problems arise because of frequent absence and decreased productivity due to lack of stamina and problems with memory and concentration. A person with Chronic Fatigue Syndrome may therefore feel more stress and job insecurity at the workplace. Because this disability is invisible, it can even cause mistrust in relationships.

And now, I will pass it on to Dr. Jones to talk about the diagnostic process. (00:18:51)

Dr. James Jones

Good afternoon. Thank you Dr. Boneva. This portion of the program addresses clinical aspects of Chronic Fatigue Syndrome and concentrates primarily on the diagnosis process with an introduction into management of the patient.

The first slide emphasizes three important points. Chronic Fatigue Syndrome is a syndrome and is identified only by symptoms, particularly certain patterns of symptoms.

Secondly, early in the course of consideration of fatiguing or syndromic illness, the search for the origin of specific patient's illness is paramount.

Lastly, as of this month, Chronic Fatigue Syndrome remains a diagnosis of exclusion. (00:19:50)

This process is exemplified in the next slide where an overview of the evaluation is portrayed. Diagnosis is dependent on obtaining a thorough history and physical examination. The obvious purpose of these actions is to identify factors that contribute to the illness and may assist in identifying underlying processes and suggest intervention. (00:20:17)

Screening lab tests assist in this process. Likewise, a screening neurological exam including observation of the patient activity level and purpose during the interview is required. The observation will also assist in identifying factors that might lead to a specific psychiatric evaluation. (00:20:42)

Obviously this process cannot be completed during a single or first office visit. If a specific diagnosis or formal differential diagnosis can be made, appropriate therapy and follow-up plans can be instituted as suggested in the first row of the figure. If no exclusionary process is found, the nature of the illness needs further exploration as seen in the boxes on the left of the slide.

Following down these boxes leads to consideration of Chronic Fatigue Syndrome. If the duration of fatigue is less than six months, fatigue or illness does not impair function, and 4 of 8 symptoms are not present, continued evaluation and symptomatic therapy is recommended. Underlying illness may evolve in such a patient or the symptoms may spontaneously clear. It is also possible that a typical Chronic Fatigue Syndrome picture may evolve. (00:21:42)

Consideration of a Chronic Fatigue Syndrome diagnosis is dependent on complaint of fatigue and additional symptoms. If one relied on fatigue, one might miss a number of patients with a full syndrome since only 40% identify fatigue as the primary problem. After the evaluation, if other diagnoses were not found, and there are adverse consequences of the illness and importantly, the onset is new. This illness has not persisted for a prolonged period of time, or the onset of the constellation. (00:22:29)

Diagnostic. Let's go into more detail regarding the process of determining the origin of the patient's illness. Obtaining an accurate history requires that it be given in the patient's own words and not reliance on a check-off list or simply filling out a review of systems form. Requiring a verbal description allows the patient to prioritize his or her problems and gives the interviewer an opportunity to judge the patient's cognitive functioning. Having the patient prioritize their symptoms and then determine their interpretation of their complaint is very important for identification of the problems and subsequent intervention. (00:23:26)

As seen here, the complaints of tiredness or fatigue can have many meanings. If the patient has difficulty in labeling their condition, these examples can be given for recognition purposes. For example, lethargy may not be a familiar term. Sleepiness as a consequence of not sleeping well may be readily recognized however as a fatigue homologue. A thorough explanation of the patient's description is necessary to identify or exclude underlying processes. (00:24:06)

For example, seven questions regarding sleep might lead to identification of a sleep problem if the patient likened fatigue to lethargy requiring intervention or further evaluation. Specific testing may be required based on the answers to these questions. Remember, not all sleep problems can be identified with a

polysomnogram. All of these conditions as well as many others have been seen in patients presenting with fatigue in our population studies and in patients seen in the clinic. Obviously, there are many others. (00:24:54)

The 1994 International Definition suggested a list of screening laboratory tests in the initial evaluation. As seen in this slide these tests address the underlying conditions previously shown where lack of energy may be the patient's perception of fatigue.

