

Patient involvement in the decision making process of transfer: palliative patients' perspective

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Background

Seamless integration of patient centered care is a challenge when transferring palliative patients from one setting to another. Demographic changes (people living longer, having multiple chronic diseases etc.) and social changes (more people living alone), make palliative care more complex and transfers more usual. Transfer to another setting (from home to hospital or hospital's palliative unit etc.) is needed for medical (symptom control; complications...) or social reasons.

Palliative patients' involvement in the decision making process when being transferred is however unclear.

This research focuses on palliative patients' involvement: what are the perceptions and expectations of palliative patients towards involvement in the decision making process about transfer?

Methods

Semi-structured interviews with 20 palliative patients in different settings: home, nursing home, hospital's palliative unit, oncology unit, palliative day care center. Variation in age, gender and main pathology was taken into account. A grounded theory approach was used to analyze data.

Findings

Patients perceived transfer from home or nursing home to the hospital as the physicians' decision. Patients felt more involved in the decision making process if the transfer concerned the palliative care unit or palliative day care center. In hospital settings, patients reported to be hardly or not involved. On the contrary, they were informed without mutual deliberation about the feasibility.

In general, patients expected to be involved in transfer decisions. There was variance, depending on age and setting. Younger patients expected active involvement. Elderly patients in nursing homes preferred the general practitioner to take decisions. In home care situations physicians' decision for transfer to the hospital was accepted, due to patients' medical condition. The perceived need of involvement in the decision process was high when patients were transferred from the hospital to the home situation.

Discussion

The findings show room for improvement for palliative patients' involvement in decision making. Patients accept less involvement in transfer decisions to the hospital, as they might experience this as a medical decision. Patients' age is an influencing factor for shared decision making. Further research on transfer conditions and patient involvement is recommended to optimize patient care.