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DISSERTATION

**Safety in advanced home care – a qualitative study on the perspective of home
mechanical ventilated users and their family caregivers**

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List of Abbreviations

COPD	Chronic obstructive pulmonary disease
HMV	Home Mechanical Ventilation
NPR	Nurse-patient relationship
PCC	Person-centred care
PCI	Problem-centred interview
QSA	Qualitative secondary analysis
SGB V	Book V of the German Social Code (Sozialgesetzbuch V)
WHO	World Health Organisation

Zusammenfassung

Hintergrund: Der Diskurs zum Thema Patientensicherheit ist vorwiegend auf stationäre Einrichtungen und objektiv messbare Parameter ausgerichtet, wobei der Fokus auf der Vermeidung sog. „unerwünschter Ereignisse“ liegt. Ziel dieser Arbeit ist es daher, Patientensicherheit in der häuslichen Intensivpflege ins Blickfeld zu rücken. Dabei wird im Sinne einer personenzentrierten Versorgung besonderes Augenmerk auf die Erfahrungen und Sichtweisen von schwerstkranken und technikabhängigen Menschen und ihren Angehörigen gelegt.

Methodik: Im Rahmen eines mehrphasigen, qualitativen Versorgungsforschungsprojekts wurden problemzentrierte Interviews mit (non-)invasiv beatmeten Menschen (n = 21) und deren Angehörigen (n = 15) durchgeführt. Der iterativ angelegte Forschungsprozess orientierte sich an den Prinzipien der Grounded Theory. Zudem wurde im Rahmen einer qualitativen Sekundärdatenanalyse eine zusammenfassende Inhaltsanalyse durchgeführt, um das Phänomen des interpersonalen Vertrauens in gegebenem Kontext näher zu untersuchen.

Ergebnisse: Aus der Sicht der häuslich beatmeten Menschen werden v. a. vertrauensvolle zwischenmenschliche Beziehungen zu den Pflegefachpersonen als sicherheitsrelevant angesehen. Sie fühlen sich sicher, wenn personelle Kontinuität gegeben ist, die Pflegefachpersonen mit ihren Bedürfnissen und ihrer Situation vertraut sind und sie ihnen u.a. bezogen auf Ihre Kompetenzen vertrauen können. Bedeutsam sind ferner ihre Möglichkeiten sich mitteilen zu können, das Gefühl mit ihren Bedürfnissen von den Pflegefachpersonen wahrgenommen zu werden sowie die Gewissheit, dass vertrauenswürdige Pflegefachpersonen oder Angehörige anwesend sind. Gestaltet sich die Kommunikation und Interaktion als schwierig oder werden patienten- oder technikbezogene Überwachungsaufgaben vernachlässigt, können risikobehaftete Situationen entstehen. Wenn Kooperations- und Abstimmungserfordernisse unterschätzt sowie Aushandlungs-, Edukations- und Supervisionsaufgaben vernachlässigt werden, leisten Angehörige einen entscheidenden Beitrag zur Sicherheit der beatmeten Personen, indem sie z. B. sicherheitsrelevante Informationen mit den professionellen Akteuren teilen, die Versorgung koordinieren und qualifikatorische und organisatorische Defizite kompensieren.

Diskussion: Aus Sicht beatmeter Menschen ist Sicherheit in der häuslichen Intensivpflege weitaus mehr als lediglich die Abwesenheit „unerwünschter Ereignisse“. Die zentrale Erkenntnis ist, dass beatmete Menschen einem relationalen, subjektiven Sicherheitsverständnis folgen. Zudem konnte gezeigt werden, dass Pflegefachpersonen einen wesentlichen Beitrag zum subjektiven Sicherheitsgefühl leisten können, wenn sie die Pflegebeziehung vertrauensvoll und bedürfnisorientiert gestalten. Gelingt dies nicht, können Risikosituationen entstehen. Der wesentliche Beitrag involvierter Angehöriger verdient Anerkennung, birgt jedoch auch Sicherheitsrisiken. Es bedarf an dieser Stelle daher einer bedarfsgerechten, professionellen Unterstützung, die auf partnerschaftlichen Einbezug und gezielte Förderung ihrer Expertise setzt.

Fazit: Vertrauensvolle Pflegebeziehungen sind für das subjektive Sicherheitsgefühl häuslich beatmeter Menschen von zentraler Bedeutung. Sie verantwortlich zu gestalten stellt eine pflegerische Kernaufgabe in der häuslichen Intensivpflege dar. Die Gewährleistung von Patientensicherheit liegt im pflegerischen Verantwortungsbereich. Entsprechende Voraussetzungen und Rahmenbedingungen bedürfen gezielter Entwicklung.

Abstract

Background: The discourse about patient safety focuses traditionally on inpatient settings and objectively measurable outcomes, specifically the avoidance of any adverse events. The aim of this thesis is to explore safety in advanced home care and, in the spirit of person-centred care, to pay special attention to the experiences and perspectives of severely ill and technology-dependent people and their relatives.

Methods: Problem-centred interviews with (non)-invasive mechanically ventilated people (n = 21) and family caregivers (n = 15) have been conducted as part of a larger multiphase qualitative health services research project. The iterative research process was based on the grounded theory methodology. In addition, a qualitative secondary analysis was carried out to explore the interpersonal trust in this context further.

Results: Particularly, trusting interpersonal relationships with their nurses enhance safety for people receiving home mechanical ventilation (HMV). They feel safe when nurses are familiar with their needs and situation, and when they can rely on, *inter alia*, their professional abilities. Additionally, the possibility of communicating their needs and being noticed by nurses is important for them. Other themes are the continuity and feeling the presence of trustful nurses or relatives. Critical situations occur when the nurse-patient communication and interaction are strained or when patient- or technology-related monitoring tasks are neglected. Further problems occur when co-ordination and co-operation are lacking and if the negotiation process, education and supervision is neglected. Family caregivers make a decisive contribution to patient safety by fostering mutual information sharing, co-ordinating informal health care and undertaking compensation for nurses' qualification deficits and organisational shortcomings.

Discussion: From the perspective of people receiving HMV, safety is far more than the absence of adverse events. The main finding is that those receiving HMV have a relational approach to safety. In addition, it could be shown that nurses can make an essential contribution to safety when they build a trustful and needs-oriented nurse-patient relationship (NPR). If this is not successful, critical situations might occur. Family caregivers' substantial contribution to safety deserves to be acknowledged but also constitutes potential risks. Needs-based, professional support and education should be offered which focus on joint decision-making and targeted promotion of their expertise.

Conclusion: Trustful NPRs are of central importance for the feeling of safety of people receiving HMV. Developing a trustful NPR is, therefore, an essential component of nursing practice in advanced home care. Patient safety should remain the responsibility of the nurses and requires appropriate preconditions and framework conditions.

1 Introduction

The number of severely ill people receiving home care who depend on advanced life-prolonging technology and extensive assistance from others has grown over the last decades in many industrialised countries (Gately et al., 2008; Ten Haken et al., 2018). One example of this trend is the increasing use of home mechanical ventilation (HMV) (King, 2012; Köhler, 2019; Lloyd-Owen et al., 2005; Rose et al., 2015; Windisch et al., 2019). Caring for an individual having advanced medical technology at home (understood as advanced home care) carries substantial risks. One precondition for providing advanced home care is that the quality of care and patient safety is guaranteed (Ten Haken et al., 2018; Windisch et al., 2017). However, little attention has been paid to safety in this context. It is particularly unclear how the recipients of care and family caregivers perceive their situation and understand safety. This research gap will be addressed in this thesis by providing insight into the users' perspectives in a previously relatively unexplored setting.

2 Background

2.1 Patient safety

Definitions of patient safety emanate from the inpatient setting and see the concept commonly as preventing error and adverse events to patients in health-care settings (Kim et al., 2015; Schrappe, 2018). Since the publishing of "To Err is Human: Building a Safer Health System" it has become a worldwide concern (Kohn et al., 2000). The topic received significant research and media attention due to studies revealing the magnitude, incidence of adverse events and costs to the health-care system related to harm received in the hospital setting (Schrappe, 2018). The report by Kohn et al. (2000) has led to patient safety being viewed as a failure of systems rather than humans. The systems approach to safety was drawn from other ultra-safe industries (mainly aviation and nuclear power) (Schrappe, 2018). Vincent and Coulter comment that "*lessons are sought from other industries and experts (...) but the one source of experience and expertise that remains largely ignored is that of the patient*" (Vincent & Coulter, 2002, p.170).

Instead, patient safety research is dominated by outcome measures and is conceptualised from the professional health-care providers' perspective (Harrison et al., 2013). Simultaneously, the sole focus on adverse events has been criticised as it narrows down the issue of patient safety (Amalberti et al., 2011). It is necessary to comprehensively understand the system to mitigate risks and the occurrence of adverse events (Masotti et al., 2010). It has been argued that the understanding of patient safety will only be complete if the patient perspective is included (Hovey et al., 2010; Vincent & Coulter, 2002).

2.1.1 The role of patients and family caregivers in patient safety

Meanwhile, attention to the patient's active role in patient safety has increased. There is a growing recognition of patient involvement in patient safety improvement (Davis et al., 2011; Doherty & Stavropoulou, 2012; Schwappach, 2010; Trier et al., 2015). By contrast, the literature on family caregiver and patient safety still focuses on two aspects. Family caregivers are seen either as "*secondary patients*" who are similarly at risk of being harmed and need to be protected from harm or as unpaid providers who need to become competent in order to protect their family member (Reinhard et al., 2008, p.341). The World Health Organization (WHO) has recently promoted patients and family caregivers' engagement in patient safety as they provide a valuable source of information (WHO, 2017).

2.1.2 The patients' perspectives in patient safety

Although studies regarding patients' perceptions and definitions of patient safety are limited, there has been a growing interest in their perspectives. Earlier studies involving patient perspectives have shown that recipients of care understand patient safety differently from health professionals. They consider interpersonal problems and service lapses as patient safety issues (Entwistle et al., 2010; Jones, 2016; Kuzel et al., 2004; Lang et al., 2009; Rathert et al., 2012; Scott, Dawson, & Jones, 2012; Weingart et al., 2007). Recent studies with a socio-cultural theoretical underpinning have confirmed that recipients of care articulated safety in terms of interpersonal safety. These studies also indicate that safety is conceptualised as a co-produced accomplishment by the interaction of patients, families and health professionals (Collier et al., 2016; Doherty & Saunders, 2013; Hor et al., 2013; Rhodes et al., 2016).

Patients often describe the concept of patient safety through discussion of what made them feel safe. Based on the results of a *concept analysis*, the defining attributes of perceived safety during hospitalisation are a) trust in the nurse, b) the feeling of being cared for, c) the presence of the nurse and the family, and d) knowledge of the health-care provider or the provider's provision of knowledge to the patient (Mollon, 2014). The concept of feeling safe has been investigated mainly in intensive care units. A systemic review of these studies concluded that nursing care is an essential factor promoting intensive care unit patients feeling of safety. On the other hand, a recent review found that patients feel unsafe when they perceive that nurses are not available or lack engagement in helping when needed and when patients cannot summon help due to vulnerability (Kenward et al., 2017). All the studies reviewed of patients' perceptions of safety suggest that nursing care plays a significant role in patients' perceptions of safety (Hupcey, 2000; Russell, 1999; Wassenaar et al., 2014).

2.1.3 Patient safety in home care

There has been a marked shift from the location of care from the hospital setting to home care in Germany, similar to other western countries (Genet et al., 2011).

Research on patient safety has always had an orientation towards the institutional setting, thus, leaving the home care sector relatively unaddressed, although the latter will soon become the most important setting for health-care delivery (Görres et al., 2018; Romagnoli et al., 2013; Vincent & Amalberti, 2016).

This trend has started to change as several publications on patient safety in home care have been published (Görres et al., 2018; Harrison et al., 2013; Kivimaki et al., 2020; Lette et al., 2020; Macdonald et al., 2013; Masotti et al., 2010; Vincent & Amalberti, 2016). It can be concluded from this growing body of literature that patient safety at home cannot be equated with that in hospitals (Vincent & Amalberti, 2016). It differs in terms of the care environment, the roles and responsibilities, and the care providers' processes, standards, supervision and regulatory context of home care (Harrison et al., 2013; Vincent & Amalberti, 2016). In addition, private homes are primarily designed for living and privacy and not providing health care (Henriksen et al., 2009).

Current evidence has shown that adverse events are also found in home care (Baker et al., 2018; Harrison et al., 2013; Madigan & Tullai-McGuinness, 2004; Sears et al., 2013). Görres et al. (2018) cite reasons for adverse events in home care as the lack of communication and co-operation among the actors involved, nurses' lack of knowledge and competencies, family caregivers performing nursing tasks where they lack the knowledge and nurses working conditions, and the spatial and structural conditions. Although these studies focus on general home care, they support the findings from a recent review that the main reason for adverse events in home care with advanced medical technologies is caused by human factors (Ten Haken et al., 2018).

Very few studies have explored safety perceptions from the perspective of the recipients of care and their family caregivers in home care. These studies have broadened the perspective of patient safety in home care by showing that patient safety is inextricably linked with families, caregivers and providers' safety, there are multiple dimensions of safety in home care (functional, emotional, physical and social safety) (Lang et al., 2009) and that both patients and family caregivers actively participate in the delivery of safe care (Jones, 2016).

2.2 Home Mechanical Ventilation

Home mechanical ventilation is a therapeutic option for individuals with chronic respiratory failure, which can be caused by a broad spectrum of medical conditions, for example, pulmonary and neurological disease and spinal cord injuries (Windisch et al., 2017). The population number of cases utilising HMV is small, but a growing number of individuals require mechanically ventilated support both in Germany and internationally (Köhler, 2019; Lloyd-Owen et al., 2005; Rose et al., 2015; Windisch et al., 2019). The exact prevalence of HMV patients in Germany is unknown due to the lack of a national registry or national surveys (Stark et al., 2016). Mechanical ventilator

support can be delivered in the home care setting via tracheostomy (invasive mechanical ventilation) or nasal or face mask (non-invasive mechanical ventilation) and is used either part-time or continuously (Brochard, 2003; Laub et al., 2006; Rose et al., 2015).

Outside the hospital, HMV in Germany is provided in the patient's own home, in shared flats and in specialised nursing homes (Ewers & Lehmann, 2017). "The guideline for non-invasive and invasive HMV for treatment of CRF" (chronic respiratory failure) set the non-mandatory formal competence requirements for nurses who work for nursing services providers which are responsible for their often extensive care needs and safety (Windisch et al., 2017). Care is provided by often specialised nursing care providers with whom the statutory health insurance has contracted for qualified nurses (§132a SGB V). The presence of nurses is seen as necessary because critical situations, such as power failure, ventilator malfunction, accidental disconnection, or other unforeseen medical problems can occur (Simonds, 2006).

Multiple qualitative studies have provided insights into the perspectives of adults with HMV (e.g. Ballangrud et al., 2009; Dyrstad et al., 2013; Lindahl et al., 2005; MacLaren et al., 2019), but safety has been marginally discussed in these studies. In comparison to the patient perspective research, there is less research on the families' perspectives. Most research in this sector explores the perspective of parents caring for children undergoing HMV. However, it is known from the existing research that the intrusiveness of technology, the perceived responsibility and the constant presence of health-care providers, which means a loss of privacy, are a burden for informal caregivers caring for patients with HMV (Evans et al., 2012; Gately et al., 2008; Lindahl & Kirk, 2019; Lindahl et al., 2011; Ten Haken et al., 2018; Wang & Barnard, 2004; Winther et al., 2020). Reviews of the international qualitative literature show that living with HMV is ambiguous regarding experiences or what they call creating a "*dependent independency*" (Ortenblad et al., 2019 p.1167). On the one hand, HMV has a positive impact on people's quality of lives, enabling a self-determined, independent and active life. However, on the other hand, it is difficult for them to be independent without the help of others and technology (Nelissen et al., 2018; Ortenblad et al., 2019; Ten Haken et al., 2018).

3 Research aim and research questions

This thesis aims to *increase the knowledge and understanding of safety in advanced home care from the perspective of the adult recipients of care and the family caregivers*. Their perspectives on safety can offer considerable details which help to identify issues that professionals may not recognise and, thus, can foster patient safety (King et al., 2010; Weingart et al., 2007). It further broadens the (scientific) discourse about patient safety, including the subjective perspective in the specific context of

advanced home care. In order to meet this aim, a qualitative study has been conducted guided by the following two main research questions:

- *How do adult recipients of HMV understand safety?*
- *What strategies are described by HMV recipients and their family caregivers as safety-enhancing, and which factors are described as compromising HMV safety?*

The following sub-questions support these main research questions:

- *How do HMV users perceive their situation, and what makes them feel safe or unsafe?*
- *How do family caregivers perceive the home care situation and their relatives' situation and how do they contribute to safety concerning HMV?*
- *Which underlying causes lead to critical situations from the perspective of HMV recipients and their family caregivers?*
- *What role does trust play in the context of safety in HMV? Which preconditions promote trust and what are the consequences of missing trust in the nurse-patient relationship (NPR) for safety?*

This doctoral thesis is part of a larger multistage health services research project called SHAPE. (Safety in Home Care for Ventilated Patients) funded by the German Federal Ministry of Education and Research under the research priority "Qualitative Health Services Research" (funding code 01GY1315).

4 Methods

4.1 Design

An explorative, qualitative approach has been chosen due to the limited knowledge base on users' perception of home care safety. Qualitative research is well-suited to explore understudied concepts and provides ways of understanding patients and their relatives' experiences and eliciting their subjective perspectives in-depth (Chenail, 2011; Corbin & Strauss, 2015; Wang & Geale, 2015). It is apt for the purpose of this study as it puts the perspective of the patients and their family caregivers in focus and regards them as the experts of their situation (Morse, 2012). Although it was not the primary aim to generate a theory, grounded theory by Corbin and Strauss (2015) is the methodology that has guided this study, recommended when studying social problems or situations to which people have to adapt. It was deemed an appropriate approach because the area of interest focused on how patients and relatives experience life with HMV, their social interaction and perception of the social world (Corbin & Strauss, 2015). Selected empirical methods from grounded theory have been applied in sampling (maximum variation sampling), data collection and data analysis (iteration, constant comparison methods and memos).

4.2 Recruitment

This study's target population are HMV recipients and their family caregivers because a user's perspective of safety is sought. The majority of participants were approached by the nursing staff of participating nursing services providers (gatekeepers). It was arranged that they forwarded an information sheet about the study and provided some general information about its aim and content orally. Inclusion criteria for HMV users were either invasive or non-invasive ventilated, living in their own homes or shared flats, being older than 18 years and communicating in German. Inclusion criteria for family caregivers were an age of at least 18 years, speaking and understanding German, and being involved in an adult HMV user's care. Those HMV users and family caregivers who were interested were invited to notify the nursing services providers or the research team directly of their interest to participate in the study or consent to be contacted by the research team. The nursing services providers forwarded the replies received to the research team who, in turn, contacted those who responded by phone or e-mail.

Further participants were recruited via a hospital-based specialised respiratory care centre, personal contacts, organisations such as the German Association for Muscular Dystrophy and patient advocacy groups to address the risk of selection bias.

4.3 Sample

Maximum variation, which involves purposefully selecting a wide range of individuals, was chosen as a sampling strategy (Polit & Beck, 2018). Accordingly, in this case, HMV users with a wide variety of underlying diseases, ages, nature and extent of care needs, care arrangements, hours of ventilator use, socio-economic status, living and life situation, and family caregivers with a wide range of ages, level of education, employment status, relationship to the care recipient and degree of involvement in care. It was chosen to find common patterns related to safety that cut across socio-demographic variations among the participants (Palinkas et al., 2015).

A total of 21 HMV users participated, comprising 8 women and 13 men, ranging from 26 to 84 years old, 11 lived in their own household and 10 in shared flats, 17 were ventilated invasively and 4 non-invasively. Their ventilation experience ranged from 1 to 26 years and a ventilation duration between 10 and 24 hours a day (see table 1 for more details in the Appendices).

A total of 15 family caregivers participated (12 women and 3 men) in this study, with ages ranging from 31 to 83 years old. Six were living separately from and 9 together with the care recipient (see table 2 for more details in Appendices).

4.4 Data collection

Data was collected in Northeast and South Germany on two separate visits. The participants received additional information about the study on the first visit, and oral

and written informed consent was obtained. They were asked to provide basic socio-demographic and disease- and treatment-related information. In addition, the family caregivers were asked to fill in the Burden Scale for Family Caregivers (Gräßel, 2001). This information was meant to help to put the qualitative data into context.

When an in-depth understanding of an individual's perspectives is sought, the qualitative interview is the most widely used and best choice for data collection in the qualitative paradigm (Brinkmann et al., 2018; Sandelowski, 2002). In this study, data were collected through problem-centred interviews (PCIs) between April 2014 and June 2015. The PCIs are semi-structured interviews that draw on the symbolic interactionism and a grounded theory approach. The interviewer asks open-ended questions to explore the participant's perspective, allowing for an open conversation, which focuses on a socially relevant problem with practical relevance for the interviewee, in this study – "safety". The PCI gives equal weight to inductive and deductive modes of reasoning. On the one hand, the researchers' prior knowledge serves as a pre-structure for the topic guide (deduction). On the other hand, the interviewees' practical or everyday knowledge are used to expand and modify questions in the interview (induction) (Witzel & Reiter, 2012). A topic guide was developed for interviewing HMV users and family caregivers based on knowledge from the literature and one of the author's previous work within the field (Barnard & Sandelowski, 2001; Ewers, 2003; Fex et al., 2009; Lehoux, 2004). Questions were added based on the emerging concepts from the interviews conducted previously during the study (Witzel & Reiter, 2012).

The interviews were conducted at a location convenient to the participants, usually their current residence or, for some family caregivers, in the HMV user's home. Interviews were digitally recorded. Only one participant (family caregiver) requested that the interview was not recorded and notes were taken instead and verified on completion of the interview.

The PCIs lasted from 13 to 107 minutes with the HMV users and 32 to 250 minutes with family caregivers. Two researchers carried them out in almost all cases. One researcher was designed as the lead interviewer to facilitate interaction with the interviewee. The second researcher focused on keeping field notes and monitored nonverbal behaviour and contributed to the interviews by asking follow-up questions at the end of the interview as needed. The roles of the two researchers were explained to the participant before the interview. Both researchers wrote down impressions during data collection and specifics of the interview situation immediately (detailed interview protocols) after the interview to ensure rigour.

Along with the interviews, notes were made about the dialogue before and after the interview, the home environment and the researchers' intuitive feelings surrounding the interview situation (context protocols).

Some interviews posed methodological challenges to data collection due to communication difficulties that HMV users' experience. These challenges are related to the reduced speech intelligibility of two interviewees, the inability of some HMV users to provide detailed accounts of their experiences and three participants with neuromuscular disease using augmentative and alternative communication. These challenges were addressed by using nurses as interpreters (Schaepe et al., 2016; Schaepe, 2019) and e-mail interviews (Schaepe, 2019).

4.5 Data analysis

Interview recordings were transcribed verbatim by a professional transcription service, double-checked immediately on return by the researchers. Transcripts were entered into MAXQDA, a qualitative data software package (verbi GmbH, Berlin Germany) used to analyse the interview data thematically, drawing on grounded theory techniques. The data analysis could not occur in a real iterative process as planned due to initial recruitment difficulties. The thematic analysis began with repeated readings of the first transcripts to become familiarised with the data. In the next step, the data were coded inductively (Braun & Clarke, 2006). The three phases of coding from grounded theory were employed (Corbin & Strauss, 2015). The coding started with *open coding* with *in vivo* coding. The constant comparison technique was used with codes and concepts and clustered to create preliminary categories. Connections between categories were built into the *axial coding*. Categories in *selective coding* were saturated with data from new interviews. Throughout the analysis process extensive memos were written to record impressions and reflections about the emerging codes and categories. After coding, the categories were sorted and combined into themes. Lastly, the relevant themes were defined, named and condensed for reporting (Schaepe & Ewers, 2017, 2018).

4.5.1 Qualitative secondary analysis

It became apparent during the analysis in the original study that "trust" within the NPR was a key theme for investigation. Consequently, it appeared worthwhile to further explore it by undertaking a qualitative secondary analysis (QSA) of the original data. A QSA analyses pre-existing primary data to find answers to new research questions (Beck, 2019). By applying a new perspective on the original data set, additional insights could be produced without an additional burden to the vulnerable population (Long-Sutehall et al., 2011). The purpose of this QSA was to explore the meaning and characteristics of interpersonal trust for the relationship between HMV recipients and nurses. The interview transcripts were read and systematically, deductively screened for the fourth sub-question by the author of this thesis, who is very familiar with the original data set. All with "trust" coded text passages were extracted here. Additionally, other text passages were searched for by keyword searching with terms associated with "trust". Attention was paid to the context where the parts of the text were

embedded. The parts of the text identified were analysed using summarising qualitative content analysis (Mayring, 2004).

4.6 Ethical considerations

Approval was received from Charité – Universitätsmedizin Berlin Ethical Committee (Ref EA2/028/14) before the commencement of the research project.

Participation was voluntary and confidential, and oral and written informed consent was gained before data collection. When HMV users could not give consent on their own behalf, their legal representatives gave written consent. All identifying data were anonymised in the transcripts and participants were assigned pseudonyms.

5 Results

This chapter provides a summary of the main findings presented in the four articles. However, to understand the findings, it is necessary to, firstly, briefly present the participants' living situation, which was derived from the interviews and the context protocols.

The HMV users experience a double dependency, which means that they are dependent on the (life-saving) technology and the help of the nurses and/or their relatives up to 24 hours a day. The turnover of nurses is a concern for family caregivers and having "*strangers*" in the home is especially burdensome for family caregivers living in the same household as the care recipient. The technological intrusiveness in the home and the adaption of the home environment to the technology transforms the home into an intensive care unit atmosphere. Care recipients experience limitations in mobility and spontaneity, and, consequently, social activities and travel opportunities diminish. As their living environment is becoming narrower, these opportunities are very important to their quality of life because they break up the monotony of being predominately housebound (Ewers et al., 2017).

