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# **When technology enters the home – a systematic and integrative review examining the influence of technology on the meaning of home**

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## **Abstract**

**Aim:** To analyse and synthesise the research that has investigated the experience of home in relation to home mechanical ventilation (HMV).

**Method:** Systematic integrative review. Four electronic databases (CINAHL, PubMed, Scopus and ISI Web of Knowledge) were searched between January 2010 and April 2017 as well as reference lists of included studies. Quantitative and qualitative studies meeting the inclusion criteria were critically appraised. Study findings were inductively analysed and synthesised using the integrative approach.

**Results:** Twenty-one studies were included in the review. Two main themes emerged: home and at home-ness and altered inter-personal relationships. The literature suggests that the technology alters the meaning of home through its structural and conceptual reconfiguration. Paradoxically the space is experienced as both a home and a workplace which creates tensions and ambiguities for HMV users/families and care workers. HMV users and their families attempt to recreate a sense of home and identity while gaining control over space and decision-making. Nevertheless, the home is seen as the preferred place to live and close bonds can develop between the different actors.

**Conclusions:** The literature suggests that the transformation of the meaning of home by the presence of technology and workers poses challenges that are often under-recognised. Health care professionals and personal care assistants need preparation for the complexities of working in the home setting in addition to clinical aspects of caregiving. Home adaptations need to be carefully planned and include design principles that retain 'at homeness' while enabling the creation of a safe workplace.

**Keywords:** Systematic literature review, home mechanical ventilation, assistive technology, home care, home health care, technological caring, health geography

Word count: 4459 words

## Introduction

The home is often conceptualised as a place of shelter and privacy and a place for socializing with others where key life events are shared. Thus the home is more than a physical space, it possesses multiple meanings associated with identity, safety, security, privacy, control, memories and nurture (1). However, this idealisation has been criticised for neglecting that the home can also be a place of oppression, despair and loneliness (2). The home can also be a site for care-giving and care-receipt. Since the 1990s the European health care system has undergone changes in service organization and provision that has led to the transfer of care from the hospital into private homes. Consequently, the home has become a changed geography (3) that risks becoming a public sphere due to its redefinition as a work-place for various health care professionals (HCPs) and personal care assistants (PCAs) (4, 5). The nature of caregiving within the home has become increasingly complex and includes the use of ventilators. Today home mechanical ventilation (HMV) is a well-established treatment in the Western world for children and adults suffering chronic respiratory failure, i.e. alveolar hypoventilation (6, 7). This paper examines how the presence of technology and health care workers influences the values and practices associated with the home in the context of HMV.

### *On the concept of home and nursing*

While the home reflects a person's identity, status and culture (8, 9), certain spaces are loaded with more private values than others, such as the bedroom and bathroom (4). Indeed, the Norwegian nursing philosopher Kari Martinsen (10) claims that a place where you can dwell provides a feeling of belonging. Such a place she says, metaphorically 'sings' beautiful songs. However, places and rooms can scream and cry out when this sense of belonging is lost. The phenomenologist van Lennep (8) writes about loss of habitableness when a room has been neglected and worn out. Related to this, an analysis of Scandinavian nursing studies analysed the meaning of the concept 'at-homeness' in connection to illness and revealed that athomeness occurred through a continuum from being metaphorically at-home to being metaphorically homeless (11). The nursing environment has long been considered as a metaconcept within the discipline. While geography has adopted a human sciences perspective through the emergence of the discipline of health geography, Nursing has not significantly adopted a geographical orientation in research or in underpinning practice (12, 13). However, a nursing geography has evolved through a philosophical foundation grounded in existentialism and phenomenology (14, 15) meaning place (location) and space (the experienced meaning people ascribe to places) is considered as individually lived.

### *On the concept of technology and health*

Technological developments in medical and health care practices have advanced care and treatment (16). However, the high value placed on medical technology (17, 18) and its presence in the private home risks changing the feeling of at-home-ness (19, 20). Idhe (18) describes how, from a phenomenological perspective, technological devices are lived bodily. They are perceived as both a part of and an extension to the body (21, 22) that offer the possibility of maintaining relationships with others and living a life beyond the home (19, 23). NN and co-workers (24) have interpreted such statements as examples of technology as lived.

### *On living with a ventilator*

HMV has become a well-established treatment regimen in western society that can be administered either invasively through a tracheostomy or as a non-invasive treatment via a face or nose mask. People may need HMV for part of the day or continuously for 24 hours. Their need for HMV is associated with alveolar hypoventilation often due to chest wall malformations, neuro-muscular conditions, congenital injuries and trauma to the spinal cord (7, 20, 25).

