

DILEMMAS AND CONSEQUENCES OF CHRONIC DISEASE-LIVED EXPERIENCES OF COELIAC DISEASE AND NEUROPATHIC PAIN

Akademisk avhandling som för avläggande av medicine doktorsexamen
vid Sahlgrenska akademien vid Göteborgs Universitet kommer att offentligt
försvaras i lokal Arvid Wallgrens Backe, Hus 2, 2118, Sahlgrenska Akademien, Göteborg.
torsdagen den 27 september 2007, kl 13.00.
av Annette Sverker

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Avhandlingen baseras på följande delarbeten:

- I. Sverker, A., Hensing, G. & Hallert, C. "Controlled by food" – lived experiences of coeliac disease. *Journal of Human Nutrition and Dietetics* 2005; 18: 171-180.
- II Hensing, G.K.E., Sverker, A.M. & Leijon, G.S. Experienced dilemmas of everyday life in chronic neuropathic pain patients – results from a critical incident study. *Scandinavian Journal of Caring Sciences*. 2007; 21: 147-154.
- III Sverker, A., Östlund, G., Hallert, C. & Hensing, G. Sharing life with a gluten-intolerant person – the perspective of close relatives. *Journal of Human Nutrition and Dietetics*. 2007; 20: 1-11. In press
- IV Sverker, A., Östlund, G., Hallert, C. & Hensing, G. "I lose all these hours..." Exploring gender and consequences of dilemmas experienced in everyday life with coeliac disease. Submitted.



GÖTEBORGS UNIVERSITET

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DILEMMAS AND CONSEQUENCES OF CHRONIC DISEASE-LIVED EXPERIENCES OF COELIAC DISEASE AND NEUROPATHIC PAIN

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Background: A more patient-centred health care needs to be based on patients' and their close relatives' experiences of the daily life with a chronic disease. Coeliac Disease (CD) and Neuropathic pain (NP) are common chronic diseases where such knowledge is missing. Individuals with CD and associated gluten-free diet often experience a relief when they receive the diagnosis, but long-term follow-up have shown declined quality of life and self-perceived health especially in women. No treatment that gives patients with NP a complete pain relief is available. Patients need to learn to live with pain.

Aims: The overall aim of this thesis was to extend our knowledge of what it is like to live with a chronic disease, from the perspective of NP and CD. The specific aims were to explore the experienced dilemmas, consequences and strategies of patients with chronic NP, and of persons with CD and their close relatives.

Method: Qualitative methodology was used in all four studies, combined with a quantitative method in study IV. The critical incident technique (CIT) was chosen as the method for data collection, with a questionnaire on household activities for the fourth study. Interviews were carried out with 39 informants suffering from NP, with 43 informants suffering from CD, and with 23 close relatives to the CD informants. Questions were asked about occasions in their everyday life when they were hindered or reminded of the NP or CD. Interviews were transcribed verbatim and analysed qualitatively. Categories were identified and the analysis and results were continuously discussed in the research group and at seminars.

Results: A broad range of dilemmas, disturbances and consequences were experienced in the daily life with chronic disease. Emotional reactions, relationships and the management of daily life were the main categories of dilemmas experienced by the persons with CD. Failures, inability and restrictions were identified as disturbances in the everyday life with NP. Disease-related worries, management of daily life and disturbances in social life were identified in the interviews with close relatives. The overall pattern and types of consequences experienced in relation to dilemmas of CD were similar in women and men, irrespective of whether they were gluten-intolerant or close relatives, both women and men reported in the questionnaire that women had the main responsibility for household activities.

Conclusion: This thesis showed that persons suffering from CD or NP had several lived experiences in common regardless of the chronic disease. In spite of the differences in clinical presentation and treatments between the two diseases, there were several similarities in the variation and quality of lived experiences identified, and the influence of these in the men's and women's lives. A possible explanation to lower quality of life in women with CD compared to men might be the unequal distribution of household work. The informants pointed out that information and knowledge on the diseases and the necessary adjustments in everyday life were insufficient among personnel and in the society. This indicates that there is a need of knowledge improvements of chronic diseases in society.

Keywords: Burden of dietary restriction, chronic disease, coeliac disease, critical-incident technique, dietary dilemmas, neuropathic pain, next of kin experiences, quality of life.

ISBN: 978-91-628-7225-0

Göteborg 2007