5.1 HMV patients' perceptions of safety (Article I)

In this article, the HMV patients' perceptions of safety have been explored and six themes emerged in the data.

Nurses being familiar with the care needs, health condition and activities of daily living of the HMV users promote a feeling of safety. Only nurses who comprehensively understand the HMV users and their situation can provide individualised care, which is important for the latter's feelings of safety. This means that activities of daily living, including certain nursing procedures, can run smoothly and do not have to be elucidated repeatedly. Familiarity with each other is also a precondition for trust in nurses, which is pivotal for the perceived safety of the HMV users. The HMV users judge whether nurses are trustworthy or not either due to joint experiences where the nurses have proven their competence or through the former's observations of perceived professional abilities (skills, competence and knowledge). Having trust in the expertise of nurses means that HMV users can have confidence that the nurses will

provide adequate care in critical situations and take the right action when necessary. The more dependent the HMV recipient is on the help of the nurses, the more urgent the need to trust in the abilities of the nurses (Schaepe & Ewers, 2017).

Safety is closely related to the HMV user's ability to express their needs, wishes and concerns and that nurses act upon these concerns appropriately and immediately. Verbal communication can be tedious for HMV recipients or only possible to a limited extent due to the ventilation. That is why HMV users with impaired communicative abilities develop very specific ways of nonverbal communication, such as facial expressions or minor gestures. These specific ways of nonverbal communication might be incomprehensible for someone who is not familiar with them. Only nurses familiar with these individual signs notice them when they are attentive and can correctly understand them and act accordingly. The quick reaction and response time of the nurses are essential when HMV users need help. They call nurses in different ways using various technical communication tools (e.g. pressing a button on an alarm system, using a baby monitor or a radio device). In this way, they ensure that nurses notice their care needs (Schaepe & Ewers, 2017).

The HMV users need to experience continuity in their daily life in order to feel safe. This refers to both the continuity of care and nurses. The HMV users want to be cared for by the same small team of nurses, where safety-related information can be shared more easily among them and care continuity is guaranteed. When nurses carry out the same nursing procedures (e.g. tube exchange) repeatedly, they are probably carried out in the same way. Nurses learn to know their care recipients over time, for example, their health condition and care needs, and can provide the individualised care the HMV users would like to receive. In addition to experiencing continuity, the availability and the accessibility of the nurse are important to them. Especially for those participants who are continuously dependent on the ventilator support, the rapid response of the nurse is essential to safety so that help can be provided immediately. That is why nurses must be close enough to come quickly if needed. Thus, knowing that the nurses are there is essential for feeling safe (Schaepe & Ewers, 2017).

5.2 Family caregivers' contribution to safety in HMV (Article II)

In this article, the safety experiences of family caregivers in the context of HMV are explored. This article aimed to understand how family caregivers contribute to the patients and their safety in HMV.

There are significant differences regarding the extent to which family caregivers can contribute to HMV safety. There are those relatives who leave the primary responsibility to the nurses. Some are active and committed continuously to safety work because they generally mistrust nurses and feel that they possess the final responsibility for safety. Additionally, their ability to trust nurses, the roles and the extent to which they are involved also depends on whether family members live in the

same household as the HMV user or not. However, three strategies to enhance safety have emerged from the data, and each will be elucidated.

Participants regard mutual information sharing between all actors within the team as important for strengthening patient safety. They see themselves as part of the care team, where they play a pivotal role. Due to their longstanding care experience and intimate knowledge of the person receiving care, they regard themselves as a valuable source of information on the individual care needs. The care recipient is often impaired in their communicative abilities and family members significantly become their voice to ensure that their relative's needs are met. In return, they expect to receive safety-relevant information from health professionals. This is particularly important for those family members who live separately or are more often absent (Schaepe & Ewers, 2018).

Family caregivers contribute to safety by informally co-ordinating health care. This is a role which is described as burdensome, as it implies an organisational effort and is perceived as a frustrating task. They identify when medical equipment or care aides are needed, apply for them and occasionally negotiate with the health insurance to receive them. In the absence of a formal care co-ordinator, family caregivers become a conduit of information between health-care providers, which is a very responsible and exhausting but essential role for safety (Schaepe & Ewers, 2018).

Some family members put little trust in the competence of nurses because they have had negative experiences (e.g. nurses fell asleep during the night shift or could not intervene appropriately in a life-threatening situation). These participants reported that they must compensate for qualification and organisational shortcomings. A precondition for all the compensative strategies they have adopted is that they have developed expertise about HMV. Nurses have taught some, whereas others have taught themselves by observing nurses providing care. Some even try to teach themselves specific care procedures (e.g. the change of a tracheostomy tube) behind the nurses' backs, whereby they can unintentionally place their family members at risk (see Article III) (Schaepe & Ewers, 2018).

They can monitor the nurses providing care due to the knowledge and skills they have acquired. Thereby, they are making sure that tasks are completed. If necessary, they remind the nurses if they have forgotten something. In the absence of an on-the-job training for new or inexperienced nurses, family members feel obliged to provide the instruction themselves. The instructions they perform range from providing information about the care recipient's needs, preferences and routines to teaching about nursing procedures or the HMV. Family caregivers assess the nurses' qualifications and/or experiences in charge. If a new, inexperienced nurse who is perceived as insecure is in charge, they make arrangements to monitor the nurse and the proper function of the technical devices and intervene if necessary (Schaepe & Ewers, 2018).

5.3 Underlying causes leading to critical situations in HMV (Article III)

In this article, HMV recipients and their relatives' narratives about situations in their everyday life where they felt unsafe are reported. Even though the specific risk situations differ from case to case and the care recipients and family caregivers' perspectives are not always consistent, common causes for risk situations could be identified in their accounts and are presented here.

Risk situations from the HMV users and family caregivers' perspective often result from communication and interactions problems. According to their accounts, inexperienced nurses or those who are only temporarily working for the HMV users often fail to notice or ignore the person's communication attempts, do not understand them and react appropriately. In the users' view, foreign nurses encounter communication problems and might present a risk factor in HMV. On the one hand, they have difficulties understanding the shortened, every day and eventually slurred language HMV recipients speak. On the other hand, these nurses have difficulties expressing themselves in the German language. The HMV recipients then react to this fractured communication with impatience, anger or mistrust. The more pronounced these communication difficulties are and the more technology-dependent the person is, the more serious the safety hazards (Ewers et al., 2017).

Participants stressed that critical situations resulted from nurses' negligence of their monitoring and surveillance duties. The HMV users or family caregivers' concerns were not taken seriously, or careless or inexperienced nurses are not working proactively. When nurses are not working carefully and lack the awareness of potential risks, HMV users lose trust in them (see article IV) (Ewers et al., 2017).

Some participants highlighted being worried about their own health and the potential failure of the technology; however, what worries them the most is that nurses might not be able to use the medical technology adequately and be able to intervene promptly and adequately in a critical situation. In this case, the nurses present become the main safety risk factor. The HMV recipients' lives depend on the nurses' actions. Thus, every little sign of uncertainty from the nurses is registered and experienced as very distressing (Ewers et al., 2017).

Family caregivers are taking risks and may even disregard the recommendations of the health professionals when trying to increase the HMV users' well-being, help them in their rehabilitation and to become less dependent on the help of others. Examples of these risk situations are a mother trying to wean her son on her own or a husband who feeds his wife soup to make her swallow and is, therefore, unblocking the tracheal cannula against the physicians' recommendation. Instead of negotiation, education and adequate supervision, the family members are doing it secretly and taking the responsibility themselves (Ewers et al., 2017).

5.4 The role of trust in the context of patient safety in HMV (Article IV)

The fourth article examines the meaning and characteristics of interpersonal trust for the relationship between ventilator-assisted individuals living at home and nurses. It specifically explores the preconditions for the development of trust and the consequences of a lack of trust in the NPR.

A trusting relationship develops in a dynamic process of getting to know each other, which requires personal continuity. Previous positive experiences with each other or a shared experience of crisis facilitates the development of trust. On the other hand, some participants describe having an inherent trust in nurses regardless of experience. They assess intuitively if a nurse is trustworthy or not. According to the HMV users' accounts, a further precondition for developing trust in the NPR is the reliability of the nurses, demonstrated by their professional behaviour and through professional and social competences (Czakert et al., 2020).

Some HMV users have developed a comprehensive expertise about the medical technology used and potential risks involved in their treatment over time and can judge whether nurses also possess the knowledge and skills required and, thus, are trustworthy. In addition to the technical competencies, they expect nurses to be able to anticipate predictable risks. Participants described potential critical situations, such as changing the mask or the tube, the transfer and the ventilator's malfunction. In these situations, it is imperative that the nurses know what to do. This is especially important due to the temporary or continuous communicational impairments that many HMV users experience. Besides the technical expertise, nurses showing caring behaviour is important for the reinforcement of trust. Trust can be established with empathetic nurses, who can engage with the HMV users and be aware of their unvoiced needs and react accordingly (Czakert et al., 2020).

When nurses make a mistake, expected behaviour or actions do not occur, therefore, care recipients develop mistrust of them and feel unsafe in their presence. As a consequence of losing trust in one's nurse, the HMV users develop various strategies to remain in control and be safe. Some HMV recipients teach and train the nurses to undertake a nursing procedure, and those who live together with their relatives ask the latter to carry out the task. Some participants reported that they limit their own activities to the essential things to reduce risks hazards, for example, by not moving, not even using the toilet, and not doing activities outside the house (Czakert et al., 2020).

5.5 Summary of results

In sum, the findings suggest that from the patients' perspective, safety is mainly realised in the continuous social interaction between patient and nurse, which is characterised by familiarity, trust and effective communication (Schaepe & Ewers, 2017). From the users' perspective, critical situations in HMV occur when nurses are perceived as inexperienced, incompetent and insecure or neglect their duties (Ewers

et al., 2017). This not only compromises trust in nurses and, thus, a feeling of insecurity, but it may also lead to serious safety risks (Czakert et al., 2020; Ewers et al., 2017). To avoid these risks and to remain in control, family caregivers and patients themselves play an active part in ensuring safe care (Czakert et al., 2020; Schaepe & Ewers, 2018).

6 Discussion

6.1 Patients' understanding of patient safety

This study explored the patient's understanding of safety. The accounts of HMV recipients suggest that safety is realised in the interaction between nurses and themselves (and their family members), which leads to the conclusion that they seem to have a relational approach to patient safety (Schaepe & Ewers, 2017). This is in line with the work from researchers with a socio-cultural perspective on patient safety stating that safety depends on the quality of the ongoing interactions between patients, family caregivers and professional caregivers (Collier et al., 2016; Doherty & Saunders, 2013; Hor et al., 2013; Rhodes et al., 2016). This also supports similar findings in the literature across health-care settings and disease contexts (Kuzel et al., 2004; Scott et al., 2012; Stenhouse, 2013; Vaismoradi et al., 2011; Wassenaar et al., 2014).

The findings confirm that patients' understanding of safety diverge from the professional perspective (Fitzsimons & Cornwell, 2018; Jones, 2016; Lang et al., 2009; Mollon, 2014). In accordance with these findings, this study has shown that patients' perceptions of safety are broader than the narrowly defined professional providers' definition of patient safety. This is because patients focus on emotional and psychological aspects, such as trust, meeting their needs and interpersonal communication issues, and less on adverse events and physical harm (Schaepe & Ewers, 2017). From a professional perspective, these aspects might be described by the term 'quality of care'. But in the context of advanced home care, where individuals are dependent on medical technologies and the continuous help of others, the study has shown that these emotional and psychological aspects can result in critical situations and harm (Ewers et al., 2017).

It might be problematic that there are disparities between what health care is trying to achieve (by focusing solely on physical safety) and what patients perceive as good and safe care (when emotional and psychological aspects are addressed). Therefore, a broader definition of patient safety is suggested which incorporates the perspective of users and does not exclusively adopt an approach that derives from the ultra-safe industries.

6.2 Safety-enhancing strategies and factors compromising safety in HMV

Traditional safety-enhancing approaches, such as incidence reporting systems, checklists and protocols, which primarily focus on physical harm, will fail to address the emotional and psychological dimension of safety. Instead, building and maintaining

a trustful NPR is more likely to improve this relational approach to patient safety (Schaepe & Ewers, 2017; Czakert et al., 2020). Therefore, a person-centred approach (PCC), which emphasises the interpersonal relationship between the person receiving care and the health-care providers, is more likely to enhance patient safety and the users' experiences of care in HMV. This approach is widely suggested in the nursing literature and has recently been suggested in a review of qualitative studies exploring users' experiences with HMV (Ortenblad et al., 2019). There seems to be some evidence that the effective NPR and the PCC approach is having a positive impact on some aspects of patient safety (Rossiter et al., 2020), but further research is needed.

The QSA findings revealed that interpersonal trust is of great importance in the NPR for promoting the HMV users' feelings of safety (Czakert et al., 2020). Necessary preconditions, such as nurses' professional qualifications, experiences and professional attitudes, which are described by the participants, are also identified in the nursing literature for the development of trust in the NPR (Dinç & Gastmans, 2013; Rørtveit, 2015). However, the peculiarity in advanced home care is that recipients of care are very vulnerable to the actions of the nurses and the latter should be very aware of their professional responsibility (Czakert et al., 2020). It is important to organise and maintain continuity among the nurses who perform care because interpersonal continuity is necessary to develop and strengthen a trustful NPR. Building a trustful relationship takes time and, thus, necessitates interpersonal continuity (Dinç & Gastmans, 2013). Having small and stable teams, which means interpersonal continuity, was also a wish expressed in earlier studies on HMV patients (Ballangrud et al., 2009; Lindahl et al., 2005; MacLaren et al., 2019; Swedberg et al., 2012). Becoming familiar with each other is important and well-documented in the nursing literature to be the foundation and an essential element of the NPR (Dinç & Gastmans, 2013; Rørtveit, 2015). It has been demonstrated in previous studies to enhance patients' feelings of safety (Lang et al., 2009; Tong, Sims-Gould, & Martin-Matthews, 2016; Wassenaar et al., 2014). Nevertheless, this study does provide further evidence of its importance.

From the insider perspective, patient safety is compromised when the building and maintenance of a trustful relationship are not successful due to communication failures, nurses lacking experience, the necessary knowledge and competencies and/or neglect their monitoring and surveillance duties (Ewers et al., 2017). These factors are also described in the literature as some of the underlying causes of adverse events in (advanced) home care (Görres et al., 2018; Ten Haken et al., 2018). This highlights the insufficient caregivers' competence which is also highlighted in other studies as one of the most concerning issues in HMV (Ballangrud et al., 2009; Dybwik et al., 2011; Swedberg et al., 2012). That is the reason why a thorough assessment of the nurses' competence prior to practice is indispensable. Furthermore, some initial workplace

training and supervision by experienced nurses is needed in order to become familiar with each individual person receiving HMV (Schaepe & Ewers, 2017).

Both recipients of care and their family caregivers are actively engaged in patient safety activities by employing various strategies to maintain control and, thus, protect themselves, respectively, their relatives against physical and psychological harm (Czakert et al., 2020; Schaepe & Ewers, 2017, 2018). These strategies are also seen in former studies in the context of HMV (Dybwik et al., 2011; Swedberg et al., 2012; Wang & Barnard, 2004; Winther et al., 2020) and in other health-care settings (Collier et al., 2016; Hor et al., 2013; Rhodes et al., 2016). In support of previous findings that state all actors in home care are creating and maintaining safety (Lang et al., 2009), it may well be assumed that users take a greater responsibility for safety in home care than institutional settings. Given that care takes place in their own home and that there is greater autonomy than in hospital settings (Lang et al., 2008), this could be explored in further research.

Moreover, the present study's findings broaden the body of literature on family caregivers and safety by indicating that in many cases, family members are the ones to ensure patient safety in advanced home care by employing several strategies. This finding proposes a change in focus from considering family members as "*secondary patients*" or harmful to the recipients of care (Reinhard et al., 2008, p.341) to acknowledging their underestimated contribution to patient safety. Raising the awareness of family caregivers' valuable contribution to patient safety among nurses and other health professionals and conducting further research on family caregivers' contribution to safety would be ways towards such a change (Schaepe & Ewers 2018). However, the study findings illustrate that relatives can indeed expose HMV users to risk unintentionally at the same time. This is related to the relatives' lack of knowledge and competence and lack of co-operation and role negotiation, which could be improved by education, support and better co-operation between family members and nurses, which echoes previous research (Görres et al., 2018; Ten Haken et al., 2018).

Despite its promotion by the WHO and the potential positive aspects of patient and family caregivers' engagement in patient safety improvement (WHO, 2017), it should be stressed that participants in this study are not intentionally taking over this responsibility. They do so to compensate for the quality and safety deficits in current HMV care. They would rather rely on qualified nurses being responsible for safety. Thus, an HMV user's engagement in patient safety should not equate with compensating for health-care providers deficits. Patient safety should remain the nurse's responsibility and the nursing care providers through which they provide care and cannot be handed over to either patients or family caregivers which would just increase the burden they already perceive.

This requires necessary preconditions and framework conditions. Nurses need the necessary knowledge, skills and attitudes to deliver safe care. Nursing education is

seen as the key for patient safety, and it is essential for how patient safety is understood and finally put into practice (Milligan, 2007; Neudorf et al., 2008; Steven et al., 2014). It seems to be essential here not only to focus on the hospital setting but instead to consider the findings from emerging evidence about patient safety in home care, which should be taught to health-care providers working in this setting. Particular attention should be paid to the specific challenges of patient safety in home care (Harrison et al., 2013; Vincent & Amalberti, 2016) and to the emerging evidence regarding the multidimensionality of safety in home care (Lang et al., 2008). The findings suggest that when all dimensions of safety are considered, it requires technical and social skills as well as a professional attitude (Czakert et al., 2020; Schaepe & Ewers, 2017). Furthermore, structural barriers which have also been described, such as the nursing turnover and the lack of initial workplace training, impede the building of a trustful NPR.

6.3 Limitations

This qualitative study has drawn data from a small population of people requiring HMV and their family caregivers. However, the participants were a broad group of HMV recipients and relatives concerning demographic characteristics covering a broad range of experiences. Effective communication is an important aspect of safety (which is also seen in these findings) and research tends to include the healthiest and most communicative individuals of a population (Kirkevold & Bergland, 2007). It is reasonable to assume that the sample does not echo the more communicatively impaired individuals' perspectives and those who do not have German as a mother tongue. These non-participants may have other perspectives on safety in HMV, which threatens the requirements of maximum variation and the study's validity. The methodological issues and ethics of recruiting and including communicatively impaired vulnerable patients to qualitative research could be further discussed. However, the consistency of the findings with other studies suggest some generalisability. Although it can be assumed that the results have some relevance for other populations using medical technology at home, it should be considered that the findings of qualitative research are context-bound (Polit & Beck, 2018). Caution should be exercised in generalisation to a broader context. Studies using grounded theory in other settings are suggested for further research. This emerging study theory on patients' understanding of patient safety could subsequently be tested empirically.

The involvement of the nursing care providers in recruitment poses a potential risk of bias. On the one hand, nurses could have purposively chosen satisfied HMV users and their relatives who are not seen as "problematic or difficult" cases, resulting in selection bias. On the other hand, the recruitment of participants being cared for by nursing care providers heightens concerns for social desirability bias. Patients and family caregivers are dependent on their services and might fear offering criticism. However,

confidentiality was guaranteed and other recruitment strategies were used to address these risks of bias.

7 Conclusion

Given the growing importance of (advanced) home care, it is imperative to pay more attention to safety in this context. This thesis adds to this by increasing the knowledge and understanding of patient safety in this context from the recipients of care and the family caregivers' perspective. The research has shown that patients have a relational approach to safety and that the trustful NPR is crucial for patients' feelings of safety. Developing a trustful NPR is an essential component of nursing practice which should be taken more into account in practice and in education. It is a responsible task which requires technical and social skills as well as a professional attitude (Czakert et al., 2020; Schaepe & Ewers, 2017). A shift to PCC, which focuses on the NPR (Ekman et al., 2011; McCormack & McCance, 2017) is therefore recommended.

This thesis also demonstrates, in line with previous research, that patient safety from the patients and family caregivers' perspective is co-produced between patients, family caregivers and professional health providers (Collier et al., 2016; Doherty & Stavropoulou, 2012; Hor et al., 2013; Rhodes et al., 2016). Therefore, a closer collaboration between all these actors involved is essential for the provision of safe care. Patients and family caregivers should be seen as active partners and valuable resources for resilient home care. Their active involvement entails obvious advantages for patient safety but also carries risks which needs to be further discussed and researched. However, additional education and support for family caregivers is needed to avoid them putting the care recipient unintentionally at risk. The overall responsibility for safety in advanced home care should rest on the nurses in charge and nursing services providers and should not be handed over. Nurses should become aware of their central role in providing safe care and take responsibility for it, which requires improved qualifications and professionalism.

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Appendices

Table 1: Characteristics of HMV users

Age	Min	26
	Max	84
	Median	61
Sex	Female	8
	Male	13
Diagnosis	Neuromuscular disease	10
	Lung disease	7
	Tetraparesis	2
	Metabolic disease	1
	Infectious disease	1
HMV Regimen	Invasive	17
	Non-invasive	4
Hours per day	<24	6
	24	15
Living circumstances	Shared flats	10
	Living alone	7
	With family caregiver	4

Table 1: Characteristics of HMV users (Schaepe & Ewers 2017, p.950)

Table 2: Characteristics of family caregivers and care recipients

Characteristics of family caregivers		
Age	Min	31
	Max	83
	Median	61
Sex	Female	12
	Male	3
Relationship to the care recipient	Parent	2
	Married	9
	Sibling	1
Level of Education*	Basic	4
	College or University	3
	High School	7
Employment Status	Retirement	9
	Employment (part-time/full-time)	4 (2/2)
	Unemployment	2
Living arrangement	Separated from care recipient	6
	Together with care recipient	9
Burden Scale for Family Caregivers Results**	No burden (0-24 points)	7
	Moderate burden (25-55 points)	6
	Severe burden (56-84 points)	-
Characteristics of the care recipient		
HMV regimen	Invasive	13
	Non-invasive	2
Disease group	Neuromuscular disorder	8
	Lung disease	1
	Tetraparesis	3
	Vegetative state	1
	Infectious disease	1
	Metabolic disease	1
Hours of HMV	Continuously	10
	>16 hours	2
	< 16 hours	3
Hours of Nursing Services per day (one is having no nursing service)	24 hours	10
	8-11 hours	4
Years of experience of HMV in the home**	Min	1
	Max	41
	Median/Mean	6/12

Table 2: Characteristics of family caregivers and care recipients (Schaepe & Ewers 2018, p.5)

*data of one participant is missing

**data of two participants are missing

Statutory Declaration

“I, Christiane, Schaepe by personally signing this document in lieu of an oath, hereby affirm that I prepared the submitted dissertation on the topic “Safety in advanced home care – a qualitative study on the perspective of home mechanical ventilated users and their family caregivers”, “Sicherheit in der häuslichen Intensivpflege – eine qualitative Studie zur Perspektive von häuslich beatmeten Menschen und ihren pflegenden Angehörigen” independently and without the support of third parties, and that I used no other sources and aids than those stated.

All parts which are based on the publications or presentations of other authors, either in letter or in spirit, are specified as such in accordance with the citing guidelines. The sections on methodology (in particular regarding practical work, laboratory regulations, statistical processing) and results (in particular regarding figures, charts and tables) are exclusively my responsibility.

Furthermore, I declare that I have correctly marked all of the data, the analyses, and the conclusions generated from data obtained in collaboration with other persons, and that I have correctly marked my own contribution and the contributions of other persons (cf. declaration of contribution). I have correctly marked all texts or parts of texts that were generated in collaboration with other persons.

My contributions to any publications to this dissertation correspond to those stated in the below joint declaration made together with the supervisor. All publications created within the scope of the dissertation comply with the guidelines of the ICMJE (International Committee of Medical Journal Editors; www.icmje.org) on authorship. In addition, I declare that I shall comply with the regulations of Charité – Universitätsmedizin Berlin on ensuring good scientific practice.

I declare that I have not yet submitted this dissertation in identical or similar form to another Faculty.

The significance of this statutory declaration and the consequences of a false statutory declaration under criminal law (Sections 156, 161 of the German Criminal Code) are known to me.”

Date

Signature

Declaration of own contribution

I, Christiane Schaepe, contributed the following to the publications listed below:

Publication 1

Schaepe C, Ewers M.: "I need complete trust in nurses" – home mechanical ventilated patients' perceptions of safety. *Scandinavian Journal of Caring Sciences*, 2017, 31(4), 948-956.

I, Christiane Schaepe, am the sole first author of this publication. Detailed declaration of own contribution and responsibilities:

- Major contributor in recruiting participants
- Co-developed research question and aim of the study
- Significant contribution to obtaining approval of the ethical committee
- Significant contribution to the development of the topic guide
- Major contributor to data collection (conducted qualitative interviews with people with HMV in tandem with a colleague, wrote protocols)
- Major contributor in data analysis (conducted the thematic analysis together with a colleague)
- Wrote the manuscript: drafted the manuscript, conducted literature search, created all tables, revision according to the feedback from the second author
- Corresponding author throughout the whole submission process

Publication 2

Schaepe C, Ewers M. "I see myself as part of the team" – family caregivers' contribution to safety in advanced home care. *BMC Nursing*, 2018, 17, 40

I, Christiane Schaepe am the sole first author of this publication. Detailed declaration of own contribution and responsibilities:

- Major contributor in recruiting participants
- Developed research question and aim of the study
- Significant contribution to obtaining approval of the ethical committee
- Significant contribution to the development of the topic guide
- Major contributor in data collection (conducted qualitative interviews with family caregivers in tandem with a colleague, wrote protocols)
- Major contributor in data analysis (conducted the thematic analysis with second author)
- Wrote the manuscript: drafted the manuscript, conducted literature search, created all tables, revision according to the feedback from the second author
- Corresponding author throughout the whole submission process

Publication 3

Ewers M, **Schaepe C**, Lehmann Y (2017): Alles sicher? – Risikosituationen in der häuslichen Intensivpflege aus Sicht beatmeter Patienten und ihrer Angehörigen. *Pflege. Wissenschaftliche Zeitschrift für Pflegeberufe*. *Pflege* 30(5), 365-373.