Increasing numbers of children and adults are living at home with a ventilator. Analysis of the Swedish HMV register (26) discovered that 530 new HMV users were registered between 2011 and 2015. A European survey (27) involving 16 countries and 329 centres estimated that the prevalence of HMV users was 6.6 per 100.000 inhabitants with the highest numbers in France, Portugal and the Nordic countries. Studies suggest that there has been a rapid increase in HMV treatment in recent years (28-30) which may relate to a growing group of people with obesity hypo-ventilation syndrome (26, 28, 31).

Research has shown that there is a lack of knowledge among HCPs in general concerning HMV (e.g. 20, 30, 32, 33) which may be because expertise in the area is centralized in specialized respiratory units. This is concerning as it is important that HCPs caring for ventilator-assisted people in private homes are not only competent managers of the technology but that they understand how the technology and their own presence might impact on the home.

### *Theoretical perspective*

This paper is grounded in a caring science perspective (10, 34) whose fundamental principles are seeing human care as a natural responsibility to others (*caritas*) and as doing good (*ethos*). Moreover, it implies the alleviation of human suffering (35). Consequently, professional care is seen as involving a greater responsibility for the delivery of care as HCPs are educated and paid to care in a way that maintains health, integrity and life and alleviates suffering. Thus, research from a caring science perspective provides knowledge about the experiences of illness and disease, the delivery of care and how it may be improved.

### **Aim**

The aim of this integrative literature review was to analyse and synthesise the research that has investigated the experience of home in relation to HMV. The review was guided by the following questions: how does the presence of a ventilator and related equipment change the experience of home? How does the presence of and support from HCPs and PCAs change the experience of at-home-ness?

### **Method**

The systematic literature review used an integrative review design (36-38) that followed the approach of Whittemore and Knafl. This approach enables the summarizing and synthesising of research findings from studies using diverse methodologies (both empirical and theoretical papers).

### *Data collection*

A systematic search of four electronic databases (CINAHL, PubMed, Scopus and ISI Web of Knowledge) was conducted for the period January 2010 to April 2017 using a range of search terms. Search terms for CINAHL and PubMed databases were identified, controlled and also used as a guide for the two other databases which work with free search terms. The searches were done in close collaboration with a librarian at the department for Professional Services, at the University's library. Strategies selected were the basic search terms 'Patient', 'Adult', 'Child', 'Family', 'Home' and 'Ventilator'. These basic terms were refined to synonymous terms and controlled in each database as related terms. All terms were then systematically combined and searched for in the various databases. The inclusion criteria were: focus on the HMV experience; data collected from HMV users (child or adult), family carers, health care professionals or personal care assistants; empirical, secondary research or theoretical papers. Papers were excluded if they focused on the clinical management of HMV (e.g. ventilator

management, pressure area care), aetiology or epidemiology of HMV (e.g. prevalence studies, mortality/morbidity studies).

In total, 114 records were identified by the electronic database search for potential inclusion (Fig 1). After the removal of duplicates each title and abstract were screened by both authors against the inclusion criteria. Following assessment of abstracts, 45 full papers were retrieved for further screening with 21 articles being included in the review.

*Insert Figure 1. Flowchart*

No additional papers were identified from the reference lists of included papers. Of the 21 papers included in the review, 15 used a qualitative approach, four a quantitative approach, one was a mixed-method study and one was a case study. The data set represents publications from eight countries (Table 1.). The total number of research participants constituting the data set was 493 which included patients, family members, HCPs and PCAs.

*Insert Table 1.*

#### *Appraisal and synthesis*

All articles were read, re-read and critically appraised by both authors in relation to credibility, robustness and the review aim (36). As our dataset included research conducted using a range of methodologies we used Hawker and co-workers' (39, appendix C&D) guidelines in appraising each study (Table 1.). No papers were excluded on the basis of the quality assessment. The findings from each paper were summarized and transformed into separate matrices to enable the relationships across studies to be explored. Codes identified within each article and across studies were compared, pooled and then abstracted into subcategories and categories (Table 2). The latter were synthesized and presented in a narrative style. Table 3 presents the development of one category.

*Insert Table 2.*

*Insert Table 3.*

## Findings

Two main categories emerged from the synthesis: experiences of home and at-home-ness and the influences of altered inter-personal relationships (Table 2).

### **Experiences of home and at-home-ness**

Studies highlight how at the beginning of living with a ventilator at home there is a need to rearrange and redefine the home in response to the new life situation (40-43). As well as structural reorganisation, the home now becomes loaded with new and significant meanings and by becoming a work-place for HCPs and PCAs is transformed into a public environment (20, 44). There is a risk that the home becomes a place of loneliness with feelings of being 'locked-in' (45) but it may also be a place where new friendships develop and a place from which to reach out to the world outside (23, 46).

