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Taking control: what do we mean and how can it work for parents and children with chronic illness? A systematic review

Vallianatos S

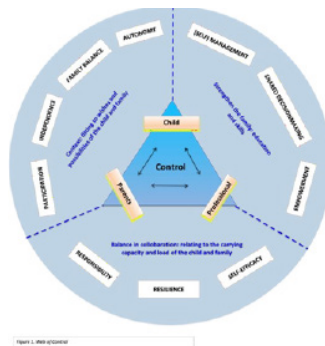
Dutch Knowledge Centre for Children's Palliative Care, The Netherlands

Background: Personalized care and taking control are well known phrases in the field of (child) healthcare in many countries. Given the shift in health care to person-centered care and the role and responsibilities of persons themselves, attention is needed for what we mean with 'taking control'. Childcare is special because when we talk about clients, we are referring to a sick child within a family. Also, more families with children with chronic illness are expected to deal with the care of their child at home. The aim of the review is to get a deeper understanding about the concept of 'control' in the context of families with a child with chronic illness at home and how this is operationalized. Methods: A systematic search was performed (n=1266). In total 78 articles and guidelines were included for qualitative synthesis.

Results: Eleven different terms were identified for control or related issues. Together they are needed to understand the scope of the concept of control. They are presented in the 'Web of Control', helps illustrate what 'taking control' means in practice, and summarizes the inter-relationship between the terms needed for operationalization of 'control'.

A wide variety of interventions were described as having an influence on control. None of them did have increasing control as main goal. Also, a variety in the instruments are used to measure outcomes in the studies. It is not clear to what extent these instruments are correlated with the degree of control.

Conclusions: In practice, control and issues related to it are introduced as separate topics, but when we consider the shift in health care to person-centred care, a more integrated approach is necessary. The Web of Control is developed based on these insights. By providing an overview, the model helps to evaluate the concept of control in practice.



Biography

Stephanie Vallianatos is an innovator, advisor and researcher in the broad field of healthcare. She is trained as a nurse and studied the master Healthcare management. Since 1991, she worked as a district nurse and care-manager in de home care. From 2006, she started her own business as innovator and project leader to focus fully on quality improvement in healthcare with focus on patient's perspective. In recent years, her activities switched more to advice and research. Driven by the fact that innovations really stick, she wants to deepen the connection between practice and science. Here portfolio contains various projects in the social domain, with projects in the field of intensive childcare as a common thread. Parallel to her work, she started a PhD research about 'How control plays a role in the interaction between the care-professional and the family with a medical care-intensive child in order to achieve better outcomes

stephanie@vallianatos.nl