I, Christiane Schaepe am the second author of this publication. Detailed declaration of own contribution and responsibilities:

- Major contributor in recruiting participants
- Co-developed research question and aim of the study
- Significant contribution to the development of the topic guide
- Major contributor in data collection (conducted qualitative interviews with HMV users and family caregivers in tandem with a colleague, wrote protocols)
- Significant contributor to data analysis
- Critical revision of the manuscript
- Read and approved the final manuscript

Publication 4

Czakert J, **Schaepe C**, Ewers M (2020): Vertrauensvolle und sicherheitsgenerierende Beziehungsgestaltung in der häuslichen Intensivpflege – Eine qualitative Sekundärdatenanalyse. In: Pflege & Gesellschaft 25(1). Weinheim: Beltz Juventa, 34-49.

I, Christiane Schaepe, am the second author of this publication. Detailed declaration of own contribution and responsibilities:

- Major contributor in recruiting participants
- Co-developed research question and aim of the study
- Major contributor to data collection (conducted qualitative interviews with HMV users and family caregivers in tandem with a colleague, wrote protocols)
- Significant contributor in qualitative secondary data analysis
- Critical revision of the manuscript
- Read and approved the final manuscript

Signature, date and stamp of first supervising university professor / lecturer

Signature of doctoral candidate

Publication 1

Schaepe C, Ewers M: I need complete trust in nurses – home mechanical ventilated patients' perceptions of safety. *Scandinavian Journal of Caring Sciences*, 2017, 31/4), 948-956

'I need complete trust in nurses' – home mechanical ventilated patients' perceptions of safety

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Scand J Caring Sci; 2017; 31; 948–956

'I need complete trust in nurses' – home mechanical ventilated patients' perceptions of safety

Background: Although home care has advanced over the last few decades, little research on patient safety has been carried out in this setting. Furthermore, it is unclear how patients perceive their situation and safety. The insiders' views might be especially relevant for technology-dependent individuals, such as users of home mechanical ventilation (HMV).

Aim: The aim of this study was to examine how HMV patients perceive their situation and what makes them feel safe or unsafe.

Design: Explorative qualitative study.

Methods: Data were collected in two regions in Germany between April and December 2014 by means of semi-structured interviews with 21 HMV patients. Thematic analysis was used to analyse data.

Findings: Three themes emerged: the meaning of an interpersonal relationship between the nurse and

HMV patient is expressed in the theme *Being familiar – Having trust*. The importance of the attentiveness of nurses for the patients' feeling of safety is described in the theme *Being able to communicate – Being noticed*. The theme *Experiencing continuity – Feeling presence* points to the organisational dimension of HMV care provision.

Conclusions: The interpersonal nurse–patient relationship plays a key role in promoting HMV patients' feeling of safety. Thus, HMV patients have a relational approach to safety. In order to enhance the patients' feeling of safety, nurses should strive to develop a trusting relationship with patients and demonstrate their presence and attentiveness. Regarding the provision of care, competent and continuous care should be made a priority.

Keywords: feeling safe, home mechanical ventilation, nurse–patient relationship, patient safety, patients' perceptions, qualitative research.

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Introduction

The number of severely ill patients in home care depending on advanced life-prolonging technology and extensive assistance from others has increased over the last few decades in many industrialised countries (1). One example of this development is the growing number of individuals receiving home mechanical ventilation (HMV). They not only are dependent on life-supporting technology, but also need advanced nursing care and several medical and therapeutic procedures daily. Although caring for an individual receiving HMV carries substantial risks, little attention so far has been paid to patient safety in this context. It is particularly unclear how patients perceive their

situation and what makes them feel safe or unsafe. In this study, we address that need by providing an insight into a generally unexplored and hidden field of home care from the user's point of view.

Background

Research concerning patient safety has traditionally focused on the acute inpatient setting. However, differences between institutionalised healthcare settings and home care call for research examining home care. That is particularly relevant because private homes are not designed for providing professional health care, and they are meant for living and privacy. The home lacks the uniformity which exists in hospitals, healthcare professionals are guests in this setting and, in many respects, home care can be considered as uncontrolled and unregulated (2).

Home care has advanced over the last few decades and has become more complex, largely due to the shift of

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patients and to technological development in this area. This care delivery model called 'hospital in the home' or 'home health care' or 'high-tech-home care' is considered as a safe environment for the patient (3). However, having medical devices in the home setting implies that they are used by lay people or healthcare professionals with varying levels of education and different degrees of experience and training. Previous research in the field of advanced home care has found that caregivers' competence is one of the most concerning issues from the patient and caregiver perspective (4–6).

The issue of safety in home care has been recently recognised, leading to a growing body of literature on this topic, and although evidence is still limited (7), a broader 'understanding of patient safety issues among home care clients is developing' (8) (p. 166). This understanding is based on results from an analysis which show that around 13% of the Canadian home care clients had experienced at least one adverse event (9, 10). There are no specific data available to date for Germany about adverse events in home care.

As in the case of hospital care, the existing research on safety in home care is generally focused on the prevalence of adverse events, thus addressing these phenomena from an outsider's perspective on a quantitative basis. At the same time, research focusing on the patient's perspective using a qualitative approach is limited (11). It has been primarily studied in the hospital setting, particularly in intensive care units. These studies have shown that patients felt safe when their psychosocial needs were met, when they regain control and when nurses and other healthcare professionals were trustworthy. The presence of their family and being under technological surveillance further promoted patients' feelings of safety (12, 13).

The importance of the clinician–patient relationship for safety was reported by primary care patients in a previous study (14). For elderly patients being transferred from one setting to another, the quality of their communication with their clinicians and the latter's responsiveness were paramount for their feeling of safety. Trust in the clinicians and the avoidance of traditional risks were also related to their perception of safety. In this respect, patients also named organisational issues, including waiting times, as well as the healthcare providers' interpersonal skills (15). Oncology outpatients reporting on service quality issues framed waiting and delays, miscommunication and poor coordination as factors of an unsafe experience (16). The patient–provider collaboration has been found to reinforce feelings of safety among patients with critical and chronic conditions (17).

Although patient safety has been studied extensively in the past decades, little attention has been paid to the user's perspective and how safe they feel in home care. One exception is the Pan-Canadian Home Care Safety

Study, which found that patients' and their families' understanding of safety is multidimensional and inextricably linked with the safety perception of caregivers and providers (2). It shows that studying the patient's perspective is important, as it provides a rich source of information for healthcare professionals and policy-makers and, thereby, for continuous quality improvement (15). Because patients play the leading role in their care, their experiences and perceptions have to be integrated into care concepts (2). The current lack of knowledge about the patient's views prevents healthcare professionals from providing a safe, effective and patient-centred care, which might be especially relevant for technology-dependent individuals.

Users of HMV can be distinguished into two categories: (i) those with elective long-term mechanical ventilation resulting from conditions leading to progressive respiratory failure, such as neuromuscular diseases, and (ii) emergent long-term mechanical ventilations due to failure to wean from mechanical ventilation after an episode of acute respiratory failure (18). Mechanical ventilation is provided either in a noninvasive (NIV) or in an invasive (IV) manner. In spite of the well-being limitation associated with requiring mechanical ventilation, having a home ventilator has shown to improve the patients' quality of life, independent of the underlying disease (4, 19). It is estimated that up to 20 000 IV patients in Germany are in advanced home care, which is provided as a hospital substitute by qualified nurses who are present on a 24/7 basis in the client's home. Their primary task is to guarantee an immediate intervention in life-threatening situations (20). Although relatives are occasionally involved in daily care, it is the nurse's obligation to guarantee their safety.

Qualitative studies in which adult HMV users have been interviewed have focused on specific experiences and feelings of their life situation, such as how they experience care and the supervision by healthcare personnel (4, 21), communication (22) and technological dependency (23–27), and/or on specific disease groups being either tracheotomised or ventilated noninvasively (28–33). How HMV patients experience their care and in which situations they feel safe or unsafe have not been explored to date. Thus, an understanding of HMV users' perceptions of safety is important for conceptualising and planning safe and effective patient-centred home care for this vulnerable population.

The present study is part of a larger health services research called SHAPE 'Safety in Home Care for Ventilated Patients' and aims to examine how HMV patients perceive their situation and what makes them feel safe or unsafe. Results of this research project shall be used by nurses and other healthcare professionals to conceptualise their safety work in advanced home care for ventilated patients.

Methods

Design

As little is known about the phenomena under research, an exploratory qualitative design was deemed appropriate in this study. Selected empirical methods based on grounded theory methodology (34) have been applied for sampling, data collection and data analysis.

Participants

Inclusion criteria were that participants were mechanically ventilated regardless of the underlying disease, residing in their own home or in a shared residential setting, were older than 18 years of age and were able to communicate. Maximum variation was chosen as a sampling strategy, which involves purposefully selecting a wide range of variation of individuals (35) in relation to, for example, age, disease and hours of ventilator use.

Participants were recruited in various ways, but mainly via the staff of different outpatient nursing care providers (gatekeepers), who are most frequently in contact with HMV users. These healthcare professionals were thoroughly informed about the aim and design of the study, after which they provided eligible patients with written study information and inquired whether there was any interest in participation. Any patient interested then contacted the research team themselves or asked their

healthcare providers or relatives to contact the research team on their behalf. Further participants were recruited via hospital-based specialised respiratory care centres, personal contacts and organisations such as the German Association for Muscular Dystrophy and patient advocacy groups. A total of 15 interviews were initially planned, but subject recruitment continued until saturation was reached after interviewing 21 HMV users. A basic description of the 21 participants is shown in Table 1.

Data collection

Data collection occurred in an iterative process between April and December 2014 on two visits with each participant. During the first visit, informed consent and sociodemographic information was collected. During the second visit, the two nurse researchers conducted the interview. While one was asking the interview questions, the other made notes on the interview situation (including the interviewee's appearance, mood, nonverbal reactions, key messages before, during and after the interview, disruptions) and the living environment of the participant. The notes were brought together in detailed protocols and written down directly after the interview.

The qualitative interviews, 13–107 min in length, were audiotaped and conducted in accordance with a semi-structured interview guide. Participants were initially asked to describe their everyday life and the role HMV and safety have in it. They were then invited to give an

Table 1 Characteristics of participants

<i>Pseudonym</i>	<i>Regimen</i>	<i>Hours per day</i>	<i>Age</i>	<i>Gender</i>	<i>Living circumstances</i>	<i>Diagnosis</i>
Ms. Müller, Ute	NIV	>16	60	W	Single	Neuromuscular disease
Ms. Schmidt, Elke	IV	24	73	W	Single	Lung disease
Mr. Schneider, Michael	IV	24	34	M	Single	Neuromuscular disease
Mr. Fischer, Helmut	IV	24	84	M	Shared living	Lung disease
Mr. Schäfer, Jan	IV	24	26	M	Shared living	Tetraparesis
Mr. Klein, Jürgen	IV	24	73	M	Shared living	Neuromuscular disease
Ms. Huber, Daniela	NIV	10–14	37	W	Single	Neuromuscular disease
Ms. Lange, Marion	IV	24	61	W	Single	Lung disease
Mr. Köhler, Rolf	IV	24	74	M	Single	Neuromuscular disease
Mr. Krause, Frank	IV	24	46	M	Single	Neuromuscular disease
Ms. Schröder, Karin	IV	10	74	W	Shared living	Lung disease
Mr. Neumann, Holger	IV	12	61	M	Shared living	Lung disease
Ms. Schwarz, Doris	IV	10	57	W	Shared living	Lung disease
Ms. Krüger, Ilse	IV	24	84	W	Shared living	Lung disease
Mr. Schulz, Torsten	IV	24	46	M	Shared living	Metabolic disease
Mr. Werner, Norbert	IV	24	62	M	Shared living	Neuromuscular disease
Mr. König, Hans	IV	24	67	M	Shared living	Neuromuscular disease
Mr. Peters, Matthias	NIV	24	41	M	With parents.	Neuromuscular disease
Mr. Koch, Manfred	IV	24	81	M	With spouse	Infectious disease
Mr. Zimmermann, Markus	NIV	10	35	M	With mother	Tetraparesis
Ms. Hoffmann, Edith	IV	24	78	W	With husband	Neuromuscular disease

NIV, noninvasive ventilation; IV, invasive ventilation.

example of a situation in which they felt unsafe and to explain what could have been done differently or better in order for them to feel safe. Finally, they were asked to sum up what safety at home means to them. The questions became more specific and focused during the analysis process. The majority of participants communicated verbally during the interviews. However, some were extensively impaired in their verbal communication abilities, and special measures needed to be taken in order to capture their perspective. Consequently, two participants needed the nurses as interpreters, because they were whispering and nonvocal.

Data analysis

The research team used coding, categorisation and analytic reflection as means to identify relevant themes in the data (36, 37). The thematic analysis began soon after the first interview had been conducted and continued at the same time as the data collection. Data collection and analysis were planned to occur concurrently, but could not always be implemented due to initial difficulties in recruitment. The *open coding* started with multiple readings of the transcripts and *in vivo* coding and continued until first themes emerged. This process involved portioning the interview transcript into parts, categorising data, comparing differences and similarities and going back and forth between the parts (constant comparison method). Themes were developed and linked with sub-themes during *axial coding*. Memo writing was carried out throughout the analysis process for reflecting upon the emergent themes. After identifying the core themes during *selective coding*, the findings were integrated, refined and condensed. Verbatim data transcription and coding were performed in German and managed using MAXQDA 11 verbi GmbH, Berlin, Germany.

Ethical considerations

Written and oral information on the study was given prior to data collection, and informed consent was obtained. It was made clear that participations were voluntary and that they can withdraw at any point of the study. Participant's confidentiality was guaranteed, and identifying information like names and places were pseudonymised in transcripts.

Rigour

Credibility was strengthened by pilot-testing the interview guide, which used open-ended questions, and by peer debriefing. Data were derived from heterogeneous participants in order to capture a broad spectrum of experiences and perceptions. Two data collection areas (North-East and South Germany) with urban and

suburban regions were chosen so that findings are not restricted to a limited geographic area or cultural particularities. Dependability was enhanced by a detailed description of the data collection and analyses and by discussing the findings within the research team in order to reach consensus. Findings are applicable to the context they emerged from and might be cautiously transferable to other contexts in which advanced home care is similarly organised to that in Germany.

Findings

Patients undergoing HMV are dependent on the assistance of technology in order to survive and equally dependent on the assistance of others, who monitor their condition and the proper functioning of the technology. In this context, three core themes emerged in this qualitative study: 'Being familiar – Having trust' draws attention to the quality of the interpersonal relationship between the patient and the nurses, 'Being able to communicate – Being noticed' points out that patients' safety relies on the attentiveness of the nurses and 'Experiencing continuity – Feeling presence' highlights the organisational dimensions of HMV. These core themes are described separately for analytic reasons and to improve the presentation, but from the patients' point of view, they are equally important, interwoven and seen as a whole.

Being familiar – Having trust

Receiving personalised care is crucial for study participants, who describe it as receiving care tailored to their individual condition, needs and preferences. It is utterly important for their feeling of safety that nurses are familiar with all aspects of their situation, as illustrated by the following quote:

Having familiar people around me, who know my situation and how to deal with it, so that I don't have to explain every single step again and again. (Mr. Peters)

Mr. Peters feels safe when someone is nearby who is well acquainted with his situation and knows how to handle it. Not having to elucidate every detail over and over again is related to his feeling of safety.

In accordance with this, the participants expect their nurses to be well-informed about their everyday routines, their characteristics and preferences and integrate them into their practice. Nurses should almost intuitively understand what needs to be done, without the patient having to use many words to explain it. Furthermore, patients expect nurses to be accustomed to their home environment, their specific mechanical ventilators and other care devices in use. Familiarity gives patients the confidence that the nurse present knows how to deal

with their situation and is accordingly able to readily recognise and respond to impending problems.

Familiarity contributes further to patients' ability to have trust in nurses, which is essential for them to feel safe. Depending on how physically or verbally impaired patients are, the urgency of trust in a person varies. A continuously invasively ventilated participant, who cannot walk, can hardly swallow or speak, expressed it like this:

I need to have complete trust in nurses, because five minutes without the respiratory support and I would be dead. (Mr. Krause)

Mr. Krause puts his life in the hands of nurses, because without their help he would not be able to handle a critical situation with the respiration by himself. Even a short disruption of the mechanical ventilation could lead to his death. Thus, he is very vulnerable to nurses' actions and that is the reason why relying on them is the only way for him to cope with his situation.

Similarly, other participants also expect to be able to have confidence that the nurse would take the right action to preserve them from harm when needed, as in the case of technical failure. A prerequisite is, therefore, that they must first consider the nurse as trustworthy. Participants' decisions to rely on their nurses are based on both joint experiences and professional abilities (skills, competence and knowledge). It is only with nurses do they have complete confidence so that HMV users can relax and feel safe.

Being able to communicate – Being noticed

Receiving mechanical ventilation affects speaking and communication abilities, and many participants experienced difficulties with their speech and voice production. Hence, it is essential for them to be able to express themselves and their individual needs, and point out what nurses have to pay attention to and, if necessary, what nurses have failed to check. Being able to communicate is an important contributor to a patient's perception of safety, and that is the reason why they are making every effort to make themselves understood.

Patients who cannot communicate verbally develop very individual forms of communication, such as facial expressions (e.g. winking) or minor gestures (e.g. finger movements), and they expect the nurses, firstly, to perceive and, secondly, to understand their meaning and react accordingly. Mr. Zimmermann uses nonverbal communication when he is ventilated via his mask during the night.

These signs with the eyes, or signs which you use to clarify without using language what the other should do. When they are not understood directly, it feels depressing or somewhat frustrating. (Mr. Zimmermann)

In this quotation, the patient's speech is impaired; yet, at the same time, he needs the nurses' help. Therefore, he tries to give instructions using his individual body language. If the nurses are not able to decode such ambiguous signs, the patient feels discouraged and unsafe. Consequently, to help these patients feel safe, nurses need to encourage patients to express themselves in this way and to learn the meaning of this specific nonverbal language very well. This, in turn, again requires a close relationship in order to develop a special form of communication between the technology-dependent patient and the nurses.

It is of great value for individuals receiving HMV's perceived feeling of safety to be noticed and be able to establish direct contact with the nurses or relatives who are present. In situations where they need immediate help, for example, with the endotracheal suctioning or when the tube is disconnecting from the ventilator, it is very important to them that the nurse notices their need quickly and addresses it in a timely manner. It is for this reason that participants used a variety of technical communication tools, such as ringing a bell, using a baby monitor or a radio device. Ms. Hoffmann, for example, whose communication abilities are impaired, is dependent on the use of a baby monitor to attract attention when the tracheostomy tube is blocked:

Because I'm not able to speak, because I'm blocked, we use the babyphone. And I'm doing ppp [illustrating sound], they hear it then. (Ms. Hoffmann)

When Ms. Hoffmann expresses a need, the baby monitor helps her to get noticed. By means of this technical communication device, she becomes visible and can draw attention to her needs. Although technology might help to amplify patients' verbal signals, they are useless without the nurses' attentiveness.

Experiencing continuity – Feeling presence

Participants reported feeling safe when they experience continuity in their everyday life. They want the same care measures (e.g. the tube exchange) and daily routines to be performed preferably by the same nurses. Because personal continuity is a precondition for feeling safe from the patients' perspective, nurses should work for them not only temporarily, but on a regular basis. This is why Ms. Huber, similar to all other participants, wishes to be cared for by a small team of nurses.

The communication [between health-care providers] works or works better. You can rely on that, because they work it out among themselves. (Ms. Huber)

Ms. Huber's assumption is that safety-related information will and can be communicated effectively within a team, which is stable and has a manageable size. Within this core team, an unhindered and secure flow of information should be ensured by 'their' nurses and they

should guarantee the undisturbed operation of patients' routines by all team members.

Feeling the presence of these few nurses contributes to patients' perceived safety. In this respect, patients mentioned that nurses do not necessarily have to be at their bedside, but they should be within a perceptible distance. Ms. Schwarz exemplifies this in the following quote.

That is safety to me: I hear someone outside; the light is on in the hallway; I know someone is there. Simply, the certainty that someone can be here quickly.

That gives me the feeling of safety. (Ms. Schwarz)

Without seeing them, Ms. Schwarz perceives the nurses' presence by the noises they make and by the light in the hallway. Thus, the patient is given the feeling that the nurses are close enough to hear her calling for help or the alarms of the medical devices. Just the knowledge of their presence or their 'being there' creates the assurance that they are available and ready to attend to their patients' needs whenever required.

Discussion

This study explored HMV patients' perceptions of safety. The findings suggest that from an insider perspective, it is the familiar, trustworthy nurse and continuous actions combined with technology that matter and, more importantly, the social interaction between the care provider and the patient which plays a key role in their perception of safety. Thus, patients tend to have a *relational approach to safety*. Interestingly, this perception of safety seems to be consistent regardless of the healthcare setting (12–16, 38), whether the patient has a chronic or an acute condition (17, 38) or who is providing the care (13, 14).

The care of HMV patients in Germany is provided by qualified nurses. That might be the reason why the latter are the main healthcare providers who are systematically mentioned in HMV patients' accounts of what makes them feel safe or unsafe. Accordingly, implications for nursing practice will be given in order to enhance patients' feeling of safety.

Building trust relationships

Showing and experiencing a genuine interest in all aspects of the patients' situation and progressively becoming familiar with each other is important for developing trust, which, in turn, helps patients to feel safe. This insight does not only apply to HMV patients, but also to a broad range of patients in other settings (11–13, 39–41). Our findings emphasised that trust in nurses is especially important to patients who are completely dependent on others. This is supported by previous research, stating that trust is not only essential in risk situations, but also relevant in situations in which the patient is vulnerable to the actions of others (42). Hence,

it is imperative for nurses to be aware of HMV patients' need to trust them.

Building and maintaining a professional trust relationship is an important part of nurses' everyday safety work with HMV. They should behave in such a way as to constantly demonstrate to patients that they are trustworthy, in order to deliver safe, effective and patient-centred care. Having healthcare providers satisfying these requirements has been shown previously to be important to HMV patients (22, 24, 27, 28, 32). Nurses can foster trust relationship by providing information, and demonstrating their expertise prevent patients from physical harm (43).

Being there and being with the patient

Nurses can maximise patients' feelings of safety by their presence and by being attentive and responding immediately. According to a meta-synthesis, one of the necessary conditions of the presence process is that nurses are willing to enact their presence (44). This goes beyond the physical presence and once again draws attention to the interpersonal nurse–patient relationship. According to Fredriksson (45), there are two modes of presence: 'being there' and 'being with'. 'Being there' is grounded in the nurse's attentive attitude towards the patient and can be understood as an answer to a need expressed by the patient. In this condition, patient and nurse act in accordance with their specific, traditional roles. 'Being with' the patient involves being available and at his or her disposal as a whole person.

In our study, feeling the caregiver's presence was found to be important for HMV patients' perceptions of safety, which is in line with the findings of previous studies (11, 12, 41, 44). In this respect, the nurses should not just be completing a nursing intervention, they should fully focus their attention on the patient, including the technical solutions they use to express their needs. The availability of a nurse call system is a way for patients to communicate a need. Furthermore, in a recent study, it is seen as a means of exercising control by initiating a call for help (46). Some of the HMV patients expect the nurses to anticipate their needs without words or without pressing the button. However, when calling for help, HMV patients expect a short response time, because certain actions cannot wait and might even be life threatening.

To have nurses around who avoid waiting and are very attentive in order to notice patients' needs is important for the patients' ability to feel safe in HMV.

Providing competent and continuous care

Although nurses in HMV in Germany require a 3-year, mainly hospital-based, vocational training, they are not necessarily prepared for the specific conditions in this

field. In addition to a specific training, workplace training has been shown to be more important from the perspective of both patients and caregivers than formal training (47). Patients feel safe when nurses know their tasks and duties and no longer have to be instructed by the patients. It is important, from their point of view, that nurses are well-informed and that their habits exude confidence and competence.

Moreover, personal continuity helps HMV patients to build trust and familiarity over time and to feel safe. The advantage of a primary nurse system and a small nursing team is that they can make themselves very familiar with the patient's personal needs, preferences and often very specific ways of communication, such as nonverbal language. Previous studies exploring patients' perceptions of safety in other settings have identified effective communication as an important factor for safe and patient-centred care (40, 48). This is especially important for HMV patients, whose biggest challenge is communication. Earlier studies on HMV patients also indicate that personal continuity is important (4, 21, 23) and that having a small team means greater safety and less need to repeat instructions (26).

However, there are specific challenges to consider when having continuous and close relationships to patients. One example is the phenomenon of 'familiarisation', meaning that the nurses in 24/7 home care are at risk of being gradually included into the patients' family. A challenge for them is to recognise the degree of closeness required for establishing trust, while, at the same time, maintaining the necessary professional distance to the patient and his or her family. They have to find a balance between their own knowledge and skills and patients' and families' emotional needs (49). A strategy to counter this challenge is to have a professional attitude (50), whose development should be particularly emphasised in the advanced training of nurses in HMV.

Study limitations

Limitations of the present study include a potential selection bias. Given that access to participants was dependent on the help of gatekeepers, it is likely that they have influenced participant selection by deliberately choosing certain patients. However, in order to address this risk, further recruitment strategies were used.

The users of HMV are generally seriously ill and experience communication impairments (22). Therefore, an additional potential limitation of the study was the reporting bias resulting from participants' communication impairments. In two cases, nurses who were very familiar with the patient were used as interpreters. Although their presence facilitated the communication process between study participants and the research team, it might have also influenced patients' answers.

