

Home-ventilated children. Daily life with a ventilator-dependent child from the perspective of the family: A literature review

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Background

The number of ventilator-dependent children is increasing steadily. The reasons are numerous: due to medical advances preterm infants have better chances of survival, children with life-limiting diseases are increasingly cared for at home and seriously ill children can be cared for at home thanks to new technological possibilities. Ventilator-dependent children, who receive homecare, are able to grow up in their familiar environment and to participate in social life. In comparison to children living in institutions, these children show advantages in their physical, psychological, emotional, social and cognitive development.

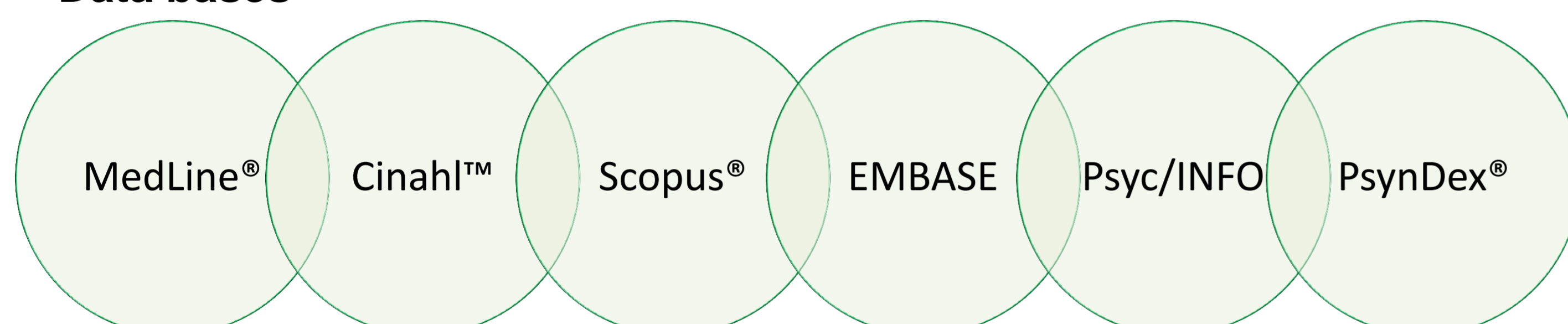
However, homecare of a ventilated child places high demands on all the members of the family. Managing a chronic disease is a process in which the whole family is involved. The focus of this review is directed at the experiences made by the ventilated children and their parents from their individual perspectives.

Aim

The aim of this literature review is to describe the existing knowledge about the experiences of families with a ventilator-dependent child at home from the families' perspective.

Method

Data bases



Keywords

artificial respiration OR ventilator-dependent OR long-term ventilation

AND

caregiver OR home care OR ambulatory care

AND

experienc* OR coping OR cope OR situation OR negotiate

AND

children

n=204

n=3

hand search

after duplicates removed n=95

after 1st screening title and abstract n=19

after 2nd screening full-text articles assessed for eligibility and screening with CASP n=13

Inclusion criteria

- ✓ Language: English or German
- ✓ Published: 1990-2015
- ✓ Studies and reviews of invasive or non-invasive home-ventilated children that highlight the experience and/or coping behavior from the perspective of one or more family members

Results I

Twelve studies and one review were included, three of them from the perspectives of children and adolescents. It is remarkable that the studies doing research on the family perspective predominantly reflect the perspective of parents, mostly of mothers. Only Carnevale et al. (2006) examined the view of the siblings in addition to the perspective of ventilated children and their parents.

Parents' Perspective

Many mothers quit their job to cope with the care of their child. They **feel isolated**, partially through self-imposed isolation because they are exposed to difficult ethical debates.

Living with a ventilator-dependent child requires **absolute commitment** of the parents. After hospital discharge the parents assume, partly unprepared, a variety of tasks.

In addition to the child's ventilator-dependence there are **dependencies** that affect the whole family. The dependence on nursing services, doctors, therapists and healthcare workers is burdensome and leads to frustration.

Families with ventilated children are often confronted with negative reactions from their environment. However, they **have no choice**-to decide against ventilation would mean letting the child die.

With self-imposed standards mothers try to keep the child's health condition stable in order to maintain the care of the child at home as well as everyday family life. The motivation for this effort is fundamentally **striving for stability**.

If a nursing service is involved, the parents **feel disturbed in their privacy** and restricted in their children's upbringing by the constant presence of the caregivers.

Results II

Children's Perspective

Ventilator-dependent children do not wish to be reduced to their ventilation. They appreciate their lives, irrespective of all limitations. Similarly, they expect to be **respected** by their fellows as a person.

The children want to **live like normal children**. They want to meet their peers without the support of nurses or parents. Home care services are not geared to the needs of these children that go beyond the personal care.

Ventilator-dependent adolescents **strive for independence** in their daily lives and relinquish the support of caregivers in favor of their independence.

The children **see the ventilator as something positive**. They report that their ventilator has saved their life, supports breathing and gives them more power.

Conclusion

There are only a few studies about the experience of families with a ventilator-dependent child. Most studies are concerned with the mother's perspective. Parents and children attribute different importance to the ventilation. Parents are concerned about this dilemma, talk about their anxieties and strive for stability. Children focus aspects that have nothing to do with their ventilation. They underline the importance of friends. They strive for normalcy and independence like healthy children, asking for acceptance of themselves and their wishes.

Implications

There is a need to explore further the experiences of families with a home-ventilated child, taking into consideration the different perspectives of all family members, in particular those of the ventilator-dependent children and their siblings.

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