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Who Cares? Fragmentation or Integration of Cancer Care

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Abstract

Background: New cancer treatments and increased accessibility of palliative care have resulted in improved treatment outcomes. Coordination and communication between different health care professionals and providers may impact patient satisfaction and quality of care. The phases of curative treatments, palliative and end-of-life care, are now less distinct and often overlap, which may challenge clinical decision-making and the assessment of the patient's prognosis. It is recommended that palliative care is integrated alongside acute cancer care and introduced earlier in the disease trajectory concurrent with ongoing cancer treatment and follow-up. Health care utilization can be defined as the description and quantification of how a patient uses health care services to improve a health problem and/or increase wellbeing. One of the ways of measuring the quality of care and the performance of a health care system is to analyze different aspects of health care utilization. Intensity of treatment and care at the end of life is a measure of quality and may identify areas of end-of-life care organization that are in need of improvement. Recent research indicates that certain socioeconomic factors might impact health care utilization and intensity of treatment and care at the end of life.

Aim: To explore different aspects of health care utilization for patients with complex cancer care trajectories in a changing cancer care.

Methods: In this thesis a combination of quantitative data, both population-based registry, survey (studies I-III) and qualitative data from focus group interviews (study (IV)), were used. The participants are patients with complex cancer care trajectories (studies I-III), nurses and physicians from acute cancer care and specialized palliative care at home (study IV) in the region of Stockholm, Sweden. The purpose was to explore health care utilization from diagnosis to the end of life.

Results: The results of studies I –III show several factors associated with higher levels of health care utilization; living alone, younger age, more advanced disease stage and multimodality treatment. In addition, the group with both acute cancer and SPC at home are a vulnerable group with higher levels of symptoms and unplanned/acute care, risking unnecessary care transitions. Study I (203 patients with head and neck cancer) revealed lower satisfaction with the amount of information received regarding diagnosis and treatment in the group having a palliative care referral. Study II (1718 patients with head and neck, gynecological, upper gastrointestinal or hematological cancer) found that nearly a quarter of those with both acute cancer and SPC at home care had multiple (three or more) unplanned hospital admissions. Study III (1726 patients with lung or pancreatic cancer) found increased levels of intensity of care when comparing the years 2010 and 2017, and a shift of care from inpatient to outpatient care. The results of study IV (23 participants in six focus groups) indicates uncertainty among health care professionals in both acute and palliative cancer care regarding their organization, mandate, and responsibilities as well as the prognosis of the patients. Participants from both settings (acute and palliative cancer care) discussed their responsibilities and it appeared to be clear for them who was responsible for symptom management (palliative care) and cancer treatments (acute cancer care). However, uncertainties about the overarching, holistic responsibility.

Conclusions and clinical implications: In summary, our findings describe cancer care in one large region of Sweden and issues related to fragmentation and health care utilization. These issues have consequences that may impact patients, informal caregivers, the health care system, and health care professionals in terms of quality and safety. There are several suggestions for improvements, such as a focus on integration of care on all levels (policy and organization) and building a system steered primarily by the quality of care in a person-centered integrated system.

Keywords: Health care utilization, end-of-life care, integrated care, palliative care, clinical decision-making

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