Patients undergoing HMV are considered the most vulnerable among chronically ill patients (26, 51). Accordingly, it can be assumed that only those who were healthy enough participated in the study. Consequently, study participants might be healthier and more active than the wider HMV population. However, efforts were made to include a broad spectrum of participants.

Conclusion

Our research intended to inform nurses and other healthcare professionals about ways to conceptualise safe, effective and patient-centred HMV. The core themes emerged in this qualitative inquiry make clear that the *relational dimensions of safety* should be the centre of attention and not the clinical or technical aspects or adverse events. From the users' point of view, establishing trustworthy nurse-patient relationships turns out to be one of the most important elements of safety work in HMV. This leads to the conclusion that nurse education should go beyond teaching clinical and technical skills because profound social competencies are necessary to build a trustworthy relationship with the patient. In addition, nurses require more specific training encompassing tracheostomy and ventilator care, emergency response, and advanced skills in emotional and supportive care in order to ensure that patients can feel safe in HMV. This could be supported by an advanced competency-based training programme.

In relation to nursing management, our findings point to the need for a thorough assessment of the healthcare professionals' competence prior to practice. In addition to this, some initial standardised workplace training and supervision for new staff by experienced nurses are necessary, encompassing the use of patients' technology, their situation, routines, preferences and their home environment, in order to become familiar with each individual patient. Moreover, personal continuity should be made a priority through a primary nurse system and a small nursing team.

However, some research questions still need to be answered, that is how nurses in HMV are able to establish emotional bonds which promote feelings of safety of ventilated patients on a 24/7 basis without gradually becoming a part of their family, thus losing their professional distance and attitude. Models of HMV implemented in, for example, Scandinavia, using healthcare assistants as the main caregivers and having healthcare professionals who have the formal responsibility located at a distance, might be more appropriate to the patient's needs. International comparisons of models of HMV care provision could be an effective approach in health service research to answer these questions.

Nevertheless, regardless of who is providing the care, paying more attention to the aspects discussed above

and considering more carefully patients' experiences and perceptions are essential for a safe, effective and patient-centred HMV. Nurses and other healthcare providers have to find a good balance between *keeping the patient safe* by necessary task completion (including hygiene, medication management, surveillance of technology) and *helping patients feel safe* by building a trust relationship (11).

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Author contribution

Michael Ewers was responsible for the design of the study. Christiane Schaepe and Armin Hauss collected the data. Both authors contributed to analysis and prepared the manuscript.

Ethical approval

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Publication 2

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RESEARCH ARTICLE

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“I see myself as part of the team” – family caregivers’ contribution to safety in advanced home care



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Abstract

Background: The use of medical technology and the various contributing and interdependent human factors in home care have implications for patient safety. Although family caregivers are often involved in the provision of advanced home care, there is little research on their contribution to safety. The study aims to explore family caregivers in Home Mechanical Ventilation (HMV) safety experiences and how safety is perceived by them in this context. Furthermore, it seeks to understand how family caregivers contribute to the patients’ and their own safety in HMV and what kind of support they expect from their health care team.

Methods: An explorative, qualitative study was applied using elements from grounded theory methodology. Data were collected through individual interviews with 15 family caregivers to patients receiving HMV in two regions in Germany. The audiotaped interviews were then subject to thematic analysis.

Results: The findings show that family caregivers contribute to safety in HMV by trying to foster mutual information sharing about the patient and his/her situation, coordinating informally health care services and undertaking compensation of shortcomings in HMV.

Conclusion: Consequently, family caregivers take on considerable responsibility for patient safety in advanced home care by being actively and constantly committed to safety work.

Nurses working in this setting should be clinically and technically skilled and focus on building partnership relations with family caregivers. This especially encompasses negotiation about their role in care and patient safety. Support and education should be offered if needed. Only skilled nurses, who can provide safe care and who can handle critical situations should be appointed to HMV. They should also serve as professional care coordinators and provide educational interventions to strengthen family caregivers’ competence.

Keywords: Qualitative research, Family caregivers, Advanced home care, Home mechanical ventilation, Patient safety

Background

Advanced technology for the provision of enteral tube feeding, home-based dialysis, intravenous therapy and home mechanical ventilation (HMV) is widely used in the community in many western countries. Multiple factors have contributed to this converging trend, such as advances in technology, increased availability of ‘hospital at home’ services, demographic changes paired with an increasing number of people living with chronic

conditions or surviving congenital conditions, reduced institutional care and cost savings [1, 2]. These developments enable technologically dependent patients with complex needs to remain at home while receiving intensive nursing care on a comparable level to that provided in the hospital setting [3]. Advanced home care, thus, promises to be a cost-efficient and patient-centered alternative to institutionalized care [4, 5].

This paper will focus on HMV as an example of advanced home care. The latter is a therapeutic option for individuals with various underlying diseases ranging from conditions leading to progressive respiratory failure to unsuccessful weaning after an acute respiratory

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failure. The HMV can be delivered noninvasively (via mask) or invasively (via tracheostomy) on a continuous or intermittent basis [6]. Users of HMV represent a vulnerable, heterogeneous, small, but increasing group of technology-dependent individuals in many western countries [7, 8]. Although the number of patients on HMV in Germany is unknown due to a lack of prevalence data, it is estimated that 20,000 individuals are living with HMV in Germany [9]. Caring for an individual receiving HMV is very complex, because it entails the care of a person who is receiving life support due to their critical illness and has substantial care needs. Their condition makes patients dependent on technological assistance and skilled nursing services providing personal care, several daily medical and therapeutic procedures, and educational and psychosocial support for the patients and their family.

The fact that ventilator-dependent patients receive up to 24-h professional nursing services and medical treatment in their private homes funded by the Statutory Health and Nursing Care Insurance in Germany is of particular relevance. The main goal of this form of advanced home care is to guarantee a hospital-like immediate and qualified intervention in life-threatening situations [10]. Thus, providing intensive care in a private home brings challenges for all actors involved, including health professionals, patients and family members [3]. For families, the intrusiveness of medical technology in the private home care setting and the constant presence of nurses, flanked by occasional visits of other health care providers, results in a lack of privacy, which often proves to be a great challenge [11–13].

Furthermore, advanced home care has implications for patient safety. Various contributing and interdependent human factors have an impact on patient safety in home care. The individual characteristics of the patients and their caregivers, the nature of health care tasks, the home and social environment, medical devices and new technology are major components [14, 15]. The home care setting, for example, has distinctive characteristics that are very different from institutional environments and that have an impact on patient safety. Home care nurses work in isolation and their role is rather that of a guest in the family's home [15, 16]. The unique nature of each individual home contributes to home care being viewed as unregulated and uncontrolled [17]. Despite this background, corresponding research is mainly conducted in institutional settings and little attention has been paid to safety in home care [17, 18]. Recent research from Canada has gleaned information that adverse events in home care are not rare [19, 20]. The Pan-Canadian Home Care Safety Study reports that 10.1% of the clients experience adverse events annually and that 56% of these were predictable [21]. Existing

studies on safety in home care focus on safety risks and specific adverse events, such as falls, pressure ulcers, unplanned hospital admissions and medication errors, which are reported from the perspective of the health care provider [18, 20, 22, 23]. Very few studies have, however, focused on patient safety in home care from the perspective of the patient and family caregiver [24, 25]. Among these studies, the Pan-Canadian Home Care Safety Study has found that patient safety is strongly influenced by the understanding of family members, caregivers and providers regarding safety [26]. Consistent with these findings, another Canadian study found that safety concerns from the perspective of patients and family caregivers are multidimensional and intersectional, and are influenced by physical, spatial and interpersonal factors [25]. That is also a reason why the general definition of *patient safety* needs to be broadened by incorporating the perspective of all actors involved, including the family caregivers [17, 27].

A recent scoping review found that the compulsory enrollment to take on the caregiver role, the lack of preparedness and support, and loss of control have an impact on family caregiver safety [28]. In addition, psychological and physical health impairments and financial problems create a safety concern for caregivers [28]. Whether this applies to advanced home care is not known. To date, most qualitative research on family caregiving in advanced home care focuses on the perspective of parent caregivers to children. These studies have shown that family caregivers play a pivotal role in advanced home care, providing complex caregiving tasks, including technical procedures in daily care. They advocate for their family members within the health care system, take care of the equipment and coordinate health care services [29–31]. The responsibility for care has been shifted from the personnel to the parents [12, 13, 32]. Consequently, physical and emotional burdens and social isolation among caregivers of technology-dependent children are widely reported throughout the literature [13, 31, 33]. The main concern of family caregivers regarding adult HMV users is the constant struggle with health care services, including the lack of involvement in decision-making processes, the lack of continuity of care and the inadequate professional support [34]. Accordingly, access to psychosocial support was reported as being important to family caregivers [35, 36].

Family caregivers might be the first to witness any safety-related issue in the home setting due to their daily interaction with the care recipient and the formers' often extensive shared life experience, and can, consequently, provide a unique perspective of home health care delivery. Given that the number of patients who require advanced home care in general and HMV specifically will probably increase, there is a need to better understand the role of the various actors involved in patient safety

in this context. Nevertheless, the literature on family caregiving and safety remains focused on two aspects. Family caregivers are either referred to as “secondary patients” who need to be protected from physical and emotional harm, or as easily available providers of care with the potential of harming their family members [37]. Family caregivers’ own perspective of their role in providing safety in home care has not yet gained attention from the research community. However, a better understanding of family caregivers’ perspective of their contribution to safety their perspective could provide health professionals with additional strategies for providing safe, effective and patient-centered care in the home setting. To date, little empirical work has been undertaken to examine family caregivers’ perspective of safety [28]. The present study, therefore, aims to fill this research gap by exploring family caregivers in HMV safety experiences and how safety is perceived by them in such a special care arrangement. Furthermore, it seeks to understand how family caregivers contribute to the patients’ and their own safety in HMV and what kind of support they expect from their health care team.

Methods

An explorative, qualitative research design using elements of grounded theory methodology [38] has been chosen for this study.

The study was part of a larger, multistage qualitative health services research project called SHAPE (“Safety in Home Care for Ventilated Patients”) which aimed at providing impulses for the conceptualization of safety work in advanced home care based on empirical data from the perspective of both users and providers. Partial results of this study, which has been funded by the German Federal Ministry of Education and Research and was performed from 2013 to 2017, have been published elsewhere [39].

Recruitment

Recruitment was facilitated by the staff of nursing care providers (gatekeepers) who are in daily contact with the families. They provided some basic verbal information and distributed an introductory letter about the study to eligible participants. Other ways of approaching participants were through a hospital-based specialized respiratory care center, a health care insurance company, personal contacts and organizations, such as the German Association for Muscular Dystrophy and patient advocacy groups. Those who were interested in participating contacted the research team themselves and or via the nursing care providers and a mutually convenient appointment for the interview was scheduled. Participants were recruited in rural and urban areas in Northeast and South Germany to identify regional differences.

Family caregivers had to be at least 18 years, speak and understand German, and be involved in the care of an adult HMV user in some way to be included in the study. Maximum variation in participant characteristics, for example age, relationship to the care recipient, years of experience of HMV in the home, was used as a sampling strategy. It aims to include a wide spectrum of participants to gain a broad insight into their diverse perspectives and experiences [40].

Data collection

Data was collected on two visits, as part of an iterative process over a period of 12 months (from June 2014 to June 2015). Potential participants were given additional information prior to the onset of the study.

Written and oral informed consent to participation was obtained on the first visit. Participants were asked to provide sociodemographic information (e.g. age, hours of caregiving, income and educational level) and to fill in the Burden Scale for Family Caregivers [41]. In addition, sociodemographic-, disease- and treatment-related information of the patients was collected. It was made clear that participation was voluntary and that they could withdraw from the study at any point in the data collection or analysis. Participants’ confidentiality was guaranteed. On the second visit, a pilot tested, semi-structured interview guide with open-ended questions was used to elicit information on the everyday life of caregivers (“I would like to get an idea of how your everyday life looks like and therefore ask you to tell me how your day yesterday looked like”) and the role of HMV and their caregiving. They were further asked to give examples of situations where they felt particularly unsafe (“Can you describe a situation where you felt particularly unsafe?”), what they did in this situation, how the professionals reacted and what could have been done better or differently. At the end of the interview, they summed up their meaning of safety in home care. New questions evolved during data analysis and topics became more focused in later interviews.

Apart from a few exceptions, most of the interviews were conducted in the HMV recipient’s home. The interviews lasted between 32 and 250 min and were audiotaped (with one exception; permission was refused by one informant and detailed notes were recorded). Two researchers were present during the interviews in most cases. Nonverbal expressions and gestures, potential disruptions, and the topics addressed before and after the interview were recorded in an interview protocol. An additional, detailed observational protocol was written on the home environment.

Data analysis

Although data collection and data analysis were intended to occur concurrently in an iterative process,

this could not always be realized due to initial recruitment difficulties. The interviews were transcribed verbatim and identifying information were pseudonymized in this process. The analysis was performed in German and the software MAXQDA 11 (verbi GmbH, Berlin Germany) was used to organize and manage the data. The thematic analysis began after the first interview with repeated reading of the first transcripts in order to become immersed in the data [42–44]. In the next step, the data were coded. Three forms of coding were employed: *Open coding* with in vivo coding was performed. The constant comparison technique was used with codes and concepts and clustered to create preliminary categories. Connections between categories were built in the *axial coding*. In *selective coding*, categories were saturated with data from new interviews. Memos were written throughout the whole analysis process to document ideas and reflections about the emerging codes and categories. After all the data were coded, the categories were sorted and combined into themes. Finally, several relevant themes were defined and named and condensed for reporting.

Trustworthiness

Strategies that were used to evaluate the rigor of the study were based on the concept of trustworthiness by Lincoln and Guba [45]. Credibility was strengthened by the prolonged engagement in the field and by maximum variation sampling [46]. Prolonged engagement means that the researcher spent extended time in the field in order to gain a deeper understanding of the social context of the interviewees' narratives, which helped to gain their trust and thereby facilitated authentic data collection. Dependability was enhanced by performing the analysis as part of a research team. To this end, several discussions and reflections were done throughout the analysis process. The team discussed and reflected for example on alternative ways of approaching participants in order to avoid selection bias, if more variation was needed in the sampling, the next analytical steps that had to be taken, the themes that emerged from the data. A thick description of the sample, setting and data collection, and analysis are presented for the reader's judgment of transferability.

Results

Sample description

A total of 15 relatives of HMV patients gave consent to participate in the study (see Table 1 for participants key characteristics). Nine of them are spouses or partners, three mothers, two children and one sister. The participants' age ranged from 31 to 83 years, with three males and 12 females. Four caregivers were employed, eight retired and three partially retired or unemployed. Eight of

the 15 participants were living in a common household with the HMV users and seven were living separately.

The nature of family caregivers' involvement in everyday care varies. While some of them provide 24-h care (including endotracheal suctioning, supervision of the functioning of the technical devices and constant vigilance over the care recipient), others merely visit the patients in their homes on a regular basis. The degree of involvement ranged from 1, 5 to 24 h per day. All but one family were receiving (professional) nursing services. The extent of skilled nursing care offered ranged from 8 to 24 h per day. Despite this variation, the results of the Burden Scale for Family Caregivers in our sample show that most of the participants experience little and moderate burden (see Table 1).

Apart from using HMV, the care recipients are similarly a heterogeneous group. The reasons for HMV dependency varied from neuromuscular diseases, restrictive, thoracic disorders to chronic obstructive pulmonary disease. Average daily ventilation use ranged from 10 to 24 h. A more detailed description of the care recipient's characteristics can be found elsewhere [39].

Contribution of family caregivers to safety in HMV

Several themes emerged from the interview data during analysis exploring the broad spectrum of safety experiences and perspectives of relatives of HMV users. It also became apparent that family caregivers of ventilated patients use several strategies to cope with their specific situation and to guarantee the care recipients' and their own safety. "Fostering mutual information sharing about the patient and his/her situation", "coordinating health care services" and "compensating for shortcomings in HMV" are the most evident contributions family caregivers make to guarantee safety in advanced home care for technologically dependent patients based on our empirical data.

Mutual information sharing

Family caregivers in this study often try to foster mutual information sharing about the patient and his/her situation based on their familiarity and their intimate knowledge about their relatives' needs, wishes and personal preferences. That is particularly the case when the patients themselves have limited communication possibilities due to the ventilation or when they cannot express themselves due to their vulnerable physical or mental status. They not only intend a more personalized care by sharing their information with members of the health care team, but rather to prevent adverse events and promote patient safety. Exemplarily, this strategy is being applied by Ms. Yilmaz, who has been caring for her ventilated and bedbound husband 24-h a day for many years. Due to her long-standing marriage and her

Table 1 Characteristics of family caregivers and care recipients

Caregivers Pseudonym	Age of caregiver	Gender of caregiver	Level of Education	Employment status	Relationship to the care recipient	Living arrangement	Years of experience of HMV in the home	BSFC Results*	Care recipients Disease group	Hours of HMV	Hours of nursing service	IV or NV
Mrs Becker, Katrin	31	Female	High School	half-time employment	daughter	separated from the patient	1	40	neuromuscular disorder	continuous	24hs	IV
Mrs Wagner, Monika	63	Female	College or University	part-time retirement	wife	together with the patient	2	13	neuromuscular disorder	continuous	24hs	IV
Mrs Yilmaz, Fatma	60	Female	High School	full-time employment	wife	together with the patient	7	23	neuromuscular disorder	continuous	24hs	IV
Mr Meyer, Peter	56	Male	College or University	early retirement	son	separated from the patient	10	27	pulmonary disease	continuous	24hs	IV
Mrs Wolf, Christa	71	Female	Basic	retirement pension	wife	together with the patient	1	16	neuromuscular disorder	> 16hs	24hs	IV
Mr Richter, Karl	79	Male	College or University	retirement pension	husband	separated from the patient	missing	missing	vegetative state	> 16 hs	24hs	IV
Mrs Bauer, Ursula	70	Female	High School	retirement pension	mother	together with the patient	41	19	tetra paresis	< 16 hs	9hs	IV
Mrs Braun, Sabine	56	Female	Basic	early retirement pension	wife	together with the patient	6	21	Tetra paresis	< 16 hs	without nursing service	IV
Mrs Schulz, Angelika	62	Female	Basic	half-time employment	sister	separated from the patient	4	28	metabolic disease	continuous	24hs	IV
Mrs Werner, Gabrielle	54	Female	High School	full-time employment	wife	separated from the patient	3	23	neuromuscular disorder	continuous	24hs	IV
Mrs König, Renate	61	Female	High School	early retirement pension	spouse	separated from the patient	1	37	neuromuscular disorder	continuous	24hs	IV
Mrs Peters, Birgit	59	Female	High School	no gainful employment	mother	together with the patient	41	7	neuromuscular disorder	continuous	8hs	NIV
Mrs Koch, Ingrid	69	Female	Missing	retirement pension	wife	together with the patient	missing	missing	infectious disease	continuous	8hs	IV
Mrs Zimmermann, Andrea	56	Female	Basic	unemployment	mother	together with the patient	15	45	tetra paresis	10hs	11hs	NIV
Mr Hoffmann, Günther	83	Male	High School	retirement pension	husband	together with the patient	14	31	neuromuscular disorder	continuous	24hs	IV

*BSFC Results: no/little burden: 0–24 points, moderate burden: 25–55 points, severe burden: 56–84 points

extensive experience of caring for her technologically dependent husband, she is convinced that she knows his needs, wishes and preferences very well. She wants to share this unique information with the nurses so that they can act accordingly. In exchange, she herself wants to be informed regularly about what happens in everyday care and how her husband reacts to the care services offered. The following quotation illustrates her motivation:

"Well, I see myself as part of the team, I would say, I do other things, but anyway. However, if this exchange happened more often, my husband would be or feel better. If he was better, then that would mean safety for me." (Ms. Yilmaz).

Although Ms. Yilmaz is aware that she is not performing the same duties as the nurses, she perceives herself as a constitutive member of the care team. Regular information exchange between family caregivers and the health care team about the patients' needs, wishes and preferences would, according to her assumption, benefit the patient's health and, thus, promote safety for all parties involved.

Many other family caregivers from our sample wish to be seen as a relevant source of information about the patients and, therefore, get more involved in caring for their loved ones, albeit to a varying extent. Family caregivers wish to be taken seriously so that they can speak for the care recipient and offer insights into their individuality. However, this mutual information sharing is not always valued, and some health professionals make the family caregivers feel like they are an unwanted factor in HMV. In such cases, decisions regarding the patient are made without them, their opinion and experience is deemed insignificant, their perspective is not heard, and information is withheld. Feelings of insecurity on the side of the users, or even worse, near misses and adverse events are consequences that might arise from this disregard of the family caregivers and the information they have to share in advanced home care.

Informal coordination

Family caregivers contribute to safety in HMV by coordinating care. This is not a formal function assigned to them, it is rather imposed on them accidentally. However, this implies a substantial organizational effort and is sometimes a burden for them. They identify what equipment is needed for the provision of care (e.g. wheelchair, second back-up ventilator, consumable materials, care aides) and make sure it is available in time. Occasionally, they have to negotiate with the health insurance company in an attempt to gain access to fully functional replacement devices or other equipment on site. Moreover, family caregivers sometimes perceive the need to link and coordinate the activities of the several

isolated working health professionals involved in HMV. This is demonstrated by the experiences of Ms. Becker. Although she is not living together with her 24-h a day ventilated father, she is still actively involved in his everyday care:

"Well, I am also the link between the therapists, physicians, nurses and suppliers of care equipment. I am often present, so that I know what is being said, so that I can transfer this to everybody. I am part of this." (Ms. Becker).

This citation shows that Ms. Becker takes on the responsibility of bringing together the different health care providers involved in the home care of her father. She is the one who transmits information among them, which otherwise would not have been transmitted, which might cause severe safety problems. This requires her presence when the health professionals are doing home visits and to remember all the appointments of the different parties involved. She also keeps an information diary, where she expects the health professionals to write to her when something unexpected occurred.

This role of an informal care coordinator is not only very responsible, but also an exhausting one for the family caregivers. Sometimes they find themselves between the different sides, especially when some parties are withholding information from them or each other. If the family caregivers are actively excluded from the team, feelings of uncertainty, worry and anger are triggered.

Compensating for shortcomings

Experiences with professional home nursing services differ widely. Those who have positive experiences can rely completely on nurses in terms of safety. Others who have had negative experiences (e.g. when nurses fall asleep during the night shift) put little trust in them and want to be prepared for compensating of shortcomings in HMV.

Some family caregivers seek to expand their knowledge and skills in order to ensure a high degree of safety for the patients using various strategies. Some report having been instructed by nurses, while others have learned by observing nurses performing the tasks. When they are not instructed regarding care and emergency situations, it is not uncommon that they try to acquire skills behind the nurse's back in order to be prepared. The elderly married couple Mr. and Ms. Bauer who are taking care of their ventilated and multi-morbid adult son can be seen as an example of that strategy:

"What I have also done, yes, is that I have changed the cannula myself together with my husband. I said I would simply like to do it, because I have to be able to do it in an emergency." (Ms Bauer).

The context of this citation suggests that neither Ms. nor Mr. Bauer have been taught how to change a

tracheostomy tube, although they would like to know how to do it so that they can handle critical situations themselves when the professionals are not observing or available. The Bauers – like other family caregivers in HMV – want to be prepared for handling emergency situations, but are prevented from doing so.

Most of the family caregivers in our study tried to keep control over the home care situation, making sure that the care recipient is well cared for and nothing is overlooked. Some of them reported that they had to remind the nurses of different nursing measures, such as changing the tube or administering medication. Some family caregivers, such as Ms. Zimmermann, even try to instruct the nurses to ensure the HMV recipient's safety in the absence of a proper initial on-the-job training for new and inexperienced nurses. She cares for her adult son during the daytime, whereas a nurse is on duty and responsible for his care and safety at night when he is mechanically ventilated. However, Ms. Zimmermann is constantly alert.

"I instruct them always. I, I as mother, have to instruct qualified personnel, show them how to catheterize, I have to do it, that isn't my job." (Ms. Zimmermann).

Ms. Zimmermann is well aware that instructing or supervising professional caregivers is not her task as a mother. She must do it anyway and compensate for qualification deficits as well as organizational shortcomings so that her son gets proper help when necessary during the night.

Some family caregivers even feel the need to prepare themselves and the health care team for emergency situations. Exemplarily, Mr. Hoffmann's wife cannot move or breathe by herself because of her advanced neuro-muscular disease and so she is completely dependent on the medical devices and human assistance. Mr. Hoffmann simulates critical situations like a power failure and observes the nurses' reactions:

"And you know, my presence is necessary. The women are not able to do it alone. I understand that, nervous, making mistakes and then this and that happens. And you have to have that under control. The more you train, the better it is." (Mr. Hoffmann).

Mr. Hoffman guides the "training" to make sure that everybody on the care team is prepared for a potentially hazardous situation. Thereby, he is the one who tries to gain control in order to prevent potential risks for adverse events. The citation further illustrates the shift of roles: He is in charge, guiding the training and not the nurses, as it should be from a professional point of view.

Not all family caregivers in our study might go as far as Mr. Hoffmann. However, most of them are on alert and constantly on call for supervision. They need to be sure that the ventilated care recipient is monitored closely and that someone can intervene quickly at any

time. When nurses perceived as inexperienced or insecure are in charge, relatives feel indispensable and make arrangements to be at home to supervise the care recipient and the functioning of the technical devices themselves. Being present enables family caregivers to intervene if necessary. As a result of their feeling indispensable for the patient's safety, some family caregivers mentioned not having taken time off for many years and being trapped in their own house. However, they are convinced that they make an important contribution to patient safety in advanced home care by undertaking this form of compensation.