#### *The need to recreate home*

Starting HMV treatment involves moving from a hospital environment to the home accompanied by technology and is both a life-changing and life-saving event (42, 44, 46). This necessitates multiple re-arrangements and changes to the home environment. The new form of living and refurbishments often requires an increased domestic space that could host the equipment as well as provide an appropriate working environment for HCPs and PCAs i.e. hygiene and ergonomic requirements (47). Research highlights the importance of ensuring that the design of any refurbishments integrates the technology into the existing style of the home and fits with habits of social interactions (41). Manhas and Mitchell (44) described how physical changes in the home can interfere with families' connection to their lived space as the presence of medical equipment means that the home no longer resembles a 'normal' home. Indeed a secondary analysis (19) of 35 interviews with HMV users revealed how the home risked being altered into a hospital in miniature not just as a result of the influx of equipment but also due to the imposition of routines, values and surveillance associated with hospital care being transferred into the home environment.

While the studies reported that there was a consensus on the home being the preferred place to live, it involved changes in responsibilities, roles and practices within the home setting. The home could become a site for education as family members and PCAs were taught how to care for the HMV user (41, 47-49). However, these new roles, activities and routines could further medicalise the home as they extended the nature of domestic practices (42, 46, 47).



Practical issues have also been highlighted. The physical adaptation of the home environment or moving to a larger home may place a demand on personal finances and delay discharge (40). Dyrstad and co-workers (43) found that domestic refurbishments were planned too late with the installation of adaptations such as ramps, lifts and alterations to toilets and bedrooms incomplete.

### *Home as a part of identity*

Using the term 'dependence' in relation to HMV may be considered as having a static and negative social connotation. Gibson and co-authors (50) argue that the terms connective-ness or connectivity is better suited when it comes to a description of a life on a ventilator. This points to an identity established on being in an open system and an identity in motion. Furthermore, that a person's actions and productions may say more about a life on a ventilator than focusing on the machine and medical equipment. Indeed HMV treatment may be seen as a time of renewal and incorporating a tension between sustaining and/or losing oneself (42). In a study based on interviews with 35 people who were totally reliant on ventilator treatment to sustain their life, the home was described as the place where you find solutions to your ideas and plan life projects (51). Thus the home was associated with being a place of creativity. The home was also associated with being a place for socializing with others and to be active in (41, 46, 51) – a place where friendships are developed with PCAs and where you “do” a family (50).

A life with HMV may result in feelings of social exclusion and of existential loneliness (19, 23). Parents of children with HMV (20, 52) described their inability to leave the home. Consequently, socializing via the internet becomes important (20, 51). However, leaving the home is no longer a taken-for granted event as it involves learning and planning about what equipment needs to accompany the HMV user (41). For parents, leaving home is loaded with a double meaning in terms of preparing the child for a grown-up life. Thus, finding appropriate and supportive PCAs is important in promoting independence (44, 47).

### **The Influence on Inter-Personal Relationships**

The included studies highlight how the presence of technology influences and mediates relationships within the home. This reflects how the presence of HCPs and PCAs combine with the technology itself to change the home environment and its meaning. The studies have largely focused on the relationship between the family/HMV user and HCPs and PCAs,

although a small number of studies (45, 50, 53) have considered the relationship between the family and the HMV user themselves.

### *Close connections*

Studies describe the intense relationships that develop between patients, family, PCAs and HCPs due to their close physical proximity to one another in the home as a result of the nature of caregiving and the need for patient surveillance (33, 45, 47, 50, 53). Close relationships also develop due to the constraints patients experience in physically leaving the home which may mean that their social lives revolve around their PCAs (23, 51). Indeed the presence of PCAs in the home can make others disinclined to visit (23). Consequently the only 'visitors' to the home may be HCPs and PCAs (33, 47, 48).

Families position their relative as vulnerable (33). Consequently, family members feel a sense of obligation and responsibility towards their child, parent or partner and a need to ensure that both the quality of care they receive and the quality of life they experience is optimized (53). To achieve these goals their responsibilities widen as their role incorporates advocacy and they develop 'professional' expertise and skills in caring for a person on a ventilator (44, 48, 53). However, engaging in these activities comes with personal costs as family members may feel that they have sacrificed their own lives and become imprisoned within the home under surveillance from services (45, 51, 53, 54). Nevertheless, they describe a sense of achievement and pride in their caring and the quality of life they are providing for their relative (53).

