

# Summary

## **Impact of potential disease Experiences of healthy women when cervical cellular changes are found by a cervical cancer screening program**

### **A field-research project**

This thesis is based on long-term fieldwork among healthy women who participated in a screening program for cervical cancer and were diagnosed with a potential disease: abnormal cells in a cervical smear test. The study was done in collaboration with the Department of Gynaecology and Obstetrics, Skejby Hospital, the University Hospital of Århus.

The aim of the study was to gain insight into the significance the women placed on the potential disease and how its incorporation in everyday life necessitated reviewing existing values and perceptions. The study focuses specifically on the women's understanding of the concepts of illness and disease, the role of their life history, and their contact with health professionals.

The basic scientific theory of the study is a phenomenological hermeneutic approach. The analytical method illuminated women's views and experiences during the course of illness and disease. The method is characterised by a dialectic process between spontaneous comprehension and critical interpretation. Twelve women were consecutively enrolled as participants. The research material was generated from fieldwork: participant observation and ethnographic interviews during the examinations and treatment of the women at the hospital, and interviews in the women's homes. There were 89 contacts included in the material.

The study showed the women were unprepared for the result of abnormal cells and that they were unaware of its significance and consequences. The result of the screening was interpreted as an incipient genital cancer; it initiated thoughts concerning life and termination of life. Some women expressed fear of an imminent death from cancer, others that a cancer would prevent them from having children. The result of the screen test was a releasing factor of fear; the dread of serious disease was so dominating for some women that they had difficulties in living their everyday lives.

Living through their fear showed to be a reflective process: for those who received surgery, the vegetative phase during their absence from work was an important period. The women gave significance to their daily life by, for example, relating to their family-history. Parts of the history of illness and disease of other family members had previously been unknown to the women. Through systematisation and interpretation of the experiences of family illness and disease, the history of the women slowly developed: a coherent story of a life in good health which, when influenced by the result of the test, changed to one of fear and anxiety.

Nevertheless, it was shown that over time the women were able to manage the fear. Through care from persons close to them and guidance from health professionals, they were able to continue life with new knowledge and a more differentiated self-perception or identity.

Health promotion and preventive medicine are in focus in health politics. Consequently, it is likely that an increasing number of patients will be healthy persons with a potential disease. The findings of this study demonstrate the importance of involving research of patient perspectives in ongoing professional and political discussions. This is necessary to secure the quality of care and treatment in future population-based screening programs.