Discussion

Moving advanced medical technology from institutional settings to the community equates partially with a shift of responsibility for patient care from professionals to family caregivers [13]. Even if nurses are responsible for advanced home care up to 24 h day, such as in Germany, family members still have an active, complex and demanding part to play. The findings of this study extend previous research by showing that family caregivers take considerable responsibility for patient safety by being actively and constantly committed to safety work. This is in line with the findings of the Pan-Canadian Home Care Safety Study stating that all actors (clients, family members, caregivers and paid providers) in home care are creating and maintaining safety [26]. Moreover, the findings of the present study broaden the body of literature on family caregivers and safety by indicating that in many cases, family members are the ones to ensure patient safety in advanced home care by applying several strategies. Exemplarily, their intimate knowledge of the needs, wishes and preferences of the care recipient is a valuable resource for the health care team and family care givers are acting a guarantor of patient safety by sharing this information. Therefore, a change in focus from considering family caregivers as "secondary patients" or harmful to patients [37] to acknowledging their valuable contribution to patient safety in HMV is needed. Raising awareness about family caregivers valuable contribution to patient safety among nurses and other health professionals and conducting further research on family caregivers' contribution to safety would be ways towards such a change.

However, the study findings illustrate that some of the family caregivers' actions are putting the client at risk, for example, when relatives whose need for preparedness is not met through proper professional instructions execute advanced nursing tasks, such as changing the tracheostomy tube behind the nurse's back or simulating emergency situations. Their intention is certainly not to put the care recipient in danger, but they need to be sure that they can offer immediate assistance in life-threatening

situations when professionals cannot. Our findings show that even qualified nurses sometimes lack expertise regarding HMV care, which makes family members feel indispensable and responsible, as reported in previous studies [34, 47]. Therefore, they feel forced to gain knowledge and technical skills regarding HMV therapy to compensate for this lack of professional expertise. It is problematic that family members must take the initiative to (re)gain control, instead of the nurses enabling them to handle critical situations and strengthening their self-management competence through educational interventions.

The partnership approach

The need for family members to participate in the provision of home care has been highlighted before in research on technologically dependent children [12, 13], but has not been discussed previously either in relation to family caregivers of adult patients or to safety. The current findings indicate that family caregivers are involved in care, even if qualified nurses are in charge. Furthermore, they feel responsible and indispensable for the safety of their loved ones, as reported previously [34]. This perceived responsibility also entails supervising and educating nurses in the management of the devices, as seen in previous studies [32]. Family caregivers feel forced to take on these tasks because they do not feel that the nurses in charge are sufficiently prepared to care for the HMV recipient properly. Similar to previous findings [34], they compensate for their health care professionals' perceived lack of competence by being present and constantly alert. However, participation in care should not equate with compensating for health care providers' deficiencies or training professionals, but valued as an important resource. The rationale for their need to participate in the provision of home care is that they see themselves as patients' advocates due to their closeness to their loved ones and due to their long caring experience, which agrees with other studies [31, 48]. This valuable perspective helps to identify issues that professionals may not recognize and, therefore, foster patient safety.

Our study further shows that being involved in HMW means knowing that the loved one is well cared for and makes the family caregivers themselves feel safer. That patient safety is inextricably linked with family caregivers' safety has even been found in previous research [17]. Therefore, advanced home care draws attention to the partnership approach between health professionals and family caregivers. So far, caregiver roles and responsibilities have not been clarified and should, therefore, be openly negotiated between partners and not be imposed upon families against their will [49]. Due to the complex nature of caring for this high-risk population and the numerous professionals involved in advanced home care,

negotiation of roles might be even more relevant in this setting than in usual home care. It also seems important that this role negotiation does not result in an over-reliance on family caregivers to keep the patient safe, this being the key role of contemporary nursing [50].

Family caregivers should be offered support

The results of the Burden Scale for Family Caregivers show that most participants in our sample experience some burden due to their participation in home care provision, although in most cases qualified nurses are in charge up to 24 h a day, which could be expected to ease the burden. One explanation might be that they cannot rely completely on the health professionals providing safe and quality care. As a consequence of their lack of trust in professional care, and mutual information sharing as well as difficulties with health care team coordination, they are concerned about the patients' safety and feel forced to partially take on professional roles and responsibilities which can be burdensome. Thus, it is of utmost importance that they have permanent access to professional problem-solving support along with psychosocial and emotional support, which echoes previous studies about technology-dependent patients' close relatives, emphasizing the importance of the availability of professional support either in-person or by phone [31, 36, 51, 52]. It is imperative that nurses and other health professionals acknowledge the relatives' perception of their own support needs, offer targeted support themselves or refer them to relevant services. The support should be easily available to promote a sense of safety. This support is particularly important at the beginning of HMV [36]. Furthermore, it is equally important that family caregivers are educated on how to handle unexpected situations and properly supervised to protect them from becoming a risk factor for the care recipient. This is a key nursing task, which is apparently not fulfilled sufficiently in HMV in Germany.

Limitations

The strength of this study lies in integrating the family caregivers' voice into home care safety research. At the same time, it is its major limitation that these findings only reflect a single perspective. Future studies triangulating our findings with the perspectives of patients and nurses or other professionals need to be undertaken to provide a holistic understanding of patient safety in home care.

As in all qualitative studies, findings are context-bound. The care provision of HMV in Germany is different to that in other countries and it remains unclear whether family caregivers' contribution to safety is dependent on the qualification of formal caregivers. It is, however, likely that the findings will have some relevance for other family

caregivers in advanced home care, which could be investigated in further research.

Furthermore, recruiting participants through nursing service providers can be a disadvantage, because these might have selected relatives who are satisfied with their services. However, further recruitment strategies were used to address this risk of selection bias (see above).

Conclusions

As advanced home care is gaining momentum, there is an increasing need to focus on patient safety in this setting. The perspective of family caregivers presented yields interesting insights into the multiple tasks family caregivers take on to guarantee safety for their loved ones. In conclusion, nurses and other health professionals should meet family caregivers with respect and value their considerable role and the responsibility that they take for patient safety. Given the essential role they play in advanced home care, family caregivers should be seen as important, valuable and trustworthy partners.

However, the fact that family caregivers are performing nursing and medical tasks and even train professionals raises serious concerns. Instead, only competent personnel should be in charge of helping family caregivers feel less indispensable for patient safety. Nurses and other health professionals should act in partnership with family caregivers and allow them to deliberately choose their role in patient care and safety.

Implications for nursing practice

Given family caregivers' enormous commitment to ensure patient safety, nurses need to regain their professional responsibilities and duties from families. Our findings suggest that only skilled nurses who can provide safe care and handle critical situations should be appointed for HMV. Nurses should also serve as professional care coordinators and provide educational interventions to strengthen families' competence. An adequate training should encompass providing concrete instructions on areas in which family caregivers would like to be involved, such as the proper use of the medical equipment or preparedness for emergency situations. Another important family nursing intervention should be the negotiation of roles in advanced home care.

Abbreviation

HMV: Home mechanical ventilation

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Availability of data and material

The data generated for this study were used under license for the current study as so are not publicly available. Data are however available from the

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Authors' contributions

ME designed the health services research project SHAPE. CS collected data and CS and ME made substantial contributions to the analysis and interpretation of data. CS drafted this manuscript and ME revised it critically. Both authors read and approved on the final manuscript.

Ethics approval and consent to participate

Approval of the study was granted by the Charité – Universitätsmedizin Berlin Ethics Commission (Ref EA2/028/14). Written informed consent was obtained from all participants.

Consent for publication

The participants gave written consent to publication of the data.

Competing interests

The authors declare that they have no competing interests.

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Publication 3

Ewers M, **Schaepe C**, Lehmann Y (2017): Alles sicher? – Risikosituationen in der häuslichen Intensivpflege aus Sicht beatmeter Patienten und ihrer Angehörigen. Pflege. Wissenschaftliche Zeitschrift für Pflegeberufe 30(5), 365-373



Alles sicher? – Risikosituationen in der häuslichen Intensivpflege aus Sicht beatmeter Patienten und ihrer Angehörigen

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Zusammenfassung:

Hintergrund: Die Zahl häuslich versorgter beatmeter Patienten/Patientinnen in Deutschland wächst seit Jahren. Über Strukturen, Prozesse und Ergebnisse der technikintensiven häuslichen Intensivpflege ist indes wenig bekannt. Aspekte der Patientensicherheit werden kaum thematisiert.

Fragestellung/Ziel: Gefragt wurde nach Erfahrungen mit der häuslichen Intensivpflege und nach Situationen, in denen sich beatmete Patienten/Patientinnen und Angehörige (un-)sicher fühlten. Ziel war es, Einblicke in den Versorgungsalltag zu ermöglichen, Risiken aus Nutzersicht aufzudecken und Impulse zur Förderung der Patientensicherheit zu setzen.

Methode: Durchgeführt wurde eine qualitativ-explorative Studie, basierend auf leitfadengestützten Interviews (beatmete Patienten N = 21; Angehörige N = 15). Samplebildung, Datenerhebung und -auswertung orientierten sich an Prinzipien der Grounded Theory.

Ergebnisse: Risikosituationen entstehen aus Sicht beatmeter Patienten/Patientinnen und Angehöriger, wenn (non-)verbale Kommunikationsangebote übersehen oder missverstanden, patienten- oder technikbezogene Überwachungsaufgaben vernachlässigt, Kooperations- und Abstimmungserfordernisse unterschätzt sowie Aushandlungs-, Edukations- und Supervisionsaufgaben unterbewertet werden. Auch mangelnde Kompetenz, Selbstsicherheit und Professionalität auf Seiten der Pflegenden können Risikosituationen provozieren.

Schlussfolgerungen: Patienten/Patientinnen und Angehörigen aufmerksam zuzuhören, trägt dazu bei, Qualitätsmängel in der häuslichen Intensivpflege zu identifizieren, Risikosituationen vorzubeugen und patientenzentrierte Sicherheitskonzepte für dieses Setting zu entwickeln.

Schlüsselwörter: Patientensicherheit, häusliche Intensivpflege, beatmete Patienten, qualitative Studie

Everything safe? – Risk situations in advanced home care from the point of view of ventilated patients and their relatives

Abstract:

Background: The number of home mechanically ventilated (HMV) patients has been growing for years. However, little is known about requirements, processes and effects of advanced home care, provided in distance from clinics and doctors. To date, safety related aspects of the above mentioned issues have scarcely been examined.

Aim: Users of advanced home care were asked about their experiences and about situations in which they felt safe or unsafe. The aim was to gain insights into the daily care provision, explore safety risks from the users' point of view, and to develop new approaches to enhance patient safety in home care for the severely ill.

Method: A qualitative explorative study has been carried out, based on semi-structured interviews (ventilated patients N = 21; relatives N = 15). Sampling, data collecting and data analysis were guided by principles of Grounded Theory.

Results: Risk situations occur when (non-)verbal communication offers of HMV patients are overseen or misunderstood, patient- or technology related monitoring tasks are neglected, if coordination and collaboration requirements are undervalued and if negotiation processes as well as education and supervision needs are disregarded. Furthermore, nurses' lack of competence, self-confidence and professionalism may produce risk situations.

Conclusion: Listen carefully to patients and relatives can help to identify quality shortcomings in advanced home care, to prevent risk situations and to develop patient-centered safety concepts for this particular setting.

Keywords: patient safety, advanced home care, ventilated patients, qualitative study

In Deutschland wächst die Zahl häuslich versorgter, beatmeter Personen jeden Lebensalters. Sie leiden an unterschiedlichen Grund- und Begleiterkrankungen, befinden sich oft in kritischen Gesundheitssituationen und haben ausgeprägten Bedarf an therapeutisch-technischer Unterstützung und alltagsnaher Fremdhilfe. Aussagefähige epidemiologische Daten zu dieser heterogenen Patientengruppe sind kaum verfügbar. Zudem fehlen aufbereitete Routinedaten der Krankenversorgung und einschlä-

gige Register, weshalb ihre genaue Zahl unbekannt ist (Stark, Lehmann, & Ewers, 2016). Schätzungen zufolge werden derzeit in Deutschland ca. 20 000 beatmete Patienten/Patientinnen häuslich versorgt – mit steigender Tendenz (Lehmacher-Dubberke, 2016). Befördert wird dieser Trend durch den demografisch-epidemiologischen Wandel sowie eine Zunahme komplexer chronischer Erkrankungen und von Multimorbidität, besonders im höheren Lebensalter. Hinzu kommen erweiterte Be-

Was ist (zu dieser Thematik) schon bekannt?

Beatmete und andere technikabhängige Patienten/Patientinnen werden vermehrt häuslich versorgt. Damit verbundene Sicherheitsaspekte werden kaum diskutiert.

Was ist neu?

Als Nutzer der häuslichen Intensivpflege berichten beatmete Patienten/Patientinnen und Angehörige von zahlreichen Risikosituationen.

Welche Konsequenzen haben die Ergebnisse für die Pflegepraxis?

Patienten/Patientinnen und Angehörigen zuzuhören trägt dazu bei, Sicherheitsrisiken zu identifizieren und durch geeignete Strategien zu minimieren.

handlungsoptionen am Anfang und Ende des Lebens oder in kritischen Lebenssituationen, technische Entwicklungen und ökonomische Anreizsysteme (Ewers & Lehmann, 2017).

Über Strukturen, Prozesse und Ergebnisse der häuslichen Versorgung beatmeter Patienten/Patientinnen ist wenig bekannt. Aufgrund der latenten Lebensbedrohung benötigen sie in der Regel eine besonders aufwändige und anspruchsvolle Form der häuslichen Pflege, die basierend auf bundesdeutschen sozial- und leistungsrechtlichen Grundlagen eine kontinuierliche Krankenbeobachtung und medizinisch-pflegerische Interventionsbereitschaft durch qualifizierte Pflegenden bis zu 24 Stunden am Tag einschließt. Die Forschung, die sich mit dieser auch als häusliche Intensivpflege bezeichneten Form der Versorgung, deren Entwicklung und besonders deren Qualität auseinandersetzt, ist begrenzt (Ewers, 2003, 2010; Paul, 2013). Inzwischen verdichten sich Hinweise auf eine zunehmende Unübersichtlichkeit und Intransparenz des Versorgungsangebots, wenig patientenorientierte Formen der Versorgungsgestaltung, substantielle Steuerungsprobleme, erhebliche Qualitäts- und Qualifikationsdefizite sowie spezifische Sicherheitsrisiken für die beatmeten Patienten/Patientinnen und deren Angehörige – sprich für die Nutzer dieses Versorgungsangebots (Lehmann, Stark & Ewers, 2016; Lehmann & Ewers, 2016).

Patientensicherheit in der häuslichen Intensivpflege

Gemeinhin wird Patientensicherheit als Abwesenheit unerwünschter Ereignisse definiert (Wischet & Eitzinger, 2009; APS, 2014; ÄZQ, 2015). Sie gilt als professions- und situationsübergreifendes Konstrukt, das durch Wechselwirkungen personaler, prozeduraler und struktureller Komponenten zustande kommt (Kocks et al., 2014). Ziel ist das Vermeiden von Fehlern, Abweichungen, Unfällen und das vorausschauende Management von Risikosituationen. Problematisiert wird das Thema Patientensicherheit überwiegend für das Krankenhaus und das dortige Behandlungsgeschehen (Porzsolt, 2007; Feng, Bobay & Weiss, 2008). Die häusliche Pflege ist von diesen Initiativen weitgehend ausgenommen (WHO, 2008; DPR, 2014), dabei hat deren Umfang, Komplexität und Gefahrengene-

igkeit seit geraumer Zeit deutlich zugenommen (Ewers, 2003; Lang & Edwards, 2006; Lang, Edwards & Fleischer, 2008). Der in Deutschland rasant verlaufende und durch die Auslagerung von Patientengruppen und Behandlungsformen aus dem stationären in den ambulanten Sektor geförderte Auf- und Ausbau der häuslichen Intensivpflege ist hierfür ein eindrückliches Beispiel.

Als kritisch für die Gewährleistung von Sicherheit gelten der vermehrte Einsatz umwelt- und therapiebezogener Technik, drohende oder tatsächliche soziale Isolation der Nutzer, deren Autonomieanspruch sowie Art und Umfang der Selbstversorgung. Sicherheitsrelevant ist auch, dass häuslich Pflegenden überwiegend alleine agieren, fernab der im Krankenhaus verfügbaren ärztlichen Unterstützungs- und Notfallsysteme, dass sie sich häufig abwechseln und trotz ihres Versorgungsauftrags lediglich Gast im Lebensumfeld der Nutzer sind (Lang, 2010). Thematisiert werden in der Literatur zum Thema Sicherheit in der häuslichen Pflege im Allgemeinen erhöhte Kommunikations- und Abstimmungserfordernisse, schwer beeinflussbare hygienische Bedingungen, Besonderheiten der Medikamentenversorgung und generelle klinische Risiken wie Stürze, Wunden, Infektionen oder Mangelernährung (Madigan, 2007; MDS, 2014). Letztgenannte Risiken erfahren im Kontext der Qualitätssicherung Aufmerksamkeit, werden in ihrer Relevanz für die Patientensicherheit aber noch selten untersucht und pflegewissenschaftlich reflektiert (Macdonald et al., 2013; Harrison et al., 2013; MDS, 2014).

Die häusliche Pflege ist grundsätzlich schwer kontrollier- und steuerbar; es fehlt an eindeutigen Verantwortungsstrukturen, aussagefähigen Routedokumentationen, einem konsentierten Verständnis von unerwünschten Ereignissen (Masotti et al., 2009) sowie an der routinemässigen, systematischen Erfassung von Risikosituationen in Form eines Critical Incident Reporting Systems – kurz CIRS (Doran et al., 2009). Über das Ausmass der Sicherheitsprobleme in diesem Feld ist folglich wenig dokumentiert. Einige Daten aus kanadischen Querschnitterhebungen zeigen auf, dass unerwünschte Ereignisse in der häuslichen Pflege (meist älterer Menschen) weit verbreitet sind (Doran et al., 2009; Sears, Baker, Barnsley & Shortt, 2013). Auch Ergebnisse externer Qualitätsprüfungen des Medizinischen Dienstes der Krankenversicherung von Pflegediensten in Deutschland lassen erahnen, dass es um die Patientensicherheit in diesem Versorgungsbereich nicht gut bestellt ist (MDS, 2014). Für die häusliche Intensivpflege fehlen valide und aussagefähige Daten vollständig.

Vermisst werden auch Informationen über die subjektiven Dimensionen des Themas (Porzsolt, 2007; Rathert, Brandt & Williams, 2011), denn Patienten/Patientinnen und Angehörige folgen anderen Relevanzkriterien bei der Beurteilung von Risikosituationen als professionelle Akteure (Porzsolt, 2007). Sie erfahren Sicherheit vornehmlich als emotionales Phänomen und messen Prozessen grössere Bedeutung bei als konkreten Versorgungsergebnissen (Rathert et al., 2011; Lovink et al., 2015). Ihr Sicher-

heitsempfinden muss daher mit objektiv ermittelten Daten nicht unbedingt übereinstimmen (Lovink et al., 2015). Diese gefühlte Sicherheit wird im quantitativ orientierten Patientensicherheitsdiskurs jedoch unterbewertet (Wischet & Eitzinger, 2009). Lediglich vereinzelt wird gefordert, Nutzersichtweisen einzuholen, um Patientensicherheit künftig in all ihren Dimensionen erfassen, beschreiben und fördern zu können (Dowell et al., 2005; Lang et al., 2008).

In bisher durchgeführten qualitativen Studien sind Sicherheitsaspekte aber eher unreflektiert geblieben – auch bei Befragungen von beatmeten Patienten/Patientinnen und deren Angehörigen. Sie haben sich v. a. auf Erfahrungen mit der durch die Abhängigkeit von Technik und Fremdhilfe charakterisierten Lebenssituation konzentriert (Ballangrud et al., 2009; Swedberg, Chiriac, Törnkvist & Hylander, 2012). Orientierung bieten qualitative Studien aus der stationären Intensivversorgung, die u. a. die Verantwortung der Pflege für die Förderung des Sicherheitsempfindens von Patienten/Patientinnen betonen (Vaismoradi, Salsali, Turunen & Bondas, 2011; Wasenaar, Schouten & Schoonhoven, 2014). Neben der technischen Überwachung, der Kontrolle von Umweltbedingungen und dem vorausschauenden Handeln wird die Vermittlung emotionaler Sicherheit durch Achtsamkeit, Zuwendung und Selbstsicherheit im Umgang mit anstehenden Versorgungsaufgaben als zentral für die gefühlte Sicherheit angesehen (Hupcey, 2000; Lasiter, 2011; Vaismoradi et al., 2011). Ob und inwieweit sich diese Erkenntnisse auf die häusliche Intensivpflege beatmelter Patienten/Patientinnen in Deutschland übertragen lassen, ist klärungsbedürftig.

Zielsetzung und Fragestellung

Von 2013–2016 wurde ein öffentlich gefördertes, mehrteiliges, qualitatives Versorgungsforschungsprojekt zum Thema „Sicherheit in der häuslichen Versorgung beatmter Patienten“ (SHAPE.) durchgeführt. Ziel des Gesamtprojekts war es, empirisch basierte Empfehlungen für die Gestaltung von Sicherheitskonzepten für die häusliche Intensivpflege zu formulieren und Impulse zur Förderung der Patientensicherheit in diesem Versorgungssetting zu setzen. In einer Teilstudie, deren Ergebnisse in diesem Beitrag vorgestellt werden, wurde daher nach dem subjektiven Sicherheitsempfinden der Nutzer häuslicher Intensivpflege gefragt. Wie sieht der Alltag in der häuslichen Intensivpflege aus Sicht von Patienten/Patientinnen und Angehörigen aus? Wann fühlen sie sich sicher oder unsicher und welche Faktoren sind dafür ausschlaggebend? Was bedeutet Sicherheit für sie? Durch die Beantwortung dieser Fragen sollten Einblicke in den Versorgungsalltag „hinter geschlossenen Türen“ ermöglicht, Risiken aus Nutzersicht aufgedeckt und Relevanzkriterien von Patienten/Patientinnen und Angehörigen zum Thema Patientensicherheit identifiziert werden.

Methodisches Vorgehen

Wegen des begrenzten Forschungs- und Erkenntnisstands zum Thema wurde ein qualitativ-exploratives Design gewählt. Für die Datenerhebung und -auswertung wurden Methoden genutzt, die auf die Grounded Theory Methodologie (Corbin & Strauss, 1996) rekurrieren.

Sampling: Einbezogen wurden über ein Tracheostoma oder über eine Maske beatmete, in der eigenen Häuslichkeit oder in einschlägigen Wohngemeinschaften versorgte Patienten/Patientinnen über 18 Jahre (N = 21; davon acht Frauen und 13 Männer zwischen 26 und 84 Jahren) sowie Angehörige solcher Patienten/Patientinnen (N = 15; davon zwölf Frauen und drei Männer zwischen 31 und 83 Jahren), sofern sie in deutscher Sprache kommunikationsfähig waren. Bei den in ihrer Kommunikationsfähigkeit eingeschränkten beatmeten Patienten/Patientinnen kamen mitunter computergestützte Sprachsysteme oder die Methode des Pseudoflüsterns zum Einsatz (Näheres hierzu Schaepe, Ewers & Tegethoff, 2016). Aus forschungspragmatischen Gründen beschränkte sich das Sampling auf Nordost- und Süddeutschland. Maximale Variationsbreite hinsichtlich Alter, Grund- und Begleiterkrankungen, Art und Umfang des Pflegebedarfs, Beatmung, Bildungsniveau, sozioökonomischem Status sowie Wohn- und Lebenssituation wurde durch eine zielgerichtete Auswahl gewährleistet. Rekrutiert wurde durch Mitarbeiter kooperierender Intensivpflegedienste sowie über stationäre Spezialeinrichtungen, Fachgesellschaften und Patientenverbände.

Datenerhebung

Zwischen April 2014 und Juni 2015 wurden im Rahmen eines iterativen Prozesses in mehreren Erhebungswellen 36 problemzentrierte Interviews geführt. Dabei erfolgten in der Regel zwei Besuche: der erste zur Einholung des Einverständnisses und Erfassung relevanter Kerndaten, der zweite zur Durchführung des Interviews. Beteiligt waren je zwei Mitglieder des Forscherteams. Während eine Person das Interview anhand eines semistrukturierten Interviewleitfadens führte und audiotekhnisch aufzeichnete, erstellte die andere Person ein Beobachtungsprotokoll. Die Datenquellen wurden später zusammengeführt und gemeinsam ausgewertet. Die Interviews dauerten zwischen 13 und 107 Minuten (Patienten/Patientinnen) sowie zwischen 32 und 250 Minuten (Angehörige). Die Befragten wurden gebeten, ihren Alltag mit der Beatmung zu beschreiben und sich dann zu ihren Erfahrungen mit der Versorgung sowie zu Situationen, die sie als (un-)sicher wahrnahmen, zu äussern. Abschliessend wurden sie gebeten zu charakterisieren, was Sicherheit in der häuslichen Versorgung für sie bedeutet. Datenerhebung und -auswertung wechselten einander in mehreren Wellen ab, wodurch im Verlauf der Analyse weiterführende, klärende und vertiefende Fragen in die Interviews integriert werden konnten.

Datenauswertung

Die audioteknisch aufgezeichneten Daten wurden als Basistranskript verschriftlicht, mehrstufig kodiert, kategorisiert und schliesslich analytisch reflektiert bis aus Nutzer-sicht relevante Themen identifiziert werden konnten. Die thematische Analyse begann unmittelbar nach der Datenerhebung und wurde, orientiert an den durchgeführten Erhebungswellen, in Form einer Vor-und-Zurück-Analyse bis zur Verdichtung der zentralen Themen und Unterthemen und zunehmender Datensaturierung im gesamten Forscherteam fortgeführt. Ergänzend und kontrastierend wurden Memos und Beobachtungsprotokolle eingebunden. Als Hilfsmittel für die Auswertung wurde die Software MAXQDA 11 genutzt.

