

A qualitative research analysis of the relationship between fatigue and social interaction in patients with Friedreich's ataxia

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Background

Friedreich's ataxia (FRDA) is a genetic disease which involves progressive damage to the nervous system, including movement and muscle coordination problems. Quality of life in patients with FRDA may be significantly lower than the general population due to physical and mental strain on relationships, economic challenges, and social support. The symptoms and fatigue involved with FRDA may deter or inhibit patients from participating in transitional life events, therefore lowering quality of life. This subject requires qualitative research analysis to determine how to improve social interactions and quality of life for patients with FRDA.

Goal

The goal of this qualitative research study is to describe the impact of fatigue in patients with FRDA on social interaction, relationships, and overall quality of life.

Methods

As part of a larger study, adults with FRDA were interviewed to discuss the impact of the disease on their life and were asked to complete a 14-day fatigue journal. Individuals range in age from 20 years old to 64 years old and are typically Caucasian/Not Hispanic apart from one individual who is Middle Eastern. Participants include seven females and six males.

In the larger study; three participants frequently discussed the impact of their fatigue on their social interactions, relationships, and overall quality of life. In the current study, we examined these participants' responses in further detail. Demographic information for the three participants selected can be found in table 1.1.

Table 1.1

Participant	Gender (M/F)	Age	Race/Ethnicity
FA08	M	59	Middle Eastern
FA09	M	64	Caucasian/Not Hispanic
FA12	F	40	Caucasian/Not Hispanic

"I have taught myself more and more to just say no, to myself and to others."

Results

Effects of Fatigue on Social Interactions

FA08

"We used to have a lot of dinner parties with friends, just maybe from 4 or 5 people to 35-40 people. That has pretty much come to a halt."
"So I have taught myself more and more to just say no, to myself and to others."

FA09

"Unfortunately when it comes down to health issues, a lot of people are a little reluctant to have someone that may require attention from them."
"Brought lunch home in take out box cuz hands were shaking too bad to eat in public."

FA12

"Oh yeah staying out late, no. The latest out is 8 o'clock."
"I don't work anymore. I stopped working about 13 years ago."
"When she's fatigued, she's not paying attention. She falls asleep. She closes her eyes more."

Effects of Fatigue on Relationships

FA08

"Let's say friends call and ask to go out this afternoon for dinner. I used to force myself and do it which is good mentally to be with friends and not think about it, but physically it was tough. I have learned...it didn't matter how fatigued I was. I used to say sure and go. Now I say no more often."

FA09

"My romantic social life has fallen off a cliff. If I were so graced with a date, they see my shaking hands. If I'm eating a bowl of soup and half of it's on me. That's a date killer right from the beginning. It usually doesn't go to a second date."

FA12

"I hate having to ask my husband to feed me like a child."
"He [their husband] works at night. He usually gets home around 6:30 in the morning and he'll help me from my bed to my chair. Help me get dressed. Help me get ready and everything."

Effects of Fatigue on Quality of Life

FA08

"It's mentally I'm not ready for retirement, but physically I pretty much have to stay home and that's the most difficult emotionally. But physically walking is the most thing. And yesterday morning, I told my wife if I were doing a diary, I would write that I can see my health deteriorating daily."

FA09

"I just don't know how long I can live. I'm trying to live independently as long as I can."
"I wish there was something closer to explain to my relatives and to others. It's the most difficulty I have...they don't understand that I'm not the same as I used to be. There's been a change in an activity level, a change in ability."

FA12

"It [the fatigue] just makes me have to stay around the house a lot. I try to do things around the home."
"If she sits in her chair for more than an hour or 2, it gets painful. Even though she wears a belt in her chair now, she's always afraid of tipping out and falling...She's just more scared that she'll fall for sure. Which is a lot."

Figure 2.1

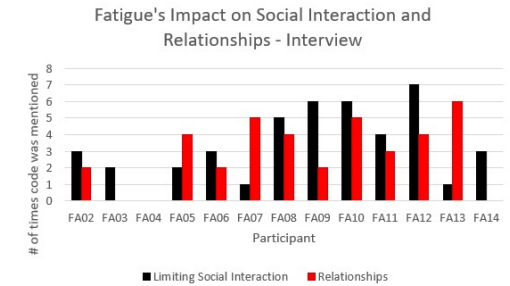
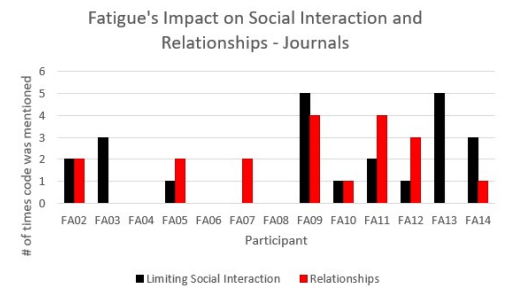


Figure 2.2



Discussion

Patients with FRDA frequently comment about relationships and social interactions when discussing fatigue, suggesting that there is a connection between these concepts. Fatigue may keep individuals from participating in social interaction due to complications related to mobility, social anxiety, and need to prioritize energy for other events. Additionally, fatigue may place strain on relationships by placing more responsibility on loved ones and causing individuals with FRDA to feel self-conscious about the effects of their fatigue on those around them.

References

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