PCAs similarly describe feeling an intense sense of responsibility although this was associated with an awareness that the HMV user's life was dependent on their care and their management of the technology (33, 47). Respecting the HMV user's (and their families') values, norms, traditions and habits is seen as fundamental in developing positive relationships (20, 54). The close proximity of home carers, HMV users and family members may lead to the development of close emotional connections (19, 33, 44, 47, 48). Although at the same time working in the home can be boring, lonely and isolating for HCPs and PCAs due to the lack of co-workers.

### *Battles for control*

Many of the included studies describe the conflicts between the different groups within the

home which emanate from battles for control over expertise and over the environment itself (20, 44, 46-48, 53, 55). These studies reveal the core tension in how the home is defined and that while it is a home for patients and family members, it is a workplace for professionals and home carers (20, 33, 47). Families can feel that their homes have been invaded by strangers and the association of home with privacy has been lost (54). Studies suggest that there may be a battle over the control over the home environment in relation to the organisation of daily life, who can come into the home (and when) and its spatial organization (20, 43, 47, 48). This can extend to determining what information passes to the outside world and what remains within the home (20, 47).

Conflict between patients/family and PCAs/HCPs over the control of caregiving is described in several studies (42, 44, 46, 48, 51, 53, 54). Fundamental to this is a conflict over who has the legitimate expertise for decision making, for example, over how clinical procedures are performed or over the PCAs themselves (44, 46, 47, 51, 53-55). When the battle for control is discussed in relation to the HMV user, it is transformed into a battle for their independence, autonomy and individualization (42, 46, 51). Studies describe the difficulties HCPs/PCAs can experience and how they can feel that they are 'between a rock and a hard place' due to being positioned between the conflicting goals, values and practices of the family/patient and the health care organization (33, 48, 53).

### *Ambiguous Boundaries*

Studies highlight the ambiguous role and physical boundaries experienced by HCPs/PCAs in the home and how these boundaries are not openly negotiated (20, 23, 33, 43, 47). This has been largely examined from the perspective of HCPs/PAs who describe the unclear role boundaries and relationships they experience with HMV users and whether their role could be constructed as that of being a friend, a guest or a worker/professional within the home setting (33, 44, 47, 53). To some extent the relationship may be mediated by the PCAs status as either an employee of the HMV user/family or as an employee of statutory services (23). Similarly the legitimacy and scope of their role may be unclear with uncertainty over whether it extends beyond patient care to assistance with housework, looking after siblings or parenting ('childrearing') (47, 48). Moreover, PCAs in particular may be concerned about whether they possess the autonomy to refuse to carry out certain roles or procedures in ways that they consider to be unsafe, inappropriate or in conflict with how they have been taught (47). As previously discussed patients' social and emotional lives may involve or revolve around their PCAs which may further blur the boundary between friend and worker.

Physical boundaries within the home may also be ambiguous with studies describing how HCPs/PCAs attempted to be physically unobtrusive and 'blend in' while still remaining close enough to ensure safety (33, 47). Maintaining a low profile was described as a means of avoiding conflict (33). As the home operates as a *de facto* workplace, the presence of HCPs/PCAs focusses attention on the spatial organisation of the home and its ergonomic features (20, 43, 47).

### *Trusting relationships*

Trust appears to be an important characteristic of positive relationships between patients/families and HCPs/PCAs. Studies highlight how families and HMV users need to feel confident in the skills and compassion of the staff who support them in the home (19, 43, 53, 55). Prerequisites for developing a trusting relationship from a patient/family perspective appear to be staff continuity and competency (19, 43, 51, 53, 55). However, maintaining continuity of care may be problematic as studies report high staff turnover due to the nature of the working environment in the home (19, 44, 53, 54). Consequently, families may feel the need to be careful in their relationships with PCAs in an attempt to retain their support (19). Studies that have examined PCA/HCP experiences suggest that they can feel untrusted and judged by patients/families (33, 48).