Ethische Aspekte und Studienqualität

Die Teilnahme an der Befragung erfolgte freiwillig und konnte von den Befragten jederzeit abgebrochen werden. Sie wurden vorab schriftlich und mündlich über die Studie und die Verarbeitung der Daten informiert und es wurde eine schriftliche Einverständniserklärung eingeholt. Im Zuge des Bearbeitungs- und Auswertungsprozesses wurden die Daten pseudonymisiert. Die Studie erhielt ein positives Votum der zuständigen Ethik- und Datenschutzkommission. Zur Sicherung der Studienqualität wurde nach einem ersten Probeinterview mit einer beatmeten Person eine kritische Revision des Interviewleitfadens durchgeführt. Die Zuverlässigkeit der Studie wurde – orientiert an gängigen Standards qualitativer Forschung – durch detaillierte Dokumentation der Datenerhebung und -auswertung sowie kontinuierliche Diskussion und Reflexion im Forscherteam gesichert (O'Brien et al., 2014).

Ergebnisse

Die Lebenssituation der Befragten

Für die Einordnung der von den Befragten geschilderten Risikosituationen sind Informationen über deren spezifische Lebenssituation notwendig: Wesentlich ist die *weitreichende Angewiesenheit auf lebenserhaltende Beatmungstechnik und flankierende Fremdhilfe*. Variationen zeigen sich beim Alter der Patienten/Patientinnen, bei den Grund- und Begleiterkrankungen, der Beatmungsform (z. B. invasive Beatmung über Tracheostoma, nicht-invasive Beatmung über Maske; dauerhaft oder intermittierend), der Gesamtdauer der Beatmung, dem Ausmass der gesundheitlichen und funktionalen Einschränkungen, dem Grad an Selbstmanagement und informeller Unterstützung. Der Bedarf an Fremdhilfe reicht von hauswirtschaftlicher Unterstützung über Hilfe bei den ATLS bis zu speziellen pflegerischen und therapeutisch-

technischen Leistungen. Wegen der latent lebensbedrohlichen Situation der beatmeten Patienten/Patientinnen müssen in Deutschland aus leistungsrechtlichen Gründen in der Regel qualifizierte Pflegendе mit einer mindestens dreijährigen Ausbildung bis zu 24 Stunden am Tag anwesend sein. Meist sind sechs bis acht, häufig deutlich mehr Pflegendе bei einer beatmeten Person im Einsatz; bei längeren Betreuungen und aufgrund hoher Personalfuktuation, Urlaubs- und Krankheitszeiten mit entsprechend häufigem Wechsel.

Den Alltag in der häuslichen Intensivpflege prägen *immer gleiche Pflege- und Therapieroutinen* (z. B. Unterstützung der Patienten/Patientinnen bei den ATLS; Absaugen und Trachealkanülenpflege; Überwachung der Vitalwerte und Beatmungsparameter; physiotherapeutische oder logopädische Massnahmen). Vor allem auf Seiten der meist in 8- bis 12-Stunden-Schichten arbeitenden Pflegenden gehen diese Routinen mit dem Risiko von Unachtsamkeit einher; insbesondere in den Nachtstunden. Zugleich kommt es aus Sicht der Befragten immer wieder zu *Phasen hektischer und fremdbestimmter Betriebsamkeit*, etwa wenn Ärzte/Ärztinnen, Therapeuten/Therapeutinnen, Hilfsmittellieferanten oder andere Personen (z. B. vom Medizinischen Dienst) unkoordiniert, zur gleichen Zeit, zu früh oder zu spät in der Häuslichkeit erscheinen. Gelegentlich werden Angehörige in die direkte Pflege einbezogen, zuweilen auch bewusst ferngehalten. In jedem Fall ist eine Vielzahl von Akteuren beteiligt, was angesichts der räumlichen Distanz der Akteure zum Ort der Versorgung erhöhte Koordinations- und Kooperationsanforderungen nach sich zieht. Auch das kann mit Sicherheitsrisiken einhergehen, z. B. durch Informationsverluste.

Dies alles vollzieht sich im intimen Lebensumfeld der Patienten/Patientinnen, das dadurch dem *Risiko der sozialen Überfremdung und Kolonialisierung durch (Medizin-) Technik* ausgesetzt wird. Einige Patienten/Patientinnen teilen sich eine Wohnung mit dem Ehe- oder Lebenspartner oder anderen Verwandten, andere leben alleine oder in betreuten Wohngemeinschaften. Einmal wird die Rund-um-die-Uhr-Pflege in einer beengten Zwei-Zimmer-Wohnung durchgeführt, ein anderes Mal in einem grosszügig bemessenen Eigenheim. Die Pflegenden nutzen Funktionsräume wie Badezimmer und Küche mit und sind physisch stets präsent. Dies dient zwar der Sicherheit der Patienten/Patientinnen und Angehörigen, schränkt aber zugleich deren Intimsphäre ein. Die beatmeten Patienten/Patientinnen selbst sind meist in zentralen Räumen untergebracht, etwa dem Wohnzimmer, um ihre Teilhabe am Alltagsleben zu ermöglichen. Rund um das Patientenbett finden sich neben dem Beatmungsgerät oft weitere Artefakte wie z. B. Zweitbeatmungsgerät, Überwachungsgeräte, Elektrorollstuhl, Lifter, Sprachcomputer. Zudem werden Pflegeutensilien und Hilfsmittel in greifbarer Nähe gelagert. Diese Transformation des privaten Lebensumfeldes zu einer „Intensivstation im Wohnzimmer“ ist einerseits notwendig, um die Sicherheit der latent lebensbedrohlich erkrankten beatmeten Patienten/Patientinnen zu gewährleisten, z. B.

durch ein kontinuierliches Monitoring. Andererseits entstehen dadurch auch neue Sicherheitsrisiken wie Unfallgefahren durch herumliegende Kabel oder auch hygienische Herausforderungen.

Risikosituationen in der häuslichen Intensivpflege

Die befragten Patienten/Patientinnen und Angehörigen berichteten bei der Beschreibung ihres Alltags von Situationen, in denen sie sich in der häuslichen Intensivpflege unsicher gefühlt haben. Wenngleich sich die konkreten Risikosituationen von Fall zu Fall unterscheiden und auch die Perspektiven von Patienten/Patientinnen und Angehörigen nicht immer konsistent sind, finden sich in den Schilderungen doch einige übereinstimmende Ursachen für Risikosituationen, die hier datengestützt und zu Themenclustern verdichtet präsentiert werden.

Kommunikations- und Interaktionsprobleme

Im Pflegealltag entstehen Risikosituationen aus Sicht der Befragten oftmals durch Kommunikations- und Interaktionsprobleme. Das kennt auch die 62-jährige Frau Yilmaz, deren 70-jähriger Ehemann an fortgeschrittener Amyotropher Lateralsklerose (ALS) leidet. Er hat eine PEG-Sonde und einen Dauerkatheter, wird seit sechs Jahren invasiv beatmet, ist in seiner Mobilität stark eingeschränkt und kann nur noch über Augenkontakt kommunizieren. Eines Tages bemerkt Frau Yilmaz, dass er kalte Füße hat. Weil gerade eine neue Pflegende vor Ort ist, die sich noch nicht auskennt, greift die Angehörige selbst ein und legt ihm eine Wärmflasche direkt auf die Füße:

„Ich hab's vergessen und dann in der Küche angefangen, dann komm ich wieder rein und sehe meine Manns Gesicht ganz rot und die Augen sind, wie soll ich sagen, wie Blut geworden. Dann fällt mir plötzlich ein, er kann ja nicht schreien, er kann ja nichts sagen, (...) Es brauchte ein Jahr, bis diese Wunde, ist ganz schwarz geworden. (...) Ich habe mir so viel Schuld gegeben, warum ich nicht aufgepasst habe.“ (81210: 18).

Beatmete Patienten/Patientinnen sind in ihrer Kommunikation häufig stark eingeschränkt. Um mit ihrer Umwelt in Kontakt zu treten, greifen sie dann auf individuelle mimisch-gestische Zeichen zurück. Werden diese nicht erkannt oder fehlinterpretiert, kommt es mitunter zu unerwünschten Ereignissen. Warum die anwesende Pflegende die Krankenbeobachtung vernachlässigt und die Verbrennung am Fuss nicht rechtzeitig erkannt und abgewendet hat, bleibt im Dunkeln. Tatsächlich finden sich im Datenmaterial wiederholt Hinweise darauf, dass unerfahrene, häufig wechselnde oder aushilfsweise eingesetzte Pflegende Schwierigkeiten haben, die Kommunikationsversuche der beatmeten Patienten/Patientinnen wahrzunehmen, zu deuten und situationsadäquat zu handeln. Auch in der häuslichen Intensivpflege vielfach eingesetzte ausländische Pflegende stossen auf Pro-

bleme. Einerseits tun sie sich schwer, die verkürzten, alltagssprachlichen Kommunikationsangebote zu verstehen, andererseits können sie sich selbst oftmals nur mühsam in deutscher Sprache mitteilen. Patienten/Patientinnen und Angehörige reagieren mit Ungeduld, Verärgerung oder Misstrauen auf die gestörte Kommunikation. Je ausgeprägter die Verständigungsschwierigkeiten sind und je komplexer die Versorgungssituationen, desto grösser ist das Sicherheitsrisiko.

Vernachlässigung von Überwachungs- und Kontrollpflichten

Die Befragten schildern wiederholt, dass Überwachungs- und Kontrollpflichten vernachlässigt, Anliegen von Patienten/Patientinnen oder Angehörigen nicht ernst genommen oder aus Unachtsamkeit oder mangelnder Erfahrung wenig vorausschauend gearbeitet wird. Das hat auch die 61-jährige Monika Lange erfahren, die aufgrund fortgeschrittener chronisch obstruktiver Lungenerkrankung (COPD) seit 2010 dauerhaft invasiv beatmet und 24-Stunden am Tag pflegerisch betreut wird. Sie berichtet, dass bei der regelmässigen Bestellung ihrer Hilfsmittel Trachealkanülen in falscher Grösse geliefert wurden. Dieser Fehler ist aber, trotz geltender Kontroll- und Dokumentationspflichten, weder bei der Lieferung noch beim wöchentlichen Wechsel durch die Pflegenden aufgefallen:

„Die setzt mir die Kanüle ein und ich denk, ich krieg ja so schlecht Luft. Und die zischte so, bsbs. Da sag ich, hören Sie das nicht? Doch höre ich auch, ja, müssen wir mal gucken. Dann haben wir den Cuff geprüft. (...) Na jedenfalls sage ich, also ich habe hier Probleme. Dann sagt die: Na, Sie müssen mal inhalieren, vielleicht sitzt da wieder irgendwas. Ah, denk ich, gut, inhalierst du. Die hatte aber Feierabend und abends hatte ich eine Aushilfe hier, eine Griechin.“ (87214: 16).

Mit der Aushilfe, die gebrochen Deutsch spricht und die Patientin kaum versteht, kommt es zu keiner Problemlösung, weshalb Monika Lange mit ihrer Atemnot mehr schlecht als recht durch die Nacht kommt. Erst am nächsten Morgen fällt einer seit längerem mit der Patientin vertrauten Pflegenden der Fehler auf. Die Interviewsequenz schliesst Monika Lange mit folgendem Kommentar:

„Ich vertraue denen mein Leben an, im Grunde genommen, und die (...) sind so unaufmerksam, dass sie das nicht merken, das geht nicht. Also wenn die jetzt eine TK-Kanüle legen, lass ich mir das zeigen: Gucken Sie mal Frau Lange, das ist jetzt eine Neuner und auch die Chargennummer stimmt. Also so was geht doch nicht. Ich habe jetzt bei allem, was gemacht werden muss, Zweifel.“ (87214: 17).

Unpräzises Arbeiten, Unachtsamkeit und mangelndes Problembewusstsein führen dazu, dass Patienten/Patientinnen Vertrauen in die Pflegenden verlieren – dies zeigt sich auch in anderen Interviewpassagen. Als Reaktion darauf bildet sich bei einigen der Befragten ein ausgeprägtes Kontrollbedürfnis, das die Zusammenarbeit im Pflegealltag erschwert und den Vertrauensverlust eher fördert denn beseitigt.

Fehlende Kompetenz, Selbstsicherheit und Professionalität

Risikosituationen entstehen ebenfalls durch fehlende Kompetenz, Selbstsicherheit und Professionalität im Umgang mit anspruchsvollen klinischen Aufgaben, sei es – wie zuvor aufgezeigt – bei der kontinuierlichen Krankenbeobachtung, der Durchführung therapeutisch-technischer Massnahmen wie einer Katheterisierung, der Lagerung immobiler Patienten / Patientinnen, dem Umgang mit Medikamenten oder – wie bei Frank Krause – mit der Medizintechnik. Er ist Tetraplegiker, zum Zeitpunkt des Interviews 46 Jahre alt, invasiv dauerbeatmet und sondenernährt. Er lebt alleine und wird rund um die Uhr von einem Pflegedienst betreut, der für sein komplexes Medikamentenregime verantwortlich ist. Um sich mitteilen zu können, nutzt er ein mit den Augen gesteuertes, computergestütztes Kommunikationssystem. Die Beatmungsmaschine und die übrigen Geräte, so sagt er, gehören zu seinem Leben, genau wie die Leute, die sie bedienen. Umso wichtiger ist ihm ein kompetenter und (selbst-)sicherer Umgang damit im Pflegealltag, „denn 5 Minuten ohne Luft kann meinen Tod bedeuten. Das muss mir und meinem Team klar sein.“ (87202: 2).

Tatsächlich aber erlebt er immer wieder Situationen, die ihn an seiner Sicherheit zweifeln lassen. Mal löst sich in der Nacht der Verbindungsschlauch zwischen Beatmungsgerät und Trachealkanüle, mal werden die Alarmsignale der Geräte von Pflegenden überhört und wiederholt kommt es nur durch Zufall nicht zu gravierenden unerwünschten Ereignissen:

„Ausserdem ist mir passiert, dass ich eine Aushilfe als Pflegekraft bekommen hatte und eine Einarbeitung war aufgrund der Zeit nicht möglich. Sie kannte mein Beatmungsgerät nicht. Als sie in der Nacht wahllos auf dem Gerät umherdrückte, fühlte ich mich schon komisch. Nicht, dass sie es noch ausschaltet. Sie kannte das Gerät nicht und wusste nicht, dass man nur einen Knopf zum Parameterablesen betätigen muss.“ (87202: 7).

Sorge bereitet nicht nur die eigene labile Gesundheit oder dass die Technik eines Tages versagen könnte. Es ist auch die Befürchtung, dass die Pflegenden mit den eingesetzten Gerätschaften nicht adäquat umzugehen wissen und so selbst zum Risiko für die beatmeten Patienten / Patientinnen werden. Nicht zuletzt, weil deren Leben von den Pflegenden und ihrem Handeln abhängt, wird jede noch so kleine Unsicherheit registriert. So resümiert die Angehörige eines anderen Beatmungspatienten:

„Mein Mann, wenn der gemerkt hat, dass jemand unsicher ist, dann ist er auch unsicher geworden und hat einfach Angst gehabt.“ (71223: 7)

Derartigen Verunsicherungskaskaden zu entgehen und den Patienten / Patientinnen oder Angehörigen durch kompetentes, (selbst-)sicheres und professionelles Handeln das Gefühl von Sicherheit zu vermitteln, gelingt aus Sicht der Befragten nur wenigen Pflegenden.

Vernachlässigung von Aushandlungs-, Edukations- und Supervisionsaufgaben

Risikosituationen entstehen in der häuslichen Intensivpflege zusätzlich durch unkoordiniertes Vorgehen und die Unterbewertung von Aushandlungs-, Edukations- und Supervisionsaufgaben, wie sich am Beispiel des Ehepaars Hoffmann zeigt: Die zum Zeitpunkt des Interviews 78-jährige Edith Hoffmann ist aufgrund ihrer ALS-Erkrankung schwerstpflegebedürftig. Sie wird seit 2006 invasiv beatmet und eigentlich per PEG-Sonde ernährt. Der 84-jährige Günther Hoffmann berichtet jedoch davon, dass er mit seiner Frau eigenständig Schluckversuche mit Suppe durchführt. Zudem entblockt er deren Trachealkanüle entgegen ärztlichem Rat zweimal täglich für ca. zwei Stunden, um mit ihr Sprechen zu üben:

„Und das haben wir auch mit dem Logopäden abgestimmt, der sagt auch, es gibt da neue wissenschaftliche Erkenntnisse, dass die dauerhafte Blockung gefährlich ist (...), Also je mehr man eigentlich trainiert, die Muskulatur im Bereich Schluck und so weiter, je besser ist es. Und das machen wir. Die Ärztin will das nicht (...), das Pflegepersonal darf es nicht. Und ich habe dafür unterschrieben, dass ich das mache.“ (31929: 2)

Angehörige sind oft darum bemüht, das Wohlbefinden der Patienten / Patientinnen zu steigern, ihnen in der Rehabilitation zu helfen und ihre Unabhängigkeit von Fremdhilfe zu erhöhen. Dabei gehen sie mitunter Risiken ein und setzen sich über Empfehlungen professioneller Helfer hinweg. Warum es in diesem Fall nicht möglich war, das Anliegen des Angehörigen zwischen der beteiligten Ärztin, dem Therapeuten und den Pflegenden zu besprechen und eine für alle Beteiligten sichere, untereinander abgestimmte Vorgehensweise auszuhandeln, geht aus den Daten nicht hervor. Ebenso ist unklar, warum Herr Hoffmann nicht zumindest sorgfältig angeleitet und von den Pflegenden bei seinen Rehabilitationsbemühungen supervidiert wurde. Tatsächlich finden sich in den Daten viele Hinweise darauf, dass derartige Aushandlungs- und Abstimmungsprozesse unter den an der häuslichen Intensivpflege beteiligten Personen unterschätzt, pflegerische Informations-, Anleitungs- und Supervisionsaufgaben vernachlässigt und stattdessen – wie auch in diesem Fall – weggeschaut und die Verantwortung für das häusliche Pflegegeschehen einseitig auf die Patienten / Patientinnen oder Angehörige übertragen wird.

Die Liste der von den Patienten / Patientinnen und Angehörigen geschilderten Risikosituationen liesse sich fortsetzen, wobei sich die hier angesprochenen Handlungsweisen oder Unterlassungen in Variationen wiederholen. Oft können Patienten / Patientinnen und Angehörige diesen nur dadurch begegnen, dass sie eigenständig Strategien entwickeln, um für ihre Sicherheit zu sorgen. Dazu gehört nicht zuletzt, in kritischen Situationen kurzerhand den Notarzt zu rufen und den Transfer in die nächste Klinik zu veranlassen. Allerdings haben sie sowohl beim Transfer wie auch in der stationären Versorgung zuweilen erfahren müssen, dass ihrem individuellen Sicherheitsempfinden auch dort selten die notwendige Aufmerksamkeit geschenkt wird.

Diskussion

Die empirischen Einblicke in den Alltag der häuslichen Intensivpflege haben zahlreiche Risikosituationen aufgedeckt. Sie entstehen, wenn (non-)verbale Kommunikationsangebote übersehen oder missverstanden werden und es infolgedessen zu weitreichenden Interaktionsproblemen oder gar Vertrauenskrisen zwischen Patienten/Patientinnen, Angehörigen und Pflegenden kommt (vgl. dazu auch Lademann, Schaepe & Ewers, 2017). Wenig achtsames und vorausschauendes Arbeiten, die Vernachlässigung patienten- oder technikbezogener Überwachungsaufgaben sowie fehlende Kompetenz, Selbstsicherheit und Professionalität auf Seiten der Pflegenden können ebenfalls sicherheitsgefährdende Situationen provozieren. Das Risiko unerwünschter Ereignisse steigt ferner, wenn Kooperations- und Abstimmungserfordernisse unterschätzt sowie Aushandlungs-, Edukations- und Supervisionsaufgaben unterbewertet werden. Die damit angesprochenen Themen und Problemfelder decken sich in weiten Teilen mit denen, die in internationalen Studien zum Thema Sicherheit in der häuslichen Pflege (meist älterer Menschen) dokumentiert sind (Lang et al., 2008). Zudem weisen sie deutliche Übereinstimmungen mit Erkenntnissen auf, die über das Sicherheitsempfinden von Patienten/Patientinnen in der stationären Intensivversorgung vorliegen – einschliesslich der darin betonten Verantwortung der Pflege für die Förderung der gefühlten Sicherheit (Wassenaar et al., 2014). Das Sicherheitsempfinden von Patienten/Patientinnen auf Intensivstationen wird gefördert, wenn Pflegendе Kompetenz und v.a. in kritischen Situationen Ruhe ausstrahlen, wenn sie souverän aufmerksam im Umgang mit technischen Geräten und bei körpernahen Unterstützungen sind, bei Alarmen und Rufen zügig zur Stelle sind und angemessen und vorausschauend agieren sowie über Massnahmen informieren und Fragen beantworten (ebd.).

Die hier gewonnenen Erkenntnisse zum Sicherheitsempfinden beatmeter Patienten/Patientinnen und deren Angehöriger verdichten Hinweise darauf, dass derzeit nicht „alles sicher“ ist in der häuslichen Intensivpflege: es bestehen gravierende Mängel auf personaler, prozeduraler und struktureller Ebene (vgl. hierzu weiterführend Lehmann et al., 2016). Über das tatsächliche Ausmass an Sicherheitsrisiken in diesem Versorgungsbereich ist indes nichts bekannt. Nähere Informationen könnten weitere Forschungsaktivitäten, etwa zu den Sichtweisen professioneller Akteure in diesem Feld, sowie eine Ausweitung von Selbstberichten von Pflegenden unter Zuhilfenahme standardisierter Fehlermeldesysteme speziell für die häusliche Pflege bieten. Zwar gibt es erste Initiativen in diese Richtung (Meyer-Masseti et al., 2016); eine routinemässige und flächendeckende Anwendung solcher Systeme zur Erfassung und Analyse von Risikosituationen in der häuslichen (Intensiv-)Pflege steht aber in allen deutschsprachigen Ländern noch aus.

Dabei dürfte sich als hinderlich erweisen, dass das Risikobewusstsein in diesem Versorgungsbereich – wird den

Erfahrungen der hier befragten beatmeten Patienten/Patientinnen und Angehörigen gefolgt – unterschiedlich stark ausgeprägt ist, und dass die patientenbezogene Sicherheitsarbeit von Seiten der Pflegenden eher wenig Aufmerksamkeit erfährt. Zu ähnlichen Einschätzungen kamen auch vorangegangene internationale Studien (Ballangrud et al., 2009; Swedberg et al., 2012). Als problematisch gelten die geringe Bereitschaft zur Verantwortungsübernahme durch Pflegendе, zahlreiche Führungs- und Qualifikationsdefizite auf allen Handlungs- und Entscheidungsebenen sowie fehlende Sicherheitskonzepte und Handlungsleitlinien (Berland, Holm, Gundersen & Bentsen, 2012). Insgesamt wird beklagt, dass es in der häuslichen Pflege an einer Sicherheitskultur fehlt, die der gewachsenen Bedeutung dieser Versorgungsform entspricht (Lang et al., 2008; Rose et al., 2015).

Um dem zu begegnen, bietet die SHAPE.-Studie interessante Anhaltspunkte. Sie dokumentiert das relationale Sicherheitsverständnis, dem die Nutzer in der häuslichen Intensivpflege folgen: Patienten/Patientinnen und Angehörige fühlen sich dann sicher, wenn sie von kompetenten, selbstsicheren Pflegenden umgeben sind, die mit ihrer Situation vertraut sind und denen sie in allen Belangen jederzeit vertrauen können (Schaepe & Ewers, 2017). Die Einbeziehung der Nutzerperspektive in den Patientensicherheitsdiskurs kann – in Ergänzung und Kontrastierung zu quantifizierbaren Routinedaten – das Problembewusstsein aller Beteiligten schärfen. Patienten/Patientinnen und Angehörigen aufmerksam zuzuhören, ihre Erfahrungen mit dem Versorgungsgeschehen zu dokumentieren und ihre Relevanzkriterien herauszuarbeiten trägt dazu bei, hemmende und fördernde Bedingungen für eine sichere häusliche Intensivpflege zu identifizieren. Schliesslich können die Sichtweisen und Erfahrungen der Nutzer dazu dienen, patientenzentrierte Sicherheitskonzepte zu entwickeln und die Entstehung einer Sicherheitskultur in der häuslichen Pflege im Allgemeinen und der häuslichen Intensivpflege im Besonderen zu fördern (Dowell et al., 2005; Lang et al., 2008).

Limitationen

In dieser Studie wurden nur Sichtweisen und Erfahrungen kommunikationsfähiger beatmeter Patienten/Patientinnen in der häuslichen Intensivpflege und deren Angehöriger berücksichtigt. Wenngleich vermutet werden kann, dass andere technikabhängige Patienten/Patientinnen (z. B. Dialyse; Kunstherz) und deren Angehörige ähnliche Erfahrungen mit dieser Form der Versorgung sammeln, sind die Befunde zunächst auf diese Gruppe der Befragten begrenzt. Der Rekrutierungsweg über kooperierende Leistungsanbieter könnte zu einem Auswahl-Bias geführt haben, unmittelbare Beeinflussungen durch diesen Vermittlungsweg waren aber nicht zu erkennen. Zudem werden für eine umfassende Analyse der geschilderten Risikosituationen ergänzend und kontrastierend u. a. auch Sichtweisen anderer Beteiligter einzubeziehen sein, insbesondere

der von professionellen Akteuren wie Pflegenden, Haus- und Fachärzten, Hilfsmittelanbietern oder Fallmanagern der Leistungsträger. Dies ist im Rahmen einer weiteren Teilstudie von SHAPE. bereits geschehen und wird zeitnah aufbereitet und dokumentiert. Die hier präsentierten Ergebnisse sind kontextabhängig und bedingt auf strukturell ähnliche Versorgungssettings übertragbar.