As seen here, fatigue and other behaviors likened to a flu-like feeling may be described by the patient. Exclusion of an ongoing inflammatory process begins with this group of tests, also included in the 1994 definition. (00:25:41)

Obviously further evaluation may be required as in the case of foreign travel, a history of insect bites, and required evaluation of specific diseases such as Hepatitis B and C. (00:25:56)

Bullets 2 and 3 suggest that illness behavior as associated with infection is a normal phenomenon. It becomes abnormal when it persists for a prolonged period of time and interferes with functioning as in the case definition. (00:26:16)

Leaden legs or feeling as if one has exercised heavily is another patient descriptor of their fatigue. This constellation of symptoms may suggest an endpoint of neurally mediated hypotension (NMH) or postural orthostatic tachycardia syndrome (POTS). But it does not identify the root cause. Specific laboratory or physiological testing may be necessary. An example is an adolescent male who developed NMH symptoms following a meal. This is not uncommon for adolescents. As such these conditions need to be addressed as separate entities and not necessarily considered a part of CFS, as they require different and specific types of intervention. (00:27:11)

Identification of additional contributing factors is a critical component of the history. Use of medications or stimulants found in alternative therapeutic agents may contribute to the illness. Likewise, the other components of - that we typically perform, - review of systems, past medical history, and a daily accounting of medication used, both over-the-counter and prescription, are required. (00:27:47)

Cognitive problems are frequently the consequence of other underlying processes such as sleep disturbances, medications such as sedatives or stimulants, even caffeine. Perseveration of the illness and lack of attention to the task at hand may lead to perception of cognitive problems. Cognitive problems should be new to the patient and occur in the conjunction of the symptom complex. (00:28:18)

COMORBID CONDITIONS: Conditions listed here may occur with CFS or vice versa. Frequently the label given to a patient is dependent on the background of the caregiver. The goals in evaluation of these individuals remain the same. Type of onset appears to impact duration of illness and perhaps recovery and prognosis. Some of the prospective studies following an acute infection, severity of the illness was a factor in development of the syndrome. (00:28:59)

Additional variables that can affect outcome are described here. Younger age fits in a better prognosis as does shorter illness duration, milder fatigue, and absence of comorbid psychiatric illness. Changes in symptoms and relapse or remitting pattern is common, in fact it should be expected. (00:29:29)

A great individual variation is expected. If one calculates the combination of 4 of 8 symptoms there are at least 70 different such combinations. Many people improve over time but still have their symptoms. (00:29:47)

MANAGEMENT: The initial and long-term management is summarized here. Accurate diagnosis is paramount. An example is as follows; a 42-year-old store clerk was referred for further evaluation of fatigue and cough over several winters. She carried the diagnosis of recurrent pneumonia and Chronic Fatigue Syndrome. On exam, she had crackles in her lung bases, tachycardia, and a heart murmur. Testing and further evaluation revealed mitral valve stenosis and hyperthyroidism. This patient obviously did not

have CFS. Education of all involved persons, assessment and alteration of behavior is required as is tailored physical activity and continued evaluation. (00:30:42)

Lastly, Chronic Fatigue Syndrome should not be considered an endpoint diagnosis. Short term goal of therapy is not immediate return to pre-illness status. Therapy and subsequent process should be determined by the individual patient's need. Failure to achieve resolution is not helpful, particularly if it is promised to the patient. (00:31:11)

Initially, symptom reduction without increasing fractional capability is a primary goal. The patient should contribute to how much they need to function and then determine what levels of capability they are capable of. Gradual increase in functional level is a reasonable goal. (00:31:35)

These final slides address supportive and specialized care of the overall syndrome. It should be clear that therapy is symptomatic and supportive. There is no one size fits all approach in these illnesses. In many cases, multiple specialists may not be available. Those with expertise in formal CBT, or graded exercise in particular may not be available in every area. Therefore, the primary physician may need to be the therapist as well. Fortunately this management process is practical and the bread and butter of most providers. (00:32:22)

I will now turn it over to Dr. Raison.

