



The Perspective of Families With a Ventilator-Dependent Child at Home. A Literature Review



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ABSTRACT

This literature review gives an overview about the existing research concerning the experiences of families with a child with ventilation at home. The number of children with home-ventilation is increasing. Children who receive homecare have the possibility of growing up in their familiar environment and participate in social life. In comparison to children living in institutions, children at home show advantages in their physical, psychological, emotional, social and cognitive development. However, homecare of a child with ventilation places high demands on all family members. Parents assume divergent roles and live with losses. Especially mothers feel isolated, partially through self-imposed isolation. While parents are concerned about this dilemma, talk about their anxieties and strive for stability, children focus on other aspects of their life. They see the ventilator as a positive technique that helps them breathe. The children underline the importance of friends and would like to meet them without nurses in attendance. They strive for normalcy and independence like healthy children, asking for acceptance of themselves and their wishes. There are only few studies about the experience of families with a child with ventilator. Most studies are from the mother's perspective. Parents and children ascribe different importance to the ventilation. Further research should usefully explore the experiences of families with children using home-ventilation. The different perspectives of all family members have to be taken into consideration.

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Introduction

Annually, 10,000 children and adolescents are cared for by home care services in Germany (German Federal Statistical Office, 2013). One group of patients are children and adolescents who need long-term ventilation. At present, an estimated 2000 children in Germany are ventilator-dependent due to a traumatic brain injury, muscle and nerve disorders, infections, malignant diseases or a premature birth (German Federal Association of pediatric home care, registered association, 2012).

The estimation of the incidence and prevalence of children with ventilation is problematic in Germany because no register of patients with ventilator-dependence exists (Geiseler, Karg, Börger, Becker, & Zimolong, 2010).

Long-term ventilation is defined as:

"...any form of invasive or non-invasive continuous or intermittent ventilation therapy, in due consideration of the primary disease is not foreseeable that a complete weaning of ventilation within a reasonable period of time can succeed."

(Medical advisory service of the German association of statutory health insurance funds (MDS), 2004, p.10).

A time frame of six months is defined as reasonable because it can be assumed that in the case of permanent ventilation questions will occur concerning the provision of medical aids, placement and home care (MDS, 2004, p.10). While the prevalence of the group of children and adolescents who are ventilator-dependent is comparatively small, they are exposed to specific health risks and burdens and they have special needs, which present significant challenges for the health professions when the patient is cared for at home (Peter & Richter, 2009).

In the past, the use of respirators was limited to intensive care units, although in recent years the use of respirators at home has steadily increased (Zernikow, 2008).

Since the establishment of Diagnosis Related Groups in Germany in 2003/2004, the length of stay in hospitals has been drastically reduced (Braun, Buhr, Klinke, Müller, & Rosenbrock, 2009). This reduction of length of stay affects the utilization capacity of intensive care and thus the care of patients with a dependence on ventilation. Owing to the statutory provisions in the German Social Code XI and the UN Convention on Rights of People with Disabilities, inquiries for care at home for patients with complex needs has steadily risen (Büscher, 2011; Ewers, 2003; Ewers & Schaeffer, 2002; Geiseler et al., 2010; Lademann, 2007).

Children with ventilation who receive home care are able to grow up in their family environment and participate in social life. In comparison to children living in institutions, children at home show advantages in their physical, psychological, emotional, social and cognitive development (Kirk, 1999). Homecare supports a child's own identity development. By participating in activities that convey implicit or explicit familial values and beliefs, they can acquire social skills they would not have been exposed to in an inpatient setting (Kirk, 1999). Both children and parents benefit from home care, because now the center of family life is located in the protected home atmosphere, away from the prolonged hospitalization (Wang & Barnard, 2008). Despite the advantages of home care for the patients themselves, it is important not to lose sight of the family as a whole. Indeed, managing a chronic disease is described as a process in which the whole family is involved (Corbin & Strauss, 1998; Metzger, 2007; Schaeffer & Moers, 2008). Caring for a child needing ventilation at home is perceived as being especially burdensome when compared to other disabilities. The reason for concern is the constantly life-threatening condition of the child (Montagnino & Mauricio, 2004). These children are dependent on life support and require the most complex care that is given outside a hospital. There are

significant risks involved in caring for a child at home. This implies that families of children who are ventilator-dependent have more and different needs than those of children with chronic conditions or families of children requiring other technologies (Wang & Barnard, 2004). Therefore, the focus of this review is placed upon the experiences of the children who are ventilator-dependent, their siblings and parents from their individual perspectives.

Aim

This literature review is part of a Grounded Theory study about the experiences of families with a child with ventilation at home in Germany. Strauss and Corbin (1996) advise a literature analysis during the research process to contribute to the theoretical sensitivity for the topic. Hence, the aim of this review is to explore preconceptions and identify which issues were central to this field. Additionally, we attempt to discover preliminary findings and identify gaps about the international knowledge of the experiences of families with a child needing ventilation at home, as seen from the families' perspective (Dunne, 2011). Furthermore, the literature review is also conducted to develop questions for our own empirical phase.

Consequently, the following questions will be considered in this review:

- How do families experience everyday life with a child/adolescent who is ventilator-dependent at home?
- What burdens are described by families of children and adolescents who are ventilator-dependent?
- What coping strategies are used by the family members?

Method

The review presents the relevant literature exploratively and systematically and was guided by the method of Polit, Beck, & Hungler, (2004). This literature review process included eight steps as outlined in Fig. 1. As the figure shows there is one feedback loop with the opportunity to retrace in an early step in search of more literature.

The literature research was performed using the computer databases MedLine®, Cinahl™, Scopus®, EMBASE, Psyc/INFORMA and PsynDex®. These were searched systematically using the following terms: respiration artificial, artificial respiration, mechanical ventilation, long-term ventilation, ventilator-dependent, homecare, ambulatory care, caregiver, children, experience*, situation, negotiate, cope and coping. The terms were linked with AND and OR. Additional research was performed on the prevalence of ventilator-dependent children and adolescents on the websites Destatis®, Statista® and GBE – Bund, which provide statistical data.

At the beginning of the literature research, no limitations were made to obtain a preliminary overview of when and in which countries research has been conducted concerning the experience of children with ventilation at home. The review was conducted in a multistage process, presented in Fig. 2. The computer-based search yielded 204 results. In addition, three studies were found by hand-search in journals and reference lists of relevant publications. In a first step, all duplicates were excluded. Three studies were excluded due to the lack of an abstract. In a next step, the search was limited to documents written in English or German. Consideration was given to studies published between 1990 and 2015. This decision was based on a paradigm shift in childhood research (Heinzel, Kränzl-Nagl, & Mierendorff, 2012). During the late-1980s and 1990s, a new sociology of childhood arose highlighting

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