Resümee

Die häusliche Intensivpflege von beatmeten Patienten / Patientinnen erfährt in der Pflegeforschung wenig Aufmerksamkeit. In dem sich intensivierenden Patientensicherheitsdiskurs hat bislang weder diese spezielle Form der pflegerischen Versorgung noch das subjektive Sicherheitsempfinden ihrer Nutzer das Interesse auf sich gezogen. Diese Desiderata wurden mit der SHAPE.-Studie aufgegriffen. Sie lenkt die Aufmerksamkeit auf ein pflegerisches Handlungsfeld, das weiter an Bedeutung gewinnt, und deckt dabei aus Nutzersicht zu bewältigende Sicherheitsrisiken auf, die künftig im Hinblick auf ihre Ursachen und Wirkungen intensiver analysiert werden sollten. Nicht zuletzt unterstreicht sie mit ihren Ergebnissen, dass die Gewährleistung einer patientenorientierten, effektiven und sicheren häuslichen Versorgung beatmeter und anderer technikabhängiger Menschen eine pflegerische Kernaufgabe darstellt, die künftig mehr Aufmerksamkeit erfahren muss.

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Beiträge der einzelnen Autorinnen und Autoren

Substanzieller Beitrag zu Konzeption oder Design der Arbeit: ME, YL

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Was war die grösste Herausforderung bei Ihrer Studie?

Zugang zu den hauslich versorgten beatmeten Patienten und deren Angehörigen zu finden.

Was wünschen Sie sich bezüglich der Thematik für die Zukunft?

Eine stärkere Berücksichtigung von Nutzersichtweisen und hauslicher Versorgungssettings im Patientensicherheitsdiskurs.

Was empfehlen Sie zum Weiterlesen/Vertiefen?

Macdonald, M., Lang, A.; Macdonald, J. (2011). Mapping a Research Agenda for Home Care Safety: Perspectives from Researchers, Providers, and Decision Makers. *Canadian Journal on Aging*, 30 (2), 233 – 245.

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Judith Czakert, Christiane Schaepe, Michael Ewers

Vertrauensvolle und sicherheitsgenerierende Beziehungsgestaltung in der häuslichen Intensivpflege – Eine qualitative Sekundärdatenanalyse

Trustful and security-enhancing nurse-patient relationships in intensive home care – a qualitative secondary analysis

Interpersonal trust is of vital importance in nurse-patient relationships – in particular when it is characterized by high levels of vulnerability and dependency, such as in home mechanical ventilation. Hence, we examined the meaning and characteristics of interpersonal trust for relationships between ventilator-assisted individuals living at home and nurses in a qualitative secondary analysis. The findings show that reliability, nurses' professional and social skills as well as familiarity with each other promotes trust. If trust is missing, the nurse-patient relationship might be burdened, e.g. due to patients' strategies for maintaining control. The degree of trust in the nurse-patient relationship also affects the patients' sense of safety. However, to develop a trusting nurse-patient relationship that enhances the patients' sense of safety is part of the nurses' professional responsibility.

Keywords

Nurse-patient relationship, trust, high-tech homecare, home mechanical ventilation, patient safety, secondary qualitative analysis

Interpersonales Vertrauen spielt eine wesentliche Rolle in tragfähigen Pflegebeziehungen – gerade dann, wenn die Beziehung durch Vulnerabilität und Abhängigkeit besonders stark geprägt ist, wie etwa in der häuslichen Intensivversorgung der Fall. Im Rahmen einer qualitativen Sekundärdatenanalyse, wurde daher nach Bedeutung und Merkmalen interpersonales Vertrauens für die Beziehungsgestaltung zwischen häuslich beatmeten Menschen und professionell Pflegenden gefragt. Die Ergebnisse zeigen, dass sich v. a. Verlässlichkeit, fachliche und überfachliche Kompetenzen der Pflegenden und Vertrautheit zwischen den Beteiligten fördernd auf die Vertrauensentwicklung auswirken. Fehlt es an Vertrauen, kann dies die Pflegebeziehung belasten, etwa durch kontrollierhaltende Verhaltensweisen der beatmeten Menschen. Der Grad des Vertrauens in der Pflegebeziehung wirkt sich auch auf das subjektive Sicherheitsgefühl der Patient_innen aus. Die Pflegebeziehung verantwortlich zu gestalten und damit Vertrauen und subjektive Patientensicherheit zu stärken, obliegt der professionellen Verantwortung der Pflegenden.

Schlüsselwörter

Pflegebeziehung, Vertrauen, häusliche Intensivpflege, beatmete Patient_innen, Patientensicherheit, qualitative Sekundäranalyse

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1. Hintergrund

Interpersonale Beziehungen – verstanden als wechselseitige Verhältnisse zwischen zwei oder mehreren Personen – gelten als Grundlage professioneller Pflege. In der einschlägigen Literatur werden Pflegebeziehungen breit diskutiert und unterschiedlich charakterisiert – etwa als „professionelle Freundschaft“ (Lindahl et al. 2011: 454), „gemeinsame Geschichte“ (Strandås et al. 2018: 11), „co-kreativer Prozess“ (Bergdahl et al. 2019: 177) oder schlicht als „caring relationship“ (Walivaara et al. 2013: 89). Der pflegewissenschaftliche Beziehungsdiskurs ist durch eine begriffliche und konzeptionelle Vielfalt charakterisiert, weshalb sich die Essenz einer Pflegebeziehung in heterogenen Auffassungen verliert. Ein verbindendes Element scheint die professionell Pflegenden obliegende Verantwortung für die Gestaltung von Pflegebeziehungen zu sein (ex. Büker et al. 2019; Peplau 1995). Die Bedingungen für die professionelle Beziehungsgestaltung unterscheiden sich je nach Setting und Konstellation der beteiligten Personen. Dies erschwert generelle Aussagen zu Möglichkeiten und Grenzen der Beziehungsgestaltung durch professionell Pflegenden. Zudem wird die Beziehungsgestaltung durch schwer kontrollierbare Faktoren beeinflusst – etwa das Vertrauensphänomen.

Vertrauen gilt je nach Blickwinkel als besonderer Modus sozialer Regulierung (Grünberg 2014), der mit einer „Nicht-Schaden-Zufügens-Erwartung“ (Laucken 2005: 102) verbunden ist. Andere sehen darin eine institutionelle oder persönliche Eigenschaft sowie eine Grundlage und ein Merkmal personaler Beziehungen (Petermann 2013; Dederichs 1997). Generell wird eine „wenig konturhafte Begriffswelt“ (Petermann 2013: 18) im Umgang mit dem Vertrauensphänomen beklagt; gelegentlich ist auch von einem „widersprüchlichen Wissenschaftskonzept“ (Hupcey et al. 2001: 282) die Rede. Vertrauen wird als heterogener und komplexer, empirisch schwer fassbarer Gegenstand bezeichnet, was „die Tendenz zu theoretischen Auseinandersetzungen mit dem Phänomen erklärt“ (Grünberg 2014: 53).

Vor allem von Seiten der Psychologie sind seit einiger Zeit Bemühungen erkennbar, dem zu begegnen. So wurden auf der interpersonalen Mikroebene Faktoren identifiziert, die für die Auseinandersetzung mit dem Vertrauensphänomen relevant sind, wie etwa Risikohaftigkeit, Kontrollverlust, Ungewissheit, Verlässlichkeit, Abhängigkeit und Zukunftsorientiertheit (Petermann 2013: 15f). Während die einen Vertrauen als zeitlich stabile Persönlichkeitseigenschaft ansehen, wollen andere darin eine situationsspezifische Variable erkennen (Grünberg 2014). In der differentiellen Vertrauentheorie versucht Schweer (2008) beide Positionen zu verbinden: Personale Faktoren sind für ihn die individuelle Vertrauentendenz einer Person und deren implizit zugrundeliegende subjektive Vertrauentheorie. Der Grad der Symmetrie und der Freiwilligkeit einer Beziehung, der Grad der Möglichkeit zur offenen Kommunikation innerhalb einer Beziehung, die zeitliche Dauer einer Beziehung sowie die Qualität des Anfangskontaktes sind für ihn relevante situationale Faktoren (ebd.: 18ff).

Auch pflegewissenschaftliche Autor_innen befassen sich intensiv mit dem Vertrauensphänomen, vielfach im Zusammenhang mit Pflegebeziehungen. Vertrauen und Vertrauenswürdigkeit gelten dabei als wesentlicher Teil gelingender Pflegebeziehungen.

gen (Dinç et al. 2013) und auch als essentielle Komponente pflegerischer Praxis (Pask 1995: 194). Vertrauen wird in pflegewissenschaftlichen Kreisen als Konzept verstanden, das als emotional provokativ, multidimensional, essentiell sowie kontextabhängig gilt (Rushton et al. 2007: 21) und häufig sowohl als Voraussetzung wie auch als Ergebnis professionell gestalteter Pflegebeziehungen diskutiert wird (ex. Dinç et al. 2013; Dinç et al. 2012; Leslie et al. 2016). Allerdings wird in der Literatur eine Operationalisierung und empirische Auseinandersetzung der Pflegewissenschaft mit dem Thema vermisst (Hupcey et al. 2001; Rørtveit et al. 2015).

Aus vorliegenden Reviews ist bekannt, dass auf Vertrauen basierende Pflegebeziehungen u. a. dann entstehen, wenn Patient_innen das Gefühl haben, gut versorgt zu sein, wenn ihre Interessen gewahrt werden und in ihrem Sinne gehandelt wird (Dinç et al. 2012; Dinç et al. 2013). Kommunikative Kompetenzen, praktische Fertigkeiten und Fähigkeiten sowie Fachwissen der Pflegenden wirken sich fördernd auf die Vertrauensbildung aus (Rørtveit et al. 2015; Schaepe et al. 2017). Aber auch Tugenden wie Freundlichkeit, Geduld und Wärme, ein respektvoller Umgang, Pünktlichkeit und Verlässlichkeit fördern die Entwicklung vertrauensvoller Pflegebeziehungen. Große Bedeutung haben die (unausgesprochenen) Erwartungen der Patient_innen sowie deren Wahrnehmung durch die Pflegenden (Hupcey et al. 2000), was besonders in der Anfangsphase von Pflegebeziehungen relevant ist (Leslie et al. 2016). Laut Hupcey et al. (2000) hängt die weitere Vertrauensentwicklung dann davon ab, inwieweit die Erwartungen von Patient_innen an die Pflegebeziehung erfüllt werden.

Die besondere Relevanz von Vertrauen in Pflegebeziehungen wird vor allem mit der Abhängigkeit der Patient_innen von pflegerischer Versorgung und dem dadurch entstehenden asymmetrischen Verhältnis zueinander begründet (Dinç et al. 2013; Dinç et al. 2012; Peter et al. 2001; Hupcey et al. 2001). Patient_innen müssen darauf vertrauen können, dass ihnen durch die Pflegenden kein Schaden entsteht, ohne die Gewissheit zu haben, dass ihr Vertrauen gerechtfertigt ist. Vertrauen entsteht prozesshaft und ist ausgesprochen fragil – es kann leicht zerstört werden (Rørtveit et al. 2015: 196). Fehlt es an zuvor genannten Voraussetzungen, prägen Respektlosigkeiten, pflegerische Inkompetenzen sowie unethische Pflegepraktiken den Versorgungsalltag oder werden Erwartungen enttäuscht, entsteht leicht Misstrauen. Mitunter belasten dann kompensatorisch zur Risikominimierung ergriffene Strategien der Patient_innen die Pflegebeziehung. Dies kann von Verfahren zum Testen der Pflegenden (Hupcey et al. 2000) bis hin zu Pflege vermeidenden und (selbst-)gefährdenden Verhaltensweisen führen (Jones 2015). Je ausgeprägter die Vulnerabilität von Patient_innen und deren Abhängigkeit von Fremdhilfe und je begrenzter die Möglichkeiten zur offenen Kommunikation, desto bedeutsamer und zugleich fragiler ist das Vertrauen in die Pflegebeziehung. Diese verlangt von Pflegenden ein ausgeprägtes Bewusstsein für die ungleiche Verteilung von Macht und Handlungsmöglichkeiten zwischen ihnen und den Patient_innen und eine entsprechende Demonstration ihrer professionellen Vertrauenswürdigkeit und Kompetenz (Dinç et al. 2012: 234f).

Beziehungsgestaltung in der häuslichen Intensivversorgung

An dieser Stelle soll es um die Beziehungsgestaltung in der häuslichen Intensivversorgung vorwiegend beatmeter Patient_innen gehen. Dabei handelt sich um eine verhältnismäßig kleine, in sich sehr heterogene Personengruppe jeden Lebensalters, die aufgrund verschiedener Krankheitsbilder und damit einhergehender Beeinträchtigungen lebenswichtiger Organfunktionen in erheblichem Umfang auf therapeutisch-technische und pflegerische Unterstützung angewiesen ist (Lehmann et al. 2016: 9). Deren Versorgung erfolgt in Deutschland aufgrund spezifischer rechtlicher Rahmenbedingungen und finanzieller Anreize überwiegend in der eigenen Häuslichkeit oder in Wohngemeinschaften durch meist Rund-um-die-Uhr anwesende professionell Pflegenden mit Zusatzqualifikation in Verbindung mit einem hohen Einsatz medizinisch-technischer Hilfsmittel. Bislang liegen über diese spezielle Form der häuslichen Intensivversorgung wenig empirische Forschungserkenntnisse vor (ex. Lademann 2007; Lehmann et al. 2018b; Ewers 2003; Lehmann et al. 2018a; Schaepe et al. 2017). In einer unlängst durchgeführten qualitativ-empirische Studie wurde danach gefragt, was Sicherheit für beatmete Patient_innen und deren Angehörige bedeutet und welche Strategien aus ihrer Sicht ergriffen werden müssen oder bzw. welche sie selbst ergreifen, damit sie sich in der häuslichen Intensivversorgung sicher fühlen können. Die Ergebnisse zeigen, dass die befragten schwerkranken Patient_innen und deren Angehörige vorwiegend einem relationalen Sicherheitsverständnis gefolgt sind. Mit anderen Worten: die Beziehung zu den meist Rund-um-die-Uhr anwesenden Pflegenden war entscheidend dafür, ob sie sich im häuslichen Setting sicher gefühlt haben oder nicht (Ewers et al. 2017a; Ewers et al. 2017b; Lehmann et al. 2018a). Zugleich wurden in dieser Befragung hohe Kompetenzerwartungen an die Pflegenden, insbesondere auch im Hinblick auf die Gestaltung der Pflegebeziehung formuliert. Sie lassen sich dadurch erklären, dass die Patient_innen gleich in doppelter Weise existenziell abhängig sind: Sie müssen sowohl auf die Funktionsfähigkeit der eingesetzten technischen Artefakte vertrauen können (Dederichs 1997), wie auch auf die Pflegenden, die diese Technik bedienen und pflegerische Unterstützung anbieten (ex. MacLaren et al. 2018; Wassenaar et al. 2015). Zudem bietet die Versorgung im privaten Lebensumfeld den Pflegenden zwar viele Möglichkeiten zum Beziehungsaufbau und zur Vertrauensbildung; sie geht aber auch mit spezifischen Risiken einher – etwa denen der Entgrenzung, Domestizierung oder Familialisierung (ex. Dybwik et al. 2012; Lindahl et al. 2011; Friesacher 2008; Schaeffer et al. 2002).

Aus der eingeschränkten Autonomie, die aus der latenten Lebensbedrohung sowie krankheitsbedingten Selbstversorgungsdefiziten der Patient_innen resultiert, sowie aus kontextuellen Faktoren der häuslichen Intensivversorgung, dürfte sich ein prekäres Beziehungsgefüge ergeben, dass durch mehr oder weniger ausgeprägte Asymmetrien und Risikopotenziale gekennzeichnet ist (Alpers 2018: 314; Friesacher 2008; Dinç et al. 2012: 231). Welche Auswirkungen dies auf die Vertrauensbildung in der häuslichen Intensivversorgung hat, welche Möglichkeiten die Pflegenden haben, diese zu beeinflussen und welche Hindernisse sich ihnen dabei in den Weg stellen, ist empirisch weitgehend ungeklärt und kaum reflektiert.

2. Fragestellung, Zielsetzung und methodisches Vorgehen

(1) Welche Bedeutung hat Vertrauen in der Pflegebeziehung aus Sicht beatmeter Patient_innen in der häuslichen Intensivversorgung und welche Merkmale von Vertrauen lassen sich vor gegebenen Kontext identifizieren? (2) Was fördert oder hemmt den Aufbau vertrauensvoller und sicherheitsgenerierender Beziehungen in diesem Kontext? (3) Was geschieht, wenn das Vertrauen zwischen den beteiligten Personen fehlt?

Durch die Beantwortung dieser Fragen sollten erste Hinweise zur Gestaltung vertrauensvoller und sicherheitsgenerierender Pflegebeziehungen in der häuslichen Intensivversorgung beatmeter Patient_innen in Deutschland explorativ erschlossen, an die zuvor skizzierten Überlegungen angeknüpft und ein Beitrag zur Beantwortung der zuvor aufgezeigten Forschungslücke geleistet werden.

Zu diesem Zweck wurden Befragungsdaten aus einer qualitativ-empirischen Studie mit beatmeten Patient_innen aus dem Jahr 2013-2017 einer sekundären Analyse unterzogen. Eine veränderte Perspektive auf das vorhandene Datenmaterial sollte weiterführende Erkenntnisse ermöglichen (Sherif 2018), zugleich aber sollten die zuvor aufwändig generierten Daten effizient genutzt und die mit einer erneuten Befragung verbundenen Belastungen für die beatmeten Patient_innen vermieden werden. Der Forderung, sich bei einem solchen Vorgehen zunächst „[...] mit der Natur der vorliegenden Daten, ihren Erhebungsmethoden und deren Implikationen für die Analyse und Interpretation“ (Medjedović 2014: 216) zu befassen, wurde durch einen engen Austausch mit dem Primärforschungsteam und deren Einbindung in die Manuskripterstellung entsprochen.

Für die Primärdatenerhebung wurden problemzentrierte Interviews (Witzel 2000) mit narrativen Sequenzen genutzt, die u. a. mit häuslich versorgten invasiv und nicht-invasiv beatmeten Menschen ab 18 Jahren durchgeführt wurden. Ziel war es, Erkenntnisse zum Thema Patientensicherheit in der häuslichen Intensivpflege aus subjektiver Sicht zu generieren. Um ein möglichst umfassendes Bild zu erhalten, wurde in einem iterativen Prozess ein theoretisches Sampling mit maximaler Varianz bezüglich Alter, Erkrankungsbilder, Art und Umfang des Pflegebedarfs, Beatmungsdauer und sozioökonomischem Status realisiert. Die Interviewpartner_innen wurden hauptsächlich über Gatekeeper in den Intensivpflegedienste rekrutiert (ausführlicher zum Sampling: Schaepe et al. 2017: 3). Insgesamt konnten 24 Interviews geführt, audiotekhnisch aufgezeichnet und aufbereitet werden. Die Datenerhebung, die von April bis Dezember 2014 stattfand, wurde von jeweils zwei Forscher_innen im häuslichen Lebensumfeld der Patient_innen durchgeführt. Die Interviews waren durch die Erkrankung bzw. Beatmungssituation beeinflusst, was z. T. adaptierte methodische Herangehensweisen erforderte (ausführlich dazu: Schaepe et al. 2016). Die Auswertung der so erhobenen Daten erfolgte angelehnt an Prinzipien der Grounded Theory in Form einer thematischen Analyse (ausführlicher dazu: Schaepe et al. 2017: 4).

Das reichhaltige Datenmaterial enthielt zahlreiche Hinweise auf die besondere Relevanz der Pflegebeziehung für das Sicherheitsempfinden der befragten Personen sowie

auf damit einhergehende Vertrauensphänomene. Dies ließ eine qualitative Sekundärdatenanalyse unter den zuvor genannten Fragestellungen lohnend erscheinen; die für derartige Analysen angeratene thematische Verbindung zwischen primärer und sekundärer Datenbearbeitung (du Plessis et al. 2009) war eindeutig gegeben. Bei der Sekundärdatenanalyse wurde mehrstufig vorgegangen: Die in MaxQDA aufbereiteten Interviewdaten aus der Primärerhebung wurden zunächst systematisch deduktiv gesichtet, wofür sämtliche zuvor mit „Vertrauen“ kodierte Textstellen extrahiert wurden. Dabei wurde zum einen auf den jeweiligen Kontext geachtet, in den diese Textstellen eingebettet waren, um diese bei der Interpretation berücksichtigen zu können. Zum anderen wurden in Form einer Schlagwortsuche nach weiteren, ggf. nicht kodierten Textstellen gesucht, in denen mit Vertrauen assoziierte Begriffe verwendet wurden. Die so identifizierten Textstellen wurden einer zusammenfassenden qualitativen Inhaltsanalyse nach Mayring (2015) unterzogen. Das der Analyse zugrundeliegende Selektionskriterium bezog sich dabei auf Themen der forschungsleitenden Fragestellungen. Die inhaltstragenden Texteinheiten wurden in einem mehrstufigen reduktionistischen Verfahren (Paraphrasierung, Generalisierung, Reduktion) zu einem induktiven Kategoriensystem verdichtet. Die Ergebnisse dieser Analyse wurden für diese Publikation thematisch aufbereitet.

Die Primärstudie wurde von der Ethikkommission der untersuchungsleitenden Institution genehmigt (Ref EA2/028/14). Die Interviewpartner_innen erklärten mündlich und schriftlich ihr Einverständnis zur Nutzung und Publikation der Daten im Rahmen von Forschungszwecken – dies umfasst auch sekundäre Analysen der Daten. Die Namen der Interviewten wurden pseudonymisiert.

3. Ergebnisse

Der Aufbau vertrauensvoller und sicherheitsgenerierender Pflegebeziehungen in der häuslichen Intensivversorgung beatmeter Patient_innen wird basierend auf den Ergebnissen der Sekundäranalyse durch unterschiedliche Aspekte gefördert. Hierzu zählen zum einen die sich im Zeitverlauf allmählich einstellende Vertrautheit zwischen den an einer häuslichen Intensivversorgung beteiligten Personen sowie zum anderen die fachlichen und sozialen Kompetenzen der Pflegenden im Umgang mit den beatmeten Patient_innen. Darüber hinaus wurde deutlich, was den Aufbau vertrauensvoller Beziehungen behindert und welche Strategien Patient_innen verfolgen, wenn die Pflegebeziehung von Misstrauen geprägt ist.

3.1 Voraussetzungen für das Entstehen von Vertrauen

Für einige der Befragten ist die Vertrautheit, die durch das gegenseitige Kennenlernen entsteht, unverzichtbare Grundlage für eine vertrauensvolle Beziehung. So zum Beispiel für die 61 Jahre alte Frau Lange: Sie lebt ohne Angehörige in ihrer Wohnung und wird dort wegen ihrer Lungenerkrankung 24 Stunden am Tag invasiv beatmet und pflegerisch unterstützt. Sie fasst ihre Erfahrungen wie folgt zusammen:

„Die Leute, die ich kenne, denen vertraue ich, die kennen mich, ich weiß, wie ich die zu nehmen habe, ich weiß, wie umsichtig die sind oder nicht umsichtig“ (Lange, 5)

Vertrauensvolle Pflegebeziehungen entwickeln sich in einem dynamischen Prozess des Kennenlernens, der vor allem Zeit und personale Kontinuität erfordert. Dass es daran oft fehlt, wird von der Patientin an anderer Stelle beklagt. Wichtig ist, dass es sich um ein gegenseitiges Kennenlernen handelt – die Patientin muss mit den verschiedenen Persönlichkeiten der Pflegenden ebenso zurechtkommen können wie diese mit ihr. Damit ist die reziproke Dimension von Vertrauen in Pflegebeziehungen angesprochen.

Eine besondere Form des Kennenlernens schildert die 37jährige, nicht-invasiv beatmete Frau Huber, die an spinaler Muskelatrophie leidet. Sie beschreibt Pflegenden, denen sie vertraut, als solche, „mit denen es von Anfang an funktioniert hat“, und die gemeinsam mit ihr in die Beatmungssituation „mitreingewachsen“ sind (Huber, 15f). Die neuen Versorgungsumstände werden miteinander gestaltet und die dabei gesammelten Erfahrungen, das mühsame Aneignen von Kompetenzen sowie das Sich-Zurechtfinden in der häuslichen Versorgung wirken vertrauensbildend. Voraussetzung dafür sind aus ihrer Sicht v. a. zwischenmenschliche Aspekte. Vergleichbar spielt auch für die 57 Jahre alte, aufgrund fortgeschrittener COPD invasiv beatmete und in einer WG lebende Frau Schwarz, die fürsorgliche Präsenz der Pflegenden eine bedeutsame Rolle. Sie erinnert sich an die Zeit, in der sie durch eine Lungenentzündung stark geschwächt war: „Jedes Mal, wenn ich wach wurde, war sie da und hat mich gestreichelt und das“ (Schwarz, 8). Miteinander geteilte Erfahrungen oder durchgestandene Krisen können sich demnach vertrauensbildend auf die Pflegebeziehung auswirken.

Es gibt aber auch Befragte, die bereits beim ersten Aufeinandertreffen erkennen wollen, ob jemand vertrauenswürdig ist. So sieht das bspw. der an einer neuromuskulären Erkrankung leidende 74jährige Herr Köhler. Ausschlaggebend für ihn ist schlicht, dass „die Chemie stimmt“ (Köhler, 21). Aus seiner Sicht entscheidet die sprichwörtliche Magie der ersten Begegnung darüber, ob eine vertrauensvolle Pflegebeziehung möglich ist. In ähnlicher Weise setzt auch die hochaltrige, multimorbide Frau Krüger voll und ganz auf ihre Intuition, wenn sie argumentiert: „Das merkt man doch. Ob ich Menschen vertrauen kann. Und denen kann ich vertrauen“ (Krüger, 11). Woran sie diese Vertrauenswürdigkeit bei der ersten Begegnung festmacht und was Pflegenden tun können oder wie sie sich verhalten müssen, um das Vertrauen von Frau Krüger oder anderen beatmeten Patient_innen in der häuslichen Intensivversorgung zu gewinnen, bleibt an dieser Stelle offen.

