PATIENT AUTONOMY IN HIGHLY TECHNOLOGICAL CARE ENVIRONMENTS FROM A CARING PERSPECTIVE

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Abstract

Background

Patients in highly technological care environments are severely ill, and are often suffering from a reduced physical and/or cognitive capacity following their illness and treatment, making them exceedingly vulnerable. The most severely ill patients are cared for in the intensive care unit. These vulnerable persons are cared for in an environment traditionally associated with a paternalistic care culture, which implies that patients are at risk of being overridden in relation to ethical issues, and of having their autonomy compromised. The question is whether it is possible for the patient to be capable and autonomous in this context. Advanced home care involves an increasing amount of advanced medical technology, and is then to be characterized as a highly technological care context. The advanced home care context is different from the intensive care context in that the patients are not sedated, they are cared for at home, and they are expected to be the masters of their home environment. They recognize their home as private territory which gives them the right to decide what to do and how and when to do it. Their need for technology and care from formal/informal carers points to a vulnerability on the part of the patient, risking a hidden paternalism in terms of overprotectiveness, including excesses of care. These aggravating circumstances may exert an influence on the patient's everyday life, threatening the patient's possibilities of remaining/becoming autonomous. This thesis is a response to the absence of consensual understanding in nursing of the concept of patient autonomy in a highly technological care context, as well as an answer to the lack of knowledge of the phenomenon of patient autonomy in highly technological care environments from the patient perspective and in a caring context.

Aim

The overall aim of this thesis was to describe and elucidate patient experiences of autonomy in highly technological care environments, and to create an extended understanding of the concept of patient autonomy in a highly technological care context, from a caring perspective.

Methods

In answering to the aim of this thesis, a diversity of qualitative methods for data collection and data analysis was used. Two empirical studies comprising individual patient interviews (n=23) within highly technological care environments were carried out, in intensive care (II) and in advanced home care (III). The patient experiences were analyzed through inductive content analysis (II) and descriptive phenomenology (III). Theoretical development was accomplished through a concept analysis (I) from scientific literature, and a concluding metasynthesis (IV) of the previous studies (I-III).

Findings

The concept analysis (I) revealed that increased vulnerability was the antecedent of patient autonomy in a caring context. It further showed that patient autonomy is not to be understood as absolute but as changing throughout the care episode. The interviews with patients being cared for in intensive care described patient autonomy in this highly technological care environment as a “trajectory towards partnership in care depending on state of health and mutual understanding”. Patient autonomy, in advanced home care including advanced medical technology, was differently described as “befriending everyday life when bringing technology into the private sphere”. The findings of the concept analysis (I) as well as the findings from the empirical studies of patient experiences of autonomy (II-III) resulted in the concluding theoretical framework (IV), adding new knowledge to ameliorate the clarity of the concept. A tentative framework, the Control-Partnership-Transition framework of patient autonomy, was delineated. This framework comprises four strategies, the strategy of control, of partnership, of trust, and of transition, used by patients to preserve or obtain autonomy in highly technological care environments. To experience autonomy, patients in highly technological care environments want to be considered as capable agents, and not only as a vulnerable person in need of care. Their thoughts and experiences reveal that patient autonomy should be understood as a process, something that changes over time, and is dependent on their health conditions as well as on others around them and the care environment. The knowledge obtained could be used to facilitate the adherence of health care professionals to ethical principles and codes related to patient autonomy, hence strengthening the patients’ position in regard to their autonomy.

Keywords: autonomy caring context co-determination concept analysis concept development control descriptive phenomenology highly technological care inductive content analysis
metasynthesis partnership patient experiences theoretical development transition trust vulnerability