Dr. Charles Raison

All right, well hello everybody. Now we are going to shift gears somewhat and talk specifically about how to think about nationally helping patients with Chronic Fatigue Syndrome in the context of emergencies and disasters. (00:32:45)

First off, let's talk about what we mean by a traumatic event. These events, or event, that cause moderate stress reactions in people. Now of course a traumatic event can be personal. Today we are focusing on large scale traumatic events, emergencies, natural disasters that induce traumatic reactions in large groups of people. Human beings respond to these type of events with rather stereotyped reactions that include cognitive emotional, physical, and behavioral symptoms. People have difficulty thinking, concentrating, they can feel confused, they have a hard time making decisions. People can have a range of emotional reactions from shock and feeling abandoned to feeling emotionally dead and numb. Many times people will feel, as they say, very spaced out or that things are unreal. That is a particularly worrisome finding because it portends later development of post-traumatic stress disorder problems. Physically people respond to large-scale stresses with increases in heart rate, their sleep declines, they feel pain, headaches, they can feel dizziness, they can have all sorts of non-specific physical problems that are a result of the stress system activation. (00:34:05)

And people behave differently when they are stressed out in the context of natural disasters or large disasters in general. Sometimes it brings out the best in people, other times people respond with irritability, withdrawal, people can become excessively silent, they can be suspicious of their neighbors, almost anything is possible. And again, some of it good, some of it bad, but in terms of maladaptive responses to large scale traumatic events, we have listed here some behaviors that are problematic. (00:34:36)

It is very important to highlight here that although we are talking about Chronic Fatigue Syndrome, the fact that stresses can worsen the course and severity of Chronic Fatigue Syndrome is not unique to CFS. In fact, we know now beyond a shadow of a doubt that stress is a risk factor for, and worsens symptom status in all the major modern illnesses from cardiovascular disease and stroke to diabetes, autoimmune conditions, HIV, cancer, dementia and depression. The fact that Chronic Fatigue Syndrome also is worsened by stress is not -- sorry folks, -- is nothing unique to CFS and that is a very important point to make, that we are not talking about something unique to Chronic Fatigue Syndrome, that in fact, we know that from, again, when a stressor happens, some large scale disaster for example, it causes changes in

people's autonomic nervous systems here called the ANS and the HPA axis and the immune system. These changes lead, rather predictably, to a host of changes in how the body functions in terms of the autonomic nervous system, you get a fight or flight response that drives up your blood pressure and your heart rate. In terms of the HPA axis you develop a number of changes that you see in a lot of psychiatric conditions such as post-traumatic stress disorder and major depression. (00:36:03)

These changes are fairly normal in the context of extreme stress. The changes in the HPA axis and the autonomic nervous system promote changes in the immune system and the two majors changes you see there are increases in inflammatory signaling and we now know these types of increases in inflammation are at the root of many modern medical illnesses. You also unfortunately see reductions in the types of adaptive immunity that are so important in protecting us from bacterial and viral infections. (00:36:31)

So, at the end of the day you get a whole bunch of disease consequences as shown in this slide. All the major modern illnesses are worsened by stress and stress is a risk factor for their development. (00:36:44)

Now, natural disasters as an example of large scale traumatic events cause all sorts of increase in stressful events and situations. This is an interesting slide because what it shows is the percentage of people that reported a wide range of stressors, for instance evacuating, moving out, having their property damaged, bad emotional distress, thinking that they were going to die. All those stressors compared in Dade county versus Broward county, two areas around Miami in the days and months after hurricane Andrew. Hurricane slammed right into Dade county and it took the brunt of the hit. Broward County was relatively spared. And so what you can see is that in Dade county, that had a huge natural disaster, there is a much larger rate of all sorts of stressors compared to Broward County that got off a lot lighter. This really highlights the fact there is a very strong relationship between the severity of the natural disaster or the emergency situation and how much stress it will induce. (00:37:48)