Was auf Grundlage der vorliegenden Daten eine Rolle spielen könnte, ist die Verlässlichkeit der Pflegenden, symbolisiert durch deren professionelles Auftreten und demonstrierte fachliche und soziale Kompetenzen. Der alleinlebende, 45-jährige Herr Krause etwa, der durch seine fortgeschrittene neuromuskuläre Erkrankung rund um die Uhr auf pflegerische Unterstützung angewiesen ist, legt viel Wert auf ebenjene Kompetenzen der Pflegenden:

„Es bedarf eines kompetenten Teams und mir. Nur wenn ich Bescheid weiß über Technik und mir die auftretenden Gefahren bewusst sind, kann ich mir selbst ein Urteil machen und [...] einschätzen, was kann ich wem zutrauen. Volles Vertrauen muss ich zu meinen Pflegekräften haben, denn 5 Minuten ohne Luft kann meinen Tod bedeuten. Das muss mir und meinem Team klar sein. Ein vorausschauendes Handeln müssen alle beherrschen“ (Krause, 6).

Herr Krause verdeutlicht hier zum einen, dass er selbst über einschlägiges Wissen zur Beatmungstechnik und den sich daraus potenziell ergebenden Risiken verfügen muss. Dies ermöglicht ihm, die Vertrauenswürdigkeit der Pflegenden zu beurteilen und sein Verhalten entsprechend anzupassen. Vertrauen in andere steht damit durchaus in enger Verbindung mit dem Vertrauen in die eigenen Kompetenzen. Seiner existenziellen Abhängigkeit von der Beatmungstechnik und der sie bedienenden Personen ist er sich dabei durchaus bewusst. Neben technischen Kompetenzen erwartet Herr Krause von den Pflegenden daher vor allem die Fähigkeit absehbare Entwicklungen zu antizipieren und entsprechend umsichtig zu handeln. Eben darauf gründet er sein Vertrauen in sie. In eine vergleichbaren Richtung argumentiert auch die 60-jährige, neuromuskulär erkrankte Frau Müller, die nicht-invasiv beatmet wird:

„Seit [Jahreszahl] habe ich die 24-Stunden-Pflege, ist also immer jemand da und in der Hinsicht wäre das nur ungünstig, wenn jemand da wäre, wo ich wüsste, der beherrscht sein Fach nicht. Aber da ich mitreden kann, wer zum Pflorgeteam dazugehört und so, und sind schon immer Leute da, auf die ich mich verlassen kann“ (Müller, 3).

Frau Müller hat langjährige Erfahrungen mit der häuslichen Intensivversorgung und das Privileg, mitentscheiden zu können, wer ihrem Team angehört. Sie will selbst Einfluss darauf nehmen, wem sie vertrauen kann. Woran genau sie die Fachkompetenz und damit auch die Vertrauenswürdigkeit ihres Gegenübers festmacht und ob sie sich – ähnlich wie Herr Krause – entsprechendes Hintergrundwissen angeeignet hat oder die Eignung der Pflegenden eher intuitiv erfasst, bleibt in dem Interview offen.

Besondere Erschwernisse in der häuslichen Intensivversorgung ergeben sich aus temporären oder dauerhaften Kommunikationseinschränkungen, mit denen sich auch der maskenbeatmete 41-jährige Herr Peters konfrontiert sieht; etwa beim Maskenwechsel, Transfer oder bei Funktionsunterbrechungen der Beatmung:

„In solchen Situationen ist es äußerst wichtig, dass die Person neben mir weiß [...] was zu tun ist, um die Beatmung schnell wieder sicherzustellen“ (Peters, 3).

Gerade in Situationen, in denen er sich nicht mitteilen kann, ist es für ihn notwendig, dass die Pflegenden seine Situation richtig einschätzen sowie rasch, umsichtig und kompetent handeln – auch darauf muss der Beatmungspatient vertrauen können. Worauf es darüber hinaus ankommen kann, verdeutlicht ein Auszug aus dem Interview mit Frau Huber:

„Der andere geht auf einen ein, er erkennt, was los ist, er sieht, was los ist oder sie je nachdem. Er kann handeln, agieren und halt sehr viel auf diese nonverbale Kommunikation“ (Huber, 2).

Es geht also nicht allein um die fachlichen, sondern auch um die sozialen Kompetenzen der Pflegenden, ihre Empathie und ihre Fähigkeit sich auf andere Personen und ihre Situation einzulassen. Die Pflegenden müssen aus Sicht der Befragten über die Fähigkeit verfügen, die unausgesprochenen, bzw. lediglich durch Mimik und Gestik artikulierten, Bedürfnisse und Präferenzen der Patient_innen wahrzunehmen und adäquat darauf zu reagieren. Das wiederum setzt – wie eingangs verdeutlicht – ein gewisses Maß an Vertrautheit miteinander voraus.

3.2 Folgen fehlenden Vertrauens

Die Befragten schildern immer wieder Situationen, in denen das interpersonale Vertrauen in der Pflegebeziehung fehlt, angezweifelt wird oder verloren gegangen ist, was auf den dynamischen, volatilen und fragilen Charakter des Vertrauensphänomens verweist. Oft geht es um Situationen, in denen sich Pflegenden aus Sicht der Befragten ungeschickt verhalten haben, in denen sie ihre Verpflichtungen vernachlässigten, inkompetent auftraten oder Fehler in kritischen Situationen machten. Weil die Patient_innen aus ihrer Abhängigkeitssituation nicht einfach ausbrechen oder das Pflegepersonal beliebig austauschen können, entwickeln sie unterschiedlich weitreichende und z. T. risikobehaftete Strategien, um sich trotz des fehlenden Vertrauens in der Pflegebeziehung sicher fühlen zu können. Einige der Befragten versuchen, sich selbst Fachwissen zu ihrer Erkrankung, deren Behandlung oder die eingesetzten Techniken anzueignen, damit ihre Gesundheitskompetenz zu erweitern und auch in heiklen Situationen auf sich selbst vertrauen zu können. Das auf unterschiedlichen Wegen erworbene Wissen hilft ihnen dabei, die eigene Situation einschätzen und ihre Kontroll- und Handlungsfähigkeit erhalten zu können. Einige von ihnen weisen neue Pflegenden in die Arbeit ein und schulen sie in der Beatmungstechnik, um sicher zu sein, dass sie diese auch beherrschen – so beispielsweise der zuvor erwähnte Herr Krause. Andere gehen noch weiter und schildern, dass sie Tätigkeiten, die zu den Aufgaben ihres Pflegedienstes gehören nach Möglichkeit selbst durchführen oder ihren Zu- und Angehörigen übertragen. So berichtet Frau Lange davon, dass ihre Pflegenden es wiederholt versäumt haben Medikamente rechtzeitig zu bestellen.

„Das ist die Aufgabe des Pflegepersonals. Dafür sind die da, sonst kann ich allein bleiben. [...] überall hab' ich meine Finger mit drin [...] ich verlass mich auf keinen anderen, damit eben sowas nicht mehr passiert“ (Lange, 15).

Obwohl sie der Auffassung ist, dass es sich um eine Aufgabe handelt, die den Pflegenden obliegt, nimmt sie das Medikamentenmanagement lieber selbst in die Hand – und das ist nicht der einzige Bereich, in den sie sich einmischt. Sie hat schlicht das Vertrauen in die Pflegenden verloren, wie sie mehrfach und deutlich betont. Wie lange sie diese Strategie durchhalten kann und wann sie aufgrund ihrer gesundheitlichen Situation nicht mehr umhinkommt, sich – wohl oder wehe – wieder den Pflegenden anzuvertrauen, spricht sie in dem Interview nicht an. Für die Patient_innen ist es generell nicht einfach, zu entscheiden, ob das Vertrauen in die Pflegenden gerechtfertigt ist, weshalb die Pflegebeziehung immer wieder von Zweifeln überlagert wird. Auch Frau

Huber, die zuvor auf die Bedeutung gemeinsam durchgestandener Erfahrungen für das Entstehen vertrauensvoller Pflegebeziehungen hingewiesen hat, will sich absichern. Deswegen stellt sie die Pflegenden auf die Probe:

„Fehler provoziert man gerne [...], um zu gucken, was die Mitarbeiter können oder nicht können. Und da baut sich halt Verlass, Verlässlichkeit, Vertrauen auf“ (Huber, 6).

In der Interviewpassage wird deutlich, dass die Patientin gezielt Störungen herbeiführt – wie etwa Ventile zuhalten, Luft anhalten, Schläuche lockern, Husten simulieren –, um zu überprüfen, ob neue Mitarbeiter_innen verlässlich arbeiten und ihr Vertrauen verdienen. Die drastisch anmutenden Tests begründet Frau Huber damit, dass sie *„sich sicher fühlen muss, man muss ja wissen, woran man ist“* (ebd., 7). Darüber hinaus führt sie aus, dass in ihrer Pflege häufig Menschen eingesetzt werden, die kein fließendes Deutsch sprechen. Ihnen könne sie nicht ohne Weiteres vertrauen, da gegenseitige Verständigung nur sehr bedingt möglich sei. Sieht sie ihr Misstrauen gegenüber den Pflegenden dadurch bestätigt, dass ihre Experimente negativ ausfallen, wird ihre Situation zunehmend prekär, wie in folgendem Auszug ersichtlich:

„[...] man geht nicht auf Toilette, weil man Angst hat, man erstickt. Oder [...] man trinkt nicht [...], man isst nicht, um eine sichere Schiene zu haben. Man beschränkt sich wirklich auf das Luftholen. Hoffen, dass man nicht irgendwie Spucke mal verschluckt, husten muss“ (ebd., 9).

Aufgrund des fehlenden Vertrauens in die Pflegenden beschränkt sich die Befragte im Alltag also auf das absolut Notwendige und verharrt oftmals in der Bewegungslosigkeit, um nicht ungewollt in gefährliche Situationen zu geraten.

Mit patientenseitigen Strategien wie Kompensation, Testverfahren und Risikovermeidung steigt – aus pflegfachlicher Sicht betrachtet – nicht selten das Risiko in der häuslichen Intensivversorgung; zudem wird das Entstehen vertrauensvoller und sicherheitsgenerierender Pflegebeziehung beeinträchtigt. Denn Vertrauen ist ein wechselseitiges Phänomen und auch die Pflegenden müssen den Patient_innen und ihren Angehörigen in der häuslichen Intensivversorgung vollumfänglich vertrauen können.

4. Diskussion

Die durchgeführte Sekundärdatenanalyse hat interessante Einblicke in die häusliche Intensivversorgung beatmeter Patient_innen gewährt und relevante Merkmale vertrauensvoller und sicherheitsgenerierender Pflegebeziehungen aus subjektiver Sicht aufgedeckt. Dabei zeigen sich deutliche Übereinstimmungen mit den Ergebnissen anderer qualitativer Studien, die sich mit dem Thema Vertrauen in Pflegebeziehungen aus Patientenperspektive befasst haben (Rørtveit et al. 2015). Als Besonderheit zu berücksichtigen ist hier, dass technikgestützte Beatmungstherapie und die sie flankierenden pflegerischen Leistungen lebenserhaltend sind und somit existenzielle Bedeutung für die Patient_innen haben. Sie müssen darauf vertrauen können, dass die Pflegenden jederzeit körperlich und geistig präsent sind und so handeln, dass möglicher Schaden

von ihnen ferngehalten und ihr (Über-)Leben gesichert wird. Die ohnehin relevante Abhängigkeitssituation als Bedingungsfaktor vertrauensvoller Beziehungen ist in diesem Fall also besonders stark ausgeprägt.

Das sich Einlassen auf die Pflegebeziehung dürfte von den Patient_innen in diesem Fall einen erheblichen Vertrauensvorschuss gegenüber den professionell Pflegenden verlangen. Dieser wird der Berufsgruppe zwar per se entgegengebracht (Müller et al. 2018: 29); ob sich aber im konkreten Fall eine vertrauensvolle Pflegebeziehung entwickelt, entscheidet sich erst im Laufe der Zeit in Abhängigkeit von personalen und situationalen Vertrauensfaktoren wie sie von Schweer (2008: 18ff) beschrieben werden. Wesentlich scheinen dabei zum einen die Qualität des Anfangskontakts und zum anderen der Prozess des gegenseitigen Kennenlernens zu sein. Die Relevanz des Erstkontaktes wurde von einigen Interviewten angedeutet und ist auch in der pflegewissenschaftlichen Vertrauensforschung (Leslie et al. 2016) sowie der Forschung zu Pflegebeziehungen (ex. Walivaara et al. 2013) ein Thema. Gelingt es den Pflegenden bspw. zu Beginn einer Pflegebeziehung die (unausgesprochenen) Erwartungen der Patient_innen zu antizipieren und erweisen sie sich über die Zeit hinweg auf Grundlage der miteinander gesammelten Erfahrungen als verlässliche und vertrauenswürdige Partner_innen, wird der inhärente Vertrauensanteil in der Pflegebeziehung gestärkt. Die Entstehung stabiler vertrauensvoller Pflegebeziehungen ist somit in komplexer Wechselwirkung sowohl an die sich zwischen den Beteiligten entwickelnde Vertrautheit wie auch die Verlässlichkeit der Pflegenden gekoppelt (Schweer 2008).

Wichtig ist aber nicht nur die Entwicklung des Vertrauens der Patient_innen in die Pflegenden; auch das Vertrauen, dass die Pflegenden nach und nach in die Fähigkeiten und Ressourcen der Patient_innen entwickeln, ist in Betracht zu ziehen. Dies deutet einerseits auf die Notwendigkeit zur Förderung von Autonomie und Gesundheitskompetenz der Patient_innen hin, andererseits auf den vielfach erwähnten reziproken Charakter (etwa in: Robinson 2016; Dinç et al. 2013) der Vertrauensbildung in der Pflegebeziehung. Pflegenden, die Patient_innen als mündige Menschen behandeln, sie aufklären, beraten und in die pflegerischen Prozesse einbeziehen – kurz: ihnen und ihren Ressourcen vertrauen, diese unterstützen und fördern – stärken das Selbstvertrauen der Patient_innen und damit letztlich auch das Vertrauen in der Pflegebeziehung. Strandas und Bondas (2018: 11) betrachten eine Pflegebeziehung daher auch als gemeinsame Geschichte (common story) aller Beteiligten. Wichtig ist dabei die Beobachtung, dass ein gewisses Gefühl von Sicherheit einerseits Voraussetzung dafür ist, dass Patient_innen sich auf eine Pflegebeziehung einlassen können, dass andererseits aber eine vertrauensvolle „gemeinsamen Geschichte“ dazu führen kann, dass im Ergebnis das subjektive Sicherheitsempfinden der Patient_innen gestärkt wird (Entwistle et al. 2006; Rørtveit et al. 2015).

Wie risikobehaftet das Sich-Einlassen auf die Pflegebeziehung für Patient_innen in der häuslichen Intensivversorgung sein kann, wurde weiter oben bereits angesprochen. Risiken ergeben sich einerseits aus der krankheitsbedingten Vulnerabilität und andererseits aus dem spezifischen Setting, in dem die Versorgung stattfindet. Den beatme-

ten Menschen bleibt kaum eine andere Wahl als den Pflegenden und der medizinischen Technik gleichsam blind ihr Leben anzuvertrauen. Zudem müssen sie ihnen Zugang zu ihrem intimen Lebensraum eröffnen, wobei sie (ungewollt) viel von sich, ihren Lebensweisen und ihren Wertvorstellungen preisgeben. Die Beziehung zwischen Pflegenden und beatmeten Menschen in der häuslichen Intensivversorgung ist daher per se von Unfreiwilligkeit und Asymmetrien gekennzeichnet. Diese Faktoren gelten im pflegewissenschaftlichen Vertrauensdiskurs als wesentliche Merkmale von Vertrauen in Pflegebeziehungen, die bei deren Gestaltung stets mitzudenken sind (Delmar 2012, Dinç et al. 2013; Dinç et al. 2012). Das ausgeprägte kontextspezifische Risiko für die Patient_innen wird durch das generelle Risiko, das vertrauensbasierte Beziehungen auszeichnet, noch zusätzlich verstärkt: Menschen, die Vertrauen schenken, machen sich verletzlich, denn stets ist die Möglichkeit des Vertrauensbruchs gegeben (Schweer 2008; Dinç et al. 2012).

Diese Erkenntnis lenkt die Aufmerksamkeit schließlich, auf die besondere professionelle Verantwortung der Pflegenden im Umgang mit den spezifischen Risiken bei der Gestaltung von Pflegebeziehungen im Kontext der häuslichen Intensivversorgung. In den Daten wurde wiederholt die Notwendigkeit ausgeprägter fachlicher und sozialer Kompetenzen der Pflegenden im Umgang mit den Patient_innen hervorgehoben. Wie sehr sich die Kompetenzen der Pflegenden und ihre Professionalität förderlich oder – im Fall ihres Fehlens – hinderlich auf die Entstehung vertrauensbasierter Pflegebeziehungen auswirken können, wird auch in der Literatur viel diskutiert (ex. Dinç et al. 2013; Leslie et al. 2016; Rørtveit et al. 2015). Darüber hinaus wird aber auch stets auf eine spezifische und für Professionen typische Werteorientierung und moralische Verpflichtung gegenüber den anvertrauten Menschen hingewiesen – auch in den Daten war diese Erwartung zu beobachten. Es liegt demnach in der Verantwortung der professionell Pflegenden die Pflegebeziehung aktiv auf eine Weise zu gestalten, dass sie (implizite) Erwartungshaltungen der Patient_innen mit ihren pflegerischen Möglichkeiten abgleichen, über Bedingungen der Versorgungsgestaltung aufklären und in einem partizipativen co-kreativen Aushandlungsprozess verlässliche Vereinbarungen mit ihnen treffen. Wie wichtig die Wahrnehmung dieser professionellen Verantwortung auch für die Sicherheitsarbeit in der häuslichen Intensivversorgung ist, zeigt sich anhand des Umgangs mancher Patient_innen mit enttäushtem Vertrauen: Sie entwickeln Strategien, die das fehlende Vertrauen in die Pflegenden kompensieren. Solche Vorgehensweisen werden in Ansätzen auch in der pflegewissenschaftlichen Literatur diskutiert (Jones 2015; Hupcey et al. 2000; Swedberg et al. 2012). Sie entstehen aus dem Bedürfnis heraus, das Risiko der eigenen Verletzlichkeit selbstständig zu minimieren und Kontrolle zu erhalten bzw. wiederherzustellen. Das dadurch entstehende Gefühl von Kontrolle und subjektiver Sicherheit kann jedoch trügerisch sein, da die Strategien selbst bisweilen ein erhebliches Sicherheitsrisiko bergen. Hinzu kommt, dass die Patient_innen damit eine mehr oder weniger bewusste Entscheidung gegen Vertrauen und für Kontrolle treffen, was die Pflegebeziehung womöglich weiter belastet und zusätzliche Vertrauenskrisen provozieren kann. Angesichts dessen sind die Pflegenden gefordert, mangelndes Vertrauen in der Pflegebeziehung wahrzunehmen und ange-

messen darauf zu reagieren – etwa indem sie diese offen ansprechen und so zum Gegenstand eines konstruktiven Aushandlungsprozesses zwischen ihnen und den Patient_innen machen. Dabei sollten sie bedenken, dass die Patient_innen nach Beziehungen suchen, in denen sie Vertrauen, das richtige Maß an Autonomie, Fürsorge und Expertise erfahren (Epstein 2006: 272).

5. Limitationen

Methodische Limitationen des Forschungsprojektes, aus dem die Befragungsdaten zur Sekundäranalyse entnommen wurden, wurden an anderer Stelle ausführlich erörtert (Schaepe et al. 2017: 7). Mit Blick auf die Sekundärdatenanalyse ist darauf hinzuweisen, dass die Primärdaten nicht konkret zum Thema der vorliegenden Untersuchung erhoben wurden. Dies ist insofern als Limitation zu bewerten, als dass zielgerichtete (Nach-)Fragen hinsichtlich der hier bearbeiteten Fragestellungen womöglich zu tieferen und breiteren Erkenntnissen hätten beitragen können. Unter inhaltlichen Gesichtspunkten ist einschränkend außerdem zu bemerken, dass hier lediglich die Perspektive von Patient_innen, nicht aber die von anderen Beteiligten an der Pflegebeziehung (beispielsweise Angehörige und die Pflegenden selbst) berücksichtigt wurden. Zudem wurden die institutionellen Rahmenbedingungen der häuslichen Intensivversorgung außer Acht gelassen. Angesichts vielfältiger skandalisierender Medienberichte über diesen Versorgungsbereich, wäre durchaus interessant gewesen zu erfahren, wie sich dies auf die Vertrauensbildung in der Pflegebeziehung auswirkt (zu diesem Aspekt: Grünberg 2014).

Die Sekundärdatenanalyse bot jedoch insgesamt einen pragmatischen, effizienten und unter forschungsethischen Gesichtspunkten vertretbaren Zugang, um dem Phänomen Vertrauen in der Pflegebeziehung mit Blick auf den spezifischen Kontext der häuslichen Intensivversorgung beatmeter Patient_innen unter einer explorierend-sondierend angelegten Fragestellung nachzugehen. Die Reichweite der dabei gewonnenen Erkenntnisse ist begrenzt, eine Generalisierung oder einfache Übertragung auf andere Kontexte verbietet sich aufgrund des gewählten Vorgehens. Dennoch konnten wichtige Hinweise und Anknüpfungspunkte für künftige empirische und theoretische Auseinandersetzung mit dem Thema erarbeitet werden.

6. Fazit

Vertrauensvolle und sicherheitsgenerierende Pflegebeziehungen sind für die häusliche Intensivversorgung beatmeter Patient_innen von zentraler Bedeutung; sie verantwortlich zu gestalten ist eine professionelle Verantwortung der dort tätigten Pflegenden. Dieser Beitrag hat die Aufmerksamkeit dabei nicht allein auf die dabei zu berücksichtigenden Erkenntnisse aus der Literatur der verschiedenen, am Vertrauensphänomen interessierten Wissenschaftsdisziplinen gelenkt – nicht zuletzt der Pflegewissenschaft. Sie zeigt anhand der durchgeführten Sekundärdatenanalyse auch einige Bedingungsfaktoren auf, die bei der Gestaltung von Pflegebeziehungen mit dieser besonderen Ziel-

gruppe im häuslichen Setting zu berücksichtigen sind. Besondere Aufmerksamkeit verdient dabei die herausragende Bedeutung fachlicher und überfachlicher Kompetenzen und einer an gesellschaftlichen Zentralwerten ausgerichteten Haltung der Pflegenden gegenüber den auf sie angewiesenen und von ihrer Unterstützung abhängigen Patient_innen. Mit anderen Worten: die Professionalisierung der Pflegenden ist eine zwingende Voraussetzung dafür, dass den Anforderungen an die Beziehungsgestaltung in diesem (und anderen) pflegerischen Kontexten künftig begegnet werden kann. Dabei gilt es jedoch zu bedenken, wie oft in der einschlägigen Literatur auf die unzureichende wissenschaftliche Auseinandersetzung mit und vor allem die fehlende Operationalisierung und empirische Erforschung von Vertrauensphänomenen hingewiesen wird, insbesondere im Kontext von Pflegebeziehungen. Hierdurch fehlt es an notwendigem Wissen darüber, welche Strategien der Vertrauensbildung erfolgreich sind, wie vertrauensvolle und sicherheitsgenerierende Pflegebeziehungen bereichsspezifisch befördert und stabilisiert oder wie zuwiderlaufende Bedingungsfaktoren – etwa ökonomische Restriktionen und fehlende Zeit für Zuwendung – kontrolliert oder eingedämmt werden können. Insbesondere auch über die Zusammenhänge zwischen vertrauensbildenden Maßnahmen und dem subjektiven Sicherheitsempfinden von Patient_innen sowie objektiven Indikatoren für Patientensicherheit und anderen Ergebnissen pflegerischer Versorgung sind viele Fragen offen. Die Impulse aus der Literatur aufzugreifen und künftig sowohl theoretische wie auch empirische Auseinandersetzung mit Vertrauensphänomenen in Pflegebeziehungen voranzutreiben, dürfte sich als lohnend erweisen.

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Curriculum vitae

Mein Lebenslauf wird aus datenschutzrechtlichen Gründen in der elektronischen Version meiner Arbeit nicht veröffentlicht.

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Oral presentations and Poster

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Schaepe C, Ewers M: Using infographics based on interview data as an opening incentive in Focus Groups: a reflective report. Nordic Conference in Nursing Research, Copenhagen; (postponed to the 21.- 23.06.2021) (poster)

Schaepe C, Ewers M: Making their voices heard - Conducting qualitative interviews with patients with communication impairments. 16th World Congress of the European Association for Palliative Care, 23 - 25.05.2019, Berlin (poster)

Schaepe C, Ewers M: Angehörige in der häuslichen Versorgung beatmeter Patienten – Sicherheitsrisiko oder Sicherheitsressource? 26. Jahreskongress der DIGAB, 07.- 09.06.2018, Hannover (presentation)

Schaepe C: „Zu Hause, das ist eine ganz andere Sicherheit“ – Sichtweisen von beatmeten Patienten in der häuslichen Versorgung. 11. Jahrestagung Aktionsbündnis Patientensicherheit, Berlin, 15.04.2016 (presentation)

Schaepe C, Ewers M: Erfahrung von Angehörigen in der häuslichen Intensivversorgung. 21. Kongress Armut und Gesundheit, Berlin, 17.03.2016 (poster)

Schaepe C: Sichtweisen heimbeatmeter Patienten und Angehörigen zum Thema Sicherheit. 23. Jahreskongress der Deutschen Interdisziplinären Gesellschaft für Außerklinische Beatmung e.V., Düsseldorf, 12. 06.2015 (presentation)

Schaepe C: Die Situation in der häuslichen Versorgung dauerbeatmeter Patienten aus Nutzersicht. 14. Deutscher Kongress für Versorgungsforschung, Berlin. 07.09.10.2015 (poster)

Schaepe C: Da hab ich mich unsicher gefühlt“- Teilergebnisse des qualitativen Forschungsprojektes SHAPE. 8. Münchner Außerklinischer Intensivkongress, München, 30.-31.10.2015 (presentation)

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