

Women's experiences of living with fibromyalgia: Struggling for dignity.

Siv Söderberg, Department of Nursing, Umeå University, Umeå, Sweden.

ABSTRACT

The purpose of the thesis is to elucidate the illness experiences of women with fibromyalgia (FM), a chronic pain syndrome which mostly affects middle-aged women. The thesis is focused on giving a view from the inside of the experiences of living with the illness. Data were based on interviews and scales. Fifty-three interviews were conducted with women with FM and 25 interviews with healthy women. Thirty women with FM and 30 healthy women completed three different scales. All the women with FM who participated in the studies were diagnosed according to the American College of Rheumatology criteria for the diagnosis FM. The tape-recorded interviews were analysed using content analysis and a phenomenological hermeneutic approach. The scales were submitted to statistical analysis.

Findings show that pain and fatigue strongly influence the women's life. The women used metaphorical language to narrate their lived experiences of pain. The use of metaphorical expressions was interpreted as being a way in which the women could disclose tacit knowledge. Using metaphorical pain language women with FM described their experience of pain as a like being tortured. The meaning of the lived experience of fatigue showed that the lived body becomes urgently present. In illness the surrounding world looks and feels different than it do in health, because the relation between the lived body and the environment is altered.

Thirty women with FM and 30 healthy women, matched on Type A behaviour, completed scales about sense of coherence (SOC), well-being and stress in daily life. Findings show that on a group level women with FM experienced a sense of coherence in life, despite a multiplicity of symptoms. When a median split was used to create high and low groups regarding SOC there was a distinction. The women with a stronger SOC perceived a greater well-being than the group with the weaker SOC. This result suggests that SOC can be used to identify women who may need extra support in managing to live with the illness.

The meaning of women's experiences of living with FM are illuminated in three major themes, i.e., loss of freedom, threat to integrity and struggle to achieve understanding and relief. The lives of the women with FM were strongly influenced by the illness in a variety of ways. There is a strong feeling of struggle in the women's narratives. The women described transitions in daily life pattern, family life, working and social life. They emphasised that they have to learn to live with the changes.

A model was developed on the basis of the findings from the studies performed, in order to provide a deeper understanding of the illness experience of women with FM. The main findings are discussed in relation to the model, which discusses the women's experiences of living with FM as a struggle for cure, palliation and consolation and a struggle against the illness, symptoms and suffering.

Key words: Fibromyalgia, Women, Lived experience, Pain, Fatigue, Transitions, Struggle, Dignity, Content analysis, Phenomenological hermeneutics