There is a wrinkle, it's a sad wrinkle but it's a powerful wrinkle in the story which makes things even worse. So we now know, and many studies attest to the fact, that individuals who are subjected to various types of adversity early in life, neglect, abuse, it could be the death of a parent, are at greatly increased risk for having stress related disorders later in life and moreover, unfortunately they will often replicate the conflictual and abusive situations in which they grew up. It causes them to lead adult lives characterized either by isolation or conflict. (00:38:25)

When these people have children, the pattern can often be replicated and this is how it passes through the generations. The point for today however is that when something like a natural disaster strikes, it put tremendous stress on this already very stressful, vulnerable system and it makes all the stressors that have been going on chronically much, much worse. (00:38:50)

So in addition to stressors that are directly related to a natural disaster or large scale emergency, you get an amping up or an increase in all the chronic, interpersonal stresses that caused so much misery and so much disease in people's lives. So there is multiple ways in which large-scale disasters and emergencies worsen stress. And there are all sorts of studies showing that by worsening stress, they worsen health. (00:39:17)

So here are four graphs. Let's start with the graph in the upper left hand corner. What this shows is changes in blood pressure in people after a very large earthquake. These are not patients, just normal folks. What you can see here, they divided the groups by their albumin status in their urine. Whether or not people had albumin in their urine or not, you can see that blood pressure, both systolic and diastolic, skyrocket in the weeks after a major earthquake. It takes quite a while to come down. There is a mortality consequence to this. The graph right below that one, so now we are talking about the lower lefthand corner, shows rates of people dying from heart disease in the year after an earth quake or in the weeks after an earthquake versus the same time of year the previous year. So what this graph shows is that if you look at days after an earthquake, and here you see the number of deaths by time of day starting at 5 AM and going through the day, that in the week or two after an earthquake there is a significant rise,

especially in the early morning and late evening of people suddenly dying of heart attacks compared to the same time of year, same time of day, the year before. (00:40:33)

This is one of many studies showing that Earthquakes, tornadoes, hurricanes cause a significant increase of people dropping dead from heart attacks and sudden cardiac arrhythmias. The effects of stress are actual and they are very powerful. (00:40:48)

In the upper right hand corner, this is data from hurricane Andrew. What it says is that people that underwent the experience of hurricane Andrew have reductions in natural killer cell activity. Natural killer cells play a key role in the immune system. The reduction in natural killer cell activity was especially bad for people who had a lot of property damage from the hurricane, people who developed post traumatic stress disorder and people who could not stop thinking about the hurricane. (00:41:15)

Finally, in the bottom right, this is a med analysis of 14 studies looking at the effect of stress on multiple sclerosis. You can see that there is one study that is an outlier on the right but all the other studies are saying that stress takes a disease like MS and makes it much worse. (00:41:32)

Now we are looking at the effect of hurricane Andrew on Chronic Fatigue Syndrome. We can put it in a context of these other illnesses, and see that like these other studies, this is a study of 50 people that had Chronic Fatigue Syndrome. Some of them lived in Dade County which was very badly hit by the hurricane and others lived in Broward County which was much less hit. The graph on the left says that people with Chronic Fatigue Syndrome who lived in Dade County had much greater impairment in work and fatigue and sleep and muscle weakness and cognitive complaints, all the symptoms of Chronic Fatigue Syndrome got much worse in them as a result of taking on that stressor, compared to people who did not have that level of stress. The graph on the right shows that the people in Dade County with Chronic Fatigue Syndrome had significantly higher rates of having a full relapse of their illness compared to people living in Broward County, again consistent with the fact that natural disasters and large scale emergencies are likely to worsen symptom presentation in Chronic Fatigue Syndrome. (00:42:32)