## **Discussion**

An integrative review aims to provide a comprehensive understanding and develop new perspectives on a concept or a given topic while drawing conclusions for the future (36, 56). Our findings show that control and conflict appear to run through the findings from the included studies. These conflicts took place between HMV users, families, HCPs, PCAs and those who organized support in the home. Moreover, it appeared that it was not home ventilation treatment per se that posed challenges for participants but the transformation of the meaning of home by the presence of technology and workers. A recently published study (25) examining the relationships between HMV users, their informal and formal caregivers discovered similar issues to this review in relation to the complexities of negotiating boundaries in the home in relation to independence and privacy and in balancing HMV users' needs with families' needs. The study highlighted the importance of finding a 'fit' between the patient, family and professional care team in boundary setting. A study of mothers of children with long-term caring needs (2) similarly discussed the home as an idealized place and home as lived, highlighting the tension that affected the physical, emotional and

psychological meaning of home. Mothers described how the aesthetics, smells, sounds and the health care workers presence influenced how they conceptualized both space and place. The lack of a child's voice in the included studies was notable which suggests further research is needed about the meanings children and young people living with HMV attach to home. A recent study indicates that their life perspective is different and that they do not necessarily have a self-identity associated with illness (57). Furthermore, their constructions of home may incorporate the presence of technology and workers as most children will have been HMV users since birth or early childhood.

The research highlights the need for improved education and training of HCPs and PCAs that not only includes the provision of safe clinical care but includes preparation to work in this very particular home environment. Lewarski and Gay (7) similarly identified the need for HMV home care providers to be better prepared for the challenges of working in the home setting. The organisation and provision of HCPs and PCAs varies in different countries regarding HMV care. In the Nordic countries, UK, Canada and in the US (e.g. 7, 30, 47) lay people can receive specialised training to work as a PCA. In addition PCAs can be employed by the municipality (or local health/social care services), private agencies, the patient or patient's family. Whereas in Germany (58), which has seen a significant increase in HMV care, registered nurses provides the care. There seems to be a wide variation internationally and also within each country in the organisation and management of support for HMV. Thus more research is needed about how such differences might influence the meaning of home. We would recommend the development of curricula that includes developing skills in reflective practice, role negotiation and managing conflict in relationships as well as developing an understanding of the meaning of home for individuals and families. This is consistent with a caring science approach to nursing which emphasizes patient experience and preferences as core values (59-61). As the gift of care (62) is grounded in a sense of charity and generosity without expectations of receiving anything back (10, 63), this means that entering a private home as a professional demands openness and sensibility for patients' values and preferences and protecting his/her integrity (10). However, our findings suggest that this is something that not can be taken for granted but needs to be problematized and reflected on during education programmes.

The population of adult and children having ventilator assistance at home is increasing internationally (e.g. 28, 30). However, research has consistently highlighted the need for the

development of more sustainable, competent and coordinated support for people using HMV (24, 64-66). In addition there is a lack of clarity about organisational responsibility for the provision of support and the appropriate level of PCA involvement. HMV requires the adaptation and refurbishment of the home which needs careful planning and design if it is to retain the features and feelings of a home whilst simultaneously acting as a workplace for HCPs and PCAs. Currently the intersection of design, architecture, technology and the home has been under-researched.

### *Methodological considerations*

The strengths of this review are its robust and transparent methods. The search strategy was developed and tested with guidance from a librarian with specialist expertise in information science. Both authors screened records, applied inclusion criteria and appraised studies. When reviewing the methodology of integrative reviews Hopia, Latvala and Liimatainen (67) criticised published reviews for a lack of reporting of the data collection and synthesis stages. We have attempted to be transparent and rigorous about how we analysed, appraised and synthesised the findings from the primary studies. There are limitations to this review. We have excluded papers published before 2010. This was both to focus on the most up-to-date literature and to ensure that the number of included papers enabled us to conduct an in-depth analysis of the research. A further limitation is that papers from Nordic countries are overrepresented in the review which may influence the transferability of the findings. A reason for this could be that changes in the homecare organisation in the Nordic countries has led to a move of patients with complex caring needs from hospital care to municipal care. Another reason could be that nursing research in the Scandinavian countries is influenced of philosophies of caring that stress of the perspective of the unique human being (68). Finally, as previously noted there is also the absence of a child's perspective in the review – a perspective that may be very different to that of the adult participants.

### **Clinical and Research Implications**

Besides locating, evaluation, synthesising and reporting our findings we propose the following areas for further development of clinical practice and to consider for future research:

- Hospital and community services should work together in planning home adaptations and refurbishments to ensure they are completed prior to discharge.
- Home adaptation and refurbishment should employ design principles that retain the physical features of a home while incorporating elements necessary for a workplace.

- HCPs and PCAs need to be prepared for the complexities of working in private homes.
- Strategies need to be developed to retain PCAs e.g. overlapping working schedules to prevent isolation and clinical supervision offered to promote emotional wellbeing.
- Social Insurance Agencies and service commissioners need to be better informed about the realities of living with HMV for users, families and service providers.
- Research is needed to explore home design, the meaning of home and the influence on the wellbeing of HMV users, families and HCPs/PCAs.
- Research is needed to investigate on how home is experienced by children/young people who are living with HMV.

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