

CHILDREN AND YOUNG PEOPLE LIVING WITH HOME MECHANICAL VENTILATION TREATMENT

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Background

Developments in medical technology, care and treatment have increased the survival of children with serious illnesses or injuries, which have contributed to a shift of health care interventions. This means that a raising numbers of technology-assisted children with chronic illnesses can live their lives in their own homes. One such group comprises those using home mechanical ventilation (HMV).

Children with HMV are a mix of people with varying underlying medical conditions such as neuro-muscular diseases and primary pulmonary conditions. In common is alveolar hypoventilation. Ventilator support may be required either during sleep or over 24 hours invasively (with tracheostomy) or non-invasively (with a facemask).

Aim

The overall aim of PhD thesis in progress is to investigate and develop knowledge concerning ventilator-assisted children and young people's experiences of daily life, including a family and close related perspective.

Importance of the thesis

This project will create knowledge about a new form of childhood and parenthood to a group of growing children who risk being excluded from future education, work and social life. These children and young people have the right to a good and safe life in participation. They have a positive psychological development, like other children, and can contribute to valuable work in our society, provided they are given the opportunity.



A multi-disciplinary cooperation

– a prerequisite for developing a sustainable participation in society including a social, economic and environmental aspect

Children with respiratory support at home will be in need of highly qualified support from the community. Being cared for at home with medical technology is a complex interactive process involving both the person in need of care but also family, personal care assistants, social care and professional health care.



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