This is a summary picture that says we now know that the diseases like Chronic Fatigue Syndrome probably arise from a combination of vulnerability change and adversities in the environment. These can include stress, trauma, infection, and that when these two things interact with each other they set up a pattern of increased inflammation and a range of other issues, for instance depression, diet, infection, stress. These inflammation interacts with these factors to produce illness. But then sadly, what the large arrows say is in the illness, in this case Chronic Fatigue Syndrome feeds back into the processes and worsens them. So you get a nasty feed forward circuit going where the illness then further contributes to the very processes that are driving the illness itself. (00:43:16)

With that background, let’s talk specifically about how to prepare Chronic Fatigue Syndrome patients for large scale emergencies and natural disasters. The first and most important point is that people with Chronic Fatigue Syndrome should be prepared for traumatic events in the same way as people with other chronic illnesses. They should have a written emergency and evacuation plan. They should have a contact list of friends, family, or caregivers that should be shared with a friend or two so that somebody has that for them. They should have a list of all their medications and doctors and they should have an emergency kit for evacuations that should include essentials of life including a five day supply of their medications. You should be informed. People with Chronic Fatigue Syndrome, like everybody, should know where their local emergency contacts and shelters are. As clinicians, we need to recognize that no two patients with Chronic Fatigue Syndrome are alike. So you can't make blanket judgments about what patients with Chronic Fatigue Syndrome will need in the face of a large scale emergency. (00:44:15)

We can make a couple of generalizations. The first arises from many studies in animals showing that an animal can be very badly infected, it can be very sick. But if all of a sudden it's life is put in danger, that animal can override the sickness response and run for its life. Humans can do the same thing. So it turns

out very often that people, who are very sick with Chronic Fatigue Syndrome, in the face of life-threatening emergencies, will perform normally. They will tap into that same ability of the stress system to override sickness and they can perform normally in times of life-threatening emergency. For instance, what data like I showed you a moment ago from the hurricane Andrew studies suggests is that the big risk for patients with Chronic Fatigue Syndrome is after the disasters have abated. The risk is there will be long term declines in functioning as the acute stressor passes and the damage from that stressor really settles in to people's hearts, minds and bodies. (00:45:14)

It is especially important for Chronic Fatigue Syndrome patients to follow all basic rules of disaster perparedness. Being proactive and ready and having a sense of confidence really help to reduce stress in these types of situations and increases the sense of mastery. Mastery reduces stress. If you can do that you will help people with Chronic Fatigue Syndrome likely not have as bad a reaction over time to the natural disaster or the emergency situation. (00:45:41)

Similarly, and this is not just people with Chronic Fatigue Syndrome, but certainly especially people with CFS can be helped if they can limit trauma exposure and avoid physical overexertion. Many people with CFS have as a primary or a very cardinal symptom, the fact that when they overexert physically it really worsens their disease course, their symptoms. So you really want to encourage people and try to help them limit their trauma exposure over and overexertion. And also I think it is reasonable to expect, as a clinician that disaster related consequences will emerge over time in many people with CFS. Be patient as we work with these patients because it will take time for these symptoms often to resolve. (00:46:22)

I think it is important as clinicians that we explain to the patient with CFS that a worsening of symptoms and perhaps some new symptoms may be normal after a traumatic event. We need to remind patients to try to keep to as usual a routine as possible. Normalizing abnormal situations can often be very stabilizing and reduce stress. We can help patients identify ways to relax. We need to help them identify ways to resolve day-to-day conflicts to reduce stress. Very often there is a major stressor itself of a natural disaster and there are ongoing stressors caused by that first stressor, almost like stress aftershock. Anything we can do to reduce the damage from those stress aftershocks will also enhance long-term outcomes. We certainly want to encourage patients with CFS to maximize their contact with support networks. We know that social support is very protective against the disease causing proclivities. (00:47:20)

So to summarize, we know that stress increases the risk of developing Chronic Fatigue Syndrome and worsens symptoms in people with the disorder. This is not unique to Chronic Fatigue Syndrome, we see it in other medical conditions also. Stress induces physiological changes that is seen in Chronic Fatigue Syndrome and other diseases. So stress actually causes changes in the body that have been identified in the disease of Chronic Fatigue Syndrome itself at least in some studies. These changes include increased sympathetic and decreased parasympathetic tone, glucocorticoid resistance and increased inflammation. (00:47:51)

