Being in the treatment course for esophageal cancer - a qualitative study of Patients' and relatives' experiences and the process of decision making during the treatment period

Kaas Larsen, Malene; Birkelund, Regner; Mortensen, Michael Bau; Schultz, Helen

Publication date:
2019

Citation for published version (APA):
Introduction
Cancer of the esophagus is a serious and potentially lethal disease. Surgery and perioperative chemotherapy is the established treatment resulting in a treatment course of 6-8 months.

Aim
To explore patients with esophageal cancer and their relatives' experiences during the treatment period and the process of participation in treatment decisions.

Methods
The study employed a qualitative methodology, scientifically placed within a phenomenological-hermeneutic framework with a prospective longitudinal design. A field study with participant observations and interviews was conducted with 16 patients and 16 relatives. See figure below.

Results
Article 1: Themes related to patients
• Dealing with the definitive diagnosis
• Being between expert knowledge and everyday life knowledge
• Being in no man’s land

Article 2: Themes related to relatives
• Being an anchor on the sideline in uncertainty
• Surveying the scene of treatment
• Making decisions is not my department

Conclusion
Patients with esophageal cancer encounter an alien world of disease and treatment and are struggling to gain control of their new life situation. Maintaining everyday life activities was important and helped the patients and relatives deal with the diagnosis and forthcoming treatment. The patients and relatives felt they did not have any option but to accept and go along with treatment decisions. When it came to participating in decisions about treatment, relatives had a passive and subordinated role.

References:

Funding: Odense University Hospital, Louis-Hansen Foundation