Children living with Home Mechanical Ventilation

The everyday life experiences of the children, their siblings, parents and personal care assistants

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ABSTRACT


Aim: The overall aim of this thesis was to explore the everyday life experiences of living with home mechanical ventilation (HMV) from the perspective of the children and their siblings, parents and personal care assistants.

Methods: Study I describes the experiences of personal care assistants (PCA) working with a ventilator-assisted person at home, based on qualitative content analysis of 15 semi-structured interviews. Study II, using qualitative content analysis focuses on exploring everyday life experiences from the perspective of children and young people on HMV, by means of interviews with nine children and young people receiving HMV. Study III, using a phenomenological hermeneutical method, illuminates the everyday life experiences of siblings of children on HMV, based on ten interviews. Study IV explores health related quality of life, family functioning and sleep in parents of children on HMV, based on self-reported questionnaires completed by 85 parents

Main results: In the care context of children with HMV is it important to acknowledge that children on HMV may experience themselves as fit and living an ordinary life, just like their healthy peers. At the same time the results of this thesis indicate that everyday life in the context of HMV is a fragile construct that in some respects resembles walking on a tightrope. This fragile construction also includes and affects the everyday lives of the families and PCAs. The siblings' stories mirror a duality: being mature, empathetic, and knowledgeable while simultaneously being worried, having concerns, taking a lot of responsibility, being forced to grow up fast, and having limited time and space with one’s parents. One out of four parents reported moderate or severe clinical insomnia. Compared to previous research, which addresses health-related quality of life (HRQoL) among parents of children with long-term conditions, parents of children with HMV reported low HRQoL and family functioning. The PCAs described working in an environment where the limits were indistinct and their responsibility was complex and in which they simultaneously felt pleasure and loneliness, and experienced ethically challenging situations.

Conclusion: This thesis contributes with new knowledge how everyday life can be for families where a child has HMV, where health and vitality seem to coexist with a fragility and vulnerability to the outside world. With increased knowledge, it is possible to develop care strategies that support children with HMV, their families and personal care assistants where challenges are identified and understood - and the families' unique knowledge and strengths are supported and embraced.

Keywords: Home Mechanical Ventilation, children, siblings, parents, family, personal care assistants, health, family functioning, everyday life

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