Disasters are major stressors in themselves and they also exacerbate more chronic stressors that worsen their ability to cause harm. Disasters may worsen long-term functioning in people with Chronic Fatigue Syndrome, even if these people do well over the short-term and responding to the acute danger. And reducing traumatic experiences and severe overexertion in the context of emergency situations may provide long-term protection against disaster worsening of Chronic Fatigue Syndrome and its symptoms. (00:48:22)

With that, I believe that is the end of our presentation. So I believe I am turning it over to you Loretta?

Callie Campbell

I believe I will bet taking this is we are going to do the questions and answers now. I'd like to go ahead and let everyone know once again that the question and answer section is located at the top left portion of your screen if you want to ask a question through the system. You may also ask a question over the audio line. I'll have the operator come on and provide instructions for that.

Operator

Thank you. If you would like to ask an audio question please press star one. Please unmute your phone and record your name clearly when prompted. Your name is required to introduce your question. To withdraw your request, please press star two. One moment please while we wait to see if there are any questions or comments.

Callie Campbell

Okay, and we do have some questions in the system. This will just go to whomever would like to answer it. I would like to know why are the reported estimates of prevalence so different ?

Dr. Boneva

Hi. This is an excellent question. The reported estimates of prevalence vary widely because of the populations studied, the type of the population involved in the study and the methods employed. Some studies screen large populations and they involve telephone screening and questions that will allow to capture a large group of people who may potentially have the illness. So they increase the ability to capture more patients. Other studies, for example, are based on physician referral. The study is designed to include physicians that may potentially see patients who have Chronic Fatigue Syndrome. In such cases, the results will depend on how many physicians agreed to participate, how many patients they referred, what type of physicians agreed to participate and also how the physicians who agreed to participate, for example, differed from those who did not agree to participate. (00:50:45)

Callie Campbell

Okay.

Dr. Boneva

It also depends on what variables were collected, what data were collected and how they would allow us to make the diagnosis.

Callie Campbell

Okay great. Can any of you tell me, I'm sorry, was there something else?

Dr. Boneva

Excuse me?

Callie Campbell

I'm sorry. I thought somebody had something else to add to that question.

Are there any questions on the phone line right now?

Operator

I show no questions. Again, if you do have any questions or comments, please press star one and record your name.

Callie Campbell

The next question through the system is, "How often should a clinician see a Chronic Fatigue Syndrome patient?" (00:51:48)

Dr. Jones

There are probably no specific recommendations. The general guidelines are if the patient continues to have problems, they need to be seen when the problems are interfering with the function of the patient. That may be monthly, every three months, etc. Likewise, if a patient has improved, they need to be seen

because the therapy may be terminated if the patient is getting better and oft times that is the case. They get better spontaneously. So it is a problematic question and has never really been studied. (00:52:36)

Callie Campbell

Okay, and also related to that one , "Why is it necessary to have more than six months of fatigue for a Chronic Fatigue Syndrome diagnosis?"

Dr. Jones

In the early stages of looking at the syndrome, that was the proposed period of time in the 1988 definition, the initial definition. Once people started applying that definition and analyzing the duration of illness, it became clear that many times the patient would get better after 2 to 4 months. Six months seemed to be the average period. It is based on a number of studies, a number of clinical observations that weren't published but all discussed in several workshops that took place before the 1994 definition was formulated. (00:53:33)

Callie Campbell

Okay. Do we have any questions on the phone ?

Operator

Yes we do. One moment please. Your line is now open.

