

"I got my life back!"

A qualitative study of fatigue and everyday life in patients cured for chronic hepatitis C

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Research team

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Background

- Fatigue is a leading patient-reported symptom in Chronic Hepatitis C (CHC)
 - impairment of quality of life
 - patients' subjective well-being
 - everyday functioning

Zalai et al 2015
- Direct Acting Antivirals (DAA) seems to have a positive effect on fatigue and other patient reported outcome

Younossi et al 2015, Younossi et al 2016
- Experienced in patients' everyday life?

Aim

1. To explore how CHC and fatigue is experienced in patients' everyday life
2. How being cured for hepatitis C is experienced and influences everyday life



Participants

- Ten participants
 - Four men and six women
 - Six participants with CHC caused by injecting drug use
 - Three men and three women
- 27-66 years (mean 51)
- CHC diagnosis 1-25 years (mean 11)
- Time since DAA 78-308 days (mean 234)
- Four were in employment
- All participants were cured in 2015

Methods

- Qualitative semi-structured interviews performed by an experienced clinical nurse
- Recorded, transcribed and analyzed using systematic text condensation

Results

1. CHC and fatigue as framework for everyday life
2. Being cured and new meaningfulness
3. Anxiety of death and suffering in everyday life
4. Stigma experiences in everyday life

CHC and fatigue as framework for everyday life

- Physically, psychologically, socially and cognitively impairment

"I have been in a condition of mental and physical paralysis [...] I was very, very slow in my thinking [...] slow to react, slow to engage in conversations and was physically exhausted"
(woman, 66 years)



CHC and fatigue as framework for everyday life

"..it was as if you were wearing.. like a suit made of lead [...] if you try to do something with your hand it is as if it is pushed down with such a force as if a heavy blanket is un top of you.." (man, 32 years)

- Priority of necessary activities
 - Household
 - Job
 - Family and network - minimum



Being cured and new meaningfulness

- Physically, psychologically, socially and cognitively changes
 - Cope with more
 - Feeling "clear headed" and having "a head working at full throttle"
- New and more activities
- Social engagement
- A strong sense of meaningfulness



"It was [...] I don't know how to describe it [...] it was something between a feeling of happiness and total bewilderment [...]"
(Man, 52 years)

"I got my life back [...] it was a fundamentally different feeling from one day to the next.."

(Woman, 50 years)

Anxiety of death and suffering in everyday life

- Anxiety
 - Early death
 - Suffering



"..fear has been lurking in my sub consciousness [...] you can never relax [...] it has been a nightmare [...] I have been unbelievably sad.."

(woman, 60 years)

- New hope

"I am no longer on the death roll.."

(man, 56 years)

Stigma – experiences in everyday life

- CHC as self-inflicted and contagious
 - Avoiding intimacy
 - Strategies to avoid interaction when injured



- Being cured unleashed feelings of shame and worry

"..now I don't have to worry about that anymore. It's a whole new world (laughs) – it is actually [...] it is a relief in one way or another.."

(Woman, 62 years)

Conclusion

- Complexed interrelated aspects influenced everyday life negatively
- Being cured was experienced positively – for some even life changing