Participant

Hi. My question is, have they considered looking at the international consensus criteria yet and my second part of that is I feel women are completely under prescribed pain medication and if you look at the suicides with this illness, I think that needs to be addressed. Proper pain management. Are they working on that? So the doctors aren't afraid to adequately treat the patients in pain. (00:54:17)

Dr. Jones

The answer to the second part of the question is that pain therapy is important. Particularly if the individual has pain as one of the primary components of their illness. The recommendation that narcotics be used judiciously or not at all initially is for the protection of the patient. Unfortunately too often, they are used with adverse consequences. Certainly pain does leads the list of problems with the syndrome that need specific intervention. And I'm sorry, the first part of your question was unclear. (00:55:00)

Participant

If they are going to consider looking at the international consensus criteria as far as defining patient subsets? Are they going to look at that in the future? It is a new publication with 32 scientists worldwide. (00:55:17)

Dr. Jones

We are familiar with it. I think it needs to be tested in a lot of different places.

Participant

So you are looking at it still?

Dr Jones:

Oh yes. We are looking at it.

Participant

OK. I appreciate the comment about getting adequate pain relief because website after website it just seems like it is really unfair and the doctor wants to follow the law but the patients need to be treated.

That is my main advocacy. I have had this 18 years. Thank you for agreeing. I really, really appreciate that.

Operator

I show no further questions.

Callie Campbell

OK. I have one from the system. “Should persons with Chronic Fatigue Syndrome get a flu vaccine?”

Dr. Boneva

Definitely so. Only if they have other contraindications, then they should not get a flu vaccine. But it is generally much better to have the vaccine than to have the illness. Flu is a very serious illness and it sets patients back. (00:56:33)

Callie Campbell

OK. “Does having CFS increase your chance of getting other illnesses?”

Dr. Raison

That is a great question and the answer is we are not totally sure. There are not strong data to support that it does and people have looked at that in some ways. Our research group has looked at physiologic processes in people in Chronic Fatigue Syndrome, for example inflammation. We found in a large study that folks that had Chronic Fatigue Syndrome, had increased markers of inflammation and these markers are in turn associated with increased risk of a number of illnesses such as heart disease and diabetes and over great periods of time also perhaps dementia and maybe cancer. But it is speculative at this point to say that in the Chronic Fatigue Syndrome population, that observation will translate into enhanced risk of illness down the road. That is one of the things that the CDC and the research group here is very interested in trying to understand is whether or not prior illness is or is not a portal into other disease states that have high mortality risks. (00:57:52)

Callie Campbell

OK and can you also answer, “Can persons with Chronic Fatigue Syndrome go to emergency shelters?”

Dr. Raison

Most certainly. There is no evidence that people with Chronic Fatigue Syndrome are, they are certainly not contagious. There is not really any strong evidence that I have ever seen that they are at increased risk of getting viral infections. I’m trying to think of why would you want to avoid a shelter? So, no I think in a situation of real risk to life and limb, the most important thing for people with Chronic Fatigue Syndrome to do is get to the safest place they can possibly get to. A very important point is that in many cases, people with Chronic Fatigue Syndrome will function better in the face of the acute trauma or incident and may have increased difficulty down the road, slowly over time. So most definitely, a strong recommendation is that people with CFS be as proactive in doing things like going to shelters and assuring their safety. (00:58:57)

Callie Campbell

Okay, and I'm going to check on the phone line one more time. Do we have any audio questions in queue?

Operator

I show no questions.

Callie Campbell

Okay, then I will go ahead and pass this off to Loretta Jackson Brown.

Loretta Jackson Brown

Thank you Callie. On behalf of COCA, I would like to thank everyone for joining us today with a special thank you to our presenters, Dr. Boneva, Dr. Jones, and Dr. Rasion. If you have additional questions for today's presenters, please e-mail us at COCA@CDC.gov. Put Dr. Boneva, Jones and Raison in the subject line of your e-mail and we will assure that your question is forwarded to them for a response. Again, that email is COCA@CDC.gov.

The recording of this call and a transcript will be posted to the COCA website at emergency.CDC.gov/COCA within the next few days.

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Thank you again for being a part of today's COCA webinar. Have a great day.

[Event Concluded]